The National Institute for Health Research at 10 years
An impact synthesis
Summary report

RAND Europe and the Policy Institute at King’s
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The Policy Research in Science and Medicine (PRiSM) unit brings together research expertise from RAND Europe and the Policy Institute at King’s College London.

The PRiSM unit delivers research-based evidence to the UK’s National Institute for Health Research (NIHR) to support NIHR’s research strategy, Best Research for Best Health, and contributes to the science of science policy field in the UK, Europe and internationally.

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To mark its tenth anniversary, the National Institute for Health Research (NIHR) commissioned the Policy Research in Science and Medicine (PRiSM) unit to examine ways in which its investments in clinical, applied health and social care research, as well as support of research infrastructure, have benefitted the health research landscape.

This summary report identifies 100 examples of positive change and impact, based on available evidence, resulting from NIHR’s support of research over the last 10 years. It provides an overview of more detailed case studies, published separately in a full report, grouped under 10 thematic headings. It concludes with a reflection of what the evidence suggests about NIHR’s wider impacts.

Drawing together – for the first time – examples of the breadth of NIHR’s impacts in a single resource, the report will be of interest to healthcare professionals involved in research, academics working in health and social care, and members of the public wishing to understand the value of research in the NHS.

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RAND Europe is a not-for-profit organisation whose mission is to help improve policy and decisionmaking through research and analysis.

The Policy Institute at King’s College London acts as a hub, linking insightful research with rapid, relevant policy analysis to stimulate debate, inform and shape future policy agendas.

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Introduction

The National Institute for Health Research (NIHR) funds and supports world-leading clinical and applied health and social care research.

Providing £1 billion of funding per annum to support research and the research infrastructure in the NHS, NIHR aims to: drive faster translation of new treatments, technologies and diagnostics to improve outcomes for health and care services; promote the wealth of the nation, including via inward investment from the health research community; pull basic science discoveries through into tangible benefits for patients and the public; and provide research evidence to support more effective and cost-effective NHS delivery.

NIHR looks to achieve these aims through strategic partnerships, including with charities, industry, other government funders and academia, and it does so with patients and the public at the heart. It supports centres, units, facilities and expert research teams within the NHS, as well as programmes and systems to deliver high-quality research. This enables NIHR to respond rapidly to research priorities and opportunities identified by commissioners, front line staff, service users/patients and the health research community. By connecting academia, the NHS and other parts of the health and care system, NIHR funding supports research that is improving lives, reducing costs and advancing science for national and international benefit.

NIHR celebrates its tenth anniversary in 2016. It is an appropriate time to step back and consider how NIHR has changed the wider health research landscape. In light of this, the Department of Health commissioned the Policy Research in Science and Medicine (PRiSM) unit to consider the question ‘What are the ways in which NIHR has benefited the health research landscape in the past 10 years?’ The objective was to identify and celebrate examples where benefits to and wider impacts on the health research landscape have occurred and to synthesise this evidence in one report.1

100 examples of NIHR’s impact

Our report summarises the impacts and benefits of NIHR’s support for clinical, applied health and social care research and research infrastructure across 100 case studies, clustered across 10 themes of delivery, collaboration and achievement, as shown in the figure below.

Looking across the breadth of these 10 themes and the depth of the benefits synthesised in the 100 case studies, we see evidence that, over the past 10 years, NIHR has transformed R&D in and for the NHS and the millions of patients it serves.

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1 This report was not commissioned as an evaluation. A full list of caveats and limitations is provided below.
as well as supporting, enabling and delivering research through its partners. Specifically, it shows that NIHR supports research that is:

- **Delivering benefits to patients.** NIHR is developing innovations that can be delivered throughout the health and social care system, such as more personalised and cost-effective dementia care, the first ever implant of a fully synthetic trachea, new treatments for breast cancer and dedicated partnerships to support research in rare disease areas.

- **Improving the health of the public nationally and internationally.** NIHR-supported public health research is leading to reductions in alcohol-related harm, improving smoking prevention strategies and increasing vaccination coverage for H1N1 and childhood immunisation. Worldwide, more than 1 million people stand to benefit from NIHR-funded research into the off-label use of tranexamic acid to aid clotting during traumatic bleeding.

- **Making the nation’s healthcare system more effective, cost-effective and safer.** NIHR-funded research into patient safety has informed the World Health Organization’s (WHO) Surgical Safety Checklist, which is significantly reducing post-operative complications. Other research is identifying cost-effective solutions that save money in areas ranging from physical therapy, to dementia, to diabetes.

- **Putting patients and the public at the heart of research.** NIHR is a world leader in patient and public involvement, and there have been tangible improvements to how research is able to deliver patient benefit. INVOLVE, the NIHR-funded national public involvement centre and advisory group, helps ensure that patients and the public are effectively involved at all stages of research studies, making them more acceptable and meaningful for research users of all ages.
Supporting a research infrastructure in the NHS. NIHR supports a national research infrastructure of world-class research centres, units and facilities, as well as the Clinical Research Network. Together these provide coverage across the health research system in England and enable and facilitate both research funded by NIHR itself and research funded through charities, industry and other government funders. In 2014/15, from an initial investment of £227.8 million, NIHR research infrastructure leveraged over £918 million in research funding from NIHR’s charity, industry and public research funding partners.

Background

NIHR was created in April 2006 under the government’s health research strategy, Best Research for Best Health, and is funded by the Department of Health. This strategy outlined the direction that NHS research and development should take in order to deliver NIHR’s vision ‘to improve the health and wealth of the nation through research’. At the time, the perception was that there were weaknesses in NHS R&D funding; it was thought that the funding too often resulted in poor-quality research. There was also significant concern about the funding being diverted to support service delivery, rather than research, and about a decline in the number of clinical academics. The ambition of NIHR, led by the then-incoming Director of R&D and now Chief Medical Officer in England, Professor Dame Sally Davies, was to turn this around and create an environment that valued clinical research as highly as basic research and that maximised opportunities for patient benefit. The strategy Best Research for Best Health set out the roadmap for how to get there. At its core were five strategic goals through which it would transform the research landscape:

- Establish the NHS as an internationally recognised centre of research excellence;
- Attract, develop and retain the best research professionals to conduct people-based research;
- Commission research focused on improving health and social care;
- Manage our knowledge resources; and
- Act as sound custodians of public money for public good.

