SHARED-CARE SCHEMES FOR CHRONIC DISEASES IN THE UK AND THEIR APPLICABILITY TO SPAIN

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ABSTRACT

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Failures in the organisation of traditional care for patients with chronic disease have led to the development of new strategies of care. Despite evaluation studies showing the benefits of shared-care schemes its uptake has been slow. This study aimed to identify new schemes of care for four chronic diseases (diabetes, hypertension, thyroid disease and rheumatoid arthritis) and to investigate doctors' attitudes to shared-care schemes.

The methodology for the study consisted of a literature review, snowball sampling and a postal survey with both descriptive and analytical components.

The setting of the study was Health Authorities and Health Boards in Great Britain.

The population surveyed consisted of 147 consultants responsible for the care of patients with diabetes, hypertension, thyroid disease and rheumatoid arthritis and 208 general practitioners (GPs) from 16 Family Practitioner Committees (Primary Care Divisions in Scotland).

Twenty nine schemes were identified of which 18 were shared-care schemes. The survey's response rate was 70%

for consultants and 64% for GPs, in both cases after one reminder.

Forty three (42%) consultants and 45 (43%) GPs claimed to have participated in shared-care schemes. However, and despite our efforts to define 'shared-care' schemes in the questionnaire, there were obvious different understandings. Only 25 (58%) of 43 consultants who were 'claimed' participants met our classification for 'classified' participants in shared-care schemes. Diabetes was the specialty most likely to have shared-care schemes, 20 (47%) consultants with responsibility for diabetes were participants compared to only five other consultants.

In general practice, nearly a third of GPs were participating in shared-care schemes for diabetes and another third had set up mini-clinics for diabetes and hypertension. However, more than a half and nearly two thirds did not have special arrangements for the follow-up of patients with thyroid disease and rheumatoid arthritis respectively.

Consultant participants in shared-care were more likely than non-participants (29% vs 7%) ($X^2 = 16.2$; df = 4; $p<0.005$) to think that responsibility for ensuring that all patients in the area are screened for complications at regular intervals should be the consultant's alone.

Participating consultants were more likely (82% vs 42%) to take the view that not all GPs provide good follow-up and consultants need to take a more active approach, and were more likely (80% vs 51%) to take responsibility for making contact after a patient non-attendance . Only 21% of the GPs thought that setting up a shared-care scheme should be their responsibility.

Although shared-care has been shown to be cost-effective, the number of identified schemes was few, just 18 in Britain. Different factors seem to influence the individual decision to take up a new idea. For example compatibility of shared-care with professional roles and attitudes seems to have a large influence. This study has shown that shared-care schemes have been set up by hospital consultants who have more of a "population approach" to care and enough enthusiasm for this to overcome the difficulties of initiating a scheme.

Even so, few of the schemes identified in this study have had the explicit aim or mechanisms for ensuring that all patients in a given area are being followed-up.

There is now a clear responsibility for purchasers to buy equitable, efficient and effective health care for people with chronic disease. Evaluation studies suggest that formal shared-care schemes are more likely to achieve these aims. The indications are that most doctors are willing to co-operate in shared-care but need the extra impetus which can come from purchasing teams requiring consultants to establish such schemes. However, purchasers and providers will have to ensure that they are very clear about what exactly they mean by shared-care.

CHAPTER I

INTRODUCTION

INTRODUCTION

Chronic disease is the major problem facing health services in developed countries today. A number of factors are responsible for this. The battle against infectious diseases which before this century were the foremost cause of death has largely been won. Furthermore, the reduction of infant mortality rates, has led to an increase in the life expectancy in industrialized societies in general and in the British population in particular. Therefore, although there has been a remarkable decline in birth rates (20% in the decade 1964-1974), the population of the UK has increased this century from 38 millions to 56 millions [1]. The result is that there has been a profound change in the age structure of the population. So, whereas the proportion of the elderly (65 and over) in 1901 accounted for only 5% of the population, in 1977 the proportion had risen to 15% [2]. About 5 million people in the UK are currently aged between 65 to 74 and another 2.7 million are 75 and over [1].

The increase in life expectancy is reflected in the median age of death. In the UK in 1973, fifty per cent of all deaths of men occurred at the age of 70 or over and in women at 76 or over [1].

An increased number of old people is inevitably related to an increase in the number of chronic conditions and subsequently with a higher degree of disability in that population [1].

MORBIDITY AND MORTALITY OF SOME CHRONIC CONDITIONS AND THEIR IMPLICATIONS FOR HEALTH SERVICES

Given that primary care is usually the first professional level of care contacted by people with ill health, it can serve as a frame of reference to study the impact that chronic diseases have had on population morbidity.

Figures extracted from Trends in General Practice in 1977 showed that 21% of general practice consultations are due to chronic conditions [2]. The number of persons consulting per year for some specific chronic disorders in an average British General Practice of 2500 people are shown below:

Conditions	Persons consulting per year
High blood pressure	50
Chronic heart failure	30
Coronary artery disease	20
Cerebrovascular disease	15
Diabetes	10
Rheumatoid arthritis	10
Thyroid disease	7

Regarding the use of hospital facilities, cerebrovascular disease is one of the commonest causes of hospital admissions (over 110,000 admissions a year in the UK) and one of the greatest demands on hospital beds (about 20,000 beds occupied every day) [1].

Diseases of the heart and circulation, including strokes, occupy first place in terms of length of time spent in hospital. About 3500 hospital beds are in use every day in the UK for the treatment of patients under 65 suffering from coronary heart disease [1].

When talking about mortality, the most important causes of death in the UK nowadays are heart disease, cancer and stroke, representing 66% of all mortality causes in England and Wales. Moreover, coronary heart disease is the foremost cause of death in men in middle-age and 43% of all male deaths between 45-64 years are due to this cause. It is also responsible for more years of productive life lost than any other single disease [1].

It could be said that the nature of health problems today is a consequence of a failure in the three levels of prevention. Firstly, regarding chronic diseases, primary prevention seems to be difficult to apply because of the lack of knowledge about the real aetiology of almost all chronic diseases. However, since a series of risk factors have been identified as influencing their development, health education would be the most important primary prevention measure to take. Health education with the aim of changing people behaviours which are related with the development of those risk factors.

Secondly, a failure in early detection and early treatment of those patients already affected by the disease, will lead to the onset of unwanted complications. It is here where it seems there is a shortfall. Long-term surveillance of chronic patients seems to be therefore, crucial as a measure of secondary prevention.

Finally, a failure in tertiary prevention will lead to a great degree of disability and suffering in people with established chronic disease.

Therefore, the preventive approach to any chronic condition should aim for two main objectives [3]:

1. Early detection and early treatment as well as patient health education.

2. The decrease of disability by early detection of complications.

With these measures it has been proved that undesirable complications derived from chronic diseases can be largely avoided.

All sectors of the health service are involved in the care of patients with chronic disease and therefore, it could be argued, some responsibility to ensuring that these services are well organised.

Hence, health services need to find methods of care delivery which are effective, efficient and equitable. The best options of care will vary with changes in treatment, funding, technology and the structure of the health services.

A BRIEF EPIDEMIOLOGICAL PERSPECTIVE OF SOME CHRONIC DISEASES

DIABETES

"Diabetes Mellitus is unique amongst chronic disease in that it can develop at any age, requires life-long treatment and with treatment carried out effectively and diligently, is compatible with a full and active life-style and longevity". [4]

Chronic hyperglycaemia is a common condition affecting people of all ages and leading to a high morbidity and premature mortality. [5]

It has been estimated that there are at least 30 million diabetics around the world and this figure tends to increase as the age structure of the population becomes older [6].

The prevalence of diabetes is difficult to determine because of different standards in diagnosis, but figures between 1% to 3% have been reported [3]. In the UK it seems that the prevalence is between 1 to 2 percent. Twenty percent of the affected population has been identified as being insulin dependent and the remaining are non-insulin dependent [7].

Incidence rates are even more difficult than prevalence to measure accurately. Yet, the annual incidence of Type I diabetes seems to be between 8 and 13 per 100000 population whereas Type II is about 70 per 100000 [7].

Diabetes has a high cost in human, as well as in economic terms. The diabetic patient is susceptible to a variety of distressing complications which results in high hospital admissions rates [6], as well as a high mortality [3].

In the diabetic the risk of coronary heart disease and peripheral vascular disease is increased [8]. It has been found that at least 25% of patients having major amputations are diabetics [3]. Diabetic nephropathy is a leading cause of death and disability in diabetes [5], and it is a major cause of end-stage renal failure [6]. In addition, diabetic retinopathy is the single commonest cause of blindness below age 65 [3]. Lastly, diabetic neuropathy is a major cause of morbidity, being responsible for the development of ulcers of the feet and lower extremities in diabetics [5].

The critical question in diabetic therapy is whether good metabolic control reduces the risk of complications.

It has been pointed out that genetic factors independent of hyperglycaemia levels could be the primary cause influencing the development of such complications. This theory is drawn from the fact that typical diabetic complications may be found in patients at the time of diagnosis [5].

However, studies in animals [9] and observations of kidneys in donors and recipients with and without diabetes suggest that at least neuropathy and nephropathy appear to develop directly as a consequence of prolonged hyperglycaemia. In addition meticulous control with infusion pumps has been reported to decrease capillary leakage of fluoresceine in the retina. [5] Nevertheless, it seems that currently, the only effective treatment for preventing diabetes' blindness is photocoagulation provided that it is given at an early stage [10]. In this sense, the importance of a timely ophthalmic assessment has been emphasized by Donovan [11].

Although there is no firm evidence that a tightening metabolic control prevents the onset of complications, normoglycaemia and strict follow-up of those patients already diagnosed have been seen as the objective in diabetic care [5,9,11,12].

Therefore, there is a great concern about identifying asymptomatic cases before the onset of complications, as well as, a clear need for adequate clinical evaluation and monitoring of those patients already diagnosed. As Professor Sonksen says "unless you screened routinely for nephropathy, neuropathy, retinopathy and hypertension to identify these complications at an early stage and prevent irreversible progression you were not providing even the minimum of modern care" [12].

HYPERTENSIVE VASCULAR DISEASE

Hypertension is one of the foremost public health problems facing developed countries. Its importance derives from its high prevalence, asymptomatic course and its clear relationship with a high risk of morbidity and mortality from the cardiovascular and cerebrovascular diseases associated with it [5,13].

Hypertensive disease is characterized by sustained elevation of diastolic and/or systolic arterial pressure above arbitrary levels (normally 160/90) which have been stabilised to define those who have an increased risk of developing a vascular complication [5,14].

The prevalence of hypertension depends on both the racial composition of the studied population and the cut-off points used to define the condition. Prevalence rates between 10 and 20 percent have been reported [5,14,15]. Rates have been seen to increase with age [14].

Patients with untreated hypertension are at an increased risk of suffering from heart disease, stroke and renal failure which result in chronic illness, disability and premature death [5]. In the Framingham study, blood pressures over 140/90 mm Hg were found in 73% of the men and 81% of women who died of CHD [16].

In fact, hypertension has emerged as probably the most important risk factor for coronary heart disease (CHD), both because of its potent effect on arteriosclerosis and its high prevalence in the population [13].

The World Health Organisation [17] stated that even a small reduction in the average blood pressure of the population could bring about a large reduction in CHD.

In addition, the younger the patient when hypertension is first diagnosed, the greater the reduction in life expectancy if left untreated [5]. Moreover, morbidity and mortality rates from cardiovascular diseases will increase if other risk factors such as smoking, hypercolesterolemia and diabetes coexist with hypertension [5].

Although the levels of systolic or diastolic pressure which justifies treatment in the absence of pathological symptoms or signs are not agreed [18,19], the beneficial effects of treating certain categories of asymptomatic hypertension have been shown to include reduction of morbidity and mortality from stroke, congestive heart failure and renal failure [20,21,22]. It has been pointed out that if the diastolic pressure is consistently higher than 90 mm Hg, therapy is almost always indicated unless contra-indications exist [5].

Stason & Milton [23] studied the health benefits derived from the treatment of people with diastolic pressures of 110 mm Hg. They found that life expectancy was increased in women by 2.3 to 5.0 years and in men from 1.4 to 8.1 years. Quality adjustment of life expectancy for prevention of the disability associated with strokes and myocardial infarctions and medication side effects results in increases in quality-adjusted life expectancy of 0.1 to 0.4 years.

Nevertheless, in the 1970s surveys showed what was called the rule of halves [15,24] and twenty years later it seems to be still valid [25,26]. In an unscreened population, half the hypertensive patients are not identified. Of those identified, half are under treatment and half out of those are being treated inadequately.

Three points have been identified as responsible for this situation. Firstly, the asymptomatic feature of hypertension makes its diagnosis difficult by the normal process of general practice where symptomatic patients go to the doctor for relief [24]. For example, Hodes et al [27] found that only 11% of the general practitioners interviewed always measured the blood pressure of middle aged patients. Moreover, it seems that general practitioners follow their own individual criteria in defining hypertension. Smith et al [28] found that only 12% of the patients had their pressures recorded on three occasions and so fully met the criteria for diagnosing hypertension. Secondly, a high percentage of patients although aware of the condition drop out of treatment because of different reasons [14,29], or because many people found by doctors to have hypertension are not treated [15,30,31]. Lastly, a percentage of patients receiving treatment had blood pressures above the criteria set up as abnormal levels because they are not being treated effectively [14].

On the other hand if a decrease in morbidity and mortality from hypertensive complications is wanted, then long treatment of hypertensive patients becomes necessary since the failure to take the prescribed medication has been associated with a high risk of complications [29].

Therefore, identification of asymptomatic cases, rapidity in instigating treatment and continuity in follow-up will be of crucial importance in the management of hypertensive patients. Recently a report by the Royal College of General Practitioners concluded that, about half of all strokes and a quarter of all deaths from coronary heart disease in people under the age of 70 are probably preventable by the application of existing knowledge [32].

THYROID DISEASE

"It is now widely recognised that many branches of curative medicine are producing a steadily increasing public health problem in the form of iatrogenic disease appearing as late undetected complications of treatment" [33].

Thyroid disease is a term which includes two main forms of metabolic disorder: hyperthyroidism and hypothyroidism.

Hyperthyroidism: develops as a consequence of the over-activity of the thyroid gland leading to an increase in the systemic levels of thyroid hormones.

The prevalence in Britain is between 2.1 and 2.7 percent with incidence rates reported of 0.05 per annum [34].

Although relatively easy to treat, the possibility of severe late onset complications after treatment is what makes this disease a potential health problem.

The three kind of treatments which aim to reduce the quantity of thyroid hormones secreted by the gland are:

1. Antithyroid agents: its mission is to block the hormone synthesis. The effect is operative only as long as the drug is administered. Therefore, it is a reversible form of treatment [5]. This therapy is mainly recommended for children, young adults and pregnant women.

2. Subtotal thyroidectomy: it is a surgical procedure whose objective is to reduce the gland mass to decrease the production of thyroid hormones while leaving enough to avoid hypothyroidism. However, 20% of the patients treated by this method will develop hypothyroidism within six years of surgery and another 5% will suffer recurrent hyperthyroidism [7].

3. Radioactive iodine: it is a relatively simple effective and economical procedure of treatment and

avoids the usual complications of surgery [5]. The principal disadvantage is the tendency to produce hypothyroidism with a tendency which increases with time. Between 40% and 70% of patients are at risk of developing such a complication within ten years after treatment [5]. This kind of treatment because of its potential carcinogenic effect in children and mutagenic effect in pregnant women, is usually reserved for patients aged over 40. However, it can be chosen for patients with systemic diseases which contraindicate surgery.

Hypothyroidism: this condition results from insufficient synthesis of thyroid hormones which can be due to congenital, acquired or induced cause [34]. The most common cause of thyroprivic hypothyroidism is surgical or radioiodine ablation of the gland [5].

Jones reviewed studies where a point of prevalence of 1.9% for females and 0.2% for males had been reported [34].

The treatment of hypothyroidism is by the intake of thyroxine in a single daily dose of 0.1-0.2mg [7].

Side-effects of treatment and life long follow-up: All patients treated for hyperthyroidism are at risk of developing long-term complications [33]. Those who are under treatment with replacement therapy will experience problems either through patient non-adherence to treatment of a change in the individual's requirements [34]. Patients treated with radioactive iodine will be at risk of developing hypothyroidism. Finally, a proportion of those who were surgically treated will develop either hypothyroidism or hyperthyroidism.

The time at which these complications will appear is as unpredictable as insidious is the onset of either hypothyroisism or hyperthyroidism. Therefore, a long term follow-up of these patients will be crucial to ensure early detection of complications [34].

RHEUMATOID ARTHRITIS (RA)

Rheumatoid arthritis is a chronic multisystemic disease of unknown aetiology. What characterizes this condition is the persistent inflammatory synovitis which potentially leads to joint deformities and as a consequence, to a severe degree of disability [5].

Rheumatoid arthritis is distributed worldwide and affects all races.

The prevalence varies between 0.3 and 2.1 percent and increases with age. Women are three times more likely to be affected than men. Eighty percent of the patients suffering from RA are between the ages of 35 and 50 [5].

The course of the RA can vary widely and it is difficult to predict. Some patients will suffer only a mild oligoarticular illness and therefore, a first-line treatment (non steroidal anti-inflammatory drugs) could give enough relief. However, around 10% of RA patients will develop a progressive disease with marked deformity and severe disability [5]. These later patients therefore, will be suitable for more aggressive treatment. The second-line treatment as it is called, includes the use of disease modifying drugs such as gold compounds, D-penicillamine and antimalarials.

It has been documented that the use of these drugs has had a favourable effect on the course of RA, at least in two thirds of patients [5].

However, the use of these drugs is largely associated with high toxicity and therefore, patients under treatment require regular and careful monitoring [5].

For example, the use of antimalarials has been related with the development of retinopathy. Therefore, it has been recommended that ophthalmologic examinations should be performed every six months to detect such a complication.

The use of gold, is related with the onset of a rash, thrombocitopenia, granulocitopenia and proteinuria as a consequence of medular and renal damage respectively. In patients under gold therapy, the control of CBC, platelet count, and urinalysis should be performed at monthly bases.

The use of D-penilillamine a part from the potential of producing medular and kidney damage, it can produce gastrointestinal intolerance. The same parameters as those measured in patients under gold therapy should be controlled but at two weeks intervals during the six first six months of treatment and every month afterwards.

Therefore, as in the previous conditions, once again the importance of monitoring these patients during a long term period is crucial to ensure early detection of complications.

HISTORY AND CURRENT SITUATION IN THE MANAGEMENT OF PATIENTS WITH CHRONIC DISEASES

"One of the major problems confronting medicine today is the follow-up of identified at risk groups and the detection of presymptomatic subclinical, or even overt but undetected disease" [33].

As already discussed it is widely recognized that early detection, suitable treatment and appropriate follow-up are of great importance in preventing major complications. Therefore, there is great concern about identifying asymptomatic cases before the onset of complications as well as a clear need for adequate clinical evaluation and monitoring of those patients already diagnosed.

Despite this however, the management of patients with chronic diseases has proved difficult to organize in an efficient and effective way. The main problems in the organisation of long term care are, on one hand, to maintain contact with the patient and ensure the desirable follow-up intervals; on the other hand, to make sure that the routine examinations needed are performed when follow-up is due.

Traditionally, diabetes has been thought of as a hospital condition and patients with diabetes (at least insulin treated ones) have been referred to hospital diabetic clinics (35). It became a common practice for the general practitioner to regard the detection of glycosuria as the signal for referral of the patient to hospital [36].

