Shared Care
The Future Imperative?

by Peter Pritchard and Jane Hughes

The Nuffield Provincial Hospitals Trust
Royal Society of Medicine Press

Shared Care
The Future Imperative?

Peter Pritchard and Jane Hughes

The ROYAL
SOCIETY of
MEDICINE
PRESS Limited

Published by the
Royal Society of Medicine Press
1 Wimpole Street, London W1M 8AE

ISBN 1-85315-259-5

59 New Cavendish Street, London W1M 7RD

Phototypeset by Dobbie Typesetting Limited,
Tavistock, Devon and printed in Great Britain
by Biddles Ltd, Guildford, Surrey

ABOUT THE AUTHORS

◆

Peter Pritchard is a former general practitioner with a specific interest in management development in primary care. He was the author of: *Manual of Primary Health Care* 1978, 2nd edition 1981; (jointly) of *Management in General Practice* 1984; and (jointly) of *Teamwork for Primary and Shared Care: a practical workbook,* 2nd edition 1994, (all Oxford University Press); also numerous reports and articles on patient participation (of which he was an early pioneer) and on the application of information technology to primary care, especially knowledge-based decision support systems.

He has been a part-time tutor on management courses for general practitioners at the King's Fund College, and is currently senior medical adviser to the Advanced Computation Laboratory, Imperial Cancer Research Fund. He is founder and honorary secretary of the UK–Nordic Medical Educational Trust, a registered charity.

Jane Hughes is an independent researcher and writer with a special interest in primary health care. She has a Master's degree in medical sociology from the University of London and has worked in health services research and development for twenty years. She has also been a member of a Community Health Council and for some years was part of a small group producing the journal *Critical Public Health.*

From 1981–1988, Jane Hughes was co-ordinator of the London Programme at the King's Fund Centre, managing demonstration projects on inner city health care and disseminating the results. More recently she has written and edited a number of reports for the King's Fund on topics such as the future of the community health services, medical audit and primary health care in London. Publications include *An optimal balance? Primary health care and acute hospital services in London* (with Pat Gordon), and *Audit and development in primary health care* (with Charlotte Humphrey).

FOREWORD

◆

In today's complex and changing health care, the patient's needs cannot all be met by one professional acting in isolation. The patient must have the opportunity to move around, with care and responsibility shared within teams and across organizational boundaries. Teamwork will often suffice, but when more specialized skills are needed—whether in hospital or at home—then shared care is an option.

In the past, there was a tendency for the hospital to take over care of all patients with, for example, diabetes. Now the reverse trend is in evidence, towards primary care and care in the community. These shifts in the boundaries of care require a shift in knowledge, skills and resources if quality of care is to be improved.

This book, probably the first monograph of its kind, looks at the organizational context of shared care and the issues of boundary management. Concepts of knowledge and time in relation to shared care are explored. The second section consists of a selective review of the literature of shared care with a critical commentary on lessons to be drawn. But how can we put these lessons into practice, with the aim of effective shared care with the patient playing an active part? Some innovative ways forward are described in the third section, with emphasis on teamwork, a shared understanding, and making use of guidelines where appropriate. New technology for communication such as the video consultation, and decision support are regarded as promising. Developing a learning organization and auditing the interface are not forgotten.

Shared care is seen as difficult, and patchy in its effectiveness, yet having an essential part to play. How do we get the balance right? This book is to be welcomed as a challenge to new thinking about today's and tomorrow's health services, very much in the Nuffield Trust tradition.

Barbara Stocking

PREFACE

Shared care, and the changing boundaries between primary, hospital and community care, are prominent topics for debate and have prompted many initiatives. Shared care schemes for certain chronic diseases have an extensive literature, but little has been written about shared care in general. Following a discussion with Dr Michael Ashley-Miller in January 1994, this book was planned at his suggestion.

The aim is for it to fill a gap, by looking at the ways in which shared care is organized and how it functions, by a critical review of selected literature, and by setting out some steps that might lead to effective shared care.

The target readership includes all professionals working in shared care, and also policy makers and service managers, as well as researchers and students of this field.

Peter Pritchard and Jane Hughes
April 1995

ACKNOWLEDGEMENTS

The authors are grateful to many colleagues who have freely shared their ideas, including Richard Baker, Michael Bull, Martin Eccles, Tyrrell Evans, John Fox, Maria Ginzler, Colin Gordon, Jeremy Grimshaw, Linda Marks, James Pritchard, Wendy Pritchard, Jill Russell, David St George and Nicki Spiegal. Alison Langton has allowed reproduction of copyright material and Barbara Stocking has kindly written the foreword. Lisbet Clements processed the text.

Many librarians have been generous with their time and skills, including the staff at the BMA and King's Fund Centre (particularly Valerie Wildridge), Margaret Hammond at the Royal College of General Practitioners, Kate Macpherson at the Cairns Library, Oxford, Enid Leonard at the Anglia and Oxford RHA, and David Perrow and Lynn Winkworth at Templeton College, Oxford.

The authors are particularly grateful to Dr Michael Ashley-Miller, Secretary of the Nuffield Trust for suggesting this monograph, and to Max Lehmann and Patricia McKellar for their help and support.

ABBREVIATIONS

◆

A & E	Accident and Emergency Service
BTS	British Thoracic Society
CHD	Coronary Heart Disease
CPCDP	Camberwell Primary Care Development Project
DETU	Diabetes Education and Training Unit
DHA	District Health Authority
DoH	Department of Health
ENB	English National Board for Nursing, Midwifery and Health Visiting
EPICS	Elderly people's integrated care system
FHSA	Family Health Services Authority
GMSC	General Medical Services Committee
GP	General practitioner
GRASSIC	Grampian Asthma Study of Integrated Care
GREAT	Grampian Region early antistreplase trial
HA	Health Authority
HMSO	Her Majesty's Stationery Office
MIT	Massachusetts Institute of Technology
MSAC	Maternity Services Advisory Committee
NAHAT	National Association of Health Authorities and Trusts
NHSME	National Health Service Management Executive (now NHS Executive)
OA	Organizational audit (**KFOA**= King's Fund OA)
QED	Quick and early diagnosis
OHE	Office of Health Economics
PHC	Primary health care
PHCT	Primary health care team
RCGP	Royal College of General Practitioners
RCP	Royal College of Physicians of London
SHHD	Scottish Home and Health Department of the Scottish Office

SHSPC	Scottish Health Services Planning Council
TQM	Total quality management
UKCC	United Kingdom Central Council for Nursing, Midwifery and Health Visiting
WHO	World Health Organization

INTRODUCTION
The scope and context of shared care

Shared care involves people in different organizations—usually primary and hospital care—sharing the responsibility for the care of a patient. The boundaries between organizations are changing and major shifts are taking place in the style and location of health care. Examples are day surgery, minimally-invasive surgery, shorter hospital stay, less reliance on in-patient care, closure of beds, and (in the UK) general practice fundholding (Stocking 1992). This is set against a background of increasing demand, an ageing population, developing technology and the need for cost containment.

These changes are likely to increase the need for, as well as the complexity of shared care. Complementary or alternative options to shared care are self-care, lay care, individual professional care, alternative therapies, transferred care, or care solely within one provider team. The ultimate (but probably unattainable) goal is integrated care, where each patient's varied needs in all sectors are met, whatever the obstacles.

While specialists become ever more expert and specialized, operating in narrower domains of knowledge and technology; general practitioners try to retain generic knowledge and skills, at the same time taking on a wider role including health promotion, anticipatory care and management. Unless this shift of patient care towards primary and community care is accompanied by a corresponding shift of knowledge, skills, technology and resources, there will be an inevitable fall in quality and effectiveness. The shift of knowledge and skills will have a better chance of success with shared rather than transferred care. Three-way knowledge flow across the boundaries between patient, general practitioner and specialist is part of the lifelong learning process.

Specialists will not be marginalized by a shift towards primary care: quite the reverse. Their role in patient care will increase, but when the patient is remote from the specialist unit, ways of providing care may alter. Territories will become less exclusive and boundaries less firmly drawn. Shared care is a dynamic and changing process of great complexity. Will it settle into a stable pattern of care, or will it be more of a stepping stone towards greater competence and autonomy for primary care?

Knowledge transfer is not straightforward, but it has been illuminated by recent studies based in Sweden on the 'three kinds of knowledge'. Propositional knowledge is explicit, and can be transferred in writing. Practical knowledge and knowledge of familiarity are implicit and are employed in daily professional practice. Awareness of the limitations of these categories when used alone, and the need for an integration of the three kinds of knowledge, are important for shared care as well as for computerization.

Referral to hospital is dogged by delays in the National Health Service. For shared care to be effective, a quick response time is essential. Delay is hard to justify when the diagnosis is in doubt, or biological processes are at work that are logarithmic. Linear clock and calendar time can distract us from the way time operates and is perceived in daily life. Computers reinforce the process.

Shared care schemes have been in place in certain domains for many decades, but the obstacles to effectiveness—both organizational and attitudinal—have been considerable. These schemes have often been promoted as a means of integrating primary and secondary services, particularly for chronic diseases like diabetes. They have also been seen as a way of shifting care to general practice, and reducing the burden on hospital services—usually outpatient clinics. Some general practitioners are keen to reclaim, and play a greater part in, the care of chronic illness. Others are less keen, and consider that this is using them as junior doctors. In some domains, nurses and midwives have been eager to shoulder more responsibilities and expand their roles in planning and providing systematic patient care.

Few papers have been published on the general principles and practice of shared care that could be applied more widely. This book attempts to fill this gap. Shared care schemes in certain clinical domains have an extensive literature: in others it is scanty. The second section of this book contains a review of selected literature and a commentary. This review is grouped as follows:

(i) shared care for chronic illnesses (e.g. diabetes, asthma and hypertension).
(ii) shared maternity care
(iii) shared care in investigation and diagnosis (e.g. endoscopy and cardiac investigations)
(iv) acute or emergency shared care (e.g. thrombolytic therapy)
(v) rehabilitation and community care (e.g. stroke)
(vi) terminal illness and palliative care (e.g. cancer)
(vii) health promotion (e.g. prevention of cardiovascular disease).

Shared care of chronic illness may involve a substantial transfer of knowledge, skills and technology from secondary to primary care. Some schemes have a strong hospital focus and have used computer systems to organize and structure shared care. Other approaches emphasize working at the 'grass roots' with GPs and practice teams, often using facilitators with educational and organizational skills to help introduce changes. Successful schemes for shared care of chronic illness typically have an explicit strategy that offers a framework for establishing structured care, but which also allows sufficient flexibility for practices to devise their own ways of providing effective care, and to progress at their own pace.

Shared maternity care is in a state of upheaval and uncertainty, with moves towards community-based and midwife-led care which need evaluation. Opening up direct access by GPs to specialist services has been successful when schemes resulted from careful planning and the encouragement of links between primary and secondary care. Acute shared care schemes are novel, and in the example chosen, require close collaboration between cardiologists, GPs and ambulance services, which has to be built up.

Care of stroke patients and palliative care are examples of the need to coordinate community-based services to an extent that has seldom occurred to date. This is a priority area in view of the common occurrence of stroke and cancer, and the resources required for these patients. Care in the community is likely to assume increasing importance in the future, but the obstacles to shared care are even greater than between primary and hospital care.

In the case of health promotion, one of the barriers has been the need to need to make a cultural shift away from traditional medical thinking, towards applying social models of health, including health beliefs and participation. This issue is of particular relevance today, as is the role of the patient as an active participant in patient-centred shared care.

In describing the potential strengths and pitfalls of shared care and shared care schemes, the aim is to help health care teams to develop *effective* shared care. We still have a long way to go before we can say with confidence when shared care is appropriate and effective. Competent practice must be developed and evaluated, applying existing knowledge and experience in a learning setting. This book might be seen as a primitive map to point us towards effective care, rather than a prescription. Even maps show many alternative pathways and leave many questions unanswered.

Seven steps to shared care are described in section III, the first being effective teamwork. Shared care is distinct from teamwork, but builds on it as a firm foundation. Primary care and specialist teams need to be equally competent and effective if they are to keep in tune. Teamwork skills can be learned.

The next step is to reach a shared understanding across the divide of culture, structure and knowledge, and develop shared goals. One way of achieving a shared understanding is by conceptual modelling. The traditional model of continuing medical education has been shown to be less effective in bringing about a shared understanding and changing behaviour.

Developing agreed guidelines is the next step. Guidelines require a solid base of knowledge and evidence, not just a coding of current practice. They must be adapted to local circumstances and flexible enough to include patient preferences. A very large number will be needed to cover a broad spectrum of practice.

Shared care requires an exchange of information that is more sophisticated than the traditional referral letter and reply. Information technology can help, and the model preferred by Hickman *et al.* (1994) in their important report is 'computer-assisted shared care'. Video consultation is an emerging option that has great promise to make referral more immediate and flexible, and represents a powerful educational tool. Technology is a strong stimulus to learning, but for it to take root the *milieu* must be right—namely individuals in 'a learning mode', working in a learning organization.

Conventional computer technology can help in a number of ways, of which the most basic is the electronic patient record—preferably compatible across the boundary between general practice and hospital. The next step is the 'knowledge-based' decision support system. This will enhance the supply of relevant knowledge, available at the right moment and in the right form. Guidelines can work much more smoothly in a knowledge-based system, and be addressed before the decision is made, thus opening the way for 'concurrent audit'. Retrospective audit is also made easier and more powerful, in that the guidelines themselves (and the decision processes) can be tested against patient outcomes and refined for future use. The electronic patient record, in a knowledge-based system, can make the guidelines patient-specific, and take account of knowledge already in the system.

Technology should not distract us from the central role of the patient in shared care. Only patients have direct experience of both sides of the boundary, so who better to audit the processes of shared care? Yet they have been underused as a resource for helping to design, operate and audit shared care.

The authors' views on shared care are that it is not as widespread or effective as it might be, yet it is an increasingly important way forward for applying coordinated specialist and generalist skills to the care of patients outside hospital. Shared care is also a valuable mechanism for three-way knowledge transfer. Achieving the full potential of shared care, with innovative methods and adequate technological support, is seen as a high priority for today's health care services.

Authors' footnote:

Shared care is a diffuse subject with many ways of looking at its varied facets. This does not lend itself to a neat analysis and classification. The authors ask for the reader's indulgence for topics cropping up in several places, and for some repetition.

CONTENTS

SECTION I The nature of shared care

SECTION II Shared care schemes in action. A literature review and commentary

SECTION III Developing shared care—making it work

SECTION I
The nature of shared care

Chapter 1
WHAT IS SHARED CARE?

◆

This chapter explores definitions of shared care and suggests a working definition which distinguishes it from team care and transferred care.

Health care starts when an individual with a health concern makes contact with a health service provider (Pendleton *et al.* 1984). Some might argue that it starts earlier when the concerned individual seeks lay advice beforehand. The first contact with formally-organized primary health care is likely to be with the receptionist, and then the general practitioner or practice nurse. This could open up contacts with a number of health professionals comprising the primary health care team (Hasler 1994, Marsh 1991, Pritchard 1981). Models of team work are well established, as are training programmes for team development (Rubin *et al.* 1975, Pritchard & Pritchard 1994).

A team can be defined as *'a group of people who make different contributions towards the achievement of a common goal'*, so in this broad sense, shared care can be equated with teamwork. However, if we qualify teamwork further, then distinctions appear. Teamwork has certain essential characteristics which Gilmore *et al.* (1974) have described as follows:

1. The members of a team share a common purpose which binds them together and guides their actions.
2. Each member of the team has a clear understanding of his or her own functions, and recognizes common interests.

3. The team works by pooling knowledge, skills and resources and all members share responsibility for outcome.
4. The effectiveness of a team is related to its capability to carry out its work and to manage itself as an independent group of people.

In the shared care of diabetes, for example, primary care and specialist teams might find it hard to meet the first three criteria explicitly. The fourth criterion is the final stumbling block to equating teamwork with shared care. Whereas an effective primary health care team can act as an independent and autonomous work group, this would not be possible for shared care, where the two organizations are separate, and too large to function as a joint team. However, teamwork is an essential ingredient of effective shared care, and is a good starting point, and this will be considered in Chapter 14.

Shared care is complex for a number of reasons, one of which is the weight of numbers. For teams to work effectively, they have to be small (say 10) and preferably work under the same roof. General practitioners and specialists rarely work under the same roof[1], and the numbers involved can be large. For example in a health district with a population of 250,000 served by a single district general hospital, there are likely to be at least 20 specialist teams interested in shared care (out of a total of 56 recognized specialist categories). About 125 general practitioners arranged in 30 practice teams would serve the population. The number of links between teams would be around 600. The number of individuals involved could be over 500. The conclusion is clear. Cooperation as a team, with shared vision, goals and procedures, would be hard to achieve—there would be no time left to do the job. But merging the two organizations into a single team would be unattainable. We will, therefore, be looking for other ways of working together towards a common goal. Short cuts and effective systems of cooperation and communication are needed, which will be considered in Section III.

---

[1] Exceptions to this statement can be highly productive of shared care, such as specialist doctors and nurses doing 'outreach' clinics in health centres, general practitioners acting as clinical assistants in hospital, and shared use of obstetric units.

When a patient's needs cannot be met within the primary health care team, then referral to specialist care is an option. In this case, the referring general practitioner may hand over responsibility for care to the specialist or specialist team (*transferred care*), or responsibility may be shared between the professional or teams involved. The latter alternative leads to the following definition of shared care:

> **Shared care applies when the responsibility for the health care of the patient is shared between individuals or teams who are part of separate organizations.**

This definition distinguishes shared care from *transferred care* and *teamwork*, where people work closely together with common goals and tasks. Shared care is much more complex, in organizational terms, than transferred care and teamwork. It can focus on a single patient with unique needs for shared care, or it could apply to a whole group such as patients with diabetes. In this case a *shared care scheme* may be the answer. Such schemes may be specific to the care group (or domain), but certain features and patterns are likely to be in common, so that implementation of such schemes may become less of a burden. Shared care may be long-term in the case of a chronic illness, or short-term for a critical incident.

The proposed working definition of shared care focuses on professional responsibility and organizational setting. It distinguishes between teamwork and shared care. However, it is affected by how we define an organization. Is the unit of organization in a hospital the clinical team or the whole hospital? For example, care shared between a surgical team and an oncology team, even in the same building, may work better when treated as shared care. Physical and organizational boundaries, as well as the numbers involved may make teamwork difficult to operate. To cover this, a rider could be added to the definition:

> *Shared care applies when the responsibility for the health care of the patient is shared between individuals or teams who are part of separate organizations,* ***or where substantial organizational boundaries exist.***

This definition covers shared care with community health staff and social services. It could also include shared care with alternative practitioners, provided that they could be seen as an 'organization' and there were no insuperable barriers to sharing responsibility.

Hickman *et al.* (1992 and 1994) prefer a narrower definition of shared care for the purposes of their research, namely:

> *Shared care is joint participation of general practitioners and hospital consultants in the planned delivery of care for patients with a chronic condition, informed by an enhanced information exchange, over and above routine discharge and referral letters.*

This definition stresses the planned and participative nature of shared care, which will be addressed later. By limiting it to chronic conditions, they are including most examples of shared care *schemes*, rather than shared care in general, which could include *acute* shared care schemes, for example for myocardial infarction. Their definition is entirely justified in the circumstances in which it was used, but the omission of nurses as major participants in shared care was unfortunate. The question of enhanced information exchange and classifying ways of communicating information is discussed later.

The changing nature of clinical responsibility

Responsibility is not engraved in stone. Clinicians tend to think of responsibility as between individual doctor and patient, and find it hard to come to terms with the more diffuse responsibility of the team. Responsibility shared across organizational boundaries is even more difficult to accept, because of the more tenuous lines of communication and control. This makes it harder for doctors to give an opinion without seeing and examining the patient. As a consequence, some doctors are reluctant to give an opinion on the telephone. This may lead to the patient being moved bodily, when there might be alternatives. Examples are the everyday practice of radio advice in remote areas, such as the Australian outback, circumpolar regions and ships at sea. New technological initiatives such as video consultation, discussed later, may allow a reappraisal of how the patient's interests are best served.

Size and boundaries are important factors

Boundaries between organizations and institutions, and even between departments in the same institution, can be a serious obstacle to effective shared care, both in terms of the management and communication processes and in negative attitudes. Teamwork, with a desirable team size of around 10 or less (Belbin 1981, Pritchard and Pritchard 1994), would be out of reach, and other means of cooperation would have to be sought. Not only is there the question of numbers, there is the difficulty of sharing goals and understanding each other's role, across organizational boundaries. Even when care is shared between organizations like primary and secondary care, with known structures and much common culture and training, the difficulties are formidable. Knowledge of, and familiarity with, each other's working arrangements cannot be taken for granted, particularly in conurbations where general practitioners may relate to several large hospitals and to many providers of community services (Hughes and Gordon 1992).

Shared care is a complex field and a precise definition may help to clarify our thinking, but it should not blind us to the many factors at work in addition to responsibility and organizational boundaries. For example, Nkobi *et al.* (1993) and Zimpelmann *et al.* (1994) described shared care as:

> *Continued and coordinated activities from different persons, in different institutions, with the application of different methods, to different periods of time, with the aim of aiding patients in medical, psychological and social aspects as optimally as possible.*

These authors saw it as an alternative to hospital stay, and a synthesis of primary, secondary and home care. This description brought out the continuing and holistic aspects of shared care, centred on the patient.

Patient-centred shared care

In well-established shared care schemes, for example for asthma, diabetes and maternity care, patient responsibility and choice are an important theme. The patient is seen as an active partner in care, not as a passive recipient. Self-management, where feasible, is the aim. In the newly-emerging domains of shared care, such as palliative care, HIV/AIDS and substance abuse, patient autonomy is also a strong feature, with well-informed patients sharing in decision making (Greenwood 1992). Shared care needs to bridge the organizational boundaries between self-care, lay care, professional health care (primary, secondary and tertiary) and social care in the community. People working in these settings need to cooperate, but the one person with direct experience of what happens on both sides of the boundary is, of course, the patient.

When shared care is viewed in terms of the links between institutions, departments, teams and networks involved, the complexity is alarming (see Figure 1).

All networks and 'socio-technical systems' are complex and fluid in their operation and relationships and a simple model will not suffice. This is considered in later chapters.

Crossing the boundaries between organizations is either by self-referral or by professional referral—usually initiated by the general practitioner. This process is not well understood (Coulter 1992, Wilkin 1992, Wallace 1992, Armstrong 1992). Referral may be attributed to the general practitioner's uncertainty about the patient's problem and whether they have the knowledge and ability to deal with it. As well as reducing uncertainty, knowledge transfer is an important element—between specialist, general practitioner and patient and relatives. This is considered in Chapter 4. Referral is considered further in Chapters 2, 3 and 17.

Integrated care

Some reports refer to 'integrated' care (NHS Management Executive 1991). This is a noble aim, recommended by the World Health Organization in the Alma-Ata Declaration (WHO/UNICEF 1978). Integrated care covers coordination between local services, between levels of health and social care, and between the

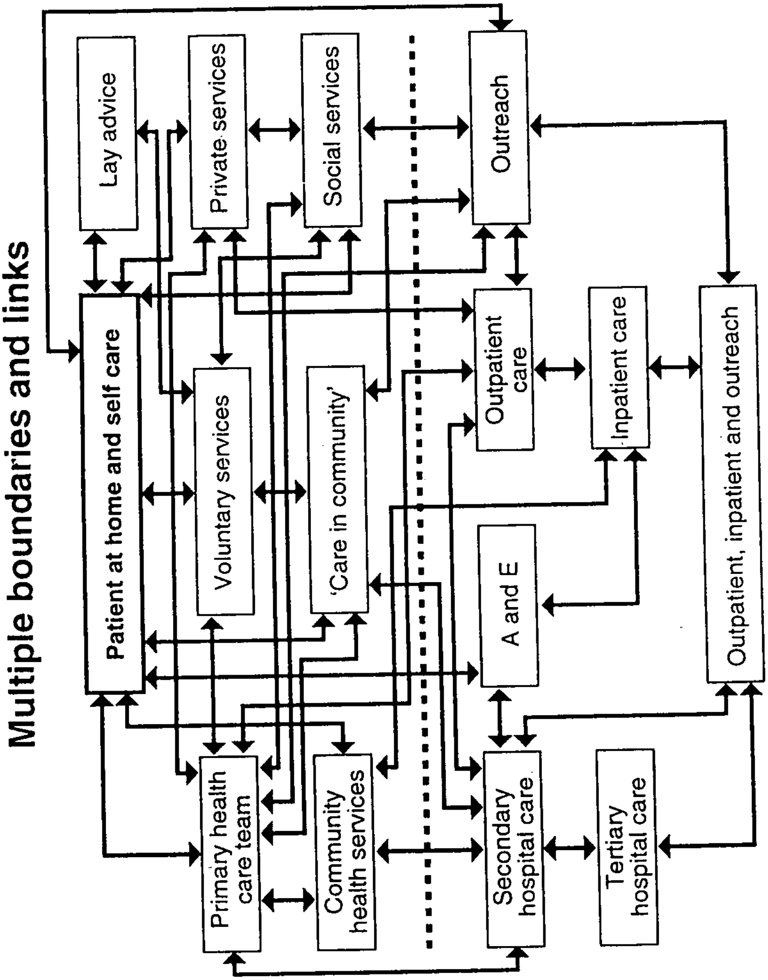

Figure 1. Care needs to cross many boundaries

various 'sectors' such as education, employment, housing etc. Integrated care is the overall goal of health services, but meanwhile we have to surmount the immediate hurdles of effective teamwork and shared care. The term 'seamless care' is even more extreme. It implies an obstacle-free integration across organizational boundaries that is so far from attainment, that it may be misleading. For shared care we need to focus on the boundaries—to highlight the seams—not imagine that they do not exist.

With the aim of increasing our understanding of the nature of shared care, we will attempt, in the next chapter, to tease out some of the elements that make up shared care.

The authors' preferred working definition of shared care is:

Shared care applies when the responsibility for the health care of the patient is shared between individuals or teams who are part of separate organizations, or where substantial organizational boundaries exist.

Chapter 2
FACTORS CONTRIBUTING TO SHARED CARE

◆

In this chapter, a distinction is made between shared care and shared care schemes. The latter are categorized and their varieties and desirable features described.

The context for cooperation with other organizations

Health professionals, committing all their energies to their immediate work, may find it difficult to focus on the world outside their boundaries. Professionals in other organizations face the same issues. Boundaries are difficult to define. Are patients regarded as within the organization, or in the outside world—or both? General practice and specialist teams can be characterized as an organization or 'system' with a poorly defined boundary with the outside world—that is to say an 'open system' (Pritchard *et al.* 1984). Open systems are closely integrated with the world in which they operate. They contain people, working at tasks in a structure, and linked by many processes such as communication, cooperation and decision making. People, tasks and structure are interdependent, so changing one inevitably alters the other, for example appointing new staff affects tasks and organizational structure.

An open system has an input of people with health problems, of information and money; and an output (one hopes) of improved health, and satisfied patients and staff. Input and output are linked by 'feedback' so that the system remains stable in spite of changes in demand, information, cash flow and so on. By understanding and mapping one's own organization in open system terms, it becomes easier to transfer this understanding to outside organizations that are also open systems, and this could make cooperation easier. So the first step in managing the outside world is to understand how one's own organization works and then consider the workings of outside organizations as well. It is tempting just to look after those parts of the organization that are under our control. But we are subject to outside influences, and should be able to exercise some influence when this is thought to be beneficial.

ACTIVE MANAGEMENT OF THE OUTSIDE WORLD

How do we go about 'active management' of the outside world? Is it possible? Or is it an interference in other people's affairs? Assuming that we have goals for our work and for our patients, many of them will involve people outside, and if we cannot influence them our patients will suffer. For example, if a general practitioner wishes to have an elderly person with abdominal pain admitted to hospital, they will have to influence people in other organizations, and bring them round to their way of thinking or seek some compromise. If resources are needed for a new service, people must be persuaded to take action that suits everyone's needs. Even for everyday matters, we need to operate in an organization that fits well into its environment, and is respected and well treated by people in other organizations. This means developing a climate of cooperation and goodwill in which people are keen to help, because we have helped them, or because we can make out a convincing case for cooperation, or both.

Just as we have to understand the workings and complexity of our own organization, so do we have to understand other people's viewpoints and problems. We can only do so if we have some knowledge of their problems and priorities, and how they view us. The more we can know key people personally and appreciate their viewpoint, the easier it becomes to communicate ours. The analogy with empathy in the consultation is apt. If people working in organizations can respond empathically to one another, the whole culture of the organizations can become more cooperative rather than competitive or mutually hostile.

So far the impression might be gained, that if practice and specialist teams and members of other relevant organizations were all one happy family, then plans would go through and everyone's aspirations would be met. Life never was like that, as people's aims inevitably conflict, and some of the opportunities for cooperation (for example with social workers) seem to be diminishing in the UK, in spite of increasing need for such links. Whereas, in the past, planning in a relatively stable environment was possible, now the world outside is so turbulent, that it may be necessary to abandon traditional planning, and just aim to survive until there is a lull in the storm.

COMMUNITY NETWORKS AND AGENCIES

When it comes to sharing care with community networks and agencies, both lay and professional, the complexity increases markedly. For example, Knight and Gann (1988) list over 700 health-related self-help groups. Such, predominantly lay, sources of advice are more likely to reflect the information that patients perceive that they need, rather than complying with doctors' perceptions (Tuckett *et al.* 1985, McIver 1993). This is a rapidly moving field, with an explosion of publications about medicine and health aimed at lay readers, and greater public access to medical databases.

BUILDING AND MAINTAINING NETWORKS

Team members may need to draw up a list or map of all the people and organizations with whom links are needed, and check that these links are regularly reviewed. In this way it may be possible to ensure a shared understanding of what each team is trying to achieve and how they need to work together. How often do people fail to cooperate because their goals are disparate or not articulated clearly, or the other's role or viewpoint is not clearly understood?

COOPERATING WITH SOCIAL SERVICES

Sharing care across boundaries such as those between health care and social services poses special problems. Social workers have different value systems to doctors, and do not subscribe to the disease-oriented 'medical model' of illness (Dalley 1989). This can make cooperation difficult, but not impossible. 'Attachment' of social workers to the primary health care team has been one way round the difficulty. This can be successful, but only if the attached social worker has enough autonomy to make decisions on behalf of his or her organization. This can, but rarely does, achieve teamwork. Usually referrals to social workers have to be decided outside the team, so that it functions as a 'matrix organization' (Pritchard and Pritchard 1994 pp. 14–16) rather than a team.

Strathclyde Region has pioneered cooperation between health and social services, by recruiting social workers specifically to work in health centres, with their own management tier (quoted in Pritchard 1993). This overcame the barriers between health and social workers, but produced conflict between 'health centre' social workers and colleagues working primarily in the community. Such is human nature, and the apparent need for barriers in order to feel secure. This may be a reflection of the size and complexity of organizations today, and the need to focus once more on 'small is beautiful' (Schumacher 1973). The more experience that people gain of working together, the less do boundaries seem important (see Bruce quotation on page 209).

COOPERATION WITH ALTERNATIVE THERAPISTS AND VOLUNTARY AGENCIES

Pioneer experiments have shown that cooperation across major conceptual and organizational barriers is possible (Pietroni 1986). These have succeeded when a professional had a particular enthusiasm to overcome all the obstacles to innovation. Once they are working and knowledge has been disseminated, wider replication becomes easier, particularly if help is at hand in the form of a voluntary services organizer or facilitator (see Chapter 18).

What constitutes shared care?

Two characteristics of shared care included in the working definition are *shared responsibility* between individuals or teams, and operating across *organizational boundaries*. These are essential criteria for shared care and for shared care schemes. To fulfil them, responsibilities must be made explicit, with a clear understanding of who is responsible for what. This can occur *ad hoc* for an individual patient or problem. When the circumstances recur often, then a pattern emerges and people come to accept the working together implicitly. When people know and trust each other, cooperation just arises spontaneously, but staff changes or the passage of time can erode these relationships and lead to misunderstanding. The aim is to make the division of responsibility as explicit as possible, and ensure that all the parties concerned accept it. From this a shared care scheme can emerge, in order to develop good habits of cooperation in recurring circumstances, for example in a chronic disease like diabetes.

Shared care schemes

These have been described for a number of care groups and diseases (domains) and also in relation to certain activities or methods. Shared care may involve cross-boundary transfer of knowledge, skills, attitudes, technology and resources (money, manpower, training, equipment, supplies etc). This may be one-way transfer (but preferably two-way) particularly in the case of knowledge transfer. Ideally, knowledge transfer should be three-way if the patient is included. Though the specialist is bound to have more technical knowledge, the general practitioner and patient have knowledge that is unique and important for defining the context and appropriateness of shared care. Another dimension of knowledge transfer is between professionals such as doctors, nurses and complementary therapists. Each profession has different kinds of link with patients. Knowledge transfer will be further addressed in Chapter 4.

In successful shared care schemes (eg. Hickman *et al.* 1994), the nature of communication between primary and secondary care changes, and involves contacts that are less formal. Arrangements for transferring patients between sites of care became more flexible and there was greater use of the telephone and more face-to-face contact. Shared care schemes have been described for over

20 domains, but some of them have common characteristics, particularly in relation to what is being shared. Though the boundaries of care are constantly changing (Marks 1991), an attempt will be made to group the domains, so that some common concepts and methods of shared care can be sought. The alternative is to have to build separate shared care schemes for each domain, as well as tailoring each scheme to a patient's individual needs. Examples of domain groups are given below (those underlined are reviewed further in section II):

Categories of shared care schemes

1. **Shared care of chronic illness—focus on knowledge and technology transfer:**
   Asthma, diabetes, hypertension, drug delivery pumps, intravenous nutrition, mechanical ventilation (responauts), renal failure and stoma care. See Chapter 6.
2. **Focus on knowledge and skill transfer:**
   Child health, epilepsy, maternity care, prescribing, rheumatology and thyroid disorders. Chapter 7.
3. **Greater access to diagnostic resources**
   Cardiac investigations, open access endoscopy. Chapter 8.
4. **Acute, emergency care**
   Thrombolytic therapy. Chapter 9.
5. **Shared rehabilitation and community care**
   Stroke illness, 'hospital at home'. Chapter 10.
6. **Focus on changed attitudes**
   Shared care in terminal illness and palliative care Drug use/abuse, care of frail elderly, HIV/AIDS and mental illness. Chapter 11.
7. **Shared care in health promotion**
   Prevention of cardiovascular disease. Chapter 12.

This categorization is by no means hard and fast, but might help to clarify the general principles of shared care, and provide a way of assessing schemes for shared care.

RESOURCE TRANSFER

This is an issue in all shared care, but with the current trend to move the less complex forms of care outside hospital, resources need to move also. Primary care has lower overheads and lower marginal costs than hospital, so money should be saved. However, the money saved may be from a different pocket, so that more cost falls on primary care, the patient, the family and community networks. This is hard to quantify, but one of the driving forces for shared care is the need to lessen hospital expenditure, so this may initially be used as a yardstick of success, rather than considering cost more broadly.

Ways of applying shared care

Shared care can occur in a number of ways—at its simplest for the care of a single patient, where information is transferred by letter or telephone, and the patient may or not be moved. Shared care schemes may use one or several of the following methods, which may overlap. The majority of shared care schemes are initiated by hospital specialists, though this may not be the case for long. Their organizational base may be in primary care, in the community (outside primary care) or in hospital—or a combination. Some examples are listed below:

PRACTICE-BASED SHARED CARE SCHEMES

- General practice miniclinics (eg asthma, diabetes and maternity care)
- Consultant sessions in primary care centre (eg psychiatry, orthopaedics).
- Facilitators working in primary care, in various domains.

OUTREACH FROM HOSPITAL

- Diabetic specialist nurse, stoma nurse,
- Hospital-based midwife and obstetric team, HIV/AIDS teams,
- Surgical early discharge.

HOSPITAL AT HOME

- Direct access to laboratory services and near-patient testing.
- Separate outpost of the hospital (usually surgical or oncology)
- Integrated with existing primary care services (usually medical or generic).

COMMUNITY-BASED SHARED CARE

- Community teams (eg mental health team, palliative care)
- Day care services (eg elderly)

COOPERATIVE ACTIVITY

Guidelines/protocols/procedures. These are seen as an essential tool for shared care schemes, both in providing a manageable precis of domain knowledge, and as a guide to joint action. Guidelines are generated by cooperative action between specialists and generalists, and applied with the patient's agreement or suggestions for modification (see Chapter 16).

Shared records are an important feature of shared care, and can take many forms. An electronic patient record has so much to recommend it, that its implementation should be a high priority (see Chapter 17).

Application of communication and information technology. This is an important issue for shared care, because of the bulk and complexity of knowledge, the number of guidelines that will eventually be needed, the need for support of record systems, and the rapid development of knowledge-based decision support systems (see Chapter 19). Telemedicine is opening up possibilities for sharing the problem without transferring the patient (see Chapter 17).

Most of the shared care schemes described in the medical literature relate to links between primary and hospital specialist care. Few examples have been found, in the *medical* literature, of care shared with voluntary and social services. There is a long history of joint working between health and social services, but it is not described in the same terms, nor does it work in the same way as shared care between the different professions within the health services. This should not imply that such shared care does not exist, but that information about it is not so widely disseminated. However, the current 'Care in the Community' scheme (DoH 1989a) is aimed at being a gigantic shared care scheme. It still has a long way to go, and much research remains to be done.

Essential and desirable features of shared care

As for teamwork, we can look for criteria that must be met in order to meet the definition and also are associated with success. The essential criteria are those contained in the definition on page 3, namely that responsibility is shared across an organizational boundary. However for success, much more is needed. The examples here will mainly refer to shared care schemes between primary and secondary care, as this is where most experience lies. Generalization to other fields should be possible.

DESIRABLE FEATURES OF SHARED CARE:

1. **A shared understanding of the domain**
   Far and away the most important determinant of success, in the authors' view, is a shared understanding of the domain. This is an almost universal law of cooperation that applies in the consultation (Pendleton *et al.* 1984) and the team (Gilmore *et al.* 1974, Pritchard and Pritchard 1994). Without this shared understanding, consultations are 'dysfunctional'; teams are ineffective 'nominal' or 'convenient' rather than 'committed' (Bruce 1980); and shared care schemes do not result in any behavioural change (Carlson 1990, Rosenqvist *et al.* 1990). Ways of bringing about this shared understanding, and incorporating patients' viewpoints, will be addressed in Chapter 15.

2. **Effective teamwork in primary and specialist teams**
   It should go without saying that if either team is ineffective or dysfunctional, then the chances of successful patient care, let alone shared care are very low. But how many teams in hospital or primary care have undergone training for teamwork or have evaluated the effectiveness of their team? (see Chapter 14).
3. **A shared patient record—preferably patient held**
   A core record that contains the minimum data set and the transactions that affect day-to-day care, needs to be shared between the members of the two teams and the patient. An electronic patient record that can be held and used by all concerned is an enormous advantage (GRASSIC 1994), but in the case of new technology such as smart cards, there may be difficulties of access by the patient. Ideally, the shared record should be the main working record. If it is an extra, it may not be used nor updated. Patient-held records have proved their value in many fields. A computerized register of all patients with a condition such as diabetes in a population has also proved valuable (Carlson 1990, Hickman *et al.* 1994).
4. **A shared body of knowledge expressed in agreed guidelines**
   Many of the problems encountered by general practitioners are repetitive, and to work each one out *de novo* would consume an unacceptable amount of time and energy. To get round this, people develop habits, described by Young (1988) as 'the flywheel of society'. Without habits, we would never survive. The question in medicine is whether these explicit habits are acceptable to those who have a stake in the decision process, and whether they conform to norms of professional behaviour, both explicit and implicit.

   In a well functioning team, norms become embedded in everyday behaviour and may be largely implicit—'this is how we do things here', though the more explicit they are the better. In shared care across professional boundaries, to develop implicit norms would consume too much time, so agreed standards and procedures are needed to guide the behaviour of members of primary care and specialist teams towards a common goal. These are guidelines, which combine a distillate of a very large body of (often volatile) knowledge, with a suggested course of action in certain circumstances. Guidelines will be considered further in Chapter 16.

5. **Effective three-way communication**

   Because of the difficulty that the parties to a shared decision have in meeting one another face to face, other means of communication must be sought. The ideal is a dialogue including, for example, the patient, a general practitioner and a specialist doctor or nurse. This can happen in a domiciliary consultation, or when the specialist does 'outreach' sessions in the community. Different methods of communication will be discussed later in the context of 'sharing the problem, not shifting the patient' on page 31 and chapter 17.

   Communication with the patient must include using them as a source of knowledge in the widest possible sense. They are repositories of wisdom and beliefs about their illness and how it affects them; about the context of their illness in socio-economic and psychological terms; and about the wider world in which health care operates. They are active participants in the decision process as well, as it is they who provide much of their own care. Without this shared understanding of the nature of the problem, of underlying health beliefs and of plans for care, effective care will be problematical.

6. **Knowledge-based decision support**

   To gain access to relevant, accurate knowledge, with the right level of detail and at the exact moment it is needed for an individual decision, is way beyond the capability of paper-based information systems. Similarly, guidelines on paper will lose their usefulness, when the practitioner has to sort through several hundred in order to get the appropriate one.

   Work by Covell *et al.* (1985) and Williamson *et al.* (1989) has shown that 'look up' systems are not enough (see page 37). Practitioners need prompting, or 'watchdog' systems to alert them to knowledge that is relevant to a particular decision or context. The practitioner, when presented with all the appropriate knowledge, is more likely to make better decisions. However, decision support systems using logic programs (so called 'artificial intelligence') can help to sort the options in the light of the evidence, and help the practitioner to be aware of all the possibilities and not overlook anything important or life-threatening. The use of new decision support systems will be considered further in Chapter 19.

7. **Effectiveness as shown by continuing audit**
   Shared care is an extremely difficult area to audit, because of the boundary problems. Auditing an individual practitioner's work is hard enough. Auditing teamwork and organizational activity across the 'interface' is in its infancy. Auditing the effectiveness of shared care will require sophisticated methods, linking activity to outcomes and health gain. With all the features listed above, such as an electronic patient record, a library of agreed guidelines, effective communication and a knowledge-based decision support system, audit becomes manageable—much of it automatic.

   Meanwhile, we can learn from the audit of teamwork, using measures such as achieving stated goals and patient satisfaction. The topic of interface audit is addressed further in Chapter 20.

IS IT SHARED CARE?

So far, we have postulated two essential criteria of shared care and seven desirable features. As shared care schemes become more widespread and the subject of further research, more of the criteria could be regarded as essential. This would be a great step forward. When looking at shared care schemes, a checklist of questions reflecting essential and desirable features might be useful, such as the following:

- Is responsibility shared and is this spelled out explicitly?
- Is care shared across an organizational boundary?
- Is there a shared understanding of the domain?
- Is teamwork effective in both settings (eg primary and specialist care)?
- Is there a shared patient record, and does the patient use it too?
- Does the patient have a say, and play as full a part as possible, in the process? Is the patient's knowledge fully utilized?
- Is there a computer register of shared care patients?

- Are agreed guidelines, protocols or care plans employed? Are they computerized? What is the level of conformity to guidelines?
- Is communication and information exchange satisfactory? Is this mainly as monologue or dialogue? (see page 30)
- Are meetings of principals and facilitators held regularly to share understanding and plan action?
- Are computers used for information retrieval, reminders or decision support?
- Is the effectiveness of shared care audited, and the results used for improving performance

Not all shared care schemes will have all these desirable features, but a checklist like this could be used for scoring the processes of shared care, in the absence of solid outcome data. As part of the 'New Health Promotion Package', the General Medical Services Committee (GMSC 1993) of the British Medical Association has produced a list of questions concerning programmes for chronic disease management. These are described in chapter 6 (for diabetes on page 64, and asthma on page 85).

The important features of shared care schemes include:

— *responsibility shared explicitly across a boundary*
— *a shared understanding of the domain*
— *effective teamwork in both settings*
— *a shared patient record, also used by the patient*
— *patient has a say in the operation of shared care*
— *a computer register of shared care patients*
— *agreed guidelines in use, preferably on computer*
— *satisfactory communication and information exchange, preferably as dialogue*
— *regular meetings of principals and facilitators to plan action*
— *effectiveness of shared care audited, and the results used for improving performance*

Chapter 3
THE ORGANIZATION OF SHARED CARE

◆

This chapter explores some organizational aspects of shared care, particularly in relation to boundary and communication issues, and the need for dialogue.

Ways of looking at the organization of shared care

Shared care appears in many guises and can be described in the terms listed below, some of which will be considered in this chapter.

- **Responsibility** for care of the patient, by a carer or professional, or the patient's own responsibility for self-care.
- **Skills and knowledge** of individuals concerned, whether professional or lay, and *including the patient, the carer and self-help groups* as unique sources of knowledge.
- **Organizations** undertaking the care, such as the general practice team, community health services, social services, or a specialist hospital team, and the settings in which they work.
- **Boundaries** between organizations, and the procedures for functioning across boundaries, such as referral, gatekeeping, hospital discharge planning and audit.
- **Method and quality of communication** between the individuals and agencies involved in shared care. This can be a monologue or a dialogue, two-way or several ways.
- **Care groups (or domains)** affect the nature of shared care. For example shared care of diabetes differs from shared care of stroke, AIDS or mental illness (considered in Section II).
- **Power** hierarchies exist within health teams and organizations, and *vis-à-vis* the patient. The complexity of shared care is likely to disempower the patient. Power may be linked to control of resources such as information, training, time and finance.

- **Timescale** of shared care may vary between the long term (e.g. in diabetes or other chronic illness), acute episodes (e.g. myocardial infarction or unstable diabetes), or transient (e.g. when a general practitioner telephones a consultant for advice). Workers in primary care, hospital and social work may work to very different frames of urgency from each other and in relation to the patient (see Chapter 5).

Sharing responsibility, knowledge, skills, and understanding

The main reason for a patient needing shared care is for the application of knowledge, skills or resources that are not available in, for example, primary care. When the problem is straightforward and short term, as in providing an X-ray or an appliance, then the specialist scarcely needs to assume responsibility and shared care is transient. Shared care is more of an issue in longer term illness and disability, where each professional applies specific knowledge, skills and resources, and responsibility is shared.

For shared care to be effective, there must be a common care plan for the patient and a shared understanding of who does what. The patient must be part of this planning process, if they are to share ownership of the problem (Carlson 1990). The patient's knowledge must be added to the pool, as well as the professionals', and the patient's skills valued. This development of a shared understanding plays a crucial part in effective one-to-one communication. A shared understanding of, say diabetes, among patients and professionals will be an essential part of effective shared care (Day *et al.* 1988, Day and Spathis 1988). This has rarely been undertaken explicitly in shared care schemes in the United Kingdom, to the authors' knowledge, and is explored further in Chapter 15.

Knowledge transfer

Evidence-based medicine (Chalmers *et al.* 1992) is still a distant goal in general practice. This is partly due to major gaps in reliable knowledge and partly to failure to apply what we know already. There are other factors, connected with implicit knowledge and expertise that will be considered in the next chapter. One of the functions of shared care is to provide a channel for two-way transfer of knowledge—to provide the general practitioner with a window into the broad fields of specialist knowledge, and the specialist a closer view of the context of the patient's illness.

Communication may get off to a bad start when a patient comes for help to a general practitioner who is perceived as having greater knowledge and status. Likewise, general practitioners usually refer to a specialist with superior knowledge and skill in a particular field. Both transactions are 'uphill'. They do not meet the ideal of the consultation expressed by Tuckett and colleagues (1985) as 'a meeting between experts'. Yet patient, general practitioner and specialist all have unique stores of knowledge that are relevant to the health problem. Can this be recognized, so that shared care can be implemented in a spirit of equality? Serious obstacles stand in the way, and these will be addressed in later chapters.

GUIDELINES

With medical knowledge advancing at an increasing rate, its appropriate transfer needs to be facilitated. The sheer quantity of knowledge, as well as its uncertainty and volatility over time, all point to the need to encapsulate knowledge in guidelines (Grol 1990, Gordon and Christensen 1995). The likely number of guidelines, and the need to adapt them to the context and the patient's needs, will make knowledge-based decision support an imperative. An 'active' electronic patient record, a large medical knowledge base in logically-structured form, and a reliable decision support program will all be essential ingredients of shared care as well as clinical care (Fox *et al.* 1990, Gordon *et al.* 1993, Gordon and Christensen 1995). New techniques of information technology have the potential to make knowledge transfer much more effective (see Chapter 19).

A SHARED PATIENT RECORD

Shared care is unlikely to work with each organization keeping separate records. Shared records should be easier to implement electronically than on paper. Patient input into the record and preferably a patient-held three-way record is the ideal (Winn and King 1987, Essex *et al.* 1990). Smart cards could meet these criteria, provided the patient can read the card also.

Health and social care organizations and their boundaries and settings

Shared care, in its essence, involves the patient in receiving care from different organizations. In large and complex organizations, where internal boundaries are substantial, the shared care concept may be more appropriate than the team model of care, as outlined earlier. Delivering shared care involves crossing boundaries between settings, professions and organizations, but it is the organizational boundary which is dominant, because obstacles to cooperation may be part of the structure. Examples are the difficulty in setting up cooperation between health and social services, which have such different structures and culture, and where mutual understanding is hard to achieve (Lieberman 1990, Hudson 1994, Higgins *et al.* 1993, 1994, Lewis and Castleton 1992). Care in the community will be a severe test of whether patients' needs can be met across these boundaries, or whether they will remain as obstacles to shared care.

THE REFERRAL PROCESS AND ITS BOUNDARIES

Health professionals in different organizations may find themselves looking after the same patient, usually following referral—including self-referral. This can only be regarded as shared care when there is a clear sharing of responsibility. There may be no communication between the professionals, or it may just amount to a series of letters—a 'serial monologue' rather than a true dialogue.

What are the boundaries of a general practitioner's responsibility when the patient is in a specialist hospital for an operation? What are the boundaries of a specialist's responsibility for an inpatient's problems that are outside his or her specialist field? In these circumstances, the responsibility is transferred not shared. We have the anomaly of patients having access to their general practitioner at all times, except when they are in hospital. Links, where they exist, are tenuous, as when the junior doctor rings the general practitioner, or on the rare occasions when the general practitioner finds time to visit the hospital. Where shared care exists, there is a more diffuse boundary between organizational domains, but is this area a 'no man's land' of uncertainty as to who is responsible, or is there an explicit sharing of responsibility? This issue is addressed in later sections.

Referral is a complex and uncertain process, in spite of much recent research, summarized in Roland and Coulter (1992) and Hopkins and Wallace (1992). The variances in referral rates are hard to explain (Wilkin 1992, Roland 1992b), as are the reasons for referral, both explicit and implicit (Armstrong 1992). When there is a hidden reason for referral, or the specialist and general practitioner have different perceptions of why the patient has been referred, the prospects for an explicit sharing of responsibility are bleak. It is akin to consultations in general practice in which there is not a shared understanding of why the patient has come. These have been described as 'dysfunctional' (Byrne and Long 1976) or 'ineffective' (Pendleton *et al.* 1984, Tate 1994). This has a parallel in dialogue in everyday life. If people are not on 'the same wavelength', cooperation is faulty. Similarly, the work of Harris and Harris (1986) and others has shown that interaction works best between individuals who see themselves as having similar status. 'Parent–child' transactions have less chance of success than 'adult–adult'.

THE ROLE OF THE GATEKEEPER

The gatekeeper role of the general practitioner is crucial in today's health care. Many countries which have had open access to specialist services are moving towards gatekeeping by the general practitioner (Fry and Horder 1994). The gatekeeper may, however, become an obstacle to quality of care, if the referral process is faulty (Roland *et al.* 1991). The converse—open access to non-emergency services—might not necessarily be in the patient's best interests. It would certainly be expensive.

Time delay in accepting referrals or arranging treatment are serious obstacles to shared care, which are hard to justify (Jones and Dudgeon 1992 and see Chapter 5). Availability of resources, and the equity and affordability of services are all factors operating at the shared care boundary. Shared care focuses attention on the boundaries and referral processes. By viewing them from several standpoints (including the patient's), we may be able to redefine the boundaries and change the movement across them. The *status quo* of referral for, mainly, transferred care is an extremely clumsy process, for which alternatives exist, such as video consultation (see page 233).

CHANGING BOUNDARIES OF HEALTH CARE

The boundaries of care are shifting in a dramatic fashion (Marks 1991). Many influences are at work to bring this about, some technological, but mostly from pressure for cost containment, as mentioned earlier. More patients are being treated at home rather than in hospital. Some examples, drawn from Marks 1991 and other sources, are listed below:

- increase in day care services and day surgery as an alternative to admission
- increased use of outreach services, based on the hospital but operating in the community
- development of 'hospital at home'
- provision of high-technology care at home or in primary health care, e.g.: mechanical ventilation (responauts), renal failure, diabetes, drug delivery pumps, nutrition (intravenous and nasogastric)

These developments depend on more sophisticated and dependable levels of primary and community care, organizational capability and also the provision of staff, information, training and other resources. Marks noted that these boundary shifts produced organizational and professional tensions, and that the central role of the hospital needed to be reassessed. Some of these hospital-at-home schemes involve shared care and are an extension of primary care (Mowat and Morgan 1982), but others are run from hospital in isolation from primary care services (Ferguson 1987). As previously noted, most shared care schemes are about changing the boundary between the general practitioner's surgery and the outpatient clinic, and doing more in primary care, with some input and supervision from secondary care.

Trends to shorter hospital stay are likely to continue. Demographic changes will increase the trend towards care outside hospital, and overall budgets are likely to stay the same or shrink, in spite of greater demands and public expectations. Care outside hospital is likely to be cheaper, but not necessarily so, particularly if indirect and social costs, such as those incurred by carers, are taken into account.

SETTINGS OF CARE

Patients receiving care may be resident at home, in hospital or in other institutions. While resident in any of these they may also receive care in another setting. An example is the hospital outpatient or the visitor to their general practitioner, when resident in an institution. Shared care would apply when it was received in two or more settings. Such a definition has to exclude self-care and lay care, otherwise all care would count as shared—as indeed it really is. However, looking at shared care as 'health care in two or more organizational settings' (excluding self-care and lay care) would cover much of shared care, shown as a conceptual model in Figure 2.

The methods and quality of communication

One-to-one communication is difficult enough in the privacy of the consulting room. Communication across the boundaries shown in Figure 1 is a formidable undertaking, particularly when confidentiality is also an issue. Successful shared care

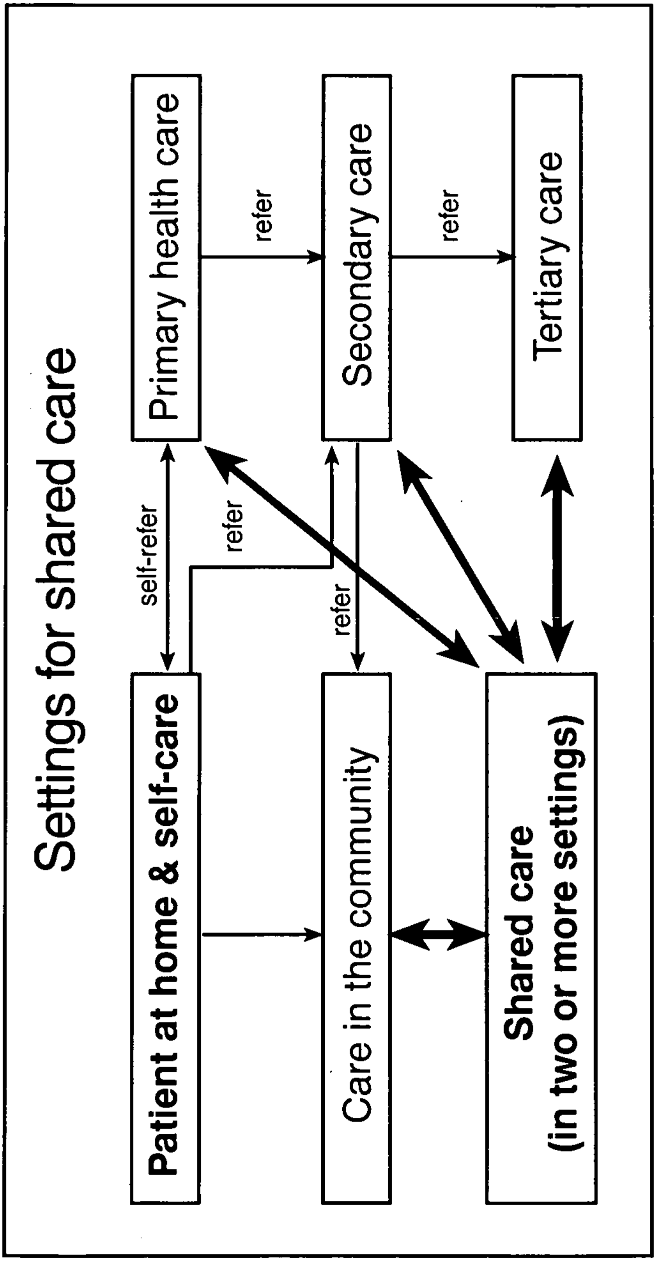

Figure 2. Conceptual model of settings for shared care

schemes tend to replace the formality of the written referral to transferred care with a more flexible system. Communication is addressed more fully in Chapter 17, but is relevant to all aspects of shared care.

