Deprivation and health : Social inequality and equity of access to health care services.

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Deprivation and Health: Social Inequality and Equity of Access to Healthcare Services

Anita Sims

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Abstract

The major aims of this research were to investigate and analyse the connections between social deprivation, health inequality and equity of access to health care. Local and national case studies were used to illustrate inequity of access and to explore and assess policies and procedures that attempted to address such inequities at a local level. The available data sources, their limitations and scope were reviewed and described. In depth examinations and critical reviews were made of concepts and tools to measure deprivation and equity. A case study using the (then) new 1991 Census variable, limiting long term illness in a policy context together is described together with validation via a local survey in Shirebrook in North Derbyshire. The use of techniques for operationalising equity as extended to GP allocations is examined in some action research undertaken in North Derbyshire. Social class variations and their influence on place of death amongst cancer patients are examined, quantifying and describing apparent inequity in patterns of access to place of final care for cancer patients in both a local and national context. This work described, analysed and interpreted the connection between social class and access to hospice, home, and hospital deaths.

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Papers and presentations undertaken relating to the research

URPERRL, Spatial Targeting, University of Liverpool, October 1994, presented paper 'Limiting long term illness in the coalfield area of North Derbyshire'

The Faculty of Public Health Medicine conference, December 1995, St. Catherine's college Oxford, poster presentation, 'Deprivation and health in North Derbyshire'.

Association of Public Health annual conference, University of Leeds, April 1996, workshop presentation, 'Resource allocation to general practice, a new approach.'

The Society of Social Medicine annual scientific meeting, Dundee University, September 1996, joint presentation of paper, 'Fair shares or rough justice'.

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Poster presentation "Equity of access to home care and hospice facilities for terminal cancer patients in Doncaster" Association for Public health conference in Brighton, March 1999.

Paper presented at Nordic Public Health conference at University of Bergen, August 2001. "Inequalities in access to home and hospice as a place of death between social class in England and Wales, 1994-7"

Chapter One: Introduction

This thesis describes action research undertaken in a public health environment which was supported by in depth study and review of relevant research and literature. The work examines and tests the assertion that there is a lack of equity in access to health care by using a series of 'real life' case studies'. These case studies describe how the abstract concepts of equity can be assessed locally and illustrates the barriers and processes of promoting understanding and the difficulties of implementing change as a result.

The concepts and definitions discussed in chapter 2 provide a background to the description and analysis of the types of data that may be used to assess health and deprivation and inequity which follows in the next chapter. This is further developed in the fourth chapter which applies the use of a measure of poor health and deprivation to analysing data at GP practice level. This work leads to the political process of operationalising equity, in the fifth chapter, whereby local resource allocation to primary care is reviewed in the context of resulting equity of access to health care. The concept of equity of access is explored in the context of final care for cancer patients in the final chapter.

Because the work was undertaken in a real life, Public Health work environment the research is essentially reflexive, monitoring of action and keeping in touch with the grounds and reasons for actions, but not acting purely on past precedents, i.e. how things have been done, for example in resource allocation, continuing with current patterns because that is how it has always been done, but by taking a principled viewpoint and promoting change in the light of new and increasing knowledge and understanding.

This research examines equity of access to health care, an issue which is fundamentally a matter of social justice. Although the last 20 years have brought a marked increase in prosperity and substantial reductions in mortality to the people of the UK as a whole, the in gap inequality of health and access to health care between those at the top and bottom of the social scale may have widened. In this work, many different aspects of this area have been examined including Sir Douglas Black's ground breaking report "Inequalities in Health"[1]. The work has also examined and been inspired by the work of the World Health Organisation, in its European "Health for All" Policy[2] which gives precedence above all other objectives to the promotion of equity in health within and between countries. The research was undertaken (between 1994 and 2000) during a period of change in perceptions by Government of the nature of inequity and inequality and desirable actions and policies to mediate the effects and impact of variations.

Undertaking sponsored research whilst working in service Public Health provided the rare opportunity to extend the exploration of equity related issues which would not otherwise have been examined. This produced stimulating personal study opportunities but also provided important research results that were used to influence policy and practice locally that would not have become available without the research described in this thesis.

This thesis examines the definitions of equity, inequality and health. The second chapter highlights and discusses the impact and importance of various publications and methodological developments in the measurement of health and equity of access to health care and health inequality. A distinct stage in the thesis was to describe and review various methods and tools available as proxies for estimating and understanding the interactions of factors influencing equity of access to health care. It was important to assess potential tools for measurement in the context of their origin and the intended use for which they had been developed, to decide whether, the tools were appropriate for local circumstances in which they were being applied.

The research aimed to examine issues relating to health care, therefore it was important to ensure that this was what was being examined using adequate data and chosen tools. This was a crucial issue; data measured illness, use of health care provided, levels of ownership of, and access to material resources. There was not and still is not, an entirely objective gauge for assessing whether people are able to access health care in a 'fair' way relative to their health need and not influenced by their ability to demand, or not demand and obtain health care. There was also a challenge to engage and convince stakeholders and policy makers that the direction and measures adopted were both valid and appropriate locally. The initiation of the work required a description and review of data and methods available and its limitations. This enabled an understanding of what it would be possible to use the data for and also a development of ideas to adapt available data to the purpose of measuring and understanding equity of access. Reviewing the complexity of the data sources and their appropriate uses, reinforced the need for clear explanation and engagement to policy makers and stakeholders, that the research was attempting to influence and encourage to implement and support changes in practice and funding to support changes in practice and funding to facilitate increased equity of access to health care. As there are no specific measurement scales or types of data that allow clear cut measurement, the use of data to measure inequity and inequality has become a process of using sets of interwoven information to look at the "Big Picture" using many different types of proxies.

The third chapter provides insights into data that is used later in the research about workforce, health care processes, the performance of the health care system, levels and types of clinical activity and the outcomes of health care. Ultimately the influences that have determined data collections relating to health and health care have focused on finance and performance management processes and have therefore restricted the scope of the datasets.

The chapter focusing on data underlines not only the importance of understanding the origins and properties of data but also makes clear the fact that there are substantial gaps in data and discusses the weaknesses of the types of data that are currently available. The review of available data shows that information about "health" tends to focus on the output from registration procedures such as births and deaths and the process of health care provided by the NHS, however the uptake of health care indicated by these data may not encompass or reflect actual need for health care but rather may be influenced by the resources available to supply health care services and the ways in which people are accustomed to accessing health care services. Perpetual changes in the structure and geographical organisation of the NHS have restricted the continuity of data flow and usefulness of comparison of data over time.

Chapter four of the thesis details research undertaken in North Derbyshire that made use of the 1991 Census limiting long term illness variable and undertook local validation of these data. The 1991 Census produced the limiting long term illness variable data, which provided a well validated self- assessed measure of individual level morbidity. This made available an indicator providing information about the health of the whole population, not just information about those seeking and obtaining health care. This provided another facet of knowledge with which to attempt to assess need and measure levels of access and resulting equity patterns. The research reported shows local use of the data at a GP practice level and also a practice level validation of the data undertaken using a survey of the practice population. The 1991 census variable, limiting long term illness, provided information which was initially used as a component of a general health profile produced in conjunction with a general practice in Shirebrook in North Derbyshire, comparing the area with local North Derbyshire levels of self reported limiting long term illness and also those of England. The work was undertaken to assist the practice in increasing their understanding of different aspects of health needs and demand on health care locally. The information promoted awareness locally for a group of dispirited GPs about how they might quantify not only differences in the health needs of their patients, but also the impact of this on demand. The practice knew that they were received similar or less funding than practices with an obviously healthier population. The limiting long term illness measure was seen as a particularly enlightening variable that was not simply self assessed limiting long term illness, but need and demand for primary care, if a higher than local and national average number people assessed themselves as having an limiting long term illness then it was logical to the GPs that these people would be likely to demand higher than average access to the 'gatekeepers' of health care in England, general practitioners. This realisation and the existence of data that the GPs felt was credible provided a catalyst for GPs to begin to question locally the equity of resource allocation procedures to primary care. The engagement of GPs with limiting long term illness was a starting point for local political activity providing an impetus which extended to other practices to agree principles of equity and influence future resource use. The work brought together research and local need and demand limiting long term illness provided a practical, relevant and population based measurement tool to quantify concepts otherwise difficult to measure. The work was a starting point for increasing political awareness and motivation to engage. Limiting long term illness was a pragmatic tool for helping to assess and promote equity in provision of primary care.

The energy and interest generated by the Shirebrook led to the health authority facilitating the 'Equity Group'. The group was formed from the local GP opinion leaders and activists to explore the possibilities for operationalising equity via health care resource allocation to primary care. The research had a key contribution to this process, supporting the group in exploring and demonstrating what and how equity could be measured; testing different tools and processes for relevance, plausibility, usefulness and transparency. This process promoted stakeholder engagement and participation and there was a fascinating evolution of ideas emanating from the adoption of equity as a desirable fundamental principle in allocation of resources to health care. There was a clear conflict between the GPs supporting the principles of equity agreed and the impact this would have on practice and personal income. The equity group process was a meeting of academic and research based findings and notions and the real world. The process allowed an integration, rather than imposition of the research findings of seeming inequity of access to health care. The involved a process of utilising and exploring concepts and measurement processes available, using routine data described earlier in the research. It describes how this information was used to build the "Big Picture" in North Derbyshire and influence the political processes for resource allocation to primary care. The primary aim of the equity work was to ensure that any existing inequities in the resourcing of primary care were not perpetuated in future resource allocation. The research encompassed gaining acceptance of moral and philosophical concepts of equity that led to the use of a (then) new national tool for resource allocation, the York index, to assist in understanding and making changes to the situation at a local level. The approach combined qualitative and quantitative solutions to a very subjective issue and developed local use and confidence in routine data. The data available was neither complete or ideal but there was a strong will to make a change, having agreed that the inequity identified could not just be left to continue.

Changes in political momentum relating to equity are harder to achieve in community and secondary care as those changes will require engagement of a greater number of systems; GPs referring, hospital providing care and community services supporting discharges. However in the Doncaster Health Authority area (Where I was employed), following concerns by the director of the palliative care service about differences in levels of access to care for the dying by all sections of the community, an audit was undertaken. Over 25% of all deaths are as a result of cancer and this work clearly has relevance to the experiences of a large number of people dying of cancer locally and nationally each year. The audit examined patterns of population access to services and, provides evidence to show that cancer patients are not getting what surveys suggest they would prefer and describes inequity in access to this type of provision for different population groups. The audit examined who accessed care provided by secondary, community and voluntary care services. The study suggested a clear difference in where different social groups (defined by former occupation) were cared for during their final illness. It appeared that the lowest social classes gained the least access to specific palliative care services such as hospices and community based palliative care. This work showed how relatively inexpensive solutions could be found by moderate redesign of the service to provide appropriate and acceptable care for local people, which enabled increased levels of equitable access to health care.

The study had initiated local action based on analysis of a relatively small dataset, but there was considerable interest both at a local and national level in investigating whether the differences observed were similar in other areas. The use of a larger dataset allowed the specific investigation of the impact of factors such as gender, age, type of cancer on the place of death.

The combination of these various elements of the research allowed the investigation of a complex set of aspects of equity of access to health care. The challenge was to apply research questions and principles to real life situations to make changes.

The thesis describes research that includes the examination of the theoretical background and tools available for the task of understanding and examining patterns of equity in the utilisation of health care resources. The work relates how concepts and measures have been examined and applied locally to support the investigation of patterns in health care utilisation and how the work has supported and influenced local action research to influence local health policy and planning.

Chapter Two: Equity in Health

2.1 Introduction:

This chapter reviews the definitions of equity, inequality and health and discusses some of the important interpretations and publications relating to equity and inequality relating to health. The development of methods for assessing and measuring inequality and deprivation is reviewed and the ways that the various tools have been applied are examined. It was to be crucial later on in the research to use indicators and measures that the strategists and practitioners would find credible and which were also transparent enough for general use. . An initial problem is related to clarity concerning the definition and significance of key terms in the debate about equity and health inequality and continues through to ideological differences about the nature of a good society. Various understandings and interpretations exist of the underlying causal mechanisms. Different assessments and interpretation may be found to describe which inequalities are the most inequitable.

The World Health Organisation defines equity in health as follows[2]: "Equity in health implies that everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that none should be disadvantaged from achieving this potential if it can be avoided"

The concept of equity in the NHS was articulated by Aneurin Bevan[3], the Minister of Health responsible for introducing the NHS, and later by the Royal Commission in 1979[4]. The concept of health was envisaged as multifaceted, incorporating the following principles:

A service for everyone - Everyone was to be included in the scheme as of right, without having to undergo a means test or any other test of eligibility.

Sharing financial costs and free at the point of use - In the words of Bevan: "It has been the firm conclusion of all parties that money ought not to be permitted to stand in the way of obtaining an efficient health service. The method of funding chosen, through general taxation, was linked to the ability to pay.

Comprehensive in range - There was a clear commitment to extend coverage - to preventive, treatment, and rehabilitation services, covering mental as well as physical health, and chronic as well as acute care.

Geographical equality - With the intention of creating "a national service, responsive to local needs,"[5] came a commitment to improve the geographical spread of services.

The same high standard of care for everyone - The Royal Commission emphasised that this principle must be based on levelling up, not levelling down: "The aim must be to raise standards in areas where there are deficiencies but not at the expense of places where services are already good."[5]

Selection on the basis of need for health care, not financial position in situations *of scarcity.* People had the right to expect that no one would be able to gain access to a service ahead of others, by money or social influence.

The encouragement of a non-exploitative ethos, to be achieved by maintaining high ethical standards and by minimising incentives for making profits from patients.

As the Royal Commission noted: "We are well aware that some of these objectives lack precision and some are controversial. We are aware too that some are unattainable, but that does not make them any less important as objectives."[5]

Most of the debate about equity and inequality in the UK has centred on geographical inequalities and social class inequalities. These often overlap (Occupational social class was first introduced in 1911 by the Registrar General and is still used as a general but basic measure to discriminate between life chances for different sections of the population) but in some contexts other inequalities are also significant e.g. differences by age, sex and ethnicity. There is also a broader issue to consider, namely how important for the welfare of the population is the reduction of inequalities in health compared with raising the average level of health. There may be cases where these two objectives conflict, for example in the access to treatment for older people versus the access to treatment of a younger potentially economically active group and then the issue of “which matters most” will arise in this broader context. Some inequalities are likely to be regarded as being worth larger sacrifices in population health than others.

The concept of equity is somewhat elusive and research evidence on the nature and size of inequities is patchy and difficult to interpret. It is not straightforward to decide whether inequities in access pose significant policy problem and how this might be tackled. Goddard and Smith[6] suggest a framework for assessing this but the problem remains that it is difficult to establish the causes of inequities which in turn limits the scope for recommending appropriate policy to reduce inequities. The framework suggests assessment of a provision of health care in the following areas:

- Need
- Access
- Utilisation
- Demand

Goddard and Smith used an example of assessing inequities of access in the UK for primary care, acute hospital care, mental health services, preventative medicine and health promotion and long term care, looking for differences in levels of equity between different social class groups. One of the main barriers to the framework will undoubtedly be the lack of an agreed definition for particularly need and access. The work showed that there were important inadequacies in the evidence which was available to illustrate and measure the levels of equity. While this type of work is important for reflecting upon equity locally, the inadequacies of a rigid framework limits the scope for its use in policy review and change.

Greater equity in access to health care in the UK is a desirable outcome of the NHS. An initial problem is related to clarity concerning the definition and significance of key terms in the debate about equity and health inequality and continues through to ideological differences about the nature of a good society. Various understandings and interpretations exist of the underlying causal mechanisms. Different assessments and interpretation may be found to describe which inequalities are the most inequitable.

In 1972 a GP, Dr Julian Tudor Hart observed that the quality of health services tends to vary inversely with the health needs of the population. He called this the "the inverse care law"[7]. Tudor-Hart described how the range and quality of services available were more extensive in his former practice in an affluent part of London, which had a relatively healthy population, than the opportunities he observed in his later practice in a mining village in South Wales. In South Wales there were far higher levels of ill health and therefore there was greater need and demand for health services.

Thunhurst and others[8] have called the process of identifying disease patterns and relating this to environmental, social and economic policies social epidemiology. This distinguishes the process from the conventional definition of epidemiology, which studies the effect of medical intervention and curative procedures. Social epidemiology looks for evidence of correlation between social, economic and environmental characteristics and health problems. There are not definitive ways of measuring the distribution of social, economic and environmental circumstances. Most of the measurement methods for these types of concepts examine experience of ill health and not health.

The Black report and subsequent policy and action

The "Black report"[1] was produced by the working group on inequalities in health, this group was convened by David Ennals, the Labour Secretary of State For Social Services 1976-9,and this authorised by government, attempted to explain, trends in inequalities in health and relate these to the policies intended to promote health. The group met at frequent intervals over a three-year period and had the support of a large Department of State, and assembled a mass of statistical data "which compelled attention"[9] The Black report become a symbol of political suppression. The report was intended for the Labour government rather than for a Conservative one committed to reducing public expenditure. But members of the committee could not agree on their recommendations. Medical and scientific civil servants urged the committee on, aware of the impending political change. The committee, however, was more concerned to get its analysis right. Black in particular was a case study of the issues around scientific advice to government, not least the way in which events were played out in and through the media.

Questions that were important and open to research were identified. Attention was drawn to imperfections in the available indices of health and social status. The differences in mortality associated with social class and material deprivation were seen to be considerable and were shown to be at their greatest in the early stages of life. Major differences in death rates and life expectancy between social classes apply to children and babies. Infant mortality rates are lower among babies born to those of higher social classes. In 1994-96, nearly five out of every thousand babies born to parents in class I and II (the professional and managerial group) died in their first year. For those babies born to families in classes IV and V (the semi skilled and unskilled workers), the infant mortality rate was over seven per thousand babies. Infant mortality rates in each class, however, have been decreasing over the last twenty years[10].

The Black Report played a part in influencing the decision of the member states including the UK, of the European Region of the World Health Organisation to agree a common health strategy in 1985. In 1981 the World Health Assembly adopted the 'Global Strategy for Health for All by the Year 2000' consolidating the European strategy. Its aims are not the eradication of all disease and disabilities, but to ensure that resources for health are evenly distributed and that essential health care is available to all. (This strategy was renewed in May 1998, with the adoption of the World Health Declaration by the 51st World Health Assembly.) Equity in health was a theme running through the strategy and reduction of inequities was the subject of the first of 38 targets to be achieved by the year 2000.

The central finding of the working group on Inequalities in Health was that there were large differences in mortality and morbidity, to the disadvantage of lower social classes, which were not being adequately addressed by health or social services. The report also identified four possible explanations for observed health inequalities, which have formed the basis for further research. The different arguments have been summarised by MacIntyre[11] and Davey Smith et al[12 13] as follows:

Artefact explanations which suggest that the observed differences in levels of deprivation may be produced as an artefact of the process of measurement, such as errors of misclassification. This is shown on a small scale by examination of the coronary heart disease deaths in the civil service and army data.[14]

Social selection explanations These suggest that health may somehow determine socio-economic position, with the unhealthy being downwardly socially mobile, leading to a group of people with greater morbidity and/or a higher risk of dying among lower socio-economic groups. There is little evidence to support this as the major explanation for the observed differences.

Behavioural and cultural explanations which suggest that health related behaviours, like cigarette smoking, poor diet and lack of exercise, lead to the observed inequalities. The cultural and behavioural explanation focuses on the way individuals in different social groups live their lives. That is the behaviour and voluntary lifestyles they adopt.

Material and social life circumstances; The Black report described these as "materialist" explanations. These explanations suggest that there are hazards inherent in society to which the more disadvantaged have no option but be exposed. For instance, hazards relating to poor housing, certain occupations, pollution, unemployment and psychosocial stress have all been associated with poorer health.

The first three explanations, at best account for only some of the observed health inequalities in relation to social class. The most widely accepted explanation is "material and social life circumstances", although there may be some interdependence with other explanations. Health related behaviour in particular is not independent of, and is likely to be closely related to, life circumstances. The processes by which life circumstances determine risk and the mechanisms by which exposures produce disease however are not yet well understood.[12]

In 1987, an update of the evidence in the Black Report was published under the title of the Health Divide[15]. This stimulated widespread debate and led to renewed calls for greater priority to be given to the issue of inequalities in health and how these should be addressed. It was not until the 1990s, however, that significant political movement on the issue was beginning to happen, there was however little change in strategy or development of initiatives that would lead to significant changes in the levels of health inequalities. The Chief Medical Officer for England set up a sub-group under the auspices of "The Health of the Nation" a national health strategy, to look into what the Department of Health and the NHS could do to reduce variations in health. The report of the sub-group was published in 1995[16]. In the same year, the King's Fund published an independent analysis of the wider policy options for tackling inequalities in health in relation to housing, family poverty, and smoking as well as to the NHS[17]. The 1995 report, Variations in Health, recognised that the onset of ill health could lead to impoverishment, and also those shifts of individuals between classes could be statistically confounding. The position was adopted that, in the main, it was social deprivation that was the independent variable, damaging health in a variety of ways, acting differently at various stages of life.[18]. These initiatives, together with a growing body of evidence from a great many in the public health field, were influential in convincing the new Labour Government elected in May 1997 of the need to set up the Independent Inquiry under Sir Donald Acheson.

In July 1997 shortly after taking office under the new labour administration, Frank Dobson, the secretary of state for health invited Sir Donald Acheson (the former chief medical officer) to conduct an inquiry into health inequalities in Britain. The report was published in November 1998 and signalled a clear indication of the new labour government's commitment to understand and tackle inequalities in health. The report was the result of a review by an expert committee appointed by the Department of Health of the latest information on inequalities in health and an identification of the trends. The review was intended to identify priority areas for policy development, which were indicated by scientific and expert evidence to be able to offer cost-effective and affordable interventions.

A socio-economic model of health and its inequalities was adopted in the report[19]. This is illustrated in Figure 1

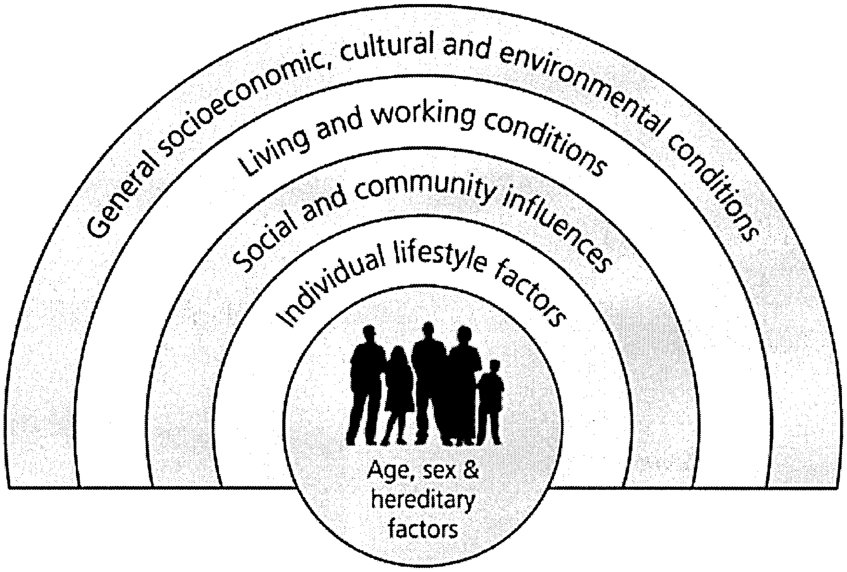


Figure 1 the main determinants of health (Dahlgren and Whitehead)[19]

The main determinants of health were viewed as layers of influence. At the centre are individuals endowed with age, sex and constitutional factors which undoubtedly influence their health potential, but which are fixed. Surrounding the individuals are layers of influence that, in theory, could be modified. The innermost layer represents the personal behaviour and way of life adopted by individuals. It contains factors such as smoking habits and physical activity, which have the potential to promote or damage health. Individuals do not exist in a vacuum and interact with friends, relatives and their immediate community, and come under the social and community influences represented in the next layer. Mutual support within a community can sustain the health of its members in otherwise unfavourable conditions. The wider influences on a person's ability to maintain health (shown in the third layer) include their living and working conditions, food supplies and access to essential goods and services. Overall there are the economic, cultural and environmental conditions prevalent in society as a whole, represented in the outermost layer.

The model emphasises interactions between these different layers. Socio-economic inequalities in health reflect differential exposure - from before birth and across the life span - to risks associated with socio-economic position. These differential exposures are also important in explaining health inequalities, which exist by ethnicity and gender.

The model illustrates various intervention points. Medical care, for example, might intervene at the level of morbidity to prevent progression to death, or earlier, at the level of patho-physiological changes to interrupt transition to morbidity. Preventive approaches might act at the level of attempting to change individual risk, by encouraging people to give up smoking or change diet. Interventions in the workplace or the social environment might encourage a climate which promotes healthy behaviour or improved psychological conditions. Interventions at the level of social structure would reduce social and economic inequalities. To be effective such interventions, of course, need to be facilitated for and accessed by those in need.

The Inquiry took a broad view of the causes and impact of health inequalities and the impact of the health inequalities on individuals and society. The papers explored the life course of the economic, social and physical environments and of the behaviours that affect individual health. The panel noted the lack of evidence to support many policy changes and recommended that the Inquiry should be explicit about the quality of evidence and argument used to support proposed areas for policy development. The group received a number of other presentations and briefings from experts in the field, apart from those provided by departmental officials.

There were other recommendations in areas over which the NHS has no direct control such as poverty, income, tax and benefits, education, employment, housing, environment, mobility, transport and pollution, nutrition, common agricultural policy, mothers, children and families, young people, adults of working age, older people, ethnicity and gender.

The report suggested that improved access to health care interventions for disadvantaged groups may not be the most important way of reducing health inequalities but does have a significant contribution to make. Poor health outcomes were thought to be often associated with problems of gaining timely and good quality access to health care. These initiatives marked an important stage in the setting up of systems to provide state funded care and the evolution of national policy and definitions of inequality and equity relating to health care.

2.2 The meaning of the term health

There are many different ways of representing how "healthy" a person is and these tend to focus attention on a particular attribute of a person's situation.

A former Chief Medical officer, Kenneth Calman, defined health, euphemistically to be "having a life with meaning"[20]. Calman emphasised the mechanism of health maintenance and health improvement as being a societal and individual responsibility. This adds an active element to the somewhat passive definition of the World Health Organisation of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".

The concept of health, which is adopted when assessing equity and inequality, should relate to the policy issues under examination. In general terms a hierarchy may be examined which reviews how much of the whole lifetime experience of health the measurement covers. For example, age at death covers the summary of lifetime health; childhood illness only examines the beginning of a lifetime experience but may be seen as a good predictor of lifetime health experience.

Health concepts that are frequently examined in the investigation of inequalities are biomedical in nature. Such concepts refer to diseases and their prevalence, incidence and risk, length of life reflected in life expectancy and quality of life such as pain and limiting long term illness. These may be measured for a population at a point in time by looking at trends over time by following a panel of individuals over time or by estimating the whole life cycle experience of individuals.

2.3 The meaning of “equity” in health care

Equity is about fairness and justice, and implies that everyone should have an opportunity to attain their full potential for health. Equality or inequality is about comparisons between the levels of health or ability to obtain access to health care of individuals or communities. Some inequalities may be unavoidable and while others might be avoided or at least reduced or minimised and so may be considered inequitable. Natural, biological and genetic variations may have unavoidable health inequalities related to them. But the extent of such inequalities may be reduced given access to health care on the basis of need, i.e. a more equitable access.

Lifestyle and behaviour patterns chosen by individuals can also result in inequalities in health; an obvious example is that of cigarette smoking. However, lifestyle and behaviour that is not freely chosen but began because of social pressures which results in poorer health might be considered avoidable and thus inequitable. Health inequalities that arise as a result of or which are exacerbated by, lack of resources, poor housing conditions, limited education, hazardous working conditions or exposure to environmental hazards would also be examples of such health inequities. There are, in addition, inequalities that arise as a result of the range of health care facilities and quality of care and outcomes of treatment available across Britain.

Defining equity and equality is relatively straightforward compared with measuring their extent. Questions that need to be explored relate not only to equity but also to priority setting and rationing. Decision-making is made even more difficult because of uncertainty of outcome as most problems are complex and there is no "right" answer and choices need to be made within fixed resources. The knowledge base is only a part of the decision making process and logical argument also has to compete with the public and media view. These components lead to scope for considerable differences of opinion.

Issues of fairness, justice and equity have been discussed for many centuries[21],[22] and there are no commonly agreed views as to the basis of decision-making. There is now general agreement that each person should have equal right to opportunities especially through education. Most of the health issues related to equity come under the category of "distributive justice", i.e. how benefits, resources and burdens of society are distributed to each individual. The rules that a society chooses to adopt relating to distributive justice may mean equal shares relating to each person, shares relating to individual needs, shares relating to individual efforts, shares relating societal contribution or shares relating to merit. Very different choices are made depending on the option selected. It is clear that such principles are incompatible. For example those with the greatest health care needs may be those least able to contribute to society in an economic sense. These principles are, however, closely related to basic ethical principles that can also be mutually incompatible. These ethical principles for distributive justice may be autonomy and the rights of the individual, beneficence or doing good, malevolence or not doing harm, utility, "the greatest good to the greatest number", or equity- justice and fairness. The concept of equity in relation to the NHS in Britain demands priority for ethical values, monitoring of policies for their effects on equity, some national planning, and a continuing debate about the entitlement to services such as continuing care which is examined and discussed in details in this thesis.

2.4 Equity and access to health care

Primary care

Access to effective primary care is influenced by several supply factors including the geographical distribution and availability of primary care staff and the range and quality of primary care facilities. Levels of training, education, recruitment and retention of primary care staff, cultural sensitivity, timing and organisation of services to the communities served, and also distance, and the availability of affordable and safe means of transport influence the supply of primary care in the UK. Demand factors such as lay health beliefs and knowing what services are available locally, and the wider socio-economic influences such as financial insecurity, social mobility and lack of informal carer support will also affect patterns of utilisation and access to health care. Communities most at risk of ill health tend to experience the least satisfactory access to the full range of preventive services, an “inverse prevention law”. Prevention services include cancer screening programmes, health promotion and immunisation. Sub-regional and small area analyses illustrate this inequity for areas such as Liverpool[23] and Birmingham where, using nine indicators of primary care services, the most deprived areas tended to be the least well served[24]. Within London, health promotion claims by GPs were shown to be highest in the least deprived and lowest in the most deprived areas[25].

Access to primary care is important for two fundamental reasons. First, the GP is the initial point of contact with the health care system for most people. Second, inequities in access to secondary care may originate in, and therefore need to be addressed in, the primary care sector. Studies in the early 1990s show that there was a bias in favour of the "poor" in access to local primary health care in the UK[26][27] [28]. However Blaxter[29] in the mid 1980s and more recent studies such as Goddard and Smith[30] suggest otherwise. Goddard and Smith reviewed many local studies and showed that higher rates of consultation were associated with greater deprivation (after adjusting for need) but quality and length of time of consultation was lower for lower income groups. Some ethnic groups had low consultation rates relative to need. The study showed that there was an inequitable distribution of GPs and the position had been worsening for those in the most deprived parts of the country while improving in the least deprived.

Deprived areas suffered increasing difficulty in recruiting GPs because of poor quality primary care premises, large number of single handed GPs and practices without teaching status and the less enticing locations that these practices were likely to be in.

Secondary care

Evidence on variations in access to secondary care is often difficult to interpret, since many studies do not adjust for case mix or distinguish between emergency and elective care. Monitoring equity of access to secondary care from routine data sources is also fraught with difficulties since the collection of data on ethnicity, socio-economic status and utilisation of the private sector is not well developed at secondary care level. UK evidence[30 31], however, shows a strong positive relationship between levels of deprivation in an area and hospital admission rates.

There is a positive relationship between levels of deprivation in an area and hospital admission rates, although there are great variations in hospital admission rates between GP practices[32,33]. Deprivation is not the only factor influencing hospital admission and higher admission rates could also reflect poorer access to primary and community care services for some diseases, e.g. diabetes and asthma[34]. Inequity in access to investigation and specialist cardiac services treatment has been observed in relation to socio-economic factors, ethnic group, gender, age and geography. Payne and Saul[35] explored the relationship between rates of coronary artery revascularisation and prevalence of angina to assess whether apparent use of health services reflected need. They concluded that the use of interventional cardiology services in Sheffield was not commensurate with need even though the supply of care was the same across a city area. Hence this appeared to exhibit the inverse care law[7].

The private sector

A number of studies suggest that the distribution of, and access to, private health care compounds existing inequalities[36,37]. Information on levels of activity and quality of private sector services however is not routinely available to the NHS. This means that no complete picture exists for both public and private sectors concerning access, resources and the outcomes of treatment in relation to need. In order to enable monitoring of access to treatment and also in the pursuit of clinical governance it was suggested by the Acheson report[38] that those providing private health care should be required to give the same routine information on activity and quality of services as NHS caregivers are obliged to supply. This is already statutorily required in the case of assisted conceptions, abortions and nursing home care and such arrangements could be extended as part of the performance assessment framework. An independent review of private practice would enable full consideration of the relationship of private practice to the NHS, and its impact on equity issues, particularly in relation to access to services.

2.5 Measuring inequalities and inequities

Unlike the traditional notions of poverty which tend to use measures of material wealth, deprivation and equity cannot be studied adequately through a unitary focus on income. The implementation of change or initiatives to alleviate some of the effects of deprivation and inequity are often complicated by the problems of communicating the concepts and gaining local, political agreement about how problems may be tackled. A broad range of factors is required to identify and measure the various dimensions of equity and deprivation. If healthcare resources are to be limited then it is necessary to be able to identify the distinct areas of need and of demand and make some assessment of differences in access to resources. Measurement of inequality is a measurement of a factual concept, the measurement of equity is the measurement of an ethical concept, which is inherently more difficult to quantify and measure.

It is not possible to measure the magnitude of people's aversion to inequalities or the strength of political importance of inequalities but it is important to be aware that the ethical dimension may be measured in various ways. There are two ways to approach decisions about which inequalities are more inequitable. One is a theoretical decision that itself explores the merits of mutually exclusive or overlapping principles of distributive justice. The other way is to consider and study and quantify public and professional opinion about which inequalities should be addressed by public policy. Defining need for healthcare is not a process that may be clearly defined. Donabedian [39] described the need for healthcare as "some disturbance in health and well being.... need is defined therefore in terms of phenomena that require medical care services". This definition is devoid of any rationing limitation. This limitation is partly addressed by Cochrane[40] who suggests that "need should be recognised only when it can be met with some intervention which actually alters the prognosis at reasonable cost." Once need has been defined it is necessary to investigate how much need there is and where it is. Acheson[41] suggests that need is dependent on fully understanding the underlying issues which determine the need for healthcare.

Although the importance of the socio-economic determinants of ill health is now widely recognised, socio-economic risk factors have yet to be effectively incorporated into the clinical practice. Health care professionals have no simple, ways of asking and recording the various dimensions describing the lack of access to material resources that are important, such as low income, inadequate education, unemployment, poor housing, and social isolation. Without the routine use of such recording, it is impossible for health care professionals to target prevention and treatment interventions effectively to individuals or to judge whether their interventions are of benefit. Better monitoring of who benefits from health services is also required. There is a need to develop ways of assessing access to specific groups, using methodologies that can be routinely applied at the local administrative level. One useful instrument is the "equity audit"[42], which is used to review health services systematically on the basis of quantitative criteria to establish whether obstacles to accessibility occur during the various steps in the care process.