Diabetic clinics were started to deal with insulin treatment and were among the first hospital specialist clinics. There are currently about 360 diabetic clinics in the United Kingdom. Most of these are staffed by a general physician with special interest in diabetes, senior registrar or registrar, one or more clinical assistants who are general practitioner and some times a senior house physician. Most diabetic clinics have one or more dieticians attached and hospital sisters. There are as well, chiropody service and close liaison with ophthalmogists, orthopaedic and vascular surgeons [37].

A similar situation is found in relation with patients suffering from hypertension. Special clinics have been set up in several centres for the care of such patients since the introduction in 1950-51 of effective drug treatment for hypertension [38].

Regarding the care of Rheumatoid Arthritis patients on "second-line" treatment and Thyroidism disease follow-up, the responsibility is also usually held by the hospital clinic [34,39].

But with growing and ageing population the number of chronic patients is increasing rapidly. Therefore, these clinics have such a large workload that they are unable to devote sufficient time to difficult cases. Many out-patient clinics have become saturated with patients who no longer need specialist care while higher risk patients may be overlooked, inadequately treated and ineffectively followed-up [40].

Medical manpower to deal with the growing workload is usually met by increasing use of junior staff [36] whose single contact with the patient may have little meaning for either. Therefore, the desirable continuity care of the patient is lost.

For the hospital this is a waste of time and resources, and the financial aspects of the out-patients attendance should be taken into account; primary care services are considerably cheaper than hospital care [36,41].

For the patient it means extra visits, given that hospital attendance do not necessarily replace visits to the surgery for similar reasons [41].

On the other hand, some general practitioners are currently claiming that the management of such conditions is an intrinsic primary care activity [41]. It has been suggested that a more active role for GPs in the delivery of chronic patients care, may be due to the existence of better organized and better equipped practices as well as more freely available laboratory facilities [42].

As a result of the variety of problems described, a shift from hospital to primary care has started to develop.

But, together with the factors already quoted, one other issue should be seen as responsible in influencing such a process. As a consequence of international change about the idea of health, the primary care level has been seen as the proper setting within the Health System for the management and follow-up of patients with chronic diseases. That is so because it is clear that it will be the chronic patient who will benefit more from a type of assistance as that offered at primary level: continuous, global and within a multidisciplinary team. Moreover, a good treatment of chronic conditions implies a great deal of patient health education and again, it is at this level where it can be easier to achieve.

However, although general practice has been seen as the best place for dealing with the control of these patients, a transference of the chronic conditions care in its entirety to the GPs, perhaps, is not the best way of using health services resources [43]. On the other hand, it has been largely documented that if the monitoring of chronic patients is transferred to general practices where no kind of structured methods of care have been set up, the quality of the care delivered is usually poor [30,42,44,45,46,47,48,49].

Surveys show that many patients who are known to have hypertension, diabetes or thyroid disease are inadequately identified, treated and/or monitored. For example, retrospectives studies in patients treated with radioiodine for thyrotoxicosis have shown an unacceptably high incidence of undetected morbidity as a consequence of a failure in the follow-up of these patients [50]. In the USA, community surveys have shown that the majority of people with hypertension are either undetected, untreated or inadequately monitored [15].

Although some studies do not find clear benefits from treatment of mild hypertensive patients [51] some others have shown that the treatment in those patients with moderate and severe hypertension decreases morbidity and mortality from stroke and renal failure [20,21] Furthermore, the European Working Party on High Blood Pressure in the Elderly [22] found a significant reduction in total cardiovascular mortality rates, in those patients who were double-blind randomised to active treatment. That decrease was due mainly to the fall in the cardiac mortality rate since the fall in cerebrovascular mortality was not significant between the two groups (active treatment and placebo).

On the other hand, it is widely agreed what clinical history and clinical features and investigations are necessary for the proper management of patients with high blood pressure [52,53,54]. Even so, a variety of studies has found that many of these features are not always recorded and this situation has been found in both hospital and general practice settings [30,31,55,56,57].

For instance, Frohlich et al [31] in their study in a group of hospitals in Oklahoma City, found that the history, physical examination and diagnosis evaluation of the 200 patients discharged with the primary diagnosis of hypertension were clearly inadequate. Descriptions of the optic fundi and comments about neurological signs or symptoms were present only in 65% and 24% of the records respectively. Heller and Rose [30] in an examination of 697 patient's records in general practice, found that relatively few people had a blood pressure recording. Even more worrying, many people found by GPs to have raised blood pressure had not received treatment. Wilber and Barrow [15] examined the results derived from The Atlanta Community High Blood Pressure Program one year after to its implementation. It was found that amongst those hypertensive patients receiving treatment, 21% still had elevated blood pressure. Jachuck [56] in a review of 171 records of hypertensive patients in general practice found that there was no mention of urine analysis and blood test results in 43% of the records and in 61% fundal examination was not recorded. The disappointing results found by Stern [57] about the overall management of hypertension in twelve undergraduate teaching practices provide another example. After the analysis of 2371 hypertensive patients' records, it was found that nearly half of patients were started on hypotensive treatment on the basis of only one recorded blood pressure reading and that the weight was not recorded for 69% of the patients.

Similar examples can be quoted regarding the management of diabetic patients. Nevertheless, it seems that it is routine care provided by general practitioners which is less satisfactory than routine care by hospital clinics.

Medical audits of simple practices in which the care of diabetics is not formally organized have shown inadequate recording of essential parameters and lack of routine follow-up and surveillance of complications [42,45,46,48,49,58,59].

After the assessment of the quality of care that diabetics patients were receiving in a practice of 5000 patients in Great Ouse [42], it was found that 50% of the insulin dependent were in poor glycaemic control and nearly one third of the diabetics had lapsed from any regular care from hospital or general practitioner. Fifty one percent of non-insulin-dependent and thirty three percent of insulin-dependent diabetics had multiple and serious complications unrecorded. An audit of the case notes in an inner city practice, detected no record of fundoscopy for 26% of the patients suffering from diabetes [58]. Metabolic control in patients cared for in general practice has been found to be poor comparing to those looked after in hospital clinics [44,47] For example, Hayes [44] found that the haemoglobin A1 concentration was higher in those patients looked after by the GPs when compared with those attending hospital clinics. Moreover, Jones et al [60], pointed out that these patients were at more risk of late referral for photocoagulation treatment than those attending diabetic hospital clinics. Mellor et al [59] in a survey carried out in general practice in Leicestershire, found that more than half the GPs who completed the questionnaire, never checked the visual aquity of their diabetic patients and less than one third checked it on at least an annual basis. Almost 80% did not indicate that they would refer maculopathy for laser treatment. General practitioners seemed to be more tolerant regarding glycaemic control than the hospital clinic since over 60% preferred their patient's urine not to be free of sugar.

Even so, inadequate recording of crucial information in hospital clinics has also been documented.

Data completeness of standard diabetic out-patient clinic records was analysed by Jones and Hedley [61]. They found that over one third of insulin-treated patients did not have a record of screening for various complications including retinopathy.

But even in the case that a good clinical control for chronic patients was achieved, other inherent problems to the long-term management of chronic patients can often be found. Those include: Losses to follow-up [30,31,44,62,63,64,65,66,67,68]; patient non-adherence to treatment [4,14,29,69]; and duplication of work by specialist and general practitioner [70]. Many of them are due to inadequate communication and lack of co-ordination between the different levels of care.

It would be worth bearing in mind that the chronic patient is one who will need the contribution of more than one health professional, and this is so because of various reasons. It has been argued that it is probably unrealistic to expect GPs to have the necessary degree of experience in performing some clinical examinations as for example retinal screening [43]. Moreover, a lack of the necessary resources to do the job thoroughly can be another great factor. For example, specialist manpower such as an optometrist, chiropodist and dietitian are not always easily available from general practice.

Laboratory facilities are largely based on hospital settings like other diagnostic procedures whose use is required for the surveillance of chronic patients. Thence the fact that from time to time they will need the expertise of a specialist and the use of technical resources for routine investigation. Hence, a good quality life-long follow-up will involve, sooner or later the contribution of more than one level of care.

Communication is of special relevance when the care of a patient is shared between more than one practitioner. The interchange of information becomes complicated and insecure when different health professionals are in charge of one patient. Consistency and completeness in the information gathered become problematic. The provision of regular surveillance is often lost in the gap between the hospital clinics and the general practitioners [42]. This implies the necessity for establishing a close relationship between Primary Health

Care and the rest of the health levels assuring the necessary feed-back mechanisms to achieve integrated care.

Continuity of follow-up and adherence to treatment are essential in chronic patients to avoid major complications and to ensure that these which are treatable are detected at an early stage. Nevertheless, as it was mentioned above, failures in their achievement have been frequently reported.

Surveys have indicated that half of already diagnosed and treated diabetic patients do not attend a hospital or another form of structured diabetic care [4,46,71]. Many of these patients will be therefore, at risk of developing complications. The results of a survey carried out by Doney [45], showed that 52% of the diabetic population were attending neither their general practitioner nor the consulting physician's clinic regularly for medical supervision. In the seven Southampton group practices' study, it was found that 20% of patients with diabetes did not receive a regular review [70]. In an audit carried out by Jones et al [64], the proportion of diabetic patients attending a traditional diabetic clinic who were lost to follow-up was 29% in five years. Degoulet et al [65], found that 15% of patients attending at the hospital's hypertension clinic were lost to follow-up during the first year. In one year, 50% of patients diagnosed as having hypertension had been lost from the hypertension clinic at the Henry Ford Hospital [29]. The same authors pointed out that many patients who arrived to the Emergency Room with a hypertensive crises had stopped previous antihypertensive treatment. It has been estimated that up to 50% of patients started on treatment for high blood pressure do not continue it [7].

From the literature review it can be argued that a variety of factors will influence the higher levels of losses to follow-up. For example, younger age, lower social class and lower educational level [65,68,72]. But, these characteristics could be regarded as inherent to the patient and hence, arduous if not impossible to modify.

However, it seems that other "external" factors which are probably easier to vary, have been found to be the main obstacles for achieving an efficient and effective care of chronic conditions. These are, inappropriate monitoring systems, administrative errors and unstructured records [64,66,72,73,74,75,76,77,78].

The two first points, have been related with unwareness by GPs and out patient clinics that the patient is no longer followed-up, as well as with a great difficulty in identifying who has been lost. Comparisons of losses to follow-up in patients who were followed-up by conventional techniques and in those who were followed up by a computer assisted register, showed that the proportion of patients who were lost was higher in the first group. In addition, development and implementation of a computer assisted register for detecting and monitoring patients with thyroid disease has been demonstrated to be successful as a way to identify defaulters and to achieve a cost-effective follow-up [33,63].

The third point was that regarding the structure of the records. Records have been largely criticized as being poor and deficient instruments for follow-up [77]. They make systematic collection of data difficult [74,75,76]. The quality of contents of the existing general practice records has been seen as unsatisfactory for medicolegal, educational epidemiological and research purposes [56]. This is so because important facts about patients and their problems are obscure. For McIntyre records do not represent a clear picture of illness or of clinical management [74]. The anarchy of many clinical records make it impossible to review and retrieve information easily [79].

Jackuck et al observed some factors contributing to the inadequacy of general practice. Firstly, the inconsistency in the structure and contents of the records; secondly, the lack of interest and motivation to promote uniformity of the records and improve the quality, and finally the consulting time available [56].

Yet, the key to good quality care is the medical record. When more than one health care level is involved in the care of a patient, the record is of special relevance as a form of communication between them.

The requirements of a good record are rarely met. As McIntyre and others have commented [45,61,73,74,75,79,80], medical records must be available when they are needed. They must be easy to understand; the information should be correct and be able to be found quickly. It might guide the collection of clinical information by including check lists. Records should allow the evaluation of the quality of care provided. Ultimately, a medical record should be compatible with eventual computerisation. The benefits of computerisation would be: immediate access, record linkage between hospitals and GPs, and rapid availability of data for research, health planning and evaluation of quality care [74].

Moreover, some requirements have been identified as important [6,81,82] to achieve good quality care for patients with chronic disease. Most of them derive from studies about the care of diabetics, however, they can be applied to the rest of the chronic diseases in which a long term follow-up is mandatory. These requirements are as follows:

1. Continuity of care. The overall responsiblity for patient's management rests with the general practitioner.

2. Integrated care. That is, close and continued co-operation between patient, primary care team and hospital specialist team.

3. Effective and efficient communication between the different levels of care.

4. Development of agreed protocols of care between GPs and hospital consultants.

5. Development of structured records for primary care and hospital.

6. Development of computer based registries.

7. Implementation of computer recall systems which allow the identification of defaulters.

8. Patient education.

9. Continued education for health professionals.

Recognition of the problems mentioned above and awareness of these requirements has led to the planning of new strategies for the care of chronic patients by both consultants and general practitioners. As a result, a variety of care schemes has been developed.

The objectives of such schemes are to prevent morbidity and mortality by means of an improvement in the process of care.

However, not all the schemes have the same characteristics. They differ in patient coverage; degree of general practitioner and hospital consultant's involvement in its development and implementation; the methods to assure an effective and efficient follow-up for patients; and lastly the continued co-operation between the primary and secondary levels of care.

The first part of this study will try to identify these innovations in care and to investigate their characteristics.

CHAPTER II

AIMS AND OBJECTIVES I

AIMS AND OBJECTIVES I

1. To identify and review the innovations in care currently existing for patients with diabetes, hypertension, thyroid disease and rheumatoid arthritis.

2. To classify these innovations based on their main characteristics.

3. To identify how many of these innovations are shared-care schemes.

CHAPTER III

METHODS I

METHODS I

IDENTIFICATION OF INNOVATIONS IN THE CARE OF PATIENTS WITH CHRONIC DISEASE

The identification of different care schemes was carried out by 3 methods:

1. Literature Review

That consisted of a computerized search through Medline and a subsequent ascendent search from the studies identified. After the review, it was realised firstly, that either very few innovations had been really carried out or that only few of them had been published. Secondly, that most of these innovations had been described in the literature by consultants. Therefore, if more consultants were contacted then more schemes would be probably identified. So, the following step was taken to identify new hospital consultants by means of a snowballing sampling method.

2. Snowballing Method

A snowballing method was used to find more doctors involved in this kind of schemes. This method has been used in the social sciences to study sensitive topics, rare traits, personal networks and social relationships

[83]. Snowballing is not only useful in observational studies, but can simply be used as a non-random method of contacting people to take part in a standard quantitative study such as an interview-based survey [84]. The method involves the selection of samples utilizing "insiders" knowledge and referral chains among subjects who possess common traits that are of research interest [83].

Through this method, some doctors identified by the literature review as having a structured method of care for patients suffering from the conditions of interest were sent a letter. The same letter was also sent to other doctors whose names I was provided with and who were thought to be possibly involved in some kind of shared-care. They were asked to supply names of other consultants who could be involved in similar schemes in other regions of the country and to confirm their participation in schemes. In total 26 letters were sent.

3. **Pilot Study**

At this stage a first questionnaire for consultants was designed (See Methods II). This questionnaire was going to be used in the second part of the study, where attitudes about shared-care schemes were going to be investigated. Then, taking advantage of a British Diabetic Association Meeting held in Glasgow from the 22nd to 23rd March 1990 a pilot study was carried out.

The researcher interviewed those consultants who kindly agreed to answer the questionnaire, a total of 25 doctors. The aim of this pilot study was, apart from piloting the questionnaire, to identify more doctors involved in schemes.

As a result, it was found that the term shared-care was interpreted in a variety of ways and not always corresponding to the definition on which this study was based on (see Methods II). Therefore, the questionnaire was modified and piloted again with the same doctors. After this it was decided to print the definitive questionnaire. (Appendix I).

CHAPTER IV

RESULTS I

RESULTS I

Once the three steps mentioned in the preceding chapter were compiled a total of 31 doctors seemed to be involved with new schemes of care. By literature review 22 doctors were identified as being involved in some kind of innovative care scheme. Six other doctors were identified by the snowballing method but, none of them had published data about their schemes. Lastly, in the pilot study 3 more doctors said to be involved with new schemes were identified. They also did not have published data.

However, although 31 doctors were thought to be involved with innovations in care only 29 schemes were clearly identified and from these only 21 had published data (Tables I, II and III).

These 21 were the ones which were reviewed for this study and a summary of them will be provided next.

SCHEMES DEVELOPED TO IMPROVE THE CARE OF PATIENTS WITH CHRONIC DISEASE

From the various schemes existing in Great Britain three of them could be considered the pioneers. A computer-assisted follow-up register for thyroid disease patients [33,50], the general practice diabetic mini-clinics at

Wolverhampton [37,40] and the Community Care Service for diabetics in the Poole [85]. Basic points highlighted in such schemes can be found in later schemes which have been developed in other areas of the country. All of them emphasize the idea of restoring the proper role of the primary care team in the surveillance of chronic patients.

However, the monitoring role of the secondary level regarding the degree of control and follow-up of the patients discharged to general practice varies within each scheme. In this way, some general practice mini-clinics can be found which are entirely autonomous whereas in some shared-care schemes, patterns of care are agreed between the GPs and specialists involved, adopting mutually supportive roles.

The search through published data on this subject showed that while some schemes are accurately described and therefore, give a clear idea about how they work, others are incomplete and obscure.

1. COMPUTER-ASSISTED FOLLOW-UP REGISTER FOR THE NORTH-EAST OF SCOTLAND [50]

A central follow-up computer based recall system was developed in 1969 in Aberdeen with the aim of detecting late complications derived from destructive therapy for thyrotoxicosis [33]. In addition, patients in remission after antithyroid drug therapy and all patients receiving lifelong thyroxine replacement therapy for primary, secondary and iatrogenic hypothyroidism are also followed-up by this system.

The system was designed to process, screen and store clinical and biochemical follow-up data and report results to the patient's general practitioner and to the hospital records department.

Once a patient who had received destructive therapy had been stabilized and was euthyroid, he was entered into the register for long-term follow-up. Identification data and details about treatment were used to create a computer record for each patient.

At this stage the patient's GP was contacted and offered the use of the system for the surveillance of his patient.

When follow-up was due, the computer created letters for the patients reminding them to attend their general practitioner for a check-up. The GP simultaneously received a follow-up kit which contained: a letter indicating that follow-up was due, the follow-up form, a syringe capable of conversion to a sample bottle for collection of blood, and a prepaid package in which to return the form and the sample to the registry.

Once laboratory results were ready, they were entered into the computer and the patient's file was updated.

If the results were normal, the GP was informed and the follow-up procedure continued automatically. If the results were abnormal, the patient was contacted and recommened to attend the out-patient clinic until he was restablized.

The authors found lots of advantages in this method of follow-up. For example, the system ensured continuity of care, automated all the stages which do not require a decision by the doctor, guaranteed contact between general practitioner, hospital laboratory and patient, and lastly, records in general practice and in hospital were always updated with follow-up results.

At the beginning of 1970, there were 400 patients on the register and by the end of the year the authors expected to have 1000 patients in total.

In 1982, a study was carried out to compare the level of surveillance and long-term outcome of treatment in one group of patients being conventionally followed-up with the results in another group registered in the computer assisted system [63].

A cost effective analysis of both methods was one of the objectives of such a study.

The results showed the existence of high levels of undetected hypothyroidism in the group of patients who were conventionally followed-up. Moreover, the overall cost of follow-up and treatment for patients in the register was less than 60% of that for the other group of patients.