TELEMEDICINE AND TELEMATICS

As mentioned earlier, there could be more use of the telephone. This requires some formal arrangements if it is to succeed, such as a telephone hour for the general practitioners to communicate with their patients. Some specialists have a similar system so that they may be contacted more easily by general practitioners and directly by patients. The next stage is to use new technology such as the videophone and transmission of text and images electronically. This has been found useful where populations are scattered and communication difficult, for example in Northern Canada (Jennett *et al.* 1993) and Norway (Pedersen *et al.* 1994). It has been tried at several sites in the UK and shows great promise as an alternative to moving the patient (see Chapter 17).

DIALOGUE OR MONOLOGUE

The quality of communication is strongly affected by feedback, both in conversation and it correspondence. The most effective communication is a dialogue[2] face to face, in order to catch the non-verbal cues and the nuances of intonation (Argyle 1983). Pehr Sällström (1991) had this to say:

> *'Dialogue is a process of finding something out together. It helps to achieve clarity and is a means of gaining insight through inner reflection. It can produce agreement, but also reveal disagreement which would not otherwise be explicit. Dialogue helps us to accept paradoxes. It is a way of looking beyond the words, and helps to*

---

[2] Dialogue—definition: 'a conversation carried on between two or more persons; a colloquy, talk together' *Oxford English Dictionary 2e.*

> *bridge the gap between language and intuition. The purpose of dialogue is to set knowledge in motion, to stop it fossilizing in empty forms. Dialogue with a machine cannot express the full richness of human dialogue'.*

To expect written or electronic communication to replace dialogue is unrealistic.

SHARING THE PROBLEM OR SHIFTING THE PATIENT?

Below are listed (Table 1) some methods of sharing the problem rather than shifting the patient, in an order that reflects the potential for dialogue. New technologies like e-mail, fax and smart cards will speed up communication, but represent an arid monologue, rather than 'a setting in motion of knowledge'.

Methods of shared care that allow a dialogue rather than a monologue will provide better knowledge transfer, but there are other factors at work. For example, automatic transmission of data by E-mail has major benefits over letters. Also, when life is threatened or major surgery needed, the niceties of three-way dialogue must take second place. However, many of the published examples of shared care schemes, for example in chronic illnesses such as diabetes, asthma, oncology or palliative care, show considerable scope for better communication. In

Table 1. Share the problem or shift the patient

Share the problem	
▶ Joint consultation in home or PHC centre	***=3-way dialogue***
▶ Video-consultation in home or PHC centre	***=3-way dialogue***
▶ Telephone advice and knowledge transfer,	***=2-way dialogue***
▶ Agreed guidelines, knowledge-based decision support (proxy for specialist)	***=dialogue***
▶ Refer to community hospital, shared care	***=dialogue***
▶ Admit by phone call to hospital—transferred care (admission to hospital by letter only=monologue)	***=dialogue***
▶ Data transfer, e-mail, fax, smart card	***=serial monologue***
▶ Refer by letter to hospital outpatients, =transferred or shared care	***=monologue***
or . . . Shift the patient	

obstetrics, it has often been the patient who is shuttled to and fro, rather than the problem. In 'acute shared care', for example for myocardial infarction, instant, two-way communication is essential.

From individual to integrated care—some variables

Integrated care is the ideal (as mentioned earlier), one step beyond shared care, involving all the determinants of health, including those outside traditional health and social services. By way of summary, some of the factors at work in the spectrum of individual care, team care and shared/integrated care are set out in Table 2 below.

At the one-to-one end of the spectrum, individual care is private and rewarding, but cannot encompass modern high-technology, rapidly changing, multi-disciplinary medicine. It will have to adapt in order to survive. Adaptation is possible in either direction, either by more referrals of patients to hospital, or by distributing more knowledge, skills, technology and resources to primary care. In the case of cold surgery, the trend is towards fewer more specialized units, with greater emphasis on day surgery and less invasive methods. For chronic illness and the care of the elderly, the trend will inevitably be towards primary and community care. Teamwork, whether in primary care, hospital specialist units or in community services has an important role.

Shifting services means shifting resources and power

Methods of care are enshrined in habits, attitudes, institutions and budgets. Any change in the balance of care between primary, community and hospital services involves a shift in the balance of power. Unless the alternatives are much worse, such change will be resisted. Major changes have already occurred in health services in UK, but have exacted a toll in low motivation and morale of staff.

Finding the optimal balance between care in hospital and care at home, and between shared and transferred care, will be a challenge for the next decade. Sharing of care implies a transfer of knowledge and learning. The extent to which learning takes place will limit the quality and value of shared care.

FUTURE STRATEGIES

Though shared care seems to be a logical way of disseminating specialist knowledge for a patient, or a group of patients, this may just be a step along the road towards alternative strategies, whereby primary health care becomes better informed and more

Table 2. From individual to shared (or integrated) care—some variables

Care setting factors	Individual care	Team care	Shared & integrated care
Privacy	Total, one-to-one	Total within group	Variable
Confidentiality	Easily achieved	Usually not a problem	Harder to maintain
Personal relationship & responsibility	Strong, if personal doctor/ nurse policy	Strong and more flexible	Feasible but harder to achieve
Organizational, and facilitator support	Minimal support needed	Substantial support needed	High level of support needed
Range of skills and knowledge	Limited by generalist role	Wider range, but still limited	Very high level and range is possible
Guidelines, care plans or protocols	Needed, but few in current use	Care plans and procedures essential	Essential because of organizational barriers
Information technology	Helpful for medical records, prescribing	Helpful for shared records, screening etc	Essential for shared record and telemedicine
Communication and boundary management	Achievable with training	Additional team skills and training needed	Additional skills and training essential
Decision support	Essential for medical knowledge and for guidelines	Helpful for some professional team members	Essential for guidelines and more complex decision making

self sufficient. Shared care must be evaluated against these alternative strategies which might be simpler to implement in the long run. However, the flow of knowledge—mainly from specialist to generalist—will have to continue, whatever the means of transfer.

Key organizational features include:

— *a shared understanding of the situation on each side of the boundary*
— *effective knowledge transfer*
— *effective communication across the boundary*
— *sharing the problem, rather than shifting the patient*
— *using telematics appropriately*

Chapter 4
KNOWLEDGE TRANSFER AND SHARED CARE

◆

This chapter explores the knowledge dimensions of shared care, in terms of its certainty, stability and its varieties. Three kinds of knowledge are described and their significance for shared care discussed.

Effective decisions require appropriate knowledge

One important reason for referral or sharing care is a perceived lack of knowledge or skill by the general practitioner. Shared care cannot be viewed solely in terms of care plans, but rather as part of a wider context of knowledge and skill transfer. Shared care can play an important part in knowledge transfer and in maintaining professional competence—in other words it has an educational function.

Much of the knowledge needed by a clinician is in a constant state of flux. New information from the patient's changing condition, new drugs, new medical facts and procedures, and changes in services, all can add up to information overload. In this context, general practitioners need to decide when a problem is beyond their competence, and referral for shared or transferred care is indicated. This decision may require a level of knowledge that the general practitioner does not possess. Whereas, if they did possess the knowledge, referral for transferred or shared care might not be needed.

The prime function of a clinician is to make decisions—jointly with the patient. Decisions will be based on knowledge about the patient, about medicine and about the availability and quality of services. These decisions should, where possible, have favourable outcomes in terms of health gain and patient satisfaction. A

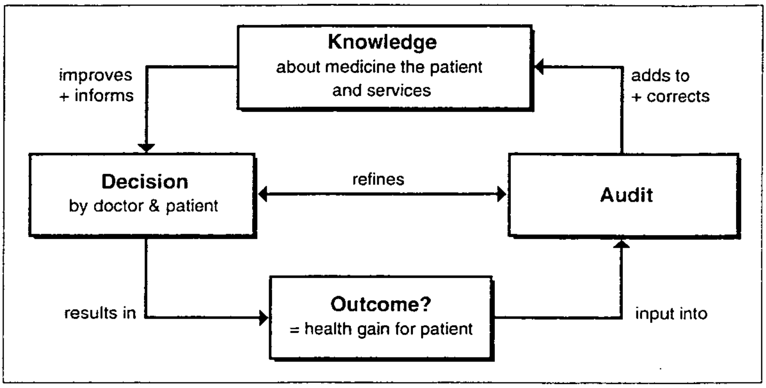

Figure 3. Conceptual model of the application of knowledge to the decision process.

much-simplified conceptual model of this process, which is basic to all health care, is shown in Figure 3 above, along with the feedback loops which ensure that the knowledge is refreshed by experience.

INFORMATION OVERLOAD

Before exploring other dimensions, let us consider the problem of the *quantity* of medical information that is inhibiting the application of appropriate knowledge in practice. Most authorities agree that there is too much to know, with the boundaries stretching to infinity (Lock 1991). There is a clutter of data that is useless to the practitioner, so that it is hard to pinpoint what is essential for a decision. Much of the literature is seldom or never referred to. 70–80% has been assessed as having little or no practical value (Weiss 1986). The level of production of papers is awesome, with over 75,000 scientific papers being published every week and the same number of books every year. We have an Aladdin's cave of information, with nuggets of knowledge and gems of wisdom. But over the years the cave has silted up, with sand occupying 80% of the space, so how do we get at the gold? Brian Haynes (1991) has described lucidly how difficult it is to keep up to date:

> *Medical practitioners suffer from information problems leading to declining clinical competence as time passes from formal training. . . . Most practitioners prefer to keep up to date by reading clinical journals, but they serve a meagre fare that consists of too little nourishment to sustain competence and too much that is potentially toxic to patient care.*

THE SEARCH FOR COMPETENCE

Competence in practice, based on valid knowledge, is surely the yardstick, but how can this be achieved? One problem is that practitioners are seldom aware that they need information during a consultation. According to Williamson *et al.* (1989), *Doctors don't know what they don't know.* Covell *et al.* (1985) reported a discrepancy in practitioners' *perceived* need for information (one question a week), and their *observed* need (two questions every three patients), 70% of which were unanswered. Of the 30% answered, over half were answered by peers and less than one fifth from paper sources. This argument strengthens the case for some sort of decision support that operates in 'prompt' or 'watchdog' modes, rather than waiting for the user to look up missing knowledge (see Chapter 19).

Sir William Osler (1849–1919) was not one to mince words:

> *For the general practitioner, a well-used library is one of the few correctives of the premature senility which is so apt to overtake him. . . . It is astonishing with how little reading a doctor can practice medicine, but it is not astonishing how badly he may do it.*
>
> quoted in Bean (1951)

A lack of awareness of gaps in knowledge can be serious. In UK there is even a denial of the problem, so that general practitioners justify getting by with just what they can recall (Barley 1988). Being unaware of gaps in knowledge is one thing: denying their existence is quite another—particularly nowadays when patients can be so well informed and have access to electronic sources of medical information.

The dimensions of knowledge

In medicine, there is a particular problem—worst of all in general practice—where decisions have to be made in conditions of great uncertainty. Much of general practice does not yet have a theoretical basis, and some may never have. Some empirical practice may be unsupported by evidence. As well as the uncertainty of the general practice knowledge base, there is the dimension of volatility. Some knowledge is very stable over time: some is so unstable that there is little chance of it diffusing into general practice before it becomes obsolete. The dimensions of validity and volatility of knowledge are shown graphically in Figure 4 which shows the two axes *certainty-uncertainty* and *stability-volatility*. From this, four categories can be derived as under:

A. Certainty+stability

This part of the field contains a solid core of well-proven knowledge, including the results of valid randomized controlled

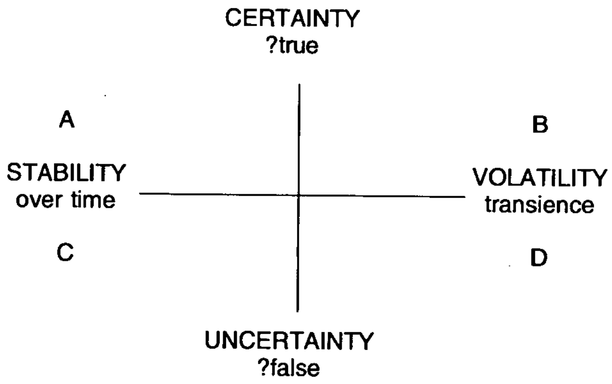

Figure 4. Dimensions of medical knowledge

trials that have stood the test of time, and are internationally acceptable in comparable populations. They do not have to be re-invented.

B. Certainty+volatility

Much 'state of the art' knowledge seems well founded at the time, but in rapidly growing fields of research it is quickly disproved. Practitioners must learn fast, and *unlearn* fast, if they are to keep up to date. It is easy to delete files from a computer: habits firmly engrained in memory do not change so easily. Perhaps, volatile knowledge need never get into our memory in the first place—just reside in the computer until needed or deleted!

Knowledge accrues by replacing old with new. Constantly disproving what was previously accepted as true gets into the popular press as a 'story', and this lowers public confidence in the validity of scientific knowledge.

C. Uncertainty+stability

Firmly-held empirical knowledge and folk wisdom fall in this category, but there are wide variations between cultures and countries. Little of it has been evaluated. Scientific methods can be used to evaluate such 'soft' data, and this is happening, though slowly.

D. Uncertainty+volatility

Here lie the fashionable alternative therapies and medical myths. These are mostly unevaluated, and some fringe therapists set their faces against any objective evaluation. If the livelihood of some therapists depends on the placebo effect, their position is understandable! The public are prepared to pay for subjective benefit, but should the taxpayer pick up the bill when evidence is lacking? Archie Cochrane had an early slogan that 'All *effective* treatment must be free'. Was he implying the converse, that ineffective treatment should not be free?

Some alternative therapies are effective, and their practitioners have skills that doctors lack, but their explanations and 'theory' are often implausible to scientists, so the practice is discredited. The key question is 'does it work?', not 'why does it work?' When we cannot be sure what does work, guesswork and habit play a big part.

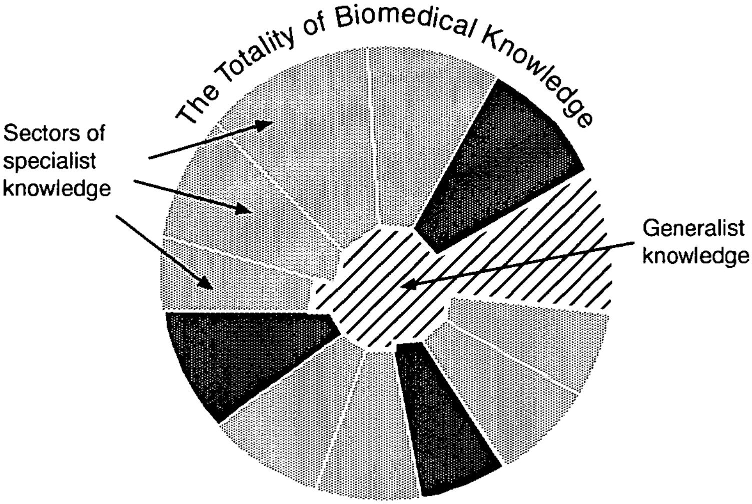

Figure 5. General and specialist knowledge domains

For a start, we can try to apply firm knowledge, but this does not always exist. The new Cochrane Collaboration (Chalmers *et al.* 1992) plans to develop and disseminate an easily accessible register of randomized controlled trials, and studies based on firm evidence. This is important, as valid knowledge may be ignored for a decade or more—for example the evidence for the effectiveness of thrombolytic therapy.

The domains of specialist and generalist knowledge

Specialist knowledge is accruing at such a rate, and the skills demanded so diverse, that specialist domains are constantly narrowing as they fragment into sub-specialties or super-specialties. General surgeons and general physicians are rare in the UK among the 56 categories of specialist. Increasing fragmentation of specialties is driven by the growth of knowledge, but it cannot go much further because the costs are greater than most developed countries can afford. Figure 5 shows

12 out of the 56 specialist domains, with general practice in the centre, as well as acting as a specialty.

Specialists act as an essential bridge between the whole body of biomedical knowledge and general practice. General practitioners' knowledge has to cover a small segment of each specialty in order to have enough knowledge to communicate and refer appropriately. The level of the general practitioner's knowledge in each specialty will affect referral to specialists. Across this interface must flow a large amount of knowledge, mostly from specialist to generalist.

Having a generalist link between the patient and multi-specialist medicine is regarded as important in most developed health systems (Fry and Horder 1994), but this puts an increasing strain on general practitioners in trying to keep up to date. In addition, as an exercise in cost containment, general practitioners are being encouraged to take on a wider role, and refer fewer patients to specialists. Giving general practitioners a limited budget for referrals to secondary care is fuelling this trend.

The boundary between the general practitioner's knowledge and competence, and specialist domains varies for each individual. We need to know more about what goes on at this boundary if we are to understand the linked processes of referral and shared care. The more knowledge transfer that occurs at this point, the better for the dissemination of new knowledge. This might argue for more referral and more shared care, for educational purposes, than we can afford. Alternative pathways for knowledge transfer will have to be opened up. New information technology could make the general practitioner better informed, and so influence the conditions at the boundary.

Three kinds of knowledge

In the past 20 years, the concept of artificial intelligence has prompted a re-examination of the nature and application of knowledge in practice. This dialogue has been going on for over 2000 years, since the time of Socrates, Plato and Aristotle. A Swedish initiative seven years ago, has brought our view of knowledge into sharper focus (Göranzon and Josefson 1988). Many meetings have been held and several books published about the nature of knowledge and its application in a variety of work settings. This international group has postulated three complementary and interacting kinds of knowledge—*'propositional, practical* and *knowledge of familiarity'* (Göranzon 1993).

Propositional knowledge. This term covers theoretical and academic, logical and scientific knowledge, answering questions like 'what is?' and 'why?'. Most of this knowledge is explicit and can be written. It is stored as linear text or symbols and is the substrate of most education and research. Computers can handle it very well.

Practical knowledge. This merges with practical skills 'how to?', 'when to?' and 'what to do?' It includes the application of technology, and the sort of knowledge needed—say—to work a computer, drive a car or communicate with a patient, which is very hard to describe in text. The competence of the expert is largely practical and difficult or impossible to express in words. If an expert is asked to explain an action, propositional knowledge is often used inappropriately. Practical knowledge is the substrate of apprenticeship. Schön's (1990) 'knowing-in-action' is an excellent example of this category—*the knowing is in the action* (see below).

'Knowing-in-action' *(Schön 1990)*

- Knowing is expressed in the action, spontaneously and dynamically
- Allows continuous detection and correction of error
- Usually cannot be described, except in static terms
- May be unrelated to taught professional knowledge
- New 'knowing-in-action' generated from 'reflection-in-action'

Knowledge of familiarity. This too is an ingredient of competence, and the use of experience to generalize, to take short cuts and work on 'auto-pilot'. Such knowledge is probably stored in 'chunks' to make recall simpler. There is much in common with the habits that we use in order to save energy when doing repetitive acts—described by Michael Young (1988) as the 'flywheel of society'. If practical knowledge is seen as expertise, then knowledge of familiarity is experience, but the distinctions are not clear cut. Referral of a patient with a rare condition to a specialist utilizes the specialist's greater familiarity. Donald Shön's *reflection-in-action* ensures that the alert practitioner becomes aware of faulty habits and corrects them (see below).

'Reflection-in-action' (*Schön 1990*)

- Spontaneous routine responses produce expected outcomes
- Unexpected outcome that does not fit our 'knowing-in-action', gives a surprise, which leads to reflection
- The assumptions of 'knowing-in-action' are questioned
- Different actions are tried that meet the new situation
- The new information is incorporated in our 'knowledge-in-action'

INTERDEPENDENCE OF THE THREE KINDS OF KNOWLEDGE

The three kinds of knowledge need to overlap and interact. Equally, they are dependent on each other. Practical knowledge is illuminated and justified by theory, but much practice is empirical and not explained by theoretical concepts. We can try to tease the elements of knowledge apart, but in practice they need to be combined as a unitary whole.

Theoretical knowledge cannot stand alone, without the other kinds (Molander 1992). The aim could be to integrate it all into a body of knowledge described by Göranzon and colleagues as *the practical intellect*. This concept could be helpful in understanding the nature of medical practice, and its knowledge and training needs. General practice, where uncertainty is high and knowledge hard to apply, might well benefit from this reappraisal. Bengt Molander (1992) also stressed the importance of subjective dialogue in learning, and that knowledge is continually on the move, so that we do not *have* knowledge, we *participate in it*.

Guidelines can be viewed as a synthesis of the three kinds of knowledge (but expressed as propositional knowledge) in a compact form, relevant for a particular task or patient. In making the compromises necessary for practical action, the validity of the knowledge may suffer. This reinforces the need for guidelines to be applied flexibly and tailored to the patient and the context, while bearing in mind the difficulty of transmitting knowledge in explicit form.

THE PRACTICAL INTELLECT

Theoretical knowledge is a desirable arbiter of practical action, but in circumstances where it is lacking, we may be inhibited from following intuitive decisions because of doubt about their theoretical basis. Perhaps we need to have more confidence in our *practical* and *familiar* knowledge and skills. Each kind of knowledge contributes to the sum of professional knowledge and the wisdom of decisions. A deeper understanding of the three kinds of knowledge, and a creative interaction between them may be essential before we can apply new technology effectively. The three kinds of knowledge overlap and reinforce one another. The synthesis of all three kinds represents *the practical intellect.* Professionals working in the uncertain field of medicine have to rely on their practical intellect, not just on explicit propositional knowledge.

Shared care is the end point of a very large amount of knowledge transfer. The main, but not the only, route is from biomedical sciences into specialist medicine, and so into primary care, informing both the staff and patients. The reverse route is also important, where the patients are characterized as experts (Tuckett *et al.* 1985), and the knowledge flows—or perhaps just trickles—the other way. If the new information technology is to provide a greater flow of relevant knowledge, then patients will need to have a stake in the process, so that their 'practical intellect' is fully utilized, not submerged.

Guidelines, applied alone, require a sharing of knowledge across many boundaries, both in their development and their application. This may not strictly be shared care, as the sources of knowledge are at one remove, but the principle is the same. By becoming involved in the development of local guidelines, general practitioners and specialists can gain the habit of sharing knowledge which can then be applied to shared care schemes.

Knowledge transfer is happening during every contact across the boundary, so the more effective these contacts are, the better will be the flow of knowledge. The same applies to referral letters, telephone calls, postgraduate education sessions and chance encounters. This is an argument for making the hospital wall less of a boundary, and making communication easier when really needed, by whatever route is available. Shared care is a favourable setting for knowledge transfer, and the mechanisms for it have to be in place. Where face-to-face contact is not possible, other ways of sharing or transferring knowledge assume greater importance.

AUDIT AND THE THREE KINDS OF KNOWLEDGE

Although practical knowledge and the knowledge of familiarity cannot easily be expressed explicitly, yet their application in practice leads to outcomes for the patient which can be audited in terms of propositional knowledge. This reinforces the importance of outcome studies and randomized controlled trials, which can influence implicit knowledge through reflection. Audit of shared care is addressed in more detail in Chapter 20.

Knowledge can be categorized in relation to its certainty/uncertainty and its stability/volatility. Different strategies are needed for each. More fundamental to medical care are the three kinds of knowledge—'propositional' (theoretical, explicit); 'practical' (expertise, implicit); and 'knowledge of familiarity' (experience, implicit). A synthesis of all three provides 'the practical intellect'. How to transfer the three kinds of knowledge, and incorporate written knowledge into the practice of shared care is an elusive goal.

Chapter 5
TIME DIMENSIONS OF SHARED CARE

◆

This chapter looks beyond linear clock/calendar time to a consideration of its cyclical, social and psychological dimensions. The relevance to delays in referral and shared care is discussed.

Time as a factor in shared care

Shared care involves a complex coordination of events—often 'embedded' in one another—such as appointments and waiting lists and of perceptions of urgency. Illnesses have their natural history, with different time scales and biorhythms. Arranging an appointment involves the expenditure of many people's time. This time can be very valuable, so everyone feels a duty not to waste other's time—particularly that of 'busy doctors'. If problems can be dealt with in primary care, this can save a lot of people's time as well as saving money.

When referring a patient, practitioners are faced with a balancing act of benefit to the patient set against time and money. But when the decision to refer is taken, they can do their best to minimize waste of other people's time, for example by a letter containing all the necessary information and a clear statement of the problem. A thorough workup of the patient's problem before referral can also save much time. But a workup will take time, and the short average consultation time in general practice in the UK (Fry and Horder 1994) may dissuade the general practitioner from doing more than the minimum. Fundholding and knowledge-based decision support could join forces to improve the level of workup before (or instead of) referral.

Urgency, and delay in diagnosis

In the UK National Health Service delays of three months to see a specialist and a year for admission for treatment are commonplace. The Patient's Charter (January 1995) now aims to limit the wait for 90% of outpatient appointments to 13 weeks and for all to be seen within 26 weeks. Subsequent hospital treatment is to be given within 18 months. That is a long time to wait for a second opinion. A lot can happen to a patient's condition in that time. All delay is unpopular, and it remains as a major structural barrier to communication and shared care. Delay is used as a rationing tool and an expression of power. The weak have to kick their heels: the strong—or the articulate—get attention. Yet all delay, in the context of potentially life-threatening illness, is upsetting and emotionally harmful, even if no physical harm follows. So we need to know more about when delay is harmful physically and psychologically, and how scarce time should be spent to greatest effect.

Shared care requires two-way communication of messages across the organizational boundary, and the speed and responsiveness of this communication are critical elements in shared care. The first step towards shared care may be referral from a general practitioner to a hospital specialist. When problems arise in shared care, prompt advice and referral are needed. Long delay in referral to hospital makes a nonsense of shared care. This may be inevitable when the problem is clearly delineated (for example the request for a hip replacement), and delay will cause no serious harm. But referral behaviour is a very obscure subject where rationality does not always rule (Armstrong 1992 pp. 25–32). A long delay gives a clear message that services are inadequate or that the patient's condition is of little concern.

What is delay?

Delay can be described as 'patient-related'—between the patient recognizing a cardinal symptom and seeking help; 'doctor-related'—between the patient's visit and diagnosis or specific treatment; and 'system-related'—when there are constraints outside the doctor's control. One of the problems of deciding on action is the lack of discriminatory power of many cardinal symptoms (Ginzler *et al.* 1992). This is more obvious in general practice than in specialist care, as it includes all the patients who are not referred. However the gap between the perceptions of urgency across the boundary need to be resolved by closer collaboration.

Studies of delay are mostly concerned with cancer, but the evidence that delay affects prognosis is equivocal in some cancers. This may be related to the late point on the tumour's time scale that a lump is clinically apparent. For example, breast tumours are thought to have undergone 30–35 doubling times before they become palpable: another six doubling times leads to death (Gershon-Cohen *et al.* 1963 and Fisher *et al.* 1977, quoted in Ginzler *et al.* 1992). The main determinant of prognosis is the virulence of the tumour, which cannot usually be decided at the first visit. While the evidence for the seriousness of delay is so tenuous, it is hard to justify delay in seeking specialist opinion. Patients can suffer serious anxiety from uncertainty that cannot be codified in terms like 'two weeks delay is acceptable'. Where cancer is a possibility, a logarithmic time scale might be more appropriate, whereby, doubling the delay would quadruple the hazard.

Most of general practice consists of handling uncertain and poorly differentiated illness (Fry 1988), where a tardy referral system is inappropriate. The general practitioner needs far more help in resolving doubts, and a wait of three months is unacceptable. A long wait for outpatient appointments polarizes demand into immediate emergencies or a three-month wait. Emergencies have increased in recent years—for example, acute medical admissions rose between 7% and 13% in 1993–4 (Court 1994).

Access to primary and secondary care

Compared to other European countries, access to primary care in the UK is prompt (Fry and Horder 1994), whereas access to hospital is extremely sluggish. Referral for shared care cannot qualify as a dialogue, with a delay of three months for a reply. The general practitioner's gatekeeper role is seriously inhibited by delay. The function of the gate is more like a time-lock on a strong room, rather than an accessible pathway to comprehensive health care.

When referring a patient with undifferentiated illness, or even some more concrete problem, such as a suspect breast lump, the general practitioner cannot predict how quickly the condition will change during the waiting period, so the fewer barriers to a second opinion the better. Relying on single symptoms with a low predictive value could be obviated by a more logical approach, such as knowledge-based decision support can offer (see Chapter 19). Minimizing delay is not an argument for large increases in resources, but rather for a look at new ways of providing second opinions, such as protected telephone time for consultants to be available for a second opinion, or better still, a video consultation (discussed in Chapter 17). Time effectiveness is an integral part of cost effectiveness.

So far we have considered linear time, but time has other dimensions, some of them important in the context of health and illness.

Perceptions and models of time

People's lives are increasingly governed by the clock and calendar. This is a recent feature of human history, supported initially by churches and now a part of industrial society, as a method of control (Adam 1990). Those societies who do not have clocks use the heavenly bodies and the seasons to direct their activities. Their time is more episodic and cyclical rather than a linear continuum. Now, the management of time and travel is so complex, that we cannot escape the tyranny of the clock and the calendar. Some people adapt well: others cannot. Though linear time is the basic measure, it must be adapted to meet the social, biological and personal context of health care.

Time is a very difficult concept to grasp or explain, as St Augustine[3] described in the 4th century. We have to resort to metaphors, and these mostly picture time as freedom, time as control, or time as structure (Pritchard 1992). Knowledge of the

---

[3] What is time? Who can explain this easily and briefly? Yet what do we speak of, in our everyday conversation, more than of time? We surely know what we mean when we speak of it. What then is time? Provided that no one asks me, I know. If I want to explain it to an enquirer, I do not know. (St Augustine, 354–430, *Confessions XI, xiv 17, translation by Henry Chadwick,* Oxford University Press, 1992)

range of metaphors can help us to understand the way patients view time and delay.

Doctors find it hard to get to grips with their own time problems, whereas, in practice, they need to be able to help patients with theirs. This can give rise to a gap in understanding the way a patient perceives the time frame of their life or illness. If doctors only understand their own model of time, they will find it difficult to put themselves in their patients' 'time shoes'. To bridge this gap requires a conscious effort described elsewhere as 'time empathy' (Pritchard 1992). Without it, doctors may find it hard to understand their patients' feelings of urgency, nor the catastrophic disruption of time that occurs when a patient is informed, or perceives, that their illness is terminal. We need to handle the many facets of time, if we are to use our scarce time to good effect.

Punctuality

If being late only affected oneself, it could be disregarded. In today's complex world, being late for a meeting multiplies the total time wasted, and this may lead to a sequence of time-wasting events. The more complex the organization, the more important is punctuality. Episodes of time are embedded in one another in a manner that is hard to conceive—until someone is late!

People's attempts to control time vary, in the same way that the 'locus of control' of other features of life vary, according to control being perceived as internal, external or 'external other' (Strickland 1978). When the patient has a larger element of control of their health care (as in the USA), delay in seeing a specialist or long waiting periods for surgery are less common and less acceptable.

Time and knowledge transfer

A shared care scheme for the chronically ill allows a continuing flow of information across the primary/secondary care boundary. If the trend of care is towards primary care, the opportunities for knowledge transfer may be fewer, and learning may be more episodic and depend on the ebb and flow of transferred care. Less traditional ways of learning may be needed, and operating in different time frames, such as 'real time' concurrent audit (see Chapter 20) and lifelong self-directed learning.

Time and computers

Digital computers are increasingly being used in shared care (see Chapters 17 and 19) and these operate in linear, clock/calendar time. When using them in a human context, we need also to consider the time frames in which patients, doctors and other professionals function, and ways of representing time in computer programs. Otherwise there is a danger that using a computer will encourage us to behave as if time were only a linear function, just as it can bias us towards propositional knowledge. Recent work in chronobiology and the social and behavioural sciences has confirmed the complex, pluralist nature of time as lived and perceived (Young 1988).

The popular metaphor of time as a valuable commodity must not blind us to the many ways that time operates in our daily lives. Shared care schemes offer a good example of saving time by following routine procedures, rather than working out every problem *ab initio*. By anticipating what might go wrong, and having procedures in place, we take time 'by the forelock'. Shared care schemes are mostly concerned with chronic and episodic illnesses. This may, in part, be due to the time it takes to set up shared care. However, a few shared care schemes do cover acute illness, such as myocardial infarction, in which rapid communication is essential.

Examples of shared care schemes are described in the next section.

The complexity of life today makes us more dependent on linear time, whereas human evolution has produced a more episodic and cyclical model of time. The dissonance between these perceptions of time may explain some of the difficulty that people experience in accepting delay. Computers may emphasize our dependence on linear time.

SECTION II

Shared care schemes in action

A literature review and commentary

INTRODUCTION

◆

This section brings together the findings of a literature search on shared care in a number of selected domains. It is not a comprehensive review, but aims to give an overview of initiatives, identifying where shared care has been established, describing the forms it takes and how it is evolving, assessing its impact on quality of care, looking at the potential for further development and drawing out the implications for services in the future.

The literature search was carried out during the year April 1994 to March 1995 and concentrated mainly on mainstream medical and health service publications from the UK available in the libraries at the King's Fund Centre, British Medical Association and the Royal College of General Practitioners. We began by carrying out searches using computer databases, including Medline, the Department of Health's database Health, and the King's Fund database. References in relevant publications were followed up and occasionally information sought directly from authors. We did not, however, seek information about unpublished work or work in progress, though we were grateful for receiving several reports from workers in the field.

The searches were guided by the broad definitions of shared care discussed in Chapter 1, allowing us to gather a wide range of material. Not all of it has been included in the reviews: we have selected the reports and papers that in our view are most relevant and interesting. There are obvious limitations to this approach which we acknowledge. It would be wrong to conclude that an absence of published accounts of shared care means that it is not happening in practice. Papers in journals reflect only a fraction of current activity at the 'cutting edge' of rapidly expanding developments such as shared care. A recent survey in Scotland and one regional health authority in England found 65 shared care schemes in operation and approximately one third of these had started in the previous two years (Hickman *et al.* 1992). Relying entirely on the literature may give an incomplete picture of the extent of shared care and how schemes are evolving, but we are confident that the material we have gathered allows us to describe broad trends in the development of shared care in each domain and identify similarities and differences across different domains.

As the literature was searched, papers and reports were initially collated by domain, with the aim of getting an overview of the development of shared care in each domain. It became clear at this stage that we had neither the time nor the resources to cover all domains in full, so a decision was taken to concentrate on what was considered to be a manageable number. We selected those in which shared care was well-established and there was a substantial body of literature (diabetes and maternity care); those which conventional wisdom held to be suitable for shared care (asthma, hypertension and mental illness); those in which we found new and interesting developments relevant to shared care (heart disease, gastroenterology, cancer); and those in which shared care would be a more complex enterprise than collaboration between primary care and hospital services, typically involving social services and the voluntary sector as well (stroke, HIV/AIDS, palliative and terminal care, and health promotion).

After the first stage of analysis, it emerged that some domains had special features that needed to be considered separately, while others had themes in common and examples could usefully be discussed together. This sorting of shared care into different 'types' provided the basis for the organization of this section. However, we were not able to incorporate the material we had gathered on mental illness and HIV/AIDS, simply due to pressure of time.

Seven main types of shared care were identified, which had different characteristics in terms of:

- the type of illness or condition to which they relate
- the stage of management they address

- the organizational boundaries across which care is shared, and hence the main players or partners in sharing care
- the nature of their relationship
- the timescale of their involvement.

Our working definition of shared care emphasized responsibility for the care of the patient being shared between individuals or teams that are part of separate organizations. Four types of shared care are concerned principally with sharing across the boundary of secondary and primary health care, when responsibility for care is jointly held by hospital specialists and general practitioners. However, as other health professionals, such as midwives, take increasing clinical responsibility and become more equal partners in some shared care arrangements, they are also key participants. Other players may be involved, but in supporting roles. These four types of shared care are:

- **shared care in chronic illness**, perhaps the best known and most widespread form of shared care, which we discuss in Chapter 6 with reference to diabetes, asthma and hypertension.
- **shared maternity care**, which is equally well-established and familiar, but because of its special characteristics and important recent developments in policy and practice merits separate consideration, and is discussed in Chapter 7.
- **shared care in investigation and diagnosis**, a developing area which is discussed in Chapter 8, with special reference to open access to endoscopy and cardiac investigations.
- **acute, or emergency, shared care**, which is a much less familiar context for collaboration. The possibilities for acute shared care are discussed in Chapter 9, in relation to one example, namely the early management of heart attack.

The other three types of shared care are characterized by collaboration in a much larger arena and across numerous organizational and professional boundaries. The focus is not just bridging the divide between hospital and community, but integrating services from a variety of sectors and agencies and care from a multiplicity of professionals, according to the needs of individual patients. The patients involved have many different problems and their main need may not be for medical care or regular monitoring, but for a blend of continuing nursing care, rehabilitation, and social and domestic support. Thus hospital services play a much smaller role: the most important links are with health and social services in the community. The three types of shared care are:

- **shared care in rehabilitation and community care,** which is discussed in Chapter 10 with special reference to services for stroke patients.
- **shared care in terminal illness and palliative care,** which is discussed in Chapter 11 with particular reference to people with advanced cancer.
- **shared care in health promotion,** which is discussed briefly in Chapter 12, in relation to developments in prevention of cardiovascular disease.

Chapter 6
SHARED CARE FOR CHRONIC ILLNESS

◆

This chapter considers three chronic illnesses for which shared care has been established: diabetes, asthma and hypertension. The literature on diabetes is the most extensive and shared care schemes are an important part of the history of the development of diabetic care over the past 25 years. Shared care schemes in asthma and hypertension are fewer and more recent and many have been modelled on developments in diabetic care. We explore each domain in turn and describe how services have evolved, and discuss selected examples of shared care. Finally, we identify some common themes and issues from all three domains.

Introduction

Shared care has been promoted as a way of integrating primary and secondary care services in the NHS, particularly for patients with chronic illnesses, who require long term monitoring, regular review of treatment and education about their illness and its management. Shared care for chronic illness has become perhaps the most widespread and familiar form of shared care, along with shared antenatal care. The main players are hospital specialists and primary health care teams who collaborate to provide structured care for well-defined groups of patients, who themselves have an important role to play in self-management of their illness. The emphasis is on systematic monitoring of patients over a period of years, often within a framework of jointly agreed guidelines or protocols.

Shared care schemes have developed in response to a variety of pressures. The strongest initial influence appears to have been from hospital specialists, who needed to reduce demands on their overstretched outpatient clinics, and who were concerned to use hospital facilities and resources more efficiently and effectively. In recent years the push to transfer care from hospitals to general practice has been supported by national policy. Some GPs have also been keen to reclaim from hospital departments care of their chronically ill patients, to enable them to use their knowledge and skills more fully, and to offer more comprehensive care in what they believe to be the most appropriate setting. Furthermore, as evidence from research has accumulated, it has shown that quality of care for patients with chronic illness has often been poor: they have received haphazard and inadequate services, and hence ineffective treatment.

Diabetes

Diabetes is a prevalent chronic condition characterized by raised levels of glucose in the blood. It is thought to affect between one and two per cent of the population in Britain (Laing and Williams 1989). There are a variety of forms of diabetes, the two main types being insulin dependent diabetes mellitus (IDDM) and non-insulin dependent diabetes mellitus (NIDDM). People with IDDM require treatment with insulin throughout their lives. NIDDM is controlled by either dietary therapy or a combination of diet and oral hypoglycaemic agents. Diabetics suffer increased mortality and high levels of morbidity resulting from the complications of diabetes, which affect the eyes, kidneys, peripheral nerves and cardiovascular system. Consequently, diabetics are heavy users of health services, and it has been estimated that 4–5% of the health budget is spent on their care, the main expense being accounted for by hospital treatment of diabetic complications (Laing and Williams 1989). Controlling blood sugar levels is generally held to be the key to preventing or delaying complications, and the complications themselves may be treatable if detected early enough (Ward and MacKinnon 1992).

There is general agreement that a programme of diabetes care should include the following elements:

- identifying new patients and selecting appropriate therapy;
- providing initial and continuing education for patients and carers;

- facilitating improved control of blood sugar levels;
- identifying and treating the long-term complications and their risk factors; and
- managing acute episodes of care.

Guidelines for clinical monitoring of diabetic patients have been produced by national organizations, expert professional groups and consensus conferences, and those most widely used have been reviewed by Greenhalgh (1994). The St Vincent Declaration, prepared jointly by the International Diabetes Federation and the World Health Organization, sets global targets for diabetes care (Anon 1990) and these have been adopted by the British government in the strategy document *The Health of the Nation* (DoH 1992).

The elements of diabetic care and many of the guidelines imply a need for a wide range of educational, clinical, diagnostic and administrative facilities and resources. Good diabetic care is continuous rather than episodic and requires coordinated inputs from a variety of professions and disciplines. Because of the nature of diabetes, patients themselves must play a central role in managing their condition, supported by a multidisciplinary clinical team. While there is consensus about the elements of diabetic care, there is still dispute about the most appropriate configuration of services to deliver optimal care. One of the key questions concerns the balance of services between hospital and general practice-based care.

Hospital outpatient clinics have been the focus of care for the majority of diabetics. Diabetic clinics were developed in the 1920s in response to the need to supervise insulin treatment and over the years accumulated increasing numbers of patients with all forms of diabetes. They gained an 'evil reputation, owing mainly to the frustration of overloaded clinics with a consequent lack of time for education and screening for complications' (Worth *et al.* 1990). More than 20 years ago it was recognized that diabetic care in both hospitals and general practice was haphazard, poorly-organized and incomplete. During the late 1960s and early 1970s, primarily in response to overwhelming demands on their time and pressure on hospital resources, some hospital consultants began to explore how to get GPs to take on more of the routine care of their diabetic patients, particularly those with NIDDM.

These consultants, in collaboration with GPs interested in reclaiming diabetic care, were the pioneers of shared diabetic care. More recently, those involved in diabetic care have begun to reappraise the role of the hospital clinic and to seek ways of improving the integration of hospital and primary care, often by developing new and more comprehensive shared care schemes.

EVOLUTION OF SHARED DIABETIC CARE

Some early initiatives simply relocated the hospital outpatient clinic to the GP surgery, allowing GP and consultant to review patients together. For example, in 1967 one practice arranged for all its diabetic patients to be seen annually at a special evening clinic session held in the surgery. This was organized along the lines of a hospital diabetic clinic with GPs sitting in to discuss treatment. Follow-up appointments were normally made with the GPs, although more difficult cases would be reviewed at the hospital clinic (Malins and Stuart 1971). These 'shifted outpatient clinics' were thought to be preferred by patients because they were more convenient, in familiar surroundings and offered continuity of care by the GP. GPs benefitted from the arrangement by developing their expertise and gaining confidence in the management of diabetes.

Two other schemes established in the 1970s which involved larger numbers of general practices have provided models for subsequent initiatives. They are the general practice miniclinics developed in Wolverhampton and the community care service in Poole.

WOLVERHAMPTON MINICLINICS

In 1970 a scheme began in Wolverhampton that combined care in specially-organized general practice clinics (miniclinics) with hospital services (Thorn and Russell 1973). One or two partners in each practice cultivated a special interest in diabetes and set aside a session a month dedicated to reviewing the practice's diabetic patients. Selected patients (NIDDM and IDDM) were discharged from the hospital clinic to GP miniclinic care after being seen once at the hospital. The GP was 'entirely responsible for the continuing care of these patients, so there is no further visit to hospital for a miniclinic patient unless referral is made for consultation' (Thorn and Russell 1973). About 75% of a GP's patients were able to be discharged to the miniclinic. All children, adolescents and many young adults continued to attend the hospital clinic on a long term basis. Patients whose diabetes became difficult or who developed complications were likely to return to the hospital clinic either temporarily or permanently (Thorn and Watkins 1982). Consultants visited the miniclinics annually, and special record cards were created. Practice nurses became involved in the running of miniclinics, and later accounts of the scheme emphasize the role of the practice nurse or health visitor in routine monitoring and patient education (Thorn and Watkins 1982). Meetings and lectures organized by the hospital encouraged GPs and practice nurses to learn more about diabetic care.

THE POOLE COMMUNITY CARE SERVICE FOR DIABETICS

This scheme began in 1972 as a way of relieving the heavy workload on a diabetic clinic serving an area with a large and increasing elderly population, and as a means of generally improving the standard of diabetic care (Hill 1976). The consultant initiated discussions with local GPs about increasing their involvement in diabetic care and most wanted to look after their own diabetic patients rather than establish practice miniclinics. A working party was set up to organize the service; a refresher course for GPs was arranged and talks given to other members of practice teams. After an initial visit to the hospital clinic, selected patients (mainly NIDDM and with no complications) were returned to GP care. Each patient was given a community care co-operation booklet, which was a means of communication among all those involved in the patient's care. GPs were able to refer patients directly to the dietician and chiropodist at the hospital clinic. The Poole scheme now involves all practices in the district and is supported by a computerized system for assessing follow up and diabetic control.

The reports of these early initiatives showed that GP-based diabetic care was feasible and satisfactory to most people involved. The Wolverhampton scheme was formally evaluated, demonstrating that patients attending miniclinics had the same degree of metabolic control as those attending the hospital clinic. During the 1980s more reports of pilot schemes were published, reflecting the growing trend towards GP-based diabetic care. A review of the literature in 1990 by Wood lists 19 initiatives, of which six had been evaluated, comparing care in general practice with care in the hospital clinic.

BETTER CARE IN GENERAL PRACTICE?

Wood's review of the six evaluative studies provides equivocal evidence on the outcomes of general practice-based diabetic care. In four of the studies (in Sheffield (Wilkes and Lawton 1980), Cardiff (Hayes and Harries 1984), Kirkcaldy (Porter 1982) and Ipswich (Day *et al.* 1987)) people discharged to GPs had worse outcomes than those retained by hospital clinics or their care fell short of the evaluators' expectations (Sheffield). In all these schemes GPs had agreed to take on routine diabetic care when requested by the hospital consultant, but they had not necessarily been helped to organize recall of patients and practice-based care; been provided with guidelines or training; or given access to essential facilities such as diabetic advice, chiropody and hospital-based laboratory services.

Two studies found that people discharged to GP care had equally good, or better, clinical outcomes than those still attending the hospital clinics. The Wolverhampton miniclinics described above performed as well as the hospital clinic on three measures of metabolic control. The miniclinics also had a smaller proportion of defaulters (Singh *et al.* 1984). Three pilot practices in Tower Hamlets achieved a fall in patients' mean glycosylated haemoglobin levels during the study period, with no change in the group followed up in hospital (Yudkin *et al.* 1980). People seen in general practice were also more thoroughly reviewed than those seen in the hospital outpatient clinics. These practices had been provided with a computerized protocol-based recall system for glycosylated haemoglobin measurements and were supported by diabetes specialist nurses.

Wood (1990) was very cautious in drawing conclusions from the review. She clearly felt that the evaluative studies were unsatisfactory in many respects, particularly because most failed to state their objectives and measured a very limited set of outcomes. All the studies collected data about metabolic control, and several looked at complications and deaths. Only one study looked at patients' knowledge and views and one provided data on the relative costs of diabetes care in hospital and general practice. Wood was only prepared to go as far as saying that: 'When viewed in the context of the growing trend to discharge people with diabetes from hospital outpatient clinics, evidence of the outcomes of such services is extremely scarce and is totally inadequate for those wishing to replicate them'.

However, this review gives some important clues about the circumstances in which GPs are able to provide effective diabetic care, and these have been confirmed by a more recent and comprehensive review by Greenhalgh (1994). The first point is that self-selected GPs or practices with a strong interest in diabetic care, providing a structured service, and with support from hospital specialists are likely to be able to manage the routine care of a selected group of their diabetic patients as effectively as hospital outpatient clinics. Secondly, a wider group of less motivated GPs and practices are likely to be able to match the quality of hospital-based care **only** if they are given help and resources to prepare themselves to take on structured diabetic care and access to continuing specialist advice and support. Greenhalgh (1994) comments '. . . ordinary general practitioners can provide quality care if they have the motivation, basic equipment, and a structured protocol'.

It is clear that many of the early schemes were not genuine shared care, but attempts to shift care to general practice, which GPs themselves were not involved in planning and for which many were ill-prepared. Consequently, they felt no sense of ownership of the schemes and had no commitment to making them work. The early trials also demonstrated the importance of the principles of registration, recall and review in the management of chronic disease, and these principles, along with better planning and implementation, have been built into many of the later studies, which have shown more favourable results for general practice based care. Greenhalgh (1994) concluded that 'The introduction of structured care in general practice was without exception associated with comparable levels of process and outcome to patients in hospital care, insofar as these factors were measured'. However, she cautions that, because these encouraging findings come from experiments and trials, run by enthusiasts and often with fairly short periods of follow up, there are still unanswered questions about the applicability of the findings to all practices in all areas.

INTRODUCING STRUCTURED CARE

Until recently, surveys found that only a minority of GPs were offering structured care to their patients. The new contract for GPs, introduced in 1990, encouraged many practices to establish diabetic clinics and involve practice nurses in monitoring patients, although each practice was free to determine how care was provided. The recent changes in remuneration, offering specific payments to GPs providing a programme of diabetic care, also have a clear framework based on the principles of chronic disease management and multidisciplinary working (GMSC 1992). To qualify for a flat rate payment of about £350 per annum per GP (it does not vary with list size) a practice must

- maintain a register of diabetic patients
- ensure that systematic call and recall of patients on the register is taking place, in either hospital or GP setting
- give advice to newly diagnosed patients or their carers
- ensure all diabetic patients (or their carers) receive continuing education
- prepare with the patient an individual management plan
- ensure that on initial diagnosis and at least annually, a full review of the patient's health is carried out, including checks for potential complications and a review of the patient's own monitoring records
- work together with other professionals (e.g. dietitians and chiropodists) where appropriate

- ensure any health professional involved in the care of diabetic patients is appropriately trained
- refer patients to other services and supportive agencies as required, using locally agreed referral guidelines where these exist
- maintain adequate records and audit the care programme.

By October 1993, over 87% of GPs in England and Wales were offering their patients diabetes management programmes (DoH 1994a). It is by no means clear whether this upsurge of activity represents a real growth in interest in diabetic care or is simply financially motivated. It is also too early to assess its impact on the quality of diabetic management in primary care.

There is still debate about the best way to organize diabetic care within a practice, and the miniclinic and personal care approaches still have their advocates. Arguments in favour of miniclinics are that they provide the necessary 'protected time' for care; allow an interested and knowledgeable GP to 'specialize'; and make it easy to involve practice nurses in structured care. Miniclinics are easiest to implement in larger group practices. Arguments against miniclinics are that they are time-consuming; more costly; and patients lose continuity of care with their own GP.

The case in favour of personal care has been made by Foulkes *et al.* (1989) in Southampton. Two practices established a system of diabetic review in which GPs retained responsibility for management of their own patients. The practice nurse and reception staff were responsible for organizing the service, sending appointments for annual review, maintaining the practice's disease register and recalling non-attenders. Protected time for annual reviews was set aside once a month, during normal surgery hours. The nurse saw the patient first for 15–20 minutes, then the GP joined the consultation to examine the patient, make an overall assessment and discuss plans and follow up. The practices found that this model of care was a satisfactory alternative to the miniclinic.

In general, miniclinics have been associated with structured programmes of care, which have led to better glycaemic control and fewer hospital admissions (Farmer and Coulter 1990). Pringle *et al.* (1993) confirmed this association in a study of diabetic care in 12 Nottinghamshire practices. Larger and better equipped practices, and those with access to dietetic advice also had better controlled patients. Of all the doctor factors that were measured only doctors who professed a special interest in diabetes achieved significantly better glycaemic control. The authors concluded that 'the findings support concentrating diabetic care on partners with a special interest in diabetes in well equipped practices with adequate dietetic support'. However, Kinmonth (1993) has pointed out that although the multiple regression analysis showed that the only modifiable factors independently influencing glycaemic control were access to a dietitian and a GP interested in diabetes, the analysis left 85% of the variance in glycosylated haemoglobin concentrations unexplained. She questioned the narrow focus on blood glucose concentrations as a proxy measure of outcome, and advocated taking a broader view with 'more attention to the beliefs and behaviour of patients, doctors, and nurses as these probably strongly affect morbidity and mortality in diabetes'.

Other studies have also found doctors' attitudes and beliefs to be important. A study in the US compared a group of 12 physicians who were 'more successful' in caring for their diabetic patients with 12 who were 'less successful' defined by their patients' glycaemic control. Knowledge about diabetes did not discriminate between the two groups, but their beliefs about diabetes and its management did. The more successful group believed most strongly in the benefit of strict blood glucose control (Weinberger *et al.* 1984). In the UK, Kinmonth and Marteau (1989) compared general practitioner teachers' and hospital doctors' beliefs about diabetes. GPs had a more pessimistic outlook, believing that diabetes carried more risks and having less confidence that achieving goals of treatment would reduce these risks. Accordingly, their approach to treatment was less rigorous than that of the hospital doctors. The authors speculate that these differences in beliefs may be a barrier to the development of shared care, and emphasize the importance of the two groups meeting to share experiences in case discussion, seminars and audit, to prevent polarization of views.

The most recent attempts to implement GP-based diabetic care tend to emphasize the need for structured care but not to prescribe a particular way of organizing care in a practice. GPs are offered a high degree of flexibility in the extent of their involvement in diabetic care and are given support and resources to enable them to undertake their agreed responsibilities effectively. In many schemes, practice nurses are key figures in developing well-organized and up-to-date diabetic care. Nurse facilitators have played a central role in enabling practices to develop their own approaches to diabetic care, fitting in with established routines, progressing at their own pace and within their resources. Some schemes use guidelines or protocols to structure care and may link practices to a centralized computer register and recall system that allows care of all patients to be standardized and monitored.

It is now widely accepted that GPs and practice teams can provide diabetic care as effectively as outpatient clinics, and that primary care is the right setting for the monitoring and routine management of diabetic patients. The question now is how to enable the majority of practices to provide a high standard of diabetic care for the majority of their patients. We look next at some examples of different approaches to developing diabetic care in general practice, which illustrate a variety of ways of sharing care with hospital services. This raises questions about the future role for hospital diabetic departments, which are addressed in the following section.

EXAMPLES OF SHARED DIABETIC CARE SCHEMES

We have chosen five examples of schemes that illustrate a range of approaches to developing shared diabetic care, and illuminate some of the problems of establishing high standards of care in general practice. Greenhalgh (1994) found that the wide range of shared care schemes she reviewed fell into two broad categories: those which are centralized, hospital-based and consultant-led, and those which are decentralized, community-based and multidisciplinary. Two of the examples discussed here fall unequivocally into the first category: the computer-assisted prompted care schemes in Islington, north London and Grampian, Scotland, offer a framework designed by the hospital department in which GPs can make their own contribution to a standard package of diabetic care. The example from Camberwell, south London, comes into the second category. This scheme was proposed and developed by a few local GPs who wanted to take back some responsibility for care of patients with chronic illnesses. Eventually, the vast majority of practices in the area were helped to join the scheme by facilitators who were part of a primary care development project, based in the department of general practice. A nurse facilitator, based in the hospital diabetic centre, was also a key figure in the example from Greenwich. Although this was a central initiative, an important feature of the approach was to let practices determine the extent, style and pace of their involvement. The final example, from Sweden, describes how facilitators were unable to get the majority of health centres in Stockholm to implement a centrally-designed programme of structured diabetic care. Their success increased when they changed to a more participative approach, involving health centre staff and patients in designing and implementing their own plans to improve the organization of diabetic care.

PROMPTED CARE IN LONDON AND SCOTLAND

In Islington, north London, attempts during the early 1980s to promote miniclinics in general practice were largely unsuccessful. However, local GPs said they were keen to take more responsibility for the care of non-insulin treated diabetics if review could be scheduled in normal surgery time and did not include retinal screening. The prompting system was devised with these requirements in mind and in 1987 38 practices (including 15 singlehanded and 13 two-doctor practices) agreed to take part in a pilot project (Hurwitz *et al.* 1993).

In Grampian, Scotland, three group practices took part in a trial of integrated care for insulin and non-insulin treated patients. Two practices ran diabetes miniclinics delegated to a single partner and the third spread consultations among partners in routine surgeries (Diabetes Integrated Care Evaluation Team 1994).

The prompting systems set up in the two centres were organized along similar lines. In both a computer-based patient record system was run from the hospital clinic and prompts were sent to patients when a routine review was due. The Islington system was based on a six-monthly cycle of testing and clinical review by the GP and a yearly cycle of eye testing by local optometrists. Patients could choose the most convenient site to give blood and urine samples (general practice, health centre or hospital) and they were sent the results along with a request to take them to their GP within 10 days. A clinical review was then carried out by the GP, guided by a simple form which also allowed the results to be fed back to the hospital department and enabled any necessary referrals to be made. The clinical review form is based on guidelines for outpatient care that are also used by doctors in the hospital clinic. In the Grampian study, patients allocated to integrated care were seen in general practice every three or four months and in the hospital clinic annually. A division of responsibility between hospital and general practice was agreed and GPs were given written guidelines on integrated care.

Both trials found no significant difference in metabolic control between patients receiving conventional hospital care and those receiving GP care. In Grampian, integrated care was found to be as effective for insulin dependent as non-insulin dependent patients. In Islington, one third of all reviews in the prompted group actually took place in the hospital. There may have been some duplication of care, but most referrals were thought to have been made appropriately as part of the shared care arrangements. Over two and a half years, the prompting system shifted two-thirds of care from the hospital clinic to general practice. Patients in the prompted group also received greater continuity of care. In both trials fewer patients defaulted from GP care than from hospital care, and patients and GPs were very satisfied with GP-based care.

