# Review of rural and urban factors affecting the costs of services and other implementation issues

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# Final Report of the Research Team

## Contents

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# Introduction

The purpose of this report is to provide scientific advice on implementation issues arising out of the Townsend Review for allocating NHS resources to Local Health Board areas. In particular, this report examines whether specific urban and rural factors result in unavoidable additional costs when providing health services in such areas and whether the NHS Resource Allocation Review formula for calculating allocations should be adjusted accordingly.

In August 2000, the National Assembly commissioned the University of Bristol to assemble a research team to produce an independent report on the best methods of allocating NHS resources to small areas. This report was written by a very experienced, multidisciplinary team comprising some of the UK's leading experts in the fields of clinical epidemiology, medical geography, medical sociology and policy studies from the Universities of Bristol, Cardiff and Lancaster. Additional external statistical work was undertaken by the Office for National Statistics.

The independent Research Team's report proposed that Welsh NHS resources be allocated using a novel and innovative method based on a range of direct indicators of health need. After an extensive consultation exercise with both the public and NHS staff, the National Assembly for Wales decided to implement the proposed NHS resource allocation formula by 42 votes to eight.

Work is now being undertaken to implement the Assembly's decision and this report examines whether additional modifications are needed to the resource allocation formula to allow for unavoidable additional costs arising from:

- The difficulties of providing health care in rural areas
- The cost of treating HIV/AIDS patients
- Additional costs associated with the health care of Asylum Seekers/Refugees
- The implications of the prison medical service changes
- Additional costs of meeting the health needs of homeless people
- The allocation of drug and alcohol abuse health costs
- Additional costs arising from the ethnic composition of Local Health Boards

Additionally, this report examines the contentious issue of the optimum frequency with which the resource allocation formula should be revised and updated. (For example, every year, once every five years and so on.)

# Chapter 1: Resource Allocation for Rural Areas

## Summary and Recommendations

*Age*
Rural areas have an older age profile than urban areas so a larger proportion of their residents will require more expensive hospital treatments (*eg* because of longer lengths of stay) and more time-consuming GP consultations, especially as visits to patients' homes or nursing homes are age-related. Resource allocation estimates based on treatment costs and consultation frequencies by condition (from the Welsh Health Survey (WHS) may not fully reflect these age-related influences. As the WHS samples by age, health condition and LHB are too small to be reliable, the age adjustment should be accomplished by the same method used previously in producing the NHS Resource Allocation Review – Consultation (October 2001). However, the previously used DRG costs by age reflect only average lengths of stay, so the possibility of obtaining duration related costs by age needs to be investigated.

*Temporary residents*
Tourists, seasonal workers and other temporary visitors are likely to be more numerous in more rural (especially coastal) areas and in Cardiff. Consultations by temporary residents should be extracted from the General Practice Morbidity Database (GPMD) and these should be added to the permanent resident consultations already used in the GMS estimates (Gordon *et al*, 2001).

*Scale economies in hospital provision and Health Authority hospital expenditures*
To produce a Welsh version of the Scottish rurality analyses may be infeasible because of the poorer availability and quality of cost data in Wales and too few Health Authorities for statistical analysis. If possible, a comparison of samples of costs of purchasing hospital care by episode type in urban and rural Health Authorities should be undertaken.

*The community nursing cost model* developed by the National Assembly should be subject to further sensitivity testing. A general validation of the organisational and cost features of this model would be a major exercise. In Scotland, only a limited number of field visits were made to obtain information which could inform the assumptions made.

*General Medical Services (GMS) and the new GP contract*
As the new GP contract is not being negotiated separately for Wales but at the UK-level, the new GMS formula being developed by the Department of Health (DoH) and the University of York could be imposed on Wales. It would thus be sensible and efficient **not** to pursue the development of a Welsh version of the Scottish GMS formula for rural costs, as the proposed rurality formula to underpin the new GP contract is based on superior Inland Revenue data. Rather, given that rurality and remoteness influences on service delivery costs are likely to be more prominent in Wales and Scotland, the National Assembly (in conjunction with the Scottish Executive?) should request that the DoH/York formula development team investigate whether or not there are significant inter-country differences in their effects. It has been suggested that there are sufficient Welsh data available in the Inland Revenue data set for this to be feasible.

## The Rural Context

Rural areas differ from urban areas in terms of both health needs and service delivery. In part, different health needs stem from the older demographic and higher social profiles of rural areas. Of greater concern have been the difficulties and costs of serving a more geographically dispersed population and the attendant problems of access to, and utilisation of, services. A range of possible sources has been identified of unavoidable extra costs incurred in providing services in rural areas. These include a lack of scale economies in service provision; lower bed occupancy rates; more staff on higher grades; increased staff travel time and thus more unproductive use of staff time and poorer access to support services (Asthana *et al*, 2002). The most comprehensive coverage of these costs for resource allocation purposes is provided in the Scottish formulas (SEHD, 1999a; 1999b; 2000).

Hence, there are two main resource allocation questions to be assessed.

- How well are the health needs of rural populations measured?
- What evidence is there for unavoidable extra costs of providing health services in rural areas?

## Rural Health Needs

*Needs and utilisation*

It is commonly argued that rural residents utilise both primary and secondary health services less than urban residents, although the evidence is not always convincing because of the difficulty of controlling for other influences, especially varying needs (Watt *et al*, 1994). It is argued that, as rural patients suffer increased personal costs to access health services, they are less likely to seek medical attention until conditions become severe. For example, White (2001) argues that mental health problems in rural areas are underestimated compared with those in inner cities and suggested causes include *"isolation, stigma and low service expectations"* (Asthana *et al*, 2002, p8). It has been concluded that 'indirect', utilisation-based resource allocation methods will underestimate rural health needs. Moreover, additional need indicators, especially the use of no car ownership in the English formula (NHS Executive, 1999) are seen as favouring urban areas (White, 2001).

These criticisms of indirect approaches ignore the use in the Scottish (*eg* SEHD, 1999b), English and Northern Irish formulas of statistical procedures to try to eliminate supply-induced utilisation. Indeed, the latest research for a new English formula (Sutton *et al*, 2002) includes measures of access cost in the utilisation models.

*Issues in Wales*

The 'direct' approach to resource allocation (Gordon *et al*, 2001) avoids these criticisms of utilisation data. Hence, the issue in Wales is whether direct measures of health need and the costing of treatments are systematically biased against rural areas. Potential concerns about direct methods of resource allocation between rural and urban areas include:

- how comprehensively health needs by age are measured. The major concern here is that the WHS does not record children's health (National Assembly for Wales, 1999).
- age-related costs of treatment, especially for the elderly. Both the Scottish and English resource allocation formulas have costed hospital episodes using fixed treatment costs plus variable length-of-stay costs (SEHD, 1999b; NHS Executive, 1999). As elderly people tend to need longer lengths of stay, their hospital episodes tend to be more expensive. This issue also arises for General Medical Services, as GP consultations with the elderly are often longer, especially as

home visits and trips to nursing homes, rather than surgery consultations, are much more likely for the elderly.

*Demographic profiles*

Rural areas tend to have demographic profiles with smaller proportions of children and larger proportions of elderly persons (Asthana *et al*, 2002). Table 1.1 presents 2001 Census data on the age composition of Local Health Board (LHB) populations in Wales. The LHBs are ranked according to their percentages of residents aged 65 or more. With the exceptions of Swansea and Neath Port Talbot, the LHBs with proportions of the elderly exceeding the national proportion are the more rural LHBs of North, Mid and South West Wales (including the coastal retirement resorts, notably in Conwy). Below average proportions of elderly residents are found exclusively in the more urban LHBs of South and North East Wales. On the other hand, almost all these latter urban LHBs have percentages of children aged 0-4 and 5-14 years above the corresponding figures for Wales as a whole, while most of the rural LHBs have relative child populations smaller than the national percentages.

Hence, it appears that rural LHBs will be disadvantaged more than urban areas if the resource allocation formula does not adequately reflect age-related treatment costs and age-related GP consultation times. However, it is the urban LHBs which may have their resource needs understated if child health needs are not adequately measured.

Table 1.1 also reveals a high proportion of 15-24 year olds, particularly in Ceredigion and Cardiff (both nearly 17%) but also in Swansea (14%), Gwynedd (13%), Rhondda Cynon Taff (13%) and Wrexham (12%). These LHBs have their populations boosted by students, who are recorded at their term-time addresses in the 2001 Census. Again, students' health needs are likely to be under-represented in the WHS.

*Age cost adjustments*

The WHS cannot be used to make age adjustments to the direct health needs estimates as it does not contain sufficiently large sample sizes by LHB of health conditions by age. However, age adjustments can be made by the method used previously in producing the NHS Resource Allocation Review – Consultation (October 2001). However, the previously used DRG costs by age reflect only average lengths of stay, so the possibility of obtaining duration- related costs by age needs to be investigated.

*Temporary residents*

A further consideration for primary care and prescribing is the number of temporary residents. These will be mainly tourists, who are likely to be more numerous in rural LHBs and Cardiff. The Scottish General Medical Services (GMS) formula incorporates temporary residents, who are also included in prescribing formulas in England and Scotland. Limited evidence from two practices in Scotland suggests an average annual GP consultation rate of 1.5 per temporary resident. This can be checked for Wales using equivalent data on temporary resident consultations from the General Practice Morbidity Database (GPMD). The Scottish formula obtains data on temporary residents by health board from GP claims, so the same data source could be used in Wales. More recent research for the new GP contract (Carr-Hill *et al*, 2002) has produced evidence that temporary registrations for more than 16 days (*eg* by seasonal workers) generate 50% more work (and not much less than a permanent resident) than shorter registrations. As consultations by health condition for permanent residents have been used already in the direct estimates for GMS (Gordon *et al*, 2001), the same or similar data from the GPMD for temporary residents should be checked and used.

### Table 1.1: Age profile of Local Health Board populations in Wales, 2001 (%)

| Local Health Board | 0-4 | 5-14 | 15-24 | 25-64 | 65+ |
|---|---|---|---|---|---|
| *Conwy* | 5.2 | 12.0 | 9.9 | 49.8 | 23.1 |
| *Denbighshire* | 5.5 | 12.8 | 10.7 | 50.8 | 20.2 |
| *Powys* | 5.4 | 12.8 | 9.6 | 52.3 | 20.0 |
| *Carmarthenshire* | 5.5 | 12.7 | 11.1 | 51.3 | 19.5 |
| *Pembrokeshire* | 5.9 | 13.4 | 10.5 | 51.0 | 19.2 |
| *Gwynedd* | 5.9 | 12.3 | 12.8 | 50.0 | 19.0 |
| *Isle of Anglesey* | 5.4 | 12.9 | 10.8 | 52.1 | 18.9 |
| *Ceredigion* | 4.7 | 11.2 | 16.9 | 48.7 | 18.5 |
| *Neath Port Talbot* | 5.4 | 12.9 | 11.3 | 52.1 | 18.3 |
| *Swansea* | 5.4 | 12.2 | 13.6 | 50.5 | 18.3 |
| *Monmouthshire* | 5.3 | 13.4 | 9.7 | 53.6 | 18.0 |
| ***WALES*** | ***5.8*** | ***13.1*** | ***12.2*** | ***51.5*** | ***17.4*** |
| *Blaenau Gwent* | 5.6 | 14.3 | 11.5 | 51.8 | 16.9 |
| *Torfaen* | 5.8 | 14.1 | 11.4 | 51.8 | 16.8 |
| *The Vale of Glamorgan* | 6.2 | 13.9 | 11.2 | 52.0 | 16.8 |
| *Bridgend* | 5.9 | 13.2 | 11.0 | 53.3 | 16.6 |
| *Rhondda, Cynon, Taff* | 6.0 | 13.5 | 12.7 | 51.5 | 16.3 |
| *Merthyr Tydfil* | 5.8 | 14.2 | 12.0 | 51.8 | 16.2 |
| *Newport* | 6.6 | 14.4 | 11.7 | 51.2 | 16.1 |
| *Wrexham* | 5.8 | 12.6 | 12.4 | 53.0 | 16.0 |
| *Caerphilly* | 6.3 | 14.0 | 11.8 | 52.7 | 15.2 |
| *Flintshire* | 6.0 | 13.2 | 11.5 | 54.4 | 14.9 |
| *Cardiff* | 6.2 | 13.2 | 16.5 | 49.5 | 14.6 |

## Unavoidable Costs of Service Provision in Rural Areas

*Hospital services*

In Scotland, hospital cost and patient activity data have been used to relate ratios of actual to (average) expected costs to the volume of patient activity, measured as inpatient/day cases or weeks or as number of births for maternity services (SEHD, 1999b). Other influences on costs, such as number of specialties and case complexity have been controlled for in some of the regression analyses. Separate analyses were conducted for total, nursing, medical and allocated costs within each of acute, mental illness, elderly care and maternity services. In all four services, economies of scale were found to be significant, with smaller hospitals in rural areas typically having higher unit costs.

To the extent that Health Boards send their patients to these smaller rural hospitals rather than larger urban ones, their costs will be greater. Additionally, day surgery may be less feasible for patients from remoter rural areas, thus necessitating more expensive inpatient treatment. The Scottish research examined variations in health boards actual hospital expenditure divided by their expected expenditure based on national average costs. Initially (SEHD, 1999b) such variations were related to population density and three measures of sparsity (proportions of residents in settlements of more than 500, 1000 and 10000 people). Subsequently (SEHD, 2000) just one rurality/remoteness indicator, road kilometres per thousand population, was used. It is this latter formula that has been exemplified for Wales using the Scottish coefficients (Senior and Rigby, 2001).

To replicate this research using Welsh data will be difficult because of the poorer availability and quality of cost data in Wales and too few Health Authorities (assuming hospital expenditure cannot be allocated to LHBs) for statistical analysis. Even the Scottish analyses had to use annual cost data for three years to increase the number of observations from 13 health boards to 39. Table 1.2 lists the data requirements. Assuming (as seems likely) that a Scottish-style regression analysis cannot be undertaken, an alternative might be to examine samples of available cost data to see if rural health authorities are having to pay more than urban ones to purchase hospital care for similar patient episodes, especially if the care is purchased from English hospitals.

Research in England on Accident and Emergency (A&E) services (MHA and Operational Research in Health Ltd, 1997) has found different results. It assessed the need for rural areas to maintain more (and less efficient) acute general hospitals to ensure acceptable access to A&E services. Requirements for A&E services were sensitive to the access standards set and did not consistently support the need for more A&E provision in rural areas. While there were economies of scale in relation to the number of A&E attendances, there were diseconomies associated with increases in the range of specialties offered by and the total number episodes in, the hospital trust.

## Table 1.2: Data requirements for analysis of hospital scale economies and health board hospital expenditures

| **Data Required** | **Data Availability** |
|---|---|
| *1.__Hospital unit costs__*:<br>(*data required for each hospital/maternity unit*) | |
| annual unit costs for the following services (if possible for each of two or more years):<br>- acute (cost per case)<br>- mental illness (cost per inpatient week)<br>-care of elderly (cost per inpatient week)<br>- maternity (cost per birth) | Availability of cost data uncertain. Detailed definitions of these costs need checking with Scottish Executive |
| annual number of acute inpatient and day cases | PEDW, but will need special analysis for hospital site data |
| average number of staffed beds | QS1 |
| number of specialties | QS1 or PEDW |
| complexity of acute caseload | Performance Analysis toolkit. Further advice needed from Scottish Executive |
| annual number of mental illness inpatient weeks | PEDW does **not** contain details of unfinished episodes |
| annual number of elderly care inpatient weeks | PEDW does **not** contain details of unfinished episodes. Also, definition of elderly care problematic because of re-labelling of some geriatric medicine as general medicine |
| annual number of births | PEDW, but incomplete data |
| | |
| *2. __Health Authority hospital expenditure__* | |
| annual expenditure on (all) hospital services for each of three or more years | Availability of cost data uncertain. |
| road kilometres per thousand population | available for HAs and LHBs from NAfW |
| population density | available for HAs and LHBs from NAfW |
| population inside and outside settlements of varying size | available for HAs and LHBs from Pion Economics/NWRRL (1999); or from NAfW's community health service GIS |

*Community health services*

NERA's (1999) cost model for community nursing services in Scotland has been constructed afresh for the population of Wales (Health Statistics and Analysis Unit, 2001). Essentially, 1991 enumeration district populations have been aggregated, using density and size criteria, into settlement clusters of 300 residents or more and population numbers inside and outside these settlements calculated. Smaller settlements deemed unable to generate sufficient visits to keep one nurse fully occupied are treated as satellites to be visited by nurses based in nearby larger settlements. Residents outside settlements are assumed to be located uniformly along the road network and can be allocated to settlements from which they are served on the basis of road distance.

Importantly, this does not involve transferring to Wales any parameters calibrated on Scottish data but it has meant using largely the same assumptions about nursing grade mix, salaries, travel speeds, duration of visits, time spent at nursing bases or clinics and so on. These assumptions have been subjected to sensitivity tests and the Welsh results show greater sensitivity than the Scottish ones. Further research to explain this sensitivity and to replace straight line distances with road distances (for inter-settlement distances) has apparently been requested. Additionally, the following tasks might be undertaken:

- replace the assumption of a uniform 20mph travel speed with varying speeds (say, according to road classifications) and allow travel times within settlements to vary in direct proportion to settlement size. The latter adjustment would reflect longer travel times in larger, more congested urban areas.
- if possible, check the assumption that there are proportionately more nurses on the highest grades in rural LHBs.

More generally, neither the Scottish nor Welsh versions of this community health provision model have been subject to detailed validation against the actual organisation and cost of such service provision in urban and rural areas. To undertake this validation would be a major exercise which, apart from some limited field visits, was not deemed necessary for the Scottish resource allocation (SEHD, 1999a).

A partly similar approach to estimating the travel costs (but not staff costs) of delivering health and personal social services in rural areas has been adopted in Northern Ireland (DHSSPS, 2000). Optimum routing models and GIS software are used to estimate the minimum travel times incurred by professionals and patient transport services (*eg* to day centres) to meet given levels of demand. By contrast, English research on patient transport services could not convincingly identify any extra costs due to rurality (MHA and Operational Research in Health Ltd, 1997).

*General Medical Services (GMS)*

Resource allocation for GMS was discussed in previous reports. Senior and Rigby (2001) exemplified for Wales the Scottish formula adjustments for rurality, but, because of data availability, this could only be done at LHB, not practice, level. Subsequently (Senior, 2001), the requirements for calibrating a Welsh version of the Scottish GMS model were detailed and these are now repeated in Table 1.3. Further statistical analyses of the Scottish GMS formula (McConnachie *et al*, 2002) have included variables measuring the number of partners in practices and, as an indicator of the severity of remoteness, the average rural practice payment per rural practice patient. Nonlinear effects on costs of rurality and remoteness variables have also been investigated.

