THE CONSUMER CHALLENGE IN THE NHS:

the development and application of new approaches to obtain and compare lay and professional views on the quality and need for services.

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Thesis submitted to the Faculty of Medicine of the University of Glasgow
for the degree of Doctor of Philosophy
April 2001

Dedicated to Hugh for his tolerance

ACKNOWLEDGEMENTS

I am indebted to several hundred people who have helped and guided me through the course of the studies that form the basis of this thesis. The majority of these people lived and/or worked in Ayrshire & Arran and helped in the construction and application of the research tools. Whilst some may no longer be alive, I would, nevertheless, like to thank the patients in the long-stay wards for the elderly who generously gave their time and allowed me to interview them. I am equally indebted to the members of the public and service providers who agreed to be interviewed. I am additionally grateful to the service providers who recruited their colleagues to be interviewed.

My gratitude and respect are also extended to my two distinguished supervisors, Jim McEwen and Rex Taylor. Each has contributed to the development of the theoretical context for this work by identifying deficiencies and flaws in my arguments. Above all else, I am grateful for their patience at times when I have struggled with the competing demands imposed by short-term contracts of employment. Without their patience and encouragement, it would have been even more difficult to bring this work to a conclusion.

I am also grateful to my good friend, Graham Watt, who taught me the skills of my trade and who, together with my family, ‘embarrassed’ me into completing this work.

Finally, I would like to thank three statisticians, Graeme Hutcheson, Harper Gilmour and Alex McConnachie, who at various times have provided advice on the analyses of the data.

FOREWORD

" The NHS was formed in 1948, when the consultant was king. Well, we live in a different century now and it is the consumer who is king and the NHS has got to reflect this"
(Alan Milburn, Health Secretary, speaking on BBC television 'Breakfast with Frost', 4 June 2000).

This declaration by the present Health Secretary was set in the context of an acknowledgement of recent reports of health service management that permitted practices within the National Health Service (NHS) that *"tarnish the reputation of the whole medical profession"*. Whilst not referred to directly, these practices are likely to include those which have sustained media attention such as the removal and storage of organs from dead babies without parental consent, and the failure to protect women from undergoing surgical interventions despite compelling evidence of the clinical incompetence of the surgeon. The extent to which the Health Minister believes that patient sovereignty in the NHS will address or eradicate such concerns is not clear. However, within the context it was made, the comment does suggest that it would have some part to play in improving the management and/or delivery of services.

Despite the flourish of publicity that has accompanied the Health Minister's comment, the notion of consumer sovereignty cannot be described as revolutionary. Indeed, throughout the 1980s and 1990s, the new role for patients as consumers was consistently promoted by the previous Conservative administration as part of its marketing strategy for public services. Whilst the tactics employed by opposing political parties to affect change may differ, there is little doubt that a consensus has been reached concerning the promotion of consumer power in the NHS. But there is also little doubt that this agenda has still to be translated into action.

The absence of progress in defining the role of the consumer raises a number of questions. For example, do consumers of health services have sufficient knowledge to make decisions on the provision of health services and, if so, do they want this responsibility? Also, do health professionals believe that consumers can make such decisions and, if so, are they happy to relinquish this responsibility? More pragmatically, is it known whether or not there are differences between the views of professionals and consumers? To address this question methods are required for assimilating consumers' views so they can be compared and contrasted with those of professionals.

The studies on which this thesis is based were undertaken as part of a programme of service evaluations and health needs assessments funded by Ayrshire & Arran Health Board. Within the context of this work, I have sought to undertake a methodological study with the aim to develop methods to determine if there are differences between the views of service providers and service users or the general public. These methods are applied in two studies. The first focuses on the quality of service delivery and the second addresses the broader issue of the nature of service provision.

This work was undertaken during the first half of the 1990s, almost a decade after I had left the NHS as a nursing sister in a cardiothoracic intensive care unit to work and train in the field of epidemiological research. The intervening period coincided with many developments that promoted consumer sovereignty in the NHS. The studies were carried out before the impact of devolution, but there have always been some differences in health care policy and organisation between Scotland and the rest of the United Kingdom. Where relevant, these are highlighted throughout the thesis.

Against the background of my clinical experience in an intensive care unit, where patients were passive and completely relied on the decisions of professionals, the notion of patients as consumers was not immediately apparent to me. To better understand this transition, I set about tracing the roots of consumerism and charting the progress of initiatives that have promoted a consumer-orientated culture. I have also sought to determine the extent to which these initiatives have been reflected in the NHS. The results of this exercise provide the theoretical context for this thesis and the rationale for the approaches adopted in the empirical studies on which it is based. Throughout the thesis the challenge to the NHS in adopting a consumer-orientated approach is explored.

Chapter 1 describes the historical background to the emergence of the consumer voice in relation to industrial management techniques and relates these to similar developments in the NHS. Within this context the potential for consumers to challenge the nature of service provision in the NHS is explored.

Chapter 2 describes the historical background to the rise of consumerism and how this impacted on publicly funded services, particularly the NHS. Within the context of the consumer movement, the potential for consumers to challenge the nature of service provision in the NHS is explored.

Chapter 3 reviews the literature on consumer evaluations of the quality of health services and public assessments of the need for health services. The extent to which the NHS has embraced the challenge of developing a consumer-orientated culture is then assessed.

Chapter 4 describes the background to this programme of research and states the aims of each of the studies.

Chapter 5 reviews the range of methods that can be used to obtain the views of consumers on the quality of services. The strengths and weakness of different approaches are highlighted, providing the rationale for the choice of methods for the present study. It describes the development of methods and reports the results of their application.

Chapter 6 reviews the range of methods that can be used to obtain the views of the public on the need for services. The strengths and weakness of different approaches are highlighted, providing the rationale for the choice of methods for the present study. It describes the development of methods and reports the results of their application.

Chapter 7 summarises the results of the empirical research on consumer views on service quality and public views on the need for services. The relevance of the findings is discussed in relation to (a) the existing literature on organisational management theory, consumerism, and consumer/public consultation and (b) methodological issues. Throughout these discussions, the political and organisational implications for embracing a consumer approach are explored.

Chapter 8 draws conclusions and makes recommendations in relation to political, organisational and methodological developments to promote a consumer-orientated culture in the NHS.

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I. CONSUMER VOICE: THEORY, POLICY & PRACTICE

1. ORGANISATIONAL MANAGEMENT THEORY AND THE CONSUMER VOICE

This chapter describes the historical background to the emergence of the consumer voice in relation to organisational management techniques and relates these to similar developments in the National Health Service (NHS). Within this context the potential for consumers to challenge the nature of service provision in the NHS is described.

1. Overview of Management Theory

People who have managed organisations have been concerned with increasing productivity, improving performance, and learning new and better ways to accomplish objectives. In pursuit of these aims they have, at various times, focused their attention on different characteristics of organisations - ie technical, administrative and institutional.

Historically, attention first focused on technical issues such as, how to accomplish individual tasks or pieces of work more rapidly and efficiently. Subsequent research and management attention related to administrative issues such as, how the whole organisation, rather than each individual, could become more productive. Then the focus broadened again to encompass the organisation as an institution that is influenced by its environment. However, each new organisational theory and the management systems it informed did not totally supersede what had gone before. Watson's image of waves usefully describes this notion of past ideas co-existing with their would be successors:

> *"Waves do arrive on the shore one after the other but the impact of each one does not replace the impact of what came before. Every wave both collides with its predecessor and combines with it. And the pattern that is left is rarely a neat one and it is never predictable"*
>
> (Watson 1986).

The Focus on Technical Issues

The first wave of organisational theory was concerned with technical issues involving production systems and the problem of how to increase efficiency. After the Industrial Revolution hand tools were replaced by machines and the development of interchangeable parts allowed mass production. Work became fragmented; each person did a small portion of the job and passed it on. Masters of their craft and apprentices were replaced by supervisors and labourers. This led to the need for greater supervision, work-study and monitoring of work done by others.

Systematic attempts to determine the best way of doing a job and specify the skills required to perform it were characteristic of scientific experimentation and theory testing. The term scientific management was introduced by Frederick W Taylor, an American mechanical engineer, who is considered the pioneer of this development and of time and motion studies.

He observed that whilst managers had clear expectations of the output of machines, they were uncertain of the expected output of workers. His system of Scientific Management for organisations was based on the following premises:

- there is only one right way to perform a task and that specialist industrial engineers should plan work methods to the very last detail;
- workers only work for economic reward (ie there was no other motivation to work) and differential piecemeal schemes that reward effort should be the basis of payment; and
- in terms of organisation, line and functional specialisation was optimal.

(Taylor 1911).

Taylor was given the opportunity to test his ideas in the steel industry. He simplified the job of steel workers into its most basic form; redesigned equipment and the layout of the shop floor; trained workers in the 'best way' of doing the job; and used financial incentives to motivate workers. The result of this early experiment was a 362% increase in production against 61% increase in wages through the incentive payment system.

The best known example of widespread implementation of 'Taylorism' occurred in the motor industry where Henry Ford extended Taylor's 'robotising' of the worker by placing him on the assembly line. Components for sophisticated technological products were made by workers who required minimum training and who, due to the repetitive nature of their task, became skilled rapidly. Like cogs in the machine, each worker had a particular task and the speed and quality of that task could be inspected and controlled. Moreover, workers were expendable since replacements could be easily trained.

Taylor's influence was significant in the organisation of work; assembly lines dominated not only manufacturing but also service industries and office work. An example of its application can be seen in the fast food service industry, which can provide a consistent, standardised product and service using staff with very limited skills. Taylorism in the office was achieved by the same means; fragmentation, standardisation and control. This system logically lends itself to organisations that process large quantities of routine data. For example, each worker receives a set of documents in an in-tray, carries out designated and controlled tasks and then places the documents in an out-tray indicating the next step in the paper processing job.

Critics of the Scientific Management Systems, particularly advocates of the Human Relations School of Management, claim that the impact of bureaucracy and rationalisation is not satisfying for the individual employee. Indeed, there was high turnover of labour in the Ford assembly. This was countered by a guarantee of a high wage - the famous *$5 Day* for which the worker had to have six months continuous service.

Widespread adoption of scientific management occurred during the First World War when the need for speed and efficiency became paramount. There was a comparative lull during the Great Depression of the 1930s when there was little money for equipment and developing production lines and a further surge during World War II. The subsequent introduction of automation and computer assisted design and analyses have enabled managers to further streamline the production process.

The Focus on Administration

Around the same time that Henry Ford was improving technical efficiency, Henri Fayol, a French mining engineer, was devoting his attention to improving the efficiency of the administration of organisations. He argued that the success of an organisation depended as much on the effectiveness of its managers as on the skills of the individual worker or engineer. He produced a practical guide for managers that included the following principles of administration:

- *Unity of Command* - everyone should have only one boss.
- *Unity of Direction* - there should only be one manager and one plan for all operations of the same type.
- *Centralisation* - the number of managers employed should reflect a balance between the need to be accountable and the need to delegate authority and responsibility.
- *Hierarchy and Communication* - lines of authority and communication should run from the top to the bottom of the organisation in straight lines.
- *Subordination* - the goals of the organisation take prominence over those of the individual worker.
- *Order* - there is a place for everything and everything should be in its place.
- *Equity* - workers should be treated in a friendly and fair manner.
- *Remuneration* - payment should be an incentive to perform.
- *Stability of Staff* - long term commitment from staff should be encouraged.
- *Initiative* - workers should be encouraged to plan and execute tasks.
- *Esprit de Corps* - the morale of the workers should be cultivated.

(Fayol 1949, original 1916).

Whilst Fayol concentrated on the role of the manager, Max Weber, a German academic, focused on the structure of the organisation. He believed that the ideal typical bureaucracy represented the most efficient type of organisation in which individuals gave and received orders underpinned by a rational system of rules. The defining characteristics of Weber's ideal type of bureaucracy were:

1. There is a pyramid shaped organisation hierarchy in which superior offices control lower ones, like a military command structure, with no horizontal lines of communication across levels.
2. Individuals are appointed to offices on the basis of their expertise, certified by written qualifications and not, for example, because they are personable or through nepotism.
3. The work of each office is conducted on the basis of precise rules and regulations; each worker and client is fairly and equally treated with no hint of favouritism.
4. Ownership is divorced from control, with power deriving entirely from the occupation of an

office. All tasks in the organisation are assigned to various 'positions' in the form of official duties, usually made explicit in the job description for that role - ie the duties are not directly given to the individual, but to the job position that the individual holds.

5. Free contractual relationship between organisation and its officials.
6. Written records of all important transactions.
7. The complete separation of official activity from the private, personal and emotional lives of the officials so that personal friendship or animosity would not take precedence over the good of the organisation and the achievement of goals.
8. A system of promotion and careers based on the combination of seniority and achievement.

(Weber 1968)

Weber predicted that all organisations would move towards this ideal type of bureaucracy in search of greater efficiency.

Subsequent approaches to management systems were developed for idealistic as well as pragmatic reasons. For some, the mechanisation of the worker was simply considered to be bad or morally wrong whereas others believed that it was impractical or inappropriate. Academics, inspired by concern to improve the human lot, criticised the dehumanising potential of employment and advocated alternatives to rationalised work patterns and the use of crude methods of motivation. Amongst those with pragmatic concerns were people who believed that the cost in terms of quality of work, labour stability and flexibility, and industrial relations would outweigh the short-term benefits of increased efficiency of this approach.

Elton Mayo, a clinical psychologist at the Harvard Business School, is mainly remembered for the famous Hawthorne experiments (Mayo 1933, 1949). In 1927, Mayo and colleagues were invited by the Hawthorne factory of the Western Electric Company in America to identify factors that had an impact on productivity. In an earlier in-house investigation on the effect of the level of illumination on productivity, the initial observation of a direct effect was confounded when productivity increased further when the level of illumination was kept constant or even decreased. The data generated in the subsequent studies are so rich that they are still subject to different theories and interpretations. However, the main points that emerged were that paying attention to employees has a positive effect on productivity, and that subjective factors such as attitude and morale appeared to be more important than objective factors such as temperature or level of illumination. Mayo and his followers established the field of industrial social psychology which was promoted during World War II, at the end of which, related fields such as group training and leadership selection began to flourish.

Major contributions were made after the war by those who were influenced by the work of Abraham Maslow. His initial interest was clinical, in the relationship between human needs and behaviour. He argued that needs are genetic and instinctive in nature, and that it was possible to categorise them in a hierarchical order (Maslow 1943). The first category related to *physiological needs* such as for food, drink, sex and sensory satisfaction. The second were *safety needs* which motivate people to avoid danger. The third were *love needs* which include the need to belong and to affiliate with others. The fourth were *esteem needs* which include prestige, status and appreciation. The fifth were needs which relate to *self-actualisation* or the desire to achieve one's ultimate potential. The basis of his theory is that only unsatisfied needs act as motivators and, that once a person satisfied his needs at one level, the next level of unsatisfied needs will manifest itself and motivate him to fulfil it. Although this hierarchy of need was not developed with the motivation to work in mind, 'Maslovian' ideas appealed to those with a humanistic cause and were translated for management practice.

Douglas McGregor, on the basis of his own experience, highlighted basic assumptions held by managers about the nature of subordinates. These assumptions which are known as Theory X and Theory Y, were based on the opposing views

- that workers are inherently lazy and need to be driven and, alternatively,
- that they are creative and should be given responsibility.

(McGregor 1960)

Managers who hold Theory X believe that subordinates dislike work and avoid it if they can. They believe that workers have limited ambition, avoid responsibility, prefer supervision and see security as a priority. Consequently managers must make people work either by threats (dismissal or disciplinary action) or inducements (manipulation, bonuses, or promotion). Under Theory X, managers will control work and closely supervise its completion. There are many similarities between these views and those of Taylor and other proponents of scientific management. McGregor argued that whilst workers' behaviour often supports the assumptions of Theory X, it occurs not because they have these basic qualities but because the very nature of organisations and management make it difficult for them to operate in any other way. In other words, there is a tendency for self-fulfilling prophecies to occur in individual motivation.

Managers who hold Theory Y believe that people are naturally active and enjoy work. They assume that people do want responsibility and are keen to work to their full potential. To do this, workers require to be integrated into the organisation so that their own goals are successfully married to those of the organisation. Under Theory Y, managers will be less like an authority figure but more like an enabler. McGregor argued that if workers were allowed to work under these conditions the organisation would benefit as the full potential of their talents were realised and that on an individual level, the worker would be more satisfied as the 'Maslovian' higher level need for self-actualisation would be met.

Frederick Herzberg, who was also influenced by Maslow's hierarchy of human needs, developed the motivation-hygiene or two-factor theory of work motivation (Herzberg 1966, 1968). The basis of this theory was a study of 203 Pittsburgh engineers and accountants who were interviewed to ascertain the incidents that caused satisfaction and dissatisfaction at work. Content analysis revealed that the factors that caused satisfaction at work were quite different from those that caused dissatisfaction. Factors associated with dissatisfaction were called *hygiene factors* and included company policy, salary, status, security, working conditions and supervision. Factors associated with satisfaction were called *motivators* and these included achievement, recognition, work itself, responsibility, advancement and growth. Herzberg concluded that job satisfaction and dissatisfaction were not the opposite extremes of the same scale but two quite different measurements. In other words, hygiene factors if absent caused dissatisfaction, however, their presence did not produce job satisfaction. Motivators as well as hygiene factors had to be present before job satisfaction was achieved. These motivators clearly relate to Maslow's higher order needs whereas hygiene factors relate to lower order needs.

Critics of the Human Relations movement claim that too much emphasis is placed on the human factors of individuals at the expense of maintaining the clear and efficient work patterns of the rational model. In extreme cases, management's preoccupation with maintaining a happy workforce resulted in losing sight of the primary goals or functions of the organisations.

Chester Barnard, a successful businessman, recognised the need for workers to realise their needs for self esteem, but he focused on the critical role of the executive as the shaper and manager of shared values in an organisation (Barnard 1938). Unlike the scientific approach to management, Barnard did not see the manager as an external operator of the organisational machine through a system of rewards and sanctions. In his view the manager is part of organisation whose role is to strive to achieve a state of equilibrium between the rationalistic aspects of organisation structures and the limited or bounded rationality of individuals who have to be induced to work towards organisational goals. He identified the essential functions of the executive as providing systems of communication; promoting and securing essential efforts; and formulating and defining purpose. Barnard's important contribution to the development of organisational theories was his stress on the organisation as a whole and the manager's role as the promoter and communicator of shared values. He became an inspiring figure for the subsequent institutional wave of organisational theory.

Whilst Barnard clearly identified the role of the manager in ensuring harmony between human relations and organisational structures, systems theorists concentrated on the relationship between the technical and social components of the organisation and advocated that the overall system should be designed so that there is a marriage between the two. As in most marriages, the success of the relationship lies on the ability of the individual components to adapt to each other.

The principles of socio-techno system theorists was clearly illustrated in the work of Eric Trist and colleagues who attempted to ascertain why technical innovations introduced to post World War II British mining companies failed to yield expected levels of job satisfaction or levels of productivity (Trist et al 1963). This study showed that the work patterns that had been designed to accommodate the new machinery changed the traditional shift patterns and role potential of the workforce. Redesign of the use of the machinery resulted in the reinstatement of some of the social and cultural roles preferred by miners. In effect, the researchers had demonstrated that there was no *one best way* to perform a job and it was possible to achieve the desired output by ensuring the best possible fit between the technical and social components. In other words, concepts from Scientific and Human Relations schools were recognised but neither was utilised at the expense of the other. The system concept of management helped managers re-conceptualise the organisation's activities as a series of interdependent components and introduced terminology such as, inputs, process, outputs, subsystems and feedback in the management of organisations.

A number of studies conducted since the late 1950s examined the extent to which successful organisational structures were determined by prevailing circumstances of contingencies. Joan Woodward's study of one hundred manufacturing firms in Essex found that companies involved in more complex technologies were more successful when the hierarchical structure was tall and narrow whereas those of successful traditional and craft producers had short and squat administrative profiles (Woodward 1965). This study concluded that the production process determined the administrative style.

A further series of studies conducted during 1970s by British (Child and Mansfield 1972) and American (Blau and Schoenherr 1971) researchers have shown a positive correlation between the complexity of bureaucracy and the size of the organisation.

Whilst system and contingent theories were a significant developments to the understanding of organisations, they remain limited in terms of their myopic vision that organisations exist as discreet entities that are not affected by, or need to adapt to, external influences. For example, it could be argued that the differences found in Woodward's study related as much to the need for companies with complex technological orientations to respond to a relatively new and changing market and that market forces determined the administrative structure.

The Focus on the Institution

The third wave in organisational theory addressed these shortcomings by focusing on the combined technical and human aspects of work and how they, as a system, fit, or adapt to, their environment. This approach viewed the organisation as an institution designed to meet the needs of society. With such an approach, organisations are required not only to review how intrinsic factors, such as inputs and process, relate to output but also to review how outputs relate to the organisational goals and how these, in turn, relate to extrinsic factors such as, social, political and economic forces.

On both sides of the Atlantic the importance of external influences on the structure of organisations was identified. Burns and Stalker (1961) and Chandler (1962) found that where the business environment was relatively stable, organisational structures tended to be like Weber's ideal bureaucracy, whereas, in changing environments, structures tended to be looser with less emphasis on prescriptive patterns of work. Lawrence and Lorsch (1967) detected the same pattern between individual departments within the same organisation.

Additional extrinsic contingencies were identified by Pugh and colleagues of Aston University during the mid 1970s (Pugh and Hickson, 1976, Pugh and Hinings 1976, and Pugh and Payne 1977). A series of studies showed that the flexibility of organisational structures was related not only to the size of the organisation but also to the extent to which the organisation had to respond to parent and other organisations. With the recognition of the influence of extrinsic forces, subsequent management theories concentrated on developing strategies to anticipate and to respond to environmental changes. A company's ability to temporarily disengage itself from bureaucratic structures and employ *adhocracy* to address issues was found to be one of the key features of the successful organisations (Peters and Waterman 1982).

Selznick further developed the institutional analogy of organisational theory (Selzneck 1948). He believed that an organisation was not merely a response to specific societal demands but, with the passage of time, it too became like an institution as it became infused with values and developed its own culture. Almost thirty years later Handy identified the appropriateness of different cultures depending on the activities that predominantly characterise individual departments within an organisation (Handy 1976). He postulated that the culture of departments routinely involved in the management of innovation should be different from which support the infrastructure of the organisation.

A few years later, Pettigrew advocated the deliberate promotion of the notion of culture in organisations, arguing that in the pursuit of day-to-day activities, it was all too easy to lose sight of the organisational philosophy and objectives (Pettigrew 1979). In his view, the organisation's culture provides direction to employees and distinguishes it from its competitors. Peters and Waterman noted the predominance of the notion of cultures amongst America's best run companies (Peters and Waterman 1982). This was nurtured by the creation and management of language, symbols, slogans, ideologies and myths that pervaded the whole organisation. The emphasis of the culture was different for different companies, and for different departments within the same company, depending the main activity of the company or department. For example, companies promoted a culture of 'pioneering enterprise' when it required its workers to be innovative, whereas, companies that were not pushing back the frontiers in technology were more likely to promote cultures based on 'first class service and attention to the individual customer'. The identification of the importance of these characteristics of organisations as cultures explains the subsequent development of *quality* as a management system.

The roots of quality management can be traced to pioneering work in the United States during the early 1930s by Walter Shewhart. He was the first to propose that improving the quality of products in manufacturing process resulted in lower production costs (cited by Karatsu 1984). He advocated that improving the manufacturing process so that more products met the set specification saved materials, labour and energy. In order to eliminate the manufacture of products that fall outside the set specification range, it is necessary to understand and stabilise the factors that produce variation. This entails identifying and utilising statistical techniques to solve every problem at every step before and during the manufacturing process. This system of scientific management became known as Statistical Quality Control.

World War II prompted the next phase in the development of Total Quality Control. The high danger of risks to life attached to many military products, and the fact that they might have to be used in extreme climatic conditions and after long periods of storage, necessitated the development of an intensive system of inspection. This continuous system of inspection operated throughout the entire cycle of manufacture and was intended to eliminate doubtful components during manufacture and minimise scrap and reworking.

After World War II, outside the sphere of defence procurement, the development of quality systems was non-existent in many western industries, particularly in the field of domestic consumer products. The majority of firms concentrated on productivity and almost completely ignored their obligations to quality and reliability. They were in the middle of an unprecedented boom. In 1958, for example, Harold Macmillan, the then Prime Minister, was leading a general election with the slogan *"You never had it so good"*. Western companies were in a situation where they could sell everything they could make, and in these circumstances, Quality Control was not a concern.

By contrast, the Japanese were compelled to concentrate on improving the quality of their products in the process of rebuilding industries destroyed during the war. Much of Japan is mountainous and although the valleys are intensely farmed, there is tremendous competition for space from industry and housing. Without land to grow enough food to be self sufficient and lacking mineral deposits to trade internationally, Japan's greatest potential resource for trade was her workforce. However, prior to the war Japanese products were considered cheap and inferior copies of the West. In their successful bid to reverse this poor reputation, the Japanese embarked on a sustained programme to increase not only productivity but also the quality of goods produced. This involved large-scale investment in mechanisation and training of the potential workforce through compulsory senior high school education.

Paradoxically, the Japanese were introduced to Statistical Quality Control by the US army, and particularly by Dr W E Deming (cited by Ishikawa 1984). In 1948, a Quality Control Research Group was organised in the Union of Japanese Scientists and Engineers (JUSE). The members of this group were academics, statisticians and engineers and this is probably the reason for the highly statistical approach taken - one which was too formal and academic to engage management.

To combat this problem the Japanese acted on advice from Dr J.M Juran from the USA who advocated that Quality Control should be conducted as an integral part of management control. As a result the Company Wide Total Quality Control movement started. This development de-formalised quality control by training and engaging all employees, from top management to foremen and workers, in solving problems in the manufacturing process by utilising statistical quality control techniques. In essence, each worker was encouraged to improve his or her part of the manufacturing process so that the product would meet the required specifications of the consumer. By these means the needs of the external consumers (those who purchase the products) as well as the internal consumers (the workers in each stage of the manufacturing process) are satisfied. Moreover, the Quality Control focus infiltrated the company to include all departments of company such as, planning, accounting, research and design, manufacturing, sales, after sales, personnel, clerical and management. The impact of this approach filtered beyond the company gates: as workers within the organisation became more adept at meeting the needs of their consumers, they, in turn, placed greater demands on their suppliers to meet their own requirements.

This process was further enhanced by the development and promotion of Quality Control Circles in 1962. Quality Control Circles are small groups of five to ten workers who voluntarily work together under leadership to identify, analyse and solve their own work-related problems. The role of the circle leader, whose participation is also voluntary, is to train the other members of the circle the techniques to identify, prioritise and find solutions for problems that are consistent with corporate goals. One of the main strengths of Quality Circles is that workers are allowed the opportunity to identify problems with which they are in a position to deal. Problems are not only dealt with at the level where they occur but also workers are less likely to disengage themselves from problems by assuming that they originate from other people or departments. The prerequisite of voluntary participation distinguishes Quality Circles from other working groups. In practice, this prerequisite will mean that an organisation will only be able to introduce Quality Circles on a small scale and wider applications is only possible at the pace dictated by workers wanting to join in. For this reason, workers will be less likely to feel that they are obliged to respond to the next in a long line of management gimmicks. Proponents of Quality Circles claim that they are effective tools for moulding the organisational culture so that there is common ownership of corporate goals and widespread commitment of the workforce. Although the Japanese are not renowned for being innovative in terms of products themselves, they have achieved *process innovation* through harnessing the commitment of the workforce to meet the needs of the customer.

The impact which Japanese companies have subsequently had on the world market has forced Western companies to re-examine their organisational strategies and practices in order to remain competitive. Some have adopted the *Japanese Approach* to Total Quality Management. Although others have opted for different management approaches, quality improvement continues to underscore organisational activities. In some cases, these techniques might not be so radically different from those developed by the Japanese. For example, Peters and Waterman found that the role of a volunteer worker to *champion* initiatives was crucial to their successful implementation (Peters and Waterman 1982). Parallels can be drawn between these champions and Quality Circle leaders and members whose dedication to new projects is also voluntary. Whether the structure of the organisation was rigid or loose, the researchers found that the hallmarks of excellent companies were clear organisational goals and a dedication to quality and service.

2. The Evolution of the Consumer Culture in the NHS

The NHS has undergone similar organisational trends to those in industry. As in industry, the evolution and recession of different trends have not been discreet; they have not begun and ended at precisely determined dates and there has been considerable overlap between them. In its infancy, the NHS concentrated on technical issues such as, improving and increasing medical interventions to treat illness. As it developed there have been a number of attempts to reform the service so that practice reflects not only the latest technical ability but also nationally determined objectives. The earlier reforms attempted, largely unsuccessfully, to do this by changing the administrative structure of the organisation. The most recent reforms have adopted a different approach to divert attention from technical developments by remoulding the culture of the organisation to one that is underscored by attention to meeting the needs of consumers.

Technical Predominance

For the first twenty years or so the NHS, as it developed, was primarily about delivering appropriate medical care to those in need, particularly hospital care. This was a consequence of the government's commitment to nationalising hospitals, the influence the medical professions exerted over the decision makers and their perceptions of health priorities.

To Aneurin Bevan, the Minister of Health who launched the NHS, hospitals were the keystone of the service. The hospital was, and still is, the focal point for training doctors and provided opportunities for qualified practitioners to improve their knowledge and technical skills. At a legislative stroke, the country's voluntary and municipal hospitals became the responsibility of Hospital Management Committees that were funded by Regional Hospital Boards which, in turn, were responsible to the Ministry of Health. By these means, the government attempted to centralise the finance of the nation's hospitals and ensure equity of service provision regardless of the relative wealth of individual regions.

To obtain their agreement to join the service, Bevan made significant concessions to the more prestigious hospital doctors who feared loss of professional autonomy. Teaching Hospitals were given special status: with governing bodies of their own directly financed by the Minister of Health, instead of being integrated into the regional administrative structure of the hospital service. Further concessions included granting these specialists the right to private practice in hospital and the introduction of monetary awards of merit. Finally, and more importantly in terms of allowing the medical profession to monopolise service development by expanding technical expertise, doctors were allowed to serve on the new authorities. Bevan justified this concession to his Cabinet Colleagues in a memorandum introducing his scheme for a NHS:

"The full principle of direct responsibility must, of course, be maintained, but we can - and must - afford to bring the voice of the expert right into direct participation in the planning and running of the service".

(quoted in Klein 1995)

General practitioners and other professionals, including dentists, opticians and pharmacists, were administered under a separate structure. Executive Councils were established in the same geographical areas as local authorities and were composed of a mixture of lay and professional people appointed to manage the contractor services. General practitioners' opposition to government proposals to make them employees of local authorities and organise their services in health centres almost delayed the launch of the NHS. At the eleventh hour Bevan conceded that they could work as private contractors to the NHS on the sole condition that patients would have 24 hour access to a general practitioner or deputy service. In further concessions it was agreed that general practitioners would continue to receive payment by capitation fee for each patient and practice outwith central and local government control. In an effort to redistribute medical manpower to areas that were poorly served, general practitioners were encouraged through finance incentives to merge with colleagues and practice in local authority health centres.

Medical Officers of Health comprised the third branch of the new NHS and they continued to work within the control of local authorities. Their function was to provide services relating to public health within the constraints of local budgets. These services included maternity and child welfare; health visiting; home nursing; health education; vaccination and immunisation; environmental; ambulances and health centres. Paradoxically, this group of practitioners had less scope for professional autonomy in the NHS although they had undoubtedly achieved significantly more to improve the health of the nation through the implementation of sanitary reforms and the eradication of infectious diseases.

In its formative years, central policy relating to the NHS was primarily concerned with the provision and distribution of health services. Whilst the NHS was based on the responsibility of central government to determine and finance health policies, the concessions made to the medical professions to safeguard their professional autonomy meant its power to control the actual use of resources was weak. Decisions about expenditure and, therefore, about resource allocation within hospitals were made primarily by consultants within clinical specialities, and general practitioners were free to prescribe medications and refer to specialist care without constraint. The financial impact on the Treasury of the NHS was evident almost immediately: actual expenditure in the first year exceeded the original estimate by £59 million. This overspend was explained by Bevan to Cabinet colleagues in a memorandum only four months after the launch of the NHS:

> *"The rush for spectacles, as for dental treatment, has exceeded all expectations ...... Part of what has happened has been a natural first flush of the new scheme, with the feeling that everything is free now and it does not matter what is charged to the Exchequer. But there is also, without doubt, a sheer increase due to people getting things they need but could not afford before, and this the scheme intended".*

(quoted in Klein 1995)

In a further memorandum in 1950 to the Cabinet, Bevan predicted that there was little likelihood of containing the future expenditure of the service:

> *"Allowing for all sensible administrative measures to prevent waste, the plain mfact is that the cost of the health service not only will, but ought to, increase. Most of the hospitals fall far short of any proper standard; accommodation needs to be increased, particularly for tuberculosis and mental health - indeed some of the mental hospitals are very near to a public scandal and we are lucky that they have not so far attracted more limelight and publicity. Throughout the service there are piling up arrears of essential capital work. Also in this field, particularly, that constant new development will always be needed to keep pace with research progress (as, recently, in penicillin, streptomycin, cortisone etc.) and to expand essential specialist services, such as hearing aids or ophthalmic services. The position cannot be evaded that a nationally owned and administered hospital service will always involve a very considerable and Exchequer outlay ...."*

(quoted in Klein 1995)

From the mid 1950s a number of reports highlighted weaknesses in the tripartite structure of the NHS (Ministry of Health 1956 and 1959). Of particular concern was the administrative division between hospital and community based services which was seen to (a) undermine the importance of preventive medicine and (b) cause gaps and overlap in service provision for particular client groups. For example, the Royal Commission on the Law relating to Mental Health and Mental Deficiency (1957) recommended care in the community as an alternative to institutional care but stressed that this could only be achieved if there was closer collaboration between hospital and community medical and social services.

In an effort to achieve closer co-ordination between health and welfare services, the Ministries of Health and National Insurance were amalgamated to form the Department of Health and Social Services (DHSS) in 1968. Following this health authorities and social service departments were asked to produce joint plans for future capital and revenue expenditure for the period 1973 to 1983 to assist service development and co-ordination. Although the final plans did not reflect much in the way of co-ordinated effort, their production did nevertheless promote dialogue between the different service providers (Webb and Falk 1975).

The years of formation and consolidation was followed by a decade and a half of expansion and planning. The 1962 Hospital Plan sought to rectify the persistent problem of regional inequalities of hospital bed provision (Ministry of Health 1962). It specified national targets for hospital bed provision at 3.3 acute beds per 1,000 population and promoted the district general hospital as the basic unit for the delivery of services. It was initially envisaged that each district general hospital would have between 600 and 800 beds to serve populations between 100,000 and 150,000. The proposed scale of this enterprise was subsequently doubled in 1969 by the Central Health Services Council, which was set up to examine the function of the district general hospital (Department of Health and Social Security and Welsh Office 1969). The Committee was served mainly by doctors who saw the function of the district general hospital primarily as a vehicle to promote technical expertise and efficiency. In the district general hospital medical expertise would be concentrated and medical consensus would determine the nature and range of specialities provided. The development of the district general hospital further reinforced the dominance of the hospital sector and, consequently, the preoccupation with technical achievement. The implications of this development were twofold; resources were diverted from community care developments and from the less acute sector such as, care of the elderly and the mentally ill.

Although these plans were never fully implemented, the growth of the number and range of services was paralleled by an expanding workforce. During the 1960s, principles of scientific management were adopted following the Salmon Report on Senior Nursing Staff Structure (Ministry of Health and Scottish Home and Health Department 1966). Divisions were created between nurse managers and nurse practitioners. The upper level of nurse manager was responsible for the development of policy whilst the lower levels of nurse practitioner were responsible for its implementation. A similar attempt to promote a managerial consciousness in the medical profession was made through the setting up of the Cogwheel Working Party (Ministry of Health 1967). Unlike the Salmon Committee, Cogwheel had substantial representation of medical interests and was not chaired by a businessman. The strategy for change for doctors was based on persuasion rather than the imposition of a new structure. The report recommended the grouping of clinicians into Firms and Divisions, with a representative Medical Executive Committee to make and co-ordinate decisions in relation to the medical resource allocation over the hospital as a whole. The Cogwheel system for managing medical decisions was based on the premise that individual consultants would be accountable to colleagues for their practices that impinged on the common resources for the hospital. Other persuasive tactics included the development of a new information system; Hospital Activity Analysis provided consultants a breakdown of their practices in relation to their colleagues. Whilst there was some evidence that efficiency measures were adopted, for example, the length of stay in hospital fell, consultants failed to be persuaded to become managers and largely continued to make major decisions on the use of resources with little reference to their colleagues (Allsop 1995).

Throughout this time the emphasis was clearly on clinical standards of care rather than on the quality of services. It was assumed that if the service achieved equity and professionally determined clinical standards, then quality would naturally flow. This assumption was, however, challenged by a number of enquiries, the best known being the Ely Report (Department of Health and Social Security 1969). This report of the Committee of Enquiry into Allegations of Ill Treatment of Patients and other Irregularities at Ely Hospital suggested that poor quality of care had as much to do with inadequate internal arrangements as insufficient provision. In 1969 the UK Hospital Advisory Committee was established to inspect long-stay hospitals and improve standards of care. Despite these developments the concerns of the public, particularly patients, remained peripheral in the organisations of services; indeed, writing of this period, Klein and Lewis described them as

> *"....the ghosts in the NHS machinery: lacking any institutional representation ...."*
>
> (Klein and Lewis, 1974).

Administrative Predominance

The 1974 reorganisation of the NHS introduced an administrative system that sought to integrate the tripartite structure so that service provision could be rationalised in line with central policy (Department of Health and Social Security 1974). The new system not only reflected an attempt to clarify lines of authority and accountability in relation to service planning and implementation but it also attempted to increase the role of the general public in decisions relating to service provision.

The new administrative model adopted principles of classical organisational theory and bureaucratic control. The hierarchy of the organisation was pyramid shaped. At the apex, the Secretary of State for Social Services was responsible for developing and disseminating national priorities through officers of the DHSS to Regional Health authorities which were charged with strategic planning of hospital and community services at a regional level within central resource allocation. The Regional Health Authority provided the link between the civil service and the next administrative level which consisted of Area Health Authorities/Boards that were charged with identifying needs, planning and providing a comprehensive range of hospital and community health services within the resources allocated by the Regional Health Authority. Teaching Hospitals were integrated into the new structure and lost their special status. District Management Teams formed the base of the pyramid, and their role was to run the individual hospital and community services within the resources allocated by the Area Health Authority/Board.

In England and Wales, the Regional Authorities were also charged with administering, and collaborating with, the Family Practice Services, which managed general practitioners, dentists, pharmacists and opticians. In Scotland, general practitioners were administered by health boards. Regardless of the administrative structure, general practitioners remained self-employed contractors financed directly by the DHSS and continued to operate autonomously.

Regional and Area Authorities were managed by management teams, comprising an administrator, a treasurer, a nurse and doctors (representing, hospital consultants, general practice, the Royal Colleges and the Medical Executive Committee). All members had equal status and management was by consensus. The influence of the medical professions on determining health service priorities was strengthened not only by their representation on the management teams at regional and area level but also at district level where they had the right to veto any decision. In appointing officers for reasons other than their managerial ability the reorganised NHS departed from the principles of classical bureaucratic organisation theory. This departure was made to silence professional disquiet concerning the managerial emphasis of the reforms, and reflected the reliance of policy makers on practitioners to implement decisions relating to the actual use of resources.

The geographical boundaries of the Area Authorities/Boards were drawn to match those of local authorities. It was hoped that if health and social services were bedfellows there would be better co-ordination of service planning and provision. Additional mechanisms were built into the new organisational structure to ensure collaborative consideration in service planning and provision. In relation to planning, each level of the hierarchy, whether regional, area or district, was obliged to consult with a host of advisory committees representing the separate and joint interests of health and local authority services.

A formal mechanism to introduce public representation was incorporated into the structure by the creation of Community Health Councils. Appointments to these were made by the Regional Health Authorities, the local authority and local voluntary groups. Their function was to represent the interests of the public and to give patients an opportunity to express their views on service provision. They were entitled to observe health authority/board meetings, to inspect NHS premises, and to be consulted on any major development in local services; any decision not approved by a Community Health Council had to be referred to the DHSS. The consumer's voice in the reorganised health service remained muted despite the institution of Community Health Councils. From their inception, they have had mixed fortunes but, in general, they failed to make much impact and were paid scant attention by most health authorities/boards (Klein and Lewis, 1974). In practice, they had the power to complain but not to compel a change in action. As an additional measure, a Health Service Commissioner or Ombudsman was appointed in 1974 to investigate and adjudicate patients' complaints about the service, but issues involving clinical judgement were specifically excluded from his remit.

After the reorganisation, the Resource Allocation Working Party (RAWP) was set up to develop a method to reduce the extent of regional inequalities in health services and to divert resources from acute services to chronic and community services such as, mental health, elderly, and physical and mental disability (Department of Health and Social Security 1976a). The formula devised by RAWP weighted populations primarily by age and mortality factors to define allocation of resources. The intention of this system was to address inequalities in service provision by differentiating the rate of growth and not by cutting funds to any region or service. The formula not only made explicit the rational process by which resources were allocated but also made public the extent to which inequalities existed.

Paving the way for the reorganisation of the NHS, the DHSS published its planning system which required health authorities/boards to produce strategic plans, reflecting DHSS guidelines and national policies (Department of Health and Social Security 1972). Further DHSS directives established service priorities for different services (Department of Health and Social Security 1976b and 1977). The publication of these documents, which committed services to a whole series of policy objectives, coincided with a period of relative national economic decline during which the government imposed cash limits on public expenditure so that the Treasury no longer subsidised services whose expenditure exceeded predicted levels. Despite financial constraints, commitment to capital investment in new hospital construction continued so that the emphasis on containing costs rested on running cost, particularly salaries which accounted for 70% of the NHS budget (Klein 1995).

In this climate, public and professional faith in the reorganised structure of the service based on the fundamental principle of rational planning eroded quickly. The second half of the decade saw the intensifying of trade union representation of health workers and the emergence of industrial disputes. In effect, health workers demonstrated their willingness to resort to industrial action to vent their frustration against, and assert their will over, the rational planners throughout the complex administrative structure of the organisation.

In 1978 the then Labour government set up the Royal Commission to investigate the apparent failure of the reorganisation of the NHS to carry out rational planning (Report of the Royal Commission of the NHS 1979). It criticised the overweight administrative planning structure which dulled the worker's awareness of, and responsiveness to, central policies. It found that managers were not always furnished with sufficient information or guidelines to make decisions to implement central priorities. It also criticised consensus management for hindering the decision making process. Not surprisingly, given the mixed nature of representation on these teams, conflicts of interest occurred which resulted in states of inertia where no management decision could be agreed.

The reorganisation had also failed to achieve the desired closer collaboration between health and social services. Despite the introduction of DHSS financial incentives to encourage joint schemes, health and local authorities had stronger incentives during this period of marginal economic growth to offload problems and service response on each other.

The Royal Commission condemned the dehumanising manner in which the reorganisation of the service had been imposed on its workers. It indicated that insufficient preparation had preceded the reorganisation not only in terms of training management for their new roles but also to safeguard the worker's role potential and need for security. The Report stated that the imposition of the organisational changes had resulted in:

> *"An immense amount of administrative work in the preparation for the new machinery; disruption of ordinary work, both before, and after, reorganisation caused by a need to prepare and implement changes; the breakdown of well-established formal and informal networks and the loss of experienced staff through early retirement and resignation; stresses and strains on some staff of having to compete for jobs".*
>
> (quoted in Allsop 1995)

These problems were again highlighted by the incoming Conservative government in 'Patients First, a Consultative Document' on the reorganisation which formed the basis of the legislation and consequent reformation of the NHS in 1982 (Department of Health and Social Security 1979). In line with its election campaign manifesto in relation to health policy to *"simplify and decentralise the service to cut back bureaucracy"*, the 1982 remodelled structure eradicated a planning tier of the administration so that the locus of decision making occurred closer to those responsible for providing services. District Health Authorities serving populations in relatively small geographical areas were charged with the responsibility to define local need, plan and provide services accordingly. The emphasis on localism and small size is consistent with organisational theory that short, squat bureaucracies are able to respond more effectively to changing environments.

Along similar lines, membership of the District Health Authorities was reduced to around twenty and revised so that there was greater local representation at the expense of local authority representation. They continued to manage by consensus and the members included a consultant, a general practitioner, a nurse, a university nominee, a trade union member and generalists representing the local community.

The function of the Regional Health Authorities and Family Practitioner Committees remained unchanged and general practitioners continued to work as before. Community Health Councils survived the reorganisation although their *raison d'être* had been challenged by the increased local representation on District Health Authorities. Collaboration with local authorities was still encouraged through the formal mechanisms of Joint Consultative Committees.

The 1982 reorganised structure fulfilled Conservative commitment to decentralisation and introduced an increased focus on the patient that was to persist through their subsequent reforms of the service. Explicit in the government's approach to reorganisation was the assumption that local people know best and hence were best placed to determine the responsiveness of services. However, it is likely that, given subsequent developments, the implicit intention of this approach was to challenge the historical assumption that the medical professions were the expert voice in determining service provision.

Although these were significant accomplishments, the government was still left with the dilemma of how to manage the conflicting perspectives of central policy and the autonomy of the medical professions. Increasing demands on the service continued due to technological advancement and the ageing population in an economic climate of financial constraint. Given the government commitment to contain public expenditure and the decision to continue to finance the service from central resources, the emphasis of policies was on economy (cost containment), efficiency (providing services of a predetermined standard for the lowest possible cost), and effectiveness (providing services so that the cost did not exceed the derived benefits).

The Consumer Culture Predominance

The appointment of Roy Griffiths, the Chief Executive of Sainsburys, to head a small team of four to advise the Secretary of State for Health and Social Services was highly significant and symptomatic of the government's revolt against technical expertise. Over a period of six months, the team consulted widely without resorting to formal evidence. This approach heralded the end of the tradition of setting up Committees and Royal Commissions representing all the interested parties to produce consensus documents. The style of this inquiry set the tone for the new approach to managing the NHS - ie management by consensus was replaced by quick, authoritarian management.

The central thrust of the first Griffiths Report, the NHS Management Inquiry, was for a more clearly defined managerial role (Department of Health and Social Security 1983). While he called for greater involvement of clinicians in management, his report marked the beginning of a progressive transfer of control from clinicians to managers. His recommendations for an entirely new management structure throughout each tier of the organisation were implemented. At the top, the Chief Executive was responsible for the implementation of policy objectives by providing leadership and monitoring performance. General managers were appointed on performance-related pay at regional, district and unit level and were accountable for the services within their individual remits. Most of the managers appointed were former NHS administrators or managers from private industry. Critics, particularly amongst the medical professions, opposed this supermarket approach to management and the consequent commodification of health care. In attempts to reassure them, Griffiths argued that there was no reason why general managers could not be appointed from the pool of professions but he also stressed that management principles from the private sector were applicable to the NHS:

> *"As the professions saw the report as the introduction of economics into the care of patients, believing that this was inimical to good care. There was a deep-seated feeling that what distinguished the Health Service from the private sector or business or commerce was the very immunity of the Health Service from the supposedly corrupting influence of profit making and that this very immunity guaranteed high quality. This denies the fact that the hallmarks of the truly great organisations in the private sector is that they have placed quality and customer satisfaction first and profit for a long time simply emerged as the by-product of effective services".*
>
> (quoted in Klein 1995)

Throughout the 1980s and 1990s, the NHS was increasingly incorporated into the market economy. Arguably the most important aspect of these reforms was the introduction of market-style competition in the provision of health care. Health had become a commodity and the major concerns of the NHS became indistinguishable from those of a business organisation. This was achieved primarily through the separation of the main purchaser of health - ie health authorities/boards, from the main providers of health care - ie hospitals and community services. In theory, health authorities/boards were obliged to define which services best met the needs of their resident populations. They then demanded these services from service providers. In response to these demands, provider institutions competed with each other to secure contracts with the purchasers. The basic idea was that by forcing providers to compete for purchasers' business, a more efficient provision of health care would result since, in theory, purchasers would only offer contracts to those institutions that operated in an efficient manner. The notion of efficiency includes both *allocative efficiency* - ie the most appropriate mix of health care services, and *technical efficiency* - ie provision at the least cost. Whilst the pursuit of improved efficiency and the increase accountability of professionals to managers dominated discussions and debates on the new NHS, the new role for consumers and the services responsiveness to them received relatively little attention.

The new role for patients as consumers in the reformed NHS has been consistently promoted in subsequent policy documents and legislation. For example, one of the stated objectives of the 1989 White Paper, Working for Patients (Secretary of State for Health 1989) was:

> *"..........to give patients, wherever they live in the UK, better health and greater **choice** of the services available"* (p 3)

Among the government's proposed key changes to achieve its objectives was the creation of NHS Trusts which:

> *"will therefore have an incentive to attract patients, so that they will make sure that the services they offer is what their patients want. And in turn they will stimulate other NHS hospitals to respond to what **people want** locally"* (p 4).

Another proposal involved the creation of fund holding practices which would:

> *".. be encouraged to compete for patients by offering better services. And it will be easier for patients to **choose** (and change) their own GP as they wish"* (p 5).

Finally, in a separate section dealing specifically with patient choice:

> *"The government also remains determined that patients must be able to exercise real **choice** between GPs".*

This emphasis towards patient choice and greater patient autonomy was further emphasised in the policy document, Promoting Better Health (Department of Health and Social Security 1987) which outlined change:

> *"... to give patients the opportunity to make better **informed choice**"* (p 55).

This was followed by the Health of the Nation (Secretary of State for Health1991) which stated that action must be taken to:

> *"ensure that people are properly **informed** and have freedom to exercise **choice**"* (p viii/ix).

This document also asserts that achieving the key objective means:

> *"involving people more ...... at both strategic and operational levels in discussion and decisions about options and priorities, and through that involvement generating a shared commitment"* (p viii).

The NHS and Community Care Act 1990 formalised these proposals and provided a framework within which service users would know how, and to whom, they could complain should things go wrong (Department of Health 1990). Providers were charged with the development of procedures that were accessible and responsive to users.

Both the Citizen's Charter (Prime Minister 1991) and the subsequent Patient's Charter (Secretary of State for Health 1991) outlined how the NHS, and other public services, were to become more consumer oriented. In the foreword to the Citizen's Charter, the Prime Minister writes of making public services more answerable to their users and raising overall quality. He perceived this as continuing a programme of reform begun in the 1980s in schools. housing and hospitals, which

> *".......gave people more say in how their services are run"*

The four main aims of the Citizen's Charter were detailed as:

- improving the quality of public services
- increasing choice for consumers
- setting standards for services
- improving value for money

Whilst the Patient's Charter was not enshrined in legislation that offered service guarantees, it set out seven existing rights and affirmed three new rights for patients of the NHS. The patient's existing rights were specified as:

- to receive health care on the basis of clinical need, regardless of ability to pay.
- to be registered with general practitioner
- to receive emergency medical care at any time
- to be referred to a consultant, acceptable to the patient, when the GP thinks it necessary and to be referred for a second opinion
- to be given a clear explanation of any treatment proposed, including any risks and any alternatives
- to have access to health records and for them to treated confidentially
- to choose whether or not to take part in medical research or medical education

The three new rights were:

- to be given detailed information on local health services, including quality standards and maximum waiting time
- to be guaranteed admission for virtually all treatments within 2 years of being placed on a waiting list
- to have any complaint about NHS services investigated and to receive a full and prompt reply from the chief executive of the health board/authority or general manager of the hospital. If the patient is still unhappy, the case can be taken to the Health Service Commissioner.

The Patient's Charter specifically enjoined health boards/authorities to ....

> *"expand their use of questionnaires and surveys to find out what [consumers] think of the current services and to get suggestions of how things could be done better"* (p 18).

The national Patient's Charter was followed by local charters, mission statements and applications for NHS trust status, all of which purported to give patients a greater voice in the NHS. In most of these there is explicit recognition of the new-found status of patients as consumers, for example,

> *"The Trust will recognise that our users are the judge of the services provided, measurement of patient satisfaction, reviews and performance monitoring will be integral aspects of Trust activity"*
>
> (Ayrshire & Arran Health Board Application for Community Health Care Trust 1992)

Within health authorities/boards, individual posts and, some times, whole departments were given a quality and consumer service remit. These staff commissioned or undertook consumer consultation exercises. They worked with providers to determine standards of practice that took into account the views of the organisation's internal and external consumers – ie other service providers and patients. Systems for auditing performance against these standards were introduced and quality circles and groups were formed to determine strategies to improve performance. Although these developments contained many of the elements of the Quality Management systems in industry, they differed radically in terms that they resulted, in the main, from management directives rather than voluntary endeavours of the workers.

The Patient's Charter was accompanied by the document Framework for Action which was directed at everyone working in the NHS A (Scottish Office 1991). In early 1992, Sir Robert Kendell, the then Chief Medical Officer for Scotland, stated that these documents:

> *"...... should play a crucial role in helping to make the Scottish Health Service not just the fine service staffed by skilled and dedicated doctors and nurses which it has always been, but a health service which pays more attention to health promotion and health education, sets itself explicit targets based on an assessment of local needs and strives to be more sensitive to the wishes and feelings of its patients"* .
>
> (Kendell 1992)

Purchasers were further stimulated to take more account of the wants or preferences of local people not only on the quality of existing services but also for setting health care priorities in the NHS Management Executive's document Local Voices (NHS Management Executive 1992). The emphasis of Local Voices was on market research techniques (NHS Management Executive 1993).

In the foreword to Scotland's Health: A Challenge to Us All, Ian Lang, the then Secretary of State for Scotland, further promoted the role of public when he articulated the need for partnership arrangements between the government agencies, service providers and the public to improve the health of the nation:

> *"In order to reduce our appallingly high death rates from coronary heart disease, cancer and strokes we will have to change our smoking and drinking habits, make major changes in our diet and take more exercise. Fundamental changes in lifestyle of this kind depend on individual decisions, but they cannot be left to individuals. We will only succeed if everyone – central and local government, statutory and voluntary agencies, communities large and small – shares the same common purpose and same determination "*
>
> (Scottish Office, 1992),

This policy not only reiterated the desire for increased public participation to achieve the goals of the NHS but also represented recognition of the contribution of public health in defining the need for health care provision of local communities. Although academics had long argued for an extension of health service provision so that it embraced political, social and economical concerns, the traditional public health approach to needs assessment was based on epidemiological data. However, the promotion of public health in the new consumer and value-for-money orientated NHS led to a redefinition of the basis of needs assessment from "*has a disease*" to "*has the ability to benefit from an intervention*". As a result, the framework for needs assessments that was promoted included political, social, professional and consumer perspectives (McEwen 1995).

Unlike England, Scotland did not initially receive central investment to develop methods and programmes for need assessments in order to meet the challenge set out in this policy. In 1992, the Scottish Forum of Public Health Medicine established the voluntary network, Scottish Needs Assessment Programme (SNAP), in recognition of the central requirement for health needs assessment and the need to share ideas and practices in this area throughout Scotland. Since 1994, the NHS Management Executive has funded SNAP's central administration and co-ordination, and its activities are now considered a key resource in the commissioning process.

SNAP comprises a Core Group and seven interactive subgroups or networks. The Core Group consists of the leaders of each of the networks and representatives from academic public health and the Directors of Public Health Group. Initially, six of the networks covered the specific topic areas of Acute Services, Priority Services, Women's Health, Health Promotion, Communicable Disease/Environmental Health and Child Health. These were subsequently redefined so that they now address the topic areas of Acute Services, Priority Services, Women's Health, Health Promotion, Oral Health and Primary Care. The seventh network, the Information Advisory Network, was established to support the others by providing advice on data availability and development.

In addition to the Core Group and Networks, a small Editorial Committee was established, with representation from public health medicine, academic public health and general management, to referee and advise on publication. The final component of SNAP was a Programme Advisory Group with representation from the Core Group, the Chief Scientist Office, the NHS Management Executive and Health Board General Managers and Directors of Public Health.

Priority topics for health needs assessment in the initial SNAP programme were agreed by public health specialists and NHS managers. Thereafter, individual public health consultants were given the responsibility of undertaking or commissioning the health needs assessments that incorporated the views of relevant health service professionals and users. The reports produced for each topic were based on a critical review of the best available evidence on the epidemiology and the impact of interventions in terms of effectiveness and associated health gain. In practice, it soon became evident that there was no single best method of undertaking the assessments; different topics required different approaches and differed greatly in terms of the quantity and quality of available evidence.

The ultimate aim of the SNAP reports was to collate the evidence from the disciplines of epidemiology, demography, statistics, health promotion, social science, health economics, health services management, health services research and the voluntary sector in order to identify the patterns of health and disease and the epidemiology of specific diseases, to define appropriate outcomes, to evaluate current service provision and to assess patient satisfaction and consumer views (McEwen 1995).

While there is a good deal of rhetoric in these developments, it would no longer to be appropriate to describe the consumers *as the ghost in the NHS machine.* Indeed, it is possible to detect a sense in which the patient has become an expert in the appraisal of health services (Steele 1992). Thus the stage was set for the patient/public-as-consumer to play a decisive role in (a) evaluating service performance and (b) determining the nature of local service provision.

3. The Potential for Consumer Challenge in the NHS

It has been argued that central government's promotion of consumer interests in the NHS has challenged the autonomy of the medical professions. For example, by creating a climate that allows patients and communities to determine their own service requirements.

Consumerism, however, may pose a second, and greater challenge, to professional autonomy that has been previously unrecognised. Whether intentional or not, focusing attention on consumer satisfaction creates an organisational culture that is underpinned by commitment to the standardisation of the quality of the product or service at the expense of innovation and pushing back the frontiers technology. If parallels were drawn with the business community, health professionals have traditionally operated like providers in high technology companies in that they, to a large extent, have driven the market. For example, regular computer users may find that they install newer and more sophisticated software even when they have not exploited the full potential of the previous version. By contrast, companies driven by satisfying the basic needs of the consumer, like the food fast industry, provide a limited and unvarying menu.

2. CONSUMERISM AND THE CONSUMER VOICE

This chapter describes the historical background to the rise of consumerism and how it impacted on publicly funded services, particularly the NHS. Within this context, the potential for consumers to challenge the nature of service provision in the NHS is explored.

1. Overview of the Rise of Consumerism

Whilst there appears to be general consensus that Britain has become a 'consumer society', there is considerable debate as to when the phenomenon had its origins. The roots of consumerism have been traced to the period of the Great Discoveries and globalisation between the 15th and 19th centuries; to the last quarter of the 16th century and the politics of Queen Elizabeth I; to the great inventions of the middle of the 18th century and the Industrial Revolution; to the early 20th century and the period between the Great Wars; to the aftermath of World War II, when the Marshall Plan laid the foundations for an economic boom lasting quarter of a century; and to no further than the 1980s when ordinary people endowed the commodity, the object of consumption and of exchange, with a social or cultural identity to confirm membership to particular communities (Fraser 1981, McKendrick 1982, Cross 1993, and Benson 1994)..

The different origins are partly explained by the use of different definitions of the term 'consumer society'. In a study of the rise of consumerism between 1880 and 1980, Benson distinguishes between two popular definitions of a consumer society, the 'social-cum-cultural' and the 'economic' (Benson 1994).

The author's social-cum-cultural definition encapsulates:

> *"societies in which choice and credit are readily available, in which social value is defined in terms of purchasing power and material possessions, and in which there is desire, above all, for that which is new, modern, exciting and fashionable "*

Thus, consumerism is more than consumption. It is consumption to satisfy a higher need than mere subsistence and on the basis of a particular set of values. A social-cum-cultural definition also underpins the Catholic Church's social doctrine. For example, in the encyclical *Centesimus Annus*, Pope John-Paul II referred to the 'affluent or consumer society', stating that:

> *"A given culture reveals its overall understanding of life through the choices it makes in production and consumption. It is here that the phenomenon of consumerism arises ".*
>
> (John Paul II, 1991)

Whilst the *social-cum-cultural* definition appears to reflect characteristics of a consumer society, Benson argues that it lacks the precision of the *economic* definition, as articulated by Hirst :

> *"Most people, I think, would use the phrase 'the consumer society' to refer to the sort of life we live today and to certain features of it which seem likely to become more prominent in the future such as car and colour television ownership and holidays abroad. .... But the economist also distinguishes that part of the economy which is responsive to the preferences of the individual consumer from that which is controlled by collective decision. Very broadly the distinction is between the private and the public sectors of the economy and it [Britain] is the consumer society in the sense of an economy directed by the purchasing decisions of millions of individual consumers"*
>
> (Hirst 1977 quoted by Benson 1994)

Unfortunately, neither definition is unproblematic. The social-cum-cultural definition presupposes that there is an agreed benchmark against which choice and credit, material assessment of value and the desire for novelty in a society can be measured. Whereas, the economic definition produces a conclusion which appears to defy common sense. For example, as Benson explains, the proportion of the national product devoted to consumer expenditure (the most obvious indicator of individual spending) declined by more than 20% between 1880 and 1957, suggesting that Britain became less, rather than more, of a consumer society. For the purposes of this thesis, the economic definition is accepted because it not only defines the consumer as one who has choice and willingness to purchase but also because it implies that the consumer also has some power to influence the nature of goods or services on offer.

Notwithstanding the difficulties described above, the remainder of this section sets out to describe the rise of consumerism, focusing on the contributory factors and its impact on British society since the Industrial Revolution.

Factors Contributing to the Rise of Consumerism

The rise of consumerism in any society occurs when there is a change in the expression of demand for goods and/or services, generally as a consequence of an increase in demand for them. Scholars in this field broadly agree that there are three ways in which demand for goods can increase; firstly through an increase in the number of consumers; secondly through an increase in spending power; and thirdly through a change in fashion or taste, whereby there is a demand for something which was previously undesirable (Benson, 1994, Corrigan 1997, Lees 1993).