Less encouraging findings were that, in Islington, there was some confusion about who was taking clinical responsibility for the prompted patients: 26% of GPs thought they were; 10% thought it was the hospital; 55% thought both; and 10% said they didn't know. In Grampian, estimates of the costs of hospital and integrated care found that integrated care was more expensive to the NHS, but cheaper for patients. Conventional hospital care was estimated to cost £55 per patient year; integrated care cost £78 in one practice and £101 in another. The discrepancy between the two practices may be explained by differences in the organization of care. The practice with lower costs operated a 'personal care' system, spreading diabetic appointments throughout routine surgeries, and typically seeing patients twice a year when they spent ten minutes with the practice nurse and ten minutes with the GP. The practice with higher costs ran a weekly diabetic miniclinic, many patients attended three times a year and spent 20 minutes with the health visitor and 20 minutes with the GP.

GP-LED CARE IN CAMBERWELL

The Camberwell scheme for shared diabetic care grew out of the work of the Camberwell Primary Care Development Project (CPCDP), which is based in the Department of General Practice and Primary Care at King's College Hospital and uses a multidisciplinary team-based approach to primary care development. In the mid-1980s the project found that many local GPs were concerned about the care of patients with long-term illness, who seemed to 'disappear' into outpatient clinics, from which their GPs would receive little or no information. Some GPs were keen to offer integrated care but felt that their skills were underused and had become rusty. The GPs themselves suggested that there was potential for a 'shared care' approach to some chronic illnesses, with clearly identified roles and responsibilities for GPs and hospital departments.

In 1986 the CPCDP convened a small working group—two diabetic consultants and three local GPs with an interest in diabetes—which proposed a diabetic shared care scheme. The working group and the CPCDP took this idea forward.

The CPCDP's approach to development is to work at the grassroots with all practices, not just the innovators, and to provide practical support and education to enable the practices to introduce the changes they want at their own pace. Local GPs are consulted and asked to make an input to all the project's initiatives to ensure that they not only support developments but also have a sense of ownership of them (Morley *et al.* 1991).

In line with this philosophy, the idea of a shared care scheme was canvassed as widely as possible among local GPs. The working group's outline scheme was presented at an open meeting between the hospital diabetic team, GPs, chiropodists, dieticians, nurses and others involved in diabetic care. The plan was greeted with enthusiasm and various practical aspects of it were discussed. The preferred model of care was for patients to attend the hospital clinic for initial diagnosis, education and stabilization, and for the hospital clinic to screen patients for diabetic complications at least once a year. A computerized register would be established to underpin the system of registration, recall and review. GPs would have access to help from the diabetic department at any time. Standards of care were to be agreed and a shared care booklet would be held by the patient.

A month or so after the meeting, all GPs in Camberwell were asked if they would like to join a diabetic shared care scheme. 90 GPs in 30 practices said they did. Over the next year (1987) the mechanics of the scheme were worked out stage by stage. Five meetings explored clinical and administrative issues; preparation for the scheme included designing a shared care booklet, agreeing standards of care and management protocols, establishing in the hospital department a computerized register of all diabetics, with a recall and review system. All diabetic patients in Camberwell are registered in the scheme in one of three categories:

- **hospital care**: care is provided entirely by the diabetic department, e.g. pregnant women and children with diabetes; diabetics with major complications.
- **shared care**: both GP and hospital are involved. The GP provides the majority of care, with an annual review by the diabetic department.
- **GP care**: care is provided entirely by the GP, including the annual review, e.g. housebound elderly patients.

GPs decide whether or not to take on a patient for shared care.

The shared care system was launched in January 1988. Regular meetings continued for participants in the scheme, at first focusing on administrative and organizational issues, then becoming more concerned with clinical topics and skill development. In March 1989 two health visitors were employed as nurse facilitators to develop the scheme. These posts were funded for two years from a combination of sources: charitable funds, the regional primary care development fund and the FHSA. The two health visitors appointed had complementary skills and experience: one had previously been a diabetes liaison health visitor based in the hospital, and the other had a degree, postgraduate research experience in biochemistry and a certificate in adult education.

When the nurse facilitators took up their posts, seven practices (12%) were offering structured diabetic care and taking part in the shared care scheme. The facilitators began by contacting all the other practices which had expressed an interest in the scheme, offering to meet GPs, practice nurses and other staff to discuss diabetes care and help them set up miniclinics. After two years work the facilitators had increased the number of participating practices to 23 (38%). Ten further practices were in the process of developing diabetic care. The facilitators found that 21 practices were interested in providing diabetic care but could not progress during the timescale of the project, mainly because their premises had insufficient space for a practice nurse. Only six practices (five singlehanded) declined to join the scheme (Wilson *et al.* 1991).

Employment of a practice nurse can be the factor which determines whether a practice is able to provide structured diabetic care. When the shared care scheme was launched in 1988, only 10% of practices in Camberwell employed practice nurses. By March 1991, the figure was 62%: 38 practices had 42 practice nurses. An important part of the facilitators' work has been to enable practice nurses to use and extend their skills in diabetic care. Nurses were encouraged to take part in the regular meetings about shared diabetic care, and these meetings offered an opportunity for multidisciplinary learning, with a mixture of specialist or 'expert' input and small group work. The facilitators also taught practices nurses in the surgeries on a one-to-one basis. Although effective, this did not seem a very efficient use of their time, so they devised a training course for practice nurses, with multidisciplinary teaching and practical sessions. Twenty-four nurses completed the courses that were offered during the two years of the project.

In contrast with other facilitators, who have been based in diabetes departments (for example in Sheffield (MacKinnon *et al.* 1989) and Greenwich (Jones and Marsden 1991)), the Camberwell facilitators were based in a department of general practice. They found that this helped them work effectively with local practices but, although they endeavoured to maintain close links with the hospital, 'they would have liked to promote greater involvement on the part of staff in the diabetic department in the scheme'. However, the shared care scheme was thought to have had a positive impact on the hospital department, allowing the clinic 'to sharpen its focus on special problems associated with diabetes'. At the time the report of the scheme was written, the hospital department had not established the promised computerized register and recall system that would support shared care and promote audit.

The Camberwell shared care scheme has not been formally evaluated. A questionnaire sent to GPs in 1988 and again in 1991 showed a change of attitudes in favour of diabetic care in general practice. At the end of the two-year project, the FHSA and DHA accepted the need to continue the role of the facilitators and committed funding for a full-time post. The intention is to increase the diabetic department's two liaison health visitors to three and to give each nurse the responsibility of linking with one-third of the practices in Camberwell. Approximately one-third of the working time of each nurse would be devoted to this developmental role.

WORKING WITH PRACTICES IN GREENWICH

In 1988 a specialist nurse facilitator based in the diabetic centre at the district general hospital visited all practices in the district to collect information about diabetic care and identify constraints on providing a service in general practice (Jones and Marsden 1991). She found the major constraints to providing good quality diabetic care were:

- **organizational**: absence of a diabetes register, no separate time for diabetic patient appointments, no diabetes literature for patients.
- **doctors**: no diabetes experience during training, a negative attitude towards providing diabetic care, competing interests in medicine.
- **professional help**: absence of a practice nurse or district nurse.

There was considerable variation in the number of constraints found in individual practices. The nurse facilitator directed her time and energy at those practices with a medium number of constraints.

Individual practice plans were devised for developing diabetes care, combining a variety of methods: advice, help and support from the facilitator; encouraging practices to use the resources of the diabetic day care centre and the automated retinal photographic screening programme; offering literature packs; and using GPs who had already established good diabetes care as educators of their less skilled peers. Using a non-prescriptive approach, GPs were encouraged to become involved in diabetes care in the way they felt most appropriate for the practice. GP involvement increased from 17% to 53% during the three years of the project.

The trend was for practices to start miniclinics, and the proportion with miniclinics rose from 11% to 46%. However, the authors state that 'We regard it as an important principle not to prescribe any particular kind of formal diabetes care. We are keen to encourage more GP care, but to allow different methods to evolve according to the facilities and preferences of individual GPs'.

As the practices began to organize their own diabetes care, the hospital systematically discharged varying degrees of care, with the agreement and cooperation of practice staff.

A PARTICIPATIVE APPROACH IN SWEDEN

In 1980 a diabetes training unit (DETU) was set up in Stockholm, Sweden, to provide continuing medical education courses in diabetology for general practice staff. Its aim was to put into practice national policy on providing effective diabetic care in the community. GPs and practice nurses were encouraged to attend the course together. From 1980 to 1984 three or four courses a year were held and between courses the DETU team (physician, nurse instructor, dietician, chiropodist) visited health centres for discussions with staff on diabetes-related topics. By 1983, one or more members of staff from 80% of Stockholm's 94 health centres had taken part in a DETU course. However, evaluation by the team, with help from psychologists, showed that only 10 centres had implemented structured diabetes care that met the following six criteria derived from national policy guidance:

- at least one nurse has special responsibility for care of diabetic patients
- there is a register of diabetic patients
- there are written guidelines for diabetes care
- the nurse modifies the patient's treatment
- special office hours are reserved for diabetic patients
- checklists are used

Staff in centres with well organized diabetic care were found to attend more meetings, participate more in discussions and decisions about diabetic care, and be more satisfied with interprofessional cooperation than those in other centres. The evaluation also showed that patients benefited from structured diabetes care, in that they had received more advice about diet, exercise, foot care and glucose testing, and were more knowledgable about foods. There were, however, no differences in metabolic control or complications (Rosenqvist, Carlson, Luft 1988).

In retrospect the DETU team realized that they had tried to impose on the health centres a centrally designed programme, without allowing the participants to adapt it to local conditions. This led DETU to rethink its approach. From 1985 participative organizational development measures were combined with the education courses, and this new approach was evaluated. Seventeen centres initially took part in the new development programme which included:

- an introductory meeting at the health centre
- interviews with staff members and patients
- a one-day conceptual modelling seminar for staff and patient representatives
- the CME course held at DETU
- practical work in a hospital day care unit
- on-the-job training
- three follow up visits by DETU staff to the health centre at six monthly intervals
- evaluation and feedback after 18 months

The views of staff and patients about problems with diabetes care in the health centre were sought during the interviews. A list of problems and solutions that had been suggested was sent to all participants before the seminar. Health centre staff selected participants for the seminar, with the aim of representing all categories of staff and patients. During the seminar, groups of 8–12 people, led by a DETU member, constructed a 'conceptual model' of diabetic care. The process of conceptual modelling involves analysing existing diabetic care, identifying problems, and suggesting solutions. This way of working allows all participants to be involved in the process and ensures that plans for development are based on participants' collective experience of diabetic care. The seminar also nominated key staff for the DETU course. Time was allowed in the DETU course for work on the development plan for each health centre. A further description of conceptual modelling appears in Chapter 15.

Evaluation showed that this approach was successful in getting the centres to change and improve the organization of diabetes care. The majority of problems identified at the seminars were organizational and after 18 months solutions to 76% of these problems had been implemented. 'We believe that the success rate of implementation of the local plans must be due to the fact that they originated from within the group itself'. However, the centres were less successful in solving the problems they identified concerning communication between staff and patients and relationships with hospitals and specialists in diabetes (Carlson 1990, Carlson and Rosenqvist 1990).

FROM HOSPITAL CLINICS TO DIABETES CENTRES

Although the main thrust for improving diabetic care has been to develop services based in general practice, there have also been changes in hospital-based provision. There is a consensus that traditional hospital outpatient clinics have outlived their usefulness and that, in particular, they are an inappropriate setting for providing the education and continuing support needed by people with diabetes. A growing number of hospital consultants have established diabetes centres as the focus for diabetic care in a district, and the British Diabetic Association recommends that every district should have one (Day and Spathis 1988). Diabetes centres are not simply a replacement for routine clinics, but embody a new approach to diabetes which emphasizes education and prevention; more accessible and comprehensive services that are community rather than hospital-based and delivered by a multidisciplinary team; better integration of primary and secondary care; and patients taking more responsibility for managing their condition. According to Ward and MacKinnon (1992) the primary role of a diabetes centre is educational, but it is also a resource giving advice and support about diabetes to everyone with the condition, as well as to professionals in hospitals and primary care. A workshop in 1987, designed to explore the aims and experience of existing centres, thought the centres should act as a 'catalyst, particularly in improving communications, liaison, and integration of care' (Day and Spathis 1988). The functions of a diabetes centre include:

- holding a register of all diabetic patients in the district
- providing appropriate organization and environment for effective patient education
- acting as a communication centre: to give advice to patients; to coordinate members of the diabetic team; to provide integration with other hospital departments and staff; to help GP cooperative care schemes; to act as a focal point for training medical and non-medical staff
- providing a comprehensive system of clinical care and evaluation, including:
  outpatient care of all new and follow up cases; screening for complications; treatment of diabetic complications and referral for non-diabetic problems; development and support of shared care schemes;

Enthusiasts have written most of the published papers about diabetes centres, for example Brown (1987), and they seem to have fallen into the trap of promoting centres as the single solution to the problems of organizing and integrating diabetic care. Although there have been no formal evaluative studies of the impact of diabetes centres, Ward and MacKinnon (1992) are so convinced of their value that they go as far as claiming that 'The development of diabetes centres and the philosophy behind them are probably the most important contributing factors to improvement in diabetes care in the past decade'. It is clear that diabetes centres with a community orientation could be an important focus for developing services in general practice and establishing shared care schemes, especially if they have facilitators who can create strong links with general practices as in the example from Greenwich that we described above.

Some issues in successful shared diabetic care

THE IMPORTANCE OF PRACTICE NURSES

Practice nurses, receptionists and administrative staff in general practice are pivotal to most forms of shared care because they organize appointments, maintain registers of patients, operate recall systems and collect data for audit. Many routine aspects of reviewing patients, and providing information and education appropriate to individuals are increasingly being delegated to practice nurses (Bradshaw and Spencer 1990). The successful involvement of the majority of practices in shared care in Camberwell, Greenwich and Sheffield (MacKinnon *et al.* 1989) coincided with substantial increases in the number of practices employing nurses. Greenhalgh (1994) observed that 'There is a strong impression that a well-trained and confident practice nurse is vital to the smooth running of a diabetic service in the general practitioner's surgery'. Facilitators in a number of districts have found it important to work as closely with practice nurses as with GPs, particularly to build up nurses' knowledge, skills and confidence to undertake structured diabetic care (Wilson *et al.* 1991).

FRAMEWORKS AND FLEXIBILITY

A feature that many successful shared care schemes have in common is an explicit framework for services which has been agreed between hospital specialists and primary care teams. As shown by the examples, this may take a variety of forms. In Sweden, national policy guidance on the organization of diabetic care provided a framework for the DETU initiative. In Greenwich, the facilitator appears to have adopted the implicit standards of the diabetes centre to assess the constraints on services in general practice. In Camberwell, ideas and plans were first developed by a small group of local champions before being canvassed with a broader cross-section of GPs in the district. In Islington and Grampian, a structure for the service was built into the computerized systems, which were designed with GPs' needs in mind. In future, the requirements laid down by the Department of Health for chronic disease management programmes may provide a general framework within which practices can develop their diabetic care.

In some schemes, especially the early ones, hospital specialists were the local champions who succeeded in getting practices to conform to one model of providing care or the use of a standard protocol. However, more recent schemes have shown that, while it is necessary to work within a framework, it is also important, at least initially, to offer practices sufficient flexibility to build up diabetes care at their own pace and to organize it to suit their own needs as well as those of their patients. Diversity is often considered a strength of Britain's primary care system and the message from our examples is that it should also be allowed in shared care schemes, as long as basic standards of care are met. Some groups, particularly in Greenwich and Camberwell have worked on the principle of encouraging practice teams develop their own systems rather than trying to convince them to conform to a single protocol. Greenhalgh (1994) has described a similar approach to shared care in North Tyneside, where there is a programme of care but no protocol, and participating practices develop their own ways of achieving the common standard, a way of working that DETU found effective in Sweden.

THE ROLE OF FACILITATORS

Facilitators have played a central role in the development and spread of shared diabetic care schemes. A facilitator's main role in many schemes has been to provide information, expertise and support to GPs and their practice staff. A key task that has been emphasized is to help practices prepare and organize themselves for systematic and structured care, and many facilitators have a professional training and clinical experience in diabetic care. Many facilitators are specialist diabetic nurses, or have previously worked in this capacity (MacKinnon *et al.* 1989). However, there is increasing recognition that abilities other than those required to transfer clinical knowledge and skills may also be necessary to be an effective facilitator. An important focus of the Camberwell project was extending the role of practice nurses and helping their professional development. The unit in Stockholm also found that they needed to work on more than just an educational front and combine giving specialist training with providing team and organization development in order to enable the majority of health centres to implement structured diabetic care. The role of the facilitator in team development and change management has also been emphasized by those involved in a facilitator project in Southampton (Spiegal *et al.* 1994). They found support for their approach to facilitation which offered practices confidential consultations and help with multidisciplinary team building as part of a project to improve diabetic care in general practice. The skills required for the different facets of a facilitator's job may rarely be found in one person. There seems to be much to recommend 'team facilitation' of the kind developed in Camberwell and Sweden, which allows facilitators to offer practices a much wider range of expertise than a single facilitator with clinical experience in one domain.

COMPUTERS AND AUDIT

Centralized diabetes registers are said to be an essential feature of district-wide shared care schemes (Burnett *et al.* 1992, Howitt and Cheales 1993). Indeed, central computer systems for registration, recall and review of patients are pivotal to some schemes, such as those in Islington and Grampian. However, Greenhalgh (1994) and others are cautious about their value, especially those systems that demand recording of standard information about each patient. Schemes which rely too heavily on centralized organization and compliance with top-down directives may never succeed in gaining participation of all general practices. As practice-based computer systems become more sophisticated and GPs and teams more knowledgeable and confident about diabetic care, the trend seems to be to develop practice-based systems which allow teams to introduce structure while retaining control and flexibility in how they organize care.

Computer systems can clearly facilitate audit at whatever level it is carried out—in an individual practice, by groups of collaborating GPs or across a whole district. Shared care schemes are now emphasizing the importance of audit and more sophisticated initiatives are being undertaken than ever before (for example Benett *et al.* 1994). All GPs receiving payment for diabetes management programmes are required to collect information that enables them to audit their diabetic care, and some FHSAs expect to receive audit findings (Greenhalgh 1994). It is encouraging to find that some practices are managing to 'close the feedback loop' in their audit activities and develop services rather than simply compiling data (Lawrence 1992). However, Greenhalgh (1994) believes that many practices would benefit from being offered a standard, simple and rapid audit package for diabetic care as part of a shared care scheme.

SUMMARY

Some important elements for successful shared diabetic care seem to be:

- GPs and practice staff who are motivated and interested in improving care for their diabetic patients
- clear division of responsibility between general practice and hospital teams
- a structured approach to providing general practice-based diabetic care, with clear aims and systematic follow up of patients
- a register of patients with diabetes, preferably computerized, to enable easy recall of patients and facilitate audit
- patient-held shared care cards or records for good communication
- access to facilities that are normally unavailable to a practice—dietician, chiropody, laboratory services, specialist nurse advice, retinal screening, education support, etc.

- support and training for GPs, practice nurses and others to motivate them and keep them in touch with developments in diabetic care
- ease of communication and close cooperation with hospital clinic or diabetes centre
- facilitators to help the practice team gain the knowledge, skills and confidence to establish effective diabetic care
- financial incentives for practices to take on more chronic disease management
- involvement in audit of diabetic care and encouragement to use findings to continue to improve services.

In her review of shared care for diabetes, Greenhalgh (1994) sees greatest potential for the future in schemes with a 'radical ideology' of encouraging comprehensive care in general practice for almost all diabetic patients. These schemes are practice-centred rather than hospital-centred and multidisciplinary rather than doctor-dominated. The main examples are in South Glamorgan and North Tyneside. Greenhalgh (1994) describes how the North Tyneside scheme operates: 'The hospital-based team, which includes the consultant, specialist nurse facilitator, dietitian and chiropodist, offers practice-based support in all aspects of clinical care and organization, but patients do not routinely attend the hospital either at diagnosis or any time thereafter. Strong emphasis is placed on evaluation and audit, and on the application of common standards of care throughout the entire district. The district guidelines for diabetes care were drawn up in a series of workshops with guidance from the consultant but major input from the general practitioners'. She believes that initiatives like this take the concept of shared care a stage further than most other systems. In these schemes it is not necessarily the patients who are shared at all but the resources and overall strategy for care. They reflect both the expanding role of the general practitioner and practice team in chronic disease management and the changing role of the hospital specialist.

Asthma

Around two million people (6%) in the UK suffer from a wheeze or asthma requiring treatment. Asthma is the commonest chronic disease affecting all age groups in England and a major cause of preventable deaths and ill health (Harrison and Partridge 1991). It is estimated that one in 10 children and 2–5% of adults have asthma and there is evidence that its prevalence and severity are increasing, despite the availability of effective drug treatment (Burney 1991). Death rates have remained fairly constant over the last twenty years: asthma kills approximately 2000 people each year in the UK. Asthma is a major reason for hospital admission in all age groups and an important cause of absence from work and school. The estimated cost of asthma to the NHS in 1988 was £344.4 million, of which £228 million was for medicines prescribed by GPs (NAHAT 1994).

MANAGEMENT OF ASTHMA

There are guidelines on the management of acute and chronic asthma in adults and children, the most influential being those developed by the British Thoracic Society (BTS) in collaboration with a number of other interested groups. These were the first national guidelines to be published in the UK, and they were the result of discussions between a group of clinicians in primary and secondary care who reached a consensus on how asthma in adults should be managed (British Thoracic Society *et al.* 1990). They have since been revised and extended to include guidance on the management of asthma in children (British Thoracic Society and others 1993, Woodhead 1993). The guidelines describe the aims of management as to recognize asthma; abolish symptoms; restore normal or best possible long-term airway function; reduce the risk of severe attacks; enable normal growth to occur in children; and minimize absence from work or school.

The main elements in the guidelines are

- the use of 'stepped' plan of care for managing chronic asthma, with treatment increasing from occasional use of bronchodilators alone for patients with mild asthma (step 1) through to a combination of several drugs for patients with more severe asthma (step 5). Gradually 'stepping down' treatment, when this is indicated, is also emphasized.

- the use of objective measures of airway obstruction to assess severity, particularly the measurement of peak flow rates. Patients themselves are expected to play a major role in monitoring their progress by measuring peak flow rates. Clear descriptions are given of what represents control of asthma.
- the emphasis on patients managing their asthma themselves as much as possible, through 'guided self-management plans'. Patients should be given instructions, tailored to their own particular needs, about increasing medication when their asthma deteriorates and reducing medication gradually as it improves, according to their symptoms and peak flow measurements.

Management of asthma clearly involves more than prescribing drugs. Of equal importance to appropriate drug treatment are educating patients about the proper use of medication; regular review of symptoms and treatment; and establishing individual management plans. The majority of known asthma patients are managed almost entirely in general practice without recourse to specialist advice, or with very infrequent attendance at hospital. However, those with more severe asthma have typically been long term attenders at hospital chest clinics.

During the 1980s, in response to evidence that current management of asthma was less than optimal (see below), some GPs began to explore ways of improving asthma care. Their typical approach, as with other chronic conditions, was to introduce systematic and planned care, with regular reviews and greater emphasis on educating patients about their illness and its treatment. Practice nurses became more involved in the management of asthma and some practices established asthma clinics in which nurses carried out much of the routine follow up of patients.

These trends were reinforced by the introduction of the new contract for GPs in 1990, which encouraged practices to establish asthma clinics and involve practice nurses. In the same year publication of the first BTS guidelines also drew attention to the therapeutic aspects of asthma care, and gave GPs a yardstick against which to compare the treatment of their own patients. In a leader in the British Journal of General Practice, Jones (1991) predicted a 'revolution in asthma care' in the 1990s. He welcomed the guidelines, but commented that they 'provide good advice on asthma treatment, but do not cover some of the important organizational points such as when practice nurses providing follow up for asthmatics should refer back to the general practitioner'. His assessment was that the guidelines would 'pose a considerable organizational challenge for general practice. At present many primary health care teams are some way from being able to provide such proactive care'.

However, the introduction of a new health promotion package for general practice in 1993 may be an important factor in bringing about the revolution more quickly than anticipated. The new package replaced the original arrangements for health promotion clinics in the GP contract, and GPs may now claim a fee specifically for organizing a chronic disease management programme for asthma (GMSC 1993). Certain requirements laid down by the Department of Health must be met, and all programmes must be approved in advance by the FHSA. In an organized programme for the care of patients with asthma practices must:

- maintain a register of all patients with asthma
- ensure that systematic call and recall of patients on the register is taking place, either in hospital or general practice
- give advice to all newly-diagnosed patients or their carers
- ensure all patients (or their carers) receive continuing education, including supervising inhaler technique
- prepare with the patient an individual management plan
- regularly review the patient (including peak flow measurement) generally every six months, but more or less frequently as required
- ensure any health professionals involved in the care of asthma patients are appropriately trained
- refer patients to other necessary services as required
- maintain adequate records and audit the care programme.

Despite Jones' assessment in 1991 that providing proactive asthma care of this sort would pose a 'considerable organizational challenge' for many practice teams, by October 1993, only six months after the new health promotion package was introduced, over 88% of practices in England and Wales were claiming fees for offering their patients an asthma management programme (DoH 1994a). Although many practices had set up asthma clinics under the original provisions of the contract, it is surprising that such a high proportion satisfied their FHSAs that they could meet the Department of Health's rather exacting list of requirements. It is perhaps even more surprising that so many were prepared to go to such lengths for an estimated £350 per GP per annum. Until audit information filters through from FHSAs it is impossible to assess the quality of asthma care practices are offering within this organizational framework. However, earlier evaluations of asthma care in general practice suggest that outcomes as well as structure and process should be measured.

QUALITY OF CARE

A number of studies in the 1980s highlighted deficiencies in asthma care, particularly in general practice. It is well known that asthma is under-diagnosed in primary care or, more specifically, diagnosis of asthma by GPs is often slow (Jones 1989). Furthermore, being diagnosed as asthmatic does not necessarily mean that a patient will receive the appropriate treatment (Gellert *et al.* 1990). A national survey of asthma attacks carried out by the General Practitioners in Asthma Group found that GPs' management of asthma differed from the BTS guidelines in a number of respects. Nebulized bronchodilators and systemic steroids appeared to be underused and, contrary to the guidelines for asthma management, 'step up' in maintenance therapy after an attack was not often practised. Neville *et al.* (1993) concluded that the standard of clinical care reported was less than acceptable. They suggested that 'a simple, relevant and attainable set of goals for the management of acute asthma in the community and in hospital is clearly needed. This needs to be supported by educational initiatives and a means whereby doctors can receive relevant personal feedback on how individual patients have been managed'.

In a survey of a random sample of patients on the repeat prescription register for anti-asthma drugs, Jones *et al.* (1992) found that 49% were wheezy or asthmatic at least once a week, 11% had their daily life interrupted due to asthma at least monthly and 31% had stayed off school or work because of asthma in the last year. 'Many deaths and much unnecessary morbidity have been associated with the underuse of inhaled and oral corticosteroid treatment, the underuse of objective measures of asthma severity and inadequate patient supervision and education' (NAHAT 1994).

IMPROVING ASTHMA CARE IN GENERAL PRACTICE

In view of the rising mortality and morbidity from asthma, and the evidence for under-diagnosis in primary care, suboptimal treatment and unnecessary morbidity among patients, a strong case has been made for improving asthma management in primary care (Jones 1989). Throughout the 1980s papers from general practice were published that described attempts to improve asthma care, mainly by establishing a systematic approach to management. For example Modell *et al.* (1983) reported an attempt by a group of GPs to standardize asthma management in their practice and assess its impact on morbidity. The doctors were able to agree on a plan of management and new record cards were printed as an *aide memoire*, to be used opportunistically when patients came to consult about their asthma. After one year there was an appreciable reduction in the severity of asthma among children, but the effect was less among adults. The clearly disappointed authors found that a small group of patients remained severely affected, indicating they had been inappropriately assessed and inadequately treated. Barritt and Staples (1991) also introduced structured consultations with the GP for asthma patients and reported improvements in patients' knowledge about their asthma and in certain symptoms.

During the late 1980s an important trend was the establishment of asthma clinics in general practice, and these clinics often involved practice nurses or were entirely run by a nurse. Asthma clinics were based on the same ideas and principles as diabetic miniclinics, which had already gained popularity as a way of organizing structured management and regular review of patients with diabetes. Greta Barnes and Robert Pearson pioneered nurse-run asthma clinics in general practice, and went on to train other nurses at the Asthma Society Training Centre at Stratford upon Avon (Levy and Hilton 1992). The involvement of nurses in asthma management, as with other chronic illnesses such as diabetes and hypertension, goes hand-in-hand with setting up a practice register of asthmatics, organizing a systematic recall and follow up system, using a protocol or plan of management, and putting more effort into educating patients about their illness (Menzies and Stearn 1990).

Martys (1992) evaluated the introduction of an asthma clinic to a group practice in Derbyshire. His account does not make clear what part the nurse played in running the clinic, but it appears to be largely administrative. The clinic resulted in improved record keeping, but little overall improvement in asthma morbidity. Other accounts of initiatives in individual practices are cited by Levy and Hilton (1992).

NURSE-RUN ASTHMA CLINICS

An asthma clinic run entirely by a practice nurse was evaluated by Charlton *et al.* (1991). The clinic was set up in a four-partner Norfolk practice in 1987 and a before-and-after study of patient morbidity undertaken. Two hundred and thirty-five patients with 'moderate to severe' asthma were identified from the repeat prescribing register and invited to attend the asthma clinic. The first interview with the nurse took about 45 minutes, during which she took a history of the patient's asthma and its treatment; corrected or revised the patient's inhaler technique; explained the mechanism of asthma and how the medication works; gave the patient a booklet about asthma and antismoking literature; gave the patient a self-management plan and explained how to use it. One week later the patients were reviewed again by the nurse for a further 15 minutes, when spirometry was performed, inhaler technique checked and progress with self-monitoring and self-management discussed. Medication was altered only after discussion with the GP. All patients were then asked to attend for review every two months, or more frequently if necessary. After the clinic had been running for 18 months 115 patients had attended and had been monitored for a year. The study was based on these patients.

In the clinic's first six months, consultations with GPs fell significantly, but the total number of consultations with GP and nurse remained fairly constant, indicating a redistribution of workload between them. Significant reductions were found in the patients' requirements for courses of oral steroids, acute nebulizations and days lost from work or school. However, it is difficult to interpret these encouraging results, since the introduction of the clinic also coincided with a change in patterns of asthma treatment, namely an increase in the number of patients receiving regular bronchodilator therapy and prophylactic medication. Eighty per cent of patients had their medication modified as a result of attending the clinic, but the cost of prescribing remained stable. Improvements in the morbidity measures were found in the first six months of the clinic's operation but these were not sustained for the second six months.

The study was unable to determine which elements of the package of care introduced with the asthma clinic—more education, the use of self-management plans, regular recall, improved inhaler technique, seeing a practice nurse, and more regular use of inhaled steroids—contributed most to patients' improved morbidity. The authors conclude that a 'nurse-run asthma clinic represents one way of dealing with asthma patients in general practice. The results show that a nurse in general practice using organized care and self-management plans can effectively manage asthma and reduce the number of general practitioner consultations for asthma, the need for oral steroids, acute salbutamol nebulizations and time lost from work or school' (Charlton *et al.* 1991).

According to Dixon (1993), only one controlled trial of a nurse-run asthma clinic in general practice has been undertaken. It found no 'clinically or statistically significant improvement in the asthma status of patients in the intervention group when compared with the control' (Jones 1993, cited in Dixon 1993). Dixon concludes that 'there is a strong belief that nurse-run asthma clinics can be effective, but there is no sound evidence that shows that such a service delivers a great amount of health gain'.

INTRODUCING AUDIT

A study in Tayside, Scotland, used an audit facilitator to try to improve diagnosis and treatment of childhood asthma (Bryce *et al.* 1995). The facilitator reviewed the case notes of all children in 12 practices and identified those being treated for asthma or with symptoms suggesting asthma. Over 3000 children were then randomly allocated to the intervention or control groups of the trial. Those in the intervention group had their case notes clearly marked with a sticker and the facilitator placed inside the notes a letter suggesting the GP review the patient, a chart entitled asthma diagnosis, a protocol for managing acute asthma attacks, and guidelines on maintenance treatment with prophylactic drugs. All practices were given a list of children in the intervention group, supplies of equipment (inhaler devices, peak flow meters and nebulizers for emergency use) and patient education material, so that all these children could receive a systematic or opportunistic review, appropriate follow up, assessment, education and emergency treatment in line with modern recommendations. The facilitator had no direct patient contact and no regular meetings with practice staff.

One year later children in the intervention group were found to have had more practice-initiated consultations for asthma, new diagnoses of asthma and past diagnoses reaffirmed and they were more frequently prescribed inhaled cromoglycate than the control group children. Compared with the year before the trial, the intervention group showed a reduced use of hospital services and the control group an increased use. Estimates of costs indicated that better management of childhood asthma led to increased general practice costs, increased prescribing costs, and a decrease in hospital costs. The authors concluded that 'An audit facilitator can favourably influence the pattern of diagnosis and treatment of childhood asthma in general practice'.

Much of the published work on asthma care research and development in general practice emphasizes organizing better and more systematic management of patients within primary care. The consensus seems to be that the main focus for asthma care should be the primary care team. Little attention has been given to improving coordination of care between hospital and general practice, for example following hospital attendance or admission with an acute asthma attack. Levy and Hilton (1992) express concern about the interface and the problems of 'poor follow-up arrangements after life-threatening attacks of asthma, and inappropriate referrals—both acute and outpatient—from primary care'.

THE DEVELOPMENT OF SHARED CARE

Asthma is often mentioned as an example of the kind of chronic illness that requires good coordination between hospital and primary care and is deemed to be suitable for the development of shared care. For example, a recent NAHAT Update (1994) states that 'With the increasing trend towards management of asthma in the primary care sector, it is important that there is co-ordination of patient care between primary and secondary sectors. Protocols for asthma should therefore be agreed between GPs and DHAs to cover topics such as criteria for referral to outpatient clinics and admission, GP follow-up after acute admission and patient education on discharge'. Surprisingly, however, there are very few reports in the literature of such initiatives, or of shared care schemes for asthma, although a survey in Scotland and North West Thames region identified five shared care schemes (Hickman *et al.* 1992).

Three schemes are described below. The first account is of how a GP-led scheme was set up in Camberwell, South London, by a primary care development project with the help of an asthma physiotherapist who worked as a facilitator. The second is an evaluation of an unique initiative taken by a hospital paediatric department to improve children's asthma care. The main innovation was a nurse-run clinic in the hospital, but an important theme of the work was to 'bridge the gap' between hospital and general practice. The third account was of the evaluation of an 'integrated care scheme' for patients with asthma in the Grampian region of Scotland. The scheme was supported by computerized patient records and a recall and review system that linked the hospital clinics and general practice. This scheme is the only fully developed asthma shared care scheme that has been evaluated and the results published.

SHARED ASTHMA CARE IN CAMBERWELL

This scheme was initiated by the Camberwell Primary Care Development Project (CPCDP) which, from its base in a department of general practice, had established strong networks with GPs and members of practice teams (Morley *et al.* 1991). Their approach to developing shared care was to involve as many GPs and other members of primary health care teams as possible at all stages of development of the scheme, in the belief that this would promote greater participation and support, and ultimately a sense of ownership of the scheme, than if the initiative was seen as coming from an individual or a single department. Keynotes of the scheme were flexibility, allowing practices with different needs, facilities and expertise to take part; working with practice nurses, in recognition of the central role they play in managing asthma in primary care; and the development of agreed standards of care. A similar approach was used to develop shared diabetes care in the district (see page 70). The project described the principles behind shared care as:

> *'...the highest quality care should be offered to the patient, combining continual and personal care from the primary care team, with the support and expertise of hospital specialists both working within an agreed framework for the management of illness. Care should be provided in a manner accessible and appropriate to the individual and there should be support for patients and their families to take increased responsibility for their illness'*
>
> (Holley and Evans 1992).

In September 1986 a working group of three consultants in thoracic medicine from King's College Hospital and two GPs with an interest in asthma began meeting regularly to discuss how to develop asthma care in the light of the needs of local GPs, the hospital department and patients. In the spring of 1987 a questionnaire was circulated to Camberwell GPs to obtain their views on asthma care; 77 of 136 GPs responded, of whom 61 said they would be interested in a scheme of increased cooperation with the department of thoracic medicine. Most wanted greater access to diagnostic facilities, agreed guidelines, a district strategy for the care of asthma and a worker to link the GP, hospital department and families. Seventy-seven per cent of respondents supported the idea of a physiotherapist specializing in asthma to work with them in their practices and to coordinate and develop a shared care scheme.

The working group drafted guidelines for asthma management and a job specification for an asthma physiotherapist, who would work with practices as a facilitator. The proposal for shared care and the guidelines were discussed and amended at a meeting between local GPs and the department of thoracic medicine in November 1987. Two years' funding from the RHA's primary health care development fund was obtained for the physiotherapist who took up post in April 1989.

Personal contact with practices was thought to be the best way for the physiotherapist to support change and develop services in Camberwell, so she visited all interested GPs and practice nurses. These meetings were followed up by the physiotherapist providing literature on new developments in asthma management; helping practice nurses establish asthma clinics; and organizing a series of seminars and practical workshops for GPs and nurses. A great deal of effort was put into providing education and training for practice nurses. Links with secondary care were also encouraged and GPs were given access to diagnostic lung function testing facilities at the hospital.

The physiotherapist's work was not formally or independently evaluated, but information about asthma care in local practices was collected at the beginning and end of the two years (in 1989 and 1991). Some important indicators of improvements in asthma care were documented, in particular there were increases in the number of practices with asthma registers; those holding asthma clinics or offering structured care; those using treatment protocols; those using recall systems; those asking patients to keep peak flow diaries; those providing literature to help patients understand their illness; those teaching inhaler technique; and those with equipment and facilities for asthma care. No information was collected on asthma mortality or morbidity as this was beyond the scope and resources of the project.

It is difficult to assess how far these changes in asthma management were due to the activities of the facilitator, because she was in post at a time when there were a great many other influences on primary care in general and asthma care in particular. National policy developments, positive attitudes among GPs to taking on more chronic disease management, and an increase in the employment of practice nurses may have created a climate in which many practices were ready to implement change. At the end of the project a questionnaire to GPs asked which factors they rated as important to their development of asthma care. The most important were the prevalence of asthma, the presence of a GP or practice nurse with a special interest in asthma (a champion), and the asthma physiotherapist (facilitator). 'The asthma physiotherapist was of particular value as she was able to act as a back-up, supporting the development of asthma care through the provision of information, education and training' (Holley and Evans 1992).

During the course of the project the consultant community chest physician began to hold clinic sessions in some local practices. He provided a consultant opinion on difficult cases of asthma and the clinics also offered an opportunity for joint learning by consultant, practice team and patients. There are plans to extend the clinics to more practices.

NURSE-RUN PAEDIATRIC ASTHMA CLINIC

A nurse-run asthma clinic, based on experience gained in general practice (Charlton *et al.* 1991), was established in the paediatric department of a district general hospital. A randomized controlled study was carried out over two years to assess its impact (Charlton *et al.* 1994). Children admitted with asthma or being seen in outpatients were recruited to the study. Those seeing the nurse had a 45 minute interview which was similar to that developed in general practice (see page 88). Patients were given a peak flow meter and a diary card to record symptoms, peak flow and medication. However, instead of being recalled for regular review at the hospital, patients were sent a letter every three months reminding them to have their asthma reviewed by their GP or practice nurse. The letter suggested that they should have their inhaler technique, diary card and self-management plan reviewed during their visit. GP cooperation with the study had been established at an early stage and GPs and practice nurses were invited to a series of meetings before the start of the study to discuss their involvement and the principles of asthma self-management that would be used in the intervention group. Newsletters giving information about the progress of the study were sent to GPs throughout.

The authors found that patients in the intervention group had significantly less restriction of activity; fewer episodes of peak flow below 30% of best; and were more likely to make the correct response to an acute exacerbation of their asthma than the control group. They also had fewer school absences and fewer home visits by a GP. The authors felt that they had demonstrated only 'limited gains', and speculate that their programme may have benefited from more intensive follow-up by the asthma nurse. There was an increase in readmission to hospital for the intervention group.

One of the aims of the project was to improve communication between primary and secondary care, by means of the newsletter to GPs, evening meetings for members of practice teams and the patient-held diary card. The reminder letters may have changed patients' expectations and GPs' attitudes about follow up of asthma in general practice. The authors report that a number of parents commented that since having the diary card they felt more able to speak to their GPs and were surprised to find that the GPs did care about their child's asthma.

Although this study was not referred to as shared care by the authors, it clearly has elements that are found in shared care schemes, although GPs were not expected to follow written guidelines or protocols or to enter into any special communication with the hospital department.

GRAMPIAN ASTHMA STUDY OF INTEGRATED CARE (GRASSIC)

This formal shared care scheme has been evaluated by randomized controlled trial and the results published (GRASSIC 1994). In 1989 a shared care scheme was developed for adult outpatients with asthma attending hospital clinics in Aberdeen and other centres in Grampian, NE Scotland. The scheme was coordinated by means of a hospital based computerized patient record system, which has also been used in shared care for patients with diabetes (see page 68) and hypertension (see page 102). Patients were seen by the hospital specialist annually. Reviews were initiated by computer-generated letters to patients every three months, inviting them to consult their GP, and to GPs informing them that the patient was due to attend for an asthma review. Both letters included a short set of questions intended to describe the condition of the patient's asthma over the preceding weeks. The patient was asked to complete the first questionnaire and give it to the GP. In the light of the patient's responses and the rest of the consultation, the GP completed the second questionnaire, which included questions on such topics as sleep quality, restrictions on daily activity and drug use, and returned both to the consultant. These questionnaires were developed before publication of the British Thoracic Society guidelines, but they prompted the recording of many of the same items of clinical data as the BTS guidelines. The questionnaires were intended to give structure to the consultation but were not management protocols. The information from the questionnaires was used to update the patient's computerized record (profile) which was held in the hospital department. One printed copy of the updated profile was then sent to the GP, while another was placed in the hospital notes. Both GP and specialist were kept informed of the patient's condition and either could suggest changes in medication or request more frequent hospital clinic attendance.

Patients receiving shared care were compared with a group who continued to receive conventional outpatient care, typically every three months. During the study year they too were sent a clinical questionnaire before each visit, to be returned to the specialist. As well as comparing conventional outpatient care and shared care, patients in this trial were also independently assigned to peak flow self-monitoring or conventional monitoring, and enhanced education or conventional education. Patients whose asthma was considered too difficult for shared care were included in the other dimensions of the study. The study was designed to evaluate, in clinical, social and economic terms, the effectiveness of integrated care, self-monitoring of peak flow and personalized, computer generated education for patients with asthma. A separate, qualitative survey of a sample of GPs was also carried out to investigate GP views of the scheme (Van Damme 1994).

Seven hundred and twelve patients were eligible for randomization (89 patients were considered ineligible because their asthma was too severe) and 363 were allocated to shared care and 349 to conventional outpatient care. After one year there were no significant differences in pulmonary function between the two groups. There were also no significant differences in the number of prescriptions for bronchodilators and inhaled steroids, the number of courses of oral steroids, the total number of GP consultations, hospital admissions, reported sleep disturbance and restriction of activity. When asked to rate their perceived level of asthma control, shared care patients were significantly more likely to describe themselves as being in control all the time. Patients who had experienced shared care were also more likely to select it as their preferred course of future management. Integrated care was calculated (at 1991 prices) to save the hospital £3.06 per patient per year; to save GPs (assuming they were fundholders) £2.41 per patient per year, and to save the patients themselves £39.52 per year. The authors concluded that 'integrated care for moderately severe asthma is clinically as effective as conventional outpatient care, is cost effective, and is an attractive management option for patients, general practitioners and hospital consultants'.

When patients finished their first year in the scheme GPs were asked to recommend either complete discharge to general practice care, continuation of integrated care, or a return to conventional outpatient care. The GPs wanted 64% of patients to remain in integrated care. Three quarters of all patients wanted to continue in the scheme. Integrated care patients were significantly less likely to describe themselves as 'very satisfied' with the medical care they had received for asthma during the course of the year (77%) than conventional care patients (86%). This may be due to patients' perceptions of hospital consultants as 'experts' and GPs as 'generalists', a point of view which may be particularly prevalent among those who have become long-term attenders at outpatient clinics. The authors describe this as a 'credibility gap' in patients' views of shared care, and suggest that efforts should be made to establish patients' confidence in the ability of GPs to manage asthma.

Van Damme (1994) interviewed 38 of the 317 GPs who took part in the Grampian scheme (most of the GPs had only one patient in shared care). He found that the relationship between GPs and chest consultants had been good before the scheme started and did not worsen afterwards. The consultants in Aberdeen were thought to be communicative and easily accessible and there was consensus about the respective roles of GP and specialist. Most GPs in the study wanted to take responsibility for the care of patients with asthma and keep involvement of specialists to a minimum. Specialist were needed to back up GPs and provide education about new treatments and improved management.

GPs thought the scheme had several advantages: the continuity and quality of care provided was improved, and the transmission of information between GP and specialist was enhanced. The regular GP reviews, instigated by standard letters generated by computer, were favoured as being clearly structured. Some concerns were raised about the processing of paperwork and the possibility that unnecessary reviews might be generated.

A few GPs had mixed feelings about the shared care scheme and the comments of one GP, reported by Van Damme (1994), shed light on a view of shared care that may be more widely held, if not often voiced:

> *'I have a slightly cynical view on integrated care. The stimulus for integrated care partly comes from the idea that hospitals are overloaded with work, and this is a convenient way of off-loading some of this work. In my mind it is not terribly integrated in that we tend to act as peripheral outpatient clinics for consultants. We are, if you like, the junior staff outside, just keeping them addressed of what is going on; and they will take action if and when they need to. This has certainly been the case with antenatal and hypertensive care in my experience. So I am a bit cynical in the motivation for it. In theory it sounds good and I am sure a lot of people are attending hospital clinics unnecessarily. But these initiatives by and large have been hospital-stimulated and they haven't come from general practice'.*

The Grampian scheme appears to have been welcomed by most GPs because it enabled them to extend their existing expertise to a group of patients with asthma of moderate severity and allowed them to consolidate their role as primary carers.

SUMMARY

The main thrust of developments in asthma care documented here is to improve the management of asthma in general practice, and there is an extensive literature about how this could be achieved. Much less emphasis has been placed on establishing large-scale shared care schemes. This may be because the majority of asthma patients are already managed almost entirely in general practice, and for routine care GPs have no need to use specialist services or hospital facilities. They may also be more confident about treating patients with asthma than, for example, those with diabetes.

Many of the developments in primary asthma care parallel those in diabetes and other chronic illnesses—the implementation of systematic and structured care, with regular reviews and an emphasis on educating patients about self-management of their illness. The growing involvement of practice nurses in routine monitoring and patient education is a common trend and facilitators have been used to help practices organize more effective asthma care.

The three shared care schemes described here have different starting points and different aims. The approach in Camberwell was to help practices extend and improve the care they gave to all patients with asthma, as well as to develop better links between those working in primary care and the hospital department. Much of the work focused on practice nurses and their role in routine asthma management. The two other shared care schemes were concerned with groups of patients who previously would have been considered to require follow up in hospital: children and adults with moderately severe asthma. Both schemes were initiated by hospital departments, involved regular 'prompting' of patients to have their asthma reviewed by their GPs, and were evaluated by randomized controlled trials. The attempt to improve collaboration between specialists in the hospital paediatric department and local GPs was relatively low key: GPs and practice nurses were not asked to follow protocols or to enter into any special communication with the hospital department. However, personal contact was established by inviting them to meet hospital staff to discuss the initiative. They were also kept informed of its progress. The Grampian study used a computerized system to set up a shared care scheme in which patients were reviewed annually at the hospital clinic and every three months in between in primary care. Standard information from the reviews was exchanged between GP and hospital. Although GPs and patients were in general satisfied with these arrangements, questions remain about the longer term impact of such schemes on patterns of care. The danger of creating information systems which reinforce rather than help to break down the strict separation between primary and secondary care is that current patterns of care will be perpetuated. Other projects, such as Camberwell, have placed high value on personal contact and an educational strategy to transfer knowledge and skills from specialists to those working in primary care to enable them ultimately to take on much more of the care of patients with asthma.

Hypertension

Raised blood pressure is a cardiovascular risk factor: the higher the blood pressure the higher the risk of both stroke and coronary events. It is well established that lowering even mildly raised pressures reduces morbidity and mortality from cardiovascular disease (Subcommittee of WHO/ISH 1993). Despite the accepted importance of controlling hypertension, the DHSS Hypertension Care Computing Project (1992) found that control was poor in patients treated in both hospital outpatient clinics and in general practice, although outpatient clinics achieved marginally better results. A more recent population study in Scotland found that the 'rule of halves' still applied: half the hypertensive population was undetected, half of those detected were treated and in half of those treated hypertension was not controlled (Smith *et al.* 1990). Even applying less stringent criteria than the WHO definition of raised blood pressure ($\geqslant$160/95 mmHg) this study found that hypertension was detected and treated satisfactorily in only a quarter of men and 42% of women. Other studies in general practice have consistently found that follow up of hypertensive patients is inadequate, with haphazard recording of information in records (Mant *et al.* 1989, Payne *et al.* 1993).

Most patients with hypertension are discovered and managed by the GP. Emphasis has been placed on introducing a structured approach to screening and treating hypertension in primary care. If specialist advice is required the patient is generally referred back to GP care as soon as possible. There are a number of published guidelines and protocols for managing hypertension which have been devised by local groups, for example by Hoffbrand and Ross (1992) and the Lothian Hypertension Group (1984a, 1984b); national organizations, such as the British Hypertension Society (Sever *et al.* 1993); and international organizations, such as WHO and the International Society of Hypertension (WHO/ISH 1993). Several sets of guidelines on the management of hypertension in elderly people, based on randomized controlled trials, have been published recently (Danhlof *et al.* 1991, Systolic Hypertension in the Elderly Program Cooperative Research Group 1991, Medical Research Council Working Party 1992), along with editorials and review articles in leading medical journals (Anon 1991, Beard *et al.* 1992, O'Malley and O'Brien 1992). Despite the dissemination of these findings, Fahey and Silagy (1994) found wide variations in GPs' reported management of elderly patients with hypertension with 'room for further improvement'. However, compared with an earlier survey of a different group of GPs, management had moved closer to that recommended by the guidelines, in particular towards a lower blood pressure threshold for initiating treatment.

Over the last decade practice nurses have played an increasing role in organizing and running hypertension clinics in general practice (Barnes 1983). A group in Birmingham reported a successful experiment with a nurse using a computer-based treatment protocol (Kenkre *et al.* 1985). Jewell and Hope (1988) in Southampton carried out a small randomized controlled trial showing that a nurse was as effective at controlling hypertension and as acceptable to patients as a group of GPs.

SHARED CARE FOR HYPERTENSION

The value of shared care in managing hypertension has been recognized since the 1970s. Ezedum and Kerr (1977) reported having used a shared hospital-GP record for three years. Patients without complications were returned to GP care after initial investigation and control of their hypertension at the hospital clinic. Patients with complications were issued with a shared record card on which hospital staff and GPs could record blood pressure readings and information about drug treatment. The GP was left to decide how often he would see the patient between visits to the outpatient clinic. These changes were introduced without any discussion with GPs, but the majority of GPs and hospital staff found the record a useful aid in the care of patients with hypertension. The benefits of the shared care record, according to the authors, were that it established a two-way flow of information about patients who were being followed up long term (rather than the previous one-way flow from hospital to GP); it provided hospital staff with more blood pressure readings on which to base changes in treatment; and for the GPs it conveniently tabulated information which would otherwise be dispersed in GP records and hospital letters.

SHARED CARE IN GRAMPIAN

A computer-assisted shared care scheme was started in 1980 in the Grampian region of Scotland (Petrie *et al.* 1985, 1989). Its purpose was to simplify and improve the long term management and follow up of patients with hypertension by facilitating exchange of information between doctors. Patients referred to the Aberdeen blood pressure clinic were entered into the scheme. All patients had a record held on the hospital computer. After assessment they were allocated to follow up by the GP or at the hospital clinic. Patients to be seen by their GP were sent a letter inviting them to attend the surgery and instructing them to take all medication to show the GP. The GP was sent a 'patient profile' based on the hospital record which he was asked to update when he saw the patient and to return to the hospital clinic. Hospital staff screened each patient profile before it was sent to the GP and could write comments for the GP about possible drug interactions and suggestions for changing treatment if blood pressure targets had not been attained. When the updated profile was returned to the clinic, it was again screened by hospital staff and a decision made about scheduling the next appointment. The new data were entered on to the computer and the appropriate letters sent to patient and GP.

The authors reported that the scheme was well received by GPs and referrals to the hospital clinic increased. They believed that greater contact between hospital doctors and GPs improved the care of hypertensive patients. The scheme also reduced the number of patients under regular long-term follow-up at the hospital clinic: only 18% of patients assessed for shared care were assigned to long-term hospital follow-up. Thus specialist resources had been concentrated on these highest risk patients.

THE WEST OF SCOTLAND SCHEME

A scheme similar to that in Grampian was set up in the west of Scotland in 1986 and evaluated over two years (McGhee *et al.* 1994). A computerized register of all patients held at the Glasgow Blood Pressure Clinic was used to generate for GPs an annually updated, two-page medical record on each patient enrolled in the scheme and, for patients, a patient-held summary record. Each year patients were prompted by a letter from the registry to arrange a review with their GPs. This included a clinical examination, serum biochemistry and an electrocardiograph (done in the practice or in hospital). After the review the GP returned to the registry the medical record, amended to include information collected during the year, the results of the clinical examination and the patient-held record. Results of biochemical investigations were sent directly from the laboratory to the registry. The full set of results was flagged by clerical staff for abnormalities and then seen by a specialist physician. An updated medical record was posted to the GP with a standard letter, including suggestions for changes in follow up plans. If necessary, a hospital appointment could be made at short notice.

For the evaluation, outpatients with well-controlled blood pressure attending the Glasgow Blood Pressure Clinic were paired, matching for age, sex and clinic attendance, and randomly assigned to shared care or continuing outpatient follow up. A total of 554 patients were successfully matched and randomized over a period of a year. The 277 patients allocated to shared care were cared for by 176 GPs. A further group of 277 patients were selected from a hospital-based nurse practitioner clinic in Glasgow.

After two years, significantly more patients had received a complete annual review in the shared care group (82%), compared with outpatient care (54%) and the nurse practitioner clinic (75%). There were no significant differences between the groups in clinical variables, including measures of blood pressure control. Shared care was popular among patients and with GPs, the majority of whom wanted the scheme to continue. The costs of shared care compared favourably with outpatient care, in particular shared care was shown to be a much cheaper option for patients. The authors list the benefits of this approach to shared care of patients with hypertension as more complete follow up, continuity of care, standardized follow up procedures, convenience for the patient, continuing specialist involvement and better auditing and evaluation of care.

Both the Grampian and the west of Scotland schemes were initiated by hospital specialists but required cooperation and participation by local GPs for their success. The specialists in Aberdeen consulted GPs and invited them to participate before the scheme began. 'The continuing exchange of profiles and letters about individual patients, as well as personal contacts, have helped to avoid misconceptions and to allow successful implementation of the shared care scheme' (Petrie *et al.* 1985). In Glasgow, the hospital consultants formed a steering group including academic GPs and public health professionals. GPs who used the hospital clinics were originally informed about the new scheme by letter, but a GP-specialist liaison group has been formed to discuss shared care. The protocols for annual reviews were developed initially from those used in the hospital clinic; the next generation of management plans are being devised in collaboration with GPs. 'Nurses now take the lead role in day-to-day administration of the scheme and the collaboration extends to practice nurses in the participating general practices' (McGhee *et al.* 1994).

SUMMARY

Hypertension is a chronic condition that requires prolonged treatment and regular monitoring and it is often cited, like diabetes and asthma, as being suitable for collaborative management between hospital and primary care. However, while it is clear from the literature that diabetic shared care is now well established and widespread, shared care for hypertension is less fully documented and its extent is difficult to assess. The two main initiatives described here are centralized, computer-assisted schemes in which the GP is prompted to review the patient at regular intervals. No examples were found of GP-led schemes, such as those in Camberwell for diabetes and asthma.

As in the management of diabetes and asthma, practice nurses are taking increasing responsibility for managing patients with hypertension, and the care they give is often guided by written protocols. No examples were found of facilitators helping to establish general practice based care or shared care for hypertension, although they have played an important part in the development of primary care services for diabetes and asthma.

Commentary on shared care for chronic illness

This review of shared care for chronic illness found a much larger body of literature on shared care for diabetes than for asthma or hypertension. However, there is an extensive literature on the development of asthma care and hypertensive care in general practice, much of it without reference to the need for patients to continue to be seen by hospital specialists, as in traditional shared care schemes. It may be that many shared care schemes for patients with asthma and hypertension are organized more informally than those for diabetics; that they have not been evaluated or are not considered worthy of publication. A more likely explanation is that shared care for asthma and hypertension has not developed as extensively as shared diabetic care because GPs are more confident about their management of these conditions and the continuing involvement of hospital specialists is not required by the majority of patients. A current trend, in some ways competing with the development of shared care schemes for chronic illness, is for GPs and practice teams to take on routine management and follow up of patients entirely themselves, using guidelines and protocols to ensure systematic and structured care, referring patients to hospital services only when necessary. Shifting care entirely to the practice team rather than sharing it with hospital specialists, may be the preferred way of managing most patients with asthma and hypertension, and some diabetic care schemes are also following this model. However, as Greenhalgh (1994) has pointed out, successfully transferring care to general practice can also be seen as a legitimate form of shared care, in which hospital specialists and primary care teams collaborate to establish an overall strategy for care and agree standards, but do not share responsibility for individual patients (referred to later as 'shared care at one remove', page 221). They may also need to negotiate over sharing resources and finding the best methods for transferring knowledge and skills to primary care.