**Table 1.3: Practice data required to calibrate a Welsh version of the Scottish GMS rurality formula**

| Practice data required | Possible source of data |
|---|---|
| Total payments per patient (excluding: improvement and training grants; other payments for trainees and for temporary residents) | Exeter database |
| The LHG and Health Authority (HA) in which the practice is located | Health Solutions Wales and Exeter database |
| A measure of list inflation | NHSAR and National Strategic Tracing Service (Health Solutions Wales) |
| Numbers of patients by gender and age groups (Scottish analysis uses 0-4, 5-14, 15-24, 25-44, 45-64, 65-74, 75-84, 85 and over) | GMS Census (Exeter) |
| Rurality indicator 1: hectares per patient | Area (ward) data needs attributing to practices via patient postcodes. |
| Rurality indicator 2: % rural practice patients | GMS Census (Exeter) [already used by Senior and Rigby, 2001] |
| Rurality indicator 3: % of patients in settlements of less than 500 population | National Assembly's work on defining settlement clusters. Area data needs attributing to practices via patient postcodes. |
| Deprivation measure(s).<br>Could be Welsh Index of Multiple Deprivation, Welsh Jarman score or Townsend's material deprivation index. (Scottish Arbuthnott index likely to be time-consuming and expensive to create) | Requires linkage of small area deprivation score with each patient via latter's postcode |
| Postcodes for all patients by practice in Wales | NHS Administrative Register (Health Solutions Wales) |
| ***Additional indicators*** | |
| *Average rural practice payment per rural practice patient* | GMS Census (Exeter) |
| *Number of GPs per practice* | GMS Census (Exeter) |

However, it is no longer cost-effective to consider developing a Welsh version of this Scottish GMS formula because of the development of formulas to underpin the new GP contract in the UK as a whole. All of the existing or proposed GMS formulas will presumably be superseded by these new formulas (Carr-Hill *et al*, 2002) throughout the UK, although there may be scope for adding a 'Welsh dimension'.

Importantly, the rurality component of this research for the new GP contract improves on the Scottish formula by using Inland Revenue accounts data for some 20,000 GPs throughout Britain. The Scottish use of total payments has the undesirable consequence of introducing an element of circularity into the analysis, because those payments include existing rural practice payments. The Inland Revenue data, however, conveniently separates accounts for income and expenses claimed for service delivery (although these will include varying non-GMS expenses). Therefore, total expenses per patient by GP and by practice have been related to the following rurality influences (both significant), controlling for a variety of other effects.

Rurality:
- weighted population density of the wards from which the GP draws patients
- average distance of the patients from the practice.

GP/Practice:
- GP's age and gender
- list size (to investigate impacts of scale)
- number of partners
- contract status (*eg* full-time, half-time etc.)
- dispensing status
- staff market forces factor

Social/economic/demographic:
- proportion of patients in Social Classes I and II
- proportion of patients with more than one car
- limiting long-term illness rate
- proportion of patients on income support
- age-gender weighting of list

Given the suggested greater importance of rurality influences in Wales (and Scotland), it would be desirable to request that the research being conducted by Carr-Hill and colleagues (2002) be extended to determine whether there are any significant differences between the constituent countries of the UK. It appears that there are sufficient data on Welsh GPs in the Inland Revenue information for this to be feasible. This research would require a member of the York research team to spend a day using the Inland Revenue's computer in London and write up a short paper on the results.

*Ambulance services*

As the ambulance service in Wales is now organised on a national basis, it does not form part of the resource allocations to LHBs. Hence, the research informing the English Emergency Ambulance Cost Adjustment (MHA and Operational Research in Health Ltd, 1997) is not discussed here.

*Welsh language provision in health services*

Misell (2000) has examined the issue of Welsh language provision throughout the NHS. He has identified four key groups for whom such provision is a clinical need: people with mental health problems; people with learning difficulties or other special needs; the elderly; and young children. Ability to speak Welsh is also seen as crucial for health professionals involved in speech and language therapy and as very important for Health Visitors and midwives.

The need for Welsh language provision varies significantly between LHBs (Table 1.4). While Misell (2000) correctly asserts that there are no *"non-Welsh speaking"* regions in Wales, the burden of provision will fall particularly heavily on certain rural LHBs. Thus, Gwynedd and Anglesey have between 60% and 70% of their residents (aged three and over) speaking Welsh, while just over half do so in Ceredigion and Carmarthenshire. These LHBs also have the largest numbers of Welsh speakers. Conwy and Denbighshire have over a quarter of their residents speaking Welsh, while Powys and Pembrokeshire both exceed the national average of 20%. The more urbanised LHBs of south and north-east Wales have lower proportions of Welsh speakers. However, their numbers of Welsh speakers are, in most cases over 10,000, with Cardiff having about 32,000.

The last column in Table 1.4 presents the percentage allocation to LHBs of any budget for Welsh Language provision on the basis of absolute numbers of Welsh speakers. Gwynedd and Carmarthenshire LHBs would attract at least twice the resource allocation of any other LHB.

**Table 1.4: Welsh Language speakers, 2001[1]**

| **Local Health Board** | **All people aged 3 and over** | **Number of Welsh speakers aged 3 and over[2]** | **% Welsh speakers aged 3 and over[2]** | **% allocation of any Welsh Language Provision budget** |
|---|---|---|---|---|
| Gwynedd/Gwynedd | 112,800 | 77,495 | 68.7 | 13.5 |
| Isle of Anglesey/<br>Sir Ynys Mon | 64,679 | 38,709 | 59.8 | 6.7 |
| Ceredigion/Sir Ceredigion | 72,884 | 37,772 | 51.8 | 6.6 |
| Carmarthenshire/<br>Sir Gaerfyrddin | 167,373 | 83,802 | 50.1 | 14.6 |
| Conwy/Conwy | 106,316 | 31,042 | 29.2 | 5.4 |
| Denbighshire/Sir Ddinbych | 90,085 | 23,540 | 26.1 | 4.1 |
| Pembrokeshire/Sir Benfro | 110,182 | 23,686 | 21.5 | 4.1 |
| Powys | 122,473 | 25,516 | 20.8 | 4.4 |
| **WALES/CYMRU** | **2,805,701** | **575,640** | **20.5** | **100** |
| Neath Port Talbot/<br>Castell-nedd Port Talbot | 130,305 | 23,182 | 17.8 | 4.0 |
| Wrexham/Wrecsam | 124,024 | 17,895 | 14.4 | 3.1 |
| Flintshire/Sir y Fflint | 143,382 | 20,227 | 14.1 | 3.5 |
| Swansea/Abertawe | 216,226 | 28,581 | 13.2 | 5.0 |
| Rhondda; Cynon; Taff | 223,924 | 27,505 | 12.3 | 4.8 |
| The Vale of Glamorgan/<br>Bro Morgannwg | 115,116 | 12,734 | 11.1 | 2.2 |
| Caerphilly/Caerffili | 163,297 | 17,825 | 10.9 | 3.1 |
| Cardiff/Caerdydd | 294,208 | 31,944 | 10.9 | 5.5 |
| Torfaen/Tor-faen | 88,062 | 9,425 | 10.7 | 1.6 |

| | | | | |
|---|---|---|---|---|
| Bridgend/ Pen-y-bont ar Ogwr | 124,284 | 13,155 | 10.6 | 2.3 |
| Merthyr Tydfil/ Merthyr Tudful | 54,115 | 5,428 | 10.0 | 0.9 |
| Newport/Casnewydd | 131,820 | 12,608 | 9.6 | 2.2 |
| Blaenau Gwent | 67,795 | 6,141 | 9.1 | 1.1 |
| Monmouthshire/Sir Fynwy | 82,351 | 7,428 | 9.0 | 1.3 |

(Source: 2001 Census: Key Statistics for Local Authorities)

Notes: 1. The numbers of Welsh language speakers are less than the numbers with a Knowledge of the Welsh Language as defined by the 2001 Census and presented in table 3.3.

2. Welsh speakers are derived from the Census categories: speaks Welsh; speaks and reads Welsh; and speaks, reads and writes Welsh. It does not include the category *"other combination of skills"*.

# Chapter 2: HIV and Infectious Diseases

This section of the report addresses the issue of how much it costs to treat people with HIV/AIDS. First, the incidence and prevalence of infectious diseases in Wales and of HIV/AIDS in particular, is considered.

### The Incidence of Notifiable Diseases in Wales

Table 2.1 presents the number of reported Notifiable Diseases by Health Authority and for all of Wales in 2002. A total of 4816 cases of Notifiable Diseases were reported for Wales, the majority of which were 'food poisoning' – over 78%. In terms of the proportion of total cases accounted for by diseases other than food poisoning, only viral hepatitis, mumps, measles, tuberculosis, meningococcal septicaemia, meningitis, scarlet fever and rubella account for between 4% and 1% of the total. All other diseases account for less than 1%.

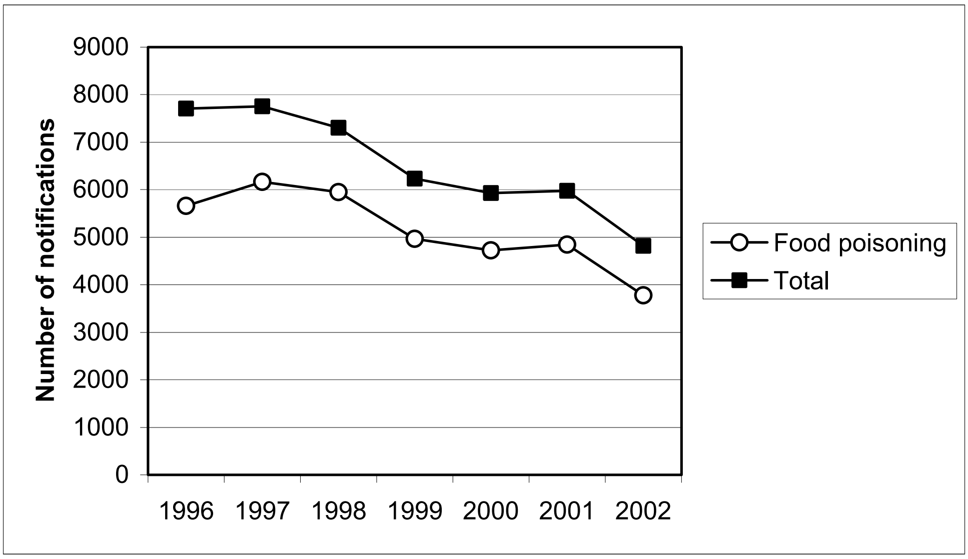
**Table 2.1: Numbers of Notifiable Diseases by Health Authority, Wales, 2002**

| | **Bro Taf** | **Dyfed Powys** | **Gwent** | **Morgannwg** | **North Wales** | **WALES** | **% of total** |
|---|---|---|---|---|---|---|---|
| Acute encephalitis | 0 | 1 | 0 | 0 | 0 | 1 | **0.02** |
| Acute poliomyelitis | 0 | 0 | 0 | 0 | 0 | 0 | **0** |
| Cholera | 0 | 0 | 0 | 0 | 0 | 0 | **0** |
| Diphtheria | 0 | 0 | 0 | 0 | 0 | 0 | **0** |
| Dysentery | 11 | 7 | 1 | 1 | 8 | 28 | **0.58** |
| Food poisoning | 1178 | 260 | 753 | 558 | 1028 | 3777 | **78.43** |
| Leptospirosis | 0 | 0 | 0 | 0 | 0 | 0 | **0.00** |
| Malaria | 1 | 3 | 0 | 2 | 1 | 7 | **0.15** |
| Measles | 9 | 27 | 30 | 18 | 53 | 137 | **2.84** |
| Meningitis | 10 | 20 | 15 | 22 | 29 | 96 | **1.99** |
| Meningococcal septicaemia | 13 | 30 | 6 | 6 | 41 | 96 | **1.99** |
| Mumps | 23 | 15 | 64 | 15 | 51 | 168 | **3.49** |
| Ophthalmia neonatorum | 0 | 0 | 0 | 0 | 0 | 0 | **0** |
| Paratyphoid fever | 0 | 0 | 0 | 0 | 0 | 0 | **0** |
| Rubella | 5 | 14 | 15 | 15 | 15 | 64 | **1.33** |
| Scarlet fever | 17 | 9 | 26 | 9 | 18 | 79 | **1.64** |
| Tetanus | 0 | 0 | 0 | 0 | 0 | 0 | **0** |
| Tuberculosis | 58 | 16 | 12 | 21 | 24 | 131 | **2.72** |
| Typhoid fever | 1 | 0 | 1 | 0 | 0 | 2 | **0.04** |
| Viral hepatitis | 19 | 55 | 8 | 28 | 95 | 205 | **4.26** |
| Whooping cough | 1 | 10 | 1 | 1 | 12 | 25 | **0.52** |
| **Total** | **1346** | **467** | **932** | **696** | **1375** | **4816** | **100.00** |

Source: PHLS Wales

Figure 2.1 shows the trends in the number of reported Notifiable Diseases over the past seven years, for all diseases and for food poisoning. Both show a general downward trend, particularly between 2001 and 2002, although food poisoning notifications rose between 1996 and 1997.

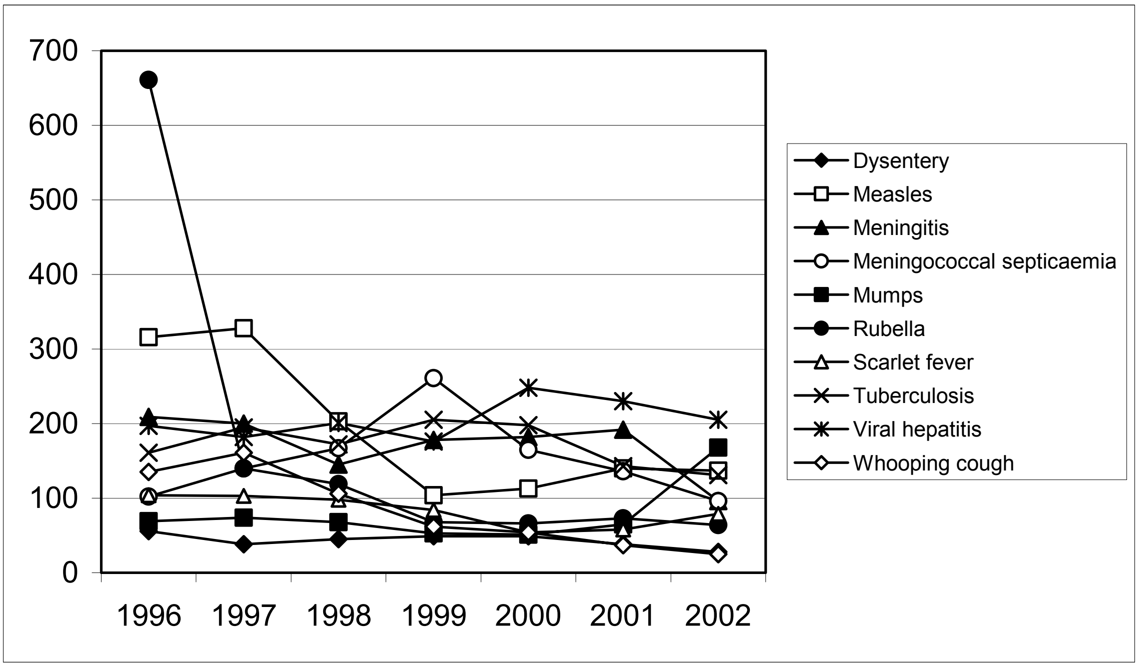
**Figure 2.1: Trends in the number of notifications of total Notifiable Diseases and food poisoning, Wales, 1996-2002**



Source: PHLS Wales

Figure 2.2 shows the main diseases other than food poisoning. Most account for less than 200 cases per year, although rubella was particularly high in 1996 (661 reported cases).

**Figure 2.2. Trends in the number of notifications of selected Notifiable Diseases, Wales, 1996-2002**



## The incidence and prevalence of HIV/AIDS in Wales

HIV and AIDS are reported via a different mechanism to the Notifiable Diseases referred to above. In the UK, all reporting of diagnoses of HIV infection and AIDS is voluntary and confidential (AIDS/HIV Quarterly Surveillance Tables, 2003).

As HIV is a chronic disease and a new diagnosis does not necessarily mean a recent acquisition, multiple surveillance sources are necessary and these are listed in Box 1. These different sources of data understandably give slightly different totals for the number of new HIV infections.

**Box 1. Methods used in the surveillance of HIV in the UK**

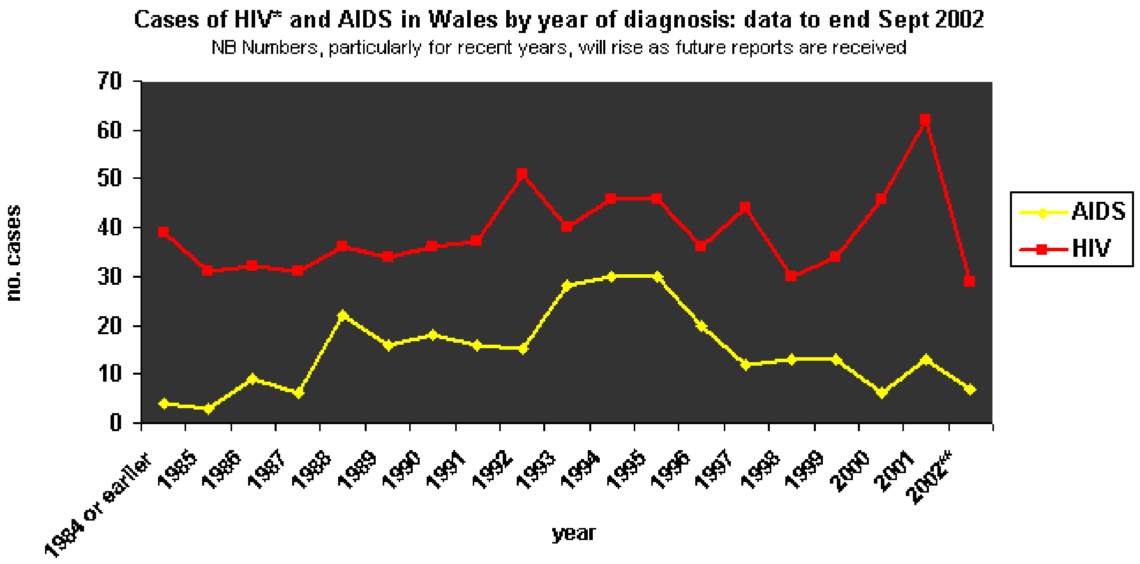
**1. Reporting of:**
    First UK diagnosis of AIDS and of HIV diagnoses (from January 2000) made in clinics
    Newly diagnosed HIV infections from laboratory tests
    Pregnancies in HIV infected women
    Infection in children
    CD4 cell counts from immunology or haematology laboratories
**2. Blood donation screening**
**3. Unlinked anonymous surveys in:**
    GUM clinic attendees
    Injecting drug users
    Pregnant women and their new-born babies
    Women undergoing termination of pregnancy
**4. Annual survey of prevalent diagnosed HIV infections (SOPHID)**
**5. Surveillance of occupational exposure in healthcare workers**
**6. Results of HIV tests (negative and positive) from sentinel laboratories**
**7. Surveillance of other STIs from GUM clinics**
**8. Surveillance of behaviours relevant to transmission of HIV and other STIs**

Source: PHLS (2002)

Clinical reports to CDSC HIV and STI Division of *newly* diagnosed HIV positive patients in Wales reached their highest point in 2001, with 61 new cases diagnosed. Prior to this, numbers of new cases were relatively constant at around 40 per year. The number of new reports of AIDS has been steadily decreasing since the mid 1990s due to advances in treatment, *ie* the progression from HIV to AIDS is delayed (PHLS in Wales, 2002).