Between 1801 and 1911, the population of the United Kingdom increased by between 12 and 18 percent each decade from around 12 million to 45 million (Fraser 1981). In other words, in just over a century, there were almost four times as many mouths to feed, bodies to house and clothe, and tastes to satisfy. As the population grew it redistributed to become predominantly urban. For example, at the beginning of the 19th century only one in five of the population lived in a town with over 10,000 inhabitants, whereas in the middle of the century, this ratio increased to one in three. The geographical redistribution of the population continued so that by the beginning of the 20th century, almost 77 per cent of the population were in urban areas. The main reason for the growth of the city population was the increasing number of births over deaths, but another major reason was migration for employment opportunities from country areas. The rate of growth varied between areas, with the most spectacular rates in the industrial heartlands. For example, between the censuses of 1851 and 1911, the populations in Lancashire, Glamorgan and Lanarkshire increased twofold, fivefold and threefold respectively (Fraser 1981). This geographical redistribution of populations had the effect of concentrating demand from consumers.

Obviously an increase in the size of the population is important in relation to the demand of consumer goods. However, if the majority of the population had a standard of living below subsistence level, then the effect of demand on anything but food was only likely to be marginal. In Britain, however, population growth was accompanied by economic growth, with the result that wealth, income, and free time all grew significantly and thereby increased the capacity of the population to consume. The increase in wealth, measured by personal savings, home ownership and assets bequeathed on death, is well documented. For example, Benson calculated that home ownership increased twelvefold from the first half of the 19th century to the early 1980s, ie from 5% to more than 60% (Benson 1994).

In a complex analysis of the rise of the mass market between 1850 and 1914, Fraser describes an upward trend in income from wages when set against prices and unemployment (Fraser 1981). As a caveat to this general picture, the author recognises inadequacies of the indexes available to historians. For example, the figures for unemployment were based on returns from some established trade unions and, therefore, took no account of casual or irregular labour. During the same period, a number of social investigators (Booth 1889 and Rowntree 1901), disclosed widespread destitution in particular areas where the chief industry was declining or long-term employment could not be sustained. However, whilst industrialisation resulted in the decline of some crafts and cottage industries, the overall outcome for the population was positive as workers moved to better paid work; agricultural and unskilled labourers became urban and semi-skilled workers. Post industrialisation also brought unprecedented opportunities for 'blue-collar' workers to move into 'white-collar', and, generally better paid, employment as managerial and professional occupations expanded.

The increase in spending power occurred in ways that benefited particular groups in society more than others. The middle class benefited mainly from a redistribution of wealth and the working class benefited from the redistribution of income, and both at the expense of the upper class who sustained a loss in economic, political and social authority (Benson 1994). Women, elderly people and teenagers emerged with unprecedented economic power. As more women entered paid employment and commanded access to greater total family income, they exerted pressure on the market for goods that were previously produced at home and for labour saving domestic appliances (Corrigan 1997). The combination of demographic and material changes transformed the economic circumstances of many elderly people so that more accumulated property, personal possessions, pension rights and other assets during their working lives. However, the extent to which this 'new' wealth translated into purchasing power is less clear. By contrast, adolescents, who do not have accumulated wealth, enjoyed increased spending power since the inter war years. They benefited directly from increased wages and indirectly from the improved economic status of their parents.

The third factor contributing to the rise of consumerism is change in taste or fashion. McCracken traced consumerism and attention to fashion to the ceremonial splendour of the nobility at the court of Elizabeth I (McCracken 1988). Although this behaviour was beyond the reaches of the general masses, it is historically noteworthy as it marks a departure from basing social valuation solely on the accumulation of assets and honours that were sustained across generations. The social competitive circumstances of the court marked an era where new and exotic commodities were consumed not only for their material or functional utility but also symbolically, as a social meaning or as a cultural good.

McKendrick distinguishes between 'elite' and 'mass' consumption and locates the beginning of consumerism in England to the economic prosperity of the 18th century when the world of fashionable goods, such as Wedgewood pottery, became more available to ever more social classes (McKendrick et al 1982). Benson identifies three factors which influenced the subsequent pattern of consumption; manipulation, emulation and amelioration (Benson 1994). Manipulation implies that consumer behaviour was deliberately manoeuvred by those with commercial interests, emulation suggests that consumers were influenced by the desire to attain goods associated with those of a higher social status, whereas amelioration suggests that consumption satisfied a material need rather than a desire of the consumer. The three explanations, however, are not mutually exclusive. The inter-relationship between the manipulation and emulation explanations is demonstrated by Wedgewood's approach to marketing in the 18th century which was initially directed at high society ladies in the hope that their taste would subsequently be adopted by those in lower the lower classes. Josiah Wedgewood explained the rationale to this approach:

> *"Few ladies, you know, dare venture at anything out of the common stile [sic] 'till authoris'd by their betters - by the Ladies of superior spirit who set the ton"*
>
> (initially quoted by McKendrick 1982 and reproduced by Corrigan, 1997)

Similarly, the approach adopted to advertise domestic appliances, such as vacuum cleaners, washing machines and refrigerators demonstrates the inter-relationship between the manipulation and amelioration explanations. Advertising of such goods was used not only as a means by which women could be guided into particular modes of consumption but also to demonstrate the ameliorative benefits to be found in the functional and constantly improved use of new consumer goods (Lees 1993).

The Impact of Consumerism

In combination, mass production and the increase in purchasing power directed at consumer durables transformed the way of life of the wage earning classes. Whilst it is difficult to determine the extent to which supply stimulated, rather than merely satisfied, demand changes occurred to the way in which the market responded to consumer demand. As the modern consumer society emerged, a train of events was set in motion that was to change the social and cultural fabric of everyday life.

The revolution that occurred in retailing provides a powerful example of the way in which the market responded to consumer demand. Historically, when faced with the problem of produce outstripping demand, manufacturers had tended to concentrate their efforts on geographical, or horizontal, market expansion. The increase in spending power of the masses, therefore, opened up previously untapped potential and allowed producers unprecedented opportunities for vertical expansion. From 1870s shopkeepers became aware of the lucrative markets to be tapped and paid more attentive to cost and quality (Benson 1994). Change occurred partly as a response to the demand generated by rising incomes and partly as a response to the changing supply of goods. The growth of retailing was central to the growth of supply; new range of firstly foodstuffs and then gradually of manufactured goods became available as the five continents were opened up by railway and steamboat. The development of co-operative, department and multiple stores enabled retailing to begin to enjoy some of the economies of scale that had been pioneered by the manufacturing industry.

In most cases, the traditional shopkeeper was slow to make adjustments to the new market. New firms emerged during the late 19th and early 20th centuries to develop multiple stores. The most famous of the multiple-branch grocer was Thomas Lipton who was unusual in that he exploited the national market rather than confining his businesses to a particular region. In 1871, after spending four years in America, Lipton established his first shop in Stobcross Street, specialising in Irish ham, butter and eggs. By the end of the decade, he had nine branches throughout Scotland and in 1881, he expanded his horizons and opened branches in a number of the major cities in England, Wales and Northern Ireland.

In general, there were two kinds of multiple traders in groceries. The first were high class grocers carrying a large range of goods whereas the second concentrated on a limited range of items with mass appeal. The latter were geared to the working class market and tended to expand rapidly. Unlike the traditional corner-shops, the golden rule of the new retailers was 'no credit'. In its place, they traded on cheapness. This was achieved by maintaining a relatively low ceiling on gross profits and reducing operating costs by eliminating home deliveries, minimising book-keeping, and keeping shop-fittings simple. A limited range of carefully selected items allowed retailers to buy in bulk and undercut the prices demanded by their competitors.

The survival of the small shops was mainly secured by their willingness to offer credit and a delivery service.

The other group of food retailers who concentrated on cheapness and quality were the co-operatives which traded under a number of premises including quality by selling unadulterated products. The first grocery co-operative was set up in 1769 for an Ayrshire weaving community; and shortly after its formation in 1812, the Co-operative Society in Stirlingshire was the first to introduce the payment of dividends to customers on purchases. There was rapid expansion of the co-operative movement during the late 19th century and early 20th century so that by 1914, there were 1,385 societies which had in excess of 3 million members and a turnover of £88 million a year (Benson 1994). In the main, the co-operatives were established by social and Christian idealists who were concerned with the plight of the working classes.

Although the general rule was 'no credit', a number of Scottish societies operated a system of monthly accounts. The system of paying a dividend based on purchases inspired a loyalty in their members who, at first, were offered very little customer service and customers were expected to queue (Fraser 1981). The growth of competition during the 1880s and 1890s forced societies to improve their service and to diversify: whilst they continued to concentrate on groceries and provisions, they also started to sell meat, milk, bread, fruit and vegetables, clothing and household goods. Although they extended the range of goods, co-operatives did not afford a great deal of choice of individual items such as dresses, coats, blouses, materials, haberdashery and trimmings.

Ironically, given the idealism on which the societies were pioneered, the success of co-operatives was not sustained as the working classes grew more affluent and relied less on credit and/or sought greater choice and variety of goods. From the 1950s there was gradual shift from the village co-operative store to town supermarkets and department stores following the establishment of housing schemes and better public transport (my mum, personal communication).

Traditionally, department stores were geared for the upper ends of the market. They courted their middle class customers with services like elevators, escalators, restaurants and restrooms rather than low prices or quality (Fraser 1981). They were very attentive to customers often employing large staffs to assist customers with their purchases. However, their main attraction was in the wide selection of goods they stocked. Self-service stores, however, paid less attention to servility but concentrated on selling high quality groceries and household provisions (Fraser 1981). As competition increased they extended their range of goods to include a limited selection of clothing and consumer durables such as pottery and electrical goods. They also began to turn their attention to the quality of service by introducing customer service departments and by conducting customer surveys on their needs, priorities and preferences for goods and services. Recently, in an attempt to win an even greater share of the market, many of the giant supermarkets have adopted a scheme, similar to the dividends of the co-operative societies, of awarding customers bonus points based on purchases that can be exchanged for goods or cash.

In addition to changes in retailing, there have been other factors of a more socio-cultural nature. Even during periods of relative prosperity, groups have emerged to challenge basic assumptions on how their society was organised. For example, during the 1960s a number of mass movements organised around a variety of national issues, such as feminist and environmental concerns. Whilst the culture of such groups appears to be relatively autonomous, it is not conceived from within some kind of ideological or ethical vacuum. It will always be influenced by the material and symbolic structures of the social reality within which it is located. For example, Hebdige argued that underprivileged marginalised youths used clothes to distance themselves from the status quo (Hebdige 1979). Similarly, state education gave some sections of the youth culture new social and political literacy, which was used to challenge the mechanism of the state.

Throughout the 20th century, the agencies of cultural regulation operated to secure conditions appropriate for the reproduction of labour power. Their principal aim was to establish the social conditions required to sustain labour-power. To a large extent this relied on the provision of sufficient wages to purchase consumables that would satisfy a socially determined standard of living. The result of an increasing standard of living has been the creation and commodification of a greater diversity of cultural needs. Under these conditions, cultural needs assume the same legitimacy as physiological needs and their satisfaction an integral dimension of labour-power. Thus real value of wages is defined by their ability to satisfy physical and cultural needs.

The culture which emerged was one in which production and consumption, whilst mutually reinforcing for the economy, became quite separate activities for the individual. Social valuation was based less on the individual's productive skills and more on income and the ability to acquire and display commodities. The prevailing culture was one that reinforced traditional patriarchal practices in which the man was the bread-winner and the woman was firmly placed in the home as the child bearer/rearer.

Within this culture the household was viewed not only as the space needed for the recuperation from the intensive working practices demanded by Taylorism, but also as the heart of consumption. The domestic space had gradually been transformed from a unit of general self-sufficiency into one of consumption. Advertising emerged as a major force that helped translate the principles of industrial modernisation into the domestic domain. Advertising aimed at women undermined traditional handicrafts and home-production, especially in the areas of food and clothing. For example, there was a sustained reduction in the amount of bread baked at home so that by World War I, most people had bread supplied by local bake houses (Fraser 1981).

Changes to domestic labour mirrored those of productive labour as they became increasingly dictated to by the same principles of Scientific Management, namely through the introduction of mechanisation and the rationalisation of labour. This drive for efficiency was visible in the construction and design of modern houses, such as continuous work surfaces and integrated appliances and equipment. In essence, the changes to the domestic space resembled the reorganisation of the working environment of the factory or office.

Consumer Sovereignty

The economic conditions which created the consumer market through modern production methods increased both the number and range of goods available to the consumer and the number and range of retail outlets. Suppliers became obliged to compete for, and find their own niche in, the market by identifying and providing consumers the most attractive terms such as low cost, quality, servility, convenience or credit. Under the conditions of perfect competition, consumers are sovereign in that they can choose to purchase goods and services that best meet their requirements. Producers of goods and services devote considerable resources through market research to determine consumers' needs, priorities and preferences and to ascertain the extent to which these are met. By these means they are able to ascertain their shortfall and to develop strategies to secure or expand their share of the market. Thus consumer sovereignty extends beyond the simple purchasing decisions of a number of individual customers to include the influence that the can they exert on producers.

Hirschman differentiated between two types of consumer control: 'exit' and 'voice' (Hirschman 1970). The exit approach embodies consumer actions whereby they remove their custom from a provider and find an alternative provider. The voice option is used by consumers who wish to stay with a particular provider but who wish to change its mode of service provision. The choice of the exit option over the voice option is not solely dependent on the extent to which there is a free market - ie one in which alternative provision is available. In his analysis, Hirschman identifies 'loyalty' as an important factor that can deter consumers from leaving one provider for another.

Consumer sovereignty can also operate as a means of social control of business practices. Smith advances the theory that producers respond to ethical concerns of their consumers by focusing on one form of consumer sovereignty, ethical purchase behaviour (Smith 1990). He draws on the experiences of pressure group-organised consumer boycotts which occur when consumers feel that a company is acting unethically. These groups not only boycott the company's products but also make the company aware of the reasons. The boycott is deemed successful when the company responds by changing the policy or practice that is perceived to be unethical. Boycotts are more likely to be successful under conditions of perfect competition and least likely to be effective if the company in question has a monopoly on the market. As well as negative sanctions, consumer sovereignty can have positive forms, such as purchasing products because of a company's firm anti animal-testing stance.

In contrast to the attention that the history of mass production and consumption have generated within the social sciences, the role of consumerism in the development of the modern society has received very little attention. For example, there have been no comprehensive studies on the genesis and consequences of the consumer protection legislation of the 1960s and 1970s or about the policies and achievements of consumer organisations (Benson 1994). In an attempt to advance greater understanding of consumer organisations, Hermann drew on social movement theory to create a taxonomy for consumer movement organisations (Hermann 1991). It consists of four categories. It firstly separates organisations into those which are based on achieving benefits for themselves, and those seeking benefits for others or the public at large. These categories are then subdivided according to the nature of leadership into organisations which are managed by volunteers and those managed by professionals.

Volunteer-led organisations with a beneficiary constituency are the most common type of organisation within the consumer movement. Typically, they are local groups protesting about specific issues and their tactics consist of boycotts and pickets designed to attract media attention and embarrass their target. Their success depends largely on the appeal of the subject of concern, such as price increases or product shortages, and the accessibility of the target such as local supermarkets. Most of these groups tend to be short-lived perhaps due to the resolution of the issue underpinning the protest or due to the inability to sustain the commitment and resources from its volunteer members.

Volunteer-led organisations with a conscience constituency typically focus on a single or a few related issues, such as working conditions or the transport of livestock. Their tactics consist of raising not only public consciousness of the issues but also enlisting support of influential individuals such as politicians and legislators. Their success also relies on the extent to which the public shares their concerns. However, because the focus of their concern extends beyond a local population, they tend to rely more heavily on obtaining media attention to obtain public support for their actions. Another distinguishing characteristic of this kind of movement is that their members tend to be people with relatively flexible schedules, such as retired people, housewives, students, academics and lawyers. It is also pertinent that these groups tend to have a level of education to understand the political and economic systems pertinent to their cause. The continued existence of these groups depends largely on sustaining the commitment of its leaders but in some cases, the success in achieving a desired outcome has resulted in the group extending its interests and activities to other areas of public concern.

Professionally-led organisations with a beneficiary constituency generally have paid staff and hence their activities are less likely to be dictated by the resources provided by volunteer members. For this reason, they are able to sustain campaigns on a wider range of issues. They survive largely from the revenue obtained from commercial activities such as magazine sales that feature product testing and other consumer related issues. The fortunes of these groups reflect the general economic climate so that revenue fluctuates depending on their members' ability to purchase consumer durables.

Professionally-led organisations with a conscience constituency also employ salaried staff and their activities are generally directed at complex issues such as representation of consumer interests in corporate and government organisation, environmental protection, and evaluating the performance of government agencies responsible for consumer protection. Typically, these organisations rely on leaders with entrepreneurial skills to acquire sufficient funds to establish and maintain their activities. The chief sources of their revenue are obtained from private contributions and public grants. Their survival depends on their ability to develop an on-going programme of activities that is successful in sustaining sufficient financial backing.

Charting the rise of these organisation in the United States, Hermann relates the emergence of each type to discreet eras (Hermann 1991). The earliest, and least complex in terms of organisational structure, were the consumer boycott groups with a beneficiary constituency. Volunteer groups addressing issues of public concern emerged around the beginning of the 20th century as Christians, socialists, and reformers disclosed the terrible living and working conditions of the general masses. The 1930s produced the professional-led organisations that focused on product testing, and in the 1960s, the professional public interests groups. Hermann links the development of consumer movements with the increase in bureaucratisation of state and commercial organisations and to the increasing public affluence and education. The author, however, does not investigate further the association between the development of the more complex consumer organisations and these factors. It is possible that the development of a more complex structure to the consumer movements was necessary as bureaucracy made it increasingly difficult for the consumer voice to be heard. Alternatively, the development of more complex consumer movements could simply mirror the organisational evolution that occurred to state and commercial organisations as the focus of their interest broadened from local to more global issues.

2. The Evolution of Consumerism in the NHS

As the state encroached more into the lives of ordinary people, the consumerism front extended as citizens, or groups of citizens, challenged public service provision. The emphasis within the private sector on customisation, decentralisation, quality, human resources and flexibility of organisational management techniques assumed increasing relevance by those concerned with the provision of public services (Hoggett 1990 and Taylor et al 1992). Thus the promotion of consumerism in the welfare services has been influenced by forces emanating from each of the major stakeholders - ie the professionals, the public and politicians.

Professional Forces. The growth in consumerism in the welfare services has run parallel to the increasing professionalism of the service providers. Within the health service, the successful eradication of many communicable diseases was followed by the development of services for an increasing range of acute illnesses. As they gained the necessary expertise, the medical professionals increased in power and the gap between their knowledge and that of their patients widened. Patients were further alienated from services by bureaucracy, inflexible job descriptions, and impersonal work practices (Powles 1973). In 1975, Mahler advocated a shift in service provision from 'medicine' to 'health' and described the 'mystification' of medical technology thus:

> *"...... By legislation, by training, by organisation, and by the way in which health-related interventions are stated and restricted there has been a progressive 'mystification' in medical care which is continuing almost unchecked. As our understanding of cause and effect has grown, 'medicine' has continued to restrict the range of problems for which it considers itself*

> *responsible and the gap between 'health care' and 'medical care' has become wider. This has been coupled with an organisational change which has influenced the manner of dealing with these problems, a gross restriction in the information available and decisions to be made by people outside the health professions, and an unnecessary but inevitable dependency of the population upon the holders of these mysteries".*
>
> (Mahler 1975, reproduced by McEwen et al 1983)

This disempowerment of patients was accompanied by mounting criticisms that challenged the remarkable consensus, which had existed since 1948, about the benefits of medicine. A number of critical studies were published that showed that medical services had a limited impact on the major factors that undermined the health of most people such as poverty, unemployment and poor housing. In an epidemiological study of Britain's death records from 1847, McKeown not only provided empirical evidence for this argument but also cast serious doubts on the authenticity of medicine's claims to past victories (McKeown 1962). He did this by demonstrating that the decline in mortality rates during 19th century predated the developments of the relevant medical innovations. He advanced the alternative explanation that improved standards of living, particularly reflected by better diets and hygiene measures, was the most significant factor in reducing death rates.

Illich was the harshest critic of modern medicine (Illich 1976). He argued that medicine is often not only ineffective but also causes damage, or iatrogenesis, at three levels. At the first level, damage occurs to individual patients in the form of side-effects from approved, ill-considered or mistaken courses of clinical treatment. At the second level, damage occurs to the individual's capacity for self-care and self-responsibility because of the medicalisation of normal life events, from pregnancy and childbirth to old age and dying. Allied to this, damage occurs at a third level to a community's ability to deal with vulnerability and weakness because medicine undermines traditional cultural rituals associated with the universal experience of pain, suffering and death.

Some critics, most notably Hayek and Friedman of right wing policy institutes, challenged the broad assumptions of the benefit of social welfare (Hayek 1960, 1967, 1988; Friedman 1962; and Friedman and Friedman 1980). They argued that state intervention distorts market forces and has a detrimental effect on the economy for two reasons. First, excessive taxation to fund the public sector blunts risk taking and entrepreneurial effort. Second, the public sector does not create wealth and hence does not enhance economic prosperity.

Others commentators have focused on the manner by which services were delivered. For example, Hadley and Hatch likened welfare provision from the 1940s to the early 1980s to a Fordist model characterised by rigidity, uniformity, bureaucracy and alienation of consumers (Hadley and Hatch 1981). They were amongst the first of a number of commentators to advocate the need for diverse and decentralised services with providers contractually accountable and user participation in provision (Harris and Seldon 1979, Hadley and Hatch 1981, Williams 1989, Burrows and Loader 1994, Jessop

1994a, Jessop 1994b, Means and Smith 1994).

The arguments for the defence initially focused on restating the general principles underlying social welfare (Bean et al 1985, Wilding 1986). Later commentators on the political Left recognised that the defence of the principle of public services was quite different from the defence of the existing form of provision of services:

> *"Attention to the needs of producer groups (fortified, in the case of the Labour party, by an institutional attachment) has not been matched by an equivalent concern for the needs of the consumer. The belief in collective provision has tended to become a belief in uniform provision. Defining needs has become confused with meeting them. Provision has too often become paternalism. Excessive dependence on using the state, centrally and locally, as the means for service delivery has fostered an administrative, 'top-down' version of socialism".*
>
> (Deakin and Wright 1990)

Such views represent a radical shift in attention from the interests of producers to those of consumers. The shift also recognised the change in the structure of post-industrial societies. For example, between 1971 and 1990, manufacturing employment in Britain fell by over one-third with a corresponding increase in the service sector (Department of Employment 1993). Consumption of major services such as housing, health, education has become as important an area of social change as production. For example, Saunders argues that it is

> *"in the realm of consumption that personal autonomy and freedom may be cultivated"*
>
> (Saunders 1985).

He suggested that the power in capitalist society may be more usefully transferred to the less well off by enhancing their power as consumers. He believed that this could be brought about by the New Right's emphasis on privatised consumption solutions in conditions where there was effective autonomy and control for providers and real choices and freedoms for consumers. This analysis led him to suggest an interesting paradox ie

> *"we must draw on the methods of redistributive socialism in order to achieve the ideals of the New Right".*
>
> (Saunders 1985).

Public Forces. In the 1960s, groups of people who, for whatever reason, found themselves at the margins of society formed a collective voice to express their sense of exclusion and subjugation. During this period there was the rise of civil rights movements; most notably, the American Black Power movement which successfully highlighted cultural differences and fought racial discrimination. From the impetus of this powerful movement and others, like the successful War on Poverty programmes, a new social consciousness evolved. This aided the resurgence of feminism to contest patriarchal authority, and led to the birth of movements, such as the disabled peoples movement which struggled against discrimination, dependency and segregation (Barnes and Mercer 1995).

During the late 1960s and early 1970s, civil rights campaigners and their ideology began to permeate the welfare system, and the 'right' of the professional to decide what a client needed was challenged. In Britain, the initial focus of groups challenging bureaucracies and arguing for more active participation in how they were run was on local authority services such as housing, planning and education. The Patients' Association was founded in 1963 as consumer awareness gained momentum and entered the context of health services. Whilst these new movements were grounded in the mass protests of the 1960s, the two eras are thought to have quite distinguishing characteristics. The earlier protest campaigns were organised around a variety of national issues whereas, the later 'grassroots' associations were born of disillusionment with the management of government agencies (Perlman 1976).

The 1980s were characterised by a sustained attack on the elite institutions in society from both pressure groups and the New Right Conservative Government. Although the challenges emerged for different reasons, Hutton describes their effect as complementary:

> *"The powerful forces of social change in which people became more questioning of tradition and hierarchy and more ready to assert their individuality happily complemented the Thatcherite attachment to freer market, greater choice and rampant individualism. The top-down, monolithic organisation of the Keynesian welfare state - from trade unions to comprehensive schools and public housing estates - no longer met the spirit of the age; nor commanded the same allegiance. They were institutions from which the upwardly mobile wanted to escape - and Thatcherism was their ally ".*
>
> (Hutton 1996)

Against this background, people who were previously perceived to be primarily the subjects of social policy developed their own discourses which related to the emergence of organisations, campaigning and the development of traditions and cultures (Croft and Beresford 1998). These groups included disabled people, people who had received psychiatric care, older people, people with learning difficulties and people with HIV and AIDS.

Feminists constitute another significant group that challenged modern medicine. They contested the gender ideologies, embedded in medical ideologies, that control and disempower women, both as providers (paid and unpaid) and as consumers of health care.

As providers, feminists argue that they have been marginalised in the medical professions by a series of historical alliances with the Church, state and universities (Ehrenreich and English 1979). Whilst Florence Nightingale created a professional role for women, it was as a subordinate - as the 'doctor's handmaiden'. Traditional gender ideologies assign women the primary role as carer of the infirm and disabled and feminist analysis has disclosed the enormous contribution of caring by women, often at personal cost (Land 1978, Finch and Groves 1980, Walker 1981).

As consumers, feminists argue that women's health, both physical and mental, is related to social causes that are rooted in the inequalities of power they experience in their everyday domestic and working lives. They concur with Illich that modern medicine causes harm; in the case of women, it provides only symptomatic relief and fails to treat the primary source, the diseased social system (Oakley 1981).

On an individual level, the public also voiced criticisms about publicly funded services. These related to the nature of the services offered and also how they were delivered. For example, results from population surveys, such as those conducted by the Institute of Economic Affairs, indicated that the public felt that the welfare state and social services were bureaucratic and oppressive and that choice was suppressed, particularly for private services. (Harris and Seldon 1979, 1988)

Political Forces. The incoming Conservative government in 1979 was faced with the task of resuscitating a flagging economy which could not stimulate sufficient production to sustain full employment or achieve a balance between exports and imports. The economic climate of the 'inveterate consumer' Britain as described by Hutton could hardly have been more depressing:

> *"The government of the country and management of the economy could only proceed, it seemed, by grace of the trade union movement withholding strike action in pursuit of high wage claims. The economy languished, apparently locked in a spiral of high inflation, currency depreciation and low investment. Internationally the country's stock was falling. In 1976 it suffered the indignity of being the first advanced industrialised country to be bailed out by the International Monetary Fund. Public spending outran economic growth, and it seemed that the sinews of British industry were being gnawed away by inflation, wage demands and a collapse of entrepreneurship. Public intervention was synonymous with subsidy and nationalisation ".*
>
> (Hutton 1995)

As the faith in Keynesian economic management declined there was a shift from state intervention, regulation and ownership to deregulation, flexible prices and private ownership. These changes were set against the backdrop of criticisms of the inflexibility and unresponsiveness of collective forms of welfare provision. Neo-liberals argued that welfare was the responsibility of individuals rather than the state and that taxing citizens to pay for welfare services from which they may, or may not, directly benefit was an unacceptable infringement of personal freedom to decide how best to provide for themselves. Instead they advocated that individuals should be able to purchase welfare services in the market place and that the role of the state should be constrained to providing services only for cases of extreme poverty or where services were unavailable in the market place. With the exception of such cases, the state's role would be redefined to one of policing the market.

The belief that market-type mechanisms were the solution to economic difficulties was an international phenomenon during the 1980s. However, it appeared to be more warmly embraced by Britain, perhaps because its welfare state was financed more centrally and its provision more comprehensive than anywhere else. Barnes argues that the UK experience is distinctive because the changes to the provision of welfare in other countries have not been driven by such an explicit ideological force (Barnes 1997). She contends that the dominant role of neo-liberalism inbred in British policy thinking since the late 1970s had a pivotal influence in restructuring welfare provision.

From the late 1980s, the government introduced a set of radical reforms with the common aim of dismantling the system by which the state both financed and provided services via a bureaucratic command economy. In its place, a system was erected in which the state continued to finance services but their provision became the responsibility of independent providers competing with one another in internal or 'quasi' markets.

The first of the reforms to the welfare service was introduced as part of the Education Reform Act of 1988 (Department of Education and Science 1988). This Act set out provisions for 'opting out' (whereby schools could opt out of local government funding arrangements and choose instead to be funded by central government); 'open enrolment' (whereby parents could choose the school to which they sent their children); 'formula funding' (whereby the resources dedicated to a school relied on the number of pupils it attracted); and 'local management' (whereby schools were given control over the internal allocation of their resources). The next major quasi-market developments were implemented as a result of the NHS and Community Care Act of 1990 (Department of Health 1990). These entailed the allocation of 'purchasing' responsibilities to health authorities and GP fundholders and 'providing' responsibilities to local hospital and community non-profit trusts. In theory, the management of the trusts was independent of the purchasing units. The same Act also contained provisions for local government social service departments to reduce their role as providers, becoming instead primarily 'purchasing or enabling' authorities, buying care services from independent 'provider' units.

The notion of an internal market in the NHS as set out in the publication of the White Paper, Working for Patients (Department of Health 1989) evoked widespread dissent from professional organisations, trade unions, patients' associations, charities, churches, think-tanks, health authorities and political groups within and outside parliament (Butler 1992). The Government was accused of harbouring a hidden agenda aimed at destabilising the NHS. Some believed that the government's ultimate goal was the privatisation of the NHS (Lock 1989, Sheaff 1991). Others were convinced it was laying the foundations for two-tier service in which the wealthiest would be encouraged to seek health care privately, leaving the remainder under the care of a cheaper state service (Currie 1989).

Amidst this intellectual and political rebuttal of the role of markets in the welfare services, the issue of consumer choice opened an opportunity for a more constructive contribution from those opposed to the extremes of the New Right. Even the most cynical had to acknowledge that the quasi-market reforms, at least in theory, promoted the interests of service users in a number of ways. First, the emphasis on moving from service-led to needs-led assessment stressed the importance of the consumer over the professional. Second, the purchaser/provider split aimed to increase consumer choice by promoting alternative suppliers. Third, an emphasis on encouraging alternative suppliers sought to shift the balance of power from monopoly providers.

During the 1990s, a consensus in welfare politics emerged on the significance of the consumer/customer. A number of publications, including the 1992 Labour Party manifesto, illustrated the extent the political Left had embraced the cause of the consumer (Labour Party 1992, Meacher 1992 and Blackstone et al 1992). In 'Next Left: an Agenda for the 1990s', the authors argue that:

> *"...... welfare services succeeded in achieving basic levels of provision but were not flexible enough truly to empower people, too many parts of the public sector paid insufficient heed to the needs of citizens as consumers"*
>
> (Blackstone et al. 1992)

Thus the push towards welfare pluralism was not simply a product of the New Right, but a wider concern of some commentators on the Centre and Left. Furthermore, the government's marketing strategy articulated some of the service users' criticisms and thereby, gained some legitimacy.

The Significance of Consumer Identity

The 'consumer revolution' which has been taking place in the welfare state has played a significant role in legitimising organisational changes in the delivery of publicly provided and/or funded services. The creation of the consumer identity is interesting not only in terms of its linguistic significance but also for its political significance in redefining the relationship between those who produce and those who use public services.

The language used to describe those who make use of public services is fraught with difficulties and, as yet, there does not appear to be a term that is not already associated to particular ideologies and discourses (Taylor 1992 and Clarke 1994). Despite the wide adoption of the term 'consumer' many activists, particularly in the mental health movement, reject this label for deceptively implying a freedom of choice when, in fact, treatment options are limited and the power to exercise choice is minimal, particularly in cases when treatment is involuntary. Indeed, some users of mental health and social services describe themselves as 'survivors' rather than consumers of services (Barnes and Wistow 1991). Even the term 'user', which has been adopted as a neutral descriptor, still implies volition and, for some, the term carries negative connotations of reckless use or misuse, such as in the case of the drug user. The terms 'customer', 'consumer', 'user', 'citizen' and 'survivor' all imply substantially different kinds of relationship between those who provide and those who receive services. None of these terms overcomes the problems of the client/patient terminology in that each fails to differentiate between those who choose to utilise and those who are obliged to receive welfare services. Moreover, such terms which maintain a notion of individualised benefit, mask the complexity of defining the true beneficiaries of welfare services. In other words, the care and support provided to the individual often has impact on others associated with the individual (eg respite care) and in some cases, the wider community (eg immunisation programmes).

There is also a political significance which cannot be ignored. The creation of the consumer identity has been described as a salient feature of the neo-conservative attack on welfare (Clarke 1994). He argues its creation undermined the archetypal figure of the British citizen, who supported the state through taxation and was supported by the state through the provision of social welfare. Clarke advances the thesis that the citizen and his reciprocal relationship with the state were dismantled and replaced by three new identities with differing relationships. The first of these is the 'tax-payer', who is a responsible figure burdened by excessive public spending and who provided the focus for the first waves of public sector reforms, the quest for 'value for money'. The second figure, the 'scrounger' is irresponsible in that he exploits the generosity of the state and tax/rate payer by seeking unearned and undeserved benefits. The third figure, the 'consumer', on the other hand, is respectable and seeks to be responsible for decisions concerning the future welfare needs of himself and family. In Clarke's typology, the taxpayer and scrounger are clearly differentiated; the characteristics of each appear to be in direct opposition. However, the distinction between the taxpayer and consumer is less clear; the characteristics of each are intertwined. Indeed, the neo-conservatives have used the language and discourse of consumerism and citizenship almost interchangeably, as exemplified by the increasing emphasis in the flush if citizen's charters on individual consumer entitlements in relation to service quality over a range of services.

An alternative hypothesis on the political significance of the consumer approach is that it centres on individual rather than collective identity. Such an approach, it has been suggested, is hostile to any ideas that citizens should develop a collective voice to represent their views (Politt 1994). It has been suggested that this change in ideology, which shifts from collective responsibilities to individual ones, and organising welfare and care as a commodity on the market are means by which the government can abdicate from particular areas of responsibility (van Rees 1991). Government ministers have denied such allegations, for example;

> *"the government had not altered or undermined the basic structure of public services to Parliament and hence to individual citizens....... [but] had made it more user-orientated since formal lines of accountability were strengthened by making public services directly accountable to their customers"*
>
> (William Waldegrave 1993, reproduced by Cooper et al 1995)

In constructing the figure of the consumer, the neo conservatives created an image in which the welfare consumer was promised the same degree of choice that was available in other domains of life. This image did not marry well with a large bureaucratic monopolistic supplier welfare state and thus a sense that the two were not compatible was created. It could be argued, the true significance of the creation of the consumer identity is that it encouraged a critical evaluation of the responsiveness of state provision of welfare services to the individual's need. In doing so, neo conservatism created a climate in which it was possible to disempower the paternalistic and unresponsive welfare monopolies and replace them with a market in which the consumer could exercise power.

Consumer Sovereignty in the Welfare Market

Quasi-markets were established as the mechanism to disintegrate the monopolistic state provision of welfare services. They were 'markets' in the sense that they were based on the creation of a number of independent competitive suppliers. They were 'quasi' in that they differed from conventional markets in a number of fundamental ways that impacted on the degree of choice afforded to consumers. These differences relate to both the demand and supply sides of the market (Le Grand 1990, Taylor et al 1992, Le Grand and Barlett 1993).

Unlike conventional markets, the supply side of quasi markets is not solely comprised of profit maximising organisations. Instead, the greater share of the welfare market is made up of established institutions, albeit with new state independence, such as schools, universities, hospitals, residential homes, and housing associations. In the absence of a profit-maximising motive, the objective of competing for customers within such organisations is often not clear to the consumer.

Competition in health service provision has been likened to a 'defence-industry procurement' model of competition, in which relatively few suppliers submit tenders to provide goods or services stipulated by a Government agency (Green 1990). Such a model produces results which are different from a 'consumer sovereignty' model of competition in which the paying customer can choose from a range of suppliers, thus signalling their approval or disapproval of the service offered.

For a conventional market to be efficient and offer genuine choice there must be competition or the potential for competition - ie there should be many providers, and the opportunity for new providers to enter the market and for existing providers to exit it. A study of the mixed economy of community care showed that there were a number of factors that impeded the achievement of these market conditions (Hoyes et al 1993). These factors related to all the main participants in the market: purchasers, providers and users.

On the purchaser side, there was a tendency to use the independent sector only to deliver pre-defined or trusted models of care. In such cases, the use of the independent sector does not necessarily increase consumer choice; it is merely a substitution rather than an addition to the range of services. On the provider side, there was evidence that the market in social care was not always attractive to potential providers. In some cases, traditional voluntary sector organisations and user and carer groups felt that as formal providers, their role as independent advocates would be compromised. On the user side, there was less concern about the extent to which choice existed than with access and reliability of services.

Similarly, on the demand side, conventional market forces do not operate. Purchasing power within quasi-markets is not expressed in the form of cash but as a budget or 'voucher' to be spent on specific services allocated to users. Moreover, in most cases, the consumer does not make the purchasing decisions; such choices are exercised by agents such as GPs or care managers. As a result, purchasing power is centralised to a limited number of 'quasi' consumers. In some cases, where purchasers have block contracts with particular providers, patients may have less rather than more choice because freedom to refer patients or clients generally throughout the system will have been lost.

In its widespread support for universal access to health care, society defines health care as a common necessity such as food, clothing and shelter. However, whilst some health care services are life-sustaining for some, other medical interventions are more like luxury goods which place additional demands on resources. Unlike conventional markets, purchasing is not financed by consumers themselves from their own resources; instead it is financed by from a predetermined budget paid for ultimately by tax revenues. During the NHS review, commentators frequently observed that the demand for health care was infinite and that there was a limit to the government's ability to pay for an unchecked demand for services through taxation.

Moreover, many service consumers are not in the position to make optimal decisions about their need for care, such as people with learning difficulties, elderly people with dementia, young children and people with life-threatening emergency conditions (Knapp 1984). For other patients, the ability to exercise choice is severely constrained by the geographical location of services, for example little or no choice of a general practitioner in rural areas.

General doubts about the validity of the consumer approach in health care were expressed in response to the White Paper *Working for Patients*:

> *"a fundamental problem inherent in the view of the patient as a consumer is that the service provided is only an imperfect means to the desired end. The commodity sought by patients is health, not medical care per se. While patients may be the best judge of this desired commodity they may not possess the necessary competence to judge the quality of care provided".*
>
> (Leavey et al BMJ 1989)

In summary, genuine 'choice' among consumers is severely restricted by resource constraints, organisational constraints, the mix of welfare, producer ideologies, clients' demands and knowledge of caring options, carers' demands and knowledge of caring options.

3. The Potential for Consumer Challenges in the NHS

For most users of NHS services, consumer sovereignty is limited to the extent to which they can exercise their voice option. The emphasis on consumerism in the Welfare Reforms was on the identification of opportunities for consumers to exercise their voice and by these means granting more power to service users and the general public.

Within the health service, empowerment of service users exists to different degrees. The hierarchy of participation, developed by Quayoom, provides a useful model to describe the degree of power that can be conferred on, or taken by, users:

HIGH	users have the authority to take decisions
↓	users have the authority to take some decisions
	users have the opportunity to influence decisions
	user views are sought before making decisions
	decisions are publicised and explained before implementation
LOW	information is given/sought about decisions made

(Quayoom 1990)

In this model the extent of empowerment is determined by the point, if any, at which service users are allowed or willing to participate in the decision making process. At the lowest two levels, health service users have no power to determine or influence service provision or delivery. Examples of these lower levels of empowerment in the health services might include the distribution of leaflets informing service users of a hospital's actual or intended 'no smoking policy' when it has been agreed without prior user consultation. At the middle two levels, although service users are either consulted prior to decisions or can influence decisions, their powers remain limited because they do not make the decisions themselves. Examples of these levels of empowerment might include notices to the public or local health council of a proposed or intended hospital closure. At the highest two levels service users have more power because they have the authority to make decisions for themselves. In most instances, service users will have authority to make only <u>some</u> decisions. Even in the case of the decision of whether or not to consent to treatment, the service users' power is still constrained because the range of treatments offered are determined by professional experts.

The potential for consumers to challenge the NHS is directly related to the degree to which individuals and communities are empowered and willing to participate in strategic and operational decisions relating to service provision.

3. REVIEW OF CONSUMER CONSULTATIONS

This chapter reviews the literature on consumer consultations in relation to (1) the quality of health services provision and (2) the need for health services. Due to the sheer volume of studies in these fields, this review does not attempt to be comprehensive. Instead, a selective approach has been adopted whereby studies have been chosen to illustrate their scope, common findings and different methodological approaches. Some studies based on Scottish populations have been chosen as illustrations of local initiatives in these fields. The approaches adopted in the reviewed studies are discussed in relation to their fit with Quayoom's model of empowerment, described in the previous page (Quayoom 1990). By these means, the extent to which the NHS has embraced the challenge of developing a consumer-orientated culture is assessed.

1. Consumer Views on the Quality of Services

Studies of patient satisfaction with service provision have appeared in health care literature for more than four decades. The initial preoccupation with patients as consumers of health care emerged in North America during the late 1950s as competition amongst health care providers increased. The seminal work of Abdellah and Levine, which reported a direct relationship between patient satisfaction and the number of professional nursing hours, was based on 8,660 patients in sixty district general hospitals (Abdellah and Levine 1957).

This work was followed by a number of studies conducted on both sides of the Atlantic that focused on assessing the quality of health care from the patient's viewpoint. An early British study by Raphael included patient views to compare the care provided in four non-teaching general hospitals (Raphael 1967). Raphael later developed and published the King's Fund Questionnaire, 'Patients and their hospitals' which has been used widely and has proved significant in raising the profile of the concerns of the consumers of health care services (Raphael 1969).

The boom in consumer ideology in the NHS has its roots in the management changes of the early 1980s when, as a result of the first Griffiths Report (Department of Health and Social Security 1983), consensus style management was replaced with executive management. On short-term contract, these new style managers were employed on the same basis as their counterparts in private businesses; working to targets to achieve 'efficiency savings' and 'value for money'. In line with this development, there was an increasing emphasis on monitoring and auditing the quality of NHS services. Individual posts, sometimes whole departments, were established with remits in customer services and quality assurance. The managerial led consumer surveys that followed these developments were criticised for focusing only on non-health related aspects of the service such as, accessibility, catering and physical amenities (Winkler 1987, Fitzpatrick 1991). Surveys based on 'hotel aspects' were considered limited by service providers who underlined a wider contribution from patients on matters such as information needs; interpersonal and organisational aspects of care; and the value of medical treatments (Rempusheski et al 1988, Calnan 1988, Hall and Dornan 1988a, Williams 1994, Cleary 1998).

Whilst political, economic and managerial pressures were undoubtedly the major driving forces behind the burgeoning interest in patient satisfaction, professional and academic interest was subsequently stimulated for a number of reasons. Patient satisfaction was recognised as a useful measure of the quality of the health care process (Vuori 1987), particularly in relation to communication (Ley 1982) and compliance (Kincey et al 1975, Ley 1982) and the patient's decision to attend or re-attend for treatment (Larsen and Rootman 1976; Deyo and Inui 1980; Weiss and Senf 1990). Donabedian, who is widely considered to be a guru in evaluating the quality of health services, argues that patient satisfaction is not only a desired outcome of care, but also an element in health status itself (Donabedian 1966). This view is supported by a number of studies which show a positive correlation between satisfaction and health following the care intervention (Fitzpatrick et al 1983, 1987).

The Scope of Patient Evaluations

It is difficult to estimate the total number of patient satisfaction studies that have been carried in any given year since the publication of the first Griffiths Report. A trawl of this activity by health authorities and community health council in England and Wales showed that number of individual studies exceeded three hundred during the first five years (Dixon and Carr-Hill 1989). In order of frequency, this review identified studies of maternity services [47]; in-patients [35]; out-patients [32]; general population [22]; elderly [15]; women's health [13]; community health [10]; mental health, accident & emergency and child health [9 each]; ethnic minorities and transport [5 each], geriatric [3]; chiropody and day cases [2 each]; and dental, hospital discharge, food, nursing care, terminal care, x-ray and unclassified [1 each]. A literature review during the same time concluded that the level of activity in this field in Scotland was relatively low (Jones et al 1987). These reviews revealed that most of the studies were conducted by Community Health Councils, in some cases in collaboration with a health authority/board. In addition, a substantial amount of work had been carried out by interested third parties such as, academics, the King's Fund, the Consumer's Association and popular magazines. The value of this activity should be viewed in the context of two general observations made by the reviewers. First, it was found that activity was fragmented so that individual agencies were unaware of the findings or methodological problems of studies carried out by others. Second, and perhaps more significant in relation to addressing patient concerns, many authorities were unable to demonstrate that they had successfully acted on the findings of any local survey. For these reasons alone, it appeared that five years after the promotion of consumerism in the NHS, considerable effort was still required to develop a responsive approach to customer relations throughout the NHS. Whilst both reviews uncovered a significant volume of studies, neither reflects the true level of activity in this field since they do not include the many carried out by individual health practitioners for academic and professional qualifications.

Given the sustained political and professional interest in promoting the patient as customer, it is unlikely that the level of activity in determining consumers' views has abated during the past decade. In 1991 a search of the BIDS medical literature database identified 572 studies that specifically focused on patient satisfaction. These reflected specific interest in all aspects of health care including in-patients, out-patients, general practice, rehabilitation, maternity, community services and health promotion. In addition to studying patients who receive different types of health care, patient satisfaction has been studied in relation to characteristics of the health care provider such as, empathic skills (Jarski 1988, Squier 1990); communication skills (Falvo and Tippy 1988, Calnan et al 1994), humanistic attributes and behaviour (Johnson et al 1988 , Klessig et al 1988, Holloway et al 1989, Blanchard et al 1990), gender (Fennema et al 1990), and style of dress (Friis and Tilles 1988). Other studies have specifically focused on patient attributes that affect their perceptions of, and attitudes towards health care (Weiss 1988, Brody et al 1989, Chew 1989, Cleary et al 1989, and Blanchard et al 1990). It now difficult to imagine any category of patient, aspect of service, or characteristic of health care provider on which the patient's view has not been canvassed. These studies probably reflect the tip of the iceberg of research activity in patient satisfaction since they represent only those that are published in peer reviewed health professional journals. Studies published elsewhere and unpublished studies of health authorities, local health councils, interested third parties, and the theses and dissertations of individual practitioners undoubtedly comprise a far greater volume.

Structure-Process-Outcome Models of Evaluation

Donabedian, was the first to utilise the triadic structure-process-outcome model for evaluating health care (Donabedian 1980).

Structure

The structural approach to evaluating care involves the study of the setting and circumstances in which care takes place. This includes not only the premises and facilities, but also the accessibility and continuity of care and staffing.

Premises and Facilities: In relation to other aspects of the health care experience, studies purport to show that patients tend to give low priority to the facilities of health care setting (Smith and Armstrong 1989). However, these are often cited by patients as areas for improvement (Curtis 1987). A meta analysis of two hundred and twenty-one published satisfaction studies, found that care facilities featured in 16% of the evaluations and were ranked 5th out of the 11 aspects of medical care with which patients were most satisfied (Hall and Dornan 1988). Hospital toilet and bathing facilities were common sources of dissatisfaction in early studies but less so in recent studies (Raphael 1969, Gregory 1978, Scottish Office 1989). However, leisure amenities in hospitals, outpatient clinics and GP surgeries remain persistent sources of dissatisfaction (Williamson 1989, Scottish Office 1989).

Accessibility and Continuity of Care: With few exceptions, research studies of patient satisfaction indicate that it is positively related to the accessibility, availability and convenience of the service

(Pascoe 1983, Curtis 1987, Hopton et al 1993, Lewis 1994). One study of accessibility of care found significantly lower satisfaction amongst patients who had difficulty getting through on the telephone to make an appointment and who had to wait longer for an appointment (Allen et al 1988). Although continuity of care can be maintained even when numerous providers are seen, several studies have found that having a regular source of care and length of time with the same provider are positively related to satisfaction with care (Pascoe 1983, Lochman 1983, Curtis 1987, Smith and Armstrong 1989, Chao 1988, Weiss and Ramsay 1989, Hayes 1989). One study of patient satisfaction with the general practitioner deputising service found lower satisfaction rates amongst patients who had erroneously expected to be seen by a doctor from their own doctor's practice (Dixon and Williams 1988).

Staffing levels: Abdellah and Levine found no relationship between patient satisfaction and the total number of nursing hours per day given by non-professionals, however, satisfaction was directly related to the number of professional nursing hours (Abdellah and Levine 1957). Other studies have reported higher satisfaction among patients who are nursed under the system of primary nursing, in which care was perceived to be more personalised, than under a traditional more task oriented systems (Ciske 1974, Daeffler 1975, Watson 1978, Hegedus 1979).

Process

Reflecting on the complexity of the health care process, Donabedian has stressed the importance of evaluating both the technical and interpersonal aspects of care (Donabedian 1980). Many, if not most, health care providers assume that the quality of medical care is determined by the technical competence of the provider but there is considerable debate as to whether or not patients are competent to evaluate it. Several studies have found that patients' perceptions of competence is directly related to satisfaction (Pascoe 1983). However, the relationship between actual competence and patient satisfaction is less clear. For example, lay persons gave higher ratings to more competent interactions or more relevant activities in stimulated consultations (Chang et al 1984), but patient satisfaction with care was higher when tests of no diagnostic value were performed (Sox et al 1981).

The most frequently studied aspects of the health care process relate to the inter-personal skills of the provider such as, humanness, attentiveness and communication (Lochman 1983, Hall and Dornan 1988). During the developmental stage of a study on patients' perceptions of the function of nursing, interviewers found that patients responded more frequently in terms of attitudes and interpersonal relationships rather than practical activities even when procedures were specifically discussed (Buckenham 1986). Similarly, one study found that patients mentioned aspects relating to the interpersonal relationship between doctor and patient more commonly than any other issue when asked to define a 'good doctor' (Lupton et al 1991).

Poor communication has been shown to be a common source of dissatisfaction to patients across all fields of health care, and is thought to be the primary cause of formal complaint (Palmer 1990). For example, between 1977 and 1982, when complaints against general practitioners averaged 720 per year (three per cent of all doctors), the commonest cause for complaint was 'bad manners'. For out-patients, dissatisfaction relates to the failure to communicate causes for delays prior to consultation and lack of information on progress (Palmer 1990). For hospital in-patients, providers' skill in communicating has consistently received low patient satisfaction ratings (Cartwright 1964, Ley et al 1976, Hansson 1989). For example, in a survey of patients in coronary care units, huge discrepancies were found between the information wanted and what they received (Wallace et al 1985). Ninety per cent wanted information on the cause of their illness, their diagnosis, and length of recovery but only 40%, 70% and 40% reported receiving this respectively.

The communication skills of service providers have a direct influence on the extent to which patients feel that they have participated in their care which, in turn, influences satisfaction and compliance with treatment. A small study of 45 male patients demonstrated that patients who offer information as well as answer physician questions are significantly more likely to comply with recommendations for new medication (Rost 1989). This study also showed that the frequency with which patients interrupt physicians positively correlates with patient satisfaction, and the frequency with which physicians interrupt patients negatively correlates with patient satisfaction.

Outcome

Outcome is the observed or measured effect of health care and treatment on individuals or populations. Depending on the patient's condition or illness, the optimum outcome of the health care intervention may range from reduced illness, deterioration and suffering to increased longevity, mobility and well-being. Even when the desired outcome of health care is known, it is difficult, if not impossible, to measure. One reason for the difficulty is that, for many conditions, outcome cannot be assessed until some considerable time after the clinical intervention. Furthermore, the long term results for individual patients will not only be attributable to the health care intervention but also reflect external influences such as personal, social and environmental factors. Not surprisingly, few studies have focused on the relationship between health status outcomes and satisfaction (Fleming 1981, Carmel 1985).

The Correlates of Patient Satisfaction with Services

Factors reported to be related to patient satisfaction include patient sociodemographic characteristics; physical and psychological status; and expectations and attitudes relating to health care. However, studies report considerable variation in the weight, if any, afforded to each of these factors in determining patient satisfaction with care. It is likely that much of the variability is due to differences in the questions asked, the timing and place of their administration, and the setting in which care is received.

Sociodemographic Characteristics: A number of studies have found substantial associations between patient satisfaction and sociodemographic characteristics such as age, gender and social class (Pascoe

1983, Cartwright 1964, Hulka et al 1971). Results, however, are inconsistent and sometimes contradictory, except for the finding that older patients tend to report higher levels of satisfaction than younger patients (Adellah and Levine 1957, Raphael 1967, Locker and Dunt 1978, Cleary and McNeil 1988, Weiss and Ramsay 1989). The finding that women tend to be slightly more satisfied than men (Cleary and McNeil 1988) has not been confirmed elsewhere (Weiss and Ramsay 1989, Williams and Calnan 1991). Similarly, the relationship between satisfaction and social class, level of income, education and race is inconsistent across studies (Locker and Dunt 1978, Weiss and Ramsay 1989).

Physical and Psychological Status: Associations have been shown to exist between patients' health status and their satisfaction with the care they received. Cleary and colleagues found that perceived health status was almost as strong a predictor of overall satisfaction as were some of the specific satisfaction measures for various aspects of the health service (Cleary et al 1989). Lochman found that patients with few symptoms were more satisfied if physicians paid more attention to their problem, though the correlation was not significant for those with chronic diseases (Lochman 1983). However, these findings were not consistent with those of earlier studies (DiMatteo and Hays 1980, Greenlay and Schoenherr 1981).

Positive associations have also been also been found in relation to psychological status. For example, one study found that patients who did not discuss, or denied, their psychological problems with their general practitioner were less satisfied with the consultation (Greenlay and Schoenherr 1981). However, almost a decade later, no association was demonstrated between psychosocial problems and satisfaction in general practice (Savage and Armstrong 1990). A review of the wider health care literature found that people who report higher satisfaction with health care were also more likely to be happier with other aspects of their lives (Linn 1975). One author has postulated that patients with poorer psychological profiles may be more dissatisfied because treatment does not entirely relieve them of their distress (Calnan 1988). A number of studies have found that patients with persistent problems, whether physical or psychological, have reported that providers are less likely to respond positively (Tessler and Mechanic 1975, Pope 1978, Chaska et al 1980).

Expectations: It has been argued that the expression of satisfaction or dissatisfaction reflects the level of people's expectations more than the character of the service provided (Allanach and Golden 1988, Brown and Swartz 1989). However, the effect of patient expectations on satisfaction with health care is far from clear. One study showed that patients with low expectations also reported low satisfaction (Greenlay and Schoenherr 1981). Conversely, low expectations and grateful attitudes have often been often cited as reasons why elderly patients are generally the most satisfied (Hall and Dornan 1988a).

A large exploratory study, involving more than 2,500 Baltimore-area residents, found that patients whose experience confirmed their health care expectations were most satisfied, regardless of gender, age or social status (Fox and Storms 1981). The relationship between satisfaction and expectations is difficult to demonstrate since expectations are likely to be influenced by knowledge and experience.

It is possible for an earlier experience of health care to either raise or lower the patient's expectations. Furthermore, it may be difficult for patients to evaluate their satisfaction with a single care episode against a background of earlier encounters with the same service and/or health care providers. On the basis of their knowledge and experience of the service, it might be assumed that health providers who become patients themselves would have realistic expectations of the health service. Whilst there is no evidence to show that health care providers are the most dissatisfied patients, doctors and nurses are more critical than patients themselves when asked to predict their patients' satisfaction with the care delivered (Raphael 1967, Merkel 1984, Rashid et al 1989).

Attitudes: Some studies have attempted to associate differences in patient satisfaction to differences in their attitudes towards health care and health care professionals. In general, attitudes are inherently difficult to measure since they are formed from a whole host of external influences including knowledge, personal experience, the experience of others, and media accounts. A small number of satisfaction studies have focused on differences between voluntary and compulsory psychiatric hospital in-patients - ie those who did not willingly consent to be admitted (Weinstein 1979, Hansson 1989). The majority has shown significantly lower levels of satisfaction in compulsory admitted patients. Similarly, differences in patient attitudes to health care provider, particularly in relation to the degree to which the patient is willing to allow others to assume control, has been shown to influence satisfaction with care (Wallston and Wallston 1978).

The level of confidence that patients have in physicians or in medical care has received relatively low attention as a predisposing factor relative to satisfaction with specific care episodes. In an experimental study using video recordings of simulated consultations, respondents recorded higher satisfaction rates when the physician did not disclose uncertainty about the efficacy of treatment than when he did, regardless of how it was resolved (Johnson et al 1988). As early as 1975, it was noted that patients who lacked confidence in their doctor were more likely to complain about other aspects of their care (Kincey et al 1975). More recently, a north American survey of 400 hundred households found that whilst the amount of confidence in the medical care system in the country did not affect patient satisfaction, the level of confidence in the medical care system in the community was the single best predictor (Weiss 1988).

Despite anecdotal evidence to the contrary and general disquiet within the health professions regarding the quality of the services they provide, studies have consistently shown high satisfaction rates. Using a global evaluation, surveys usually report overall satisfaction rate of more than 80% or 90% (Harper Petersen 1989, Fitzpatrick 1991). The commonly held explanation is that patients' loyalty to the NHS and fears of alternative forms of health care provision refrain them from expressing negative views about any particular aspect of the service. This conventional explanation has been challenged by those who argue that these high satisfaction rates may be an artefact of methodological considerations.

Methodological Considerations of Patient Evaluations

Studies based on global measures of satisfaction are unlikely to elicit specific concerns of patients (Harper Petersen 1989, Fitzpatrick 1991). A number of studies have shown that specific measures of satisfaction provided more information, were more discriminating, and resulted in significantly lower satisfaction rates than global measures. For example, one study found that whilst 95% of patients were happy in general, 38% were dissatisfied with personal problem discussion, 26% with the information received, and 25% with the length of consultation (Williams and Calnan 1991). On the basis of such findings, it has been argued that specific measures are more useful in evaluating the quality of care (Cleary and McNeil 1988) and their application prior to global evaluation will reduce the skewedness of satisfaction ratings (Ware and Hays 1988). However, the vast majority of studies based on such specific measures still show that a minority of patients express dissatisfaction about any single aspect of care.

Recently, criticisms have been voiced concerning the sensitivity of the questions and scoring systems on which satisfaction studies are based. In particular, evaluations which are based on professional and/or managerial criteria are thought to be insensitive to the valid concerns of patients (Williams 1994, Cleary 1998). Others have shown that adopting the scoring system used in commercial services that ranges from 'excellent' to 'poor' produced greater response variability than the more commonly used 'very satisfied' to 'very dissatisfied' scoring system (Ware and Hayes 1988).

Studies Using Service Provider Determined Evaluation Criteria

The use of questionnaires based on criteria defined by service providers and/or managers is a common approach to eliciting user views in periodic surveys to provide a summary evaluation of medical care during a specific time period, usually 6 months or 1 year. A variety of approaches are taken: self completion or administered by an interviewer, either at the time of service delivery, on discharge or posted at a later date. The questionnaires themselves sometimes consist only of structured [closed] questions that limit the information recorded, or sometimes of unstructured [open] questions which allow greater scope for recording respondents' views. More often, they contain both structured and unstructured sections.

An early example of a questionnaire survey that included a combination of structured and unstructured questions was carried out on behalf of the Royal Commission on the NHS (Gregory 1978). A special trailer was appended to the 1977 General Household Survey [GHS] to identify people who had been in-patients or outpatient during the preceding 12-month period. An additional postal survey was conducted to identify potential respondents in Northern Ireland which was outwith the remit of the GHS. The achieved sample was 2223 outpatients and 768 inpatients, representing 87% and 88% response rate respectively. The questionnaires for each sample were administered by trained interviewers and dealt principally with the following five main areas in which the Commission had expressed a particular interest:

i. the provision of hospital transport for patients to and from the hospital;
ii. the length of time spent waiting for a first appointment or as in-patients for a hospital bed;
iii. the provision of facilities and amenities in the out-patient clinics for patients and those accompanying them, and similarly the facilities in the hospital wards and rooms for in-patients;
iv. communication between hospital doctor and patient; and
v. the degree of privacy afforded to patients.

In addition, the questionnaires included sections designed to collect information on provisions for children; patients' attitudes to service providers; and for in-patient only, discharge arrangements. No attempt was made to obtain patients' views on technical aspects of their care for two reasons. First, it was felt that there was no objective standard against which to set their answers and second, it was felt that patients' views on treatment would not be a sound basis on which to make recommendations for changes or improvements.

The focus of the questionnaires was not only in documenting patients' experience but also their satisfaction with provision. Given these different foci, the questionnaire used questions that tapped not only into experiences but attitudes. However, in some cases, when the aim was presumably to gain information on experience, the question elicited information on the patient's belief - ie information thought to be true. For example, outpatients were asked *"Would people have any difficulty finding where to go for a cup of tea, or was it quite easy to find?"*

Another flaw of the questionnaire related to questions that were prefaced in such a way as to induce a particular response set. For example, hospital in-patients were asked *"Some people have told us that they felt that the meals were served at unsuitable times in hospital .... How would you personally feel about the times that the meals were served to you while you were in hospital?"*

Finally, the wording of some questions and the range of response options provided may have produced greater variability than others. Sometimes, patients were asked to respond in the affirmative or negative to their general experience, for example *"At night were you generally disturbed by noise going on or not?"*, the responses given were *"yes, disturbed"* or *"not disturbed"*. Whereas, on other occasions, patients were given a middle option that could possibly afford them the opportunity to express some dissatisfaction without appearing completely negative, for *example "Did you feel that you could ask the doctors to tell you what you wanted to know, or not?"*, the responses given were *"yes could ask all the doctors", "yes could only ask some of the doctors, not others"* and *"no, could not ask any doctor ..."*.

