

CONSUMER HEALTH  
INFORMATION PROVISION  
IN  
GENERAL PRACTICE

BY

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## ABSTRACT

A study is made in the area of consumer health information provision in UK general practice.

Research is based on a literature review and through contact with professionals in the health field who have contributed to developments in practice-based consumer health information provision and/or voiced an interest in this area.

Existing and developing areas of consumer health information provision are highlighted with the objective of emphasising both the value and potential for such provision in general practice.

The main emphasis of the study is on areas of consumer health information provision which have been developed in general practice during the past 10 to 15 years, but some more recent government legislation is also discussed in the light of its relationship to developments in practice-based consumer health information provision.

Various types of consumer health information provision are highlighted, among them: provision of written information on health and illness at a lay level; provision of information on local self-help groups and health-related services and activities in the community; improved general practice provision of information to patients through access to a local consumer health information service, and provision of information on the facilities offered to patients by the general practice itself.

Some of the training implications for practice staff involved in the different areas of consumer health information provision are considered. A number of recommendations relating to practice-based consumer health information provision and suggested by people working in the health field are then given. Based on both these recommendations and on the different forms of consumer health information provision detailed in the study, a proposal is then made for a model consumer health information-oriented general practice for the year 2000.

The study concludes that there are important areas of consumer health information provision currently being developed in general practice. Such provision is valuable, for different types of consumer

health information provision enable different forms of patient participation in the health-care process.

Several different agencies have shown support for practice-based consumer health information provision, but developments to-date have been uneven among UK practices overall. The study therefore recommends that national standards be set for consumer health information provision in general practice. The setting of national standards is seen as a means of ensuring that practice-based consumer health information provision is developed nation-wide.



## INTRODUCTION

### (a) Mission statement

The purpose of this research is an exploratory one: it aims to clarify the different types of consumer health information provision that have already emerged in the general practice setting over the past ten to fifteen years, and to examine what has happened more recently, such as the implications of recent Government legislation on practice - based consumer health information provision. This study aims to highlight rather than to measure: developments are outlined and discussed, but no attempt is made to present a survey - analysis of the existing levels of consumer health information provision across UK general practices overall. The study seeks rather to encourage recognition of the value and real potential for general practice as a consumer health information resource.

Certain developments that are mentioned may actually only be functioning in a small number of general practices overall. However, it is felt important to outline any development, however limited its spread has been to-date, as a means of emphasising the several - faceted nature of the potential for surgery-based consumer health information provision.

There are various information paths that any one practice may choose to follow. The diagram that concludes chapter six draws these possibilities together in a single model.

### (b) Definitions

(i) Consumer health information - the definition of consumer health information when used in this study will be based on that given by Gann:

*information about health and illness at a lay level; information about health care services available from the statutory and voluntary sectors; and information about choices in treatment and care'.*

(ii) Health education and health information - these two terms will be treated as falling under the broader concept of consumer health information as defined above. Their meaning will be based on the interpretations given by Sally Knight who distinguishes between health education as,

*the teaching of the population at large about the concept of health in the broadest sense; how to stay well through preventive strategies and the adoption of a healthy lifestyle<sup>2</sup>.*

and health information as,

*focussed directly on informing an individual (sometimes, but not always, a patient) and/or his family of a particular disease or condition<sup>3</sup>.*

(iii) Primary health care team - this includes all practice staff, and not just the GP. For many patients the practice nurse, health visitor and receptionist are in fact considered as greater providers of consumer health information than the GP.

(iv) Consumer health information in general practice - this includes any piece of information of the categories defined in (i) above and which are accessed in the general practice setting. It looks beyond the minimum information that patients would expect to receive from their family doctor, concerning diagnosis and prognosis of a particular medical condition.

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## 1.0 BACKGROUND

### 1.1. THE VALUE OF CONSUMER HEALTH INFORMATION PROVISION: PARTICIPATION IN THE HEALTH-CARE PROCESS

*'The key to increased involvement is access to information'...*

Information about health gives the public increased opportunities to become involved in its own health-care. Taking the three facets of consumer health information as given in the definition used by Gann in the Introduction it can be seen in what ways consumer health information provision enables different forms of individual participation in health matters:

(a) information about health and illness at a lay level: participation through the very fact of gaining new insight and improved understanding about matters of health and illness; participation through a more informed discussion of health matters with health professionals, enabled by the new knowledge acquired; participation through implementing self-care measures learnt from the new information available.

(b) information about health-care services available from the statutory and voluntary sectors and,

(c) information about choices in treatment and care: participation through choice of health-care service, for information on services available enables comparisons to be made between different facilities offered and differences in quality of service; participation through choice, as information on different treatments available for the same condition lets the patient make an informed choice on the kind of treatment he feels happiest with; participation through seeking out and using relevant non Health Service health-related services and organisations to benefit the management of one's own health.

### In conclusion

- providing consumer health information is therefore valuable for it enables the individual to participate in different ways in his own health-care.

- this involvement increases the individual's sense of responsibility, and hence dignity, in the management of matters of health and illness.

## 1.2 THE INCREASING EMPHASIS ON CONSUMER HEALTH INFORMATION PROVISION

There is clear general public interest and growing demand for consumer health information provision. In health, people are increasingly aware of the part they can play in remaining so, by attention to exercise, diet and leading healthy life-styles. In sickness, people want to be informed of what is happening to their bodies and of how they can contribute to the management of their condition. To lead healthy life-styles and to live a disease or condition as 'healthily' as possible, the individual requires certain information.

### 1.2.1 Public demand for consumer health information

The public's interest in information on health and illness is illustrated in many ways in present-day society. One example is the interest shown in knowing the nutritional value of foods and the avid reading of the detailed nutritional breakdown of foodstuffs which most manufacturers now give on packaging. People want the necessary information to know how to eat healthily and sensibly.

Similarly, the popularity of media programmes on health and illness issues illustrates the Nation's interest in this area of information provision: there is wide coverage of consumer health information issues on television documentary programmes and health matters are also covered in topical chat shows such as I.T.V.'s doctor slot on the 'This Morning' programme where viewers can make phone-in calls to the resident doctor who reports 2,000 phone calls per week<sup>2</sup>. Health matters are covered in radio programmes, some

phone-in also. And a wealth of popular magazines dedicate regular pages to health issues. The high turnover of health-related queries addressed to the agony aunts of popular magazines again reflects a public demand for consumer health information. Already in 1983, figures suggest that top agony aunt Claire Rayner received 1,000 letters per week and that letters addressed to UK agony aunts as a whole numbered as many as 10,000 per week<sup>3</sup>. A qualification is that not *all* queries are medical ones, but a significant number are.

The coverage of medical media materials exemplifies the public's interest in different types of consumer health information, among others: explanation of rarer diseases in lay terms, information on alternative therapies for a certain condition and information on the effects of diet and exercise on health.

The public demand for information on health and illness, especially on how to lead a healthy life-style, reflects the realisation that ultimately the responsibility for maintaining personal health lies largely with the individual. With the explosion of the AIDS virus, added to the existing concern over Cancer, Multiple Sclerosis and other chronic conditions for which there has yet been no identified cure, there is increased recognition of the limitations to medicine and science in maintaining the health of the nation.

*As we approach the year 2,000 there is a growing recognition that, following eras of advances in public health and medical science, the key to further real improvements in health is the involvement of the informed individual in his own well being<sup>4</sup>.*

To participate in the maintenance of his own health the individual requires information on how the body functions in sickness and in health, on how to lead a healthy life-style, and on (community) services, which will help him maintain his health, and help him manage the day to day living with a particular condition, e.g: information on sports centres and voluntary support groups among others.

In an article which gives a brief historical outline of the public's participation in self-care<sup>5</sup> Gann emphasises that it is when medical science's limitations in further improving the Nation's health are recognised that there has been official recognition of the

importance of public participation in the well-being of the population as a whole.

#### 1.2.2 Demands for consumer health information provision at Government level

The last ten years have witnessed a number of papers and declarations at both an international and a national level which emphasise the importance of the individual's increased participation in his own health. Parallel to this emphasis runs the need for adequate provision of the necessary information to enable such participation to take place. The following are examples of official recognition of the importance of a population's contribution to its own health:-

(a) The World Health Organisation's Alma Ata Declaration, 1978

134 nations agreed to this declaration, the fourth of whose ten points endorses the following:

*The people have a right and duty to participate individually and collectively in the planing and implementation of their health care.*

(b) The World Heath Organisation's Global Strategy for Health for All by the year 2000, 1979 was followed by Member States agreeing on global, regional and national strategies and targets:

W.H.O.'s Regional Office for Europe established Targets for Health for All. Targets in support of the European Regional Strategy for health for all, 1985.

Many of the 38 targets stress that Member States must set up systems and programmes which encourage the individual and society to lead healthy life-styles and to participate in their own health-care. Parallel to this is stressed the need for adequate provision of the necessary information to enable such participation to take place.

This is summed up in Target 35:

*Before 1990, Member States should have health information systems capable of supporting their national strategies for health for all.*

This 1985 W.H.O. document can be seen as important endorsement at international level of the need for adequate provision of consumer health information at a national level within each Member State.

*An underlying theme which emerges from this document consistently is the emphasis on self-empowerment stemming from access to information<sup>6</sup>.*

(c) The British Department of Health and Social Security's report Prevention and Health: Everybody's Business, 1976.

As the title indicates, this statement emphasised the individual's responsibility to participate in his own health-care by leading a healthy life-style.

(d) The British Department of Health's White Paper, Working for Patients, 1989.

Among the proposals made were some which concern the area of consumer health information provision relating to provision of information on health-care services available. Information on services available enables participation through informed choice. Proposals were made that both general practices and hospitals provide information leaflets for patients on facilities available. Practice leaflets will be further discussed in 4.1.1. (b).

(e) The British Department of Health's Green Paper, The Health of the Nation, 1991.

This paper sets national targets for health under 16 areas selected for attention for: being major causes of death, disease or disability; because interventions are known to be effective; because it is possible to set targets in the proposed area<sup>7</sup>.

Emphasis is on the part the individual can play in contributing to health promotion and disease prevention. Key health areas include smoking, eating and drinking and prevention of accidents. Such improvements in health clearly depend on availability of the necessary consumer health information. The Government's introductory pamphlet to the Green Paper makes the connection between participation and information clear when making a reference to a drop in smoker numbers which it refers to as part of - 'the trend towards awareness of



*healthier life-styles - reflected by a vast increase in information available to people about healthy living<sup>o</sup>.*

### In conclusion

- This section has tried to illustrate the clear public demand for information on health and illness and,
- how there have been recent declarations at an official level which endorse personal participation in health care.
- The crucial underlying theme is the need for adequate levels of consumer health information provision to enable participation.

### 1.3 UNCO-ORDINATED DEVELOPMENT OF CONSUMER HEALTH INFORMATION SOURCES

Until the Patient's Charter, October 1991, no Government legislation had been passed in Britain which demanded a specified level of consumer health information provision nation-wide. In a 1984 article which reviews consumer health information services in Britain, Elaine Kempson contrasts this to the situation in Sweden and in America<sup>o</sup> where Government legislation pertaining to consumer health information provision *does* exist:

In Sweden the 1983 Law, Hälsa och Sjukvårdsnämnden, made it the responsibility of each health authority to both collect patient information materials and make these available to the public, and also to help self-help groups publish their own information.

In America no legislation has designated precisely who must provide consumer health information, but it has become a joint public and hospital library mission to do so.

With no Government legislation on co-ordinated provision of consumer health information Britain has witnessed a growth in varied sources of such provision, which includes provision by a number of established organisations, by public and medical libraries and by developing consumer health information services.

## Established Organisations

Among the established organisations: the Health Education Authority (HEA) and the various Regional and/or District Health Promotion Units (Departments/Centres) provide mainly health education information. Local Units hold information on local self-help groups and voluntary organisations; Community Health Councils (CHCs) provide information which generally includes information on patients' rights, on local NHS services and on patients' complaints procedures, but areas of information provision will vary between districts; Councils for Voluntary Service provide information on local voluntary services, and Citizens Advice Bureaux (CABx) provide information of a generalist nature but constitute an important public access-point to health information.

## Libraries

There have also been developments in consumer health information provision in the library setting, both in public and health-care libraries: there is a great potential for consumer health information provision in the public library setting for it is on open access to the whole of the community. Knight<sup>10</sup> observes however that British public libraries fall far behind America in levels of consumer health information provision. There are however some examples of good practice. Rotherham, Humberside and Westminster are mentioned as good examples for other public library services to model themselves on.

Nottingham County Library, Angel Row also deserves a mention for its good consumer health information collection within the section on medicine on Level Two. There is a fairly wide ranging collection with texts on the management of specific illnesses and conditions in lay terms - alternative medicine texts and health-related fiction and biography among others.

Even public libraries in smaller towns will often offer at least some health-related texts in lay language. For instance, divided between the Medical, Health, Diseases, Childbirth and Welfare Sections, Loughborough Public Library offers popular texts on different diseases and disorders, texts on teach yourself yoga, how to

eat healthily and a few health-related fiction and biographical works among others.

Perhaps significant advances in public library consumer health information provision are slowly being made: even if collections are as yet limited in the smaller libraries, libraries offering *no* such collection whatsoever are maybe becoming more uncommon.

However small the collection of popular medical texts on the public library shelf, the past 15 years has seen *some* development in consumer health information provision in public libraries through the development of community information provision. Gann<sup>11</sup> describes how some public libraries have established specific community information services which offer advice and information on a variety of topics, such as on housing, welfare benefits and money matters, and also including health topics such as living with a specific disease or illness. And many community topics may have an important health-related element to them, such as financial advice on sickness benefits or housing advice on suitable accommodation for the disabled. There may be provision of advice sessions given by different agencies, such as by the Community Health Council.

Whether or not a public library actually provides a community information service,

*today, most larger public libraries provide community information collections as an extension of their traditional reference services, and these usually contain a good deal of health related material<sup>12</sup>.*

There have been significant developments in the acceptance of consumer health information provision in the health-care library setting. There is increasing interest in patient information provision but the move away from a strong tradition of medical library doors being closed to the public has been a slow one, and one that can not be witnessed in *all* hospital libraries. The hospital library has traditionally been the domain of the health-care professionals only. Within the hospital there was a clear distinction between the medical library for health professionals and the purely recreational library for patients.

Some hospital libraries are now opening their doors to the public

and developing popular health collections for them, but some doors remain firmly closed.

There is therefore no general co-ordinated library provision of consumer health information. This lack was a matter discussed by the Joint D.H.S.S./Regional Librarians Group working party on district library services and led to the recommendations published as part of the Kings Fund's Providing a District Library Service, 1985. Point 3.19. describes the state of consumer health information provision at library level as 'not well developed at present', and it is recommended that there be provision at district level of a library for health consumers.

### Consumer health information services

Parallel to these slower developments in consumer health information provision in the library setting the past 17 years have seen rapidly increasing appearance of consumer health information services such as the Health Information Service, Lister Hospital, Stevenage which was the first to be set-up, in 1975. This service was followed by the establishment of Help for Health, originally at Southampton General Hospital and now based in Winchester, in 1979. These services and the ones which developed subsequently, were responding to the clear need for provision of consumer information on matters of illness and health. Since the founding of the Consumer Health Information Consortium (CHIC), April 1991, consumer health information services have been brought together with CHIC acting as an umbrella networking group for all such services. To the question What does CHIC do?<sup>13</sup> the Consortium gives a three-fold reply: 'it gives support and acts as a self-help network for those working in the consumer health information field; it organises conferences and training for consumer health information workers; it provides a National Directory of consumer health information services'.

CHIC's 1992 Directory<sup>14</sup> lists and details 19 existing consumer health information services, yet present numbers will amount to considerably more due to both the rapid development of such services and to the effects of the Patient's Charter (please see 1.4) on the growth of such services at Regional level. Furthermore, related

services, but which offer consumer health information in a specific area only, such as on AIDs or women's issues, are not listed in the directory.

Any particular consumer health information service may offer additional services or have a bias towards a specific area of information provision, but in general the aims of services included in the directory are encapsulated in the aims of Health Matters, Milton Keynes:

*to provide reliable, accurate, easy to understand information on health, illness and disability, to enable people to understand their own health and health care, to take part in decisions which affect their health, and to live a full life despite disability'<sup>5</sup>.*

Consumer health information services are sited in a variety of settings: within a hospital (such as the Health Information Service, Lister Hospital, Stevenage); within a Health Centre (such as Nottingham Health Information Service, Victoria Health Centre, Nottingham); within a public library (such as Healthpoint, Poole Central Library, Poole); as an independent unit with a shop front (such as Health Matters, Milton Keynes). Some mobile services are also being developed (such as Sunderland Health Information Centre's recently started Health Bus).

### In conclusion

- This section has aimed to show how the United Kingdom lacks co-ordinated provision of consumer health information. Unlike Sweden and the USA, widespread provision of such information has not been ensured by government legislation.

- It has been outlined how, through lack of co-ordinated consumer health information provision, different sources have emerged:

(a) established organisations, such as the HEA and CHCs, each provide specific areas of consumer health information;

(b) there have been recent but very gradual developments in consumer health information collections in both some public and medical libraries, but no co-ordinated provision at district level as

recommended by the King's Fund in 1985.;

(c) the last 15 years have seen the emergence of a significant number of consumer health information services such as Help for Health. Their development can be seen as a response to a clear need for co-ordinated provision of consumer health information across the country.

### **1.3.1 Recommendations for co-ordination**

In reaction to these differing access-points to health and patient information there have been calls for co-ordination.

On a national level, the HEA has been forwarded as 'a strong contender to co-ordinate nationally a health information network'<sup>6</sup>. The functions of such a body are outlined and would embrace such tasks as organising awareness conferences, developing a national consumer health information database and forging links with health information providers internationally. An important function would be the identification of consumer health information provision on both a regional and a district basis and the encouragement of the development of consumer health information services on both these levels.

Similarly, Kempson<sup>7</sup> recommends that 'at the very least there needs to be a resource unit within each Regional Health Authority' for consumer health information provision. The two functions she outlines for a Regional consumer health information unit are that the unit act as a support unit for consumer health information provision initiatives at a local level and act as an enquiry referral point for these local units.

The few years leading up to the Patient's Charter, 1991, have therefore seen emphasis on the need for co-ordination of consumer health information provision at, at least, a Regional level.

### **1.4 THE PATIENT'S CHARTER, OCTOBER 1991**

Against the background of these demands for co-ordinated provision of consumer health information at a Regional level the implications of the Patient's Charter can be viewed as a significant breakthrough: the Three New Rights as outlined in the Patient's

Charter summary contain an important information element. The public is told that it can now expect to be given detailed information on local health services, quality standards and maximum waiting times.

To support these new declared consumer health information rights each Region was told to set up, by April 1992, a Consumer Health Information Service to support the Patient's Charter. The Wessex Help for Health Consumer Health Information Service was given as an example for the Regional Patient's Charter information services to model themselves on.

This demand at Government level for Regional provision of consumer health information closely echoes the recommendations made four years earlier that there be, at national level,

*The encouragement of the setting up and growth of regional health information units, using the example of 'Help for Health' as a model<sup>18</sup>.*

Each region is to provide a consumer health information service that provides information in the following six areas:

- *services available within the NHS as a whole*
- *services available to patients locally*
- *waiting times for out-patients and in-patients treatment by Consultants.*
- *common diseases, conditions and treatments (including relevant self help groups)*
- *complaints procedures (with referral to appropriate bodies such as CHCs and FHSAs*
- *how to maintain and improve personal health<sup>19</sup>.*

#### **1.4.1 The Patient's Charter and the GP**

In the Three New Rights section of the summary of the Patient's Charter the public is told that it can access the new information from the local health authority, GP or community health council. This is evidence of recognition at Government level of the general practice as a viable setting for specified areas of consumer health information

provision, i.e. on NHS services available, standards and waiting times.

The following chapters attempt to highlight the potential for consumer health information provision in the practice setting, and in areas other than solely those outlined in the Patient's Charter summary.

For, against a background of developing consumer health information services, (such as the Health Information Service, Stevenage), of consumer health information collections in medical and public libraries, and of various other sources of consumer health information provision, such as CHCs and CABx, the general practice may constitute another viable access-point in a network of consumer health information providers.



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## 2.0 THE POTENTIAL FOR CONSUMER HEALTH INFORMATION PROVISION IN GENERAL PRACTICE

*...the GP, the Surgery and other surgery staff e.g. Practice Nurses and Health Visitors can play an important role in the provision of patient information ...<sup>1</sup>.*

*The primary care setting offers many opportunities for information provision ...<sup>2</sup>.*

*It is agreed by most commentators that the ideal focus for health information is the Doctor's Surgery<sup>3</sup>.*

Statements such as these illustrate the recognised potential for consumer health information provision in the practice setting by professionals working in the health field.

In literature which reviews current sources of consumer health information provision the general practice is frequently mentioned: one example is in Chapter Three of Gann's The Health Information Handbook<sup>4</sup> where the author reviews existing sources of consumer health information. Primary care is given as one heading among others which include the media, Community Health Councils, Citizens Advice Bureaux and others. Similarly, in Kempson's review of consumer health information sources<sup>5</sup>, she looks at general practice - based services as one area of consumer health information provision.

During the past 10 to 15 years different studies have shown the potential for *practice-based* consumer health information provision in areas of information also available in other settings. For instance, there has been emphasis on: general practice provision of health educational information, already provided by media campaigns and in the school and work place; general practice provision of written drug information as opposed to provision in the pharmacy; general practice

provision of health information literature, also available in the public library and local consumer health information service; general practice provision of information on NHS facilities available, otherwise provided by local health authorities and CHCs.

## 2.1 WHAT MAKES THE GENERAL PRACTICE AN APPROPRIATE PLACE FOR CONSUMER HEALTH INFORMATION PROVISION?

### 2.1.1 Provision of consumer health information

#### Accessible location

The general practice is accessible to all. Most people are registered with a GP and make a visit at least once a year, if not more frequently. If the value of consumer health information provision is recognised for the opportunity it gives an individual to participate in his own health-care then it is appropriate that such information be provided in an accessible location. Consumer health information provided in the surgery setting can be seen as more accessible than its provision in other settings, such as in the medical libraries that *do* permit public access. Most patients will feel more at ease in their local general practice than in the library of a large hospital.

Also, more people know of and visit the general practice than are aware of the existence of a local consumer health information service, such as Help for Health. General practices are more widespread than consumer health information services. Therefore, to develop a policy of consumer health information provision in general practice would mean widespread provision of consumer health information in a place to which all have right of access.

#### Total health-care environment

The total health-care environment of the general practice makes it both appropriate and logical to offer consumer health information there. It is likely that the individual who comes to the general practice will be in a frame of mind that is particularly receptive to

consumer health information. He will be as it were *pre-conditioned* to matters medical. It is logical to 'take advantage' of this receptivity and offer the patient the opportunity to benefit from consumer health information. In the non health-care environment of a public library the individual may not even recall that a health information section exists, and if reminded may not feel motivated to browse through it. Outside the health-care setting there is no reason why the individual should be in a particularly health-concerned mood. By contrast, the same individual finding himself in the general practice setting may find it only natural to feel an interest in any written health information that is available. The health-care setting provides the right background for such information seeking to seem normal and logical.

Furthermore, it is likely that the individual's curiosity about health information will be at its most acute when he is in a health-care environment, and that it is the setting most likely to encourage an individual to actually seek out health information.

### 2.1.2 Provision of specific types of consumer health information

It is also possible to distinguish, for specific areas of consumer health information provision, why the general practice may be an appropriate place to provide this information.

#### Information on further sources of health-care

For many patients the surgery is the first point of contact with medical support outside the primary source of self-care, family and friends. It therefore seems logical that this community-based health service serve not only as a first point of contact but also as an access-point to further sources of health-care support. It seems a natural role for the general practice to link patients up with other statutory and non-statutory health-care services, and thus prove its concern for the patient's continuing care. The appropriateness of general practice provision of information on other health services is strengthened by the nature of the work of the Health Visitor and Community Nurse. For although attached to the general practice, their

responsibilities include a lot of domiciliary and other community-based work. This involves contact with various community-based services such as local voluntary organisations. It seems logical that information about such services be passed onto patients who might benefit from their help and support.

#### Constructive use of waiting time

In the health-care environment of general practice it is appropriate that the patient be given the opportunity to use the time spent in the waiting area constructively by provision of written consumer health information. Whether this be information provided by posters, leaflets or books, or by means of video or computer interface, it is appropriate that the public be given access to health-related self-educative materials as well as to the more common provision of generalistic popular magazines.

For, if it is taken for granted that hairdressers provide magazines on hair styles and on hair-care for waiting clients, and similarly that banks provide racks of leaflets on different banking facilities for queuing clients, then it seems equally appropriate that general practices provide written information on health and health-care services to waiting patients.

#### Availability of health professionals for back-up information

Furthermore, the general practice can offer patients not only written consumer health information but also the added benefit of having a health professional close at hand to whom the patient can direct enquiries and seek clarification on health information read in the waiting-room. This is a speciality of consumer health information provision in the general practice setting, for it is not always the case with other consumer health information provision settings that a health professional is there for back-up consultation. A public library may offer a consumer health information collection but not a health professional. Similarly, although many consumer health information services are located in a health-care setting (Health

Centre or Hospital) with access to health professional advice, not all of them are.

### In conclusion

- This section has proposed the general practice as a viable setting for consumer health information provision. The case for this area of information provision in the surgery has been argued by:

a). giving reasons to support provision of consumer health information provision in general: e.g. patients being well-motivated to receive health information in a health-care setting due to its engendering a health-oriented mood, and by,

b). giving reasons to support provision of specific areas of consumer health information in a location where a health professional is nearby to explain and clarify what the patient has read.

## 2.2 DIFFERENT LEVELS OF CONSUMER HEALTH INFORMATION PROVISION BETWEEN PRACTICES

*This apparent reluctance of the majority of doctors to use written material, contrasts with the enthusiasm of the few...<sup>6</sup>.*

Regarding general practice provision of consumer health information overall, if it is unfair to explain all developments solely on 'the enthusiasm of the few', it is nevertheless true that levels of provision appear to vary a lot between practices. There is no uniform general level of consumer health information provision.

The individual practice's level of consumer health information provision will depend mainly on that particular practice staff's recognition of the value of consumer health information provision and of its own role in such provision. Character dynamics are all important.

The health literature gives many examples of innovative practices which give a lot of attention to the development of consumer health information provision. One example is that of a Hackney GP, Dr

Christopher Dobbing, who was responsible for creating Health Data, a free view data service on health information and education:

*his patients, especially the young, were bored with health information leaflets. His answer was to set up Health Data<sup>7</sup>.*

There are other examples of individual general practice experimentation in the area of consumer health information provision but the impression often given is that these are one-off cases of innovation against a background of a generally low level of general practice enthusiasm for consumer health information provision.

### 2.2.1 Reasons for different levels of consumer health information provision

#### Insufficient resources

It may be the case that a general practice is in favour of the underlying philosophy of consumer health information provision - that patient information enables increased patient participation in health-care, but lacks the necessary financial resources, time, facilities or staff to further develop consumer health information provision.

For instance, a practice may fully support the provision of patient information collections (please see 3.5.4) but lack the necessary financial resources to develop one itself.

#### Hesitance about consumer health information provision

Poor levels of consumer health information provision may however be accounted for by feelings of uncertainty about consumer health information provision. This might involve: concern that provision of written health information about conditions and diseases may increase patient anxiety; uncertainty about the actual benefits of some areas of consumer health information provision, such as doubts about the extent to which health education information does actually influence people's behaviour - increased knowledge may lead to changes in attitude but not necessarily to behavioural changes; anxiety about

possibly confusing patients, by for instance providing them with information on all possible treatments, 'orthodox' and 'alternative', available for a specific condition; doubts about having enough knowledge to pass on information with confidence - for instance, a GP may hesitate on giving health education information on diet and exercise if he is unsure about the extent to which they influence disease prevention.

#### Reluctance to recognise a consumer health information provision role

However, some general practices may show little enthusiasm for consumer health information provision because influential members of the staff do not recognise that general practice has a role in consumer health information provision.

GP's who refuse a role in general consumer health information provision may be those who favour *'a more traditional role for the general practitioner focusing specifically on organic illness... the medically orientated',<sup>6</sup>*

The more traditional GP will continue to attach paramount importance to his role as the healer of the sick who uses his medical knowledge to treat the ill. He will attach much less importance to the provision of information giving both the ill and the healthy potential for increased knowledge on how they can contribute to their own health-care - the ill by informed management of their condition and the healthy by taking measures to ensure the maintenance of their present health.

The GP who sees his role as one of predominantly *healing* rather than one of encouraging patient participation in self-care has little time for providing the healthy with general health information and health education. His time is for the sick.

#### The balance of power

Underlying some GPs' attachment to their healer role, and their unwillingness to develop consumer health information provision lies



the fear of upsetting the balance of power in a situation where the power lies with them. For in the consultation situation between GP and patient the power has traditionally been with the GP who has the necessary medical knowledge for medical diagnosis, treatment and prescription. Over history the patient has been the mere passive acceptor of the GP's medical care. Some GPs are reluctant to lose the aura of mystique that their medical knowledge gives them.

*...the doctor remains a powerful figure where he refuses to share information with his patients... information sharing is power sharing and diminishes paternalism...?*

To provide information on diseases in lay terms lets the patient realise that up to a certain point medical knowledge is within his grasp. It is not a domain totally closed to all but the GP.

Similarly,, to provide health education information makes the patient aware that it is not only the GP who can contribute to health-care. The patient has an important part to play by the very way in which he leads his daily existence. Not *all* health-care depends on the GP's mystical medical powers. Some GPs begrudge this seeming diminishing of their own powers brought about by a better informed public.

However, surely a better informed public leads to a more balanced and therefore more positive and healthy GP/patient relationship?

As consumer health information provision increases, any lingering notion of the mystical GP figure will decrease and the GP/patient relationship will become more of a partnership. The patient will always depend on the GP's medical expertise, but provision of consumer health information allows him to take a more participative and responsible role in the health-care process.

### In conclusion

- This section has forwarded reasons for different levels of consumer health information provision between general practices. These may vary from:

- a) the more 'healthy' reasons: e.g. belief in the value of

consumer health information provision but insufficient funds to develop it, to

- b) the less 'healthy' reasons: e.g. a GP's unwillingness to diminish his power-role by developing consumer health information provision which enables more informed patients to take on a more participative role in the consultation set-up.

### 2.3 DIFFERENCES AMONG PRACTICE STAFF

It is important to recognise that in general patients have different consumer health information expectations from different members of the primary health care team.

#### GP and practice nurse information provision

Expectations will clearly vary between different practices due to the personalities of individual members of the surgery staff, but the general tendency is for patients to turn to their GP for information of a more strictly *medical* nature and to the practice nurse and health visitor for what can be termed information of a more *social*-related nature. This might include information on how to lead a healthy life style, and advice and information relating to the patient's social problems, such as family, housing and financial problems. As a broad generalisation, patients are more prone to expect information for the care of their *physical* well-being from the GP and information for the care of their *social* well-being from other members of the surgery staff. Maintaining the health of the social self is crucial, for if it deteriorates so too does the patient's physical well-being.

A study by Stilwell et al.<sup>19</sup> illustrates this distinction between patients' information expectations from GP and practice nurse; a comparative analysis was made of patient problems presented to a nurse practitioner in general practice and those made to GPs in three earlier studies. The nurse was actually given, and patients knew this, greater autonomy than the average practice nurse. She could diagnose, prescribe and treat patients, and only needed to refer patients to GPs if she felt it necessary.

The analysis emphasised the social role of the practice nurse as

compared to GPs: 60.4% of problems presented to the practice nurse were 'supplementary classification': i.e. not strictly medical problems. This classification mainly covers health prevention and education, as well as 'social, marital, family problems and maladjustments'<sup>11</sup>. This class of problems only made up 8.4% and 11.4% respectively of problems presented in the three GP studies. Patients mainly came to GPs seeking medical diagnoses and prescriptions.

This study emphasises the nurse's important social counselling role as compared to the GP's more medically-related one.

A follow-up article to this study<sup>12</sup> further emphasises the trend for patients to seek more of an advisory/counselling role from the practice nurse than from the GP.

#### The GP's social role and social information

The Stilwell study confirms the findings of another study which looks at the extent to which the GP's role has moved away from the more traditional medical dimension to a more social one<sup>13</sup>. The GP with a social orientation is one who recognises not only the medical but also the psycho-social aspects of health-care. This is to recognise the 'role of social and behavioural factors in the causation of disease and the maintenance of health'<sup>14</sup>. The GP with social orientation would therefore recognise the importance of maintaining the patient's social well-being and would see the importance of providing the same types of information that Stilwell's study suggests patients seek more from the practice nurse.

Calnan explains how the GP's holistic solution, 'or the idea that general practitioners should have both a medical and a social role...'<sup>15</sup> evolved in the 1950's/60's in an attempt to give general practice a distinct flavour as compared to hospital medicine which was more highly regarded. But his 1988 study concludes that GPs could on the whole become yet still *more* involved with the social concerns of their patients.

Only when GPs generally show a clear interest in their patients' social background and how this might effect their state of health will patients start to *expect* information related to social well-being from their GP.