COMPUTER-ASSISTED SHARED CARE

Examples of computer-assisted shared care are found in all three domains. This particular method of organizing shared care for chronic conditions has been labelled the 'Grampian model', because it has been pioneered and developed most extensively in this region of Scotland, centred on the hospital and computing facilities in Aberdeen (Hickman *et al.* 1992). Its main feature is a central computerized register of patients, held in the hospital department, which is used to recall patients at predetermined intervals and to control and facilitate the exchange of clinical information. As well as being used for the management of patients with diabetes, asthma and hypertension, the Grampian model has also been applied to thyroid disease (Jung *et al.* 1991). Similar systems for shared care have been established in Islington, north London (diabetics), and the west of Scotland (hypertension).

This model of shared care has been shown to be successful in shifting routine care from hospital clinics to general practice, without any reduction in the effectiveness of care. It has also proved to be cheaper than hospital based care and it is popular with GPs and patients. Other advantages claimed for this model are that it results in more complete follow up of patients; allows flexibility in where care is provided but ensures that each patient receives a standardized package of care; provides some choice for patients about where they are seen for which tests, since prompts are sent to patients; improves the transmission of information between GP and specialist; and enables easy audit and evaluation of care. Although this model provides a highly structured framework within which GPs and specialists make their agreed contributions to shared care, it allows each participating practice the freedom to decide how much care to provide and how that care should be organized, for example in special clinics or in ordinary surgery time. Thus shared care is not just an option for those with special clinical interests, it can be incorporated into the routines of most practices and allow GPs to reclaim the care of many patients with chronic illnesses.

Criticisms of this model and its possible disadvantages have not been so thoroughly aired, since most accounts have been written by enthusiasts. It is clear that the early schemes in particular were initiated and controlled by hospital consultants and were largely imposed on GPs who had little say in their design and content. This situation may be changing, as GPs and practice nurses appear to be getting more involved in the management of at least some schemes. In her review of shared diabetic care, Greenhalgh (1994) observed that 'few centralised schemes today profess to adopting a peremptory or autocratic approach'.

A danger that has been noted is that the GPs may feel that their role in care is diminished to routine testing and filling in forms and that important decisions are taken by hospital consultants. However, it is almost impossible to assess from most published reports exactly how much involvement GPs have in decision-making about shared care, either at the organizational or clinical level. The survey by Hickman *et al.* (1992) asked specifically about GP participation. They found that most of the schemes had been initiated by consultants, but patients were selected jointly for shared care in two-thirds of schemes:

> *'General practitioners were involved in the production of less than half of the guidelines issued for their use, and participated in the decision to discharge a shared care patient into primary care in only a third of schemes. Fewer than 10% of the schemes*

> *recognised 'request by the general practitioner' as a criterion for a patient's entry to or discharge from shared care'.*
>
> (Hickman *et al.* 1992)

To establish the true extent of cooperation between GPs and consultants in the schemes described here would clearly need further research. However, it is important to note that while aspects of these highly organized computer-assisted schemes are valued by GPs, they do have a strong hospital focus. The work carried out in primary care is mainly routine monitoring of patients, which may lead to GPs feeling subordinate; that their clinical skills are undervalued by consultant colleagues; and that they are being used principally to lighten hospital workloads. Factors which might alter these attitudes are the extent to which schemes result in GPs gaining easier and more frequent access to consultants to discuss patient management and the extent to which GPs feel they have the autonomy to take decisions about treatment themselves or are able to influence the decisions taken by hospital teams.

In the case of diabetic care, it has been reported that GPs' interest in centralized organization seems to wane as their knowledge and self-confidence increases. The growing sophistication of computerized practice administration systems may also make shared care orchestrated by a distant hospital department less attractive. Some GPs may want, and may ultimately take, more control over shared care than they currently feel they are given by centralized, computer-assisted schemes.

PARTICIPATION AND FACILITATION

In contrast to computer-assisted schemes, other initiatives have started at the grass roots and used educational approaches to encourage GPs and practice teams to extend and improve their care of patients with chronic illnesses. Typically, facilitators have been employed to make personal contact with practices, create networks of interested team members and establish links with hospital specialists. Facilitators help practice staff to acquire the necessary knowledge and skills for chronic disease management, and may also help to introduce the organization needed to provide effective structured care.

A strength of using facilitators for shared care, is that they respond to the particular needs of individual practices and professional groups, targeting their input most appropriately to achieve goals that have been agreed jointly by those working in primary and secondary care. In the United Kingdom, the work we have described in Camberwell offers a successful model for expanding the role of inner city practice teams in managing patients with diabetes and asthma. The approaches adopted by facilitators in other areas, such as Greenwich and Southampton, are similar. In Sweden, DETU has combined an educational approach with organization design techniques that allow patients and professionals to participate in planning and implementing changes in care. DETU has used the process of conceptual modelling to help participants express their ideas and views about diabetic care in order to create a shared understanding of the illness and its treatment, and to forge a sense of common purpose in improving services. The technique is described more fully in Chapter 15. The role of facilitators and the management of change is discussed in Chapter 18.

CONCLUSION

The studies of shared care for chronic illness described in this chapter, suggest that it can be as clinically effective, economic and acceptable to patients as conventional hospital outpatient care. However, they also show that implementing shared care schemes may not be a quick and easy process, even when all agree that it is a desirable option.

Starting points for introducing shared care are enabling primary care teams to acquire the necessary knowledge and skills for managing chronic illness and ensuring that they have the resources to provide an effective service. Local champions of shared care have been important in getting schemes off the ground, and facilitators of various kinds have played a vital role in their wider implementation. The examples also indicate that there are less obvious, but equally important, organizational issues in introducing shared care.

At policy-making level, establishing shared goals and a framework for shared care development, can lead to progress. Some schemes have emphasized the value of participation by all concerned in the planning and implementation of change. Important steps in this process are developing a shared understanding of the domain, and finding ways of solving problems as a team. Teams may need to learn to work together.

Shared care often requires changes in ways of working, for example in practice administration and organization and the need to change routines, follow protocols or redistribute tasks between staff. Particular features of shared care schemes for chronic illness are delegation to practice nurses of tasks traditionally carried out by doctors, and the arrangements for the recall and monitoring of patients and recording information.

Guidelines or protocols are commonly associated with shared care schemes. They have also been promoted as a way of achieving consistent standards of care. However, rather than use guidelines to impose uniformity on practices, some schemes have found it preferable to accept diversity, provided that practices can demonstrate that they are meeting agreed standards of care.

Excellent three-way communication among specialist hospital departments, primary care teams and patients is a hallmark of shared care schemes. Patient-held records are a tried and tested way of enhancing communication. Information technology has been used more recently to facilitate rapid and reliable exchange of information. Computers have an important role to play in supporting shared care in various ways, but we suspect that some of the systems in current use may paradoxically reinforce the barriers between hospitals and primary care, rather than help break them down.

Continuing evaluation and audit of shared care schemes need to be built in from the start, if feedback is to be provided to allow services to evolve. Audit is still in its infancy, and systems need to be developed that assess the performance of shared care as a whole, rather than providing unconnected information about its constituent parts.

These themes are considered in more detail in Section III of this book, which focuses on the practical development of shared care.

Chapter 7
SHARED MATERNITY CARE

◆

Shared care in maternity services became commonplace in the 1970s. However, it has come under increasing criticism from professionals and consumers. A recent national review even suggested that it should be abandoned. This chapter examines the problems and explores the possibilities for improving the integration of maternity services, including the shifting of antenatal care away from hospitals to GPs and community midwives, so allowing midwives to take responsibility for the care of women throughout pregnancy, birth and the postnatal period.

Introduction

Over the last 50 years there have been dramatic changes in the content, organization and style of delivery of health services for women during pregnancy and childbirth. At the beginning of the century home birth, attended by a midwife, was the norm, with only around 1% of births taking place in hospitals or other institutions. Widespread concern about high levels of perinatal and maternal mortality led to an increasing proportion of births taking place in hospital and growing medical involvement in maternity care. By 1946 54% of births were in hospitals; by the mid-1980s the proportion had reached 98%, a level which has been maintained (House of Commons Health Committee 1992a). In 1992 there were 689,656 births: 98% of deliveries were in NHS hospitals and just over 1% at home, a slight increase on recent years (OPCS 1994).

General practitioners played a greater part in maternity care after the inception of the NHS, when they were able to claim a fee for providing services, and they have continued to play a central role, although the nature of their participation has changed with the increasing hospitalization of childbirth. Midwives were displaced as the main provider of maternity care and have been limited to a supporting role alongside medical staff, although it is often conveniently forgotten that throughout these changes midwives continued to provide most of the care for the majority of women, and they currently deliver around three-quarters of all babies born in England (NHSME 1993).

The main change since the beginning of the NHS, and particularly since the Peel Report of 1970, has been the shift from home to hospital birth (DHSS 1970). Until very recently, national policy supported this trend by emphasizing the safety of confinement in large hospital obstetric units (Harrison and Prentice 1993). The trend towards hospital birth and a falling birthrate allowed consultant obstetricians to assume responsibility for all pregnant women booked into 'their' beds for delivery. The dominance of the hospital has also been bolstered by the increasing application of technology in obstetrics. However, hospital outpatient clinics were unable to cope adequately as sole providers of antenatal care and this led to the development of the system of shared care which became widespread during the 1970s and 80s (Bull 1988). A pregnant woman would be referred by her GP to the care of a consultant and the hospital midwifery team for a hospital delivery, but responsibility for her antenatal and postnatal care would be shared with the GP and the community midwifery team.

Definitions and current patterns

Shared maternity care has been defined as follows:

> *'. . . the arrangement whereby the consultant obstetrician and the hospital obstetric team share with general practitioners and their community nursing colleagues the responsibility for antenatal and postnatal care whilst retaining ultimate responsibility for the obstetric management of the patient throughout her pregnancy'*
> (SHSPC/SHHD 1983).

> *'Where hospital and family practitioners or midwives share the care of the pregnant woman, the conventional system is for*

> *patients to shuttle back and forth between the two in the antenatal period, for delivery to take place in hospital and for the postnatal period care to be shared, with a final check by hospital personnel at about six weeks'*
>
> (Taylor 1984).

> *'. . . the division of care of the pregnant woman between a GP and a consultant obstetric unit, both acting independently but in cooperation. In practice, the system means that the GP is responsible for the bulk of antenatal care, the consultant team for the delivery and postnatal hospital stay and the GP again for continuing postnatal care after the patient returns home'*
>
> (Bull 1989).

By the 1980s shared care was the predominant pattern in maternity care in the UK: in England and Wales in 1986 GPs claimed payments for antenatal and postnatal care in 97.5% of maternities but in only 10.5% of confinements (Bull 1989). This pattern has continued but with dwindling numbers of GPs providing intrapartum care either in GP units or for home deliveries. In 1988 only 6% of deliveries in hospital were under GP care, compared with 15% in 1975 and 50% in 1946.

The detail of shared care programmes varied, but they typically consisted of a rather inflexible schedule dividing between hospital outpatient clinic and GP/community midwife clinic the dozen or more antenatal appointments a woman was required to make. After the birth in hospital, postnatal visits and appointments were also allocated according to a prearranged plan. Communication between hospital specialists, GPs and midwives was usually via a 'cooperation' or 'shared care' card held by the patient. A similar system of shared care has been established successfully in Australia (Halloran 1991, Del Mar *et al.* 1991, Halloran *et al.* 1992).

Aims of shared maternity care

The original aims of shared care were to reduce the number of times women with normal pregnancies had to attend hospital antenatal clinics and to provide antenatal and postnatal care close to women's homes, while allowing birth to take place in the apparent safety of the hospital. Arguments put forward in favour of shared care concerned its convenience for women in terms of reduced travelling and shorter waiting times; the appropriateness of preventive care taking place in the familiar, more relaxed atmosphere of GP surgery or health centre; the continuity of care provided by her GP and community midwives; utilizing the knowledge and skills of the primary health care team; and taking pressure off hospital services and allowing hospital teams to focus on 'high risk' pregnancies.

Since the early 1980s, however, evidence has been accumulating that many shared care arrangements have neither fulfilled their promise nor provided a good service for women. Innovators have sought to make improvements and research projects have investigated and evaluated often quite minor changes in the organization of maternity care, sometimes comparing women receiving the altered service with a control group of women receiving traditional shared care. More wide ranging national inquiries have illuminated serious problems in the delivery of maternity services, including the difficulties of integrating care between hospital and community and dividing work between professionals, and have suggested a variety of solutions. A recent inquiry, and perhaps the most radical in its approach, was carried out by the House of Commons Health Committee in 1991, and found profound dissatisfaction among consumers and many professionals providing maternity services. The report includes the following conclusion:

> *'We have concluded from the evidence presented to this inquiry that the present pattern of 'shared care' for women is failing to meet their needs. It has developed in such a way as to provide a fragmented, sometimes inefficient and rigid pattern of care often more determined by the needs of the professions, the unimaginativeness of managers and the self-validating arguments drawn from current prejudices about the division of labour than the wishes of women.* ***We recommend a radical reappraisal of the current system of shared care with a presumption in favour of its abandonment****'*
>
> (House of Commons Health Committee 1992a).

Debate on changing childbirth

In response to this hard-hitting report the government established the Expert Maternity Group with the objective of improving NHS maternity services. The group's report *Changing Childbirth* reiterated many of the criticisms made by the Health Committee and proposed changes in line with the committee's recommendations (DoH 1993b). In brief, the main thrust of national policy is now to make maternity services more 'woman centred'; to give women more informed choice about who provides their care and where they have their baby; to shift more care away from hospitals and into the community; and to ensure better continuity of care by creating a pivotal role for the midwife as the key worker in the planning and provision of care. The Department of Health has made available development funds for pilot projects to introduce the changes recommended in *Changing Childbirth* and many hospital and community trusts are currently in the process of reorganizing services. Far from being abandoned, shared care is still an option for most pregnant women, but the nature of the system is being transformed.

One of the most striking features about the debate on improving maternity services over the last 10 years is the increasing expression of consumer views about services and an apparent growing willingness among professionals and official bodies to listen to them. The 1980s have been described as the 'decade of the consumer', when maternity care pressure groups sprang up and began to question the medical model of childbirth (Dillner 1991). Their influence on the shape of maternity services has been substantial. In 1982, the Maternity Services Advisory Committee (MSAC) noted the 'groundswell of consumer dissatisfaction' with antenatal care (MSAC 1982). One result of the committee's report was the setting up of a Maternity Services Liaison Committee in each health authority, with professional and consumer representation, to review and monitor the quality of maternity services. However, these committees have tended to be dominated by professionals, although attempts are now being made to strengthen consumer input. Women and the organizations representing them presented a large volume of evidence to the Health Committee's inquiry in 1991, which clearly influenced its findings. *Changing Childbirth* continues the Health

Committee's emphasis on women's needs for continuity of care, choice, and control in maternity services, and states as a first principle that 'the woman must be the focus of maternity care'. However, as in all health services, stating principles may be easier than putting them into practice.

These developments in current policy for maternity services and in the delivery of shared care in particular are explored in more detail below, dividing the service into antenatal care, and care during birth and afterwards. This is followed by a commentary drawing together some of the main points.

Antenatal care

PROBLEMS WITH SHARED CARE

There is no doubt that shared antenatal care represented an improvement on women with normal pregnancies making frequent visits to crowded and impersonal hospital antenatal clinics. However, as the system became more popular its problems became more apparent. In theory, shared antenatal care is a safe and convenient system of care for women with normal pregnancies, which uses the knowledge and skills of primary care practitioners and gives easy access to specialist advice and hospital-based facilities. But to work efficiently and effectively it depends heavily on good cooperation and communication among the hospital specialists, GPs and midwives providing care. Over the last decade experience and research have shown that collaboration has often been poor, resulting in less than optimal care for mothers and their babies, dissatisfaction among consumers and disaffection among practitioners. The system also appears to have failed to adapt quickly enough in response to technical and scientific advances and changes in medical knowledge about effective care in pregnancy (Chalmers *et al.* 1989).

The accepted format of antenatal care in this country is based on a pattern established in the 1930s: antenatal examinations monthly until 28 weeks, fortnightly until 36 weeks, then weekly until delivery. This system was the basis for the development of most shared care programmes, with women typically visiting the hospital for booking early in pregnancy, for prenatal screening tests, and two or three times later in pregnancy. Protocols for antenatal visits would be established locally, usually determined by the consultant obstetrician, so there was little uniformity, but it was generally 'accepted that the patient should attend a specialist clinic a minimum of four to six times' (Wood 1991). Visits in between would be made to the GP/community midwife clinic at the GP surgery. However, even after introducing shared care, hospital antenatal clinics continued to be overburdened with work, resulting in a rushed and impersonal service for many women.

By the late 1970s the value of the established format for routine antenatal care was being questioned, particularly the need for women to be seen so many times in antenatal clinics. Doubts were also raised about whether specialists could predict which women would develop problems later in pregnancy or during labour (Hall *et al.* 1980). Despite the demonstrable lack of a scientific basis for, and an absence of clinical benefits from much of the routine monitoring carried out during pregnancy, professionals have been slow to abandon redundant procedures. On the other hand, however, they have been quick to incorporate into existing programmes new technological advances, especially in prenatal screening and diagnosis, even without good evidence for their safety or effectiveness. The result was an increasingly unwieldy programme of visits to hospital and community clinics for women receiving shared care.

A further problem was that the schedule of visits was often poorly coordinated. Far from being 'shared' or integrated, programmes of care carried out in hospital antenatal clinics and in GP surgeries were separately planned and carried out, resulting in duplication of care and unnecessary appointments. A study in East Anglia found that because of poor coordination between providers, women receiving shared care were often required to make a greater number of visits than would be considered necessary during a normal pregnancy (Thomas *et al.* 1983). The Munro report (MSAC 1982, 1984 and 1985) emphasized the need to ensure that 'care is properly shared, and not organized in unconnected compartments' and 'to avoid a situation where the woman is seen at ill-spaced intervals by a series of unidentified strangers all asking the same questions without any co-ordination or explanation'. Research projects also identified 'the dualism which can result between hospital and community giving rise to descriptions such as "fragmented care" or "parallel care"' (Field *et al.* 1984).

Shared care cards were intended to provide an effective means of communication between hospital and primary care and avoid duplication of effort. However, it appears that in many schemes they were not used properly or even ignored, particularly by hospital doctors (Fawdry 1990).

In his evidence to the House of Commons Health Committee, Geoffrey Marsh, a general practitioner, criticized the inefficiency of shared care:

> *'There is probably no more wasteful area in the National Health Service than the present system of maternity care. Gross overlap and duplication takes place between community midwives, general practitioners, hospital based midwives and consultant obstetricians and their junior staff'*
>
> (House of Commons Health Committee 1992a para 203).

Among providers of care, midwives in particular have expressed long-standing dissatisfaction with the organization of shared antenatal care. This is mainly because they feel that their skills are not used to the full, but also because they have been expected to duplicate rather than complement the medical input to antenatal care. This is not just a problem of duplication between hospital-based services and primary care: the division of labour between GPs and community midwives has also been a source of concern. In a study in East Anglia, Field *et al.* (1984) found that professional relationships in GP antenatal clinics were sometimes far from ideal. In nine out of the 15 practices studied, the GPs and midwives agreed that relationships were good: they held joint clinics, they communicated well and made joint decisions about patient care. In the remaining six practices, however, teamwork was much less evident and one or both partners assessed their relationship as poor.

CONTINUITY OF ANTENATAL CARE

One of the advantages claimed for shared antenatal care is that it ensures a high degree of continuity of care and of carers during pregnancy. The GP is the first point of contact for a woman when she suspects she is pregnant and the GP and community midwife provide the bulk of antenatal and postnatal care. However, some shared care schemes have not lived up to the promise of giving continuity of care, mainly because clinics may be staffed by several GPs and a number of community midwives, and little attempt would be made to schedule appointments for a woman with the same GP or midwife at each antenatal visit. More importantly, shared antenatal care typically offers no continuity with care during labour and delivery. If the birth is in hospital a woman is likely to be cared for by unfamiliar staff in unfamiliar surroundings. In their evidence to the House of Commons Health Committee many women and organizations which represent consumers argued strongly for better continuity of care *throughout* pregnancy, labour, birth and the postnatal period. This theme was taken up by the Expert Maternity Group, which recommended that 'Throughout her pregnancy, and most particularly during labour, the woman should be cared for by people who are familiar to her and aware of her plans for delivery' (DoH 1993b).

OVERCOMING THE PROBLEMS

By the 1980s the problems described above were well recognized and many consumer groups and professional bodies were calling for changes in the delivery of antenatal care (MSAC 1982). There was general agreement that more antenatal care should take place in primary care settings and that this would improve services and reduce perinatal mortality rates (Wood 1991). A shift away from hospital-based antenatal care remains a current policy objective (DoH 1993b). Moving services into the community may improve their accessibility, but simply relocating care is unlikely to resolve completely the problems of effectiveness, communication, integration, division of responsibilities between professionals and continuity of care for patients that have been discussed. Most schemes to improve antenatal care that have been tried in the last 10 years have not only decentralized services, they have also changed other aspects of how care was delivered. Many early schemes featured specialist clinics held in GP surgeries and health centres, and these 'outreach' initiatives are discussed first. Other schemes gave GPs and midwives responsibility for providing all antenatal care for women with 'low risk' pregnancies. However, the most radical schemes aimed to integrate community antenatal care, delivery in hospital units and postnatal care for women who did not need specialist attention. GPs were the linchpin of the original integrated care schemes, but in recent years developments in midwifery services, such as team midwifery and midwife-managed units in hospitals have shifted the focus from GP-led to midwifery-led initiatives. Schemes which aim for integration across the whole spectrum of maternity care are discussed later.

OUTREACH SCHEMES

Some of the initiatives that were taken during the 1970s and 80s to establish 'community antenatal care' and evaluate its effectiveness and acceptability have been reviewed by Wood (1991). She particularly selected 'outreach' schemes, involving hospital and community staff working together in health centres, GP surgeries or community clinics. Thus most schemes are similar to traditional shared care in that there is collaboration and division of labour between hospital specialists, GPs and midwives, but women are seen by specialists at a local clinic rather than at a hospital outpatient clinic. The initiatives also create opportunities for GPs, specialists and midwives to discuss patients face to face rather than relying mainly on the shared care card or other written communication. Other innovative aspects of some schemes are that women held their own definitive obstetric notes, rather than a shared care card; the number of antenatal visits they were required to make was reduced; they saw hospital specialists less frequently; individual management plans were agreed for each woman; GPs, midwives and obstetricians cooperated according to a written protocol; the only visit to hospital was for an ultrasound scan. These features, which might be considered an improvement on traditional forms of shared care, are summarized in Table 3.

Two of the schemes reviewed by Wood, in Easterhouse, Glasgow and in Birmingham, have been omitted because they

Table 3. Features of community antenatal care schemes

Scheme	Date started	Site	Woman holds own notes?	Written protocol for visits	No. of times seen by specialist in normal pregnancy
Lambeth London	1975	Three large group practices	Yes	Individual management plan devised	Twice
Sighthill Edinburgh	1976	One health centre serving 30,000 patients	?	Yes, and for management	No single plan: according to risk assessment and protocols for management
East Barnwell Cambridge	1982	Three-GP practice in one health centre	Yes	Yes	Three times
Tower Hamlets London	1982	Four practices	Yes	Yes	Twice
Hackney London	1985	Seven community clinics	Yes	Yes, plus guidelines for referral to specialist	?

Source: Wood 1991.

simply created peripheral hospital clinics in deprived areas, and involved community midwives but not GPs. Three schemes, in Lambeth, East Barnwell, Cambridge and Tower Hamlets, are described in more detail.

LAMBETH

In Lambeth, south London, an integrated antenatal care scheme was established in 1975 between consultants from St Thomas's Hospital and GPs in three large group practices. Community clinics staffed by midwives and a consultant were set up at two other sites in the district, to be used by patients of GPs in smaller practices. At the GP clinics, all antenatal and postnatal care was routinely given by the GP and community midwife, with a consultant attending the clinic once a fortnight. The consultant saw women with the GP soon after their initial booking visit, when a management plan was agreed, and again at about 36 weeks. He was also available to discuss any problems with the GP and midwife. Each woman held her own obstetric records (Zander *et al.* 1988).

An evaluation of the scheme compared 237 consecutive patients receiving integrated antenatal care with a matched group receiving hospital antenatal care. There were no significant differences in obstetric outcome but the women saw fewer doctors in the integrated clinic than the hospital clinic (Taylor 1984).

EAST BARNWELL, CAMBRIDGE

An integrated community antenatal clinic was set up in January 1982 at the East Barnwell Health Centre in Cambridge. It was staffed by GPs from one practice in the health centre and a community midwife who administered the clinic and also saw women for antenatal appointments. A senior obstetric registrar from Cambridge Maternity Hospital visited the clinic fortnightly. Patients of the three GPs based in the health centre received all their care from the clinic. Patients of three other GPs in a practice nearby received their GP care at the surgery and attended the health centre to see the hospital specialist (Thomas *et al.* 1987).

The women attending the community clinic carried their own obstetric records. A protocol for visits was drawn up, based on the traditional pattern, but the number of appointments with the obstetric specialist was reduced from the usual four or more visits to three: at 16 weeks, 30–32 weeks and at term.

An evaluation of the scheme compared the 96 women who used the clinic in the first year with a consecutive sample of 100 women receiving traditional shared care at two practices elsewhere in the city. Data were collected on obstetric outcomes and women's views of their care. In terms of obstetric outcomes there were few significant differences between the two groups. However, only 4% of women attending the community clinic developed hypertension compared with 13% of the shared care group. Women receiving shared care made on average four times as many visits to hospital doctors as women attending the community clinic (a mean of 8.1 visits compared with 2.4) although there were no differences in the rates of complications in the two groups. Community antenatal care reduced the inconvenience and cost of travel. The women attending the community clinic saw fewer hospital doctors and were more satisfied with communication with practitioners. They found the clinic atmosphere friendly, relaxed and personal. The practitioners involved in the community clinic appreciated the closer working relationships and were enthusiastic about the educational gains.

The researchers commented that the scheme was successful in avoiding duplication of visits, but it was not clear whether this was attributable to the protocol, the practitioners being in the same clinic or their use of a single obstetric record. Indeed, it may have been due to a combination of these factors. They concluded that integrated community antenatal care was medically safe and offered women and practitioners an acceptable alternative to traditional patterns of shared care (Thomas *et al.* 1987).

TOWER HAMLETS

In Tower Hamlets, east London, a community antenatal care scheme was established in 1982 in four practices and it is still in operation. Women are seen throughout their pregnancy by their

GP and community midwife. A hospital specialist visits each of the participating surgeries monthly to see women after the booking visit and again later in pregnancy if problems are anticipated. Women carry their own obstetric notes.

An evaluation of the scheme showed that it reduced delays in booking (Robson *et al.* 1986). More recently, a study of women's experiences of antenatal care has been carried out. Women find community care convenient because of reduced travelling times, but the majority say they prefer it to hospital clinics because of the personal nature of the care they receive at their local surgeries. Data from this study, shown in Table 4, confirm that women having community-based care are more likely to see only one or two different professionals than those have hospital-based or shared care (House of Commons Health Committee 1992c).

The results of the evaluations of these outreach schemes have been summarized by Wood (1991), who concluded that they can result in improvements in accessibility, uptake, communication between women and professionals, and consumer satisfaction. Pregnancy outcomes for mother and baby were at least as good as for traditional shared care.

A number of schemes that attempted to improve on traditional shared care replaced shared care cards with women holding their full obstetric record. Two randomized controlled trials found that this had positive results in terms of women feeling in control of

Table 4. Percentages of women seeing different numbers of practitioners according to type of antenatal care in Tower Hamlets

	Type of antenatal care		
Number of practitioners seen	hospital (% of women)	shared (% of women)	community (% of women)
1–2	7.6	2.2	17.0
3–4	32.4	24.8	52.9
5–6	40.0	43.3	25.6
7 or more	20.0	29.7	4.5

Source: Mrs Ruth Cochrane's evidence to the House of Commons Health Committee (1992 vol III p737).

their antenatal care and able to talk to midwives and doctors about their care. There were also savings in clinical time and no evidence of an increase in lost notes (Lovell and Elbourne 1987, Elbourne *et al.* 1987). It is current national policy that women should be able to carry their own obstetric notes (DoH 1993b).

FURTHER DEVELOPMENTS IN COMMUNITY ANTENATAL CARE

Other initiatives have reduced the number of visits women made to hospital, but have not established outreach clinics. For example, in 1986 three consultants in Oxford changed their policy on shared care for low risk multiparous women to seeing these women only twice (at 16 weeks and 41 weeks) at the hospital antenatal clinic unless complications developed. All other routine visits were made to the GP and community midwife (Hill *et al.* 1993). The aim of the change was to relieve the pressure on hospital antenatal clinics, reduce waiting times and to increase satisfaction with antenatal care. Criteria for low risk pregnancy were laid down and women were selected at their booking visit to the antenatal clinic. The new policy was successful in reducing visits to the hospital antenatal clinic: the proportion of women with only one or two visits increased from 20% to 58%. However, the study did not find reduced waiting times, which may have been due to the methodology used or to the modest nature of the changes that were introduced. The proportion of women fully satisfied with their antenatal care increased. The change in policy had one other major and unexpected effect, which was to more than double the percentage of women who reached 42 weeks gestation, and this led to a review of the hospital's policy for booking inductions.

There is also evidence that the number of visits to GP antenatal clinics may be safely reduced for low risk women. Marsh (1985) reported cutting the number of appointments for low risk nulliparous women from 15 to 8, and for multiparous women from 15 to 6. The time saved by the primary care team was used to offer longer, more structured consultations for all women and to provide more intensive care for women with high risk pregnancies, according to a protocol developed by the team.

WEST BERKSHIRE SCHEME

Overcrowding in hospital antenatal clinics and long waiting times were two of the reasons for introducing community antenatal care in West Berkshire in 1989 (Street *et al.* 1991). Women who met the criteria for community care laid down by the consultant obstetricians did not have the choice of opting for consultant care: the GP and community midwife assumed full legal responsibility for managing them. A booking form was completed by the GP and assessed by one of the specialists. If community care was agreed, the woman would attend the hospital only for an ultrasound scan, seeing her GP or community midwife at all other visits. Community midwife antenatal clinics were introduced into nearly all practices to reduce the pressure on GP antenatal clinics. Women held a cooperation card. Referral procedures were streamlined: any GP or midwife could refer a woman for a specialist opinion on the same day without prior appointment.

The labour ward at the hospital was altered to provide an integrated GP/midwife and consultant unit. Women receiving community antenatal care were delivered in the GP/midwife unit by their GP, community midwife or hospital midwives. This system has replaced traditional shared care in West Berkshire and the changes represent a considerable increase in responsibility for midwives.

The first year of the new scheme was evaluated. Fifty-nine per cent of women were booked for community care, but 49% of these were transferred to consultant care, 31% antenatally, 16% during labour and 2% after delivery. The remaining 1618 women (30% of all women delivered in West Berkshire) had their entire care provided by their GP and midwife. Perinatal mortality rates did not change significantly. The high rate of transfer to consultant care was considered a problem, but as experience with the scheme grew consultants were more willing to return women to community care after one or two visits to the hospital antenatal clinic. The authors concluded that 'antenatal care of low risk pregnant women may safely be provided by their general practitioner and midwife' (Street *et al.* 1991).

Most hospitals have now reduced the number of visits to antenatal clinics that women are expected to make. However, the Expert Maternity Group expressed concern that this change had not always been accompanied by a 'reappraisal of the purpose of antenatal care, in particular the number and content of antenatal check-ups' (DoH 1993b).

Community antenatal care schemes are likely to give more women greater continuity of care from a smaller group of professionals during pregnancy, but they do not necessarily ensure that a woman will be cared for during labour and birth by a midwife or doctor she knows. The importance of this aspect of continuity of care has been particularly emphasized by women and the consumer groups which represent them and recently has led to fundamental changes in the organization of intrapartum care and midwifery services, which are discussed in the next section.

ANTENATAL ASSESSMENT UNITS

A further development in antenatal care which may contribute to shifting care away from hospitals is the establishment of antenatal assessment units, which women requiring investigation or assessment of problems can attend as outpatients as an alternative to hospital admission. The work of one unit in Northampton has been described in detail (Anthony 1992). Community midwives and GPs, as well as hospital staff, referred women to the unit, according to strict criteria. The main problems assessed were hypertension and intra-uterine growth retardation. Hospital admission was avoided for 76% of patients with hypertension. The Expert Maternity Group, however, was cautious about the claims made for antenatal assessment units: they vary greatly in the range of tests they offer and have not yet been properly evaluated (DoH 1993b).

Care during childbirth and afterwards

The main consequence of centralizing maternity services in acute hospitals has been to deny women effective choice in childbirth (Campbell *et al.* 1991, House of Commons Health Committee 1992, Harrison and Prentice 1993). Only a very small proportion of babies are now born at home. Maternity homes, units in small hospitals and isolated GP units have been phased out on grounds of safety and cost. The number of GPs directly involved in intrapartum care has declined sharply. A survey of maternity units in 1988 found that only 6% of deliveries in hospital were under GP care: 31% in separate units alongside consultant units in acute hospitals; 42% in 'integrated' units, using the same wards and delivery rooms as consultant staff, and 27% in isolated GP units. The authors warned that 'we may be witnessing not only the terminal decline of general practitioner intrapartum care but also the start of a long process in which general practitioners are excluded from having any say in obstetric care' (Smith and Jewell 1991a). The debate about the relative safety of birth in different settings and of GP obstetrics continues with conflicting evidence being presented and assessed (Campbell *et al.* 1991, Macfarlane and Campbell 1994).

Midwives, on the other hand, have been gaining visibility and recognition for their role as the practitioners who provide intrapartum care for the majority of women. In recent years they have reclaimed some of their former autonomy and are taking full responsibility for delivering some women who do not need specialist care or medical intervention during childbirth.

Now the Department of Health has reversed its policy and is encouraging providers to offer women more choice in where their babies are born and who delivers them. Fundamental changes are taking place in maternity services, including a reappraisal of the roles played by GPs and midwives in intrapartum care. Current policy documents have focused attention on how best to provide services for the majority of women who are unlikely to need an obstetrician at delivery and whose babies are at low risk of developing problems (DoH 1993b, NHSME 1993, SHHD 1993). These documents reflect the transformation that is taking place in both professional attitudes to intrapartum care and ways of organizing and delivering services. Initiatives which aim to improve hospital facilities for women in labour and to meet current policy objectives of offering women choice and continuity of care in childbirth are discussed below.

MAKING HOSPITAL BIRTH MORE HOMELY

Quite minor and simple changes in hospital facilities and procedures can make birth in hospital a less clinical and more pleasant experience for women. Most hospitals now encourage women to prepare birth plans and discuss them with staff before labour begins. Many also offer 'low tech' alternatives to birth in clinical delivery rooms dominated by medical equipment. Such 'homely' delivery rooms and a policy of minimal intervention, combined with early discharge back to community midwife/GP care, have usually been associated with GP units, but more recently hospitals have created specially designated midwife-managed units with these features. One example is the midwives unit at Aberdeen Maternity Hospital, which opened in 1990.

The midwives unit in Aberdeen has five single rooms, decorated in a comfortable, 'homely' style, a sitting room and kitchen, and is located in the labour ward. It is staffed and run by the same midwives who work in the labour ward, medical cover is provided by an obstetric team and an on-call paediatrician. Labour is managed traditionally, with minimal intervention. There are strict criteria for booking women assessed as 'low risk' and for transfer to the labour ward (SHHD 1993). A randomized controlled trial of delivery of low risk women in the midwives unit and on the labour ward found significant differences between the two settings in monitoring, fetal distress, analgesia, mobility and the use of episiotomy. Midwife-managed intrapartum care resulted in less intervention and no increase in neonatal morbidity. There was, however, a high rate of transfer to consultant care. Only 46% of women allocated to the midwives unit actually delivered there: 34% transferred antenatally, 16% during labour. The authors of the study comment that such a high rate of transfer shows that antenatal criteria are unable to determine who will remain at low risk throughout pregnancy and labour (Hundley *et al.* 1994). It may also reflect the need for midwives to adjust to having greater autonomy of practice: by their own admission midwives were over-cautious in the early days and transferred women to the obstetric unit who could have remained in the midwife-led unit (SHHD 1993).

Developments such as the unit in Aberdeen are important because they offer women a choice of style of hospital delivery. However, they do not necessarily provide women with continuity of care throughout pregnancy and during birth or even ensure that she has met the midwife who delivers her baby until she is admitted to the unit in labour. Although only a minority of GPs are now involved in intrapartum care, the enthusiasts have argued that GPs, in partnership with community midwives, are best placed to provide both continuity of care and a 'low tech' birth in hospital. Two examples of integrated care by GPs are described below. The first is a pioneering scheme which began many years ago in Oxford, in which GPs, obstetricians and midwives worked together closely. The second is from Bath Health Authority where community based services, including isolated GP units, provide a service for many women.

INTEGRATED MATERNITY CARE IN GP UNITS

The work of an integrated GP unit at the John Radcliffe Maternity Hospital in Oxford has been described and evaluated in comparison with shared care and delivery in the consultant unit for low risk women (Klein *et al.* 1983a; 1983b; 1985). In 1981, 62 GPs in 28 practices were authorized to use the GP unit. Most of the activity, however, was concentrated in 17 practices. Deliveries in the GP unit were by community midwives and/or GPs; deliveries in the consultant unit were by hospital midwives and/ or the consultant team. All low risk women received antenatal care from GPs and community midwives. Women booked for the GP unit were also visited at home by a community midwife when they went into labour, and were more likely to be admitted at a more advanced stage of labour. A randomized controlled trial found that both systems provided good care for women and there were few differences between the two, although women in the GP unit had fewer inductions, fewer forceps deliveries and less analgesia and epidural analgesia than women in the shared care system. These findings are consistent with the philosophy of the GP unit, which was in favour of less intervention in labour. Outcomes for the newborn infants were similar in both systems. The authors conclude that 'These comparisons demonstrate the simplicity and safety of delivery of low risk women in the GP unit compared with deliveries of similar women in a shared care (consultant) unit' (Klein *et al.* 1983b). A subsequent study found that women using the GP unit had a high level of satisfaction with the care they received. Transfer rates from GP to consultant care were low: 64% of women had GP care throughout; 10% were transferred in pregnancy; 13% in labour and 5% postpartum. The remaining 8% received consultant help in the GP unit (Klein *et al.* 1985).

An important feature of the Oxford GP unit was the close and constructive relationship between GPs, midwives and consultant obstetricians. The emphasis was on communication, information sharing and appropriate transfer of responsibility of patient care where indicated. Practitioners attended joint meetings and rounds. Klein *et al.* (1983b) describe the two systems as:

> *'operating side by side, with excellent inter-relationships, but markedly different styles of care for low risk women. The midwives working in the shared care system have an intrinsically more difficult task because they need to manage women with a wide range of problems at the same time as those at low risk. The difficulty of the shared care system is that they are grouped with high-risk women, and there is the natural tendency for high risk care to spill over into their management. We believe there is a need to identify women at low risk and to tailor their management so that it is based primarily on supportive care by midwives in their traditional role'.*

Bath health authority is unusual in that it has had a long-standing policy of providing community based maternity services, including supporting its small isolated GP maternity units offering 'low tech' deliveries to low risk women. About one third of all births are in the seven peripheral (isolated) maternity units that are spread throughout the district. Most antenatal care is provided by GPs and community midwives; consultant obstetricians also hold clinics locally, away from the district general hospital. Suitability for delivery in the isolated units is decided according to criteria that have been drawn up jointly by obstetricians, GPs and midwives (Mr R Porter's evidence to the House of Commons Health Committee, 1992b pp 606–8).

In 1992 a small, interdisciplinary study team was asked by the Department of Health to look at good practice in providing maternity services in units led by midwives and GPs (NHSME 1993). The team visited six maternity units, including Bath, West Berkshire (see page 126), and Leicester (see page 135) and reported on its findings, emphasizing that:

- interdisciplinary working is essential for safety. There should be easy access to specialist anaesthetic and paediatric advice and support, which can be achieved most readily by locating the unit within or alongside the consultant maternity unit. 'Successful schemes displayed high levels of inter-disciplinary team working'. Regular joint meetings to update knowledge and skills are a feature of the peripheral units in Bath Health Authority.
- jointly owned guidelines are important. The roles and responsibilities of all doctors and midwives should be clearly defined. Guidelines should be soundly-based and specify booking procedures, including selection of 'low risk' women; criteria for care being led by a midwife or GP; and the circumstances under which care should be transferred to a consultant. However, informal consultant advice should also be easily available so that unnecessary transfers are avoided. In midwife-managed units, midwives may require additional training to increase their range of skills and responsibilities.
- commitment to the unit by consultant obstetricians was critical. 'Generally we found that obstetric consultant commitment was greatest where GP and midwife maternity unit objectives were widely discussed, understood and agreed'. However, the survey found that paediatricians and anaesthetists did not always share in the support and enthusiasm for the units.
- strong leadership of a unit brought many benefits in terms of interdisciplinary working, a sense of common purpose and integrated operational policies. '. . . a strong 'champion', from any of the professional groups, who took responsibility for leading and developing the unit, was a vital ingredient in the effective running of midwife and GP units'.

The examples from Oxford and Bath, described above, have many unique features, not least that GPs play a major part in intrapartum care. They are required to sign a contract which allows them to use the hospital facilities, and lays down criteria of care that they must meet. In other areas smaller proportions of GPs are involved, controls are less tight and those who offer GP unit or home delivery may rarely attend the actual birth (NHSME 1993). Two recent surveys have raised questions about the feasibility of GPs playing a central part in shared maternity care, including intrapartum care, for more than a small minority of women. In the south western region of England in 1992 40% of GPs booked care for women in hospital (27% did home deliveries), but nearly half of them booked 10 or fewer women a year (Smith LFB 1994). In Nottinghamshire in 1993 27% of GPs wanted to provide intrapartum care, but only 36 out of 550 had attended two or more deliveries in the previous year (Brown 1994). Although GPs who were already booking home deliveries were keen to do more, most Nottinghamshire GPs were unwilling to increase their role in intrapartum care, the main reasons being their current workload, disruption to their personal life, fear of litigation and perceived lack of confidence. Lack of remuneration was not reported as an important deterrent. Developing GP obstetrics as a sub-specialty in general practice has been suggested as one way of maintaining a GP contribution to intrapartum care.

Developments in team midwifery

Another model of maternity care which offers continuity from early pregnancy through to the end of the postnatal stage is the 'domino' scheme (an acronym for domiciliary in and out). Domino schemes were introduced in the late 1960s as a means of offering an alternative to low risk women who wanted a home birth, but who were encouraged to deliver in hospital on grounds of safety. The community midwife is the key practitioner who provides care, usually shared with the GP or consultant obstetrician. When labour begins the midwife visits the woman at home to assess progress; accompanies her to hospital; delivers the baby; remains with the woman for 4–6 hours after the birth; and sometimes accompanies her home. Ideally, a named midwife is responsible for all a woman's care, supported by a small team of colleagues (SHHD 1993).

Domino schemes are offered in most areas, but on a very small scale because of the high level of input needed from community midwifery services. In the 1988 survey of maternity units, only 1.4% of hospital deliveries in England and Wales were domino and a similar proportion is estimated for Scotland (Smith and Jewell 1991b, SHHD 1993).

The personal care and continuity of carer offered by domino schemes are also important elements of the 'know your midwife' initiative, pioneered by Caroline Flint at St George's Hospital in London, which popularized the idea of a woman having a 'named' or 'primary' midwife whom she would get to know during the antenatal period and who would be with her in labour and deliver the baby. Developments in team midwifery have extended this idea beyond the original small hospital-based projects, and various models of team working have been tested on a larger scale. Team midwifery aims to offer women greater continuity of care and the choice of a less medical model of childbirth; and to give midwives more responsibility, autonomy and a chance to use their skills more fully (Flook 1992, Flint 1992). However, a recent survey of team midwifery in operation found that not all schemes were arranged in ways that enabled them to meet these aims. Teams of midwives could 'be of almost any size, include some or all midwives, give part or total care, be based within the hospital or the community' (Wraight *et al.* 1993). Schemes were most successful if teams were arranged so that midwives could work in both hospital and community—wherever women needed them, when they needed them—and provided total care for a defined group of women, one of team being the named midwife or primary midwife for each woman. In general teams were thought to work best if they:

- consisted of no more than six midwives;
- each had a defined caseload;
- provided total care for that caseload;
- worked in all areas according to client need;
- 50% or more women were delivered by a midwife known to them.

There are now many examples of team midwifery in practice. Small scale, community based schemes appear to be very effective, but provide care for only small numbers of women. For example, Riverside Health Authority in west London established a team of six midwives, based in community clinics, who provided continuity of care for women through pregnancy, labour and during the postnatal period. They were fully responsible for the care they provided and worked in liaison with consultant obstetricians and GPs (Harrison and Prentice 1993).

Larger-scale, fully integrated schemes that offer care for greater numbers of women are slowly being established in a number of areas. Leicester Royal Infirmary became a leader in the field by developing a midwife-led unit and team midwifery combined with an existing consultant unit, a GP unit and a domino scheme. The aim of these developments was to provide both choice and better continuity of care for women at low risk of complications *and* those in higher risk groups. The midwife-led 'home-from-home' unit was established in 1988 and staffed exclusively by 10 hospital midwives. They initially had three delivery rooms, furnished like ordinary bedrooms, close to the hospital labour ward. These midwives also ran their own antenatal clinics in the hospital, seeing women booked for the 'home-from-home' unit at 26, 36 and 41 weeks. The intervening care was given by the GP or community midwife. A randomized controlled trial compared this scheme with consultant-led care and delivery in the labour ward. There were few significant differences between the two groups in outcome measures, but there were generally higher levels of satisfaction among those women who received midwife only care. There was a high level of transfer to consultant care: 23% antenatally, 18% during the first stage of labour and 4% later (MacVicar *et al.* 1993). About one-fifth of all births in the hospital take place in the 'home from home' unit (NHSME 1993).

Subsequently, hospital and community midwives were reorganized into integrated teams covering defined geographical areas, linked to general practices and to one consultant obstetrician, so that they could give better continuity of care to all women. GPs refer women to their linked midwife, who becomes the primary provider of care for the woman and is known as the primary midwife. She carries out the booking procedure and discusses options for birth. Women assessed as being at low risk have the choice of home birth, GP delivery (domino scheme), 'home-from-home' scheme, or delivery by team midwives in the labour ward. Women who need obstetric care are referred by the midwife to a named obstetrician for hospital booking. The obstetrician and team midwives share the woman's care, but the pattern of antenatal visits and type of delivery are decided by the obstetrician (O'Brien 1993). This development gives hospital midwives links with their community colleagues, autonomy over their low risk caseload and strong links with an obstetrician who leads the care in consultation with the midwives for the high risk caseload (Harrison and Prentice 1993).

Developments in team midwifery, if well planned and managed, plus the creation of midwife-led units in hospitals could be decisive steps in establishing midwives as the prime providers of maternity care for women with normal pregnancies and no complications in labour and delivery. These developments are also vital if some of the objectives set for maternity services in *Changing Childbirth* are to be met, for example:

> *'Every woman should have the name of a midwife who works locally, is known to her and whom she can contact for advice. She should also know the name of the lead professional who is responsible for planning and monitoring her care. Within five years, 75% of women should be cared for in labour by a midwife whom they have come to know during pregnancy'.*
>
> *'A woman with an uncomplicated pregnancy should, if she wishes, be able to book with a midwife as a lead professional for the entire episode of care including delivery in a general hospital'.*
>
> (DoH 1993b)

Introducing team midwifery and achieving these objectives present a huge challenge to midwives and their managers. They must break away from the familiar, rigid routines associated with hospital nursing and introduce new patterns of practice that give midwives much more flexibility and autonomy to organize their own day-to-day work. The independent midwifery practices in the Netherlands are seen by some as a model for the future, but most midwives here would welcome an increase in responsibility and more control over their work within the existing system (Oppenheimer 1993).

Commentary

Maternity services in the UK have a long and well-established tradition of the professionals involved—midwives, GPs and obstetricians—working together and sharing responsibility for the care of women throughout pregnancy, birth and in the postnatal period. However, over the years there have been important changes in the patterns and place of care, and in the roles and responsibilities of practitioners and the nature of their collaboration. The last five years have seen particular attention given to the problems of providing maternity services and a fundamental shift in national policy on the organization and delivery of maternity care.

Traditional arrangements for sharing antenatal, intrapartum and postnatal care have been severely criticized by professionals and consumers alike. Applied to maternity services, the term 'shared care' has become so devalued that it has almost fallen out of use. The case against traditional shared maternity care can be summarized as follows.

Shared care has:

- been too strongly influenced by a medical model of pregnancy and childbirth, that led to an undue emphasis on abnormality and a tendency to intervene unnecessarily during labour
- been too reliant on hospital-based services
- incorporated many outdated procedures of unproven safety or effectiveness
- been inefficient, particularly in terms of lack of coordination between different practitioners working in different settings
- failed to provide good continuity of care throughout pregnancy, birth and the postpartum period for the majority of women
- offered women no real choice in the way services are provided, where, and by which professionals
- not used to the full the knowledge and skills of some professionals involved, notably midwives.

In response to these criticisms, midwives, GPs and obstetricians have sought new ways to provide shared maternity care. Different patterns of care are being developed and new roles and relationships are being forged in attempts to improve services for all women. Some of the key developments that have been discussed here are:

- shifting most antenatal care to the community and introducing more streamlined schedules of antenatal visits

- defining more precisely the content of antenatal care, to include only procedures for which there is evidence of safety and effectiveness; agreeing the division of responsibilities and tasks between professionals; and confirming these in written protocols and guidelines
- women carrying their own obstetric records, rather than shared care cards
- specialist hospital staff holding antenatal clinics outside hospitals, including attending GP/midwife clinics in surgeries and health centres
- midwives extending their skills and taking on more responsibility for the care of women with uncomplicated pregnancy and labour.
- redefining and re-evaluating the role of midwives and GPs in intrapartum care, including developing more midwife- and GP-led units in hospitals.

As well as improving care for patients, these developments have also brought with them more of the 'desirable features' of shared care that we listed in Chapter 2 as important for the success of shared care schemes.

TRUE COLLABORATION?

Many of the initiatives described appear to be truly collaborative ventures between professionals and which span the boundary of primary and secondary care. Some schemes, particularly the developments in hospital maternity units, have involved extensive discussion among participants of ideas and philosophies, lengthy planning, careful implementation, and thorough evaluation. There is also evidence of a willingness to discover the views and preferences of the women who use maternity services, and to provide what they want. As far as we know none of the schemes have used conceptual modelling or a similar technique as a way of establishing shared aims and goals, but substantial effort must have been put into creating a sense of shared ownership of the changes that have been introduced. Exceptions to this are some of the team midwifery schemes and some developments in hospital maternity units, which regrettably appear to have been introduced without any real involvement of GPs.

Developments in community antenatal care and in GP- and midwife-led intrapartum care depend on teamwork being effective in primary care and in the hospital as well as on collaboration across the boundary. The requirements for good teamwork seem to be increasingly recognized. Most recent schemes are built on teams of reasonably small numbers, and regular personal contact and joint meetings are encouraged. However, there are no reports of schemes including team development or training as part of implementation.

In many of the integrated maternity care schemes women now carry their own records rather than shared care cards, which held a limited amount of information and involved duplication of recording of information. A woman's notes should record her preferences and plans for birth and other aspects of care. Plans are being discussed to introduce a standard national patient-held pregnancy based record, based on one developed in the West Midlands region. Computerized records are being tried, but are likely to take longer to come to fruition (Macfarlane *et al.* 1995).

GUIDELINES

Guidelines or protocols are features of many of the initiatives described here, especially where care is being shifted out of hospital clinics or delegated to midwives. The Sighthill scheme in Edinburgh pioneered the use of protocols for risk assessment and in management of antenatal complications such as hypertension (McKee 1984). Most schemes have set guidelines for selecting women at low risk of developing complications, but the criteria appear to be of low value in predicting which women will actually require specialist care, either during pregnancy, in labour or after the birth. Thus most schemes offering GP or midwife care are characterized by high levels of referral or transfer to specialist care. Guidelines also usually specify the circumstances under which a specialist opinion should be sought or care should be transferred. However, they rarely indicate the circumstances under which care can be safely returned from the specialist to the midwife or GP. The high level of transfer that is a feature of many shared care schemes needs further investigation.

Given the unpredictable nature of problems in pregnancy and childbirth and the current state of medical knowledge, it may be that referrals or transfers should not necessarily be considered a problem, but an essential part of shared care that need to be properly planned for in any integrated system.

COMMUNICATION

All shared care schemes should make provision for effective informal channels of communication, which can be essential for rapid referral, transferring knowledge, solving problems and joint decision making. Written guidelines and formal procedures for transfer of care tend to emphasize 'shifting the patient', often quite slowly, rather than sharing the problem and solving it quickly. The antenatal 'outreach' clinic initiatives reviewed by Wood (1991) provided excellent opportunities for dialogue about patient management that may be difficult to replicate in shared care schemes where specialists stay within the confines of the hospital. Organizing teams of midwives on a geographical basis, linking each team to several general practices and one consultant, is another way of facilitating personal contact and good communication. Computerized information systems are not a particular feature of shared maternity care—the patient-held record and arrangements which give easy access to informal advice may be sufficient to support effective communication.

INFORMATION AND AUDIT

Maternity care would be a particularly good domain for the implementation of decision support (see Chapter 19). The knowledge is well structured, for example the Cochrane Pregnancy and Childbirth Database leads the field (Cochrane Collaboration 1994). Many protocols and guidelines exist that would be easier to use in a decision support system. Missing data could be prompted. In obstetrics, accurate and speedy decisions are needed, often at night and at many locations. This could be a suitable application for a narrow-domain decision support system on a 'notebook' portable computer.

Changing Childbirth (DoH 1993b) emphasized the importance of audit, particularly monitoring women's satisfaction with services and improving performance, but it is not clear to what extent useful audit is being built into new developments that are being introduced. Audit that involves GPs and hospital doctors working together in collaboration (so-called interface audit) is rare and appropriate approaches to auditing shared care may take time to become accepted (Baker 1994). Most of the studies described here have compared outcomes of care for women and babies but we would suggest that more attention should be given to the processes of shared care, to ensure that it is working effectively and efficiently, and continues to evolve and improve. One issue for study might be transfers from GP/midwife to specialist care; whether they are necessary; how disruptive they are for professionals and patients; and whether they might be managed differently.

Concern has been expressed that routinely collected data on maternity services are of poor quality and inappropriate for audit purposes. Mortality statistics are no longer considered very useful measures of outcome because there are so few deaths among mothers and babies. The focus should be on morbidity, including iatrogenic risk, when different systems of care are compared (Macfarlane and Campbell 1994). National information on GPs' contribution to maternity care and the work of community midwives is totally inadequate for monitoring the changes recommended by the Department of Health (Drife 1995). Macfarlane and colleagues from the National Perinatal Epidemiology Unit (1995) have argued strongly for 'information systems which transcend the barriers created by the internal market and bring together relevant information about women and their babies'.

A NEW ERA

Maternity services throughout the UK are going through a period of intense review and reorganization. In many areas, traditional 'shared care' is being replaced by new forms of collaboration between GPs, midwives, obstetricians and pregnant women. Professional roles, responsibilities and relationships are changing rapidly. Many of the initiatives prompted by *Changing Childbirth* clearly represent enormous improvements and will be welcomed by women and professionals alike. However, some schemes are still largely experimental, and require careful monitoring of the evidence whether they really do improve patient care.

Chapter 8
SHARED CARE IN INVESTIGATION AND DIAGNOSIS

◆

In this chapter we explore the possibilities for shared care in investigation of patients by considering two domains in which open access for GPs to hospital based testing is becoming more common and is the subject of considerable current debate. The first is gastroenterology, in which a number of hospital departments have offered GPs open access to endoscopy for some years. The second is cardiology, in which open access to exercise electrocardiography and echocardiography have been tried more recently in a small number of centres.

There is growing interest in building a partnership between primary and secondary care to facilitate investigation of symptoms, increase the accuracy of diagnosis, and improve the subsequent management of disease. A number of schemes involving collaboration between GPs and hospital specialists have been tried. They focus on simplifying or streamlining the referral process, ensuring more appropriate and timely referrals for hospital-based tests, or making it easier to get a specialist opinion. 'Outreach clinics', held by consultants in primary care settings are commonplace in some specialties, particularly psychiatry (Bailey *et al.* 1994), and have even been tried by cardiologists (Flugelman *et al.* 1990). However, the number of practices that can benefit from these arrangements and the number of patients that can be seen are relatively small. An increasingly popular option in some specialties is to give GPs direct or open access to certain hospital facilities for investigation and diagnosis. Patients are sent directly for testing, rather than first attending an outpatient clinic. Protocols or guidelines for referral are often used in such schemes.

Arguments in favour of direct access are that it is quicker and more convenient for patients; reduces pressure on busy outpatient clinics and saves money; and enables GPs to improve their management of common illnesses. Arguments against are that it encourages inappropriate testing of patients, therefore increasing costs, but results in neither more diagnosis of serious illness nor better management of patients.