They concluded that since the greater efficiency of follow-up procedure in the second group was achieved at a lower cost per patient, this type of follow-up register would be a more cost-effective use of NHS resources.

2. DIABETES MINI-CLINICS IN GENERAL PRACTICE. THE WOLVERHAMPTON EXPERIENCE [40]

The mini-clinic scheme in Wolverhampton started in 1970.

The main characteristic in that method was that one or two members of the practice with a special interest in diabetes became responsible for seeing not only their own diabetic patients but also those of their practice colleagues.

The programme of care was as follows: once the patient was diagnosed by the general practioner, he was seen at the hospital clinic which provided the patient with a hospital record. If necessary, at this stage the patient contacted the health visitor and the chiropodist. After the initial consultation, the patient's continued care became the general practitioner's responsibility. Only if referral was needed, did the patient again attend the hospital clinic.

In order to exchange information about individual patients or about diabetes in general, the consultant visited the mini-clinic once a year.

The patients under the scheme were issued with a mini-clinic record card which they carried with them in case a hospital visit was required.

Practitioners had full access to laboratory and chest X-ray facilities which were seen as enough techniques required for competent care.

At every visit either to the hospital clinic or to the mini-clinic the patient was weighed and urine and blood sugar tests carried out. The intervals at which the patient was followed-up by the GP was not stated.

By the end of 1972, 14 practices in Wolverhampton had started mini-clinics. Twenty two percent of doctors on Wolverhampton Executive Council's list were in practices which had set up mini-clinics. From the 104514 patients covered by these practices 541 were diabetics; 428 of whom were discharged to their practice mini-clinics. The patients who continued to attend the hospital clinic were those whose diabetic diagnosis was made before age 35, half of the patients with insulin treatment and those who needed extra care (children, pregnant woman and difficult patients on insulin). In 1984, Singh et al [86] published the results of a trial designed to compare the degree of metabolic control achieved by mini-clinics with that achieved by hospital clinics.

The metabolic control was assessed by using mean clinic blood glucose and HbA1 concentration.

They found no significant differences in these concentrations between patients looked after in hospital clinics and those in mini-clinics. They concluded that the mini-clinics achieved the same degree of metabolic control in their diabetic patients as the hospital clinic.

Yet by 1982 a review of the type of diabetes care in Wolverhampton showed that of 3043 registered diabetics 1916 (63%) were attending the hospital clinic and 1127 (37%) were attending some of the 23 mini-clinics although from these, 123 (11%) also attended the hospital clinic.

3. THE COMMUNITY CARE SERVICE FOR DIABETICS IN THE POOLE AREA [85]

In this scheme in contrast to mini-clinics, each GP was responsible for his own diabetic patients. The main intention in this scheme was the integration of all services available within the community for the diabetic's care. There was also the intention to monitor the degree of control and follow-up of patients who were under the GPs care.

This service had been in operation since 1972 and the method's procedure is described below.

The majority of diabetics were diagnosed by the GP. Once the diagnosis was established, the patient will attend two diabetic educational sessions at the hospital before being referred to the diabetic review hospital clinic. Before that, the patient is followed-up by the GP and routine investigations are requested (ECG, HbA1, serum creatinine, LFTS, cholesterol and triglycerides).

At the end of the second educational meeting, the patient receives an appointment for attending the hospital diabetic clinic. History, clinical examination and recording of data in the diabetic clinic notes are performed at this stage. The examination includes, distant visual acuity measurement, dilation of the pupils and examination of the eyes. Between one and three months patients will return to the clinic for a follow-up appointment. At this second visit, patients are classified regarding the glycaemic control achieved and the possible problems associated. Usually, non-insulin-dependent patients are then transferred to the GP for routine follow-up. A list of ophthalmic opticians or ophthalmic medical practitioners is given to each patient who is asked to attend once a year for screening of retinopathy. A completed form with the results of this eye's examination is sent to the consultant. If some kind of deterioration is observed, the patient is asked to attend the diabetic clinic.

The general practitioners in this scheme have direct access to the diabetic clinic dietitian chiropodist and laboratory. The long term follow-up of the patients is based on a protocol of care designed in the hospital clinic.

Each patient in this service is a holder of a community care co-operation booklet which provides communication between hospital doctors, GPs, nurses and health visitors.

In order to assess how well and frequently a patient is being followed-up at primary level, a computer based register was developed. Apart from having a register with all the diabetics in the area, the idea was to store clinical and laboratory results for checking details about frequency of blood sugar test and standards of control which have been achieved. On the other hand it would serve as a mean of identifying defaulters. However, by October 1988 only data from patients attending hospital clinics had been entered into the register.

4. COMMUNITY CARE OF DIABETES IN ISLINGTON [87]

Hurwitz found that, in Islington, nearly 100 general practitioners were prepared to take responsibility for the care of non-insulin-dependent patients but could not set up mini-clinics. Therefore, they decided to develop a diabetic recall system to support community diabetic care. Forty practices and thirteen optometrists were included in the scheme.

A computerised register of patients under this care sent request forms for blood and urine test to the diabetics at six months intervals. When the results were available they were entered into a computer printed medical record which was sent to the patient asking him to contact his GP for clinical assessment.

The kind of examination the family doctor had to perform was specified in the record and it could be either a "regular" review or an "annual" review. In the first case, only weight and blood pressure were the parameters to be checked. In the annual review apart from these two examination of lower limbs looking for ischaemia and diabetic neuropathy signs were also performed.

The results of the assessment were noted on the two part medical record form. A top copy was kept in the GP notes and the bottom copy was sent back to the prompting office.

The GP by means of that record could easily refer the patient for dietary advice, chiropody control or consultant assessment to the hospital diabetic clinic.

This method allowed sending of reminders to both the patient or the family doctor if laboratory results or the review GP record were not received by the prompting office within a month. Therefore, it was a way of controlling the required patient follow-up.

Moreover a prompt was sent annually to remind patients to attend the optometrist for eyes screening. This included a list of all the optometrists who performed fundoscopy in the area as well as a two part structured record. The bottom copy with the results was returned to the prompt office which sent a copy to the GP.

The question arising from this scheme, is that of the relationship between the system and GPs and the hospital unit. There is a doubt about how and when the consultant should intervene. Evaluation of the scheme was under study at the time of the publication of the article.

5. DISTRICT DIABETIC SERVICE IN SOUTHAMPTON [88]

The responsibility for an effective control and education of all patients was allocated to either the hospital clinic or the family doctor according to the characteristics of the patients. So, general practitioners were responsible for the surveillance of non-insulin-dependent patients and hospital clinic for insulin-dependent and complicated cases.

The service depended upon a hospital based computer register. The aim was to prompt care and evaluate its outcome. The register stored names, address, and clinical data for the patients in the district.

Southampton Health District has a population of 420000 from which it has been estimated the existence of 5500-6000 patients with diabetes. By 1988, 28 group practices (140 GPs) were planning or running a diabetic service in Southampton.

Specialist support to general practice was undertaken in two ways. By establishing evening meetings which covered all the aspects of diabetic care including diabetic retinopathy and by a protocol of care. Such a protocol had been agreed and developed between the specialist and GPs regarding clinical management and referral policies.

The system operated in relation to general practice as follows.

Those patients due for a visit were identified by the computer monthly. Review duplicated forms were printed for each patient and sent to the general practitioner.

The forms presented data on metabolic control and diabetic complications. Letters and laboratory request were also printed by the computer asking the patient to contact his family doctor to arrange an appointment for a blood test and later consultation. The top copy of the completed and updated form was sent to the computer secretary where the data was entered on the register. The bottom copy was kept in the patient's practice record. The next review was prompted automatically by entering the data for the following appointment. In that way non-attenders could be identified and sent reminders to attend.

Identical review forms were used in both the hospital clinic and general practice as a way of ensuring consistency in the recorded data.

At the time of publication a study was being carried out to examine patient's response to the scheme. However, the authors believed that given the effectiveness and efficiency in which the patient's care and professional education was being performed, the benefit for all diabetics would be great.

6. STIRLING SHARED-CARE SCHEME [43]

This scheme covered a large geographical area of Central Scotland surrounding the District General Hospital in Stirling which represents a population of 150000. All the practices in the district were included with 93 general practitioners involved in the scheme.

The computerized recall programme for Stirling aimed to identify all patients in the district and to record them on the diabetic register. However, at the time of publication the computer program was not being used for clinical data recording.

After registration the care of the patient could be under supervision of the hospital clinic, under the general practitioner or shared by the hospital and the general practitioner.

Most patients in the area were under a care programme in which supervision was shared by the hospital and the general practitioners.

All patients in the shared-care scheme attended the hospital diabetic clinic for an annual review which included, control of blood pressure and weight, urine and blood tests, examination of fundi, peripheral pulses, reflex and feet. At the end of this review an appointment was given to attend an education session.

The interval for a hospital review was three months for insulin-treated patients and twelve months for non-insulin treated patients. However, patients looked after in general practice were sent letters via the computer recall system to remind them to visit the GP at three months intervals. A list of patients due for review was also sent weekly to each practice.

Review records were identical in the hospital clinic and in general practice. At each three months attendance to either hospital or surgery, blood glucose and HbA1 are measured, the results were entered onto in the record and this was used as a way to detect non-attendance. Defaulters were sent a further appointment automatically.

At each hospital visit the patient was given a printed record of his serial blood glucose and Hba1 results. A copy was also available for the general practitioner.

The provision of dietitian advice and chiropodist facilities were provided at the hospital clinic as well as the educational sessions.

The advantages of the system as seen by the authors, were the decrease in the admission rate to the Stirling Royal Infirmary for diabetes and the low cost of the service. However, a formal evaluation of the scheme had not been carried out when the article was published.

7. SHARED-CARE FOR DIABETES IN CHESTER [89]

This scheme was set up in 1985 by agreement of hospital consultant and some local general practices. It was expanded later on and in 1989 almost all patients with insulin-dependent diabetes and non-insulin dependent diabetes were incorporated into the scheme.

The objectives of the system were: firstly, to develop an integrated system of shared-care between hospital and all local GPs for all patients attending the hospital clinic. Secondly, the hospital would be responsible for annual screen of complications. Thirdly, availability of prompt advice to patients and fourthly improvement of educational updating.

The scheme worked as follows: Patients attended the hospital once a year for the annual review. In this review a proforma including all the necessary screening information was completed. A copy of this with a covering letter was sent to the GP.

The interim reviews were carried out by the GP. A co-operation card allowed recording of weight, urinalysis, blood glucose and blood pressure. The interim checks were quarterly initially and subsequently adjusted based on patient needs.

At least one specialist nurse was available every weekday morning in the diabetes unit for advice on the telephone or on a 'drop in basis' should some patient require it.

An evaluation study of the scheme showed no deterioration in diabetic control. Moreover, both patients and GPs were enthusiastic about the new scheme of care.

8 IPSWICH, SHARED-CARE SCHEME [90]

In 1981, 164 General Practitioners were providing care for 330000 people in the Ipswich district. 4000 of them were known to be diabetics.

Given the GPs' interest in developing new systems of care, meetings about diabetes care were organised. The aim was to develop and agree a protocol of care for patients suffering from diabetes including follow-up and recording guidelines.

In 1981 all well controlled hospital patients were discharged to general practice care without distinction between those been insulin-dependent or non-insulin-dependent. Before discharge, all the patients had blood glucose and HbA1 concentrations and their urine examined and recorded.

All were provided with co-operation books including clinical data. The data from these co-operation books were used to create a hospital recall register.

After two years of general practice care all these patients were going to be fully evaluated at the hospital clinic.

The standards of care agreed by the practitioners are described below.

Review of the diabetic patient at least once a year if they were controlled, if not the review should be more often. At each attendance, blood glucose, HbA1, urine glucose and weight should be monitored. And at least once a year visual acuity and blood pressure should be measured, fundoscopy performed and the feet inspected.

After two years, an evaluation study was carried out to assess the degree of supervision that these patients have had in general practice. The recall system was used to produce a list of suitable patients for review at the hospital clinic. A postcard was sent to the GP asking if the patient could attend the hospital clinic. If no response was received within four weeks an appointment was sent.

At the patient's clinic attendance, blood glucose, HbA1 and urine tests were performed. Clinical findings were compared to those collected when the patient was discharged and the following was recorded: change in blood pressure; development of new diabetic foot ulcers, new retinopathy or cataracts, fall in visual acuity or the development of albumin in urine.

Moreover, a questionnaire was designed to determine, for example, the number of visits to the general practitioner and the purpose of such visits.

The authors found the results disappointing. The standards of diabetes care provided to the patients by their general practitioners were inadequate. 40% of patients had no biochemical, eye or foot evaluation, despite the fact of having been seen by the doctor at least once. The failures seemed to be due to poor organisation. They concluded that "comprehensive mini-clinic care in all general practices is an utopian ideal".

9. COMPUTER ASSISTED SHARED-CARE IN HYPERTENSION IN THE GRAMPIAN REGION [91]

The Aberdeen Blood Pressure Clinic included a population of 500000 which is served by 250 principals in general practice.

The shared-care scheme for hypertension developed between the hospital clinic and the GPs of the area started in 1980 and around [63] patients had been registered and 1426 were followed-up in 1985. 257 out of the 1631 were allocated to the hospital aspect of the system and the remaining 1169 to the general practice aspect. The severity of the condition and the existence of associated risks are what determined the inclusion of the patients within one or another aspect of the scheme.

This scheme encouraged the referral of the newly diagnosed patients to the hospital clinic where assessment of the condition was undertaken before entering the patient into the computer shared-care scheme.

The computer system produced two letters one of them asking the patient to visit the family doctor for follow-up. The other one which was the "patient profile" was sent to the general practitioner inviting him to update it at the time of the contact with the patient. The "patient profile" was the clinical document which included patient identification, a listing of active and inactive problems, current medication and information regarding blood pressure follow-up. Each "patient profile" was screened by a member of the hospital team before being sent out to the practitioner. If target blood pressure had not been achieved, advice about care management was given by handwriting.

After the patient-GP contact, the updated record was returned to the hospital for auditing and then was entered on the database. At this stage, a production of a letter to the general practitioner and a new follow-up appointment was scheduled by the computer.

All the letters to the practitioner included updated problem and drug listings specific to the patient. The new listings replaced previous versions in the practitioner and hospital case notes.

Patients who attended the hospital clinic normally, those with chronic renal failure, polycistic renal disease or complex regimens followed the same scheme of care as those transferred to general practice. In all instances general practitioners were sent an appropriate informative letter.

The authors highlighted in the article some positives points derived from the implementation of the shared-care scheme. Firstly, the flow of clinical information as well as the review of records by the two parts involved, allowed improvement in the awareness of factors influencing the management of hypertension and therefore an improvement in the quality of care. Secondly, the introduction of the scheme had lead to a reduction in the number of patients who were followed-up at the hospital clinic which allowed a much better attention to those who were at most risk. Lastly, patients with particular pathology had been identified.

10. WEST OF SCOTLAND SHARED-CARE SCHEME FOR HYPERTENSION [92]

This scheme was set up in 1985 and based in the Glasgow Blood Pressure Clinic. The scheme was based on a clinical information system which produced a register of patients, protocols of care and designed patients records. Communication between the participants (GPs, consultants laboratory and patients) was by means of a central computer registry.

All patients registered in the shared-care scheme were attending the blood pressure clinic and their records were created immediately after registration. Well controlled patients whose family doctors decided to participate in the scheme, were discharged to the control of general practice. General practitioners were invited to provide routine follow-up as well as an annual review equal to that performed in the hospital clinic. Those who agreed to participate were sent a copy of the patient's record.

Patient's records for family doctors and consultants were the same. They had two pages, one contains patient's problems, treatments, personal details and habits; the other one contains details about blood pressure readings, weight, height, urine and blood test results, ECG, symptoms and treatment. The GP record was a duplicated form so that the top copy, once completed, was returned annually to the registry for screening by the specialist and updating the computer record. The bottom copy was kept by the GP until an updated version was received from the registry.

The frequency of follow-up contacts during the rest of the year was adjusted by either the doctor or the patient according to independent hospital's criteria. The review procedure operated as follows.

At the same time that the patient was prompted to arrange a review with his GP, the GP was sent a shared-care pack consisting of laboratory request forms, sample bottles and a procedure checklist.

After the patient's examination, the top copy of the record was sent to the registry where the data was entered and abnormal results were marked according to a protocol. The results were checked by the specialist who will suggest to the GP what kind of action to take on the basis of the results.

The next stages were: the sending of the updated copy of the record to the GP enclosed with a standard letter depending on the results, the input of the results into the hospital case notes and the delivery of an updated "personal health record" to the patient.

If as a consequence of the results the GP was advised to repeat the examination, to change treatment or to make a referral and no response had been received within one month, a contact was made with the GP.

After four years of the implementation of the scheme an evaluation study was carried out regarding its feasibility, acceptability and cost-effectiveness in relation to other methods of care. On the basis of the results, the authors concluded that the scheme had been as effective as the hospital clinic in assuring the quality of follow-up of the patients; the acceptability by general practitioners was high and the cost-effective analysis was favourable when compared to other traditional methods of care.

11. THE WELSH AUTOMATED FOLLOW-UP REGISTER FOR PATIENTS WITH THYROID DISEASE [93]

This service became operative in January 1974 and was based on the same principles that the Scotland Automated Follow-up Register (SAFUR).

Its function was to detect both hypo or hyperthyroidism in patients treated for hyperthyroidism, hypothyroidism and non-toxic goitre. It also checked patients on thyroxine therapy.

Patients whose disease was in stable condition were registered in to the system at the University Hospital of Wales, under four categories:

1. Patients with hyperthyroidism who have been at least one year without medication.

2. Patients with hyperthyroidism who have become hypothyroid after treatment.

3. Primary hypothyroid patients under thyroixn treatment.

4. Non-toxic goitre patients mainly those who have had surgery and are receiving thyroxine as a prophylactic measure against recurrence of goitre.

After the patient's registration the general practitioner was invited to collaborate in the patient's follow-up which was usualy carried out once a year, except for the first follow-up which was six months after registration.

A computer printed letter was sent to the patient and doctor to prompt the follow-up. Besides the letter, the doctor was sent a syringe, needle, and bottle for a specimen of blood and a diagnostic form before the patient's visit.

After the patient-doctor contact, the completed diagnostic index and the blood sample was returned to the hospital.

The computer was run monthly in order to produce a list of patients with abnormal results. These patients were then reviewed at the hospital clinic and eventually recategorized in the system.

If the patient had normal results they were informed as well and the follow-up was automatically activated for the next visit to the GP.

In the 1978 publication, 232 practitioners out of 245 (95%) were participating in the scheme and 340 patients had been registered into the system.

An evaluation study comparing cost of the WAFUR system with routine out-patients care showed that WAFUR saved 18% on day-to-day expenses over a period of one year.

The authors found the following advantages in the system: the possibility of the long-term management of these patients into the community; the acceptability of the system by patients and general practitioners; the reduction on costs; and the use of the system as an on-going medical audit resource.

12. SHARED-CARE SCHEME FOR PATIENTS WITH RHEUMATOID ARTHRITIS [39]

Rheumatoid arthritis patients on gold and penicillamine treatment (second line treatment) require regular follow-up for potencial toxicity. Given the long-term nature of this treatment the number of patients to be monitored at the Glasgow Royal Infirmary second-line clinic was increasing rapidly in recent years. On these grounds, the consultants decided to investigate the possibility of running a shared-care scheme between the hospital and the patients' general practitioners.

