



Hospitals are told to produce cancer survival league tables

IVF postcode lottery that means heartache for thousands of couples

New guidelines may end postcode lottery

**MONEY**  
Long-term care: has Ruby changed the landscape?

Couples denied the chance of a baby in IVF postcode lottery

# Who's winning the postcode lottery?

Open any newspaper and you'll be besieged by stories about regional healthcare differences. We ask why they exist and see what you can do to get the best service possible

In an ideal world, you'd receive the same quality of medical care and treatment whether you lived in Land's End, John O'Groats, or anywhere in between. But, in reality, depending on where in the UK you live you might wait a lot longer for treatment, receive a lower standard of care or even have to pay for drugs or treatments which are available on the NHS in other areas.

For example, if you need an MRI scan to find out the cause of your back pain, you could wait an average of 213 days in Bath

compared with a mere seven days in East Grinstead. And people with multiple sclerosis (MS) in Ipswich receive free beta interferon drugs to ease their symptoms, while those in neighbouring Norwich can't get the drugs on the NHS.

The term 'postcode lottery' is frequently bandied around in the media to describe seemingly random and unfair differences such as these – the headlines above are just a tiny selection. However, while some differences in healthcare are planned, others are examples of where the system isn't working as it should. We look at the truth behind the postcode lottery headlines, and more importantly, see whether there is anything you can do about it if it affects you.

## Planned differences

Government officials around the UK agree that local health variations exist but say that most are 'planned' in order to meet the needs of local communities. The structure

of our healthcare system encourages some regional differences.

Each UK country manages its own health services – the Department of Health (DoH) in England, the Scottish Executive Health Department, the Welsh Assembly Department of Health and Social Services (DHSS) and the Department of Health, Social Services and Public Safety (DHSSP-SNI) in Northern Ireland.

Each country has its own NHS, which implements the guidance from above and runs healthcare services on the ground. Local NHS trusts or health boards in each

## OUR RESEARCH

In June 2007, we carried out face-to-face interviews with 1,040 people across the UK to ask about their views and experiences of health services in their area of the UK. Thanks to all those who took part.

## Regional differences

Targets across the UK are not the same

Targets in England, Scotland, Wales and Northern Ireland vary and different statistics are available. Where possible we have looked at the most recent statistics for all four countries. Due to

space we haven't always been able to list all equivalent health organisations around the UK – but see 'Contacts', p17, for details about who deals with what in each country.

country, such as primary care trusts (PCTs) in England, control most of the budget. They decide how money is spent in their area and which services to prioritise. But do they always make the right decisions?

In our survey, three quarters of people said that they were broadly satisfied with their local healthcare provision. Seven out of ten agreed that regional healthcare differences exist in the UK, but more than half think that this is acceptable as long as differences are based on local needs.

### 'Unplanned' differences

However, there are certain differences in healthcare provision which are not viewed so positively. Unsurprisingly, people who felt they'd been denied a service, paid more or had to wait longer for treatment were almost three times more likely to be dissatisfied with the system (34 per cent compared with the average 12 per cent).

To try to tackle these kinds of difference, and ensure consistency, health departments make important decisions nationally and set guidelines and standards to which local organisations are supposed to adhere.

The National Institute for Health and Clinical Excellence (Nice) was set up in England along with the Scottish Medicines Consortium (SMC) and the All Wales Medicines Strategy Group (Northern Ireland follows Nice) to try to end the postcode lottery in access to drugs and treatments. Part of their job is to evaluate

## Patient choice

**If you have concerns about your hospital, you have the right to try another**



### What is it?

If you're not sure about your local hospital you can now choose to go somewhere else. All patients in England needing non-emergency treatment should be given a choice of at least four hospitals or clinics, as well as any NHS foundation trust and selected private hospitals nationwide. 'Free choice' will be introduced in England in April 2008, meaning that patients can choose from any NHS-approved hospital in the country.

There is no formal system of patient choice in the rest of the UK. However, the 'second offer

scheme' in Wales and the 'waiting times guarantee' in Scotland both allow patients to choose another hospital, if their local hospital cannot meet their waiting times target.

### How does it work?

If you are referred to a specialist or for tests, your GP should inform you of your choices, but it's your decision where you go. However, a recent DoH survey showed that not all GPs are doing this yet. If you need treatment, it's a good idea to question your GP about the choices available.