Figure 2.3 shows the number of cases of HIV and AIDS in Wales since the mid 1980s (note: the figure for 2002 includes only the first quarter).

**Figure 2.3: Cases of HIV and AIDs in Wales by year of diagnosis: data to end September 2002**



Source: PHLS in Wales, 2002.** the figure for 2002 includes only the first quarter.

This recent increase in HIV diagnoses in Wales indicates that it is not going away. Many of the newly identified infections are in women and an increasing proportion are in heterosexuals reporting a history of living or travelling overseas (PHLS, 2002).

By comparison, data collected as part of the CDSC HIV denominator scheme – the results of clinical testing for HIV infection reported by the PHLS at Cardiff, Swansea, Hereford, Bangor and Rhyl and the NHS laboratory at Royal Glamorgan Hospital, Llantrisant, lists the number of people tested and newly diagnosed for HIV in Wales in 2001 by Health Authority (see Table 2.2). In this source the number totals 72.

**Table 2.2: Number of people diagnosed HIV positive in Wales**

| Health Authority | Number |
|---|---|
| Bro Taf | 43 |
| Dyfed Powys | 3 |
| Gwent | 3 |
| Morgannwg | 14 |
| North Wales | 9 |
| **WALES** | **72** |

Source: PHLS in Wales (2002)

Alternatively, SOPHID data refer to patients diagnosed with HIV and seen for care and are perhaps the most useful source for our purposes.

**Table 2.3: Diagnosed HIV-infected patients when last seen for care in 2001***

| Government office region of residence | Number of cases |
|---|---|
| Yorks and Humberside | 767 |
| North East | 314 |
| East Midlands | 787 |
| West Midlands | 931 |
| North West | 1874 |
| Eastern | 1135 |
| London | 15037 |
| South East | 2504 |
| South West | 916 |
| ENGLAND | 24269 |
| **WALES** | **398** |
| N IRELAND | 128 |
| **TOTAL** | **25203** |

Source: SOPHID (2001)
*patients seen for statutory medical HIV-related care at services in England, Wales and Northern Ireland in 2001.

Of these 398 patients resident in Wales, the clinical stage was as follows: 137 were asymptomatic, 114 had symptoms pre-AIDS, (SOPHID 2001), 127 had AIDS, five died with AIDS and 14 were unknown as to stage of progression. Thus, 34% were asymptomatic.

By level of anti-retroviral therapy, 109 were receiving none, one was receiving mono, none were receiving dual, 227 were receiving triple and 41 quadruple or more (21 unknown). Thus 67% were having anti-retroviral therapy, the vast majority of them receiving triple (or more) therapy.

### The Cost of Treating HIV/AIDS

A review of journal publications and ‘grey’ literature produced only a limited number of relevant sources as most papers on this topic cover either the cost-effectiveness (rather than the cost) of treating people with HIV or the relative cost of treating people in developing countries and the pricing policies of pharmaceutical companies.

However, one key paper was located which considered: ‘The economic costs of caring for people with HIV infection in England and Wales’ although it is somewhat out of date (Petrou *et al*, 1996). The cost of treating people with HIV/AIDS will depend on the stage of their disease, *ie* whether they are (a) asymptomatic HIV; (b) symptomatic HIV or (c) AIDS patients. The costs involved included drugs costs and hospital, community and informal care.

The paper by Petrou and colleagues took into account both stage of progression and the range of care received in order to estimate annual total direct costs of care, total lifetime costs of care and present and future total national care costs for England and Wales.

**Table 2.4: Cost of treating HIV/AIDS**

| Source | Asymptomatic HIV | Symptomatic HIV | AIDS |
|---|---|---|---|
| Petrou *et al*, 1996 | £4514 | £8836 | £15628 |
| At 2003 prices* | **£5552** | **£10867** | **£18778** |

* allowing for 3% inflation per year

Most of the costs involved in the later stage of disease development arise from hospital admissions due to opportunistic infections. According to a SHPIC Report (1997), at that time, drug costs, laboratory monitoring of viral levels and CD4 counts were only a small part of the total cost of care. However, since the introduction of newer combination therapies, such as the highly active antiretroviral therapy (HAART) in 1996, costs have increased at the latter stage. The use of HAART has had a major impact on AIDS incidence and deaths from HIV, leading to a rising number of people living with HIV. The cost of combination therapy, including this, were estimated to be £7,000-8,000 per year (SHPIC Report, 1997). At 2003 prices, this would be £9000.

In 2001, 65% of HIV diagnosed patients were on anti-retroviral therapy, most on triple therapy (PHLS, 2002).

Allocations to Health Authorities in England would appear to be **£9,190 per person** with HIV/AIDS[1].

**The Total Cost Implications for Wales**

**A**. If we take the costs from Petrou *et al* (1996), allowing for inflation at 3% per year since and taking the number at each stage of progression as above:

137 asymptomatic at £5552 = £760,624
114 symptomatic at £10867 = £1,288,838
127 AIDS at £18778 = £2,384,806

= **£4.384 million**, or **£11,600 per person.**

**B.** If 65% of the 398 people with HIV/AIDs in Wales are on antiretroviral therapy at £9,000 pa, then this will cost Wales an additional **£2,328** million pa (or £**5850** for each person with HIV/AIDS).

However, the use of antiretroviral therapy will reduce the care costs somewhat. Nonetheless, these figures suggest that the figure of £9,190 per person allocated in England is inadequate.

**Conclusions**

The NHS resource allocation formula proposed by the independent research team (Gordon *et al*, 2001) only included food poisoning as a measure of health need for infectious diseases. Food poisoning cases represent approximately 75% of measured infectious diseases in Wales. However, it is feasible to modify the formula to include HIV/AIDS and other infectious diseases such as TB,

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[1] Authors calculations of 2001/02 HIV/AIDS treatment and care targets – centrally funded initiatives and services, special allocations and distributional adjustments.

Viral hepatitis, Mumps, etc. The main problem with this modification is that there are thankfully only a few hundred cases of these diseases each year in Wales, which means that the prevalence at LHB area can fluctuate considerably from one year to the next.

# Chapter 3: Ethnicity and Health Resource Allocation in Wales

## Introduction

There is now a large literature that documents the importance of taking account of ethnicity when allocating health resources. Different ethnic groups in Wales (and other parts of the UK) have different prevalence rates for a wide range of health conditions. With members of certain ethnic groups suffering from both higher and lower rates of ill health than would be expected after allowing for age, gender and socio-economic status. Similarly, there are differential costs of delivering health services to some members of certain ethnic groups, which often result from translation, interpretation and staff training cost. For example, the Welsh Language Board (1996) has argued that "*It should no longer be the case that Welsh speakers have to press for a service in Welsh… A request to use Welsh should become no more than making a choice*". Additionally, Missel (2000) has argued that there are four key groups of health care consumers who are particularly vulnerable if health services are not available in a language they can understand well. These are: people with mental health problems; people with learning difficulties or other special needs; the elderly and young children.

However, there is a great deal of misunderstanding about the extent, causes and consequences of variations in health status by ethnic group. Notions of 'ethnicity', 'identity' and 'race' are often confused and/or assumed to be similar. Much research in the past has attributed health differences between ethnic and/or 'racial' groups in Wales to be a result of genetic difference between these groups, *eg* some groups have more 'unhealthy' genes (for example, see Harper and Sutherland, 1986). Modern genetic studies have clearly demonstrated that this idea is untrue. Ethnic group health differences are entirely a result of socio-economic, behavioural and cultural differences and not genetic differences. It is, however, not sufficient to just assert this fact as the idea of genetic differences between ethnic groups is unfortunately widely believed by both the general population and many health professionals. The purpose of this chapter is to deal with health resource allocation. However, in order to clarify the complex relationship between ethnicity, culture and health outcomes in Wales, this is discussed in more depth in Appendix I. Similarly, Appendix II looks at the issue of history of ideas of identity, race and ethnicity in Wales and the light that can be shed on these issues by modern genetic research.

## The Health Costs associated with Ethnicity

In England, the Advisory Committee on Resource Allocation (ACRA) examined the issue of the health costs associated with ethnicity during 1998-1999. They commissioned two reports from University of Warwick - The Centre for Research in Ethnic Relations (CRER) and Centre for Health Services Studies (CHESS). This literature review (University of Warwick, 1998a) on *The Unavoidable Costs of Ethnicity" A Review for the NHSE* identified two types of unavoidable cost. The first was the additional cost of providing the same service to an ethnic population. This principally reflects language needs, *ie* the cost of providing interpreter, advocacy and translation (IAT) services. The second type of unavoidable cost was the additional cost associated with differences in the incidence/prevalence of specific diseases in ethnic populations, combined with differences in treatment costs (ACRE, 1999). This report found evidence of additional costs associated with the provision of IAT services. However, due mainly to a severe lack of good quality data, they were not able to attribute reliable cost estimates for IAT services. Another limitation of the Warwick team's report was that it did not examine the additional costs that arise as a result of functional illiteracy in English in the general population (*eg* longer consultations, failure to follow written health/prescribing advice, etc) as this issue was beyond the remit of their work.

In order to assess the costs of IAT services in England, the Warwick team produced a detailed analysis on relatively detailed cost data supplied from a sample of 13 English Health Authorities (HA). This data showed a very wide range in total IAT spending, from £847 in Doncaster HA to over £2.3 million in East London and the City HA. The researchers used this cost data - and data indicating the degree of language difficulty experienced by various ethnic minority populations - to produce a regression model that gave a predicted cost per person with language difficulties for all 100 HAs. By multiplying a HA's predicted cost per person by estimates of the number of people experiencing language difficulties, it is possible to determine the total costs of IAT provision at HA level (University of Warwick, 1998b).

There is currently a lack of data on IAT costs in Wales. One Trust recently estimated that they spent a minimum of about £250,000 on translation into Welsh. It would seem highly likely that, since Wales is a bi-lingual country (unlike England), NHS IAT costs will be greater in Wales than in England. However, any resource allocation of IAT and other such costs in Wales should look at the distribution of these needs amongst all ethnic groups in the population as a whole and not just amongst the ethnic minority populations of Wales (the 'Welsh' are not an ethnic minority in Wales).

## The Measurement of Ethnicity in Wales

Ethnicity is a socially constructed concept which is inherently variable and fluid (Nazroo, 1998). It is an amalgamation of notions of nationality, family background, religion, cultural practices and language (see Appendix I for discussion). It is therefore a very complex phenomena to try to measure, indeed, a whole field of academic endeavour (social anthropology) is largely devoted to studying ideas and consequences of ethnicity. The measurements of ethnicity in Wales that can be used for NHS resource allocation purposes at LHB level are somewhat crude and are derived from the 2001 Census.

**Table 3.1: Ethnic group results from the 2001 Census for Wales**

| **Ethnic Group** | **%** |
|---|---|
| White British | 95.99 |
| White Irish | 0.61 |
| White Other | 1.28 |
| Mixed White and Black Caribbean | 0.21 |
| Mixed White and Black African | 0.08 |
| Mixed White and Asian | 0.17 |
| Mixed Other | 0.15 |
| Asian British Indian | 0.28 |
| Asian British Pakistani | 0.29 |
| Asian British Bangladeshi | 0.19 |
| Other Asian | 0.12 |
| Black British Caribbean | 0.09 |
| Black British African | 0.13 |
| Black British Other | 0.03 |
| Chinese or other ethnic group Chinese | 0.22 |
| Chinese or other ethnic group Other ethnic group | 0.18 |
| **Total** | **100.00** |
| | |
| **People identifying themselves as Welsh** | 14.39 |

Table 3.1 shows the ethnic group results which were recently published as part of the *2001 Census Key Statistics*. In Wales overall, less than 1% describe themselves as Asian or Asian British (compared with nearly 5% in England), 0.6% as mixed ethnic group and 0.2% as Black or Black British. Cardiff has the highest proportions in Wales of most minority ethnic groups (ONS, 2003).

However, the 2001 Census question in Wales contained a substantial error in that, under the 'White' ethnic group, respondents were only given the option of ticking three boxes for: White British, White Irish or White Other – there was no box for White Welsh, which would have allowed people who considered that they had a 'Welsh' national identity to record this easily on the form. By contrast, in Scotland, the first option in the Census ethnic group question was 'White Scottish'. Nevertheless, as Table 3.1 shows, fewer than 15% of people wrote that their ethnic group was 'Welsh' on their Census form. This is a severe underestimate of the extent of 'Welsh' national identity in Wales. The Welsh Labour Force Survey included a specific question on national identity and is therefore a more reliable indicator. This gives the much higher figure of 69% who consider themselves as Welsh.

The Office for National Statistics plans to issue new guidance on measuring ethnic group in the summer of 2003. It is likely that they will argue that this should be done using a minimum of two questions: the first on 'national identity' (*eg* English, Irish, Scottish, Welsh, etc) and the second on 'ethnic group' (*eg* White, Black, Asian, etc) which will be similar to the 2001 Census question (ONS, per com). Nevertheless, it is unclear how some ethnic minority groups, such as Sikhs or Kurds, would answer these questions.

**Table 3.2: Religion in Wales**

| **Religion** | **%** |
|---|---|
| Christian | 71.9 |
| Buddhist | 0.19 |
| Hindu | 0.19 |
| Jewish | 0.08 |
| Muslim | 0.75 |
| Sikh | 0.07 |
| Other religions | 0.24 |
| No religion | 18.53 |
| Religion not stated | 8.07 |
| **TOTAL** | **100.00** |

In order to refine the measurement of ethnic identity, the 2001 Census also asked a voluntary question on religion for the first time in over 100 years. Table 3.2 shows the results produced as part of the first release of the *2001 Census Key Statistics*. In Wales as a whole, nearly 72% describe their religion as Christian. This varies from 64% in Blaenau Gwent to more than 79% in the Isle of Anglesey.

Although the next most common religion in Wales - after Christian - is Muslim, this makes up just 0.7% of the population. In Wales as a whole, there are 0.2% Buddhists, 0.2% Hindus, 0.1% Jews and 0.1% Sikhs. However, over 18% state they have no religion (compared with just over 14% in England). More than a quarter of people in Rhondda; Cynon; Taff and Blaenau Gwent say they have no religion.

There are a number of different indicators of cultural identity that were measure by the 2001 Census in Wales. Table 3.3 summarises some of these measures at the LHB level.

**Table 3.3: Indicators of cultural diversity in Wales (%)**

| Local Health Board | Welsh Identity | Knowledge of the Welsh Language | Ethnic Minority Group | Not Born in Wales | Non-Christian |
|---|---|---|---|---|---|
| Gwynedd | 26.8 | 76.1 | 3.5 | 30.2 | 25.5 |
| Carmarthenshire | 23.4 | 63.6 | 2.8 | 19.9 | 25.4 |
| Ceredigion | 21.8 | 61.2 | 4.2 | 41.4 | 29.2 |
| Anglesey, Isle of | 19.4 | 70.4 | 2.8 | 32.4 | 20.6 |
| Neath Port Talbot | 17.0 | 28.8 | 2.4 | 10.5 | 27.9 |
| Rhondda, Cynon, Taff | 16.6 | 21.1 | 2.5 | 10.1 | 35.1 |
| Merthyr Tydfil | 16.2 | 17.7 | 2.1 | 8.0 | 30.2 |
| Bridgend | 15.8 | 19.9 | 2.9 | 15.3 | 29.8 |
| Caerphilly | 15.5 | 16.7 | 2.2 | 10.1 | 34.2 |
| Swansea | 15.3 | 22.5 | 4.3 | 17.9 | 29.0 |
| **WALES** | **14.4** | **28.0** | **4.0** | **24.6** | **28.1** |
| Cardiff | 13.2 | 16.3 | 11.7 | 25.1 | 33.1 |
| Pembrokeshire | 13.1 | 29.4 | 3.1 | 31.3 | 24.4 |
| The Vale of Glamorgan | 12.8 | 16.9 | 4.2 | 24.3 | 27.0 |
| Powys | 12.6 | 30.1 | 2.5 | 44.4 | 25.2 |
| Conwy | 12.1 | 39.7 | 3.2 | 46.0 | 22.3 |
| Blaenau Gwent | 12.0 | 13.3 | 1.8 | 7.9 | 35.8 |
| Denbighshire | 10.6 | 36.0 | 2.8 | 42.1 | 22.2 |
| Torfaen | 9.8 | 14.5 | 2.1 | 14.5 | 29.2 |
| Wrexham | 9.4 | 22.9 | 2.6 | 28.1 | 22.7 |
| Newport | 9.0 | 13.4 | 6.9 | 18.9 | 28.1 |
| Monmouthshire | 6.9 | 12.9 | 2.8 | 38.7 | 25.2 |
| Flintshire | 5.8 | 21.4 | 2.3 | 48.9 | 20.8 |

Note: Welsh Identity – people who defined themselves as Welsh by writing on the Census form
Knowledge of the Welsh Language – people who can speak, read, write or understand some Welsh
Ethnic minority group – people who identified themselves as belonging to a group other than 'White British' – this does not include those who wrote they were Welsh on the form.
Not born in Wales – people born outside Wales
Non-Christian – people who belong to another religious group or who have no religion or who did not sate a religion on this voluntary question..

