SECTION 2.2: Policy and engagement
Policy and engagement

The MRC recognises the immense value of researchers engaging with audiences outside of academia, and this is why the MRC strives to embed public engagement and dialogue with policymakers at the heart of everything we do.

From the centenary open days we held in 2013 to the annual Max Perutz award¹, the MRC runs a varied public engagement programme involving many of our researchers. But public engagement is not limited to these MRC-run events. The MRC encourages our scientists to engage, educate and inspire the public through a variety of mediums, should that be participating in exhibitions or workshops, giving lectures or being interviewed by the media. MRC researchers are often also involved in the many public engagement activities run through their own university or research organisation.

The MRC has a long history of engaging and consulting with parliamentarians. The MRC as an organisation frequently submits evidence relating to biomedical research to inquiries and consultations by government departments, Select Committees of the House of Commons and the House of Lords, and to other organisations, drawing on the expertise of particular researchers or research boards and panels as necessary. Our researchers are also often called upon as experts in particular areas of research to give advice or evidence.

The MRC also plays a critical part in shaping and influencing national and international policy, ensuring that public policy decisions and health interventions are based on research of the highest quality. MRC researchers contribute regularly to the development and revision of clinical guidelines — recommendations to clinicians on the diagnosis, management and treatment in specific areas of healthcare based on systematic evidence, such as NICE and WHO clinical guidelines. MRC researchers also have an influence on policy through membership of guideline committees, participation in national consultations, and the training of practitioners. The MRC has played a leading role in critical areas of research and subsequent policy and strategy development, from our public health work on obesity and smoking to the establishment of UK Biobank. Examples of where MRC-supported researchers have influenced policy and been involved in public engagement can be found throughout this chapter, and are categorised by the following research areas:

» Obesity and nutrition
» Infectious diseases
» Neurodegeneration and neurology
» Cancer

Further information on each piece of research can be found on the Research Councils UK (RCUK)’s information portal — the Gateway to Research² — by entering the project reference number listed under each case study in the search field.
The UK is a world leader in nutritional science and in research aimed at improving health and reducing the burden of nutrition-related illness. The need for basic, strategic and applied nutrition research has never been greater. We face a double burden of disease caused by the combination of classical nutritional deficiencies and the rapidly increasing problem of ill-health associated with dietary excess and imbalance.

Obesity is one of the greatest threats to health today. Research has shown that obesity severely increases the risk of type 2 diabetes, heart and liver disease, some forms of cancer, and also increases the likelihood of developing other long-standing illnesses. Figures released by Public Health England in January 2014 showed that 64 per cent of adults are now overweight or obese, with a body mass index (BMI) of more than 25 and 30, respectively. The number of adults classed as obese has increased by 60 per cent in the last two decades (from 15 per cent in 1993 to 25 per cent in 2014). Health problems associated with being overweight or obese cost the NHS around £5 billion every year, compared to £3 billion each for smoking and alcohol-associated health problems.

Influence on policy: Food portion sizes and content

In October 2013 the British Heart Foundation (BHF) published its report ‘Portion Distortion’ comparing the portion sizes of 245 products sold today with the portion sizes listed in a 1993 Food Standards Agency (FSA) publication showing “typical weights and portion sizes of foods eaten in Britain”. The BHF report showed that the majority of portion sizes had increased dramatically in the 20 years since the FSA publication. The report cites research on portion size undertaken by Professor Susan Jebb at the MRC Human Nutrition Research Group (HNR).

Professor Jebb has shown that on the UK market the range of portions was often highly variable, and as a result could lead to consumer confusion and subsequent distrust in on-pack portion size messages, suggesting that there is a need for greater consistency in the portion sizes.

As part of the Government’s Foresight report, Professor Jebb also recommended decreasing portion sizes as an effective intervention in helping to combat the obesity crisis.

