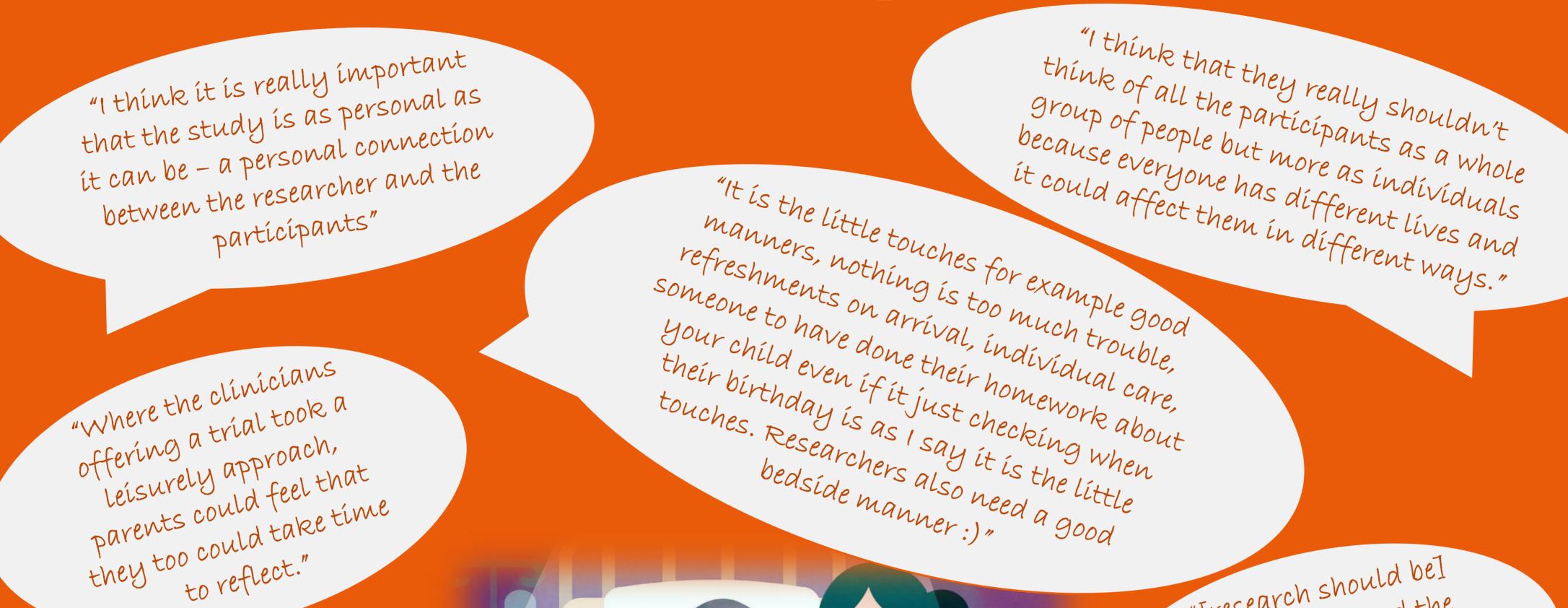


## Researchers' responsibilities



"So often I hear, from young people in particular, that they often participate in research but they never hear back about what happened. "

to reflect."

"Research in children is somehow still seen as remarkable, that only a small number of doctors and professionals will engage with, and that limited numbers of children will want to take place. A child's participation in research is too often seen as "exceptional", and to have overcome significant difficulties with ethics/RSD etc to have achieved that

"It may also be valuable to consider tailoring

"Among older children, researchers have a

great responsibility for ensuring that

both children and parents are equally

informed about all aspects and potential

discomfort of the research, including the

knowledge that the research may not

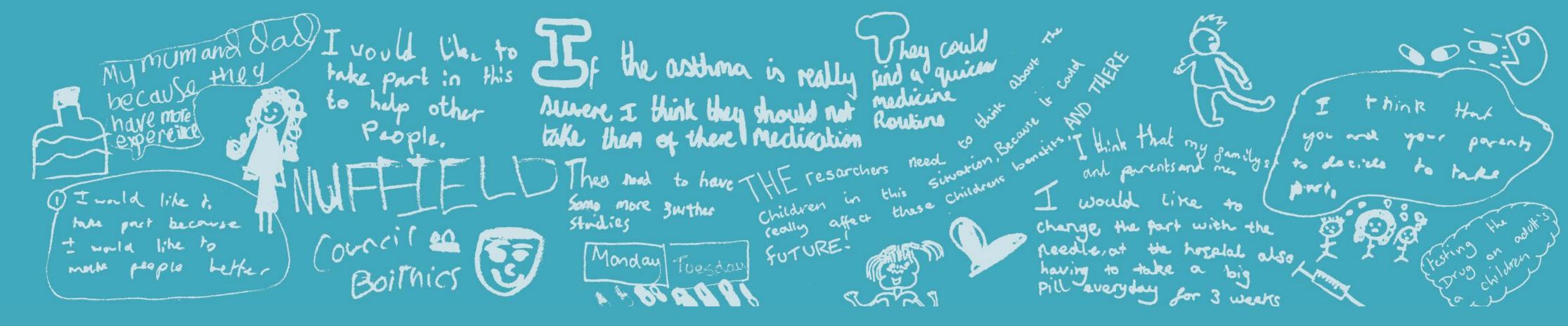
actually benefit themselves necessarily."

