



CHILDREN FIRST

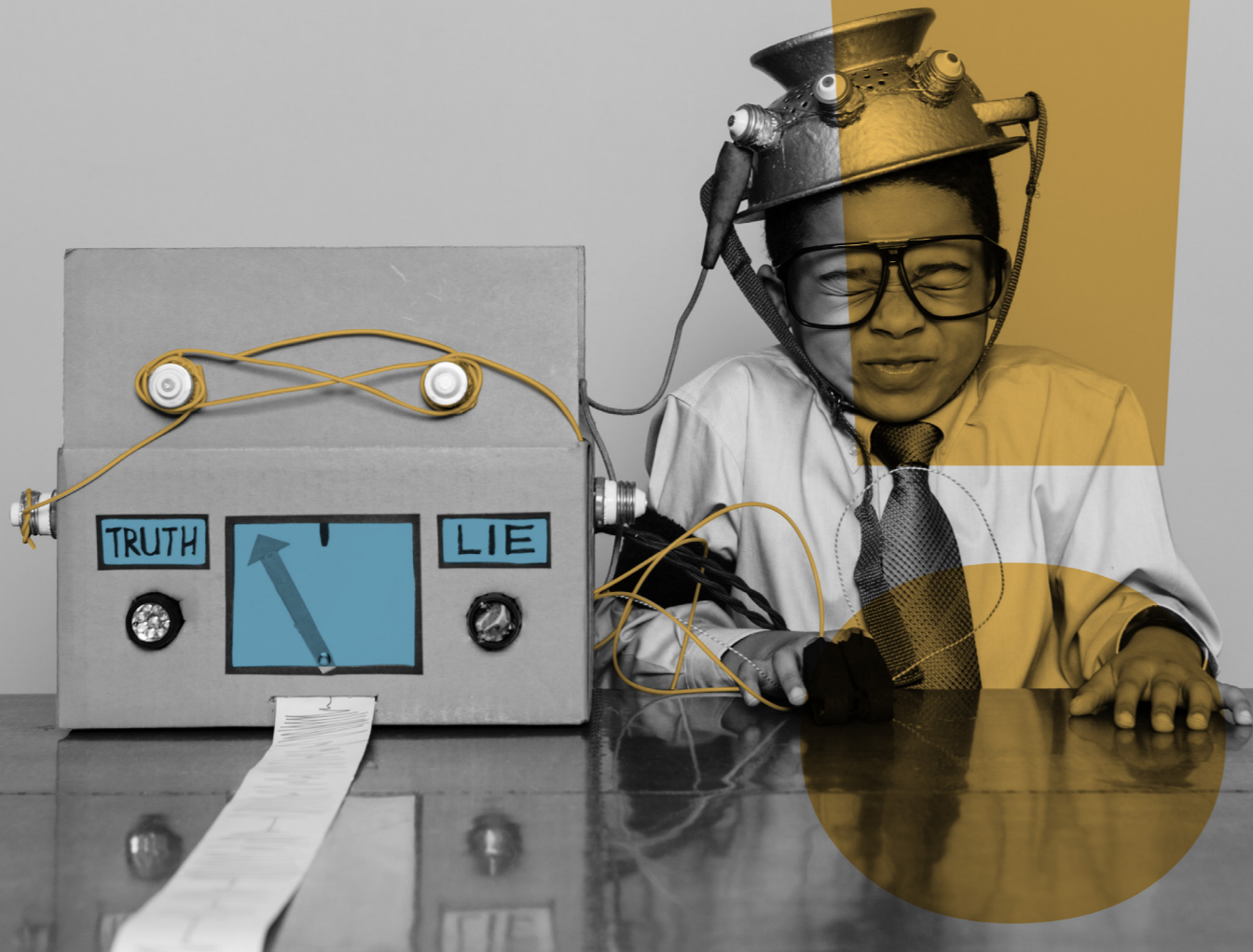
LESSONS FROM
PAEDIATRIC RESEARCH

EphMRA 

EphMRA Excellence in MR Awards

Excellence in fieldwork – Winner 2018

CHILDREN HAVE MORE 'UNFILTERED' RESPONSES



Healthcare market research often focuses on healthcare professionals (HCPs) as they are the primary decision-makers when it comes to prescribing treatments. However, HCPs aren't the ones using those treatments. In an industry moving towards patient-centricity, patient research is on the rise as pharmaceutical companies strive to develop a greater understanding of their products' end users. This can prove very difficult if the end users are children.