### How do I choose?

The NHS Choices website ([www.nhs.uk](http://www.nhs.uk)) was relaunched in June 2007 to give more information about NHS choices in England.

Now, as well as giving details about certain conditions and treatments, it lets you compare hospitals for particular treatments or procedures, giving information on things like infection rates and waiting times. There's also a feedback facility so you can see what other patients think about a certain hospital. Be warned: there are concerns over the accuracy of some of the data, which the site is currently trying to address. For more information about your local hospital, visit the sites listed in 'Contacts', p17.

## SAME TREATMENT FREE 40 MILES AWAY

**Jean Floodgate 49, HR consultant**

In 2005 Jean's gynaecologist suggested a hysterectomy after finding that Jean had two large fibroids (benign tumours) in her womb. Jean, from Sussex, felt that this procedure was 'like using a sledgehammer to crack a nut'. She was aware of a cheaper, quicker, non-invasive treatment for her condition called fibroid embolisation. A friend of hers had successfully had the procedure carried out on the NHS in Surrey the previous year.

Jean's radiologist recommended the treatment and put forward a case for it to be available on the

NHS but her PCT refused to pay for it – despite the fact that it would have been cheaper than a hysterectomy. Jean's health deteriorated and, not wanting to go through a needless hysterectomy, she paid £1,700 to have the non-invasive procedure done privately in February 2007.

Jean said: 'How can some PCTs deny patients the same treatment that others get free? It's frustrating that I ended up having to pay for it myself. I was opting to have a quicker, less expensive and less risky procedure and so should have saved the NHS money and time.'



the clinical and cost effectiveness of drugs and treatments and decide which ones should be available on the NHS. Some of Nice's guidance also applies in the other nations, complemented and reviewed by local health organisations.

National standards with local flexibility? Sounds great. But, in practice, things don't work quite as they should.

## Missing the target

Official statistics show that compliance with national targets and standards across the UK is haphazard – some NHS bodies struggle to meet them and others miss them by a mile. There are huge variations in waiting times for diagnosis or treatment, with many local trusts not meeting the targets set by their country's health department (see 'Why are we waiting?', right).

The health watchdog, the Health Care Commission, carries out an annual health check on NHS trusts in England. In 2006, it revealed that 12 PCTs failed to follow Nice guidelines and a further 46 could not provide sufficient evidence that they were meeting guidelines.

Although Nice recommendations are supposed to be binding, there are no statutes in place to force local trusts to follow them. As a result, there are significant variations in how local health trusts implement these recommendations (see 'Are we getting what we need?', p16).

## Money management

There may be many reasons why targets are missed. The NHS often blames money, saying that it doesn't have the resources to do everything. It's true it has only a finite pot of money, which can't stretch to giving everyone the treatment that they need. But an Audit Commission investigation in September 2005 said that poor financial management at local level was the biggest cause of the postcode lottery.

Whatever the reason, the decisions made by local trusts have a big impact on the lives of those affected. Unfortunately, it's not always clear to patients who is making these decisions on their behalf or what the decisions are based on.

However, those in need shouldn't feel helpless. There are several ways to challenge the postcode lottery if you feel you are being treated unfairly (see 'Patient choice', p13, 'How to complain', opposite and 'Take action', p16).

# Why are we waiting?

One of the key complaints about the 'postcode lottery' is the length of waiting times

**Waiting times topped the list of patients' bad experiences**

In our survey, waiting times topped the list of patients' bad experiences, with 11 per cent feeling that they had to wait longer than they would have done in other areas of the UK. Some people felt they'd had no option but to pay for private treatment to avoid long waits on the NHS. One woman told us: 'I had to go privately to get a hysterectomy; it would have been an 18-month to two-year wait on the NHS.'

UK health departments set target waiting times for local NHS organisations, covering aspects such as urgent medical care, diagnostic tests and treatment. Waiting times in England have shortened in recent years but they have either stayed the same or got worse in other parts of the UK. So which bodies are meeting targets and what can you do about it if they're not?

