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**THE DESIGN, IMPLEMENTATION AND EVALUATION
OF A SHARED-CARE SCHEME FOR HYPERTENSION**

IN 2 VOLUMES

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**Submitted for the degree of Doctor of Philosophy
to the Department of Public Health, University of Glasgow.**

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THE DEVELOPMENT, IMPLEMENTATION AND EVALUATION OF A SHARED-CARE SCHEME FOR HYPERTENSION

Summary:

Hypertension is a risk factor for stroke and for coronary heart disease but treatment could reduce the incidence of both. However, treatment is costly and requires lifelong follow-up. Current follow-up of hypertension is inadequate with duplication of medical work, inconsistencies in standards of care, poor information and inefficient use of resources.

Registers, clinical information systems, nurses, facilitators, community programs, mini-clinics and shared-care have all been used for the follow-up of hypertensive patients. Formal evaluation of the costs and benefits of these new methods of care is important and the cost-effectiveness of shared-care for hypertensive patients has not been examined.

The West of Scotland Shared-Care Scheme for Hypertension was developed to co-ordinate specialist, general practitioner and laboratory services. The patient carries a summary record and arranges annual reviews with his/her general practitioner after prompting by the Scheme. Results of annual review are screened by a specialist, the computerised medical records are updated and copies are sent to the general practitioner. A re-referral clinic visit is available at short notice if required.

The feasibility, acceptability and cost-effectiveness of the Shared-Care Scheme was compared with that of outpatient and nurse-practitioner care by measuring the number of complete reviews in year 2 for three comparable groups of 277 patients (SC, BPC and NPC groups respectively) as well as variables relating to health status, acceptability of each method and costs to the health service and to patients.

Over the two years the SC drop-out rate was significantly less than the BPC and NPC rates (3%, 14% and 9% respectively) and

the SC group had more complete reviews than the BPC group (82% versus 54%). There were no differences in self-perceived health status. Two thirds of the SC group apparently maintained or improved their blood pressure control over the two years. Seventeen people attended the re-referral clinic and all but 2 returned to shared-care. Mortality was similar in the three groups.

Only two general practitioners withdrew from shared-care and 61% wanted the Scheme to continue with a further 25% having no clear opinion. Shared-care increased the number of general practitioner visits by one per year but the patients in the BPC and NPC groups visited the clinic approximately twice per year. SC patients spent less time and money on attending the consultation, The Personal Health Booklet was used by almost all SC patients and only 4% did not like it. Approximately half of the patients preferred shared-care to outpatient care while 22% had no preference. Around one third of general practitioners preferred shared-care but two thirds preferred their own routine care.

The cost-effectiveness ratios for total costs were £28.96, £50.55 and £30.95 per successful review for the SC, BPC and NPC groups respectively; the SC cost is based on a generous twenty-minute consultation. Shared-care was most cost-effective for patients, the NP clinic was most cost-effective for the NHS. The annual medicine cost is £160.60 for a shared-care patient, £142.35 for a BPC patient and £156.95 for an NPC patient. Including the costs of medicines does not change the ranking of the ratios.

The conclusion drawn is that shared-care is acceptable to a majority of patients and general practitioners, provides a cost-effective way of ensuring patient follow-up, standardises care, improves specialist coverage of the population and provides the basis for ongoing evaluation of patient care.

THE DESIGN, IMPLEMENTATION AND EVALUATION OF A SHARED-CARE SCHEME FOR HYPERTENSION

CHAPTER ONE: INTRODUCTION AND STRUCTURE OF THE THESIS

This thesis describes the design, implementation and evaluation of a shared-care scheme for hypertensive patients set up in 1986 in Glasgow. The study began in 1985 as a proposal by four academic researchers in the University of Glasgow, Professor AJ Hedley, Department of Community Medicine, Dr GT McInnes, Department of Medicine, Dr TS Murray, Department of General Practice and Professor JL Reid, Department of Materia Medica. A shared-care scheme was to be set up as a pilot study and evaluated for feasibility, acceptability, effectiveness and cost by comparison with two existing methods of follow-up - a traditional outpatient clinic and a nurse-practitioner clinic. The proposal was funded by the Chief Scientist's Office, Scottish Home and Health Department over four years and the British Heart Foundation provided a grant for hardware and software.

I was appointed as Project Leader in 1985 to design, implement and evaluate the shared-care scheme, in collaboration with the Steering Group. This included managing the Project, setting and evaluating the specific operational objectives, day-to-day problem solving, liaison with the members of the Steering Group, the consultants, general practitioners and laboratory staff involved in the Project, organising and chairing Steering Group and other meetings, designing the medical records and project protocols and designing and implementing the evaluation framework, including the economic appraisal. For the latter, I completed the Certificate in Health Economics with the Health Economics Research Unit, Aberdeen. Also necessary for this role were research methodology, programming and data processing skills which were gained both formally and informally. I analysed the collected data and reported the results of the evaluation to the funding bodies in March 1990. Several presentations of the findings have been given; the

principal papers are in Appendix 2. In 1991, the Shared-Care Scheme is being operated by the Glasgow Blood Pressure Clinic; it is being further developed and information about the potential of this approach is still being actively disseminated.

This thesis describes the background, design, implementation and evaluation of the pilot scheme. The structure of the thesis is as follows:

Background

Chapter 2 presents a review of the literature concerning the problem of hypertension with particular reference to Glasgow and the West of Scotland. It assesses the current effectiveness of delivery of care to hypertensive patients, summarises current knowledge about treatment and follow-up of hypertension and the reasons why follow-up may fail. It describes alternative approaches to follow-up for chronic conditions, including shared-care. Finally, it reviews methods which can be used to evaluate alternative arrangements for delivery of care and summarises the extent to which these methods have been applied to shared-care.

Chapter 3 describes the existing system for care of people with hypertension in Greater Glasgow Health Board in 1985/1986 when this study began. It describes, in some detail, the workload of the Glasgow Blood Pressure Clinic and the results of some initial investigations carried out prior to the design of shared-care. It presents the results of pilot studies of the methods of patient selection and the acceptability of the concept of shared-care and the medical records to general practitioners.

Methods

Chapter 4 describes the hardware, software, documents, procedures and operation of the West of Scotland Shared-Care Scheme for Hypertension. It states the aim and specific

objectives of the evaluation, describes the populations and recruitment methods and the statistical analysis. The framework of the evaluation is summarised under the headings of effectiveness, acceptability, cost-effectiveness and feasibility; sources of data are listed and the development, piloting and response to the questionnaires are discussed.

Results

Chapter 5 is the first of the results sections and deals with the **effectiveness** of shared-care, the outpatient clinic and the nurse-practitioner clinic. The initial section of the chapter gives further detail of the methods used. The results are then presented and the findings discussed.

Chapter 6 describes in more detail the methods used for the measurement of **acceptability** of shared-care. The results are then presented and discussed.

Chapter 7 deals with the **economic** evaluation. The methods of costing are presented along with the resulting estimates of costs to the National Health Service and to patients. These are combined and, with the results of the evaluation of effectiveness reported in Chapter 5, they are used to derive cost-effectiveness ratios for each method of care. The final parts of this chapter discuss the validity of the methods used, the findings and their implications for use of resources.

Discussion and conclusions

Chapter 8 draws together results from Chapters 5, 6 and 7 and discusses the **feasibility** of shared-care, its future development and ongoing evaluation. It attempts to derive implications for other chronic diseases and for the care of hypertensive patients in the longer term. The whole evaluation is discussed and suggestions for the next steps in this area of health services research complete the main report.

CHAPTER TWO: REVIEW OF THE LITERATURE

2.1 HYPERTENSION

Summary: Hypertension is a major risk factor for stroke and a risk factor, with age, smoking and cholesterol level for coronary heart disease. Raised blood pressure presents a continuum of risk but its effect on the risk of stroke is at least partly reversible. The treatment of hypertension could, in theory, reduce the incidence of stroke and coronary heart disease events by 50% and 20%-30% respectively. Optimal benefit on coronary heart disease mortality is likely to be obtained if hypertension is managed within a multifactorial risk profile. Anti-hypertensive drug therapy requires careful monitoring due to possible loss of control of blood pressure and side effects and is normally lifelong although some practitioners recommend stopping therapy and observing the patient. The cost of treatment is high and non-pharmacologic treatments remain to be proven.

2.1.1 The size of the problem:

"Hypertension presents the single biggest problem in continuing primary care" (Hart 1987).

Hypertension (ie sustained high blood pressure) is a common chronic condition afflicting between 5% and 20% of the population and is a major risk factor for arterial disease, particularly ischaemic heart disease and stroke (Schofield 1987). It is also an independent risk factor, with age, smoking habit and total cholesterol concentration for coronary heart disease (CHD) (Heller et al 1984).

A recent UK survey found 14.3% of males and 12.5% of females of all ages to be either on anti-hypertensive treatment or have a blood pressure greater than or equal to 160/95mmHg (Health Promotion Research Trust 1987). The rates for Scotland were 13.7% and 11.7% respectively. Schofield (1987) estimated that 3.9% men

and 5.5% women between the ages of 35 and 65 in the United Kingdom (UK) had even higher blood pressure levels of greater than or equal to 170/110mmHg with 30% of men and women having diastolic pressures between 90-109mmHg.

In the West of Scotland, a case-finding survey was carried out in general practices in 1985 involving a total patient population of sixty-nine thousand (Gilmore & Barber 1985). The investigators succeeded in screening 52% of the target age group of 35 to 64 year olds and found 10% of screened men and women to have diastolic blood pressure between 90 and 109mmHg while 4% had diastolic pressure greater than 109mmHg. Of those who were already being treated for hypertension (10% of the screened group), 20% had diastolic pressure greater than 109mmHg; while 52% of the newly detected (4% of the screened group), had the same diastolic pressure.

Even in comparison with other common chronic conditions, hypertension is a widespread problem. For example, Fry (1983) estimated that 18.7 people per thousand consult their general practitioner for hypertension compared with 4.5 per thousand for diabetes and 11.5 per thousand for chronic bronchitis.

2.1.2 The attributable risk associated with hypertension

Stroke: The relationship of stroke with blood pressure has now been well established; indeed, high blood pressure is the most important known risk factor for stroke in otherwise healthy people. It is estimated that one third of strokes occur in those with diastolic blood pressure greater than 90mmHg and 50% in those with systolic pressure greater than 160mmHg (Kannel 1975). Many of these strokes occur in those over 65 years old. Rose (1981) calculates that of the stroke deaths in men aged 55-64 which can be attributed to high blood pressure, 25% occur in those with diastolic blood pressure below 99mmHg, 52% between 100 and 109mmHg and 27% in those with pressure greater than 110 mmHg. This distribution reflects the higher risk but lower prevalence of the higher blood pressure levels.

Myocardial infarction: In women, smoking is apparently the most important independent risk factor for acute myocardial infarction (MI) (Croft & Hannaford 1989) but has a strong influence in association with other factors such as hypertension, toxæmia of pregnancy and diabetes. The risk of MI in both sexes rises with the level of blood pressure. The relative risk (RR) of developing coronary heart disease with a pressure greater than 159/94mmHg is 2.9 for a male and 2.7 for a female (Kannel 1988). However, the risk of developing CHD in both sexes is also related to serum cholesterol levels, glucose intolerance, cigarette smoking and ECG abnormalities and the combined effects of these risk factors are more than additive. For example, a systolic pressure of 180mmHg carries a RR of 1.5, raised cholesterol has RR of 1.4 and smoking 1.4 individually. For someone with all three, the RR is approximately 7 (estimated from Kannel 1988).

Of the attributable MI deaths in men aged 55-64, 47% occur in those with diastolic blood pressure below 99mmHg, 20% between 100 and 109mmHg and 33% in those with pressure greater than 109mmHg (Rose 1981). The effect of blood pressure level on risk of MI is less pronounced than on risk of stroke. However, because of its much greater incidence, CHD is the commonest sequela of hypertension.

In a recent re-analysis of the data from several large studies, MacMahon et al (1990) estimate that a 7.5mmHg difference in usual diastolic blood pressure is associated with a 46% difference in the risk of stroke. The same difference in diastolic blood pressure is apparently associated with a 29% difference in risk of coronary heart disease. These differences seem to apply no matter what the level of usual blood pressure.

Between them, cerebrovascular disease (ICD 430-438) and coronary heart disease (ICD 410-414) account for a greater number of deaths in Greater Glasgow Health Board (GGHB) than any other condition. The figures for 1985 are shown in Table 1. The treatment of victims of stroke and coronary heart disease accounts

for over 20% of all hospital beds occupied at any one time in Scotland (ISD 1986) with stroke accounting for 75% of these. The resulting residual disability places a burden on medical and social services as well as on victims and their families (Editorial 1976).

2.1.3 Potential benefits from the treatment of hypertension

High blood pressure is usually symptomless and self-accelerating unless controlled (Hart 1987). It presents a continuum of risk with no clear cut-off points for treatment; the lower the blood pressure, the lower the risk (Pickering 1968). The effect of high blood pressure on the risk of stroke is apparently reversible, at least to some extent. Hart estimated that current methods of blood pressure control might prevent 45% of the strokes attributable to high blood pressure and in the re-analysis of the data from randomised trials of anti-hypertensive treatments, Collins et al (1990) agree with a figure of approximately 50% of strokes being prevented by treatment. They also suggest that almost all of this reduction in attributable stroke mortality is achieved rapidly, within two to three years of pressure reduction.

The benefit of blood pressure reduction on coronary heart disease is less certain than that for stroke at present. The Medical Research Council trial (MRC Working Party 1988) indicated that around half the expected MIs in non-smoking, high-risk men might be prevented with propranolol treatment; no evidence of benefit was shown on MIs in any other group of individuals. Collins et al estimate that 20%-30% of fatal CHD events might be preventable with treatment for high blood pressure and they found no evidence that non-fatal events were different (Collins et al 1990). They suggest that about half of any expected reduction in CHD mortality may be achieved over the first two to three years.

In practice, however, the Glasgow Blood Pressure Clinic mortality study suggested that antihypertensive treatment in an outpatient clinic did not fully normalise the risk of high blood pressure (Isles et al 1986). It has been suggested that part of the reason may be other CHD risk factors, with the top 15% of a multifactorial CHD

risk distribution contributing 32% of the MI cases in the succeeding five years. A further reason may be sub-optimal treatment and management.

2.1.4 Treatment of hypertension

When to treat: The level at which blood pressure is treated has changed as information on the effects of treatment has become available. However, opinion is likely to vary between doctors because of differences in knowledge and assessment of acceptable risks. In an attempt to offer guidance to practitioners, Hart (1987) has deduced, from recent trials, that 175/105 mmHg represents a pressure above which a steep rise in individual risk begins and therefore at which treatment should definitely be initiated. Below this level, treatment should be considered when there are other factors such as end-organ damage. There is some controversy over the benefits of blood pressure reduction in those with ischaemia (Cruickshank 1989, McInnes 1989).

Who to treat: All of the data used for the estimation of attributable risk comes from large studies and applies to populations. While a small reduction in overall risk of stroke may be important in population terms in that it prevents a significant number of deaths, at the individual level it results in many people taking antihypertensive medication when their personal risk of a morbid event is low. This means that deciding whether or not to treat a mildly hypertensive patient can be difficult.

Drug treatment: In the past, the antihypertensive drugs used often had severe side-effects but newer drugs are safer and more effective than their predecessors; this has given non-specialists more confidence in treating hypertension. However, opinions on optimum drug treatment methods vary and there is a great deal of literature on this subject. Some aspects of drug treatment which are relevant to the delivery of care to hypertensive patients are discussed here.

Stepped-care: In many cases, high blood pressure cannot be adequately controlled on a single drug. A "stepped-care" method is often adopted where drugs are added one by one until blood pressure is controlled (Swales 1985). If control is subsequently lost, further adjustment of treatment may become necessary. Thus drug therapy can be a continually changing process requiring careful monitoring, at least in the early stages of treatment.

Supervised withdrawal: Treatment is usually considered lifelong (Consumers' Association 1988) and hypertension can recur if drugs are withdrawn. However, some practitioners now believe that withdrawal of drugs should be attempted in the hope that it may prove successful. This again requires careful monitoring.

Non-pharmacologic treatments: Stress reduction and weight reduction have been recommended in place of drug treatment for hypertension (Editorial 1985, Patel and Marmot 1988). These are often cheaper than drug treatment and have fewer side-effects. However, while weight reduction has been shown to be successful in reducing blood pressure, the efficacy of other methods is, as yet, unproven (Consumers' Association 1988).

All of the above factors stress the importance of careful follow-up of those patients being treated.

Costs of treatment: The treatment of hypertension is costly. The cost of drugs alone was estimated at £100 million in the UK per annum in 1987 (Schofield 1987). To this must be added the other costs of treating hypertension; these have been identified by Jachuck (1982) as staff costs, other NHS costs and patient costs - monetary, physical (for example, drug side-effects), social and psychological.

Medical workload: The management of hypertension and other chronic conditions accounts for a large proportion of a general practitioner's time. Fry (1983) calculated that approximately 10% of an average practice population of 2500 would have hypertension;

between 4% and 18% of the population may require intervention and life-long follow-up, depending on treatment criteria (Hasler 1987).

Management of hypertension is also undertaken in some specialist medical clinics and occasionally by inpatient services. Even when followed-up in a specialist clinic, patients will also attend their general practitioner. Bulpitt, Raymond & Dollery (1982) carried out a trial of outpatient care versus general practitioner care and counted 4.9 outpatient consultations plus 8.7 general practitioner consultations for each patient in the outpatient group over two years. The number of new outpatient attendances at one hypertension clinic in Glasgow in 1986 was 168 with 2228 return attendances per year (unpublished statistics, Glasgow Blood Pressure Clinic). The policy at this clinic was to continue specialist follow-up indefinitely. This continuous monitoring generates large workloads for the outpatient clinic.

In conclusion, there have been recent improvements in knowledge about high blood pressure and its treatment; however, some uncertainty remains over the attainable benefits. Treatment has high monetary and non-monetary costs. It is likely that treatment and knowledge of the condition will continue to improve. However, benefits of new treatments will not be realised unless they can be translated into improved practice. The next section assesses the delivery of care to hypertensive patients.

2.2 DELIVERY OF CARE TO HYPERTENSIVE PATIENTS - A CURRENT PERSPECTIVE

Summary: The "rule of quarters" appears to hold in published surveys of the detection and management of hypertension. Current practice does not apparently match published guidelines or targets for screening of populations, investigations before and during treatment and maintenance of follow-up in general practice or specialist clinics. Some of the identified factors in the poor delivery of care are: lack of co-ordination at the primary/secondary care interface, lack of systematic follow-up, patient drop-out and non-adherence to treatment regimens and poor information in medical records. These result in the inefficient use of available resources.

2.2.1 Introduction

The previous section has shown that a significant amount of morbidity and mortality attributable to hypertension could, in theory, be prevented. However, improved medical procedures and treatment will not result in lower morbidity and mortality unless translated into effective practice. There is evidence that the current delivery of care to hypertensive patients is not effective.

The **rule of halves** (Figure 1) was drafted after the Framingham study in the United States and describes the unsatisfactory situation where half of the hypertensive individuals were undetected, half the detected were untreated and half the treated were uncontrolled. A review of recent surveys in the UK shows that we are not far from the **rule of quarters**. For example:

Number of hypertensives detected: In the West of Scotland in 1985, 14% of a screened, adult population had diastolic blood pressure greater than 90mmHg (Gilmore & Barber 1985). Of these, 28% were newly detected of whom half had diastolic blood pressure greater than 110mmHg; that is, nearly one quarter to one third of the hypertensives in this survey were previously undetected.

Number of detected who are treated: When a high blood pressure was recorded in general practice in Heller and Rose's study (1977), only 60% had a further blood pressure noted. In a study in London, Kurji and Haines (1984) found that 16% of those with a raised blood pressure were not followed up at all. Thus between 16% and 40% of those initially detected were not treated or monitored.

Number of treated who are well-controlled: Surveys have shown that many of those on treatment have unsatisfactory blood pressure control (Russell et al 1983, Curzio et al 1987, DHSS 1982). For example, in the DHSS Project which monitored the care of hypertensive patients in various parts of the UK, 13% of outpatients and 26% of general practitioner patients had diastolic blood pressures greater than 105mmHg.

We could add a further sub-division to Figure 1: that a proportion of those controlled on treatment are not followed up. For example, drop-out from regular follow-up amounts to around 8% per year in traditional outpatient clinics (Russell et al 1983). Bulpitt et al (1982) showed a loss from organized follow-up of 10% for outpatient attenders and 6% for general practitioner patients over two years.

Various groups and individuals have drafted guidelines of recommended practice for the detection, treatment and follow-up of hypertensive patients; these are summarised in Table 2. In order to determine whether and where deficiencies in the delivery of care might contribute to ineffectiveness, current practice as determined from the published literature is compared with that recommended in the guidelines.

2.2.2 Audit of delivery of care:

Recommendation: all adults should have their blood pressure measured at least every 5 years.

From 1977 (Heller & Rose) to 1986 (Grout) there has been a steady rise in the percentage of adult general practitioner attenders

reported to have any blood pressure recordings in their notes (for example Michael 1984, Kurji & Haines 1984). Even so, the best that Grout could report was 65% in one practice while another practice only achieved 34%.

Recommendation: Before starting treatment, all patients should have at least three blood pressure measurements.

Because of the unreliability of single blood pressure readings, it is recommended that three measurements of blood pressure are taken before treatment is started. However, around 30% of general practice patients were started on treatment after only one blood pressure reading (Parkin et al 1979, Taffinder & Taffinder 1984) - a "reckless gamble" according to Hart (1987).

Recommendation: Blood pressure control should aim for a diastolic pressure of less than 95mmHg.

Parkin et al, in 1979, found that only 66% of general practitioners stated that they aimed to maintain a diastolic pressure of less than 95 mmHg in 40-60 year old hypertensives and that overall, general practitioners were not even achieving their stated aims in blood pressure control. Other studies have shown that general practitioners disagree over what blood pressure to aim for and about how to measure it. Fulton et al's study of general practitioners in Lothian (1979) showed a wide variation in target blood pressures. More recently, Bucknall, Morris & Mitchell (1986) found disagreement over whether phase 4 or 5 should be used to measure blood pressure with a possible difference of 5mmHg in diastolic readings at different phases. If general practitioners use different phases to measure blood pressure, even if the same apparent cut-off point is used for treatment, they estimate a difference of 10% in the number of patients treated.

Recommendation: All treated hypertensives should have their blood pressure measured approximately every three months and those not on treatment every year; all treated hypertensives should have regular screening for biochemical and ECG abnormalities.

Hypertensive patients need continuous monitoring for loss of blood pressure control, complications and metabolic effects. However, loss to follow-up from organized care can be high. In Degoulet's clinic, the loss was 15.5% in one year even when measures were taken to minimise non-attendance (Degoulet et al 1983). In one study in Michigan, 42 individuals were seen in a casualty department over one year with a hypertensive emergency after having dropped out of anti-hypertensive treatment (Caldwell et al 1970).

Deficiencies are reported in recorded clinical assessments of hypertensives in both outpatient clinics and in general practice. For example, in 1983, in Edinburgh hospitals, 87% of hypertensive outpatients had no height recorded, making the computation of BMI impossible, while 30% had no urea and electrolytes, urinalysis or ECG results (Russell et al 1983). Even so, the amount of investigation is higher in outpatient clinics than in general practice where Parkin et al, in 1979, found that 42% of cases managed by the general practitioner alone had no recorded investigations, over 60% had no urea and electrolytes or urinalysis and over 80% had no ECG result. Jachuck, Price and Bound (1984) found no mention of urinalysis or blood tests in 43% and of ECG in 32% of general practice patients. Kurji & Haines (1984) found no record of physical examination in 74% of treated hypertensives, no record of general practitioner-initiated investigations in 72% and no blood pressure reading for one or more twelve-month period in 69%. Neville & McKellican (1984) estimated that only one third of the hypertensives in a general practice were adequately managed.

As Van Veen (1980) said, "deficient care...(may be)..the major obstacle to controlling hypertension in the community". Even where doubt may exist over the effectiveness of treatment methods, there are strong ethical and economic arguments to ensure that the delivery of what is considered the current "best" is optimal. That this is not the case is indicated above; some of the possible reasons behind the reported deficiencies are now discussed.

2.2.3 Reasons for identified deficiencies in the process of care

Literature dealing with the delivery of care to patients with chronic illness identifies many reasons for poorer than optimal performance.

The treatment and follow-up of detected hypertension may fail for a number of reasons which include lack of information and inadequate record systems, poor communication between general practitioner and specialist or between doctor and patient, poor co-ordination between different sources of care, lack of policy, lack of organisation of follow-up procedures, lack of agreement about follow-up protocols and patient drop-out from follow-up.

Lack of successful blood pressure control in treated patients may result from patient non-adherence to treatment, inadequate investigation or review of blood pressure, the doctor's uncertainty about what blood pressure level to aim for or unavoidable clinical factors, for example, refractory hypertension.

And finally, an inability to monitor the process and outcome of delivery of care means that many of the above may not be apparent to practitioners.

Some of these factors are discussed in more detail because of their relevance to the current study.

Poor coordination at the primary/secondary care interface: Systems for coordination of care between general practice and specialist clinics do exist (see section 2.3) but are not widespread. Specialist care is recommended, for example, in cases of resistant hypertension or complications; guidelines for referral have been published (Padfield et al 1983). Nonetheless, there are very wide variations in the rates of referral for hypertension. For example, Parkin et al (1979) found differences of 32% between general practitioners in the number of hypertensives referred and Christie (1979) quotes 21%; that is, some general practitioners were referring one fifth to one third more patients to specialist care

than other general practitioners. This same variation is mirrored in all clinical specialties (Wilkin and Smith 1987) but, up till the point of starting this study, no studies had reported on the appropriateness of referrals for hypertension.

Furthermore, there has been a growing belief for some time that most hypertensive patients whose blood pressure is controlled could be satisfactorily cared for by their general practitioner (for example, Editorial 1979). Bulpitt et al showed, in 1982, that well-controlled hypertensive outpatients could be managed adequately when discharged back to their general practitioners. Russell et al estimated in 1983 that 10% of return outpatient attenders in one clinic were discharged back to their general practitioner in one year although their subsequent care was not audited. However, some patients are retained in outpatient clinics for follow-up when they already have well-controlled blood pressure and Parkin et al (1979) estimated that duplication of visits to a source of care was occurring in up to 82% of the attenders at an outpatient clinic.

Lack of systematic follow-up for chronic conditions: While Petrie, in 1978, felt that effective therapy to treat specific problems such as hypertension was available, he claimed that many of the potential benefits were lost because of the lack of systems to follow up patients. Jones, Hedley & Gale (1986) attempted to identify treated diabetic patients using prescriptions, general practice disease registers and medical records. They estimated under-reporting of 13%-24% and over-reporting of 13%-15% in the registers. The thyroid system, SAFUR (Scottish Automated Follow-Up Register), a computer-based follow-up system, had a 10 year cumulative loss of only 8% per year compared with conventional follow-up which lost up to 40% of patients over 10 years (Jones et al 1981); the health status of the lost patients was unknown.

Patient drop-out from treatment: Non attendance at consultations may be a waste of clinic resources and can be a cause of unnecessary morbidity. The causes may be simple. Features of the health-care system, for example, the site of care, can affect drop-out rates. When a tuberculosis service moved from a central site to

local sites, non-attendance dropped from 26% to 5% (Curry 1968). Reminders can be used to reduce non-attendance because patients sometimes simply forget to attend (Shepard & Moseley 1976). Moreover, some "non-attendance" is apparent, rather than real and due to administrative errors such as failing to record a cancellation. In Cardiff, poor communication and administrative errors were responsible for 17% of recorded non-attendance at a dental clinic (Evans & Murdock 1973).

Patient-related factors which have been related to drop-out from hypertension care include gender, marital status, age, obesity, cigarette smoking, patient-doctor relationship, convenience of the site, perceived seriousness of the condition and socio-economic factors (Degoulet et al 1983, Caldwell et al 1970, Gillum et al 1979, Strogatz & Earp 1983).

Patient non-adherence to treatment regimens: Patient non-adherence to therapy is often quoted as a major cause of failure of management (Degoulet et al 1983, Sackett et al 1975). Degoulet felt that successful medical management needed the combined resources of patient and doctor. Badenoch (1986) agrees and considers patient participation to be particularly important now when dangerous and complicated therapies are often administered and careful instruction and education are needed to make lifestyle changes. Misunderstanding by patients can account for some apparent "non-compliance" (Feely, Singleton & McGibney 1984). The doctor may fail to impress on the patient that treatment must be continued or the patient may not have sufficient perception of the seriousness of the condition or the treatment efficacy.

Poor information: Medical records are the information base for medical care; however, they are often inadequate for this purpose. For example, they tend to be orientated to institutions rather than to individuals and there might, therefore, be no-one who has an overall view of any individual patient's care (Dollery et al 1976).

Inaccuracy in records might account for some of the poor results obtained when hypertension care was audited. For example,

Jachuk, Price & Bound (1984) examined general practice records for indications of tuberculin skin test or BCG immunisation and found neither in 78% of records; however, 89% of patients had had one or both. The discrepancy between procedures carried out and results recorded was 67%. Unfortunately, it is impossible, with most medical records, to distinguish between unrecorded, probably normal, results and tests not done. However, on most occasions, the record is the only source of information available to medical staff and missing information could, therefore, have an adverse effect on patient care. Even though more investigation may be carried out than is actually recorded, poor quality records may be associated with poor quality care. A correlation was found, in an early study, between the number of items which were simply not recorded and the number of investigations not done (Rosenfeld 1957); poor recording and poor quality care may have a common basis.

Communication between doctors: Concern is often expressed over inaccurate drug information in traditional medical records and poor transfer of this information between professionals and with patients (Feely et al 1984, Price et al 1986, Beveridge & Petrie 1972, Claque & Elkington 1986). Possible consequences include over-prescribing, excess cost and iatrogenic disease. Many of the potential benefits of anti-hypertensive therapy may be lost because of unintentional drug interactions primarily due to poor communication between medical staff (Petrie 1978). The existence of separate sets of medical records encourages the development of inaccuracies. For example, Price et al (1986) found wide discrepancies between the drugs which hospital notes indicated that a patient was taking, those which general practitioner notes indicated and those which the patient was actually taking. Studies in general practice have highlighted the levels of inaccuracy in existing records in identifying details, diagnoses and drug information (Tomson 1985, Baldry et al 1986).

Registers: Good recording systems are vital to ensure continuous follow-up. Age-sex, "at-risk" and area registers for the follow-up of severe hypertensives have all been recommended so that

"forgetfulness" does not result in loss to follow-up (Editorial 1984a, Neville & McKellican 1984). However, there can be difficulties in maintaining the accuracy of these registers (see section 2.3).

Information for follow-up of individuals: Hannay, in 1972 found that almost half of a sample from a health centre in Glasgow had incorrect addresses recorded. He concluded that this health care system could not meet its objectives of patient care with this level of inaccuracy. Information systems built up from existing inadequate record systems will also suffer from the same inaccuracies and limited effectiveness.

Information for monitoring standards of care, for planning and research: The medical record is the only source of information for audit of care which is a vital step in the improvement of practice yet Shaw (1980b) considers existing general practitioner records inadequate for auditing patient care. The inadequacy of existing registers and sources of information also presents difficulties in monitoring patient care on a population basis. As already described, Jones et al (1986) had difficulty identifying diabetic patients because the available information was of poor quality with both over-reporting and under-reporting.

Inefficient use of resources: Hart (1984b) claimed that there are three levels of care - primary, secondary and none at all. The proportion of patients at each level has implications both for the effectiveness and for the cost of care. Since resources are limited, inefficiency and overtreatment of some patients leads to ineffectiveness and undertreatment of others. For example, in the case of a hospital clinic, if many patients are retained in the clinic unnecessarily, people who require specialist care must wait with possible deleterious consequences on health. Inappropriate targetting of care can also be a misuse of resources. Neville & McKellican (1984) found that what little effort was given to the follow-up of hypertension, in a particular general practice, was directed principally at females over 70; however, benefit from treatment in this group has not been shown.

The dual care system of specialist and general practitioner care can cause duplication of medical work, for example, in investigations and consultations. Parkin et al (1979) found that patients referred to hospital clinics had just as many tests carried out by their general practitioner as those not referred but the referred patients also had the tests carried out in hospital. Some repeat testing may be due to abnormal results but some is likely to be unnecessary duplication. Furthermore, of the patients still attending the outpatient clinic after a year, 82% also visited their general practitioner at 3 monthly, or shorter, intervals.

The failure to adequately monitor chronic conditions can be an inefficient use of resources (Wilkin et al 1987). The inadequately managed hypertensive patient may have serious ill health in later life and consume greater resources than would otherwise have been required. An economic evaluation of the cost-effectiveness of treatment for hypertension concluded that it would be more cost-effective to improve the existing follow-up systems than to extend care to further individuals (Stason & Weinstein 1977). Regardless of monetary cost, there is great social, psychological and physical cost to be paid for inadequate management. However, there is very little information available at present on the relative effectiveness and cost of different methods of organizing follow-up for chronic conditions (Wilkin et al 1987).

Figure 2 depicts these deficiencies in delivery of care. This review suggests the areas in which patient care could be improved. These include better information through better record systems, agreed protocols and policies, better patient and doctor education and motivation, agreed goals for blood pressure control, follow-up systems for investigation, recall and review procedures and better co-ordination of follow-up care.

We also need to incorporate more efficient procedures so that the available resources can be used to greater effect. We need to be able to audit the effectiveness of current methods of care and evaluate the cost-effectiveness of any new methods.

The next part of the review looks at ways of achieving improved delivery of care to hypertensive patients by describing various approaches used, not only for hypertension, but also for other chronic conditions such as diabetes.

2.3 ALTERNATIVE APPROACHES TO THE MANAGEMENT OF HYPERTENSIVE PATIENTS

Summary: The early use of registers for maintaining contact with patients and recording incidence and prevalence has given way to more sophisticated clinical information systems which have comprehensive databases and can be used for patient care. These have reduced losses to follow-up, improved information and stimulated more frequent clinical investigations. Nurses can improve aspects of preventive care and follow-up of chronic illness in general practice while being 'cheaper' than doctors. Facilitators, occupational and community programs have all shown some success in the follow-up of hypertensive patients while various arrangements in general practice such as mini-clinics have been shown successful for diabetes. Shared-care, which co-ordinates care from several sources for one individual has had variable success in several chronic disease areas.

Given the problems noted previously, in the long term follow-up of chronic illness, several alternative approaches to follow-up have been implemented.

2.3.1 Registers and Information Systems:

Registers have long been used for the collection of long-term patient information. Brooke (1974) states the two purposes of a register as

- a) maintaining contact with patients for follow-up, provision of medication and education and
- b) obtaining information on incidence and prevalence.

Most early registers had the latter as their main purpose and were designed to store details of all cases of a particular condition in a defined area, for example, cancer registries.

As computer systems have become cheaper, easier to use and more powerful, manual registers have become computerised.

Furthermore, the range of data stored has widened to include detailed clinical information, useful for day to day patient care. These are better termed clinical information systems (CIS). The usual components of a CIS are shown in Figure 3.

A CIS could be defined as a computer system designed to improve patient care; there have been many examples since the late sixties in several clinical areas. Some of the earliest in the United States were designed for ambulatory care and were successful enough to be still in use, for example, COSTAR (Computer Stored Ambulatory Records) which is used at sites in the United Kingdom (Young 1984, Wild and Paddle 1984). Other systems were designed for single clinical areas, including systems for hypertensive patients (Beilin et al 1974, Kennedy et al 1968, Petrie et al 1985, Padfield et al 1987). Because of the importance of the medical record in ongoing patient care, these systems are designed around a continuous case record. However, as the potential for the use of the data has been realised, the requirements of such systems have expanded. Jones (1988) suggested that, ideally, a CIS should have certain minimum features including a patient index, outpatient booking functions, the ability to print lists of defaulters, display data, print medical records, letters and summaries, prompt for missing data, create dictionaries, for example, of problem list entries and produce ad hoc statistical summaries.

The methods of evaluation which might be applied to new methods of care, including clinical information systems, are discussed in section 2.4. However, the effectiveness of such systems in improving patient care are described here.

In maintaining contact with patients, registers and information systems have proved superior to traditional methods. For example, a computer-based register with reminders for follow-up appointments significantly improved the follow-up of hypertensive patients in Massachusetts (Barnett et al 1983); the Nottingham diabetes register reduced loss to follow-up from 5% to less than 1% per annum (Jones & Hedley 1988) and the register-supported shared-care thyroid system in north-east Scotland had a loss to

follow-up rate one third of that of conventional care (Jones et al 1982). In the third case, the system was designed to minimise loss to follow-up; in the first two cases losses were reduced possibly more because of the quick identification of those defaulting rather than because of procedures to reduce default.

An important aspect of a CIS is that it allows the success of the system to be monitored; Jones and Hedley were able to audit, fairly easily, the use of the Nottingham system and took only a few days to extract details on all of the patients lost to follow-up compared with months for the manual system.

The system also included procedures for alerting staff to missing and abnormal results. Recording of results of screening for retinopathy was improved by a combination of better recording and more complete investigation. Finally, this system was also able to produce a summary of the clinical information for use by the patient.

Rogers et al (1982) assessed the use of computerised records compared with manual records in three clinical areas, hypertension, obesity and renal disease. They found no difference in blood pressures between the groups but the obesity clinic attenders with computerised records lost more weight and the renal group had more normal urinalysis results than the control groups. The experimenters also noted that more investigations and diet reviews were carried out on the patients with computerised records. Furthermore, they considered that the greater awareness of test results which the information system generated would induce more appropriate care and hence improve subsequent test results and that this might explain the positive results.

Finally, clinical information systems can also support new forms of care. The system for the follow-up of thyroid disease, fully computerised in 1970, was supporting, in 1974, shared follow-up care for over 3000 patients in the care of 850 general practice units throughout the United Kingdom, mostly in Scotland (Hedley

1984). This "shared-care" approach is discussed more fully in section 2.3.2.

Accuracy of registers: Maintaining accuracy can be a fundamental problem with registers. Jones, Nutt & Hedley (1984) found that 10% of patients in the diabetic system had addresses which differed from those recorded in the master patient index. A study by Lockwood (1971) showed errors in hospital patient registers of 3%-30%. The rate of build-up of errors increases with the size of the register. Hedley (1977) recommended that each smaller area should be responsible for the maintenance of their own part of a larger register in order to limit the number of errors.

New developments in information technology should improve the quality of data in population registers. For example, the community health index (CHI) contains details of all people registered with a general practitioner throughout Scotland. The file is maintained by the primary care department of the health board. It is linked to a patient administration system which may be implemented in a number of hospitals throughout Scotland so that the information may be shared (Leckie 1986). Provided that updating of any smaller registers is automatically or regularly sent on to the CHI centre and registrations are periodically validated, this sort of system should reduce errors overall by having fewer sets of information stored for each individual and by ensuring that everyone has access to the most up-to-date version of the data only.

2.3.2 Alternative arrangements for follow-up care

Using nurses:

Nurses can have an important role to play in the follow-up of chronic illness in specialist clinics or in general practice. In recent years, the number of practice nurses in Glasgow has risen dramatically; Fallon et al estimated, in 1988, that 25% of practices in Glasgow employed a practice nurse. In one practice, 16% of the

nurse's workload was devoted to the measurement of blood pressure alone.

In the white paper "Promoting Better Health", the Government gave its approval to the concept of "nurse practitioner" mainly because "they come cheaper than doctors" (Warden 1988). At least part of the reason for the recent increase in the number of practice nurses is likely to be the reimbursement by the Government of part of the salary as well as the potential for improvement in those services which attract financial payments as "items of service". However, Fallon argues that the employment of a practice nurse does not "pay for itself" in the generation of income from items of service but that it does offer the opportunity for improving preventive care (Fallon 1988).

A nurse-run clinic in Southall (Honey & Mather 1987) was set up for patients who had defaulted from the hospital clinic. It proved popular with patients and general practitioners. Two cases of diabetic maculopathy and five previously undiagnosed hypertensives were detected among 102 attenders. It was felt that the nurse provided a useful link between the general practitioner and the specialist.

However, a Swedish experiment (Lindholm 1984) found that using a district nurse for the follow-up of well-controlled hypertensives was not totally successful since many patients had other chronic conditions necessitating visits to the health centre during which they had their blood pressure measured. However, of those who did continue to attend only the nurse, 86% maintained their blood pressure control.

In Glasgow, a nurse-practitioner clinic has been operating since 1982 (Rubin et al 1984). They have been unable to report success in weight reduction (Curzio et al 1987) but in 1984 the annual non-attendance rate was 10% compared with 19% in the medical outpatient clinic.

Using a "facilitator":

In Oxford, as part of the Oxford Prevention of Heart Attack and Stroke Project, general practices are encouraged to organise preventive activities by a specially trained facilitator (Fullard, Fowler & Gray 1984). The facilitator helps the practice to set objectives, trains nurses in measuring blood pressure and providing patient education and helps to set up a system for screening, recall and evaluation of progress. The use of the system has resulted in improvements in recording of blood pressure, smoking details and weight (Fullard, Fowler & Gray 1987). In 1984, after reimbursement, tax relief and fees, the net cost of the prevention programme to a practice was calculated to be £7 per week.

A programme in the workplace:

Care for hypertension can be offered at places of work. In Massachusetts, one such project resulted in blood pressure control in 70% of hypertensives and although there was no overall change in absenteeism, those who participated actively in the programme had fewer days absence than those who did not (Alderman & Melcher 1983).

The North Karelia project:

This project is a comprehensive community control programme for cardiovascular disease. Part of the programme is designed to lower high blood pressure by improving the quality of care given to hypertensives in the North Karelia area in Finland by early detection, rational drug therapy and intensive health education (Tuomilehto, Rajala & Puska 1976). A register is used to follow-up patients and to evaluate the project. After one year 91.5% of hypertensives had been reviewed and the information had been received by the project office. The principal reason for failure was that forms were not passed from the physician to the register centre. Six years later, blood pressure was compared with a

neighbouring control area (Nissinen et al 1982); the average blood pressure was higher in the control area as was the proportion of patients with diastolic blood pressure greater than 105mmHg. The number of blood pressure measurements was also higher in the control area but measurement was less regular. Although the proportion who had stopped drug therapy was similar in the two areas, more in North Karelia had stopped on the advice of medical staff and more had their blood pressure still under control. The investigators concluded that utilisation of the health care system was more effective and the results of treatment better in the North Karelia area than in the control area. They also felt that the better blood pressure control might be due to some non-pharmacologic aspect of the programme such as health education.

Arrangements in general practice:

Several arrangements for the care of diabetics patients have been set up within general practice.

A **mini-clinic** in Norfolk has 320 patients, 2 doctors and 1 nurse and has operated successfully for 8 years (Tasker 1987). The clinic is run in the practice for 3 hours every week and patient waiting time is only 15-20 minutes. The practice have developed their own diabetic card to fit Lloyd George envelopes. Their experience suggests that there are certain pre-requisites for this type of clinic: an enthusiastic doctor, a large enough patient population to give medical staff experience in dealing with problems, protected time for the clinic sessions, secretarial facilities to follow-up defaulters, close co-operation with the biochemistry laboratory and availability of educational resources and expertise.

In central London, Koperski (1987) has developed a **diabetic day** which integrates the care of diabetics into the normal surgery. A computerised recall system makes it possible for a few of each general practitioner's diabetic patients to be invited on a particular day and the surgery is oriented that day towards diabetic care. They now have 130 patients on their diabetic

register; previously, only 70 were registered of whom one third were not reviewed regularly. They use a checklist for review and a flowchart for recording information. They also use a patient-carried record card. The attendance rates are high, around 78%, and patient comments are favourable. They believe the model could be used for other chronic conditions.

In Southampton (Davidson & Parker 1987), a **recall system** is used to maintain regular contact with the patients and 30 minute appointments are scheduled - 15 minutes with the nurse and 15 minutes with the doctor. They use a specially designed record card and have 95 patients. The authors claim that patients prefer this system to the outpatient clinic, doctors and nurses have improved their skills and have a sense of achievement, early diagnoses of other conditions have been made and the improvement in staff relations has led to more organised care in other areas, for example, cervical screening. Reported disadvantages include: extra work in setting up the system, making time during surgeries, finding time to discuss cases and unmotivated partners. Some of the difficulties have been resolved as the system improves, for example, partners are becoming more motivated and the reviews fit more easily into surgery time. They conclude that regular review of asthmatics and hypertensives seems no longer impossible.

Shared-care:

The term "shared-care" usually refers to a system set up to coordinate the care given to an individual patient from different sources over a period or throughout life. It can be used for a team approach, for example, in primary care or it can operate at the level between primary and secondary care. The following discussion reviews those shared-care systems which bridge primary and secondary care.

Shared-care is a concept that has been around for a long time. For example, Barclay describes a shared-care scheme for the after-care of surgical patients in 1975; he makes the point, echoed

by those interested in chronic disease, that a specialist-general practitioner shared-care system in surgery goes a long way towards achieving an integrated patient record. In another clinical area, shared-care in obstetrics involves co-operation between hospital and community medical and nursing staff and has been a successful exercise for around 40 years (McGlone 1975). A feature of obstetric shared-care is that the patient is involved, as a carrier of a shared record card.

For chronic disease, shared-care has been used as a means of coordinating long term follow-up and attempting to match the provision of specialist care to the patient groups most in need of it.

The SAFUR thyroid shared-care scheme in Scotland was set up in Aberdeen in the 1960s to review post-treatment thyroid patients. It operated in eleven centres in the UK (Hedley 1984). The screening investigation, to assess the patient's clinical status, is a simple blood test which is carried out by SAFUR on a sample sent to the registry by the general practitioner. Results are screened by a specialist thyroid physician and notified to the general practitioner. Only if the results are abnormal is the patient recalled for further investigation. Evaluation of the scheme showed it to be effective in maintaining follow-up; loss to follow-up was only 5% to 8% over eight years (Jones et al 1981). The scheme was estimated as costing 60% of the cost of equivalent conventional care (Jones et al 1982).

The WAFUR thyroid shared-care scheme in Wales operates on the same principle as the Scottish scheme (Lazarus 1978). A part-time secretary administers the system and it has operated in the University Hospital of Wales since 1974. It has been estimated, in a very simple evaluation, to cost less than outpatient follow-up although effectiveness could not be compared.

In Poole, a shared-care scheme for patients with well-controlled diabetes was popular with patients and their general practitioners (Hill 1976). The system required the general practitioner to refer

new patients to the clinic for assessment, carry out routine investigations, monitor well-controlled patients for developing complications and refer any diabetic patient, as required, to the specialist, dietician, chiropodist or health visitor. It was admitted that the general practitioner's workload was increased but the increase was not as great as feared and was accepted by the general practitioners. Time was freed in the outpatient clinic and subsequently used to increase the time spent on those patients with more complicated diabetes. This system was initiated through consultation between the specialists and general practitioners in the area and developed by a working party.

A more recent shared-care scheme for diabetic patients relies on patient-initiated review with general practitioners (Day, Humphries & Alban-Davies 1987). Evaluation has shown the scheme to be successful in recalling patients to a hospital clinic but unsuccessful in ensuring regular review. After two years, 44% of 209 patients had no written evidence of assessment by their general practitioner in a shared-care record book. Five percent of patients believed that their diabetes had been cured and so had not arranged an appointment. Seventeen percent had attended their general practitioner regularly but no mention of their diabetes had been made. Of those who were reviewed, only 42% had urine tested, 40% had blood glucose, 73% had weight, 58% blood pressure, 44% eyes and 53% feet examinations recorded. At the two-yearly clinic review, new cases of eye problems, foot problems and blood pressure requiring treatment were found which general practitioner review had not detected. The organisers felt that more instruction about follow-up plans should have been given to patients and that computer "prompting" would have been useful. They also felt that a locally-based register, for example, a practice diabetic register, would have been easier to maintain, and that combining review by a nurse might make this an effective method of follow-up.

Although several investigators have used a shared record card for the care of patients with hypertension, shared-care is not common. Ezedum and Kerr (1977) showed that a shared record was a useful

method of transferring information between clinic and general practitioner; however, their system did not attempt to coordinate a patient's care.

In 1982, Bulpitt et al compared community care with hospital outpatient care; the "community care" is not "shared-care" in that there was no coordination between specialist and general practitioner. However, long term care was planned and duplication of medical work avoided. Although the authors estimated that blood pressure control was not so effective in general practice as in the clinic, the difference was small and not significant (1-5mmHg diastolic). Fewer patients defaulted from general practice follow-up than from clinic follow-up (12/189 versus 19/187) but, again, not a significant result.

In Aberdeen, a computer-assisted patient record system for hypertension was developed originally to facilitate the exchange of clinically important information between doctors in hospital and those in general practice (Petrie 1985). This was extended to allow the follow-up of clinic patients at "lesser risk" to be undertaken in general practice (72% in 1985) and those at greater risk in the blood pressure clinic. Risk was determined by the hospital doctors on the basis of an individual's risk factors and blood pressure control but no explicit criteria are described. The patient is prompted to attend for follow-up either with their general practitioner or in the clinic; if in general practice, the general practitioner completes a "turnaround" clinical record which is reviewed by a specialist and new follow-up plans scheduled. The number of patients under long term follow-up in the clinic has been reduced leading to a reduction of about half in clinic sessions.

Patient-held records:

One approach to improving long term care is to involve the patient by giving them a copy or summary of the medical record. None of the shared-care schemes described above give summary records to the patients although most provide a card for recording of

important clinical variables. The following discussion describes some of the main features of patient-held records and experience to date.

In the UK, **summary records** have been given to general practice patients (Dowell 1983, Sheldon 1982) and to diabetic outpatients (Jones & Hedley 1987). The summaries have included problem lists (such as principal diagnoses and other health problems) and details of treatments. Since the patient carries this record he or she has full access to its contents with the associated benefits and problems.

In the United States, several practitioners (Bronson, Rubin & Tufo 1978, Giglio et al 1978). felt that the process of creating a **shared record** could clarify treatment goals with resulting benefit for both patient and doctor. In general practice in the United Kingdom, Dowell (1983) found that patients had "worrying gaps" in knowledge and understanding of their past medical histories which might have led to incorrect diagnoses and treatments but was detected during the drafting of a patient summary card. Ten percent of Sheldon's patients had items missing from their general practice records including pregnancies, previous operations and drug sensitivities so that the checking of medical summaries with patients resulted in more accurate clinical information in the practice records (Sheldon 1982).