Although health inequalities may be the concept that is being explored most analysis in this area actually uses information about death, disease or illness. There are no widely available measures of health that allow us to explore comparative levels of health. There are five main sources of data that are used to examine health inequality:

Civil registrations of births and deaths

Population Census

Registers of disease or attendance (e.g. Diabetes registers, hospital episode data)

Cross sectional surveys at national level

Longitudinal surveys

Amongst the subgroups that are often analysed when measuring inequality are:

Biological and genetic: age, sex, ethnicity, and genetic propensity

Socio economic status: social class, education level, culture, occupation, and income

Geography: place of residence and work, environmental hazards

Risk factors: alcohol and drug consumption, homelessness, tobacco consumption, and dietary factors

Just as there are many different concepts of health that might be used, so there are many different ways of measuring inequalities within each of these groups and they will each have their own characteristic measurement properties. This can be seen at its simplest with the choice between measures of central tendency, where the comparison of means, medians and modes between different groups may give quite different results. This is equally true (though not so easily discerned) in conventional summary measures of variance, skewness and inequality, each of which assigns specific weight to individuals according to where they are in the distribution of health. When to all this is added the further interpretative complications caused by the use of imperfect data (which may nevertheless be the best available) it is obvious that even when the conceptual difficulties have been cleared away, there is still plenty of room for disagreement about the interpretation of empirical findings due to the actual measurements that have been presented. Measures should ideally be assembled at a variety of area levels to enable problems specific to individual, family or household to be distinguished from those affecting community or area, e.g. debt, disability versus inadequate public transport, shortage of social workers, and lack of accessible NHS dentistry.

Many different spatial frameworks using existing zonal systems may be utilised and these may be administrative areas or specific zones, which may be created such as socially homogeneous areas. Electoral wards or enumeration district may be aggregated to form areas that may be studied to assess levels of deprivation. Service areas defined for health services, or social services, or educational purposes could be aggregated or separated for study to produce areas with perceived social characteristics. Policy areas for example education or health action zones may be studied by defining the ad-hoc areas by land use type or location. (e.g. social housing, inner city areas, suburban areas, rural locations.)

It is not correct to assume that all individuals living in households in an area will possess the average socio-economic characteristics of an area will experience problems associated with high levels of poverty and deprivation,- the so called ecological fallacy.

The use of Census based indices to measure deprivation has been the most common method used but non-Census data sources are increasingly available, particularly data derived from the benefits system. These data are regularly updated, measuring income for many of the poorest groups more consistently than is possible using Census proxies. New indices are emerging that use combinations of Census and administrative data. Administrative data sources provide a wide range of new material to use for the measurement of deprivation and there is a trend towards more extensive and complicated measures. This can result in the need for complex interpretation of the meaning of what is being measured. It important to ensure that indicators chosen cover a suitable range of topics that will provide information for the intended of the measure and that the categories included represent an appropriate period of (or point in) time. The components often undergo some type of transformation to give all the components similar distributional characteristics (transforming to a Z score is the most common); and the application of some type of weighting (often using statistical packages). Regularly updateable data must be available to compute index values. It is important before using an index to be aware of its properties, especially whether it actually measures what is desired. Indices are usually assessed on three criteria: validity, reliability, and responsiveness. There are however, there are many different interpretations of these three, and their distinct differences are not clear.

Deprivation indices

There are a variety of deprivation indices which are used to relate deprivation to health which have been developed to meet a variety of different objectives. Deprivation indices "measure the proportion of households in a defined small geographical unit with a combination of circumstances indicating low living standards or a high need for services, or both"[43]. It is important to reiterate the limitations of this type of index, ecological measures of deprivation are based on geographic areas, and "not all deprived people live in deprived wards, just as not everybody in a ward ranked as deprived are themselves deprived"[44]. In an extensive study using the samples of anonymised records and small area statistics for the 1991 Census, Kershaw[45] demonstrated considerable differences within small areas for all the major deprivation and policy indices. Deprivation indices may be used to identify the relative concentration of disadvantage but where data at an individual level is available it is much more relevant to examine the features of the geographical area. Sloggett and Joshi[46] emphasise this, noting that "for maximum effectiveness, health policy needs to target people as well as places".

When interpreting deprivation scores it is important to remember that many deprivation scores are relative measures – where the score for any one area is standardised by referring to the mean for the total of all areas included in the comparison calculation. For example, scores derived for all the wards in one Health Authority area cannot be compared to scores derived separately for all the wards in another Health Authority, because the scores for each set of wards are relative to the mean for the respective Health Authority. There are many different measures of deprivation in common use. Mackenzie et al[47] showed that different organisations have preferences for different measures when using measures to support resource allocation decisions. They showed that the Townsend Material Deprivation Score[44] is favoured by Health Authorities but Local Authorities favour the use of Index of Multiple Deprivation. The Jarman Underprivileged Area Score[48] is used by the Department of Health for making additional payments to general practitioners. The Breadline Britain Score has been used by the media to estimate the percentage of poor households in a particular area.

The Townsend Score and the Carstairs Score[49] (a very similar measure that was developed specifically for the analysis of Scottish health data) were both developed as measures of material deprivation. They are used widely in epidemiological analyses, e.g. Trends in Cancer Survival (Coleman et al, 1999)[50]. The Jarman Underprivileged Area Score was not originally constructed to measure deprivation but as a measure of General Practice workload. The Jarman Score was derived to take account of geographic variations in the demand for primary care based on a survey of GPs subjective expressions of the social factors among their patients that most affected their workload. The indices that have been produced by the Department of the Environment (DoE)[51], and the Department of the Environment, Transport and the Regions (DETR)[52], were designed as general measures used to identify areas of greatest need in order to assist central government when allocating resources to Local Authorities. The characteristics and mechanisms of calculation of some of the most widely used tools over the last twenty years are described in the appendices. They fall into two main categories, Census derived indicators and non-Census derived indicators.

Deprivation is undeniably multi-dimensional, however aggregation of variables and resulting composite indicators could be said to hide the social reality by reducing the social measure to a single dimension. Even if a single measure or index were to appear to adequately describe the situation it does not then provide guidance in terms of aspiration for a service provision. Thunhurst's[53] Grass Roots Survey of Sheffield illustrates that by providing extra information about other deprivation factors in Sheffield, that it is instructive and useful to include local people in the process of defining their experience in a qualitative way. An index can be used to supplement the process of deprivation study but not encapsulate the total situation. The indices do not highlight a cause but may summarise a large variety of associations.

Most summary measures of the extent of inequality give weights to different parts of the distribution and weight people according to where they are in the distribution. There is therefore an implicit commitment to the method by which the weights have been derived. Overall there seems to have been an incoherent approach to the development of deprivation indices and these indices have been developed for use in many different areas, and have consequently been compared out of context. There is a large variation in selection criteria for included variables and the definition of weights, transformations and the final method of combination. Few studies describe the true burden of ill health in deprived areas, as characterised by the number, severity and complexity of health and social problems within families. Health care that is increasingly driven by protocols derived from studies of single disease conditions seems likely to disadvantage those with multiple morbidity.

2.6 Resource allocation and equity

Equity is a principle concerned with fairness in the distribution of some or other resource. Operationalising equity implies reducing inequalities, which are unnecessary or unfair. It is important to ensure that resources are distributed in proportion relative to the needs of local population. The UK makes extensive use of formula funding to fund the NHS. The NHS is developed as a centrally planned organisation with part of its operation being the allocation of resources to various devolved centres of responsibility. Budgets from within the public expenditure system are devolved to the NHS and subsequently split between the hospital and community health services (HCHS) and the general medical services (GMS) and central services. These budgets are then allocated geographically to the regions, which in turn are allocated to local areas such as Health Authorities and primary care trusts. There is much local interest in how this money is divided and local power discretion rests formerly with health authorities and now with PCTs as to how parts of budget is ultimately allocated for use for hospital services. Implementing change in type of resource allocation methods used is not straightforward as there are always competing interests and priorities and the inevitable creation of 'winners and losers' in the allocation process. It is therefore a process that has to be undertaken with a great deal of thought, clear explanation and engagement of stakeholders.

The methods of weighted capitation employed, attempt to identify, and using routinely available statistics, increased need for care over and above demographic factors. Most of the relevant formulae reflect need for provision except perhaps the use of the standardised mortality ratio for under seventy five years; this reflects a final outcome but one which is intended to show a need for care to prevent early or premature death. Allocation might reflect need but actual delivery of care may be very different. These types of formulae take into account the higher needs and use by lower socio-economic groups and build these into the weighted capitation. These types of models are under fairly constant scrutiny by the Department of Health and review and to consider how they can now contribute to the reduction in avoidable health inequalities[54].

However, use of formula funding does not distribute resources with an aim of achieving equitable outcomes. The mechanisms for distribution of resources may take into account historical allocations, some measure of need, but funding will also be influenced by local lobbying for funds as well as local political imperatives and influences. For example local opposition to reductions or cuts in services may influence or prevent changes in resource distribution. The use of resource allocation formulae to distribute funds appears to treat everyone in the same way taking account of perhaps some measure of current need. This however will not achieve equity as the initial equity position of communities will vary enormously.

The introduction in 1976 of a national resource allocation formula (RAWP) was the first concerted attempt to base resource allocation for hospital and community health services on the need for health care rather than on the historical pattern of services. As the standardised mortality ratio was used as a proxy for need, the formula favoured the relatively poorer regions of Britain, with their higher mortality rates.[55] In 1976 the health care expenditure per head of population in the wealthiest regions was about 30% higher than that of the poorest regions. After a decade of the RAWP formula the gap had fallen to less than 10%.[56]In that respect the formula succeeded in reducing regional inequalities and what noteworthy was that it was applied at a time of severe financial restriction, the reduction was achieved by cutting the resources to the wealthiest regions at the same time as improving those to the poorest. Since the publication of the report of the RAWP the issue of equitable distribution of funds in the health service had been firmly on the agenda. Despite the controversy that has been caused[57,58] resources had been shifted between regions and between districts using a variety of formulae. In addition, since 1990 the Jarman UDP (8) index[59] had, despite criticism[60], been used to allocate deprived area payments to general practitioners.

Regions were encouraged to use the same formula for sub regional allocations, but again the effect was seen to shift resources away from some deprived inner city districts with high mortality and morbidity to more prosperous, healthier districts[61], which was not supporting any efforts to reduce inequalities nor secure more equity of access to health care. Such attempts were abandoned in some areas in favour of approaches which explicitly recognise areas that are poorly served, and with poorer health profiles. RAWP had developed a measure of relative need that had acknowledged the role of demographic characteristics. The populations of each area were disaggregated by age and sex, thereby permitting adjustment for the variations of use of NHS resources made by different age-sex groups. This measure was used as a basis of allocation to the regions until 1990.

Many of the resource allocation policies did represent a serious attempt to tackle geographical inequities in access to health care. For example the use of standardised mortality ratios in the new capitation formula introduced in 1991, potentially could have channelled resources into $^{\text{the}}$ less affluent regions with high premature mortality, mainly in the North, from those with lower premature mortality, mainly in the South and East [62] if it had been applied widely across budgets. It was actually only applied to parts of the budgets which prevented large movement of resources away from the South and East.

In 1994 another approach to weighted capitation was suggested by Carr-Hill et al[63,64] using new formulae. The Department of Health justified this fairly rapid review of formulae on the importance of incorporating newly available Census 1991 data to be used in the process. The work had been commissioned from the University of York Centre for Health Economics by the Department of Health to attempt to identify the principal determinants of NHS inpatient utilisation in England. This work is described in some detail here as it was used as a fundamental part of the political process of operationalising equity described later in chapter four.) This was part of the Department of Health's review of the use of weighted capitation, which was begun by the RAWP work. Carr-Hill et al were commissioned to develop a more sensitive, empirically based model of demand for hospital inpatient care for small areas that could be used to distribute Hospital and Community Health Services (HCHS) for hospital and community services funds to Health Authorities. It was suggested [65] that the work could be used with caution to infer allocation of resources between geographical areas.

Following the publication of "Working for Patients"[66] in 1989, hospital and community health services (HCHS) resources available to Health Authorities after regional top slicing were allocated to Regional Health Authorities based on a weighted capitation formula which took into account four elements:

Forecast resident population

Average treatment costs in different age bands

Relative health needs measured by SMR

Market forces adjustment where relevant

The aim of the commissioned York work was to develop an empirically based model of demand for health care in the secondary care sector. Principles of the underlying work produced had been accepted but it was hoped that a more comprehensive and up-to-date dataset could be used to model the resource implications of utilisation more accurately and to rectify some of the shortcomings identified in earlier work.

Two types of demand determinant were considered to be important by the York group in driving utilisation,

The healthcare needs of the population

The supply of healthcare facilities.

The York group aimed to build a statistical model which related utilisation to the indicators of need and supply. It also made use of the fundamental insight that past need and utilisation may influence supply. It was therefore important to separate the impact of supply from the impact of needs in the past. An important part of the study was to build a statistical model that disentangled the impact of supply from the impact of needs on utilisation. That is, although utilisations in an area is a function of needs and supply it is also plausible to suggest that supply might in turn be influenced by utilisation and other determinants. It was assumed that present needs and utilisation are reasonable proxies for previous levels. This is difficult to elaborate empirically due to limited availability of data. The method of two stage least squares was used to take account of simultaneous determination of utilisation and supply. The York work used 4985 synthetic wards as units of analysis, which were small areas with average populations of about 10,000; these covered the whole of England. These small areas were electoral wards aggregated with contiguous wards so that none had a population of less than 5000. For each synthetic ward, data were assembled relating to socio-economic conditions, the supply of health services and the utilisation of inpatient services.

The socio-economic variables comprised of detailed demographic data prepared by the Office of National Statistics, health status variables and also broader socio-economic variables that were derived from 1991 Census. The demographic data were used to standardise all variables for age, which was acknowledged to be an important determinant of health need. The national rates for the variables age group and sex were applied to the local population sizes, which yielded the expected number of observations in the area. The indirectly standardised rate was then the ratio of observed number of occurrences to the expected number. The health status variables included various age-standardised mortality rations and standardised limiting long term illness, which had been derived from the Census. The Census variables covered the following aspects of social and economic circumstances:

housing tenure, amenities, overcrowding, car ownership

migrants

ethnic origin

elderly living alone, lone parents students concealed families

unemployment, educational qualifications non-earning households

social class

There was scope for many other variables to be used but the range of issues encompassed was considered by the team likely to be sufficient to capture the majority of important social causes of the need for healthcare. Many of the variables tested were highly correlated so therefore the omission of a variable did not imply the effects measured by it were ignored. Four supply variables were created to reflect the availability of health services to the ward population. They were created to measure the accessibility of NHS inpatient services, the accessibility of GP services, the provision of residential and nursing homes and the accessibility of private inpatient facilities.

In deriving accessibility measures it was necessary to reconcile supply of facilities, their proximity to the electoral ward of interest and the impact of competing populations. This was done by undertaking spatial interaction modelling. The measure of accessibility can be interpreted simply as the ratio of population to hospital size, both weighted by distance. This is perhaps analogous to “beds per head” but taking account of distance and competition from other hospitals. Utilisation rates standardised for age and sex were calculated from hospital episode statistics (HES) data taking into account defined specialty groups. Costs were attached to episodes-(this was a very crude approximation as only 12 reference costs were then available, much more is available in 2003). Standard costs employing national average costs were utilised but also specialty specific costs based on length of stay in the specialty. The following standard specialty groups were used:

Surgery,

Medicine,

Geriatrics,

Psychiatry,

Mental handicap,

Maternity,

Gynaecology,

Radiotherapy,

The costing exercise enabled age-cost curves to be constructed. These consisted of average costs per head of population within age bands. The age cost curves formed the basis for regional populations to be weighted for age. Utilisation at ward level was modelled as a function of supply and needs using two stage least squares regression methods. Three separate models were estimated for acute, long stay and maternity specialty models.

In the first instance in addition to the supply variables a large number of potential determinants of healthcare needs were included in the model. The initial selection of the variables was on the basis of high statistical significance and a prior judgement about the importance of the variable. Removing variables until the deletion of further variables would significantly alter the model in a statistical way progressively restricted the model. The model was tested to ensure that it was well specified and the two-stage least squares were justified in preference to ordinary least squares. For the acute model the variables arrived at in the final model were:

Access to NHS acute beds

Access to GPs

Proportion of population aged 75+ not in nursing or residential homes

Access to private hospital beds

Density- persons divided by hectares

Proportion in manual social classes

Proportion of elderly living alone

Proportion of dependants in single carer households

Proportion of economically active unemployed

Standardised mortality ratio for ages 0-74

These results suggested that access to GPs and private inpatient services are positively related to utilisation but provision of nursing homes depresses NHS inpatient use. NHS inpatient provision was not found to influence utilisation significantly. Density of population in the model shows there are aspects of supply, which were currently not being captured in existing supply measures. There were five variables that were clearly linked with health care needs;

SMR 0-74

Elderly living alone

Single carer households

Unemployment

Manual workers

These remaining variables in the model support the belief that unemployment and social class are major determinants of health.

The next part of the analysis was to use the results to derive a formula for distributing funds to Health Authorities. Although the results of the modelling had produced a satisfactory statistical model of utilisation the model was not directly useful for developing a resource allocation formula because the supply terms may or may not reflect legitimate healthcare needs. The formula needed to develop a measure, which showed normative utilisation, or the level of utilisation, which would arise in an area if it adopted national utilisation rates in line with healthcare needs. Thus the measure should be sensitive to needs but independent of supply.

The next stage was to produce a multi level model (to abstract from district policies and practices) based on the unambiguous needs indicators of the first model. The final stage in the analysis was to carry out this least-squares regression and recommend the resultant coefficients as the basis for an equation. The results for the acute sector produced a model using the five variables above and this model was recommended to the Department of Health as a basis for a formula for resource allocation.

The new model suggested changes to the current situation in health care resource allocation in England. The approach took into account a wide range of social and economic and supply variables. There would always be much scope for debate about the strengths and weaknesses of the index but essentially it was a positive move to introduce more emphasis on need into the allocation of resources. In response to the publication of the York work there was academic interest and also debate[67] [68] [69] [70] about how the Department of Health was using the results of the work. It was clear that huge changes would not take place quickly as this would not be politically acceptable any changes would have to take place as part of a transitional process. The use of 1995-6 as transitional year was viewed as a way of cushioning the impact of the formula on the Southern counties such as Surrey, Oxford and East Anglia that would lose money rapidly. Unmodified, Anglia and Oxford, South-West Thames and

Wessex regions would have lost money rapidly with Mersey, the North West and the Northern regions gaining. The NHS executive added in a market forces weighting and a London pay weight and allowed for land value differences and building costs.

Assessing the effect of each of the components of the national capitation funding formula and population projections and age and mortality weightings at regional at district level, Raftery[71] suggested that the robustness of methods used to derive projected capitation populations requires re-examination to ensure changes are well-founded on appropriate and accurate information. This is especially important as most of the changes suggested in allocations by RAWP and other formulae such as York encompass age, sex and mortality.

Sheldon discussed the use of formula resource allocation to primary care and the appropriateness of using such formulae in an editorial in the BMJ[72]. Sheldon had raised this debate already in 1993[73] prior to the completion and publication of the York formulae and suggested then that extreme caution needed to be used with formula resource allocation. In the 1980s regression analysis had begun to be developed to estimate the influence of health and socio-economic factors on health care use. The York work in 1993 used more statistically appropriate techniques, which also adjust better for the effect of variations in supply and consider resource use rather than just bed days. The resulting indices of need for acute and psychiatric health services are more sensitive to the influence of socio-economic factors and, had they been implemented, would have redistributed resources from richer to poorer districts. The Department of Health decided to allocate only around 75% of the funds using these needs weights and most of the community health services budget was excluded. The justification given was that that the research was based on hospital episodes and community health service data are not routinely recorded. The decision not to weight the community health services budget according to need contradicted the epidemiological evidence[74]. This suggested that community services delivery was particularly influenced by level of need. The effect of the restricted allocation was to dampen the re-distributive effects of the York formula, resulting in losses for poorer districts.[75] As a result of the aforementioned problems, the Conservative Secretary of State commissioned Buckingham et al[76] to undertake research on weighting community health needs. Buckingham and colleagues reported that the allocation of community funds needed to allow for differences in the health and socio-economic characteristics of Health Authorities. Alongside other research on the use of community health services and a refinement of the market forces factor, which takes into account geographical differences in the cost of providing care, this research was then adopted as a basis on which to allocate resources to Health Authority area[77]. It is likely that the methods used for working with community health services data are necessarily cruder because of the general lack of good data and the dependence on a few providers for records of community health contacts.[78].

2.7 The “causes” of inequalities in health and inequities in health care

Evidence about the existence of inequities in access to health care is easier to find than is detailed guidance about interventions to tackle the problem. Public policy implications are inevitably the principal focus of interest. This is perfectly understandable if official intervention at some level in the system is likely to be needed even to stimulate and facilitate changes in individual attitudes or behaviour. It is important to assess and recognise the potential and limitations of different public and private agencies, if feasible and effective remedies are to be devised. Even with a good working understanding of the causal mechanisms, and good data indicating their relative importance and susceptibility to particular interventions, there is still a need to find feasible mechanisms that can effect improvements at reasonable cost.

Poverty reduction is likely to contribute to reducing inequalities in health, and yet the field of welfare benefits, incentives and redistribution policy is complex. Public health practice will always focus on the needs of disadvantaged groups, and direct policies and services towards them. Such efforts would include the encouragement of behavioural change facilitating inter-sectoral collaboration and improving the quality of medical care.

At an organisational level, particularly in the light of a primary care led service, general practices can do much to enable equity. All barriers to consultation should be examined to ensure that the poor are not disadvantaged. An obvious example concerns those without a phone who may be easily disadvantaged if appointment systems are rigidly enforced and largely organised by telephone. Equity audits can be used to check that all the services of a practice are used by the appropriate range of patients and that, overall, patients from different socio-economic groupings have access to service which is appropriate to their needs[79]

2.8 Effectiveness and costs of policy options to change patterns of equity

In the health care literature, an effective intervention from the view of the health care professional is one where desired outcomes are achieved[80] or more generally where a greater improvement in health is brought about compared to standard care. It is difficult to apply this definition directly to interventions to reduce health inequalities, where the desired outcome is not simply an overall improvement in morbidity but the narrowing of the health gap between higher and lower socio-economic groups[81]

The notion that policies should be based on systematic evidence raises a set of issues as to why that kind of evidence might be so sparse. It could be that the difficulties are methodological. For example, formulating the policy issue in a manner that makes it empirically "researchable", given the available research tools, is very difficult. It could be that people are unwilling to embark upon the kind of information-gathering activities that rigorous hypothesis testing requires.

It may be that existing knowledge is so fragmented that it is not exploited efficiently. It may be important to form a view on which is likely to generate the most progress in the short or medium term so that it is known where resources might be concentrated.

The provision of universal access to health care free at the point of delivery could itself be classed as a health intervention in tackling social and regional health inequalities. Most interventions are found to have targeted the general population and/ or a specific health problem. While this will also include low socio-economic status (SES) groups, this does not necessarily mean that such interventions are effective or suitable if they are not specifically tested among these groups. As Woodward and Kawachi[82] point out:

"Strategies to reduce smoking, increased cholesterol, and high blood pressure, have been designed to achieve overall reduction in these risk factors. But any preventative strategy that relies on access to the health care system for delivery – such as the detection of high cholesterol or blood pressure may worsen socio economic gradients in outcomes (such as stroke, heart disease) if there are disparities in access to primary care".

In an information-orientated world, where health investments are increasingly driven by an emphasis on high quality evidence about what works, there is a real paucity of studies about the best way of reaching people with appropriate and effective services. Reaching the most deprived is problematic because of the difficulty in identifying the deprived population in the first place; this contributes to explaining some of the scarcity of work in this area.

2.9 Improving equity of access: Barriers to reducing health inequalities in the UK

Whitehead[83] discusses concerns about the size and nature of socially determined variations in health and access to health care. These concerns have now reached such a level that governments in the UK, Netherlands, Finland and Sweden have been convinced of the need to set up national research programmes in order to better understand the various pathways leading to health related inequalities. This implies that there would be support for the health system contributing towards reducing socio economic inequalities in health. For example, influence can be exerted from within the health care system on the three major risk areas from coronary heart disease. It can provide support for smoking cessation, can discover and treat high blood pressure and find and treat high serum cholesterol levels. A systematic approach to coronary heart disease might be developed via primary care in deprived communities. At the very least the health care system is responsible for establishing equal accessibility to effective health care, regardless of socio-economic status. This involves national polices of resource allocation and appropriate local practices geared to health care needs, in particular of groups with low socio-economic status, and also the development of adequate facilities for these groups. This involves both national policies for allocating resources properly according to need and appropriate local practices.

Even if health care services were distributed between areas in direct proportion to the relative needs of their populations this would not automatically result in equal access to care for all. Services may not be arranged in a convenient way and some social groups face greater barriers than others. As Dixon [84] describes, the long-standing problems of primary care in deprived inner cities of the UK, particularly London, have been the subject of many past reviews and subsequent initiatives by the Department of Health and other bodies. For example, between 1993 and 1999, the London Initiative Zone sought to address problems regarding recruitment, retention and training of GPs in areas where they were most needed. Yet while improvements in standards of premises took place, the initiative did not have a major impact on accessibility and quality of care in large parts of the city.

Physical and practical access to health care may be a problem for some groups, such as homeless people, and those people in rural areas who may lack transport. However, as well as universal access, effective health care depends on two closely related factors, the provision of adequate and appropriate services and the capacity and ability of people to maximise their benefits from these services. The inverse care law[7] applies at every level of the health service. A study of cancer treatment showed that patients from deprived areas present to specialist services at later stages of disease compared with those patients from more affluent areas[85] Patients who are more educated and better informed about their condition and who feel more involved in management decisions, achieve better clinical outcomes and are more likely to adhere to suggested treatments. Demand may well outstrip need in accessing health care.

Trade-offs have to be made between the often conflicting multiple objectives of public policy in relation to equity and efficiency. If efficiency is interpreted as getting best value and output while undertaking those activities that fulfil organisational objectives (which for health should be including equity of access to health care), then it is possible to assert that equity and cost effectiveness are compatible. Therefore policy recommendations should implicitly take a stance on what these trade-offs might be, but ultimately will have to be explicit about will change or be sacrificed.

The Acheson report[19] took the approach of emphasising the importance of addressing inequalities across the whole social spectrum. This emphasises the general problem that interventions that are effective in general public health terms may be ineffective in reducing health inequalities. For example, health promotion messages may be taken up more by those who need them least, such as the well-off and well-educated, while interventions which do not need to be mediated by the effects of education may have better prospects for improving health without increasing inequalities, e.g. fluoridation. Therefore interventions that improve access to the health system may actually increase inequalities, if there are socio economic differences in how groups access health services.

2.10 Conclusion

This chapter provides a context for the work undertaken in the rest of the research by actually exploring some of the definitions and issues. The section explores the differences between health equity and inequality reviews and its relationship with access to health care. The chapter reviews some of the important influences on attempting to provide an equitable system of state health care in the UK. This process was marked by the establishment of the NHS in 1948 under the guidance of Aneurin Bevan. During the 1970s and 1980s there was an increasing awareness of the inequalities in health, which were leading to inequity of access to health. Relevant analyses and interpretations were provided by the "Black Report"[1] and the "Health Divide"[15].

There are many tools that have been developed which are used to attempt to measure the extent of deprivation and to ultimately attempt to ensure that there is equitable allocation of health care resources. Many measures are used in a different context to the original reason for their development. The causes of inequity are not explicit and time to achieve change may be long with barriers to equity relating to the interaction between resources available to make changes and priorities for change. Research may not always reach the stage of policy and implementation to empower change.

The next chapter initially explores the data available and its limitations, and then develops into a focus on local interest in using these. This includes the use of limiting long term illness data at a GP practice level in Shirebrook in North

Derbyshire. This work resulted in the increased political will to make changes relating to the allocation of resources to primary care. Chapter five describes using measures of deprivation and resource allocation tools along with other supporting information to produce a “big picture” and support a political process to make primary care resource changes.

Chapter Three: The measurement and monitoring of equity in access: Data Sources

3.1 Introduction

Inequality in health has been defined[86] as a situation where groups in a population are in some way excluded from the style of life and standard of living of the population in general. This "inequality in health" seems to extend to the inequity of access and use of health care services in proportion to need for care[87,88]. To be able to assess and understand these disparities locally it is necessary to have access to relevant information and analysis and understand the basis for the collection of this data and the limitations of its application. Such information will provide understanding and context of similarities or differences relating to ease of access to facilities and the levels of use of health care with respect to need.

Access to health care is a complex concept with many dimensions. It therefore cannot possibly be monitored by a small number of "high level" indicators. In order to plan equitable services, monitor the implementation of changes and compare institutions and geographical areas, focused information is required. In particular, as well as data about utilisation of services, data are needed on resources available for care, the characteristics of the geographical areas for which services are provided, the health of the population and the socio-economic characteristics of groups within the population. Although there are considerable volumes of data collected on these subjects, they are collected in a disparate way and at different levels of disaggregation. Indeed much information is not collected on a population basis. Preoccupations about data quality tend to focus on completeness rather than the quality of the data in terms of the accuracy. As a result, the data available are not used to their full potential and there are gaps in the data available. Most administrative data collection systems relate to the process of care within NHS hospitals and community services and within primary care. The uptake of this care can reflect levels of need within the population but also the resources available to provide such care. Lack of resources may not only impede access by marginalised groups but also lead people to use the private sector in response to perceived or actual gaps in NHS care. There is little data about care in the private sector and even less about people who do not access care. The use of record linkage both within NHS datasets and with data collected by other organisations such as social services and use of data about NHS resources can potentially enhance the usefulness of the data currently collected. There are not direct measures of equity relating to access and use of health care and it is inevitable that proxies are used to measure differences. It is therefore important to have a clear understanding of the origins and properties of the data that are used for monitoring and measuring equity of access to health care.

The use of health related data are a fundamental part of this thesis, as extensive use is made of proxies and measures relating to population health, health care usage and the determinants of health This research required the assembling and examination of a wide array of data and analysis from many sources. These could provide insight into the current use of resources and how this could be changed using information relating need and demand for health care. The final chapter of the thesis uses a specific data set relating to deaths from cancers in England and Wales and analyses what type of settings and institutions people die in, the work examines equity issues around these differences and utilises not only the deaths data but also socio economic, gender and age factors. All of this work was dependent on the availability of the information that could be used to assess equity issues in various ways.

This present chapter focuses on an examination of the types of information that are currently available to assess and understand patterns of health care utilisation and its interaction with social deprivation. This information provides insight into different rates of access to health care by different social groups experiencing varying rates of material deprivation. The main types of data available that may be used in the assessment of equitable access to health care fall into the following categories:

Information about the health care workforce[89] and its composition and distribution, e.g. the number of GPs per head of population

Information about the processes which take place in health care provision[90], e.g. the number of district nurse contacts with a defined population.

Information about the performance of the health care systems, e.g. performance of a health economy in relation to financial constraints, such as reduction of numbers of patients waiting for health care on waiting lists[91]

Information about clinical activity, e.g. rates of clinical procedures or admissions for specific diagnoses.

Information about the outcomes of health care, e.g. readmissions to hospital or deaths

These types of information may then be related to the known or attributed characteristics of an individual or an area. These categories of health care related information have become available as a result of various processes. This chapter explores their development and how this may influence and restrict their usefulness as tools to measure inequity of access to health care.

The different aspects and influences of access to health care and examples of data sources are illustrated in the schematic diagram in Figure 2

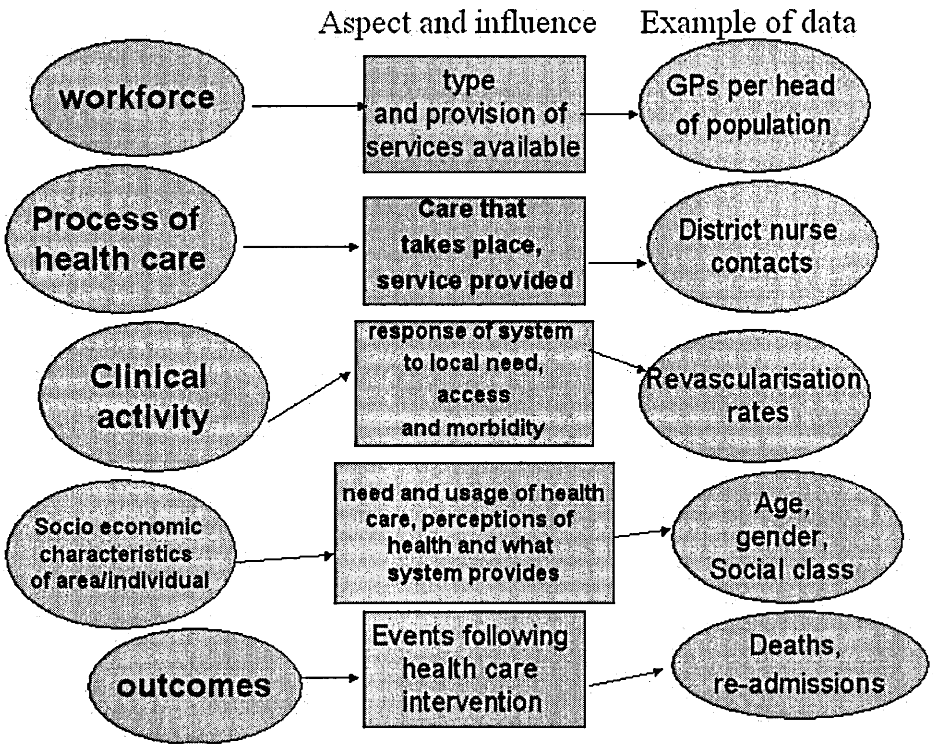


Figure 2 Aspects and influences in access to health care and possible data sources.

3.2 Data collections relating to provision of health services

Current systems of health service data collection, which assemble information relating to the NHS, have developed mostly as a result of the requirement to monitor the use of public expenditure on health care, public health and health promotion. This process began in the 1920s and 1930s with the beginning of centrally funded services administered by local authorities and voluntary organisations and the requirement for them to make returns about the services provided and the numbers of people using them[78].

The establishment of the NHS in 1948 expanded the range of services funded by the state and there was therefore an impetus to collect data about how services were used. Aggregated returns were designed to collect information about a range of services, activities and resources. An example was the SH3 hospital return that collected data about numbers of inpatient stays and the average length of stay in each specialty by hospital. In 1969 each English health region started to collect data about all discharges and deaths. In the mid 1950s the first survey of morbidity statistics from general practice collected data about consultations during a one year period from a small set of volunteer practices in England.[92]

The reorganisation of the NHS and local government in 1974 moved the responsibility for community health services away from local authorities and placed such responsibility with district and area Health Authorities. These Health Authorities also had responsibility for provision of hospital services. The Regional Health Authorities had responsibility for coordinating data collection and collating and analysing data for their regions.

In 1980 the steering group on health services information was established. This body reviewed and influenced the ways in which health data were collected in England.[93,94] The steering group saw as its main concern, information for health service management. It thus concentrated on data about the use of NHS resources which defined data collections about NHS activities, manpower and finance.