### Patient perceptions of the GP

Reasons have also been forwarded for why patients as a rule turn to the nurse or health visitor rather than to the GP for general information<sup>16</sup>. Elements to be taken into consideration include patients feeling daunted by the educated GP, feeling less embarrassment with the nurse who they consider to be generally more forthcoming, and patients finding it easier to identify with the nurse whose education will have been more practically based than the GP's. What is important is that for various reasons patients find non-medical staff more approachable than the GPs and so come to depend on them as their main information sources.

### The health visitor - a special information role

The health visitor deserves special mention as the member of the primary health care team whom patients turn to, rather than to their GP, for information on community-based support groups. This can be explained by the very nature of the health visitor's work which involves a lot of time spent outside the surgery in the community. Patients are aware of the traditional emphasis on the health visitor as the surgery staff member with

- *a key responsibility for linking patients with sources of help and information in the community*<sup>17</sup>.

### In conclusion

- This section has tried to show that as well as levels of consumer health information provision varying between practices, patients have different *expectations* on types and amounts of information to be received from different members of the primary health care team.

- Studies such as Stilwell's<sup>18</sup> and Calnan's<sup>19</sup> suggest that patients tend to expect information of a more specifically medical nature from their GPs and find other members of the practice staff

easier to approach for other types of information, such as for information on leading a healthy life style or for information on support groups available in the community.

- The health visitor has a specially recognised role as supplier of information on community-based groups of help to patients.

## **2.4 PUBLIC EXPECTATIONS**

Levels of consumer health information provision may vary between different practices, for reasons such as those outlined in 2.2.1. Patient expectations will also effect general levels of consumer health information provision. The relationship between expectations and provision can be seen as a circular one: if there is little evidence of consumer health information provision in the general practice, patient expectations of such provision will remain low. Low expectations will not encourage the level of patient demand which is needed to spur the practice into developing consumer health information provision. Consequently, unless the primary health care team already has a particular interest in developing its consumer health information provision, it may feel little incentive to do so. As long as this situation continues, the traditional concept of the general practice as place of medical diagnosis rather than as place of learning and patient participation in health-care will prevail.

However, if it is so that we are living in times of increasing levels of consumer health information provision and that 'informed health care consumerism is now the orthodoxy<sup>20</sup>' it seems probable that increased public expectations will see a gradual increase in demands for consumer health information provision in all potential settings, the general practice among them.

*As people's health expectations become more sophisticated, the role of the doctor and his team in communication and explanation will continue to increase<sup>21</sup>.*

Expectations will be raised for instance by the recent Government legislation which emphasises consumer health information provision, such as the new rights to information on National Health Service

facilities, quality standards and waiting-times as outlined in the Patient's Charter, October 1991. As the general public gradually reaches a fuller understanding of its new information rights expectations may increase and further demands be made.

The following two chapters focus on the areas in which consumer health information provision is being developed in the general practice setting. The underlying aim is to thus illustrate the *potential* that this setting holds as a focus for such information provision.

A distinction is made between *existing* and *recent* developments. The former are in areas of consumer health information provision which may be in a state of continual development but which originated during the past 10 to 15 years. The latter are those which have been encouraged by (mainly) Government legislation over the past two years.

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### 3.0

## EXISTING DEVELOPMENTS

This chapter concentrates on developments in provision of consumer health information in general practice made during the past 10 to 15 years. Several different developments are highlighted with the objective of thus emphasising the strong potential for such information provision in general practice. The following areas will be discussed:

the work of patient participation groups (PPGs); general practice as patient access-point to self-help groups and to statutory and non-statutory health-related services in general; general practice access to consumer health information services to improve levels of practice-based consumer health information provision; developments in written consumer health information provision in the surgery and provision of information on welfare rights assessment.

The linking thread is that the information provision enables patient participation in matters of health and health-care. It is hoped that this fundamental relationship between information provision and participation remains clear throughout.

### 3.1 PATIENT PARTICIPATION GROUPS

PPGs are important for their collective contribution to developments in several areas of practice-based consumer health information provision. The emphasis put on consumer health information provision will vary a lot from one group to the next but most groups do focus to some extent on patient information provision. Also important is that PPGs illustrate active *patient* participation in improving levels of information provision in the surgery.

PPGs are groups of patients and practice staff representatives attached to one practice. Most PPGs are associations to which all patients automatically belong, with a committee acting as executive body, but in some cases the committee *is* the PPG and represents the interests of the practice-population.

The first PPG was set up at Berinsfield Health Centre, Oxon in



1972 and the 1980's saw a steady rise in PPGs' with development at a growth rate of 10% in 1983<sup>2</sup>. By 1981 there were 40, 50 by 1983 and this had doubled to about 100 by 1987<sup>3, 4</sup>.

Focus of attention can vary considerably between different PPGs, for all-important is their response to local needs. This individuality is supported by the National Association of Patient Participation Groups (NAPP) which set up in 1978, for it 'encourages groups to develop according to the needs and wishes of the patients and doctors (and health staff) in a practice and not according to a model'<sup>5</sup>

The work of PPGs in general has however been divided up into five main core areas<sup>6</sup>. Four of these areas are: consumer feedback, health promotion, community care and fund raising. The fifth is described as 'providing information - practice guides, leaflets, local facilities',<sup>7</sup>

The PPG has an important role in the provision of practice-based consumer health information. This includes various areas of information provision:

#### Health education/promotion information

PPGs generally have an important role in providing information on health education. The recognition of this potential was the main reason for which the first PPG was set up in Oxon:

*they hoped a patient group would provide a means of transmitting information about health education... proved to be a good channel for health education.*<sup>8</sup>

In his 1983 survey of UK PPGs<sup>9</sup> Paine describes how PPGs organise regular health education meetings and debates, often with local consultants or practice GP participation. Aberdare PPG was involved in producing videos of the health education talks to take out to patients in their own homes.

Producing publications is also a common way in which PPGs provide health education information: the same survey by Paine refers to two

such booklets produced by Birchfield PPG - one on health in the over 60's, the other on prevention of accidents at home .

#### Health information literature

PPG involvement in literature production is important because the leaflets and booklets produced cover various areas of consumer health information: these may include health education literature as mentioned above, practice guides, regular newsletters offering health information, and displaying information on the practice notice-board (e.g. information about patient rights<sup>10</sup>).

Concerning provision of written health information Paine also refers to two PPGs 'arranging medical book lending services for their patients'<sup>11</sup>. The concept of patient libraries will be discussed at 3.5.4.

#### Information on local facilities/services

This area of consumer health information provision is an important aspect of the PPG's information role: Paine's survey<sup>12</sup> mentions how 10 groups carried out surveys into practice facilities and those provided in the practice vicinity, and produced guide books based on their findings.

Reporting on Paine's survey Gann writes, 'about half are providing information, usually in the form of newsletters or directories of local health care facilities'<sup>13</sup>.

Information provided might also concentrate on a *specific* area of service provision such as the example of the group at Whiteladies Health Centre which produced an informative booklet on homes for the elderly in the area<sup>14</sup>.

#### General consumer health information provision

This is provided by what Paine's survey describes as the 'voice and interaction' activity of PPGs<sup>15</sup>. For PPG general meetings give patients the opportunity to direct general enquiries at practice staff and to obtain clarification on health issues. Meetings can be seen

therefore as forums for the transmission of consumer health information from GP to patients. The same survey also reports how 12 groups held regular 'brain trusts': GPs are 'quizzed on matters relating to health, the practice and the National Health Service'<sup>6</sup>.

### 3.1.1 The need for further developments

PPGs can therefore make important contributions to consumer health information provision in general practice. Their general value has been recognised by the Royal College of General Practitioners (RCGP): the College's occasional paper no.17 promotes the concept of patient participation in general practice, and at a conference on PPGs, held some 10 years ago<sup>17</sup>, the College's President supported the PPG concept and stressed how trainee GPs should learn more about them.

However, in 1986 only about 1% of practices had a PPG<sup>18</sup> and eight months research carried out on 80 groups by the Policy Studies Institute found that 17 of the 80 groups were no longer functioning. Furthermore, only 25% of PPGs were in the inner city and suburb areas which are most in need of the good they can do<sup>19</sup>.

Lack of sufficient publicity of PPGs in general and of the actual activities of individual groups is seen as a main cause for the poor provision of PPGs. These are often short-lived because they do not attract a wide enough representation of the practice population overall.

It has been suggested that one reason for insufficient publicising of PPGs is due to GP fears that they may be accused of going against medical ethics by advertising for the practice<sup>20</sup>.

Each individual PPG must increase its publicity efforts. This will give the PPG a firmer base by attracting interest in it from a more representative sample of the practice-population. And increased awareness of PPG activities will also ensure that greater numbers do benefit from the areas of consumer health information provision that the PPG is involved in.

### In conclusion

- This section has emphasised the PPG role in practice-based

consumer health information provision.

- This role focuses mainly on provision of health education information and on production of health information literature.

- PPGs are not widespread and often lack widely-based practice-population representation. It has been suggested that improvements in future developments depend on increased publicity efforts.

### 3.2 ACCESS TO INFORMATION ON SELF-HELP GROUPS

*Participating in a self help group can be part of the curing process<sup>21</sup>.*

It seems a logical and natural extension of the GP's role that, where appropriate, he refers patients to self-help groups. By providing patients with information on self-help groups the GP is fulfilling his role as consumer health information provider in a valuable area and thus showing that his concern for the patient's welfare is a total one: his concern goes beyond what he himself can do to help, and seeks to give the patient access to further health support outside of the surgery.

The relationship between general practice care and self-help group care is a complementary one, for the self-help group provides patients with the support and guidance that the GP not only does not generally have the *time* for but is not equipped to give. For the special value of a self-help group is that members can give each other mutual support and strength by exchange of feelings about a shared handicap or problem. However sensitively a GP fulfils his counselling role it is rare that he can give equivalent support to that of a mutual sufferer. For example, a GP can check on the physical health of a woman who has recently suffered a miscarriage and monitor her recovery but can not contribute to her psychological recovery from the trauma in the same way as a self-help group might, where the woman will have contact with others who have similarly suffered and who can better understand and share in the emotional after-effects of miscarriage. For,

*the unique feature is the shared experience of different ways of coping with disease<sup>22</sup>.*

Self-help groups exist for a multitude of conditions. If a group does not already exist sufferers can investigate into setting one up.

Considering the important part that the self-help group can play in the curing process, it is surely a valuable aspect of the GP's role as consumer health information provider that he informs patients of relevant groups.

### **3.2.1 Information: a key to participation**

*The whole field of self-help is an important one, with the lay people involved demonstrating their wish to participate in health care<sup>23</sup>.*

Informing a patient of the existence of a relevant self-help group enables the patient to participate in his own health-care. Not only is he participating through choice, for it is up to him to decide whether or not to join the group, but by attending group meetings he is participating in his own healing process. For through the group he will gain strength and insight into how to manage his particular handicap or problem.

There is also participation in the sense of a patient's consequent increased understanding of his condition.

Lock<sup>24</sup> defines five possible principal roles of a self-help group: information, contact, expert counselling, lobbying and fund raising for research.

The information role is the main one for some self-help groups whose aim is to provide sufferers with information about their problem. Information may be accessed through written literature, telephone or meetings. In this way the self-help group can be a specialised health information service for the patient. The group takes on,

*the importance of an information exchange which contributes to a greater factual understanding of the problem<sup>25</sup>.*

Therefore, by telling the patient of the group's existence the GP acts as information provider whilst enabling the patient to access an information source (the self-help group) which is specialised in his problem area. The result is a more informed patient who participates through increased understanding of his condition.

### 3.2.2 GP referrals and attitudes to self-help groups

The recent past has seen real gaps in patient numbers learning about self-help groups through their GP. It was one of the nine main information gaps outlined by Agony Aunt Claire Rayner in 1979:

*what never ceases to amaze me is the number of them who are not told of the many services that are available and of the voluntary bodies who gladly help<sup>26</sup>.*

Lock<sup>27</sup> refers to a 1983 Policy Studies Institute Survey which found that only 18% of respondents had learnt of their self-help group from their GP or health visitor. Main information sources on self-help groups were through hearsay, newspapers and magazines.

Low GP referral of patients to self-help groups may be explained by mixed attitudes towards such groups: some GPs may feel jealous of the special support a self-help group can give the patient and feel that they have somehow failed by being unable to supply all the help the patient requires; some GPs may feel a certain suspicion and uneasy about self-help groups: suspect them of being anti-doctor, raising false hopes of patient recovery or making members become obsessed by their condition. This shows a lack of awareness about the aims and activities of self-help groups. This is emphasised in an article reporting on a King's Fund Centre Conference on self-help groups<sup>28</sup> relationship with health professionals<sup>29</sup>. GPs seemed unwilling to become involved in self-help groups or to refer patients to them because of an uncertainty about the groups' aims and general quality.

It may however be the case that GPs *approve* of self-help groups but feel unable to pass on information about them to patients because of their own difficulties in finding out about what groups exist in the area.

Lock<sup>29</sup> sent out a questionnaire on knowledge and attitudes to self-help groups to doctors from the British Medical Journal's list of referees. Replies showed that a clear majority approved of groups, thought them useful and would inform patients about them, but most only knew of a small number of groups. However, 75% would use/probably use groups more if lists were available.

### 3.2.3 Developments in GP access and awareness

Problems of both access and awareness seem in the past to have limited the extent to which GPs fulfil their role as providers of information on self-help groups.

During the past decade however there have been important developments in these two areas - reason therefore for improved levels of GP consumer health information provision on self-help groups.

#### Difficulties of access and the Helpbox breakthrough

GP access to information on existing self-help groups has been difficult because of no recognised central listing of them. Time pressures on surgery staff leaves little time to either do the research necessary to compile a surgery-directory on groups or to research into which local organisation may have already compiled such a list. This might be, for instance, the local public library, local health promotion department or other source.

For it is difficult to produce and maintain an up-to-date directory on self-help groups: they may change their name or assume an acronym, change address, start up or disband, or merge with another group. A group that exists nationally does not necessarily have a local branch and vice versa.

However, over the past decade a series of directories on voluntary organisations and self-help groups have been compiled. Gann cites five such<sup>30</sup> and there are others, such as The Health Directory<sup>31</sup> and The Self-Help Guide<sup>32</sup>.

But such directories are of limited use to a GP seeking immediate access to information on groups in his practice vicinity, for they mainly list national associations only. Some directories do indicate

existence of local branches. The Health Directory for example does so by inclusion of the letter 'B' after a group's details to indicate local branches. Precise locations are not given however.

Difficulty of access has led a few GPs to actually research and produce their own local directory. Dr Chris Varnavides, a Leeds GP, is one example: recognising the importance of self-help he began to compile his own directory of them when he first set up practice some 15 years ago<sup>33</sup>. Now he uses the published directories as a tool in keeping his own directory updated locally.

A major breakthrough in access to information on self-help groups at both a national and local level came with the introduction of Helpbox in 1980. Helpbox is a database of national and local (originally of the Wessex Region) self-help groups. It was the result of a research project funded by the British Library and administered by Help for Health, Wessex. It originated from recognition of the need to improve health professionals' access to information on self-help groups.

*Research confirmed that tracing relevant voluntary and self-help groups was a major need, particularly for community-based health professionals such as general practitioners, community nurses, health visitors and social workers<sup>34</sup>.*

Research confirmed suspicions of little consistency of approach among surgeries on how to access self-help group information. This was due to lack of centralised information on existing voluntary organisations.

Interviews with health professionals revealed a heavy reliance on personal knowledge and contacts for information rather than on formal information agencies<sup>35</sup>.

Information agencies used included (in descending order of reference): councils of community service; health district libraries; public libraries; health promotion departments and community health councils.

Published sources such as directories and journals were little used. Directories when used, were often out-dated editions.

The research findings discovered heavy GP reliance on health



visitors to put patients in contact with self-help groups. This is important as it emphasises an area of consumer health information where provision is clearly associated more with some members of the primary health care team than with others (please see 2.3). Findings revealed that about a third of GPs relied on health visitors being 'in the know about sources of voluntary help'<sup>36</sup>.

Health visitors have the opportunity to build up contacts with community-based voluntary organisations which have proved to be of help to patients in a way that GPs do not. The nature of the health visitor's work involves more contact with patients in other than the surgery setting alone, and gives opportunities to learn of their experiences with self-help groups. Listening to patients' accounts raises the health visitor's awareness and knowledge of self-help groups and puts this member of the primary health care team in a better position than the GP to refer the next patient on to an appropriate group.

And yet there is great value in the GP as well as the health visitor referring patients on to self-help groups. If the GP could personally recommend an appropriate self-help group to his patient during or at the end of the consultation process, surely it would give the patient increased confidence in his GP, for it would emphasise the GP's concern in his patient's continuing and total care. It is not a concern which abruptly stops once the GP has done all he can do to help. It shows that the GP is happy to recommend further sources of patient support.

Helpbox was an important advance for it gave GPs and other health professionals the opportunity to access, mainly by telephone (and computerized access is also now available) a central source of information on self-help groups at national and local level.

And with the purchase of the Helpbox database by consumer health information services in other Regions of the country, this access to a centralised source on local self-help groups is becoming increasingly widespread. It is not now Wessex GPs alone who can benefit from a self-help group database.

The Help for Health project intended to develop an information package which could be bought by other Regions and which would give information on national groups, guidelines on collecting information

on local groups and which would indicate the likely range of such groups<sup>37</sup>.

This has happened: Health Matters, Milton Keynes; Health Matters, Walsall; Healthpoint, Poole; Health Information Centre, Loughborough and Health Information Service, Nottingham are just a few of the consumer health information services which hold the Helpbox database.

Helpbox gave the potential for GPs to have easier access to information on self-help groups and to better fulfil their role in this area of consumer health information provision. The extent to which practices in the vicinity of an information service which holds Helpbox are actually aware of and take advantage of the facility will however very much vary. GPs' use of consumer health information services will be discussed in 3.4.

Government stipulation that each Region establish an information service similar to Help for Health to support the Patient's Charter<sup>38</sup> should lead to country-wide provision of Helpbox (or a comparable self-help database) at Regional level and ensure that all GPs have access to self-help group information at this level at least. Some practices may already use the facility as provided by a consumer health information service at District level.

Gann foresees that Regions will subscribe to Helpbox and the database which was already available on disks in November 1992 was to be made available online via a modem<sup>39</sup>.

There seem to be as yet few examples of general practice computerized access to self-help databases. For example, both the Health Information Centre, Loughborough and the Health Information Service, Nottingham have the Helpbox database but no local GPs access the system by computer. Most common form of GP access is by telephone.

However, perhaps the development of Regional Health Information Services will increase GPs' computerized access, for patients' increasing awareness of these services and of what they offer the public may lead to increased patient demands for information on self-help groups from their GPs. GPs may consequently look to computerised access to the database for the benefits of having information on self-help groups ready-to-hand rather than having to spend time phoning up for information. Computerized access also has the advantage of

offering a browsing facility.

Health Link Wales, launched at the Morriston Hospital, Swansea, April 1992, is a new self-help group database for Wales which holds information on 'more than 1,400 self-help health groups, on community, local and national level<sup>40</sup>'.

It deserves a special mention here for the role played by general practice. General practices make up three of the 21 delivery sites at which the database can be accessed. The other sites include libraries, hospitals, health promotion units, pharmacists and a resource centre for the disabled. All sites have computerized access (online or disk) to the database which is held at the Health Promotion Authority, Cardiff.

The GP practices were 'chosen because of size, and enthusiasm for self-help groups. We are certainly not able at present due to resource constraints to offer the service to all GP practices, although this may happen in the future<sup>41</sup>'.

The practice delivery points can only be used by the practice's own patients, but this provision means that at three large practices patients, via their GPs, have immediate access to up-to-date information on self-help groups at local, community and national level.

GP practices acting as delivery sites shows a clear recognition of the appropriateness of surgery staff providing in this area of consumer health information provision. They can be expected, as much as libraries, health promotion departments and the other locations used as delivery sites, to provide access to self-help groups.

The direct computerized access to self-help groups that these three Welsh practices offer patients can perhaps be seen as a model for other GP practices across the UK to attain. It remains to be seen to what extent this example will be followed by surgeries which access the developing Regional Health Information Services.

#### GP awareness of self-help groups and the role of self-help teams

*... there has been an alteration in GP's and the practice staff in awareness of self help groups. ... I am receiving more enquiries*

about self help groups from practice staff and GPs than in years gone by <sup>42</sup>.

Significant improvements in access to information on self-help groups must however be accompanied by satisfactory levels of awareness of the value of these groups. Improved access raises the *potential* for GPs to help patients in this area of consumer health information provision, but awareness of what self-help groups actually do is needed to dispel uncertainties and misinterpretations of the groups' work. And there have been developments in the area of raised awareness. In fact, the very growth in self-help group numbers is in itself an important contributor to the gradual acceptance of such groups among health-care professionals.

One suggestion has been that health authorities or self-help groups employ 'link workers' to act as mediators who explain the group's work to doctors<sup>43</sup>.

The work of self-help teams is important for this aspect of link work, for such teams support local self-help groups and generally concentrate on actively publicising them; even if numbers of self-help teams in Britain is currently fairly low and patchy<sup>44</sup> the work that existing teams do to promote self-help groups among GP practice staff is valuable.

The Self Help Team, Nottingham is one such team. Set up in 1982 the Team aims to promote awareness of self-help generally and within the health service it recognises GP practice staff as an important group with which it feels that 'slow but secure links<sup>45</sup>' are being forged, and with which it wishes to work more closely.

Ways in which the Team actively contributes to raising practice staff's awareness of self-help groups include: sending copies of the Team's Self Help Directory out to all GPs and to several health centres, practice nurses and practice managers; a recent family health service authority (FHSA) training evening where self-help groups came to discuss their work with GP practice staff; a recently published article in the FHSA periodical In Practice explaining the Team's activities and aims, and during the last three years two study days have been held 'where self-help groups, GP's and other health professionals met to discuss issues involving self-help<sup>46</sup>'.

The Team has also produced publications in collaboration with Nottingham's Family Practitioner Committee (FPC) which aim at raising GPs' awareness of self-help groups and encouraging a health-care partnership between the two. One such publication is a pamphlet directed at GPs - A Self-Help Group for your Patient?, 1988.

The Team has also been involved in holding seminars on self-help groups for fourth year undergraduates of the Department of General Practice, Queens Medical Centre, Nottingham<sup>47</sup>.

Holding undergraduate seminars on self-help groups has been taking place within the Department since 1984. Members of self-help groups take part, 'often giving moving accounts of their experiences and the way the group has helped them<sup>48</sup>'.

Surely this practice should be encouraged generally across UK Departments of General Practice as an effective way of raising future GPs' awareness of self-help groups.

In collaboration with FHSA health promotion advisors the Team is currently exploring other ways of informing GP practice staff about self-help groups.

If the Team's work in this area is representative of the work of self-help teams generally then such teams are making an important contribution to raising GP practice staff's awareness of self-help groups, and their further development should be encouraged. In fact in 1986 the National Self-Help Support Centre (renamed The Self Help Centre as from July 1992) was set up at the National Council for Voluntary Organisations, London, to support the work of self-help teams. The Centre also aims to increase awareness of self-help groups at a national level. The Centre targets health professionals as one of the groups to which the value of self-help groups must be publicised.

An effective way for GPs and other health professionals to become more aware of the value of self-help groups is by participation in the group meetings. Attendance can give first-hand insight into what self-help groups are really all about. The Centre favours this participation:

*How useful it must be then for doctors, and other health professionals, and social workers to participate in this process too.*

*They are not to become members of the self help group, but they can be "resource people" to the group<sup>47</sup>.*

### In conclusion

- This section has focused on information to patients on self-help groups as an important area of practice consumer health information provision.

- Informing patients of relevant self-help groups enables continuation of the curing process beyond the surgery doors. It enables patient participation through choice (i.e. whether or not to attend the group meetings), through attending meetings as part of the curing process, and through increased knowledge about his condition as learnt from the self-help group.

- GP attitudes to self-help groups and consequent willingness to inform patients about them may vary between practices.

- Two main obstacles have been problems of GP access and awareness of self-help groups: access to information on self-help groups has been improved by the introduction and spread of Helpbox in consumer health information services; awareness has been improved by an increase in self-help group numbers, by some GPs' active involvement in self-help groups, and by the publicising work of self-help teams.

- This combination of developments in GP access to and awareness of self-help groups strengthens the potential for increased levels of practice provision in this area of consumer health information.

Being able to provide patients with information on self-help groups falls under a wider information role for the general practice - that of providing information on all community health activities/services of relevance and help to patients. This will be considered next.

### 3.3 PRACTICE PROVISION OF INFORMATION ON HEALTH ACTIVITIES AND SERVICES IN THE COMMUNITY

General practice is often a patient's first contact with formal health-care and is thus ideally placed to act as a gateway to information on other statutory and non-statutory health activities. For it is an important aspect of the GP's information role that he can give patients information not only on the statutory health authority services (i.e. on hospital and community care, the latter including dentists, opticians and day hospitals among others) but on the many health-related activities and services of the local authority and non-statutory sector. These activities and services may either contribute to continuing care and support for the sick and disabled, or give information and contribute to the continuing health of the fit.

To provide in this area of consumer health information places the GP practice in the centre of a spider's web image: the GP practice acts as central access-point to a network of other community-based health-related services.

The following gives examples of the different types of services the practice could provide patients with information on and refer them on to:

#### Under local authority control

For example: information on the practical aid that the *Social Services* provides for the disabled, such as meals on wheels, home helps, care attendants and aids and equipment; information on the help available from the *Welfare Services* also; information on the *local public library's* health literature collection or community information service; information on leisure and *recreational facilities* available, such as swimming facilities to help a sufferer of back pain and general sports facilities to maintain the health of the physically well.

### Non-statutory sector

For example: information on the health activities of voluntary organisations; community health projects; self-help groups; private and alternative health-care.

GPs must be aware of these diverse health activities existing in the community and also of the necessary contact points to find out details for patients. Contact points might include local social and welfare services departments, local consumer health information services, local councils for voluntary service, local community health council and citizens advice bureau. The practice's health visitor will act as an important contact for information on self-help groups, community health projects and other community health activities.

GPs may contact such services to find out information on the patient's behalf or pass on details of the contact-point so that the patient can choose to follow up the information or not. This gives the patient the opportunity to take an active participation in his own health-care.

In this way the GP can be seen as contributing to his consumer health information provision role 'by providing a network of local access points to health information'<sup>50</sup>.

Itself a node on the health information network the general practice should be capable of directing patients to other nodes - such as to CABx, CHCs and public libraries where patients may wish to go in person for health information rather than receive information only on GP intervention. An existing local consumer health information service should constitute one such access-point for it is a valuable source of health information.

The next section will consider how practice staff can use consumer health information services to support their own role as consumer health information providers.

### 3.4 PRACTICE STAFF AS USERS OF CONSUMER HEALTH INFORMATION SERVICES

GP practices can use local consumer health information services to strengthen their own role as consumer health information providers. A local consumer health information service constitutes a central



information source which practice staff can exploit for information rather than spending limited practice time seeking out the information themselves. Different sorts of information may be accessed and the service acts as a resource tool for the primary health care team in its role as provider of consumer health information.

GPs may refer their patients to the consumer health information service or access it in person and filter the information through to the patient. A referred patient is able to participate in his health-care both by *choosing* whether or not to contact the service, and if he *does* choose to do so then he participates by actively seeking out information that will benefit his health.

Benefits of the GP mediating between the consumer health information service and the patient is that he can filter the information and be in a better position to discuss the information in detail with the patient and pick up any patient anxieties.

#### 3.4.1 Patient information that practice staff can access

##### Information on self-help groups

As has already been mentioned (please see 3.2.3) a local consumer health information service can be used by the primary health care team as a central information source on local self-help groups. Many services now hold database files on national and local self-help groups.

##### Written information

Another important area of information that practices can access through the consumer health information service is written information in lay terms which facilitates a patient's better understanding of his condition. For instance, at Lister Hospital, the 'HIS' is geared to working closely with GPs to channel information to patients, pitched at a lay level they can understand<sup>51</sup>.

GPs can contact the service and ask for a literature search on a specific condition and the service will scan its literature resources to provide leaflets and photocopied articles on the requested topic.

Materials held by any one service may vary but resources will generally include leaflets from self-help groups, pharmaceutical companies, the HEA and local health promotion department as well as medical, nursing and popular journals and popular medical texts.

Some services compile their own subject folders, each one containing a variety of written information on a particular condition. Folders will include relevant press-cuttings and photocopied articles. The Health Information Service at Lister Hospital stocks about 3,000 such folders and uses a wide range of written sources to carry out its literature search enquiries<sup>52</sup>.

A consumer health information service may be used simply to obtain easy-to-read information to facilitate a patient's understanding of his condition. A GP may also access the service to get a *selection* of articles on the same condition to give his patient access to a more rounded selection of viewpoints on his condition than the GP's alone.

#### Service-specific information provision

Any one consumer health information service may also have a particular information emphasis and be able to help practice staff with the provision of that particular area of consumer health information. For example, the Health Information Centre, Loughborough has a special role in provision of health promotion to NHS staff in the area<sup>53</sup> and GPs access the service for information on running health promotion clinics and might ask the service to do health promotion displays for the practice. The service is thus used to aid GP practice staff in the specific area of health promotion information provision to patients. The Centre also puts special emphasis on meeting the information needs of Charnwood's ethnic minorities and stocks several leaflets in ethnic minority languages. GPs can use the centre to trace written information in ethnic minority languages which it is hard to trace elsewhere.

Similarly, the Health Information Service, Nottingham has inputted additional information on courses, classes and activities relating to health<sup>54</sup> into its self-help group database. GP practice staff can use the service to access information for patients on local

yoga classes and similar activities. By accessing this information from the service the GP practice is able to widen its own range of consumer health information provision.

With the development of Regional patient's charter information services GP practice staff will have the opportunity to access additional Government-specified areas of patient information (e.g. information on NHS services) from a central source (please see 4.1.3). This will result in more efficient practice provision of the specified areas of information than previously possible.

### 3.4.2 Influencing factors on practice use of consumer health information services

The extent to which different GP practices access local consumer health information services will vary. It is possible to distinguish at least three influencing factors: to whom the individual service publicises itself; personal dynamics; location of the service.

#### To whom the consumer health information service publicises itself

Practice awareness of a service's facilities will clearly effect how well it uses the service. The extent to which consumer health information services publicise themselves to health-care professionals (and the degree to which the primary health care team is specifically targeted within this group) will vary. And even if a service *claims* to be there for professional and public alike, there may in practice be clear biases in the way the service publicises itself.

Health Facts Centre, Frenchay Hospital, Bristol, cites both health visitors and GPs among those health-care professionals who 'figure prominently<sup>55</sup>' among its users, and though the Centre was set up mainly for the public, 1989 statistics showed that 40.9% of users were in fact health-care professionals<sup>56</sup>. This good GP usage correlates with the way the Centre promotes itself, for not only is publicity of the service good generally but GPs are targeted as a *specific* user-group: 'GPs in local practice or on refresher courses'<sup>57</sup> are listed among those health-care professionals who are made aware of the Centre through 'induction sessions' in the Centre's group

discussion room, and health centres are listed as one of the places through which the service has been publicized. Regarding the same publicity/user correlation, in a 1987 survey it was found that the users of Help for Health were 86% professional: 14% public as compared to Lister Health Information Service's 44% professional: 56% public. And it was 'found that the differences were related to the expressed goals of each service<sup>56</sup>'. Help for Health was known to have originated from research into health-care practitioners' needs for information on the voluntary sector, whilst the Lister service publicised itself more as a service for health professionals and the public alike.

Another important influence on primary health care team usage of consumer health information services is that of personal dynamics.

#### A question of personal dynamics

The service at Lister Hospital for example is very well used by practice staff within the district and the personal enthusiasm of the Librarian in charge has been all important. Her personal contact with GP practice staff has influenced their recognition of the importance of consumer health information provision in general practice. It has influenced GPs' recognition and use of the service. A colleague writes that her 'contact with GPs has been invaluable... she has successfully demonstrated the need for health information and convinced local doctors that the HIS is not about threatening their role but rather about complementing it<sup>57</sup>'.

Equally important is the personal enthusiasm of *practice staff* towards using consumer health information services. Personal conviction of the importance of consumer health information provision in general practice together with awareness of a local consumer health information service should lead to good GP exploitation of the service's information resources.

The constant use of the Lister Hospital service by local GP, Dr. L. Pike, illustrates this enthusiasm. Since discovering the service in 1988 he has used it extensively to access information for patients.

Just as *positive* personal dynamics can lead to good GP use of a consumer health information service individual practices can have

*negative* approaches to the service: some GPs feel that such services are a threat to their relationship with patients - a sense of being usurped by the service. For some GPs fear that such services try to give patients medical advice.

The CHIC directory<sup>40</sup> shows however that certain services actually make a policy of stressing that they offer information, not advice, and that if necessary they refer patients on to more medically-based services.

Staff of a health information desk set up in a Manchester health centre felt this initial wariness from the GP practice staff<sup>41</sup> for more 'traditional' GPs who are unconvinced of the general value of consumer health information provision will tend to make little use of consumer health information services. This was markedly obvious regarding one service visited where the service was actually located within a health centre but very rarely used by the practices housed within the same building. The very proximity of the two services (i.e. general practice and information service) made GPs' non use of the service quite striking. For it could be thought that close proximity of the two services would *encourage* rather than deter GP usage of the consumer health information service.

