Information in GP's Surgeries
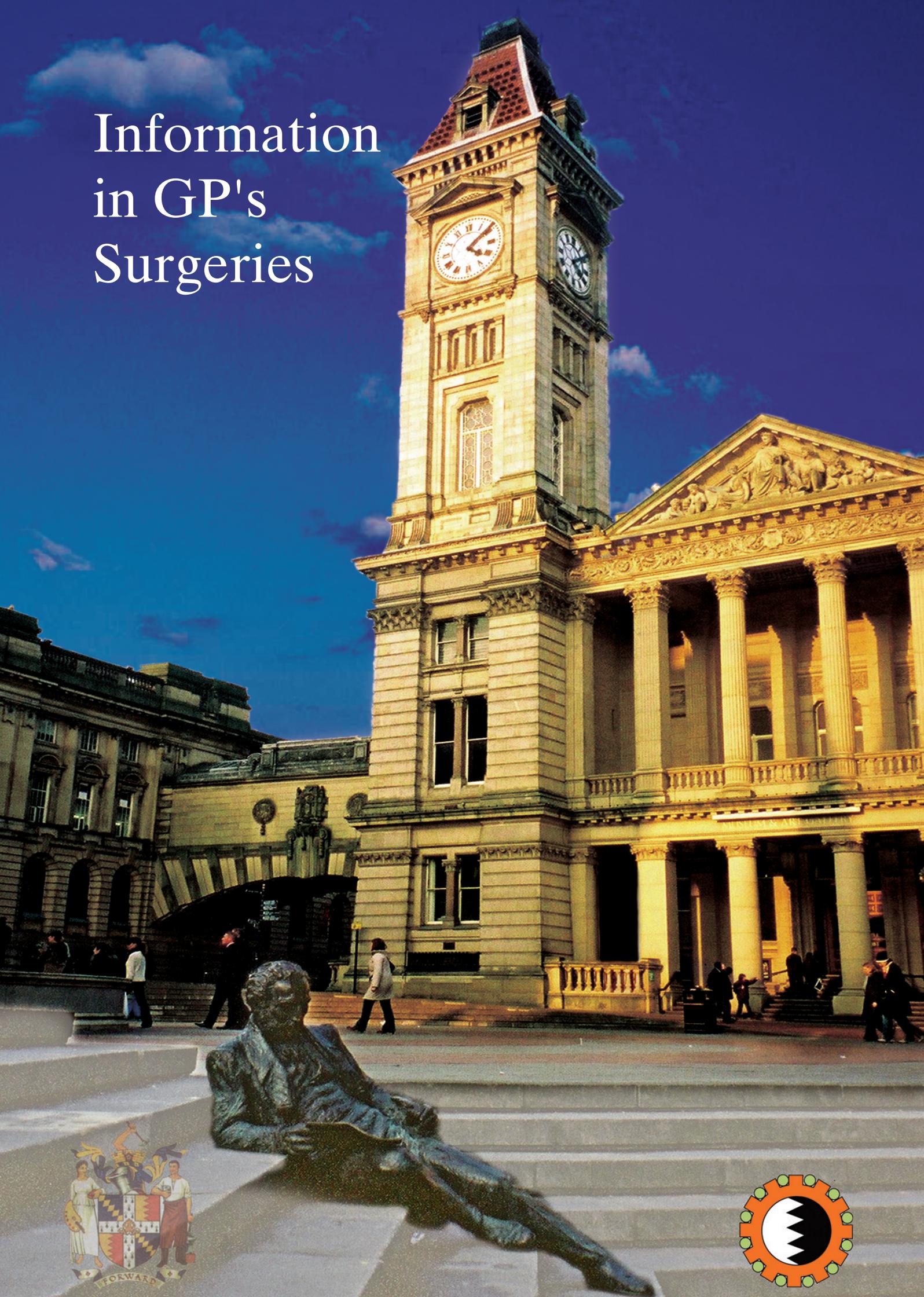
4 May 2004

Report to the City Council

Information provided to NHS patients at doctors' surgeries

Information in GPs' Surgeries

Contents

Preface

Councillor Bryan Nott
Chair, Health Overview and Scrutiny Committee

It is recognised that people with chronic and disabling conditions need a wide range of information in order to better manage and understand their situation. In the majority of cases a patient will first find out about their condition within a doctor's surgery. Thus, it is vital that quality information is made available at this point.

It is also recognised that the availability and quality of information available in surgeries is extremely varied. The purpose of this review was to obtain the views of patients and patients' groups on the extent to which information is made available in surgeries, as well as to examine the current practice in surgeries and to recognise the reasons behind the variations.

The NHS plan sets out a commitment to engage patients and the public in all areas of the Health Service and there is no more important starting point than engaging patients in the management of their own conditions. This can only be achieved through empowering patients and providing them with the tools to understand better all aspects of their care.

The on-going changes within the Health Service will have a very real impact on patients and the methods and systems that provide them with care. Policies such as Patient Choice and the new contract for GPs will require patients to be better informed of the care they can expect.

