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Equity of access to adult hospice inpatient care within north-west England

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There is a growing debate about the question of equity of access to hospice and palliative care services. Even countries with relatively well developed palliative care systems are considered to have problems of access and inequity of provision. Despite these concerns, we still lack a relevant evidence base to serve as a guide to action. We present an analysis of access to adult hospice inpatient provision in the north-west region of England that employs Geographical Information Systems (GIS). Measures of the possible demand for, and supply of, hospice inpatient services are used to determine the potential accessibility of cancer patients, assessed at the level of small areas (electoral wards). Further, the use of deprivation scores permits an analysis of the equity of access to adult inpatient hospice care, leading to the identification of areas where additional service provision may be warranted. Our research is subject to a number of caveats – it is limited to inpatient hospice provision and does not include other kinds of inpatient and community-based palliative care services. Likewise, we recognise that not everyone with cancer will require palliative care and also that palliative care needs exist among those with nonmalignant conditions. Nevertheless, our methodology is one that can also be applied more generally. *Palliative Medicine* 2004; **18**: 543–549

Key words: accessibility; deprivation; equity; geographical information systems; hospice inpatient services

Introduction

It is well known that in many countries the development of hospice and palliative care services has been the product of opportunistic and unregulated forces, often driven by charismatic leaders and enthusiastic ‘product champions’.¹ Because the work of palliative care touches on questions of human mortality that are common to all individuals, it has even been suggested that its growth has been the product of ‘emotional planning’.² The particular history of palliative care in the UK has made it the paradigm case for such interpretations, and guidance issued in 2002 by the UK government states: ‘Access to and availability of specialist palliative care services is variable and inequitable throughout the country’.³ As palliative care services in the UK reach a level of maturity there is increasing attention on the part of policy makers to questions of equity of access. The issue was first raised in the early 1980s,⁴ but has recently become a more salient feature of discussions relating to palliative care funding. In 2002 the UK Department of Health announced a new £50 million investment in palliative care services and made it clear that ‘Ensuring this additional funding reaches the services for which it is intended will mean a fairer deal for hospices and address

inequalities in access to the full range of palliative care services’.⁵ The debate about access revolves around certain key questions: can services of equal quality be utilised by all who may need them, regardless of diagnosis; can services be accessed equally, regardless of age, social class, gender, or ethnic grouping; and are services equally accessible, regardless of geographic location? The issue of access is at the forefront of policy making in palliative care. Yet despite such political rhetoric, we remain remarkably ignorant about one key dimension of the ‘access’ issue: the spatial distribution of palliative care services and the populations they serve. It is an issue that has been highlighted in recent policy debates in the UK, but will nevertheless be recognized as a matter of importance in many other countries, especially as the level of palliative care provision increases.

Here we examine current provision and access to hospice inpatient beds in the north-west region of England, though our approach is widely applicable in other settings. We assess the extent to which those living in particular small areas (electoral wards) have equity of access to adult inpatient hospice services. We also seek to demonstrate how a measure of potential accessibility to such services can be obtained, and go on to identify areas that are relatively poorly served and relatively deprived. Access using straight-line distance between different healthcare sites and location of demand can be under-

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taken relatively simply. Analysis using estimated drive times, though perhaps of greater utility, is more complicated. We therefore consider briefly whether the use of different measures of access to hospice services produces markedly different results in identifying groupings of wards with greater 'health needs', in this case the need for adult inpatient hospice care. We seek to offer both a methodology and an empirical contribution to shed light on current debates about access to hospice care.

In the UK, over 96% of hospice patients have a diagnosis of cancer.⁶ The National Health Service (NHS) Cancer Plan⁷ highlights how more than one in three people in England will develop cancer at some stage in their lives and that one in four will die of the disease. Each year in England, over 200 000 individuals are diagnosed with cancer and it is the cause of around 120 000 deaths. Recent guidance strongly implies that most of these will benefit from some form of palliative and supportive care and that a 'significant proportion of people with advanced cancer suffer from a range of complex problems – physical, psychological, social and spiritual – which cannot always be dealt with effectively by generalist services in hospitals or the community'.³ Many of these will receive care in hospices and it is therefore appropriate to ask whether such services are distributed equitably across the country.

