

# Participatory paediatrics

Professor Monica Lakhnpaul discusses how her passion for improving child healthcare has been the driving force behind her exemplary career as a consultant paediatrician and researcher



**You have had a long and varied career working in paediatrics. How did your interest in this field first develop, and how has your focus evolved over time?**

Over the course of my medical training, I knew that I wanted to focus on children and families. However, I soon became aware that the evidence base for paediatrics was very poor and I wanted to make a contribution towards improving child health for the future. I was passionate about changing health practice on the frontline and from a holistic perspective.

Throughout my career, I have always taken hold of opportunities as they arose, pursued my passions and taken risks by not following a traditional path. I started out as a hospital clinical paediatrician and then progressed to a community-based clinical academic. Just after I completed my thesis on guideline development and consensus methods, I became Clinical Director of the National Collaborating Centre of Women's and Children's Health developing guidelines for the National Institute of Clinical Excellence (NICE). This role facilitated my move towards health services research, health

policy and quality improvement. My current integrated roles include being a researcher and consultant paediatrician at the University College London (UCL) Institute of Child Health and Whittington Health; and Programme Director of the UCL Partners Academic Health Science Network (AHSN) Integrated Children and Young People's Programme.

**Your Management and Interventions for Asthma (MIA) study aimed to develop an integrated intervention for South Asian children with asthma. How important was it to engage community facilitators in the study?**

Community facilitators were key to the success of this study; helping to access groups that were previously considered hard to reach. The MIA project engaged community members as partners rather than subjects, involving them in all stages of research. Engaging community members as collaborators is powerful on multiple levels. Developing a research project from the bottom up, and working with community members to identify important issues and factors, has the potential to improve a population's participation and enthusiasm for a project. This can subsequently mobilise the community, while improving the effectiveness of the intervention. Previous research has suggested that to engage successfully with minority ethnic groups, earning the trust of potential study participants is important. Strategies to achieve this include ensuring ongoing involvement with community groups, key community representatives and faith organisations, with emphasis placed on the employment or involvement of community representatives as study personnel.

**Is provision of important information a particularly pressing concern in paediatrics?**

Information is the root to empowerment. If parents have information, they are more

equipped to be equal with professionals when it comes to making important health-related decisions about their child. However, the information they are given needs to be high quality and evidence-based. It should be delivered consistently by all professionals in formats that are useable and accessible. Poorly developed information with little consideration for the users can sometimes cause more confusion – therefore, we need to ensure that information resources are tailored to the needs of parents.

**In 2010, you were awarded one of the first ever NICE Fellowships. How has this helped your career development?**

This opportunity provided me with mentors – senior leaders in the health service – who were available whenever I needed them, and provided me with different perspectives to my clinical training mentors. It also enabled me to advance my own leadership skills; providing me with a robust platform for my current position. I was given an insight into how an organisation like NICE functions, including the processes they use as well as their aims and goals. This has been invaluable, not only to my clinical work, but also to my research and my new role at UCL Partners.

**How do you see your research progressing in the future?**

I want to build and strengthen my interest and expertise working collaboratively with parents, carers and children – ensuring they are at the centre of any future research project. I also want to continue to treat them as research partners so that, as health professionals, we can be sensitive to their needs rather than simply presuming we know what their needs are. Each project I undertake builds on my previous experience, aiming to cross boundaries and develop innovative health delivery models and interventions that others can utilise.

# Families first

In response to cultural barriers that affect the quality of child healthcare in the UK, a number of forward-looking, holistic and community-based projects have been implemented by a group led by **University College London**, UK, that aim to empower individuals and groups

**ASTHMA AFFECTS ONE** in 11 children in the UK, and while there are multiple risk factors associated with the condition, it has been highlighted as a particular problem for children in South Asian communities. These children are more likely to escape diagnosis and suffer poor health outcomes than their White British counterparts – and even when they have been diagnosed they are less likely to receive prescriptions for reliever and preventer medications. While there is no indication that South Asian children have more severe asthma than other children, data demonstrate that they are much more likely to display uncontrolled symptoms and be admitted to hospital with acute asthma.

Unfortunately, there is widespread recognition that care for asthmatic children in minority ethnic groups is suboptimal, with discrepancies in the quality of treatment they receive. In view of this, British Thoracic Society (BTS) guidelines recommend that healthcare professionals should develop awareness and understanding of the complex needs of ethnic minority groups. This involves increased dialogue with patients and their families, moving towards a more integrated approach to asthma diagnosis and care.

## CULTURAL CONCERNS

Monica Lakhanpaul, Professor of Integrated Community Child Health and Consultant Paediatrician at University College London (UCL), is passionate about improving paediatric healthcare for the future – placing children and families at the centre. This attitude has motivated her to focus on improving health-related outcomes for children from all backgrounds through engagement with them, their families and the wider community.

Lakhanpaul is particularly concerned about cultural barriers in healthcare. Many health promotion programmes fail to impact minority ethnic groups due to their lack of cultural sensitivity, and this problem is especially noticeable with asthma: "Most interventions to improve asthma care are directed at majority populations, with few having been developed using a participatory approach," Lakhanpaul explains. "Tailoring interventions to the needs of specific populations is an increasingly popular approach and, if it promotes collaboration between children, families, communities and healthcare professionals, it can be very successful."