Professor Jebb is chair of the Department of Health Food Network, which is part of the Government’s Public Health Responsibility Deal. The Public Health Responsibility Deal aims to encourage businesses to contribute to improving public health through signing up to a series of pledges, such as reducing the calorie, salt and saturated fat contents of foods and improving nutritional labelling. 82 different organisations have signed up to the pledge to reduce salt in their food and 37 have signed up to the calorie reduction pledge. Major food companies are using the Responsibility Deal to shape their business strategies. In particular Subway® have signed up to six of the food pledges, on average have almost halved (48 per cent) the salt content across the entire range of their food and all of their stores have menu boards with calorie content displayed.

Project reference number: MC_U105960389
Engagement activities: How obesity-risk gene is linked to obesity

Researchers from the MRC Clinical Sciences Centre’s Metabolic Signalling Group, in collaboration with scientists at UCL and King’s College London, have shown for the first time how variations in the FTO gene – the strongest obesity risk gene – are linked to obesity. This study demonstrates that FTO gene variations affect circulating levels of ‘hunger hormone’ ghrelin in the blood. Ghrelin stimulates appetite and so levels are normally high before a meal and then decrease afterwards. However, for one in six people who carry two copies of the high obesity-risk FTO variant gene, ghrelin levels do not drop off after eating, and so they soon start to feel hungry again.

The MRC has been investigating obesity for more than three decades and has led the way in examining the links between obesity and genetics. In 2007, a consortium of researchers led by the MRC identified the obesity-risk FTO variant gene after undertaking a genome-wide search for type 2 diabetes-susceptibility genes. This gene variant does in fact predispose the carrier to diabetes through its effect on body mass index. The researchers discovered single ‘letter’ variations in the genetic code of the FTO gene and showed that those with the obesity-risk variant were on average 3kg heavier than those with the low-risk version. The link between this gene and obesity was confirmed by MRC researchers at Imperial College London.
Until now however, it was unknown exactly how these variations were linked to obesity. In the 2013 study, researchers, led by Dr Rachel Batterham, studied two groups of male participants – those with two copies of the high obesity-risk \textit{FTO} variant (AA group) and those with the low obesity-risk version (TT group). Men with the AA variation had much higher circulating ghrelin levels and felt hungrier after eating than the TT group. The researchers also investigated the situation at the molecular level. Boosting the expression of \textit{FTO} in mouse cells effectively increased the production of ghrelin. When they compared this to human cells from the high-risk group, they found levels of \textit{FTO} expression were significantly higher, and correspondingly more ghrelin mRNA was found than in cells from the low-risk group. The \textit{FTO} gene itself encodes a protein enzyme, which changes the methylation status of ghrelin mRNA; increased \textit{FTO} mRNA lowered methylation levels on ghrelin mRNA, which raised production of the protein itself.

The study uncovers a novel mechanism for manipulating ghrelin levels whether by drug or behavioural means. There are some drugs in the pipeline that suppress ghrelin, which might be particularly effective if they are targeted to patients with the obesity-risk variant of the \textit{FTO} gene.

The results of the study were covered widely by the national media, including the BBC, \textit{The Telegraph}, and the \textit{Daily Mail}.

\textit{Project reference number: MC	extunderscore U120097114}

\textbf{Influence on policy: Calcium}

All living cells require calcium to remain viable and it is also required for a number of specific functions in the body so it is crucial that people consume sufficient amounts in their diet. Calcium is essential for bone growth as it is needed for the mineralisation of bone; the rate of bone growth is proportional to the rate of calcium deposition in bone. Insufficient calcium intake may lead to a low bone mineral density, which has implications for bone health in later life, such as a risk of osteoporosis. Calcium also plays a role in regulating muscle contraction (including the heart) and blood pressure, digestion and ensuring blood clots normally.

As part of the Government’s Red Tape Challenge on ‘Hospitality, Food and Drink’\textsuperscript{13} to reduce regulatory burdens on business, the Department for Environment, Food and Rural Affairs (DEFRA) was asked in 2013 to review whether mandatory fortification of bread with calcium, iron, niacin and thiamine should continue. \textbf{Professor Ann Prentice}, director of the \textit{MRC HNR}, as chair of the Scientific Advisory Committee on Nutrition (SACN), gave advice to the government on this issue. The SACN in particular demonstrated that removal of calcium and iron would adversely affect the intake of certain population groups\textsuperscript{14}. \textbf{Drs Jonathan Powell}, \textbf{Gail Goldberg} and \textbf{Dora Pereira} at the \textit{HNR} also took part in the subsequent national consultation. In line with the views of the SACN, they commented that the current system provided equal health benefits for all consumers and that flour should be preserved as a vehicle for population nutritional intervention. They specifically made reference to the fact that flour was a particularly important source of calcium, especially for those who do not consume dairy products. The Government has since concluded that the mandatory fortification of bread should continue.

