

THE PROCEEDINGS FROM A CONFERENCE FOR EUROPEAN HEALTHCARE POLICY MAKERS

FROM HOSPITAL TO HOME CARE

*The potential for acute service
provision in the home*



Edited by David Costain
and
Morton Warner

Welsh Health Planning Forum
The NHS in Wales



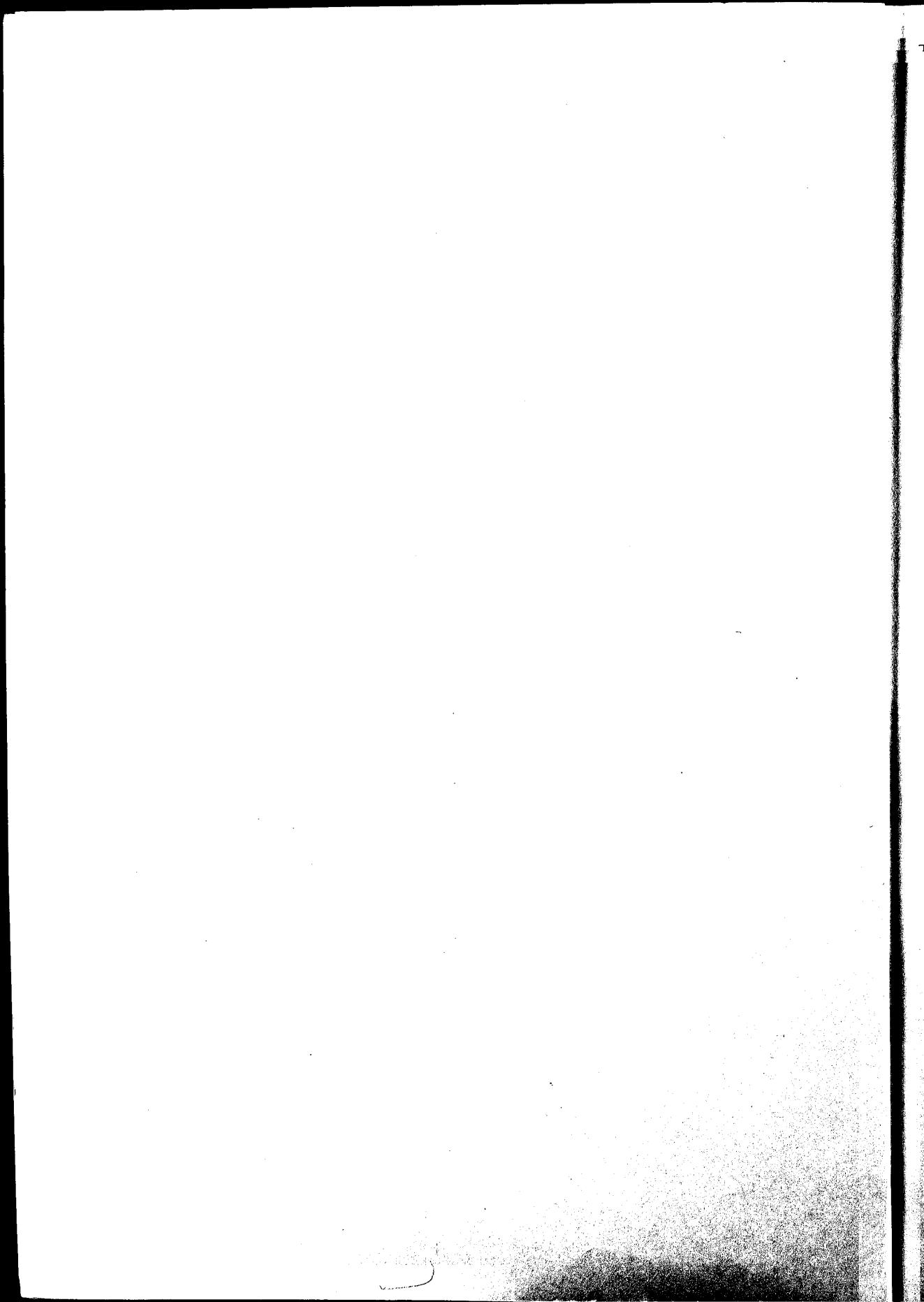
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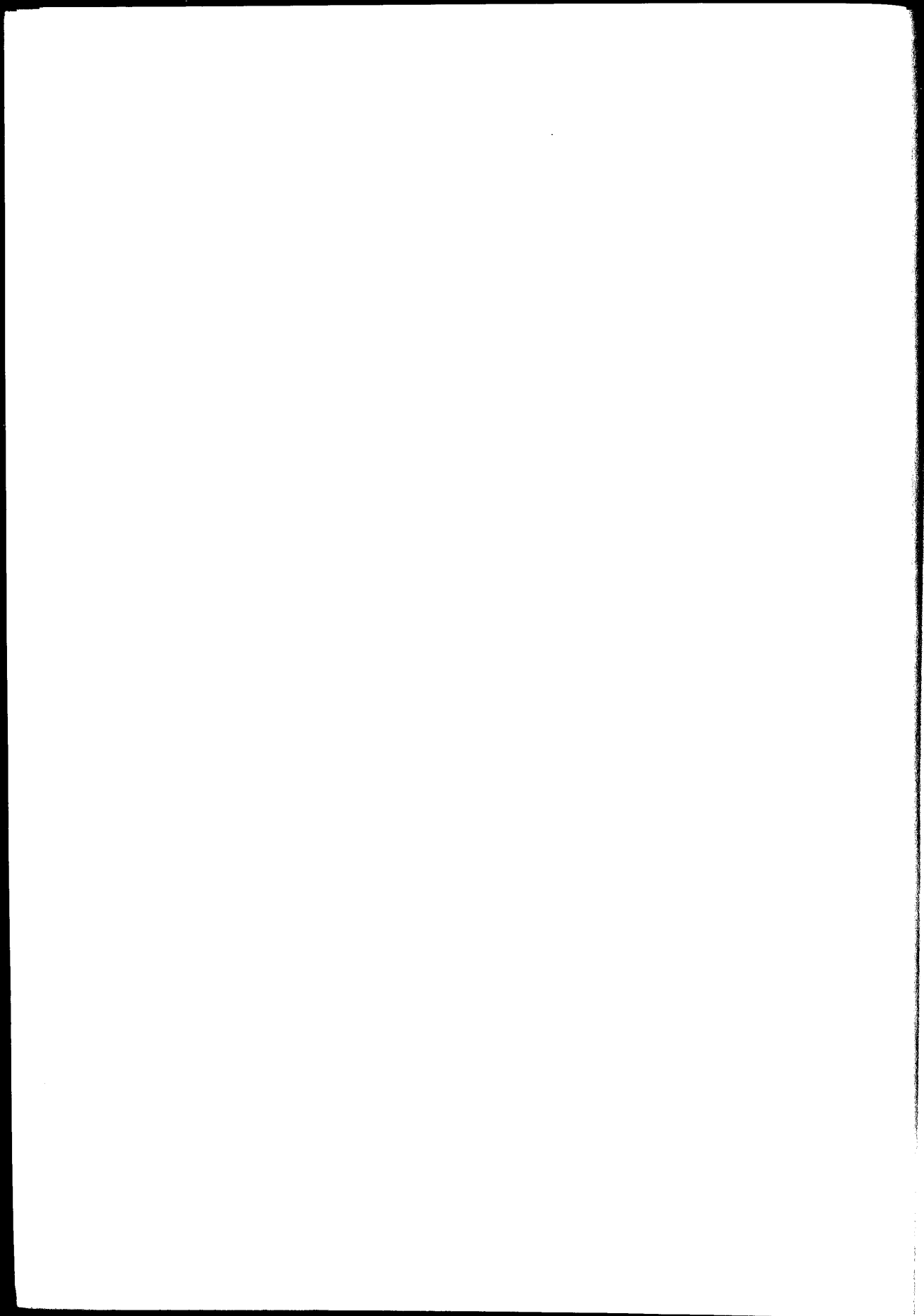
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PREFACE

The conference that led to this book brought together people from all over the world who had an interest in developing health care. They shared their views and experiences of moving care and treatment out of hospitals into the community and especially the home. The aim was to look at how the emergence of new technologies – technologies in the widest sense, to include not only high and low tech equipment, but also new procedures – would facilitate this move.

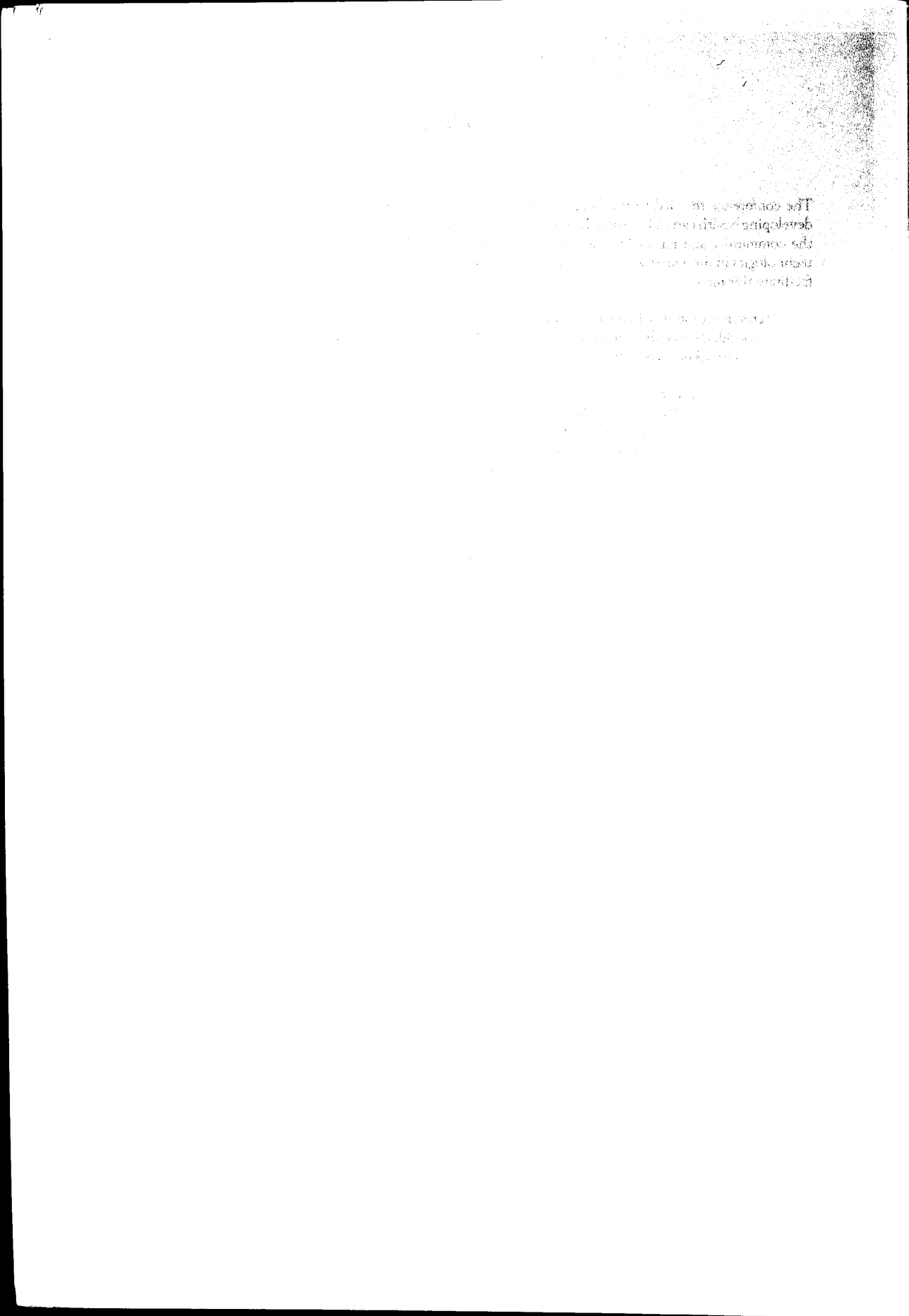
The interest in this shift is driven not so much by the technologies themselves – although these do have a part – but more by considerations which recognise the limits and disadvantages of hospital based care, and the need for health care systems to acknowledge the social and environmental components of health.

Most people accept that community and home-based care are not a lesser or a cheaper option to hospital care, but are a purposeful and ethical approach to serving patients. Homecare is now a sufficiently strong concept in itself to be a driving force for developments in health care technology. Indeed, the technology it has stimulated is increasingly accessible to and understandable by the consumers of health care. The focus, in the UK at least, on the customer has led to great improvements in the reliability and relevance of the technology. More than one commentator saw the increase in 'user involvement' rapidly facilitating the goal of self-determination of care.

Overall, it was striking to see how similar were the developments in different countries, and how solutions to problems could be transferred from one country to another, despite significant differences in their health systems and states of economic development. It is clear that the trend towards homecare has a purpose and momentum, and this will ensure it will continue to be a high priority.

Anthony Clare

August 1992



INTRODUCTION



In October, 1991, 160 people, some totally committed, others sceptical or enquiring, assembled in Cardiff to review the role of technology to enable sick people to be cared for at home rather than in hospital. Seventeen countries were represented – from the USA in the west to Israel on the eastern shores of the Mediterranean, with a north–south spread from Scandinavia to Yugoslavia. Equally diverse, the participants came from different health care sectors – WHO, national health systems, insurers, educational institutions, private health care provider organisations and technology suppliers.

Specifically, the purpose was to stimulate a critical debate among those actively involved with health care policy, concerning the application of technology to homecare as an alternative to acute hospital treatment. And stimulate a debate it did, as discussion groups examined the implications of the speakers' presentations! But more of that later.

First, though, what are the reasons behind the shift to acute homecare? Barbara Stocking lists six: improved home environments; patients' dislike of hospitals; the dangers of hospitals; changes in medical technology; assumptions about cost-effectiveness; and demography – the inability of hospitals to cope with the elderly.

The WHO, too, emphasises in its HFA 2000 Target 28 that: the primary care system . . . should provide a wide range of health promoting, preventive, curative, rehabilitative and supportive services to meet the basic needs of the population.

Stocking, in her overview paper, provides an outline of acute homecare examples – from renal and peritoneal dialysis to enteral and parenteral nutrition, and intensive nursing and rehabilitation therapy. And David Banta from Holland, using a broad definition of 'technology' (at the soft end represented by 'organisation' and at the hard end by 'hi-tech equipment'), takes a futuristic view emphasising, in particular, the further developments that will be forthcoming for intelligent pump systems; and he observes the potential for manpower specialties to proliferate alongside every new development. Better, perhaps to retrain existing personnel than to let this happen!

Linda Marks, whose recent publication on hospital care at home leads the field in the UK, picks up on the organisational theme, providing a framework in which

different examples of homecare can be placed. This consists of: technology-dependent care; intensive nursing and rehabilitative care; intermittent health care; and domiciliary terminal care. And suppliers range from hospital outreach programmes, expanded community services and independent agencies, to new 'extra-mural' hospitals and equipment manufacturers. Examples are cited from New Brunswick in Canada, the Peterborough experiment in the UK and regional organisations in France.

Various speakers provide case material or research findings on a variety of clinical conditions and patient groups for which homecare is now possible:

- ◆ Taeke van Beekum from the Netherlands, funded by an insurance company, is gradually building up a list of clinical procedures formerly undertaken in hospital which can now be carried out at home. In his paper he identifies the precautions necessary for success, ranging from patient selection, to the availability of home nursing and equipment maintenance.
- ◆ David Silk, a consulting physician in London, expresses his medical concerns that if homecare is to be successful, nutrition, both enteral and parenteral, must be properly organised.
- ◆ Barbro Beck-Friis, a consultant geriatrician from Sweden, reports on a hospital-based homecare programme begun in 1976, predominantly for patients with cancer, cardiovascular and pulmonary disorders and sets out her 'imperatives' for a high quality approach.
- ◆ Shirley Goodwin, with extensive experience of health visiting, reviews the essential nursing prerequisites for a successful homecare programme. She cites: willing and motivated staff; district nursing sisters with managerial and clinical skills; high quality inter-professional relationships based on mutual trust; the availability of necessary specialised equipment; and a patient-centred approach.

Wherever in Europe and elsewhere home health care programmes are to be found they demand a well-organised support and supply infrastructure. Using the example of anti-coagulant therapy, Torben Jørgenson

from Denmark, together with colleagues from the Netherlands and the UK, discusses future laboratory technologies for community care. From their Delphi study of 40 haematologists and clinical chemists in five countries they conclude that the number of non-hospital monitoring tests will increase by 40–60 per cent in the 1990s thereby increasing the number of people and conditions that can be treated at home.

From Sweden, Ingvar Mohlin reports on a supplies project covering incontinence, dialysis, medical gases, equipment for the handicapped, food and drugs – all run by the National Corporation of Swedish Pharmacists. Cost savings are possible, he says, but the data are incomplete.

Financing and reimbursement of home care are a difficult problem throughout Europe. Russell Selinger, in his wide ranging review, concludes that while the limited success of home health care is in part due to lack of clinical consensus on safety and efficacy, and to structural difficulties, funding and reimbursement have been insufficiently addressed. He suggests: there should be the creation of a payment mechanism for home care that puts it on a comparable footing with hospital care; and hospitals and physicians need incentives to consider cost-effectiveness as well as clinical efficacy. In these proposals he is joined by Pierre-Jean Lancry from CREDES in France and Werner Gerdemann of Verband der Aggestellten - Krankenkassen in Germany, both of whom also emphasise the need for more data on direct and indirect costs in order that better resourcing decisions can be made by policy makers.

Last, but by no means least, what do patients and carers think of home health care? Both Julia Neuberger from the UK and Nicolaas Mul of the Netherlands agree that patients prefer it. Neuberger, however, raises several issues: cost transfer to families; the health of the carers; and the possibility of self-referral. Mul echoes these but adds the requirement for care standards to be developed.

And so back to the conference discussion groups. Their concerns were legion; and their questions form the agenda for future acute home health care discussion:

- ◆ How can patients and carers be empowered? And will this increase with the next generation who will be computer literate and more able to handle technology in the home?
- ◆ Across Europe, are home circumstances suitable for this form of care?
- ◆ How can the purchaser/provider process enhance home care and resolve reimbursement problems?
- ◆ How are technological innovations to be evaluated for cost-effectiveness?

- ◆ What should be the role of insurers?
- ◆ Should one agency or a number attempt to cover all aspects of home care?
- ◆ What extra training will be needed by health workers?
- ◆ How can shifts in care be seen to enhance clinicians' perceived interests?

Finally, to return to WHO and its new HFA 2000 Targets 31 and 28, which link ethical behaviour to the application of the most effective interventions. How do home health care innovations compare with in-hospital approaches? Are they the most effective? In many cases the answer is 'yes'; but a code of practice is needed to ensure that all aspects are taken into account – appropriateness, cost, efficiency, efficacy and effectiveness, together with patient and carer views.

August 1992

SECTION I

**INTRODUCTORY
PAPERS**

CONFERENCE INTRODUCTION

John Wyn Owen
Director of the NHS, Wales



For the next day and a half over 160 people here will be joining in lively debate on the shift of provision of care from the hospital to the home. The statement of purpose set out in the programme is:

to stimulate a **critical** debate among those actively involved with health care policy concerning the application of technology (in its broadest sense) to home health care as an **alternative** to acute hospital treatment.

Even a rapid look across the European states indicates the interest of many governments, health care providers, purchasers and insurers in shifting care away from acute care institutions whenever possible. Attempts are made to diagnose and treat patients at home or in the primary care setting who would, in earlier times, have been referred to hospital. In other cases the interest is in treating patients in the community or on an out-patient basis who formerly would have been looked after in hospital.

Changing technology has often been the trigger for the substitution of non-institutional for acute institutional care. But major questions remain unanswered. Do such new approaches result in health gain; will they bring about reductions in premature death, and improve people's quality of life? How do patients and their carers view the changes: do they feel adequately supported? Given that most purchasers and insurers operate under severe financial constraints, what are the implications on the resource side – for manpower and training, general practice and primary care, and hospitals themselves? Lastly, at the macro level, how will policy-makers and managers plan strategically for health systems where the boundaries between primary, secondary and tertiary care are becoming increasingly blurred?

Both I and my colleagues from the Welsh Health Planning Forum look forward to a highly productive meeting. We are delighted that you all could join us for this exploration of an important policy area.

MOVING ACUTE HEALTH CARE INTO THE HOME

Barbara Stocking
Director
King's Fund Centre, London



I start with a quotation from our Minister of Health, Mrs Virginia Bottomley. She is reported to have said 'I am sick and tired of people talking about beds. The NHS is not a furniture repository.' In the second half of the twentieth century, we do seem to have been obsessed with hospital beds. I think, though, we are seeing a trend now to provide acute care in a range of different settings, one of which is in patients' own homes. The question now will no longer be how many beds, or even hospitals, but how many patients have been treated, and increasingly whether this treatment led to a gain in health.

What do we mean by acute home (health) care?

Two definitions of acute homecare

Provision of equipment and services to the patient in the home for the purpose of restoring and maintaining his/her maximum level of comfort, function and health
Council of Scientific Affairs, USA 1990

Provision in the home of levels of diagnosis and care associated with hospitals
Linda Marks, UK 1991

The first definition describes what is being done at home. However, in those countries which already have very developed systems of nursing care in the community this does not make clear the differences which are now taking place. Marks's definition gives the flavour of what we are talking about in this conference: not just nursing in the community (although nursing care is a likely component of acute homecare) but about (a) intensive levels of support obviating the need for hospital admission or shortening lengths of stay, (b) sophisticated medical technologies which can be used at home, and (c) sometimes a combination of both.

Before we look at why there is an interest in moving acute care into the home, perhaps we should start with an understanding of why acute care originally came to be associated with hospitals:

Factors in the development of hospitals

- ◆ a place to care for the poor sick
- ◆ improvements in medical technology
- ◆ efficiency: centralisation of specialist staff and expensive equipment.

In the nineteenth century hospitals were places where the poor sick could be cared for away from often overcrowded, insanitary and frequently damp housing conditions. Only in the twentieth century did it come to be accepted that the hospital was the place where most of us would be born (at least in the UK), where a significant number of us would die, and where we expect to be when seriously ill or requiring an operation. This change resulted in large part from biomedical advances (in radiology, in surgical techniques, including anaesthesia, and in drugs) which allowed people to be investigated and treated much more successfully. Many of these advances required the use of expensive equipment and facilities by specialist staff. In hospitals, these resources could be centralised and used efficiently.

Why is it that there is now a movement of health care out of the hospital into the community and into the patient's home?

Factors in the trend to acute homecare

- ◆ improved home environment
- ◆ patients' dislike of hospitals
- ◆ dangers of hospitals
- ◆ changes in medical technology
- ◆ assumptions about cost-effectiveness

- ◆ demography – inability of hospitals to cope with the elderly.

First, there is the improvement of the home environment: telephones, refrigerators, electricity and good sanitation all make home care more feasible than ever before. Second, there is patients' dislike of hospitals – though patients will by no means always prefer to be at home: if they are gravely ill, alone and frightened they may well prefer to be in a hospital. Overall, though, with adequate support most of us would prefer to be at home. Hospitalisation itself can be psychologically damaging, particularly to children and elderly people – and, of course, the risks of infection are significant in hospitals.

Changes in medical technology have made home care more feasible and manufacturers are developing streamlined, tamper-proof equipment designed specifically for the home care market.

The two most significant forces towards home care have, though, been changes in the population and financial constraints, and these are inter-related. Two-thirds of acute hospital beds in the UK, and I believe this is similar in other countries, are used by people over 65. As the elderly population in our countries continues to rise, there is concern about the cost of maintaining patients in sophisticated and expensive acute settings, and much questioning of who needs to be there and for how long. More generally, all our health systems have been concerned with the rising costs of health care and have an interest in getting more out of the money available.

Acute care at home has, then, been seen as a cheaper means of providing treatment – often without evidence to support that claim. However, there are concerns about this which I know will be taken up by other speakers. First, although the costs *may* be less there may be no cost savings unless the level of care in hospitals is correspondingly reduced; on the other hand, the hospital may be used to treat more patients needing far more intensive care. Second, cost savings may be achieved only at the expense of families and friends. The burden on carers should not be underestimated, and there are worries that the effects on carers are being ignored.

Economic forces are clearly behind the movement of acute care into the home in all countries; however, different national financial systems may make it easier or harder to support home care or to make savings in acute hospital care. This theme will come out strongly in many of the contributions later.

What sort of care is being given at home?

In planning this conference we have not succeeded in getting an overall picture of the extent and range of home health care in our countries. This is a reflection of the state of the art of acute home care. There are examples of particular schemes or types of home care for specific conditions, but it has been difficult to find individuals or statistics which give an overview of where we are now. I will be drawing heavily on a recent study by Linda Marks, *Home and Hospital Care: Redrawing the boundaries*, published by the King's Fund Institute.¹

Examples of acute home care

- ◆ renal and peritoneal dialysis
- ◆ intravenous infusion of antibiotics, cytotoxic drugs, or pain-killing drugs
- ◆ enteral and parenteral nutrition
- ◆ respiratory therapy, including use of ventilators and oxygen cylinders/concentrators
- ◆ home monitoring of patients
- ◆ intensive nursing and rehabilitation therapy.