Accessibility to health services, and the equity of healthcare provision, has been of concern to health service managers and geographers for some years now.^{8–12} There is a growing use of Geographical Information Systems (GIS) to undertake analyses of the relative accessibility of health services and we draw upon these methods in the work reported below.

Methods and data

Our study setting is the north-west of England, a region comprising the major conurbations of Manchester and Merseyside, former industrial areas of Lancashire, and large rural areas (parts of Lancashire and much of Cumbria). Administratively, there are five counties (Cheshire, Merseyside, Greater Manchester, Lancashire and Cumbria). Counties, and districts within counties, are subdivided into small areas called electoral wards, the smallest unit of local government in Britain.

There are 1019 census wards within the north-west region (which, historically within the National Health Service, includes a small part of High Peak district in the county of Derbyshire). Population data for these wards were obtained from the most recent National Health Service (NHS) Executive North West Small Area database 2000.¹³ Data comprised latest available population estimates, for 1991 census wards, in 5-year age bands; at

the time of the study, small-area data from the 2001 census were not available.

Given that the vast majority of hospice in-patients have a diagnosis of cancer, the expected number of people who are likely to die from cancer in a given year within a given area can be used as a reasonable proxy for hospice demand. Adult hospice inpatient facilities are potentially open to anyone with advanced malignant disease, though uptake may be influenced by clinical estimates of need in any individual case. Whilst not everyone with a diagnosis of cancer will die from their disease, and the survival rates for different cancers vary appreciably, age-specific mortality rates for all cancers, when applied to north-west England populations, were used to derive a reasonable proxy for potential demand.

Three year average age-specific death rates for all cancers, for all persons aged over one year, were obtained from the Compendium of Clinical and Health Indicators (CCHI) 2001.¹⁴ Adult demand for hospice inpatient beds was derived for those aged 15 years and over, by linking age-specific cancer mortality rates to populations in given age bands. This analysis enabled the anticipated demand for hospice beds to be estimated for the small areas (electoral wards). The CCHI three-year average mortality rates for 2000 indicate that 18 868 adults (aged 15 years and over) died that year within the north-west from all cancers. The cancer death rates increase rapidly with age, from 8.4 per 100 000 persons aged 15–34, to 178.6 between the age of 35 and 64, to 971.9 between the ages of 65 and 74, and to 1690.5 aged over 75 years.

Electoral wards in retirement areas have appreciably higher proportions of older residents and, given increasing cancer incidence with age, hospice provision is, other things being equal, most likely to be required in such areas. However, whilst retirement areas (particularly in some coastal areas) have relatively high proportions of older people, they tend to be less heavily populated than more urban areas in Manchester and Merseyside. When we apply age-specific cancer incidence rates to ward populations it is these urban areas that show the greatest 'demand' for hospice services.

Since we wish to assess the relationship between current provision and access to levels of deprivation we require small-area data on the latter. A range of indicators has been developed in recent years to describe levels of 'material deprivation', at the neighbourhood, local area, regional or national level. Widely used indicators include the Jarman, Townsend and Carstairs scores, which combine a range of 1991 census indicators (such as unemployment and lack of car ownership) to highlight relative deprivation.¹⁵ More recently, these have been supplemented by the Index of Multiple Deprivation (IMD), which recognises different 'domains' of deprivation, including (for example) income, employment and education.¹⁶ Deprivation indices assign a numerical

weighting to electoral wards, enabling comparisons to be made between different small areas. In general, deprivation indicators show a strong correlation with a variety of health outcomes. However, such indicators do not always measure exactly the same things. The Jarman Underprivileged Area (UPA) Score was designed to measure the need for primary care; Townsend and Carstairs are considered proxy value for levels of material wealth/poverty. Here, we use Townsend scores, obtained from the NHS Executive North West for all wards within our study area.