Today NIHR organises its activities around four main areas of work:

- Infrastructure – providing facilities and people to the research enterprise
- Faculty – supporting and developing individuals to lead, support and carry out research
- Research – commissioning and funding research
- Systems – creating systems to manage and support research and its outputs

The main impact synthesis report contains 100 case studies outlining examples of positive change as a result of NIHR-supported research.

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2 This was implied in a statement in the so-called ‘Cooksey Report’, which was released in December 2006, that there were, at the time, ‘perverse incentives that value basic science more highly than applied research’. (Cooksey D. 2006. A review of UK health funding. London: Stationery Office. p. 1)


In 2014/15, NIHR research infrastructure leveraged over £918 million in research funding

As an impact synthesis, not an evaluation, the report aims to provide an analytical understanding, based on available evidence, of the ways in which the activities of NIHR have led to positive change within the health research landscape. A list of related caveats and limitations is provided in the box below, and the full details of the methodology used can be found in the main report.

This report summary provides an overview of the full set of 100 case studies, grouped under 10 thematic headings. We describe ways in which NIHR’s support of clinical and applied health and social care research has had an impact on the wider health and research landscape. We also provide summaries of the evidence across all 10 themes, including snapshots of the more detailed case studies in the full report. We conclude with a reflection on what the evidence suggests about NIHR’s wider impacts.

Methodology
The 100 case studies included in this report were selected and produced as follows:
• An initial set of more than 200 examples which broadly reflected the original five goals of Best Research for Best Health were identified from the following sources: consultations with senior managers from the Department of Health and across NIHR, a review of annual reports and the list of more than 200 impact case studies submitted to the 2014 Research Excellence Framework (REF) that cited NIHR-funded research.
• This long list was reviewed, and examples were subsequently clustered to arrive at 10 thematic areas.
• Individual case study examples were explored further, and those where only limited evidence of benefit was readily available were discarded.
• A final short list was agreed with senior Department of Health and NIHR managers.
• Evidence of impacts and other benefits was synthesised from a variety of sources, including published reports, peer-reviewed articles and short interviews with relevant researchers or individuals associated with the research and its benefits. No primary research was done to generate new evidence of impacts or benefits.

Caveats and limitations
There are several caveats and limitations to this report:
• This study was commissioned as a synthesis of impacts and benefits, not an evaluation. Its aim was not to generate new evidence of NIHR’s impact, nor to evaluate it against a set of aims and objectives. Rather, we set out to identify and synthesise existing evidence about NIHR’s impacts over the past 10 years, as demonstrated through a series of case study examples.
• One of the primary criteria in selecting case studies was availability of data and evidence of impact. Generation of primary data was outside the scope of this report, so where there was little or no readily available evidence of impact, a case study was not included.

5 This does not imply an absence of negative impacts on the health system arising from NIHR’s creation.
Benefits and impacts of NIHR, 10 years on

The impacts summarised in the case studies of NIHR’s investment in and support of research cover many areas. The 10 themes span this breadth, and the evidence from the case studies (presented as bullet points) highlights the depth of this work and examples of impact. We expand upon and reference details of each case study in the full report.

Bringing breakthroughs to patients

NIHR-funded research on new and existing drugs, devices and diagnostics provides an evidence base for changes to treatments, policies and guidelines where existing treatments are unsatisfactory or where more evidence is needed to support new approaches. To this end, NIHR supports both novel trials and scale-ups of trials, building on existing studies.

Findings from NIHR-funded research are changing guidelines for clinical practice at both the national and international levels. These guidelines support improvements to commissioning practices, medical education and clinical communication. All three types of improvement are crucial if new treatments are to translate into patient benefits. For example:

- Safer methods of screening for Down’s syndrome, using non-invasive prenatal genetic testing, stand to reduce the number of women needing diagnostic tests that carry

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6 The Research Excellence Framework is the system for assessing the quality of research in UK higher education institutions (www.ref.ac.uk). In the REF, impact case studies were submitted by all participating higher education institutions, which provided summaries of the wider impacts, defined as any effect on, change to or benefit beyond academia to the economy, society, culture, public policy or services, health, the environment, or quality of life. The full database of impact case studies submitted in the last REF is available at http://impact.ref.ac.uk/CaseStudies/. See also King’s College London and Digital Science. 2015. The nature, scale and beneficiaries of research impact: An initial analysis of Research Excellence Framework (REF) 2014 impact case studies. London: King’s College London and Digital Science. As of 9 May 2016: http://www.kcl.ac.uk/sspp/policy-institute/publications/Analysis-of-REF-impact.pdf

a risk of the woman losing her baby. This research is now feeding into UK national screening policy.

- Fewer patients with Bell’s palsy face hospitalisation, following research to demonstrate the benefits of treating this form of facial paralysis with steroids rather than antivirals. This work has informed the first definitive treatment guidelines for this condition in the UK, India, Spain and Ireland.

- A trial demonstrating the effectiveness of mindfulness-based cognitive behavioural therapy led a local Primary Care Trust to commission a clinic providing this therapy for patients with treatment-resistant depression. The findings generated considerable media interest, helping to raise patients’ awareness of treatment options available to them.

By filling gaps in evidence of clinical effectiveness, NIHR-funded research helps to develop treatments that are safer, less invasive and more focused on patients’ quality of life. Further evidence of the cost- and time-efficiency of treatments helps to ensure that a greater number of patients have access to healthcare resources. This is illustrated by the following:

- An intelligent knife (or ‘iKnife’) uses real-time information on the molecular profile of cancerous tissue as it cuts. This knife is now in trials to determine whether it can improve cancer surgery by identifying the boundaries between healthy and diseased tissue.

- Risk-adapted radiotherapy for breast cancer is a less toxic form of radiotherapy shown to be as effective as conventional whole breast radiotherapy in preventing recurrence of cancer, while requiring far fewer hospital visits.

- The Hall technique is a less painful and minimally invasive treatment for child tooth decay that is now included in dental guidelines and clinical education curricula following findings that it is more acceptable to both patients and clinicians.

- Challenging ‘breakthrough’ status in new antipsychotic drugs has shown that older classes of drugs for schizophrenia can be just as effective as new drugs, and at a fraction of the price. This is resulting in cost savings to local NHS Trusts.