The system was based on “episodes of care” for which a “minimum data set” of items would be recorded. The majority of statistics about the NHS in England since the late 1980s are based on the steering group’s recommendations. Much of the data collection and transmission is electronic. In some areas, such as maternity and child health surveillance, stand-alone systems have been developed without linkage to other systems. This makes data difficult to transfer directly and introduced potential for incomplete data may be seen, in particular in maternity and child health data systems where comprehensive electronic data relating to the provision and operation of these services and not easily available.

The introduction of the internal market in 1991 had important implications for NHS data collection. Data collection and analysis systems had to be adapted in order to recognise the split between Health Authorities, which purchased care, and Trusts, which provided the health care... The increasing emphasis on information relating to finance and purchasing of services resulted in less information being collected on clinical data items, and a less important role being focussed on quality in diagnostic and procedural coding.

In 1999 Primary Care Groups (PCGs) were established to commission health care service for populations in areas smaller than those for Health Authorities. This led to the emergence of Primary Care Trusts (PCTs) and the abolition of Health Authorities in April 2002. The latest change poses a significant threat to the continuity of data flows and collation and analysis, and therefore access to important information about the health and health care utilisation of populations. Changing geographies from Health Authorities to PCTs has led to a lack of trend data and a reduced provision of analytical support locally. The frequently changing configuration of NHS boundaries means that unless the data are available at individual record level there is no opportunity for comparing patterns of access to health care.

Information about the workforce in the NHS

The way in which individuals access health care services is clearly the result of many influences. Including both individual patient needs and the supply of services. The availability of services will be constrained by the provision of staff to supply these services. The provision of a service may be constrained by shortages of labour available to recruit to a service. For example, in June 2002 vacancy rates in England for health care assistants in NHS trusts ranged between 0% and 37% in parts of the South East[95]. Constraints may also derive from the lack of financial resources available in a health economy to employ staff. Information relating to the provision of NHS staff and their specific skills in providing relevant services is therefore an important source of information.

Each year the Department of Health undertakes an annual census of the medical, dental and non-medical workforce directly employed by the NHS in England. This type of data are useful in assembling a "big picture" of the stock of resources available in an area but needs to be viewed in context. For example the reduction of junior doctors working hours initiated in the late 1990s and the reduction of the nursing working weeks to 37.5 hours, resulted in a reduction of the resulting resources available to the health care system. Therefore the same numbers of staff were providing less health care resource to the system.

The General Medical Service database is a computerised register of all doctors who have a contract with the NHS in England to provide general medical services. It contains details of all General Practitioners and information about the practice environment in which they work as described by list size, deprivation allowances that are payable, practice staff employed, services offered and target information relating to immunisations. PCTs hold information about the numbers of community pharmacists and opticians that are contracted to supply services. Information about dentists in general practice, as opposed to those employed by hospitals or community trusts, is collated nationally by the dental practice board.

As part of the process of registering private hospitals and nursing homes, the

NHS collects information relating to the numbers of qualified and unqualified nursing staff and resident doctors employed. These data do not cover the activities of doctors who work in private institutions but are not employed by them. Information is not available about the work of dental practitioners outside the NHS or about care given by self-employed practitioners in a range of professions including home nursing, chiropody, physiotherapy and osteopathy.

Information on numbers of contacts between staff groups and patients is collected but little information is available about who is treated, what treatment is provided and what the health problems patients may have. This process-derived information must therefore be examined in conjunction with other information such as levels of morbidity and social need. This type of information can give crucial insights into questions such as whether provision of care is equitable across an area and whether the patterns of access are determined by manpower available.

Data relating to clinical activities in hospitals and in the community and NHS inpatient and outpatient care

Waiting lists have had a high political profile[96],[97] over the last few decades and considerable investment has been made in data collection relating to this area. This is despite the fact that only about half of admissions made to NHS hospitals are derived from waiting lists[91]. The aggregated, high-level form in which waiting lists are published means that there is a lack of information contained in them which relates to need and the characteristics of patients waiting for treatment. This limits their usefulness in the assessment of absolute or relative equity with respect to access to health care resources.

Information about health care taking place in NHS hospitals is derived from the aggregated returns that are made to the Department of Health[98] by Trusts. These returns count events but person based datasets, Hospital episode statistics[99] (HES), provide information about inpatient and day case care provided to individuals. The fundamental limitation of this type of data are the lack of routine opportunity to be able to examine the progress of individuals or groups through a course of treatment. For example, using routine data it is not practically possible to track an individual from initial GP consultation to outpatient referral, inpatient treatment and outcome of treatment. Though some special studies have shown that this it is feasible[100].

The HES database[99] generates around eleven million records per year and contains information about all episodes of care in NHS hospitals. The information collected on each HES record includes demographic characteristics, length of stay, information on diagnosis and procedures and methods of discharge. The HES dataset was designed to count individual episodes of care and one of its big disadvantages is the fact that a single stay in a trust may generate several episodes of care by different specialties and thus generating multiple records for one person. The dataset does, however, provide the opportunity for relating need via ecological measures for place of residence, as this information may be used to associate various area based deprivation measures to the place of residence of the patient. It is also possible to make an assessment of equity of utilisation by geographically defined populations by different diagnoses and procedures.

While a large volume of data are available for inpatient care, little information is available on other care provided at an individual level such as outpatient or community based care. Some of this type of data has become available slowly over the last few years[90], though the emphasis has been very much on the process of the care rather than the diagnosis or treatment provided or the socio demographic profile of the patients. Analyses are routinely undertaken at high-level geographical aggregations such as Health Authorities but the frequent reorganisations of NHS administrative boundaries mean that trend analyses over time do not routinely take place. Access to this type of data at a level which would allow the building of analyses at various geographies is severely restricted by the sensitivity of the information collected. This has meant that use of wide ranging analyses of the data for equity auditing has tended to be limited to applications in performance and financial management.

Private health care

Health care that takes place within the private sector is not routinely monitored and hence information is generally not published in the public domain. An exception is the information collected about the private health care sector in the registration and inspection of premises in which services are provided. Data are collected privately and published annually in Laing's review of private health care[101]. These data, however, describe the process of care rather than the morbidity of the recipients or their demographic characteristics. It is conceivable that use of the private sector by individuals personally choosing to buy care from this sector could promote greater equity of access in an area if this relieved pressure on state provided services. The lack of information about the private sector means that it is not possible to explain whether high usage of the private sector in an area is due to lack of service provision by public services or whether private usage leads to greater availability of services for patients unable to pay for health care. . There is the contentious issue of whether those resorting to private care are discriminated against by ultimately paying once through taxation and national insurance and again through direct payment. The opportunity to undertake these types of comparisons would create greater understanding of the process of equity of access to health care, which is clearly influenced by many constraints.

Community based care

Aggregated returns[102] provide limited information about services such as paramedical staff, midwives, health visitors, community nurses and services based in the community or hospitals including physiotherapy, chiropody, and speech therapy. The information is limited to numbers of contacts with some breakdown by source of referral, age breakdown and venue of care. Information is also collected about ambulance services in England and provides data on patient journey numbers by priority and response times for urgent journeys. The NHS collects information about health promotion activities in local health communities in the form of the performance of breast and cervical cancer screening programmes, immunisation and vaccination rates, the activities of family planning and genitourinary medicine clinics and statistics about drugs misuse. This is largely information about contact rather than information which provides insight in to the users and their needs. The data collected and the summaries made available probably provide more of an insight into the supply of the service than into the need of the population in an area and are only available at Health Authority (now PCT) level. There is no possibility of linking this information to other data sets or analysing the data at locally defined aggregations. The information is therefore of limited use in the assessment of equity of access to health care in an area.

General Practice

The main centralised source of information about general practice in England is the general medical services database, General Medical Services (GMS). GMS statistics are a summary of data relating to GPs, their patients, partnerships and services. The GMS division of the NHS executive collects twice yearly statistical returns from Health Authorities for each registered general practice in England and Wales. A wide range of information is collected including the age and sex breakdown of patients for each registered general practice in the country. Details are provided about service provision such as asthma and diabetes services and immunisation. This provides limited information about process type activities undertaken where reimbursement is due. Little information (except vaccination and immunisation uptake) is systematically collected by all practices about the clinical activities undertaken in general practice.

Primary care has a crucial role as gatekeeper to the NHS and should theoretically be a rich source of information about needs and utilisation of care in the NHS, both for individuals and for populations. However, so far only two significant national attempts have been made to derive data from general practice records. Data about consultations were collected in a series of studies in 1971/2[103], 1980/1[104], 1991/2[105] with GPs taking part undertaking to collect data for a one year period, keeping an age and sex register and supplying certain details about each consultation. Data were recorded about each episode of illness and each consultation and information was also collected about socio-demographic status, including marital status, tenure, household composition, and occupation and employment status. Participation in this type of survey involves considerable commitment, so volunteer practices were used rather than a random sample of practices. Validation of the data has suggested that the characteristics of the patients appeared to be similar to those given by Census analyses for the same period and area. While these data do not allow small area comparison or conclusions to be drawn they provide a resource that may be used for extrapolation purposes locally.

The other types of project in general practice that have collected data have used routine data collection systems and extracted it electronically for epidemiological studies as practices became computerised. The best known of these is the General Practice Research Database[106], originally set up by VAMP health Ltd. and subsequently operated by ONS and owned by the Department of Health. In 1999 ownership was transferred to the medicines control agency. In the mid 1990s the database contained information about two million people registered with 288 practices. It contains information on prescribing, diagnoses, chronic conditions and whether a referral is made. Its huge limitation is the high cost of accessing the data. Therefore its use in the public sector is relatively limited, though pharmaceutical companies make extensive use of the data.

Since 1996 MIQUEST[107] has been an integral component of the Collection of Health Data from General Practice (CHDGP) project and has been included as a standard for all GP systems, MIQUEST interpreters for GP systems, and support for them, are available from the GP systems suppliers. This project has now become part of the evolved PRIMIS[108] initiative. Those practices, Health Authorities and PCTs taking part have used the information extracted for many purposes including health promotion and audit support.

Both types of approaches have strengths and limitations. Continuous download of information from GP systems such as MIQUEST provides a live database, which allows individuals to be monitored over time but the MIQUEST approach depends on consistent and accurate clinical coding and recording of other information. The GP based surveys did however collect socio economic data, recorded all consultations and made comparisons with previous surveys. It is likely that as it was a specially designed study with a specifically defined dataset, these data are more robust than data downloaded from operational systems in the absence of specific agreement about coding and recording. The general practice setting in England is the source of all referral to secondary care for elective and most emergency care. However, the systems for collection and publication of data relating to diagnoses, treatment and referral and outcomes to secondary care are extremely poor. GPs have a key influence on the way secondary care is accessed and therefore in influencing equity of access to health care resources. It is therefore bizarre and frustrating that this sector has so few obligations to provide epidemiological, socio demographic and process data about the pathways patients may take through the services of the NHS. The lack of a primary care minimum dataset is probably determined by the status of GPs as independent contractors to the NHS rather than employees of the service. The re-issue of the GP contracts may be an opportunity to define and specify minimum data set return from this part of the NHS.

3.3 Conclusion

A considerable amount of information in the NHS is recorded about resources, activities and finances of the NHS. However; the types of data collected do not directly support the assessment of health needs of a population or an assessment of the equity or inequity of the provision of health care available to a community. The data collected largely describes the extent of the process rather than the availability, need or quality of that provision. Geographical aggregations mean that much of the data collected can only be used in analysis for large areas such as Health Authorities or local authorities. This leaves only the opportunity of extrapolating or approximating the data to the required level. This in most cases will not be acceptable or useful, as monitoring of equity of access to health care requires the ability to examine data attributable to individuals or real areas. The most comprehensive set of data available to describe utilisation of health care is that provided by the HES system. This information lends itself to analysis at small area levels and gives much information about the most expensive part of the health care system. In order to assess and audit equity of access and provision of health care it would be important to be able to combine information from various sources, such as HES with general practice derived data. The possibility of undertaking this type of analysis is severely limited as the role of the general practice as the "gatekeeper of equity" in access to health care services is virtually a "data free zone" in terms of routine sources of data.

This chapter has summarised and assessed the range of data available for examining and analysing patterns of health care provision and delivery, particularly in the light of the equity issue. These data mostly provide information about who delivers the care and where and gives very little information about the recipients of the care or their needs or characteristics. It becomes apparent from this consideration that in order to relate the needs of the population to the delivery and availability of health care it is necessary to combine different types of information to provide proxies for assessing equity of access and therefore availability and delivery of health services.

Subsequent chapters of this thesis utilise different types of data as proxies for need, as measures of equity of access to health care and also as direct measures of ill health or funding such as the cancer mortality data and the funding information used in the “Operationalising Equity” chapter of the thesis. The next chapter explores the use of a specific indicator not generated by NHS procedures, the limiting long term illness of a general practice population, and examines how useful this is to predict or explain the needs and demand for health care in an area

Chapter Four: Limiting long term illness.

4.1 Introduction

Information is readily available about the users of health care services and also on details generated by registration processes such as births and deaths but there is little information about general health of the whole population. Some of the sources and issues surrounding information about those making contact with health services were discussed earlier in the thesis in the previous chapter. This chapter initially concentrates on the use of morbidity information about the general population and then investigates how one particular self reported measure, limiting long term illness, first collected nationally in the 1991 Census, may be used to assess need and demand for health care. In the light of a primary care led NHS; the focus is on primary health care. Conventional NHS data measures use and demand for the services provided, but does not provide a population measure of general health or levels of illness. The limiting long term illness question presented a self-assessed population measure that covered all types of morbidity.

The work includes a local validation survey of the Census question undertaken with the cooperation of a GP practice in a deprived area of North Derbyshire. The work supported a process of increasing political awareness about health inequality in the area and the issue of inequity in funding for primary care in relation to need. This development is elaborated in the next chapter

"Operationalising equity"... The current chapter describes the beginning of the development of a process of using routine data about local areas in this research to form proxies and indicators for measuring and understanding how and why different groups use and need health care services in varying ways.

The Census data in 1991 produced a dataset that was available to analyse at local levels, which could be aggregated to form areas of enumeration district size upwards. This provided the opportunity to analyse the data at a community level – as is described in this chapter for Shirebrook in North Derbyshire. The limiting long term illness data gave an opportunity to assess self-perceived health status from a well-tested question in locally defined geographical areas. There must, however, be a question as to the validity and acceptability of such a self reported health indicator in the local policy context. Thus this also describes how the validation survey was undertaken in Shirebrook in North Derbyshire to assess how closely the question used in the Census generated a measure of ill health that GPs would clinically corroborate. The survey sought to corroborate the measure of ill health rather than the actual levels of limiting long term illness that was produced by the Census in the area, as a survey in a health care setting would inevitably generate a "sicker" population to survey. The GP practice in Shirebrook had begun to work with the Public Health Department at the Health Authority to develop and undertake primary care health needs assessment. The practice had felt that their fund holding allocations did not reflect the health care need of the population. The GPs were keen to influence the impending total fund allocations in 1995 in an attempt to ensure that allocations did not disadvantage their population in the future. There was considerable local interest in assessing whether levels of self-perceived need matched the demand for primary health care in the local GP practice and also whether the provision of care was meeting this need. The study generated a high level of both commitment from the local primary care team and interest in measuring health status. The use of such information in local health care planning reinforced the importance of examining data other than that which describes the delivery of current services. The validation survey undertaken in conjunction with the practice subsequently drove efforts to review local resource allocation to primary care in the context of examining the wider characteristics of the population. The survey work played a significant role in encouraging subsequent participation by the Shirebrook practice. This practice was formerly a practice that had not generally participated to any great extent in local primary care "politics" in the political process of influencing how need should be a major consideration in a policy of equitable resource allocation to general practice. This work and the consequent political aspects provide the main focus of chapter five. The interest and enthusiasm generated drove efforts to review methodologies on local resource allocation to primary care in the context of examining the wider characteristics of the resident population. This is described in Chapter Five.

4.2 Measuring morbidity in the general population in national surveys

Questions about morbidity have historically been asked in various forms by several types of large-scale surveys. Censuses carried out between 1851 and 1911 included questions about infirmity and diseases in various different forms.

These early censuses collected information about deafness, blindness and "lunacy". This provided some early data on the occurrence of some types of morbidity amongst the general population. After 1911 questions about ill health were not used in national Censuses as it was felt that the results produced were neither useful, meaningful nor complete[109]. Since 1971 questions about long standing illness and acute illness have been part of the General Household Survey (GHS) alongside questions about use of hospital and general practitioner services. Analysis of the data[110] suggests that people reporting long standing illness in the General Household Survey are more likely to report having recently experienced inpatient care. The quarterly Labour Force Survey[111] provides information about long term disability limiting work in the general population surveyed. The General Household Survey, the labour force survey and other disability surveys such as the Surveys of Disability[112] in Great Britain that are carried out sporadically do not provide small area information. Neither do they provide uniform information about large populations. However, such information is both interesting and has many different uses including extrapolation to smaller areas. The introduction of a question about limiting long term illness was proposed for the 1991 Census and produced the potential to examine more readily the patterns of limiting long term illness in the whole population at lower geographical levels. The1991 Census was the first dataset collected nationally which had the potential to produce general health information about every person and household in Great Britain since the 1911 Census and to provide information at a small area level.

The data collected comprised a comprehensive assessment and was obtained via a thoroughly tested question[113],[114]. This could be used to estimate the level of chronic illness and disability and used at many levels and types of geographical aggregation. In addition it potentially provided a basis for analysis of trends over time by comparison with the next Census in 2001. A positive response to the question asked in the 1991 Census to define limiting long term illness has been shown[115] to be strongly associated with physical limitations. The positive response suggests that common health conditions are two to three times more prevalent amongst those with limiting long term illness. An illness that limits activities will have a different meaning for people at different life stages and those leading different types of lives and carrying out different occupations. A manual worker, for example with a limiting long term illness will be more restricted from a physical task than a non manual worker with a limiting long term illness. Thus, response to the question will be influenced by the physical demands everyday life makes upon a person. The limiting impact of the illness will be influenced also by the level of access to public and private transport and also the existence or not, of social networks to provide care and support. Geographical location will influence the impact of limiting long term illness and also access to material resources and the resulting capacity of individuals to access assistance and mobility to carry out daily tasks and occupations. These types of social and economic considerations impact on ability to demand and access health care.

The Census question may incorporate a level of subjectivity as it is not supported by the diagnosis of a clinician as has been the case for other surveys such as the Health Survey of England[116, 117, 118.] However, the data on limiting long term illness from the Census has been shown to be comparable with the findings from the General Household Survey and the Health Survey of England[119, 120, 121] in measuring levels of ill health. The strength of the limiting long term illness data are not so much in identifying absolute totals of people with limiting long term illness, but is in its versatility in providing comparisons at many different geographical, service and political aggregations. Due to the relatively low levels of aggregation possible with Census data, such analyses are available for small areas and this provides potentially valuable material for local planning and research purposes.

The limiting long term illness data are a reflection of a person's or a household's own assessment of their health. In turn their own perception of their health may influence how much they attempt to access to local primary care services. Primary care is available in England by self-referral and is free at the point of delivery. The limiting long term illness data could therefore be viewed as an indicator of illness or health, both perceived and real, in an area. Measuring limiting long term illness could also be seen as a method of measuring potential demand and self assessed need for health care services. If a person believes that they have a limiting long term illness they are more likely to demand health care, this will have a particularly significant impact on use of primary care services. Limiting long term illness has been shown[122] to correlate highly with level of health service usage in the validation carried out after the 1989 Census test.

Response to a question about self perceived limiting long term illness is probably less likely to be dependent on the influence of local historic access and supply of health care provision. This is because it is not a question which when answered will need definite confirmation of illness by a health professional. Therefore, where a strong correlation between self assessed limiting long term illness and level of health service usage is found this indicates perhaps that an area with high self perceived illness might lead to the generation of higher than average demands being made upon local primary health care services and subsequently hospital services.

Local policy and planning use of the limiting long term illness question was likely to occur if the relevant authorities were convinced that the data had been derived via a well-tested and robust question on health. The proposed inclusion of a question about limiting long term illness in the Census was an innovation and it was therefore necessary to ensure that any question that was used was thoroughly tested before application. Two questions relating to health were tested, one of the questions proposed for the Census asked about limiting long term illness, the other about disability. After the Census test[123] had taken place it was clear that the question about disability had not been successful. Non-response to the question was observed for 21% of the sample and the follow-up interviews showed that the non-respondents were actually those who were more likely to be suffering from disabilities. Only 30% of those who were subsequently assessed as being disabled at interview had indicated that they considered themselves to have a disability when responding on the Census test form. The Census test showed that the level and nature of disability varied immensely which suggested a significant problem in defining and measuring the level of disability. This also implied that the disability question was not an adequate and robust tool that could be included in the 1991 Census itself.

The question that was designed to obtain information about limiting long term illness for a population appeared more satisfactory for the following reasons. Results were consistent with the results obtained from the General Household Survey and correlated with reported health care service usage. The Census test[123] had shown that, when validated the data gave information which provided a variable in the Census that could indicate levels of general ill health within the population. In the 1989 Census test, 91% of respondents were obviously able to understand the question and filled in the limiting long term illness question on the form correctly. The post enumeration survey validation of the responses showed that 72% of those with a limiting long term illness as defined by the question had correctly assessed themselves as having a limiting long illness as corroborated by a nurse interviewer. The test seemed to have shown the value of including a question about limiting long term illness in the 1991 Census and it was included in the final survey.

4.3 Results available from the 1991 Census relating to limiting long term illness.

The actual question that was included in the 1991 Census was:

"Do you have any long term illness, health problem or handicap which limits

your daily activities or the work you can do? (Include problems that are due to old age)"

Responses permitted were *"Yes, have a problem which limits activities"* or *"Have no such health problem."*

Data generated by this question had the potential to provide local information that could influence and support planning and provision of health care services. It was available at many geographical and community aggregations and could provide summary information about groups of communal establishments in areas. The question was answered for all residents in households and communal establishments. These results from the Census provided data from which OPCS produced seven tables for publication at various regional, district and many sub district geographical aggregations. These tables produced information about limiting long term illness for households, persons and communal establishments and gave limiting long term illness tables about age, gender, ethnicity, economic activity, tenure and amenities and household types.

At a national level, results from the 1991 Census show that the areas where the highest rates of self reported limiting long term illness were in the traditional coal mining areas and areas of heavy industry in the North East of England[124]. This was of particular interest to the study of Census data being undertaken in North Derbyshire where coal mining had been a significant part of the local economy.

The following graph illustrates the differences in levels of limiting long term illness between the standard English economic regions.

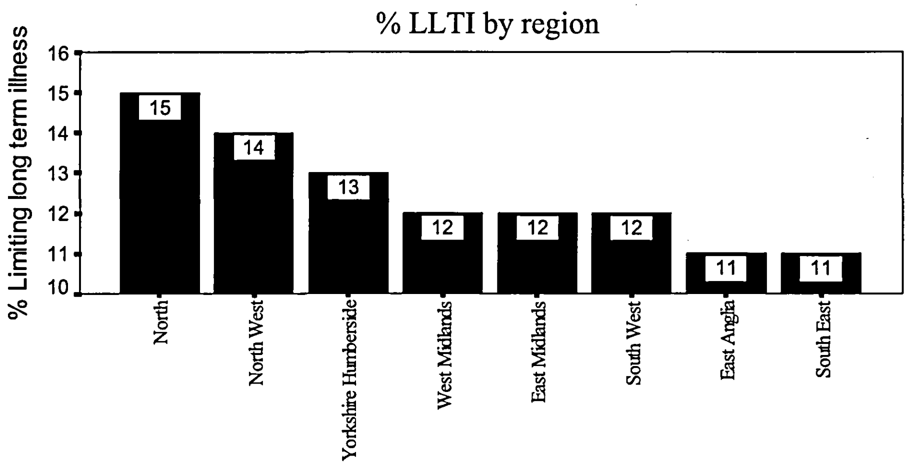


Figure 3 percentage reporting limiting long term illness in the1991 Census by standard economic regions:

The regional analysis of the national data showed a clear gradient in levels of limiting long term illness from the North (where the majority of heavy industry and mining had taken place) to the South of the country.

Age and Gender

As age increases the likelihood of illness and disability increases, therefore levels of self assessed limiting long term illness increase with age. There are known differences in life expectancy[125] between men and women and it is also therefore important to examine limiting long term illness levels in the separate contexts of men and women.

Nationally results showed that the proportion of residents reporting limiting long term illness increased, unsurprisingly, with age for both men and women. For men there were high rates of limiting long term illness in the 55-69 year age group and high rates for women after the age of 64 years. The question asked respondents to include problems due to old age, so the item therefore leads to answers influenced by age and changing expectations of health. It is likely that there is a difference perceived between fitness to perform daily activities and the limitations applying to performing tasks in the workplace[126]. This suggests that respondents answer the limiting long term illness question with respect to the current tasks they would be faced with, so expectation for health differs between different age groups. For example an active 75-year old man would probably have a different expectation of "normal health" to a 25-year old male manual worker. Therefore it is important to realise that limiting long term illness is not an absolute measure of health but a measure of how much health or illness limits the current expectation of fulfilment of everyday tasks. There will be a baseline of need for health care different for different age groups. Older people will inevitably need and demand more health care than younger people but there will be different expectations of care by age and therefore varying demand and need for health care by age for perhaps the same level of illness or disability.

In order to provide adjustment for the increased reporting of limiting long term illness as age increased age-gender standardised limiting long term illness ratios were calculated for England and Wales by Wallace and Charlton[127]. By implication this standardisation helps to adjust for areas which had high levels of young or elderly people that might mask any high or low levels of limiting long term illness. The analysis by Wallace and Charlton showed that even with the standardisation the highest ranked areas for limiting long term illness were still the areas of the old coalfields and other areas of former heavy industry such as the North East of England. This ranking of the standardised limiting long term illness is the same for men and women but the rate for women is consistently lower than that of the men in the same areas. However the pattern reverses when the overall rate of limiting long term illness falls, that is in areas where there is a lower than average experience of limiting long term illness, women on average have a higher rate of limiting long term illness than males in the same areas. The areas displaying the lower rates of limiting long term illness (i.e. less than the national average of one hundred) are mostly in the South of England and have large proportions of rural areas within the county. Wallace and Charlton also compared standardised limiting long term illness ratios with English standardised mortality ratios for those less than 75 years of age by local authority areas for deaths from all causes, circulatory disease, all types of cancers and respiratory disease for males and females. This analysis indicated a strong relationship between premature mortality in an area and limiting long term illness in the same area. There was a correlation of 0.8 for men and 0.82 for women. It was felt that higher rates of limiting long term illness locally were likely to be as a result of similar influences to those operating nationwide and supported the use of the limiting long term illness data at a local level.

Economic Activity

The state of health experienced by an individual has a large influence on ability to work and therefore the ability to be economically active. Limiting long term illness data could be used locally in conjunction with data relating to economic status such as unemployment and disability benefit claimant levels. The Census definition of limiting long term illness defines a health problem or handicap limiting a person's daily activity or work that a person can do. This does not however preclude economic activity on the part of the respondent. In 1991 in the 16-59 year age group nationally, 45% of men with a limiting long term illness were economically active and 30% of women were economically active[127]. Unemployment amongst the population of limiting long term sick was 23% for men and 55% for women compared to 7% and 11% amongst the general population. This suggests a strong relationship between limiting long term illness and unemployment or entitlement to permanent sickness benefit. This was of particular relevance to the work in North Derbyshire where high levels of permanent sickness, limiting long term illness and unemployment were apparent (See Figure 3) in the old coal mining areas. It should also be noted that limiting long term illness is a measure of morbidity not life threatening illness. Senior[128] showed that current or former employment in the coal industry, unskilled and semi-skilled occupation, high deprivation score, overcrowded housing conditions and, higher than average percentage of non white population were predictors of high rates of limiting long term illness. Rees[129130] suggested that an important influence on levels of limiting long term illness is the nature of working environments. Areas of high limiting long term illness tend to have or have had hazardous working environments such as coal-mining or the chemical industry. In an analysis of the Census data from 1981 and 1991 for the 65 wards of South Yorkshire, Green et al[131] found a correlation of 0.58 between the 1981 percentage of male unemployment in the mining industry and 1991 standardised limiting long term illness rates. High levels of lifestyle hazards such as smoking confound these factors. These were patterns, which were likely to be relevant to North Derbyshire and would have an effect on need and demand for health care. Limiting long term illness clearly has an impact on capacity to undertake economic activity where there has been heavy industry.

Haynes has suggested[132] that there is a bias in reporting limiting long term illness and permanent sickness due to labour market conditions but that these same patterns do not reappear in mortality data. Haynes examined all cause standardised mortality rate for those under 65 years of age and limiting long term illness amongst those under 65 and permanent sickness amongst 16 to 64 year olds and compared the results with Carstairs deprivation scores. Haynes then performed multi-level modelling at three geographical levels. These geographical areas were Census based electoral wards, travel-to-work areas and standard economic regions. Ward and regional effects were held constant and variations between travel to work areas were compared for limiting long term illness and long term unemployment. There were 8690 wards and 262 travel to work areas. Variations in mortality, limiting long term illness and permanent sickness were related to Carstairs deprivation scores and standard region. With these relationships controlled, permanent sickness was shown to be significantly related to long term unemployment in travel to work areas but mortality was not affected.

4.4 Analysis of limiting long term illness in North Derbyshire

Local analysis of the Census data and particularly of the limiting long term illness question clearly provided the opportunity for increasing and clarifying local knowledge and understanding of the health care needs and the factors that had influenced these patterns of need. At the time of the Census in 1991 North Derbyshire Health Authority comprised of five administrative health localities covering geographic, demographic and economically contrasting areas of the Derbyshire Dales and High Peak in the relatively affluent west of the district and the more deprived eastern areas of Chesterfield, Bolsover, Clay Cross and North East Derbyshire. The Census data relating to limiting long term illness in North Derbyshire showed that for all ages and all persons the overall rate of limiting long term illness was 14%. However, the range amongst the electoral wards was between 8% and 22%, revealing large variations within the one Health Authority area.

Analysing the North Derbyshire limiting long term illness data using an indirect method of standardisation and standardising data by age, a ratio, analogous with the standardised mortality rate may be calculated at various levels, e.g. electoral ward, GP practice, and enumeration district. This approach was first introduced by Smith and West[133] and produces the standardised morbidity rate (SMBR) which measures the numbers reporting limiting long term illness in relation to the number that would be expected if the rate of long term illness for the whole Health Authority population was homogenous across the entire area. Comparative work was undertaken using the Census data on limiting long term illness to support planning and ultimately this could contribute to the allocation of the provision of care and resources within North Derbyshire. It was therefore important that the SMBR calculation standardised the rates to the North Derbyshire population as the comparison was being made within the Health Authority area. Therefore taking an overall district value as 100, a ward or GP practice area, for example, which had an SMBR of 125, would have 25% more reported long term illness than would be expected. Using 1991 Census data for limiting long term illness, SMBRs were calculated at electoral ward level for the North Derbyshire area to produce a measure which might assist in planning for health care provision in the North Derbyshire Health Authority area. SMBRs were calculated for all North Derbyshire electoral wards for all ages. The lower rates of limiting long term illness were indeed found in the three relatively affluent areas of North-East Derbyshire, the Derbyshire Dales and the High Peak area. The highest rates of limiting long term illness were apparent in the areas of coalfield closure and industrial decline in the east of Chesterfield and in Bolsover as illustrated in table 1. Bolsover experienced 26% more self reported limiting long term illness than the North Derbyshire average, Chesterfield 11% more. This illustrates the variation across the district, clearly apparent even using locality level analysis. These results seemed to confirm the general belief within the Health Authority about levels of use of health care resources overall and patterns of mortality in these localities.

Table 1 SMBRS 1991 and percent with 1991 limiting long term illness, by Health Authority locality

Locality	SMBR	% With limiting long term illness in the population
Bolsover	126	16.9
Chesterfield	111	15.1
Derbyshire Dales	86	12.3
High Peak	96	12.1
North East	105	13.7

4.5 Patterns of limiting long term illness in the North Derbyshire coalfield

The analysis at locality level suggested that the main areas of higher than average limiting long term illness were in the localities where there had been coal mining. These were large areas of Bolsover and parts of Chesterfield and North East Derbyshire. In 1981 there were eleven active collieries in North Derbyshire that employed 11,550 miners[134]. When, in the 1980s, the coal industry was confronted with increasing demands for higher productivity and greater efficiency, colliery closures, mergers and job losses took place. Throughout the 1980s this trend continued and in 1992 the "Coal Review"[135] recommended a severe reduction in production. This resulted in the final closures of North Derbyshire's last remaining pits in 1993. Derbyshire overall was very badly affected by the protracted run down of the coal industry over a long period of decline[136]. At first job losses through closures were generally absorbed by transfers to other longer life collieries or by early retirement packages. Following the 1992 Coal Review these types of options were no longer available as pit closures and mothballing had taken place extensively in three Nottinghamshire and Doncaster coalfields where transfers had previously taken place and the final decline of the coalfields took place.

In 1991, at the time of the Census, there were 3,400 miners working in the pits, with an additional 7,398 people employed in coal and energy related industry. This comprised over 15% of the male and female working population in the North-East Derbyshire, Bolsover and Chesterfield areas. Ill health connected with unemployment as a direct result of the pit closures is difficult to specify and even harder to quantify. Moser et al[137] demonstrated how suicide and lung cancer was highest amongst unemployed men who were seeking work. In the 1950s Cochran and Carpenter[138] conducted radiological surveys in areas where miners and ex-miners lived. The twenty-year follow-up study[139], [140] of 8,526 men aged 20 and over from the Rhondda, South Wales showed that miners and ex-miners had an excess mortality compared with non-miners. This was attributed to the high incidence of pneumoconiosis. Bronchitis and emphysema have been described as "miners' disease" since the nineteenth century. Using data collated for the "Housing and regeneration of coalfields" study, Grimsley[141] and Green showed a correlation of 0.59 between the 1981 percentage of male employment in coal mining and under 75 respiratory disease mortality rate 1992-96 for the 65 wards in the South Yorkshire coalfield. Hazards are not confined to coal dust, as fatal and disabling injuries have been a significant risk. More recently a number of studies have examined the possible contribution of ill health to the many significant changes in the mining communities. Beatty and Fothergill[142] reported increased rates of permanent sickness in coalfield communities which are exposed to job loss and loss or closure of the coalfield. Dicks[143] examined stress-related ill health in communities affected by closures and the Silverhill Study[144] notes a higher presence of psychological disorder in unemployed-miners.

In order to explore further the patterns of limiting long term illness in the North Derbyshire coalfield areas, data for each electoral ward in North Derbyshire Health Authority were examined. This provided information on the age-sex structure and numbers with limiting long term illness. From the 105 wards in the district, 26 were classed as areas in which miners were likely to work and/or live. This classification was made by selecting wards where either a colliery was located or that where there was a higher percentage of men of working age working in the mining industry than the North Derbyshire average according to the 1991 Census. [145]

In Figure 4 the shaded area shows the electoral wards of North Derbyshire where either a colliery is located or miners travelling to a local colliery are likely to live and/or work. There "likely to live areas" are concentrated around Chesterfield and Bolsover.