#### Location as an influencing factor

Considering the often quite true significance of the dictum 'out of sight out of mind' it is probable that a consumer health information service's physical location in relation to the general practice will influence the latter's use of the service. Even though GPs are usually under considerable time pressure and will more often phone up rather than visit a service in person, *seeing* the consumer health information service every day will at least act as a constant reminder of its existence.

Those responsible for setting up a health information desk for a one year experimental period in a central Manchester health centre considered health centres to be 'ideal locations' for consumer health information services<sup>42</sup>. The service can refer enquiries to on-the-spot practice staff if medical advice is being sought and the practice staff have the service's health information resource on hand.

Manchester found that the service was well-used by the GP practice staff and recommended that the district health authority establish similar health information desks at other health centres also.

Recently in Scotland there have been a number of consumer health information services set up in health centre locations<sup>63</sup>. It is also the case that *existing* consumer health information services which plan to extend their service points consider the health centre as a possible location: in 1990 Health Facts Centre, Bristol was considering establishing a similar service in a health centre<sup>64</sup>. And Health Matters, Milton Keynes has plans to set up service points in a range of different locations, a health centre among them<sup>65</sup>. The plan is to set up a health information service in each location with Health Matters acting as an important backup service.

An increase in numbers of consumer health information services being located within health centres, and therefore in close proximity to GP practices, may result in significant improvements in GP exploitation of the consumer health information service as an information resource.

### The Health Visitor

Influencing factors on general practice use of consumer health information services have been outlined. It is also important to stress that individual members of the primary health care team use such services more extensively than others.

Knight<sup>66</sup> reports on a 1987 survey which emphasised the importance of the health visitor as user of two important health information services - Help for Health and Health Information Service, Lister Hospital. This was felt to reflect the caring nature of the health visitor's role, and to emphasise the predominance of the health visitor as provider of information on self-help groups to patients.

An analysis of Help for Health users, 1985-1986, showed that health visitors made 17% of enquiries compared to only 3% made by GPs<sup>67</sup>.

Health visitors make up almost a fifth of all enquiries at Help for Health<sup>68</sup> and this importance of the health visitor as consumer health information service user as compared to the GP is also the case

for the Lister service: among GP practice staff the service is used probably predominantly by health visitors, and 'Apart from a few interested doctors....' most interest comes from other members of the primary health care team<sup>67</sup>.

Considering the important areas of consumer health information that can be accessed from consumer health information services, there seems to be great potential for their increased usage by *all* members of the primary health care team, especially by GPs. The enthusiasm shown by a few GPs, such as Dr Pike, who do exploit the information potential of consumer health information services can be seen as an example for other GPs to follow.

### In conclusion

- Practice staff can use a local consumer health information service as an important information resource in fulfilling their role as consumer health information providers.

- The relationship between the practice and the consumer health information service can ideally work as a fruitful mutual referral mechanism whereby GPs refer patients to the service for health information in popular lay language, and the service refers patients to the GP when expert medical advice - perhaps a diagnosis - is being sought.

- Information on voluntary and self-help groups and written health information in lay language were mentioned as two key areas of consumer health information which GPs can access from consumer health information services.

- Some GPs, such as Dr Pike, will exploit such services to the full whilst others will use them to a lesser extent, some perhaps never.

- Health visitors, more than GPs, tend to access consumer health information services for information on self-help groups.

- Publicity of the service, personal dynamics and location will all have some bearing on degree of practice staff usage of any one consumer health information service.

GPs can access a consumer health information service to trace simply-written health information for patients. Provision of written consumer health information is an important area in which there have

been developments in general practice during the past decade. The next section describes some of these developments and explores the potential for written consumer health information in the surgery.

### 3.5 WRITTEN CONSUMER HEALTH INFORMATION PROVISION IN GENERAL PRACTICE: FROM LEAFLETS TO LIBRARIES

This section aims to stress the potential and value of written consumer health information provision in the GP practice. The following areas will be considered:-

- the importance of making written consumer health information accessible to the public, with emphasis on the advantages of its availability in the surgery setting;

- factors which might limit levels of written consumer health information provision in the surgery;

- GP initiatives for improving their provision of written consumer health information. These initiatives are highlighted as examples of good practice for other GP practices to explore.

#### 3.5.1 Benefits of written information with emphasis on its provision in general practice

There are several different forms of written consumer health information provided in general practice: diagrams drawn by hand onto a blackboard or onto paper which can be taken away; illustrations drawn by hand onto a write on/wipe off pre-printed diagram produced on a plastic sheet; illustrations drawn by hand onto a pre-printed diagram which is one of identical multiple copies that make up a pad from which the GP can tear off individual sheets for the patient to take away; (these last two examples are now produced for GPs by some pharmaceutical companies) diet and fact sheets; leaflets, brochures and booklets to take away; books.

When referred to in this section written consumer health information will be written information as found in leaflet/booklet form in general practice, either as handed directly to patients by the GP during the consultation or picked up by the patient in the waiting-room.



Leaflet subject coverage will vary. Any particular leaflet may give information in one of the following areas among others: information on a specific condition and/or how to manage it; information on general health education topics (e.g. issues of health promotion and disease prevention); information on the self-care of particular symptoms.

*Written information, usually in the form of leaflets may be a useful adjunct to verbal advice. It may reinforce and supplement the spoken word, save time, provide reference material and act as a reminder. Research has shown it may enhance the effectiveness of advice giving<sup>70</sup>.*

Different arguments are given to support the provision of written consumer health information in the surgery. A few among them will now be highlighted.

A backup to the oral consultation: increased patient recall and comprehension

An important benefit of leaflet provision is that it is known that an important part of what a patient is told about his condition during the oral consultation is soon forgotten. Additional written information acts as a backup to the consultation, a tool for reinforcement and recall which the patient can refer to consequently for clarification on details he has not understood from the GP. Gann<sup>71</sup> refers to a 1973 study showing how within five minutes of seeing their GP patients were forgetting about 50% of what they had been told.

Various contributing factors have been suggested for poor oral communications between GP and patient, which makes written information such a valuable backup: GPs may withhold detailed information on purpose, perhaps through fear of upsetting the patient or because of a wish to retain the sense of power that unshared information may give; the GP may use medical jargon above the patient's level of understanding, again through a wish to cling onto power<sup>72</sup>; medical jargon may be used because it has become second nature to the GP and

patients' non-comprehension passes unnoticed; the patient may feel too intimidated to ask for clarification and the GP will receive a false notion of the patient's degree of understanding; the patient may not take in what the GP tells him because he is in an anxious state - perhaps in pain, or because he refuses to accept an unfavourable diagnosis.

The number of public queries addressed to agony aunts for clarification on medical diagnoses illustrates that significant patient numbers leave the GP consultation still unclear about the precise details of their condition. GPs' use of unexplained medical terminology is often at the root of this search for further information. And agony aunts are often asked to send on written information about the condition. One agony aunt explains how most people who write have already seen the GP but wish to become more informed: 'the largest category is patients who simply want more information<sup>73</sup>'. They seek leaflets and explanations of what a diagnosis means. Cases of misunderstood medical terminology used by GPs in consultation are a common problem.

Agony aunt Claire Rayner writes:

*Far too many readers ask me to explain to them what a doctor meant when he said they had high blood pressure, low blood pressure, angina, fibroids, ovarian cysts, mastitis: the list is long<sup>74</sup>.*

These requests demonstrate clear public demand to be better informed. Written health information in the surgery can make an important contribution to this.

Various studies have been done which compare patients' knowledge on a specific condition in cases where only half the group has received additional written information on the condition. These tend to demonstrate how written information increases patient levels of comprehension and recall on the condition and how to manage it:

One such study<sup>75</sup> administered a 40 question questionnaire to 100 patients who had attended a blood pressure clinic three months earlier. Only half of the patients had then received a booklet on their condition, and results showed the increased knowledge of this group.

The GP can recommend leaflets to patients as an extension of the consultation and other members of the primary health care team can do likewise. Health visitors for instance can recommend written health information to patients as a follow up to clinic sessions.

#### Participation through Knowledge

Provision of leaflets which explain a condition and how to manage it gives a patient the opportunity to improve upon his (often limited) knowledge of the condition as learnt in the consultation and means patient participation through knowledge. For,

*there are those who wish to participate only by having the opportunity to learn about their condition principally by reading literature<sup>76</sup>.*

#### Improved understanding: a key to informed patient contribution to the consultation

Another important benefit of written health information is that it allows the patient to make a more informed contribution to the consultation process. With his new understanding about his condition the patient is in a better position to discuss it with the GP and to ask questions. The consultation becomes a participative process. Some GPs welcome this development. Instead of passively relying on the GP as figure of total medical authority the patient assumes a more inquisitive role. Increased patient knowledge through access to written information improves levels of patient feedback.

And it is important for the patient to be able to participate more in the consultation process. In an article which examines changes in patient attitudes and expectations one GP mentions the patient's desire for involvement and describes participation in the consultation as 'morally desirable as an end in itself, acknowledging the autonomy, dignity and intelligence of patients'<sup>77</sup>.

### Improved patient confidence and allayed fears

Additional benefits of written information include increased feelings of confidence and control that improved levels of understanding give a patient who faces an illness and the possible reduction in patient fears about his condition. Clear and objectively written information on a condition may allay some patients' more wild imaginings on that a diagnosis may signify. The following comments from users of the Health Facts Centre, Bristol illustrate this benefit of access to written information:

*'the information made me realise that my condition is nothing to worry about long or short-term', said one ...*

*'by providing easy-to-read information, myself and client were able to clarify many points and thus allay anxiety' (health visitor) ... 70*

### Written information and increased levels of self-care

Written consumer health information provision of an educative self-care content can increase the extent to which patients are happy to manage their illnesses at home before seeking help from the surgery. This is of clear practical advantage to the practice as more time can be spent on treating patients whose conditions really demand expert intervention.

This hypothesis was tested regarding a patient information booklet on how to manage six common symptoms<sup>79</sup>. The booklet aimed at encouraging self-care, and it was found that during a 15 month period the number of home visits and surgery consultations requested by the study group who *had* received the booklet were significantly fewer than those made by the control group who had *not*.

### Disadvantages of written information

Certain drawbacks to written consumer health information provision have however been raised. One concern is that GPs increasingly rely on written information to provide explanations and

information to the patient and become less forthcoming in the oral consultation. A 1988 study on GPs' use of written materials during consultations found that GPs themselves often 'suspected that patients might consider the leaflets to be a substitute for explanation by the doctor ...<sup>90</sup>.

There is also criticism of leaflets in that they will always remain too general and non patient-specific.

These two concerns make it all-important that written information never be regarded by either patient or GP as a replacement of the oral consultation process (please see 3.5.6).

### In conclusion

- Despite such anxiety about possible drawbacks to written information there are therefore several important benefits of surgery-based written consumer health information provision. It results in:

- Improved patient recall and understanding of the oral consultation;
- Patient participation through increased knowledge;
- More informed patient participation in the consultation process;
- Patient participation through increased administration of self-care remedies.

Despite the benefits of written consumer health information provision in general practice the comprehensiveness of leaflet collections in general practice can vary greatly. There are limiting factors to the comprehensiveness of such collections. The next section will outline some of these factors before going on to highlight GP practice initiatives taken to develop levels of written consumer health information provision.

### 3.5.2 Leaflet provision in general practice: limiting factors

#### Variety of leaflet suppliers: lack of a central resource

Patient leaflets are produced by a wide range of organisations which include the following: the HEA, District and Regional health promotion departments (units or centres), pharmaceutical companies, national and local voluntary organisations and self-help groups, the Department of Health (DOH) environmental health departments, the British Medical Association (Family Doctor series), and popular magazines.

Such variety in leaflet provision sources can give rise to difficulties for GP practices building up their collections.

For example, a recent piece of research carried out by the Department of Information and Library Studies at Loughborough University on behalf of The Help for Health Trust looked at the health promotion information needs of practice staff<sup>61</sup> and interviewees' general comments included the following:

*... the material was there, if you knew where to look... There was a need to find out where the information was, rather than receive more<sup>62</sup>.*

This illustrates an awareness of the existence of written information but the need to know where to look.

In theory the HEA acts as a national distribution centre for written health materials, with District and/or Regional Health Promotion Departments acting as local distribution sources. They stock not only HEA and their own publications but also a selection of other organisations' publications. In practice however there are some problems of access to leaflet publications: the HEA produces Resource Lists on materials available and these include a section on pamphlets and leaflets. Lists emphasise the many different leaflet suppliers. It is not the case however that a GP consulting a Resource List can obtain all the required leaflets from the HEA Distribution Centre. In the Notes Section of each Resource List the HEA emphasises that a selection of items may be viewed at the HEA Health Promotion

Information Centre but that the HEA can only actually supply items for which it gives itself as supplier on the list. This is for a minimum of listed publications overall. Individual suppliers' addresses are given at the end of each Resource List and the Notes also direct interested parties to their local health promotion department where materials may be viewed and/or borrowed.

This creates problems of access for GP practice staff, for they are under time pressure and need time to not only choose useful publications from the Resource List but to contact each individual supplier to obtain materials. Publications *may* be available from the local health promotion department. Not all practices however seem to be aware of this: a 1988 study<sup>63</sup> of 106 GPs discovered that only 26 were aware that patient education materials could be obtained from local health promotion departments. The remaining 80 had no contact with these departments.

Similarly, only 5 of the 29 interviewees in the research carried out by the Department of Information and Library Studies, Loughborough University mentioned using a health promotion department to access patient materials<sup>64</sup>.

The same study revealed a complaint about the HEA only allowing visiting health care professionals to take away a minimal number of leaflets<sup>65</sup>.

#### GP reliance on pharmaceutical companies

Difficulties of access to patient leaflets via the HEA combined with pharmaceutical companies' increased interest in production of patient leaflets results in some practices depending on leaflet supplies from drug companies. For,

*the pharmaceutical companies publish a range of leaflets on coping with health problems, not necessarily connected with a particular drug... <sup>66</sup>.*

Their coverage is fairly extensive.

One GP interviewed spoke of his practice's dependence on drug companies for patient leaflets. An important point is the ease of access, for drug representatives come to the surgery to promote and deliver their materials. Drug companies service practices in a way which the HEA does not, and which facilitates GPs' access to patient materials. The same GP finds that pharmaceutical companies produce leaflets on a wider subject coverage than the HEA which does not give out enough materials either.

The previously mentioned study of 106 GPs' use of written materials<sup>57</sup> showed that 63% accessed leaflets from pharmaceutical companies compared to only 23% from the HEA. There were clear reservations felt by some about this reliance on drug companies because of the opportunity it gives such companies to promote their own particular drugs via patient leaflets. This will remain an issue, for it is perhaps inevitable that drug companies (being commercial agencies) try to promote their own particular products. But this does not negate the general value of the information-content of their leaflets.

GPs have said that they feel that such companies are becoming less promotional in patient leaflets. For companies must know that practices are less willing to display leaflets which promote a company's particular products rather than a health message.

The research carried out at Loughborough also showed a heavy reliance on drug companies rather than on the HEA and recommends further investigation into the role of drug companies in primary health care<sup>58</sup>.

Before discussing means used by some GP practices to build up their written consumer health information provision, gaps in certain areas of leaflets available will be outlined. These gaps constitute obstacles to GP attempts to build up comprehensive leaflet collections in the surgery:

#### Gaps in leaflets available on certain conditions

The growth of voluntary organisations concerned with specific conditions and the publications that most of them produce means that there is now leaflet coverage on a wide range of chronic disorders,



disabilities and illnesses. Gann stresses the importance of these publications in the light of the fact that health education services such as the HEA 'have strayed infrequently beyond the bounds of preventive health and have produced little on coping with illness and disability'<sup>99</sup>.

For instance, a glance at the subject coverage of Resource Lists produced by the HEA (listed on the back cover of each individual Resource List) shows an emphasis on preventive health rather than on management of specific conditions.

The need for more information in some subject areas has been voiced by primary health care workers: the research carried out by the Department of Information and Library Studies, Loughborough University discovered practice staff's demands for greater production of written information on diabetes and asthma<sup>100</sup>; the need has also been voiced for more written information on some rarer specific conditions<sup>101</sup>.

It must however be recognised that in some cases where GPs identify gaps in subject-coverage leaflets are produced by a relevant voluntary organisation but the practice may be unaware of this. Hence the importance of access to self-help group databases (please see GP usage of consumer health information services in 3.5.3 below).

There does however seem to be an overall demand for wider subject-coverage from health education services' publications. For there is a problem with leaflet production on the rarer conditions for which no voluntary organisation has as yet been established and hence no publication produced.

#### Gaps in leaflet production in ethnic minority languages

An important gap in leaflet provision is the scarcity of leaflet production in ethnic minority languages.

The results of the research done by the Department of Information and Library Studies, Loughborough lists 'black or minority ethnic (the problems of language stressed)'<sup>102</sup> as one of the most frequently cited client groups for which more information was requested by GPs and practice nurses.

Similarly, Dr. C. Varnavides, a Leeds GP, spoke of a real need

for more patient health information provision in ethnic languages<sup>73</sup>. For his practice the main concern is lack of written health information provision for Asian women.

Lack of patient leaflets in languages other than English poses a serious gap which must be rectified, for in a multi-racial society it disadvantages sectors of the practice-population in the crucial area of health-care. Not only are ethnic minorities deprived of the advantages of written consumer health information provision, as outlined in 3.5.1, but they are handicapped in a way that English-speakers are not.

The HEA's Strategic Plan, 1990-1995 states the Authority's aim to 'take account of the special needs of vulnerable groups, and of women and black and minority ethnic groups'<sup>74</sup>.

However, the Resource List, Health Education for Ethnic Minorities<sup>75</sup> shows that despite a variety in subject-coverage and producers of ethnic minority language leaflets, there is a real lack in HEA publications. Most ethnic minority publications are produced either by national voluntary organisations and associations, such as the Sickle Cell Society, which produce ethnic minority language leaflets on the specific condition they are concerned with, or by local health promotion departments which recognise the need to meet the health information needs of the ethnic minorities in their area.

The number of leaflets produced by local health promotion departments reflects the gap in the HEA own provision of leaflets for ethnic minorities. The July 1990 Resource List for ethnic minorities lists only, eight HEA leaflets in ethnic minority languages, and in the limited area of pregnancy, child welfare, breast screening and vitamin D only<sup>76</sup>. Furthermore, six out of the eight leaflets are to be 'discontinued when stocks run out'.

GPs trying to provide leaflets in languages appropriate to the ethnic minorities of their practice-population may therefore encounter considerable difficulties.

The contributions made by local health promotion departments are valuable, but there must be emphasis on provision at *national* level, for in some case locally-produced leaflets may be of valuable local relevance (i.e. relevant to a health issue of particular local concern) but not always of national relevance - or rather, not dealing

with an issue that is of *widespread* general public concern.

Is there a role for the HEA to adopt an active policy of automatically producing its own leaflets in ethnic minority languages and of encouraging other main leaflet suppliers to do likewise?

There is the additional problem of unsatisfactory levels of translation into ethnic minority languages. There are cases of DOH and HEA leaflets translated into other languages but at too technical a level for the average reader<sup>77</sup>.

### A question of currency

An additional gap to mention is that of up-to-datedness of some patient leaflets. This is a problem raised by some GPs, for instance in the area of 'up-to-date health promotion information that keeps up with the changing issues and concerns...<sup>78</sup>'.

This is important to remember as a possible contributing factor to why some practices' patient leaflet collections may seem to contain a lot of out-of-date material. This may be through lack of availability of more up-to-date leaflets rather than through practice negligence in maintaining an up-to-date stock.

### In conclusion

- This section has looked at factors which may limit any one practice's ability to provide a comprehensive leaflet collection despite good intentions to do so. Areas covered include:
  - Variety of leaflet suppliers and the need for a central access-point to facilitate busy GPs' access to leaflets;
  - The HEA as distribution centre and practice staff difficulties in obtaining sufficient numbers of leaflets from the HEA itself;
  - Hence, some practices' dependence on drug companies as leaflet suppliers;
  - General gaps in:
    - production of leaflets on certain conditions;
    - production of leaflets in ethnic minority languages;
    - production of up-to-date leaflets in some areas.

Levels of leaflet provision may vary greatly across practices but it is uncommon to find a practice which offers no written consumer health information whatsoever.

The next section looks at practice initiatives to build up and strengthen their collections of written consumer health information. They serve as examples of good practice and highlight the potential for developments in written consumer health information provision in the practice setting.

### 3.5.3 Practice initiatives to develop written consumer health information provision

#### Using the support of local consumer health information services

Consumer health information services do not usually have the necessary resources to act as actual bulk leaflet suppliers to the GP who should address the local health promotion department to obtain leaflets in any quantity. Only if the consumer health information service works in conjunction with the health promotion department, such as is the case with the Health Information Centre, Loughborough, will it usually be able to provide multiple copies of leaflets.

The consumer health information service is however valuable both as,

- a) a bibliographic resource on self-help group/voluntary organisation leaflet suppliers for the practice, and as,
- b) a supplier of written information for a patient on a condition for which a leaflet can not be accessed elsewhere:

*Literature from self-help groups forms a major area of 'grey literature', difficult to trace and rarely appearing in major bibliographies and databases".*

GPs can access the consumer health information service's database to trace self-help group leaflet publications which can be sent off for to strengthen the practice's leaflet collection. The Helpbox

database for instance currently details about 2,000 self-help leaflets<sup>100</sup>.

By accessing the consumer health information service's database the GP can also locate suppliers in areas of written consumer health information which are particularly difficult to trace elsewhere: by entering 'ethnic minorities' for instance, Helpbox will supply details of national and local groups which provide leaflets in ethnic minority languages, such as the Asian Community Action Group, London which produces a leaflet on maternity rights for working mothers, or the Chinese Community Hospital Care Centre, London which produces AIDs literature.

The GP can also use the consumer health information service to provide the one-off leaflet/written information for a patient with a condition on which the practice leaflet collection has no written information. This might for instance be on a rare condition for which no leaflet exists but on which the consumer health information service has collated some written information from scanning popular and medical journals and other sources.

#### General practice leaflet production

One way in which GPs can make up for gaps in the practice leaflet collection is by stocking encyclopedic medical works from which they can produce photocopies for patients. Gann<sup>101</sup> gives examples of such works which give useful concise summaries of various illnesses and self-care measures;. One is 'a loose leaf compendium of patient information sheets designed to be photocopied and handed out by the doctor<sup>102</sup>'.

GPs could perhaps fill gaps in surgery leaflet provision by doing multiple photocopied copies of the information sheets covering the more common illnesses, and by doing one-off photocopies on rarer conditions when the need arises.

A 1988 study on 176 GPs found that 21% used a Patient Counselling Compendium as a health education aid, and that 'some had photocopied information from sources that they had found useful<sup>103</sup>.

In this study it was also found that a few GPs had considered producing their own written materials but that none had as yet done

so.

Some practices have pioneered in their own leaflet preparation as a means of strengthening surgery leaflet collections. Attempts have been successful too, witnessed by practice-produced leaflets which have consequently been approved and published by the HEA and become nationally available: for example, a London group-practice wrote a cartoon-illustrated 16 page patient booklet on how to manage six common symptoms to encourage self-care of these conditions<sup>104</sup>. The booklet was then published by the HEA as Minor illness: how to treat it at home.

*The well-prepared leaflet is a useful medium for communication which has had a bad press. If prepared by the general practitioner for his own patients it can make an effective contribution<sup>105</sup>.*

Literature production has been an important function of PPGs as mentioned in 3.1., and even if practice literature production is currently made up by 'the enthusiasm of the few'<sup>106</sup>, it can be seen as a valuable development in consumer health information provision in general practice.

For it is a means for the primary health care team to strengthen its leaflet collection in areas of general deficiency - perhaps to explain a rarer condition, or a condition/self-care procedure that is assumed to be so simple that no literature has yet been produced on it.

Practice-produced leaflets are also important in that they can be tailored to local needs: this was an advantage raised by Dr C. Varnavides, Leeds<sup>107</sup> who is very much in favour of practice preparation of patient leaflets, and whose own practice has produced its own literature. The patient leaflet Acute Lumbago. What is it?, edited and designed by Leeds Health Education Department, is based on materials produced by the Dib Lane Surgery. A copy of this leaflet is included in the Appendices.

Varnavides would like to see more wide-spread leaflet production among practices and stresses that it gives practice staff the opportunity to voice their own opinions on health issues. He admits the danger of patients being confronted by leaflets which reflect

conflicting health beliefs but feels that this is outweighed by the good of a practice having the chance to provide its patients with literature that fits in with its own particular health philosophy.

There are two other important areas of local emphasis that practice-produced literature can meet: leaflets can be written on health topics that are currently of particular concern in the area but on which there is no existing adequate leaflet coverage; and practice produced literature can include details of local relevance, with for instance a leaflet on a specific condition including the address of a relevant local self-help group, or with details of when the surgery holds a clinic relevant to that condition.

Practice-produced leaflets can therefore be important not only as a means of local production of *nationally* relevant literature (i.e. filling gaps in general leaflet production) but for producing literature that is of particular *local* relevance (i.e. reflecting the practice's views on a condition; covering a topic of local concern; including particular information which is specific to the practice area, such as on clinics and voluntary support groups).

Examples of practice-produced leaflets show that they cover various areas of consumer health information. They may be: on specific conditions, such as the Leeds pamphlet on Lumbago; on self-care procedures, such as the London practice's one on how to manage six common symptoms<sup>108</sup>; of a general health education emphasis such as a Birmingham practice's booklet on child care<sup>109</sup>.

General practices have also included general information on preventative measures within the practice brochure which primarily serves to describe the primary health care team and facilities available<sup>110</sup>. (For further discussion of the practice brochure and its relevance to consumer health information provision in general practice please see 4.1.1 [b]).

Producing their own literature for patients is a means by which some practices have worked to build up written consumer health information provision in the surgery. The need to produce leaflets in clear and simple language and consequent training implications will be outlined in 5.1.

### Practice-based consumer health information services

Some practices have developed their patient leaflet collections into what can be seen as constituting mini consumer health information services - practice-based mini-models of such services as the Health Information Service, Stevenage. Such collections extend beyond the more usual provision of a simple selection of leaflets only.

Practices which are developing in this way illustrate how some practice staff are recognising the potential and value of providing written consumer health information to patients in the surgery.

One example is the Health Information System established in 1987 in a Cambridge general practice. This mini consumer health information service was set up through the practice staff's belief in patients' need and right to be informed about their illness<sup>11</sup>. The system, like the Health Information Service, Stevenage, centres on a collection of subject-folders. There are currently 50 folders on a variety of topics.

*Each folder contains a collection of relevant leaflets and inform the patient of the name, address and telephone number of relevant organisations, both national and local, and inform the patient where they are able to obtain supplies of leaflets<sup>12</sup>.*

Leaflets are supplied by a variety of self-help groups and from the local health promotion unit.

And there is evidence of current GP interest in this area of development: Health Matters, Milton Keynes was recently visited by a local GP who was interested in looking through the service's stock to get an idea of the sorts of materials to include in a practice-based consumer health information service<sup>13</sup>.

These two examples illustrate GP initiative in developing mini-consumer health information services within the surgery. Enthusiasm also comes from existing consumer health information services: Health Matters, Milton Keynes and Health Facts, Bristol were mentioned in 3.4.2 as two services considering health centres among possible new service points. Both services have similarly considered establishing



a service point within general practice. Health Matters is actually currently using a GP surgery as a location to pilot the planned introduction of its database and a literature collection into various other locations<sup>114</sup>.

The viability of practice-based mini consumer health information services has thus been recognised and acted upon by successfully established consumer health information services.

One example of a GP who developed his own mini information service is Dr Pike, Baldock, Hertfordshire. A heavy user of the Health Information Service, Stevenage he then went on to develop his own collection of 20 subject-folders 'full of readable articles on diet, contraception, pregnancy, the menopause, and other regularly requested topics'<sup>115</sup>.

The Baldock practice then further developed its written consumer health information provision by becoming the pilot practice in a Health Information Service, Stevenage project which in 1989/90 was responsible for setting up six patient libraries in general practice. The development of practice patient libraries can be seen as the next stage in the progression from leaflets to libraries in general practice. The next section considers this important development in consumer health information provision in general practice.

#### 3.5.4 Patient libraries in general practice

*A patients' library in a surgery or health centre can include books, journal articles, videotapes and audio cassettes which are available for loan to patients. Its purpose is to provide health information, at an appropriate level and at the time of consultation, on a range of medical conditions and health topics'*<sup>116</sup>.

Whilst carrying out research on practice libraries (i.e. for practice staff) the RCGP's, Stuart Librarian discovered clear GP enthusiasm for the patient library concept<sup>117</sup>. Most of the surgeries visited (1987) still kept books suitable for patients on closed access among the practice library collection. In her follow-up publication, The Practice Library<sup>118</sup> the Stuart Librarian mentioned that practice libraries can contain books suitable for clients but that 'a library intended exclusively for patients should be a separate entity'<sup>119</sup>.

The patient library as 'separate entity' constitutes an important advance in written information provision for patients.

#### First developments in UK patient libraries in general practice

The first recorded patient library in the UK was set up by a Leeds surgery in 1981, the only previously recorded one being the patient health library set up in a large group practice in Oakland, California, 1969<sup>120</sup>.

The Leeds surgery patients library was opened to enable patients to become more informed about health and illness. The practice partners realised that they were increasingly recommending health texts to patients as a follow-up to the consultation process, that the local public libraries had poor consumer health information collections and that patients 'might welcome the opportunity to seek information for themselves on health subjects ...<sup>121</sup>'.

The partners' philosophy is that informing patients enables increased patient participation in the consultation process. The patient understands more and is better able and willing to take on a questioning role. GP opinions are questioned rather than blindly accepted. The partners consider that the more complex the questions asked the better. They welcome the patient entering into a more participative role<sup>122</sup>.

The Leeds patient library was initially set up with the help of a Regional Health Authority research grant. It is now self-funding.

The library is on open access in the surgery waiting-area and comprises mainly books (but also a cassette and video collection), with a good subject-coverage on both health education issues and on specific conditions. The collection is simply arranged under subject-headings by a colour-spot system. It includes a selection of fiction/biographical works on living with specific conditions or handicaps. The practice librarian comments that this is a popular section. There is also a considerable selection of texts for children. The surgery hopes to engage patients' enthusiasm for the library through their children's interest in it. The librarian chooses materials by scanning book lists and book shop collections, and is also helped by suggestions made by patients and staff. Books

are donated, mainly by GPs and patients, as well as bought.

An analysis of the library's first year of use illustrated its success<sup>123</sup>: it was steadily used over this period, and by a well-balanced cross-section of the practice-population, used by patients of all ages, education, social background and gender - though predominantly by women<sup>124</sup>. These findings dispelled 'a lingering doubt that the library would be ignored by most patients and monopolised by a small group of hypochondriacs and health fanatics'<sup>125</sup>. The Leeds surgery patient library proved a success and continues to be used steadily by patients.

Since the establishment of the Leeds patient library the most important UK development in the spread of such libraries was the 1989/90 project organised by the Health Information Service, Stevenage: a pilot patient library was set up in February 1989 in a six-partner practice, Baldock, and favourable results of a survey analysis of the library's first 15 months of use<sup>126</sup> led to the Office of Arts and Libraries' Public Library Development Incentive Scheme (PLDIS) agreeing to fund the establishment of six more such libraries by the Health Information Service. Six Hertfordshire practices were chosen as locations for the patients' information collections (PICs) and these were established 1989/90 by joint funding of the PLDIS, the Regional health service, Regional library service and the practices involved.

Unlike the Leeds example, the PICs were set up not due to the initiative of the individual practice but under the auspices of a Health Information Service project. A Health Information Service Development Officer was actively involved in the setting up of the PICs. Her responsibilities included selection and classification of PIC stock, training of surgery staff in how to run the PIC (involving production of a Procedures Manual) and purchase of additional materials.

For administrative reasons there were poor returns on a survey-analysis evaluation of PIC usage covering a nine-month period<sup>127</sup>. However, the final report on the project concludes that 'Positive verbal feedback from the practices with a PIC, including comments from medical, nursing and administrative personnel, indicate that the project has been a success.... met with a good deal of enthusiasm from

both patients and health care professionals alike<sup>128</sup>.

The philosophy behind the establishment of the initial Baldock PIC and the subsequent six reflects that of the Leeds practice partners: patient access to written information on health matters augments the consultation process. It enables patients to expand their knowledge on either a specific condition or on general health education issues. Better informed patients may take a more participative role in the consultation process and be able 'to make better informed decisions about their individual health care needs'<sup>129</sup>.

#### The benefits of patient library provision in general practice

The following outline some of the benefits to patients of practice-based library provision:

- Provision of an information resource for patients on both specific conditions and on general health education. GPs can refer patients to the collection as an extension of the consultation process. This is the first of a number of reasons given for the establishment of the first ever recorded patient library in general practice in Oakland, California. It was to provide;

*a centralized service to which the physician may refer patients for clarification, explanation, and information leading to adequate comprehension of the nature and management of specific disease or other health problems*<sup>130</sup>.