Table 3.3 shows some of the complexities involved in measuring ethnic identity. For example, over three-quarters of the people living in Wales at the time of the Census were born in Wales, with 20% were born in England, less than 1% in Scotland and Northern Ireland. Just over 1% were born in the rest of the European Union and nearly 2% outside the EU. Of the 22 LHB areas in Wales, Blaenau Gwent, Merthyr Tydfil, Caerphilly, Rhondda; Cynon; Taff and Neath Port Talbot have the highest proportions of the population born in Wales (nearly 90% or more) while in Flintshire, Conwy and Powys, more than 40% of the population were born in England.

Table 3.3 shows that Welsh identity ranges from nearly 27% in Gwynedd to less than 6% in Flintshire (although, as previously discussed, these data underestimate the extent of Welsh identity). Knowledge of the Welsh language ranges from 76% of the population over three years old in

Gwynedd to 13% in Monmouthshire. Cardiff has 12% of its population from ethnic minority groups compared with less than 2% of the population of Blaenau Gwent.

**Ethnicity, Literacy and Resource Allocation**

The direct method of NHS resource allocation adopted by the National Assembly for Wales allows for the variation in health need by ethnic group and identity. However, the formula proposed by the Independent Research Team (Gordon *et al*, 2001) makes no allowance for the additional costs of health service delivery arising from ethnic differences. Since Wales is a bilingual country, the method proposed by the University of Warwick team for allocating interpreter, advocacy and translation (IAT) service costs for England is clearly inappropriate for Wales.

Health service provision in a language that the patient understands is not just a medical necessity it is also a right of NHS patients in Wales. The 1996 Patient's Charter in Wales stated that "*You can expect the following…to be given information as far as possible in English and Welsh*". Similarly 'The Patient Charter – Services for Children and Young People in Wales' stated " *Your doctor, nurse or health visitor will explain any treatment, as far as possible in English and Welsh*" The 1998 White Paper on the NHS in Wales looked at the information needs of all patients in the NHS and argued that:

"*If patients are going to be equal partners in their health care, they need clear, comprehensive and personalised information about risks, befits and treatment options for their condition*"

It is clear from these policy priorities that an 'ethnic' cost adjustment to the NHS resource allocation formula should have two main components:

- a cost adjustment for translation into the Welsh language
- a cost adjustment for functional illiteracy in English

This second cost adjustment for functional illiteracy is designed to capture the additional costs of explaining treatment options and so on to patients who have difficulty in understanding and reading English, irrespective of their ethnic group or identity. The University of Warwick report only looked at English literacy issues amongst ethnic minority groups in England.

Information on functional illiteracy in Wales is available from the results of the International Adult Literacy Survey (IALS), which defined literacy as (ONS, 1999):

*"the ability to understand and employ printed information in daily activities, at home, at work and in the community, to achieve one's goals and to develop one's knowledge and potential."*

This definition implies the need for a range of skills and, to reflect this, the IALS measured literacy using three categories:

1. **Prose literacy**: the ability to understand and use information from texts such as editorials, news stories, poems and fiction.

2. **Document literacy**: the ability to locate and use information from documents such as job applications, payroll forms, transportation schedules, maps, tables and graphs.

3. **Quantitative literacy**: the ability to perform arithmetic functions such as balancing a chequebook, calculating a tip, or completing an order form.

The specific literacy tasks designed for IALS were scaled by difficulty from 0 to 500 points. This range was subsequently divided into five broad literacy levels:

**Level 1** indicates very low literacy skills, where the individual may, for example, have difficulty identifying the correct amount of medicine to give to a child from the information found on the package.

**Level 2** respondents can deal only with material that is simple, clearly laid out and in which the tasks involved are not too complex. This is a significant category because it identifies people who may have adapted their lower literacy skills to everyday life but would have difficulty learning new job skills requiring a higher level of literacy.

**Level 3** is considered as the minimum desirable threshold in many countries but some occupations require higher skills.

**Levels 4 and 5** show increasingly higher literacy skills requiring the ability to integrate several sources of information or solve more complex problems. A necessary requirement for some jobs (ONS, 1999).

Respondents whose literacy skills were only at Level 1 were considered to be ‘functionally illiterate’, and just over a quarter of the Welsh population were estimated to have only Level 1 skills in document literacy. Higher rates of functional illiteracy were found amongst ‘poorer’ groups, those with no academic qualifications and ethnic minority groups.

It should be possible - when the 2001 Census statistical tables are released (during summer 2003) - to produce a synthetic estimate of the extent of functional illiteracy at LHB area. The 2001 Census also measured knowledge of the Welsh language (see Table 3.3). Therefore, a cost adjustment for IAT and other associated costs to the NHS resource allocation formula is feasible if these costs can be estimated from the NHS accounts data that are available. These costs are likely to be higher in Wales than in any other part of the UK, however, they are still relatively small compared with the overall NHS budget. Therefore, a pragmatic decision with regard to the materiality of this cost adjustment needs to made, *eg* does the size of the cost adjustment to the resource allocation formula justify the cost and expense of the research work that would be required?

# Chapter 4: Other Potential Urban Issues

## Introduction

A number of additional possible influences on health-care needs and costs associated with an urban environment were identified by Task Group A during the NHS Resource Allocation Review[2]. Some further concerns were also raised during the consultation phase and four additional areas were identified which are listed below:

- Asylum Seekers/Refugees
- Prison Services
- Homelessness
- Drug and Alcohol Abuse

The issue of Haemophilia was also raised as a possible urban concern. Haemophilia is fortunately a rare disease which affects few people in Wales but can be very expensive to treat. For example, the cost of immune intolerance treatment can be £1 million per patient[3]. The research team believes that the cost of Haemophilia treatment, like other high cost, low prevalence health needs should be met from top-sliced funding and should therefore not form part of the resource allocation formula at LHB level.

## Asylum Seekers

All asylum seekers are entitled to free medical treatment by the NHS. However, the BMA (2002) has claimed that there is a lack of government funding, planning and coordination of health services for asylum seekers and has argued for additional payments to doctors offering an extended range of services to this group of patients. Primary care trusts can approve additional payments, funded by Local Development Schemes under the NHS (Primary Care Act 1997), if any extended range of services is provided to asylum seekers. Such services may include a detailed medical assessment following current BMA guidance:

a) Assess current health status and address any immediate concerns.

b) Test for tuberculosis. Tests for other conditions such as Hepatitis A, B, C and HIV may be deemed necessary after a full history. (It should be noted that considerable time is needed to provide appropriate pre and post counselling for Hepatitis and HIV tests. It is preferable for the same person to provide the pre and post counselling.)

c) Take history of immunisations and vaccinations. Where there is uncertainty, the appropriate vaccinations and immunisations should be given.

d) Take maternity history. Cervical smears and family planning advice should be offered to women, if appropriate. Men may also require family planning advice.

e) Assess special needs, *eg* for amputees.

f) Assess nutritional needs, *eg* malnourished children, children of HIV positive mothers.

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[2] See *Targeting Poor Health Volume 3, Report of the Task Groups*

[3] http://www.thepolitician.org/politician/article_012.html

g) Assess psychological wellbeing and refer to the appropriate health professional if necessary.

h) Note any evidence of physical or psychological torture or maltreatment and refer the patient to a specialist centre, *eg* The Medical Foundation for the Care of Victims of Torture, if there is evidence of torture or if torture is alleged.

The BMA has argued that certain health problems are common among asylum seekers and some are specific to them. The threats to health are mostly posed by diseases linked to poverty and overcrowding, whether communicable, degenerative or psychological. Therefore, most of the health problems of asylum seekers are not specific to refugee status and are shared with other deprived or excluded groups. Health problems that are specific to asylum seekers originate from physical or mental torture or other harsh conditions from which they have escaped (BMA, 2002).

There has been relatively little research into the specific health needs of the refugee population in the UK. Carey Wood and colleagues (1995) found that one in six refugees (17%) has a physical health problem severe enough to affect their life, which is a similar rate to the UK population as a whole. However, two-thirds of refugees had experienced significant anxiety or depression, which is a far higher prevalence rate of mental health problems than the general population.

Given these facts, the health of asylum seekers should be a consideration for LHBs, so information on their geographic distribution is required. The Home Office publishes *Asylum Statistics* every quarter (www.homeoffice.gov.uk/rds/immigration1.html), in which is recorded the location of those asylum seekers supported by the National Asylum Support Service (NASS). NASS provides accommodation and/or subsistence payments to asylum seekers while they await decisions on their asylum applications. The following table presents some recent counts of NASS-supported asylum seekers resident in Wales. At the time of writing (mid-April 2003) the First Quarter statistics for 2003 were not available.

**Table 4.1: National Asylum Support Service supported asylum seekers**

| **Area** | **December 2001** | **December 2002** | |
|---|---|---|---|
| | **Subsistence and/or accommodation** | **Subsistence payments only** | **In Accommodation** |
| *Cardiff* | 555 | 70 | 1000 |
| *Newport* | | 25 | 115 |
| *Neath Port Talbot* | | | * |
| *Swansea* | 80 | | 410 |
| *Wrexham* | 65 | | 55 |
| *Other* | | 85 | |
| not specified | 140 | | |
| *TOTAL* | *845* | *180* | *1585* |

Note: figures rounded to nearest 5 and do not sum to the totals because of rounding;
* indicates 1 or 2

Although numbers are small, they have increased rapidly over 12 months. Hence, it will be important to use the most recent numbers and update them frequently. A specific adjustment to the NHS resource allocation formula could be made which would better reflect the health needs of asylum seekers. Some Health Authorities in England have recently made specific resource allocations to meet the cost of the additional health needs of asylum seekers. For example, Wakefield has an Local Development Scheme that adds £40 to the GP capitation fee for each asylum seeker[4]. A simple way of adjusting the Welsh formula would be to assume that two-thirds of asylum seekers will have significant mental health needs and adjust the mental health allocations accordingly.

**Prison Services**

Providing health care for prisoners has historically been the responsibility of the prison service not the NHS. Prison Governors have been responsible for allocating resources to health care but there is considerable variation between prisons in the way in which health care services are provided. However, across the prison service, per capita expenditure on formal health care services are higher than equivalent expenditure for young adults in the NHS (Marshall, Simpson and Stevens, 2000).

Directly employed health care staff include health care officers (prison officers with some training in nursing), nursing staff (some whom may also be prison officers) and medical officers. Many prisons also contract with local general practitioners, hospital trusts, medical, dental and other specialists. In addition to access to NHS in-patient facilities, many prisons also have their own in-patient facilities. A substantial part of the work of prison health care services involves routine medical examination at entry and prior to release and preparing medical reports for legal reasons (Marshall, Simpson and Stevens, 2000).

The range and frequency of physical health problems experienced by prisoners appears to be similar to that of young adults in the community. However, prisoners have a very high incidence of mental health problems, in particular neurotic disorders, compared to the general population (Bridgwood and Malbon, 1995; Smith, 1998). By ICD-10 criteria, in any week, almost half of prisoners are suffering from a neurotic disorder such as anxiety or depression. One in ten prisoners has suffered from a psychotic disorder in the past year (Gunn *et al*, 1991; Maden *et al*, 1995; Singleton *et al*, 1998). Half of prisoners are heavy alcohol users and about one in twenty has a serious alcohol problem. About half of prisoners are dependent on drugs (principally opiates, cannabis and stimulants) and at least one quarter have injected drugs (Bridgwood and Malbon, 1995; HM Chief Inspector of Prisons, 1998).

Per year of imprisonment, prison inmates consult primary care doctors three times more frequently and other health care workers about eighty to two hundred times more frequently than young adults in the community. Prison inmates are admitted to NHS hospitals as frequently as young adults in the community but are also admitted to prison in-patient facilities two to sixteen times more frequently than this. Inmates are also heavy users of medical specialists and professions allied to medicine. (Marshall, Simpson and Stevens, 2000).

In April 2001, Ministers at the Department of Health, National Assembly for Wales and the Home Office agreed the establishment of a new formal partnership between the Prison Service and the NHS in an effort to secure better health care in prisons. Leading this partnership were two new national joint units - a Prison Health Policy Unit and Prison Health Task Force - to help support and drive the reform of prison healthcare from the centre. The remit of Prison Health Policy Unit and Task Force is clear:

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[4] http://www.doh.gov.uk/hsd/asylumseekers.htm

*"At any time, 65,000 people are held in one of 135 prisons in England and Wales. A high proportion of prisoners come from socially excluded sections of our community, and a recent survey showed that 90% of those entering prison had a mental health or substance misuse problem.*

*Although the greater part of most prisoners' health care is delivered by the Prison Service rather than the NHS, it has always been the aim to ensure that prisoners get decent health care to standards equivalent to those in the NHS. But it is generally recognised that this aim is not being met everywhere; in some places the gulf between NHS standards of care and prisoner care is very disturbing. In particular there are problems with inadequate provision for prisoners with mental health problems and with the recruitment and retention of properly trained healthcare staff.*

*Effective health care delivered to a good standard while in custody, even for a short period can make a significant contribution to the health of individuals, as well as improving their capacity to benefit from education, drug treatment and other programmes. As many people are in prison for less than 6 months it is essential that we ensure better continuity and through care if we are to meet our obligation to them as professionals to meet their needs effectively in prison and in the community."*[5]

It should be noted that, since this policy statement was written in 2001, the number of prisons in England and Wales has increased from 135 to 137 and average prisoner numbers have increased from 65,000 to 72,000. The Government has also made a commitment to invest over £100 million in health services for English and Welsh prisons over the next three years, to improve health centres and drug detoxification services, tackle infectious diseases and develop the health care workforce. The Government has also made a clear commitment to improving mental health services for prisoners. The aim is to have 300 additional mental health staff working in prison in England by 2004.

In Wales, the Assembly is working closely with the Prison Health Team to take forward programs aimed at improving health in the four Welsh prisons. Funding has been provided for substance misuse programme and for mental health in-reach in prisons[6]..

*Prisons in Wales*
The prisons (HMP) and Young Offenders Institutions (YOI) in Wales are:

1. HMP Cardiff in Cardiff

2. HMP and YOI Parc in Bridgend, Mid Glamorgan

3. HMP/YOI Usk and Prescoed in Usk, Gwent.

4. HMP Swansea in Swansea.

There are three types of healthcare service provided in English and Welsh prisons:

**Type I** – Healthcare services provided only during normal hours (8 a.m.–5 p.m.).
**Type 2** – Healthcare services provided over an extended period (8 a.m.–9 p.m.).
**Type 3** – 24 Hour Healthcare service cover provided.

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[5] Source: http://www.hmprisonservice.gov.uk/life/dynpage.asp?Page=190

[6] Ministerial statement by Hilary Benn MP,( Home Office) Jacqui Smith MP (Department of Health Minister for Health and Social Services) and Jane Hutt MP (Minister for Health & Social Services, Welsh Assembly Government) http://www.doh.gov.uk/prisonhealth/index.htm

HMP Cardiff has a Certified Normal Accommodation (CNA) of 525. CNA is the uncrowded capacity of the prison. However, most prisons in England and Wales are overcrowded for most of the year and Cardiff prison has an Operational Capacity of 722. Operational Capacity is the maximum safe, overcrowded capacity of the prison. Cardiff prison has Type 3 health care centre status which provides 24 hour cover. The health care centre has three full-time medical officers (MOs) and fifteen beds for treating patients. The prison makes use of various NHS provided facilities including psychiatric services, substance abuse treatment, occupational therapy and a genito-urinary medicine clinic.

HMP and YOI Parc has a CNA of 800 and an Operational Capacity of 920. Healthcare is provided by Bro Morgannwg NHS Trust. The in-patient area is staffed by registered nurses and provides for both the physical and mental health needs of those patients requiring 24 hour nursing presence. Primary care at out-patients is delivered by medical staff and registered nurses and the healthcare centre has the opportunity to draw upon the broader expertise of the range of healthcare services within the Bro Morgannwg NHS Trust. There is an in-patient ward with 24 beds, all with integral sanitation. Dentist visits twice weekly, Optician weekly, Psychiatrist twice weekly, also Physiotherapist, Genito-Urinary, Chiropody and Dietetics available.

HMP/YOI Usk and Prescoed has a CNA of 128 and an Operational Capacity of 211. Usk and Prescoed has Type 1 healthcare centre status. There is a part-time medical officer who is on call 24 hours. NHS services are used as and when required.

HMP Swansea has a CNA of 219 and an Operational Capacity of 346. Swansea has Type 3 healthcare centre status and provides 24 hour care. There are 12 beds in the health care centre and the prison makes use of NHS facilities as and when needed[7].

Both the number of prisoners held and their health needs will vary throughout the year and the CNA can also change from year to year. The most recent prison statistics showed that, on 30 June 2001, Cardiff had 616 prisoners and a CNA of 404, Parc had 918 prisoners and a CNA of 844, Usk and Prescoed had 329 prisoners and a CNA of 251 and Swansea had 187 prisoners and a CNA of 141 (Home Office, 2003).

*The future of prison health care*

The 2002 spending review process set out a timetable to implement the recommendations of the 1999 report on *The Future Organisation of Prison Health Care (*Joint Prison Service and National Health Service Executive Working Group, 1999) to begin a phased transfer of responsibility for prisoners' health care to the NHS.

In England, the Secretary of State for Health has agreed that full transfer of funding responsibility for prison health to the NHS should be completed by April 2006. Three key phases for the transfer process have therefore been identified (Department of Health, *Transfer of Budget Responsibility Q&As Issue 2 (2 March 2003))*[8]:

<u>September 2002 – March 2003</u>: preparation for the departmental budget transfer from the Home Office to the Department of Health by 1 April 2003. This included a financial exercise to establish the final sum to be transferred on 1 April 2003 and will determine next year's budgetary allocations from DoH. HMPS and DoH undertook this work with Treasury and Trades Union involvement. It

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[7] Source http://www.hmprisonservice.gov.uk/prisons/

[8] http://www.doh.gov.uk/prisons.htm

included work to agree the scope of the resources that are being transferred. Prison Service Area Managers recently received information about health care allocations for 2003/04. This information will be copied to PCT Chief Executives via the Regional Development Teams. Major capital costs are excluded from the transfer and will remain with the Prison Service.

