



# Turning the Tide: Harnessing the power of child health research

A report by the Royal College of Paediatrics & Child Health  
Commission on Child Health Research

## Executive Summary

**RCPCH**

Royal College of  
**Paediatrics and Child Health**

*Leading the way in Children's Health*

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## EXECUTIVE SUMMARY

November 2012

The full report can be accessed at:  
<http://www.rcpch.ac.uk/harnessing-the-power-of-child-health-research>



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# Contents

- Child health research .....4
- The UK landscape ..... 5
- Solutions ..... 8

## Child health research

### Introduction

Children deserve, and parents expect, the best healthcare for their children. Over the last 50 years there has been a substantial increase in our understanding of illness and our ability to treat or modify many diseases successfully. Our care of the new-born has also improved with many more neonates surviving now than previously. Much of this progress has been underpinned by research led by paediatricians but, in spite of children never having been so healthy, there is much more that can and should be done. Current health indicators suggest that we have fallen from our position as a leader in child health to one where our outcomes are poorer than most of our European neighbours. We need research to tell us why. There has also been a revolution in our scientific understanding and ability to investigate disease, and in the way that research in the NHS has been funded, but there are worrying signs that paediatricians have taken insufficient advantage of these opportunities. The RCPCH recognises that its primary role is the education and training of tomorrow's paediatricians, and advocacy for the best healthcare for babies and children. Research is vital to progress and the RCPCH has therefore produced this report, identifying the issues, and making recommendations as to how we might take advantage of the opportunities available.

### Child health research

Child health defines wellbeing across the life-course. In the UK, children are not well served, with higher all-cause mortality in comparison to other European countries, and the lowest ranking position for all measures of child wellbeing among 21 countries in the industrialized world. Children are not small adults; they need biomedical and health services research that takes account of their changing physiology, and addresses their problems directly, generating evidence to improve the quality of the treatments and healthcare they receive, and the policies that affect their wellbeing. There are other reasons why children's research is important to the nation. Early life exposures, many mediated through disadvantage and deprivation, impact on adult health and on succeeding generations. The growing burden of chronic, long-term conditions that have a substantial component of their origins in early life, obesity, cardiovascular disease, vascular dementia, and diabetes, are placing an intolerable strain upon the National Health Service (NHS) and adversely affecting the health and economic wellbeing of the nation.

### Recent advances

Children's research is needed to define the causal biological mechanisms, alter the development of aberrant trajectories, preserve health, and reduce the costs of healthcare in adult life. The UK population is aging; health and wellbeing in old age are a matter of growing national concern. Sciences that hold great promise for health in old age, such as tissue regeneration, stem cell biology, neural plasticity, and immune modulation, require basic research that begins in infancy. In recent years there has been an explosion in powerful technologies, in-vivo imaging, non-invasive monitoring, high-throughput analytical techniques employing tiny sample volumes, bio-informatics, and epigenetics, that provide opportunity to involve children in research as never before, and unravel the molecular basis of links between early life exposures,

development, deprivation, and disease. In parallel, the organisational structures of the NHS, the largest universal healthcare system in the world, provide a unique platform to integrate clinical research and patient care, speed the translation of new treatments into practice, and test preventive interventions rigorously. Research harnessing the wealth of post-genomic sciences and the power of the NHS, offers unparalleled opportunity to improve the wellbeing of infants and children, turn the tide of the growing burden of the major non-communicable chronic diseases that have their origins in early life and lead to premature adult death, and benefit the health of future generations.

The Royal College of Paediatrics and Child Health Commission on Child Health Research was established in view of concerns about child health biomedical and health services research in the UK, and charged with considering how this might be strengthened and increased. We evaluated training, infrastructure and capacity, support within the NHS, the extent to which paediatricians are able to support clinical research, activity and funding, parent, public and young people's involvement, whether national clinical guidelines and policies affecting child health are adequately informed by research evidence, and the visibility of children's research.

## The UK landscape

### Education and training

We found superb opportunities for the research leaders of the future through the 'Integrated Academic Training Pathway', excellent support for the delivery of medicines studies through the National Institute for Health Research Medicines for Children Research Network, sterling examples of NHS consultant paediatricians supported to become research leaders, trainee paediatricians eager to be involved in research, major contributions to the international scientific literature by UK paediatricians, multiple research funding streams available through the National Institute for Health Research and research councils, dedicated charities, parents and young people keen to be active partners, and a strong Government commitment to biomedical research. All of this should be applauded loudly.