"Iresearch should be I designed around the participant, and in consultation with them."



As part of our project on the ethics of involving children in clinical research we spoke to over 500 children, young people, parents, professionals and others in the UK and internationally. This is what they told us about researchers' responsibilities. More at www.nuffieldbioethics.org/children

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## Making shared decisions about

research

"A key question of integrity is

important, particularly in those

cultures where children's rights are not

emphasised and there may be undue

and inappropriate pressure on a child

from parent or community leader to

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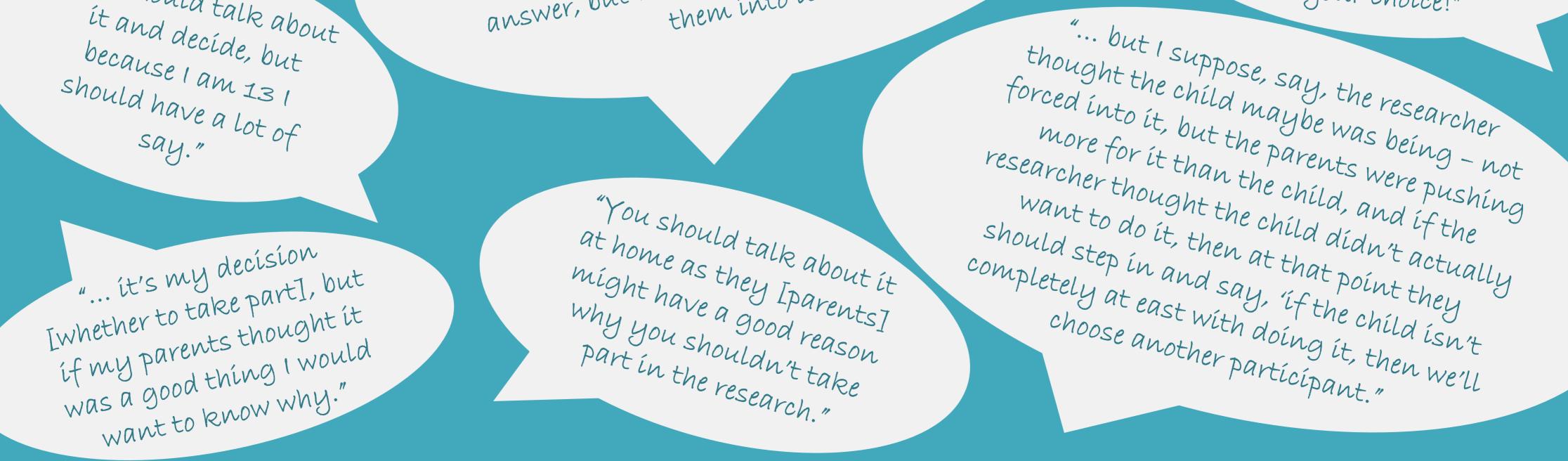
"... a child is already part of society, not simply a trainee adult."

"The decision of whether a Ours as parents is to try to a right to be part of any child participates in clinical decisions regarding his research should ideally be a help them ... " treatment and the risks joint one supported by all they may be exposing Parties, including the child." themselves to." "I would always ensure my child was involved in decision-"The parent has seen the sun earlier so she has... I mean she making processes, recognising knows a lot... she has experienced her level of maturity and a lot and she has seen a lot... development." whatever she tells you, you can also think well about it, that parents Love you unconditionally, she can never "children in Particular have bad intentions for you." need time, they need to know that we value "If a child's, like, four or something - so is quite young – and then the parents want their opinion..." them to do research that maybe they don't want to do, obviously don't take their first "Well, you should let answer, but I don't think you should force your parents maybe give an opinion but it is your choice!"