General practitioners who decided to follow-up these specific patients were sent a protocol of care. This protocol stated; dose regimen, frequency of monitoring and reasons for discontinuing therapy. A record card was produced for the patient to enter results of blood and urine tests. Both patients and GPs had open access to a rheumatologist at all times.

Every three months patients who were looked after by the GPs attend the hospital clinic for assessment and identification of problems arising from the method of care.

After a period of time running such a scheme, a comparative study was carried out to detect differences between patients monitored by the GP and those controlled solely at the rheumatology clinic. The results showed no differences in efficacy or frequency of adverse effects between the two groups.

The authors concluded that shared-care for second-line treatment provided that adequate communication exists between hospital and GPs permits more patients to benefit.

13. SHARED-CARE AND MINI-CLINICS FOR PEOPLE WITH DIABETES IN STOCKPORT [94]

In 1989 a study was carried out in Stockport to investigate how many diabetes mini-clinics were already in existence and how many GPs were interested in starting their own clinics.

Although this study does not give a clear idea about how the system works it was chosen by the researcher as an example of another area of the country in which innovation in the care of patients with diabetes was taking place.

The results showed that from 49 practices who answered a questionnaire, 10 (20%) had set up mini-clinics for the care of Type 1 and Type II diabetic patients and 24 more practices were prepared to start the same scheme.

In nine out of the ten practices with mini-clinics, the care of insulin-dependent-patients was shared with the hospital (although it is not specified in what way). Moreover, in eight of them the care of non-insulin-dependent was also shared with the hospital.

The follow-up interval for the patients' check-up were between three and six months independently of being a Type I or Type II diabetic.

The facilities available in the mini-clinics varied. For example, only seven out of ten had a blood glucose machine; five out of ten had access to chiropodist; only in seven had the patient his eyes examined and none of the mini-clinics had a dietitian.

The conclusions were that although some degree of innovation was noticeable there was still a heavy demand on hospital resources.

14. INTEGRATED DISTRICT CARE BASED IN A DIABETES CENTRE [95]

It affected all diabetics in the Bromley Health District.

This scheme described the development and implementation of a new hospital diabetes centre which was equipped with the required staff and a computer system to take in charge the organisation of all diabetics in the district.

The scheme involved primary care in two ways: 31 GPs covering 25% of Bromley's population set up mini clinics the rest of the practices were going to be involved in a shared-care system. Patients from these practices would be seen by the GP two or three times a year and every third year in the Diabetes Centre for a screening examination including an Eye Test.

In both systems the patient was given a Co-operation Booklet.

15. DIABETES CARE IN THE NORWICH COMMUNITY CARE SCHEME [96]

This scheme started in 1984 when several GPs in the Norwich Health District expressed an interest in organizing the follow-up of their diabetic patients.

The scheme was developed by consultants and GPs based on the Wolverhampton mini-clinics model.

The aim was to encourage routine follow-up of non-insulin dependent patients.

Practices interested joined a steering group where guidelines for routine care, hospital referral and evaluation of care were agreed.

Three years after the commencement of the scheme an evaluation study was carried out. It was found that firstly, more diabetic patients were identified and carried for by GPs; and secondly, the recording of investigations, examinations and procedures had improved significantly.

16. NON CONSULTANT PERIPHERAL DIABETIC CLINICS ON THE ISLE OF WIGHT [97]

In December 1980 a diabetic service consisting of four weekly held peripheral clinics was set up on the Isle of Wight. The population covered was 130000.

Before the implementation of the service all diabetic patients had to attend the hospital clinic at Newport for routine follow-up.

The function of such peripheral clinics was limited to the continued patient's education as well as the assessment of biochemical control. The annual physical and eye examination remained under the responsibility of the hospital diabetic clinic.

The staff of the peripheral clinics comprised one clinical assistant, two nurses and one medical laboratory scientific officer. A portable blood sugar auto-analyser was available for each clinic.

The parameters to be controlled at each attendance were, weight, urine and random blood sugar tests, HbA1, results of domiciliary tests for urine/blood sugar carried out by the patient, and frequency of hypoglycaemia.

The results were entered on a triplicate form. The top copy was given to the patient who gave it to the GP, the second copy was sent to the consultant who monitored the standard of care and the bottom copy was kept at the peripheral clinic.

A study was carried out by the members involved in the service comparing standards of care between a group of patients attending the hospital clinic and other group controlled by the peripheral clinics. The results showed that there were no statistically significant differences between the two groups regarding HbA1 and random blood glucose levels. On the other hand, 90.5% of the surveyed patients indicated their preference of attending peripheral clinics since it provided a great saving in cost and time.

The characteristics of such scheme have been seen as relevant to diabetic care in sparsely populated areas where access to facilites is difficult, for example in developing countries.

17. DIABETIC CLINIC IN GENERAL PRACTICE. THE BIRMINGHAM EXPERIENCE [98]

An unusual and original method is that which was initiated at Coleshill general practice in 1967.

The scheme was first set up in a practice of four doctors covering a population of 9500 of whom 50 were known as diabetics. Most of them were attending the diabetic clinic at the Birmingham General Hospital.

Normally these patients attended the hospital clinic once a year and the follow-up during the intra-review period was performed by the general practitioner.

However, it was decided that the staff of the diabetic clinic should visit the practice for the benefit of the patients. Therefore, one day every year was devoted to the diabetics control, by the hospital team.

The hospital team was made up of two consultants, a senior registrar, a nursing sister, a secretary and a technician. The practice team consisted of four partners, a nurse and two secretaries. Three consulting rooms were in use during the review period and the method was as follows.

When the patients arrived they were weighed and a sample of urine and blood was taken for later examination. Then the clinical examination was made in the presence of a hospital physician and a member of the practice. Results were entered on both hospital and practice records.

As mentioned above, the follow-up appointments were made with the GP unless difficult cases were presented.

At the time of publication, two other practices in the area were using this method of care. The authors considered the scheme successful and welcomed by the patients. But no formal evaluation had been carried out.

18. DIABETIC CARE IN GENERAL PRACTICE IN ABERGAVENNY [99, 100].

This scheme was developed by general practitioners in rural mid-Wales.

It consisted of: a practice manual diabetic register where the patients card were stored in alphabetical order and patients notes were tagged with a coloured sticker.

A protocol of care was developed in agreement with the hospital consultant. It defined the patient follow-up intervals as well as the kind of investigations to be carried out.

There was a recall system based on the pre-exisiting card index of diabetic patients. In this schemes, GPs could arrange referral to paramedical services such as dietitians, chiropodists, ophthalmic opticians and consultant clinics.

Patients could be seen in various ways. Each GP could see his own patients or one GP could see all the diabetics in the practice.

There was a trained nurse who saw the patient and checked some parameters before he was seen by the doctor.

The authors recognized that the pattern of care in each practice would be different depending on the facilities available for them.

They carried out an evaluation study and found great improvements in all the criteria measured and a very low default rate.

19. THE EXETER EXPERIENCE [101]

The Exeter scheme consisted of a diabetic protocol and a patient record card.

A multidisciplinary team (primary care and hospital level) draw up a diabetic protocol. They set out a list of the checks each patient should have but left to the patient and GP to determine how this could be achieved. There was no attempt to demand GPs to do anything.

The annual retinal examination which was recommended in the protocol could be done by either the GP, the optician or the hospital clinic.

Patient record card was used as a co-operation card between GP practice nurse, hospital diabetic clinic, ophthalmology clinic or optician.

The authors recognised that "the continuation of the project depends upon the goodwill and enthusiasm of the research team".

There is no evaluation study of the project at the moment.

20. NURSE MANAGEMENT OF HYPERTENSION CLINICS IN GENERAL PRACTICE ASSISTED BY A COMPUTER [102]

In this scheme, 377 hypertensive patients from 3 general practice in Birmingham, were referred and controlled by a Practice Nurse with the help of a computerised management protocol.

The computerised management protocol was agreed by the 17 participating practitioners. It included, targets for systolic and diastolic blood pressure, treatment, criteria for referral, investigation and follow-up. Patients were seen at three monthly intervals once stability of blood pressure had been attained. The nurse had received training in the use of a random-zero sphygmomamometer and ophthalmoscope, the clinical assessment of patients and the use of a micro-computer.

The results of a study carried out to see the acceptability of such a scheme showed that patients and GPs welcomed the experience. Moreover, skilled nurse care and computer guidance improved the attainment of target figures in relation to blood pressure, stopping smoking, and losing weight.

21. COLLABORATIVE CARE OF HYPERTENSIVES USING A SHARED-RECORD [103]

This experiment consisted of sharing a hospital GP record for the control of hypertensives with complications. Patients with grade 3 or 4 retinopathy, cardiac failure, renal damage and primary renal disease attended hospital for long-term follow-up. They carried a blood pressure record to the hospital and the same to the GP. The GP decided the intervals at which to see the patient (between hospital appointments) and the blood pressure level at which to take action.

The authors found the method successful with better flow of patient information between hospital and primary care.

CLASSIFICATION OF INNOVATIONS IN CARE

After the revision it seems clear that the schemes, can be divided into 3 groups with quite distinctive characteristics.

1. General Practice mini-clinics with and without shared-care (Table I).
2. Shared-care schemes (Table II).
3. Other schemes (Table III).

MAIN CHARACTERISTICS OF GENERAL PRACTICE MINI-CLINICS

This term describes a way in which the care of patients with some special chronic diseases can be organised in primary care. Normally, in this type of scheme, only one or two GPs with an interest in the given disease care for all the practice's patients suffering from that condition.

The classical example of general practice mini-clinics in which the consultant's involvement has been of crucial importance were those started by Thorn in Wolverhampton [37,40].

In this scheme the general practitioner took total responsibility for the care of those patients, that is the follow-up intervals and the procedures to be carried out at the patient review visits were all decided by the general practitioner. Only in the case of complications was the patient referred to the hospital for consultation.

However, there are some variations within this scheme. So, in some cases the hospital consultant and the general practitioners agree a protocol of care and even intervals at which the clinical reviews are due. Once a year the patient is offered a review at the hospital clinic.

Patients under this method of care usually have a special record card which is an essential part of communication between hospital and general practice.

With this method of care, there is no hospital or community based computerized register for prompting for follow-up and for identifying defaulters. Neither is there any intention to monitor the degree of control of these patients looked after in general practice.

MAIN CHARACTERISTICS OF SHARED-CARE SCHEMES

Although there is no clear agreement about what shared-care means there are however, a variety of aspects which can be identified from the different publications [6,91,92,107] as characteristics of shared-care schemes.

Firstly, each general practitioner is responsible for his own chronic patients. That is, the overall management of the patient is undertaken by his/her GP. But there is always specialist support by different means. That means that there is no need to identify a GP with special interest and skills in the disease in order to set up the scheme.

Most of these schemes are characterised by the development of agreed protocols of care, intervals of follow-up and referral policies between primary care and hospital clinic [33,43,85,87,88,91,92]. Furthermore, there is a continuous cooperation between the primary and secondary levels of care allowing for integrated patient care.

Most of them have also developed hospital or community based computerised registers [33,43,85,87,88,91,92,93]. This facility provides the possibility of supporting general practice with recall systems and identification of defaulters. Moreover, clinical and laboratory results can be introduced in the register which allows their scrutiny by the consultant who can, at any time, give advice to the GP. Furthermore, this latest facility allows for continuing audit.

Another characteristic, is the use of standardised, sometimes identical, records by consultant and general practitioner [33,43,85,87,88,91,92]. Moreover, in some of these schemes, patients are provided with a personal record [85,92].

INDEPENDENT INITIATIVES

These group covers schemes which have been identified as differing from traditional care. Although they were described in the review, they were not of further interest for the study since they did not involve a collaboration between primary and secondary levels of care.

CHAPTER V

DISCUSSION I

DISCUSSION I

It has been said that patients suffering from chronic disease benefit from being looked after at primary health level. This is so because the general practitioner is more likely to be familiar with patient's other medical problems than the specialist and, therefore, the patient will receive more comprehensive care. Moreover, some studies have shown that patients prefer to attend the health centre or the surgery instead of the hospital [40,104].

The mini-clinic approach therefore could be seen as the answer to the problem. However, many criticisms regarding practical and medical issues have been made of the mini-clinic approach.

Firstly, the fact that an interested GP is in charge of all patients suffering from a given disease in the practice destroys the concept of continuity of care on one hand and, on the other hand, implies a degree of specialization within primary health care which is neither desirable nor acceptable by some general practitioners. Secondly, the cost-effectiveness of such an option depends greatly on the type of practice involved. Mini-clinics have been considered cost-effective only in large practices where the number of patients justify a special section and the number of doctors is enough to ensure patients access to another doctor if their GP is tied up in a special session [87]. Even so, Koperski [105] found that the cost to the NHS of each patient attendance to the practice in which a "monthly diabetic day" had been set up was greater than estimates of the cost of attendance at the hospital clinic.

Furthermore, if the practices are not large enough, problems with insufficient space to set up the session, shortage of practice nurses to help, and lack of access to some facilities will make it impossible to develop such alternative care.

But pitfalls can be identified in this approach even if we take the hypothetical case in which a large practice with all kind of facilities has set up mini-clinics. What happens with patients' follow-up when the interested GP is on holiday? What happens if he moves to another practice? How many different mini-clinics is a diabetic patient going to attend if he is hypertensive and suffers from rheumatoid arthritis? And, what happens when no doctor in the practice is interested in any of the diseases? But above all, why should some general practitioners be prevented from doing a job which is inherent to general practice?

Perhaps it could be said that there is no need for setting up a mini-clinic for every specialty and that only diabetes mini-clinics should be set up because of the implicit benefits for the patient. However, this could be easily refuted as the importance for structured and organized care for the follow-up of patients with chronic disease has been widely reported. In that case why should diabetics benefit instead of hypertensives or patients with thyroid disease? And we arrive again at the same point, there is a need to develop a mini-clinic for each chronic disease. However, this is impractical.

The first question which comes to mind then is, if mini-clinics are not the solution, which other method of care, apart from traditional care, could be given to these patients?

It should not be forgotten that the care of these patients requires a long term follow-up and, therefore, the use of a variety of resources and the skills from different professionals. We cannot expect general practice to be provided with the same diagnostic methods and specialist facilities as hospitals. But what should be expected is the same degree of control in patients cared for in general practice as in those monitored at hospital level.

Therefore, the best thing is to use the best aspects of both levels by an integrated approach to the patient with shared responsibilities between general practitioners and hospital consultants. This is the purpose of shared-care schemes.

Shared-care schemes could be described as a method of care whose aim is to make the best use of health service resources by co-ordinating all the levels of care involved in looking after patients with chronic disease. It provides continuous collaboration between primary and secondary levels of care.

But although shared-care schemes have been shown to be cost effective [63,92] the number of identified schemes was few, just 18 in Great Britain.

The obvious question to ask, therefore, is, if integrated shared-care schemes are such a good method of care, why have they not been more widely adopted? Why are they successful in some areas but not in others?

As the review of the published data did not give a clear indication about possible reasons, a survey was carried out in order to identify how doctors' attitudes, functional or structural problems could influence the decision in setting up and implementing shared-care schemes.

CHAPTER VI

AIMS AND OBJECTIVES II

AIMS II

1. To investigate why some shared-care schemes have been set up and are successful in some areas but not in others.

2. To assess the applicability of such schemes to Spain.

OBJECTIVES

1. To investigate the attitudes of general practitioners and hospital consultants towards shared-care schemes.

2. To determine what characteristics in general practitioners and consultants influence the decision to develop and implement shared-care schemes.

3. To see if there are any differences between those doctors who participate in schemes and those who do not regarding patient care policy.

4. To identify the main problems in setting up such schemes.

CHAPTER VII

METHODS II

METHODS II

DESIGN OF THE INVESTIGATION

The type of study is an observational survey with both descriptive and analytical components.

DEFINITIONS

Shared-care schemes - These schemes are those which have at least three of the following characteristics: (1) agreed protocols of care by general practitioners and consultants, (2) structured records for use in hospital and in general practice, (3) hospital or Health Authority based district recall system supporting general practice and (4) hospital based database for scrutiny of annual reviews and giving advice to GPs. These requirements were chosen as characteristic of a shared-care scheme based on the information gathered from the literature review.

"Case" - A "case" is a hospital consultant who was thought to be involved in a shared-care scheme or had been very involved with the development of mini-clinics in general practice.

"Hospital Case" - A "hospital case" is one in which there was at least one "case". The "controls" sample was chosen based on the total number of "hospital cases" which had been identified instead of on the number of consultants. (See consultants sampling method).

"Controls" - They were all the hospital consultants who were not known to have participated in such schemes.

"Characteristics of the Hospitals from where the "controls" were taken" - The hospitals from which the "controls" were chosen, were acute general hospitals and had a minimum of 150 beds. Such conditions were chosen in order to guarantee the presence of physicians with interest in at least one of three conditions of the study's interest.

POPULATION

The population under study is all the hospital consultants responsible for the care of patients with either diabetes, hypertension, thyroid disease and rheumatoid arthritis and all the general practitioners in Great Britain.

Identification of Hospital Consultants

The identification of some consultants, those who were called "cases" was based on the identification of the innovations of care carried out by the different means explained in Methods I.

However, although 31 doctors were identified as being involved in some kind of new schemes of care, only 25 were thought to be involved in shared-care or/and mini-clinics. From these, two were identified too late as to be included as "cases". Therefore, a total of 23 consultants were used as "cases".

The remaining consultants, those who were called "controls" were chosen based on the total number of "hospital cases". (See sampling method)

Consultants: Sample Size

The method used to calculate the sample size was based on the formula for the difference of two proportions. We wished to have an 80% chance of finding a difference between consultants participating in schemes and those who did not of 30% vs 65% at the 5% significance level. Thus, a sample of n=100 is sufficient [106].

Consultants: Sampling Method

Twenty three consultants thought to be involved in shared-care schemes or mini clinics were defined as "cases". In order to achieve the number of consultants needed for the sample, it was decided that for each of the 23 "cases", 7 consultants with an interest in the same diseases would be chosen ("controls").

For each "case" in a given hospital, another doctor with interest in any of the chronic conditions mentioned above, was chosen at random in the same hospital. Within the same Regional Health Authority, one other hospital was chosen at random and from this hospital 3 general physicians with interest in any of the four conditions were chosen. Lastly, from the nearest Regional Health Authority another hospital was chosen and 3 other consultants were taken at random. The Regional Health Authorities and Health Boards included in the study, and the areas from where the "cases" and "controls" were identified are shown in Table IV and Table V.

However, there were some exceptions. For example, in the case of Aberdeen Royal Infirmary (Grampian Health Board) as the four consultants in charge of the four specialities were participating in shared-care schemes, no controls were chosen from the same hospital.

As a result of that, 124 "controls" were chosen for taking part in the study.

Identification of General Practitioners

Given that one of the aims of the study was to investigate the attitudes of general practitioners towards shared-care schemes, I was interested therefore, in contacting both GPs who had participated in shared-care schemes and those who had not. However, there was no method to identify such a characteristic before the completion of the questionnaires.

GPs: Sample Size

The method used to calculate the sample size was the same as that used for consultants. In order to get a 5% significance level a sample of n=200 general practitioners was required.