We also identified problems. There is frustration in a rigid postgraduate medical training system that offers poor opportunity for experience and education in core skills to support clinical research. Only a small minority of paediatric clinical trainees report having received teaching in basic research methods, research regulation, organisation and governance, and in their final years of training many are not confident in basic skills such as taking informed consent for research participation. In previous years all consultants were expected to be involved in research; today the majority of newly appointed consultant paediatricians have little or no research experience and only one in ten has a higher research degree, compared with one in three paediatricians nearing retirement.

### Capacity and infrastructure

There has been a decline in children's research capacity in the UK with few university posts to realise the potential of the next generation of world-class researchers. Since 2000, there has been an 18% reduction in the number of university-employed child health researchers and a fall

in the proportion of university employed paediatricians from 8.7% of the total consultant-level workforce in 2001 to 5.2% in 2011. There are now only about two hundred paediatric professors, readers, and senior lecturers in the UK and the number of lecturers, the research leaders of the future, has fallen to 28, the lowest level ever. Two-thirds of senior lecturers in paediatrics are above the age of 45 and over the next ten years 50% of current professors of paediatrics will retire, indicating the likelihood of further decline in leadership in children's research. Many child health research groups, while doing sterling work to promote research, are too small and lack critical mass. At the same time researchers report poor support for the development of collaborations, citing impediments arising from institutional rivalries and often insurmountable bureaucracy.

The infrastructure and support for children's basic science and non-medicines applied research is not consistent. There is, for example, little activity in children's primary care, health technologies, and health services research. In the most recent round of awards in 2012, the National Institute of Health Research funded one children's Biomedical Research Centre and no children's Research Units. Regardless of whether this reflects the number and quality of the applications or strategic priorities, it is a situation that we need to improve upon in the future. Less than 5% of National Institute of Health Research portfolio studies and around one in ten applications for national research ethics approval involve children; in comparison, internationally, children's research represents 10-15% of all registered trial activity. Of the 20 children's hospitals in the UK, 10 have no children's research facility.

## Activity

The complex organisational structure of the NHS means that despite strong leadership in attempting to improve both research integration and the regulatory framework, there is still marked variability in progress around the country, particularly in relation to the needs of infants, children, and young people. Support for the delivery of children's non-medicines clinical studies in the NHS through the National Institute for Health Research networks is also variable. It is extremely encouraging that around 50,000 children were recruited to research studies over 2011/12, a huge increase over previous years; however, this still represents less than 2.5% of the total 2 million NHS consultant episodes for children each year. Two-thirds of paediatric consultants have no time allocated to support clinical research, and overall less than 5% of all contracted consultant time is for this purpose. Many processes common to NHS care and children's research, such as data collection and follow-up assessments, are duplicated and this is an unnecessary and off-putting burden on families. The EU Regulation on Medicines for Paediatric Use (2007) was an important milestone in ensuring a Paediatric Investigation Plan for all new medicines, but still over 90% of medicines for infants are used off-label or off-license because the necessary clinical studies have not been carried out. A large number of clinical treatments in wide use lack an adequate evidence base. Many other low risk but essential studies, such as dosing data for widely used medicines, and long-term safety monitoring, are not being carried out because of a prohibitive regulatory environment, and escalating research costs consequent upon a growing bureaucracy, in which the benefit to patient care from a proportionate, less rigid, approach to risk assessment is inadequately recognised. Only a fifth of people are aware that research is a key activity for the NHS, though four-fifths consider it important to be offered the opportunity to participate. Two-thirds of healthcare professionals say that research is peripheral in their NHS Trust.

## Funding

Funding for child health research is fragile, representing 5% of the annual UK public and charitable research expenditure of approximately £2.2 billion, equivalent to less than £10 per child each year. Commercial studies now make up 60% of the Medicines for Children Research Network portfolio, but we found no evidence of significant industry support for children's biotechnologies, devices, and nutrition research; there are no commercial studies in the National Institute for Health Research Paediatric Non-Medicines Portfolio. Paediatricians are twice as likely to receive a research grant from a local or national charity, than from the National Institute for Health Research, Medical Research Council, and Wellcome Trust combined, but of the large number of national children's research charities, only one has a research spend that exceeds £1.5 million per annum, largely precluding their ability to support large clinical trials and major research programmes, establish substantive research posts, create regular opportunities for research experience, or fund infrastructure.