I have put **home dialysis** for end-stage renal failure at the top of the list because it is the high technology at home most widely accepted in the UK. This is not so true in other countries, especially the USA, where home dialysis is limited and hospital dialysis much more prevalent. It has been argued by a number of people that the reason home haemodialysis, and in recent years continuous ambulatory peritoneal dialysis, have been so significant in the UK has been the limited hospital facilities for people with end-stage renal failure. As many of you are aware, the overall numbers of patients treated in the UK by dialysis or transplantation have been lower than in most European countries, although steps have been taken to increase them. But this is one area where home care has worked very well.

Perhaps the fastest growing area of acute home care concerns **drug delivery**. It used to be thought that intravenous infusions could be given safely only in hospitals. With improved technology and good patient/family instruction this is no longer the case. In particular, new pumps that deliver a measured dose of drugs have been significant. Examples of drugs being given intravenously at home include cancer chemotherapy, antibiotics, drugs for pain relief, and clotting factor for the treatment of haemophilia.

It is also possible to provide artificial nutritional support to people who are unable to eat either parenterally, by

feeding them intravenously (usually through a catheter in a central vein), or enterally, through nasogastric tubes or other openings into the stomach or intestines (for those who can absorb nutrients but cannot take them by mouth).

In the USA blood transfusion is also becoming accepted at home. Usually, home care is thought suitable for all these groups when the only reason for a patient being in hospital is to receive the particular treatment.

Developments in oxygen treatment are also allowing more patients to be treated at home. This ranges from babies with respiratory distress syndrome to adults with chronic obstructive lung disease. Mechanical ventilation is also allowing people to live at home who have spinal cord injuries or skeletal or neuromuscular disease.

The other areas of technology I have noted above include the ability to monitor patients at home – whether women during pregnancy or individuals with heart disease. Current technology also allows data from the relevant monitoring equipment to be transmitted to hospitals or doctors elsewhere if appropriate.

Diagnostic testing kits do not obviously come to mind when we talk of acute home care but they are important to consider because they are part of the overall trend to giving people much more control over their own health. Pregnancy testing kits illustrate this nicely: women used to have to go to their GPs to confirm pregnancy. They can now test themselves and then decide when to enter the health care system (admittedly, not always making the wisest decision). Testing kits are available worldwide for a variety of conditions, although not always over the counter. Some of the new testing devices may also be linked to drug delivery systems – insulin infusion in response to blood glucose levels being the most familiar example.

Finally, in discussing types of acute home care we must consider seriously the general nursing and rehabilitative care which may not require sophisticated items of equipment but is providing a level of support usually only found in hospitals. There have been 'hospital at home' schemes in several countries. The better known ones include 'hospitalisation à domicile' in Bayonne (south-west France),² the Peterborough hospital at home scheme³ in the UK, and the New Brunswick Extra Mural Hospital in Canada.⁴ The purpose of all these schemes is to reduce the need for hospital admission by providing high levels of support at home and to allow very early discharge – for example, after operation for hip fracture or replacement. These schemes are, of course, only at the extreme end of a spectrum of care known as general community nursing in the UK.

Is acute home care a good thing?

There are, then, a number of examples of different kinds. However, there are still questions to be asked about whether we should be promoting the development of acute home care and, if so, what are the prerequisites to make it work well. I am going to raise a number of issues which will, I hope, be discussed and better understood as a result of this meeting.

The first question must be about whether patients prefer it and those of their carers; of course, the two may be quite different. The information below gives the results of a study of the impact of home care on the family for children who require ventilator support for all or part of the day.

Main concerns and problems reported by families of children on ventilator support⁵

◆ themes related to general health status	28%
child's continued health	41
long-range development worries	21
◆ themes related to technical issues	23%
finances	26
nursing	16
equipment	7
home construction	3
◆ themes related to personal/family issues	20%
being unable to leave house	18
locus of responsibility for child	8
professional boundaries/authority	8
loss of privacy	6
feeling alienated	6
◆ other themes	29%

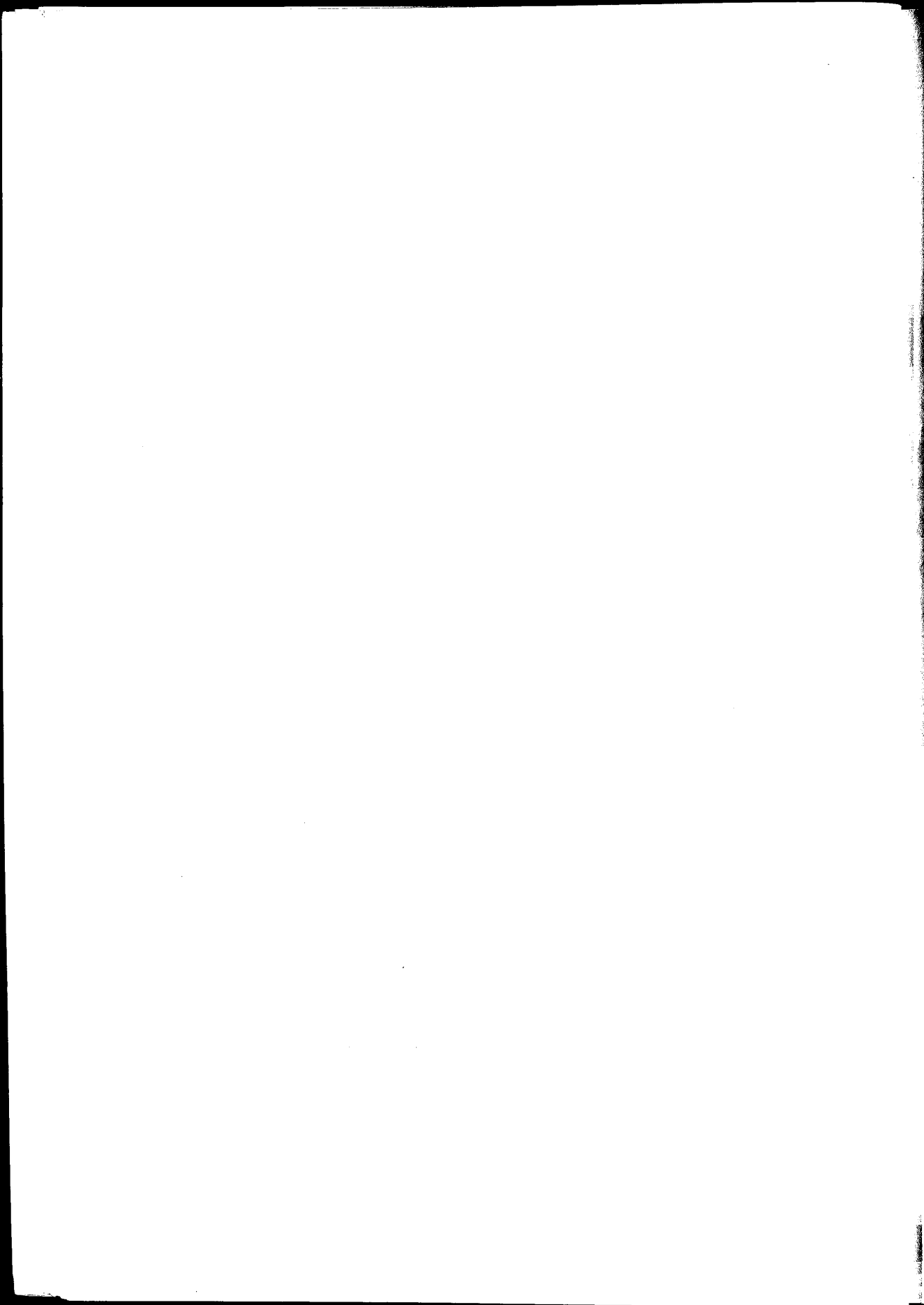
The parents naturally raised significant concerns about their child's health, but also about the burden on the family in both emotional and financial terms. Overall, though, 95 per cent saw it as a positive experience to have their child at home.

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SECTION 2

**FINANCIAL
CONSIDERATIONS**

EUROPEAN FINANCING OF ACUTE HOME HEALTH CARE

Russell Selinger
Bain and Company, London



The provision of acute health care in the home has received significant attention over the last decade as a possible solution to managing escalating health care expenditures¹ and as an alternative environment that provides the patient with a higher quality of life.² The potential to increase the number of patients being treated at home is largely the result of technological developments that have made equipment either easier to operate in the home or more cost-effective to provide in a home setting. Many of the technological changes, however, are not recent. Continuous ambulatory peritoneal dialysis (CAPD), a home treatment for end-stage renal disease, has been available since 1977; home total parenteral nutrition (TPN) has been available in France since 1971.

While only very limited data exist on the extent of acute home health care in Europe, the information that is readily available suggests that a relatively small number of patients are actually treated at home. A variety of reasons might explain the lack of success of acute home health care in Europe: different cultural factors, lack of clinical consensus on safety and efficacy, structural difficulties, and funding. While a number of papers have addressed the first three issues,³ there have been relatively few addressing the issue of reimbursement or funding.

The primary objectives of this paper are to survey the information that exists on reimbursement and funding in the major European markets and to suggest a framework for assessing the issues that arise. More specifically:

- ◆ to estimate the size of the acute home health care market in Europe in relation to over-all health care spending
- ◆ to summarise the existing process of reimbursing homecare in the major European countries and address some of the issues that arise either because of a lack of a specific funding mechanism or because the funding mechanism favours hospitalisation over homecare
- ◆ to review briefly some recent initiatives and some key steps that might be taken to encourage the development of home health care.

Acute home health care: definitions and benefits

No commonly agreed definition of acute home health care exists. For the purposes of this paper, acute home health care will be defined as treatments at home for the conditions defined in Figure 1, where intravenous therapy includes therapies such as intravenous antibiotics for patients with cystic fibrosis and parenteral nutrition for patients with Crohn's disease or other intestinal disorders. I have also explicitly included the use of continuous monitoring systems for infants at risk of cot death and adults with heart conditions. This definition of acute home health care is broadly consistent with Marks's 1991 definition of "home-based high technology care" ('provision in the home of levels of diagnosis and care associated with hospital').

Although a variety of treatments exists, relatively few are commonly used in Europe, home haemodialysis or CAPD probably being the only ones readily available in almost every European country. Home respiratory therapy is probably the next most popular, being available in France, the UK, Spain, the Netherlands and Germany. In France and other countries, home respiratory therapy developed in the 1960s, in response to the growing number of polio patients in intensive care units. Total parenteral nutrition (TPN) is becoming more available in the UK, France, Italy and Spain, but the patient numbers are low.

The key potential benefits of homecare are clinical, social and/or economic. No single treatment is universally appropriate for treating all patients at home: each must be applied to properly selected patients and conditions. With that caveat, clinical benefits include: faster recovery for certain conditions and reduced risk of hospital-acquired infections. Social benefits relate primarily to increasing patient choice and improving the quality of life. Economic benefits can include reduced operating costs, reduced overall systems costs, improved capital efficiency and savings in future capital expenditure.

Conditions	CAPD/Home haemodialysis	Enteral nutrition	Infusion therapy (types)	Monitoring	Respiratory therapy
Renal failure	X				
HIV+/AIDS (acute and maintenance)		X	TPN, antibiotic/fungal/viral pain management		Nebulised pentamidine
Cancer patients (treat cancer and chemo side effects)		X	Chemo, TPN, pain management		
Cot death				X	
Cystic fibrosis (4-6 infections/year)			Antibiotic		
Haemophilia (response to acute episodes)			Factor VIII		
Heart function				X	
Hypogammaglobulinemia			Gammaglobulin		
Intestinal failure (Crohn's)			TPN		
Terminally ill (symptoms)			Pain management		X

Figure 1. Scope of home health care available

SOURCE: INTERVIEWS, LITERATURE

The question of economic benefits is frequently raised. The issue is whether acute treatment at home is more cost-effective than acute treatment in the hospital. Many studies have addressed this issue and the conclusion is that home care is generally less expensive: typically anywhere from 20 to 40 per cent less expensive than comparable hospital-based care.³⁻⁵ The debate over these studies is typically caused by some confusion over what costs should be included or excluded.

Clearly, all direct costs of treatment and supplies need to be included. On this basis, there are generally no savings in supplies, but there may be savings in labour costs if more expensive hospital staff are substituted by the patient doing something for himself or herself. Many of the infusion therapies and CAPD, for example, are less expensive, in part because the patient can be trained in the appropriate use of the device or system. There is usually some consensus on the cost savings that arise from comparing only direct costs.

Other costs that are also often included are the capital or indirect costs of keeping a patient in hospital. These are effectively reduced if the patient is recovering at home, but there are two objections to the inclusion of these capital costs. One objection points out that hospitals already exist: the assumption is that there is no marginal cost from using them as otherwise they might go empty, and as there is no incremental cost there can be no actual savings. This argument may seem reasonable in the short term, but it leads to poor capital investment decisions and poor resource allocation. Keeping hospital beds full leads to more capital investment in hospitals, not less. If the capacity is not actually needed, beds or hospitals can be closed

in the medium term, which leads to real savings. Alternatively, if demand is generally high, beds full of patients who could be treated at home can lead to people who actually need a bed being turned away.

The other objection is that if the capital costs of hospitals are included so should those of homes be. The trouble with this argument is that most patients already have homes. There is no incremental capital cost of being ill at home, which unlike hospitals are not built only as places to treat people when they are ill. If everyone could be treated at home there would be no need for hospitals. Thus the cost of hospitals is incremental to the costs of treating people in homes.

Capital costs do need to be considered if the appropriate utilisation of resources is to be achieved. Their inclusion generally increases the potential savings from providing acute treatment in the home instead of the hospital.

Estimates of expenditure on home health care

Home health care spending comes out of an over-all budget for health care. Between 1970 and 1987, costs of health care in Europe rose from \$52bn to \$320bn and from 5 to 7.2 per cent of GDP (Figure 2, next page).

Hospital-based health care has been the primary focus of this spending, but limited home care programmes have been available throughout this period, for example CAPD, home haemodialysis and the French scheme for home respiratory therapy and hospitalisation à domicile.

If we focus on the seven largest countries (excluding Spain, where data are not available) we can break health care expenditure down into four major categories (Figure 3):

- ◆ inpatient, accounting for almost 50 per cent
- ◆ ambulatory care, representing about 25 per cent of the total and comprising mostly ambulatory physicians' services and ambulatory care facilities
- ◆ pharmaceuticals at 15 per cent
- ◆ other costs of 10 per cent.

Within this classification it is difficult to find data for home health care: in some countries it is included in the ambulatory figures; in other cases it is classified as part of the hospitals' spend, when it is included in their budget; or in the pharmaceutical category when, for example, a pharmacist is required to approve the product being delivered to the home patient.

Extracting exact data from official health care statistics is difficult, but using a variety of sources, including the academic and health care literature, the EDTA for renal numbers, and discussions with health care companies serving this market, we have arrived at an estimated total of 40,000–60,000 patients, of whom 15,000 receive CAPD or home haemodialysis, 7,000–

12,000 treatment for acute respiratory problems (with many more receiving some oxygen therapy), 6,000–8,000 cancer patients (many in France) receiving some infusion therapy, not necessarily on a continuous basis, and a slightly smaller number of cystic fibrosis patients receiving antibiotic treatment, but only for 6–8 weeks a year on average.

This level of home health care, at 1990 estimated average annual prices for treatment, results in an estimated expenditure level of \$300–500m for 1990 for UK, France, Germany, Italy, Spain, Netherlands and Belgium. This figure represents only 0.1–0.2 per cent of the approximately \$300bn spent by these countries on health care. In contrast, the USA spends an estimated \$15–17bn on home health care, or 6–7 per cent of health care expenditure.

The largest item of home care expenditure in Europe is for renal treatment, accounting for approximately 40 per cent of expenditures on home treatment. Even within this area, which is probably the best established, there are significant differences between countries in Europe. Figure 4 shows very different levels of penetration of home dialysis in different European countries.

Although the UK, the Nordic countries and the Netherlands have achieved reasonable levels, most European countries have not, despite the demonstration by six studies between 1975 and 1983 that this form of

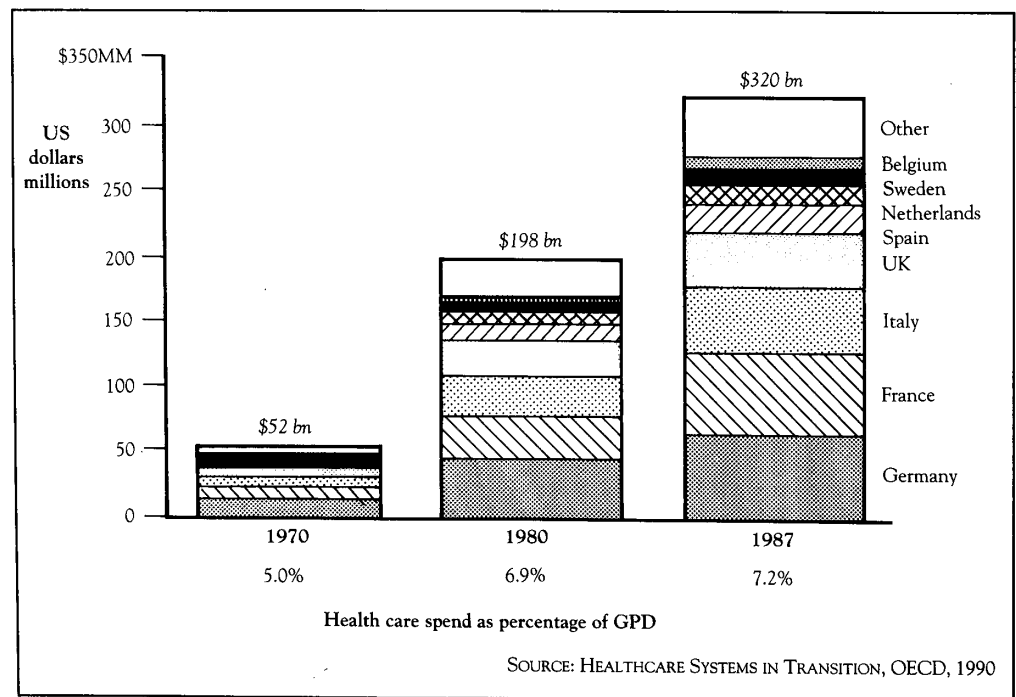


Figure 2. European health care spending in 1970, 1980 and 1987

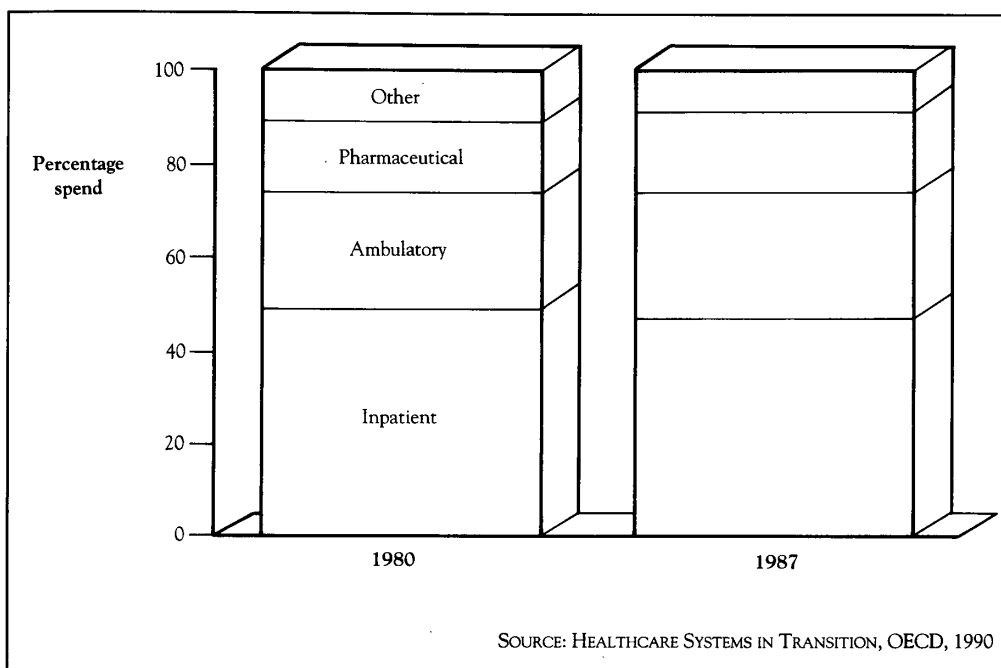


Figure 3. Health care expenditure channels for the seven largest spending countries (Germany, France, Italy, UK, Netherlands, Sweden, Belgium)

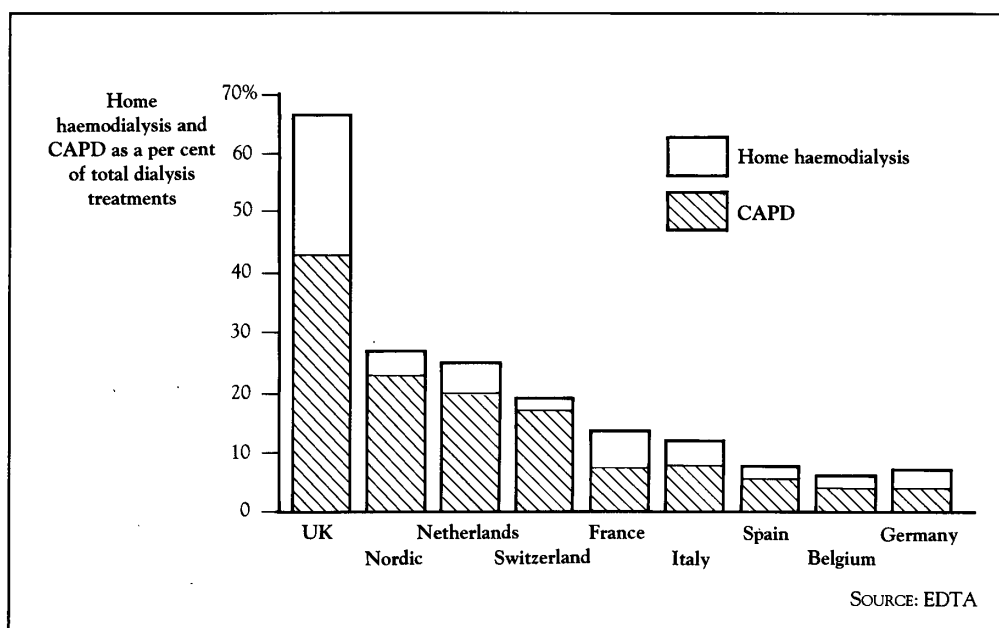


Figure 4. Penetration of CAPD and home haemodialysis, 1989

treatment is at least 15–55 per cent less expensive than hospital or institution-based haemodialysis. Fewer than 10 per cent of the population are treated at home in Germany, Belgium and Spain, while in Germany the penetration has actually decreased from over 20 per cent in 1981 to 8 per cent today.

Financial factors affecting development of home health care

Why not choose homecare when it can provide equivalent treatment at potentially lower cost?

The factors that influence a physician's decision to use home health care include:

- ◆ clinical and social factors (clinical disagreement over treatment efficiency, different social perceptions)
- ◆ strong hospital, weak community infrastructure
- ◆ financial factors: payment mechanisms limiting or biased against homecare; low reimbursement levels; payments to physicians that differ between home and hospital care.

Each of these factors can and arguably should play a role in the decision to use home health care.

Usually, where acute treatment is needed, patients are initially admitted to a hospital (although there are schemes where the focus of homecare is to prevent unnecessary hospital admissions). The decision, therefore, of where future treatment needs to be given is often taken by a hospital specialist, who may be influenced by hospital administrators, the patient and the patient's GP. All these constituents have a variety of incentives or preferences that make the choice between homecare and hospitalisation a fairly complicated one. The working assumption of this paper is that physicians ought to choose between two like treatments on the basis of cost-effectiveness, and when choosing between *different* treatments they need to have reliable cost/price data to be able to judge the cost effectiveness and make appropriate trade-offs.

If this decision-making process is to work, there needs to be:

- ◆ an unbiased reimbursement or funding mechanism for homecare
- ◆ prices for homecare fairly set relative to hospital reimbursement

- ◆ physician incentives not distorting the most appropriate clinical and cost-effective choice.

Of the various financial factors that influence the choice of homecare, the most important is the funding mechanism. In most cases, a formal mechanism does not exist.

Mechanisms for inpatient funding

In Belgium, the system of health care financing is based on the reimbursement of 'acts' and of 'drugs'. Hospitals' income results from acts, drugs dispensed, and through the *per diem*; they are not permitted to sell drugs to patients for home treatment and in general there are no provisions for acute homecare.

France, on the other hand, actually has a specific channel for homecare activities and funding. Since the 1960s, France has had a hospital at home scheme that negotiates a *per diem* with the local branch of the Sécurité Sociale. Despite their long history, the HADs account for only 3,500 beds, versus about 560,000 inpatient beds.

In Germany, the system of funding hospitals and the clear separation of hospital and ambulatory services create an environment in which it is difficult for homecare to develop. Hospitals are paid *per diem* and early discharge is therefore discouraged. Even if he wanted to transfer a patient to his home, the doctor would either have to transfer all responsibility for care to a GP or apply for special approval from the Physicians' Association to be allowed to continue to monitor the patient's progress.