Consequent increased patient knowledge on health matters feeds back into the consultation process where the informed patient can play a more participative role.

- Ready access to written information on health topics that may well be difficult to locate elsewhere: public library provision may be poor (one reason which encouraged the Leeds surgery to develop its library); medical library provision may be difficult to access and house a poor stock of popular health texts.

- Provision of an accessible collection for those who lack the initiative to seek out health information but who perhaps most need

it. About 95% of the population visit their GP over a three-year period compared to only about 30% who visit their local public library<sup>131</sup>. Having a PIC is therefore a way of bringing health information to the public. Varnavides stresses this point<sup>132</sup> and says how more than a third of the PIC users very rarely/never used a public library. Similarly, the pilot Baldock PIC found that roughly the same proportion of users did not use a public library<sup>133</sup>. Also important is that only 35% of PIC users would have sought the information elsewhere had it not been provided in the surgery<sup>134</sup>.

- (The following argument has been previously forwarded in 2.1.1 as a contributing factor to the appropriateness of general practice as a setting for consumer health information provision in general). It is appropriate to house a PIC within a health-care setting (as opposed to a public library) for it will reach a public more likely to consult it for,

a) being in a health-oriented mood;

b) having time to fill whilst waiting to be seen by the GP.

- (This argument has been previously forwarded in 2.1.2). Locating a PIC in the surgery has the advantage of a health professional being near-at-hand to clarify what the patient has read and to discuss it in relation to the patient's particular experience of the condition.

- Offering a surgery PIC gives the opportunity 'for the doctor-patient relationship to be enhanced in that the patient feels there is approval to become informed<sup>135</sup>'. The patient will see PIC provision as encouraging information - seeking behaviour and as an invitation to health information and self-care.

This feeling of being encouraged to seek information will contrast to patient reactions when faced with a poor leaflet collection only - and also when conscious that any patient texts which are available are kept on closed access.

- Improved patient satisfaction with levels of consumer health information provision in the practice setting: the survey-analysis of users' reactions to both the Baldock pilot PIC and to the Leeds patient library found similarly high percentages of users who had read most or all of the book, who now understood more about their condition, who found the book useful and would recommend it to a

fellow-sufferer, and who would definitely use the library again.

Patient feedback emphasises clear patient appreciation of the PIC facility in general practice.

Some practices remain wary of the PIC concept however.

#### GP wariness of the PIC concept

There is the worry that PIC materials (a) increase patient anxiety, and also that (b) a surgery PIC will increase the practice's workload:

##### (a) Patient anxiety levels

There is concern that some texts may cause distress to patients. This is clearly not good for the patient's state of mind and may also increase the practice's work load because there will be increased visits from worried patients.

It is of course true that certain texts may distress particular patients. Whilst remaining committed to the PIC concept Dr Varnavides (Leeds) recognises this as a possible drawback: he mentions two books that have had to be withdrawn from the collection for disturbing patients<sup>136</sup>. One was a text on cancer and death, the other on living and dying which contained distressing photographs. Varnavides also realises that you can never tell how many patients go away from the patient library worried but saying nothing.

However, referring to GP concerns about raising patients' anxiety, Dr Pike (Baldock) emphasises that in his experience, 'the vast majority become less anxious when they know more about their condition'<sup>137</sup>.

The survey-analysis figures on both the Baldock PIC and the Leeds patient library support this belief: only five Leeds patients found their book 'too upsetting'<sup>138</sup> and only 5% of the Baldock patients admitted increased anxiety. In contrast 44% claimed becoming less anxious, and 51% claimed no change in anxiety levels. And of the 5% who admitted increased anxiety, almost half of them said that despite this they 'had derived increased awareness or specific benefits from the information'<sup>139</sup>.

(b) Increased workload

Some GPs are wary of patient libraries for the increased workload that the daily running of a library involves, but the example of the Leeds Library shows that this does not have to be so: the librarian runs the library single-handed and it only constitutes a *part* of her varied workload in the practice.

Another anxiety is that workload will be increased through better informed patients demanding more involved discussions, hence longer consultations.

Some GPs may also be concerned about better informed patients putting them 'on the spot' by showing up their ignorance in some areas. Some GPs are reluctant to let their power status be reduced by a more balanced two-way consultation.

But the more open-minded progressive GP, such as Dr Varnavides, will welcome this increased patient participation and questioning. For it reflects a patient's healthy curiosity and quest for knowledge in the important area of health.

GPs' developing interest in the PIC concept

There is evidence of developing GP interest in the PIC concept. The RCGP Stuart librarian found, in 1987, 'that there is growing interest in the development of patient libraries'<sup>40</sup>.

A recent example is the patients library started early 1991 by the Cambridge practice cited in 3.5.3 for its 1987 development of a mini consumer health information service. The library has about 60 books and a small collection of video and audio cassettes available for loan<sup>41</sup>. The library's book-list is included in the Appendices as an example of the variety of health topics that a practice PIC may cover.

Both the Leeds patient library and the Hertfordshire PIC project have had considerable GP follow-up enquiries: the Leeds librarian has had a lot of GP enquiries on how to set up a library and has compiled her own set of guidelines for requesting GPs. A copy of these guidelines is included in the Appendices. Enquiries have come from as far afield as Australia<sup>42</sup>. Dr Varnavides feels that there is steady

development of patient libraries in general practice, both in Leeds and elsewhere. His partner also feels that there are significant numbers of general practices developing patient libraries but that little is heard about them as they keep a low profile and, unlike the Leeds practice, do not produce articles on their experiences.

The Health Information Service, Stevenage has set up three more PICs since the pilot Baldock PIC and the subsequent six. There are a further 12 practices on a waiting list who hope to receive a PIC through the Health Information Service.

The Service's Development Officer feels 'fairly confident about the development of PICs across the country'<sup>143</sup>. She reports on about 10 to 15 general practice follow-up enquiries to the paper on the pilot PIC<sup>144</sup> and to more follow-up enquires to the report going to the British Library.

The Leeds practice librarian sees no reason why patient libraries cannot be developed among practices generally.

#### Two practical points: PIC funding and relationship with local public library and consumer health information service

To finish this section on patient libraries two important practical issues for any general practice establishing a library will be outlined. These are questions of (a) funding and of (b) the relationship between the patient library and both the public library and (c) the local consumer health information service.

Different solutions will be found for each patient library for on both these issues much will depend on local circumstances.

##### (a) Funding

Funding sources for patient libraries to-date have varied. Contributions have come from the public library service, Regional Health Authority (RHA), local funding bodies, patients, PLDIS money (Hertfordshire PICs) and from general practice funds.

For instance, the Leeds patient library was set up with the help of a Yorkshire RHA research grant and is now self-funding. Pharmaceutical company donations are channelled into the patient



library fund. The Hertfordshire 1989/90 PIC project was funded by PLDIS monies, Hertfordshire library service, North West Thames RHA and by general practices. These and subsequent PICs set up by the Health Information Service have continued to be funded by Hertfordshire Library and Information Service (HLAIS) through the Health Information Service's budget, but the latter is uncertain on whether HLAIS will continue funding PICs into 1992/93.

A practice patient library set up in Clitheroe, Lancashire, the Medical Education Foundation, has charitable status and is funded by patients and local funding bodies<sup>145</sup>.

Perhaps there can be no one recommended solution for *all* patient libraries. Local circumstances will determine the best funding solution for each patient library, and may involve one or a variety of funding sources. Various factors must be taken into account, among them: the size of the practice - population - hence of patient library required, the financial position of each potential funding body and the commitment of each one to the patient library concept.

The Health Information Service Development Officer does however suggest that perhaps the county library services should *not* be depended on for patient library funding. She suggests that practice-funded patient libraries would prove a practice's genuine commitment to the concept of health information provision, and that the practice could seek additional funding from such bodies as the FHSA and RHA.

#### (b) Practice PIC and local public library service

This relationship must be considered because both are providers of books on health information. The relationship will vary between locations and depend on both the strength of the public library's collection and its involvement in funding the patient library. The relationship might involve: the public library using the patient library as an outlet for its own health information collection (i.e. the patient library borrows from the public library's stock); the public library referring the public to the patient library as a back-up to its own *poor* health information collection; a mutual referral system; no existing co-operation. The RCGP's Stuart librarian suggests 'co-operating with the local public library service to obtain

books for loan; i.e. as an extension of the public service<sup>146</sup> and suggests that the practice contact its local public library service to enquire about borrowing books before buying them for the patient library<sup>147</sup>. She quotes this as being the case with a Kentish Town health centre, London. Similarly, a West Midlands GP has borrowed books from the local public library to stock his patient library<sup>148</sup>.

This depends however on a strong public library health information section. For the Leeds surgery one of the very reasons for setting up a patient library was to make up for *poor* public library health information provision. There is no existing co-operation between the two services.

And for the Baldock pilot PIC (Hertfordshire) the survey-analysis results showed that 73% of those who would not have sought the health information elsewhere were *public library users*<sup>149</sup>; i.e. they would not expect the public library to have a strong health information collection.

In Hertfordshire there is co-operation between the PICs and local public libraries. The PIC may act as a back-up to the public library stock: public libraries are told of an existing local PIC, and can refer members of the public to it but only on a limited basis, for as PICs are only open to their own practice patients, the public library can only refer someone to a PIC if it has ascertained that the person is a patient at that particular PIC practice. Furthermore, the public library does not hold information on the contents of the PIC stock. It is not therefore an open referral system. This is because it is not feasible to expect a PIC to provide for patients outside its own practice: it would be impossible for the practice to deal with a potentially continuous stream of interested readers; it would be more difficult to keep a trace on the books than if they were borrowed by registered patients only; and the actual practice patients would be angry that a GP-recommended text was never in because patients from outside the practice had access to it also. A major benefit of the patient library is the *ready-access* to health information that it offers practice patients. This benefit would be reduced by an open-to-all policy. Some of the books would just never be on the shelves.

The ideal situation would be that PICs develop to such an extent that the public library were able to refer any reader onto his local

practice patient library: i.e. be able to assume that the practice would have one.

Hertfordshire public libraries may refer patients on to their practice's PIC, and the referral system can work both ways. The Health Information Service PIC leaflet explains the collection to patients and ends by reminding them that books on health topics can also be found in the local public library. The back cover of the leaflet lists Hertfordshire public library services.

It must be noted that the extent to which a public library will expect local practice PICs to act as a back-up to its own health information collection will be influenced by the public library service's involvement in the PIC's funding. Hertfordshire public libraries are told of the existence of local PICs but this would perhaps not be the case if Hertfordshire Library and Information Service was not the principal PIC funding body.

(c) Practice PIC and local consumer health information service

The extent to which a practice continues to use its local consumer health information service (assuming that it has done so to-date) once it has established its own PIC is important. That a practice develops its own PIC in no way makes the consumer health information service a redundant one for the practice:

*Where follow-up material is required in addition... it could be supplied from a central collection, such as Lister HIS<sup>150</sup>.*

The ideal continuing relationship might be a complementary one, with the consumer health information service acting as a back-up to the PIC in the same way that the PIC might act as a back-up to the public library's health information collection.

The consumer health information service may be used by a PIC-holding practice to access: written information on a subject about which the PIC holds no information; supplementary written information on a subject about which the PIC does have *some* information but on which additional information is required; information in areas other than written information: e.g. information on local self-help groups

and on local NHS services.

Having a PIC will modify the practice's use of the consumer health information service in that the PIC may be able to provide written information in subject-areas for which the practice previously depended on the consumer health information service for provision. But the latter remains a valuable information resource for the practice.

The experience of the Health Information Service, Stevenage is that PIC-holding practices tend to endeavour to be self-sufficient, but that they will use the consumer health information service both to access 'information on rarer more complicated issues than their collection can deal with'<sup>51</sup> and also to fill gaps in the PIC by asking the consumer health information service to produce subject-folders for them in specified subject-areas.

It must however be noted that the relationship between the Stevenage service and local PICs is a special one. The PICs were set up as a Health Information Service project. It is therefore negotiable whether other consumer health information services would be prepared to spend time compiling subject-folders for local practice PICs - or even to what extent local practices would expect them to do so.

### In conclusion

- This section has tried to emphasise the value of the patient library in general practice by highlighting the main benefits as witnessed by the Leeds and Hertfordshire experiences.

- The philosophy behind the establishment of these patient libraries is that improved information provision raises the potential for better-informed patients and hence increased patient participation in the consultation process.

- Follow-up enquiries to the Leeds and Hertfordshire PIC Initiatives show that there is general GP interest in the PIC concept.

- Practical issues of (a) PIC funding and of (b) the relationship between PIC and local public library and consumer health information services were raised. Current PIC examples demonstrate a variety of existing situations. It was suggested that local factors

are all-important in determining the outcome as regards these two issues for the individual PIC.

- Development of PICs raises the potential for significant improvements in levels of written consumer health information provision in general practice.

- Training implications for practice staff developing PICs will be outlined in 5.2.

### 3.5.5 Written drug information provision

Provision of drug information as a specific area of written consumer health information provision will now be discussed. For it is an area in which there have been studies during the past decade which have implications for general practice. Studies have shown clear benefits of written drug information provision and have used both the pharmacy and the practice as experimental distributors for patient information leaflets on drugs.

A 1978 paper<sup>152</sup> recognised the need for increased written patient information on drugs to increase the public's safe and effective use of prescribed medicines. At that time very little information on individual medicines was available for patients except for *some* package inserts (written information included with the packaged drug). Professional organisations had designed some information leaflets but these were not usually on *individual* medicines and were not readily available<sup>153</sup>. The paper drew up guidelines on the minimum information that package inserts for drugs should include: how to take and store the drug, how it is expected to help and how to recognise its adverse side-effects.

#### The Southampton studies

The need for more written drug information was the focus of a series of 1980s studies carried out by a team from the University of Southampton's Medical School, headed by Professor Charles George, Professor of Clinical Pharmacology.

A 1986 paper<sup>154</sup> reports on a Southampton-based study undertaken to determine the public's knowledge and attitudes to medicines.

Findings showed that more information was needed on how to safely store and dispose of medicines, and about possible adverse side-effects of taking the drug. 62% of the study-group felt that GPs and pharmacists do not explain enough about drugs and 83% favoured the idea of patient information leaflets<sup>155</sup>. The team concluded that more information was needed on prescribed medicines with particular attention to adverse side-effects.

Based on the premise that 'to use medicines properly patients require certain basic information'<sup>156</sup> and that this information is inadequately conveyed by the oral consultation process a series of studies were carried out by the Southampton team, aimed at determining the benefits to patients of provision of information leaflets on drugs: a pilot study<sup>157</sup> was followed up by three further studies<sup>158, 159, 160</sup>. The objective of each study was to test the effect of drug information leaflets on both patients' knowledge of the prescribed medicine and patients' satisfaction with levels of information provision.

Each study focused on study-groups who received information leaflets and on a control-group which did not. Each of the three studies used three different information leaflets to test out benefits of providing information on drugs. The first two studies were based in Hampshire. The third study was a national postal survey, carried out on a one in twelve sample of pharmacies in England, Wales and Scotland.

The findings of the Hampshire-based studies were confirmed by the wider national sample. Results from all four studies (pilot and follow-ups) showed the following important benefits of information leaflets on drugs:

#### Benefits of provision of written drug information

(a) Increased knowledge and understanding of the prescribed medicine.

(b) All studies stressed the advantage of information leaflets increasing patient awareness of possible adverse side-effects. This improved patients' recognition of drug-related symptoms when these *did* occur, hence reducing patients' concern about other possible origins

of sudden new symptoms. Knowledge of possible side-effects did *not* lead to an increase in imagined adverse reactions to the prescribed drug.

(c) Generally increased satisfaction with the levels of information received.

(d) Some evidence of increased satisfaction with the medicine itself and with the consultation process<sup>161</sup>.

Provision of information on prescribed drugs has clear benefits as regards patient participation in the health-care process. For drug information leaflets enable: patient participation in the sense of participation through increased knowledge and understanding; more informed, hence effective participation in following the prescription (i.e. greater knowledge about how and when to take the medicine); potential for increased patient participation in the consultation process through the informed patient having a firmer knowledge-base on which to ask questions and voice anxieties about the prescribed medicine.

#### General practice as distribution-point for written drug information

The Southampton studies had implications on the question of general practice provision of written drug information. For as well as determining the *benefits* of drug information leaflets the studies sought to determine the most appropriate source of *distribution* for the leaflets. Comparisons were made between the pharmacy and the general practice as potential distributors. This focus on general practice is important as it shows a clear recognition of the potential for general practice provision in this important area of written consumer health information.

Overall findings favoured the pharmacy as distributor but it will be argued that in fact potential remains for a general practice role in this area. In the pilot study, information leaflets were distributed by both pharmacists and GPs. It was found that GPs often *forgot* to hand out information leaflets, and some GPs also felt that it would be hard to store and issue the leaflets on a routine basis<sup>162</sup>. The first follow-up study confirmed these negative

findings: not only did GPs tend to forget to hand out information leaflets, but it was found 'likely that some selection of suitable patients occurred...<sup>163</sup>'. GPs distributed leaflets predominantly to the older patients and to those from the higher social classes. In Professor George's opinion, 'only about 1 in 5 patients eligible to receive a leaflet obtained one from the general practitioner...<sup>164</sup>'.

It was also found that patients who had received leaflets from pharmacists were both more knowledgeable about their medicines and better satisfied than those who had received them from the GP<sup>165</sup>.

However, some pharmacists also tended to forget to distribute leaflets, and it was also found that 'more patients who received a leaflet from the pharmacist said it made them 'feel anxious about taking their medicine'<sup>166</sup>'.

However, this study seemed overall to favour pharmacy rather than GP distribution of information leaflets. The last two Southampton studies therefore used the pharmacy alone as distribution-point. Following the Southampton studies the Association of the British Pharmaceutical Industry (ABPI) asked the team's help in drawing up guidelines for leaflet-production and distributed a pamphlet on the subject to pharmaceuticals. And a 1987 ABPI Working Party document recommended that pharmaceuticals provide patient information leaflets with *all* medicines that they produce, and that these leaflets be distributed as patient package inserts: i.e. with the medicine at the pharmacy counter. This was considered to be 'the most reliable and economic method'<sup>167</sup> of distribution. The ABPI had clearly taken heed of the negative findings of the Southampton studies regarding GP distribution of information leaflets.

An EC directive is expected to make patient package inserts (written information included with dispersed medicines) obligatory this year<sup>168, 169</sup>. And in 1989 Gann<sup>170</sup> reported on more than a 1000 package inserts already produced and submitted for DOH approval. There is increasing awareness among pharmaceutical companies of the importance of patient package inserts on drugs, and of patient information provision in general.



### In support of a general practice role

Even though the ABPI recommends the pharmacy rather than the general practice as distributor of written drug information, it seems justified to argue that there *is* still a potentially important role for general practice in provision of written drug information.

#### (a) An interim role?

There is potential for a GP role in this area - at least for an interim period until package inserts have been produced by pharmaceuticals for *all* medicines: GPs could take on the important role of identifying current gaps in pharmaceutical provision of package inserts and then provide their patients with the necessary supplementary information. This could be done by GPs procuring written drug information from external sources, by for instance accessing the local consumer health information service to trace self-help groups which produce leaflets on drugs.

Alternatively, GPs could themselves contribute to the production of written drug information. The ABPI provides GPs with a Data Sheet Compendium on drugs. These data sheets are also made available for public consultation through libraries<sup>171</sup>.

It is however negotiable to what extent the general public is aware of the availability of these data sheets and to what extent the sheets would be understood. For they are written for the medical profession.

GPs could however make a photocopy of the appropriate data sheet and read through it, explaining it and annotating it for the patient during the consultation process. The patient could have the photocopy to keep for reference.

GPs could also use the data sheets as useful material on which to base their *own* production of drug information leaflets written in a simpler popular language. The practice would then have its own compendium of drug leaflets (aimed at patients rather than at the medical profession) from which to make photocopies for patients. GPs could use previously produced drug leaflets, such as those produced by the Southampton team, and also the ABPI's guidelines to

pharmaceuticals on leaflet production, to design and produce their own collection of drug leaflets. For legal reasons it is crucial that leaflets be consistent with the information contained in the ABPI Data Sheet Compendium<sup>172</sup>.

It has been observed that few GPs will want to produce their own leaflets in this area<sup>173</sup>. However, leaflet production is an area in which, as pointed out in 3.5.3., there is evidence of some GP enthusiasm. Some GPs may be willing to set a precedent in the area of production of written drug information. It is possible that their leaflets be approved of and produced at national level, in the same way that other general practice-produced patient leaflets have gained HEA recognition.

(b) More than an interim role?

Furthermore, should the GP's role in provision of written drug information be an interim one only?

It is possible to argue in favour of the general practice, rather than the pharmacy, as most suitable distribution-point for written drug information - produced by pharmaceuticals or by other sources:

*Ideally, the doctor should inform and guide the patient on these matters within the limits of the patient's ability. The doctor has been shown to be the one from whom patients are most likely to accept information on medicines...<sup>174</sup>.*

The Southampton studies showed that GPs tended both to forget to distribute leaflets and to distribute to some whilst not to others. It would however be unfair to consequently attribute these tendencies to *all* GPs. Furthermore, the studies revealed the important fact that patients who received leaflets from GPs, rather than from pharmacies, were less likely to be made anxious by the leaflet. Reducing patient anxiety is an important issue to consider, and if, as the above quote suggests, patients are generally more receptive to drug information received from GPs than from other sources, it seems preferable that written drug information is received in GP consultation with the patient. GP and patient are then able to discuss the written

information and sort out any patient doubts and anxiety together.

It seems a natural extension of the GP's prescribing role that *he* then be the one to actually distribute and explain any written information on the medicine. It is less likely that at the busy pharmacy counter there will be equal opportunities for the patient and pharmacist to together scan the package insert. And an anxious patient will probably feel low incentive to voice his concerns in public to the unknown pharmacist.

Furthermore, the GP is the patient's personal health carer and has a knowledge about the patient's case-history and general background that the pharmacist lacks. This increased knowledge would enable the GP to pinpoint areas in the written drug information that he feels may be of particular concern and relevance to the patient in question. By this means he can *personalise* the drug information leaflet, perhaps even add additional notes to the leaflet, in a way that the pharmacist is unable to.

### In conclusion

- Written drug information provision is an important area of written consumer health information provision in which there have been recent advances with an increase in pharmaceutical-produced patient package inserts.

- Through increased knowledge of how and when to take the medicine the patient is able to more safely and effectively participate in this area of self-care.

- The increased knowledge also lets the patient ask his GP more informed questions and express his doubts about the medicine - hence increased patient participation in the consultation process.

- This section on written drug information has tried to suggest that, despite the ABPI's recommendation that such information be distributed at the pharmacy counter, there *is* a potential role here for GPs: GPs could not only identify and fill gaps in written drug information but also be reconsidered as an appropriate distribution-point for written drug information.

The Southampton studies discovered that patients who had received information leaflets were generally more satisfied with their

medicines that those who had not. Some surprise was felt that there was no parallel increase in patient compliance with treatment<sup>175</sup>. One possible explanation suggested was that even though patients were more satisfied with the information provision they did not feel increased satisfaction with the *oral* consultation process. The team concluded that improvements in GP/patient oral communication were needed to bring about improved patient compliance, for,

*it is only in combination with verbal counselling that the best effects of written information can be realised*<sup>176</sup>.

This will be stressed in the next section.

### **3.5.6 Written and oral consumer health information provision: the need for a complementary relationship**

Section 3.5 has tried to outline the main benefits to patients of written consumer health information provision and to then follow general practice developments in this area.

It must however be emphasised that whilst recognising the value of written consumer health information provision as a back-up and extension of the oral consultation, oral and written information provision must *co-exist*. Poor GP/patient oral communication may be partly 'made-up for' by the support of a strong provision of written health information. But the primary importance of the one-to-one oral consultation must never be lost sight of. The patient must never find himself *relying* on written sources for consumer health information. Similarly, a GP must not be allowed to excuse a poor provision of oral information by pointing out that his patients may find the required additional information in the practice's good collection of written health information. Those with poor literacy skills would clearly be unfairly disadvantaged in such a situation.

Oral and written consumer health information provision must be maintained and developed in a complementary relationship: a user-questionnaire carried out by the Health Facts Centre, Bristol showed that patients do not generally favour having to depend on either oral or written health information provision alone. For whilst only five

users wished health information to be imparted verbally by health professionals and nine in written/leaflet form, *fifty-two* wished it to be imparted by a combination of the two<sup>177</sup>.

Information provided in leaflets lacks the *personal* element that only the GP can give by oral back-up. A patient can read a general explanation of his condition or of a health education issue but the personal element is missing. The GP can give this by supplementing the leaflet by oral advice that is particular to the patient's experience of the condition. The impersonal of leaflets is a main patient criticism of them, and it means that they can only ever back-up, but never replace, the oral consultation. Attempts have been made to produce leaflets with a personal touch to them: one community physician suggests that the ideal would be a personal summary of the consultation written for each specific patient, 'but this is impossible and a leaflet suitable for all people who have a particular condition or problem has to serve instead'<sup>178</sup>. The physician goes on to give advice on GP preparation of leaflets and suggests that a space is left on leaflets to write in patient-specific advice.

Similarly, in a study done to test patients' reactions to written health information in general practice, 12 illness-specific cards were produced, and each contained a boxed area in which GPs could write in *patient-specific* notes. However, results showed that only an eighth of GPs in the study had made use of these boxes. GPs were reluctant to write down advice that could become out-dated, on a card meant for long-term retention and future reference.

Furthermore, personalising leaflets in this way would only really work with leaflets that are distributed by the GP during the consultation process, and not for leaflets left on open-access in the waiting-area.

Oral consultation is therefore desirable to personalise the general. This is demonstrated in the way that GPs use consumer health information services: whilst some refer patients to the service others tend to obtain the information themselves so that they can filter the information before then passing it on to the patient. In this way the GP can familiarise himself with the written information and be in a better position to discuss it with the patient, able not only to emphasise what bears on the patient's particular experience of the

condition but also to detect and relieve patient concerns. Dr Pike, user of the Health Information Service, Stevenage writes:

*Then the patient and I can get together and discuss what they have read and I will pick up any anxieties,.....'<sup>179</sup>*

If the Health Information Service, Stevenage senses that a patient-enquirer's GP would prefer them *not* to have used the service directly they suggest that the patient discuss the written information with the GP<sup>180</sup>. And for any patient who has obtained written information without GP mediation, it is valuable for him to be able to feel that the GP would be happy to discuss the written information with him.

Similarly, one important benefit of having a patient library within the surgery setting is that a patient has a health professional close at hand both to explain any written information that he does not understand, and to explain the relevance of the general written health information to the patient's specific experience of the condition:

*A doctor can adapt the information from the general to the specific, relating it to a particular patient. Patient information collections can help facilitate that'<sup>181</sup>.*

Oral GP/patient communication is clearly of primary importance. To improve patient satisfaction and compliance with treatment the oral transfer of information from GP to patient must be maintained and improved. Written information acts as a valuable back-up to the consultation process but in turn demands further oral explanations. These serve to adapt the general written information to a patient's specific situation (i.e. experience of the condition), and to explain what puzzles or causes anxiety in the written information. Just as written information backs up the oral, so too then does supplementary oral information allow a patient to exploit the benefits of written health information to the full.

That this written/oral information relationship must be a co-existing one is often insisted on by those who encourage the development of patient leaflets: the importance of such leaflets existing in *conjunction* with oral GP/patient communication is repeatedly stressed<sup>182, 183, 184</sup>.

Before concluding this chapter on existing developments in consumer health information provision in general practice one final area of consumer health information provision which exists in some general practices will be mentioned. It is included as an example of *computerized* access to consumer health information provision, a form of access considered by some workers in the health-field to be the key to future developments in this area of information provision (please see 6.4).

### 3.6 WELFARE RIGHTS ASSESSMENT

*.... the GP is ideally placed to detect those suffering financial hardship and to advise them on their benefit entitlement*<sup>185</sup>.

Several reasons contribute to the potential for GP provision of information on welfare rights assessment to patients: the fact that the GP is in contact with the majority of his practice-population during the year; the fact that many of those who visit the GP may not be claiming benefits to which they are entitled: e.g. maternity, disability and sickness benefits; the fact that some patients may visit their GP feeling ill through financial stress, and the GP can help the patient by detecting this and ensuring that the patient is receiving the financial aid he is entitled to.

That the general practice is considered an appropriate place for advice on welfare benefits is given by the example of the Whiteway Health Project, Bath - a community health project<sup>186</sup>: Gann describes how the project's philosophy is to spend resources supporting *existing* information services rather than establish new ones. As part of this philosophy, up-to-date information on welfare benefits is given monthly to 'those best placed to improve take up of benefits - local GPs, health visitors and relevant professionals'...<sup>187</sup>. General practice is therefore proposed as a suitable access-point for the community to turn to for such information.

Lisson Grove Health Centre, London has recognised this potential and in 1982 developed a welfare rights assessment computer programme to facilitate the complex process of calculating social security benefits. The programme was developed in recognition of the fact that

'a disturbing number of ailments could be traced to financial stress'<sup>188</sup> and to ensure that all entitlements were being claimed.

The programme has been a success: there are currently about 400 user organisations of which about 25% are health-related, 20% social services and the rest generalist advice centres<sup>189</sup>.

Several other general practices have bought the programme and now offer patients instant access to details on welfare benefits. The initial developer of the system, Professor B. Jarman feels that it is definitely 'a useful instrument for patient information provision', confirmed by results from a Lisson Grove user survey<sup>190</sup>.

The development of the Lisson Grove programme can be seen as an innovative advance in the area of consumer health information provision in general practice, and one which has spread, as witnessed by the purchase of the programme by other surgeries.

Provision of welfare benefits information contributes to a patient's participation in his own health-care: a patient who is ill through financial worries can use the benefits information provided by his GP to claim financial assistance, and by this means reduce his worries and restore his state of health; a patient who is entitled to sickness, disability or maternity benefits can learn of this from his GP, claim financial benefits and by this means participate in his own health-care by ensuring that he lives his condition as 'comfortably' as possible.

### In conclusion

- This chapter has focused on existing developments in consumer health information provision in general practice in an attempt to emphasise both (a) the *potential* for such provision in general practice and (b) the *variety and value* of areas of practice-based consumer health information provision to-date.

- The common element which links the different areas of consumer health information provision covered is the way in which they each contribute to increased patient participation in the health-care process.

- The following areas of consumer health information provision were discussed: -



- types of information provided through the work of patient participation groups;
- the general practice as provider of information on self-help groups and on other health information/support bodies in the community;
- general practice use of consumer health information services as a back-up to surgery provision of information to patients;
- developments in written consumer health information provision in general practice, including practice-produced patient leaflets and establishment of patient libraries in general practice;
- the potential role for general practice in provision of written drug information, and
- surgery provision of information on welfare rights assessment.

- Existing developments have often been the work of an innovative minority, and advances may be slow to 'catch on' in other general practices.

- Nevertheless, it is considered important to highlight the value of *all* existing developments as a means of encouraging their more widespread acceptance among general practices in general. Much depends on the individual primary health care team's recognition and enthusiasm for the general practice role in consumer health information provision.

Chapter three has looked at areas of development that have emerged during the past 10 to 15 years. The next chapter examines the more recent developments in general practice provision of consumer health information. It considers the period from 1990 to the present day.

Whilst Chapter three emphasised the role of individual practice initiatives in setting examples of good practice in consumer health information provision, Chapter four focuses on *recent Government legislation* and how it might influence future developments in specific areas of practice-based consumer health information provision.

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## 4.0

### RECENT DEVELOPMENTS

1990-1992 has witnessed the potential for important emerging developments in the area of consumer health information provision in general practice. This comes against a background of the continued development of certain of the areas of consumer health information provision as discussed in Chapter three. For instance, there were keen general practice follow-up enquiries to the Hertfordshire patient library projects, and groups involved in the self-help movement (such as the Self Help Team, Nottingham) have witnessed increased GP interest in learning about the movement and in passing self-help group information on to patients.

This chapter mainly focuses on recent Government legislation which encourages developments in specific areas of consumer health information provision.

#### 4.1 RECENT GOVERNMENT LEGISLATION

Government legislation has been recently passed which has implications for consumer health information provision developments in general practice:

The General Medical Practitioners' Contract, April 1990;  
Access to Health Records Act, July 1990;  
The Patient's Charter, October 1991.

These three pieces of legislation will be separately considered for their influence on the development of specific areas of consumer health information provision in the surgery setting.

##### 4.1.1 The General Medical Practitioner's Contract, April 1990

The new GP contract has significant implications for general practice development of information provision in the areas of (a)

health promotion information provision and (b) provision of information on practice facilities and services available.

(a) Provision of health promotion information

This is one area of consumer health information provision where the value of information provision as key to patient participation is a clear one: adequate provision of information on the relationship between leading a healthy lifestyle and disease prevention/maintenance of good health enables an individual's active contribution to his own health-care. He can act on advice about exercise, diet, alcohol consumption and cigarette smoking by adapting his behavioural patterns to the health professional's recommendations.

Recognition of a primary health care team role in health education has come fairly recently, with it being first considered primarily a health visitor's role and only afterwards a GP one also'.