Representation by paediatricians on major research boards is weak, and parent and young people's advocacy is fragmented. The scant evidence-base for child healthcare is impeding the development of effective national guidelines and policy with less than 20% of outputs from the National Institute of Clinical Excellence applicable to children. There is inadequate primary research evidence to support many clinical guidelines, inadequate translation of scientific research into policy, and little in the way of objective assessment of the impact of policy on children's health outcomes.

The relevance of early years' research to children's immediate health, their health in adult life, the health of future generations, and the economic wellbeing of the nation is one of the great but hidden challenges in public life. We call on all those parties involved in research to come together to develop a national vision which will ensure this is recognised and acted upon.

## Solutions

### A call to action to all key stakeholders

The purpose of this report is not to apportion blame, not least when such progress has been made by all those working in the field. Our overarching aim is to catalyse action by bringing a spotlight to bear upon the importance to the nation of research to improve children's health and wellbeing. This matters not only to today's children, but equally to tomorrow's adults. Children's research is of critical importance if we are to have any prospect of turning the rising tide of chronic non-communicable diseases that have their determinants in early life, that lead to premature adult death and disability, and that place an increasing burden upon the NHS.

Only co-ordinated joint action will achieve this. We therefore call upon Royal Colleges, universities, the biotechnology, pharmaceutical and infant nutrition industries, philanthropists, research charities and research councils, the NHS and UK government, as well as parents, young people and the public to join us in creating a national vision to increase the evidence-base for healthcare and policy that affects the well-being of infants, children, and young people, their life-long health, and the health of future generations

*We have identified six priorities that we must address collectively if the power of children's research to improve their wellbeing, and the health of the nation, is to be harnessed. In taking responsibility for these actions, it is right that we start with what we, the RCPCH will do to play our part.*

### The Royal College of Paediatrics and Child Health commitment

We recognise that many factors may have contributed to a fall in research capacity and capability, including some of the ethical and practical considerations surrounding research involving children, the historical and contemporary priorities of grant-giving bodies, and even some aspects of the culture of paediatrics. Therefore unless we start with our own commitment to supporting the development of the next generation of child health researchers and to ensuring high calibre funding applications, no amount of broader national support will address the problems.

#### 1. Education, training and guidance

We will improve training in research skills for all paediatricians in our training programmes. *A Guide to Training in Child Health Research* has been prepared and is widely available; an Academic Training Committee has been established to supervise activities and ensure these objectives are met. Specifically we will:

- ground paediatric training in the tools of science
- foster opportunities to join a clinical or non-clinical child health research group at undergraduate level, and during paediatric clinical training

- sign-post medical students and paediatric trainees to child health researchers who are able to provide research opportunity and supervision
- provide clear, consistent guidance on routes into research, and requirements for obtaining approval to take time out of clinical training to obtain research experience
- assess progress in attaining the core, generic research competencies included in the General Medical Council approved paediatric curriculum as part of the Annual Review of Competency Progression required of all paediatric trainees

We are updating our *Guidance for the Ethical Conduct of Research Involving Children*, an influential document first published in 1980, and revised in 2000. This will include a *Code of conduct for paediatricians working with industry* to guide children's researchers working with the infant nutrition, pharmaceutical, and medical devices industries.

## **2. Children and families**

Children, young people and parents should be at the centre-stage of efforts to increase and strengthen research to benefit their life-long health. They are partners in the process and have a vital role to play in advocating for research to reduce uncertainties in their treatments and delivery of care. We will heed the messages from parents, young people and children about the way in which they wish to be involved in and be told about research, promote their engagement, and support them in conveying these message to the research community and research regulators.

We applaud the recommendation for a *Children's Charter* proposed by the Children's Outcomes Forum, and will collaborate with key partners to ensure it reflects the importance of research. In particular we will work with our Youth Advisory Panel, our Patient and Carer's Advisory Group and other relevant lay groups to ensure the Charter sets out the ways in which children, young people and their families can support research in order to better understand the biology of their health and disease. Just as importantly, the Charter must stress the critical importance of ensuring that research evidence is incorporated in a timely way into national clinical guidelines and policies, and that these are implemented, audited, and evaluated.

We have a duty as a College to support professionals in communicating with parents and children about the benefits of participating in research and will provide relevant guidance, training and support to ensure that all clinicians involved in research activity are confident in such communications.