Within north-west England, 27 hospices provide adult inpatient care. Data on hospice sites and bed numbers were obtained from the Hospice Information website, a joint venture between the national UK charity Help the Hospices and St Christopher's Hospice, London.⁶ A follow-up telephone call was made to each hospice to confirm bed numbers. Whilst the majority of hospice bed numbers were confirmed as being the same as published summaries, in a small number of cases hospices reported lower bed numbers. In June 2002, north-west hospices provided 380 adult inpatient beds (range 4–36).

Grid references were obtained for the population centres of all electoral wards. The postcode for each adult hospice was matched to a grid reference using Streetmap, a web-based gazetteer for matching postcodes to point locations (grid references). Straight-line distances between hospices and ward centres were then calculated. At a regional scale, the use of straight-line distance may well be a reasonable proxy for measuring access. However, it fails to take into account barriers to movement, or transport routes. We therefore estimated travel times between hospices and ward centres, using typical national speed estimates for different classes of road. We consider here the results using 'drive time' measurements, but compare these briefly with those based on straight-line distance in order to highlight any differences between the two approaches.

In human geography and urban and regional planning, 'gravity-type' models are frequently used to model access to services.^{9,12} Essentially, these suggest that the likelihood of travel to a site is directly related to its relative size (or 'attractiveness') and inversely proportional to how far away it is from the user. In the present study the relative location (distance) component is quite straightforward, but issues of attractiveness or 'size' are more complex. As a starting point we have measured this simply on the basis of hospice bed numbers. We then construct an accessibility score for each small area (electoral ward) by taking (for each hospice) the number of beds divided by the distance from that hospice to the ward, then summing these over all such hospices.

A similar approach was used to measure access using drive times between sites and wards. Time, as opposed to distance was used as the denominator, with a maximum

drive time of 30 minutes used for analysis of access; in other words, hospices located more than 30 minutes from a ward centre were discounted.

The analysis was conducted using a GIS. This is a computer-based information system with a geographical dimension.^{8–10,17,18} It stores, manipulates and analyses spatially-linked data and displays summary information on a map. Apart from its ability to visualise health, and other, data on a map, thus adding locational context to analysis, it enables the researcher to undertake analysis which other databases cannot readily perform, notably spatial analyses (for example, assessing how many people live within a particular distance of a healthcare facility). We used the desktop GIS 'MapInfo', in most of the work reported below.¹⁹

Results

Accessibility

Accessibility scores for small areas, based on assumed drive times, are shown in Figure 1, along with the locations of hospices. Given the greater number of hospices in the Manchester conurbation and the relative dearth in Cheshire, north Lancashire, and Cumbria, it is unsurprising that those living around the Manchester area have greater potential accessibility.

'Demand' and accessibility

The relationship between 'demand' and potential accessibility (Figure 2) reveals a generally positive relationship; those wards with high expected demand tend to be those which are reasonably accessible to hospices. Of particular interest, however, is the group of wards (highlighted in a box) where demand is greater than the regional average, *and* accessibility is less than the regional average. Here, we use the median as a measure of the average; the median expected demand for hospice beds was 16 adults per ward, while the median 'accessibility' score for hospice beds was 11.4. Based on drive time measurement, of the 139 wards where demand is greater than median values and access is below median values, adult demand equates to 3495 adults. In other words, there are about 3500 adults likely to have cancer, who could thus benefit from inpatient hospice care at the later stage of their lives, and who are living in areas that are relatively inaccessible to one or more hospices.