## Urgent medical care

All NHS organisations in the UK work towards a target that no patient should wait longer than four hours in A&E. Between January and March 2007, most trusts in

England saw 97 per cent or more patients within this target. But some fell below 90 per cent, with one trust seeing only 83.1 per cent within four hours. In our survey, one patient had to wait in casualty for six and a half hours, as there was only one doctor in A&E that night.

In Wales and Scotland, fewer bodies met the target. At the bottom of the scale in Wales, Cardiff and Vale saw just 82.7 per cent of patients in A&E within four hours. In Scotland, NHS Highland saw only 66 per cent within the target time. There are no statistics collected for Northern Ireland.

## Diagnostic tests

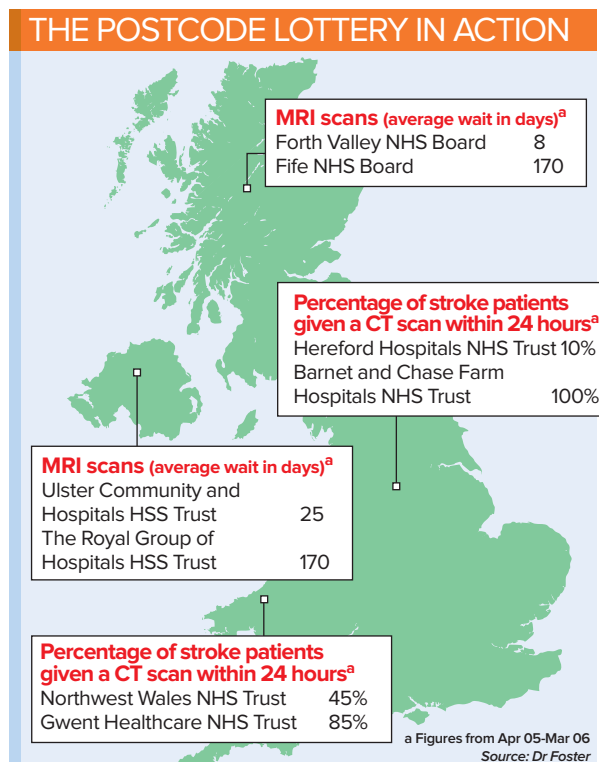
In England, if you need diagnostic tests, such as MRI scans or X-rays, the DoH recommends they should be carried out within 13 weeks of referral. It recently set this target to help trusts meet the 18-week target that comes in at the end of 2008.

While some NHS organisations are already beating this target, others fall short. Research company Dr Foster told us that, from April 2005 to March 2006, patients at the Queen Victoria Hospital NHS Foundation Trust in East Grinstead waited an average of seven days for an MRI scan, whereas those at the Royal United Hospital Bath NHS Trust had to wait 213 days. The average waiting times for an MRI scan ranged from eight to 170 days in Scotland, 20 to 189 days in Wales and 25 to 130 days in Northern Ireland. One person surveyed said he had to wait 'over nine months'.

Once you've been diagnosed, the time you'll have to wait for treatment also varies, depending on your address. Each country has its own national plans that set out long-term strategies and target waiting times for the treatment of certain conditions such as cancer and strokes.

## Cancer patients

England's Cancer Plan sets a target that all cancer patients should start treatment within one month of diagnosis. Recent statistics show that two thirds of PCTs hit 100 per cent. But at the other end of the scale, more than 40 per cent of cancer patients diagnosed at Moorfields Eye Hospital Trust,



London had to wait more than a month.

If you think that's a long time, some cancer patients in Scotland had to wait longer than seven months for treatment. In Scotland, the target waiting time between GP referral and treatment is two months for all urgent cases. In the first three months of 2007, 73.6 per cent of patients in NHS Highland were treated within this target and only 70.3 per cent in Lanarkshire.

A spokeswoman from NHS Highland said: 'We recently monitored each patient's pathway through the system to identify bottlenecks and have improved systems and recruited new staff. This is beginning to show results. But waiting times can be increased by a lack of specialist equipment.'

### Stroke patients

Strokes are the third biggest cause of death in the UK and the largest cause of severe disability. Quick diagnosis can help decide on the best course of treatment. It's recommended that all stroke patients are given a CT (all-round) scan within 24 hours. A 2007 survey of NHS organisations by Dr Foster discovered that while some hospitals were giving CT scans to all stroke patients within 24 hours, this dropped to a worrying 10 per cent at Hereford Hospitals NHS Trust and Doncaster and Bassetlaw Hospitals NHS Foundation Trust.

