



2009 ANNUAL REPORT
OF THE CHIEF MEDICAL OFFICER

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On the State of Public Health



Progress check



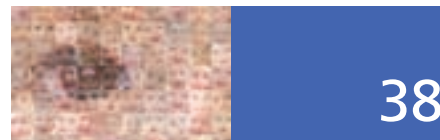
Moving to nature's cure



Winter kills



Rare is common



Grandparenting for health



Climate change and health



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On the State of Public Health

The Chief Medical Officer post was created in the mid-19th century in response to the great cholera epidemics that swept Victorian England. Addressing the major health challenges of the time, the early Annual Reports of the first Chief Medical Officer, Sir John Simon, described the high childhood mortality caused by infectious diseases. They addressed the need for sanitary reform and vaccination.

The Chief Medical Officer has produced an Annual Report in most years since that time. Last year, my Annual Report celebrated the 150th anniversary of the Chief Medical Officers' reports. I am the 15th Chief Medical Officer in this line of succession that stretches back to 1855.

In December 2009, I informed the Government that I intend to step down in the summer of 2010. I will have been in post for 12 years. I have prolonged my intended departure by a year to lead the response to the influenza pandemic that started in April 2009. This Annual Report is therefore my last.

In each of its predecessors, and in this current report, I have tried to focus on health problems, challenges and subjects where I believe that action is necessary or that awareness needs to be raised. Through one means or another, these reports have sought to achieve progress to improve the health of the population, the quality of care for patients, and the working lives and careers of healthcare professionals. The main topics of my earlier Annual Reports are listed in an annex to this introduction.

During my time in post, I have provided a wide range of other policy recommendations to the Government.

Many of these have been conveyed in formal documents and reports. Most have been implemented – some through legislation, such as smoke-free public places, embryonic stem cell research and consent for organ and tissue retention – others through reform to the structure and functioning of the health service, for example the establishment of the Health Protection Agency, the Expert Patients Programme and the National Patient Safety Agency. Others have been achieved by creating a new philosophy of medical practice, including the introduction of clinical governance, changes to the General Medical Council and revalidation of doctors. Others have prompted more specific ways to protect patients, such as the abolition of general anaesthetics in the dentist's chair, and the introduction of standards to reduce the risk of paralysis and death resulting from errors in the spinal injection of cancer drugs. In a second annex to this introduction, I have listed the special reports in which these policy recommendations were first put forward. In a third annex I have listed additional reports that I commissioned during my time in office.

Other initiatives prompted by a Chief Medical Officer flow from ideas, proposals or suggestions made to Ministers that are not necessarily part of a formal Chief Medical Officer document or report but may appear in other government documents. In my time, these have included the school fruit scheme, legislation to control healthcare-associated infection, and establishment of the Public Health Observatories.

In last year's Annual Report, I promised to describe the work of the Chief Medical Officer over my time in post. I am

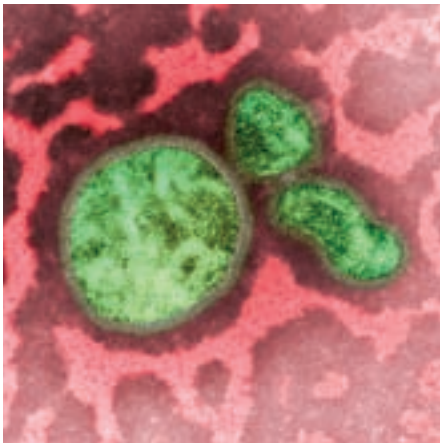
publishing this as a separate report, available electronically. The issues and challenges will continue to evolve from one decade to the next. This report illustrates the breadth and value of the Chief Medical Officer post.

The predominant challenge of 2009 was the emergence of the first influenza pandemic for 40 years. All who know the history of 'flu pandemics felt a twinge of fear in April 2009, when news came from Mexico of atypical pneumonia cases scattered around the country. From Mexico, the illness spread fast around the world. England was amongst the first countries to have cases of what was rapidly confirmed as a new 'flu virus – influenza A/H1N1 2009. The World Health Organization indicated that a pandemic was imminent. For weeks, the spread of 'swine 'flu' ran at the top of the news worldwide.

England was well prepared. In the first weeks of the pandemic, the Health Protection Agency coordinated efforts to isolate those affected by the virus. They traced the people with whom those infected had been in contact and treated them with antiviral medication. A number of schools were temporarily closed. These efforts to slow transmission were maintained for several weeks. Inevitably, the number affected grew. Evidence of severe cases emerged. A growing number of people were admitted to hospital. In June 2009, the country sadly saw its first death.

Demonstrating the unusual way in which pandemic 'flu viruses behave, rates of infection continued to swell into the summer months. General practice felt much of the strain, and handled it well.

When the strain was approaching a critical level, the National Pandemic Flu Service was activated. This was an entirely novel concept for the country, and formed an important part of the pandemic plan. The public had never previously been able to access an internet and telephone-based diagnostic and treatment service that provided medication when appropriate. The National Pandemic Flu Service was well used, and relieved significant pressure on the mainstream NHS.



As summer turned to autumn, the picture was mixed. There had been deaths. Hospital capacity had been stretched significantly, particularly in intensive care. But rates of infection had peaked in August 2009 and were falling. For most people, the disease was milder than had been anticipated based on the early information from Mexico. The number of deaths was small compared with what it might have been with a more virulent virus.

Each of the three 'flu pandemics of the 20th century behaved in a different way. The 2009 pandemic has been different again. Our Government took the

approach, as did many governments around the world, of hoping for the best but preparing for the worst. The pandemic has brought illness, anxiety, disruption and tragedy – but not on the scale that it could have done. 'Flu viruses are unpredictable and we have been right not to let down our guard. But we are now approaching a time in the UK when we can breathe a sigh of relief, for the most part. This pandemic could have been far worse.

I have been heartened by the response of colleagues throughout the NHS in the most difficult periods, and pay tribute to them. The pandemic has not tested them to the extremes that it might have done. Nevertheless, I am confident that they would have fared well had the situation been worse.

Much has changed since the previous pandemic in 1968–70. Advances in critical care medicine have saved lives in the current pandemic. Advances in virology and vaccination technology enabled us to start vaccinating those most at risk within just a few months of the disease emerging. Real-time data have allowed us to track the pandemic in primary and secondary care, and respond accordingly.

Some have called the public health response to the pandemic an overreaction. In so doing, they draw attention to the overall costs of antiviral drugs and vaccines. They speak of the relatively small number of deaths compared with previous influenza pandemics and seasonal influenza outbreaks. In describing the number of deaths in the present pandemic, they often use the prefix 'only'. In response, it is important to ask a number of questions. Would it have been acceptable not to plan as well as we

did for a pandemic nor procure countermeasures? Having done so, and in the face of emerging, worrying evidence from the first phase of the pandemic in Mexico, would it have been right not to deploy existing countermeasures and not to strengthen our holdings? Would it have been acceptable to hide and conceal statistical projections provided by statistical modellers of international standing, even though releasing them publicly caused alarm in some quarters? Would it have been right to take the view that it was acceptable to 'tolerate' a certain number of deaths, considering them low enough to accept, when a way of preventing them was available?

The reality is that much of the prior planning and investment was an 'insurance' against a range of possible scenarios, including worst-case scenarios. From the BSE catastrophe, the 'precautionary principle' emerged. This principle is not free of cost, and, if the threat does not fully materialise, leads some to cast stones at the originators of the plan. That is inevitable. Public health professionals cannot afford to be gamblers hoping to be wise after the event.

Moreover, although the number of deaths was relatively small, the virus killed younger people and those who had previously been healthy. This is different from the 'flu we experience each winter. Deaths amongst younger adults from pandemic ('swine') 'flu were more than 30 times higher than those in the last 'flu season. In the 20th-century pandemics, there was no choice other than to accept the illness – and the deaths associated with the illness. In the first pandemic of the 21st century, we had the option of fighting the illness to protect children and adults from

its adverse consequences. It is vital that we learn from what we have seen in this pandemic, for the sake of those who find themselves tackling – and affected by – the next. It is likely to be worse.

The pandemic has occupied a great deal of time for many in 2009, but much else has also been achieved.

In the years since the first Chief Medical Officer took up post, England's vaccination programme has grown to become a central pillar of public health. Today's children are vaccinated against many conditions with which their parents and even grandparents are unfamiliar, thanks to the success of the programme. A further important vaccination was added in 2009. Every year, 2,000 women are diagnosed with cervical cancer. Sadly, approximately 800 die. It is a disease that often affects women in the middle years of life. Infection with human papillomavirus is responsible for 70% of cases. The introduction of a vaccine against human papillomavirus for teenage girls promises to markedly reduce the incidence of this disease in the future.

My 2008 Annual Report highlighted the problem of passive drinking. Alcohol consumption does not affect only drinkers – it has a substantial negative effect on the rest of society. I made several recommendations, including the introduction of a minimum price per unit of alcohol. I have been pleased to see public health and medical leaders engaging so widely with this issue. Many of its representative bodies have spoken out in favour of a minimum price policy, including the Royal College of Physicians and the British Medical Association. In July 2009, I gave evidence to the parliamentary

Health Select Committee's inquiry into alcohol. Its report, published in January 2010, also calls for a minimum price per unit. I remain convinced of the need for this. The price of alcohol is a crucial determinant of its consumption. Tackling the substantial harms caused by alcohol in this country requires this decisive action.

I remain concerned about young people's drinking. The evidence shows that 11 to 17 year olds drink 20 million units of alcohol (the equivalent of 9 million pints of beer or 2 million bottles of wine) every week. Young people who binge drink in adolescence are more likely to be binge drinkers as adults, and have an increased risk of developing alcohol dependence. In December 2009, I published guidance on the consumption of alcohol by children and young people. I did so at the request of the Secretaries of State for Health and Children, Schools and Families, and the Home Secretary. Based on a review of the scientific evidence, I advised that an alcohol-free childhood is the healthiest and best option. Children under the age of 15 years should certainly drink no alcohol. If young people aged 15 to 17 years do consume alcohol, it should always be with the guidance of a parent or carer, in a supervised environment. I hope that this advice is valuable to parents, helping them to establish a healthy mindset about alcohol with their children. It should also provide information to help health professionals and support services when talking to parents about alcohol and their children. On the basis of my advice, the Department for Children, Schools and Families has launched a major media campaign entitled 'Why Let Drink Decide?' to communicate these important messages widely.

Published in 2008, Lord Darzi's report *High Quality Care for All* marked an important milestone. Its central tenet is that quality should be the 'organising principle' of the NHS. It aims to set the health service on a path defined by the quality of its care. It seeks to promote quality from being the focus of specific workstreams to being at the heart of how the service operates and thinks. In 2009, the health service began working on a particularly key means of achieving this. It has been collecting the necessary data to produce 'Quality Accounts' for 2009/10. Trusts will report their key measures of quality in the same way in which they report their key measures of financial performance. This is vitally important. Focus shifts to where measurement is made. The act of making and reporting measurements of quality will itself catalyse improvement, helping the NHS to continue developing the quality of the service that it provides to patients.

In 2009, two hospitals found their names becoming synonymous with low-quality care. In March 2009, Stafford Hospital was the focus. In November 2009, it was Basildon University Hospital. Such care is unacceptable and it is right that quality should be at the forefront of the public's minds. Excellent quality needs to be a goal to strive for continually, as well as poor quality being identified early and rooted out.

Patient safety problems remain all too common in healthcare systems around the world. The National Patient Safety Agency continues to do important work in highlighting and tackling these problems within the NHS. My 2007 Annual Report, describing surgical safety, highlighted the fact that over 100,000 errors involving surgical patients were reported to the National Patient Safety Agency in that year.

My report recommended that clinical teams should pilot the World Health Organization's Surgical Safety Checklist. A subsequent pilot study of this checklist involved hospitals in London and seven other locations around the world. It demonstrated that using the checklist could reduce the risk of death and post-operative complications significantly. In 2009, the National Patient Safety Agency started to implement its use nationwide.

The use of checklists is common in other high-risk industries, such as aviation and nuclear power. The practice has much to offer healthcare. From May 2009, the National Patient Safety Agency led 19 pilot sites in implementing a checklist in their intensive care units. This checklist was developed in the United States, where it was shown to contribute to a dramatic reduction in the number of central venous catheter-associated bloodstream infections in intensive care units, and so to save lives. In late 2009, 80% of hospital trusts in England joined the implementation of this important work.

I remain Chair of the World Health Organization's Patient Safety Programme, a programme with which the National Patient Safety Agency works closely. Such international collaboration allows the benefits of leading work to be shared rapidly around the world. England has adopted solutions from other countries, but has also made important contributions to patient safety improvement internationally. In November 2009, the National Patient Safety Agency announced a world-leading initiative to tackle a particularly tragic form of medical error. Currently, there is no physical barrier preventing a doctor injecting the wrong medication into the spine. The connectors



between syringes and spinal needles are the same as those between syringes and venous needles. Medications intended for a vein can accidentally be injected into the spine. The tragic consequences of this have been seen repeatedly around the world.

I highlighted this in my report *An Organisation with a Memory* and in my 2002 Annual Report. A series of interim actions were taken, such as using a 'minibag' rather than a syringe to reduce the risk of wrong-route error, re-labelling packaging, and issuing a safety alert that required the NHS to restrict the number of individuals authorised to give spinal injections. But still, there has been no 'fail-safe' physical barrier to prevent the error. The National Patient Safety Agency's latest initiative will lead to physical solutions to this problem being designed for use throughout the NHS.

The task of bringing clinical quality, including safety, to the heart of the health service demands clinical leadership. Doctors and other clinicians need to be skilled in thinking about the whole service, not just individual patients. I am pleased to have played some part in assisting this. For the last four years, I have had junior doctors seconded to my office for a period as clinical advisors. The benefit has been mutual. They have brought a welcome clinical perspective to the work of the Department of Health, whilst gaining skills and experience of health policy and management. The Clinical Advisor scheme offers the opportunity to new individuals every year to work with me and with

senior colleagues elsewhere in the Department of Health, the NHS and national health agencies. Twenty doctors have been appointed, selected from over 600 applicants. I see strong evidence that many in the current generation of young doctors are hungry to engage with the task of improving health and healthcare more broadly than through clinical work alone. Giving them the skills and confidence that they need to succeed is an important investment for the future.

The proportion of doctors who are women has been climbing rapidly over recent years. It now stands at 41%. In my 2006 Annual Report, I discussed some of the particular issues that this group faces. I formed a National Working Group on Women in Medicine to consider the issues and to develop solutions. I was pleased to receive its report in October 2009. The group proposes a series of steps to enhance opportunities for female doctors. The report makes clear recommendations for a number of bodies, including government departments, universities and NHS employers. I look forward to seeing the fruits of many people's labour.

On a similar theme, my 2007 Annual Report drew attention to the barriers of racial discrimination that still exist within the medical profession. Substantial improvements have occurred in recent years, but work remains to be done. In 2009, I chaired a series of round-table meetings on this issue. These brought together high-level representatives from the NHS, the General Medical Council and medical Royal Colleges, amongst others. Both junior and senior doctors were represented. I am pleased by the progress that many of the national bodies are making in this area. I hope that this important issue

will continue to receive the attention it deserves throughout the country.

I am also pleased with the progress that is being made to introduce revalidation for doctors. In 2009, the General Medical Council introduced the necessary categories of registration that will allow doctors to obtain and renew their licence to practise. The Department of Health has established a series of pilot sites through which the operational details of revalidation will be tested and refined. I hope that doctors will welcome revalidation. Between qualification and retirement, competence is simply assumed at present. For the vast majority, this assumption is justified. The revalidation process will allow doctors to move from assumption to demonstration. The process will also play an important part in identifying the small number for whom the current assumption is flawed. It is in the best interest of patients, and of the medical profession as a whole, that we properly ensure that every doctor is a good doctor. However, for doctors revalidation will be most successful if we fulfil our aim of making it generally a supportive and positive experience, helping them to make their good practice even better.

In this year's Annual Report, I address five new health topics.

First, I address the importance of establishing and maintaining regular physical activity throughout life. The benefits of exercise are well known. Health benefits include: stopping and reversing weight gain; reducing the risk of diabetes, heart disease, stroke and some cancers; and preventing osteoporosis and reducing falls in older people. Indeed, at every stage of life, physical activity has something to offer. It is never too late to begin and we are

never too old to continue. Over the last 50 years, activity levels, particularly amongst the young, have fallen. As individuals and as a society we pay a high price for inactivity. Despite knowing the importance of exercise, we have not created an active society. In this chapter I review the benefits of physical activity at different life stages, and make recommendations on how to promote a culture of activity throughout life. Although this is a frequently reviewed topic, the potential benefits of nature's finest cure are still not widely appreciated.

Cold weather kills. A one degree drop in average winter temperature results in an additional 8,000 deaths in England. This is mainly through increased cardiac deaths, strokes and respiratory problems. In a bad winter, this could amount to an additional 50,000 deaths or more. After a cold snap, it takes 40 days for levels of illness and death to return to normal. In my second chapter I show how this is not inevitable. Colder countries, such as Finland, experience much smaller rises in deaths in winter. Staying warm both indoors and outside is essential for winter health. Tracking cold weather data would allow better planning and coordination of health services to prevent and treat ill health caused by cold weather.

Third, approximately 3 million people in the United Kingdom are affected by rare diseases. Each individual rare disease affects fewer than five in 10,000 people, but taken together they are common, with one in 17 people affected by a rare disease. Although there are many thousands of different rare diseases, they share common characteristics. These include a severe, chronic, often degenerative and life-threatening course. Most rare diseases are incurable and lack effective treatment. Services for children

with rare diseases have improved, increasing life expectancy, but the transition into adult services is often unsatisfactory. Rare diseases have reached public consciousness, with a Rare Disease Day in February 2009. However, there is a lack of focus in services, an absence of coordinated care, and a paucity of research to improve the quality of life of those with rare diseases, and of their relatives.

Fourth, grandparents are a great asset to children, and are frequently overlooked in discussions about child health. Grandparents are in a special position of love and respect, which creates a unique opportunity for them to support young people in adopting healthy lifestyles. The role of grandparents in family life has grown over the last century. People are living longer and enjoying a longer retirement. The two-parent family is now only one model of family life, and children benefit from the additional support and care of grandparents. Having greater life experience gives grandparents a knowledge of life's tribulations that they can pass on to children. They can support children through emotionally difficult periods and gently advise them on being healthy and safe in a world where cigarettes, alcohol and drugs, violence and injury are all too common. Finally, what could be a better role model for children than a healthy grandparent, living actively and well to a ripe old age, helped by the good life choices they made when they were younger?

Climate change is a much-discussed topic. Health does not feature in most of these discussions. It should. In the fifth chapter of this report, I explore the complex relationship between climate change and health. World Health Organization figures demonstrate that climate change is already

robbing millions of healthy years of life every year. Amongst many other things, it is causing malnutrition, childhood infection and the spread of diseases such as malaria. Its impact is everywhere, but unjustly distributed. The health impact in Africa is almost 600 times as great as the health impact here. Fortunately, a number of the measures that England can take to reduce climate change also offer the promise of improving the country's health in other ways. This country has the ability to play a leading role in minimising the impact of climate change as a global health disaster. We have a responsibility to be bold in doing so.

A number of colleagues within and outside the Department of Health have contributed to the production of this report. I am most grateful to all of them. As always, the opinions expressed and the conclusions drawn are my own.

As I write this, a few months from leaving my post, I look back on those who preceded me as Chief Medical Officer.

I think of the first in the line, Sir John Simon, architect and champion of many of the public health laws that laid the foundation for improved longevity and better health. I think of Sir Wilson Jameson, who gave the first radio broadcast to the nation during the dark days of the Second World War and who worked tirelessly to help secure the establishment of the National Health Service. I think of a man whom I had the honour to know, Sir George Godber. Described as a 'colossus', he made an immense contribution to public health and to the development of healthcare in the 1960s. He died in 2009 at the age of 100.

I remember Sir Donald Acheson – my predecessor but one – who died a few months ago. I worked closely with Donald during my days as a Regional Director of Public Health. His strong leadership when HIV and AIDS emerged helped mitigate the impact of a new and frightening threat to health.

I look back and think myself fortunate and privileged to have been able to follow these illustrious predecessors into a post that works within government but is not political, that works for the Government but has an independent dimension, and that serves and speaks to the people and to those in power without fear or favour.

Looking forward, I hope that some of my unfinished business will be concluded. The introduction of smoke-free public places in July 2007 was a public health landmark. It marked a recognition that people should not have to suffer the health consequences of somebody else's smoking. I look forward to an equivalent realisation about alcohol. The alcohol pricing recommendation that I made in last year's Annual Report has gained wide support more rapidly than did my 2002 call for smoke-free public places. I hope that it will pass into legislation more rapidly too. In my 2006 Annual Report, I recommended the introduction of an 'opt-out' organ donation system. People are still needlessly dying whilst on the waiting list for an organ transplant. I greatly look forward to the day when this important change is made. Patient safety and clinical governance have become important foci for the NHS, but I look forward to the time when they are such deeply embedded concepts that the terms themselves are almost redundant.

The work of public health practitioners is never complete. I hope that I have advanced awareness of the obesity health time bomb and, in this report, of the disastrous health impacts of climate change. Both of these – and more besides them – will be ongoing health issues for the 21st century. I look forward and think about the day when I hand the baton of history to my successor. I wish them every success, whoever they – she or he – may be. I urge them to be ambitious – not for headlines, but for the prize of better health and better, safer healthcare that can be won by the strong and the brave.

In signing off, I must express my deep gratitude to all who, as a result of reading my reports, have been inspired to help advance the causes and actions that I have championed. The fight goes on to save lives, reduce human suffering and increase the years spent in the glow of health, rather than the shadow of disease. I would ask you to play your role in ensuring that the important issues covered in this report receive the same attention.