Open access endoscopy

Use of endoscopy to investigate upper gastrointestinal symptoms, such as dyspepsia, has increased enormously over the last 10 years. It is generally accepted that endoscopy is a sensitive and effective procedure for confirming the presence of disease. Increasing demand for endoscopy led many hospital departments to offer GPs open access to the service and it is now available in about half of Britain. There has been fierce debate about whether this is appropriate for the procedure (Heatley 1993). However, with a growing number of centres reporting positively on the experience of trials of open access endoscopy, opinion now seems to have swung in favour of more widespread availability of the service. A working party has recently published guidelines for referral (Axon *et al.* 1995). Jones (1995) has assessed the case for providing endoscopy in general practice, concluding that 'improving the facilities for open access endoscopy in hospital gastroenterology departments may be a better option than setting up services based in the community'.

Open access to endoscopy has been offered to GPs by Gloucester Royal Hospital since 1976, and Gear and Wilkinson (1989) have reported on their eleven years' experience of the service. Increasing numbers of patients were referred by GPs over the years, but the number of positive diagnoses remained fairly constant. As the numbers of endoscopies increased the number GP-requested barium meals fell. Thus Gear and Wilkinson concluded that open access endoscopy does not lead to an unnecessary duplication of investigations, which was one of the findings of a smaller trial by Holdstock *et al.* (1979). The Gloucester study also found a correlation between GPs' use of the open access service and moderation in prescribing cimetidine (a drug for treating ulcers). About a quarter of the GPs surveyed seldom used the service and were prescribing at a rate between three and four times the average level, which Gear and Wilkinson argued was both wasteful of resources and potentially dangerous.

One of the concerns of early schemes was that unrestricted open access would lead to a massive increase in workload for endoscopy units, many unnecessary referrals and a very high proportion of normal findings. A two year retrospective audit of the endoscopy service at Halton District Hospital found that patients referred by GPs and those referred from hospital clinics had remarkably similar results (Kerrigan *et al.* 1990). About 40% of patients in each group had normal findings, and the proportions with different types of disease were the same in each group, except for cancer, which was more common in the patients referred by hospital doctors. The authors concluded that open access did not increase the number of unnecessary investigations and should be more widely available. They also recommended limiting the service to patients aged over 40 to reduce referrals and increase the diagnostic yield.

DEVELOPMENTS IN MIDDLESBOROUGH

A group from Middlesborough General Hospital has described the development of an open access gastroscopy service and evaluated its impact on both the hospital and GP services (Bramble *et al.* 1992, Hungin *et al.* 1994). They describe the careful planning that took place by a group of physicians, surgeons and GPs to establish and staff the new service; agree a request form, with guidelines for GPs; organize a rapid and reliable system for relaying results to practices; standardize information for patients; computerize and build in audit requirements; and publicize and explain the service to GPs. Clinical assistants were appointed to cope with the increased workload and they now perform just over half the open access gastroscopies. Waiting time for a gastroscopy was kept short: on average 17 days; and during the first two years of the service waiting time for a medical gastrointestinal outpatient appointment fell from 120 days to 37 days. The authors comment that 'Fears about being unable to cope with the numbers have not materialized and the number of normal gastroscopies has remained constant at around 35%' (Bramble *et al.* 1992).

The group also followed up all patients referred by GPs for gastroscopy in one year to discover how they were managed, particularly those with normal results (Hungin *et al.* 1994). They found a rationalization of drug therapy (60% of those with normal findings had their drug treatment stopped or reduced in grade after the investigation); a reduction in the number of consultations (there was a fall in consultations for dyspepsia in all groups of patients); and a low re-referral rate (19% of patients were subsequently referred to hospital). They concluded that 'Open access gastroscopy has a major effect on patient management in general practice, and a normal endoscopy result has as important an impact as an abnormal one'.

Other clinicians have developed open access services with the aim of achieving earlier diagnosis of cancer, particularly gastric cancer, which is typically discovered at a late stage and has a poor prognosis. In the UK the overall five year survival rate of patients is only 5%. In Japan mass screening and treatment of early disease produces a five-year survival of 97% (Hallissey *et al.* 1990).

BIRMINGHAM AND QED

Clinicians at the Queen Elizabeth Hospital Birmingham in collaboration with 10 general practices offered endoscopy to all patients aged over 40 presenting with dyspepsia for the first time, to see whether this would increase the proportions with early and curable disease (Hallissey *et al.* 1990). GPs were asked to refer patients to the hospital team which held a regular dyspepsia clinic in each surgery. Patients' symptoms were recorded and they were offered an appointment for endoscopy within two weeks. A full report on the findings was sent to the GP. Two thousand five hundred and eighty-five patients were investigated of whom 115 (4%) were found to have cancer, a proportion which surprised the researchers who expected a much lower yield. Clinical diagnosis of gastric cancer by both GPs and hospital doctors was very inaccurate. The proportion of cancers detected as early lesions increased from 1% to 26%, and the proportion of potentially curative resections rose from 20% to 63%.

The authors used these results to argue for a low threshold to investigate patients with dyspepsia and immediate access to endoscopy. They take issue with other researchers who have tried to find ways of 'filtering' patients in order to reduce the number of endoscopies and increase the yield of positive results (for example Mann *et al.* 1983, Davenport *et al.* 1985) on the grounds that they are including only those patients with the most advanced disease and thus failing to meet the objective of earlier diagnosis.

The study established good relationships between the GPs and hospital doctors, and the service to the practices was continued, omitting the dyspepsia clinics and allowing the GPs to refer patients directly for endoscopy. Subsequently the Queen Elizabeth Hospital established the flagship Quick and Early Diagnosis Unit (QED) to which all local GPs can directly refer patients with dyspepsia, and a variety of other common but worrying symptoms (e.g. rectal bleeding, haematuria, hoarse voice) for immediate investigation and diagnosis. GPs refer patients directly to the unit by telephone. They are given clear criteria for referral to each clinic within QED and must complete a referral form with personal and clinical details about the patient. For some clinics patients are given instruction leaflets which explain what they must do before arrival at the clinic. Patients are offered an appointment as quickly as possible, usually within two weeks. All necessary investigations are carried out at one visit and the aim is to provide a diagnosis as soon as possible, often before patients leave the unit. GPs are notified within 24 hours (usually by post) but the intention is to install computers and rapid communication systems that will improve links between practices and the unit (QED, undated).

The research described above is the basis for QED's policy on investigating patients with dyspepsia, although the services are continually monitored and assessed. To reduce unnecessary endoscopy, the age limit has now been raised to 50 instead of

40 years. A protocol for managing patients under 50 has been developed, with the emphasis on eradicating *Helicobacter pylori* infection (QED, undated).

Open access to cardiac investigations

Some hospitals have begun to offer open access to certain cardiology services for GPs who want to investigate patients with chest pain, whom they suspect have angina (exercise testing), or patients who complain of breathlessness and who may have heart failure (echocardiography). The aim is accurate diagnosis, effective treatment and generally better management of patients with heart disease. There are a number of studies of open access to exercise testing, and these are discussed first. Then we consider echocardiography, which is only just beginning to be made available to GPs.

EXERCISE ELECTROCARDIOGRAPHY

Chest pain is a common symptom presented to GPs, but the presence of coronary heart disease is often difficult to determine at a preliminary investigation. Patients with chest pain suspected to be due to ischaemic heart disease form a large proportion of new referrals from GPs to cardiology outpatient clinics. Prompt and accurate diagnosis of the cause of pain is important to the management of these patients, but some writers have questioned whether automatic referral to outpatient clinics is a good use of hospital resources (Piercy 1993). Guidelines on the management of angina issued by a working party of the British Cardiac Society and the Royal College of Physicians in 1993 suggest that assessment of patients with chest pain in general practice should include clinical assessment of symptoms; clinical examination of the patient; and appraisal of coronary risk factors. Further investigation in primary care might include a 12-lead ECG (either in the practice or via an open access service), to identify high risk patients, and cholesterol measurement. Management at general practice level focuses on advice and explanation, risk factor reduction and medical treatment with drugs. The working party recommends referral to a cardiologist for further evaluation if the diagnosis is in doubt and for all newly diagnosed cases of angina in patients under the age of 70 (De Bono and Hopkins 1993, Royal College of Physicians 1993).

Despite advocating referral of the majority of patients to hospital for further assessment, the guidelines emphasize that hospital doctors and GPs share the care of patients with angina. 'Management at secondary care level is essentially an extension of that at primary care level, and will often be a collaborative venture with the primary care team' (Royal College of Physicians 1993).

Since exercise electrocardiography is a test that is usually carried out on patients who are referred to hospital with suspected ischaemic heart disease, some cardiologists consider that offering GPs direct access to exercise testing is a way of improving the management of ischaemic heart disease and reducing the number of referrals to cardiology outpatient clinics. Exercise testing can provide valuable diagnostic information, especially in patients with a moderate probability of the disease, and can be of prognostic value in patients with known heart disease. It is, however, of little value in screening asymptomatic patients. Three schemes in which GPs were given direct access to the test are described below.

SOUTH EAST KENT

The first scheme, in South East Kent, began in 1987 and was evaluated after one year, during which 47 GPs referred a total of 110 patients (Paul *et al.* 1990). The scheme appears to have been started with little preparation for participating GPs, who were asked to complete a postal questionnaire before and after each referral. Before the referral, GPs were asked for their clinical assessment of the patient, the reason for the request and what their management of the patient would have been without the open access service. The second questionnaire asked the GP to reassess the patient in the light of the test result and to say how the outcome had influenced management of the patient.

GPs referred patients for exercise electrocardiography mainly for diagnostic reasons (88%). They tended to overestimate the risk of ischaemic heart disease and referred a large proportion of patients for whom testing was inappropriate (46%). These were mainly a group of young patients with non-cardiac chest pain. The test results caused GPs to alter their management of patients in 85% of cases. Without the open access service all the patients would have been referred to the cardiology clinic at the local hospital. Twenty-three of the 110 patients were eventually referred: 15 to the district hospital and eight to a cardiac centre with facilities for invasive investigation. However, the researchers felt that management of patients following testing was not always appropriate. They concluded that 'Although the provision of open access stress testing has much to offer (and may be a cost-effective way of reducing unnecessary district general hospital outpatient referral) it rarely, in its present form, improves the management of cardiovascular disease in the community' (Paul *et al.* 1990).

The scheme, however, was not abandoned. Modifications were made to its organization and attempts were made to help GPs use the service more appropriately. GPs were invited to attend lectures and were sent information about the use of exercise electrocardiography, including the findings of the first study. The results of a further year's referrals to the modified service were reported by the same group in 1991 (Sulke *et al.* 1991). The main changes were that GPs were sent guidelines for referral, the request form was altered and a registrar reviewed all requests. If they did not conform to the guidelines, the registrar would discuss the request with the GP. Twelve per cent of requested tests were cancelled at this stage. The test results were also reported back to the GP on a different form, with a more comprehensive description of test performance and a categorization of the result, which was intended to help GPs interpret the results. GPs were always informed by telephone of strongly positive results, allowing further discussion of possible management options. The results of the second study were more encouraging. The researchers estimated that 67% of referrals were now appropriate; fewer patients with non-cardiac chest pains were referred; and there were more patients with a moderate risk of ischaemic heart disease. More patients with known heart disease were referred for prognosis and evaluation of drug therapy. Over the two years, referral of patients with clinically suspected ischaemic heart disease for cardiological opinion at the district general hospital decreased by 50%.

The changes made to the open access service improved the utilization of exercise testing by local GPs. At the end of the second study the researchers conclude 'Open access exercise electrocardiography is a facility that is potentially highly cost effective in terms of reduction of unnecessary district general hospital cardiology outpatient referrals whilst also allowing more rapid invasive diagnosis and treatment of patients at high risk of ischaemic heart disease in the community' (Sulke *et al.* 1991).

BELFAST

Open access exercise electrocardiography has been offered on a trial basis for two years to 122 general practitioners in north and west Belfast (McClements *et al.* 1994). They were sent an information pack about the service six weeks before its launch. Criteria were laid down for referrals, and the service was restricted to patients aged 65 or under with undiagnosed chest pain in whom, after clinical assessment, ischaemic heart disease was genuinely suspected. The pack also contained a guide on the usual appropriate actions after negative, inconclusive, positive and strongly positive test results. GPs were required to complete a request form for each patient. Requests were checked by a hospital doctor and exercise tests were usually performed within two weeks. Reports were sent to GPs within 48 hours, along with a short questionnaire. GPs were telephoned by the senior doctor if the exercise test was strongly positive.

Over two years, 212 requests were received from 43% of participating GPs. If the service had not been available, the GPs said they would have referred 97% of these patients to the hospital cardiology clinic. Only 10% of patients were referred after testing. Eighteen per cent of tests were positive, although GPs had assessed the probability of ischaemic heart disease as high or moderate in 68% of referrals. The researchers comment that in most cases the action taken by GPs on receiving exercise test results seemed appropriate. They conclude that . . . 'direct access exercise electrocardiography for patients with suspected ischaemic heart disease is safe, feasible and helpful to general practitioners. The service seems to reduce the number of patients referred to outpatient clinics and to facilitate the management of these patients in the community' (McClements *et al.* 1994). As part of the future development of the service, efforts were to be made to involve GPs who had not yet used the service.

NORTH LONDON

The Whittington Hospital in north London has offered an ECG service to GPs for many years. In 1990 direct access was extended to echocardiograms, 24-hour ambulatory ECGs and exercise stress testing for 'accredited' GPs, who had attended a half day training seminar run by the cardiac department (Cripwell and Patterson 1992). Audit of the use of the service showed that GPs were less likely than hospital doctors to provide inadequate information on test requests (7% v 22% respectively) but there were no significant differences in the proportions of inappropriate requests (Aszkenasy *et al.* 1994).

At first GPs were slow to use the direct access service, which may reflect an initial lack of confidence. The authors report that 110 GPs have been accredited (out of approximately 300 who regularly refer to the cardiac department) and the number of requests is increasing. GPs are kept informed about the service by a newsletter and through continuing clinical meetings (Aszkenasy *et al.* 1994).

ECHOCARDIOGRAPHY

Although echocardiography (ultrasound examination of the heart) has been made available to GPs at the Whittington Hospital, this is a very recent development in open access services. Echocardiography is a useful investigation for confirming heart failure and detecting other heart abnormalities.

Studies have shown that patients with heart failure are often inadequately investigated and treated (Clarke *et al.* 1994) and more widespread use of echocardiography has been advocated (Dargie and McMurray 1994). The test is usually only available by referral to hospital specialists, but open access schemes have now been tried in Nottingham and Edinburgh as well as in London (Hampton and Barlow 1995).

The aim in Edinburgh was to limit the service to patients thought to have heart failure or impaired left ventricular function and the first five months' referrals have been assessed (Francis *et al.* 1995). The new service was launched by holding a meeting for GPs, giving them an information pack about echocardiography, request forms and patient information leaflets. In the first five months 259 patients were referred by GPs and only 12% of these were considered inappropriate. Among the patients who were already being treated for heart failure, 26% were found to have serious left ventricular systolic dysfunction. Changes in treatment were recommended in nearly 70% of treated patients. Only 8% of untreated patients had positive findings. After investigation GPs were sent a report summarizing the findings and recommending changes in treatment or further investigation. The cost of each echocardiogram was estimated at £55.

The open access service was popular with GPs, who apparently used it responsibly, and there was no unmanageable increase in workload for the hospital. The authors concluded that echocardiography 'was most valuable in assessing those patients in whom a presumptive clinical diagnosis of heart failure has been made and treatment begun. In this group, echocardiography led to an important change in clinical management in nearly 70% of cases' (Francis *et al.* 1995). This study also demonstrates the value of normal investigation results, not only for reassuring patients and doctors but also for enabling unnecessary treatment to be stopped.

Commentary

These examples of open access to endoscopy services for GPs and the more recent initiatives with cardiac investigations show

how cooperation between hospital specialists and GPs can facilitate investigation of common symptoms, and assist diagnosis and subsequent management of illness. Some early pioneers of open access services were concerned that removing the specialist as gatekeeper to expensive hospital-based tests would lead to overwhelming workloads for hospital departments, unnecessary investigation of patients, and result in an unacceptably low proportion of positive findings, thus making the service uneconomic. However, these fears seem to have been allayed as experience of open access has grown, and information has accumulated about utilization and outcomes. The published studies of open access discussed here are all descriptive (there are no randomized controlled trials) and generally written by enthusiasts, but their results all point in the same direction. If the open access service is well planned and GPs sufficiently prepared, they will use it as responsibly as hospital doctors. Patients are not investigated unnecessarily, and the gains in terms of reducing pressure on outpatient clinics can be substantial. A relatively high proportion of normal findings is to be expected and is acceptable. A normal result may be as valuable as a positive result in making decisions about treatment. Given appropriate feedback on test results, GPs' clinical management of patients improves.

There is still debate about whether the development of more open access services would be beneficial (Hampton and Barlow 1995, Jones 1995). Clearly many tests should remain under the control of hospital specialists, but there is agreement that open access is appropriate for techniques that are non-invasive, harmless, reliable and relatively cheap and can be carried out by a technician. Hampton and Barlow (1995) define a successful service as one in which the test *replaces* the need for a specialist opinion. 'The more a test can be reported in simple numerical terms the more it is suited to open access; the more a report depends on opinion the more important that it is made in the light of a clinical assessment of the patient. One of the problems of both open access exercise testing and echocardiography is couching reports in terms that general practitioners can use in patient management. As with all open access investigations the key to optimal use is for strict guidelines to be agreed between specialists and general practitioners'. They suggest that GPs who want a specialist opinion need to refer their patients to a clinic, rather than simply sending them to hospital for a test.

Hampton and Barlow seem to be arguing that open access is valuable only in terms of streamlining services and improving efficiency and economy: that it is simply a short cut for GPs and patients to investigations that require hospital based technology and skills. In some cases open access may amount to nothing more than a way of avoiding formal referral and lengthy waits for outpatient appointments. There may be no change in the relationship between GPs and consultants; no additional communication or exchange of better quality of information (except perhaps that guaranteed by use of a standard referral form and a system for rapid feedback of results); and no consequent increase in the knowledge and skills of those working in primary care. This type of open access would offer no gains in the development of shared care.

All the examples discussed here, however, indicate that open access is more than just a short cut to testing: it can lead to more fundamental changes, including improvements in clinical management of patients and increased effectiveness of care. Indeed, in most of the examples the consultants involved wanted to improve the quality of care and increase collaboration with GPs as well as reduce pressure on their outpatient clinics. These gains require more than just creating direct routes to testing for GPs. For example, the trial of open access exercise testing in South East Kent illustrates how offering a short cut to investigation was successful in reducing outpatient referrals, but to achieve their aim of improved management of cardiovascular disease the consultants had to share their expertise with GPs, by providing better information and increasing opportunities for discussion, which enabled GPs to use the service appropriately and make more informed decisions about treatment.

Developing open access services can clearly help to break down barriers between hospitals and primary care, pave the way for more cooperation between consultants and GPs in diagnosis and management of patients, and help to transfer knowledge and skills. Open access of the kind described here may be just one aspect of an evolving shared care programme, or it may be the first step towards changing relationships between primary and secondary care.

The greatest gains from open access are likely to result if:

- **schemes have been planned in collaboration with all those who will be involved in providing and using the open access service**
- **GPs are well informed and prepared before the service begins, and are kept informed about developments**
- **precise guidelines are agreed for referral**
- **GPs are given appropriate feedback about test results that is easy to translate into decisions about clinical management**
- **provision is made for direct contact between GPs and specialists to discuss results and subsequent management of patients, in more serious or complex cases**
- **the service is audited, and modified if necessary.**

Chapter 9
ACUTE (EMERGENCY) SHARED CARE

◆

In this chapter we consider the possibility of shared care in situations where a rapid response to acute illness is required. There are few examples in the literature, but the recent debate about early management of heart attacks, and the place of thrombolytic therapy, provides a case study that illustrates the issues in acute shared care.

Shared care in acute illness

Shared care is now an accepted way of organizing maternity care and the management of certain chronic illnesses. The idea of planned collaboration and shared responsibility across organizational boundaries is less familiar in the management of acute illnesses or in an emergency when a rapid response is required. However, there are some examples of cooperation between primary and secondary care that might be described as 'acute shared care' and one is the collaboration required between GPs, ambulance staff and hospital services in the management of patients with suspected heart attacks.

A coordinated response to suspected heart attacks has always been considered desirable, but until recently the main aim, as with most other acute illnesses, was to get the patient to hospital for specialist care as rapidly and comfortably as possible. The recent discovery that giving thrombolytic therapy (drugs to dissolve blood clots) as early as possible after a heart attack can substantially reduce mortality has led to a fundamental rethink of how heart attack patients should be managed and, in particular, to a reappraisal of the role of the GP in this emergency situation.

Heart attack and thrombolytic therapy

Heart attack (myocardial infarction) is the greatest single cause of premature death in the UK. About half of all deaths that occur after a heart attack take place within two hours of the start of symptoms. Many patients die before they can be seen by a doctor and mortality is high in the month after a heart attack. In the last decade, the management of myocardial infarction has been revolutionized by thrombolytic treatment, which clinical trials have shown to reduce mortality by half when combined with low doses of aspirin (British Heart Foundation Working Group 1989). A crucial factor, however, is that to obtain maximum benefit this treatment must be given soon after the onset of symptoms, preferably within 90 minutes. This has led to a lively debate in the medical press about whether GPs should administer thrombolytic therapy before patients are transported to hospital.

The UK has no standard system for providing pre-hospital coronary care—patients experiencing sudden, severe chest pain may call their GP, summon an ambulance or go directly to a hospital accident and emergency department. Important requirements for optimal treatment of patients with suspected acute myocardial infarction are speed of response; clinical assessment and diagnosis; relief of pain and anxiety; correction of autonomic disturbances and arrhythmias; and resuscitation. Some countries, for example the US, provide specially staffed coronary ambulances to meet all these requirements and they have successfully added thrombolytic therapy to the treatment provided before admission to hospital (Waine *et al.* 1993). Some GPs in this country may be able to fulfil all these requirements but the majority do not have a defibrillator. The British Heart Foundation Working Group (1989) concluded that both the GP and ambulance should attend the patient without delay, 'with the general practitioner contributing personal knowledge of the patient, diagnostic skill, and pain relief with opiates and the ambulance service contributing resuscitation facilities and rapid transport'. The working group, however, was not in favour of GPs giving thrombolytic treatment. Their concern was to streamline the care of patients with myocardial infarction and get them to hospital rapidly enough to benefit from thrombolytic therapy given by a hospital doctor. They called for better coordination of services between health authorities, hospital physicians, GPs and ambulance services; guidelines for organizing the care of patients with heart attacks; and continuous audit.

Hospitals, however, have found it difficult to incorporate giving rapid thrombolytic treatment into their existing routines for emergency admission, and a number of studies have found that most patients are not treated within the optimal 90 minute 'call to needle' time (Birkhead 1992, Pinkney *et al.* 1993). A leader in the *British Journal of General Practice* made the case for GPs giving thrombolytic treatment at home and announced a Royal College of General Practitioners' study to investigate its safety and benefits (Kay 1991). A two-year, randomized, double blind trial in the Grampian Region of Scotland of GPs giving thrombolytic treatment at home showed that GP involvement was feasible and effective (GREAT Group 1992). All the practices participating in this study were equipped with an electrocardiograph and a defibrillator. The study found that GPs responded quickly to patients with suspected myocardial infarction (median response time 10 minutes) and administered thrombolytic drugs reliably, safely and effectively some two hours before they would have received this treatment in hospital. The benefits of earlier treatment were considerable: three months after trial entry there was a relative reduction in death of 49% in patients treated at home.

However, even following publication of these results there is still controversy about the role of GPs, generally focusing on whether they are competent to give thrombolytic treatment. Questions have been raised about how proficient GPs are at diagnosing heart attacks, whether they can read electrocardiograms, and whether an electrocardiogram is necessary before instituting treatment (Colquhoun 1993, McCrea and Saltissi 1993, Julian 1994). As Waine and colleagues (1993) pointed out, trials like GREAT provide an important stimulus to initiatives that increase the dialogue and collaboration between hospital specialists and GPs. They argue that GPs who wish to provide thrombolytic treatment, possibly in conjunction with paramedical services, should be supported by local cardiac services. Some GPs may need to develop their skills in interpreting electrocardiographs and in resuscitation. They should also be involved in regular audit of patients given thrombolysis in the community.

The most recent guidelines, issued in 1994 by the British Heart Foundation Working Group, concede that GPs have a role to play in giving thrombolytic treatment and specify the conditions under which such treatment may be given safely:

> *'General practitioners may wish to start thrombolytic treatment outside hospital providing that they have facilities for managing arrhythmia and for resuscitation, including defibrillators (which may be provided by an attending ambulance); they can accurately diagnose acute myocardial infarction by using clinical and electrocardiographic criteria; and they believe that pre-hospital treatment in each case will result in an appreciable time saving, particularly if this is the only way of achieving a 90 minute 'call to needle' time'*
>
> (Weston *et al.* 1994).

The working group assume that GPs intending to use thrombolytic agents will obtain the necessary training, but a great deal of encouragement, preparation and planning is also likely to be required. A recent survey of all GPs who refer patients to Plymouth's coronary care unit (where all the thrombolytic treatment for myocardial infarction is given in that district) found that although the GPs were well informed about managing suspected myocardial infarction, only 21% considered that giving thrombolytic therapy was part of their job. In the three months over which this survey took place, only one GP had given thrombolysis (Round and Marshall 1994). Even after the successful Grampian trial, many of the GPs who participated in the study stopped giving thrombolytic treatment when the trial was over. Rawles (1994) carried out a postal survey of GPs in Grampian and elsewhere and found that although most were convinced of the benefits of giving thrombolytic treatment, only 17% had given it in the previous year. Important factors preventing GPs from giving treatment were the need for more training and lack of encouragement by local cardiologists.

It may be unrealistic to expect GPs immediately to change their ways of working and incorporate new practice, even if it is based on sound evidence, without practical help and support. Recent studies have shown that many GPs are still not following simple, important and well-established aspects of the British Heart Foundation guidelines on early management of myocardial infarction, namely giving aspirin as soon as possible and providing adequate pain relief. In the Plymouth survey, 89% of GPs said they gave aspirin routinely but on checking the authors found that only 29% of patients with a final diagnosis of myocardial infarction had been given aspirin by their GP (Round and Marshall 1994). Two other studies found that only 26 out of 137 patients and four out of 133 patients admitted by their GPs to hospital with a suspected heart attack had been given aspirin (Moher and Johnson 1994, Wyllie and Dunn 1994). Only 40% of a random sample of GPs in Oxford region carried aspirin in their doctor's bag (Moher, Moher, Havelock 1994). Wyllie and Dunn (1994) also found that only 21% of patients had been given intravenous opiates as recommended in the guidelines, and many patients were in pain on admission.

Commentary

Acute shared care has been discussed here with reference to only one example of collaboration between GPs, ambulance services, A&E departments, coronary care units and cardiologists in the early management of patients with suspected heart attacks. Currently, this type of shared care is rare, and has only been tested on a relatively small scale in the context of a specially organized trial. The trial showed that acute shared care needs to be carefully orchestrated: all the players had agreed and planned in advance the roles they would play, and knew what to expect of each other. In this sense care of the patient was being shared, albeit for a very short period of time compared to the shared care schemes for chronic illnesses which involve follow-up of patients for years. In other settings, as the study in Plymouth showed, current practice is not so well ordered. GP participation in early management of suspected heart attacks is very variable; there appears to be little local planning and no agreement on the roles of the various agencies and professionals who may become involved. In most areas there is unlikely to be any information about the extent to which accepted standards of care are being met.

Shared care for patients suffering a heart attack is unlikely to develop further unless cardiologists, GPs and ambulance services are prepared to work together to establish the necessary trust that underpins all successful forms of collaboration, and cooperate to change and improve current practice.

Chapter 10
SHARED CARE IN REHABILITATION AND COMMUNITY CARE

◆

This chapter considers what happens to patients discharged from hospital who require continuing rehabilitation, and health and social care in the community. It looks particularly at services for stroke patients, although it is often difficult to single out services for this group, who have very variable needs for care, from the broad range of provision for people with all types of physical disabilities. It explores a wide spectrum of collaboration between health, social services and the voluntary sector, and focuses on examples of shared care in very complex circumstances.

Shared care for stroke patients

Once acute care has ended, the majority of stroke patients return to their homes, but a significant proportion still require some form of care or support. Coordination of services across organizational and professional boundaries is needed to discharge patients from hospital successfully and safely, and to provide continuing care that meets changing individual needs. The potential players here are hospital based professionals, informal carers, primary health care teams, community health staff, paramedical services, social services and the voluntary sector. Their involvement with a patient may be short or long term, continuous or intermittent, and central or peripheral to the patient's network of care and support. Because of the complexities of coordinating care from so many agencies and professionals, often over months or years, a variety of ways of facilitating cooperation have been tried. We first set the context for discussing stroke and stroke services, then look in turn at hospital treatment, discharge from hospital, rehabilitation and care at home. The chapter ends with a commentary on shared care for stroke patients.

Stroke is the third leading cause of death in industrialized nations, accounting for one in eight of all deaths. It is the commonest reason for people over the age of 65 being in hospital, and the commonest cause of severe physical disability (Wilson 1994). Around 4% of the NHS budget is spent annually on cerebrovascular disease, most of which is directed towards the aftermath of stroke. Up to 75% of patients who have a stroke are admitted to hospital and around 12% of those who survive are in institutional care one year after their stroke, but there are wide variations between districts (Freemantle *et al.* 1992). The government has set a target of a 40% reduction in death from stroke in people under 75 by the year 2000 (DoH 1992, 1993a).

There is no effective treatment for acute stroke (Sandercock and Willems 1992). However, there is agreement that coordinated, specialized, multidisciplinary care can lead to a better outcome for patients (Wade DT *et al.* 1993, Langhorne *et al.* 1993, Wolfe *et al.* 1993, Young 1992, Lincoln 1994). In 1988 a King's Fund Consensus Conference stated that the services provided for stroke patients in hospital, primary care and the community seemed haphazard, fragmented and poorly tailored to patients' needs. There is little evidence that this situation has changed substantially or that the principles of good practice agreed by the consensus conference have been widely implemented. However, a number of organizations, including the Royal College of Physicians in 1989 and the Scottish Office (SHHD/SHSAC) in 1993, have published guidelines on the management of patients with stroke. One of the early *Effective Health Care* bulletins reviewed the literature on stroke rehabilitation (Freemantle *et al.* 1992), and advice on contracting for stroke services has been compiled by the York Health Economics Consortium (Wilson 1994).

A stroke service should aim at achieving a prompt and accurate initial diagnosis; rapid identification of those needing specific acute medical and surgical treatment; provision of skilled and knowledgeable nursing care and (for some patients) terminal care; an early assessment of the patients' disabilities; and implementation of a multiprofessional care plan, including rehabilitation, secondary prevention, discharge from hospital, and follow up to prevent or identify later problems (King's Fund Consensus Conference 1988, Dennis and Langhorne 1994).

Where stroke patients are best cared for is a controversial topic. In practice, the majority are admitted to hospital, where they may stay for some weeks. A recent survey in three health districts in southern England found an admission rate of 78% and a median length of stay of 21 days for patients under the age of 75 (Wolfe *et al.* 1993). Stroke units have been shown to be an effective way of managing patients with acute stroke and some hospital trusts are now striving to establish a specialized, centralized service (Wade *et al.* 1993, Dennis and Langhorne 1994). However, in a recent *Controversies in management* feature in the *British Medical Journal*, Young (1994) argued forcefully that a more appropriate balance needs to be struck between hospital based care and care at home for stroke patients. Although hospital admission has become the norm for acute stroke, there are no medical reasons why this should be the case. Young claimed that the hospital is being used simply as a 'rapid access sanctuary' for those who have insufficient support at home and as a source of terminal and palliative care for those most severely affected. He made a strong case for the home to become the focus of care and long term rehabilitation. The arguments in favour of hospital care were put by Lincoln (1994). She cited the current lack of services in the community and their fragmentation as reasons for concentrating care in specialized hospital units, where it is easier to coordinate the necessary expertise and skills for treatment and rehabilitation. Clearly, well organized services for stroke patients should be available in both hospital and community. Current practice and some of its problems are examined below.

Hospital treatment

One of the difficulties of coordinating services for acute stroke is that not all patients are admitted to hospital and those who are admitted are likely to be under the care of different specialties and spread throughout the hospital. A survey in southern England found 79% of admissions were to medical beds, 11% to geriatric beds, 4% to intensive care and 1% to neurology beds (Wolfe *et al.* 1993). In Riverside Health Authority in west London acute stroke patients were managed by 13 different consultant teams on 13 different wards, and no patients received care on a stroke unit. A recent investigation there found that no protocols were generally agreed nor guidelines available for managing acute stroke, and there were no general guidelines or care pathways for accepting patients from primary care or A&E departments (Darkins 1995). Even in hospitals with stroke units it may be difficult to ensure that patients on other wards are managed according to protocols (Duncan *et al.* 1995). Admission to hospital by no means guarantees that patients receive coordinated care and rehabilitation during their stay. To overcome these problems, the King's Fund Forum recommended that hospitals develop an integrated stroke service, with a core team of nurses, therapists, social workers and doctors (King's Fund Consensus Conference 1988).

A review of the effectiveness of specialist stroke units, undertaken as part of the Cochrane Collaboration, showed that patients managed in stroke units were less likely to die than those cared for in general medical wards (Langhorne *et al.* 1993). The evidence for stroke units reducing disability in survivors is less clear cut, but the case for creating specialist multidisciplinary teams and acute and rehabilitation units for stroke patients has been persuasively put by Dennis and Langhorne (1994). Recent evidence-based advice to purchasers is to 'aim for all patients with stroke to be admitted to a specialist ward and to remain under the care of a single service throughout their illness, including when at home' (Wade *et al.* 1993). However, the authors admit that it may be idealistic to expect providers to create stroke units from scratch and advise a gradual process of evolution over a number of years, beginning with clustering all patients in a single ward.

An attempt to coordinate hospital care for stroke patients has been described by a group from West Lambeth Health Authority in south London (West Lambeth Health Authority Stroke Steering Group 1992). A district stroke register was established and a multidisciplinary stroke steering group created at St Thomas's Hospital, including representatives from general practice, community nursing, social services, hospital and community rehabilitation, psychology, geriatrics and neurology. The group used the King's Fund and Royal College of Physicians reports as the basis for its work but adapted the RCP guidelines for local use, particularly emphasizing the need for multidisciplinary working in stroke care. All new cases of stroke admitted to St Thomas's Hospital are immediately notified to the stroke register and information is collected on a standard form. A weekly stroke meeting, open to all those involved in the management of individual patients, is held at the hospital at which cases are discussed by therapists, the stroke register staff and consultants in geriatric care.

The King's Fund Consensus Conference (1988) also suggested establishing and evaluating different models of stroke care, including a mobile stroke team, which could span the hospital and community. However, few such experiments appear to have been carried out or reported in the mainstream medical press. A project has recently been established in one health authority in London to develop a comprehensive stroke service that integrates primary and secondary care, and promotes the transfer of acute care from hospitals to the community (Darkins 1995).

Discharge from hospital

An important part of good stroke care is to ensure that hospital stay is not unnecessarily prolonged and that patients are discharged home or to other settings in a way that enables their treatment and rehabilitation to continue without interruption or delay. However, surveys indicate that discharge from hospital, when responsibility for care is usually transferred from one sector or service to another, is often the weak point in the system when coordination breaks down and patients may fail to receive the care they need (Marks 1994). Poor coordination of services within hospitals and with agencies in the community may lead to 'clinically unnecessary' lengths of stay or to patients being discharged home with inadequate preparation and without essential aftercare arrangements being in place. One result of poor planning may be that patients are subsequently readmitted to hospital within a short time, often as emergencies (Marks 1994, Tierney *et al.* 1994). Researchers in one London health authority estimated that at least 38% of acute stroke patients in hospital on one day could have been managed in the community. Their delayed discharge was due to a need to provide adequate social care and rehabilitation (Darkins 1995).

In a thorough review of discharge policy and practice, Marks (1994) has shown how difficult it is to achieve the ideal of seamless care. The discharge process is at best a 'patchwork quilt' of initiatives with important weaknesses that may adversely affect quality of care. Broadly, there are two sets of related problems: those concerning the process of discharge itself, both within the hospital and in collaboration with other agencies, and those caused by inadequate services and resources for immediate and longer-term post discharge support in the community.

Research into services for elderly people has consistently found that poorly planned hospital discharge can result in a breakdown of care (Tierney *et al.* 1994, Neill and Williams 1992). Patients and their carers typically receive little preparation for discharge, complain that they are rarely consulted and given insufficient information about plans being made by hospital staff (Tierney *et al.* 1993). There is also long standing dissatisfaction among GPs over communication with hospital doctors about patients who have been discharged (Harding 1987). Delay in receiving information and the inadequate content of discharge summaries are the usual problems documented by researchers. A number of organizational solutions have been tried to bridge the gap and improve continuity of care for patients being discharged from hospital. These include creating liaison posts; providing short-term intensive post-discharge support for patients; tackling discharge planning as a management issue; establishing outreach services from hospital units that provide continuity of care for patients after discharge; and offering specialist services in the community to which patients can be discharged directly. These initiatives are discussed, in turn, below.

LIAISON POSTS

Much of the planning and coordination for discharge is done by nurses: hospital nurses refer patients who need continuing nursing care to their colleagues in the community or in nursing homes (Tierney *et al.* 1994). Problems at this interface have led to a growth in the number of liaison nurse posts, which are intended as a link between hospital and community. Liaison nurses facilitate communication, but Marks (1994) comments that such a profession-specific response can only be a partial solution to the complex problem of discharge planning, which 'involves crossing numerous professional and organizational boundaries'.

SHORT-TERM SUPPORT AFTER DISCHARGE

When elderly people who need continuing support are discharged from hospital one of the recognized difficulties is that statutory health and social services have been unable to respond quickly and flexibly enough to their needs, or to provide a wide enough range of personal, domestic and social support. Thus, in some areas the voluntary sector, mainly in the form of Age Concern and the Red Cross, has stepped in to offer short term (three to six weeks) generic help in the home, while the statutory services that will provide care on a longer term basis are mobilized. Many schemes were initially funded by the DHSS *Helping the Community to Care* programme in the mid 1980s, which established a number of projects run by voluntary organizations in partnership with health and local authorities. Crucial to the success of these initiatives is the use of generic staff who can immediately provide whatever blend of basic personal and domestic care is required, including simple nursing tasks, without the restrictions of traditional health and social service demarcations. Marks (1994) sees these schemes as 'a vital link in the community care chain, demonstrating creative collaboration between the statutory and voluntary sectors, and exploring the benefits of "hybrid" care assistants'. However, they may also be an unreliable link, since they are not available to all groups of patients or in all areas and are often insecurely financed. There are also difficulties in ensuring that standards of care are met consistently. Unfortunately, the fact that the voluntary sector has stepped in to fill this gap does not seem to have encouraged the statutory agencies to meet their responsibilities more reliably.

A MANAGEMENT ISSUE?

Another approach to improving discharge arrangements has been to tackle discharge as a management issue and lay down procedures that staff must follow. This approach was given impetus by the publication in 1989 of a health circular on discharge of patients from hospital (HC(89)5) which emphasized establishing written discharge procedures and allocating responsibility for managing and monitoring discharge procedures (DoH 1989b). However, Marks's (1994) assessment is that the circular has had limited impact, with 'implementation being both partial and patchy'.

The government's community care reforms have also focused attention on discharge procedures, especially for patients with complex and continuing needs for health and social services. Although all but the simplest discharge planning has always relied on collaboration between health and social services, implementation of the NHS and Community Care Act 1990 has created a new climate in which joint working is mandatory rather than optional. Since April 1993 hospitals have not been able to discharge patients directly to private residential and nursing care if public funds are to be used to pay for their care. Social services hold the budget for residential care and domiciliary services, and are now responsible for organizing assessments of patients who will need intensive support after discharge. The new and more precise arrangements for discharge have not only shown up the inadequacy of previous discharge planning (Henwood and Wistow 1993) but have also highlighted tensions at the interface of health and social care, many of which may be difficult to resolve (Marks 1994).

It is not yet clear whether the reforms will help to improve discharge arrangements for patients across the whole spectrum of dependency and aftercare needs. Nine months after implementation a monitoring team appointed by the Department of Health found that the standard of hospital discharge was very variable (DoH 1994b). Attention had been concentrated on the small group of highly dependent patients whose complex needs place them on the boundary between nursing home or residential care and home care. 'Improvements in hospital discharge have probably been experienced by those clients who are formally care managed, with much less change being evident for everyone else'. The team found that the main problems were still improper or premature discharge, insufficient information being provided either on admission or discharge, under-assessment prior to discharge and lack of involvement of GPs and primary health care teams. A manual for hospital staff to help them plan discharge for all groups of patients has recently been published by the Department of Health (1994b). It provides detailed guidelines and checklists for all those involved and is an attempt to spread good practice throughout the hospital system (Henwood 1994). A recent study of elderly patients awaiting discharge in Charing Cross Hospital, London, indicated that the new community care legislation has helped to facilitate earlier discharge (Ajayi *et al.* 1995).

OUTREACH FROM HOSPITAL

In the United States, discharge planning is much better developed than in the UK. Many hospitals employ, under a variety of titles, their own discharge planners, sometimes linked to outreach services, which provide short term nursing and social care in the patient's home immediately after discharge (Marks 1994). This kind of outreach model has been suggested for stroke units, but few operate in this way. It could certainly help to smooth transition from hospital to home, as the voluntary sector post-discharge support schemes have been shown to do for elderly people. The process of discharge is simplified because changing the place of care is separated from the problems of professionals sharing care or handing over to other agencies. The approach does not resolve these problems, only postpones them to the point at which transfer of care must eventually take place, but it can allow transition to be more gradual, which might help. Only a dedicated and fully integrated stroke service, for example as envisaged by Wade *et al.* (1993) and Darkins (1995) (which spans acute and long term care and rehabilitation and includes the full range of professional skills), might overcome the difficulties of transferring care from hospital to home. However, this represents a radical alteration to current practice and would require reallocating resources between provider units and professional groups, as well as integrating services across health and social services. It is by no means clear how this might be achieved and it remains an ideal rather than a reality within the foreseeable future.

SPECIALIST COMMUNITY SERVICES

Another way to simplify or focus the process of discharge is to create distinct specialized services in the community to which patients can be referred directly by hospital staff for assessment and planning of post-discharge care. Some hospital care at home schemes operate in this way, and have been successful in reducing lengths of stay in hospital and ameliorating the difficulties in getting optimal services that patients may experience on discharge from hospital (Marks 1994). For example, stroke patients are one of the largest categories of patients cared for by the Peterborough Hospital at Home Scheme (Marks 1991). This and similar initiatives are discussed below in the section on care at home.

Rehabilitation

Rehabilitation for patients after acute stroke may take place in general hospital wards, specialized stroke units, dedicated rehabilitation departments and the community. The range of services that constitute a package of formal rehabilitation care include those provide by nurses, remedial therapists, physiotherapists, occupational therapists, speech therapists, doctors, social workers, counsellors, orthoptists and chiropodists, among others (Freemantle *et al.* 1992). The availability of these services and how well they are planned and coordinated seems to be extremely variable. Freemantle and colleagues (1992) have assessed the evidence on the effectiveness of rehabilitation after stroke, but found that it was difficult to draw conclusions because of the paucity and poor quality of rehabilitation research. Physiotherapy and occupational therapy after stroke seem to be effective, but the evidence for the effectiveness of speech therapy is conflicting. 'Well organized multidisciplinary rehabilitation increases the rate of improvement in patients with stroke, though long term effectiveness is unclear'. A randomized trial of physiotherapy for stroke patients in Bradford found that patients treated at home made significantly greater improvements than those treated at a day hospital, although the home group received less treatment (Young and Forster 1992). The authors believe that home physiotherapy is a more flexible service—treatment can be given that is appropriate to the patient's needs—and they have shown that it can be more cost-effective than hospital based treatment (Young and Forster 1993). In addition it is likely that physiotherapists working in the patient's home also facilitated access to other essential services—'. . . they also undertook other activities such as liaising with community staff and organizing appropriate disability equipment'—which may have helped the patients' recovery (Young and Forster 1992).

Care at home

After a stroke, many people are able to continue to live at home, supported by family, friends and voluntary and statutory health and social services. Two recent studies found that three-quarters or more of stroke survivors lived at home, and that this group included a wide range of levels of disability. A study of stroke patients under 75 in southern England found that of those who survived for three months, 16% were still in hospital, 82% were living at home or with relatives, and 2% were in residential care. Fifty-three per cent of survivors had no disability, 21% were mildly disabled and 26% were moderately or severely disabled (Wolfe *et al.* 1993). A study in Newcastle of people who had survived for three or more years after being hospitalized for acute stroke found that 76% were living at home. Seventy one per cent of survivors were independent or only mildly disabled and most of these were living at home (Greveson *et al.* 1991).

For many years it has been government policy to provide care in the community for elderly and disabled people. However, providing an appropriate level and mix of services and coordinating care between the various statutory and voluntary agencies in the community has been an elusive goal. There is evidence that many stroke survivors living at home do not receive the equipment, services and support that are appropriate to their needs. For example, simple aids for the home to increase mobility and independence are not provided for many patients who would benefit from them (Wilson 1994). The survey in southern England offered some evidence of the limited contact stroke survivors had with health services after they were discharged from hospital. Fifty-seven per cent of patients were followed up in hospital outpatient clinics. After three months only 69% had seen their GP and 7% saw neither a GP nor a hospital doctor. Sixty-seven per cent of patients received no outpatient physiotherapy during the three months (Wolfe *et al.* 1993). The Newcastle study of long-term stroke survivors showed how heavily those living at home relied on their immediate family for care and support; 39% had not seen their GP in the last six months. Although the other 61% were seen regularly, GPs were less likely to see patients who were more severely disabled or who had speech problems. Greveson *et al.* (1991) concluded that 'targeting of services seemed poor, there was no relationship between level of dependence and level of support from voluntary or statutory services'.

Patients and carers often said they felt abandoned after hospital discharge and that they did not know who to approach for help. 'Sixty per cent would approach their GP if problems arose, but from previous experience patients and carers had gained the impression that GPs, although sympathetic, could offer no help' (Greveson and James 1991). Although GPs have long cherished their role as 'gatekeeper' to other health and social services, it seems that they have not always been able to ensure that their patients receive an appropriate level or range of services.

A number of approaches have been tried to provide better care and improve integration of services for elderly and disabled people living at home. These include:

- establishing hospital care at home schemes, for those who require high levels of nursing care;
- attaching social workers to general practice, to achieve better coordination between practice teams and social services;
- appointing care managers, following the community care reforms, to 'take responsibility for ensuring that individuals'

needs are regularly reviewed, resources are managed effectively and that each service user has a single point of contact' (DoH 1989a).

- merging health and social services staff into single, multidisciplinary teams to provide care.

Each of these approaches is discussed in turn.

HOSPITAL CARE AT HOME

Hospital care at home (HCH) has been defined by Marks (1991) as 'the provision of intensive levels of care for acutely ill people in their own homes'. It involves bringing a hospital level of care to the home, supplying medical, nursing and rehabilitation services as well as social support and equipment. This intensity of care distinguishes HCH from the broad spectrum of social and rehabilitative care encompassed by the term 'community care' and the levels of care normally provided by community health services.

Broadly, there are two organizational models for HCH. The most common is the creation of a specialized team, usually hospital based and often linked to a surgical specialty, but which may seek to involve generalist staff working in the community. The other model is a community based, generic hospital at home service for a geographically defined population which admits patients with a variety of different illnesses. The Peterborough Hospital at Home Scheme is this country's best known example, but there are similar, smaller scale schemes elsewhere (Marks 1994, Hughes and Gordon 1992). Stroke patients are one of the largest categories of patient cared for by the Peterborough scheme, but specialized HCH services for stroke patients have also been tried, for example in Bristol (Wade *et al.* 1985) and north Manchester (Brown and Gordon 1987).

The Peterborough Hospital at Home scheme began in 1978 and now covers the whole district. Its aim is to treat at home patients who would otherwise be occupying hospital beds, either by preventing admission or by facilitating early discharge. In addition to providing 24-hour nursing care, the team includes patient aides, who carry out a wide range of domestic tasks, physiotherapist, occupational therapist and social worker. GPs take medical responsibility for patients. Care of elderly patients with terminal illnesses dominates the scheme. (Marks 1991).

A controlled trial of a specialized home care service for stroke patients was carried out in Bristol in 1983 by Wade and colleagues (1985). GPs in the Frenchay district were divided into two groups, one of which provided the control group of stroke patients. A new home care service for the first six months after acute stroke was established to supplement the services already available to stroke patients being cared for at home. The home care team included a district nurse, physiotherapist, occupational therapist, speech therapist and social worker. The nurse acted as team leader and coordinator, clinical responsibility rested with the GP. The aim of the new service was to encourage earlier discharge of stroke patients and to prevent hospital admission. Patients from the control group did not receive the new service.

The results of the trial showed no difference between the two groups in terms of mortality or functional recovery, but there was a *higher* use of hospital bed days for the intervention group, quite the opposite result to that expected. Hospital staff did not take advantage of the scheme to discharge patients earlier. Marks (1991) comments that there are lessons here for those establishing HCH programmes. 'The distinctive contribution of the new service was not clear to GPs nor to hospital staff with the result that it was partially ignored by the former and viewed as competition by the latter. This underlines the importance of ensuring that new programmes are carefully introduced and integrated into existing services'.

In the case of stroke, many HCH schemes are basically part of early discharge schemes, reflecting the fact that nursing and rehabilitation are often the main reasons for being in hospital after the first few days. Most HCH schemes include a social worker to ensure that patients gain access to the necessary local authority social services. However, for patients who do not need the intensity of nursing care provided by HCH schemes other means of coordinating primary care and social services may be required. One method is to develop attachments or liaison arrangements between social workers and general practices.

ATTACHING SOCIAL WORKERS TO GENERAL PRACTICE

Attachment schemes have a long history, but most have been one off 'pilot studies' which, despite having many advocates and being widespread if not numerous, have not expanded far beyond the group practices in which they originated. Attachment arrangements vary from social workers being full members of the primary health care team, with their workloads reflecting the team's needs and priorities, to a more detached model whereby the social worker's primary responsibility is to the social services department and the workload is subject to its priorities and constraints (Nocon 1994). A recent example of the former type of arrangement comes from Cardiff and was reported to have been 'a resounding success' (Ruddy 1992). It is generally acknowledged that attachments can help to foster mutual understanding and closer working, as well as providing an opportunity to help people who would not otherwise receive help from social services.

A similar but more recent development is for social services departments to locate care managers in GP surgeries. East Sussex Social Services Department was an early pioneer, establishing six pilot projects in 1991. The pilot projects focused on care of elderly people and those with physical and sensory disabilities and also included developing joint assessments of need (Hoddinott and Royston 1991, Murphy and Rodriques 1992). Despite their acknowledged success, the East Sussex care management pilot projects have not been extended, mainly because of financial constraints within the social services department (Clode 1992). In general, placing care managers in GP surgeries has been seen as successful in improving joint working and offering a more coordinated service to users (Nocon 1994), and this way of working has been commended and encouraged by the Audit Commission (House of Commons Health Committee 1993). The Department of Health's monitoring team also found that real improvements in joint working between social services and primary health care teams had only occurred where face to face relationships had been established, especially between GPs and social workers. They made various recommendations to increase the contact and communication between GPs and care managers (DoH 1994c).

CARE MANAGEMENT

This is now the accepted way of ensuring high quality, coordinated services for clients whose needs are complex and require significant resources. A number of pilot projects carried out in the 1980s established the value of care management in orchestrating community care for elderly and disabled people and those with mental handicaps (Nocon 1994). More recent accounts have also claimed that it can deliver a more effective service to clients and carers (Woolham 1994). The library search found no published trials of care management specifically for stroke patients, but the results of experiments using care management for patients with head injury, terminally ill cancer patients and people with long term mental illness have recently been published (Greenwood *et al.* 1994, Addington-Hall *et al.* 1992, Marshall *et al.* 1995). At best these trials show that care management is ineffective and confirm the warnings of some commentators that it should not be seen as the only solution to the problems of collaboration or the availability of resources. 'It cannot resolve difficulties of fragmented services, inappropriate or insufficient care options and failures of collaborative working' (Nocon 1994).

This point is well illustrated by the trial of care management for patients who had suffered severe head injury (Greenwood *et al.* 1994). The aim of the study was to see whether having a care manager to assess patients' needs and coordinate delivery of rehabilitation services would help their recovery. The care managers were independent and without a budget and adopted an enabling rather than a therapeutic role, not providing any treatment themselves but recruiting staff from other agencies to contribute to rehabilitation programmes. Patients joined the trial within seven days of their injury to explore whether care management influenced the provision of rehabilitation services in hospital. The results show that this model of care management significantly increased the number of patients in contact with formal rehabilitation in hospital and in the community. The effect was greatest for clinical psychology, social work and speech therapy, services to which referrals are usually made relatively rarely. Despite care management increasing contact with services, no difference in outcome was found between patients who had care managers and the control group during the two years of follow up. The problem appeared to be that although care managers were able to put patients in touch with the right services, they were not able to ensure that they received more or higher quality rehabilitation services because of the shortfall of skilled and specialized rehabilitation for head injured patients in this country. Greenwood and colleagues (1994) concluded that care management 'is not a substitute for improvement in provision of skilled and specialist rehabilitation for patients'.

JOINT HEALTH AND SOCIAL SERVICES TEAMS

A number of projects have specifically addressed the problems of working across health and social services boundaries by merging health and social services staff into a single, multidisciplinary team. None work exclusively with stroke patients, their focus is typically elderly and disabled people living at home. Three examples, in Stirling, central Scotland; Rothwell, Leeds; and the elderly people's integrated care system (EPICS) in several locations, are discussed here.

EPICS is the most inventive and ambitious of the schemes, with a very clear philosophy of responding to the needs of elderly people and their carers, multidisciplinary team working and individual care planning (Hunter and Wistow 1990). An EPICS resource centre provides day care facilities and is a single point of access to services. It is also the focus for the multidisciplinary team, which as well as workers employed by health and social services, includes generic care staff who provide wide-ranging help, support and treatment across traditional organizational, agency and professional boundaries, both in the centre and people's own homes. Clients are assessed by members of the team and a package of care worked out that is tailored to the needs of each person. Client-held, joint health and social care records are also a feature of the scheme. Elderly people would use the record themselves to express their own wishes and preferences for care and refer to it in dealings with professionals (Wright and Young 1994). However, the aspirations of EPICS have so far only been described; its performance has not been evaluated.

The initiative in Stirling and the Rothwell project were attempts at joint management of services that would normally be separate and to develop a 'seamless' approach to service delivery. The Stirling elderly people in the community project was established in 1990 to test multidisciplinary care management for frail elderly people. It had equal backing from health and social services and the aim was to maintain vulnerable elderly people, aged 75 and over, at home by deploying domiciliary care and support. The team, led by a senior social worker and made up of health visitor, community psychiatric nurse, occupational therapist, social worker and clerical officer, was based in the Stirling Royal Infirmary (Lieberman 1990).

The Rothwell Community Care Project was also established in 1990 when a community care manager was appointed to manage two joint locality teams, one headed by a principal social worker and the other by a clinical nurse team leader. Unlike most other experiments in collaboration which focus on a clearly defined care group, usually elderly or disabled people, the Rothwell project was much more ambitious: it was generic, embracing all community services. Joint management and joint working took much longer than anticipated to evolve and were considered to be more effective in some areas of work (notably care of elderly people) than others (work with children). Barriers to joint working were both 'cultural'—the way referrals were dealt with and cases assessed—and practical—some of the mechanisms that would have facilitated working together such as a common base for staff, common assessment forms, agreed referral procedures and integrated information systems were not in place when the project began (Higgins *et al.* 1993). Rothwell has been the subject of much scrutiny and the verdict after three years was that 'much of the original vision remained unrealized' (Higgins *et al.* 1994).

The community care reforms have stimulated a new agenda for joint working. They are seen by some as an opportunity to improve quality of care for patients and their carers, including many stroke survivors, who need both health and social care (Lloyd *et al.* 1994). Key features of all the approaches to home care that have been described here are that they attempt to ensure adequate resources are provided to meet people's needs and preferences for care, restructure the way care is delivered and achieve closer collaboration between health and social services practitioners. However, it is still too early to assess the impact of the community care reforms on the quality of care received by groups such as stroke patients.

Commentary

The management of stroke is complex and illustrates the importance of professions and agencies working together to plan and deliver care to patients. At all stages in diagnosis, treatment, rehabilitation and long term care, multi-agency and multidisciplinary collaboration is the key to providing an effective and high quality service. In its most general sense 'shared care' is one of the hallmarks of good stroke management. However, perhaps because of the complexity of stroke services and the very varied needs of people who have suffered a stroke, no single systematic approach to sharing care has been developed.

From the literature two general trends can be identified. In terms of coordinating services across the interface between primary and secondary health care, the main emphasis has been on finding ways of *transferring* care more smoothly from one sector to the other, and occasionally on *shifting the boundary* so that transfer is not necessary (for example by creating outreach services from specialist hospital units), rather than on *sharing* care across existing boundaries. In the community, where many patients living at home and their carers need support from both health and social services, the community care reforms have made care management the main method for coordinating inputs from staff working for statutory agencies and the voluntary sector and for ensuring that care is shared. Creation of jointly managed multidisciplinary teams in the community has also been tried as a way of developing better integration of services for groups such as elderly and disabled people. Whether either of these approaches represents an improvement in care has yet to be convincingly demonstrated.

