

## 2. Excellence in Fieldwork - Sponsored by SERMO



Successfully engaging children in filmed ethnographic interviews enabled us to achieve richer insight into paediatric growth hormone deficiency (GHD).  
Florence Chopin, Pfizer and Victoria Guyatt, Ipsos Healthcare

This award focused on an international case study from a company involved in healthcare fieldwork and data collection and will demonstrate best practice.



Read more about this winning paper on page 47



Akash Degan from SERMO the Award sponsor with Victoria Guyatt and Karsten Trautmann



## EphMRA Award – Excellence in Fieldwork

Undertaking research with children: lessons from a global paediatric growth hormone deficiency project



**Speakers:** Victoria Guyatt, Ipsos Healthcare and Florence Chopin, Pfizer

**Chair:** Bernadette Rogers, EphMRA

Victoria Guyatt and Florence Chopin presented their EphMRA Award-winning paper demonstrating excellence in fieldwork. They broke the cardinal rule of “never working with children and animals” to demonstrate that including children in their market research revealed deep emotional and practical insights that helped Pfizer to truly put the patient at the heart of their activities.

Victoria introduced us to the study, which was conducted in the area of Growth Hormone Deficiency (GHD). This is a rare condition requiring daily injections of growth hormone for young children. Victoria noted that, typically, we talk to HCPs as the prescribing decision-maker, and increasingly talk to patients as the end users. However, she observed, children are sometimes excluded from MR due to concerns about compliance constraints and the quality of responses that can be expected from children. Instead, their parents may be consulted as the proxy decision-maker for the child.

For this particular project, an ethnographic approach was selected. Observing behaviours in their natural setting can provide a rich understanding not only of the behaviours, but also their relationships and unmet needs, both practical and emotional. This is particularly vital when the condition in question may be emotionally difficult for the family involved.

Florence highlighted Pfizer’s key objectives for the work, which were to act upon the company ethos of “patient first” - putting the patient at the centre of their activities. The team wanted to base their insight not only on conversations with HCPs or parents but on a full understanding of the real life and experiences of children with GHD, in order to identify a point of differentiation for their GH devices and improve the patient experience.

### Pfizer’s objectives

#### EVERYDAY LIFE

To understand the daily lives of GHD patients and families and the emotional and practical challenges they face in their management of GHD

#### DIFFERENTIATE

To understand the differences in patient experience of devices, support services and educational support

#### ENGAGE

To identify how Pfizer can put the patient at the centre of decision making to improve the patient experience

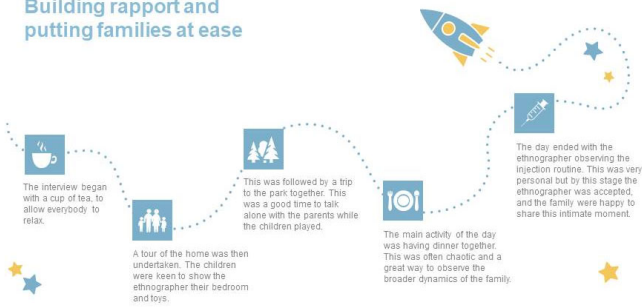


Victoria outlined the project methodology, which involved 18 families from the Czech Republic, Spain, Turkey and the UK with children aged between 7 and 17.

The ethnographic approach involved an immersive day in the life of the families, with 5-7 hours spent observing, first hand, the daily reality of living with GHD. Using just one ethnographer to act as interviewer, observer and cameraperson facilitated rapport and an empathetic relationship to be built with the families. They were able to integrate into family life, going to the park and eating with the family, to become part of an intimate setting without sacrificing the empathetic environment for the child. Victoria explained that it was a “patient-led” interview, with the ethnographer allowing the topics of interest to fall out of conversation and activity, rather than asking a formal set of questions. Ethnographers, she reminded us, learn as much from family dynamics and what is NOT said and done than they do from asking questions. She noted that some of the family dynamics and stresses of living with GHD were not being openly discussed.



## Building rapport and putting families at ease



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The immersive day began with a cup of tea to get to know each other and encourage the family to relax. Then the children led a tour of the home, including rich description of favourite toys and pets, before a trip to the local park where the children could play while the ethnographer talked to the parent and developed an understanding of the community (school, local doctor etc). The evening meal was a particularly important part of the day. The family were usually all present, and the ethnographer could observe the dynamics of the parents and children together. Typically, the children received their injection last thing in the evening, and the research revealed a highly ritualised injection routine. This was a very emotional and personal time, but by this point the ethnographer's presence was accepted.

Victoria outlined several approaches and techniques that were essential to the success of the observation period, including a personable ethnographer who could quickly build rapport with the child, sitting on the floor with them and involving them directly in the discussion. The period of acclimatisation was essential to enable the family to feel comfortable discussing GHD. Giving the family autonomy helped them to feel comfortable with the process and encouraged them to ask some of the questions that the ethnographer had intended to ask. Demystifying the camera was another important element to help the children feel comfortable, and the children responded well, even volunteering more shared experiences because the camera was present. Similarly, teenagers often surprised their parents by expressing their thoughts and opinions more openly than expected. The time without the children was also important to be able to discuss any elements that parents might not want to discuss with their child.

The ethnographic exercise generated over 100 hours of video footage, so a workshop was held with Pfizer to look at the emerging insights, with a team of medical anthropologists on hand who noticed some key behaviours that would be relevant to later business decisions. The video clips were used to create high-quality, emotionally engaging outputs for the project.

Victoria highlighted some example observations from the work that led to interesting insight, such as the "taboo" around discussing GHD with the school, and the feeling of isolation that many children absorbed from their parents' decision not to inform the school about the condition. It also highlighted practical issues, such as identifying a suitable adult to administer the injection when the child was away from home (for example on a school camp). There were also very positive insights, such as the bond of trust between the child and parent that allows the parent to inject their young child night after night.

We were then shown a short videoclip (with the participants' permission) which highlighted in a very powerful way the isolation and emotion that the children and their families experience due to GHD.

Florence emphasised the impact that the video footage had in communicating insight to the internal stakeholders, demonstrating the value of the research and capturing the attention of the marketing team. The impact for Pfizer was clear – Florence explained that they obtained a greater depth of understanding about the emotional and psychological impact of GHD and were able to identify new ways in which Pfizer could support the families affected by GHD, such as patient support programmes to educate the school. Florence believes passionately that these insights would not have been obtained by traditional market research interviews with physicians and parents.

The outcome of the project was that the Pfizer team could challenge their previous mindset and draft a communication platform that was based upon a very deep understanding of the day-to-day reality of GHD for the children and their families, enabling them to identify ways to truly improve the patient experience and ensuring that they were always putting the patient first.

**Impact for Pfizer**

- Clearer picture of emotional and psychological impact of the condition
- Patient support programmes that met family's functional and psychological and needs
- Informed communication platforms & challenged mindsets truly 'walking in our young patient's shoes'

*"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

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