Within the context of these changes it is essential to consider how patients interface with Primary Care and the extent to which they understand the choices that are expected of them.

The review could not have been carried out without the input from GPs across the city, as well as patients and the Primary Care Trusts.

1:   Summary

1.1   This review has been carried out by the Health Overview and Scrutiny Committee.

1.2   The purpose of this review was to: -

- Obtain patients' and carers' views on the extent to which information is made available to them at doctors' surgeries.

- Identify variations in current practice and the reasons for observed differences.

- Recommend what steps (if any) need to be taken to ensure that all patients have access to information which meets their particular needs.

1.3   Communication of information is fundamental to a patient's ability to understand and manage their condition. The method and quality of this information can also have a major impact on the outcome of any health intervention that is carried out, both in and outside of a doctor's surgery.

1.4   Good quality information can dramatically alter patients' perceptions of their conditions, as well reducing the psychological trauma associated with a new and challenging situation.

1.5   The 1993 Audit Commission Report '*What Seems to be the Matter: Communication between Hospitals and Patients*' defines a need for improved communication of information in an acute or hospital setting. It should be noted that for the majority of patients, their main or only contact with the Health Service actually takes place within Primary Care settings such as GP surgeries and health centres. Thus, provision and clarity of information is important and integral to patient care.

1.6   During the course of this review the Committee learnt that there is no organised system of information provision in GPs' surgeries.

1.7   The information that is available to GPs comes from a variety of disparate sources and is often of variable quality.

1.8   Information Technology can provide a solution to many of the problems associated with providing information to patients. Systems can aid quick access to specific information as well as preventing problems of storage.

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1.9 However, current IT systems are not designed to provide information as a core function and in many cases the information that is available is not of sufficient quality to be provided to patients.

1.10 More training, relating to IT, is required for primary care workers from both IT suppliers as well as Primary Care Trusts.

1.11 Quality Internet resources are available to primary care workers, but a lack of training and promotion means these are not utilised as well as they should be. In addition, constraints on the length of consultations make them impractical to use.

1.12 There is no current impetus on Primary Care Trusts to set information provision at the core of the consultation.

1.13 NHS policy changes such as Patient Choice will increase the profile of information provision.

1.14 Primary Care Trusts should co-ordinate the availability of information and its quality. There should be an increased commitment to utilise existing resources such as the Health Promotion Unit.

1.15 Patient Groups believe that a lack of information can cause undue stress to patients when a diagnosis is made.

1.16 Patient Groups have examples of high quality information resources, but these require investment from the Primary Care Trusts.

1.17 Patients themselves indicate that information is rarely provided as part of the consultation process.

1.18 Actions to address these issues lie chiefly within the remit of PCTs. The Committee therefore recommends that :

	Recommendation	Responsibility	Completion Date
R1	The PCTs in Birmingham develop a strategy for all practices in their area, to improve provision of information to patients and promote health literacy. The strategy should encourage a more systematic use of IT for accessing patient information by GPs and primary care workers.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	May 2005

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R2	The PCTs create a basic template of culturally appropriate, quality assured information on each of the ten major disease areas identified by GMS2, for use and adaptation as necessary by primary care professionals.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	May 2005
R3	The PCTs develop and actively promote a directory of statutory and voluntary services for the communities they serve with the aim that these services become more accessible, connected and integrated to patient care.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	September 2005
R4	The PCTs liaise with the Department of Health in requiring that IT suppliers should work to a common specification for IT systems which more easily produce patient information as a routine part of chronic disease management.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	September 2005
R5	Progress towards achievement of these recommendations should be reported to the Health Overview and Scrutiny Committee on a six-monthly basis until completed. The first report should be made November 2004.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	November 2004

2: Introduction

2.1 Reason for the Review

2.1.1 Communication of information is fundamental to a patient's ability to understand and manage their condition. The method and quality of this information can also have a major impact on the outcome of any health intervention that is carried out, both in and outside of a doctor's surgery.

2.1.2 Good quality information can dramatically alter patients' perceptions of their conditions, as well reducing the psychological trauma associated with a new and challenging situation.

2.1.3 The 1993 Audit Commission Report '*What Seems to be the Matter: Communication between Hospitals and Patients*' defines a need for improved communication of information in an acute setting. It should be noted that for the majority of patients, their main or only contact with the Health Service actually takes place within the Primary Care setting. Thus, clarity of information is a much more pressing concern.

2.1.4 The 1993 report sets out some of the underlying causes for a lack of available information or its perceived irrelevance. These can be summarised as: -

- **Information is not available** – often because it has simply not occurred to staff that there is a need to produce it.

- **Information is not accessible** – sometimes information is produced but due to inadequate provision for distribution it never reaches the patients it was originally intended for.

- **Poor quality information** - in some cases information can be poorly designed, meaning the content is difficult to read. However, a more common problem is that the information itself is not produced with the end user in mind.