Prompts: The patient-held record can act as a useful prompt to the patient who can then inform the doctor when a regular review is due. For example, in Oxfordshire, uptake of cervical cytology screening, blood pressure recording and tetanus immunisation increased with the use of summary records which displayed the date on which a review was due (Lawrence 1986).

Patient knowledge: Adequate knowledge is essential to allow patients to make informed decisions and take a more important role in their own health care (Zander 1985). While access to the medical record alone was not found by Bronson and O'Meara (1986) to improve patient knowledge, it did facilitate information exchange

between patient and doctor and it stimulated discussion with hospital patients (Stevens, Stagg & Mackay 1977). Furthermore, after sharing records with patients, Bronson and colleagues found that 97% felt less worried about their health and, of these, 80% were more careful about following treatment recommendations and 78% had made changes in their patterns of eating or drinking (Bronson et al 1978). A more recent experiment produced a significant difference in awareness of smoking as a health problem (Bronson and O'Meara 1986) and a study with older patients showed differences in knowledge of health problems and treatment (Bronson, Costanza & Tufo 1986).

Audit: Access to a patient-held version of the medical record gives patients an opportunity to audit the contents of their medical notes. Some studies have incidentally revealed the level of inaccuracies in traditional records. For example, Baldry et al (1986) discovered that 12% of their general practice records had inaccuracies and Tomson (1985) found that 35 additions, deletions or amendments were needed to 100 problem lists as a result of feedback from the patients. However, access alone may not be enough to encourage audit by patients because two thirds of the inaccuracies found in Baldry's study were not reported to staff. Bronson et al (1978) found that only a small number of patients audited their summary record well. Patient questionnaires for collection of the information may help; however, Sheldon (1982) reported that 18% of medical summaries were still inaccurate even after use of a patient-completed questionnaire plus validation of the questionnaire by interview. It appears that maximum accuracy was only achieved when patients were given the opportunity to check the medical record and were encouraged to report the inaccuracies or amend the record.

Language: The way in which medical information is presented is important to understanding. Jones et al (1988) found that 14% of diabetic patients did not understand something on their patient-held record. Stevens et al (1977) drew attention to the differing interpretations placed on medical language by practitioners and patients which could create misunderstanding or anxiety while

Tomson (1985) felt it was important to phrase medical problems in a non-pejorative way. However, Bronson et al (1978) felt that they could write their records in unambiguous lay language; furthermore, they assert that this exercise clarifies the ideas of physicians as well as improving the understanding of patients.

Anxiety: One of the arguments which might be raised against patient-held records is that they could increase patient anxiety. For example, Burrows (1986) claims that access to the medical record could destroy the rapport between patient and doctor and the issue of a summary record might provoke concern over what has been missed out. There is some evidence to support this view. Tomson (1985) and Baldry et al (1986) have reported that 2% to 11% of patients who read their notes claimed that this caused anxiety or confusion, even though these records were vetted before being made available. Nonetheless, both these studies also found that a high proportion of patients were reassured by access to their primary care records. Furthermore, Bronson et al (1978) found that sharing records improved doctor-patient communication which helped the patients deal with their condition. Even in the case of psychiatric patients, positive effects of seeing medical records were felt to outweigh any negative ones (Showalter 1985).

Censoring: Even when supporting the principle of access to information, medical attendants may have good reason for wishing to censor some records, at least initially. In Tomson's practice, 6% of patients were not shown their problem cards; Sheldon (1982) did not issue a summary to 2% of patients and excluded diagnoses in a further 19%. In Birmingham (Bird and Walji 1986), 0.3% of patients were denied access to the full notes. However, in a general practice in Fife (Melville 1989) no patients were denied access to their records. In the Nottingham diabetic follow-up system, censoring of the summary records was permitted. Jones and Hedley (1987) investigated the censoring and found that doctors initially censored 13% of all problems and that 41% of patients had at least one censored problem. However, in a follow-up audit, 69% of the censored problems were re-instated with doctors eventually censoring only 1% of problems and patients a

further 2% (Jones et al 1988). There was no apparent pattern in the censoring of sensitive items, such as cancer, compared with other diagnoses.

Format: Patients appear to prefer smaller-sized records; a wallet-sized summary was carried to consultations more often than larger versions (Giglio & Papazian 1986). Melville (1989) found a preference for access to medical summaries rather than access to the whole record probably because patients found the summary easier to understand and could carry it away with them.

From the above discussion, it appears that there is potential for new approaches to be taken to the care of patients with hypertension, based on those approaches which have been shown successful for other chronic illnesses; these include the use of computerised registers and recall systems, the extension of the nurse's role, coordinated systems between specialists and general practitioners such as shared-care, protocols and management plans, and the use of patient-held records. Any new approach needs to be carefully evaluated. The next section reviews evaluation methods.

2.4 EVALUATING MEDICAL CARE MANAGEMENT

Summary: Early evaluations considered only the effectiveness of care but more recently, acceptability and use of resources have been included. Effectiveness can be measured in process or outcome variables. When evaluating the effectiveness of delivery of health care, process measures are likely to be more appropriate, especially in the short to medium term. Evaluation of acceptability to date has been mainly by recording the use of a system and the methods are not well developed. On the other hand, methods of economic evaluation are becoming much more sophisticated and a more frequent feature of the evaluation of new methods of working. The only shared-care system to be subjected to a rigorous evaluation is the SAFUR thyroid scheme and no similar evaluation has yet been attempted with shared-care for those with hypertension.

2.4.1 Introduction:

Evaluation has been defined by the World Health Organisation as "the systematic and scientific process of determining the extent to which an action or set of actions was successful in the achievement of pre-determined objectives". Nowadays, this definition would normally be applied to effectiveness evaluation. Holland in 1983, expanded the areas with which evaluation should be concerned to include acceptability and efficiency along with effectiveness. These three areas are discussed separately after a general discussion about methods.

2.4.2 Methods of evaluation:

The methods used, measurement of a selected group of variables and judgement of achievement based on the result, have not changed over the years although the areas of interest and the standards applied have changed. Furthermore, similar processes tend to be applied whatever aspect of evaluation is being considered.

The evaluation process should be iterative with the implementation of appropriate change as an end product; it is often described by a loop, for example, Figure 4 (Shaw 1980a). A very recent version (Russell 1990) has the final box of each iteration as a review of the standards; this approach is suited to the current interest in audit in the UK since it is most appropriate when reviewing practice for the purpose of improving it rather than comparing it against an ideal. The methodology of both approaches to evaluation is, however, similar and both have been used to illustrate the following discussions.

2.4.3 Evaluation of effectiveness:

In the early days of the National Health Service (NHS) evaluation of the quality of medical care was usually concerned only with structure such as staff and equipment (McLachlan 1976). Structure was relatively easy to measure. However, interest soon turned to what could be done with the structure and to measurement of the outputs from the health care process.

The health care process is a hierarchical system with low order activities, such as data entry to the computer system, intended to produce an output of good quality data which itself is an input to the process of achieving good quality care, which in turn is an input to the process of improving the quantity and quality of life for patients. Evaluation of achievement should be at an appropriate level in accordance with the objectives of the system being evaluated and the measured variables should relate closely to those objectives (Donabedian 1966, Baker, Lant & Sutters 1988).

The ultimate aim of any health care process is to improve health but it can often be impractical or unhelpful to attempt to evaluate the operation of a procedure in terms of health outcomes - they can be difficult to measure, develop over long time periods, are affected by many factors and do not highlight particular deficiencies or strengths of the process of care (Donabedian 1966).

An alternative is to measure the activities which occur during the process of care. This approach overcomes the difficulty that the effects of an intervention become more diffuse as we move up the hierarchy and other factors come into play. Any such process outputs must be assumed to lead to improved health outcomes. It is not usually the function of the evaluation to verify this nor is it often possible for it to do so.

Rogers et al (1982) suggest that evaluation should measure how well new technologies aid the occurrence of what is "currently and locally considered good medical practice" even if that practice is less effective in terms of outcome than would be hoped. Advances in knowledge should improve the relationship between the process and the outcome.

The measurement of process outputs is particularly applicable in the evaluation of clinical information systems where the provision of appropriate, accurate and timely information is indeed likely to lead over time, by several routes, to improved delivery of health care and hence to improved outcomes, but the effect is likely to be masked by other factors over short time scales. An example of the appropriate use of process measures is the early evaluation of registers where the measured variables included the completeness, accuracy and validity of the data in the register (Goldberg, Gelfand & Levy 1980).

Nonetheless, from early days, attempts have been made to evaluate the effect on health of alternative methods of patient management and "intermediate" outcomes have been used. These variables, such as control of blood sugar or reductions in loss to follow-up are often appropriate because the program being evaluated is designed precisely to achieve these objectives, current knowledge indicating that they lead directly to improved health outcomes. One example is the use of blood pressure levels to evaluate the use of computerised medical records. Rogers et al (1982) compared the experiences of a group of patients with computerised records and a group without; while they found no difference in blood pressure

levels they did record more frequent investigations in the computer-record group of patients.

Many evaluations incorporate several output measures and a mix of process and intermediate outcomes. Bulpitt et al (1982) used process measures (such as completeness of information and number of risk factors recognised) and intermediate health outcomes (such as blood pressure control and loss to follow-up) in the evaluation of the effectiveness of a computerised record system for the management of patients with hypertension. They too found no difference in the health outcomes but an improvement in the process outputs in the computer record group and continued to use their system.

It is also possible to use process and intermediate outcome measures to model the potential effects on health of an intervention. For example, to evaluate the effectiveness of screening for breast cancer based on a register, the investigators are collecting information on stage of presentation of each cancer detected (Bull, Mountney & Sanderson 1989). Any changes in stage distribution can be used to predict any likely changes in mortality due to breast cancer in the future.

2.4.4 Acceptability:

In his early paper on evaluation, Donabedian (1966) considered acceptability of a process to be an aspect of effectiveness. However, like Holland (1983), most recent writers have considered acceptability as separate from effectiveness although perhaps affecting it. For example, Shaw (1980b) claims that individual patient risk and social acceptability are factors which modify the relationship between structure and intermediate outcome measures.

However, in many evaluations, while effectiveness is usually measured quite carefully, acceptability is often missed out altogether or only briefly mentioned. In Bulpitt et al's paper, acceptability of the new record system to the staff was mentioned but does not appear to have been formally measured.

Acceptability to the users is, however, of fundamental importance in any patient management system; a system that is not acceptable will not continue to be used. One report on the acceptability (or unacceptability) of a computerised medical record system admits that the system was so unacceptable that the pilot system was abandoned after only four months (Dambro et al 1988). Difficulties were reported by physicians using the system, the computer was slow, the burden of work in typing in the data caused large backlogs with resulting non-availability of results and users had to consult the paper records as well as the computerised version. The final breaking point came when resources would not permit the existing staffing level to continue.

When considering alternative forms of patient management, the concept of acceptability includes aspects of workload, social effects, methods of working, individual preferences, experiences and even prejudices of those involved, all of which will have a substantial effect on the success of the new system. Acceptability is not therefore a single factor and, like effectiveness, requires that the most appropriate individual factors be defined and measured for each study.

Methods for measuring acceptability are not currently well developed. There is, on the other hand, a large amount of literature on measuring patient satisfaction with care. However, Baker (1990) casts doubt on the validity and reliability of most of these instruments for use in the United Kingdom since many were designed for particular situations in the United States. Furthermore, showing changes in patient satisfaction or interpreting the implications of any such changes can be difficult. There is also very little published literature to date on measuring doctor satisfaction with methods of care.

An early evaluation of the SAFUR shared-care system deals with acceptability to general practitioners by exploring loss to follow-up and the reasons for this which are routinely recorded in the system (Jones et al 1981). The study indicated some degree of unacceptability due to the doctors' existing methods of working.

The authors felt that the regular assessment of drop-out from the system provided a model for testing the acceptability of the follow-up procedures.

A study of three methods of caring for patients on anti-coagulant therapy measured acceptability to patients and general practitioners by asking for their preferences between the methods (Stamp et al 1985). This yielded fairly clear preferences in both groups for outpatient care. The perceived advantages and disadvantages of the less-favoured options were explicitly asked for providing information for improving their acceptability.

2.4.5 Efficiency:

Economic efficiency means that the choices made about resource use should derive the maximum total benefit and not necessarily that the cheapest options should be implemented. Indeed, the most efficient options may involve spending a little more to obtain a great deal more benefit. The costs need not be monetary but could be stated in terms of other resource use, for example, staff time. In contrast with measurement of acceptability, methods of measurement of economic efficiency have been developing rapidly in recent years.

Methods of economic evaluation: To carry out an economic evaluation, one should identify, measure, value and compare as many of the costs and benefits of alternative options as possible.

There are several types of appraisal (Drummond, Stoddart & Torrance 1987). The most frequently used is cost-effectiveness analysis (CEA) in which two or more alternative strategies are compared. Each strategy must produce the same output although the amounts produced can differ. The total cost and the amount of output is used to give a cost-effectiveness ratio for each, that is, cost per unit of the output. These cost-effectiveness ratios can then be directly compared.

In CEA the output is not valued but is assumed to be worth having. On the other hand, cost benefit analysis (CBA) values the costs and benefits in monetary terms and can then indicate whether the benefits exceed the costs or vice-versa. This can be difficult since many benefits do not have obvious monetary values.

In order to introduce better measures of outcome, cost-utility analysis has become more popular. This is a type of cost-effectiveness analysis where the output is quality-adjusted life years (QALYs), that is, a combination of the extra years of life gained and an estimation of the quality of those years of life (Gudex & Kind 1988). In theory, this allows comparison of different types of strategy or treatment. However, the measurement of QALYs still raises questions of validity, reliability and comparability (for example, Rawles & Rawles 1989).

Economic analyses of new methods of delivering health care are not common; the following are a few recent examples in the United Kingdom.

The SAFUR system was evaluated for cost-effectiveness using euthyroid status as the outcome and comparing the cost and effectiveness of register-based follow-up with traditional follow-up. The costs measured were staff time, costs of tests, clinic time and patient travel and time costs and the totals were presented as workload and as estimated monetary cost. This analysis showed that, to achieve the same outcome, the register-based system cost 60% of the traditional system.

An evaluation of the diabetes register already described went further and computed the likely benefits due to improved screening for developing retinopathy. It concluded that the benefit of preventing blindness more than justified the cost of the register (Jones & Hedley 1986). However, it is more difficult to use a CBA like this as an argument for the expansion of a method of care because the benefits and costs often fall on different groups; in this case, the benefits were to the patients, their family and

community services, for example, for the blind, while the costs were to the hospital or health board providing the screening service.

This drawback also surfaces in the discussion about whether patient's costs should be included and, if so, which costs. Usually, it depends on the viewpoint for the evaluation; any likely bias which might result by their inclusion or exclusion must be considered. For example including the costs of lost working time implies that costs of care are greater for employed patients than for those with no paid employment. The evaluation by Stamp et al (1985) of anti-coagulant therapy made this assumption.

One way of looking at alternative patterns of care is to determine the "needs" of the population in some way, set specific standards to meet these needs and let the balance of care be determined by these two sets of factors. Fordyce, Mooney & Russell (1981) applied this technique to the problem of determining the optimal balance of care for elderly people. They identified those in their own home who might benefit from hospital care and vice-versa by asking the opinions of the medical care teams caring for them. They described the characteristics and current costs of care for each group. Subsequent comparisons of marginal benefit to marginal cost in each service allowed judgements to be made about which service should be expanded.

2.4.6 Evaluation of shared-care:

Since this study is concerned with the evaluation of a shared-care scheme, I have attempted to review the evaluation of similar schemes, even after the present study began. Systematic searches of computerised databases of published papers for the years 1966 to 1989 did not reveal very many relevant studies. The terms "shared-care", "ambulatory care", "specialist", "general practitioner", "medical records", "outpatient clinics", "family practice" were all used in various combinations. The searches identified a few studies dealing with sharing care between members of primary care teams; ante-natal shared-care and communication

of information between specialist and general practitioner (these are discussed in the section on medical records), There were two studies on care for hypertensives using a shared record card (Osbourne & Beevers 1981, Ezedum & Kerr 1977), an early and later evaluation of the Grampian system for hypertensive patients (Petrie et al 1985, 1989), an evaluation of the Welsh Automated Follow-up Register (Lazarus 1978), two evaluations of the Scottish Follow-up Register for thyroid disease (Jones et al 1981, 1982) and two evaluations of shared-care for diabetic patients (Hill 1976, Day et al 1988). I have summarised the latter papers.

The Grampian Hypertension System (Petrie et al 1985, 1989): Outcome indicators of the effectiveness of this system were the percentage of patients with blood pressure below an arbitrary target level; the 1989 evaluation included the "existence of key management problems" which could influence decisions on follow-up. No process indicators were reported in either paper. Acceptability was reported as favourable comments made by general practitioners and patients and by the high rates of co-operation between all the participants. Costs have not so far been considered other than the unquantified saving of clinic resources and the subsequent treatment of newly referred patients.

WAFUR (Lazarus 1978): The evaluation was concerned with numbers of abnormal results detected and approximate costs of follow-up. Ninety-five percent of general practitioners who referred patients to the specialist clinic cooperated with the system. Thirty-eight percent of test results had initial abnormal results, but only 10% required a change of follow-up status. The comparison of costs of care using WAFUR compared with routine outpatient care resulted in an estimation that WAFUR saved approximately 18% of day-to-day expenses. However, the cost of a general practitioner consultation was estimated at only £1.95 compared with £12.77 for an outpatient attendance. No estimate of patient costs was made.

SAFUR (Jones et al 1981, 1982): This system was been evaluated for cost-effectiveness compared with routine care for these

patients; effectiveness was defined as euthyroid status and all relevant costs of consultations and treatments to the NHS and to the patient were included. Routine care was defined as a mixture of general practitioner and outpatient care and the data was collected by review of case records. Acceptability was commented on and estimated in so far as drop-out from the scheme was low.

Shared-care for diabetes (Day et al 1987): Effectiveness was defined as reduction in loss to follow-up, number of reviews carried out and complications detected. Acceptability to patients was measured by questionnaire and acceptability to general practitioners was ascertained by discussion at a group meeting. Costs were not considered and no comparison with effectiveness of other methods of care was made.

Shared-care for diabetes (Hill 1976): This is the earliest evaluation reviewed; it consisted of assessment of acceptability to patients and to general practitioners by questionnaire, sampling of the time that patients had to wait for their routine tests at the laboratory and observation that the clinic workload had eased sufficiently to allow more time to be spent on those patients with complications.

The only evaluation to deal in detail with costs of alternative follow-up plans is the SAFUR evaluation. The cost-effectiveness of shared-care compared with other methods of follow-up for hypertensive patients has not, to date, been examined. The acceptability of shared-care for hypertensive patients has not been explicitly assessed, nor the feasibility of this approach in a large conurbation.

CHAPTER THREE: EXISTING SOURCES OF CARE FOR HYPERTENSIVE PATIENTS IN GREATER GLASGOW HEALTH BOARD

3.1 HYPERTENSION IN GREATER GLASGOW HEALTH BOARD

Summary: Cerebrovascular and ischaemic heart disease together cost over 5,000 lives a year in over 45 year olds in Greater Glasgow Health Board (GGHB). Extrapolation of the results of local screening exercises suggests that around 19,000 individuals in GGHB have diastolic blood pressures greater than 110mmHg and around 50,000, 35-64 year olds may be known hypertensives. If the need for hypotensive therapy is assumed, this represents a large workload for general practitioner and specialist services.

3.1.1 Introduction:

Greater Glasgow Health Board (GGHB) is made up of five geographical areas with a total population of 998,101 in the 1981 census (Registrar General 1981) and an estimated population in 1986 of 968,801 (ISD 1986). These figures imply an average depopulation rate of 6,000 people per year over that period. The standardised, all-ages mortality rate in 1985 was thirteen per thousand, equal third highest in Scotland. In the same year, cerebrovascular disease and ischaemic heart disease (ICD codes 410-414 and 430-438) claimed 5,094 lives among over 45 year olds, of which 1,009 (20%) were in the 45-64 year age groups. The ischaemic heart disease death rate for both men and women in GGHB was higher than the average for England being 411/100,000 for men against 372 in England and 323 for women against 277 (ISD 1986).

As discussed in Chapter 2, morbidity and mortality from cerebrovascular disease and ischaemic heart disease rise with increasing blood pressure levels and some reduction at least in strokes, can be brought about with effective anti-hypertensive treatment (Hart 1987). Evidence points repeatedly to the need to improve both the detection and the follow-up of individuals with

raised blood pressure throughout the United Kingdom (for example, Russell et al 1983, Jachuck et al 1984).

A recent blood pressure screening exercise in and around Glasgow suggests that the same need for improvement exists here. Gilmore & Barber (1985) screened 11,817, that is, 51.5% of the target population of 35 to 64 year olds in eight general practices. Of those screened, 14% were confirmed as having diastolic blood pressures greater than 90mmHg and 28% of these had pressures greater than 110mmHg. Ten percent in total were already known to be hypertensive although the number under active follow-up is not known. A comment was made that the screening exercise resulted in the re-identification of some hypertensives. Only 4% of the screened population were newly detected hypertensives but half of these had diastolic pressures greater than 110mmHg as well as 20% of those already known to be hypertensive. The investigators also looked at the blood pressure control of 177 mild to moderate hypertensives (diastolic 90-109mmHg) started on treatment as a result of screening and followed up in general practice. After two years, 63% were controlled with diastolic blood pressure below 90mmHg; the remainder had either lost control or never achieved it.

An earlier but more extensive screening exercise carried out in the neighbouring burgh of Renfrew (Hawthorne, Greaves & Beevers 1974) found that the percentage of 45 to 64 year olds with newly detected diastolic blood pressure greater than 100mmHg, on two occasions a year apart was 5.5%, and the number already on anti-hypertensive medication was 5%. This study also found that only around a quarter of identified hypertensives were on treatment at the time of screening and 57% of these had diastolic pressures greater than 100mmHg. This is a fairly old study and it is likely that, at the present time, the proportion of detected hypertensives on treatment would be higher.

Applying the figures from both these studies to the GGHB population gives the estimates shown in Table 3. While the populations investigated are probably not strictly similar to the

whole population of GGHB, the comparison does give some indication of the approximate blood pressure distribution in the GGHB area.

The extrapolated figures imply that 2% to 7% of those under 65 years of age in GGHB, somewhere between 20,000 and 70,000, may have diastolic pressures over 90mmHg. While opinion is divided as to the need for drug therapy in mild hypertensives, these individuals nonetheless require regular blood pressure checks. There may be over 19,000 individuals in GGHB, 2% of the population, with diastolic pressures over 110mmHg. This represents a large population in which there is no doubt that effective treatment could significantly reduce the risk of morbidity and mortality. Gilmore's study provides the estimate that in GGHB almost 50,000, 35 to 65 year olds may be known to be hypertensive although not all will be on treatment. While there is clearly a continuing need to identify those with raised blood pressures, there is a large workload associated with proper follow-up. This workload is likely to be carried mainly by general practitioners; the majority of hypertensive patients in GGHB, as elsewhere, are currently managed solely by their general practitioners.

There appears to be a need for greater access to specialist care for investigation and treatment at least for those with severely raised blood pressures who are currently not being adequately managed in general practice; that is, possibly around 19,000 individuals in GGHB.

The next part of this section looks at these two main levels of the referral chain for hypertensives in GGHB, the specialist clinic and general practice.

3.2 THE REFERRAL CHAIN FOR HYPERTENSIVES IN GREATER GLASGOW HEALTH BOARD

Summary: Most hypertensives in GGHB are cared for by their general practitioner. The main sources of specialist care are the Glasgow Blood Pressure Clinic (GBPC) and the Stobhill nurse-practitioner clinic. Summary statistics suggest that the GBPC has lost up to 35% of the registered patients in spite of a policy of maintaining continuous follow-up. In recent years, increases in referrals, particularly in the east of the city, have prompted greater numbers of patients to be discharged to general practitioner care.

3.2.1 Introduction:

The three main components of the referral chain for hypertension in GGHB are self care, general practitioners and specialist services. Because of the nature of the chain and finite resources, any change in the use of one service, for example, screening or case-finding in general practice, has implications, not only for the delivery of care to hypertensives at that level but also for the workload of the other parts of the chain and hence for the delivery of care to hypertensives at other levels too.

Specialist services in GGHB are provided by outpatient clinics and, if necessary, inpatient facilities. The main outpatient sources of care are the Glasgow Blood Pressure Clinic and the Stobhill nurse-practitioner clinic.

3.2.2 The Glasgow Blood Pressure Clinic:

The Glasgow Blood Pressure Clinic (GBPC) was set up in 1968 to co-ordinate the services provided by several local centres studying and treating hypertensives. The individual clinics continued to operate using their existing outpatient facilities and staff but data was collected in an agreed manner and processed centrally. In 1985, when this study began, the GBPC was funded by GGHB and directed by an Executive Committee. Cardiologists, radiologists,

computer specialists and representatives of the University Department of Medicine were on the Committee as were the consultants of the outpatient clinics, several of whom were employed by the Medical Research Council's Blood Pressure Unit. The Committee's aim was to formulate and maintain an integrated policy for the examination, treatment and follow-up of all hypertensive patients and to co-ordinate clinical trials in the several hospitals (GGHB 1969).

In 1985, outpatient clinics were being held in The Western Infirmary (WIG), the Royal Infirmary (GRI) and Stobhill Hospital in Glasgow. Both the GRI and Stobhill Hospital are sited in areas of deprivation. The majority of postcode sectors surrounding them score 4 or 5 on a 1-5 scale of percentages of households with two or more indicators of deprivation, where 5 is most deprived (GGHB, based on Census 1981). In contrast, the WIG clinic is surrounded by postcode sectors scoring mainly 2.

The GBPC used a computerised system, SWITCH (System at the Western Infirmary for the Total Computerisation of Case-Histories) for the storage and retrieval of data (Kennedy et al 1968). This system was initially introduced for peptic ulcer patients in WIG and modified for use with hypertensives. It ran on an ICL KDF9 mainframe computer using punched tape input from coded documents and produced paper summaries for insertion in the case notes. Most data retrieval for research required individually written routines. Several studies have been published using this data (for example, Isles et al 1986). The system is now outdated and has been off-line since August 1989. A new system based on the PICK operating system will allow on-line access to the full database.

The Clinic's policy was that patients should not be discharged unless they have been incorrectly referred and do not have hypertension, unless they leave the district or unless they persistently default. Those requiring long term follow-up should attend annually for a review to an agreed standard (described in Chapter 5) to ensure the maintenance of follow-up, updating of

clinic records and availability of patients for clinical trials. Routine statistics were gathered in the clinic and I used these to estimate the effectiveness of the clinic in maintaining contact with patients.

Result of estimation of patient follow-up using routine statistics:

The most accurate estimate using these statistics was that since 1968, 816 (19%) of 4294 registered patients had died, 1074 (25%) had been discharged to their general practitioner or another source of care, 902 (21%) were almost certainly current attenders and the remaining 1502 (35%) of patients were "lost"; that is they had not been seen at the clinic within three months of their last scheduled appointment and no further information was available. The Clinic appeared, therefore, not to be achieving one of its main objectives since it was losing touch with up to 60% of patients if we include those who were transferred to another site of care.

While the desirability of the clinic retaining an interest in the follow-up of even well-controlled hypertensives is not in doubt, the practical aspects of achieving this by having all patients continue to attend the clinic annually would be considerable. A large number of patients had apparently discontinued their own attendance at the GBPC. If this "loss" was stopped, it would result in an enormous increase in the number of currently attending patients and would be difficult to accommodate. Furthermore, even if up to 20,000 people in GGHB could benefit from specialist care, the Clinic's resources could not cope with this number of patients.

In addition, any increase in the referral rate up the chain, if not matched by a corresponding movement downwards, would give rise to an increase in the numbers attending the clinic and hence lack of access for other patients. Changes in the detection and treatment of hypertensives had been taking place during the seventies and eighties in Glasgow. One initiative was "Good-hearted Glasgow" - a programme involving screening for cardiovascular risk factors, including hypertension, and taking place initially in the east of the city where the GRI clinic was based. To investigate the effect

of this programme on use of resources, the available figures were used to estimate the workload in the WIG and GRI clinics over the years from 1980 to 1985.

Estimation of the effect of changes in numbers of referred patients using routine statistics: The number of currently attending patients in the two clinics in 1985 was 888 and does not change greatly from year to year (Figure 5). The change in each clinic, however, is different with the GRI clinic numbers increasing over the five years. Figure 6 shows the cumulative effect of additions and losses in each clinic between 1983 and 1985. Over the two years, there is an increase of approximately 3% in the numbers of current attenders in GRI. The numbers of patient attendances do not show any increase over the years and so the extra patients must be fitted in by increasing the intervals between the attendances of other patients. The additions to the clinic numbers due to new referrals and the removals due only to discharges both vary over time in each clinic. In the WIG clinic, however, the absolute numbers show no apparent trend over 1980 to 1985 (Figure 7) whereas in GRI, the referrals increase from 1984 and the discharges apparently increase from 1985 (Figure 8).

Figure 9 shows a CUSUM (Cumulative sum) plot of these figures (Chaput de Santange & Vere 1974). Taking the average referrals and discharges for the years 1981 and 1982 as a base, the cumulated differences from this base are plotted for 1983 to 1985 and the result shows the trend over time. In WIG, referrals are increasing and discharges decreasing over the three years but in GRI, the referral rate increases from early 1984 and discharges follow this with an increase from early 1985. In total, 43 people were discharged from GRI in 1985 which is a fourfold increase over the average of the previous four years. It appears that the rate of referrals to the GRI clinic increased and the clinic absorbed the extra numbers for a time. However, the burden of attending patients has eventually prompted an increase in discharges. This was confirmed by the consultant in the GRI clinic.

3.2.3 Nurse-practitioner care:

In addition to the SWITCH-based blood pressure clinic in Stobhill Hospital, a nurse-monitored clinic was set up in 1982 and patients, usually well-controlled, are regularly transferred from the SWITCH clinic to the nurse clinic (Rubin et al 1984). This clinic uses a computerised clinical information system based on DBASE 3 and running on Apricot micro-computers with floppy disc backups. Several research studies have been published using the data from the system (Curzio et al 1987, Curzio 1983, Rubin et al 1984). In 1986, approximately 600 patients had been enrolled and were followed up in the system.

3.2.4 General practitioners:

Most hypertensives in GGHB are cared for solely by their general practitioner. There were 638 general practitioners in the Greater Glasgow area in 1986; the average list size was 1687 compared with 1668 in Scotland and each general practitioner had an average of four visits from each man and five visits from each woman on their list (ISD 1986).

From the figures in section 3.1, we can estimate that each general practitioner in GGHB might have a total of 105 individuals over 35 years old with diastolic pressures over 90mmHg including up to 30 patients with a diastolic pressure above 110mmHg, half of whom are already detected and some of whom may require specialist care.

General practitioners both within and outside GGHB can refer patients for specialist care to the GBPC in any of the hospitals in which it is based. Referral may also be made to the medical outpatient clinics in district hospitals. A survey carried out in 1987 (unpublished dissertation, Abdullah 1988) estimated that 50% of general practitioners in the whole of Glasgow used the GBPC in WIG despite the fact that only 22% of the sample surveyed were in the western area. Interestingly, those who used the GBPC differed from those who did not in the number of partners with more

likelihood that they were in a two-man practice ($p=0.0017$); no other differences were discovered and no explanation for the observed difference was found.

3.3 INITIAL INVESTIGATIONS

Summary: Four initial investigations were carried out. An audit of the Glasgow Blood Pressure Clinic patient population in one clinic indicated that up to 60% of referrals did not meet published standards for referral to specialists. General practitioners working in health centres were more likely to make a referral which met the standard. The "aim achieved" variable recorded for each patient in SWITCH was identified as a useful first step for selection of patients suitable for shared-care. The selection process eventually involved four steps of checking suitability and attendance status; this process identified 510 patients. A further 170 suitable patients were subsequently identified by consultants at clinic attendances and they differed from the first group only in having shorter clinic attendances. An algorithm was used to select a group of 401 comparable patients from the nurse-practitioner clinic. The proposed shared-care letters and computerised medical records were favourably received by a group of forty general practitioners.

3.3.1 Introduction:

Several investigations were carried out to obtain some initial information prior to the design and evaluation of the shared-care scheme.

Four studies were carried out to answer the following questions:

1. Who is referred to the Glasgow Blood Pressure Clinic, by whom and how appropriately?
2. What is the likely number of patients in the SWITCH system suitable for shared-care?
3. Can a method be devised to identify patients from the Stobhill Clinic who are similar to the patients identified as suitable for shared-care in terms of blood pressure control?
4. What do general practitioners in GGHB think of shared-care and the proposed records?

3.3.2 Investigation one: Who is referred, by whom and how appropriately?

Introduction: In order to assess and improve the efficiency of the referral process to the GBPC, some specific information would be required on the types of referral made, types of patient referred and the sources of referrals. This information was not available. I considered that assessing referrals against a standard obtained from the literature would provide a starting point for a study of the efficiency of the referral process.

I began the design of this study in 1986 but the data collection and analysis were eventually carried out by a postgraduate student as part of the requirement for the Master of Public Health degree and supervised jointly by Dr RB Jones and me. The results have been published (Juncosa, Jones & McGhee 1990).

Methods: The medical records of all new referrals made to the GBPC in the Western Infirmary over two years (May 1986 to May 1988) were audited for source of referral, gender and age of the patient, completeness of the referral letter and whether the reason for referral met one of two previously devised standards drawn from information available in the literature (Table 4).

Results: Two hundred and ninety-eight referrals to the GBPC in WIG were audited. Two hundred and six (69%) referrals were from general practitioners and 60 (29%) of these were from general practitioners in health centres. One hundred and nine (59%) of the patients referred by general practitioners were female and the mean age was 48 years. The mean blood pressure at referral was 168/101mmHg. Eighty four (41%) referrals met standard one and 134 (65%) met standard two. Referrals from general practitioners working in health centres were more likely to meet both standards ($p < 0.01$).

Discussion: The audit showed an interesting difference in the numbers of referrals from health centres which met the standards compared with the referrals which were not from health centres.

However, in total only 41% met a standard which was taken from the literature and probably represents a consensus view of the type of patient who requires referral. Some margin must be allowed because the standard is arbitrary and there will always be cases where the decision of whether or not to refer is difficult to make. However, 59% is a large margin. This small study indicates that some general practitioners may wish to use the clinic for the initial investigation and treatment of all hypertensives and are therefore referring not only those requiring specialist care. If this is so, perhaps the Clinic needs to consider whether and how to fulfil this perceived role. It indicates that there is a need for definition of the roles of specialist and general practitioner in the care of hypertensives in GGHB, although the roles of each need not be strictly determined. It perhaps also indicates a need for validation of the standards to be used in assessing referral practice.

3.3.3 Investigation two: Which patients are suitable for a shared-care scheme?

Introduction: Consultants at the GBPC felt that a large number of patients might have well-controlled blood pressure and be suitable candidates for shared-care between the specialist clinic and the general practitioner. Since the subjective opinion of the consultant in charge of a patient is likely to be the main determinant of whether a patient is transferred to shared-care, an attempt was made to identify those patients who were considered by their consultant to have well-controlled blood pressure rather than to use an arbitrary blood pressure level for selection. A pilot study was carried out to determine the precise methods to be used.

Stage one, pilot study:

At each consultation in the outpatient clinics of the GBPC a recording is made in the SWITCH patient record of whether the "aim of treatment" has been achieved. A sample of records was audited to determine the completeness of recording of this

variable, the numbers of patients with "aim achieved" and the numbers currently attending the clinic.

Method: The computer-produced summaries for the first 50 referred patients to the blood pressure clinics at WIG, GRI and Stobhill Hospital in the years 1975, 1980, 1982 and 1984 were audited; that is, 600 summaries in total.

The variables recorded were a) attendance status (whether current attender, dead, lost to follow-up b) treatment status (whether "aim achieved" or not). The status of "current attender" was given if no other attendance status was recorded in the summary.

Results: Two hundred and twenty-one (37%) of 600 patients sampled were classed as currently attending the clinic (Table 5). Of the current attenders, 210/221 (95%) had a recording of whether or not aim of treatment was achieved and 166 (75%) had "aim achieved". Since the total number of patients recorded on SWITCH for GRI and WIG in October 1985 was 4056, up to 1480 patients may be currently attending these clinics and 1110 may have aim achieved. Forty-four (20%) (95% confidence interval (95%CI): 15-25%) of the current attenders were recorded as having aim of treatment not achieved; in contrast, 77/241 (32%) (95%CI: 26-38%) of the "lost" patients were recorded as not having the aim of treatment achieved.

Discussion: The pilot study showed that recording of the target achieved variable was sufficiently complete to enable it to be used as a first step in identifying patients with well-controlled blood pressure. It also showed that up to 75% of the currently attending patients might be well-controlled. Of some concern is the fact that those who are "lost" are recorded as having poorer blood pressure control at their last clinic visit.

Stage two, identification of patients suitable for shared-care:

Methods: The steps in the process were

1. Selecting all those with "aim achieved" and apparently currently attending the WIG and GRI clinics.
2. Checking by project staff and consultants
3. Final check on attendance status
4. Analyses of the resulting patient characteristics.

1. Since the required information could not be extracted automatically from the records, the summary notes for every registered patient at the WIG and GRI clinics were screened and variables recorded as in the pilot study. Printed summaries were then obtained for all with "aim achieved" and apparently currently attending the clinic.

2. The printed summaries were checked by the medical staff working with the project to exclude obviously unsuitable patients, for example, patients whose therapy was clearly not yet settled or who were being actively investigated. The remaining summaries were given to the consultant responsible for each patient who was asked to classify the patient as suitable or unsuitable for shared-care.

3. Those classed as suitable for shared-care were screened again for attendance and only those with a definite future appointment were considered as potentially suitable candidates for a shared-care scheme since the intention was that the patients would be recruited at their next clinic visit.

4. The patients identified as suitable for shared-care in step 2 were compared with those classed as unsuitable. The characteristics compared were those considered likely to have affected the decision of suitability.

Additional step: During the recruitment of patients to the shared-care scheme, patients attended the clinics in WIG and GRI who were considered by their consultant to be suitable for shared-care but who had not been identified by the process outlined above. This gave a further 170 suitable patients. The characteristics of

these patients identified in the clinic were compared with those of the originally identified group.

Results: The numbers of patients at each step in the selection process is given in Figure 10. Of the 4046, 1384 (34%) were apparently currently attending while 1052 (26%) had been transferred to another source of care, 716 (18%) were dead and the current follow-up and clinical status of the remaining 891 (22%) was completely unknown.

Step 1 yielded 829 potentially suitable patients which was reduced to 644 by step 2. After step 3, 510 patients were still considered suitable candidates for shared-care.

Hence, of 1384 apparent current attenders, 644 (46%) were eventually considered suitable for a shared-care scheme, 829 (60%) having been selected on the basis of blood pressure control and 185 (13%) being subsequently excluded for clinical reasons, mainly by their own consultants. Characteristics of the excluded patients are shown in Table 6. The excluded patients had attended the clinic longer on average, their mean systolic and diastolic blood pressures were higher and the number of current drugs was greater than the others. Also, a patient at GRI had more likelihood of being excluded than one at WIG; perhaps reflecting the previously noted reluctance to discharge patients from the GRI clinic. Unfortunately, 134 (21%) of the 644 potentially suitable patients were subsequently found not to be current attenders mainly through loss to follow-up.

Comparison of the pre-selected patients with the clinic-selected group (Table 7) shows the clinic-selected group to have a shorter mean length of attendance at the clinic, fewer identified problems, slightly higher systolic pressure and slightly fewer recorded drugs.

Discussion: The clinic statistics described in section 3.1 may have underestimated current attendances at the clinic, with the number of attenders being 1384 (34%) of the 4046 audited patients rather

than 902/4294 (21%) as the statistics indicated. The actual numbers lost were 891/4046 (22%) compared with the previous estimate of 1503/4294 (35%). Nonetheless, 22% is a minimum figure and a further 21% of the patients suitable for shared-care were subsequently found also to be probably lost to follow-up. There was no mechanism in the clinic to follow-up patients after three defaults from clinic attendance. Since the pilot study had indicated that the "lost" patients included a third who had not achieved blood pressure control, these figures are a matter of concern.

A further 170 patients suitable for shared-care were identified at subsequent clinic attendances. These patients may in some cases have been too recently referred to be included in the selection process; this is borne out by the shorter average length of attendance. Some may have recently had poor blood pressure control although mean diastolic blood pressure at selection was not significantly different and this second group were now recommended as suitable by their consultant. The clinic-selected group also have fewer problems and slightly fewer drugs recorded in their record but this may be a function of their shorter clinic attendance. There is no significant difference in the number of patients classed at higher risk nor in the number selected from each of the clinics. The slightly different methods of selection appear to have resulted in two groups differing mainly in their length of attendance at the clinic.

In total, up to 59% of currently attending Blood Pressure Clinic patients were initially considered to be suitable for shared-care although 18% were unsuitable for this project having apparently recently defaulted from follow-up. Forty percent of the attending patients at the Clinic were eventually recruited, half to shared-care and half to the control group.

3.3.4 Investigation three - A method of selection of patients from the Stobhill Clinic:

Introduction: The Stobhill Hospital nurse-practitioner clinic computerised database includes a target blood pressure for each

patient. This target blood pressure is based on an arbitrary level of 160/90mmHg for over 60 year olds and 140/85mmHg for younger patients although it can be altered for individuals. Some of the patients registered on the Stobhill system are also on the SWITCH system. I wished to devise a method of selecting a group from this clinic comparable to the WIG and GRI groups identified as suitable for shared-care.

Methods: The records for 65 patients registered on both the Stobhill system and SWITCH were compared.

Results: An algorithm using the Stobhill target blood pressure was developed which classified 51/65 (78%) of the sample into the same group with respect to assessment of blood pressure control as the SWITCH test did (Table 8). This algorithm was: "those patients from the Stobhill Clinic whose most recent diastolic pressure is within their target diastolic + 5". When applied to the whole nurse-practitioner clinic population, using automatic selection from the database, the algorithm identified 401 patients currently attending the Stobhill Clinic.

Discussion: It appeared difficult to equate an assessment of blood pressure control based on arbitrary target blood pressures with one in which target blood pressures are not explicitly employed. However, the good correspondance achieved with the above algorithm probably indicates broad agreement among specialists about what constitutes good control of diastolic pressure. No such good agreement could be reached when systolic pressure was taken into account indicating perhaps that, in practice, systolic pressure is still not considered as important a prognostic factor as diastolic pressure despite the general burden of epidemiological evidence to the contrary (for example, Schofield 1987, Lichenstein, Shipley & Rose 1985).

3.3.5 Investigation four - Pilot study of general practitioners' opinions of shared-care and the computerised records:

Introduction: Before attempting to recruit general practitioners to the Shared-Care Scheme, a small survey was undertaken to determine the likely number of general practitioners who would participate, their opinions on the type of medical record to be used and the acceptability of the initial letters and documents explaining the Scheme.

Methods: A random group of 40 general practitioners were selected from those whose patients were considered suitable for shared-care. These general practitioners were sent drafts of the initial letter, an explanation of the Scheme, a copy of the proposed layout of the record and a covering letter asking for comments. This letter was signed by the Adviser in Postgraduate Medical Education.

Results: 37 (92%) general practitioners replied of whom 60% agreed to participate, 20% declined and 20% did not say. Many comments were made on the procedures, concept, documents and clinical record. These comments were mainly favourable; a few changes were made to the layout of the documents. In the light of the favourable response rate, the same method of contacting general practitioners was adopted for the main study.

CHAPTER FOUR: THE SHARED-CARE PROJECT

4.1 THE WEST OF SCOTLAND SHARED-CARE SCHEME FOR HYPERTENSION

Summary: The Shared-Care Scheme aims to co-ordinate specialist, general practitioner and laboratory services via the shared-care registry. The patient is given a role by carrying a summary record and having the responsibility to arrange annual reviews with his/her general practitioner after prompting by the Scheme. All procedures and checking of clinical results follow protocols agreed by the project Steering Group. The computerised medical records are updated annually and copies sent to the general practitioner and entered in hospital case notes. A re-referral clinic visit is available at short notice if required.

4.1.1 Introduction:

The problems inherent in the medical management of a patient by more than one agency have been described in Chapter 2. The aim of shared-care is to reduce these problems and to achieve a more cost-effective use of resources by integrating the contributions of several agencies to long-term follow-up. Patients with chronic disease are particularly suited to shared-care. Their care usually involves more than one medical care provider and more than one site of medical care. For example, an individual patient may be under the care of several general practitioners throughout his or her life; some of the routine follow-up may be undertaken by a nurse, specialist resources may be required at any stage, facilities such as laboratory services are required for routine investigations and long term therapy will require frequent contact with the pharmacist. Shared-care aims to co-ordinate the activities of these various groups in one patient's care and to improve the collection and utilisation of clinical information relating to that patient.

Various procedural designs of a shared-care scheme are possible; for example, this approach has been used for the care of patients with diabetes - (Hill 1976, Day et al 1987) thyroid disease - the WAFUR (Lazarus 1978) and SAFUR Schemes (Hedley 1984) and hypertension (Petrie et al 1985). These schemes have been described in Chapter 2.

4.1.2 Chronological development:

Since 1968, the Glasgow Blood Pressure Clinic has provided a secondary referral service to general practitioners and other hospital departments. There has been a long-standing interest in shared-care in the Clinic and both the SAFUR thyroid scheme and the Grampian hypertension shared-care scheme were considered. It was, however, felt that an approach different from that adopted in Grampian was required in GGHB and the system was therefore designed as a fully evaluated pilot study based on the SAFUR system.

A multidisciplinary Steering Group was formed with representation from the Glasgow Blood Pressure Clinic, University of Glasgow departments of Community Medicine, General Practice, Materia Medica and Medicine. A preliminary protocol was designed and obtained funding from the Scottish Home and Health Department and the British Heart Foundation. Project research staff were appointed in 1985 to design, implement and evaluate the Shared-Care Scheme and clerical staff were appointed in 1986.

4.1.3 Overview of the Scheme:

The purpose of the Scheme is to ensure patient follow-up based on general practitioner care with specialist back-up when required. Each participant in the patient's care has a specified role and the Shared-Care Scheme acts as a co-ordinator maintaining communication between them.

A central office with a computerised register maintains links with general practitioners, patients, specialists and laboratories (Figure 11). Communication between patient and general practitioner takes place without necessarily involving the Scheme but is assisted by annual reminders to patient and general practitioner and the issue to the patient of a copy of the medical record which can be carried to each consultation. Communication between the general practitioner and laboratory or electrocardiograph (ECG) department normally takes place via the Scheme as does communication between specialist and general practitioner or patient. This arrangement has the advantage that one agency, the shared-care registry, maintains a complete and up-to-date picture of an individual patient's care which is communicated to all relevant parties.

Patient follow-up is based on a cycle of care (Figure 12). Each part of the cycle is described in section 4.1.4 but briefly, the system aims to ensure that all patients have an annual review with their general practitioner and re-assessment of their clinical status by a specialist with adjustment to their follow-up plans if necessary. Protocols are used for follow-up, review and screening of results.

In contrast with more traditional methods of care, patients are given a substantial role in the shared-care system. They initiate the annual consultations with their general practitioner after prompting by the registry, carry a copy of their medical record, are encouraged to audit and amend the data in the record and have access to advice and assistance from the shared-care registry at any time.

The hardware used to maintain the register and print the patient records is a DEC PDP 11 micro-computer with hard disc and two dot-matrix printers, one of which is a colour printer. The system software is based on the diabetic register in operation in 1985 in Nottingham and now adopted by Trent Regional Health Authority. This system is written in MUMPS (Young 1984) and I learned the MUMPS language in order to

rewrite all of the sub-routines which were required for the hypertension system. The data collection routines were altered to allow input of the information relevant to the care of hypertensive rather than diabetic patients and the output routines were formatted to produce the re-designed records. The routines required further alteration to tailor the processes to a shared-care approach. As Project Leader, I was responsible for all maintenance and upgrading of the system software while it remained in MUMPS. The shared-care system will eventually be part of the new GBPC clinical information system in PICK Libra but, for the duration of the project, shared-care operated as a stand-alone system.

4.1.4 The database, records and procedures of the Scheme:

The database: Each patient has a record in the shared-care database which contains personal, social, demographic details and clinical information, including previous history, problem and treatment lists and flowcharts for cumulative clinical data. The data recorded was agreed by the project steering group as that useful for the long-term follow-up of this patient group and is totally compatible with the GBPC database. Table 9 lists the items recorded for each patient and Table 10 gives details of the biochemistry and urine screening tests required. Initial data, taken from existing outpatient records, is supplemented by a patient questionnaire completed at registration (see Appendix 1). The computer record is created when the patient is registered and updated whenever new information is obtained from patient, general practice, hospital or laboratory. Full updating of clinical details normally takes place once a year after the annual review.

Computerised dictionaries are used to store problem and treatment list items. Each new entry is compared against a list and, if already present, that dictionary code is stored in the patient's record. If not already present in the dictionary, the new item is added and given a new code. This assists standardisation of the entries, facilitates identification of

patient groups by items listed in the dictionary and also makes possible some of the features of the records, for example, the lay translation of medical terms in the patient-carried record. Figure 13 shows how the items in the problem list dictionary are linked to the other dictionaries by their code.

The records: Although only one set of data is held on each patient, three sets of records are produced - for patient, general practitioner and specialist - so that all participants can contribute to, audit and share the same information. This has benefits in reducing manual duplication of information and the consequent errors and in ensuring that no set of records has missing information. The records are structured to assist the collection of relevant information, to display it conveniently and to allow easy updating when required.

Doctors' record: The records for the general practitioner and the specialist have the same format (Appendix 3). They have two pages - page one contains personal details, smoking and drinking habits, family history, problem and treatment lists and a problem checklist. Page two contains the latest clinical details and space for recording the results of further consultations. The general practitioner's record is printed on two-part paper so that the top copy can be returned annually to the registry for updating of the computer record while the bottom copy remains in the practice notes until an updated version is received from the registry. The specialist's version on one-part paper can be put into the A4 hospital notes.