In Italy, funds flow from central taxation via the regional local health organisations (USLs) to the hospitals. What little homecare exists is done via the hospital system.

In the Netherlands, individuals are insured either through the Sickness Fund or through private insurers for most health care. Hospitals receive a fixed global budget that is negotiated with the private insurers and the Sickness Fund. Although the government would like to encourage more homecare, acute homecare as we have defined it is not regularly available – although there are some community-based organisations. When a patient would like to receive homecare, his or her insurer – whether the Sickness Fund or a private insurer – needs to approve the transfer of the patient to the home if any treatment is to be reimbursed. This creates a somewhat cumbersome system.

In Spain, hospital budgets are set by the social security, but there are few incentives to be cost-effective, and hospitals regularly overspend their budgets. Acute home health care is essentially limited to oxygen

therapy and dialysis, prices for which are set by the social security.

In the UK, acute homecare has been relatively more successful. Dialysis, oxygen therapy and various infusion therapies have been moderately or very successful here. The financing for some of the activities has been somewhat indirect in that the funding has come via GP prescribing through the local pharmacy. While the UK has promoted community care, this is more nursing based and generally not targeted to acute homecare.

What is apparent from this seven-country review is that there are few specific provisions (except in France) for funding or encouraging acute homecare; what homecare there is has been funded or reimbursed in a haphazard fashion.

Who should control the financing of home health care?

The lack of a specific mechanism to fund homecare has led to a variety of approaches being used in Europe today. Broadly, homecare may be funded in four ways:

- ◆ through direct negotiation with the public or private funding body
- ◆ via a local health authority that has budget allocation capabilities
- ◆ through a non-hospital pharmacy
- ◆ through a hospital.

While none of these approaches is in itself better than any other they each have various advantages and disadvantages.

Funding bodies like insurers are not usually health care experts. Although they may be responsible for setting over-all policy for homecare spending, they are not in a good position to decide on specific issues; the process is often slow and cumbersome – it has to work on an exception basis and it is difficult to assess benefits.

Local health authorities, where they exist, are probably one of the best channels for reimbursing homecare as they often have responsibilities for budgets and can allocate funds to hospitals and homecare organisations as appropriate. They are often hampered, though, either by a lack of a specific policy encouraging homecare or by a lack of resources or data to decide on the appropriate allocation of funds.

The GP and pharmacy route is not ideal, as the GP is usually not the key decision maker. This route has been successful in the past and could become more widely used if co-ordination between the hospital clinician, the GP and the pharmacy could be developed.

Finally, the hospital budget could be used as a source of funds for homecare; the degree of difficulty here depends on the hospital's own funding mechanisms and incentives.

Effect of type of hospital funding

Hospitals are funded in one or a combination of three ways: by an annual budget, per treatment or *per diem* (Figure 5). In Belgium, for example, hospitals receive an initial fee for an 'act', and are then funded *per diem* for the remainder of the hospital stay.

The method of hospital funding is not necessarily an issue if other incentives are in place to encourage home health care but, as we have seen, such incentives do not generally exist. What, then, should we expect hospitals to do with regard to homecare?

With annual budgets, hospitals can be encouraged to use homecare if there is a separate budget for homecare or the hospital's budget is not reduced in the next financial year because of an increased amount of homecare. Unfortunately, the latter is not usually the case: hospital budgets generally depend on capacity in the previous year. Per treatment payment mechanisms can encourage homecare if the hospital gets the benefit of any saving – that is, if the fee is not lower if the treatment is at home. It is generally believed, and supported by empirical evidence, that *per diem* reimbursement encourages longer hospital stays, unless strict capacity constraints operate. Both Germany and Belgium have a surplus of beds by international norms.

In general, when hospitals have no capacity constraints or no financial incentives they have little reason to encourage homecare: managing it requires, as a minimum, some degree of co-ordination with non-hospital services, whereas keeping patients in hospital is relatively easy.

Thus, only France has a formal channel to allocate funds to home health care; in some countries the hospital funding mechanism exerts a positive disincentive to moving care into the home.

Other financial factors

The other set of financial distortions apply to specific products and countries: the rate at which homecare is paid for, and the financial implications for physicians choosing between home and hospital-based treatments.

Reimbursement rates for homecare

There have been a number of examples, primarily when new treatments are introduced, where the reimbursement level for home treatment has been set at a level below the cost of providing the treatment.

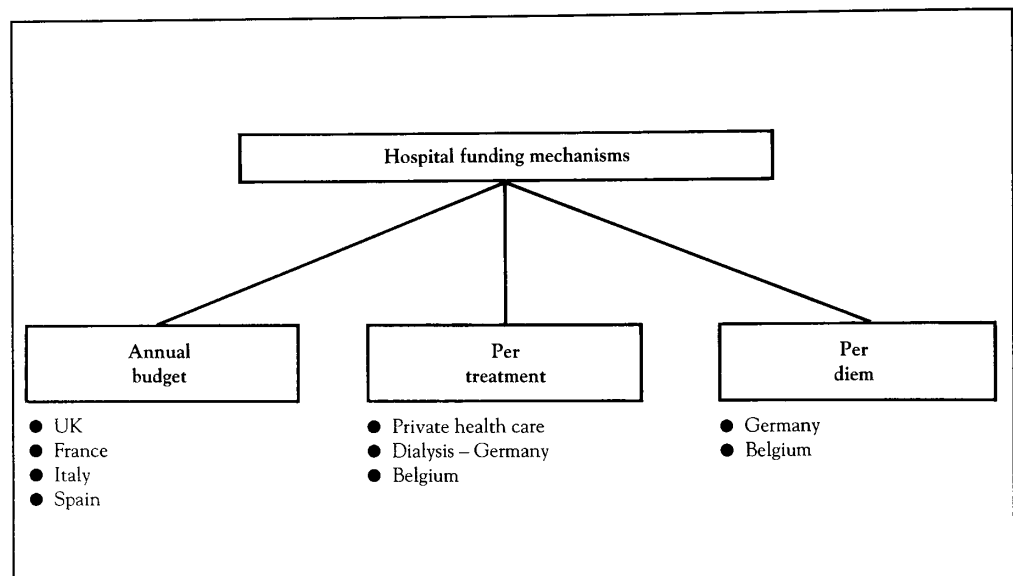


Figure 5. Hospital funding mechanisms

In these cases, very little homecare developed as it required patients to pay the difference.

In general, the issue of reimbursement is a complex one as agencies that set reimbursement levels are trying to keep costs down and companies selling products and services are trying to make profits. Certain situations have existed, however, that appear to set relatively unequal incentives for providing treatment in the home versus the hospital or an alternative site.

The example in Figure 6 is from the Arthur D Little analysis of haemodialysis in hospital, kuratorium (alternative clinical centre specialising in renal dialysis), and at home. The two bars for each type of treatment correspond to the range of reimbursement levels for a month of care. The unshaded portion at the top of the bars represents the fees to physicians and the entire bar the payment to cover total costs. There is no physician fee in the hospital because he or she is paid a salary.

The key decision maker is generally the nephrologist, who is often affiliated with a kuratorium. This person needs to choose not only the type of treatment but also the location, and is faced with different financial payments as a result of the decision. Moreover, the financial incentives to the physician do not necessarily coincide with the cost-effectiveness of the treatment: if the physician earns less, the treatment is more cost-effective. This difference in reimbursement for essentially the same type of treatment is difficult to justify. If reimbursement were based on a diagnosis-related group the nephrologist would be encouraged to consider cost-effectiveness as well as treatment efficacy.

Fees for physicians

Physicians in Europe are paid in one or a combination of three ways: a salary, per capita or per service/treatment (Figure 7). Hospital physicians are generally salaried in the public sector and paid on a fee for service or treatment in the private sector. Ambulatory physicians (GPs or family practitioners) are rewarded in a greater variety of ways: in Spain, salaried with some financial incentives for certain work; in the UK and Italy, by capitation; and in France and Germany and in the private sector, per treatment.

The main decision maker on home versus hospital treatment is usually the hospital physician, and salaried physicians might be assumed to have little incentive for one location over another. However, in practice one of three issues may arise:

- ◆ the hospital budget process is usually based on how busy a particular department is, which creates incentives to keep the department full
- ◆ in some countries it is difficult for the physician to maintain any contact with a patient transferred to the community
- ◆ the hospital specialist in the public sector may also have a private practice and there are sometimes incentives to transfer patients to that facility.

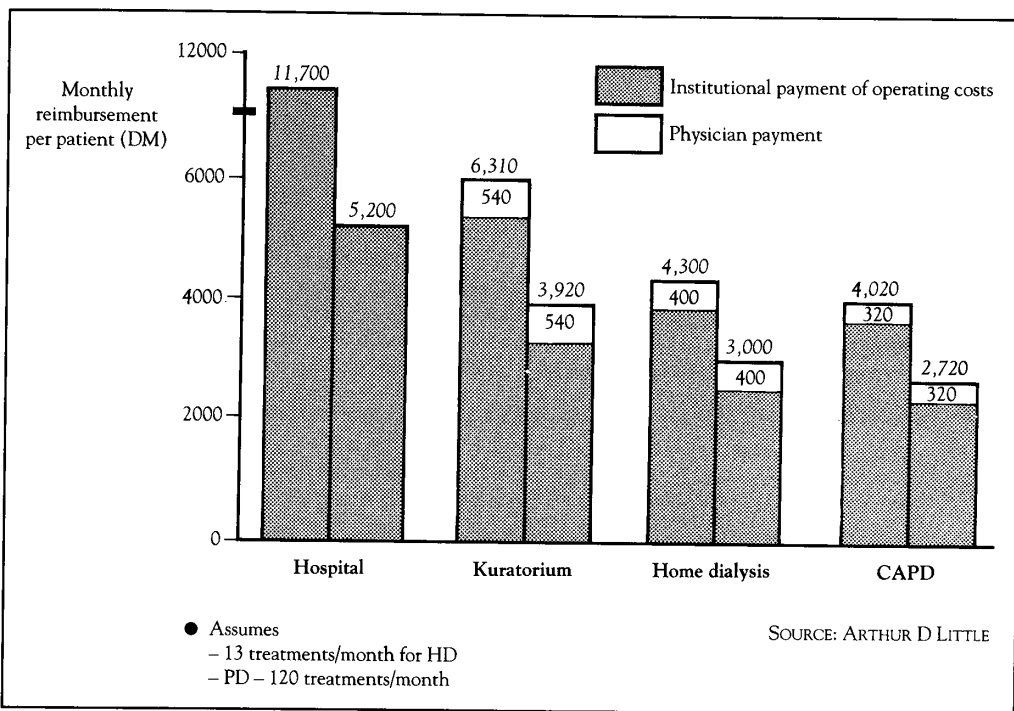


Figure 6. Range of operating cost reimbursement for different locations of haemodialysis

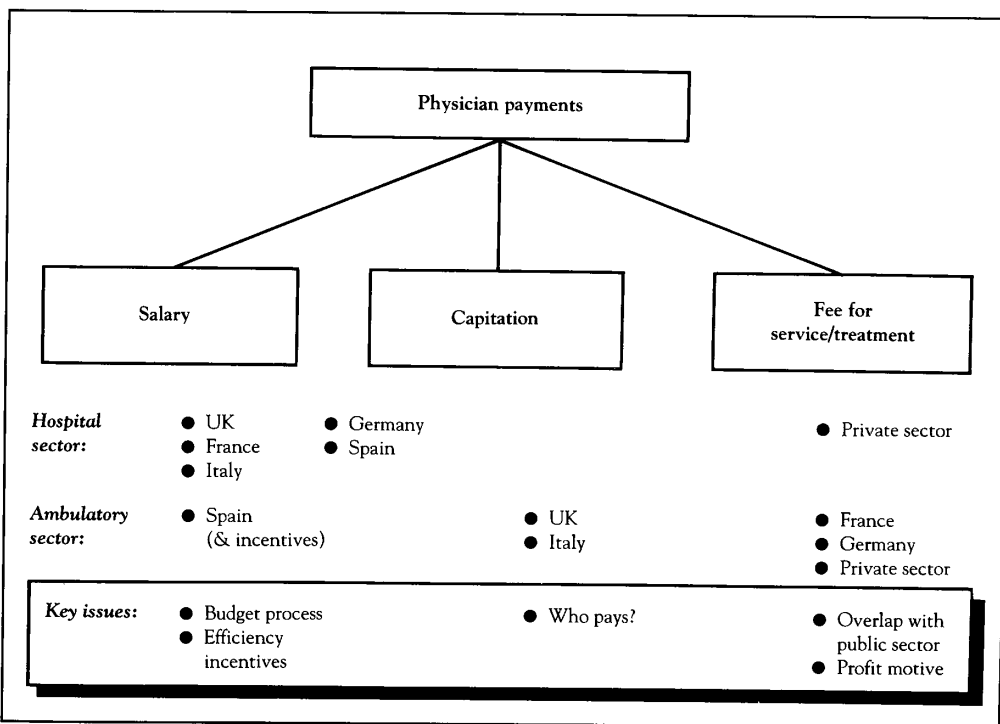


Figure 7. Methods of payment of physicians

The issue quite often reduces to the fact that hospital physicians usually receive some benefit from treating patients in hospital and little, if any, from treating them at home.

What now needs to be done?

Almost every European country has at some time expressed an interest in home health care as an attractive alternative to hospital care for certain patients and conditions. Pilot schemes assessing costs and benefits as well as the organisational requirements have been documented in most of the major countries. We are also witnessing some significant reorganisations of public health care: the UK and Germany have completed some major changes, the Netherlands is in the midst of defining new systems, and in each case emphasis has been placed on creating a larger role for home care.

The focus of many of the structural changes in the UK, Germany and the Netherlands is to encourage a more 'market-based' approach to setting prices for health care. This sort of system could increase the penetration of home care, but only if some of the other structural issues are addressed. The 1989 Act reforming the NHS, for example, makes provision to encourage certain conditions to be treated on an outpatient basis, but it is too early to judge the results.

Other countries such as Italy have also announced projects to promote hospitalisation at home for the care and treatment of the chronically and terminally ill.

Reviewing all this recent activity, one might be tempted to conclude that home care will grow quickly in the future and become an important part of health care. This view might be overly optimistic. The treatments and technology that have made home care feasible and economical are not new. Nor is the discussion of the merits and benefits of home care. The 1984 conference in Brussels on 'Advanced Technologies at Home' dealt with the same products and technologies. At that conference another consultancy (McKinsey) identified⁶ various structural, legal and financial problems that needed to be overcome for home care to continue to develop. Eight years have passed and we have yet to address most of those issues.

So what should health care officials do, especially in those countries that are reorganising their existing systems? First of all, they should establish a policy on home care which does not merely encourage it but sets out a series of specific steps to develop home care. They should define targets and milestones and monitor progress on a regular basis. One of the main issues to be addressed, but not the only one, will be the structural issues related to the financing and funding of home care.

The first objective should be the creation of a payment mechanism for home care that puts it on a comparable footing with hospital care. This does not mean there should be no limits or constraints, only that it should not be any more difficult to fund the treatment of patients at home.

Secondly, hospitals and physicians need incentives to consider cost effectiveness as well as clinical efficacy. For a start, this means that hospital physicians need to have the option of a continuing role in the treatment of a patient at home. It means that the hospital might in some way benefit from a decision to treat at home, and that the pricing and payment practice that are obviously biased against home care are made more neutral.

Finally, more data are needed on costs; not just the direct costs but the entire systems costs of various treatments provided in different ways. It is only with this information that physicians can consider cost-effectiveness of a treatment and that health care policy-makers and officials can see that appropriate resourcing decisions are made.

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REIMBURSEMENT ISSUES AND COST-EFFECTIVENESS

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For over 100 years there has been statutory health insurance in Germany which today covers more than 90 per cent of the population of 80 million. It is administered by seven different types of insurance fund: regional, company and occupational. There are currently 1147 individual health insurance offices. Most people can choose which health insurance fund(s) to join.

Most, and certainly all the occupationally related, health insurance funds are financed by equal contributions from the insured and their employers. The fund managers have to ensure that the expenditure is covered by the income. Costs of treatment are reimbursed directly to the provider of the service.

Home health care has always been reimbursed by German health insurance funds: insured persons are legally entitled to medical treatment at home (including consultants' visits) as well as physiotherapy and provision of equipment such as wheelchairs, plus up to 4 weeks of home nursing care (including household help) if hospital treatment can be avoided or shortened or if home care can provide appropriate medical treatment. The period can be extended at the discretion of the doctors attached to the insurance fund. Home health care is reimbursed only if there is no one living in the house who can provide the necessary care.

Normally, the insurance fund provides a suitable home nurse or home help. Should that be impossible the patient can hire a nurse and will be reimbursed at a previously determined rate.

Home nursing care

This is medical treatment which has been delegated by a doctor to a nurse. It may include injections, enemas, irrigation by catheter or tube, treatment of pressure sores, catheterisation, bandaging, physiotherapy, suction of secretions, blood pressure monitoring,

stoma care, insertion and changing of stomach tubes, emergency control of blood glucose, or assistance with putting on medical support stockings.

Nursing of patients with mental illness may include the giving of medication and monitoring of its effects and side effects, monitoring of the taking of prescribed drugs including continued explanation and motivation, persuading the patient to visit the doctor and accompanying him/her there, advising the patient on problems of daily life after consultation with family members, clinical monitoring and crisis intervention.

The main aim of home nursing is to avoid hospital treatment or to shorten hospital stay.

Basic care

This is provided by trained staff other than nurses, and is provided only if the family is unable to cope, either through physical weakness or lack of the requisite knowledge. It may consist of putting the patient to bed; monitoring of pulse, blood pressure or temperature; prevention of pressure sores, pneumonia or thrombosis; bathing and hygiene; feeding and help with feeding, particularly tube feeding; monitoring of blood glucose; mobilisation; application of trusses, support corsets and other orthotic appliances or prostheses; application of ice-bags, hot water bottles, bandages and compresses; providing information and advice to patient and family.

Household help

Home help is also part of home health care. It includes cleaning the patient's room, cooking or warming up meals, washing up, cleaning the kitchen, shopping for food and medicines, dealing with local authorities on behalf of the patient.

Suitable nurses and helpers

The nurses or helpers are either employees of the health insurance fund, employees of home care organisations, or freelance workers hired by the patient. Nursing treatment may be provided only by qualified nurses, paediatric nurses or nursing assistants. For basic care and household help no qualifications are required: it is sufficient that the home help is suitable for the job, but he or she has to have had relevant experience.

Homecare and household help in pregnancy or home delivery

The health insurance funds also provide basic care and household help in pregnancy or home delivery, in order to enable the patient to avoid hospital stay if she has problems in pregnancy or prefers to deliver the baby at home.

Advice in enteral and parenteral nutrition

A fairly new development in home health care is the provision of advice for enteral and parenteral patients. The health insurance funds have engaged specialist nurses for this purpose. The service provides intensive consultation about the therapy and prognosis of the illness and a 24-hour emergency telephone service. Information is instantly available to the hospital doctor, GP or team doctor.

Technical aids

Technical aids such as catheters, injection equipment, incontinence articles, special bed pads or bandages are reimbursed if prescribed by the doctor.

Payment

The health insurance funds have contracts with suitable organisations for the provision of home health care. Patients have free choice among the providers near their home (extra costs of travel by providers further away will not be reimbursed).

Basic care is paid for in work units of about seven, two of which per day may be claimed. Other forms of service are reimbursed by item of service – for example, stoma treatment 3, pressure sore treatment 2.30, insertion or change of stomach tube 4.10. The average total per day is around 7. Care of enteral or parenteral patients costs about 18 per service unit.

In order to compare homecare with hospital costs one must add the doctor's fee, the cost of technical aids and the cost of drugs and other remedies. It is difficult to draw valid conclusions as to which is cheaper, although it is clearly true that homecare per day is cheaper than a day in hospital, currently about 103.

Expansion of expenditure on home-care

In 1986 the health insurance funds spent 160.3 million DM (55 million) on homecare and in 1990 1,046 million DM (359 million). This is an increase of 553 per cent in only 4 years.

The substitution of hospital care by homecare has not (yet?) resulted in substantial savings, as expected by politicians: the over-all rise in hospital expenditure has not slowed. It increased by 22 per cent from 1986 to 1990 (from 36.6 billion DM to 44.7 billion DM).

This is not surprising, since the costs of the two systems are not directly connected. Hospital costs are influenced by many factors, including changes in disease prevalence and medical innovations. In Germany they are influenced by the financing system itself, which still rests on the traditional *per diem* rate for hospital care, which means it is in every hospital's interest to fill as many beds for the longest possible time. No wonder that Germany has the longest periods of hospital stay of all comparable countries. The consequence is that savings expected from homecare cannot materialise since hospitals have no incentive to reduce length of stay. The only way for homecare to make any impact on hospital costs is to change the financing system.

Of course, homecare cannot be judged on economic aspects only. There are many good reasons, particularly humanitarian ones, to treat patients at home. Who wants to go to hospital if they can be treated as well in their own family? For this reason alone we are resolved in Germany to continue promoting home health care.

SECTION 3

TECHNOLOGY

HOME HEALTH CARE TECHNOLOGY: FUTURE PERSPECTIVES

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Home health care is obviously an increasingly important issue. With the ageing of the population, the number of chronically ill, disabled and frail people is increasing rapidly, straining the ability of the health care system to care for them. This increase will continue during the next decades. Home health care is one way of meeting the needs without greatly increasing costs.

Home health care means the provision of health care services in the patient's home rather than in an institutional setting or a provider's premises. Barbara Stocking has discussed acute medical care in the home, which is the area of growth at this time. In the long run, other types of care will become more important.

Home health care has been found to be as effective as institutional care in a number of areas, and may be cheaper; but if a home health care system is not carefully designed and controlled, it can merely add to the cost of services. Also, hopes to save money through home care based on the expectation that families will take on increasing burdens of care may be dashed if policies to deliver substantial support to carers are not developed.

There seems little doubt that bringing health care services to people in their own homes can decrease hospitalisation and institutionalisation in nursing homes; people can be discharged from hospital earlier; and properly developed home care services can vastly enhance the quality of life of those under long-term care.

The most important aspect of home care is indeed care. So how can technology support or enhance these services, and improve quality of life? Technology used in home health care includes:

- ◆ medical technology such as dialysis machines, respirators, insulin pumps and devices for controlled infusion
- ◆ devices to assist personal functions, including moving, reaching, preparing meals and toileting

- ◆ communication technology (computers, telephone attachments, physiological monitoring and alarm systems) enabling patients to communicate easily with others, including care providers of all kinds.

Medical technology

Medical functions that have already been extensively provided in the home include respiratory care (ventilators and oxygen concentrators), renal dialysis, infusion therapy or pain control, and parenteral or enteral nutrition for those unable to eat. These technologies are well established, and surely will spread.

Treatment of a chronic disorder like diabetes mellitus has been revolutionised by self-monitoring and injection of insulin. Extension of self-testing for abnormal levels of chemicals other than sugar will also surely spread, despite the known hazards of lack of quality control and misinterpretation by patients and carers without adequate training.

The earlier discharge from hospital that is made possible by modern, less invasive endoscopic surgical procedures may require active monitoring at home for infection and bleeding, but this can be provided by a well-trained health care worker using the simplified testing kits now available.

Devices to support daily living

About 15 per cent of the Dutch population has impairment of activity due to chronic conditions, including ailments of the back, spine, lower extremities or hips. Problems that often lead to institutionalisation are difficulties in reaching, bending or kneeling, poor balance, loss of co-ordination, and impaired use of the lower extremities. Publications on home health care seldom pay this topic any attention, but I believe the greatest potential for future technology lies here. Many of the technologies needed are low-tech, such as long-handled soapers, clothes that open in front and adapted kitchen utensils – many of which are now available

from retailers such as Boots and Tesco in the UK; others are high-tech and include remote controllers of light switches and door openers. Developments in materials science and electronics should contribute greatly to home care, but as is mentioned below, many health care systems do not foster the purchase of such technology, so that industry is correspondingly unenthusiastic.

One technological success story is in the production of acceptable incontinence garments using superabsorbers made of modern polymers, and the convincing of industry that this offers commercial opportunities.

With time, I foresee a virtual revolution in this area. Almost any functional problem can be ameliorated, if not solved, by technology. Functional limitations could essentially cease to be a factor in determining place of residence for the elderly. However, policy changes will be needed before such developments actually occur.

Communication technology

Modern communications can connect all parts of health care into a system, charting the flow of events and providing optimal information and standards by which to judge performance. The system thus unified can identify individuals and groups responsible for decision-making and for performing specific tasks. It is hardly conceivable that home care can develop far without such a system.

Through modern telecommunications, data on every measurable aspect of the patient's function can be electronically transmitted, analysed, diagnosed and delivered to the site where it is most useful. How far this will go in home health care is still uncertain. What does seem clear is that people under long-term home care will increasingly be tied into the general system of health care.

The development of telecommunications will not be driven by the needs of home health care: it is determined largely by external events. In the future, such non-health care developments as two-way cable television and video telephones will have great impact on health care. The main problem here is understanding how to use the power of these technologies most constructively.

Patient monitoring is an area of great interest. Many people are hospitalised solely in order to monitor their vital functions closely. Intensive care units expend much of their effort in pure monitoring. As knowledge develops concerning which patients are truly at risk (and such information is developing rapidly), many of them can go home for less intensive monitoring.