GPs: Sampling Method

The sampling method was determined largely by the problem in identifying participants and non-participants as we did not have a known group of GPs involved in the schemes. Therefore, the 16 FPC in which the 18 hospitals running shared-care schemes were located and identified.

In total, 16 Family Practitioner Committees (FPC's)/Primary Care Divisions (PCD) were chosen from the Regional Health Authorities and Health Boards in which there was at least one hospital consultant involved in some scheme. (Table VI) These FPC's/PCD were chosen to maximise the chance of including GPs who participate in shared-care schemes in the sample.

The 16 Family Practitioners Committees/PCD were contacted by letter asking them to provide the medical list containing the names and addresses of all the National Health Service General Practitioners in their area. Then, from each list a random sample of 13 general practitioners was taken giving a total sample of 208 GPs.

DATA

Sources of data

The collection of data was carried out by postal questionnaire. A short letter accompanied the questionnaire explaining the aim of the study. Doctors were offered a summary of the study results when available. The letter was printed on the University of Glasgow headed notepaper.

Every questionnaire sent included a prepaid envelope for its return.

DESIGN OF QUESTIONNAIRES

Consultants: Questionnaire

The questionnaire consisted of 10 questions asking about non-attendance policy, responsibility for long-term follow-up, the role of different providers of care, organisation of care, and experience of shared-care schemes. Question number 10 was an open question allowing the consultants to make comments about the advantages and disadvantages of shared-care schemes, mini-clinics and traditional care. A copy of the questionnaire is included in Appendix 1.

Consultants: Pilot Study

See Methods I

GPs: Pilot Study

When the first questionnaire for general practitioners was designed, some doctors from the University Department of Public Health and from Townhead Health Centre (Glasgow) were asked to complete it and make comments. As a result, some modifications had to be made.

After that, from the first 6 FPCs' list received, a random sample of 10 GPs was taken from each and, 60 modified questionnaires were sent. Although 39 GPs answered the questionnaire (65% response rate), 5 of them (13%) were useless. The main reason was the different ways in which doctors interpreted what was meant by shared-care schemes.

As had been already noted from the very beginning of the study, it was perceived that the term shared-care was interpreted in a variety of ways and, not always corresponding to the definition I gave. The literature review had as well, confirmed such perceptions. The completion of the first questionnaires, corroborated that suspicion. Therefore, it was decided to devise a new questionnaire in which the term shared-care schemes was supported by explanations and examples of what the researcher defined as such. After that the definitive questionnaire was printed.

GPs: Questionnaire

The questionnaire consisted of 10 questions and had the same division as the one for the consultants, that is, non-attendance policy, responsibility for long-term follow-up, the role of the different providers of care, organisation of care, and experience of integrated shared-care schemes. Question number 10 was intended to allow more specific comments about all the different schemes. There was not however, a question as in the case of the consultants questionnaire, which asked specifically how many shared-care scheme characteristics had the schemes in which GPs said they had participated. (Appendix 2).

FOLLOW-UP OF THE NON RESPONDERS

The follow-up of non responders was carried out by the distribution of an identical version of the former questionnaire. Only the accompanying letter was different, emphasizing again the importance of the requested information.

ANALYSIS

Two ad-hoc databases were compiled for the data obtained from the questionnaire once it was coded. One for the consultants and another one for the GPs.

Once all the data was entered into the computer, it was transferred and analysed using the Statistical Package for the Social Science (SPSS PC) and Minitab as convenient depending on the analysis.

An Amstrad PC 2086D was used for creating the database and for the SPSS analysis and the University of Glasgow's mainframe computer when running Minitab.

The differences in the questionnaire answers between doctors who had participated in schemes and those who had not were assessed by cross-tabulation and chi-square tests or Fisher exact tests. When necessary Yates correction was carried out.

Consultant participants and non-participants in shared-care were defined and analysed in three groups.

1. "Cases" - participants in identified schemes.

   "Controls" - those not thought originally to be participants.

2. 'Participants and non-participants' - in shared-care according to self declaration in questionnaire answers' ('claimed participants').

3. 'Classified participants and non-participants' - based on the definition of shared-care. (See Methods II)

GPs were asked if they had ever participated in a shared-care scheme and later were asked for their current method of follow-up for each of the four conditions. The first of these was used to define participants in shared-care. It was not possible to divide general practitioners into claimed and classified participants. However, although examples and characteristics of shared-care schemes were given in the questionnaire, it was not possible to know if the schemes in which the GPs said they had participated were really shared-care schemes.

CHAPTER VIII

RESULTS II

RESULTS II

CONSULTANTS: QUESTIONNAIRE REPLY

The sample consisted of 147 consultants, 23 "cases" and 124 "controls". Four of them were interviewed personally and 143 were sent a postal questionnaire. The total number of consultants who answered the questionnaire was 103 including those who were interviewed; a response rate of 70%. Eighty five (58%) answered the questionnaire at the first approach and the remaining 18 (12%) did so after a reminder. Sixteen questionnaires had to be sent out again at some stage, as the first consultant approached was not in charge of any patients with the specified conditions.

A breakdown of figures by "cases" and "controls" showed the following:

20 out of 23 "cases" answered the questionnaire; a response rate of 87%. Nineteen of them replied at the first approach and 1 after the first reminder. Eighty three out of 124 "controls" answered the questionnaire; a response rate of 67%. From these, 66 replied at the first contact and 17 after the first reminder. (Fig.1)

Forty three (42%) out of 103 consultants said they had participated in shared-care schemes ("claimed participants"). Nineteen out of 43 were "cases" and 24 were "controls". One of the consultants chosen as "case" was found, after completing the questionnaire, not to have participated.

Among the 83 "controls", who at the start of the survey were not known to participate in shared-care, 24 (29%) were claimed participants. (Fig 1)

SPECIALTY FOR WHICH THE CONSULTANTS WERE RESPONSIBLE AND DEGREE OF PARTICIPATION IN SHARED-CARE FOR THE FOUR CONDITIONS

From 103 consultants who answered the questionnaire, 56 were responsible for the care of diabetic patients, 52 were in charge of hypertensive patients, 43 were looking after patients with thyroid disease, and 37 were involved with the care of patients suffering from rheumatoid arthritis. Sixty one consultants were responsible for only one condition and 42 were responsible for more than one. These 42 consultants were all within the control group. (Table VII)

Cases:

All of the 20 "cases" who answered the questionnaire were responsible for only one of the four chronic conditions of interest. So, 14 were responsible for the care of patients with diabetes; 2 for the control of hypertensive patients; 2 for the care of patients with thyroid disease; and 2 for the care of patients suffering from rheumatoid arthritis. (Table VIII)

One of the consultants who was identified as a "case" through the literature review, said, when filling in the questionnaire, that he had never participated in shared-care schemes. Therefore, 19 out 20 (95%) "cases" had participated. 12 out of 19 had been involved with diabetes schemes; 2 with hypertension schemes; 3 were participating in schemes for patients with thyroid disease and 2 in rheumatoid arthritis schemes. (Table IX)

Controls:

Table I shows the number of "controls" responsible for each specialty. 42 out of 83 "controls" were in charge of more than one of the study's chronic conditions. It was found that only 6 consultants were responsible for the care of diabetics solely; 14 for the care of hypertensives; 1 for patients with thyroid disease; and 20 were caring only for patients with rheumatoid arthritis.

24 out of 83 (29%) said they had participated in shared-care schemes. From these, 2 consultants had responsibility for patients with all of the four chronic

conditions; 8 consultants were in charge of diabetics, hypertensives, and patients with thyroid disease; another 3 were responsible for diabetics and patients with thyroid disease. The remaining 11 were only in charge of one condition (Table VIII).

One out of 24 participating consultants did not specify in what kind of scheme he was involved. For the remaining 23, 7 (30%) were involved in schemes for diabetics, 3 (13%) for hypertensive patients, 3 (13%) for patients with thyroid disease, and 8 (35%) had participated in schemes for patients suffering from rheumatoid arthritis. Two consultants said they had participated in two schemes, one of them for hypertension and thyroid disease, and the other one for diabetes and hypertension (Table IX).

All those in the "case" group were responsible for only one specialty compared to 49% in the "control" group. However, no difference was found between rates of participation in shared-care between consultants responsible for one specialty and those responsible for more than one, in the "control" group. (Fig. II)

ARE THE SCHEMES IN WHICH THE CONSULTANTS SAID THEY HAD PARTICIPATED TRULY SHARED-CARE SCHEMES?

As one of the aims of the study was to determine what characteristics in consultants influence the decision to develop a shared-care scheme, I tried to identify the number of true shared-care schemes from all the schemes reported.

With this in mind, the different schemes identified were classified based on the number of shared-care scheme's characteristics they had, that is, agreed protocols of care, development of structured records, hospital or Health Authority recall system and hospital based database for scrutiny of follow-up results. As mentioned in Methods II, for a scheme to be considered a shared-care scheme it has to have at least three out of four characteristics.

When questionnaire answers were analysed based on that definition only 25 (24%) out of 103 consultants could be classified as having really participated in shared-care schemes (classified participants) (Table X).

Among the 83 "controls" who at the beginning of the survey were not known to participate in shared-care, 11 (13%) were classified participants.

GPs: QUESTIONNAIRE REPLY

The sample consisted of 208 general practitioners belonging to 11 different Regional Health Authorities and Health Boards in the United Kingdom.

The total number of GPs who answered the questionnaire was 134 which gives a response rate of 64%. Ninety four out of 208 (45%) answered the questionnaire without a reminder and 40 (19%) answered the questionnaire after the first reminder.

There was no significant difference between those who needed a reminder and those who did not for participation in shared-care schemes. Furthermore, there was no significant difference when comparing the time of response and the Regional Health Authority (RHA). However, 89% of the doctors in Wales (RHA 15) replied without a reminder, while only 33% of the GPs in North East Thames (RHA 6) did so (Table XI).

The Regional Health Authority with the highest response rate was South East Thames (RHA 7) in which 11 out of 13 GPs (85%) answered the questionnaire. The lowest response rate was for North Western Regional Health Authority (RHA 14) where the percentage of answers was 31% (Table XI).

GPS: PARTICIPANTS IN SHARED-CARE SCHEMES BY REGIONAL HEALTH AUTHORITY

88 (66%) out of 134 GPs who answered the questionnaire had never participated in an integrated shared-care scheme. 30 (22%) had participated in at least one scheme and 15 (11%) said they had participated in more than one scheme. One doctor did not answer this question.

The impact of the various schemes differed a lot between Health Authorities/Health Boards. All of the 8 GPs from Grampian who responded had participated in a shared-care scheme, as had 7 out of 11 in SE Thames, and 11 out of 20 in Wessex. Grampian has shared-care schemes for all four conditions running in Aberdeen, SE Thames a scheme for diabetes in Bromley and Wessex a scheme for diabetes in Poole. On the other hand none of the four GPs in North Western RHA (Stockport: Diabetes) and only 2 of the 17 GPs in Trent (Nottingham: Diabetes) had participated. (Table XII)

GPS: PARTICIPANTS IN SHARED-CARE SCHEMES AND SCHEME'S SPECIALTY

From the 45 general practitioners who said they had participated in one or more shared-care schemes, 14 had participated in shared-care schemes for hypertensive patients, 33 in schemes for monitoring hypertensive patients, 33 in schemes for monitoring diabetics patients, 16 had ben involved with schemes for patients with thyroid disease and 9 had participated in schemes for the care of patients suffering from rheumatoid arthritis.

CURRENT ORGANISATIONAL METHOD OF FOLLOW-UP FOR PATIENTS WITH CHRONIC DISEASE IN GENERAL PRACTICE

Table XIII shows the current method of follow-up for patients with each of the four conditions. Nearly a third of GPs were participating in schemes for diabetes and a third had set up mini-clinics for diabetes and hypertension. However, more than a half and nearly two thirds did not have special arrangements for the follow-up of patients with thyroid disease and rheumatoid arthritis respectively. The "others" arrangements shown in Table VII include "protected time" appointments, and a number of GPs who said they "controlled the patient in routine surgery", when the patient attends for repeated prescriptions. Therefore, the proportion of patients with "no special arrangements" may be considerably higher than shown in column 1.

COMPARISON BETWEEN GP PARTICIPANTS IN SHARED-CARE SCHEMES AND THEIR CURRENT METHOD OF PATIENT'S FOLLOW-UP

The comparison between the answers to question 4 and 8 in the GP questionnaire (Appendix 2) illustrates the confusion over the idea of integrated shared-care. Question 4, which immediately follows the definition of shared-care schemes ("GP and consultants agreed protocols of care, structured records for use in hospital and general practice, hospital or Health Authority based district recall system supporting general practice, and some times, hospital based database for scrutiny of annual reviews and giving advice to GPs") has 88 people who said they have not participated. However, when they turn over the page of the questionnaire to question 8, thirty three of those who said no, now ticked shared-care for a particular patient group (Table XIV).

ATTITUDES TO NON-ATTENDERS

Consultants

One hundred and two consultants answered this question. Overall 58 (57%) of them thought that it was the responsibility of the 'clinic' to make a clinic-patient contact if the patient failed to attend.

"Cases" were more likely than "controls" (80% vs 51%) ($X^2 = 5.4$; df = 1; $p<0.05$) to take responsibility for making a clinic-patient contact (Table XV).

A smaller difference although still significant, was found when comparing claimed participants and non-participants regarding patient's non attendance policy where 70% and 47% consultants respectively took responsibility for making the contact. (Chi-square = 5.0; df=1; $p<0.05$) (Table XVI).

However, no significant difference was found when classified participants were compared to "classified" non participants. (Table XVII)

In the case that the patient fails to attend more than twice, responsibility for follow-up is usually passed to the GP. There was no difference between participants and non-participants for this.

General Practitioners

Fifty eight out of 132 (44%) general practitioners who answered this question said that if the patient fails to attend a follow-up review once or twice it is the patient's responsibility to arrange a new contact. GP's who had never participated in shared-care schemes were nearly three times more likely to think it was the patient's responsibility. However, this difference was not significant. (Chi-square = 3.1; df = 1; p = 0.08) (Table XVIII).

Consultants vs General Practitioners

Table XIX compares consultant's and GP's answers to this question of responsibility for follow-up.

Nearly half of the GPs said that the patient was normally responsible to make contact with the surgery in the case of an attendance failure, compared to only 6% of the consultants. (Chi-square = 41.5; df = 1; p<0.0001).

ATTITUDES TO RESPONSIBILITY FOR SCREENING FOR COMPLICATIONS

Consultants

One hundred and two consultants answered the question about who has the main responsibility for ensuring that all patients in their area with chronic disease are screened for complications at regular intervals.

From these nearly half agreed that responsibility should be shared with GPs depending on the type of the patient.

Consultants in the case group were more likely (32% vs 12%) than those in the control group to think that assuring screening for complications was the consultant's sole responsibility. (X^2=9.7; df=4; p<0.05) (Table XX).

No significant difference was found between claimed participants and non-participants.

Classified participants were more likely than non-participants (29% vs 7%) (X^2 = 16.2; df = 4; p<0.005) to think that responsibility should be the consultant's alone (Table XXI).

General Practitioners

Eighty eight (66%) out of 134 GPs thought that the main responsibility for ensuring that all patients are screened for complications depends upon the patient's condition and the degree of complications. So, they said the consultant will be responsible for some patients and the GP for some others. 20% thought that the general practitioner has the main responsibility, and only 3% gave the consultant the main responsibility. 7% GPs agreed that the Health Authority should have this responsibility and 4.5% thought that this responsibility should be shared by patient and GP, patient and consultant etc.

The GP was considered to have the main responsibility by 23% and 15% of non-participants and participants respectively. Only 3% of GPs thought the consultant was responsible for screening complications.

Consultants vs General Practitioners

Table XXIII shows that GPs tended to favour the sharing of responsibility between themselves and the consultant to ensure that all patients in the area are screened for complications at regular intervals. However, consultants were more likely to assume the main responsibility for the screening for complications, nearly half (50) agreed that responsibility should be shared with GPs depending on the type of patient. (X^2= 17.1; df = 4; $p<0.005$)

ATTITUDES TO THE CONSULTANT'S ROLE

Consultants

Overall 53 (52%) out of 102 consultants shared the opinion that not all GPs provide good follow-up for patients with chronic disease and it is necessary for hospital consultants to take a more active approach for all patients in their area.

Significant differences were found when analysing the data in the three different ways. So, 85% "cases" comparing to 44% "controls", 65% claimed participants comparing to 42% non participants and 82% "classified" participants comparing to 42 non participants supported that idea. (Chi-square = 9.3; df = 1; $p<0.005$) (Table XXIV). (Chi-square =4.3; df=1; $p<0.05$) (Table XXV). (Chi-square =10.1; df=1; $p<0.005$) (Table XXVI).

General Practitioners

Overall 53 (40%) out of 133 GPs thought that the follow-up of patients must be a co-operative arrangement between the GPs and the specialist consultant each with defined and agreed areas of responsibility and that the hospital consultant should have an active approach regarding the degree of control and follow-up. Forty six (34%) thought that the patient's follow-up should be agreed by general practitioners and hospital consultants but that the consultant should not monitor the control of patients under GP care. Lastly, 35 (26%) thought that the hospital consultant provides a specialist advisory service but the type of long-term follow-up for patients must be decided by the GP.

In order to be able to compare results between GPs and consultants, regarding the answer to this question, it was decided to modify the variable's categories. So, from the three possible answers the GP's questionnaire had for this question, the two first were collapsed into one, since in both the consultant could be considered as having only an advisory role.

Once the data was reorganised, and analysed by participants and non participants it was found that, 21 (46%) general practitioners who were participating in schemes thought that the hospital consultant should have an active approach compared to 32 (36%) in the group which had never participated. However, the difference was not significant (Table XXVII).

Consultants vs General Practitioners

Lastly, consultants' and GPs' answers to this question were compared. Although 52% of the consultants defended the idea about their active aproach compared to 40% of the general practitioners, the difference was not significant (Table XXVII).

INITIATION OF SHARED-CARE SCHEMES

Only general practitioners were asked this question, and 10 out of 134 did not answer.

Overall seventy out of 124 GPs (57%) thought that the initiative for setting up shared-care schemes should come from the hospital consultant compared to 21% who thought it should be a GP initiative. Fifteen percent however, thought that an agreed decision among consultant, GPs and Health Authority should be the first step to initiate the development of the scheme. And lastly, 7% agreed that

Health Authorities should be responsible for launching such initiative.

Half (22) of the particpating GPs thought the consultant should be the initiator of the schemes compared to 48 (61%) non-participating GPs. Four per cent (2) in the participants group and 7% (9) in the non-participant group said that the Health Authority/Health Board should be the initiator. However, the differences were not statistically significant (Table XXIX).

Fifty per cent of the family practitioners who said that the GP has the main responsibility for ensuring screening for complications thought however, that the initiative in setting up such schemes should come from the hospital consultant.

From those who thought that the main responsibility sometimes rest with the consultant and some others with the GP, 66% thought the consultant should be the initiator and only 18% said it should be the general practitioner (Table XXX).

INITIATOR OF THE SCHEMES IDENTIFIED

Amongst the 43 schemes claimed by consultant respondents, the consultant was the initiator of 72% and the GP of 7%; 21% had been a joint initiative.

From the 45 GPs who claimed to be participants, 30 had participated in one shared-care scheme and 15 in more than one giving a total of 72 schemes.