- **Staff and patients perspectives differ** – much information is produced without considering the needs of the patient. This can be explained by the fact that staff who are familiar with conditions find it hard to 'step back' and be objective about what information is needed.

2.1.5   The NHS is shortly to implement a new policy (Patients' Choice) which means that surgical patients will be offered a degree of choice in where their care will take place. The initial stage will see patients who have waited in excess of six months being offered the chance to change hospital or provider. This choice will then be extended to all patients who require surgical care. If this choice is to be a true reflection of patients' wishes then it is essential that adequate information be provided within the Primary Care context.

2.1.6   The new contract for GPs (GMS2) will allow GPs to opt-out of providing certain services. In respect of information provision itself, the new contract will have little impact. GPs will be offered additional payments if they can demonstrate that they have provided smokers with support and literature to give up. There will also be an additional payment if it can be shown that the practice provides information on the services of the GPs themselves and any further Primary Care services. Although the contract does not oblige GPs to provide specific information, it is a natural consequence of changes to services that patients can expect to be informed of what services their surgery will provide.

2.2   Terms of Reference and Membership

2.2.1   Terms of Reference for the review can be found in Appendix 1.

2.2.2   Members of the Health Overview and Scrutiny Committee who carried out the review were:-

- Councillor Bryan Nott (Chair)
- Councillor Chaman Lal
- Councillor Susan Axford
- Councillor Ansar Ali Khan

2.2.3   Officer support for the review was provided by the Scrutiny Office and consisted of

- Dr. Jacky Chambers (Committee Link Officer)
- Narinder Saggu (Scrutiny Manager)
- Darren Wright (Lead Review Officer)

2.3 Methodology

2.3.1   In order to compile this report the Committee drew on a variety of sources. These included: -

- Site visits to a variety of surgeries across Birmingham (See **Appendix 2**).

- Other research papers related to information provision.

- Results of Primary Care Trusts Patients' Surveys.

- Submissions from the public.

- Evidence from Egton Medical Information Systems, West Midlands Library Service Development Units Department, Diabetes UK, Eastern Birmingham PCT, South Birmingham PCT, Heart of Birmingham Teaching PCT and the Birmingham Health Promotion Unit.

2.4 Critique of Methodology

2.4.1   The original plan to interview selected GPs about specific information provision proved to lack sufficient scope. The provision of information to patients within a surgery is the responsibility of all members of staff; therefore the interviews were extended to take account of the roles played by Primary Care nurses and Practice Managers.

2.4.2   The visits to surgeries gave a 'taster' of a variety of different practice settings, but were by no means all encompassing.

2.4.3   The increasing reliance on IT systems within surgeries has meant that a large amount of information is provided through computers. The evidence provided by Egton Medical Information Systems demonstrated clear applications of a widely utilised system but time constraints prevented the balancing this against other companies' products.

2.4.4   Time constraints prevented a wider public consultation taking place thus the public submissions received are not representative.

3:   Information Available to Patients

3.1   What is Information?

3.1.1   Within the context of this review the Committee considered 'information' to mean any knowledge or guidance that enabled a patient to understand and take control of their condition. Information is not restricted to leaflets and posters and could also include referrals to support groups.

3.1.2   Providing information is not simply the action of giving a patient a leaflet. This illustrates the dichotomy between information and education. This can result in patients being given information that they do not absorb or understand and therefore do not gain the tools required to manage their condition. This is quite often the case because patients: -

- Do not understand the information because it is complex.

- Cannot absorb the information because they are anxious or in pain.

- Might not appreciate the relevance of the information because they might not be able to make a link. For example the link between smoking and high blood pressure.

- Might not believe the information. This could be because the deliverer lacks credibility or the information may challenge their beliefs or values.

- May not act on the information as it may disrupt their lifestyle.[1] Therefore the process of providing information should help the individual to feel empowered and thus take control of the management of their condition. This can be achieved through an open dialogue that engenders mutual respect between the parties involved.

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[1] Source: Continuing Professional Development: Communication, Nursing Standard July 9th / Volume 17.

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3.2   Format of Information

3.2.1   The most common forms of information provided to patients are leaflets or posters. These can be readily found in most surgeries but are generally of a very specific nature. Leaflets that are available tend to be driven by needs perceived by the Department of Health rather than the requirements of the surgeries themselves.

3.2.2   Language creates a great barrier to providing information to patients that do not have English as their first language. It is the experience of many of the practices visited by the Committee that producing information in different languages is of limited value. This is generally because the incidence of literacy of some languages is not high enough to make them viable.

3.2.3   As a result of the language barrier some information is now being produced on audio and video tape in order to make it accessible to all members of the community.

3.2.4   Some materials that are produced relating to conditions are not created with the patient in mind. This results in highly technical materials being produced that can confuse patients. In cases where patients do not understand the information provided, it has the effect that they do not take ownership of their condition and it hinders their ability to manage it.

3.2.5   Some surgeries have approached the provision of information to their patients in a variety of innovative ways. For example, Jiggins Lane surgery have developed their own website (http://www.jigginslane.org.uk/) that gives information on practice staff and services that are provided.