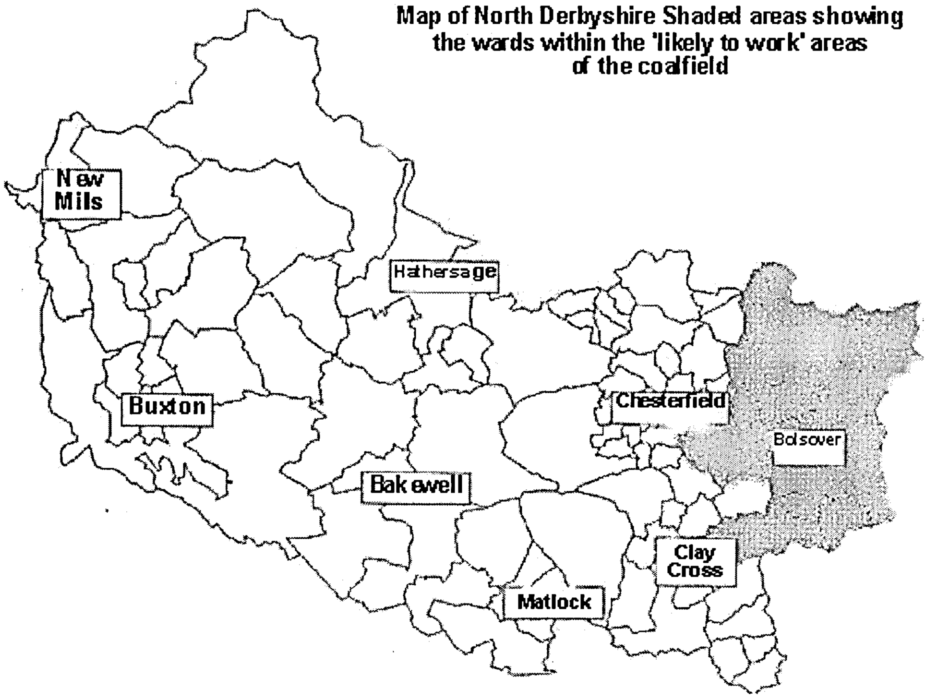


Figure Map of North Derbyshire showing likely to work areas of the coalfield.

The second map in Figure 5 illustrates the distribution of SMBRs and it is clear that the concentrations of the highest SMBRs are in the east of the district, particularly in Bolsover and Chesterfield. These are the main locations of the former collieries in North Derbyshire. There is an obvious coincidence between those areas where collieries were located and the associated travel to work areas and wards with high SMBRs in North Derbyshire. This suggests a connection between residual morbidity and employment in the coal industry in the North Derbyshire coalfield areas.

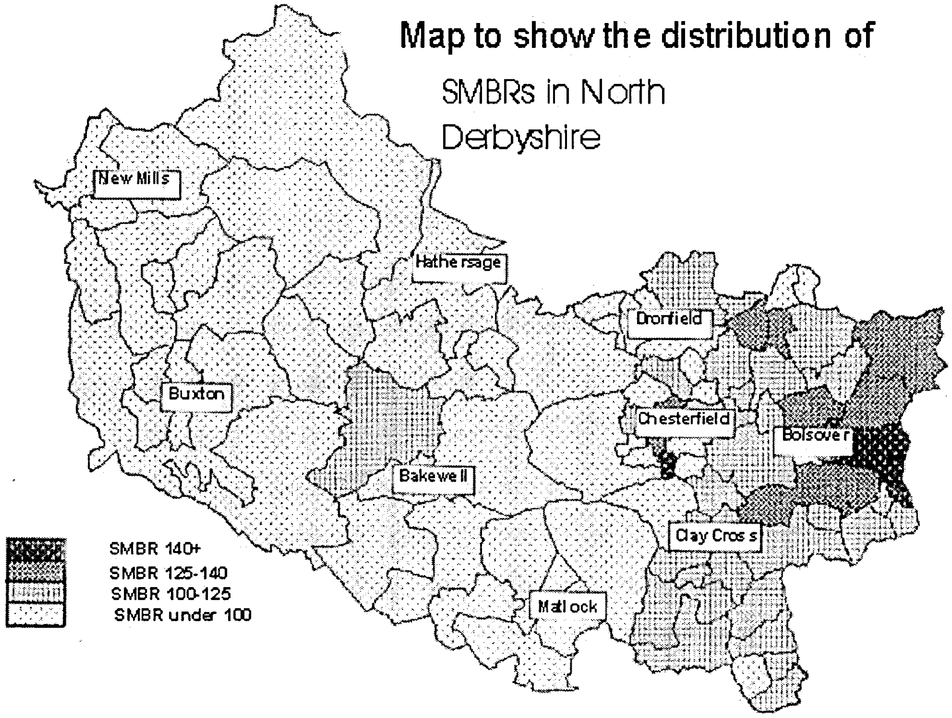


Figure 4 Map showing the distribution of SMBRs in North Derbyshire 1991

Colliery closures and the ensuing influence on unemployment and permanent sickness levels may well have a disproportionate effect on the population below retirement age[146]. In addition to the more general effects on whole communities, SMBRs for the population have also been examined for North Derbyshire, separating the pit and non-pit areas. The analysis is illustrated by the boxplot in Figure 6.

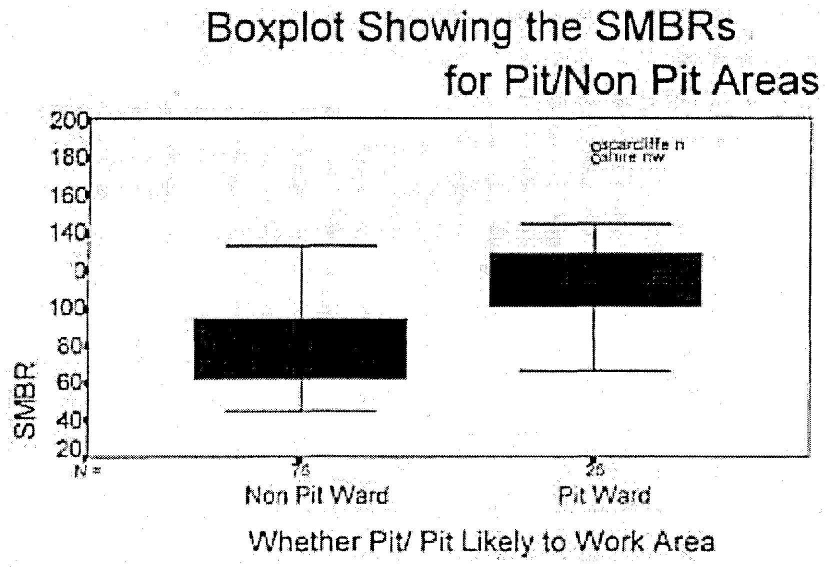


Figure 5 Boxplot of SMBRs 1991, electoral wards with and without a pit

The boxplots of "pit/ no pit" wards and SMBRs in Figure 6 show a clear pattern of wards with a pit, or within the travel-to-work area of a pit, exhibiting predominantly above average SMBR values. Of these, 80% have an SMBR greater than 100 and 36% have a SMBR greater than 120. In areas without a clear mining connection only 3% show an SMBR greater than 120.

The distribution of SMBRs by wards suggests a definite concentration of higher rates of reported limiting long term illness in the former areas of mining and heavy industry. This finding is consistent with the national picture[147]. Coalfield areas may experience features of social and economic deprivation, which inevitably confound the task of identifying ill health as being directly associated with working in the mines. It seems reasonable to suggest a link between coalfield areas, general under privilege and therefore raised levels of ill health and demand for primary health care.

The analysis of the North Derbyshire data focused attention on the declining areas of Bolsover. Primary care health needs assessment was already being undertaken by the Health Authority Public Health Department with a general practice in Shirebrook- an area of Bolsover. This area included the two electoral wards with the highest SMBRs in North Derbyshire: Scarcliffe with an SMBR of 180 and Shirebrook North West with an SMBR of 190. The practice was keen to understand the implications of these data and how they impacted on their population and their workload. The practice wanted to use data locally to raise questions about whether current resource allocation was equitable with respect to need and also whether patients were able to access health care at a level appropriate to the seemingly high levels of need. The limiting long term illness data seemed to provide evidence in support of what the Shirebrook practice believed. This was that demand was high and was being driven by need and was not a result of poor demand management- as had been suggested to them by the Family Health Services Authority in 1993. The practice agreed to collaborate with the Public Health department to undertake a validation survey of the limiting long term illness question.

4.6 Validating limiting long term illness as a measure of morbidity in Shirebrook, North Derbyshire

Case study: limiting long term illness

- Practice profiles produced to support practices in understanding social, economic, mortality, morbidity and health care usage by their populations, in relation to other practices.
- Generated great interest from one particular practice in an isolated, deprived part of North Derbyshire. There was particular interest in local results of limiting long term illness question from census and its implications for health care need and demand locally.
- Undertook a validation exercise of the limiting long term illness question with practice GPs making a clinical assessment of the presence of limiting long term illness and patients independently doing the same. Researchers comparing the paired results. Suggested to GPs clearly that limiting long term illness produced a good proxy for likelihood of demand by patients.
- Facilitated an increased interest in levels of equity of resource allocation to primary care locally and a new confidence to assert themselves and suggest review of resource allocation to primary care- resulted in the formation of an 'equity group'.

Background

Shirebrook is a town to the East of North Derbyshire in the Bolsover locality. It is on the Derbyshire/ Nottinghamshire borders in an area of the former coalfield. Shirebrook is a relatively isolated rural community, with poor public transport provision. The coalfield was formerly the main source of employment in the town. The proportion of households without access to a car in Shirebrook was 10% higher than the North Derbyshire average according to the 1991 Census. This indicator is less an indicator of affluence in this semi rural area than an indicator of reduced access to amenities and services and coupled with poor public transport links suggests that ease of access to services such as hospitals outside the town will be limited.

The overall picture of health and socio economic characteristics of Shirebrook suggested that the area was likely to have a higher than average need for health care than other parts of the district. The GPs agreed that they would be prepared to clinically assess whether they believed patients attending their surgery had a limiting long term illness and also that they would request patients to independently make an assessment of their own limiting long term illness status.

The Shirebrook practice in 1993 provided services to most of the population in the area and had a list size of about ten thousand. The male population of the area showed a lower than average concentration (when compared to North

Derbyshire in 1991) of males from the middle, economically active group (aged 24-55). This was probably a result of reduced opportunities in the Shirebrook area following the closure of the pit. This had led to migration away from the area by younger men in search of work and better prospects. The female population of Shirebrook showed a larger than average concentration of elderly and young women. The result was an "economically dependent" population structure. In Shirebrook there were fewer houses that were owner occupied than in North Derbyshire on average and this is shown in Table 2. Shirebrook had a larger than North Derbyshire average proportion of persons registered as permanently sick and similarly the percentages of those on a government scheme, unemployed or "other economically inactive", were higher than in Health Authority or locality averages. Table 2 indicates some of these contrasts:

Table 2 Socioeconomic characteristics of Shirebrook, Census 1991

Indicator	*Shirebrook*	*North Derbyshire Health Authority*
% owner occupied housing	60	69
% rented accommodation	39	30
% overcrowded (Defined as more than 1.5 persons per room of living space)	2	1
% of households with no car	35	23
% of dependants in single carer households	30	28
% of population from black and ethnic minorities	0.4	0.7
Of the population 16 -65 years:		
% permanently sick	8	5
% of "other inactive"	22	16
% unemployed or on a government scheme (Census 91)	12	10

Table 3 indicates the rates of limiting long term illness in Shirebrook compared to North Derbyshire.

Table 3 Percent with long term illness in Shirebrook (Census 1991)

% of population with limiting long term illness	*Shirebrook*	*North Derbyshire Health Authority*
aged under 65	12	8
aged 65 and over	46	41
all ages	18	14

Use of the Standardised Mortality Ratio enables comparisons with other local and national mortality patterns. Table 4 shows that all cause mortality, deaths from accidents, breast cancer and lung cancer were significantly high; these raised rates were indicators of general high levels of illness and inferred need for access to health care services.

Table 4 SMRs Shirebrook and North Derbyshire Health Authority. (1987-91)

Cause of death	*SMR Shirebrook*	*SMR North Derbyshire Health Authority*
all causes	108	100
all cancers	128*	88
breast cancer	143*	92
lung cancer	147*	91

(An asterisk denotes a statistically significant low or high result, i.e. a difference that does not occur by chance)

The general fertility rate for Shirebrook was much higher than the average rate for North Derbyshire Health Authority and England and Wales. There was a higher likelihood of low birthweight in Shirebrook than locally or nationally.

The infant mortality rate was higher than the England and Wales rate and also the North Derbyshire rate. This is shown in Table 5.

Table 5 :Child Health Indicators, Shirebrook 1987-91

Indicator	*Shirebrook*	*North Derbyshire Health Authority*	*England and Wales*
Low (%) birthweight (under 2500g)	7	6.9	6.7
general fertility rate (Live births per 1000 population)	79	61.2	63.6
infant mortality rate (deaths per 1000 live births under 1 year old)	7	4.2	6.5

The survey

The aim of the survey was to examine the relationship between patients' perception of their limiting long term illness and to validate this by comparing it with independently assessed GP opinion. This study was not intended to validate the Census 1991 results. The work was undertaken as a piece of original research as part of the PHD study The work subsequently informed local policy and political processes but would not have been undertaken otherwise. As this survey was targeted at a group who were attending a doctor's surgery for diagnosis and/or treatment there was a probable bias towards "illness". Respondents would be likely to produce rates of limiting long term illness higher than that measured by the Census in the area. The intention of the survey was to provide evidence that limiting long term illness was a concept that measured an illness phenomenon that the primary health care team recognised. Thus there should be high levels of correlation between patient and GP assessed limiting long term illness. The GPs believed that the survey would confirm that limiting long term illness was a measure that reflected illness translating into demand for primary health care.

A survey was undertaken in the main GP surgery in Shirebrook of 500 patients in September 1994. The survey questionnaire consisted of two separate parts; the first part was completed by the patient, the second part by the GP with whom the patient had had a consultation. (See Appendix: Chapter Four) Patients were also asked to provide some basic socio-economic information about age, gender and economic status. Neither the GP nor the patient had any knowledge of each other's response having completed the questionnaire independently. An identifier could however match the responses to determine whether patient and GP opinions were the same or different.

The survey was piloted by GPs for two surgery sessions to test whether the method of administration would work and to assess whether patients would be prepared to participate. This pilot survey proved the questionnaire and survey method to be valid and the practice proceeded to the full survey.

The survey method employed was a complete enumeration of all patients attending all surgeries (except emergency surgeries) until a quota of 500 questionnaires had been distributed. A "census" of patients was undertaken for ease of administration by the GPs but also it was hoped this would produce a typical cross section of patients consulting over a time period. The data collection period lasted approximately two weeks. Of the 500 questionnaires distributed 336 responses were returned and were completed by both GP and patient with both pairs being usable. This result represented a response rate of 68%. The survey had been completed sooner than the estimated four weeks that the practice had predicted, suggesting high levels of compliance by patients and commitment from the GPs. The data were entered into a data base package and analysed using SPSS.

The percentage of the responding patient population, who considered they to have limiting long term illness, was 55% (184) for all ages. This was considerably higher than the rate for the practice extrapolated from 1991 Census data of 18.4%. This was an expected outcome as the sample was essentially a self-selecting sample of "ill" people seeking health care.

The percentage of the population aged between 16 and 60 in Shirebrook who perceived that they had a limiting long term illness, according to the Census, was 14%. The survey at Shirebrook suggested that 49% (107) of those between 16 and 60 years believed they had a limiting long term illness. In the all ages group the GPs considered 42% (140) of the sample to have a limiting long term illness. In the 16-60 year age group the GPs considered 37% (99) of the age group to have a limiting long term illness. Overall there seemed to be general agreement, see Tables 6 and 7, between the GP assessment of the presence of limiting long term illness and self-reported limiting long term illness. This in 77%, or 242/315 of the paired questionnaires for all ages there was agreement between the presence or absence of limiting long term illness by patient and GP.

Table 6 Comparison between limiting long term illness assessments by patients and GPs for all ages.

Total %	GP assesses LLTI present	GP assesses LLTI not present
Patient self-assessment of LLTI present	38% (120/315)	17% (53/315)
Patient self assessment of LLTI not present	6% (20/315)	39% (122/315)

Agreement was weaker for the patient assessed limiting long term illness group but GPs agreed with 120 of the 173 patients who reported that they had suffered from a limiting long term illness.

Table 7: Comparison between limiting long term illness assessments by patients and GPs for those aged 16-60.

Total %	GP assessment of limiting long term illness present	GP assessment of limiting long term illness not present
Patient assessment of limiting long term illness present	33% (83/251)	16% (40/251)
Patient assessment of limiting long term illness not present	6% (16/251)	45% (112/251)

Overall in 78% of the paired questionnaires for those aged 16-60 there was agreement between the GP and the patient about the presence of limiting long term illness. Just over two thirds of this age group who reported a limiting long term illness found that their GP agreed.

In the Census test validation assessment of the limiting long term illness question in 1989 there had been 72% agreement between GP assessment of limiting long term illness and patient assessment so the overall Figure for agreement between GP and patient assessment of limiting long term illness of around 77% seemed a satisfactory result.

Analysis of the characteristics of the groups whose assessments varied from the GP's assessment are summarised in Tables8-10

Table 8 Comparison by gender, where GP and patient opinion differed about whether limiting long term illness was present

Row %	Male	female
Overall limiting long term illness	41	59
GP: limiting long term illness , patient: no limiting long term illness	44	56
GP: no limiting long term illness, patient: limiting long term illness	38	62

The chart in table 8 suggests that men are more likely than women to assess themselves as not having a limiting long term illness when the GP considers that they do. Overall GPs are more likely to assess women as not having limiting long term illness than men. This may be as a result of inaccurate assessment of limiting long term illness by women or it could be as a result of GPs assessing men in the context of their ability to work. Women may be perceived by the GP as being able to undertake their required routine tasks living with higher levels of limiting long term illness than the levels of limiting long term illness with which GPs would expect men to be able continue paid employment.

Table 9: comparison between overall population in the survey and the subgroups where GP and patient opinion differed about presence of limiting long term illness and characteristics by economic status

Row %	Unemployed	Employed	retired	Permanently sick
Overall	19	41	24	16
GP: limiting long term illness , patient: no limiting long term illness	18	53	24	5
GP: no limiting long term illness, patient: limiting long term illness	13	36	31	20

The graph in table 9 indicates that those in employment are least likely to assess themselves as a having limiting long term illness when the GP does consider this to be the case. This suggests a connection between individual feelings of well being or perhaps economic need to remain working and therefore a reluctance to assess oneself as having limiting long term illness. Retired people are more likely to believe they have a limiting long term illness when the GP considers that they do not. This could again be a reflection of the GPs perceptions of the threshold of limiting long term illness in relation to lifestyle and needs for daily living and perhaps a bias towards those who are actually employed in paid work. It is interesting that there is a significant group of respondents who are economically classified as having permanent sickness for benefit purposes, presumably by a medical opinion but the GP does not consider the group to have a limiting long term illness. This once more suggests that the GP's assessment is based around his or her perception of the threshold of limiting long term illness for paid work purposes. The GPs may be imposing a higher threshold for limiting long term illness classification on patients not in paid work. There is also perhaps some inaccuracy in the classification for benefit purposes as permanently sick or disagreement with this classification by the GP...

Table 10: comparison between overall population in the survey and the subgroups where GP and patient opinion differed about presence of limiting long term illness and characteristics by age

Row %	16-25	26-35	36-44	45-59	60-75	75+
Overall	9	10	20	19	10	32
GP: limiting long term illness , patient: no limiting long term illness	11	50	17	0	22	0
GP: no limiting long term illness, patient: limiting long term illness	0	14	28	28	26	5

Table 10 shows that the younger respondents, particularly those between 26 and 35 years are much less likely to classify themselves as having limiting long term illness when the GP does, than the older groups. This is perhaps a reflection of their greater prospect of employment than the older respondents in population. The older groups are much more likely to view themselves as having limiting long term illness when the GP does not than the younger respondents.

This analysis has shown some interesting patterns in the characteristics of the groups where GP and patient assessment of limiting long term illness differ. The analysis raises question about the clinical assessment and its relationship to GP expectations of what level of functioning is needed by those in different economic and life stage circumstances. There is, in particular, a suggestion of either a gender difference in perceptions of personal limiting long term illness or the GP's attitude towards limiting long term illness thresholds of women. This is an interesting finding as the literature suggests[147] that in areas of high limiting long term illness such as Shirebrook, one would expect higher rates of limiting long term illness amongst the men than the women. Though the setting of a survey in a health care environment may just suggest that women, in general, are more likely than men to seek advice or treatment in health matters.

The finding of much higher limiting long term illness rate in a survey undertaken in a health care setting (i.e. 18% in the 1991 Census and 49% in the Shirebrook survey) has also been shown in a survey carried out in Scotland in 1993[148]. In Lothian there was a rate of 15% limiting long term illness in the 1991 Census, but in the limiting long term illness survey undertaken in Lothian GP practices, there was a rate of 42% reported by patients surveyed. These types of results, where higher GP rates are found than Census measures rates, are not surprising. The real value of the Shirebrook survey, however, was in the clinical assessment of limiting long term illness which overall showed a high level of agreement between GP and patient. This survey goes some way to validating the limiting long term illness data as an indicator of health care need and demand in primary care. The data describes not only perceptions about limiting long term illness but also potentially perceptions that are influencing how patients may demand or need health care from their GP. Primary care in the UK is available free on demand at the point of delivery (i.e. in GP surgeries) and therefore perceived need as measured by limiting long term illness may translate into demand for primary care services. This would indicate that there are higher than average levels of demand for primary care in Shirebrook. The data collection had therefore confirmed the suspicions of the GPs and raised confidence in the use of the limiting long term illness measure as an indicator of need induced demand for their services. Here was, also, some encouraging evidence that a change in policy on resource allocation on the basis of need, which made use of the limiting long term illness question, might be politically acceptable to the "gatekeepers".

4.7 Conclusion

The question about limiting long term illness in the 1991 Census provided a measure which reflected general population health that had never been collected before. The data provided information about perceived morbidity of the general population which is widely available and may be aggregated to many different chosen geographical areas.

From the limiting long term illness data available it was possible to summarise differences in how levels of limiting illness were reported in different geographical areas and to begin to explore the reasons for these differences. In addition the possible differences in interpretation of the question or possible influences on the responses to the question could be investigated. A major finding of analysis of the data has been that the highest reporting of limiting long term illness was in those areas of the country, which had formerly been associated with heavy industry. These were now in economic decline and the populations subsequently experiencing high levels of unemployment. Areas which had high rates of morbidity and mortality and high rates of social and material deprivation were also generally shown to have high rates of limiting long term illness.

Limiting long term illness is a useful indicator at many geographical levels and provides a flexible tool that may be used with other measures of illness or health. While limiting long term illness is not a direct measure of need for health care, it is likely that those perceiving themselves to have a limiting long term illness are likely to expect or need to access health care. Therefore at a primary care level, this is likely to be reflected in the way that they demand and access health care. The limiting long term illness analysis undertaken in the east of the North Derbyshire Health Authority area showed Shirebrook to have the highest rates of limiting long term illness in the district. This was investigated, as part of the health needs analysis work in primary care in the area, and was brought to the attention of the GPs in a way that indicated to them the contrast of the area with the rest of the district. They were, unsurprisingly, aware of the deprivation and ill health in their area but saw the process of using the information and undertaking the survey as a valuable exercise in examining data. Such data were not directly connected with the process of the supply of health care. Limiting long term illness measurement was seen in the Shirebrook study as a way of illustrating community demand for primary care and as a reasonable proxy for need. Analytical results indicated that the majority of GP opinion agreed with patient's own assessment of whether or not they had a limiting long term illness. The survey did illustrate for that part of the population, where perception of their own health status differed from that of the GP, an interesting dilemma as to whether GPs were making value judgments about relative worth and need for fitness when looking at women, older people and those who were unemployed. The research provided an impetus to greater local involvement by the Shirebrook GPs. It encouraged lobbying for review and a chance to influence the resource allocation processes to primary health care in the district for the purchase of secondary care services. The Shirebrook practice was particularly interested in ensuring that the review of resource allocation should consider proxies such as limiting long term illness to indicate levels of measures of health care need and their subsequent influence on need and demand for health care. It was clear that the limiting long term illness data had its shortcomings; it was self assessed and therefore very subjective and also was only available at an electoral ward level every ten years via the Census but it could be collected at practice level. The Shirebrook work showed the importance of fair allocation of resources where demand is driven by self-perceived need and this type of need was clearly higher than average in Shirebrook. Despite its methodological shortcomings this study informed the work described in the following chapter of the thesis. Chapter Five "Operationalising Equity" deals with the development of proxies for measuring health and need and how these were used to influence the resourcing of primary health care.

Chapter Five: Operationalising equity in primary care- a case study in North Derbyshire

5.1 Introduction

Following the Shirebrook pilot investigation described in the previous chapter, this part of the research describes work undertaken which made significant progress towards raising awareness about the principles of equity in the allocation and expenditure of health care resources in primary care across the North Derbyshire Health Authority area. The work gives an account of a political process which was considerably influenced by research work. This led to a fundamental change in attitudes towards equity and primary care resource allocation in North Derbyshire. This project was generated by the research undertaken as part of this PHD, funded by North Derbyshire Health Authority and was utilised as part of local service public health work. It is unlikely that the process described in the chapter would have come about without the impetus of the research. The work described in this chapter illustrates the steps and obstacles to making changes in resource allocation and engaging stakeholders in the process using equity issues.

The process aimed to investigate and describe inequalities in access to health care and engage primary care and the Health Authorities to do something about perceived inequities locally. The work provided a focus and resource for local GPs and the Health Authority to undertake and participate in an informed debate about how equity might be considered and included in the allocation and use of resources locally.

This chapter utilises the concepts and measurement of equity in health care described in chapter two and describes the situation with routine data, building up a picture using the types of NHS data and health related information discussed in chapter three and four. This chapter leads into the final part of the thesis, which examines the impact of local funding, and local need on provision of final care for cancer patients and the resulting equity picture.

The work about "Operationalising Equity" was initiated following growing concern amongst some general practices and Health Authority representatives about how financial resources would be allocated to a local total purchasing pilot (TPP) and to a locality purchasing initiative (LPI) in the district. Both of these initiatives meant that a proportion of the total resource available to primary care in North Derbyshire would be allocated to practices participating in these initiatives. There was general concern that if an historical basis was used for allocation this would perpetuate any local inequities. It was therefore important to understand what was the current situation occurring and how this might be reconciled with patterns of perceived and measured need for health care resources as part of the process of allocation to the TPP and LPI. Some practices outside the two projects felt that the projects were likely to attract resources greater than their "fair share" from the total resource available to North Derbyshire for primary care. It was felt that there was an opportunity to understand and change possible inequity. No one really knew if the current resource allocation was "fair" or not.

There was considerable interest in exploring not only the conventional proxy measures of need that were familiar to primary care such as unemployment, the Jarman and the Townsend index and all cause SMR, but also the newer devices, such as the Census variable of limiting long term illness. There was also considerable interest in the formulae being developed at the University of York[63] for national use as a tool in resource allocation. The work moved in the direction of considering the many ways of viewing the local community and its need for and usage of health care. It became clear that no single measure adequately described the area nor was there one definitive formula that could be used to allocate resources but much insight was gained by using the array of information available to describe the "big picture" of health care need and historical usage in North Derbyshire.

The GP practice at Shirebrook had undertaken a validation survey with the public health department at the Health Authority of the limiting long term illness question from the 1991 Census (described in Chapter four in the thesis). This practice was particularly anxious to ensure that the new allocations made were informed by careful consideration of more than purely secondary care historical referral patterns. This type of interest and enthusiasm appeared to have emerged as a result of the transparent process of assessing and measuring local need via limiting long term illness data in their practice. This work had created alliances and opportunities for joint work between provider and purchasers, with an emphasis on assessing and understanding links between social deprivation and health need and utilisation.

The explicit question that was addressed was whether starting a process where equity had a higher priority than had been the case in the past in local primary care delivery could be facilitated, using routine data. The work of “operationalising equity” was fundamentally about how data, which describe the characteristics of the relevant population and the way that they associate with access to health care, was used to inform a political process. The work describes the application of quantitative solutions to a highly subjective issue. The approach of this part of the research was to use a “big picture” of data to inform and understand the current picture and use this routine information to focus on the issue of equity.

5.2 Examining the relationship between resource use and need in North Derbyshire

Case study:

- Clear result of increased interest in equity of access to health care for patients.
- Innovative formation of a group of locally nominated GPs, representative of areas and local opinion to work through aspects of equity and its impact with researchers.
- Innovative, engagement to discuss and agree local principles of equity.
- Educational process for equity group working through different models, tools and measurements.
- Local engagement in equity and existence of health inequalities, well before it was on the national agenda.
- Operationalisation of equity within local health care system, acknowledgement of its importance.

The North Derbyshire equity project aimed to do the following:

- To promote ownership of principles of fairness in resource allocation to primary care and to eventually address the problem of ownership of the equity issue and find a way to implement potentially contentious changes.
- To develop a way to describe how resources had been historically used by different general practices in North Derbyshire.
- To find ways that might be used to measure need for health care, which could assist and inform equitable and rational allocation of resources.

Finding solutions to these types of problems was an important part of the planned "primary care led NHS" as set out in Department of Health documents [149] [150] [151]. This envisioned primary care as the lead influence in the planning and delivery of health care.

North Derbyshire

The North Derbyshire Health Authority, in 1993 covered an inland, semi-rural district in the North Midlands. The population of the North Derbyshire Health Authority area according to the Census in 1991 was about 377,000. Overall, North Derbyshire was an area of relatively low deprivation within the then Trent Health Region and experienced, on average, similar patterns of mortality as the England average. There was, however a, contrast between the relatively affluent rural commuter and retirement areas of the Peak District in areas such as Bakewell and Buxton and the industrial towns and villages based largely on a now extinct coal industry [152,153] such as Chesterfield and Bolsover.

Fund holding was introduced, together with other major changes, in the National Health Service in 1990. This split the organisation of the NHS into those who provide services, such as hospitals, district nursing or physiotherapy, and those who purchase these facilities for the patients in their care. General practices which became fund holders were in a mixed position because most of the time they were providers of primary care, services such as that of the GP, the practice nurse, child heath and vaccinations. But when practices acted as fund holders they became purchasers of secondary care. Each practice was allocated a fund, which covered five areas of expenditure, hospital services, (except emergencies), drugs prescribed by the practice, community services, staff in the practice and management allowance. At the end of the financial year any remaining funds were kept as planned savings. These could be spent on any improvements at the surgery that were agreed to be for the general benefit of patients. There was much debate[154],[155],[156]about whether having both fund holding and non fund holding practices in a district led to a two tier service, with patients registered with non fund holding practices getting less equitable access to health care services than those with fundholding practices who could purchase in a locally sensitive way.

GP fund holding promoted the position of the GPs and placed with them the responsibility for purchasing and monitoring the health economy and shifted resources to the fund holding part of the economy. In 1994 there were 67 general practices in North Derbyshire. A five practice consortium was one of the Department of Health pilot sites for total fund holding. Ninety- three percent of the North Derbyshire Health Authority population was covered by fund holding practices. Fund holding in North Derbyshire was much higher than the 45% average fund holding coverage in England in 1994. In North Derbyshire fund holding was embarked on more widely and more quickly than in most parts of the country, GPs rapidly got used to thinking about how they believed was best to use resources on behalf of their patients at an early stage in the evolution of GP purchasing.

The total fund project would mean that substantial resources would be allocated to those GPs participating in the scheme. Other practices felt that before the allocation was made a review should take place of how equitable the current allocation was. The Locally Sensitive Purchasing (LSP) project was started in North Derbyshire in the autumn of 1992 and the Health Authority worked closely with fund holding and non-fund holding practices to find out how they would like services to be developed for patients. LSP was essentially a pre-cursor to total fund holding. Policy deficiencies and national attempts to link GP fund-holding budgets to capitation or at least a fairer system[157] had not produced a substantial shift in methods used to allocate resources. This indicated substantial financial risk especially in an area such as North Derbyshire where there were a high proportion of practices involved in fund holding, total purchasing pilots or locally sensitive purchasing. The Equity Group approach described later in this chapter was seen as a method of gaining ownership and commitment to the process where GPs would perceive the local benefits and the Health Authority would be able to demonstrate proper stewardship of the resources.

The "Big Picture": measuring need and examining historical access to health care in North Derbyshire

It was apparent, from extensive debate, that the current distribution of resources and the methods by which they were allocated in North Derbyshire Health Authority were haphazard and unscientific and liable to be rewarding inefficient practice. Resource allocation did not appear to be based on any measurement of need for health care but purely on a basis of past demand. There were two major problems at this stage. A locally acceptable measure of need had to be found and value judgements would eventually have to be made on how to apply the measure of need to allocate resources to practice populations in North Derbyshire.

Different indices and measures of need were examined and the usefulness of each measure and its limitations to the local situation was assessed. Included for consideration were well established measures of deprivation that have been applied in a health care context and suggested by GPs as useful such as the Townsend score[158] and the Jarman index[159], unemployment rates[160], the standardised mortality rate (SMR) for all causes[161] and the standardised limiting long term illness rate for those under 75 years [162]. All these measures were known to have limitations[163] [164]. These types of indices and their characteristics were discussed in the second chapter and the appendices of this thesis. The most common criticisms of all of the indices examined were that the work in North Derbyshire would not be applying the indices to the specific uses for which they had been designed. It was clear that no single measure was entirely suitable for the purpose of measuring deprivation and subsequently allocating resources. However, it was important to examine a wide range of descriptors to obtain a wide-ranging view of the "big picture" using socio economic characteristics in conjunction with health care usage in the area. It was thought that examining information in this way might provide a framework from which to assess historical and current equity of access to health care.

Measuring usage of health care in North Derbyshire

One of the major achievements of the local sensitive purchasing project was the beginning of the development of an information system that would enable primary care and Health Authorities to have a clearer and more accurate picture of the way resources were currently spent and such resources distributed. This could support both primary care and the Health Authority to plan for the future. The development of access to this type of information was innovative, as knowledge of how resources were used had been largely anecdotal and intuitive, despite the monitoring requirements of contracting. While information was collected on what activity took place, little analysis or comparison between practice and locality was made. The rapid development of information technology in the early 1990s and increasing expertise in its use provided an opportunity to understand what was happening in the local health economy in much more detail than before. These developments enabled North Derbyshire Health Authority to begin to make strategic plans[165] for the future based on more sophisticated information than had been available in the past. These plans included the development of "locally sensitive purchasing" (LSP) which devolved large parts of the commissioning budget to GPs, extending the limits of GP fundholding and allowing non fund holders to participate in purchasing the "best" services for their populations.

Secondary health care utilisation data

In addition to Census and other socio economic data about the use of secondary care, information was obtained by interrogating the North Derbyshire Health Authority databases. A range of information could be analysed at the level of GP practice. This included:

Attendances at outpatient clinics for each specialty.

Admissions to hospital for each specialty, by elective, emergency and day case.

Allocation of community nursing and health visitor services.

Overall prescribing, and prescribing of different categories of drugs.

Resources spent on General Medical Services provided by GPs.

Uptake of services in general practices, e.g. immunisations and cervical smears.