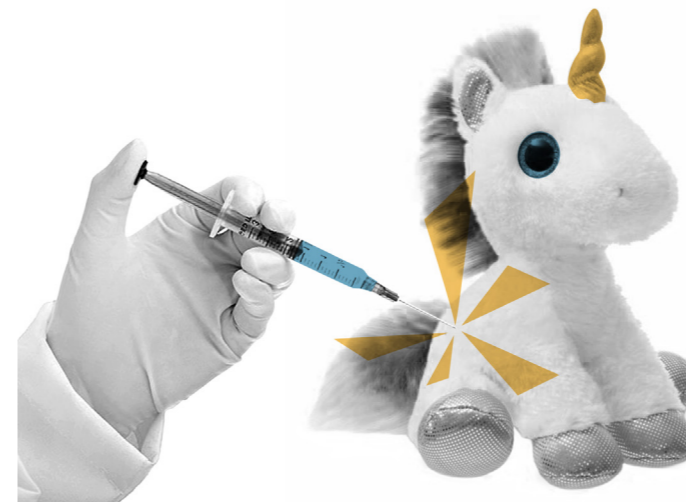
Pharmaceutical market researchers often shy away from including children, since it can be challenging from a regulatory perspective, and particularly for young children, questions can be raised around the value their participation might bring. For this reason, if children are to be the subject of market research, traditional methods like in-home interviews tend to be used and interviews often only involve the parents.

The main reasons that children are excluded from market research studies are because:

- Children do not have adult cognition so may not answer questions reliably.
- Children have few decision-making powers and are not the focus of HCP conversations.
- Tentativeness in going into patients' homes (due to fears of being constrained by compliance rules) is amplified when vulnerable audiences e.g. children, are involved.

However, children can add really great value to research. And, whilst researching children has its regulatory challenges, these are not insurmountable.

- A question-and-answer approach with children won't provide you with detailed insights, however observing children's behaviour can provide you with a rich understanding into their lives, which is natural, unobtrusive and close to reality.
- Children have more 'unfiltered' responses, and are not bound by the desire adults often have to provide a socially acceptable response.



PFIZER'S CHALLENGE

Pfizer wanted to develop their understanding of paediatric patients who are diagnosed with Growth Hormone Deficiency (GHD). GHD is a rare condition which is often identified when children are of noticeably short stature. Treatment of GHD entails daily self-administered injections of growth hormone (GH).

Pfizer recognises the importance of listening to the evolving needs of GHD patients and caregivers, and understanding the impact of their condition on their quality of life. To gather fresh insight into their global strategy and support HCP awareness and education, they decided to revisit their patient group. To deliver more holistic support for families affected by GHD, they needed to take a more rounded approach to their research, and understand all aspects of their patient's daily life.

METHODOLOGY

Pfizer and Ipsos believed that to understand paediatric GHD, in research as in real life, the children had to take centre stage.

In-home ethnographic [observation-based] interviews were conducted with 18 families across the UK, Spain, Czech Republic and Turkey. All families had a child aged between 7 and 17 years old who was being treated with GH for GHD.

A specialist ethnographer spent five to seven hours with each family – observing in the main but asking questions where appropriate. Their brief, in line with Pfizer's holistic goals, was ultimately to 'be' with each family – to spend time in the presence of the children and to learn comprehensively about life with GHD.

It was important for the day's routine to unfold naturally and the entire day to be as close to 'typical' as possible. Whilst the ethnographer had an extensive list of suggested questions and moments/routines to observe, the ethnographer took a 'back seat' throughout, and conversations with families were prompted by what was happening – for instance, observing a parent helping a child with their homework elicited a conversation about the child's school life.

Data in-field was collected using a small hand-held camera, which recorded continuously. Naturally, the ethnographer was only in the presence of the child with a caregiver present. The interview followed the model shown below.



The interview began with a cup of tea, to allow everybody to relax.



This was followed by a trip to the park together. This was a good time to talk alone with the parents while the children played.



A tour of the home was then undertaken. The children were keen to show the ethnographer their bedroom and toys.



The main activity of the day was having dinner together. This was often chaotic and a great way to observe the broader dynamics of the family.