Interestingly, respondents were asked for global evaluations of the service at the beginning and again at the end of the interview. Unfortunately, no comparisons between these measures are made, indeed, it is not stated whether the reported ratings refer to the evaluation at the start or the end of the interview. In-patients reported higher satisfaction ratings than out-patients; 51% rated the overall service very good, 33% good, and 16% thought it had it faults or was poor compared to 40%, 34% and 26% respectively.

For in-patients, dissatisfaction was highest in relation to early waking times; 43% of adult patients thought that they were woken too early. Just under one-third of patients (31%) were dissatisfied with the amount of information they were given on their progress. More than one-quarter of patients who were admitted as an emergency (26%) and one-fifth of non-emergency admissions (20%) were dissatisfied with the delay in first receiving medical attention. Approximately one-fifth of all in-patients were dissatisfied with hospital food (20%) and washing and bathing facilities (19%). In order of frequency, other sources of dissatisfaction related to objections to smoking in the ward/hospital room (16%); toilet facilities (15%); difficulty understanding doctors (15%); comfort of beds (13%); noise during daytime (12%); notice of discharge (12%); and privacy during examination and treatment (11%).

For out-patients, dissatisfaction was highest in relation to provisions for children; 47% of parents of child patients felt that there was insufficient toys in the waiting room. Approximately one-quarter of patients relying on hospital transport expressed dissatisfaction relating to the detours ambulances made to collect other patients to take them to hospital (23%) and the time spent waiting for transport home (28%). One quarter of all out-patients (25%) were dissatisfied about the amount of information on progress. Approximately one-fifth of patients were dissatisfied with the time waiting for a first appointment (21%), the length of time spent in hospital (19%), and adequacy of space in the waiting room (18%). In order of frequency, other sources of dissatisfaction related to length of wait to see a doctor (16%); difficulty in understanding medical terminology (15%); other difficulty in understanding doctor (15%), appearance of waiting room (14%); and number of seats in waiting room (11%).

A more recent example of the same approach, and one of the largest ever conducted, was the Scottish Office national survey 'Consumer Attitudes to the NHS in Scotland' (Scottish Office 1989). This was carried out to ascertain public satisfaction with the NHS in general and also their experience of the care delivered. The research was conducted on four separate but interrelated groups each including over 1000 individuals in one or more of the following: hospital in-patients, hospital out-patients, general practitioner (GP) patients, and the general public. Each patient group included individuals who had used the particular service in the preceding 12 months. The sample groups were designed to represent elderly patients, maternity patients, parents of child patients, and other adult patients. Respondents were interviewed in their own homes by trained interviewers using questionnaires containing mainly structured questions, although some unstructured questions were included. The questionnaires for the patient samples covered much the same areas as the above study, but they contained additional questions to elicit respondents' views on the relative importance of each aspect of care. In addition, all sample groups were asked their opinion on the 'standard' of treatment.

The questions themselves were technically sound. Respondents were asked for their global evaluations of the service midway through the large interview schedule, after providing mainly demographic data and factual information on their service contact, and before rating specific aspects of the service and providing information on any formal complaints made. For some questions, including the global evaluation, satisfaction was expressed on the four point scale *'very satisfied' 'fairly satisfied' 'fairly dissatisfied'* and *'very dissatisfied'*. For other questions, respondents were given a fifth and middle option *'neither satisfied nor dissatisfied'*. The use of these scales is problematic because it is not possible to control respondents' interpretation of the terms. For example, some respondents may use the term *'fairly satisfied'* to describe a service which met all their needs but did not excel, whereas others might use the same term to describe a service which met most but not all their needs. Using the former interpretation, the option *'fairly satisfied'* is a positive response, whereas the latter suggests it is negative. The provision of the fifth and neutral option for some questions suggests that it is intended as a positive measure of satisfaction. The problem with the scale is further compounded during the analysis when numerical values were applied to each option and means calculated for each of the measures. Whilst calculating means on ordinal scales is not uncommon, this action is methodologically flawed, particularly in this case where there is interpretation problems, because they do not represent a continuum of satisfaction.

The manner by which the responses were interpreted showed that general attitudes to the NHS were favourable across the six health boards. The 'general public' rated the NHS, along with the police, as the best run out of eight public services. The three patient sample groups also expressed high levels of overall satisfaction when asked about different areas of the service; only 6% of in-patients, 6% of out-patients and 4% of GP patients were in any way dissatisfied.

Satisfaction with specific aspects of care was also reported to be high. For hospital in-patients, the highest satisfaction rates were related to the way the hospital was run, the standard of nursing care, attitude of doctors and nurses, standards of medical treatment and visiting arrangements. The highest dissatisfaction rates related to hospital food, facilities available for passing time, and transport arrangements. Hospital out-patients were most satisfied with the helpfulness and attitude of staff/nurses and the standard of medical care received. They were most dissatisfied with facilities in waiting areas, time spent waiting in hospitals for appointments and transport arrangements. GP patients were most satisfied with the standard of medical treatment and the understanding attitude of the doctors. They were least satisfied with the time taken to get an appointment and the time waiting in the surgery.

Studies Using Patient Determined Evaluation Criteria

A different approach to evaluating health care is to narrow the time frame and focus of the evaluation to specific medical encounters or institutions. In theory, this approach increases the programmatic usefulness of patient satisfaction surveys in evaluating specific facilities, providers, and services.

Review of formal complaints is probably the simplest means of using unsolicited data to evaluate service performance from the patients' perspective. However, such data can never be representative of all dissatisfaction since formal procedures may inhibit many people from registering dissatisfaction. Furthermore, review of these data can describe only the negative side of the service in that complaints give no indication of which aspects of the service give satisfaction. These data could be counterbalanced by reviewing the contents of unsolicited letters of praise by patients and family members. However, the task of collating and analysing the hundreds of such letters received by any institution is likely to be administratively cumbersome.

Comment cards on which patients record complaints or praise about their health care experience is a quick and relatively inexpensive method of soliciting unstructured patient feedback. They can be left in a prominent position at the point of service delivery. Alternatively, they can be administered to all or a representative sample of patients at the time of service delivery, on discharge, or posted out at a later date. A study using this method was carried out in York District Hospital (Learmouth in 1990). In this study, 193 patients were contacted at home by post after attending an out-patient department. Each patient was sent an explanatory letter which stressed anonymity and invited criticisms as well as praise, a complimentary pen, a sheet of paper *headed 'My comments on the out-patient department'*, and a reply paid envelope. Rather surprisingly, in view of the low return from most exercises of this kind, 62% of the study population returned comments. Consistent themes were then identified. Waiting times and the importance of nursing quality were frequently mentioned, but the facilities in waiting rooms figured in very few replies.

Interviews conducted on a one-to-one basis or in the form of focus groups, which obtain the collective views of a group of individuals, are commonly used to obtain unstructured views of patients. Pryce Jones used the 'Critical Incident Technique' to conduct individual interviews with patients in an out-patient department to identify their good and bad experiences of the service (Pryce Jones 1988). They were encouraged to relate *'critical'* incidents which caused them to form an opinion of the service. The highlighted incidents were then classified according to areas of common interest; the majority was found to relate to communication.

Buckenham used group interviews as a method of eliciting views in four groups of patients in acute wards in order to investigate their perceptions of nursing care (Buckenham 1986). The patients were shown a card from a pack of alphabet cards and asked to identify functions performed by nurses beginning with that letter. The majority of patients' responses related to attitudes and interpersonal relationships rather than activities of care. Most patients were reluctant to criticise nurses and the majority of the comments made were positive. Their negative comments concerned inadequate or unsatisfactory service provision such as poor communication.

The above approaches are undoubtedly useful in providing qualitative data that highlight patients' concerns. However, their use in evaluating services is limited since they do not quantify the extent to which these concerns are representative of all users. A number of questionnaire surveys have been carried out on representative samples of patients to ascertain their views on a specific medical encounter or selected institutions. Relative to periodic surveys, the questionnaires for surveys of specific medical encounters are short and easy to use. The extent to which these questionnaires have been based on concerns which are known to be valid to patients is not always clear. However, a number exist which were informed by qualitative studies specifically designed to elicit this information.

The widely used King's Fund Questionnaire, 'Patients and their hospital' was developed by Raphael who earlier had conducted intensive qualitative studies during which the views of patients in four teaching hospitals were compared with those who look after them (Raphael 1967, 1974). In these earlier studies, patients and staff, including nurses, orderlies, administrators, doctors and committee members, were interviewed using a spontaneous, unstructured interview technique. Interviewees were also asked to estimate how well the hospital was carrying out its task of caring for patients by choosing one of five options from *'very satisfactory'* to *'unsatisfactory'*. The majority of patients (73%) rated the hospital *'very satisfactory'*. The overall rating of staff and committee members was 34%, less than half as much as expressed by patients.

The later questionnaire study, which included a combination of structured and unstructured questions, was conducted in 68 hospitals between 1970 and 1974, after intensive piloting in 10 general hospitals. The self-completion questionnaires were distributed by the ward sisters to patients, aged 15 years or older, who at the time of discharge had been in-patients for at least four nights and who could read and write English. 10,863 patients took part in the study representing a 73% response rate from all eligible for the study. The questionnaires comprised 28 questions covering five areas of hospital life: the ward and its equipment, sanitary accommodation, food activities and care, and overall contentment. Patients were also invited to add comments and to record what they liked best and least about their stay in hospital.

The questionnaire was designed for mass use and in its design some concessions were made to technical purity for conciseness and ease of completion. For example, some questions simultaneously addressed more than one aspect of the care process. Double-barrelled questions such *as 'Were you told enough about your illness and your treatment?'* pose a problem for the respondent who may be satisfied with only one of these aspects of communication. This, in turn, causes problems in the analytical stage since there is likely to be inconsistency between the responses of individual respondents. As a result, feedback to providers may not be an accurate reflection of performance. Regardless of its accuracy, the feedback will be vague since it cannot distinguish which aspect of communication was most problematic for patients.

Two other major concessions were made. First, all questions, except the final question on overall contentment, offered only two possible responses *'Yes'* or *'No'*. Second, these questions were phrased so that the *'Yes'* response was always the most favourable. Absolute measures rather than graded responses have been criticised for inhibiting respondents from expressing dissatisfaction (Carr-Hill et al 1987). Furthermore, the phrasing of questions and responses in a consistent manner are more likely to produce response bias that may artificially inflate satisfaction rates (de Vaus 1991).

The study reported high overall satisfaction; only 6% expressed any dissatisfaction. However sanitary accommodation was criticised in some way by 40% of patients. Other aspects of service received fewer critical ratings: the ward radio was criticised by 23% of patients, wake-up times by 21%, diversions by 19%, temperature and choice of food by 15%, and information by 14%. Less than 10% of patients made any critical comment on any other dimension of the service. The highest satisfaction rate (98%) related to the delivery of care by nurses. Analysis of the positive comments revealed that 93% made reference to human or organisational aspects of their care and 49% to physical factors. Similar analysis of the negative comments revealed that 46% cited human or organisational aspects they liked least.

While this pioneering work was undoubtedly valuable in the promotion of patient concerns, its use today would be of limited value. With the exception of communication of information, it could be argued that the other areas of the service which received the relatively high dissatisfaction ratings would have been apparent to service providers without resorting to the expense of a formal survey. Furthermore, the general poor response variability of the other variables suggests a suspect method of measurement which may not be sensitive enough to distinguish between satisfied and dissatisfied patients. Despite the inherent methodological problems, the simplicity of this questionnaire, and a similar one developed for evaluating psychiatric hospital care, is attractive and they have been utilised in subsequent studies (Raphael 1972).

In 1988, MacDonald et al observed that there had been no large scale surveys of psychiatric hospitals since the pioneering work of Raphael in 1972 (MacDonald et al 1988). Their survey of patients in long-stay wards in a large London psychiatric hospital was preceded by a series of consultations with both patients and staff to elicit criteria to inform the questionnaire content. The authors did not elaborate on the nature of these consultations in terms of their number or style, nor about the relative weight awarded to patient and staff criteria in the final questionnaire. The questionnaire was administered to patients by trained interviewers who recorded all spontaneous comments to the questions. One hundred and four patients were interviewed, representing 63% of the hospital's long-stay patient population. The interview schedule contained 42 closed questions covering the following 8 issues: fearfulness, isolation and apathy, lack of individualisation, unsatisfactory surroundings, lack of autonomy, unsatisfactory personal hygiene arrangements, lack of status and recognition, and restriction of actions. The respondents were also invited to comment on the best and worst aspects of being in hospital, but not their overall satisfaction with life in hospital.

The interview schedule contained a curious mix of questions, unexplained by the authors, which not only tapped into patients' experience but also their beliefs. The extent to which responses to questions such *as 'Are people put here when their friends and relatives don't want them around anymore?'* reflect the patient's belief, experience or satisfaction with hospital care is difficult to interpret. This questionnaire utilised a *'Yes/No'* format for responses but, unlike the previous study, the phrasing of questions was varied so that sometimes the *'Yes'* response indicated satisfaction and sometimes dissatisfaction.

With this approach, the authors reported higher levels of dissatisfaction than commonly found in other studies. Dissatisfaction was reported to be greatest in relation to the issue 'lack of individualisation' on the basis that 73% of patients responded that they had no say in how the ward was run. However, without evidence of the weight which patients put on 'having a say in the way the ward is run', it is not possible to say whether this result does in fact reflect dissatisfaction. Other results seem contradictory and difficult to interpret. For example, only 11% of respondents felt that staff were not kind, however, 35% reported that nurses did not talk to them enough, 31% reported that they feared staff, and 34% reported that staff made fun of patients. Analysis of the responses to the most and least satisfactory aspects of hospital showed that 70% of the best and 80% of the worst aspects related to human factors such as inter-personal relationships, whilst only 30% of the best and 20% of the worst aspects related to physical factors such as the ward, food, grounds and buildings.

Published studies of periodic and specific health service surveys so far raise a number of methodological issues about the sensitivity of their content and construct. There is, however, a methodological problem common to all that outweighs any of those previously discussed. It concerns the validity of evaluating the service at all. The studies, to date, have concentrated on obtaining the views of users, or potential users, on existing services without first determining whether patients, if given the choice, would have chosen to use them or opted for alternative forms of provision. In the commercial field, this would translate into an organisational obsession with inspection without first determining if there was a market for the product or service.

2. Public Views on the Need for Health Services

The 1992 publication *Local Voices* by the NHS Management Executive specifically enjoined health authorities to increase the public's role in shaping local health services (NHS Management Executive 1992). It outlined their requirement to extend consultations from obtaining patient's views on the quality of services to obtaining the views of users and potential users on the need and priority for health services. In an earlier guidance document, the NHS Management Executive clearly defined health need as *'the ability to benefit from health care'* (NHS Management Executive 1991). *Local Voices* contained nineteen examples of good practice and recommended established market research techniques. As a consequence, health authorities/boards were required to develop radically different approaches to assessing the need for health services for the populations they serve. To date, assessments have focused on the needs of specific categories of patient (such as the elderly and people with mental illness) and on the priorities of communities for services to treat a range of health problems.

There is general acceptance amongst the public and the health professions of involving local communities in the planning of local health services (Cumberlege 1986, Richardson et al 1992, Bowling 1993a, Shanks et al 1995). Younger people are more likely to agree to open consultations (Grooves 1993) and people in higher social groupings are more likely to approve in principle with the rationing exercises (Research Services of Great Britain 1991). Assessments which have focused on comparing different services have experienced more difficulties than those with a narrower focus of determining priorities within individual service areas (Ham 1993). A number of studies have found that the public give higher priority to life saving interventions, middle and low priority to care for people with chronic conditions or mental illness, and low priority to cosmetic treatments, health education and family planning (Richardson et al 1992, Grooves 1993, Bowling et al 1993).

Methodological Considerations to Needs Assessments

By comparison to patients evaluations on the quality of service delivery, studies on eliciting the public's priorities for health services is in its infancy. Methods include public panels, focus groups, rapid appraisal, postal questionnaires and interview surveys (Nichter 1984, Murray et al 1994, Hopton and Dlugolecka 1995, Dicker and Armstrong 1995, Knox and Chapman 1995, Neve 1999). There is no national agreement on the best approach to obtaining the views of the public on the range of, and priorities for, health service provision (Shanks et al 1995). Regardless of the methods employed, these studies can be classified according to whether they are based on the professional definitions of health and health need, or whether they are based on the public definitions.

Studies Underpinned by Professional Definition of Health Need

The brief for health needs assessment is held by public health medicine professionals who are informed by epidemiology. Tthey have traditionally used mortality and service utilisation data as indicators of the public's need for services. The medical or epidemiological approach to health needs assessment is underpinned by a medical definition of health as the *absence of disease*, and health need as the *presence of disease in the population*. However, as a result of the new emphasis from management and health economists, the definition of health need has been modified. It still accepts the traditional medical definition of health but stresses, that since service provision occurs in the context of finite resources, that need should reflect the *ability to benefit from health care* (Stevens and Raftery 1994).

In 1994, the Scottish Needs Assessment Programme carried out a review of all needs assessment reports in 14 areas of clinical interest produced in Scotland in the previous three years (Kelly et al 1996). The review found that although the reports varied greatly in terms of scope and level of detail, the contents when driven by the "*ability to benefit*" definition concentrated on the health care implications of needs assessment. The authors advocated that this balance should be redressed towards the wider public health needs that are not solely the remit of the NHS. Surprisingly, in the same year that SNAP published this recommendation, it produced a screening tool for determining priorities for health needs assessments based solely on hospital discharge data on health service outputs or outcomes (Scottish Forum for Public Health Medicine 1994). A review of the SNAP publications during 1994 in the areas of addiction (Wrench et al, Gardner and Boswell, Kohli and McGowan); mental health (Donaghy et al); stroke (Webb et al), breast feeding (Campbell and Jones); and teenage pregnancy (McIllwaine et al) showed that assessments on the need for services were based predominately on the traditional interpretation of epidemiological data, such as mortality and morbidity data, complemented, to varying degrees, with published evidence from academics and other professionals in relevant fields. Where it existed, evidence of user or public views was constrained to information that might explain the causes for particular phenomena or trends. For example, the report on teenage pregnancy extrapolated from the findings in the 1994 Sexual Attitudes and Lifestyle Survey based on interviews with 19,000 people to estimate the number of sexually active teenagers in Scotland. Whilst some of the reports, for example, the Mental Health Overview and Programme, consulted representatives from voluntary or user groups, this was generally to comment on issues identified by professionals. Despite the stated intentions of the SNAP programme (McEwen et al 1995), none of the reports used evidence based on user or public views to determine the need for, or efficacy of, service provision.

An example of a medical/epidemiology approach to needs assessment is provided by Murray et al who conducted an investigation of the needs for care of people with major mental illnesses in Hamilton, a socially deprived district in Scotland (Murray et al 1996). In this study need was defined as (a) a problem in one or more of seven clinical and eight social areas of functioning, for which (b) there was a suitable intervention, and which (c) had not been given an adequate, recent trial. The definition of need was not dependent on the local availability of an intervention.

The study population consisted of male and females, aged 18-65 years who had been residents of Hamilton between 1 June 1993 and 31 May 1994 and who had received professional attention during the previous five years for a severe mental disorder. Severe mental disorder was defined to include schizophrenia, manic-depressive illness, psychotic depression, schizoaffective disorder and some organic psychoses. Potential subjects who received attention from psychiatric specialists were identified by electronic searches of hospital admission and discharge data and by manual trawls through hospital records, community nursing Kardexes, daily nursing returns, all appointment diaries, and a clinic database. 263 patients were identified from these sources. The search for potential subjects who may not have come to the attention of psychiatric service providers was less thorough: GPs from the 15 local practices were simply asked to confirm that subjects identified from the other sources were their patients and to quantify the number of additional patients on their practice lists who met the study's inclusion criteria. Only 20 additional patients were identified by seven practices, five practices knew of no additional patients and three practices failed to provide information. The implications of the differences between the number of patients identified between the practices that responded and the failure of the other practices to respond were not explored by the authors. The twenty additional patients identified by the GPs represent only 7% of the total study population (ie 20 of 283). Other studies have consistently found that the proportion of patients with psychosis who have no contact with psychiatric services and are entirely looked after within general practice is around 25% (King 1992). In view of this evidence, it is likely that the methods used to identify eligible patients were inadequate and failed to capture a considerable proportion of cases that were known only to general practice. It is unclear why the authors attempted to identify these patients since they were subsequently excluded from the needs assessment exercise. The reason given for their exclusion was that patients' identification details were not made known to the researcher in order to protect GP–patient confidentiality. Despite the exclusion of these patients, the authors discuss the results of this study as if they pertain to a representative sample of people with major mental illness in a community. In reality, the needs, met or unmet, of such patients who are in contact only with general practice services were not assessed.

Interviews were conducted with 71 individuals and their main carers, representing a one-in-three random sample of all patients identified from the search of contacts with psychiatric services in the Hamilton area during the previous five years. The interviewing process comprised a combination of structured and unstructured questions that were based on a number of previously tested schedules. Information was elicited in relation to five distinct areas:

1. need, as assessed by the carer's observations of the patient's behaviour or, in the absence of a carer, on the patient's presentation and home circumstances at interview,
2. prescribed medication, treatment compliance and service use,
3. smoking, alcohol and drug use,
4. carer's view of the service, and
5. patient satisfaction with the service.

The authors reported that forty-one patients (58%) had no clinical needs, and 36 (51%) had no social needs. However, these results must be viewed in the context of the authors' definition of need. For example, 21 of the 29 patients who had a problem relating to side-effects of drugs were assessed as having "no need" in this clinical area because all known interventions had previously been unsuccessful. Similarly, 4 patients who had problems relating to domestic skill were not defined as "in need" in this social area because of the prior failure of known interventions. In other words, the population's health problems did not translate into needs unless they were within the scope of the expertise of the medical professions and existing service provision. Whilst this approach provides valuable information on professionally defined clinical and social problems of specific patient populations and service response to them, it ignores the possibility that service users, if given the opportunity, may define their own needs quite differently and have views on alternative forms of service provision.

The main conclusion derived by the authors was that most needs of patients with severe mental illness could be dealt within the community if resources were diverted from people with less severe disorders. However, their data could not support this conclusion for a number of reasons. For example, given the lack of representation of patients known only to general practitioners, it is not known what proportion of these patients would benefit from, or even want to accept, specialist psychiatric services. More importantly, the needs of patients with less severe disorders were not assessed in this study so it is impossible to determine whether or not they would benefit more from the available resources. It is possible that the investment of resources in such groups of patients is more effective, particularly in view of the high proportion of failed interventions for patients with more severe illness.

Other studies have focused on integrating professional and public views on the priority of different forms of service provision (Garland 1991, Bowling 1993a, Ham 1993, Murray et al 1994, Dicker and Armstrong 1995). The elaborate public consultation exercise in Oregon involving 3 million citizens in determining their basic requirement for health care provision has been described as pioneering, brave, naive, flawed, and part of NHS folklore (Schwartz and Aaron 1990, Dixon and Welch 1991, Bowling 1993b). Commentators on public consultation on needs assessment refer to lessons, positive and/or negative, learnt from the experience of the Health Service Commission in Oregon.

Prior to the public consultation, the Commission consulted with medical experts to develop a list of 'condition-treatment' pairs, eg 'appendicitis-appendectomy', which were ranked by priority of clinical effectiveness. Public views were sought to identify and attempt to integrate social values into the priority list. In this way, the professional view on the benefit of each treatment, in terms of the quantity or duration of benefit, could be weighted by quality of life measures as defined by the public. A preliminary telephone survey of local citizens produced results that caused the Commission to rethink its approach. For example, cosmetic breast surgery was ranked higher than surgery for an open thigh fracture. The revised strategy focused on generating social priorities for general categories of medical intervention, such as preventative or curative interventions, rather than for individual conditions. The help of health care interest groups, such as advocates for the poor, the uninsured and for consumers in general, was utilised to actively encourage the public to attend Health Service Commission meetings and hearings and provide testimony and information. In total 47 town hall meetings were held across the state. After each meeting the opinions of participants were tabulated.

The integrated professional/public priority list, completed in February 1991, consisted of 709 condition-treatment pairs that could be classified according to 17 categories. Services in the highest ranking categories were those for acute, fatal conditions where treatment prevented death and returned the individual to his/her previous health status. The lowest ranking categories contained services for minor conditions, futile care, and services that had little or no effect on health status. The cost was then estimated for each of the services on the list. On the basis of the results of this exercise, the 1991 legislature funded the first 587 of the 709 condition-treatment pairs.

World-wide media attention focused on the Oregon experiment after public outcry about the decision not to fund some transplant operations. The medical professions proclaimed the process of putting monetary values for the comparison of treatments unethical since it implied that for a given degree of suffering, patients who required less expensive therapies would be treated before patients who needed more expensive therapies (Hoffenberg 1992). Critics have also questioned the extent to which the results reflected the social values of the Oregonians: only 600 citizens attended the public meetings to discuss priorities, and of these more than half worked in the health care system. Furthermore, the Health Service Commission was predominately comprised of health professionals, and it was not clear what weight was given to the technical measures of cost and effectiveness relative to public opinion on value in calculating the overall benefits for each intervention. Despite these ethical and methodological criticisms, the Oregon experiment was successful in making public the debate on how priorities for health care should be determined.

A similar ranking exercise on the priorities for different types of service provision was conducted in City and Hackney (Bowling 1993b). The principle aims of the study were to elicit the views of a random sample of the public and members of local community groups and compare these with those of hospital doctors, general practitioners and public health doctors. The survey tool was a self-completed questionnaire based on a range of 16 services/treatments, with examples of specific client groups and outcomes. Some questions were deliberately biased in order to tap opinion about highly specialised services for specific patient groups, such as, *"treatment for children with life threatening illnesses (eg leukaemia)"* and *"intensive care for premature babies who weigh less than one and half pounds and are unlikely to survive"*. Respondents were asked to prioritise the services in relation to the needs of local residents by ranking *"4 essential", "4 most important', "4 important"* and *"4 less important"*.

The questionnaires were posted to a random sample of 454 residents, 121 general practitioners, 197 hospital consultants and 7 public health doctors. However, personal interviews were subsequently employed to increase the response rate of the public from 11% to 78%. A further 359 people from 27 community groups and tenant associations were given questionnaires to complete when they attended routine meetings. Only 9 of these people failed to participate in the study. The response rates of the doctors to the postal survey, after four mailings, was 68% for general practitioners, 66% for hospital consultants, and 6 out of the 7 public health doctors.

Overall priority was calculated by averaging the scores for each service (coded as 1 for *"essential"* down to 4 for *"less important"* and ranking the services from 1 to 16 (high to low). The level of agreement between the rankings of the random sample of the public and the representatives of the community groups was remarkable; treatment for children with life threatening illnesses (eg leukaemia) and special care and pain relief for people who are dying (eg hospice care) were ranked 1 and 2 respectively by both groups, and high technology surgery and procedures which treat life threatening conditions (eg heart/liver transplants) and medical research for new treatments were either ranked 3 or 4. At the lower end of the rank there was also close agreement; complementary medicine and cosmetic surgery were ranked 15 and 16 by both groups and health education, family planning, treatment for infertility were either ranked 12, 13 or 14. With two exceptions, the rankings of the other services were either identical or within 1 or 2 ranks of each other. The two exceptions were preventive services (eg screening, immunisations) ranked 9 and 5 and community services/care at home (eg district nurses) ranked 5 and 11 by the random sample of the public and the community representatives respectively.

The small number of public health doctors in the survey made it difficult to compare their views with those of other doctors. Nevertheless, concordance between the rankings of general practitioners, hospital consultants and public health doctors was apparent in relation to community services/care at home (ranked 1, 3 and 1 respectively) and services for people with mental (ranked 2, 1 and 1 respectively). There was similar agreement between the services given the least priority were treatment for infertility (ranked 14, 14 and 15), complementary medicine (ranked 15, 16 and 13), and cosmetic surgery (ranked 16, 15 and 13. The public health doctors awarded greater priority than the other doctors to family planning (1 versus 9), health education (3 versus 10 and 11) and therapy to help people with disabilities (3 versus 7 and 10).

For many services, the medical and public rankings were similar. However, their rankings were significantly different for services for mental illness, long stay care, and community care (which the doctors prioritised higher) and for high technology surgery and procedures for life threatening conditions and medical research (which the doctors prioritised lower). Unfortunately, it is not possible to determine the extent to which question bias influenced the public's higher ranking of high technology surgery. Leaving aside methodological considerations, this study showed that basing service provision on community values alone would result in low priority for community services and services for the mentally ill. This would not only be contrary to the philosophy of the NHS of equity and equal access according to need, but also defy all political efforts to redistribute resources from acute hospital sector to community services. Whilst this study poses questions on the ethical implications of using public ratings for health planning purposes, discussion of these remain premature until a valid means of consultation is constructed. To be valid, survey tools require not only to reflect respondents' views of the community's health need but also their views on the range of services to meet them.

Studies based on professional definitions of health and health care are limited in that they focus response within the scope of the expertise of the medical professions and existing service provision. This is a token approach to public consultation because views are not sought in relation to needs as defined by the community itself or on alternative ways to meet needs.

Studies Underpinned by Public Definition of Health Need

The social approach to needs assessment adopts the World Health Organisation's broader definition of health as *the state of physical, mental and social well-being* so that health need is viewed not only in terms of the disease process, but also in relation to the individual's personal and environmental resources (Bradshaw 1994). The primary aims of studies adopting this approach are to involve the community in diagnosing its own needs and in formulating these into practical solutions. Consequently, the research framework is flexible to allow the process to be modified to accommodate new information gained during earlier stages. For example, discussion on the priority for service provision is able to incorporate additional options informed by the community's self-diagnosis of problems, previously unrecognised by service providers. A number of active participatory research techniques lend themselves to this approach including the locality needs approach (Colledge 1996) and the life cycle framework (Pickin and St Leger 1993), rapid appraisal (Murray et al 1994), community appraisal (Wainwright 1994), and priority search (Garland and Hasnain 1990). Within this context, there is not only greater scope for need to be determined according to the lay person's view but also for more imaginative responses to satisfying it from within and outwith the medical model of service provision.

A public consultation exercise was carried out in Lothian, Scotland in 1992 to determine patients' perceptions on the need for primary health care services (Hopton and Dlugolecka 1995). In this study, a broader definition of health need was employed so that it included both primary health and primary social services. Although the range of services was defined by professionals, the public had the opportunity to enhance it during an extensive pilot study involving 606 patients. The pilot showed that the public had insufficient knowledge to differentiate between the work of some professionals such as district nurses, health visitors, clinical psychologists and counsellors. The final questionnaire was drafted so that the names of services and providers were replaced by short explanations of their function and roles. In the final survey, a questionnaire was mailed to 6328 patients from five general practices in the Lothian region. The practices were chosen to represent the age, sex and deprivation distribution of Lothian and the patient sample from each practice was stratified by sex and age groups. Respondents were asked to rate the helpfulness of each type of care provision in relation to their personal circumstances. The questionnaire also incorporated measures of health status and patterns of service use.

In 680 cases the questionnaire was returned by the post office because the patient was not known at the address. Of the remainder, 3478 questionnaires were returned, representing a 62% response rate. This ranking exercise showed some similarities and differences in the perceived helpfulness of different services between healthy and unhealthy respondents. 'Regular visits to the practice for health checks' and 'help or advice about coping with stress' were the first and third highest rated services of both groups respectively. Services promoting advice on lifestyle were also universally popular. The greatest discrepancies were for 'help or advice about coping with pain' which was the 2nd most popular service of the unhealthy group but only the 24th of the healthy population, and 'help and advice about HIV infection or AIDS' which was the 11th most popular service of the healthy compared to the 34th of the unhealthy. In general, the unhealthy group rated more services as helpful. Rankings on the basis of severity of need were almost the inverse of popularity rankings in the whole sample. For example, services consistently rated helpful by the small numbers of people in the poorest health (such as help getting out and about, home visits, and advice about equipment) were not contained in the list of the ten most popular services for the sample as a whole.

For a number of reasons, this approach increases the potential for public participation in determining service provision in relation to needs as defined by themselves. First, participants were consulted prior to the rating exercise and given the opportunity to add to the professionally determined range of services. Second, their opinions were more likely to be informed since the ratings were based on clear statements about the role and function of the service. Third, views on services were sought in relation to the respondent's personal circumstances, and not in relation to professionally determined definition of need.

However, the results of this approach may be of very limited value in terms of increasing public participation in determining the need for services in their own community. It is likely that the results, at best, could only be used after they had been subjected to some statistical manipulation on the relative weight to put on the views of various sub samples of the population. For example, the difference between the ratings of 'healthy respondents' and 'unhealthy respondents' indicate a need for separate analysis. This would be required to maintain equity since decisions based solely on the needs of the majority would mask the needs of the minority in greatest need.

The results can only be interpreted as representing the views of a number of individuals which cannot be aggregated to express community values. Respondents were specifically asked to rate services in relation to their own needs and not in relation to their perceptions of the need of their community. The views expressed may have been quite different if they had been sought in relation to the individual's neighbourhood, including people in poorer health and the elderly.

Another Edinburgh based study adopted a rapid appraisal approach to determine the public's views on the health and social priorities of the community (Murray et al 1994). This study used three main sources of data: existing records, observations of people's homes and neighbourhood, and interviews with selected key informants who had local knowledge of the community. Each of these sources was used to collect information on the composition and organisation of the community; the physical and socioeconomic environment; prevalence of disease and disability; and existing health, social and educational service. The research team included health, social work and education professionals who devised the semi-structured interview schedule.

The public consultation part of the appraisal was in three parts. The first involved interviewing an extensive range of key informants including representatives of professional, self-help and religious groups and voluntary organisations. As part of this process seventeen residents and a local shopkeeper were also interviewed. The second part of the consultation involved presenting the data from the interviews and other sources at a public meeting. The third part involved forming two focus groups in order to allot priority to the identified problems and to explore potential improvements.

The results of this process were unremarkable in terms of disclosing previously unidentified medical problems; the main illnesses were thought to be asthma, bronchitis, heart problems and arthritis. The perceived causes of ill health were equally predictable and included unemployment, stress, dampness, poor diet, smoking, drug misuse among younger people, and social isolation among the elderly. Environmental problems in the estate related to hills, steps, poor access, lack of play areas and dog fouling. The solutions prioritised by the focus groups had little medical content such as re-routing a bus service and creating small play areas and dog free zones.

Unfortunately, the authors neither described the data generated from other sources nor the extent to which these were incorporated into the public consultation exercise. Without this information it is impossible to determine if the public's opinion on priorities were fully informed. Analysis of routine activity data may reveal problems that are not obvious to the public, for example, teenage pregnancy and termination of pregnancy. Without access to this kind of information, the general public are unable to make informed decisions on the priority for services that have a less visible impact such as family planning and sex education.

Full participation of the public in prioritisation of services can only be achieved if information held by professionals is placed in the public domain. In other words, the exchange of information must be a two way process between the public and professionals. Without this, professional paternalism prevails and democratisation of decision making is inhibited.

It is clear that survey and consultation tools require refining to overcome professional bias and enable respondents to make informed decisions. As in the case of service evaluations, the approaches adopted in these prioritising exercises raise a greater methodological question concerning their validity. The studies, to date, have concentrated on obtaining the public's priorities for existing services without first determining, if given the choice, they would have prioritised alternative forms of provision. For example, it is possible that the public may have different views from professionals on the qualifications and functions of people who provide support in the community. In other words, these studies attempt to prioritise treatments in order to address the question *what should be done* without first addressing the question *how should it be done.* Addressing the first of these questions without first answering the second is illogical since there is the potential to generate sufficient resources within services for particular categories of need to effect decisions on resource allocation between services.

3. The Consumer Challenge in the NHS

The customer service orientation is still fundamentally management-led and in its use of the tools of the market (customer surveys, complaints procedures, standard setting, customer panels and public attitude testing) takes an individualistic rather than a collective approach. Despite policy guidance that calls for the development of partnership arrangements with the public and for user 'control', the approaches discussed so far are merely concerned with information and intelligence gathering. These approaches fit more closely to the lower levels of Quayoom's model of empowerment (Quayoom 1990) and, for this reason, the extent to which the NHS has embraced the challenge of empowering consumers can only be described as cautious.

II. THE CONSUMER VOICE: EMPIRICAL STUDIES

4. BACKGROUND AND RESEARCH AIMS

The developmental and survey work for these studies were undertaken between 1991 and 1994 as part of a programme of research commissioned by Ayrshire & Arran Health Board through the funding of a research fellowship to the Department of Social Policy & Social Work, University of Glasgow.

The broad remit set by the Board's Director of Quality and Service Development was to undertake research in the field of patient satisfaction. The service chosen for evaluation was long term hospital care for the elderly because existing evidence suggested that these patients were least likely to be critical of service delivery. The approach adopted was influenced by the question of the reliability of this evidence given that it was unknown to what extent service evaluations were based on criteria that were known to be important to the patients as opposed to service providers or managers. Thus, the particular research aims of this first phase of the research were to elicit the criteria by which consumers of long term care judge a good service, to compare these criteria with those of others traditionally used as patient advocates, and to measure service performance against the consumer criteria.

The second phase of the research built on the methods used in the previous study. During this phase, the focus shifted from obtaining consumers' views on the quality of service delivery to determining the public's views on the need for services. The choice of field for this research was mental illness and was influenced by increasing national and local press coverage of concerns for public safety following the transfer of patients from mental health institutions to the community. During the single month of April 1993, a study commissioned by the Scottish Health Working Group identified 562 items on mental illness/health reported through newspaper, television, radio and magazine (Philo 1993). Analyses of the content of these items showed that violence by people with mental illness towards others was not only the most common type of coverage but also was more likely to feature as headline news, whereas sympathetic views were more often covered in the problem pages of magazines. Locally, there was a much publicised successful attempt by a group of Ayr residents to thwart a plan to convert an Edwardian villa into a community home for eight Ailsa Hospital patients. One of the residents bought the £200,000 residence while others contributed to the legal costs. There was a decision by a District Council to refuse planning permission for a similar development in Kilmarnock, responding to a petition signed by 84% of local residents.

Against this background, this second phase of the research provided an opportunity to collect information in a systematic way on the views of both the public and service providers on the need for services and supports for people with mental health problems. The particular research aims of the second phase of the research were to define a comprehensive range of services to support people with mental illness that reflects both consumer and professional views; to elicit the informed views of the public on the need for services to support people with mental illness in their community; and to compare these views with those of health and social workers.

Although the developmental work concentrated on services for the elderly people and people with a mental illness, it was intended that the consumer-based methods would be applicable across a wide range of health service activities.

5. CONSUMER VIEWS ON THE QUALITY OF SEVICES

This chapter reviews the range of methods that can be used to obtain consumers' views on the quality of services. The strengths and weakness of different approaches are highlighted, providing the rationale for the choice of methods for the present study. It describes the development of methods and reports the results of their application.

The central research questions dictated a combination of qualitative and quantitative methods. In the first instance, a qualitative approach was required to elicit the criteria by which patients and their advocates judge a good service. A quantitative approach was then required to determine the extent to which the service routinely met the patients' criteria for a good service.

The choice of the precise methods for both approaches was influenced by factors relating to the study population - ie patients in long stay wards for the elderly. In particular, the methods employed had to be sensitive to the diverse range of conditions that might affect these patients' physical and mental ability to participate in a study. The methods employed were designed to minimise difficulties that the patients may have experienced. In relation to the final survey tool, the length and content were influenced by the requirement to overcome problems relating to the patients' ability to concentrate. For this reason, it was unlikely that it could comprehensively cover all the consumer criteria for a good service. Therefore, the method for eliciting these incorporated a means by which they could be prioritised so that the final survey tool addressed those which were known to be the most important to the consumer. This approach can be further justified in relation to the value of the information it provides to service providers. Since the capacity of any organisation to respond to change is limited, its efforts should be directed towards those which are most important to the consumer.

1. Review of Methods

A number of qualitative research techniques could be used to explore the criteria by which consumers judge a good service. Exploratory research is undertaken when the researcher assumes total ignorance of the subject area or recognises that the phenomenon is familiar but may be subject to misconceptions. Under either of these circumstances, the method employed cannot rely on specific hypotheses or a well defined list of variables that are likely to be significant. The relative strengths and weaknesses of individual techniques were examined prior to deciding on the most appropriate method for the present study.

Participant Observation: Participant observation refers to a range of activities varying from actually becoming a bona fide member of the study population to observing its members either explicitly or secretively as an outsider. An early example of a study which utilised both these approaches is provided by Julius Roth in his study "Timetables, Structuring the Passage of Time in Hospital Treatment and Other Careers" (Roth 1963). Roth carried out this research, based on observation, shortly after attaining a PhD and when his first academic post was interrupted by an admission to a tuberculosis (TB) sanatorium. Instead of accepting this as an interruption to his career, Roth used this experience as an opportunity to further his studies on the social psychology of institutions and occupations. His hospital bed became an observation post to study covertly the processes by which patients (a) gauged their progress during a long stretch of hospitalisation and (b) bargained with service providers to hasten progress between the various benchmarks that were associated with the road to recovery. One year after he was discharged from hospital, Roth carried out a second series of observations in the treatment of TB, this time as a sociological observer. The intention was to complement the data from the original study which concentrated patients' perspectives with those of various staff groups.

During the 1950s and 1960s, the treatment of TB required long periods of hospitalisation of uncertain duration. Roth described the patients' chief preoccupation with discharge from hospital and their efforts to define a timetable of norms against which they could measure their progress. Some norms were based on a series of privileges granted to patients throughout their hospital stay. These included being allowed up to use the toilet/bathroom; the length of time allowed out of bed; being allowed to go to the dayroom; being allowed to go to occupational therapy; being allowed outdoors for a walk; and being granted an overnight or weekend pass. Some aspects of diagnosis and treatment were also used by patients as reference points to measure their progress. These included the regularity of case conferences and the timing of X-rays and blood culture tests.

Roth's work provides an insight to the extent to which patients could influence decisions made by health professionals in their efforts to accelerate their progress through the various benchmarks of the timetable. Patients employed both positive and negative tactics in their attempts to alter their treatment timetable and ultimately the length of their hospital stay.

Positive tactics involved patients trying to impress physicians with the degree to which they followed treatment recommendations, particularly those that related to rest and restriction of activities. Such patients believed that they "should get time-off for good behaviour" compared to those who flagrantly disregarded physicians' recommendations. The "good behaviour" tactic had a low chance of success for TB patients: physicians were much more likely to be influenced by the clinical evidence in the patient's X-rays and bacteriological cultures than by his or her behaviour. Drawing on the work of Goffman, Roth described how the "good behaviour" tactic is a much more powerful tool for patients in mental hospitals (Goffman 1961). Since mental illness is often characterised by behaviour outwith what is considered normal, changes in the patient's behaviour that are perceived by professionals to be more compliant can be interpreted as evidence of recovery.

Negative tactics by TB patients to influence physicians' decisions included threats, name-calling and (in the case of women) tears. Whilst physicians varied in terms of the amount of resistance they would exert to such tactics, these tactics were generally considered successful. Roth observed that it was common for physicians to decide not to discharge "borderline cases" unless they were "anxious to go home" and/or "putting up a fuss". In some cases, patients used people outside the hospital to apply pressure on their behalf. Roth believed that hospital physicians frequently paid more attention to the demands made by mothers, wives, sons, daughters, employers and clergymen than to the patients themselves. Roth hypothesised that once again this tactic had the opposite impact for patients in mental institutions. For the same reasons that positive or compliant behaviour by patients with mental illness could be interpreted as evidence of recovery, negative or demanding behaviour could be interpreted as a sign that they are not yet ready for discharge.

One of the most interesting findings of Roth's study of TB patients was that they appeared to hold a trump card in the bargaining game they played with physicians. This was the threat of leaving hospital against medical advice. Physicians did sometimes counter this by telling patients that they could "leave at anytime… and good riddance". However, in the main, the physicians tended to make concessions in the treatment timetable to placate and retain patients, not only because of concerns for the wellbeing of individual patients but also for the health of the public who might be exposed to a contagious disease. With the virtual eradication of polio and TB in Britain, it is possible that no single group of patients has since enjoyed the same degree of consumer sovereignty in the NHS as those who were hospitalised as the result of a contagious disease during the 1950s and 1960s.

Although, Roth sent copies of the initial drafts to interested patients and ex-patients whom he had met during the course of his fieldwork, his report does not contain any discussion relating to their views on his interpretation of their behaviour. By contrast, the report contains several footnotes indicating where physicians disagreed with the author's interpretation of their actions. For example, some physician critics believed that Roth had laid too much stress on the uncertainties of diagnosis and treatment. It is entirely possible that these criticisms are unfounded and that the physicians were simply unhappy that the report highlighted incidences where decisions were made in the absence of established evidence. On the other hand, the author may have misinterpreted his observations, with or without intention, because he was influenced by his own preconceptions (perhaps derived from his experience as a patient) or was ignorant of all the relevant facts (during the second part of the study, the author was not resident in the hospital and may have missed pertinent observations). Concern regarding the validity of their interpretation is a major drawback of research based on observations.

Kitwood and Bredin spent years developing the highly disciplined observational method, Dementia Care Mapping, to evaluate services from the consumer's perspective, regardless of the extent of their cognitive impairment (Kitwood and Bredin 1992, Kitwood 1993). This method employs trained observers who work in teams of two or three for periods of four to six hours in each care setting. Each observer is capable of 'shadowing' up to five people for whom they complete two coding frames. The first, the Behaviour Category Coding, summarises what has been happening to each individual in relation to 95 separate categories during successive five minute time frames. The second, Personal Detraction Coding, records every interaction which results in the person with dementia being discounted or demeaned in any way. The categories are designed to show whether a person has been engaged or neglected, stimulated or bored, affirmed or devalued, helped or hindered as a result of care practice. A scoring system is applied which indicates whether the care enhanced or diminished the individual's personal wellbeing. A 'dementia care quotient' is calculated to indicate the overall quality of care allowing for client/staff ratio.

Using more than one observer to collect data in such a systematic manner is a particular strength of Dementia Care Mapping as it addresses the common concern regarding the reliability of the observation. As a research method, the validity of the interpretation of these observations is problematic. In particular, the system is based on the assumption that the actions of care givers or the process of care can be translated into care outcomes. For example, evidence that a patient was not stimulated during a particular interaction may not necessarily have diminished the individual's sense of wellbeing.

In relation to the present study, participant observation was not considered a viable approach because recording patients' responses, whether positive or negative, to various components of the service would not provide information on their relative value to patients. For example, whilst patients may appear happy when nurses spend time chatting to them, it is not possible to determine whether this is viewed by the patient as an essential component of the service or a peripheral concern. Furthermore, the information generated by this method may also be limited because opportunities to observe would be limited. For example, some aspects of care are delivered in private. A further disadvantage is that the method does not allow the opportunity to describe aspects of a service which may be valued by patients but which the service does not deliver.

Asking Questions: The most straightforward method of obtaining information on a subject is to question respondents directly. The approach to questioning can be described as structured or unstructured depending on whether the subject of the research requires to be explored or quantified.

Questionnaires administered by post or telephone or in person tend to be highly structured. With a highly structured questionnaire, not only are the questions pre-determined but also the range of possible answers and respondents have no opportunity to elaborate on any point. Less structured questionnaires include some open-ended questions that elicit free-ranging answers. With questionnaires, the scope of the research is largely pre-determined by the focus and range of the questions and, for this reason, the respondents' influence in determining the research issues remains limited.

A useful review of the use of questionnaires in surveys in health care field is provided by Ann Cartwright in "Health surveys in practice and in potential: a critical review of their scope and methods (Cartwright 1983). The review is structured under seven broad headings (1) health and illness, (2) the nature of disease, (3) needs for different sorts of care, (4) factors associated with the use of services, (5) the effects of care, (6) acceptability of care and (7) the organisation of care. Quality of care was not considered separately because the author argues that quality is dependent on the extent to which needs are met, services are used effectively, outcomes of care are good, care is acceptable and the organisation is efficient and effective. As part of the review of the acceptability of services, a comparison was made between two national surveys of patients' attitudes to hospital care. The first was carried out by Cartwright herself in 1961 (Cartwright 1964) and the other by Gregory between 1977-78 (Gregory 1978). Both used the electoral register as a sampling frame and each involved around 750 interviews. Cartwright identified her sample by means of a postal screen, while Gregory identified hers by appending additional questions to the General Household Survey. Although there was a great deal of similarity in their field of enquiry, the wording of the questions in the two surveys was quite different. Cartwright is critical of this and also criticises Gregory for not making any comparisons between the results of the surveys. One example cited by Cartwright concerned the time at which patients were woken. The studies used different cut-off points in their scales which Cartwright hypothesises would make considerable differences as respondents would be likely to round off to a precise hour or half hour. The scales used in the studies were:

Time of Awakening in the Two Studies

Cartwright 1961		***Gregory 1977-78***	
Range Provided	% respondents	Range Provided	% of respondents
Before 5 am	7		
5 am < 5.30 am	28	5.00 - 5.30	12
5.30 am < 6 am	27	5.31 - 6.00	32
6 am < 6.30 am	26	6.01 - 6.30	32
6.30am < 7 am	7	6.31 - 7.00	16
7am or later	5	7.01 - 7.30	6
		7.31 - 8.00	1
		After 8.00 am	1

The criticism by Cartwright is harsh since Gregory's scale can be justified for two reasons. First, the results show that during the intervening sixteen years, there was a clear movement towards later waking-up times in hospital. Second, Cartwright's use of the arithmetical symbol '<' in the range of time intervals is open to misinterpretation. For example, "5 am < 5.30 am" correctly interpreted means "5 am is less than 5.30 am". Cartwright presumably means this to be interpreted as "at least 5 am but earlier than 5.30 am". If so, the correct arithmetical expression would be "5 am < t < 5.30 am" (where t denotes the time of awakening). However, this would be an unnecessary complicated way in which to define time intervals in any survey tool and Gregory's simplified approach avoids any confusion which researchers and respondents may have over interpreting arithmetical symbols.

Cartwright is also critical of the approach used by Gregory to obtain information from respondents on the adequacy of information whilst in hospital, a major source of dissatisfaction in both surveys. Cartwright's main question was: "While you were in hospital were you able to find out all you wanted to know about your condition, your treatment and your progress?" She defends the inclusion of three separate variables (ie condition, treatment and progress) in a single question by arguing that as people do not always distinguish between them, it is more realistic to combine them. The defence is weak since this approach to questioning may lead to difficulties for respondents who may have been satisfied with some but not all of the variables. In such cases, it is not possible to determine whether each respondent overcomes the dilemma consistently which, in turn, causes difficulties in the analyses of their responses. Gregory has attempted to overcome these difficulties by asking a series of questions on the adequacy of information. She does this in relation to treatment and progress but omits to address the adequacy of information on condition. Gregory's first question addresses information given in relation to eight specified treatments or tests. For each of these, respondents were asked: "Were you told enough about why it was necessary? As Cartwright rightly observes, the question is limited in that it does not address other information needs that patients may have on these, and indeed others outside the specified range, such as what the test or treatment entailed, whether or not it would hurt, and how it might help. The approach adopted by Gregory to address adequacy of information on progress whilst in hospital is more general and, as such, avoids these limitations: "While you were in hospital do you think you were always told enough about how you (and the baby) were progressing?"

Similar differences between the researchers' approaches existed in other questions. For example, in the Cartwright study, respondents were asked: "In general did you ask about things or did people tell you of their own accord?" The responses distinguished between those who mainly asked; those who were mainly told; those who neither asked nor were told; and those who did not answer in these terms. Once again, Cartwright seems to have tried to elicit information on more than one variable with a single question – ie information seeking behaviour of patients and information giving behaviour by service providers. Once again, this question is likely to pose problems for some respondents who were unable to distinguish the actual division between their role in the information exchange. It is likely that in many patient/service provider dialogues both these means to obtaining information are employed. For example, even when the patient initiates the exchange of information, the service provider may address the patient's particular question, then supplement it with additional information. In the Gregory study, this distinction between how the information is received was not made. Instead, respondents who indicated that they were not always told enough were further asked follow-up questions: "Did you feel that you could ask the doctors to tell you what you wanted to know or not?" and "When you asked the doctors what you wanted to know did you generally get a satisfactory answer? Although, Gregory's first general question overcomes the difficulties posed in the earlier study, the supplementary questions are limited as they assume that doctors were the sole sources of information.

In her discussion of the likely effect of differences in the way questions are framed, Cartwright suggests that respondents may not be too concerned about the precise form of the question but instead answer the question that they feel that they ought to be asked and tell the interviewer what they feel is important. Rather surprisingly given her experience of survey research, which depends on collecting the same information from a number of subjects, Cartwright does not highlight this as a particular area of concern. Difficulties will arise, unless questions are being administered by an interviewer who is sensitive to how respondents are interpreting questions, because different information will be collected from different respondents according to what their perceptions of the question they ought to have been asked or the relevant issues. If this is the case, the implications for surveys which rely on self-completion of questionnaires are that researchers must not only ensure that the questions accurately reflect the valid concerns of the respondents but also that the they are worded in a way that avoids ambiguity of interpretation.

More recently, a study was carried out in Scotland which sought to explore if different patient satisfaction measures yield consistent results (Cohen et al 1996). This study compared the results from three questionnaire surveys of patient satisfaction with selected aspects of hospital care. The findings of the study are based on the responses of residents in the Lothian region to two identical surveys employing interviewers, in 1992 and 1994, commissioned by the Management Executive of the NHS in Scotland, and a third postal questionnaire commissioned by Lothian Health during the intervening year. All three studies were based on randomly selected members of the general adult population in the Lothian region who had received hospital care in the previous 12 months. The response rates were 76% (total number of respondents =1187), 78% (total number of respondents =2569) and 80% (total number of respondents =1498) for 1992, 1993 and 1994 surveys respectively.

The two NHS interviewer surveys included a series of similar questions referring to the respondents' most recent experience of hospital care in relation to "information", "involvement" and "treatment as an individual". The questions themselves were structured around a set of negative statements, such as, "I was not given enough information", "I was not encouraged to ask questions". These statements were presented to the respondent by the interviewer who asked: "Thinking about the information you were given at hospital, did any of these things happen at your visit?" Respondents were then invited to rate the seriousness of any problem identified on a five point scale, and finally asked how satisfied they were overall with the amount of information they had been given. Similar approaches were used to elicit views on "involvement" and "treatment as an individual". The sets of negative comments relating to these areas of enquiry included "I was not encouraged to get involved in the decisions about my treatment", "Nobody listened to what I had to say", "My privacy was not respected" and "The staff were insensitive to my feelings". The set of questions on "treatment as an individual" also included the neutral question "Did you feel you were treated as an individual or just another case?"

The Lothian Health postal survey differed not only in the way in which the questions were administered but also in the way in which the questions were framed. The postal survey was based on responses to two distinct sets of positive and negative statements, the content of which were similar if not identical, to those used in the NHS interviewer survey. The positive statements were preceded by the written instruction: "*Thinking generally about your experience in hospital in the last year, please tell us if you agree or disagree with the statements below*" and included statements like "Your privacy was respected", "Staff were sensitive to your feelings" and "You were encouraged to ask questions about your treatment". The negative statements were preceded with the instruction: "*The National Health Service in Scotland published a booklet called Framework for Action. They listed* *some of the things that upset patients. In your experience of hospitals in Lothian are any of these things a cause for concern?*" The statements that followed included "doctors who have no time to listen", "Doctors who ignore what you say", and "Feeling that you are seen as a medical condition, not as a whole person".

As there were no significant differences between the results of the two NHS interview surveys, these were pooled and compared with those of the Lothian Health postal survey. For the 10 items which were considered comparable, the Lothian Health postal survey consistently showed more patient dissatisfaction than the NHS interview survey. There were no statistical significance between the reported levels of dissatisfaction regarding 'patient privacy' and 'patient dignity' (< 5%) and 'sensitivity to patient's feelings', 'being treated as an individual', and 'clear explanation of care or enough information' (between 5% and 10%). However, significant differences between the surveys were evident in the responses to other questions relating to other areas concerning communication. The most striking difference was between the responses to the question about being encouraged to ask questions: 6% of respondents in the NHS interviewer survey agreed with the statement "I was not encouraged to ask questions", whereas 24% of the respondents to the Lothian Health postal study disagreed with the statement "You were encouraged to ask questions about your treatment". The authors argued that different results can be obtained if patients are presented with a negative statement about care and asked to agree that something "bad" had happened, as opposed to presenting them with a positive statement and asking them to disagree that something "good" had happened. On the basis of this, they conclude that over-reliance on negative statements to elicit information on users' perceptions may provide a misleading picture and a poor foundation for policy directed at improving the quality of care. Disregarding the issue of using the word 'treatment' in one statement and not in the other, this argument may be flawed as the two statements may not be measures of the same thing. It is possible that each is measuring patients' perceptions on two quite different behaviours. For some people, the statement "I was not encouraged to ask questions" could be interpreted as "there were negative reactions on the occasions when I asked questions". On the other hand, the statement "You were encouraged to ask questions" could be interpreted as "staff actively encouraged me to ask questions about my treatment, irrespective of whether I felt the need to". On the basis of these interpretations, the statements cannot be viewed as converse images of each other; one may be a measure of patients' perceptions of staff's tolerance to questions whereas the other may be a measure of the patients' perceptions of staff's behaviour in relation to encouraging questions.

The authors also advance the argument that patients would find it more difficult and time-consuming to be openly critical of care when the questions are administered by an interviewer rather than by a self-administered questionnaire. This may have been a factor in the NHS interviewer studies which relied on the interviewer showing the respondent a card with a list of negative statements and only pursuing those for which a problem was indicated. The interviewer's schedule, which had the instruction "Multicode OK", may also have encouraged the interviewer to pass quickly through items which respondents completing a self-administered questionnaire would have spent more time considering.

The above are examples of fairly structured interviews – ie the questions and the range of responses were largely predetermined prior to the interview itself. Interviews can have a looser structure so that the exact wording and sequence of questions are not determined until the time of the interview itself, usually at the discretion of the interviewer. A non-directive interview is the most extreme form of the unstructured interview where the interviewer's sole objective is to get respondents to talk and to keep them talking. In this situation, respondents have total control over the content and style of the conversation. As a survey technique, this approach has very limited application since the results are unlikely to be comparable from one respondent to another. Its application is more commonly found in therapeutic situations such as psychoanalysis. There is no distinguishable dividing line between the structured and the unstructured interview. Structured and unstructured approaches to interviewing represent the opposite ends of a continuum, which encompasses a whole range of techniques.

The focused interview is also unstructured but the interviewer has more control over the direction of the discussion. In this situation, the interviewer requires respondents' views on one or more pre-selected issues or topics, however, the questions themselves are not pre-determined. The manner by which the information is elicited is largely determined by the natural course of the discussion. This method offers respondents greater scope in defining the research issues than structured interviews.

When attempting to obtain the views of any population, the researcher can choose to conduct a number of interviews with representative sample of people either on an individual basis on in group situations. Individual interviews are particularly useful when the issue to be explored is considered sensitive or when it is organisationally difficult to obtain the collective views of a representative group. Group interviews offer more than the obvious benefit of economy of time in terms of obtaining the views of a number of individuals during a single interview. The information may represent more considered responses because participants have the opportunity to modify or affirm their views within the context of the views expressed by others. Moreover, additional insight into the research subject matter may be gleaned from the language and behaviour of participants as they interact with their peers as opposed to trained interviewer or academic. The evolving relations among group members has been identified as a crucial stimulus to elaboration and expression of ideas and these can provide some insight into the nature of relationships in the field, such as strong differential or allegiance patterns (Barbour and Kitzinger 1999).

In her study Hard-Earned Lives: Accounts of Health and Illness from East London, Cornwell likens her approach to interviewing more akin to social anthropology than to other disciplines in the social sciences, in so far as the emphasis was on investigating "the whole and on links between apparently discrete areas of social life" (Cornwell 1984). By contrast, other disciplines in the social sciences, such as medical sociology or social psychology, tend to investigate matters relating to health in isolation from other aspects of social life.

The study was based on a series of interviews with twenty-four people who lived in East London. It was chiefly concerned with the respondents' common sense ideas and theories about health, illness and health services. Cornwell used a case study approach whereby she interviewed a number of respondents repeatedly, establishing relationships with them in the process. The interviews were constructed around a schedule of topics. They included some standard questions that were put to everyone and also questions developed specifically for each individual each time he or she was interviewed, that made use of information from earlier interviews with them and other people. Her approach was governed by two assumptions. First, that the significance of peoples' views on their health, illness and health services could only be understood if they were studied in the context of their lives as a whole such as family, work and community. This required repeated interviewing to permit a level of detail and thoroughness. Second, repeated interviewing and establishing relationships with her research subjects was a more ethical approach to research than the one-off interview that employs methods calculated to "*get what one wants out of them*". It is questionable whether or not either of these assumptions is supported by the study findings.

A key finding of the study was that people gave different accounts of their attitudes or experiences depending on to whom they were talking and the context in which they conversation occurred. Cornwell uses the terms 'public accounts' and 'private accounts' to distinguish these differences. Public accounts denoted the type of responses given when the respondent was either predisposed to giving favourable impression or was reluctant to give what might appear a disrespectful response. These responses were most apparent during initial interviews when the interviewer was still a relative stranger to the respondent and to direct questions. Private accounts were derived from personal experience and the thoughts and feelings accompanying it, regardless of their perceived social desirability. These accounts were most common during later interviews when the researcher and respondent had established a relationship and when the respondent was encouraged to tell a story, particularly when there was a third person present. The difference between the two types of account was illustrated throughout the interviews, regardless of whether they were talking about their families, work, health or health services. It is the commonality of this finding that makes it questionable whether or not it was necessary to extend the enquiry beyond the main research interest. The difference between the accounts also raises doubts about whether this approach is ethically more acceptable. The private accounts were mainly provided after the researcher had established a relationship/friendship with the respondent. It could be argued that the researcher, who was motivated to gather data for her thesis for a higher degree, created or manufactured relationships (ie these would not have occurred naturally) in order to obtain information that would generally only be divulged in these circumstances.