It is thought to be difficult to conduct research projects with minority ethnic groups due to perceived cultural and language barriers. As Lakhanpaul points out, many South Asian families – particularly those who cannot speak English – are often excluded from research studies. Effective and practicable interventions are vital if health inequalities are to be reduced, requiring an understanding of how patients and families experience the illness, as well as the factors that both prevent and enhance these interventions. Yet while researchers and health professionals should consider the impact of cultural and community beliefs, it is also important that they take into account the common experiences of different ethnic groups.

## MANAGEMENT AND INTERVENTIONS FOR ASTHMA

In response to cultural inequalities in asthma diagnosis and care, Lakhanpaul set up the Management and Interventions for Asthma (MIA) study. The major goal of the project – which was funded by the National Institute for Health Research (NIHR) – was to develop a collaborative, participatory healthcare intervention programme for South





Asian children with asthma. The study's researchers wanted to improve services for minority ethnic communities by discovering and understanding how culture-specific beliefs, languages and values may impact behaviours.

The MIA project began by identifying the barriers and facilitators of asthma management in South Asian children. This initial step, funded by Asthma UK, paved the way for the NIHR-funded phases of the project, which included focus groups and interviews with community members, healthcare professionals and, crucially, families and children from both South Asian and White British families. Interviewing participants from both communities provided a point of reference for identifying both common and culture-specific barriers to asthma healthcare and, consequently, highlighted which interventions should be tailored. These phases then led to the design of an intervention framework aimed at enhancing asthma management in South Asian children and, in response to a priority area flagged up by families and children, a prototype for an intervention aimed at improving asthma diagnosis.

Importantly, the MIA project has shown the successful collaboration between researchers, health professionals and families, as well as demonstrating the necessity of creative, diverse engagement with so-called 'hard-to-reach' communities. The development of a holistic approach to asthma management has successfully placed the needs of the patients and their families at the centre of the model.

#### ASK SNIFF

Lakhanpaul is currently leading another major programme termed ASK SNIFF – Acutely Sick Kids Safety Netting Interventions For Families – a WellChild-funded initiative. Working closely with families and health professionals, she is co-developing an information resource that helps parents make an informed decision about when to seek medical help for their child. At present, there is no standardised information resource concerning acute childhood illness to which families can refer.

Focusing on the five most prevalent presenting symptoms of acute childhood illness – breathing difficulty, fever, diarrhoea, vomiting and rashes – parents and healthcare professionals are working together to compile important information on

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these symptoms for parents to access: "The final resource that will be developed will help to empower parents and carers to manage their child at home with more confidence, and recognise when they need to seek help," Lakhanpaul explains. "The use of videos will also help parents to better understand some of the words used by healthcare professionals – for instance, the term 'breathing difficulty' may mean one thing to a health professional and another thing to a parent."

#### PARTICIPATORY FEMALE VOLUNTEERING

Lakhanpaul's next NIHR research project is based on a model that is being successfully used in parts of South Asia, based around the active participation of female volunteers to drive real change in the health of young people. The framework is being tested in a project that aims to tackle obesity and undernutrition in the UK's population of Bangladeshi children. The project will draw on the learnings from MIA, particularly in the preparatory phase, which is already underway. It involves investigating parents' and carers' perspectives on healthy weight and feeding practices in their children, as well as establishing what they know about feeding practices. After assessing the feasibility of this model's introduction, female health workers will spend time in local women's groups in east London, helping them advance their knowledge and skills regarding health and nutrition.

The emphasis in this new initiative is on the volunteers themselves. With the UK's National Health Service (NHS) struggling for resources, Lakhanpaul believes it will become increasingly important to implement alternative approaches to healthcare that place individuals and communities first. In these new models, it is people who will serve as the greatest asset.

## A PIONEERING PAEDIATRICIAN

Professor Monica Lakhanpaul's diverse and successful career has been rewarding but also challenging. As a mother of three children, her training as a consultant paediatrician and researcher meant that she had to balance long working hours with home life, finding ways to keep her family happy while delivering clinically and academically. She is satisfied that provisions for women researchers wishing to start a family are improving: "Initiatives such as Athena Swan have brought the need to support women in senior positions to the forefront and has been a driver for further discussions and deliberations on this matter," she reflects. Her hardworking parents, who initially migrated to the UK from India, have been a source of inspiration, as have a strong network of family, friends and mentors: "I have learnt how to turn challenges into opportunities, and that if you have the drive, passion and energy you can usually find someone to advise and help you," she concludes.

## INTELLIGENCE

REACHING OUT: USING COLLABORATIVE PARTICIPATORY METHODS TO OVERCOME BARRIERS AND DEVELOP CHILD-CENTRED, MULTIFACETED INTERVENTIONS

### OBJECTIVES

To work collaboratively with children, parents/carers and healthcare professionals to develop and test multifaceted tailored interventions to improve outcomes for children.

### KEY COLLABORATORS

**Professor Anthony Costello; Professor Russell Viner; Dr Charlotte Hamlyn Williams; Professor Atul Singhal; Dr Logan Manikam**, University College London (UCL), Children and Young People Team, UCL Partners, Tower Hamlets NHS Trust, London • **Dr Deborah Bird; Dr Noelle Robertson; Narynder Johal; Dr Damian Roland**, University of Leicester • **Professor Lorraine Culley; Dr Nicky Hudson; Melanie McFeeters; Professor Mark Johnson**, De Montford University, Leicester • **Dr Sarah Neill**, University of Northampton • **Sue Palmer Hill; Lesley-Anne Hamilton**, Northampton NHS Trust • **Dr Matthew Thompson; Dr Caroline Jones**, University of Oxford • All parents, carers, children and community facilitators

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Whittington Health **NHS**