If you're dissatisfied with waiting times or the service received at your local NHS trust, see 'How to complain', below.



### COSTLY ADDRESS CHANGE

#### Colin Dobson, 74, retired

Colin was prescribed the drug warfarin by his GP in May 2006 and was told that he must take it for the rest of his life. Warfarin helps prevent strokes by altering the time it takes for blood to clot. However, the blood needs to be monitored regularly.

Colin needed frequent testing. On the advice of his Cumbrian GP, he bought a machine that enabled him to test at home. The GP prescribed needles and strips for the machine. As he's over 60, Colin got these free.

Soon after, he and his wife Philippa moved to Hertfordshire, and Colin started to run out of strips. His new GP refused to prescribe them, saying it was a PCT decision.

However, in a letter to charity Anti-Coagulation Europe, which supports Colin's cause, the Secretary of State for Health wrote: 'The testing strips are listed in the drug tariff and are available on prescription if GPs believe the patient will benefit. Local PCTs cannot direct GPs to withhold the prescription.'

Philippa said: 'The strips will cost us £116 for 24. We assumed we'd get the same treatment here.' They are appealing against the GP's decision.

## How to complain What to do if you are not satisfied with the service

■ **PROCEDURE** If you're not happy with an NHS service, follow the NHS complaints procedure as soon as the problem arises – you have six months to register the complaint from that date. You must go through the following stages.

■ **ADVICE** Every local NHS body in the UK offers an advice or support service for complaints. In England, you can contact the Patient Advice and Liaison Service (Pals) or the Independent Complaints Advocacy Service (Icas). In Scotland, contact your local citizens advice bureau; in Wales,

your local Community Health Council; and in Northern Ireland the Northern Health and Social Services Council (NHSSC).

■ **LOCAL RESOLUTION** Raise your concerns with a staff member. If they can't resolve the issue, make a formal complaint, either written or oral, to the NHS organisation. In Scotland, complain to your local board's



complaints officer if you don't wish to talk to those involved.

■ **REVIEW** If you're not satisfied with the response, ask for a free and impartial independent review of your case. In England, this is carried out by the Healthcare Commission; in Wales, by the Independent Review Secretariat; and in Northern Ireland by local health boards. This stage does not exist in Scotland.

■ **OMBUDSMEN** These are free, impartial referees. In England, contact the Parliamentary and Health Service Ombudsman; in



Scotland, the Scottish Public Services Ombudsman; in Wales, the Public Services Ombudsman for Wales; and in Northern Ireland, the Northern Ireland Ombudsman.

■ **JUDICIAL REVIEW** If you are unhappy with the decision of a public body or an ombudsman, you could challenge the decision by taking judicial review proceedings in the high court. You'll need to seek expert legal advice at this stage.

# Are we getting what we need?

Access to drugs, treatment and specialist staff is also a big issue for patients



**Two aspects of the postcode lottery: some eligible patients are not getting beta interferon to ease their symptoms while the frequency of health visitors fluctuates across the country**

It's bad enough knowing that patients elsewhere are getting treatment more quickly than you, but imagine being denied life-saving or sight-saving drugs that someone a few miles away is getting free on the NHS.

In our survey, 3 per cent of people said they believed they have been denied a health treatment, service or medicine on the NHS that is available in other parts of the UK. But numbers could be higher – as one respondent told us: 'I wouldn't know exactly how people in other areas are treated.'

treatment for specific conditions, such as IVF for infertility, are called clinical guidelines. Although these are also binding they must only be 'taken into account' and a health professional's judgement comes first.

As a result, some local trusts choose to ignore or modify Nice guidance, meaning that patients around England are still treated differently, despite national guidelines. For example, if you have certain types of MS, and meet eligibility criteria, you should be able to get beta interferon on the

**If you are denied a drug or treatment, you can try to appeal**

NHS to ease your symptoms. However, a recent survey by research company Dr Foster showed that one in ten patients eligible for the drug was not receiving it. And 19 out of 156 trusts admitted not following Nice guidelines on beta interferon.