3.3   Why is Information Important?

3.3.1   Information is important as it not only helps patients to understand the reasons for any medication that might have been prescribed, but also helps to alleviate anxiety that can be associated with a diagnosis.

3.3.2   For example, when initially diagnosed with diabetes many patients suffer anxiety, which in itself can prove very detrimental to their health. Their major concerns are the possible serious consequences of the disease e.g. blindness, strokes or limb amputation. However, these outcomes can be averted by careful management and adequate provision of information.

3.3.3   Adequate information can reduce stress and anxiety in a wide range of conditions and thus improve eventual outcomes. This can be especially true in cases of heart disease or hypertension where the stress itself can cause further complications.[2]

3.3.4   Information can also create an increase in compliance with medical instructions. This can then increase a patient's ability to function in their day-to-day life.

3.3.5   There is also a consensus that informed patients are also efficient users of services. This has benefits to GPs in that it decreases the amount of erroneous consultations as well as reducing the required amount of long-term care.

3.4   Supply and Storage of Information Materials

3.4.1   At present there is no organised system of supplying information to GPs. It is incumbent on the surgeries themselves to source all information and then assess its quality. In the majority of cases this is the responsibility of the practice manager. This can create a problematic situation in small practices or those suffering staff shortages.

3.4.2   Much of the information available is sent unsolicited to surgeries by pharmaceutical companies and is therefore intended to promote certain medication or products. Many of the surgeries visited expressed a reluctance to use these resources as they were perceived as biased. The branding contained on such leaflets can indicate to patients that only a very specific medication is appropriate for their condition.

3.4.3   Some surgeries generate their own materials to provide to patients but this is a costly exercise and often has to be supported out of existing budgets. Some surgeries have experimented with using local businesses to sponsor literature, but within areas of high deprivation there are fewer businesses in a position to provide such support. Ironically, it is highly deprived areas that also experience higher indices of chronic conditions.

3.4.4   Surgeries must utilise all of their capacity for service delivery and thus storage space is at a premium. There is no spare capacity to hold large volumes of paper-based materials. This is especially true where those materials concern uncommon conditions for which there might be little demand for information literature.

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[2] Source: 1993 Audit Commission Report '*What Seems to be the Matter: Communication between Hospitals and Patients'*.

4:   Technology and Patients

4.1   Information Systems in GP Practices

4.1.1   Information provision and technology relates to GP surgeries within two broad headings:

- The main implementation relates to information systems that exist within the surgeries themselves.

- In addition, there is a wealth of internet resources that provide information on conditions as well as 'signposting' to support groups.

4.1.2   The Committee heard evidence from Egton Medical Information Systems (EMIS), who provide IT systems to 55% of the GP practices in Birmingham. The central purpose of this system is to record interventions that occur within a consultation. In addition the system facilitates dedicated information resources that can be printed off and provided to patients as part of the consultation.

4.1.3   The broad purpose of all surgery based systems is to :-

- Record details of patients.

- Record details of consultations.

- Record any interventions that have occurred with a patient.

- Monitor prescribing both for individual patients and the surgery as a whole.

- Monitor activity of the surgery and produce reports that comply with the GP contract for the Primary Care Trust.

- Facilitate the provision of information for patients.

4.1.4   It should be noted that information provision is not a core function of IT systems as set out under the Department of Health preferred bidding system. EMIS have added this function in order to provide added value to their system.

4.1.5 The EMIS system's information resource is an application integrated with the EMIS clinical/ main consultation system. It allows GPs to browse through some six hundred leaflets that are dedicated to specific conditions. The leaflets are produced by GPs contracted to EMIS and can be regularly updated within the system via the Internet. Periodic updates are produced by EMIS and updated remotely.

4.1.6 The system can be used separately or with online services for patients and/or clinicians. Details about these online services are provided in appendix 3.

4.1.7 In the Committee's view, the process of finding a leaflet related to a condition is not intuitive and gives no indication of either the quality of the leaflet or the relevance of the information contained therein. It is the responsibility of the individual GP to assess the materials and make a decision on how appropriate the leaflet is to the specific consultation. System administrators are permitted to add their own source material.

4.1.8 Within the context of the consultation the user is able to attach alerts to specific conditions in order to prompt a particular intervention. In practice this means that if a patient is diagnosed with a specific condition, then a box will appear on the screen prompting the GP to provide a relevant leaflet. This is not a provision that is available within the system by default and it would require practice staff to know how to set up such alerts as well as having previously assessed which materials are of adequate quality to be circulated to patients. It is unclear how many practices are familiar enough with the system to be able to achieve this.

4.2 Training

4.2.1 In the course of the visits to surgeries some Primary Care workers expressed concerns around the amount of training that is associated with the system implementation. The current policy of EMIS is to train certain dedicated staff within a practice and then allow knowledge to disseminate throughout the practice. During the course of our visits primary care workers said that due to the constraints on staff time this is quite often not a viable solution and has inherent consequence that staff do not gain sufficient training or ownership of the process.