'Demand', accessibility, and deprivation

We now link areas of high demand and low supply to data on material deprivation, a major determinant of health. The north-west is a relatively deprived region within the UK, with the average (mean) Townsend deprivation score for all wards in the north-west being 0.5. The mean for the country as a whole is zero, the

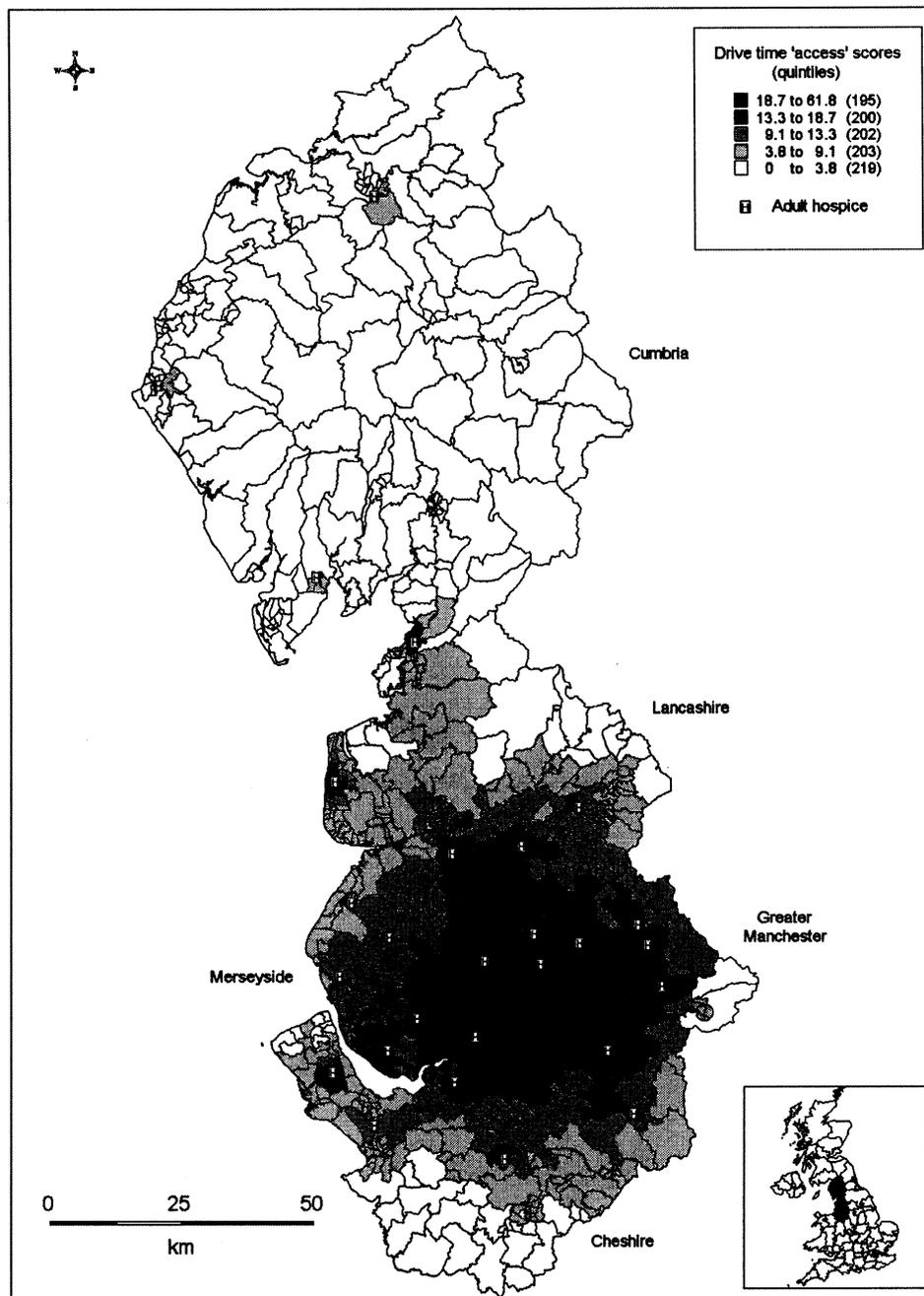


Figure 1 Accessibility to adult inpatient hospice services in north-west England (based on estimated drive time).

higher mean value for the north-west reflecting the legacy of relative poverty in a deindustrialising region. Four hundred and sixty wards within the north-west (45.1% of the total) exhibit levels of deprivation above the regional mean.