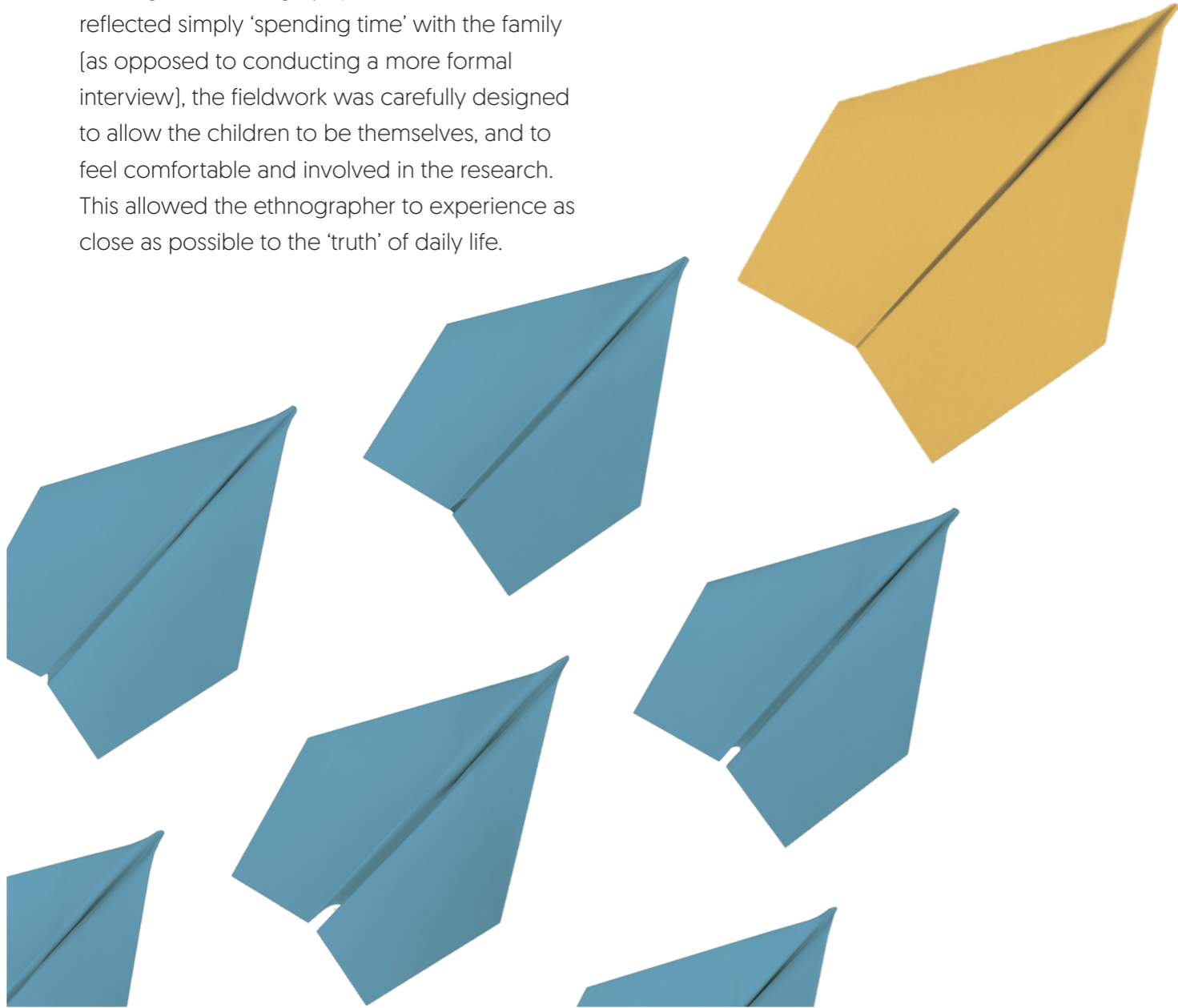


The day ended with the ethnographer observing the injection routine. This was very personal but by this stage the ethnographer was accepted, and the family were happy to share this intimate moment.



SPECIAL TECHNIQUES

Although the ethnography was relaxed and reflected simply 'spending time' with the family [as opposed to conducting a more formal interview], the fieldwork was carefully designed to allow the children to be themselves, and to feel comfortable and involved in the research. This allowed the ethnographer to experience as close as possible to the 'truth' of daily life.



BEING PERSONABLE

Inclusion was promoted by showing children that the research wasn't an adults-only conversation that was going on above their head and that they were as much a part of it as they wanted to or felt comfortable with. The ethnographer sat on the floor with them, and made sure to talk to them about things they would find interesting.

ACCLIMATISATION.

We allowed five to seven hours of unhurried exploration of daily life to allow the family to 'be themselves' around the researcher. The first hour was aimed only to build a relationship with the family. This created the right environment to encourage the family to 'open up' to the ethnographer.

AUTONOMY

Handing over control of the interview to the family gave the parents the freedom and space to ask children questions themselves. This created a safe 'bridge' between the ethnographer and the child. It also meant that parents could craft and deliver the 'right' questions, e.g. naming teachers and friends in scenarios, referring to specific previous episodes /experiences.