Electronic surveillance of the elderly and frail will become important. Many elderly people seek institutionalisation because they are afraid of what could happen when they

are alone – for example, if they fall and break a hip. Electronic monitoring can solve such problems and indeed already does to some extent.

A major problem is that home health care systems have not been planned and developed systematically, but instead have grown to meet obvious needs. There is therefore no model home health care system but a set of unco-ordinated services. Technology requires a supporting system. It must be developed in accordance with needs; a clear market must be evident; it must be provided and paid for; it must be evaluated.

Designing the system to make full use of the technology

Complex technology can be a valuable part of home health care, but its role is severely limited without developments in the system. The organisation of care is at least as important as the technology, especially when different actors and different but related technologies are involved. The community care system must be strengthened and better co-ordinated.

Barriers to the development of home health care services need to be identified and overcome: a task for policy-makers. At present, home health care in the Netherlands does not offer a good market for industry because of its dispersal, the lack of planning and the limited resources that go into it. We must develop policies and projects that stimulate co-operation within the field. At present, no country has a well worked out system of home health care. Planning for the incorporation of technology is critical; however, planning often means rigidity and dogmatism.

Is there hope, then? I think there is, particularly in view of the present moves towards decentralisation. Governments seem increasingly to be moving out of management of health services and taking the role of providing frameworks and (perhaps) critical intelligence.

In the USA, development of home health care technology is well under way. People are beginning to demand care away from hospitals. Such demands will inevitably grow with time. Tomorrow's elderly will not be the same as today's: each cohort is more demanding and readier to criticise services than the previous one. Financing developments in Europe move in the direction of having the money follow the patient, which enhance the potential for patient choice.

MOVING TECHNOLOGY FROM HOSPITAL TO THE HOME: A SYSTEMATIC APPROACH

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This paper describes a planned evaluation of potential forms of home health care which still lies in the future. Current experiments in the broadening of home care in The Netherlands focus on terminal care and extending the role of general practitioner and district nurse: provision of more intensive nursing care and guaranteeing 24-hour cover necessitate new forms of organisation and reimbursement.

In these experiments little attention has been paid to exploring the use of equipment normally deployed only in hospitals, because traditional home care providers' training had a more psychosocial than technical emphasis, the per capita payment of GPs does not encourage investment in equipment, and the reimbursement system does not support extensive use of equipment in home health care.

The Dutch Sickness Funds Council commissioned our work on the basis that more extensive use of equipment might yield more possibilities for substitution of hospital care by home care. This in itself is considered beneficial not, as was at first thought, for economic reasons but because of growing patient demand (resulting from a less humble attitude to care providers) and for 'quality of life' reasons.

Aim and organisation of the project

The over-all aim is to identify technologies which if installed in homes are expected to reduce or prevent hospital stay. In phase 1, potential candidates were selected from lists of hospital equipment by use of the criterion that their use could be the only reason for keeping a patient in hospital. The feasibility of transferring them to a home environment was then checked by reference to a variety of specialists. When opinions differed, the item was retained for further consideration.

The next step excluded technologies which could result in little or no extra substitution of care: usually, technologies that are already widely used in home health care such as dialysis equipment and insulin pumps, mechanical ventilators and oxygen supply, intravenous immunoglobulin therapy, parenteral administration of cytostatics and transcutaneous electrical nerve stimulation.

A second reason for exclusion was obsolescence – for example, continuous parenteral infusion of heparin, which is expected to be displaced by subcutaneous injection of low molecular weight heparin; or at the other end of the spectrum, technologies whose clinical effectiveness is as yet unproven – for example, infusion of FSH for treatment of female infertility.

The remaining technologies were then ranked according to the estimated size of the potential patient population and the expected length of reduction in hospital stay. Both these estimates must be very approximate, since neither the incidence of patients with a particular disorder nor the proportion of that population for whom home health care would be feasible and acceptable is known.

A further criterion was the possible effect on quality of life – which is psychological, physical and social – even more approximate. In a late stage of this first phase we asked some 40 experts to comment on the draft report, and this led to amendment of our initial ideas in some cases.

The next estimates had to do with infrastructural and organisational considerations such as the feasibility of delivering drugs and ensuring the 24-hour availability of medical, nursing and technical expertise, and the amount of extra training necessary in order to guarantee quality care.

Finally, in order to carry out the feasibility studies in phase 2, we had to identify hospital-based medical and other professionals willing to co-operate with care providers in the community. For several topics people could be found who were already engaged in experiments similar to those we wished to conduct.

Results of the selection

The first group had a clearly higher potential, mainly because of the size of the target population and because precedents already exist. This group comprised:

- ◆ parenteral administration of antibiotics, analgesics and cytostatics
- ◆ use of adjustable beds
- ◆ home monitoring of at-risk pregnancies
- ◆ use of air fluidised mattresses.

Infusion therapy

Parenteral administration of antibiotics is used if infections are lodged in a pharmacologically deep compartment as in endocarditis or osteomyelitis, or if the bacteria are resistant to oral antibiotics, or the patient is allergic to them. Quite often the treatment takes six weeks or more, so that substitution of home-care for hospital would represent major saving. The estimated number of patients in the Netherlands is 2,000 a year.

Parenteral administration of analgesics improves the quality of life of cancer patients in the palliative and terminal phases.

Parenteral administration of cytostatics often has a palliative function and again improves quality of life. Outpatient administration is omitted from this study. Eligible cancer patients number up to 5,000 a year.

Adjustable beds

These are necessary for patients recovering from hip and knee implants and fractures of the neck of the femur. In many cases of knee implants a passive motion device is needed. For this expanding group of patients home health care can considerably reduce the waiting list and probably improve mobility and psychosocial function. The number of patients receiving a hip prosthesis is 11,000 per year and fast growing; the number of fractures is at least as high.

Home monitoring of at-risk pregnancies

These number about 10,000 per year. The central technology here is a cardiotocograph, which a specialised

midwife uses to assess the condition of the foetus once or twice daily. Because of the custom of home deliveries in the Netherlands, patients prefer to avoid hospital during pregnancy; however, in assessing this home health care technology, clinical outcome will be critical.

Air fluidised mattresses

There is some experience of using this technology for home nursing of patients with bedsores, severe wounds or bone metastases. The patient population could reach 5,000 per year.

The second group, with lower potential, comprised:

- ◆ enteral and parenteral nutrition
- ◆ traction for children with congenital dysplasia of the hip
- ◆ phototherapy for treatment of neonatal jaundice.

Enteral and parenteral nutrition

Enteral nutrition is already more or less routine in home health care; its extension is hampered by organisational and financial problems.

Parenteral nutrition at home is also used to a small extent. Because of the rather small patient population extra substitution would not have much effect.

Traction for congenital dysplasia of the hip

There is some experience with providing this in the home. Although the number of patients is small, the expected reduction of institutional stay may be considerable (about 30 days), and for children this is of major importance.

Phototherapy for neonatal jaundice

The conventional mode of treatment is not appropriate for home care, but there are now fibre-optic blankets which can be wrapped around the neonate. However clinical effectiveness has not yet been established.

Second phase: experimental introduction

The effectiveness of the technologies selected in home health care will be evaluated using clinical outcome and quality of life as main criteria. Economic aspects will also be evaluated.

Requirements for the proper use of the technology in the home will be determined. Provisional guidelines will be developed before the field experiment starts. They will include:

- ◆ requirements concerning patients and their home situation, such as necessary skill
- ◆ requirements concerning the quality of the equipment, including ergonomic as well as technical aspects, with emphasis on safety and reliability
- ◆ requirements concerning professional care such as necessary skills, necessary infrastructure and logistics.

If the evaluation is positive, the requirements will be published as guidelines. After validation of the guidelines and possibly consensus development of their contents they may be used to promote further spread of appropriate applications of medical equipment in home health care. That at least is the plan.

SECTION 4

**SHORT-TERM
HOMECARE**

HOSPITAL-BASED HOMECARE: A POST-DISCHARGE HOSPITAL OUTREACH SYSTEM IN SWEDEN

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Hospital-based home care (HBHC) started in Motala in 1976. Staff stationed at the department of geriatrics are on stand-by duty day and night to call on patients who live at home with the support and assistance of the hospital's resources. We usually describe our HBHC service as 'a hospital bed in the patient's own home' – that is, the expertise and technical resources available at the hospital can quickly be moved to the patient's own home whenever needed. This hospital outreach system covers a population of 87,000.

At night the emergency cover is provided by the doctor on duty in the department, with consultant backup. Other staff are shown below.

Staff of the hospital outreach service

◆ Consultants	2
◆ House physicians	1–2
◆ SRNs	21.5
◆ SENs	24.5
◆ Occupational therapists	2.5
◆ Physiotherapists	1
◆ Medical secretaries	2

We make scheduled calls both day and night, as well as emergency calls when the need arises: 34,700 per year by day and 17,500 by night, 10 per cent of them by doctors.

There is 24-hour access to advice and consultation. By using a special phone number, patients can immediately contact someone who can help and answer questions. Staff transport is available in a fleet of cars leased by the hospital.

About 95 per cent of our patients go home directly from the hospital's acute departments. About 40 per cent of our patients live alone. The service can provide 24-hour nursing at home for up to one week. Where there is a family it is imperative to give them advice and support. It is very important to ensure that the care given accords with the wishes of both patient and family. There are therefore always empty beds available at the hospital to ensure security for the patient, family and staff and that the arrangement is voluntary on the part of the patient.

The most common diagnoses are cancer, cardiovascular and pulmonary disorders. The cancer patients are at all stages, most of them terminal. A patient is regarded as terminal when a diagnosis has been made, death is expected within 30 days and the treatment is no longer curative but palliative.

The patients display a great variety of symptoms, ranging from severe pain to nausea, vomiting, itching, dyspnoea, coughing, constipation or dryness of the mouth as well as fungal infections, anxiety, confusion and terminal restlessness. What can HBHC do to cope with such variety?

After 15 years of continuous experience, I offer the following imperatives:

- ◆ an empty bed at the hospital. Knowing there is one available will supply the courage, not only to patient and family but also to staff, to continue caring
- ◆ doctors and nurses available round the clock
- ◆ the possibility of reaching them day or night – co-operation of specialists such as dentists, oncologists, surgeons, anaesthetists and a working relationship with medical services (for example, x-ray department) for patients dependent on a permanent sinus catheter, a part-time ventilator or central venous line

- ◆ a well-organised community-based home help organisation (this the patient has to pay for, whereas home health care is paid for by the county council)
- ◆ technical aids such as electrically operated beds, different kinds of lifts and hoists, security alarms linked to treatment such as blood transfusion, continuous intravenous drug delivery, ventilators, oxygen concentrators, infusion pumps for pain killers and central vein catheters, all requiring special skills
- ◆ sufficient transport to guarantee arrival of staff within 30 minutes
- ◆ support to staff
- ◆ economic support
- ◆ clear recognition that palliative care is intensive care which requires trained and skilled staff who know how to provide adequate symptom control to patients with advanced disease
- ◆ family support. Life must be worth living for supporting family, even after the death of a dear and close relative.

Statistics for hospital-based homecare at Motala, 1990

◆ average number of patients	113/day
◆ patients in terminal care	216/year
◆ mean cost, all patients	36
◆ mean cost, terminal patients	50

SHORT-TERM CARE AND TREATMENT IN THE HOME: NURSING PERSPECTIVES

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This paper deals with the optimal organisation of nursing services for home health care and the essential prerequisites for successful acute home nursing programmes. It is based on experience with the Peterborough hospital at home programme, and distinguishes between the types of patient for whom a community-based model and those for whom a hospital outreach model is appropriate.

Organisation of nursing services to support home-based acute care

The two main models for acute home care provision, hospital outreach and community-based, exist in the UK alongside a long-established district nursing service which has traditionally been dominated by the home nursing needs of the elderly, the chronically sick and the disabled.

The hospital outreach model

In this model a specialist nurse, or specialist team of nurses and other staff, is based in a hospital ward or unit and staff go out from there to care for patients after discharge and sometimes before admission, as well as patients referred for specialist hospital care but who can receive it at home.

Such schemes are attractive to hospital nurses, consultants and managers because admissions can be avoided or curtailed while the hospital retains control of resources which can be released within the hospital. The problem arises, however, that the outreach team must provide care for a geographically dispersed population and maintain high levels of staff with an expensive skill mix to be able to deal with all eventualities, with the result that staff time and expertise may be under-utilised.

Outreach scheme nurses are usually qualified in the specialty but not necessarily additionally qualified to work in the community. Their clinical knowledge and skills may be more advanced and more readily

maintained than those of the average generalist district nurse, but they may have less knowledge of and contact with nursing and other services in the locality and, more importantly, may be less comfortable with or unaware of the different mode of operation required of primary health care professionals.

At their best, especially where hospital and community nursing staff are members of the same team (as is true in some schemes), outreach schemes are able to complement and liaise closely with primary health care teams of general practitioners (GPs) and district nurses, requesting and supplying information in a two-way flow so that patients needing any continuing home care can be transferred wholly to the primary care team with minimum disruption. And by teaching and advising they support the practice of district nurses who can then increasingly respond to patients' acute care needs as they gain the necessary knowledge, skills and confidence.

One of the main attractions of this model is that specialised nursing care is given by specialised nurses, which is particularly valuable for patients with uncommon conditions or unusual nursing needs requiring high-technology care where access to hospital-based technical backup may be essential.

At worst, however, according to the District Nursing Association,¹ the growth of such specialist nurses threatens to fragment the care of patients and undermine the role of the district nurse by cutting across the holistic approach and de-skilling the district nurse and to risk being confusing for patients. The hospital outreach model may, indeed, serve to confirm the Cinderella identity and marginal status of the district nursing service, left to cope with the elderly, the disabled and the chronic sick. Consequently, district nursing has been slow to involve itself in acute home care provision, causing Linda Marks in her recent review² of hospital care at home to observe:

It is ironic that such services, which led the way in the provision of domiciliary care, should now lag behind in the provision of hospital levels of care at home.

The community-based model

However, there is now growing interest in and enthusiasm for involvement in homecare on the part of district nurses and their managers, partly as a result of experiences in developing the other model to which I now turn: the community-based scheme fully integrated with the district nursing service, covering the whole resident population rather than providing only for those patients of particular hospitals or specialist hospital units.

Specialist posts and teams

In some localities individual specialist posts or small teams have been created within the district nursing service to provide augmented or supplementary home nursing to patients needing intensive care, either through high-dependence chronicity or acute or terminal illness. Paediatric district nurses are used in an increasing number of places to provide general or specialist nursing care to a range of acutely or chronically sick children, the disabled or the dying. Many district nursing services also now employ a variety of specialists to support and advise staff and patients in relation to stoma care, continence and other special needs, as well as liaison nurses who facilitate communication between hospital and district nursing staff.

Hospital at Home

I now describe a scheme which I think illustrates possibilities for a more comprehensive approach. The Peterborough Hospital at Home (HAH) scheme was launched in 1978 and was based on the Bayonne hospitalisation à domicile programme in France. Initially it was run as a team of nursing and other staff separate from the district nursing service, although it was based in the community from the start, and provided care for a catchment area with a population of 24,000. In the first year only 32 patients were admitted to the scheme. Many inappropriate referrals were made, GPs found it difficult to liaise with the HAH nurses, and the nurses from the district nursing service objected to their patients being cared for by nurses from the scheme whom they did not know.³

In 1979 the scheme was remodelled, extended to cover the whole health authority population of over 200,000 and fully integrated into the district nursing service. It now cares for approximately 400 patients each year (up to 24 at any one time). The criterion for admission to the scheme is that without HAH the patient would be admitted to or remain in hospital, and patients with a wide variety of nursing needs are catered for.

Nursing care is arranged and supervised by the district nursing sister attached to each patient's GP, the latter agreeing to hold medical responsibility for the case. On referral, the district nursing sister consults the GP or hospital staff caring for the patient, makes a nursing

assessment of the patient's needs and decides what help is required beyond what the district nursing team can provide. The district nursing sister calls on a small establishment of nursing staff contracted to the scheme and on a much larger 'bank' (100), half of qualified nurses and half of patients' aides, to provide care for up to 24 hours a day. This allows for great flexibility in staffing levels, since bank staff work only when needed. The scheme also has access to dedicated physiotherapy and occupational therapy, and other services available to patients in hospital. Patients' aides are a vital element of the scheme, providing basic nursing care and domestic support and, latterly, acting as physiotherapy helpers.⁴

After its problematic start, the Peterborough scheme is now enthusiastically supported by doctors, nurses and patients and their families⁵ and is being emulated in other areas. The initial hostility evinced by district nurses has been dissipated by making them central to its operation and enabling them to use and develop their nursing skills to the full.

Within the Hospital at Home scheme, subschemes have been developed: for early discharge after surgery for hip fracture,⁶ gynaecological patients, and acutely ill children – alongside the well-established nursing of chronic paediatric cases at home. But the scheme remains primarily homecare in acute illness – including acute episodes within a chronic disorder – either after early discharge from hospital or instead of admission to hospital.

What are the essential prerequisites for successful acute home nursing programmes, as suggested by the Peterborough and other British schemes?

First, nursing staff must be available, willing and able to be involved, and their increasingly scarce human resource must be used cost-effectively by varying the skill mix of homecare teams to suit the needs of individual patients and their families. The scheme must cover a large enough population to justify the time and money spent on organising and equipping the service appropriately, on providing and training the nursing and other staff to provide intensive and sometimes complex clinical care, and on keeping them updated so that they can give this care with safety and confidence.

The lead worker, probably the district nursing sister, must possess both managerial and clinical skills to enable her to function as the co-ordinator of care and of resources, to assess suitability for homecare, to monitor recovery, and to act as a clinical expert in specific areas.

The quality of the personal and professional relationships between all the individuals and parties concerned is central to the success of any scheme. Fully involving the primary health care team must be one starting point, as must shared protocols for treatment agreed between the relevant doctors and nurses, both in and out of hospital. One important spin-off of setting up and running HAH schemes of this type is that hospital and community medical, nursing and other staff get to know and respect each other's contribution.

The scheme must be trusted and supported by medical and other colleagues, and by the patients and their families, to work reliably and efficiently. This means that the scheme must be led by a nurse with sufficient seniority and managerial experience to ensure good management and organisation and strong professional leadership for staff. The nursing services provided must be flexible, available round the clock, in sufficient quantity and quality, and at short notice. Carefully worked out procedures must exist for admission and discharge. Admission criteria must be rigorously applied so that those with the hour-by-hour responsibility for home care are able to control entry to the scheme by careful patient selection, assessment and monitoring.

A dedicated nursing post for liaison between the hospital and community staff is likely to be essential for good co-ordination and communication, as is the facility for patients to summon help, for example by radio or mobile telephone.

The necessary specialised equipment must be available and in good order, and there should be no delays or difficulties in obtaining supplies or medication. (Legislation is expected in the UK soon which will allow qualified district nurses to prescribe drugs from a limited formulary, which should greatly assist in this.)

The key, however, to an effective scheme must be the extent to which it is patient-centred rather than organised for the convenience or benefit of the service or the people who work in it. Some schemes have found that, while many people given the choice would prefer to be nursed at home in an acute illness, the price paid by their families is often high in terms of the stress and disruption caused, and in terms of the contribution to care which relatives and friends may have to make. Home-based acute care will not be successful from the users' point of view if their time is seen as a cheap alternative to hospital care. And patients and their families must be given comprehensive written information about the scheme and be fully involved in decisions about levels and types of care needed, so as to retain a sense of control over their care.

This is where patients' aides – note, not nurses' aides – come in. If a family's personal, social and economic life

is to go on around the sickbed of an acutely ill patient, the family will need help with aspects of the patient's personal care and housekeeping requirements – bathing, catering, cleaning, laundry and so on. Special provision must be made for meeting these needs, ideally with a dedicated trained workforce under the direction and control of the district nurse, and it must also be available day and night if necessary.

Two conclusions from the nursing point of view

First, we need to separate in our thinking those patients who need intensive and highly specialised acute care of the kind they would receive in a specialised hospital or unit from those who need intensive nursing care, therapy and hotel services of the kind they would receive in a general hospital. In the former case, hospital outreach schemes with close links with the community services are likely to be the best, while properly organised community-based schemes will be well able to cope with most patients needing acute care, and probably represent a more cost-effective use of resources.

Second, the number of district nurses being trained has been falling for some time now, and entrants to nursing in general will in any case become scarcer as the result of demographic change. The appropriate use of unqualified (though trained) staff therefore represents a major challenge, since no scheme to provide acute care at home can function effectively without them, whether for nursing or domestic support. Responsibility for social care in the UK is held by local authority social services departments, not by health authorities. But the dividing line between health and social care is unclear, whether we are talking about acute or longer-term nursing or community care. Here is a matter of organisation which remains to be resolved.

In my opinion, the answer to the question posed by Barbara Stocking in her keynote address 'Can community nursing cope with the intensity of nursing required for high-quality acute home care?', is that it can, given the kind of organisation typified by schemes such as Peterborough HAH, and a commitment by all concerned to break down the barriers between hospital and community, so that patients can receive sensitive, safe and appropriate care wherever they may be. It is now up to the commissioners or purchasers of health services to demand such schemes – adopting the specifications for quality I have outlined – and up to community providers, including district nurses, to show that they are willing and able to deliver.

I appreciate the help received in the preparation of this paper from a number of colleagues, particularly Liz Allen, Alison Barnes, the District Nursing Association, Linda Marks and Lynn Young.

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SHORT-TERM HOMECARE: PATIENTS' ISSUES

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The trend towards home health care has been stimulated by more than economic considerations and technological advances. The wishes expressed by patients and their desire for personal attention are the driving force behind the planned shift in the Netherlands from hospital to homecare.

Most of the 'marketing potential' in homecare lies not in the discharge of acute inpatients to the community but in the phase before admission to a residential institution, and takes the form of aids and apparatus enabling people to remain at home for as long as possible.

Dr van Beekum examined the technological options for shifting from hospital to homecare. There is a danger, although I know this was not his intention, of creating the impression through such an analysis that homecare is primarily a technological question. In order to dispel this impression, I shall look at the subject from a different viewpoint, disregarding the economic approach which concentrates on the marketing potential of home health care and on ways of reducing government expenditure.

In February 1991 the Dutch Health Council published a report, unfortunately available only in Dutch, on the issues which merit attention when patients in the terminal stages of cancer who can receive only palliative treatment are moved back home. A number of the technological advances to which Dr van Beekum referred are relevant to such patients: the parenteral administration of analgesics and cytostatics, adjustable beds, air fluidised mattresses and enteral and parenteral nutrition.

When cancer patients are receiving palliative care, and certainly when they are terminally ill, the scope for specialist care decreases and general care becomes increasingly important. Patients starting from widely different standpoints begin to enter a common clinical pathway. The primary aim of care is now to ensure that the best possible quality of life is maintained for as long as possible. As the number of patients with similar characteristics grows, the need for patient care to be

concentrated in one place declines. The proportion of medical care needed decreases and the proportion of nursing care, with psychological counselling of patient and carers, rises. The conclusion is that ways must be found of transferring a fairly large number of patients from hospital to their own homes.

The Health Council report lists five points which must be satisfied if homecare is to be of an acceptable standard. They are dealt with in turn below.

1 Support for home carers

Before a patient who still needs a considerable amount of care and support is discharged, a detailed care and support regime must be compiled showing what such care and support consist of and how they can be provided in the care environment.

The length of time for which family and friends are expected to provide care, and the depth of support available, are crucial here. Both professionals and non-professionals providing care in the home will need information, counselling, assistance and relief. Activities in this regard should be co-ordinated. If the patient needs more human contact than the regular carers can offer, consideration should be given to calling in other volunteers. Other important points include an allowance to cover expenses, the possibility of respite care and a care budget.

2 Co-ordination of care

Contributions from the wide variety of organisations – hospital, GP, home nursing organisations, family, psychological services, physiotherapists and those who supply and maintain equipment – must be co-ordinated from a single central point.

3 Maximum participation by patients and families

Truly informed consent of the patient and the immediate family must be given, especially if homecare is not an

obvious option. This is particularly important if homecare is likely to be extended and if the technical aids will be prominent in the home.

Because homecare can be at odds with the need for personal privacy, especially if care is to be provided by volunteers outside the family, patients and carers must participate in the decisions on exactly what form professional help will take. If the patient or the immediate family is the central point from which care is organised, most of his/their time will be spent organising care providers, and there will be serious doubt about the quality of life thus achieved.

4 Trained primary carers

Carers must be sufficiently well trained before the patient is sent home. This may mean non-professionals gaining experience in operating apparatus or administering treatments. This is extremely important, as anxiety and uncertainty impose a heavy psychological burden on carers and patient. The specialist and/or GP may need to draw up instructions on how to cope with pain and other symptoms. It is important that respite carers can also adhere to any agreements made on the nature of care and the way it is to be provided.