Cornwell advances the theory that public accounts of health-related matters were generated for another reason that was not applicable to the other topics. She claims that, because our culture assumes that health is a subject for experts (ie something that only learned doctors know about), in their public accounts, people made sure that what they said was not only non-controversial, and thus likely to be acceptable, but that it conformed with their notion of the 'medical point of view'. This may have been the case when respondents were discussing their, or their perceptions of others', experience of ill health, in so far that they made attempts to legitimise the experience by a medical diagnosis or, in the absence of this, to justify it so that the onus of the illness did not rest with the individual concerned. For example, one respondent expressed the view that his nephew's eczema was a medical condition for which neither his nephew or his parents were to blame:

> *"It's a disease, isn't it? And I don't think they really know how it occurs or anything like that. And it's definitely not through dirt because, as Bet will tell you, my sister's house is as clean if not cleaner than most people's. Hygienic, you know. And it wasn't through the food because her cooking, she's a real good cook so it's not through neglect, not eating bad foods or tinned foods."*

In their discussions of doctors and health services, Cornwell maintains that the differences between the respondents' accounts were sustained so that the public accounts tended to be complimentary and respectful of the medical professions and it was only in private accounts that people were critical or derogatory about doctors. However, her evidence does not always support this conclusion. For example, in response to general questions about doctors, such as 'What is your image of a good doctor?' and 'How easy do you find talking to your doctor?', some respondents were openly critical not only of their doctor's professional ability but also of the doctor's manner:

> *"He was useless to me, he didn't give me no confidence at all. I thought to myself. 'If I'm really ill, I wouldn't like to go to him because I don't think he'd be able to diagnose a pimple on the end of my nose'........"* and
> *"All you do is go in there and all they do is keep writing and grunting. Don't say nothing to you. And you've got to keep making yourself look like an idiot and keep saying, 'Well, what about so and so? Is that all right?' 'Mm'. 'Well, what about that?' 'Mm'. And that's all you get. I know it's probably their time, they haven't got the time. But surely the time you take to go 'Mm' is the time to say 'Yes' or 'No' or 'No, it's all right'. It can only take as much".*

One possible explanation for criticisms in these public accounts which was not explored by Cornwell is that by the time these issues were discussed, relationships between the researcher and respondents were well established and respondents were less guarded in relating their views. In other words, the design of the study, which relied on repeated interviews and the establishment of relationships, eroded the differences between the accounts that people gave in response to formal questions and the accounts derived from anecdotes.

Cornwell contrasts her findings with those of Stimson and Webb who found that respondents were highly critical of doctors during focus group interviews (Stimson and Webb 1975). The explanation offered by Cornwell for the difference in findings was that the effect of the group on the people taking part in it was to legitimise the content of what would have otherwise remained a private account. This is a highly plausible explanation. In the Cornwell study, the researcher was a middle class female pursuing a higher degree in a part of London where it was unusual for people, especially women, to have been educated beyond secondary level and to have professional occupations. Under these circumstances, it is not surprising that the researcher had to expend considerable time and effort before respondents felt able to divulge their private accounts. By contrast, research based on the explicit use of peer group interaction to generate data is likely to overcome difficulties associated with respondents' reticence about relating controversial material to an academic. In focus groups, the researcher is not concerned with obtaining the responses from a number of individuals. Instead, respondents are encouraged to ask each other questions, exchange anecdotes and views, and respond to the contributions of others. The outcome of focus group interviews is greater than the sum of the individual contributions since the respondents create an interactive audience for each other. Additional insight is gained not only in terms of the way in which information is recounted but also about the processes involved in negotiating and understanding exchanges.

Scope of Focus Group Interviews

Although developed by social psychologists, focus group interviewing is more strongly associated with market research (Frey and Fontanna 1991, Barbour and Kitzinger 1999). It has been adopted by market researchers as a major data gathering technique to elicit responses on the appeal of advertising strategies or in consumer product preference (Goldman and McDonald 1987, Greenbaum 1987). Social scientists have used the technique to inform questionnaire development and as part of programme development (Basch 1987).

Interest in focus group interviews is gradually gaining momentum. Studies based on focus group interviewing have been conducted in the fields of epidemiology (Joseph et al 1984), health education (Basch 1987), service evaluation (Pryce-Jones 1988) and programme planning (Howland et al 1989).

Guidelines for Focus Group Interviews

There are no hard and fast guidelines for conducting focus group research. Decisions on the size and number of groups, their recruitment, composition and structure are all influenced by the subject matter and the availability of participants.

Group Size: The most frequently recommended size for a focus group is between 6 and 12 respondents, although smaller groups may be preferable for particularly sensitive subject matters (Bowling 1997). Any perceived advantage to smaller groups must be weighed against the risk of losing data by limiting the number of members ie the data sources. Experiments on the optimum size of focus groups have shown that eight members generated significantly more information than groups of four members (Fern 1982). On the other hand, twelve respondents were viewed as the maximum number that could be successfully moderated (Mendes de Almeida 1980). The greatest risk associated with larger groups is that they will disintegrate into two or three smaller groups whose discussions are independent of each other.

Number of Groups: The relatively small number of respondents used in focus groups to represent a study population is one of the criticisms most frequently levelled at focus groups. Counter critics maintain that whilst increasing the size of a sample by increasing the number of group interviews may decrease sampling error, non-sampling errors are more likely due to interviewer and respondent fatigue, inconsistency in coding, and interviewer bias due to the replication of information (Lipstein 1975).

Recruitment of Participants: Locating individuals who meet the study's inclusion criteria is frequently difficult, regardless of the nature of the research. In the absence of access to a comprehensive sampling frame, potential recruits for the study can be identified using a number of pre-recruitment techniques commonly used by market researchers such as postal, telephone and door-to-door surveys. In practice, there are often mitigating circumstances for employing a less systematic approach to identifying potential recruits. These include the available resources in terms of the researcher's time and budget.

Regardless of the means by which potential respondents are identified, the recruitment procedure should, as far as possible, eliminate bias in their selection. In particular, the procedure should minimise the exclusion of those who are busy or inaccessible and be aware of the effects of *"volunteer bias"* evidenced in the Oregon experiments (Bowling 1993b).

Composition of Groups: The composition of the focus group is largely determined by the research interest. In general terms, however, members should be fairly homogeneous but with enough diversity to allow for the exchange of different ideas and hence discussion. The risk of assembling any heterogeneous group, whether for a dinner party or research purposes, is that frank and fruitful discussion is delayed until individuals have established common grounds and overcome differences. In relation to a focus group, the time taken to achieve this is generally at the expense of the time available for the focused discussion.

Opinions differ over the reliability of the information gathered from individuals who have previously met as a group, either in a previous research project or in any other context such as church, voluntary or organisational committees. Opponents argue that data generated by pre-existing groups may be influenced by previous behaviour and culture of the group (Mendes de Almeida 1980). For example, a heated exchange between members may be more of a reflection of an earlier disagreement of which the researcher is ignorant than of genuine diversity of opinion. It is also argued that over time a group can become skilled in intellectualising and considering matters but at the same time loses its ability to provide the spontaneous reaction and perhaps qualitative insight into the research matter (Mendes de Almeida 1980).

Proponents recognise the existence of pre-established group cultures but argue that they add, rather than detract from, the reliability of data (Kitzinger and Farquhar 1999). They reason that an individual's views are not only influenced by the exchange of ideas during a single encounter but also by the validation and rejection of ideas in previous encounters. Opinions are not created in a vacuum; the weight accorded to two different but equally convincing arguments is affected by the individual's perception of the credibility of the campaigners on the basis of previous experience. Allied to this, some argue that respondents are more likely to express honest views if other members are in the position to challenge on the basis of previous discussions or deeds (Barbour 1999).

Structure of Groups: The structure of the focus group is largely determined by the research interest. In research of sensitive subjects, such as termination of pregnancy, general issues relating to women's health or contraception may be discussed before focusing on the specific research interest. On the other hand, if the aim of the research is to obtain spontaneous views, such as the public's natural reaction to a health promotion campaign, the general rule is to start with the specific and progress to the general since it is highly unlikely that members of the public would spend 45 minutes or so "contextualising" issues before formulating their views.

The degree of structure applied to focus group interviews is determined by the extent to which the researcher is required to ask pre-determined questions and control group dynamics. Calder addressed the issue of how structure affects data by making the distinction between phenomenological and exploratory approaches to focus groups (Calder 1977). The emphasis of the former lies on learning the participants' perspectives on the focal topic, whereas in the latter, as the name implies, it lies in increasing the knowledge base on previously identified issues.

The phenomenological approach described by Calder is a relatively relaxed process during which the researcher seeks responses to pre-determined questions but exercises limited control over the interactions within the groups. Central to the phenomenological approach is the belief that individuals are self-interpreting and that their interpretations have an essential place in understanding. Since reality is constructed and interpreted by individuals many realities exist, none of which can be identified as more objective or truthful than any other. There are some obvious limits to this extreme position but it has been influential in a number of recent studies employing the focus group approach. For example, in a study of spinal cord injury this was the explicit theoretical perspective (Carpenter 1994).

The exploratory approach is a more tightly structured, in which a moderator controls both the questions and group dynamics. This is the most common approach and it is appropriate when the research issues are unproblematic but it seems necessary to refine them. It has been applied to probe the bases for participants' perception on, or preferences for, pre-defined alternative hypotheses. This approach underpinned the use of focus group interviewing in a recent study that sought explanations for risk-taking behaviour among gay men (Hospers et al 1994).

The remainder of this section describes one technique, the Nominal Group Technique, which combines elements of the phenomenological and exploratory approaches to focus group research. Although highly structured in terms of controlling group dynamics, its design respects the participants' perspective in defining the phenomena before exploring these further.

The Nominal Group Technique

The Nominal Group Technique was developed by Andre L. Delbecq and colleagues in 1968. The authors describe its evolution from social-psychological studies of decision conferences, management-science studies of aggregating group judgements, and social work studies of problems surrounding citizen participation in programme planning (Delbecq et al 1975). Its use is most appropriate in situations where individual ideas and judgements need to be tapped but where a group consensus is the desired outcome.

The Nominal Group Technique is a group meeting of five to ten individuals who are assembled round a table in full view of each other and the group moderator. At the start of the meeting the moderator explains the research interest usually in the form of a single research statement or question. Members are not allowed to communicate with each other, instead they are asked to silently and independently record their own ideas in response to the question or statement. At the end of five to ten minutes, a structured sharing of ideas occurs. Each individual, in a round robin fashion, presents one idea from his or her own private list. The moderator records each of the ideas onto a flip chart in view of the other members. There is still no discussion at this point of the meeting, it is simply a mechanical exercise of transferring the privately generated ideas into the public domain. The round-robin exercise continues until all members indicate that their private list is exhausted, usually the combined list will contain between eighteen and twenty five ideas. Group discussion follows during the next phase of the meeting when each idea on the chart is systematically reviewed in order to seek clarification and support or non support from members. This is then followed by another independent exercise whereby participants privately select and award a numerical score to the ideas they consider the most important. The individual scores are then arithmetically pooled to achieve an overall ranking of ideas.

To summarise, the Nominal Group Technique comprises the following five stages:

1. Individual "silent generation" of ideas in writing.
2. Round-robin feedback from group members of their ideas, which are recorded in a succinct form on a flip chart.
3. Systematic discussion of each idea for clarification and evaluation.
4. Individual selection of and voting on priority ideas.
5. Aggregation of individual scores and arithmetical calculation of overall group rating.

Writing on its effectiveness, Sink advocates that the fifth stage should include discussion of the group consensus results and focus on potential next steps (Sink 1983).

The term "nominal" acknowledges the process by which the group dynamics are controlled -ie individuals are brought together but their opportunity to communicate verbally to each other is constrained. The activities of the group are nominal at the start of the meeting during the generation of the individuals' ideas and at the end of the process during the individual voting on the priority of ideas. It is important to note that the group process is not entirely nominal. During stage three the individuals are given the opportunity to interact and re-evaluate their ideas in the light of the views of others.

Applications of the Nominal Group Technique

Consistent with the level of interest in focus group interviews in general, the Nominal Group Technique has received relatively low attention as a research method. A mere trickle of studies using the technique, either on its own or in conjunction with other methods, appear in the health care literature. A search of two major databases, BIDS EMBASE and MEDLINE, identified only twenty-six Nominal Group studies published in the twenty year period from 1970 to 1990. In order of frequency, it has been applied in the following health care settings: staff education/training [8], problem solving [5], problem identification [3], programme planning [3], activity analysis [2], and decision making [1]. These studies specifically relate to the work of the nursing profession [7], public health providers [4], medical educators [3], medical clinicians [2], pharmacists [2], anaesthetists [1], health educators, [2], laboratory workers [1], and dentists [1]. The studies have focused on a number of different client groups including people with learning difficulties (Bostwick and Foss 1981), people with mental health problems (Vega et al 1985), aphasic patients (Lomas et al 1987), and patients of outpatients and community nursing services (Butterfield 1988).

The acknowledged strengths of the Nominal Group Technique include (1) the ease by which it is learned, (2) its applicability to a wide variety of situations, (3) the ease by which it can be integrated into programmes and projects of larger scope, (4) the satisfaction derived by participants, and (5) the resultant commitment to action.

Whilst all of the above strengths are pertinent to the present study, the greatest strength of the Nominal Group Technique is that it allows participants to define and explore the phenomenon during a single interview.

The highly structured process of the technique is appropriate because it creates the opportunity for participants to define and prioritise the research issues without influence from the researcher. This is particularly important since the intention is to interview a number of different groups about the same issue. There is little scope within this interview technique for the researcher to unintentionally gloss over ideas or promote ideas which have been generated by earlier groups. The rigid structure is also appropriate when the intention is to compare the output of different groups since it minimises the risk of differences being artificially created by subtle changes between application of the data gathering technique.

The opportunity afforded by the Nominal Group Technique for the exploration and prioritisation of ideas is also particularly useful for the present study. It is the intention to use the top ranking ideas as the basis of a questionnaire to evaluate the quality of services from the patients' perspective. Prioritisation of the patient defined criteria is desirable for two reasons. First, given the variable attention spans of the study population, the survey tool can be informed by criteria that are known to be the most valued by patients. Second, in terms of the feedback that will be generated by the survey tool, recommendations for service change can be placed in the context of their relative importance to consumers.

2. Development of Methods

The central research aims of this part of the study dictated a patient-led approach in which the first task was to elicit the criteria by which patients judge a good service. These criteria were then used to inform the content of a questionnaire that was used in a survey of patient satisfaction with the provision of services. A subsidiary aim was to compare the patient defined criteria against those of others traditionally used as patient advocates ie relatives and nurses.

The initial focus was on patients in long stay wards for elderly people but the intention was to develop consumer-based methods that would be generally applicable.

The study population for the developmental work consisted of men (over 65 years) and women (over 60 years) whose place of residence was a hospital in Ayrshire and Arran Health Board, irrespective of the length of residence. The fieldwork for the study was carried out during the first four months of 1991 after obtaining approval from the Board's research ethical committee and hospital managers.

Eliciting the Criteria for a Good Service

In relation to eliciting the criteria for a good service, the method employed with elderly participants was a modification of the Nominal Group Technique. In its original form, the Nominal Group Technique requires group members to record their individual responses on paper and then to prioritise the list of the group's collective responses itemised on a flip chart. During a pilot exercise with a small group of elderly patients, it soon became clear that the unmodified method was inappropriate. Many of the participants had failing eyesight and arthritic hands, which prohibited them from engaging in the exercise.

The modified form of the exercise involved meeting groups of patients on two separate occasions. The first group meeting was loosely structured during which patients were asked to focus on a single question: *"What makes* [name of hospital] *a good place for you to live in?"* Every topic aired was explored for clarification and to reach group consensus on the precise definitions of terms. The whole session was audio taped. Later, the transcript of the tape was scrutinised independently by three researchers to identify key items (such as size of ward and staff attitudes). Each item was then printed in large type on an A5 sized card.

The second meeting was highly structured and entirely nominal so that each individual participated independently. Each patient was given a set of these A5 cards and asked to review each card and place it in one of three categories: *Very Important, Important* and *Not Important.* Patients were then asked to review, and if necessary reallocate, their cards until there were ten cards in the *Very Important* pile. Once this had been achieved, these cards were laid out in front of each patient who then selected the one he/she considered the most important and this was awarded 10 points. The patients were then asked to select the next in importance and award it 9 points and so on, until each of the ten cards had been reviewed and given a score. Finally, the individual scores were transferred onto a flip chart, totalled and ranked according to the highest score.

The above procedure was conducted with two groups of six patients from two of the six hospitals in Ayrshire that had long stay wards for elderly people. Individual members were recruited by senior nurse mangers who had been asked to obtain representation from as many wards as possible. As a result, group members resided in the same hospital but not necessarily in the same wards.

Since many service evaluations are based on criteria defined by patient advocates, for comparative purposes, four additional six-member groups were interviewed - two of relatives and two of nurses representative of the hospital's staffing skill mix. Members were recruited from the same two hospitals as the patients by the senior nurse managers who once again sought representation from as many wards as possible. Members of each group agreed to act as patient advocates and to address the single question:

> *"What are the requirements for a good service in long-term hospital care?"*

Group members were given pens and paper to record their individual ideas. Using a round robin approach, these ideas were then transferred onto a flip chart that everyone could see. Once this was done, each item on the flip chart was discussed for clarification, then members were given ten blank cards and asked to study the flip chart and choose the ten items that they considered the most important. They recorded one item per card. With their ten cards displayed in front of them, members were instructed to choose the most important and award it 10 points. From the remaining nine, the most important was chosen and awarded 9 points and so on, as in the procedure described for patients.

In order to test the robustness of the method employed in eliciting consumers' views, the Nominal Group Exercise (the unmodified version) were repeated with groups of patients, relatives and nurses in long stay wards for young people with mental illness.

Pilot Questionnaire Survey

The criteria identified and prioritised by patients in long stay wards for the elderly were used as the basis of a questionnaire to assess patient satisfaction with their lives in hospital. The questionnaire was piloted on twenty-three elderly people from two residential care settings: a private nursing home and a local authority sheltered housing complex. It was administered by the author who documented all spontaneous comments to questions.

Whilst minor modification was indicated for a few questions, the questions produced sufficient response variability between the residents of the two different care settings. In general, the residents of the private nursing home appeared to be more critical, perhaps because of differences in their consumer status and/or health status. However, the precise reasons were not explored as they were outside the remit of the pilot.

The pilot questionnaire contained three questions that were rephrased and repeated as a *test-retest method* of measuring the reliability of the questionnaire and of the respondent's responses. As a result of the pilot, one of these repeat questions was omitted because it was not a valid measure of what it was intended to measure. In general, there was a good match between the chosen response options and the respondents' spontaneous comments to the questions. This suggested that the respondents had understood the meaning of the questions in the way that they had been intended. As the questionnaire was based on the criteria for a good service as defined by the patients themselves, there was no reason to suspect it had problems associated with content validity.

Questionnaire Survey of Patients in Long Stay Wards for the Elderly

The final questionnaire was designed in three parts and was administered by the author during March and April 1991 in a form in which all spontaneous comments to questions could be recorded (Appendix A).

The first part of the questionnaire contained 19 questions that sought to describe patient and ward characteristics. Seven of these were completed by observation and included questions on the name and size of ward; and the location of dining area and lounge areas in relation to the sleeping area. The remaining eleven questions sought information on patient characteristics such as age, marital status, length of residence in the hospital. This information is conventionally collected at the end of interviews, but the chosen format assisted the researcher to establish rapport with patients and to determine the reliability of their responses. These questions were asked in an informal conversational manner and often one question elicited sufficient information to address a number of questions. For example, when asked where they resided prior to coming to stay in the hospital, respondents would not only describe the area of residence but also their marital status, the location of their families and length of residence.

The second part of the questionnaire contained 23 closed questions with a varied range of responses. Twenty-two of these questions addressed the patients' top thirteen ranked criteria for a good service and simply sought to establish if these were routinely met. They were worded so that the 'optimum' responses were evenly distributed between the beginning, middle, and end of the response range. Two questions were duplicated in order to test for reliability of responses. The final question to this part of the questionnaire was a global measure of the patient's satisfaction with his/her life in hospital. A pack of cards that listed the response options for all the closed questions was used as a visual aid.

The third part of the question comprised two open questions addressing the worst and best aspects of staying in a hospital.

Recruitment

A nurse in each ward identified patients who did not meet the inclusion criteria for the study - ie patients under retirement age and/or temporary residents. The remaining patients were systematically approached and given an explanation of the study and its purpose. Interviews were initiated only if the patient expressed consent. They were not initiated if the patient appeared too confused to respond reliably, and abandoned if their responses were incoherent or inconsistent.

Data Analyses

The patients' responses were analysed to explore differences between hospitals, ward size, length of hospital residence, age, gender and frequency of visitors. The data were presented in contingency tables and statistical analyses were carried out using traditional bivariate methods for categorical data - ie the Chi Square test of significance except for cases where the frequencies were small (< 5) in which case Fisher's Exact test was used. Where significant differences were demonstrated, the dependent variables were re-coded to produce a set of dichotomous variables. Logistic regression coefficients were then calculated to estimate odds ratios of the independent variables in the model. By these means, it was possible to predict the presence or absence of patient satisfaction based on a set of predictor variables.

Repeat Questionnaire Survey of Patients in Long Stay Wards for the Elderly

At the request of Ayrshire & Arran Health Board's Director of Service Quality and Development, the survey was repeated one year later. The objective of the Board was to determine if there had been any improvement in the levels of satisfaction amongst patients in long stay wards for the elderly. On completion of the first survey, copies of the full report and summary papers (Appendices B and C) had been sent to all the hospital wards where the patients had been recruited.

Whilst it was acknowledged that service developments may have been introduced during the intervening period, the researcher felt that it was unlikely that these would have a significant impact on patients' ratings of the extent to which hospitals met some of their criteria for a good service. In particular, changes in patients' perceptions of the personal attributes they most valued in nurses would require long-term investment to achieve the cultural shift. It was felt that the impact of service developments in this area, should they exist, would not have been measurable one year after the original survey.

It was initially hoped that this second survey would offer the opportunity to test the reliability of the questionnaire by administering it to the same population. However, in the intervening year substantial changes had occurred to the study population. In particular, around 100 patients had been transferred from one large NHS hospital to the private health care sector. Whilst some of the patients who had been interviewed in the original survey participated in the second survey, it was not possible to match their records because basic identification data had been eliminated from the original dataset. For these reasons, analyses could not be performed on the assumption that the achieved sample was either the same or completely independent. At best, the responses of the two samples could only be explored to determine whether or not there were significant differences between the levels of satisfaction reported.

3. Application of the Methods

During two focus group interviews with residents in long stay wards for the elderly, the patients were keen to praise the general organisation of their hospitals and the dedication of their carers. However, it soon became clear that they did not perceive themselves as customers with any choice in determining their living conditions. This quotation from the transcript of one of the group interviews illustrates a patient's association of choice with private care, or more significantly, the association of lack of choice with NHS care:

> *"There are plenty of Homes round here. There're over a dozen which you can pick and choose for anyone who really wants to get into a place where they've got private rooms, who can make their tea whenever it suits them......but you've got to go into a Private Home........this is a NHS hospital"*

Despite this difficulty, 26 items were identified from the transcripts of the focus group interviews with patients. These were subsequently ranked in order of importance by patients in a card game. During the Nominal Group Interviews with the patient advocates, 29 items were generated by the relatives and 39 items were generated by the nurses.

The Key Criteria for A Good Service in Long Stay Wards for the Elderly

Table 5.1 lists the top 13 criteria of the patients, one half of all the criteria they considered essential for a good service. Each item has a potential score of 120. The other 13 items not listed in the table scored less than 20 and were ranked by fewer patients than those with higher cumulative scores.

The patients' top three criteria related to people. In order of priority, these were personal attributes of nurses, visitors, and the company and friendship of other patients. Three attributes of nurses were specifically considered essential for a good service. These were that nurses were “cheerful”, “attentive”, and that they “listened”.

Table 5.1. The top 13 criteria for a good service as ranked by patients in long stay wards for the elderly.

Patient Criteria	**Rank**	**Score**
Nurses attentive/cheerful/listen	1	82
Visitors	2	75
Company/chance to make friends	3	45
Cleanliness of wards	4	45
Church Services	5	42
Knowing what your tablets are for	6	38
Privacy/ dignity	7	37
Permanent place in the ward	8	36
Eating at a table	9	35
Occupational therapy	10	29
Food - variety & choice	11	28
Visiting times	12	28
Concert parties	13	26

The large majority of the patients' criteria (8 out of 13) focused on organisational aspects of their care - ie company/chance to make friends (ranked 3); church services (ranked 5); a permanent place in the ward/not being moved (ranked 8); eating at a table (ranked 9); occupational therapy (ranked 10); choice and variety in food (ranked 11); visiting times (ranked 12) and concert parties (ranked 13). It is important to note that the patients' adopted the traditional definition of occupational therapy which professionals would now define more appropriately as diversional therapy. In the context of this study, patients referred to occupational therapy as organised activities that were meaningful pastimes.

Only two criteria related to management of care for the individual - ie knowing what your tablets are for (ranked 6) and privacy and dignity (ranked 7).

Patients ranked only one criterion relating to their physical environment - ie cleanliness of the wards (ranked 4).

Although relatives agreed with patients on the importance of the personal qualities of their carers, they did not recognise their own importance (Table 5.2).

The majority of the relatives' criteria (6 out of 13) related to management of care for the individual. These were privacy and dignity (ranked 2); continuity of care/same staff (ranked 7); carers with a vocation for work with the elderly (ranked 9); patient toileting (ranked 10); patients having their own clothes and toiletries (ranked 11) and personal grooming (ranked 13).

Table 5.2. The top 13 criteria for a good service as ranked by relatives of patients in long stay wards for the elderly.

Relatives Criteria	**Rank**	**Score**
Nurses attentive/cheerful/listen	1	53
Privacy/dignity	2	52
Cleanliness of wards	3	49
Physiotherapy	4	49
Safe/appropriate aids	5	31
Unqualified nurse carers	6	30
Continuity of care/same staff	7	30
Food -choice & variety	8	29
Carers with a vocation	9	28
Toileting	10	24
Own/choice clothes & toiletries	11	23
Aggressive medical treatment	12	21
Grooming	13	21

Approximately one-third of relatives' criteria (4 out of 13) related to service inputs- ie physiotherapy (ranked 4); safe and appropriate aids (ranked 5); unqualified nurse carers (ranked 6); and aggressive medical treatment (ranked 12).

Only one criterion related to the patients' physical environment - ie the cleanliness of the wards (ranked 3).

In contrast to the patients' criteria, only one of the relatives' criteria related to organisational aspects of patient care ie having a choice and variety of food (ranked 8).

The nurses were clearly aware of the importance which patients attached to their own qualities of themselves- ie attentive, cheerful and listening (Table 5.3). Although staff recognised the importance of visitors, their ranking of them was much lower than the patients' ranking (6 versus 2). The importance which staff placed on outside information (ranked 10) may relate to both visitors and the personal qualities of nurses.

Approximately one third of the nurses' criteria (4 out of 13) related to the patients' physical environment ie decor and furnishings (ranked 4), personal belongings (ranked 8), TV/radio/books (ranked 11), and warmth and lighting (ranked 12).

Table 5.3. The top 13 criteria for a good service as ranked by nurses of patient in long stay wards for the elderly.

Nurses Criteria	**Rank**	**Score**
Nurses attentive/cheerful/listen	1	71
Food - choice & variety	2	49
Own clothes & toiletries	3	49
Decor & furnishing	4	43
Respect for personal habits	5	40
Visitors	6	39
Privacy/dignity	7	37
Personal Belongings	8	35
Toilet facilities	9	31
Outside information	10	23
TV/radio/books	11	22
Warmth & lighting	12	20
Safe/appropriate aids	13	20

Three criteria related to care management of the individual: own clothes & toiletries (ranked 3), respect for personal habits (ranked 6), and patient privacy and dignity (ranked 7).

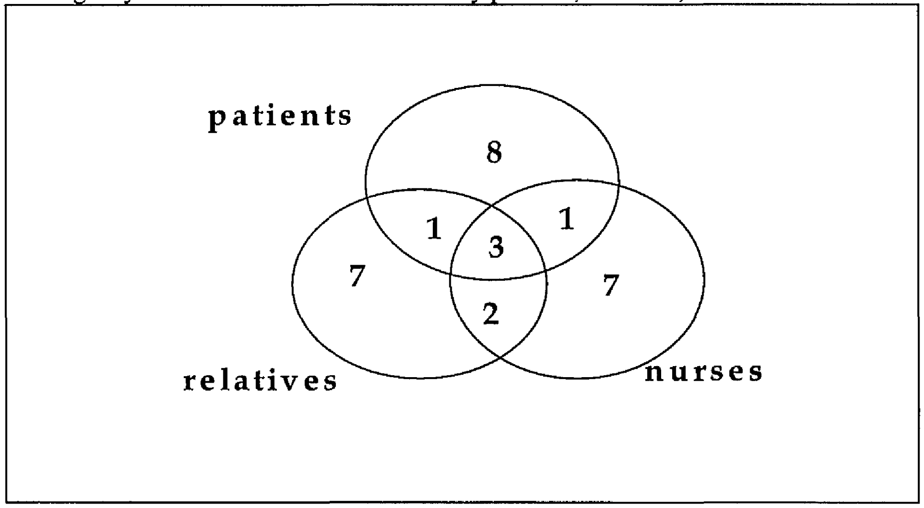
In contrast to the relatives' criteria, only two of the staff criteria might be related to service inputs ie toilet facilities (ranked 9) and safe and appropriate aids (ranked 13). In contrast to the patients' criteria, only one of the staff criteria related to organisational aspects of patient care ie choice and variety of food (ranked 2).

Figure 5.1 illustrates the extent of concordance between the 13 top ranked criteria of patients, relatives and nurses. Only 3 items (ie less than quarter of the patients' criteria) were held to be important by all 3 groups. These were nurses who were the personal attributes of nurses; privacy and dignity; and having variety and choice of food.

There was strong agreement on the importance of the personal attributes of the nurses ie it was the top ranked criterion of the three groups. The importance which patients attach to privacy and dignity was accurately assessed by the nurses (ie ranked 7) but was overestimated by the relatives (ie ranked 2). On the other hand, the relatives were closer than the nurses in ranking the relative importance of having choice and variety of food (7 and 2 versus 11).

Only the relatives identified the importance to patients of the cleanliness of the wards whereas only the nurses appreciated the value of visitors to patients.

Figure 5.1. Relationship between the top 13 criteria for a good service for patients in long stay wards as defined and ranked by patients, relatives, and nurses.



There was substantial concordance between relatives and staff - ie 5 out of 13 criteria were identical. In addition to agreeing on the importance of the personal attributes of nurses, choice and variety of food, and privacy and dignity, both groups erroneously believed that patients would have prioritised safe & appropriate aids and own clothes and toiletries.

The importance which patients attached to having company/chance to make friends and to knowing the purpose of their medication was not recognised by either the nurses or relatives. The remaining 6 unidentified patient criteria related to organisational aspects of care - ie church services, having a permanent place in the ward, eating at a table, diversional therapy, visiting times, and concert parties.

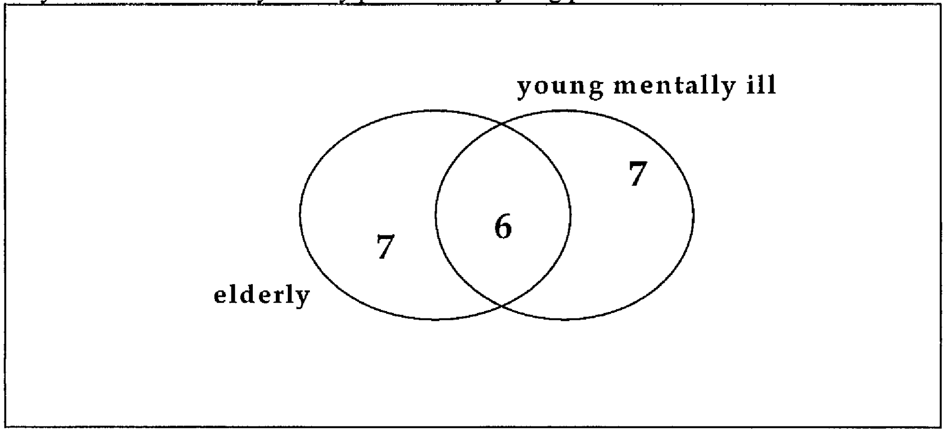
The Key Requirements for A Good Service in Long Stay Wards for the Mentally Ill

In this study, nurses and relatives were also only successful in identifying one third of the criteria which the patients thought the most essential for a good service. Once again, the three groups had quite different agendas. The criteria identified by patients mainly related to interpersonal relations with staff and others; contact with animals; and outdoor activities. By contrast, relatives mainly focused on the physical environment of the hospital and staff stressed empowerment and the opportunity for patients to self regulate their daily activities.

Comparison of the two sets of patient criteria revealed that the level of agreement achieved between them was much higher than that achieved by their respective groups of advocates ie relatives and nursing staff (Figure 5.2).

Both patient groups identified 3 identical criteria (personal attributes of nurses, patient privacy, and ward cleanliness) and further 3 criteria were strongly related ("meaningful work option" and "occupational therapy", "safe medication" and "knowing what your tablets are for", and "good food" and "food-choice/variety").

Figure 5.2. Relationship between the top 13 ranked criteria for a good service in long stay wards as ranked by elderly patients and young patients with mental illness.



Survey of Patient Satisfaction in Long Stay Wards for the Elderly

One hundred and seventy-nine patients in long stay wards for the elderly in Ayrshire and Arran participated in the survey. The proportion of patients (34%) able to complete the questionnaire was evenly distributed across the six hospitals with long-stay wards in the health board (Table 5.4). Without exception, nurses in each ward underestimated the number of patients who were able to answer questions reliably about their routine care.

Table 5.4. Breakdown of the study population in each hospital in 1991 in relation to the proportion of (a) all patients in the hospital who met the inclusion criteria and (b) the total study population.

HOSPITAL	**Number of patients**	**(a) % of patients in ward**	**(b) % of the Total Sample**
A	51	32	28
B	28	32	16
C	16	32	9
D	19	33	11
E	56	37	31
F	9	35	5
TOTAL SAMPLE	**179**	**34**	**100**

Analysis of the responses to the repeat questions on 'cleanliness of wards' showed that the responses obtained were reliable (Cronbach alpha coefficient = 0.76). The second repeat question on whether or not patients 'had enough things to occupy their time' was omitted because patients appeared distressed by it. Only a small number of patients (approximately 2 in each ward) refused to be interviewed or were not in the ward at the time of the survey.

Patient Characteristics

One hundred and twenty-eight patients (71.5%) were female. The ages of the patients ranged from 60 to 99 years, with a mean age 81 years. Twenty patients (11%) were unable to give their date of birth or age.

One hundred and sixty-one patients (90%) were local ie they formerly lived in Ayrshire prior to their hospital admission, and 141 (83%) had families who lived locally. Forty patients (22%) were visited daily, 54 (30%) at least weekly, 66 (37%) at least monthly, and 12 (7%) claimed that visitors were infrequent. Seven patients (4%) were unable to say how often they received visitors.

Eighty-three patients (46%) had been in hospital for more than 1 year, 40 (22%) less than 1 year, and it was not possible to determine the length of hospital residence in 56 cases (31%).

Satisfaction with the Criteria for A Good Service

The patients were asked to say how satisfied they were with each of the key requirements for a good service that were identified by the patient groups during the modified nominal group exercise. The results are presented so that they address the requirements in the order of priority as ranked by patients ie criterion 1 addresses the requirement which patients considered the most important. The general ratings for each criterion are reported with some of patients' spontaneous comments that illustrate differing views and problems. Unless otherwise stated, only statistically significant differences are reported in relation to hospital, ward size, length of residence in the hospital, gender, age and frequency of visitor.

Patient Criterion 1: Nurses attentive/cheerful/listen

Less than half of the patients (44%) expressed satisfaction with all three of the personal attributes that they valued most in nurses. Fifty-three patients (30%) felt that the nurses could be more attentive, 58 (33%) felt that they could be more cheerful, and 65 (37%) felt that their nurses only sometimes or hardly ever listened to them (Table 5.5).

Table 5.5. Patients' rating of their satisfaction with the personal attributes they most value in nurses.

PERSONAL ATTRIBUTES OF NURSE MOST VALUED BY PATIENTS	Number (%) of patients indicating satisfaction	Number (%) of patients indicating dissatisfaction	Total Sample
Attentive to patient	126 (70%)	53 (30%)	**179**
Cheerful with patient	121 (67%)	58 (33%)	**179**
Listens to patient	114 (63%)	65 (37%)	**179**
All 3 attributes	78 (44%)	101 (56%)	**179**

From the recorded comments it was clear that many patients felt that the physical demands of nursing made it difficult for nurses to be always cheerful or attentive, or have time to listen:

"They don't have time to be cheerful, they're far too busy......run off their feet. We could do with more staff",

"They are too busy to attend to you always. I need two people to help me to the toilet, so if only one person is

available then others, more mobile patients, are taken before me." and
"...if they have time, they'll sit down and listen"

It was also clear from the recorded comments that there were problems with individual nurses:
"One bad nurse can make your life miserable." and
"There is one that is awful cheeky".

Others associated difficulties with particular times of the day:
"If you ask for help, they say - give me 2 minutes - then they're off and you're lucky to see the same one again. I think we are left on our own too often, especially in the mornings"
" We're put in the day room and then you scarcely see a nurse 'til lunchtime because they've got others to attend to and tea breaks. It's not easy getting a nurse's attention once you've been put in the day room" and
"This morning I got a telling off. To be civil costs nothing. I was blamed for something I wasn't guilty of but the nurse just didn't take the time to find out".

Patient Criterion 2: Visitors

One hundred and forty two patients (79%) were satisfied with the frequency of visits from families and friends but 37 (21%) would have liked to see them more often. Differences were found when patients were classified according to gender; 31% of males compared with 16% of females reported that they would like to see their visitors more often (x^2=4.98, 1 d.f., $p<0.05$) (Table 5.6).

Table 5.6. Patients' ratings of their satisfaction with the frequency of visitors

FREQUENCY OF VISITORS	**Number of patients (%) indicating satisfaction**	**Number of patients (%) indicating dissatisfaction**	**Total Number in Sample**
MALE	35 (69%)	16 (31%)	**51**
FEMALE	107 (84%)	21 (16%)	**128**
TOTAL SAMPLE	**141 (79%)**	**37 (21%)**	**179**

It is possible that patients qualified their response and took account of the declining health and travel difficulties of their visitors:
" I don't see visitors much at all. I wouldn't like them trailing here, it's a blooming nuisance"
"They're not all free. They can't just rise and run and it can be very expensive traipsing about. Ken yourself, your pay doesn't go as far as it did a few months ago".

Patient Criterion 3: Company/chance to make friends

One hundred and forty-five patients (81%) felt that they had enough opportunities to meet and make friends with other patients in their own ward, but only 110 patients (65%) reported that they had the opportunity to meet and make friends with patients in other wards (Table 5.7).

Table 5.7. Patients' ratings of their opportunities to meet and make friends with other patients.

OPPORTUNITY TO MAKE FRIENDS WITH PATIENTS	**Number (%) of patients indicating satisfaction**	**Number (%) of patients indicating dissatisfaction**	**Number of patients in Total Sample**
In own ward	145 (81%)	33 (18%)	**179**
In other wards*	110 (65%)	60 (35%)	**170**
In the two areas combined	110 (62%)	69 (38%)	**179**

* Hospital F was excluded from this analysis as it had only one ward

To explore further the importance of companionship of others, patients were asked their views on the amount of time that they spent in the company of other patients. The majority of patients (71%) felt that the time they spent with other patients was just right. However, 40 patients (22%) felt that they were in the company of others too long. Only 11 patients (6%) felt that they did not spend enough time in the company of other patients (Table 5.8).

Table 5.8. Patients' ratings of the time they spend in the company of other patients

PATIENTS' OPINION OF THE LENGTH OF TIME SPENT IN THE COMPANY OF OTHER PATIENTS	**Number of Patients**	**% of Patients**
Too Long	40	22
Just Right	127	71
Too Short	11	6
Don't Know	1	1
TOTAL SAMPLE	**179**	**100**

Although relatively few patients believed that the time they spent in the company of others was too short, many felt that the opportunities to make and develop friendships were limited:

"It's limited who you can talk to. Some might be able to have a conversation but sit on the other side of the room",

"It's not easy sitting by your bed, you've got to shout. I don't see very well so I'm not sure who I'm talking to. Not keen on the day room, there are quite a few geriatrics. I don't like that, it can be quite depressing", and

"I don't hear......they don't hear......they don't speak up, so we don't have a chance to talk to one another".

Patient Criterion 4: Cleanliness of wards & rooms

One hundred and fifty-six patients (87%) felt that the cleanliness of their wards could not be improved but 23 (13%) felt that there was some scope for improvement. Male patients were more critical than female about the cleanliness of the wards: 11 men (22%) compared to 12 women (9%) thought that the wards could be cleaner (x^2=4.84, 1 d.f., $p<0.05$) (Table 5.9)

Table 5.9. Patients' ratings of their satisfaction with the cleanliness of their wards

CLEANLINESS OF WARDS AND ROOMS	**Number of patients (%) indicating satisfaction**	**Number of patients (%) indicating dissatisfaction**	**Total Number in Sample**
MALE	40 (78%)	11 (22%)	**51**
FEMALE	116 (91%)	12 (9%)	**128**
TOTAL SAMPLE	**156 (87%)**	**23 (13%)**	**179**

The large majority of patients who made comments thought that the hygiene in their wards was of a very high standard:

".....you could eat your dinner off the floor" and

"It's spotless and I get a lovely clean bed every night".

A few patients thought that staff were a bit over-enthusiastic about cleaning;

"The woman who cleans is excellent though you sometimes lose things that have been tidied away in drawers", and another patient reported;

"This morning, I was given a row for tidying my locker. I had my own way of doing things but they told me that someone was paid to do that".

Patient Criterion 5: Church services

One hundred and seventeen patients (65%) felt that the frequency of church services in their hospital was just right. Only 4 patients (2%) felt there should be fewer church services in the hospital, while 56 (31%) wished that they could attend a church service in the hospital more frequently. Two patients did not express an opinion.

The majority of patients who expressed a desire for more frequent church services, would have liked weekly services:

"I think more would be a good thing....every week, if it could be arranged. I like the hymns" and

"...a full Roman Catholic service every week would be good".

Patient Criterion 6: Knowing what your tablets are for

Only 117 patients (65%) felt that they were always/nearly always given enough information regarding their treatments and medications. Men were less satisfied with the amount of information received; 25 men (49%) compared with 37 women (29%) reported that they were only sometimes or hardly ever given enough information ($x^2=6.52$, 1 d.f. $p<0.02$) (Table 5.10).

Table 5.10. Patients' ratings of the information given about their medications and treatments.

PATIENTS' VIEWS ON THE AMOUNT OF INFORMATION THEY ARE GIVEN ON THEIR TREATMENTS	**Number (%) of patients responding ALWAYS/NEARLY ALWAYS GIVEN ENOUGH INFORMATION**	**Number (%) of patients responding SOMETIMES/HARDLY EVER GIVEN ENOUGH INFORMATION**	**Total Sample**
MALE	26 (51%)	25 (49%)	51
FEMALE	91 (71%)	37 (29%)	128
TOTAL SAMPLE	**117 (65%)**	**62 (35%)**	**179**

Although the majority of patients were satisfied with the information they received, many clearly wanted more:

"If you ask what your tablets are for, they tell you - just take these -. My bowels never bothered me 'til I came here",

" I'm never given any information. I get 5 tablets at a time. I asked what they were for and was told - they all do

their job - it puts you off asking anything again",

"You would need to be quick to catch the doctor in here. The doctor is in and out of the ward in a flash" and

"The OTs[occupational therapists] *and physiotherapists always tell you how you are doing. It would be good to occasionally get a report from the Top Men".*

Patient Criterion 7: Privacy in dressing/toileting/bathing

Approximately one-fifth of patients (21%) reported that other patients were able to see them whilst they were dressing and/or toileting and/or bathing (Table 5.11). Patient privacy during bathing and toileting appeared to be well respected. One hundred and seventy-one patients (96%) reported that the only persons able to see them in a state of undress before, during or after a bath were nurses, and 166 patients (93%) reported that using the toilet was always private. However, only 152 patient (85%) reported that they had they had this kind of privacy when dressing or undressing at other times.

Table 5.11. Patients' rating of their satisfaction with the extent to which privacy is respected during personal care.

PERSONAL PRIVACY DURING	**Number (%) of patients indicating satisfaction**	**Number (%) of patients indicating dissatisfaction**	**Total Sample**
Dressing	152 (85%)	27 (15%)	**179**
Toileting	166 (93%)	13 (7%)	**179**
Bathing	171 (96%)	8 (4%)	**179**
All 3 aspects of personal care	142 (79%)	37 (21%)	**179**

Although patients felt that they were protected from the view of other patients during bathing and toileting, a few felt that the nurses themselves could afford them more privacy;

"I don't think other patients can [see you] *but it's not very private. Nurses come in and chat to the nurse helping you in the toilet".*

Another patient identified this same problem during bathing;

"Other nurses come in if they are nosy. ....they come in and say,- Who have you got in there now? -, or if they want a blether with your nurse "

Although the rating of privacy whilst dressing was lower, patients appeared less concerned that others could see them. Their comments indicated that they had more control over this situation;

"I'm always getting into trouble for not pulling the screens round me. I don't mind who sees me dressing" and

"I'm not bothered about that; after all, we're all Jock Tamson's weans".

Criterion 8: Permanent place in the ward

Eighty-eight patients (49%) reported that their bed space had not been changed since their admission, 36 (20%) had been moved once and 28 (16%) had been moved at least twice. The remaining 27 patients (15%) were unable to say if their bed space had been changed.

Of the 64 patients who reported that they had been moved, 19 (30%) found the move an improvement and 33 (51%) did not mind being moved. However, 12 patients (19%) found the move upsetting.

Criterion 9: Eating at a table

One hundred and sixty-three patients (91%) felt that they were free to choose whether to eat their meals at a table or by their bedside. Thirteen patients (7%) felt that they did not have any freedom of choice and 3 patients (2%) did not know whether they had such a choice.

Patient Criterion 10: Diversional therapy

One hundred and eighteen patients (66%) were satisfied with the current frequency of diversional therapy. Only 1 patient said he would like less diversional therapy and 59 patients (33%) wished they could have it more often.

The desire for more diversional therapy was also related to the length of hospital residence; 19 of 40 patients (48%) who had lived in the hospital for less than one year would have liked occupational therapy more frequently compared with 22 of the 83 patients (27%) who had been resident for more than one year (x^2=5.35, 1 d.f. p =0.02).

The desired frequency of diversional therapy was also directed related to levels of boredom which patients experienced during a routine day. More diversional therapy would have been appreciated by 16 of the 73 patients (22%) who reported that they always had enough things to do compared with 11 of the 31 patients (35%) who nearly always had enough things to do and 13 of the 36 patients (36%) who only sometimes had enough to do and 10 of 21 patients (48%) who had hardly ever enough things to do and 9 of the 14 patients (64%) who never had enough things to do (x^2=11.51, 1 d.f. p=0.01) (Table 5.12).

Table 5.12. Patients' ratings of the frequency of occupational therapy in relation to their ratings of having things to do to occupy themselves.

	PREFERRED FREQUENCY OF DIVERSIONAL THERAPY		
PATIENTS VIEWS ON WHETHER THEY HAVE ENOUGH THINGS TO DO DURING A ROUTINE DAY	**Number (%) of patients who responded THE SAME**	**Number (%) of patients who responded MORE OFTEN**	**Number (%) of Total Sample**
ALWAYS/NEARLY ALWAYS	57 (78%)	16 (22%)	73 (42%)
NEARLY ALWAYS	20 (65%)	11 (35%)	31 (18%)
ONLY SOMETIMES	23 (64%)	13 (36%)	36 (20%)
HARDLY EVER	11 (52%)	10 (48%)	21 (12%)
NEVER	5 (36%)	9 (64%)	14 (8%)
TOTAL SAMPLE*	**116 (66%)**	**59 (34%)**	**175**

* 4 patients failed to respond to question about whether or not they routinely had enough things to do

Although many patients admitted that they had little to do to occupy themselves, they were despondent about their ability to do more and felt occupational therapy was futile:

"I just sit here. If I was young, there wouldn't be a problem but I'm too old to do anything",
"Therapy for me is no use because I'm no use. I can't do anything" and
"If I was fit for that kind of thing, I wouldn't need to be in here".

Others were more positive and suggested activities which interested them;
"I would do it if we had it. ..making cards at Christmas and that sort of thing?"
"I can't do much physically but perhaps we could play mental games or reminisce" and
"I'd go if they would organise something that gave you a bit of exercise but nothing too strenuous!"

Patient Criterion 11: Food -Choice & Variety

One hundred and forty-seven patients (82%) reported that they were always or nearly always served their choice from the menu of food, but 32 (18%) said that this only sometimes or rarely happened.

One hundred and fifty-seven patients (88%) reported that they were satisfied with the variety of the food served and 22 (12%) reported dissatisfaction.

Satisfaction with the variety of food served was directly related to the degree of choice which patients felt that they had over the food served to them. Dissatisfaction about the variety of menu was expressed by only 10 of the 147 patients (7%) who reported that they were generally served food they had chosen compared to 3 of the 18 patients (17%) and 9 of the 14 (64%) who reported that they were only sometimes or rarely served their choice respectively (x^2=39.54 , 2 d.f. $p<0.001$) (Table 5.13).

Table 5.13. Patients' rating of satisfaction with the variety of their menu in relation to their ratings of having choice in the food served to them

CHOICE IN FOOD SERVED	**VARIETY OF FOOD ON THE MENU**		
	Number (%) of patients indicating satisfaction	**Number (%) of patients indicating dissatisfaction**	**Total Sample**
Generally served choice	137 (93%)	10 (7%)	147 (82%)
Only sometimes served choice	15 (83%)	3 (17%)	18 (10%)
Rarely served choice	5 (36%)	9 (64%)	14 (8%)
TOTAL SAMPLE	**157 (88%)**	**22 (12%)**	**179**

Patient Criterion 12: Visiting times

In general, patients were satisfied with the length of visiting times; 137 patients (76%) felt that the visiting times were the right length, 14 (8%) felt they were too long and 28 (16%) felt that they were too short.

The length of visiting times related to the time visitors could spend with the patients rather than constraints imposed by the organisation of the ward:

" My visitors can stay over the time if they want. Nobody bothers"
"People spend whatever time they can afford" and
"My visitor takes 3 buses to get here. It's the shortest hour of the day".

Patient Criterion 13: Concert parties
Concert parties held in the hospital were generally appreciated by the patients; only 4 patients (2%) expressed the desire for less concerts. Although 95 patients (53%) thought the current frequency of concerts in their hospitals was adequate, a large minority (45%) expressed the desire for more concerts.

The desire for more concert parties and entertainment was related to the length of hospital residence; 25 of 40 patients (63%) who had lived in the hospital for less than one year would have liked concert parties more frequently compared with 35 of the 83 patients (42%) who had been resident for more than one year (x^2=4.47 , 1 d.f. $p < 0.05$).

Overall Satisfaction with Life in Hospital
The reported level of overall satisfaction with life in hospital was high; 86 patients (48%) were very satisfied and 72 (40%) were satisfied. Only 21 patients (12%) reported dissatisfaction.

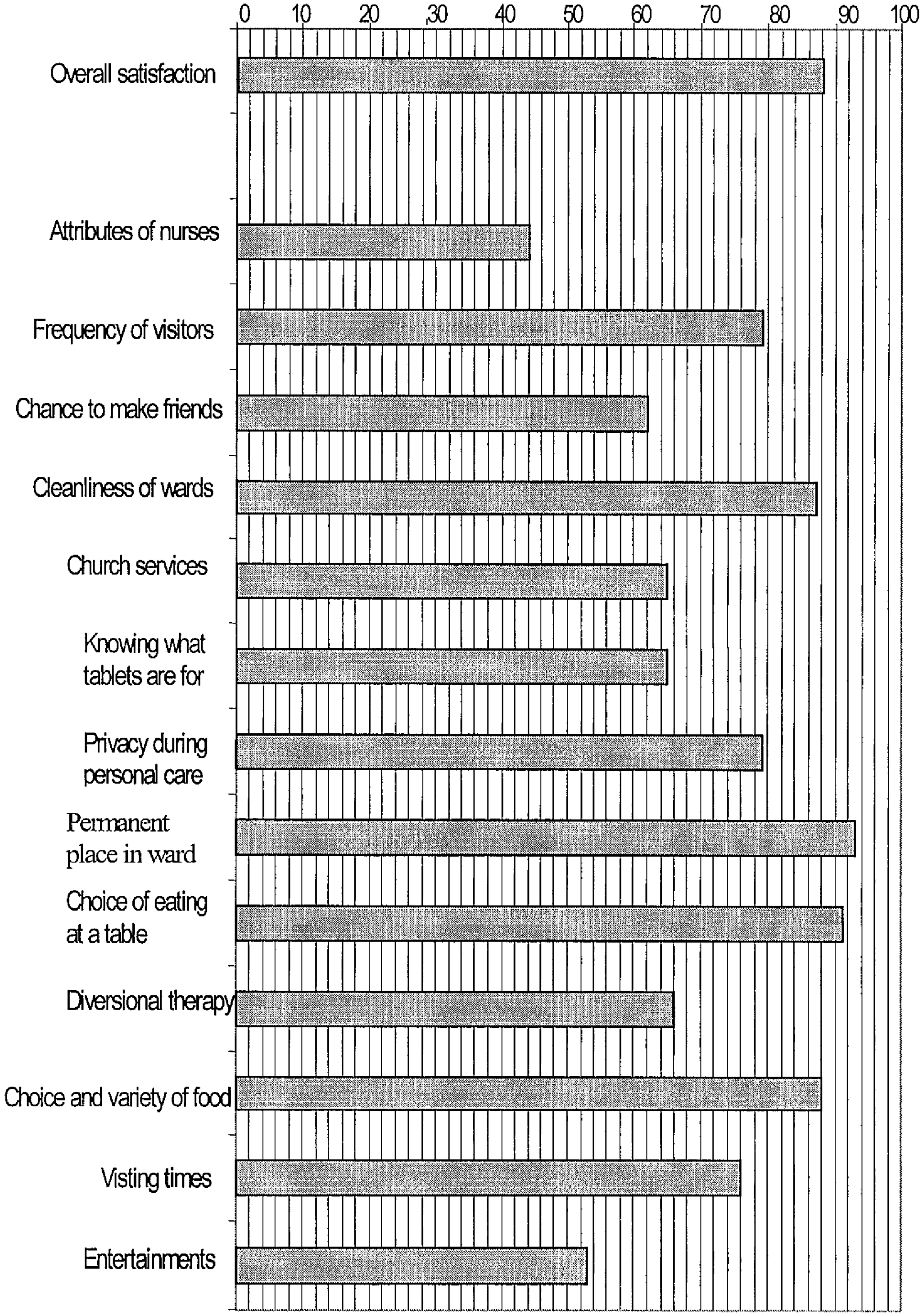
Many patients stated that they had no objections to anything in their hospitals and could not make any suggestion for improvement:
"I don't see that I could do any better if I was organising" and
"Under the circumstances, I couldn't do any better".

Some patients who expressed dissatisfaction had no specific complaints but were generally unhappy because they were no longer at home:
"I'm not happy here. I'd like to be home with my own friends and neighbours" and
"I just don't like it here. I would recommend it as a good hospital but not a good place to live in............might be all right if you were ill"

For others, the dissatisfaction rating reflected specific complaints about the staff or the organisation of activities in the ward:
"It's how they talk to you. This morning I told the nurse that my tea was cold and the nurse snatched it from me and said - I haven't got time for this; I've got to go home and get two children up",
"I wouldn't recommend this place to a friend. I think that patients should be able to go outdoors if only for a few minutes", and
"I would be a lot happier if I could be taught how to pass the time".

Figure 5.3 summarises the patients' ratings of satisfaction with overall life in hospital and the individual criteria for a good service. With the exception of cleanliness of wards, having a permanent place in the ward, having the choice of eating at a table and choice and variety of meals, the overall satisfaction rating exceeded the satisfaction ratings of the criteria by which patients judge a good service.

Figure 5.3. The percentage of patients who were satisfied with (a) life in hospital and (b) the criteria for a good service



The high overall satisfaction rating masks the extent to which patients were dissatisfied with the individual criteria by which they judge a good service. Only 8 patients expressed satisfaction with all thirteen criteria. The number of criteria with which the remaining patients expressed dissatisfaction ranged from 1 to 10, mean 4 criteria (Figure 5.4). There was a strong linear relationship between the number of criteria with which patients were dissatisfied and their overall rating of dissatisfaction ($p<0.001$, Table 5.14).

Figure 5.4. Number of criteria with which patients were dissatisfied in relation to ratings of overall satisfaction

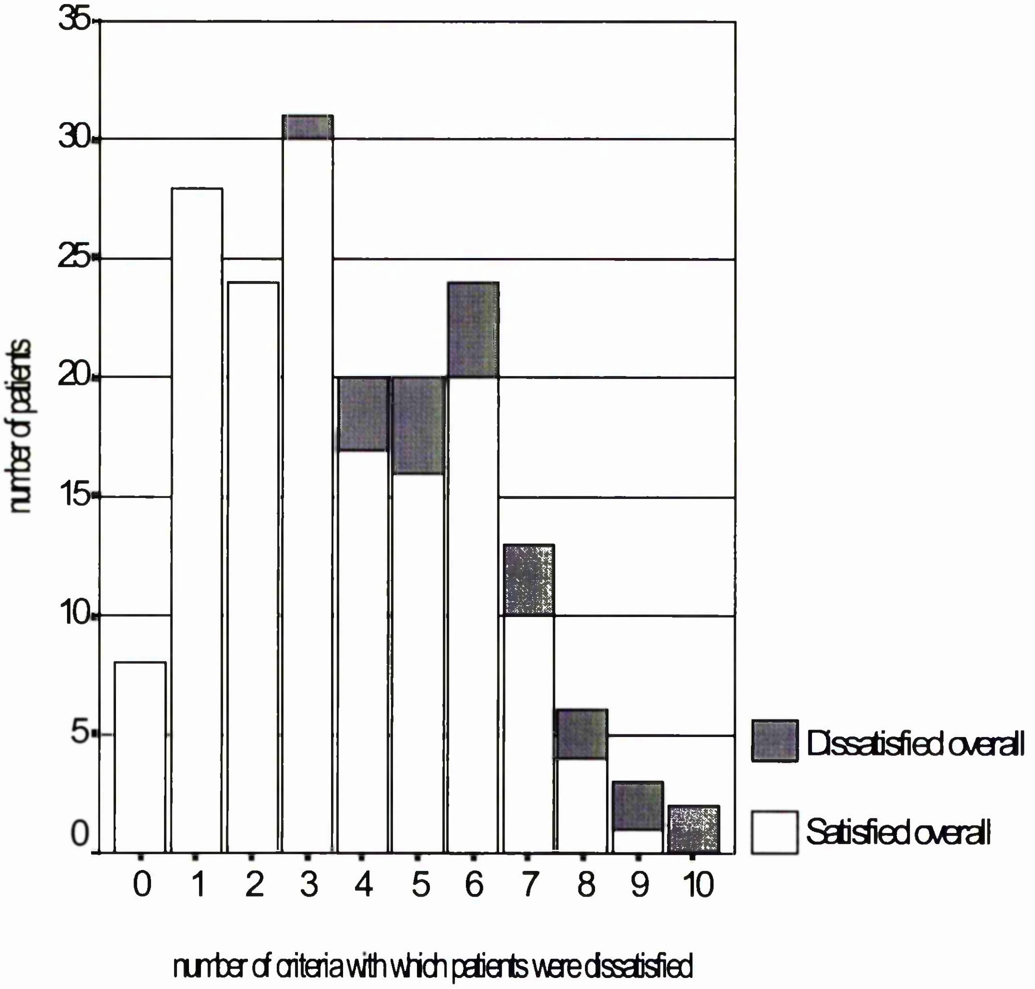


Table 5.14. The number of criteria with which patients were dissatisfied in relation to overall satisfaction

NUMBER OF CRITERIA WITH WHICH PATIENTS EXPRESSED DISSATISFACTION	**Number (%) of patients indicating OVERALL SATISFACTION**	**Number (%) of patients indicating OVERALL DISSATISFACTION**	**Total Sample**
None	8 (100%)	0	8 (4%)
One	28 (100%)	0	28 (16%)
Two	24 (100%)	0	24 (13%)
Three	30 (97%)	1 (3%)	31 (17%)
Four	17 (85%)	3 (15%)	20 (11%)
Five	16 (80%)	4 (20%)	20 (11%)
Six	20 (83%)	4 (17%)	24 (13%)
Seven	10 (77%)	3 (23%)	13 (7%)
Eight	4 (67%)	2 (33%)	6 (3%)
Nine	1 (33%)	2 (67%)	3 (2%)
Ten	0	2 (100%)	2 (1%)
TOTAL SAMPLE	**158 (88%)**	**21 (12%)**	**179**

Pearson chi-square 40.341, 10 d.f., $p < 0.001$.
Linear-by Linear Association 29.073, 1 d.f., $p < 0.001$

Table 5.15 summarises the patients' ratings of satisfaction with the 13 individual criteria for a good services in relation to the overall satisfaction with life in hospital. Using the individual criteria that are significantly related to overall rating of dissatisfaction in a logistic regression model, the best predictors of overall satisfaction were attributes of nurses ($p=0.0282$), information about medication ($p=0.0323$) and diversional therapy ($p=0.0249$).

