

Pioneering global collaboration in children's health research

Professor Neena Modi is the President of the Royal College of Paediatrics and Child Health – a charity that, as one of its main aims, champions advocacy on behalf of children worldwide to ensure their fair representation in medical research. She recently spoke to *Research Features* about this aspect of the Royal College's current and future strategy, to highlight the importance of global research collaboration.

The Royal College of Paediatrics and Child Health (RCPCH) have been at the forefront of promoting children's health research since their inception 20 years ago. They work tirelessly to improve outcomes for children in scientific research, ensuring clinical paediatricians are trained effectively to deliver care to those who need it most.

Today in 2016, collaboration is the word of the day and, as such, RCPCH have made it their mission to ensure that children's health

charities work together wherever they are in the world. Professor Neena Modi, the President of RCPCH, recently spoke to *Research Features* about the institution's latest campaigns, seeking to guarantee a fair representation for children in research, while also ensuring effective training to paediatricians both in the UK and worldwide.

What does your role involve as President of the Royal College of Paediatrics and Child Health (RCPCH)?

The presidency of the RCPCH is an elected post which involves all of the charity's 17,000

members. My responsibility is to lead the development of RCPCH's strategy and really be the outward face and spokesperson for them, overseeing the streams of work and advocacy that the royal college is involved in. It's an extremely interesting role and it's a great honour to be in it.

Could you tell us some more about RCPCH's background and the kind of work into children's health that is done there?

The RCPCH is one of a small number of royal colleges. We are unique because we are not solely a royal college of paediatricians, but we are a Royal College of Paediatrics and Child's Health. Inherent in our title is that our primary responsibility is supporting improvements in children's health. We are a membership organisation predominantly comprised of paediatricians, but we also have affiliate memberships for non-paediatricians as well. One fifth of our 17,000 members also come from abroad so we are an international organisation.

We were actually first established in 1928 but at that time we existed as the British Paediatrics Association (BPA), which was a part of the Royal College of Physicians (RCP). We separated from the RCP 68 years later in 1996 when we received our royal charter – so we have quite a long history.

There are a number of things we are extremely proud of. The formation of the BPA was really a recognition that children's health required its own speciality and expertise in demonstrating that children were not just small adults. That was a vital evolution of the way in which we care for children and is really the first and foremost thing we are proud of here.

As the years have gone on, and particularly when we became a royal college, we took over examinations for paediatricians – so that has been another major achievement. The main examination we run is the Membership of the Royal College of Paediatrics and Child's Health which trainees complete once they have committed to becoming a paediatrician. It isn't an exam they do when they finish their training but instead they do it at the point on which they commit to being a paediatrician. It's an exam that shows they have fulfilled the knowledge-based requirements for becoming a paediatrician.

We are also proud to continually produce large numbers of training materials to support paediatricians in the work they do for children's health. Overall though, we are hugely proud that we have advocated very, very hard for children's science research.

And how about on a more personal level?

I'm only 18 months into my role as President so it may be a bit premature to be saying this, but one of the things I am really pleased about is having established something called the Children's Research Fund. This is particularly aimed at supporting the professors of paediatrics of the future – the people who are really going to push forward paediatric science in the future.

During 2012, RCPCH released a report called Turning the Tide, on which you were one of the lead authors. What was this report about?

This was a report we released because we are very keen to ensure that children benefit from science and clinical research. What we wanted to do in the first instance was to define the extent to which children were represented in ongoing medical research, by determining really hard objective facts and figures. What this report showed was that children were under-represented in science and research.

One of the headline figures we found was that, on average, each UK adult had £50 a year spent on affiliated research, compared to children who had only £10 spent on them. We also established lots of other facts and figures which proved that children were under-represented in scientific research, so having that document meant we had a basis on which to advocate for improvements.

What kind of influence has the report had on children's health since it was released?

A number of things have happened since that report which I am also very pleased about. First of all, we established something called a Children's Research Collaboration, which was a forum that brought together a large number of children's research funders – foundations who are very hard working but have a relatively small annual turnover. Most clinical trials these days cost upwards of £1.5 million, and the training and academia required for a paediatrician costs an estimated £1 million – so substantial sums of money are required to support clinical research. We established the Children's Health Research Collaboration to bring together these smaller charities so that they could collaborate with each other. This involves not only the bigger charities like the MRC and the NIHR, but also lots of the smaller charities such as Action Medical Research and Sparks. So we can now provide a forum and mechanism for these charities to work together.