4.2.2 Further training is available at an additional cost but usually this relates to the core function of the system.

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4.3   Internet Resources

4.3.1   In addition to the systems within the practice itself there is a wealth of resources available via the Internet. Dedicated websites contain information relating to a variety of conditions as well as support groups (see also appendix 3).

4.3.2   Although the information relating to conditions is readily available, it often requires a degree of in-depth searching. Within the constraints of the limited time available in a consultation this is generally not practical. This can largely be put down to a lack of dedicated training in Internet research techniques as well as the need to assess each site for integrity and quality. In addition the length of a consultation prohibits extensive searches.

Electronic Quality Information for Patients

4.3.3   The Committee heard evidence from the West Midlands Library Service Development Units Development Unit who have developed the Electronic Quality Information for Patients (EQUIP) site (http://www.equip.nhs.uk/).

4.3.4   EQUIP consolidates health care information that relates to conditions into a gateway for both healthcare professionals and patients. The Library Service assesses each site in order to ascertain its appropriateness and quality.

4.3.5   EQUIP was created in response to national requirements for improvements in information available to patients. The project was funded through the Public Health Development Fund. Each site contained within it is regularly assessed to ensure its continued relevance and is developed using patient input. The site is a primary resource of the NHS Direct call centre.

4.3.6   The Library Service has involved patient support group members to check that the content and format suits their needs. As well as assessing the information-rich websites, EQUIP lists over 1400 national and local support groups in over sixty topics covering health and social care.

         This resource is intended to be used by primary care workers in order to identify information that relates to specific conditions as well as organisations that might support patients. Although the resource is valuable to professionals in the West Midlands it currently suffers from a lack of promotion. This can be put down to insufficient recurrent funding.

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Birmingham Index of Voluntary Organisations

4.3.7   Throughout the course of our visits to practices, GPs also expressed an interest in obtaining a resource of available support and voluntary groups across the Birmingham area. Such a resource had previously existed in paper form but, due to the ever changing nature of the voluntary sector, quickly became out of date.

4.3.8   In order to address this issue the West Midlands Library Service Development Unit, in conjunction with Eastern Birmingham PCT, have created the Birmingham Index of Voluntary Organisations (BIVO). The index will sit on the Internet (http://www.bivo.nhs.uk) in a similar format to EQUIP and provide details of voluntary organisations that have a broad health remit. This will be subject to yearly, revision by the Library Service to ensure that each group's details are up to date.

4.3.9   In much the same way as EQUIP, such an index can only be utilised if sufficient funding is made available to ensure its continuing promotion to surgeries across Birmingham.

4.3.10   Resources such as EQUIP and BIVO are essential resources for surgeries but their effectiveness is dependant on primary care workers being given sufficient training to be able to use the Internet efficiently as well as the sites being adequately promoted to the intended audience.

5: The Role of Primary Care Trusts

5.1 Evidence from PCTs

5.1.1 As part of the review process the Committee heard evidence from the Directors of Primary Care and their representatives of Eastern Birmingham PCT, Heart of Birmingham Teaching PCT and South Birmingham PCT.

5.1.2 Each PCT acknowledged that the provision of information to patients should be at the core of each consultation and is essential in order to promote better management of a patient's condition. The diverse nature of the population of Birmingham, coupled with issues surrounding varying capacity, has made such provision very difficult to plan.

General Medical Services Contract

5.1.3 Equally they acknowledged that currently there are no "levers" in place to ensure the consistency of information provision across the city. The implementation of the General Medical Services contract (GMS2) should help to provide just such a lever. It should be noted that (as stated in section 1.2.6) the new GP contract does not specifically oblige a GP surgery to provide information to patients but it does instigate a cultural change in the approach to information provision.

5.1.4 The new GP contract (GMS2) concentrates on improving the clinical outcomes of 10 major disease areas. These are:-

- Coronary Heart Disease (CHD)
- Stroke or Transient Ischaemic Attacks
- Hypertension
- Diabetes
- Chronic Obstructive Pulmonary Disease (COPD)
- Epilepsy
- Cancer
- Mental Health
- Hypothyroidism
- Asthma

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5.1.5   The Committee and the Primary Care Trusts felt that it is important that common information should be available for each of these key disease areas. At present there is no organised system for producing or collating such information.

5.1.6   Each PCT is required to produce a directory of services which is then made available to the public. The directory lists health providers in a given locality along with contact details.

5.1.7   With the implementation of GMS2, GPs will have the option to opt out of providing certain services. For example a GP could choose to no longer provide out of hours services or minor surgery. This does not relate to the provision of information within a consultation but does have an impact on the type of services that a patient might expect from their surgery. As services across Birmingham change, this information needs to be made publicly available.