Sir Liam Donaldson
Chief Medical Officer
March 2010

Annex 1: Content of the present Chief Medical Officer's Annual Reports



2001

Health inequalities
High blood pressure
Alcohol and liver cirrhosis
E. coli O157
Epilepsy



2002

Second-hand smoke
West Nile virus
Obesity
Intrathecal chemotherapy
Poor medical performance



2003

Smoking and health
Smoke-free: the economic case
Better blood transfusion
Focus on academic medicine
Early diagnosis of HIV



2004

Smoking and borders
Chronic obstructive pulmonary disease
Public sector food procurement
Gastroschisis
Patient safety alert compliance



2005

Variation in clinical practice
Patient safety and aviation
Early recognition of kernicterus
Public health spending and staffing levels
Planning for the 'flu pandemic



2006

Healthcare-associated infection
Organ transplantation
Radiotherapy errors
Intrapartum-related deaths
Women in medicine



2007

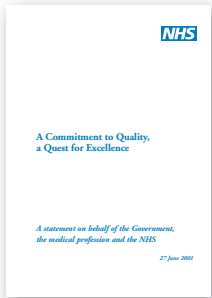
Teenage health
Making surgery safer
Vaccines for the future
Oesophageal cancer increases
Racial equality in medicine



2008

Passive drinking
Prostate cancer
Chronic pain
Antimicrobial resistance
Safer medical practice through simulation

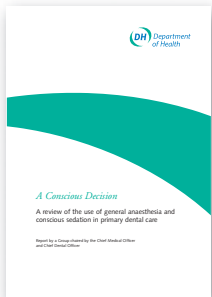
Annex 2: Special reports produced by the present Chief Medical Officer



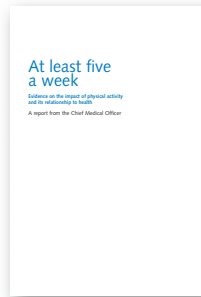
A Commitment to Quality, A Quest for Excellence: A statement on behalf of the Government, the medical profession and the NHS (2001)
Set out the first systematic framework to ensure the quality of NHS services, including standard setting, guidance, action on patient safety and a commitment to collaborative working



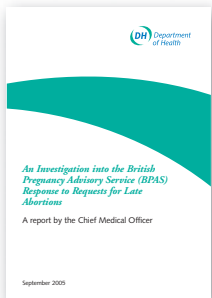
Assuring the Quality of Medical Practice: Implementing Supporting doctors protecting patients (2001)
Led to the establishment of effective assessment and retraining for doctors and other health professionals with problems, thereby improving quality of care



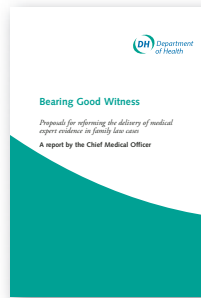
A Conscious Decision: A review of the use of general anaesthesia and conscious sedation in primary dental care (2000)
Led to a series of actions aimed at eliminating deaths of unconscious patients in the dentist's chair



At Least Five a Week: Evidence on the impact of physical activity and its relationship to health (2004)
Demonstrated the compelling evidence for recommending increased physical activity and the resulting health benefits



An Investigation into the British Pregnancy Advisory Service (BPAS) Response to Requests for Late Abortions (2005)
Led to changes in the handling of requests for late abortions, improving the speed of referral and provision of information to patients



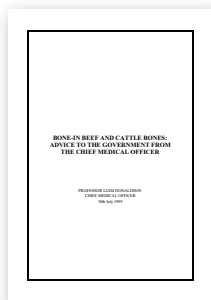
Bearing Good Witness: Proposals for reforming the delivery of medical expert evidence in family law cases (2006)
Improved the quality and supply of health expert witnesses through piloting new ways of commissioning witnesses to family courts in public law childcare proceedings



An Organisation with a Memory: Report of an expert working group on learning from adverse events in the NHS (2000)
Established a comprehensive patient safety programme in the NHS, one of the first in the world



Best and Safest Care: Report on the quality and patient safety national workstream of the NHS Next Stage Review (2008)
A report presented by the Chief Medical Officer to Lord Darzi, which informed the quality and safety element of the NHS Next Stage Review



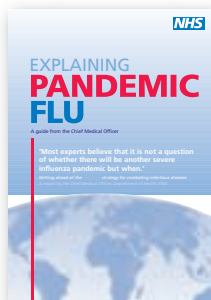
Bone-in Beef and Cattle Bones: Advice to the Government from the Chief Medical Officer (1999)

Took a cautious approach to the timing of the removal of a ban on potentially high-risk material that had been excluded from the food chain as part of BSE controls



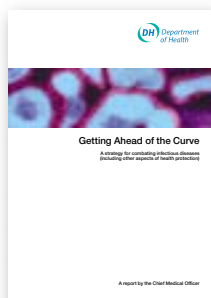
Building a Safer NHS for Patients: Implementing An Organisation with a Memory (2001)

Established the National Patient Safety Agency, which has gathered more than 2 million incident reports of unsafe care and has used them for learning and to take action to reduce the risk to patients



Explaining Pandemic Flu: A guide from the Chief Medical Officer (2005)

Explained the need to prepare for pandemic influenza and set out the steps to do so effectively



Getting Ahead of the Curve: A strategy for combating infectious diseases (including other aspects of health protection) (2002)

Set out a major reform of health protection arrangements, leading to the establishment of the Health Protection Agency, improving surveillance and control of infections, and responding effectively to serious incidents



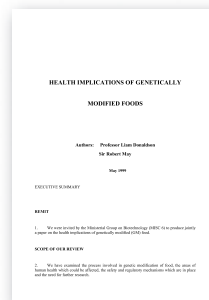
Good Doctors, Safer Patients: Proposals to strengthen the system to assure and improve the performance of doctors and to protect the safety of patients (2006)

Established a far-reaching programme of reform of medical regulation, including changes to the General Medical Council and the revalidation of doctors



Guidance on the Consumption of Alcohol by Children and Young People: From Sir Liam Donaldson, Chief Medical Officer for England (2009)

First ever evidence-based advice for children, their parents and health professionals recommending an alcohol-free childhood. Informed a major awareness campaign



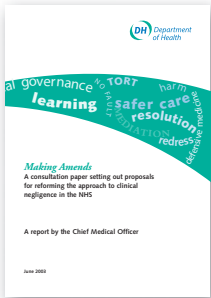
Health Implications of Genetically Modified Foods (1999)

Found that genetically modified foods were unlikely to be harmful, but recommended key safeguards to be taken forward by the Food Standards Agency



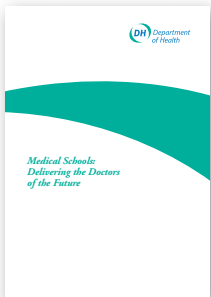
Health is Global: Proposals for a UK Government-wide strategy (2007)

Led to the first comprehensive UK Government-wide strategy for global health, launched in May 2009



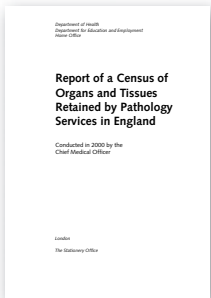
Making Amends: A consultation paper setting out proposals for reforming the approach to clinical negligence in the NHS (2003)

Set out a new scheme to help those suffering harm as a result of clinical treatment; however, the NHS Redress Scheme has not yet been implemented



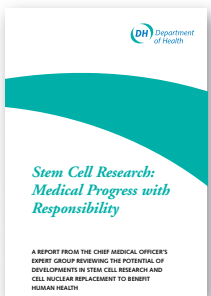
Medical Schools: Delivering the doctors of the future (2004)

Provided a comprehensive review of medical education, the expansion in medical schools, and measures to make future doctors more representative of the populations they serve



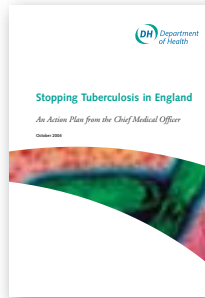
Report of a Census of Organs and Tissues Retained by Pathology Services in England (2001)

Identified the scale and nature of the problem of retained organs and tissues in response to public concern, and set out the need for corrective action



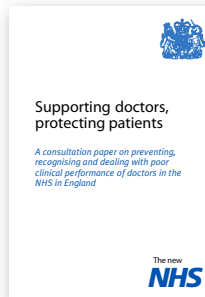
Stem Cell Research: Medical progress with responsibility (2000)

Led to new legislation that allowed research into therapeutic cloning and other techniques aimed ultimately at treating incurable diseases and injury



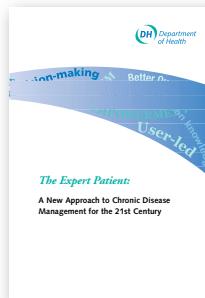
Stopping Tuberculosis in England: An action plan from the Chief Medical Officer (2004)

Set out action to tackle the resurgence of tuberculosis, including prevention, treatment and control



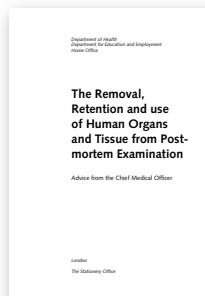
Supporting Doctors, Protecting Patients: A consultation paper on preventing, recognising and dealing with poor clinical performance of doctors in the NHS in England (1999)

Gave early protection to patients from poor practice and reduced the emphasis on long suspensions of doctors



The Expert Patient: A new approach to chronic disease management for the 21st century (2001)

Created a programme to give patients the skills to manage their own illnesses, improving their quality of life and reducing their dependency on services

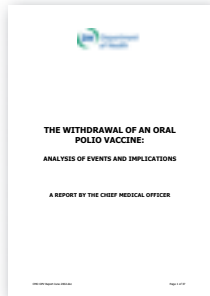


The Removal, Retention and Use of Human Organs and Tissue from Post-mortem Examination (2001)

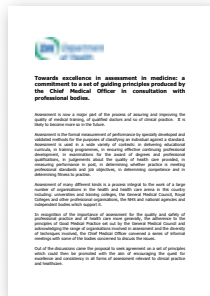
Initiated comprehensive changes in practice, including legislative change, to prevent a repetition of organ retention scandals such as Alder Hey



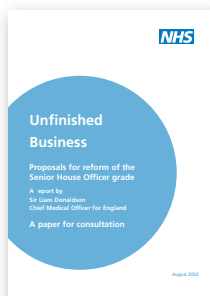
The Report of the Chief Medical Officer's Project to Strengthen the Public Health Function (2001)
Reinvigorated the public health system in England, strengthening national, regional and local public health delivery



The Withdrawal of an Oral Polio Vaccine: Analysis of events and implications (2002)
Examined the circumstances leading to the withdrawal of oral polio vaccine and initiated a review of procedures to ensure the validity of information supplied by pharmaceutical companies on the safety of their products



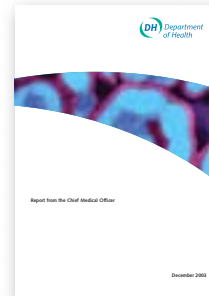
Towards Excellence in Assessment in Medicine: A commitment to a set of guiding principles (2007)
Put forward for comment a set of guiding principles for assessment in the training of doctors



Unfinished Business: Proposals for reform of the Senior House Officer grade (2002)
Initiated much-needed reform to the training of doctors in the first years after qualification

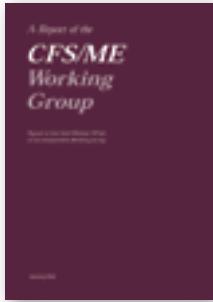


West Nile Virus: A contingency plan to protect the public's health (2004)
Ensured full preparation against a possible future new disease threat



Winning Ways: Working together to reduce healthcare associated infection in England (2003)
Established the first systematic and comprehensive campaign to reduce healthcare-associated infection in the NHS

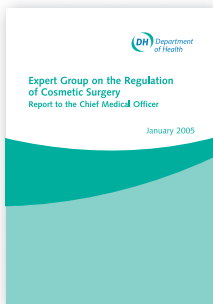
Annex 3: Special reports commissioned by the present Chief Medical Officer



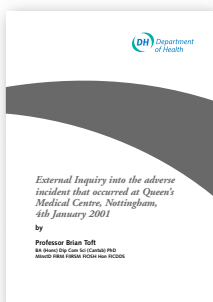
A Report of the CFS/ME Working Group (2002)
Examined in depth how the NHS could improve care for people who suffer from chronic fatigue syndrome or myalgic encephalomyelitis



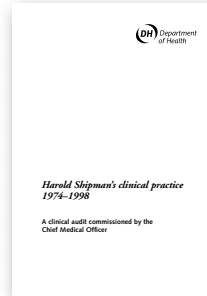
Association of Public Health Observatories Indications series
A series of quantitative analyses presenting data from the English regions in a form that has assisted policy development in a range of public health domains



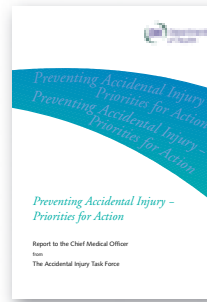
Expert Group on the Regulation of Cosmetic Surgery: Report to the Chief Medical Officer (2005)
A comprehensive review of cosmetic surgery regulation. Progress has been slow and controversial in this area



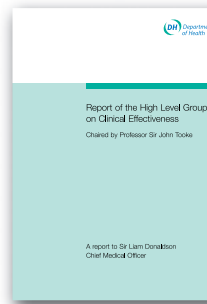
External Inquiry into the Adverse Incident that Occurred at Queen's Medical Centre, Nottingham, 4th January 2001 (2001)
A detailed investigation into the tragic death of teenager Wayne Jowett. This report was pivotal in establishing patient safety concepts in the UK



Harold Shipman's Clinical Practice 1974-1998: A clinical audit commissioned by the Chief Medical Officer (2001)
The first convincing demonstration that Shipman was responsible for many more deaths than those he was convicted of, confirming that his behaviour had remained undetected for many years



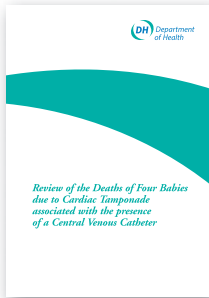
Preventing Accidental Injury – Priorities for action: Report to the Chief Medical Officer (2002)
Report by the Accidental Injury Task Force, recommending specific cross-government actions to help prevent accidental injury



Report of the High Level Group on Clinical Effectiveness (2007)
Flowed from the 2005 Chief Medical Officer's Annual Report. This group examined variations in clinical practice and made important research, clinical and policy recommendations

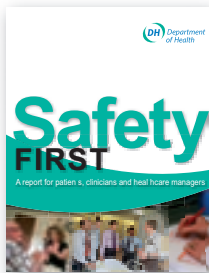


Report of the Independent Expert Working Group on the Prevention of Venous Thromboembolism in Hospitalised Patients (2007)
Set in train a national approach to reduce the 25,000 deaths a year from venous thromboembolism in NHS hospitals. This approach is now firmly embedded in NHS policy and practice



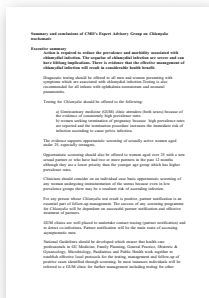
Review of the Deaths of Four Babies due to Cardiac Tamponade Associated with the Presence of a Central Venous Catheter (2001)

Enhanced awareness of this safety problem, and led to advice being issued to the NHS about avoiding recurrence



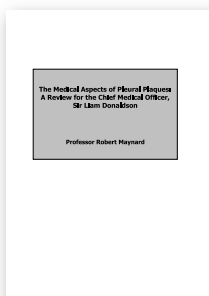
Safety First: A report for patients, clinicians and healthcare managers (2006)

Reviewed progress in patient safety within the NHS since the publication of An Organisation with a Memory in 2000, and set out a comprehensive action plan which has now been almost completely implemented



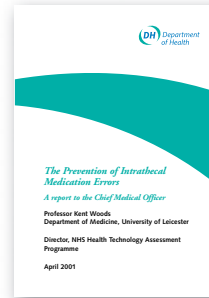
Summary and Conclusions of CMO's Expert Advisory Group on *Chlamydia trachomatis* (1998)

Led to the introduction of an opportunistic screening programme to tackle low awareness of, and testing for, sexually transmitted chlamydial infection in young people



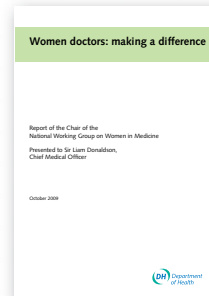
The Medical Aspects of Pleural Plaques: A review for the Chief Medical Officer (2009)

Set out recommendations based on a review of the published research evidence to establish the extent to which people who are diagnosed with pleural plaques are likely to develop asbestos-related conditions



The Prevention of Intrathecal Medication Errors: A report to the Chief Medical Officer (2001)

Led to a comprehensive series of actions designed to prevent recurrence of this important safety issue



Women Doctors: Making a difference. Report of the Chair of the National Working Group on Women in Medicine (2009)

This working group, established as a result of the Chief Medical Officer's 2006 Annual Report, formulated practical solutions to tackle the barriers that female doctors may face

Progress check: Last year's Annual Report



Passive drinking: the collateral damage from alcohol

Last year my Annual Report highlighted the harm that alcohol causes to society. Alcohol does not just harm those who drink it. It causes family problems. It causes crime and disruption in our streets. It places a huge burden on the NHS. In my report, I put forward the case for these 'passive drinking' effects being taken more seriously. Alcohol harms even those who do not drink, and this should represent a strong rationale for action. I made a series of recommendations to reduce the collateral damage that alcohol causes.

One of my recommendations was that the Government should institute a minimum price per unit of alcohol. I suggested that this might be set at 50 pence. This proposal has a strong evidence base. The evidence is that such a policy would barely affect those who drink moderately. It would have a far greater impact on those who drink heavily.

During my 12 years as Chief Medical Officer, my Annual Reports have attracted a good deal of political, media and public attention. This topic attracted more attention than any previous Annual Report topic and ignited a much-needed debate.

The Government initially rejected my minimum price recommendation outright. Over the course of the year, however, opinion within government and public opinion have both shifted palpably. I am particularly pleased by the strong and vocal support from key medical institutions. The Royal College of Physicians spoke out powerfully in favour of the proposal. At the annual meeting of the British Medical Association, members voted in clear favour of supporting the minimum price recommendation.



Individually these voices are strong. Together they have real volume. The Alcohol Health Alliance UK brings together the Royal College of Physicians, the Royal College of Surgeons, the Academy of Medical Royal Colleges, the Faculty of Public Health and 20 other such organisations. To see such a group of medical bodies speaking together with one voice is very powerful. They speak in particular of the passive harms of drinking. They, too, call for a minimum price per unit.

Other professionals have echoed this call. The Faculty of Public Health represents 3,000 public health specialists from the United Kingdom and elsewhere. The Royal Society for Public Health has 6,000 members from health-related professions. In January 2010, these two institutions joined forces to publish a public health manifesto. It listed 12 actions that government could, and should, take to tackle a range of public health concerns. The first action on the list was a minimum price per unit of alcohol.

In mid-2009, the parliamentary Health Select Committee held an inquiry into alcohol. It also concluded that the Government should introduce a minimum price per unit of alcohol.

It is quite clear that action is needed. Alcohol continues to cause needless ill health and misery across this country. No individual measure is going to tackle this problem in isolation – instead, a package of actions is required. The evidence consistently shows that two factors in particular affect alcohol consumption – access and price. Price is a crucial mechanism by which the Government can have a positive impact on the country's alcohol consumption, and therefore its health.

Over the last year, support for a minimum alcohol price has increased rapidly. Support for smoke-free public places, for example, which I called for in my 2003 Annual Report, took far longer to build.

I reiterate the call for action. The introduction of a minimum price per unit of alcohol will save lives and improve health.

Prostate cancer: what to do with the pussycats?

Prostate cancer is the most common cancer amongst men. Last year I drew attention to the difficulties faced by many men diagnosed with prostate cancer. Prostate cancer behaves differently to other cancers. It grows slowly and often does not cause symptoms or harm. Affected men are three times more likely to die of something other than the prostate cancer itself.

Whilst there are effective treatments for prostate cancer, such as surgery or radiotherapy, they produce impotence or incontinence. This leaves many men with a difficult decision about whether to treat their cancer and risk experiencing these symptoms or to delay treatment and risk the cancer spreading beyond the prostate and causing death.



The ability to accurately differentiate the cancers that will spread and cause extensive disease from those that will remain localised to the prostate is important. Last year I called for ongoing work on the early identification of which low- and intermediate-risk tumours will progress to life-threatening tumours to be monitored closely. I am pleased to see that work is continuing into methods to differentiate these cancers. Projects such as the Bristol-based ProtecT trial are looking at the effectiveness of different treatment approaches for low-risk prostate cancer. ProtecT has recently finished recruiting subjects, although the results are still many years away.

My report also considered a national screening programme for prostate cancer. The prostate specific antigen (PSA) test may identify prostate cancer at an early stage. However, most cancers identified by screening fall into the low-risk category, and their management is uncertain. In 2009, two major studies were published that looked at the effectiveness of screening: one from the United States and one from Europe. The American study found no benefit from screening. The European study found a slight reduction in mortality. However, 1,400 men would need

to be screened and 50 men treated to save one life. Many of those 50 men would be left impotent or incontinent following their treatment. Since publishing my Annual Report, I have asked the UK National Screening Committee to review the results of these trials and assess the implications for screening for prostate cancer in England.

I also found that men living in the most affluent parts of the country were more likely to have a radical prostatectomy, the main form of surgical treatment for prostate cancer. It is unlikely that the true incidence of prostate cancer is greater in men living in the most affluent parts of the country. The higher rates of surgery may represent some unnecessary treatment for these men, with its associated risk of impotence or incontinence. Equally, they may reflect that men in the least affluent areas are not getting appropriate treatment. The South West Public Health Observatory in Bristol will be carrying out an investigation into inequalities in prostate cancer care across the country at my request. It is due to report later this year.

Pain: breaking through the barrier

Each year, 5 million people in the United Kingdom develop chronic pain, but only two-thirds will recover. Chronic pain can ruin the lives of those living with it and those close to them. People with chronic pain need high-quality services. However, service provision is variable across the country, and over a third of patients have reported inadequate control of their pain. In England, there is currently only one pain specialist for every 32,000 people in pain.

In last year's Annual Report, I recommended that training in chronic pain should be



included in the curricula of all health professionals. The British Pain Society recently launched a survey of the curricula of United Kingdom health professions, looking at the content of material related to pain. The shortcomings identified will no doubt give further impetus for improvement.

I also recommended that all chronic pain services should supply comprehensive information to a National Pain Database. In September 2009, Dr Foster Research and the British Pain Society launched a three-year audit of pain services, which should form the backbone of data collection in the future.

In my Annual Report, I proposed that chronic pain should be addressed as a public health problem. I am pleased that a group has now been established at the Royal College of General Practitioners to examine my suggestions in more detail.

In July 2009, the Department of Health launched a consultation on new Essence of Care benchmarks on pain. An important component is ensuring that people have an 'ongoing, comprehensive assessment of their pain' based on initial and ongoing identification of pain by trained staff and assessment using evidence-based tools.

Much has been achieved through the work of a voluntary coalition of organisations that have worked with my office to pursue the agenda I set out in my report. Together, these organisations – the British Pain Society, the Chronic Pain Policy Coalition, the Faculty of Pain Medicine, the Patients Association and the Royal College of General Practitioners – have drafted three important proposals.

First, they have applied for funding from the national e-Learning for Healthcare programme to develop online educational material for all health workers who come into contact with patients. Everyone, from care assistants to senior clinicians, should be able to assess pain and know how best to respond.

Second, the group has produced a submission to the National Quality Board of the National Health Service, whose task it is to set priorities within the service and select areas that require national attention and input in order to develop excellent services for all.

Finally, the possibility of holding a National Pain Summit has been raised. In other countries, such as Australia, this has been important in bringing together expertise and experience to develop a coherent national plan for pain services. I support this initiative, and believe it will be an important step in revitalising pain services in this country.

There is no question that a great deal of work remains to be done. However, I hope that through my report, and the hard work of those who are striving to implement its recommendations, there is the potential to improve the lives of the millions of people who live with chronic pain.

Antimicrobial resistance: up against the ropes

Antibiotics have had a dramatic effect on reducing infection and disease, saving many lives since their discovery. But in the 21st century, resistance to antibiotics is becoming a significant problem. In last year's Annual Report, I discussed the problem of antibiotic resistance, and made recommendations to improve the situation.

I was pleased that my recommendation to consider novel ways to stimulate research into and development of new antibiotics was considered in December 2009 by the European Council. Its conclusions included a requirement for the European Commission to develop proposals to create new effective antibiotics and ways to secure their rational use. I had suggested that antibiotic packages should contain a warning about the importance of taking antibiotics responsibly and appropriately. This may require a change in European Union regulations, and I hope that the United Kingdom will take a lead in championing these changes.

My report also called for the prohibition of the use of certain types of antibiotics in animals. I am pleased to note that the Committee for Medicinal Products for Veterinary Use at the European Medicines Agency has taken steps to promote rational prescribing of fluoroquinolones in animals. Precautionary phrases are also to be included on the labels of all veterinary medicines for animals bred for food.