Attempts to coordinate acute stroke services have focused on establishing centralized stroke units and specialist multidisciplinary teams within acute hospitals. It has frequently been suggested that more acute care for stroke patients should be provided in their own homes, and that the best way to achieve this would be to develop a specialized, integrated service that spans both hospital and community. This vision has much to recommend it, but it is not likely to be easily or quickly realized, since it requires making fundamental changes to current ways of managing, financing and delivering services. However it is encouraging to discover that in some districts, such as Riverside in west London, local health care providers, health care commissioning agencies and social services departments have developed a strategy that will promote a collaborative and integrated approach to managing stroke in hospitals and the community.

Discharge from hospital has been highlighted as a point at which stroke patients are vulnerable to care breaking down. Effective planning for discharge requires good communication and cooperation between patients, their carers and hospital staff and between professionals working in the hospital and other organizations and sectors of care. For patients with the most complex needs for continuing health and social care, multidisciplinary assessment, discharge planning and care management are currently offered as an effective method of coordinating services.

For a small number of patients who are discharged early from acute hospital beds and who need a high level of nursing care, specialized community health services or hospital at home schemes provide an easily accessed form of coordinated care to which patients can be transferred. For the majority of patients, however, discharge from hospital means a transfer of care to mainstream primary and community health services. Since quite a high proportion of stroke patients are followed up in hospital outpatient clinics, it is surprising that there have been no trials of shared care schemes, involving collaboration between specialist hospital based staff and primary care teams to ensure that rehabilitation and support services are being provided, at least in the short term.

Collaboration between primary care workers and social services staff has been shown to increase where attachments have been made or joint teams have been established, but improvements have not always been easy to achieve or quick to materialize. Joint teams are still exceptional and in most areas there is no ready-made framework for collaboration between primary care staff and social services.

It must be emphasized that the effectiveness of all the methods described here for facilitating transfer of care between sectors and improving coordination of services for stroke patients depend on adequate resources being made available for rehabilitation and care. No amount of effort or inventiveness put into joint management, multidisciplinary assessment, planning, coordinating, transferring or sharing care can overcome the problem of lack of resources. Although studies have described the less-than-optimal services received by stroke patients, the trial of care management for patients with head injury has perhaps shown most convincingly that it is futile to give increased attention to coordinating care if the services patients need are insufficient and inadequate. The simple message is that patients will not benefit. In many districts the solution to improving outcomes and quality of life for stroke patients may depend as much on increasing the volume of services provided as on improving their integration.

Chapter 11

SHARED CARE IN TERMINAL ILLNESS AND PALLIATIVE CARE

◆

In this chapter we discuss terminal and palliative care with particular reference to people with advanced cancer, a significant group of service users, since 27% of men and 24% of women die from cancer. Well-organized forms of shared care have developed in recent years with the expansion of the hospice movement and the growth of multidisciplinary palliative care support teams which operate in hospitals and the community.

Many different professionals may be involved in the care of a person who is terminally ill, and coordination of services is essential. There is an extensive literature on terminal and palliative care, much of it descriptive, but it includes a number of evaluative studies assessing quality of care from the patients' and carers' points of view, and guidelines and standards for both institutional and home-based care.

Palliative care has been defined as:

> *'active total care offered to a patient with a progressive illness and their family, when it is recognized that the illness is no longer curable, in order to concentrate on quality of life and the alleviation of distressing symptoms within the framework of a coordinated service. Palliative care neither hastens nor postpones death, it provides relief from pain and other distressing symptoms, and integrates the psychological and spiritual aspects of care. In addition it offers a support system to help relatives and friends cope during the patient's illness and in bereavement'.*

(Standing Medical Advisory Committee and
Standing Nursing and Midwifery Advisory
Committee 1992 page 384).

The principles on which palliative care is based were originally developed within the hospice movement and remain closely associated with it, but are now widely accepted, if not extensively implemented. As the definition quoted above implies, care is focused on the family unit and may involve professionals from a variety of disciplines as well as informal carers. Palliative care now takes place in hospitals, hospices, residential care or patients' own homes, but the research evidence shows that not all patients who might benefit from it have access to palliative care, and the provision that exists is of variable quality (Higginson 1993).

Guidelines and standards for palliative and terminal care have been published by a number of organizations and groups, and these have been reviewed by Higginson (1993). They have a variety of target audiences, from purchasers and providers in general, through multidisciplinary teams, to a single profession. They may relate generally to care in all institutional and community settings or be intended for use in one specific setting, such as inpatient hospice care. For example, NAHAT (1991) has laid down standards for purchasers and providers of terminal care; the Royal College of Physicians (1991) has produced guidelines for inpatient hospice care; and guidelines on palliative care for patients with cancer have been published by the Scottish Partnership Agency for Palliative and Cancer Care and the Scottish Home and Health Department (SHSPC/SHHD 1994). Some palliative care teams and primary health care teams have developed their own guidelines and used them to audit the care they provide (Robinson and Stacy 1994).

The players

Unpaid, 'informal' carers—usually relatives—undertake the vast majority of care for people with advanced cancer. The professionals involved may include GPs; hospital staff such as general physicians, oncologists, surgeons, specialists in palliative medicine and medicine for elderly people, and nurses; community nurses; social workers; physiotherapists; hospice staff; and, in some cases, psychiatrists (Higginson 1993). Since 1980 a national network of 1200 Macmillan nurses has been developed to advise and support community nurses and GPs

(Bennett *et al.* 1994). They have special training in dealing with the more difficult and distressing symptoms of cancer. In some areas Marie Curie nurses provide night cover in the dying person's home. Effective palliative care may thus require coordination of a multiplicity of professionals and integration of services across many organizational boundaries. One common technique used to improve cooperation is to remove some of the existing boundaries by bringing the key players together as a multidisciplinary team. However, creating specialist teams may also set up new boundaries which must be bridged.

Palliative care support teams usually work in an advisory capacity offering symptom control and psychological support to patients and carers as well as playing an important role in providing education and advice to professionals working with dying patients. There are several models of team, ranging from just one or two specially trained nurses (often Macmillan nurses) to large teams with medical, social work, administrative and volunteer support. Some teams work exclusively in hospital, some only in the community, but many work in all settings. A few hospitals have NHS palliative care units, led by consultants and staffed by specialists in palliative medicine (a specialty that emerged during the 1980s), and which have attached support teams. Teams may be also be attached to general hospital cancer units, in-patient hospices, the community nursing service, or be 'freestanding'. For example, the two palliative care teams evaluated by Higginson *et al.* (1990) were both multidisciplinary, with doctors, nurse specialists, a social worker, a secretary or administrator, and volunteers. Both had offices in the grounds of district general hospitals and worked with patients and families at home and in several local hospitals. 'Their aims were those of the hospice movement: to control symptoms, to give support and advice, to coordinate care, to meet practical and financial needs, and to provide education and bereavement support when necessary' (Higginson *et al.* 1990).

The settings

The main settings for palliative and terminal care are hospital or nursing home, the patient's own home and hospice. In 1990 54%

of people died in hospital, 23% at home, 13% in nursing or residential homes, and 4% in a hospice. However, these figures do not reflect the extensive movement of patients between settings shortly before they die or the recent shift of institutional deaths away from NHS hospitals. It is common for patients to be admitted to hospital shortly before death, so these figures also disguise the extent of involvement of GPs and primary care teams in palliative and terminal care. On average, patients now spend about 90% of their terminal year at home being cared for informally (i.e. by relatives), with primary health care team back up (Field and James 1993). Less than 10% of patients receive support from specialist palliative care services (Neale 1993).

Each of the settings is considered in turn and the possibilities for shared care outlined. Hospice care is dealt with first because it has been the most important influence on the development of NHS palliative and terminal care services, although its contribution is small in terms of number of patients cared for.

Hospice care

The hospice movement has expanded rapidly since the 1970s. Initially, increasing numbers of inpatient units were established: a trend that was evident by the end of the 70s when a DHSS working group on terminal care reviewed provision. Although the Wilkes report (Working Group on Terminal Care, 1980) described hospices as 'dynamic and outward looking centres of skill', it also stated that the development of palliative care did not require the proliferation of inpatient hospices. The way forward was 'to encourage the dissemination of the principles of terminal care throughout the health service, and to develop an integrated system of care with an emphasis on coordination between the primary care sector, the hospital sector and the hospice movement' (Working Group on Terminal Care 1980). Since this report was published the number of inpatient hospices has continued to rise, but many have also developed outreach teams that work in hospitals and the community. In 1992 there were 175 inpatient units; 186 day care facilities; 360 home care teams; and 160 support nurse teams in hospitals (Field and James 1993). A survey by Johnson *et al.* (1990) found that 72% of hospices provided a home care service but about one third did not provide 24-hour or weekend cover, and there was a great deal of variation in the way care was delivered.

Hospice organizations are funded through both the voluntary and statutory sectors and cater mainly for cancer patients. The average length of stay in hospices has been reducing, not least due to improvements in community care and the development of Macmillan and hospice home care teams (NAHAT 1991).

Evaluation of inpatient hospice care has focused mainly on St. Christopher's, the first and best known hospice in the UK. Parkes' studies compared relatives' assessments of hospice and hospital care and found that the aims of the hospice were generally being met (Seale 1991). A random national sample of deaths was the starting point for a study by Cartwright and Seale (1990), who interviewed relatives about their experiences during the last year of the patients' lives. Only a small proportion (7%) had received some form of hospice care and all but two of these died from cancer. Comparing the cancer patients who received hospice care with a group who did not, Seale (1991) found that the hospice group was more likely to be reported as knowing their diagnosis and prognosis; having better pain relief; and being more satisfied with their care. More recently doubts have been raised about whether all hospices fulfil their aims, especially those that have been taken over by the NHS, which show a shift away from the psychosocial care of the family to the physical care of the patient (Neale 1993). However, there is not enough evidence to clarify how widespread this trend is or how it affects quality of care.

Because of the movement of patients between home and hospice during the course of their terminal illness, good relationships and communication between hospice staff and GPs and primary health care teams are essential ingredients of high quality care. However, the relationships between some hospices and primary care teams have been described as 'strained' and Hull *et al.* (1989) believe there is clear evidence of a problem. They sent a questionnaire to departments of general practice asking about the state of relationships locally: whether they were improving or deteriorating; an indication of problem areas and how relations might be improved. Only a quarter of departments considered relationships to be good or excellent, and half the respondents thought they were deteriorating. Problems were reported with Macmillan nurses in home care teams and with the rigidity of admission criteria to hospices. There was a fear that the trend for hospices to take over from GPs would result in a deskilling of staff and subsequent drop in standards of care. More teaching and involvement of GPs in hospices were seen as solutions.

Hospital care

Since the majority of people in Britain die in hospital, the quality of hospital care for dying patients is of great importance. However, a number of studies have suggested that care is inadequate: symptoms are often poorly controlled and basic nursing needs may not be met (Mills *et al.* 1994). A study of terminally ill cancer patients and their families found that they rated hospital services less highly than care from GPs and district nurses or support teams. The main criticisms were of the quality of communication with hospital staff, particularly when giving information about diagnosis, and poor coordination of services (Higginson *et al.* 1990).

An increase in specialist palliative care units and support teams over the last 10 years can easily be demonstrated, but it is more difficult to assess whether this has resulted in better care for patients dying in hospital. Education and training for palliative care has expanded and there seems to be a better understanding among professionals of what influences the quality of care for terminally ill patients. Higginson (1993) sees the next challenge as translating this knowledge into practice.

Since hospital care during terminal illness tends to be episodic, some hospitals have tried to find ways for GPs and primary care teams to stay involved in the care of their patients while they are receiving hospital-based treatment. Hull *et al.* (1989) have reported that they are experimenting with a patient-held cooperation card at the Queen Elizabeth Hospital, Birmingham. The scheme is called ONCARE and its aim is to improve communication between people with cancer and all those who help to care for them. 'The idea started with the appointment of the Macmillan Senior Lecturer in Palliative Care at the Medical School in Birmingham in 1987'. A group including representatives from many branches of medicine, nursing, social work, the clergy and others was established to consider problems of communication. After two years' work the ONCARE scheme was launched. It has two elements: a patient-held cooperation card and a meeting place where patients can discuss their care with volunteers. The cooperation card was designed by a GP and refined by the committee. Any patient who wants an ONCARE card will be given one and anyone caring for the patient may write in it. 'The important aspect of the ONCARE card is that it establishes the patient at the centre of the caring circle and gives him or her custody of information'. The card can give the patient information about the progress of treatment, symptoms and side effects. 'It can also be a means of a consultant asking the GP for, say, a full blood count before the next outpatient appointment'.

Home care

Most patients wish to die at home or remain at home as long as possible (Thorpe 1993). While the trend in palliative care is away from inpatient care towards care in the community, the majority of people still die in institutions. Townsend *et al.* (1990) interviewed patients in their last year of life and found that of those who stated a preference for place of final care, 58% wanted to die at home, 20% in hospital, 20% in a hospice and 2% elsewhere. What actually happened was that most of the patients died in hospital, although 69% of these had expressed a preference to die elsewhere. The researchers comment that 'two-thirds of patients in hospital for the last admission did not need 24-hour care but could have been looked after with the support of visits from the continuing care and district nursing services, short term use of equipment such as a pressure-relieving mattress when needed, and home care support'. They estimated that over a quarter of those dying in hospital had a carer willing to care for them at home and wished for this option, which would have been possible with fairly limited flexible short-term support from health and social services. This suggests that, including the 29% who died at home and for whom this was their and their carers' place of choice, 44% of patients could have been supported to die at home' (Townsend *et al.* 1990). It is generally agreed that more people could remain at home if better support were provided.

Cartwright's survey (1991a) of the experiences of the carers of a random sample of people dying in 1987 showed deficiencies in provision of terminal care and coordination of services. She also sought the views of the hospital consultants, general practitioners and nurses who had cared for the dying patients. All three professional groups wanted more people to be looked after in their own homes rather than in hospital if adequate care could be arranged at home.

> *'But it is clear from their replies to other questions and from the views and experiences of the relatives of people who died that more resources are needed in the community if this is to be achieved. In particular more home helps, more district nurses and more night nursing and night sitting services are called for. In addition, it is reported that one in five relatives in this survey felt that it would have been helpful if the general practitioner had visited the person at home either at all or more often'.*
>
> (Cartwright 1991b)

Community nurses reported that pain was not controlled satisfactorily for patients dying at home as often as it could be, and there was some evidence from relatives that pain control was better in hospital than at home.

All the literature shows that home care provided by specialist services, such as palliative care teams, is highly valued by patients and their carers. Higginson *et al.* (1990) found that support teams were a popular service that met the needs of patients and families, who consistently rated them more highly than GPs, district nurses, and hospital doctors and nurses. Carers and patients particularly value the communication skills of support teams and the emotional support they are able to give.

Some GPs recognize that they do not have the skills and experience to meet all patients' and carers' needs but want to remain involved in terminal care (Haines and Booroff 1986). In Cartwright's 1987 survey, GPs were rather less enthusiastic than consultants and community nurses about specialist medical or nursing domiciliary terminal care services. They were, however, more convinced of the helpfulness of these services if they had some experience of them (Cartwright 1991a, 1991b).

A study in Devon found that GPs working alone or with only a specialist nurse provided less complete terminal care than if a district nurse and social worker were included in the team (Jones *et al.* 1993). The most notable deficit in care was patients' and carers' lack of information about financial benefits and sources of help outside the health service. Patients cared for by teams including a social worker had fewer unmet needs for domestic help (Jones 1993). An audit in one general practice found that GPs were more critical of the quality of terminal care than patients' relatives (Blyth 1990). Despite being satisfied with care in general, some relatives would have liked more help with caring for the patient and more information about available services. Bereavement counselling was also badly organized. Poor communication with patients and relatives was identified as a serious problem, and in part attributed to 'the large number of people who may be involved in the terminal care. Members of a multidisciplinary team must know each other's roles and must be able to develop strategies to allow them to work together'. The author does not discuss how the practice team responded to these findings, or whether they changed their ways of working to improve terminal care for their patients.

It may not be realistic to expect a large increase in community-based resources for palliative and terminal care, but the evidence indicates that more could be done to mobilize existing resources, coordinate them to better effect and offer more education and training for generalist staff in the community.

Better care by the practice team

One way to start is for practices to review and try to improve the care they provide, including the quality of their own teamwork and their collaboration with professionals in other agencies. Four practices in Newcastle upon Tyne used audit, in the form of facilitated multidisciplinary case discussions, to help them review palliative care and draw up guidelines for the management of dying patients (Robinson and Stacy 1994). Over the course of a year, each team held monthly meetings at which they discussed two recent cases in which patients had died. Discussion was structured using the critical incident technique: the team was asked by the facilitator to describe good aspects of care and identify areas of concern. This discussion was recorded on audiotape and a summary feedback sheet sent to the team within two weeks. Review sessions were held after discussing ten cases and at the end of the year, to reconsider areas of concern and to see if suggestions for change had been acted on. If not, the facilitator encouraged the team to identify individuals to accept responsibility for initiating change. The two facilitators involved in the project used the information they had gained from this process to draw up guidelines for managing dying and bereaved patients.

All practices felt that cohesive teamwork, coordinated management, early involvement of nursing staff and the identification of a key worker were essential for good terminal care. Concerns arose in clinical and administrative areas, but the majority were linked to poor communication, either between patient and professionals within the primary care team or between primary and secondary care. These findings echo those of other studies. However, the guidelines drawn up as a result of this work suggest some fairly simple mechanisms that primary care teams can use to build good practice into their work and avoid common problems. Guidelines, however, should not be seen as an end in themselves. Taking part in this type of audit ought to have produced many additional benefits for the practice teams. The authors comment that 'The process of developing multidisciplinary, as opposed to medical, guidelines allowed the teams to create standards that were acceptable to them and stimulated individuals within the teams to accept responsibility for initiating the change necessary for more effective care' (Robinson and Stacy 1994).

Coordinating community-based care

Other writers have also suggested that a key worker is needed to ensure good teamwork and coordination between all those involved in terminal care (Thorpe 1993). Some go further and argue that since effective community-based palliative care requires the coordination of informal care and formal provision by health and social services, it makes sense to apply the idea of care management which has proved an effective method of coordinating other forms of community care (Neale 1993). However, a recent trial using nurses as care managers to coordinate care for terminally ill cancer patients found that their intervention had little measurable beneficial effect (Addington-Hall *et al.* 1992).

The trial was carried out in Wandsworth Health Authority in inner London. Two nurse coordinators were employed from 1987 to 1990 to ensure that all terminally ill cancer patients received appropriate, adequate and well-coordinated services, tailored to their changing needs and circumstances. A randomized controlled trial was used to evaluate the service, after it had been established for a year. The nurses had some special training in care of the dying, but their role was to act as 'brokers' of services rather than provide practical nursing care. They assessed patients' needs for services from agencies in the NHS, local authority and voluntary sector; offered advice on how to obtain services; ensured that services were provided and well coordinated; and stayed in regular contact to monitor the changing needs of patient and family for services. Patients were encouraged to contact the coordinators if they needed help or advice.

Few differences were found in symptoms and symptom control, service provision and satisfaction, and social and psychological support between those patients and families who had received the services of nurse coordinators in addition to routinely available services and those who received routine services only. Carers in both groups were equally likely to report that services were well coordinated. The authors concluded that the coordinating service was not a useful addition to the range of services available for terminally ill patients.

In an attempt to try and explain these negative findings, the authors considered whether care was already of such a high standard that there was little or no room for further improvement. Palliative care services in Wandsworth at the time of the trial were quite comprehensive, including a medical oncologist and attached multidisciplinary team, Macmillan nurses and a hospice in addition to standard hospital, primary care, community nursing and social services. However, the trial took place at a time of major restrictions in financial resources and staff, and it discovered unmet needs and dissatisfaction among some patients and families, therefore existing high standards were unlikely to explain the results. The authors suggest that the coordinators may have been more successful if they had been given a budget to purchase some types of care, rather than having to rely entirely on the goodwill of service providers. They also question whether there may have been a conflict between the professional skills and background of the nurse coordinators and the requirements of their new 'care manager' role. Other studies have found that care management activities tend to be neglected if the care manager has other professional skills to offer.

Although this particular coordinating service failed to produce either better service coordination or improved outcomes for patients and families, the authors do not reject this model entirely, but imply that it needs to be refined and improved. They feel that care management has much to offer in situations where care is shared between primary care, the hospital sector and voluntary organizations.

Commentary

The principles of palliative care are well-established: strong emphasis is placed on meeting the needs of patients and their carers in ways that are acceptable to them, by professionals working in collaboration. Guidelines and standards have been drawn up based on these principles. The literature shows that palliative and terminal care seems to be provided most effectively by professionals working within one organization, such as a hospice, or when they have been grouped together in a specialist team. When collaboration across organizational boundaries is required, particularly when specialists based in institutions and generalists in the community need to provide different elements of care, communication, coordination and the quality of care are usually inferior.

These findings are important for several reasons. First, terminally ill patients tend to move between home and hospital, and sometimes to and from hospices, during the last months of their lives. Their needs for services may change rapidly. These transfers and transitions are recognized as points at which problems may arise, and professionals need to give attention to communication with patients and carers, and to their own collaboration. Secondly, the trend towards meeting patients' wishes to die at home, or to stay at home for as long as possible, is a particular challenge to all those involved in palliative and terminal care. Establishing effective shared care is therefore vital to creating high quality services for the future.

The issues are similar to those involved in developing shared care in other domains. For terminally ill patients, however, an especially important factor is establishing and maintaining excellent communication with the professionals providing services and ensuring that patients and carers are fully involved in decisions about care.

This dialogue may be helped by using shared care records to which everyone contributes. A clearly identified keyworker to channel communication and coordinate services has also been tried and recommended in some situations. The one trial of care management for terminally ill patients failed to show any benefits, but other approaches need to be tested before abandoning this model of coordinating care.

More evaluation of current practice and continuing audit of terminal care are needed within primary care. The approach to audit and practice team development used by the facilitators in Newcastle would be a good place to start. Involving members of specialist palliative care teams could add a further dimension. This might enhance the transfer of knowledge and skills to the primary care team, and altering attitudes to providing comprehensive terminal care for patients at home. No-one working in palliative care has, to our knowledge, tried the organizational techniques used by DETU in Sweden to improve diabetic shared care. Investing in team problem solving and learning could bring about more lasting change in several domains, rather than the 'quick fix' approach of creating short term additional posts of coordinators or care managers.

Furthermore, we must emphasize a conclusion about community care from Chapter 10, namely that it is futile to spend time devising even better methods of coordinating and sharing care, if the underlying problem is a shortage of resources to provide comprehensive terminal and palliative care to those patients who need it. Many studies in this domain have identified services that require more staff, better facilities and more equipment, as well as improved use and integration of the resources that are already available. Providing adequate resources for a service of high quality is just as important to the development of shared care, as ensuring that care is coordinated effectively and efficiently.

Chapter 12

SHARED CARE IN HEALTH PROMOTION

◆

In this chapter we consider one major area of health promotion—prevention of coronary heart disease (CHD) and stroke. Most activities fall within the boundaries of primary health care, but some initiatives have been developed in collaboration with local authorities and the voluntary sector. These partnerships or alliances in health promotion can be seen as analogous to shared care in other domains.

Prevention of cardiovascular disease

Since the early 1980s general practitioners and primary health care teams have been increasing their involvement in prevention and health promotion. In 1990, for the first time ever, health promotion became part of a GP's terms of service. The government's new contract for GPs offered financial incentives for running health promotion clinics and enabled practices to employ a wider range of ancillary staff. The new contract was highly successful in encouraging GPs to organize and staff clinics, and some practices used the opportunity to establish innovative schemes which extended the scope of health promotion in primary care. In the first year after the new contract was introduced, payments to GPs for health promotion clinics totalled approximately £30 million; this amount doubled in the following year (Russell 1995).

Prevention of coronary heart disease (CHD) and stroke has been identified as a national priority in *The health of the nation*, the Department of Health's strategy document published in 1992 (DoH 1992, 1993a). The approach advocated by the government is to ascertain in the population as a whole the level of the main cardiovascular risk factors—smoking, diet and blood pressure—and to modify these so that the incidence of heart attack and stroke is reduced. Primary health care teams have been allocated the main responsibility for achieving the government's targets. In July 1993 the GP contract was modified to link reimbursement to screening patients and offering personal advice about prevention, and the obligation to provide 'health checks' and the payments for running health promotion clinics were ended. This 'new health promotion package' was intended to provide a framework that would allow all practices to work towards meeting *The health of the nation* targets and, perhaps more importantly from the DoH's point of view, give better control over expenditure on health promotion in general practice (GMSC 1993).

By October 1993 almost 90% of GPs in England and Wales were claiming fees for 'band 3' health promotion programmes (DoH 1994a). To qualify for these payments, GPs must satisfy their family health services authority that they are monitoring their patients' smoking habits, blood pressure, diet, alcohol consumption, physical activity and family histories of cardiovascular disease; maintaining registers of those with established hypertension, CHD and stroke; and offering patients advice about changing their lifestyle, or making other interventions where appropriate. These requirements focus almost exclusively on CHD and stroke risk factors and put a strong emphasis on data collection. For many practices, the former represents a restriction on reimbursed health promotion activity and the latter is seen as an unwelcome burden (Russell 1995).

The new arrangements for health promotion also emphasize opportunistic activity in consultations rather than special clinic sessions, but much of the screening and health promotion activity in primary care has been delegated to practice nurses or specially trained health promotion nurses. Nurses played a leading role in establishing health promotion clinics in general practice, and have become a key resource for screening patients, counselling them about their risks and monitoring those with established disease. The number of practice nurses has increased by over 50% since the introduction of the GP contract in 1990 (Pratt 1995).

EVALUATION OF CURRENT INITIATIVES

However, government policy on health promotion and prevention in primary care is being increasingly criticised (Russell 1995). The results of two large scale evaluative studies of nurses working in general practice to identify and modify cardiovascular risk factors have called into question the effectiveness of current approaches to preventing heart disease and stroke. The OXCHECK study (ICRF OXCHECK Study Group 1994) and the British family heart study (Family Heart Study Group 1994) both found that nurses screening and counselling middle aged patients led to little change in their smoking habits, blood pressure, weight and blood cholesterol and glucose concentrations. The researchers on both studies conclude that other approaches need to be tested. In particular they suggest that practice nurse resources might be used more effectively by focusing them on treating and following up patients known to be at high risk of cardiovascular disease—those with hypertension, lipid disorders, diabetes and established coronary heart disease. 'Given the proved success of simple interventions in reducing mortality in those already diagnosed as suffering from cardiovascular disease and the high prevalence of proved cardiovascular disease in the general population, practice nurses may be more effectively used with patients at established high risk' (ICRF OXCHECK Study Group 1994). Haines and colleagues (1992) also suggest that a 'special care group' be defined by the practice and offered regular follow up.

One approach to prevention in primary care with a 'high risk' group has been tested in a randomized controlled trial (Cupples and McKnight 1994). A sample of patients under 75 years old with established angina were identified from 18 general practices in Belfast. The intervention group saw a health visitor every four months for two years and received personal health education. This group of patients increased the amount of exercise they took, improved their dietary habits and reported less restrictions on their everyday activities compared to the controls. However, they showed no changes in objective cardiovascular risk factors. Over the two years there were 29 deaths (out of 300) in the control group and 13 (out of 317) in the intervention group. The authors are at a loss to explain the differential mortality, since the trial produced no differences between the two groups in blood pressure or body mass index, but they suggest psychological factors may play a part. Stott *et al.* (1994) comment that it is difficult to interpret the data because we are not told exactly what the health visitors did. They argue that while 'blanket' approaches to health promotion in primary care appear to have failed, the primary care setting offers the opportunity for more sensitive matching of interventions to individuals, but we need to know more about the practical details of changing individual behaviour.

Other examples of 'high risk' strategies for prevention include identifying and treating people with hypertension and other established vascular disease. These are discussed in Chapter 6.

Although the effectiveness of screening for CHD risk factors and lifestyle intervention in primary care has been questioned, there are still advocates for the value of 'mass' or 'population' approaches to prevention. Dennis and Warlow (1991) argue that it is preferable to reduce the prevalence or shift the distribution of a risk factor across a whole population than to target high risk individuals. They claim, for example, that a modest 5 mm reduction in mean population diastolic blood pressure, achievable by reducing the mean salt intake by 50 mmol/day, might reduce the incidence of and mortality from stroke by 22%. But it seems clear that mass strategies are not likely to be successful if they rely solely on individual health education in primary care and neglect the context in which lifestyle changes are expected to take place.

ALTERNATIVE APPROACHES

For many years the World Health Organization, through its *Health for All* initiative has emphasized 'intersectoral collaboration' and community participation as ways to improve social conditions and make it easier for people to lead healthier lives. In the case of cardiovascular disease, many campaigners have argued that significant reductions in mortality and morbidity are only likely to come about if concerted action is taken across all relevant sectors. For example, legislation to ban tobacco advertising is recognized as a vital step in reducing smoking and changes in national agricultural policies could promote consumption of healthier food (Stott 1994). Others have argued that local community action is also important as a way of facilitating individual change, for example setting up food cooperatives to provide fresh food cheaply and pressing local authorities to provide accessible sports and leisure facilities.

Some primary care teams have become involved in these broader, community-based health promotion initiatives, which are characterized by agencies working together in 'healthy alliances' (Stott *et al.* 1994, Heritage 1994). For example, a number of practices are collaborating with local authority leisure services to 'refer' patients who have been 'prescribed' a programme of exercise to leisure centres and gyms (Chaplin 1993, Green and Lord 1994). A recent article in *The Guardian* described how patients, some with quite serious illnesses, are being referred by their GP to a team at the local leisure centre, which includes a nurse, exercise physiotherapist and fitness consultant, who devise programmes for them in the cardiovascular gym (Slee 1994). Despite apparent enthusiasm among GPs for prescribing exercise, caution has been advocated by academics such as Illife and colleagues (1994) because there is only anecdotal evidence of the effectiveness of these initiatives, which have not yet been evaluated thoroughly.

Other practices are linked to community health projects, which attempt to involve local people in activities that promote health. The Heeley Health Project in Sheffield, for example, has a wide range of activities, including a food group which has investigated healthy eating, including buying and cooking healthier food (Heller 1994). A number of projects in which GPs, primary health care teams, FHSAs, health promotion units and community health initiatives have been working together are described by Russell (1995). Their approach is very different from the kind of health promotion fostered by the GP contract—most are based on a social rather than a biomedical model of health and do not focus exclusively on CHD risk factors and individual lifestyle or seek to modify them directly. However, these kinds of collaborative and community-based approaches to health promotion, once 'seen as the property of a radical few' (Russell 1995), now appear to have the approval of the Department of Health (DoH 1994d).

Commentary

Most schemes for primary prevention of cardiovascular disease are located entirely within the boundaries of primary care. The players are usually all members of the primary care team, therefore joint activities are probably better described as teamwork than shared care. Some health authorities and FHSAs have employed facilitators to get teams started on prevention, but they are rarely involved in direct patient care (Fullard *et al.* 1984). However, they have become a major source of training and professional development for practice nurses, and are an important force for change in primary care (Allsop 1990, and see Chapter 18).

Approaches to secondary prevention of cardiovascular disease, involving established 'high risk' groups, such as patients with angina, could potentially have elements of shared care if these patients were being followed up in hospital clinics, or in the community by hospital based staff. However, no examples were found in the literature of preventive initiatives that crossed the interface between primary and secondary care, except in the management of patients with hypertension, and these are described in Chapter 6.

Some GPs have looked beyond the traditional primary care team and, indeed, outside the health sector in their attempts to encourage their patients to adopt healthier lifestyles. 'Referring' patients for exercise is one example. This may be attractive to GPs because it follows the familiar model of referring a patient to a hospital consultant—the physiotherapist or exercise teacher is a source of specialist advice and treatment. Some prescription for exercise schemes may be similar to shared care initiatives if the patient continues to see the GP or practice nurse for monitoring blood pressure, weight etc, while taking part in an exercise programme. However, there is usually no equivalent to the shared clinical responsibility for care of an individual patient, use of agreed guidelines or protocols, or the planning of care and exchange of information that usually characterize care shared between hospitals and primary care.

Primary health care staff who are involved with community health projects are undoubtedly collaborating across boundaries with workers in other agencies such as voluntary groups, community health services and various local authority departments. They may have established a shared commitment to achieving common aims by agreed means for a defined community or groups within that community. While parallels can be drawn with shared care schemes, this kind of activity might be better described as an alliance or partnership arrangement than as shared care.

What are the prospects for expanding these collaborative, multidisciplinary, multisectoral and community-based initiatives and incorporating them into mainstream practice? *The health of the nation* encourages health workers to think in these broad terms, but as Russell (1995) has pointed out, current government policy on health promotion is a 'strange hybrid' which embraces ideas put forward by the World Health Organization, considers primary care as the main focus for prevention, but only remunerates GPs for a very limited range of activities with individual patients, aimed at documenting and influencing their CHD risk factor status. There are no financial incentives for the demanding and time consuming work that may be required to build collaborative ventures across the boundaries of primary care, local authority services and the voluntary sector. In addition, some practices and teams may not subscribe to the same aims and goals as workers in other settings, who may have different ideas about health and how to promote it in partnership with local communities. The first step for primary health care teams may be to make a 'cultural shift' away from traditional medical thinking about prevention towards applying social models of health that include unfamiliar principles such as participation and empowerment. Developing the necessary shared understanding with potential partners in health promotion is likely to require time, appropriate help and resources. Without these, initiatives in health promotion that are analogous to the development of 'shared care' in other domains are likely to remain few in number, limited in scope and at the margins of mainstream practice.

SECTION III
Developing shared care—making it work

The essential and desirable features of shared care have been described in Section I. In Section II, examples of shared care schemes in certain domains have been critically reviewed. This section aims to look again at practical ways of implementing the desirable features in order to achieve effective shared care. This chapter gives a brief overview of the seven steps to effective shared care.

Chapter 13
INTRODUCTION—SEVEN STEPS TO SHARED CARE

◆

What are the essential building blocks of shared care? How can we put them together into a functional whole? This is the theme of this section, which may appear prescriptive, but many of the methods described are adaptive self-learning processes that could be applied in several domains of shared care, and even to cooperative patient care as a whole.

Key factors in shared care

Descriptions and assessment criteria of shared care schemes have provided a number of essential and desirable features aimed at effective shared care. The key features are summarized below:

- **Shared—or at least congruent—goals** of primary care and specialist teams and their members. Unless everyone is pointing in roughly the same direction, chaos will follow.
- **Effective teamwork in primary care and specialist teams** This should go without saying, that competent, coordinated teamwork is essential for today's health care, whether the patient is receiving care in one organization or several.
- **Shared understanding of the domain from all viewpoints,** including its concepts and intentions; and its problems, their causes and proposed solutions. Without this, progress is inhibited.
- **Shared knowledge base and agreed guidelines** Enough shared knowledge is needed to form the basis of guidelines. Guidelines represent a compact capsule drawn from a large body of knowledge, as well as a plan for action.
- **Effective communication, technology and learning** All professionals, as well as patients and lay carers, who are concerned in shared care, need to be included. Shared patient records and a register of all patients in the scheme or the district are valuable. Using appropriate information technology will be essential in the future, if not now. Developing a *learning organization* is a versatile tool for making progress on a broad front.
- **Working towards decision support and concurrent audit** Major technological advances are beginning to appear, that could radically alter the style and effectiveness of clinical practice, so future plans will have to take *knowledge-based* decision support systems into account.
- **Evaluation of processes and outcomes** Without audit, progress to a desired goal will be blind. Fortunately, new technology will make audit much easier. Clinical and organizational audit will have to include the views of patients and other stakeholders.
- **Learning from audit** is a part of continuous improvement in the quality of patient care. This could also provide pooled data on outcomes to enhance the knowledge base and refine the guidelines.

These points are taken a step further in the summary table below, and will be covered in greater detail in the ensuing chapters.

Table 5. Developing effective shared care—seven steps

Goals	Methods	Key workers	Incentives
1. Well-functioning PHC and hospital teams	Team building exercise and continuing evaluation	Visionary leader Facilitator	Linked to resource allocation?
2. Develop a shared understanding of the domain and its organization	Conceptual modelling leading to organization design	Facilitator	Linked to resource allocation?
3. Develop shared guidelines/protocols	National guideline program. Adapt locally. Patient input	National Institute. Local enthusiasts. Facilitator	Central and local funding. Indemnity insurers
4. Develop effective communication, review of patients, and learning	Shared record. Telemedicine. Smart card. e-mail. Patient register. Learning organization	Local enthusiasts. Facilitator	Funding. External audit
5. Implement decision support	Involve users. Work on climate for change	Product champion. Teachers	Peer influence. Indemnity insurers
6. Evaluate and audit processes and outcomes	Concurrent and retrospective audit. Feedback to users	Audit facilitator. Data clerk	Peer influence. Contract. Job satisfaction
7. Refine knowledge base and guidelines	Feedback of outcome data into decision support system	User group. Expert editorial team	Validate medical knowledge and practice

Chapter 14
DEVELOPING EFFECTIVE TEAMWORK IN ALL TEAMS

◆

This chapter introduces the topic of making teamwork more effective, as a first step towards shared care. Without a basic level of team function, cooperation is unlikely to succeed.

Cooperation between teams working at different sites, in separate organizations and with divergent (or unstated) goals and methods sounds an impossible undertaking. Yet shining examples of shared care have shown that it can work well in applying guidelines and improving outcomes in certain domains such as diabetes. As a first step, primary care and specialist teams need to put their own houses in order by ensuring that their teams are functioning adequately. If team function is satisfactory, team members will have the ability and confidence to build cooperative relationships with other teams, as described below. If the team is dysfunctional, this will adversely affect professional work as well as cooperation and morale.

Teamwork has been intensively studied in various organizations over the past 25 years, and certain general principles have emerged. (Beckhard 1972, Rubin and Beckhard 1972, Rubin *et al.* 1975, and Tichy 1977). In brief, effective teams and their members will have the following characteristics:

- shared and explicit goals and tasks
- an understanding of their own and each other's roles and values
- effective procedures will be in place (for communication, leadership, cooperation, decision making etc)
- interpersonal relationships will be good enough for the team to function harmoniously.

(Pritchard and Pritchard 1994).

Team members need to have some core values in common, but individuality and diversity of approach can be a source of strength. However, the more values are held in common, the fewer will be the barriers to cooperation. Perhaps, this explains why cooperation may be easier between doctors and nurses, than it is, for example, between doctors and social workers. This is not an argument for expecting everyone to think alike, nor for ignoring dissonant values, but rather for knowing and understanding other people's perspectives and motivation. In order to understand patients' beliefs and viewpoints, we must be aware of them.

The strong message from the work quoted above is that if we go through the first three steps (goals agreed, roles understood and procedures working well), and get on with the tasks in hand, then interpersonal relationships will not be a problem, and mutual respect will increase. In this climate, each team member will be valued for their contribution and all else will be forgiven or forgotten. Synergy replaces conflict. Nigel Bruce (1980 p 165) described it this way:

> *Cooperation between professionals has not been found to result automatically either from physical proximity or from being involved with the same client. It appeared to develop step by step as the frequency of contacts increased, as the relevance of such contacts became clearer, as a better understanding of roles emerged, accompanied by the disappearance of stereotypes, as social proximity increased, as mutual trust began to grow and problems of confidentiality to shrink.*

HOW CAN WE DEVELOP TEAMWORK?

If primary care and specialist teams can develop comparable levels of team functionality, then shared care can get off to a flying start. But how can this happen? Several methods are available, such as residential courses or 'away days' for whole teams. A method that is particularly appropriate in the setting of team care is an 'in house' learning programme. Such a programme, based on the original Massachusetts Institute of Technology model (Rubin and Beckhard 1972), is set out in detail in *'Teamwork for primary and shared care'* by Pritchard and Pritchard (1994). This is a generic method that can be applied to all health care contexts. Each team can train themselves in about 13 meetings of one hour each. A facilitator can help to get the process going (see Chapter 18). The steps in the learning process are set out below:

STEPS IN TEAM DEVELOPMENT PROGRAMME

- Plan programme, agree ground rules. Decide if facilitator is needed.
- Diagnose functioning of the team and consider the implications.
- Discuss team goals and tasks, and develop written, shared goals.
- Gain an understanding of own and others' roles in the team.
- Develop agreed procedures for effective team working.
- Develop leadership and help new team members to settle in.
- Ensure good interpersonal relationships, and 'this is a good place to work'.
- Take a look at the world outside and 'manage' better cooperation.
- Seek ways of involving patients in the team.
- Evaluate what has been learned and the effectiveness of teamwork.
- Continue the development process as a 'learning organization'.

TEAM DIAGNOSIS BEFORE TREATMENT

The first step is a 'team diagnosis' to assess perceptions of how the team is working and what are the areas of strength and weakness. This is in eight parts, covering the four areas described above. An example appears as Table 6.

The full 'team diagnosis' will highlight strengths, and will give team members the confidence to work on the weaknesses that need attention. A simpler diagnostic instrument was described by Bruce (1980) to assess the level of cooperation in the team. He proposed three types of team cooperation, 'nominal', 'convenient'

Table 6. Confidential questionnaire on team working. TEAM GOALS

Please read both statements, and decide where your team stands
by ringing one letter only

Statement I 'I often wonder why we work as a team. We seem to spend a lot of time and energy doing things which I do not think important, rather than concentrating on things which help us to achieve our main goals'.

Ring one letter which seems closest to the way your team functions:

a. Just like statement I
b. More like I than II
c. In between I and II
d. More like II than I
e. Just like statement II

Statement II 'I am very clear about what our team is trying to achieve, and we all put our efforts into it. Whenever a question arises about what needs doing we are able to get our priorities right by referring back to our main goals'.

Describe below any examples of situations in your team which illustrate your response to this question:

. . . .

---

and 'committed' in ten contexts. Their characteristics are set out in Table 7, which can also be used for a quick team diagnosis of the level of cooperation, and where it is succeeding or failing.

Motivation to undertake team development in general practice, hospital and community teams requires strong and inspiring leadership and (usually) an effective facilitator. Support from management is needed in reimbursing time spent by facilitator and staff, and expenses. By carrying out the training 'in house' it remains by far the most economical option for team development, and probably the most effective, because it examines real problems.

Table 7. Team cooperation questionnaire (from Bruce 1980)

Cooperation in:	Nominal	Convenient	Committed
Team goal setting	No explicit goals	Follow doctors' goals	Shared explicit goals
Role perceptions	Stereotypes common	Some understanding	Roles clearly understood
Professional status	Wide differences	Differences inhibit cooperation	Differences ignored
Referral of patients	To agency not to individual professional	Referral by delegation	Easy two-way referral, and open access
Interaction within team	Very little and irregular	Some interaction	Close regular interaction, formal & informal
Mutual trust	Lacking	Guarded	Strong and developing
Communication failure	Often	Sometimes	Exceptional
Confidentiality	A problem	Problems partly solved	Not a problem
Advice to patients	Inconsistent	Poor coordination	Consistent
Preventive care	Not possible	Possible	Optimum
Totals:	....	....	....

For each line, tick one box, then add up the totals in each column.

Key issues in developing teamwork include:

- — ***'team diagnosis' before 'treatment'***
- — ***shared (or compatible), explicit goals***
- — ***an understanding of one's own and each other's roles, and how other organizations function***
- — ***efficient procedures and communication***
- — ***harmonious interpersonal relationships***
- — ***audit of effectiveness of teamwork***

Chapter 15
DEVELOPING A SHARED UNDERSTANDING OF THE DOMAIN

◆

Just as a shared understanding is required for effective one-to-one consultations, so is a shared understanding of each other's domain necessary for successful shared care. This chapter outlines a method for achieving this.

Unless all concerned in shared care have a common understanding of, for example, the nature and treatment of diabetes and its complications, they will have different expectations and their common purpose will disintegrate. The notion of a 'shared understanding' being needed before progress can take place is familiar in teamwork and in the one-to-one consultation (Pendleton *et al.* 1984 pp 55–6).

One way of developing this common understanding, which has worked well in the care of diabetes in Sweden (Rosenqvist *et al.* 1990, Carlson 1990), is to use *conceptual modelling*, which is a method for getting complex ideas out in the open. This has been mentioned earlier and is described below.

Conceptual modelling—the role of the facilitator

Following an initial meeting, the next step is for the facilitator to interview all the key people involved. In the case of diabetic care, this would include members of primary and specialist teams as well as some patients with diabetes and also the providers of resources. The interview would be a confidential discussion of the nature of diabetes and its care, and would end with the participant making a list of problems and their suggested solutions. The lists would be circulated to all participants, anonymously, but not used further. These interviews help to get people talking and to articulate problems, and their possible solutions, as they see them. It also helps the facilitator to gain an overview of the whole domain and potential points of conflict.

Building a model of the organization

The next step is the conceptual modelling event, lasting a whole day. It includes patients, specialists, general practitioners, nurses, social workers and other staff involved in the domain, but the number has to be limited to between 12 and 20. They hold a brainstorming session in which named objects, relevant to the domain, in the form of **nouns** (person, place or thing) or noun clauses ('my patient'), are written on white cards and stuck on the wall. People group themselves at the wall and move around in a way they cannot do sitting round a table. These objects are then sorted into groups and clustered, and this provokes discussion about the **relationships** between the objects.

These are tackled next, by linking all the objects on the cards by lines (or masking tape) on which a **verb** is written. In this way, everyone can share their perceptions and come to a common understanding of the disease, what it is like to suffer from it, and the dimensions of care. Adding the verbs introduces **concepts** and may lead to heated discussion—provoked, if necessary, by the facilitator.

The next step is to look at the 'conceptual map' as a whole and define where the **problem areas** were located. Each problem is written on a red card and then attached to an appropriate spot on the wall. When this step is complete, the **causes** of each problem are written on a yellow card and placed near the relevant red card. Then the problems can be put in order of priority, and **solutions** suggested and written on blue cards.

This all sounds like a very elaborate process for helping a disparate group to come to terms with complex and uncertain concepts and problems. The answer is that it works in practice, and leads to coordinated action, and develops the kind of organization needed for the particular project. It can be regarded as tailor-made 'organization design'. All the people concerned come to a better understanding of the interlocking problems, and they all share and own the ideas and solutions.

In industry, the method is extended to build a more detailed model of the organization in terms of concepts, intentions, objectives, resources and rules, which all can understand and share. This has not proved necessary in the work quoted on shared diabetic care. Just going through the modelling process seems to produce the shared understanding as if by magic. The conceptual modelling session is best coordinated by a specially trained facilitator, who could then carry on with the process in other teams throughout the district, so that each primary health care team can jointly develop its own organization and plan.

Practical points about conceptual modelling

The session is a group meeting, but instead of being round a table, the participants are on their feet facing a clear wall, with plenty of space for moving around. A wise move is to cover the wall with a sheet of clear horticultural polythene (about 4 x 2 metres). A stock of cards is needed of about A6 size (148x105mm): white for 'objects', red for 'problems', yellow for 'causes' and blue for 'solutions'. Broad black permanent marker pens (one for each participant) can be used for the cards, and for the 'verbs'. Masking tape (25mm) can be used to join the objects, or alternatively write on the polythene sheet.

A tacky removable adhesive is needed for the cards, so that they can be moved around, such as a Pelikan 'Rollfix'. Alternatively 'Post-it' notes can be used, but need to be A6 size. Making a permanent record of the model is difficult. It can be transcribed, photographed or put on to a flowchart computer program such as Visio or Hexagons during the session. Although, for shared care, it may not be necessary to keep a record, people who have missed the session would like to see it, and it can always be modified as concepts develop. A trained facilitator is needed, and few have experience of this method in UK, so a specific training course will be required. This could be incorporated in existing facilitator training.

Other ways of achieving a shared understanding

The method described is not the only way to achieve a shared understanding of the domain and the problems, but it has the advantage of having been tested in shared care settings, and this saves reinventing the wheel. Consultants experienced in organization development all have their own ways of improving organizational effectiveness. They are more costly than a facilitator, but their services could be a worthwhile investment, particularly if conflict is a prominent feature.

For people to be motivated to develop shared care, a critical level of perception of the need for change is required. This is more likely to occur if there is strong and inspiring leadership, and a persuasive, skilled and persistent facilitator. Financial incentives may help, but at least, time spent in developing shared care should be reimbursed, so that participants are not poorer for their efforts.

The complexity of shared care is such that short cuts to understanding the underlying concepts and beliefs are needed. All those involved (including patients) can work together to get round problems and develop plans for shared care. Conceptual modelling is a technique that has been successful in shared diabetic care in Sweden, and is worth a try elsewhere. A trained facilitator is needed.

Chapter 16
DEVELOPING AND IMPLEMENTING GUIDELINES

◆

This chapter explores the nature of guidelines, and their necessity, both organizational and clinical, for effective shared care.

Definition

Guidelines have been variously defined, but that of the US Institute of Medicine carries weight (Field and Lohr 1990 p27), namely:

> ***Guidelines are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances***

Eddy (1992) uses 'practice policies' as the generic term and defines them as:

> ***Practice policies are preformed recommendations issued for the purpose of influencing decisions about health interventions***

The nature of guidelines

Eddy (1992) described practice policies as helping clinicians to think through decisions before the fact, and apply policies to simplify future decisions. *'In essence, practice policies distil the lessons of research, pool the knowledge and experience of many people, and convey the conclusions to practitioners, patients and administrators'*

Eddy further subdivided policies into *'standards'*, *'guidelines'* and *'options'*. *Standards* represent a high level of certainty and unanimity. *Guidelines* are widely supported but not unanimously, therefore they must be applied flexibly and be tailored to suit individual patient needs and preferences. *Options* are alternative actions that carry no recommendations.

ARE GUIDELINES EFFECTIVE?

The action plans for shared care, that arise from the conceptual modelling process described earlier, lead naturally to agreed procedures and guidelines. By involving all those concerned, including patients, in the development of the procedures and guidelines, they have a better chance of success.

Initiating clinical guidelines requires considerable research into all reliable data on the topic. This is a major task, best undertaken by a National Institute but implemented locally. The work will be made easier when the Cochrane Collaboration bears fruit (Chalmers *et al.* 1992), and all validated data can be accessed electronically. This will produce a world database of written evidence-based knowledge, which would be a good foundation.

Procedures for cooperation are relatively easy to draw up, and the process itself can be valuable, but they are not so easy to follow. However, firm evidence is accruing of the effectiveness of guidelines in changing general practitioners behaviour (Russell and Grimshaw 1992). Grimshaw and Russell's (1993) survey is a landmark. In response to the question 'are clinical guidelines effective?' they reported:

> *'Out of 59 published evaluations of guidelines that met defined criteria for scientific rigour . . . all but four detected significant improvements in the process of care after the introduction of the guidelines. Of the 11 studies that assessed the outcome of care, all but two reported significant improvements'*

Their conclusions about what made guideline-based quality initiatives effective were (in brief):

(i) that users were involved in development of the guidelines;

(ii) that the guidelines were disseminated by a specific educational intervention (not just on paper); and
(iii) that a patient-specific reminder was included at the time of consultation.

(*Russell and Grimshaw 1992*).

Why do we need guidelines for shared care?

The overall aim of guidelines is to improve the quality of health care (RCGP Clinical Guidelines Working Group 1995). 'Guidelines should identify recommendations for appropriate and cost effective management of clinical conditions or the appropriate use of clinical procedures with the principal aim of promoting good performance' (Effective Health Care Project 1994). Shared care requires agreed practices across a boundary, so explicit guidelines become all the more necessary. Some ways in which guidelines can be viewed are listed below:

GUIDELINES AS 'HABITS'

If every patient's problem had to be studied in depth, and reasoned *ab initio*, consultations would be much longer—perhaps several hours each. Fortunately, it is in the nature of man to develop 'habits', whereby familiar patterns of behaviour can be repeated with less effort. Michael Young (1988) has described habits as 'the flywheel of society' and essential for survival. The question arises whether we fall too easily into habitual behaviour when 'one-off' reasoning is more appropriate. If we view guidelines as time-saving habits, we then have to ensure that they are effective.

GUIDELINES AS SIMPLIFYING DECISION PATHS

The basic problem addressed by practice guidelines is that many, if not most health decisions are too complicated to be made on a one-by-one, day-to-day basis. They involve, among other things, identifying the options; identifying the important outcomes;

evaluating the evidence that relates the options to the outcomes; estimating the consequences of each option; weighing the benefits of each option against its harms and costs; factoring in a variety of logistic, economic, legal, social, and personal considerations; and choosing the option that is in some sense the 'best' (Gordon and Christensen 1995). If every practitioner attempted to do this for every decision, the result would be either paralysis or chaos.

The explosion of technology in medicine has led to an increase in the number and complexity of diagnostic tests available to the clinician. It has been found that doctors often order large numbers of laboratory tests but only about 5% of the data is subsequently utilized (de Dombal 1988). Even for highly specific diagnostic problems there can be a large choice of procedures. For example, in the detection of colorectal cancer, a doctor can choose any combination of faecal occult blood tests, digital examination, rigid sigmoidoscopy, flexible 30cm or 60cm sigmoidoscopy, barium enema (plain or air contrast) and colonoscopy. Some of these tests are outside the scope of general practice, so referral would be necessary. The wide choice of available tests is not accompanied by information about the sensitivity and specificity of each test, the order in which to carry them out, nor how the results should be combined (Ginzler *et al.* 1992).

A RESPONSE TO INCREASING SPECIALIZATION

A further argument for the development of practice guidelines is provided by the effects of the fragmentation of medicine into specialties and sub-specialties. Increasing specialization in medicine and the clustering of expertise in regional or national 'centres of excellence' means that doctors on the periphery are often called upon to undertake procedures and treat conditions with little experience of how to do so. This adds serious difficulty to the task of selecting the optimal pathway for referral or shared care.

GUIDELINES AS VEHICLES FOR KNOWLEDGE TRANSFER

Guidelines have another function in providing easily digestible morsels of knowledge. The rapid growth of medical information and technology (discussed in Chapter 4), and the difficulties this presents for the clinician, have led to questions about how medical knowledge should be imparted. The bulky medical textbook in which vital facts are buried and which is rapidly outdated is clearly an inappropriate means of disseminating volatile information.

A study in America found that doctors wanted information presented in a concise format that told them what to do (Kanouse *et al.* 1989). Clinicians, therefore, require up-to-date, relevant, concise and readily accessible information. Practice guidelines containing specific recommendations could, it is argued, fulfil this requirement and lead to higher quality medical care (Peachey and Linton 1990, Brook 1989, Grol 1990). They can provide an *'intellectual vehicle through which the profession can distil the lessons of research and clinical experiences and pool the knowledge and preferences of many people into conclusions about appropriate practices'* (Eddy 1990).

In some areas of medicine, guidelines drawn up in consultation with experts in a particular field may provide a way of disseminating their expertise. They may be particularly useful in general practice where even relatively common conditions such as colorectal cancer may only be seen once or twice a year. Furthermore, guidelines can be used to specify who should perform a particular practice, when it should be performed (for example, when to refer) and on whom it should be performed.

GUIDELINES AS 'SHARED CARE AT ONE REMOVE'

Guidelines have to draw on a very large body of knowledge and experience, and take patients' attitudes and preferences into account. The development and adoption of guidelines requires cooperation between generalists, specialists and patients at central and local levels. Even if their final application is in one organization such as general practice, their development requires a sharing of expertise and ideas, so guidelines can be seen as *shared care at one remove,* and sometimes provide an effective alternative to shared care. Guidelines are an essential tool if shared care is to function in line with best practice and suit the local context. In a district, there are advantages in general practitioners and specialists working to compatible guidelines.

What issues do guidelines for shared care raise?

GUIDELINES AS 'COOK-BOOK MEDICINE'

That practice guidelines can contribute to medicine as an educational tool and as a source of guidance to aid clinical decision-making is generally agreed. However the development and introduction of guidelines raises several issues. Some clinicians object on principle to guidelines believing that such initiatives impinge upon clinical freedom, stifle innovative thought and will inevitably lead to a form of *cook-book medicine.* Although the effect of guidelines on clinical autonomy will depend to a large extent on who develops them (clinicians or non-medical bodies), how strictly they are enforced and how often they are reviewed, closer consideration of their intended role in medicine may dispel some of these fears. Competent cooks do not mind using cookbooks!

GUIDELINES BASED ON OUTCOMES

Although Eddy (1990) suggested that guidelines can and should be developed even in the absence of hard data, it is probable that the credibility of recommendations supported by objective, scientific facts will be higher. If guidelines are to be outcome-based, then more data on the outcomes associated with particular interventions will be required. Unfortunately, measuring outcomes in medicine is a particularly difficult task. First, it is expensive and time-consuming (for example, waiting to measure the five-year survival rate of cancer patients following chemotherapy). Secondly, many diseases are so rare that, in order to conduct the ideal clinical trials, it would be necessary to collect tens if not hundreds of thousands of participants.

GUIDELINES AND PATIENT PREFERENCES

Lack of information on outcomes and patient preferences results in there being few rigid standards, particularly in general practice. Most practice policies need to be flexible, allowing the clinician to tailor the recommendations to fit individual patient needs. They are designed essentially for the *generic* patient and recognize that, because patients will vary in terms of their response to illness and their preferences for outcomes, deviation from the guideline will be fairly common. It may also be argued that clinical freedom is only conferred upon a doctor by society in the expectation that such freedom will used for the benefit of patients. It implies an obligation upon the doctor to make the best judgements he can, using what additional source of help he needs (de Dombal 1988). If guidelines can improve the quality of clinical judgement, then their development is justified. Even if the knowledge contained in the guidelines has not yet been fully validated, by undertaking controlled outcome studies of the use of guidelines in practice, their validity can be established later (see Chapters 19 and 20).