Moreover, by supporting research across multiple disease areas, from rare diseases to cancer, NIHR ensures that the benefits of novel research reach a diverse range of patients. For example:

- Dramatic improvements in survival rates for patients with chronic granulomatous disease, a rare immunodeficiency disease which affects around 100 people in the UK, are the result of research to determine the long-term effectiveness of bone marrow transplantation.

- The world’s first ever implant of a fully synthetic trachea was possible after NIHR-supported research led to ground-breaking uses of nanocomposite materials for rejection-free tissue transplants.

Finally, NIHR-funded work aimed at revolutionising the way clinical data is collected and utilised is helping to ensure that England remains at the forefront of the types of novel research described above. An example of this is:

- The 100,000 Genomes Project – which is funded as a partnership with NIHR, Public Health England, NHS England and Health Education England – is combining genomic sequence data with medical records in order to better understand causes and potential treatments of cancer and rare diseases, and is facilitating future research.
NIHR contributes to breakthrough discoveries with international impact. For example:

- More than 1 million people worldwide who would otherwise die each year from traumatic injury stand to benefit from NIHR-funded research into the novel, off-label use of a drug, tranexamic acid, that has been shown to significantly reduce the risk of bleeding to death if administered within the first three hours of trauma.

- More than 1,700 healthcare organisations worldwide are using the WHO’s Surgical Safety Checklist, a tool that significantly reduces post-operative complications and that was developed from a series of indicators informed by NIHR-funded research into patient safety.

- Hundreds fewer people are at risk of fatal poisoning following the withdrawal of co-proxamol in the UK, other EU member states and a number of other countries on the basis of findings from NIHR-backed studies.

NIHR provides researchers with the means to draw together and apply evidence of international best practice. NIHR-funded programmes of patient, and patient-focused, research are improving lives and patient safety worldwide:

- The 1 in 600 babies born each year in the UK with cleft lip and palate will benefit from more equitable and better quality surgery, following NIHR’s investment in research on centralising cleft services in fewer specialist centres. As a result, the clinical infrastructure is now in place to support national and international trials of new approaches in order to improve cleft care.

- Children with eczema now receive therapies based on internationally validated guidelines, with standardised methods to self-report their responses to treatment feeding in to a global resource of clinical trials.

- Stroke survivors have access to advanced assistive technologies to support one-to-one rehabilitation, which are being put into practice as part of an internationally relevant programme of research that has trained more than 2,500 therapists.

- Elderly people with dementia will receive a more personalised approach to their care, via an NIHR programme on the impact of behavioural – as opposed to solely pharmacological – interventions.

- Artificial knee joints produced by foreign manufacturers are being tested to strict quality standards, using advanced bioengineering simulators. These devices are being manufactured and trialled as part of a collaboration involving the Leeds NIHR Musculoskeletal Biomedical Research Unit.

NIHR also undertakes research which impacts on global health, for example, within its Biomedical Research Centres and within NIHR centres dedicated to patient safety research, as shown by the following examples:

- NIHR is protecting patients’ and communities’ rights, working to safeguard all participants in research by improving international ethical standards designed to ensure appropriate consent mechanisms and minimise the risk of creating inequalities.

- NIHR is playing a part in trials of candidate vaccines for Ebola through its support of the Oxford Biomedical Research Centre, which is part of a study enrolling more than 500 participants in vaccine trials in Europe and Africa.
The National Institute for Health Research at 10 years

Making the nation’s health and care system the best it can be

The NHS is committed to providing high-quality healthcare for all, irrespective of age, health, race, social status or ability to pay. To do this, the NHS must continue to adapt to take advantage of new opportunities offered by science and technology.

At the disease level, numerous studies about the cost-effectiveness of specific treatments contribute to improved accessibility and better coverage of targeted populations. NIHR funds research aimed at providing higher-quality, safer and more effective and cost-effective products and solutions. Examples include the following:

- Studies into continuous subcutaneous insulin infusion for patients with diabetes are helping to educate and empower patients, improving their quality of life and likely minimising the burden on the health system by reducing their reliance on other services.

- Research into methods of expediting treatment for patients suspected of having a transient ischaemic attack (‘mini-stroke’) has provided a route to preventing 10,000 strokes per year, potentially saving £624 per patient and up to £200 million annually in acute care costs in the NHS.

- Research into cognitive stimulation therapy has shown it can improve memory and language functions for people with mild and moderate dementia. This therapy could save the NHS an estimated £54.9 million a year as a result of decreased use of antipsychotic medication.

NIHR funding is directly impacting on the quality of patient care through workforce interventions and knowledge sharing, as exemplified by the following:

- The Radiotherapy Trials Quality Assurance Team ensures that medical staff respect the highest standards when it comes to clinical research that has a radiotherapy component, helping professionals to transfer research knowledge to regular care through a continuous exchange of ideas.

- The Hyper-Acute Stroke Research Centres offer stroke patients the option to participate in trials of the latest ‘clot-busting’ therapies and have led to efforts to capture data that enhance the quality of emergency care and improve stroke care organisation and delivery. NIHR’s funding facilitated research that is difficult to conduct in traditional settings due to tight time constraints.

- The Enabling Research in Care Homes programme is helping to develop and sustain a network of ‘research-ready’ care homes so that residents, especially those with dementia, can take part in appropriate studies and trials. NIHR invested over £10 million in 2013 in care home research, contributing to a more inclusive health and social care system.

By financing research into service organisation and delivery, NIHR also contributes to a health and social care system which makes better use of information and resources. Examples of such research include the following:

- Studies to advance the European EQ-5D framework have allowed further development of measurement instruments that capture the health preferences of the general public. The framework fosters a culture of health system monitoring, providing accountability and transparency in healthcare decisions.

- The findings of the Birthplace in England study are providing evidence for services that offer women a choice of birth setting and are steering the healthcare system towards safer and more cost-effective births in England.

NIHR funds research to inform, support and improve the quality, accessibility and organisation of health services. By making better use of information and resources, the evidence that this research generates offers options for sustaining and improving the NHS.
• The Clinical Record Interactive Search and the Clinical Practice Research Datalink –
  systems that capture and link medical data from different sources for use in research –
  promote the development of more efficient and resilient information systems. Both
  are helping to inform changes in clinical practice, for example, by identifying
  appropriate services for people with severe mental health illnesses on the basis of the
  severity of their symptoms.