Table 5.15. Patients' ratings of satisfaction with individual criteria in relation to ratings of overall satisfaction

SATISFACTION/ DISSATISFACTION WITH CRITERIA FOR A GOOD SERVICE IN LONG STAY WARDS FOR THE ELDERLY	**Number (%) of patients indicating OVERALL SATISFACTION**	**Number (%) of patients indicating OVERALL DISSATISFACTION**	**x^2 value, p value.** (1 d.f.)
Attributes of nurses			
Satisfied	76 (97%)	2 (3%)	11.220
Dissatisfied	82 (81%)	19 (19%)	0.001
Frequency of visitors			
Satisfied	129 (91%)	13 (9%)	4.405
Dissatisfied	29 (78%)	8 (22%)	0.036
Chance to make friends			
Satisfied	101 (92%)	9 (8%)	3.473
Dissatisfied	57 (83%)	12 (17%)	0.062
Cleanliness of wards			
Satisfied	142 (91%)	14 (9%)	8.915
Dissatisfied	16 (70%)	7 (30%)	0.003
Church services			
Satisfied	107 (90%)	12 (10%)	0.931
Dissatisfied	51 (85%)	9 (15%)	0.335
Knowing what tablets are for			
Satisfied	111 (95%)	6 (5%)	14.225
Dissatisfied	47 (76%)	15 (24%)	0.000
Privacy during personal care			
Satisfied	127 (89%)	15 (11%)	0.906
Dissatisfied	31 (84%)	6 (16%)	0.341
Permanent place in the ward			
Satisfied	148 (90%)	17 (10%)	4.159
Dissatisfied	10 (71%)	4 (29%)	0.410
Choice of eating at a table			
Satisfied	146 (88%)	20 (12%)	0.221
Dissatisfied	12 (92%)	1 (8%)	0.638
Diversional therapy			
Satisfied	78 (98%)	2 (2%)	11.905
Dissatisfied	80 (81%)	19 (19%)	0.001
Choice and variety of food			
Satisfied	130 (93%)	10 (7%)	13.067
Dissatisfied	28 (72%)	11 (28%)	0.000
Visiting times			
Satisfied	124 (91%)	13 (10%)	2.836
Dissatisfied	34 (81%)	8 (19%)	0.920
Entertainments			
Satisfied	90 (94%)	6 (6%)	6.008
Dissatisfied	68 (82%)	15 (18%)	0.014
TOTAL SAMPLE	**158 (88%)**	**21 (12%)**	**179**

Repeat Survey of Patient Satisfaction in Long Stay Wards for the Elderly

One hundred and forty-three patients in long stay wards for the elderly in Ayrshire and Arran participated in the second survey. As in the previous study, the proportion of patients (35%) able to complete the questionnaire was evenly distributed across the six hospitals with long-stay wards in the health board (Table 5.16).

Table 5.16. Breakdown of the study population in each hospital in 1992 in relation to the proportion of (a) all patients in the hospital who met the inclusion criteria and (b) the total study population.

HOSPITAL	Number of patients	(a) % of patients in ward	(b) % of the Total Sample
A	43	36	30
B	29	37	20
C	15	33	10.5
D	15	30	10.5
E	33	35	23
F	8	40	6
TOTAL SAMPLE	**143**	**35**	**100**

The smaller number of patients surveyed in the second study compared to the original survey (143 c.f. 179) reflects a decrease in the overall study population.

Table 5.17 summarises the responses of patients in long stay wards for the elderly in 1991 to those in 1992 in relation to questions on overall satisfaction and their criteria for a good service.

Table 5.17. Patients' ratings in 1991 and 1992 of overall satisfaction and of satisfaction with individual criteria for a good service in long stay wards for the elderly

OVERALL SATISFACTION AND SATISFACTION WITH CRITERIA FOR A GOOD SERVICE	Number (%) of patients IN 1991	Number (%) of patients IN 1992	p value. (1 d.f.)
OVERALL SATISFACTION			
Satisfied	158 (88%)	134 (94%)	0.0953
Dissatisfied	21 (12%)	9 (6%)	
ATTENTIVENESS OF NURSES			
Satisfied	126 (70%)	102 (71%)	0.8541
Dissatisfied	53 (30%)	41 (29%)	
CHEERFULNESS OF NURSES			
Satisfied	121 (67%)	92 (64%)	0.5388
Dissatisfied	58 (33%)	51 (36%)	
NURSES WHO LISTEN			
Satisfied	114 (63%)	86 (60%)	0.5144
Dissatisfied	65 (37%)	57 (40%)	
FREQUENCY OF VISTORS			
Satisfied	141 (63%)	115 (80%)	0.7893
Dissatisfied	37 (37%)	28 (20%)	
CHANCE TO MAKE FRIENDS (OWN WARD)			
Satisfied	145 (81%)	122 (85%)	0.3589
Dissatisfied	33 (18%)	21 (15%)	

OVERALL SATISFACTION AND SATISFACTION WITH CRITERIA FOR A GOOD SERVICE (continued)	**Number (%) of patients IN 1991**	**Number (%) of patients IN 1992**	**p value. (1 d.f.)**
CHANCE TO MAKE FRIENDS (OTHER WARDS)			
Satisfied	110 (65%)	104 (77%)	**0.0194**
Dissatisfied	60 (35%)	31 (23%)	
CLEANLINESS OF WARDS			
Satisfied	156 (87%)	126 (88%)	0.7950
Dissatisfied	23 (13%)	17 (12%)	
FREQUENCY OF CHURCH SERVICES			
Satisfied	117 (65%)	86 (60%)	0.1667
Dissatisfied	56 (31%)	57 (40%)	
KNOWING WHAT MEDICATION IS FOR			
Satisfied	117 (65%)	96 (67%)	0.7388
Dissatisfied	62 (35%)	47 (33%)	
PRIVACY DURING DRESSING			
Satisfied	152 (85%)	117 (82%)	0.4563
Dissatisfied	27 (15%)	26 (18%)	
PRIVACY DURING TOILETING			
Satisfied	166 (93%)	131 (91%)	0.8700
Dissatisfied	13 (17%)	11 (8%)	
PRIVACY DURING BATHING			
Satisfied	171 (96%)	135 (94%)	0.8461
Dissatisfied	8 (4%)	7 (6%)	
PERMANENT PLACE IN WARD			
Satisfied	52 (81%)	47 (85%)	0.3942
Dissatisfied	12 (19%)	7 (15%)	
CHOICE OF EATING AT A TABLE			
Satisfied	163 (93%)	115 (80%)	0.0749
Dissatisfied	13 (7%)	18 (13%)	
DIVERSIONAL THERAPY			
Satisfied	118 (66%)	95 (66%)	0.9647
Dissatisfied	59 (33%)	47 (33%)	
CHOICE OF FOOD			
Satisfied	147 (82%)	106 (74%)	0.0823
Dissatisfied	32 (18%)	37 (26%)	
VARIETY OF MENU			
Satisfied	157 (88%)	124 (87%)	0.7899
Dissatisfied	22 (12%)	19 (13%)	
VISTING TIMES			
Satisfied	137 (76%)	120 (84%)	**0.0278**
Dissatisfied	42 (24%)	19 (13%)	
ENTERTAINMENTS			
Satisfied	95 (53%)	78 (55%)	0.9631
Dissatisfied	80 (45%)	65 (45%)	
TOTAL SAMPLE	**179**	**143**	

Overall, there was remarkable similarity between the patients' responses in 1992 when compared to those obtained in 1991. No significant differences were detected in the level of overall satisfaction and in the responses to 17 of 19 questions that addressed the criteria for a good service. In the case of the exceptions, the responses showed improved levels of satisfaction in the second survey. These related to the criteria "Chance to make friends with patients from other wards" (77% c.f. 65%, p<0.02) and "Visiting Times" (84% c.f. 76%, p<0.05). Further analyses showed that patients from 2 of the study hospitals (A and B) were responsible for the improved satisfaction ratings for the "chance to make friends with patients from other wards" (Table 5.18).

Table 5.18 Patients' Ratings of their satisfaction with the opportunity to make friends with patients from other wards in relation to hospital of residence

PATIENTS RATING OF THE OPPORTUNITIES FOR MAKING FRIENDS WITH PATIENTS FROM OTHER WARDS	**Number (%) of patients IN 1991**	**Number (%) of patients IN 1992**	**p value. (1 d.f.)**
HOSPITAL A			
Satisfied	32 (63%)	35 (81%)	0.0465
Dissatisfied	19 (37%)	8 (19%)	
HOSPITAL B			
Satisfied	12 (43%)	25 (86%)	0.0006
Dissatisfied	16 (57%)	4 (14%)	
HOSPITAL C			
Satisfied	13 (81%)	13 (87%)	0.6820
Dissatisfied	3 (19%)	2 (13%)	
HOSPITAL D			
Satisfied	11 (58%)	8 (53%)	0.7903
Dissatisfied	8 (42%)	7 (47%)	
HOSPITAL E			
Satisfied	42 (75%)	23 (70%)	0.5861
Dissatisfied	14 (25%)	10 (30%)	
TOTAL SAMPLE	**170**	**135**	

Hospital F was excluded from this analysis as it only comprised one ward.

When asked for possible reasons for the change in patients' response, the nurse manager from Hospital A reported two service developments that could have increased the opportunities for patients to meet and make friends with patients from other wards. The first was a substantial increase in the number of motorised wheelchairs which meant that patients relied less on nurses to take them to other parts of the hospital. The second was the introduction of a patient cafeteria where patients could socialise with each other and their visitors. The nurse manager from Hospital B did not know of any specific service development that could possible explain the increase in patient satisfaction with the opportunities for making friends with patients in other wards.

The increase in patient satisfaction in relation to "Visiting Times" was not associated with any individual hospital. When asked if there had been any service development in the preceding twelve months, the nurse managers could not identify anything that might account for this improved rating. They reported that visitors were accommodated outwith official visiting hours and that the duration of visiting was determined by the time which visitors could spend with patients rather than constraints imposed by the organisation of the ward.

6. PUBLIC VIEWS ON THE NEED FOR SEVICES

This chapter reviews the range of methods that can be used to obtain the views of the public on the need for services. The strengths and weakness of different approaches are highlighted, providing the rationale for the choice of methods for the present study. It describes the development of methods and reports the results of their application.

The choice of the most appropriate survey approach for this part of the study was influenced by three considerations. The first related to the specific focus of the research – ie mental illness. The second and third related to more general considerations of research methods and procedures such as measuring attitudes and obtaining a representative sample of the public.

Issues Relating to the Measurement of Mental Illness.

The need for mental health services is difficult to measure because of the diverse nature of mental illness. A range of conditions exist from those which require repeated and/or prolonged hospital treatments to those which never come to the attention of mental health specialists.

Classification/Recognition of Mental Illness by Professionals: Estimates of psychiatric morbidity in the community are subject to wide inter-practice variation. Whilst true differences in the prevalence of psychiatric morbidity in communities may exist, technical reasons such as different diagnostic classification and recording procedures largely contribute to these discrepancies. In a review of early studies of psychiatric illness in the community (Shepherd et al 1981) demonstrated how one researcher (Kessel 1960) reported widely differing estimates of psychiatric morbidity in one London general practice by employing different diagnostic criteria. Using categories of psychiatric illness specified in the International Classification of Diseases, he reported prevalence rates of only 50 per 1,000. However, when he included all patients with "conspicuous psychiatric morbidity" ie manifest psychological disturbance regardless of diagnosis, the rate rose to 90 per 1,000. When he added patients presenting with physical complaints which had no detectable organic cause, the rate became 380 per 1,000. Finally, if all cases of "psychosomatic disorder" such as asthma and peptic ulcer were included, the total rose to 520 per 1,000.

Despite the wide disparity in the estimates of the distribution of mental illness in the community, it is maintained that between one-quarter and one-third of all illnesses treated by the general practitioner falls into this category (Shepherd et al 1981). More recently, this assertion has been backed in a report of the mental health services needs in Greater Glasgow Health Board (Brogan, personal communication). Describing an "Ice berg of Morbidity", the author claims that between one in three and one in four people in any year suffer a significant mental health problem which may require some treatment and lasts longer than two weeks.

Classification/Recognition of Mental Illness by the General Public. Hall used 4 short case histories, developed in consultation with psychiatrists, describing people with paranoid schizophrenia, depression, obsessional neurosis and schizophrenic defect state to survey knowledge of mental illness and mental health services in two English communities (Hall et al 1993). For each case, the respondents were shown a list of possible causes of the condition portrayed and asked to select the most likely cause(s). Whilst there were significant demographic differences between subgroups, identification of the subject as mentally ill was surprisingly low. Only about one quarter of respondents mentioned mental illness in relation to the two case histories of schizophrenia. Mental illness was identified as a possible cause for the depressive illness by only 9% of the respondents, and for the obsessional neurosis illness by only 6%. Similarly, the awareness of treatment agencies was low. For example, less than 26% of the respondents knew of the existence of the community psychiatric nurse.

The authors caution against the over simplistic view that the low levels of awareness of mental illness is a "bad" thing. While knowledge of mental illness may be regarded as important by the health professional, society's reluctance to label deviant behaviour as mental illness may actually reflect a healthy tolerance.

Regardless of whether a low level of awareness is a good or bad thing, needs assessments for mental health services which do not provide respondents with a well defined frame of reference will be limited in the sense that they reflect needs that fall within popular but constrained perceptions of mental illness. For the same reason, the survey method may have to provide a range of services from which respondents can be asked to choose the most appropriate in relation to the research question. Whilst it is important to provide information on the range of mental health problems and services, it may be equally important to present the information in such a way that key characteristics of people with mental illness are stated without using a mental illness label.

Relative Needs for Services by Individuals within Diagnostic Groups of Mental Illness. Even if the prevalence rates in a community could be accurately determined on the basis of some agreed classification of psychiatric morbidity, the level and nature of support required by any one individual in a particular classification is unlikely to remain static. For example, support groups may be of no value to individuals in the early stages of clinical depression when they may lack the motivation to attend but be beneficial in a less acute phase of the illness. For this reason, it is likely that an evaluation of the need for services to support individuals with mental health problems based on the relative needs of individuals would be more helpful than one based on the number of individuals within particular diagnostic groups.

In summary, the methods employed in any study to determine the needs for services must consider the diverse nature of mental illness, the reluctance of the general public to label individuals as mentally ill and the non-static pattern of need within any particular diagnostic classification.

Issues Relating to Methods and Procedures

Public opinion on the needs, priorities and preferences for services will be underpinned by more general attitudes. For example, if a survey found that the general public prioritised institutional care for people with mental health problems, without general attitudinal data, it would not be possible to determine whether their preference was influenced by intolerance or fear of people with mental illness.

The most common approach to eliciting data about normative beliefs involves providing people with statements and asking them to indicate how strongly they agree or disagree. Although the agree-disagree question format is one of the most widely used, it can suffer from the 'acquiescent response set' problem where some people agree with the statements regardless of their content. Another problem with attitude measurement is that the questions are often abstract and vague. It is not uncommon that in response to questions, people answer "it depends" ie their answer depends on a context. For example, if people are asked whether they would be prepared to live next door to a person with a history mental illness, many would answer depending on the nature of the illness and the relationship they have with their neighbours. The problem when asking simple, abstract attitude questions is that this sort of context is not provided. In these circumstances, respondents make up their own context and answer in relation to it. This can result in respondents answering different questions impossible for the researcher to interpret without lengthy and detailed interviews.

Since, by definition, a quantitative survey entails systematically asking the same question in the same manner of all sample members, it is necessary to provide a context. It is only when the context is standardised that it is possible to aggregate the individual responses and perform statistical analyses.

One of the chief problems associated with adopting a population approach to needs assessment has been in obtaining a representative sample of the general population. For example, meetings to which the general public of Oregon were invited to debate issues concerned with health service provision were largely attended by people with a vested interest - ie health professionals and service users. The NHS Management Executive reports, Local Voices and Listening to Local Voices, provide examples of innovative approaches in a number of English health authorities which used qualitative rather than quantitative methods in population health needs assessments (NHS Management Executive 1992, 1993). These included the use of focus group interviews with individuals recruited from a random sample of passers-by, and rapid appraisal which involved conducting informal individual interviews with 'key informants' of a community such as professionals, shopkeepers, local council leaders and members of self-help groups. Such methods are valuable in gaining insight about the subjects as individuals and their collective experiences of health care provision. However, unless they are complemented with information from quantitative surveys, their findings are limited in that they cannot be generalised to provide information on the extent to which these views and experiences are held by the general population.

1. Review of Methods

The commonest technique employed in survey research is the questionnaire. However, other methods such as structured and in-depth interviews, observation, and content analysis are also appropriate. The distinguishing characteristics of a survey are the systematic collection of data for a number of cases and the process of analysis which seeks to understand variation between the cases. Unless the study population is small, or if very detailed analysis is required, such as that of the decennial census, a population survey collects information from only a sample of the total population of interest.

There are two broad forms of sampling: probability and non-probability. Probability sampling requires that each person in the population has an equal, or least a known, chance of being selected while in non-probability sampling, some people have a greater, but unknown, chance than others in the selection. Probability samples, particularly those based on the principle of random selection, are preferable because they are more likely to produce representative samples which enable estimates of the sample's accuracy. However, the technique employed to derive a sample is largely dependent on the availability of a good sampling frame. For example, using the straightforward random principle with the general household register might produce a sample in which the number of individuals with mental illness would be under-represented since these individuals are more likely to have unstable households. If it is important to have individuals with mental illness accurately represented and no other sampling frame is available, it would be necessary to employ other sampling techniques which would bias the selection of individuals with mental illness.

The next hurdle to overcome in population surveys is obtaining the interest and participation of those sampled. There are a number of tried and tested techniques that have been shown to increase participation in general surveys. These include contacting respondents before the questionnaire is administered, employing trained interviewers to administer the questionnaire, and the offer of incentives such as monetary payment, or the promise to donate £x to the respondent's named charity.

Population surveys of the needs for mental health services may have to overcome the resistance of some who feel that the research has nothing to do with them personally and that health professionals are best equipped to deal with such issues. Conversely, the research tool may have to overcome the resistance of others for whom the question of mental illness is a sensitive and personal subject.

The remainder of this paper discusses one technique that may be an advance on some other survey methods: the vignette. A survey tool based on vignettes could potentially overcome some the difficulties described above. Vignettes which provide information on a range of mental health problems without the use of diagnostic labelling could be used so that informed views on the relative needs for services can be obtained within a standardised context, and in a way that the issues of mental health in the community will be both interesting and non-threatening to the general public.

The use of vignettes in a population survey of needs, preferences and priorities for health services may represent an innovative approach. Before discussing the development of vignettes for the proposed study, studies employing vignettes are reviewed in order to assess their particular advantages as a survey technique.

Applications of Vignettes

A vignette is a stimulus which can take a number of different forms: pictorial, spoken, video or written, but probably the commonest format of the vignette is the written word, and it is in this format with which this review is largely concerned. The best general definition of the written vignette is provided by Finch (Finch 1987):

> *"Vignettes are short stories about hypothetical characters in specified circumstances to whose situation the interviewee is invited to respond"*

In general, the vignette, which can be a single sentence, or more complex and detailed, is presented, and in relation to it, one question, or more, is asked of the respondent, and a range of responses is elicited. Traditionally, vignettes have been used in two different ways. The first use is mainly aimed at standardising the context and then asking questions given the common context. The second use is in causal analysis which involves developing a set of related vignettes in which some part of the story relating to the research interest is systematically varied between vignettes.

Vignettes have been used most widely in studies to identify and measure attitudes, beliefs and norms. Examples of this application include studies of the attribution of responsibility to a victim for a crime (Jones and Aronson 1973, Luginbuhl and Mullin 1974, Smith et al 1976); for an automobile accident (Walster 1966, Shaw and McMasters 1975); for rape (Smith et al 1976); in studies of simulated jury decision making (Prytula et al 1975, McGlynn et al 1976, Feldman-Summers and Linder 1976); decision-making in Juvenile Courts and Children's Hearings (Asquith 1983); assessments of social status and normative beliefs about marriage and divorce (Clark and Samphier 1983, 1984), obligations between relatives to provide practical or material support for each other (Finch 1987); about public preferences for the care of dependency groups (West 1884, West et al 1984, Thompson and West 1984); about different groups of welfare claimants (Lomax Cook 1979); in studies of the variation in professional and lay definitions of child mistreatment (Giovannoni and Becerra 1979, Fox and Dingwall 1985); how social workers perceive and identify mental health problems (Freeman 1989); and measuring attitude to and tolerance of the mentally ill (Brockington et al 1993, Hall et al 1993).

As can be seen by the above list, vignettes are in general used for identifying and/or measuring attitudes, beliefs and norms. The vignette, like the questionnaire or interview, is still basically a survey method and as such it capitalises on the main strength of survey methods in that the data elicited can be used to make generalisations about a given population. However, the vignette offers an advance on other survey methods in a number of different ways. For example, by asking questions about hypothetical third parties, the vignette may distance threatening or sensitive issues from the respondent thus reducing bias in responses. Furthermore, the vignette offers a contextualised stimulus which allows more specific and concrete questions to be asked of the respondent. Related to this is that unlike the question formats employed in questionnaires which tend to be bland, alien and uninteresting, the vignette is thought to stimulate more meaningful and considered responses. The strength and applicability of these and other advantages depend, however, on the vignette design. These variations are now reviewed in more detail.

There have been almost as many variations in vignette design as there has been studies employing their use. However, two main approaches in their use have been identified (West 1982). These are the 'interpretative or non-directive' approach and the 'experimental social psychology' approach. These approaches have widely differing standpoints and may be viewed as opposite extremes with many models falling somewhere in between.

The Interpretative or Non-directive Approach. In the interpretative or non-directive approach to vignette design, the story portrayed in the vignette is deliberately ambiguous, containing only limited information so that the onus is on the respondent to flesh out the story to make sense of. By these means, there is a cue relevant to the research interest, but it is one which encourages the expression of subjective definitions.

McLean and Jeffrey provide an example of this approach in a study of attitudes towards disabled people (McLean and Jeffrey 1974). This study sought to identify the extent to which the public supported integration as opposed to segregation of disabled people in areas of housing, leisure activities and occupation, and the underlying reasons for their views. The respondents were asked to imagine a man of working age, confined to a wheelchair but otherwise healthy, and to say whether he was better off living and spending his leisure time among disabled or non-disabled people. The results of this study indicated a large measure of support for integration.

With this approach, an interpretation of respondents comments, judgements or decisions was revealed by subsequent non-directive probing so that the factors influencing the respondents' definition of the vignette character or situation could be ascertained. These might include direct experience of a disabled person or second-hand experience through relatives, neighbours, friends, or the media.

Provided the vignette character or circumstances is a fairly typical example of, say, disabled people in general, and that this typicality is implicitly acknowledged by the respondent, then the data obtained in response to the vignette can be described as pertaining to the general features of that social category rather than to the particular features of the vignette itself (Fox and Dingwal 1985). The brief sketch therefore acts as a cue to the production of general images and attitudes (West 1982).

A weakness of this approach is that it is not known exactly what is being responded to in the vignette. In the above example, it is not clear whether the significant cues are the nature of the disability itself, the fact that the character is of working age, or that the character is a man. In essence, the interpretative or non-directive approach is valuable provided that it is the general imagery that is to be tapped and not fine detail.

This approach was adopted in order to determine the general public's knowledge of, and attitude towards, the mentally ill in two English communities, Malvern and Bromsgrove (Brockington et al 1993). By means of quota sampling, approximately two thousand residents of the two districts were asked to respond to four vignettes by market researchers. The vignettes were updated and Anglicised modifications of the Star vignettes (unpublished) which were originally developed in 1956 in consultation with psychiatrists. The vignettes portrayed classic text-book type descriptions of the characteristics of people within particular diagnostic groups ie paranoid schizophrenia, depression, obsessional neurosis and schizophrenic defect state. For example, paranoid schizophrenia was described as:

> *"People of this type are very suspicious. They believe everyone is against them. Sometimes they think people in the street are talking about them, or following them. They can be heard muttering to themselves. They have been known to pick fights with strangers because they thought they had been spying on them. They may even accuse their own relatives of plotting against them, and be abusive or aggressive towards their own parents".*

In relation to each vignette, each respondent was asked:
(a) the most likely cause of the person's behaviour,
(b) what action they would take, and
(c) what agencies would be the most likely to help the person concerned.
For each question the respondent was shown lists of possibilities from which they selected as many responses as they liked. After that, they were prompted for less structured responses.

Whilst the information on the typical characteristics of the individual in each of the diagnostic groups was sufficiently detailed to allow the competent student physician or nurse to hazard a guess at a likely diagnosis, no attempt was made to provide a context to assist the respondent in the decision making process. Without details of a real life background for individuals with these characteristics, it is likely to be a difficult exercise for the respondent to assess probable causes for and responses to the behaviours portrayed. For example, the respondent's choice of agency which would be of the most benefit to the portrayed character may be different if the respondent assumes that the individual described was single and living with elderly patients, as opposed to married with young children. In these circumstances, the researcher can neither control nor interpret the variables within the decision making process.

The Experimental Social Psychology Approach. Whilst the above approach to vignette design attempts to capitalise on ambiguity, this is exactly the reverse of what other investigators have viewed as the potential value of vignettes. These investigators adopt the experimental social psychology approach to vignette design which attempts to control the cues which are responded to. The most distinguishing feature of the experimental approach is that it allows an analysis of the effects of specific factors by systematically varying the characteristics used in the vignette description. An experimental approach to the previously described vignette might be:

> *"John/Jane is a physically/mentally handicapped person who lives in an inner city/residential suburban, working class/ middle class area. He/she has been moderately/severely disabled since birth and is now aged 20/50 years".*

If these variables are systematically altered across a set of vignettes, variations in responses to a simple question such as 'Should John/Jane work?" can be attributed to the age, sex, class, level or nature of disability. In this way, causal assertions about the relationship between the variables and the responses to them can be made.

As well as variations between the interpretative and experimental approaches to the design of vignettes themselves, there has also been considerable variation in the number of vignettes used and the types of responses elicited; factors which are, in fact, related. That is, the more detailed the vignette and the more questions asked about it, the fewer vignettes the interviewee can be asked to respond to before fatigue sets in. For example, in the above vignette five dichotomous variables results in 32 versions of the basic vignette which is clearly a ridiculous number to present to any one respondent. This problem was first addressed in a study by Lomax Cook of public support to welfare groups by the introduction of the incomplete-within-blocks" design (Lomax Cook 1979). To avoid presenting 64 vignettes to each respondent, combinations of the vignettes characteristics were designed so that each respondent received eight vignettes and within blocks of eight respondents, each of the 64 were covered.

Responses to the vignettes can be fixed choice, open-ended, or a combination of both. Open-ended questions are subject to the criticism that some comparability between respondents is lost. On the other hand, the list of fixed-choice responses may not accurately correspond to the respondents' beliefs. In general, the most common use of the vignette has been the experimental approach, and the tendency among those adopting this approach has been to use fixed choice responses. For example, Lomax-Cook, using only 8 vignettes per interview in her study of public support for different groups of welfare claimants, followed each vignette with a set of 5 questions as to whether the interviewee was sympathetic to the situation described to which the responses were Yes/No/Don't Know (Lomax Cook 1979). Alves and Rossi, in a study of beliefs about distributive justice in respect of household income, included 50 vignettes in a single interview (Alves and Rossi 1978). For each vignette the respondent was asked a single question whereby he/she was to rate whether the distribution of household resources was fair or unfair on a nine point scale. In a study of social status, Nosanchuk presented respondents with 10 vignettes and in relation to each, asked two sets of questions, (Nosanchuk 1972). The first was a set of semantic differentials on which the 'family' in the vignette was rated on a seven point scale, and the second consisted of a list of nine occupational categories of which the respondent had to select the two the 'family' were least likely to mix with socially.

A departure from this general pattern appears in three British studies: one examining beliefs about marriage and divorce (Clark and Samphier 1983, 1984), one exploring public preferences for the care of dependency groups (West 1984, West et al 1984, Thompson and West 1984), and one exploring beliefs about obligations between relatives to provide practical and/or material support for each other (Finch 1987).

In these studies, the use of the vignette leans more towards the interpretative approach and departs from the essentially static response models described above. Instead of asking respondents to make judgements on a given set of circumstances at one point in time, these studies built certain changes into the story which occurred over time, allowing fixed choice and open-ended questions to be asked at a series of points and also allowing questions to focus on what should happen next. The technique of altering the circumstances within a single vignette is a distinctive feature of these British studies. It does, however, appear to curtail the number of vignettes which can be employed; both West and Finch suggest that about 4 vignettes appear to be the maximum before respondent fatigue sets in (West 1982 and Finch 1987).

The Controlled Non-experimental Approach. The experimental and interpretative approaches to vignette design and the range of response obtained as described above characterise some of the more common uses of the vignette in social surveys. Recently, a third approach to vignette design was identified by workers in the Department of Social Policy, University of Glasgow in a study, funded by the Scottish Office, of the performance of community care teams (Bennet-Emslie, personal communication). This approach will be referred to as the "controlled non-experimental approach". The vignette produced by this approach can be differentiated from the interpretative vignette in that, in general, it is more specific and detailed, often derived from reality, so that the respondent is not required to flesh it out in order to interpret it. It differs from the experimental approach to vignette design in that none of the variables within it are systematically varied. In essence, the vignette produced by the controlled non-experimental approach is a hybrid of the interpretative and experimental approaches and as such possesses the advantages of both methods as a survey method.

Like the experimental approach, the controlled non-experimental vignette provides more specific and detailed information so that respondents require to define less of the meaning themselves which helps to reduce the number of unknown factors involved in their responses. The researcher knows in what circumstances the responses apply, and can avoid making assumptions about their transferability to other situations (Finch 1987). Furthermore, as a result of their specific nature, detailed questions can be asked of the respondents thus moving from generalised issues (West 1982). This also helps to avoid answers which are bland generalisations and which are difficult to interpret. By holding the vignette constant over a respondent population as in the interpretative approach, the researcher can achieve a degree of uniformity but still control the stimulus in a similar manner to researchers using experimental approaches (Nosanchuk 1972, Rossi et al 1974, Alexander and Becker 1978).

Perhaps as a result of these advantages, the controlled non-experimental vignette has been employed in comparative studies which try to tap into the definitions, decisions and actions of individuals in response to specified situations or circumstances.

The first reported study of this kind was designed to measure the level of agreement between different occupational groups in the health and welfare fields as to what should be defined as child abuse and neglect and how seriously particular situations should be regarded (Giovannoni and Becerra 1979). The respondent sample represented lawyers, paediatricians, police officers and social workers in Los Angeles. The content of the vignettes were derived from recorded cases in law and local practice, the professional literature and the authors' own practice experiences. The situations covered included physical and sexual abuse; failure to physically care for a child (such as nutritional neglect, medical neglect, poor supervision, and inattention to cleanliness, clothing and housing); emotional mistreatment; and educational neglect. The study demonstrated significant differences in the responses to 69 of the 78 vignettes employed in the study, although there was considerable agreement between members within particular occupations.

This study was modified and partly replicated in Britain in order to compare the responses of social workers and health visitors (Fox and Dingwall 1985). Whilst this later study failed to identify significant differences in the way health visitors and social workers as occupational groups perceived either the absolute or relative seriousness of incidents which could be described as mistreatment, some differences were identified within the occupational groups.

This approach to vignette design was also used during a collaborative project by Strathclyde Regional Council and local health boards which sought to identify and promote co-ordinated community based services for people with mental health problems. As part of their review of current service provision, three hypothetical referrals based on real cases, were presented to a sample of social workers in order to gain comparative information on how social workers identified and responded to individuals with mental health problems (Freeman 1989). For example, one referral concerned John, a 27 year old married man with two young children who was admitted to hospital after taking an overdose. He had been treated by his general practitioner for depression, had severe marital problems and spent a lot of his time in pubs and betting shops where he spent a lot of the family's DHSS income. His wife, it was stated, was not a competent housewife, the children always had colds or something wrong with them and, according to John, his wife slept around. In relation to each of the vignettes, the social workers were asked to identify the specific indications of a mental health problem, how they would respond to receiving the case as a referral, and the level of priority they would give the case.

This study revealed high levels of disparity in the social workers' perceptions of what constituted a mental health problem, the nature of their responses, and the degree of priority accorded to each. The author concluded that meaningful discussion about what constituted mental health social work and how such work could be developed could only take place if these differing views were identified and addressed. Furthermore, she recommended that vignettes could be used as a means of identifying issues and stimulating discussion within and between professional groups.

The above studies illustrate the use of vignettes which have been composed by researchers in collaboration with professionals and in most cases, the stories portrayed in them are based on real instances. The use of such vignettes as a survey method appears to be a natural progression of the conventional use of case studies as a teaching model in the training of these occupational groups, particularly the medical professions. The vignette appears to be a legitimate survey method to tap into the knowledge, attitude and likely responses of professionals when it is based on the particular type of work or particular client groups with which they are experienced. In other words, the vignette requires to be both realistic and applicable to the respondent population.

The studies to be reported here adopt the controlled non-experimental approach for three reasons. First, this approach in which respondents are not required to define the context for the research issues will help reduce the number of unknown factors involved in their responses. Second, as a result of their specific nature of the vignettes, the research questions can be focussed rather than generalised. Third, this approach, which relies on holding the vignette constant over a respondent population, enables comparisons of responses between and within study populations.

No previous studies utilising this approach have been identified in any population determined health needs assessment. Building on the principal that the content of the vignettes should be familiar to the respondent population, the vignettes were designed in collaboration with residents of the study population who had experienced mental health problems. By these means, the context and the characteristics of individuals with mental health problems approximated real life situations of the general population. Moreover, the approach adopted was designed to stimulate public interest in the research question and elicit more considered responses from respondents.

This shift of focus in the development of vignettes to first hand experiences of residents of the study population also shifted the focus from the traditional diagnostic model of vignette design. The vignettes sought to illustrate relative needs of individuals with mental health problems irrespective of diagnostic classification. This decision was taken for three reasons. First, the needs for support and services are likely to alter within the natural course of many illnesses. Second, the presentation of characteristics without a mental illness label may overcome some of the problems associated with differing definitions of what constitutes a mental health problem. Third, characteristics of individuals can be presented to, and issues related to them can be discussed by, the general public who may be cautious of mental illness.

A further advantage of employing vignettes was that they provided the opportunity to complement the respondents views on the needs for services with information on their attitudes to the mental illness.

2. Development of Methods

The central research aim of this part of the study was to document public opinion on the needs for local services. The study focused on the needs of individuals with mental health problems rather than on differences that may exist between people who have different mental health diagnoses. Although the focus was on mental health problems, the intention was to develop an approach that would be applicable across a wide range of care settings.

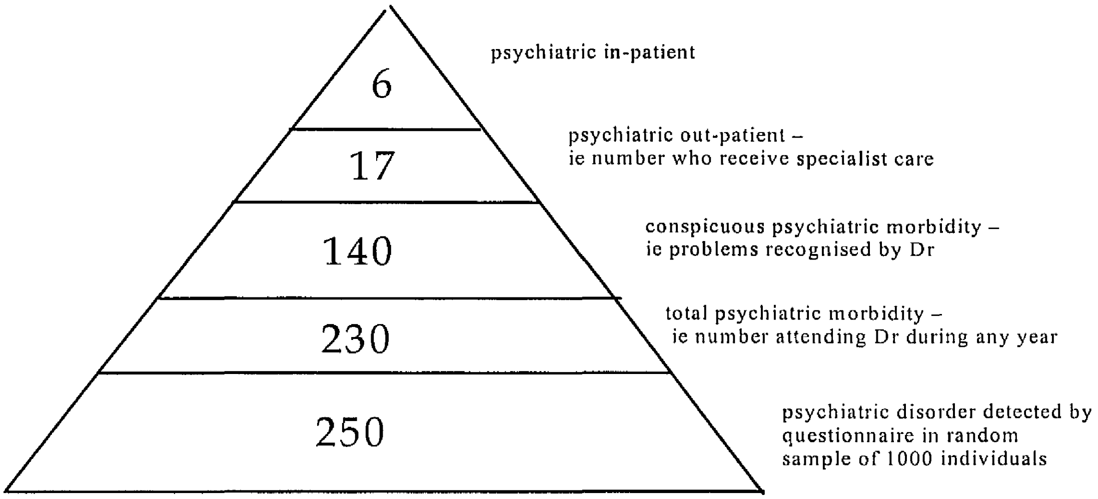
The approach adopted entailed developing hypothetical cases describing individuals with varying mental health needs and in relation to these, members of the public were asked to identify potential sources of support from a given list of services. In addition to this activity, the hypothetical cases were used to collect information on the respondents' attitude towards and experience of mental illness.

A subsidiary aim was to compare public views on the need for services against those of health and social workers.

Vignettes and List of Services

Five vignettes were composed to portray individuals with mental health problems with varying need. Each vignette related to one of the five different levels in the "Iceberg of Psychiatric Morbidity" described by Goldberg in 1970 (Figure 6.A).

Figure 6.A. Golberg's "Iceberg of Psychiatric Morbidity"



Thus one vignette described someone with a psychiatric problem who had not attended a GP. Another two described people with problems that necessitated a visit to a doctor, however, the psychiatric nature of the problem was only recognised in one case. The remaining two vignettes portrayed individuals who received specialist psychiatric help, one as an out-patient and the other as an in-patient.

In general terms, the vignettes were designed so that they could be readily followed and understood. Their characters and story lines had to be believable and applicable to the study population. In addition, the vignette could not contain characteristics of individuals or situations outwith the research interest as these could potentially confound interpretation of the responses.

In the context of this study, the vignettes had to portray key and realistic characteristics of individuals experiencing mental health problems. For this reason, the vignettes were developed in collaboration with a group of Ayrshire residents who regularly used a purpose built day resource centre for people with mental health difficulties. With the help of the Project Manager for the centre, a meeting was held with a group of people attending the centre during which the proposed survey and its intent were described. Thereafter, four semi-structured group meetings were conducted with approximately twelve participants representing a core of four individuals who attended every meeting; the attendance of others fluctuated.

<u>1st Group Meeting.</u> At the start of the first group meeting the aim of study was reiterated. Whilst it was stressed that personal experiences were not sought, participants were asked to reflect on their own experiences in order to describe the needs of two individuals [named Joe and Julie by the group] who had either no, or relatively low contact, with health or social services. Once this had been accomplished, a modified Nominal Group Exercise was conducted during which participants independently listed various forms of services which, in their opinion, would support each of these individuals if they lived in their community. At this juncture, participants were encouraged to concentrate on the portrayed needs of the individual and identify potential sources of support, irrespective of whether, or not, they were routinely available. The individual lists were then combined on a flip chart that everyone could see and each of the proposed supports was discussed and concisely defined.

<u>2nd Group Meeting.</u> The second group meeting followed the same format. This time the group focused on composing another vignette [Mary] to represent an individual with chronic mental health problems whose general practitioner may, or may not, decide to refer for specialist intervention. Once this had been achieved, participants were asked to review the combined list from the previous meeting, and to independently generate additional services that, in their opinion, would be appropriate forms of support for the needs of the individual portrayed in the new vignette. These new services were then combined, discussed for clarification, defined, and appended to the existing list.

3rd Group Meeting. Following the same format, the third group meeting focused on composing the fourth and fifth vignettes of the series [David and John] to describe individuals with mental health problems who had required hospital in-patient treatment. Two vignettes were used in order to differentiate between the chronic and acute needs of such individuals. As in the previous meeting, additional forms of support for these hypothetical individuals were identified, defined and appended to the existing list of supports.

4th Group Meeting. The output of the previous meetings was reviewed and refined during the fourth group meeting. In relation to the composition of the individual vignettes, attention was paid to removing variables that could potentially confound the interpretation of responses obtained during the subsequent survey of the general population. For example, in one vignette it was considered inappropriate to portray one of the characters as a former soldier or policeman since it would not be possible to determine to what extent the nature of the character's employment might influence respondents' views. Whist the potentially confounding impact was recognised by the researcher at an earlier meeting, it was not thought appropriate to address it then for fear of undermining the contribution of the group. At this final meeting when the overall aims of the study were more apparent to participants, negotiation on the removal of confounding variables was less problematic. In relation to the list of services, participants were asked to reflect on their own experiences, and those of their acquaintances, in order to identify additional forms of support. In the event, the participants were unable to identify other potential sources of support.

Validation of the Vignettes and List of Services

Two groups of mental health specialists agreed to assess the validity and comprehensiveness of the vignettes and the list of services. Since part of this study would entail administering the vignettes to groups of professionals in order to obtain their views on the need for services, it was important from the outset to establish that they were satisfied with the nature and range of needs portrayed.

The first group comprised 3 psychiatrists; 3 hospital nurses; 1 community nurse; 1 pharmacist; 1 hospital and 1 community occupational therapist; and 1 social worker. In response to their comments, one vignette was modified. It concerned the individual [Julie] who was portrayed as a young single parent who felt guilty and depressed over the breakdown of a personal relationship, and who, despite financial difficulties, spent a considerable amount of money on strong alcoholic drinks. In the professionals' opinion Julie's behaviour was an understandable and normal reaction to domestic and social distress. Furthermore, her "misuse" of alcohol introduced an unnecessary element of controversy regarding the classification of addiction as a mental illness. A review of the literature, particularly the inventories used in community surveys, identified a number of common psychiatric symptoms including somatic symptoms, fatigue, sleep disturbance, irritability, lack of concentration, depression, anxiety and worry, phobias, obsessions and compulsions, and depersonalisation. The 'Julie' vignette was modified to incorporate a number of these symptoms, and it was subsequently accepted as a valid representation of someone with a mental illness. Indeed, one psychiatrist stated that the case presented was typical of someone who required psychiatric rather than general medical attention. The health professionals did not recommend further modification to the other vignettes or the list of services.

The second group of professionals comprised 2 community nurses; 1 hospital nurse; 1 social work practitioner; 1 social work manager; 2 community project managers; and 1 housing officer. They accepted the vignettes and list of services as valid and comprehensive. Interestingly, two workers commented that the modified 'Julie' vignette was very typical of some of their clients. However, unlike the health professional group, they did not appreciate the need for specialist psychiatric help. Instead, they believed that the needs of individuals like 'Julie' would be met by various forms of social support. Whilst recognising these differences, the consensus of the group was that there was no need to modify the vignette.

Pilot Survey

A pilot survey was conducted to test the questionnaire based on the series of five vignettes and the comprehensive list of services. In relation to each vignette, respondents were required:

(a) to rate the helpfulness of each of the listed services,
(b) to identify the three services which were the most important sources of help,
(c) to suggest other potential sources of support, and to say
(d) if they would be happy living next door to the individual portrayed in the vignette. In those cases involving in-patient psychiatric care, participants were also asked if they would be happy if a small group of such individuals lived next door under staff supervision.

The questionnaire was piloted to assess its ease of use for self-completion and also as an interviewer-administered schedule. Twelve questionnaires were either administered or left with residents in two different localities. The first was a council estate in north Lanarkshire, the other was a predominately owner-occupier area in the west end of the city of Glasgow. Despite the small size of the pilot, responses were obtained from a wide variety of people including academics, health professionals, industry and service workers, an artist, unemployed people, retired people, single people and parents of dependent children.

Two interesting findings emerged from this pilot. First, respondents, without exception, enjoyed participating in the exercise. Commenting on this, one respondent likened the activity of commenting on hypothetical cases to, her and a favourite national pastime, discussing characters and situations portrayed in soap operas. Second, perhaps for the same reasons, respondents who were given questionnaires to self-complete tended to do this after discussion with other members of their households. One respondent described how she, her husband and two teenage sons had sat round the kitchen table and jointly addressed the questionnaire. On reflection, she felt that this had been a particularly useful activity as it prompted exchange of views on issues that they had previously not considered, in particular community care for people with long-standing mental illness.

The different approaches adopted by the respondents to completing the questionnaire resulted in a great deal of variation in the time taken to self-complete the task. As an interviewer administered schedule, the time taken to complete the schedule containing 5 vignettes ranged from 20 minutes to 50 minutes. Following completion, some respondents felt that the exercise was too long and that there was considerable overlap between the three vignettes which portrayed the individuals with less pronounced needs [ie Julie, Joe and Mary].

Several respondents in the pilot survey felt unable to prioritise services because they felt that access to some services which were potentially most beneficial relied on other services, perhaps less beneficial in terms of treating the underlying mental health problem, being in place. For example, access to specialist mental health services relied on referral by the general practitioner. As a result of this concern, the other respondents in the pilot survey were questioned about their rationale for prioritising the services. In some cases, this was not always clear and there was some suspicion that they had been selected with the same consideration as choosing one's lottery numbers.

The final survey tool comprised a questionnaire based on the series of vignettes that described individuals with different mental health problems (Appendices D and E). Although there were 5 vignettes, each respondent only had to consider 3. This economy was designed to reduce the overall time taken to complete the questionnaire and achieved by administering separate questionnaires to a split sample; one vignette being common to both questionnaires.

In the final survey, participants were not asked to identify the three services which were most important sources of help. In relation to each vignette, respondents were simply asked to rate the helpfulness of each of the listed services; to suggest other potential sources of support, and to say if they would be happy living next door to the individual portrayed in the vignette. In those cases involving in-patient psychiatric care, participants were also asked if they would be happy if a small group of such individuals lived next door under staff supervision.

Study Populations

Using quota sampling techniques, a market research company was employed to recruit and interview a sample of 200 Ayrshire residents in five geographical areas within Ayrshire & Arran Health Board: Ayr, Kilmarnock, Irvine; Ardrossan, Saltcoats & Stevenston, and Mauchline & Cumnock. The quotas were based on the Registrar General's mid year population estimates for 1991 for Ayrshire & Arran Health Board. The quota for each sub sample of 40 residents is shown in Table 6.A.

In order to test the questionnaire as a self-completion instrument, the interviewers were asked to identify a matched sample, in relation to the criteria above, and leave a questionnaire to be completed and returned in a stamped addressed envelope. As an incentive to do this, every respondent who returned a questionnaire was given the opportunity to nominate a charity to which Ayrshire & Arran Health Board would donate £1.

Table 6.A. Predetermined characteristics of each sub sample of 40 Ayrshire residents

	MEN		**WOMEN**
age	housing tenure	age	housing tenure
18-44 years	owner occupier	18-44 years	owner occupier
	owner occupier		owner occupier
	owner occupier		owner occupier
	owner occupier		owner occupier
	owner occupier		owner occupier
	rented		rented
	rented		rented
	rented		rented
	rented		rented
	rented		rented
45-64 years	owner occupier	45-59 years	owner occupier
	owner occupier		owner occupier
	rented		owner occupier
	rented		rented
	rented		rented
65 + years	owner occupier	60+ years	owner occupier
	owner occupier		owner occupier
	owner occupier		rented
	rented		rented
	rented		rented

only 2 men and 2 women could be registered unemployed

Ideally, the survey of health and social work providers would have been based on a random sample of all health and social work providers working with people with mental health problems in Ayrshire & Arran. However, this would have relied not only on having access to a comprehensive sampling frame but also on having sufficient time and administrative resources to follow up non-responders, particularly amongst the health professions. In their account of the natural history of a survey, Cartwright and Seale describe the efforts required to receive information from hospital managers on the identity of consultants under whom certain patients were admitted (Cartwright and Seale 1990). These extended over a period of 3 months, and involved 2 mailings and 204 telephone calls. The authors describe their experience of obtaining responses from hospital consultants as even more frustrating: secretarial support was more likely to be part-time, consultants were less likely to be in their office, or even on site; and there was the strange phenomenon of the disappearing letter.

As the aim of the present study was to describe the application of new survey methods and because resources were limited, a **snowball approach** was employed to recruit a sample of providers from health and social work services. The first contact was a general practitioner with responsibility for co-ordinating courses for general practitioner trainees based in practices in Ayrshire. He distributed questionnaires to the trainees and asked them, in turn, to pass them on to all their colleagues in their placement practices. The second contact was with members of mental health task groups in Ayrshire who distributed questionnaires to their colleagues. The third contact was with lecturers at two Glasgow universities who agreed to recruit nursing and social work students. The fourth contact was a senior nurse at an Ayrshire psychiatric hospital who distributed questionnaires among doctors, nurses and allied health and social work professionals in this large psychiatric hospital. Since all of the above approaches failed to recruit any psychiatrists, they were recruited through secretarial staff at the psychiatric hospital. Finally, a senior social work manager agreed to distribute questionnaires among social work practitioners in Ayrshire.

Data Analyses

The public's responses relating to their attitude to living next door to the individuals with mental illness were analysed to explore differences between gender, educational status, employment status, and personal experience of mental illness. The data are represented in contingency tables and analysed using differences explored using traditional bivariate methods for statistical analysis of categorical data - ie the Chi Square test of significance. Where significant differences were demonstrated, the dependent variables were re-coded to produce a set of dichotomous variables. Logistic regression coefficients were then calculated to estimate odds ratios of the independent variables in the model. By these means, it was possible to predict the response to the question about attitude to living next door to the individuals with mental health problems based on a set of predictor variables.

The responses of the general public and service providers relating to the helpfulness of services and supports are presented in contingency tables and differences explored using traditional bivariate methods for statistical analysis of categorical data - ie the Chi Square test of significance.

3. Application of the Methods

The focus group meetings with users of a day resource centre for people with mental health problems produced a series of 5 vignettes portraying hypothetical characters with differing mental health needs. In relation to these characters and their own experience, they identified and defined a list of 23 potential sources of support. These were used as the basis for the questionnaires used in the surveys of the public and professionals on the need for mental health services.

Vignettes and List of Services

The first two vignettes (Julie and Joe) depicted individuals whose mental health needs had not, as yet, been recognised by service providers – ie cases typical of those at the base of Goldberg's Iceberg of Psychiatric Morbidity (see page 138).

Julie is 22 years old and lives with her three year old daughter, Sarah. She often has weepy spells because she feels guilty that the relationship with Sarah's father didn't work. Although her parents help financially, Julie worries that she can't manage on her DSS income. She has stopped going out in the evenings with friends mainly because she would be the only one without a partner. Julie finds it increasingly difficult to sleep and often lies awake worrying about things that happened that day. Although she makes an effort, she often feels too tired to take Sarah to nursery school. Recently, she has been unusually irritable with Sarah and has noticed difficulties in concentrating: she cannot concentrate on a book or a TV programme, and often goes into a room or shop only to find that she cannot remember why she did so.

Joe is 35 years old and lives with his parents. He rarely goes out with friends and it has been a number of years since he's had a steady girlfriend. About a year ago, he started taking the odd day off work because he couldn't face it. He has also had several short absences because of colds and other minor infections. He has now been off work for six weeks with a broken arm. His GP thinks that he is fit enough to go back to work but Joe has lost all motivation to return. When he tried to phone personnel to inform them of his return, he felt physically sick. On several occasions since then, he has felt a choking lump in his throat; his heart thumping in his chest; and cold and clammy.

The third vignette (Mary) portrayed an individual whose mental health needs were currently being treated by her GP. Given the long-term nature of her mental health problems, Mary could have portrayed someone who had been referred for specialist treatment. Mary was designed to fit in the middle of Goldberg's Iceberg of Psychiatric Morbidity.

Mary is in her mid 40s, married with two daughters aged 11 and 8. Apart from minor ailments, she has good physical health. Her GP has been treating her on-and-off with tablets for depression since the death of her mother five years ago. Since that time, Mary has felt less able to cope with things she normally took in her stride. After her house was broken into, she gave up a part-time job in the local supermarket and now misses the company of the women she worked with. She has become increasingly withdrawn and weepy, and rarely goes out of the house. Her eldest daughter does most of the housework and shopping. Although her husband tries to understand, she doesn't find any of his suggestions helpful.

The fourth and fifth vignettes (John and David) both portrayed individuals who had received in-patient care for their mental health problems. Both cases would fit the apex of Goldberg's Iceberg of Psychiatric Morbidity. The differed from each other as John's mental health needs were likely, at times, to be acute whereas David's were of a more chronic nature.

John is 34 years old. He first became acutely distressed when he was 17 and a student at university. He claimed that he could hear voices that no one else could and that these voices told him that everyone was trying to harm him. When he feels like this, his concentration is poor and he tends to forget most things, even routines like washing and eating. Over the past 17 years John has had numerous admissions to hospital. During this time, he has lost contact with his school and neighbourhood friends and relationships with his parents have become very strained. When he is acutely ill, he can be unpredictable and at times, he is loud and verbally aggressive. He is in hospital at the moment. The doctor feels that his symptoms are well controlled with a monthly injection and he could be discharged.

David is a 55 year old bachelor who spent most of his adult life in a psychiatric hospital. Since his discharge, six years ago, he has been living with his elderly mother who does everything for him. His only responsibility is to manage his pocket money which he spends on cigarettes and sweets. He looks older than his years: he shuffles his feet when he walks, his back is stooped and he persistently looks down. He is often seen picking up things from the ground which he sometimes throws away and sometimes puts in his pocket. He looks a bit scruffy but is very friendly and will smile at anyone who says hello to him in the street. It has been many years since he has required medication. Sadly, David's mother has passed away. He has no other close relative living locally. David is keen to live in his mother's house.

The 23 potential sources of support for people with mental health problems were:

Acute Psychiatric Hospital
temporary in-patient care for people with mental health problems

Bereavement Service
counselling service providing support to individuals with difficulties dealing with death

Buddy Support
access to an individual with personal experience of similar problems who could offer moral support

Community Centre for the General Public
building which provides domestic and recreational facilities (such as cafeteria, laundry rooms, bath and shower rooms, games rooms, organised group activities) for everyone in the community.

Community Centre for People with Mental Health Problems
building which provides domestic and recreational facilities (such as, cafeteria, laundry rooms, bath and shower rooms, games rooms, organised group activities) for people with mental health problems

Community Psychiatric Nurse
nurse who specialises in the management of symptoms and treatments relating to mental illness

Domestic Help
individual employed to give practical support with domestic chores such as, cooking and shopping.

Citizens Advice Bureau
centre which provides free, impartial and confidential advice on any subject, including welfare benefits, claims, grants, and legal and financial matters

Directory of Services
list of all services provided by health, social work and voluntary organisations which gives details on nature of service and how to access the service. Could be a book like the "yellow pages" or, a Free Telephone Helpline

Employment Resettlement Officer
individual in Jobcentre to give support in obtaining future training and/or employment.

General Practitioner
medical practitioner who diagnoses, provides treatment and refers to specialists

Health Promotion Centre
centre which runs health education projects/talks aimed at achieving healthier lifestyles.

Health Visitor
nurse trained to offer advice, support and information on the prevention of ill health and the promotion of good health and who refers to other agencies

Institutional Care
permanent in-patient care for people with a mental health problem

Occupational Therapy/ Training
instruction and practical experience in an occupational/diversional activity.

Patient Supporter
individual who accompanies and/or advises a person during any visit to a service provider such as, the doctor or social worker

Psychologist
specialist, not necessarily a doctor, in the treatment of human behaviour

Psychiatrist
doctor specialising in the treatment of mental disorders

Supported Housing
which would include hostels, halfway houses, lodgings, flats/houses supervised by staff

Relate (Marriage Guidance)
counselling service to help people through difficult and unhappy stages in their relationships with partners.

Self-Help Group
local group of people with similar problems who meet to provide mutual support and advice eg Lone Parent Group or, Coping with Anxiety/Depression Group

Social Worker
individual trained to give support with personal and social problems and to arrange other services such as, benefit advice and help in the home.

The Samaritans
24 hour telephone line which provides a listening service for anyone going through a crisis in their lives - the lonely, depressed and suicidal.

Public Survey of the Needs for Services for People with Mental Health Problems

The 200 people who were recruited and interviewed by the market researchers were reasonably representative of the general adult population of Ayrshire (Table 6.1.1). The market research company employed five individuals who each concentrated on obtaining responses in a single geographical area. Unfortunately, as a result of this strategy it was no longer possible to analyse the results in relation to localities since any differences that occurred may have been attributable to differences in the researcher's technique as opposed to real differences between the population.

Table 6.1.1 Age and gender composition of study sample and the adult population served by Ayrshire & Arran Health Board.

	AAHB Males %	**STUDY SAMPLE** Males %	**AAHB** Females %	**STUDY SAMPLE** Females %	**AAHB Total %**	**STUDY SAMPLE Total %**
18 -44 yrs	50	44	50	56	**50**	**49**
45 - 64/ 59 yrs (male/female)	55	56	45	44	**26**	**29**
65/60 - 74 yrs (male/female)	33	42	67	58	**15.5**	**17**
75 + yrs	32	50	68	50	**8.5**	**5**
TOTAL	**47**	**47**	**53**	**53**	**100**	**100**

Source: 1991 mid-year population estimates for Ayrshire and Arran, General Register Office.

The response to the postal survey was disappointing. After an initial response rate of 16%, a letter was sent to the entire second sample because the market research company had failed to apply any mechanism to identify responders. The response rate to this reminder was only around 4%, much lower than anticipated. In an effort to explain this, the company's letter of reminder was reviewed (Appendix F). It was believed that neither the language nor tone of this letter would encourage people to respond. At this stage, a second letter was drafted for the company and sent to the non-responders (Appendix G). The response to this was around 30%. The reversal of the normal pattern of response caused concern. Preliminary analysis of age and postcode code data suggested that some individuals completed more than one questionnaire. For this reason, the data from the postal questionnaire have not been analysed further.

Characteristics of the Interviewed Respondents

One hundred and six respondents (53%) were female, 100 (50%) were aged between 18 and 44 years, 89 (45%) between 45 and 74 years, and 11 (5%) were 75 years or older.

Other salient features of the sample were: 132 participants (66%) were married, 35 (18%) were single, and 32 (16%) were either widowed or divorced. In one case, it was not possible to determine the marital status.

The majority of the participants (75%) had completed full-time education by the age of 16 years. Of the 154 participants under retirement age, 86 participants (56%) were employed, 28 (18%) registered unemployed, 33 (21%) housewives and 7 (5%) had retired early.

Of more direct relevance to the study, 29 participants (15%), 18 women and 11 men, reported that they had a history of mental health problems.

Public Attitudes to People with Mental Illness

As a measure of attitude to people with mental illness, the participants were asked if they would be happy to live next door to the hypothetical cases of Julie, Joe, Mary, David and John who were portrayed in the vignettes which formed the basis of the questionnaire.

It is important to remember that there were two versions of the questionnaire so that each respondent was required to consider only three vignettes. The first version was constructed on the cases of Julie, Mary and John, and the second on Joe, Mary and David (Appendices D and E). The details of these vignettes are reported with the findings of the study.

Attitudes to the Hypothetical Cases of Julie and Joe

Julie and Joe were designed to depict individuals who had minimal or no contact with any service but who, nevertheless, had mental health problems.

Julie is 22 years old and lives with her three year old daughter, Sarah. She often has weepy spells because she feels guilty that the relationship with Sarah's father didn't work. Although her parents help financially, Julie worries that she can't manage on her DSS income. She has stopped going out in the evenings with friends mainly because she would be the only one without a partner. Julie finds it increasingly difficult to sleep and often lies awake worrying about things that happened that day. Although she makes an effort, she often feels too tired to take Sarah to nursery school. Recently, she has been unusually irritable with Sarah and has noticed difficulties in concentrating: she cannot concentrate on a book or a TV programme, and often goes into a room or shop only to find that she cannot remember why she did so.

Joe is 35 years old and lives with his parents. He rarely goes out with friends and it has been a number of years since he's had a steady girlfriend. About a year ago, he started taking the odd day off work because he couldn't face it. He has also had several short absences because of colds and other minor infections. He has now been off work for six weeks with a broken arm. His GP thinks that he is fit enough to go back to work but Joe has lost all motivation to return. When he tried to phone personnel to inform them of his return, he felt physically sick. On several occasions since then, he has felt a choking lump in his throat; his heart thumping in his chest; and cold and clammy.

There was no significant difference between the respondents' views on having Julie or Joe as a neighbour (x^2=2.17 , 2 d.f. p=0.34). One hundred and fifty-five respondents (77.5%) reported that living next door to Julie or Joe would pose no problem for them; only 8 (4%) said that they would definitely not be happy to have Julie or Joe as a neighbour, and 37 (18.5%) expressed reservations (Table 6.1.2). The reservations expressed mainly related to participants' concern for the welfare of the individuals or in the case of Julie, for the child.

Table 6.1.2. Public response to the question "In the case of Julie/Joe, would you be happy if (s)he lived next door to you?"

CHARACTER PORTRAYED IN VIGNETTE	**Number (%) of respondents answering YES**	**Number (%) of respondents answering MAYBE**	**Number (%) of respondents answering NO**	**Total Number (%) of respondents**
Julie	80 (79%)	19 (19%)	2 (2%)	101 (50.5%)
Joe	75 (76%)	18 (18%)	6 (6%)	99 (49.5%)
TOTAL SAMPLE	**155 (77.5%)**	**37 (18.5%)**	**8 (4%)**	**200 (100%)**

No significant differences in the responses were found in relation to gender, age group, age on completing full-time education, employment status, marital status or previous history of mental health problem.

Attitude to the Hypothetical Case of Mary

Mary was included as a typical example of a patient who some GPs might choose to manage themselves whilst others might refer to a psychiatric specialist.

> Mary is in her mid 40s, married with two daughters aged 11 and 8. Apart from minor ailments, she has good physical health. Her GP has been treating her on-and-off with tablets for depression since the death of her mother five years ago. Since that time, Mary has felt less able to cope with things she normally took in her stride. After her house was broken into, she gave up a part-time job in the local supermarket and now misses the company of the women she worked with. She has become increasingly withdrawn and weepy, and rarely goes out of the house. Her eldest daughter does most of the housework and shopping. Although her husband tries to understand, she doesn't find any of his suggestions helpful.

Many of the participants claimed to know people just like Mary:

"....you know that could be my mother 20 years ago" and

"I know someone just like that".

Only 3 participants stated that they would not be happy if Mary lived next door. 174 (87%) said that this would pose no problem for them and the remaining 23 (12%) had reservations (Table 6.1.3).

Table 6.1.3. Public response to the question "In the case of Mary, would you be happy if she lived next door to you?"

RESPONSES IN RELATION TO THE VIGNETTE OF MARY	**Number of Respondents**	**% of Respondents**
YES	174	87
MAYBE	23	11.5
NO	3	1.5
TOTAL SAMPLE	**200**	**100**

The reservations expressed mainly related to the possibility that Mary might be a nuisance:

> *"she might be a problem if she was aye* [always] *at your door.....looking for company"* and
> *" I'd help all I could but I'd be frightened she would become dependent and aye be at the door".*

No significant differences were found in the responses in relation to gender, age, marital status, age on completing full-time education, employment status or previous history of mental health problem.

Attitude to the Hypothetical Cases of John and David.