INFORMATION TECHNOLOGY AND GUIDELINES

Guidelines will be needed in all the domains of shared care, and many other aspects of general practitioners' work, such as diagnosis, investigation, prescribing, preventive and anticipatory care and referral. This is likely to total several hundred guidelines. For these to be held on paper and accessed manually is unrealistic. An early task must be to get all guidelines onto a computer, so that they can be called up instantly during the consultation. Unless they can be integrated in the electronic patient record and employed in a flexible manner, they are unlikely to be valued by the doctor, and will fall into disuse. By making care plans explicit, they can be useful as input into medical knowledge-based systems, whose agendas have been transformed in the past five years by the emergence of practice guidelines (Gordon and Christensen 1995). This is considered in Chapter 19.

Clinical guidelines should improve the quality of patient care, whether individual or shared, by enabling the profession to benefit from the collective knowledge of the profession as a whole, and apply this collective knowledge and advice in practice, at the point of decision.

Guidelines help in planning and carrying out shared care. They are also convenient capsules of knowledge. Shared care has an important role in the two-way transfer of knowledge by means of guidelines. They can be effective in changing professional behaviour.

Chapter 17
DEVELOPING EFFECTIVE COMMUNICATION

◆

Communication is the life-blood of shared care. This chapter describes and assesses ways of communicating, in particular the value of electronic methods, now and in the future.

Communication is an overused word, and a scapegoat when things go wrong. *'If only communication had been better . . .'*. None the less, without effective communication, all organizations and most useful activity would fail. It is much more than the passing of data. Argyle *et al.* (1970) showed that (in perception of attitudes in a particular context) the actual words only expressed 7% of the message. Voice tonality and body language accounted for the rest. So the passing of written messages may be a relatively barren way of communicating. Yet even face-to-face contact has its failures, as Byrne and Long (1976) so realistically recorded, and Pendleton *et al.* (1984) and Tate (1994) have tried hard to remedy. The clinician must first listen, otherwise the patient will not listen, comply with advice, nor regard the consultation as satisfactory (Ley 1988). Just sitting back and listening is not enough. It must be an active process.

'Active listening' is widely taught in industry, and this is a basic skill for health professionals. It requires the transmission of information and underlying feelings, and a check that the appropriate message has been received. The skills of active listening are learnable, and a brief summary of hints follows as Table 8 (with acknowledgement to The Conflict Resolution Network).

Table 8. Active listening—some hints

Things to try	Things to avoid
Focus attention on the speaker	Avoid talking about yourself
Repeat tentatively, in your own words, your understanding of the speaker's meaning	Do not introduce your own reactions or well-intentioned comments
Feed back feelings as well as content (eg: *'how did that affect you?'*)	Try not to ignore feelings. Avoid advising, diagnosing, reassuring, encouraging or criticizing
Reflect back, not only to show you understand, but also so the speaker can hear and understand his/her own meaning	Dispense with thinking about what you will say next. Avoid parroting the speaker's words, or only saying 'mmm'.
Try again if your active listening statement is not well received	Don't pretend you have understood if you have not
Be as accurate in the summary of meaning as possible	Avoid letting the speaker drift to less significant topics because you have not shown you understood
Challenge hopelessness and powerlessness subtly (eg: 'it is hopeless'—*'it seems hopeless to you now'*. 'there is nothing I can do about it'—*'you can't find anything that could fix it?'*	Avoid fixing, changing or improving what the speaker has said. Don't change topics
Allow silences in the conversation	Resist filling in every space with your talk
Notice body shifts and respond to them by waiting. Then, eg: *'how does it all seem to you now?'*	Don't neglect the non-verbal content of the conversation.

©The Conflict Resolution Network. PO Box 1016 Chatswood, NSW 2057, Australia.

Ways of communicating

This emphasis on listening skills may indicate a bias towards face-to-face as opposed to paper or electronic communication. However, each method has its advantages and snags. Voice messages are linear, and once uttered are lost (unless tape-recorded). Written messages can be read several times by many people, and can include pictures, diagrams and maps that are difficult or impossible to transmit verbally. With a map, one can start at any point and take a number of routes to any other point. With electronic methods, missing data and failure of a patient to attend can be highlighted. Perhaps we can achieve a mix of methods so that each is used where it is most effective.

Improving communication between GPs and specialists

Roland (1992a pp 108–122), in his chapter on this topic, emphasized both the necessity for succinct and adequate information in referral and discharge letters, but also the need for messages to be timely. These factors may work against each other. If time is critical, then electronic mail is the fastest, though fax and telephone run it close. As mentioned in Chapter 4, dialogue may have to give way to monologue when time presses. Roland recommends a structured format for written communication, made much easier with electronic patient records.

The referral process—is it working satisfactorily?

Current practice in referring patients to a hospital specialist, which may be the entry point into shared care, is poorly understood. Reasons for referral have been extensively studied (eg: Armstrong 1992, Weaver *et al.* 1992, Bradlow *et al.* 1992, Wilkin and Smith 1987), but the results are hard to compare. Seeking an 'opinion on diagnosis' rates high, as does 'advice on management' and 'reassurance'. All these might be influenced by improved knowledge transfer. The reason for many referrals was to provide a specific treatment or investigation not available in primary care. The cognitive process leading to referral is unclear, and the reasons given may be *post-hoc* rationalization—as occurs when an expert is asked to explain an intuitive action. The wide variances in referral rates are also hard to explain in rational terms.

Referral does not function satisfactorily from the viewpoint of the general practitioner or the patient. The general practitioner writes a referral letter and encloses it with a request for an appointment with a time marker such as 'immediate', 'within two weeks', or 'routine'. The letter may be addressed to a consultant in person. The request for an appointment within a certain time may bear no relationship to the availability of appointments, and the named consultant may delegate to a junior. After a variable delay, the patient is sent an appointment, which may be several months ahead. After the outpatient consultation, the general practitioner receives a letter with suitable advice about future care and follow up. Referral is a laborious process in which the amount of information passed falls far short of the ideal. Time delay is unpopular and hazardous, with the patient in limbo, and no one knowing what is happening at a given moment. The fact that many shared care schemes include short cuts to referral, such as open access to diagnostic testing (see Chapter 8), is an indication of the need for concern about the existing process.

Electronic communication

Electronic transfer of data between compatible computer systems in general practice and hospital would be ideal, and this is beginning to happen in pilot projects. An alternative is a shared patient record on paper or the 'smart card' in which the data is transferred on a silicon chip carried by the patient. These methods will be discussed later, but should be seen in the context of the patient being an active participant in the process, and even as the 'owner' of the information. Can the traditional methods of communication by letter be improved, or should we be looking for radical alternatives to current referral and shared care practices?

Ways of communicating

These were considered in Chapters 2 and 3 in an organizational context. Hickman *et al.* (1994) undertook a landmark survey of shared care schemes in operation in two regions. Many factors were involved in determining the feasibility and success of the different methods, such as the availability of a suitable computer system. Their effectiveness was seen in terms of ensuring that patients who did not attend were recalled, and that patients received a standardized clinical review. They described six methods which they listed in order of sophistication (see below, along with the number of examples they encountered).

- Community clinics (4 examples)
- Basic communication by letter or standard record sheet (10 examples)
- Liaison meetings between the hospital team and general practitioners (3 examples)
- Shared care record (22 examples)
- Computer-assisted shared care (14 examples)
- Electronic mail (e-mail) (no examples)

The Hickman *et al.* 'taxonomy' listed above has many of the same features as the Table on p 31. The rank order using sophistication as the yardstick does not necessarily equate with utility. Each way of communicating is different and can be applied to different circumstances. Computer-assisted shared care was seen as the clear leader. This survey had the enormous advantage of describing what was actually going on, rather than judging from papers published by enthusiasts in a particular domain. Overall, they concluded that shared care for chronic disease was not common.

COMMUNITY CLINICS

This method has a long history, for example when consultants did clinics in community hospitals attended also by the general practitioner. Specialist clinics in a surgery or health centre have had a boost from fundholding, whereby the practice could choose the more economical option of a sessional fee for the specialist, rather than pay for a number of referrals. This method gains from being able to draw up a joint care plan with all the parties involved. It is also a learning experience for all, and knowledge and skill transfer is likely to change the way care is delivered over time. Confidence is gained and resources shifted from specialist to primary care. An example is the orthopaedic clinic, where patients with backache may be seen more promptly and this may lead to the employment of a physiotherapist in the practice. Some of these clinics used shared patient records. Reduction in admissions has been reported. This is a pattern of shared care with great potential for learning and gaining a shared understanding: it should not be limited to fundholding practices.

Personal experience of community clinics has indicated that they bring about a closer mutual understanding between general practitioners and specialists. Specialists have a deeper knowledge and experience of the problems for which referral has been sought, so it is an ideal learning opportunity. General practitioners can receive much useful knowledge and 'rules of thumb', and enlarge their repertoire of enquiry. The same applies even more to domiciliary consultations by specialists, which can be an intense three-way learning experience.

BASIC COMMUNICATION BY LETTER OR STANDARD RECORD SHEET

Regular letters or standard record sheets in a shared care scheme can go beyond the normal level of exchange of letters to and from outpatient clinics. The records can be more formally structured and more complete, and a coordinator alerted when patients did not respond. Many schemes used a hospital computer, but could not be classified as 'computer-assisted shared care' (see below).

LIAISON MEETINGS BETWEEN THE HOSPITAL TEAM AND GPS

Regular meetings can be held to discuss the shared care of individual patients until a joint management plan was agreed. One scheme, for drug dependency, formalized their agreement on care in a contract (Greenwood 1992). In another scheme for drug dependency there were no guidelines, and the general practitioner's role was mainly to monitor care and issue prescriptions.

SHARED CARE RECORD

A card or booklet can be used for joint data entry, and usually held by the patient. This was popular in schemes for diabetes and hypertension. It has long been used in maternity care (a domain not included in the Hickman *et al.* survey). The shared record was considered good for transfer of information, but does not quickly find those who fail to attend. The patient, by holding the record, is brought into the circle of knowledge and trusted. Rarely has this trust been misplaced.

COMPUTER-ASSISTED SHARED CARE

Information was transferred after each patient's visit to hospital or practice. An agreed data set was used, including results of investigations on either site. A specialist reviewed the information from each visit and the computer record was updated. The practice was informed by standard letter, including recommendations. Alerting for non-attendance can be automatic. The key to success was the cycle of information transfer at predetermined times. It was flexible enough to cover patients treated mainly in general practice or in hospital.

Other computer-assisted methods have been used. In one, the records were reviewed by the hospital specialist or nurse, without seeing the patient. Thereby the problem and the responsibility were shared without shifting the patient, but success would depend on a high level of trust and competence. Another example was a hybrid of communication by telephone and shared record card, along with an exchange of computerized summary sheets. Eleven of the schemes used a central mainframe computer: three used microcomputers. The latter have the advantage of greater flexibility, and integration of the practice computer in the shared care scheme. Duplication of hardware in the consulting room, and inputting data twice have to be avoided at all costs.

Computer-assisted shared care has been highly developed in the Grampian Region of Scotland and the majority of general practitioners are involved in the scheme. The advantages of this method have been established. Adding value with a decision support system will be considered in the next chapter.

ELECTRONIC MAIL (E-MAIL) AND FACSIMILE

Electronic mail is in daily use in the business and academic world, but it has been slow in reaching shared care, as evidenced by Hickman *et al.* (1994) meeting no examples of it. Though it only transfers data, with none of the body language and voice tonality of face-to-face or video contact, it is immediate and commands attention. This is partly due to its novelty, as in the case of facsimile transmission.

Results of investigations can appear directly in the records at both sites. Use of e-mail has been described in the Netherlands, and it some projects in UK, for example the Derbyshire diabetes project (Bainbridge and Cowley 1992). Several pilot projects are using it successfully in UK. It can serve multiple sites and personnel using an agreed data set. Prompts can be provided automatically where data is missing or other action was needed. Faxes can be handwritten and contain images, though the quality is poor. This can be improved by direct transmission between computers, which has many advantages, such as speed and single data entry (see below).

TELEPHONE LINKS

Telephone contacts between UK general practitioners and specialists for advice about a patient have a long history, but little formal structure. They are uncommon as a regular way of getting a second opinion, partly because of the difficulty of making contact and the intrusiveness of a call. Hartog (1988) reported that a telephone call could replace more than a quarter of endocrinology outpatient appointments. Roland and Bewley (1992) described an orthopaedic telephone consultation service which obviated 45% of referrals (22% definitely, 23% possibly). This is a form of shared care. Even if the specialist has not seen the patient, giving advice on the telephone involves some shared responsibility. The service was not used enough to have an impact on referrals, but it is a start.

Telephone consultations have long been neglected in the UK (Hallam 1991). Doctors have regarded them as second best and risky, and indeed this may sometimes be true. Yet an evaluation of a telephone consultation service for patients in one practice (Nagle *et al.* 1992) showed that it was valued by patients, three quarters of whom would otherwise have made an appointment. Doctors were moderately satisfied. Conversely, Stafford (1993) has complained of the avalanche of 'non-contact' patient services now facing the primary care physician in the US, and the stress that this caused.

In Iceland, however, each general practitioner has a regular spell of telephone consultation, lasting 30–60 minutes every working day (Sigursson 1992). The doctor sits at the computer screen with a headset, and calls are channelled through a small dedicated switchboard, similar to that used for a radio phone-in. This is very popular with patients, but many of the doctors find it their least rewarding activity, though they agree on its effectiveness in saving workload and patients' attendances. Telephone consultations between general practitioners and patients have also been evaluated in Finland (Kvist 1991) with many benefits and few snags.

VIDEO CONSULTATIONS

This is the next step from telephone consultation, in that the specialist can 'see' the patient, and enter into a three-way dialogue, accompanied by facial expressions and body language. Rapport is better and the risk is likely to be reduced. These methods have been pioneered in Arctic regions like northern Canada and Norway (Jennett *et al.* 1993 and Pedersen *et al.* 1994), where moving the patient is hazardous and expensive by helicopter or motor sledge. Some pilot schemes are running in the UK for minor injuries, dermatology and image transfer. Though strongly indicated in remote areas, video consultation could play a major part in relieving the 'log jam' afflicting the referral process. It could also be used for group sessions in the community (e.g. for weight reduction) with a remote group leader.

The technology has greatly improved in the past year, so that systems are available at reasonable cost, that should pay for themselves many times over. Some have a full screen image at high resolution: others have a post-card sized picture, with the remainder of the computer screen containing the patient record.

To give an idea of the cost, the British Telecom VC7000 retails at £6000 a station. Leasing might cost about £1500 for two sets. Special telephone lines are needed (ISDN2[4]) costing £400 to install, and a quarterly rental of £84 per location. Video conferencing systems could have many other uses in practice, for example to save going to meetings. The IDSN2 telephone link could also be used for all data transfer needs between hospital and practices, including images such as X-rays, scans and ECGs.

In the authors' view video consultation could revolutionize traditional patterns of shared care, and drastically reduce the need for patients to travel to and from hospital. The eventual aim would be for both general practitioner and specialist to have a shared electronic patient record on their computer screens as well. Consultants' time schedules would need to be rearranged, and this might result in much more economical use of specialists' time. Ideally, the service should be provided by specialists at the local general hospital, who are well known to general practitioners, and could accept referrals. However, distance is no obstacle, and specialists with the time and aptitude could provide the service from remote sites—even from home.

There is no overriding reason why an agency entirely outside the National Health Service should not provide a video consultation service, just as other sources of advice, like books and journals, are independent. Video consulting is very close to the normal consulting patterns, so would not need a lot of training to use. The major advantage would be that problems would be sorted out the same day, rather than go through the delays inherent in current working methods. There is an urgent need to develop and evaluate pilot projects in video-supported shared care.

General practitioners working in hospital

Clinical assistant posts, whereby general practitioners spend a session a week in an outpatient clinic or casualty, are older than

---

[4] ISDN is short for Integrated Services Digital Network, a specially installed telephone line capable of supporting the quantity and speed of data transmission needed.

the NHS. General practitioners welcome the paid session away from the practice, working in a domain in which they have an interest and expertise at sub-specialist level. The specialist team could benefit from having a general practitioner in the team, whose advice could be sought about situations arising outside the hospital. Both could learn from each other, and build bridges of knowledge and goodwill. Examples of successful shared care of this kind are in open access endoscopy (Gear and Wilkinson 1989), and maternity care (Bull 1980). In the former case, about 200 general practitioners in Britain (0.6%) are working as clinical assistants or hospital practitioners in endoscopy units (Jones 1995).

Shared maternity care

Bull (1980 and 1989) worked in a joint specialist teaching unit with open access for suitably qualified general practitioners. Evaluation of the total care of low-risk patients showed that specialist and general practitioner care achieved equally good results in matched groups of patients (Klein *et al.* 1983). In the early days of the scheme, the specialists had a much higher intervention rate: after a few years of working together each had moved closer to the average, indicating a two-way learning process. This was shared care at its most sophisticated, where the general practitioner had been accepted for intra-partum care in the specialist team.

— ***The critical importance of communication for effective shared care goes without saying.***
— ***Electronic methods, such as video consulting and e-mail show great promise for enhancing shared care.***
— ***Face-to-face contact, and listening skills are still needed.***
— ***The telephone could be used more effectively.***

Chapter 18
LEARNING TO CHANGE AND FACILITATION

◆

Changing to new ways of working is a difficult process. This chapter describes the learning organization and the facilitator as helpful for managing change

Managing change

People providing health care have wonderful goods on offer—better health, better quality of life, relief of pain, a trusted mentor, happiness! But what is the state of the delivery vehicle? Are the wheels seized up solid, and does the driver know the destination and have a map? As mentioned elsewhere, goals that are clear, explicit and agreed are essential for progress. Likewise, we need a clear vision of the future that we wish to build for ourselves and our organization. This vision must be shared among all who have a stake in what the organization is trying to do. Last, but not least, all units need a high level of management competency in view of the critical importance of shared care for patients' lives and wellbeing.

A full guide to the management of change is beyond the scope of this book, and the reader is referred to some of the standard works in this field such as Beckhard and Harris (1977), Pascale (1991), Beckhard and Pritchard (1992), and Kanter *et al.* (1992). What this chapter aims to provide is a simple toolkit that can be used on the scale of shared care, namely ***developing a learning organization*** and ***facilitation***. These devices may get the wheels of change turning in the direction of our aspirations.

Resistance to change seems to be part of the human condition, particularly in organizations, yet curiosity and the excitement of the new are equally strong forces. How do we get the balance right? We do not want change for its own sake, nor stagnation. How do we overcome the inertia described by Stocking (1985) and implement changes that are appropriate for our own context? The smaller the scale of operation, the easier it should be to change. Change in very large organizations (like the NHS) can be seriously mismanaged, when applying its policies locally. So in this chapter we will concentrate on relatively small organizations like the primary care and a specialist team, that have some capability to initiate and control the processes of change themselves.

It is easy to use organizational size or complexity as an excuse not to change, yet enthusiasts who can inspire their own immediate groups to achieve a worthwhile goal can often succeed. One tip is not to give up easily—not to take 'No' for an answer. The late C Northcote Parkinson had various ploys to circumvent the negative influence of 'the abominable no-man' in an organization: in brief, 'if he could not be won round, then by-pass him!'

The learning organization

Ideally, all health professionals should be involved in lifelong professional learning and personal development. They should work in a 'learning organization' that is part of a 'learning society'. Individual learning and competence are essential for the mutual respect on which effective teamwork and shared care is built. This is beyond the scope of this book, and the reader is referred to classic texts such as Donald Schön's *'Educating the reflective practitioner'* (1990), and Chris Argyris' *'On organizational learning'* (1992). The 'learning society' is a noble aim on which educational policy seems to have turned its back. Society rewards achievement—mostly of knowledge or material goods—rather than the capacity to learn and benefit from learning. Academic institutions also seem to be moving away from learning and teaching, towards a tally of published work as a yardstick for funding or promotion. This trend makes the local development of the learning organization all the more important, as it may have to struggle against the tide, but struggle we must.

DEVELOPING A LEARNING ORGANIZATION

A learning organization is one that is continually expanding its capacity to create its future, that is not just learning to adapt to the changing environment but learning in a way that enhances its members' capacity to create (Beckhard and Pritchard 1992). A single occasion, like attending a workshop, is a good start, but learning for doctors and other professionals is a lifelong process to which they are committed. This should make it easier for them to develop a learning organization as a natural consequence of their personal learning, but it does not happen automatically.

For success, organizations need to be concerned with learning as well as achievement. At each review point we need to ask ourselves what we have learned as well as what we have achieved for our patients and our organization, as well as for ourselves. Some features of a learning organization are listed below:

Key features of a learning organization

- A team must be driven by their vision of the future, though they can learn from the past
- The values and priorities of the team and of team members must be made explicit. Values cannot all be shared, but differences need to be known and understood
- All team members must be open minded and prepared to innovate and to acknowledge mistakes made and lessons learned
- Learning should be combined with doing in all the team's activities
- Improvement in learning must be acknowledged and rewarded, not just improvement in performance
- Team strategies and plans should be flexible. Planning must be seen as a learning process (eg care plans)
- Information needed to carry out tasks must be shared openly and updated in response to learning by experience
- Training must be a catalyst for further learning and doing
- Becoming a learning organization is a fundamental change and must be managed as such.

(*W Pritchard, personal communication*)

As a first step we can go through the check list above and see where we fall short and what steps we can take to remedy any shortfall. The rewards are great. A learning organization should be an effective, a fulfilling and a happy organization, in which all members are valued and have the opportunity for personal development. For further reading on the learning organization, see Argyris (1992), Senge (1990) and Swieringa and Wierdsma (1992).

Facilitation

Developing shared care involves a change in ways of working, and this requires learning. There are many ways of approaching this, and most organizations benefit from some help to get the change process going. Industry employs consultants skilled in helping members of organizations to change. Small organizations like primary care, or very complex ones like shared care, might not be able to afford their services. In this case they might choose to use a facilitator as a 'change agent'.

Facilitators appear as key figures in the implementation of many of the shared care schemes discussed in Section II, particularly in shared care of chronic illness. Who are facilitators, and what part do they play in primary and shared care? What training do they need and are they receiving adequate training? Some facilitators are employed to operate in primary care, some in secondary, and some in both. Outreach nurses, in such areas as palliative care and diabetes, need to be facilitators and change agents as well.

THE PRIMARY CARE FACILITATOR

Over 300 facilitators are deployed in primary health care to assist with many functions, some of which are listed below:

- promoting health and preventing illness
- developing primary health care services
- training nurses in practice and community
- developing quality of care and audit

- team building
- developing shared care of diabetes, asthma, cardiovascular disease, mental health etc
- ethnic minority issues
- computerization

Spiegal *et al.* (1994) have described the role of the facilitator in the primary health care team, but the message applies to specialist and community teams also. In the Camberwell project, described in Chapter 6, team facilitation was based in a Department of General Practice. Facilitators need to respond flexibly to whatever issues the clients and facilitator jointly define as the problem. When team members were questioned, general practitioners, nurses and receptionists responded differently. Many saw facilitators as providing information and solutions—perhaps in tune with the prescriptive nature of primary health care. However, some saw them as generators of enthusiasm, a role extender, a planner and a communicator. There was a discrepancy between what team members expected and what facilitators saw as their role.

FACILITATORS IN SECONDARY AND SHARED CARE—OUTREACH

A number of facilitators are part of hospital specialist teams. Their base is in the hospital, but they often operate mostly in the community. They are a diverse group, including diabetic specialist nurses, palliative care nurses, community mental health nurses, stoma nurses and a host of others. Their importance is increasing with the implementation of care in the community. Their role includes liaison, teaching, influencing and negotiating. They may act as a researcher, an innovator, a counsellor and a manager. The emphasis is on encouraging self-reliance and self-care by the patient or client, not fostering dependency.

In many cases the hospital-based facilitator has a service role. If this is undertaken in isolation from primary and community staff, the effect may be to deny locally-based staff the opportunity to learn, and result in their leaving the work to the 'expert'. This may bring short-term technical benefit, but ends up de-skilling and demotivating the local staff. Hospital outposts and 'hospital at home' may be advantageous in certain circumstances, but the consequences for learning and integration have to be borne in mind.

The facilitator's role can be circumscribed, for example in stoma care; or it can be frighteningly open ended, as in primary care development. Here the facilitator may be pitched into a situation riven by conflict, and have to find remedies to suit. This requires a level of training and confidence more appropriate to a consultant in organizational effectiveness, who are rare and expensive. In giving facilitators of shared care such an open-ended and difficult role, provision of appropriate training and support is essential.

TRAINING OF SHARED CARE FACILITATORS

For those with an extended role as change agents, many 'toolkits' are needed—particularly 'diagnostic instruments', such as those described in Chapter 14. Facilitator training is a major challenge (Allsop 1990). The National Facilitator Development Project has run a number of induction and refresher courses for facilitators. They have also published a handbook for facilitators (Wilson 1994).

A survey of primary care facilitators' training needs in 1992, from over 100 responses, identified the following:

- managing change
- building effective teams
- developing facilitative skills
- linking primary health care to other organizations.

Some recent training courses for primary care facilitators aimed to develop their skills and confidence as change agents. Facilitators need independence from the organizations they are trying to help. They should be both ***structurally*** independent (not subordinate in the organization) and ***psychologically*** independent (not isolated from or colluding with the organization). Even if well set up structurally, there will come a point when the facilitator feels their psychological independence is threatened. This was borne out by the issues brought by

Chapter 19

HOW CAN INFORMATION TECHNOLOGY SUPPORT SHARED CARE?

◆

This chapter explores the potential for new information technology in the form of knowledge-based decision support, to make shared care more effective. Evidence-based practice using guidelines could become a reality.

Introduction

Anyone involved in health care can be excused for being a bit cynical about the benefits of information technology and computers. Instead of ushering in a golden age of effortless and relevant information flow, many systems have been expensive and useless. In the early days, the system developer produced a product, but it was not necessarily what the user wanted or needed. The program developer has to work to a strict 'functional specification', but often the users are given little or no part in drawing it up.

We are now entering a new age of applying 'artificial intelligence' to medical problems. Once again, there is a danger that the research and development priorities will not match the way the users work. Instead, the users will be expected to change their ways of working to suit the requirements of the system. In other words, the computer takes control of clinical activity, rather than supporting it. This is not acceptable, but there are signs that the lessons of early failures have been learned. Potential users are now being more closely involved in developing a functional specification. How to do this is not clear. Conceptual modelling (see Chapter 15) could be tried as a starting point, and this could involve all stakeholders, including patients. Once the model of the organization was clear and agreed, then the data and decision support models could be built up. They would have to include concepts, goals and flows, not just flows as is common practice. Another promising approach, also pioneered in Sweden, is 'Action Design' (Timpka *et al.* 1993). This is focused on the requirements of decision support systems and the methodology for developing them in a practical user-orientated context.

Many conventional computer applications have been mentioned that are relevant to shared care: this is a summary:

Conventional computers can (and do) provide:

- an electronic patient record
- guideline support programs
- warnings of deviation from a guideline or procedure
- quick access to medical data sources
- electronic communication such as e-mail and video links
- diagnostic support of a simple nature
- prescribing support and warnings of adverse reactions
- audit systems (some automatic)

These systems can be simple to use and help to improve and coordinate shared patient care, but they have limitations.

'Knowledge-based' decision support systems

New systems using logic programs can bridge the gap between raw data and knowledge (as mentioned in Chapter 4). Technical terms like 'artificial intelligence', 'expert systems' and 'neural nets' have come into use, and though justifiable in the research context, they may mislead clinicians and patients, so raising expectations that cannot be met. These systems are in a different category to conventional computer systems, and they do need a label. The one favoured now is 'knowledge-based' decision support systems. They can enhance many of the functions listed for conventional computers, as well as having powerful functions of their own. Many of the processes that now have to involve the user, can take place automatically, and only alert the user when necessary.

Because the system can gain access to the meaning contained in information, it can be linked to other 'facts' or events[5]. For example, if the patient has a history of tuberculosis in the past, the occurrence of persistent cough or loss of weight would automatically lead to a reminder to check for a recrudescence. A human could also do it, but would they always remember to check all possible associations, and screen large quantities of records? It would be very laborious, whereas the computer can do it in a second.

Knowledge-based systems need, none-the-less, to be 'transparent' so that the user can always ask why a particular answer appeared and check the logical steps. 'Black box' systems are unlikely to find favour with clinicians and this is as it should be.

WHAT IS A DECISION SUPPORT SYSTEM?

Shortliffe and Perreault (1990) defined it broadly as *'a computer-based system designed to help health professionals make clinical decisions'*. Decision support can take several forms, as they also noted.

1. Tools for information management (*'look-up' mode*)
2. Tools for focusing attention (*'prompt' or 'alerting' mode*)
3. Tools for patient-specific consultation (*'knowledge-based system'*)

Decision support is not just about the decisions themselves. It is also concerned with enabling clinicians to carry decisions into practice. Optimal decisions are unlikely without the essential data and knowledge needed for a particular decision. But without the capability to carry out the decision, the service will not be effective, nor will the patient benefit. The minimum requirements are an improvement in the patient record as an information source, the implementation of care plans and effective communication.

---

[5] Knowledge in this context can be defined as 'knowledge with which to perform reasoning' (Oxford Dictionary of Computing 3rd edn). Knowledge can be coded as 'facts' which are statements regarded as true. They take the form of a 'logical *n-tuple*' which a logic program can handle. An example is 'Causes *of* acute breathlessness *include* asthma'.

WHAT CAN KNOWLEDGE-BASED SYSTEMS PROVIDE;

The range is very wide, but these are some examples that could soon be implemented using existing technology. They are not science fiction.

- 'Active' (intelligent), problem-oriented, electronic patient record linked logically to other information sources.
- Ability to search for missing data that is relevant to a particular path of reasoning or possible diagnosis.
- More focused search of medical knowledge and data bases.
- Flexible help with patient-specific guidelines so that the clinician is not overwhelmed by their sheer number and complexity.
- Reminders of deviation from guidelines.
- Support with problem identification and diagnosis.
- Improved prescribing support, and monitoring of adverse reactions between patient and drugs, and between drugs.
- Concurrent 'real time' audit in the consultation.
- Retrospective audit, linking patient outcomes to the use of guidelines and decision strategies.

SUPPORT FOR EVIDENCE-BASED PRACTICE

There is great concern at present that practice in the NHS should be based on evidence. A recent leader in the British Medical Journal (Smith R 1994) was timely in calling for a 'knowledge-based health service'.

> *'Few decisions are based on evidence... The failure stems from those who work in health services being unaware of evidence that is available, from the evidence being disorganized and inaccessible, and from the evidence simply not existing. The ambitious mission of the NHS R & D programme is to create a national health service in which decisions are based on evidence.'*

The building blocks of evidence-based practice and its implementation, include an electronic patient record, a knowledge-based decision support system, systematic guidelines and electronically-accessible sources of knowledge. Examples are the Cochrane Collaboration databases, and full-text journals and textbooks on CD-ROM. Producing valid evidence is not enough. It must be widely disseminated and applied, and the effectiveness of its application audited. This is where knowledge-based systems have an unique capacity to enhance learning at the point of decision—described as 'hot learning' (Pritchard 1991), rather than rely on traditional educational methods that have proved relatively ineffective (Haynes 1991).

THE ELECTRONIC PATIENT RECORD

The importance of the electronic patient record is emerging as a major issue from many studies in the literature (Purves 1993 and 1994). Without an adequate electronic patient record our best efforts will be frustrated. We still have a long way to go to achieve useful and integrated patient records, though the position in primary care is much more advanced than in hospital.

The patient record is essential for patient-specific advice, so without it, effective decision support is hard to deliver. There are several unsolved, or partially solved, problems for example, how to structure a database so that essential data can be clearly and adequately represented, and also the terminology to allow users to name those things that they want to name in a systematic way. There is work in progress in this area. In addition, users may want images and sounds and video. To ensure compatibility, international standards and development on a national scale are indicated.

SUPPORT FOR USING GUIDELINES

Knowledge-based systems have the potential to revolutionize clinical practice and make it more logical and evidence-based, and also safer. Whether they would be more economical is open to doubt, but at least they should provide more logical choices and better value for money. Evaluation has already shown that guidelines can improve referral practices and prescribing. These developments could produce a radical change in the relationship between general practitioners and specialists, and between primary care and specialist teams, which are bound to have an impact on shared care.

One effect of decision support could be a much more thorough 'work up' of complex problems in primary care—perhaps obviating referral in some cases. Holding guidelines in a conventional database system would make them more accessible, but the ideal, as described earlier, is the 'patient-specific guideline'. This presupposes a link with patient data, and the capability to influence the care plan in accordance with the patient's preferences. These conditions would be too demanding for a conventional computer system, so we have to ask ourselves whether a 'knowledge-based' system would meet these criteria. For further details see Gordon and Christensen (1995), Purves (1995) and Glowinski *et al.* (1995).

SUPPORTING COMPLEX DECISION PATHS

People do not have just one diagnosis, and there are numerous determinants and models of illness—medical, social and psychological. To take account of patients' preferences, numerous alternative pathways for shared care need to be considered. Alternatives need to be made explicit, so that the doctor's judgement can be brought into play, rather than jumping to a 'best fit'. The implementation of decision support for shared care need not all be done at once. Domains can be selected in order of priority, and a modular development path followed. This presupposes generic decision support software, such as DILEMMA and the Oxford System of Medicine (Fox *et al.* 1990, Gordon 1991), so that the modules can all be integrated eventually into a single comprehensive system. Development of decision support is well advanced, and should be available to clinicians in two or three years time.

SHARING THE ELECTRONIC PATIENT RECORD

Patients are entitled to access to their medical records, and this may cover electronic records as well. This should be no problem when dealing with the usual medical data and problem lists.

Patients can reasonably claim 'ownership' of the data as it concerns them intimately. When we come to consider knowledge-based decision support, this is a different field, in that the clinician is working out the problem on the screen, as if thinking aloud. The screen contains the doctor's thoughts and worries, particularly if the 'worst case scenario' is being explored, as in suspected or possible cancer. For the patient to view the screen in those circumstances might be threatening for both parties. It would entail the doctor taking the patient on a guided tour of thinking processes that would take time and raise many anxieties.

However, in the longer term, when doctors and patients are familiar with decision support, they might find that sharing the problem in this way was a useful learning experience for both. The doctor would learn more of the patient's health beliefs and the patient would come to realize that medicine was not a simple matter of black and white issues (B. Stocking personal communication). This could lead to a new and more mature doctor-patient relationship. In a shared care setting, the situation would be more complex, as general practitioner and specialist might both be making their thoughts explicit. However, the learning potential would be greatly enhanced, with the ultimate aim of patient, general practitioner and specialist achieving a shared view of the problem and the care plan.

TRAINING NEEDS

In order to retain the confidence of their patients, clinicians will have to be as adept with the computer as they are with a pen or a stethoscope. Decision support systems have a reasoning program that may be complex and multi-layered, with many alternative pathways. Users will have to invest in learning until they have the required confidence, or even an enhanced confidence because of the enormous intellectual gain—the added value—they can obtain from the system. This will take time.

HUMAN FACTORS IN IMPLEMENTATION

The computer may not fit easily into the pattern of the one-to-one consultation. The screen may distract both parties from eye contact. A keyboard may be less distracting than a mouse that requires close visual concentration. Let us hope that new methods of control and data input will be available, such as voice and freehand writing. Intuitive programs and interface will help the user to learn, but not without training.

The computer is more than a tool, yet it is not human. 'It excites reflection about the nature of mind and the nature of life' (Turkle 1984). Clinicians will need to come to terms with the power of system, but studiously avoid giving it human characteristics. Loose talk can be dangerous in misleading both doctor and patient about the nature of the system. Knowledge-based systems are not *intelligent*, in the normal sense of the word. They do not think. They cannot make a decision or a diagnosis. They can only support these activities. Yet, when observing doctors using prototype systems, their language often gives away their belief in the supernatural power of the system. As a starting point, there follows a list of anthropomorphic expressions that might best be avoided in the consultation.

> 'Let us see what the computer *thinks—or tells us*'
> 'This is a tricky problem, shall we let the computer *decide*?'
> 'I think the computer *knows* the answer to this'
> 'The computer can *remember* things better than I can'
> 'This computer is an *expert system* and uses *artificial intelligence*!
> 'What is the computer's *diagnosis*?'

Increasingly we will be dealing with a sophisticated public who are familiar with using computers, and even have computerized medical databases at home. We need to be quietly confident that we have a powerful tool at our disposal, but know its limitations, and when our judgement has to overrule the computer.

Ideally, general practitioners and specialists will be in step as regards the use of decision support, with linked systems. General practitioner systems will need to cover a very wide field, but not in too great detail, so that access is immediate. Specialists need much more depth of information, but a broader coverage might be useful for the problems presented by their patients that lie outside their own domain. We have the paradox that a patient has access to their general practitioner at all times, except when in hospital. Perhaps a decision support system could fill this gap!

- *Conventional computers can provide an electronic patient record, and make guidelines easier to use.*
- *They can also provide access to large databases.*
- *Knowledge-based decision support systems (now under active development), could revolutionize clinical work, and make evidence-based practice feasible.*
- *Shared care would benefit from a shared 'active' electronic patient record and shared guidelines, with patient-specific prompts.*
- *Implementation problems will not just be technical, but include human factors and training needs.*

Chapter 20
INTERFACE AUDIT AND QUALITY DEVELOPMENT

◆

Audit of the constituent elements of shared care

Shared care will not make progress towards a goal unless its effectiveness can be monitored, but we must be sure that the effort and cost of audit are balanced by measurable benefits? Audit is an essential tool for quality development in all the constituent parts of shared care, and to the process as a whole. Because shared care is complex, there is much to go wrong and much to monitor. Audit—even self-audit—carries a threat of exposing substandard performance, so it tends to be undertaken behind safe boundaries. Clinical audit involves more than one profession, and Total Quality Management (TQM) has wider coverage. In order to audit shared care, there must be a scrutiny of boundaries, and what happens on both sides, as well as what crosses the boundary. We can, however, look first at the constituents of shared care and see how they function, before addressing the broad spectrum of shared care *in toto*.

If primary and specialist teams are effective and are all working in a learning mode, then this style of working will look after many of the details of quality maintenance and development, particularly those parts which are subtle and difficult to measure. High quality of staff and concentration on their training, commitment and morale will also go a long way towards high quality of care. These indirect and adaptive methods of quality development may obviate the need for more than spot checks in the areas in which they operate.

However, the application of audit on a narrow front may lead to an improvement in quality, but may equally result in getting the best figures rather than optimum patient care. The relevance of audit can be maintained by including patient-generated measures (such as satisfaction, quality of life and health profiles), as well as involving patients in the implementation of audit programmes and the generation of data (Humphrey and Hughes 1992 and see below).

AUDIT—INDIVIDUALLY MOTIVATED OR AUTOMATIC?

Clinical audit consumes the time and energy of clinicians in checking and improving what may appear to them to be sound decisions and favourable outcomes. Only the very energetic and dedicated pursue it as a continuing process of self-appraisal and quality development on a broad front—not just their favourite diseases. It is no surprise that clinical audit is such an uphill struggle. Yet in a climate of cost containment, it is all the more essential to ensure that patients get value for money, not just the cheapest option. Automatic audit using conventional computers has made progress, but the potential of knowledge-based systems for concurrent (real time) auditing of processes, and retrospective audit of outcomes remains to be realized.

Shared care of, for example, diabetes can be audited clinically and the measures compared with standards from shared, primary or transferred care (Diabetes Integrated Care Evaluation Team 1994). The structure and processes of shared care, such as have been described earlier in this section, can also be audited, as these are important determinants of outcomes. This is more in the nature of organizational audit (OA), pioneered at the King's Fund College (KFOA 1994 and King's Fund 1994). KFOA focuses on the effectiveness of practice, or hospital organization, the interface, access to services, and lines of communication. It is a way of preparing an organization for accreditation. While not simultaneously auditing the two sides of the boundary, OA seems to be a valuable (though costly) tool for improving the effectiveness of care over a broad spectrum.

Audit of the interface

On the more specific audit of the shared care process, we need to look at the boundary, and measure what is happening across the boundary. The appropriateness of referrals is a better measure of quality than their numbers. Time delay and the ease of referral would both be good measures. The quality of communication across the boundary and its sophistication (Hickman *et al.* 1994) are also important. As described earlier, the movement across the boundary of patients, information and resources is complex. Added to this is the two-way flow of learning and knowledge. Auditing all these flows for optimum performance is a formidable undertaking, so some short cuts are needed.

Baker (1994) in a review of interface audit inferred a definition from the way the term was used, namely:

- Complete audit cycles conducted by professionals from both primary and secondary care working together
- patients attending both settings
- audit of the quality of communication

He considered that interface audit, in terms of the complete audit cycle, 'had virtually never taken place'. TQM as 'a way of managing to improve the effectiveness, flexibility and competitiveness of the business as a whole' (Oakland 1990), was not in evidence. Baker (*ibid*) stressed that a fundamental principle of TQM was the avoidance of critical 'finger pointing', which was endemic across the boundary between general practice and specialist care. He was also critical of 'one-way audit' (the audit of one party by another), as unlikely to be useful for improving cooperation and quality. He emphasized the cultural barriers to shared care and the need to work towards a patient-centred cultural change.

Wright *et al.* (1993) and Eccles *et al.* (1994) described interface audit as involving members of both primary and secondary care, ideally with equal involvement of both sides. They suggested its use as a combined problem solving approach across the boundary. In a preliminary survey of 41 groups concerned with auditing shared care, 34 were involved with disease management, 11 with referral, nine with discharges. Interest was shown in notification of death and the direct use of secondary services. These authors stressed the need to involve all parties, otherwise changes would not be implemented, and relationships would be soured. They questioned who should be responsible for initiating interface audit, and how to establish common aims before data collection started. Their conclusion was that interface audit was in the early stages of development and that potential barriers could be avoided with forethought.

Eccles and colleagues (1994) found a correlation between completion of audit and small numbers involved. This raises the question of how to involve the larger groupings needed for shared care, so that they all feel part of the learning process. These authors produced an excellent summary of messages for those wishing to undertake interface audit. A selection is listed below:

Messages on interface audit:

- Should include representatives from both primary and secondary care
- Areas where improvement is most likely are: patient/disease management; referrals to and discharges from secondary care; communication between primary and secondary care
- Best to focus on where the problems seem to lie
- For effectiveness, interface audit must be multidisciplinary, not dominated by doctors
- Audit groups should have a clear idea of their tasks and the skills needed to carry them out
- Appropriate skills include: group leadership; managerial skills (e.g. timetabling and planning); technical skills as indicated
- Communication should be clear and effective
- Mutual commitment, protected time, and resources are needed
- Group membership should be clearly defined, to keep the numbers down; members should attend regularly
- Audit cycle and re-audit essential with the aim of improving the quality of patient care.

(Eccles *et al.* 1994)

Total Quality Management (TQM)

The combined audit of clinical care and organizational effectiveness are key functions of TQM, the principles of which have been described by Berwick (1992) as:

- Intention to improve—in partnership with others—declared openly.
- Definition of quality—meeting needs—in patients' terms.
- Measurement of quality—in pursuit of improvement.
- Understanding interdependence—work together, or risk 'sub-optimization'.
- Understanding systems—and their faults and causes.
- Investment in learning—inhibited by fear and stress.
- Reduction in costs—waste, duplication, complexity and unwanted variations all work against quality.
- Leadership commitment—many ways of leading.

TQM encourages a broad-spectrum approach to quality improvement that is particularly appropriate in shared care (Lawrence 1992). Baker (1994) emphasized the 'flow process' nature of TQM which made it particularly appropriate for studying the patient's progress:

> *TQM provides a framework for examining the service from the patient's point of view. The stages in the patient's use of the service are broken down into steps. The problems that the patient may encounter at each step are identified, studied and resolved. It is this emphasis on the patient's perspective that makes flow-process audit particularly valuable.*
>
> *(Baker 1994)*

Significant event auditing (Pringle *et al.* 1995) is a new and promising way of initiating flow-process auditing. Any breakdown in cooperation in shared care could be the starting point for patient-focused auditing. This idea has much in common with Schön's (1990) 'reflective practitioner' approach. In this, any deviation from what is expected, triggers the reflection which leads to altered behaviour in future. The steps in Schön's model were listed on pages 42 and 43.

Where to start with audit?

When care operates across an organizational boundary the complexity is multiplied. So can we find some short cuts to audit of shared care? Some possible strategies are:

- Achieving agreed goals and targets for shared care. This has been mentioned in Chapter 14 and in more detail in Pritchard and Pritchard (1994) pp 39-44.
- Learning to conform to standards and guidelines (indirect outcome measures). This is part of clinical audit, and the reader is referred to standard texts (eg Lawrence and Schofield 1993).
- Objective process measures such as metabolic control of diabetes (outcome assumed), or time delays in the provision of care.
- Subjective process measures such as the quality of cooperation and quality of life.
- Subjective outcomes such as health gain, or patient and staff satisfaction with quality of care.
- Objective outcomes—patients cured/survived/active.
- Significant event auditing (Pringle *et al.* 1995) see above.

Concurrent, 'real time' audit

Most audit is retrospective, but 'concurrent' audit is not new. An early mention in the literature was by Barnett *et al.* (1978) who collected and acted upon audit data at the time of consultation. By using a computer-based medical information system, they were able to detect deviations in the care of individual patients, before treatment decisions were taken. They characterized concurrent audit as having two important educational and therapeutic advantages:

1. The notification of a deviation is specifically relevant to a particular patient care situation, and
2. information is provided in time for the clinician to take corrective action.

They were able to show that this improved the quality of care. The learning was immediate and powerful, because it took place at the moment of decision ('hot' learning). Only with the advent of a computerized knowledge base and guidelines, has concurrent (or real time) audit become accessible on a daily basis (Pritchard 1991). A conceptual model of concurrent audit is shown in Figure 6.

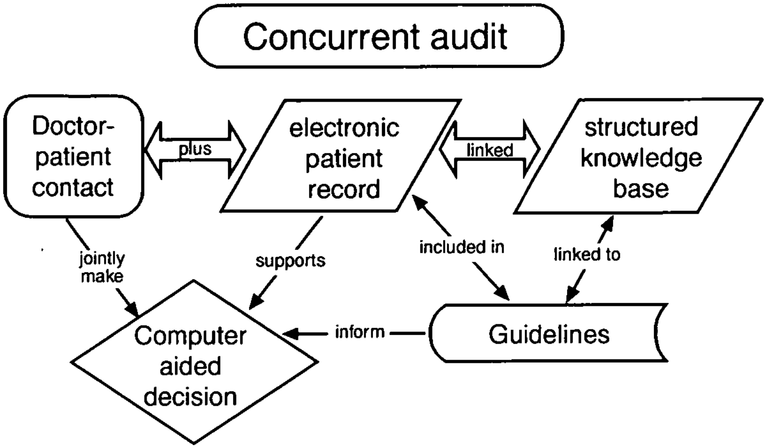

Figure 6. A conceptual model of concurrent audit in the consultation

Yet, 17 years have passed since the initiative by Barnett and colleagues, and concurrent audit is hardly discussed, let alone implemented. The relevance for shared care is that clinicians in different institutions could work to a shared knowledge base and agreed guidelines, and could even use a common electronic patient record at different sites. This is already available in prototype form for cardiovascular disease (Pitty *et al.* 1995).

Retrospective audit requires the measurement of past performance against standards, and applying an educational process to improve performance, which is then re-measured. This is laborious, and the educational process is not very successful. To apply the audit before the decision is taken has enormous potential for improvement of quality and learning. Decision support computers will make concurrent audit feasible, even in shared care, where common standards and guidelines will be the aim.

Linking audit data to decision pathways and to validate guidelines

The potential for concurrent audit improving the quality of care is so great, that the cost of the system should be recouped in a very short time. Once the automatic audit of outcomes in an active electronic patient record is in place, the data could be used for retrospective audit of the decision processes and the guidelines. This would add a new dimension to medicine, in validating or refuting much of current clinical medical practice. Eventually, a comprehensive knowledge base could arise from pooled data that reflected the natural history and prevalence of illness overall, not just as seen in hospital or primary health care.

Involving the patient in audit

Published studies of interface audit have not all stressed the importance of input from patients, let alone their close involvement in the design and operation of audit. Yet, as mentioned earlier, who is in a better position to evaluate shared care than the patient (or relative) who alone sees and experiences both sides of the boundary? Parents have been used successfully as auditors of childhood asthma. Patients' health status, health gain and satisfaction all require input from the patient.

Shared care of diabetes in Stockholm (Rosenqvist *et al.* 1990) is a notable exception. Patients played a key part in conceptual modelling (see pages 213–15), and their involvement was encouraged at every stage. The hospital staff reinforced the message with lapel badges reading 'Good care on *your* terms'.

Doctors seem to have an in-built reluctance to enlist the help of their patients, to benefit from their store of knowledge and to use them as a resource for improving quality of care. Avedis Donabedian (1986) put this point strongly, yet tactfully, in the form of a statement and three questions about the Royal College of General Practitioners' quality improvement programme:

> *Though this programme is, first and last, a solemn declaration of unwavering commitment to patient welfare, consumers were not directly involved in its genesis, nor do they have a part in its implementation.*
>
> 1. *Could the opinion of consumers be sought as part of an attempt to decide what the concept of quality should subsume?*

2. *Could consumers be included, at least, as a source of information about process and outcomes of care?*
3. *When assessing the way a practice is organized, is it important to know whether there are informal and formal mechanisms of 'consumer participation', and of what kind and to what end?*

(Donabedian 1986)

Patient-centred shared care needs patient's involvement in audit?

Perhaps the best starting point for interface audit would be to seek patients' help in setting it up; to recruit and train current patients as auditors; and see then what they reported!

- ***Audit of shared care can start with traditional audit of its constituents, such as teamwork and clinical outcomes.***
- ***The challenge now is to audit the interface.***
- ***The use of knowledge-based computer systems and guidelines will allow the audit of decisions before they are taken (concurrent or real-time audit).***
- ***This could produce rapid learning and behaviour change.***
- ***Retrospective audit of outcomes and linking them to the decision processes could refine these processes and the guidelines, and build up a knowledge base.***
- ***Patient involvement in audit is difficult to achieve, but is essential for patient-centred care.***

Chapter 21

A BALANCE OF BENEFIT AND COST AND THE WAY FORWARD

When is shared care appropriate?

Shared care schemes cannot be regarded as a universal panacea. Shifting care of patients from secondary to primary care, or setting up shared care, requires a transfer of knowledge, skills, attitudes, technology and resources. If the patient is transferred without these accompaniments, care could easily get worse, and this has been recorded (Day *et al.* 1987 and Hayes and Harries 1984). For shared care, the communication of information, by many channels is essential, but methods that are easy to use and have built-in safeguards have the best prospect of success.

Shared care can, in general, offer substantial benefits and opportunities, such as:

- keeping the patient nearer to home
- sharing the problem, rather than shifting the patient
- providing an opportunity for specialist input, and flow of knowledge and technology into general practice (and *vice versa*)
- encouraging the application of guidelines, computer-assisted shared care and knowledge-based decision support
- improving the quality of patient care
- improving communication between primary and specialist care professionals
- involving the patient more closely in the care process
- potential for saving some of the cost of transferred care

Disadvantages and costs of shared care are difficult to predict accurately. As outlined in earlier chapters, shared care is difficult to achieve, and requires a high level of competency in both settings. Raising the level of managerial and technical competency in general practice to that of the best, is already a high priority, not just for shared care. The pay-off would reflect on the effectiveness of the NHS as a whole. The cost of doing this, against a background of past neglect would be heavy, but a good start has been made. Most general practices are computerized, more than in any other country.

The next step would be the universal use of compatible electronic patient records, with facilities for automatic and focused audit. This would make electronic communication between hospital and general practice much easier and more effective.

Video consulting is a new initiative, which for a relatively small outlay, could revolutionize the referral process and the sharing of care and knowledge. Fundholding practices, and patients, might find it a very attractive option.

The development of guidelines and knowledge-based decision support could be next. This would also be a major investment, but with the potential for far greater savings, for example in prescribing costs.

Retrospective audit is proving difficult to implement over a wide field. Concurrent audit should have a rapid and beneficial effect on the technical quality of patient care, which would be reflected in improved outcomes. It could also provide a much more rapid learning process. Outcomes could be audited retrospectively, as outlined earlier, with a consequent refining of guidelines and building up a reliable knowledge base based on actual practice. This could fill some of the major gaps in evidence where randomized controlled trials are inappropriate or take too long.

As outlined in Chapters 14 and 15, effective team working and achieving a shared understanding are essential for shared care. This requires commitment and hard work, and might need a major investment in team development and conceptual modelling, or other ways of achieving a climate more favourable to change and learning.

With medicine and the provision of health care in such a rapid state of change, prediction is difficult. Medicine is advancing so fast, that specialists have to narrow their fields of interest. That option is not open to the general practitioner, so other ways of maintaining competency must be explored. The way forward is more to select promising initiatives to improve the effectiveness of primary and shared care; and to pilot and follow them through if they work. Different methods might be needed in different domains of shared care, to reflect their very different nature.

REFERENCES

◆

Adam, Barbara. *Time and Social Theory*. Cambridge: Polity Press, 1990 (Chapter 5).

Addington-Hall JM, MacDonald LD, Anderson HR, *et al.* Randomised controlled trial of effects of coordinating care for terminally ill cancer patients. *British Medical Journal* 1992;**305**:1317–22.

Ajayi V, Miskelly FG, Walton IG. The NHS and Community Care Act 1990: is it a success for elderly people? *British Medical Journal* 1995;**310**:439.

Allsop J. *Changing primary care: the role of facilitators.* London: King's Fund Centre, 1990.

Anon. Diabetes care and research in Europe: The St Vincent Declaration. *Diabetic Medicine* 1990;**7**:360.

Anon. New trials in older hypertensives. *Lancet* 1991;**338**:1299–1300.

Anthony J. Improving antenatal care: the role of an antenatal assessment unit. *Health Trends* 1992;**24**:123–5.

Argyle M, Salter V, Nicholson H *et al.* The communication of inferior and superior attitudes by verbal and non-verbal signals. *British Journal of Social and Clinical Psychology* 1970;**9**:221–31.

Argyle M. *The psychology of interpersonal behaviour, 4th edn*. London: Penguin Books, 1983:Chapter 2.

Argyris C. *On organizational learning*. Cambridge, Mass: Blackwell, 1992.

Armstrong D. *Factors that precipitate referral.* In: Hopkins A, Wallace P (Eds). *Referrals to medical outpatients*. London: Royal College of Physicians, 1992:25–32.

Aszkenasy OM, Dawson D, Gill M, *et al.* Audit of direct access cardiac investigations: experience in an inner London health district. *Journal of the Royal Society of Medicine* 1994;**87**:588–90.

Axon ATR, Bell GD, Jones RH, *et al*. Guidelines on appropriate indications for upper gastrointestinal endoscopy. *British Medical Journal* 1995;**310**:853–6.

Bailey JJ, Black ME, Wilkin D. Specialist outreach clinics in general practice. *British Medical Journal* 1994;**308**:1083–6.

Bainbridge MA, Cowley C. *Measuring health gain in patients; an integrated approach*. In: Richards B (Ed). *Current perspectives in health care computing.* British Journal of Healthcare Computing Books, 1992:32–38.

Baker R. What is interface audit? *Journal of the Royal Society of Medicine* 1994;**87**:228–31.

Barley S. *The literature of general practice*. In: Westcott R, Jones RVH (Eds). *Information handling in general practice*. London: Croom Helm, 1988.

Barnes GR. Nurse-run hypertension clinics. *Journal of the Royal College of General Practitioners* 1983;**33**:820–1.

Barnett GO, Winickoff R, Dorsey JL, *et al.* Quality assurance through automated monitoring and concurrent feedback using a computer-based medical information system. *Medical Care* 1978;**16**:962–970.

Barritt PW, Staples B. Measuring success in asthma care: a repeat audit. *British Journal of General Practice* 1991;**41**:232–36.

Bean WB. *Aphorisms. From Sir William Osler's bedside teachings and writings.* Springfield Ill. Charles C. Thomas, 1951.

Beard K, Bulpitt C, Mascie-Taylor H *et al.* Management of elderly hypertensive patients with sustained hypertension. *British Medical Journal* 1992;**304**:412–6.

Beckhard R. Organizational issues in team delivery of health care. *Milbank Memorial Quarterly* 1972;**50**:287–316.

Beckhard R, Pritchard W. *Changing the essence. The art of creating and leading fundamental change in organizations.* San Francisco: Jossey-Bass, 1992.

Beckhard R, Harris RT. *Organizational transitions: managing complex change.* Reading, Mass: Addison-Wesley, 1977.

Belbin M. *Management teams: why they succeed or fail.* Oxford: Heinemann, 1981.

Benett IJ, Lambert C, Hinds G, Kirton C. Emerging standards for diabetes care from a city-wide primary care audit. *Diabetic Medicine* 1994;**11**:489–492.

Bennett M, Alison D, Simpson K. Care of dying patients in hospitals. Palliative care teams have helped. *British Medical Journal* 1994;**309**:1017.

Berwick DM. Heal thyself or heal thy system: can doctors help to improve medical care? *Quality in Health Care* 1992;**1**:Supplement 2–8.

Birkhead JS. Time delays in provision of thrombolytic treatment in six district hospitals. *British Medical Journal* 1992;**305**:445–8.

Blyth AC. Audit of terminal care in a general practice. *British Medical Journal* 1990;**300**:983–6.

Bradlow J, Coulter A, Brooks P. *Patterns of referral. A study of referrals to outpatient clinics from general practices in the Oxford Region.* Oxford: Health Services Research Unit, 1992.

Bradshaw C, Spencer J. Nurse-run diabetic clinics in general practice. *Diabetic Medicine* 1990;**7**:572–3.