• NIHR has put systems in place to improve the efficient and prompt set-up and
  delivery of clinical research itself, such as the introduction of contracts between
  the Department of Health and Local Clinical Research Networks and the initial
  introduction of a ‘research passport’ to streamline permissions to undertake
  research across multiple clinical locations, now managed by the Health Research
  Authority.

Working with charities and the third sector on common agendas

NIHR’s research infrastructure in the NHS helps to enable charities and the third sector to
undertake high-quality, cost-effective research. Charities invested over £1.7 billion into studies
enabled by and using NIHR infrastructure over the period 2009/10 to 2014/15, including
£436 million in 2014/15 alone.

Partnering with charities enhances NIHR’s ability to reach out to specific patient groups
and to support major national campaigns. Equally, it allows charities to access the entirety
of NIHR’s infrastructure to realise patient benefits. For example:

• NIHR’s network of Experimental Cancer Medicine Centres is jointly funded with
  Cancer Research UK and is increasing the number of patients taking part in trials of
  innovative new cancer treatments, such as those for refractory myeloma. More than
  2,500 patient participants were recruited to 389 trials in 2015.

• England’s largest programme to tackle stigma and discrimination against people
  with mental health, Time to Change, bases its interventions around principles of social
  contact validated as part of an NIHR research programme. The research team worked
  closely with the charities Mind and Rethink Mental Illness, who lead the programme.

Charities provide over a third of all public funding for medical research in the UK, and
many national charities partner with NIHR. One example is Arthritis Research UK. This
charity is working across the breadth of the health research innovation pathway and NIHR
infrastructure, including with the University College London Hospitals Biomedical Research
Centre, to establish the world’s first centre for adolescent rheumatology; with NIHR’s
Translational Research Partnership, to begin the first translational research programme
in Lupus; and with NIHR’s Collaboration for Leadership in Applied Health Research and
Care Greater Manchester, to promote self-management of their disease for patients with
rheumatoid arthritis.

NIHR, in collaboration with the Association of Medical Research Charities – the UK’s
membership body representing 133 charitable research funding organisations – and other
stakeholders, including the Health Research Authority and the Medical Research Council, is
implementing guidelines which will help reduce the burden of research funding on charities. The
guidelines will provide a mechanism through which the NHS will pay for additional costs that
could otherwise make the price of research prohibitively high.
NIHR works with charities to tackle urgent health issues where there are unmet research needs. Pooling resources with charities significantly speeds up the process of bringing new technologies into clinical practice. Examples of these partnerships include the following:

- The British Tinnitus Association is working as part of an NIHR-supported Priority Setting Partnership (via the James Lind Alliance, featured on p. 12) to inform research results into the first ever evidence-based clinical practice guidelines for tinnitus, which stand to benefit the 5 million people living with this condition in the UK.

- Globally more than 10,000 patients with a rare genetic form of diabetes have benefitted from a personalised medicine approach that allows them to control their blood sugar without the need for insulin injections. The screening method used to identify these patients arose from research funded via a strategic partnership with the Wellcome Trust, as well UK diabetes charities.

- Stroke survivors with cognitive impairment receive a diagnosis earlier and more efficiently as a result of NIHR’s championing of a screening tool originally developed with funding from the Stroke Association.

- Researchers working in partnership with the charity Sue Ryder are improving practices on how to better communicate with patients and their families about end-of-life plans.

Networks of volunteers support research within their community. NIHR sponsors research to assess the impact and cost-effectiveness of these local, often experimental, initiatives. Below are two examples of NIHR randomised controlled trials which helped demonstrate significant benefits:

- One volunteer group now operates as its own charity, Speak with IT, to deliver enhanced, computer-based rehabilitative therapies for stroke victims with aphasia (a speech and language disorder) in the north-east of England. This follows results from NIHR’s pilot trial indicating that this therapy improved patients’ language abilities, and was more cost-effective, when compared to standard speech and language therapy and linked support groups.

- The charity Sing for Your Life reaches more than 1,000 elderly people in community and care settings each month. An NIHR-funded trial demonstrated that the singing programme the charity delivers significantly improves participants’ quality of life and well-being.

Charity and third sector partnerships also provide a platform from which NIHR can undertake research into topics viewed as sensitive or challenging:

- The Equality Trust is an educational and campaigning organisation set up to share findings of an NIHR research programme examining the social and health-related determinants of inequality. The findings have been cited in World Health Organization policy documents and by senior policymakers from the United Nations and the International Monetary Fund.

**Supporting public health delivery**

NIHR’s investment in public health research strengthens the country’s resilience to disease. It helps to prevent disease through improved screening and diagnostics, increases emergency preparedness and promotes health in both medical and non-healthcare settings.

NIHR supports research into novel methods to screen for and prevent non-communicable diseases, which saves money and enables healthier lives. NIHR research into broader
prevention initiatives also helps to reduce the impact of chronic conditions on the health system. Examples of NIHR-funded research in this area include the following:

- New interventions to reduce alcohol-related harm save primary care trusts an estimated £650,000 annually.
- Research into the use of pulse oximetry – a cost-effective method to detect critical congenital heart defects in newborns – means 92 per cent of babies with such defects are now diagnosed before leaving hospital.
- Studies of low-hazard nicotine products reduce the harm from smoking by providing the evidence to underpin smoking prevention strategies.
- Research investigating the potential of stratified care for nonspecific low back pain – where treatment is matched to patients’ risk of a poor prognosis – is estimated to lead to more than £700 million in overall savings.
- Research into the clinical effectiveness and cost-effectiveness of screening for human papillomavirus is contributing to the evidence base for effective cervical cancer screening methods, both in England and internationally.

NIHR’s support of vaccination research is an important component in preventing the spread of potentially life-threatening communicable diseases. NIHR research contributes to public preparedness for outbreaks and epidemics, enabling a rapid response in times of crisis. Examples of NIHR initiatives include:

- NIHR-supported research into meningococcal meningitis has led to policy changes on childhood immunisation and national vaccine coverage, which has contributed to better protection of the population against this dangerous condition.
- As part of the response to the H1N1 epidemic, NIHR put in place a rapid commissioning mechanism to fund a range of research initiatives to combat the epidemic. This contributed to increased vaccination coverage, with more than 500,000 children receiving an H1N1 vaccination within a few months of the epidemic beginning, and with a doubling in the number of pregnant women immunised against influenza in England between 2008 and 2015.