John depicted an individual who has been hospitalised for long periods during acute phases of a chronic mental illness, and David depicted a discharged long-term patient unaccustomed to caring for himself on a day-to-day basis.

John is 34 years old. He first became acutely distressed when he was 17 and a student at university. He claimed that he could hear voices that no one else could and that these voices told him that everyone was trying to harm him. When he feels like this, his concentration is poor and he tends to forget most things, even routines like washing and eating. Over the past 17 years John has had numerous admissions to hospital. During this time, he has lost contact with his school and neighbourhood friends and relationships with his parents have become very strained. When he is acutely ill, he can be unpredictable and at times, he is loud and verbally aggressive. He is in hospital at the moment. The doctor feels that his symptoms are well controlled with a monthly injection and he could be discharged.

David is a 55 year old bachelor who spent most of his adult life in a psychiatric hospital. Since his discharge, six years ago, he has been living with his elderly mother who does everything for him. His only responsibility is to manage his pocket money which he spends on cigarettes and sweets. He looks older than his years: he shuffles his feet when he walks, his back is stooped and he persistently looks down. He is often seen picking up things from the ground which he sometimes throws away and sometimes puts in his pocket. He looks a bit scruffy but is very friendly and will smile at anyone who says hello to him in the street. It has been many years since he has required medication. Sadly, David's mother has passed away. He has no other close relative living locally. David is keen to live in his mother's house.

In general, respondents were more reticent about having either John or David as a neighbour compared to having neighbours like Julie, Joe or Mary.

There were significant differences between the respondents' views on having a neighbour like John compared to David: 28% c.f. 50% stated that they would be happy if he lived next door, 49% c.f. 40% expressed reservations, and 24% c.f. 10% stated that they definitely would not be happy (x^2=12.38, 2 d.f. p=0.002) (Table 6.1.4).

Table 6.1.4. Public response to the question "In the case of John/David, would you be happy if he lived next door to you?"

CHARACTER PORTRAYED IN VIGNETTE	**Number (%) of respondents answering YES**	**Number (%) of respondents answering MAYBE**	**Number (%) of respondents answering NO**	**Total Number (%) of respondents**
John	28 (28%)	49 (49%)	24 (24%)	101 (50.5%)
David	49 (50%)	40 (40%)	10 (10%)	99 (49.5%)
TOTAL SAMPLE	**77 (38.5%)**	**89 (44.5%)**	**34 (17%)**	**200 (100%)**

Housewives were the least likely to say that they would be happy to have John as a neighbour and the most likely to say that they would not be happy at the prospect (x^2= 24.4 with 6 d.f. $p < 0.01$) (Table 6.1.5).

Table 6.1.5. Public response to the question "In the case of John, would you be happy if he lived next door to you?" in relation to the total sample and employment status.

RESPONSES IN RELATION TO THE VIGNETTE JOHN	**Number (%) of respondents answering YES**	**Number (%) of respondents answering MAYBE**	**Number (%) of respondents answering NO**	**Total Number (%) of respondents**
Employed	19 (37)	26 (50)	7 (13)	**52**
Unemployed	4 (31)	4 (31)	5 (38)	**13**
Housewife	1 (5)	9 (47)	9 (47)	**19**
Retired	4 (23)	10 (59)	3 (18)	**17**
TOTAL SAMPLE	**28**	**49**	**24**	**101**

No significant differences were found in the responses in relation to John by any other population characteristic.

Participants expressed several reservations about having John a neighbour. Some were worried that his unpredictable and aggressive behaviour might endanger themselves or others:

"I would lock my door if he was my neighbour".

This was particularly the case where there were children in the household or neighbourhood:

" I understand that these people should live in the community but I would be afraid for my children..." and

"I probably wouldn't mind until the first time he roared at the kids".

Others believed that service provision was inadequate to support an individual like John in the community:

"These people are let out of hospital and have to fend for themselves......." and

"...The neighbours would end up being the unofficial carers".

In the case of David, respondents who had continued in full time education after the age of 16 years were more likely to have reservation but less likely to state that they would be unhappy if he was a neighbour (x^2= 6.1.53 with 2 d.f. $p < 0.05$) (Table 6.1.6).

Table 6.1.6 Public response to the question "In the case of David, would you be happy if he lived next door to you?" in relation to the total sample and age on completion of full-time education.

RESPONSES IN RELATION TO THE VIGNETTE DAVID	**Number (%) of respondents answering YES**	**Number (%) of respondents answering MAYBE**	**Number (%) of respondents answering NO**	**Total Number (%) of respondents**
Completed education ≤ 16 yrs	38 (52%)	25 (34%)	10 (13%)	73
Completed education >16 yrs	11 (42%)	15 (58%)	0	26
TOTAL SAMPLE	**49**	**40**	**10**	**99**

No significant differences were found in the responses in relation to David by any other population characteristic.

Some participants were concerned about the potential risk that David might pose to himself and others:

" I think he might be a fire risk...he could burn the house down with a cigarette".

Others again expressed reservations about the adequacies of existing services to support an individual like David in the community:

"I would try to help with shopping and things......I would probably end up as the only source of back-up for him".

Attitude to Groups of Individuals Like John and David.

The respondents were further asked if they would be happy if a group like John or David lived next door with staff supervision. For both cases combined, just over one-quarter of respondents (27%) said that they would not be happy to live next door to the group of individuals even with staff supervision, and the remainder were evenly divided between those who held reservations (37.5%) and those who said that they would be happy (37.5%) (Table 6.1.7). There was no significant difference in the responses to the question regarding the group situation when it was posed in relation to John as opposed to David (x^2= 2.98 with 2 d.f. $p = 0.23$)

Table 6.1.7. Public response to the question "Would you be happy if small groups of individuals like John/David lived with staff supervision next door to you?"

HAPPY TO LIVE NEXT DOOR WITH GROUPS OF INDIVIDUALS LIKE "JOHN/DAVID" WITH STAFF SUPERVISION	**Number (%) of respondents answering YES**	**Number (%) of respondents answering MAYBE**	**Number (%) of respondents answering NO**	**Total Number (%) of respondents**
John	31 (31%)	40 (40%)	30 (30%)	101 (50.5%)
David	42 (42%)	33 (33%)	24 (24%)	99 (49.5%)
TOTAL SAMPLE	**73 (36.5%)**	**73 (36.5%)**	**54 (27%)**	**200 (100%)**

There was a strong linear association between age and the response of "not happy to live next door to small supervised groups of individuals like John and David": 15 respondents (15%) aged between 18 and 44 years said that they would be unhappy compared to 20 respondents (37%) aged between 45 and retirement age, and 19 respondents (41%) aged post retirement age (x^2= 5.78 with 1 d.f. p <0.02) (Table 6.1.8).

Table 6.1.8. Public response to the question "Would you be happy if small groups of individuals like John/David lived with staff supervision next door to you?" in relation to Age Group

HAPPY TO LIVE NEXT DOOR WITH GROUPS LIKE JOHN AND DAVID WITH STAFF SUPERVISION	**Number (%) of respondents answering YES**	**Number (%) of respondents answering MAYBE**	**Number (%) of respondents answering NO**	**Total Number (%) of respondents**
18 – 44 years	39 (39%)	46 (46%)	15 (15%)	100 (50%)
45 – 59/64* years	18 (33%)	16 (30%)	20 (37%)	54 (27%)
60/65* years or older	16 (35%)	11 (24%)	19 (41%)	46 (23%)
TOTAL SAMPLE	**73 (36.5%)**	**73 (36.5%)**	**54 (27%)**	**200 (100%)**

*female/male

Housewives and retired people were most likely to be unhappy about the prospect of living next door to small supervised groups like John and David: 42% of respondents in each of these categories said that they would not be happy compared to 14% of respondents who were either employed or students and 21% of respondents who were either unemployed or on invalidity benefit (x^2= 21.62 with 6 d.f. p =0.001) (Table 6.1.9).

Table 6.1.9. Public response to the question "Would you be happy if small groups of individuals like John/David lived with staff supervision next door to you?" in relation to Employment Status

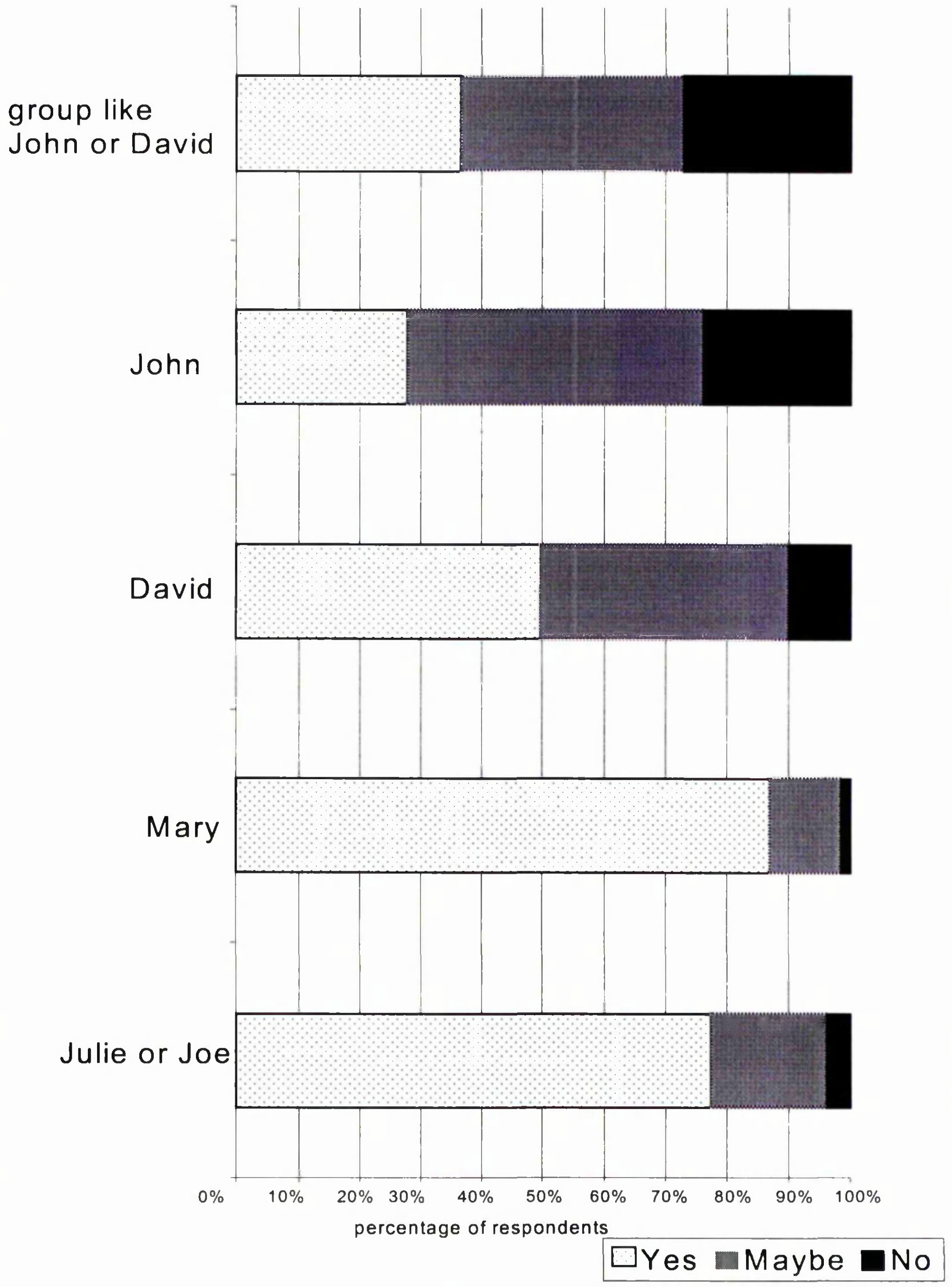
HAPPY TO LIVE NEXT DOOR WITH GROUPS LIKE JOHN AND DAVID WITH STAFF SUPERVISION	**Number (%) of respondents answering YES**	**Number (%) of respondents answering MAYBE**	**Number (%) of respondents answering NO**	**Total Number (%) of respondents**
Employed or Students	31 (36%)	43 (50%)	12 (14%)	86 (43%)
Unemployed or Invalid	13 (46%)	9 (32%)	6 (21%)	28 (14%)
Housewives	13 (34%)	9 (24%)	16 (42%)	38 (19%)
Retired	16 (33%)	12 (25%)	20 (42%)	48 (24%)
TOTAL SAMPLE	**73 (36.5%)**	**73 (36.5%)**	**54 (27%)**	**200 (100%)**

Using a logistic regression model, it was not possible to identify predictors of the response "yes, would be happy to live next door to a supervised group. The employment status "employed or student" was the best predictor of the ambivalent response "it depends" (p=0.0007), (r=0.0249). The best predictor of the response "no, would not be happy to live next door to a supervised group" were age greater than retirement age (p=0.04) and the occupational status of housewife (p<0.02).

Summary of Public Attitudes to Individuals and Groups with Mental Health Problems.

Figure 6.1.1 illustrates the responses to the questions "In the case of Julie/Joe/Mary/John/David, would you be happy if (s)he lived next door to you?" and "Would you be happy if a small group of individuals like John and David lived with staff supervision in the house next door?"

Figure 6.1.1 Attitude to Individuals and Groups with Mental Health Problems: Percentage of the public saying "Yes", "No" or "Maybe" to the question about being happy to living next door to X.



Public Views on the Need for Services

Participants were shown this list of services with their definitions and asked to rate their helpfulness for each of the individuals portrayed in the vignettes.

List of Services/Supports

Acute Psychiatric Hospital
temporary in-patient care for people with mental health problems

Bereavement Service
counselling service providing support to individuals with difficulties dealing with death

Buddy Support
access to an individual with personal experience of similar problems who could offer moral support

Community Centre for the General Public
building which provides domestic and recreational facilities (such as cafeteria, laundry rooms, bath and shower rooms, games rooms, organised group activities) for everyone in the community.

Community Centre for People with Mental Health Problems
building which provides domestic and recreational facilities (such as, cafeteria, laundry rooms, bath and shower rooms, games rooms, organised group activities) for people with mental health problems

Community Psychiatric Nurse
nurse who specialises in the management of symptoms and treatments relating to mental illness

Domestic Help
individual employed to give practical support with domestic chores such as, cooking and shopping.

Citizens Advice Bureau
centre which provides free, impartial and confidential advice on any subject, including welfare benefits, claims, grants, and legal and financial matters

Directory of Services
list of all services provided by health, social work and voluntary organisations which gives details on nature of service and how to access the service. Could be a book like the "yellow pages" or, a Free Telephone Helpline

Employment Resettlement Officer
individual in Jobcentre to give support in obtaining future training and/or employment.

General Practitioner
medical practitioner who diagnoses, provides treatment and refers to specialists

Health Promotion Centre
centre which runs health education projects/talks aimed at achieving healthier lifestyles.

Health Visitor
nurse trained to offer advice, support and information on the prevention of ill health and the promotion of good health and who refers to other agencies

Institutional Care
permanent in-patient care for people with a mental health problem

Occupational Therapy/ Training
instruction and practical experience in an occupational/diversional activity.

Patient Supporter
individual who accompanies and/or advises a person during any visit to a service provider such as, the doctor or social worker

Psychologist
specialist, not necessarily a doctor, in the treatment of human behaviour

Psychiatrist
doctor specialising in the treatment of mental disorders

Supported Housing
which would include hostels, halfway houses, lodgings, flats/houses supervised by staff

Relate (Marriage Guidance)
counselling service to help people through difficult and unhappy stages in their relationships with partners.

Self-Help Group
local group of people with similar problems who meet to provide mutual support and advice eg Lone Parent Group or, Coping with Anxiety/Depression Group

Social Worker
individual trained to give support with personal and social problems and to arrange other services such as, benefit advice and help in the home.

The Samaritans
24 hour telephone line which provides a listening service for anyone going through a crisis in their lives - the lonely, depressed and suicidal.

The list of services was constructed in collaboration with service users and providers, and it included some not presently available in Ayrshire. For the rating exercise, a four-point scale (0 to 3) was used: from "not at all helpful" to "may help a lot". The results of this exercise are summarised in Figures 6.1.2 – 6.1.7.

Public Rating of Helpfulness of Services for Julie

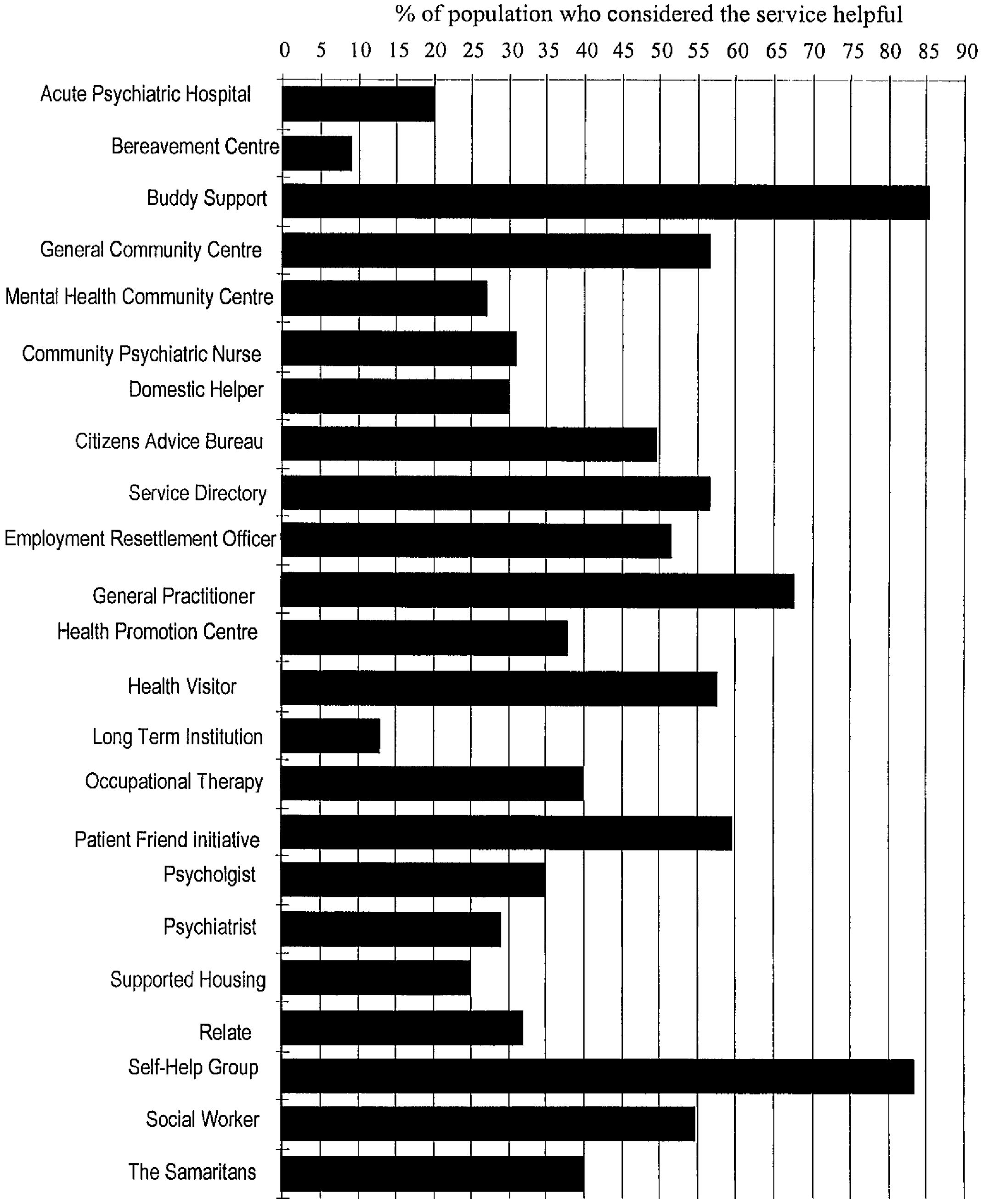
For individuals like Julie, the general public rated lay support as being the most helpful: more than four-fifths of respondents rated Buddy Support (85%) and Self-Help Group (83%) as helpful (Figure 6.1.2). Two-thirds of respondents (66%) rated the general practitioner as helpful. Around half of the respondents believed in the helpfulness of a number of statutory and non-statutory supports; Patient Supporter (59%) Health Visitor (57%), General Community Centre (56%), Service Directory (56%), Social Worker (54%), Employment Resettlement Officer (51%) and Citizens Advice Bureau (50%). Two-fifths of respondents (40%) believed that Occupational Therapy and The Samaritans would be helpful. Specialist mental health services were rated less helpful: Psychologist (35%), Community Psychiatric Nurse (31%), Psychiatrist (29%), Community Centre for People with Mental Health Problems (27%), Supported Housing (25%), Acute Psychiatric Hospital (20%), Institutional Care (13%), Bereavement Service (9%). Less than one-third (30%) rated a Domestic Helper as a source of support for Julie.

Public Rating of Helpfulness of Services for Joe

In the case of individuals like Joe, the public awarded equally high ratings of helpfulness to Self-Help Group (83%), Buddy Support (82%) the General Practitioner (68%)(Figure 6.1.3). However, their ratings of the helpfulness was lower for the Employment Resettlement Officer (37%), Social Worker (28%), Health Visitor (27%), Citizens Advice Bureau (24%) and Domestic Helper (19%). On the other hand, the public's perception of the helpfulness of a psychologist was higher for Joe than for Julie (49% c.f 35%). Otherwise the pattern of public support for Joe was similar to that of Julie: Patient Supporter (62%), General Community Centre (51%), Service Directory (49%), Community Psychiatric Nurse (39%), Health Promotion Centre (39%), Occupational Therapy (35%), Psychiatrist (35%), Community Centre for People with Mental Health Problems (25%), Acute Psychiatric Hospital (14%), Bereavement Service (7%), Supported Housing (13%), Relate (8%) and Institutional Care (4%).

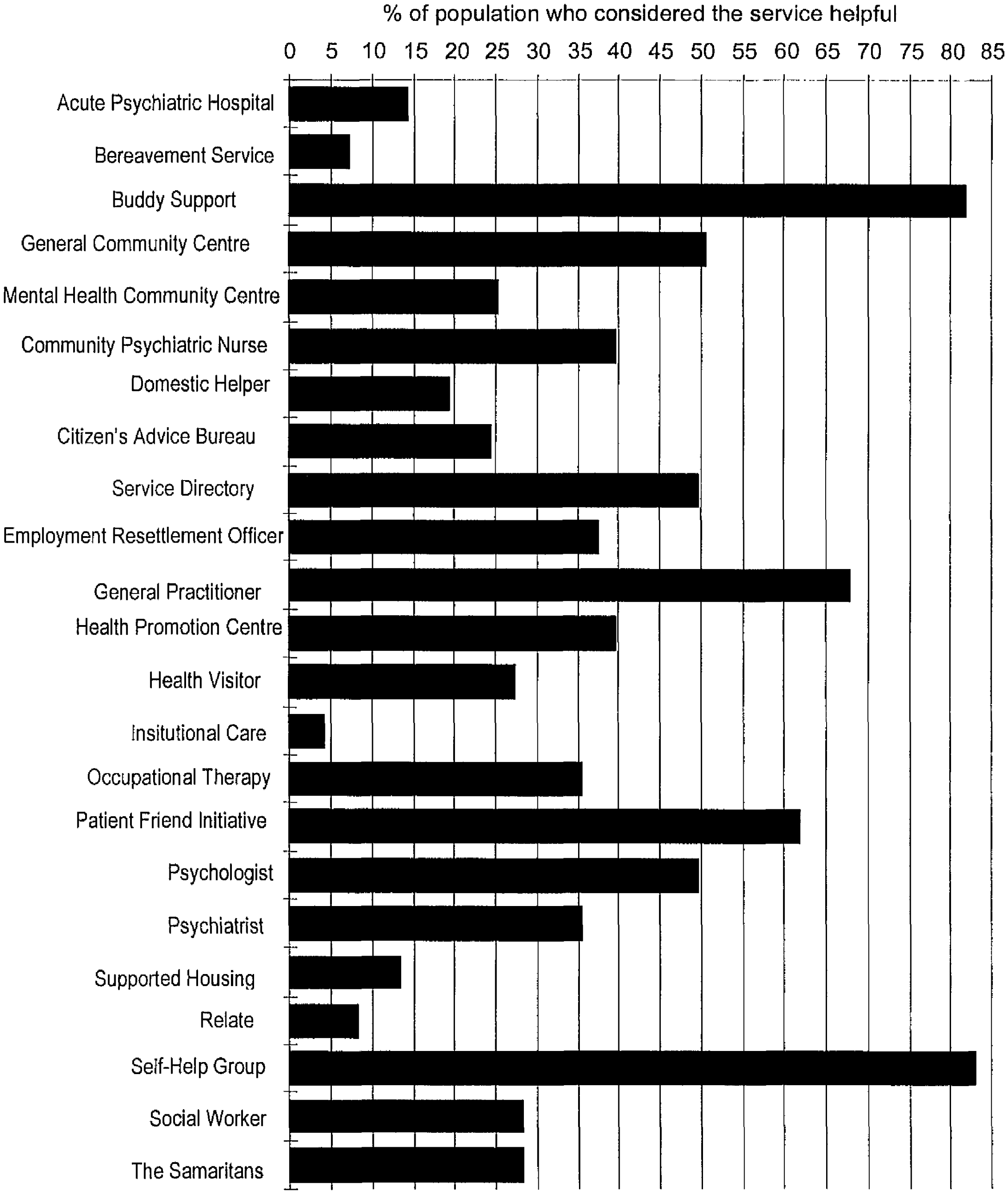
Julie is 22 years old and lives with her three year old daughter, Sarah. She often has weepy spells because she feels guilty that the relationship with Sarah's father didn't work. Although her parents help financially, Julie worries that she can't manage on her DSS income. She has stopped going out in the evenings with friends mainly because she would be the only one without a partner. Julie finds it increasingly difficult to sleep and often lies awake worrying about things that happened that day. Although she makes an effort, she often feels too tired to take Sarah to nursery school. Recently, she has been unusually irritable with Sarah and has noticed difficulties in concentrating: she cannot concentrate on a book or a TV programme, and often goes into a room or shop only to find that she cannot remember why she did so.

Figure 6.1.2. Public Ratings of the Need For Services to Support an Individual like Julie



<u>Joe</u> is 35 years old and lives with his parents. He rarely goes out with friends and it has been a number of years since he's had a steady girlfriend. About a year ago, he started taking the odd day off work because he couldn't face it. He has also had several short absences because of colds and other minor infections. He has now been off work for six weeks with a broken arm. His GP thinks that he is fit enough to go back to work but Joe has lost all motivation to return. When he tried to phone personnel to inform them of his return, he felt physically sick. On several occasions since then, he has felt a choking lump in his throat; his heart thumping in his chest; and cold and clammy.

Figure 6.1.3. Public Ratings of the Need For Services to Support an Individual like Joe



Public Rating of Helpfulness of Services for Mary

As in the previous two cases, the rating by the public of the helpfulness of services for individuals like Mary was highest for Self-Help Group (82%) and Buddy Support (70%) (Figure 6.1.4). There was also little change in the rating of the helpfulness of the General Practitioner (60%). There was, however, a stronger support for a Bereavement Service; perceived helpful by 60% of respondents. Between three-fifths and fourth-fifths of respondents rated a mixture of statutory and non-statutory services as helpful: Community Psychiatric Nurse (40%), Health Visitor (40%), Psychologist (38%), The Samaritans (37%), Relate (35%), General Community Centre (35%), Health Promotion Centre (33%), Social Worker (33%), Psychiatrist (31%), Occupational Therapy (30%). There was slightly less support for a Domestic Helper (29%) and a Directory of Services (28%) and poor support for an acute Psychiatric Hospital (16%), Community Centre for People with Mental Health Problems (16%), Citizens Advice Bureau (15%), Supported Housing (7%) and Institutional Care (5%).

Public Rating of Helpfulness of Services for John

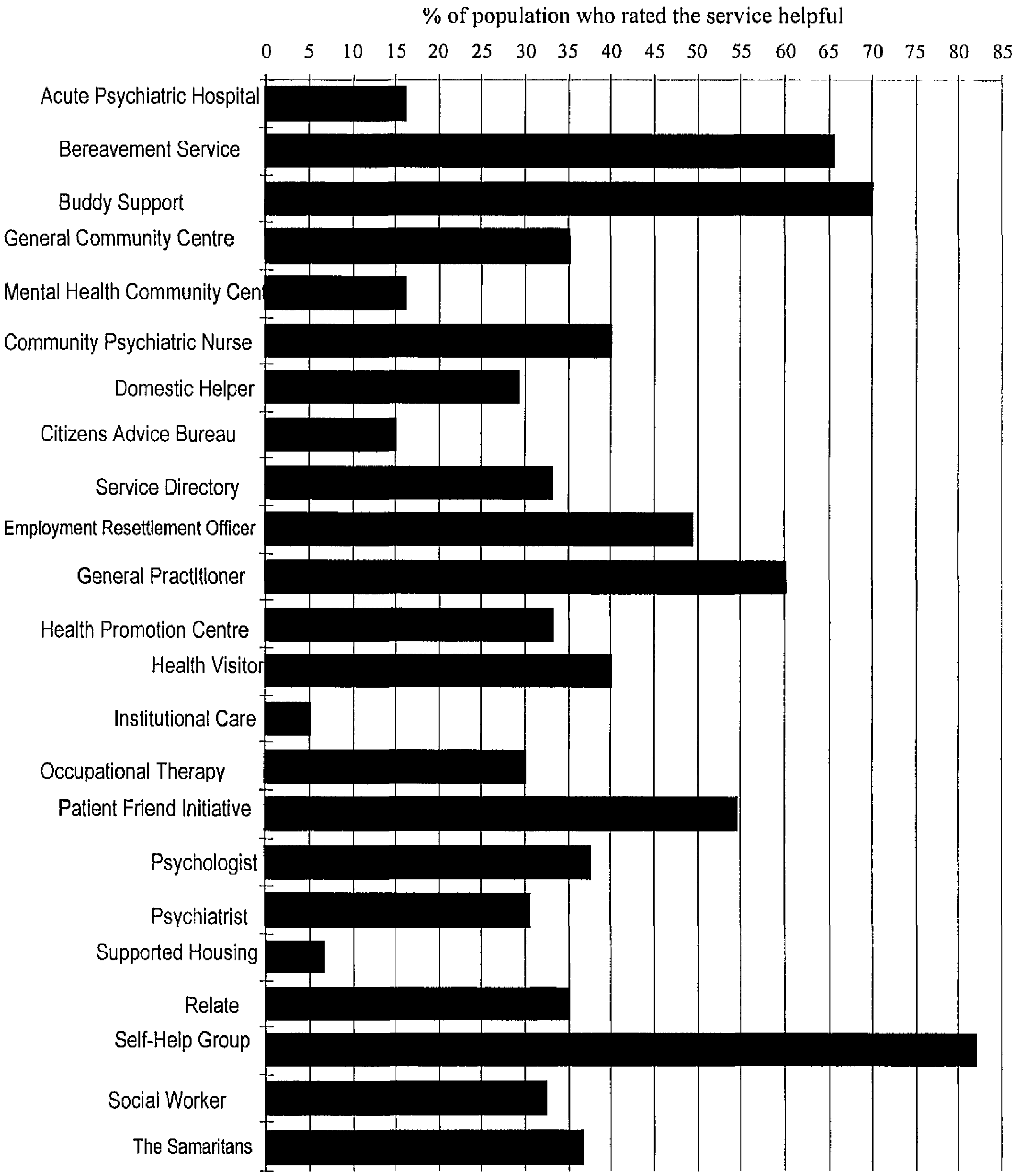
For individuals like John, the ratings were highest for specialist services: Psychiatrist (93%), Community Psychiatric Nurse (92%), Acute Psychiatric Hospital (87%) and Community Centre for People with Mental Health Problems (87%) (Figure 6.1.5). Almost three-quarters (72%) believed that Supported Housing would be helpful and as in the previous cases, almost two-thirds (63%) rated the General Practitioner as helpful. A similar proportion (67%) rated a Patient Supporter as helpful. Approximately half of the respondents rated the support of a Domestic Helper (56%), Self-Help Group (50%) Institutional Care (46%) and Health Visitor (45%). There was less support for a Health Promotion Centre (38%), The Samaritans (36%), Buddy Support (35%), General Community Centre (27%), Employment Resettlement Officer (25%) and Service Directory (22%), and virtually no support for the Citizens Advice Bureau (12%), Bereavement Service (6%) and Relate (4%).

Public Rating of Helpfulness of Services for David

For individuals like David, the public ratings of the helpfulness of services were highest for those which provided a range of health and social support: Community Centre for People with Mental Health Problems (82%), Domestic Helper (81%), Community Psychiatric Nurse (73%), Patient Supporter (70%), Supported Housing (70%) and Social Worker (68%) and Psychiatrist (66%) (Table 6.1.6). A small majority believed that a Bereavement Service (58%) and Occupational Therapy (52%) would be helpful for people like David. In contrast to the previous cases, less than half of the respondents (47%) felt that the General Practitioner would be helpful. Approximately two-fifths of respondents rated the support of a Psychologist (45%) Acute Psychiatric Hospital (43%), Buddy Support (41%) and Self-Help Group (38%). Only one quarter of respondents (25%) perceived Institutional Care as helpful, and approximately one-fifth (22%) thought that a Health Promotion Centre would be helpful for people like David. There was marginal support only for The Samaritans (19%), Citizens Advice Centre (16%), Service Directory (13%) and Employment Resettlement Officer (11%).

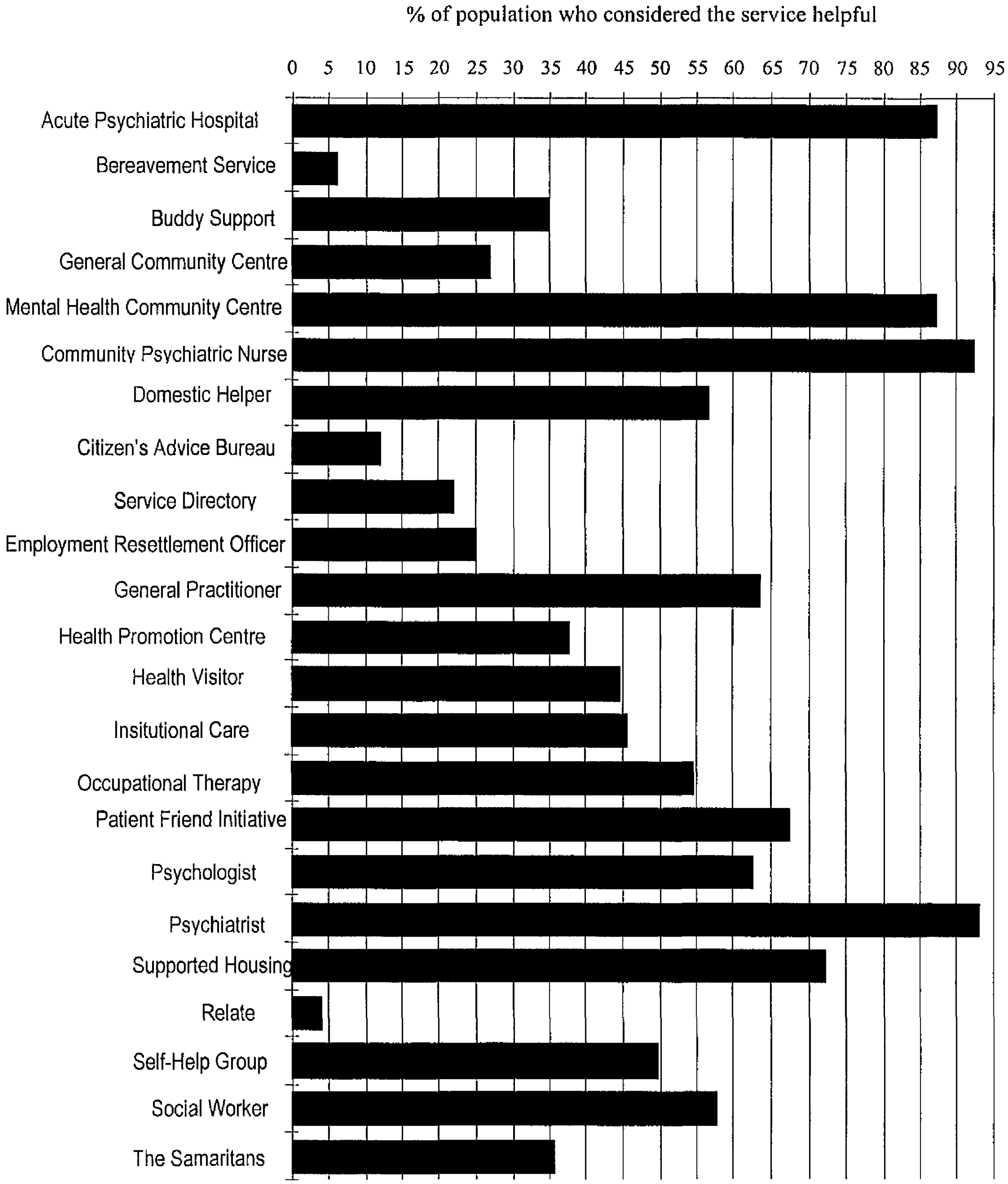
Mary is in her mid 40s, married with two daughters aged 11 and 8. Apart from minor ailments, she has good physical health. Her GP has been treating her on-and-off with tablets for depression since the death of her mother five years ago. Since that time, Mary has felt less able to cope with things she normally took in her stride. After her house was broken into, she gave up a part-time job in the local supermarket and now misses the company of the women she worked with. She has become increasingly withdrawn and weepy, and rarely goes out of the house. Her eldest daughter does most of the housework and shopping. Although her husband tries to understand, she doesn't find any of his suggestions helpful.

Figure 6.1.4. Public Ratings of the Need For Services to Support an Individual like Mary



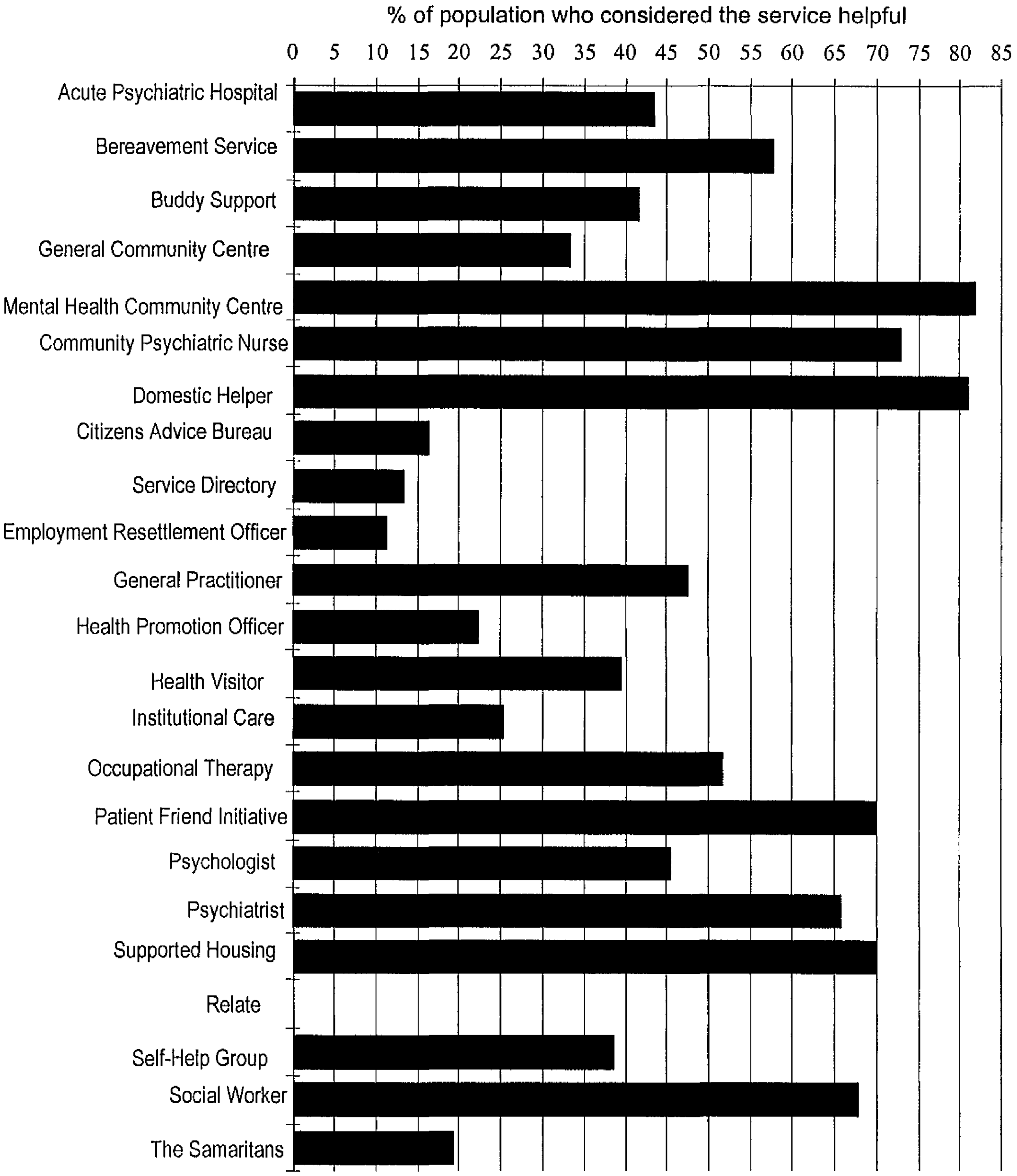
<u>John</u> is 34 years old. He first became acutely distressed when he was 17 and a student at university. He claimed that he could hear voices that no one else could and that these voices told him that everyone was trying to harm him. When he feels like this, his concentration is poor and he tends to forget most things, even routines like washing and eating. Over the past 17 years John has had numerous admissions to hospital. During this time, he has lost contact with his school and neighbourhood friends and relationships with his parents have become very strained. When he is acutely ill, he can be unpredictable and at times, he is loud and verbally aggressive. He is in hospital at the moment. The doctor feels that his symptoms are well controlled with a monthly injection and he could be discharged

Figure 6.1.5. Public Ratings of theNeed For Services to Support an Individual like John



<u>David</u> is a 55 year old bachelor who spent most of his adult life in a psychiatric hospital. Since his discharge, six years ago, he has been living with his elderly mother who does everything for him. His only responsibility is to manage his pocket money which he spends on cigarettes and sweets. He looks older than his years: he shuffles his feet when he walks, his back is stooped and he persistently looks down. He is often seen picking up things from the ground which he sometimes throws away and sometimes puts in his pocket. He looks a bit scruffy but is very friendly and will smile at anyone who says hello to him in the street. It has been many years since he has required medication. Sadly, David's mother has passed away. He has no other close relative living locally. David is keen to live in his mother's house.

Figure 6.1.6. Public Ratings of the Need For Services to Support an Individual like David



Additional Supports Rated Helpful by the Public

Respondents were given the opportunity to name and rate services not contained within the list. Thirty-four respondents (17%) suggested alternative forms of support. Twenty-two respondents felt that the individuals' parents or family would be helpful, particularly for the cases of Julie, Joe and Mary. Ten respondents felt that local church groups could provide help. The remainder suggested other forms of formal service provision such as shopping service (2) physical exercise (2), art therapy (1). These services could be contained with the provision of the listed services of a community centre and domestic helper.

Public Rating of the Helpfulness of Services in relation to Provider Sector

The individual services and supports were classified according to the key below in order to determine the public's views on the helpfulness of specific service providers for supporting individuals with mental health problems.

Health Services = Acute Hospital, Community Psychiatric Nurse, GP, Health Visitor, Institutional Care, Psychologist, Psychiatrist, Occupational Therapy and Health Promotion Centre;

Local Authority Services = Community Centre for the General Public, Community Centre for People with Mental Health Problems, Domestic Helper, Supported Housing, Social Worker, Employment Resettlement Officer, Bereavement Service and Directory of Services; and

Lay Supports = Buddy Support System, Patient Friend Initiative, Self-Help Group, The Samaritans, Citizen's Advice Bureau and Relate.

Figures 6.1.7 to 6.1.11 illustrate the publics' ratings for supports for each of the individuals portrayed in the vignettes.

As far as Julie (Figure 6.1.7), Joe (Figure 6.1.8) and Mary (Figure 6.1.9) were concerned, there was an overall similarity in the way in which the services/supports were rated. For all three cases, public ratings of services were fairly evenly distributed between those provided by the health services, social services and lay or voluntary supports.

For John (Figure 6.1.10), the rating pattern was different. As far as the public was concerned, John was a case for statutory support. More than half (51%) of the services rated helpful were provided by the health service, just under one-third (31%) by social services and about one-fifth (18%) by voluntary or lay services.

For David (Figure 6.1.11), the pattern was different again and the services considered to be most helpful were more equally balanced between the health (41%) and local authority social work services (41%). As in the case of John, 18% of services rated by the public as helpful for David were provided by lay or voluntary organisations.

Figure 6.1.7 Public Ratings of Helpfulness of Services for Julie in relation to Provider

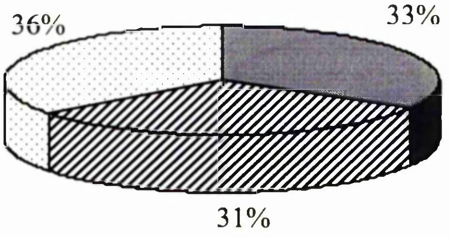


Figure 6.1.8 Public Ratings of Helpfulness of Services for Joe in relation to Provider

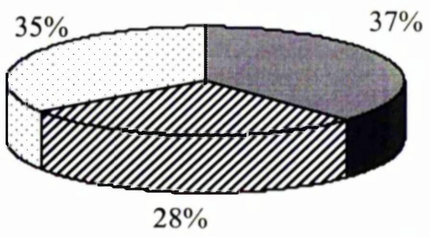


Figure 6.1.9 Public Ratings of Helpfulness of Services for Mary in relation to Provider

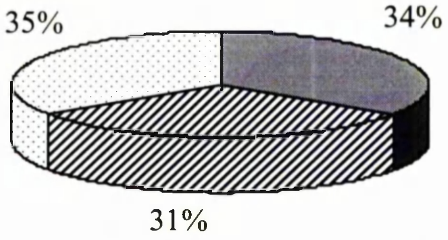


Figure 6.1.10 Public Ratings of Helpfulness of Services for John in relation to Provider

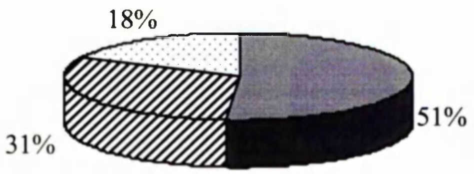
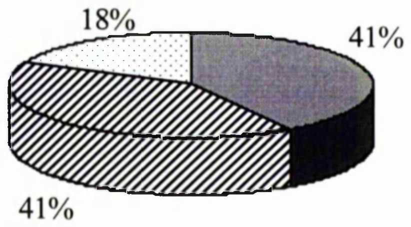


Figure 6.1.11 Public Ratings of Helpfulness of Services for David in relation to Provider



▩ Health ▨ Social ☐ Lay

Provider Survey of the Needs for Services for People with Mental Health Problems

Service providers were recruited for the survey from March to July 1994. In total, 158 questionnaires were returned. Despite the variety of approaches to recruitment, the majority of the respondents were employed in the health sector (72%). Just over half the respondents were qualified (55%), a similar proportion were female (54%), approximately two-fifths reported that they had been in their current occupation for more than 5 years and around a third (30%) were 40 years or older. Table 6.2.1 summarises the characteristics of the study population in relation to their occupation.

Table 6.2.1 Characteristics of the study population: occupation, qualification, experience, gender, age.

Occupation	Number (%)	Qualified (%)	Over 5 yrs Experience (%)	Female (%)	> 40 yrs Age (%)
TOTAL SAMPLE	**158 (100)**	**87 (55)**	**67 (42)**	**86 (54)**	**48 (30)**
Community Psychiatric Nurse	15 (10)	9 (60)	7 (47)	7 (47)	6 (40)
Community Worker	11 (7)	4 (36)	8 (73)	3 (27)	3 (27)
District Nurse	10 (6)	0	0	8 (80)	2 (20)
General Practitioner	37 (23)	22 (59)	17 (46)	9 (24)	11 (30)
Health Visitor	15 (10)	9 (60)	6 (40)	15 (100)	7 (47)
Occupational Therapist	2 (1)	2 (100)	2 (100)	2 (100)	1 (50)
Physiotherapist	2 (3)	2 (100)	1 (50)	2 (100)	1 (50)
Psychologist	4 (3)	4 (100)	3 (75)	2 (50)	1 (25)
Psychiatrist	6 (4)	5 (83)	0	3 (50)	2 (33)
Registered General Nurse	5 (3)	5 (100)	3 (60)	5 (100)	1 (20)
Registered Mental Nurse	19 (12)	19 (100)	13 (68)	11 (58)	9 (47)
Social Worker	31 (20)	6 (19)	6 (19)	19 (61)	4 (13)
Not Known	1 (1)	0	1	0	0

Comparison of Public and Provider Attitudes to People with Mental Illness

The main focus of the analyses was to explore differences between the responses of providers and the public in relation to whether or not they would be happy to live next door to the hypothetical individuals portrayed in the vignettes. The service providers' responses have been analysed further to explore differences between gender, age, whether employed by the health or social sector, length of experience in current occupation, and qualified and unqualified staff. Discussion of the results includes some of the recorded comments in order to highlight possible explanations for differences in ratings.

Attitudes to the Hypothetical Cases of Joe

This vignette was designed to depict an individual who had minimal contact with services but who, nevertheless, was experiencing problems that affected his mental wellbeing.

> Joe is 35 years old and lives with his parents. He rarely goes out with friends and it has been a number of years since he's had a steady girlfriend. About a year ago, he started taking the odd day off work because he couldn't face it. He has also had several short absences because of colds and other minor infections. He has now been off work for six weeks with a broken arm. His GP thinks that he is fit enough to go back to work but Joe has lost all motivation to return. When he tried to phone personnel to inform them of his return, he felt physically sick. On several occasions since then, he has felt a choking lump in his throat; his heart thumping in his chest; and cold and clammy.

Service providers were less reticent than public about the prospect of having someone like Joe as a neighbour: 89% c.f. 76% reported that living next door to Joe would pose no problem for them, only 7% c.f 18% expressed reservations and 2% c.f 6% said that they would not be happy (x^2=7.89, 2 d.f. $p<0.02$) (Table 6.2.2).

Table 6.2.2. Service Providers and Public Responses to the question "In the case of Joe, would you be happy if he lived next door to you?".

RESPONSES IN RELATION TO THE VIGNETTE Joe	**Number (%) answering YES**	**Number (%) answering MAYBE**	**Number (%) answering NO**	**Total Number (%) of respondents**
Service Providers*	125 (89%)	12 (9%)	3 (2%)	**140 (59%)**
Public	75 (76%)	18 (18%)	6 (6%)	**99 (41%)**
TOTAL SAMPLE	**200 (84%)**	**30 (13%)**	**9 (4%)**	**239**

* 18 providers were administered an earlier version of the questionnaire in which did not feature Joe.

No significant differences were found between service providers' responses in relation to gender, age, sector of employment, time in current occupation, and qualified and unqualified staff.

The reservations expressed by service providers mainly related to concerns that Joe and/or his parents may rely on the respondents' professional skills: *".... dependency is created when a client knows there is someone next door who can help and it generally leads to abuse of the assistance that's available".*

Attitudes to the Hypothetical Case of Mary

Mary was included as a typical example of a patient with long-standing problems who some GPs may or may not choose to manage themselves.

> **Mary** is in her mid 40s, married with two daughters aged 11 and 8. Apart from minor ailments, she has good physical health. Her GP has been treating her on-and-off with tablets for depression since the death of her mother five years ago. Since that time, Mary has felt less able to cope with things she normally took in her stride. After her house was broken into, she gave up a part-time job in the local supermarket and now misses the company of the women she worked with. She has become increasingly withdrawn and weepy, and rarely goes out of the house. Her eldest daughter does most of the housework and shopping. Although her husband tries to understand, she doesn't find any of his suggestions helpful.

There were no significant differences between the responses of service providers and the public when questioned if they would be happy to live next door to an individual like Mary. One hundred and forty-two service providers (90%) said that this would pose no problem for them, 12 (8%) had reservations, and only 4 (2%) stated that they would not be happy if Mary lived next door.

No significant differences between service providers' responses were found in relation to gender, sector of employment or between qualified and unqualified staff. However, service providers aged less than 30 years and those with less than one years experience in their current occupation were less likely to say that they would be happy and expressed more reservations about having an individual like Mary as a neighbour (Table 6.2.3).

Table 6.2.3. Service Providers' response to the question "In the case of Mary, would you be happy if she lived next door to you?" in relation to age and time in current occupation.

SERVICE PROVIDERS' RESPONSES IN RELATION TO THE VIGNETTE Mary	**Number (%) answering YES**	**Number (%) answering MAYBE**	**Number (%) answering NO**	**x^2 value, p value. (2 d.f)**
AGE				
less than 30 years	27 (79%)	6 (18%)	1 (3%)	6.32
30 years or older	115 (93%)	6 (5%)	3 (2%)	0.04
EXPERIENCE IN CURRENT OCCUPATION				
Less than 1 year	38 (81%)	8 (17%)	1 (2%)	8.48
1 year or longer	104 (94%)	4 (4%)	3 (2%)	0.01
TOTAL SAMPLE	**142 (90%)**	**12 (8%)**	**4 (2%)**	**158**

The reservations expressed were similar to those relating to the previous vignette. Indeed, 9 of the 15 service providers (60%) who did not state that they would be happy to have Joe as a neighbour expressed the same reservations concerning Mary.

Attitudes to the Hypothetical Cases of David

David was included to depict a discharged long-term patient who was still not accustomed to managing on a day-to-day basis.

> **David** is a 55 year old bachelor who spent most of his adult life in a psychiatric hospital. Since his discharge, six years ago, he has been living with his elderly mother who does everything for him. His only responsibility is to manage his pocket money, which he spends on cigarettes and sweets. He looks older than his years: he shuffles his feet when he walks, his back is stooped and he persistently looks down. He is often seen picking up things from the ground which he sometimes throws away and sometimes puts in his pocket. He looks a bit scruffy but is very friendly and will smile at anyone who says hello to him in the street. It has been many years since he has required medication. Sadly, David's mother has passed away. He has no other close relative living locally. David is keen to live in his mother's house.

The proportion of service providers who responded that they would not be happy if an individual like David was their neighbour (3%) was similar to the responses to vignettes relating to Joe and Mary. However, significantly fewer respondents (51% c.f. 84% and 90%) stated that they would be happy to live next door to David than Joe and Mary respectively. There was no significant difference between the responses of service providers and the public in relation to living next door to David ($X^2 = 5.69$, 2 d.f. $p > 0.05$).

No significant differences were found between service providers' responses in relation to gender, age, length of experience in current occupation, or between qualified and unqualified staff. However, staff from the social work sector were more likely than health sector staff to respond that they would be happy (73% c.f. 45%) and less likely to express reservations (30% c.f. 51%) about having David as a neighbour ($X^2 = 6.89$, 2 d.f. $p = 0.03$, Table 6.2.4).

Table 6.2.4. Service Providers' Responses to the question "In the case of David, would you be happy if he lived next door to you?" in relation to sector of employment

SERVICE PROVIDERS' RESPONSES IN RELATION TO THE VIGNETTE David	**Number (%) answering YES**	**Number (%) answering MAYBE**	**Number (%) answering NO**	**Total Number (%) of respondents**
HEALTH	51 (45%)	58 (51%)	4 (4%)	**113 (81%)**
SOCIAL	19 (73%)	7 (27%)	0	**26 (19%)**
TOTAL SAMPLE	**70 (50%)**	**65 (47%)**	**4 (3%)**	**139**

18 providers were administered an earlier version of the questionnaire which did not feature David and in 1 case it was not possible to determine the sector of employment.

The majority of respondents who had reservations about David as a neighbour did not elaborate. Those who did, stated that their decision would be influenced by the level of community support that would be available for David: *"he would most definitely require support from trained staff and not be left to his own devices "*.

Attitudes to the Hypothetical Cases of John

John was an individual who had been hospitalised during acute phases of his chronic mental illness.

> **John** is 34 years old. He first became acutely distressed when he was 17 and a student at university. He claimed that he could hear voices that no one else could and that these voices told him that everyone was trying to harm him. When he feels like this, his concentration is poor and he tends to forget most things, even routines like washing and eating. Over the past 17 years John has had numerous admissions to hospital. During this time, he has lost contact with his school and neighbourhood friends and relationships with his parents have become very strained. When he is acutely ill, he can be unpredictable and at times, he is loud and verbally aggressive. He is in hospital at the moment. The doctor feels that his symptoms are well controlled with a monthly injection and he could be discharged

There were no significant differences between the responses of service providers and the public in relation to living next door to an individual like John. Only 46 service providers (29%) stated that this would pose no problem with them, 86 (54%) expressed reservations, and 26 (17%) stated that they definitely would not be happy (Table 6.2.5)

Table 6.2.5. Service Providers' responses to the question "In the case of John, would you be happy if he lived next door to you?"

SERVICE PROVIDERS' RESPONSES IN RELATION TO THE VIGNETTE OF John	**Number of Respondents**	**% of Respondents**
YES	46	29
MAYBE	86	54
NO	26	17
TOTAL SAMPLE	**158**	**100**

No significant differences were found between service providers' responses in relation to gender, age, sector of employment, length of time in current occupation, or between qualified and unqualified staff.

Only 7 participants recorded comments that qualified their reservations. In the main, these related to John's unsociable behaviour and the provision of community support:

"Being a single woman, I might feel threatened by his behaviour",

"John's diagnosis and repeated admissions may worry me and I'd like to know the exact level of staffing input ie 24 hours daily etc before deciding. Also I have no dependent/ no children which would make me more accepting of John" and

"Would be a bit apprehensive about the levels of support offered to John - know from my work that these are not high, and in no respect replace the protection afforded by institutional hospital care. Would hope he was well monitored by skilful staff -ie well trained and well paid!".

Attitudes to Groups like the Hypothetical Cases of David and John

Service providers were further asked if they would be happy if small groups like John or David lived next door with staff supervision. Less than one-third of the service providers (28%) stated that they would be happy to live next door to a group like John and David, approximately one-half (52%) expressed reservations and the remaining 31 (20%) stated that they would not be happy. There were significant differences between the public's and service providers' responses to these questions and between service providers' responses in relation to sector of employment. Health sector providers were less likely than providers from the social sector and the general public to state that they would be happy living next to such a group (19% c.f. 54% and 37% respectively) and were more likely to express reservations (57% c.f. 40% and 37%). Providers from the social sector were less likely than health sector providers or the public to say that they would not be happy with this situation (7% c.f. 24% and 27%) ($X^2 = 25.91$, 4 d.f. $p < 0.001$, Table 6.2.6).

Table 6.2.6. Public, Health Sector Service Providers and Social Sector Providers Responses to the question "Would you be happy if a small group of individuals like John/David lived with staff supervision in the house next door?" for both cases combined

HAPPY TO LIVE NEXT DOOR WITH GROUPS LIKE JOHN AND DAVID WITH STAFF SUPERVISION	**Number (%) Responding "Yes"**	**Number (%) Responding "Maybe"**	**Number (%) Responding "No"**	**TOTAL SAMPLE**
HEALTH SERVICES	22 (19%)	65 (57%)	27 (24%)	114
SOCIAL SERVICES	23 (54%)	17 (39%)	3 (7%)	43
PUBLIC	73 (36.5%)	73 (36.5%)	54 (27%)	200
COMBINED RESPONSES	**118 (33%)**	**155 (43%)**	**84 (24%)**	**357**

No significant differences were found between service providers' responses in relation to gender or age. However, unqualified staff and staff who had been in their current occupation for more than one but less than five years were more likely to state that they would be happy to live next door to a supervised group of individuals like John and David (Table 6.2.7).

Table 6.2.7. Service Providers' Responses to the question "Would you be happy if a group of individuals like John/David lived with staff supervision next door to you?" in relation to whether or not qualified and length of experience in current occupation.