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The next thing I'm really proud about is the development of a children's research charter. This was developed in April this year and really enables children and young people to speak in their own voices about how they want to be involved in research. And then the third thing that I'm really proud of is the creation of the Children's Research Fund, as I mentioned earlier.

So these are three really big things that have emerged subsequent to the *Turning the Tide* report. We have actually just received some very preliminary data from the National Institute of Health Research as well showing that the overwhelming majority of acute trusts, around 90% of them, are now recruiting children into clinical studies – so there has been a very positive effect since the report was released.

The RCPCH have produced many campaigns over the years on key issues within children's health. Can you give some examples of your current campaigns? Well the major one that's involved us over the past few months has been children's obesity, which is a huge issue. We've been campaigning quite heavily on that, as indeed have a lot of other children's organisations.

The main issue with this has been the disappointment with the UK government's children's obesity strategy. This was originally supposed to be a 50-page document, but was reduced to just 10-pages when it was released, and many of the things that we had hoped to see have not transpired, apart from the sugar tax, which we welcome.

The other big issue for us at the moment is the treatment of child refugees. This is a very acute and ongoing issue, and we are concerned about the fate of the children who are waiting to enter the UK. We feel that the UK should be more welcoming of child refugees and we really want to see them having access to the full range of support they need when they do get into the country. Our recent campaigns have been about, firstly, enabling them to get into the country, and then, secondly, the care that they receive when they get here.

What impact have these campaigns had? Many of our campaigns have a positive effect – the children's obesity story is by no means over yet because we really do need to turn around the epidemic. We were very strongly engaged in all sorts of collaborative



advocacy work with other organisations to combat this issue and we are a member of the children's obesity alliance. We've got a lot of collaborative campaigning that is very much still ongoing.

Aside from being President of the RCPCH, you are also the Professor of Neonatal Medicine at Imperial College London. Not only that, but you run clinical duties as an Honorary Consultant in Neonatal Medicine at the Chelsea and Westminster NHS Foundation Trust. How does it feel to be such a recognised peer of children's health and how do you find the time to balance each of these positions?

As I say, it's a great privilege and a great honour to be in this position. How do I find the time? Well I guess I find the time!

I have three main roles: first of all, I have a clinical role because I'm a clinician. Secondly, I have an academic role and I lead a big research group of about 22 people in a huge

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research programme at Imperial College London. And my third role accounts for all of my wider professional activities as the RCPCH president.

It is a lot of work but nobody comes into this kind of job without recognising that. Both my trust (Chelsea and Westminster NHS Foundation Trust) and my university (Imperial College London) have been extremely supportive. I also have an extremely supportive husband and my kids are both grown up so my time is my own. I don't get much spare time – there is no denying that there's a lot to do – but that is by no means a complaint, because it's all extremely enjoyable work.

Children's health is often an area of ethical dispute within science. How does the RCPCH work within these ethical boundaries during its research?

Ethical conduct in research is absolutely paramount – we want children to benefit from research but we want research to be conducted to the highest possible standards. RCPCH has been at the forefront of really developing a lot of the ethical guidance available, and we have produced a lot of publications for children's researchers and ethics committees who are considering children's health research. This has allowed us to really make sure that the voices of children and young people are heard. We have also done this via our children's research charter.

RCPCH is renowned for its collaborative work worldwide, with programmes in Africa, Asia and the Middle East. Why are these global collaborations and programmes so important to you?

These programmes are largely what our international members request of us. We run examinations overseas, where countries approach us to deliver the RCPCH membership examination for paediatric trainees. We also support the training of child health staff in different countries so, for example, we provide training in the emergency treatment of children and newborn babies to paediatric staff overseas. Not only that, but we also run all other sorts of training programmes. It is mainly education-based training but we also ask to support paediatricians who wish to establish their own specialty organisations, so we are moving into the development of research programmes abroad.