April 2003 – March 2006: service development and preparation for devolution of full commissioning responsibility to PCTs by 1 April 06. It is anticipated, for the first three years, that the majority of resourcing for prison health will be transferred back to the Prison Service which will continue to deliver or commission most services through individual prisons as it does now. The deployment of these resources will be closely monitored and adjustments made in the light of experience if that proves necessary. A Prison Health Development Network will also be established to develop a programme to support PCTs and prisons in the transfer process. This will involve the selection, in early 2003, of a number of volunteer prisons and PCTs to pilot the proposed changes locally, probably from April 2004. Learning from this exercise will be drawn out to inform wider work in preparation for full devolution of prison health resources to PCTs from April 2006. There are a number of detailed issues around the practical operation of the transfer and the longer-term operation of services at local level, which can only be resolved adequately through a period of piloting and testing.

April 2006 onwards: PCTs will assume responsibility for commissioning health care for prisons within their boundaries and will work in partnership with those prisons to secure appropriate health services for the relevant population. This development may require legislation.

In Wales, negotiations are continuing (at time of writing) between the relevant Welsh Assembly Ministers and the UK Government. Therefore, the research team recommends that no changes are made to the NHS resource allocation formula until these negotiations are completed.

## Homelessness

### *Homelessness and health*

The connection between housing - whether in terms of the conditions of housing or housing tenure - and health, has been known for many decades (Filakti and Fox, 1995; Wanamethee and Shaper, 1997). As homelessness became a more prominent feature of the social landscape through the 1980s and 1990s, a number of small-scale studies were conducted to explore the health status of homeless people and issues related to access to health care for this severely deprived group.

This area presents particular challenges for researchers (Shaw *et al*, 1999). Unlike the traditional housing tenure categories, homelessness is much more difficult to define and to enumerate. There is no easy, single definition of homelessness as the ‘homeless’ are not a homogeneous group (Everton, 1993; Balazs, 1993). Although there have been various attempts to enumerate the number of non-statutory homeless, there are no reliable figures at the national level (Bines, 1994). With rough sleepers, there is an even greater uncertainty as to their number. What we can be more certain of is that counts of rough sleepers will almost certainly underestimate the true numbers (Pleace, 1998). This should be taken into account when estimating the number of homeless people and their need for health care.

Studies have consistently found that homeless people have particularly poor health outcomes, such as respiratory disease, alcohol and drug dependence, mental health problems and suicide, accidents and violence (Bines, 1994; Hibbs *et al*, 1994; Hwang *et al*,1997; Victor, 1997). It is also the case that they suffer from a number of minor ailments - *eg* skin conditions such as scabies and problems with their feet – that particularly affect (and result from) their day-to-day living conditions (Bines, 1994). In terms of more serious/chronic diseases, studies have shown relatively high rates (compared to the housed population) of tuberculosis, HIV/AIDS, schizophrenia, diabetes and Hepatitis C.

In terms of mortality, there have been only a handful of studies which have considered the relative life chances of homeless people. A study of male rough sleepers in London (Shaw *et al*,1999) revealed that their average age at death to be 42 – a figure lower than that of 171 of the 174 countries listed by the United Nations for the same time period (1995). Average life expectancies were only lower in Malawi, Uganda and Sierra Leone, with life expectancies of 41, 40.5 and 34.7, respectively (UN, 1998). In the same study, residents of homelessness hostels were estimated to have a life expectancy of 63, similar to the average for 'all developing countries' (62.2); whereas bed and breakfast residents (many of whom are statutory or non-statutory homeless) had a life expectancy of 67 - more than seven years below the England and Wales national average and equivalent to life expectancy in Brazil (66.6), Kazahkstan (67.5) and the Phillipines (67.4). These figures show that homelessness in the UK has very real health outcomes.

*Homelessness and health care*

Homeless people have higher rates of morbidity and mortality yet report persistent problems in gaining access to health care (Stern *et al*, 1989; Williams and Allen, 1989; Lowry, 1991; Fisher and Collins, 1993; Shiner, 1995). Homeless people may be reluctant to use health services because they have chosen to opt out of many aspects of mainstream society. Also, they may anticipate that they will not be treated sympathetically by health care workers and the experiences of many homeless people support this presupposition. In addition, the chaotic lifestyles of many homeless people mean that they find it difficult to keep appointment times. Some studies have suggested that they are more likely to choose or prefer A&E departments. These varied factors combine and mean that homeless people often do not use primary care services according to their levels of need. Pleace and Quilgars (1996) point out that there are two ways to tackle this: existing services can be made more accessible and less intimidating for the homeless or, alternatively, specialist services can be set up.

*Homelessness, health and health care in Wales*

This section details the results from a survey of Big Issue vendors in Wales, conducted in September 2002 (Cookson and Shaw, 2002). The survey included all vendors (total 100) arriving at the five distribution Big Issue distribution centres in Wales (Cardiff, Newport, Swansea, Wrexham and Llandudno) during one week. While these data only cover a sample of a certain type of homeless person in Wales, the results are nonetheless informative of their health status and use of health care services.

The results showed that:

- The average age of vendors was 30.5 years. The youngest vendor was 17 and the oldest 57. The majority were aged between 20 and 34.
- The majority of vendors were men (83%).
- 52% were born in Wales. 37% were born elsewhere in the UK and 11% were from outside the UK.
- 10% of vendors speak Welsh with 8% of these born in Wales and the other 2% born in other parts of the UK.

Vendors were asked to indicate which of a number of health problems they had experienced in the last six months and whether they had received help. A high number reported dental problems, backache, headaches, respiratory problems, diarrhoea and vomiting.

**Table 4.2: Self-reported health: % of vendors who said they have had this problem in the last six months**

| Health Problem | Had problem |
|---|---|
| Dental problems | 52% |
| Depression | 47% |
| Backache | 45% |
| Stress | 45% |
| Headaches | 32% |
| Foot problems | 31% |
| Chest and breathing problems | 29% |
| Asthma | 23% |
| Diarrhoea and vomiting | 21% |
| Other mental health problems | 17% |
| Skin problems (e.g. eczema) | 16% |
| Other health problems | 16% |
| Suicide attempt | 14% |
| Eye problems | 11% |
| Muscular/skeleton problems | 6% |
| Epilepsy | 3% |
| Hepatitis C | 3% |
| Diabetes | 2% |
| HIV/AIDS | 2% |
| Schizophrenia | 2% |
| TB (Tuberculosis) | 1% |
| Sexually transmitted disease | 0% |

Note: vendors could answer 'yes' to more than one item

Other health problems listed by the vendors included cancer, bone cancer, stomach ulcers, high blood pressure, heart murmur and agoraphobia.

Rates of reported mental health problems were particularly high. 47% of vendors reported depression and 45% reported stress. 14% of vendors reported attempting suicide in the last six months. The proportion of vendors reporting suicidal thoughts in the past few weeks is also disturbingly high – 45% reported that they have contemplated taking their own life in the past few weeks.

75% of vendors were registered with a GP, compared to almost 100% of the non-homeless population in Wales. Only 34% of vendors reported being registered with a dentist, compared to 47% of all adults in Wales (Dental Practice Board). Vendors were asked which health services they have used in the last six months. The most commonly used health service was a GP at a surgery, although A&E care at a hospital has been used by 40% of the vendors and 39% have used drug and alcohol services.

**Table 4.3: Use of health services in the last 6 months**

| Service used | Per cent |
|---|---|
| GP at surgery | 52% |
| A&E | 40% |
| Drug/alcohol services | 39% |
| Dentist | 29% |
| Optician | 16% |
| Mental health/psychiatric | 8% |
| Outreach nurse | 8% |
| Health care at a hostel | 4% |
| Walk-in centre | 4% |
| NHS direct | 4% |
| Sexual Health | 4% |
| Other | 1% |

Note: vendors could answer ‘yes’ to more than one item

Contrary to what might be expected, being registered with a GP does not appear to lessen the use of A&E services. 52% of those registered with a GP have used A&E in the last year, compared to 27% of those not registered with a GP. This might suggest that vendors are not using A&E departments instead of attending a GP but in addition to consulting a GP, perhaps reflecting true health needs (such as the high levels of violence they face), rather than patterns of preference.

Only 8% have used an outreach nurse and only 4% hostel-based health care, indicating that these services are either not available or are not used. Almost one in four vendors have not used any of these health services in the past six months. NHS Walk-in centres have been open since January 2000 but are in England only. These centres provide treatment for minor injuries and illnesses seven days a week. Appointments are not necessary and patients are seen by an experienced NHS nurse. They may therefore suit the homeless population more than other primary care services. Only 4% of vendors report having used Walk-in centres in the last six months. Not surprisingly, the use of Walk-in centres is dependent upon area and availability. The few vendors who have used them presumably did so prior to being in Wales.

Vendors were asked to indicate if they thought any of a number of factors were affecting their health in a bad way. Not eating properly is seen to be as problematic as drug and alcohol use. Even though the survey was conducted when it was relatively mild, 17% say that the weather is affecting their health in a bad way – these were people in different types of accommodation, not just rough sleepers.

More vendors identify drugs rather than alcohol as a problem affecting their health. A substantial number of vendors think that basic things, such as not eating properly and not keeping clean, have a negative impact on their health. Those in secure housing do not think these factors have less impact on their health than those in less secure accommodation. Across all accommodation groups, at least one in four see poor eating as a problem.

Almost 14% of vendors thought that violence was having a detrimental effect on their health – split almost equally between men and women. Contrary to what might be expected, violence was not more likely to be identified as a problem by those who also identify their drug use as problematic.

**Table 4.4: Negative factors affecting health of Big Issue Vendors in Wales**

| Factors | Per cent reporting yes |
|---|---|
| Poor Eating | 37% |
| Drug use | 37% |
| Alcohol use | 28% |
| Poor housing | 24% |
| Weather | 17% |
| Keeping clean | 14% |
| Violence | 14% |
| Problems getting medical care | 8% |

Note: vendors could answer 'yes' to more than one item

These results indicate that there are high levels of health need amongst Big Issue vendors in Wales, both with respect to mental and physical health.

*The measurement and distribution of homelessness*

As discussed above, there is little scientific agreement on the definition of homelessness or on how it should be measured. The National Assembly for Wales produces annual statistics on homelessness as part of the *Welsh Housing Statistics.* Table 4.5 shows the distribution of homeless households that were found to be eligible for assistance in 2001 at LHB/Unitary authority level

**Table 4.5: Households found to be eligible for assistance in 2001, unintentionally homeless and in priority need**

| **Local Health Board** | **Number** |
|---|---|
| Isle of Anglesey | 110 |
| Gwynedd | 123 |
| Conwy | 153 |
| Denbighshire | 72 |
| Flintshire | 233 |
| Wrexham | 95 |
| Powys | 192 |
| Ceredigion | 124 |
| Pembrokeshire | 195 |
| Carmarthenshire | 332 |
| Swansea | 703 |
| Neath Port Talbot | 60 |
| Bridgend | 586 |
| The Vale of Glamorgan | 130 |
| Cardiff | 679 |
| Rhondda, Cynon, Taff | 467 |
| Merthyr Tydfil | 101 |
| Caerphilly | 303 |
| Blaenau Gwent | 72 |
| Torfaen | 344 |
| Monmouthshire | 63 |
| Newport | 44 |
| **Wales** | **5,181** |

Table 4.5 shows that, in Wales as a whole, 5,181 households were ‘accepted as homeless’ in 2001. However, more than twice that number (13,675) of homelessness cases were considered by Local Authorities but were turned down for assistance for a wide range of reasons. An even larger number of homelessness enquiries were received but not all of them proceeded to the formal application stage. There is a considerable body of academic research which shows that different Local Authorities may exercise their digression in interpreting the homelessness legislation in different ways, resulting in households in some authorities being given assistance whereas they might not be if they lived in another Authority (for example, see Cowan 1997; 1998a; 1998b). This makes the ‘official’ published homelessness statistics very hard to interpret for health resource allocation purposes.

A possible solution to the problem of interpreting current homelessness statistics has been proposed by Eurostat (the European Union Statistical Office) which set up a working party in 2002 to try to developed a statistical definition to be used in EU Member States. The current working definition is shown below (INSEE, 2003):

Part 1.

A homeless person is someone who does not have access to accommodation which they can reasonably occupy, whether this accommodation is legally their own property or whether the property is rented; provided by institutions; provided by employers; or occupied rent-free under some contractual or other arrangement.

Part 2.

In consequence they are obliged to sleep either:

(a) outdoors;
(b) in buildings which do not meet commonly agreed criteria for human habitation (eg. privacy; hygiene; space);
(c) in night-time emergency hostel accommodation provided by public sector or charitable organisations;
(d) in longer-stay hostels provided by public sector or charitable organisations (eg. non-emergency centres, refuges for battered women, deportation centres for asylum seekers and illegal immigrants);
(e) in Bed & Breakfast accommodation
(f) in other short-stay accommodation (duration less than 1 month);
(g) in the homes of friends or relatives;
(h) in registered squats;

Note: excludes persons living in the following sorts of accommodation:

- hospital wards; mental homes; old-age centres
- prisons; prison cells; borstals
- college halls of residence; boarding schools
- orphanages; foster homes
- military barracks; seamen’s missions
- ships at mooring;
- mobile homes (eg. circuses; Roma)

- au-pairs; domestic servants; live-in hotel staff
- tourists living in hotel rooms
- supported accommodation (low income)

This definition has been circulated to the relevant authorities in EU Member States and is currently being modified based upon the consultation responses. INSEE (the French Statistical Office) will process the replies received and prepare a synthesis report by end-June 2003. This report will also include an analysis of the sorts of information about housing which are available from National Statistical Institutes survey sources. The results will be used to draw conclusions about the feasibility of alternate methodologies to collect official statistics about homelessness.

This report will be discussed by the expert group at a meeting in October 2003 and modified if necessary. An enlarged meeting will then be organised by Eurostat in January 2004 to discuss the report, inviting various actors in the field. The conclusions from the enlarged meeting will be annexed to the report which will then be submitted to the Indicators Sub-Group of the Social Protection Committee of the European Union for discussion at a meeting during Spring 2004 (INSEE, 2003).

Given these developments, the research team recommends that further research will probably be required before an adjustment is made to the NHS resource allocation formula to include the health needs of the homeless.

*Drug and alcohol abuse among the homeless in Wales*

Studies in the past have found that rates of drug and alcohol abuse have been high amongst homeless people, although the extent to which these problems precede or result from homelessness is unclear. This study also collected some data on drug and alcohol use. Two in three vendors reported that they regularly drink alcohol with 20% saying they drank less than a can a day and 30% reported drinking more than three cans a day. 11% said they drank more than 10 cans a day. Beer (bitter, lager or stout) was by far the most popular drink – 26 out of the 48 vendors who answered the question said they preferred it. Five prefer cider, five spirits and five report ‘anything’.

One in four vendors said they regularly worry about their alcohol use and one in five said they would like to stop drinking as soon as possible. 36% said they want to stop drinking some time in the future. Those who report heavy drinking are more likely to be those who would like to stop.

**Table 4.5: Whether vendors would like to stop drinking**

| | Per cent |
|---|---|
| No, it doesn’t cause me any problems | 39% |
| Yes, at some point in the future | 36% |
| Yes, as soon as possible | 21% |
| No, I don’t think I could | 4% |
| Total | 100% |

Twenty vendors say they have tried to access alcohol services. Of these, nine have been successful and 11 were still waiting. The average wait was one and a half months, with a maximum of six months. These figures suggest that there is under-provision of alcohol services for this group.

Regarding drug use, 36% of vendors report using Class A drugs. 39% of vendors do not take drugs and 15% were using only Class B drugs and 9% were using drugs recreationally.

Looking in more detail, 32 vendors reported taking heroin regularly; two vendors taking cocaine regularly and 12 vendors taking crack regularly. Some vendors listed prescription drugs in this section, which we presume means they are obtaining them illegally. Six were taking prescription drugs regularly, including Valium, Diazepam, Temazepam and Methadone.

**Table 4.6: Whether vendors would like to stop taking drugs**

| | Number of vendors |
|---|---|
| Yes | 43 |
| No, it doesn't cause me any problems | 14 |
| No, I don't think I could | 4 |

Notably, 71% of the drug users wanted to stop using drugs. Twenty of the 32 heroin users wanted to stop using the drug as soon as possible and seven wanted to stop at some point in the future. Only one said ‘no it doesn’t cause me any problems’ and two said ‘no, I don’t think I could’. So, the vast majority of regular heroin users wanted to stop.

Of all the drug users who said they would like to stop using drugs as soon as possible, four out of five had already tried to access drugs services but only one in four of them had tried to get a place in rehab. This may show that vendors don’t think they will get a place in rehab or get it quickly enough, so they do not bother trying to access it. Overall, 41 vendors had tried to access drugs services, 21 had been successful and 20 were still waiting. Those who got a place had to wait for an average of six months. One vendor had to wait for two years. 18 vendors had tried to get a place in rehab – eight had been successful and 10 were still waiting. Those who were given places had to wait on average for four months. One vendor had to wait for one year. (People can only apply for rehab once they have made contact with the drug services referred to above.) These figures all indicate considerable unmet need in terms of drugs services.

### Drug and Alcohol Abuse

The figures in Table 4.7 refer to the per cent of people in Wales who are estimated to drink more than the recommended number of units of alcohol each week (14 units for women and 21 units for men). More than a moderate alcohol intake is related, in the long term, to cardiovascular mortality and liver disease. In the shorter term, alcohol intake can affect health through violence and accidents.

**Table 4.7: Percent drinking above recommended limits each week**

| | Estimate (%) |
|---|---|
| Blaenau Gwent | 25.9 |
| Rhondda Cynon Taff | 23.8 |
| Caerphilly | 21.7 |
| Merthyr Tydfil | 21.5 |
| Bridgend | 21.4 |
| Cardiff | 20.7 |
| Denbighshire | 20.3 |
| Vale Of Glamorgan | 20 |
| Neath Port Talbot | 19.8 |
| Torfaen | 19.7 |
| Swansea | 19.4 |
| Wrexham | 19.1 |
| Flintshire | 18.1 |
| Newport | 18.1 |
| Gwynedd | 16.8 |
| Conwy | 16.4 |
| Powys | 15.9 |
| Pembrokeshire | 15.8 |
| Ceredigion | 15.3 |
| Ynys Mon | 15.3 |
| Monmouthshire | 15 |
| Carmarthenshire | 14.5 |
| **WALES** | **19.2** |

Source: 1990, 1993 and 1996 Health in Wales Surveys

Figures such as this are likely to suffer from under-reporting and, additionally, do not adequately measure 'problem' drinking because the health implications of drinking 10 units of alcohol are very different if those units are spread over a week compared to if they are drunk in one session. 'Binge drinking' is defined as eight or more units of alcohol for men and six or more for women, in one session.