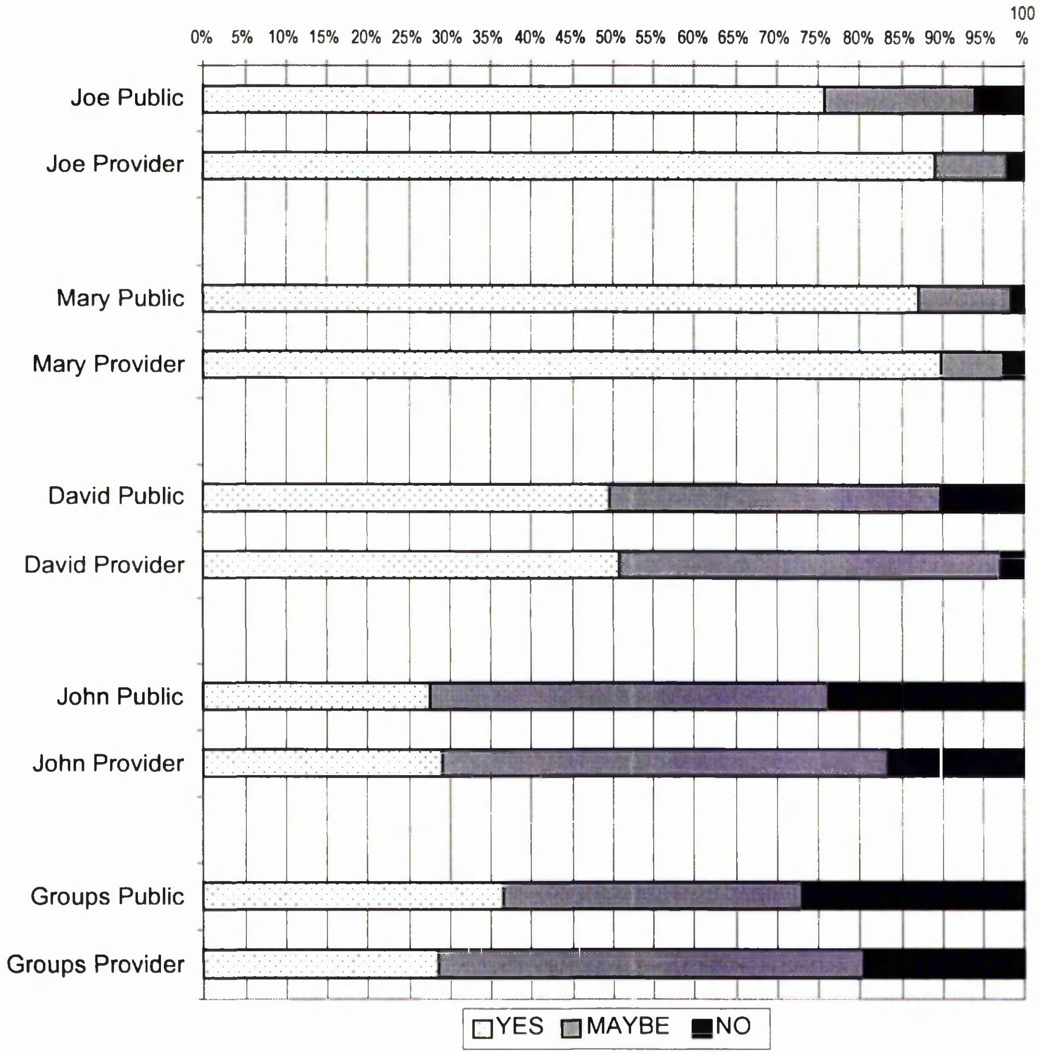
HAPPY TO LIVE NEXT DOOR WITH GROUPS LIKE JOHN AND DAVID WITH STAFF SUPERVISION	**Number (%) answering YES**	**Number (%) answering MAYBE**	**Number (%) answering NO**	**x^2 value, d.f. p value.**
QUALIFIED				9.361
yes	17 (19%)	52 (60%)	18 (21%)	2
no	28 (42%)	27 (40%)	12 (18%)	0.01
EXPERIENCE IN CURRENT OCCUPATION				
Less than 1 year	11 (23%)	23 (49%)	13 (28%)	15.594
Between 1 and 5 years	22 (49%)	19 (42%)	4 (9%)	4
More than 5 years	12 (18%)	40 (61%)	14 (21%)	0.003
TOTAL SAMPLE	**45 (28%)**	**82 (52%)**	**31 (20%)**	**158**

Summary of the Comparison of Attitudes of the Public and Providers.

Figure 6.2.1 illustrates the extent of concordance between the responses of the general public and service providers in relation to living next door to the individuals and groups of individuals portrayed in the vignettes.

There is an overall similarity between the responses of the public and service providers in relation to their responses when the question concerned an individual. In both groups the large majority responded that they be happy to live next door to individuals like Joe and Mary; around a half felt the same about David; but less than one-third about John. In general the public gave negative responses where service providers expressed uncertainty. When the question concerned living next door to a supervised group, service providers again expressed more uncertainty whilst a greater proportion of the public were able to give a definitive 'Yes' or 'No' answer.

Figure 6.2.1 Attitudes to Individuals and Groups with Mental Health Problems: Percentage of public and providers answering "Yes", "No" or "Maybe" to the question about being happy to live next door to X



Comparison of Public and Providers' Views on the Need for Services.

The service providers were asked to perform the same exercise as the public and rate the helpfulness of each of the services listed below for each of the individuals portrayed in the vignettes. The results of this exercise are summarised in Figures 6.2.2 – 6.2.5.

List of Services/Supports

Acute Psychiatric Hospital
temporary in-patient care for people with mental health problems

Bereavement Service
counselling service providing support to individuals with difficulties dealing with death

Buddy Support
access to an individual with personal experience of similar problems who could offer moral support

Community Centre for the General Public
building which provides domestic and recreational facilities (such as cafeteria, laundry rooms, bath and shower rooms, games rooms, organised group activities) for everyone in the community.

Community Centre for People with Mental Health Problems
building which provides domestic and recreational facilities (such as, cafeteria, laundry rooms, bath and shower rooms, games rooms, organised group activities) for people with mental health problems

Community Psychiatric Nurse
nurse who specialises in the management of symptoms and treatments relating to mental illness

Domestic Help
individual employed to give practical support with domestic chores such as, cooking and shopping.

Citizens Advice Bureau
centre which provides free, impartial and confidential advice on any subject, including welfare benefits, claims, grants, and legal and financial matters

Directory of Services
list of all services provided by health, social work and voluntary organisations which gives details on nature of service and how to access the service. Could be a book like the "yellow pages" or, a Free Telephone Helpline

Employment Resettlement Officer
individual in Jobcentre to give support in obtaining future training and/or employment.

General Practitioner
medical practitioner who diagnoses, provides treatment and refers to specialists

Health Promotion Centre
centre which runs health education projects/talks aimed at achieving healthier lifestyles.

Health Visitor
nurse trained to offer advice, support and information on the prevention of ill health and the promotion of good health and who refers to other agencies

Institutional Care
permanent in-patient care for people with a mental health problem

Occupational Therapy/ Training
instruction and practical experience in an occupational/diversional activity.

Patient Supporter
individual who accompanies and/or advises a person during any visit to a service provider such as, the doctor or social worker

Psychologist
specialist, not necessarily a doctor, in the treatment of human behaviour

Psychiatrist
doctor specialising in the treatment of mental disorders

Supported Housing
which would include hostels, halfway houses, lodgings, flats/houses supervised by staff

Relate (Marriage Guidance)
counselling service to help people through difficult and unhappy stages in their relationships with partners.

Self-Help Group
local group of people with similar problems who meet to provide mutual support and advice eg Lone Parent Group or, Coping with Anxiety/Depression Group

Social Worker
individual trained to give support with personal and social problems and to arrange other services such as, benefit advice and help in the home.

The Samaritans
24 hour telephone line which provides a listening service for anyone going through a crisis in their lives - the lonely, depressed and suicidal.

As in the previous section of results, the main focus of the analyses was to explore differences between the responses of providers and the public. The service providers' responses have been analysed further to explore differences between gender, age, whether employed by the health or social sector, length of experience in current occupation, and qualified and unqualified staff.

Rating of Helpfulness of Services for Joe

The public and service providers were in agreement about the potential benefit of some services for Joe; around four-fifths of both groups rated a Buddy Support and a Self-help Group as helpful (Figure 6.2.2). They were also in agreement about the limitations of some services to help Joe; around one third or less of both groups believed in the helpfulness of the Acute Psychiatric Hospital, Bereavement Service, Community Centre for People with Mental Health Problems, Domestic Helper, Citizens Advice Bureau, Employment Resettlement Officer, Health Visitor, Institutional Care, Occupational Therapy, Supported Housing, Relate and Social Worker.

However, there were marked differences between the ratings of the public and service providers on the potential helpfulness of other services for an individual like Joe. In general terms, the public placed a higher emphasis than service providers on social and lay supports such as a General Community Centre (52% c.f. 34%, p=0.008); Service Directory (50% c.f. 29%, p=0.001) and Patient Supporter (62% c.f.37%, p<0.001) (Table 6.2.8). Service providers, on the other hand, placed a higher emphasis than the public on health services, particularly those provided by the Community Psychiatric Nurse (87% c.f. 41%, p<0.001); General Practitioner (81% c.f. 69%, p=0.035); Psychologist (91% c.f. 51%, p<0.001); and Psychiatrist (63% c.f. 37%, p<0.001). The exception to this observation was that the public gave higher ratings than service providers to a Health Promotion Centre (39% c.f. 24%, p=0.009) and the service providers gave higher ratings than the public to The Samaritans (45% c.f. 30%, p=0.013).

Joe is 35 years old and lives with his parents. He rarely goes out with friends and it has been a number of years since he's had a steady girlfriend. About a year ago, he started taking the odd day off work because he couldn't face it. He has also had several short absences because of colds and other minor infections. He has now been off work for six weeks with a broken arm. His GP thinks that he is fit enough to go back to work but Joe has lost all motivation to return. When he tried to phone personnel to inform them of his return, he felt physically sick. On several occasions since then, he has felt a choking lump in his throat; his heart thumping in his chest; and cold and clammy.

Figure 6.2.2 Public and Provider Ratings of the Helpfulness of Services to Support an Individual like Joe

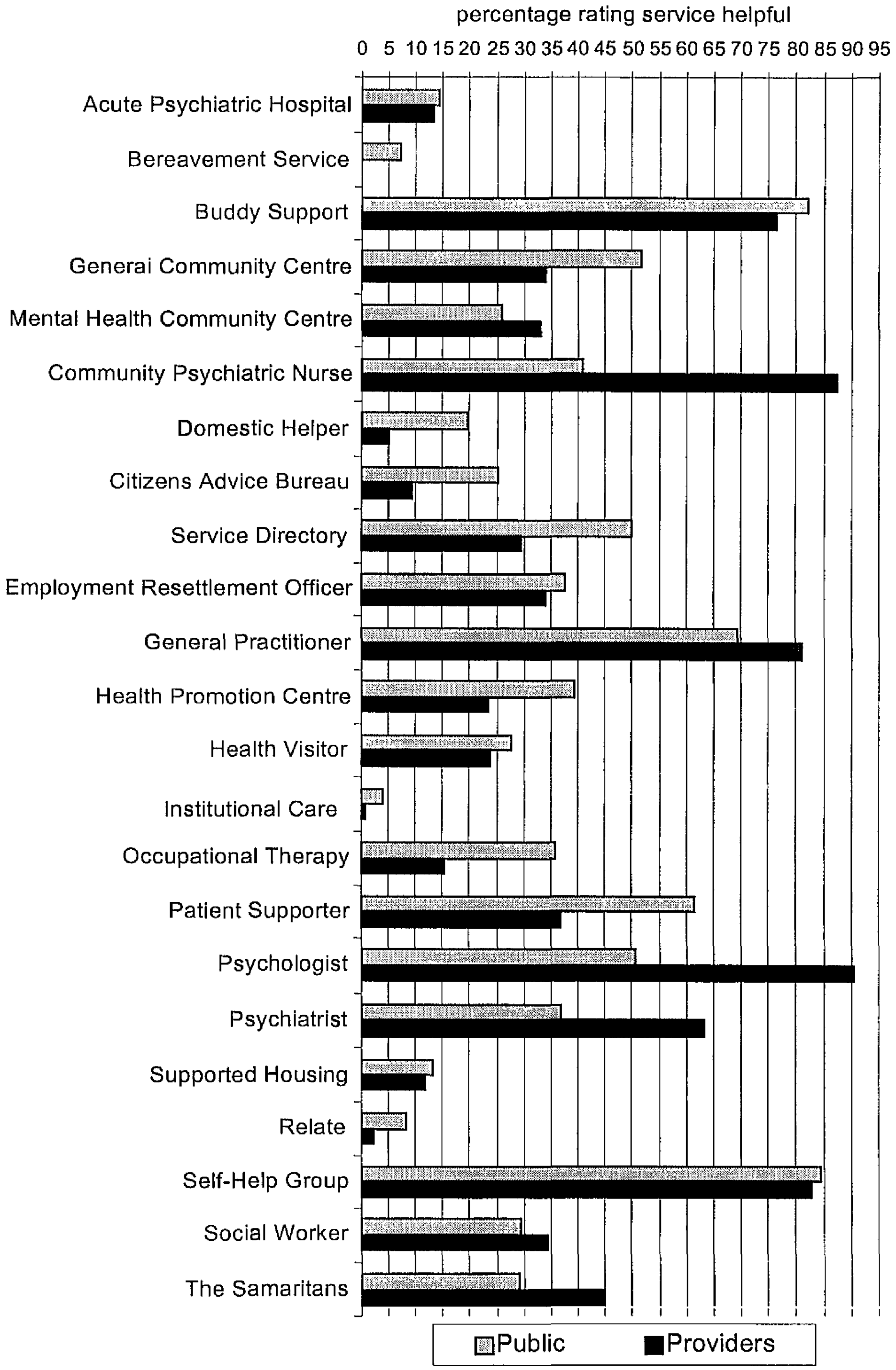


Table 6.2.8. Significant differences between the Ratings by the Public and Service Providers of the Helpfulness of Services for an Individual Like Joe

Service/Support	**Number (%) of Public Rating Service Helpful**	**Number (%) of Providers Rating Service Helpful**	**x^2 value; p value. (1 d.f.)**
General Community Centre	50 (52%)	46 (34%)	7.104; 0.008
Community Psychiatric Nurse	39 (41%)	121 (87%)	56.323; 0.0001
Service Directory	49 (50%)	40 (29%)	10.244; 0.001
General Practitioner	67 (69%)	111 (81%)	4.455; 0.035
Health Promotion Centre	39 (39%)	32 (24%)	6.839; 0.009
Patient Supporter	61 (62%)	49 (37%)	13.971; 0.0001
Psychologist	49 (51%)	124 (91%)	47.136; 0.0001
Psychiatrist	35 (37%)	86 (63%)	15.620; 0.0001
The Samaritans	28 (29%)	61 (45%)	6.130; 0.013

Differences Between Service Providers' Ratings of the Helpfulness of Services for Joe

Service providers were in agreement on the potential helpfulness of services for Joe for 16 out of the 23 services contained in the list. Table 6.2.9 summarises the difference in ratings between providers for the remaining 7 services ratings' in relation to age, gender or employment characteristics.

Female providers were more likely than their male counterparts to rate a Self-Help Group as helpful (95% c.f 67%, p<0.001).

Service providers aged less than 30 years were more likely than older colleagues to rate the helpfulness of Buddy Support (96% c.f. 71%, p=0.005), General Practitioner (96% c.f. 77%, p=0.026), Health Visitor (39% c.f. 18%, p=0.019), and Psychologist (100% c.f. 87%, 0.045).

Providers employed by the health sector were more likely than staff employed by the social sector to rate the GP as helpful (85% c.f. 64%, p=0.017).

Unqualified staff were more likely than their qualified colleagues to rate the helpfulness of The Samaritans (61% c.f. 35%, p =0.003).

Providers who were in their current occupation for less than one year were more likely than their more experienced colleagues to believe in the potential helpfulness of The Samaritans (67% c.f. 30% c.f. 36%, p=0.001). However, providers who had more than 1 but less than 5 years experience in their current post were less likely than colleagues with less or more experience to perceive Buddy Support to be helpful (54% c.f. 80% and 83% respectively, p=0.011)

The perceived helpfulness of a Psychiatrist for Joe was indirectly related to the length of time staff had been in their current post; 34 staff (76%) who had been post for less than one year rated this service helpful compared to 18 (67%) who had been in post for at least one but less than five years, and 34 (53%) of those who had been in post for more than five years (Linear-by-Linear Association = 5.96, 1 d.f. p = 0.016).

Table 6.2.9 Service Providers Ratings of the Helpfulness of Individual Services for Joe in relation to Gender, Age and Employment Characteristics.

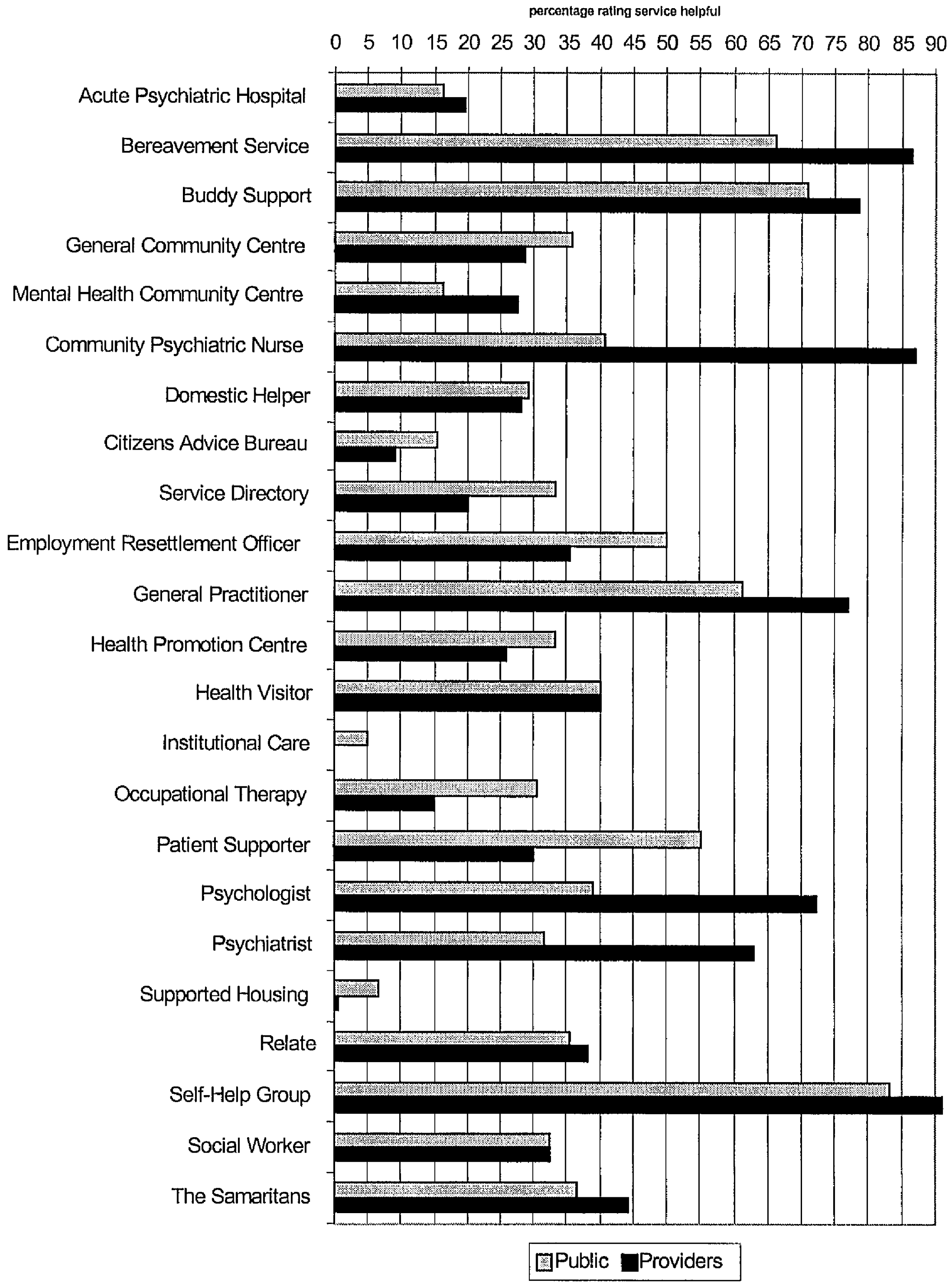
HELPFULNESS OF **"SERVICE"**	**Number (%) answering HELPFUL**	**Number (%) answering NOT HELPFUL**	**x^2 value, d.f. p value.**
"Self-Help Group"			16.908,
Male Staff	39 (67%)	19 (33%)	1
Female Staff	70 (95%)	4 (5%)	0.0001
"General Practitioner"			5.646
Health Sector Staff	94 (85%)	17 (15%)	1
Social Sector Staff	16 (64%)	9 (36%)	0.017
			5.337
Aged less than 30 years	27 (96%)	1 (4%)	1
Aged 30 years or older	78 (77%)	23 (23%)	0.021
"The Samaritans"			8.612
Qualified Staff	29 (35%)	54 (65%)	1
Unqualified Staff	30 (61%)	18 (39%)	0.003
Less than 1 year in current occupation	30 (67%)	15 (33%)	13.243
Between 1-5 years in current occupation	8 (30%)	19 (70%)	2
More than 5 years in current occupation	23 (36%)	41 (64%)	0.001
"Buddy Support"			8.004
Aged less than 30 years	27 (96%)	1 (4%)	1
Aged 30 years or older	70 (71%)	29 (29%)	0.005
Less than 1 year in current occupation	37 (80%)	9 (20%)	9.039
Between 1-5 years in current occupation	14 (54%)	12 (46%)	2
More than 5 years in current occupation	52 (83%)	11 (18%)	0.011
"Health Visitor"			5.517
Aged less than 30 years	11 (39%)	17 (61%)	1
Aged 30 years or older	18 (18%)	81 (82%)	0.019
"Psychologist"			4.008
Aged less than 30 years	28 (100%)	0	1
Aged 30 years or older	88 (77%)	13 (13%)	0.045
"Psychiatrist"			
In current occupation less than 1 year	34 (76%)	11 (24%)	5.796
In current occupation between 1 and 5 years	18 (67%)	9 (33%)	1 d.f
In current occupation more than 5 years	34 (53%)	30 (47%)	0.016

Rating of Helpfulness of Services for Mary

Both the public and service providers gave strong support to two services: more than seven-tenths of each group rated Buddy Support and a Self-Help Group as helpful for Mary (Figure 6.2.3). Between one-third and two-fifths of each group rated a Health Visitor, Relate and The Samaritans as helpful. They were also in agreement about the limitations of some services to help Mary: one third or less of both groups believed in the helpfulness of an Acute Psychiatric Hospital, General Community Centre, Mental Health Community Centre, Domestic Helper, Citizens Advice Bureau, Service Directory, Health Promotion Centre, Institutional Care, Occupational Therapy, Supported Housing, and Social Worker.

Mary is in her mid 40s, married with two daughters aged 11 and 8. Apart from minor ailments, she has good physical health. Her GP has been treating her on-and-off with tablets for depression since the death of her mother five years ago. Since that time, Mary has felt less able to cope with things she normally took in her stride. After her house was broken into, she gave up a part-time job in the local supermarket and now misses the company of the women she worked with. She has become increasingly withdrawn and weepy, and rarely goes out of the house. Her eldest daughter does most of the housework and shopping. Although her husband tries to understand, she doesn't find any of his suggestions helpful.

Figure 6.2.3 Public and Provider Ratings of the Helpfulness of Services to Support an Individual like Mary



As in the case of Joe, there were marked differences between the ratings of the public and service providers on the potential helpfulness of other services for an individual like Mary. Once again, the public placed a higher emphasis than providers on lay supports such as a Patient Supporter (55% c.f. 30%, $p<0.001$) whereas the providers placed a higher emphasis than the public on statutory services such as Bereavement Service (87% c.f. 66%, $p<0.001$); Community Psychiatric Nurse (87% c.f. 41%, $p<0.001$); General Practitioner (77% c.f. 61%, $p=0.002$), Psychologist (72% c.f. 39%, $p<0.001$) and a Psychiatrist (63% c.f. 32%, $p<0.001$) (Table 6.2.10). The exception to this observation was that the public gave higher ratings than the providers to an Employment Resettlement Officer (50% c.f. 36%, $p=0.006$).

Table 6.2.10. Significant Differences between the Ratings by the Public and Service Providers of the Helpfulness of Services for an Individual Like Mary

Service/Support	**Number (%) of Public Rating Service Helpful**	**Number (%) of Providers Rating Service Helpful**	**x^2 value; p value.** (1 d.f.)
Patient Supporter	109 (55%)	46 (30%)	22.720 0.0001
Bereavement Service	131 (66%)	134 (87%)	19.125 0.0001
Community Psychiatric Nurse	80 (41%)	134 (87%)	78.211 0.0001
General Practitioner	120 (61%)	119 (77%)	9.632 0.002
Psychologist	75 (39%)	111 (72%)	37.471 0.0001
Psychiatrist	61 (32%)	97 (63%)	34.011 0.0001
Employment Resettlement Officer	99 (50%)	55 (36%)	7.449 0.006

Differences Between Service Providers' Ratings of the Helpfulness of Services for Mary

Service providers were in agreement on the potential helpfulness of services for Mary for 12 out of the 23 services contained in the list. Table 6.2.11 summarises the difference in ratings between providers for the remaining 11 services in relation to age, gender and employment characteristics.

Female providers were more likely than their male counterparts to rate an Employment Resettlement Officer (41% c.f.23%, $p=0.031$), and Relate (45% c.f. 26%, $p=0.023$).

Service providers aged less than 30 years were more likely than older colleagues to believe in the helpfulness of an Employment Resettlement Officer (64%% c.f. 25%, $p<0.001$) and The Samaritans (70% c.f. 37%, $p=0.001$).

Providers employed by the health sector were more likely than social sector staff to rate as helpful: the Community Psychiatric Nurse (91% c.f. 75%, $p=0.009$), General Practitioner (84% c.f. 56%, $p<0.001$), Psychologist (77% c.f. 58%, $p=0.018$) and the Psychiatrist (73% c.f. 35%, $p<0.001$).

Whereas, providers from the social sector were more likely to rate social supports as helpful: a General Community Centre (43% c.f. 24%, p=0.025) and Social Worker (61% c.f. 23%, p<0.001).

Unqualified staff were more optimistic than their qualified colleagues about the helpfulness of an Employment Resettlement Officer (46% c.f. 27%, p=0.013) and The Samaritans (62% c.f. 33%, p<0.001).

Providers who were in their current occupation for less than one year were more likely than their more experienced colleagues to rate as helpful the Community Psychiatric Nurse (98% c.f. 82%, p=0.008), Health Visitor (55% c.f. 33%, p=0.01), and The Samaritans (66% c.f. 36%, p=0.001). However, providers who had more than 1 but less than 5 years experience in their current post were less likely than colleagues with less or more experience to believe in the helpfulness of a General Community Centre (48% c.f. 19% and 22%, p=0.004) and a Social Worker (50% c.f. 32% and 22%, p=0.009).

The perceived helpfulness of an Employment Resettlement Officer for Mary was indirectly related to the length of time staff had been in their current post: 21 staff (45%) who had been post for less than one year rated this service helpful compared to 17 (39%) who had been in post for at least one but less than five years, and 17 (27%) of those who had been in post for more than five years (Linear-by-Linear Association=4.002, 1 d.f. p=0.045). A similar finding was observed in the ratings of the potential helpfulness of The Samaritans for Mary: 31 staff (66%) who had been in post for less than one year rated this service helpful compared to 19 (43%) who had been in post for at least one but less than five years, and 20 (31%) of those who had been in post for more than five years (Linear-by-Linear Association=12.823, 1 d.f. p<0.001).

Table 6.2.11 Service Providers Ratings of the Helpfulness of Individual Services for Mary in relation to Gender, Age and Employment Characteristics.

HELPFULNESS OF "SERVICE"	**Number (%) answering HELPFUL**	**Number (%) answering NOT HELPFUL**	**x^2 value, d.f. p value.**
"General Community Centre"			4.992
Health Sector Staff	27 (24%)	86 (76%)	1
Social Sector Staff	17 (43%)	23 (57%)	0.025
Less than 1 year in current occupation	9 (19%)	38 (81%)	11.200
Between 1-5 years in current occupation	21 (48%)	23 (52%)	2
More than 5 years in current occupation	14 (22%)	49 (78%)	0.004
"Community Psychiatric Nurse"			6.781
Health Sector Staff	103 (91%)	10 (9%)	1
Social Sector Staff	30 (75%)	10 (25%)	0.009
Less than 1 year in current occupation	46 (98%)	1 (2%)	7.105
Between 1-5 years in current occupation	35 (81%)	8 (19%)	2
More than 5 years in current occupation	53 (83%)	11 (17%)	0.029
"General Practitioner"			13.143
Health Sector Staff	95 (84%)	18 (16%)	1
Social Sector Staff	23 (56%)	18 (44%)	0.0001

HELPFULNESS OF **"SERVICE"** (continued)	**Number (%) answering HELPFUL**	**Number (%) answering NOT HELPFUL**	**x^2 value, d.f. p value.**
"Employment Resettlement Officer"			4.629
Male Staff	13 (23%)	46 (77%)	1
Female Staff	34 (41%)	50 (59%)	0.031
			16.509
Aged less than 30 years	21 (64%)	12 (36%)	1
Aged 30 years or older	27 (25%)	80 (75%)	0.0001
			6.122
Qualified Staff	23 (27%)	63 (73%)	1
Unqualified Staff	30 (46%)	35 (54%)	0.013
Less than 1 year in current occupation	21 (45%)	26 (55%)	4.002
Between 1-5 years in current occupation	17 (39%)	27 (61%)	1
More than 5 years in current occupation	17 (27%)	47 (73%)	0.045
"Health Promotion Centre"			10.197
Health Sector Staff	21 (19%)	92 (81%)	1
Social Sector Staff	18 (44%)	23 (56%)	0.001
"Health Visitor"			
Less than 1 year in current occupation	26 (55%)	21 (45%)	6.882
Between 1-5 years in current occupation	13 (30%)	30 (70%)	2
More than 5 years in current occupation	23 (35%)	42 (65%)	0.032
"Psychologist"			5.554
Health Sector Staff	87 (77%)	26 (23%)	1
Social Sector Staff	23 (58%)	17 (42%)	0.018
"Psychiatrist"			17.835
Health Sector Staff	82 (73%)	31 (27%)	1
Social Sector Staff	14 (35%)	26 (65%)	0.000
"Relate"			5.138
Male Staff	14 (26%)	43 (74%)	1
Female Staff	37 (45%)	46 (55%)	0.023
"Social Worker"			19.579
Health Sector Staff	26 (23%)	87 (77%)	1
Social Sector Staff	25 (61%)	16 (39%)	0.0001
Less than 1 year in current occupation	15 (32%)	32 (68%)	9.372
Between 1-5 years in current occupation	22 (50%)	22 (50%)	2
More than 5 years in current occupation	14 (22%)	50 (78%)	0.009
"The Samaritans"			10.641
Aged less than 30 years	23 (70%)	11 (30%)	1
Aged 30 years or older	40 (37%)	67 (63%)	0.001
			12.561
Qualified Staff	28 (33%)	58 (67%)	1
Unqualified Staff	40 (62%)	25 (38%)	0.0001
Less than 1 year in current occupation	31 (66%)	16 (34%)	12.823
Between 1-5 years in current occupation	19 (43%)	25 (57%)	1
More than 5 years in current occupation	20 (31%)	44 (69%)	0.0001

Rating of Helpfulness of Services for David

Both the public and service providers gave strong support to four services for David: more than four-fifths of each group believed in the helpfulness of a Community Centre for People with Mental Health Problems and a Domestic Helper, and almost three quarter of each group rated a Patient Supporter and Supported Housing as helpful (Figure 6.2.4).

Between one-half and two-thirds of each group believed in the helpfulness of a Bereavement Service, General Practitioner, Occupational Therapy, and Psychiatrist. Approximately one-third to two-fifths of each group rated Buddy Support, a General Community Centre, Health Visitor and a Self-Help Group as helpful.

One third or less of both groups believed in the helpfulness of Service Directory, Employment Resettlement Officer, Health Promotion Centre, Institutional Care, Relate, and The Samaritans.

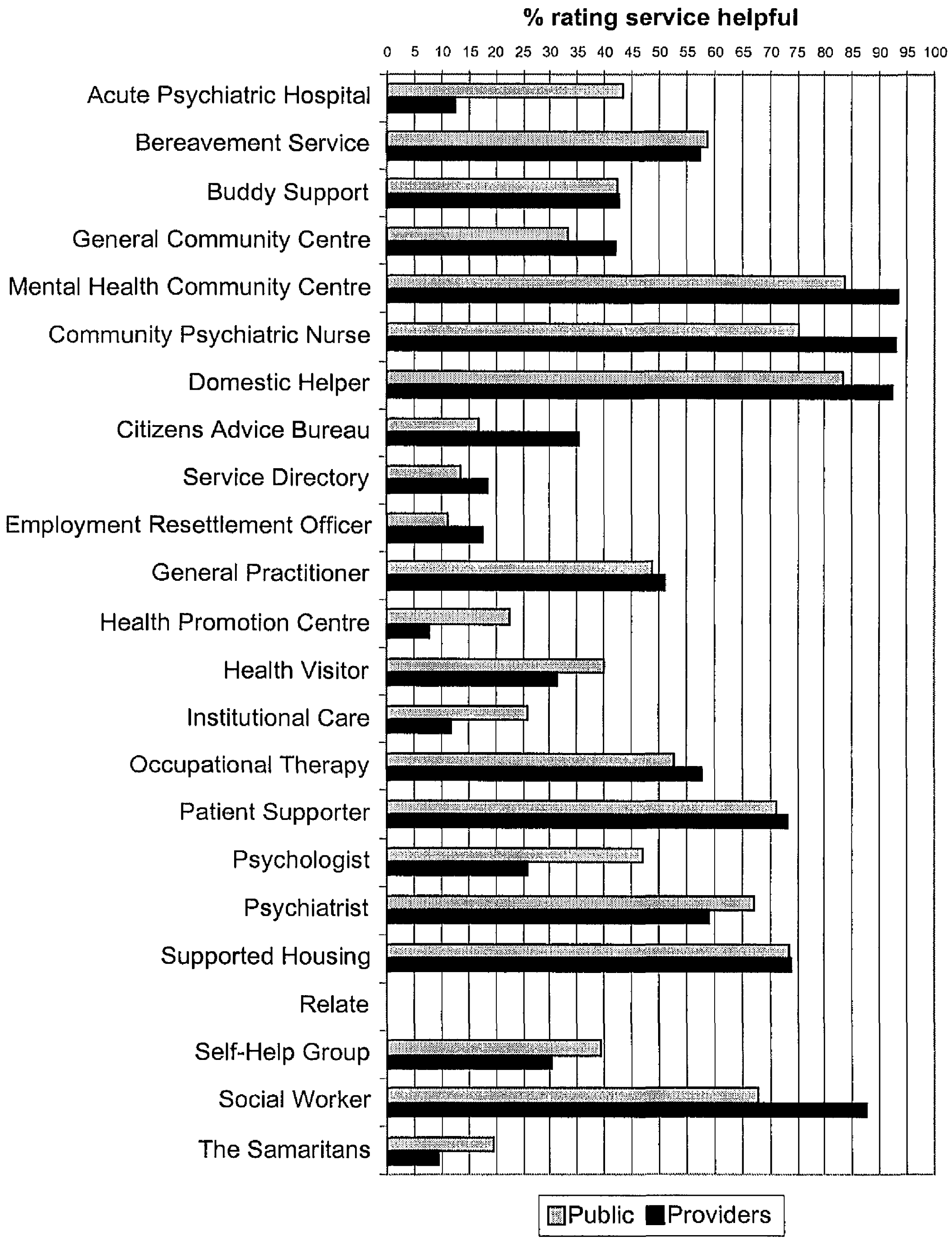
As in the previous cases, there were differences between the ratings of the public and service providers on the potential helpfulness of other services for an individual like David. This time the public placed higher emphasis on some health services such as an Acute Psychiatric Hospital (43% c.f. 13%, $p<0.001$) and a Psychologist (47% c.f. 26%, $p=0.001$) whereas, providers placed a higher emphasis than the public on some community health and social services such as Community Psychiatric Nurse (93% c.f. 75%, $p<0.001$); and a Social Worker (88% c.f. 68%, $p<0.001$) (Table 6.2.12). Although not strongly supported by either group, the Citizens Advice Bureau was perceived to be more helpful by service providers than by the public (35% c.f. 17%, $p=0.002$).

Table 6.2.12. Significant Differences between the Ratings by the Public and Service Providers of the Helpfulness of Services for an Individual Like David

Service/Support	**Number (%) of Public Rating Service Helpful**	**Number (%) of Providers Rating Service Helpful**	**x^2 value; p value.** (1 d.f.)
Acute Psychiatric Hospital	43 (43%)	17 (13%)	28.836 0.0001
Community Psychiatric Nurse	72 (75%)	128 (93%)	14.369 0.0001
Citizens Advice Bureau	16 (17%)	48 (35%)	9.775 0.002
Psychologist	45 (47%)	35 (26%)	11.132 0.001
Social Worker	67 (68%)	120 (88%)	13.854 0.0001

David is a 55 year old bachelor who spent most of his adult life in psychiatric hospitals. Since his discharge, six years ago, he has been living with his elderly mother who does everything for him. His only responsibility is to manage his pocket money which he spends on cigarettes and sweets. He looks older than his years: he shuffles his feet when he walks, his back is stooped and he persistently looks down. He is often seen picking up things from the ground which he sometimes throws away and sometimes puts in his pocket. He looks a bit scruffy but is friendly and will smile at anyone who says hello to him.. It has been many years since he has required medication. Sadly, David's mother has passed away. He has no other close relative living locally. David is keen to live in his mother's house.

Figure 6.2.4 Public and Provider ratings of the Helpfulness of Services to Support an Individual like David



Differences Between Service Providers' Ratings of the Helpfulness of Services for David

Service providers were in agreement on the potential helpfulness of services for David for 15 out of the 23 services contained in the list. Table 6.2.13 summarises the difference in ratings between providers for the remaining 8 services in relation to age, gender and employment characteristics.

Female providers were more likely than their male counterparts to rate as helpful the General Practitioner (62% c.f. 35%, p=0.002), Occupational Therapy (66% c.f. 48%, p=0.038), and a Patient Supporter (80% c.f. 64%, p=0.041).

Service providers aged less than 30 years were more likely than older colleagues to believe in the helpfulness of the Citizens Advice Bureau (50% c.f.29%, p=0.038) and Supported Housing (93% c.f. 68%, p=0.009).

Providers employed by the health sector were more likely than social sector staff to rate as helpful: the Community Psychiatric Nurse (96% c.f. 84%, p=0.035) and the General Practitioner (55% c.f. 32%, p=0.038).

Unqualified staff were more optimistic than their qualified colleagues about the helpfulness of a Bereavement Service (73% c.f. 49%, p=0.007), General Community Centre (55% c.f. 35%, p=0.024) and Citizens Advice Bureau (46% c.f. 27%, p=0.031).

Providers who were in their current occupation for less than one year were more likely than their colleagues who had been in post for more than one but less than five years and those in post for more than five years to rate the Citizens Advice Bureau (50% c.f. 26% and 29%, p=0.036) as helpful. However, providers who had more than more than 5 years experience in their current post were less likely than colleagues with less experience to believe in the helpfulness of a General Practitioner (39% c.f. 61% and 63%, p=0.030).

The perceived helpfulness of a Bereavement Service was indirectly related to the length of time staff had been in their current post: 32 staff (71%) who had been post for less than one year rated this service helpful compared to 18 (64%) who had been in post for at least one but less than five years, and 28 (44%) of those who had been in post for more than five years (Linear-by-Linear Association=7.883, 1 d.f. p=0.005). A similar finding was observed in the ratings of the potential helpfulness of a Community Psychiatric Nurse: 46 staff (100%) who had been in post for less than one year rated this service helpful compared to 26 (93%) who had been in post for at least one but less than five years, and 56 (88%) of those who had been in post for more than five years (Linear-by-Linear Association=6.151, 1 d.f. p=0.013).

Table 6.2.13. Service Providers Ratings of the Helpfulness of Individual Services for David in relation to Gender, Age and Employment Characteristics.

HELPFULNESS OF "SERVICE"	**Number (%) answering HELPFUL**	**Number (%) answering NOT HELPFUL**	**x^2 value, d.f. p value.**
"Bereavement Service"			7.267
Qualified Staff	41 (49%)	43 (51%)	1
Unqualified Staff	35 (73%)	13 (27%)	0.007
Less than 1 year in current occupation	32 (71%)	13 (29%)	7.883
Between 1-5 years in current occupation	18 (64%)	10 (36%)	1
More than 5 years in current occupation	28 (44%)	35 (56%)	0.005
"General Community Centre"			5.128
Qualified Staff	29 (35%)	54 (65%)	1
Unqualified Staff	27 (55%)	22 (45%)	0.024
"Community Psychiatric Nurse"			4.431
Health Sector Staff	107 (96%)	5 (5%)	1
Social Sector Staff	21 (84%)	4 (16%)	0.035
Less than 1 year in current occupation	46 (100%)	0	6.151
Between 1-5 years in current occupation	26 (93%)	2 (7%)	1
More than 5 years in current occupation	56 (88%)	8 (13%)	0.013
"Citizens Advice Bureau"			4.324
Aged less than 30 years	14 (50%)	14 (50%)	1
Aged 30 years or older	29 (29%)	71 (71%)	0.038
			4.629
Qualified Staff	23 (27%)	61 (73%)	1
Unqualified Staff	22 (46%)	26 (54%)	0.031
Less than 1 year in current occupation	23 (50%)	23 (50%)	6.640
Between 1-5 years in current occupation	7 (26%)	20 (74%)	2
More than 5 years in current occupation	18 (29%)	45 (71%)	0.036
"General Practitioner"			9.965
Male Staff	20 (35%)	38 (66%)	1
Female Staff	46 (62%)	28 (38%)	0.002
			4.302
Health Sector Staff	61 (55%)	50 (45%)	1
Social Sector Staff	8 (32%)	15 (68%)	0.038
Less than 1 year in current occupation	28 (61%)	18 (39%)	6.989
Between 1-5 years in current occupation	17 (63%)	10 (37%)	2
More than 5 years in current occupation	25 (39%)	39 (61%)	0.030
"Occupational Therapy"			4.306
Male Staff	28 (48%)	30 (52%)	1
Female Staff	49 (66%)	25 (34%)	0.038
"Patient Supporter"			4.163
Male Staff	37 (64%)	21 (36%)	1
Female Staff	59 (80%)	15 (20%)	0.041
"Supported Housing"			6.802
Aged less than 30 years	26 (93%)	2 (7%)	1
Aged 30 years or older	69 (68%)	32 (32%)	0.009

Rating of Helpfulness of Services for John

Both the public and service providers were virtually unanimous in there support for three services for John: around nine-tenths of each group believed in the helpfulness of a Community Centre for People with Mental Health Problems, Community Psychiatric Nurse and a Psychiatrist (Figure 6.2.4). More than three quarter of each group believed in the potential helpfulness of an Acute Psychiatric Hospital and Supported Housing, though the ratings of the public were significantly higher for hospital care (87% c.f. 76%, p=0.033) whereas there were higher by providers for supported housing (87% c.f. 75%, p=0.016) (Table 6.2.14). Between three-fifths and three-quarters of each group rated the General Practitioner as a potential source for John.

The views of the public and providers were more equivocal for three of the listed services: between one-half and two-thirds of each group believed in the helpfulness of a Domestic Helper, Occupational Therapy, and a Self-Help Group. There was also no significant difference in the ratings of Buddy Support, perceived helpful by between one-third and one-half of respondents in each group.

One-third or less of each group rated as helpful a Bereavement Service, General Community Centre, Citizens Advice Bureau, Service Directory, Health Promotion Centre, Relate, and the Samaritans.

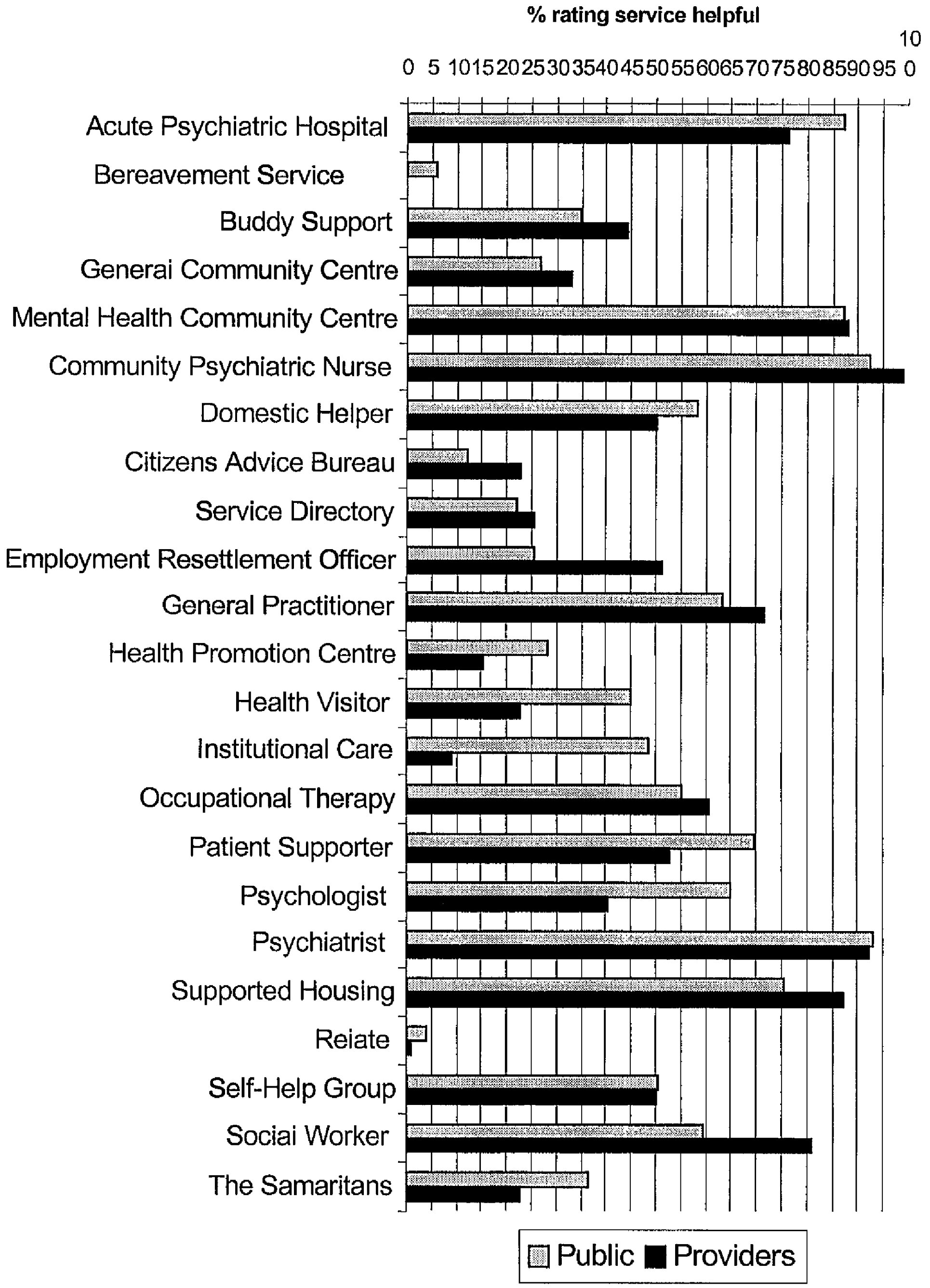
As in the previous cases, there were significant differences between the ratings of the public and providers for the other listed supports and services. The public was more optimistic than providers about the potential helpfulness of a Health Visitor (45% c.f. 23%, p<0.001), Institutional Care (48% c.f. 10%, p<0.001), Patient Supporter (69% c.f. 53%, p=0.008), Psychologist (65% c.f. 40%, p<0.001). The only other services about which providers were more optimistic than the public were an Employment Resettlement Officer (51% c.c. 25%, p<0.001) and a Social Worker (81% c.f. 59%, p<0.001).

Table 6.2.14. Significant Differences between the Ratings by the Public and Service Providers of the Helpfulness of Services for an Individual Like John

Service/Support	**Number (%) of Public Rating Service Helpful**	**Number (%) of Providers Rating Service Helpful**	**x^2 value; p value.** (1 d.f.)
Acute Psychiatric Hospital	88 (87%)	116 (76%)	4.543 0.033
Employment Resettlement Officer	25 (25%)	79 (51%)	16.887 0.0001
Health Visitor	45 (45%)	35 (23%)	14.190 0.0001
Institutional Care	46 (52%)	14 (9%)	49.691 0.0001
Patient Supporter	68 (69%)	81 (53%)	6.986 0.008
Psychologist	63 (65%)	61 (40%)	14.587 0.0001
Supported Housing	73 (75%)	135 (87%)	5.803 0.016
Social Worker	58 (59%)	126 (81%)	14.047 0.0001

<u>John</u> is 34 years old. He first became acutely distressed when he was 17 and a student at university. He claimed that he could hear voices that no one else could and that these voices told him that everyone was trying to harm him. When he feels like this, his concentration is poor and he tends to forget most things, even routines like washing and eating. Over the past 17 years John has had numerous admissions to hospital. During this time, he has lost contact with his school and neighbourhood friends and relationships with his parents have become very strained. When he is acutely ill, he can be unpredictable and at times, he is loud and verbally aggressive. He is in hospital at the moment. The doctor feels that his symptoms are well controlled with a monthly injection and he could be discharged

Figure 6.2.5 Public and Provider rating of the Helpfulness of Services to Support an Individual like John



Differences Between Service Providers' Ratings of the Helpfulness of Services for John

Service providers were in agreement on the potential helpfulness of services for John for 13 out of the 23 services contained in the list. Table 6.2.15 summarises the difference in ratings between providers for the remaining 10 services in relation to age, gender and employment characteristics.

Table 6.2.15. Service Providers Ratings of the Helpfulness of Individual Services for John in relation to Gender, Age and Employment Characteristics.

HELPFULNESS OF **"SERVICE"**	**Number (%) answering HELPFUL**	**Number (%) answering NOT HELPFUL**	**x^2 value, d.f. p value**
"Buddy Support"			4.948
Health Sector Staff	43 (38%)	69 (62%)	1
Social Sector Staff	24 (59%)	16 (41%)	0.026
			12.520
Qualified Staff	27 (32%)	58 (68%)	1
Unqualified Staff	40 (61%)	26 (39%)	0.0001
"General Community Centre"			7.412
Qualified Staff	21 (24%)	65 (76%)	1
Unqualified Staff	30 (46%)	36 (54%)	0.006
"Citizens Advice Bureau"			9.000
Aged less than 30 years	13 (39%)	20 (61%)	1
Aged 30 years or older	16 (15%)	90 (85%)	0.003
"Domestic Helper"			4.873
Qualified Staff	36 (42%)	50 (58%)	1
Unqualified Staff	39 (60%)	26 (40%)	0.027
"Employment Resettlement Officer"			6.739
Qualified Staff	36 (42%)	49 (58%)	1
Unqualified Staff	42 (64%)	24 (36%)	0.009
"General Practitioner"			7.651
Health Sector Staff	88 (80%)	25 (22%)	1
Social Sector Staff	22 (55%)	18 (45%)	0.006
"Occupational Therapy"			13.236
Health Sector staff	78 (69%)	35 (31%)	1
Social Sector Staff	15 (37%)	26 (63%)	0.0001
"Patient Supporter"			
Less than 1 year in current occupation	31 (66%)	16 (34%)	5.670
Between 1-5 years in current occupation	23 (52%)	21 (48%)	1
More than 5 years in current occupation	27 (43%)	36 (57%)	0.017
"Self-Help Group"			12.370
Health Sector Staff	46 (41%)	66 (59%)	1
Social Sector Staff	30 (73%)	11 (27%)	0.0001
			9.150
Qualified Staff	33 (39%)	52 (61%)	1
Unqualified Staff	42 (64%)	24 (36%)	0.002
"The Samaritans"			4.512
Health Sector Staff	21 (19%)	92 (81%)	1
Social Sector Staff	14 (35%)	26 (65%)	0.034

Service providers aged less than 30 years were more likely than older colleagues to believe in the helpfulness the Citizens Advice Bureau (39% c.f.15%, p=0.003).

Providers employed by the health sector were more likely than social sector staff to believe in the helpfulness of the General Practitioner (78% c.f. 55%, p=0.006) and an Occupational Therapist (69%

c.f. 37%, p<0.001). Social sector staff, on the hand, gave higher ratings than their health sector colleagues to Buddy Support (59% c.f. 38%, p=0.026), General Community Centre (49% c.f. 27%, p=0.013), Domestic Helper (65% c.f. 45%, p=0.031), Self-Help Group (73% c.f. 41%, p<0.001) and The Samaritans (35% c.f. 19%, p=0.034).

Unqualified staff were more optimistic than their qualified colleagues about the helpfulness of Buddy Support (61% c.f. 32%, p<0.001), General Community Centre (46% c.f. 24%, p=0.006), Domestic Helper (60% c.f. 42%, p=0.027), Employment Resettlement Officer (64% c.f. 42%, p=0.009) and a Self-Help Group (64% c.f. 39%, p=0.002).

There was an indirect relationship between the length of time staff had been in their current post and the perceived helpfulness of a Patient Supporter: 31 staff (66%) who had been post for less than one year rated this service helpful compared to 23 (52%) who had been in post for at least one but less than five years, and 27 (43%) of those who had been in post for more than five years (Linear-by-Linear Association=5.764, 1 d.f. p=0.017).

Public and Provider Ratings of the Helpfulness of Services in relation to Provider Sector

The individual services and supports were classified according to the key below in order to explore similarities and differences between the public's and providers' views on the helpfulness of services by providing sector.

Health Services = Acute Hospital, Community Psychiatric Nurse, GP, Health Visitor, Institutional Care, Psychologist, Psychiatrist, Occupational Therapy and Health Promotion Centre;

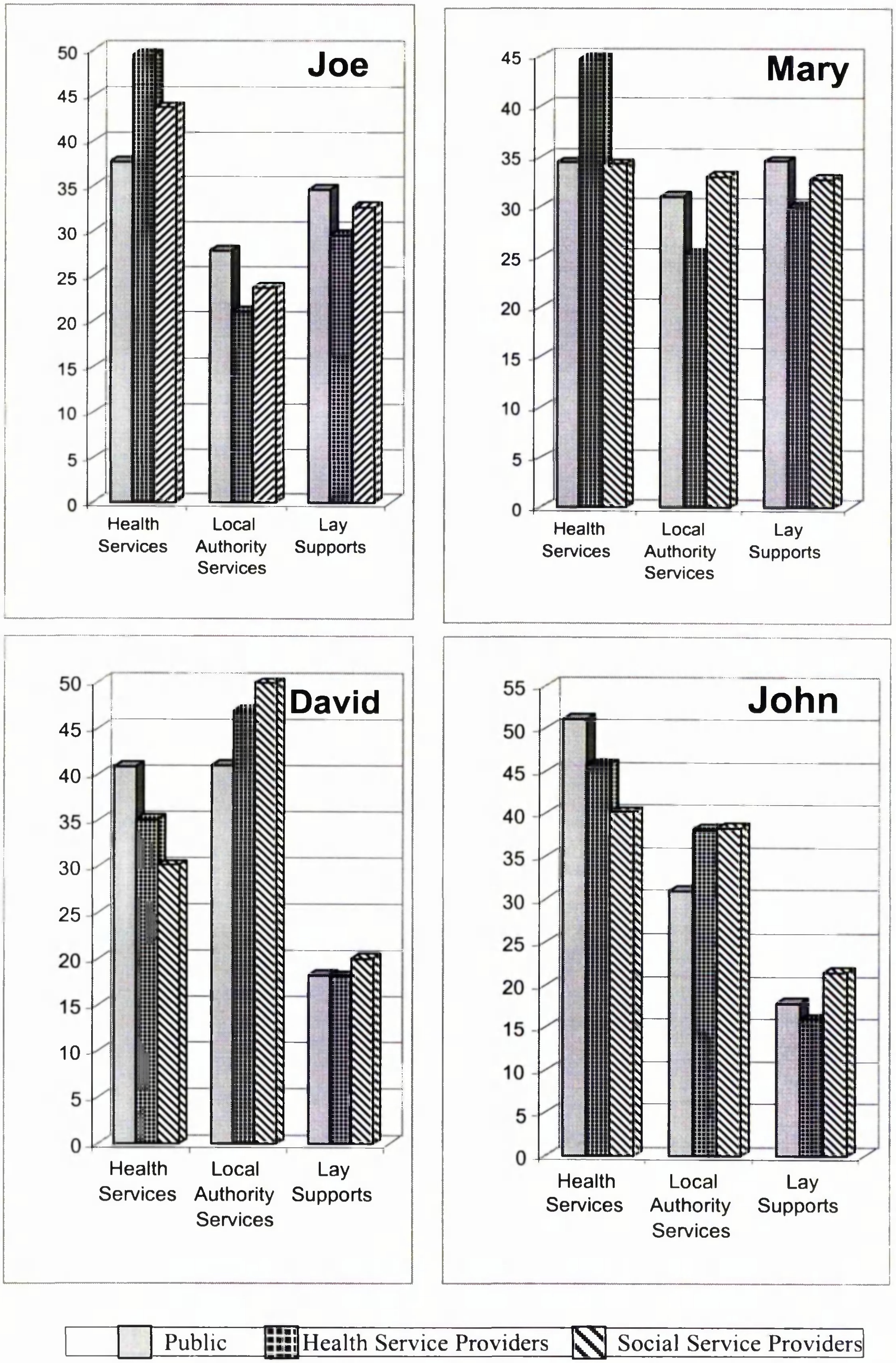
Local Authority Services = Community Centre for the General Public, Community Centre for People with Mental Health Problems, Domestic Helper, Supported Housing, Social Worker, Employment Resettlement Officer, Bereavement Service and Directory of Services; and

Lay Supports = Buddy Support System, Patient Friend Initiative, Self-Help Group, The Samaritans, Citizen's Advice Bureau and Relate.

As the provider sample was heavily biased towards health care providers (72% health care professionals c.f. 28% social care professionals), their ratings have been reported independently in relation to the public. The results of this analysis for the individual cases of Joe, Mary, David and John are summarised in Figure 6.2.6.

In the case of Joe who had relatively less pronounced mental health needs, there was an overall similarity in the rating of the helpfulness of provider sectors by the public, health care professionals and social care professionals. All three groups rated health services as the most helpful, then local authority services followed by lay supports. However both health care and social care providers rated health services more helpful whilst the general public placed greater emphasis on local authority services and lay supports.

Figure 6.2.6 Public, Health Service Providers and Social Service Providers ratings of the Helpfulness of Services by Sector Provider: Individual Cases.



In the case of Mary, there was strong concordance between the views of the public and social care professionals. Both these group placed equal emphasis on all three providing sectors whilst health service professionals perceived a greater utility in the services provided by the health service sector.

In the case of David, there was concordance between the views of all three groups on lay supports as a source of potential help. In this case, the perceived utility of these supports was much less than in the cases of Joe and Mary. The public placed equal emphasis on the health services and local authority services whereas both professional groups placed a far greater emphasis on local authority services.

In the case of John, all three groups were again agreed on the potential of lay supports as a source of potential help. The ratings of their helpfulness were similar to those for David. Social care professionals placed equal emphasis on the health services and local authority services whereas both the public and health care professionals perceived greater utility from health services.

III. IMPLICATIONS OF THE EMPIRICAL RESEARCH

7. SUMMARY AND DISCUSSION OF FINDINGS

This chapter summarises the results of the empirical research on consumer views on service quality and public views on the need for services. The relevance of the findings is discussed in relation to (a) the existing literature on organisational management theory, consumerism, and consumer/public consultation and (b) methodological issues. Throughout these discussions, the political and organisational implications for embracing a consumer approach are explored.

1. Summary of the Findings of the Studies on Service Quality

The main findings of the studies on the quality of services in long stay wards for the elderly were:

- The Nominal Group Technique was a useful method of eliciting views on the key criteria for a good service in long stay wards. It was quick (the unmodified version took around 90 minutes); it provided immediate feedback to the participants; it was enjoyable for the participants (particularly the scoring and ranking of criteria which resembled voting at the Eurovision Song Contest).
- The criteria for a good service in long stay wards most valued by elderly patients related to people – ie personal attributes of nurses, visitors, and the company and friendship of other patients.
- The majority of the patients' essential criteria for a good service in long stay wards for the elderly related to organisational aspects of their care. In particular, the ability to exercise choice such as having the opportunity to meet other patients; attend church services and concert parties; have a permanent place in the ward; eat at a table and choose their food.
- A number of the patient criteria for a good service related to communication such as having nurses who listened to them and being informed of the purpose of medications.
- Male patients tended to be more critical than female patients about particular aspects of their care such as the frequency of visitors and information provided about medications/treatments.
- When asked to act as patient advocates, relatives and nurses were only able to identify one-third of the criteria for a good service that were most valued by patients in long stay wards.
- There was greater concordance between the views of patients in long stay wards for the elderly and those of young patients in long stay wards for the mentally ill on the key requirements for a good service.
- About one-third of all patients in long stay wards for the elderly were able to participate in the survey on service quality. Without exception, nurses in each ward underestimated the number of patients who were able to answer questions reliably about their routine care.
- Although lower than reported in other studies of this kind, the reported level of overall satisfaction with life in hospital was high: only 12% of patients reported dissatisfaction.
- The high overall satisfaction rating masked the extent to which patients were dissatisfied with the individual criteria by which they defined a good service. However, the patients who did express overall dissatisfaction were also more likely to be dissatisfied with the individual criteria.

- Less than half of the patients (44%) expressed satisfaction with the three attributes that they most valued in nurses – ie nurses who were cheerful, attentive and who listened.
- The best predictors of overall satisfaction were the personal attributes of nurses, information about medication and diversional therapy.
- Despite the provision of full reports to each participating hospitals and summary papers to each ward, few nurses were able to recall the purpose or findings of the first survey one year later when it was repeated.

2. Summary of the Findings of the Studies on the Need for Services

The main findings of the studies on the need for services for people with mental health problems were:

- The overall level of tolerance for people with mental health problems was similar in the general public and service providers: for both groups tolerance was inversely related to the severity of the mental health problem.
- Whilst service providers were marginally more tolerant of individuals with less profound mental health needs, some expressed concern that their professional status might be abused if they had a neighbour with mental health problems.
- Social work professionals were least likely to state that they would be unhappy to live next door to small groups of individuals with profound mental health needs.
- The concerns expressed by service providers regarding living next door to small groups of people with mental health problems mirrored those of the general public - ie the possibility of unsociable behaviour and inadequate community support by statutory services.
- Overall, service providers and the public agreed that service input was directly related to the severity of the mental health needs. In both groups, services were perceived as being helpful more often for the characters with the most profound needs.
- For individuals who had no history of psychiatric hospital admission, there was strong support for the general practitioner, Buddy Support and Self-Help Groups.
- For individuals who had a history of psychiatric hospital admission, support was strongest for statutory health and social services.
- For both simple and complex cases, the public perceived a greater role for lay supports than did service providers.
- Service providers were more likely than the public to rate the helpfulness of statutory services. Social workers were more likely to rate local authority services as helpful whereas health service workers rated health services, particularly the community psychiatric nurse.
- Staff with more than 10 years work experience were consistently less optimistic than their less experienced colleagues about the helpfulness of services.
- The views of the public and service providers on the helpfulness of various supports revealed widespread appreciation of the need for a collaborative approach to service provision; both groups identified a contribution from health, social and lay services.