5.1.8   In a development separate to GMS2, new contracts between the PCTs and the practices require that there is a certain level of IT literacy. This will enable primary care workers to be able to develop such systems as EMIS as well as providing a greater degree of confidence when utilising services such as EQUIP and BIVO. A failure to comply with the contract for each practice could result in the PCT cancelling the practice's licence. IT training is being actively promoted by each of the Primary Care Trusts.

5.1.9   In addition to GMS2 there are a number of other drivers for promoting better provision of information to patients. These are:-

- Patient Choice

- Clinical Governance

- Expert Patient Programmes

Patient Choice

5.1.10 The Government's intention to provide patients with a choice of acute providers for surgery will inherently mean that patients must be better informed about their conditions. Patients will need to have a very good understanding of their diagnosed condition as well as the implications of future interventions in order to be able to make an informed decision about where they would like receive services. This information will need to be provided as part of the consultation process and must be based on consistent information. In order to ensure that this process succeeds it is important that each PCT provides information to each surgery that is consistent and easily absorbed by patients.

5.1.11   Patient information also has an impact on the way that Primary Care Trusts implement structures of clinical governance. Clinical governance can be defined as :-

> *"a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish[3]"*

Primary Care Trusts attempting to monitor standards of clinical governance must ensure that patients do not just passively receive services but are involved in the decision making process while also understanding the interventions they receive and the reasons behind them. Improvements to services will only be capable of measurement if patients can be asked about their experience of services and how these have altered.

Expert Patient Programme

5.1.12   Expert Patient Programmes are currently being implemented across Birmingham by each of the Primary Care Trusts. Such programmes were originally planned by the Department of Health as a part of the 1999 Health Strategy White Paper "Saving Lives - Our Healthier Nation". A task force was set up in 1999 to look at how Expert Patient Programmes should be implemented and its report, "The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century", set out key recommendations for creating self - management training programmes for patients.

5.1.13   The programmes are based on the assumption that it is those patients living with a chronic or disabling illness that are best placed to make recommendations on ways of managing a condition. Each patient that passes through the programme is given tools to enable them to deal with issues such as pain management, stress, self-image and coping skills.

5.1.14   The Expert Patient Programmes not only give individual patients more information to manage their conditions, they also enable practices to refer "experts" to other patients who have recently been diagnosed with a similar condition. This can then create a valuable support network.

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[3] Primary Care Pharmacy, March 2000 Vol. 1 No 2 p50-51

5.1.15   Each of the Primary Care Trusts agreed that in order to meet commitments for the implementation of GMS2 and Patient Choice, as well as developing structures of Clinical Governance, there is a greater need for working closer together in order to ensure that information provided to patients is consistent and of adequate quality.

5.1.16   The Primary Care Trusts also acknowledged that the current "seven minute" consultation limit does not facilitate effective information provision. It was suggested that the average consultation should be extended to ten minutes, though a strategy would be required to implement this in busy practices.

5.2   The Health Promotion Unit

5.2.1   The Birmingham Health Promotion Unit is a resource funded by Heart of Birmingham Teaching PCT and South Birmingham PCT with a funding contribution from Eastern Birmingham PCT. Its role is to co-ordinate information provided by the Department of Health and disseminate it to health professionals as required.

5.2.2   The Committee heard evidence from the unit that set out some of the hurdles that it currently experiences in obtaining and circulating information.

5.2.3   The unit holds extensive information leaflets on a wide variety of conditions, but stocks are based primarily on what is available from the Department of Health. The major problem that this creates is that bulletins from the Department advise when a current leaflet will be going out of print but do not state if a replacement will be available. The unit must then take a decision whether to order a large number and store them, or wait and see if a replacement is sent at a later date. This also means that health professionals who get used to using one information leaflet must go through a process of assessment to ensure that the new information resource is of a similar quality.

5.2.4   The unit also has extensive "in-house" expertise in the design and production of information materials. This resource is available to professionals within the funding PCT areas but is limited by the internal capacity of the unit. At present the unit can help with the development of literature but does not have sufficient funding to produce useful quantities of materials.

5.2.5   The Health Promotion Unit is a valuable resource to the health economies of Birmingham, but requires a coherent strategy that will secure its long term funding, as well as clarifying how the funding Primary Care Trusts perceive its continued role.

6:   Patient and Public Perception

6.1   Patient Groups

6.1.1   The Committee heard extensive evidence from Diabetes UK, which is the largest organisation providing information and support to people with the condition. Diabetes is the subject of its own National Service Framework, as well as being one of the major disease areas identified by GMS2.

6.1.2   As diabetes is a chronic and potentially disabling condition, it is one that must be supported with extensive information after diagnosis. This is all the more important due to the importance of a good diet in managing the condition and the lack of available dieticians.

6.1.3   Diabetes UK was of the view that it is better for the diagnosis to be communicated when sufficient supporting information is available. If good quality information is provided to a patient at an early stage then the condition can be better managed by patients themselves.

6.1.4   At present Diabetes UK carries out a yearly campaign, within GP surgeries, to alert people to the symptoms of diabetes. This takes the form of leaflets that are available to be taken away as well as a number of posters in five Asian languages. In addition a video/DVD has been produced that provides simple tools for managing the condition in a variety of languages. The video/DVD is made available to surgeries and can be played in the waiting room.