Clearly this type of information provided a very useful tool. It meant GPs and the Health Authority were able to analyse in more detail what was happening in their practices in terms of the care provided and patterns of referral. The information provided insight into the health needs of particular groups of patients. It also enabled GPs to compare their patterns of care with other practices in the area. The information could also then be used as a basis for planning service provision in the future. The recognition of the database as a source of this type of practice level information was a significant tool in the process of examining the "big picture" of distribution and use of health care resources in North Derbyshire and the resulting examination of equity in access to health care resources. Financial allocations to practices for acute and community services within the fund holding scheme, were traditionally based upon historic activity. This included, for example, the number of referrals and admissions initiated by each practice in the previous year. These allocations reflected the ways in which practices in primary care had evolved over time.

In order to examine the current patterns of resource allocation in North

Derbyshire for services accessed via general practice and to general practice itself, four steps were taken to develop this rich source of information into a resource to support purchasing decisions into an "allocative matrix":

All acute hospital activity data were disaggregated to individual GP practices by specialty and provider;

Cost information was applied in the form of either fund holder tariffs, where available, or crude average cost per case by specialty;

Community budgets were disaggregated to practice level and costed;

GP prescribing budgets were obtained.

This information had not been obtained or analysed in this form before and the comparative assessment of how health care resources were used at GP practice level provided new and exciting information. To provide context for the information, analyses of social and economic characteristics and proxy need measures were also aggregated or extrapolated down to GP practice levels.

Mapping data to GP practice level

The baseline practice populations were taken from the Family Health Services (FHS) register. The number of North Derbyshire residents registered with each of the North Derbyshire responsible GP practices were taken from the register. To produce data at GP level post-coded data was mapped to electoral ward and enumeration district level and vice versa.

The age and cost weights used in the national York formula were applied based on the national expenditure per head 1991-94. This reflected above average resource use by the very elderly and the under-fives. It was felt that relative resource use by this group was unlikely to vary in North Derbyshire from the national picture, despite absolute levels of expenditure varying. These weights were therefore used to calculate the effect of the age profile on the each practice's population on their target allocation, by applying the weights to the age distribution of each practice's population as obtained from the FHS register.

Using the allocative matrix as a tool

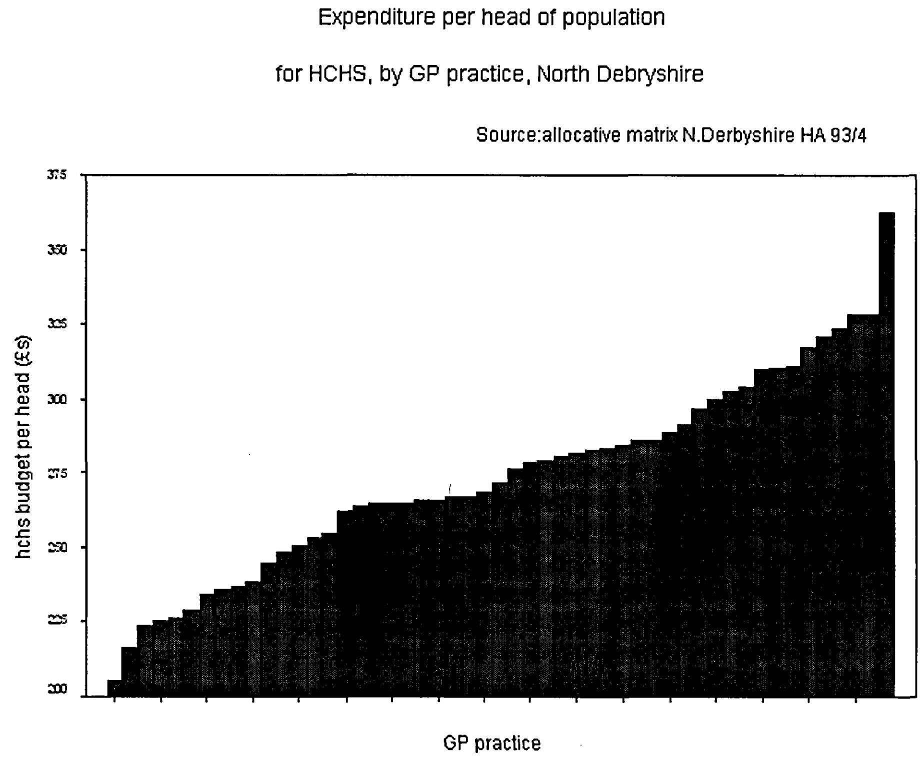
Alongside basic practice information described above, the allocative matrix (see earlier in this chapter) made it possible to analyse elective secondary care use at practice level and the extent of variation observed raised the issue of how far patients were able to have had equal access for seemingly equal need.

The technique used to map social and economic characteristics to GP populations was similar to the method described by Majeed[166]. Majeed's methodology enabled individual Census variables or compound indices, such as Jarman scores[167], to be attributed more accurately to general practices than had been previously possible using electoral ward based data. This method does inevitably have the limitation described by the "ecological fallacy". Thus despite a practice having a calculated, specific profile this does not mean all patients experience the average health profile of this practice. However, it was felt important to begin a process of understanding better local need and patterns of use of health care and added to this there was a need for access to profiling information. As long as the limitations of the database were acknowledged valid information could probably be derived and used.

Data were recorded on 53 of North Derbyshire's 63 practices. The reasons for not including all practices were that, during 1993/4, five practices had large changes in practice population and for five practices there was difficulty in obtaining activity data that was complete for the year. These ten practices had no other common characteristics. That is they were not clustered in particular parts of district and did not have similar socio-economic or socio-demographic characteristics.

Patterns of resource use by general practices in North Derbyshire

Examining data on expenditure by GP practice for elective hospital services revealed variation in the amount per head of population spent on acute care by different practices as shown in Figure 6:


Expenditure per head of population

for HCHS, by GP practice, North Debryshire

Source:allocative matrix N.Derbyshire HA 93/4

Figure 6: Age weighted HCHS expenditure per head in North Derbyshire 1993/4, by GP Practice.

The graph indicates that, after standardisation for the age profile of practices, large variations are evident in resources used for hospital and community health services (HCHS) per head of population in different practices. Figure 7indicates that in 1993/4 the range was from £205 per head to £362. The average spending per head in the district was £268. Notionally a practice of average size, some 5,200 patients, would be responsible for approximately £1.4 million for HCHS. Comparing two average sized practices, however, one used £1.9 million and the other used £1.1 million. Data suggest that historic budgets may have reflected the patient or GP led demands for care and the preferences and habits of individual practitioners rather than the need for care as there is such a wide variation in levels of resource use. The high level of fund holding meant that the process of determining annual budget allocations to funds required substantial amounts of management time to resolve numerous disputes. There was therefore good reason to work towards understanding and moving forward to a better appreciation of current usage of health care and the agreement of a fair approach to resource allocation between GPs and the Health Authority. This was the fundamental task of operationalising equity of access.

The initial part of the work was concerned with examining historical patterns of allocations and trying to convey, both numerically and graphically, the current patterns of resource allocations. It was not intended that historically allocated budgets would be used as a basis for developing future suggestions for allocations, but the information was valuable as a direct aid to understanding current allocations and the "big picture".

This investigation revealed much about the way resources were spent on patients at the level of each general practice. The results suggested that the use of resources might be haphazard and inequitable. Practices showed a wide range of resource usage and it seemed important that work should be done to examine the context of the resource use in relation to "need" for health care. The choice of measures used to describe need for health care was required to be part of a process that gained the ownership and support of primary care stakeholders.

The formation of the Equity group

Defining technical solutions to resource allocation is relatively easy when compared with changing the way resources are allocated and used. Changing the way resources are distributed has crucial managerial and political dimensions and processes. These are dependent upon identifying a solution which is acceptable to, and owned by, the majority of GPs, the health economy and, ultimately, the public who access the services.

In February 1995 the chief executive of North Derbyshire Health Authority commissioned a group of GPs from different localities and from practices with dissimilar characteristics of size, purchasing status, and location and so on, to formulate proposals for moving towards a fair system of resource allocation at practice level. A health service management academic, with considerable experience of management consultancy, was appointed to lead the project. Fewtrell[168] has described the management aspect of this project. The group that was formed was known as the "Equity Group" and was given until October 1995 to report back to the Health Authority and GP community.

The Equity Group met seven times and encompassed a range of enquiries and discussions outside these meetings. It had been established to attempt to agree on a measure of material deprivation, which was an appropriate measure of need for health care, to choose a methodology for applying it and to develop a pragmatic implementation plan.

The Equity Group needed to:

Examine and understand data, which reflected and described the current situation.

Define and agree principles of equity for the process.

Review the current mechanisms of resource allocation.

Ultimately suggest a way forward which would be acceptable to the primary care community and also the Health Authority.

The Equity Group approach aimed to enable all GPs to influence purchasing of all patient services against a strategic commitment to target services towards those with greatest need. The group considered HCHS expenditure and also prescribing costs and cash limited General Medical Services (GMS). It was recognised that different types of expenditure may need different approaches. HCHS was the first and most costly subset to be examined, prescribing and GMS were to be considered next.

Resources for primary care

The national approach since the mid-1970s that had been used for allocating HCHS funds was based on the conclusions of the Resource Allocation Working Party[169] work. Regions had used variations on the needs based formulae to allocate their funds to Health Authorities. In 1993 a review of this was announced which resulted in the formulae produced by the York group[170]. It was envisaged that this would be used for allocations to regional Health Authority areas beginning in the year 1995-6. Allocations based on these need formulae had always been phased in gradually and applied to only a proportion of the budget. The Department of Health had also commissioned a review of possible allocations to GP fund holding budgets. The results[171] suggested that they were unable to establish a rigorous scientific application of their formulae to the GP fund holding level. The Equity Group felt, however, that the formula was to be used to allocate resources to whole budgets, not just GP fund holding budgets and that the current situation was indefensible. It was therefore unethical to make no change from of moral justice viewpoint, the group felt that they now knew that equal shares of resource were not being allocated to practices with what they believed to be equal need and this situation could not be left as it was currently. It was agreed that use and application of the York formula should be investigated. Though the group were aware that the original purpose of the York work was different from the North Derbyshire intended use, it was believed to be important that change was considered and initiated. It was decided to experiment with the formulae and apply it to parts of the budget, showing commitment to the principles of fairness. It was acknowledged that the formulae were not an instant answer to the problem of equity and access to health care but a move in the general "right" direction.

In 1991 the Regional Health Authority had responsibility for allocating funds for prescribing to Family Health Service Authorities. Health Authorities had responsibility for allocating indicative allocations to non-fund holders and prescribing budgets to fund holders. Data were available to monitor and analyse the trends connected with this. In 1988 using the Prescribing Analysis and Cost (PACT) system a weighting system was used to convert list size to prescribing units (PUs) where greater weight was applied to over 65s. In 1993 age, sex and temporary resident originated prescribing units[172] (ASTRO-PUs) were developed which examined age-sex and temporary resident influences. These needs based measures for allocating resources had been adopted in North Derbyshire. It was felt by the Equity group that they were adequate and generally accepted and therefore the prescribing budgets were already being allocated in an equitable way and alterations should not be proposed. The only alteration to prescribing needs based assessment was agreed to be an extra weighting for the prescribing needs of those resident in nursing homes.

Cash limited GMS covers the cost of wages for practice staff, rent of premises and costs of computing in general practice. This money was allocated centrally to regions from the Department of Health and then to FHSAs and subsequently to Health Authorities. Cash limited GMS monies reflect entitlement by practices to monies, which are governed by national regulations and historic spending. It was felt by the Equity group that this was not a part of the budget where it would be possible to make local changes based on equity; therefore the group did not review this area of resourcing.

Resource allocation, need and equity: relating and measuring in North Derbyshire.

Any attempt to match resources to health needs would lead to some general practices gaining and others losing. However, this did not necessarily imply that losers were currently receiving more resources than they needed. It was simply saying that, given the current level of resources available to the NHS, it was necessary to try to ensure that they were distributed equitably. The Equity Group felt that local efforts should be made to review and understand how resources were being used in the context of apparent need for health care.

The York Acute Needs Index

When the work in North Derbyshire was begun the findings of the York work had not been formally published and information on the final form of the research and intended use by the Department of Health was not available However, though the relevant components and the proportions applied were known. The Equity Group were enthusiastic about the use of the new York Index, as it was to be used to allocate from Regional level and appeared to have statistical robustness and included more relevant areas as influencing need and demand for health care than the more commonly used Jarman or

Townsend measures. Initial "testing" of the indices by analysing practices by Jarman, Townsend and York had shown that the York index described a picture in familiar detail with intuitively feasible scores.

Studying the work done by the York group, the conclusions relating to the needs variables that were the most influential in utilisation of acute services were of particular interest in North Derbyshire. These appeared to include some of the areas that the Equity Group had felt would describe important issues affecting how patients may need and access health care, they included:

Standardised Mortality Ratio ages 0 to 74,

Standardised limiting long term illness ages 0 to 74,

Proportion of elderly living alone,

Proportion of economically active unemployed,

Proportion of dependants in single carer households,

From these variables an index of relative need for acute services by general practice population was produced. This measure and its constituent parts seemed intuitively useful to the group and the York index became a focus for examining need and proposing changes to resource allocations. It seemed logical to compare this index with current utilisation patterns in the form of expenditure on inpatient services per capita.

Stimulated by the evidence of widening inequalities in health between different sections of the community there were several national publications[173],[174] around the time of the equity work in North Derbyshire, which further encouraged the debate about variations in health and the need for differing levels of access to health care services regionally and locally. Using the data collected it was possible to begin to examine various characteristics of each practice using these data. Proxies for social deprivation (reviewed in chapter two of this thesis) were available using indices such as Jarman, Townsend, unemployment, standardised limiting long term illness (the SMBRs are described in chapter four of this thesis) and all cause standardised mortality ratios (SMRs) were also readily available. However, after much deliberation the group seemed to favour the more recent York tool that was being used nationally for reviewing needs based allocations. After presenting the results of the analysis of measures of need at GP practice level, the Equity Group believed that the component variables of the index formed an intuitively logical measure of deprivation and need that they could recognise locally.

The levels of analysis of HCHS spend per head of population was analysed and compared to assessed "need" as defined by the York index. This is shown in Figure 8; each point on the graphs represents a practice. The average practice population size was 5000 people in North Derbyshire but there were outliers with practice population of up to 10,000, such as the Shirebrook Practice, and small, often single handed practices with populations of less than 2000 people.

The larger practices were mostly in Bolsover and Chesterfield; the more deprived parts of North Derbyshire, so the visual impact of this graph may in fact under represent the number of patients living in deprived areas and their resulting high needs and high or low expenditure.

Scatterplot of expenditure per head

HCHS 1993/4 and York acute needs index by GP practice

(source: allocative matrix N.Derbyshire HA, Rsq=0.0627)

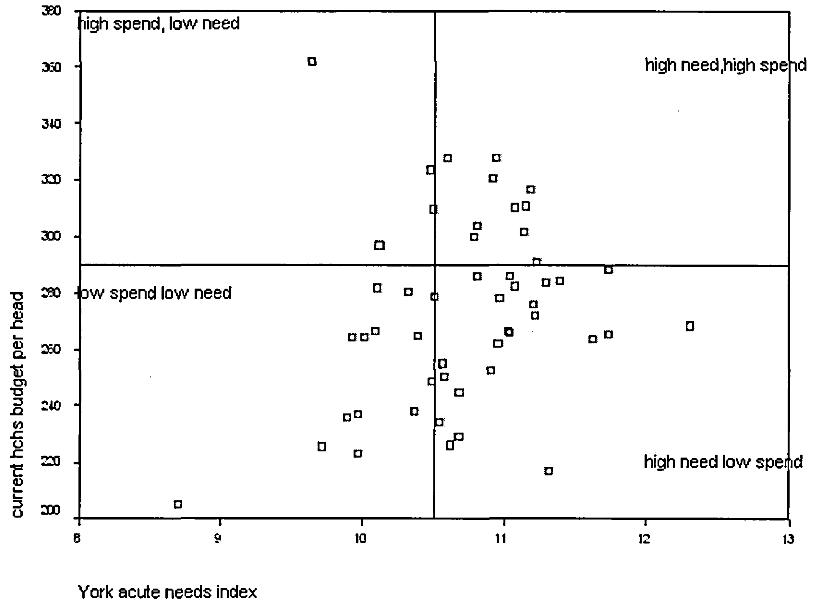


Figure 7: Age weighted HCHS expenditure per head. 1994/5, by practice; n=53, plotted against the York acute needs index by GP practice

The scatter plot in Figure 7 reveals a large number of practices with similar needs levels as measured by the York acute needs index but showing very different expenditure. Conversely, practices with similar expenditure levels frequently display very different levels of need. The practices would seem to group into four different categories to a greater or lesser extent (as illustrated in Figure 8)

High need high expenditure,

Low need high expenditure,

High need low expenditure,

Low need low expenditure.

This analysis revealed apparent contrast between assessed need and level of expenditure. At the extremes there were high spenders with apparently low need and low spenders with high levels of need. There was a correlation of only 0.25 between need and expenditure. This lack of a substantial positive relationship suggests that the resources were not being distributed appropriately. Tudor Hart[175] believed that this inverse care law operates more completely where medical care is most exposed to market forces (in an area of high fund holding such as North Derbyshire), and less so where such exposure is reduced.

The variable weightings that the York Index produced provided an empirical, semi-objective measure of need. The formula was not a mechanistic tool that instructed where resources should be put. The Equity Group saw the York acute needs index as a basis for measuring need that could help suggest how resources might be allocated. Essentially the York tool was proving to be part of the process and was gaining political acceptability as a descriptor of the situation and a tool to signpost possible change. The York acute needs index was specifically developed to measure need that impacted on demand and utilisation. The Index did not give clear directions about what decisions should be made regarding HCHS budgets to primary care or how to use the weightings. The index was used as an aid to inform local decision making about equity.

The York model was derived from nationally based data and therefore produced a nationally average model. Sensitivity analysis undertaken suggested that the model could not be substantiated at lower levels of aggregation. The York acute needs formula indices, however, were calculated for the North Derbyshire data and these results were compared with "traditional" measures of material deprivation which were currently being used in North Derbyshire such as the Townsend index[176], the Jarman index and the under 75 all cause SMR. The Equity Group found fewer unexpected results using the York work than with more conventional measures and saw the constituent parts of the index and its construction as being more transparent than other choices. They felt that the recent derivation of the index and its intended purpose was close to their desired use of the tool in North Derbyshire. This consideration of the York index in the context of other indices produced a confidence in the use of the York index by the Equity Group.

While the York team found no rational or reasonable model for allocating GP fund holding budgets for elective procedures[177], the Equity Group did not feel that this invalidated the process undertaken. A broader picture of need and use including all in-patient, outpatient, day case and community services had been looked at and a politically acceptable situation was evolving: "something had to be done", no change was not an option.

An attempt was made to analyse the financial impact of applying the various proportions of the York acute needs index and capitation funding to GP budgets across the district. The patterns that emerged seemed intuitively reasonable. Resources would be shifted towards practices that have high need but currently receive less than their fair share of resources. Distributions looked less idiosyncratic and arbitrary.

The group concluded that national weighted capitation formulae should be adopted as a benchmark for appraising current parts of HCHS expenditure at practice level in North Derbyshire and used for setting targets. This conclusion was arrived at as the group perceived the index as demonstrably needs based and also fully and recently researched. It was important that changes should be made, changes which would have a significant impact on increasing equitable distribution of resources. But it was also important not to de-stabilise the access to care by suddenly removing suddenly large amounts of resource from areas deemed to be over resourced. The proportion of the budget left unweighted has in almost all allocations been arbitrary and with little scientific basis. This is possibly due to the scale of change full or greater application would inflict on resources. The group considered the impact of these changes and other changes on the allocations of different localities.

Some practices would become net donors and some net gainers under the new allocations which would be implemented over five years, but both net donors and net gainers would need support from the Health Authority to ensure that services to patients would not suffer and that resources were not wasted. Motivational issues were crucial to the GPs on the group. Education, audit, peer support, shared learning and comparative performance information was seen as an integral part of change and continued access to data analysis and interpretation.

Certain practical steps were taken to implement formula based resource allocation. The principles behind the work of the Equity Group were debated with general practice in a number of forums and received broad support. Following these discussions each practice received a detailed statement comparing its current use of resources with its proposed needs-based allocation. Subsequently the agreed approach was used to allocate part of Health Authority development allocations to GP practices for primary care development in an equitable way.

It was clear that any progress was likely to be slow. There would be no financial opportunity to allow for the practices, which were over-target to maintain their current position and allow the others to "catch-up". Any changes would be based on re-distribution. The budgets were largely indicative so the route would be via willing compliance. There was no right answer, but it was felt there must be change. Constant monitoring, flexibility and organised support were key to the progress and success of the project.[178]

The impetus for the work with the Shirebrook GPs provided confidence locally in the power of data, analysis and interpretation to influence and inform change, which might promote equity of access to health care. Following detailed discussions, the Group reached key conclusions that the current pattern of allocations was illogical and indefensible and that some concept of equity should underlie any attempt to allocate resources rationally. Future resource allocations therefore should be based on an appropriate and acceptable formula and should take into account differential levels of need for health care. It was felt that Equity considerations should take into account if equity across both social class and geographic divisions and the York work on relative need offered the best current estimate of need locally as it was one of the few measures which combined morbidity, mortality and socio economic information.

The work undertaken on limiting long term illness in Shirebrook had begun a political process that had fed into the initiation of the Equity Group project. This process would not have been embarked on without the analysis and support of the data that had been examined and utilised as part of this innovative project to inform local resource allocation. There was local enthusiasm for the new techniques becoming available for examining resource use via the York Index. There was also considerable increase in IT capacity and the opportunity to handle large datasets and produce analysis much more easily than in the past. The Equity Group process provided an opportunity to make transparent use of data that local stakeholders understood and associated with factors influencing with workload and health care need. Application of the York Index in North Derbyshire as a whole produced a result that was intuitively reasonable to most GPs and Health Authority staff, ranking practices from those with most to those with least need. The York Index and the available information provided a basis for discussion and promoted increased understanding of the "big picture" of health care usage. Comparative information was subsequently provided to practices on a regular basis across a range of indicators to highlight how their use of resources differed from that of other practices in their locality and in North Derbyshire. Development money for 1996/7 was allocated to practices according to their equity position. Practices that were farthest above their target were more likely to benefit from additional audit resources.

An original feature of the North Derbyshire approach was that those key decisions regarding the redistribution programme were made by locally nominated GPs. Other Health Authorities, such as Doncaster have used a more "top down" approach and experienced greater difficulty in achieving acceptance and ownership of decisions by GPs. The method adopted by North Derbyshire Health Authority has enabled an initial move towards greater equity.

The technical detail of the approach could be refined over time more readily than an outright rejection of the approach can be reversed. The Equity Group's credibility with colleagues was enhanced because throughout the discussions they were ignorant of their own practice's equity positions in relation to expenditure targets. The Equity Group "process" was a stage in the development of local policies incorporating equity as a fundamental concept in the provision of health care. It is inevitable that any work examining equity needed to critically examine funding levels and distributions relating to need and relate this to target setting, and service delivery.

5.3 Conclusion

The quality of data available on the health status of the population and the use of health services by different sections of the population had improved in North Derbyshire as a result of improvements in IT and information management. In North Derbyshire elementary data analysis revealed that there appeared to be considerable inequity of resource allocation within the local health services. Tudor Hart's Inverse Care Law[179] was evidently still relevant in the 1990s. Equitable allocation of resources within the district was seen as one of the core functions of the new Health Authority. If agreement could be reached with General Practice on this issue, then it would provide a clear indication that Health Authority and primary care could work together to begin to address long-standing and seemingly intransigent problems

To prepare practices for changes that might happen as result of this process detailed discussions were undertaken to help them understand the reasons for their equity position. Comparative information was provided across a range of indictors to highlight differences. An original feature of this work was the key decisions being made and owned by locally nominated GPs. This process had been initiated by the perception of the GPs in Shirebrook who believed that local funding for primary care needed to be examined in the context of Equity.

The technical details of application the index and data sources used would need to be refined over time but the process which was begun will offer the opportunity for future engagement in the difficult decisions that will need to be undertaken relating to fairness in health care access for patients. The case study described in this chapter illustrates the evolution of a piece of action research that was undertaken, building on the local awareness of financial changes taking place and the probability of inequity in the existing situation of resource use and subsequent health care access and utilisation for patients.

The formation of the Equity Group was an innovative management and leadership idea, which provided the environment to openly discuss principles around equity, the measurement of need and the translation into resource allocations and the barriers to changes. The new methods for resource allocation described were a step forward on previous ad hoc methods that had developed in an unplanned way over the years and the redistribution of resources is an ongoing issue and the techniques involved will be further refined.

North Derbyshire Health Authority's method of using the York acute needs index may not work in all types of health district. The York Index was not designed for use at the low geographical levels in this work and the derivation of the index required substantial manipulation and extrapolation of local data. These issues were not felt by stakeholders to invalidate the use of the York Index, as its use was part of a "big picture" examined to assess and understand local conditions. The main barrier to use of the Index locally was the need to be entirely transparent about its use and this involved lengthy work with the Equity Group and others to explain and justify the components of the index and how they were assembled. This, while time consuming, did result in local engagement and commitment to the notion of what was being measured by the index and its components.

The work using this index was begun in 1994; at this time the Census data was relatively new and felt to be representing a current picture. However the ten years between Censuses and the strong dependence of this index on Census variables would mean that the validity of the York Index in this form would decline rapidly between Censuses. However, overall use of the York Index was appealing as it produced eventually transparent results, which were intuitively sensible and provide a basis for debate and a springboard for change.

One of the most important outcomes to emerge from the project was the extent to which it generated debate between the Health Authority and individual practices concerning resource usage and the reasons for variations in clinical practice. In North Derbyshire, reducing the haphazard and inequitable characteristics of current resource allocation was considered to be challenging but it was considered necessary to begin to fully understand the situation.

The full and vastly extended community role of GPs[180], which has evolved from fund holding to the formation of PCGs and PCTs, has encompassed the concept of equity. Primary care is shaped incrementally by external pressure and particularly the need to contain cost and demonstrate improved quality. Primary health care teams and PCT boards have been given massive responsibility to influence the health service and therefore equity rather than simply their own professional practice. This project provided an impetus for the concepts of equity to be identified and measured using routinely available data and established a local system for providing surveillance of equity of access to health care at GP practice level. This would hopefully influence the awareness of equity in allocation and access to be an adopted local principle. The type of process adopted here is one that should have been used when introducing the new GP contract in 2003.

The work described in the chapter shows how local action research and use of routine data was an integral part of re-defining resource policies locally to integrate the concept of equity. The work marked a general change in political thinking and an evolving acceptance and involvement in by GPS in North

Derbyshire in acting and making changes relevant to their new acceptance of the importance of equity in health resourcing to primary care. The work uses the techniques and data of chapter two and three. This chapter provides a context for the final section, which focuses on equity of access to secondary care and also care provided by primary care, the voluntary sector and community based services in a particular service area- final care for cancer patients. The work examines how social differences and not the actual disease may define how people access the services.

Chapter Six: Patterns in place of death for cancer patients

6.1 Introduction

This chapter continues the investigation of equity of access to health care that has been explored throughout this research. The major focus is on, what is taken to be, a significant concrete example of access to health care and relates this to a proxy measure of deprivation and need. Access to care for patients and their families with terminal cancer encompasses the use of treatment and care ranging from symptom control, spiritual well being, palliative treatments and the general delivery of care that enables comfort, solace and dignity. This work concentrates on equity of access to the aspects of the care provided once a terminal diagnosis has been established. This work involves exploring and modelling the relationship between social class, as a proxy for need, age gender and types of cancer and where people with cancer may die. The work relates the finding of the analysis undertaken to evidence about informed choice relating place of death for cancer patients. This section of the thesis analyses and interprets the processes, which define and determine the place of final care and support that is accessed by cancer patients and their families. This work therefore extends information available relating to equity of access to health care for different groups of people. It extends work first done at a local level to the national level. The research examines equity of access to care provided by community, voluntary, secondary and primary care services and extends the focus of the previous chapter on primary care equity of resource allocation to the equity of access to health care for a specific disease area across a spectrum of providers.

In England and Wales from 1994-7 of the two million people that died of all causes, 550,000 were certified as having died as a result of malignant neoplasms[181]. This represents 26% of the total number of deaths taking place. Palliative care and treatment for those patients with cancer therefore represents a significant amount of the work undertaken by the NHS and a significant cause of illness and death in England and Wales. The following research which investigated place of death for this large group of people first examined in Doncaster and then across England and Wales, is an analysis of major significance in assessing equity of access to health care.

The influences, which are believed to impact on place of cancer death, may be summarised by the schematic diagram in Figure 8.

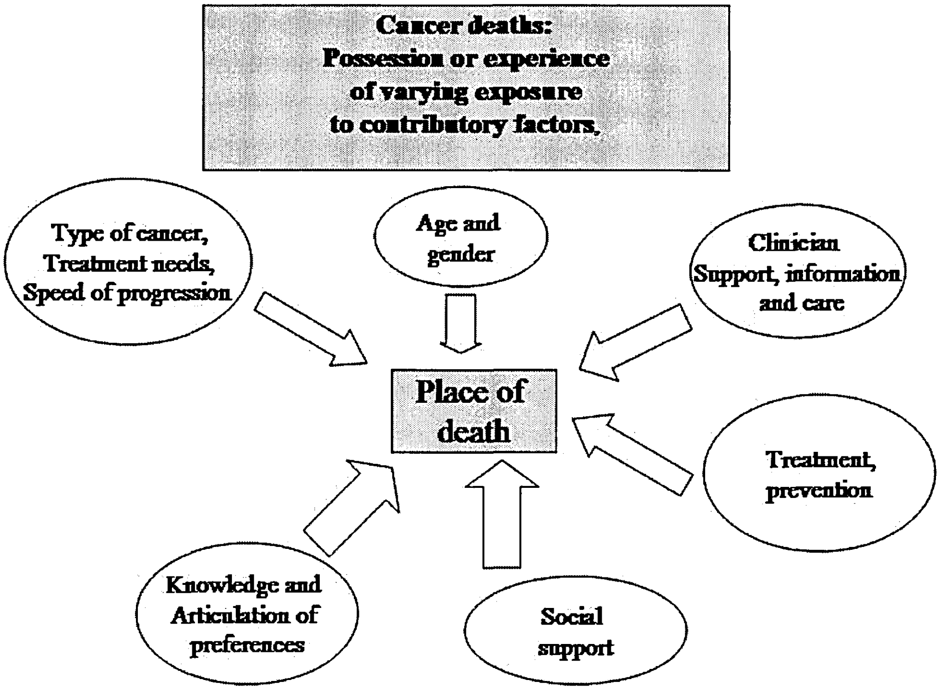


Figure 8: Schematic diagram of influences on place of cancer death

Case study: equity of access to palliative care.

- Research undertaken resulting from local question about inequity of access to choice in place of final care.
- Analysis of where people died by social class.
- Clear differences between place of deaths for different social groups locally
- Study extended to national dataset observing similar patterns, larger dataset allowed investigation of the impact of gender, age and site of cancer.
- Local work resulted in opportunity to make rapid, relevant, inexpensive change to provide care in a different way.

This chapter gives an account of action research work in Doncaster that aimed to discover whether the differences that appeared between social groups in how they accessed hospice and home deaths rather than hospital deaths, were as a result of specific choice by them or their GPs or as a result of lack of informed choice and then provided valuable information to support the review of services. The work explores a pattern of use of palliative care resources that may be reflecting historical demand and utilisation and had concentrated resources in particular areas and formats. This may, as a result, have made home or hospice death more attractive and accessible to some social groups rather to everyone across the full social spectrum, even within this generally relatively deprived community. The local analysis undertaken in Doncaster was then applied and extended to a data set containing all information about cancer deaths of individuals in England and Wales between 1994 and 1997. This allowed further study of the same types of concepts explored in Doncaster about equity of access to services for those dying of cancer. The large data set allowed the exploration of the influences of type of cancer on place of death and also the specific role of age and gender on choice or lack of choice when accessing home or hospice death.

Rapid, recent improvements in health and longevity have dramatically changed the burden of illness on the health care system. Such changes have increased the load for health care delivery for chronic illness and produced greater need for the integration of palliative care management into primary and community health care services and also the provision of carer support. The natural acceptance of "death as a biological reality"[182] has diminished and increased expectation of treatment and cure has perhaps led to the migration towards the belief that death is an event that should be taking place in hospital. Research has shown[183] that when asked to state a preference many patients and their carers, across the social class spectrum, said they would prefer the death to take place at home, with the support of outreach palliative care. This suggests it is crucial to monitor where people die, where they might choose to die, where they spend their last year of life, the reasons for admission for terminal care and to assess whether more people dying of cancer can be cared for at home. This type of information could be used to inform and influence the financing and provision of palliative care.

Physical complexities relating to the type of cancer that patients suffer from and the accompanying emotional and psychological consequences in terminal illness require coordination in care across some or all of primary care, community health care, and tertiary and secondary care services. Place of death is influenced[184] not only by specific symptoms but also by practical issues such as family concerns and ability to support and, also, psychological factors and beliefs and values about longevity versus quality of life of care givers and patients.

6.2 Patterns in place of death and influences on place of death

The place where those dying of cancer have their final care has changed significantly over the last thirty years. It has been shown[184] that between 1969 and 1987 in England and Wales the proportion of all patients dying in hospitals increased from 46% to 50% and from 5% to 18% in hospices and other institutions. The proportion that died at home reduced from 42% to 24%. There was also an increase in the proportion of people who were resident in care institutions such as nursing homes, being admitted into hospitals for medical care in the last year of life. This overall pattern describes a large increase in the numbers of those dying in general acute hospitals. Some patients do die at home and one UK study by Higginson[185] illustrated that when asked to state a preference, between 50% and 70% of patients felt that they would prefer to die at home. Yet Figures show that there appears to be a trend towards the hospitalisation of the dying. Higginson analysed ten year trends in place of death, patient age, cancer type and place of death. Information was derived from all cancer death registrations between 1985 and 1994 by English Regional

Health Authority area. Home death was at its lowest rate in the two Thames regions (25%) and highest in the West Midlands and Anglia and Oxford (29%). These differentials were maintained across the different age groups and diagnoses. Older people and women were less likely to die at home than younger people and men. Those with breast cancer, lymphatic cancers or haematological cancers were less likely than average to die at home.

Addington-Hall[186] analysed which categories of terminally ill patients received inpatient care in hospices and other specialist inpatient units. The research used in depth interview surveys to collect information about care in the last year of life from relatives. A representative sample of English District Health Authority populations was selected thus gaining an insight into provision and uptake of palliative care provision in all types of areas: inner cities, suburban areas and rural areas. The study showed that five factors seemed to independently predict inpatient hospice care. These five factors were levels of pain, constipation, extent of dependency on others for help with daily living, breast cancer and being under 85 years of age. Of those with all five factors, one third were admitted for inpatient care. Symptom severity, age, dependency level and cancer site played a role but overall admission seemed to be governed more by chance than need. The decision to admit is largely determined by the GP and the local availability of beds. Although this analysis did not directly define social class and deprivation issues, it indicated that the level of social support networks and the ability to articulate and assert choice may influence the type of care received.