The postcode lottery in IVF has also been in the news recently. A survey conducted by Infertility Network UK on behalf of the DoH in August this year showed that more than half of PCTs in England aren't following Nice guidance on IVF, with many setting their own eligibility criteria for treatment and others simply not offering it at all (see Mikaela's story, opposite).

The Healthcare Commission told us that local trusts that didn't follow Nice guidelines get an 'action plan' giving them advice on what to do to improve the situation – this might mean employing more staff or re-allocating funding.

But in reality nothing can be done to force local trusts to meet guidance and there are no penalties if they don't. If you are denied a drug or treatment that Nice guidance says should be available, you can try to appeal (see 'Take action', below).

## Specialist staff

Getting access to specialist staff, such as neurologists and other consultants, can also vary around the country and that in turn

## Access hits the headlines

Although there's a shortage of comparative information on which trusts are following Nice advice and which aren't, you only have to read the papers to know that problems do exist. In recent years, many 'postcode lottery' cases have hit the headlines – for example, patients being denied the drug Herceptin for breast cancer, couples being denied in vitro fertilisation (IVF) treatment and patients in Scotland getting certain sight-saving drugs on the NHS that aren't available in England.

## Nice drugs and treatment

Nice recommendations about which drugs and medicines should be available on the NHS are called technology appraisals. PCTs must find funding for these within three months. Recommendations about

## Take action How to appeal if you are a postcode lottery victim

■ **STARTING POINT** If you think that you've been a victim of the postcode lottery – for example, you have been denied drugs by your local NHS body that Nice or the SMC has recommended – you can take action and appeal against the decision.

■ **SPEAK TO YOUR GP** If they recommended a particular drug or treatment they may be able to help you fight for it. If they can't help directly they may be able to offer advice.

■ **GET THE FACTS** Find out your local health organisation's policy on the treatment that you are looking for and the national standards of care recommended for your condition. Check out Nice or SMC guidance on the drugs you want. Contact the charity for your particular condition – for example, the Infertility Network UK about IVF, the MS Society about multiple sclerosis and Cancer Research UK for cancer.

■ **JOIN FORCES** Contact charities and patient groups and join forces with other patients who are lobbying for the same treatment. Check out health information website [www.patient.co.uk](http://www.patient.co.uk) for details of relevant patient groups, charities and organisations.

■ **RAISE THE PROFILE OF YOUR CASE** Contact the local and national media and write to your local MP.

## FORCED TO GO PRIVATE FOR IVF

**Mikaela Price, 33**

Mikaela and her husband Richard discovered in January 2006 that they couldn't have children naturally. Nice recommends that women aged between 23 and 39 meeting certain conditions should be given three IVF cycles on the NHS. Mikaela, from Winchester, met the criteria but was refused treatment by her local PCT as it funds IVF only for people aged between 36 and 39. If Mikaela had lived less than 30 miles away in Salisbury, she'd be in the correct age bracket there, which is 30 to 35.

The couple have already spent £6,000 on private treatment and the next round will cost £4,000. Their local MP is championing their cause and they are currently following the

NHS complaints procedure but, so far, nothing has changed. Mikaela told us: 'I feel that Hampshire PCT is relying on the fact that most couples will self-fund IVF as they won't wait until 36, when chances of success decrease. Why are PCTs allowed to set their own criteria and why aren't they held accountable?'

Hampshire PCT blamed a lack of finances. It said that following Nice guidance would cost 'about £10 million' whereas its current policy costs only £1.5 million. 'We must think carefully. If we spent such a large sum on IVF treatment...we would not be able to spend that money on services such as cancer, stroke and heart disease.'



can affect quality of care. One respondent in our survey said: 'There appears to be too many people in need of care and too few people in healthcare to help us.' Another told us: 'I was waiting ages to see a neurologist and was told the waiting list would have been shorter if I'd been living in Cheshire.'

A recent survey by the Family and Parenting Institute highlighted these variations. It found that in Doncaster PCT, for example, there is one health visitor per 1.61 children under the age of five. In Redbridge,

London, there is only one health visitor per 1,142 children. Differences such as this can affect quality of care for children and parents.

Some families said that they received visits from a health visitor every couple of weeks after the birth of their child. Others had received only two visits in two years.