This section focuses on the potential for health education in general practice. Various studies over the past 10-15 years have shown the potential for practice-based health education - that patients desire it and GPs recognise the appropriateness of a GP role in this area, but have also shown that active health education has been slow to develop in general practice. Against this background the health promotion implications of the new GP Contract will be outlined.

Patients and GPs favour health education in general practice.

Evidence of both patient and GP positive attitudes to health education in general practice suggest that it is an appropriate setting for this area of consumer health information provision.

In the 1980s two health studies were carried out using self-administered questionnaires to determine patient attitudes to health promotion in general practice<sup>2,3</sup>. The first study was based on two London practice-populations and the second extended this to 47 English and Scottish practices. The first study showed that in the four areas of weight, smoking, drinking and fitness, a range from 72% to 83% of patients felt that their GPs *should* show an interest. Similarly, in the extended study, responses showed a majority in favour of GP

Interest in patient lifestyle factors.

Similarly, a 1988 study based on a Southampton practice showed that patients support a GP health educative role<sup>4</sup>. In this study 77% of patients claimed that for them the GP was the member of the practice staff who would be looked to as the most essential source of health education.

These studies tend therefore to support the claim that,

*personal doctors are credible and trusted - that they are regarded as particularly reliable sources of information on health matters<sup>5</sup>.*

Studies have also been carried out to determine GP attitudes to health education in general practice and have shown mainly positive reactions:

a study in Avon based its findings on an analysis of 371 returned GP questionnaires<sup>6</sup>. GPs had been asked to reply, on a graduated agreement scale, to six negative statements on health education. For instance - 'I find giving health education dull and boring'. Four statements pertained to GP attitudes to health education and two to patient attitudes. A high percentage of GPs disagreed with the four statements suggesting negative GP attitudes to health promotion - 78.6%, 74.2%, 96.2% and 80% respectively<sup>7</sup>.

These findings were confirmed by a second study which sent questionnaires out to 282 GPs in Avon, Somerset and Gloucestershire<sup>8</sup>. Questions were included on the extent to which GPs felt that, in nine different areas of lifestyle, it was appropriate for them to give health education, and also on their competence in this role. Findings showed that except for 'coping with poverty' GPs felt overall that it was appropriate for them to act as health educators<sup>9</sup>. Those responsible for the study felt justified in extending those positive GP attitudes to neighbouring counties also.

Similarly, a Wessex-based study on GP attitudes to health education showed that GPs generally accepted having a role in health promotion and disease prevention<sup>10</sup>. Findings showed that GPs generally considered the health education role to be a shared responsibility between themselves and other members of the primary

health care team. The role of the health visitor was especially emphasised.

These and similar studies together suggest that,  
*most patients and most doctors expect general practitioners to be actively involved in health promotion*'.

#### General practice: an appropriate setting for provision of health education information

Other reasons have been given which support the potential for health promotion in general practice.

Given that a majority of the general public, irrelevant of age, sex or social background, visit their GP at least once a year the GP is in a key position to take advantage of this contact and ensure that health education reaches those who are clearly most in need of it but who would perhaps not have taken the initiative to go and actively seek out health education advice.

Furthermore, it is argued that health education received in general practice is more effective than many other sources of health education. This is because, for various reasons, the patient is more receptive to health advice in the practice setting: patients in GP consultation may often feel above-average motivated to listen and act upon health education because of the feelings of anxiety about health that incited the GP appointment to be made in the first place<sup>12</sup>; patients given health education by their GP are more motivated to act upon it because they suspect that the GP will monitor and follow up on advice given; the one-to-one contact of a GP/patient consultation is more effective than health education to the masses, for the patient appreciates the personal emphasis from a (usually) known and trusted health-care figure.

#### Health education in general practice is favoured at 'official' levels

That there is a valuable potential for health education in general practice has been recognised and encouraged by different 'official' bodies during the past decade:

the RCGP published a 1981 report - Health and Prevention in

Primary Care, an optimistic view on a GP role in health education. The report based its views on the findings of a 1979 study on GPs' influence as health educators in the area of cigarette smoking<sup>13</sup>.

The study of 2,138 cigarette smokers attending 28 London surgeries found a correlation between those who had received most health education in GP consultation and those most likely to give up smoking and still not be smoking one year later.

The RCGP Occasional Paper no.22, Promoting Prevention, 1983, further encouraged a general practice health education role.

On a European level, Target 28 of WHO's European Region Targets for Health, 1985 (please see 1.2.1 (b)) clearly recognised the importance of health education in general practice by its recommendation that,

*By 1990, the primary health care system of all member states should provide a wide range of health-promotive, curative, rehabilitative and support services to meet the basic health needs of the population and give special attention to high-risk, vulnerable and under-served individuals and groups<sup>14</sup>.*

And at a national level, the HEA's Strategic Plan, 1990-1995<sup>15</sup> declares its commitment to supporting the development of health education in general practice:

*In recognition of the importance of providing support to those who are in close contact with members of the public and have the prime responsibility for direct personal or group education, the HEA will give priority to developing and supporting health education in primary health care settings<sup>16</sup>.*

Pages seven and eight of the HEA's Strategic Plan emphasise the Authority's plan to support health education in general practice. The HEA declares its continuing support for health education in 'schools, colleges and youth settings<sup>17</sup>' and its top priority to supporting health education initiatives in both primary health care settings and in the work-place. The HEA's commitment to supporting health education in general practice is further emphasised on page 13 of the

Plan where it outlines the functions of a special Primary Health Care Unit to be set up for a five-year period at the Department of General Practice, Oxford University. The Oxford Unit is to facilitate the primary health care team's health education role by acting as a resource centre on health education (please see 5.3 (b) for an outline of the Unit's contributions to general practice training needs in the area of health promotion).

#### Lost opportunities for health education in general practice: Why?

Despite both patient and GP recognition of general practice as an appropriate location for health promotion information provision, studies have shown that,

*'theoretical' interest in opportunistic health education does not seem to be reflected in the routine practice...<sup>18</sup>.*

Opportunities to raise health promotion issues are often not taken up by GPs during consultation, and when health promotion talk *does* take place it is most likely to be problem-related, i.e: related to the specific health problem which brought about the consultation in the first place. Far rarer is a health education issue raised in isolation to anything else discussed in consultation.

One study<sup>19</sup> analysed recorded consultation interviews to determine the extent to which GPs gave health education advice in the areas of alcohol consumption, diet and smoking when opportunities for both problem-related and non-problem related advice arose. It was found that many opportunities for health education were neglected by GPs, that unless *patients* raised health education topics many opportunities were lost, that non-problem related health education was rarely given and that *one* GP raised smoking as a health education issue on a regular basis.

Other studies also confirm GP reluctance in giving *non-problem* related health education<sup>20, 21</sup>.

GP reluctance in health education information provision leads to discrepancies between what health education a patient *expects* his GP to give and what is actually provided. This is shown by the two

Wallace studies on patient attitudes to health promotion in general practice<sup>23, 24</sup>:

In the 1984 study, whilst a range from 72% to 83% of patients thought that GPs should show interest in the four specific health education topics, it was felt that GPs had shown interest on the much lower range from 38% to 51%. The corresponding 1987 figures showed patient expectations on a range from 49% to 67% and evidence of GP interest on a range from only 2% to 24%.

GPs may voice a genuine interest in their role as health educators, but theory does not match practice. Various reasons have been suggested for this discrepancy:

owing to the fairly recent focus on health education in general practice some GPs may lack the necessary communication skills to feel confident in a health promotion role, and will not be 'in the habit' of assuming such a role.

There is also evidence of GP unease in the health education role through fear of adverse patient reactions to being given advice on how to improve their lifestyles. This is the fear of being considered 'intrusive and moralising<sup>25</sup>'. An American study<sup>26</sup> based on a two-year period observation of 11 practices discovered clear signs of discomfort between patients and GP when health education topics were raised during consultation. The study reports on evidence of the following signs of 'conversational disruption': conversation speed ups, voices raised, gaze shifting and nervous laughter<sup>27</sup>.

That some GPs fear negative patient reactions to health education was supported by the findings of the two studies based on general practices in Avon, Somerset and Gloucestershire<sup>28, 29</sup>: in the first of the two studies, 15% of GPs agreed that patients *do* get upset if the topic of smoking is mentioned when it is not specifically problem-related. Also, 20% of GPs agreed that when a health education topic was raised patients soon lost interest. An equivalent percentage of GPs in the second study also agreed with this last statement.

Lack of time is also suggested as a contributing factor to missed opportunities in health education. Effective health promotion is time-consuming and the average consultation-slot does not allow for this. A 1986 study<sup>30</sup> focused on the effects of time constraint on the verbal content of consultations. It analysed the different types of



patient and GP statement contained in tape-recorded consultations banded into three groups of - five, seven-and-a-half or ten minutes duration. Findings showed that statements of the health education category 'were more likely to be recorded in surgeries booked at longer intervals'<sup>31</sup>. The study concluded that this is because the 10-minute consultations put GPs under much less time-pressure than the shorter time-slots: the five-minute consultations usually overran whilst the ten-minute consultations left an average of two point six minutes to spare<sup>32</sup>.

Reduced GP power-status resulting from health education information provision has also been forwarded as a reason for minimal GP activity in this area<sup>33</sup>. To provide health education information is to provide general information of a social rather than a technical/scientific nature, and some GPs may feel that this reduces their power-status in the patient's eyes. Similarly, health education information enables active patient participation in the health-care process and some GPs may fear that if the patient recognises that not only the GP but he too can significantly contribute to his own health-care, GP prestige may suffer.

Other reasons given to explain minimal evidence of health education information provision in general practice include: lack of some GPs' belief in the value of health education in that there is 'no automatic relationship to compliance'<sup>34</sup> i.e: increased knowledge may change attitudes but does not necessarily change behaviour; GP lack of confidence in giving advice in certain areas of health education, e.g: on the precise benefits of certain foods/exercise on the body mechanism.

#### Health education and the GP's new Contract, 1990

Against this background of discrepancy between the *potential* for health education information provision in general practice and the poor levels of health education being undertaken in practices generally, the General Medical Practitioners' Contract, 1990 is important. The Contract puts a strong emphasis on health promotion and disease prevention in primary health care. Its encouragement of provision of health promotion information in general practice may

prove to be a valuable incentive for this area of consumer health information provision to be developed in the surgery setting.

The health promotion emphasis of the new Contract was heralded by the Government's White Paper, Promoting Better Health, 1987. This paper already stated that,

*the Government intends positively to encourage family doctors and primary health care teams to increase their contribution to the promotion of good health<sup>35</sup>.*

The 1990 Contract encourages increased health promotion information provision in general practice on two levels: orally in consultation and through provision of health promotion clinics.

(a) The general health check - inclusion of a health promotion element

The Contract ensures a certain level of one-to-one transfer of health promotion information from primary health care team to patient. It states that all registering patients are to be given a general health check and that this is to be given three-yearly to all practice patients. The general health check includes procedures such as height, weight and blood pressure measurement and a urine analysis, and a health promotion element is included:

*an enquiry about the patient's lifestyle, alcohol consumption, exercise and diet;*

*offering of advice and, where appropriate, treatment in those areas<sup>36</sup>.*

The general health check also includes the 'offering of new patients on the GP's list a 'health promotion' consultation and take a medical history<sup>37</sup>'.

#### (b) Health promotion clinics

The 1990 Contract introduces many areas of financial incentive into general practice. For instance, it introduces target payments for child immunisation and cervical cytology - lower and higher levels of payment to be made according to percentage targets achieved in these two areas. It also introduces special fees that can be claimed for instances of the following: minor surgery, child health surveillance, out of hours service and *health promotion clinics*<sup>38</sup>.

The Contract encourages the development of health promotion clinics, for the practice is eligible to claim a fee of £45 for each clinic held<sup>39</sup>.

The Contract therefore encourages general practice developments in health promotion information provision not only in the one-to-one consultation process but to patients in group sessions also. The stipulated number for an 'approved' clinic session is 10 people. This is the number for which a fee can be expected<sup>40</sup>.

Health promotion clinics may include clinics on specific conditions such as diabetes and heart disease, or on general health education topics such as anti-smoking and alcohol control.

Health Promotion Facilitators are to assist the primary health care team in developing health promotion clinics. Practice staff training needs in relation to health promotion information provision will be outlined in Chapter 5.3 (a).

#### Health promotion clinics and patient participation

Development of health promotion information provision through clinics has implications for improved patient participation in health-care:

- patient participation by attending a clinic where information learned can be used to benefit the patient's health;

- patient participation through reaching greater understanding of the health issue covered in the clinic;

- patient participation by acting upon the knowledge gained to maintain/improve one's health, e.g. by adapting one's present lifestyle to recommendations made in the clinic.

Looked at objectively therefore the Contract can be seen in a

positive light for the emphasis it places on encouraging health promotion information provision in general practice - both on a one-to-one basis and in group sessions. For health promotion information provision enables increased patient participation in the maintenance of his own health and the consequent benefits include: better physical health, increased feelings of control and confidence for the patient, and an increased sense of responsibility as the health-care process develops into a patient/GP partnership in which the patient has a part to play.

#### Levels of practice clinic development may vary

Certain qualifications must however be made, for on both levels, i.e: one-to-one health promotion and health promotion clinics, the Contract encourages but cannot ensure marked improvements in health promotion information provision.

By the introduction of three-yearly health checks the Contract does regulate the provision of health promotion consultations, but the *quality* of health promotion information offered by different GPs may vary greatly. One GP's concept of what constitutes a satisfactory level of health promotion discussion and information transfer may be very different from another's.

Regarding health promotion clinics there is the danger that whilst the Contract's emphasis on clinics may spark off a genuine commitment to clinic development in some practices, others may be motivated by the promise of financial gain alone - the £45 fee. In this case some clinics may be developed with minimal practice commitment to their effectiveness. This danger is exemplified in the following quote from a GP being asked his reactions to the new Contract:

*the only reason we would run a clinic would be to make money, not to improve the service we offer or to improve outcome for patients<sup>41</sup>.*

The 1990 Contract has however clearly led to developments in clinic provision in some practices. It is reported that about one million health promotion clinics were held in general practice during

the first year of the Contract<sup>42</sup>. The same article gives examples of practice commitment to the development of clinics:

a group of Derbyshire practices have appointed a community dietician to hold clinics and to also train practice staff in this area<sup>43</sup>. These practices have also recognised the importance of targeting health promotion information provision at those in need, for the dietician is employed to also organise health promotion clinics in the community, through liaison with supermarkets and other workplaces. And some Wakefield practices are developing their clinics and using the clinic income to subcontract health promotion work out to other community-based specialist services such as the Relate counselling service<sup>44</sup>.

Some practices are therefore being encouraged by the 1990 Contract to develop their provision of health promotion clinics, and are, furthermore, extending their responsibilities in this area into the wider community.

Commitment to developing clinics is not however uniform across the country. Just as the development of patient libraries in general practice is an area of consumer health information provision being developed on a limited basis, there are similarly discrepancies in levels of clinic development across general practices generally. For instance, a study of five practices 'chosen to represent contrasting settings and type of practice<sup>45</sup>' found little evidence of clinic development. The practices were visited during a 13-month period nine months after the introduction of the 1990 Contract. Regarding clinic development it was found that for 11 different health topics, only *one* out of the five practices held clinics for *all* (except one of) the 11 areas. The other four practices relied mainly on opportunistic health promotion information - given during patient/GP consultation. In fact, for seven out of the 11 health topics only *one* of the other four practices held a clinic at all.

These differences show the need to recognise that although the 1990 Contract encourages health promotion information provision through development of clinics there are certain obstacles to a widespread and rapid development of clinics.

### Possible obstacles to widespread development of health promotion clinics overall

Some primary health care teams may not believe that clinics are the most effective means of giving health promotion information and 'argue that health promotion work should be done as opportunities arise when people come to the practice for other reasons<sup>46</sup>'.

Opportunistic health education given on a one-to-one basis during patient/GP consultation may be seen as more individualised, hence effective, than health education directed at a group. Some fear that mainly middle-class women dominate at clinic sessions rather than those who are more in *need* of the information given in clinics but who may feel less inclined to attend sessions<sup>47</sup>.

Some GPs may feel that the fairly low attendance figures that clinics usually achieve does not merit the effort taken to organise them. Those suffering a specific condition may feel motivated to attend a related clinic, but it can be more difficult to motivate a good patient turn-out at clinics of a more *general* health education subject-coverage.

Furthermore, depending on practice location it may be hard to get good clinic attendance. For example, practices in areas with widely scattered communities may consider it unrealistic to expect patients to travel long distances to the clinic. And practices in areas with severe social problems such as poor housing and high unemployment may consider it unrealistic to expect health promotion clinic attendance to be one of the local population's top priorities<sup>48</sup>.

### Time Factors

Some practices, especially the busy inner city ones, may feel that they lack the necessary staff, space and time to run effective clinics. The 1990 Contract increases practices' administrative workload and therefore yet further increases time pressures: for instance, the new target payments on child immunisation and cervical cytology demand that practices keep a carefully monitored record of how near they have come to reaching the lower and higher target levels.

### Health needs assessment

Effective development of health promotion clinics requires that they reflect the practice-population's actual health needs. A health needs assessment demands detailed analysis of the prevalence of disease and the high risk status of the community. This involves the administrative task of recording and updating the health needs of individual patients, for the community's overall health needs are based on intimate knowledge of its individuals' health risk statuses.

Some practices may lack the necessary time and skills to develop this administrative task. Skills in health needs assessment will be further discussed in 5.3 (a) as an area of practice training needs.

### In conclusion

- This section has tried to highlight how the GP's new 1990 Contract encourages the provision of health promotion information in general practice.

- Both (a) health promotion consultations (by the introduction of the three-yearly health check) and (b) health promotion clinics (by financial incentive) are encouraged.

- This section also outlined certain limitations to widespread immediate development of health promotion clinics in general practice: differences in practice attitudes towards clinics, time constraints and the need for detailed health needs assessment.

- Nevertheless, emphasis on health promotion clinics can be seen as an important recent development in the encouragement of health promotion information provision in general practice.

- It remains to be seen to what extent the 1990 Contract influences active development of health promotion information provision in general practice during the years to come.

(b) Information to patients on practice facilities available

*The key question must be 'why is this information being provided?'. If it is to 'facilitate an informed choice by patients seeking treatment.... then this is acceptable'<sup>49</sup>.*

Practice information leaflets provide patients with details on facilities and services offered by the individual practice. In a paper which examines the concept of such leaflets the RCGP emphasises how such leaflet provision is important for enabling informed patient choice of general practice<sup>50</sup>.

Provision of information on practice facilities is an area of consumer health information provision which contributes to patient participation in the health-care process by enabling both potential new patients and dissatisfied registered patients to base their choice of new practice on *informed* choice. For if adequate information is provided on practice facilities, patients may join the practice whose facilities most appeal and most closely reflect their particular needs. Information given might include details on practice staff, services provided and on particular arrangements made, such as for out-of-hours service.

The new Contract's encouragement of practice provision in this area will be outlined, but it is felt useful to first highlight the RCGP's emphasis on practice information leaflets during the five years previous to the 1990 Contract. This will show how the Contract's inclusion of a section on practice information leaflets can be seen as a Government response to RCGP recommendations.

RCGP recommendations

Provision of practice information leaflets is an area much considered by the RCGP, especially since 1984 when its Patients' Liaison Group (PLG) treated the subject in its first published paper which appeared in the College Journal, December 1984 (page 672)<sup>51</sup>.

The PLG had been set up in 1983 with the aim of representing patient interests in issues and concerns of general practice.

The College's Information Service held over 60 practice



information leaflets in November 1985 and was receiving an increasing number of requests for advice from practices on how to produce leaflets<sup>52</sup>. Helping GPs in this area has since become an accepted responsibility of the Service.

Analysis of leaflets held, and discussions with the College's Communications Division and the Council of the College led to the formulation of a list of areas the Council found it acceptable to include in a practice information leaflet<sup>53</sup>.

In September 1985 the Council of the College made its position on practice leaflets clear by stating that,

*The provision of a wide range of information to patients about services provided by general practitioners is welcomed<sup>54</sup>.*

And in 1987 the RCGP produced Practice Information Booklets, a guide for GPs on how to produce a practice information leaflet. The guide covers such areas as explanations of the purpose of leaflets, details on what to include, style and suggestions for additional areas of coverage, e.g: details about a practice's patient library. A list of further relevant readings is also given. In 1987 the RCGP also produced a paper in consultation with its PLG on the range of services it felt practices should offer<sup>55</sup> and section 2.10 - 2.11 of this paper stresses the importance of information provision on practice services and suggests that this information is best provided in leaflet form.

The RCGP's 1985 recommendations on what to include in both practice leaflets and in Family Practitioners Committee (FPC) lists of local GPs (at that time the only source of information on practices widely available to the public) can be seen as a forerunner to the stipulations of the 1990 Contract.

### The new Contract

The new 1990 Contract demands that practices provide practice leaflets which contain information on practice staff, services and facilities. These leaflets will provide more detailed information on practices than that previously given in FPC lists.

The Contract demands that practice leaflets provide a certain information coverage. Among areas to be covered are details on: practice staff (including dates of doctors' qualifications), special arrangements, e.g. for home visits, clinics and other services, and patient participation activities<sup>56</sup>.

Exercising informed choice in the area of choice of GP is further facilitated by the Contract both making it easier to change GP and also requesting that FPCs publish local directories of family doctors: a patient wishing to change GP will no longer have to first approach the FPC or his current GP, but simply need ask the new GP to accept him onto his list<sup>57</sup>. And the FPC local directory of family doctors will be available in the public library for prospective patients to consult when deciding on a new GP. A minimum set of data is to be included in the directories. These are less detailed than the practice leaflets<sup>58</sup>.

The new Contract is therefore important for it regulates the provision of practice information at official Government level: uneven provision amongst practices will be replaced by provision country-wide. Patient participation through informed choice of GP is encouraged.

However, it remains to be seen to what extent the 1990 Contract actually does increase the numbers of patients who choose a new GP through informed choice.

#### Possible obstacles to participation through informed choice of GP

*it is by no means inevitable that patients will in reality be able to exercise that choice<sup>59</sup>.*

Although the new Contract can be seen to encourage informed choice of GP there are certain obstacles to exercising this choice:

Gann<sup>60</sup> argues that patients may lack the necessary motivation to exercise choice in the area of changing GPs because the infrequency of surgery visits makes it easier to simply choose the nearest practice. He also suggests that the information provided in the practice leaflets is not sufficiently detailed for a sound choice to be made. Additional details, on quality of care for instance are needed.

The active investigation that a patient must carry out to make an informed choice may also act as a deterrent to the less motivated: the FPC family doctor directories held by public libraries do not contain sufficient information on which to base informed choice. For instance, Loughborough public library holds a directory of GPs in the Charnwood area in which details on 20 surgeries are fitted onto only *three* A4 sides of paper. Very minimal detail is given on each practice, most common being practice address, practice and practice staff names, and surgery opening hours only. Only one of the 20 surgeries has also provided a more detailed practice leaflet for inclusion in the directory. If this example is standard for FPC directories a patient would also need to visit each individual practice and consult its practice information leaflet to obtain a more detailed level of information on which to base choice. Even then, as indicated by Gann, it is negotiable whether individual practice leaflets supply adequate information on which to base choice.

Could the prospective patient's task be facilitated by it being required that GPs (like the one out of 20 in the Charnwood area) supply actual practice leaflets for inclusion in FPC directories, rather than these only containing, as currently, more minimal data? The RCGP for instance, suggested in 1987 that practice information leaflets be both given to practice patients and also made 'available through such outlets as family practitioner committees (FPCs) and health boards, community health councils, citizens advice bureaux, reference libraries and other local information services'<sup>1</sup>.

However, the Association of Community Health Councils for England and Wales suggests that there will be cases when even the most highly motivated cannot exercise choice of GP because there is no real alternative choice<sup>2</sup>:

there is no feasible alternative choice for patients in either rural areas where there may only be one practice for miles around or in isolated areas where there may be more than one practice but transport difficulties prevent access to any other than the nearest; group practices may merge to form consortia and a patient may find it difficult to change GPs because his new choice of GP is part of the same group practice as his previous one; furthermore, GPs are not *obliged* to accept a patient who wishes to leave his previous doctor.

And whether a patient is motivated to change GP or not, and whether there is a real alternative choice or not, some will be deterred from seeking out a new GP because of the trauma involved: for many it will raise feelings of unease and embarrassment at leaving the old practice. And it is a particularly traumatic experience for a dissatisfied patient in the middle of a course of treatment for a serious or complicated condition, for it will take time and energy for the patient to pass on adequate details of his case-history and particular concerns to ensure that the new GP fully understands his experience of the condition and its treatment. And the patient will only feel happy when enough information has been transferred to his new GP.

In spite of these obstacles to patients exercising informed choice of GP, the new Contract increases the potential for choice to be made and its moves 'to enhance patient information and choice are certainly to be commended<sup>63</sup>.

#### Additional benefits of practice leaflets

Even if in practice there are hindrances to patients using practice information leaflets to exercise an informed choice and by this means participate in their own health-care process, there are additional benefits to provision of such leaflets.

For instance, leaflets enable patient participation through increased understanding about not only the range of services and facilities available but also about the expertise of the various practice staff. Information provided about the different practice staff roles may for instance increase patients' awareness of the fact that a practice nurse may be consulted without appointment for certain treatments and enquiries for which it is not necessary to see the GP.

There is also the opportunity to increase patients' understanding about the particular practice aims, for these may be outlined in the leaflet.

Provision of a practice leaflet also acts as a public relations tool, for it reinforces to patients that the practice cares and wants its users to be 'in the know' about what is on offer.

These additional benefits of the practice information leaflet

were highlighted in the findings of a 1980 study<sup>64</sup> which sought to determine patient attitudes to the introduction of a practice brochure giving details on staff expertise and on practice services available.

### In conclusion

- This section has tried to outline the new Contract's encouragement of a specific area of consumer health information provision in general practice - that of provision of information to patients on practice staff and services.

- This area of consumer health information provision encourages patient participation in the health-care process through *informed choice* of GP.

- The degree to which patients are motivated to exercise choice, and the existence of any real alternative choices will vary for each practice-population.

- Gann<sup>65</sup> reports on a 1989 British Medical Journal survey on recently registered patients in Reading which showed that only four percent of patients had based their choice of GP on comparing practices. It is for future surveys to determine the degree to which more widespread provision of practice information leaflets influences numbers of practices chosen through informed choice.

### The 1990 Contract and general encouragement of consumer health information provision in general practice

In addition to encouraging developments in *specific* areas of consumer health information provision - provision of health promotion information and practice information, the new Contract could very possibly have an important effect on the *overall* development of consumer health information provision in general practice. This is due to the combination of various elements outlined in the new Contract:

if the Contract does increase competitiveness between practices as a result of (a) capitation fees (i.e. fees claimed per registered patient) being increased from 40% to 60% of the doctor's paid income and because it has (b) been made easier to change GPs, then doctors

will want the practice to have maximum appeal to patients in (c) the practice information leaflet which will include details of the different aspects of consumer health information provision (such as health promotion clinics and patient participation activities) offered by the practice.

It seems likely that GPs will be spurred by these combined factors to develop good consumer health information provision, such as up-to-date health information leaflets, to be able to include them in the practice information leaflet and attract existing and new patients.

The new Contract also introduces (d) FPC consumer surveys for general practice<sup>66</sup>. These will measure patients' satisfaction with GP services. GPs will have access to completed questionnaires and will therefore learn about patient assessment of the practice. If levels of consumer health information provision are criticised it is likely that GPs (especially in the new competitive climate) will endeavour to remedy gaps. The Association of CHCs sees the survey as 'a valuable tool for FPCs in assisting practices to develop services in directions which are sensitive to consumer needs and preferences<sup>67</sup>.

Improvements in consumer health information provision will of course only be made if patients do mention this as an area requiring increased practice attention. This depends on the survey giving patients the opportunity to voice their opinions on levels of consumer health information provision in the practice. The Association of CHCs favour local CHC involvement in the formulation of the surveys<sup>68</sup>. If CHCs were involved it is likely that patients *would* be encouraged to voice their expectations in the area of consumer health information provision, for CHCs would recognise this as an important area of service provision in general practice and ensure that it was covered in the survey.

### In conclusion

- The General Medical Practitioner's Contract, April 1990 has been considered with respect to its influence on the development of areas of consumer health information provision in general practice.

The Contract makes important contributions to both (a) health

promotion information provision through its introduction of regular health checks (containing a health promotion element) and through the encouragement of health promotion clinics, and to (b) provision of information on practice staff and facilities through its introduction of practice information leaflets.

- The ways in which these two areas of consumer health information provision enable patient participation in the health-care process have been outlined.

- However, although the Contract can be seen as important for in theory encouraging developments in health promotion information provision and informed choice of GP through access to the necessary information on which to base such a choice, certain obstacles to immediate widespread development in these two areas have been highlighted.

- Future studies will show the extent to which the new GP Contract influences the development of these two areas of consumer health information provision in general practice.

#### **4.1.2 Access to Health Records Act, July 1990**

This Act is the second piece of recent Government legislation which will be discussed for its implications on consumer health information provision in general practice. The Act came into force from November 1, 1991 and contributes to consumer health information provision in general practice in the area of provision of written health information for patients.

The Act covers a very specific area of written health information provision: it gives patients the right to see and/or be supplied with a copy of their health record or extract thereof. This includes anything the GP may have written in their records from November 1, 1991. Access can however be denied if the GP feels that the notes requested constitute 'information likely to cause serious harm to the physical or mental health of the patient or of any other individual<sup>67</sup>.

Already under the Data Protection Act, 1984, patients have a right to see their medical records if these are held on computer record, and under the Access to Medical Reports Act, 1988, patients

have a right to see reports written by their GP for employment and insurance purposes<sup>70</sup>.

The 1990 Act gives patients access to handwritten as well as to computer-held medical records. Gann<sup>71</sup> cites recent survey findings which emphasise the clear public support for such access.

#### The 1990 Act: written consumer health information provision and participation

Access to medical records has several benefits. For instance, it gives patients the opportunity to both correct inaccuracies in their records and to add information which enhances the comprehensiveness of records.

The following three benefits are of particular relevance to the relationship between written consumer health information provision and patient participation in the health-care process:

##### (a) Participation through increased knowledge

Access to medical records gives patients important back-up to what is retained from the oral consultation. It can improve patients' understanding of their condition and its prescribed treatment. This enables patient participation in the sense of an improved level of insight into their condition.

Chapter three (please see 3.5.1) referred to the benefit of general written consumer health information as a back-up to the oral consultation, as a prompt to patients' recall on what is covered orally by the GP. However, it was also mentioned (please see 3.5.6) that patient leaflets lack a *personal* element. Hence the importance of access to medical records: they have the advantage of providing valuable written support to the oral consultation which is individualised. For, unlike patient leaflets, medical records are clearly patient-specific and increase patients' understanding of how their condition specifically affects *them* as individuals. Non patient-specific written health information remains valuable as general background reading on the nature of an illness or condition.



(b) Participation through greater compliance

Access to medical records can result in more effective patient participation in his own self-care. For instance, a patient can ask to see/have copied the section of his medical records which details how and when to take his prescribed medicines and what precautions the GP advises him to take. These details may be forgotten from the oral consultation alone.

(c) Improved participation in the consultation process

*Face to face consultations between patients and doctors will be enriched by the additional dimension to the interaction that a shared knowledge of recorded information can bring<sup>72</sup>.*

Having read notes from his medical record the patient will have a sounder knowledge base from which to discuss his condition and treatment with the GP, pick up points and raise questions.

In the oral consultation it is as much as many patients can do to understand and retain what the GP tells them. Possession of a copy of the relevant section of his medical records can act as a support to the patient and give him the confidence to go over and discuss his condition with the GP.

Access to medical records can increase patient knowledge and understanding of a prescribed treatment plan and can result in patient and GP planning future treatment strategies together. This is an important element of participation, for as Knight emphasises,

*Good medical decisions are often made when doctor and patient can arrive at a reasoned judgement together<sup>73</sup>.*

Furthermore, patient access to medical records has the potential to generally improve the GP/patient relationship: it is likely that a patient whose GP encourages him to consult his medical records will interpret this as encouragement to the development of the GP/patient relationship into more of a partnership, where knowledge is not withheld but shared.

In theory therefore development of access to medical records gives patients a new source of written health information which has an important advantage over written health information given in patient leaflets - that of being patient-specific.

However, it is necessary to recognise that access to medical records does not necessarily provide patients with access to *understandable* written health information.

#### Intelligibility of medical records

Medical records may be difficult for patients to decipher due to some GPs' poor handwriting. Some GPs make heavy use of abbreviations, and may even use their own private coded shorthand. This may be (a) an innocent habit of the GP, i.e: the way he has become used to writing patient notes, or (b) a ploy used by GPs to purposefully make it difficult for patients to understand their notes. For some GPs begrudge sharing information, and hence power, with the patient.

To prevent patients sharing information some GPs may even resort to making less detailed patient records than they did previously to the 1990 Act.

To purposefully write unintelligibly will not only harm the GP/patient relationship (rather than actually improve it, which as mentioned above is one of the Act's potential benefits) by causing patient mistrust. A further drawback is that unintelligible notes will be of little use to a new GP or 'Outpatients' to which a patient may be referred. There is the possibility of a patient receiving poor care because of this lack of transfer of adequately detailed information<sup>74</sup>.