Various studies have examined the relationship that may exist between deprivation and cancer. Research discussed previously[183,186] shows that fewer people die at home than would like to. Grande[187] showed that the ability to gain access to death at home varied by patient characteristics. Grande suggested that further improvements in availability of home and hospice based care, unless targeted, will advantage those social groups who already seem to be gaining disproportionately high levels of access to home care and hospice services and subsequently produce an increased "equity gap" between social groups. Older people were less likely to gain access to home care and therefore home death. Women were less likely than men to die at home but of those who did, women were more likely to gain access to home care. This perhaps is underlining the role of women as the majority of informal providers of home care. These studies concentrated on survey based information of fairly small samples of the carer population who were prepared to cooperate. There is little empirical work available that focuses on whole populations and their inherent characteristics.

Social factors seem to be linked to where people die. Higginson[188] et al showed that there are wide variations in the percentage of cancer deaths at home in different electoral wards. The study examined the proportions dying by electoral wards over a ten-year period and correlated these proportions with Townsend and Jarman scores by electoral ward. The index scores were grouped in to three bands of deprivation. High levels of deprivation were shown to be inversely correlated with home cancer death. This work applies the ecological fallacy to the population studied associating individuals with the social characteristics of the majority of residents in that electoral ward. This seems a particularly flawed method where it is a small part of the population in an area that is actually dying of cancer, so there is a risk of wrongly attributing deprivation characteristics to those dying of cancer. The study undertaken in this research attributes “personal” social class to individuals based on lifetime occupation.

These types of study happen to support the view that if an informed choice is permitted then, with appropriate support, people are likely to opt for a home or hospice death rather than to die in an acute general or teaching hospital. This suggests that although analysing the numbers actually dying at any hospice site or at home does not represent a full reflection of access to services, death in a hospice or at home is a strong indicator of having made an informed choice about a home or a hospice death for cancer patients and their carers. This is supported by work undertaken by McGaughey and Field[189] who carried out an interview survey of satisfaction with palliative care service provision, interviewing lay carers of those dying of cancer in Northern Ireland. The study showed general satisfaction with services but the highest level of satisfaction was with community-based services such as home based palliative care and hospice outreach services, and the lowest level of satisfaction was with hospital inpatient services. This type of qualitative conclusion motivated the case study undertaken in Doncaster (which is described later) to attempt to quantify the local scale of differences and to investigate whether socio-economic status influenced or was associated with place of death locally. Such an association might imply a lack of equity of access to health care for those dying of cancer[190].

The analysis of the national dataset of cancer deaths undertaken as part of this study shows that there are important differences between access to home, hospice and hospital as a place for final care. The differences are apparent by age groups, by gender, by social class group and also by different types of cancer. The review of the literature seems to suggest that when people are given informed choice and social and health support networks are present, people favour community based or hospice supported care for final care.

The Doncaster study was undertaken as an Equity Audit, which was subsequently a means of understanding the social mechanisms that define where people die and influencing patterns of provision. In Doncaster there were substantial differences across social class groups in how equitably different groups were actually able to access the health care support and services needed to facilitate deaths outside acute hospitals. The extension of the approach to a much larger national data set allowed the research to undertake analysis of the social class alongside other factors such as gender, age and cancer site which had not been possible with the smaller dataset.

6.3 Social Class Variation in Place of Cancer Death in Doncaster Health Authority

Background

An equity audit of access to palliative care services for cancer patients was undertaken in the Doncaster Health Authority area. The work was motivated by the desire locally to assess equity of access to health care services. There was a commitment to make a corresponding assessment of whether the current allocation of resources to palliative care was equitable across the district to different social groups and in its distribution to particular parts of the service. Palliative care services are delivered across all three main NHS sectors, primary, secondary and community and also interact with the voluntary sector. The largest voluntary sector input into palliative care is the Hospice movement to which the NHS in Doncaster (as is the case in many other health economies in England and Wales) makes a significant financial contribution. Analysis of place of final care for cancer patients in Doncaster provided an opportunity to look across a picture where local Doncaster caregivers provided almost all of the final care services available. This enabled assessment of the interactions and results of service provision in the context of issues such as social class. It was, therefore, intended to attempt to assess whether equity of access to the service was defined by local needs and preferences or by purely historical allocations that were driven by preferences of specific groups of people or clinicians. The Doncaster study used a census of all cancer deaths amongst Health Authority residents to investigate variation in place of cancer death by social class as a proxy for access to health care services amongst the terminally ill.

Methods and results

The Public Health Mortality File (PHMF) is a database of all death certificates, compiled by the Office of National Statistics (ONS) [181]. It is supplied on a monthly or annual basis. The dataset contains all information, which is collected by the Registrars of Births and Deaths for every death in each district, from death certificates and additional information such as occupation collected from the informant at the time of registration. Cause of death was coded by ONS using the International Classification of Disease, ninth revision (ICD9)[191] in 1995.

The PHMF for Doncaster was examined and deaths of Doncaster residents in 1995 where the underlying cause of death was cancer (ICD140-239) were extracted. The information is coded by ONS using the ONS Component Code. The ONS component code is a detailed coded classification of occupation. Using ONS Tables showing the relationship between the Standard Occupational Classification (SOC) codes and the component codes are regularly published by ONS. [192] Using component and SOC codes it was possible to attribute social class to individual records. Data for the Doncaster deaths were further aggregated into the following three categories: I and II, (Professional, managerial and technical) IIIM and IIIN, (Skilled manual and non-manual workers), IV and V, (Semi-skilled and unskilled group)[193]. This merging of groups was not ideal but the relatively small numbers of deaths in the population, particularly in social classes I and II suggested that collapsing the categories was necessary to obtain robust results with sufficiently large numbers in each group. The resulting mergers produced three intuitively sensible groups, broadly describing managerial and professional middle classes, the skilled working classes and a semi and unskilled working class group (The later analysis of the national data set further split the largest group the IIIM and IIIN skilled working class group into two sections, one manual and one non manual, which was possible due to the large amount of data available.) Place of death was extracted using the unique code for each communal establishment and the data were then classified by place of death in the categories, home, hospice, hospital or other.

A total of 831 cancer deaths were identified amongst Doncaster residents in 1995. For eleven there was insufficient information provided by the certification procedure to classify their former occupation and therefore attribute social class.

Table 8 compares the social class breakdown of the Doncaster deaths with the social class breakdown of the England and Wales deaths for the same period. It illustrates that the Doncaster deaths are skewed to the social classes IV and V group with fewer deaths than shown by the national pattern amongst the other two social groups. Looking also at the differences in the Census 1991 population for England and Wales this is probably some reflection of the general social structure of the Doncaster population both in the past and in 1995.

Table 8 Social class breakdown for Doncaster and England and Wales cancer deaths in 1995 and comparison of 1991 Census populations.

	England and Wales social class breakdown amongst population. Dying of cancer 1995	England and Wales population-social class (Census 91)	Doncaster social class breakdown amongst population. Dying of cancer 1995	Doncaster population-social class (Census 91)
I and II	24%	40%	19%	28%
IIIM and IIIN	44%	42%	30%	47%
IV and V	32%	18%	51%	24%

Analysis was carried out on the 820 deaths in Doncaster remaining; of these 53% of the deaths occurred in hospital, 27% at home, 14% in the hospice and 6% in other institutions (nursing or residential homes). This information is shown in Table 9. The hypothesis that social class and place of death are not associated was tested and rejected (χ^2=172.08; df=6; ρ<0.001). This overall distribution probably reflects the pattern of current service provision. Though it is unlikely to reflect a service providing informed choice, but one that has evolved historically based on demand.

Table 9: Place of death by social class 1995, Doncaster Health Authority

Social Class, Place of Death Count row per cent column %	I and II	IIIM and IIIN	IV and V	Row Total
Home	26 12% 21.5%	76 35% 38.8%	115 53% 22.9%	217 26.5%
Hospital	59 13.6% 48.8%	40 9.2% 20.4%	335 77.2% 66.6%	434 52.9%
Hospice	28 23.9% 23.1%	68 58.1% 34.7%	21 17.9% 4.2%	117 14.3%
Other (Nursing home, residential home etc.)	8 15.4% 6.6%	12 23.1% 6.1%	32 61.5% 6.4%	52 6.3%
Column Total	121 14.8%	196 23.9%	503 61.3%	820 100%

(χ^2=172.08; df=6; ρ<0.000).

Figure 9 illustrates that in Doncaster there were fewer cancer patients who died at home compared to those dying at home amongst the England and Wales population(32% nationally, 28% in Doncaster). In Doncaster more of the population were likely to die in hospital than for the national population as a whole. Doncaster cancer patients were also less likely to die in a hospice than those in the national population dying in a hospice.

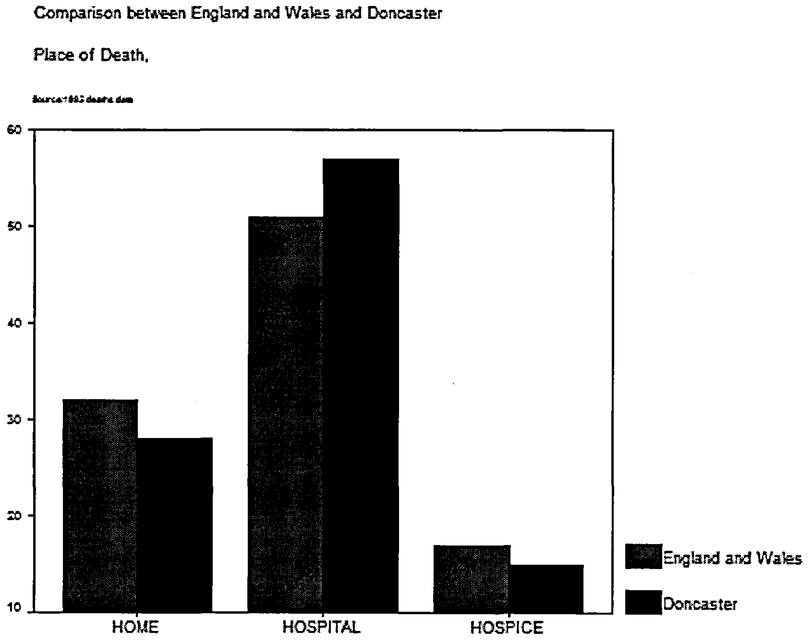
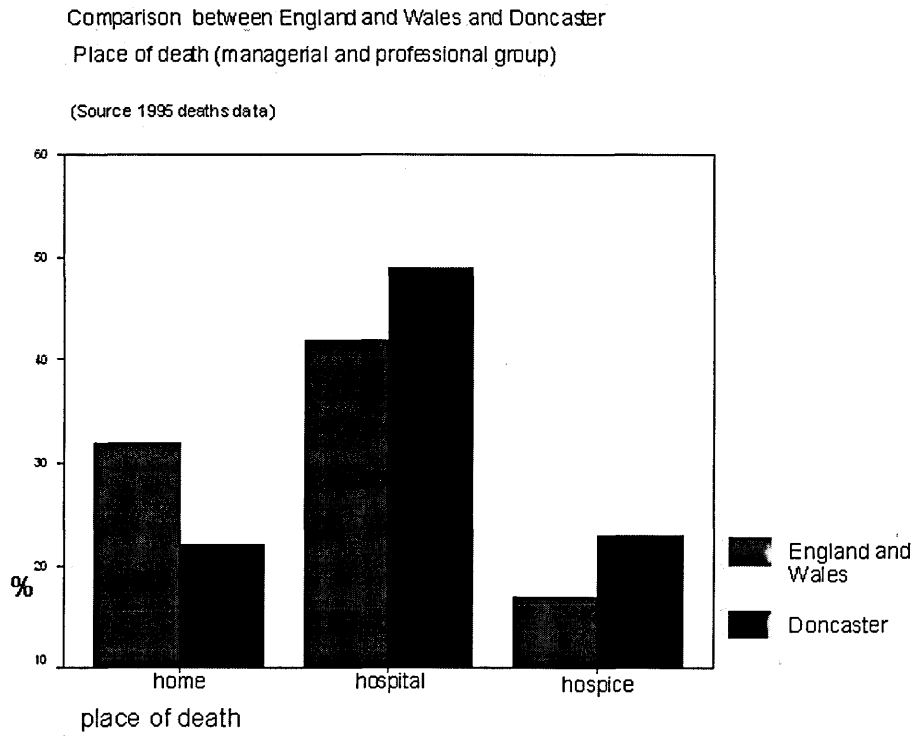


Figure 9 Comparison between place of death by social class, England and Wales, percentages 1995.

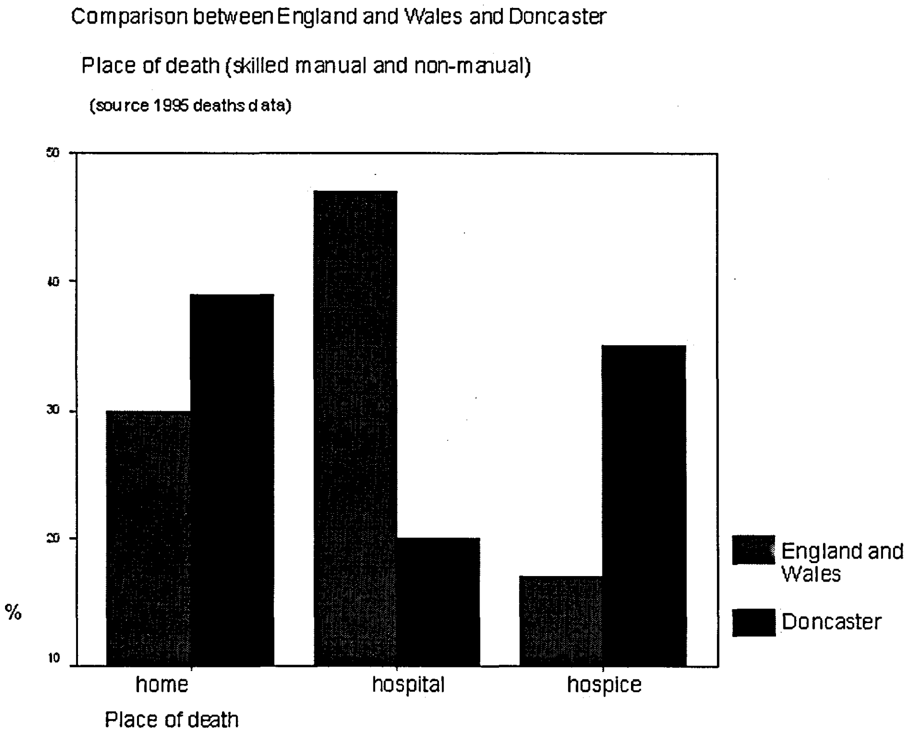
Figure 10 shows that amongst the managerial and professional population more people died at home nationally than those in Doncaster. More people amongst this social group in Doncaster died in hospital than in the general population. The managerial and professional classes in Doncaster were also more likely to access the hospice as a place to die than the general England and Wales population.


Comparison between England and Wales and Doncaster
Place of death (managerial and professional group)

(Source 1995 deaths data)

Figure 10 comparison between England and Wales and Doncaster, place of death, managerial and professional workers 1995

Figure 11 illustrates that in Doncaster more skilled workers died at home and less died in hospital than in the same social group, nationally, in Doncaster skilled workers were three times as likely to access the hospice than is shown by the national pattern.


Comparison between England and Wales and Doncaster

Place of death (skilled manual and non-manual)

(source 1995 deaths data)

Figure 11 comparisons between England and Wales and Doncaster, place of death, skilled manual and non manual workers 1995

The skilled manual and non manual group showed a large variation from both national patterns for the same social group, and also for the general Doncaster population. Nationally there was not a large variation from the pattern for place of death for all social groups within the national group of skilled workers.

Figure 12 shows that nationally semi skilled and unskilled workers were less likely to die at home than the general population, they were more likely to die in hospital and less likely to access the hospice.

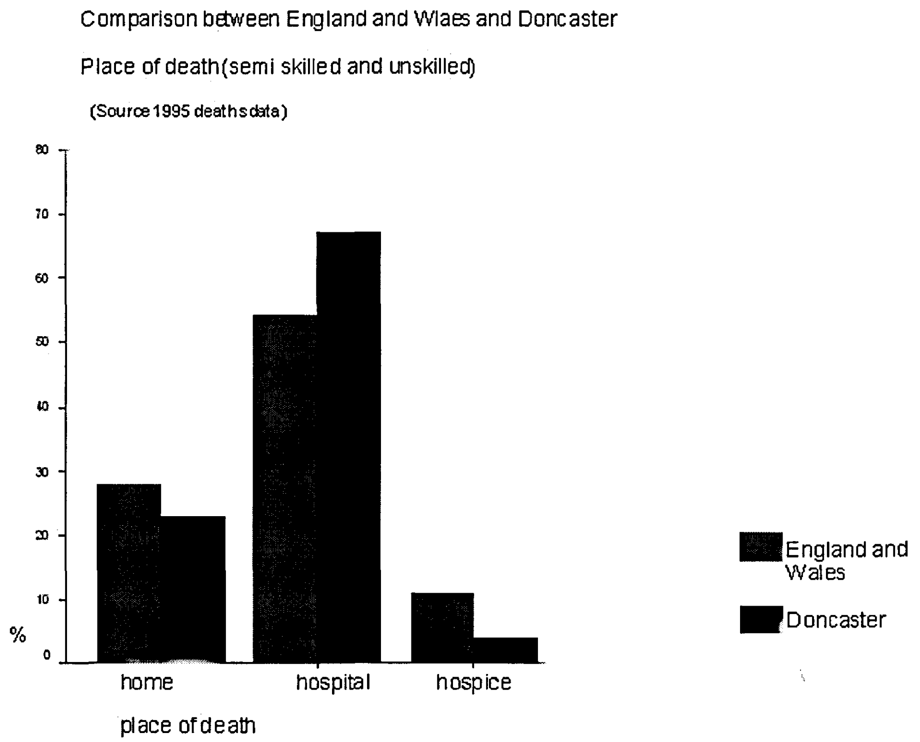


Figure 12 comparisons between England and Wales and Doncaster, place of death, semi and unskilled workers 1995

This general pattern was mirrored in Doncaster though there was a more marked pattern in Doncaster of the semi-skilled and unskilled workers not accessing the hospice but dying in greater proportions in hospital.

Overall this analysis reflects an interesting pattern where the Doncaster population, compared with the national population experienced lower overall access to hospice and home death and correspondingly higher use of acute hospital as a place to die. Yet within the social classes in Doncaster there was a clear inequity in access to home and hospice facilities with the skilled workers and the managerial and professional groups gaining higher than "average national" access to home and hospice care. There was clear predominance of access to non-hospital based facilities amongst the group of skilled workers in Doncaster.

Discussion

Much of the published literature on place of death and social class examines the reasons for variations in place of death in relation to samples of carers willing to be interviewed. The Doncaster study used an analysis of routinely available death certification data to perform a census of place of death for Doncaster. This objective study into place of death describes what was actually happening in Doncaster in 1995.

Although the supply of services to all social classes is theoretically the same, this work demonstrated differential access according to social class. These findings in Doncaster were consistent with a large study on place of death in Australia where socio-economic status was a significant predictor of place of death for all causes of death[194].

Variations in patterns of use reflecting the supply of or availability of beds and services are largely obviated in a single health district served mainly by one hospital, one hospice and a single district nursing service, where access is to the same level of beds or care[195]. A large District General Hospital and a second much smaller acute hospital providing a small number of acute medical beds served Doncaster. This second hospital was situated in one of the District's most deprived areas. It is possible that a local preference for admission to this small hospital would bias the findings. However only 5% (68) of total cancer deaths occurred at this hospital.

Possible explanations related to patient awareness or prejudice could reflect differences in the informed choices of patients from different social classes for example the perception of the hospice only as a place to die rather than for palliative care. Distance and the availability of patient's and families' own transport for visiting may be a real or perceived barrier to choice of place for care. Although transport can be provided across the district in Doncaster to enable patients to attend the hospice day-care centre, the journey may be daunting. The hospital was more accessible by public transport than the hospice. Patients who were able to attend the hospice day-care centre were more likely to choose the hospice as a place to die[196].

Access to the hospice or homecare service is mainly via the patient's General Practitioner. Most final admissions to the hospice occur in a semi-planned manner, as beds become available. This is in contrast to the hospital service where admission is on "demand" and may be independent of the GP via the accident and emergency department of the hospital or deputising services. Paradoxically, admission to the hospital as an emergency for terminal care reduces a patient's chances of being admitted to the hospice, since priority for hospice admission is given to those being cared for at home. The work showed that in the interests of equity this policy may need reviewing. Dying at home may not be considered appropriate where housing, social support networks or nursing services are perceived as inadequate. Carers or patients need GPs to be able to assist them make informed choices about what care is available and appropriate to their needs.

It is unlikely that health professionals consciously discriminate for or against patients on class grounds, but they may subconsciously select patients for hospice or hospital referral on some perception of their suitability for and acceptance of different services based on their own prejudices or lack of full information. GP perception of the hospice on behalf of their patients may be that it is culturally inappropriate in the range of supportive activities provided. There may be a collective primary care team bias arising from the level of affluence of the population served by a practice.

The duration of a patient's illness or specific care and treatment needs as a result of particular cancers may determine access to a certain type of care. It was possible that the findings reflected the differing pattern of cancer incidence across the social classes and the cancer site's specific need for care. A consistent gradient for social class exists for both males and females[197] for lung cancer. In the Doncaster study group 67% (n=151) of lung cancer deaths, were in social class IV or V.

The literature[188,186] makes it clear that given an informed choice many people would opt for non acute hospital based care, yet amongst one particular social group in Doncaster equitable access was clearly not occurring. The work in Doncaster influenced the re-examination of criteria for admission and access to hospice and home based services and a review was undertaken of patterns of GP access to community based palliative care services. The role of geographical location of the hospice was probably a significant factor as it is based in a fairly affluent area of Doncaster where public transport access is poor from the less affluent parts of Doncaster. This suggested that physical access would be poor for families of cancer patients. A review of how the acute hospital delivered final care was undertaken and several of the "care of the elderly" beds in the local district general hospital were designated as an earmarked terminal care facility with, specialist nursing support available to offer an additional and different form of services for those dying of cancer in Doncaster.

Following the analysis of cancer death patterns in Doncaster data was sought to extend the analysis of the Doncaster area to assess whether the patterns of access observed were limited to Doncaster or whether these inequities in access to home and hospice for place of final care would be observed nationally over several years. Using a larger dataset it was possible to examine patterns of access to final health care for those with different types of cancer and also to attempt to determine how much influence age and gender had on place of death as well as patterns by social class.

6.4 Analysis of cancer deaths in England and Wales 1994-97

Introduction

An analysis of the national dataset was undertaken partly to validate the local analysis and also to use a larger dataset providing information about more years over a much larger geographical area to try to understand whether the patterns observed differed when gender, type of cancer and age were examined in conjunction with social class. In Doncaster, local providers of palliative care were keen to understand in greater depth the type of factors that influenced both patient access and clinician's decisions. A broader analysis of the national data would provide background and support for local decisions to change or influence how care was delivered. It was felt important in Doncaster that there should be equitable access to palliative care. The local analysis, however, showed very different use of home care and hospice care by different social groups and this did not seem to reflect patterns of use that were necessarily influenced by need for care. In Doncaster there appeared to be a strong connection between levels of deprivation as measured by social class and the type of final care accessed by cancer patients. The Chief Medical Statistician at ONS agreed that Doncaster Health Authority could access the national data and felt that this analysis could provide useful general and national insight into final care for cancer patients.

National studies[198],[199],[200],[201] in England have attempted to analyse patterns in cancer death. These studies show that residence in an electoral ward with high levels of social and material deprivation was an indicator of lower than average access to home or hospice death. The analysis described here examines the patterns of place of death and the influence not only of social class but gender, age group and type of cancer at an individual level. This in depth examination of a large, national cancer dataset is an original analysis of data, which has continued and expanded a local initiative, examining the possible causal relationships between social inequalities and equity of access to health care. The major difference between this and other work is the use of individual deprivation measures for each death- derived from occupation and using social class as a proxy for deprivation. Whilst indices of social deprivation such as Jarman, which are based on the place of residence of the patient, may be used to attribute and estimate material and social deprivation, the number of deaths in any ward are very small, so any results would be prone to the ecological fallacy. In this study it proved possible to attribute social class via former occupation or occupation of spouse, the "household" social class, to approximately 506,000 of the 550,000 records.

The data

The deaths files were obtained from ONS to undertake this study, liaising with the Chief Medial Statistician Dr. Michel Coleman, following discussion with him and encouragement to extend and validate the local study. Data were derived for all cancer deaths taking place in England and Wales in the years 1994-7 for all of the death registrations, from the national deaths files from the Office of National Statistics.

This file contained for each death (552,097) the following variables:

Social class of deceased (or mother if a child), Social class of husband (or father if a child) based on former or current occupation

Codes for both were as follows:

1=professional

2=managerial and technical

3=skilled occupations (non-manual)

4=skilled occupations (manual)

5=semi skilled occupations

6=unskilled occupations

7=armed forces

8=inadequately described

9=other

Aggregating these codes into the following created a further variable that could be used to provide analysis to produce analysis that was comparable to the Doncaster work

1=1 and 2 above- managerial and professional, social class I and II

3=3 and 4 above- skilled manual and non-manual, social class IIIM and IIIN

5=5 and 6 above- semi skilled and unskilled workers, social class IV and V

7=7, 8 and 9 above- other

Final underlying cause of death was available as 4-digit ICD9 code; these data were further coded to aggregate the standard groups of cancers together using the convention of ICD9:

Malignant neoplasm of the lip, oral cavity and pharynx

Malignant neoplasm of digestive organs and peritoneum

Malignant neoplasm of respiratory and intra-thoracic organs

Malignant neoplasm of bone, connective tissue and skin

Malignant neoplasm of the breast

Malignant neoplasm of the genitourinary organs

Malignant neoplasm of lymphatic haematopoietic tissue

Other malignant neoplasm

Gender

Postcode of usual residence

Communal establishment codes (*or coded as home or elsewhere.)*

Age in years- this was further coded into the following age bands:

0-15 years

16-44 years

45-59 years

60-74 years

75 years and over

Place of death, using the following standard categories:

NHS psychiatric institution

Non-NHS psychiatric institution

Hospices

Other hospitals (NHS, includes NHS nursing homes)

Other hospitals (non-NHS, includes non-NHS nursing homes)

Other communal establishments (includes old people's homes)

Home

Elsewhere

Around 44,000 of the records were not usable in an analysis relating to social class as these related to women who had no listed former occupation themselves and no information related them to a spouse; it was therefore not possible to attribute a social class classification based on former occupation.

Place of death and Social class

Overall, for all social classes the most common place to die from cancer is in a hospital. The next largest group of those dying of cancer are those who die in their own homes. A hospice is the third most usual place of death for cancer patients. Within each social group the overall pattern of place of death is the same but the magnitude of the difference varies between each social group.

Figure 13 shows a breakdown of place of death by social class, nationally 36% of social class I and II will die at home compared 32% of the general population and 31% of social class IV and V. The managerial and professional group also have greater access to hospices than the rest of the overall population. On average semi skilled and unskilled workers are less likely to die at home or in the hospice than the general population and the managerial and professional or skilled workers and but more likely to die in hospital. Fifty-three percent of this group die in hospital compared to 47% amongst social classes I and II.

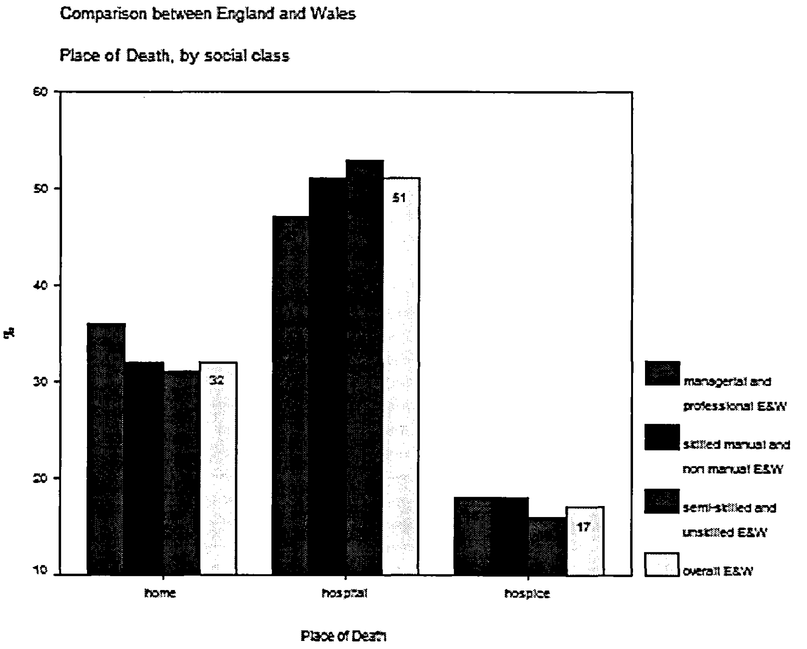


Figure 13 comparison of place of death by social class, England and Wales

Place of death and Cancer site

Figure 14 shows that where patients die is directly influenced by the type of cancer, it is apparent that those with malignant neoplasm of lymphatic haematopoietic tissue are more likely to die in hospital than any other group. Those dying from malignant neoplasm of digestive organs and peritoneum are more likely to die at home than those with other types of cancer. Those with malignant neoplasms of respiratory organs such as lung cancer are less likely than those with other types of cancer to die in a hospice or at home and are more likely than those with other types of cancer to die in hospital.

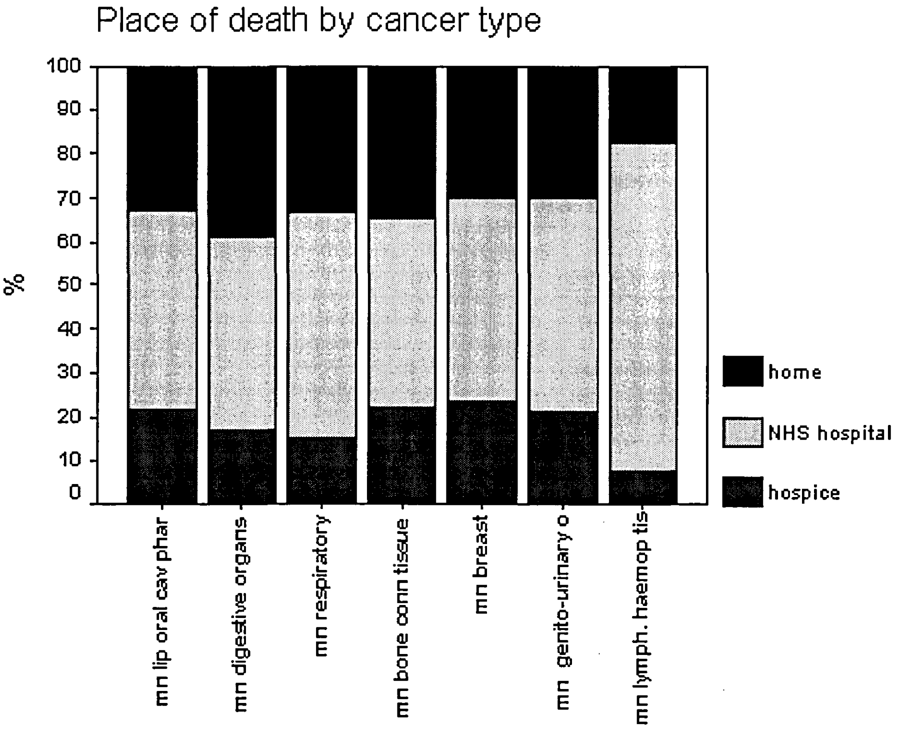


Figure 14 Place of Death by cancer site

Some of these differences may be due to types of care appropriate to different types of cancer and their relative speed of progression and also differences in average ages of patients as well as possible differences by social class.

Table 10 social *class and type of cancer*

% of deaths within social class by each type of cancer	I and II	IIIM and IIIN	IV and V
Lip, oral cavity and pharynx	1.64	1.61	1.68
Digestive organs and peritoneum	30.99	23.89	27.46
Respiratory and intrathoracic organs	22.88	29.83	33.43
Bone connective tissue and skin	3.34	2.29	1.76
Breast	7.53	7.45	7.37
Genitourinary organs	10.07	9.57	9.52
Lymphatic and haeompaetic tissue	9.75	7.75	6.67
Other	13.81	13.11	12.11

Table 10 shows that overall, and for most types of cancer, there is little evidence to suggest a social class difference by cancer type overall. However, for malignant neoplasms of respiratory organs there is a noticeably lower percentage of deaths amongst the managerial and professional group and a higher percentage of deaths amongst the semi and unskilled group. There are decreasing social gradients in the opposite direction in the bone and skin and lymphatic groups that are as large as the increasing gradient amongst the respiratory group.

Respiratory cancers account for almost a third of all cancer deaths in England and Wales and therefore account for the largest proportion of deaths from any single type of cancer. There is evidence in many studies[182,184,] that those with a terminal illness, if empowered to do so would choose locally provided palliative care support. This type of care may be provided by hospice outreach services and other community-based services, which may mean people, can die in a hospice or at home with appropriate support. The analysis undertaken here shows an over representation of social class IV and V amongst lung cancer deaths and it suggests that lung cancer patients do not appear to be obtaining similar levels of access to hospice and home care as those dying of other types of cancer. It would seem that this group are not therefore gaining equitable access to the type of health care they might be most likely to need or want.

Place of death and gender

Analysis of the data by gender shows that women are more likely to die in the hospice than men but less likely to die at home than men. The patterns are illustrated in figure 15. This may be due to men being more likely to have predeceased their partners removing for most women the option of being cared for at home by spouses.

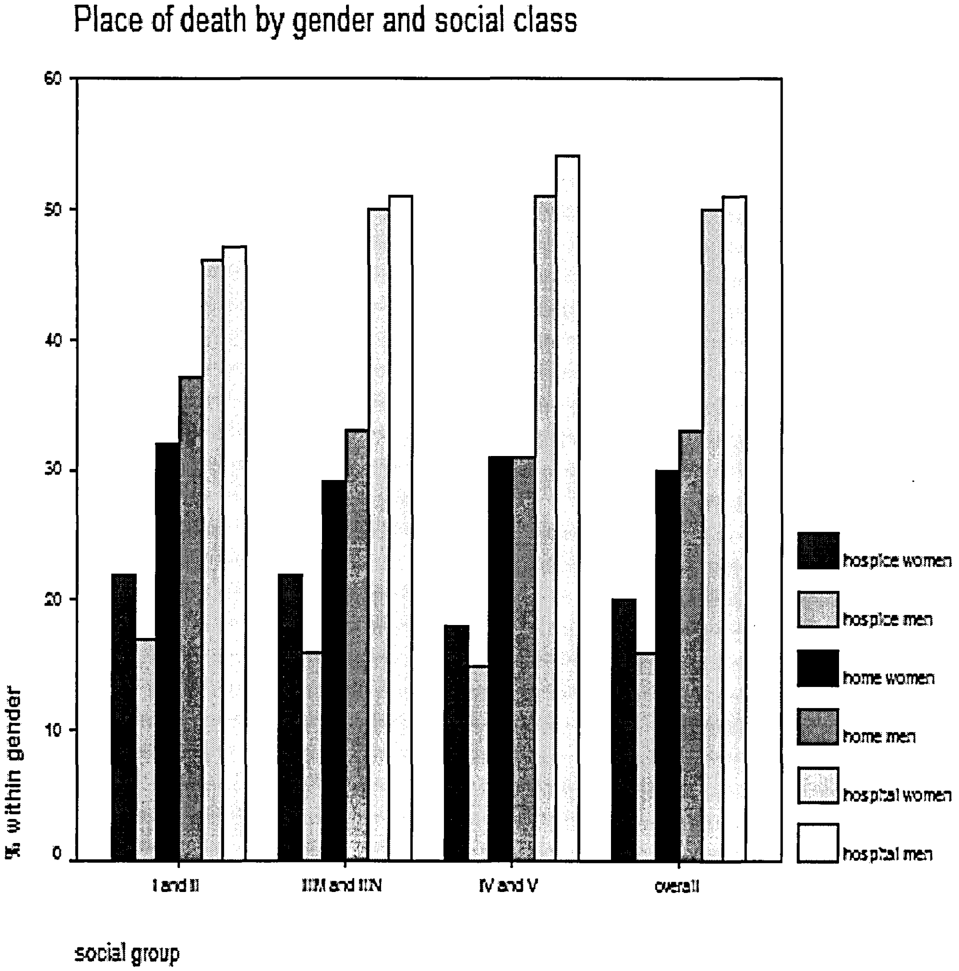


Figure 15 place of death by gender and social class (% within gender)

Men and women in social class IV and V are less likely than others of the same gender in other social classes to die in a hospice.