The patient-carried record: This is printed from the same database as the doctors' records (Appendix 3). It contains past and present treatment lists, inactive and active diagnoses, personal details and habits. All of these are exactly as printed on the doctors' records except that the problem list does not contain any diagnosis which is put under the heading "Not on patient-held record". A protocol for determining which items should be put under this heading was devised during the study (Table 11). Space is provided for recording blood

pressure measurements, weight and targets. The booklet is therefore a detailed summary of a patient's social, medical and therapeutic profile.

Items in the problem list are printed with a "lay" translation alongside. This was achieved by building up a separate dictionary of lay translations of the items in the problem list dictionary (see Figure 13). Each problem list item can have two lines in the problem dictionary; the first line is a standardised statement of the problem and the second is a descriptor or comment. These two lines are printed in full on the doctors' records but the second line is replaced by the lay translation, from the lay dictionary, on the patient's copy.

A colour printer is used to print the information on the patient's record to make it more legible and attractive. This record is made up in the form of a booklet so that it is easily carried. The booklet contains lifestyle advice tailored to hypertensive patients, is called a Personal Health Booklet (PHB) and is sent either to the general practitioner or direct to the patient depending on a protocol developed during the study (Figure 14). It is returned to the registry annually for updating.

Procedures of the Scheme:

Patient registration: all patients who have been registered in the shared-care scheme to date were originally hospital outpatients. The patient was told of the scheme and registered at the outpatient visit. The patient record is created immediately following registration and a Personal Health Booklet is sent to the patient either directly or through the general practitioner. Subsequent communication with patients is made routinely by post but may also be by telephone or through the general practitioner. Contact with patients is normally only made when the annual review is due or if either the specialist or general practitioner requests that the patient be contacted.

Patients are invited to contact the Scheme at any time for advice, assistance or further information.

General practitioner registration: General practitioners were contacted at the beginning of the study and asked to participate. Thereafter, the general practitioner is notified immediately a patient is transferred to the Scheme and is sent a copy of the record very shortly afterwards. Further contact is only made by the Scheme when the annual review is due unless problems occur before then. General practitioners are also invited to contact the Scheme at any time for advice or further information.

Review procedure: The procedure at each stage is as follows:

1. Patient is prompted to arrange a review with his/her general practitioner. The general practitioner is sent a shared-care pack - completed laboratory request forms, sample bottles and a procedure checklist.
2. Results of the clinical review are returned by the general practitioner to the registry on the top copy of the shared-care record form; biochemistry results and ECG tracings come direct from these departments to the registry. The data is entered and abnormal results flagged according to a protocol (Table 12). The specialist screens all sets of results and classifies them into four categories:

Category:	Description:	Suggested action:
(1)	unremarkable results	none
(2)	slightly incomplete or slightly abnormal results	suggest repeat tests*
(3)	definite abnormal results	advise repeat* and offer re-referral appointment
(4)	loss of BP control	advise change in therapy* and offer re-referral appointment

* The general practitioner is asked to notify the registry of any repeat test results or therapy changes and these results are screened again

3. Each of the above categories is linked to a standard letter which is enclosed with the updated copy of the record to the general practitioner. An updated PHB is sent to the patient or general practitioner and results entered into the hospital case notes.

4. If the review was classified as 3 or 4, a further contact is made with the general practitioner if no response has been received within one month. If a re-referral visit is requested, this is arranged as soon as possible.

5. During the intra-review period, the frequency of medical care contacts is determined by the general practitioner and patient.

Re-referral clinic: Shared-care patients can have a clinic appointment at short notice on the request of their general practitioner. The patient can be seen between one and six times at this re-referral clinic before a decision is made to return him or her to shared-care or to the outpatient clinic.

The re-referral clinic was run, during the period of the study by a middle-grade registrar with a strong background in the management of hypertension and in clinical research in this area.

4.2 THE EVALUATION OF THE SHARED-CARE PROJECT

Summary: The aim of the evaluation was to examine the feasibility, acceptability and cost-effectiveness of the Shared-Care Scheme. The null hypothesis was that "there is no difference in the acceptability, effectiveness and cost of shared-care, traditional outpatient care and nurse-practitioner care. The effectiveness of shared-care was compared with that of outpatient and nurse-practitioner care by measuring the number of complete reviews in year 2. In order to have 80% power to detect a difference in follow-up of 10% at the 5% level of significance, approximately 300 patients were required in each study group. Loss to follow-up, patients' perceptions and attitudes to their health and blood pressure control were compared. Acceptability of shared-care was compared by several approaches using subjective and objective data, for example, preferences and changes in cost of travel for patients. A cost-effectiveness approach for the economic evaluation gave a directly comparable unit cost per satisfactory review for each of the three patient groups. Data were collected from medical records, questionnaires, comments and observations.

4.2.1 Aims and objectives:

Aim: The aim of the shared-care project is to examine the feasibility, acceptability and cost-effectiveness of shared-care for hypertensive patients.

Objectives:

1. To examine the feasibility of the West of Scotland Shared-care Scheme for Hypertension both in the short and longer term.
2. To examine the acceptability to patients and general practitioners of the Shared-care Scheme compared with traditional outpatient care and nurse practitioner care.

3. To compare the cost-effectiveness of each method of care in maintaining regular patient follow-up.

Null hypothesis: there is no difference in the acceptability, effectiveness and cost of shared-care, traditional outpatient care and nurse-practitioner care.

4.2.2 Patient populations and recruitment methods:

Populations:

Three comparable groups of patients were monitored; they comprised patients who were:

- a) enrolled and followed-up in the Shared-care Scheme (SC group)
- b) followed-up in the outpatient clinic (BPC group)
- c) followed-up in the nurse-practitioner clinic (NPC group).

The outpatients attending GBPC in the two large teaching hospitals, the Western Infirmary (WIG) and the Royal Infirmary (GRI) were taken as the sampling frame for the selection of patients for the SC and BPC groups and those attending Stobhill Hospital nurse-practitioner clinic formed the sampling frame for the NPC group.

Sample size: One should plan a study so that differences large enough to be clinically important are likely, if they really exist, to be statistically significant and thus to be detected; that is, the power of the study should be sufficiently high (Armitage and Berry 1987). One of the main factors affecting the power of a test is the sample size. Since some parameters are often unknown at the start of a study, for example, the proportion of the control group who exhibit a particular feature, assumptions may need to be made in order to determine an adequate sample size.

In this case, the number of patients required to give adequate power to the study was initially calculated assuming a) that the

cumulative incidence of unsatisfactory follow-up in any group at between twenty and thirty months of follow-up might be around 20% (p_0), b) that we would require to detect a minimum difference of plus or minus 10% (p_1) between the groups and c) that we want to have an 80% ($1-\beta$) chance of detecting such a difference at the 5% (α) level of significance. With these estimates and using the formula for calculating the minimum number of individuals required

$$\text{number} = 2\bar{p}\bar{q}(z_{\alpha} + z_{\beta})^2 / (p_1 - p_0)^2$$

$$\bar{p} = .5(p_1 + p_0) \quad \bar{q} = 1 - \bar{p}$$

(Schlesselman 1982, p145)

we require 199 individuals in the smallest group. This formula is for unmatched samples; any relevant matching will increase the power of the study. Up to 100 additional patients in each group would be desirable in order to compensate for deaths, migration and withdrawals. Thus the optimum number in each of the clinic and shared-care groups is around 300 patients. This calculation verified that the GBPC would be a suitable source of patients since the pilot study had indicated that more than this number of suitable patients were attending the Clinic.

Matching, randomisation and recruitment of patients:

Methods: A matched design was chosen to minimise possible bias in the randomisation and recruitment of patients to the shared-care and outpatient groups and to ensure similarity for important variables. The variables used in the matching were a) whether pre-selected or clinic-selected b) the clinic attended (WIG OR GRI) c) gender d) age e) length of attendance at clinic. Age was matched to within five years or closer, length of attendance was best possible match.

Within the pairs, patients were randomly allocated to shared-care (SC) or continuing outpatient attendance (BPC). Recruitment of the patients took place over a year (April 1986 to March 1987) in order to minimise disruption of the outpatient clinic and to allow patients to be recruited at their normal

clinic visits. Prior to their visit, all SC and BPC patients were sent a questionnaire and asked to return it at their next visit.

Recruitment took place at the next outpatient appointment and only those who attended were recruited. Those allocated to shared-care were transferred to the Scheme at this appointment, if their general practitioner had agreed to participate. If the general practitioner had not agreed or the patient did not attend, the partners were re-matched and re-randomized. If the selected patient was no longer considered suitable for shared-care by the consultant in charge of the patient, both patient and partner were dropped from the study. The group allocated to continuing outpatient attendance was not approached other than to return the questionnaire.

The 170 patients identified in the clinic were matched and randomized at the appointment at which they were identified as suitable for shared-care. If the general practitioner was not participating, the patient was dropped from the study. Those allocated to shared-care were registered with the Scheme and asked to complete and post back the questionnaire. Those allocated to continuing outpatient attendance were asked only to complete and post back the questionnaire.

The 401 selected patients in the nurse-practitioner clinic (NPC) were matched for age and gender with the recruited SC patients. The resulting group of 277 patients was asked to complete a questionnaire and return it at their next appointment in the nurse-practitioner clinic.

The patients recruited were compared with those not recruited either because they were declared no longer suitable or because they did not attend. The characteristics compared were those which might have affected recruitment and been known in advance, that is, age, sex, length of attendance at clinic, the number of problems recorded and the number of drugs being taken.

The power of the study was calculated, based on the number of patients actually recruited.

Results: The sampling frame for patients is shown in Figure 15. Two hundred and seventy-seven (277) pairs in total were recruited to the shared-care and outpatient groups and 277 to the nurse clinic control group.

Of the 510 pre-selected patients, 196 pairs, that is, 392 individuals, were recruited (Figure 16). This was 77% of those expected to be recruited. Eleven patients did not attend, 5 had not been matched, 64 had been allocated to shared-care but were not recruited, 26 because their general practitioner had not agreed to participate and 38 for other reasons (Table 13); the partners of these 38 were also not recruited.

From the clinic-identified group, 81 pairs were recruited and 8 could not be matched.

These 196 and 81 pairs made up the total number of 277 pairs of SC and BPC matched patients.

Characteristics of the patients are shown in Tables 14 and 15. There are no significant differences between the recruited and non-recruited patients in the characteristics listed except that the non-attenders are younger. However, the numbers of non-recruited patients are small. There is a trend for the unsuitable patients to have been attending for a shorter time and for the non-attenders to have a larger number of problems and to be female. The patients recruited to the shared-care and outpatient groups by the two methods differ only in length of clinic attendance, number of drugs and number of recorded problems. It has been assumed for the purposes of the evaluation that these patients form one group although their similarity for all measured variables will be further verified as required.

The actual number of patients recruited into each group (277) was used in the formula for calculation of the power of the study with estimates (as before) that unsatisfactory follow-up could be 20% over two years and that we require to detect a difference of at least plus or minus 10% between groups. The formula used is

$$z_{\beta} = [277(p_1 - p_0)^2 / 2\bar{p}\bar{q}]^{1/2} - z_{\alpha}$$

$$\text{and power} = 1 - \beta$$

(Schlesselman 1982, p149)

For 95% certainty of detecting this difference, the calculated power is 91%. The power remains above 80% even if 78 (28%) patients were lost from each group and could not be compared. With 277 patients, we can detect a difference of plus or minus 5% from the baseline of 20% with 95% certainty and a difference of 5% in loss to follow-up might be important. The power reduces to just over 60% power to detect a difference of 5% from a baseline of 10% with 95% certainty. This calculation applies to the main outcome variable of unsatisfactory follow-up although a similar power will be obtained for comparisons of other variables under the same assumptions. As already mentioned, the matching increases the power of the study to detect a difference in the variables which are likely to be affected by the matched attributes of method of selection, clinic attended, age, gender and length of clinic attendance.

Discussion: The younger age of the non-attenders has been shown in other studies (for example, Degoulet et al 1983). The tendency for the non-attenders to be female does not agree with previous studies and the possible tendency for them to have a higher number of problems may be of concern. Unfortunately, their numbers were possibly too few to uncover significant differences in these variables.

Similarly, the small number of unsuitable patients may have given inadequate power to detect a significant difference in the length of attendance; these patients may have been attending for a shorter period. However, the values for all other variables are very similar to those for the recruited patients.

Interestingly, the reasons given for the exclusion of some patients from shared-care, such as diabetes and renal disease include conditions found among the recruited patients. There appears to be no clear agreement of the type of patient suitable for shared-care in terms of current or past organ damage.

4.2.3 Recruitment of general practitioners, laboratories and ECG departments:

General practitioners: The population of general practitioners chosen for the study was determined by selection of their patients into the shared-care study group.

Methods: A letter inviting participation, signed by the Regional Adviser in Postgraduate Medicine, was sent to these general practitioners (n=297) with information explaining the procedures of the Scheme. Two reminders and letters asking that they reconsider were sent as appropriate. Participators and non-participators (replied negatively or did not reply) were assessed for gender, date of qualification, type of practice, whether they belonged to a training practice, number of partners and geographical area. The characteristics of those who agreed to participate were compared with those of the non-participators and of all general practitioners in GGHB.

Results: The sampling frame is shown in Figure 17. Of those invited, 251 (85%) accepted, 9 (3%) did not reply and 37 (12%) refused. The most frequent reason given for not participating was imminent retirement and two of those who gave no reason retired within a few months. A few general practitioners were unwilling to take on the extra work which they perceived would be generated and two felt there was no need for the Scheme, one because he had his own follow-up system and one who felt that the present arrangement with the GBPC was adequate.

The comparison of invited general practitioners in GGHB with those not invited shows no significant differences (Table 16); it appears that the invited general practitioners are a representative sample of all GGHB general practitioners.

The only significant differences between those who agreed to participate and those who did not is in the number who work from health centres (43% of the participators and only 22% of the non-participators) and in the numbers qualified in the last five years (51% and 35%) (Table 17). One hundred and eighty two general practitioners eventually had a patient enrolled in the Scheme.

Discussion: The high percentage of general practitioners who initially agreed to participate is encouraging and indicates a degree of acceptability of the concept and proposed procedures of the Scheme.

The difference in rates of participation between health centre general practitioners and non-health centre general practitioners is interesting in light of the previous finding that referrals from health centres were more likely to meet an arbitrary standard for appropriate referral (section 3.3.2). There appears to be a difference between the groups in their attitude towards the use of specialist services. The only detected demographic difference which might contribute to this difference in attitudes was the excess of more recently qualified, and hence probably younger, doctors among the participants.

Biochemistry laboratories and ECG departments: The laboratories used by individual general practitioners were identified, informed about the requirements of the Scheme for biochemistry services and asked to identify any potential problems in supplying these. In total, ten laboratories were approached and none anticipated problems; two commented particularly that the number of samples involved was relatively very small, a "drop in the ocean".

Arrangements were made for ECGs to be offered to patients whose general practitioner was unable to offer this service. These arrangements were made via two ECG departments, one in WIG which offered an open facility in the hospital where patients could "walk in" and one in GRI which operated a service on certain days in local health centres or a bookable service in the hospital. Forty-eight percent of general practitioners claimed to be unable to carry out their own ECGs at the start of the study. This affected 126 (49%) of the SC patient group.

4.2.4 Framework of the Evaluation

Introduction: The three patient groups, shared-care (SC), outpatient clinic (BPC) and nurse-practitioner clinic (NPC) were to be monitored over two years for variables relating to the effectiveness, acceptability and cost of the process of care and the SC group was to be monitored for variables relating to the feasibility of shared-care.

There are many possible variables which could have been measured and at different stages in the project. It was considered important to define the principal measured variables as early as possible in the study and the following framework was determined before any evaluation began. The precise methods used in this study are described under the four headings of effectiveness, acceptability, economic evaluation and feasibility and further detail of methods is given at the beginning of each of the Chapters 5, 6 and 7, with the results. Some of the variables measured provided information for more than one aspect of the evaluation.

Evaluation of effectiveness: The objective of this evaluation was to compare the three methods of care in terms of the achievement of their stated objective of maintaining continuous follow-up and review of well-controlled hypertensive patients. It was not possible, in this study, to measure the success of the three programmes in health outcomes such as reduced

mortality or morbidity because of the confounding effects of many other variables. Furthermore, these outcomes would only be measurable with accuracy over a long time scale. Even intermediate health outcomes, such as the maintenance of blood pressure control present difficulties as an outcome measure because they cannot be attributed solely to the method of follow-up and are notoriously difficult to compare between sites.

In order to restrict, as far as possible, the effect of other variables and to minimise measurement error, an output which was easily measurable and which depended directly on the activities of the programmes was chosen. The variable chosen was "the number of satisfactory reviews in year 2 in each patient group" where "satisfactory" means that three specified investigations were carried out. This output variable reflects directly the success of each method of care in achieving continuous review of the patients. It is assumed that this output is directly related to improvements in health. This seems to be a valid assumption; if well-controlled patients are reviewed regularly they should experience reduced morbidity and mortality since complications are likely to be detected at an earlier stage than if review were infrequent or non-existent.

As discussed earlier, the study is able to detect with a power of greater than 80%, a difference of 5% or more from a baseline of around 20% unsuccessful follow-ups (or unsuccessful reviews) in the control groups. The study sample size was chosen to give adequate power to the comparison of the main outcome variable. In the case of secondary outcome variables, where subgroups of patients are being examined, it is quite likely that the power of any statistical test may be inadequate to detect significant differences. In these cases, the power is calculated to ascertain whether inadequate power may be an explanation for the insignificant result.

Besides the main outcome variable of number of satisfactory reviews, several intermediate health outcome variables were

measured; blood pressure control was monitored, patient perceptions of and attitudes to their own health was compared and the number and reasons for re-referral visits for the SC group were noted. Other process variables measured were the percentage of patients lost to follow-up and the completeness of the investigation results recorded in the clinical database. Results of the effectiveness evaluation are in Chapter 5. The use of the medical records, the number of consultations and the number of investigations also reflect the effectiveness of each method of care and, to some extent, their acceptability, cost and feasibility; they are discussed, as appropriate, in later sections.

Evaluation of acceptability: The objective of this evaluation was to measure the acceptability of the Shared-Care Scheme to patients and general practitioners.

At its crudest level, the acceptability of shared-care was measured by the drop-out rate. To refine this measure, reasons for drop-out were recorded when possible though these could not usually be verified.

The SC group were asked which method of care they preferred. General practitioners were asked to rank shared-care with the other possible methods of care.

As a direct comparison, the SC and BPC groups of patients were asked to list the advantages and disadvantages which they considered to apply to their current method of care. Similarly, shared-care general practitioners were asked to list advantages and disadvantages of shared-care, comments and suggestions.

As a more subtle approach, the perceptions of each patient group as to the most appropriate location of care, that is, clinic or surgery, were sought.

Finally, an objective approach was used in which factors which could be considered to relate strongly to acceptability were measured and compared.

Whenever possible, each of these approaches was tested for validity by cross-checking results with those from related questionnaire items. Characteristics of subgroups were analysed with the intention of identifying any associations between the characteristics and preferences for methods of care. Results are presented in Chapter 6.

Economic evaluation: The objective of the economic evaluation was to compare the effectiveness of each method in combination with the costs incurred. Shared-care, the Blood Pressure Clinic and the nurse-practitioner clinic all aim to provide regular follow-up and review of well-controlled hypertensive patients. It is likely that they will each achieve this objective to differing degrees while incurring different costs. A cost-effectiveness analysis can be used where programmes with a similar output are being compared (Drummond et al 1987). The question to be answered is "How much does it cost to produce one unit of output from each method of care?". The cost-effectiveness analysis consists of measuring the amount of output from each programme, measuring all relevant costs and calculating cost per unit of output; these cost-effectiveness ratios can then be directly compared. This method of analysis was considered to be suitable for this evaluation; the precise costs included and results of the analysis are described in Chapter 7.

Evaluation of feasibility: If shared-care is to be a feasible method of care, it must be possible to implement the procedures, obtain a reasonable level of effectiveness, at reasonable cost and with a reasonable degree of acceptability. This draws on results of all the above areas of evaluation and is discussed in Chapter 8.

4.2.5 Sources of data, methods of collection and statistical analysis:

Data was collected

- 1) by monitoring of patient records for all three groups of patients over two to three years
- 2) from questionnaires to patients, doctors and laboratories
- 3) by observation of procedures in the relevant clinics and offices
- 4) from recording of comments made at all stages by all participants and
- 5) by calculation of costs of care using the above data and published information, where relevant.

Monitoring of patient records: All patients in the study were registered on the shared-care database. The SC patient records were updated from the routinely collected information coming in to the shared-care registry. The BPC patient records in the clinic were regularly audited for the variables in the shared-care database and the computer records updated. Copies of the NPC patient records were obtained from the nurse clinic computer system and used to update the database.

After thirty-eight months, an audit of the computerised database was carried out. The variables recorded were: current status of the patient, that is, dead, attending, lost; number of visits to the clinic (BPC and NPC groups and re-referred SC patients); number of annual reviews; completeness of annual reviews (that is, whether blood pressure, blood test results and/or ECG result present); clinical variables (weight, blood pressure), number of problem list entries and risk factors; number and details of current drugs.

Each of the above was recorded at recruitment, after one and after two years.

Patient-completed questionnaires:

The principal questionnaire was designed to:

- 1) check patient details collected from hospital records such as current general practitioner, date of birth, smoking and drinking habits and family history;
- 2) collect information relating to the acceptability of methods of care
- 3) collect information relating to the self-perceived health status of the patients in each group and
- 4) collect information on costs of care.

This questionnaire was distributed both at the beginning of the study and thirty months later.

A further questionnaire (Appendix 1) was sent to SC patients at thirty months to investigate the acceptability of the Personal Health Booklet (PHB).

Development: Purpose-designed questionnaires were used because a large amount of specific information was sought. In the initial stages, the Nottingham Health Profile (Hunt, McEwen & McKenna 1986) was considered for assessment of health status but rejected as being too extreme for hypertensive patients who are often symptomless. This limitation of the Health Profile has also been noted by other groups (for example, Jenkinson, Fitzpatrick & Argyle 1988). As far as possible, parts of other, previously validated, questionnaires were used. These included the Heartbeat Wales and the Good-Hearted Glasgow questionnaires which were obtained from the relevant project staff.

The development of the questionnaires was a lengthy process involving several drafts which were distributed to the Steering Group and GBPC consultants whose comments were incorporated. The main questionnaire was long since it included many questions relating to knowledge and health beliefs which are the subject of another thesis and were written by another researcher; I designed those questions relating to the data I wished to collect.

Pilot: A blood pressure clinic which would not contribute any patients to the study was used to pilot the main questionnaire. Fifty questionnaires were distributed, returned and analysed and further changes to the layout and language were made. The final draft of the questionnaires was approved by all consultants likely to contribute patients to the study.

The questionnaires at the beginning of the study were sent out by post and patients were asked to return these to the clinic. The two questionnaires at thirty months were sent out and returned by post. Where necessary, two reminders were sent out.

The questionnaire on the PHB was piloted by staged administration. It was posted, initially, to a small group of patients; since no problems were detected, it was sent to the remainder.

Response rates: These are shown in Table 18. The response to the main questionnaire was over 80%. Only those patients who had answered both the first and second questionnaires were included in the analyses. This gave final response rates of over 70% for the two control groups and over 80% for the SC group. The completeness of response for each question varied but was fairly high in most cases. Of the 218 who completed questionnaires for the SC group, between 94% and 96% answered each question on attitudes and 93% to 99% answered the questions on costs. Each table of results shows the denominators on which the results are based. It has been assumed that any missing data would not be significantly different from that which was obtained. The large numbers of patients in each group justify this assumption.

Characteristics of the responders and non-responders are very similar (Table 19); there are no significant differences in any group.

The response to the questionnaire on the PHB was also over 80%.

General practitioner questionnaire:

This is in Appendix 1 and was sent by post at the end of the two year follow-up to all of the general practitioners who had been allocated SC patients. It investigated the acceptability of shared-care from the general practitioner's point of view and encouraged comments and suggestions for improvements.

Development and piloting: There is very little previous work on the assessment of acceptability of methods of care to general practitioners and no suitable, existing questionnaires. Again, a questionnaire was designed and approved by the Steering Group. The first twenty participating general practitioners on an alphabetical list were used to pilot this questionnaire and, since no problems were detected, the remainder of the questionnaires were distributed. Two reminders were sent, as necessary.

Response rates: 147/176 (84%) of general practitioners responded to the questionnaire (6 had died, left the practice or retired). Characteristics of responders and non-responders show no differences (Table 20). Again, it has been assumed that the missing data is no different from that collected.

Biochemist questionnaire:

This is in Appendix 1 and was sent by post to the chief biochemist in all participating laboratories. It investigated the acceptability of the shared-care procedures for testing of blood samples.

Development: This was a purpose-designed questionnaire, approved by the Steering Group. No reminders were required since the initial response rate was 100% (10/10).

Observations:

Clinic procedures: Observation of clinic sessions gave information on a) numbers and types of staff b) length of consultations and c) activities carried out in the clinics.

GBPC and Stobhill data books: Numbers of patients attending, numbers of visits and numbers of patients lost or dead were obtained from sources of data within the GBPC and the Stobhill Clinic.

Comments: All comments recorded on shared-care documents or made by telephone were noted in a log book and analysed.

Published sources: The details of the costing are given in Chapter 7. Information relating to costs, for example, salaries, was obtained from published sources and the source is quoted in each case.

Statistical analysis:

In most cases where interest was in the difference between the initial and two year values, the three groups have been compared at the outset and the initial and two year values are then compared within each group using the appropriate test for matched samples. In the two year comparison of the clinical variables, in order to take account of changes over time as well as possibly different baseline data, the changes from initial results to year 2 results are compared using one-sample t-tests with the pairs being the matched patients in the SC group with their BPC and NPC partners.

The statistical tests used are:

a) **Wilcoxon test** for matched samples for comparison of non-parametric initial and two year data within groups; this is used, for example, for comparison of changes in responses to the questions about attitudes to health.

- b) **McNemar's test** for matched samples for the same type of data as above when the variable being tested is dichotomous.
- c) A **one-sample t-test**, for comparing matched pairs or before and after parametric data which fits the necessary assumptions.
- d) Calculation of **95% confidence intervals** for comparison of proportions between groups; this method has been used as much as possible because of the extra information given by displaying the interval. Where interest is principally in the size of the difference between proportions, the appropriate 95% confidence interval for the difference is displayed with the actual difference.
- f) **Chi-square test** to detect association between independent variables.

All analysis was carried out on the University's mainframe computer using an interactive SPSSX package.

CHAPTER FIVE: EVALUATION OF EFFECTIVENESS

5.1 POPULATION AND METHODS

Summary: Recruitment resulted in three comparable groups of 277 patients. The main outcome variable was "satisfactory reviews" in year two and was determined by whether certain investigation results were available. Several other secondary outcome measures were used including changes in clinical variables. Standard statistical tests were used and bias reduced by not disclosing the nature of the evaluation to those involved.

5.1.1 Introduction:

The framework of the effectiveness evaluation is described in section 4.2.4. This section describes the recruited population and precise methods used for the evaluation. The outcome variables are summarised in Table 21.

5.1.2 Population:

Three matched groups of outpatient attenders were compared. Randomisation and recruitment of patients to the study is discussed in Chapter 4 and resulted in 277 patients being allocated to the shared-care (SC), Blood Pressure Clinic (BPC) and nurse practitioner clinic (NPC) groups.

5.1.3 Methods used for the measurement of the maintenance of follow-up and the completeness of reviews:

The principal process variable is the ability of each method of care to maintain patient follow-up including a review with a particular set of results, that is, a "complete" review. The number of complete reviews in year two was determined by monitoring the appropriate set of medical records for each group of patients. All review results were categorised (A to C) according to completeness (see Table 22) with categories A and B being considered satisfactory.

The "percentage effectiveness" (the proportion satisfactorily reviewed out of those in the group at the start of follow-up, excluding the deaths) was calculated. Reasons for a failed review and characteristics of the unreviewed patients and their general practitioners were examined.

5.1.4 Methods of assessment of health status

Self perceived health status and patient attitudes to their health: Patients were asked to rate their own health state before and after the study period in the questionnaires described in Chapter 4. Three items (Table 23) assessed changes in patient perceptions of and attitudes to their own health. A further item determined whether more patients knew their blood pressure measurement in year two.

Clinical information: The maintenance of health status was also measured by monitoring clinical variables (serum potassium, creatinine and body mass index) at the beginning and end of the study. Target blood pressure levels for different age groups were set and patients were classed into levels 1-5 representing good to poor blood pressure control (Table 24). The targets used were derived from a survey of members of the British Hypertension Society (Waller, McInnes & Reid 1990). All clinical information was collected retrospectively from the appropriate medical records. Finally, the number who died during the study was recorded.

5.1.5 Statistical analysis:

The statistical tests used are described in section 4.2.5. In each case, the test used is indicated in the Table with the test statistic, if appropriate. The probability (p), 95% confidence interval of an estimate (95%CI) or 95% confidence interval for the difference between two estimates (95%CI diff) is given in the text or table.

5.1.6 Control for bias:

Bias might exist if any of the three groups of medical attendants were aware of which patients were being studied or the evaluation methods. As far as possible, this was avoided by a) not identifying the clinic patients, b) not indicating the outcome measures to specialists or nurses and c) not indicating to general practitioners that the Scheme was being evaluated.

There is also an unquantifiable degree of measurement bias in the comparison of blood pressure readings due to different observers, instruments and techniques. One example of this is demonstrated by the analysis of terminal digits which is discussed in section 5.2.5. However, the values for other biochemical measurements, for example serum creatinine, are not so susceptible to this type of bias, because their estimation is made, not subjectively by observers, but objectively by machine within known limits of error.

5.2 RESULTS

Summary: There were no initial differences between the groups in demographic or clinical characteristics. Over the two years the drop-out rate from shared-care was significantly less than that from the Blood Pressure Clinic or the nurse-practitioner clinic (3%, 14% and 9% respectively). Those shared-care patients who returned to clinic care tended to be female and have less well-controlled blood pressure. Shared-care was more effective than both clinics in ensuring a review (91%, 70% and 81% respectively) and more effective than the outpatient clinic at ensuring a complete review (82% versus 54%). The NPC records tended to be more complete than the BPC or SC records but all were fairly complete, at least for certain variables. There were no recorded differences between groups or over the two years in self-perceived health status or attitudes to health care. However, both the SC and BPC groups had more patients in year 2 than in year 1 who knew their own blood pressure reading. The only change in clinical variables was a rise in the mean serum potassium level in the SC group over the two years. There was very clear terminal digit preference in blood pressure measurements for the SC group. Two thirds of the SC group apparently maintained or improved their blood pressure control over the two years. Seventeen people attended the re-referral clinic and all but 2 returned to shared-care. Mortality was similar in the three groups.

5.2.1 Introduction:

The results are presented to correspond with section 5.1 and in four parts: description of patients, maintenance of follow-up and completeness of review, self-perceived health status and clinical variables.

5.2.2 Description of the recruited patients:

The characteristics of the three groups are shown in Table 25. The only difference between the groups is that more in the NPC group live in GGHB. As described in section 4.2.3, there were no detected differences in demographic or clinical characteristics between the responders to the questionnaires and the non-responders.

5.2.3 Maintenance of follow-up and completeness of review:

Of the 277 enrolled SC patients, 258 (93%) were still monitored by the Scheme at the end of two years while 232 (86%) of the BPC group and 245 (91%) of the NPC group were still monitored by their clinic. Reasons for withdrawals, where known, are shown in Table 26.

Shared-care was more effective than either clinic in keeping contact with patients with a lapse rate, excluding the dead of 3% (9/267) (95% CI:1-5%) after two years compared with 14% (38/270) (95%CI:10-18%) and 9% (25/270) (95%CI:6-12%) in the BPC and NPC groups respectively.

Characteristics of those lost to follow-up from shared-care: Six patients were withdrawn from shared-care within the first year. Of these, 2 were withdrawn by their general practitioner as normotensive and 4 failed to attend for annual review even after repeated requests from their general practitioner. The reasons given by the patients themselves for withdrawing are shown in Table 27. The withdrawn patients are about ten years younger on average than the others (49 years versus 59 years); furthermore, those who withdrew themselves are all male while both of those who were withdrawn by their general practitioner are female. However, numbers are too few to give adequate power to test the differences in the characteristics shown in Table 28.

Characteristics of SC patients returned to the clinic: Of the 258 SC patients who were still being monitored after two years, 247 (96%) were under shared-care and 11 (4%) had been returned to the clinic. Reasons for return to the clinic are shown in Table 29 and the characteristics of these patients are summarised in Table 30. There are more females in the returned group, 82% (9/11) compared with 51% in the remaining group (95%CI for diff:45-93%) and there are fewer in the returned group who started in category 1 for blood pressure control, 18% compared with 60% (95%CI diff: 19-65%).

Annual reviews: These had been carried out and results obtained for 93% (95%CI: 90-96%) of the SC group in year 1 and 91% (95%CI: 87-95%) in year 2. Using the definition in Table 22, 84% (95%CI: 79-89%) of the SC group in year 1 and 82% (95%CI: 77-87%) in year 2 had a complete review (Table 31). In the clinic groups, 70% (95%CI: 64-76%) and 81% (95%CI: 76-86%) in the BPC and NPC groups respectively had been reviewed in year 2 and 54% (95%CI: 46-62%) and 75% (95%CI: 69-81%) had complete reviews (Table 31).

Shared-care was therefore more effective than both clinics in ensuring a review in year 2 (with BPC, 95%CI diff:14-28%; with NPC, 95%CI diff:4-16%). In ensuring an effective review, shared-care was again more effective than the BPC clinic (95%CI diff:18-38%) but not significantly different from the NPC clinic (95%CI diff:0-15%).

Approximately the same number of SC reviews were satisfactorily completed in each of years 1 and 2 (228 and 220 respectively) but 58 (23%) were totally complete in year 1 compared with 94 (39%) in year 2 (95% CI diff: 8-24%) (Table 32). There were approximately the same number of unsatisfactory reviews in each year, 27 (10%) and 23 (9%) respectively while the number of missing reviews was 12 in year 1 compared with 15 in year 2.

Characteristics of those not reviewed on shared-care: Of the monitored SC patients (n=258), 15 (6%) had no review in year 2 (Table 32). Eleven of these were on shared-care; 4 were in the group who had returned to the clinic and their characteristics are not further analysed. Reasons for the lack of a shared-care review were known in 6 cases and all were too ill. The remaining 5 were male; after three years, 2 were still unreviewed but 3 had an up-to-date set of results (Table 33)

Those who had an incomplete review: Twenty-three SC patients had a review in year 2 which lacked an important result and was therefore classed as incomplete. Twenty-two were shared-care reviews; the missing items were ECG in 7 cases, creatinine results in 12 cases, blood pressure measurements in 2 cases and blood pressure plus ECG in 1 case. One further review, carried out in the clinic, lacked a creatinine result. The patients with incomplete reviews were more likely to consider themselves in poor health (71%) compared with the rest (47%, 95% CI diff: 4% to 44%) but more likely to have well-controlled blood pressure (87% versus 64% overall, 95% CI diff: 7% to 49%); fewer favoured the surgery as the site of care (6% versus 35%, 95% CI diff: 17% to 41%) (Table 34).

Completeness of investigation results: There were differences between the SC, BPC and NPC groups in the number of investigation results recorded (Table 35). The NPC records were more complete than the SC or BPC records for urinalysis measurements and cholesterol; the SC and NPC records were more complete than the BPC records for ECG results; SC records were more complete than the BPC records for urinalysis but least complete of all three for weight and serum potassium. In total, 13% of the SC samples were haemolysed and therefore lacked a potassium assessment; up to a further 19% may have been slightly haemolysed.

5.2.4 Self-perceived health status and attitudes to health:

There were no significant differences over the two years between or within the groups in the self-assessment of their health status (Table 36). In year 2, 17% of the SC group considered themselves in very good health, 37% in good health, 33% in average health and 13% in poor health; 58% had remained the same, 21% had improved and 15% had moved to a lower level of health.

There were no changes in the number who considered that there was something which could be done to reduce their blood pressure in any of the three groups (Table 37). Nor were there differences between the groups. In the SC group, 74% did not change their opinion while 12% became more positive and 9% less positive.

There was no significant change in the numbers who considered there was something they could do personally to reduce their blood pressure and no significant difference between groups (Table 38).

There were significantly more individuals who either stated their most recent blood pressure measurement or a relevant comment in the SC group after two years (95%CI diff for no. who knew measurement: 20-36%) (Table 39); 36% changed from knowing nothing to stating a measurement or comment while only 11% moved the other way. There was a slight rise in the BPC group. Nonetheless, neither the SC nor the BPC group approached the level of 86% who stated a blood pressure reading in the NPC group.

5.2.5 Clinical variables

Biochemical measurements: At the start of the follow-up, the only significant difference from the mean values in the SC group was a higher creatinine level (95%CI diff:3.2-12.8) in the NPC patients (Table 40). The only significant difference

between changes in the SC group and those in their matched controls in the BPC group was a rise of 0.4 in serum potassium in the SC group ($p=0.03$).

Mean blood pressures: There were no differences in mean blood pressure between groups at the start of the follow-up nor in the changes over two years (Table 40).

Target blood pressures: Initially, the percentages of patients at each level of blood pressure control in each group were very similar (Table 41). After one year, the percentage in grade 1 differed between groups and, at the end of the study period, the SC group had more blood pressure measurements in grade 1 than the BPC group. However, as Figure 18 shows, there is a clear terminal digit preference in the SC group measurements with a high prevalence of measurements ending in zero and a smaller excess of terminal fives. Even the BPC group apparently shows some digit preference but there is very little in the NPC group. This is explained by measuring techniques (see section 5.3). After altering the target blood pressures so that those measurements ending in zero are included in the higher blood pressure level (that is, altering the targets to $<140, <90$ etc), all three groups have fewer patients in grade 1 and the SC group has the greatest drop in numbers (Table 42). The remaining difference between groups is not statistically significant.

Using this second set of targets, 42% of the patients on shared-care maintained their initial levels of blood pressure control compared with 36% in the BPC group and 44% in the NPC group (Table 43). Approximately one quarter of SC patients have a final measurement indicating a better level of control than when they started and approximately one third have apparently poorer control.

Characteristics of those SC patients with poorer initial blood pressure levels: Of the 22 SC patients who had initial blood pressures in categories 4 or 5, 11 (50%) responded to the

questionnaire; 7 (64%) were female, their mean age was 51.3 years (sd: 9.1) and 5 (45%) had attended the GRI clinic. Over the two years, 1 returned to the clinic and 1 died; the other nine were being followed up in shared-care in year 2. Seven (78%) indicated a preference for shared-care and 2 (22%) for the clinic.

Re-referral: Seventeen individuals were re-referred from shared-care to the re-referral clinic over the two years. Numbers of visits ranged from 1 to 7 with a mean of 3 (Table 44); all but 2 patients were returned to the care of their general practitioner.

The variable reasons for re-referral are listed in Table 45 and the characteristics of the re-referred patients are described in Table 46

Number of deaths: The number of deaths in the three groups was very similar giving a mortality rate of 4% (95%CI: 0-16%), 2% (95%CI: 0-12%) and 2% (95%CI: 0-12%) over two years in the SC, BPC and NPC groups respectively.

5.3 DISCUSSION

Summary: The strength of shared-care in ensuring completeness of reviews may be due principally to the prompting procedures and the ability to keep in touch with the patients both at their home address and via their general practitioner. It is estimated that an extra 10% of the BPC group would have been monitored had they been transferred to shared-care. There appears to be an improvement in the completeness of shared-care reviews as those involved become used to the procedures; nevertheless, haemolysis of blood samples remains a problem. The improvement in the SC patients' knowledge of their blood pressure levels may be due to the Personal Health Booklet, an increased tendency for the doctors to tell patients the blood pressure levels or a generally increased awareness on the part of the patients. The terminal digit preference noted corresponds with the type of sphygmomanometer used in each site, being least with the use of an automatic sphygmomanometer.

The shared-care drop-out rate of 3% over two years is significantly less than both clinics. The shared-care system of continuous prompting until a review is carried out or a positive decision to opt out of review is made, may have yielded better results than the clinic approach which was to take no further action except notifying the general practitioner after three defaults.

The SC system also ensured that the fate of every patient was known; in contrast, an unknown number of individuals in the BPC group may have moved out of the area but the system was unable to identify this. The shared-care system was also the only one which was able to keep track of patients at different levels of care; for example, individuals who attended the clinic for a period and then returned to their general practitioner had no break in the continuity of their shared-care record. On

the other hand, BPC or NPC patients who were discharged to their general practitioner during the course of the study had no further information in their clinic record.

All of the patients who withdrew from shared-care did so within the first year and appear to be a group at lesser risk. They indicate, by their reasons for withdrawal, that they consider regular monitoring an unnecessary inconvenience. It is possible that these individuals would have discontinued follow-up even if they had remained in the clinic. Furthermore, the group withdrawn by their general practitioner seem also to be at lesser risk. There may be difficulty in persuading a small number of patients and general practitioners of the necessity for continuous review of those with well-controlled or mild hypertension.

By comparing the drop-out from the SC and BPC groups, we can estimate that, *ceteris paribus*, 23 individuals classed as "lost" from the BPC group would have been "monitored" had they been in the SC group (32 lost minus 6 withdrawn from SC minus an estimate of 3 who may have moved). This would represent continued follow-up information on, at least, a further 10% of well-controlled patients which would otherwise have been lost. Furthermore, as the pilot study shows, the "lost" patients may include a significant number in whom the aim of treatment is not achieved and hence who might be at risk of complications.

Nine patients returned to the specialist clinic before the re-referral clinic was operational; it is possible that a number of these would have been returned to shared-care had they been seen in the re-referral clinic; however, it is not known exactly how many of these 9 returned to the clinic because of patient preference. It may be of interest to note that more females returned to the clinic than males while more males opted out of regular follow-up altogether; however, numbers were too small to draw any firm conclusions.

Shared-care was more successful at ensuring a review than the Blood Pressure Clinic; between 14% and 28% more patients are reviewed on shared-care. Shared care was also 4% to 16% more successful than the nurse practitioner clinic. Both clinics have a reminder system to prompt clinic staff when a review is due or has been missed. However, the system in the Blood Pressure Clinic is not always effective (personal communication from Clinic staff) because it relies on observation of the paper records rather than being part of an automatic system as in the nurse-practitioner clinic.

Shared-care was 18% to 38% more effective than the Blood Pressure Clinic at ensuring a complete review but not significantly more effective than the nurse practitioner clinic. The main problem in the BP Clinic appeared to be arranging an ECG since the ECG department was situated some distance from the outpatient clinic. Shared-care achieved a very satisfactory level of ECG investigations, particularly in view of the fact that 48% of the general practitioners had no ECG facilities at the outset of the study.

The completeness of SC reviews appears to have improved in year 2, possibly because patients and general practitioners became more used to the procedures. However, a continual problem was haemolysis of blood samples making estimation of serum potassium impossible. The SC patients were asked to make morning appointments for review in order to reduce this problem but nonetheless, 13% of SC samples were definitely haemolysed and were included as missing values; a further 19% may have been slightly haemolysed. The detected rise in serum potassium over the two years in the SC group is more likely to be due to slight haemolysis of blood samples rather than to clinical deterioration since there was no similar rise in any other biochemical variable.

Shared-care has succeeded in achieving a standard level of care for a high proportion of follow-up patients outwith the outpatient clinic. Although there could be disagreement about

what standard to apply, the fact that it can be applied effectively gives opportunities for further evaluation.

Of those with no explanation for their lack of review (n=5), 3 had reviews in the following year. This discloses a strength of shared-care in that once a patient is registered, the prompting continues each year until the patient's name is withdrawn from the register. Hence there is the likelihood that follow-up will continue even if it is interrupted at some stage. This would not be the case in either clinic.

There are no measured differences in patient attitudes to their high blood pressure but two years is probably too short a period in which to estimate this type of change. The significant difference in the number who knew their own blood pressure measurement is interesting because there was also a slight increase in the BPC group who had no intervention; this increase in the BPC group may represent a general increase in awareness of health matters due to health information from the media, from doctors in the outpatient clinic or even from heightened awareness due to the first patient questionnaire. The remaining increase in the SC group is likely to be due to many of the patients having a note of their most recent blood pressure reading in their Personal Health Booklet.

The terminal digit preference (TDP) observed corresponds with the information which we have on the type of sphygmomanometer used at each site. The majority of general practices use mercury sphygmomanometers, the BP Clinic often uses the automatic, electronic version while the NP Clinic only uses the automatic version. The amount of TDP corresponds with the use of mercury sphygmomanometers and hence, observer-estimated measurements.

Many factors affect blood pressure control and the study was not designed to measure these. It has been assumed that these results indicate no deterioration in blood pressure control in

the SC group relative to the other groups over the study period.

Whether the assumed link between the delivery of care and eventual health outcomes is valid could not be assessed by this study because of a) the lack of information on those who opted out of regular review in the three groups, b) the self-selection of patients and general practitioners into the reviewed group which prevents generalisation of the results to those who dropped out and c) the short time scale. To validate this assumption would require a different study design.

The superior performance of shared-care in maintaining contact, ensuring review and doing so with a fairly high degree of completeness of the results has implications for the potential improvement of patient care. The indications are that using such a system could improve the coverage of patients requiring long-term care over that provided by a long-term follow-up clinic.

CHAPTER SIX: EVALUATION OF ACCEPTABILITY OF SHARED-CARE TO PATIENTS AND GENERAL PRACTITIONERS

6.1 METHODS

Summary: The acceptability of shared-care and the other methods of care to patients and general practitioners was measured by assessing four groups of factors. These were 1) participation, 2) effect of each method of care on convenience of attendance at the consultation, 3) use of and statements about the records and procedures of shared-care and 4) opinions of patients and general practitioners about each method of care of which they had experience.

6.1.1. Introduction:

As described in section 4.2.4, four main approaches to the measurement of acceptability were used. In summary, they are:

- 1) Monitoring of participation by patients and general practitioners and reasons for non-participation.
- 2) The effect of shared care on workload, time used, convenience, cost and hence acceptability of the method of consultation.
- 3) Assessment of satisfaction with procedures and aspects of shared-care, such as the annual review procedures and Personal Health Booklet.
- 4) Determining opinions on shared-care, measuring change in the attitudes of the participants towards follow-up which was based in general practice and recording perceived advantages and disadvantages of shared-care and clinic follow-up.

Further details of the methods used are described below.

6.1.1 Measurement of participation:

Patients: Those who dropped out of follow-up for any reason from which acceptability cannot be excluded are taken as the

maximum number who found that method of care unacceptable. On the other hand, those who died or were transferred to another source of care are excluded from this count. Within this group, there will be individuals who would also have been unable to participate in other methods of follow-up but it is not possible to quantify this. Those who were not reviewed in the general practitioner aspect of shared-care are included, since patients in shared-care are given the major responsibility for ensuring that review takes place; in some cases, however, there may have been other reasons for the failure of review. However, in the clinics, the unreviewed are not counted as evidence that clinic care was unacceptable, since their lack of review might well be due to clinic procedures rather than patient choice. Furthermore, those who were discharged from the clinic are excluded even though some of these will be people who did not wish to continue clinic follow-up, since this cannot be quantified. This gives a conservative or pessimistic view of the acceptability of shared-care relative to the two other methods.

General practitioners: Refusal of the initial invitation to participate in shared-care, dropout during the follow-up period and the reasons given for both were recorded. At the end of the follow-up period, a questionnaire item asked whether the general practitioner wished the Scheme to continue or not. Characteristics of the preference groups of general practitioners were compared.

6.1.2 Features related to acceptability:

Visits to general practitioners: In order to estimate the effect of shared-care on the total number of general practitioner consultations, a count of all general practitioner visits made by patients in the BPC and SC groups over four years, commencing two years before shared-care began, was made retrospectively.

A short form was sent to the general practitioner, with a request that the number of times that a patient attended for any reason other than repeat prescription, in the two years prior to the study (1985 and 1986) and in the two subsequent years (1987 and 1988) be written on the form and returned. A mean figure for visits before and visits after was calculated for each group.

Clinic visits: These were directly counted from the clinic medical notes. The notes indicated whether each was a review or routine intermediate consultation.

Other features measured included the mode of travel, how easy the journey was, the length of time it took, the cost of travel and how long patients spent at the consultation. This information was obtained from the patient questionnaires.

6.1.3 Procedures of shared-care:

Personal Health Booklet: Full details of the Personal Health Booklet (PHB) are given in Chapter 4. Half of the patients had a "lay" translation of the medical terms in the medical history section. The acceptability of the PHB was evaluated by monitoring its use over the period of the study, by a specific questionnaire sent to all patients in the SC group in year 2 (Appendix 1) and by an item in the general practitioner questionnaire.

Annual review: General practitioners were asked, in a questionnaire in year 2, to state whether they considered each annual review investigation necessary and to comment, in an open-ended question, on the procedures. They were also asked for comments and suggestions about the review procedure.

6.1.4 Measurement of opinions and attitudes, advantages and disadvantages

Patients: Information was obtained from the questionnaires on patients' preferred location for care, their assessment of the worth of the visit and in the case of the SC group only, their preference for the method of care. The SC and BPC groups were given the opportunity to comment on the Shared-Care Scheme or the outpatient clinic as appropriate, at the end of the study period; advantages and disadvantages were asked for in an open-ended format.

General practitioners: The questionnaire at the end of year 2 asked general practitioners to rank four methods of care, specialist clinic, nurse-practitioner clinic, shared-care and routine general practitioner care, in order of preference; they were also asked to rate the effectiveness and usefulness of shared-care and state advantages, disadvantages, suggestions and comments. In order to ascertain the reasons why some general practitioners preferred that shared-care should not continue, the stated advantages and disadvantages were analysed by preference group.

6.1.5 Statistical analysis:

The statistical tests used are described in section 4.2.5. All questionnaire items were included in both the initial and follow-up questionnaires.

6.2 RESULTS

Summary: Participation in shared-care was at a level between the nurse-practitioner clinic and the outpatient clinic with the nurse-practitioner clinic apparently having the highest level. Only two general practitioners withdrew and 61% wanted the Shared-Care Scheme to continue with a further 25% having no clear opinion. There were no apparent differences between the sub-groups of general practitioners. Shared-care increased the number of general practitioner visits by one per year while the patients in the BPC and NPC groups visited the clinic approximately twice per year. On shared-care, fewer of the SC group used public transport and more walked to their consultation, more found their journey very easy, it cost them £1.48 less, they saved an average of 30 minutes travelling and 42 minutes at the consultation, fewer required time off work and fewer took a companion. The Personal Health Booklet (PHB) was used by almost all patients and only 4% did not like it. Approximately half the medical records were returned as requested by the general practitioners but 26% used the PHB instead and most general practitioners liked it. Annual ECG, glucose and cholesterol assays were least favoured by general practitioners. Approximately half the SC patients preferred shared-care to outpatient care while 22% had no preference. Around one third of general practitioners preferred shared-care but two thirds preferred their own routine care. The main advantage of shared-care mentioned by general practitioners and patients were fewer losses to follow-up and greater accessibility of the doctor. The main disadvantage mentioned by the general practitioners was difficulty of organisation in the practice while patients were concerned at the need for more than one visit to have the annual review procedure carried out.