The Act does however make provision for back-up explanations of unclear terms, for where terms are not understood by patients 'an explanation of those terms shall be provided with the record or extract, or supplied with the copy<sup>75</sup>'.

Patients do therefore have a right to additional explanation of unintelligible terms used.

If GPs for whom it has become second nature to write patient notes in a very personal way are repeatedly asked for clarification from their patients, it is hoped that they will gradually learn to

write fuller and clearer notes generally. It is likely that such GPs, who are not *intentionally* keeping back information from patients, will be prepared to explain the notes orally. Their patients may in fact learn more from a detailed *oral* explanation of unclear written notes than they would from access to clearer written notes alone.

Regarding GPs who intentionally write unintelligibly it is to be hoped that they constitute only a small minority of GPs overall. If a GP should consistently produce cryptic patient records and produce unsatisfactory further explanations it is probable that the patient would eventually bring a complaint against him. For it is unlikely that a patient who had the confidence and motivation to ask to see his records in the first place would be satisfied with poor provision of information. Similarly, it is hoped that the health professional who realises that a certain GP constantly refers patients on to him with unintelligible medical records would also file a complaint.

Some patient records may seem at first glance incomprehensible, but, as mentioned, the Act does provide for further explanation of unclear terms. And poor patient notes accompanied by good oral explanations may give patients access to equal levels of health information as do clearer written notes alone.

Furthermore, the RCGP is aware of the need for legible medical records. A month after the Access to Health Records Act came into force, the RCGP Connection supplement to the RCGP journal published an article on good practice in the sharing of medical records health information<sup>76</sup>. The article is based on PLG guidelines and one section suggests that 'some educational support for GPs in the construction of patient records so that they are legible, lucid and pertinent would obviously facilitate meaningful patient access and minimize the potential for misunderstanding and resentment<sup>77</sup>'.

However, even if patient notes are lucid and clear, procedures involved in formal access of notes may deter the less determined patient from actively exercising his rights to this new source of individualised written health information:

### Bureaucratic procedures may deter

(a) The Act<sup>78</sup> states that patients must apply in writing for access to their medical records;

(b) The Act states that 21 days is the 'requisite period' within which a request to see medical records is to be satisfied<sup>79</sup>. However, if the requested records were written more than 40 days prior to the date of application, a period of 40 days must be allowed.

(c) The Act states that a fee will be charged to access medical records written more than 40 days prior to the date of application, in accordance with fees prescribed under the Data Protection Act, 1984<sup>80</sup>. (This fee would currently not exceed £10<sup>81</sup>).

Therefore, legislation demands that patients apply for access in writing, expect a minimum of a 21 day wait before seeing their records, and also expect to pay a fee if the requested notes are over 40 days old.

These formal constraints may deter patients from seeking access, and opportunities to benefit from this specific area of written consumer health information provision will be lost. Some GPs however *will* let their patients see their records, without written application<sup>82</sup>. In its article on good practice in the sharing of medical records health information<sup>83</sup> the RCGP refers to the legal requirements of written application and of giving 21 or 40 days for a request to be satisfied. It stresses that it could be considered good GP practice to both accept oral requests and to give speedier access to medical records.

*the implicit assumption should be that most patients in most circumstances can see their records virtually on demand with the minimum of bureaucratic rules and regulations<sup>84</sup>.*

### In conclusion

- This section has tried to emphasise the implications of the Access to Health Records Act on consumer health information provision in general practice.

- The area of consumer health information provision which the Act provides for is the very precise one of patient-specific written information.

- It has been outlined how patient access to notes on his own condition and treatment allows fuller participation in the health-care process on three levels:

participation through increased knowledge;

increased knowledge facilitating participation through more effective compliance with treatment;

participation through informed discussion in the consultation process with, in some cases, joint patient/GP planning of future treatment.

- This three-fold participation depends on medical records being easily understood by the patient. Intentionally or not, GPs may not always write clear notes. This problem should however be to some extent alleviated by the Act stipulating the patient's right to further explanations of unintelligible terms used in medical records.

- With this recent piece of legislation, of only nine months' duration to-date, it will be for future studies to measure the extent to which patients *are* asking to see their written medical records and *are* taking the opportunity to access this specific area of written consumer health information provision.

#### 4.1.3 The Patient's Charter. October 1991

The Patient's Charter is the final of the three recent pieces of Government legislation to be considered in the light of its influence on the development of consumer health information provision in general practice.

##### Information on local health services

The Patient's Charter tells the public that one of its new rights is to receive 'detailed information on local health services, including quality standards and maximum waiting times' and gives the following as access-points to this information: 'your Health

Authority, your GP or your local Community Health Council<sup>65</sup>.

The general practice setting is therefore designated at Government level as one of three suitable sources for this area of consumer health information provision - the GP can be used by patients to access information on local health services available.

#### Participating through choice

Information on local health services available enables patient participation through informed choice. The new Contract's introduction of practice information leaflets gave the potential for patient participation through choice of GP. Similarly, with the new patient right to information on local health services, patient and GP can together discuss the different options available, compare the different standards and waiting times and make an informed choice of the best available option for the patient.

Information given on local NHS service quality standards will cover the areas included in the Local Charter Standards, to be set and publicised by local authorities as from 1 April 1992<sup>66</sup>. Standards are being set in areas such as waiting times for being taken home by NHS transport after treatment, and signposting to help patients find their way around hospitals<sup>67</sup>.

The PLG Chairman emphasises the positive nature of patient participation through choice when she writes of,

*the positive aspects of enabling people to make choices about their health. In doing so, patients are in a better position to ensure that the services they receive reflect their needs more closely. Indeed exercising choice is often a positive step towards helping oneself<sup>68</sup>.*

The GP's role in providing information on local health services, quality standards and waiting times is facilitated by the establishment of Regional Information Services to support the Patient's Charter. The Charter outlines the information role of these Regional services<sup>69</sup>. The range of information to be provided by such

services goes beyond information on health services available alone. It also covers information on common diseases, conditions and treatment, complaints procedures, and maintenance of personal health.

Previous to the development of Regional Information Services GPs had to rely on various sources to obtain information on health services: CHCs give information on local services and monitor their quality<sup>90</sup>; district health authorities collect information on waiting-lists and give quarterly returns to the DOH and some will distribute local GPs with bulletins detailing local waiting-lists also<sup>91</sup>; GPs can also telephone local hospitals to find out consultancy waiting-list details.

With the development of Regional Information Services GPs have the surety of centralised access to information on health services, standards and waiting times at Regional level. Whilst most Regions will develop one central information service to cover all the areas of information to be provided at Regional level, some may divide up the responsibility for information provision. For example, the Health Information Service, Stevenage has been developed into the information service for the South West Thames Region. The College of Health however has responsibility for collation and provision of information on waiting-lists for the Region. However, even if the responsibility for providing information is shared out among several different organisations within the Region, provision is still assured at Regional level. The deadline set for the establishment of Regional Information Services was 1 April 1992. There will however have been differences in Regions' ability to meet this deadline, and some services will still be in the process of being developed.

#### Accessing health service information for patients

Means of GP access to information for patients on local health services, standards and waiting times will vary from Region to Region and between different practices. Whether GPs access information for patients by computerized means or not will depend on several factors, among them: whether the Regional Information Service provides the information in computerized form or on hard copy only; practice financial resources and levels of computerization to-date; levels of

patient demand for information on local health services, standards and waiting times, i.e: are costs of computerized access justified?

For instance, Help for Health, now recognised as the information service for the Wessex Region, provides waiting-list information in computerized form - currently on disk and with plans for on-line access<sup>72</sup>. GPs are therefore able to access the information by computerized means as well as on a phone-in basis. By September 1991 the waiting line database had been installed at over 30 GP practices in Wessex<sup>73</sup>.

In contrast, a GP from a different RHA writes, 'I would very much like to use external information services more, but I feel that these people are actually still finding their feet... Local waiting times are only available as hard copy, not available on any sort of computer<sup>74</sup>'.

The Patient's Charter therefore, especially in conjunction with the development of Regional Information Services, encourages the development of a specific area of consumer health information provision in general practice - that of provision of information on local health services to patients. The Charter directs patients to their GP to access this information.

The local CHC or health authority are also given as information sources, but out of the three, the general practice is for most patients probably the most known and least intimidating location to turn to.

However, the degree to which this new GP information role develops will depend on patient demand which in turn depends not only on the extent to which patient's are made *aware* of their new rights to obtain health service information from their GP, but, once aware, depends also on the patient's *motivation* to seek out the information and exercise his choice of health service. Just as motivation levels will effect patients enthusiasm for consulting practice information leaflets to exercise choice of GP (please see 4.1.1 (b)), so will motivation effect numbers of patients asking GPs for information on health services.



## Motivation and exercising choice

Several factors may effect a patient's motivation to seek out information necessary to enable informed choice of health service, among them:

### (a) Faith in GP's considered choice

Patients may prefer the 'easy option' of leaving their GP to choose the place of treatment. Those who have less faith in their GP's determination to choose the best possible option will feel more motivated to participate in the choice themselves.

### (b) Willingness to travel

Patients who are prepared to travel further to receive treatment sooner will feel more motivated to investigate the waiting-lists of other than their nearest NHS hospital. Some argue that access to information on waiting-lists is good in theory but that in practice patients are unlikely to want to travel away from home territory for treatment. Patients' willingness to travel will depend on the seriousness of their condition and on how long they have already been waiting for treatment.

### (c) Perceived seriousness of condition

A patient's attitude towards his illness and perception of how serious it is will effect the extent to which he can 'put up with it a little longer' or will feel motivated to seek out the possibility of faster treatment.

### (d) 'Locus of control'

*'locus of control' - the extent to which individuals feel that what happens to them is determined by their own actions or by external factors beyond their control*<sup>25</sup>.

This effects the degree to which a patient feels that he should just let things take their course or should actively bring about faster treatment himself by investigating into the waiting-lists for

different hospitals.

Finally, it seems important to emphasise that the Patients' Charter may have implications on consumer health information provision in general practice in other areas than that of information specifically on NHS services, standards and waiting times.

#### Information on how to complain

It seems likely that the Patient's Charter will result in increasing numbers of patients turning to their GPs for information on how to complain about NHS services. The Charter tells patients that they have the right to have any complaint about NHS services fully investigated<sup>96</sup>. Although the Charter does not give the GP as access-point to this information it is probable that patients will consider the general practice as the most accessible and appropriate place to turn to, especially as the Charter has already suggested the GP as appropriate source for information on health services. It is likely that,

*With respect to the Patient's Charter, GPs are obvious contact points for patients requiring the type of information specified in the Charter<sup>97</sup>.*

#### Consumer health information in general

The Patient's Charter and its reference to the establishment of Regional Information Services will probably influence the development of consumer health information provision in general in general practice: GP awareness of the function and value of consumer health information services will be heightened and they will recognise that the rich health information resources of such services can be used to strengthen their own role as consumer health information providers.

GP awareness of consumer health information services will be raised by:

(1) the Charter's emphasis on the development of consumer health information services on a Regional basis: it is likely that GPs will

hear about Regional Information Services and consequently also about existing consumer health information services which are to be developed into the Regional Information Services. GPs will hear about such services both through formal channels (e.g: the Patient's Charter document itself and through meetings with other health professionals) and informally through daily contact with colleagues and associates;

(ii) patients asking for detailed information on NHS services available: through contacting the Regional Information Service to access this information for patients, GPs will probably learn of the other areas of health information (e.g: information on common diseases, conditions and treatments) that the service provides;

(iii) patients asking for information on how to contact the Regional Information Service: patients who have learnt about their establishment of health information services on a Regional basis may assume that their local GP will be able to tell them how to contact it. For some GPs the patient's enquiry may be the first time they learn of the existence of the information service. Further investigations may make such GPs realise how they can strengthen their own provision of consumer health information by accessing the Regional Information Service for patient information on a range of health information topics.

Furthermore, some patients who learn of the establishment of Regional Health Information Services may *assume* that their local GP can access the consumer health information service for them. Patients may prefer to approach the surgery for information rather than make direct contact with the Regional Information Service itself.

### In conclusion

- This section has tried to outline the implications of the Patient's Charter for consumer health information provision in general practice:

- under the first of the three new patient rights, patients are directed to seek information on NHS services, quality standards and waiting times from their GP. Provision of information on health services available is important as it enables patient participation

through informed choice in selection of which health service to be treated under.

The establishment of Regional Information Services facilitates the GP's task of accessing this information, for it concentrates the information at a central location;

- it is probable that the Charter's introduction of the patient's right to have complaints fully investigated will see demands on general practice provision of information on how to complain;

- the Charter's focus on Regional Information Services will raise general GP awareness of such services. This should increase GP use of health information services to improve their own levels of surgery-based consumer health information provision.

- It has been pointed out that patient motivation levels will determine the degree to which the general practice is used to access information on NHS services.

- Owing to the Charter's recent nature it is for future studies to measure its full impact on consumer health information provision in general practice, e.g: the degree to which patients do turn to their GP for information on NHS services, standards and waiting times, and on how to complain about these services.

#### 4.2 CHIC AND GP AWARENESS OF CONSUMER HEALTH INFORMATION PROVISION

The new GP Contract 1990 and the Patient's Charter were both seen as important for encouraging not only *specific* areas of consumer health information provision in general practice but *general* levels of provision also. Another important encouragement to the general development of consumer health information provision in general practice, not this time part of Government legislation, is the emerging work of CHIC in raising health professionals' awareness of the importance of consumer health information provision. It is felt appropriate to conclude this chapter which has concentrated on recent Government legislation and encouragement of consumer health information provision in general practice by referring to the important contribution made by CHIC in this area.

CHIC, as mentioned in 1.3., was founded in April 1991 as 'a network of people and organisations involved in making information

about all aspects of health and health services available to the public<sup>98</sup>. It acts as a self-help network for those working in consumer health information services. The report of CHIC's first conference, September 1991, concludes with an outline of five CHIC aims, the third of which is that:

*CHIC will persuade health care professionals of the importance of health information to their clients by becoming involved in their basic training and professional development<sup>99</sup>.*

Successful developments in CHIC's awareness campaign among health professionals should result in GPs, as part of the health profession, becoming gradually more aware of the importance of consumer health information provision, and more encouraged to organise provision of such information in their own general practices.

The following are some of the ways in which CHIC is working to raise awareness. The organisation is aware of the importance of targeting health professionals as early as possible - as they are being trained for their profession - and hopes to make considerable developments in raising practice staff's awareness of consumer health information provision at this stage<sup>100</sup>:

CHIC promotes consumer health information provision to trainee GPs on a local level and in small groups;

CHIC encourages student nurses to go on placements in consumer health information services and hopes to extend this placement scheme to other groups within the health profession (i.e. possible implications for practice staff);

CHIC holds national training days for health professionals. Practice staff are invited to attend.

### In conclusion

- Section 4.1 of this Chapter has tried to show how recent Government legislation encourages the development of specific areas of consumer health information provision in general practice.

- Emphasis has been on:

- areas of consumer health information provision encouraged by the legislation;
- how provision of this information contributes to patient participation in the health-care process;
- possible obstacles to both a widespread development of the area of information provision and/or to patients' use of it, and,
- that future studies will be necessary to measure the extent to which such recent legislation does in fact effect developments in practice-based consumer health information provision.

- CHIC's work in encouraging general levels of consumer health information provision in general practice is also important. Its work in raising awareness of the value of consumer health information provision constitutes a general training for health-care professionals, training them to recognise and understand the importance of consumer health information provision.

With a *general* awareness of the overall value of consumer health information provision, general practices may then turn to actively developing *specific* areas of consumer health information provision.

Chapters three and four have discussed certain areas of developing consumer health information provision with the aim of emphasising the potential for such provision in general practice. No reference has however yet been made to the training implications for practice staff who are developing their provision of consumer health information.

CHIC is becoming involved in training health professionals in the importance of general consumer health information provision to patients. Each *specific* area of consumer health information provision will also have its own particular training implications for the primary health care team. Chapter five will focus on this aspect of consumer health information provision in general practice.

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## 5.0 TRAINING IMPLICATIONS FOR THE PRIMARY HEALTH CARE TEAM

This chapter concentrates on training implications for practice staff developing consumer health information provision in the surgery. For the main areas of consumer health information provision detailed in Chapters three and four, suggestions will be made for both (a) training needs for the effective provision of this area of consumer health information and (b) sources of help for the primary health care team in meeting these training needs. The following four areas will be considered:

- general practice leaflet production;
- patient libraries in general practice;
- health promotion information provision in general practice, and,
- general practice computer literacy.

### 5.1 GENERAL PRACTICE LEAFLET PRODUCTION

General practice leaflet production as an area of written consumer health information provision includes both leaflets written on health education and health information topics (please see 3.5.3) and practice leaflets written for patients on practice facilities available (please see 4.1.1 (b)).

#### (a) training needs

The primary health care team needs training in how to produce attractively designed leaflets which convey their message effectively in an easily understood language. It is not easy to write a leaflet which manages to hit just the right reading level, but if not there is the danger that,

*comprehension is reduced... recall is sketchy and inaccurate, and motivation for further instruction and information from printed sources is reduced*<sup>1</sup>.

A recent study on a sample of patient information leaflets carried out by the Reading & Language Information Centre, University of Reading, found that '35% of the UK adult population would be unable to understand most leaflets in this study<sup>2</sup>'. The 32 sample leaflets had been selected from general practice surgeries, supermarkets and pharmacies.

There are several factors to be considered by practice staff producing patient leaflets. The following eight criteria cover the main areas to consider: 'accuracy, currency, point of view, audience level, scope of coverage, organization, style, and format<sup>3</sup>'. These actually constitute selection criteria produced by a group of American health professionals for public librarians on how to evaluate printed health information. But they are equally useful as guidelines for ~~health-professionals~~ producing their own patient literature.

*That patients do have problems of understanding, particularly where medical jargon is concerned, is now accepted*<sup>4</sup>.

It is important that written information aimed at the public is not rendered incomprehensible by inclusion of too much medical terminology. A lot of patient frustration in the oral consultation process may be caused by the GP's frequent use of medical terminology that is unfamiliar to the patient. It is similarly frustrating to find written patient information full of medical terminology. The public's knowledge of medical terminology will vary. It will depend on the individual's degree of involvement with illness, the ill, doctors and medicine, and his general level of education. Written information for patients must therefore be written at lay level.

Several studies have been carried out to test the public's understanding of medical terminology. These have involved techniques such as multiple-choice questionnaires which ask for a choice of preferred definition for a given medical term, and straight definition-giving techniques<sup>5</sup>. One such study carried out in 1979<sup>6</sup>

asked 60 patients in a waiting-room and 60 students in a common room to fill in a self-completion multiple-choice questionnaire. Definitions had to be picked for 15 medical terms taken from health education materials. Results showed that 'seven of the 15 words were given inadequate definitions by over one-third of all respondents'.

The study concluded that it is necessary to check health education literature for clearly unfamiliar medical terminology, and to either include an explanation of the term, include it in a glossary or substitute it by a more common synonym.

This emphasis on producing written information at a lay level has been the clear policy of the Health Information Service, Stevenage. When an enquiry is received on a health topic for which no written information can be traced in the popular medical literature, the Service will produce a precis of relevant *professional* literature, in simple language and with an appended glossary to explain technical terms used<sup>6</sup>.

In writing patient leaflets the primary health care team must therefore consider the general familiarity of medical terms used as well as the general readability level of the leaflet and its style and presentation.

#### (b) sources of help

The following are suggested as possible training resources for practice staff:

##### producers of patient leaflets

Guidelines and advice can be given by organisations currently producing their own leaflets on health topics:

Regional and/or District health promotion departments can give 'advice and sometimes technical assistance in producing your own publications'.

local self-help groups and FHSA usually have experience in leaflet production and could give advice;

practices which are known to have become involved in leaflet production could also be contacted.

##### guidelines

Existing guidelines on production of patient leaflets can be

consulted. For example, Guide Lines: better information literature for hospital patients was recently published by the King's Fund and 'explains how to produce leaflets and booklets for patients, giving a practical, step-by-step description of the different stages of production...'

And the Shire Hall publication Consumer Leaflets - a write off? includes five pages of useful tips on general readability criteria<sup>19</sup>.

Specific to leaflets on practice facilities there is the RCGP's 1987 guide, Practice information booklets which also includes a section on further useful readings on how to produce practice booklets.

To trace useful guidelines on leaflet production, practice staff can request a literature search in this area from, for example, the RCGP's Information Resources Centre or the HEA's Health Promotion Information Centre.

#### Review existing examples

Practice staff may find it useful to look at existing patient information leaflets to get an idea of successful lay-out, style, content, tone and presentation, e.g: ways in which colour and simple cartoon figures can be used to good effect. The primary health care team can consult not only patient information leaflets amongst their own waiting-room leaflet collection but also browse patient leaflet resources at, for example, the Regional and/or District health promotion unit or at the HEA's Health Promotion Information Centre.

### 5.2 PATIENT LIBRARIES IN GENERAL PRACTICE

Patient libraries were discussed in 3.5.4. The amount of training needed by the primary health care team in setting up and maintaining a patient library will vary between practices:-

Practices may already have a reasonably sized staff library and have developed adequate collection management skills to run a patient library also. Some practices may employ a qualified librarian to set up and run their patient library (as did Dr Varnavide's Leeds surgery) and not need extra help; some patient libraries may constitute such a

small collection of books that some areas of training are not needed, e.g: the collection can be organised under a very simple classification system, and no outside help is needed in applying a more complex system, such as an adaptation of the National Library of Medicine's classification scheme.

However, without experience in organising a staff library and without sufficient resources to employ a practising librarian to develop the patient library, most practices will require some basic training.

(a) training needs

These will include training in:-

setting up the library, for example: stock selection and buying; cataloguing and classification of stock;

daily library procedures, for example: how to issue, renew, reserve and recall stock; how to deal with overdue stock, and fining systems;

on-going procedures, for example: stock selection and buying; weeding and repair work; maintaining statistics on stock and users; devising evaluative surveys on use of the library.

(b) sources of help

Practices can seek help and advice from those with (health information) collection management skills.

The local library may be willing to give advice and training in collection management skills. The individual public library's willingness to help the surgery may depend on its relationship with the patient library, i.e: whether a referral system is to be developed between the patient library and the public library, the public library's involvement in funding the patient library. The possible relationship between the two services has been discussed in 3.5.4.

A local consumer health information service may also be prepared to share its skills in health information collection management with the practice staff. The involvement of the Health Information Service, Stevenage, in the development of Hertfordshire practice patient libraries has been discussed in 3.5.4. This involvement is however an exception, for the development of the patient information collections was a special Health Information Service project. The

Service did provide training in some areas (e.g: it produced a procedures manual and gave reception staff training sessions on how to operate the library) but in other areas the Service was itself responsible for carrying out the work, and on a continuing basis too (e.g: book selection, buying, cataloguing and classification, and evaluation of the library's success).

However, even if this level of involvement could not be expected from *all* consumer health information services, others may be willing to give some help. For example, Health Facts Centre, Bristol, will give 'Help and advice... on setting up health information collections in wards, department, health centres, surgeries and local settings'<sup>11</sup>. And in an article on patient libraries<sup>12</sup> the RCGP's Stuart Librarian gives the addresses of two consumer health information services (Help for Health and Health Information Service) as useful contact addresses for practices thinking of setting up patient libraries. Consumer health information services are clearly a possible training aid for practice staff.

It has also been suggested that local colleges that do courses in Library Studies could be contacted for training<sup>13</sup>.

Colleges could perhaps organise student placement schemes whereby library students help practice staff set up patient libraries as part of their assessed project work for the course.

Other practices which have already established patient libraries could also be contacted for advice and guidance. It is of course negotiable whether a general practice would have the time to offer active involvement in the setting up of another practice's patient library, but they may consider drawing up useful guidelines. This has for instance been done by the Leeds practice. The Practice Librarian has drawn up a sheet of guidelines which is sent to other practices on request. The guidelines cover areas such as shelf guidance and staffing. A copy of these guidelines is included in the Appendices. guidelines

Useful guidelines on health information collection management may also be found from other sources. General practices could ask organisations such as the HEA and the RCGP to do them a literature search to trace useful published guidelines on aspects of setting up and maintaining a health information collection.



For example, as recommended by the RCGP's Stuart Librarian<sup>14</sup> a useful text for practice staff to consult would be Gann's The health information handbook<sup>15</sup>. Chapter five of this text, Getting started: collecting and organising health information, would be invaluable for a practice setting up a patient library, for it aims 'to help those setting up health information services to make the right contacts, establish basic collections of health-related publications and to organise this material for use'<sup>16</sup>. It includes useful bibliographies, for example: one for useful reference works and one for useful texts on specific subject areas.

### 5.3 HEALTH PROMOTION INFORMATION PROVISION IN GENERAL PRACTICE

4.1.1.(a) outlined how the GP's new Contract, 1990, encourages health promotion information provision in both the one-to-one consultation and in health promotion clinics.

#### (a) training needs

Training implications for general practice staff include:  
communication skills

Studies referred to in 4.1.1.(a) emphasised both the frequency with which health education opportunities are missed in general practice<sup>17, 18</sup> and the clear discomfort felt by both patient and GP in instances where health education is raised in consultation<sup>19</sup>.

It would seem that because the idea of health education information provision in general practice is a fairly recent concept<sup>20</sup> some GPs lack the necessary communications skills and confidence to provide it successfully to patients.

Some studies emphasise the importance of an individual's particular attitudes to health and how these will influence his reactions to health education<sup>21, 22</sup>. This suggests that GPs must be trained not only in general communication skills but trained also in the importance of perceiving the individual's health beliefs before trying to initiate successful health education. This means taking into account the patient's 'health-belief model'.

*The 'health-belief model' focuses on patients' beliefs in determining their health-directed behaviour<sup>23</sup>.*

It is all-important that the GP be aware of the patient's personal health beliefs because these will effect the way in which he reacts to GP attempts at giving health education. Fowler<sup>24</sup> emphasises the importance of certain features of the 'health-belief model', for example: how concerned a person is generally about the place of health in his life and how he perceives the seriousness of getting a certain condition.

In the same article Fowler stresses the importance of also understanding the individual's perception of the 'locus of control' - how the individual perceives the balance between his *own* influence on what happens to him and the influence of external forces outside his control. Those who feel that they do have significant influence on what befalls them will be more responsive to health education.

Fowler's article thus emphasises how there are important considerations to be included in GP health education training. He goes on to sketch out key communication skills and to suggest a 'counselling model' for the GP to use in a health education consultation. This model combines Fowler's key communication skills and being also aware of a patient's health beliefs.

#### how to hold a health promotion clinic

Some primary health care teams may have already been running health promotion clinics prior to the new Contract's emphasis on them. However, for those general practices with little previous experience of holding clinics there is need for training in the skills of communicating health promotion information to patient groups.

#### skills in health needs assessment

Some practice staff may need training in how to plan *effective* health promotion clinics which are based on accurate analysis of the practice-population's health needs. For it has been suggested<sup>25</sup> that many practices lack experience in determining the health needs of their practice-populations, with health needs analysis being mainly a health authority, less frequently a combined health authority and FHSA, responsibility: 'but in few sites is this work carried out in partnership with practices<sup>26</sup>'.

Planning clinics depends on adequate knowledge of the risk factor status of the practice-population as a whole, and, to determine this, of each individual patient within it. The practice must have

sufficient awareness of 'the prevalence of preventable disease within the practice's population, and identification of those at risk<sup>27</sup>'. Adequate knowledge in this area depends on maintenance of good medical records which include accurate data on a patient's risk of suffering from a preventable condition or illness. Such records should be regularly monitored and up-dated to be kept as current as possible. Only then will practices be able to plan health promotion clinics which reflect current health needs.

Training therefore involves learning how to assess health needs through access to well maintained and sufficiently detailed medical records. Data on risk factor status and prevalence of disease must be lifted from medical records as a basis to planning effective health promotion clinics.

The primary health care team is to a certain extent helped in this task by the new Contract's emphasis on three-yearly health checks and on annual reports: the three-yearly health check will help by making GPs accustomed to obtaining information on their patient's health risk status on a regular basis; and the annual report, to be submitted to the FPC, will similarly make GPs more accustomed to collating health risk factor data, for GPs have the option of including a section on the practice-population's state of health and incidence of disease.

However, the health checks are only three-yearly, and it is not *obligatory* for the annual report to include a section on prevalence of disease<sup>28</sup>.

#### sources of help

The FHSA has been suggested as an important source of help in training GPs in health needs assessment<sup>29</sup>.

It is reported that some FHSAs assist GPs in organising the health risk factor data that is included in the annual report to the FPC<sup>30</sup>. The article goes on to suggest a further training role here for the FHSA: it could help GPs by monitoring differences in quality of health needs data produced by different general practices, and then research into why this is so and 'then disseminate this learning, enabling practices whose data is less well developed to learn from those which are further forward<sup>31</sup>.

Some FHSAs (and health authorities also) have helped GPs by

running primary care team workshops which give GPs support in planning health promotion clinics and preventive work based on health needs assessment and on their available resources<sup>32</sup>.

#### on holding clinics

There are various sources for practice staff seeking training in how to hold clinics:

#### health promotion facilitators

During the past five years health promotion facilitators have been increasingly employed by FHSAs or health authorities to work with practices in the development of health promotion work. This includes giving training in how to give health promotion clinics.

Most District Health Authorities have about two facilitators. Derbyshire has four, but this is an exception<sup>33</sup>. Leicestershire District Health Authority for example has two health promotion facilitators. However, Leicestershire FHSA also employs two additional specialist health promotion facilitators - one in drug abuse and one in alcohol advice. Health promotion facilitators train practice staff in holding clinics but do not actually hold clinics themselves. They also often look more generally at what health promotion training is available for practice staff in the area, and try to improve on inadequate training provision.

Health promotion facilitators may, as in the case for Leicestershire, work closely with health promotion units in training practice staff in health promotion work.

#### health promotion units

General practices can seek training in holding clinics from local health promotion unit staff who have expertise in this area. For instance, in its Annual Report, April 1990 - March 1991, the Victoria Health Centre Health Promotion and Health Information Service reports that 'Requests for Staff Training have increased, particularly from Practice Nurses developing Healthy Promotion Clinics,...'

Similarly, since 1990 the Health Information Centre, Loughborough, has had increased numbers of practices seeking health promotion advice<sup>34</sup>. The Centre is not the District's official health promotion unit, but an outline of its aims in CHIC's 1992 directory emphasises the Centre's strong health promotion function<sup>35</sup>.

If the health promotion unit staff cannot offer practical aid

themselves they should at least be able to direct GPs to other sources of aid, for a community will generally have several sources of good practice and contacts in health promotion activity.

contact others with experience in health promotion activities

In its Strategic Plan for 1990 to 1995 the HEA writes that,

Effective practice in health promotion is found in many places - for example, in schools, general practices, environmental health departments, leisure and recreation services, community groups and the voluntary sector<sup>36</sup>.

The HEA goes on to recommend increased contact between these various groups as a means of optimising the dissemination of good practice.

Practices could approach organisations, such as those quoted above, with experience in holding health promotion clinics and ask for training assistance. For example, community health specialists with health promotion experience could be approached. A group of Derbyshire practices has done this: a community dietician has been employed not only to run clinics but also to give training to the practice staff<sup>37</sup>.

The HEA's Oxford Unit

As previously mentioned, in 4.1.1.(a)., the HEA's Strategic Plan states its commitment to supporting the development of health promotion information provision in general practice. As part of this commitment the HEA is funding a Primary Health Care Unit in Oxford. The Unit is a specialist unit set up for five years at Oxford University's Department of General Practice, 'to help primary health care staff undertake health education<sup>38</sup>'.

It can be seen as an important training resource tool for practice staff in their task of health promotion information provision, for the Unit acts as a resource for information on: examples of good practice, different methods used within primary health care in the provision of health education, and appropriate materials for practices to use in health education provision<sup>39</sup>.

The Unit is also to have a more direct role in the training of practice staff: it is to 'be responsible for developing practice team-working for health promotion through professional development<sup>40</sup>'.

Appendix II of the Strategic Plan states that professional development involves workshops and in-service training. For example, the workshops run by some FHSAs to develop practice skills in basing health promotion clinics on health needs assessment are supported at national level by the Oxford Unit<sup>41</sup>.

The HEA is developing a national database for the Oxford Unit. The database is to be a health promotion information resource for primary health care workers. Research staff at the Department of Information and Library Studies, Loughborough University, have recently carried out a sample telephone survey of Leicestershire practices to determine which primary health care team health promotion information needs could be usefully covered by the database.

Section three of the survey concentrated on particular health promotion information to which primary health care workers would like increased access. The importance of the Unit as a training resource for general practices is emphasised by the inclusion of the following information areas under the 'General Information' heading: training for professionals and aspects of running health promotion clinics.

Completed surveys put these two areas among the top eight areas most often chosen by GPs and practice nurses for inclusion in a national database<sup>42</sup>.

The HEA's Oxford Unit and the planned national database have the potential to make a significant contribution to facilitating the primary health care team's role as health promotion information provider.