It is even more important for pregnant women to obtain sufficient calcium in their diet, both to assist the growth of their baby’s developing skeleton, for breast-feeding and also the growth of their infant. Calcium is considered to be key in the regulation of blood pressure throughout life and particularly during pregnancy, to help women avoid developing pre-eclampsia.
The MRC has funded several studies to determine whether calcium supplementation in Gambian women — whose calcium intake is low and whose infants experience poor growth and bone mineral growth is poor compared to those in Western populations — would be beneficial.

In 2006 researchers from the MRC Unit, The Gambia, in collaboration with those in the MRC HNR showed in fact that calcium supplementation of pregnant Gambian women had no significant benefit for breast-milk calcium concentrations, or infant birth weight, growth or bone mineral status in the first year of life\(^1\). The study found for women who are accustomed to a very low calcium diet, increased calcium intake does not increase the transfer of calcium to the offspring, during either foetal life or subsequent breastfeeding. This supports research showing that metabolic adaptations occur during human pregnancy and lactation to provide sufficient calcium for foetal growth and breast-milk production\(^1\).

These results were followed up with a clinical trial in 2013, which showed that calcium supplementation had no significant effect on either mother’s blood pressure or infant growth\(^2\).

Researchers from the MRC Unit, The Gambia, the MRC HNR and the MRC International Nutrition Group also investigated whether there was an association between maternal calcium supplementation and offspring blood pressure at age five-10 years old\(^3\). The researchers found no association between maternal calcium supplementation and offspring blood pressure, suggesting that additional calcium was not transferred to the offspring in utero, supporting previous studies\(^4\).

An MRC study undertaken by researchers in these research groups has however conversely demonstrated that calcium supplementation in Gambian children aged 8-12 may increase bone mineralisation and, ultimately, peak bone mass\(^5\).

These findings have implications for nutrition policy in The Gambia and other populations with low calcium intake.

*Project reference numbers: MC_U105960371, MC_U105960371*

### Unexpected impacts of MRC research

#### Engagement activities: Nutritional advice to the BBC’s One Show

Dr Gail Goldberg at the MRC HNR was asked to provide nutritional advice on yams to the BBC’s One Show on account of the HNR’s global work on nutrition. The programme was to host the Olympic gold medallist sprinter Usain Bolt, who had claimed that the secret of his success was Jamaican yams.

*Project reference number: MC_U105960371*
Influence on policy: Importance of sufficient iodine intake during pregnancy

The MRC-funded Avon Longitudinal Study of Parents and Children (ALSPAC) has shown that iodine deficiency in pregnancy has an adverse effect on children’s mental development. Iodine is essential for producing the hormones made by the thyroid gland, which have a direct effect on foetal brain development. The potentially harmful effects of severe iodine deficiency are well-established, however, the link between mild or moderate iodine deficiency and cognitive development has until now not been extensively examined. For many years, iodine intake in the UK was thought to be sufficient. A study conducted by researchers at the Universities of Surrey and Bristol has however shown that two thirds of pregnant women are deficient. They measured the iodine concentration in urine samples taken in the first trimester from 1,040 pregnant women and classified those who had an iodine-to-creatinine ratio of less than 150 μg/g as being iodine deficient, and those with a ratio of 150 μg/g or more as iodine sufficient. More than two thirds (67 per cent) of the women were classed as being iodine deficient.

The researchers assessed the mental development of the women’s children by measuring their IQ at age eight and reading ability at age nine. The researchers found that children of the women in the iodine-deficient group were significantly more likely to have scores at the low end of verbal IQ, reading accuracy and reading comprehension, even after adjusting for external factors likely to affect the scores, such as parental education and breast-feeding. The lower the mother’s level of iodine, the lower the average scores for IQ and reading ability were.