The results are presented in four parts to correspond with the methods in section 6.1.

6.2.1 Participation

Patients: As described in section 5.2.3, 6 patients were withdrawn from shared-care over two years. Furthermore, 8 SC patients returned to the clinic for reasons which may have included general practitioner and patient preference and 5 had no review carried out in year 2 for reasons other than ill health or attendance at a hospital clinic. This gives a maximum of 19 individuals, 7% of the SC group (excluding deaths), who were no longer fully participating in general practitioner-shared-care follow-up in year 2 for a reason which may be other than clinical. From the BPC and NPC groups, 32 (12%) and 9 (3%) individuals respectively dropped out of follow-up for reasons which were not stated and therefore may have included patient and general practitioner preference. The reasons are summarised in Table 47.

Hence, taking participation as a measure of acceptability, shared-care falls between the traditional clinic and the nurse-practitioner clinic.

Table 48 shows that the drop-out from shared-care in year 1 was approximately twice that in year 2; furthermore, the dropout in year 1 includes most of those cases where the general practitioner or patient indicated a preference for the patient to return to the clinic.

General practitioners: When the patients were finally recruited, 182 general practitioners had at least one patient on the Scheme and participated in the study. The modal number of patients per general practitioner was 1 (69% of general practitioners).

During the two years, two general practitioners withdrew and twenty joined. The reasons given for withdrawal were that the two patients were normotensive and one general practitioner had his own follow-up system. Reasons for joining were that an existing shared-care patient transferred to another general

practitioner, sometimes in the same practice, sometimes in a different practice; all of these general practitioners agreed to continue their patient's follow-up in shared-care.

In the questionnaire survey at the end of the follow-up, 61% of general practitioners stated that they wanted shared-care to continue, 25% were unsure and 14% preferred that it did not continue. There were no significant differences between those who wished it to continue and those who did not (Table 49). There is, however, a trend for those who prefer shared-care to continue to be less likely to work from a health centre or be in a single-handed practice.

6.2.2 Features of the consultation process related to acceptability

General practitioner visits: The SC group had a skewed distribution of general practitioner visits with a mode of 3-4 visits before shared-care and of 4-5 visits after; however, as Figure 19a shows, the range is wide. The number of cases for which we have information in the BPC group is fewer because details of general practitioners were often out of date and the graph for the BPC group is less smooth but shows no overall change between the years studied Figure 19b.

Both the SC and BPC groups visited their general practitioner just over five times per year prior to the two-year follow-up (Table 50); after two years, the average annual number of visits was still just over five for the BPC patients but had risen to just over six for the SC group. The mean rise is 0.9 per patient or a 20% increase in patient visits. The actual change in number of visits for any one SC patient varied from a drop of 8 visits per year to a rise of 9 (Figure 20) with a mode of +1. For the BPC group, the range is a drop of 7 to a rise of 11 with a mode of -1.

Clinic visits: Table 51 shows the number of visits made to the clinic in year 2 by each group; there were 489 BPC patient visits, 466 NPC patient visits and 76 SC patient visits of which 53 were visits to the re-referral clinic. The mean number of clinic visits made by BPC and NPC patients is very similar at 2.11 and 1.92 per patient in year 2 respectively. Of these 0.81 and 0.89 visits per patient were for review and slightly more, 1.30 and 1.01 per patient were other routine visits. Figures 21a and 21b show the frequency of numbers of visits. In the BPC, the mode is 1 but a large number of patients (32%) had three or more visits and 9 (6%) had none at all. In the NPC, only 3% had no visits and the mode was 2 with 11% having 3 or more visits.

Adding visits to general practitioner and to clinic gives an average of 7.3 visits to both sites for the BPC group in year 2.

Journey to and from the consultation:

Mode of travel: As can be seen in Table 52, 6% of the SC and BPC groups and 10% of the NPC group walked to their consultation at the start of the study; 59% of the SC, 52% of the BPC and 33% of the NPC groups used public transport and 34%-47% used a private car. At the follow-up assessment, only 39% in the SC group now used public transport (95%CI diff:12-30%) while 26% walked (95%CI diff: 13%-27%). There was no significant change in the mode of transport in the other groups after two years.

Ease of the journey: At the start, over 90% in all three groups considered their journey very easy or quite easy (Table 53). After two years, 45% in the SC group found the journey very easy, an increase of 13% (95%CI diff: 4-22%).

Length of journey to clinic: Table 54 shows the mean and ranges of the time used in travelling to and from the consultation. The NPC group took a slightly shorter time at

the start (95%CI diff from SC group: 3-19 minutes). The only significant change after two years is that the SC group saved, on average, 30 minutes travelling time per consultation compared with previously (95%CI diff: 23-37 minutes).

Cost of journey: This was calculated from the information provided by the patients on the cost of public transport and the number of miles travelled with petrol at £0.07 per mile for those who used their car. The costs were similar at the start, £1.10 to £1.24 for a return journey. There is a drop of £1.48 per consultation (95%CI diff: £1.24-£1.72) in the SC group. Four times as many in the SC group (27%) have no cost for travel compared with the BPC group (7%).

Time off work: All three groups, at the start, had 28%-32% always requiring time off work to attend the appointment (Table 55). The SC group subsequently had fewer (19%) who always required time off, a drop of 13% (95%CI diff:10-16%). The BPC group also had a drop of 6% and the NPC group a drop of 5% but neither of these reductions were significant.

Consultation time: Table 56 shows the average total consultation times and the ranges. There is a significant drop of 42 minutes (95%CI diff:36-48 minutes) in the time spent at the consultation by the SC group but no change in the BPC or NPC groups. The lower end of the SC range is lower than in the clinics (5 minutes versus 10) but the upper end is similar (180 versus 240 and 164 minutes).

Companions: Twenty percent of the SC group had brought a companion when they had attended the clinic, but on shared-care this dropped to 10% (95%CI diff: 3%-17%). Twenty percent in the BPC group became 21% and 26% in the NPC group dropped to 22% but neither were significant (Table 57). In each group, 95% claimed to be able to come on their own and this did not differ in any group at the follow-up questionnaire.

6.2.3 Procedures of shared-care:

Use of PHB by patients:

In year 2, 64% of the sets of review results were accompanied by a patient booklet; 26% of results had the PHB as the only record returned (Table 58). Ninety-two percent of the returned booklets had been used for recording of blood pressure during the year and 36% had been amended. The PHB was used more through time as the results for year three confirm.

The questionnaire about the PHB, at the end of year 2, was responded to by 209 (81%) of the monitored shared-care group. The comments below correspond with the sections of the questionnaire.

Learned something new: Eleven patients claimed to have learned something new due to their booklet. Examples included understanding what high blood pressure is and that the person's kidney function was impaired.

Incorrect items: Twenty percent of the responders claimed that some item was incorrect and 15% supplied the corrected information. Out of 25 corrections, 15 were recent changes but 10 items had been incorrectly recorded for a number of years. Two of the corrections were dates of birth.

Items missed out: Eight missing items were mentioned; one drug sensitivity, 3 weight measurements, 2 drug changes, one item of family history and an NHS number.

Censoring: Two requests for censoring resulted from the patient questionnaire; one for censoring of smoking details and the other for drinking details and family history. During the study period, two patients asked for the removal of anxiety and depression. In total 33 items were censored on patient records. The censored items are shown in Table 59.

Understanding of medical terms: Only two patients claimed they did not understand medical terms; the terms were pyloroplasty, vagotomy, ischaemic heart disease and myocardial infarction. Neither of these patients had received a booklet with lay translations. Fifty-nine percent (208/354) of the medical problems encountered were given a lay translation in the booklet; the remainder were considered not to need such a translation.

Explanation requested: One patient asked their general practitioner for further information about Raynaud's disease which appeared on the problem list. One of the above patients who did not understand the medical terms asked the general practitioner for an explanation. Many comments were made about aspects of the treatment and follow-up that patients asked or wanted to ask their general practitioner about; these included the cause of high blood pressure and its effects, why certain investigations were necessary, about cholesterol, circulation, effects of sunbathing and many comments about drugs such as why treatment was changed, what the effects of different drugs are, how long will treatment last and could particular symptoms be side-effects. Two patients commented that the general practitioner had insufficient time to answer such questions.

Usefulness: The booklet was considered useful by 130 (62% of the responders) and not useful by 61 (29%). In total, 107 comments were received of which 44 (41%) related to its usefulness as a general reminder and in monitoring progress, 21 (20%) as a source of information for reference, 20 (19%) as a record of blood pressure, 20 (19%) as a portable medical record for use in emergencies, 7 (7%) as a treatment record, 2 (2%) as reassurance, one specifically as a motivator (though this aspect was included by many in the first category) and one person claimed it was useful "to impress cronies"!

One hundred and twenty-three (59%) responders liked having the booklet, 8 (4%) did not and 77 (37%) had no opinion.

Use of records by general practitioners:

The shared-care medical record: This should be returned by the general practitioner to the registry each year; in year 2, 52% of records were returned as requested but 26% of review results were accompanied by the PHB only and 22% had no record returned at all although 2% had the procedure form or a note enclosed (Table 58). Approximately half of the general practitioner records returned contained both copies so only the remaining half retained a copy in their practice notes while waiting for the updated version.

Personal Health Booklet: Eighty-six percent of responding general practitioners (n=147) admitted to having seen the PHB and all were happy to have it sent directly to their patients. Comments were made in the open-ended section on the questionnaire and indicate a high degree of acceptability although one general practitioner was not sure of the purpose of the PHB, two considered all the information to be in the medical record anyway and three did not consider the PHB useful. However, 13 commented spontaneously that they did consider the PHB useful and one general practitioner felt that although it duplicated the practice record it must improve the hospital information. Comments about particular sections of the PHB are summarised below.

Treatment lists: It was suggested that these should include adverse reactions and side effects to watch out for. One general practitioner thought that frequent changes were difficult to follow and one that the information was all in the general practitioner's record anyway.

Blood pressure and weight record: This was considered good for data transfer between clinic and general practitioner and a good reminder for the patient, especially the weight record.

Lifestyle advice: This "augments and makes a useful addition to the routine advice given to the patient"; it was also "good propaganda" and should be "very prominent". However, one general practitioner doubted whether the advice would be adhered to and another felt it was an unnecessary addition to the Booklet.

Annual review procedure:

In their questionnaire responses, 36% of general practitioners favoured an annual ECG and 76% annual biochemistry (Table 60); 91% and 95% thought that urinalysis and weight respectively should be carried out but only 60% and 80% respectively of shared-care annual reviews had this information. Annual random glucose was only favoured by 28% and cholesterol by 48% although their completeness was 88% and 86% respectively.

Practice nurses: 50% of shared-care general practitioners stated that they had a practice nurse but only 7% used the nurse for all or part of the annual review procedures.

Comments on the annual review procedure: These were made in open-ended questions but could be classed into three groups: those dealing principally with the concept of shared-care, those dealing with the practical aspects and those relating to the details of the investigation or annual review protocol. They are summarised separately for those general practitioners who wished to continue in shared-care and for those who preferred not to continue or did not express an opinion.

From those wishing to continue in shared-care, there were 17 comments in total. Three (18%) comments involved the concept of shared-care and mentioned duplication with the general practitioner's own follow-up (2) and that shared-care was impersonal for the patient (1). Eleven (65%) comments involved the procedure and ranged from satisfactory through good to

excellent (5), confusing at first (2), requiring two appointments (1) and suggestions (3) - patient should arrange a longer appointment, an early appointment and blood sample bottles and forms should be sent to the patient rather than to the general practitioner. Three (18%) comments posed questions about the protocol; is an annual serum cholesterol really necessary, are all the tests necessary, is the annual review worthwhile?

From those who preferred not to continue in shared-care or did not say, there were 13 comments. Eight (62%) involved the concept of shared-care and expressed the opinion that it offered the general practitioner no benefit particularly if they already had computerised follow-up systems for mild hypertensives. The remaining 5 (38%) comments claimed that the shared-care forms were confusing and time-consuming.

Finally, some general comments were made. These include the opinion that shared-care is good for patients who are difficult to control (2) (in this case, it was suggested that the hospital interest could reduce as blood pressure control improved) or those who required hospital assessment. Two general practitioners felt that they had no need of shared-care because they already had adequate back-up, from the Stobhill clinic in one case and a practice nurse in the other.

6.2.4 Preferences, attitudes, advantages and disadvantages

Patients' attitudes and preferences: There was a significant rise of 25% (95%CI diff: 17-32%), after two years, in the number of patients in the SC group who considered their general practitioner's surgery as the most appropriate site of care but there was no significant change in the BPC or NPC groups (Table 61).

The only significant difference in the number of patients in any of the groups who considered that visiting the site of care, whether clinic or surgery, was worthwhile, was a drop

of 7% in those in the SC group who thought it definitely worthwhile (Table 62). However, in each case, around 98% thought the visit worthwhile.

Of the responders in the shared-care group, at the end of two years, 48% preferred shared-care, 22% had no preference but 30% still stated a preference for attendance at the outpatient clinic (Table 63). The demographic characteristics of those who preferred each method of care, attributes linked to convenience of shared-care and attitudes are shown in Table 64. The only significant differences are that those who preferred the clinic had longer mean clinic attendances, about 8 years compared with 5-6 years for those who preferred shared-care and about 4 years for those with no preference. Numbers are too low to test the statistical significance of other differences.

The association between the preference for the method of care and the preferred site of care is shown in Table 65. Of those who like the surgery (n=72), 83% favour shared-care and of those who like the clinic (n=34), 82% favour outpatient care. This indicates a linking of preference for method with preference for the site. This association is further supported by the observation that the preferred method of care for those who like both clinic and surgery is evenly divided between shared-care, outpatient follow-up and no preference.

A comparison of preference for shared-care with whether the cost of travel was reduced by > £2.00, >£0.30 or not at all showed no association (chi square=6.09, 9df, p=0.73).

Advantages and disadvantages to patients:

In total, shared-care attracted 271 comments from the SC group of which 232 (86%) were classed by the patient as "advantages". The outpatient clinic attracted 218 from the BPC group, of which 122 (56%) were considered advantages.

Advantages of shared-care: The SC group made 232 comments on advantages of shared-care; 78 (34%) related to accessibility of the general practitioner compared with the specialist, 38 (16%) to better continuity of care, 32 (14%) to a better relationship with the doctor, 40 (17%) mentioned that shared-care saves time and 28 (12%) that it was more convenient.

Disadvantages of shared-care: There were 39 comments on disadvantages from the SC group; 20 (51%) dealt with the need for more than one visit for the annual review, 5 (13%) claimed less expertise available and 4 (10%) relative inaccessability.

Advantages of the clinic: The BPC group made 122 comments on advantages of the clinic; 82 (67%) mentioned the expertise and resources available and 23 (19%) the ability to have everything attended to in a single clinic visit.

Disadvantages of the clinic: The BPC group made 96 comments on disadvantages including 36 (38%) comments about the relative inaccessability of the clinic, 20 (21%) about the long waiting time for consultation, 12 (13%) the long total time taken to get to and attend an appointment and 11 (11%) the unsuitability of appointment times.

In several cases, the same advantages and disadvantages were quoted by SC and BPC patients; these "common" advantages include accessibility (37 comments from SC, 4 from BPC), personal relationship with doctor (32, 2), having all investigations at one visit (4 and 23) and continuity of care (38 and 1). The common disadvantages include inaccessability (4 and 36), unsuitability of appointments (1 and 11), long waiting time (2 and 20), impersonal care (3 and 6) and lack of continuity (2 and 4).

Those comments made exclusively of shared-care include time saving (40 comments), suitability of appointments (21), more than 1 visit required (20), patient more relaxed (17), less expertise (5) and easier parking (2). Those comments made

only by the BPC group were more expertise and resources available (82), uses a lot of time (12), more time available for discussion (8 comments), provokes anxiety in patient (3), difficulty in parking (3), crowded reception area (1) and gives opportunity to travel by air (1) (this patient lived quite a distance from Glasgow)!

General practitioners' preferences and attitudes: General practitioners were asked to place four methods of care in rank order. Thirty-two percent of responding general practitioners (n=147) ranked shared-care in first place, 64% preferred routine general practitioner care, 2% preferred the nurse-practitioner clinic and 2% the outpatient clinic. Routine care by general practitioner obtained 94 first and 23 second place while shared-care had 47 first and 49 second places (Table 67). Thirty-one percent (46/147) of the responders did not rank shared-care at all while the outpatient and nurse-practitioner clinics were not ranked by 41% (60/147 and 61/147).

Advantages and disadvantages to general practitioners:

When given an opportunity on the questionnaire to state any advantages or disadvantages experienced, 45 positive and 55 negative comments were received.

Advantages of shared-care: The main advantages quoted were less loss to follow-up (15 comments), better communication between doctors involved (7), greater confidence in treatment for patient and general practitioner (6), up-to-date information (5) and more patient involvement (4).

Disadvantages of shared-care: The disadvantages quoted were difficulties in fitting shared-care into the practice organisation (12), increased workload (10), extra paperwork (8) and interference with the general practitioner's responsibility (3).

6.3 DISCUSSION

Summary: Shared-care appears an acceptable method of health care even although the methods used to evaluate participation may have been biased against shared-care. The main advantages of shared-care quoted by patients and general practitioners were non-practical aspects of care but the main disadvantages were practical. The lack of difference detected between the general practitioners who support and those who do not support shared-care may be partly due to the fact that practical difficulties are likely to be a consequence of arrangements in the practice and not reflected by general practitioners' characteristics. In this pilot phase, the increase in general practitioner's workloads seems small; however, the effects are variable. Similarly, the benefits to patients are variable. In spite of the lay dictionary, patients indicated that they want further information. Finally, in light of the acceptability evaluation, changes are being made to the operation of the Scheme.

The comparison of participation as a measure of acceptability has biased the results against shared-care in comparing the probable maximum number of dropouts from shared-care in which patient choice played a part with a possible underestimate for the clinic groups. There may be a further element of bias in that the three groups will all be, to some extent, self-selected for clinic attendance. Nonetheless, shared-care still appears more acceptable than outpatient clinic attendance by this measure.

There clearly are a number of individuals to whom clinic-based follow-up is more acceptable than shared-care. Apart from longer lengths of clinic attendance, no clear distinctions between these people and those who prefer shared-care have emerged. The only tentative suggestions are that female patients who do not like shared-care tend to return to the clinic while male patients may opt out of follow-up altogether.

However, longer follow-up will be required to support or refute this hypothesis.

Over the two years of follow-up, there was an increase in the number of SC patients who considered the surgery as the appropriate place for care with 13% classing it as the appropriate site in year one rising to 38% in year two, perhaps demonstrating greater acceptance of a procedure once it has been experienced. However, 20% still prefer the clinic to the surgery and 30% prefer outpatient care to shared care. It appears that there will always be a group of patients who favour attending the clinic. This has implications if one considers patient choice to be an important determinant of site of care.

There is a tendency for the SC group to perceive their visit as less worthwhile when on shared-care than before. If a true effect, this may be due to a poorer perception of general practitioner care compared with clinic care or lowering of perception of the condition as a serious disorder requiring continuous medical intervention.

Those in the SC group who preferred the clinic had been attending the clinic for longer than the others. There were no other significant differences between the groups and, perhaps, surprisingly, saving in transport costs were not related to a preference for shared-care. This is borne out by patient comments where saving time and convenience are mentioned as advantages of shared-care but not as frequently as accessibility of the doctor, continuity of care and a good patient-doctor relationship.

The SC group could compare the two methods of care while the BPC group could not do so; hence, their comments are not strictly comparable. Nevertheless, the most common disadvantage quoted by the SC group was more than one visit for annual review while some of the BPC group appreciated that they needed only one visit. Only 13% of the disadvantages

quoted by the SC group mention lack of expertise while 67% of those from the BPC group consider its availability an advantage. Perhaps this also demonstrates the attitude noted above where the surgery as site of care is less favoured before shared-care than after.

In the case of general practitioners, the most commonly mentioned disadvantages are practical aspects such as difficulty in organising the reviews and paperwork; objections to the concept of shared-care were only made by 3 general practitioners. This is encouraging for the future of shared-care since the practical aspects are likely to simplify with time, as technology such as automatic data transfer becomes available, as people become used to procedures and as nurses take over routine tasks.

The Shared-Care Scheme did not apparently have a large effect on general practitioner's workload. The SC group had a mean of approximately one visit (0.9) extra per year. There was however, a large spread of number of visits and some patients did appear to attend their general practitioner more often while some attended less often. There may, therefore, have been a disproportionate effect on some general practitioners' workloads. The total general practitioner consultations used by the SC group was 1654 over the second year, 236 (14%) of which were probably due to being part of the Shared-Care Scheme. Each shared-care patient therefore takes approximately 117% of the time used by a similar non-shared-care patient in a year.

The number of extra visits implies that, on average, one extra visit may have been made for the annual review but that otherwise, shared-care patients did not visit their general practitioner more frequently than those also attending the clinic and the majority did not attend the outpatient clinic at all. Any other consultations with their general practitioner at which hypertension was discussed appears to have been absorbed into the normal consultations made by these patients.

The number and type of visit appears to be more uniform in the SC group with the majority attending only their general practitioner. The variation in the number of general practitioner visits is no less for the BPC group than for the SC group and to this must be added variation in the number of clinic visits. Although the follow-up period was fairly short for established patterns to be seen to change, there does seem to be some evidence that shared-care could improve the uniformity of care.

The SC group had fewer total consultations in year 2 than the BPC group, a mean of 6.6 visits compared with 7.3 visits. If the visits made to a doctor by the SC group are considered to be adequate, the BPC patients have possibly had an excess of medical time, estimated here as $.7/7.3$ visits or 10% of their consultations.

The fact that most general practitioners felt that they would like shared-care to continue implies that they considered the benefits to outweigh any extra time required. No clear distinctions emerged between those who preferred that the Scheme continue and those who did not but given the fact that the most frequent disadvantages mentioned are practical, it is likely that preference is related to aspects of the practice itself and the reasons may therefore be heterogeneous and not reflected by general practitioner characteristics.

Fewer visits to the site of care results in a saving of time and cost for the patient. The SC group are also more likely to walk, to spend less on travel and to use less time for attendance at the consultation. One would assume therefore that shared-care is more convenient for most of the SC group. Furthermore, there is a tendency for the SC group to consider their journey as easier compared with previously and with the control groups.

All three groups had fewer patients requiring time off work to attend the appointment although the number is greater in the SC group. The slight increase in the clinic groups might represent some patients retiring. Allowing for the same number retiring in the SC group, around 8% need less time off work due only to a change to shared-care. This might represent the greater convenience of shared-care. On the other hand, one patient commented that clinic visits can be considered a valid reason for taking time off work while general practitioner visits may not be and therefore may need to be fitted into non-working hours.

Although the average SC consultation time decreased by 42 minutes, the range of times (5 minutes to 3 hours) shows that some individuals still had a lengthy wait. It appears that the benefit of shared-care is variable and probably very dependent on the practice attended and, for example, their appointment system.

Almost half of the SC individuals who took a companion to their clinic consultation attended their general practitioner alone, probably implying greater convenience of a visit to the surgery and perhaps less anxiety associated with it. It is interesting that 20% of the other groups took a companion although only 5% claimed that they could not attend alone; this may be an indication of the stress (or boredom) attendant on a clinic visit.

Very few general practitioners made use of practice nurses to carry out parts of the review. At the time of the questionnaire, the employment of a practice nurse was becoming more widespread and their role more far-reaching; several general practitioners commented that they would like to use their practice nurse for annual reviews.

Very few items in the medical history section of the Personal Health Booklet were censored by doctors or patients themselves. The items censored by patients were often not

medical details but aspects of social habits. In a similar study with diabetic patients, Jones et al (1988) found that 14% of patients claimed they did not understand something in their record. In this study, this was only reported by 2 patients, neither of whom had had a lay translation in their Booklet and none of those with lay translations reported a lack of understanding. Nonetheless, in spite of the apparently better understanding of medical terms in this study, it appears that a large amount of information is still wanted by patients and is not always supplied, even by their general practitioners. All shared-care patients now have Booklets with lay translations.

Only a small number of general practitioners considered the two-part record a useful feature of the Scheme, so we have now reverted to one part paper for the record. We no longer insist on the return of the general practitioner record every year since the PHB has proven to be a more effective means of obtaining the required information, We intend to include further specific areas in the PHB for the recording of results of regular investigations such as urinalysis. Furthermore, we have begun to audit the usefulness of the various investigations required in the annual review protocol. Following this and discussion with general practitioners, the annual investigation protocol may be re-drafted to be more in line with the opinions expressed by the general practitioners.

CHAPTER SEVEN: ECONOMIC EVALUATION

7.1 INTRODUCTION AND MEASUREMENT OF BENEFITS

Summary: Health service and patient costs were calculated separately for each of the three groups. The main benefit is satisfactory reviews, that is, an annual review including a blood pressure measurement, serum creatinine and an ECG, as calculated in Chapter 5. The number of reviews was also used to calculate the percentage effectiveness, 82%, 54% and 75% for the SC, BPC and NPC groups respectively.

7.1.1 Introduction:

Section 4.2.4 introduced the economic evaluation and explained why cost-effectiveness analysis was preferred as the method of evaluation. In the first part of this chapter, the effectiveness of each method is summarised and the methods used to measure the costs of care are described; costs incurred by the health service and by the patient are dealt with separately. At the end of each sub-section on costing, the actual costs attributable to each of the three groups of patients are presented. In the results section, the total costs and the cost-effectiveness ratios are calculated and the validity of the methods and estimates used is discussed. Finally, section 7.6 discusses the results and their implications.

7.1.2 Measurement of benefits:

Methods: The main benefit obtained in each case is the outcome of "satisfactory reviews". A satisfactory review is one which includes results for, at least, the principal investigations - blood pressure, serum creatinine and Electrocardiograph (ECG). The number of satisfactory reviews in year 2 in each group (see section 5.2.3) is used in the cost-effectiveness calculation; shared-care achieved 220 satisfactory reviews in year 2, the BPC group achieved 146 satisfactory reviews and the NPC group achieved 202.

The number of satisfactory reviews is also expressed as a proportion of those originally in the group, excluding the dead. This "percentage effectiveness" is an indication of the degree to which each method achieved the objective of reviewing patients. The percentage effectiveness for shared-care is 82% (220/267), for the Blood Pressure Clinic 54% (146/270) and for the nurse-practitioner clinic 75% (202/270).

Some benefits of each method of care may be difficult or impossible to measure but should, at least, be identified so that they can be considered when comparing the methods. The previous chapter has suggested that patient convenience and reassurance may be benefits of shared-care and clinic care respectively.

7.2 MEASUREMENT OF COSTS TO THE NATIONAL HEALTH SERVICE

Summary: NHS costs measured are staff, investigations, medicines and administration costs. Fixed costs were excluded from the analysis. The staff cost for a consultation is £9.35 for a review and £6.22 for a routine consultation in the Blood Pressure Clinic, £9.60 for a doctor-attended consultation and £5.68 for a nurse only consultation in the nurse-practitioner clinic and £9.34 for a shared-care consultation in general practice under a generous assumption of consultations lasting twenty minutes. Investigation costs are £1.01 per annual review, shared-care administration is £6.11 per monitored patient per year and clinic postage is £0.14 per visit. The annual medicine cost is £160.60 for a shared-care patient, £142.35 for a BPC patient and £156.95 for an NPC patient; the mean daily number of medicines rose in both the SC and NPC groups over the two years but the cost for the SC group remained approximately the same. The final total NHS costs of follow-up for each patient group, not including the costs of medicines, are £4478.52, £3888.36 and £3786.86 for the SC, BPC and NPC groups respectively.

7.2.1 Introduction:

The full costs of outpatient care, nurse-practitioner care and shared-care to the National Health Service (NHS) include all costs involved in continuing patient follow-up which are paid for by the NHS. This includes a portion of the costs involved in providing outpatient clinics within hospitals and general practitioner surgeries. Some of these costs are "fixed" costs, that is, they do not change over the period of the study. For example, the cost of clinic overheads such as lighting and rates will not reduce given the number of patients transferred to shared-care over the two year study period, though they might vary if transfer to shared-care continued over a longer period. Similarly, the fixed costs of the outpatient clinic will

be the same regardless of whether the BPC group attend or not and the fixed costs in general practice will not alter with the relatively small number of shared-care patients.

Other costs, however, may vary over the period of the study since they depend on the number of patient attendances. These "variable" costs are: staff time (medical, nursing and secretarial), costs of investigations, medicines, clinic postage, other administrative costs and the cost of the shared-care registry. Staff time has been considered as a variable, rather than a fixed cost, because changes in patient numbers are likely to result in changes in staff numbers over relatively short time intervals. Only the variable costs have been included in this analysis. The fixed costs are discussed further in section 7.5.1.

The next three sections present the methods of costing and the calculated costs to the National Health Service for each main category of cost.

When any costs were considered to be identical in each group, they were excluded from the analysis but their exclusion is noted. All costs measured are those in the second year of the study and have been calculated as though they applied throughout the whole year.

7.2.2 Costs to the NHS of patient consultations:

Medical, nursing and secretarial staff time in clinics: The staff time taken into account in this costing is that involved in follow-up consultations for hypertension at the identified site for each group, irrespective of other sources of care. For example, although the BPC and NPC groups are likely to have also attended their general practitioner over the study period, only the costs of their clinic attendances are included. Although the clinic groups may have made hypertension-related visits to their general practitioner, the shared-care patients are likely also to make such visits; the relevant measurement

is, therefore, the difference in the number of visits made by a patient on shared-care and a clinic patient.

The total staff types and number of sessions assumed necessary to operate each of the BPC and NPC follow-up clinics were obtained by counting the number of staff over several days and verifying with the staff involved that these figures were representative. The result was converted into number of sessions per week and is shown in Table 67.

The medical staff in the BP Clinic are calculated on the basis of two-third sessions because approximately one third of the clinic consultation time is taken up with new, rather than follow-up, patients. This does not apply to the nursing staff in this clinic who see follow-up patients, as well as new patients, throughout the session, nor to the NP Clinic which has a different arrangement for medical staff (see below) nor to the secretarial staff who have similar amounts of work for new, review and routine patients.

The grades of secretarial staff employed in each clinic are different and not directly comparable because of different employing authorities. In order to reduce discrepancies due to circumstances unique to one clinic, staff have been categorised and all clerical and secretarial activities have been grouped together even though they may be done by different people, on slightly different grades, in each clinic.

The staff resources used in each clinic were compared by converting the staff time into portions of salaries. The salary scales used for this are shown in Table 68 (SHHD 1988). Thus, a total staff cost per year can be derived for each clinic.

The total staff cost and the number of consultations in each clinic per year were used to derive an average staff cost per consultation for each clinic. Details specific to each clinic are now described.

Derivation of a staff cost per consultation at the Blood Pressure Clinic: There are two types of consultation in this clinic, routine and review consultations, which vary in length because of the extra investigations and full clinical examination carried out at review. The amount of time a patient spent with the doctor for both types of consultation was measured and resulted in a mean of 6 minutes (range 1 to 8) for a routine consultation and 12 minutes (range 5 to 20) for a review consultation.

A validation of the measured average time used was carried out. From clinic records, there were 3258 follow-up attendances in the BP Clinic in the second year of the study. The total medical time required, assuming all BPC group review patients as well as all non-study patients (probably a less well-controlled group) require the longer consultations while all BPC routine patients require only six minute consultations, is shown in Table 69. The result is very similar to the actual clinic time used over one year. This estimate for the duration of consultations has therefore been used to calculate the portion of staff time attributable to each type of consultation and hence, to derive the cost in staff time per consultation. For a review appointment the cost is £9.35; for a routine appointment the cost is £6.22.

Derivation of a staff cost per attendance at the NP Clinic: From clinic records, there were 2142 attendances at this clinic in year 2. Although the NPC patients also have routine and review consultations, their system requires that a nurse sees the routine patients and calls a doctor only if necessary, while both nurse and doctor attend to a review patient. Therefore, both review and uncomplicated routine consultations use approximately the same amount of nurse's time, but the review has doctor's time added. Observation over several weeks revealed 56% of all consultations to be attended by a nurse alone and the remaining 44% to be attended by both doctor and nurse.

To calculate the amount of medical time used in this clinic, the time that doctors actually spent with patients in the clinic was measured over one week's sessions and gave a mean of 7 minutes (range 2 to 17) when a doctor was called to the consultation. The nurse spent, on average, 13 (range 10 to 28) minutes at each consultation. A validation is shown in Table 70. This estimate implies that the medical staff only required to be in the clinic for 24% of the total session. This was regarded as an underestimate by the nursing staff who considered that 50% was more realistic. Furthermore, some time was used in doctors getting to and from the clinic and reading the patient's notes before the consultation. Whether the rest of the medical time should be counted as a cost or not is discussed in section 7.5.2.

Several estimates for cost could therefore be made for the NPC group assuming varying amounts of the available medical time is not available for other activities. In the cost-effectiveness calculations, an estimate of 50% is used which gives the nurse-practitioner clinic credit for freeing approximately half of the medical time. The effect of varying this assumption is shown in section 7.5.6.

The above estimates together with the estimate of secretarial time give a staff cost per review consultation of £9.60 and per routine consultation of £5.68 at the nurse-practitioner clinic. These costs would be £13.45 and £5.68 if none of the medical time had been saved.

Medical and secretarial time used for shared-care consultations in general practice: Estimating the proportion of a general practitioner's time which is taken up by SC patients, in a manner comparable to the estimation of the medical work done in the clinics, would require that the length of a shared-care visit be measured. This was too difficult to carry out with any precision since there are nearly 200 general practitioners, in different practices, with differing consultation styles and

arrangements for the annual review. Furthermore, the number of total consultations per year of each participating general practitioner was not available. Therefore, published figures for the average general practitioner list size and number of consultations per person on a general practitioner's list in the GGHB area were used to estimate the average cost of a consultation with a general practitioner.

In 1988, the average number of consultations per general practitioner was 6855 (ISD 1988). One participating practice logged all consultations and made the summary data available to me; their practice consultation rate was 5942 per general practitioner per year. Both these estimates imply an average consultation length of about 11 minutes which is similar to the usual length of 10 minutes quoted by five separate practice receptionists. Therefore I initially used an estimate of ten minutes per shared-care consultation. However, as described in section 7.5.6, sensitivity analyses showed that the result of the cost-effectiveness analysis was sensitive to the estimate of medical time used. In order not to favour shared-care by underestimating the amount of general practitioner time required, this estimate was doubled to a generous estimate of twenty minutes for each shared-care consultation.

Using the above estimates and the salaries given in Table 68, the cost in medical and secretarial time of a shared-care consultation varies from £2.34 to £4.67 to £9.34 for estimates of 5, 10 and 20 minutes consultation time. The highest estimate of £9.34 has been used in the cost-effectiveness calculation.

Investigations: The investigations costed are those which the project Steering Group considered to be essential for the annual review, that is, urinalysis, serum biochemistry and ECG. The cost of urinalysis is estimated as the cost of one Clinistix per review (£0.04). Serum biochemistry costs were estimated as £0.85 (for reagents) per review by the laboratories involved in the Scheme. The average variable cost of an ECG (again, materials used), was estimated by the ECG

department in the Western Infirmary as £0.12. This gives a total investigation cost per annual review of £1.01.

In general practice, the costs of each investigation have been assumed to be precisely the same as in the clinic because the same laboratories and facilities are used. The transport costs have not been included in this case since the cost of transport of BPC and NPC samples from clinic to collection point and thence to the biochemistry laboratory (in another hospital for the majority of the BPC group) could not be accurately costed in the hospitals, were likely to be similar in each group and could, moreover, be regarded as a fixed cost.

7.2.3 Shared-care registry and clinic administration costs

Shared-care registry: The system had been automated as much as possible during the project in order to standardise procedures, simplify the routines and reduce the amount of required supervision to a minimum. Thus, standard letters, flowcharts for procedures and automatic computer routines for printing of lists and labels were incorporated. Since the follow-up was based on a cycle of care, the registry activities also followed a cycle which began, but was not necessarily completed, each month as a new batch of patients were prompted to attend their general practitioner for review. The cycle continued with updating the computer database as results arrived in the registry, checking results, printing updated records and sending these out along with any further notifications to general practitioners and patients. At pre-determined intervals, reminders were sent to defaulters. The length of the cycle varied for each patient and the activities relating to one cycle of patients went on alongside those relating to a previous cycle. In order to estimate the amount of secretarial time used to operate the Shared-Care Scheme, these activities carried out by the secretary were timed and analysed.

Secretarial time costs: The average amount of time spent by the secretary, in one month, on each of the above activities is shown in Table 71. On average, the time for the activities amounted to 1.26 hours per monitored SC patient per year. The resulting cost per SC patient per year is £4.34 based on an estimate of £3.47 per hour (including 15% National Insurance and superannuation) for a secretary's time. The implications of alterations to this assumption are examined in a sensitivity analysis in section 7.5.6.

Cost of screening results: The time taken for a consultant to screen SC review results was measured as two minutes per review, that is £0.81 per review. This estimate is adequate for costing purposes since it has been derived in a manner comparable with the clinic staff time calculations. However, in practice and particularly with a larger number of patients, it is likely that a regular consultant session or part session would be allocated to this activity, perhaps as part of the re-referral clinic.

Postage and telephone costs: Postage costs were incurred for routine prompts to patients and general practitioners, updated records and Booklets, reply-paid envelopes for results from general practitioners and reminder letters. Biochemistry results from laboratories and ECG tracings usually came via the internal mail and a zero cost is assumed for this postage, as has been assumed in the clinics. Telephone costs were incurred when the telephone was used to remind patients or general practitioners rather than post. The mean costs per patient per year are shown in Table 72.

Printing costs of records, standard letters and Booklets: All of these costs have been measured because all are of interest in deriving an absolute cost of the Shared-Care Scheme and in investigating its feasibility. However, since the BPC and NPC clinics also had computer-produced records and letters, the costs of printing these have been dropped from the cost-effectiveness comparison. The costs of the patient Booklet have

been included in the total cost since it is an integral aspect of the Scheme for which there is no equivalent cost in either clinic. This cost is shown in Table 72.

Clinic administration costs: All costs of secretarial salaries in the clinics have been included in section 7.2.2 as staff costs. Postage costs were also incurred in both clinics since a letter is sent to the general practitioner after every clinic visit. The cost of second class postage in 1988 was £0.14.

7.2.4 Costs of medicines:

The cost of patient medication was taken into account for two reasons. First, to determine whether being transferred to the Shared-Care Scheme resulted in a change in the overall costs of medicines and second, to gain some idea of the relative cost of drug therapy beside the costs of the other components of a patient's care. A survey was carried out to compare the cost of medicines at the start and end of the two year period in all three groups.

Method: The number of drugs listed on the patient computer-produced records at the beginning and at the end of the two year follow-up was counted for a random sample of 100 patients in each of the SC and BPC groups and 114 in the NPC group. The daily cost was calculated using the prices in the British National Formulary for 1988 for both initial and two year data so that both figures could be easily compared. Since it was sometimes impossible to determine from the medical records whether proprietary or generic drugs had been prescribed and since the actual prescribing of medicines for all patients in all three groups was carried out by the general practitioner, it was assumed that there would be no difference in the use of proprietary and generic drugs between the groups and proprietary costs were used. Where the actual brand of drug used was in doubt, the most frequently prescribed option was assumed.

Number of drugs: The number of drugs mentioned on the record in year 2 was greater than in year 1 in both the NPC ($p=0.016$) and the SC ($p=0.001$) groups, though most markedly in the SC group, while the number fell in the BPC group ($p=0.009$) (Table 73).

Cost of drugs: The mean drug cost for each group is shown in Table 74. There is little difference between the three groups at the end of the two years although the NPC group exhibit a significant rise in cost over the two years having started at a slightly lower level.

7.2.5 Total costs to the NHS incurred by each group of patients over year 2:

Table 75 summarises the variable costs calculated in the previous sections.

In order to calculate the total costs for each study group, it is necessary to have several other items of information:

- a) how many consultations of each type were attended by each group
- b) how many reviews were carried out
- c) how many reviews were satisfactory
- d) how many patients were monitored and
- e) how many shared-care patients required to attend the hospital for an ECG. All of these have already been counted and are summarised in Table 76.

The costs of staff time, investigations and administration in year 2 were totalled for all monitored patients in each study group (Table 77). The cost for unmonitored patients was taken to be zero.

These costs assume that no investigations are carried out at a routine visit. From the BPC clinic notes, it was estimated that about 5% patients did have serum biochemistry carried out at routine visits. The extra cost of this can be calculated as £12.79. However, this small extra cost has been ignored in the

total cost because it is impossible to ascertain how many of these extra investigations are part of routine follow-up and how many are used to assess patients' suitability for clinical trials. Furthermore, it is possible that both the SC and the NPC groups also had extra tests carried out which were not recorded by the study.

7.3 MEASUREMENT OF COST TO PATIENTS

Summary: The patient costs measured are travel, consultation time and companion costs. In all three, at the end of year 2 the cost for the SC group was lower than the other groups and lower than the SC costs at the outpatient clinic at the start of the study. Extra cost was incurred by about half the SC group in attending hospital for an ECG. However, the final total patient cost for the SC group was £1891.88 compared with £3491.36 and £2465.14 for the BPC and NPC groups respectively.

7.3.1 Introduction:

The costs taken into account here are variable costs to the patient, that is, transport, the cost of time spent travelling, the cost of time spent at the consultation and companion travel and time costs. All of the information on which these costs are based was obtained from the patient questionnaires at the beginning and end of the study. Differences between the mean initial and follow-up levels have been compared using 95% confidence intervals for the difference.

As discussed in section 4.2.5 the non-responders were not significantly different from the responders in demographic characteristics. It has therefore been assumed that their costs would be no different. At the beginning of the study, all SC patients attended the outpatient department and so their initial costs are those attributable to an outpatient consultation; their later costs are those attributable to a shared-care consultation.

7.3.2 Travel costs:

These are calculated as transport costs and time spent in travelling to and from the consultation in clinic or surgery.

Transport costs: Transport is costed assuming zero cost for those walking, actual transport costs (from questionnaire) for

those taking some form of public transport and at £0.07 per mile for those using a private car. This is the estimated petrol cost in 1988 and avoids any bias which would result from including an amount for depreciation of the car (see section 7.5.3).

The estimated mean initial and two-year transport costs are shown in Table 78. There is a slight, but insignificant rise after two years in the mean BPC and NPC costs but a significant drop in the mean SC transport costs from £1.24 for the journey there and back initially to £0.50 on shared-care.

Travel time cost: The cost to the patient of time spent travelling to and from a consultation was costed at £0.03 per minute. The method of costing patient time is discussed in section 7.5.3. The time taken, as stated by the patient before and after the two year follow-up, was used to give the estimated cost (Table 79).

There is a significant drop, of £0.91 in the mean time cost per return journey for the SC group while there is a slight, but non-significant rise for the BPC and NPC groups.

Total travel cost: Adding the mean transport and travel time costs together gives mean travel cost per visit. There is a significant drop of £1.65 (49%) for the mean travel cost per visit in the SC group but a non-significant rise of £0.26 and £0.16 in the BPC and NPC groups respectively.

7.3.3 Patient time cost at the consultation:

The time spent in the clinic or surgery when attending an appointment was estimated by patients themselves in the questionnaire.

The average times and calculated mean costs are shown in Table 80. On shared-care, the SC group claimed to spend significantly less time at their appointment than previously but

the BPC and NPC groups were approximately the same as before.

7.3.4 Companion costs:

In order to estimate the costs of taking a companion to the consultation, the questionnaire contained an item asking whether the respondent came to the consultation alone. Before the intervention, there was no difference between the SC, BPC and NPC groups in the number who came on their own (about 80%, Table 57). However, after the intervention, while there was no change in the BPC and NPC groups, the SC group had 90% coming on their own. This has cost consequences either to the patient or to the companion and so the cost has been estimated and included with patient costs.

Bringing a companion is assumed to incur the same time costs as the patient, that is, travel and waiting time. Transport costs are also assumed to be the same as those of the patient unless the patient comes by car, in which case the extra transport costs of the companion are assumed to be nil.

Table 81 shows that for the SC group, 80% have initially no companion costs which rises to 90% when on shared-care. Furthermore, the companion costs after shared-care, when they do occur, are less than before. Before shared-care, the average companion cost for patients who do take a companion was £5.87 per consultation which dropped to £2.68 per consultation on shared-care. Averaging the cost of a companion over the whole SC group gives £1.17 per patient initially. Combining the reduced numbers who take a companion with the drop in cost for each companion taken, these figures give a mean drop of £0.90, from £1.17 per consultation to £0.27 per consultation when on shared-care. In contrast, the mean companion costs for the BPC and NPC groups remain roughly similar over the two years of the study, averaging just over £1.00 per consultation for the BPC group and just under £1.00 per consultation for the NPC group.

7.3.4 Costs of attending at hospital for an ECG:

When a general practitioner had no ECG facilities to allow him or her to comply with the SC annual requirement for an ECG, the patient was offered an appointment at the ECG department in the nearest suitable hospital ECG department. To estimate the cost of this attendance to the patient, the average cost of travel to the hospital was taken as equal to the mean travel cost for the BPC group and the time spent in the ECG department was estimated as ten minutes.

This gives a mean patient cost per ECG attendance of £3.88.

7.3.5 Total patient costs for each study group:

The unit costs used to derive the total costs are given in Table 82 while the number of consultations has already been summarised in Table 76. Using these figures, the total patient costs for each group are £1891.88, £3491.46 and £2465.14 for the SC, BPC and NPC groups respectively (Table 83).

7.4 RESULTS OF THE COST-EFFECTIVENESS EVALUATION

Summary: The measurements of benefits and costs are used to derive cost-effectiveness ratios (CER) of £28.96, £50.55 and £30.95 for the SC, BPC and NPC groups respectively. Including the costs of medicines does not change the relative ranking. The ratios which take into account only patient costs have the same ranking with shared-care costing the patients less per successful annual review than either clinic. When only NHS costs are considered, the nurse-practitioner clinic is most cost-effective and shared-care is still more cost-effective than the outpatient clinic.

7.4.1 Components of the evaluation:

The total benefits and total costs for each group are summarised in Table 84 with and without the costs of medicines. Including medicines multiplies the SC group cost seven-fold.

7.4.2 Cost-effectiveness ratios:

The derived cost-effectiveness ratios (total cost per successful review) are £28.96 for the SC group, £50.55 for the BPC group and £30.95 for the NPC group (table 84). The CER including medicines is £217.30, £276.75 and £221.31 for the SC, BPC and NPC groups respectively.

NHS costs only: NHS cost per successful review is £20.36, £26.63 and £18.75 respectively (table 84). In this case, the ranking now has the nurse-practitioner clinic as the most cost-effective. Shared-care costs the NHS 72% of the cost of following patients in the outpatient clinic and 111% of the NHS cost of the nurse-practitioner clinic.

Patient costs only: Patient cost per successful review is £8.60, £23.91 and £12.20 for SC, BPC and NPC groups respectively.

A successful review on shared-care therefore costs the patient 36% of the cost of a successful review in the outpatient clinic and 70% of that in the nurse-practitioner clinic.

7.4.3 Incremental costs and benefits to the NHS:

If the SC group had continued to attend the clinic rather than being transferred to shared-care, it is likely that they would have used resources equivalent to those used by the BPC group and derived equivalent benefits. Hence we can calculate that the incremental cost-effectiveness to the NHS (extra cost to the NHS/extra benefit) is £7.97; that is, achieving the extra benefit that shared-care offers costs the NHS £7.97 for each of the 74 extra successful reviews.

7.5 VALIDITY OF METHODS AND SENSITIVITY ANALYSES

Summary: Due to the incomparability of the fixed costs for each group of patients and the difficulty of measurement, only variable costs have been included in the analysis. This would affect any comparison of the absolute costs for each group. Half of the medical time dedicated to the nurse-practitioner clinic has been considered cost-free but this is, in reality, a generous assumption because the medical staff are "on call". Patient time costs are valued at £0.03 per minute and lost working time has not been included as a cost to the patient. The cost of car journeys to and from the consultations has been taken as petrol costs only in order not to weight this cost unfairly. There could be a case for excluding companion costs but, in this case, the cost of companion time and travel were assumed to be necessary to patient attendance and therefore were included. Discounting is not appropriate in this costing, missing information is compensated for by assuming no difference between these patients and those who supplied information and patients who were not monitored are assumed to have no cost or benefit. The main assumptions are summarised in this section and several estimates are subjected to a sensitivity analysis. This analysis shows that the results are most sensitive to the estimates of medical time and, in the case of shared-care, to the secretarial time; halving the clinic visits would give the BPC group a cost-effectiveness ratio similar to that of the SC group if the benefits remained the same.

7.5.1 Fixed costs:

All costs relating to the programmes of care could be classed as either fixed - do not vary over the period of the study - or variable - vary with the number of patients, reviews or visits.

Fixed costs relating to the provision of premises and some running costs, for example, heating and lighting, have been excluded from the analysis. These costs are impossible to estimate other than in a very approximate fashion, for example, a cost per unit of area of a clinic. In this study the comparison was between two clinics and a large number of general practitioner surgeries. While costs obtained for the clinics may have been comparable, it is likely that they would have differed significantly from the equivalent published average costs of surgeries and even the surgeries would vary depending on such factors as locality (rates), type of premises (maintenance), type of heating used (heating bills). It was important that all three groups were costed in precisely the same way to ensure comparability of the results.

Other features of the clinics and shared-care further reduced the comparability of the fixed costs; these specific features are discussed below.

SC Group: In this case the patients are so thinly spread, with most general practitioners having only one SC patient at present, that the proportion of a surgery's rental, heating and lighting would be very small indeed; there would be no saving to the general practitioner, in respect of these costs, by a reduction in the number of SC patients.