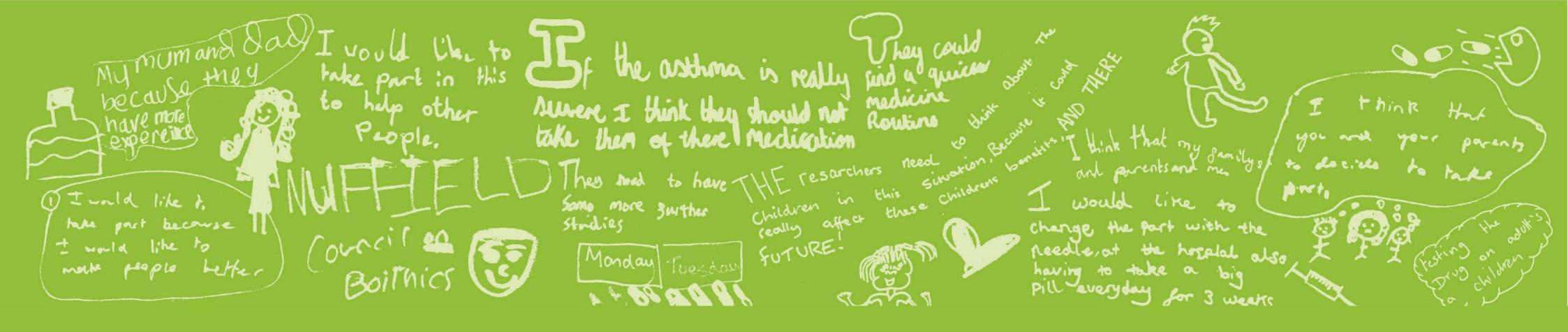
"I thínk ídeally ít's ímportant to involve the whole family. A child is part of a family not really just themselves."

become a participant in a study." "... those from eleven onward, aah, those should "I believe that my child has make their own decision...

"We should talk about it and decide, but



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## Inviting children and young people to take part in research

"Involving parents and children in the design of studies, wherever possible and relevant, could also help to encourage recruitment and retention."

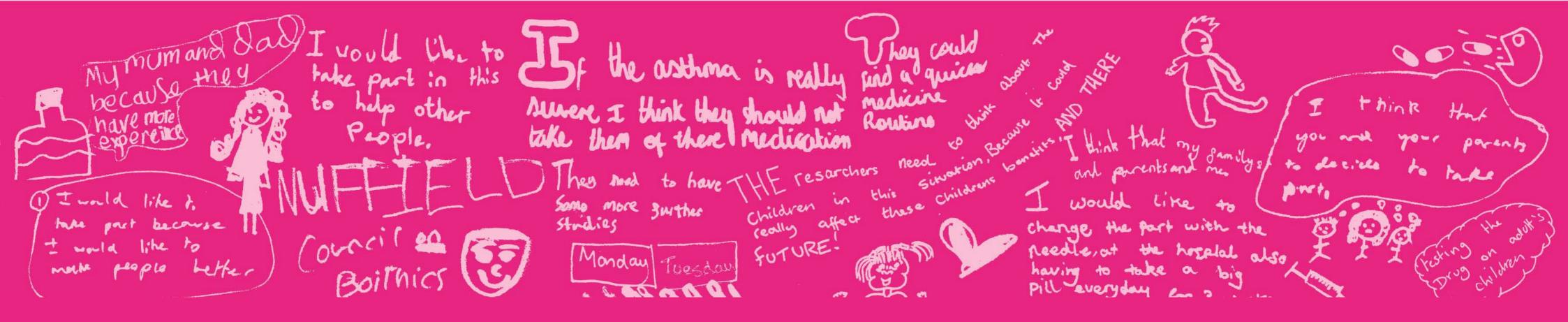
"Children ItakingI part in research should be treated as research participants and not just a means to research findings."

"... researchers should give clear information about dífferences between medical care and research participation."



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## **Deciding what research happens**

"A coordinated approach to funding can help to ensure key problems are addressed, encourage collaborative working, and to avoid duplication."



"... charítíes set targets that they

wish to achieve through their research

funding activity, identifying gaps in

knowledge and capacity and finding

the most appropriate way to address

M



make best use of limited "... research should be prioritised to the need of the country or Population where the resources are to be invested... A second layer of decísion-making is to determine, based on available evidence, where the

"Those involved in decision."

making should include

Pharma and academia

experts, also regulators and

Patients' organisations."

"All stakeholders including researchers, funders, policymakers and communities who are end-users of the interventions should be involved in making these decisions."

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"... a consensus

process should be

developed among the

key stakeholders to

identify priority

areas."



... work is required

to facilitate more

effective partnership

working in order to

maximize impact and

resources."

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