6.1.5   Diabetes UK has created a comprehensive information pack that should be provided to all patients upon diagnosis. The pack sets out levels of care that should be expected, advice on diet, retinopathy, foot care and hypoglycaemia. The pack costs £5 per unit which must be covered by the Primary Care Trusts themselves.

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6.2   The Public

6.2.1   In order to understand better patients' perception of information provision the committee invited submissions from members of the public. The submissions were sought in conjunction with the Citizens Advice Bureau's Primary Care workers and surgeries across Birmingham.

6.2.2   Thirteen members of the public submitted views on the availability of information in GPs surgeries. Of these, three stated that they were provided with information relating to their condition, as part of the consultation.   Ten said they were not provided with any information at all.

6.2.3   Of the three that were provided with information, two were happy with its quality. The third patient did not find the information useful.

6.2.4   The information was provided in leaflet form to two members of the public and as a print out to the third. This indicates that the information provision within surgery IT systems is not currently being used to its full potential.

6.2.5   The ten patients that received no information relating to their condition were also not informed of other sources where information could be obtained. In addition, only two of the remaining ten were informed of support groups that could provide a better understanding of their conditions.

6.2.6   One member of the public stated "All information relating to my condition was provided from the hospital not my GP." This could indicate that there was a gap between the original diagnosis and any further information being provided. Such a delay in providing information can cause undue stress on a patient and does not help them to begin immediate management of their condition.

6.2.7   It is clear that on a day to day basis, provision of information is not seen as a priority within GP surgeries.

7:   Findings & Recommendations

As a result of its investigations, the Committee's main findings and conclusions are that

1. *There is a need for Primary Care Trusts to have standard information resources that can be provided to patients. To achieve this an information strategy needs to be created ensuring a consistent approach across all of the PCTs. Furthemore, this strategy should encourage greater use of IT by Primary Care Workers in systematically providing information to patients. The Health Promotion Unit needs to be placed at the heart of any Information Strategy for Birmingham.*

2. *The Primary Care Trusts need to co-ordinate and 'quality assure' the production of templates for each of the ten major disease areas identified by GMS2 so that these can be adapted for use by GPs and primary care workers.*

3. *The PCTs need to develop directories of services identifying the range of statutory and voluntary services in each include web resources such as EQUIP and BIVO.*

4. *Although not the primary purpose of EMIS, the capability to identify leaflets to provide information on certain conditions during the consultation is potentially a great benefit in identifying information for patients. Standard information resources created by the Primary Care Trusts must be integrated into IT systems to ensure they are available to all patients who are diagnosed.*

5. *When recommending new IT systems to practices PCTs should ensure that the systems are capable of storing and providing information leaflets.*

Information in GPs' Surgeries

R1	The PCTs in Birmingham develop a strategy for all practices in their area, to improve provision of information to patients and promote health literacy. The strategy should encourage a more systematic use of IT for accessing patient information by GPs and primary care workers.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	May 2005
R2	The PCTs create a basic template of culturally appropriate, quality assured information on each of the ten major disease areas identified by GMS2, for use and adaptation as necessary by primary care professionals.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	May 2005
R3	The PCTs develop and actively promote a directory of statutory and voluntary services for the communities they serve with the aim that these services become more accessible, connected and integrated to patient care.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	September 2005
R4	The PCTs liaise with the Department of Health in requiring that IT suppliers should work to a common specification for IT systems which more easily produce patient information as a routine part of chronic disease management.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	September 2005
R5	Progress towards achievement of these recommendations should be reported to the Health Overview and Scrutiny Committee on a six-monthly basis until completed. The first report should be made November 2004.	Chief Executives of Primary Care for North Birmingham PCT, South Birmingham PCT, Eastern Birmingham PCT and Heart of Birmingham Teaching PCT.	November 2004

Appendix 1: Terms of Reference

A1.1 Terms of Reference

Scrutiny Review: Information Provided to NHS Patients at Doctors' Surgeries

Terms of Reference

Key Objectives

To obtain patients' and carers' views on the extent to which information about chronic health conditions, health education, medication and other community services is available at doctors' surgeries.

To identify variations in current practice and reasons for observed differences.

To recommend what steps if any need to be taken to ensure that patients' and carers' needs for information are met.