Closer to home, there is much that can be done. There has been much progress on my recommendation to raise the profile of existing public education campaigns. The Advisory Committee on Antimicrobial Resistance and Healthcare Associated



Infection has developed plans to use video systems in general practitioner surgeries and slots on television to highlight antimicrobial resistance. The Department of Health continues to promote its public campaign on sensible antibiotic use, as well as supporting the annual European Union Antibiotic Awareness Day.

Another recommendation was that no further antibiotic classes should be made available over the counter without careful consideration. Since then, applications to reclassify antibiotics for pharmacy that were being considered last year have been withdrawn.

Certain resistant strains of bacteria can often be imported from other countries, and some, such as *Neisseria gonorrhoeae* (a common cause of sexually transmitted infections), are becoming increasingly common in England. Action at an international level will be necessary. I hope that the summit between the European Union and the United States on antimicrobial resistance will be an opportunity to address some of the issues at an international level.

Safer medical practice: machines, manikins and Polo mints

Medical simulation offers an important route to safer care for patients, and in last year's Annual Report I called for it to be more fully integrated into the health service.

I was extremely pleased to see that the Health Select Committee report on patient safety, published in July 2009, called for improved training in patient safety for clinicians, with an emphasis on non-technical skills. Simulation was specifically singled out in the evidence as a potential means to achieve this.

Since publication of my report, there have been a number of simulation conferences. The National Association of Medical Simulators met in Manchester to define the role of simulation in clinical education and in the NHS. The London Deanery's Simulation and Technology-enhanced Learning Initiative (STeLI) conference focused on human factors and training for safer medical practice. Both events showcased the cutting edge of simulation use in medical education.

Additionally, new simulation centres have been established, such as the one at the Whittington Hospital in London, which opened in December 2009. Funded by the London Deanery, this high-tech training and assessment facility will collaborate with nine other simulation centres across the capital to meet the growing demand for scenario-based training.



The 2009 Health Service Journal Award for Patient Safety was given to STeLI, while the Royal College of Obstetricians and Gynaecologists appointed its first director of simulation and recently held the first European conference on simulation in women's health.

I hope that these separate strands will continue to develop in order to embed simulation as a core element in medical training.



Moving to nature's cure

Key points

- Inactivity affects 60–70% of the adult population: that is more people than obesity, alcohol misuse and smoking combined.
- The physical fitness of children is declining by up to 9% per decade.
- By increasing the risk of developing more than six major diseases, inactivity poses a significant risk to the population's health.
- Physical activity tends to decline with age, but this decline is not inevitable.
- The potential benefits of physical activity to health are huge. If a medication existed which had a similar effect, it would be regarded as a 'wonder drug' or 'miracle cure'.

The benefits of regular physical activity to health, longevity, well being and protection from serious illness have long been established. They easily surpass the effectiveness of any drugs or other medical treatment. The challenge for everyone, young and old alike, is to build these benefits into their daily lives.

Table 1: Incidence of ischaemic heart disease in bus drivers and bus conductors

Age (years)	Conductors Incidence rate per 100 men in 5 years	Drivers Incidence rate per 100 men in 5 years
40–49	1.6	7.6
50–59	5.1	9.8
60–69	7.4	7.9
Total	4.7	8.5

Source: Morris JN, Kagan A, Pattison DC and Gardner MJ. Incidence and prediction of ischaemic heart-disease in London busmen. *Lancet* 1966; 2(7463): 553–9

On 28 October 2009, Professor Jerry Morris died aged 99 years in London. In the 1950s and 1960s, his inspirational study of heart disease amongst sedentary drivers and more active conductors on London buses provided early evidence of a link between physical activity and health (see **Table 1**). Since this time, the evidence for a positive effect of activity on health has grown inexorably. Levels of physical activity have not increased in tandem.

According to the Health Survey for England 2008, over 60% of the adult population in England fail to meet the minimum recommendation of 30 minutes of physical activity five times a week. This poses a substantial risk to public health. Everyone, irrespective of their age, can take action to reverse this dangerous trend, with significant benefits to their health and general well-being.

The human body evolved to move; physical activity should be as much a part of everyday life as breathing or eating. Why, then, are so many people continuing to ignore nature’s cure?

The size of the problem

Inactivity pervades the country. It affects more people in England than the combined total of those who smoke, misuse alcohol or are obese (see **Table 2**). On average, inactivity costs each primary care trust £5 million per year due to health consequences. In 2008, 61% of men and

71% of women aged over 16 years failed to meet the minimum adult recommendations for physical activity, according to self-reported surveys. Such reports are of grave concern. Even these figures are likely to underestimate the true burden of inactivity. When a sample of respondents in the Health Survey for England had their physical activity levels measured directly, only 8–10% of adults who claimed to exercise for 30 minutes at least five times a week actually did so.

Levels of inactivity amongst children are startlingly high. Amongst 2–15 year olds, 68% of boys and 76% of girls do not meet the minimum recommendation of an hour of moderate physical activity per day.

As a result, children are being exposed to health risks including obesity, weak bones and future heart disease.

The proportion of the population meeting recommended levels has increased in recent years, but the change is small. The Government aims to get 2 million adults more active by 2012. The latest Government strategy, *Be Active, Be Healthy* (2009), describes collaborative working and targeted local delivery. This will move the population closer to this goal. Achieving this target will require more than central and local government commitment. Such rapid increases in activity have not been seen before in any country. What is needed is nothing less than a societal shift so that physical activity, rather than inactivity, becomes the norm in everyone’s behaviour.

The trend of inactivity

In recent years, the role of physical activity in daily routines has significantly reduced. During the last century, the proportion of

Table 2: Inactivity is a major public health threat

	Alcohol misuse	Smoking	Obesity	Inactivity
Percentage of adult population affected in England	6–9%	20%	24%	61–71%
Estimated cost to the English economy per year	£20 billion	£5.2 billion	£15.8 billion	£8.3 billion
Estimated cost to the NHS per year	£2.7 billion	£2.7 billion	£4.2 billion	£1–1.8 billion

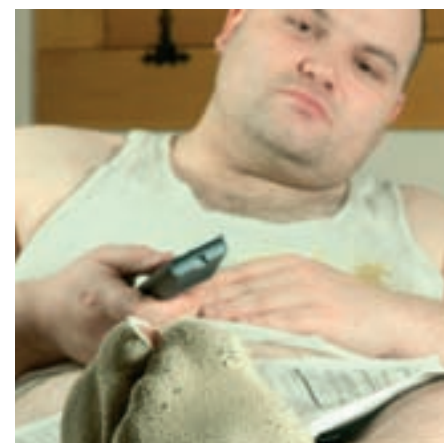
Source: Adapted from a number of reports of official statistics and other published work

people employed in non-active professional or managerial roles has more than doubled. There has been a corresponding decline in the number of people employed in more active partly skilled or unskilled jobs (from 49% to 28%). This has been only partly offset by a small increase in the number of people taking part in physical activity for leisure. Time pressures and accessibility have influenced transport patterns. Over the last 25 years, the average number of miles per year travelled on foot has fallen by 25% and by cycle 33%. In stark contrast, the average number of miles per year travelled by car has increased by 70%. Fear of traffic and concerns over 'stranger danger' combine with pressures on childcare to promote sedentary childhood leisure activities within the home environment. Two-thirds of adults are sedentary for six or more hours on weekdays and the average adult watches

2.8 hours of television per weekday, increasing on weekends. This is 16 times greater than the average time currently spent in physical activity which would count towards the recommendations. This is a substantial threat to health, given that high levels of sedentary behaviour have been associated with increasing risk of mortality. These days, sport is largely a spectator activity providing entertainment by watching, rather than participating.

General health risks of inactivity

In my 2004 report, *At Least Five a Week*, I described the evidence for the impact of physical activity on health. Physical inactivity is estimated to cause 1.9 million deaths globally, making it one of the top 10 leading risk factors contributing to death in developed countries. In Europe, 10.4% of all premature deaths would be prevented if everyone who is currently inactive became



active. It also significantly increases the risk of chronic diseases, including type 2 diabetes, heart disease, stroke, osteoporosis and some cancers (see **Table 3**). The relationship between inactivity and obesity is well recognised. In my 2002 Annual Report, I highlighted the need for action to arrest the obesity epidemic. It is of concern that the prevalence of obesity has continued to increase in recent years. The majority of the adult population and 30% of children are either overweight or obese. Almost a quarter of adults are now obese. These increases are partly due to declining levels of physical activity. More heart disease deaths are due to inactivity than due to smoking or high blood pressure, and up to 3,000 cases of cancer per year could be prevented by becoming more active.

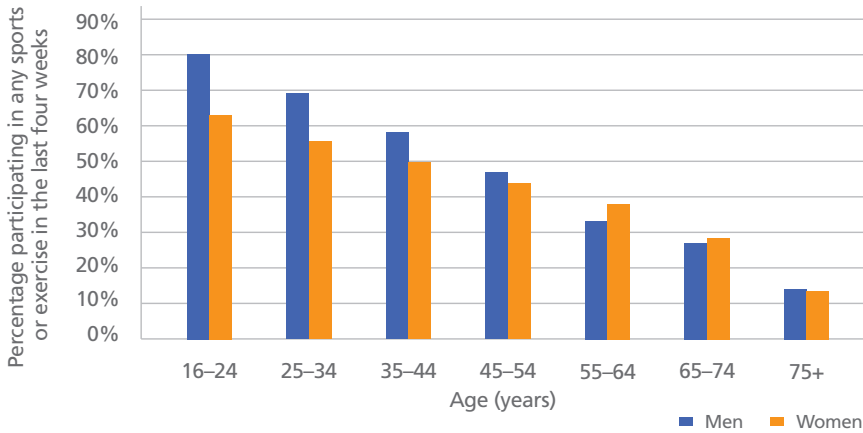
The London 2012 Olympic and Paralympic Games provide a unique opportunity to encourage individuals to commit to an active lifestyle. If the Government's target of 2 million more adults active by 2012 can be achieved, this will provide a lasting legacy for health by reducing the burden of disease in years to come.

Table 3: Physical activity substantially reduces the risk of common diseases

Disease	Effect of physical activity
Coronary heart disease	Moving to moderate activity could reduce risk by 10%
Stroke	Moderately active individuals have a 20% lower risk of stroke incidence or mortality
Type 2 diabetes	Active individuals have a 33–50% lower risk
Colon cancer	The most active individuals have a 40–50% lower risk
Breast cancer	More active women have a 30% lower risk
Osteoporosis	Being physically active reduces the risk of later hip fracture by up to 50%

Sources: Chief Medical Officer's report on physical activity and a range of published studies – full references listed at the end of this Report

Figure 1: The relationship between age and physical activity



Source: Health Survey for England 2008

age. By encouraging physical activity throughout life and instilling exercise skills and attitudes, the course of these diseases can be modified. The health and wider benefits of physical activity are not restricted to a sub-group of the population. Anyone at any age can significantly improve their health and general well-being by becoming more active.

This influence of age on physical activity reflects diverse motivating factors and barriers at different stages of life. The benefits of physical activity are also not uniform through the life course (see Table 4). By understanding these influences, targeted strategies can be developed to encourage individuals of all ages to become and remain active.

Educating parents and carers is central to promoting activity in the early years. By school age, the focus needs to shift to making physical activity more accessible,

Wider benefits of physical activity

Becoming more active will not only improve the nation's health. Engaging in social physical activities also enhances mental and social well-being and reduces adverse reactions to stress. Physical activity is associated with a reduced risk of developing depression and may be as effective as medication in its treatment. Engaging in physical activity also keeps the brain active, particularly in older age.

In younger age groups, increasing fitness may mean that an individual can now play a new sport or run faster. For an older person, maintaining fitness levels may mean the difference between independent living and needing help to climb the stairs or get out of bed. This has a huge impact on quality of life in the older years.

Physical activity: age matters

Age is the best predictor of participation in physical activity (see Figure 1). With increasing age, the proportion of adults

who are physically active reduces. This is not inevitable. Unsurprisingly, the prevalence of obesity, cardiovascular disease and falls significantly increases with



Table 4: The seven stages of an active person

	Specific benefits	Key motivating factors	Likely barriers
Pre-school	<ul style="list-style-type: none"> • Communication • Exploration • Motor development 	<ul style="list-style-type: none"> • Parental influence 	<ul style="list-style-type: none"> • Influence of parents/carers
School age	<ul style="list-style-type: none"> • Maintain healthy weight • Develop core skills (eg throwing and catching) • Teamwork 	<ul style="list-style-type: none"> • Parental influence • Variety of activities in and out of school 	<ul style="list-style-type: none"> • Access • Promotion of sedentary activities
Adolescence	<ul style="list-style-type: none"> • Bone mineralisation • Reduce risk of mental health problems • Promote healthy habits 	<ul style="list-style-type: none"> • Team and peer influences • Role models 	<ul style="list-style-type: none"> • 'Buddies' • Popular sedentary activities
Young adult	<ul style="list-style-type: none"> • Modify cardiovascular risk factors • Maintain healthy weight • Reduce stress 	<ul style="list-style-type: none"> • Accompanying children 	<ul style="list-style-type: none"> • Motivation • Availability and accessibility of facilities
Middle age	<ul style="list-style-type: none"> • Maintain flexibility • Limit weight gain • Reduce stress 	<ul style="list-style-type: none"> • Weight loss • Accompanying children 	<ul style="list-style-type: none"> • Time • Motivation and prioritisation
50–65 years	<ul style="list-style-type: none"> • Reduce cardiovascular risk • Reduce osteoporosis risk 	<ul style="list-style-type: none"> • Perceived health risks • Improved quality of life 	<ul style="list-style-type: none"> • Perceived inability and lack of fitness • Health concerns
Over 65 years	<ul style="list-style-type: none"> • Social benefits • Improve activities of daily living and mobility • Improve cognition 	<ul style="list-style-type: none"> • Social/enjoyment • Help with injury and disability 	<ul style="list-style-type: none"> • Health concerns

including emphasising its importance within the school curriculum. Increasing physical activity within the curriculum does not adversely affect academic outcomes. In fact, it may actually improve educational attainment.

At puberty, the mineralisation of bones increases rapidly. The greatest benefits of exercise on bone health are therefore seen at this time. Weight-bearing activities that stress the bone may increase bone

mineralisation by up to 15% with substantial reduction in the risk of osteoporotic fractures in later life. This is an important target for action, with significant health and economic benefits. Peer influences are particularly important at this time and team activities are often well received. The effects of activity on boosting self-esteem, promoting health and reducing stress and anxiety may protect against adverse social and health behaviours. Children are more active than

adults. Over the adolescent period, sport drop-out rates are high. This has informed a recent Sport England target to have 25% fewer 16–18 year olds dropping out of at least five selected sports.

With increasing age, the risk of heart disease is reduced by keeping physically active. Weight gain increasingly motivates individuals to become more active, but the time pressures of hectic lifestyles prevent regular participation. This is reflected in the growing trend of non-attendance despite gym membership: one-fifth of gym members attend once a month or less. As age increases further, health may become a limiting factor to activity. In the Active People Survey, 'health isn't good enough' was the main reason given for non-participation in an active sport. This is a vicious cycle: although ill health may limit physical activity, inactivity can also lead to a decline in health and physical functioning.

Many people accept weakness, pain and loss of function as inevitable consequences of ageing. Many of these are not due to increasing age however, but are due instead to the accompanying inactivity. A quarter of women aged 70–74 years do not have sufficient strength in their legs to get out of a chair without using their arms. However, there is strong evidence that this decline can be halted and even reversed by regular training. This has informed recommendations in Scotland and the United States. By maintaining strength, the risk of falls decreases and overall mobility improves, enabling older people to preserve their independence and participation in the activities of daily living, such as climbing the stairs, using the bathroom and getting dressed. Low-impact activities to improve flexibility and muscle strength can also help to reduce the pain

Table 5: Comparison of current minimum recommendations on physical activity in different countries

	Early years	For children of school age, moderate intensity activity:	For young adults, moderate intensity activity:	For older adults, moderate intensity activity:
England	Not specified	For 60 minutes each day	For 30 minutes five times a week	For 30 minutes five times a week
Scotland	Not specified	For 60 minutes on most days of the week	For 30 minutes on most days of the week	For 30 minutes on most days of the week + Three bouts of strength and balance exercises per week
Wales	Not specified	For 60 minutes five times a week	For 30 minutes five times a week	For 30 minutes five times a week
Northern Ireland	Not specified	For 60 minutes each day	For 30 minutes five times a week	For 30 minutes five times a week
United States	Not specified	For 60 minutes each day	For 150 minutes each week or 75 minutes of vigorous activity each week + Strength activities two days per week	For 150 minutes each week or 75 minutes of vigorous activity each week + Strength activities two days per week
Australia	Draft guidelines under consultation	For 60 minutes each day	For 30 minutes on most days of the week	For 30 minutes on most days of the week

Source: A variety of official guidance from the respective governments

and loss of function caused by injury and physical impairment. These activities must therefore be a core component of regular physical activity for older adults in England.

By focusing interventions on each life stage, participation in physical activity can be improved. It is crucial to encourage a culture of physical fitness in the population which spans all ages.

Current recommendations

Current recommendations on physical activity differ between countries (see Table 5). In England, the current recommendation is to engage in a minimum of 30 minutes of physical activity of at least a moderate intensity on five or more days a week. This can be achieved either by doing all the daily activity in one session, or through multiple shorter bouts

of 10 minutes or more. However, recent recommendations from the United States suggest that this volume of physical activity – 150 minutes – can be spread over the week in a variety of ways. Some people may prefer to be active for 50 minutes on three occasions per week, while others who like vigorous exercise may achieve comparable health benefits from just 75 minutes per week. Moving to a weekly

Box 1: Change4Life and physical activity

- **60 Active Minutes campaign:** encourages children to do at least 60 minutes of physical activity per day, such as jumping, skipping, dancing, running or swimming.
- **Up and About:** aims to decrease the amount of time children spend in sedentary activities.
- **Start4Life:** provides ideas for active infant play.
- **Let's Dance with Change4Life:** offers free taster dance classes across the country.

target may prove more convenient for some people in planning their physical activity. However, there are some concerns: the current recommendation is consistent with other public health messages, which provide daily recommendations for fruit and vegetable consumption or alcohol intake. The simplicity of a 'prescribed' amount is easy to understand. By unravelling the intricacies of moderate versus vigorous exercise and the relative contributions to the weekly target, the overall message may lose its clarity. However, in light of this new evidence, it is timely to review the current recommendations, and consultation is already under way to achieve this.

There are currently no physical activity recommendations in England that focus on the pre-school age group. It is becoming increasingly clear that activity is particularly important in this group to promote development and that many pre-school children spend too much time engaged in sedentary activities. This evidence is currently being considered to inform a United Kingdom-wide recommendation for physical activity in the early years. In addition, an expert group is considering the evidence for the development of specific recommendations on limiting time spent being sedentary, to sit alongside recommendations on physical activity.

The case for fitness monitoring

Globally, the physical fitness of children of comparable ages is declining by 4.3% per decade. The figure is 7–9% in England. This decline is independent of increasing childhood obesity. Fitness decreases during childhood, possibly due to decreasing emphasis on physical education in older age groups. Comprehensive fitness testing in Texas showed that about 30% of eight year olds were 'fit', but the figure was down to 10% by 17 years. Having a normal body mass index (BMI) but being unfit confers greater health risks than being 'fat and fit'. This makes the trend of declining child fitness particularly alarming. It highlights the need for greater awareness of inactivity so that it sits alongside childhood obesity as a national priority.

The Department of Health's *Let's Get Moving* pathway in primary care aims to identify inactive 16–74 year olds through a structured primary care questionnaire, and help these individuals become more active. The Change4Life campaign endeavours to get the population more active (see **Box 1**).

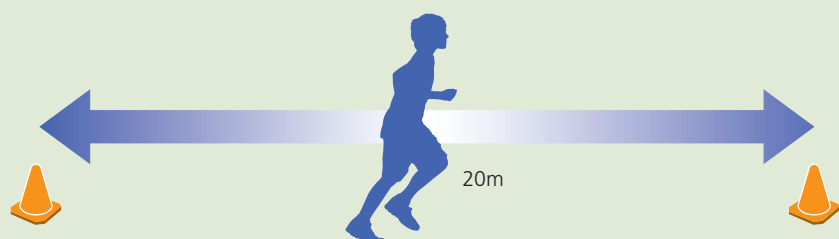


The National Child Measurement Programme annually records weight and height. There is no equivalent standardised measurement strategy for fitness in children. A number of objective measures of child fitness exist but in England these have primarily been used as research tools (see **Box 2**).

Standardised fitness assessments for children have been successfully introduced

Box 2: The 20 metre shuttle run, or 'beep test'

This common test of cardiorespiratory or 'aerobic' fitness involves an individual running between two cones 20 metres apart. They must get to the opposite cone before a 'beep'. The beeps sound with increasing frequency as the test proceeds, requiring the individual to run faster to keep up. The number of completed runs in a specified time has been shown to closely predict a child's heart and lung fitness.



Box 3: Lessons from California

In 2003, physical fitness testing (PFT) became mandatory for 10–15 year olds in California. Each year, over 1.3 million students are assessed in six fitness areas.

A score in the 'healthy fitness zone' represents a level of fitness thought to provide some protection against potential health risks. Over three years, up to an 8.2% improvement has been seen in the number of students achieving scores in the 'healthy fitness zone' across all six areas.

In 2007, a similar mandatory test was introduced in Texas for children aged 8–17 years.



in some areas of the United States (see **Box 3**). The introduction of a standardised school-based fitness assessment in England may have multiple benefits that extend beyond the benefits for the individual (see **Box 4**). The latest government strategy, *Be Active, Be Healthy*, has emphasised the importance of measuring physical activity in order to accurately monitor trends and the effect of interventions. By objectively measuring fitness, trends could be accurately quantified each year. By analysing data by region, school and age group, structured interventions could be appropriately targeted and educational curricula could be modified. Each individual child could also assess their fitness and monitor changes over time.

Extensive piloting would be required to determine the feasibility and scope of such an assessment. In addition, evidence must be gathered to assess whether the true strength of child fitness testing lies in surveillance, screening, health promotion,

or all of these. Crucially, by formalising such an assessment, awareness of physical fitness as an area of health importance would increase throughout the population. This may provide a stimulus for the cultural change that is so desperately needed.

Box 4: The benefits of improving physical fitness in children

- Lowering the lifetime risk of six diseases.
- Building a lifelong habit of participation in physical activity.
- Higher educational attainment.
- Maintaining a healthy weight.
- Improving social and mental well-being.

Over many decades, the importance of physical activity has repeatedly been emphasised, most recently within *Be Active, Be Healthy*. Government action in these areas has been strong but further targeted interventions and a population-

wide cultural shift will be required for us to become a truly active nation.

The health and wider benefits of physical activity are substantial. If a medication existed that decreased the risks of chronic disease to a comparable extent, it would undoubtedly become one of the most widely prescribed drugs within the NHS. As a population, we can harness all of these benefits by taking simple and inexpensive steps to become more active. The scourge of inactivity has been ignored for too long. This is the time for action.