Analysis was undertaken to highlight the location of small areas (electoral wards) where demand for hospice care is high, access is poor, and where deprivation levels are above the regional mean. Residents of these wards are

likely to suffer from a variety of factors, including relatively low incomes, poor housing and lack of access to private transport. Thus, poor access to hospice care may be problematic. Of the 164 wards where access to inpatient hospice services was poor and demand relatively high, 67 (41%) of these small areas also had high deprivation. The map of these wards (Figure 3) shows both the set of wards where access is poor and demand high, but also the subset of wards where, in addition,

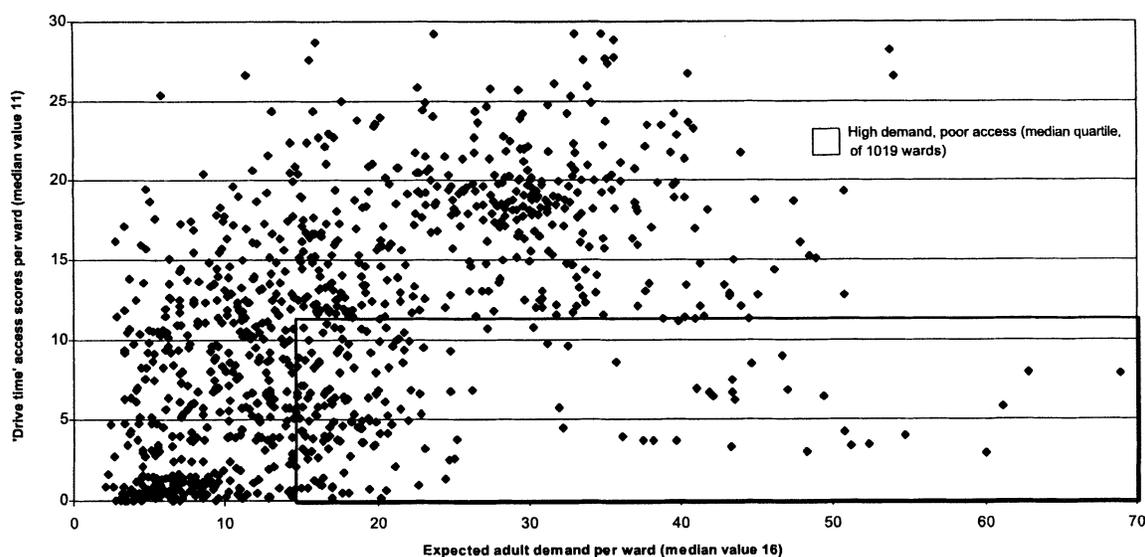


Figure 2 Relationship between accessibility to adult inpatient hospice services and expected demand, by electoral ward.

there are above-average levels of deprivation. Pockets of high demand/low access are apparent, although scattered across the region. In particular, industrial Barrow-in-Furness in South Cumbria, the Wirral, Lytham, Southport, and some rural wards in the Ribble Valley of central Lancashire, and some rural wards in South Cheshire demonstrate poor access and high demand. However, taking into account deprivation (and hence 'need') there is a case for further hospice provision in the Wirral area of Merseyside in particular.