Place of death and age

The data in table 11 suggests that as people get older they are more likely to die in hospital than at home or in the hospice than those dying at younger ages. This may be related to the lack of availability of social support networks to care for older people at home or assist them in articulating a choice other than hospital care. Those aged 85 and over in social class I and II are more likely to die at home than those aged 85 and over in the general population. This is perhaps due to strong social support available to this group.

Table 11 age and place of death

Age, place of death % within age groups	Hospice	NHS hospital	home
under 16	3.13	43.20	53.67
16-44	19.05	51.50	29.45
45-59	18.43	47.53	34.04
60-74	16.66	51.42	31.92
75-84	15.81	58.27	25.93
85 and over	11.92	66.28	21.80
all ages	16.17	54.54	29.28

Children are more likely to die at home than other age groups. Those aged between sixteen and forty-four are the age group who are most likely to die in the hospice. Forty-five to fifty-nine year olds are more likely to die at home than other age groups. These differences for the younger age groups may reflect the greater likelihood of available social support. There is also likely to be greater emotional energy associated with obtaining care and treatment for young people facing the prospect of their premature death.

Modelling the cancer data

The initial analyses of the data described briefly differences in place of deaths by age, gender, social class and type of cancer. This analysis suggested that there were relationships that should be explored further within the data. Further exploration of these relationships could provide information about how these variables were influencing and affecting how patients and their families accessed final care and the overall resulting pattern of equity of access to health care related to terminal cancer.

The use of binary logistic modelling was investigated as it offered the opportunity to compare access to hospital care with home or hospice care in conjunction with age, gender, social class and cancer site in greater depth than the initial analysis and begin to understand in depth the patterns that influence equity of access to care for cancer patients. Binary logistic modelling was chosen as there was a clear dichotomy of choice that was being examined-home and hospice death or hospital death.

Modelling can be used to determine both the joint effect of the explanatory variables on the dependent variable and to determine the association between the dependent variable and a single explanatory one corrected for the confounding effect of the remaining factors. Logistic regression extends multiple regression to cover the case of a qualitative dependent variable. Logistic regression works with a transformed dependent variable by running a multiple regression on the transformed variable. The magnitude of resulting regression coefficients indicates the relative importance of various factors in producing the probability of particular types of scenario; e.g. being male, being social class IV or V, dying in a hospice etc.

Logistic regression entails the use of the odds ratio as the parameter of association. It is able to deal with a large number of variables and account for quantitative confounders without having to categorise them and can examine effect modification (interaction) easily. Logistic regression enables the finding of an appropriate combination of predictor variables that would satisfactorily explain the dependent variable and assess the relative strength of the effect of each independent variable. When searching for an appropriate model it is relevant to consider several different possibilities rather than test a specific hypothesis. The process is facilitated by using SPSS, which enabled particular models to be statistically evaluated and then produced an opportunity to iterate the process until a satisfactory model was reached.

Logistic Modelling 1: Place of Death

Initial crude logistic modelling was carried out using SPSS on place of death. The data used related to all types of cancers.

The dependent variables were:

Place of death hospice, (yes=1/no=0)

Place of death home, (yes=1/no=0)

Place of death psychiatric hospital (NHS/non-NHS) (yes=1/no=0)

The Predictors were:

Social Class of Household

Sex (male=1, female=2).

Age at death in years (covariate).

Model 1: Hospice - Age, Sex, And Social Class of Household with five codes: I&II, IIIN IIIM, IV, V, the remainder excluded, using social class V as the base. A main effects binary logistic model was produced with odds ratios

Using social class V (unskilled workers) as the base, all other social classes were on average more likely than those in social class V to die in a hospice as follows:

Social class I and II (managerial and professional); 28%

Social class III (non manual): 43%;

Social class III (manual): 18%;

Social class IV (semi-skilled): 12%.

The analysis shows that all predictors are significant. It was shown that taking age, sex and social class into account where relevant, the older the patient is, and the less likely they were to die in a hospice. Women were on average 25% more likely than men to die in a hospice. This supports the earlier findings from the initial analysis and reinforces the indication of women's traditional role as the carers rather than those who are being cared for, perhaps often, as a result of being widowed.

Model 2: place of death Home - Age, Sex, Social Class of Household with five codes: I&II, IIIN, IIIM, IV, V, the remainder excluded, using social class V as the base. A main effects binary logistic model was produced with odds ratios.

Using social class V (unskilled workers) as the base, other social classes were on average more likely than those in social class V to die in a hospice as follows:

Social class I and II (managerial and professional); 19%

Social class III (manual): 13%;

Social class IV (semi-skilled): 5%.

The analysis shows that all predictors are significant. It was shown that taking age, sex and social class into account where relevant, the older the patient is, and the less likely they were to die at home. Men were on average 11% more likely than women to die at home. This modelling confirms the earlier suggestions from the initial analysis, reinforcing the indication that women are less likely to be able to access the social support and carer input needed to articulate and access the choice of home care. Planned home death requires patients to have access to social support networks and care at home from family and friends and community based palliative care support. In this model the analysis showed that social class IIIN (the non manual skilled workers) were less likely than all other groups to die in the hospice. Non manual skilled workers were 5% less likely to die at home than those in social class V), this is perhaps not a reflection of their lack of informed choice in accessing the home deaths but their successful use of informed choice accessing the facilities of the hospices as shown in model 1.

Logistic modelling 2: place of death by cancer site.

Binary logistic analyses were undertaken using SPSS, analysing data for hospice and home deaths for all years (1994-7), and using the following eight cancer groupings from ICD9:

Malignant neoplasm of the lip, oral cavity and pharynx

Malignant neoplasm of digestive organs and peritoneum

Malignant neoplasm of respiratory and intra-thoracic organs

Malignant neoplasm of bone, connective tissue and skin

Malignant neoplasm of the breast

Malignant neoplasm of the genitourinary organs

Malignant neoplasm of lymphatic haematopoietic tissue

Other malignant neoplasm

The Predictor variates for main-effects models that were used were age at death, sex and social class.

Models: Place of death home or hospice, cancer site, age, sex and Social class.

Binary logistic modelling was undertaken and place of death (Coding place of deaths as hospice or home) was used with cancer site by age (covariate), sex (male=1 base) and social class of household (social class I and II=1 base), for all four years of data (1994-7).

Results of modelling

(Multinomial modelling results shown in appendix Chapter 6)

Malignant neoplasm of respiratory and intra-thoracic organs: Place of death: hospice

Age, gender and social class all influence whether people dying from malignant neoplasm of respiratory and intra-thoracic organs die in a hospice. Young people are more likely to die in a hospice than older people. Women are 13% more likely than men are to die in the hospice when dying from respiratory cancer. Skilled non-manual workers are 9% more likely than social class I and II to die in a hospice. All other social classes are less likely to access the hospice,as place of final care with social class III (manual) being 8% less likely, the semi-skilled workers being 11% less likely and social class V being 19% less likely than social class I and II.

Malignant neoplasm of respiratory and intra-thoracic organs: Place of death: home

Younger people dying of respiratory cancers are more likely to die at home than older people. Gender does not have a significant effect on place of death for respiratory cancers. All social classes are less likely to die at home than social class I and II with the non manual skilled workers being the least likely group to die at home. This is probably accounted for by their high rate of access to hospice care. The semi skilled and unskilled workers with respiratory cancers do not appear to be accessing equitably home or hospice care and a greater proportion are dying in hospital than from any of the other social groups. This seems to indicate inequalities in access to different types of care amongst the social groups for those with malignant neoplasm of respiratory and intra-thoracic organs.

Malignant neoplasm of bone, connective tissue and skin Place of death: hospice

Age and gender influence whether people dying from malignant neoplasm of bone, connective tissue and skin die in a hospice. Women are 15% more likely than men to die in the hospice when dying from this type of cancer and the older a person is the more likely they are to die from this type of cancer in a hospice. There is no significant effect of social class for this type of cancer which influences whether people die in a hospice or not.

Malignant neoplasm of bone, connective tissue and skin Place of death: home

Younger people dying of malignant neoplasm of bone, connective tissue and skin are more likely to die at home than older people. Women are 13% less likely than men to die at home. Non-manual skilled workers are 22% less likely to die at home than social class I and II and unskilled workers are 26% less likely than social class I and II to die at home.

Malignant neoplasm of the breast, Place of death: hospice

Age does not influence whether women dying from malignant neoplasm of the breast die in a hospice. The social group most likely to die in hospice are the non-manual skilled workers. This group is 12% more likely than the managerial and professional workers to die in the hospice, but the semi skilled and unskilled workers are 9% and 17%, respectively, less likely to die in the hospice than social class I and II. This suggests that the female skilled non-manual workers are gaining far more access to the hospice than women in any other social groups.

Malignant neoplasm of the breast, Place of death: home

Age does have an influence on whether women dying from malignant neoplasm of the breast die at home. Younger women are more likely to die at home. Non manual skilled workers are 21% less likely than social class I and II to die at home, this is however probably a reflection of their high rates of access to hospice facilities.

The models for home and hospice deaths show that women dying of breast cancer in the semi skilled and unskilled and manual skilled groups do not appear to gain equitable access to home or hospice care compared to the managerial, professional and skilled non-manual groups.

Malignant neoplasm of the genitourinary organs, place of death: hospice

Younger people and women are the most likely group to die in the hospice from malignant neoplasm of the genitourinary organs. The group most likely to die in the hospice are the skilled manual workers with all others being less likely to die in the hospice.

Malignant neoplasm of the genitourinary organs, place of death: home

Age and gender have an influence on whether those dying from malignant neoplasm of the genitourinary organs die at home. Men and younger people are more likely to die at home. All other social groups are less likely than social class I and II to die at home. Skilled non manual workers 18% less likely, semi skilled workers 10% less likely, unskilled workers 11% less likely.

Malignant neoplasm of lymphatic haematopoietic tissue Place of death: hospice

Age and gender and social class have an influence on whether those dying from malignant neoplasm of the lymphatic/haematopoietic tissue die in the hospice. The older a person is the more likely they are to die in the hospice. Women dying of malignant neoplasm of the lymphatic/ haematopoietic tissue are 17% more likely than men to die in the hospice. For these types of cancers social class I and II have more chance of dying in the hospice than any other social group. The unskilled workers are 25% less likely to die in the hospice than social class I and II.

Malignant neoplasm of lymphatic haematopoietic tissue Place of death: home

Age and gender and social class have an influence on whether those dying from malignant neoplasm of the lymphatic/haematopoietic tissue die at home. The analysis shows that the home deaths for these types of cancers have an opposite pattern to the hospice deaths when examining gender and age. The younger a person is the more likely they are to die in the home. Men dying of malignant neoplasm of the lymphatic/ haematopoietic tissue are 12% more likely than women to die at home. Examining patterns by social class, for these types of cancers social class I and II have more chance of dying at home than any other social group. The unskilled workers are 28% less likely to die at home than social class I and II, skilled non manual workers are 12% less likely, semi skilled workers and unskilled workers 15% less likely.

This model suggests that for malignant neoplasm of the lymphatic/ haematopoietic tissue the managerial and professional classes are achieving greater access to hospice services and also services to support home deaths.

Other malignant neoplasm Place of death: hospice

For all other types of malignant neoplasm, age and social class have an influence on whether people die in a hospice. The younger a person is the less likely they are to die in the hospice. There is not significant difference by gender. For these “other neoplasms” social class I and II have more chance of dying in the hospice than any other social group. The unskilled workers are 35% less likely, the skilled manual workers are 16% less likely and the semi skilled workers are 27% less likely to die in the hospice than social class I and II.

Other malignant neoplasm Place of death: home

Age and gender and social class all have an influence on whether those dying from other types of malignant neoplasm die at home. All social groups are less likely to die at home than those in social class I and II. Older people and men are more likely to die at home than women or young people.

Table 12 Summary of statistically significant results

(odds ratios shown in table 11)

Site of cancer	Most likely to die hospice	Least likely to die in hospice	Most likely to die at home	Least likely to die at home
All sites	Young, female, skilled, non manual workers	Unskilled workers	Older, male, managerial and professional workers	Skilled, non manual workers
Malignant neoplasm of the lip, oral cavity and pharynx	Women		Young	
Malignant neoplasm of digestive organs and peritoneum	Young, female, skilled, non manual workers	Unskilled workers	Younger, male, managerial and professional workers	Unskilled workers

Malignant neoplasm of respiratory and intra-thoracic organs	Young, female, skilled, non manual workers	Unskilled workers	Younger, Managerial and professional workers	Skilled, non manual workers
Malignant neoplasm of bone, connective tissue and skin	Older women	Unskilled workers	Young, Managerial and professional workers	Unskilled workers
Malignant neoplasm of the female breast	Skilled, non manual workers	Unskilled workers	Young	skilled, non manual workers
Malignant neoplasm of the genitourinary organs	Young, female, skilled, non manual workers	Unskilled workers	Men, young, managerial and professional workers	skilled, non manual workers
Malignant neoplasm of lymphatic haematopoietic tissue	Older, female, managerial and professional workers	Unskilled workers	Men, young, managerial and professional workers	Unskilled workers
Other malignant neoplasm	Young, managerial and professional workers	Unskilled workers	Older, men, managerial and professional workers	Unskilled workers

Table 13 Summary of statistically significant results- odds ratios

Site of cancer	Most likely to die hospice	Least likely to die in hospice	Most likely to die at home	Least likely to die at home
All sites	Young, female, skilled, non manual workers	Unskilled workers	Older, male, managerial and professional workers	Skilled, non manual workers
Odds ratios (base as unskilled workers)	Age:0.99 Sex:1.21 Social class: IIINM:1.43	Social class: I & II:0.28, IIINM:0.43, IIIM:0.18, IV:0.12	Age:1.11 Sex:0.89 Social class: I&II:1.19	Social class: IIINM:0.96
malignant neoplasm of the lip, oral cavity and pharynx	women		Young	

Odds ratios (base as managerial and professional workers)	Sex:1.25		Age:0.98	
Malignant neoplasm of digestive organs and peritoneum	Young, female, skilled, non manual workers	Unskilled workers	Younger, male, managerial and professional workers	Unskilled workers
Odds ratios (base as managerial and professional workers)	Age:0.99 Sex:1.20 Social class: IIINM:1.24	Social class: V:0.81	Age:0.99 Sex:0.88 Social class: IINM:0.76 IIIM:0.92 IV:0.83 V:0.75	Social class: V:0.75
Malignant neoplasm of respiratory and intra-thoracic organs	Young, female, skilled, non manual workers	Unskilled workers	Younger, Managerial and professional workers	Skilled, non manual workers
Odds ratios (base as managerial and professional workers)	Age: 0.99 Sex:1.13 Social class: IIINM:1.09	Social class: V:0.81	Age:0.99 Social class: IIINM:0.85 IIIM:0.96 IV:0.90 V:0.87	Social class: IIINM:0.87
Malignant neoplasm of bone, connective tissue and skin	Older women	Unskilled workers	Young, male Managerial and professional workers	Unskilled workers
Site of cancer	Most likely to die hospice	Least likely to die in hospice	Most likely to die at home	Least likely to die at home
Odds ratios (base as managerial and professional workers)	Age:1.01 Sex:1.15	Social class: V:0.99	Age:0.99 Sex:0.87 Social class: IIINM:0.78 IIIM:0.88 IV:1.02 V:0.74	Social class: V:0.74
Malignant neoplasm of the female breast	skilled, non manual workers	Unskilled workers	Young	Skilled, non manual workers
Odds ratios (base as managerial and professional workers)	Social class: IIINM:1.11	Social class: V:0.84	Age:0.99	Social class: IIINM:0.79

Malignant neoplasm of the genitourinary organs	Young, female, skilled, non manual workers	Unskilled workers	Men, young, managerial and professional workers	skilled, non manual workers
Odds ratios (base as managerial and professional workers)	Age:0.99 Sex:1.21 Social class: IIINM:1.16	Social class: IIINM:0.79	Age:0.99 Sex:1.09 Social class: IIINM:0.82 IIIM:1 IV:0.90 V:0.89	Social class: IIINM:0.82
Malignant neoplasm of lymphatic haematopoietic tissue	Older, female, managerial and professional workers	Unskilled workers	Men, young, managerial and professional workers	Unskilled workers
Odds ratios (base as managerial and professional workers)	Age:1.01 Sex:1.17 Social class: IIIMN:0.98 IIIM:0.94 IV:0.83 V:0.75	Social class: V:0.75	Age:0.99 Sex:0.88 Social class: IIINM:0.82 IIIM:0.88 IV:0.85 V:0.85	Social class: V:0.85
other malignant neoplasm	Young, managerial and professional workers	Unskilled workers	Older, men, managerial and professional workers	Unskilled workers
Odds ratios (base as managerial and professional workers)	Social class: IIINM:0.96 IIIM:0.84 IV:0.73 V:0.65		Social class: IIINM:0.80 IIIM:0.90 IV:0.85 V:0.77	

Discussion

The analysis and modelling using the national cancer dataset showed that overall there was a clear pattern of higher proportional rates of access to home care and subsequent death at home by social classes I and II. The skilled non manual workers gained greater proportional access to the hospice as a place of death than any of the other social groups. The modelling and analysis showed that women were, in general more likely to die in the hospice than men and less likely than men to die at home. The older a person was the more likely they were to die in hospital. These differences may relate to social support available in different classes and phases of the lifecycle but perhaps raise the question of not only equitable access relating to need but also age.

Respiratory cancers represent a large number of the total cancer deaths and there are proportionately more deaths n the semi and unskilled groups than all forty-four other social groups; however this group did not gain high levels of access to the hospice and home care services and therefore did not appear to have secured equitable access to final care services. For those dying of both bone and respiratory cancers young, female patients were most likely to gain access to the hospice. Patterns of access to the hospice and home care show no age effect but there is a clear social class difference with semi and unskilled classes gaining poor access to home and hospice services. Those with malignant neoplasm of the lymphatic/haematopoietic tissue were more likely to die in the hospice the older they were this provided the only exception to the apparent decreasing likelihood of hospice death as age increased.

6.5 Conclusion

The study of the national cancer dataset provided the opportunity to work with a comprehensive dataset that gave a large amount of information about a cohort of people dying of cancer in England and Wales. As the information collected was at the level of individual patient it represented an opportunity to analyse the data in many ways, looking at different types of cancer, gender, age, occupation and social class and place of death.

Examining data about place of death not only gave information about access to facilities for place of final care but it also indicated the extent of provision of service and also provided the opportunity to investigate how patterns of provision and access across social groups varied for different types of malignancy. A different pattern of final care emerged for different social classes, the lower social class a person was, and the more likely they were to die in hospital. The higher the social class, the more likely they were to access the hospice as a place to die or to arrange to have home deaths. The analysis does not provide any data indicating the element of informed choice that influenced final place of care but evidence was discussed which indicated that most people's preference would be for supported home deaths or access to specialist care such as is provided by a hospice.

Examining the data using logistic modelling techniques it was clear that there were significant differences in access to the hospice facilities by different social groups. Overall the group with highest, proportional access to hospice facilities were those in skilled non-manual occupations. The group least likely to access hospice care was the group of unskilled workers. Those most likely to die at home were predominantly men; this perhaps reflects the traditional role of women as carers and the differences in life expectancy between men and women, with women generally outliving men and therefore providing support as carers for men. The social groups most likely to access home deaths were the group of managerial and professional workers, predominantly men.

The groups having least access to death at home were skilled non-manual workers. This was perhaps a reflection of their high overall access rates to hospice care. Unskilled workers seemed to have poor access to death at home or in the hospices. This national pattern is reflected at a local level by the study of cancer deaths in the Doncaster Health Authority area.

Palliative care is a major area of healthcare provision and the results of the analysis undertaken within this study of the national data provide robust information about patterns in place of death. The results of this study provided information, which could inform services to target the support to those sub-groups of the population not currently achieving equitable access to final care services. The work in Doncaster starts to explore the interesting relationship between patient and family informed choices and how the ability to assert themselves to gain this choice and how this seems to be a greater influence on access to final care than clinical need. While it is unlikely that clinicians and professional carers consciously discriminate between social groups by social class alone it conceivable that they make judgements and decisions about care based on their perceptions of what they feel is appropriate to offer based on judgement of social class. For instance, hospice care may be offered more readily to the assertive professional and. skilled classes. Some people prefer to die in hospital; and patient perception of the hospice or hospital may be different for different groups. It is important to develop a range of services that are sensitive to the needs of all social classes. For patients who choose to die in hospital, at home or in the hospice it is important to provide a range of palliative care services appropriate to their needs. Neither Health Authorities, providers of health care nor individuals should retain a taboo on discussion about place of death. Place of death is perhaps less important than a collaborative approach to palliative care which ensures that patients and their carers needs are met. Joint arrangements between hospice, homecare and the hospital should be based on need not social class.

The need for institutional substitutes to home care to provide support for the dying was perhaps particularly brought about by the dislocation of the extended family and the entry into the labour market of traditional home carers, and partly because a high value was placed upon hospital care involving medical expertise. Hospital care was the major response for many serious health problems and many automatically look to the hospital system for care and management of those dying of cancer.

The findings of the Doncaster study were confirmed by the national study and should have major implications for the hospice movement, perhaps necessitate a radical rethinking of admission and care policies. It would be informative to ascertain what the distribution of preference for place of death from cancer would be in an informed population with access to a range of services. There is information available as a result of this research to inform a discussion about whether variation in the access to services for those dying of cancer is due to failure of the services to offer adequate information, equity of access, or other factors which individual healthcare professionals and/ or commissioners can modify.

Chapter Seven: Conclusions, recommendations and contribution to knowledge

The research underlines the clear differences between inequality and inequity of access to health care. Inequality is a state where there may be differences between how groups access health care but if there is differing health status these differences may not be "unfair". An obvious example is rates of access by men to cardiology interventions such as coronary artery bypass grafts, men have much higher rates of access to these procedures but this inequality is not to be considered inequitable as men have a higher incidence of the coronary heart disease than women so therefore we would expect higher rates of access. Inequity exists where there is inequality between, for example, access to a service between different individuals or groups with apparently the same need. This research has focused on the measurement and influencing of policy and strategy relating to inequity of access, particularly by different social groups to different types of health care.

There was an emphasis throughout the work on reflexive monitoring of action, the process of keeping in touch with the grounds and reasons for actions, as an integral element of doing the work legitimised not by the relation to tradition, i.e. how things have been done, but by their principled defence in the light of new and increasing knowledge. This was a particularly innovative process when attempting to increase equity because inequality and equity issues were not firmly on the health agenda at this time and it began to change the nature of the methods of validation and the source of authority, because this incoming knowledge had not been justified by tradition.

The influences and principles that established and shaped the state funded NHS in England were based on a clear philosophy of ideas that suggested equity was a fundamental issue. Political will and changes in political priorities and direction have altered the emphasis that governments are prepared to place on issues relating to equity. The societal value of both health and equity are very subjective issues. Equity is also related not only to the supply of resources but also to whether these resources, can be made available to deserving recipients. For example there may be resources available to recruit extra nursing staff but labour shortages may be the reason that is causing inequity of access to services between different areas rather than the existence of the financial resources to promote them. The influences of market forces and the emphasis on financial accountability have led over the years to the development of data collections from the NHS health care systems that focused on financial resources and processes with little information being made available about the nature of health and illness, equality or equity, need for service or the quality of the service. The perpetual changes in NHS structures and geographical boundaries have made analysis of patterns of change over time difficult to track.

Information that is used for monitoring and measuring equity and inequality provides proxies based on many sources of information and different aspects that could be considered as possible variations. Proxies and indices have been derived for many different and specific purposes and many of these have been subsequently applied to diverse purposes. The data and tools available for application and analysis were perhaps a particular weakness in the research; the nature of the concept being measured meant that tools available were inevitably imperfect. These indices and measures provide information about a mixture of factual and ethical concepts, many of which are subjective and difficult to attach values to. However a significant incentive to use the data available for this work was the opportunity to influence the improvement of data quality and to show that it had important moral and ethical uses apart from the widely perceived single use of finance and performance monitoring. These types of issues that are being examined often require the guidance and support of a variety of information and data and the construction of the "big picture" of information discussed and widely used in this research.

Limiting long term illness was used in this research as a population based measure for need for health care and this 1991 Census variable provided a proxy that could be used for demand, need and use of health care services. The concept of limiting long term illness was validated for local use by a survey of limiting long term illness undertaken in Shirebrook in North Derbyshire. The survey provided an interesting illustration of differences in perceptions of the GP and patients about the presence of limiting long term illness. The GPs appeared to be less likely to agree with patients' own assessment of having limiting long term illness when they were not in paid employment, e.g. women and older people, than when people were economically active.

The survey provided local information about the GP practice and encouraged local confidence in the use of routine data relating to the population rather than purely the use of data which described processes of health care. The process of undertaking the limiting long term illness survey raised local awareness of the need to ensure that future allocations of resources to primary care looked at a wide range of information and issues. Equity clearly had an increased importance to the GPs. Information was beginning to be seen to have a central role in the understanding and monitoring of equity of access to health care locally, to support changes and improvements.

The work described in the research relating to operationalising equity revealed large differences in funding between seemingly similar practices and suggested a pattern of funding that was haphazard and inequitable. There was a need and desire for any change processes to be owned by the primary care community. The process that was undertaken reviewed the current situation relating to equity of resource allocation, studied the information and available and agree a process for change that would rely on the delivery and analysis of information to support it. There was a clear commitment to build on this momentum and the Equity Group grappled with various technical solutions and the political dimensions of these changes. Much information and many mechanisms for resource allocation were examined and the York indices presented to the group a transparent but sophisticated solution to be used locally with other information and local knowledge as an empirical but semi objective measure. This part of the research was an important influence operationalising not only the use of information to inform policy but also to enable the concepts and principles of equity to be operationalised into local practices via resource allocations to more deprived areas that had previously been clearly under resourced.

The last part of the research described in chapter six was produced as a result of analysing local and national data and studying the influences that seemed to determine where cancer patients were receiving their final care. The work was begun in Doncaster as a development of the North Derbyshire work on equity. It was felt locally that access to the hospice and home care services were not equitable across all groups of people in the area and an equity audit was instigated. National and international evidence[182,183] had clearly shown that given an informed choice patients would opt for home assisted care or hospice care, yet in Doncaster and later in the national analysis it was clear that the more deprived sections of the population were most likely to die in a hospital than their counterparts in the higher social classes. This contrast was particularly noticeable for respiratory cancers where there is a social class gradient. Those in the lowest social classes are more likely to die from respiratory cancers. These deaths account for over a third of all cancer deaths (and nearly a tenth of all deaths from all causes) and the research shows an example of systematic social class inequity of access to home care and hospice care for those dying of cancer both in Doncaster and nationally. Modelling also showed that there were inequalities relating to age and gender. The older a person was the less likely they were to die in the hospice or at home. This indicated an inequity of access to hospice care, but the access to home care was probably more as a result of the increasing likelihood of lack of spouse to undertake home care. This is also probably reflected in the differences in access to home deaths by gender. Women were less likely to be cared for at home than men, probably as a result of their greater life expectancy compared to spouses rather than inequity. This work is to be extended into a study in the South East Region making use of hospital episode system data, cancer registration data and deaths information to analyse and monitor patterns of equity and support local mechanisms for relevant change.

The research underlines the lack of adequate tools and information to monitor and analyse access to health care but goes on to make use of the current tools available in innovative and imaginative ways. The research was undertaken during a time of immense change in political attitudes to health inequality and equity and made a significant contribution in North Derbyshire and Doncaster to the way that changes towards more equitable delivery of services could take place as a result of this. The work makes extensive use of building the "big picture" and increasing locally the use and credibility of information from diverse sources to influence policy and increase awareness about equity issues in health care and support changes.

Census Derived indices

Townsend

The Townsend Score is based on four variables originally taken from the 1981 Census selected to represent material deprivation using unemployment, overcrowding, lack of owner occupied accommodation and lack of car ownership. It is a summation of the standardised scores (Z scores) for each variable, where scores greater than zero indicate greater levels of material deprivation. Two of the variables – those relating to unemployment and overcrowding – are firstly transformed using a log transformation to produce more normal distributions. The four variables are combined together in an overall deprivation index, with each variable being given an equal weight.

The units of measurement of the four indicators are:

Unemployment – % of economically active residents aged 16-59/64 who are unemployed;

Car ownership – % of private households who do not posses a car;

Home ownership – % of private households not owner occupied;

Overcrowding – % of private households with more than one person per room.

Jarman

The Jarman Underprivileged Area (UPA) Score was originally constructed to measure General Practice workload. The Jarman Score was designed to take account of geographic variations in the demand for primary care using information collected via a survey of GPs" interpretations of the social factors among their patients that most affected their own workload. The variant of the score most commonly used – the UPA8 score – comprises eight variables which were individually weighted by a sample of London GPs.

Unemployment – (3.34) residents unemployed as a percentage of economically active;

Overcrowding – (2.88) % of residents in overcrowded households (more than one person per room);

Lone parents – (3.01) % of residents in "lone parent" households;

Under 5s – (4.64) % of residents aged under 5 years;

Elderly living alone – (6.62) % of elderly persons living alone;

Ethnicity – (2.50) % of households headed by a person born outside the United Kingdom;

Low social class – (3.74) % of residents where household head is unskilled (social class V);

Residential mobility – (2.68) % of residents who changed address in the previous year.

Each variable is based on the percentage of all residents in households, with the exceptions of unemployment, which is based on the percentage of the economically active population, which is unemployed and residential mobility, where the denominator is the total resident population. Each variable is firstly expressed as a proportion (between 0 and 1). The proportions are then transformed by calculating the square root and then finding the equivalent arc sine. The variables are expressed as Z scores and multiplied by their respective weighting factors. The final score is obtained by summing the variables (after statistically reworking). Higher scores indicate greater levels of GP workload.

The index has been criticised as "being better at defining inner-city deprivation because it includes factors like overcrowding and ethnicity"[202]. Talbot[203] continues this criticism focusing on the bias towards London in the proportion of the population classified as deprived. Talbot states that "the index fails to recognise the nature of deprivation in the North of England...benefit[ing] the Thames regions at the expense of peripheral regions"

Carstairs index- Scotdep

Carstairs and Morris constructed this index for the analysis of Scottish health data. Like the Townsend Score, it is based on four variables originally taken from the 1981 Census which were deemed to represent material disadvantage. Three of the indicators are the same as those used in Townsend, the fourth is social class.

The units of measurement of the four indicators are:

Overcrowding – persons in private households living at a density of more than one person per room as a proportion of all persons in private households;

Male unemployment – proportion of economically active males who are seeking work;

Social Class IV or V – proportion of all persons in private households with head of household in Social Class IV or V;

No car – proportion of all persons in private households with no car.

The deprivation measure is an unweighted combination of the four standardised variables.

Socdep and Matdep

MATDEP (material deprivation index) and SOCDEP (social deprivation index) are both indices of deprivation that were developed by Forrest and Gordon[204] using 1991 Census data. The difference between material and social deprivation has been stated by Townsend as- "Material deprivation entails the lack of goods, services, resources, amenities and physical environment which are customary, or a least widely approved in the society under consideration. Social deprivation, on the other hand, is non-participation in the roles, relationships, customs, functions, rights and responsibilities implied by member of a society and its sub-groups. Such deprivation may be attributed to the affects of racism, sexism and ageism ..." (Townsend et al)[44]. The indicators that are used in MATDEP:

Overcrowding: % households with more than 1 person per room;

Lack amenity: % households lacking or sharing use of a bath/shower and/or inside WC;

No central heating: % households with no central heating; No car: % households with no access to a car.

The indicators used in SOCDEP are:

Unemployment: % economically active population unemployed;

Youth unemployed: % economically active 16-24 year olds unemployed;

Lone parents: lone parent households as a proportion of all households;

Elderly: % households containing a single pensioner;

Long term illness: % households containing a person with limiting long term illness;

Dependent only: households containing dependants only (e.g. single pensioners with long term illness) as a percentage of all households.

MATDEP and SOCDEP scores are the summation of the unweighted standardised scores for each variable. Each variable is standardised by dividing the percentage value for each indicator in a particular geographic area by the maximum value for each indicator in all areas to give a value between 0 and 1. The maximum score for SOCDEP is 6 and the maximum score for MATDEP is 4 (the minimum score for both indices is 0). Higher scores indicate greater levels of deprivation.

Non Census Derived indices

Breadline Britain[205] [206]

The Breadline Britain Score is the result of two surveys carried out by MORI for London Weekend Television and the Joseph Rowntree Foundation in 1983 and 1990. The 1983 study pioneered the use of the “consensual” or “perceived” deprivation approach to measuring poverty. The approach set out to determine whether there are some people whose standard of living is below the minimum acceptable to society. The minimum standard of living was determined by interviewing a quota sample (based on age, sex and working status) of 1,174 adults in 1983 and 1,831 adults in 1990. Aggregated data were weighted by age, household type, household tenure and housing type to be representative of the population of Great The Breadline Britain Score is the result of two surveys carried out by MORI for London Weekend Television and the Joseph Rowntree Foundation in 1983 and 1990. The 1983 study pioneered the use of the “consensual” or “perceived” deprivation approach to measuring poverty. The approach set out to determine whether there are some people whose standard of living is below the minimum acceptable to society. The minimum standard of living was determined by interviewing a quota sample (based on age, sex and working status) of 1,174 adults in 1983 and 1,831 adults in 1990. Aggregated data were weighted by age, household type, household tenure and housing type to be representative of the population of Great Britain. In order to ensure a large sample of people living in deprived areas over-sampling was conducted in areas known to contain poor households.

In the 1990 Survey respondents were presented with a set of 44 cards onto each of which was written the name of a different item covering a range of possessions and activities that relate to standards of living. Examples are a television, a night out once a fortnight and a warm waterproof coat. Respondents were asked to place the 44 cards into one of two boxes. Box A was for items which they considered necessary; those items which all adults should be able to afford and which they should not have to do without. Box B was for items which they considered to be desirable but not necessary. They were also asked if they felt differently about any of the items in the case of families with children. An item was deemed to be a socially perceived necessity if more than 50% of respondents put it into Box A. Later in the interview the respondents were asked to assign one of the following 5 options to each of the 44 items:

Have and couldn't do without

Have and could do without

Don't have and don't want

Don't have and can't afford

Not applicable/don't know

Respondents (and their households) were assigned a deprivation index score each time they answered "don't have and can't afford" to an item that was considered to be a necessity by more than 50% of respondents.