From these, 66% had been set up by consultants, 22% by GPs and 11% had been a joint initiative. Table XXXI shows who was the initiator of the scheme by different specialties

SCHEMES CURRENTLY RUNNING

42 out of 43 schemes claimed by the consultant's study group, are still running. Only one diabetic scheme within the "cases" group was stopped. The reason was that the consultant did not have enough time to devote to it.

Within the general practitioner's group, 2 schemes had been stopped. In one of the cases the reason was that the Health Authority had stopped funding. The other one, was stopped as a consequence of co-ordination problems which made the development of a follow-up scheme difficult. Co-ordination problems between GPs and consultants was a common comment regarding the implementation of schemes from those GPs practising in Greater London.

CHARACTERISTICS OF SHARED-CARE SCHEMES REPORTED BY CONSULTANTS

Table XXXII shows the characteristics of shared-care schemes with which hospital consultants had or had not been involved. Only results from "cases" and "controls" and "claimed participants and non-participants" are shown since most of the classified participants had developed such characteristics.

More than half claimed participants had developed agreed protocols of care with GPs comparing to 28% non-participants ($X^2=6.7$; df=2; $p<0.05$). Nevertheless, half of non-participants would be prepared to develop them.

Significant differences were found regarding the development of structured records for use in hospital and in general practice. "Cases" were more likely than "controls" (70% vs 22%) ($X^2=34.75$; df=4; $p<0.0001$) and claimed participants than non-participants ($X^2=30.1$; df=2; $p<0.00001$) to have developed structured records. Nevertheless, half non-participants would be prepared to develop them.

As was expected, there was a significant difference between "cases" and "controls" and "claimed participants" and non-participants regarding the development of hospital or health authority recall system. Sixty per cent "cases" vs 12% controls (X^2 = 25.5; df=4; p<0.0001) and 37% "claimed participants vs 10% non-participants (X^2= 12.9; df=2; p<0.001) had supported general practice care with a hospital or health authority based district wide recall system. Moreover, 38% of non-participants would be prepared to develop such a facility.

Regarding the development of a hospital based database once again the differences in the results were markedly significant. More than a half "cases" comparing to 12% "controls" had supported general practice with a hospital based database allowing scrutiny of annual reviews and giving of advice to GPs.

Similarly, "claimed participants" were more likely than non-participants (39% vs 6%) (X^2=20.8; df=2; p<0.00001) to have developed such a database. Nearly half of non particpants however, would be prepared to develop it.

There was not significant difference between "cases" and "controls" regarding the organisation of continuing education courses for GPs. A small difference however was found between "claimed participants and non-participants (79% vs 53%) (X^2=7.6; df=2; p<0.05).

RESPONDENTS' COMMENTS

Consultants: Sixty (58%) out of 103 consultants used the opportunity to comment. Both claimed participants (81% vs 42% non-participants (X^2=15; 1df; $p<0.001$) and classified participants (84% vs 50% non-participants) (X^2=5.2; 1df; $p<0.005$) were more likely to have used the opportunity to comment in the questionnaire. Nine consultants commented that shared-care ensured up-to-date management, uniform standards of care by means of protocols and less losses to follow-up. Four claimed it improved communication between GPs and consultants, five that it saved consultant time for more difficult cases, two that it was a good system for large geographical areas, and two that it had well organised record systems. Eight consultants said they favoured shared-care without giving more detail, and one thought traditional care had been shown to be unsuccessful.

On the other hand three consultants thought shared-care was time consuming, four that it was difficult to set up with a need for more staff, two that it was inflexible, and one that GPs did not want to be dictated to by hospital based follow-up schemes. Four consultants thought traditional care was the best method but did not explain why.

One consultant thought mini-clinics should be encouraged but 4 thought they were a waste of time, one that they were not cost-effective, and one that they lacked formal methods of audit. Two consultants commented that for mini-clinics to be successful GPs skills had first to be improved through postgraduate education.

GPs: 68 out of 103 (51%) GPs made comments. There was no difference in the number of comments made by GPs claiming to be participants in shared-care compared to those not claiming participation. Twelve GPs commented that shared-care provided better care for patients, a number of which attributed it to the development of agreed protocols of care. Ten considered that shared-care improved co-ordination, communication and feedback between secondary and primary care. Three thought that it worked well and 2 that it was the ideal method for some conditions and in some circumstances (not specified). One GP saw shared-care as a more economic method of care, and another said that it avoided duplication of work.

Among the disadvantages of shared-care, 3 thought that there was a loss of responsibility for patients, two that it was difficult to organise, 1 that with this method of care the disease could become more important than the patients. One GP commented that shared-care was expensive, another that it implied duplication of tests and lastly one GP stated that he did not know what shared-care was.

Five GPs commented that mini-clinics were likely to increase because of the new contract and because they were financially profitable. However, 5 GPs thought that they were impractical and inappropriate for small practices. Two GPs thought that they convert GPs into 'specialist practitioners' which went against the idea of general practice. Two said that mini-clinics were not a good method of care as patients have timetable problems to attend, on the other hand two said that they are better for the care of patients and one thought they were better than traditional care. Two thought that mini-clinics can imply neuroticism and convert patients into disease group.

Regarding traditional care, 3 GPs said that it implied losses to follow-up, 1 that it was phased out, 1 that it lacked the use of protocols of care and 1 that it was hard to organise to provide good care. However, 2 thought that if it was well organised it worked well and 1 GP said that the advantage of traditional care was that the patient always sees the same doctor.

CHAPTER IX

DISCUSSION II

DISCUSSION II

Various authors have argued for the benefits of shared-care. In 1982 Jones et al [63] claimed that the use of computerized registers for the surveillance of people with chronic disease provided a uniform standard of follow-up for these patients. It also offered the possibility of well organised shared-care between hospital and primary care, and was cost-effective system when compared with traditional care.

Hayes and Harries [44] were also in favour of developing a computerised system similar to that used in SAFUR [50] or WAFUR [93] for the surveillance of patients with diabetes.

Furthermore, when Petrie described his shared-care scheme for patients with hypertension [91], he argued that this kind of system could be applied to other groups of high risk patients in whom long-term follow-up is mandatory, for example diabetics and patients with thyroid disease.

Jones et al [63] considered the reasons why this approach had not been successfully followed widley and why it was only being used in a few centres. They thought of various reasons that could influence this trend.

Firstly, there had not been any evaluative study comparing the efficiency of follow-up by both registers and other approaches. Therefore, there was no good reason to support a change in traditional care.

Secondly, the difficulty in setting up and maintaining a reliable register was mentioned. Personnel involved in the register need to be trained in the new system and furthermore, reallocation of resources is fundamental.

Alexander et al [81] pointed out that "the term shared-care embraces quite different meanings for different doctors. For example, a patient's attendance at a hospital clinic at some time is thought by some to be shared-care. Furthermore, systems where the hospital doctor and the general practitioner are working together in the same room at the same time (some mini-clinics) are also considered shared-care". Other authors are also aware of such misunderstanding [108].

To try to overcome this confusion examples of shared-care care schemes were given in this study [85,91,92], and described in terms of the main features. Nevertheless the survey encountered the same difficulty of different interpretations that are often encountered in meetings and discussions about shared-care.

For example, only 25 (58%) of 43 consultants who claimed to have participated in shared-care met the classification. Moreover, 33 GPs who answered "no" when asked if they had participated in shared-care said later on that their method of follow-up for a particular patient group was by means of shared-care (Table XIV).

So, in 1990, nine years after Jones publication [63] the percentage of doctors participating in schemes similar to SAFUR [50] is still very low in Great Britain.

During this period of time, at least two cost-effective analysis of the shared-care schemes have been carried out [63,92]. In both studies, the new approach for the care of patients with thyroid disease and hypertension were found to be efficient and cost-effective when comparing to traditional methods of care.

Why then have these schemes not been developed?

Some researchers have studied the way in which innovations are diseminated [109,110] as well as the ways of influencing the behaviour of doctors [111].

It seems that the diffusion of new ideas through a group of people follows a similar pattern. The idea is initially taken up by few innovators, then spreads to include early adopters who are respected by the group and later the majority including the laggards will take up the idea [111].

Horder [111] found that individuals generally go through different stages when changing their behaviour. These are awareness of the new idea, interest, appraisal, trial and lastly adoptions.

Furthermore, Rogers [109] has described 5 variables which seem to influence the individuals decision to take up a new idea: (1) relative advantage, (2) compatibility, (3) complexity, (4) observability, (5) trialability. Stocking [110] has analysed how these 5 variables could influence the development of changes regarding diabetes shared-care. These provide a useful framework in which the findings of this study can be discussed.

Relative advantage: Stocking argues that 'for the hospital doctor there are clearly advantages in reducing workload, but this may be offset by concerns about whether the GPs are really up to it...'. Five consultants in this survey claimed that shared-care saves consultant time for more difficult cases. On the other hand, 52% felt that not all GPs provide good follow-up and, for this reason, it was necessary for hospital doctors to take a more active approach. Participants in shared-care were more likely to have this view.

Most respondents, both GPs and consultants, were more likely to cite advantages for patients, such as fewer losses to follow-up and better communication, rather than advantages for themselves. A number of GPs attributed the better care to the development of agreed protocols of care and, as elsewhere, [112,113] favoured this development.

Compatibility: How far is shared-care compatible with people's roles and attitudes? Despite misunderstanding of the term "shared-care schemes", differences in attitudes between participating and non participating consultants were still obvious. For example the main difference found was in consultants attitudes to follow-up and the responsibility they take for the whole population.

Participating consultants were more likely (82% vs 42%) to consider it their responsibility to follow up non-attenders and to ensure screening of all patients (29% vs 7%).

There was no significant difference regarding GPs and consultants views of the consultant's monitoring role.

The survey also showed that GPs expect consultants to be the initiators of shared-care and certainly were not averse to participating in it.

There was no significant difference on any question between GPs participating in shared-care and those not suggesting that, up till now, the critical factor has been consultants' attitudes.

Complexity: A number of both consultants and GPs considered shared-care difficult to set up and time consuming. Stocking's view 'much work will be needed to agree the boundaries of responsibility between primary and secondary care...' is supported by concerns expressed by some doctors of loss of responsibility, and the inflexibility of shared-care

Observability: Of the 18 shared-care schemes identified 11 had been in the literature. Nevertheless, for most practising doctors 'observability' means being able to see it in nearby practice. Shared-care has obviously not yet reached 'critical mass' and this will remain a problem unless some other factor causes its adoption.

Trialability: The ability to try out shared-care in a limited way really rests with the initiative of the consultant or health authority, and as Stocking says 'the negotiations which need to take place within a practice and between practices and the hospital probably mean that a fairly strong commitment has to be made...'

This survey was carried out between March 1990 and August 1990 before the implications of the White Paper proposals will have been absorbed by the respondents. There are a number of ways these might affect the care of patients with chronic disease. First, it has already led to a large increase in the number of mini-clinics being set up under the heading of 'health promotion'. Some studies

[86,96] show that organised and audited general practice mini-clinics can improve the process of care for diabetic patients when compared to traditional care. However, others [87,114] think that a policy encouraging mini-clinics is unlikely to provide a solution for the care of chronic patients (especially diabetics) and in any case is undesirable. There are even those who are really worried about the suddeness of its development [115,116].

Moreover, in the case of diabetic care, Mellor [59] found that 74% of GPs interviewed preferred their patients to be followed-up in a shared-care system with the hospital compared to 19% who preferred the mini-clinic system.

The financial convenience implicit in the development of GPs mini-clinics can lead to proliferation of clinics without minimum standards of care with the potential detriment for the patient. Moreover, GPs mini-clinics which act totally independently from hospital clinics can lead to duplication of patient's visit to the doctor (hospital-surgery) which increases the patient's inconvenience, the chance of treatment errors and the failure to keep appointments [117].

The fact that nearly half of the GPs leave to the patient the responsibility to make a new appointment in the case of a failure to attend for follow-up, reflects the General Practice traditional process where GPs passively respond to symptomatic patients seeking relief. As Hart quoted (1981) "If we want to control hypertension or any other chronic condition in which needs correlate poorly with symptoms, on the mass scale required, we (the general practitioner) must move decisively from our traditional role as shopkeepers responding to sick customers to become more active guardians of the health of our registered population".

Day (1985) showed that even in places in which it was agreed by the GPs to become responsible for the follow-up of diabetic patients discharged from hospital clinics to primary care, the results were disappointing.

In this study as much as 65% consultants from those participating in schemes thought that GPs do not provide a good quality follow-up to the chronic patient and therefore, they felt responsible for taking a more active approach for the care of all the patients in their area.

It could be argued therefore, that the general practice mini-clinics approach as an isolated primary care initiative is not going to ensure the continuity of follow-up required by these patients.

Some kind of patient supervision by the hospital consultant at yearly intervals could be a way of assuring a greater commitment at primary level and at the same time would benefit patient and GP since the specialist can provide advice if needed.

The results of the survey seem to support this argument. Interestingly, there was no significant difference regarding GPs and consultants views of the role of the consultant. 53% consultants and 40% (53) GPs agreed that consultants should have a monitoring role comparing to 48% consultants and 60% GPs who thought consultants should have an advisory role only. In the case of the GPs, the difference in the answers to this question had not been associated with whether or not the GP was involved in a scheme. That is, GPs' participation in a scheme was not influenced by their attitudes about the consultant role. Furthermore, general practitioners expected consultants to be the initiators of shared-care schemes, perhaps because of the implicit use of hospital resources involved. In fact, more than a half of those shared-care schemes in which the GPs had participated had been set up by hospital consultants.

In relation to who is mainly responsible for ensuring patient screening for complications, Health Authorities should be aware that consultants and GPs expect them to be responsible. In that way, 7% GPs and 4% consultants consider HA the only ones responsible for it, while another 14% consider that HA should be responsible in the same way that doctors and patients are.

To consider HAs responsible for assuring the screening of the chronic patient is understandable, since in the end, HAs are those who should require a minimum standard of care for the patients in their areas.

What doctors expect from them is mainly support in a way in which the resources needed for developing new schemes of care were provided by them.

Purchaser provider aspects of the recent changes now put a clear responsibility on health authorities to purchase equitable, efficient and effective health care for people with chronic disease. The responsibility therefore rests with Patient Services Managers to require consultants to establish such schemes and to provide them with the resources to do so. The indications are that most GPs and consultants are quite willing to co-operate but in discussions everyone needs to be very clear about what exactly they mean by shared-care. Certainly given the lack of evidence regarding the effectiveness of mini-clinics without some element of shared-care the wholesale adoption of GP mini-clinics without evaluating their effectiveness seems unwise.

CHAPTER X

THE HEALTH SYSTEM IN SPAIN

THE HEALTH SYSTEM IN SPAIN

Origin and Evolution

The origin of the first Spanish public Health Services came from the need to address the problems of people without economic resources. It was called Beneficencia.

The responsibility for its administration rested with Local Councils, the Church and sometimes the State. The services provided consisted basically of hospital care for the sick and poor and for patients with long-term diseases such as tuberculosis and mental handicap.

It was in 1942 when for the first time an organisation of the Health Service with State intervention appeared. It was called Seguro Obligatorio de Enfermedad (S.O.E.). It was a compulsory Health Insurance for workers with low salaries. This insurance covered their relatives as well.

By the end of 1944 the S.O.E. covered 25 percent of the population and by 1963 45 percent [118].

In 1963 a more comprehensive model was established, the Asistencia Sanitaria de la Seguridad Social. This model increased the population's coverage to 84% [118]. Nevertheless, in the early 1970s the system was reorganised as Instituto Nacional De La Salud (INSALUD) and by 1985 was covering nearly 90 percent of the population.

However, it is not until 1986 that the principle of universal coverage was firmly established in the Ley General de Sanidad (LGS) [119].

The LGS radically altered the organisational structure of the Public Health System and established the administrative and legal framework of the new Spanish National Health System. That process has been known as the Reforma Sanitaria and it is still being developed and implemented.

This Reforma Sanitaria (Health Reform) involves the creation of a National Health System constituted by the bringing together and coordination of the Health Services from all the Spanish Autonomic Communities.

The characteristics of the New Health System are: [120]

1. The coverage of the total population.

2. Integrated Care.

3. Co-ordination and integration of all Public Health resources by a unique agency.

4. Financed mainly by public administration.

HEALTH SERVICES STRUCTURE

The Ley General de Sanidad defines how the Health Services have to be structured and organised at the Autonomy Level [119]. It states that the basic structures of the New Health System are the Areas de Salud. These are geographical divisions which are delimited in accordance with different factors such as socio-economic, climatic, cultural, health services resources etc. Each area comprises a population between 200,000 to 250,000 and has to have at least one public hospital.

The Areas de Salud are divided in Zonas Basicas de Salud. These Zonas Basicas de Salud are the territorial framework for the primary care services. They comprise between 5,000 to 25,000 population and they are demarcated by epidemiological characteristics of the area, health services resources and population concentration. The distance and time spent to access the health services by the population is also taken into account when divisions are made.

It is in the Zonas de Salud where the Health Centres (HC) are placed and where Primary Health Care is provided.

PRIMARY HEALTH CARE

The Ley General de Sanidad [119] defines the Health Centre as the physical structure in which integrated health care activities are developed. It also states who should be part of the Primary Health Care Team (PHCT) and the activities and functions this team should carry out. These are the promotion of health, prevention of disease, and treatment and rehabilitation of the population in that area.

Other functions similarly important are to carry out the Health Diagnosis of the Area and the Evaluation of all the health activities performed in the Health Centre.

HEALTH DIAGNOSIS

One of the most important points in the new Law regarding Primary Care work is that it should be based on the development, implementation and evaluation of Health Programmes. So, the new regulations state that the Primary Care Team should, first of all, carry out a Health Diagnosis of the area in order to know the health problems of the population. The knowledge of such problems will help to develop a Health Plan with clear health objectives.

The implementation of the Health Plan will be carried out by means of developing and implementing different Health Programmes. They will define the technical and administrative decisions and actions to be taken in order to achieve the health objectives.

So, the work at Primary care level should be planned, programmed and evaluated since this is the only way towards the solution of the community health problems.

HEALTH PROGRAMMES

A Health Programme [HP] describes a series of organised and co-ordinated activities with the aim of achieving a defined objective in a given population with the available resources.

A programme consists of 4 elements:

1. The objectives.
2. The activities.
3. The resources.
4. The evaluation method.

All Health Programmes take into account promotion, prevention, recuperation and rehabilitation activities.

In each programme the PCHT has to specify the health activities for each member of the team in accordance with the guidelines issued by the Ministry of Health, for each specific programme [121].

To elaborate the programme the team has to follow the next steps. Firstly, justification of the programme. Once the principal health problems have been identified evaluated and given priority it will be possible to justify why they choose to set up such a programme. A programme is justified by taking into account the severity and extension of the problem, its vulnerability, its local effects and the population attitudes towards it, its trend and its health and sociological consequences.

Secondly, definition of objectives and the target population.

Thirdly, development of protocols of care. The protocols state to whom the activity is addressed (women, children.....), who is going to carry out the activity (doctor, nurse, social worker...), and how many times the activity is going to be performed. These protocols are usually developed by mutual agreement between general practitioners, hospital doctors, nurses etc.

Fourthly, evaluation of the resources to try to maximise those already available.

Fifthly, a statement of the performance that can be obtained that is, how much time is need to perform a given activity. Lastly, to state the method by which the programme will be evaluated.

The Ministry of Health has published clear guidelines about the way in which the PHCT should work [121] and how health programmes should be developed and implemented [122]. Some Spanish autonomies have also published their own guidelines [123].