Discussion

We have undertaken a preliminary analysis of inpatient hospice provision for adults in north-west England. We have used a measure of potential demand for such care, based on cancer mortality, together with a measure of accessibility to such services (based on bed numbers and travel time estimates) and identified small areas within the region that are both relatively inaccessible to services and which have above average 'demand' for services. Further, we have identified a subset of these small areas, those which are relatively deprived, which may merit a more focused effort for additional inpatient palliative care provision. Further adult hospice/palliative care beds could be provided for Barrow, Central Lancashire, Carlisle, South Cheshire, and the Wirral peninsula (see Figure 3 for locations).

Our research is of a preliminary and speculative kind, subject to several caveats and limitations. First, we have looked only at inpatient hospice provision, and this is but one aspect of what most hospices and specialist palliative care services offer. We have not considered other forms of 'support', including home care and day care, nor have we

said anything about whether hospital support teams provide adequate services in those areas we have identified as being 'in need' of additional inpatient provision. Consequently, the 'supply side' needs considerable refinement if we are to offer an adequate picture of service provision. Further studies using the methodology employed here against different inclusion criteria would enhance our understanding of the spatial distribution of palliative day care, home care services and outpatient clinics. Secondly, our representation of 'demand' is oversimplified. We have applied age-specific rates for all cancers to small area population data, disaggregated by broad age-band. Yet not everyone with cancer will require palliative care. Furthermore, although people with advanced malignancies are the primary users of hospice services, there are other hospice patients whose 'demands' are not accounted for here. Our findings are limited to the likely demands from cancer patients, but again, the methodology could be applied to other life-limiting conditions.

We have used estimated travel times as a measure of spatial separation of hospices from the populations of small areas (aggregated to a single location, the ward centre, at which the population is assumed to be located). This offers a more realistic representation of such separation than does simple straight-line distance, since the geography of the study area, particularly in areas bordering the coast, means that straight-line distances are a poor substitute for transport networks. However, travel time, or estimated drive time, assumes that everyone has access to a private car and that people can travel at constant speeds on different road types. Road speeds vary depending on time of day, and accidents, road works, weather conditions, and so on, are all complicating factors. No account is taken here of the possibilities