NIHR funds health promotion–related research that is designed to safeguard the public from health risk factors. It also provides evidence to inform national and international policy changes. Some examples of NIHR policy impact include:

- Banning the use of bisphenol A in baby bottles was a policy decision influenced by NIHR-funded research investigating the effects of human exposure to this chemical.
- Violence is being prevented through interventions that make innovative use of data shared from hospital accident and emergency departments.
- Understanding public attitudes to presumed consent for organ donation – which was facilitated by NIHR’s funding of studies of different national approaches – helped to prevent a costly change in policy and informed recommendations which contributed to a 50 per cent increase in registering of organ donors in the UK.

Putting patients and the public at the heart of all stages of research

NIHR is making health research more relevant to patients and to the public it benefits by involving members of the public at all stages of research, from setting priorities to communicating and implementing study findings, as well as improving public awareness of research and actively improving public participation in research studies.

One of the main aims of patient and public involvement (PPI) is to further improve the quality of research by including patient’s perspectives on how and why the research is being conducted.
The hope is that, by involving patients who will be directly involved in, and benefit from, the outputs of the research, patient-centred research will be more targeted and relevant and have an impact on the provision of services and care.

INVOLVE is an NIHR-funded national public involvement centre and advisory group that seeks to ensure that patients and the public are effectively involved in all stages of research. As acknowledged in the international evidence gathering for the *Going the Extra Mile* report, INVOLVE has been a world leader in raising the awareness, importance and quality of public involvement over the past 20 years. It is one of the few (and longest-running) programmes of its kind in the world. Thus, through its promotion of PPI in research, NIHR is changing research culture and acting as a beacon of PPI best practice.

Examples of PPI supported by NIHR are numerous and cover the entire research process, from setting priorities for what kind of research is undertaken and how, to defining research outcomes and disseminating findings:

- Since 2008, the NIHR-funded Devices for Dignity (D4D) initiative has provided a platform for patients and the public to submit their ideas and become part of the healthcare innovation process. D4D focuses primarily on renal technologies, assistive and rehabilitative technologies, urinary continence management and paediatric technologies. D4D gives patients and the public an opportunity to underline which outcomes matter when thinking about the development of interventions and devices.

- A study of people at risk of cardiovascular disease who also have a severe mental illness received an award from the Mental Health Research Network for outstanding service user involvement. Patient engagement helped to make the intervention more acceptable and meaningful for research users and helped to shape future research.

- The Non-Executive Children’s Board at the NIHR/Wellcome Trust Cambridge Clinical Research Facility for Experimental Medicine has enabled children to have a voice in the service development of the facility and has led to changes in service re-design – for example, making the Clinical Research Facility environment more child friendly and helping inform the design of study-specific patient information.

- Funded by NIHR’s School for Primary Care Research, research to develop a smartphone app called the PainRecorder involved patients with musculoskeletal conditions in the actual design and functionality of the app, as well as in what kinds of data would be useful to collect. Their involvement resulted in changes to the app which better reflected the user experience.

- The James Lind Alliance seeks to involve the public in setting priorities for research. Funded by charities and supported by NIHR, it was established to give patients an equal voice with carers and clinicians through Priority Setting Partnerships. These identify and prioritise the Top 10 ‘unanswered questions’ concerning the effects of treatments on which they would like research to focus. Since 2007, approximately 50 partnerships have been convened, enabling more patients, carers and clinicians to get involved in the decisionmaking process, and informing future research funding.

In addition to helping research to be patient-led and patient-centred, the following efforts have

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resulted in more people participating in all stages of research:

- The Join Dementia Research initiative is a national online service that makes it easier for people with dementia, their carers and members of the public to register their interest in taking part in dementia research. The service then matches people to suitable studies. By expanding the pool of interested research participants, it aims to improve the speed of study delivery and, ultimately, to support advances in treatment.

- A study on testing and treatment for prostate cancer involved patients and the public to inform the phrasing of participant information, leading to high levels of participation in the study.

- At the regional level, NIHR’s Clinical Research Network is helping to match patients to relevant clinical trials and accelerating the pace of research. Over the past five years, more than 3 million individuals have participated in clinical research studies supported by the Clinical Research Network.

Finally, efforts supported by NIHR are raising awareness among the public and within the scientific community about the importance of PPI and the ways in which people can become involved. One of the central aims of these efforts is to be inclusive and to reach those groups which are usually not involved in research, as shown by the following example:

- The Generation R initiative provides a platform for children to engage with and learn about research both nationally and internationally. Generation R is giving children and young people a role in informing research, from funding applications through to the design and validation of materials used as part of clinical trials.

### Creating opportunities for economic and social returns

Entrepreneurial. Affordable. Effective.

NIHR creates opportunities for economic as well as social returns on health research investment, including a more effective and affordable NHS.

NIHR supports cooperative partnership models of working among companies, clinical academics and clinicians which improve patient health and benefit the economy. This is facilitated through NIHR’s support of the research infrastructure in the NHS, which is made up of world-class research centres, units, facilities and NIHR’s Clinical Research Network, which provides total coverage in England. This infrastructure plays an important role in supporting the wider health research system by supporting, enabling and delivering research through partner organisations. In 2014/15, NIHR provided £227.8 million of funding for the research infrastructure, which supported a further £130 million of research funding from industry, £436 million from charities and £354 million from research councils.

Commercial contract studies are an important part of this wider picture. In 2014/15, the Clinical Research Network supported the delivery of 4,932 open studies, 1,079 of which were from the life sciences industry. Commercial contract studies are also involving ever-greater patient numbers: 78 per cent of NHS Trusts recruited nearly 35,000 participants in 2014/15, making use of the nationwide NIHR Clinical Research Network, which acts as a unifying platform for delivery of research studies. The efforts of the Clinical Research Network are complemented by NIHR’s Office for Clinical Research Infrastructure, which provides a dedicated conduit for global industry to connect with the other NIHR-funded research infrastructure of centres, units and facilities, integrated within the world’s largest single-payer healthcare system.