As a result of this study, the British Dietetic Association (BDA) has produced a fact sheet on the importance and sources of dietary iodine, with a focus on the increased requirements of pregnant women.

Project reference number: G9815508

Influence on policy: Citation in NICE guidelines “Overweight and obese adults – lifestyle weight management”

In May 2014 the National Institute for Health and Care Excellence (NICE) published guidelines on lifestyle weight management for overweight and obese adults. The guidelines comprise multi-component lifestyle weight management approaches that aim to change someone’s behaviour to reduce their energy intake and encourage them to be more physically active in order to reduce the risk of the main diseases associated with obesity. In compiling the guidelines, the Guidelines Development Group drew on research from Professor Susan Jebb who, in 2011, showed that participating in commercial weight management programmes, such as WeightWatchers and Slimming World, can lead to a greater weight loss over a 12-18 month period than from following the advice of a doctor.

Project reference number: MC_U105960387
Engagement activities: Association between consumption of sugar-sweetened beverages and cardiometabolic risk factors in adolescents

This paper, published in 2013 by the MRC HNR, demonstrated a link between the high consumption of sugary drinks by teenagers and the risk factors, namely lower levels of ‘good’ cholesterol and higher levels of the ‘bad’ triglyceride form of fat in their blood, for heart disease in later life. This paper received considerable media interest, including from the BBC, The Guardian and The Telegraph.

Project reference number: MC_U105960389

Unexpected impacts of MRC research

Engagement activities: Science Museum Painless exhibition

As part of the Science Museum’s Painless exhibition in 2013, Professor Geoff Woods at the University of Cambridge sequenced the genome of a man with congenital analgesia, a rare genetic disorder characterised by a total inability to sense pain. Worldwide, the prevalence of congenital analgesia is estimated to be around one in a million. At the exhibition, Professor Woods identified the patient’s gene mutations, confirmed his diagnosis and was able to offer him genetic counselling. In 2006 Professor Woods discovered different mutations in the gene SCN9A responsible for this condition. SCN9A encodes a subunit of a sodium channel expressed in neurons involved in the amplification of the pain signal; the gene mutations cause the protein to lose its function.

Project reference number: MR/J012742/1

Infectious diseases

Infectious diseases — those caused by pathogenic microorganisms, such as bacteria, viruses, parasites or fungi — were the cause of approximately 12.5 per cent of all deaths worldwide in 2011. In the UK, infectious diseases have declined because of improved hygiene, vaccination and antimicrobial drugs, however, costs to the health service, labour market and the individual are still estimated to be around £30 billion per year.

Influence on policy: Addition of rotavirus vaccine into The Gambia’s Expanded Programme of Immunization (EPI)

In August 2013 the Ministry of Health and Social Welfare of The Gambian government formerly introduced the rotavirus vaccine into its Expanded Programme of Immunization (EPI), the eleventh vaccine the country has introduced since it joined the global programme in 1979. The EPI was set up by the World Health Organization in 1974 to ensure that children in all countries receive life-saving immunisations.

Research conducted by the MRC Unit, The Gambia played a valuable role in ensuring the rotavirus vaccine was added to the programme. Dr. Jahangir Hossain at the MRC Unit, The Gambia was part of an international study that confirmed that rotavirus was the leading cause of diarrhoeal disease among infants in developing countries. The Global Enteric Multicenter Study (GEMS), the largest study ever conducted on diarrhoeal diseases in developing...
Influence on policy: WHO guidelines for the screening, care and treatment of persons with hepatitis C infection

The hepatitis C virus (HCV) infects 170 million people around the world and is a major cause of liver disease, including liver cancer. Unlike Hepatitis A and B, there is currently no vaccine for HCV. Treatment can often have severe side effects such as anaemia, reduced immune system functioning, depression and flu-like symptoms; it is also expensive and only partially effective. Between 15 and 50 per cent of people clear the infection spontaneously and are free of the virus; however, the majority become chronically infected with the virus remaining in the body for many years. It is estimated that around 215,000 people in the UK have chronic HCV. Between 10 and 40 per cent of people with untreated chronic HCV will go on to develop cirrhosis of the liver. Around one in five people with cirrhosis will then develop liver failure, and one in 20 will develop liver cancer.