CURRENT SITUATION

Implementation of the new Law however, has been very irregular in the different provinces in Spain. It has depended on varying initiatives and enthusiastic health care workers. But, by 1988 20-30% of the Spanish population were receiving care from the new health centres [124].

Primary care teams are using both the skills of Public Health medicine and general practice to plan and programme the care of the population with clinical targets and evaluation of their attainment.

In this process the development and implementation of health programmes is of paramount importance. Most of the health centres have currently set up three programmes:

1. Mother and child care

2. Programme for the adult.

3, The environmental programme.

The implementation of these programmes implies the development of subprogrammes. For example, the programme for the adult consists of different subprogrammes. Among these, those which have been most widely established are the programmes for the care of patients with hypertension, diabetes and rheumatic disease.

WHAT DO SHARED-CARE SCHEMES HAVE TO OFFER TO SPAIN?

The new way of working in Primary Care in Spain implies the acquisition of a larger responsibility for the care of chronic patients.

As has been noted above, Primary Care is now responsible for developing a variety of subprogrammes for chronic diseases for example hypertension and diabetes. The intention is that most of the chronic patients should be looked after at primary level.

However, the care of chronic patients presents special problems. Quite often they need the care of more than one doctor, more than one specialty, and the use of technical resources for routine investigations. Therefore, their follow-up will involve the contribution of more than one level of care, and maybe a number of different agencies.

Many chronic patients are treated for an acute episode in an out-patient clinic and when he is discharged, the hospital consultant withdraws all responsibility for that patient losing contact with him until a new acute problem occurs.

On the other hand, it is the GP who loses contact with the patient when he is followed-up by the out-patient clinic.

Communication is of special relevance when the care of a patient is shared between more than one practitioner. However, consistency and completeness in the information gathered becomes problematic to the detriment of the patient's care. Although there is no Spanish literature about the communication problems between primary and secondary care providers, they exist as they exist in other countries [125,126,127].

The result is that quite often patients get lost in the gap between primary and secondary care or on the contrary they continue to be followed-up by both levels which implies duplication of work and some times even misunderstandings regarding treatment schemes.

The current development of programmes which include protocols of care mutually agreed by hospital consultants and general practitioners seems to facilitate communication. Moreover, they allow agreement between different doctors' responsibilities regarding patient long-term follow-up.

A shared-care scheme will facilitate the task by providing all the facilities which have been already mentioned in previous chapters. It will assure a continued communication between GPs, consultants and patients. It will offer an easy means of GP advice by consultant if needed and because of the structured way in which the care of these patients would be provided, it would allow for auditing and evaluation of the subprogramme itself.

HOW TO START?

Although the way in which the Spanish Health Care staff structure (GPs and consultants are NHS employees) would allow for a top-down regulation to implement such schemes, it would be wrong to try that way. On the other hand, the idea of letting the responsibility to develop the innovation in the hands of few enthusiastic doctors and hoping that it would spread does not seem to be right either.

Therefore, the first step in the introduction of shared-care schemes would be to carry out a pilot study in areas and hospitals in which a few innovators would be prepared to take up the idea.

If this is shown to be successful, attempts could be made to introduce it.

FIGURES AND TABLES

IGURE 1

ESPONSE TO SURVEY BY CONSULTANTS

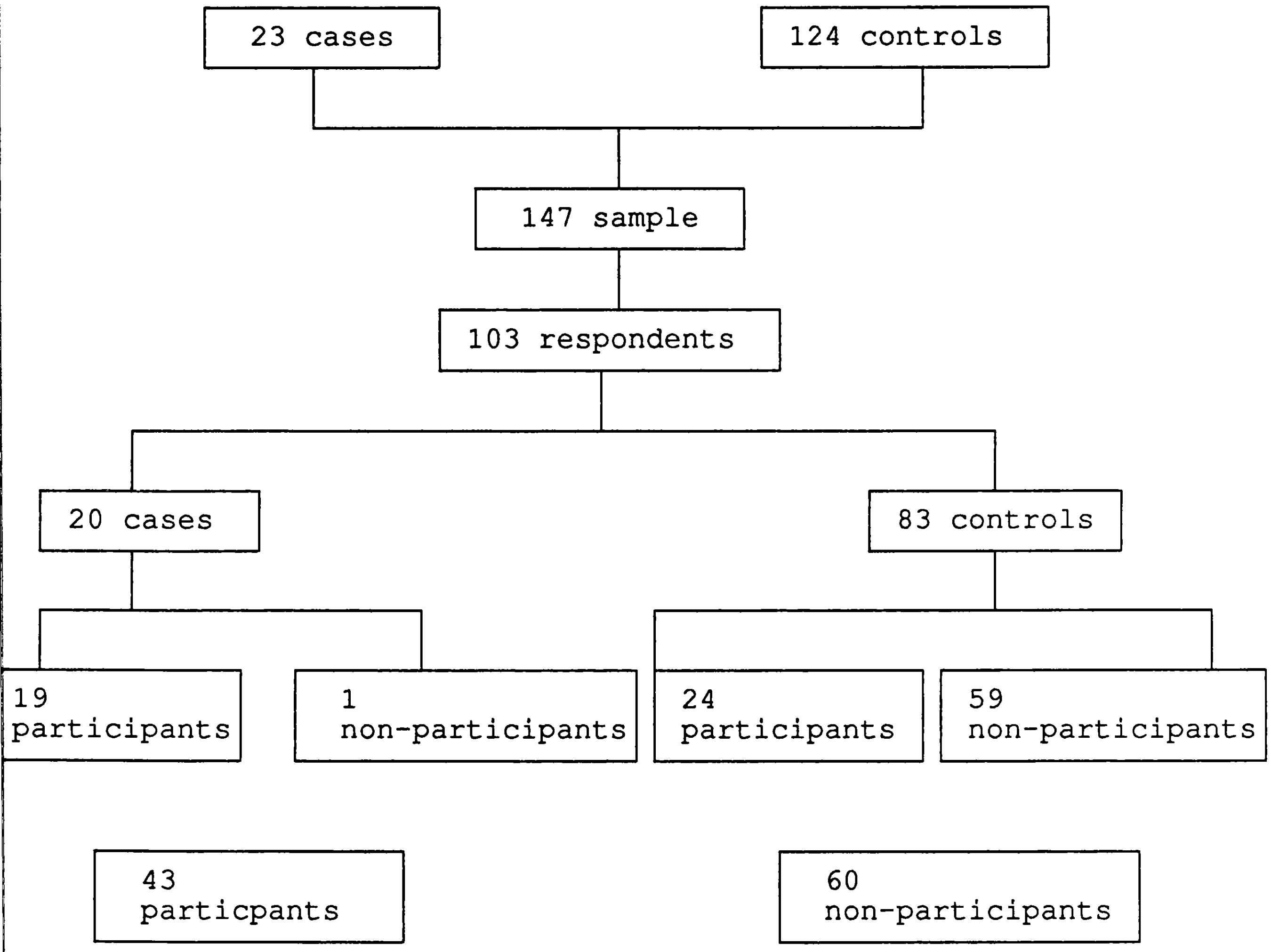
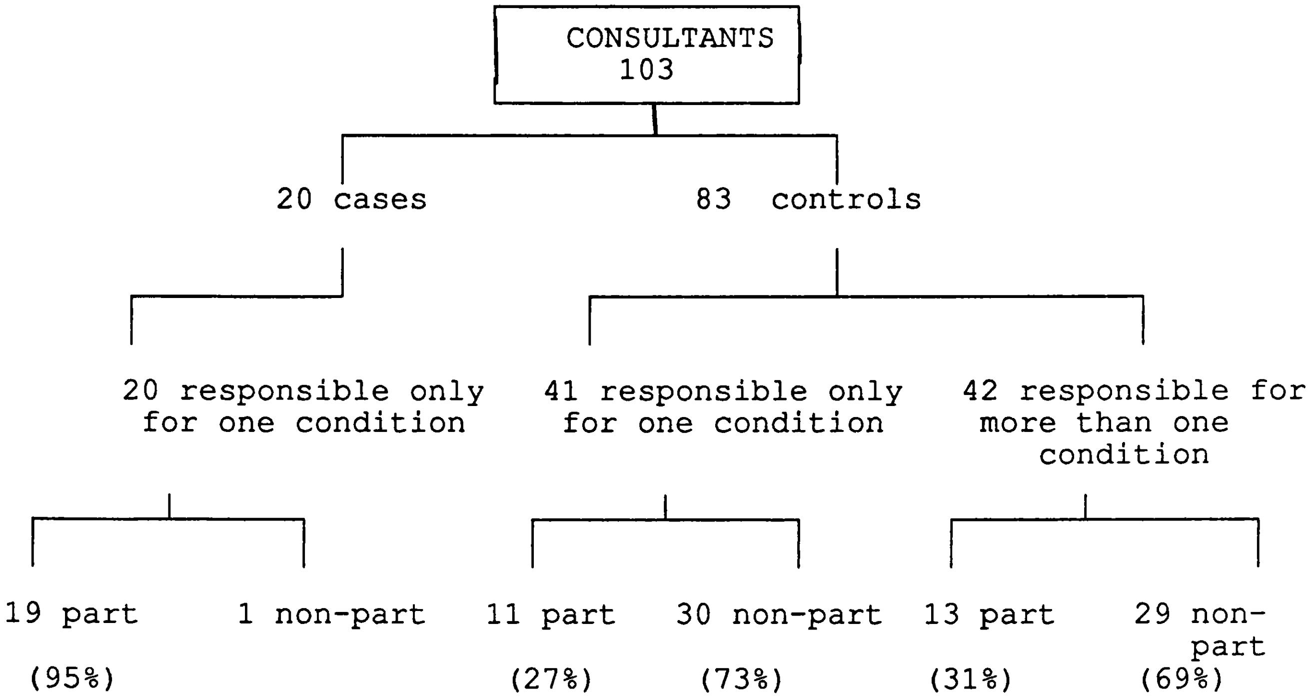


FIGURE II

NUMBER OF SPECIALTIES FOR WHICH CONSULTANTS WERE RESPONSIBLE, SHOWING CASES & CONTROLS AND PARTICIPANTS AND NON-PARTICIPANTS



BLE I

SHARED-CARE SCHEMES

		Identification Method		
ecialty	**Place**	**L**	**S**	**P**
abetes	Poole	(85)		
abetes	Islington	(87)		
abetes	Southampton	(88)		
abetes	Stirling	(43)		
abetes	Chester*	(89)		
abetes	Ipswich	(90)		
abetes	Cardiff	-	Y	
abetes	Nottingham**	-	Y	
abetes	Aberdeen	-		Y
abetes	Peterborough	-		Y
abetes	Portsmouth	-		Y
pertension	Aberdeen	(91)		
pertension	Glasgow	(92)		
yroid sease	Aberdeen	(33,50)		
yroid sease	Wales*	(93)		
yroid sease	Glasgow	-	Y	
eumatoid thritis	Glasgow	(94)		
eumatoid thritis	Aberdeen	-	Y	

Both schemes were identified too late to include as "cases"
This scheme has currently been stopped.
y: L Literature; S Snowball; P Personal Communication

ABLE II

ENERAL PRACTICE MINI-CLINICS AND GENERAL PRACTICE MINI-CLINICS WITH HARED-CARE

		Identification Method		
pecialty	**Place**	**L**	**S**	**P**
iabetes	Wolverhampton	(40)		
iabetes	Bromley	(96)		
iabetes	Norwich	(97)		
iabetes	Stockport	(95)		
iabetes	Stourbridge	-	y	

ey L = Literature review
S = Snowballing sampling
P = Pilot study

ABLE III

OTHER SCHEMES

Identification Method

pecialty	**Place**	**L**	**S**	**P**
iabetes	Isle Wight	(98)		
iabetes	Birmingham	(99)		
iabetes	Abergavenny	(100-101)		
iabetes	Exeter	(102)		
ypertension	Birmingham	(103)		
ypertension	Newcastle	(104)		

ey L = Literature review
S = Snowballing sampling
P = Pilot study

BLE IV

GIONAL HEALTH AUTHORITIES AND DISTRICTS FROM WHERE CASES AND CONTROLS RE CHOSEN IN ENGLAND & WALES

ases" gion	**Corresponding "Controls" Districts**
ent	North Lincolnshire South Lincolnshire East Surrey Merton & Surrey
st glia	West Suffolk West Norfolk Great Yarmouth & Waveney North Hertfordshire North Bedfordshire NW Hertfordshire
eater ndon	Wandsworth Oxfordshire
uth st Thames	Medway Basildon & Thurrock
ssex	West Dorset Bath Basingstoke Chichester North West Surrey East Surrey
rth Western	Lancaster Hartlepool
les	Gwynedd Bristol & Weston
st Midlands	Shropshire Wolverhampton Chester Warrington

ABLE V

EALTH BOARDS (HB) FROM WHERE CASES & CONTROLS CAME FROM IN SCOTLAND

CASES" H.B.	"CONTROLS" H.B.
RAMPIAN	GRAMPIAN HIGHLANDS
ORTH VALLEY	FORTH VALLEY TAYSIDE
REATER LASGOW	GREATER GLASGOW AYRSHIRE & ARRAN LANARKSHIRE

ABLE VI

EGIONAL HEALTH AUTHORITIES & DISTRICTS & HEALTH BOARDS & CORRESPONDENT AMILY PRACTITIONERS COMMITTEES\PRIMARY CARE DIVISION FROM WHERE THE AMPLE OF GPS WAS TAKEN.

egional Health Authorities Districts with a "Hospital ase"	**Family Practitioner Committee**
essex	
ast Dorset	Dorset
outhampton	Hampshire
ortsmouth	
outh East Thames	
romley	Bromley
reater London	
slington	Camden & Islington
ast Anglian	
uffolk	Suffolk
orfolk	Norfolk
eterborough	Cambridge
rent	
ottingham	Nottinghamshire
eicestershire	Leicestershire
est Midlands	
olverhampton	Wolverhampton
udley	Dudley
orth Western	
ockport	Stockport
les	
uth Glamorgan	South Glamorgan
eater Glasgow	Glasgow
ampian	Aberdeen
rth Valley	Stirling

TABLE VII

"CASES" AND "CONTROLS" BY CONSULTANT'S SPECIALTY.

CONSULTANT'S SPECIALTY	CONSULTANTS RESPONSIBLE FOR EACH SPECIALTY	CASES (n=20) Responsible for one specialty n = 20	CONTROLS (n=83)	
			Responsible for one specialty n = 41	Responsible for more than one n = 42
DIABETES	56	14	6	36
HYPERTENSION	52	2	14	36
THYROID DISEASE	43	2	1	40
RHEUMATOID A	37	2	20	15

TABLE VIII

SPECIALTY FOR WHICH THE CONSULTANT WAS RESPONSIBLE CASES AND CONTROLS

CONDITION RESPONSIBILITY	CLAIMED PARTICIPANTS	CLAIMED NON-PARTICIPANTS
ONLY 1 CONDITION		
DIAB	14	6
HYPERT	4	12
THYR D	2	1
R A	10	12
TOTAL	30	31
2 CONDITIONS		
DIAB & HYPERT	0	2
DIAB & THYR.D.	3	2
HYPERT & THYR D	0	3
TOTAL	3	7
3 CONDITIONS		
DIAB & HYPT & THYR D	8	9
HYPERT & THYD & RA	0	2
TOTAL	8	11
4 CONDITIONS		
DIAB & HYPERT & THYRD D & RA	2	11
TOTAL	43	60

Key: DIAB = Diabetes, HYPERT = hypertension
THYR D = Thyroid disease, RA = Rheumatoid arthritis

TABLE IX

PARTICIPANTS IN SCHEMES BY SCHEME'S SPECIALTY

Type of Scheme	Cases	Controls	TOTAL
Diabetes Only	12	7	19
Hypertension Only	2	3	5
Thyroid D "	3 +	3	6
R A "	2	8	10
Hyper & Thyro "		1	1
Diabet & Hyper		1	1
TOTAL	19 *	23 **	42

* One "case" was not involved in schemes, he was responsible for diabetic patients.

** 1 consultant who was involved with the care of diabetics, hypertensives and patients with thyroid disease did not say for what condition he had participated in a scheme.

\+ 1 responsible for the care of diabetics had been involved in shared care schemes for thyroid disease.

TABLE X

Number of characteristics of shared-care found in the schemes of those doctors who said they had participated and in those who said they had not.

No characteristics in the Scheme	Those who said they had participated		TOTAL	Those who said they had not participated		TOTAL
	CASES	CONTROLS		CASES	CONTROLS	
4	6	4	10	1	1	2
3	7	5	12		1	1
2	4	4	8		3	3
0-1	2	11	13		54	54
TOTAL	19	24	43	1	59	60

TABLE XI

GP RESPONDENTS BY REGIONAL HEALTH AUTHORITY/HEALTH BOARD

	REGIONAL HEALTH AUTHORITY AND HEALTH BOARD											
	TRENT	EAST ANGLIAN	NORTH EAST THAMES	SOUTH EAST THAMES	WESSEX	WEST MIDLANDS	NORTH WESTERN	WALES	G.G.H.B.	GHB	FVHB	TOT
Letters sent	26	39	13	13	26	26	13	13	13	13	13	208
Reply at first contact	14	19	2	7	14	9	3	8	7	8	3	94
Reply afte reminder	3	6	4	4	6	9	1	1	1	1	4	40
TOTAL REPLY	17	25	6	11	20	18	4	9	8	9	7	134
RESPONSE RATE %	65	64	46	85	77	69	31	69	62	69	54	64

Key: GGHB = Greater Glasgow Health Board
GHB = Grampian Health Board
FVHB = Forth Valley Health Board

TABLE XII

GP PARTICIPANTS IN SHARED-CARE SCHEMES BY REGIONAL HEALTH AUTHORITY

PARTICIPANTS IN SCHEMES	TRENT	EAST ANGLIAN	NORTH EAST THAMES	SOUTH EAST THAMES	WESSEX	WEST MIDLANDS	NORTH WESTERN	WALES	GGHB	GHB	FVHB	TOTAL
NO	15	19	5	4	9	17	4	4	6	0	5	88
YES	2	6	1	7	11	1	0	5	2	8	2	45
TOTAL	17	25	6	11	20	18	4	9	8	8	7	133*
Particpation Percentage	12	24	17	64	55	6	0	6	3	100	29	34

* 1 GP did not answer the question about participation in schemes.

$X^2 = 40.3$; df = 10; $p<0.0001$

Key: GGHB = Greater Glasgow Health Board
GHB = Grampian Health Board
FVHB = Forth Valley Health Board

TABLE XIII

CURRENT ORGANISATIONAL METHOD OF FOLLOW-UP FOR PATIENTS WITH CHRONIC DISEASE IN GENERAL PRACTICE

CONDITION	NO ARRANGEMENTS		MINI-CLINICS		SH/C & SH/C + MINI-CL		OTHERS		TOTAL
	N	%	N	%	N	%	N	%	
DIABETES	28	21	48	36	39	29	18	13	133
HYPERT	49	37	46	35	13	10	23	18	131
THYROID D	73	56	12	9	15	12	30	23	130
R A	86	68	6	5	14	11	21	17	127

TABLE XIV

GP PARTICIPANTS IN SHARED-CARE SCHEMES AND CURRENT METHOD OF FOLLOW-UP.