#### 5.4 COMPUTER LITERACY

Some of the areas of consumer health information provision referred to in Chapters three and four involve the possibility of computerized access by general practices for speedier and more efficient provision of information: computerized access to consumer health information services' self-help group databases; access to Regional Information Services' waiting lists and NHS services

databases; computerized access to welfare rights assessment data.

Furthermore, computer literacy in general practice is an especially important skill when considering the potential for future consumer health information provision developments in computerized form (please see 6.4).

However, it is felt that there has already been much recent emphasis on computerization in general practice and that computerized access to consumer health information provision does not introduce a new GP training need but rather extends the value of existing computer training provision. Developments in computerized forms of consumer health information provision will not therefore introduce computer skills acquisition as a new practice staff training need.

There has been important recent evidence of government support for computerization in general practice. Recent government papers emphasise this support: in Promoting Better Health, 1987 the government 'announced its intention to encourage the continued development of information and communication technology and computerization in primary care<sup>43</sup>'. Government support for further developments in general practice computerization was restated in Working for Patients, 1989<sup>44</sup>.

Government support was also shown by the DOH's putting three million pounds into setting up a fund for general practice computer development and research as from 1991/92<sup>45</sup>

And from 1 April 1990 to 31 March 1993 a scheme for the reimbursement of general practice computer costs is being run<sup>46</sup>. Claims are being dealt with by the appropriate FHSA. Reimbursements cover purchasing, leasing and upgrading costs as well as staff costs in setting up the system and maintenance costs.

And in both 1989 and 1990 the DOH carried out surveys of general practices to establish information technology development needs. These surveys emphasised the fast developing spread of computerization in general practice. The 1990 findings showed that almost 50% of practices were computerized, compared to 27.6% in 1989<sup>47</sup>. Furthermore, 77% of practices either already had or *planned* to buy a computer, and the survey predicted that by 1992/93 over 90% of practices would be computerized.

The growing importance of computerization in general practice has

been reflected by the growth of associated organisations, among them: the RCGP's Information Technology Centre, the British Computer Society's Primary Health Care specialist group and the Joint Computing Group of the RCGP and the General Medical Services Committee of the British Medical Association.

General practice computerization has developed against a background of a steady increase in information technology applications within the NHS overall. The potential for information technology facilities in general practice has been recognised: computerized medical records and financial data has the advantage of increased accuracy, speed of access and ease of updating.

In addition, the new data collection demands of recent government legislation have had a significant influence on developments in general practice computerization:

the concept of GP budget-holding in Working for Patients, 1989 has increased the need for GPs (who do choose to manage their own budgets) to hold accurate up-to-date financial data. Computerization clearly facilitates management of detailed financial data;

the new GP Contract 1990 increases the administrative workload in general practice, and administrative management can be facilitated by computerization. For the Contract puts emphasis on pay related to quantifiable data, which increases the need to maintain accurate records: for instance, accurate records on the levels of both child immunization and cancer cytology currently reached, as a means of assessing how near these levels are to the new target levels - hence, assessment of financial gains achieved to-date.

The new Contract also puts increasing importance on accurate recording of patients' risk factor status and on prevalence of disease. Maintenance of detailed data in this area is of particular importance regarding the effective development of health promotion clinics based on real health needs.

Findings of a 1990/91 study of six UK general practices' reactions to the new Contract<sup>48</sup> emphasised these important implications on practices' administrative workload: all six practices - chosen for being different types of practice and located in contrasting settings - stressed the considerable increase in administrative workload. One practice complained also of the



consequent 'increased expense on computer assisted records'<sup>49</sup>.

By increasing general practices' administrative workload the new Contract has had a clear influence on developments in general practice computerization as a means of facilitating the maintenance of the new data sets required.

Parallel to developments in general practice computerization, sources of support and training have developed. For instance, the RCGP's Information Technology Centre has run computer appreciation courses for GPs with emphasis on the introduction and management of information technology in general practice. And within most Regions FHSAs have appointed GP computer facilitators to give GPs advice on general practice computing. The names and contact addresses of these facilitators are listed for GPs in a 1990 DOH publication for GPs on practice computer systems<sup>50</sup>.

The recent emphasis on computers in general practice means that basic computer training is already being focused on. The computer training required by the introduction of computerized consumer health information facilities in general practice will involve only the additional training needed as relates to the functioning of each *specific* database programme or CD-Rom. Manuals and suppliers' training programmes should sufficiently explain the peculiarities of each particular system.

However, as computerized access to consumer health information in general practice becomes increasingly open to patients *without* practice staff acting as intermediaries, there will be new important training implications for the practice staff: they will have to acquire the skills necessary for successful user education. Practice staff must train their patients in how to use the computer facilities to full advantage. For example, Professor Jarman writes of his welfare rights assessment computer programme that, 'Generally speaking, the program is not used by patients but intelligent patients would be able to use it<sup>51</sup>'. Perhaps the programme will one day be on open access to patients. Similarly, the future may see general practices offering patients direct access to self-help group, NHS services and waiting time information held in computerized form.

The primary health care team may need training in how to most efficiently and effectively implement user training. This may involve

one-to-one or group training, demonstration sessions and provision of user-manuals - perhaps even *production* of manuals if suppliers' texts are written at too technical a level. Practice staff will need to decide on who, when and how to best train patients. This may well necessitate training assistance from outside the practice. Training in the techniques of user education could be solicited from the following among others:

local schools of library studies which offer courses in user education regarding computerized information sources; local medical and public libraries which offer open-access computerized information sources and which will therefore have experience in running user education programmes; other general practices which are already organising user education sessions in computerized forms of consumer health information provision.

If computerized consumer health information provision is made available to patients on an open-access basis there will be new practice staff training needs in the area of user education.

It is to be hoped that necessary practice staff training for effective delivery of consumer health information provision in the three areas outlined above in 5.1, 5.2 and 5.3 (and also in other areas of consumer health information provision for which formal training would be clearly advantageous) will gradually be given increasing emphasis at undergraduate training level. It would only be logical to see developing recognition and acceptance of the value of consumer health information provision paralleled by developments in relevant education provision for trainee general practice staff. And practising GPs could benefit from the introduction of new consumer health information provision training at undergraduate level by practices allocating some of the new post-graduate education allowance on attending the consumer health information provision training courses which are developed.

The new GP Contract 1990 introduced the training allowance, 'to encourage continuing medical education throughout a GPs time in active practice...<sup>521</sup> This allowance does however only constitute 'an average of 5 days training a year on approved courses<sup>521</sup>.

## In conclusion

- This chapter has looked at the training implications for general practice staff regarding three main areas of consumer health information provision:

- general practice leaflet production;
- patient library provision, and
- health promotion information provision.

- Training needs were outlined for each area, and possible sources of help in meeting these needs were given.

- The importance of the HEA's Oxford Unit as a general resource tool to support practice staff in their health promotion information provision role was emphasised.

- General practice computer literacy was included in this section on consumer health information provision and training needs because of the development of computerized access to consumer health information provision. Practice staff's computer literacy will therefore become increasingly important in general practice consumer health information provision. Computer training is however already being focused upon in general practice. Computerized consumer health information provision does not introduce computer literacy as a *new* GP training need.

- General practice training needs have only been considered for three main areas of consumer health information provision. Other new training needs will emerge with the development of existing and new areas of consumer health information provision. These training needs must be recognised and covered by practice staff training at undergraduate level.

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## 6.0

### RECOMMENDATIONS MADE BY HEALTH PROFESSIONALS FOR CONTINUING AND FUTURE DEVELOPMENTS

This chapter outlines some informal recommendations/suggestions made by health professionals on the topic of consumer health information provision in general practice. They are made by people working in different health-related fields - from representatives from 'official' organisations such as the College of Health and the RCGP's Patients' Liaison Group to the individual GP or Professor of general practice.

These suggestions mainly encourage further development of existing areas of consumer health information provision but also include some emphasis on areas of future development, such as on CD-ROM provision of consumer health information provision.

The purpose of this chapter is two-fold:

(a) to outline recommendations made by workers from a variety of health-related fields to show that there is recognition of the appropriateness and value of practice-based consumer health information provision from a wide cross-section of health professions;

(b) to take the suggestions made for both continuing and future trends and include these in the final model of a consumer health information provision - oriented practice of the future.

This model concludes Chapter Six. It reflects the aspects of consumer health information provision discussed in Chapters three and four and also takes into consideration the following recommendations:

#### 6.1 CONSUMER HEALTH INFORMATION PROVISION IN GENERAL

(1984) Professor Drury. Professor of General Practice, University of Birmingham

In an article entitled The face of general practice in the year 2005<sup>1</sup> a professor of general practice outlines his perception of trends in further general practice.

This article concludes with some suggestions of relevance to consumer health information provision, among them:

*Advice given during consultations will be supported by much better follow-up and more written material.*

*Video machines in waiting rooms and at clinics,*

*booklets handed out at consultation and*

*pre-designed advice printed out to match the computerized prescription will be general and*

*there will be a greater concentration on advice about diet, recreation, weight and exercise<sup>2</sup>.*

These suggestions mainly predict developments in the provision of written information for patients. The importance of this area of consumer health information provision has been examined in 3.5.

The fourth prediction is important with regard to written drug information in general practice, for it predicts that written advice on drugs will be distributed with the prescription, i.e. in general practice. 3.5.5 concentrated on written drug information provision and attempted to emphasise that despite the ABPI's choice of the pharmacy as most appropriate distribution-point for such information, the general practice has valuable potential in this area also.

Drury raises the issue of video machines in surgery waiting-rooms, an area of consumer health information provision which has not been discussed in this study. Providing information on health-related issues by audio-visual means can be seen as an appropriate and useful way to exploit time spent in the waiting-room. As with provision of written information, showing videos can be seen as a means of 'taking advantage' of a patient's health-oriented mood (at its most acute whilst in a health-care setting) by inviting him to become more informed on health matters.

Furthermore, the video can offer information to the illiterate patient in a way that written information clearly cannot. Some



patients may also find information provision by audio-visual means more appealing and stimulating than in written form: those with little motivation to look at patient leaflets may however be prepared to receive health information from a video screen.

To attract the widest possible patient interest, videos shown in waiting-rooms would clearly have to be on general rather than on specific health topics, i.e: on general health education issues such as diet and exercise rather than on specific illnesses or conditions. The latter may only be of relevance and/or interest to a limited number of patients.

It is important however to consider whether or not showing videos in waiting-rooms denies a patient's right to choose. Some patients do not want to become more informed and hence involved in their health-care. They are happier to leave this responsibility in the GP's hands alone. Written health information provision in the waiting-room does not force itself upon patients. It is merely there if they choose to consult it. It is not so easy to avoid hearing or looking at a television screen. Perhaps the solution would be for individual practices to investigate into their practice-population's attitudes toward video access to consumer health information provision before introducing it into the surgery waiting-room.

#### (1988) The RCGP's Patients' Liaison Group

Gann<sup>2</sup> cites the following list of recommendations made by the PLG's chairperson for patient information provision in general practice:

- *Providing a collection of leaflets in the surgery.*
- *Running their own patient library.*
- *Working with local public libraries to ensure that a stock of good health books is available to the public.*
- *Providing a welfare rights assessment package on a microcomputer in the practice.*
- *Improving the display of posters available in the waiting room.*
- *Providing information about statutory services and self-*

*help groups.*

- *Setting up patient participation groups.*

These recommendations encourage developments in areas of consumer health information provision in general practice that have been discussed in Chapter three.

#### (1989) The College of Health

Gann<sup>4</sup> also cites a College of Health list of recommendations for patient information provision.

The College of Health was established in 1983 to provide an information resource for *patients*, in the same way as the various medical professions have their own college, e.g: the RCGP for GPs. The College works in the interests of the health consumer. It has its own journal, Self Health, and aims to educate its members on matters of health and illness<sup>5</sup>.

Among the College's recommendations quoted by Gann are the following:

- *Consultants and GPs should monitor their own communication skills, using video and audio recordings.*
- *Patients should be encouraged to tape record their consultation and listen to it again in the more relaxed atmosphere of their own home.*
- *Doctors should provide notices in the waiting room saying they would like to answer patients' questions.*
- *Hospitals and GPs should keep up-to-date registers of self-help groups.*

If patients had an audio tape of their consultation this would be an important back-up reference tool for them in the same way as written patient information (leaflets and access to medical records) acts as valuable back-up to the oral consultation. Playing back the consultation a patient could recall both what he had forgotten and what he had not understood on first hearing. What remains unclear can then be noted down and the GP later asked for further explanations.

Introduction of waiting-room notices saying that doctors would like to answer patients' questions is valuable for the GP/patient relationship. As with the provision of a patient library or/and a good leaflet collection, such notices would let the patient know that the GP approves of patient information-seeking behaviour, i.e: that the GP favours information-sharing and patient/GP partnership in the health-care process.

(1992) Susan Childs. Health Information Plan Officer, Information North

Susan Childs is responsible for organising a health information plan (HIP) for the Northern Region. A HIP can be seen as a sectoral library and information plan (LIP). The LIP concept began in 1986. LIPs involve information providers entering into a partnership, discussing their area's main information needs, deciding key objectives together and working out a framework within which to achieve them in a co-ordinated fashion\*. LIPs cover geographical or subject areas, and may be of national, regional or local coverage. For instance, LIPs in music, law and art respectively were recorded as being the first developments in sectoral LIPs?

The Northern Region's HIP is a sectoral LIP in the area of health. It covers England's five Northern counties. Its members include health information providers from statutory, voluntary, academic and private sectors alike, and it is hoped that the HIP 'will provide a national model for improving health information services through co-operation and co-ordination\*'.

Susan Childs suggests that GPs fill their role as information providers to patients by the following:

*(a) by providing a network of local access points to health information;*

*(b) by identifying gaps in the provision of patient information and being involved in the development of purpose-written patient information material;*

*(c) by providing a library of patient information material on the premises, e.g: in co-operation with the local public library service?.*

The first suggestion was previously quoted in 3.3 (b) under section 3.3 which discussed GP provision of information to patients on health activities and services in the community.

The latter two suggestions encourage developments in areas of consumer health information provision also covered in Chapter three.

## 6.2 PATIENT LIBRARIES

(1988) Margaret Hammond. RCGP Stuart Librarian

Considering practice staff libraries the RCGP Stuart Librarian recommends that,

*a library intended exclusively for patients should be a separate entity<sup>10</sup>.*

She suggests that the following factors be taken into consideration when a separate patient library is being set up:

- *co-operating with the local public library service to obtain books for loan: i.e. as an extension of the public service.*
- *offering access to the waiting room for browsing or loans.*
- *creating a special category of children's books.*
- *making leaflets and booklets generally available (as opposed to doctors giving them to selected patients in the consulting room)<sup>11</sup>.*

(1989) Michael Long. Information North

Information North (IN) was set up in 1988 to implement the LIP for the Northern Region. It now acts as 'development agency for library and information services in the North East of England and Cumbria<sup>12</sup>'. IN's Manager includes among 'initiatives which provide models for future development:'

*Hertfordshire Library's experience in setting up patient information collections in GPs' surgeries<sup>13</sup>.*

(1990) Sally Knight. Health Information Service, Stevenage

Under the Review and Recommendations section of her Ph.D. thesis the following are suggested:

*(d) Development of Patient Information Collections.*

*In this way, the doctor and his primary health care team have the information to hand and patients are free to read what they like... The supply of information in this manner should be researched and developed...*

*(e) Development of back-up information<sup>14</sup>.*

She suggests that patient library resources be backed by a central collection. The Health Information Service, Stevenage is given as an example of a suitable back-up.

The concept of patient libraries was discussed in 3.5.4. The relationship between the patient library and local consumer health information service was mentioned within this section.

### **6.3 HEALTH PROMOTION INFORMATION PROVISION**

(1991) Amanda Killoran. Head of Health Policy, HEA.

June Huntington. Fellow in primary health care management, King's Fund College.

In an article which looks at the Government's green paper The Health of the Nation and its implications for general practice, suggestions are made for the future image of surgery-based health promotion information provision<sup>15</sup>:

*What will the health promoting practice of the 1990s look like<sup>16</sup>?*

Several aspects of a future model are suggested, among them: -

GPs will be 'linked to a wide range of other workers and organisations' in their health promotion role<sup>17</sup>.

'Community diagnosis will be as normal as individual diagnosis'<sup>18</sup>: GPs will be aware of the prevalence of disease and the risk factor status of the practice-population as a whole, and of that of individual patients within it.

Health promotion information provision will combine both opportunistic health-care given by GPs and based on an awareness of the patient's health beliefs, and also the more systematic provision of clinics<sup>19</sup>.

'Outreach activities' will be important, with GPs sometimes working together with community-based organisations, such as schools and places of work, to take health promotion information to targeted high risk groups<sup>20</sup>.

There will be 'rapid enhancement of practice information systems'<sup>21</sup> to provide the detail of patient record needed to plan health promotion clinics based on health needs assessment.

These recommendations for an effective health promoting practice bring together some of the issues raised in 4.1.1 (a) and 5.3 which considered practice-based health promotion information provision and practice staff training needs.

The model advanced here summarises a health education-oriented general practice in which there is both (a) effective one-to-one health education in patient/GP consultation, with a GP who is aware of the individual patient's health beliefs, and (b) effective health promotion clinics which reflect the practice-population's real health needs as monitored on good general practice information systems. The importance of accurate health needs assessment was emphasised in 5.3.

The model favours general practice responsibility for outreach health promotion work also, whereby health education is brought on-site to targeted groups within the community. Extension of health promotion work into the wider community is already being undertaken by

some practices, such as the example of the Derbyshire practices, given in 4.1.1 (a), whose appointed community dietician not only holds practice-based clinics, but provides them also in supermarkets and other targeted community locations<sup>22</sup>.

#### 6.4 CD-ROMS AND CONSUMER HEALTH INFORMATION PROVISION IN GENERAL PRACTICE

Several people working in health-related fields have suggested the potential for future exploitation of the CD-ROM (a form of portable database) for provision of consumer health information. Suggestions have been made for CD-ROM access to both indexed and full-text popular medical texts. If there were developments in this area there would surely be considerable potential for provision of this CD-ROM held information in the general practice setting.

(1992) Professor Jarman. Professor of Primary Health Care, Department of General Practice, St Mary's Hospital Medical School

Regarding patient information provision Professor Jarman (developer of the Welfare Rights assessment computer programme - please see 3.6) writes,

*I believe that CD ROMS will, in future prove to be a useful tool for this type of service<sup>23</sup>.*

(1991) Robert Gann. The Help for Health Trust

In a recent article Gann includes a section on the bibliographic control of written consumer health information<sup>24</sup>. He reviews existing indexes for written consumer health information which cover, for example, popular medical books and journals. Gann looks at indexes in manual, online database and portable database format. He writes that 'some of the most interesting developments in access to consumer health information today are in the area of "portable databases" (information on floppy disk or CD-ROM)<sup>25</sup>'.

He mentions The Consumer Health and Nutrition Index (CHNI), a US

index available on CD-ROM. CHNI has been published by Oryx Press since 1985 and aims 'to provide one-stop access to all popular health literature published in periodicals<sup>26</sup>'. In 1987 it was indexing 76 magazines and newsletters in total - 60 health magazines and 16 popular general magazines<sup>27</sup>.

An equivalent British index is the Popular Medical Index, published by Mede and edited by Sally Knight of the Health Information Service, Stevenage.

This index is not however yet available on CD-ROM. CD-ROM access would be gladly welcomed by health professionals<sup>28</sup>. For those working in consumer health information services and in general practice alike it would mean the ability to give patients immediate information on where to find current popular articles pertaining to their condition.

Gann also refers to the US Health Reference Center on CD-ROM, which not only includes an index to popular and professional health literature, but offers many in *full text* also<sup>30</sup>. This has the obvious advantage of offering immediate on-screen access to written consumer health information in the popular press.

Being, like the CHNI, a US product, the Health Reference Center is however of mainly American coverage and consequently of little use for British health settings.

This section of Gann's article ends on a positive note however, for he concludes that as CD-ROM costs are reduced, 'potential for swift and comprehensive access to information for patients and the public is enormous<sup>30</sup>'.

Gann is therefore hopeful about future developments in consumer health information provision on CD-ROM. His article recognises the value of such provision to the *providers* of consumer health information. As CD-ROM systems are developed and become increasingly user-friendly, there is also surely potential for the *consumers* of health information to access them directly, i.e: direct patient/public access to CD-ROM-held consumer health information without the health professional acting as mediator? The following vision for the future recognises this potential:



(1992) Dr Pike. A Hertfordshire general practitioner

Dr Pike clearly supports the provision of consumer health information in general practice: a frequent user of the Health Information Service, Stevenage, he also developed his own practice-based mini consumer health information service of subject folders, and since 1989 his practice has had its own patient library.

Pike sees the development of CD-ROM consumer health information provision as a next important step forward in information provision for patients<sup>31</sup>. He describes the advantage of CD-ROM access to consumer health information in general practice: it would enable a GP to diagnose a patient and at once tap into the database to trace a current popular article on the patient's condition. This could then be recommended to the patient so that he could go away and read further information on his condition. Popular texts provide valuable backup to the GP's oral explanation of a condition.

Pike suggests that ideally the consumer health information be on disks produced centrally by a database producer who would send initial disks out to general practices and also send updated follow-ups. Relevant popular journals would be scanned and *full text* inputted into the database.

Pike envisages eventual patient open-access to this CD-ROM service. By this means a patient could have *immediate access* to CD-ROM full text articles on a condition for which he has just been diagnosed.

With a 'print out' facility the system could also provide a copy of the relevant text for a patient to take away for future reference.

In addition, Pike recommends that the database include a 'patient feedback' facility: if articles are preceded by evaluative comments made by previous readers this helps the patient decide on the usefulness of reading the article for himself.

There is therefore clear interest and value in CD-ROM provision of consumer health information in general practice.

### In conclusion

- This section has outlined suggestions made by workers from different health-related fields for practice-based consumer health information provision.

- Suggestions voice a clear desire for continuing and future developments in surgery-based provision of consumer health information.

- Some recommendations cover areas of consumer health information provision already being developed in some practices, and previously mentioned in Chapters three and four: for instance, the recommendations made by the PLG cover aspects of consumer health information provision (such as provision of patient leaflets and setting up of patient participation groups) which have been discussed in Chapter three. For these are areas of consumer health information provision already being focused on in some practices. Similarly, recommendations made for development of patient libraries, by Information North, the Health Information Service, Stevenage and the RCGP respectively, focus on an area of consumer health information provision discussed in 3.5.4.

- Other recommendations however cover new areas of consumer health information provision:

Professor Drury's predictions for the year 2005 (and written 21 years previous in 1984) look ahead to general practice provision of computer-produced written advice for patients on prescribed drugs. And Jarman, Gann and Pike look ahead to future developments in CD-ROM provision of consumer health information, both in general (Gann) and for its specific value as an open-access patient information resource in general practice (Pike).

- Aspects of consumer health information provision drawn from both areas of recommendation, i.e: recommendations which encourage further development of *existing* areas of consumer health information provision, and recommendations which encourage new *future* developments, will contribute to the following model.

## 6.5 A MODEL FOR THE FUTURE?

The following model proposes a consumer health information provision-oriented general practice for the year 2000. The elements of consumer health information provision that it illustrates are drawn from:

(a) the existing and recent developments in practice-based consumer health information provision as discussed in Chapters three and four;

(b) the recommendations/suggestions made by the various health professionals in 6.1 - 6.4 above.

The model is clearly only a *hypothetical* representation of a future consumer health information provision-oriented general practice. This is because it would be unrealistic to expect any single practice to imitate the model in *all* its aspects. This would be an unreasonable expectation for various reasons, such as:

a practices<sup>2</sup> lack of the necessary levels of staff, financial and time resources to provide *all* areas outlined in the model; little purpose in some practices providing in certain areas, e.g: little use for health promotion clinics in the isolated rural practice with a far flung practice-population; individual practices will have different consumer health information provision priorities, i.e: one practice may feel that provision of a patient library would be of most current benefit to its patients whilst another practice may see focusing on provision of access to a self-help group database as its top priority; other areas of attention (outside of consumer health information provision) may be of current top priority, e.g: the under-staffed practice may need to channel all its spare cash resources into paying an additional staff salary rather than into developing its consumer health information provision.

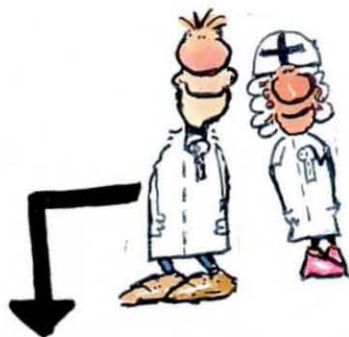
6.5.1 FIGURE:

model of a consumer health information  
provision-oriented general practice for  
the year 2000

ACCESS VIA PRACTICE STAFF

DIRECT PATIENT ACCESS

PRACTICE STAFF



PATIENTS



- \*Oral transfer of knowledge  
{eg: Explanations of patient's condition & treatment in popular medical language, health education advice, recommendation of a self-help group, recommendation of easy-to-read literature on patient's condition...}
- \*Access to medical records
- \*Provision of simply-written information on prescribed medicines
- \*Possibility for patient to tape-record the consultation
- \*Health promotion clinics  
{ie: Provision of health education information to patient groups.  
'Outreach' health promotion work in the community}

- \*Patient participation groups  
{eg: Responsible for producing literature on health topics, organising health education events, holding open forums for information-transmission practice staff/patients...}
- \*Leaflet collection  
{Including practice-produced leaflets}
- \*Practice brochure  
{Information on practice staff, facilities & services}
- \*Directory of national & local self-help groups & voluntary organisations
- \*Patient library  
{Comprehensive collection of health literature}
- \*Health education videos running in waiting-room



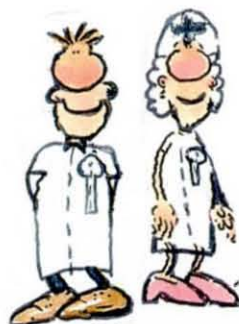
- \*Welfare benefits assessment
- \*Full-text indexed popular medical literature  
{eg: Indexed popular medical journals & texts}

{Continued...}

ACCESS VIA PRACTICE STAFF

PATIENTS

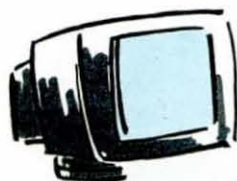
PRACTICE STAFF



\*Information on health-related activities & services in the community

{eg: Information on local consumer health information services, local self-help groups, local Health Promotion Unit, social services, welfare services, local CHC, CAB & council of voluntary service, local public library 'health' collections...}

{ie: Practice acts as access-point to local sources of health-related information}



\*Information on local self-help groups

\*Information on local NHS services available

\*Information on local NHS services' quality standards & waiting-times

{ie: via practice's computerized access to the Regional health information service}

### In conclusion

- It is not suggested that any one practice should provide in *all* areas of consumer health information illustrated in the model.

- By showing various different areas of consumer health information provision the model serves rather to underline the real *potential* that there is for the general practice as consumer health information resource. It serves as an invitation to the individual practice to consider how its own provision of consumer health information to-date may be yet further developed.

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## 7.0 REVIEW AND RECOMMENDATIONS

### 7.1 REVIEW

- This study has treated the subject of consumer health information provision in general practice. It has (a) discussed different areas of existing consumer health information provision which have been developed during the last 10 to 15 years, and (b) discussed three pieces of recent Government legislation in the light of their potential contribution to new developments in practice-based consumer health information provision.

- The main focus has been on aspects of *written* consumer health information provision, e.g: the benefits of written information provision, leaflet provision in general practice, practice use of consumer health information services to strengthen their own provision of written information to patients, developments in practice patient libraries, and the need for a complementary relationship between provision of written and oral information in general practice.

Other areas of consumer health information provision have however also been considered, e.g: practice provision of information to patients on self-help groups, provision of health promotion information and provision of information on NHS services, standards and waiting-times.

- The recent Government legislation discussed in Chapter four included:

- (a) The General Medical Practitioners' Contract, 1990 and its encouragement of practice provision of information on (i) practice facilities and (ii) health promotion issues,

- (b) Access to Health Records Act, 1990 and its encouragement of practice provision of written patient-specific information, and

(c) The Patient's Charter, 1991 and its encouragement of practice provision of information on NHS services, standards and waiting-times.

It is for future studies to determine the degree to which this Government legislation does in fact influence the areas of general practice consumer health information provision which in theory it appears to encourage.

- Each highlighted area of consumer health information provision has been discussed in relation to such factors as the main benefits and suggested drawbacks to its provision, patient and GP attitudes to its provision, and possible obstacles to widespread developments in this area of information provision in general practice.

- Chapter five looked at training implications for practice staff in the following three main areas of consumer health information provision - leaflet production, health promotion information provision, and patient library provision.

Possible sources of help in meeting these needs were suggested. These sources include other agencies working in the health field, e.g: local consumer health information services, local public libraries, Regional or District health promotion departments, local self-help groups, local FHSA, and other GP practices.

- Chapter six looked at recommendations made for continuing and future developments in practice-based consumer health information provision. These mainly covered areas of provision previously mentioned in Chapters three and four.

One important new area of future development was however raised - that of CD-ROM provision of consumer health information.

There is perhaps a role for research into this area of consumer health information. This could be funded by a DOH grant. Existing US models, such as the Consumer Health and Nutrition Index and the Health Reference Center on CD-ROM could be investigated along with current UK developments, such as Helpbox. Resources could be channelled into developing CD-ROM provision of indexed full-text popular medical journals in general practice. The ultimate goal would be to develop

easy-to-use systems which could be provided on an open-access basis to patients in the surgery waiting-room.

- The objective of highlighting the various areas of consumer health information provision evident in general practice to-date has been to show the *potential* for such provision in general practice and to thus encourage practices to concentrate on developing their own provision in the areas illustrated.

The different types of consumer health information provision mentioned during the study are drawn together in the final model.

- The underlying theme has been *information provision as a means to patient participation*. General practices are encouraged to develop their consumer health information provision because of its value as a key to patient participation in the health-care process. This has been the linking thread between all areas of consumer health information provision highlighted:

consumer health information provision is valuable because it enables different forms of patient participation in the health-care process, e.g: participation through awareness and understanding, participation through self-care, participation through informed choice, and participation through informed contribution to the GP/patient consultation.

Appendix I outlines how the various areas of consumer health information provision in general practice enable different forms of patient participation in the health-care process.

Such participation is valuable for it:

- (a) increases a patient's sense of involvement and responsibility, hence dignity in the health-care process;

- (b) has the potential to improve the general health of the nation through (i) improved levels of self-care of minor illnesses, which also leaves more GP time to dedicate to the seriously ill; (ii) increased patient numbers leading a 'healthy' lifestyle, and (iii) increased public use of, hence benefit from, *all* available health-related services (both statutory and non-statutory) in the community;

- (c) develops the patient/GP relationship into a more balanced, hence 'healthy' one.

The traditional set-up of passive patient and all-powerful GP as figure of medical expertise can be gradually replaced by a patient/GP partnership in which knowledge is shared and issues openly discussed between GP and informed patient.

As consumer health information provision develops in general practice, the surgery can become a focus for patient education and learning and move away from being simply a place for the healing of the sick.

- This study has tried to show that the potential and value of consumer health information provision in general practice has been recognised by various different agencies. Recognition has been both for general provision of consumer health information and for specific areas of provision.

Such agencies include:

the Government; other national bodies, e.g: the HEA, RCGP's Patients' Liaison Group, CHIC, and the College of Health; individual GPs; patients/the general public.

The individual general practice may therefore be encouraged to develop its consumer health information provision by any one or a mixture of the agencies listed above. For instance, a practice may be spurred into developing a patient library by its patients who have heard good reports about a local practice which provides such a service; it may be through being targeted as part of a local consumer health information service's promotional work that a practice feels encouraged to develop its own provision of consumer health information; a practice may alternatively feel pressurised into developing a specific area of consumer health information provision because of Government legislation - for instance, the 1990 Contract's encouragement of improved levels of health promotion information provision in general practice.

- However, the reading and contact with health professionals on which this study has been based strongly suggests an uneven and sporadic development of consumer health information provision across UK general practices overall.

Recognition of a general practice role in consumer health

information provision and enthusiasm for developing it in the surgery varies from practice to practice. Hence, the importance of the work of bodies such as CHIC and self-help teams in targeting health professionals (and within this group the primary health care team as a specific target-group) in their campaigns to raise general awareness of the value of consumer health information provision.

This study concludes by making recommendations for the development of standards for consumer health information provision in general practice at national level. Setting of National Standards is recommended as a means of ensuring improved levels of consumer health information provision in UK general practices overall.

## 7.2 RECOMMENDATIONS

### (A) Research into levels of consumer health information provision in UK general practice

Research into existing levels of consumer health information provision across UK general practice overall, with attention to the main areas of consumer health information provision offered. Funded by a DOH research grant?

### (B) Setting of National Standards

This research is to form the basis of discussions which will result in recommendations made for the areas of consumer health information provision to be made available in general practices.

These recommendations will constitute National Standards for general practice consumer health information provision.

The preliminary discussions to be held by a Joint Body. This Body will include all relevant/interested parties with experience in the area of consumer health information provision, e.g: CHIC, the RCGP, the RCGP's Patients' Liaison Group, the College of Health, the DOH, and FHSA representatives.