Professor Emma Thomson at the MRC-University of Glasgow Centre for Virus Research is a leading scientist in HCV research and specialises in the mechanisms behind spontaneous viral clearance and progression to chronicity. She is currently studying HCV diversity during transmission and early viral evolution using next-generation and full-length sequencing of the viral genome. She was the technical writer of the WHO guidelines for the screening, care and treatment of persons with hepatitis C infection published in April 2014 and also provided advice on the use of new direct-acting antiviral drugs for HCV and on the monitoring of patients undergoing therapy.

Project reference number: G0801822
Engagement activities: Science Inspired Tales

In 2012 Professor Peter Openshaw at Imperial College London gave a Science Inspired Tales public stage performance at the Albert Hall Theatre in Brussels. During the lecture entitled “Our germs, our guns: an uneasy peace”, he discussed infection and the immune system, recounting anecdotes and stories of his scientific inspiration.

Project reference number: MC_G1001212

Influence on policy: Chief Medical Officer seminar on future public health policy for HIV research

Professor Sheena McCormack at the MRC Clinical Trials Unit is a clinical epidemiologist who specialises in the development and implementation of biomedical interventions to prevent, or reduce, the risk of acquiring HIV. In 2013 she took part in a Chief Medical Officer (CMO) seminar on future public health policy for HIV research. As a result of the seminar, the CMO outlined plans to update the UK’s HIV policies in order to help people get diagnosed earlier. Following the seminar, Professor Dame Sally Davies wrote to all GPs advising them to test patients presenting with glandular fever symptoms for HIV. The ban on the sale of HIV self-testing kits was also lifted in April 2014 to encourage individuals to get tested as soon as possible.

Project reference numbers: G0100137, MC_U122861322, MC_U122861400

Unexpected impacts of MRC research

Engagement activities: Threat of helium depletion to medical research

The Federal Helium Reserve in Texas is the world’s only strategic helium reserve and provides approximately 35 per cent of the world’s helium. As the US had accrued a US$1.3 billion debt after a large buy-up of helium in the 1960s, the government passed the Helium Privatization Act in 1996, its goal being to sell off the reserve, with a scheduled closure date of October 2013. This triggered a supply problem, affecting many users, including Professor Mark Stokes at Oxford University’s Centre for Human Brain Activity. Professor Stokes spoke to The Independent in 2013 about how his department’s magnetoencephalography (MEG) scanners — used to study the brain — have regularly been forced to shut down due to the helium shortage. Helium is used to cool the scanners to the near-absolute-zero degrees Kelvin temperature they must operate at. Helium is currently the only element on earth that can effectively keep the equipment that cold. Highlighting the importance of helium to several industries, including medical research, persuaded the US government to extend the life of the reserve, which will now auction off more and more of its store each year.

Project reference number: MR/J009024/1
Influence on policy: Contribution to Chief Medical Officer Annual Report Volume II

The CMO published the second volume of her annual report in 2013, focusing on infection and antimicrobial resistance. The discovery of antibiotics is seen as one of the most important medical achievements of the 20th century; the use of antimicrobials benefits both the individual and society as a whole. However, antimicrobial resistance is increasing and is recognised as a significant public health issue, compounded by the fact that there are currently few new antimicrobials in development. The MRC has developed a strategy for antimicrobial resistance research that aims to tackle the mechanisms of bacterial resistance and strengthen innovation in antimicrobial development through academic-industry partnerships.

Professor Sharon Peacock at the University of Cambridge specialises in the role of sequencing technologies in diagnostic microbiology and public health. In 2013 she demonstrated for the first time that whole genome sequencing of methicillin-resistant Staphylococcus aureus (MRSA) could help to track the spread of infection on both a local and global scale. In the future challenges chapter of the CMO’s report, Professor Peacock wrote a section on the use of whole genome sequencing to track the transmission of infections to improve surveillance and control.

