

# NORTH WEST LONDON PAEDIATRIC & CHILD HEALTH RESEARCH SURVEY

## Background:



### Who?

- parents and caregivers (e.g. grandparents) of children aged 12 or under who live, or whose child receives care in North West London

### What?

Answering 10 questions relating to child health and paediatric research including:

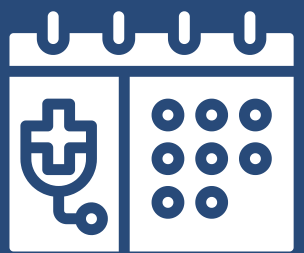
- prioritising possible research areas
- providing views on possible research methods and their own child/children being invited to take part in research



### Why?

- to understand the views of parents and family caregivers in the North West London community on child health and paediatric research
- to ensure that our research addresses these issues and has relevance and impact for our community.

## The TOP RESEARCH PRIORITIES to explore were:



The **most common illnesses** which cause children to need to go to repeated GP appointments or hospital outpatient appointments over long periods of time

**Rare illnesses** which cause a sudden life-threatening problem or cause children to need many hospital admissions.

## The TOP RESEARCH PRIORITY FOR CHILDHOOD INFECTIONS was:

Better ways to find the cause when we think a child has an infection

If we were developing a new test for children with a suspected infection, what would be most important for you?



An accurate test. Even if it takes 24 hours to get the results, it will almost always be right

## The TOP RESEARCH PRIORITIES FOR EARLY BRAIN INJURY was:

Developing new, better treatments for brain injury, to reduce the possibility of later disability

## RESEARCH PRIORITIES FOR CHILDHOOD WHEEZE

A test which can tell the 'cause of the problem' and a test which can tell us what is 'the best treatment'

If we were developing a new test for young children who had "wheeze" or breathing difficulties, what would be most important to you?



## RESEARCH PRIORITIES FOR SERIOUS ILLNESS:

If your child had been in hospital for a long time with a severe illness, but has now recovered, what would be most important to you?



- 1 Prevent the illness from happening again, even if we don't know why it happened.
- 2 Understand why the illness happened, even if that required the child taking part in research studies

**74.5%** responded that if their child was offered genetic testing to understand if there was a genetic cause to a severe illness, they would want to know as much information as possible including relevant results related to the child's illness as well as any other results which may be significant (e.g. to other family members)

## USING DATA FROM ELECTRONIC HEALTH RECORDS FOR CHILD HEALTH RESEARCH

'Do you think researchers should be allowed to use data from large numbers of children which is collected when children attend a GP or hospital appointment?'

**39.2%** said:

'yes, this data should be made easily available for research to improve the health of children, but people should be able to say if they don't want their data to be used in this way for research'

**29.4%** said: 'yes, this data should be made easily available for research to improve the health of children'

'Do you think researchers should be allowed to use routinely collected Electronic Health Record data in which individual children may be able to be identified?'

**49%** said:

Yes, but people should be specifically asked to agree for their data to be used in this way for each research project

**25.5%** said:

Yes, this data should be made easily available for research to improve the health of children, but people should be able to say if they don't want their data to be used in this way for research

## TAKING PART IN RESEARCH

'If you brought your child to hospital, how would you feel if when you were talking to a healthcare professional whilst you were there and you were asked "Would you like to hear about opportunities for your child to take part in research?"'

**56.9%** said: I would be OK with this, but would want to know more details

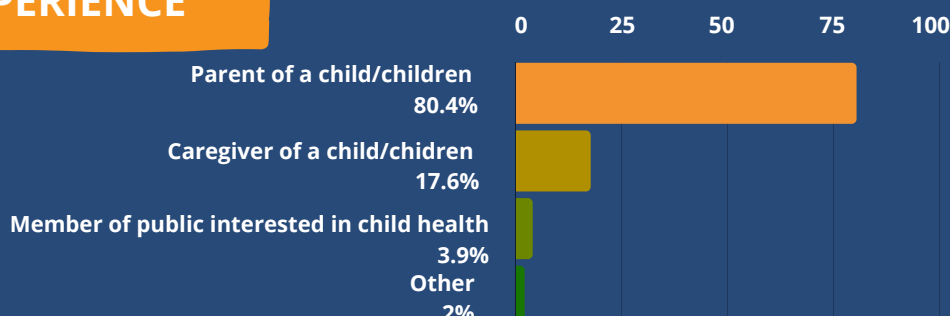
**25.5%** said: I would be happy and keen for my child to participate, because research is important to help other children



## Who took part in the survey?

Responses to the survey represent 74 children from 51 respondents

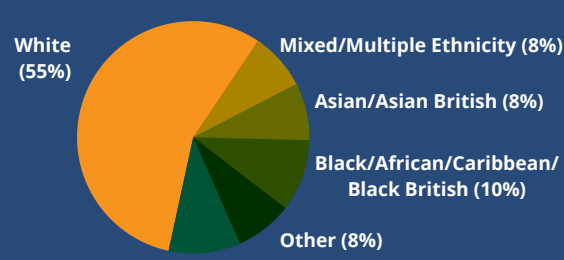
### EXPERIENCE



### CHILDREN'S AGES



### ETHNICITY



### GENDER