Department of the Environment's Index of Local Conditions (1991)

The Index of Local Conditions[207] comprises 13 variables - seven of which are Census variables and six of which are non-Census variables:

The Census variables are:

Unemployment – residents aged 16 and over who are unemployed compared to residents aged 16 and over that are economically active;

Children in low-earner households – resident dependent children (aged under 16) living in households with no one in employment or with a single parent in part-time work compared to all dependent children (aged under 16);

Overcrowding – households with above one person per room compared to all households;

Housing lacking basic amenities – residents in households lacking amenities compared to all residents in households in permanent and non-permanent accommodation;

No car – households without a car compared to all households;

Children in unsuitable accommodation – dependent children (aged under 16) living accommodation that is either purpose-built flats, non-permanent, or unshared dwellings either converted or not self-contained compared to all dependent children (aged under 16);

Educational participation – residents aged 17 years not in full-time compared to all residents aged 17 years.

The Non-Census variables are

Long term unemployment – the ratio of long term unemployment (more than one year) to total unemployment;

Income support – persons or households in receipt of income support expressed in relation to total adult population;

Low educational attainment – passes in GCSE exams at grade D or below in relation to the total number of passes;

Standardised mortality ratios – all cause SMRs expressed in relation to a value of 100 for Great Britain (1991);

Derelict land – area of land defined as derelict in DoE survey in relation to total land area;

Home insurance weightings – weightings for premiums on house contents insurance used by three national insurance companies (1991).

The index of local conditions is an unweighted summation of the selected indicators using their log-transformed signed chi-square values. The actual number of persons having each selected variable is compared to the numbers that would be expected if average English rates applied. The difference between the actual and expected numbers is squared and then divided by the expected number after which the value of one is added. A log transformation is then applied and those scores where the actual rate was below the expected rate are given negative signs. Summed scores greater than zero indicate greater levels of material deprivation.

This index differs from those previously described in using actual numbers rather than percentage rates as the input into the calculations. This has the effect of giving lower weights to those areas where the actual counts are small - and hence statistically less reliable (i.e. an area where three out of ten persons are unemployed will have a lower score than one where unemployment is 30 out of 100).

Indices of Multiple Deprivation 1999 and 2000[208]

In June 1998, following consultation, the Department of the Environment, Transport and the Regions (DETR) published an updated version of the 1991 Index of Local Conditions. The 1998 Index of Local Deprivation (ILD), based mainly on data for 1996, was calculated for all 354 Local Authority Districts as they stood at April 1998. The ward and ED level indexes are based on the 1991 Census Area definitions. There are 12 indicators in the district level ILD that relate to different dimensions of deprivation – income, health, education, environment, crime and housing. The indicators, their measures and their sources are:

Unemployment – persons unemployed compared persons economically active (ONS claimant count 1997);

Dependent children of income support recipients – compared to persons aged 16 and under (DSS 1996);

Overcrowding – households above one person per room compared to all households (1991 Census);

Housing lacking basic amenities – residents in households lacking amenities compared to all residents in households in permanent and non-permanent accommodation (1991 Census);

Non income support recipients in receipt of council tax benefit – compared to total population aged 18 and over (DSS 1996);

Educational participation – 17 year-olds not in full-time education compared to all 17 year-olds (1991 Census);

Long term unemployment – the ratio of long term unemployment (more than one year) to total unemployment (ONS claimant count 1997);

Income support – persons or households in receipt of income support expressed in relation to total adult population (DSS 1996);

Low educational attainment –fifteen year olds with no GCSE passes or gaining GCSE passes at grades D-G only compared to all 15 year olds (DfEE 1996);

Standardised mortality ratios – all cause SMRs for under 75 year olds (ONS 1996);

Derelict land – area of land defined as derelict in DoE survey in relation to total land area (DoE 1993);

Home insurance weightings – weightings for premiums on house contents insurance used by three national insurance companies (1996).

There were two main differences in the methodology between the 1991 and 1998 Indexes. Firstly, in the 1991 Index the values for the indicators were simply added together, whereas in the 1998 Index only the positive values (those where the actual count exceeded that expected) were added together to produce the overall index score. Secondly, in the 1991 Index no weightings were attached to any of the indicators. However, in the 1998 Index the values for the standardised mortality ratio and insurance premium indicators were multiplied by two to give them a similar level of influence in the overall index.[209].

Although the 1998 update of the Index of Local Deprivation was not intended to review either the methodology or the combination of indicators used, the consultation process highlighted a number of issues relating to these aspects. Since the last review was undertaken many new sources of sub-district level data become available. In the light of this, DETR decided to undertake this further review of the Index to look at:

·*the conceptual basis of the ILD as a mechanism for identifying the most deprived areas in England;*

the current indicators, to assess whether they represent the best, up-to-date measure of relative general deprivation and, if not, test and recommend robust alternatives;

the methodology used to combine the individual indicators into single indexes of general deprivation at the different spatial levels and, if appropriate, suggest improvements based on assessment of alternative methods.

Following the consultation the full Index was made available, and the DETR published a full report of the process incorporating a description of patterns of deprivation and how these differ from the 1998 ILD[210].

Appendix Chapter 3: Limiting long term illness survey questionnaires

WHAT ARE WE DOING?

We are carrying out a survey in Shirebrook. The aim of the survey is to obtain information about how you and your doctor feel about your health, we hope the results will help tell the practice about your needs.

IS THE SURVEY CONFIDENTIAL?

YES, we will not know the individual identity of who has filled in the questionnaire.
The information collected will not be released to government departments, local authorities or in any way in which individual people could be identified. The results will not show names or addresses.

THANK YOU FOR HELPING US WITH THIS SURVEY

questionnaire number:
☐☐☐☐

SELF REPORTED HEALTH

..) How is your health in general?
would you say it was....

very good ☐

good ☐

fair ☐

bad ☐

very bad ☐

2.) Do you have any long-term illness, health
roblem or handicap which limits your daily
ctivities or the work you can do?
nclude problems which are due to old age

es, have a health problem which limits activities ☐

lave no such health problem ☐

would be useful if you could give us the following formation:

ge

ider 18 ☐

-25 ☐

-35 ☐

-44 ☐

-59 ☐

-75 ☐

er 75 ☐

ex

ale ☐

male ☐

ork

ast week, was the person who you consider to be the main earner

employed ☐

rking full time ☐

tired ☐

rmanently sick ☐

questionnaire number:

☐☐☐

LONG-TERM ILLNESS

oes this person have any long-term illness, health roblem or handicap which limits his/her daily ctivities or the work he/she can do?

nclude problems which are due to old age

es, has a health problem which limits activities ☐

as no such health problem ☐

Appendix Chapter 6: Additional detailed frequencies, analysis and commentary from the National Cancer dataset

Cross Tabulations

Place of cancer death 1994-97

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Sex of deceased * Place of death (3 code)	483170	87.5%	68927	12.5%	552097	100.0%
Year of death * Place of death (3 code)	483170	87.5%	68927	12.5%	552097	100.0%
age band at death recode (4) * Place of death (3 code)	483014	87.5%	69083	12.5%	552097	100.0%
Social class household: 4 code * Place of death (3 code)	272329	49.3%	279768	50.7%	552097	100.0%
Social Class of HH: 4 code + other * Place of death (3 code)	483170	87.5%	68927	12.5%	552097	100.0%
icd cancer group * Place of death (3 code)	451148	81.7%	100949	18.3%	552097	100.0%

Sex of deceased * Place of death (3 code) Crosstabulation

			Place of death (3 code)			
			Home	Hospice	Hospital NHS	Total
Sex of deceased	Male	Count	79096	39293	141252	259641
		% within Sex of deceased	30.5%	15.1%	54.4%	100.0%
	Female	Count	62386	38857	122286	223529
		% within Sex of deceased	27.9%	17.4%	54.7%	100.0%
Total		Count	141482	78150	263538	483170
		% within Sex of deceased	29.3%	16.2%	54.5%	100.0%

Year of death * Place of death (3 code) Crosstabulation

			Place of death (3 code)			
			Home	Hospice	Hospital NHS	Total
Year of death	1994	Count	37526	18391	66603	122520
		% within Year of death	30.6%	15.0%	54.4%	100.0%
	1995	Count	36179	18683	66966	121828
		% within Year of death	29.7%	15.3%	55.0%	100.0%
	1996	Count	34523	19083	66107	119713
		% within Year of death	28.8%	15.9%	55.2%	100.0%
	1997	Count	33254	21993	63862	119109
		% within Year of death	27.9%	18.5%	53.6%	100.0%
Total		Count	141482	78150	263538	483170
		% within Year of death	29.3%	16.2%	54.5%	100.0%

age band at death recode (4) * Place of death (3 code) Crosstabulation

			Place of death (3 code)			
			Home	Hospice	Hospital NHS	Total
age band at death recode (4)	44 & under	Count	5275	3008	8576	16859
		% within age band at death recode (4)	31.3%	17.8%	50.9%	100.0%
	45 - 59	Count	22415	12139	31295	65849
		% within age band at death recode (4)	34.0%	18.4%	47.5%	100.0%
	60 - 74	Count	64580	33720	104047	202347
		% within age band at death recode (4)	31.9%	16.7%	51.4%	100.0%
	75 & over	Count	49160	29272	119527	197959
		% within age band at death recode (4)	24.8%	14.8%	60.4%	100.0%
Total		Count	141430	78139	263445	483014
		% within age band at death recode (4)	29.3%	16.2%	54.5%	100.0%

Social class household: 4 code * Place of death (3 code) Crosstabulation

			Place of death (3 code)			Total
			Home	Hospice	Hospital NHS	
Social class household: 4 code	sc1&2	Count	25275	13240	33425	71940
		% within Social class household: 4 code	35.1%	18.4%	46.5%	100.0%
	sc3nm	Count	8496	5789	14518	28803
		% within Social class household: 4 code	29.5%	20.1%	50.4%	100.0%
	sc3m	Count	31177	15747	48208	95132
		% within Social class household: 4 code	32.8%	16.6%	50.7%	100.0%
	sc4&5	Count	23843	11868	40743	76454
		% within Social class household: 4 code	31.2%	15.5%	53.3%	100.0%
Total		Count	88791	46644	136894	272329
		% within Social class household: 4 code	32.6%	17.1%	50.3%	100.0%

Social Class of HH: 4 code + other * Place of death (3 code) Crosstabulation

			Place of death (3 code)			Total
			Home	Hospice	Hospital NHS	
Social Class of HH: 4 code + other	sc1&2	Count	25275	13240	33425	71940
		% within Social Class of HH: 4 code + other	35.1%	18.4%	46.5%	100.0%
	sc3nm	Count	8496	5789	14518	28803
		% within Social Class of HH: 4 code + other	29.5%	20.1%	50.4%	100.0%
	sc3m	Count	31177	15747	48208	95132
		% within Social Class of HH: 4 code + other	32.8%	16.6%	50.7%	100.0%
	sc4&5	Count	23843	11868	40743	76454
		% within Social Class of HH: 4 code + other	31.2%	15.5%	53.3%	100.0%
	sc missing	Count	52691	31506	126644	210841
		% within Social Class of HH: 4 code + other	25.0%	14.9%	60.1%	100.0%
Total		Count	141482	78150	263538	483170
		% within Social Class of HH: 4 code + other	29.3%	16.2%	54.5%	100.0%

icd cancer group * Place of death (3 code) Crosstabulation

			Place of death (3 code)			Total
			Home	Hospice	Hospital NHS	
icd cancer group	lip oral pharynx	Count	1811	1341	2783	5935
		% within icd cancer group	30.5%	22.6%	46.9%	100.0%
	dig perit	Count	45023	22252	67047	134322
		% within icd cancer group	33.5%	16.6%	49.9%	100.0%
	respiratory	Count	36940	17438	63319	117697
		% within icd cancer group	31.4%	14.8%	53.8%	100.0%
	bone tissue skin	Count	2982	1949	4176	9107
		% within icd cancer group	32.7%	21.4%	45.9%	100.0%
	breast	Count	11852	8345	20370	40567
		% within icd cancer group	29.2%	20.6%	50.2%	100.0%
	gu organs	Count	13017	9475	26041	48533
		% within icd cancer group	26.8%	19.5%	53.7%	100.0%
	other sites	Count	14840	8825	35374	59039
		% within icd cancer group	25.1%	14.9%	59.9%	100.0%
	blood & lymphatics	Count	6125	2854	26969	35948
		% within icd cancer group	17.0%	7.9%	75.0%	100.0%
Total		Count	132590	72479	246079	451148
		% within icd cancer group	29.4%	16.1%	54.5%	100.0%

Cross Tabulations

Focus on household social class missing category

Case Processing Summary

	Cases					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Sex of deceased * Social Class of HH: 4 code + other	552097	100.0%	0	.0%	552097	100.0%
age band at death recode (4) * Social Class of HH: 4 code + other	551754	99.9%	343	.1%	552097	100.0%
Year of death * Social Class of HH: 4 code + other	552097	100.0%	0	.0%	552097	100.0%
Place of death (3 code) * Social Class of HH: 4 code + other	483170	87.5%	68927	12.5%	552097	100.0%
icd cancer group * Social Class of HH: 4 code + other	513646	93.0%	38451	7.0%	552097	100.0%

Sex of deceased * Social Class of HH: 4 code + other Crosstabulation

			Social Class of HH: 4 code + other					
			sc1&2	sc3nm	sc3m	sc4&5	sc missing	Total
Sex of deceased	Male	Count	41304	14543	59387	47100	125199	287533
		% within Sex of deceased	14.4%	5.1%	20.7%	16.4%	43.5%	100.0%
		% within Social Class of HH: 4 code + other	52.7%	46.9%	59.0%	57.6%	48.1%	52.1%
	Female	Count	37114	16488	41206	34679	135077	264564
		% within Sex of deceased	14.0%	6.2%	15.6%	13.1%	51.1%	100.0%
		% within Social Class of HH: 4 code + other	47.3%	53.1%	41.0%	42.4%	51.9%	47.9%
Total		Count	78418	31031	100593	81779	260276	552097
		% within Sex of deceased	14.2%	5.6%	18.2%	14.8%	47.1%	100.0%
		% within Social Class of HH: 4 code + other	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

age band at death recode (4) * Social Class of HH: 4 code + other Crosstabulation

			Social Class of HH: 4 code + other					
			sc1&2	sc3nm	sc3m	sc4&5	sc missing	Total
age band at death recode (4)	44 & under	Count	5383	2038	4712	3291	2430	17854
		% within age band at death recode (4)	30.2%	11.4%	26.4%	18.4%	13.6%	100.0%
		% within Social Class of HH: 4 code + other	6.9%	6.6%	4.7%	4.0%	.9%	3.2%
	45 - 59	Count	20247	6793	22611	16102	4134	69887
		% within age band at death recode (4)	29.0%	9.7%	32.4%	23.0%	5.9%	100.0%
		% within Social Class of HH: 4 code + other	25.8%	21.9%	22.5%	19.7%	1.6%	12.7%
	60 - 74	Count	52581	22098	72999	62135	8580	218393
		% within age band at death recode (4)	24.1%	10.1%	33.4%	28.5%	3.9%	100.0%
		% within Social Class of HH: 4 code + other	67.1%	71.2%	72.6%	76.0%	3.3%	39.6%
	75 & over	Count	207	101	271	251	244790	245620
		% within age band at death recode (4)	.1%	.0%	.1%	.1%	99.7%	100.0%
		% within Social Class of HH: 4 code + other	.3%	.3%	.3%	.3%	94.2%	44.5%
Total		Count	78418	31030	100593	81779	259934	551754
		% within age band at death recode (4)	14.2%	5.6%	18.2%	14.8%	47.1%	100.0%
		% within Social Class of HH: 4 code + other	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Year of death * Social Class of HH: 4 code + other Crosstabulation

			Social Class of HH: 4 code + other					
			sc1&2	sc3nm	sc3m	sc4&5	sc missing	Total
Year of death	1994	Count	20011	8237	26274	21644	63667	139833
		% within Year of death	14.3%	5.9%	18.8%	15.5%	45.5%	100.0%
		% within Social Class of HH: 4 code + other	25.5%	26.5%	26.1%	26.5%	24.5%	25.3%
	1995	Count	19912	7945	25394	20839	65068	139158
		% within Year of death	14.3%	5.7%	18.2%	15.0%	46.8%	100.0%
		% within Social Class of HH: 4 code + other	25.4%	25.6%	25.2%	25.5%	25.0%	25.2%
	1996	Count	19272	7564	24954	20057	65612	137459
		% within Year of death	14.0%	5.5%	18.2%	14.6%	47.7%	100.0%
		% within Social Class of HH: 4 code + other	24.6%	24.4%	24.8%	24.5%	25.2%	24.9%
	1997	Count	19223	7285	23971	19239	65929	135647
		% within Year of death	14.2%	5.4%	17.7%	14.2%	48.6%	100.0%
		% within Social Class of HH: 4 code + other	24.5%	23.5%	23.8%	23.5%	25.3%	24.6%
Total		Count	78418	31031	100593	81779	260276	552097
		% within Year of death	14.2%	5.6%	18.2%	14.8%	47.1%	100.0%
		% within Social Class of HH: 4 code + other	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Place of death (3 code) * Social Class of HH: 4 code + other Crosstabulation

			Social Class of HH: 4 code + other					
			sc1&2	sc3nm	sc3m	sc4&5	sc missing	Total
Place of death (3 code)	Home	Count	25275	8496	31177	23843	52691	141482
		% within Place of death (3 code)	17.9%	6.0%	22.0%	16.9%	37.2%	100.0%
		% within Social Class of HH: 4 code + other	35.1%	29.5%	32.8%	31.2%	25.0%	29.3%
	Hospice	Count	13240	5789	15747	11868	31506	78150
		% within Place of death (3 code)	16.9%	7.4%	20.1%	15.2%	40.3%	100.0%
		% within Social Class of HH: 4 code + other	18.4%	20.1%	16.6%	15.5%	14.9%	16.2%
	Hospital NHS	Count	33425	14518	48208	40743	126644	263538
		% within Place of death (3 code)	12.7%	5.5%	18.3%	15.5%	48.1%	100.0%
		% within Social Class of HH: 4 code + other	46.5%	50.4%	50.7%	53.3%	60.1%	54.5%
Total		Count	71940	28803	95132	76454	210841	483170
		% within Place of death (3 code)	14.9%	6.0%	19.7%	15.8%	43.6%	100.0%
		% within Social Class of HH: 4 code + other	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

icd cancer group * Social Class of HH: 4 code + other Crosstabulation

			Social Class of HH: 4 code + other					
			sc1&2	sc3nm	sc3m	sc4&5	sc missing	Total
icd cancer group	lip oral pharynx	Count	1061	374	1441	1274	2571	6721
		% within icd cancer group	15.8%	5.6%	21.4%	19.0%	38.3%	100.0%
		% within Social Class of HH: 4 code + other	1.4%	1.3%	1.5%	1.6%	1.1%	1.3%
	dig perit	Count	21042	8061	26003	21252	77678	154036
		% within icd cancer group	13.7%	5.2%	16.9%	13.8%	50.4%	100.0%
		% within Social Class of HH: 4 code + other	28.3%	27.2%	27.1%	27.1%	33.0%	30.0%
	respiratory	Count	15282	6490	29329	25589	53762	130452
		% within icd cancer group	11.7%	5.0%	22.5%	19.6%	41.2%	100.0%
		% within Social Class of HH: 4 code + other	20.6%	21.9%	30.6%	32.7%	22.8%	25.4%
	bone tissue skin	Count	2315	803	1911	1384	4073	10486
		% within icd cancer group	22.1%	7.7%	18.2%	13.2%	38.8%	100.0%
		% within Social Class of HH: 4 code + other	3.1%	2.7%	2.0%	1.8%	1.7%	2.0%
	breast	Count	9492	3975	8229	6294	21542	49532
		% within icd cancer group	19.2%	8.0%	16.6%	12.7%	43.5%	100.0%
		% within Social Class of HH: 4 code + other	12.8%	13.4%	8.6%	8.0%	9.1%	9.6%
	gu organs	Count	8535	3491	9703	7779	26239	55747
		% within icd cancer group	15.3%	6.3%	17.4%	14.0%	47.1%	100.0%
		% within Social Class of HH: 4 code + other	11.5%	11.8%	10.1%	9.9%	11.1%	10.9%
	other sites	Count	9700	3855	12415	9562	31761	67293
		% within icd cancer group	14.4%	5.7%	18.4%	14.2%	47.2%	100.0%
		% within Social Class of HH: 4 code + other	13.1%	13.0%	12.9%	12.2%	13.5%	13.1%
	blood & lymphatics	Count	6818	2536	6939	5238	17848	39379
		% within icd cancer group	17.3%	6.4%	17.6%	13.3%	45.3%	100.0%
		% within Social Class of HH: 4 code + other	9.2%	8.6%	7.2%	6.7%	7.6%	7.7%
Total		Count	74245	29585	95970	78372	235474	513646
		% within icd cancer group	14.5%	5.8%	18.7%	15.3%	45.8%	100.0%
		% within Social Class of HH: 4 code + other	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

regional HA code usual residence 1994-5 * Place of death (3 code) Crosstabulation

			Place of death (3 code)			
			Home	Hospice	Hospital NHS	Total
regional HA code usual residence 1994-5		Count	67801	41122	130386	239309
		% within regional HA code usual residence 1994-5	28.3%	17.2%	54.5%	100.0%
		% within Place of death (3 code)	47.9%	52.6%	49.5%	49.5%
	A	Count	5382	1116	9051	15549
		% within regional HA code usual residence 1994-5	34.6%	7.2%	58.2%	100.0%
		% within Place of death (3 code)	3.8%	1.4%	3.4%	3.2%
	B	Count	4891	3551	9054	17496
		% within regional HA code usual residence 1994-5	28.0%	20.3%	51.7%	100.0%
		% within Place of death (3 code)	3.5%	4.5%	3.4%	3.6%
	C	Count	6937	2654	13618	23209
		% within regional HA code usual residence 1994-5	29.9%	11.4%	58.7%	100.0%
		% within Place of death (3 code)	4.9%	3.4%	5.2%	4.8%
	D	Count	3979	1328	6908	12215
		% within regional HA code usual residence 1994-5	32.6%	10.9%	56.6%	100.0%
		% within Place of death (3 code)	2.8%	1.7%	2.6%	2.5%
	E	Count	3160	1101	7516	11777
		% within regional HA code usual residence 1994-5	26.8%	9.3%	63.8%	100.0%
		% within Place of death (3 code)	2.2%	1.4%	2.9%	2.4%
	F	Count	4562	2973	10267	17802
		% within regional HA code usual residence 1994-5	25.6%	16.7%	57.7%	100.0%
		% within Place of death (3 code)	3.2%	3.8%	3.9%	3.7%
	G	Count	5138	4405	8803	18346
		% within regional HA code usual residence 1994-5	28.0%	24.0%	48.0%	100.0%
		% within Place of death (3 code)	3.6%	5.6%	3.3%	3.8%
	H	Count	3136	3806	6566	13508
		% within regional HA code usual residence 1994-5	23.2%	28.2%	48.6%	100.0%
		% within Place of death (3 code)	2.2%	4.9%	2.5%	2.8%
	J	Count	4515	1684	8491	14690
		% within regional HA code usual residence 1994-5	30.7%	11.5%	57.8%	100.0%
		% within Place of death (3 code)	3.2%	2.2%	3.2%	3.0%
	K	Count	3183	1153	6058	10394
		% within regional HA code usual residence 1994-5	30.6%	11.1%	58.3%	100.0%
		% within Place of death (3 code)	2.2%	1.5%	2.3%	2.2%
	L	Count	5626	2915	7888	16429
		% within regional HA code usual residence 1994-5	34.2%	17.7%	48.0%	100.0%
		% within Place of death (3 code)	4.0%	3.7%	3.0%	3.4%
	M	Count	8487	3267	12822	24576
		% within regional HA code usual residence 1994-5	34.5%	13.3%	52.2%	100.0%
		% within Place of death (3 code)	6.0%	4.2%	4.9%	5.1%
	N	Count	3665	2133	6379	12177
		% within regional HA code usual residence 1994-5	30.1%	17.5%	52.4%	100.0%
		% within Place of death (3 code)	2.6%	2.7%	2.4%	2.5%
	P	Count	5935	4288	10026	20249
		% within regional HA code usual residence 1994-5	29.3%	21.2%	49.5%	100.0%
		% within Place of death (3 code)	4.2%	5.5%	3.8%	4.2%
	W	Count	5085	654	9705	15444
		% within regional HA code usual residence 1994-5	32.9%	4.2%	62.8%	100.0%
		% within Place of death (3 code)	3.6%	.8%	3.7%	3.2%
Total		Count	141482	78150	263538	483170
		% within regional HA code usual residence 1994-5	29.3%	16.2%	54.5%	100.0%
		% within Place of death (3 code)	100.0%	100.0%	100.0%	100.0%

Multinomial main effects logistic models

A relevant application of the logistic model is in determining the effects of explanatory variables on a discrete set of more than two, non-ordered options, states or categories. This is the so-called conditional logistic or multinomial logistic model described, for example, by Agresti[211].

Thus a multinomial main effects model may be applied to the three place of death outcomes: home, hospice or NHS hospital, simultaneously. This should be methodologically more sound than applying a series of binary logistic models. Parameters for explanatory variates can be expressed as odds ratios (together with confidence intervals), as with binary logistic models. In the multinomial case, odds ratios are given taking one of the dependent states as base. In the place of death analyses below, the base has been taken as death in an NHS hospital, the “bad” or “least favoured” place of death.

(a) Main effects

social class of household: four code, excludes missing category;

gender of deceased; age band – merges the 60-74 & 75+ as very few in 75+ category with social class code; year of death.

Case Processing Summary

		N	Marginal Percentage
Place of death (3 code)	Home	88791	32.6%
	Hospice	46644	17.1%
	Hospital NHS	136894	50.3%
Social class household: 4 code	sc1&2	71940	26.4%
	sc3nm	28803	10.6%
	sc3m	95132	34.9%
	sc4&5	76454	28.1%
Sex of deceased	Male	152669	56.1%
	Female	119660	43.9%
age band at death recode (3)	44 & under	14576	5.4%
	45 - 59	62096	22.8%
	60 & over	195657	71.8%
Year of death	1994	70947	26.1%
	1995	69016	25.3%
	1996	66793	24.5%
	1997	65573	24.1%
Valid		272329	100.0%
Missing		279768	
Total		552097	
Subpopulation		96	

Parameter Estimates

Place of death (3 code)		B	Std. Error	Wald	df	Sig.	Exp(B)	95% Confidence Interval for Exp(B)	
								Lower Bound	Upper Bound
Home	Intercept	-.619	.013	2353.378	1	.000			
	[SCHH4CD=1]	.251	.012	459.878	1	.000	1.285	1.256	1.315
	[SCHH4CD=2]	.002	.016	.010	1	.919	1.002	.971	1.033
	[SCHH4CD=3]	.096	.011	76.778	1	.000	1.101	1.077	1.124
	[SCHH4CD=4]	0[a]	.	.	0	.	.	.	.
	[SEX=1]	.045	.009	26.376	1	.000	1.046	1.028	1.064
	[SEX=2]	0[a]	.	.	0	.	.	.	.
	[YEAR_OD=1]	.072	.012	34.090	1	.000	1.074	1.049	1.100
	[YEAR_OD=2]	.034	.012	7.412	1	.006	1.034	1.009	1.060
	[YEAR_OD=3]	-.001	.013	.004	1	.949	.999	.975	1.024
	[YEAR_OD=4]	0[a]	.	.	0	.	.	.	.
	[AGEBAND3=1]	-.003	.020	.022	1	.883	.997	.960	1.036
	[AGEBAND3=2]	.147	.010	199.405	1	.000	1.158	1.135	1.182
	[AGEBAND3=3]	0[a]	.	.	0	.	.	.	.
Hospice	Intercept	-.979	.015	4074.255	1	.000			
	[SCHH4CD=1]	.286	.015	379.227	1	.000	1.332	1.294	1.371
	[SCHH4CD=2]	.291	.019	240.310	1	.000	1.338	1.290	1.388
	[SCHH4CD=3]	.113	.014	65.902	1	.000	1.120	1.090	1.151
	[SCHH4CD=4]	0[a]	.	.	0	.	.	.	.
	[SEX=1]	-.194	.011	321.696	1	.000	.823	.806	.841
	[SEX=2]	0[a]	.	.	0	.	.	.	.
	[YEAR_OD=1]	-.259	.015	297.888	1	.000	.772	.749	.795
	[YEAR_OD=2]	-.244	.015	263.223	1	.000	.783	.761	.807
	[YEAR_OD=3]	-.214	.015	201.658	1	.000	.807	.784	.832
	[YEAR_OD=4]	0[a]	.	.	0	.	.	.	.
	[AGEBAND3=1]	.046	.024	3.798	1	.051	1.047	1.000	1.097
	[AGEBAND3=2]	.151	.013	139.312	1	.000	1.163	1.134	1.193
	[AGEBAND3=3]	0[a]	.	.	0	.	.	.	.

[a] This parameter is set to zero because it is redundant.

Commentary

PoD: home – those from sc1&2 households were 28.5% more likely to die at home that in an NHS hospital than those from sc 4&5 households. Men were 4.6% more likely than women to so die. Those who died in 1994 & 1995 were 7.4% and 3.4% more likely to die at home than in an NHS hospital than those who died in 1997, respectively. Those who died aged 45-59 were 15.8% more likely to die at home compared with in an NHS hospital than those who died aged 60+.

PoD: hospice – those from sc1&2 households were 33.2% more likely to die in a hospice that in an NHS hospital than those from sc 4&5 households. Women were 21.5% more likely than men so to die. Those who died in 1997 were 29.5%, 27.7% and 23.9% more likely to die in a hospice than in an NHS hospital than those who died in 1994, 1995 & 1996, respectively. Those who died aged 45-59 were 16.3% more likely to die in a hospice compared with in an NHS hospital than those who died aged 60+.

Health region of usual residence was only coded in 1994-5. Including region in the model for those years does not significantly change the above results for the relevant explanatory variables.

(b) Main effects

social class of household: four code plus missing category; gender of deceased; age band – four groups; year of death.

Case Processing Summary

		N	Marginal Percentage
Place of death (3 code)	Home	141430	29.3%
	Hospice	78139	16.2%
	Hospital NHS	263445	54.5%
Social Class of HH: 4 code + other	sc1&2	71940	14.9%
	sc3nm	28803	6.0%
	sc3m	95132	19.7%
	sc4&5	76454	15.8%
	sc missing	210685	43.6%
Sex of deceased	Male	259606	53.7%
	Female	223408	46.3%
age band at death recode (4)	44 & under	16859	3.5%
	45 - 59	65849	13.6%
	60 - 74	202347	41.9%
	75 & over	197959	41.0%
Year of death	1994	122488	25.4%
	1995	121789	25.2%
	1996	119669	24.8%
	1997	119068	24.7%
Valid		483014	100.0%
Missing		69083	
Total		552097	
Subpopulation		160[a]	

[a] The dependent variable has only one value observed in 1 (.6%) subpopulations.

Parameter Estimates

Place of death (3 code)		B	Std. Error	Wald	df	Sig.	Exp(B)	95% Confidence Interval for Exp(B)	
								Lower Bound	Upper Bound
Home	Intercept	-.957	.009	12042.436	1	.000			
	[SEX=1]	.081	.007	145.699	1	.000	1.084	1.070	1.099
	[SEX=2]	0[a]	.	.	0	.	.	.	.
	[SCHH5MIS=1]	.406	.021	358.687	1	.000	1.501	1.439	1.565
	[SCHH5MIS=2]	.159	.024	43.717	1	.000	1.172	1.118	1.228
	[SCHH5MIS=3]	.249	.021	138.845	1	.000	1.282	1.231	1.337
	[SCHH5MIS=4]	.154	.021	51.267	1	.000	1.166	1.118	1.216
	[SCHH5MIS=5]	0[a]	.	.	0	.	.	.	.
	[AGEREC=1]	.174	.025	46.570	1	.000	1.190	1.132	1.251
	[AGEREC=2]	.308	.022	202.177	1	.000	1.361	1.305	1.421
	[AGEREC=3]	.165	.021	63.014	1	.000	1.180	1.133	1.229
	[AGEREC=4]	0[a]	.	.	0	.	.	.	.
	[YEAR_OD=1]	.069	.009	53.800	1	.000	1.071	1.052	1.091
	[YEAR_OD=2]	.031	.009	10.495	1	.001	1.031	1.012	1.050
	[YEAR_OD=3]	.000	.010	.000	1	.997	1.000	.981	1.019
	[YEAR_OD=4]	0[a]	.	.	0	.	.	.	.
Hospice	Intercept	-1.190	.010	13780.397	1	.000			
	[SEX=1]	-.132	.008	255.134	1	.000	.877	.863	.891
	[SEX=2]	0[a]	.	.	0	.	.	.	.
	[SCHH5MIS=1]	.269	.026	110.618	1	.000	1.308	1.244	1.376
	[SCHH5MIS=2]	.277	.028	97.372	1	.000	1.319	1.249	1.394
	[SCHH5MIS=3]	.092	.025	13.184	1	.000	1.096	1.043	1.151
	[SCHH5MIS=4]	-.020	.026	.616	1	.432	.980	.932	1.031
	[SCHH5MIS=5]	0[a]	.	.	0	.	.	.	.
	[AGEREC=1]	.219	.030	51.591	1	.000	1.244	1.172	1.321
	[AGEREC=2]	.329	.026	162.412	1	.000	1.390	1.321	1.462
	[AGEREC=3]	.172	.025	48.268	1	.000	1.188	1.131	1.247
	[AGEREC=4]	0[a]	.	.	0	.	.	.	.
	[YEAR_OD=1]	-.228	.011	396.193	1	.000	.796	.778	.814
	[YEAR_OD=2]	-.215	.011	353.867	1	.000	.807	.789	.825
	[YEAR_OD=3]	-.178	.011	245.214	1	.000	.837	.818	.856
	[YEAR_OD=4]	0[a]	.	.	0	.	.	.	.

[a] This parameter is set to zero because it is redundant.

Commentary

PoD: home – those from sc1&2 households were 50.1% more likely to die at home that in an NHS hospital than those from sc missing households. Men were 8.4% more likely than women so to die. Those who died in 1994 & 1995 were 7.1% and 3.1% more likely to die at home than in an NHS hospital than those who died in 1997, respectively. Those who died aged 44 and younger, 45-59 & 60-74 were 19.0%, 36.1% & 18.0% more likely to die at home compared with in an NHS hospital than those who died aged 75+.

PoD: hospice – those from sc1&2 households were 30.8% and sc3nm were 31.9% more likely to die in a hospice that in an NHS hospital than those from sc missing households. Women were 14.0% more likely than men so to die. Those who died in 1997 were 25.6%, 23.9% and 19.5% more likely to die in a hospice than in an NHS hospital than those who died in 1994, 1995 & 1996, respectively. Those who died aged 44 and younger, 45-59 & 60-74 were 24.4%, 39.0% & 18.8% more likely to die in a hospice compared with in an NHS hospital than those who died aged 75+.

Health region of usual residence was only coded in 1994-5. Including region in the model for those years does not significantly change the above results for the relevant explanatory variables.

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