Project reference number: G1000803

Influence on policy: POSTnote on the surveillance of infectious disease

POST is the Parliamentary Office of Science and Technology, an in-house source of independent, balanced and accessible analysis of public policy issues related to science and technology. Its aim is to help parliamentarians examine science and technology issues effectively in order to support their decision-making.

Dr Nick Loman at the University of Birmingham contributed in 2013 to a POSTnote that examined new technologies used in the surveillance of infectious diseases.

Project reference number: MR/J014370/1

Neurodegeneration and neurology

The proportion of people in the UK aged over 65 is 17.2 per cent, a figure that is projected to rise to 22.4 per cent in 2032. There is a strong link between age and neurodegenerative diseases, including dementia, Parkinson’s disease and multiple sclerosis, and so the number of people with these conditions is constantly increasing. Existing treatments for neurodegenerative diseases are limited and they mostly treat the symptoms, rather than the cause. Therefore, research in this area — particularly to develop our understanding of the biological processes underpinning these diseases — has never been more important.
In 2011 MRC-supported researcher Professor Nick Fox at University College London was part of a small guidelines committee that updated the US National Institute on Ageing-Alzheimer’s Association’s clinical diagnostic criteria for Alzheimer’s disease for the first time in 27 years. The previous guidelines describe only the latter stages of the disease, whereas the updated version now covers the full spectrum of the disease as it gradually changes over many years. They describe the earliest preclinical stages of the disease, mild cognitive impairment, and dementia due to Alzheimer’s pathology. The guidelines also now address the use of imaging and biomarkers in blood and spinal fluid that may help determine whether changes in the brain and those in body fluids are due to Alzheimer’s, a major change in the way the disease will be diagnosed. Professor Fox led on the section covering biomarkers.

Project reference number: G0801306

Researchers at the University of Bristol have developed a brain implant consisting of a system of tubes and catheters that allows them to pump protein therapy deep into the brains of patients with Parkinson’s disease, potentially stopping the disease from progressing. Parkinson’s, affecting around 127,000 people in the UK, occurs when a lack of a chemical called dopamine causes nerve cells within the brain to die. It is hoped that delivery of the protein — a growth factor called glial cell-derived neurotrophic factor (GDNF) — will encourage these cells to grow again. This new method of delivery will allow the protein to bypass the blood/brain barrier. A clinical trial, led by Professor Steven Gill, is on-going and has received publicity from Sky News, the BBC and Daily Mail.

Project reference number: MR/J005134/1

The House of Commons Science and Technology Select Committee held an evidence session in 2013 on variant Creutzfeldt-Jakob Disease (vCJD) and the on-going risk it poses to the UK. Professor John Collinge, director of the MRC Prion Unit, was one expert invited to give evidence, along with Professor Sheila Bird of the MRC Biostatistics Unit.

Professor John Collinge spoke about the potential prevalence of vCJD in the population, the potentially long incubation period of the disease, modes of on-going transmission, and the current UK surveillance, control and prevention strategies.

Project reference numbers: MC_U123160657, MC_U123192748
Influence on policy: Citation in US Federal Drug Administration taskforce advice on designing clinical trials in early Alzheimer’s disease

In 2011 an international taskforce of individuals from academia, industry, non-profit foundations, and regulatory agencies was convened to discuss optimal trial design in early (pre-dementia) Alzheimer’s disease. The report, advising the US Federal Drug Administration, cites research conducted by Dr Delphine Boche at the University of Southampton, which provided evidence that even successful treatment to eliminate amyloid plaques may not be sufficient to halt fatal progression in individuals already showing clinical signs of dementia. This helped the taskforce reach the conclusion that it is necessary to start therapies before the onset of clinical dementia in order for it to have any positive effect.