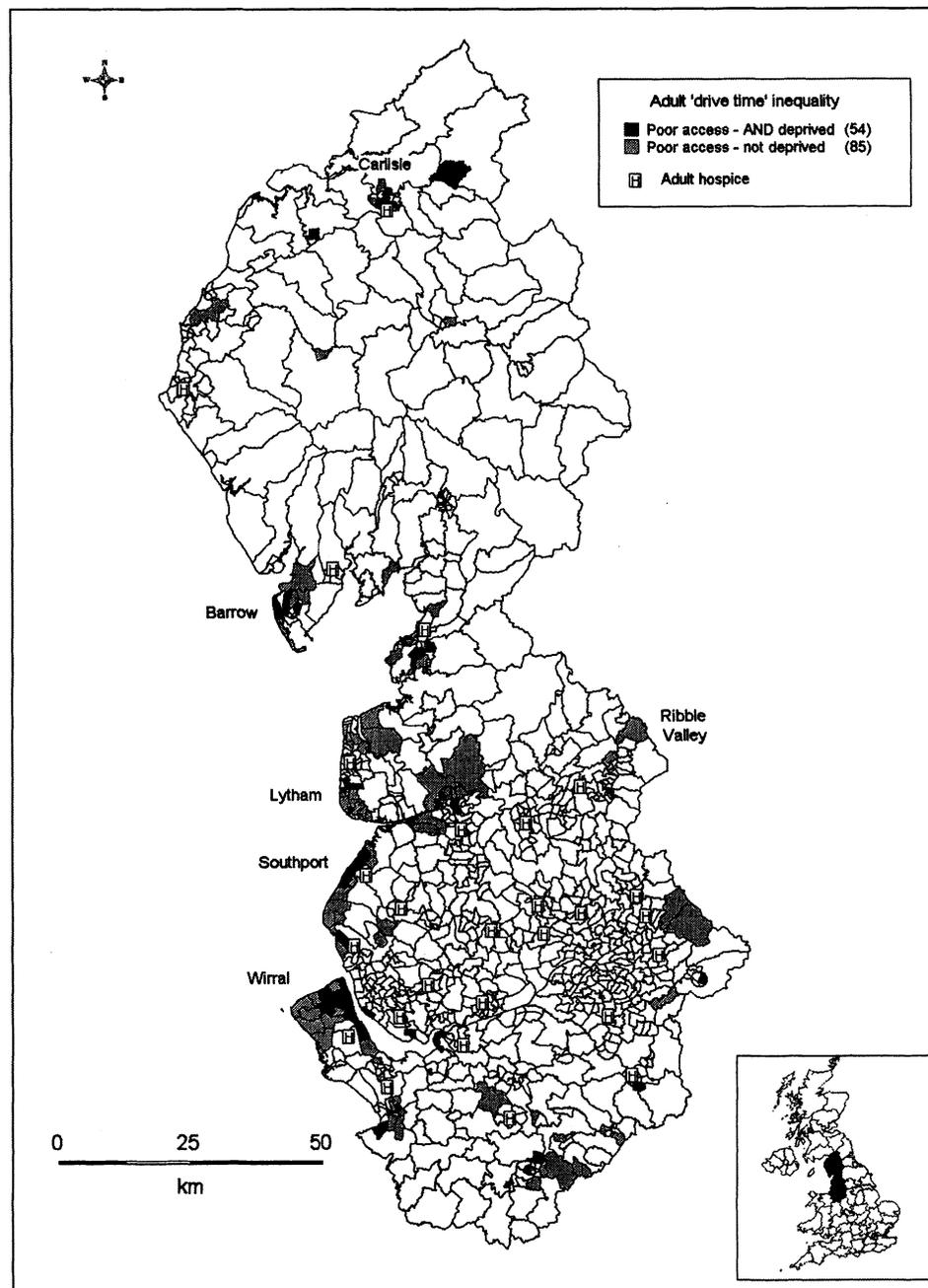


Figure 3 Wards in north-west England where accessibility to adult inpatient hospice services is below average and demand is above average, classified by deprivation score.

of public transport,²⁰ although those attending for inpatient hospice care are very likely to come via ambulance or from nursing or residential homes. Public transport may be more of a factor for day care.

When straight-line distance and drive time accessibility analyses are compared we note that 103 wards (62%) are selected using either measure of spatial separation. The same core groupings or clusters of wards exhibit inequitable access to hospice services arise whichever measure of 'distance' is used. Thus in many cases, particularly in

inland areas, it may well be the case that a simpler straight-line distance measure will suffice.

GIS can be employed to analyse a wide range of healthcare service locational issues. Our research has pinpointed localised geographical inequity in hospice service provision, which in turn contributes to the debate on funding additional beds, staff, and other cancer services. We suggest there is scope for further work in this field. One obvious proposal is to consider a wider study area, perhaps across the whole country, to identify

areas that are 'hospice-poor'. Also pressing is the need for research on actual patterns of demand for hospice inpatient care. From what areas do hospices draw users of their services? Other work conducted by one of the authors on 'place of death' of cancer patients in part of north-west England shows that there are clear proximity effects;²¹ those living close to a hospice are more likely to die there than in other settings. Further, those with some forms of cancer (notably of the lymphatic system) are tied quite closely to hospital services and are more likely to die in that setting. If adequate data were available on which population groups, with which cancers, were most likely to use inpatient hospice services we could undertake a more sophisticated representation of service utilisation, which might inform a better representation of demand. This requires the collection of data that we do not believe to be presently available. Last, we need further understanding of the policies of hospice providers towards their users; are catchment areas well defined or quite loosely based? What are the processes of referral from the primary and secondary health-care sectors? Answers to these and other questions will permit a fuller analysis of service provision in this key sector of the health-care system.

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