DEMYSTIFYING THE CAMERA

The children were allowed to hold the camera and to see themselves in the viewfinder. This put them at ease with being filmed. The ethnographer also used the camera as a tool to engage children by asking them to "show me" toys, pets, etc. - all of which seemed to come more naturally when actually showing something to the camera.

PROVIDING A PLATFORM

The research allowed the older children a platform to express their opinions. Young people are often thought by parental figures and society to be unable to hold a conversation with an adult, but, many can articulate their experience [to the surprise of their parents!] if only given a platform to do so.

SPENDING TIME

WITHOUT THE CHILDREN

Children were not around for all of the research. At points, the researcher spent time alone with caregivers in order to explore topics relating to care challenges – out of earshot of children. Spending time with caregivers in different combinations [mum; dad; mum and dad] enabled a rounded view of the family to be built and to gather everyone's perspectives independently as well as collectively.

INSIGHT AND CONCLUSIONS

Observing families with children present allowed us to build a holistic picture of the various challenges that families face in relation to GHD and revealed unmet needs. These insights should enable Pfizer to develop appropriate patient supporting programs to ultimately improve treatment outcomes.

Eduard – age 9

Eduard has a budding passion for martial arts. At one point he whispered to his mum, Eva, asking her to send his little brother out of the room. After his brother left, Eduard described to the ethnographer how he was called 'baby' at school and how he fantasised about beating up his school bullies. A separate conversation with Eva revealed that the family did not tell other people about his GHD. The combination of these insights helped us begin to understand the extent to which GHD was a closed topic. Eduard did not even want to discuss the impact of his condition in front of his own brother. This reveals an unmet emotional support need around reducing feelings of isolation for children with the condition.

Lucie – age 7

Lucie was talking about adherence with her parents in the context of a youth group trip Lucie was attending in a few weeks. Her mum asked Lucie how she'd feel if the youth leader were to administer the injection. Lucie replied that she would only feel comfortable having someone she knows and loves doing it. Later in the research we observed that Lucie's injection anxiety was such that her mother had to cuddle her whilst her father administered the injection. These observed moments illustrate the extent to which children with GHD can be 'tied' to the home, as their injections are a 'keep-it-within-the-family' matter.

Martina – age 10

Observing Martina's injection routine brought to light that although Martina, at 10, was probably old enough to self-inject, being injected by her mother was a nightly ritualised moment involving a kiss on the cheek before the injection itself. Observing Martina with her mother throughout the rest of the time showed that they were so close; in fact, the injection served as a ritualised way for mum to care for Martina, and for Martina to, night after night, place her trust in her mum.



This research enabled Pfizer to gain a deeper understanding of the emotional and psychological impact of the condition. In turn, this meant they could take an alternative approach to programmes such that they were better aligned to meet not only the rational needs, but the unique psychological needs of patients. In addition, it allowed Pfizer to spread understanding through communication platforms, [both internally and externally], to challenge mindsets on what it truly is to 'walk in our youngest patient's' shoes' and support them appropriately throughout their patient journey.

“Pfizer is committed to improving lives of patients with rare diseases such as GHD, and the only way to fully achieve that is to put patient insight first and at the heart of everything that we do. This ethnography project brought us a step closer to that aspiration.”

Dr. Roy Gomez

Medical Director
Endocrine Care, International Developed Markets



Ethnography led us to a closer and more authentic understanding of real-life with GHD, something an alternative research method would not have been able to do. The behaviours and interactions between children and parents observed in the field brought a richness and tenderness into our findings and subsequently Pfizer's knowledge in this therapy area. Observing families and children allowed Pfizer to see where challenges and unmet needs exist, and ultimately helped to inform them as to how they could improve the lives of GHD sufferers and their families.



**HEAD OF ETHNOGRAPHY,
HEALTHCARE, NORTH AMERICA**

Victoria has over ten years' experience as an ethnographer and is the head of Healthcare Ethnography at Ipsos NA.

Victoria Guyatt
Victoria.guyatt@ipsos.com



RESEARCH MANAGER

Ellie is a Research Manager in the UK Ethnography team, with experience in ethnography, behavioural science and patient research.

Eleanor Tait
Eleanor.Tait@ipsos.com



ABOUT IPSOS MORI

Ipsos MORI, part of the Ipsos group, is one of the UK's largest and most innovative research agencies, working for a wide range of global businesses, the FTSE100 and many government departments and public bodies.

We are passionately curious about people, markets, brands and society. We deliver information and analysis that makes our complex world easier and faster to navigate and inspires our clients to make smarter decisions.