A	Subject of review	Information provided to NHS patients at doctors' surgeries
B	Overview and Scrutiny Committee	Health Overview & Scrutiny Committee
C	Reason for review	People with chronic and disabling conditions need information about their medication, about the range of support groups that are locally available, written advice on how to stay healthy and advice on self-care Access to this type of information appears to vary considerably between GP practices
D	Objectives of review, including outcomes	• To obtain patients' and carers' views on the extent to which information is made available to them at doctors' surgeries (specific conditions e.g. diabetes, stroke, eczema) • To identify variations in current practice and the reasons for observed differences • To recommend what steps if any need to be taken to ensure that all Patients have access to information which meets their particular needs
E	Lead Member(s)	Councillors Bryan Nott (Chair), Chaman Lal, Susan Axford and Ansar Ali Khan

Information in GPs' Surgeries

F	Lead Review Officer	Jacky Chambers with support from the Scrutiny Office (Darren Wright and Narinder Saggu)
G	Relevant Executive Member / Decision Maker	● Councillor Susanna McCorry, Cabinet Member for Social Care and Health (for information) ● Chief Executives of PCTs ● Chief Executives of NHS Trusts
H	Council departments expected to contribute	● Social Services ● LILA Team
I	External organisations expected to contribute	• PCTs • GPs • GP Walk in Centres • CHCs • Birmingham Association of Neighbourhood Forums
J	Anticipated date of report to Overview and Scrutiny Committee	Dec 2003 /January 2004
K	Estimated Number of Working Days to Conduct Review	
	Per Member	3 days for Members
	Officers	7 days of officer time
L	Anticipated call on Scrutiny Budget	None anticipated

Appendix 2: Schedule of GP Visits

A1.2   Dates and Location of Visits

Date	Location	GP
14/10/03	Wand Medical Centre	Dr Wilson
5/11/03	Wand Medical Centre	Dr Wilson
9/12/03	Jiggins Lane Surgery	Dr Cherry
17/12/03	Rotton Park Road	Dr Frempong

Appendix 3: Patient Information Websites Linked to EMIS

Patient UK: **www.patient.co.uk** (available to patients and clinicians online)

- The Patient UK website is a definitive source of health care information for patients, used by both the general public and clinicians.

- Information is reliable, impartial, written and reviewed by independent GPs and it's free to access. Users don't even need to register.

- The site contains the same Patient Information Leaflets (PILS) that are in the EMIS clinical system and knowledge base: Mentor Library and the National NHS PRODIGY project. This is the only website offering PILS, ensuring that patients receive health care information that is consistent with the information sheets they can receive from their GP.

- The website and its contents are written in a clear, concise way, making often difficult medical topics easy to understand*.

- GPs can direct patients to Patient UK instead of printing PILS leaflets during the consultation.

- Patient UK has been independently accredited to comply with NHS requirements and is now a CHIQ (the Centre for Health Information Quality) partner.

- Patient UK posters are available to display in waiting rooms/consulting rooms. These can be requested free of charge by contacting **marketing@e-mis.com**.

*Readability is aimed at age 12 and is assessed by software developed by the University of Newcastle upon Tyne.

PILS (available to patients and clinicians online at **www.patient.co.uk** and clinicians within Mentor Library)

- PILS (Patient Information Leaflets) are written by a Doctor and critically read by two medically qualified and two lay people. The author reviews each leaflet at least every two years.

- There are over **600** leaflets about symptoms and diseases, background detail and explanatory diagrams and details, and links to nearly 2,000 UK patient support organisations/self help groups.

- Some PILS leaflets are translated into a number of languages such as Bengali, Chinese and Urdu. The set that have been translated so far have been identified as being particularly relevant/and required by members of minority communities living in the UK.

- The intention is to translate all the summary leaflets into the languages identified so far and further languages. The main target audience are asylum seekers/refugees and other immigrants recently arrived in the UK, i.e. Kurdish, Somali and French as an alternative for immigrants from Africa.

- PILS are sub-licensed to the NHS PRODIGY Project.

- These leaflets are currently only available as text, but we are working towards audio versions.

Mentor Library   (available to clinicians within the EMIS clinical system)

Mentor Library is an electronic knowledge support system that contains evidence-based information for enhanced medical decision-making. It will underpin accurate diagnosis and provide comprehensive immediate reference on disease recognition and management.

Mentor Library has two main benefits for clinicians:

- It is an immediate reference guide, providing peer-reviewed, automatically updated reference material

- Information is easy and fast to access and can be used for reference during consultations

- It can be used for research or personal development. A PDP is included, in which GPs can maintain their own learning report

- Content is continually updated so Doctors can be sure that they are always reading the most up to date information

- It can assist clinicians in formulating differential diagnoses

- Mentor Library can suggest an accurate ranked list of diseases explaining a patient's symptoms, taking multiple pathologies into account

- The comprehensive 'concept search' facility enables a clinician to search on single or multiple symptoms, generating a list of potential diseases but does not indicate inappropriate diseases

- It does not make diagnoses on behalf of the clinician, but gathers as much information as possible to allow the GP to interpret the findings

Information in GPs' Surgeries

- Mentor Library is an ever-expanding library of information. It includes concise medical articles giving key points about diagnosis and management of diseases, PILS, Concise Oxford Textbook of Medicine (COTM) with in-line graphics and PRODIGY guidance in reference form, plus many other useful reference tools

- Mentor Library is written and reviewed by experienced front line clinicians and used throughout primary care. Mentor Library has been an integral part of the EMIS clinical system for a number of years

Information in GP's Surgeries