**The dangers of alcohol**

- 65% of suicide attempts are linked to excessive drinking
- One in 6 people attending accident and emergency departments for treatment have alcohol-related injuries or problems.
- Between 60% and 70% of men who assault their partners do so under the influence of alcohol.
- More than one in 5 men and 1 in 6 women admit to having unsafe sex after drinking too much.

Source: Alcohol Concern 2000

Binge drinking is associated with alcohol poisoning, accidents (*eg* falls, RTA, drowning) and violence. It is also related to unplanned (and unwanted) sexual activity and unplanned pregnancy.

Binge drinking has been increasing in recent years, with women catching up with men in terms of drinking culture. As more women work, more of them also drink after work. People are starting to drink at a younger age and there are fewer abstainers than there used to be.

A study of binge drinking in Wales found that 28% of men and 8% of women reported binge drinking at least once a week. Moreoever, binge drinking is not confined exclusively to excessive drinkers. Fourteen percent of Welsh men and 5% of Welsh women who drank within the recommended limits also report binge drinking at least once a week (Bennett *et al*, 1991). A more recent study based on a Welsh campus-based university found that 46% of the sample had engaged in binge drinking in the previous week (Norman *et al*, 1998).

Figures on the extent of drug and alcohol abuse amongst the Welsh population indicate that, in 1991, 1,954 people started using of drugs services in Wales, compared to 1,204 in 1993 (DoH, 2001). Approximately 50% of these people were heroine users. This will, of course, reflect provision rather than need. A study by Bloor and colleagues in 1994 estimated there to be 8,384 injecting drug use and serious drug misusers in Wales, which gives a rate of 2.9 persons per 1,000 or 5.3 per 1,000 based on those aged 15-55 years. The estimated number of serious male drug users was 7,022 and the estimated number of serious female drug users was 1,300. It was also estimated that 56% of the serious drug using population in Wales was under 25 years of age giving a prevalence of 12.9 per 1,000. The two areas with highest estimated prevalence rates were South Glamorgan and Clwyd. The South Glamorgan area had an estimated 1,058 injecting drug users (4.6 per 1,000 of 15-55 year olds) and Clwyd had 936 injecting drug users (4.2 per 1,000 of 15-55 year olds).

Drug and alcohol abuse may present problems in themselves. In addition, studies have also shown that, compared with the general population, those with alcohol or drug addiction are more likely to suffer from other forms of psychiatric morbidity as well. The rates were 30% for the alcohol-dependent, 45% for the drug-dependent and 22% for the non-dependent (Farrell *et al*, 2001). In addition, Hepatitis C is significantly higher among injecting drug users.
The TRF 2 accounts for 1999-2000 in Wales apportion £238,455 for the day patient expenditure on alcoholism and £893,874 for day patient expenditure on drug abuse. The current RAR formula could be adjusted using the data in Table 4.7 to allocate the expenditure on alcoholism to LHB level. Additional work could also be undertaken to identify the in-patient cost of treatment for health conditions associated with alcoholism, for example, alcoholic cirrhosis. There are currently no reliable data on the distribution of drug addiction at LHB level.

# Chapter 5: The Optimal Rate of Updating the NHS Wales Resource Allocation Formula

Neither the academic literature on resource allocation formulae nor the experience of their implementation across the world provides a definitive guide as to the optimal time between formula updates. The decision to distribute public funds by a formula is a conscious political choice and the decision as to when to update that formula is equally so. However, there are several desirable characteristics in the operation of a resource allocation formula that can be adduced to help inform that political choice. These are set out in Section A, while Section B provides a discussion of the various trade-offs between these different characteristics in practice.

## Section A: Desirable Characteristics in the Operation of the Formula

*Social justice*
The NHS Wales resource allocation formula is designed to allocate financial resources on the basis of accurately measured need. The longer the period between formula updates, the greater the likelihood that the financial distribution produced by the formula no longer accurately reflects the distribution of need across Wales. In order to promote social justice, this possible divergence should be minimized and this implies updating the formula in real time as new data becomes available.

*Stability*
The allocation of funds should be made in a predictable manner over time. The formula allocations should be stable over some reasonable period in order to promote revenue predictability and overall budget certainty for Local Health Boards (LHBs). This will allow LHBs to engage in forward resource planning in order to ensure that all financial allocations are efficiently spent in the budget period in which they were made. One of the major criticisms that have been made of a range of area-based resource allocation schemes in the past is that short term and/or a lack of funding stability has resulted in inefficient and ineffective long term planning (Robson *et al*, 1994).

*Avoidance of large and sudden changes*
In order to promote stability, during the introduction of the updated formula, the transition system should avoid sudden large changes in funding for LHBs. Large sudden changes in cash resources are difficult to match with changes in 'real' resources and funds remain either unspent or skewed in favour of those areas that can absorb cash resources more readily.

*Incentive compatibility*
The incentives created by the rate at which the formula is updated must be compatible with the objectives of health policy in Wales as a whole. For example, neither the formula nor the rate at which it is updated should induce inefficient expenditure choices. Further, there should be an incentive for expenditure to be in line with the basis on which allocations were 'earned' in the formula, *ie* to tackle those aspects of health need in the formula that determined a particular LHBs financial allocation.

*Simplicity and transparency*
The updating of the formula should be, to the extent possible, simple and transparent. The process for updating the formula should be understandable to all stakeholders and not be subject to political manipulation in any of its aspects. Any updating process should be designed to minimise the opportunities that LHBs or local practices have for manipulating the allocation process. Within

economics, a resource allocation procedure that cannot be manipulated by its beneficiaries misrepresenting their preferences (or personal situations) in order to receive more than their needs-based share of available resources is often referred to as 'strategy-proof'. The more regularly the formula is updated the greater is the incentives for LHBs to invest in learning how to manipulate the updating of the formula in favour of their interests.

*Transaction costs*
There are transaction costs involved in updating the formula. These are the costs of calculating, negotiating, agreeing and implementing an updated formula. These are likely to be considerable for the NHS Wales formula because of the large number of variables involved. The more frequently the formula is updated, the greater these are likely to be; though it may be that the marginal cost of updating, whilst remaining positive, falls over time.

*Democracy*
The NHS Wales resource allocation formula will distribute public money. The extent to which political control of that distribution is desirable for democratic reasons will also affect how often the formula should be updated. There is an argument that previous government's views on having a formula and what variables should be included should not bind future governments. The extent to which long periods between updating the formula constrains the choice set of the incumbent government in allocating health funds is undemocratic. This is likely to put an upper limit on the time between formula updates.

### Section B: The Different Trade-offs

An updated formula implies redistribution between LHBs. In order to avoid disruption to existing health services within Wales, it has been agreed that the movement to new share allocations implied by an updated formula will be achieved using year-on-year cash increases, *ie* by redistributing financial resources on the basis of differential growth by awarding some LHBs a smaller (or zero) rate of growth compared to others. The intention is that the redistribution of resources would be achieved by a general levelling up of allocations, whereby no LHB will face a cash reduction in its allocation though, of course, their share of total financial resources may decline.

Within this constraint, the shift to the new shares implied by an updated formula should be reached as soon as practicable. In order to judge how long that period should be, several trade-offs need to be considered:

*Social justice and revenue stability*
It is one of the desirable characteristics of the formula that distributions reflect need and, therefore, the formula should be updated as soon as new data becomes available. However, there are likely to be considerable transaction costs and revenue instability associated with changing the formula. Where the trade-off between these competing desirable characteristics is made will depend on the magnitude of the redistribution implied by updating the formula. The procedure for updating the formula should not have the effect of producing a redistribution between LHBs that is small relative to the associated transaction costs and costs of revenue instability. However, if updating the formula would imply large redistributions, then these should be implemented as quickly as possible for the sake of justice, given the safeguard noted above that adjustments to share allocations will be made through overall revenue growth. It may be worth defining a trigger point in formula adjustment: a point at which the divergence between the distributions of the current formula and those implied using the most recent data is sufficiently large that the updated formula should be implemented immediately.

*Political negotiation*

The next trade-off concerns whether the period of updating should be the subject of political negotiation. The problem with allowing this is that the discussions will not take place under a 'veil of ignorance'. Rather, each LHB will adapt to the formula and which particular trends in which data positively or adversely affect their share. The availability of these data will inform their view about when the formula should be updated. On the other hand, if the updating period is fixed to avoid political negotiation, the formula loses some flexibility in its implementation and may imply distributions over some periods that do not accurately reflect need.

*Rate of updating*

If the rate at which the formula is updated is too great, this may create these perverse incentives, as LHBs are forced to find those areas where sudden cash increases can be spent quickly or alternatively avoid building formula increases into baseline funding because of uncertainty surrounding the effects of future formula updates. In this way, financial allocations may be directed into those areas that have the greatest absorption capacity or areas from which they can be most easily withdrawn rather than where they might be needed most, in particular, those areas that might have 'earned' the LHB its share, in terms of measured need, in the first place.

*Fairness*

A resource allocation formula uses a version of fairness commonly referred to as 'horizontal equity'. Under this approach, a fair allocation is one that gives each LHB an equal share for equal need; in other words, the ratio of financial allocation to measured need should be the same for each LHB. Under this version of fairness, the fair way of updating the formula is to ensure that all legitimate variations in need are measured when each LHB budget was set. This would imply that the formula was updated each time the budget was set.

However, the horizontal equity version of fairness does not capture all the features relevant to resource allocation. Sugden (1992, p319) offers this general view of fairness: *"Fairness is associated with the ideas of equal treatment and of absence of bias. It tends to be associated with procedures (tossing a coin, a trial, a debate) rather than with outcomes."*

In these terms, the fairness of the rate of updating is not strictly related to the outcome in terms of measured need and financial distribution, *ie* the allocations implied by the formula does not provide fairness *per se*, rather fairness relates to the process by which the formula is updated. Unfortunately, the literature on fair division does not provide a practical guide on what might count as a fair procedure. Thus, the extent to which this version of fairness might be operationalised is doubtful. Nonetheless, viewing the problem of rate of formula updating in terms of procedural fairness allows the insight that the rate of formula updating which commands a consensus among the stakeholders of the budget allocation process is likely to be the most fair. The updating procedure should be agreed at the formula's implementation stage, *ie* in advance of any new data changing shares. This agreement should, however, contain the flexibility for changes in formula updating to be agreed. The flexibility to change the rate of updating should be granted along with clear conditions on when, why and how the rate of updating might be adjusted.

## Conclusions

There appears to be little scientific research on the optimum frequency of updating health resource allocation formula. The most ‘socially just’ formulas are those that are updated frequently, however, LHBs need some stability in funding regime in order to plan efficiently and effectively.

Given these problems, pragmatic criteria may be the best way to currently decide on the frequency of updating. Since the direct resource allocation method is based in part on the results from the WHS, it would be sensible to update the formula every three to five years as new survey results become available. Similarly, other non-WHS based parts of the resource allocation formula are often dependent on data that has been aggregated over a number of years in order to achieve sufficiently large sample sizes to ensure reliability. This practice would also indicate that a three to five year updating period would most likely be optimal. Similar, pragmatic considerations would also lead to the formula being updated when decennial Census results become available (at least in part).

Updates of this frequency might result in large changes in funding between some Health Boards on occasion, however, if this problem occurs, then in order to minimise the detrimental effects of sudden large funding changes the results of a new updated allocation could be phased in over several years in LHBs where they exceeded a critical threshold level (for example, twice the rate of inflation).

# Chapter 6: Conclusions and Recommendations

A number of conclusions and recommendations have been discussed in the previous chapters, which are summarised below.

## Rural Issues

*Age*
Rural areas have an older age profile than urban areas so a larger proportion of their residents will require more expensive hospital treatments (*eg* because of longer lengths of stay) and more time-consuming GP consultations, especially as visits to patients' homes or nursing homes are age-related. Resource allocation estimates based on treatment costs and consultation frequencies by condition (from the Welsh Health Survey (WHS) may not fully reflect these age-related influences. As the WHS samples by age, health condition and LHB are too small to be reliable, the age adjustment should be accomplished by the same method used previously in producing the NHS Resource Allocation Review – Consultation (October 2001). However, the previously used DRG costs by age reflect only average lengths of stay, so the possibility of obtaining duration related costs by age needs to be investigated.

*Temporary residents*
Tourists, seasonal workers and other temporary visitors are likely to be more numerous in more rural (especially coastal) areas and in Cardiff. Consultations by temporary residents should be extracted from the General Practice Morbidity Database (GPMD) and these should be added to the permanent resident consultations already used in the GMS estimates (Gordon *et al*, 2001).

*Scale economies in hospital provision and Health Authority hospital expenditures*
To produce a Welsh version of the Scottish rurality analyses may be infeasible because of the poorer availability and quality of cost data in Wales and too few Health Authorities for statistical analysis. If possible, a comparison of samples of costs of purchasing hospital care by episode type in urban and rural Health Authorities should be undertaken.

*The community nursing cost model* developed by the National Assembly should be subject to further sensitivity testing. A general validation of the organisational and cost features of this model would be a major exercise. In Scotland, only a limited number of field visits were made to obtain information which could inform the assumptions made.

*General Medical Services (GMS) and the new GP contract*
As the new GP contract is not being negotiated separately for Wales but at the UK-level, the new GMS formula being developed by the Department of Health (DoH) and the University of York could be imposed on Wales. It would thus be sensible and efficient **not** to pursue the development of a Welsh version of the Scottish GMS formula for rural costs, as the proposed rurality formula to underpin the new GP contract is based on superior Inland Revenue data. Rather, given that rurality and remoteness influences on service delivery costs are likely to be more prominent in Wales and Scotland, the National Assembly (in conjunction with the Scottish Executive?) should request that the DoH/York formula development team investigate whether or not there are significant inter-country differences in their effects. It has been suggested that there are sufficient Welsh data available in the Inland Revenue data set for this to be feasible.

## Urban Issues

### *HIV/Aids and Infectious diseases*

The NHS resource allocation formula proposed by the independent research team (Gordon *et al*, 2001) only included food poisoning as a measure of health need for infectious diseases. Food poisoning cases represent approximately 75% of measured infectious diseases in Wales. However, it is feasible to modify the formula to include HIV/AIDS and other infectious diseases such as TB, Viral hepatitis, Mumps, etc. The main problem with this modification is that there are thankfully only a few hundred cases of these diseases each year in Wales, which means that the prevalence at LHB area can fluctuate considerably from one year to the next.

### *Ethnicity and Literacy*

An 'ethnic' cost adjustment to the NHS resource allocation formula should have two main components:

- a cost adjustment for translation into the Welsh language
- a cost adjustment for functional illiteracy in English

This second cost adjustment for functional illiteracy is designed to capture the additional costs of explaining treatment options and so on to patients who have difficulty in understanding and reading English, irrespective of their ethnic group or identity.

It should be possible - when the 2001 Census statistical tables are released (during summer 2003) - to produce a synthetic estimate of the extent of functional illiteracy at LHB area. The 2001 Census also measured knowledge of the Welsh language (see Table 3.3). Therefore, a cost adjustment for IAT and other associated costs to the NHS resource allocation formula is feasible if these costs can be estimated from the NHS accounts data that are available. These costs are likely to be higher in Wales than in any other part of the UK, however, they are still relatively small compared with the overall NHS budget. Therefore, a pragmatic decision with regard to the materiality of this cost adjustment needs to made, *eg* does the size of the cost adjustment to the resource allocation formula justify the cost and expense of the research work that would be required?

### *Haemophilia*

Haemophilia is fortunately a rare disease which affects few people in Wales but can be very expensive to treat. For example, the cost of immune intolerance treatment can be £1 million per patient. The research team believes that the cost of Haemophilia treatment, like other high cost, low prevalence health needs should be met from top-sliced funding and should therefore not form part of the resource allocation formula at LHB level.

### *Asylum Seekers/Refugees*

A specific adjustment to the NHS resource allocation formula could be made which would better reflect the health needs of asylum seekers. Some Health Authorities in England have recently made specific resource allocations to meet the cost of the additional health needs of asylum seekers. For example, Wakefield has an Local Development Scheme that adds £40 to the GP capitation fee for each asylum seeker. A simple way of adjusting the Welsh formula would be to assume that two-thirds of asylum seekers will have significant mental health needs and adjust the mental health allocations accordingly.

*Prison Health Services*

Negotiations are currently on going between the relevant Welsh Assembly Ministers and the UK Government on the transfer of funding and responsibility for prisoners health to the NHS. Therefore, the research team recommends that no changes are made to the NHS resource allocation formula until these negotiations are completed.

*Homelessness*

Research studies have consistently found that homeless people have particularly poor health outcomes, such as respiratory disease, alcohol and drug dependence, mental health problems and suicide, accidents and violence (Bines, 1994; Hibbs *et al*, 1994; Hwang *et al*,1997; Victor, 1997). It is also the case that they suffer from a number of minor ailments - *eg* skin conditions such as scabies and problems with their feet – that particularly affect (and result from) their day-to-day living conditions (Bines, 1994). In terms of more serious/chronic diseases, studies have shown relatively high rates (compared to the housed population) of tuberculosis, HIV/AIDS, schizophrenia, diabetes and Hepatitis C.

In terms of mortality, a study of male rough sleepers in London (Shaw *et al*,1999) revealed that their average age at death to be 42 – a figure lower than that of 171 of the 174 countries listed by the United Nations for the same time period (1995). The Homeless population clearly has significantly greater health needs than the resident population.

There are currently statistical problems in obtaining meaningful measures of the extent of homelessness in Wales. Therefore, the research team recommends that further research should be undertaken before an adjustment is made to the NHS resource allocation formula to include the health needs of the homeless.

*Drug and Alcohol Abuse*

The current RAR formula could be adjusted to allocate the expenditure on alcoholism to LHB level using HIW survey data. Additional work could also be undertaken to identify the in-patient cost of treatment for health conditions associated with alcoholism, for example, alcoholic cirrhosis. There are currently no reliable data on the distribution of drug addiction at LHB level.

*Formula Updating*

Since the direct resource allocation method is based in part on the results from the WHS, it would be sensible to update the formula every three to five years as new survey results become available. Similarly, other non-WHS based parts of the resource allocation formula are often dependent on data that has been aggregated over a number of years in order to achieve sufficiently large sample sizes to ensure reliability. This practice would also indicate that a three to five year updating period would most likely be optimal. Similar, pragmatic considerations would also lead to the formula being updated when decennial Census results become available.

Updates of this frequency might result in large changes in funding between some Health Boards on occasion, however, if this problem occurs, then in order to minimise the detrimental effects of sudden large funding changes the results of a new updated allocation could be phased in over several years in LHBs where they exceeded a critical threshold level (for example, twice the rate of inflation).