NIHR’s investment in research infrastructure also facilitates public–private partnership models that
connect ‘home-grown’ NHS research expertise with high tech manufacturing facilities. The following are examples of commercial licences and companies that are in place as a result of NIHR-funded early research:

- Autolus is developing therapies that re-programme the body’s own immune cells as a treatment for cancer. It has now raised £70 million of private capital through two rounds of funding.
- Synairgen has licensed experimental therapies to lessen the impact of viral infection in asthmatics, initially developed through proof-of-concept funding via NIHR’s Southampton Respiratory Biomedical Research Unit.

In addition to research studies, NIHR invests in proof-of-concept trials that traditional investors might consider high risk, thus helping entrepreneurs bring advanced prototypes to market. The following are two successful examples:

- ‘Smart specs’ help the visually impaired by augmenting users’ vision. Funding from NIHR’s Invention for Innovation programme enabled researchers at the University of Oxford to produce an advanced prototype tailored to patients’ needs.
- ‘Bionic eye’ prostheses in patients are a global first at the NIHR/Wellcome Manchester Clinical Research Facility; they use a retinal implant to combine artificial and natural sight to combat a form of blindness that affects millions of people worldwide.

NIHR also seeks to quantify the economic impacts of new therapies based on evidence. This has always been done, but is especially important in today’s climate of low growth. For example:

- Aiming to maximise public health gains at a price affordable to the NHS as a whole, NIHR’s Health Technology Assessment (HTA) programme conducts pragmatic research to inform policy recommendations on new drugs, devices and diagnostics. One estimate places the net benefit of putting a sample of 10 HTA study findings into practice at £3 billion, by implementing interventions shown to be either cost effective or cost saving to the NHS.
- Targeting patients at the greatest risk of malnutrition – estimated at 30 per cent of hospital patients – using a simple screening tool developed at NIHR’s Southampton Biomedical Research Centre could save the NHS £200 million.
- Improving the evidence for deciding if and when to vaccinate over-65-year-olds against pneumonia, informed by research at the London School of Hygiene and Tropical Medicine’s Health Research Protection Unit, is ensuring that resources within the NHS are spent in a cost-effective manner.
- Supporting clinicians to develop new medical devices and involve the NHS more closely in innovation, a cooperative partnership between clinicians, academics and industry at Queen Mary University of London developed a surgical stapler to resect the bowel. This device is improving patients’ lives while saving £12,000 per patient per year in treatment costs.

NIHR also helps to drive different stages of the translational pathway. A nationwide platform of Clinical Research Facilities is attractive to foreign manufacturers looking to trial innovative drugs, devices and diagnostics. Equally, NIHR’s funding of research consortia around rare diseases generates uniquely detailed data within patient cohorts. For example:

- A consortium that supports 5,000 patients with a rare form of liver disease and which has developed strong ties among industry partners, local clinical trials infrastructure and NIHR’s Clinical Research Network is generating new avenues for research – prompting one US-based pharmaceutical company to move its entire manufacturing outfit to the north-east of England.
Enabling clinical research excellence

NIHR funding and support increases the national research infrastructure in the NHS and resources available to researchers and clinicians. It provides the facilities and environment for academic and NHS researchers to leverage further funding from other partners, such as charities and industry. Examples of NIHR impact through collaborative structures include:

- **Biomedical Research Centres and Biomedical Research Units** increase research capacity and capabilities by providing research infrastructure in the NHS and opportunities for research and clinical personnel to develop multidisciplinary skills, with over £918 million in research funding leveraged in 2014/15 from NIHR’s charity, industry and public research funding partners.

- **Clinical Research Facilities** are providing a purpose-built environment equipped with the latest technology to conduct cutting edge experimental medicine research, leading to promising innovative treatments, devices and diagnostics, such as a new ultrasound technique for treating bone cancer, which alleviates pain almost immediately.

- **NIHR’s BioResource** provides a database of public and patient volunteers willing to participate in research trials and studies with a view to having an impact on health and healthcare. To date, 75,000 individuals have signed up to BioResource and are available to participate in studies.

- **Collaborations for Leadership in Applied Health Research and Care** are partnerships bringing together local providers of NHS services and NHS commissioners, universities, other relevant local organisations and the relevant Academic Health Science Network that conduct applied health research and implement evidence-based solutions to improve health. An example is the My Medication Passport – a booklet and app that holds a register of an individual’s medication and other details – which empowers patients and helps them to inform medical professionals about their own medical history.

NIHR also provides funding for rare diseases and niche areas. Collaborations targeting early translational (that is, experimental medicine) research on specific diseases include the following:

- **NIHR’s Translational Research Partnerships** create frameworks for national coordination to meet therapeutic needs in special areas, including a collaboration with Novartis that could lead to a new treatment for Sjogren’s syndrome, an autoimmune disease that affects the glands that produce tears and saliva.

- **The Rare Diseases Translational Research Collaboration** successfully supports 56 projects in the field of rare diseases, including 9 jointly funded with industry. This research benefits the 7 per cent of the UK population who suffer from rare diseases and enhances knowledge of disease mechanisms that are applicable to more common diseases.

Experienced, well-trained research staff are the foundation of robust research. NIHR funds three national schools that bring together leading academic centres in England and contribute to the professional training of researchers. The research outputs from the schools have informed national and international policy on a range of subjects:

- At the School for Primary Care Research, studies are contributing to policy change, including research which found that a
mobile device that measured patients’ blood pressure while they were ambulatory was more accurate and cost effective than either clinical or home monitoring. The National Institute for Health and Care Excellence (NICE) has since updated its hypertension guidelines to recommend ambulatory monitoring, and the research is also cited in South African guidelines for hypertension.

• Studies at the School for Public Health Research aim to improve the evidence base for applied public health practice, such as investigating whether the availability of cheap beers and ciders encourages people to cut down on drinking or whether bringing welfare advice on such problems as debt and benefits together with delivery of medical care would reduce costly demands for health services.

• The School for Social Care Research is engaging research fellows, contributing to researchers’ professional development, and supporting studies that are benefiting the social care system. A study looking at the barriers faced by unpaid carers led to changes in guidance documents issued by several national charities and was cited during readings of the Health and Social Care Act 2012 in the House of Commons.