BP Clinic: We are not assessing the cost-effectiveness of this service for all its patients but whether it is a cost-effective option for well-controlled patients only. Therefore, it is valid to exclude some of the costs relating to the provision of the building and some running costs such as heating and light from the costing since at least a large proportion and perhaps all of these costs would still be incurred even if the BPC group did not attend the clinic. While there could be some reduction in building use if large numbers from the clinic were to be allocated to shared-care, it is most likely that the freed clinic time would be used by new patients or more frequent visits for return patients.

NP Clinic: This clinic has been costed similarly although, the assumption of no cost in respect of fixed costs is, perhaps, less valid in this case because the NPC group makes up a significant proportion of the whole clinic (57%) and the clinic is run solely for well-controlled patients. A reduction in the numbers of these patients attending the clinic would make a significant difference to the number of clinic sessions required and it is less likely, in this case, that the clinic space would be used by accomodating other patients. However, all groups were costed similarly.

These "fixed" costs will not vary over the period of the study but may be different for each group. Therefore, they may have significance in determining the absolute costs if it was necessary to do this. Furthermore, were any clinic or shared-care to expand or decrease markedly, the fixed costs might have to be taken into account.

7.5.2 Stobhill staff costs:

While it is true that some of the medical staff spent a lot of time outside the clinic during their clinic sessions, they were "on call" and their availability for other duties was not as great as at other times. The activities undertaken during this time varied with the individual; some felt able to participate in ward rounds while others spent time in the library close to the clinic. Thus, although 50% of the time could be spent outside the clinic, it was not totally free time and should perhaps not be considered cost-free to the clinic. The effect of varying the 50% assumption is shown in section 7.5.6.

7.5.3 Patient costs:

Valuation of patients' time: In order to value the time a patient spent attending a consultation, an estimate of £0.03 pence per minute was used. This is the value put on lost leisure time by the Department of Transport in 1986 (personal communication,

Health Economics Research Unit, Aberdeen). It was considered more comparable to cost all time as leisure time than to attempt to cost lost working time for some and lost leisure time for others. The main reason for doing this, apart from the difficulty in measurement, is that the value to the patient of lost working time is not necessarily the same as the "lost" portion of salary and, indeed, lost working time might have a lower value to the patient than leisure time. On the other hand, some people might experience a loss of money due to a clinic attendance although this is unlikely since a clinic attendance is usually considered a valid reason for missing work. A general practitioner attendance might not be a valid reason for missing work but is also unlikely to result in loss of salary since most surgeries offer appointments outside working hours. Therefore, to avoid complications and possible imbalance in the results, all time was considered to be of equal value to the patient and costed at the same level.

Cost of miles travelled by car: Some economic evaluations value car travel using a cost per mile on which remuneration of travelling expenses is based. This cost includes an allowance for depreciation of the car during the journey. I felt that this would make the cost of car travel disproportionately high. I therefore based the cost of car travel only on the cost of the petrol consumed; this was estimated from the miles per gallon of an average car (27) and the current price of petrol (£1.80). The resulting estimate is £0.07 per mile.

Companion costs: Perhaps companion costs and benefits should not be included at all. It could be argued that any companion has made their own assessment of the costs and benefits of accompanying the patient and concluded that the benefits are greater. However, I consider that some patients feel the need for a companion, perhaps to relieve boredom or anxiety. The patient and/or companion incurs some cost and provides some benefit which we are unable to quantify but which might be very important in ensuring that the patient attends the consultation. I consider, therefore, that the cost of a

companion, where it is incurred, is a necessary cost of patient attendance. Furthermore, it cannot be assumed that this cost is the same on shared-care as for a clinic attendance.

7.5.4 Other aspects of the costing:

Discounting: Discounting would be appropriate if the costs or benefits were occurring at different points in time or over a long time period. In this case, both are measured over one year only and, therefore, discounting was considered unnecessary.

Missing information: When data on patient costs, for example transport or time costs, are missing, it is assumed that these individuals would be no different from those who supplied data. This is supported by the analysis of the non-responders. Furthermore, the response rates were high enough to inspire confidence in the data.

Un-monitored patients: Those patients who lapsed from monitoring during the study had no official review and thus measured outcome for them was zero. Similarly, since they did not attend the clinic or the surgery for a shared-care review, they incurred none of the costs associated with these activities. It is likely that they did incur costs and, perhaps, benefits due to their non-attendance. However, these costs and benefits were not included in the study question and have been ignored. It would be of interest to quantify these in a different study.

7.5.5 Summary of main assumptions:

1. The measured benefit (satisfactory review) leads to improvement in health outcomes.
2. The only costs likely to differ between programs are staff time, cost of investigations, medicines, administration and patient travel and time.

3. Discounting is not appropriate.
 4. Only variable costs have been used.
 5. Missing information is assumed to be no different to that collected.
 6. Costs and benefits for un-monitored patients are assumed to be zero.
 7. Within a staff category, all are on the mid-point of the scale.
 8. Stobhill medical staff spend only 50% of their time in the clinic and the remaining 50% of their time is available for other duties.
 9. BPC review visits use 12 minutes of medical time and routine visits use 6 minutes; both types of visit use the same amount of nursing and secretarial time.
 10. Each shared-care consultation in general practice uses 20 minutes of general practitioner time.
 11. Medical staff in the nurse-practitioner clinic spend 7 minutes and nurses 13 minutes with each patient.
 12. Shared-care clinic visits have the same cost as BPC group clinic visits.
 13. Postage by internal mail has no cost.
 14. All prescribed medicines are assumed to be proprietary brands; where the brand is unknown, the most frequently prescribed option has been assumed.
 15. Cost of patient time is £0.03 per minute.
 16. Patient travel cost in a private car has been assumed to be £0.07 per mile.
 17. Companion benefits (if any) have not been set against their costs.
- Assumptions 8 and 10 have been tested in a sensitivity analysis.

7.5.6 Sensitivity analyses:

Table 85 shows the results of analyses of some of the main assumptions and estimates. Only those changes which alter the estimate of staff time have an effect on the ranking of cost-effectiveness ratios.

General practitioners' time: Sensitivity analysis reveals that the total cost for the SC group is sensitive to the length of medical time; therefore, a twenty-minute estimate has been used for the cost-effectiveness evaluation. It is considered very unlikely that shared-care patients spent more time than this with their general practitioner and so this is likely to be a maximum estimate. The cost of shared-care is therefore unlikely to be underestimated but may be overestimated relative to the other programmes; that is, shared-care may be even more cost-effective than reported. The CER decreases by £4.93 for a 10 minute consultation and by £7.40 for a 5 minute consultation, that is, it becomes 83% or 74% of the previous CER using total costs.

Clinic visits: Halving the number of clinic visits for the BPC group would reduce the cost sufficiently to produce a cost-effectiveness ratio similar to that of shared-care provided the effectiveness remained the same.

Shared-care secretary's time: Doubling this increases the CER of shared-care by 18%; however, shared-care is still more cost-effective under this assumption than the outpatient clinic.

Stobhill staff time: Removing the assumption of saved medical staff time increases the cost of the NPC group such that the CER increases by 21%. This does not, however, change the final ranking of the cost-effectiveness of the three methods of care.

7.6 DISCUSSION

Summary: The better CER for shared-care compared with the outpatient clinic is a combination of lower patient costs and higher effectiveness in achieving completed patient reviews. Although the cost of shared-care to the NHS may be slightly higher than outpatient care, it represents a more efficient use of resources. The incremental cost-effectiveness of shared-care is only £7.97 for each extra complete review. Shared-care is particularly cost-effective for patients while the nurse-practitioner clinic is particularly cost-effective for the NHS. A strategy which combined both these strengths might represent an optimal use of resources.

This economic evaluation has highlighted the relatively inefficient use of resources in following-up well-controlled hypertensive patients in the outpatient clinic. The cost-effectiveness ratio (CER) for shared-care is only 57% of that for the clinic. There are two main reasons for this. The first is that shared-care is far more effective than the outpatient clinic in ensuring that the patients are reviewed; the number of satisfactory reviews in the BPC group is 66% of the number in the SC group and the higher effectiveness of shared-care has influenced the cost-effectiveness ratio. The second reason for the smaller CER for shared-care is the substantially lower cost to patients of shared-care compared with clinic attendance; travel and time costs for the SC group are only 47% and companion costs are 25% of those for the BPC group.

Although the second reason for the better cost-effectiveness of shared-care is important when the viewpoint is that of the patient or society as a whole and while it may be an important factor in ensuring patient participation, it might be less likely to influence those who take the viewpoint of the NHS and who would be instrumental in ensuring shared-care was adopted as a service.

In the short term, the absolute cost of shared-care to the NHS may be slightly higher than the cost of providing clinic care because of the need for the supporting structure of the registry and because patient attendance is higher with shared-care. Those who receive no follow-up care at all have no cost to the NHS and 14% (38/270) of the BPC group were costed as falling into this category; while the assumption of no cost is not likely to be strictly true in that these patients probably continued to receive follow-up care from their general practitioner, it is possible (as discussed in chapter two) that their follow-up will be patchy and may result in morbidity in later years.

Providing the shared-care structure, even at a cost, has resulted in greater cost-effectiveness; a case of a small extra input creating a much larger output in terms of the benefits obtained. In spite of the extra cost of the registry, the CER (NHS only) for shared-care is around 30% less than that for the BPC group. Furthermore, this estimated cost of shared-care is likely to be a maximum so it is likely that shared-care is even more cost-effective than reported.

Given that the SC group would have attended the clinic over the two years had they not been transferred to shared-care, the relevant CER is the incremental ratio which gives the extra cost for each extra complete review on shared-care. This shows that achieving these extra 74 reviews has cost the NHS a total of £589.78 or £7.97 per review.

The final CER for the nurse-practitioner clinic is similar to shared-care; however, the breakdown of costs shows that the nurse-practitioner clinic is more cost-effective for the NHS than either of the other two methods while shared-care is most cost-effective for the patient. Unfortunately, shortly after this evaluation, the nurse-practitioner clinic at Stobhill Hospital was disbanded due to departmental re-organisation and the patients were transferred to shared-care.

However, the results of the evaluation have been used to devise a strategy based on all three methods of care which is described in Chapter 8.

Drug costs: The outlier referred to in the SC group was a patient diagnosed as an insulin-dependent diabetic during the study by his general practitioner and so his drug costs rose markedly. This patient's costs were disregarded in the calculation of mean drug costs for the SC group although it is interesting to speculate whether shared-care might influence such diagnoses and hence costs but also benefits.

The differences from the start to year 2 in daily drug costs for the SC and BPC groups were not significant in spite of the increased number of drugs recorded for the SC group. The extra drugs may have been low cost or the actual drugs used for all the SC patients may have been cheaper than those used for the BPC group. These hypotheses have not been tested.

It is impossible to estimate how much of the apparent increase in drugs in the SC group was due to an actual increase in drugs being taken and how much was simply better recording of information, for example, via the general practitioner's copy of the medical record and the patient's booklet. The literature on poor recording of medicines (see Chapter 2) suggests that it is likely to be due to better recording.

The significant increase in recorded drugs for the NPC group may reflect the "stepped-care" approach used in this clinic where drugs are added until good blood pressure control is achieved and only very rarely is the number of drugs reduced.

This costing exercise has highlighted the enormous cost of medicines for these well-controlled patients; this cost far outweighs any cost for staff and investigations. Furthermore, it strengthens the economic argument for optimising the

effectiveness of the follow-up of these patients less this large amount of resources be wasted.

Other benefits: The economic evaluation gives no value to attendances which do not result in a satisfactory review. These attendances do however, result in costs and probably benefit the patient in ways which have not been enumerated in this chapter, for example, clinic attendance may reassure some patients. Some of these other potential benefits have been discussed in Chapter 5 and are probably reflected in the acceptability discussed in Chapter 6. It would therefore be wrong to take the results of the economic evaluation separately from the results of these other chapters unless to answer only the question of which method of care is most cost-effective at ensuring a satisfactorily complete annual review.

CHAPTER EIGHT: IMPLICATIONS OF THE RESULTS OF THE SHARED-CARE PROJECT

8.1 LONG TERM FEASIBILITY OF SHARED-CARE

Summary: The feasibility of shared-care in the long term must take into account further expansion and changes in attitudes of participants. Indications are that patient attitudes will remain favourable. There are strong clinical and economic arguments for the continuation of shared-care which may persuade doctors and health board staff. Further recruitment of less well-controlled patients or of patients who do not require referral to a specialist are both possible but would require consideration of follow-up protocols and possibly more resources. The feasibility and cost-effectiveness of this method of standardising patient follow-up, and some of the particular features of the Scheme, could be applied to the care of those with other chronic conditions.

8.1.1 Shared-care for hypertension:

Webster's Dictionary defines feasible as "capable of being done, possible of realization". In these terms, shared-care is feasible at least at the level of achievement reported in Chapter 5. However, just as the **efficacy** (in ideal conditions) of a procedure or drug may be different from the **effectiveness** (in real situations), similarly, the pilot version of shared-care will need to fulfil certain further conditions before its long term feasibility can be assumed. These conditions include

- a) that the model can be successfully expanded to a larger population of patients and that the existing recruitment methods continue to be suitable or can be successfully altered
- b) that patient attitudes remain favourable towards this approach to their care
- c) that health service staff remain in favour of this approach, particularly in light of the recent changes in the structure of NHS financing.

Expansion to a larger population: The only limitations on patient registration on shared-care at present are the resources to run shared-care (for example, secretarial time) and the accessibility of shared-care to patients, through the outpatient clinic, if their general practitioner is agreeable.

Each shared-care patient required, in the pilot study, an average of 76 minutes of clerical time per year; however, this includes a large amount of organisational time. Allowing 20-25 minutes extra per year for each new registration would allow 2,000 patients to be accommodated by a half-time clerical officer. Extrapolation of the previous results implies that 2000 monitored patients would require 170 annual reviews to be coordinated each month, six hours of specialist time for screening of results, with around 5 re-referral visits per week (the specialist workload could probably be accommodated within one session per week).

Referrals to the Glasgow Blood Pressure Clinic are around 250 per year. Continuing the existing recruitment methods, with up to 85% of general practitioners participating in shared-care and assuming that only half the patients would become suitable for shared-care within a year, around 100 patients would be enrolled per year. Therefore, if resources were to be made available for a half-time secretary and one consultant session per week, shared-care could extend recruitment and become available to a greater patient population.

Several developments may reduce the staffing requirement and permit even greater numbers on shared-care. These are a) that the shared-care system is being re-designed as an integrated part of the Glasgow Blood Pressure Clinic's clinical information system merging the clerical procedures with Clinic procedures b) that practice nurses are taking over much of the work in general practice and procedures for communication are becoming more streamlined c) that progress in implementing new technology will mean that non-paper transfer of information from general practice and from laboratories will be

possible d) that a review of the procedures for annual review may reduce the need for some investigations. The last development is discussed in section 8.2 and is the subject of further evaluation.

To whom could shared-care be extended? The patients registered on shared-care were a highly selected group having been referred to a blood pressure clinic and then selected by their consultant as suitable for shared-care. They were older (mean age 58 years, 95% CI: +/- 2 years) than newly referred patients (mean age 48 years, Juncosa et al, 1990), they had a mean blood pressure on treatment of 148/85mmHg compared with 171/104mmHg for newly referred patients and were on an average of 2 drugs. Their level of risk, as perceived by their medical attendants, may be higher than those patients not referred to a specialist but lower than those not recruited to shared-care.

To extend shared-care to a larger group of patients at lower risk, for example those patients unlikely to be referred to a specialist, would greatly increase the numbers on shared-care. A recruitment rate of around 250 patients per year would allow extra recruitment from outwith the outpatient clinic but would require consideration of staffing levels in 10-15 years and faster recruitment would require this at an earlier stage.

To extend shared-care to outpatients at potentially higher risk might require consideration of more stringent follow-up criteria and, for example, automatic recall procedures. However, given the finding in the pilot study that one third of those lost to follow-up apparently had poor blood pressure control, there must be a case for endeavouring to extend this effective method of follow-up to this group. Both of these are possible future developments now that the basic principle has been shown to be feasible among a majority of general practitioners and patients.

It is, however, likely that some general practitioners and patients will not wish to participate in shared-care, at least in the near future. The results of the study indicate a large "preference" factor due to methods of working on the part of general practitioners and perceptions of different levels of expertise on the parts of patients. For this reason, it is likely that the Clinic will continue to operate follow-up care at several overlapping levels to accommodate differing levels of need for specialist care and differing preferences, provided resources permit this approach. The potential for and costs of this approach are discussed in section 8.2.

Patients' attitudes to shared-care: From November 1991, all patients have the right of access to any information subsequently recorded in their paper medical record (Access to Health Records Act 1990). Limited right of access to computerised medical information is already permitted (Data Protection Act 1984). Consumer associations encourage the general public to take more interest in the provision of outpatient and general practitioner services (for example Consumers' Association 1987). The recent NHS changes, which encourage service providers to consider the patient as a consumer (Secretaries of State 1989), have led to changes in the administration of some services; for example, "patients' charters" have been adopted by several outpatient departments in GGHB. All of these developments will tend to increase patient awareness and possibly, their autonomy. This may, in turn, increase the demand for patient-driven services like shared-care.

Furthermore, allowing patients to have routine access to medical records is gaining favour with doctors (Kirby 1991) and, in this study, we found patient held records to be popular with both patients and doctors. Smart cards can now be adapted to carry medical information (Stevens 1988) and the possibility of shared general practitioner-specialist care is one of the advantages claimed by the manufacturers.

The main disadvantage of shared-care mentioned by patients in the study was the need for more than one visit; in many cases, this was for an ECG. As already mentioned, the frequency of investigations required on shared-care is being re-considered. An annual ECG was only considered necessary by 35% of general practitioners; reducing the frequency of ECG might increase the acceptability of shared-care to patients.

For these reasons, it is very unlikely that patient attitudes will become less favourable towards shared-care. On the contrary, its popularity with patients may increase.

Attitudes of specialists, general practitioners and NHS managers: Unfortunately, the evaluation of this project took place just before the Government's plans for the NHS were published (Secretaries of State 1989) and even in 1991, many of the implications of the changes are uncertain. However, we can speculate on the likely support for shared-care based on the apparent benefits that shared-care can offer to each of the above groups and its likely direct cost.

From the point of view of **health boards**, shared-care should be seen as a means of improving the efficiency of existing services. Our study showed that maintenance of patient follow-up could be improved by 13% (reviews) to 52% (complete reviews) over the existing service for an increase of around 15% in absolute costs to the NHS. Furthermore, shared-care ensures the achievement of a pre-determined standard of care. The very stringent requirements in this study were met for 82% of the patients. Neither of the clinics could achieve this level of success. If resources in the specialist clinic were maintained, this would also provide the opportunity for improved coverage of the patient population which could benefit from specialist care.

Shared-care provides a service which is both more convenient for patients and less costly to them in terms of travel and time; for example, the cost of travel was an average of £0.84

per journey less for those on shared-care compared with those attending the outpatient clinic and they spent 79 minutes less travelling and attending the consultation. Acceptability of the service to its consumers is one of the main points made in the white paper.

Further development of shared-care has the potential for even greater rationalisation of the use of resources and provides a basis on which liaison between specialist and general practitioner services can proceed. There is agreement that advances in care at the interface between specialist and general practice can only take place in an atmosphere of cooperation and discussion (for example, McGhee & Sullivan 1991) which a system like shared-care can offer. Furthermore, due to changes in rules for re-imburement, many general practitioners are developing health promotion clinics. In 1991, the Glasgow Blood Pressure Clinic has been approached by several individual general practitioners for assistance with the development of protocols of care and guidelines for the management and referral of hypertensive patients. Shared-care could provide the vehicle for the widespread adoption and evaluation of such protocols which could then be a basis for audit of patient care.

Hence, from the point of view of NHS management, there could be many benefits to be derived from this approach to patient care. The only costs would be the financial outlay in terms of staffing and running costs. The redeployment of resources from the specialist clinic would be an option if it is considered that shared-care can replace a part of the existing service. However, while hypertension continues to be inadequately managed (Smith et al 1990), there is perhaps a case for some further resources to be put into shared-care. Certainly, when one takes into account the enormous cost of anti-hypertensive medication (£140-£160 per patient per year in our study), there must be a case for ensuring that these resources are used effectively and efficiently. The best alternative use of freed clinic resources, due to shared-care, may be to support,

further, this type of community-based follow-up of hypertension and other cardiovascular risk factors.

From the point of view of **consultant** NHS staff, shared-care provides the opportunity for continued involvement in the long term care of patients and ensuring that a certain standard of care is maintained. It also provides both the means for implementing standard follow-up for a large number of patients and the means of evaluating its effect. It provides the potential for long-term data collection to support epidemiological and clinical research. The completeness of clinical data for the shared-care patients in our study, while not as good as for the two clinic groups in respect of a few variables, did reach acceptable levels for most variables and very high levels for some. The Scheme has been accepted by all staff of the Glasgow Blood Pressure Clinic and will expand as resources permit.

A recent major development in the NHS is the requirement for audit of patient care. Without a system like shared-care for long term follow-up of previously referred patients, monitoring of the outcome of hospital care will continue to be very difficult or very expensive.

Finally, and importantly, the freeing of a substantial proportion of consultant time (68 hours or 11% of clinic time for the SC group) may allow the development and evaluation of new services. For example, the initial investigation of all newly detected hypertensive patients and subsequent, automatic registration on shared-care is a feature of both the Grampian system (Petrie et al 1986) and one of the diabetic systems (Hill 1976).

Potential advantages to **general practitioners** include improvement in patient follow-up and standardisation of patient care, the opportunity to be kept informed of new developments and potential problems which a centralised information system can offer, access to the medical information

from the hospital records, regular contact with specialists, patient advice and support for practice nurses. These features were appreciated to varying degrees by general practitioners as the comments in Chapter 6 indicate.

There is the disadvantage that shared-care does result in more work; general practitioners will see each shared-care patient for one extra visit per year, on average, but some general practitioners will see their patients much more than this. Furthermore, the present system relies on the completion of paper forms although some of this workload is being reduced by a greater emphasis on use of the patient carried booklet.

Because of requirements to demonstrate achievements of targets, follow-up systems based in general practice may become more widespread. A few general practitioners have asked that they provide information from their own follow-up system rather than carry out the shared-care review and this is accommodated in the system.

Nonetheless, the overall benefits of shared-care are perhaps less apparent from the point of view of some general practitioners than from the other viewpoints, particularly for those general practitioners who have a strong personal interest in the follow-up of hypertension. There was a preference in our study for routine general practice care by two thirds of the general practitioners; however, the remaining third had a definite preference for shared care.

Financial aspects: With health boards in the role of purchasers of specialist and primary care services, hospitals as providers and general practitioners both providing primary care and purchasing specialist care, the relationships between primary and secondary care, in a financial sense, may become complicated. On the other hand, the discussion above shows that politically, financially and clinically, shared-care has clear benefits. The questions of whether the benefits will be

perceived to be worth the cost depends to a great extent on who pays and who benefits.

Ideally, health boards should not see shared-care as a direct cost to general practitioners, particularly those practices which elect to manage their own funds. A direct cost might be a disincentive to co-operation in shared-care since, as discussed above, some of the derived benefit will not necessarily be apparent, especially to those general practitioners who already have successful follow-up systems for their own patients. On the other hand, participation in shared-care may be a feature which attracts patients and would be worth paying for. It is difficult to know, at present, how these various forces will interact in practice.

Health boards may consider shared-care to be a service worth paying for and encourage its adoption by hospital services; hospitals might use it as an inducement to both health boards and general practitioners to take up their services.

On balance, in terms of the more efficient use of resources, improvement of coverage of the patient population, ensuring good quality, standardised, follow-up, the opportunity for ongoing evaluation of care and convenience to patients, the arguments for shared-care are powerful. These arguments may ensure the support of medical staff and managers and the continuance of financial support.

8.1.2 Other chronic conditions

The above discussion has been free of comment about the clinical nature of hypertension. The only specific aspects of hypertension mentioned are the general acceptance that its management could be improved, that its prevalence and association with cardiovascular disease and stroke make it a costly condition both in resource use and patient lives and that large amounts of resources are currently used in its treatment. However, the same argument could apply to several other

chronic conditions which can be managed within general practice with a degree of specialist involvement, for example, diabetes, thyroid disease, asthma and epilepsy. The basic features of shared-care, which have been shown to be cost-effective in practice for hypertension could be applied to these other conditions.

The main features of this Shared-Care Scheme which are different from the other schemes mentioned in Chapter 2 are the common clinical record, the patient-held record and the extensive evaluation. The patient-held record has been an overwhelming success, to such an extent that much of the communication between primary care and the registry takes place using the Booklet. The results of the evaluation could be generalised to other conditions since, apart from a different set of clinical data, the procedures required for the operation of shared-care are likely to be similar. The information from the evaluation could be used, not only to make a case for implementing shared-care, but also for designing a better or more tailored approach for other groups of patients.

8.2 FURTHER DEVELOPMENT AND EVALUATION OF SHARED-CARE

Summary: The absolute cost of shared-care for around 4,500 patients in the West of Scotland would be about £15,000 per annum. Expansion will require criteria to be agreed between specialists and general practitioners. A possible development is the combining of four levels of care - general practice, shared-care, nurse-practitioner clinic and specialist clinic - into an overlapping hierarchy. Review of the protocol for annual review is an important next step and further development and evaluation must proceed together.

8.2.1 Increased registration of patients:

If shared-care were to cater for 2000 patients with a similar intensity of follow-up as in the present study, we would have a cost-effectiveness ratio of approximately £19.71 per successful annual review (NHS costs), based on the level of effectiveness found in the study, the proportions of patients returning to the clinic and a percentage effectiveness of 82%, yielding 1640 successful reviews. This would include 560 more complete reviews than follow-up in the outpatient clinic would provide, also given the effectiveness found in the study. The total cost to the NHS of providing shared-care as an extra service for these patients would be £32,322 per annum. The equivalent cost of outpatient follow-up would be £28,760 for 1080 successful reviews; each extra successful review of the 560 therefore costing £6.36.

Furthermore, the shared-care patient consultations in general practice, under present payment rules, would not result in a direct cost to the NHS; rather, they would be absorbed within the patient's routine consultations, increasing the total by an average of one consultation per shared-care patient per year. Thus the true cost of shared-care for 2000 patients to the NHS may be only £14773 per annum (shared-care staff, clinic visits,

investigations, administration costs), not even allowing for investigations and visits which may have taken place in any case.

We can assume, from the levels of participation in the study, that at least 300 general practitioners would wish to take part. Each could have six patients on shared-care which is a small extra annual workload.

Streamlining of procedures and re-defining investigation protocols may make it feasible to consider shared-care for up to 4,500 patients in the West of Scotland. This would represent 10% of the hypertensive patients in GGHB whose general practitioners already refer patients to the GBPC and who support shared-care plus 500 patients from outwith Glasgow (number based on the proportion found in the study).

The precise criteria for registration on shared-care would require agreement between specialists and general practitioners but might include perceived degree of need for stringent, long term follow-up and perceived risk of loss to follow-up by conventional means. General practitioner preference (which would take account of an individual's level of expertise and interest in care of hypertension) and patient preference (which would take account of an individual's degree of autonomy, relative convenience of clinic and surgery and relationship with specialist and general practitioner) might also be included since they may affect the cost-effectiveness of follow-up. However, this study was unable to determine whether this was so because there were so few drop-outs from shared-care.

No allowance has been made in the above calculation for greater numbers of patients from outwith Glasgow to be registered on shared-care since the study did not indicate any difference in preferences for shared-care between geographical groups.

8.2.2 A hierarchy of care options:

In order to cater for the minority of patients who require further specialist follow-up, for example, the 7% who were seen at the re-referral clinic, an intermediate step might be introduced based on the nurse-practitioner clinic which was more cost-effective to the health service although overall less cost-effective than shared-care. A hierarchy of care could be constructed with allocation of patients to levels according to perceived requirement for specialist care, allowing for preferences as far as is compatible with efficiency and movement between the levels, both upwards and down. This hierarchy might include:

- a) the outpatient clinic for initial evaluation and the continuing management of difficult patients
- b) a nurse-practitioner clinic for those patients who have better control of blood pressure but who prefer outpatient follow-up or whose general practitioner is not participating in shared-care. This level could provide an intermediate step between the outpatient clinic and shared-care and might be the first stage of re-referral.
- c) shared-care for patients who are considered not currently in need of direct specialist care
- d) general practitioner care for patients with uncomplicated hypertension whose general practitioner can provide adequate follow-up and who are not accommodated by b) or c).

Between levels b), c) and d) there will be a large degree of overlap in terms of clinical severity of hypertension and a large amount of variation in the level of care which can be provided by the general practitioner. Ideally the flexibility of shared-care should accommodate these variations with the aim of ensuring that every hypertensive patient in the area served by the GBPC has access to a high level of follow-up care.

8.2.3 Even more cost-effective shared-care:

An important step, now that the feasibility and effectiveness of this approach has been demonstrated, is to consider the clinical requirements for follow-up of the different groups of patients registered in shared-care and to reduce, if possible, the need for investigations in the relatively low risk groups. The protocol for annual review was based on what had been considered good practice in the outpatient clinic. However, long-term follow-up will provide the opportunity to evaluate this practice, for example, by analysis of the frequency of abnormal investigation results and investigation of the short- and longer-term predictive value of the tests being recommended.

8.2.4 Current and future evaluation:

This evaluation of shared-care was designed to test the feasibility, acceptability and cost-effectiveness of the prototype system in comparison with existing outpatient services. The main limitations of this evaluation included:

- a) the low number of dropouts from shared-care which hindered investigation of the factors contributing to effectiveness
- b) the correspondence between the measured process and health outcomes could not be assessed because of the lack of information on those who opted out of the study groups and the inevitable short-term nature of the evaluation.

The first will tend to be resolved with time and the resulting increased information. The second could be investigated with special studies over a much longer time period.

Strengths of this evaluation are that:

- a) it covered many aspects of the functioning of shared-care and provided information which 1) has been valuable in improving the service as well as in arguing for its continuation and 2) has provided the basis for ongoing evaluation of follow-up care, for example, extension of the role of nurse-

practitioners into shared-care and rationalising of follow-up investigations.

b) it included many of the resources used and identified the areas in which cost-effective measures could best be implemented, for example, cutting down further on unnecessary medical work.

The further development of shared-care as a service will require ongoing research and the research will require that shared-care continues. The main task now facing the project is to have these results considered and acted on by those who can ensure the implementation of cost-effective methods of care.

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**THE DESIGN, IMPLEMENTATION AND EVALUATION
OF A SHARED-CARE SCHEME FOR HYPERTENSION**

IN 2 VOLUMES

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	No. of deaths	% of total
Coronary heart disease ICD 410-414	911	27
Cerebrovascular disease ICD 430-438	193	6
Malignant neoplasms ICD 140-208	996	30
All other causes	1277	37
Total deaths under 65 years	3377	100

Information from ISD, 1986.

Table 1: Causes of death in under 65 year olds in GGHB (1985)

Category		Time interval	Investigation
Hypertensive	treated controlled	3 months	blood pressure, weight, smoking, side effects
Hypertensive	treated uncontrolled	1 month	blood pressure, weight, smoking, side effects
Hypertensive	treated controlled or uncontrolled	5 years	urinalysis, urea, creatinine, urate, potassium
Hypertensive	untreated	1 year	blood pressure
Normotensive		5 years	blood pressure

Information from Hart , 1987

Table 2: Guidelines for investigation and follow-up of hypertension

	Gilmore 1986	Hawthorne 1974	Extrapolation to GGHB population
diastolic BP >=90mmHg	14%	-	66842 (35-64 year olds)
diastolic BP>=100mmHg	-	5.5%	20230 (45-64 year olds)
diastolic BP>=110mmHg	4%	-	19098 (35-64 year olds)
known hypertensives	10%	21%	47744 (35-64 year olds) (based on Gilmore)
on anti- hypertensives	-	5%	18391 (45-64 year olds)

Table 3: Results of screening exercises and extrapolation to the GGHB population

Patients could be referred if:

	Standard One	Standard Two
Either	Under 40 years old and DBP>104	Under 40 years old and SBP>160
or		Under 40 years old and DBP>114
or	Over 40 years old and DBP>114	Over 40 years old and DBP>114
or	Any abnormality present	Any abnormality present
or	Poor control or unacceptable side- effects after 3 months with treble or more drug combination	Poor control or unacceptable side- effects after 3 months with double or more drug combination

Table 4: Standards used to assess referrals

	n	%
Dead	55	9
Discharged	83	14
Lost	241	40
Probably current attenders	221	37
Total	600	100

Of the current attenders:

	n	%
Aim achieved	166	75
Aim not achieved	44	20
Don't know	11	5
Total	221	100

Of those lost to follow-up:

	n	%
Aim achieved	142	59
Aim not achieved	77	32
Don't know	22	9
Total	241	100

Table 5: Results of the pilot study

	Pre- selected	Not selected	95% CI diff
Number	644	185	
Attend GRI n (%)	203 (31%)	126 (68%)	29% to 45%
Mean age in years	53.1	54.2	-0.86 to 3.06
sd	12.6	11.8	NS
Female n (%)	307 (47%)	102 (55%)	0 to 16% NS
Mean systolic BP (mmHg)	143.0	151.0	4.5 to 11.5mmHg
sd	18.7	22.0	
Mean diastolic BP (mmHg)	85.7	90.8	3.3 to 6.9mmHg
sd	8.7	11.4	
Mean no. problems	2.8	3.1	-0.04 to 0.64
sd	2.0	2.1	NS
With high risk criteria* n (%)	137 (21%)	48 (26%)	-2% to 12% NS
Mean no. current drugs	1.8	2.4	0.4 to 0.8
sd	1.4	1.2	
Mean length of clinic attendance in months	66	78	3 to 21
sd	55	58	

* Criteria for definition of high risk: any one of the following present in the medical record: ischaemic heart disease, angina, present or past cerebrovascular disease, past myocardial infarction or stroke, impaired renal function, bad family history.

NS=not significant

Table 6: Characteristics of selected and unselected patients

	Pre- selected	Clinic selected	95% CI diff
Number	510	170	
Attend GRI n(%)	128(25%)	34(20%)	-2% to 12% NS
Mean age in years sd	54.3 11.8	52.4 11.8	-0.2 to 3.9 NS
Female n(%)	240(47%)	83(49%)	-7% to 11% NS
Mean systolic BP (mmHg) sd	144.4 20.4	150.0 20.0	2.1 to 9.1
Mean diastolic BP (mmHg) sd	83.7 10.5	85.4 9.4	0 to 3.4 NS
Mean no. problems sd	2.9 2.0	2.0 2.1	0.5 to 1.3
With high risk criteria* n(%)	112(22%)	31(18%)	-3% to 11% NS
Mean no. current drugs sd	1.9 1.4	1.6 1.2	0.1 to 0.5
Mean length of clinic attendance in months sd	72 55	21 58	41 to 61

Criteria for definition of high risk: any one of the following present in the medical record: ischaemic heart disease, angina, present or past cerebrovascular disease, past myocardial infarction or stroke, impaired renal function, bad family history

NS=not significant

Table 7: Characteristics of pre-selected and clinic-selected patients

SWITCH CRITERION

	Target achieved	Target not achieved	Total
PASS using Stobhill algorithm	45 (69%)	9 (14%)	54 (83%)
FAIL using Stobhill algorithm	5 (8%)	6 (9%)	11 (17%)
Total	50 (77%)	15 (23%)	65 (100%)

Table 8: Results of the comparison of SWITCH with the Stobhill system

Personal details:

Name, address, telephone, hospital number, NHS number, Date of birth, marital status, occupation, height, GPs name and address, hospital consultant

Family history details:

Parents - whether alive or dead, age at present or at death, current illness or cause of death, whether hypertensive

Siblings - same as parents

Other significant illness in close relatives

Smoking details:

Whether past or present smoker, amount smoked, length of time present/past habits continued, type of material smoked

Drinking details:

Whether present drinker, approximate amount, frequency and type of alcohol consumed

Problem list:

Significant health problems, date of onset, whether currently active or inactive, other events and date, whether item to be printed on PHB

Treatment list:

Current treatments, daily dose, start date, comment by doctor, previous treatments, maximum daily dose, start and stop dates

Clinical details:

Date of clinical reviews

For each date: systolic and diastolic blood pressures, weight, urine and blood biochemistry results, date of ECG and result.

Table 9: Data recorded in the Shared-Care database

Urine tests:	+ ++ or -
Protein	
Glucose	+ ++ or -
Blood tests:	mmol/l
Sodium	
Potassium	mmol/l
Urea	mmol/l
Creatinine	umol/l
Chloride	mmol/l
Total CO2	mmol/l
Calcium	mmol/l
Corrected calcium	mmol/l
Phosphate	mmol/
Total protein	g/l
Albumin	g/l
Bilirubin	umol/l
Alkaline phosphatase	u/l
Gamma GT	u/l
Transaminases	u/l
Urate	mmol/l
Glucose	mmol/l
Cholesterol	mmol/l

Table 10: Details of the biochemical data in the shared-care database

INCLUDE:

Each item listed as a problem or diagnosis

Other items which are clearly part of the medical history, for example, surgical procedures

Investigation results if included within the diagnosis section of the outpatient clinic record, for example, low potassium

All of the above should include the date of onset or diagnosis.

NOT ON PATIENT-HELD RECORD

Details of diagnoses, problems or procedures

Details of investigation results

Malignant disease if there is doubt as to whether patient knows

Anything entered in this section by the general practitioner, specialist

Anything which the patient asks not to be printed on record

ALTERED TERMS

Record:

Obesity as "overweight"

Alcohol abuse, alcoholism, alcohol problem as "admits to x units of alcohol per week" (if x is known) or as "high alcohol intake".

Table 11: Protocol for drafting the medical history section of the shared-care medical record

BP: Average last 3 results, if available. Flag if SBP \geq 200mmHg, DBP \geq 100mmHg+ECG criteria, DBP \geq 110mmHg, no ECG criteria, DBP persistently \geq 100mmHg, no ECG criteria

Weight: Calculate BMI and flag (for GP) if +/- 10% of ideal

Urine: Flag if results positive; if +glucose, check blood sugar, if +protein or blood, recommend MSU+dipstick to GP

Blood: **Sodium:** Flag if \leq 125 or \geq 150mmol/l

Potassium (lower): Flag if <3 and a drop of \geq 0.5mmol/l, if on digoxin, increase limit to 3.5mmol/l

Potassium (upper): Flag if 6-6.5mmol/l and creatinine $>120\mu\text{mol/l}$ or urea $>7.5\text{mmol/l}$ or if on a potassium related drug. Flag if $>6.5\text{mmol/l}$

Creatinine: Flag if \geq 110 $\mu\text{mol/l}$ and rise of \geq 30 $\mu\text{mol/l}$ since last result and rise of \geq 20% of last result. Flag if rise of $>60\mu\text{mol/l}$ (particularly if on enalapril or spironolactone)

Urea: Flag if \geq 10mmol/l and rise of $>2\text{mmol/l}$ since last result and rise of $>20\%$ of last result only in the absence of a creatinine result

Urate: Flag if <0.10 or $>0.42\text{mmol/l}$

Cholesterol: Flag if $>6.5\text{mmol/l}$

Glucose: Flag if \geq 11mmol/l for first time
Flag if \geq 22mmol/l when previously \geq 11mmol/l

Corrected calcium: Flag if <2.16 or >2.53

ECG: Flag if any criteria new (LVH, strain, ischaemia, AF, multiple VEs, VTs, heart block)

Complications: Flag if any new with no resultant change in treatment

Table 12: Criteria used for flagging of annual review results in the Shared-Care Scheme

Reason	number of patients
BP high	3
Renal problems	2
Diabetic	2
Into trial	2
Two yearly appointment	2
Previous stroke	1
Side effects	1
Investigations	1
Sub-arachnoid haemorrhage	1
Liver problems	1
Thyroid function	1
To dietician	1
Requires special care	1
Abnormal biochemistry	1
Wrong medication	1
Not hypertensive	1
Priest	1
No reason given	15
Total	38

Table 13: Reasons given for the non-transfer of 38 patients to shared-care

	Recruit -ed (1)	Not recruited unsuit- able (2)	95% CI diff between (1) and (2)	Not recruited did not attend (3)	95% CI diff between (1) and (3)
Number	392	38		11	
Mean age in years	58.5	57.0	NT	43.9	5.9 to 23.3
sd	11.8	10.3		14.6	
Female n(%)	204 (52%)	18(47%)	NT	8(73%)	-6% to 48% NS
Mean no. problems	2.7	2.5	NT	4.0	-0.1 to 2.7
sd	2.0	1.8		2.4	NS
Mean no. current drugs	1.9	2.1	-0.2 to 0.6 NS	1.7	-0.3 to 0.7 NS
sd	1.4	1.1		0.8	
Mean length of clinic attendance	79	65	-2 to 30 NS	75	-31 to 40 NS
sd	55	47		59	

NT=not tested

NS=not significant

Table 14: Characteristics of the pre-selected recruited and non-recruited patients

	Pre-selected	Clinic-selected	95% CI diff
Number	392	162	
Mean age in years	58.5	57.2	-0.9 to 3.5 NS
sd	11.8	12.2	
Mean no. problems	2.7	1.8	0.5 to 1.3
sd	2.0	2.0	
Mean no. current drugs	1.9	1.5	0.2 to 0.6
sd	1.4	1.0	
Mean length of clinic attendance in months	79	29	38 to 62
sd	55	67	

NS=not significant

Table 15: Characteristics of the pre-selected and clinic-selected recruited patients

	Invited	Not invited	95% CI diff	GGHB (1985)*
Number	297			
Number in GGHB	247	391		638
Female n(%)	49(20%)	98(25%)	-1% - 11% NS	147(23%)
Practising from a health centre n(%)	103(42%)	171(44%)	-6% - 10% NS	274(43%)
Single-handed n(%)	22(9%)	35(9%)	NT	57(9%)

* Information from ISD 1986

NT=not tested

NS=not significant

Table 16: Characteristics of general practitioners invited to take part in shared-care and those not invited

	Agreed to participate	Did not agree to participate	95% CI diff
Number	251	46	
Female n (%)	50 (20%)	6 (13%)	-4% to 18% NS
Qualified in last 25 years n (%)	128 (51%)	16 (35%)	1% to 31%
Practising from a health centre n (%)	109 (43%)	10 (22%)	8% to 34%
In a training practice n (%)	25 (10%)	3 (6%)	-4% to 12% NS
Single-handed n (%)	20 (8%)	8 (17%)	-2% to 20% NS
In GGHB	209(83%)	38(83%)	NT

NT=not tested

NS=not significant

Table 17: Characteristics of those general practitioners who agreed to participate and those who did not

	SC	BPC	NPC
No. in group - year one	277	277	277
Response to first questionnaire	251 (91%)	244 (88%)	224 (81%)
No. in group minus dead - year two	267	270	270
Response to second questionnaire	228 (85%)	239 (88%)	219 (81%)
Responded to both questionnaires	218 (82%)	198 (73%)	190 (70%)
No. monitored	258	-	-
Response to the questionnaire on the Personal Health Booklet	209 (81%)	-	-

Table 18: Patient questionnaire response rates

	SC		BPC		NPC	
	non-responders	responders	non-responders	responders	non-responders	responders
Number	49	218 (82%)	72	198 (73%)	80	190 (70%)
From GRI n (%)	14 (28%)	62 (28%)	19 (26%)	57 (29%)	-	-
Mean age in years	56.3	58.7	55.4	57.7	56.1	57.4
sd	10.6	12.1	12.9	11.4	12.7	12.4
95% CI diff		-1.0 to 5.8 NS		-1.1 to 5.7 NS		-2.0 to 4.6 NS
Live in Glasgow n (%)	41 (84%)	192 (88%)	60 (83%)	170 (86%)	75 (94%)	179 (94%)
95%CI diff		NT		NT		NT
Female n (%)	25 (51%)	118 (54%)	36 (50%)	109 (55%)	47 (59%)	93 (49%)
95% CI diff		NT		-9% to 19% NS		-3% to 23% NS
In category 1 for initial BP n (%)	27 (55%)	131 (60%)	39 (54%)	101 (51%)	45 (56%)	114 (60%)
95%CI diff		NT		NT		NT

NT=not tested

NS=not significant

Table 19: Patient questionnaire - characteristics of those who responded to both questionnaires and those who did not minus the dead.

	Responders	Non-responders	95% CI diff
Number	147	29	
Female n(%)	25(17%)	3(10%)	-5% to 19% NS
Practising in a health centre n(%)	57(39%)	10(34%)	-14% to 24% NS
Single-handed n(%)	14(10%)	5(7%)	-7% to 13% NS
In training practice n(%)	10(7%)	2(7%)	NT
Mean no. patients sd	1.49 1.06	1.83 1.44	-0.21 to 0.89 NS
No. with one patient n(%)	103(58%)	18(62%)	-15% to 23% NS
In GGHB	125(85%)	23(79%)	-10% to 22% NS

NT=not tested

NS=not significant

Table 20: General practitioner questionnaire - characteristics of responders and non-responders

Name	Type of outcome	Definition: -
No. of complete reviews	Process	Number of reviews in year two which include BP, creatinine and ECG
% effectiveness	Process	no. of complete reviews/number of patients in group (minus dead)
% monitored	Process	no. patients with result within last 18 months/number in group (minus dead)
% reviewed	Process	no. patients with a review in year two/number monitored in year two
completeness of review results	Process	no. patients with a particular result in their record in year two/number with a review in year two
self-perceived health status	Health	patient's own perception of health state
attitudes to health	Intermediate health	patient responses to several questions on attitudes to health care
knowledge of BP reading	Process	patient answer to question on whether BP reading known
maintenance of target BP level	Intermediate health	no. patients with review BP below age-related target level
serum creatinine, potassium, BMI	Intermediate health	mean levels of clinical variables
mortality	Health	no. patients who died over two years/277

Table 21: Outcome variables

Category	Description
A	All required results* present
B	One or more results missing but necessary results# present
C	One or more of necessary results missing

* Blood pressure, weight, urinalysis, serum biochemistry (sodium, potassium, urea, creatinine, urate), cholesterol, glucose and ECG.

Blood pressure, serum creatinine, ECG.

Table 22: Categories of completeness of annual review results

1. How would you describe your present state of health?

Very good / Good / Average / Not very good / Poor / Don't know

2. Which one of the following statements best reflects your view on the chances of reducing high blood pressure?

There is very little you can do for yourself, it is fate or bad luck.

There are certain things you can do for yourself which might help reduce high blood pressure

There are certain things you can do for yourself which will definitely help reduce high blood pressure.

3. Apart from taking medication, do you think there is anything you can do personally to reduce the level of your blood pressure?

Yes, definitely / Yes, probably / Not sure / Probably not / Definitely not.

Table 23: Items in the patient questionnaire which assess perceptions of and attitudes to health and health care

Age	Target
>=65	160/100
45-64	150/90
<45	140/90

Grade	
1	Both systolic and diastolic pressures at target (or below) = very good
2	One at target and one close* = good
3	Either a) both close or b) one at target and one not close = fairly good
4	One close and one not close = fairly poor
5	Neither close = poor

*"close" = ≤ 10 mmHg above for systolic pressure
 ≤ 7 mmHg above for diastolic pressure

Table 24: Protocol for classifying blood pressure levels, that is, target blood pressure levels.

	SC (1)	BPC (2)	NPC (3)	
			95% CI diff between (1) and (2)	95% CI diff between (1) and (3)
Number	277	277		277
Mean age (years)	58.7	57.6	NT	57.4
sd	11.8	11.8		12.4
Female n(%)	144(52)	144(52)	NT	144(52)
Married n(%) *	155[71]	137[69]	NT	139[73]
Employed fulltime n(%) *	78[36]	67[34]	NT	57[30]
Smoker n(%) *	83[38]	63[32]	-2% to 14% NS	66[35]
Drinker n(%) *	157(72)	146(74)	NT	141(74)
Live in GGHB n(%)	241(87%)	238(86%)	-5% to 7% NS	260(94%)
Initially from GRI clinic n(%)	77(28)	77(28)	NT	-

*Questionnaire responders only (n=218, 198 & 190)

NT=not tested

NS=not tested

Table 25: Characteristics of the recruited patients

	SC		BPC		NPC	
	Year 1	Year 2	Year 1	Year 2	Year 1	Year 2
Died	4	6	2	5	3	4
Moved	2	1	-	-	1	2
Dischar- -ged	0	0	4	2	4	9
With- drew (1)	5	1	-	-	-	-
Discon- tinued (2)	-	-	15	17	3	6
Total	11	8	21	24	11	21

(1) SC patients were withdrawn by their GP (2 patients) or by themselves (4 patients)

(2) Discontinued patients are those for whom no information could be found fifteen months after the end of the year.