Actions recommended



- New recommendations on the minimum physical activity requirements should be built immediately into public health programmes.
- Particular emphasis should be placed on the pre-school age group and on strength and balance activities for older adults.
- Recommendations on minimum physical activity requirements should be consistent across the United Kingdom.
- Further research should be undertaken to establish the most effective interventions to increase physical activity within specific age groups.
- Comprehensive physical fitness testing should be piloted in secondary schools.
- The pilot must include both standard tests of cardiorespiratory fitness and multi-stage fitness assessments.



Winter kills

England's annual winter death toll averages over 30,000 people. This death rate is far higher than that in comparable countries. With better preparation for cold weather, thousands of lives could be saved each year.

Key points

- Mortality in England rises 18% during the winter months, whereas other, colder, countries have smaller increases.
- Every 1 degree Celsius decrease in average winter temperature results in 8,000 additional winter deaths in England.
- Finland has 45% fewer winter deaths than the United Kingdom.
- Most winter deaths occur due to increased cardiac death, strokes and respiratory problems.
- People with underlying cardiovascular or respiratory disease and the elderly – especially women – are at greatest risk.
- Every £1 spent keeping homes warm can save the NHS 42 pence in health costs.
- Around two-fifths of eligible households do not claim their pension credit.
- Illnesses occur in a predictable pattern following cold weather, enabling local and national advance planning.

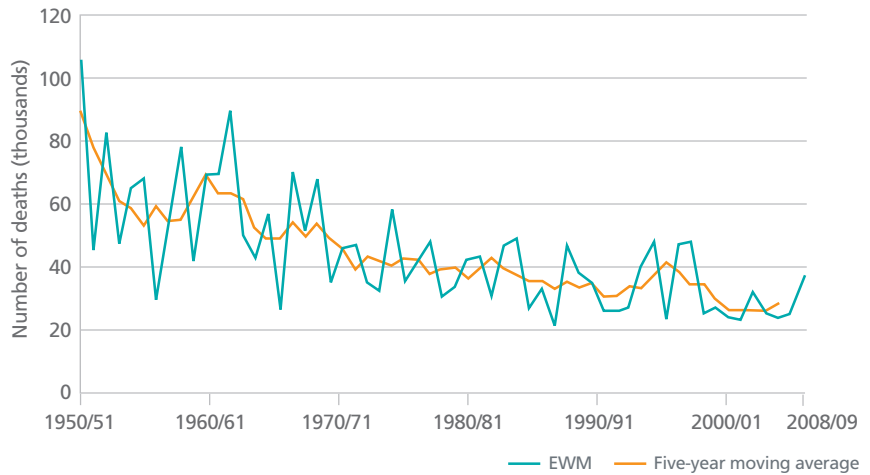
Winter can be fun for families. Children look forward to playing in the snow. Forecasters wonder whether each year's Christmas will be white. Sadly, for thousands of families, winter brings illness and death. On average, over 30,000 additional people will die in England each winter because of cold weather. Cold weather is implicated in one in twenty deaths. Some of these extra deaths are due to falls or road collisions. The vast majority are due to heart attacks, chest infections and strokes. Many are preventable.

Winter excess deaths

Cold weather is widely believed to jeopardise health. People associate it with influenza and colds. Winter bed crises affect some parts of the National Health Service. Cold weather and illnesses have been linked since ancient times. Hippocrates noted that winter brought 'pleurisy, pneumonia, coryza, hoarseness, cough, pains of the chest, pains of the ribs and loins, headache, vertigo, and apoplexy [stroke]'. Medical journals have been reporting excess winter mortality for 150 years.



Figure 1: Excess winter mortality (EWM) by year and five-year moving average, England and Wales

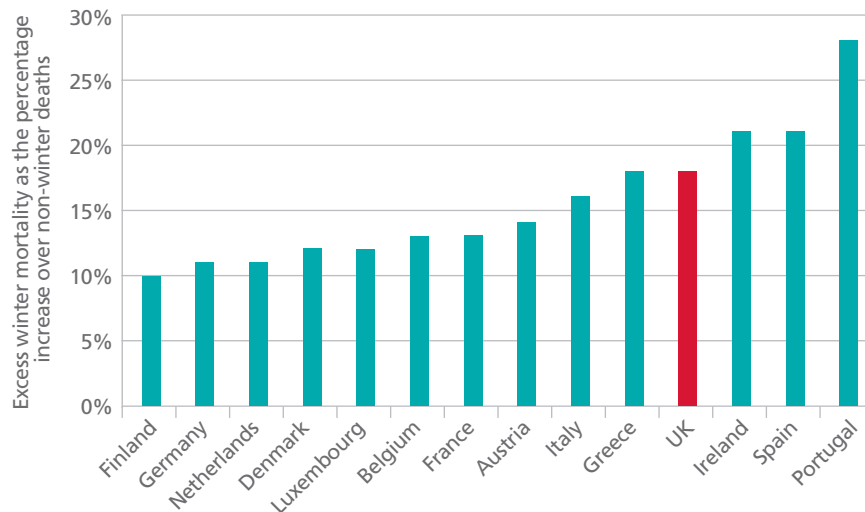


Source: Office for National Statistics

Modern evidence confirms this. From December to March each year there is a persistent pattern of increased deaths (excess winter mortality) compared with the summer months. Some winters are worse than others. Although the number varies from year to year, around a fifth more people die each year over the winter months than during the summer. Some years are particularly bad. Over the winter of 2008/09, there were 36,700 more deaths than in the previous summer. In the winter of 1999/2000, this number was over 45,000. The latest figures are not yet available, but this winter has been marked by severe weather. With improvements in living standards and general population health, the extent of excess winter mortality has gradually fallen over the last half century (see Figure 1). It is still too high.

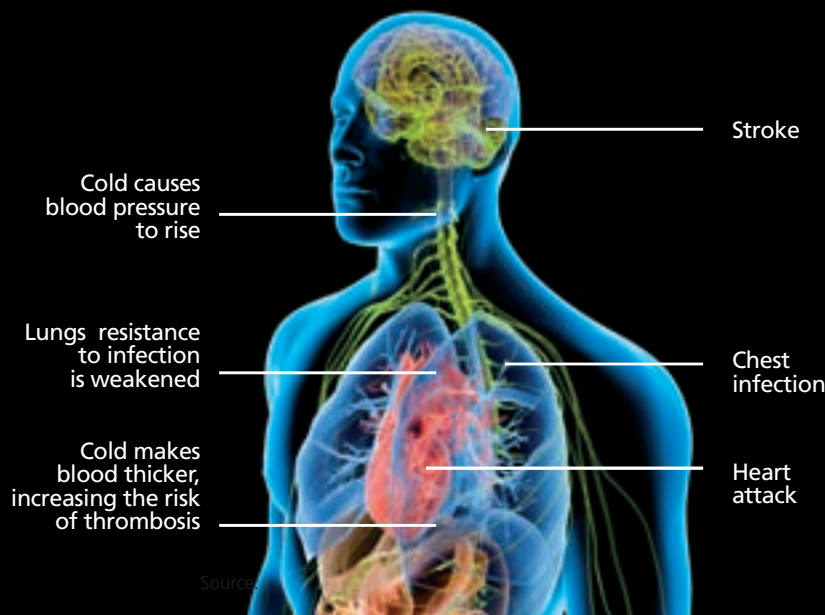
The United Kingdom overall does not compare well with other European countries. Finland – a much colder country – has a winter excess death rate close to half that of the United Kingdom. Other northern European countries, such as Denmark, Germany, the Netherlands and Belgium, all perform better than England (see Figure 2). This demonstrates the 'paradox of excess winter mortality'. The countries with the greatest excess winter mortality – Spain and Portugal – are also the ones with the mildest winters. The population in colder countries is protected from the effects of cold weather by strong cultural norms of well-heated homes and warm outdoor clothing. The lack of these norms in southern Europe can cost lives when it turns colder.

Figure 2: Excess winter mortality by country



Source: Healy JD. Excess winter mortality in Europe: a cross country analysis identifying key risk factors. *Journal of Epidemiology and Community Health* 2003; 57(10): 784-9

Box 1: Health impacts of cold weather



England is insufficiently prepared for cold weather. Staying warm saves lives. By failing to protect vulnerable people from the cold, tens of thousands of lives are endangered every winter.

The effects of cold

Extreme cold can kill directly through hypothermia. Chilled to an extreme, the body's organs simply cease to operate, and the heart stops beating. More commonly, exposure to cold causes thickening of the blood, increasing the risk of coronary thrombosis and stroke. Cold weather produces a rise in blood pressure and causes the coronary blood vessels around the heart to spasm. Together, these factors can prove a lethal mix (see **Box 1**). Diseases of the circulation – including heart attack and stroke – account for around 40% of excess winter deaths.

Around one-third of excess winter deaths are due to respiratory illness. In cold weather, people spend more time indoors in close proximity to one another. This helps infection spread. Inhaling cold air affects the lung airways, causing them to narrow and produce phlegm. This worsens chronic lung disease and asthma. Exposure to the cold suppresses the immune system and cold air diminishes the lungs' capacity to fight off infection, leading to an increased risk of bronchitis and pneumonia. Those living with underlying heart, circulatory or lung disease are at the highest risk.

The effect of cold weather is so stark that it can be measured directly (see **Box 2**). Once the temperature falls below 18 degrees Celsius, every further degree drop in outdoor temperature results in a 1.4% increase in mortality in this country, amounting to a further 8,000 excess

Box 2: The effect of temperature on health

Indoor temperature	Effect
21° Celsius	Recommended living room temperature
18° Celsius	Minimum temperature with no health risk, though may feel cold
Under 16° Celsius	Resistance to respiratory diseases may be diminished
9–12° Celsius	Increased blood pressure and risk of cardiovascular disease
5° Celsius	High risk of hypothermia

Source: Department of Health, 2009

deaths. This effect is three times greater in extreme cold.

Not everyone is affected equally. Older people, particularly women, are the most at risk. The majority of excess winter deaths are in people aged over 75 years. In part this may be due to these being the people most likely to have underlying conditions making them vulnerable. People living in poorly heated housing live in greater danger. Old, badly insulated properties offer significantly less protection against the risks of the cold than more modern, warmer dwellings. Heating matters. Not having central heating is strongly correlated to a greater risk of death.

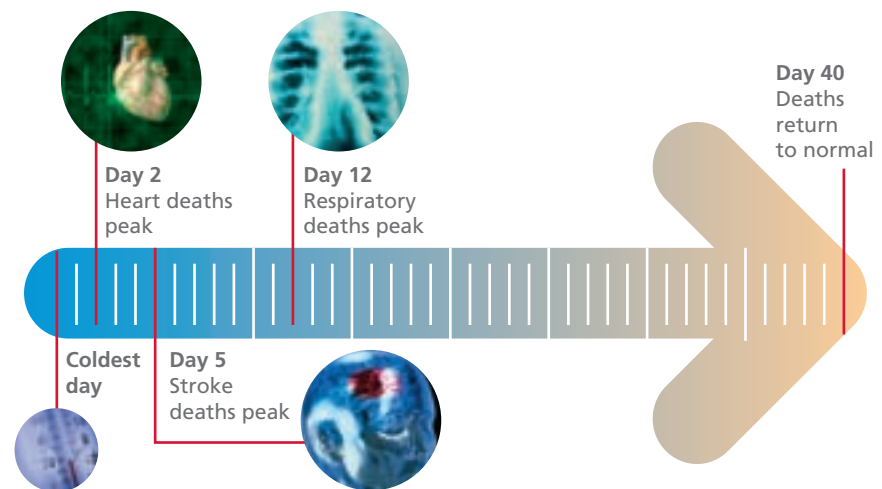
The effects of cold weather are predictable. Cold weather deaths from heart disease increase almost immediately, reaching their highest just two days after the coldest weather. The steepest rise for stroke takes place later, at five days. It takes another week for deaths from respiratory illnesses to peak. Indeed, after a cold spell, it takes over a month for death levels to return to normal (see **Box 3**).

Weather forecasts can be linked to health predictions. This allows preventive health measures to be targeted to vulnerable groups at the right time. A study by the Met Office has shown that general practices using a weather and health forecasting service were able to reduce hospital admissions from one type of chronic lung disease 17% more than other practices. There are clear benefits in communicating

directly with people when they are at increased risk of becoming unwell – given the right information at the right time, individuals are better able to self-manage their health. Using statistical estimates to predict the health consequences of cold weather allows hospitals to prepare for surges in need. However, these methods are not used routinely. More could be done to ensure that relevant health services are on a coordinated alert to cope with these inevitable rises.

Death is the most extreme consequence of exposure to cold. It is not the only problem. Increased illness due to cold conditions puts a strain on local general practices, hospitals and other health services. Lost work due to illness is a particular burden for small businesses and the self-employed. Cold weather may trigger asthma in young people. This, and other illnesses, can result in children having to stay away from school.

Box 3: Cold weather death sequence



Source: Adapted from Donaldson GC, Keatinge WR. Early increases in ischaemic heart disease mortality dissociated from and later changes associated with respiratory mortality after cold weather in south east England. *Journal of Epidemiology and Community Health* 1997; 51(6): 643–8

The cost of staying warm

In 2007, 2.8 million households in England experienced fuel poverty. Fuel poverty is defined as having to spend 10% or more of household income on heating the home. Fuel prices have risen over recent years. Between 2003 and 2007, the number of households in fuel poverty more than doubled (see **Figure 3**).

Households containing vulnerable people (the elderly, children and those with a disability or long-term illness) have been disproportionately affected by these price rises. Half of all fuel-poor households include at least one person aged over 60 years. A quarter have an occupant over 75 years old. These are the people most at risk from cold weather.

Prepayment meters are the most expensive way of paying for gas and electricity. They are disproportionately found in the homes of people on low incomes. A quarter of those using these meters are on annual incomes of less than £10,000. Over 30%



of people living with a long-term illness or disability have prepayment meters. Most do not realise that they pay extra for their energy.

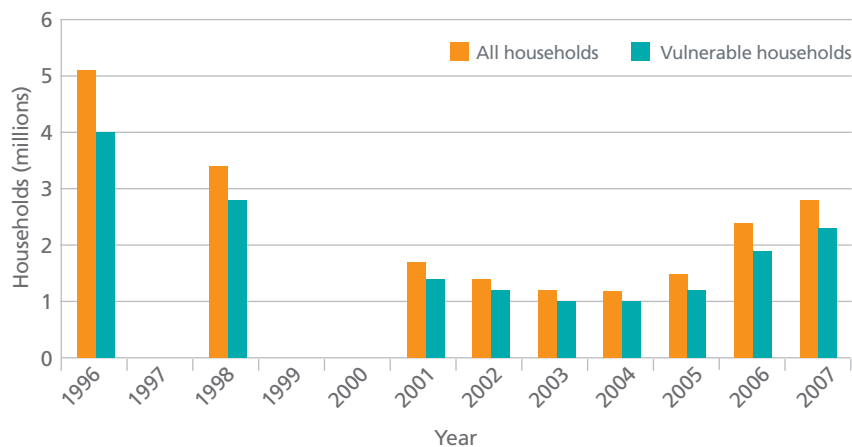
Persistent cold, together with the financial worry of being able (or unable) to afford adequate heating, can cause depression. People in fuel poverty are 2.5 times more likely to report high or moderate stress than those able to afford their heating.

The financial and emotional costs to the families of those made ill through exposure to cold is great. There are wider considerations too. The annual cost to the NHS of treating winter-related disease due to cold private housing is £859 million. This does not include additional spending by social services, or economic losses through missed work. The total costs to the NHS and the country are unknown. A recent study showed that investing £1 in keeping homes warm saved the NHS 42 pence in health costs. The idea of the NHS contributing to reducing winter injury and death in this way is not new. In the winter of 2009/10, NHS County Durham and Darlington contributed £500,000 of its budget towards the gritting of roads, paths and pavements in priority areas.

Helping people stay warm

Interventions to tackle fuel poverty work. The relief from cold and debt can reduce depression by half and visits to general practitioners by a quarter. In one study, warmer housing led to 38% fewer days off work and reduced the incidence of asthma in children. Missed school days fell by 50%, resulting in improved childhood educational achievement.

Figure 3: Fuel poverty in England



Source: Department of Energy and Climate Change, 2009



A number of government schemes aim to mitigate against fuel poverty. These include boiler replacement programmes, home insulation and draught-proofing subsidies, as well as cold weather payments to boost household budgets when the weather is at its coldest. New homes must be built to ever higher standards of fuel efficiency and insulation.

Many of those most at risk are not benefiting from these policies. Two-fifths of pensioner households who could claim pension credit do not. Each year, between £6 billion and £10 billion of benefits remain unclaimed, and the percentage of unclaimed entitlements is rising. A scheme called Warm Front includes a benefit entitlement check to ensure that vulnerable people are receiving the help they need. Following assessment, the average yearly household income increases by around £1,600. For people at risk, this can be the difference between life and death.

Simple measures can also help. Blocking draughts around windows and doors can save heat and lives. A preference for fresh air – for example, sleeping with the windows open – can undo any benefit from good daytime heating.

Outdoor protection

Keeping warm indoors is a critical part of staying healthy in the winter. Keeping warm outdoors is also essential and perhaps harder to achieve. Fully heated housing does not alone protect the elderly from winter mortality.

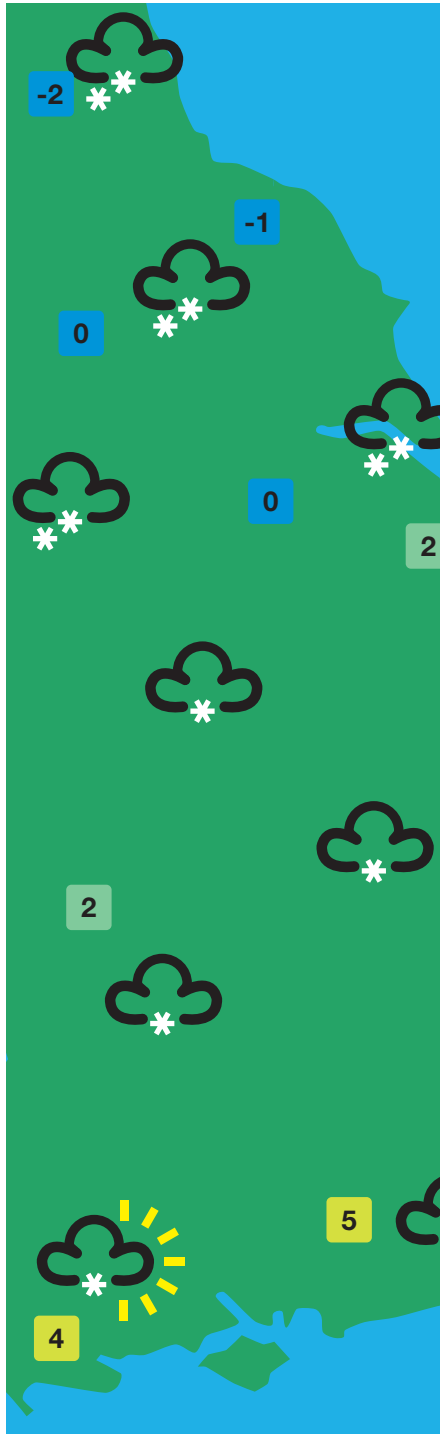
Every parent knows it is important to wrap up their children in the cold. Physical activity generates heat which protects against the harmful effects of cold weather. Older people may move more slowly, producing less heat. Not only does this make them more vulnerable when walking outdoors in the cold, it also means that their total time exposed to the cold is longer.

Research confirms that there is a striking benefit from wearing hats, anoraks and gloves in cold weather. The low excess winter mortality in Siberia has been linked to local habits of dressing warmly when outdoors in the cold. In warmer countries, like England, many people brave freezing weather without a hat or gloves. Yet it is often seen as patronising to run public information campaigns to remind people of the importance to health (or even survival) of good, warm clothing.

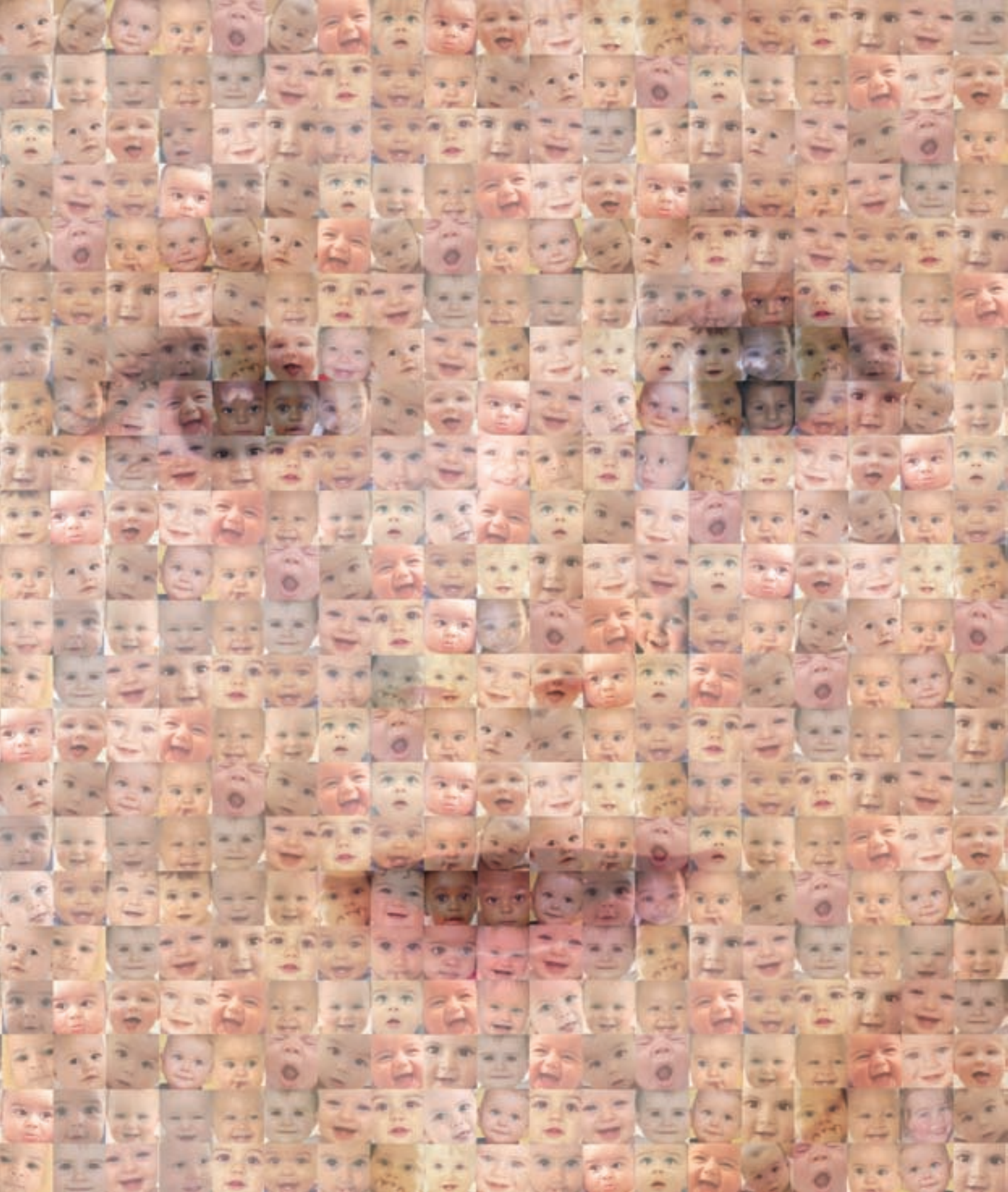
One of the most effective ways of staying warm is to wear multiple loose layers. Modern fabrics have replaced woolly garments as the best protection against cold, wind and rain. Clothing made from new materials is often more expensive and is not designed with older people in mind. Well designed winter wear can protect vulnerable people from the death threat of cold weather, but those who need it most often cannot afford it.