Bramble MG, Cooke WM, Corbett WA *et al.* Organising unrestricted open access gastroscopy in South Tees. *Gut* 1992;**34**:422–7.

British Heart Foundation Working Group. Role of the general practitioner in managing patients with myocardial infarction: impact of thrombolytic treatment. *British Medical Journal* 1989;**299**:555–7.

British Thoracic Society, Research Unit of the Royal College of Physicians of London, King's Fund Centre, National Asthma Campaign. Guidelines for the management of asthma in adults.

I. Chronic persistent asthma. *British Medical Journal* 1990;**301**:651–4.

II. Acute severe asthma. *British Medical Journal* 1990;**301**:797–800.

British Thoracic Society and others. Guidelines for the management of asthma: a summary. *British Medical Journal* 1993;**306**:776–82.

Brook RH. Practice guidelines and practising medicine, are they compatible? *J Am Med Assoc.* 1989;**262**(21):3027–3030.

Brown DJ. Opinions of general practitioners in Nottinghamshire about provision of intrapartum care. *British Medical Journal* 1994;**309**:777–9.

Brown KGE. Integrated district care based in a diabetes centre. *Diabetic Medicine* 1987;**4**:330–2.

Brown P, Gordon P. *Cumberlege in action. A directory of good practice that influenced the Community Nursing Review Team.* London, King's Fund Centre, 1987.

Bruce N. *Teamwork for prevention.* Chichester: John Wiley, 1980.

Bryce FP, Neville RG, Crombie IK *et al.* Controlled trial of an audit facilitator in diagnosis and treatment of childhood asthma in general practice. *British Medical Journal* 1995;**310**:838–42.

Bull M. GP obstetrics: making the most of shared care. *The Practitioner* 1989;**233**:211–5.

Bull MJV. General practitioner obstetrics: is there a future? *Update* 1988;October 1:599–605.

Bull M. Ten years' experience in a general practitioner obstetric unit. *Journal of the Royal College of General Practitioners* 1980;**30**:208–15.

Burnett SD, Woolf CM, Yudkin JS. Developing a district diabetic register. *British Medical Journal* 1992;**305**:627–30.

Burney PGJ. Strategy for asthma. *British Medical Journal* 1991;**303**:571–3.

Byrne PS, Long B. *Doctors talking to patients: a study of the verbal behaviour of general practitioners consulting in their surgeries.* London: HMSO, 1976.

Campbell R, Macfarlane A, Cavenagh S. Choice and chance in low risk maternity care. *British Medical Journal* 1991;**303**:1487–8.

Carlson A. *Reforming diabetes care in general practice. Evaluation of two strategies for the development of the organisation and quality of care.* Stockholm, Dept Endocrinology Karolinska Institute, Dept Psychology Stockholm University, WHO Collaborating Centre for Diabetes in Primary Care and its Evaluation, 1990.

Carlson A, Rosenqvist U. Locally developed plans for quality diabetes care: worker and consumer participation in the public health care system. *Health Education Research* 1990;**5**(1):41–52.

Cartwright A (1991a). The relationship between general practitioners, hospital consultants and community nurses when caring for people in the last year of their lives. *Family Practice* 1991;**8**(4):350–5.

Cartwright A (1991b). Balance of care for the dying between hospitals and the community: perceptions of general practitioners, hospital consultants, community nurses and relatives. *British Journal of General Practice* 1991;**41**:271–4.

Cartwright A, Seale C. *The natural history of a survey: an account of the methodological issues encountered in a study of life before death.* London: King's Fund, 1990.

Chalmers I, Dickersen K, Chalmers TC. Getting to grips with Archie Cochrane's agenda. All randomised controlled trials should be registered and reported. *British Medical Journal* 1992;**305**:786–8.

Chalmers I, Enkin M, Keirse MJN (Eds). *Effective care in pregnancy and childbirth. Volume 1.* Oxford: Oxford University Press, 1989.

Chaplin J. Helping villagers to improve their health. *Community Health Action* 1993;**30**:10–13.

Charlton I, Charlton G, Broomfield J, Mullee M. Audit of the effect of a nurse run asthma clinic on workload and patient morbidity in general practice. *British Journal of General Practice* 1991;**41**:227–31.

Charlton I, Antoniou AG, Atkinson J et al. Asthma at the interface: bridging the gap between general practice and district general hospital. *Archives of Disease in Childhood* 1994;**70**:313–8.

Clarke KW, Gray D, Hampton JR. Evidence of inadequate investigation and treatment of patients with heart failure. *British Heart Journal* 1994;**71**:584–7.

Clinical Standards Advisory Group. *Standards of clinical care for people with diabetes*. London: HMSO, 1994.

Clode D. Slamming on the brakes. *Community Care* 1992;3 December:?.

Cochrane Collaboration. *Pregnancy and Childbirth Database*. Floppy disk and manual No 1, 1994. Oxford, The Cochrane Collaboration.

Colquhoun MC. General practitioners and the treatment of myocardial infarction: the place of thrombolytic treatment. *British Heart Journal* 1993;**70**:215–7.

Colver AF. Health surveillance of pre-school children: four years' experience. *British Medical Journal* 1990;**300**:1246–8.

Coulter A. *Auditing referrals*. In: Roland M, Coulter A (Eds). *Hospital referrals*. Oxford: Oxford University Press, 1992;156–8.

Court C. Rising emergency admissions disrupt NHS. *British Medical Journal* 1994:**309**;132.

Covell DG, Uman GC, Manning PR. Information needs in office practice. Are they being met? *Annals of Internal Med* 1985;**103**:596–9.

Cripwell M, Patterson D. *Chronic heart failure*. In: Haines A, Hurwitz B. *Clinical guidelines. Report of a local initiative*. Occasional paper 58. London: Royal College of General Practitioners, 1992.

Cupples ME, McKnight A. Randomised controlled trial of health promotion in general practice for patients at high cardiovascular risk. *British Medical Journal* 1994;**309**:993–6.

Dalley G. *Professional ideology or organizational tribalism. The health service—social work divide*. In: Taylor R, Ford J (Eds). *Social work and health care*. London: Jessica Kingsley, 1989.

Danhlof B, Lindholm LH, Hanson L, *et al.* Morbidity and mortality in the Swedish trial in old patients with hypertension (STOP-Hypertension). *Lancet* 1991;**338**:1281–5.

Dargie HJ, McMurray JJV. Diagnosis and management of heart failure. *British Medical Journal* 1994;**308**:321–8.

Darkins A. A community-oriented approach to managing acute stroke patients in West London. *London Monitor* 1995;**2**:54–7.

Davenport PM, Morgan AG, Darnborough A, *et al.* Can preliminary screening of dyspeptic patients allow more effective use of investigational techniques? *British Medical Journal* 1985;**290**:217–20.

Day JL, Humphries H, Alban-Davies H. Problems of comprehensive shared diabetes care. *British Medical Journal* 1987;**294**:1590–1592.

Day JL, Johnson P, Rayman G, *et al.* The feasibility of an 'Ideal' system of integrated diabetes care and education based on a day centre. *Diabetic Medicine* 1988;**5**:70–5.

Day JL, Spathis M. District Diabetes Centres in the UK. *Diabetic Medicine* 1988;**5**:372–80.

de Dombal T. *Aids to diagnosis—an impertinent look at some pertinent questions.* In: Westcott R, Jones RVH (Eds). *Information handling in general practice.* London: Croom Helm, 1988.

De Bono DP, Hopkins A. The investigation and management of stable angina. Report of a working party of the Joint Audit Committee of the British Cardiac Society and the Royal College of Physicians of London. *Journal of the Royal College of Physicians of London* 1993;**27**(3):267–73.

Del Mar C, Siskind V, Acworth J, *et al.* Shared antenatal care in Brisbane. *Australia and New Zealand Journal of Obstetrics and Gynaecology* 1991;**31**:305–6.

Dennis M, Langhorne P. So stroke units save lives: where do we go from here? *British Medical Journal* 1994;**309**:1273–7.

Dennis M, Warlow C. Strategy for stroke. *British Medical Journal* 1991;**303**:636–8.

Department of Health and Social Security Standing Maternity and Midwifery Advisory Committee. *Domiciliary midwifery and maternity bed needs: report of the subcommittee.* London: HMSO, 1970.

Department of Health (DoH 1989a). *Caring for people.* London: HMSO, 1989.

Department of Health (DoH 1989b). *Discharge of patients from hospital.* Health Circular (89)5. London, DoH, 1989.

Department of Health (DoH 1992). *The health of the nation: a strategy for health in England.* London: HMSO, Cm 1986, 1992.

Department of Health (DoH 1993a). *The health of the nation. Key area handbook. Coronary heart disease and stroke.* London: Department of Health, 1993a.

Department of Health (DoH 1993b). *Changing childbirth. Part 1 Report of the Expert Maternity Group.* London: HMSO, 1993.

Department of Health (DoH 1994a). *Statistics for General Medical Practitioners in England and Wales 1983-1993.* Statistical Bulletin 1994/4. London, DoH, 1994.

Department of Health (DoH 1994b). *Hospital discharge workbook: a manual on hospital discharge policy and practice.* London, DoH, 1994.

Department of Health (DoH 1994c). *Implementing caring for people. The role of the GP and the primary health care team.* London, DoH, 1994.

Department of Health (DoH 1994d). *How you can help to improve the Health of the Nation. An introductory booklet for the primary health care team.* London: Department of Health, 1994.

DHSS Hypertension Care Computing Project. A comparison of blood pressure control in hypertensive patients treated in hospital clinics and general practice. *Journal of the Royal College of General Practitioners* 1982;**32**:98–102.

Diabetes Integrated Care Evaluation Team. Integrated care for diabetes: clinical, psychosocial and economic evaluation. *British Medical Journal* 1994;**308**:1208–12.

Dillner L. Maternity services: the shaping of things to come. *British Medical Journal* 1991;**302**:1198–200.

Dixon S. *Contracting for services in the management of asthma.* Occasional Paper 6. York, University of York, York Health Economics Consortium, 1993.

Donabedian A. *Impressions of a journey in Britain*. In: Pendleton D, Schofield T, Marinker M (Eds). *In pursuit of quality*. London: Royal College of General Practitioners, 1986;181.

Drife JO. Assessing the consequences of changing childbirth. *British Medical Journal* 1995;**310**:144.

Duncan M, Ritchie L, Jamieson D, Donaldson L. Stroke units. *British Medical Journal* 1995;**310**:193–4.

Eccles M, Deverill M, McColl E, *et al*. *Interface audit final report*. Newcastle upon Tyne: Centre for Health Services Research, 1994.

Eddy DM. Practice policies: guidelines for methods. *Journal of the American Medical Association* 1990;**263**:1839–1841.

Eddy DM. *A manual for assessing health practices and designing practice policies. The explicit approach*. Philadelphia: The American College of Physicians, 1992;5.

Effective Health Care Project. *Implementing clinical practice guidelines*. Effective Health Care Bulletin No 8. University of Leeds, 1994, page 2.

Elbourne D, Richardson M, Chalmers I, *et al*. The Newbury Maternity Care Study: a randomised controlled trial to assess a policy of women holding their own obstetric records. *British Journal of Obstetrics and Gynaecology* 1987;**94**:612–9.

English National Board. *Post-registration courses. Opportunities for continuing education*. London: English National Board, 1994.

Essex B, Doig R, Renshaw J. A pilot study of records of shared care for people with mental illnesses. *British Medical Journal* 1990;**300**:1442–6.

Ezedum S, Kerr DNS. Collaborative care of hypertensives, using a shared record. *British Medical Journal* 1977;**2**:1402–3.

Fahey T, Silagy C. General practitioners' knowledge of and attitudes to the management of hypertension in elderly patients. *British Journal of General Practice* 1994;**44**:446–9.

Family Heart Study Group. Randomised controlled trial evaluating cardiovascular screening and intervention in general practice: principal results of British family heart study. *British Medical Journal* 1994;**308**:313–20.

Farmer A, Coulter A. Organisation of care for diabetic patients in general practice: influence on hospital admissions.*British Journal of General Practice* 1990;**40**:56–8.

Fawdry R. Antenatal care: a consultant's comments. *The Practitioner* 1990;**234**:352–6.

Ferguson G. The New Brunswick Extra-mural Hospital. A Canadian Hospital at Home. *Journal of Public Health Policy* 1987;**8**(4):561–70.

Field D, James N. Where and how people die. In: Clark D (Ed). *The future for palliative care. Issues of policy and practice*. Buckingham: Open University Press, 1993.

Field MJ, Lohr KL (Eds). *Clinical practice guidelines. Directions for a new program*. Washington DC: National Academy Press, 1990;27.

Field S, Draper J, Thomas H, *et al*. Community antenatal care—a local study. *Health Trends* 1984;**16**:64–6.

Flint C. Name, set and match. *Health Service Journal* 1992;23 July:26.

Flook C. Women-centred antenatal care. *Nursing Times* 1992;**88**(9):62–3.

Flugelman AA, Baharir Z, Lewis BS, *et al.* An integrated model of cardiological consultation and primary care medicine. *British Journal of General Practice* 1990;**40**:259.

Foulkes A, Kinmonth A-L, Frost S, MacDonald D. Organised personal care: an effective choice for managing diabetes in general practice. *Journal of the Royal College of General Practitioners* 1989;**39**: 444–7.

Fox J, Glowinski A, Gordon C, *et al.* Logic engineering for knowledge engineering: design and implementation of the Oxford System of Medicine. *Artificial Intelligence in Medicine* 1990;**2**:323–329.

Francis CM, Caruana L, Kearney P, *et al.* Open access echocardiography in management of heart failure in the community. *British Medical Journal* 1995;**310**:634–6.

Freemantle N, Pollock C, Sheldon TA, *et al.* Formal rehabilitation after stroke. *Quality in Health Care* 1992;**1**:134–7.

Fry J. *General practice and primary health care 1940s–1980s.* London: Nuffield Provincial Hospitals Trust, 1988;2–3.

Fry J, Horder J. *Primary health care in an international context.* London: Nuffield Provincial Hospitals Trust, 1994;22–3.

Fullard E, Fowler G, Gray MJ. Facilitating prevention in primary care. *British Medical Journal* 1984;**289**:1585–7.

Gear MWL, Wilkinson SP. Open-access upper alimentary endoscopy. *British Journal of Hospital Medicine* 1989;**41**:438–44.

Gellert AR, Gellert SL, Iliffe SR. Prevalence and management of asthma in a London inner city general practice. *British Journal of General Practice* 1990;**40**:197–201.

General Medical Services Committee (GMSC). *The new health promotion package.* London: British Medical Association, 1993.

Gilmore M, Bruce N, Hunt M. *The work of the nursing team in general practice.* London: Central Council for the Education and Training of Health Visitors (now ENB), 1974;5–6.

Ginzler M, Pritchard P, Mant D. Delay in diagnosing and treating cancer 1 and 2. *Oncology in Practice* 1992;**1**:6–13 and 1993;**1**:4–10.

Glowinski A. In: Gordon C, Christensen JP (Eds). *Health telematics for clinical guidelines and protocols.* Amsterdam; IOS Press, 1995;207–218.

Göranzon B. *The Practical Intellect. Computers and skills.* Berlin: Springer-Verlag, 1993.

Göranzon B, Josefson I. *Knowledge, skill and artificial intelligence.* Berlin: Springer-Verlag, 1988.

Gordon C. Supporting acts. Primary care decision support. *British Journal of Healthcare Computing* 1991;29–30.

Gordon C, *et al.* DILEMMA: logic engineering in primary care, shared care and oncology. *Journal of Informatics in Primary Care* 1993;**July**:9.

Gordon C, Christensen JP (Eds). *Health telematics for clinical guidelines and protocols.* Amsterdam: IOS Press, 1995;3–16.

GRASSIC. Grampian Asthma Study of Integrated Care. Integrated care for asthma: a clinical, social and economic evaluation. *British Medical Journal* 1994;**308**:559–64.

GREAT Group. Feasibility, safety and efficacy of domiciliary thrombolysis by general practitioners: Grampian region early antistreplase trial. *British Medical Journal* 1992;**305**:548–53.

Green F, Lord J. Prescribing exercise in general practice. *British Medical Journal* 1994;**309**:872–3.

Greenhalgh PM. *Shared care for diabetes. A systematic review.* Occasional paper 67. London, Royal College of General Practitioners, 1994.

Greenwood J. Persuading general practitioners to prescribe—good husbandry or recipe for chaos? *British Journal of Addiction* 1992;**87**: 567–75.

Greenwood RJ, McMillan TM, Brooks DN, *et al.* Effects of case management after severe head injury. *British Medical Journal* 1994;**308**:1199–205.

Greveson GC, Gray CS, French JM, James OFW. Long-term outcome for patients and carers following hospital admission for stroke. *Age and Ageing* 1991;**20**:337–344.

Greveson G, James O. Improving long-term outcome after stroke—the views of patients and carers. *Health Trends* 1991;**23**:161–2.

Grimshaw JM, Russell IT. Effect of clinical guidelines on medical practice: a systematic review of rigorous evaluations. *Lancet* 1993;**342**:1317–22.

Grol R. National standard setting for quality of care in general practice: attitudes of general practitioners and response to a set of standards. *British Journal of General Practice* 1990;**40**:361–364.

Haines A, Booroff A. Terminal care at home. *British Medical Journal* 1986;**292**:1051–3.

Haines A, Patterson D, Rayner M, *et al. Prevention of cardiovascular disease.* In: Haines A, Hurwitz B. *Clinical guidelines. Report of a local initiative.* Occasional paper 58. London: Royal College of General Practitioners, 1992.

Hall MH, Chng PK, MacGillivray I. Is routine antenatal care worthwhile? *Lancet* 1980;**2**:78–80.

Hallam L. Organization of telephone services and patients' access to doctors by telephone in general practice. *British Medical Journal* 1991;**302**:629–632.

Hallissey MT, Allum WH, Jewkes AJ, *et al.* Early detection of gastric cancer. *British Medical Journal* 1990;**301**:513–5.

Halloran J. Shared obstetric care and the general practitioner. *The Medical Journal of Australia* 1991;**155**:614–6.

Halloran J, Gunn J, Young D. Shared obstetric care: the general practitioner's perspective. *Australia and New Zealand Journal of Obstetrics and Gynaecology* 1992;**32**:301–5.

Hampton JR, Barlow AR. Open access. *British Medical Journal* 1995;**310**:611–2.

Harding J. Study of discharge communications from hospital doctors to an inner London general practice. *Journal of the Royal College of General Practitioners* 1987;**37**:494–5.

Harris TA, Harris A. *Staying OK.* London: Pan Books, 1986.

Harrison A, Prentice S. *Maternity services.* In: Harrison A, Bruscini S (Eds). *Health Care UK 1992/93.* London: King's Fund Institute, 1993.

Harrison BDW, Partridge MR. Health of the nation. *British Medical Journal* 1991;**303**:1059.

Hartog M. Medical outpatients. *Journal of the Royal College of Physicians.* 1988;**22**:51.

Hasler J. *The Primary Health Care Team.* London: Royal Society of Medicine Press, 1994.

Hayes TM, Harries J. Randomized controlled trial of routine hospital care versus routine general practice care for type II diabetics. *British Medical Journal* 1984;**289**:728–739.

Haynes RB. *How clinical journals could serve readers better.* In: S Lock (Ed). *The future of medical journals.* London: British Medical Journal, 1991.

Heatley RV. Open access upper gastrointestinal endoscopy. *British Medical Journal* 1993;**306**:1224.

Heller T. *The Heeley Health Project.* In: Heritage Z. *Community participation in primary care.* Occasional paper 64. London: Royal College of General Practitioners, 1994.

Henwood M. Hospital discharge. Going by the book. *Health Service Journal* 1994; 31 March:22–4.

Henwood M, Wistow G. *Hospital discharge and community care: early days.* Leeds, Nuffield Institute for Health, 1993.

Heritage Z. *Community participation in primary care.* Occasional paper 64. London: Royal College of General Practitioners, 1994.

Hickman M, Drummond N, Grimshaw J. *Operation of shared care schemes: a postal survey of Scotland and North West Thames Regional Health Authority, England.* Report No 4. Aberdeen: University of Aberdeen Health Services Research Unit, Sept 1992.

Hickman M, Drummond N, Grimshaw J. A taxonomy of shared care for chronic disease. *Journal of Public Health Medicine* 1994;**16**:447–454.

Higgins R, Oldman C, Hunter DJ. *'Let's work together!' Lessons for collaboration between health and social services.* Leeds: Nuffield Institute for Health, 1993.

Higgins R, Oldman C, Hunter D. Union Trouble. *Health Service Journal* 1994;**26 May**:24–5.

Higginson I. Advanced cancer: aiming for the best in care. *Quality in Health Care* 1993;**2**:112–6.

Higginson I, Wade A, McCarthy M. Palliative care: views of patients and their families. *British Medical Journal* 1990;**301**:277–81.

Hill AM, Yudkin PL, Bull DJ, *et al.* Evaluating a policy of reduced consultant antenatal clinic visits for low risk multiparous women. *Quality in Health Care* 1993;**2**:152–6.

Hill RD. Community care service for diabetics in the Poole area. *British Medical Journal* 1976;**1**:1137–9.

Hoddinott D, Royston S. Managing community care: working with GPs in East Sussex. *Primary Health Care Management* 1991;1(5):6–7.

Hoffbrand B, Ross M. Hypertension. In Haines A, Hurwitz B. *Clinical guidelines. Report of a local initiative.* Occasional paper 58. London, Royal College of General Practitioners, 1992.

Holdstock G, Wiseman M, Loehry CA. Open access endoscopy service for general practitioners. *British Medical Journal* 1979;**i**:457–9.

Holley A, Evans T. *Asthma care in Camberwell health district 1989–1991.* London, Camberwell Primary Care Development Project, Department of

General Practice and Primary Care, King's College School of Medicine and Dentistry, 1992.

Hopkins A, Wallace P (Eds). *Referrals to medical outpatients.* London: Royal College of Physicians, 1992.

House of Commons Health Committee. *Maternity care.* Second Report Session 1991–2. Vol I. London: HMSO, 1992a.

House of Commons Health Committee. *Maternity care.* Second Report Session 1991–2. Vol II. Minutes of evidence. London: HMSO, 1992b.

House of Commons Health Committee. *Maternity care.* Second Report Session 1991–2. Vol III. Appendices to the minutes of evidence. London: HMSO, 1992c.

House of Commons Health Committee. *Community care: the way forward.* Health Committee sixth report. London, HMSO, 1993.

Howitt AJ, Cheales NA. Diabetes registers: a grassroots approach. *British Medical Journal* 1993;**307**:1046–8.

Hudson B. Breaks in the chain. *Health Service Journal* 1994;**21** Apr:24–6.

Hughes J, Gordon P. *An optimal balance? Primary Health Care and Acute Hospital Services in London.* London: King's Fund Acute Services Initiative, 1992.

Hull R, Ellis M, Sargeant V. *Teamwork in palliative care. A multidisciplinary approach to the care of patients with advanced cancer.* Oxford: Radcliffe Medical Press, 1989.

Humphrey C, Hughes J. *Audit and development in primary care.* London: King's Fund Centre, 1992.

Hundley VA, Cruickshank FM, Lang GD, *et al.* Midwife managed delivery unit: a randomised controlled comparison with consultant led care. *British Medical Journal* 1994;**309**:1400–4.

Hungin APS, Thomas PR, Bramble MG, *et al.* What happens to patients following open access gastroscopy? An outcome study from general practice. *British Journal of General Practice* 1994;**44**:519–21.

Hunter DJ, Wistow G. *Elderly people's integrated care system (EPICS).* An organisational, policy and practice review. Leeds, Nuffield Institute for Health Service Studies, 1990.

Hurwitz B, Goodman C, Yudkin J. Prompting the clinical care of non-insulin dependent (type II) diabetic patients in an inner city area: one model of community care. *British Medical Journal* 1993;**306**:624–30.

Hurwitz B, Yudkin J. *Shared Care.* Chapter 10. In: Tattersall RB, Gale EAM. *Diabetes: Clinical Management.* Edinburgh: Churchill Livingstone, 1990.

ICRF (Imperial Cancer Research Fund) OXCHECK Study Group. Effectiveness of health checks conducted by nurses in primary care: results of the OXCHECK study after one year. *British Medical Journal* 1994;**308**:308–12.

Iliffe S, See Tai S, Gould M, *et al.* Prescribing exercise in general practice. *British Medical Journal* 1994;**309**:494–5.

Jennett P, Swanson W, Watanabe M. *Remote consultative network.* Proceedings of the First International Conference on Telemedicine, Tromsø, Norway: University of Tromsø, May 1993.

Jewell D, Hope J. Evaluation of a nurse-run hypertension clinic in general practice. *The Practitioner* 1988;**232**:484–7.

Johnson IS, Rogers C, Biswas B, *et al.* What do hospices do? A survey of hospices in the United Kingdom and Republic of Ireland. *British Medical Journal* 1990;**300**:791–3.

Jones JN, Marsden P. Improved diabetes care in a UK health district. *Diabetic Medicine* 1992;**9**:176–180.

Jones K. Asthma—still a challenge for general practice. *Journal of the Royal College of General Practitioners* 1989;**39**:254–6.

Jones K. Asthma care in general practice—time for a revolution? *British Journal of General Practice* 1991;**41**:224–6.

Jones KP, Charlton IH, Middleton M, *et al.* Targetting asthma care in general practice using a morbidity index. *British Medical Journal* 1992;**304**:1353–6.

Jones RVH. Teams and terminal cancer care at home: do patients and carers benefit? *Journal of Interprofessional Care* 1993;7:239–244.

Jones RVH, Dudgeon TA. Time between presentation and treatment of six common cancers; a study in Devon. *British Journal of General Practice* 1992;**42**:419–22.

Jones RHV, Hansford J, Fiske J. Death from cancer at home: the carers' perspective. *British Medical Journal* 1993;**306**:249–51.

Jones R. Endoscopy in general practice. *British Medical Journal* 1995;310:816–7.

Julian D. Thrombolysis, the general practitioner and the electrocardiogram. *British Heart Journal* 1994;72:220–1.

Jung RT, Scott A, Chony P, *et al.* A new PICK-based computer thyroid register based on the national SAFUR requirements for local usage. *Health Bulletin* 1991;**49**:244–8.

Kanouse DE, Winkler JD, Kosecoff J. *Changing medical practice through technology assessment. An evaluation of the North American Consensus Development Program.* Ann Arbor, Michigan: Health Administration Press, 1989.

Kanter RM, Stein BA, Jick TD. *The challenge of organizational change.* New York: The Free Press, 1992.

Kay C. Management of myocardial infarction in the community: a new RCGP study. *British Journal of General Practice* 1991;**41**:89–92.

Kenkre J, Drury VWM, Lancashire RJ. Nurse management of hypertension clinics in general practice assisted by a computer. *Family Practice* 1985;2:17–22.

Kerrigan DD, Brown SR, Hutchinson GH. Open access gastroscopy: too much to swallow? *British Medical Journal* 1990;**300**:374–6.

King's Fund Consensus Conference. Treatment of stroke. *British Medical Journal* 1988;**297**:126–8.

King's Fund Organizational Audit (KFOA). *Organizational Audit: Primary Health Care Manual.* London: King's Fund College, 1994.

Kings Fund Organizational audit. London, *King's Fund News* 1994;**17** (Autumn):1–9.

Kinmonth A-L, Marteau T. Doctors' beliefs and the management of insulin dependent diabetes: implications for sharing care. *Family Practice* 1989;**6**:193–8.

Kinmonth A-L. Diabetic care in general practice. *British Medical Journal* 1993;**306**:599–600.

Klein M, Elbourne D, Lloyd I. *Booking for maternity care. A comparison of two systems.* Occasional paper 31. London: Royal College of General Practitioners, 1985.

Klein M, Lloyd I, Redman C, *et al.* A comparison of low risk pregnant women booked for delivery in two systems of care: shared care (consultant) and integrated general practice unit. I. Obstetrical procedures and neonatal outcome. *British Journal of Obstetrics and Gynaecology* 1983a;**90**:118–122. and II. Labour and delivery management and neonatal outcome. (*ibid*) 1983b;**90**:123–8.

Knight S, Gann R. *The Self-Help Guide. A directory of self-help organizations in the United Kingdom.* London: Chapman and Hall Medical, 1988.

Kvist M. *Telephone contacts in Finnish urban general practice.* Turku: Annales Universitatis Turkuensis, No 71, 1991.

Laing W, Williams R. *Diabetes. A model for health care management.* London, Office of Health Economics, 1989.

Langhorne P, Williams BO, Gilchrist W, *et al.* Do stroke units save lives? *Lancet* 1993;**342**:395–8.

Lawrence M, Schofield T. *Medical audit in primary health care.* Oxford: Oxford University Press, 1993.

Lawrence M. Audit and TQM in diabetic care in general practice. *Quality in Health Care* 1992;**1** supplement:s20–1.

Levy M, Hilton S. *Asthma in practice.* London, Royal College of General Practitioners, 1992.

Lewis R, Castleton B. Across the great divide. *Health Service Journal* 1992;**30 April**:31–4.

Ley P. *Communicating with patients: improving communication, satisfaction and compliance.* London: Croom Helm, 1988.

Lieberman S. It can be done. *Community Care* 1990;**6 Dec**:26–8.

Lincoln NB. Is stroke better managed in the community? Only hospitals can provide the required skills. *British Medical Journal* 1994;**309**:1357–8.

Lloyd M, Webb S, Singh S. Community care reforms: early implications for general practice. *British Journal of General Practice* 1994;**44**:338–9.

Lock S. *The future of medical journals.* London: British Medical Journal 1991:2–3.

Lothian Hypertension Group. Guidelines on the management of hypertension in general practice—detection and assessment of hypertension. *Journal of the Royal College of General Practitioners* 1984; **34**:405-7; and: Guidelines on the management of hypertension in general practice—drug treatment of hypertension. *Ibid.* 1984;**34**:460–62.

Lovell A, Elbourne D. Holding the baby and your notes. *Health Service Journal* 1987;**97**:335.

McClements BM, Campbell NPS, Cochrane D, *et al.* Direct access exercise electrocardiography: a new service that improves the menagement of suspected ischaemic heart disease in the community. *British Heart Journal* 1994;**71**:531–5.

McCrea WA, Saltissi S. Electrocardiogram interpretation in general practice: relevance to prehospital thrombolysis. *British Heart Journal* 1993;**70**:219–25.

Macfarlane A, Campbell R. Baby boon. *Health Service Journal* 1994;**8 December**:33.

Macfarlane A, Mugford M, Johnson A, *et al.* *Counting the changes in childbirth: trends and gaps in national statistics.* Oxford: National Perinatal Epidemiology Unit, 1995.

McGhee SM, McInnes GT, Hedley AJ, *et al.* Coordinating and standardizing long-term care: evaluation of the west of Scotland shared care scheme for hypertension. *British Journal of General Practice* 1994;**44**:441–5.

MacKinnon M, Wilson RM, Hardisty CA, Ward JD. Novel role for specialist nurses in managing diabetes in the community. *British Medical Journal* 1989;**299**:552–4.

McIver S. *Obtaining the views of users of primary and community health services.* London: King's Fund Centre, 1993.

McKee I. *Community antenatal care: the Sighthill Community Antenatal Scheme.* In Zander L, Chamberlain G (Eds). *Pregnancy care for the 1980s.* London: Royal Society of Medicine and Macmillan Press, 1984.

MacVicar J, Dobbie G, Owen-Johnstone L, *et al.* Simulated home delivery in hospital: a randomised controlled trial. *British Journal of Obstetrics and Gynaecology* 1993;**100**:316–23.

Malins JM, Stuart JM. Diabetic clinic in a general practice. *British Medical Journal* 1971;**4**:161.

Mann J, Holdstock G, Harman M, *et al.* Scoring system to improve cost effectiveness of open access endoscopy. *British Medical Journal* 1983;**287**:937–40.

Mant D, McKinlay C, Fuller A, *et al.* Three year follow up of patients with raised blood pressure identified at heath checks in general practice. *British Medical Journal* 1989;**298**:1360–2.

Marks L. *Home and hospital care: redrawing the boundaries.* London: King's Fund Institute, Research Report No 9, 1991.

Marks L. *Seamless care or patchwork quilt? Discharging patients from acute hospital care.* Research report no 17. London: King's Fund Institute, 1994.

Marsh GN. New programme of antenatal care in general practice. *British Medical Journal* 1985;**291**:646–8.

Marsh GN. *Efficient care in general practice. Or: how to look after even more patients.* Oxford: Oxford University Press, 1991.

Marshall M, Lockwood A, Gath D. Social services case-management for long-term mental disorders: a randomised controlled trial. *Lancet* 1995;**345**:409–12.

Martys CR. Asthma care in Darley Dale: general practitioner audit. *British Medical Journal* 1992;**304**:758–60.

Maternity Services Advisory Committee. *Maternity care in action. Part I Antenatal care.* First report of the Maternity Services Advisory Committee to the Secretaries of State for Social Services and for Wales (Munro Report). London: HMSO, 1982.

Maternity Services Advisory Committee. *Maternity care in action. Part II Care during childbirth (intrapartum care).* Second report of the Maternity Services Advisory Committee to the Secretaries of State for Social Services and for Wales (Munro Report). London: HMSO, 1984.

Maternity Services Advisory Committee. *Maternity care in action. Part III Care of the mother and baby (postnatal and neonatal care).* Third report of the

Maternity Services Advisory Committee to the Secretaries of State for Social Services and for Wales (Munro Report). London: HMSO, 1985.

Medical Research Council Working Party. MRC trial of treatment of hypertension in older adults: principal results. *British Medical Journal* 1992;**304**:405–12.

Menzies A, Stearn R. The future of asthma management. *Nursing Standard* 1990;**4**(27):24–6.

Mills M, Davies HTO, Macrae WA. Care of dying patients in hospital. *British Medical Journal* 1994;**309**:583–6.

Modell M, Harding J, Horder E, *et al.* Improving the care of asthmatics in general practice. *British Medical Journal* 1983;**286**:2027–30.

Moher M, Johnson M. Use of aspirin by general practitioners in suspected acute myocardial infarction. *British Medical Journal* 1994;**308**:760–1.

Moher M, Moher D, Havelock P. Survey of whether general practitioners carry aspirin in their doctor's bag. *British Medical Journal* 1994;**308**:761–2.

Molander B. *Tacit knowledge and silenced knowledge.* In Göranzon B, Florin M (Eds). *Skills and Education. Reflection and experience.* Berlin: Springer-Verlag, 1992.

Morley V, Evans T, Higgs R, *et al. A case study in developing primary care. The Camberwell report.* London, King's Fund, 1991.

Mowat IG, Morgan RTT. Peterborough Hospital at Home scheme. *British Medical Journal,* 1982;**284**,641–3.

Murphy G, Rodrigues L. Joint assessment for community care in East Sussex. *Primary Health Care Management* 1992;**2**(7):10–11.

Nagle JP, McMahon K, Barbour M, *et al.* Evaluation of the use and usefulness of telephone consultations in general practice. *British Journal of General Practice* 1992;**42**:190–3.

NAHAT. *Care of people with a terminal illness.* Birmingham: National Association of Health Authorities and Trusts, 1991.

NAHAT. *Asthma care—the challenge ahead.* NAHAT Update no. 3. Birmingham, National Association of Health Authorities and Trusts 1994.

Neale B. *Informal care and community care.* In Clark D (Ed). *The future for palliative care. Issues of policy and practice.* Buckingham: Open University Press, 1993.

Neill J, Williams J. *Leaving hospital: elderly people and their discharge to community care.* London, National Institute for Social Work, 1992.

Neville RG, Clark RC, Hoskins G, Smith B for General Practitioners in Asthma Group. National asthma attack audit 1991–2. *British Medical Journal* 1993;**306**:559–62.

NHS Management Executive. *Integrating primary and secondary health care.* London: Department of Health, 1991.

NHS Management Executive. *A study of midwife- and GP-led maternity units.* London: NHSME, 1993.

Nkobi J, Köhler CO, Ellsässer K-H. *Shared care in the near and distant future in Europe.* Report of DILEMMA workshop 5 *Linköping: 3–5 July 1993.*

Nocon A. *Collaboration in community care in the 1990s.* Sunderland: Business Education Publishers Ltd, 1994.

Oakland J. *Total Quality Management: a practical approach*. London: Department of Trade and Industry, 1990.

O'Brien C. Division of labour. *Nursing Times* 1993;**89(14)**:48–50.

Office of Population Censuses and Surveys. *1992 Birth Statistics England and Wales*. Series FM1 no 21. London: HMSO, 1994.

O'Malley K, O'Brien E. Where are the guidelines for treating hypertension in elderly patients? *British Medical Journal* 1992;**305**:845–6.

Oppenheimer C. Organising midwifery led care in the Netherlands. *British Medical Journal* 1993;**307**:1400–2.

Pascale R. *Managing on the edge*. London: Penguin Books, 1991.

Patient's Charter (Jan 1995). London, Department of Health.

Paul VE, Sulke AN, Norris ADC. Open access exercise electrocardiography: does it improve the management of cardiovascular disease in the community? *Journal of the Royal Society of Medicine* 1990;**83**:143–5.

Payne JN, Milner PC, Saul C, *et al*. Local confidential inquiry into avoidable factors in deaths from stroke and hypertensive disease. *British Medical Journal* 1993;**307**:1027–30.

Peachey DK, Linton AL. Guidelines for medical practice: a possible strategy. *Canadian Medical Association Journal* 1990;**143(7)**:629–32.

Pedersen S, Gammon D, Rinde E. Telemedicine: the Norwegian experience. *Journal of Informatics in Primary Care* 1994;**December**:19–20.

Pendleton D, Schofield T, Tate P, Havelock. *The Consultation: an approach to learning and teaching*. Oxford: Oxford University Press, 1984.

Petrie JC, Robb OJ, Webster J, *et al*. Computer assisted shared care in hypertension. *British Medical Journal* 1985;**290**:1960–2.

Petrie JC, Webster J, Jeffers TA, *et al*. Computer assisted shared care: the Aberdeen blood pressure clinic. *Journal of Hypertension* 1989;**7**:s103–8.

Piercy J. *Contracting for services in the management of coronary heart disease. Paper A: Emergency patients. Paper B: Non-emergency patients*. York: York Health Economics Consortium, 1993.

Pinkney J, Catnach S, Woods A, Fairclough P. Coronary thrombolysis: still too little too late? *Health Trends* 1993:**25(4)**:132–4.

Pitty D, Reeves P, Rickards A. *Protocol-directed shared care in cardiology*. In: Gordon C, Christensen JP (Eds). *Health telematics for clinical guidelines and protocols*. Amsterdam: IOS Press, 1995:145–56.

Porter AMD. Organisation of diabetic care. *British Medical Journal* 1982;**285**:1121.

Pratt J. *Practitioners and practices*. Oxford: Radcliffe Medical Press, 1995.

Pringle M, Bradley CP, Carmichael CM, *et al*. *Significant event recording. A study of the feasibility and potential of case-based auditing in primary medical care*. Occasional Paper 70. London: Royal College of General Practitioners, 1995.

Pringle M, Stewart-Evans C, Coupland C, *et al*. Influences on control in diabetes mellitus: patient, doctor, practice or delivery of care? *British Medical Journal* 1993;**306**:630–4.

Pritchard P. *Manual of primary health care; its nature and organization 2nd Edn*. Oxford: Oxford University Press, 1981.

Pritchard P. Can decision making be improved? *Postgraduate Education for General Practice* 1991;**2**:4–6.

Pritchard P. *Doctors, Patients and Time.* In: Frankenberg R (Ed). *Time, health and medicine.* London: Sage Publications, 1992.

Pritchard P. *Knowledge transfer for shared care: a discussion paper.* Proceedings of DILEMMA workshop 6 November 1993, Advanced Computation Laboratory. London: Imperial Cancer Research Fund, 1993.

Pritchard P, Low K, Whalen M. *Management in general practice.* Oxford: Oxford University Press, 1984.

Pritchard P, Pritchard J. *Teamwork for primary and shared care. A practical workbook (2nd Edn).* Oxford: Oxford University Press, 1994.

Purves I. *The current state and future needs of the electronic patient record for primary health care.* In: Teasdale S, Bradley P (Eds). *Proceedings of the annual conference of the Primary Health Care Specialist Group.* Worcester, British Computer Society, Primary Health Care Specialist Group, 1993: 113–22.

Purves I. An overview of electronic medical records for general practitioners. *Journal of Informatics in Primary Care* 1994;**December**;6–7.

Purves I. *Computerized guidelines in primary health care: reflections and implications.* In: Gordon C, Christensen JP (Eds). *Health telematics for clinical guidelines and protocols.* Amsterdam: IOS Press, 1995:57–74.

QED. *Quick and Early Diagnosis Unit.* Brochure from QED, The Queen Elizabeth Hopsital, Birmingham B15 2TH. Tel 0121 627 2485. Undated.

Rawles J. Attitudes of general practitioners to prehospital thrombolysis. *British Medical Journal* 1994;**309**:379–82.

Robinson L, Stacy R. Palliative care in the community: setting practice guidelines for primary health care teams. *British Journal of General Practice* 1994;**44**:461–4.

Robson J, Boomla K, Savage W. Reducing delay in booking for antenatal care. *Journal of the Royal College of General Practitioners* 1986;**36**:274–5.

Roland M (1992a). *Communication between GPs and specialists.* In: Roland M, Coulter A (Eds). *Hospital referrals.* Oxford: Oxford University Press, 1992:108–22.

Roland M (1992b). *Variations in referral rates of general practitioners: causes and their significance.* In: Hopkins A, Wallace P (Eds). *Referrals to medical outpatients.* London: Royal College of Physicians, 1992.

Roland MO, Bewley B. BONELINE: evaluation of an initiative to improve telephone communication between general practitioners and specialists. *Journal of Public Health Medicine* 1992;**14(3)**:307–9.

Roland M, Coulter A (Eds). *Hospital referrals.* Oxford University Press, 1992.

Roland M, Porter RW, Matthhews JG, *et al.* Improving care: a study of orthopaedic outpatient referrals. *British Medical Journal* 1991;**302**:1124–8.

Rosenqvist U, Carlson A, Luft R. Evaluation of comprehensive program for diabetes care at primary health level. *Diabetes Care* 1988;**11**(3):269–74.

Rosenqvist U, Larsson K, Carlson A. *Experience from the Stockholm diabetes control program.* In: *Treatment of insulin-dependent diabetes mellitus.* Stockholm: Swedish National Board of Health, 1990.

Round A, Marshall AJ. Survey of general practitioners' prehospital management of suspected myocardial infarction. *British Medical Journal* 1994;**309**:375–6.

Royal College of General Practitioners (RCGP) Clinical Guidelines Working Group. *The development and implementation of clinical guidelines*. Report from General Practice No 26. London, Royal College of General Practitioners, 1995:1–2.

Royal College of Physicians of London. *Stroke—towards better management*. London: Royal College of Physicians, 1989.

Royal College of Physicians (Working Group of the Research Unit). Palliative care: guidelines for good practice and audit measures. *Journal of the Royal College of Physicians of London* 1991;**25**:325–8.

Royal College of Physicians. *Guidelines. Investigation and management of stable* angina. Report of a working party of the Joint Audit Committee of the British Cardiac Society and the Royal College of Physicians of London. London: Royal College of Physicians, 1993.

Rubin IR, Beckhard R. Factors influencing the effectiveness of health teams. *Milbank Memorial Fund Quarterly* 1972;**50**(3):317–37.

Rubin IR, Plovnick MS, Fry RE. *Improving the coordination of care: a program for health team development*. Harvard, Mass: Ballinger, 1975.

Ruddy B. Brief encounters. *Health Service Journal* 1992;**17 Sept**:22–4.

Russell IT, Grimshaw JM. *The effectiveness of referral guidelines: a review of methods and findings of published evaluations*. In: Roland M, Coulter A (Eds). *Hospital Referrals*. Oxford: Oxford University Press, 1992.

Russell J. *A review of health promotion in primary care*. London, Greater London Association of Community Health Councils, 1995.

Sällström, P. *The Essence of Dialogue*. In: Göranzon B, Florin M. *Dialogue and Technology. Art and Knowledge*. London: Springer-Verlag, 1991:27–30.

Sandercock P, Willems H. Medical treatment of scute ischaemic stroke. *Lancet* 1992;**339**:537–9.

Schön DA. *Educating the Reflective Practitioner. Towards a new design* for teaching and learning in the professions. San Francisco: Jossey-Bass, 1990.

Schumacher EF. *Small is beautiful. A study of economics as if people mattered*. London: Blond and Briggs, 1973.

SHHD (Scottish Home and Health Department). *Provision of maternity services in Scotland. A policy review*. Edinburgh: HMSO, 1993.

SHHD/SHSAC (Scottish Office Home and Health Department, Scottish Health Service Advisory Council). *The management of patients with stroke. A report of a working group of the National Medical Advisory Committee*. Edinburgh, HMSO, 1993.

SHSPC/SHHD (Scottish Health Services Planning Council, Scottish Home and Health Department). *Shared care in obstetrics. A report by the National Medical Consultative Committee*. Edinburgh: Scottish Home and Health Department, 1983.

SHSPC/SHHD (Scottish Partnership Agency for Palliative and Cancer Care and Clinical Resource and Audit Group of Scottish Office Home and Health Department). *Palliative cancer care guidelines*. Edinburgh: Scottish Office Home and Health Department, 1994.

Seale C. A comparison of hospice and conventional care. *Social Science and Medicine* 1991;**32**:147–52.

Senge P. *The Fifth Discipline. The art and practice of the learning organization.* London: Century, 1993. (First published in USA in 1990)

Sever P, Beevers G, Bulpitt C, *et al.* Management guidelines in essential hypertension: report of the second working party of the British Hypertension Society. *British Medical Journal* 1993;**306**:983–7.

Shortliffe EH, Perreault LE (Eds). *Medical informatics: computer applications in health care.* New York: Addison-Wesley, 1990.

Sigurdsson JA. *Demography and organization of health system in Iceland.* In: Lawrence M, Pritchard P. *General Practitioner Education: UK and Nordic perspectives.* London: Springer-Verlag, 1992:119.

Singh BM, Holland MR, Thorn PA. Metabolic control of diabetes in general practice clinics: comparison with the hospital clinic. *British Medical Journal* 1984;**289**:726–8.

Slee J. Doctor's orders—on your bike. *The Guardian* 1994;**supplement 28 December**:8.

Smith LFP. Provision of obstetric care by general practitioners in the south western region of England. *British Journal of General Practice* 1994;**44**: 255–7.

Smith LFP, Jewell D. Contribution of general practitioners to hospital intrapartum care in maternity units in England and Wales in 1988. *British Medical Journal* 1991a;**302**:13–16.

Smith LFP, Jewell D. Roles of midwives and general practitioners in hospital intrapartum care, England and Wales, 1988. *British Medical Journal* 1991b;**303**:1443–4.

Smith R. Towards a knowledge-based health service. Priorities for health technology assessment. *British Medical Journal* 1994;**309**:217–18.

Smith WCS, Lee AJ, Crombie IK, Tunstall-Pedoe H. Control of blood pressure in Scotland: the rule of halves. *British Medical Journal* 1990;**300**:981–3.

Spiegal N, Kinmonth A-L, Ross F, *et al.* How can facilitators help primary care teams? *Journal of Interprofessional Care* 1994;**8**:299–309.

Stafford MA. Ad libitum: leaving. *Annals of Internal Medicine* 1993;**119**:435.

Standing Medical Advisory Committee and Standing Nursing and Midwifery Advisory Committee. *The principles and provision of palliative care.* London: HMSO, 1992.

Stocking B. *Medical advances and the future shape of acute services.* Working paper No 7. London: King's Fund Acute Services Initiative, 1992.

Stocking B. *Initiative and inertia: case studies in the NHS.* London: Nuffield Provincial Hospitals Trust, 1985.

Stott N. Screening for cardiovascular risk in general practice. *British Medical Journal* 1994;**308**:285–6.

Stott NCH, Kinnersley P, Rollnick S. The limits to health promotion. *British Medical Journal* 1994;**309**:971–2.

Street P, Gannon MJ, Holt EM. Community obstetric care in West Berkshire. *British Medical Journal* 1991;**302**:698–700.

Strickland B. Internal-external expectancies and health-related bahaviours. *Journal of Consulting and Clinical Psychology* 1978;**46**:1192–211.

Subcommittee of WHO/ISH Mild Hypertension Liaison Committee? Summary of 1993 World Health Organization—International Society of

Hypertension guidelines for the management of mild hypertension. *British Medical Journal* 1993;**307**:1541–6.

Sulke AN, Paul VE, Taylor CJ, *et al.* Open access exercise electrocardiography: a service to improve management of ischaemic heart disease by general practitioners. *Journal of the Royal Society of Medicine* 1991;**84**:590–4.

Swieringa J, Wierdsma A. *Becoming a learning organization. Beyond the learning curve.* Wokingham, England: Addison-Wesley, 1992.

Systolic Hypertension in the Elderly Program Cooperative Research Group. Prevention of stroke by anti-hypertensive drug treatment in older persons with isolated systolic hypertension. *Journal of the American Medical Association* 1991;**265**:3255–64.

Tate P. *The doctor's communication handbook.* Oxford: Radcliffe Medical Press, 1994.

Taylor RW. Community-based specialist obstetric services. In: Zander L, Chamberlain G (Eds). *Pregnancy care for the 1980s.* London: Royal Society of Medicine and Macmillan Press, 1984.

Thomas H, Draper J, Field S, *et al.* An evaluation of the practice of shared antenatal care. *Journal of Obstetrics and Gynaecology* 1983;**3**:157–60.

Thomas H, Draper J, Field S, *et al.* Evaluation of an integrated community antenatal clinic. *Journal of the Royal College of General Practitioners* 1987;**37**:544–7.

Thorn PA, Russell RG. Diabetic clinics today and tomorrow: mini-clinics in general practice. *British Medical Journal* 1973;**2**:534–6.

Thorn PA, Watkins PJ. Organisation of diabetes care. *British Medical Journal* 1982;**285**:787–9.

Thorpe G. Enabling more dying people to remain at home. *British Medical Journal* 1993;**307**:915–18.

Tichy N M. *Organization design for primary health care. The case of the Martin Luther King Jr Health Center.* New York: Praeger, 1977.

Tierney AJ, Macmillan MS, Worth A, *et al. Discharge planning for elderly people going home from hospital: experiences of patients and their carers.* Edinburgh: University of Edinburgh Nursing Research Unit, 1993.

Tierney A, Worth A, Closs SJ, *et al.* Older patients' experiences of discharge from hospital. *Nursing Times* 1994;**90**(21):36–9.

Timpka T, Nyce JM, Sjöberg C, *et al. Action Design: from modelling to support* of the software process. Proceedings of SEKE 1993. San Francisco: IEEE Press, 1993.

Townsend J, Frank AO, Fermont D, *et al.* Terminal cancer care and patients' preferences for place of death: a prospective study. *British Medical Journal* 1990;**301**:415–17.

Tuckett D, Boulton M, Olson C, *et al. Meetings between experts. An approach to sharing ideas in medical consultations.* London: Tavistock Publications, 1985.

Turkle S. *The second self. Computers and the human spirit.* London: Granada, 1984:320.

Van Damme R, *et al.* Integrated care for patients with asthma: views of general practitioners. *British Journal of General Practice* 1994;**44**:9–13.

Wade DT, Langton-Hewer R, Skilbeck CE, *et al.* Controlled trial of a home care service for acute stroke patients. *Lancet* 1985;i:323–6.

Waine C, Hannaford P, Kay C. Early thrombolysis therapy: some issues facing general practitioners. *British Heart Journal* 1993;**70**:218.

Wallace P. *What does the general practitioner want?* In Hopkins A and Wallace P. *Referrals to medical outpatients.* London, Royal College of Physicians, 1992.

Ward JD, MacKinnon M. Purchasing for quality: the providers' view. Diabetes care. *Quality in Health Care* 1992;**1**:260–5.

Weaver T, Tan G, Gabbay J. *Lessons from an audit of referrals from general practice to medical outpatients.* In: Hopkins A, Wallace P. *Referrals to medical outpatients.* London: Royal College of Physicians. 1992:63–77.

Weinberger M, Cohen SJ, Mazzuca SA. The role of physicians' knowledge and attitudes in effective diabetes management. *Social Science and Medicine* 1984;**19**(9):965–9.

Weiss P. *Health and Biomedical Information in Europe.* Copenhagen, World Health Organization, Regional Office for Europe, 1986.

West Lambeth Health Authority Stroke Steering Group. Setting district stroke standards and objectives. *Journal of the Royal College of Physicians of London* 1992;**26**:172–6.

Weston CFM, Penny WJ, Julian DG on behalf of the British Heart Foundation Working Group. Guidelines for the early management of patients with myocardial infarction. *British Medical Journal* 1994;**308**:767–71.

WHO/ISH. Mild Hypertension Liaison Committee. Summary of 1993 World Health Organization–International Society of Hypertension guidelines for the management of mild hypertension. *British Medical Journal* 1993;**307**:1541–6.

WHO/UNICEF. *Primary Health Care. Alma-Ata Declaration.* Geneva, World Health Organization, 1978.

Wilkes E, Lawton EE. The diabetic, the hospital and primary care. *Journal of the Royal College of General Practitioners* 1980;**30**:199–206.

Wilkin D. *Patterns of referral: explaining variation.* In Roland M, Coulter A (Eds). *Hospital referrals.* Oxford University Press, 1992.

Wilkin D, Smith AG. Variations in general practitioners referral rates to consultants. *Journal of the Royal College of General Practitioners* 1987;**37**: 350–3.

Williamson J W, German PS, Weiss R, *et al.* Health science information management and continuing education of physicians. *Annals of Internal Medicine* 1989;**110**:152–60

Wilson A. *Contracting for services in the management of stroke.* York, York Health Economics Consortium, 1994.

Wilson A. *Changing practices in primary care. A facilitators' handbook.* London, Health Education Authority, UK, 1994.

Wilson C, Brown V, Morley V, *et al. Camberwell diabetes shared care scheme.* London, Dept. General Practice and Primary Care, King's College School of Medicine and Dentistry, 1991.

Winn E, King C. *Breaking new ground: the Lambeth Community Care Centre.* London, King's Fund Centre, 1987.

Wolfe CDA, Taub NA, Woodrow J, *et al.* Patterns of acute stroke care in three districts of southern England. *Journal of Epidemiology and Community Health* 1993;**47**:144–8.

Wood J. A review of diabetes care initiatives in primary care settings. *Health Trends* 1990;**22**:39–43.

Wood J. A review of antenatal care initiatives in primary care settings. *British journal of General Practice* 1991;**41**:26–30.

Woodhead M (Ed). Guidelines on the management of asthma. *Thorax* 1993;**48**: s1-s24.

Woolham J. Care management: some issues of interprofessional practice in Northamptonshire. *Journal of Interprofessional Care* 1994;**8**(3):335–45.

Working Group on Terminal Care. National terminal care policy. *Journal of the Royal College of General Practitioners* 1980;**30**:466–71. (The Wilkes report)

Worth R, Nicholson A, Bradley P. Shared care for diabetes between hospital and GPs. *Nursing Times* 1990;**86**(41):52.

Wraight A, Ball J, Seccombe I, Stock J. *Mapping team midwifery. A report to the Department of Health.* Brighton, Institute of Manpower Studies, 1993.

Wright H, Eccles M, Hutchinson A. Bridging the gap—audit at the interface between primary and secondary care. *Audit Trends* 1993;**1**:48–50.

Wright F, Young E. Focusing on client-held joint health and social care records. *Journal of Interprofessional Care* 1994;**8**(3):321–8.

Wyllie HR, Dunn FG. Pre-hospital opiate and aspirin administration in patients with suspected myocardial infarction. *British Medical Journal* 1994;**308**:760–1.

Young J. Is stroke better managed in the community? Community care allows patients to reach their full potential. *British Medical Journal* 1994;**309**:1356–7.

Young M. *The Metronomic Society. Natural rhythms and human timetables.* London, Thames & Hudson, 1988.

Young JB, Forster A. The Bradford community stroke trial. *British Medical Journal* 1992;**304**:1085–9.

Young J, Forster A. Day hospital and home physiotherapy for stroke patients: a comparative cost-effectiveness study. *Journal of the Royal College of Physicians of London* 1993;**27**:252–7.

Yudkin JS, Boucher BJ, Schopflin KE. The quality of diabetic care in a London health district. *Journal of Epidemiology and Community Health* 1980;**34**:227–80.

Zander LI, Watson M, Taylor RW, Morell DC. Integration of general practitioner and specialist antenatal care. General practitioner obstetrics 1. *Journal of the Royal College of General Practitioners* 1988;**28**:455–8.

Zimpelmann B, Elässer KH, Braun I, *et al. Patients, shared care, documentation, communication and classification in Europe in the next century*. Report of DILEMMA workshop 7 *Benalmadena, 26–28 Feb 1994.*

INDEX

The complex issues raised by shared care, due to the changing boundaries between primary, hospital and community care, are of immediate interest and the source of much debate and many initiatives. Shared care schemes for certain chronic diseases have been the subject of extensive studies, and many have become established; but there is little information about the general aspects raised by the need to develop shared care in the future.

This book aims to fill a gap, by looking at ways in which shared care is organized and how it functions, by a critical review of selected literature, and by setting out some steps that might lead to effective shared care. The target readership includes all professionals working in shared care, policy makers and service managers, as well as researchers and students in this field.

The authors are a former general practitioner who has written extensively and has considerable experience of health care management issues and the application of information technology to them. His collaborator, Jane Hughes, is a health services researcher with much experience in this particular area.

ISBN 1-85315-259-5