5 Guarantee of continuity

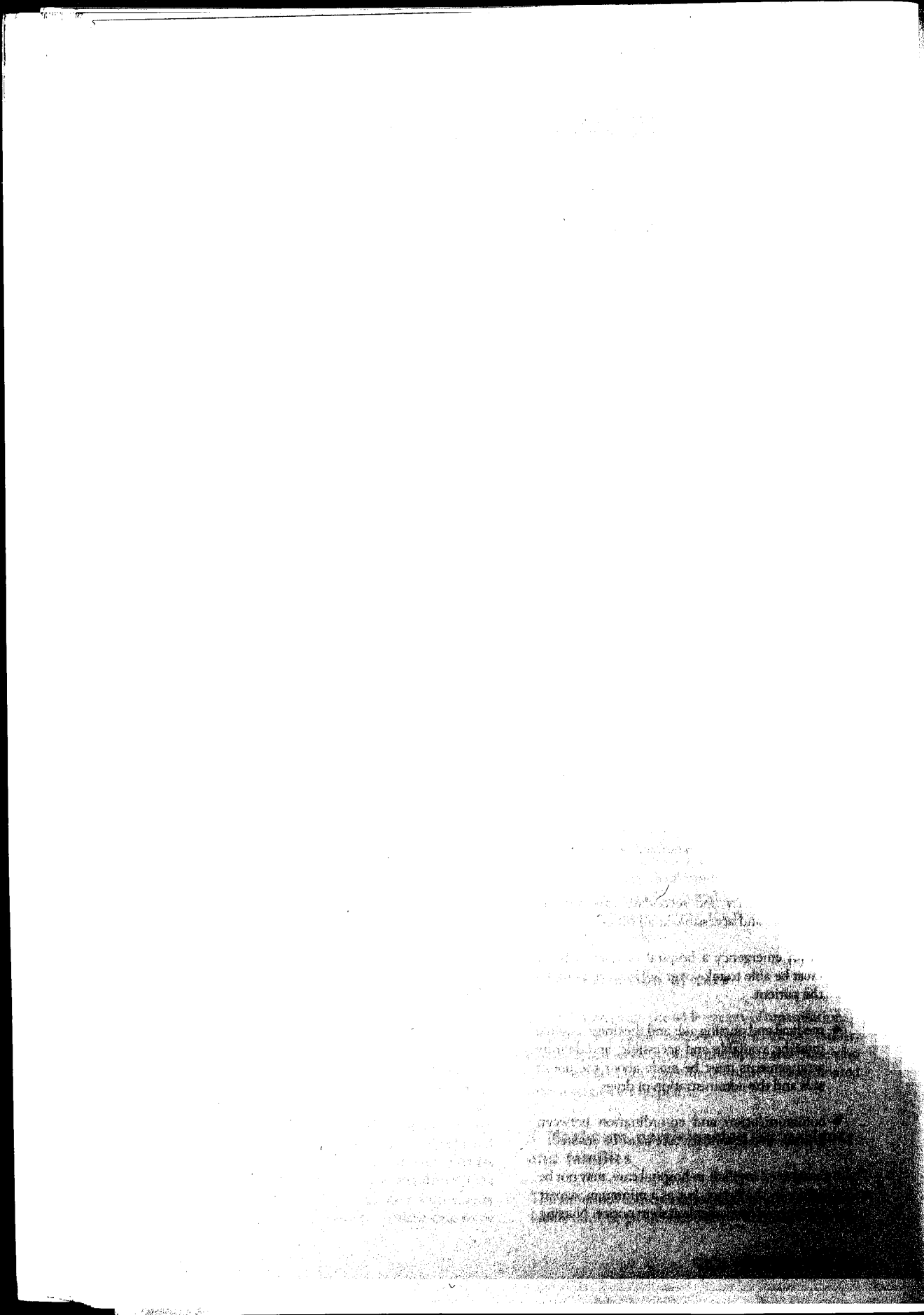
Homecare differs from hospital care in several ways. In particular, patients can expect more personal attention at home than in hospital, and I believe this to be one of the principal reasons for the demand for homecare. On the other hand, hospitals can provide guarantees of care which are not easy to furnish at home, although they are essential to the patient's trust.

The Health Council report lists the following forms of provision which must be guaranteed before a shift to homecare can be made:

- ◆ expert primary and secondary care must be available and accessible at all times
- ◆ in an emergency a hospital or nursing home must be able to take over full responsibility for the patient
- ◆ medical and nursing aids and the drugs required must be available and accessible, and definite arrangements must be made about the use of aids and the administration of drugs
- ◆ communication and co-ordination between primary and secondary care must be ensured.

These guarantees, implicit in hospital care, may not be so immediate in the home, but as a minimum, expert intensive care must be available at short notice. Nursing

homes may help to provide this assurance. In any case, health care policy measures are called for to bridge the gap between primary and secondary care.



SECTION 5

**CONTINUING CARE
IN THE HOME**

LONGER-TERM ACUTE HOSPITAL CARE IN THE HOME

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It is often argued that acute care is, by definition, short term. In practice, however, people may spend a long time on acute wards. In some cases, the use of the acute bed is generally perceived as inappropriate and patients are, rather uncharitably, stigmatised as 'bed blockers'. There are other patients who may occupy acute beds for longer periods because home health care alternatives are either not considered feasible for clinical reasons or because a framework for providing intensive home health care is lacking. This paper highlights four different kinds of continuing acute care which can be provided at home.

Examples of acute continuing home health care

- ◆ technology-dependent care
- ◆ intensive nursing and rehabilitative care
- ◆ intermittent healthcare
- ◆ domiciliary terminal care.

It then identifies different options for organising these services and finally explores specific issues raised by long-term technology-assisted home health care.

Four kinds of acute continuing care (hospital care at home)

Three caveats. First, the term 'hospital care at home' (HCH) is a transitional one: as it becomes standard practice for certain kinds of acute hospital care to be transferred into the home, so the organisational boundaries between home and hospital care are redrawn and the meaning of the term changes. Secondly, certain kinds of long-term acute home health care shade into an area better known in the UK as community care, and share similar problems. Thirdly, the four kinds of continuing acute home health care described below are not mutually exclusive, and might all apply at different times to the same patient.

Technology-dependent care

This is the kind of care in which a patient's life depends on technology: mechanical ventilation, renal dialysis or parenteral nutrition. These may or may not require nursing care. About 500 people in the UK use mechanical ventilation at home.¹ However, Goldberg² reminds us 'one should remember that the ventilator-dependent person, even when stable, can still be considered a candidate for intensive care'. In the absence of a national programme of home health care in the UK, this is where some remain. I return to this form of home care as a case study later in this paper.

Intensive nursing and rehabilitative care

The expansion of this kind of care depends on rethinking the boundaries between nursing care in hospital and nursing care at home. In practice this may involve assessing the intensity of nursing care and the degree of clinical monitoring required throughout a hospital stay in order to establish the point at which home nursing is safe, cost-effective and organisationally feasible. This may result in plans for hospital outreach, expanded community nursing services or bridging arrangements between the two. It may involve reassessment of nursing tasks, both at the clinical end of the spectrum and at the boundaries of nursing and personal and social care, particularly where longer-term care at home is involved. This form of continuing acute care raises important questions about the boundaries between health and social care, how these are represented in skill mix, and who is to pay. Longer-term acute care in the home is unlikely to be exempt from these enduring problems of community care. A particular issue in the UK, for example, is the extent to which the NHS, and which part of the NHS, bears primary responsibility for longer-term intensive nursing care. The potential of HCH schemes for altering the balance between home and hospital rests in this area of intensive home nursing care for common conditions such as cancer, myocardial infarction and stroke, and for specialties such as orthopaedics. Intensive nursing care can be provided at home for these and other conditions, witness the Peterborough Hospital at Home scheme.³

Intermittent care

The third kind of care is intermittent care, where people with complex, ongoing health problems pass in and out of the need for acute care, and where home health care may prevent or reduce repeated hospital admission – for example, people who are HIV positive or children with cystic fibrosis. A service provided for those at risk, and able to provide preventive and diagnostic care, could respond quickly to emergencies and prevent some hospital admissions.

Domiciliary terminal care

This is the longest established form of intensive home health care. Arguably, over the last 20 years it has paved the way for providing intensive levels of care at home, both in showing the standards of care and sensitivity that can be provided in a home setting and in illustrating the wealth of organisational arrangements which can be harnessed to provide flexible home and hospital care. This includes day care, hospital and hospice outreach services and specialist teams working closely with primary care. Many broad-based HCH schemes began as schemes for terminally ill people. Although the Peterborough scheme was not set up with this intention, people who are terminally ill still form the largest group there.

These 20 years' experience has important lessons for those seeking to provide HCH. Independent, ad hoc development has led to geographical variations in coverage. Private investment in home health care may well lead to the same problems of piecemeal development and poor integration with NHS services.

Ways of organising hospital care at home

Recurrent themes for those managing services, whether on a short- or longer-term basis, are:

- ◆ how to ensure quality in the home environment
- ◆ how to gauge manageable caseloads and
- ◆ how to assess the cost-effectiveness of providing acute levels of care in the home.

Six main models for HCH have emerged in the past two decades:

- ◆ hospital outreach
- ◆ new 'extramural' hospitals
- ◆ expansion of publicly funded community health services

- ◆ independent agencies providing specialised services
- ◆ the specialist resource –
 - hospital outreach
 - independent specialist staff
 - specialist teams within community health services
 - equipment manufacturers
- ◆ national, regional and state approaches:
 - developing guidelines, registers and quality control.

Hospital outreach

Hospitals may themselves develop their role in providing home health care, establishing early discharge schemes and specialist outreach teams in order to rationalise the use of acute beds. In the USA, for example, where domiciliary care is fragmented, many hospitals have set up their own home health agencies, which are subject to all the regulations and standards of the parent hospital, and quality control is equivalent to that in hospitals. Seventy per cent of US hospitals participate in some kind of home health care scheme. In the UK, it is possible that NHS trusts will set up their own schemes or enter into arrangements with agencies providing home care.

Extra-mural hospitals

Canada provides us with a different model in the New Brunswick extra-mural hospital, set up in 1981.^{4,5} Funded by the government, it has the legal status of a hospital and is a free-standing provider of acute hospital levels of care in the home. One of its aims is to explore and expand the *safe* limits of home health care. An important distinction between this arrangement and primary care services in the UK is that the extra-mural hospital retains control over admission – there is no automatic right of referral from acute hospitals or from the community. This would jeopardise the ability to guarantee standards required in acute home health care.

Expansion of publicly funded community health services

A third option is extension of existing community health services where these are already well developed, as in the UK. This may involve the creation of specialist teams and advisers or the provision of a generic HCH scheme, as in Peterborough. In general, because of the close links between community nursing and GPs rather than with hospital consultants, such

schemes have tended to reduce hospital admission rather than promote early discharge, and it has proved difficult to establish the extent to which these services provide a true substitute for acute hospital care. In addition, the emergence of HCH will expose uncertainties over the degree of specialisation that can be incorporated within existing primary health care services.

Independent agencies

Independent home health care agencies may be profit or non-profit making. They may provide a range of homecare services or specialise in particular areas, such as the services provided by certain equipment manufacturers. Thus in the USA the providers of enteral and parenteral nutrition have become the focus of intense commercial activity.

The specialist resource

A specialist resource may be provided by hospitals, the community, charities, commercial firms and others. One example of independent specialist staff in the UK is provided by Macmillan nurses, who receive training from the Cancer Relief Macmillan Fund (a charity) but who then work closely with hospitals and the community as part of the NHS. They provide a direct service to cancer patients, taking their skills in pain relief, symptom control and emotional support into people's homes. There are about 800 such nurses in the UK.

National, regional and state approaches

Finally, the organisation of acute care at home may take place on a regional or state level. For example, in France most home ventilator care is organised by 28 regional associations which provide support to over 10,000 people requiring oxygen therapy, of whom roughly 1,200 are dependent on ventilators. A national co-ordinating body provides standard setting and quality assurance. Where therapy has to be provided over a number of years, and where it is important to keep the needs of a special interest group in mind, organisations of this kind can provide the support foundation of a self-help group, the quality control exercised by a national standard-setting body and the essential practical functions of equipment purchase and maintenance.

There is clearly no shortage of organisational models for delivering HCH. While the choice of model is largely influenced by the ways in which domiciliary health care is delivered and funded, it may also be the case that some forms of intensive care at home benefit more from one model than another. Thus the preferred model for relatively uncommon types of technology-dependent care at home seems to be hospital outreach, with easy access to a specialist centre if needed.

Case study: ventilator care at home

Some of the issues raised in continuing acute home health care are illustrated by the provision of ventilator care at home. Though people requiring artificial ventilation (AV) are few, they are highly noticeable because of the time they can spend in intensive care units. Patients receiving this form of homecare are very vulnerable: their life depends on a machine and there is no margin for error in equipment maintenance or emergency cover.

Constraints on expansion of this service

It is not the technology that is the problem in expanding this service. Mechanical ventilation is neither high nor new technology: although new devices are still being developed, the prototypes have been around since the 1950s (just as those for parenteral nutrition have been since the 1960s). The patchy diffusion of AV at home within the UK and internationally, therefore, is due to (a) whether the service is organised on a national or local basis, (b) professional attitudes, (c) the priority attached to rehabilitation in general, and – particularly in this case – (d) the links between acute and intensive care on the one hand and rehabilitation on the other. Fox et al point out⁶ that the major constraint on the expansion of technology-dependent home health care in the USA was the policies of payers, not the safety and effectiveness of devices and procedures. We can contrast the rapid growth of nutritional therapies at home, where companies manufacturing nutritional support products have become involved in assessing, educating and treating patients.

Stages in preparing for home health care

As in all forms of acute care at home, there are various stages to be gone through before HCH can begin:

- ◆ patient selection
- ◆ assessments of the home
- ◆ involvement of patients, carers and families in discharge planning
- ◆ decisions over clinical responsibility
- ◆ instruction of patients and carers
- ◆ care plans, including emergency cover.

All homecare can impose strains on carers, and there has to be collaborative decision making based on a realistic understanding of the demands, benefits and consequences of home health care. A balance has to be struck, for example, between lack of privacy experienced

by families who receive long-term professional help at home and the extra strains if such help is inadequate.

The patient as expert

Individuals requiring AV become expert in managing their condition, as do carers. For example, in a US study⁷ of ventilator-dependent children, parents' skills included gastrostomy feeding, tracheostomy care, chest physiotherapy, cardiopulmonary resuscitation, and teaching and supervision of nurses and other personnel. Control rests with the family in the home, and this can be difficult for professionals to accept. It also means that a primary care team may not always be favoured as the first port of call in a crisis, people preferring to contact specialist centres.

Providing long-term personal care

Many people on ventilators require high levels of personal care. Care at home, whether it falls under the rubric of community care or of acute care, increasingly involves the creation of new kinds of professionals carrying out a blend of personal, domestic and social care – patient aides, care attendants and so on. Polio survivors living at home in the UK, who called themselves Responauts, choose their own care attendants, although a specialist unit, the Lane Fox unit at St Thomas' Hospital, monitors applicants and trains them. Continuing care at home crucially depends on the availability of suitable attendants.⁸

Ethical aspects

Medical technologies that sustain life in critically or terminally ill patients, including mechanical ventilation, dialysis and nutritional support, raise ethical issues over what has been called the 'imperative to therapy'. These are not, of course, specific to home health care.

Safety and professional liability

There are few guidelines for technology-dependent home health care, and there are wide variations in practice. Commenting on the reluctance of US physicians to become involved in home care in general, Fox et al write⁶ 'Physicians are cautious about home care because patients are fragile, therapeutic devices are often defective or unproven, and personnel are unknown to them... Hospitals, although not free from risk, have carefully selected and verified personnel procedures for ensuring safety and cleanliness and systematic back-up.' Against this backdrop, it is particularly important that successful initiatives are widely disseminated.

Cost-effectiveness demonstrated

Cost-effectiveness studies of ventilator care at home show savings of 50–90 per cent, depending on the

study. It is important to remember, however, that much depends on the substitution of professional by non-professional care. The cost-effectiveness of certain kinds of technology-assisted care is not a good indicator of the cost-effectiveness of acute home health care in general.

Conclusions

Longer-term continuing acute level care in the home provides real opportunities. However, acute home care spans two well-established areas of health policy concern. One is the provision of integrated and continuing care for frail elderly people and others with special needs in the community; the other is the variable quality of discharge procedures from acute hospitals. Developments in acute home health care may well result in clearer criteria for admission to and discharge from hospital and encourage sharper distinctions to be drawn between services to be provided by existing domiciliary service and specialised HCH teams. HCH must not, however, be allowed to suffer from the same problems of coordination that have bedevilled community care and hospital discharge. The stakes are too high.

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ARTIFICIAL NUTRITIONAL SUPPORT

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It is now over 15 years since Bistrian and co-workers drew the attention of the medical profession to the fact that, among hospital patients, malnutrition was rife.^{1,2} Up to 50 per cent of patients in general medical and surgical wards show evidence of protein calorie malnutrition. Confirmed by others,^{3,4} these early clinical surveys provided a powerful stimulus to the development of clinical and basic research in the field of artificial nutritional support, in consequence of which we now have the possibility, and the actuality, of artificial enteral or parenteral nutrition not only in hospital but in the home.

Effects of starvation or under-nourishment

A normal adult may survive for about 60 days without food, a one-year-old child for about 40 days, a normal full-term baby for about 30 days, and pre-term infants weighing 4 kg and 1 kg can survive for only 12 and 4 days respectively. When a person starves after severe trauma, major surgery and/or during infection, weight loss is accelerated, and survival without food for a previously healthy adult may be reduced to about a month. An acute weight loss of more than a third of the original bodyweight is often associated with impending death. Survival without food in small children is reduced to two to three weeks.

Recent research⁵ has highlighted how severely muscle function is impaired by under-nourishment; a period as short as two weeks during which a normal subject ingests 400 kcal daily leads to demonstrable impairment, with increased fatigability. Both the normal respiratory response to lack of oxygen is decreased⁶ and cardiac function.⁷ All these effects can be reversed by re-feeding.

The mental changes seen in normal subjects after semi-starvation (depression, anxiety, irritability, apathy, introversion and impaired mental concentration⁸) are of great clinical importance in the sick patient. Apathy and depression lead to loss of morale and of will to

recover. Inability to concentrate means that the patient cannot acquire the techniques of self-care. A general sense of weakness and illness impair appetite and the ability to eat.

Weakness affects the respiratory muscles⁹ so that it is difficult for a patient to cough and expectorate effectively, with a consequent liability to chest infection;¹⁰ this weakness and loss of sensitivity to oxygen lack may also make it difficult to wean a malnourished patient from a ventilator.¹¹ Cardiac muscle function is impaired, with reduced cardiac output and a liability to cardiac failure.¹² Reduced mobility delays recovery¹³ and predisposes to thromboembolism and bed sores.¹⁴ The malnourished patient develops impaired immune resistance to infection, which in turn worsens the nutritional status.¹⁵ Deprivation of nutrients leads to altered structure and function of the gut, with increased liability to entry and spread of intestinal bacteria within the body.

Starvation is thus an insidious factor which delays recovery after illness and hospitalisation, increases the need for high-dependency nursing and sometimes intensive care, increases the risk of serious complications of illness, and at worst leads to death from an unnecessary complication or from inanition. In economic terms, the hospital admission of a malnourished patient costs more than one whose nutrition is maintained.

Methods available for nutritional support

The simplest way of promoting nutrition is to get a patient to eat more. Frequent small meals with appetising dishes of the patient's favourite foods are easier to provide at home than in hospital, where the ward kitchen has disappeared and feeding is now regarded as part of hotel services, not nursing. An alternative to small meals, a range of liquid or semi-solid preparations, prepared in sterile portions and with flavours varying from sweet to savoury, is available.

If these measures fail or are inappropriate the techniques of artificial nutritional support become necessary. These methods range from provision of defined formula liquid diets which are drunk to the administration of defined formula diets via fine-bore feeding tubes directly into the gut (enteral nutrition) or the introduction of nutrients into peripheral or central veins (parenteral nutrition).

Artificial nutritional support (ANS) at home is a continuation of a clinical service established initially in hospital. Standards of practice will depend, therefore, on those achieved in hospital.

The Department of Gastroenterology and Nutrition at the Central Middlesex Hospital was given this name soon after a programme of research into ANS was started in 1978. Acknowledging the need for a multidisciplinary approach, we were one of the first to establish a hospital nutrition team. Because early surveys indicated that three-quarters of patients in the hospital requiring nutritional support could be fed enterally¹⁶ the programme has focused on enteral nutrition, though not to the exclusion of parenteral nutrition. We consider that ANS at home can develop satisfactorily only on the basis of a rationally organised hospital service.

In 1988, a national survey of district dietitians concerning nutritional support in UK hospitals yielded the disappointing result¹⁷ that only 27 per cent of respondents had a formal nutrition team for their hospital or district, even though an estimated 38,500 hospital patients had received enteral and 13,500 parenteral feeding during the previous year (again, three-quarters of those receiving ANS were by the enteral route). Further, our assumption that gastroenterologists would play the leading role in hospital-based ANS was wrong: only 16 per cent of the members of the British Society of Gastroenterology had a significant input to the practice of ANS.¹⁸ A more recent survey of district dietitians showed that only 32.5 per cent of respondents had access to a formal nutritional support team.¹⁹

Thus, there is an enormous diversity of nutritional support practices across Britain.²⁰ Nutritional care is badly co-ordinated, and much current practice may be suboptimal.

Various groups concerned with nutrition have been formed in recent years, mostly within particular disciplines – nurses, dietitians, gastroenterologists, and patients – and the British Dietetic Association in particular has played an active part in reviewing and promoting awareness of nutritional support practices.^{17,18} However, each group works within its own expertise. Fortunately, the King's Fund Centre has now facilitated the formation of a national multidisciplinary group combining the different skills of clinicians, dietitians,

nurses, pharmacists, microbiologists, chemical pathologists and biochemists, and it is the intention of this group to publish guidelines to improve the standards of clinical nutritional practice in the UK in a similar manner to the American Society of Parenteral and Enteral Nutrition.^{21,22} It is hoped to lobby for supply of the necessary funding for nutritional support to each district, whether via hospitals or the community. If a multidisciplinary nutrition team can be established in each district to advise colleagues about the clinical practice of nutritional support, not only will there be benefits in patient care such as the reduction of complications but the cost effectiveness of providing nutritional support will actually be improved, to judge by experience elsewhere.^{23,24}

A report on artificial nutritional support compiled by a multidisciplinary group of UK experts meeting at the King's Fund Centre²⁵ not only highlights the inadequacies that exist in the organisation and clinical practice of ANS in the UK but makes recommendations as to when nutritional support should be given, how it should be organised, and what steps are needed nationally to improve education, research and public awareness. Among the many benefits that should result will be the rationalisation and improvement of practice of ANS at home.

Home enteral tube feeding

In 1987 the Parenteral and Enteral Nutrition Group (PENG) of the British Dietetic Association²⁶ undertook a retrospective survey of home enteral nutrition in all 192 health districts in England, and identified 879 patients receiving such treatment in 1986. A home enteral feeding register was then established and, by the end of 1990, 1274 patients had been registered, one-third of them children. The number of patients starting treatment during 1990 was 698, including 258 children.²⁷

The Cambridge Health District (population 280,000 with a large cross-boundary flow of 60,000) has 1,810 hospital beds with an over-all bed occupancy of 84 per cent. In 1988 a survey investigated enteral tube feeding in the district.²⁸ At any one time, 11–12 patients were on home enteral feeding. During the two-year study the total amount of tube feeding at home was 4,192 patient-days, accounting for 37.6 per cent of the total enteral tube feeding in the district. If these figures are typical of the country as a whole, the prevalence would be about 40 per million. Eighty per cent of patients receiving home enteral tube feeding were either children under 16 or elderly patients over 60. The patients were often severely disabled by their underlying disease, and mortality was high – 45.5 per cent in two years, in agreement with the figure reported by the National Register for home enteral tube feeding: 20 per cent in one year. Although artificial feeding carries its own

risks, all deaths in the Cambridge Health District were disease-related.

Home enteral tube feeding in Britain is less common than in the USA, which had already reported a prevalence of up to 67 per million in 1985, at a time when home enteral tube feeding (HETF) was growing at an estimated growth rate of 27 per cent.²⁹

The Cambridge group report³⁰ that 'the care of patients on HETF was found to be unco-ordinated and erratic. It is suggested that a more uniform approach should be provided by an interested clinician, a specialist nurse and a trained dietitian. Appropriate selection of patients, organisation and follow-up are required. It is recommended that British standards and guidelines for home enteral tube feeding should be established in order to improve the care of patients on HETF.'

Proposed organisation for home enteral tube feeding

The King's Fund Centre report²⁵ acknowledges the current difficulties and emphasises the important role the hospital nutrition team should have in advising the community team.

The hospital nutrition team can share responsibility for care by recommending a regime, giving instruction to the patient and all carers on procedures and possible complications, providing a telephone enquiry service for all members of the community team and the patient, and by giving hospital care as needed, either in a clinic or a ward. The GP can accept responsibility for treatment at home, prescribe the nutrients and – it is hoped in future – the required equipment. Patients would of course find it convenient to have the nutrients and supplies delivered, with prescriptions sent to a commercial delivery service.

The hospital and community teams should liaise closely. When the patient is discharged from hospital, a member of the hospital nutrition team should visit the home to meet the GP or other representative of the community team and explain details of the treatment. A member of the hospital team, often the clinical nurse specialist, may be invited to make further home visits. It is likely that the patient will continue to visit a clinic at the hospital for follow-up, when suggestions about altering the feeding regime may be made.

I believe that the simple infusion pumps and drip stands used should be bought from the community budget and lent to patients. A reserve stock is needed so that new patients can be supplied quickly, and there must be an allowance for some pumps to be out of use for servicing.