Brexit is really giving us concerns primarily

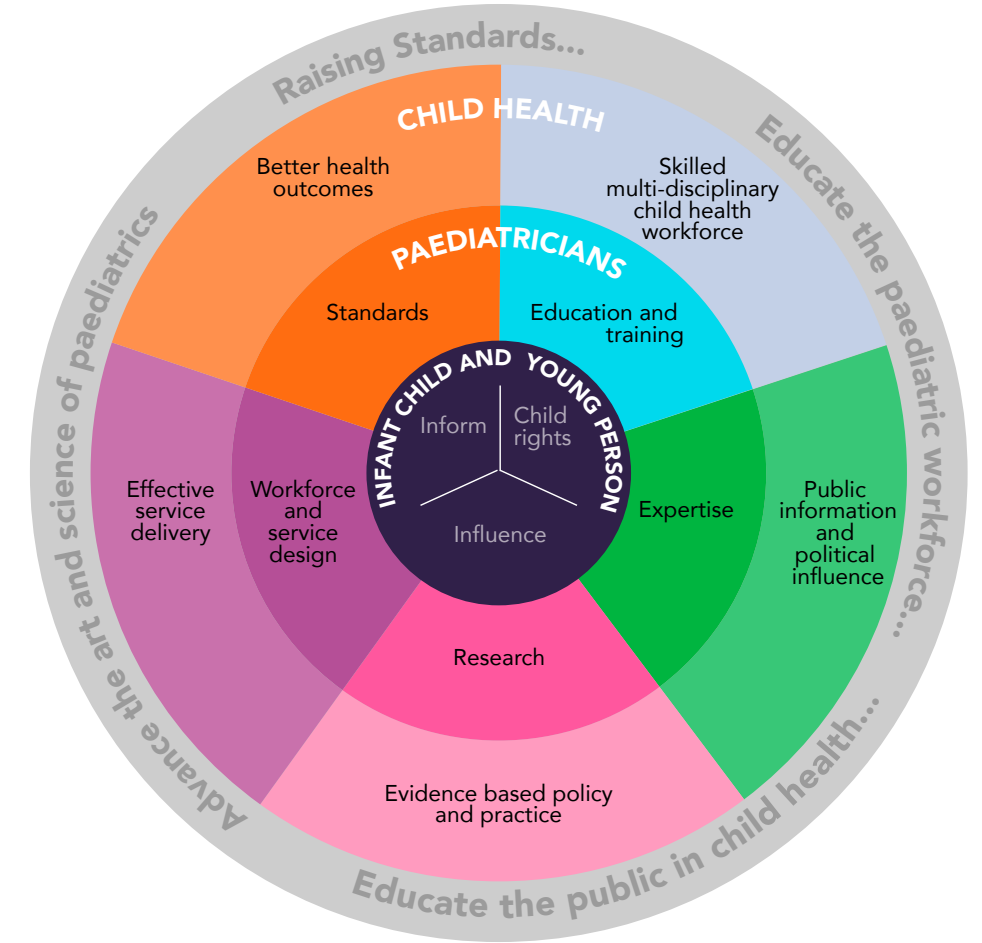


Figure 1: RCPCH's priorities wheel highlights their 2015-2018 three-year strategy

in relation to the UK child health workforce, as there are a substantial number of doctors and nurses in the NHS who are non-UK based. We are really worried about some of the language that is being used about UK doctors and we're concerned that the UK won't be seen as welcoming to doctors who have trained overseas. One in ten doctors are EU nationals and 5% of the total NHS England workforce are from the EU, so the NHS depends on doctors from overseas.

How do you see the landscape of children's health changing over the next ten years?

That's a great question – thank you for asking me that. What I hope to see is a much greater recognition that if we don't get child health right, then we're not going to get adult health right. If we want people to live long and healthy lives, and to be healthy in old age, then we really have to start thinking about this from the moment of conception. We know that so many of the long-term problems – the problems that start to afflict us in old age – actually have their origins in uterine life. So, for example, a mother who smokes, or a baby who is exposed *in utero* to atmospheric pollutants (air pollution), will be at a much greater risk of developing respiratory disease in adult life.

• If you have a particular interest in child health and would like more information on how to become a member of the RCPCH or about any of the campaigns Professor Modi mentioned, please visit their website at www.rcpch.ac.uk.



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