GENERAL PRACTITIONERS	CURRENT METHOD OF FOLLOW-UP: SHARED-CARE			
	HYPERT	DIAB	THY	RA
Those who said they had not participate (n=88)	3	17	5	8
Those who said they had participated in one scheme (n=30)	4	15	4	1
Those who said they had participated in more than one (n=15)	6	7	6	5
TOTAL	13	39	15	14

TABLE XV

WHO IS RESPONSIBLE FOR MAKING CONTACT AFTER A PATIENT NON-ATTENDANCE? NUMBERS (%) STATING CLINIC OR OTHER, BY CASE AND CONTROL

	CLINIC	OTHERS *	TOTAL
Cases	16 (80)	4 (20)	20
Controls	42 (51)	40 (48)	82
TOTAL	58	44	102**

* Others include: GP, Health Visitor and Patient

** One consultant did not answer this question

$X^2 = 5.4$; df = 1 $P < 0.05$

TABLE XVI

WHO IS RESPONSIBLE FOR MAKING CONTACT AFTER A PATIENT NON-ATTENDANCE?
NUMBERS (%) STATING CLINIC OR OTHER BY A CLAIMED PARTICIPANT AND NON-PARTICIPANT

	CLINIC	OTHERS *	TOTAL
Claimed Participants	30 (70)	13 (30)	43
Claimed Non Participants	28 (47)	31 (52)	59
TOTAL	58	44	102 **

* Others include : GP, Health Visitor and patient
** 1 consultant did not say if he had participated.
$X^2 = 5.04$; $df = 1$; $p<0.05$.

TABLE XVII

WHO IS RESPONSIBLE FOR MAKING CONTACT AFTER A PATIENT NON-ATTENDANCE? NUMBERS (%) STATING CLINIC OR OTHER, BY CLASSIFIED PARTICIPANTS AND NON-PARTICIPANTS

	CLINIC	OTHERS *	TOTAL
CLASSIFIED PARTICIPANTS	16 (72)	6 (27)	22
CLASSIFIED NON-PARTICIPANTS	27 (50)	26 (49)	53 **
TOTAL	43	32	75

$X^2 = 3.02$; df = 1; $p > 0.05$

* Others include: GP, health visitor and patient

** One doctor did not answer the question.

TABLE XVIII

WHO SHOULD MAKE CONTACT AFTER A PATIENT NON-ATTENDANCE IN PRIMARY CARE? NUMBERS (%) STATING PATIENT AND SOMEONE IN THE PRIMARY CARE TEAM, BY PARTICIPANTS IN SHARED-CARE

PARTICIPANTS	PATIENT	SOME ONE IN THE PRIMARY CARE TEAM	TOTAL
NO	43 (49)	44 (50)	87
YES	15 (33)	30 (66)	45
TOTAL	58	74	132

$X^2 = 3.1$ df = 1; $p = 0.08$

TABLE XIX

WHO SHOULD MAKE CONTACT AFTER A PATIENT NON-ATTENDANCE. NUMBERS (%) STATING PATIENT AND SOMEONE IN THE PRIMARY CARE TEAM, BY CONSULTANTS AND GPS

DOCTOR	PATIENT	HEALTH PROFESSIONAL (1)	TOTAL
CONSULTANT	6 (6)	96 (94)	102 *
GP	58 (44)	75 (56)	133 *
TOTAL	64	171	235

* 1 Consultant & 1 GP did not answer this question.
$X^2 = 41.5$; df = 1; $p < 0.0001$

(1) Health Professional includes GP and health visitor if the doctor is a consultant and other members of primary care team if the doctor is a GP.

TABLE XX

WHO HAS THE MAIN RESPONSIBILITY FOR SCREENING FOR COMPLICATIONS? NUMBER (%) STATING VARIOUS OPTIONS, SHOWING CASES AND CONTROLS

CONSULTANTS	HA	CONS	GP	GP/CONS	OTHERS	TOTAL
"CASES"	-	6 (32)	2 (10)	7 (37)	4 (21)	19
"CONTROLS"	4 (5)	10 (12)	20 (24)	43 (52)	6 (7)	83
TOTAL	4	16	22	50	10	102

X = 9.7; df=4; $p<0.05$

TABLE XXI

WHO HAS THE MAIN RESPONSIBILITY FOR SCREENING FOR COMPLICATIONS? NUMBERS (%) STATING VARIOUS OPTIONS, SHOWING CLASSIFIED PARTICIPANTS AND NON-PARTICIPANTS

CONSULTANTS TOTAL	HA	CONS	GP	GP/CONS	OTHERS	
CLASSIFIED PARTICIPANTS	-	6 (29)	3 (14)	6 (29)	6 (28)	21*
CLASSIFIED NON-PARTICIPANTS	3 (5)	4 (7)	17 (32)	27 (50)	3 (5)	54
TOTAL	3	10	20	33	9	75

* 1 Consultant did not answer this question
X^2=16.2; df=4; $p<0.005$.

TABLE XXII

WHO HAS THE MAIN RESPONSIBILITY FOR SCREENING FOR COMPLICATIONS? NUMBER (%) STATING VARIOUS OPTIONS, SHOWING GPS PARTICIPANTS AND NON-PARTICIPANTS

GPS	HA	CONS	GP	GP/CONS	OTHERS	TOTAL
PARTICIPANTS	2 (4)	2 (4)	7 (15)	34 (75)	-	45
NON-PARTICIPANTS	7 (8)	2 (2)	20 (23)	53 (60)	6 (7)	88
TOTAL	9 (12)	4 (6)	27 (38)	87 (135)	6 (7)	133*

* One GP did not say if he was a participant.
$X^2 = 5.9$; df = 4; $P<0.05$

Keys: HA = Health Authority/Health Board
Cons = Consultant

TABLE XXIII

WHO HAS THE MAIN RESPONSIBILITY FOR SCREENING FOR COMPLICATIONS? NUMBER (%) STATING VARIOUS OPTIONS, SHOWING CONSULTANTS AND GPS

DOCTOR	HA	CONS	GP	GP/CONS	OTHERS	TOTAL
CONSULTANTS	4 (4)	16 (16)	22 (21)	50 (49)	10 (10)	102*
GPS	9 (7)	4 (3)	27 (20)	88 (66)	6 (4)	134
TOTAL	13	20	49	138	16	236

* 1 Consultant did not answer this question
$X^2 = 17.1$; df = 4; $p<0.005$

Keys: Cons = Consultant
HA = Health Authority

TABLE XXIV

WHAT IS THE CONSULTANT'S ROLE IN THE CARE OF CHRONIC PATIENTS? NUMBER (%) STATING ADVISORY OR ACTIVE ROLE BY "CASES" AND "CONTROLS"

CONSULTANTS	ADVISORY ROLE	ACTIVE APPROACH	TOTAL	
CASES	3 (15)	17 (85)	20	(100)
CONTROLS	46 (56)	36 (44)	82	(100)
TOTAL	49 (48)	53 (52)	102	

$X^2 = 9.3$; df = 1; $p < 0.005$

TABLE XXV

WHAT IS THE CONSULTANT'S ROLE IN THE CARE OF CHRONIC PATIENTS? NUMBER (%) STATNG ADVISORY OR ACTIVE ROLE, BY CLAIMED PARTICIPANTS AND NON-PARTICIPANTS

CONSULTANTS	ADVISORY ROLE	ACTIVE APPROACH	TOTAL
PARTICIPANTS	15 (35)	28 (65)	43
NON PARTICIPANTS	34 (58)	25 (42)	59
TOTALS	49	53	102

$X^2 = 4.3$; df = 1; $p < 0.05$

TABLE XXVI

WHAT IS THE CONSULTANT'S ROLE IN THE CARE OF CHRONIC PATIENTS? NUMBER (%) STATING ADVISORY OR ACTIVE ROLE BY CLASSIFIED PARTICIPANTS AND NON-PARTICIPANTS

CONSULTANTS	ADVISORY ROLE	ACTIVE APPROACH	TOTAL
CLASSIFIED PARTICIPANTS	4 (18)	18 (82)	22
NON-PARTICIPANTS	31 (58)	22 (42)	53 *
TOTAL	35	40	75

* 1 consultant did not answer this question.
$X^2 = 10.1$; df = 1; $p<0.005$

TABLE XXVII

WHAT IS THE CONSULTANT'S ROLE IN THE CARE OF CHRONIC PATIENTS? NUMBER (%) STATING ADVISORY OR ACTIVE ROLE BY CLASSIFIED PARTICIPANTS AND NON-PARTICIPANTS

PARTICIPANT	ADVISORY ROLE	ACTIVE APPROACH	TOTAL
NO	56 (63)	32 (36)	88 (100)
YES	24 (53)	21 (46)	45 (100)
TOTAL	80 (60)	53 (40)	133* (100)

* 1 GP did not answer this question
$X^2 = 1.3$; df = 1; $p=0.25$

TABLE XXVIII

WHAT IS THE CONSULTANT'S ROLE IN THE CARE OF CHRONIC PATIENTS? NUMBER (%) STATING ADVISORY OR ACTIVE ROLE SHOWING CONSULTANTS AND GPS.

DOCTOR	ADVISORY ROLE	ACTIVE APPROACH	TOTAL
CONSULTANTS	49 (48)	53 (52)	102*
GPs	80 (60)	53 (40)	133**
TOTAL	129	106	235

* 1 consultant did not answer this question.
** 1 GP did not answer this question.
$X^2 = 3.4$; df = 1; $p = 0.06$

TABLE XXIX

WHO SHOULD BE THE INITIATOR OF SHARED-CARE SCHEMES? NUMBER (%), STATING VARIOUS OPTIONS, SHOWING GPS PARTICIPANTS AND NON-PARTICIPANTS

PARTICIPANTS IN SCHEMES		INITIATOR			
	CONSULTANT	GP	HA	"OTHERS"	TOTAL
NO	48 (61)	16 (20)	7 (9)	8 (10)	79
YES	22 (50)	10 (23)	2 (4)	10 (23)	44
TOTAL	70	26	9	18	123
PERCENTAGE	57	21	7	15	100

$X^2 = 4.4$; df = 3; p = 0.2

TABLE XXX

RESPONSIBLE FOR ASSURING SCREENING BY INITIATOR OF THE SCHEME PERCENTAGES ARE GIVEN IN PARENTHESIS. (GPs)

	INITIATOR OF THE SCHEME				
RESPONSIBILITY	CONSULTANT	GP	HA	OTHERS	TOTAL
CONSULTANT	1 (25)	-	1 (25)	2 (50)	4
GP	12 (50)	8 (33)	1 (4)	3 (12)	24
HA	3 (37)	-	2 (25)	3 (37)	8
GP/CONSULTANT	54 (66)	15 (18)	4 (5)	9 (11)	82
OTHERS	1 (17)	3 (50)	1 (17)	1 (17)	6
TOTAL	71	26	9	18	124

$X^2 = 25.3$; df = 12; P=0.01

TABLE XXXI

INITIATOR OF THE SCHEME BY SCHEME SPECIALTY PERCENTAGES ARE GIVEN IN PARENTHESIS (GPs)

SCHEME SPECIALITY	INITIATOR GP	CONSULTANT	OTHERS	SCHEMES TOTAL
HYPERTENSION	4 (28)	9 (64)	1 (7)	14
DIABETES	7 (21)	23 (70)	3 (9)	33
THYROID D	4 (25)	8 (50)	4 (25)	16
RA	1 (11)	8 (89)	0 -	9
TOTAL	16	48	8	72
PERCENTAGES	22	66	11	100

ABLE XXXII

HARACTERISTICS OF SHARED-CARE SCHEMES WITH WHICH HOSPITAL CONSULTANTS IGHT OR MIGHT NOT TO BE INVOLVED

haracteristics of hared-care	No Answer	Prepared to	Have Developed	P Value
rotocols of Care				
Case"	3	4	13	
Control"	16	40	27	
articipant	6	14	23	p<0.05
on-participant	13	30	17	
tructured Records				
Case"	4	2	14	P<0.0001
Controls"	29	36	18	
articipant	9	8	26	
on-participant	24	30	6	p<0.00001
ospital or Health uthority Recall ystem				
Case"	3	5	12	p<0.00001
Controls"	39	34	10	
articipant	11	16	16	p<0.001
on-participant	31	23	6	
ospital Based atabase				
Case"	1	8	11	p<0.00001
Controls"	32	41	10	
articipant	6	20	17	
on-participant	27	29	4	p<0.00001
rganisation of ourses for GPs				
Case"	0	4	16	
Control"	7	26	50	
rticipant	1	8	34	
on-participant	6	22	32	p<0.05

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APPENDICES

APPENDIX I

CONSULTANT'S QUESTIONNAIRE

METHODS OF CARE FOR PATIENTS WITH CHRONIC DISEASE

ME ....

DRESS ....

....

r this questionnaire we are interested in patients either with abetes, hypertension, thyroid disease or rheumatoid arthritis. We ll use the phrase 'chronic disease' to refer to these.

r which of these conditions are you responsible?

abetes ☐ Hypertension ☐ Thyroid Disease ☐

eumatoid Arthritis ☐ None ☐

none, could you please indicate to whom I should send the estionnaire in your hospital?

N-ATTENDERS

. If a patient fails to attend your clinic once or twice who usually has responsibility for making (clinic-patient) contact? (Tick one box only).

Patient ☐ Clinic ☐ GP ☐ Other ☐ ____________________
(Please state)

. If a patient fails to attend your clinic repeatedly who usually has responsibility for making (clinic-patient) contact?

Patient ☐ Clinic ☐ GP ☐ Other ☐ ____________________
(Please state)

NG-TERM FOLLOW-UP

. Who do you think has main responsibility (even though someone else may do the screening) for ensuring that all patients in your area with chronic disease are screened for complications at regular intervals?

☐ Health Authority ☐ Consultant ☐ GP
☐ For some patients the GP/for some patients the consultant.
☐ Others ____
(Please state)

Here are the two different views of the role of the hospital consultant in the care of people with chronic disease. Which of the two would you give more support to?
(Tick only **one**). Add additional comments if you wish.

☐ The hospital consultant provides a specialist advisory service but the long term follow-up of patients is the joint responsibility of GP and patient.

☐ Not all GPs provide good follow-up of patients with chronic disease and it is necessary for hospital consultants to take a more active approach for all patients in the area.

GANISATION OF CARE

The White Paper is likely to encourage the setting up of special mini-clinics in general practice for different patient groups. Here is a list of possible ways that a HOSPITAL CONSULTANT may or may not be involved in general practice care of chronic disease. Tick all those which you **have done** or **would be prepared to do.**

	I've done	I'd be prepared to do
No involvement (apart from the usual referral process).	☐	☐
Jointly agree with GPs how often and in what way (protocols of care) patients should be screened for complications.	☐	☐
Develop structured records for use in hospital and in general practice.	☐	☐
Support General Practice care with a hospital or health authority based district wide recall system (ie not just clinic patients).	☐	☐
Support General Practice care with a hospital based database allowing scrutiny of 'annual' reviews and giving of advice to GPs.	☐	☐
Running continuing education courses for GPs about the latest ideas of care.	☐	☐

A number of centres run shared-care schemes eg for diabetes in Stirling, hypertension in the Glasgow Western Infirmary, thyroid disease in Scotland (SAFUR). Have you ever participated in a shared-care scheme for any chronic disease?

NO [ ]   YES [ ]   If YES, please specifiy condition.

....

. If you have participated in a shared-care scheme, who was the inititiator of such a scheme?

Consultant [ ]   GPs [ ]   Others [ ]

. Is it still running?

YES [ ]   NO [ ]

. If you tried to set up or participated in a shared-care scheme and it did not work, what were the reasons?

[ ] Consultants did not like the scheme.
[ ] GPs did not like the scheme.
[ ] Patients did not like the scheme.
[ ] Health Authority would not fund it/stopped funding it.
[ ] Other reasons ....
[ ] Further comments ....

....

0. Do you have any comments on the advantages and disadvantages of shared-care schemes vs mini-clinics vs traditional care?

....

....

....

....

THANK YOU FOR COMPLETING THE QUESTIONNAIRE

PLEASE RETURN IN THE PREPAID ENVELOPE.

APPENDIX II

GP'S QUESTIONNAIRE

METHODS OF CARE FOR PATIENTS WITH CHRONIC DISEASE

ME ....

DRESS ....

....

r this questionnaire we are interested in patients either with abetes, hypertension, thyroid disease or rheumatoid arthritis (RA). will use the phrase 'chronic disease' to refer to these.

N-ATTENDERS

. If a patient fails to attend a follow-up review once or twice who usually has responsibility for making (surgery-patient) contact? (Tick one box only).

Patient [ ]   GP [ ]   Other [ ] ____________ (Please state)

ONG-TERM FOLLOW-UP

. Who do you think should have the main responsibility for ensuring that all patients with chronic disease are screened for complications at regular intervals?

[ ] Health Authority   [ ] Consultant   [ ] GP
[ ] For some patients the GP/for some patients the consultant.
[ ] Others ____

. Here are three views of the role of the hospital consultant in the care of people with chronic disease. Which of the three would you agree? (Tick only **one**).

[ ] The hospital consultant provides a specialist advisory service but the type of long term follow-up for patients must be decided by the GP.

[ ] The follow-up of patients must be a co-operative arrangement between GPs and the specialist each with defined and agreed areas of responsibility. The consultant should not monitor the control of patients under GP care.

☐ The follow-up of patients must be co-operative arrangement between the GPs and the specialist each with a defined and agreed areas of responsibility and the hospital consultant should have a monitoring role regarding the degree of control and follow-up.

GANISATION OF CARE

e next few questions are about integrated shared-care schemes with spitals for chronic disease. By this we mean a scheme of which the aracteristics are:

s and consultants agreed protocols of care, structured records for use hospital and general practice, hospital or Health Authority based strict recall system supporting general practice, and sometimes, spital based databases for scrutiny of annual reviews and giving vice to GPs.

. Please tick if you have ever participated in a scheme such as this and indicate for which chronic disease.

☐ No

☐ One scheme ______________________________

☐ More than one scheme ____________________

. If yes, who was the initiator of the scheme?

	Hypertension	Diabetes	Thyroid	RA
GP	☐	☐	☐	☐
Consultant	☐	☐	☐	☐
Others	☐	☐	☐	☐

. Is it still running?

YES ☐ NO ☐

. If not, why? (Tick as many as apply)

☐ Consultants did not like the scheme.
☐ General Practitioners did not like the scheme.
☐ Patients did not like the scheme.
☐ Health Authority would not fund it/stopped funding it.
☐ Other reasons ....
☐ Further comments ....

....

Please tick the box which describes your <u>current method of follow-up</u> for patients with chronic disease.

	<u>Hypertension</u>	<u>Diabetes</u>	<u>Thyroid</u>	<u>RA</u>
No special arrangements	☐	☐	☐	☐
General Practice Mini-clinic	☐	☐	☐	☐
Integrated shared-scheme with hospital	☐	☐	☐	☐
Mini-clinics and integrated shared-care scheme	☐	☐	☐	☐
Others	☐	☐	☐	☐

In setting up integrated shared-care schemes with hospitals the <u>initiative</u> should come from: (Tick one only)

☐ Consultants
☐ GPs
☐ Health Authority
☐ Others ______________________________

0. Do you have any comments on the advantages and disadvantages of shared-care schemes vs mini-clinics vs traditional care?

....

....

....

....

THANK YOU FOR COMPLETING THE QUESTIONNAIRE

PLEASE RETURN IN THE PREPAID ENVELOPE.