Home parenteral nutrition

The provision of parenteral nutrition at home was first established in the UK in the 1970s,³⁰ and a national register was inaugurated in 1980. This has provided data on indications, standards of practice and national requirements.³¹

Between 1977 and 1986, 200 patients were discharged home; the number of new patients starting each year plateaued in later years to about 40 each year. About half these patients are able to stop treatment, and the number receiving treatment over the country is estimated at 100–150 at any one time. The proportion of children treated in this country is smaller here than in the USA and some other countries. It seems likely that the number of children treated will increase.³²

Parenteral nutrition is usually administered overnight. Most patients eat small meals during the day to maintain social life and contribute to their nutrition. If they eat larger quantities diarrhoea, or an excessive output from an abdominal stoma, become a social problem. Forty-three per cent of patients are at work full-time or able to look after a home or family unaided.³³ Only a small proportion (7 per cent) are housebound and need major assistance with their parenteral nutrition. The remainder are able to work part-time or unable to work but able to cope with their parenteral nutrition unaided. Unlike those patients on home enteral tube feeding, the good prognosis for patients on parenteral feeding is reflected in a low mortality.³⁴

Proposed organisation for home parenteral nutrition²⁵

The cost of home parenteral nutrition is high for each patient (about £25,000 a year for nutrients and disposable equipment) but the number is small (100–150 a year). Some health districts will therefore have none of these patients in any one year, and the highest number is likely to be two or three. Parenteral nutrition is much more complex than enteral nutrition and a scrupulous procedure to avoid line infection is required twice daily – when the feed is connected and when the empty container is disconnected from the catheter. To avoid metabolic complications a strictly controlled rate of infusion is required, and since infusion occurs during sleep the pump must also incorporate an alarm system to wake the patient if the line becomes blocked or other malfunction occurs. The pump is therefore expensive and requires regular maintenance. It is not acceptable to expect a patient to assume responsibility for this complex technique without first-class training and the most efficient and comprehensive backup service possible.

Education of patients for self-administered home care is best undertaken in a hospital which already has a well-

developed system for inpatient parenteral nutrition. Training requires a skilled and experienced teacher and teaching aids. Patients who are giving themselves home treatment can also help one another by mutual support and exchange of information. The organisation of treatment at home needs considerable knowledge of the equipment and supplies required, or the facilities needed within the home, and of potential difficulties and complications. A member of the hospital staff who knows the patient and is familiar with the technique should be available for consultation by the patient 24 hours a day. If a complication develops, such as a blocked cannula or line infection, the patient needs admission without delay to a unit which understands the problem. For all these reasons, the care of patients giving themselves parenteral nutrition at home should be concentrated in relatively few hospitals, each serving more than one health district but with appropriate backup in the patient's own district in case of emergency.

As in home enteral nutrition, the hospital nutrition team should as far as possible share responsibility for treatment with the GP and the community health team. The GP should receive a booklet which describes the treatment, its benefits and complications. The indications for the treatment and any special problems in his/her patient should be made clear. Personal contact between the hospital staff and the GP should be carefully maintained.

The present financial arrangements for this expensive and uncommon treatment are unsatisfactory. The GP is often asked to prescribe the nutrient solutions, as recommended by the hospital and with the agreement of the family health service authority, but is not permitted to prescribe the disposable items of equipment, which then has to be paid for through the community health budget. In some cases, the district health authority purchases the treatment from the hospital at which the responsible clinician prescribes the treatment. The nutrients and equipment should be delivered to the patient's home either by the hospital or by a commercial firm.

In France, departments with a defined budget have been established in specified regional hospitals to which all patients possibly requiring parenteral nutrition are referred. Payment for treatment after the patient returns home remains the responsibility of this hospital. In this way the indications for treatment can be standardised, training of staff and patients is of higher quality, organisation of homecare follows established procedures without the need to negotiate funding for each patient, the total expenditure can be controlled, and the outcome of treatment can be evaluated on a national basis. Such a mechanism for funding the treatment has been discussed but not accepted by the Department of Health in England.

Role of industry

As Linda Marks points out,²⁹ there has been extensive commercial involvement in home enteral and parenteral nutrition: in the USA, companies marketing nutritional support products are concerned in the assessment, education and treatment of patients and in monitoring the quality of care. A survey of US hospitals (with a 65 per cent response rate) showed that 78 per cent used home feeding companies to train and monitor patients.³⁵

What role, if any, will commercial companies have in the UK in the provision of home artificial nutrition in the future? Unquestionably there would be advantages to the patient if enteral and parenteral feeds were delivered directly. Properly trained staff employed by such companies could provide the valuable and essential link between hospital and community-based services. The use of commercial homecare companies must be subjected to health technology assessment under conditions as stringent as in controlled clinical trials because, until this is done, medical and non-medical managers will continue to have an inherent antagonism to paying a 'third party'. Such antagonism will retard the progress that should be made in home artificial nutritional support.

Conclusions

Considerable progress, largely driven by clinical nutritionists, has been made with home enteral feeding and home parenteral nutrition, and national registers of both have been available for a number of years. Further progress in the organisation, practice and funding of home artificial nutrition will occur only when hospital-based artificial nutritional support is properly rationalised, and acceptable standards are published. The involvement of commercial homecare companies must be seriously studied.

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FUTURE LABORATORY TECHNOLOGIES FOR COMMUNITY CARE

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This paper is concerned not with medical technology in general, nor with continuing care in the home only, but with some tentative results from an ongoing international project concerning future laboratory technologies in community care. I will concentrate on our evaluation of the need for medical technology, and on our assessment of a technology which has potential for continuing care in the home.

WHO's European programme, Health for All by the Year 2000, has as Target 28 that 'the primary health care system . . . should provide a wide range of health-promoting, curative, rehabilitative and supportive services to meet the basic needs of the population', duly assessed as to their appropriate use.

The WHO programme points out that many diagnostic procedures, including screening and laboratory tests, can be offered outside hospitals – for example, at home and in health centres. The new laboratory technologies offered to community care have so far mostly been traditional methods, for example photometry (in new and automated versions), or it has been dipsticks or paper strips impregnated with chemicals and dried, brought into contact with the human tissue and read manually. However, a relatively new, promising technique uses biosensors – defined as devices incorporating an element for sensing a biochemical which gives rise to a tiny electric current. A few models are on the European market – for example, one which senses and measures the enzyme glucose oxidase.

The advantages of biosensors and a number of other new laboratory devices for community care are that a sample of one or two drops of blood suffice, they are easy to use, they need no sample preparation, and they give a fast response. They therefore have the potential to contribute to home health care. However, here as

elsewhere, the clinical and economic effectiveness have not yet been established.

Evaluation of need

The number of new laboratory technologies on the community care market is growing rapidly. To assess future developments in this field we conducted a so-called Delphi study. We collected and analysed expert opinions about future needs for laboratory technology, by means of a questionnaire sent out to 140 persons in six European countries (Belgium, Denmark, France, Germany, Netherlands and UK). The panel comprised GPs, health planners, representatives of the diagnostics manufacturers and of laboratory medicine known to be interested in, but not necessarily in favour of, decentralisation of laboratory testing. There was an average response rate of 63 per cent in the first round and 53 per cent in the second.

General aspects of laboratory technology in the community

We asked this panel about general aspects and about some specific laboratory tests. The first general question was based on the well-known S-shaped diffusion curve which plots extent of use against time. In many cases it can be shown that six consecutive stages can be identified: need, R&D, persuasion, adoption, implementation, and routine.

We made the assumption that in community care in a specific country the diffusion of laboratory technology will follow this model, and we asked each expert to indicate, for his own country, the present stage of usage of devolved laboratory technology. Most of the experts believed that this technology is at the 'persuasion' stage, and only now entering the community care market; the S-curve is just rising (Figure 1, overleaf).

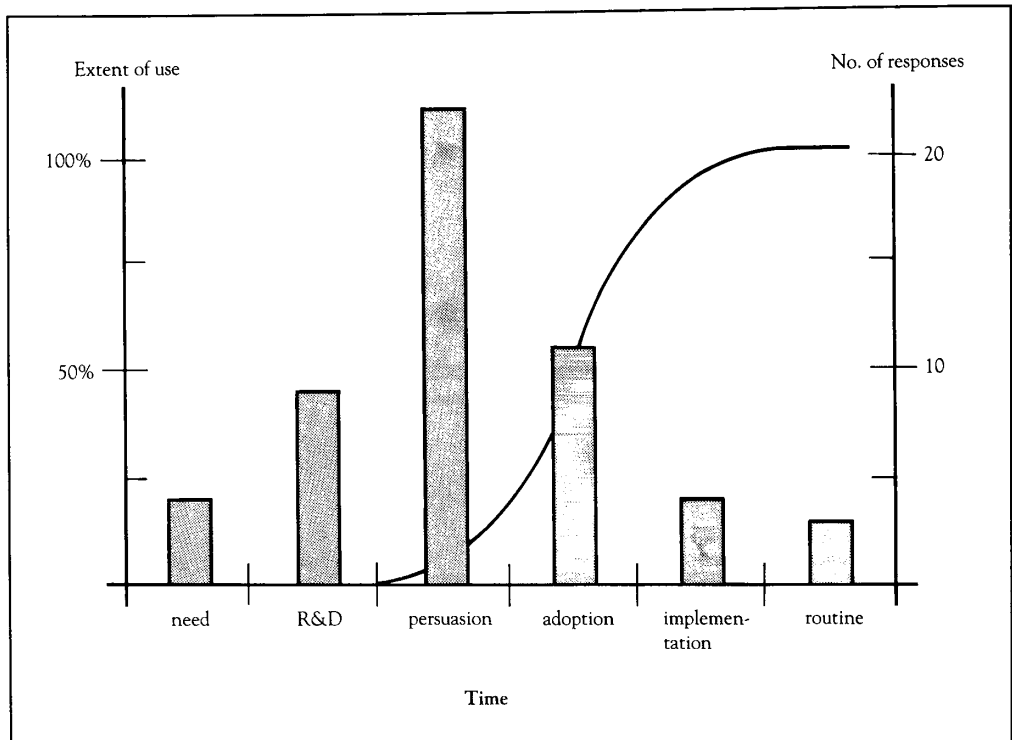


Figure 1. Stage of usage of devolved laboratory technologies in 1990 (estimated by 140 interested parties in the EC)

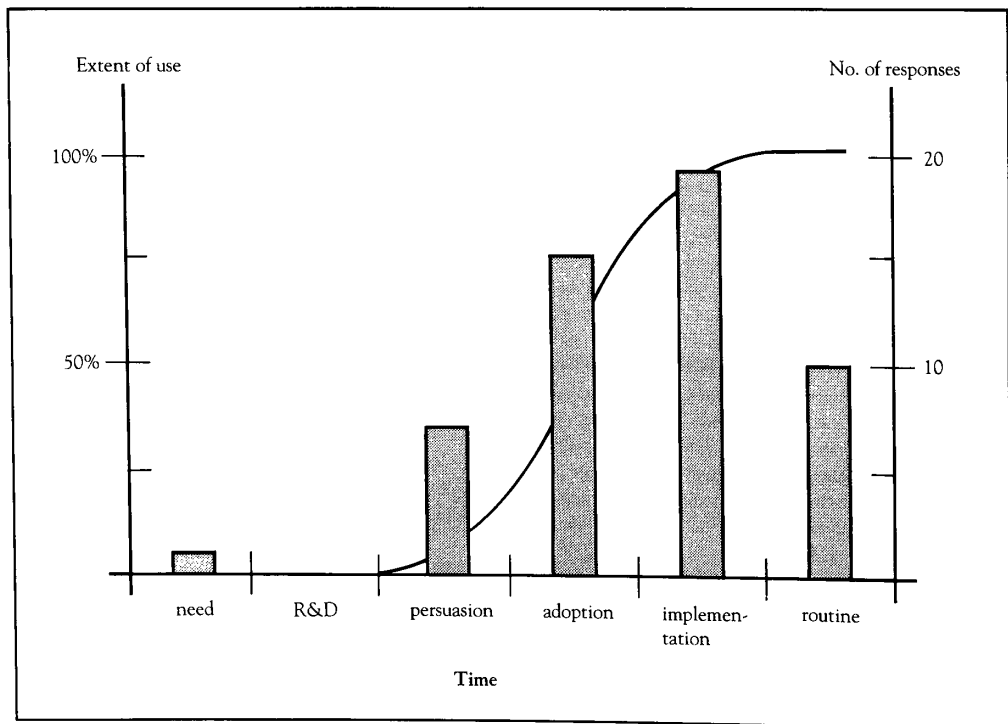


Figure 2. Stage of usage of devolved laboratory technologies in 2000 AD (forecast by 140 interested parties in the EC)

The corresponding question for the year 2000 elicited the prediction that the implementation stage would be reached by then (Figure 2).

If these predictions are correct, a very fast diffusion is expected to take place in the next 10 years, from persuasion to implementation. There appeared to be no significant difference between estimates for the different countries or from the four professional groups.

The next question concerned specific factors influencing the diffusion of community care laboratory technology. For each of these eight factors the experts were asked to indicate its importance on a scale from 0 (unimportant) to 5 (very important). The results are shown in Table 1.

Table 1. Factors influencing diffusion of laboratory technology into community care (numbers are averages on a scale of 1 to 5)

4.1	reimbursement system
3.7	clinical need
3.4	technology 'push' from industry
3.3	interest shown by community care workers
3.2	patient demand
3.0	legislative requirements/standardisation
2.9	demand for quality control

The mean of the collective estimates lies between 2.9 and 4.1. The most important factor is, not surprisingly, the reimbursement system. Technology push is considered to be much less important than in previous Danish Delphi studies. Again there was no significant difference between estimates from the different countries. Differences between the four professional groups became clear only in a few cases, namely when industry rated the importance of reimbursement higher than other groups and the importance of patient demand lower.

Laboratory tests for specific disorders that can be treated in the community

The laboratory technologies examined were divided into three types. For each technology in group 1 (already used in community care) and 2 (ready to be transferred from hospital laboratories) we asked two questions:

- ◆ How much will the number of tests in community care change up by the year 2000?
- ◆ What will be the relative distribution of these tests in different sectors of community care?

Table 2 shows the number of tests expected to be in community care use in 2000 relative to a base of 100 in 1990.

Table 2. Number of tests, relative to those currently used in the community, expected to be used there by 2000 AD

blood glucose (diabetes mellitus)	160 (150-200)
haemoglobin (anaemia)	110 (100-120)
pregnancy tests	110 (100-120)
nitrite (urinary tract infection)	108 (100-130)
occult blood (carcinoma of the colon)	120 (100-150)
streptococcus A (tonsillitis)	120 (100-150)
luteinising hormone, LH (ovulation)	120 (100-150)
chlamydia (genital tract infection)	150 (120-200)

Thus, the number of blood glucose tests in community care is expected to rise by 60 per cent within the next 10 years. Twenty-five per cent of the respondents estimated below index 150, and 25 per cent above index 200. The result agrees very well with a Danish biosensor Delphi study made two years ago.

Table 3 shows the expected location of the tests in various sectors of community care.

Thus, the majority of tests are expected still to be done in GPs' offices. Tests sold over the counter are not

Table 3. Location of specific tests expected to be more widespread in community care in 2000 AD

Numbers are percentages of the whole

	Doctors' offices	Over the counter	Patients' home	Elsewhere
blood glucose	34(19)	2	58(19)	6
pregnancy test	34(16)	14(15)	47(19)	5
LH	57(39)	5	34(39)	4
occult blood	80(25)	2	11(21)	7
urinary nitrite	88(11)	3	6	3

given much hope, except for pregnancy tests; all except urinary nitrite are, however, expected to take place at home.

We asked similar questions for the second type of test, those expected to be transferred from hospitals to community care, for example the monitoring of patients on long-term anticoagulant therapy, to which I return later. First, however, I move to the third type, those laboratory technologies yet to be developed for community use, although there is a perceived need. Here we asked the panel to estimate the likelihood of their general use in community care by the year 2000, on a scale of 0 (most improbable) to 5 (very probable) (Table 4).

Table 4. Probability (on scale of 0 to 5) of use of specific laboratory tests in community care in 2000 AD

3.6(1.0) specific allergy tests
3.0(1.2) DNA probe for chlamydia infection
2.5(1.0) antibody-antigen test for prostatic cancer
2.4(1.2) blood concentration of psychotropic drugs

We did not explicitly state this but, if we assume that 3.0 corresponds to a 50 per cent probability of general use, this is just the case for the DNA probe for chlamydia, and specific allergy tests have a higher probability of general use.

A case study in technology assessment

A proactive technology assessment is currently in progress for one community care technique which could provide a solution to a clinical problem, namely the monitoring of patients in long-term anticoagulant therapy. Final results are due in a month or two.

Patients with, for example, deep recurrent venous thrombosis, pulmonary embolism or previous myocardial infarct are treated for months, sometimes for the rest of their lives, with potent oral anticoagulants. Too low a dose can result in fresh thrombosis and too high a dose in possibly fatal haemorrhage. Coagulation status is also affected by other commonly used drugs and by diet. Blood coagulation parameters are therefore monitored monthly or less frequently and the drug dose is adjusted accordingly. These parameters could obviously be more effectively, frequently and conveniently measured at home.

The number of patients thus monitored varies greatly from one country to another: it is 1.3 patients per 1,000 population in the UK and 8.6 per 1,000 in the Netherlands. The frequency of monitoring also varies,

from once every 6.7 weeks in the UK to once every 3.8 weeks in the Netherlands (compared with once every 3.1 weeks in North America). A slightly increased clinical effectiveness and safety have been shown by an increase to one check per week.

The check is usually performed in general outpatient clinics or anticoagulant clinics. In some countries, a community nurse takes blood samples from immobile patients and in others this is done by a GP. However, in Germany and the USA a few experiments with patient's self-management have been in progress for years, apparently with good clinical results. Our case study examined prerequisites for moving this service to home care, and assessed a broad range of consequences of this organisational change.

As well as a literature survey we again used an extensive questionnaire addressed to 40 haematologists and clinical chemists in five countries.

From the Delphi study described earlier we learned that the total number of these monitoring tests is expected to increase by 40 to 50 per cent between 1990 and 2000, in agreement with another Delphi study held two years earlier. A majority of experts agreed that

- ◆ the currently accepted indicators will continue to be accepted
- ◆ two to three times as many patients with previous myocardial infarction will be included
- ◆ there will be a slight increase due to the acceptance of a few new indicators
- ◆ it is unlikely that safer drugs with less critical thresholds will be introduced
- ◆ the present laboratory methods will be refined, with a consequent simplification of extra-laboratory testing.

As to the location of the tests in the year 2000, there was very great variation between opinions in different countries. In contrast to North America, where patient self-management was expected to increase from the present 2 per cent to 28 per cent of all tests, with a decline in both hospitals/clinics and in GPs' offices, the Netherlands showed hardly any decline from the present 99 per cent in hospitals and special clinics, the UK showed a slight shift from hospitals and special clinics to GPs' offices but absolutely no patient self-management, and Denmark was much more devolved: decline from 76 per cent to 51 per cent in hospitals, rise from 24 per cent to 38 per cent in GPs' offices and from 0 per cent to 10 per cent patient self-management.

We know very little about patients' preferences here, although what we do know suggests that some patients at least would prefer fingerprick testing to venepuncture, and self-management if such testing is established as reliable.

Self-management is assumed to reduce costs. There has been no reported cost-effectiveness study of monitoring of anticoagulant therapy. However, if we assume equal clinical effectiveness and safety for the two cases, self-management will probably be more rather than less expensive (largely because of the increased number of tests). If on the other hand self-management were to reduce the adverse effects of too infrequent monitoring it could be more cost-effective.

Some generalisations

I conclude with some provocative remarks.

Politicians have all the ideal objectives, but in reality they react reluctantly, perhaps instinctively apprehending cost increase. There are, of course, exceptions.

Doctors prefer high-tech hospital care to homecare or patient self-management, claiming to defend patients' interests. I regard them as impediments to the development of home health care.

Candidates for homecare and self-management lack knowledge about technology and political or economic power to enforce their demands. There are some solutions here, but I do not present them today.

Industry will follow the medical profession and look to the sources of finance rather than ally itself with the weakest group.

ECONOMIC ASPECTS OF LONG-TERM HOME HEALTH CARE

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The Santé Service Bayonne et Région (SSB) started as long ago as 1961 as a home nursing scheme for cancer sufferers.¹ Gradually, the care of elderly and physically handicapped people was included and, by 1981, SSB managed a caseload of 1,500 people and supported up to 360 people at a time.

Nurses, nursing aides, physiotherapists, social workers and a medical director are directly employed; medical responsibility rests with the GP. In France, nursing aides provide general patient care, including bed baths. Two levels of care are provided by SSB: 'hospitalisation à domicile' (HAD) is for patients requiring skilled nursing care several times a day, whereas 'homecare' is less intensive.

Patients can be self-referred or referred by family, friends, or GP, although they are assessed for entry by a hospital coupled with an inquiry into the suitability of the home environment; finally there is a formal agreement between HAD and the patient's GP. This paper looks at the economic aspects of HAD throughout France (with an example from the Paris HAD).

Statistics on inpatient care in France are as follows. There are 560,000 beds (1 bed per 100 population), 165 million bed-days per year, average length of stay 12.8 days, total cost 248 billion FF (4,400 FF per head of population). In the service offered to ambulatory patients by various health professionals there are 106,000 physicians in private practice (189 per 1,000 population), 4,370 visits per year, total cost 156 billion FF (2,790 FF per head of population).

By comparison, the home-based hospital service, HAD, seems minute. There are 35 programmes operating in 18 départements (out of 95) and the maximum capacity is 3,500 'beds'; there are 31,000 admissions per year, with an average length of stay 37.3 days at a total cost of 610 million FF (less than 11 FF per patient).

What can HAD offer a patient? HAD offers assistance in day-to-day living, social follow-up, psychological advice, full medical care 24 hours a day, paramedical

care and co-ordination. HAD is delivered as follows. The patient himself, his family or a doctor can refer, usually to a hospital where the co-ordinating structure for HAD launches an inquiry into the patient's condition and circumstances, finally leading – if the patient is accepted – to an agreement between the HAD and the patient's GP. Currently, the composition of HADs in France is 50 per cent cancer patients, 40 per cent obstetric, geriatric and paediatric, and 10 per cent AIDS.

The number of patients treated within HAD was fairly constant at 5,000–6,000 between 1980 and 1985, but then started to increase dramatically to reach 10,300 in 1990. This breakthrough was facilitated by technical progress – for example, in continuous chemotherapy which allowed the treatment of seriously ill patients at home.

Could HAD be a cost-saving strategy in health care? We do not know: a good cost-effectiveness study of HAD has not been done. However, one can observe that whereas AIDS patients in the HAD sector consume only 1 per cent of total AIDS costs, they constitute 4 per cent of all patients.

Why is HAD not utilised more? There are two answers to this question:

- ◆ HAD is a service provided by hospitals in France. HAD care will therefore be provided only when it is in the hospital's interest. When a hospital service is operating at full capacity, HAD will be provided; conversely, a hospital with excess capacity will be reluctant to offer HAD care.
- ◆ The public sector provides no financial incentive to develop HAD because of its global budget approach.

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IMPORTANCE OF THE SUPPLY SYSTEM

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In Sweden we are currently devoting a great deal of attention to the development of home health care. Apoteksbolaget has appointed me manager of a pilot project to develop a distribution system for the total home health care requirements, irrespective of type of item or manufacturer, in the city of Jönköping.

Apoteksbolaget, the National Corporation of Swedish Pharmacists, is a government-owned company responsible for all retail drug supply in Sweden. The various organisations involved, including my own company, find the pilot project interesting and very useful, even if there are still many difficulties to overcome. Although this project was the first, many other projects with similar aims have been implemented elsewhere in Sweden. I report here our experiences.

Home care supply: the current situation in Sweden

In Sweden, various groups of medical items are distributed directly to patients' homes – for example, incontinence products, renal dialysis solutions and oxygen, under the responsibility of Apoteksbolaget. Distribution arrangements are made individually and without co-ordination, but most of them are carried out efficiently and rather cheaply. The low costs result from central agreements made with transport companies nationally. One problem is that there is no co-ordination between the different supply systems; another is that the local supply of *additional* items is not subject to the same agreements, and those transport costs are sometimes very high.

The existing distribution of home health care products can be described as follows.

Incontinence

Incontinence articles are supplied free of charge to patients' homes; government insurance covers all costs. The articles are ordered by doctors or district nurses and supplied in four deliveries a year to the

customers. Requisition procedures must be renewed each year. The goods are supplied from a single central warehouse for the whole country.

Dialysis

Home haemodialysis products are distributed via different routes. The equipment is supplied mainly by the manufacturer (Gambro) which also provides servicing. For some areas large hospitals take on the responsibility of supplying and servicing equipment.

CAPD bags can be supplied either from a central wholesale warehouse, local hospital pharmacies or local retail pharmacies. The county councils cover equipment and transport costs and the government insurance pays for the solutions.

Medical gases

Oxygen and other gases for medical use are classified as pharmaceuticals and supply therefore falls to the Apoteksbolaget. There is a central agreement between Apoteksbolaget and the manufacturers on the manner of distribution to patients' homes, and goods are distributed by local agents of the manufacturer. Costs are covered by the government insurance.