The National Standards will constitute a check-list of recommendations. The recommendations can only act as general guidelines on those areas of consumer health information provision

which the standard-setters consider it fair to expect any one general practice to offer. There are limits to how specific these recommendations can be because, e.g:

(a) the number of different areas of consumer health information provision make it unrealistic to demand that practices make provision in *all* areas: the standard-setters must prioritise between 'principal' and 'additional' areas of consumer health information provision. 'Principal' areas are to include those areas of provision which practices are *strongly* recommended to offer, and 'additional' areas are to include those areas which practices are advised to develop only once 'principal' areas of provision have received appropriate attention;

(b) local factors are important: each individual practice will have different patient needs and priorities in the area of consumer health information provision.

#### **(C) Standards: an FHSA role**

(a) FHSAs are to receive the recommendations check-list and distribute it among the general practices under its authority;

(b) FHSAs are to explain the check-list at local level and investigate into the feasibility of setting up (under each Authority) a special 'consumer health information provision Facilitator Unit'. The Unit will deal with practice enquiries regarding the meeting of the National Standards. In establishing these special Units, FHSAs are to liaise with those who have existing experience in this field, e.g: with health promotion facilitators, local consumer health information services and self-help teams.

(c) FHSAs are to regularly monitor developments in practice consumer health information provision to ensure that these are being undertaken in accordance with the National Standards.

(d) FHSAs are to consider setting *Local Standards*. These will be based upon the National recommendations and will be made in accordance with them. Local Standards will however be more detailed than the National ones because they will take account of local factors/influences on consumer health information provision among general practices under the FHSA's authority. Local Standards will

therefore constitute more realistic/precise standard-setting at a local level.

#### (D) Provision of practice staff training

Whilst National Standards are being set it is crucial to both (i) raise practice staff's awareness of the value of consumer health information provision (i.e: to give the National Standards any value and meaning to practice staff), and to meet the new training needs that the Standards raise for practice staff.

##### (a) Undergraduate training

CHIC for example (please see 4.2) recognises the importance of providing training at the earliest possible stage in the practice staff's career.

Undergraduate training to include:

(i) theory-based learning in the value of consumer health information provision *in general*, i.e: the philosophy that information is a key to patient participation, and focus on the consequent benefits of such participation;

(ii) theory and practice-based learning in *specific areas* of consumer health information provision, i.e: training in the value of and in the practical skills involved in providing a particular area of information. For instance, training to focus on the following areas among others: establishing and maintaining a patient library, and collection management skills; provision of health promotion information, and communication skills; general practice as access-point to self-help groups and other health activities/services in the community.

##### (b) Continuing education for active practice staff

(i) FHSAs to organise consumer health information provision training days for the practice staff under its authority. This will involve FHSA liaison with local workers in consumer health information provision, e.g: local consumer health information services, Health Promotion Department, self-help groups, self-help teams, and examples of good practice from local GPs.

As with Undergraduate courses, FHSA training days are to provide



theory and practice-based training in the general value of consumer health information provision overall, and with focus on specific areas of consumer health information provision.

(ii) FHSA's to encourage practice staff to spend some of the new post-graduate education allowance (GPs' 1990 Contract) on attendance of Undergraduate courses in consumer health information provision being developed at local Departments of General Practice.

#### (E) Keeping the public informed

It is crucial to ensure that the public is made aware of the areas of consumer health information provision that it can expect to access at the local general practice. This is important both to:

(i) ensure that patients have the necessary awareness to seek out, hence benefit from the different areas of consumer health information provision on offer, i.e: optimum patient benefit from consumer health information provision in general practice, and avoidance of redundant (i.e: unused) information provision;

(ii) raise patient expectations and demands, i.e: increased patient expectations will encourage practice staff to work towards meeting the new National and Local Standards in consumer health information provision.

As writes East Sussex FHSA in relation to patients' general rights regarding GP services,

*... we are intent on raising consumer expectations - and raising standards to meet them too - but first we want to make sure that consumers have a real grasp of what the basic deal is'.*

#### How to raise public awareness

(a) At national level: by distribution of National Standards to the public, e.g: through letter-boxes; through public places such as CABx and public libraries; through the general practice itself.

(b) At local level: FHSA distribution of FHSA Local Standards to the public, e.g: through the same access-points as listed for National Standards in (a) above.

(c) At general practice level: individual general practices to sufficiently promote their consumer health information provision facilities to the practice-population. Promotion of specific areas of consumer health information provision through, for example:

(i) word of mouth, i.e: receptionist-staff to patients, GPs to patients in consultation, practice nurses to patients during routine health checks;

(ii) attractively designed poster promotion in the surgery waiting-area;

(iii) inclusion of a special section on the practice's consumer health information provision facilities in the practice brochure;

(iv) book mark promotion: practices with patient libraries to issue free book marks with borrowed items - book marks to list different areas of consumer health information provision available in the practice;

(v) attractively designed information sheets sent out to patient homes - information sheets to explain the different consumer health information provision facilities offered by the practice.

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## APPENDIX I

### INFORMATION AS A KEY TO PARTICIPATION

a diagram to illustrate how different  
areas of consumer health information provision  
in general practice enable patient  
participation in the  
health-care process.

## INFORMATION: A KEY TO

- Health information on specific conditions & treatment in popular language:

leaflets, patient libraries, clinics ...

- General health education & health promotion information:

oral, posters, health promotion clinics, leaflets, books, audio-visual ...

- Information on health-related services & organisations available

information on self-help groups, consumer health information services, community health projects, social services, welfare services, health clubs, sports centres ...

- Information on an individual's condition & treatment in popular language:

oral, access to medical records (additional explanations given to clarify unclear terms) ...

- Information on local NHS Services available - their quality standards & waiting times.

- Information on practice staff, facilities & services:

oral, practice brochures ...

## PATIENT PARTICIPATION IN THE HEALTH-CARE PROCESS

- (a) Participation through increased understanding of condition;
  - (b) A more participative (informed) role in consultation process;
  - (c) Participation through self-care (e.g. a booklet on a specific condition may provide information on self-management of the condition).
- 
- (a) Participation through actively seeking out the information necessary (e.g. clinic attendance) to enable
  - (b) Participation through self-care (i.e. by implementing preventative measures learnt);
  - (c) Participation through increased knowledge on matters of health & illness.

Participation through seeking out these services and becoming actively involved in them and/or acting on their advice to the benefit of ones own (e.g. self-help groups) and/or the community health projects) health.

- (a) Participation through increased understanding of one's condition & its treatment. This can enable
- (b) Participation through improved compliance with treatment (i.e. through increased awareness of how to more effectively comply);
- (c) A more participative role in the consultation process (e.g. increased patient understanding enables GP & patient to discuss future treatment plans together).

Participation through informed choice (i.e. improved opportunities for the patient to base choice of NHS service on comparisons made between different services available).

Participation through informed choice (i.e. improved opportunities for the patient to base choice of general practice on comparisons made between different practices available).

-----

## APPENDIX II

### A REGIONAL HEALTH INFORMATION SERVICE LEAFLET:

an example of the areas of  
consumer health information a practice  
can access for its patients by contacting the  
local health information service.

0 3 4 5 6 7 8 3 0 0

A TELEPHONE HEALTH

INFORMATION SERVICE

*Better health is just  
a local call away!*

TRENT  
HEALTH  
*line*  
0345 678300

0 3 4 5 6 7 8 3 0 0

## WHO

W H O C A N U S E


T R E N T H E A L T H L I N E ?

### EVERYONE

Information will be provided by trained staff

- Over the telephone in office hours
- In response to a message on the 24hr answering machine
- By post
- In person at Victoria Health Centre
- On a minicom system for people with hearing impairments
- In written languages other than English, large print and Braille

The service could be particularly helpful for

- People wanting to use health services
-  General Practitioners
- Other health service providers

0 3 4 5 6 7 8 3 0 0

## WHY

W H Y I S I N F O R M A T I O N

A B O U T H E A L T H I M P O R T A N T ?

People can

- Make choices
- Feel more in control
- Be more confident
- Have more opportunity to get an appropriate service
- Become more able to ask the right questions



0 3 4 5 6 7 8 3 0 0

## WHAT

T R E N T H E A L T H L I N E C A N

P R O V I D E I N F O R M A T I O N O N

- Local Health Services such as hospitals, clinics, GPs and community services
- Waiting Times for out-patient, in-patient and day case operations which can be used in conjunction with a GP to find quicker treatment
- Information about any disease or condition in non-medical language and self-help groups who can provide support and further information
- How to maintain and improve your health
- Local charter standards set for health services
- How to complain about health services



0 3 4 5 6 7 8 3 0 0

HOW

A TELEPHONE HEALTH

INFORMATION SERVICE



**0345 678300**



- To write to Trent Health Line,  
address your letter to:

Trent Health Line

**F R E E P O S T**

Nottingham NG1 1BR



- To visit Trent Health Line  
go to:  
The Victoria Health Centre  
Glasshouse Street  
Nottingham

## APPENDIX III

### A PATIENT LEAFLET:

an example of a patient leaflet based  
on materials put together  
by practice staff.



# ACUTE LUMBAGO



## WHAT IS IT?

'LUMBAGO' means 'low back pain'. Although nearly half the population gets this condition at some time in life, doctors are far from certain as to its cause!

Nearly all doctors agree that it is a simple mechanical problem in one of the joints in the spine. While the majority thinks that it is due to a fragment of one of the discs in the spine bulging out of its normal position and pressing on a sensitive nerve, there are still a lot of doctors who think it is due to spasm in muscles, or to a joint which gets locked in the wrong position.

The pain may be so bad that the patient can hardly move. Sometimes it is only painful in certain positions or on certain movements. In many people the pain is just in the small of the back or to one side of it, but quite often the pain will spread into the buttock down one leg. If the pain spreads right down to the calf or foot it is called **SCIATICA**, but the cause is just the same. Sometimes sciatica affects the nerves so that the patient feels tingling or numbness in the leg or foot. In rare cases it can cause weakness of the muscles of the leg.

## WHAT WILL HAPPEN?

Most likely it will get better . . . whatever you do! Some patients improve very quickly, others take longer, but most should be back to normal in less than two months. A very small number of people are making no progress even after two or three months, and may need to be considered for surgery to the spine. Fortunately, such patients are a very small minority.

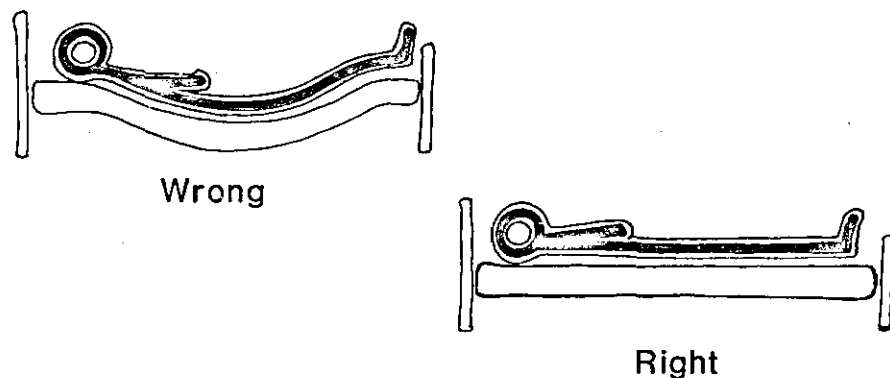
## WHAT SHOULD I DO?

There is no certain treatment for lumbago. But there **are** several things which can help:

### IN THE ACUTE STAGE:

1. **Go to bed . . . and stay there!** Lie in the most comfortable position, with no more than *one* pillow. Don't sit up in bed — you are trying to keep your spine straight! Stay put until you are able to move about freely. You may get up to go to the toilet.

You may need to stay in bed for three weeks.



2. If your bed is soft, sleep on a mattress on the floor.

3. **Relieve the pain.** Take some regular pain-relievers: either paracetamol (two tablets, four times a day) or whatever the doctor prescribes.

If your tablets don't help, let your doctor know.

4. **Be patient.** Find something to keep you occupied — radio, books, TV, anything . . . three weeks can be a l-o-n-g time.

5. **Danger signs — VERY RARE!** If you have difficulty controlling your water, or get sciatica or numbness down both legs, **CALL THE DOCTOR.**

### IN THE RECOVERY STAGE:

a) **Get up and about little by little.**

b) **Sitting is the worst position**

Lying, standing, and walking are the best. If you must sit, sit up straight, with some support in the small of your back.

c) **Do not bend at all**

If you need to crouch down, bend your knees, and keep your back straight.

d) **As you improve, go swimming.**

If you can't swim, try to get some lessons!

e) If your back is not improving, consult your doctor who may advise further treatment such as Physiotherapy.

## WHAT ABOUT AN OSTEOPATH OR A CHIROPRACTOR?

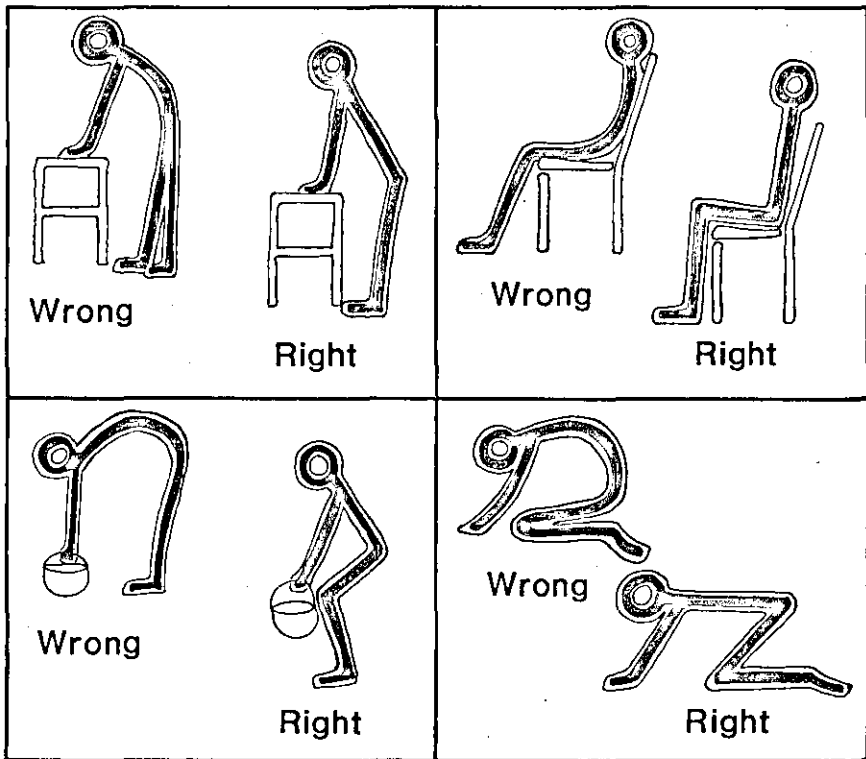
This kind of treatment sometimes seems to help, though not for everyone. Seek your doctor's advice before undertaking any treatment.

## **HOW CAN I PREVENT ANOTHER ATTACK?**

Preventing the next attack is worth putting some effort into.

The main message is:

# **KEEP YOUR BACK STRAIGHT!**



When your back is properly straight, there should be a hollow in the small of your back.

If you bend, bend at the knees . . . every time.

From material by Doctors Zermansky, Varnavides and Muncer.  
Edited and designed by the Health Education Department of Leeds Health Authorities.  
SEPT. '86.

## APPENDIX IV

### A PRACTICE BROCHURE:

an example of a practice brochure  
giving patients information on practice  
services and facilities.

Our practice area includes Loughborough, Quorn, Hathern and Shepshed.



The surgery is in a central position on the University Campus and has suitable access for all **disabled patients**.

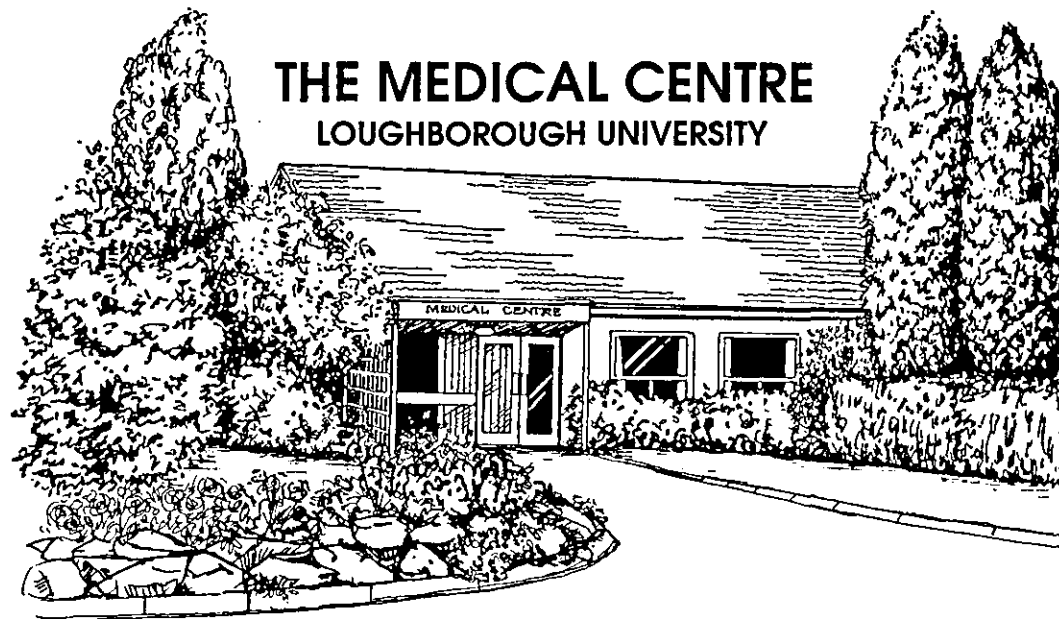
We are here to help you and would welcome your ideas and comments. If you have any ideas as to how we can improve the service, please "post" them in the **suggestion box**. If you are unhappy with our health care, don't tell others, tell us!

#### **Non-N.H.S. Services:**

Charges are payable for certain services, e.g. pre-employment medicals, sub-aqua, Kart Club and Bunacamp medicals. Please state the purpose of the consultation as some of these are lengthy.

#### **Chemists out of hours rota:**

Information available from Reception and Local Press.



Telephone Number  
For appointments, emergencies and general enquiries

Loughborough 222061 (Internal calls 2061)

#### **DOCTORS**

\*Asghar Bhojani (M), M.B., B.S. (1978 Newcastle), M.R.C.G.P.

\*Patricia Baker (F), M.B., B.S. (1955 London), D.Obst. R.C.O.G., D.C.H.

\*Naresh Vaghela (M), B.Sc (Hons), M.B., Ch.B. (1985 Leicester), D.Obst. R.C.O.G.  
(\*Full time +<sup>3</sup>/<sub>4</sub> time)

#### **PRACTICE NURSES**

Sister in administrative charge: Mrs. B. Jones

also Mrs. J. Evans  
Mrs. S. Jacques  
Mrs. S. James  
Mrs. A. Kilby

Mrs. A. Rasmussen  
Mrs. J. Sherwood  
Mrs. A. Simpson

#### **RECEPTION STAFF**

Mrs. J. Clarke      Mrs. V. Henson      Mrs. I. Jones

There are no fixed boundaries to the services available from the Medical Centre – in any situation where there is an aspect of health or well-being involved, assistance is available. Staff, students and local residents can register with our practice.

## How to see your Doctor

For appointments please call at reception or telephone **Loughborough 222061** between 8.30am and 5.00pm

### Surgery Times:

Doctor	Monday	Tuesday	Wednesday	Thursday	Friday
<b>Dr Bhojani</b>	9.20 - 11.30  2.30 - 4.30	9.20 - 11.20 Minor Ops  10.30 - 11.30	-  3.20 - 5.20	9.20 - 11.30  2.30 - 4.30	9.20 - 11.30  2.30 - 4.30
<b>Dr Vaghela</b>	9.20 - 11.30  2.30 - 4.30	9.20 - 11.30  -	9.20 - 11.30  2.30 - 4.30	9.20 - 11.30  -	9.20 - 11.30  2.30 - 4.30
<b>Dr Baker</b>	-  2.20 - 4.30	-  2.20 - 4.30	9.30 - 11.30  2.30 - 4.30 Well Woman Clinic	-  2.20 - 4.30	-  -
<b>Nurse</b>	2.30 - 4.30 Contraceptive Clinic	11.30 - 12.30 Asthma Clinic  2.30 - 4.30 Travel Advice Clinic	2.30 - 4.30 Well Woman Clinic	2.30 - 4.30 Contraceptive Clinic  2.30 - 4.30 Travel Advice Clinic	11.30 - 12.30 Skin Clinic

Saturday morning emergency surgery (term time only) 10.00 - 11.00am

If you are too ill to attend the surgery a **home visit** may be requested by contacting the Medical Centre.

We provide longer than average appointment times and try to spend time explaining the nature of illnesses and reasons for our actions.

You may consult any of the doctors, but as it is important for doctor and patient to get to know each other well, you should try to keep to the same doctor whenever possible.

If you consider your condition is **urgent** and no doctor's appointment is immediately available, you will be asked to see the nurse who will fit you into a doctor's surgery as appropriate.

### Evenings and Weekends:

A nurse is available for advice and treatment 24 hours a day during term time with support of a doctor on call. A doctor is available for emergencies 24 hours a day **throughout the year. (Tel. 222061)**. When the surgery is closed your call will automatically be answered by the University switchboard who will give you the phone number of the doctor on call.

### In-Patient Facilities:

The Medical Centre has in-patient facilities for the treatment of those students in need of medical and nursing care when hospital admission is not required. This is available throughout term-time.

### Repeat Prescriptions:

These can be issued by arrangement with one of our doctors. New patients on a regular prescription need to make an initial appointment prior to getting repeat prescriptions. Requests should be made to the receptionist. Please give 24 hours notice.

### Treatment Room:

The practice nurses are available to give advice on general health matters and minor ailments. The treatment room is open during surgery hours for services such as blood tests, blood pressure checks, dressings, ear syringing etc. If you would like to see the nurse please ask at reception, no appointment is necessary.

## Special Services

### Asthma Clinic:

We welcome all patients with Asthma/Hay Fever to come to this Clinic for regular monitoring of lung function and medication. This Clinic is held on Tuesday morning 11.30 - 12.30.

### Contraceptive Advice:

A full service, including Cervical Smears, is offered by all Doctors during normal surgery sessions. In addition we have two sessions a week (Monday and Thursday afternoons) for repeat contraceptive consultations with a practice nurse.

### Travel Advice:

Advice for travellers and all vaccinations (including Yellow Fever) - a comprehensive service is available by appointment with the nurse on Tuesday and Thursday afternoons 2.30 - 4.30.

### Well Woman Clinic:

The aim is to provide screening for breast cancer, cervical cancer, high blood pressure, diabetes etc. Dr. Pat Baker has set aside a session for this purpose on Wednesday afternoon.

### Physiotherapy:

An independent physiotherapy service is operating from the medical centre with open access for patients at a nominal charge.

### Ante-Natal Care:

This is offered during routine consultations by Dr. Bhojani and Dr. Vaghela. Please let the receptionist know as you may need a longer appointment.

### Minor Surgery:

Dr. Bhojani and Dr. Vaghela undertake a variety of minor operations in the surgery. These will be arranged after discussion with the doctor.

### Child Health:

Surveillance can be arranged by appointment with the Health Visitor.

**New Patients** will be asked to complete a questionnaire on registering with the practice and will be offered a health check.



## APPENDIX V

### THE FIRST RECORDED UK PATIENT LIBRARY IN GENERAL PRACTICE DIB LANE SURGERY. LEEDS

an example of a library  
for patients in  
general practice.



## APPENDIX VI

### DIB LANE SURGERY GUIDELINES ON SETTING UP A PATIENT LIBRARY

an example of guidelines  
produced to help other  
practices establish  
their own  
patient library.

## **Notes on Establishing a Health Education Library in General Practice**

### **Siting the Library**

The bookshelves should be situated in a place where they are easily accessible to patients - preferably the waiting room or reception area. The bookshelves themselves need not take up a great deal of space but it is an advantage to be able to display books, pamphlets, posters etc on spare shelves or display racks. If no wall space is available a possible alternative is a free standing trolley with shelves on either side.

### **Borrowing System**

If patients are to choose and borrow books without assistance, it is important to have a simple system of recording who has borrowed each book. We have a pocket inside each book containing a card on which is written the name and number of each book. The borrower then fills in his/her name, address and date of birth (optional, but useful for identification of patients with similar name). This card is left in a box for the librarian to collect later. The patient then asks the receptionist to date stamp the books and hopefully these are then returned to the reception desk within two weeks. We do not charge fines on overdue books, but a reminder letter is sent to borrowers if necessary. This system seems to work fairly well, and is designed to take up as little of the receptionists time as possible. We have lost on average about 5% of stock per annum.

### **Shelf Guidance**

It is important to have clear labels on shelves for each subject so that patients can easily find the books they are looking for. We also have a system of coloured labels on the spine of each book to indicate the subject.

### **Childrens' Books**

We felt that it was important to include childrens' books in the library both for their own sake and in the hope that parents might become interested in the library through their children. We have a fairly large childrens' section, sited on a lower shelf which includes both health care books and more general educational books of which there are now a large number available in the shops.

### **Staffing**

The initial setting up of a library is time consuming. It might take approximately ten to fifteen minutes for each book to order, process, cover and enter into the accessions register (the latter is simply a cumulative list of stock). However, once the library is established the time needed for the day to day running of a library of our size (about 400 books and about 6 to 7 borrowings per week) could be as little as one hour per week or a few minutes each day.

### **Some Other Points**

We feel that the presentation and appearance of the books is important, so we have covered all the books with P.V.C. adhesive for the paperbacks and loose P.V.C. covers for hardbacks. We have found that paperbacks last quite well when covered, so we only buy hardbacks if no paperback version is available. Replacement of worn books should be included in the budget, as although the adult books last well, childrens' books tend to disintegrate rapidly and also get lost more easily. A 10% replacement rate would cover books worn, lost and outdated.

APPENDIX VII

HURST PARK MEDICAL PRACTICE  
LIBRARY LIST:

an example of the range of books  
stocked in a general  
practice patient library.

Hurst Park Medical Practice Library List

Title	Author	Aqu. Date	Aqu. Num	Location
** PL				
* AIDS	ALISON & DAVID KILPATRICK	31/10/91	1098	PL
* ALCOHOLICS ANONYMOUS - THE BIG BOOK	ALCOHOLICS ANONYMOUS	31/10/91	1110	PL
* AN A-Z OF YOUR CHILDS HEALTH	DR DAVID DELVIN	31/10/91	1082	PL
* ASTHMA & HAYFEVER	DR ALLAN KNIGHT	11/03/92	1217	GH
* ASTHMA WHO CARES?	THE ASTHMA TRAINING CENTRE	15/06/92	1245	
AVOIDING OSTEOPOROSIS	DR ALLAN DIXON	11/03/92	1215	
* BABIES	DR CHRISTOPHER GREEN	11/03/92	1229	GH
* BABYHOOD	PENELOPE LEACH	11/03/92	1230	GH
* BIRTH TO 5	HARPER & ROW PUBLISHERS	31/12/91	1119	PL
* BIRTH TO 5	HARPER & ROW PUBLISHERS	31/12/91	1120	PL
* BREAST CANCER - THE FACTS	MICHAEL BAUM	15/06/92	1246	
* BREAST IS BEST	PENNY & ANDREW STANWAY	31/10/91	1090	PL
* BREASTS AND THE IMPORTANCE OF BREAST EXAMINATION	BUPA MEDICAL CENTRE LTD	31/10/91	1113	PL
* CANCER YOUR QUESTIONS ANSWERED	DR CHARLES DOBREE	31/10/91	1087	PL
CANCER. YOUR QUESTIONS ANSWERED	DOBREE C	01/08/89	1021	OF
* CHOLESTEROL CHECK	DR ALAN MARYON DAVIS	11/03/92	1219	GH
* CONTRACEPTION - YOUR QUESTIONS ANSWERED	CHURCHILL LIVINGSTONE	11/03/92	1222	GH
* COPING WITH BREAST CANCER	BETTY WESTGATE	31/10/91	1089	PL
* DEPRESSION	ROMANIS R	01/08/89	1019	OF
* DEPRESSION AND HOW TO OVERCOME IT	DR CAROLINE SHREEVE	31/10/91	1102	PL
* DONT BREAK YOUR HEART	DR BARRY LYNCH	30/10/91	1080	PL
* DRUG PROBLEMS WHERE TO GET HELP	ABBOTT LABORATORIES	31/10/91	1092	PL
* EASY WAY TO STOP SMOKING	ALLEN CARR	28/06/91	1073	PL
* EASY WAY TO STOP SMOKING	ALLEN CARRS	11/03/92	1221	GH
* EAT FOR LIFE DIET	JANETTE MARSHALL	11/03/92	1220	GH
* ECZEMA AND COMPLETE GUIDE	CHRISTINE ORTON	31/10/91	1107	PL

Hurst Park Medical Practice Library List

Title	Author	Aqu. Date	Aqu. Num	Location
* ECZEMA AND DERMATITIS	PROFESSOR RONA MACKIE	31/12/91	1118	PL
* ECZEMA AND OTHER SKIN DISORDERS	DR JOVANKA BACH	31/10/91	1097	PL
* ECZEMA RELIEF	CHRISTINE ORTON	28/06/91	1067	PL
* FAMILIES AND HOW TO SURVIVE THEM	ROBIN SKYNNER	11/03/92	1227	GH
* GET A BETTER NIGHTS SLEEP	PROF IAN OSWALD	31/10/91	1099	PL
* GETTING WELL AGAIN	SIMONTON O	21/01/92	1132	PL
* HOW TO TAKE CARE OF YOUR HEART	MARK PAYNE	31/10/91	1101	PL
* HYSTERECTOMY	SUZIE HAYMAN	30/10/91	1081	PL
* I HAVE ECZEMA	ALTHEA	30/10/91	1078	PL
* I HAVE ECZEMA	ALTHEA	30/10/91	1079	PL
* I HAVE ECZEMA	ALTHEA	31/10/91	1112	PL
* IVAN LIVING WITH PARKINSONS DISEASE	VAUGHAN I	21/01/92	1133	PL
* LIFE WISH	IRELAND J	21/01/92	1134	PL
* LIVING SOBER	AA GENERAL SERVICE OFFICE	31/10/91	1091	PL
* LIVING WITH ALZHEIMERS DISEASE	DR GORDON WILCOCK	11/03/92	1223	GH
* METAL JAM	TERESA MCLEAN	31/10/91	1085	PL
* MIGRAINE & HEADACHES	DR MARCIA WILKINSON	31/10/91	1114	PL
* MISCARRIAGE	ANN OAKLEY	11/03/92	1218	GH
* NEW APPROACHES TO CANCER	HARRISON S	01/08/89	1020	OF
* PAUL HAS ECZEMA	GLAXO LABORATORIES LTD	31/10/91	1093	PL
* PAUL HAS ECZEMA	GLAXO LABORATORIES LTD	31/10/91	1094	PL
* PAUL HAS ECZEMA	GLAXO LABORATORIES LTD	31/10/91	1095	PL
* PEACE FROM NERVOUS SUFFERING	DR CLAIRE WEEKES	31/10/91	1105	PL
* POSTNATAL EXERCISES	BARBARA WHITEFORD	28/06/91	1075	PL
* PREGNANCY & BIRTH BOOK	MIRIAM STOPPARD	31/10/91	1109	PL
* PREGNANCY BOOK	HEALTH EDUCATION AUTHORITY	31/12/91	1121	PL
* PREGNANCY BOOK	HEALTH EDUCATION	31/12/91	1122	PL

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15/06/92

Hurst Park Medical Practice Library List

Title	Author	Aqu. Date	Aqu. Num	Location
* SELF HELP FOR YOUR NERVES	DR CLAIRE WEEKES	28/06/91	1070	PL
* SOLVE YOUR CHILDS SLEEP PROBLEMS	DR RICHARD FERBER	05/11/91	1117	PL
* STAYING DRY - ADVICE FOR SUFFERERS IN INCONTINENCE	PROFESSOR CM CASTLEDEN	11/03/92	1225	GH
* STRESS AND RELAXATION	JANE MADDERS	11/03/92	1216	GH
* TALKING ABOUT GOING INTO HOSPITAL	PAULINE WELLS	31/10/91	1086	PL
* THE BACK RELIEF FROM PAIN	DR ALAN STODDARD	11/03/92	1214	GH
* THE COMPLETE BABY & TODDLER MEAL PLANNER	ANNABEL KARMEL	11/03/92	1226	GH
* THE MENOPAUSE - COPING WITH THE CHANGE	DR JEAN COOPE	31/10/91	1104	PL
* TODDLER TAMING	GREEN C	27/06/91	1065	PL
* UNDERSTANDING CYSTITIS	ANGELA KILMARTIN	11/03/92	1228	GH
* WELL AWAY - A HEALTH GUIDE TO TRAVELLERS	ERIC WALKER	31/10/91	1100	PL
* WHAT EVERY WOMAN SHOULD KNOW ABOUT RETIREMENT	HELEN FRANKS	31/10/91	1103	PL
* WOMAN TO WOMAN	DR MIRIAM STOPPARD	11/03/92	1224	GH



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