Death by cold weather is not inevitable. The success of countries such as Finland shows this. Much more could be done to save the lives of tens of thousands of vulnerable people each year and match the performance of the best worldwide.

Actions recommended



- A national cold weather plan should be developed to prevent and deal with the health consequences of cold weather.
- Healthcare providers should identify people vulnerable to harm from cold weather and refer them for appropriate help.
- During periods of cold weather, supermarkets and local shops should be encouraged to offer free home deliveries of groceries to vulnerable people.
- Warm clothing technology appropriate for older people should be developed and promoted.
- Further research should be conducted into the risk factors for winter mortality and how it might be prevented.



Rare is common

Key points

- A disease is rare when it affects fewer than five in every 10,000 people. There are more than 6,000 rare diseases, so in fact one person in every 17 has a rare disease – around 3 million people in England.
- As a consequence, rare diseases are an important cause of illness and death – not just in England but across the world.
- Rare diseases can affect any system in the body. They are usually chronic and difficult to manage, and – because they are rare – coordinated efforts are needed to provide effective and accessible care.
- Around four in every ten people with a rare disease report difficulty in getting a correct diagnosis.
- Many people with rare diseases do not have access to specialist services, causing delay in diagnosis, slow treatment and isolation for affected individuals and their families.
- More and more children with rare diseases are surviving into adulthood because of improved treatments and services, but their transition to adult services is often unsatisfactory as expert services for adults with rare diseases are lacking.

Rare diseases take many different forms and most doctors will see very few in a lifetime of practice. Taken together, though, people with rare diseases share many problems, including difficulty in getting a diagnosis and accessing the right services and support for themselves and their families.



One in 17 people in England (approximately 3 million people) have a rare disease. By definition, individual rare diseases affect fewer than five in 10,000 people. However, there are more than 6,000 different rare diseases. These diseases are rare individually but become relatively common when they are considered collectively as a category of illness. Rare diseases affect over 30 million Europeans and over 25 million North Americans.

The majority of affected people are children since these conditions tend to be present from birth, start in childhood and may be life-limiting. The British Paediatric Surveillance Unit, established more than 20 years ago, provides a simple and effective way of studying rare childhood disorders across the country. It allows the frequency of very rare diseases to be estimated reliably and the experiences of children and families in the period immediately before and after diagnosis to be better understood (see **Box 1**).

Rare diseases can affect all body systems (see **Figure 1**). As the number of people affected with specific diseases in any single area or region of the country is small, specialist services may be needed regionally or supra-regionally rather than locally.

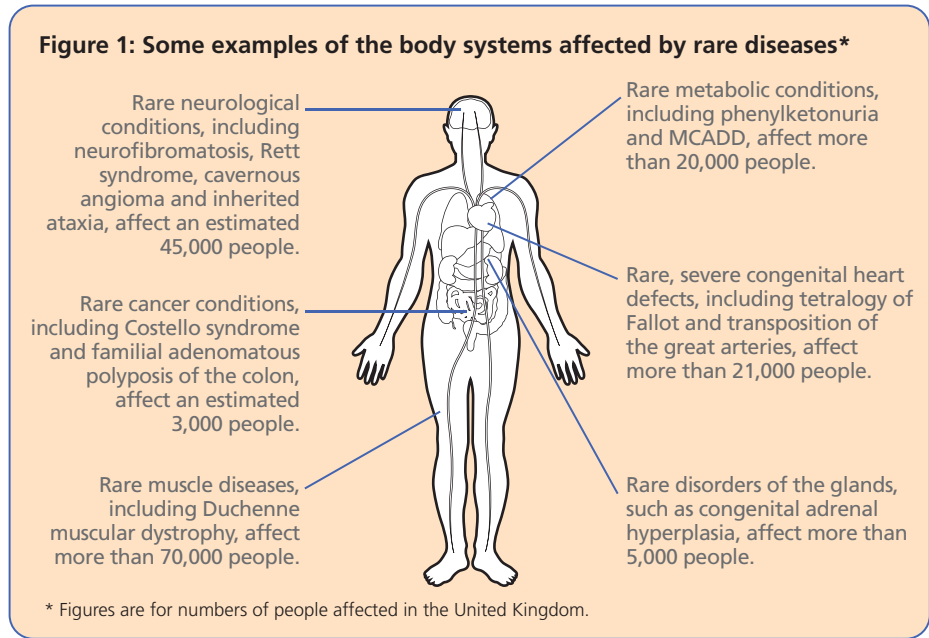
Different but similar

Despite their diversity, rare diseases share some common features. They are severe, usually chronic, life-threatening and may get worse over time. Symptoms or signs usually start in childhood. Most are incurable and often there is no effective treatment. Affected individuals and their families need support as they often face an uncertain future with a lack of therapeutic hope. The quality of life of the affected person and their family may be compromised.

These characteristics pose important practical challenges when delivering the range of services needed by people with

rare disease. It can be difficult to make a timely diagnosis and information about the disease may be hard to access. There may be a delay in referral or lack of access to specialised services, and care is usually needed from an interdisciplinary specialist team. There can be poor coordination and communication within and across care sectors, and poor social or educational support. There can also be a lack of integrated family, social care, educational and employment support.

Some aspects of this challenge were summarised by one person with an inherited ataxia, a condition that leads to problems with coordination of body movements: *'The problem is that I need treatment from several specialists – dermatologists, spinal surgeons and neurologists – and it can be hard to get them to work together.'*



Box 1: Katy's story

Ten-year-old Katy and her family had no idea that she had MCADD (medium chain acyl CoA dehydrogenase deficiency) until she collapsed during a school holiday and her internal organs began to fail. She needed intensive care and her parents were told to expect the worst. She was eventually diagnosed with MCADD and given treatment that allowed her to recover.

MCADD is a very rare condition caused by the lack of an enzyme that converts fat to energy. It affects about one child in every 10,000 in the United Kingdom. Katy was fortunate not to die during her acute illness. She should be able to avoid such episodes in the future by following simple dietary advice and going to her local hospital for emergency treatment if she can't eat or becomes unwell.

Information about children with MCADD in the United Kingdom was collected through the British Paediatric Surveillance Unit and a test for MCADD is now offered as part of the national newborn screening programme in England.

Improving services for people with rare diseases and their families

A diagnosis of a rare disease has a huge impact, not just on the individual but also on their family. There are over 1 million carers of people with rare diseases in England. Parents of such children often have no alternative but to become full-time carers. Advice about benefits and other forms of support are vital to avoid social isolation and poverty.

The Genetic Interest Group is a UK alliance of 138 charities supporting children, families and individuals affected by genetic disorders. It has developed a 'family route map' which identifies seven areas for improvement for people with rare diseases: information; communication; diagnosis, treatment and surveillance; empowering patients, families and carers; educating healthcare professionals; and ethical, legal and social issues. In 2008, the Genetic

Interest Group joined others to create Rare Disease UK. This alliance is working with government, pharmaceutical companies, academics and clinicians to develop a rare disease strategy and to raise public awareness of rare diseases.

Groups such as the Genetic Interest Group play a key role in reducing the sense of isolation for individuals with rare diseases and their families. They provide access to information, give practical and emotional support, advocate for better services, promote research funding and encourage patients to participate in treatment trials. Many patient groups for rare diseases provide better sources of information to sufferers and their families than healthcare professionals.

Diagnosing rare diseases

Training and knowledge about rare diseases are variable amongst healthcare professionals. Awareness may be higher amongst local general practitioners in an area where a specialist centre happens to be based.

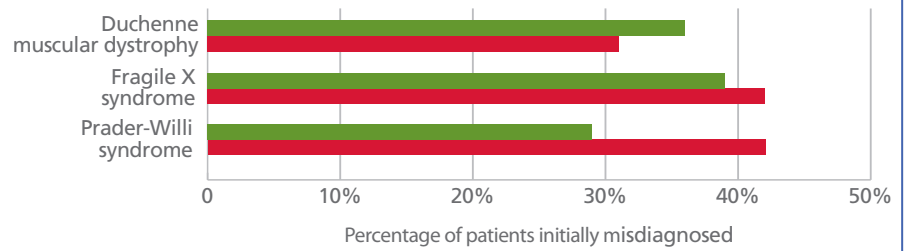
Individuals with rare diseases may complain of signs and symptoms that have other,

more common, causes or which do not always make sense clinically to a doctor or nurse who has never encountered the disease. Many people with rare diseases wait a long time, seeing many different doctors, before their condition is eventually correctly diagnosed. These delays add to the isolation and difficult emotions experienced by affected people and their families when they do finally receive the correct diagnosis (see Box 2).

General practitioners diagnose and care for the vast majority of ill people. They play a crucial role in assessing different symptoms and signs and deciding whether specialist care is needed. It is easy to see why rare causes of common or non-specific symptoms may be overlooked. A European study into rare diseases has reported that over one-third of people with a rare disease are initially misdiagnosed in the United Kingdom (see Figure 2).

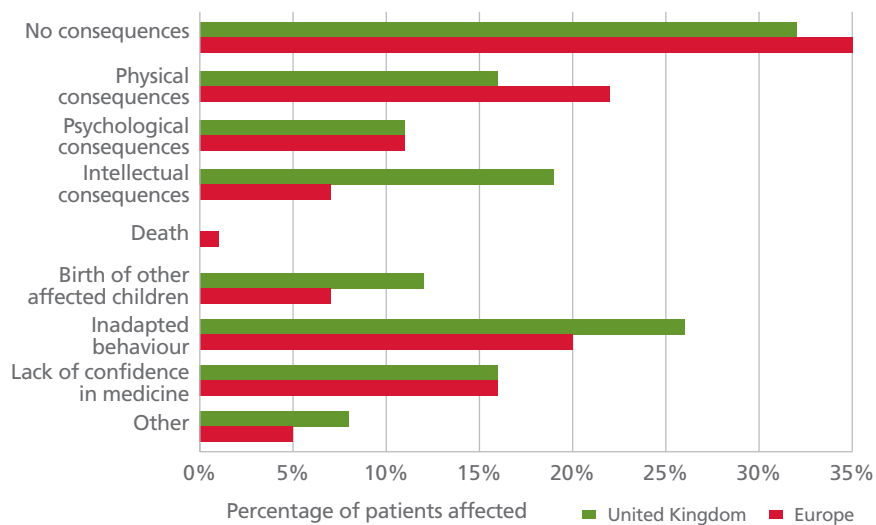
The study surveyed 6,000 patients with rare diseases throughout Europe and found that 25% experienced a delay of five to 30 years from first symptoms to the correct diagnosis being made. Overall, 40% of patients with rare diseases were

Figure 2: Rare diseases may initially be misdiagnosed



Source: European Organisation for Rare Diseases (Eurordis), 2005

Figure 3: The consequences of delaying the treatment of rare diseases are serious



Source: European Organisation for Rare Diseases (Eurordis), 2005

Box 2: Christopher's story

Christopher was born early and had frequent infections and sickness as a young child. His parents, a health visitor and a general practitioner, were not worried as he was growing well and was already a head taller than other toddlers. However, when Christopher was three years old, his mother noticed that he had developed acne and pubic hairs and that his behaviour had changed. He grew even taller and more muscular and his mother insisted on seeing a specialist.

Christopher was diagnosed with precocious puberty and congenital adrenal hyperplasia. His mother said it hit the family very hard. 'We felt incredibly alone and very guilty for what Christopher must have been feeling. The emotions of puberty are hard to cope with during teenage years, never mind when you are of pre-school age.'

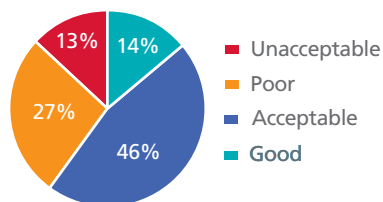
Christopher will be on medication for the rest of his life. As his bone age is advanced, he will go from being a tall child to a short adult. Yet he lives a normal family life, is popular at school, can do the same as any child of his age and can expect to lead a normal adult life.

initially diagnosed incorrectly. This led to unnecessary medical interventions: 16% had surgery, 33% did not receive appropriate medical treatment and 10% received psychological treatment because their symptoms were interpreted as 'psychosomatic'.

A delay in diagnosis may also mean a delay in commencing potentially life-enhancing or life-extending treatments with potentially serious consequences (see Figure 3).

A range of studies on breaking bad news has shown that how a diagnosis is communicated to an affected person or

Figure 4: Acceptability of communicating diagnosis of rare disease



Source: European Organisation for Rare Diseases (Eurordis), 2005

their family is vitally important. If badly handled, it may have long-term effects on how much a patient trusts the services provided. This is particularly true for individuals with rare diseases as it may affect their adherence to treatment in the longer term. In a recent European study, over a third of those receiving a diagnosis of a rare disease in the United Kingdom reported an unacceptable or poor experience when being told their diagnosis (see Figure 4).

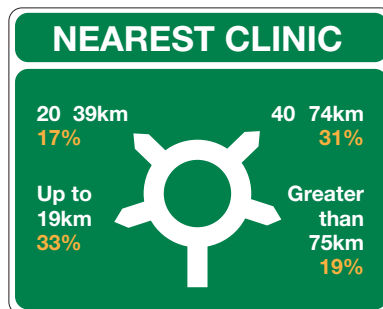
Access to services for people with rare diseases

Once a rare disease is diagnosed, it is important that all necessary services are integrated and respect patient and carer expertise. Many groups of rare diseases can be looked after by a single specialist (for example, congenital heart defects or inherited metabolic disorders) but for some several different specialists need to work together. Care pathways for individual rare diseases help identify to health services, affected people and their families what should be expected and how the services should work together.

The distances travelled to access expert specialist care can be large. Half the families taking part in a country-wide study of MCADD screening had to travel 40km (25 miles) or more to their nearest regional specialist metabolic centres (see Figure 5). For this condition, once all the diagnostic tests are completed, most subsequent care can be provided locally on a shared care basis. Unfortunately, this is not always possible for all rare diseases.

Whilst there have been significant improvements in diagnosing and treating children with rare diseases, the same is not true for adults. With earlier diagnosis and

Figure 5: Distances travelled by families attending for diagnostic confirmation of MCADD



Source: UK Collaborative Study of Newborn Screening for MCADD and the MRC Centre of Epidemiology for Child Health at the Institute of Child Health, University College London

more effective treatments, people with rare diseases now live longer. The transition into adult services is often difficult. Children leave a paediatrician they have known all their lives and may not locate an adult service with experience of their condition. This lack of continuity of care can cause distress and sub-optimal care.

People with rare diseases are estimated to cost the NHS over £1 million annually in each English health region. There are potential efficiencies in treatment if repetition of tests is avoided every time the patient sees another consultant. People may present to an accident and emergency department because they lack information and support. The paediatric passport system ('open access') allows children to fast-track to the correct department. The same system does not exist for adults with rare diseases.

Screening for rare diseases

Achieving an early, timely diagnosis is very important. Affected people and their families often do not get their concerns heard and the disease recognised and diagnosed. People with rare diseases or their family members may be referred to a clinical geneticist for diagnosis and genetic counselling. Not all rare diseases are genetic. Currently, referral to a clinical geneticist may happen only relatively late in the patient journey.

For some rare diseases (for example, severe congenital heart defects, MCADD, phenylketonuria) early identification can prevent irreversible damage or death. This is why newborns are tested shortly after birth for these very rare conditions. The vast majority of newborns do not have rare diseases, so any screening must discriminate reliably between affected and unaffected babies. The benefit for pre-symptomatic diagnosis of affected babies must be clear before a screening programme is introduced. As new diagnostic tests and treatments are constantly being developed, the need for screening for rare diseases is reviewed regularly through the UK National Screening Committee.



Research into rare diseases

There have been major advances in identifying the genes implicated in many rare diseases. While this can help with diagnosis and also shed light on the underlying cellular mechanisms involved in causing rare diseases, at present genetic testing does not always translate into hoped-for treatments. The prospects for preventing most rare diseases remain limited.

Rare diseases are sometimes called 'orphan diseases' because pharmaceutical companies are reluctant to invest in new treatments. It is simply not cost-effective to

“The rarer a condition is, the more important it is that a screening programme does no harm to all the children tested. Screening tests must reliably distinguish those likely to have the disease from those unlikely to have it. Effective treatments and specialist services must be readily available so that all those suspected of having a rare disease can obtain a definite diagnosis and, if needed, treatment as soon as possible.”

Professor Carol Dezateux, Institute of Child Health, University College London



and that this is reflected in the provision of integrated diagnostic and treatment services as well more research and, above all, help for affected people and their families to live fulfilled lives.

Many healthcare professionals provide excellent services to individuals with rare diseases and their families. However, this is not the norm. Many patients in England, particularly adults with rare diseases, struggle to access specialist services. National coordination of the management of rare diseases is needed to ensure that excellence becomes standard, no matter where a patient lives.






develop and market products for the small numbers of patients affected by each rare disease. Even where research is carried out, producing evidence about new treatments can be challenging. Alliances between networks of specialists and patient groups can often be the best way of getting such research under way. In this country, there is a strong tradition of public involvement in research as well as organised specialist clinical networks capable of contributing to disease registers and multi-centre studies. The Medical Children's Research Network was established to facilitate research trials and studies to prevent, diagnose and treat

children's diseases. Despite this, there is relatively little research into rare diseases. The amount of research funding for rare diseases collectively is relatively small compared with other conditions (see Table 1). Increasingly, international collaborations are being developed to overcome this problem.

Next steps

Rare diseases have come of age. In 2009 and again in 2010, a national Rare Disease Day was held to raise public and political awareness of these diseases. It is vital that rare diseases are recognised more widely

Table 1: Funding for research, and numbers affected, for various conditions in the United Kingdom

Disease	Number of affected individuals	Research funding (2008/09)	Approximate spend per person affected
Cancer	2,000,000	£370,087,680	£185 
Heart disease	2,600,000	£75,200,599	£29 
Alzheimer's dementia	420,000	£5,221,278	£12 
Diabetes	2,600,000	£7,073,613	£3 
Rare diseases	3,500,000	£3,595,880	£1 

Source: Research funding estimates from the Association of Medical Research Charities; affected individuals from Cancer Research UK, British Heart Foundation, Alzheimer's Society, Diabetes UK and Rare Disease UK

Actions recommended



- Strengthen the network of reference centres for rare diseases to enable better coordination of specialist services, including the transition from paediatric to adult services.
- Ensure that adequate numbers of specialists are trained so that future service needs can be met.
- Appoint a National Clinical Director for rare diseases to oversee the development of clear standards and pathways for the treatment and surveillance of rare diseases, with national registers to support service planning and delivery as well as research.
- Strengthen research, including translational research with economic incentives, to develop and market medicines for the 'orphan diseases'.
- Raise public and professional awareness of this neglected group of diseases.
- Support international collaborative efforts to share information and resources for rare diseases.



granddad

Me



Grandparenting for health

Key points

- There are over 11 million grandparents in England, more than ever before.
- Many grandparents are actively involved with their grandchildren while they are growing up.
- Changes in society mean that parents are increasingly looking to grandparents to become more involved in childcare.
- Studies of the activities that grandparents and grandchildren undertake together show that only a minority are health-orientated.
- Grandchildren often find the relationship with their grandparents supportive at times of adolescent turbulence, when health risk-taking is greatest.
- There is a significant opportunity to equip grandparents to improve the health of their grandchildren and their own health in tandem.

Grandparents and grandchildren have a special relationship and most have frequent contact. Grandparents could be a great asset to a child's health and development. They are usually overlooked in discussions about building healthy childhoods.

Over the last 50 years, the number of grandparents has doubled. There are now over 11 million grandparents in England. Today's grandparents are healthier, more active, and increasingly involved with their grandchildren. The relationship between grandparents and grandchildren is special. It is also different from many of the other important childhood relationships. Grandparents are a major influence on children, and there is great potential to build on the positive relationship between grandparents and grandchildren to improve health.

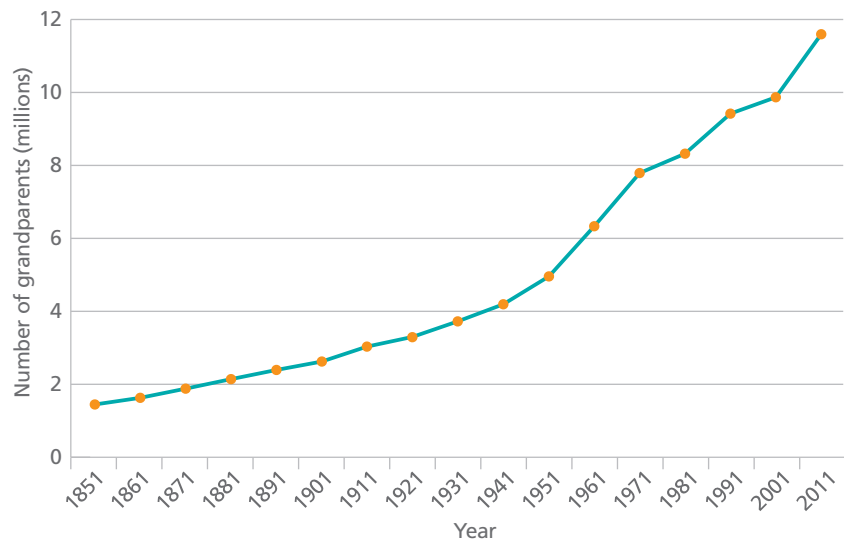
Life expectancy has now risen to 79 years. In 1901, less than 5% of the population were over the age of 65 years. Today that has tripled to around 17%. An ageing population has created more grandparents than ever before (see **Figure 1**). It is now common for children, even in their teenage years, to have three or four grandparents

Box 1: Key research findings: young children and grandparents

- Young children engage in a wide range of activities with grandparents and in doing so learn a variety of different skills.
- The child is treated as an equal partner when learning with their grandparent.
- Children's pattern of learning when engaged with grandparents is different, based on 'learning by doing'.
- Children with an involved grandmother are significantly less likely to attend accident and emergency departments with minor problems.

Sources: Kenner et al, 2005; Fergusson et al, 1998; Grandparents Plus, 2009 (full references cited at the end of this Report)

Figure 1: The estimated number of grandparents in England has increased over time



Source: Murphy M, London School of Economics, 2010, personal communication

still living. Over three-quarters of the population belong to a three-generation family. Nearly one in five is a member of a four-generation family. Within each family, parents now tend to have fewer children. As a result each grandparent has fewer grandchildren. Grandparents may therefore devote more time and attention to each grandchild.