Equipment for the handicapped

This includes many different articles. Small equipment like special scissors and other tools, and spare parts like batteries, can be provided from retail pharmacies.

Larger equipment is provided from warehouses belonging to the county councils. Most of the items are ordered by doctors, district nurses or therapists. Distribution by nurses and therapists occupies much of their time. Really large items are delivered by the transport department of the county council.

Every delivery is individual. The county council covers the total costs.

Food

Supply of food to patients in homecare and to the elderly who are unable to provide for themselves is the responsibility of the municipalities. It is brought mostly by home-help personnel, who buy food locally and bring it individually to consumers' homes. In some cases municipalities provide consumers with prepared meals from central kitchens.

Much of the working time of the home-help personnel is used for this activity: 15–20 per cent of the total working time has been reported from several investigations around the country.

Drug supply

The government insurance system normally covers the costs of transporting drugs only as far as the pharmacies, not for further transportation elsewhere, except for incontinence products and some other products under special circumstances.

Trials in Jönköping: background and concepts

One reason to start trials in Jönköping was that a new hospital was under construction with restricted bed capacity. A feasibility study showed that co-ordinated supply of necessities, including food, to all types of immobile patients in their homes would be cost-effective, and with that background the three parties – the county council, the municipality and Apoteksbolaget – started a joint pilot project. The following criteria were adopted:

- ◆ most importantly, to bring patients into the centre of the system: they should need to contact as few people as possible to acquire supplies and information
- ◆ the distribution system should give high confidence and security
- ◆ management should be local, to ensure maximum knowledge about the patients and their situations and the capacity to work for the best solutions according to individual needs.

Trials in Jönköping City: functions

The three parties agreed that Apoteksbolaget would be responsible for management of the project and development of the communication system and the county council for all the transportation tasks; the municipality would join the project only when the project was up and running, which it did after two years. The project has been in operation for three years in total.

The following now form part of a co-ordinated distribution system:

- ◆ *Supply of incontinence articles*
Nurses order via computer terminals where they have access to the item register and quote the delivery time to the patient according to the scheduled delivery routes.
- ◆ *Supply of dialysis articles*
Liquids, bags and equipment, and also any accompanying drugs, are supplied as an integrated package. In the pilot project, supplies come from the local hospital pharmacy.
- ◆ *Supply of oxygen* together with the needed equipment and drugs. The oxygen comes from a stock in the hospital.
- ◆ *Supply of equipment to ameliorate disability* from the warehouse of the county council.
- ◆ *Supply of drugs*, delivered from the pharmacies in packages for each patient, by geographic group via home helps.
- ◆ *Supply of food* from the local shops, ordered via the computer and an item register, or by telefax or written requisition delivered to the shop. Some of the other projects have started to supply food from central warehouses in order to reduce the costs; we decided to include local shops in the project so that they do not lose their normal customers. Most of the elderly persons are able to visit the shops themselves even if they cannot carry the food away: in this way they are able to maintain personal relations with the local shops.

The communication process

Communication is very important: it accounts for 50 per cent of the distribution system.

At the beginning of the project the transport department was provided with computer support to manage all the necessary deliveries, especially those made in advance. Confidence in the system was the most important thing, so we made it obligatory to keep to the delivery times agreed with the patients.

We also wanted to test the technology which enables one to make requisitions directly via computer and an item register; this uses a central minicomputer, with workstations and lines connected via telephone. The computer is also equipped with an electronic mailbox, to send messages between all users. When a requisition for one or more items is placed with a supplier, an order is automatically placed for the relevant transport that will ensure that delivery on the desired date.

We have found that the communication process can be divided into different technological levels:

- ◆ on the lowest level, documents can be delivered to the receiver and telephone calls made if necessary. This method is still very useful.
- ◆ the middle level uses telefax to send a document to a receiver. The method is simple, and the document can be sent to several addresses to request transport.
- ◆ at the highest level, computers are used to register requisitions and to order transport in a closed system. This method offers many possibilities for further communications in home health care.

The transportation system

As mentioned above, the county council is responsible for transportation within the project because they have a transport department. They use mini-buses in the city and lorries for the rural areas. The drivers are former ambulance drivers or are trained by nurses to provide some patient care. They are also required to report if something is not in order or if a patient needs nursing or other help.

Each district of the city has scheduled transport routes twice a week. The transport department operates from a centre where the goods are collected and sorted, and where the routes start. On the way to the district the drivers stop at the local shops to collect the goods ready packed for deliveries along the route.

With the help of the computer it is possible to plan the distribution so that drivers can see what goods and how many customers are booked on the routes. If necessary they can add a vehicle for the deliveries or make other changes.

Finance, costs and payment

We have found that costs of the local distribution system are reasonable – less than £4 per delivery including ordering costs. The municipality can make quite a large profit by using the co-ordinated distribution system. However, the costs of the computer itself are not covered by the distribution system: to cover the costs the computer would also have to be used for other purposes. Payment rules to cover the distribution costs have not yet been devised because the responsibilities for homecare have recently been re-allocated between the project partners.

Experiences of different trials in Sweden

The different projects on home health care in Sweden are all different; they are organised differently according

to which organisation is the principal one. They have also chosen different communication technology.

Many attempts to introduce a videotex system like the Minitel system in France have been made in Sweden in recent years, but with very limited success. The latest attempt is in Malm, the target group being the home care services. This is a rather large-scale project; the first step early in 1992 gave 200 terminals to the home care consumers, and installed a distribution system.

In Jönköping we installed at the start a computerised system for ordering goods and transport, to ensure that we could control and check everything and be able to change it if necessary. However, I must admit that too much attention was paid at first to the computer system itself; after a while we concentrated more on the supply system and started to use telefax machines to make it easier to handle.

The staff of the municipality was reluctant to accept the new distribution system, primarily because of the feeling of insecurity surrounding a variety of changes in the management division and the fact that on 1 January 1992 the responsibility for homecare was transferred to the municipality from the county councils. Thus, although the municipality can get a large profit from the trial, they are slow to appreciate the advantages of co-ordination.

In addition, the boundaries between different parts of the health care system are still very rigid.

These negative factors have also been noted in many of the other home health care projects in progress in Sweden.

Evaluation of the trial in Jönköping

The project has been subject to several types of evaluation, independently performed by universities. The department of social economics of the University of Linköping has evaluated the reactions from consumers and staff and the Transport Research Commission has evaluated the transport technology and the computer system. All evaluation reports are very positive to the project ideas and the joint conclusion is that the economics, the costs and expected payments are on the right path.

Conclusion

We are convinced that a local co-ordinated distribution system should be developed for home health care and we therefore continue our efforts to find sound solutions to the remaining problems.

PATIENTS' PERSPECTIVES

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No one who has been involved in the patient representation side of health care over the last 25 years or so could possibly fail to be anything but excited and delighted at the prospect of greater emphasis on hospital care at home. The models for hospital at home so often cited – Peterborough, New Brunswick, and Bayonne – have a proven track record. They provide an efficient service, and they excite the interest of health professionals. However, they do not necessarily provide a high degree of choice for patients, nor are they necessarily what patients would, in the first instance, request.

The importance of self-referral

Linda Marks pointed out in her paper for the King's Fund Institute¹ that a key consideration is the type of referral. The important difference between the Bayonne scheme and the other two is that Bayonne is based on self- or carer-referral. When the Peterborough scheme began, it operated on this model, and was separate from existing community services. But that proved unsuccessful, and it now admits as many as 400 patients a year and is integrated into the primary health care team, with referral therefore largely from GPs and from community nurses.

In the UK, the gateway to much health care provision is the patient's GP. Self-referral, or family and friends' referral, is uncommon, although there are exceptions – some hospices, and some community nursing services which have a close relationship with families of patients.

There is sufficient evidence of variation in referral patterns within the UK, even with a predominantly GP-based service, for it to be possible to envisage an increase in self-referral or family referral by one path or another.

If we are to go down this path of hospital at home, I believe the availability of self-referral is essential. With all the money spent on development of health care systems, on quality assurance and on scientific research,

the amount of knowledge of what patients really prefer – and what individual patients prefer as distinct from the majority – is still very small. The work now being done in several health authorities to elicit what the public would prefer is much overdue: the claims that health reforms in the UK give patients more choice are suspect when patients themselves do not act as gatekeepers into the system.

The question of cost

Those systems that claim to operate according to public demand (which I am now studying in the USA) of course do nothing of the kind, but tend to operate according to what insurance companies are prepared to pay for. And the vast interest in hospital at home to be found in medical schools and schools of public health in the USA largely stems from the huge amounts of money seen to be in it, both for the manufacturers of suitable equipment and in the savings that insurance companies might expect to make through reduced hospital bedstay – though those savings have not been as great as was anticipated.

This attitude has to be taken into account when we look at acute care at home in the UK. If it is being proposed in order to save money, the financial argument must be set against considerations of quality, patient choice, suitability, and why many people prefer to be at home rather than in hospital.

Barbara Stocking made the point that part of the cost of providing care at home instead of in hospital will be borne by unpaid family and friends who will be acting as carers. However well they may be supported by nursing services in the community, however well helped by specialist technicians and by GPs, the fact is that unless nursing services are going to be provided continually in the patient's home, which would by no means be a cheaper alternative to hospital, part of the informal nursing and caring will be provided by friends and relatives. There is a cost to that, as yet largely unrecognised and uncalculated.

The carers

Hospices, which though different, provide the nearest comparison and are well known for their provision of respite care so that the carers at home can get a break. If hospital at home is to become the norm for certain conditions – for children who are severely ill, or for people with end-stage renal failure – their carers will need a break. If we are also to see, as has been suggested, cancer chemotherapies or even blood transfusions delivered at home, let alone the oxygen treatment for those with chronic obstructive lung disease, then the carers will certainly need a break, for they will find themselves, in many cases, taking a degree of responsibility to which they have not hitherto been accustomed and in which they will need great support.

So the carers need consideration of a major kind. In the USA, where cost has been a major factor in all this, there is little in the way of a community nursing service and virtually nothing in the way of a GP or community physician service. The load falls on the family, the carers – and often on the attending physician who would otherwise have been looking after the patient in hospital. In the UK we do have community services, although we have often been unimaginative in our use of them, with the exception of the hospice homecare teams and the Macmillan nurses. So if we are going to provide home hospital care for financial reasons, some kind of calculation needs to be done of the cost of providing really good community support services for carers, specialist services for the patients, and inpatient care for respite on a regular, by right, basis.

But even supposing the carers are properly looked after, and the services provided at home are of a high standard, will all patients want these services? In the UK, roughly two-thirds of beds are filled by those who are 65 and over. They are by no means necessarily frail, but they are elderly, some very old. The hospice movement has shown without a doubt that most people prefer to die in their own homes, properly supported. But there are exceptions. There are those whose pain proves more intractable than the norm. There are, even more significantly, those who live alone – over one-third of all people aged 85 and over. There are those who live with siblings or spouses who are themselves elderly and frail. These patients, as hospices have made clear, prefer to die in the hospice rather than at home, conscious that they are putting an intolerable burden on their loved ones. Some patients live with children or relatives who work during the day, and where the economic cost of one person stopping work in order to provide the care is likely to be sacrificial. Statistics show that more than half all carers spend more than 50 hours a week in caring activities, even though many of them are likely to be working part-time as well.

However, these carers are people who are not providing acute care. Nor are they dealing, on the whole, with the

provision of acute care at home. The extent to which carers have been asked whether they would be prepared to take on the additional burden is very limited, largely because carers as a group, as a lobby, are very new indeed.

Patient preferences

But suppose carers were willing and able to take on the additional load, would all patients wish to use a hospital at home system? Many clearly would, but it would not be universal. If we are to move increasingly to acute homecare, it is essential that those who do not wish to be cared for at home can still have hospital care. It would be an enormous shame if the economic pressures to liberate inpatient beds meant that those who need the kind of acute care which can be provided at home were obliged to have it at home. Add to that the commercial pressures from equipment manufacturers to expand the use of home acute care, and there might just be a note of cynical caution from patients, however attractive acute home care might at first seem to be.

Thus Linda Marks is right to include in her conclusions' the sentence 'Although HCH is generally perceived as offering increased choice to patients, there is a real danger that a preoccupation with cost control might reduce patient choice in the location of treatment.' Where fierce cost containment initiatives exist, such as in the USA from health insurers and the health maintenance organisations, some evidence suggests that home health care can be used to prevent admission to hospital or to promote early discharge when the patient might well have preferred something else, and so might the family.

So in the UK, what can be done to promote hospital at home and the good things it can offer, while ensuring that patients and their families are given plenty of choice? First, the patient must know that a hospital at home system has been properly evaluated, with clear evidence that the care is at least as good as in hospital. There is still need for comparison of the safety of similar or the same techniques used in hospital or at home.

Secondly, in some medical conditions – for example, stroke, or myocardial infarction after the first two hours – there is no hard evidence on whether it is better to care for patients in hospital or at home.^{2,3} For these conditions patient preference should, at present, be the dominant consideration. But the fact is that the decision will largely be made by GPs. The Nottingham study³ and others demonstrate that GPs are reluctant to change admission patterns, even when an established outreach specialist team is available – for instance, in some areas of myocardial infarction, parenteral nutrition, or hip fracture. It will surely be all the truer when a newer type of treatment is offered at home, such as antibiotic therapy.

The provision of good information

Where can the decision-making be improved? Patients will need to become much more aware of what is available. This cannot be left to GPs, especially not to those with a clear financial interest in pursuing one course of treatment over another – as with budget-holding practices, if hospital at home turns out to be very much cheaper. Those who are the backbone of the community services should make sure that specialist hospital at home services are known about. Once again, the parallel with hospices is striking – the dependence of the hospice movement on public support for funds and for volunteers has made public awareness of Macmillan nurses, of hospice homecare and of inpatient hospices very great. That could be true of other kinds of acute home care. As health authorities become aware of the need to communicate with the people in their district, newsletters circulated house-to-house may become one way of making sure the public hears about what is available. Community nurses, well-loved figures where they work, could also spread the word. Community health councils and their Scottish and Northern Ireland equivalents have a key role to play here. Leaflets in GP waiting rooms and in public libraries could inform the public.

This information would enable patients to make real choices. It would also, indirectly, enable them to play a role in quality control, part of which lies in assessing client satisfaction. Even though many patients will be unable to comment on all the clinical details of the service, they can speak about the quality of nursing care, the regularity of the service and its reliability and the extent to which it has seemed of benefit compared with what they might have had – or had had previously – in hospital. Their ability to assist in the quality control process would be much enhanced if they were fully informed of what it was they might expect.

Thus a key to all this new home hospital care is information, as it so often is when speaking from the patient's point of view. Without it, no patient can

make a choice. Without it, even if happier at home, the patient has no real measure of what is to be expected, of what might be better, or worse, or simply more or less to his or her taste. Without it, the patient cannot know whether the system is in use in order to transfer the burden of caring on to the family, or because the risk of infection at home is much lower, or because there are psychological benefits in being cared for at home rather than in hospital.

If good information is provided to patients, if they are genuinely consulted about whether they wish to be at home or whether they wish to be in hospital, and if they feel that the carers are not simply being taken for granted, hospital at home has much to offer. But if it is done for financial reasons only, patients will not find the process satisfactory. Patients respond swiftly to what their carers are feeling, so if nurses, doctors and other health care workers do not themselves feel that the services are good and important and in many ways *better* than what could be provided in a hospital setting, the patients will feel the same. They will feel short-changed and deprived of choice. It is essential to make it clear that this is for patient benefit, not for cost containment. And this is as important for carers as for patients, for otherwise carers will crack under the strain, and both the patients and their loved ones will have to enter hospital as emergencies, rather than remaining well-supported, with adequate respite care, well cared for in the community.

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SECTION 6

**SUMMARY OF
DISCUSSIONS**

SUMMARY OF DISCUSSIONS



I Factors promoting the shift from hospital to home health care

Hospital bed pressures

Participants considered this the main springboard for initiatives throughout Europe in exploring the substitution of hospital care by homecare. Political pressure to reduce the number of hospital beds or (as in Denmark) severe hospital staff shortages could be relieved by the supplementation of nursing resources in the community by unqualified, suitably trained staff or carers.

Cost pressures

It was agreed that although this had not been unequivocally established, except for certain disease states or types, the common perception was that home health care is or would be cheaper than hospital care, and that this was the driving force behind much institutional change. Recognition of the steadily increasing proportion of older people in the population, with increasing need of care though not necessarily hospital care, was sharpening the pressure; and this was coupled with a general alarm about rising costs of health care, most of which is incurred in hospital. In countries where health care is mainly financed through insurer reimbursement, insurers still believe that home health care would be cheaper for them.

Thus, in the USA the rapid expansion of home health care was one result of prospective funding for hospitals at levels related to the diagnosis; this encouraged both early discharge and fewer admissions. Retrospective funding on a *per diem* basis encourages greater hospital activity – see the chapters by Russell Selinger and Werner Gerdelmann.

It was recognised that in countries underprovided with beds, long waiting lists, and hospitals operating on fixed budgets:

- ◆ early discharge does not save the hospital any money
- ◆ even if money were saved, current financing arrangements make it difficult or impossible for the saved resources to follow the patient into the community.

Because of this uncertainty about cost savings in European health systems, the arguments for development of home health care have to rest on patient benefit and expanded choice (see later). One benefit evident in the USA was that in home health care there was increased 'ownership' by patient and relatives of the condition, the treatment, the regime and the materials used in care.

It was stressed that cost considerations should not be the sole determinant of decisions: all other outcomes, including health gain, must be studied, as with the evaluation of any new procedure. (It has to be said that all studies of home versus hospital care have shown unequivocally that the health and rehabilitation outcomes of homecare have been as good as if not better than hospital care, probably because of the conservative choice of patient condition in which homecare is tried.)

Technological

The development of home health care had been made possible by technological advance, but it was not felt that the shift was technologically driven. Technology provides practical help, but family support to the patient is more psychologically based. The only question remaining was whether still further developments, or increased availability, of technology could be encouraged which would ease the burden on the carer.

It was alleged that technologies which have priority for funding seem to be those that would release beds, making the issue 'bed-driven' again. Aids to quality daily living seemed to have a lower priority. There is a message here to those who set research and development priorities.

Dissatisfaction with some aspects of hospital care

Among the factors promoting the shift were the known dangers of infection in hospital, especially in immunocompromised patients such as those with AIDS, and a widely experienced dissatisfaction with pain control in hospitals.

Consumer pressure and patient empowerment

There is in general increasing pressure from patients and relatives for greater choice in how their care is

handled. Consumerism has been acknowledged as a legitimate force by most European governments, and radical change is very much on many political agendas; both of these movements are favourable to the development of home health care. It was pointed out that even before these changes in attitude occurred, consumer pressure had markedly influenced UK government strategies towards the hospitalisation of people with mental illness or handicap.

The reality of patient empowerment is far from being achieved throughout Europe: the 'consumer revolutions' have still to take place in many European states. The loop between patient pressure for greater choice about care locations, and its impact on the responsiveness of health care delivery organisations to meet this 'demand', has yet to be closed.

Patient empowerment, which is in full swing in the UK, has potentially a huge effect on the service. The theory is that if members of the public gain confidence in a particular type of service such as acute care in the home, market forces will ensure its development. This relates to the NHS reforms (see below).

However, there is the difficulty (a general one) of patients' dependence on professional advice. Professionals and others need to have worked out different ways of doing things before they can even sensibly offer choices. Then again, too wide a choice of care locations would not be economical, especially for specialist providers, so there is some doubt whether patients would really be given choices.

The answer to the question put to the conference, 'Are health organisations – insurers, purchasers, providers – sensitive to the needs of consumers of home care?' was 'Not sensitive enough, but it's improving'. The insensitivity was thought to be in part because professionals are used to assuming that they can assess need, without checking the validity of their definition. In the community it is usually a GP-led, not client-led, definition. Services offered as a result of some corporate or government strategy do not necessarily reflect local need.

A contrast was drawn between the launch of a new commercial product and new health arrangements: the latter are not 'marketed' to the potential customer, with surveys carried out before a launch and during a product's lifetime. Perhaps this too will change: at least there are now increased efforts to publicise the outcome of experiments like the Peterborough Hospital at Home experiment.

There was reference to lobbying groups as a factor promoting the shift and hastening change, but others were wary of responding to such groups because the continuity of a community service may be endangered

by yielding to a particular pressure group, to the detriment of other groups who may be without a voice.

More general empowerment of patients, by the provision of high-quality information, was favoured. If patients were to be given choices they must be in a position to be able to make sensible choices, and in possession of the requisite knowledge to take or accept the risks. Many voices called for improved health education to lead to this more informed choice.

Finally, it was pointed out that with real empowerment will come new challenges: planning and decision making will become more messy and complex, and there will be problems in designing flexible systems in response.

Medical audit and NHS reforms

The major effect of 1990 reforms of the UK NHS is the move to a purchaser/provider split. In theory at least, health authority purchasers of health care on behalf of their resident population should be able to exercise choice between options, and there is some anecdotal evidence that this is beginning to happen, despite the pessimistic view held by some that the upheaval caused by the reforms and the current instability of the purchaser/provider relationships would impede progress for some time to come.

Some discussants believed that the players in the health care arena who market their service most successfully stand to benefit enormously in service uptake and the level of funding made available through contracts. Budget-holding GPs could be a major influence as the market develops, particularly if they recruit staff to assist them in managing patients in the community.

Others considered that medical audit is likely to be the most important driver of change in the UK and Germany. The provider market was not seen as playing this role, nor was consumer pressure thought likely to have much effect.

All these forces depend, of course, on the clearly demonstrated superiority of home health care over hospital care, whether in benefiting someone's exchequer, in consumer satisfaction, or in improved clinical outcome.

II Evidence of a shift to home health care

What kinds of home health care are we talking about?

Acute home health care:

- ◆ early discharge after hospital treatment
- ◆ rehabilitation after ordinary or day surgery
- ◆ occasional intensive therapy within chronic illness.

Continuous home health care:

- ◆ to avoid hospital admission (especially of children, the elderly) wherever possible
- ◆ to bring about supportive self-management (for example, diabetes) and 'successful ageing'
- ◆ palliative and terminal care.

It was agreed that there have been some major shifts over time, particularly in the fields of continuing care and chronic illness – for example, care of the elderly, palliative care, care of AIDS patients and the younger disabled. Indubitably more highly dependent, ill people are now being cared for at home. What was thought impossible or undesirable 20 years ago is today accepted.

However, changes are mainly related to the development of day surgery, ambulatory care and shorter hospital stays. The number of people treated in acute hospitals still continues to increase. Areas amenable to further shift are rehabilitation, maternity care, mental health care, and terminal care. It was thought that the question might be turned right round to ask 'How many people need to be in hospital and why?'

Has the case for home health care been made?

The belief that home care is cost effective was again challenged; the evidence for savings to the system as a whole is weak. Hospitals can undoubtedly save money by offering day care rather than inpatient care; this would appear to suggest an increase in acute care at home, but these resource savings are not following the patient into the community. It was stated that the cost of one day of inpatient care equals that of five home visits, although the provision of quality home care may prove more expensive, relative to inpatient care, than this suggests.

The evidence that home health care is on the increase is patchy, and largely anecdotal; despite information

being available about successful schemes (Peterborough, and Harrow¹) the UK NHS did not seem to be ardently pursuing the concept. The anecdotal evidence, referred to by Shirley Goodwin, is that purchasers of health services (health authorities, fundholding GPs) are showing keen interest – partly, no doubt, under the influence of policy changes heralded in the Community Care Act which comes into force in 1993.

Widespread concern was expressed that if the shift to home health care is argued purely on financial grounds it might become a force hard to resist, with insufficient attention being paid to quality issues. There need to be further controlled trials comparing outcome, and further attention to defining criteria for particular conditions for home treatment, paying full regard to adequacy of the home environment and the extent of carer support.

Some of the caution may be explained by the worry that home care may be inferior to hospital care. Media coverage, in particular, concentrates on failures in community care, usually the result of hasty and ill-prepared transfers. Outcome assessment must be an integral part of any scheme, and patient outcome must be at least equal to that from hospital care,¹ as all the earlier studies of well-planned schemes have in fact shown.

III Difficulties in moving to home health care

Social/cultural difficulties

The public believes that hospital is where you go when you are ill. To change this into support for a home health care policy will require an improved perception of current community care, and the following questions readily arise:

- ◆ Will home care policy be carried out 'on the cheap', with the primary motivation to save money?
- ◆ Will it pose extra and unacceptable burdens on carers? It is wrong to assume that all carers wish to have sick relatives at home?
- ◆ Will the patient/carer have any genuine choice in the matter, or will home care become an 'irreversible bandwagon' in which there is no effective choice?

All delegates were convinced that home health care should be additional to, not relegated to, family responsibility. Family support is influenced not only by the prevailing ethos of the country – the Nordic countries, for example, believing quite strongly that the elderly are mainly the responsibility of the state and not of female family members – but in the UK (for

example) by social class, with middle-class, smaller nuclear families having less opportunity and possibly willingness to cope with a sick relative at home. Short-term acute care in the home must be *acceptable* to patients, carers and families: it must not be imposed.

The problem can be solved if respite and other support is well organised and provided.