Table 26: Patient withdrawals during the study period

Reason	Frequency
Cannot afford time off work	1
Nightshift worker	1
Annual check not felt necessary	2
GP considers patient normotensive	2

Table 27: Reasons for patient withdrawals from shared-care

	Withdrawn by GP	Withdrew him/herself
Number	2	4
Live in Glasgow n(%)	2(100)	2(50)
Mean age	49.2	47.5
sd	11.9	12.7
Female n(%)	2(100)	0
Smoker n(%)	1(50)	0
High risk n(%)	0	1(25)
In category one for initial BP control n(%)	2(100)	3(75)

Numbers too few to test statistical significance of differences

Table 28: Characteristics of patients withdrawn from shared-care

Reason	Frequency
Investigations needed	1
Uncontrolled BP	3 (1 via re-referral clinic)
High cholesterol	1
Taking blood difficult	1
Consultant wished to retain	1
Patient choice	2
No reason given	2
Total	11

Table 29: Reasons for return to the clinic

	Returned	Not returned	95%CI for difference
Number	11	266	
Mean age(years)	57.1	58.8	-5.1 to 8.5 NS
sd	11.3	11.8	
Female n(%)	9(82)	135(51)	8% to 54%
Smoker n(%) *	3[33]	79[38]	NT
High risk n(%)	4(36)	90(34)	NT
In category one for initial BP n(%)	2(18)	160(60)	18% to 65%
Live in Glasgow n(%)	9(82)	232(87)	NT
Initially from GRI clinic n (%)	4(36)	73(27)	-20% to 38% NS

*Questionnaire responders only (n=9 & 209)

NT=not tested

NS=not significant

Table 30: Characteristics of those returned to the clinic

	SC		BPC		NPC	
	Year 1	Year 2	Year 1	Year 2	Year 1	Year 2
Monitored	266 (97%)*	258 (97%)*	256 (93%)*	232 (86%)*	266 (97%)*	245 (91%)*
Reviewed	255 (96%)+ (93%)*	243 (94%)+ (91%)*	212 (83%)+ (77%)*	188 (81%)+ (70%)*	238 (89%)+ (87%)*	218 (89%)+ (81%)*
Satisfactory review	228 (85%)+ (84%)*	220 (85%)+ (82%)*	161 (63%)+ (58%)*	146 (63%)+ (54%)*	217 (82%)+ (79%)*	202 (82%)+ (75%)*

* Denominator of this percentage is the number in the group excluding deaths

+ Denominator of this percentage is the number monitored in that group in that year

Table 31: Effectiveness at the end of each year of the study

YEAR ONE

	A	B	C	None	Total
SC	58 (23%)	170 (67%)	27 (10%)	12	267
BPC	58 (27%)	103 (48%)	51 (24%)	44	256
NPC	128 (54%)	89 (37%)	21 (9%)	28	266

YEAR TWO

SC	94 (39%)	126 (52%)	23 (9%)	15	258
BPC	55 (29%)	91 (48%)	42 (22%)	44	232
NPC	164 (75%)	38 (17%)	16 (7%)	27	245

A = Totally complete review

B = Minor result missing - review satisfactory

C = Major result missing - review unsatisfactory

Table 32: Standard of annual reviews

Reason	Number of reviews
Patient too ill	4
Patient hospitalised	1
Attending renal unit	1
Missed out one review but subsequently reviewed	3
Reason unknown	2
Should have had review in clinic and reason unknown	4
Total	15

Table 33: Reasons for lack of a shared-care review in year two

	SC group with incomplete reviews	Rest of SC group	95% confidence interval for difference
Number	19	199	
Mean age	62.2	58.1	-2.0 to 10.2
sd	13.1	12.0	NS
Length of clinic attendance	74	77	-26 to 32
sd	60	67	NS
Female n (%)	13(71)	105 (53)	-4% to 40% NS
Married n (%)	10(53)	139 (70)	-4% to 40% NS
In full-time employment n (%)	8 (41)	74 (37)	-19% to 27% NS
Over 70 years n (%)	7 (37)	36 (18)	-3% to 41% NS
In category one for initial BP n (%)	14 (76)	117 (59)	-3% to 37% NS
In category 1 for final BP n (%)	16 (87)	127(64)	6% to 40%
Consider surgery best site of care n (%)	1 (6)	70 (35)	16% to 42%
In poor health n (%)	13 (71)	94 (47)	2% to 46%
From outside Glasgow n (%)	3 (16)	23 (12)	-13% to 21% NS

NS=not significant

Table 34: Characteristics of patients with incomplete shared-care reviews compared with rest of SC group (questionnaire responders only)

	SC	BPC	95% CI between 1 and 2	NPC	95% CI between 1 and 3
n	243	188		218	
BP	98%	100%	NT	100%	NT
Weight	80%	95%	9% to 21%	98%	13% to 23%
Urinalysis	60%	43%	8% to 26%	81%	13% to 29%
ECG	93%	78%	8% to 22%	93%	NT
Serum potassium	86%	97%	6% to 16%	98%	7% to 17%
Serum creatinine	95%	95%	NT	99%	1% to 7%
Cholesterol	86%	84%	-5% to 9% NS	99%	8% to 18%

NT=not tested

NS=not significant

Table 35: Completeness of annual review results for those who had a review in year 2 (%)

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
Number	214	214	194	194	186	188
Very good	31(14%)	36(17%)	30(15%)	22(11%)	32(17%)	27(14%)
Good	74(34%)	80(37%)	69(36%)	79(41%)	70(38%)	68(36%)
Average	79(37%)	70(33%)	65(34%)	69(36%)	63(34%)	66(35%)
Poor	30(14%)	28(13%)	30(15%)	24(12%)	21(11%)	27(14%)
Wilcoxon test		z=-1.42 p=0.16 NS		z=0.49 p=0.63 NS		z=-1.50 p=0.13 NS

NS=not significant

Table 36: Patient questionnaire response - present state of health

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
Number	209	207	190	186	181	185
Very little one can do	8(4%)	8(4%)	12(6%)	6(3%)	8(4%)	6(3%)
Certain things might help	80(38%)	75(36%)	67(35%)	73(39%)	63(35%)	55(30%)
Certain things definitely help	121 (58%)	124 (60%)	111 (58%)	107 (58%)	110 (61%)	124 (67%)
Wilcoxon test		z=-0.83 p=0.41 NS		z=-0.48 p=0.63 NS		z=-1.50 p=0.13 NS

NS=not significant

Table 37: Patient questionnaire responses - views on chances of reducing high blood pressure

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
Number	207	205	188	188	177	179
Yes	141 (68%)	149 (73%)	138 (73%)	138 (73%)	141 (80%)	143 (80%)
Not sure	46(22%)	41(20%)	34(18%)	30(16%)	28(16%)	23(13%)
No	20(10%)	15(7%)	16(8%)	20(11%)	8(4%)	13(7%)
Wilcoxon test		z=-0.65 p=0.51 NS		z=-0.15 p=0.88 NS		z=0.89 p=0.37 NS

NS=not significant

Table 38: Patient questionnaire responses - anything one can do personally to reduce blood pressure

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
Number	205	208	186	190	173	175
Measure - ment known	30(15%)	90(43%)	34(18%)	49(26%)	154 (89%)	150 (86%)
Comm -ent known	40(20%)	31(15%)	30(16%)	40(21%)	2(1%)	6(3%)
Nothing known	135 (66%)	87 (42%)	122 (66%)	101 (53%)	17 (10%)	19 (11%)
95% CI diff in no who know m'ment		20% to 36%		0% to 16% NS		NT

NT=not tested

NS=not significant

Table 39: Patient questionnaire responses - knowledge of blood pressure measurement

	SC		BPC			NPC		
	Initial	Year 2	Initial	Year 2	t-test#	Initial	Year 2	t-test#
n	277	243	277	188		277	218	
Mean SBP	147.9	146.1	148.7	148.8	t=0.15 101df p=0.88	149.0	150.9	t=0.32 119df p=0.75
sd	21.8	21.2	19.3	23.9	NS	17.9	22.3	NS
Mean DBP	85.0	87.0	85.5	85.6	t=1.63 101df p=0.12	82.7	84.3	t=1.54 119df p=0.13
sd	10.2	9.0	10.3	11.6	NS	8.1	9.2	NS
Mean BMI	26.4	27.1	26.0	27.1	t=0.62 79df p=0.54	26.9	26.9	t=1.5 87df p=0.5
sd	4.8	4.1	6.5	3.7	NS	4.3	4.1	NS
Mean potassium	4.0	4.4	4.0	4.0	t=2.24 85df p=0.03	4.1	4.1	t=1.79 98df p=0.08 NS
sd	0.5	7.2	0.5	0.4		0.4	0.4	
Mean creatinine	91.1	89.7	92.0	93.0	t=1.92 89df p=0.06 NS	99.1*	94.2	t=1.12 103df p=0.27 NS
sd	28.1	21.4	22.8	25.9		30.0	24.0	

* 95% CI diff: 3.2 to 12.8 for difference between this value and the initial SC value

NT=not tested

NS=not significant

This test is performed on the change from the initial value for each member of the matched pair, SC with BPC and SC with NPC. A one-sample t-test is used.

Table 40: Mean of clinical variables initially and after two years

Initially:

	Very good	Good	Fairly good	Fairly poor	Poor	Missing
Grade	1	2	3	4	5	
SC	162 (59%)	41 (15%)	51 (18%)	14 (5%)	8 (3%)	1
BPC	144 (52%)	58 (21%)	48 (18%)	12 (4%)	15 (6%)	0
NPC	160 (58%)	64 (23%)	40 (14%)	9 (3%)	4 (1%)	0

After one year:

SC	161 (64%)	35 (14%)	28 (11%)	12 (5%)	17 (7%)	24
BPC	113 (53%)	34 (16%)	42 (20%)	14 (6%)	11 (5%)	63
NPC	114 (46%)	72 (29%)	42 (17%)	13 (5%)	8 (3%)	28

After two years:

SC	153 (64%)	39 (16%)	29 (12%)	6 (2%)	13 (6%)	37
BPC	83 (44%)	41 (22%)	45 (24%)	8 (4%)	11 (6%)	89
NPC	122 (56%)	38 (18%)	40 (18%)	11 (5%)	7 (3%)	59

Table 41: Number in each grade of achievement of target blood pressures using the first definition of targets

Initially:

	Very good	Good	Fairly good	Fairly poor	Poor	Missing
Grade	1	2	3	4	5	
SC	147 (53%)	50(18%)	52(19%)	19(7%)	8(3%)	1
BPC	123 (44%)	68(24%)	54(19%)	18(6%)	14(5%)	0
NPC	149 (52%)	71(26%)	41(15%)	12(4%)	4(1%)	0

After two years:

SC	120 (50%)	38(16%)	46(19%)	19(8%)	17(7%)	37
BPC	70(37%)	42(22%)	50(26%)	12(6%)	14(7%)	89
NPC	116 (53%)	41(19%)	39(18%)	15(7%)	6(3%)	59

Table 42: Number in each grade of achievement of target blood pressures using the second definition of targets to compensate for terminal digit preference

	Maintained	Improved	Deteriorated	Missing
SC	101 (42%)	61 (26%)	77 (32%)	38
BPC	67 (36%)	53 (28%)	68 (36%)	89
NPC	100 (44%)	58 (26%)	68 (30%)	51

Table 43: Maintenance of target blood pressures in individual patients over two years

Number of visits	Number of patients
1	3
2	3
3	5
4	3
5	2
6	0
7	1
Total	17

Mean number of visits: 3.1

Median = mode = 3

Table 44: Frequency of visits to the re-referral clinic over two years

Reason	Number of patients
High blood pressure	6
High blood pressure, ? renal	2
High blood pressure, ? side-effects	1
Low blood pressure, ? side-effects	1
Low blood pressure, ? no treatment required	1
Abnormal biochemistry	2
Breathlessness	2
Headaches	1
? Carcinoma	1
Total	17

Table 45: Reasons for the re-referral of SC patients

	Re-referred	Not re-referred	95% CI diff
Number	17	260	
Questionnaire responders	14	204	
Mean age (years)	55.0	58.9	-2.4 - 10.2 NS
sd	13.0	11.8	
Female n (%)	12 (70)	132 (51)	-4% - 42% NS
In category 1 for initial BP n (%)	8 (47)	154 (59)	-12% - 36% NS
Initially in poor health n (%) #	5 [36]	23 [11]	0% to 50% NS
Initially from GRI clinic n (%)	3 (19)	74 (28)	NT

NT = not tested

NS = not significant

self-reported by responders to questionnaire only

Table 46: Characteristics of those patients sent to the re-referral clinic over the two years

SC GROUP

Reason	Number
Withdrawn by GP	2
Withdrew self	4
Returned to clinic - may be GP/patient preference	5
Returned to clinic - may be specialist preference	1
Returned to clinic - may be patient preference	2
Temporarily unreviewed	3
Unreviewed	2

BPC GROUP

Discontinued follow-up - reason unknown	32
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NPC GROUP

Discontinued follow-up - reason unknown	9
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Table 47: Reasons for non-participation

Group	Reason for drop-out	No. in year 1	No. in year 2
SC	Withdrawn	6	0
	Returned to clinic	7	1
	No review	0	5
Total for SC group		13	6
BPC	Discontinued	19	11
NPC	Discontinued	3	6

Table 48: Drop-out over follow-up period which may be related to preference

	Wish to continue (1)	Do not wish to continue (2)	Don't know	95% CL diff: between (1) and (2)
Number(%)	90(61%)	20(14%)	37(25%)	
Female n(%)	15(17%)	6(31%)	4(12%)	-8% to 36% NS
Practice in a health centre n(%)	31(34%)	10(50%)	16(42%)	-8% to 40% NS
Single-handed n(%)	5(6%)	4(20%)	5(14%)	-4% to 32% NS
In a training practice n(%)	6(7%)	2(10%)	2(5%)	-11% to 17% NS
Mean no. of patients	1.63	1.55	1.11	-0.36 to 0.52 NS
sd	1.06	0.86	1.01	
In Glasgow	77(86%)	17(81%)	30(81%)	-14% to 24% NS

NT = not tested

NS = not significant

Power of the significance tests are low eg <30% because there are only 20 in the smallest group

Table 49: Characteristics of the general practitioners who wish to continue in shared-care and those who do not

	SC			BPC		
	Visits before	Visits after	Paired t-test	Visits before	Visits after	Paired t-test
n	185	185		128	128	
Mean	5.4	6.3	t=3.65 184df p<0.001	5.3	5.2	t=-.27 127df p=0.79
sd	4.7	4.6		4.2	4.5	
median	4.0	5.0		4.5	4.5	
mode	3.0	4.0		2.5	2.0	
range	0-28	0-40		0-27	0-27	

Table 50: Visits to general practitioners before and after study period by SC and BPC groups

	SC	BPC	NPC
Number monitored	258	232	245
Routine visits (mean)	0.14	1.30	1.01
Review visits (mean)	0.14	0.81	0.89
Total visits	76	489	466
Mean total clinic visits (sd)	0.28 (1.3)	2.11 (1.5)	1.92 (0.9)
range	1-7	0-9	0-4
median	2	2	2
mode	2	1	2

Table 51: Clinic visits made by each group in year 2

	SC		BPC		NPC	
	Initial	After two years	Initial	After two years	Initial	After two years
Number	216	210	194	192	178	178
Walk	14 (6%)	54 (26%)	13 (7%)	13 (7%)	18 (10%)	20 (11%)
Bus or train	127 (59%)	82 (39%)	102 (52%)	99 (52%)	59 (33%)	59 (33%)
Car	73 (34%)	70 (33%)	73 (38%)	77 (40%)	84 (47%)	79 (44%)
Other	2 (1%)	4 (2%)	6 (3%)	3 (2%)	17 (9%)	20 (11%)

Table 52: Patients' mode of travel

	SC		BPC		NPC	
	Initial	After two years	Initial	After two years	Initial	After two years
Number	215	209	193	191	177	178
Very easy	70 (32%)	97 (45%)	71 (37%)	58 (30%)	76 (44%)	60 (34%)
Quite easy	133 (62%)	101 (47%)	105 (54%)	119 (62%)	85 (48%)	92 (52%)
Quite difficult	11 (5%)	9 (4%)	15 (8%)	11 (6%)	13 (7%)	25 (14%)
Very difficult	1 (-%)	4 (2%)	2 (1%)	3 (2%)	3 (2%)	1 (-%)
95%CI diff in no who find it very easy		4% to 22%		NT		0% to 20% NS

Table 53: Ease of journey to patients

	SC		BPC		NPC	
	Initial	Year two	Initial	Year two	Initial	Year two
Number	204	204	191	191	180	181
Mean in minutes	70	40	69	75	59	62
sd	46	30	40	49	40	44
median	60	30	60	60	40	50
mode	60	30	60	60	30	30
range	10-360	4-180	10-210	10-300	10-180	10-360
95%CI diff in mean time		23 to 37		-3 to 15 NS		-5 to 11 NS

Table 54: Time used in travelling to and from the consultation

	SC		BPC		NPC	
	Initial	After two years	Initial	After two years	Initial	After two years
Number	207	202	188	186	171	174
Always/ most of the time	67 (32%)	38 (19%)	59 (31%)	47 (25%)	48 (28%)	40 (23%)
Some times/ rarely	13 (6%)	20 (10%)	12 (6%)	9 (5%)	8 (5%)	11 (6%)
Never	127 (61%)	144 (71%)	117 (62%)	130 (70%)	115 (67%)	123 (71%)
95%CI diff in no who always require time off work		10% to 16%		-3% to 15% NS		NT

NT=not tested

NS=not significant

Table 55: Patients who require time off work to attend the consultation

	SC		BPC		NPC	
	Initial	Year 2	Initial	Year 2	Initial	Year 2
Number	195	195	178	178	163	171
Mean in minutes	81	39	86	84	48	48
sd	35	30	37	39	32	73
median	60	30	60	60	30	45
mode	60	30	60	60	30	60
range	15-206	5-180	10-240	15-240	10-300	15-164
95%CI diff between mean times		36 to 48		-5 to 9 NS		-7 to 15 NS

NS=not significant

Table 56: Time spent at the consultation

	SC		BPC		NPC	
	Initial	Year 2	Initial	Year 2	Initial	Year 2
Number	216	208	191	198	190	190
Bring a companion (%)	44(20)	21(10)	38(20)	40(21)	47(26)	39(22)
Not able to attend alone (%)	9(4)	5(2)	9(5)	10(5)	12(7)	12(7)

Table 57: Number who attend with and need a companion

	Year 1	Year 2	Year 3
Number of reviews	253	233	215
Both records returned	115 (45%)	88 (38%)	80 (37%)
GP record only returned	35 (14%)	32 (14%)	36 (17%)
PHB only returned	60 (24%)	61 (26%)	78 (36%)
Substitute returned	2 (1%)	6 (2%)	2 (1%)
Nothing returned	41 (17%)	46 (20%)	19 (9%)

Table 58: Use of shared-care records

Censored by project staff:

Bundle branch block (6)
Sensitive to tielinic acid
Right-sided paresis
Cerebrovascular accident
Possible excessive alcohol (5)
Impotence
Low serum B₁₂
Gonorrhoea
Anti-nuclear factor weakly positive
Carcinoma of breast

Added to the censored section by general practitioner:

Crohn's proctitis
Anxiety (2)
High alcohol intake
Social/psychiatric problems (4)
Senile macular degeneration
Dementia
Recurrent stress incontinence
Pituitary adenoma

Censored by patient:

Anxiety
Depression

(Furthermore, two requests were made by patients to have the social history section from the Booklet removed - one because of drinking details and the other, family history)

Table 59: Items in medical history classed as "Not on patient-held record"

Annual investigation:	N(%) who consider it necessary	N(%) who consider it not necessary	N(%) who don't know
Serum biochemistry	112(76)	20(14)	15(10)
Serum cholesterol	70(48)	60(41)	17(12)
Random glucose	41(28)	90(61)	16(11)
Weight	140(95)	6(4)	1(-)
Blood pressure	147(100)	0	0
Urinalysis	134(91)	8(5)	5(3)
ECG	53(36)	68(46)	26(18)

Table 60: Necessity of individual items for annual review according to general practitioners

Preferred site	SC		BPC		NPC	
	Initial	After two years	Initial	After two years	Initial	After two years
n	189	189	169	167	166	159
Clinic	71 (38%)	37 (20%)	77 (46%)	70 (42%)	106 (64%)	91 (57%)
Surgery	25 (13%)	72 (38%)	15 (9%)	14 (8%)	9 (5%)	4 (2%)
Both	93 (49%)	89 (47%)	77 (46%)	83 (50%)	51 (31%)	64 (40%)

Table 61: Preferred site of follow-up care

	SC		BPC		NPC	
	Initial	After two years	Initial	After two years	Initial	After two years
Number	203	194	191	183	181	181
Definitely worthwhile	171 (84%)	150 (77%)	160 (84%)	151 (82%)	161 (89%)	158 (87%)
Probably worthwhile	29(14%)	40(21%)	29(15%)	28(15%)	17(9%)	22(12%)
Probably not worthwhile	1(-)	2(1%)	0	4(2%)	1(-)	0
Definitely not worthwhile	2(1%)	2(1%)	2(1%)	0	1(-)	1(-)
Wilcoxon test		z=-1.97 p=0.05		z=-1.75 p=0.08		z=-0.05 p=0.9

Table 62: Worth of the visit to clinic or surgery

	Number	%
	2180	
Outpatient care	60	30
Shared-care	97	48
No preference	44	22

Table 63: Preferred method of care - SC group questionnaire responders

	Prefer shared-care (1)	Prefer clinic	No preference	95% CI diff between (1) and (2)
Number in group	97	60	44	
Female n (%)	51 (52)	31 (52)	22 (50)	NT
Married n (%)	62 (64)	47 (78)	32 (73)	0% to 28% NS
Mean age in years (sd)	58.4 (12.4)	57.9 (12.2)	57.3 (12.4)	NT
Mean LOA in months (sd)	68 (54)	99 (71)	56 (43)	10 to 52 months
Employed n (%)	39 (40)	31 (52)	19 (43)	-4% to 28% NS
Live in Glasgow n (%)	85(88)	53(88)	39(89)	NT
Have degree/diploma n (%)	22(23)	10(17)	9(20)	NT
Travel by car n (%)	32 (33)	16 (27)	15 (34)	NT
Journey time>=30mins n (%)	46(47)	36(60)	25(57)	-3% to 29% NS
Journey cost>=£0.30 n (%)	17(18)	17(28)	10(23)	NT
Self-reported good health n (%)	54 (56)	30 (50)	25 (57)	NT
Know BP n (%)	55 (57)	33 (55)	26 (59)	NT
Can do something to help self n (%)	64 (66)	43 (72)	33 (75)	NT
Have a GP who wishes shared-care to continue	56 (58)	25 (42)	25 (57)	0% to 32% NS *

* Power of the tests of significance is low, for example, <50%.

NT=not tested

NS=not significant

Table 64: Analysis of SC preference groups:

Preferred method	Preferred location			Total
	Clinic	Surgery	Both	
Outpatient care	28(15%)	4(2%)	24(13%)	56
Shared-care	2(1%)	60(33%)	25(14%)	87
No preference	4(2%)	8(4%)	26(14%)	38
Total	34	72	75	181(100%) 37 missing

Chi-squared = 89.78, 4df
p<0.001

Table 65: Comparison of preference for method of care with preference for location

	Number of first places	Number of second places	Number of third places	Number of fourth places	Number of times not placed at all
Outpatient clinic	3	13	36	38	60
Shared-care	47	49	5	3	46
Nurse-practitioner care	3	5	35	46	61
Routine general practitioner care	94	23	8	2	23

Table 66: Ranking by general practitioners of alternative methods of care

NUMBER OF SESSIONS PER WEEK

Staff type	BPC	NPC
Secretarial/clerical	14#	8
Auxiliary nurse	4	3
Enrolled nurse	2	-
Staff nurse	1	-
Sister	2 (grade F)	3 (grade G)
Registrar	2*	1
Senior registrar	-	1
Consultant	4*	1

These 14 sessions represent 10 secretarial and 4 for medical records

* two-third sessions, not full sessions (see section 7. 2.2)

Table 67: Types and numbers of staff sessions in the BP and NP Clinics each week

Staff type	Mid-point of scale + 15% NI etc (£)	x 1/10 i.e. one full session per week (£)	x 1/15 i.e. 2/3 session per week (£)
Consultant	36225	3622	2415
Senior registrar	20194	2019	1346
Registrar	17135	1714	1142
Sister Grade G	14921	1492	995
Sister Grade F	12248	1225	816
Staff nurse	9508	951	634
Enrolled nurse	8372	837	558
Auxiliary nurse	6233	623	416
Secretary	7214	721	481

General practitioner target payment + 15% NI etc: £33120

Table 68: Staff salary scales (1988)

Total patient consultations in year two	3258
Consultations due to BPC group	489
Non-BPC group consultations	2769 (a)
BPC group review consultations	188 (b)
BPC group non-review consultations	301 (c)
Total 12-minute appointments (a+b)	2957 = 591.4 hours
Total 6-minute appointments (c)	301 = 18.8 hours
Total required hours of medical time over year two	610.2 hours
Number of medical staff sessions per week	$6 \times 2/3 = 4$
Number of available sessions in year two	$4 \times 52 = 208$
Hours of medical time available (3 per session)	624 hours

Available hours (624) are approximately equal to the required hours under the stated assumptions (610)

Table 69: Validation of measured medical time used in review and routine consultations in the Blood Pressure Clinic

Total patient consultations in year two	2142
Number seen by nurse	2142
Number seen by doctor as well	$.44 \times 2142 = 942$
Total medical time used in year two	$942 \times 7 \text{ minutes} = 110 \text{ hours}$
Total nurse time used in year two	$2142 \times 13 \text{ minutes} = 464 \text{ hours}$
Number of medical staff sessions per week	3
Number of available sessions in year two	150
Hours of medical time available (3 per session)	450 hours

Amount of medical time assumed to be used in the consultation (110 hours) is 24% of that available (450 hours)

Number of nurse sessions available in year two	150
Hours of nursing time available	450

Available hours of nurse time (450) are approximately equal to the required hours under stated assumptions (464)

Table 70: Validation of measured nursing time used in consultations in the nurse-practitioner clinic

Preparing and sending prompt letters	7 hours
Updating the database	6 hours
Printing and sending updated records	6 hours
Reminder letters	6 hours
On the telephone	2 hours
Dealing with mail	3 hours
Filing	1 hour
Screening records	1 hour
Total	27 hours

This represents 27/80 (34%) of a half-time secretary's available hours.

Table 71: Amount of time spent by secretary on shared-care registry activities in one month

	Unit cost (£)	Number	Mean cost /patient (£)
Reminder telephone calls	0.05	224	0.09
Reminder letters	0.14	92	0.10
Routine prompts	0.28	258	0.28
Reply-paid envelopes	0.16	258	0.16
Updated records	0.21	237	0.19
Total SC post and telephone cost per patient per year			0.82
Printing Booklets	0.12	237	0.11
Other printing costs	0.04	237/258	0.04
Total printing costs per patient per year			0.15

Table 72: Mean administrative costs per monitored SC patient per year

	SC		BPC		NPC	
	Initially	Year 2	Initially	Year 2	Initially	Year 2
n	100	100	100	100	114	114
Mean no. of daily drugs	1.65	1.91	2.17	1.97	1.45	1.62
sd	0.92	1.04	1.00	0.97	0.96	1.09
Median	2	2	2	2	1	1
Mode	2	2	2	2	1	1
Range	0-5	0-5	0-5	0-5	0-3	0-5
Paired t-test		3.72		2.66		2.44
df		99		99		113
p		0.001		0.009		0.016

Table 73: Number of daily medicines recorded for each group

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
n	100	100	100	100	114	114
Mean daily cost (£)	0.39	0.51 (0.44)	0.41	0.39	0.33	0.43
sd	0.32	0.32	0.28	0.32	0.28	0.37
Median	0.26	0.30	0.30	0.29	0.25	0.30
Range	0-1.60	0-7.78* (1.70)	0-1.34	0-1.49	0-1.13	0-1.68
Paired t-test		t=1.61		t=0.85		t=4.1
df		99		99		113
p		0.11 NS		0.52 NS		0.001

* The single cost of £7.78 per day in the SC group in year 2 is due to an insulin-dependent diabetic diagnosed during the study. In subsequent calculations, this cost is ignored and the figures given in brackets are used instead. Including the outlier does give a significant difference between the means of £0.03 to £0.21.

NS=not significant

Table 74: Daily costs of medicines

	SC	BPC	NPC
Clinic staff cost per review visit	(9.35)	9.35	9.60
Clinic staff cost per routine visit	(6.22)	6.22	5.68
Staff cost per SC general practice consultation	9.34	-	-
Investigation cost per patient review	1.01	1.01	1.01
Shared-care staff cost per monitored patient	4.37	-	-
Cost of screening SC review results per review	0.81	-	-
Administration cost per monitored SC patient	0.93	-	-
Clinic postage per patient visit	0.14	0.14	0.14
Cost of medicines per monitored patient per year	160.60	142.35	156.95

Figures in brackets are estimated from the costs of the BPC control group

Table 75: Summary of variable costs to the NHS (all costs in £)

	SC	BPC	NPC
Number of patients monitored in year two	258	232	245
Number of reviews	243	188	218
Number of satisfactory reviews	220	146	202
Number of routine clinic consultations	70	301	248
Number of review clinic consultations	6	188	218
Number of SC patients attending hospital for ECG	126	-	-
Number of SC general practice consultations	(232)	-	-

Figures in brackets are estimated

Table 76: Summary of information used to calculate total variable costs to the NHS in year 2

	SC	BPC	NPC
Consultation costs			
clinic staff	491.50	3630.02	3501.44
general practice staff	2166.72	-	-
investigations	245.43	189.88	220.18
Administration costs			
shared-care secretary	1127.46	-	-
shared-care administration	239.94	-	-
screening of SC reviews	196.83	-	-
clinic postage	10.64	68.46	65.24
Total excluding medicines	4478.52	3888.36	3786.86
Medicines	41434.80	33025.20	38452.75
Total including medicines	45913.32	36913.56	42239.61

Table 77: Total variable costs to the NHS for all three groups in year 2 (all costs in £)

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
n	197	185	189	183	168	168
Mean cost (£)	1.24	0.50	1.23	1.34	1.10	1.16
sd	0.80	0.33	0.69	0.92	1.20	0.74
Median	0.84	0	0.98	0.84	0.70	0.70
Range	0-11.90	0-3.60	0-12.00	0-14.00	0-8.00	0-11.00
95% CI diff:		0.63 to 0.85		-0.05 to 0.27 NS		-0.14 to 0.26 NS

NS=not significant

Table 78: Patient transport costs for a return journey to the consultation

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
n	199	192	193	191	172	173
Mean cost (£)	2.10	1.19	2.08	2.24	1.77	1.87
sd	1.40	0.92	1.20	1.48	1.20	1.32
Median	1.80	0.90	1.80	1.80	1.20	1.50
Range	0.30-10.80	0.12-5.40	0.30-6.30	0.30-9.00	0.30-5.40	0.30-10.80
95% CI diff		0.69 to 1.13		-0.10 to 0.42 NS		-0.15 to 0.35 NS

Table 79: Patient travel time costs for a return journey to the consultation

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
n	186	163	176	178	155	162
Mean cost	2.42	1.18	2.56	2.50	1.33	1.45
sd	1.05	0.93	1.12	1.17	0.98	0.74
Median	1.80	0.90	2.70	1.80	0.90	1.35
Range	0.45-6.18	0.15-5.40	0.30-7.20	0.45-7.20	0.30-9.00	0.45-5.40
95% CI diff		1.05 to 1.43		-0.16 to 0.28 NS		-0.05 to 0.29 NS

NS=not significant

Table 80: Patient consultation time costs (in £)

	SC		BPC		NPC	
	Initial	Two year	Initial	Two year	Initial	Two year
n	200	197	193	189	171	174
Mean cost (£)	1.17	0.27	1.15	1.06	0.70	0.81
sd	2.94	1.30	2.91	2.82	1.52	2.40
Range	0-17.20	0-12.00	0-19.20	0-20.20	0-8.50	0-10.00
% with zero cost	80	90	81	80	75	80
95% CI diff between mean costs		0.47 to 1.33		-0.47 to 0.65		-0.29 to 0.51 NS

NT=not tested

NS=not significant

Table 81: Companion costs

	SC	BPC	NPC
Travel per return journey to consultation	1.69	3.58	3.03
Time cost per consultation	1.18	2.50	1.45
Companion cost per consultation (travel+time)	0.27	1.06	0.81
ECG attendance (travel+time)	3.88	-	-

Table 82: Summary of unit costs used to derive total patient costs (all costs in £)

	SC	BPC	NPC
Travel	463.06	1750.62	1411.98
Time cost	323.32	1222.50	675.70
Companion cost	73.98	518.34	377.46
ECG attendance	488.88	-	-
SC clinic visits (travel+time)	542.64	-	-
Total patient cost	1891.88	3491.46	2465.14

Table 83: Total patient costs for each group in year 2 (all costs in £)

	SC	BPC	NPC
NHS cost (1)	4478.52	3888.36	3786.86
NHS cost (2)	45913.32	36913.56	42239.61
Patient cost	1891.88	3491.46	2465.14
Total cost (1)	6370.40	7379.82	6252.00
Total cost (2)	47805.20	40405.02	44704.75
Number of successful reviews	220	146	202
CER (1)	28.96	50.55	30.95
CER (2)	217.30	276.75	221.31
CER (1) NHS costs only	20.36	26.63	18.75
CER (1) Patient costs only	8.60	23.91	12.20
%effectiveness*	82	54	75
%effectiveness+	85	63	82

(1) Excluding costs of medicines

(2) Including costs of medicines

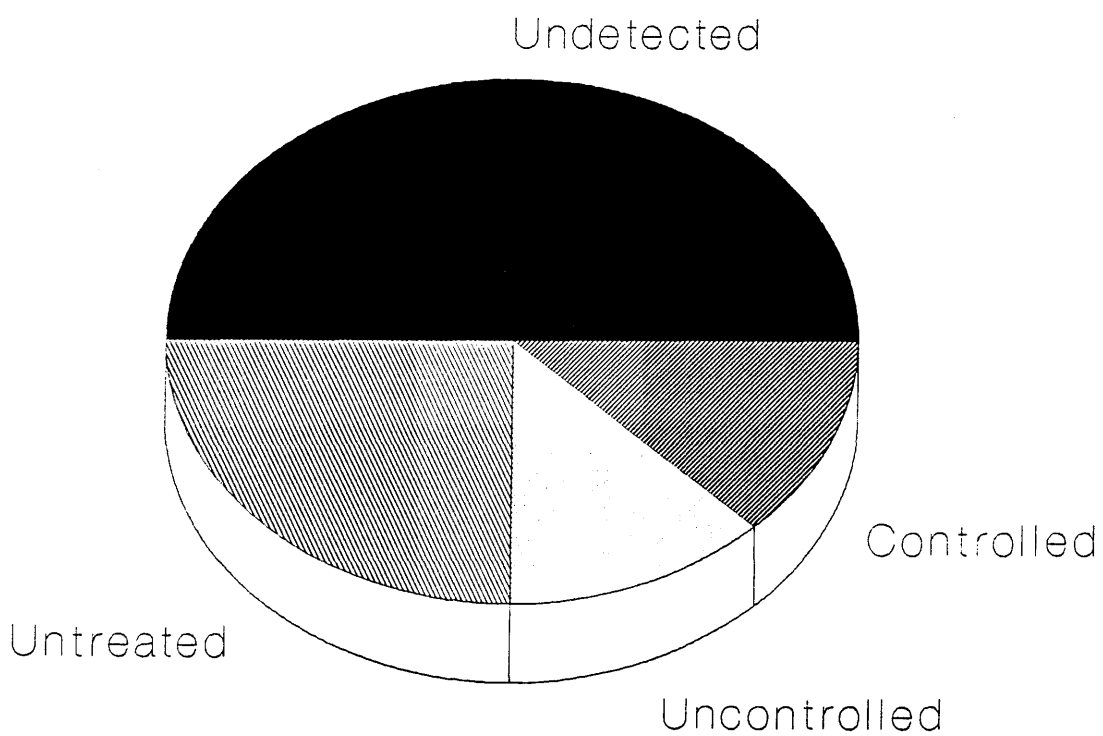
* This percentage has number not dead as denominator

+ This percentage has number monitored as denominator

Table 84: Total costs, benefits and cost-effectiveness ratios (CER) for each group in year two (all costs in £)

	CER (1)	% of baseline
Shared-care under all previous assumptions (ie with 20 minutes for GP consultations)	28.96	100
Shared-care with 10 minute GP consultations	24.03	83
Shared-care with 5 minute GP consultations	21.56	74
Shared-care with doubled re-referral visits (70)	20.44	105
Shared-care with doubled secretarial time	34.08	118
Shared-care with halved clinic ECGs (26% patients)	27.84	96
Outpatient clinic under all previous assumptions	50.55	174
Outpatient clinic with halved clinic visits (1/patient/year)	28.19	97
Nurse-practitioner clinic under all previous assumptions	30.95	107
Nurse-practitioner clinic with doubled medical time (ie all medical time included)	35.10	121

Table 85: Effects on CER (1) of altering some initial assumptions (with CER for SC group as baseline)