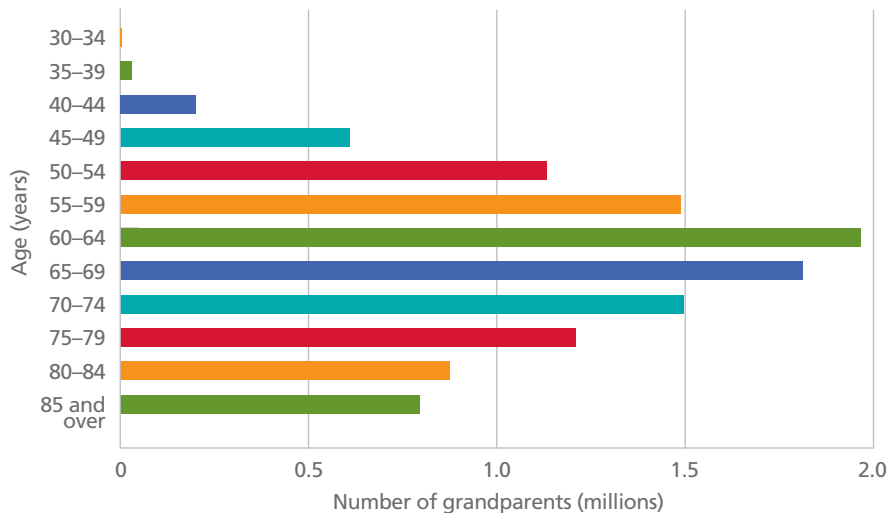
Grandparents increasingly enjoy good health for many years and nearly one in two grandparents are under the age of 65 years (see **Figure 2**). The majority care deeply about their grandchildren, and value their relationship with them. They have a growing and active role in supporting parents in bringing up children. The growing popularity of organisations like Grandparents Plus, Proud Grandparents and the Grandparents' Association reflects the growing recognition of the importance of grandparents.

Grandparents: closely involved with grandchildren

Many modern grandparents are very involved with their grandchildren. They have more spare time than parents. They also have a strong desire to spend time

with their grandchildren. Just over 60% of grandparents see their grandchildren at least once a week, and nearly 80% see them once a month. Significantly, many grandparents live close to their grandchildren. Seven out of 10 live within 10 miles, while four out of 10 are within a 15-minute journey of their grandchildren. Face-to-face contact is not the only means of keeping in touch. Many grandparents use the internet or the telephone to keep in contact with their grandchildren. Close relationships are more likely to continue into adolescence if grandparents and grandchildren spend time together when the grandchildren are younger.

Where practical, when parents are looking for childcare, they often turn to their own parents first. Grandparents are now the single biggest source of childcare after the parents themselves. Mothers increasingly return to part- or full-time work after having children. In 1971, just under 60% of women were economically active, compared with 75% today. A long-hours working culture makes English parents some of the most 'time poor' in Europe. Whilst flexible working is more common, finding childcare arrangements for evening

Figure 2: The estimated number of grandparents by age in England

Source: Murphy M, London School of Economics, 2010, personal communication

or weekend working slots is difficult. Grandparents often fill the gaps at less convenient times or at short notice. It is often grandparents who step in to care for an unwell child at short notice, or provide care for disabled children when it may be hard to find suitable alternative arrangements.

Around one in three families are now relying on grandparents to provide childcare. Some groups are more likely to ask their parents for help, such as mothers in lower-earning occupations, unmarried couples and single mothers. Around half of single mothers rely on grandparents for childcare. One study found that grandparents provide 40% of childcare when parents are working, and 70% of childcare at other times. The total value of childcare contributed by grandparents has been calculated at £3.9 billion.

Nearly 170,000 grandparents act as the primary carer for their grandchildren, taking the place of parents. Grandparents who take over the direct care of their grandchildren may be more likely to experience poor physical health and depression compared with other people of a similar age. It is important to support these grandparents in this challenging but important role. However, for most grandparents, close involvement with their grandchildren improves their quality of life.

Parents are more likely to separate today. This creates new families with 'step-grandparents' and 'step-grandchildren'. Around one in every five grandparents has step-grandchildren. Two in every five grandparents have grandchildren in non-intact families.

Grandparents are an important source of advice to parents. One in three parents would go to their own parents first for

advice about health matters, rather than consult a doctor, the internet or the media. Advice from grandmothers may help reduce unnecessary visits to a doctor. Grandchildren with close grandmothers are significantly less likely to go to an accident and emergency department with minor complaints that do not require medical treatment. Support from grandparents can also take other forms – financial, or providing help with shopping or preparing meals. One in every three grandparents in their seventies provide financial support for their grandchildren.

Grandparents and grandchildren: a special relationship

Grandparents and grandchildren are frequently in contact. Statistics fail to capture the importance and richness of this special relationship. Time and again, researchers are surprised by its importance to both grandchildren and grandparents. Traditional research methods (involving interviewing adults) have not always helped in understanding the relationship between young children and their grandparents. When researchers interviewed children, they found, for some children, that grandparents were a major



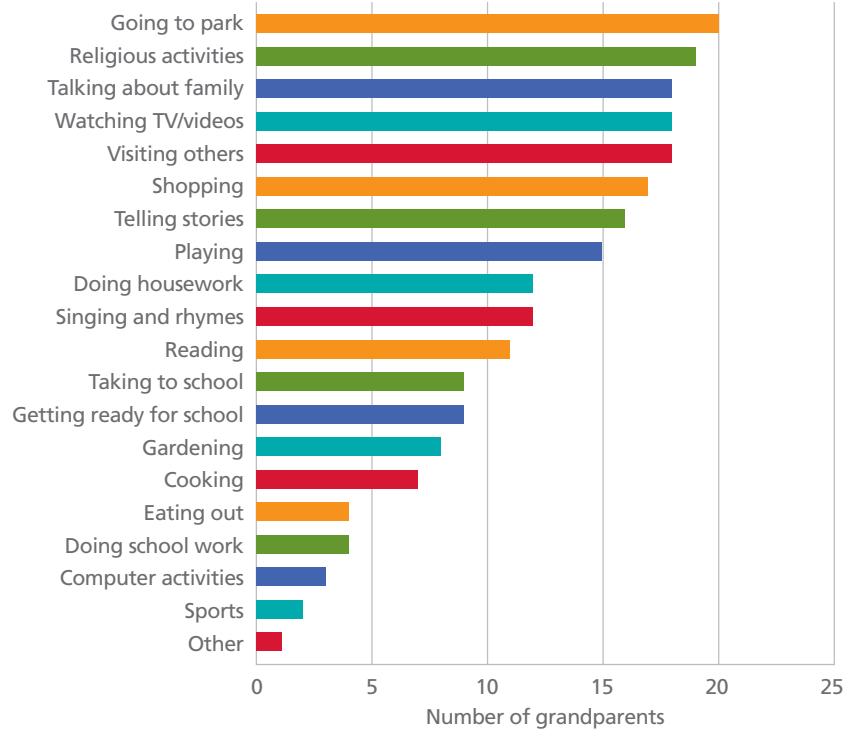
influence on their learning. This was particularly true for learning a language or learning about their culture. Observing grandparents and grandchildren interacting, researchers saw a very different relationship compared with that between parents and children: there were more activities focused on fun and enjoyment. The relationship was more equal, and because of this was characterised by mutual or shared learning.

Box 2: Key research findings: adolescents and grandparents

- The majority of grandchildren think that their grandparents are an important part of their lives.
- Grandchildren want their grandparents to be actively involved in their lives.
- Young people are better adjusted and have fewer problems when their grandparents are involved in their lives.
- Young people whose grandparents take an active interest in their education have fewer emotional and behavioural difficulties.
- Grandchildren adjust better to major life events (such as parental separation) when they have a close grandparent.
- During adolescence, many teenagers begin to take greater responsibility for caring for their grandparents.
- Grandparents are often perceived as less strict than parents.
- Grandchildren sometimes find it easier to confide in their grandparents than in their parents.

Sources: Buchanan and Flouri, 2008; Hill, 2006; Dench and Ogg, 2002; Buchanan and Griggs, 2009 (full references cited at the end of this Report)

Figure 3: The activities that grandparents do with young grandchildren



Source: Kenner C, Jessel J and Gregory E. *Intergenerational Learning between Children and Grandparents in East London: End of award report*. Swindon: Economic and Social Research Council; 2005

Children learnt by exploration and sometimes looked to teach their grandparents. This was particularly true for using modern technology, for example computers. Grandparents engaged in a wide range of activities – taking children for walks, reading books, cooking or going to the cinema (see **Figure 3**). Grandparents chose activities on the basis of enjoyment. Many of these activities help children’s general and social development. However, research has shown that only a minority of activities focused on children’s health, so there are real opportunities for improvement in this area. Grandparents may sometimes have a better opportunity than parents or teachers to influence their grandchildren’s behaviour, building on the strength of their relationship. Sport and exercise are often perceived as hard work and boring. When children enjoy exercise with their grandparents, they can appreciate the positives. Similarly, other shared activities, such as cooking, can have

an emphasis on health. Recent concerns that grandparents’ cooking may lead to children becoming overweight show the importance of using such opportunities to develop healthy behaviours. It will be important to equip grandparents with the right tools to support healthy eating.

In adolescence, most people think that peer relationships are dominant. However, researchers from Oxford University found that grandparents remain a strong and important influence on England’s teenagers. More than half of all adolescents described at least one of their grandparents as important in their life. More than a third reported that one of their grandparents was the most important person in their life after their parents or siblings. Nearly all young people reported regular contact with at least one grandparent. Surprisingly, contact was often initiated by the children themselves, for example visiting grandparents on the



way home from school. Teenagers valued the opportunity to seek advice from grandparents and confide in them about problems. Grandparents provided emotional support and advice at times of difficulty. One in four teenagers said that they talked to their grandparents about problems they could not discuss with their parents. Many sought advice about future careers and other major life decisions. Nearly eight out of ten adolescents reported that they usually respected what their closest grandparent said.

The research found that a strong grandchild–grandparent relationship was beneficial. Adolescents reported better emotional health and were better adjusted socially if their closest grandparent was involved in their life. This was particularly true for adolescents with either a single parent or separated parents. Talking about problems during an emotionally difficult period helps individuals deal better with problems. For teenagers, not being able to talk to and confide in somebody can cause emotional and behavioural problems, such as illicit drug use, unsafe sex or heavy alcohol consumption. It appears that a close relationship with a grandparent helps teenagers deal with problems and may

reduce the impact of high-risk health behaviours.

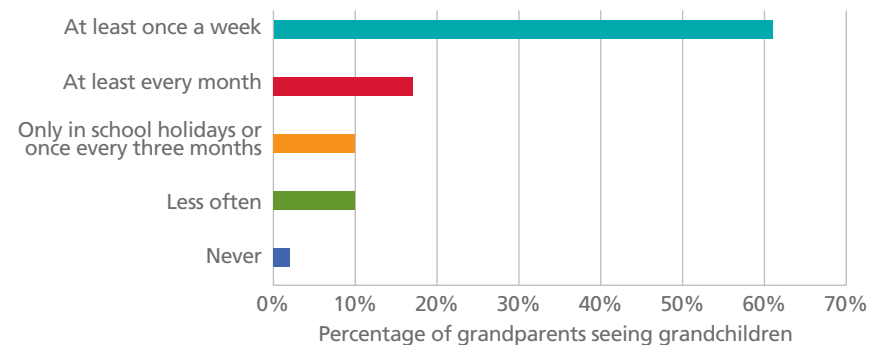
This may be particularly important when parents are splitting up. Parents are often important in promoting and validating links with grandparents, but those links may be lost when parents separate. At present, grandparents enjoy no special privilege or consideration, and are easily forgotten in agreements about children made during divorce proceedings. Grandparents and grandchildren see it as their ‘right’ to have a relationship, and this relationship can

provide an emotional buffer for children during this difficult time.

The importance of this relationship is often overlooked by outsiders. Many studies in a variety of countries have shown that the grandchild–grandparent relationship remains important during adolescence. More needs to be understood about this relationship. What do grandchildren choose to confide to their grandparents? How and when can grandparents influence their grandchildren? What is the impact of grandparents on specific health behaviours?

The relationship between adolescent grandchildren and their grandparents is often two-way. Grandchildren provide grandparents with help and support, for example with shopping or gardening, that continue throughout the grandparent’s life. Often this is not prompted by parents. The relevance of grandparents varies from family to family, with different cultures placing a different emphasis on the relationship. Levels of respect are particularly high amongst Pakistani and

Figure 4: The frequency of contact between grandparents and grandchildren



Source: Office for National Statistics



Chinese families, and lowest amongst white families. Judaism also places great importance on wider family networks, including grandparents. Families of Asian origin are much more likely to have grandparents living at home. Society risks undervaluing grandparents.

Grandparents and health

Childhood is a vital time for health. Personality develops, together with many attitudes and behaviours that persist through life. Eating and exercise habits are established. Older children may start experimenting with illicit drugs, alcohol or tobacco. Consumption patterns established in these early years have a huge impact on long-term patterns of use, and on longer-term health. In my 2007 Annual Report, I focused on many of the problems that affect teenagers. The teenage years are a period in which experimentation and risk-taking are part of the rite of passage into adult life. This can pose a threat to health in the short term, but there is also the concern that behaviours, once established, may persist and into adult life and become a hazard to long-term health. Children also begin to learn about their emotions and how to form relationships, which is important for

their long-term psychological well-being. For some children, for example those with chronic illnesses such as diabetes, childhood can be particularly difficult.

Grandparents are already an important influence on children. This may be as a source of advice and influence on parents. It can be through taking care of children, thereby supporting parents. It may be by taking children for regular exercise, or teaching children to cook. It can even be by simply setting a good example about taking medications regularly or seeing a doctor or dentist when there are problems. Importantly, many grandparents are able to offer a loving, sympathetic and supportive ear at times of emotional difficulty during

Box 3: Grandparenting in numbers

- There are over 11 million grandparents in England.
- 1 in 14 grandparents are under the age of 50 years.
- Nearly 1 in 2 grandparents are under the age of 65 years.
- Almost 61% of grandparents see their grandchildren weekly.
- 7 out of 10 grandparents live within 10 miles of their grandchildren.
- The value of care provided by grandparents is £3.9 billion.
- Nearly 170,000 grandparents are assuming the primary carer role.
- 92% of grandparents find their grandchildren very rewarding.
- The average 10 year old has 3 grandparents living, compared with 1950 when they had 2.

Sources: Office for National Statistics, 2004; Age Concern, 2004; Grandparents Plus, 2009; Dench and Ogg, 2002; Murphy M, London School of Economics, 2010 (full references cited at the end of this Report)

the teenage years. These examples show how grandparents can improve the health of grandchildren. However, the huge potential of grandparents is largely untapped. The importance of grandparents needs to be recognised and there is also a need to understand more about their relationship with grandchildren, and to develop tools to help grandparents improve the health of their grandchildren.

Numerous policy documents, initiatives and projects emphasise the role of parents, teachers and peers in building a healthy childhood and sustaining healthy behaviour into adult life. Few, if any, see a role for grandparents. Parents, teachers and the media are considered the main health educators of children. Interventions to improve children's health are specifically designed for parents and teachers. Some of these interventions might be suitable for grandparents, while others could be designed specifically for them.

When policy documents concerning children's health are developed, the role of grandparents should form part of the thinking. Developing the role of grandparents as educators and mentors of their grandchildren's health behaviour could add an important new dimension. It would build on a relationship that is mutually valued and non-confrontational and where real influence is exercised. At the moment, any focus on health within the relationship is a by-product of recreational activities. Exploring ways to equip grandparents with the tools, skills and knowledge to lay the foundation in childhood for a healthy future could provide a solution to a problem that has proved intractable.

Actions recommended



- The important contribution of grandparents to children's health and well-being should be recognised and valued.
- Research into how grandparents can improve children's health should be conducted.
- The census should routinely count the number of grandparents in the country.
- Evidence-based tools and advice should be produced for grandparents to promote the health of their grandchildren.
- Policy initiatives aimed at improving children's health should consider the potential role and impact of grandparents.
- The importance of the grandparent–grandchild relationship for a child's emotional well-being should be recognised when parents divorce.
- Grandparents who take on full caring responsibilities need to be supported in this role.
- Children should be encouraged to maintain their relationships with their grandparents and support them throughout life.



Climate change and health

Key points

- Climate change is already harming health, robbing the world's people of an estimated 5.5 million healthy years of life every year.
- Climate change damages global health through a myriad of means. It fundamentally threatens the requirements for good health – food, shelter, clean water, clean air and civil order.
- The health impact of climate change is unjustly distributed. The impact is over 500 times greater in Africa than in England.
- A series of win-win actions can both slow climate change and substantially improve England's health now. These include walking and cycling for a greater proportion of journeys.
- As it has the greatest carbon footprint of any public sector organisation in Europe, the NHS has a responsibility to be a leader in reducing greenhouse gas emissions. It can enhance its efficiency and service whilst doing so.
- Climate change spells global health disaster. Action needs to be rapid and bold.

Climate change and health are inextricably linked. Global health is fundamentally threatened by climate change. Conversely, there is an opportunity to actively improve health by taking steps that also help to slow climate change.

People speak of climate change affecting the planet. They speak of melting ice-caps, of rising sea levels, and of warmer summers. Climate change will damage the planet's inhabitants, not just the planet itself. We face an immense human cost.

The health impact of climate change is already here. It is growing, and it is unpredictable. The World Health Organization estimates that climate change is already responsible for the loss of 5.5 million years of healthy life annually. So, in health terms, climate change is not just some future threat: it is a present and worsening reality. It brings increasing temperatures, with a myriad of adverse health impacts. It also brings an increase in the climate's variability. The consequences are not easy to predict. The 2003 summer heat wave in western Europe was not foreseen; it caused 70,000 deaths. On current projections, these increased temperatures could be the norm by the middle of this century. Similarly, it was not predicted that Hurricane Katrina would cause such devastation in 2005. In 70 years' time, tropical cyclones, the most



intense form of hurricane, are projected to be four times as common as they are now. In the 1990s, weather-related natural disasters caused 600,000 deaths worldwide (see **Table 1**). It is difficult to predict how many times this figure will multiply in the years to come.

On a global scale, the increasing temperature threatens health in a number of ways. Infectious diseases are of particular concern. Global warming is opening up far greater swathes of the earth's surface to disease-carrying mosquitoes, which cannot survive in cooler climes. It is estimated that, by 2080, 300 million more people will be affected by malaria every year unless evasive action is taken. At the same time, 6 billion people around the world will be at risk of dengue fever.

Higher temperatures and more erratic rainfall will reduce the availability of clean water in poorer countries. This risks turning back the clock on recent advances in sanitation, and impeding future efforts. Dirty water carries diarrhoeal diseases such as cholera, which already kill 2.2 million

people every year worldwide. Dirty water harbours trachoma, an infection that is a leading cause of avoidable blindness. Promising developments have been made to reduce the great suffering that these simple infections cause in the world, but climate change threatens to reverse such advances with ease.

Small changes in temperature significantly affect air quality. Heat causes levels of pollen and other allergens to rise, causing diseases such as asthma. Heat affects the concentration of ozone and other pollutants at the surface of the earth, and higher concentrations cause illness and death from respiratory and cardiovascular disease. A rise in temperature of one degree Celsius increases air pollution enough to cause an additional 20,000 deaths globally in a year.

Climate variability causes great problems, bringing both flooding and drought. Floods cause drownings and injuries. They allow water-borne infectious diseases to spread and also encourage insects and rodents. Floods can be very disruptive to

Table 1: Extreme weather events already affect millions and kill many thousands worldwide. Further climate change will increase this substantially

1990s		
Extreme weather events	People affected	People killed
2,078	1,851 million	601,000

Source: World Health Organization

“Climate change is a health issue affecting billions of people, not just an environmental issue about polar bears and deforestation.”

Professor Anthony Costello

Director, University College London Institute for Global Health

normal life by damaging the infrastructure, including healthcare services. They can also cause significant psychological and psychiatric problems for those whose lives are affected.

Threatening the fundamentals of human health

Climate determines human health at its most fundamental level. Clean water, clean air, adequate shelter, food and civil order are basic requirements for health. All of these are disrupted by climate change. The combination of heat and erratic rainfall brings drought. This is a disaster for crops, and therefore also for human nutrition. Malnutrition already causes 3.5 million deaths annually. Some people die from pure starvation; others die from simple infections, their bodies weakened by a lack

of food. We risk millions more starving every year.

Climate change threatens to displace populations around the world, as people will be forced to leave flooded homes. Predicted sea rises will expose over 100 million more people to coastal flooding by 2080. Drought will also displace many. By 2090, if climate change is unchecked, extreme droughts are projected to occur twice as frequently as they do at present, and last six times as long. The total area of land in extreme drought will increase between 10- and 30-fold. Displacement causes conflict and disrupts normal living, including education and health services. The displaced often move to temporary living conditions that lack basic sanitation facilities. The perfect storm of food, water

and energy shortages worldwide is likely to lead to unpredictable human migration on a scale that ultimately risks the most severe health hazard we know: civil disorder.

The health impact in England

Climate change will affect England in similar ways to the rest of the world, although the magnitude of the impact will be less than elsewhere. The rising temperature will expose us to new infectious diseases. The population of England currently considers tick-borne encephalitis and other dangerous insect-borne diseases distant, even exotic. We risk coming to know them first-hand. Skin cancer, which already kills 1,900 people every year, will become more common. Extremes of climate, such as flooding and heat waves, will occur more frequently. The magnitude of the impact in England is as difficult to predict as it is globally. So far, the direct impact of climate change in England is small compared with other parts of the world.

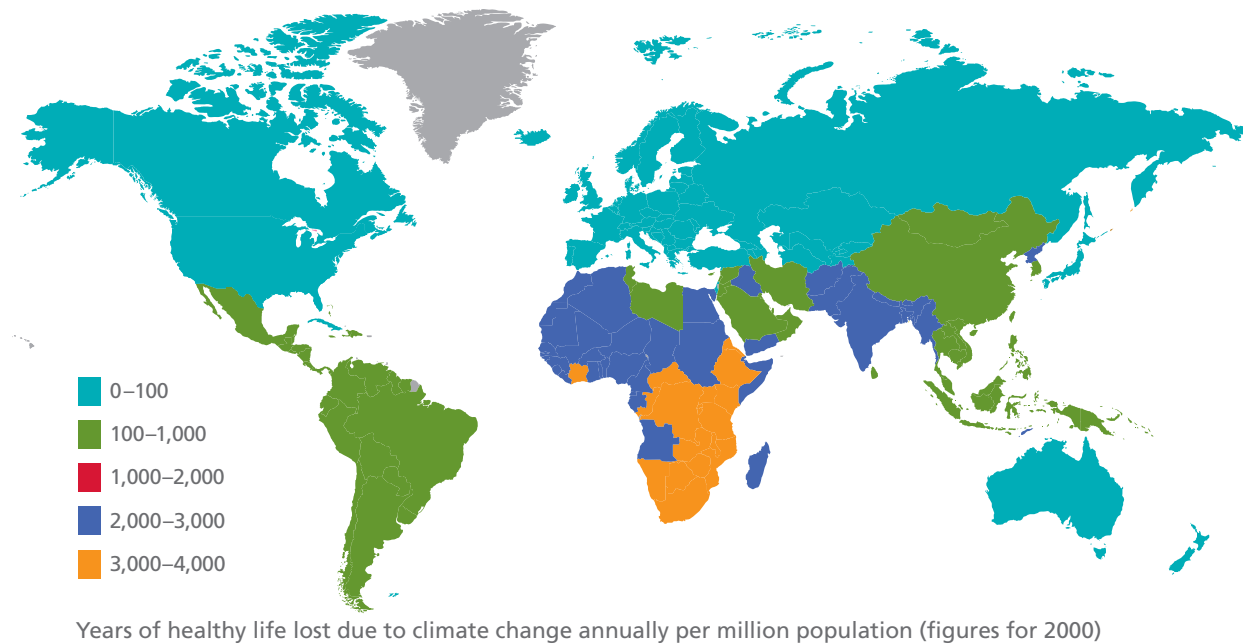
England will suffer in other ways. Many predict that mass migration will occur because of climate change. People from areas that become inhospitable will need to migrate elsewhere. England is likely to share in the challenge of housing people within our borders. This is likely to strain essential public services, including the NHS.