3. Relevance of the Findings in Relation to Organisational Culture, Consumerism and Previous Studies on Consumer/Public Consultation

In the earlier review of the literature on organisational management theory it was argued that adopting a consumer culture could pose a number of challenges to the NHS. For more than a decade, health policies have promoted a consumer oriented approach to make services more accountable to their users and to give the public more say in how services are run. Previously, it has been argued that this could potentially challenge the autonomy of the medical professions who have historically determined the service requirements not only for individual patients but also for whole communities. A second potential challenge emerged from the literature review which to date has received little, if any, attention. It was argued that if parallels were drawn with business organisations, a preoccupation with consumer concerns in the NHS could result in the creation of an organisational culture that it underpinned by standardisation of products and services at the expense of innovation and technological advancements. The extent to which this has occurred is outwith the remit of this thesis. However, it is interesting to note that concerns are beginning to emerge about the potential impact on research and service development of the full implementation of legislation and policies that will impose greater control of patient information, such as the Data Protection Act and the Health and Social Care Bill (Tondal and Axelson 1999, Denley and Smith 1999, Strobl et al 2000, Al-Shasi and Warlow 2000). The studies on which this thesis is based are largely concerned with the provision of care for individuals with chronic health needs and hence less likely to be at the forefront of new medical advances. For this reason, it could be argued that the settings in which the studies were conducted are more likely to have a consumer orientated culture than acute care settings. If so, the findings of the studies will relate to services within the NHS which would be expected to have greatest appreciation of and commitment to consumer concerns.

In the review of the literature on consumerism it was argued that the potential for consumers to challenge the NHS was directly related to the extent to which they were empowered or willing to participate in strategic and operational decisions relating to service provision. During the focus group interviews with patients in long stay wards for the elderly, it was evident that patients did not perceive themselves as consumers of services. In general discussions about care for vulnerable patients like themselves, they associated the ability to exercise choice with private care but not NHS care. However, in the more focused discussions on the essential requirements for a service, they did articulate issues that were clearly concerned with choice and the provision of information. This finding suggests that health policies promoting these values reflect genuine concerns of patients even those who historically have been most reluctant to exercise the "voice" option of the consumer, described by Hirschman (Hirschman 1970).

The conclusion drawn from the review of the literature on consumer and public consultations on the quality of and need for services was that the voice of the consumer was still relatively mute. On the basis of the available evidence, it was argued that the main reason for this related to methodological concerns – ie the approaches used marginalised the extent to which consumers could exert influence.

Despite decades of activity aimed at assessing patient satisfaction with service provision, it was still not clear whether or not valid concerns of patients had been addressed. The same methodological concerns were found in the approaches adopted to obtain the public's views on the need for services – ie the views elicited were based on a predetermined range of services which may or may not accurately reflect those which the public would have considered relevant. The challenge embraced in this thesis was to develop methods of consumer and public consultation that took account of their values in relation to defining the quality and range of health service provision. The intention was to identify methods whereby service users would be empowered not only in terms of voicing their views on the services but also in determining the issues relating to service provision on which they should be consulted.

Against the background of uncertainty about the relative values that service users and the public attach to services or particular aspects of them, views were also canvassed from others who traditionally have been their advocates. This entailed consulting groups of nurses and relatives of patients for the studies on the quality of services and health and social workers for the studies on the need for services.

When asked to act as patient advocates, nurses and the relatives of patients were only able to identify one third of the criteria for a good service that were valued most by patients. The criteria of patients in long stay wards for the elderly were mainly concerned with organisational aspects of their care such as opportunities to meet other patients; to attend church services and concert parties; to have a permanent place in the ward; to eat at a table; and to have choice and variety of menu. Relatives placed a stronger emphasis on criteria relating to service inputs (such as physiotherapy, aggressive medical treatments, and more unqualified nurses) and the nurses' emphasis was on the patients' physical environment (such as décor and furnishing, TV/radio/books, toilet facilities, and warmth and lighting). It is interesting to note that, unlike the patient criteria, the relatives' criteria had obvious resource implications. It is possible that, despite being asked to give their views on the criteria that they believed would be most important to patients, relatives felt that they had to promote a more political agenda in order to highlight their own perceptions of the limitation of resources. There were also clear differences between the criteria of the patients and their nurses. In relation to Maslow's hierarchy of human needs, the nurses' criteria most closely resembled those at the lower end of the scale – ie physiological and safety needs (Maslow 1943). The patients' criteria, however, were more in accord with the higher needs for self-esteem and self-actualisation. According to Maslow's theory, these higher needs would only manifest themselves once the lower needs were satisfied. Under these circumstances the difference between the nurses' and patients' criteria was a result of nurses failing to recognise that basic needs of patients had been satisfied and that higher needs had become their motivators for satisfaction. If Herzberg's motivation-hygiene theory of work motivation was applied to the residential conditions in long stay wards, patients would express dissatisfaction if their lower needs (such as those articulated by their nurses) were not met and satisfaction if their higher needs (such as those articulated by themselves) were met (Hertzberg 1966). In other words, satisfaction and dissatisfaction may not be the two sides of the same coin. The findings of the study of patients in long stay wards for the elderly support this assumption. The best predictors for overall satisfaction related to higher needs of patients - ie the way in which nurses interacted with them, the extent to which they were informed about their medication or treatment and opportunities to participate in diversional therapies. This finding suggests that it is not enough for managers of long-term care settings to be concerned with meeting the basic physiological needs of patients but that they should also encourage staff to interact with patients in a way that satisfies their needs for self-esteem and self-actualisation.

The way in which nurses treated patients as individuals was of paramount importance to patients. This largely relied on the personal attributes of nurses - ie nurses who were cheerful and attentive and who listened. Patients, nurses and relatives were unanimous that these attributes in nurses were essential for a good service in the long stay wards for the elderly. Despite this, less than half of the patients reported satisfaction with their experience of nurses in relation to these attributes. The level of dissatisfaction reported was not only higher than expected in a population of elderly people but also at odds with the findings of the large Scottish Office national survey in which the highest satisfaction rates for hospital in-patients included the attitudes of nurses (Scottish Office 1989).

Communication between hospital staff and patients has consistently been shown to be a source of dissatisfaction within the NHS (Palmer 1990). In the study of long stay wards for the elderly, patients expressed dissatisfaction not only with the general manner in which they were treated by their carers but also with the extent to which their information needs were met in relation to specific aspects of their care. For example, more than a third of patients reported that they were not given enough information about their medications or treatments, suggesting that their rights as set out in the Patient Charter were not always respected (Secretary of State for Health 1991). In particular, the right to be given a clear explanation of any treatment proposed, including any risks and alternatives. The Government recently abolished the Patient's Charter and replaced it with Your Guide to the NHS in which the emphasis shifts from 'patient rights' to 'what patients can expect from the service and their responsibilities' (Secretary of State for Health 2001). The patient responsibilities outlined cover issues such as not missing appointments, doing exercise and practising safe sex. This shift of emphasis represents a move from a commitment to consumerism to the promotion of partnership arrangements. When he announced plans to abolish the Patient's Charter, the then Health Secretary, Frank Dobson said: "The old Patient's Charter focused too much on patients' rights. It encouraged consumerism, but made health professionals defensive' (The Guardian, 9 October 1997). Whether or not, this is the case, issues relating to communication and sharing of information are as pertinent to partnership arrangements as to consumerism and therefore, are likely to remain a priority within the NHS.

The nurse's response *"they all do their job"* to the patient's enquiry about the purpose of his medication is not only an example of the type of communication difficulties experienced by patients but also raises questions relating to informed consent. In this particular instance, the response of the service provider had a direct impact on the extent to which the patient was able to make an informed decision on whether or not to take his prescribed medication. Whilst it is unlikely that such practices would receive the same attention as the public outcry over the removal of child organs at post-mortem in the absence of full parental consent, it does, nevertheless, exemplify a sense of a culture of paternalism within the NHS. The UK Parliament and Scottish Executive have indicated their intention to amend the Human Tissues Act 1961 to clarify the requirement for informed consent and the penalties for breaches of its provision (House of Commons Hansard Debates for 30 Jan 2001 and The Scotsman, 7 February 2001). Within the context of these debates, Alan Milburn, the Secretary State for Health made the general observation "*Practices that might have been considered acceptable in the 1950s and 1960s are not considered acceptable nowadays, for the simple reason that we live in a very different era. Public and patient expectations are very different. Systems, ways of working and, I think, the whole culture of the health service have lagged behind ………..The relationship between patients and the service today has to be based on informed consent. That will require changes in practice, policy and medical education*". In the case of organ or tissue donation, the government has made it clear that this will also require changes in legislation. However, in other areas where patients and the public have expressed the need for information, it is unlikely that legislative changes would be feasible. For example, even if their rights to information could be comprehensively enshrined in legislation, it is difficult to envisage how these could be enforced in the case of elderly patients requesting information on the purpose of their medication. Clearly, observing such rights is more dependent on changes in practice which, in turn, are likely to rely on changes in the focus of recruitment and training of health care professionals.

From their group discussions, it was clear that relatives believed that untrained nurses were better carers of elderly patients in long stay wards than trained nurses. Indeed, one of their key requirements for a good service was 'more untrained staff'. There are a number of possible explanations for this view including the belief that professional nurses were in some way either desensitised to the needs of patients or unable to communicate a sense of interest or commitment to caring for the elderly. Another of the relatives' criteria 'nurses with a vocation', by which they meant nurses who worked in an elderly care setting because this was their preferred area of clinical practice rather than because it was geographically convenient to their homes, supports these assumptions. Whatever the reason, there is clearly a need for the recruitment and training of nurses to emphasis the importance of interpersonal skills. It is possible that patients in acute wards would define an entirely different set of key requirements for a good service. However, it is equally likely that the same kind of interpersonal skills are required in the acute sector to enable nurses to communicate complex or difficult issues such as serious diagnosis and/or poor prognosis. In the recently published National Health Plan for Scotland, in which the stated aim is to translate policy into action, a commitment has been made to provide training and development for NHS staff and managers to acquire the skills and expertise they will need in order to provide the leadership and support to deliver a patient-centred approach (Scottish Executive 2001). As part of this commitment, the Scottish Executive is supporting a programme of educational events on public involvement in health care. Interestingly, a number of these events are dedicated to providing training in the use of the Nominal Group Technique, the method used in the study to determine the essential requirements for good care in long stay wards. It seems ironic that health service providers, who have been traditionally described as the caring professions, have been identified as in need of additional training in listening to their service users. Nurses, in particular, are trained to adopt a personalised approach to care which relies on identifying and meeting the needs of the individual irrespective of the diagnosis. However, evidence of professional nurses adopting a personalised approach to care was clearly not always apparent to the relatives who participated in the focus group exercises or to patients who participated in the survey on the quality of care.

Despite their low expectations, patients in the long stay wards for the elderly reported higher levels of dissatisfaction than in other studies of similar populations. In relation to the interpersonal qualities of their nurses, men tended to be slightly more dissatisfied than women. Although a difference in satisfaction between genders has been reported previously, it is not a common finding (Hall et al 1987, Cleary and McNeil 1988). Patients excused the failure of nurses to interact with them in the way that they most valued by citing pressures of workload. Despite the emphasis in nursing on personalised care and developments such as each patient being allocated a 'named nurse', a number of observations were made during the course of the surveys of long stay wards that suggested that the delivery of care was driven by tasks. To a certain extent this may be unavoidable in long stay wards for the elderly where care is labour intensive. However, on other occasions this task-oriented work culture seemed to be driven by the need to satisfy other service providers rather than service users. For example, it was observed that nurses described having '*a good day*' when they had not only completed the tasks allocated for their shift but had made some impact on those generally carried out by their colleagues on the next shift. The extent to which such practices pervade the NHS was not an aim of the present research, however, these observations suggest that there are still elements of scientific management approaches to the provision of services some twenty years after these were identified by Hadley and Hatch (Hadley and Hatch 1981). Given the continuing emphasis on the need to develop a consumer culture in the NHS, the nature of the existing organisational cultures merits further research. In addition to paternalism, the main focus of current criticism, there may be other elements to the existing NHS culture that inhibits the adoption of a more consumer-orientated approach.

During the course of the fieldwork of the surveys, it appeared that care was sometimes organised to meet organisational needs rather than those of the individual patient. For example, it was observed that patients were generally seated at tables, set with cutlery, one hour before their evening meal was served but as each patient finished eating, he or she was assisted from the table and the place setting cleared. On questioning, the nurse managers of the study hospitals explained that patients were grouped around tables before meals in order to encourage them to converse with each other. When asked why this was encouraged at the beginning of the meal rather than at the end, since this is when conversation would normally occur in wider society, they explained that as the kitchen staff were only employed between certain hours, tables had to be cleared as quickly as possible. Once again, the investigation of such practices were outwith the remit of the present study. However, it is evident that, on some occasions, the needs of the organisation are in direct conflict with the spirit of policy and guidance, such as the Framework for Action which directs everyone working in the NHS to be "*to be sensitive to the wishes and feelings of patients*" (Scottish Office 1991).

Research has only just begun to explore mechanisms by which some practices can be changed to better involve patients in decisions about their health care. For example, one recent small qualitative study explored the potential for routinely giving patients a copy of their referral letter sent by the GP to the hospital outpatient clinic (Jelley and van Zwanenberg 2000). Whilst the study was too small to be the basis for any generalisation, it did highlight some important issues that inform the current debate on the development of partnership arrangements between service providers and patients. In some cases, GPs exercised their clinical judgement and excluded patients from the study because sharing information was not deemed not to be in the patient's best interests. More interestingly, this paternalistic attitude extended to patients who, when asked if the practice should be universal, expressed reservations about some cases even though they all found that receiving a copy of the letter had helped them understand what was going on during the consultation and what to expect. Further research is required in order to determine if the concerns expressed by service providers and patients are the same and whether or not these are legitimate. In the study of service quality in long stay wards for the elderly, the best patient advocates were young patients with mental illness in long stay wards despite differences in their age and nature of health problem. This finding suggests that patients may be able to advocate for others who are less able to express their views.

The patients in the long stay wards for the elderly were even more dissatisfied with the opportunities for diversional therapy than the hospital in-patients in the Scottish Office national survey who rated this as one of the main causes of dissatisfaction (Scottish Office 1989). The need for meaningful activities was also found to be important to young patients with mental illness in long stay wards. A lack of occupational or diversional activities is likely to have greater impact on patients in long stay wards than on other hospital in-patients because they do not have the same prospect of hospital discharge and return to everyday distractions at home. When describing the tedium of their lives in hospital, many patients became upset and tearful. For this reason, a second question about this that was intended as a reliability check was omitted from the interview schedule. The patients' need for diversional activity was not recognised by either the nurses or the patients' relatives when asked to rank the most important criteria for a good service in long stay wards. Throughout the fieldwork of this research, nurses consistently underestimated the number of patients who could reliably participate in the survey. On the basis of this observation, it is likely that nurses, the principal service providers of patients in long stay wards, also underestimate the proportion of patients who would be able to benefit from diversional therapy. Considering its impact on overall satisfaction with life in hospital and the distressing levels of tedium reported by patients, it should be a priority for service providers to create a programme of diversional activities for patients in long stay wards. The programmes could be tailored to include activities that the patients valued most such as opportunities to engage with other patients and to attend concert parties and church services.

Despite significant dissatisfaction with particular aspects of the care, the patients' ratings of overall satisfaction with life in hospital was relatively high. Review of comments made by those who expressed dissatisfaction with life in hospital suggested that these were people who were generally unhappy with their lot. The association between poor physical and psychological status and dissatisfaction has previously been demonstrated but it is not clear to what extent these factors influenced the findings of the study (Greenlay and Schoenherr 1981, Cleary et al 1989). However, the dissatisfaction expressed in the present study should not be discounted entirely. In this study a direct relationship was established between overall dissatisfaction and dissatisfaction with individual aspects of care – ie as the number of individual aspects of care in which dissatisfaction was expressed increased, the likelihood of overall dissatisfaction also increased. Whilst it is not possible to determine if people who are generally unhappy are more likely to express dissatisfaction with individual aspects of care or vice versa, the comments made by patients in relation to the individual aspects of their care illustrated genuine causes of dissatisfaction.

The findings of second survey of the quality of service on long stay wards were remarkably similar to those obtained from the first, proving that the survey tool was reliable. Whilst disappointing, it was not surprising that change had not been effected during the intervening year. This would have required changes not only to the organisation of care but also to the manner in which nurses interacted with their patients. It is unlikely that such changes could be effected without a substantial shift in the culture of the long term care settings. During the second survey the researcher was recognised by some nurses as someone who had previously visited their wards, however, they generally could not recall either the purpose or the findings of the previous research. This was disappointing as each of the participating hospitals had been sent a full report and each ward a summary paper of the findings of the first survey. The failure by the organisations to promote these meant that the research had little chance of making any impact on improving the quality of service for the patients. Thus, a decade after Deakin and Wright observed that 'defining needs has become confused with meeting them', the findings of the surveys on the quality of services in long stay wards for the elderly show that even after needs have been defined and quantified, they are not necessarily met (Deakin and Wright 1990).

There were two obvious impediments to effecting the desired organisational change that are as relevant today as when the research was conducted. First, for the nurses working on the long stay wards for the elderly, there was a lack of ownership of the research findings. The research did not naturally emerge from issues identified by the practitioners themselves. Instead, it was commissioned by executives who were not directly involved in providing care. Without ownership, there were no obvious champions within the provider organisation with the motivation to effect change. The need for such champions and ownership of service development was recognised as crucial to the successful implementation of quality improvements in organisations outwith the public sector (Peters and Waterman 1982). The second impediment to change related to lack of power as opposed to lack of motivation. The research was not only imposed by non-practitioners but it occurred at a time of great organisational change, in particular, the separation of health boards from NHS Trusts. The studies were commissioned by a health board and undertaken at a time when new working relationships with the provider hospitals were being established. Whilst quality was within the health board's remit, it had limited power to impose standards as a result of the research, particularly when the findings were consistent across all 6 hospitals for care of the elderly. Unless the Board was prepared to commission services from another health board area, the Trust had no incentive to change as they monopolised the market for hospital care of the elderly. The Trust's lack of ownership of the study and the Board's limited power to impose change combined to create hurdles in terms of effectively managing quality of care. The findings of these studies suggest that the creation of quasi markets not only failed to create a sense of increased consumer choice for patients but also had limited effect in creating choice for those charged with purchasing services on behalf of patients.

The National Health Plan for Scotland identified the separation of health boards and Trusts as a barrier to developing a truly corporate approach within the NHS both locally and nationally (Scottish Executive 2001). As part of the plan to unify the health service, the separate board structures of existing NHS Health Board and NHS Trusts in each geographical area will be replaced by a single NHS Board. Whilst NHS Trusts will retain their existing operational and legal responsibilities, it is envisaged that chairs and chief executives of the NHS Trusts will sit on the new unified NHS Boards and be held jointly accountable for the performance of the local health care system. There is clearly potential for this plan to have an impact on decisions taken at a strategic level through the development of joint agendas. Whether or not the plan makes a difference at operational level will depend on identifying, and where necessary establishing, systems to translate policy into action.

The research on the need for services was also commissioned by the same health board. Unlike the studies on the quality of service provision, this research appeared to have more relevance to the direct activities of the Board in terms of its responsibilities to identify and commission services to meet the health care needs of the population it serves.

In order to provide a context for the views on the need for services to support individuals with mental health problems data were also collected on the respondents' attitude to living next door such individuals. A similar proportion of the public and service providers reported that they would be happy to live next door to each of the hypothetical individuals portrayed in the vignettes. The large majority of both groups felt this about the individuals who had no history of hospital admission; around one half about the individual with stable but chronic mental health needs but less than one-third about the individual whose chronic illness was interrupted by acute episodes. Service providers were more likely than the public to say that they would be happy but the size of the difference between the response of the two groups diminished as the severity of the mental health need increased. When asked the same question in relation to a supervised group of individuals with long-term mental health needs, service providers' responses were similar to their response regarding the individual with chronic mental health needs who had the periodic acute episodes. The responses of the public to this question indicated that they may have been a bit more reassured by this prospect; fewer respondents expressed reservations and said that they would be happy while the proportion who said that they would be unhappy showed only a marginal increase. Nevertheless, over a quarter of public said that they would be unhappy to have a small group of individuals with profound mental health needs as neighbours. Whilst this represents a significant minority, it is about one-third of the proportion of local residents who, a few months prior to the survey, signed a petition in objection to a similar development in the health board area. The difference observed between public responses to hypothetical and actual proposals of this nature may be a product of the difference in the question posed. In surveys of this kind, questions that collect data on attitudes can only be used as proxy measures of expected or likely behaviour. How people actually react to any particular situation may be quite different to the way they believed they would react. It is possible that some people who genuinely believed that they would be happy to live next to door to groups of individuals with mental health problems or expressed some reservation would find that they were more negative when the prospect of this became a reality. The context in which the question is posed can also influence responses. In the survey, members of the general public were interviewed individually by a market researcher. Under these circumstances, their responses may be to a question to which they had previously given little consideration. Respondents may also either wittingly or unwittingly give more favourable responses in order to make a good impression on the interviewer. The members of the public who did object to the community care development in their residential area, on the other hand, are more likely to have voiced their views after much more consideration involving media coverage and public debate. Under these conditions, it is possible that individuals with positive or neutral views modified them in light of the views expressed by others. It is also possible that people with less positive views felt more comfortable about expressing them in a forum where others felt the same.

Regardless of the strength of the negatives views, the findings of the survey showed that only a minority of respondents were without reservations about living next to supported accommodation for people with mental health needs. The concerns articulated by the public related to the potential for anti-social behaviour of the residents and the inadequacy of community support by statutory services. Service providers shared these concerns suggesting that they may have had some legitimacy. In terms of managing the organisational culture to promote corporate aims, these findings suggest that the health service may be required to address concerns within its own and other care organisations before it can hope to persuade the public to accept new service developments such as community care settings.

The main focus of this part of the research was to compare and contrast the views of the public and service providers on the need for services to support individuals with mental health needs. A list of potential supports and services was compiled by mental health service users in reference to the series of vignettes depicting people with different levels of need and to their own experience. The result comprised statutory and non-statutory services, some of which were not available locally or elsewhere. For example, 'Buddy Support' which was defined as access to an individual with personal experience of similar problems who could offer moral support. The list not only contained specialist psychiatric and general health services but also services that could potentially address personal, domestic, housing, information, employment, social and recreational needs of individuals. Interestingly, sources of spiritual support did not feature in the list but individuals or groups associated with churches were identified as potential sources of support by a few members of the public in the survey of their views.

Overall, there was a great deal of concordance between the views of the public and providers on the need for services when their ratings were combined for all the hypothetical individuals portrayed in the survey vignettes. Both groups perceived a need for a collaborative approach to service provision. In general, service providers had greater faith than the public in statutory services. Moreover, providers tended to believe in the efficacy of the services within their own sector – ie health service providers were more likely to rate health sector services as helpful whereas social service providers were more likely to rate local authority services. This finding suggests that there may be a lack of appreciation of the role of providers or efficacy of services in other care sectors.

Practitioners with more than 10 years experience were consistently less optimistic than their less experienced colleagues about the efficacy of various forms of statutory and non-statutory services. There are a number of possible explanations for this finding. It is possible that experience tempers practitioners' expectations of the efficacy of specialist services. Alternatively, their expectations may not change but as they become more experienced they feel less need for input from other service providers. Whilst it was outwith the remit of the present study, this finding merits further investigation with a view to determining the impact, if any, on referral patterns and health care outcomes.

For the individuals who did not have a history of psychiatric hospital in-patient care, there was greater concordance between the views of the public and social service providers. The difference between their views and health service providers' views related to the perceived benefit of health services. In particular, social service providers and the public had much less faith in the efficacy of the community psychiatric nurse, psychologist, psychiatrist, and, to a lesser extent, the general practitioner. Instead, they favoured a greater contribution from social and lay supports. One possible explanation for these findings is that health services providers tended to medicalise situations which others regarded as natural or common responses to life events. In these circumstances, health service providers would perceive support from the health sector as most appropriate whereas others would be more in favour of various forms of personal and community supports. Whereas, in cases where the health need was perceived to be outwith common experience, it is more likely that there would be more uniform support for specialist intervention. The findings of the present study support this assumption – ie all three groups of respondents agreed on a lesser contribution from non-statutory services for the individuals who had the most profound mental health needs.

It is possible that the lack of public enthusiasm for statutory service provision, which was described by Cornwell, extends to psychiatric services for people with less profound needs (Cornwell 1984). This assumption is supported by a recent German national survey that used vignettes depicting a person either suffering from depression or from schizophrenia (Angermeyer et al 1999). The study found that the public considered mental health professionals appropriate for the treatment of schizophrenia but not for depression. For depression, the public not only favoured lay supports but also believed that the family physician should be involved only when the former resources were exhausted.

The public and social service providers were also in agreement about the relative contribution of non-statutory services to overall provision for the individuals who did not have a history of psychiatric hospital in-patient care. Given that the majority of people with mental health problems do not come to the attention of specialist psychiatric services, informal sources of help are important in a community's de facto help-seeking framework. For example, a North American study of informal-help seeking behaviour found that clients raised interpersonal problems with hairdressers, divorce lawyers, bartenders and industrial supervisors that were comparable to those brought to the attention of mental health professionals (Cowen 1982). A number of different strategies were employed by these informal helpers to deal with the problems including some that were used by mental health professionals. The majority of the informal helpers felt good about providing interpersonal help and believed that they did so moderately well. The impact, if any, of this kind of informal help and how it compares to specialist psychiatric help has not been investigated. Indeed, it is difficult to envisage the design of comparative research that would take account of a host of potential confounding variables such as client populations and expectations; personal attributes of clients, informal helpers and professionals; and treatment settings, duration, activities and goals.

A number of studies have sought to determine the comparative effectiveness of professional and paraprofessional helpers with various client groups. A review based on 42 such studies concluded that paraprofessionals achieved clinical outcomes equal to or significantly better than those obtained by professionals (Durlak 1979). The distinction made between professionals and paraprofessionals related to whether or not they had received formal clinical training in professional programmes of psychology, psychiatry, social work or psychiatric nursing. The professional group contained both trained and trainee mental health specialist. The paraprofessional group comprised not only various forms of lay support but also professionals such as general physicians, nurses, and medical students. Whilst there may have been some overlap between experience of the professionals in each of the groups, the result does tentatively suggest that there is a lack of evidence that specialist training, education and experience account for much of the variance in clinical outcome. This finding combined with the expressed preference for lay and community supports suggests that there is a need to investigate the potential for alternative patterns of service provision for people with less profound mental health needs. The investigation should aim not only to determine the relative effectiveness of various personal and community supports but also to determine whether or not increased investment in them would alleviate demand on mental health services to enable a more targeted approach to provision. By these means, it may be possible to tailor service provision to health care needs.

There was strong support from both services providers and the public for Self-Help Groups for the individuals who did not have a history of psychiatric hospital care, and to a lesser extent for the individual whose chronic illness was interrupted by acute episodes requiring hospital admission. Self-help, mutual support and user groups have been shown to be effective in supporting individuals with problems relating to weight loss; addiction (alcohol, narcotics, smoking, tranquillisers); and bereavement (Albee 1995). Studies of participants in Alcoholics Anonymous, the first widely recognised self-help organisation, found that the most involved participants were more likely to develop coping strategies, including less use of alcohol (Humphreys et al 1994). Similarly, frequent attenders of self-help groups for people with mental health problems experienced more positive changes in psychosocial, interpersonal and community adjustment than infrequent attenders. Moreover, when compared with matched controls, participants of self-help groups spent less than half as many days in psychiatric hospitals over a 32 month period (Maton and Salem 1995). In the United States, it has been estimated that the proportion of the adult population in self-help groups appears equal to that engaged in psychotherapy (Borkman 1990).

It is more than a decade since Deakin and Wright observed that collective provision had somehow translated into a belief in uniform provision (Deakin and Wright 1990). With the exception of the one case whose mental health needs were chronic and stable, health service providers envisaged that the health sector was the major contributor to service provision for the individuals portrayed in the survey vignettes. In the case of the exception, health service providers believed that local authority services were the greatest source of potential support. Their perception of a more limited role of the health sector for cases like this may be a product of health service providers applying an epidemiological approach to the assessment of need – ie the need for service input is recognised only if it is likely to make a measurable impact. An alternative, but not totally unrelated, theory for this view is that chronic cases, such as the one portrayed, are less likely to have YAVIS (young, attractive, vocal, intelligent, successful) characteristics that have been shown influence service provision (Goldstein 1971). The treatment of YAVIS patients has been shown to be based on uncovering psychdoynamic concepts whereas Non-YAVIS patients are more likely to be treated with undifferentiated supportive techniques (Heim 1981). A number of studies suggest that the service providers believe that YAVIS patients are more likely than Non-YAVIS patients to derive benefit from psychotherapy (Heim 1980) and also that non-YAVIS patients are less likely than YAVIS patients to perceive benefit from treatment (Kirchner 1981).

The need for a Patient Supporter was advocated by the majority of the public for all the cases portrayed but only received substantial recognition by service providers for those who had a history of psychiatric hospital in-patient care. This lay service was defined as an individual who accompanies and/or advises a person during any visit to a service provider such as, the doctor or social worker. The value of an independent advocacy service that provides one-to-one support to vulnerable patients was recognised in the National Health Plan for Scotland (Scottish Executive 2001). It describes the Scottish Executive's intention to work with the existing network of independent advocacy organisations to ensure that they can deliver high quality, independent advocacy support to nationally agreed standards. However, the operational mechanisms by which patient advocacy services will be incorporated into the culture of the NHS are not described. In failing to do so, the Plan, which purports not to be just another policy document, falls short of its intention to be 'a plan for action and a plan for change'. In the Health and Social Care Bill, the provisions for independent advocacy services relate to services providing assistance, by way of representation or otherwise, to individuals making or intending to make a complaint relating to the provision of health services (Secretary of State for Health 2000). Other than describing the Secretary of State's duty to arrange for the provision of such services, the Bill is equally vague on the mechanisms that will ensure that this policy is translated into action. Until these are known, it is not possible to predict whether or not they will be effective in ensuring that patient concerns influence service provision. It is also questionable whether or not these patient advocates will be more effective than the Community Health Councils that they will replace given that they will be appointed by Trusts and be accountable to the chief executive.

Under the provisions made for public involvement and consultation, the Health and Social Care Bill proposes the establishment of a Patient Forum for each NHS Hospital and Primary Care Trust in England. Each Patients' Forum will include at least one member who is a representative of a voluntary organisation and one who is either a current or previous user of services provided by the Trust for which it has been established. One of the duties of the Patient Forums will be *"in prescribed circumstances, to perform any prescribed function of the trust with respect to the provision of a service affording assistance to patients and their families and carers"*, where "prescribed" means prescribed by regulations made by the Secretary of State. Until these regulations have been articulated, it is not possible to assess the potential of Patients' Forums to offer the kind of support to individual patients that was advocated by the respondents to the surveys.

The findings of this series of studies on consumer views on service quality and public views on the need for services suggest that, whilst there is a great deal of similarity with the views held by service providers, important differences exist. Recognising this poses two new challenges to the NHS. The first is to negotiate the differences between the various stakeholders. The second is to develop operational measures to ensure that resultant changes to policy can be translated into action. If these challenges are not met, consultation exercises are not only futile but also unethical.

4. Summary of The Methods Used

The review of the methodology used in studies of patient satisfaction and public involvement in health need assessments showed that the approaches used mainly relied on information gathering techniques whereby respondents views were sought in relation to agendas determined by health service providers and or managers. The main challenge embraced in this thesis was to develop methods that would empower service users and the public by giving them greater influence to determine the issues on which consultations are based.

Two series of studies were undertaken. The first concentrated on the quality of services and the second on the need for services. The studies on the quality of services were based on long care settings for the elderly because traditionally patients in these care settings have been least vocal in articulating their concerns. The studies on the need for services were based on mental health care because of public concern raised both nationally and locally about the development of mental health community care settings. Each series used common approaches comprising both qualitative and quantitative approaches.

For the studies on service quality, focus group interviews, based on a modification of the Nominal Group Technique, were conducted in order to determine patients' views on the essential criteria for a good service in long stay wards. Further nominal group interviews were carried with groups of relatives and nurses of patients in long stay wards for the elderly since their views have traditionally been accepted as expert. The robustness of the Nominal Group Technique was further tested in a similar exercise with young patients in long stay wards for the mentally ill. Thereafter, an interview questionnaire was constructed based on the criteria that the patients in the long stay wards for the elderly had prioritised as essential for a good service. This was piloted with elderly residents of local authority and private nursing homes. This series of studies culminated in two surveys, in successive years, during which patients in long stay wards for the elderly were interviewed to determine the extent to which service provision met their criteria for a good service. The study population was men and women of retirement age or older whose main place of residence was a long stay ward for the elderly in the Ayrshire & Arran Health Board area. No sampling strategy was adopted – ie all patients were invited to participate in the study.

For the studies on the need for services, a number of focus groups were conducted with users of mental health services in order to develop a series of vignettes portraying hypothetical individuals with various levels of mental health need and a list of potential services and supports. The product of these exercises was assessed by groups of mental health and social work professionals to ensure their comprehensiveness and validity. Thereafter, two questionnaires were constructed based on the vignettes and list of potential services and supports. As each questionnaire contained only three of the five vignettes used to portray the range of mental health needs, one vignette was common to both questionnaire schedules. These were piloted both as an interview schedule and as a self-completed questionnaire with members of the public who represented residents of both owner occupied and local authority houses and professional and non-professional occupations. This series of studies culminated in three surveys; an interviewer administered questionnaire to the public, a self-completed questionnaire to the public and a self-completed questionnaire to mental health and social workers. Quota sampling techniques were employed to ensure that the achieved sample was fairly representative of the adult population of Ayrshire & Arran. Whilst a similar approach would have been preferred with health and social care workers, there were insufficient resources to establish a comprehensive sampling frame or to follow up non-responders. As the main purpose of the study was to determine if a common tool could be used to compare and contrast the views of the public with service providers, a snow-ball approach was adopted which relied on recruiting key individuals to distribute the questionnaire amongst colleagues.

5. Relevance of the Findings in Relation to Methodological Issues

Focus groups, a traditional tool of market research, are now enjoying unprecedented popularity in political and academic fields. In a recent publication dedicated to this research method, the editors describe occasions when Prime Minister, Tony Blair, declared that 'there is no one more powerful than a member of a focus group', and subsequently reassured political commentators that he was not attempting 'government by focus groups' (Barbour and Kitzinger 1999). The editors also estimate that in the past few years there has been a three-fold increase in the number of focus group studies published in academic journals. The application of focus group methods in the present study preceded this boom in interest. The rationale for adopting this research method was that they not only offered potential in terms of economy of time but also for additional insight into language and reasoning of participants' views. To varying degrees the focus groups did realise their potential in relation to these outcomes. However, the capacity to achieve these depended on the extent to which the focus group activities were structured.

In general, the focus groups based on the Nominal Group Technique were much less time-consuming than those that used less structured techniques. During a nominal group interview of around 90 minutes, nurses and relatives of patients in long stay wards were able to identify and prioritise the essential requirements for a good service in long stay wards. The same exercise using less structured techniques in a 90 minute group interview with patients allowed the essential requirements to be identified. To then prioritise these requirements involved a series of 20 minute individual interview with each of the participants. However, the advantage gained in terms of time occurred at the expense of obtaining additional insight into the language and reasoning of participants. The term nominal is used in the Nominal Group Technique because for the large part of the participants activities are conducted individually. Indeed, it is structured so that participants are only allowed to communicate directly with each during the one stage when clarification and modification of their individual ideas are required. Under these circumstances, the opportunity to gain additional insight into an individual's perspectives as they operate within a social network is constrained. For example, during their respective nominal group interviews, relatives and nurses both identified a 'cheerful nurse' as essential to good care for elderly patients in long stay wards. In the course of their discussions, each group defined this criterion as a nurse who was able to 'cheer' patients who were generally perceived to be in need of stimulation and personal interaction. Patients too identified 'cheerful nurses' as an essential component to their care. However, in their less structured discussion of this attribute, a slightly different definition of the term emerged. The patients' definition was concerned less with a positive characteristic of their nurses' ability to interact in an engaging and stimulating manner. Instead, their definition was more concerned with the absence of negative traits ranging from apathy to unpleasantness. It was not only important to patients that nurses were pleasant when providing the care but also that this was carried out in an ungrudging manner. This broader definition may have been recognised by relatives who identified 'nurses with a vocation' as an essential criterion for a good service. However, the very structured approach adopted in the nominal group exercise did not allow the opportunity to explore the extent to which the different groups used similar language to express different views.

During the nominal group interviews with relatives and nurses, the group interaction phase was dedicated to the discussion of their individual ideas to ensure that there was no overlap between them and that a group consensus was reached on how each should be defined. During these group interviews, broad terms were proposed that could potentially encompass a number of related but separate criteria. 'Nurse with a vocation' and 'personalised care' are good examples of such terms proposed by relatives and nurses respectively. It could be argued that 'nurses with a vocation' would encompass not only a number of different personal attributes which in turn would reflect on the service carer's values which in turn influences the manner in which care is provided. Similarly, 'personalised care', which broadly defined means care which respects individuality, could encompass a host of criteria including respect for patients' needs for information, privacy, choice, self expression and self-esteem. In dismantling these 'ragbag' terms, the relatives and nurses derived different solutions. Both groups articulated and discussed the relative merits of the many dimensions that they understood to be contained in the term. The nurses then substituted the criterion 'personalised care' with a number of criteria reflecting its component such as 'respect for privacy/dignity', 'respect for personal habit', 'personal belongings', and 'own clothes and toiletries'. The relatives, however, were reluctant to abandon the term 'nurses with a vocation' and instead chose to define this specifically to mean nurses who worked in an elderly care setting because this was their preferred area of clinical practice rather than because it was geographically convenient to their homes. At this stage they proposed an additional criterion 'unqualified nurse carers' who they perceived to be driven more by a sense of vocation rather than their professional colleagues. It was obvious, even during the limited time afforded by the Nominal Group Technique, that many of the terms used by the participants reflected a number of issues worthy of further exploration. It is possible that further exploration of these would have yielded different results in terms highlighting common and conflicting views of the groups who participated in the exercise.

In addition to providing insight to individuals' perspectives within a social network in a relatively short time scale, the focus groups achieved an additional unpredicted outcome, which was perhaps more important given the emphasis of this thesis. Whilst perhaps not to the same degree that Prime Minister, Tony Blair, believes, the members of the focus group, particularly the service users and their relatives, were empowered as a result of the activity. The power differentials between service providers and users/and their relatives are obviously quite different from those that exist between the researcher and interviewees. In the former, the balance of power is generally with the service provider in terms of knowledge and the willingness to share information. In the latter, the interviewee is the expert from whom the researcher can hopefully gain information and insights. Whilst this shift in balance of power in favour of the respondents occurs in one-to-one interviews, it was enhanced in the group interviews during which the participants collectively worked to define, and reach consensus on, issues. This was most apparent in the group exercises that resulted in a tangible product such as the list of the priorities for a good service produced by the patients' relatives and the series of vignettes and list of services produced by the mental health service users. The participants appeared not only to be confident about their views as these had been derived by group consensus but they also appeared to share a sense of collective ownership of the product of their activities.

There was an important difference in the status of the participants that may have influenced the extent to which they felt empowered during the focus group activities. Although the relatives' travel expenses were reimbursed, relatives and patients were not paid for their contributions to the focus groups whereas staff participated during working or paid time. It is unlikely that this difference had much impact on the results generated by the relatives and patients who appreciated that their views had been canvassed as part of this consultation exercise. Whilst staff also appeared to enjoy the focus groups, their reasons may have been quite different. For some, the focus groups provided a welcome respite from routine work activities and for others, a demonstration of a research method. Given that staff views have traditionally defined service priorities, it is perhaps not surprising that they did not share the same sense of appreciation of being included in the consultation exercise. Regardless of the impact, if any, on the outcome, differences in the status between paid and volunteer contributors should be addressed if the overall aim of the activities is to empower consumers.

It was anticipated the focus groups would provide similar information to the private accounts that are obtained after repeated individual interviews by a researcher during which friendships were established (Cornwell 1984). In theory, focus groups, which rely on interaction between a group of individuals with shared experiences, have the potential to overcome problems associated with participants providing public accounts – ie those which participants might consider socially acceptable to the researcher, a complete stranger. It was argued that capitalising on the natural relationships that exist within groups was more ethical approach than manufacturing relationships (ie these would not have occurred naturally) in order to gain insight to the more private accounts of participants. The extent to which this actually occurred in practice is difficult to assess but it did depend on the activities of the focus group and the researcher's role in these.

The respective roles of the participants and the researcher were defined at the start of each of the group interviews. From the outset, it was emphasised that the participants were the experts in relation to the subject of the enquiry because they had relevant experience - ie as a service user, provider or patient relative. The researcher's role in the groups was as a scribe responsible for recording accurate accounts of the evidence that were pertinent to field of enquiry. These definitions were not only more comfortable for the researcher whose training and previous experience was in quantitative rather than qualitative research methods but also were more in keeping with the aims of the research to develop methods that would empower those who contributed to consultation exercises of this nature.

The nominal group interviews were primarily concerned with articulating the essential criteria for a good service and their structure imposed constraints on the opportunities to explore any one criterion in depth. Nonetheless, as the participants, particularly in the groups of relatives, traded experiences to illustrate their respective views on particular issues, their arguments developed generating additional data to those that would have been obtained in individual interviews. For example, the discussion on the relative importance to patients of having their 'own clothes and toiletries' started with fairly positive comments on the need to preserve patients' individuality within institutional care settings. However, as experiences were exchanged, the discussion evolved to include more negative issues such as the financial costs to relatives and the ineffective response by the service when personal belongings of patients went missing. As a result of the group exchange, additional criteria were proposed that previously had not been articulated by anyone in the independent part of the exercise. These included 'choice of clothes & toiletries', 'continuity of care/same staff' and 'staff with a vocation'.

The Nominal Group Technique was quickly abandoned during the focus group interviews with the patients from the long stay wards for the elderly when it became evident that many of the participants had failing eyesight and arthritic hands. These disabilities prohibited them from engaging in some of the activities of the exercise, such as making a written list of their ideas and selecting ideas from a list displayed on a flipchart. Instead, less structured focus groups were held during which the participants were encouraged to identify and discuss the ideal requirements for a good service in a long stay wards. From the outset, patients were quick to emphasise that the hospital in which they resided were excellent and provided a first class service. When asked to elaborate on the conditions that made it a good place to live, patients were unanimous that nurses were the biggest contributory factor. Patients described them as being 'marvellous' and 'absolute angels'. Such responses may have been a product of launching the exercise with global questions. Alternatively, the responses may have been a reflection of the patients' public accounts – ie those considered most socially appropriate to an outsider. Regardless of the reason, it was anticipated that as the activities became more focussed and as patients became more engaged with each other and less with the researcher, their responses would become more diverse. However, the patients' disabilities also curtailed the extent to which they could engage directly with each other. The researcher had to serve as a conduit to articulate the views of those with speech difficulties to those with hearing difficulties. Whilst, this may have enhanced the opportunity to keep the group activities focused, it undermined the potential for the researcher to take a more passive role in the discussions and for the expression of more private accounts. Throughout the focus group interviews the initial views that were expressed by patients were not modified. With hindsight, it may have been more productive to have a reduced number of participants in each of the patient groups. If the group had comprised three members instead of six, it is likely that the researcher would have had to expend less effort ensuring that everyone was able to hear what was being said which in turn may have enhanced the natural flow of the discussion. Despite these difficulties, the patients did enjoy participating in the group. They not only enjoyed the opportunity to talk to each other but they felt that they had participated in a meaningful activity. As a research method, the focus group interview with the elderly patients posed a number of challenges. However, as a customer relation exercise and a diversional therapy, focus groups were successful.

The questionnaire used in the patient survey of satisfaction with the quality of care was based on the top thirteen criteria by which patients, themselves, defined a good service. These represented half of the total number of criteria articulated during the patient focus group interviews. There were two reasons for focusing the enquiry. First, inclusion of all twenty-six criteria would have resulted in a substantially larger interview schedule that would have created additional demands on both the researcher and respondents in terms of concentration and stamina. Second, a comprehensive approach to the service evaluation was likely to produce a volume of results and recommendations outwith the organisation's capacity to respond to recommendations for change. In the event, patients were not only willing but were happy to devote a lot of time to helping the researcher. The majority of this time was spent exchanging information on backgrounds. Whilst some demographic information was required for the evaluation, in most cases the conversations extended beyond the remit of the study. Undoubtedly, this occurred as a direct response to the perceived and reported levels of boredom in this patient population. Given the lack of organisational response to the findings of the first patient satisfaction survey, it is likely that the field of enquiry was too extensive. With hindsight, it may have been more productive to concentrate on the single criterion which was universally accepted as being the most important to patients – ie the personal attributes of nurses.

When asked questions about the quality of care in long stay hospitals in the individual interviews, patients were much more critical than they had been in the focus group interviews. There are a number of possible explanations for the difference in responses. The most obvious is that the patients who participated in the focus groups were, for some reason, not representative of the wider patient population. It is true that patients were selected to participate in the focus groups by nurses who, theoretically, could have chosen only those likely to give favourable responses to questions about their care. However, it is more likely that nurses selected patients according to their perceptions of the individual's ability to participate in a group activity. Given that nurses consistently underestimated the number of patients who could participate in the one-to-one interviews in the next stage of this study, it is unlikely that they would have recognised a sufficient body of patients from which they could confidently produce a biased sample for the focus group interviews. The most likely explanations for the discrepancy between the results of the focus group and individual interviews related not only to differences in the questions posed to the respondents but also to differences in the contexts in which they were posed.

In the focus group interviews patients were asked to respond to global questions about the quality of the service in long stay wards for the elderly. As expected, the responses provided were equally global in that there was little diversity from the view that service was excellent and that there was no potential for improvement. As a result of the communication difficulties that curtailed the extent to which participants could engage directly with each other, the opportunity to focus on more specific questions was also curtailed. However, there may have been additional pressures that prevented patients from offering an alternative view to the global perspective. Although the patient groups were drawn from the same hospital setting, the participants generally represented different wards. Under these circumstances, individual patients may not have wanted to appear in any way critical in case their contribution to the discussion highlighted deficiencies in their particular ward. It is not difficult to appreciate the reasons for the patients' loyalty to their wards. It is likely that they were not only bound by gratitude for the care they received but it was also likely that it would be difficult for them to be frank about any perceived deficiencies in their care against the prevailing view that this was flawless in other wards.

With the exception of one question, which asked patients to rate their overall satisfaction with life in hospital, the individual interviews were not based on global measures. Instead, the questions were focused to measure the extent to which the service met the criteria by which the patients judged a good service. This resulted in responses that were much more discriminating than those obtained to the focus group interviews. The nature of information obtained during the focus group interviews was similar to the 'public accounts' described by Cornwell in her study of health and illness in East London – ie responses which are considered socially appropriate or non controversial (Cornwell 1984). By contrast, the information obtained during the individual interviews was similar to the 'private accounts' in the Cornwell study – ie responses which draws on personal experience and that usually occur only when the researcher has established a relationship or friendship with the respondent. Unlike the Cornwell study, the present study did not rely on repeated interviews in order to achieve private accounts. There were, however, differences between the researchers of the two studies that may have influenced the ease by which they established relationships with respondents. In the Cornwell study, the researcher was a middle class female who, in the pursuit of a PhD, interviewed people in a part of London where it was unusual for people, especially women, to have been educated beyond secondary level and to have professional occupations. In this situation, it is likely that some time would be required for the researcher and respondents to overcome the differences between their backgrounds and establish the grounds for a relationship. By contrast, the researcher and the respondents of the present study had remarkably similar backgrounds and these were established at the outset of the interview. Like the majority of respondents, the researcher was from a working class family and had been raised in a mining community. Her educational and professional experience was similar to those of the respondent's children and grandchildren. As a result, the respondents of the present study were highly motivated to provide frank and considered responses to the survey questions.

The focus groups that informed the research tools for the surveys on the need for services were task driven – ie the production of a series of vignettes to portray different mental health needs and a comprehensive list of potential services and supports. For this reason, the approach adopted in these was also highly structured. They did, however, differ from those that informed the study on the quality of services. In the quality of services study a series of meetings was convened with different groups during which participants worked on the same task, whereas in the need for services study the same group of individuals were invited to attend a series of meetings to work on components of a bigger task. From their feedback, it was evident that the mental health service users derived as much satisfaction from attending a number of focus groups as the patients, relatives and nurses who had participated in a single focus group. Some, like the nurses, welcomed the opportunity to witness the research method in action. Others, like the patients and relatives, derived satisfaction from the belief that they had participated in a worthwhile or meaningful activity. However, the majority, like patients, enjoyed the group meetings as an occupational or diversional therapy. Indeed, when the group had achieved its aim and produced the research tools for the next part of the study, there was some resistance to the discontinuation of the group meetings. Some participants viewed this as a discontinuation of a service from which they felt they derived benefit. By way of compromise, the researcher agreed to return after one month to report on the progress of the study. In the meantime, it was suggested that the group continue to meet on a weekly basis. On return, the researcher found that, without a facilitator or set agenda, the service users had been unable to sustain their group activities. To some extent the user group shared the characteristics of volunteer-led organisations with a beneficiary constituency, and like these, it was destined to be short-lived, perhaps as a result of achieving its principal aim and the inability to sustain the commitment of resources (Hermann 1991).

The vignettes and list of services provided the basis for the subsequent surveys on need for services to support individuals with mental health needs. It was anticipated that in providing contexts that approximated real life situations, the vignettes were more likely to produce considered responses. It was also anticipated that by standardising the contexts, the vignettes would allow more meaningful analyses. As a research tool the vignettes fulfilled these expectations. Although no information on diagnosis was provided in the vignettes, the characteristics of the individuals portrayed in the vignettes were recognised by the service providers as being symptomatic of specific mental health problems. Members of the general public also identified with the individuals in the vignettes; some claimed that they knew of real life characters with similar problems. As a result of standardising the context for the responses, it was possible to explore the data in order to identify similarities and differences within and between the study populations.

During the pilot study, an additional, previously unconsidered, strength of the vignette emerged. As part of this pilot, a number of questionnaires were administered for self-completion. When the researcher returned to uplift these, it was not uncommon to find that respondents had completed them after consultation with other members in their household. For some cases, this represented the first time that a family had discussed issues relating to mental health in general and community care in particular. In some cases, the views of the individual respondent would have been influenced by others in the household. This kind of response is more likely to reflect what would happen in a real life situation concerning a community service development. For this reason, the vignette may be a powerful tool in research that seeks to establish the views of a community. It also has potential as a tool in health promotion to encourage families to discuss sensitive issues. For example, vignettes portraying typical characteristics of teenagers could be used to explore issues relating to mental health, drug and alcohol use, and contraception and pregnancy.

Unfortunately, the full potential of vignettes in the self-completed questionnaires was not explored in the study due to the mismanagement of the postal survey. This was a result of the researcher's failure to monitor, until to late, the activities of the market research company that had been commissioned to undertake this work. Perhaps naively, it was assumed that managing a postal survey would have been routine for a market research company. In the event, the company could only be deemed competent in the part of the study that relied on door-to-door interviews.

The main aim of the pilot was to assess its ease of use as an interviewer-administered schedule and as a self-completed questionnaire. With hindsight, it may have been worthwhile extending the pilot to include an assessment of response variability to the different vignettes. Following the first survey, the number of vignettes was reduced from five to four as the responses to two of the original set were found to be sufficiently similar.

The original intention of this survey was not only to elicit respondents' preferences for service provision but also their views on the priority of these. However, during the pilot study it became evident that the research tools could only be used to determine service preferences. To elicit views on the priority of services, the research tools would have to have contained information on the relative efficacy of the various forms of supports. Research on the clinical effectiveness of existing statutory services is still in its infancy (Stevens and Raftery 1997) Unfortunately, there were no data available to inform the research tool on the relative efficacy of the various forms of statutory and non-statutory supports it contained. Despite this limitation, the study still achieved its principal aim to develop and apply research tools that would engage the public and allow their views to be compared and contrasted with those of service providers.

In the foreword to this thesis a number of questions were raised relating to the new role that is being promoted in health policies for consumers and potential consumers of services. These included the question of whether or not consumers of health services have sufficient knowledge to make decisions on the provision of health services and, if so, whether or not they want this responsibility. It was also questioned whether or not health professionals believe that consumers can make such decisions and, if so, whether or not they are happy to relinquish this responsibility. But more pragmatically, the question was raised of whether or not there are any differences between the views of professionals and consumers. The studies on which this thesis is based addressed the latter question by developing methods for assimilating consumers' views so they could be compared and contrasted with those of professionals. Whilst other studies have done this in relation to evaluating service quality (Raphael 1967, MacDonald et al 1988) and need for services (Bowling 1993b, Murray et al 1994), the present studies adopted an original approach by developing methods that empowered consumers so that they, and not service providers or managers, determined the issues to be addressed in the consultations. The results of the present studies showed that whilst there is a degree of overlap between the values of service users and providers in terms of the provision of health services, there are areas of difference. In relation to defining the criteria against which the quality of service in long stay wards for the elderly should be measured, services providers erroneously believed that patients would be satisfied if their basic physiological and safety needs were met. In relation to defining the nature of service provision, service providers were more likely than the public to articulate the need for specialist psychiatric service provision for people with less profound mental health needs.

In this methodological thesis the results of the first series of studies informed the methods used in the second. For example, in the second series of studies the Nominal Group Technique was modified over a number of interviews to allow more time for group discussion in order to gain additional insight into the interviewees' perspectives as they operated within a social network. The potential strength of the vignette as a survey tool for the second series of studies emerged during the dissemination of the results of the first. During a meeting with the matrons of the hospitals, it was evident that the qualitative data based on patients' comments and the researcher's observations during the fieldwork caused greater concern than the quantitative data based on the patients' ratings of satisfaction. Whilst the patient survey was useful in terms of quantifying levels of satisfaction and dissatisfaction, the data may have had more power if they had been complemented with the results of an observation study which illustrated the cultural context in which they occurred. Although the subsequent vignette survey of the need for services for people with mental health problems was useful in terms of highlighting similarities and differences between the views of service providers and the public, the results of this exercise are of limited value until there is more evidence on the efficacy of services. Once there is, it may be possible to develop and incorporate values into research tools similar to the ones used in the present study in order to address the specific question concerning which services and supports should be prioritised when planning provision.

8. CONCLUSIONS AND RECOMMENDATIONS

On the basis of the discussion in the previous chapter, this chapter draws conclusions and makes recommendations on mechanisms by which the NHS could more effectively embrace a consumer-orientated culture. These are discussed in relation to political, organisational and methodological developments.

1. Potential for Political Developments

Current health policy is still largely concerned with creating a service that is more openly accountable to the public but the emphasis has shifted from consumerism to partnership. Thus, the new emphasis is on shared information, shared evaluation, shared decision making, and most recently, shared responsibilities. The principal concern of policy is to equalise relationships between health professionals and the public. To date, little attention has been paid to the possibility of developing partnership arrangements between service providers and users or the public that are not dependent on equality of interest, power or activity. The findings of the research undertaken for this thesis showed that it is possible to develop methods to engage service users, service providers and the public in a dialogue about the provision of health care services.

Similar mechanisms should be employed to determine the views of service users, service providers and the public on the need for and nature of partnership arrangements in the planning and delivery of health care.

There is an urgent need to undertake such research on issues relating to shared information and informed consent. The potential impact of new and proposed legislation is likely to create problems for epidemiological research and service developments.

The UK Health and Social Care Bill and the Scottish National Health Plan, propose a number of initiatives to increase patient involvement in the NHS (Secretary of State for Health 2000, Scottish Executive 2001). In Scotland, the Executive has stated its intention to work with existing networks of independent advocacy organisations. In England, the intention is to establish Patient Forums in each NHS Trust and appoint independent advocates to represent individuals who may wish to complain about health service provision. The operational mechanisms by which these initiatives will be incorporated into the existing culture of the NHS are, as yet, undefined. If successful, such initiatives will undoubtedly create new opportunities for dialogue between representatives of service users and politicians who presumably will exert influence on service providers. This approach to encouraging partnership appears to be concerned with redressing the balance of power between service providers and users albeit through politicians. It fails to explore the potential for involving a wider contribution from local communities to influence health policy.

Initiatives should be introduced in the NHS to nurture the role of local communities in determining the pattern of service provision.

2. Potential for Organisational Developments

Service providers and relatives were only able to identify one-third of the criteria that patients considered essential for a good service.

The views of service users should be routinely canvassed to define the standards against which the quality of service are measured.

Patients' need relating to self esteem and self-actualisation were not only unrecognised by nurses but were not realised for a significant minority of patients in long stay wards for the elderly. Although nurses appreciated the value that patients placed on interpersonal attributes of their carers, more than half of the patients expressed dissatisfaction relating to the manner in which nurses interacted with them.

The emphasis of the recruitment and education of nurses should be on inter personal skills.

Patients reported distressing levels of boredom. For a significant minority this would have been alleviated by increased opportunities to socialise with other patients. For many, however, it is likely that someone would be required to facilitate communication between those with speech and hearing difficulties. Patients also welcomed opportunities to attend other social activities, particularly church services and concert parties.

It should be a priority for service providers to create a programme of diversional activities for patients in long stay wards.

The provision of care appeared to be driven by tasks. On occasions, these seemed to be more in the interest of individual service providers or the general organisation.

Further research is required to determine the extent to which such practices pervade the NHS.

The nature of organisational cultures within the NHS merits investigation in order to identify barriers and facilitators to the creation of a consumer culture.

Despite targeted dissemination, the findings of the research made no impact on the quality of care for patients in long stay wards for the elderly. The health board that commissioned the research had limited scope in introducing changes to improve the quality of services in the provider hospitals.

Mechanism should be developed by those responsible for commissioning service evaluations to ensure that these address genuine concerns of service users and/or service providers.

To encourage ownership of results and the ultimate implementation of the recommendation for change, the views of service providers should be sought during the commissioning of any service evaluation.

Provider organisations should identify a champion within each care setting who is responsible for working with colleagues to identify mechanisms to effect service improvement.

The efficacy of continuing to canvass the views of service users and the public in the absence of mechanisms to effect change should be considered.

Only a minority of respondents was without reservations about living next to supported accommodation for people with mental health needs. Both the public and service providers expressed concerns relating to the potential for anti-social behaviour of the residents and the inadequacy of community support by statutory services.

The health service managers should address concerns within their own and other care organisations before attempting to persuade the public to accept new service developments such as community care settings.

Although there was a great deal of concordance between their views, service providers and the public had different perceptions of the relative contribution of statutory services and lay supports to people with mental health needs. This was most evident in relation to individuals with the less profound needs. In general, health service providers advocated a greater input from psychiatric services whereas the public favoured a greater contribution from social and lay supports.

Further research is required to determine the relative efficacy of community and lay supports and to assess the impact of using these as an adjunct or as an alternative to existing statutory services. The investigation should aim not only to determine the relative effectiveness of various personal and community supports but also to determine whether or not increased investment in them would alleviate demand on mental health services to enable a more targeted approach to provision.

Practitioners with more than 10 years experience were consistently less optimistic than their less experienced colleagues about the efficacy of various forms of statutory and non-statutory services.

This finding merits further investigation with a view to determining the impact, if any, on referral patterns and health care outcomes.

3. Potential for Methodological Developments

The Nominal Group Technique proved a useful tool for eliciting the views of young patients, service providers and patients' relatives on the essential criteria for a good service. It was quick, it provided immediate feedback to the participants; and it was enjoyable for the participants. However, the Nominal Group Technique without modification was not appropriate for interviews with elderly patients. The modified version, utilising a less structured approach, whilst losing the advantages of economy of time and providing immediate feedback, highlighted the limitations of the Nominal Group Technique in terms of providing opportunities to gain insight to the individual's perspectives as they operate within a social network. For this reason, the subsequent focus group interviews which informed the survey tool for the need for services studies, whilst still task-driven, were structured to allow greater opportunity for group discussions. As the qualitative data generated by these discussions required to be analysed before they inform the subsequent activities of the group exercise, the task of the group had to be spread over several meetings.

Against the backgroud of the increasing use of fiocus group research methods and the promotion of the Nominal Group Technique, further work should be undertaken with the aim of developing a consultation tool which capitalises on the strength of the Nominal Group Technique but which introduces the potential for less structured group discussion.

The questionnaire used in the patient survey of satisfaction with the quality of care was limited to addressing the top thirteen criteria by which patients had defined a good service. The decision to focus the enquiry was based on the assumption that a more comprehensive approach would have placed excessive demand on the elderly patients' ability to concentrate and produced a volume of results and recommendations outwith the organisation's capacity to respond. In the event, the elderly patients were happy to devote a lot of time to helping the researcher and there was no evidence that the organisations had responded to any of the study findings or recommendations. The hospital managers did, however, express concerns when presented with the qualitative data based on patients' comments and the researcher's observations during the fieldwork.

When the aim is to improve quality, service evaluations should adopt a narrow focus. Quantitative data should be complemented with qualitative data describing the organisational culture in which the results occured. These are not only meaningful to service managers but also which provide additional insight to barriers and facilitators to effecting change.

As an interviewer administered schedule the questionnaire based on vignettes fulfilled expectations in terms of producing considered responses thus allowing meaningful analyses to identify similarities and differences within and between the study populations. The pilot study suggested that it also had potential as a self-administered questionnaire, particularly for research that seeks to establish the views of a community.

Further research should be undertaken to determine the full potential of vignettes as a self-completed questionnaire.

The study the needs of services for individuals with mental health problems achieved its principal aim to develop and apply research tools that would engage the public and allow their views to be compared and contrasted with those of service providers. However, it was only able to elicit views on the need rather than the priority of various forms of statutory and non-statutory because there were insufficient data available to inform the research tool on their relative efficacy.

Once data are available on the efficacy of various statutory and non-statutory services, values should be incorporated into research tools similar to the ones used in the present study in order to address the specific question concerning which services and supports should be prioritised when planning provision.

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