## **3. Bringing organisations together**

Children's research will benefit from a coordinated approach to tackling priorities, overcoming obstacles, identifying funding in challenging economic circumstances, and improving the evidence base for national policies that affect children. The Royal College of Paediatrics and Child Health is committed to fostering an ethos strongly supportive of research, widening the involvement of NHS clinicians, monitoring trends, assessing impact, and strengthening child health policy development. We will lead the way in establishing a Science Advisory Board to direct these activities.

A collaborative, strategic approach will help organisations work together to break obstacles to progress, maximise impact, sharpen the focus on children’s research, and maintain momentum. We have therefore begun consultations with children’s research charities, and other organisations, on the establishment of a UK *Children’s Research Collaboration*. We will support strategic alignment of smaller charities and large funding bodies to optimise returns from research funding for best long-term benefit, advocate and lobby, and raise awareness of the need to increase and strengthen children’s research in the UK

## Our proposals to national bodies and the broader NHS

### 4. Infrastructure

The infrastructure for children’s basic science and applied research in the UK is fragmented and complex. The Report of the Children’s and Young People’s Health Outcomes Forum highlighted the need to stimulate the development of children’s research, and the evidence-base for practice, to improve both physical and mental health outcomes. Alongside our own commitments to improving research capability, we believe that infrastructure needs to be improved. We recommend that national bodies consider the following options as a means of achieving this:

- the National Institute for Health Research, research councils, and universities support the formation of multidisciplinary, cross-institutional groupings of clinical and non-clinical child health researchers and their access to diagnostic and laboratory facilities suitable for children; an example of such an approach, which brings paediatricians and adult medicine researchers together, is the Southampton Life Course Respiratory Biomedical Research Unit, and the Nutrition, Diet and Lifestyle Biomedical Research Centre
- the National Institute for Health Research establishes a unified Children’s Research Network to support the delivery of medicines and non-medicines children’s studies
- the Health Research Authority ensures that regulation is mindful of the needs of infants, children and young people, risk assessment is proportionate, and review is based upon criteria that are consistent nationally

### 5. Capacity

Children’s research capacity is critically small with few posts for young researchers, and few substantive research grants awarded to paediatricians. We recommend:

- a collaborative effort by the National Institute of Health Research, universities, research councils and charities to bring about an acute expansion in clinical and non-clinical post-doctoral positions, lectureships and senior lectureships in child health, linked to established research groups to empower child health researchers to achieve success in a competitive and financially difficult environment

## 6. The National Health Service

The NHS should be the best place in the world for children's research. Within the existing government strategy to bring about closer integration of children's research with core NHS activities, we would highlight the following proposals and strategies as a means of achieving this end:

- the duplication of processes common to clinical care and research that add unnecessarily to NHS costs and are burdensome to families and healthcare staff, should be eliminated
- Clinical Reference Groups, the National Commissioning Board, Clinical Commissioning Groups, and Public Health England should specifically address integration of children's research into clinical care within commissioning frameworks; this should include the opportunity for children to participate in studies to evaluate treatments that are already in wide use, obtain pharmacokinetic data on existing medicines, and conduct long-term safety monitoring. Disease surveillance to monitor morbidity and mortality rates for key diseases, should be considered a standard of care
- as part of this commitment, NHS commissioners are in a unique position to establish a national network of infant and children's follow-up centres staffed by personnel trained to deliver neurodevelopmental and other assessments to a standard required for both clinical care and research outcome evaluation, and to ensure this information can be shared appropriately
- NHS providers should ensure children's hospitals and departments have in-patient and out-patient research facilities suitable for infants, children, young people and families, as part of the Trust Board level commitment to research
- NHS employers should adopt a flexible and individual approach to increase the contribution of paediatric consultants to children's research whether as users, contributors, or leaders, and support them to access Continuing Professional Development to maintain up-to-date knowledge of research regulation, organisation, and opportunities for trainees
- the National Institute for Health Research should recognise and reward high performing NHS Trusts for the capture of high quality clinical data used for both NHS purposes and research, in a manner analogous to the incentives received for recruitment to NIHR portfolio studies

We strongly believe that if we can achieve the national partnership working we have outlined, we can make the UK a world leader in children's research that will be of incalculable benefit to children, their life-long health, and the health of the nation and of successive generations.

**Professor Neena Modi, Vice-President (Science and Research), RCPCH**

**Dr Helen Budge, Professor Howard Clark, Dr Ingrid Wolfe, Professor Anthony Costello,  
on behalf of the RCPCH Commission on Child Health Research**

**November 2012**

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Royal College of Paediatrics and Child Health

5-11 Theobalds Road, London, WC1X 8SH

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