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# Appendix I: Ethnicity and Health

## Notions of Ethnicity and Identity

*What is 'ethnicity'?*
Ethnicity is a socially constructed concept which is inherently variable and fluid (Nazroo, 1998). It is an amalgamation of notions of nationality, family background, religion, cultural practices and language (Modood, 1997, p290). Ethnicity is characterised by the belonging to one group and therefore the exclusion from others, particularly the majority population. It can refer to *"the external creation of categories which people impose on others, and with which the people who are so categorised do not necessarily identify"* (Smaje, 1995, p16).

The term 'ethnicity' should be distinguished from that of 'race', which is originally a biological classification of individuals into arbitrarily constructed groups. According to Bhopal (2001, p23) research into ethnicity is undergoing a paradigm change, with the abandonment of the bio-genetic paradigm of race in favour of a socially constructed 'ethnicity'. In this discussion, the term 'race' will be avoided due to its predominantly biologically reductionist connotations (see Appendix II for a discussion of these issues). In population surveys, information on ethnicity is collected by combining questions on skin colour, country of birth and family origins (Senior and Bhopal, 1994). In general, little to no information is collected on cultural distinctions or self-perceived identity. As a shifting and ambiguous notion, it is therefore important to be aware of the complexities underlying the use of the term 'ethnicity' and what it is deemed to represent at any one point in time. It remains essential that *"ethnicity cannot be considered as fixed because culture is not an autonomous and static feature in an individual's life, it has a dynamic relationship to both the historical and contemporary experiences of social groups and is related to the living conditions of individuals"* (Nazroo, 1997a, p8).

In conducting a review of the literature on ethnicity and health, the terms used here will be as specific as possible, attempting to avoid the use of 'catch-all' titles such as 'Black', 'White' or 'South Asian'. As specified by Donovan (1984, p663), the term 'immigrant' will be used to *"refer only to people who have recently entered this country having been born outside the UK"*. Health differences between the immigrant population and the majority have been well documented (Marmot *et al*, 1984; Balarajan and Raleigh, 1993) and are an important phenomenon tied to the differences between ethnic minorities and the majority. Despite the crude classifications used to define the ethnic minority groups in the UK, they nevertheless allow us to determine whether inequalities in health exist between ethnic minority groups and the majority population (Nazroo, 1997b, p155).

*Ethnicity and identity*
Ethnicity is a complex and changing social phenomenon which involves imposed categories as well as self-assigned identity. Ethnic identities are changing in a socio-political world where they can make an important statement about diversity and acceptance. Ethnicity has moved *"from that which might be unconscious and taken for granted, because implicit in distinctive cultural practices, to conscious and public projections of identity and the explicit creation and assertion of politicised ethnicities"* (Modood, 1997, p337).

In studies of ethnicity and health, sparse reference is made to white minority groups. In recent years, Welsh national identity has been increasingly affirmed through cultural practices and, particularly, the Welsh language. The movement to attribute a regional identity as a means of providing a sense of inclusion and belonging to a socially distinctive group has been active in Britain through

Devolution and the creation of regional assemblies. Developments within the EU to increase the status of minority languages has increased the validity of ethnic identities such as in Wales where a substantial proportion of the population is bilingual. Through their ancient language, the Welsh have re-articulated their unique ethnic identity. Indeed, outsiders who learn the Welsh language can become *"placed within the tight-knit web of relations which characterise Welsh-speaking Wales"* (Bowie, 1993, p171).

As well as through language, diversity within ethnic identities is expressed through preferences relating to religion, marriage, choice of schools, and the wearing of clothes. Modood (1997, p305) shows that minority groups would describe themselves very differently according to 12 personal attributes including nationality, skin colour, age or religion. For example, while over half of Caribbeans would mention skin colour, a third or fewer Pakistani individuals would do so (*ibid*, p293). Furthermore, the duality between belonging to an ethnic minority group but also being a British national provides the potential for multiple and contradicting identities. Only with these considerations in mind, can research into the aetiology and frequency of disease within ethnic groups become meaningful.

## The Health of Ethnic Minorities and Immigrant Groups

Many studies of the British population have collected data with the aim of studying the distribution of various social factors in minority or migrant groups (Census 1991 and 2001, General Household Survey, Fourth National Survey of Ethnic Minorities, Health Survey for England, etc).

### *General health*

James Nazroo's (1997a; 2001) comprehensive works on ethnicity and health are based on the *Fourth National Survey of Ethnic Minorities* conducted as a cross sectional study (Modood and Berthoud, 1997). He shows that self-assessed health amongst ethnic minority groups is poorer than the majority population. In particular, Pakistani and Bangladeshi respondents were 50% more likely than the white majority to report their health as fair, poor or very poor (Nazroo, 2001, p66). All ethnic minority groups showed a gender difference with about 40% of women in Caribbean and Pakistani or Bangladeshi groups describing their health as less than good. A cross-sectional survey of the health of ethnic minorities conducted as part of the 1999 Health Survey for England found that Chinese respondents were significantly less likely to report long-standing illness than the majority population. It also showed that Pakistani and Bangladeshi groups were the most likely to report long-standing illness (Bajekal, 2001). Clear differences between the self-reported health of the various ethnic groups are obvious, leading to the conclusion that *"members of the Pakistani and Bangladeshi group had considerably worse health than white people"* (Nazroo, 2001, p73).

### *Morbidity*

Coronary heart disease is a major cause of ill health in Britain. In a study of country of birth and mortality, Balarajan and Raleigh (1993) evaluated the health of migrants in England and Wales. They present their data as standard mortality ratios and divide it into 'New Commonwealth' categories. Their results show that migrants from the 'Indian subcontinent' had a considerably higher mortality rate from coronary heart disease than the majority population. They also remark that the risk of mortality from coronary heart disease was *"greatest among the young, with a 2-3 fold excess at ages 20-39 years"*. In their classic survey of immigrant mortality, Marmot and colleagues (1984, p69) also showed that minorities from the 'Indian subcontinent' had higher rates of heart disease. Nazroo (1997a, p48) shows the relative risk of being diagnosed with coronary heart disease or severe chest pain for ethnic groups compared to the majority population. In an age and gender standardised analysis, Pakistanis and Bangladeshis had an 80% greater rate of disease than the white majority. These findings suggest that the higher rates of coronary heart disease associated with South Asians found in many studies can be especially attributed to Pakistani and Bangladeshi minorities. *The 1999 Health Survey for England* found that the variation between rates of heart disease between ethnic groups can be attributed to their different age profiles. This study showed that *"the highest prevalence of* [Ischaemic heart disease or stroke] *among men's age groups was found among Indian men aged 55 and over"* (Primatesta and Brookes, 2001).

Hypertension amongst ethnic minority groups was, on the whole, lower than for the majority population, except for Caribbean respondents who showed an age standardised relative risk of 1.79 for women, and 1.47 for both men and women (Nazroo, 2001, p78). Similar results are shown for individuals born in the 'Caribbean Commonwealth' with mortality from hypertensive diseases being four times greater for men and seven times greater for women than the white majority (Balarajan and Raleigh, 1993, p18). *The Health of Minority Ethnic Groups* found that Caribbean men and women were most likely to receive treatment for high blood pressure (Erens *et al*, 2001).

Diabetes is a principle cause of handicap throughout the UK. Findings from the *1999 Health Survey for England* show that, with the exception of Irish and Chinese groups, all other ethnic minorities had higher rates of diabetes. Pakistani and Bangladeshi groups had five times the rate of the white majority (Erens *et al*, 2001). These statistics are supported by Nazroo (2001, p79), who shows that *"those in the Pakistani and Bangladeshi group had much higher rates than those in any other group, over five times the white rate"*. Compared with national levels, 'Asians' and 'African-Caribbeans' have a high prevalence of non-insulin resistant diabetes, which is often implicated in eventual renal failure (Raleigh, 1997).

Symptoms of respiratory illness were present in 18% of men and women in ethnic minorities, with higher rates for the Caribbean group (Nazroo, 2001, p80). Overall, minority ethnic groups show the same or lower mortality from respiratory symptoms. Irish-born individuals, however, show strikingly high rates of mortality from chronic obstructive disease and other diseases linked to the respiratory system such as lung cancer, pneumonia and tuberculosis (Marmot *et al*, 1984) which is attributed to higher rates of smoking. Donovan (1984) argues that the rate of tuberculosis found in minority groups is often much higher than in their respective indigenous populations and is maintained through the disadvantaged inner-city environments in which many find themselves.

### *Health services*

Studies of the use of the health services by ethnic minorities have shown a greater overall usage of GP services by minority groups compared to the majority, however, there are important variations between ethnic groups. *The 1999 Health Survey for England* collected extensive information on GP consultations by ethnic minority group overall as well as consultations for depression and anxiety (Erens *et al*, 2001). They found that Chinese respondents tended to use the primary health services less often, whereas Indian, Bangladeshi and Pakistani respondents used them more so than the general population (Bajekal, 2001). The study also noted that the age gradient in minority groups was steeper relative to the general population, with a sharp increase in GP consultations among older people from ethnic minorities. Rates of consultation for depression or anxiety were higher among women in ethnic minorities as is seen in the general population. In comparison with the majority population, *"standardised ratios for consulting a GP for psychological stress were significantly higher for Irish men (1.51) and significantly lower for Chinese men (0.59) and women (0.41) and Bangladeshi women (0.64)"* (Bajekal, 2001). Nazroo (1997a, p127) found similar trends in the higher proportion of GP consultations for ethnic minorities but noted that the quality of their primary health care was not as good as the majority population based on various dimensions. These included *"the ease of obtaining access to a GP in addition to the quality of communication"*. Similar findings amongst migrant groups were discovered by Balarajan and Raleigh (1993, p51), though they could not determine whether such patterns were due to differences in the distribution of illness, varying cultural perceptions of ill health or a medley of such factors.

Overall, Nazroo (1997a, p116) found that ethnic minorities were less likely to be admitted to in-patient services, excluding childbirth, than the general population. *The 1999 Health Survey for England* found that, after age standardisation, Chinese men and women were significantly less likely and Pakistani men more likely to have been admitted as in-patients than the majority population. Age standardised attendance of out-patient services were no different for ethnic minorities or the majority population. Levels of attendance for young people in all minority groups were significantly lower, especially for Chinese and Bangladeshi respondents (Bajekal, 2001). Outpatient attendance was as high or higher for the oldest age group of all ethnic minorities. Nazroo (1997a, p126) suggests the possibility that *"minority respondents may not receive sufficient hospital-based care"*.

Both *The 1999 Health Survey for England* (Erens *et al*, 2001) and the *Fourth National Survey of Ethnic Minorities* (Modood and Berthoud, 1997) found that usage of dental health services was poor for all ethnic minority groups, with a particular concern for Bangladeshi respondents, where Nazroo (1997a, p128) noted that only one in four had visited the dentist in the last 12 months.

*Health behaviours*

The prevalence of smoking in ethnic minorities was assessed by *The 1999 Health Survey for England*. It found that Bangladeshi and Irish men were more likely to smoke than the general population, whereas most other ethnic minority groups were less likely to smoke. When observing the age distribution of smoking between these two minority groups, the highest proportion of Irish smokers was in the youngest age group, in contrast with the highest proportion of Bangladeshi smokers in the oldest age group (Boreham, 2001). Irish women were the only group more likely to smoke than women in the general population, with most other women in ethnic groups being less likely to do so. Cigarette smoking was extremely low among Bangladeshi and Chinese women, in particular. The highest prevalence of tobacco chewing within South Asian minorities was found for Bangladeshi men and women. Nazroo (2001, p81) noted that *"in comparison with the white group, the relative risk scores for all of the ethnic minority groups showed that they were significantly less likely to have ever been regular smokers"*.

Physical activity is an important determinant of good health. *The 1999 Health Survey for England* assessed physical activity based on the recommended 30 minutes of activity five times per week. The proportion meeting the standard was higher among Black Caribbean men and lower among Pakistani, Bangladeshi and Chinese men. Compared with the 21% of women in the general population who met the guideline, 28% of Black Caribbean and 26% of Irish women did so. The proportions meeting the guideline were lower than the general population for Chinese, Indian, Pakistani and Bangladeshi women (Erens *et al*, 2001).

With the exception of the Irish, all other ethnic groups consumed less alcohol than the majority population (Erens and Laiho, 2001). Nazroo (1997a, p29) reported *"one in three Caribbean and about one in five Indians, African Asians and Chinese reported regularly drinking alcohol"*.

## Society, Culture and Health

Differences persist in morbidity, access to health care and health behaviours between ethnic minority groups and the general population, as well as between minority groups themselves. The reasons for such variations are multiple. An increased genetic propensity to certain diseases, such as diabetes and coronary heart disease, has been the hypothesis put forward for the high rates of these diseases among some ethnic minority groups. This is based on the evolutionary history of populations and the intricate links between environment, culture and biological adaptation (McMichael, 2001). However, it is extremely difficult to distinguish between the biological and environmental facets of disease aetiology.

An adverse foetal environment of undernutrition coupled with relative affluence in later life has been associated with adult chronic diseases (Barker, 1997). Such an association could have important implications for the health of ethnic minorities recently arrived from poorer backgrounds. It is essential to extend this notion of 'accumulation of risk' from the foetal environment to the entire lifecourse, including both biological and social pathways (Kuh and Ben Shlomo, 1997). The difference in demographic distributions of disease seen above reflects the variation within ethnic minority groups who tend to have a younger population. Given their youthful nature, a lifecourse approach to understanding the aetiology of disease and implementing health promotion programs within Britain's ethnic minorities is particularly relevant.

Ethnicity is primarily a social construct, not a biological one. The role played by the social environment, albeit through geographic situation, employment, social class or cultural facets, is essential in the understanding of ethnic inequalities in health.

*Socio-economic status and health*

The importance of socio-economic status (SES) as a determinant of health has been vastly documented (Townsend and Davidson, 1982; Macintyre *et al*, 1993; Davey Smith *et al*, 1998; Marmot and Wilkinson, 2001; Gordon *et al*, 1997). The geographical distribution of ethnic minorities in Britain is mostly concentrated in the large urban agglomerations (Nazroo, 1997b, p156). Rates of long-term unemployment are higher within ethnic minorities; they are also more likely to have low-paid occupations, poor working conditions and poor housing (Smaje, 1995, p30). Berthoud (1997, p159) emphasises the extent of poverty amongst Pakistani and Bangladeshi groups, for whom four out of five households fall below the British average household income. Such inequalities across all social sectors for ethnic minorities have consequences bearing on their health.

A social-class gradient is seen in most of the health and disease examples cited above. Indeed, reporting fair, poor or very poor health was strongly patterned by socio-economic disadvantage (Nazroo, 1997b, p162). Using various indicators of SES, Nazroo (1997a, p107) showed that *"those in poorer socio-economic groups had poorer health in each ethnic group"* for heart disease, hypertension, diabetes, respiratory illnesses and health behaviours. He concluded that SES is an important predictor of health within ethnic groups and helps to explain the ethnic variation in health outcomes but only deals with part of the overall disadvantage faced by ethnic minorities (Nazroo, 2001, p138). The accumulation of socio-economic disadvantage across the lifecourse influencing the health of ethnic minorities is of particular importance given their propensity to social deprivation (Nazroo and Davey Smith, 2001, p55).

*Culture and health*

Robert LeVine (1997, p67) noted that culture is often treated as *"an area of darkness beyond the reach of currently available scientific searchlights"*. Indeed, culture is an inherently difficult notion to define or describe. Levi-Strauss (1974) described the essential interaction between language and culture. Language is of paramount importance in the identity of certain ethnic minority groups. Nearly all ethnic minority groups in Britain speak a language other than English which is strongly linked to their ethnic or religious community (Modood, 1997, p310). Nazroo (1997a, p127) considers that differences in use of language between patients and practitioners as one of the main causes of poorer quality of health services for ethnic minorities. He states that one in eight female Bangladeshi respondents and possibly even more Chinese respondents, did not understand the language used by their GP. In the *Fourth National Survey of Ethnic Minorities*, *"fewer than 10 per cent of respondents who reported language difficulties with their GP had used a translation service"*. An ethnographic study of the use of minority languages in health education settings noted that *"clients' preference to converse in* [a minority language] *with clinical staff was clearly highlighted in Galway and north Wales, where bilingual mentors described situations where they were sought after by clients for that purpose"* (Roberts and Paden, 2000, p80). Here, differences in language and literacy within ethnic minority groups has a clear impact on their access to health care, health promotion and its quality.

Culture, however, consists of many more elements other than language including beliefs, values and lifestyle. Such beliefs and practices are related to *"biological, psychological and social changes in the human organism, in both health and disease"* (Helman, 1998, p1). Perceptions of health and disease are innately linked to cultural experience and background. Increased sensitivity to cultural differences is essential in doctor-patient interactions and in understanding ethnic variations in the distribution of disease. Such cultural elements, however, are easily regarded as deviant or pathological and differing from the 'norm' (Smaje, 1995, p85). This can lead to discrimination blaming the patient for their condition.

### *Discrimination, racism and health*

Discrepancies in diagnosed mental illness are a classic example of cultural and racial discrimination within certain ethnic minority groups. Rates of psychiatric hospitalisation in Caribbean minorities for schizophrenia and Irish individuals for alcoholism, have been far in excess of any other ethnic groups or the general population (Littlewood, 1992). There are also large differences in the proportion of diagnosed mental illness between ethnic groups, such as low rates of diseases like abnormal personality in any ethnic minority groups (Littlewood, 2001). Although, in recent years, efforts have been made to address this problem in the teaching and culture within psychiatry itself, discrepancies still persist. Littlewood (*ibid*, p214) emphasises the importance of investigating *"minorities' construction of selfhood, understanding of illness, patterns of psychological adjustment, recourse to mental health agencies or, their attitudes to professional medicine in general"* in order to combat ethnic discrimination in psychiatry.

Smaje (1995, p110) distinguishes between three main forms of racism in health service delivery: a) direct racism, where an individual is treated less favourably because of their ethnicity; b) indirect or institutional racism, where the form in which services are provided favours some groups in the population over others; and c) ethnocentrism, where inappropriate assumptions are made about people from minority groups on the basis of the majority's experience.

Racism and discrimination occurring in society at large are likely to have an impact on the health of ethnic minorities. *The Fourth National Survey of Ethnic Minorities* showed that 13% of ethnic minorities reported being subject to some form of racial harassment in the past year (Virdee, 1997, p287). Direct links can be made between experience of racism and perceived health status (Smaje, 1995, p46). Krieger (2000, p63) refers to *"how people literally embody and biologically express experiences of racial oppression and resistance, (…) thereby producing racial/ ethnic disparities in morbidity and mortality across a wide spectrum of outcomes"*.