The global health impact: an unjust distribution

Climate change is disproportionately affecting parts of the world that can least afford to be affected. We live in a world of great health inequality. A baby born in the United Kingdom has a life expectancy of 79 years. A baby born in Mozambique or Sierra Leone can expect to live for just 47 years. Climate change is threatening to



Figure 1: The health impact of climate change is over 500 times worse in southern Africa than in the United Kingdom



Source: World Health Organization

widen this gulf. This effect is here already: World Health Organization calculations for the year 2000 show that the adverse health impact of climate change was over 500 times greater for the countries of southern Africa than it was for much of the developed world (see **Figure 1**).

There is a great irony in this. The average person in many African countries is responsible for less than one-fortieth of the carbon dioxide emissions for which the average UK citizen is responsible. Those who are the least responsible for creating climate change are the most affected by it.

Taking responsibility for a global problem

The unjust distribution of climate change's impact presents a clear moral imperative. Few would think it right that the lifestyle of the world's richer countries should disrupt the planet so significantly that we severely damage the health of the world's poorest people. In 2007, I produced a draft strategy for consultation, *Health is Global*. This is now a definitive UK Government strategy.

It recognises that we live in an interconnected and interdependent world. It is no longer realistic to consider one country's health in isolation. Infectious diseases do not respect international borders; displaced people need somewhere to go. The health damage caused by climate change is truly an issue for the whole world.

England has both a duty and an opportunity to lead. We were the first country to undergo industrial revolution and enter the high-carbon world. We consequently have one of the highest cumulative per capita records in the world. We are already a leading country in the transition to low carbon, being the first to enact legally binding carbon reduction targets.

Averting disaster whilst improving health

There are some substantial and fortuitous overlaps between actions that can help slow climate change and actions that would be desirable even without climate change, because they help to improve health (see **Table 2**). Where such synergies exist, making changes to the way in which we live offers an opportunity to simultaneously help slow climate change and positively improve our country's health in a sustainable way. Actions in two areas are particularly important: diet and exercise.

Worldwide, food production is responsible for at least 10% of greenhouse gas emissions. Meat farming is responsible for the substantial majority (80%) of these emissions. These come from deforestation and from the processes of slaughter and transport. They also come from the animals themselves. Cows, sheep and other ruminant animals produce significant amounts of methane, a potent greenhouse gas, as they digest their food.

Table 2: Win-win actions can both slow climate change and improve health now: some important policy choices

Action	Positive effect on climate change	Positive benefit for health
Less motorised transport use, more 'active transport' (walking, cycling).	Reduction in greenhouse gas emissions from vehicle production and fuel use.	More people achieving recommended exercise levels. Less obesity, heart disease and stroke. Greater mental well-being.
Less use of fossil fuels for energy generation.	Alternative energy sources generating fewer greenhouse gas emissions.	Alternative energy sources generating less air pollution, reducing illnesses and deaths from heart and lung disease.
Fewer animal products in the diet.	Reduction in the substantial greenhouse gas emissions produced by livestock farming.	Less saturated fat in the diet. Less obesity, heart disease and diabetes.
Improvements to household ventilation and insulation.	Enhanced energy efficiency.	Insulation reduces cold-related illness and death. Ventilation provides cleaner air, cutting respiratory diseases including lung cancer.

The agricultural industry can play an important role in meeting the emission reduction targets set by government. It can alter some of its production and transport processes and improve efficiency. We could also consider producing – and therefore eating – fewer animal products.

Reducing our consumption of animal products can also have a positive health impact. Meat, butter, cream and cheese can play a part in a healthy balanced diet. In excess they can cause health problems. Their high level of saturated fat finds its way into our diet in biscuits, cakes and pastries, as well as in meat. Some animal products can be highly calorific. They can contribute to obesity, diabetes and heart disease.

A recent study examined the health impact of reducing the United Kingdom's consumption of animal products by 30%

by 2030. This reduction would cut greenhouse gases substantially. There would also be health benefits. It would reduce heart disease by 15% – a substantial reduction – and it would prevent 18,000 premature deaths every year. Taking both deaths and disease-related ill health into account, a 30% reduction in animal product consumption would save the equivalent of 175,000 healthy years of life every year.

Our diet is warming the planet. It is also damaging our health. Changing our diet is difficult, but doing so would both help slow climate change and bring significant health benefits. These are contentious matters but they need to be openly debated and options weighed up.

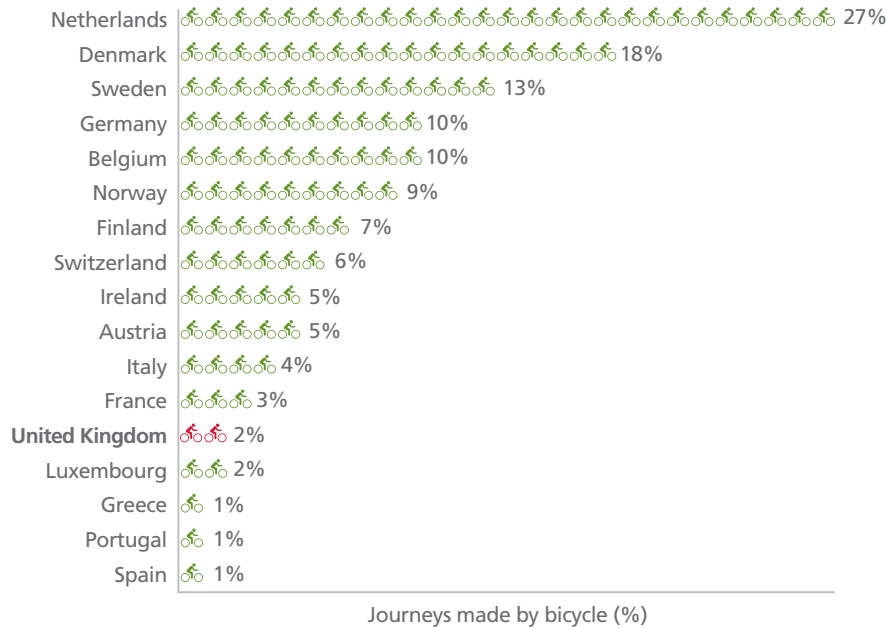
The second area in which there is opportunity for a double benefit is transport, particularly in towns and cities. Road traffic is responsible for almost 20% of greenhouse gas emissions worldwide. Decreasing these emissions is key to slowing climate change. There need to be two major strands to this effort: motor vehicles need to produce fewer emissions, and we also need to use motor vehicles less. Both strands have important health benefits, particularly the latter.

Alternatives to driving increase physical activity. Our sedentary culture is causing major health problems. My 2002 Annual Report highlighted the dangers of the obesity 'time bomb'. I reported estimates that obesity reduces life expectancy by nine years, causes 9,000 premature deaths every year in England, and costs the economy at least £2.5 billion a year.

The time bomb continues to tick. One-quarter of the adult population is now obese and over half of the adult population is overweight or obese. Being overweight causes diabetes, heart disease, stroke, cancer, and psychological and social problems. Increasing physical activity is vital



Figure 2: Cycling is rare in the United Kingdom compared with many other countries in Europe



Source: European Conference of Ministers of Transport, 2004

to reducing obesity and these health risks. As highlighted in an earlier chapter of this report, regular physical activity offers the additional benefits of enhanced general well-being and a lower risk of depression and dementia.

Crises often compete for attention and their solutions often conflict with one another. This is not the case here. Currently, road transport contributes heavily to the climate change crisis, and low levels of physical activity have created a public health crisis. The two crises share a solution: a fundamental change to transport, especially urban transport, is needed in England. The United Kingdom has one of the lowest rates of cycling in

Europe (see **Figure 2**). For a far larger proportion of journeys than is currently the case, cycling and walking need to be more feasible and appealing options than driving. Most streets in most cities in England are currently designed around cars. This situation cannot continue.

A number of European cities offer an alternative vision. In Amsterdam and Copenhagen, for example, many streets are designed with cyclists and pedestrians very much in mind (see **Box 1**). The people of these cities drive substantially less. They walk and cycle substantially more. Recently published work considers how London could look in 2030 if its transport patterns changed to mirror these cities. The findings

are striking. Carbon dioxide emissions would be reduced by nearly 40%, making a substantial contribution to tackling climate change. The health benefits would be impressive: there would be significant reductions in heart disease, stroke, diabetes, depression and dementia. In London alone, over 55,000 healthy years of life could be saved every year. Travel by bicycle or on foot needs to become the safe, viable, attractive option for a far greater proportion of journeys.

Altering lifestyle habits is difficult, but the rewards for taking these steps are clear and significant. Lifestyle changes can make a substantial contribution to slowing climate change and can significantly reduce the disease and death that are associated with a sedentary lifestyle – a lifestyle to which the current absolute dominance of motorised transport contributes.

A number of other interventions can simultaneously tackle climate change and improve health. Switching to low-carbon electricity generation can help reduce air pollution. This can reduce the number of adults who die or suffer from lung diseases, including cancer, and the number of children who suffer from asthma. Improvements in household insulation and heating mechanisms, if properly designed, can improve energy efficiency and hence reduce emissions. Such improvements can also reduce the number of deaths from winter cold and improve indoor air quality.

All of these synergies are fortuitous and interesting. More than that, they have a very practical value. England needs to take many steps to play its part in slowing climate change. Many of these steps cost money and require difficult choices and changes. The existence of simultaneous

Box 1: Cycling reduces carbon emissions and improves health. Roads need to be designed to make it appealing and safe



Amsterdam: Wide, segregated cycle lanes are common



London: Cyclists usually share the road with other traffic

health benefits offers an additional motivator. These benefits offer a valuable means to help justify the costs and to offset them. Delaying action to avert dangerous climate change will make the ultimate solution more difficult, more expensive, and less likely to succeed. It is vital to seize these current opportunities now.

The role of the National Health Service

The NHS is responsible for more greenhouse gas emissions than any other public sector organisation in Europe. NHS organisations – hospitals, general practices and ambulance services – produce many emissions directly. NHS suppliers release even more emissions, in manufacturing and transporting the equipment and supplies that the NHS uses (see Figure 3).

The NHS makes an extremely significant contribution to road travel in this country. It has 50,000 vehicles on the road. Its vehicles ferry patients to appointments. Its doctors travel between hospital sites. Its suppliers deliver goods. People drive to see their general practitioner, to their hospital clinics, and to visit their family and friends in hospital. In total, one in every 20 road journeys in the UK is related to the NHS.

It is vital that the NHS makes substantial emissions cuts. The NHS is so large that such cuts can play a significant part in reducing emissions for the country as a whole. Importantly, the NHS can also be a role model. A number of actions that can help the NHS address climate change have additional benefits that will help it become

a modern, safe, affordable and high-quality organisation. Again, these overlaps are fortuitous. Actions include more coordinated care closer to home, better use of specialist care, better use of information and communications technology, and less travelling by staff and patients. My 2004 Annual Report highlighted the public sector's food purchasing power, and the potential to enhance health through this. Serving healthier, seasonal food in hospitals could also reduce the greenhouse gas emissions associated with the transport of non-seasonal foods and the production of animal products. If the NHS can grasp these opportunities, it can enhance its performance whilst also becoming a leading public sector exemplar in the transition to a low-carbon economy.

Figure 3: More than half of emissions associated with the NHS are created in the production and transport of its supplies



Source: NHS Sustainable Development Unit, 2009

The NHS needs to be brave. The necessary reductions will not be made by tinkering. Questions about where and how health services are delivered need to be re-examined in a fundamental way. Communications technology could allow many more consultations to occur remotely, diminishing the need for travel. Disposable equipment is now the norm; this has an infection control benefit but an environmental cost. Novel solutions need to be sought. In some cases, risks and benefits will need to be re-weighed, but there are many implementable solutions that have dual benefits. Energy efficiency savings can cut financial costs as well as emissions, and the money saved can be invested elsewhere in the health service. Remote consultations can also be much more convenient and waste less time and energy. Reducing travel can make roads and communities safer as well as decreasing air pollution. Healthier, seasonal food in hospitals can benefit regional economies as well as being more nutritious and tastier for patients. More personalised knowledge online can promote better self-care and support carers in the community. There are hundreds of fortuitous synergies. Each one needs to be grasped.

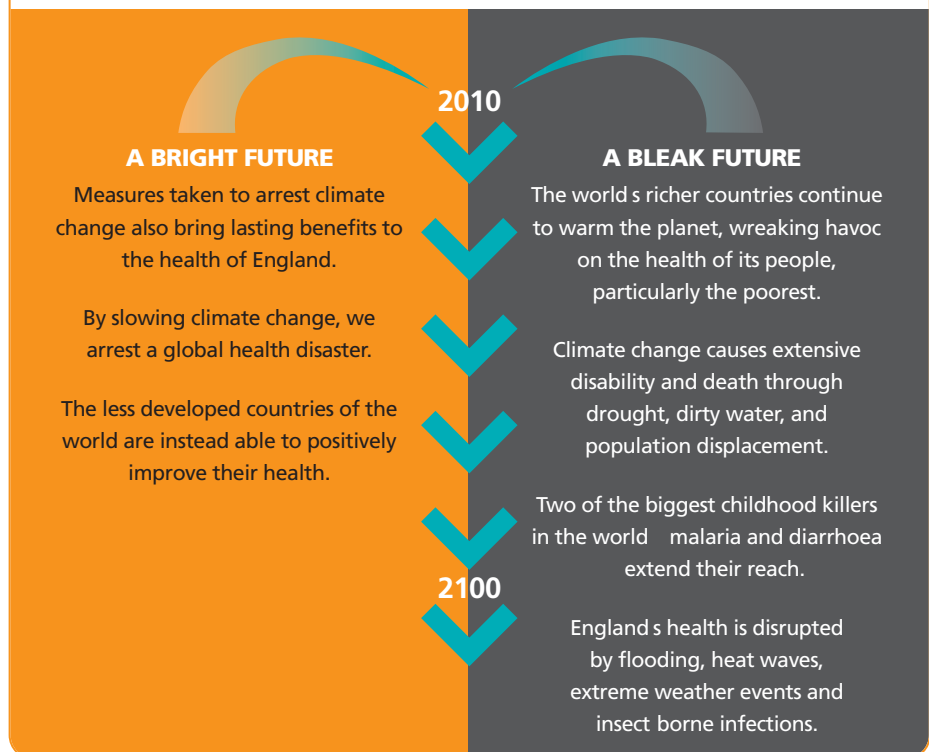
The NHS Sustainable Development Unit is leading this important work, but all organisations in the NHS need to recognise the enormity of the issue. They also need to recognise the considerable opportunity that they can benefit from – now and in the future – if they take action. The NHS deals well with emergencies that present an immediate threat to human life. It must prove itself equally capable of dealing with climate change – a slow-burning yet immense threat to human health.

Choosing the future

Climate change is a public health emergency on a global scale. A problem that is everybody's is too easily treated as a problem that is nobody's. Instead, the threat of dangerous climate change should stimulate us to address multiple challenges to our health. It should make us focus on exploiting the opportunities for synergistic benefits. The population of England needs to make substantial changes to its collective lifestyle. Many of these changes will not only help avert damage to the earth and to human health worldwide, they will also actively improve our own population's health.

We are faced with a choice between two very different futures: one is bleak; one is bright (see **Box 2**). In one we fail to meet the challenge. We substantially damage the health of the world's people, particularly the poorest. In the other, we are bold. We take the necessary major steps. Not only do we arrest this global health disaster, we also make significant improvements to England's health in the process.

Box 2: Through our actions now, we are choosing between two very different futures



Actions recommended



- The synergies between improving health and slowing climate change should be championed by the Government and health leaders to drive bold lifestyle changes.
- National targets should be set to double travel on foot in England's towns and cities, and to increase travel by bicycle eight-fold; transport policy and road design should support the achievement of such gains.
- The health impacts of climate change should feature prominently in undergraduate and postgraduate health professional education curricula.
- The NHS in England should make its facilities readily accessible by public transport, and should make services increasingly available remotely, using modern technology, to reduce travel.
- The NHS in England should use its buying power and other means to drive rapid transition to a low-carbon economy; the aim should be to reduce its carbon footprint by 10% from its 2007 level by 2015.

The Regions





A good death for every citizen

In 2007, the North East consulted on a regional public health strategy, *Better Health, Fairer Health*. The consultation confirmed support for one interesting theme: the right to a good death. Whilst there was already work taking place on palliative care, little was being done on the culture and attitude towards death – specifically death as a public health issue.

The North East has now developed the United Kingdom's first charter for 'a good death'. The charter will guide planning and provision for a wide range of services, including health and social care, to support end of life care.

The process for developing this regional charter has stressed the need to 'normalise' death, to tailor services and support around people's wishes, and to build capacity and understanding amongst individuals, communities and organisations in order to create a compassionate approach to the end of life. The charter is

about living with dying and ensuring that people have the opportunity to fulfil their potential in whatever time they have left.

NHS North East has worked with around 70 partners from a range of health, social care, voluntary and community organisations, as well as patients and carers, to produce the charter, which sets out rights and entitlements for people who are dying, their families and carers.

A three-month consultation was held from October to December 2009. Over 2,500 people in the North East shared their views and opinions on the charter and the wider subject of death and dying. The consultation included raising awareness amongst NHS staff, patient representatives, social care providers, employers, carers' organisations and community groups. Consultation and communications activity featured a dedicated website with an online questionnaire, on-street research, focus groups, telephone interviews,

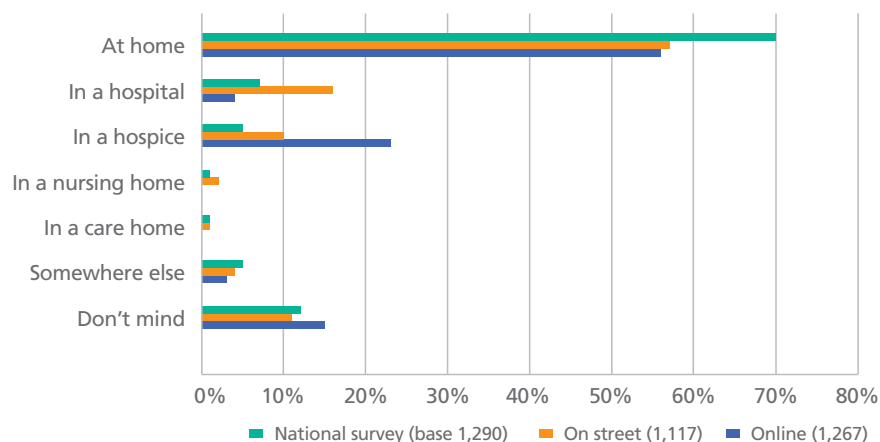
YouTube postings, media coverage and photo opportunities.

Feedback from the consultation will shape the final content of the charter and ensure that it is responsive to public views. It will help NHS North East and partners to plan and deliver end of life care. Early findings confirm that the majority of people (57%) would like to die at home. Of those, over one-third (38%) would prefer to do so even if they did not have sufficient support from family, friends or social and medical professionals.

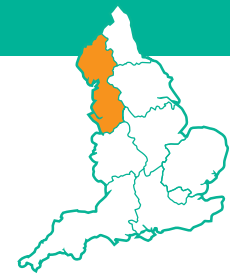
Plans are under way to pilot implementation of the charter in part of the region and to evaluate the pilot. The plans include establishing a unit to work with the new professor in end of life care at Teesside University through March 2011, to raise community and social awareness of death, dying and bereavement, and to build capacity for NHS and social care staff across a range of settings.

The lessons from the pilot will be crucial in ensuring that the charter approach is embedded and implemented throughout the North East. This will help to build a society where death is accepted as a normal part of life, where individuals recognise their responsibility to be compassionate to those who are dying and to their loved ones, and where the policies and practice of all organisations are sympathetic to the needs of dying people.

Figure 1: Survey results showing where respondents felt would be the best place to die, 2008/09



Source: National figures from a survey by the National Council for Palliative Care, 2009; on-street and online survey from the North East consultation, October–December 2009



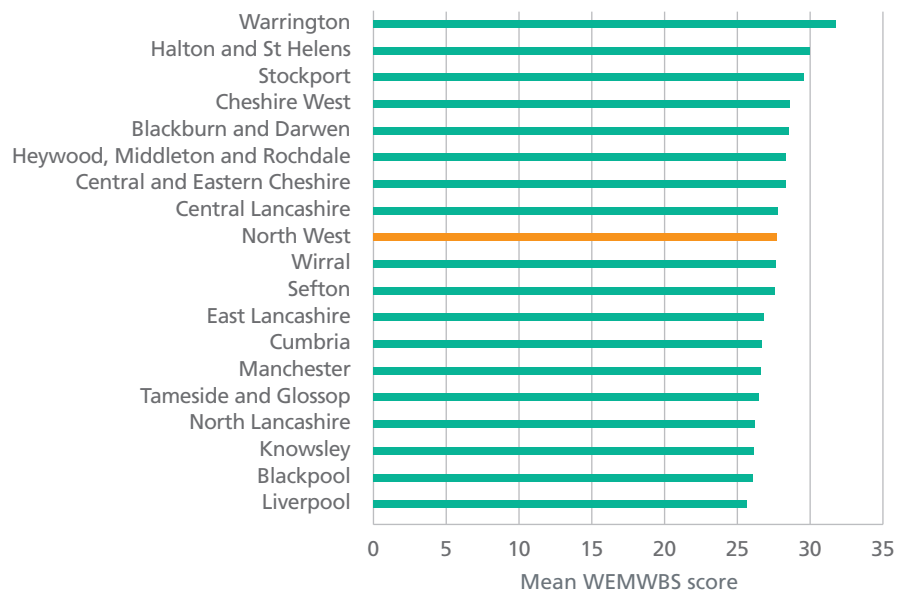
A better understanding of mental well-being

There is increasing evidence that positive mental well-being leads to a more flourishing and fulfilling life at home, school, work and in the community. There are two main elements of mental well-being: feeling good and functioning well. This does not require individuals to feel good all the time: the experience of painful emotions and the ability to manage them are essential for long-term well-being. The Government Office for Science's Foresight report found that action to improve mental well-being could have high economic and social returns.

The North West Regional Wellbeing Survey was undertaken in 2009 to establish a meaningful baseline for mental health and well-being. A total of 18,500 face-to-face interviews were conducted in 19 primary care trust areas. Interviewers used a questionnaire that incorporated the Warwick-Edinburgh Mental Well-being Scale (WEMWBS), which focuses on positive aspects of mental health. Additional questions sought to measure a wide range of determinants of mental well-being, for example feelings, relationships, health, life events and lifestyle.

The survey found stark differences in mental well-being across the North West (see **Figure 1**). Those who were aged 40–54 years, white and living in disadvantaged circumstances have much lower levels of well-being. It found that 20.4% of the population have relatively high levels of mental well-being, and these were observed to have strong associations with work, education, relationships, health, managing on an income, life satisfaction and lifestyle. Within local areas, the proportion of people with relatively high well-being ranged from 60.2% to 5.7%, and the proportion of people with

Figure 1: Levels of well-being varied throughout the region



Source: Deacon L, Carlin H, Spalding J et al. *North West Mental Wellbeing Survey 2009: Summary*. Liverpool: North West Public Health Observatory; 2009

relatively low well-being ranged from 30.3% to 5.0%.