The quality of the patient's home can be a barrier, and the adequate coverage of both thinly populated rural and overcrowded inner city areas by the support services needs to be addressed.

Before any decision is made to admit or discharge a patient to a hospital at home system, the following questions about available carers must receive a positive answer:

- ◆ Are there any?
- ◆ Can they manage?
- ◆ Do they want to?
- ◆ Do they trust, or can they be encouraged to trust the professionals to deliver?

Professionals' difficulties

Professionals may feel threatened by the introduction of a hospital at home scheme for a number of reasons, including the feeling of not being in control of the situation when having to operate outside an institutional environment and the necessity to impart information and training in certain skills to patients and their carers. There may be staff fears – which can easily be transmitted to the public – of job cuts, transfers and the need to acquire new skills.

Shortage of skills is the limiting factor. In general, community-based services are not acute skill-oriented. Staff feel that this is not what they have been trained for or are used to. Professionals working in the community lack the immediate support of the other professionals who are available in hospitals. There is a danger of role or power conflicts between professionals who would need to work together. Traditionally, most power has resided in the acute sector, where the emphasis has been on treatment, not prevention. Doctors have been invited to become managers, but mainly of hospital departments, and this will not necessarily support a shift from hospital to home health care.

Professionals have to be trained in the concept of integrated care; paediatrics seems to have been the first specialty promoting this concept. The problem of apparent isolation from the support of other hospital professionals can be solved by training in decision-making and extended roles, and development of effective

support structures. Indeed, all present seemed to consider that training or retraining would be necessary, both of nurses (community and hospital) and of less qualified professional carers; some thought the retraining would need to be extensive. However, the experience at Peterborough indicates that these problems, though real, are less daunting than they seem in the abstract. Community nurses in particular seem to have enjoyed the challenge and risen to it.

More serious may be the attitudes instilled in doctors by the nature of their training, which takes place virtually exclusively in hospitals. In Germany (and probably in Sweden and Finland in the near future), an over-supply of doctors has led to a reduction in the number of training places, and older 'immobile' doctors trained in traditional fashion continue to provide the service. In the UK there is a similar problem with older doctors, but not in the training of young doctors – although the royal colleges' training requirements are governed by (hospital) departmental size and bed numbers.

There is no doubt that the majority of doctors (and to a lesser extent, nurses) prefer their patients to be in hospital, and there is inevitably a reluctance on the part of hospital specialists to 'let a patient go'.

The attitude of general practitioners (GPs) is crucial to the success of home health care schemes; this is dealt with in section IV of the discussion, Issues to be Resolved.

Financial difficulties

The financial disincentives to promoting home health care, greater in some countries than others, were widely felt to be the most serious of the difficulties ahead.

The worst ones were the *per diem* reimbursement systems (like that described by Werner Gerdemann) which strongly encourage longer hospital stays. The next worst was the impossibility of transferring resources saved by the hospital (for example, the cost of drugs) into the community to follow the patient.

A further example in the UK is the lack of financial support for informal carers. Acute care in the home should not impose additional financial strain on the patient or family, and much still remains to be done at the legislative level to correct current deficiencies.

People were also worried as to where the capital investment for the supply of necessary equipment was to come from. Above all, the separation of the social service and the health care budgets will be a major problem. (However, joint funding by health authorities and local authorities is far from unknown, and this problem too can be solved, given good will.^{1,2})

There was a universal call for establishment of the true total costs of both types of care, under a variety of circumstances, always bearing in mind that quality care costs money.

Participants considered that financial policy would need to be so structured as to support a home health care policy. While it may in time be possible to transfer resources from acute hospitals into homecare, initially at least there will be additional costs which will need to be provided centrally on a pump-priming basis, or as bridging finance.

Organisational difficulties

It was emphasised that in any hospital at home scheme receiving patients discharged from hospital, discharge and homecare plans need to be drawn up *before* any elective hospital admission. These plans must guarantee an emergency response if necessary.¹

The major organisational difficulties in all countries from the number of people involved: co-operation between many agencies is called for, with the integration of primary and secondary health care, social care and housing. While the organisational problem in the UK is the boundary between primary health care and social services, Denmark's problem is between county councils overseeing hospitals and district councils responsible for homecare and waiting lists.

Ineffective inter-agency or inter-authority working arrangements would be a very effective barrier to success. It is essential to secure collaboration between district health authorities (purchaser), the family health services authority, hospitals (traditional providers of acute care), GPs and social services. Funding divisions might be overcome by identifying common resources¹ and agreeing common management arrangements. Mergers between DHAs and FHSAs might be one (partial) solution. Joint protocols to define the role of primary and secondary care sectors,³ and joint audit to monitor the effectiveness of treatment are recommended.

Finally, a balance needs to be struck between the resources to be applied to this form of care compared with other priorities.

IV Issues to be resolved

What is the appropriate model?

In commissioning research into home health care, people should be aware that there are two main models, hospital outreach and developed community services, variants of both, and a third type mentioned by Barbara Stocking but not further referred to: hotels/hostels/nursing bed units. It was felt that the choice of model

may depend crucially on the level (intensity) of care required (on the other hand, the Peterborough Hospital at Home service has steadily expanded to include many different levels of dependency from those with which it started).

Professional attitudes and roles

DOCTORS

The willingness and ability of GPs to be party to home health care varies. The current observed conflict between fundholding and non-fundholding GPs was cited as stifling development of the service. If some GPs are willing to accept clinical responsibility for early/acute discharges, but others are not, this may create a fragmented service.

GPs in charge of primary health care teams might not be aware of the necessity to provide multidisciplinary, multi-agency services, or unwilling to spend the time and effort needed to sort out the administrative issues involved. What was perceived as a generally poor relationship between GPs and social services was considered a major barrier to success. A German GP at the conference (Dr Matthias Klein-Lange) had enjoyed this work, but thought that few would want to do it all the time.

Although GPs may feel they have had homecare 'dumped' on them, it was reported that if communication is good and protocols can be agreed on matters like analgesia, the implications aren't anything like as great as people imagined.

NURSES

Most points are dealt with above. The only issue apparently to be resolved is where the resources to pay for the training are to come from (see below).

TECHNICIANS

Outreach from specialist (medical physics) hospital departments has not proved a problem with home haemodialysis.

Staff training and education

The training of health professionals must feature very high on the priority list of every organisation concerned with health care delivery. Much benefit would derive from a common core approach to the training needs of health professionals involved in hospital care at home.

A major need is to teach team working. Staff need to be trained to recognise the essentials for success in this area. This should form part of all health professionals' continuing education, regarded as development beyond the specialist role.

Co-ordination

The appropriate skill mix for successful home health care is complex: specialist/generalist/lay, and multiprofessional. There are bound to be difficulties in co-ordinating the inputs from such a range of professional and non-professionally qualified workers, spanning a number of different agencies, so as to ensure efficient and effective care delivery.

There are perceived difficulties of co-ordination across the secondary/primary care 'divide' within the health care sector alone. Relations between specialist and generalist nurses can be fraught, as well as between nurses and GPs.

It was stated that in Sweden the concept of a primary health care team is not working effectively – GPs are not taking on the wider co-ordinating role expected of them.

On the other hand, district nurses already have most of the expertise needed for the job and they are already well established, with good relationships, in the primary health care team. Some fear that the district nurse role would disappear with the development of a generic community nurse with clinical nurse specialists in support. (This does not seem to have happened in Peterborough: on the contrary, the role of district nurse has expanded and developed.) The proponents of the opposing views were agreed, however, that extra training rather than retraining could meet most needs. Specialist areas would need to be developed – for example, community paediatric nursing.

The problem in the UK with any form of hospital outreach which requires specialist nurses to operate in the community is that UK authorities demand a community nursing qualification for community practice; if adhered to, the additional nurse training required could have huge financial implications, tilting the cost factors heavily against home health care.

Even if this consideration could be waived, there are currently too few community nurses to provide home health care. Guernsey was quoted as one area where GPs are willing to care for people at home but there are no nurses to look after them.

There are bright spots where issues have been resolved. The Edinburgh Head and Spinal Injuries Unit provides an example of good and successful practice: continuing care at home, spurred on by bed pressures, is well led and organised, with clear agreements between hospital doctors and GPs, and with patient power central. Funding policies also agreed. Care has to be done 'obsessively carefully', yet very simply. This unit was reported to have done work on cost-effectiveness of the scheme; so has the US Spinal Injuries Research Unit.

Technology

Even further development of low-tech aids to daily living should be encouraged, but with care to establish a balance between manufacturers leading the service and responding to its needs.

V Areas for urgent action

'What are the areas where changes will be needed most urgently to support the shift from hospital to home care?'

Strategy

NATIONAL/INTERNATIONAL

It was stated that no strategy for homecare has been defined – nationally, locally, or Europe-wide. Because the UK purchaser/provider relationship is not yet mature enough to deal with the shift from hospital to home care, a broad strategic statement as to its desirability is required at international or national level. If this were done local purchasers, insurers, health authorities, family health services authorities and social services would interpret and add flesh to the strategic bones.

It is however essential to ensure that the costs of care transferred from the hospital do not become the responsibility of the patient. Examples in the UK where this does currently happen include NHS prescription charges and the transfer of hospital staffing responsibilities on to unpaid carers.

It was generally accepted that, if there is a willingness to meet costs, any type of care could be provided in the home. Urgent action is therefore required to examine and refine in-depth cost analyses of homecare programmes to provide a sound basis for decision making.

Above all, strenuous efforts must be made to identify the rewards that will get a number of organisations interested and create the momentum. Parallels with day-surgery initiatives should be drawn.

LOCAL STRATEGIES

Health service purchasers and policy makers need to develop strategies. There are signs that this is happening in forward-looking health and local authorities, and some purchasers are realising the potential strength of their influence (money talks).

Shifts in care should be so designed as to enhance, not diminish, clinicians' perceived interests. Clinicians who have traditionally seen their interests as being broadly and directly linked to those of their hospital will not readily change unless the shift to homecare is seen as non-threatening; the hospital must therefore be

actively involved in developing and delivering acute homecare programmes. One way of achieving this would be for purchasers to contract with hospitals to provide an outreach service. Another would be to develop consultant-led community services. Still another would be to give GPs more funds for contracting to manage acute care at home.

There needs to be better definition of priority targets of people and procedures in homecare, so that the over-all task becomes realistic and manageable.

Respite care agencies must be developed; the question of who is to pay for them was not addressed.

A single lead agency must be identified as the provider or co-ordinator of care.

Training and education of professionals

This was seen by all as a priority area. The urgent training tasks were:

- ◆ to train community nurses in more extended, specialised roles, while developing unqualified care workers to provide some aspects of the general nursing role
- ◆ to educate clinical, nursing and therapeutic staff as to the service *and* staff benefits (that is, to make the community job attractive and career-enhancing with potential for growth, thus attracting the right people)
- ◆ to retrain professionals with an emphasis on client/patient as part of the team (a change in attitude) and to accept the concepts of a care manager and agreed care plans.

There was general scepticism about the ability of doctors to adapt quickly, or to adopt new methods of training. One discussion leader summed up as follows. 'The medical profession is apparently sacrosanct. There was only vague reference to the possible need for a review of medical training, and that related more to potential service development than training needs. On one side was the argument for the medical model of care with exclusive medical responsibility for direction of care. On the other side were a wider range of members in favour of a social care model with a multidisciplinary/multi-agency approach with identified lines of responsibility. I hope other groups felt able to discuss the issue of medical training more directly as it appears fundamental to the success of homecare development.'

Another group recommended modifying medical training away from the classic hospital model to include the homecare option. A first and relatively easy step would be to remove the requirements for a number of

beds for a hospital to be approved for training of junior doctors.

In tandem with this, hospital consultants' views as to the primacy of the hospital as the optimum setting for acute health care should be changed (although there were no suggestions as to how this could be done).

Ultimately the group was despondent about the practicality of meeting all these training needs because of the huge financial and manpower requirements.

Harnessing patient empowerment

Special interest groups – for example, those with HIV infection should be mobilised.

Improved general education will provide the public with the skills to enquire into and make informed choices about their health requirements. Programmes of active health promotion may be even more relevant, in preventing or reducing the incidence of acute illness requiring hospitalisation.

Health education about the availability and advantages of home health care would create pressure. With more information people may feel as secure being cared for at home as they previously felt in hospital. This may be particularly true of parents wanting the best and least disruptive care for their children.

National campaigns were, however, rejected and local campaigns were preferred because the needs in different localities are different.

Fund-holding GPs with patients' interests truly at heart could become advocates for homecare on behalf of patients.

Technology

The demand-led markets for technology need to be satisfied by speculative developments. To increase the latter, incentives for businesses need to be identified. Innovations need to be marketed on the grounds of providing genuine cost savings for purchasers of services.

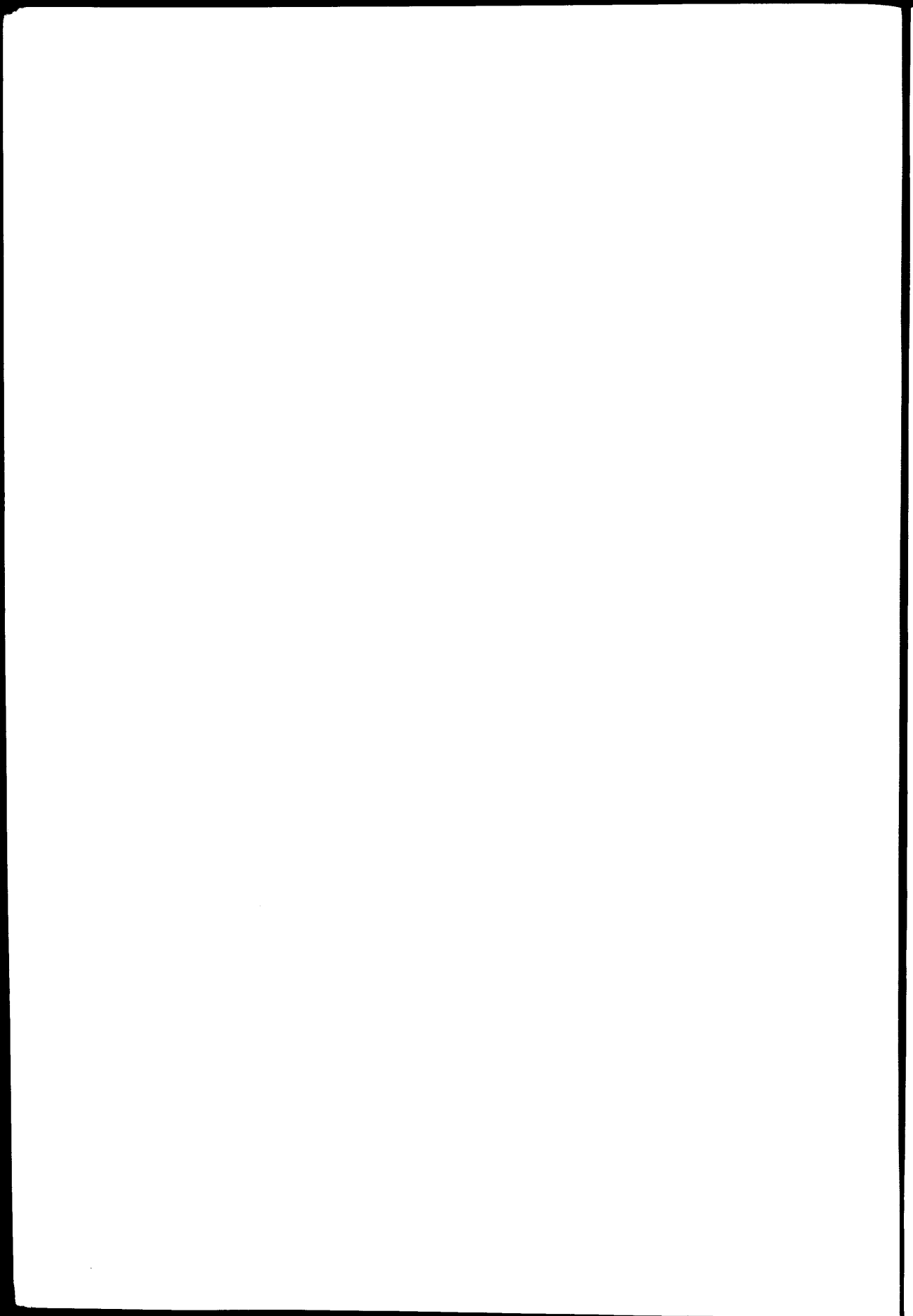
There is great potential scope for home-based information technology equipment to play a support/reassurance role. This must be emphasised and brought home to innovative companies.

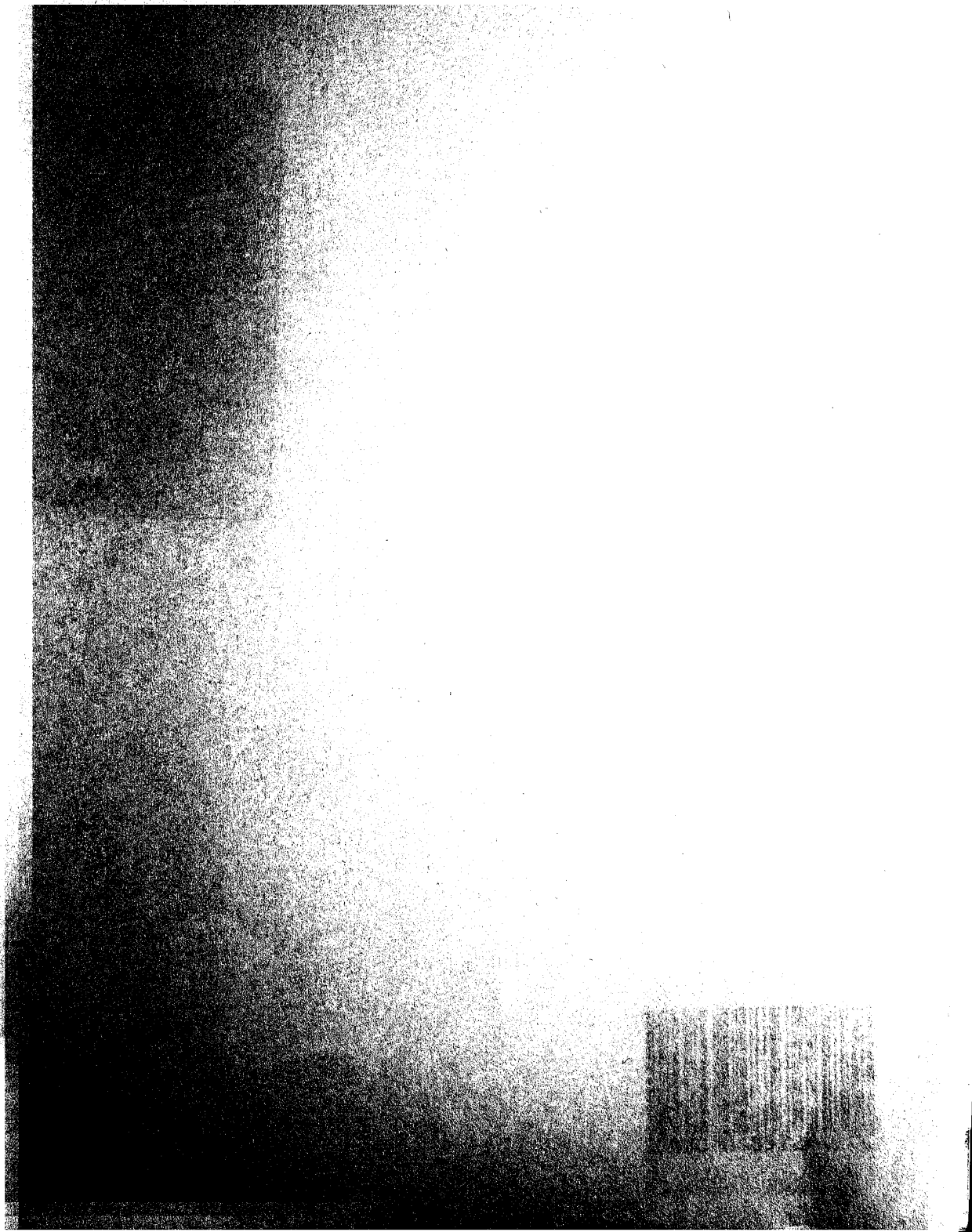
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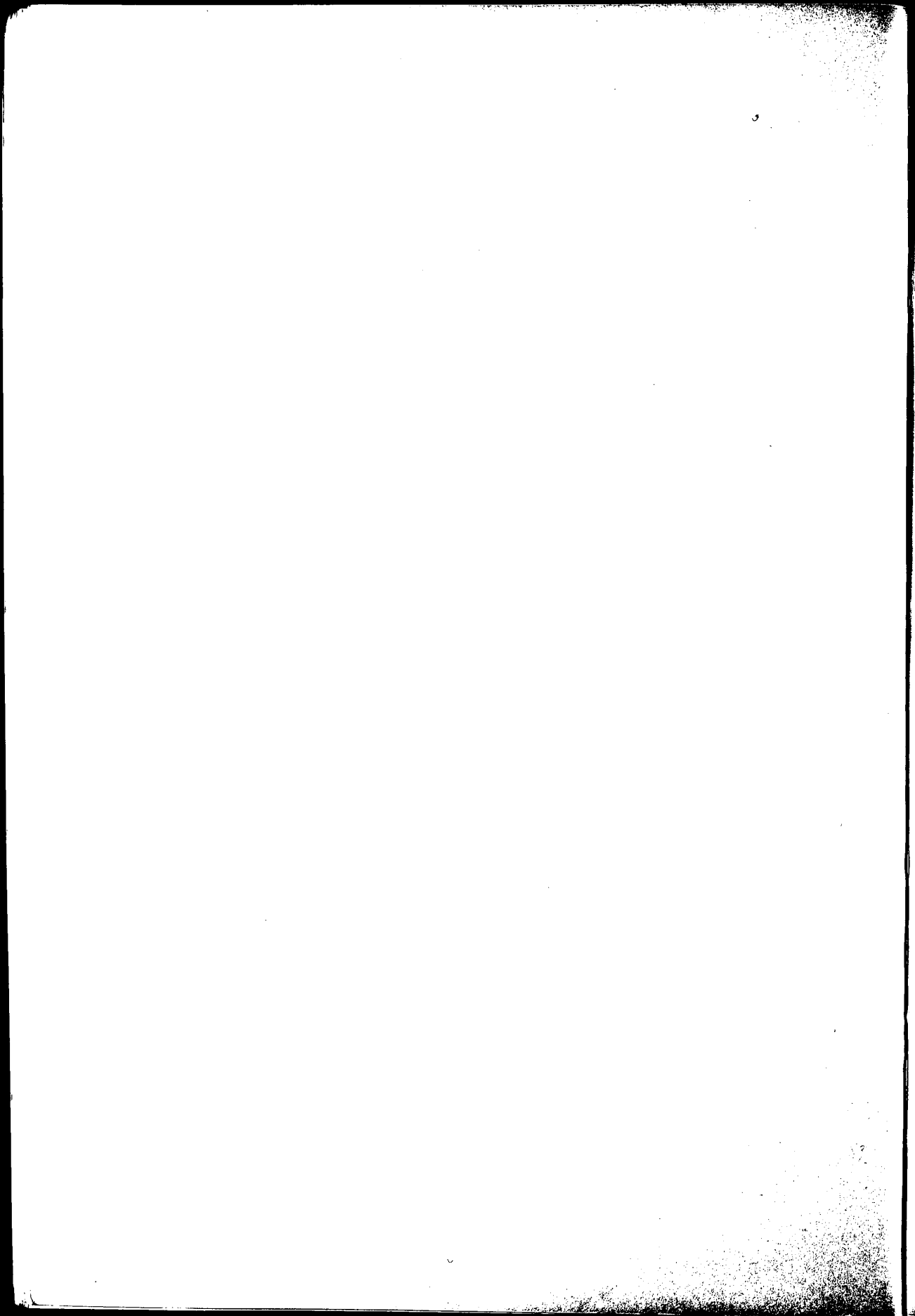
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2 For example: City and Hackney Health Authority. Discharge Planning Policy. Consultation document, 1991.

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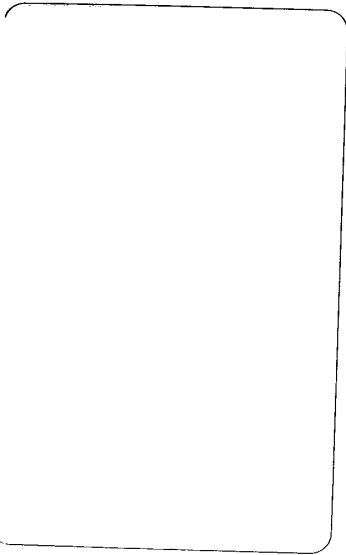




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FROM HOSPITAL TO HOME CARE

*The potential for acute service
provision in the home*

The extent to which home health care is replacing hospital treatment differs widely across Europe. Currently, technology for home health care exists in various forms including infusion therapy, respiratory therapy, renal services and incontinence support. New approaches may encourage more treatment in the home.

This publication summarises the papers and discussion at the Hospital to Home Care Conference held in Cardiff in October 1991.

The conference compared and contrasted the status of various European home care programmes, and it reviewed the key factors which have influenced their progress in terms of infrastructure, organisation, information systems, costeffectiveness, reimbursement and ethical considerations.

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