## Individuals and Populations: improving ethnic inequalities in health

As evoked by Geoffrey Rose (2000), the term 'normal' causes a lot of confusion and should be used with much caution when referring to population health. He emphasised that *"the 'normal' majority has defined what is to be regarded as 'abnormal', without realising that the standard was relative and not absolute"* (*ibid*, p61). Indeed, it has been shown that ethnic minorities have different distributions of disease and ill health to the general population. More importantly, they tend to have unfavourable socio-economic positions and face discrimination by the majority, which has a substantial impact on their health. If the health of the population at large improves, then inevitably, so does that of the marginalized groups within it. In order for this to happen, a cultural change is necessary to alter perceptions of acceptable behaviours of what is 'normal' health and of how certain groups within the population are treated. As well as focusing on Rose's ultimate aim of the healthier population, it is also important to target high-risk groups with appropriate health policy and health promotion programs.

### *Policy and action: targeting ethnic minorities*

In order to improve the current ethnic inequalities in health, the discrepancies in language and literacy present between ethnic minority patients and the health services need to be addressed. The provision of translation services and interpreters ought to be increased in areas where ethnic minorities are present. The implementation of such services needs to be established from the onset of a patient's enrolment with a specific health service. Nazroo (1997b, p166) notes that providing translation services is only one dimension of the solution, and *"effective advocacy services can be more empowering by providing knowledge and enabling discussion and negotiation"*. Furthermore, education, information and health promotion must be linguistically appropriate, providing information in culturally relevant media contexts. The Welsh Language Schemes are currently raising awareness of minority language usage in health care and are identifying education and training opportunities for health care professionals (Roberts and Paden, 2000, p81).

Sensitivity to cultural differences through training and awareness needs to be improved within the health services at large (Nazroo, 1997b). Furthermore, health services and community services need to work together in urban areas where there are higher concentrations of specific ethnic minority groups. Taking into account their cultural practices and demographics, positive community action that puts ethnic minority community leaders in decision making positions could have benefits on overall health (*ibid*, p167).

The support of ethnic minority GPs who are *"often single-handed or small practices in the most deprived areas which have heavy caseloads"* (Nazroo, 1997b, p166) is essential, as many ethnic minority patients are attracted to them for linguistic and cultural reasons. Increased training and recruitment of ethnic minority individuals into all levels of health services also needs to take place. It has been noted that many general practitioners who qualified in South Asian medical schools will retire within the next decade (Taylor and Esmail, 1999). This will have implications for their patients, who often will have chosen their GP based on ethnic minority and language usage.

All policies that aim to improve socio-economic inequalities in health should also include a focus on issues concerning ethnic minorities in particular. Shaw and her colleagues (2001, p232) suggest various socially targeted policies aimed at improving health such as: new legislation to protect the rights of minority groups concerning citizenship and employment rights; improved income support to provide an adequate standard of living for the unemployed; housing policies aiming to provide affordable housing of a good standard. Such initiatives should take into account the particularities of ethnic minority groups, such as household size and age distribution, which differ from the general population.

Health promotion needs to target the specific disease distributions within certain ethnic groups. There is a poor outreach of preventative care towards ethnic minority groups, for example, significant proportions of South Asian women report never having been recommended to have a cervical smear (Balarajan, 2001, p235). Health promotion concerning smoking and cancer awareness needs to be aimed at ethnic groups where such information is most lacking. Nazroo (1997a, p53) observed that ethnic minority smokers were less likely to give up smoking than whites. Better screening of conditions that are associated with particular ethnic minorities is necessary for example: Caribbeans and hypertension, Pakistani/ Bangladeshi groups and diabetes and respiratory illness in Irish groups. Health promotion must be carried out in languages understood by the particular ethnic groups in question in culturally sensitive manners and through appropriate media (local radio, community centres, etc). Raleigh (1997) notes that South Asian diabetic patients need more education about their illness, which will allow them to understand their condition and thereby better judge their own health decisions.

The equitable allocation of resources responding to ethnic inequalities in health is important in tackling the issue. Balarajan (2001) states that allocation of resources to small localities ought to be considered with the aim of bringing changes to the health service, as well as continuing to build awareness through community participations.

## Conclusions

Ethnic inequalities in health do exist in Britain today. The most effective ways of addressing such inequalities is through the improvement of: the quality of health services provided, the targeted health promotion campaigns and the socio-economic status of ethnic minorities.

# Appendix II: The History and Genetics of Ethnic Groups in Wales

Appendix I has reviewed the large literature on ethnicity and health. Different ethnic groups in Wales (and other parts of the UK) have different prevalence rates for a wide range of health conditions. With members of certain ethnic groups suffering from both higher and lower rates of ill health than would be expected after allowing for age gender and socio-economic status. Similarly, there are differential costs of delivering health services to some members of certain ethnic groups, which can result from translation, interpretation and staff training cost.

Much research in the past, has attributed health differences between ethnic and/or 'racial' groups in Wales, to be a result of genetic difference between these groups e.g. some groups have more 'unhealthy' genes (for example see Harper and Sutherland, 1986). Modern genetic studies have clearly demonstrated that this idea is untrue. Ethnic group health differences are entirely a result of socio-economic, behavioural and cultural differences and not genetic differences. It is however, not sufficient to just assert this fact as the idea of genetic differences between ethnic groups is unfortunately widely believed by both the general population and many health professionals. This appendix will therefore briefly discuss the history of the origins of this belief, before discussing the genetics of the Welsh population.

**The history of the racial myth in Wales (and Britain)**

The idea of a distinct Welsh 'race' is often traced by historians to the work of Geoffrey of Monmouth, a cleric whose *History of the Kings of Britain* was published around 1136 (MacDougall, 1982). It claimed that the British people were descended from the population of ancient Troy. The history begins with Brutus, grandson of Aeneas of Troy, son of Venus and continues through King Leir (immortalised by Shakespeare) and a long line of succession to its climax with King Arthur, Merlin, Guinevere and the fight against the Saxons, etc. It ends with the Saxons and Angles, aided by Gormund – King of the Africans – overrunning the country and the flight of the Britons to Brittany and Rome, leaving just the remnants of the 'British' population in Wales. Geoffrey's 'history' is a work of fiction, not a history and yet it had a huge influence and was widely believed for four hundred years. Historian's argue that the myth severed to legitimise the rule of the Norman Kings in Britain e.g. they were also descendants of the 'true' Britons (MacDougall, 1982).

However, the dissolution of the monasteries required the invention of a new myth of origin as Geoffrey's myth associates the 'true' Britons with Rome (and Catholicism). This was supplied over a period of a hundred years, beginning with John Foxe's *The Book of Martyrs* in 1563 which singled out King Alfred, "above all others, he was a king of whom all Englishmen could be proud". Thereby providing a Saxon hero to rival Arthur. William Camden developed this idea in *Britannia*, published in 1586, in which he traced the origin of the English people to Germanic tribes – thus the Anglo-Saxon 'racial origin' myth was created. The Danish and Norman conquest of Britain were considered not to have had any effect as "*the Danes and Normans were once the same people as the Germans, as were also the Saxons*". The origins of the protestant church and Parliamentary democracy were even claimed to be pre-figured by the noble leadership structure of ancient Germanic tribes. By the mid 18th century the Germanic origin of the British people was almost universally believed (MacDougall, 1982).

The Anglo-Saxon origin myth is rather excusatory of the people of Wales and during the 18th Century a rival myth of origin developed in Wales. A Welsh scholar Edward Lhuyd and a Breton chronologist, Paul-Yves Pezron, claimed that the Welsh and Breton people were descended from the Celtae or Keltoi. These Celts were supposed to be a barbarian people whose sway in antiquity stretched from Gaul to Galatia (Asia Minor) and who had even been the scourge of the Greeks and

Romans. They had a hypothetical mother tongue called Celtick. Morgan (1983).argues that "*The Celts reflected the fantasies of the age, and in Wales they provided the constricted, pathetically small nation, which had little to commend it in its present state, with an unimaginable grandiose past, by way of compensation*".

In the 19th Century, Edward Williams, a Glamorgan stonemason, took the bardic name of Iolo Morganwg (Neddy of Glamorgan) and created the idea that the ancient Welsh bards had been the heirs of the ancient Druids, their religion appearing to be a mixture of Iolo's own Unitarianism and Eighteenth Century nature worship (Morgan, 1983).

To summarise the historical myths of racial origin in Wales, the Welsh people are either descended from the Trojans, the Britons, the Germans, the Celts or the Druids. There is no historical evidence for any of these ideas, they are all myths. However, during the 19th Century, scientists tried to 'prove' these myths.

### Racial science and the Welsh people

An American, Willaim Z. Ripley divided the people of Europe into Teutons/Nordics, Alpines and Mediterraneans. All three of these European 'races' were meant to be found in Brittan – the Nordics were concentrated in the English ruling class, while Wales was filled with small dark Mediterraneans (Kohn, 1996). These 19th Century ideas are still believed by some scientists, for example, in *Genetic and Population Studies in Wales,* published by the University of Wales Press in 1986, E.G. Bowen argues that the geography of Wales was a key factor in bringing Wales its 'Mediterranean' population. Apparently, the accessibility of the southern plain left it open to Anglo-Saxons and Normans, who were then able to penetrate into the Welsh heartland and along the valleys which open up into the lowlands. This resulted in the 'settlements of strong Alpine and Nordic elements'. The high moorland of the interior provided refuge for aboriginal types: early physical anthropological studies indicated a close similarity between the skulls of people in the Pumlumon area and the Palaeolithic specimens found in France and Spain (Bowen, 1986). This idea can be traced back to the work of the founding father of Welsh biological anthropology Herbert John Fleurie, who was appointed to the chair of geography and anthropology in University Collage, Aberystwyth in 1904.

A popular account of his work describes the Welsh people of the high moorlands as having '*Heavy brow ridges, low sloping foreheads, massive and retreating lower jaw, all characteristics of Neanderthal man*' (Bradley, 1926 quoted in Kohn, 1996). Fleurie also popularised the idea of the 'inner' or 'real' welsh people whom he considered to have "a remarkable persistence of type" Watkins (1986) lends support to these ideas in his study of ABO blood group frequencies among the 'indigenous population'. He interprets higher frequencies of the B blood group in moorland areas as evidence of ancientness and concludes that "*the fundamental physical type in most of Wales is the long headed brunette, universally recognised as belonging to the Mediterranean race of Sergi*."

Many studies in the Fleuriean research tradition attempt to distinguish the 'Inner Welsh' population from the 'Outer Welsh' population for scientific study on the basis of surnames as indicators of kinship and descent. This will obviously add a huge bias to any sample as it excludes many married women. Nevertheless, studies which used this kind of methodology to look at 'Welshness and Disease' concluded that "*The people of Wales are to some extent genetically different from those of England*" and that these 'genetic factors' may cause the Welsh people to have a higher incidence of "*cerebrovascular disease, coronary artery disease, diabetes, prostatic hyperplasia and carcinoma of the stomach and oesophagus. Suggestive differences are seen in the cases of rheumatic heart disease, nephritis, peptic ulcer and malignant melanoma*" (Ashley, 1986).

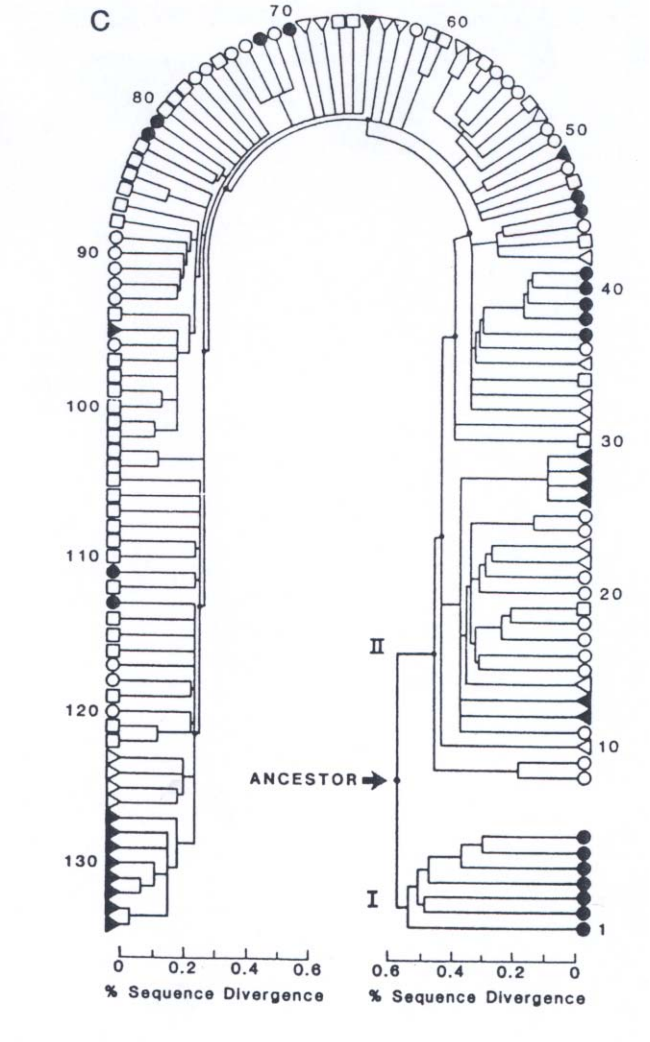
Fortunately, modern genetic studies have allowed us to dispense with both the historical myths and the offensive ‘race science’ research on the origins of the Welsh population.

## Modern Genetics and the Welsh Population

All people have two parents, four grandparents and eight great-grandparents. If we go back 25 generations then we all have over 33.5 million ancestors. We inherit our cellular mitochondria through our maternal line e.g. our mothers, mothers, mother, etc. and the Y-Chromosome is inherited through the direct paternal line e.g our fathers, fathers, father, etc. Modern molecular genetic studies of mitochondrial DNA and Y-Chromosome DNA allow men to trace two of their direct ancestors (their direct paternal and maternal ancestors) and women to trace their direct maternal ancestors.

Modern molecular genetic studies began with the work of Cann, Stoneking and Wilson in 1987 when they demonstrated from mitochondrial DNA (mtDNA) analysis that all human populations had an African origin approximately 100,000 to 150,000 years ago (e.g. 5,000 to 7,500 ancestors ago). They also showed that the genetic diversity of African populations was much greater than that of other populations, the rest of humanity had a sub-set of the genetic diversity present in Africa (Cann, Stoneking and Wilson, 1987). Figure A.1 shows their results.

**Figure A.1 Mitochondrial DNA genealogy of 148 people from five Geographic Regions**
*Closed Circles* are African, *Open Circles* are Asian, *Open Triangles* are Australian, *Closed Triangles* are New Guinea and *Open Squares* are Europe.



The figure shows two distinct groups human groups, Group I consists of only people from Africa and Group II of people from all over the World including some from Africa. You cannot tell from a person's geographic origin (or the colour of their skin) how genetically similar or distant they are. There are no obvious unique European, Asian, Australian or New Guinea mtDNA groups. For example any two 'White' Europeans may be genetically more closely related to a 'Black' African than they are to each other.

More recent mtDNA studies of the European population suggest that almost every person in Europe is descended from just seven women. Table A.1 shows that two thirds of the population in Wales (66%) are descended from just two women (Helena and Velda), similarly 62% of the population of Europe are also descended from these two women. They are both estimated to have lived between 11 and 14 thousand years ago at the end of the last ice age (Richards *et al*, 1996; Sykes, 1999). Before this date almost all of Wales would have been buried beneath a mile or so of glacial ice (the maximum ice advance in Wales occurred about 18,000 years ago).

**Table A.1: Approximate Percentage of the Welsh and European Populations descended from seven Women ancestors**

| **Mt DNA Cluster (Direct Female Ancestor)** | **Wales %** | **Europe %** |
|---|---|---|
| U (Ursula) | 2 | 7 |
| J (Jasmine) | 15 | 12 |
| T (Tara) | 5 | 8 |
| X (Xenia) | 4 | 5 |
| K (Katrine) | 8 | 7 |
| H (Helena) & V (Velda) | 66 | 62 |
| | | |
| Total | 100 | 100 |

Note the mtDNA clusters are 'officially' designated by letter e.g U,J, etc.
Professor Bryan Sykes has given them 'unofficial' women's names eg. Ursula, Jasmine, etc.

Table A.2 shows a summary of the three main waves of European and Welsh colonisation as derived from mitochondrial DNA analysis. Despite evidence of a considerable Neanderthal population in Europe (for example at Pontnewydd Cave in Wales – Green, 1984), none of this Neanderthal population has left any living ancestors in Europe or Wales (or any where else in the World). There are no Neanderthal descendants in the Welsh moorlands (Renfrew, 2000).

**Table A.2 Genetic Origin of the Welsh and European Population**

| Period | Date | Wales Contribution to modern gene pool | Europe Contribution to modern gene pool |
|---|---|---|---|
| Neanderthal | 300,000 | 0% | 0% |
| Early Upper Palaeolithic | 50,000 | 2% | 7% |
| Late Upper Palaeolithic | 14,000-11,000 | 83% | 81% |
| Neolithic | 8500 | 15% | 12% |

Tables A.1 and A.2 show that eight out of ten of the current Welsh and European populations are directly descended from just five women who lived in Europe at the end of the last ice age, between 14,000 and 11,000 years ago. The large majority of the Welsh and European populations have mitochondrial DNA which is very similar. This is unsurprising as only about 600 generations separate them from their common Late Upper Palaeolithic mothers and not that many genetic changes can accumulate in just 600 generations.

This is not to deny that there are genetic differences between population groups and individuals, for example the largest known number of mutation differences between two people in their mitochondrial DNA is fourteen which separates Teri Tupuaki, a fisherman from Mangaia in the Cook Islands from Mrs Gwyneth Roberts, who cooks school lunches in Bala, North Wales. However, the medical effects of genetic differences in the Welsh population is likely to be much smaller than the effects different socio-economic circumstances and the behavioural differences between different ethnic groups in Wales. If there are health difference in the prevalence rates of disease between the English and Welsh populations then this is almost certainly not due to genetic differences between these two populations, as genetically they are very similar.

Again this is not to deny that there are differences in the prevalence rates of genetic diseases between population groups. For example, Sickle Cell Anaemia and Thalassemia are known to be evolutionary responses of African and European population groups to exposure to Malaria. However, neither a person’s ethnic group, nor the colour of their skin, is a good predictor of these genetic diseases. They are a result of differential long term death rates from Malaria and not a result of ethnic group genetic differences.