Improving an individual's positive sense of self and their ability to change is essential in getting them to adopt healthy behaviours. Programmes aiming to tackle health-damaging behaviours cannot be delivered in isolation from improving well-being, therefore action to promote well-being must be used alongside other behaviour change programmes. Likewise, physical health and mental well-being should be addressed jointly in prevention and care pathways. Other significant findings of the survey included the importance of supporting people's ability to build and manage relationships, and of people being part of a local community and influencing decisions.

Whilst Liverpool has the lowest mean score, the city is geared up to tackling this issue through its recently launched public mental health strategy and the designation of 2010 as the Year of Health and Well-being (www.2010healthandwellbeing.org.uk). This is a high-profile, multi-agency campaign to engage partners and people in doing more to improve their health and well-being, driven by city leaders and health and well-being ambassadors. Individuals, groups and organisations are being asked to pledge to take action to improve their health and well-being, in particular through the five 'ways to well-being': to connect with others; to be active; to give; to take notice; and to keep learning. Events and activities are planned throughout the year to support people with their pledges.



The challenge of financial inclusion

The link between inequalities in income and inequalities in health was recently highlighted by Sir Michael Marmot's Health Inequalities Strategic Review Team and in books such as Richard Wilkinson and Kate Pickett's *The Spirit Level*, which captured the attention of many media commentators and social policy researchers in 2009.

In England, the life expectancy gap between those living in areas with the top 5% and bottom 5% of income is around seven years, and the difference in disability-free life expectancy is around 17 years.

Across Yorkshire and the Humber, partners in local authorities, the voluntary sector, primary care trusts and central government are working hard to promote financial inclusion and to eliminate the 'poverty premium' that sees people on low incomes pay more for essential goods and services. The City of Leeds has been carrying out a number of actions to address this,

including investing in credit unions so that people have an affordable alternative to doorstep lenders, and setting up cross-organisation collaboration to make sure that there is easy access to debt advice, benefits and welfare rights services.

Economically, this makes sense. Leeds City Council commissioned the University of Salford to carry out an evaluation of its financial inclusion activities. This showed that:

- over 50,000 people were helped to take greater control of their lives
- the activities put more money directly into people's pockets – £26 million of additional disposable income
- every £1 spent by beneficiaries generated an extra 25p in the regional economy
- every £1 invested in financial inclusion generated £8.40 for the regional economy.

Where people were helped directly to increase their incomes, they spent the extra

money mainly on food, paying bills, their children and saving. As well as feeling better off, a substantial number of people also reported that their health improved: they made fewer visits to the doctor and needed fewer prescriptions.

Whilst there is a rich tradition of work to raise income and reduce debt, this is an area that is often characterised by a patchwork approach to services and support. The challenge is to make the approach more systematic.

This costs money. It requires substantial investment up front and over time, but the work in Leeds is providing strong evidence of the scale of the potential returns on this kind of investment.

Doing nothing costs money too. In 2004/05, Leeds received £8.4 million to invest in regeneration through the Neighbourhood Renewal Fund. Whilst this funding was going into communities, between £3 million and £9.5 million was leaching straight out in 'excess' interest paid by residents in those very communities.

With support from the Department of Health and the Department for Work and Pensions, Leeds City Council is leading work to promote the case for investment in financial advice and support, and is developing a framework of principles to guide service commissioners.





Protecting children from smoke in the home

Since the successful implementation of current smoke-free legislation in 2007, exposure to second-hand smoke has been reduced in all public areas and workplaces. Current legislation does not offer protection to the families of smokers in private dwellings and vehicles.

Children exposed to second-hand smoke are at an increased risk of developing asthma, chest infections, glue ear and meningitis. They are also at an increased risk of hospital admission within one year of birth and of sudden infant death syndrome. And they are around three times more likely to become smokers themselves.

In the East Midlands, it is estimated that just over 200,000 children under 16 years (25%) live in households where smoking is allowed. To reduce this number, individual primary care trusts have established 'Smoke-free Homes' schemes in all eight tobacco control alliance areas: Nottingham City, Nottinghamshire, Derby City, Derbyshire, Leicester City, Leicestershire, Northamptonshire and Lincolnshire.

These schemes are in various stages of development, but in all the aim is to encourage residents to make a commitment either to have a smoke-free house at all times or to restrict smoking in the house, especially if children live there.

Families can refer themselves directly to the scheme in response to advertising campaigns, or they can be referred by agencies such as the fire service or the NHS, or by health visitors or schools (see Figure 1).

The widest-reaching scheme in the East Midlands is in Lincolnshire and is managed and coordinated by the Smoke-free Lincolnshire Alliance. Started in 2004, with funding from local and regional partners, the Lincolnshire scheme has grown dramatically, with over 13,000 homes signed up. As of December 2009, 14,000 children (slightly more than 10%) in Lincolnshire who are aged 0 to 16 years are protected from the effects of second-hand smoke in the home.

Figure 1: Origin of referrals to the Lincolnshire scheme, May 2004 to December 2009

Referral origin	Number
PHOENIX (the local NHS Stop Smoking Service, including the pregnancy stop smoking service)	3,975
Smoke-free Homes – direct referrals	5,816
Children's centres	1,377
NHS	721
Events	609
Schools	173
Unknown	140
Other	452

Source: Smoke-free Lincolnshire Alliance

The Lincolnshire scheme focuses on targeting the areas of highest deprivation. Smoke-free Homes referrals are plotted on maps to monitor whether the target areas are being reached.

The Smoke-free Homes scheme in Nottingham City is the subject of a University of Nottingham six-year research project (February 2009 to February 2015). The research aims to assess the effectiveness and cost-effectiveness of the use of nicotine replacement therapy (NRT) in helping parents make their homes smoke-free, thereby reducing their children's second-hand smoke exposure. It also aims to define the optimum model for implementing this intervention effectively within Nottingham City, and to test the intervention in a single-centre randomised controlled trial.





Heart attacks and ethnicity

The relationship between deprivation and coronary heart disease is well known. The same applies to particular patient groups, including those from minority ethnic backgrounds. South Asian and African-Caribbean groups have higher rates of conditions, such as diabetes, that are risk factors for premature heart disease.

Approximately 12% of the region's population of 5.4 million are from a minority ethnic community. The region has lower life expectancy than the national average and higher levels of mortality from coronary heart disease.

Hospital admissions for patients with heart attack, chest pain and cardiac arrest were examined for the period April 2008 to March 2009. Deprivation was calculated using the areas where patients lived and

was aggregated to the relevant national Indices of Multiple Deprivation (IMD) quintiles. IMD quintiles categorise households into five groups, ranging from the most deprived to the most affluent neighbourhoods. Ethnicity data were derived from the hospital admission information. Because of the small numbers involved, ethnicity groupings were limited to White, South Asian, African-Caribbean and Other.

There was a total of 35,620 admissions due to heart attacks across the whole of the West Midlands; 62% were males, and 1,026 patients had died.

Heart attacks amongst the White British population peak at the age range of 60–69 years. Admissions for South Asian and African-Caribbean groups appear to occur

at a younger age, at 50–59 years and 40–49 years respectively. Preliminary information on these patients suggests that older patients are far more likely to have other pre-existing conditions and illness compared with younger patients. This is common across all ethnic groups.

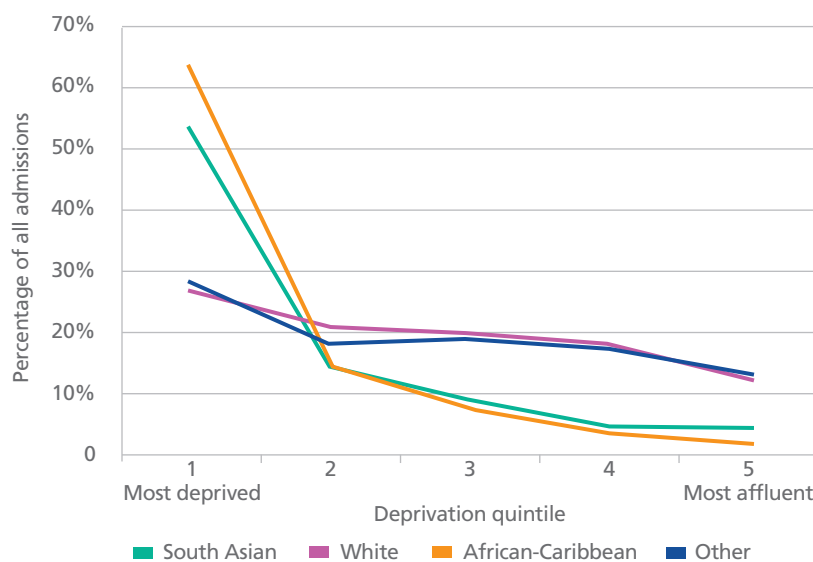
Whilst the distribution of admissions for the White population is relatively even across the deprivation quintiles, over half (53.3%) of South Asians and almost two-thirds (63.1%) of African-Caribbeans admitted following heart attacks are from the 20% most deprived communities (see **Figure 1**). This may in part be due to South Asian and African-Caribbean populations being generally less affluent. However, the finding does suggest that deprivation is the main reason for the differences in coronary heart disease between different ethnic groups.

Access rates for cardiac surgery are lower for patients from the most deprived communities. Levels of access for patients of South Asian and African-Caribbean origin are lower than those for White patients.

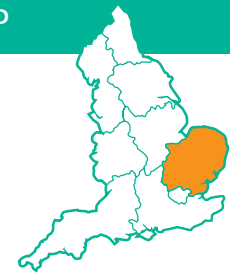
Further work needs to be undertaken to clarify:

- the differences within ethnic groups, particularly to establish the relative importance of deprivation, ethnicity, age and other pre-existing conditions
- how prevention and early identification of risk factors can be better targeted to address these differences, in particular in relation to diabetes mellitus, impaired glucose tolerance, hypertension and other cardiovascular risk factors
- the extent of the variation in differential access to treatment (rehabilitation and/or surgical intervention) with respect to deprivation and ethnicity.

Figure 1: Death and discharges for heart attacks and chest pain by deprivation and ethnicity



Source: Hospital Episode Statistics, West Midlands CBSA



Prioritising VTE prevention to save lives

Venous thromboembolic disease (VTE), including pulmonary embolism and deep vein thrombosis, is thought to be responsible for up to 10% of all deaths in hospitalised patients. It could account for up to 2,500 deaths a year in the East of England. Many cases are not detected, so prevention is key to saving lives.

VTE prevention has been the subject of a Health Select Committee report, an independent report by a working group set up by the Chief Medical Officer, and a National Institute for Health and Clinical Excellence guideline. There are relatively cheap and effective preventive approaches using mechanical prophylaxis and anticoagulation, yet the Health Select

Committee report suggested that around 40% of at-risk surgical patients and 60% of at-risk medical patients may not be receiving adequate preventive treatment.

To calculate the potential for preventing VTE, an extract of Hospital Episode Statistics data for 2007–09 was analysed and the Department of Health’s risk assessment model applied. The headline results are set out below:

- There are 2,235 admissions for VTE each year in the East of England and 385,000 admissions of high-risk patients.
- On average, 5.8 (range: 4.2 to 7.8) per 1,000 of these at-risk patients are diagnosed with VTE in hospital or within eight weeks following admission. This is

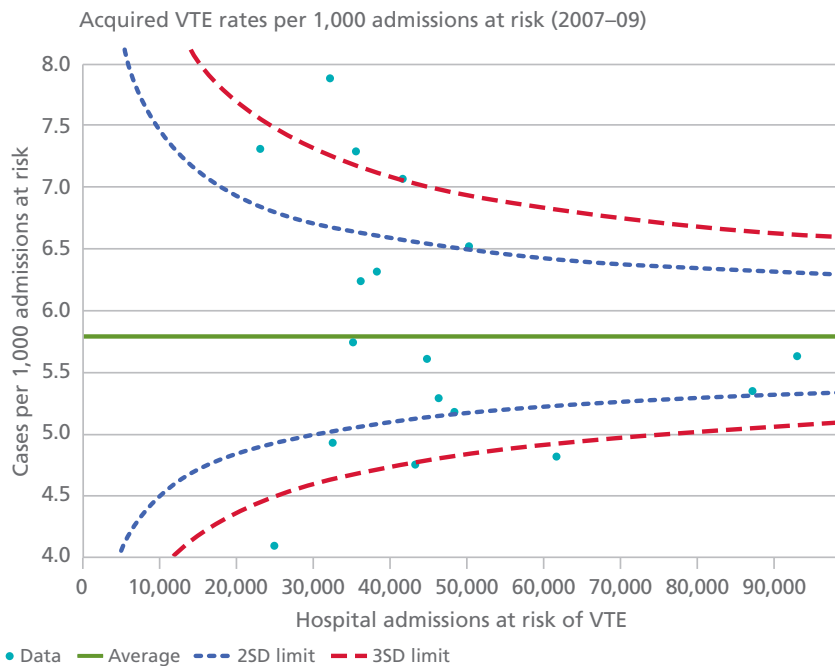
in line with recent epidemiological studies, but varies considerably by hospital (see **Figure 1**).

- Based on the Health Select Committee’s estimates that 40% of at-risk patients receive appropriate prophylaxis and that prophylaxis reduces the risk in high-risk patients by half, VTE occurs in the East of England at a rate of 7.25 per 1,000 high-risk patients not receiving prophylaxis, and at 3.63 per 1,000 high-risk patients receiving prophylaxis.
- If the rate of prophylaxis were increased to 80% of high-risk patients, up to 560 VTEs would be prevented in this group each year.

Systematic prevention of VTE is a key priority for the East of England Clinical Programme Board on Patient Safety. To reduce the number of hospital-associated VTEs in high-risk patients, the Board has set an ambitious programme of work to identify good practice. This includes the pilot of an innovative ‘nurse led, doctor completes’ scheme, in which the nurse assesses and initiates, and the doctor completes prophylaxis. After initial success at the pilot site, the scheme is being rolled out to other hospitals in the region.

Other approaches include developing training programmes for VTE champions across the region, and working with Patient Safety Champions from the National Patient Safety Agency to ensure patient and public involvement and the provision of good patient information. The inclusion of quality measures for VTE in financial contracts with primary care trusts will ensure a system-wide approach to the VTE project and will provide a further impetus to changes in practice.

Figure 1: Variation in acquired VTE rates in East of England NHS trusts



Source: Analysis of Hospital Episode Statistics, 2007–09



Fire in hospitals: learning from experience

Whilst the utmost care is taken to ensure that NHS sites are safe and resilient, they are vulnerable to the same disruptive challenges that face any large and complex building. In 2008/09, there were a number of significant fires within NHS facilities in London, which required the evacuation of part or the whole of a building.

Moving large numbers of sick patients under pressure creates complicated and demanding problems. The need to balance the health, safety and well-being of the patients against the risk of the fire is delicate. In one of the events, two patients were undergoing complex surgery in theatre; they required rapid stabilisation, closure and removal, all in smoke-filled corridors.

Management of these events provided a substantial catalogue of experiences and lessons for NHS managers and emergency planners. For instance, two sites found that not all beds would fit through exits, whilst the need to track patients as they left the affected building for transfer to other facilities was found to be an area that would benefit from improvement.

The NHS London Head of Emergency Preparedness ensured that each of the events was thoroughly debriefed. The experiences were gathered within one report, *Review of five London hospital fires and their management*, providing an evidence-based platform to enhance all NHS preparedness. The five events included in the report occurred at very different healthcare facilities – a specialist cancer hospital, a major central London teaching hospital, a paediatric tertiary referral centre, a medium-secure mental health hospital and a large district general hospital.



An initial, unstructured interview with the key managers responsible for leading the response was conducted soon after each fire. A more structured data collection tool was developed and a subsequent semi-structured interview undertaken using a modified version of the Schultz benchmarking tool for hospital evacuation. The original Schultz tool was used to review the impact on healthcare facilities affected by the 1994 Northridge earthquake in California.

The report included an overview of each hospital and a description of the event, and outlined the issues of concern and the lessons identified. To provide an easy checklist for planners and managers, the 38 lessons were categorised under seven headings:

- Planning
- Command and control
- Communication
- Staff
- Media
- Post-event
- Training and exercising.

In October 2009, the final report was launched at the United Nations/World Health Organization International Day for Disaster Reduction event in London. It was also circulated to all NHS organisations in London and to English strategic health authorities, and placed on the NHS London and World Health Organization websites.

Many NHS London organisations have mapped the checklist against their current plans, and have updated those plans where deficiencies were identified. Other organisations have used the report to run internal exercises so that managers are more confident with the decision-making processes and procedures involved in an evacuation.

The report has provided an evidence base for both United Kingdom and international healthcare managers. It supports the Department of Health's development of evacuation and shelter guidance and the World Health Organization's safer hospitals strategy.

NHS London will incorporate the lessons identified into the 2010 round of emergency preparedness performance management. This annual assurance process reviews how NHS organisations' arrangements for responding to a variety of threats compare with national guidance. NHS organisations in London will be required to provide evidence that they have integrated the lessons from the review into their planning.



Landmark decision to fluoridate Southampton's water

Water fluoridation has been used to reduce dental decay and improve dental health inequalities for many decades in many countries. Efficacy of water fluoridation is supported by recent systematic reviews of the scientific evidence and endorsed by responsible bodies. Assurance on safety comes from systematic reviews of clinical studies, toxicological reviews, and surveillance of the health of millions of people worldwide who drink fluoridated water.

The Water Act 2003 obliges water companies to adjust fluoride levels if requested to do so by strategic health authorities (SHAs) in England. The SHA must have consulted and ascertained local opinion beforehand. Poor and unequal dental health in Southampton children led the primary care trust to ask South Central Strategic Health Authority to consult on a suitable water fluoridation scheme after conducting independent reviews of feasibility and affordability.

This was the first proposal for a new water fluoridation scheme in the United Kingdom for 20 years and attracted worldwide attention, including from anti-fluoridation groups. An extensive public engagement programme was undertaken. SHA staff spent many hours at public events discussing the issues with residents. Widespread leaflet distribution was followed by three high-profile 'Question Time' events to allow informed public debate of the issues with experts. Coverage in the local press was extensive and mostly well balanced. The primary care trust actively supported the proposal.

The consultation received over 10,200 responses, some of which were duplicates: 52% of respondents thought that

fluoridation may help improve dental health, but 72% of responses were opposed to the proposal. Common arguments against fluoridation were that:

- it is a form of mass medication
- it is against human rights
- there is insufficient evidence regarding the effects
- there are potential adverse health effects and other impacts
- alternative methods are available.

An independent telephone survey of 2,000 randomly selected residents stratified by age, gender, work status and ethnicity showed a more balanced picture (see **Figure 1**), with no clear majority for or against.

Regulations require SHA boards to weigh all the arguments presented, having regard to the extent of support for the proposal and the cogency of the arguments advanced, and to decide whether the health arguments in favour of the proposal

outweigh all arguments against it.

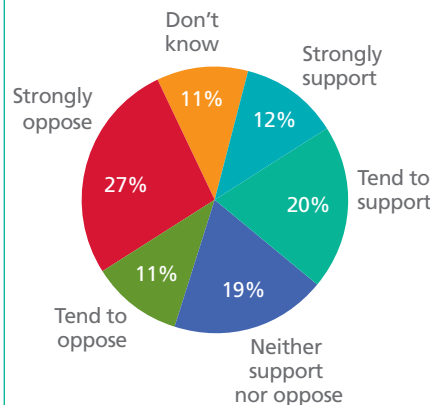
In February 2009, the strategic health authority board decided unanimously to request Southern Water to fluoridate the Southampton water supply.

Local reaction has been mixed. Many who opposed the scheme feel that their views were not taken into account. The SHA always made it clear that its decision would not be based on numbers of responses alone but on the cogency of the arguments given.

The Nuffield Council on Bioethics has emphasised the need for responsible authorities to be guided by the evidence of potential benefits and avoidance of harm. Its report on the ethical issues of public health stated: 'Stewardship is not exercised simply by following the public vote, especially where issues involve complex scientific evidence.' The report concluded that the assessment of technical evidence is not well suited to a public consultation. A recent report to the Department of Health also supports action by state authorities to protect the health of disadvantaged groups and children, even at the expense of individual choice, if necessary.

In June 2009, judicial review proceedings were issued against the strategic health authority in relation to its decision. The judge has given permission for the claimant (a resident of Southampton) to proceed with a challenge on the interpretation of government policy but has refused permission to proceed on the grounds of the consultation and decision-making process, stating that the process had been 'unimpeachable'.

Figure 1: Level of support for fluoridation in a random telephone sample of residents



Source: ICM survey commissioned by South Central Strategic Health Authority



Increasing active travel by schoolchildren

Active travel to school improves levels of physical activity and reduces carbon emissions. Active travel can help set good exercise habits in early years, and help combat the epidemic of childhood and adult obesity.

The South West is the largest and most rural region in England. It has the lowest percentage of people living in urban settlements of any English region (67%, compared with 82% for England as a whole). It has a relatively poor transport infrastructure. The region has some of the least accessible bus services in England, with 82% of people living within a 13-minute walk of an hourly service compared with 90% in England as a whole.

Levels of active travel to school depend on the distance children live from school, the transport options available, school/local authority travel planning, and a variety of socio-economic factors that may influence student and parental choice regarding travel modes.

The School Census collects a variety of information about each pupil attending school on 'census day', including how that pupil has travelled to school. Nine local authority areas in the South West region (Bristol, South Gloucestershire, Dorset, Poole, Bournemouth, Devon, Plymouth, Torbay and Somerset) commissioned the School Travel Health Check (www.viewfinder.infomapper.com/dorset/resources?id=951175). This innovative sustainable development initiative aims to provide robust data that will allow schools, planners and individuals to develop more sustainable school travel options.

The 2008/09 data show wide variations across participating local authorities,

schools and types of school in levels of active transport. A considerable proportion of children (46%) attend a school other than their nearest. This varies slightly depending on the type of school. The highest levels are in Bournemouth, where 68% of pupils do not attend their nearest school, whilst the lowest levels (35%) are in Devon.

The percentage of pupils who live within walking distance of their school (defined as within 0.8 kilometres for primary schools and 2.0 kilometres for secondary schools and colleges) is 53%, ranging from 42% in Dorset to 64% in South Gloucestershire.

Overall, 16% of those who live within walking distance travel to school by car, depending on school type. There are 25 primary schools and one secondary school where more than 60% of pupils who live within walking distance currently travel to school by car. When pupils who live within walking distance of the school are in the minority, they are more likely to travel by car.

An analysis of travel to school by all pupils shows that 48% walk, 3% cycle, 26% travel by car or van, 3% share a car, 15% travel by bus, 1% travel by taxi and less than 1% travel by train. This varies by local authority and type of school.

Levels of walking to school are higher in Bristol and South Gloucestershire, and lower in Dorset. This is not completely explained by rurality, as areas such as Bournemouth and Poole (both urban areas) have comparatively low percentages of children who walk. Levels of walking also vary between school type, and they decrease as pupils move from primary school to secondary school and sixth form.

The low level of walking at special schools is because of longer travel distances (only 5% of pupils live within walking distance) and is possibly also due to pupils' disabilities.

Active travel to school is an important source of physical activity for young people. It could be increased further. These statistics provide a useful baseline against which to measure progress, and should be used in conjunction with a qualitative assessment of local authority and school travel policies. The allocation of school places could also result in fewer active travel trips, as many areas have high numbers of pupils not attending their closest school, which is likely to mean fewer opportunities for active travel.

The South West region is planning for considerable population growth over the next two decades, and intends to build a large number of urban extensions. It is essential that these developments facilitate and encourage active travel.



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