Project reference number: G0501033

Engagement activities: Falling dementia rates

Researchers at the Cambridge Institute of Public Health at Cambridge University reported in 2013 on results from the MRC Cognition Function and Ageing Study (CFAS) showing that the number of people with dementia in the UK in 2011 was much lower than had been predicted based on trends two decades earlier. Using age- and gender-specific dementia rates collected from interviews in 1991, researchers estimated that around 884,000 people over 65 (8.3 per cent) would have dementia in 2011. However, fresh interviews in 2011 indicated around 670,000 (6.5 per cent) had dementia. The story was widely reported in the UK media, including in The Telegraph, BBC news, The Independent and the Daily Express. Much of the discussion focused on whether rates of dementia would continue to decrease in the future, considering the rising levels of obesity — shown to be a significant risk factor for dementia.

Project reference number: G0601022

Engagement activities: Alzheimer’s disease open day

Since 2006, King’s College London’s Institute of Psychiatry has held an annual open day hosted by Alzheimer’s Research UK and the MRC Centre for Neurodegeneration Research to showcase its cutting edge research into Alzheimer’s disease. In 2011 the event welcomed 150 members of the public, including carers and families of people with dementia, who engaged in workshops, talks and question and answer sessions.

Project reference number: G0700355
More than one in three people will develop cancer at some point during their lifetime, including more than 331,000 diagnosed with cancer in the UK in 2011 alone\(^5\). Although half of people diagnosed with cancer survive their disease for at least 10 years, cancer still causes more than one in four of all deaths in the UK. The annual cost to the NHS for cancer services, including diagnostics and treatment, is around £5 billion, however, the cost to society as a whole, including for loss of productivity, is £18.3 billion\(^5\).

**Influence on policy: The National Comprehensive Cancer Network’s guidelines in Oncology**

The National Comprehensive Cancer Network (NCCN\(^5\)) is a not-for-profit alliance of 23 cancer centres in the US devoted to patient care, research, and education. The NCCN Guidelines\(^5\) are a comprehensive set of guidelines detailing the sequential management decisions and interventions that currently apply to 97 per cent of cancers affecting patients in the United States. The network updated its guidance on Central Nervous System Cancers in 2013\(^3\) and cites a study undertaken by the MRC Clinical Trials Unit showing that patients with high-grade gliomas — fast-growing tumours that arise from glial cells and occur in the spinal cord or the brain — experienced a modest survival benefit when chemotherapy was given in addition to postoperative radiotherapy\(^6\). The guidelines recommend the use of combined chemotherapy and radiotherapy for a subset of patients with high-grade gliomas. The NCCN also updated its guidance on bladder cancer in 2014\(^5\) and as a result of research undertaken at the MRC Clinical Trials Unit\(^6\), recommended neoadjuvant chemotherapy (chemotherapy given in advance of the primary treatment) over adjuvant-based chemotherapy (chemotherapy given after the primary treatment) for muscle invasive cancer.

*Project reference number: MC_U122861323*
Engagement activities: Gene therapy to treat prostate cancer

In a Phase I clinical trial, researchers at the University of Birmingham are using gene therapy to treat prostate cancer that has relapsed after radiotherapy and hormone therapy. The AdUP trial uses a vector made from an adenovirus that has been modified to produce an enzyme called nitroreductase and GM-CSF — a growth factor that enhances the immune system by stimulating the number and function of white blood cells produced by the body. The vector is administered by way of an injection, which is then followed by treatment with CB1954 — a cytotoxic drug made active by the nitroreductase enzyme which kills cancer cells.

The BBC interviewed Bernard Ward, one of the first 20 patients undergoing this therapy, and the surgeons conducting the treatment. Mr Ward has suffered from prostate cancer for six years and standard treatments are no longer working. The clinical trial is designed to establish whether the treatment is safe for clinical use.

Project reference number: G0502050
End notes

2. http://gtr.rcuk.ac.uk/
5. Professor Susan Jebb is now at the University of Oxford.
8. https://responsibilitydeal.dh.gov.uk/about/
9. Figures correct as at May 2014.
22. To minimise the variation caused by variation in the urinary volume, the iodine/creatinine ratio is used as creatinine (a waste product made by the muscles) is excreted at a relatively constant rate in industrialised countries.
23. Based on World Health Organisation (WHO) guidelines on recommended levels of iodine during pregnancy
32. http://www.gavialliance.org/results/countries-approved-for-support/
55. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines)® Bladder Cancer Version 1.2014 NCCN.org