NIHR also provides resources to help advance knowledge and facilitate future research. It makes the findings of research freely and transparently available and provides resources to facilitate access to research resources, including public and patient volunteers, in the following ways:

• NIHR promotes the dissemination of research findings by requiring all NIHR-funded study outputs to include a short ‘plain English’ summary that can be easily understood by the general public.

• It also makes resources freely accessible online, including infographics, annual reports, booklets and research reports. NIHR’s Journals Library, the first of its kind to be established by a health research funder, comprises 165 published issues of five open access, permanently available peer-reviewed journals. It recorded 260,000 website visits in 2015.

• NIHR’s Research Design Service provides valuable advice on research design and methodological considerations and helps researchers improve the patient and public involvement components of their research. The service worked with more than 2,800 research teams in 2014/15 and helps lead to more successful and impactful research, as observed by researchers and funders alike.

Supporting, training and developing a diverse workforce in the NHS and academia

Skilled. Motivated. Diverse.

NIHR supports training and development opportunities to develop a diverse workforce and to embed the practice and mindset of clinical research throughout the NHS and academia.

In order to achieve clinical research excellence, research teams must possess technical knowledge and be skilled in working together to overcome difficulties, spark new ideas and inspire other researchers. NIHR is training a highly skilled workforce and developing and retaining the best clinical, health service and public health research professionals. It is also enabling leading clinicians to embark on, and successfully develop, their academic careers while continuing their clinical training.

NIHR supports more than 5,000 trainees through a range of NIHR research funding or training awards. This comprehensive range of research training opportunities includes the prestigious Fellowship Programme and the academic career pathway for doctors and dentists. These and other NIHR training programmes support people at an individual level to realise their full personal skills and potential. By offering multiple fellowships and career development awards, NIHR
creates follow-on funding opportunities that enable NIHR clinical researchers to follow a sustainable career path and build a research portfolio. This research is also likely to benefit the wider health and social care landscape, both nationally and internationally. For example:

- Between 2006 and March 2015, NIHR funded 165 Doctoral Research and Clinical Doctoral Research Fellows in England. These fellowships have had a demonstrable impact on individuals’ careers and have created a skilled research and clinical academic workforce in both medical and non-medical professions.

- NIHR is giving 27 NIHR Research Professors the unique opportunity to conduct clinical research which can, and is, moving from ‘bench to bedside’ and from ‘campus to clinic’ by translating research into benefits for patients, healthcare and society.

- Through its Leadership Programme, NIHR is supporting researchers throughout NIHR to become efficient and effective managers and leaders, in order to help improve the way research is conducted within organisations and at the system level.

- NIHR has developed a massive open online course (MOOC), in partnership with the Digital Learning Team at the University of Leeds, which was taken by 8,845 people from more than 80 countries worldwide.

A well-trained research team is a foundation for delivering high-quality research outputs. NIHR offers health professionals support to develop research skills and gives them protected time to conduct research alongside their clinical duties. This provides more flexibility and choice for individuals to determine career pathways that span both clinical and research roles. The following efforts are helping to embed research and its findings into the health system:

- NIHR’s Mentorship for Health Research Scheme supports allied health professionals, healthcare scientists, nurses and midwives in their professional development, helping them to gain valuable skills in clinical research.

- Since 2006, the Integrated Academic Training pathway has provided research training for more than 2,000 doctors and dentists. This spans the Academic Clinical Fellowships (early-career research during specialist training) to the intermediate NIHR Clinician Scientist awards. Many Clinician Scientists continue to progress on the clinical academic pathway, pursuing joint academic and research careers.

- NIHR is supporting a new training programme for carers of people suffering from anorexia nervosa, which has now been taken up by the two largest eating disorder charities in the UK. The programme is also recommended by the USA-based international charity FEAST and forms the basis of both NHS and international services, including those in the USA and Australia.

### Investing across the nation

**Regional. Societal. Needs-based.**

*NIHR supports regionally driven research to address the distinct health priorities of different regional areas and to assist the national scale-up of local initiatives.*

NIHR recognises that the diversity of England’s regions and their health profiles create unique challenges; therefore, it funds regionally focused studies that engage communities in research designed to meet their specific needs. NIHR also identifies innovations developed at the regional level which have the potential to be scaled up, and it funds research to build the evidence base for their wider implementation.

Where a region faces particularly high prevalence of a disease or difficulties in implementing effective treatment, NIHR supports research led from within the region and targeted at the affected population. The 13 NIHR Collaborations for Leadership in Applied Health...
Research and Care (CLAHRCs) play a valuable role in ensuring that research is sensitive to regional priorities and engages local populations. As a result, NIHR-funded projects have been able to produce targeted interventions that improve local patients’ health. For example:

- The West Midlands CLAHRC supported the YouthSpace study to redesign mental health services for Birmingham’s unusually large young adult population. The CLAHRC provided a platform for community engagement throughout the project, which found that the redesigned service could substantially reduce delays in treating young people for psychosis.

- A project involving the East Midlands CLAHRC led to the development of the Leicester Self-Assessment tool to aid early identification of diabetes risk in ethnic minority communities, who form a large proportion of the region’s population and are among those most likely to suffer from diabetes.

- The CLAHRC South West Peninsula has supported work to implement redesigned pathways for stroke care, initially developed within the Royal Devon and Exeter NHS Foundation Trust, throughout the region. This builds on local operational research, which used computer modelling to identify ways to cut the time taken for a person who has suffered a stroke to receive vital clot-busting treatment, with waiting times cut by almost one half.

NIHR’s community-based approach generates reliable evidence for interventions. A number of those interventions have been adopted in other regions or at the national level. This has led to changes to policy and practice, which improve outcomes for more patients. Various projects illustrate this impact:

- A stroke registry designed for targeted use in London’s ethnically diverse population was developed with NIHR support and has since been adopted by two thirds of English hospitals. The registry gathers data, which enables better prediction of stroke risk and long-term outcomes, in turn facilitates evidence-based policy and practice in stroke services, as demonstrated by citation of the work in the National Stroke Strategy.