Ultimately, the issue of access to drugs, treatments or specialists is difficult to solve. But there are certain ways you can improve your chances of getting the right treatment (see 'Take Action', opposite).

## Which? says

### We all need to be kept informed of decisions that affect us

Striking a balance between national standards and local healthcare provision is obviously an immensely difficult task. Of course there are also differences between the four nations in the UK, so there have always been, and always will be, certain regional variations in the provision of healthcare services. But people have a right to expect that guidelines and standards, where they are available, will be implemented consistently.

Later this month Which? will

launch a new campaign to improve patients' experience in hospital, because all patients, wherever they live, deserve to be treated with dignity and respect when ill.

It's vital that people are kept informed by local decision-makers about how money is being spent in their area. They must also be given real opportunities to participate in how these decisions are made and to assess what impact these have on their local health services and what services are available to them.

## Contacts

### ENGLAND

**Healthcare Commission**  
0845 601 3012; [www.healthcare-commission.org.uk](http://www.healthcare-commission.org.uk)

**Department of Health**  
020 7210 4850; [www.dh.gov.uk](http://www.dh.gov.uk)

**NHS England** [www.nhs.uk](http://www.nhs.uk)

**Nice** 020 7067 5800  
[www.nice.org.uk](http://www.nice.org.uk)

**The Information Centre NHS**  
0845 300 6016; [www.ic.nhs.uk](http://www.ic.nhs.uk)

**Parliamentary and Health Service Ombudsman** 0845 015 4033; [www.ombudsman.org.uk](http://www.ombudsman.org.uk)

**Patient Advice and Liaison Service** [www.pals.nhs.uk](http://www.pals.nhs.uk)

**The Independent Complaints Advocacy Service** 020 7210 4850

### SCOTLAND

**NHS Quality Improvement Scotland** 0131 623 4300/0141 225 6999

[www.nhshealthquality.org](http://www.nhshealthquality.org)

**Scottish Executive, Department of Health** 0845 774 1741/0131 556 8400; [www.scotland.gov.uk/Topics/Health](http://www.scotland.gov.uk/Topics/Health)

**NHS Scotland**  
[www.show.scot.nhs.uk](http://www.show.scot.nhs.uk)

**ISD Scotland** (health statistics)  
0131 275 7777  
[www.isdscotland.org](http://www.isdscotland.org)

**Scottish Medicines Consortium**  
0141 225 5552/6874  
[www.scottishmedicines.org.uk](http://www.scottishmedicines.org.uk)

**Scottish Public Services Ombudsman** 0800 377 7330  
[www.spsso.org.uk](http://www.spsso.org.uk)

### WALES

**Healthcare Inspectorate Wales**  
029 2092 8850; [www.hiwi.org.uk](http://www.hiwi.org.uk)

**Welsh Assembly, Department of Health and Social Services**  
029 2068 1239  
[wales.gov.uk/topics/health](http://wales.gov.uk/topics/health)

**NHS Wales** [www.wales.nhs.uk](http://www.wales.nhs.uk)

**Public Services Ombudsman for Wales** 01656 641150  
[www.ombudsman-wales.org.uk](http://www.ombudsman-wales.org.uk)

**Community Health Councils** (advice about complaints)  
0845 644 7814; [www.wales.nhs.uk](http://www.wales.nhs.uk)

**All Wales Medicines Strategy Group** [www.wales.nhs.uk/awmsg](http://www.wales.nhs.uk/awmsg)

### NORTHERN IRELAND

**The Regulation and Quality Improvement Authority**  
028 9051 7500; [www.rqia.org.uk](http://www.rqia.org.uk)

**Department of Health, Social Services and Public Safety**  
028 9052 0500  
[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

**NHS Northern Ireland**  
[www.ni.nhs.uk](http://www.ni.nhs.uk)

**Northern Ireland Ombudsman**  
0800 343424

[www.ni-ombudsman.org.uk](http://www.ni-ombudsman.org.uk)

**Northern Health and Social Services Council**  
0800 917 0222  
[www.nhssc.org](http://www.nhssc.org)

### GENERAL

**Dr Foster** (health statistics and research) [www.drfooster.co.uk](http://www.drfooster.co.uk)

**Citizens Advice**  
[www.adviceguide.org.uk](http://www.adviceguide.org.uk)