**We could add a further sub-division:-
that a proportion of those controlled on treatment
are not followed-up**

Figure 1: The rule of halves

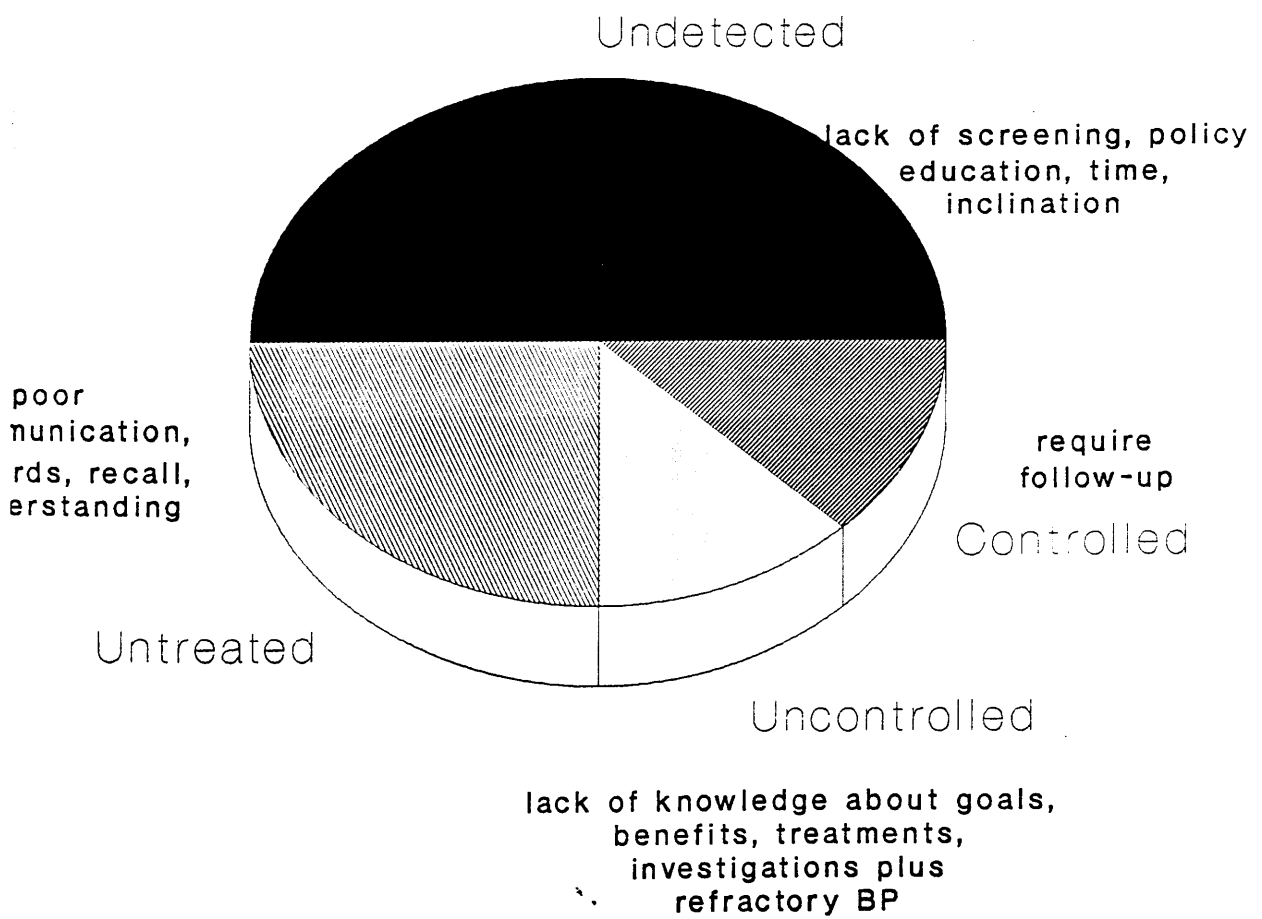


Figure 2: Factors behind the rule of halves

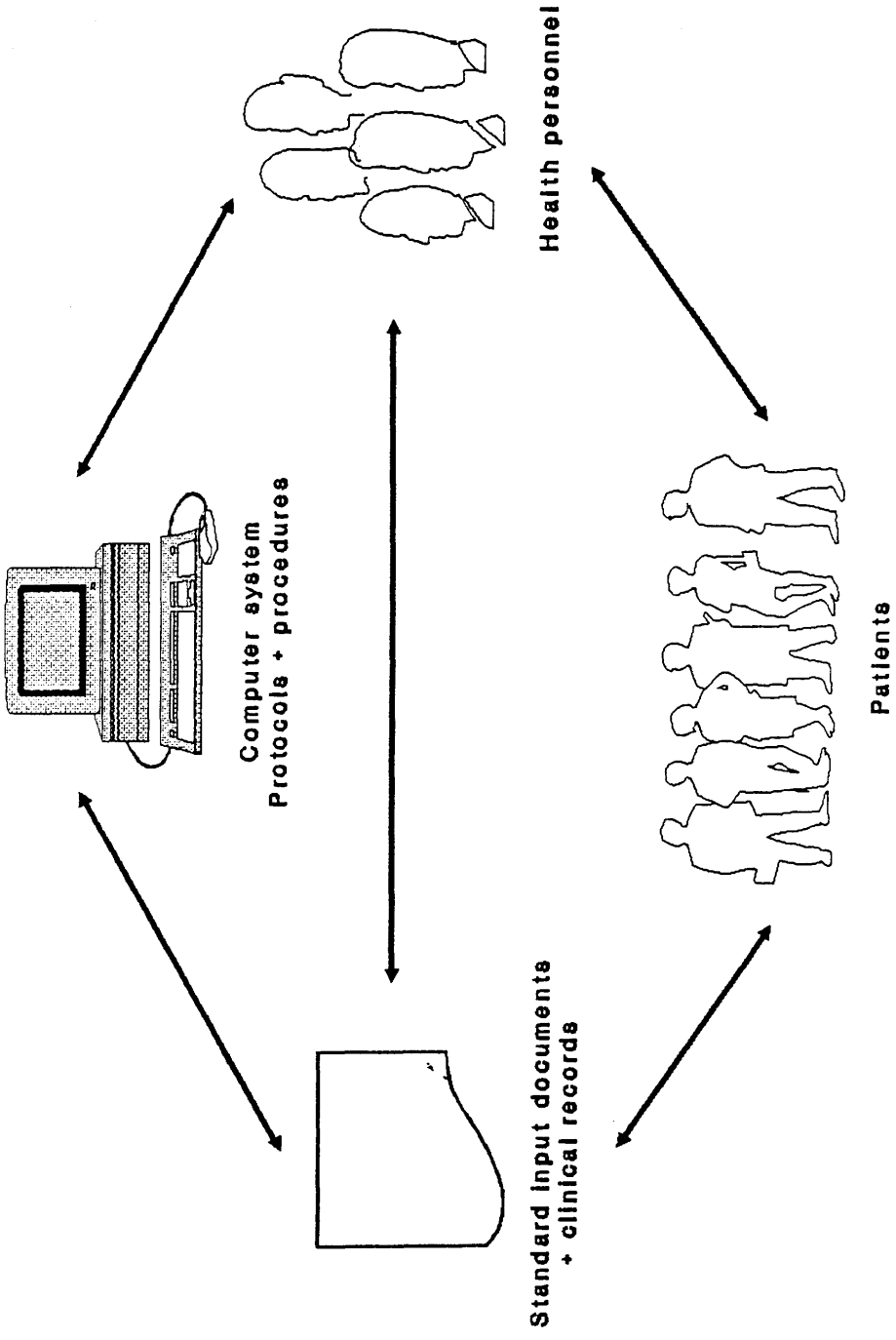


Figure 3: Elements of a clinical information system

From Shaw, 1980

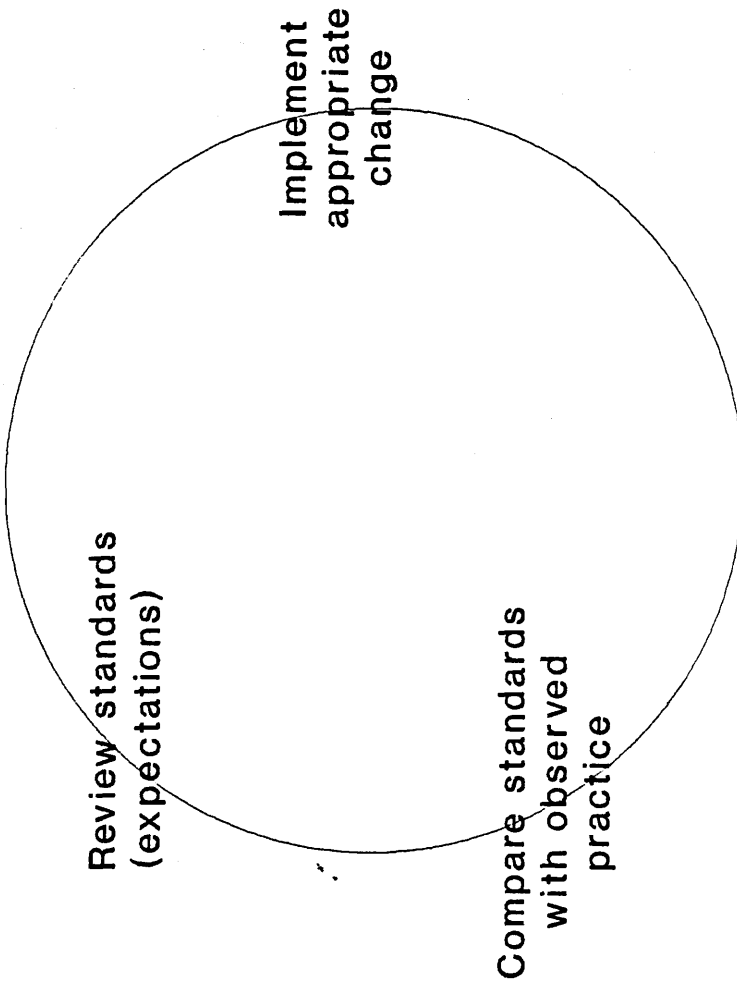


Figure 4: The circle of audit

GRI - Glasgow Royal Infirmary

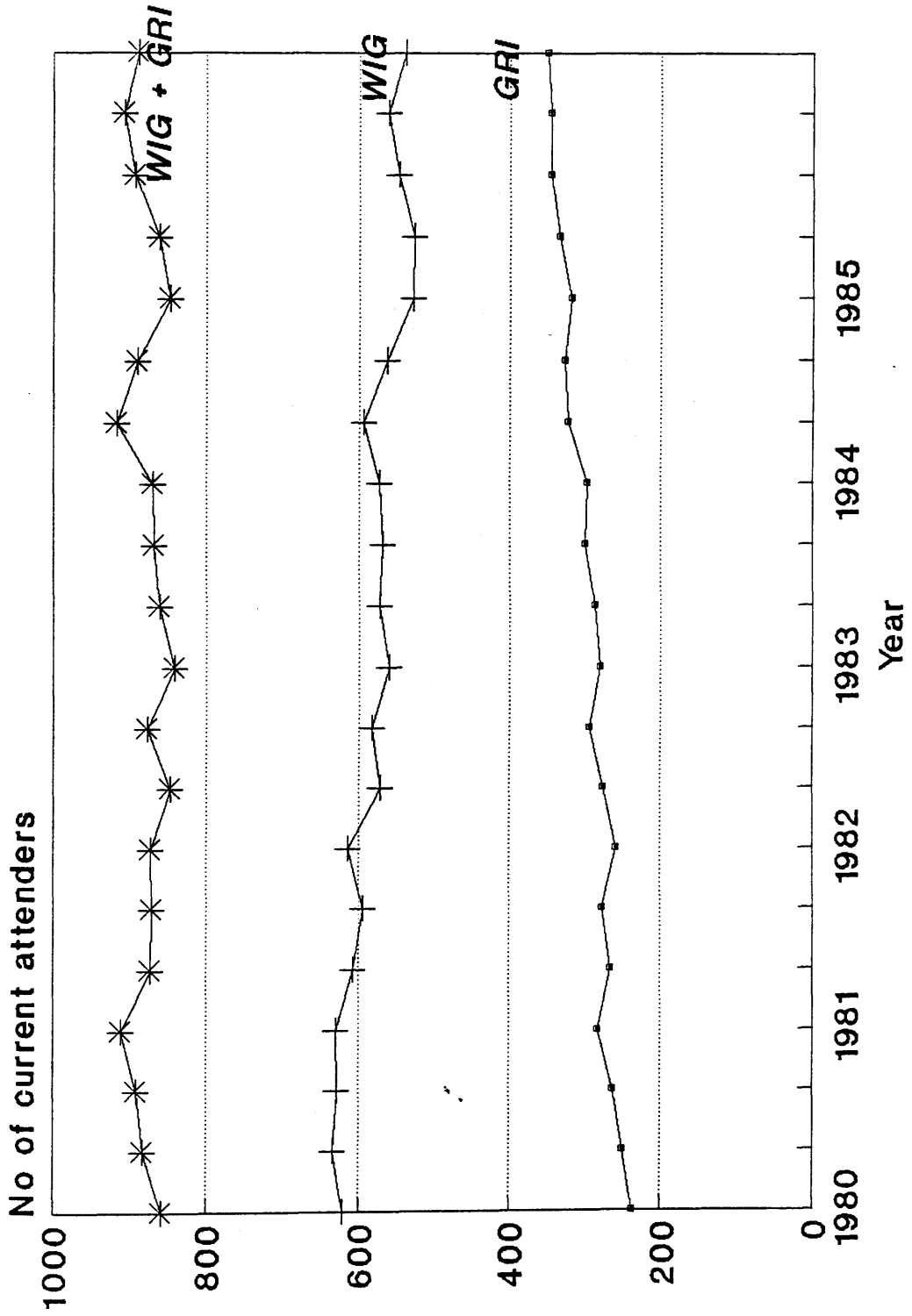


Figure 5: Number of probable current clinic attenders

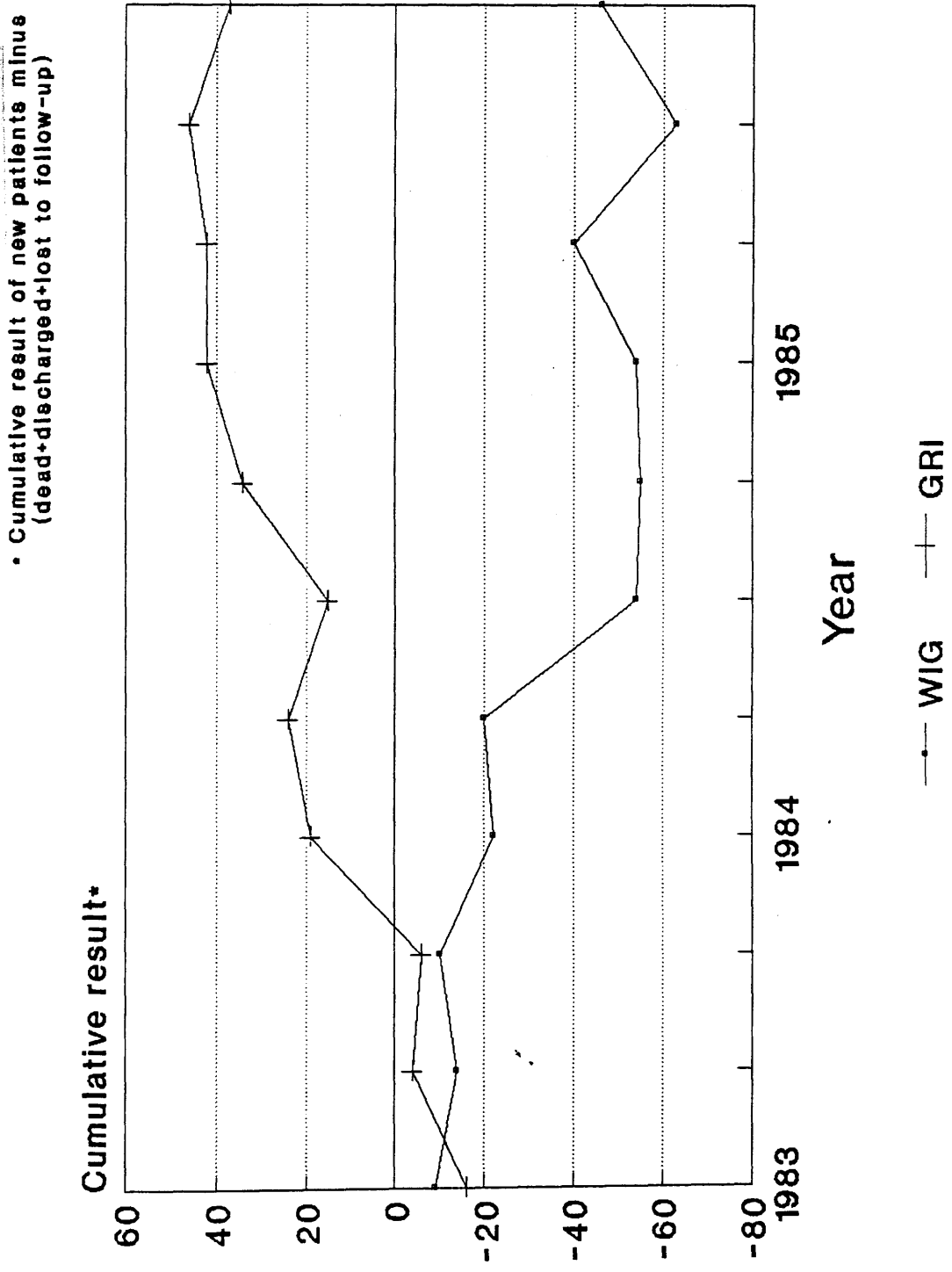


Figure 6: Cumulative result of addition and loss to clinic numbers

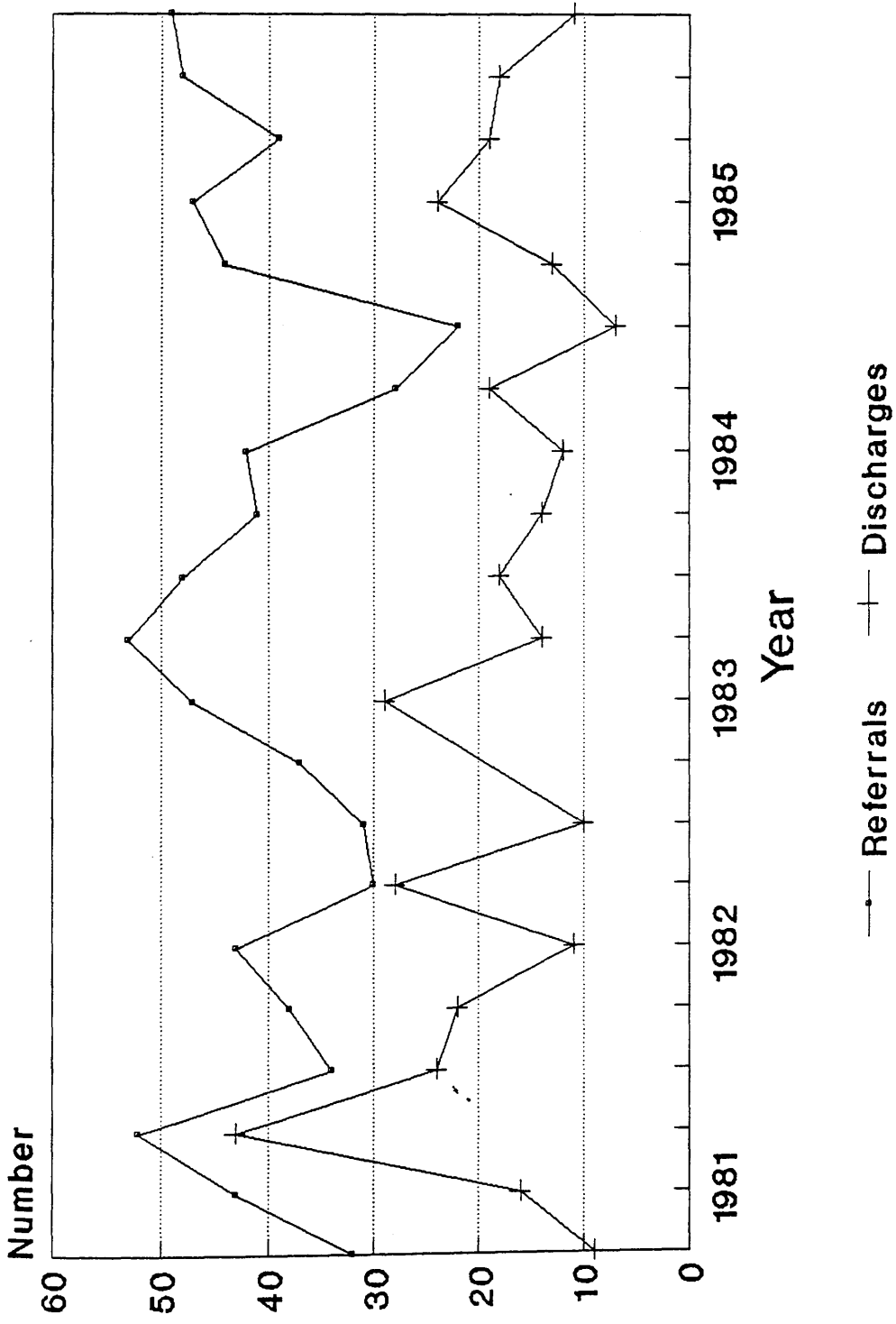


Figure 7: New referrals and discharges at the WIG clinic

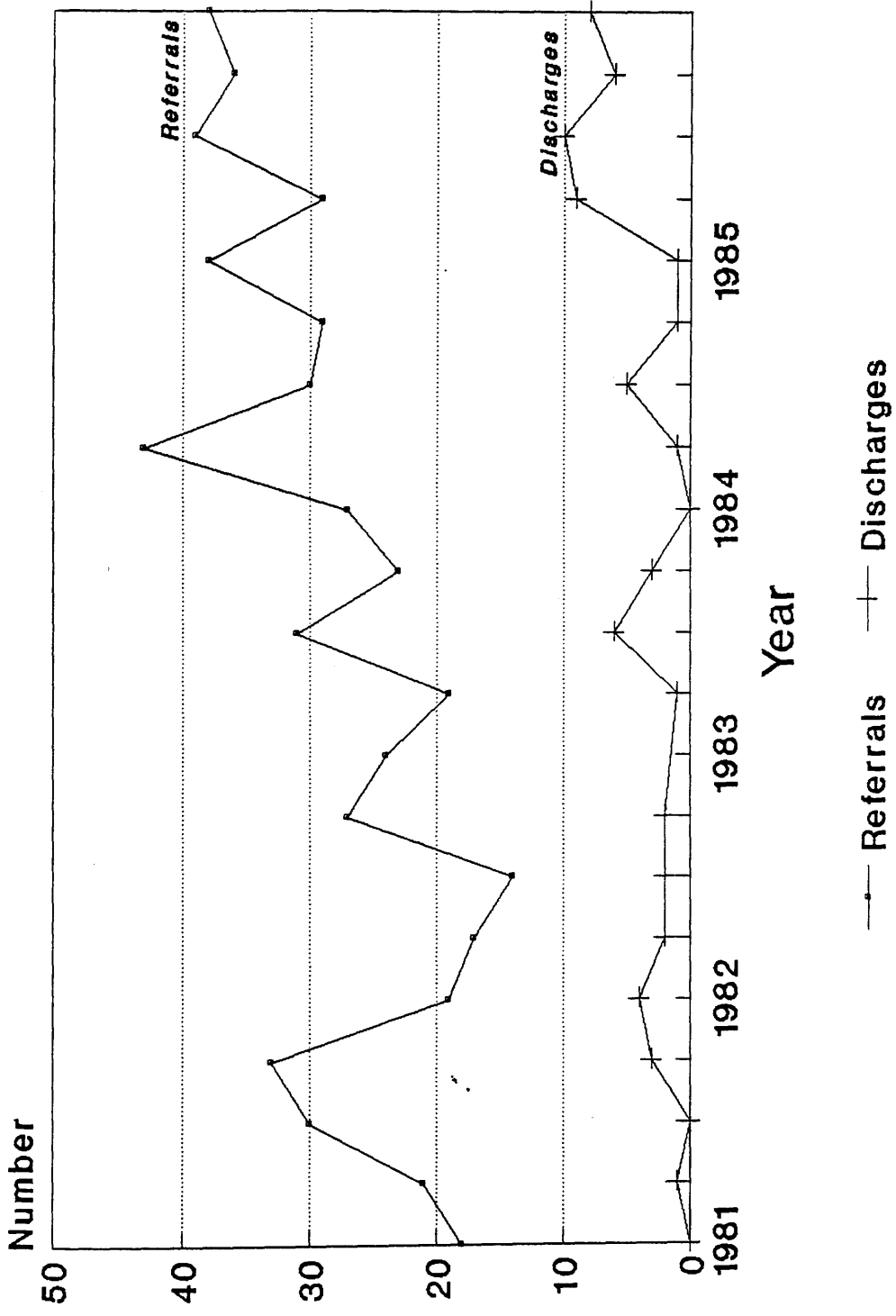


Figure 8: New referrals and discharges at the GRI clinic

The datum point is the mean figure per quarter
between Oct. 1980 and Oct. 1982

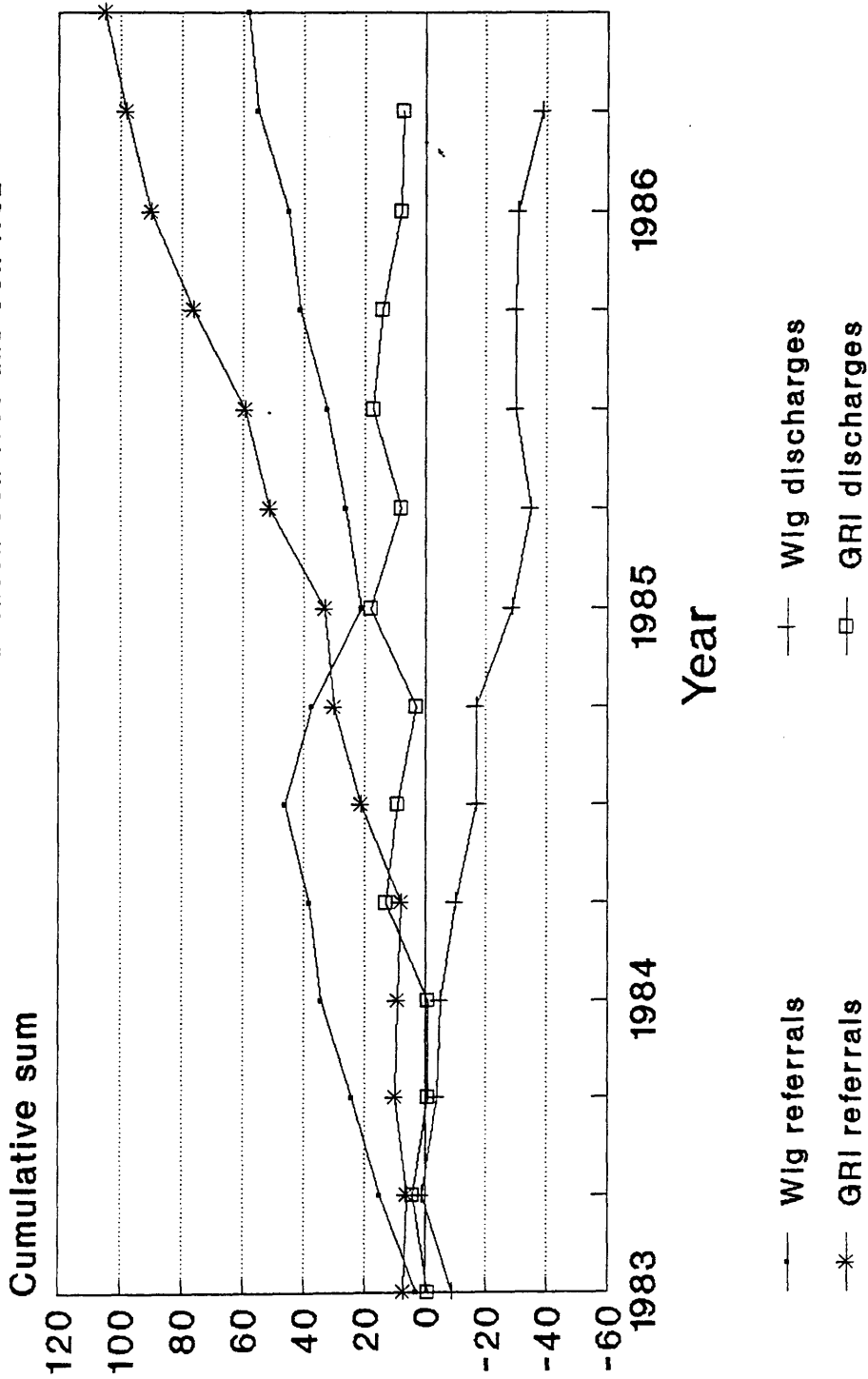


Figure 9: CUSUM plot of referrals and discharges to the WIG and GRI clinics

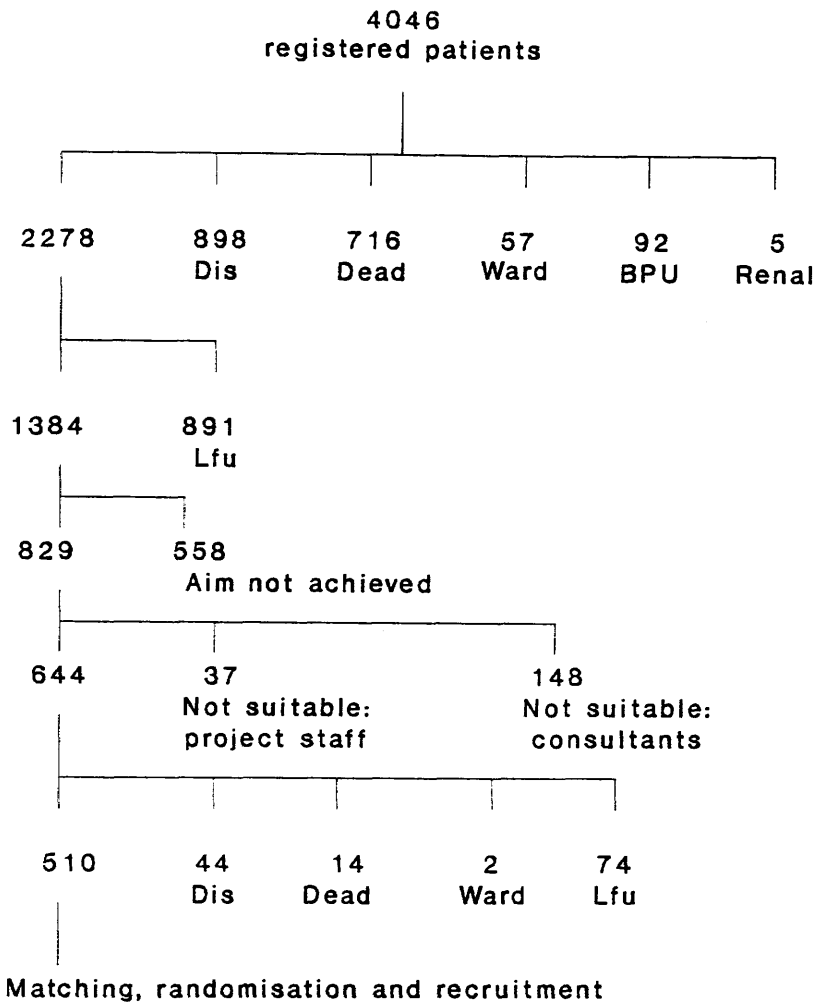


Figure 10: Steps 1, 2 and 3 of the selection process

Lfu = lost to follow-up

DIS = discharged to general practitioner

Ward = admitted to hospital

BPU = transferred to MRC Blood Pressure Unit

Renal = transferred to Renal Unit

Key to Figure 10

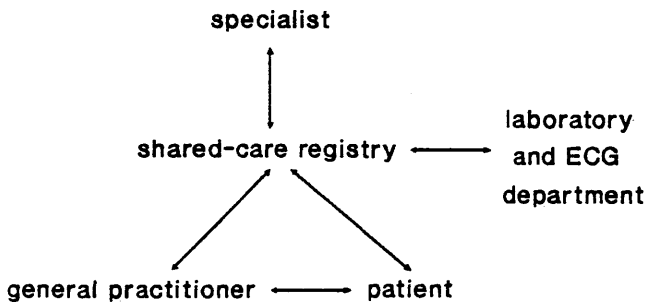


Figure 11: Shared-care links

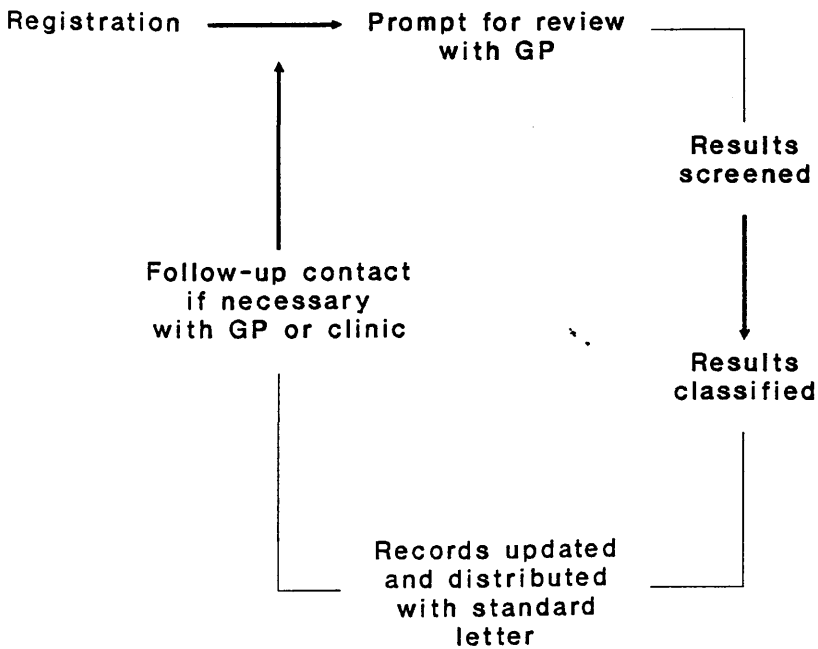


Figure 12: Cycle of care

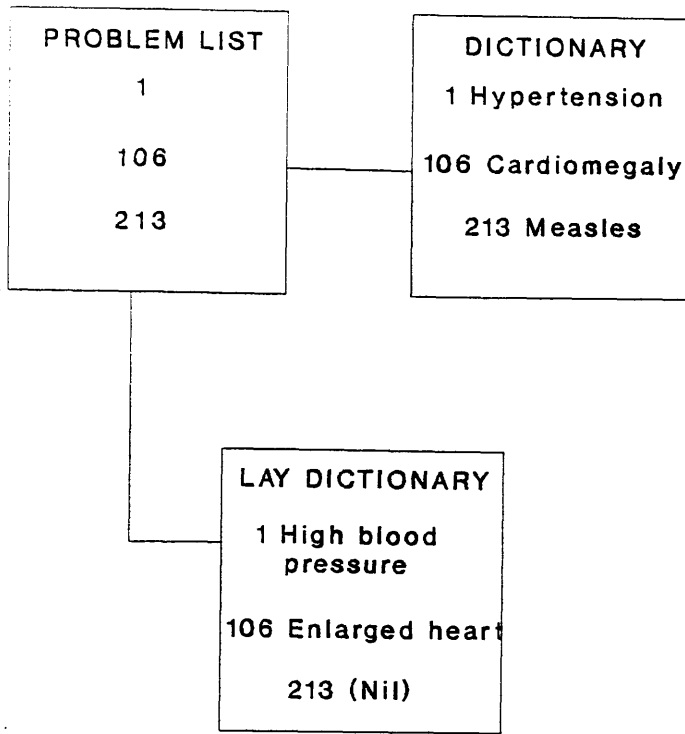
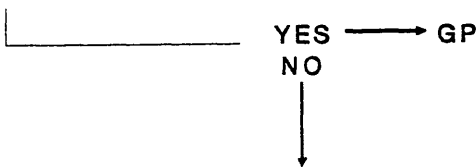


Figure 13: Computerised dictionaries for recording of medical terms and lay translations

Booklet to be sent to

1. Has the GP asked that the Booklet be routinely sent to him/her?



2. Does the Booklet contain, for the first time, sensitive items: high alcohol intake, anxiety impotence, malignant disease social or personal problems?

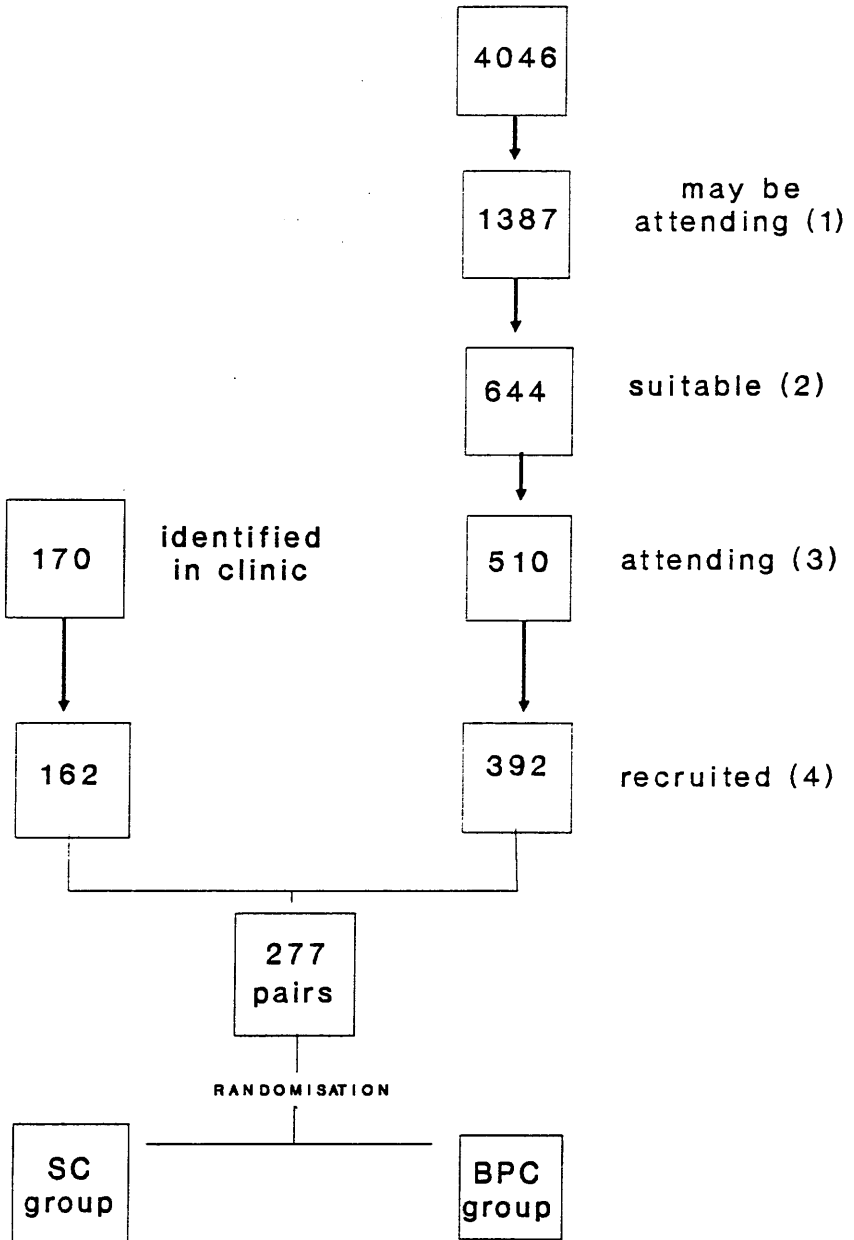


3. Has any item been added to the problem list by the specialist since the Booklet was last reviewed by the GP



Figure 14: Protocol for determining to whom the Personal Health Booklet should be sent

Patients registered in WIG and GRI clinics, Sept. 1985



(Key after Figure 15b)

Figure 15a: Sampling frame for the SC and BPC groups

Patients registered in
Stobhill nurse-practitioner clinic, Sept. 1985

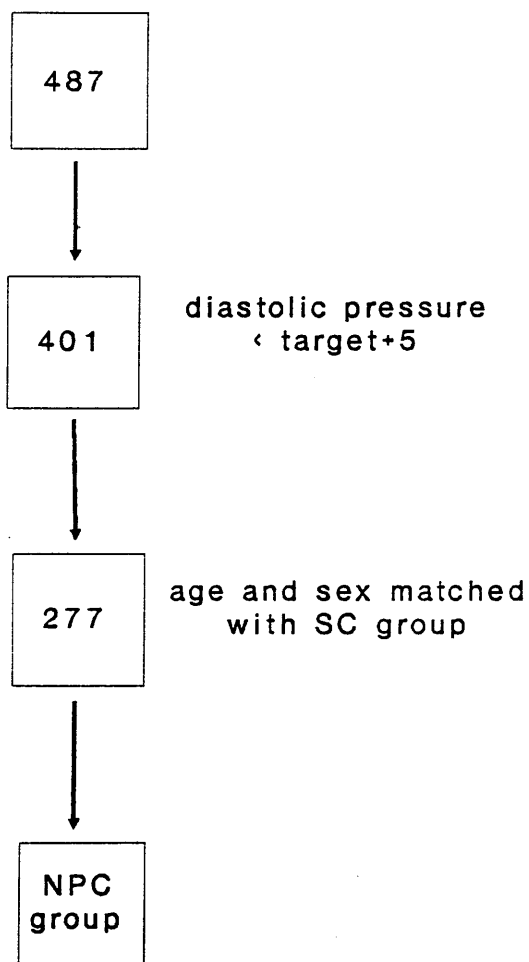
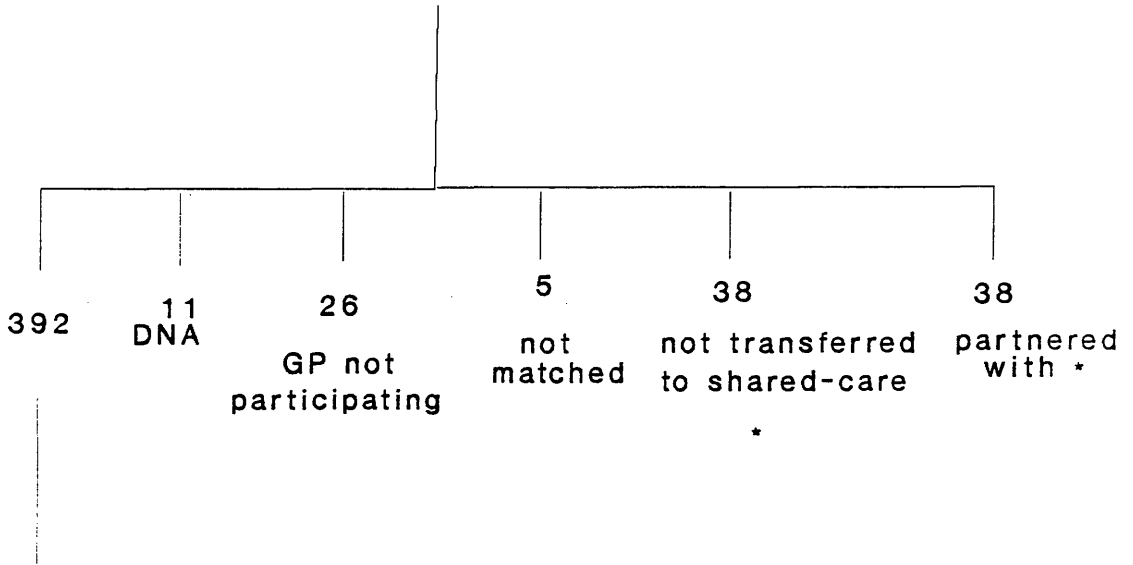


Figure 15b: Sampling frame for the NPC group

- (1) 898 discharged to general practitioner
716 dead
154 transferred to other clinic/ward
891 lost - no information
- (2) 1. aim of treatment achieved
2. screened by consultant
- (3) 44 discharged to general practitioner
14 dead
2 transferred to ward
74 lost - no information
- (4) 11 did not attend
28 general practitioner not participating
38 not suitable
38 partnered with above
5 not matched

Key to Figure 15

510 pre-selected patients



196 pairs recruited

Figure 16: Recruitment of the pre-selected patients

Greater Glasgow Health Board GPs, 1986

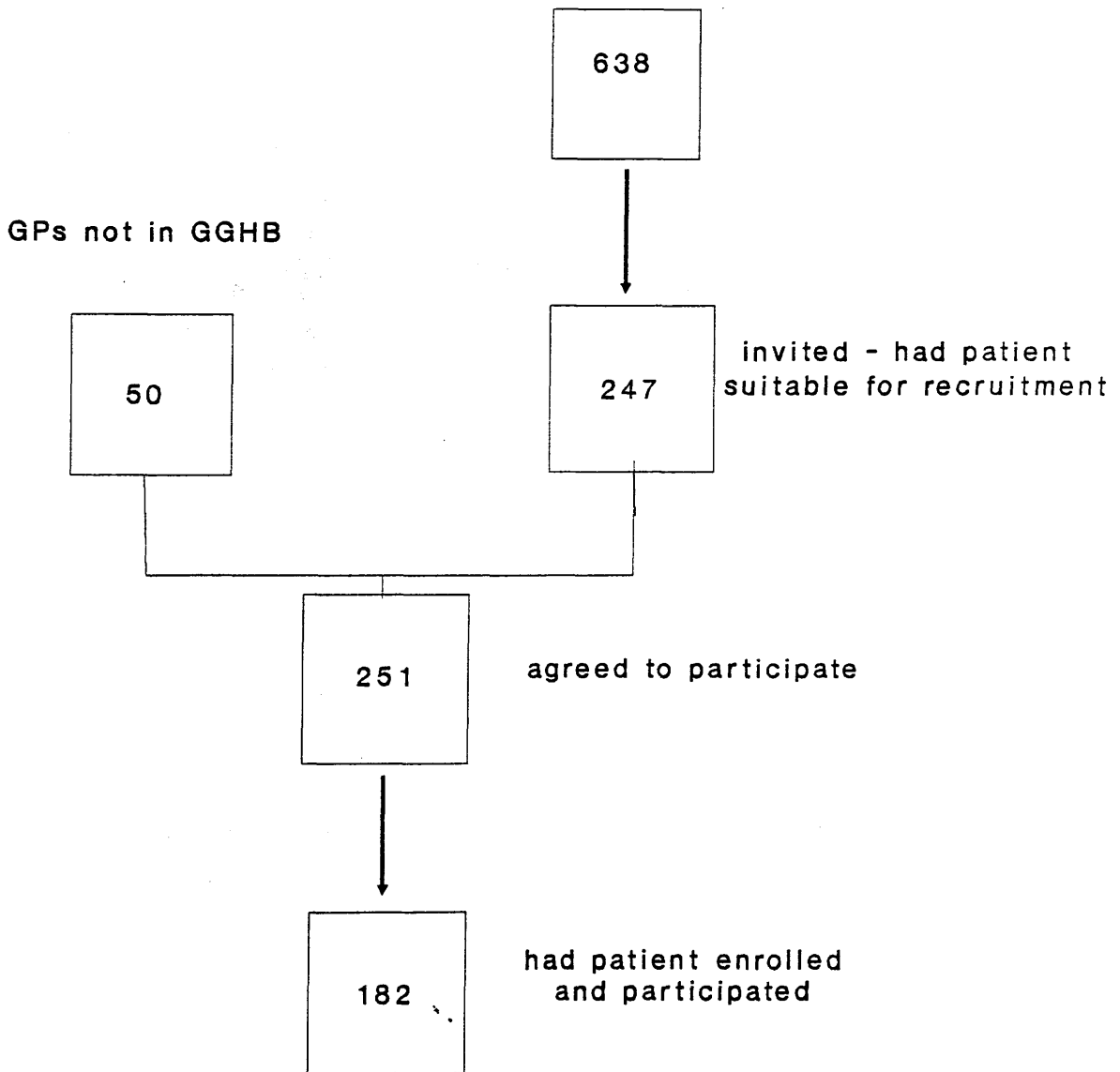


Figure 17: Sampling frame for general practitioners

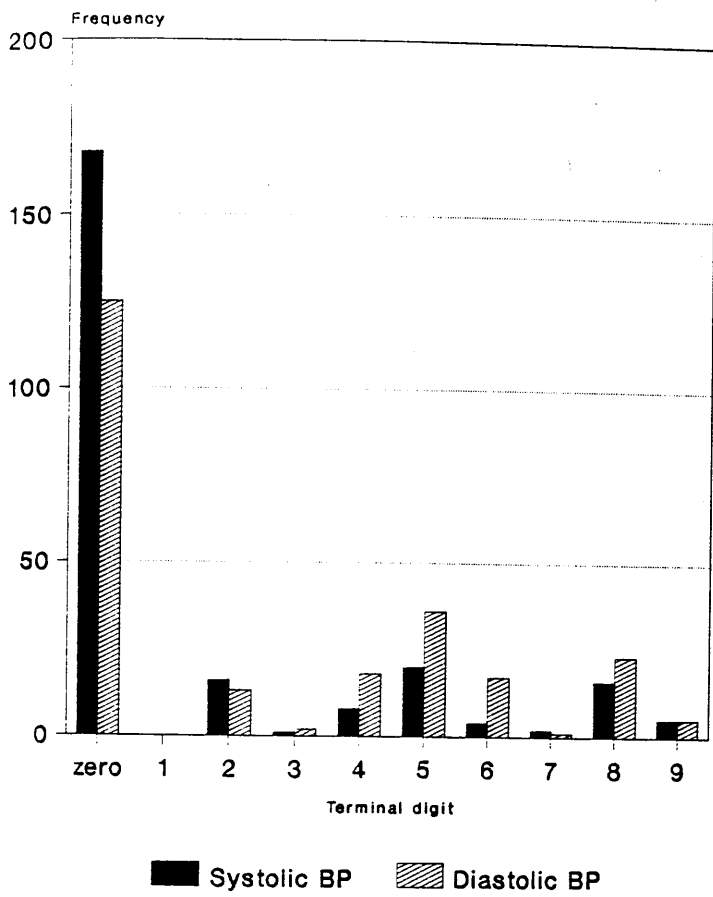


Figure 18a: Terminal digit analysis - SC group

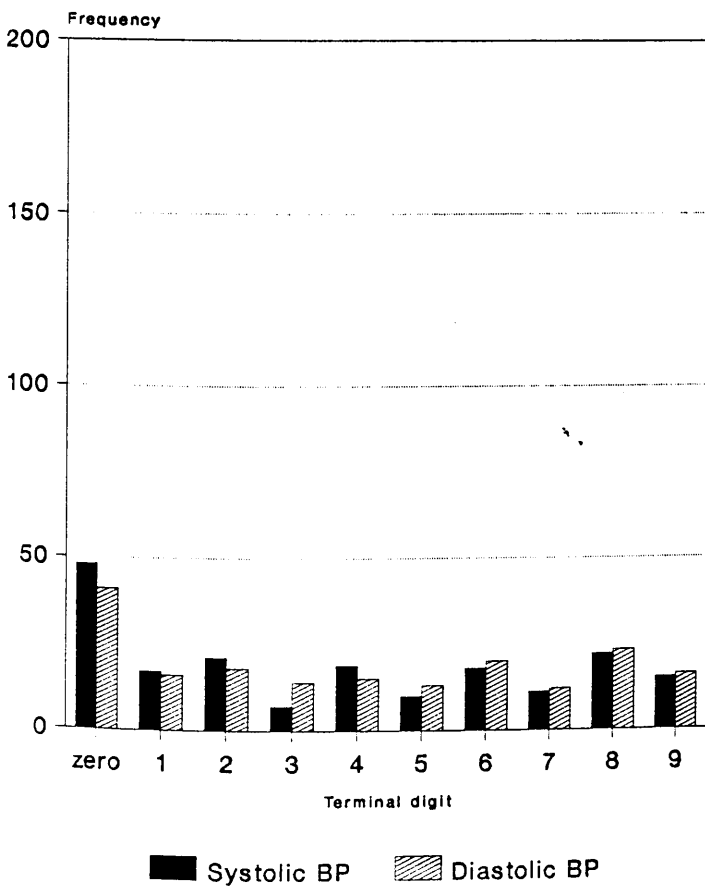


Figure 18b: Terminal digit analysis - BPC group

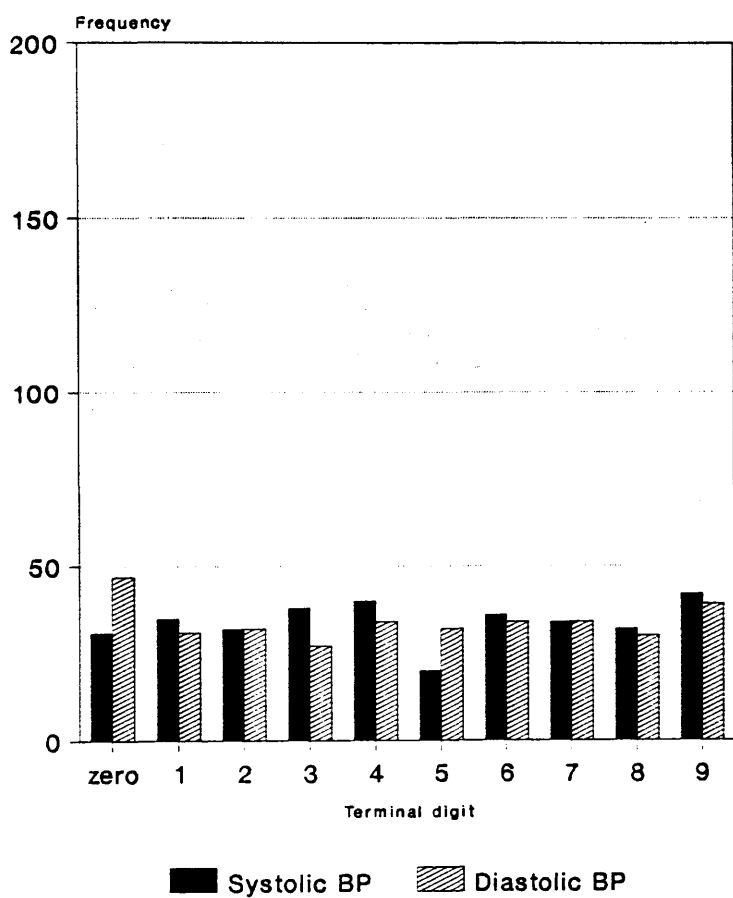


Figure 18c: Terminal digit analysis - NPC group

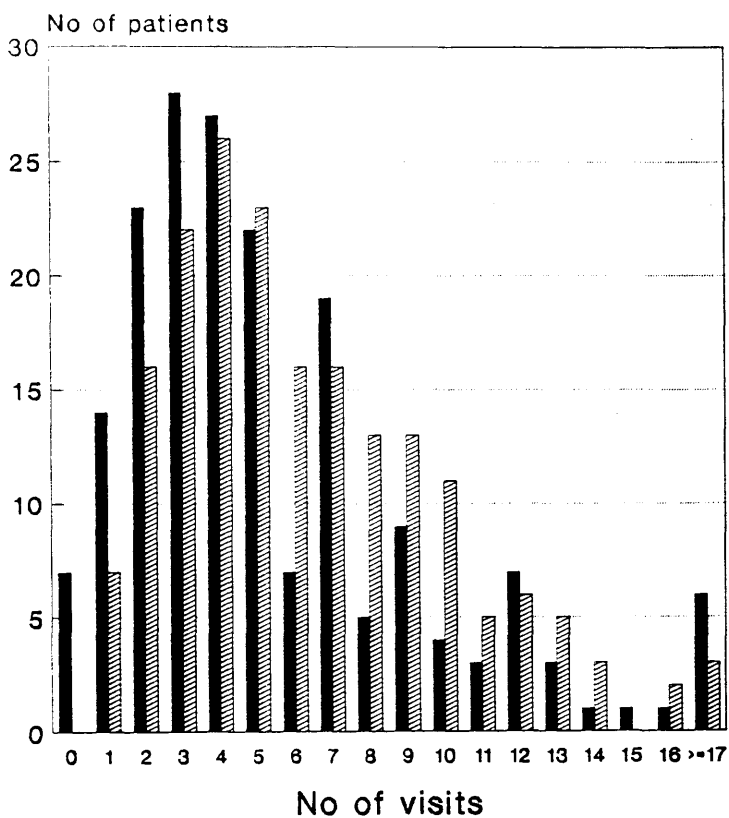


Figure 19a: Visits to general practitioners - SC group

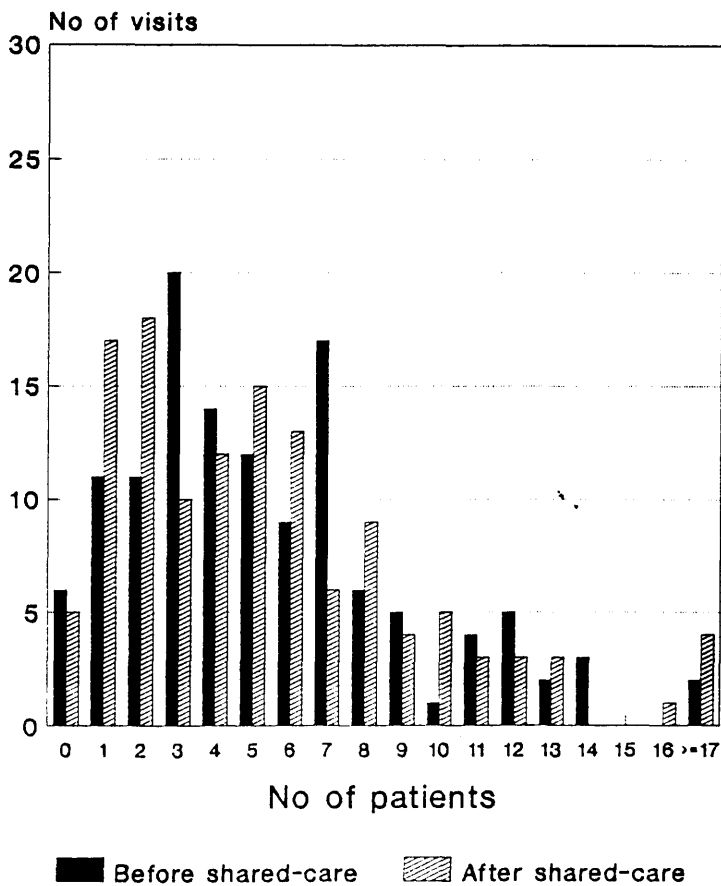


Figure 19b: Visits to general practitioners - BPC group

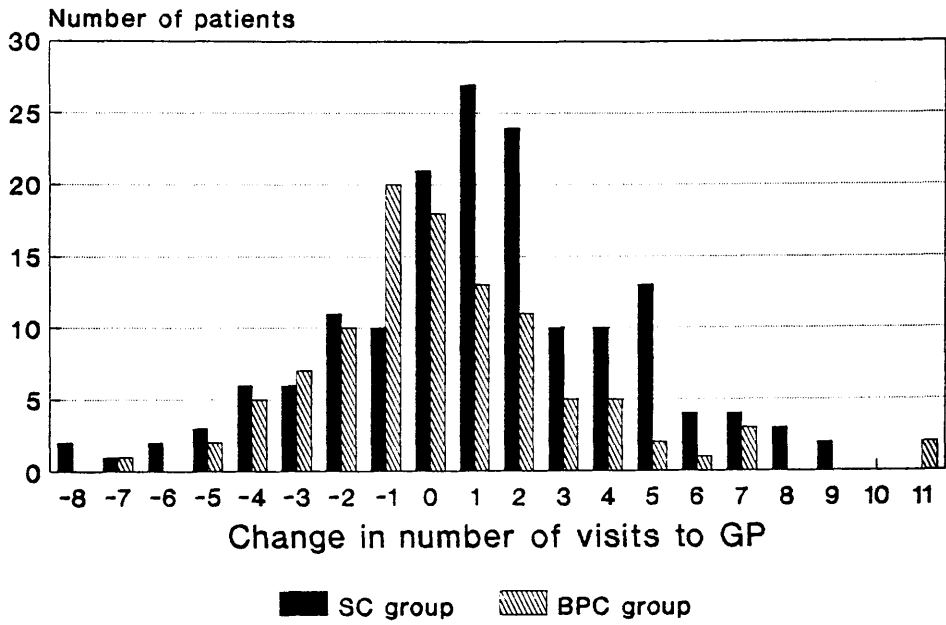


Figure 20: Change in number of visits to the general practitioner 1988/7 compared with 1986/5

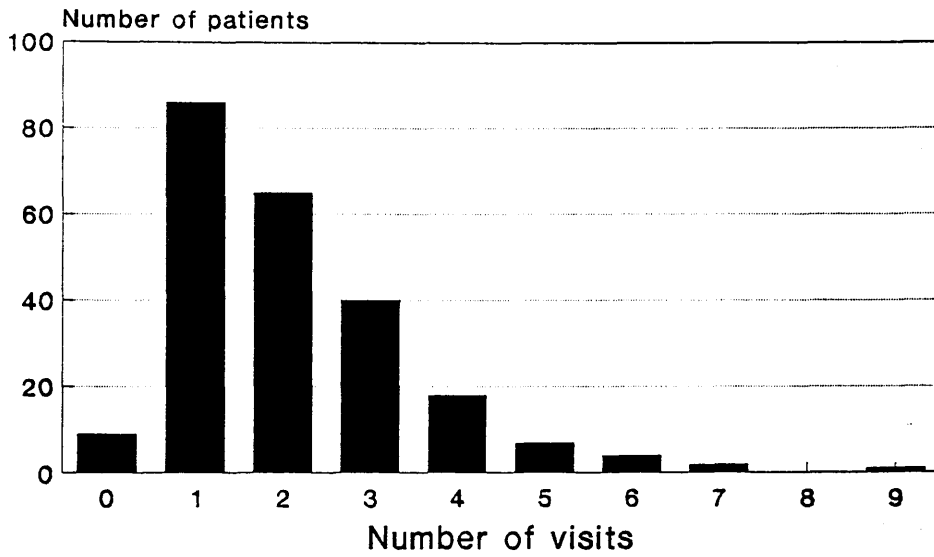


Figure 21a: Number of clinic visits made by BPC group in year 2

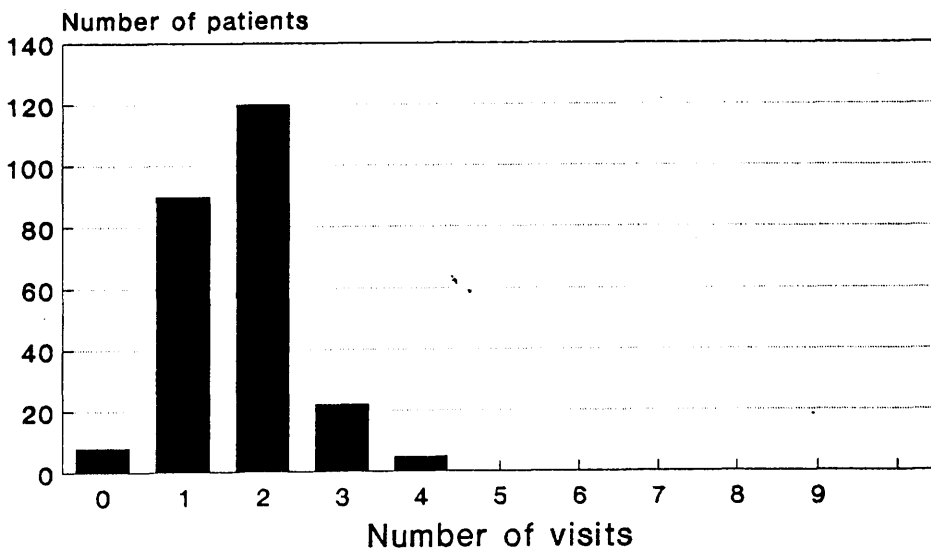


Figure 21b: Number of clinic visits made by NPC group in year 2.

**THE DESIGN, IMPLEMENTATION AND EVALUATION
OF A SHARED-CARE SCHEME FOR HYPERTENSION**

APPENDIX ONE

QUESTIONNAIRES USED IN THE STUDY

- 1. Patient questionnaire one**
- 2. Patient questionnaire two**
- 3. Questionnaire on the Personal Health Booklet**
- 4. General practitioner questionnaire**
- 5. Biochemist questionnaire**

HEALTH SURVEY

Strictly Private

Please remember your answers will be treated in confidence. Your name will not be known to anybody outside those handling the survey.

Instructions

Thank you for helping us by answering the following questions.

PLEASE READ EACH QUESTION CAREFULLY AND THEN GIVE YOUR ANSWERS BY TICKING THE APPROPRIATE BOXES OR WRITING IN THE SPACES PROVIDED.

PLEASE REMEMBER IT IS YOUR PERSONAL VIEWS WE ARE INTERESTED IN.

NAME:

Which one of the following statements best reflects your view on the chances of reducing high blood pressure?