- A study on the energy efficiency of NHS buildings found that innovative ventilation of hospitals in the London Urban Heat Island could enhance patient safety by preventing overheating as far forward as 2080, even as climatic temperatures rise. The London findings on innovative ventilation have been identified by national-level NHS management as an influence on future policy; cited by Department for Environment, Food & Rural Affairs (usually referred to as DEFRA) policy documents; and adopted internationally by private and public healthcare providers, including Skanska and the government of India.

- The Big Local study, supported by NIHR’s School for Public Health, engages local residents in designing health promotion interventions in their local communities and is being monitored by NICE as a possible example of good practice for inclusion in its future Guidelines on Community Engagement.

- A multiregional study on care transitions engaged elderly people from each region, all of whom had recently experienced transitions, as members of the research team. The resultant patient-centred and locally focused findings have led to changes in policy in each of the study regions (Solihull, Leicester, Manchester and Gloucestershire).

- The Head Up project on combating neck weakness in motor neuron disease patients, conducted at Sheffield Hallam University, engaged a local patient group alongside a multidisciplinary team of experts, through NIHR’s Devices for Dignity initiative. This active involvement of local stakeholders enabled the development of a neck support collar that responds to patients’ needs by helping them to communicate and eat.
Where appropriate, NIHR itself seeks to drive scale-up of innovative regional interventions, by funding trials and adaptations which demonstrate their potential benefits for patients throughout the country. Examples include:

- The Football Fans in Training initiative, developed in Scotland, works through football clubs to provide a culturally sensitised weight loss programme for Scottish males. The evidence produced by an NIHR-funded evaluation – showing almost half of participants achieving a target weight loss likely to reduce obesity-related health risks – led to the roll-out of the initiative in sports clubs across England and Europe-wide.

- NIHR funded a trial to determine the potential benefits of wider uptake of the New Forest Parenting Programme, aimed at families of children with attention deficit hyperactivity disorder, which was originally developed and implemented in Southampton. NIHR support facilitated local clinical involvement in the study, the findings of which are expected to inform revised NICE guidelines.

NIHR’s emphasis on regionally driven research ensures a flow of evidence-based health innovations that have the potential to improve lives on a national scale, aided by NIHR’s willingness to support wider scale-up.

NIHR at 10: 100 examples, 10 themes, 1 transformation

In the past 10 years, R&D funding by and for the NHS has changed significantly as a result of NIHR’s formation. Across the 100 case studies in our report, there is strong evidence of substantial impact across patient benefits, the delivery of health and social care, public policy, economic growth and the generation of knowledge. Therefore, transcending the individual case studies presented in this report is the possibility of an eleventh, cross-cutting benefit: the transformative effect NIHR has had, both on itself as a funder for R&D in the NHS and on the wider health research system.

While we have not systematically evaluated NIHR’s achievements against the goals in *Best Research for Best Health*, nor against any other document or set of objectives, we can say that among the 100 case studies of impact synthesised in this report, there is evidence of impact that spans the five main goals set 10 years ago. Drawing on just one example out of the 100 for each goal, we find:

- The use of tranexamic acid to prevent clotting, which could benefit more than 1 million people worldwide, is one way in which NIHR-funded research has come to be recognised internationally as world leading.

- The introduction of a leadership development programme for NIHR faculty to manage transformational research demonstrates how capacity building is used as a science policy intervention.

- NIHR’s contribution to the testing and roll-out of the World Health Organization’s Surgical Safety Checklist, a tool to reduce life-threatening complications now used by 1,790 healthcare organisations worldwide, is helping to improve health and social care.

- The drive to make all research publications open access, in NIHR’s case via a Journals Library, as well as introducing multiple initiatives to enable better and improved access to research data, ensures that knowledge is shared and managed in an efficient manner.

- The commitment to ‘principles of transparency, fairness and contestability’ is affirmed by NIHR establishing a competitive

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bidding process for its research infrastructure funding, involving international assessment panels in order to ensure that money is spent in a transparent and accountable way for the public good.

The case studies in this report also demonstrate the effects of NIHR’s investments in research infrastructure. A significant proportion of NIHR’s support for research is in the form of investing in the research infrastructure in the NHS, thereby creating an environment where high-quality research is possible by offering funding that allows for the building of new facilities, acquisition of equipment, financing of staff who are drawn towards research, training of researchers and incentivising of industry to engage in early-stage research. These wide-ranging efforts to support the research infrastructure make NIHR a unique actor that brings together clinicians, researchers and the public to advance research discoveries and improve health and care – an actor that underpins research funded by charities, industry and government departments.

Across the case studies we found evidence that a change in culture and values has occurred. A range of stakeholders, from patient groups to research funders, told us that they now feel that researchers are doing the right type of research, in the right way and for the right reasons. For example, the activities supporting trainees, clinicians and future research leaders have served to build capacity and expertise throughout the clinical career pathway, providing support for clinicians and other healthcare professionals to engage in research. INVOLVE, together with other efforts across the system in patient and public involvement and engagement, has led to a shift in the way that the public and service users are engaged in research. These efforts are an active and integral part of the process, helping to both shape and improve the quality of research that is produced.

Clinical research is also supported and valued in a way that it was not before. We can see evidence of this captured in the impact case studies for the 2014 Research Excellence Framework. A brief analysis showed that nearly 250 case studies – or about 12 per cent of those submitted in the field of life sciences – cited NIHR funding as contributing to health and patient benefits. These findings lead us to conclude that one of the things that NIHR may have helped to achieve is that a higher value is placed on clinical and applied research throughout the sector.

This all suggests that it is the interaction between the physical and the cultural, between the project and the system, between the patient and the researcher that has supported system-level change. NIHR has helped to integrate clinical research across organisational and infrastructural boundaries, thereby creating a virtuous circle of valuing and doing applied and clinical research. NIHR infrastructure allows it to draw in funding from others, including the life sciences industry, charities and research councils. NIHR’s nationwide Clinical Research Network supports the use of this infrastructure by the entire system, by finding the right patients to take part in studies. These combined efforts facilitate the translation of research into innovations for the health service, and they facilitate external partners’ funding of clinical research. NIHR has helped to create this systemic infrastructure, both technical and knowledge-based, for clinical research. This change is perhaps the most important, and we suggest it has been done in a fashion which is integrated, additive and synergistic with other parts of the wider health and research system. As one interviewee told us, ‘NIHR has changed the system for the NHS’; that, 10 years in, seems like it will endure.