TICK ONE BOX ONLY

- [] There is very little you can do for yourself, it is fate or bad luck.
- [] There are certain things you can do for yourself which might help reduce high blood pressure.
- [] There are certain things you can do for yourself which will definitely help reduce high blood pressure.

HEALTH

1. How would you describe your present state of health?

Very good [] Good [] Average []
Not very good [] Poor [] Don't know []

2. Over the last 2 years have you ever been told by a doctor or nurse that you have high blood pressure (hypertension?)

Yes [] No [] Not sure []

3. In the last year have you been advised to do any of the following?

To lose weight Yes [] No []

To eat different types of food (less fat, more fibre, less salt etc) Yes [] No []

To cut down or give up smoking Yes [] No []

To take more exercise Yes [] No []

To cut down or give up drinking alcohol Yes [] No []

To rest or relax more often Yes [] No []

4. Being very honest with yourself, do you find it difficult to change your personal habits such as smoking, drinking, eating, exercise etc?

Very [] Quite [] Quite [] Very [] Don't []
difficult difficult easy easy know

5. Are you taking any tablets prescribed by a doctor for high blood pressure (hypertension)?

Yes [] No [] Not sure []

6. What symptoms do you think high blood pressure (hypertension) causes?

..... Don't know []

7. If high blood pressure is not treated do you think it can cause any serious problems? If YES, what?

..... Don't know []

8. Apart from taking medication, do you think there is anything you can do personally to reduce the level of your blood pressure?

Yes [] Yes [] Not [] Probably [] Definitely []
definitely probably sure not not

If YES, what?

.....

9. Once high blood pressure has been diagnosed, do you think you should continue to have it checked for:

A few weeks [] 6-12 months [] 1-5 years []

As long as it [] The whole of [] Don't know []
remains high your life

10. Why do you think people receive treatment for high blood pressure?

..... Don't know []

11. What was your blood pressure reading at your last appointment?

..... Don't know []

12. Do you think that it is necessary to treat high blood pressure when nothing else appears to be wrong?

Yes [] Yes [] Not [] Probably [] Definitely []
definitely probably sure not not

SMOKING- include cigarettes, cigars, pipe

1. Which one of the following best describes you?

- I have never smoked [] Go to next section - Alcohol
- I smoke every day [] Go to Q 2
- I smoke occasionally but not every day [] Go to Q 3
- I used to smoke but do not smoke at all now [] Go to Q 10

FOR ALL CURRENT SMOKERS, BOTH DAILY AND OCCASIONAL

2. For how many years have you been smoking?

.....

3. In a typical week how much do you smoke?

.....

4. Do you think you smoke:-

- Far too much [] A little too much [] Moderately []
- Don't know [] Never think about it []

5. Would you like to give up smoking?

- Yes [] No [] Not sure []

6. Do you think that your present level of smoking is harmful to your health?

- Yes [] No [] Not sure []

7. If you tried to stop smoking, how successful do you think you would be?

Completely [] Successful for [] Unsuccessful [] Don't []
successful short time know

8. Have you made a serious attempt to give up smoking during the last 12 months?

Yes [] No []

If YES, what was the longest period you gave up for?

One week or less [] More than one week but []
less than one month

1-2 months [] 3-6 months [] over 6 months []

FOR ALL EX-SMOKERS

9. How long have you been an ex-smoker?

3 months or less [] More than 3 months but []
less than 6 months

6-12 months [] If longer than a year, give number of years []

10. How much did you smoke in a typical week?

.....

11. Why did you stop smoking?

.....

ALCOHOL

1. How often do you drink alcohol?

- Never Go to next section - **Weight**
- Used to drink but do not drink at all now Go to next section - **Weight**
- Less than once a week Answer questions 3, 4 and 5
- Once a week Answer all questions
- 2 - 3 times a week Answer all questions
- More than 3 times a week Answer all questions

FOR THOSE DRINKING ALCOHOL

In answering the next question please use the following formula:

1 pint (beer, cider etc)	=	2 units
Half pint (beer, cider etc)	=	1 unit
1 glass wine, sherry etc	=	1 unit
1 single measure (whisky, gin, vodka etc)	=	1 unit
1 double measure (whisky, gin, vodka etc)	=	2 units

2. In a typical week, how many units of alcohol do you drink?

(REFER TO TABLE ABOVE) units of alcohol

3. In a typical month, how many units of alcohol do you drink?

(REFER TO TABLE ABOVE) units of alcohol

4. Do you think your present level of alcohol drinking is harmful to your health?

Yes No Not sure

5. Have your alcohol drinking habits changed over the last year?

Drink Drink Drink Drink Drink
much a little the a little much
less less same more more

WEIGHT

1. Which one of the following best describes you?

- I am underweight []
- I am about the right weight []
- I am a little overweight []
- I am very overweight []
- I am not sure about my weight []

2. How important is it to you to be the correct weight for your height?

- Very [] Quite [] Not very [] Not at all [] Don't think []
important important important important about it

3. Would you lose weight for:

- Personal [] Health [] Both [] Don't [] No []
reasons reasons reasons know

4. What weight do you think suits your appearance best?

- Underweight [] Right [] Little [] Very []
(thin) weight (slim) overweight (well-covered/
plump) overweight (fat)

5. Do you think that your present weight is harmful to your health?

- Yes [] No [] Not sure []

6. How difficult do you find it to diet?

- Very [] Quite [] Quite [] Very [] Don't []
difficult difficult easy easy know
Does not apply []

7. Have you made a serious attempt to lose weight during the last 12 months?

- Yes [] No []

If YES,

How much weight did you manage to lose?

For how long did you maintain your reduced weight?

- One week []
- More than 1 week but less than one month []
- 1-2 months []
- 3-6 months []
- over 6 months []

STRESS

1. Thinking about stress and yourself, how do you think you compare with other people?

- I am more stressed []
- I am less stressed []
- About the same as others []

2. In your opinion, how stressed are you now compared with a year ago?

- I am more stressed []
- I am less stressed []
- About the same []

3. Do you think you can do anything personally to reduce stress?

- Yes, definitely []
- Yes, probably []
- Not sure []
- Probably not []
- Definitely not []

If YES, what

PHYSICAL ACTIVITY AND EXERCISE

1. How much time a week do you spend walking, cycling or getting other exercise? (Include both the time spent walking to and from work, shops etc).

.....

2. How do you like to spend your leisure time?

.....

3. How fit do you consider yourself to be for your age?

Fit [] Reasonably [] Slightly [] Unfit [] Very []
fit unfit unfit

4. Do you think you take enough exercise to stay healthy?

Yes [] Yes [] Don't [] Probably [] Definitely []
definitely probably know not not

5. Have you ever seriously tried to increase the physical exercise you take during leisure time?

More than [] 1-6 months [] During last [] Never []
6 months ago ago month

6. Has the amount of physical exercise you take during leisure time changed during the last 12 months?

Increased [] Increased [] Remained [] Decreased [] Decreased []
a lot a little the same a little a lot

Please indicate, for each of the things listed below how important (or not) you think it is in affecting people's blood pressure.

TICK ONE BOX ONLY FOR EACH

	Very Important	Important	Not Very Important	Not at all Important	Don't know
Inactivity (Not taking exercise)	[]	[]	[]	[]	[]
Fluoride in the water	[]	[]	[]	[]	[]
Stress or anxiety	[]	[]	[]	[]	[]
Unemployment	[]	[]	[]	[]	[]
Not getting enough sleep	[]	[]	[]	[]	[]
Not eating regular meals	[]	[]	[]	[]	[]
Drinking too much alcohol	[]	[]	[]	[]	[]
Eating food containing a lot of animal fat	[]	[]	[]	[]	[]
Taking the oral contraceptive (birth control pill)	[]	[]	[]	[]	[]
Living in a cold climate	[]	[]	[]	[]	[]
Living in an area with soft drinking water	[]	[]	[]	[]	[]
Smoking cigarettes	[]	[]	[]	[]	[]
Air pollution	[]	[]	[]	[]	[]
Drinking coffee	[]	[]	[]	[]	[]
Being overweight	[]	[]	[]	[]	[]
Atomic Radiation	[]	[]	[]	[]	[]
Using too much salt	[]	[]	[]	[]	[]
Loneliness	[]	[]	[]	[]	[]
Working in heavy industry	[]	[]	[]	[]	[]

PATIENT VIEWS ON THEIR MEDICAL CARE

1. How long have you been attending this surgery?

2. How do you usually travel to the surgery?

Walk [] Bus [] Train [] Car [] Ambulance []

Other (give details)

3. Is your journey to the surgery?

Very [] Quite [] Quite [] Very []
easy easy difficult difficult

4. How long does it take you to get to the surgery?

5. If you travel by car/motorbike how many miles do you come approximately (single journey)?

6. If you come by public transport or taxi how much does a single journey cost you?

7. Do you need to get time off work to attend your appointment?

Always [] Most of the [] Sometimes []
time

Rarely Never [] Does not apply []

8. Do you generally come to the surgery?

On your own [] With relatives/friends []

9. Are you physically able to come to the surgery on your own?

Yes [] No []

10. If you come to the surgery with a friend or relative, does that person need to get time off work?

Yes [] No [] Don't know [] Does not apply []

11. When making an appointment, do you have a choice regarding

a) Day of week?

Yes [] No [] Don't know [] Doesn't matter []

b) Time?

Yes [] No [] Don't know [] Doesn't matter []

12. Is the time of your appointment?

Always [] Usually [] Sometimes []
convenient convenient convenient

Rarely [] Never [] Don't know []
convenient convenient

13. Is changing your appointment?

Very [] Quite [] Quite []
easy easy difficult

Very [] Don't []
difficult know

14. a) When you come for your appointment, approximately how much time do you spend altogether at the surgery?

.....

b) How much time do you spend waiting?

.....

c) How long before your appointment do you arrive?

..... Arrive on time [] Arrive late []

15. Do you see the same doctor when you come to the surgery?

Always [] Most of [] Seldom []
the time
Never [] Don't []
know

16. Is it important to you to see the same doctor?

Very [] Quite [] Doesn't [] Don't []
important important matter know

17. How do you feel about the amount of time you spend with the doctor at your consultation?

Plenty of [] Enough [] Need more [] Don't []
time time time know

18. How easy do you find it to talk to the doctor?

Very [] Quite [] Quite [] Very []
easy easy difficult difficult
Don't []
know

19. When talking to the doctor do you feel that he/she?

Listens [] Pays some [] Pays little [] Pays no []
carefully attention attention attention
Don't []
know

20. When the doctor gives you advice do you feel that you?

Always [] Understand [] Understand [] Seldom []
understand what he means what he means understand
what he means most of the some of the what he means
time time
Don't [] No advice []
know given

21. How do you feel before your appointment?

Relaxed [] Slightly [] Very [] Don't []
anxious anxious know

22. How do you feel after your appointment?

Fully [] Reasonably [] A bit [] Extremely []
satisfied satisfied dissatisfied dissatisfied

Don't []
know

23. How would you describe the staff at the surgery?

Very [] Quite [] Unfriendly [] Impersonal []
friendly friendly

Don't []
know

24. If you want information about this health problem, who tells you what you want to know?

Hospital [] General [] Nurse [] Other []
specialist practitioner patients

Friends [] Relatives [] No-one [] Don't []
know

25. Regarding your own medical condition, do you?

Wish to [] Know [] Not wish [] Don't []
know more enough to know know

At your consultation, are you?

Told [] Told [] Told [] Don't []
enough nearly enough very little know

26. Regarding your treatment do you?

Wish to [] Know [] Not wish [] Don't []
know more enough to know know

At your consultation, are you?

Told [] Told [] Told [] Don't []
enough nearly enough very little know

27. **Regarding your progress, do you?**

Wish to [] Know [] Not wish [] Don't []
know more know enough to know know

At your consultation, are you?

Told [] Told nearly [] Told very [] Don't []
enough enough little know

28. **How important is medical advice to you?**

Not very [] Quite [] Very [] Don't []
important important important know

29. **Do you think people in general regard medical advice as important?**

Not very [] Quite [] Very [] Don't []
important important important know

30. **Are you ever given advice which is different from the advice which the doctor gives you?**

Yes [] No [] Don't know []

If YES, do you get this advice?

From other [] From [] From [] From []
medical staff friends relatives books

From radio/[] From magazines/ [] Don't []
television newspapers know

TICK AS MANY BOXES AS APPLY

31. **If you follow your medical advice and treatment how likely are you to stay well?**

Very [] Quite [] Not [] Not at []
likely likely very likely all likely

Don't []
know

32. How difficult do you find it to remember to take the medication prescribed?

Very difficult [] Quite difficult [] Quite easy [] Very easy []
Don't know [] Does not apply []

33. Do you think people in general follow the treatment prescribed by their doctor?

Always [] Most of the time [] Some of the time [] Seldom []
Never [] Don't know []

34. Some people do not take their medication as regularly as instructed. Do you take yours?

All the time [] Most of the time [] Some of the time [] Occasionally []
Not at all [] Don't know [] Does not apply []

35. Do you ever stop taking your medication for any of the following reasons?

Because of side effects [] Because I do not like taking medicines [] Because of cost of medicines [] Because I sometimes forget []
Does not apply []

TICK AS MANY BOXES AS APPLY

36. During the consultation, do you think you?

Have enough privacy [] Do not have enough privacy [] Don't know []

37. What do you hope to gain from visiting the doctor?

.....

38. What do you like best about your surgery?

.....

39. What do you dislike about your surgery?

.....

40. Where do you think this medical condition should be treated?

At a [] At general [] At both [] No opinion []
hospital practitioner's places
clinic surgery

Don't []
know

41. Do you feel that it is worthwhile visiting the surgery?

Yes [] Yes [] Probably [] Definitely [] Don't []
definitely probably not not know

42. Now that you have attended both the hospital Blood Pressure Clinic and your family doctor for Shared-care, which do you prefer?

Out-patient [] Family [] No []
B.P. clinic doctor preference

Please give your reasons:

.....

43. Please state any benefits there are for you by attending the hospital Blood Pressure Clinic.

.....

44. Please state any disadvantages there are for you by attending the hospital Blood Pressure Clinic.

.....P.T.O.

45. Please state any benefits there are for you by attending your family doctor in the Shared-care Scheme for Hypertension.

.....

46. Please state any disadvantages there are for you by attending your family doctor in the Shared-care Scheme for Hypertension.

.....

47. How often do you see your family doctor?

Every [] Every [] Every [] Every []
month 3 months 6 months year

Other (give details).....

If not on a regular basis, roughly how many times a year do you see your family doctor?

Answer Q.48 if you are on treatment for high blood pressure.

48. When you need a repeat prescription for your high blood pressure, do you?

arrange to see the doctor every time [] sometimes [] never []

What arrangements do you make to get your repeat prescription(s)?

.....
.....

How often do you need a repeat prescription?

49. Are there any general comments you would like to make?

.....
.....

PERSONAL HEALTH BOOKLET

Please tick

1. Have you received a copy of your Personal Health Booklet? Yes [] No []

Questions 2 - 9 refer to the personal details in your booklet (the blue pages)

2. Have you learnt anything new about your medical history or treatment? Yes [] No []

If Yes, please give details:

3. Is anything in the blue pages incorrect? Yes [] No []

If Yes, please give details:

4. Is anything missed out? Yes [] No []

If Yes, please give details:

5. Is anything printed in the blue pages which is correct but you would prefer not to have printed there? Yes [] No []

If Yes, please give details:

6. Do you understand everything in your medical history and treatment? Yes [] No []

If No, please give details:

7. Did you need to ask for an explanation of anything in your medical history or treatment? Yes [] No []

If Yes, whom did you ask?

What did you need explained?

8. Please tick the statement which best describes how you feel about your Personal Health Booklet:
- I do not like having a Personal Health Booklet []
- I am not bothered whether I have a Personal Health Booklet or not []
- I like having a Personal Health Booklet []
9. Do you find it useful to have a Personal Health Booklet? Yes [] No []
- If Yes, please say why:
10. Does your booklet contain general health advice? Yes [] No []
11. Have you learnt anything new about high blood pressure? Yes [] No []
- If Yes, please give details:
12. Have you learnt more about the conditions that can result from untreated high blood pressure? Yes [] No []
- If Yes, please give details:
13. Are there any things about your lifestyle that may be connected with your high blood pressure? Yes [] No []
- If Yes, please give details:
14. Have you tried to make any changes in your way of life because of your high blood pressure? Yes [] No []
- If Yes, please give details:
15. Is there any further information you would like about high blood pressure? Yes [] No []
- If Yes, please give details:

EVALUATION OF THE WEST OF SCOTLAND SHARED-CARE SCHEME FOR HYPERTENSION

1. ANNUAL REVIEW PROCEDURE

Please tick box

a. How many appointments do your patients require to complete a shared-care annual review, including ECG?

If more than one, is a separate appointment required for:

a) blood tests? Yes [] No []

b) ECG? Yes [] No []

b. Which tests do you feel are necessary in an annual review for hypertension?

Serum Biochemistry? Yes [] No [] Don't [] know

Random Blood Glucose? Yes [] No [] Don't [] know

Serum Cholesterol? Yes [] No [] Don't [] know

Weight measurement? Yes [] No [] Don't [] know

Blood pressure measurement? Yes [] No [] Don't [] know

Urinalysis? Yes [] No [] Don't [] know

Annual ECG? Yes [] No [] Don't [] know

c. Do you operate your own Blood Pressure clinic within the practice? Yes [] No []

d. Do you have a practice nurse? Yes [] No []

If YES,

Does the nurse carry out the annual review procedure? All of it [] Some of it [] None of it []

e. Do/would you find the Shared-Care Re-referral clinic a useful service? Yes [] No [] Don't [] know

f. Are there any general comments you would make on annual review procedure?

.....
.....

2. PERSONAL HEALTH BOOKLET

a. Have you ever seen the patient's Personal Health Booklet? Yes [] No []

- b. Are you happy to have the Personal Health Booklet sent direct to the patient? Yes [] No [] Don't know []
- c. Do you have any comments you would like to make on the different sections of the booklet? (eg. useful to the doctor, useful to the patient etc.)

Personal Details

.....

Medical History/diagnoses

.....

Current and Past Medicines

.....

Blood Pressure and weight record

.....

Lifestyle advice

.....

3. Please rank in order of preference the following methods of care for well-controlled hypertensive patients: (1 = best liked - 4 = least liked)

Out-Patient Specialist Clinic	Nurse Practitioner Clinic in hospital	Shared-Care with GP	Routine care by GP
[]	[]	[]	[]

4. Do you think that the Shared-Care Scheme provides a useful service to general practitioners?

Yes [] No [] Don't know []

5. Do you think the Scheme makes patient management more effective?

Yes [] No [] No difference []

6. Would you like the West of Scotland Shared-Care Scheme for Hypertension to continue?

Yes [] No [] No opinion []

THANK YOU FOR YOUR ASSISTANCE

Please have the enclosed slip completed and return with the questionnaire in the reply-paid envelope.

WEST OF SCOTLAND SHARED-CARE SCHEME FOR HYPERTENSION
GLASGOW BLOOD PRESSURE CLINIC
Chairman: Dr A R Lorimer
Royal Infirmary Stobhill Hospital Western Infirmary
Supported by the Scottish Home and Health Department and the British Heart Foundation

QUESTIONS ON PROCEDURE USED WITH BLOOD SAMPLES

1. We are working with a number of biochemistry laboratories which operate different procedures for dealing with our blood samples. To allow us to compare the operation of the Shared-Care Scheme in these various areas, we would be grateful if you could answer the following questions. (All answers will remain confidential).

1. Do you/your instruments have criteria by which a blood sample would be automatically rejected as unsuitable for sodium and potassium analysis?

YES / NO (please delete whichever does not apply)

If YES, could you describe these criteria? _____

2. Are you aware of any delays in the transportation of blood samples from general practitioners to your laboratory?

YES / NO

If YES, could you describe the reasons for these delays? _____

3. Are there any other factors which affect the processing of the blood samples for the Shared-Care Scheme by your laboratory?

YES / NO

If YES, could you describe these? _____

4. Finally, to assist us in costing the Scheme, do you have any idea of the cost to your laboratory of carrying out the analyses for the Scheme? An approximate cost per test would be sufficient. (I enclose a copy of the list of tests required).

Thank you for your help. Please return in the reply-paid envelope.

ORGANISING GROUP:

Professor A J Hedley Department of Community Medicine
Dr T S Murray Department of General Practice
Professor J L Reid Department of Materia Medica
Dr G T McInnes Department of Medicine

UNIVERSITY OF GLASGOW

**THE DESIGN, IMPLEMENTATION AND EVALUATION
OF A SHARED-CARE SCHEME FOR HYPERTENSION**

APPENDIX TWO

PRESENTED PAPERS

McGhee SM, Waller PC, Hedley AJ, Murray TS, Reid JL, McInnes GT
Shared-care for hypertension - the Glasgow experience
In 3rd International Symposium on Hypertension in the Community,
Tel-Aviv, December 1988.

McGhee SM, Symington EH, Jones RB, Hedley AJ, McInnes GT
Shared-care project
In Building Bridges, BJHC Books, Weybridge, Surrey
Presented at Healthcare Computing Conference, Harrogate, April 1989

McGhee SM, Hedley AJ, Jones RB, Symington EH, Murray TSM, Reid
JL, McInnes GT
**A computer-based shared-care scheme for hypertension in Glasgow:
feasibility and acceptability**
Lecture Notes in Medical Informatics, 40,. Ed O'Moore R, Bengtsson
S, Bryant JR.
Springer-Verlag.
Presented at Medical Informatics Europe, Glasgow, August 1990.

McGhee SM, Hedley AJ, Jones RB, Symington EH, Murray TS,
McInnes GT, Reid JL
**A cost-effectiveness analysis: shared-care compared with nurse-
practitioner and specialist clinics.**
In Proceedings of the first Hong Kong Medical Informatics Conference
Hong Kong, November 1990

McGhee SM, McInnes GT, Hedley AJ, Murray TS, Reid JL
Shared-care in Glasgow
Presented at the Annual Meeting of the British Hypertension Society
Dublin, June 1991 (in press)

McGhee SM, Kennedy S, Curzio J, Hedley AJ
**Sharing care for hypertension between general practice and specialist
clinics**
Workshop at the Anticipatory Care Team Conference, Nottingham,
September 1991

SM Harrigan = SM McGhee

SHARED-CARE FOR HYPERTENSION - THE GLASGOW EXPERIENCE

SMMcGhee, PC Waller, AJ Hedley, TS Murray, JL Reid,
GT McInnes

Glasgow Blood Pressure Clinic, Western Infirmary,
Glasgow G11 6NT, Scotland.

The objectives of this project are to evaluate the feasibility, acceptability and cost-effectiveness of different approaches to the long term follow-up of hypertension. Patients with previously well-controlled blood pressure have been randomised to general practice-based shared-care (n=278) or to conventional outpatient clinic care (n=278). A further group consists of patients attending a nurse-monitored clinic (n=300). The shared-care scheme is coordinated by a central computerised register and prompting system and supported by hospital facilities if required, including a re-referral clinic. All patients have blood pressure, serum biochemistry, urinalysis and ECG reviewed annually. This abstract reports preliminary experience (2 years follow-up) in the shared-care group. 85% of general practitioners accepted our invitation to participate and 94% of patients have been reviewed regularly. Reasons for failure of follow-up are mainly patient-derived. One general practitioner and 3% of patients have withdrawn. Completeness of the information available to the register is as follows: BP 100%, weight 79%, urinalysis 51%, serum cholesterol 90%, serum creatinine 96%, potassium 87%, urate 90%, blood sugar 89%, ECG 95%. These preliminary results indicate that a shared-care scheme for the long term follow-up of hypertension is feasible in an urban community. We are continuing to evaluate its acceptability to general practitioners and patients but initial findings are encouraging.

Shared-care project

Sarah McGhee

**Elaine Symington, Ray Jones, Tony
Hedley**

Health Informatics Group, Department of
Community Medicine, University of
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Gordon McInnes

Department of Medicine, Western
Infirmary, Glasgow

The potential uses of information technology (IT) are rapidly increasing with, for example, the development of flexible and comprehensive software for clinical computing,¹ new hardware such as the smart card,² and innovations in the uptake of computing such as the GP scheme.³ We need to be sure, however, that the use of such technology leads to cost-beneficial improvements in patient care. There are many examples, although few publicly reported,⁴ of computer systems that have been a waste of money.

Recurrent problems in the long-term management of chronic diseases include losses to follow-up, patient non-adherence to treatment, and duplication of work by specialists and GPs. Many problems stem from inadequate communication and lack of co-ordination. In particular, many patients may not be receiving follow-up care, while some may be followed up unnecessarily.

A shared-care scheme is an attempt to overcome these problems and to provide good quality care for patients through an appropriate balance of specialist and general practice provision, with a more cost-effective use of healthcare resources.

West of Scotland shared-care scheme for hypertension

In this scheme, set up as an evaluation study in July 1985, the roles of GP, specialist and patient are well defined and information flow between all participants is maintained via the registry. This is supported by a clinical information system providing custom-designed records, a register of patients and a series of protocols for their management.

The shared-care structure allows specialists to refer well-controlled hypertensive patients from outpatient clinics to general practice with confidence that they will remain under regular supervision and that they will quickly be offered specialist care if needed.

Regular information about their progress is included in hospital case notes and is available for the care of the individual in the future, and for evaluation of medical care and epidemiological research. The patient is given an important role in the system by initiating the consultations in general practice after prompting by the registry, and through being a record holder.

In the system, there are two formats of printed record: one for the specialist and GP, and one for the patient. Records are returned to the registry annually after the patient review, and all information is then transferred to the database that is used to produce the updated records. The specialist and GP record includes, on the first page, information on the patient's problems, treatments, personal details and habits, and a clinical flowsheet on the second page. The GP version is on two-part paper so that a copy is retained in the case notes until an updated version is received.

The patient's record is printed using a colour printer and is included within a booklet containing information about hypertension. It includes most of the information on the doctor's copy apart from some details that are censored according to an agreed protocol. As we have reported before,³ medical terms are translated by the computer, using a 'lay dictionary' so that patients will understand the record. Patients are encouraged to amend and use the record.

The Glasgow blood pressure clinic has long been supported by a computer system⁶ but this was not able to provide the facilities needed for this scheme. Instead, software developed for the Nottingham Diabetes Register⁷ was used as the basis for a system developed in MUMPS and running on a DEC Professional 350. Following the recommendations by the DHSIS for clinical computing in Scotland⁸, Greater Glasgow is developing new clinical systems in PICK LIBRA and this will include a new hypertension system incorporating the shared-care scheme. The new system should be available in the summer of 1989.

This system has been evaluated by a case-control study in which 273 hypertensive patients were followed up in shared care with their GPs, and 273 continued to be followed up in the outpatient clinic. The system has been evaluated in terms of feasibility, acceptability, and cost-effectiveness.

The system has been shown to be feasible in terms of patients being followed up, the required examinations being carried out, and the registry and computer system being able to produce the required documentation. For example, of those patients allocated to shared care, 96% were still being followed up after two years, only 2% had been re-referred to the clinic, 1% were being monitored by their GP without the use of the system, and 1% had moved away. Of the 96%, 3% had reviews that were overdue but these patients were still in regular contact with the registry.

In order to carry out an annual review comparable with that performed in the outpatient clinic, GPs are asked to provide samples for different kinds of analysis. Results obtained were over 90% complete for several key items (Figure 1). Of those items with 70-90% completeness, practical difficulties in obtaining and transporting samples seems to be the main cause of missing information. The result with only 52% completeness may indicate a low perceived importance by patients or doctors.

Evaluation of acceptability is still under way at the time of writing. GP participation has, however, been high, with 35% of those invited agreeing to participate and only one subsequent withdrawal. The cost-effectiveness of the system has not yet been examined but results will be presented in April 1989.

Figure 1

Completeness of information for those in shared-care	
>90%	Blood pressure (99%) Urea (98%) Creatinine (95%) ECG (94%)
70%-90%	Glucose (88%) Cholesterol (87%) Sodium (86%) Potassium (84%) Urate (84%) Weight (79%)
<70%	Urinalysis (52%)

The future

The inability of the outpatient clinic to provide adequate care for all patients with chronic disease has long been recognised⁹ and those receiving unsupported general practice care can be at risk¹⁰. A number of centres are tackling this problem by the establishment of various forms of shared care such as the one described here and others described elsewhere.^{11,12}

Furthermore, the shared-care approach with central register-supported care by GP has been shown to be more cost-effective for thyroid disease, with operational costs of less than 60% of the conventional alternatives.¹³ This shared-care scheme for patients with high blood pressure is certainly feasible, and appears to be acceptable, and by April we will know if it is cost effective.

For such schemes to be fully effective, an active population approach is needed to ensure full coverage of the population at risk. In the past, maintenance of population-based registers has not been easy; for example, in a study that used the Prescription Pricing Authority (PPA) to identify diabetics, we found that over-reporting for drug-treated diabetics was 13% by the PPA and 15% by the practice disease registers, while under reporting levels were 13% and 24% respectively.¹⁴ In Scotland, however, most health boards now have a computerised community health index and the general practice system (GPASS) is being widely implemented, offering the potential for more effective population-based registers. Even in England, the family practitioner committees are using their registers for population follow-up.¹⁵

There appears, therefore, to be considerable potential for using IT to institute methods of follow-up that are feasible, acceptable, provide good quality patient care and are cost effective. We should, however, continue to take a considered approach and to evaluate what we do. Otherwise, shared care, like community care, may become a bandwagon of political and commercial expediency.

Acknowledgements

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LOCALITY PLANNING

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**A COMPUTER-BASED SHARED-CARE SCHEME FOR HYPERTENSION IN
GLASGOW:
FEASIBILITY AND ACCEPTABILITY.**

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INTRODUCTION

In recent years, information technology has made possible new methods of health care which, without access to easy information collection, processing and printing, were previously difficult or impossible. One example is "shared-care" - a method of co-ordinating the care of individuals who have a condition requiring long-term follow-up, for The long term management of patients with a chronic condition like hypertension presents a number of problems for the health services. First, while life-long monitoring of all known hypertensives is desirable, the numbers involved are considerable. Second, for various reasons, a large proportion of patients are lost from regular follow-up. Third, in many chronic conditions although care should be provided jointly by both specialists and general practitioners; the need for monitoring has often resulted in many well-controlled patients being retained in the clinic for regular review while others in real need of specialist care must wait to be seen. Furthermore, a lack of co-ordination in the care provided by specialists and general practitioners for a "shared" patient can result in too many or too few investigations being carried out.

Shared-care attempts to overcome these problems by siting the regular follow-up of well-controlled hypertensive patients within general practice, maintaining contact with patients and general practitioners and co-ordinating all aspects of the patient's care. The method proved successful in thyroid disease using a batch-processing computer system (1). Later attempts to introduce shared-care for diabetes (2) and hypertension (3) have met with varying degrees of success. We have recently designed, implemented and evaluated a computerised shared-care system for hypertension in Glasgow.

THE WEST OF SCOTLAND SHARED-CARE SCHEME FOR HYPERTENSION

The Shared-Care Scheme was set up as an evaluation study in 1985 in the Glasgow Blood Pressure Clinic (GBPC). It is based on a registry with a computer management system designed to maintain communication between general practitioners, specialists and patients. The system is operated by a secretary who acts as a link between the participants. There are protocols for review, custom-designed records, a register of patients and prompts when patient review is due.

Specialists can refer well-controlled hypertensive patients from outpatient clinics to the Shared-Care Scheme; these patients then remain under the supervision of their general practitioner but will quickly be offered specialist care at a re-referral clinic if needed. General practitioners provide routine care and carry out an annual review identical to that in the outpatient clinic, returning the results of the clinical investigation to the registry. Blood biochemistry results and ECG are sent directly to the registry from the laboratory or ECG department. These annual results are screened by the specialist and, if required, advice is offered to the general practitioner. Regular information about the shared-care patient's progress is put into hospital case-notes and is therefore available for the care of the individual in the future, for the evaluation of medical care and for epidemiological research.

The patient is given an important role in the system by initiating the consultations in general practice after prompting by the registry and through being a record-holder.

Hardware and software: The hardware used to maintain the register and print the records is a DEC micro-computer with 10 Mbyte hard disc and two dot-matrix printers, one a colour printer. The software is written in MUMPS. Dictionaries are used to store problem and treatment list items; this standardizes the entries and facilitates identification of patient sub-groups. Furthermore, the inclusion of a "lay dictionary" allows medical terms to be translated into non-medical language for printing onto the patient's copy of the record.

Databases: Each patient has a record in the database containing personal details and clinical information. The data taken from existing patient records is verified and supplemented by a patient questionnaire. This record is updated any time new information is received with full updating once a year.

Records: Although only one set of data is held for each patient, three sets of records are printed - for patient, general practitioner and specialist. All participants can therefore contribute to, audit and share the same information. This reduces manual duplication of information and the consequent errors while ensuring that no set of records has missing information. The records are structured to assist the collection of relevant information, to display it conveniently and to allow easy updating when required. The records for general practitioner and specialist have the same format but the general practitioner's is printed on 2-part paper; this means that changes can be recorded throughout the year and the top copy returned to the registry with the bottom copy being retained until an updated record is received. The specialist's version on one-part paper can be put into the A4 hospital notes.

The patient-carried record contains a summary of the information printed on the doctor's record except for the results of clinical investigations and any item which either the patient or doctor do not wish printed on this copy of the record. Space is provided for recording blood pressure measurements, weight and targets. Each problem list item is printed with its lay translation underneath. A colour printer is used to make the record more attractive and it is produced in the form of a booklet which includes pages of advice on lifestyle (*Personal Health Booklet*).

Evaluation: The system has been evaluated by a controlled study in which 277 hypertensive patients were transferred from the GBPC outpatient clinic to shared-care and two comparable control groups of hypertensives were randomly selected, one from the outpatient clinic and one from a separate nurse-practitioner clinic. All three groups were monitored for two years. The shared-care system was evaluated for feasibility, acceptability and cost-effectiveness compared with these two alternatives. We report here on the feasibility and acceptability to

patients and general practitioners of the Shared-Care Scheme.

RESULTS OF THE EVALUATION OF THE SHARED-CARE SCHEME

Effectiveness: Of the 277 enrolled shared-care patients, 89% were still being monitored by the shared-care system after two years and a further 4% had been re-referred to the outpatient clinic. Excluding the dead, shared-care had a drop-out rate of only 3% (95% confidence interval 1-5%) over two years compared with 14% (10-18%) from the traditional clinic and 9% (6-12%) from the nurse clinic. Annual review results were recorded for 94% (91-97%) of the shared-care patients being monitored in year two compared with 81% (76-86%) and 89% (85-93%) recorded in the records of the outpatient and nurse-clinics respectively.

Completeness of information: Out of eleven clinical and laboratory variables, shared-care was as or more successful in obtaining complete results as the others except for weight. Slightly lower numbers of results for shared-care for serum sodium and potassium (86% versus 98% and 97% in the clinics) highlight some difficulties in the transport of blood samples from general practices to the laboratory in time for these biochemical analyses to be done. On the whole, however, laboratories reported no problems in carrying out analyses for shared-care. Approximately half of shared-care reviews required a reminder to the patient or the general practitioner; 60% of these reminders were to obtain some item of missing information from the general practitioner and 40% were to remind the patient to arrange a consultation.

Participation by general practitioners: The initial acceptance of the invitation to participate in the Scheme was 85% (251) of the 297 general practitioners asked; 85% of these general practitioners were based in Glasgow and appeared to be a representative sample of the whole Glasgow general practitioner population in characteristics such as gender, number of partners, postcode of practice, whether a training practice or a health centre. Those who participated were more likely to work from a health centre ($p < 0.05$). The modal number of patients per general practitioner was 1.0 (69% of general practitioners). During the two years, two general practitioners withdrew and twenty joined. At the end of the follow-up period, 61% of general practitioners wished to continue in the Scheme, 25% were unsure and 14% preferred not to continue. There were no significant differences between those who wished to continue and those who did not in the characteristics listed above.

Use of records by general practitioners: The medical record should be returned by the general practitioner to the registry each year; in practice, 56% of records were returned as requested but 25% of review results were accompanied by the patient's Personal Health Booklet only and 17% had no record returned at all. The patient's Booklet was liked and thought to be useful by the majority of general practitioners and 85% were happy to have it sent directly to their patients.

Advantages and disadvantages of shared-care to general practitioners: The main advantages quoted by general practitioners were: less loss to follow-up (15 comments), better communication (7 comments), greater confidence in treatment for patient and general practitioner (6 comments), up-to-date information (5 comments) and more patient involvement (4 comments). Main disadvantages quoted were: difficulties in practice organization (12 comments), increased workload (10 comments), extra paperwork (8 comments), and interference with the general practitioner's responsibility (3 comments).

Participation by patients: Four patients were withdrawn from the Scheme on their own request. When asked for their preference, 44% of shared-care patients preferred shared-care and 21% had no preference but 28% preferred clinic-based care.

Use of records by patients: 73% of the Personal Health Booklets were returned at the annual review for updating; 36% of these had changes recorded and 92% had been used for recording blood pressure and weight. Only 4% of 170 patients who replied to a questionnaire did not like having a Personal Health Booklet while 62% found it useful, for example, as a reminder of advice and treatment details (26 comments), as a source of motivation (24 comments) and as a medical record when away from home (15 comments).

DISCUSSION

From the above results, it would appear that computer-based shared-care is a feasible method of follow-up for well-controlled hypertensive patients in an urban environment. Well over half of the local general practitioners are likely to support such a scheme and, for their patients, it provides an effective method of ensuring regular review and updating of hospital and general practitioner records. Both patients and general practitioners perceive benefits from such a method of follow-up. Nonetheless, some of the results point to areas in which we must continue to make progress if even more patients are to benefit from the application of new methods of care and information technology in health care.

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A COST-EFFECTIVENESS ANALYSIS: SHARED-CARE COMPARED WITH NURSE-PRACTITIONER AND SPECIALIST CLINICS

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ABSTRACT

Information technology has made possible new forms of care such as shared-care, which is a method of co-ordinating the care of individuals who have a condition requiring long-term follow-up between general practitioners and specialists. It is, however, essential to evaluate new systems and to compare their effectiveness, acceptability and cost with the methods which they replace.

The West of Scotland Shared-Care Scheme for Hypertension was set up in 1986 to provide shared-care for well-controlled hypertensive patients attending an outpatient specialist clinic. The Scheme was examined for feasibility, for acceptability to patients and doctors and for cost-effectiveness compared with two alternatives namely, a specialist outpatient clinic and a nurse-practitioner clinic. This paper describes the methods used to carry out the cost-effectiveness analysis and the principal results.

The measure of effectiveness used was the number of patients who had a complete review carried out in one year of the study period. The costs measured were all variable costs to the patient and to the health service, that is, the costs which increase as the number of patients increase.

Briefly, the results showed that the Shared-Care Scheme is more cost-effective than the specialist outpatient clinic in ensuring patient review. The cost-effectiveness of the Shared-Care Scheme and the nurse-practitioner clinic is approximately the same; however, the nurse-practitioner clinic costs the health service less while the Shared-Care Scheme is less costly to the patients.

INTRODUCTION

Information technology has made possible new forms of care such as shared-care which is a method of co-ordinating the care of individuals who have a condition requiring long-term follow-up. The care of these individuals is shared between general practice and specialist clinics to an extent which is determined by apparent clinical need. The use of computerised systems for storing registers of patients, clinical details and protocols and for producing prompts, labels, letters and differently formatted sets of records has greatly eased the

administration of shared-care and thus made it possible in several places in the UK and for several chronic conditions. For example, this approach has been successfully applied to thyroid disease, diabetes and hypertension.

It is, however, essential to evaluate new methods of care and to compare their acceptability, effectiveness and cost with the methods which they replace. This is not always easy, especially since the effect on health may not be apparent for some time and many other factors can have an important effect on health outcome. However, it is possible to use process outcomes (measures of the amount and quality of care delivered) as a basis for a cost-effectiveness evaluation over a relatively short timescale, provided that each method aims to deliver the same type of care; the outputs on which the assessment of effectiveness is based should be identical although they may differ in magnitude. If the process of care has a beneficial effect on health, we can assume that a method which is cost-effective in delivering care will also be a cost-effective means of improving health. This paper describes the cost-effectiveness evaluation of the West of Scotland Shared-Care Scheme for Hypertension. The feasibility and acceptability have been previously reported [1].

METHODS

554 people who attended the Glasgow Blood Pressure Clinic and were considered by their specialist to have well-controlled blood pressure were matched for age, sex and length of attendance at the clinic and randomly assigned to the Shared-Care Scheme (SC) or continuing attendance at the clinic (BPC). These two groups were monitored for two years. A further matched group of 277 people who attended a separate nurse-practitioner clinic (NPC) was also monitored. The protocol for each clinic and for shared-care demanded that each person have an annual review consisting of a set of specified investigations. The effectiveness of the clinics and shared care was defined as the percentage of individuals from the original group (minus those who died) who had an annual review in the second year which included at least a blood pressure check, a serum creatinine result and an ECG. As far as possible, the effects of each method on health-related indices such as blood pressure and serum biochemistry results were monitored to ensure that, over the two years, no method appeared clearly superior or inferior to the others.

The variable costs of each method to the health service and to the patient were calculated or obtained from published sources; these included medical, nursing and secretarial staff costs, laboratory tests, postage, telephone, patient travel, time and companion costs. Patient questionnaires supplied details about patient cost, the staff resources used in each clinic were observed and general practitioner time was estimated but subjected to a sensitivity analysis. The total cost of follow-up in each group was obtained by multiplying the number of consultations and investigations for each patient by the calculated cost of each type of contact. The cost-effectiveness ratio was then calculated as the total cost per satisfactory review in year two of the follow-up.

RESULTS

Effectiveness of follow-up

Table 1 shows that, by the second year of follow-up, shared-care was more effective than either of the clinics in ensuring a satisfactory review.

TABLE 1: Effectiveness of follow-up

	SC	BPC	NPC
Number alive in year 2	267	270	270
Still attending	258(97%)	232(86%)	245(91%)
Satisfactory review in year 2	220(82%)	146(54%)	202(75%)

Cost of follow-up

On average, the SC patients visited their general practitioner 1.1 times a year more than the BPC group. These extra visits are assumed to be due to shared-care. The SC group made an average of 0.3 clinic visits per year compared with 2.1 and 1.9 for the BPC and NPC groups respectively.

The average cost of a BPC or SC clinic visit was calculated as 466(HK)\$ (assuming 14 HK\$ to the pound) of which 255\$ was cost to the health service and 211\$ to the patient. The average cost of an NPC clinic visit was 359\$ of which 218\$ was cost to the health service and 141\$ to the patient. The cost of a SC general practitioner visit was 344\$ of which 257\$ was cost to the health service and 87\$ was patient cost. The estimate for general practitioner time (20 minutes) is deliberately very generous because sensitivity analyses showed that the length of the general practice consultation had a large effect on the cost to the health service of a SC visit. The estimated cost of the SC general practice consultation is therefore a maximum cost. These estimates were used to calculate the total variable costs to the health service and to the patients in each group.

Total variable costs and cost-effectiveness

The costs and measures of effectiveness are summarised in Table 2. The resulting cost-effectiveness ratio for SC is almost half that for the BPC and just less than the NPC.

TABLE 2: Costs and measures of effectiveness

	SC	BPC	NPC
Total variable cost (HK\$)	88915	108137	87840
Effectiveness (no. of satisfactory reviews)	220	146	202
Cost-effectiveness ratio (CER)	404	741	435
CER (health service costs only)	302	406	264
CER (patient costs only)	102	335	171

Effect of each method on health

Over the last two years, no deterioration in blood pressure control or serum creatinine was detected in any group. Patients in all three groups reported similar levels of self-perceived health before and after the follow-up.

DISCUSSION

It can be difficult to estimate whether an alteration in the method of care is a cost-effective option. However, carrying out the above analysis has allowed us to say with confidence that shared-care is overall more cost-effective than the BPC in the delivery of care to these well-controlled patients and is similar in cost-effectiveness to nurse practitioner care. Moreover, shared-care has achieved a higher level of effectiveness than the clinic-based methods.

By discriminating, in this way, between the types of costs incurred, we can see that the major savings are for the patient in the case of shared-care and for the health service in the case of nurse practitioner care.

This analysis focuses on only one outcome measure, satisfactory review. There are other benefits of each method of care which have not been measured. However, continuous follow-up of well-controlled hypertensive patients was a principal objective of each of the methods of care studied. By carrying out this analysis, we can now ensure that resources available for this purpose are put to their most cost-effective use.

REFERENCE

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**THE DESIGN, IMPLEMENTATION AND EVALUATION
OF A SHARED-CARE SCHEME FOR HYPERTENSION**

APPENDIX THREE

MEDICAL RECORDS USED IN THE STUDY

- 1. Doctor's record**
- 2. Personal Health Booklet/patient-held record**

MR JOHN PATIENT
193 GLASGOW STREET
GLASGOW

REF: XR123456
NHS NO:

PROBLEM LIST

DATE RECORDED

G22 4RF
TEL : 123 4567

AGE 65 (24/08/26)
OCCUPATION:
POSTMAN
GP:DR MURRAY

Active
HYPERTENSION 1971
CARDIOMEGALY 1982
LEFT VENTRICULAR HYPERTROPHY 1982
+ STRAIN

FAMILY HISTORY

MOTHER dead(MI)-not hypertensive
FATHER dead(CVA)-hypertensive
SIBLINGS 3 : 1 hypertensive

SMOKING HABITS

Ages	Material	Amount/week
0 - 18	none	
18 - 60	cigs(unspec)	71-140

Inactive
APPENDICECTOMY 1932

DRINKING HABITS

Type	Frequency	Total/week
Wine	< 1 /week	1 units

PREVIOUS TREATMENTS

Treatment	max daily dose	start/stop
BENDROFLUAZIDE	5mg	FEB87/MAR87

Not on patient held record
ANTI-NUCLEAR FACTOR 1986
SLIGHTLY POSITIVE

PROBLEM CHECKLIST

Please tick any of the following which have occurred and are not listed above
Please ring A for active and I for inactive and add date.

CURRENT TREATMENTS inc OC PILL + NSAIDs

Name	daily dose	start
ATENOLOL	100mg	MAR87

<input type="checkbox"/>	Cerebrovascular accident	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Myocardial infarction	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Ischaemic heart disease	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Symptomatic anqina	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Peripheral vascular disease	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Renal disease(specify above)	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Airways disease	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Diabetes	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Overweight	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Anxiety	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Social/psychiatric problems	A	I	<input type="checkbox"/>
<input type="checkbox"/>	Drug sensitivity	A	I	<input type="checkbox"/>

MR JOHN PATIENT, 193 GLASGOW STREET

XR123456

DATE	21AUG87	20SEP88	18SEP89
BLOOD PRESSURE *			
systolic	130	138	120
diastolic	88	90	90
WEIGHT (kg)	92	93	89
	14st 8lbs	14st 10lbs	14st 11lbs
HEIGHT (cms)	160	160	160
	5ft 3ins	5ft 3ins	5ft 3ins
URINE			
glucose	-	-	-
protein	-	-	-
blood	-	-	-
BLOOD (latest)	AUG87	SEP88	SEP89
sodium	140	143	141
potassium	4.2	4.2	4.3
urea	4.8	4.0	4.4
creatinine	96	92	98
urate	.36	.38	.37
cholesterol	6.5	5.9	6.0
sugar	6.6	5.7	6.2
E C G			
date	AUG87	SEP88	SEP89
report	LVH+strain	LVH+strain	LVH
SYMPTOMS			
eq dyspnoea on effort, oedema (please update)			
TREATMENT			
COMPLICATIONS (please indicate whether each complication is still present and name suspected drug)			

* Note: Diastolic blood pressure should be phase V (disappearance of sound) measured in the right arm with a mercury sphygmomanometer and with the patient seated; otherwise please state.

Personal Health Booklet

WEST OF SCOTLAND

SHARED

CARE

SCHEME

FOR HYPERTENSION

The following pages contain details of your blood pressure, weight, medicines and the illnesses you have had. If you do not fully understand anything or would like more details, please ask your family doctor.

Please take the booklet with you whenever you visit the doctor. There are spaces in the middle for writing your blood pressure and weight. If your treatment is changed, please make the changes in your booklet or ask your doctor to do this for you. Please also write down any medicines which you have bought yourself.

Once a year we will send you a letter reminding you to visit your family doctor and asking you to take this booklet along with you. Please answer the questions on the last blue page before you go. Your doctor will send the booklet back to us and we will send you a new one very quickly.

MR JOHN PATIENT
193 GLASGOW STREET
GLASGOW

REF: XR123456
NHS NO:

DOB: 24/08/26
OCCUPATION:
POSTMAN
GP: DR MURRAY

G22 4RF
TEL : 123 4567

SMOKING HABITS

Ages	Material	Amount/week
0 - 18	none	
18 - 60	cigs(unspec)	71-140

DRINKING HABITS

Type	Frequency	Total/week
Wine	< 1 /week	1 units

FAMILY HISTORY

MOTHER dead(ht.attack)-no HBP
FATHER dead(stroke)-with HBP
BROTHERS 2 : 1 HBP?
SISTERS 1 : none with HBP?

MEDICAL HISTORY

DATE RECORDED

Present

HYPERTENSION	1971
(HIGH BLOOD PRESSURE)	
CARDIOMEGALY	1982
(ENLARGED HEART)	
LEFT VENTRICULAR HYPERTROPHY	1982
(THICKENED HEART MUSCLE)	

Previous

APPENDICECTOMY	1932
(REMOVAL OF APPENDIX)	

BLOOD PRESSURE RECORD

Date

BP

Target BP

BLOOD PRESSURE RECORD

Date

BP

Target BP

CURRENT MEDICINES

Medicine	daily dose	start
ATENOLOL	100mg	MAR87

PAST MEDICINES

Medicine	max dose	dates
BENDROFLUAZIDE	5mg	FEB87/MAR87

Please answer the following questions just before your next annual review:

1. Have you read the blue pages?
YES / NO

2. Is anything incorrect?
YES / NO

If YES, please change your booklet.

3. Has anything been missed?
YES / NO

4. Is anything printed there which you agree with but would prefer not to have printed in your booklet?
YES / NO

If YES, please cross it out.

For further information or advice please write or telephone:

THE SHARED-CARE SCHEME
GLASGOW BLOOD PRESSURE CLINIC
WESTERN INFIRMARY
GLASGOW G11 6NT

041-339-8822 ext.4510