

In-depth: Case studies

In this section you'll find eight case studies with a cross section of our members.

Some names have been changed for anonymity purposes.

Case study: Ayesha, the student midwife

“it's been great to show people that everyone can get involved in science”

Name: Ayesha

Age: 30

Location: South-West London

Occupation: Student Midwife

Highest science qualification: well, my GCSE double science technically, but I am about to qualify in September with a science Postgraduate Diploma (Midwifery)

Highest qualification: Master of Arts in Legal and Political Theory

Involvement with the parenting world: I have two children, both breastfed, and am about to qualify as a midwife so will remain involved in birth, breastfeeding and healthcare

My PSG journey: I have to admit that I was much more involved when it looked like we might choose a project on co-sleeping and breastfeeding in hospitals. Then the project changed to slings, which to be honest I have little interest in any more. I joined a couple more PSG groups but essentially that was an error as it just led to 'group fatigue' and I had so much else going on in my life at the time, I must admit I didn't really engage much more.

What did you get involved with when you were more engaged at the start? At the start I was arguing for my chosen study, providing some research papers, talking about the practicalities of postnatal wards. For a bit after, I was tagged if there were any questions about healthcare/maternity and I was happy to answer - for example one question was about taking babies' temperatures for the sling study and I told people how we do it on the labour ward and what is used.

Were there elements you still engaged with when life got busy? Yes, I still read a couple of Q&As. I liked the ones where a transcript had been written up as I could read in my own time. I took part in the live Q&A with a dentist about breastfeeding and teeth and found it really informative.

PSG's effect: I think it's been great to show people that everyone can get involved in science, and that we can choose topics which interest us and find out answers ourselves.

Case study: Sarah, the non-UK-based group founder of Mealtime Hostage

“PSG was instrumental in helping to create an impressive database of paediatric eating problems”

Name: Sarah

Age: 48

Location: Canada

Occupation: Parent

Highest qualification: BA [in] Communications [but] I try to take as many research related courses as I am able to [including] statistics.

Involvement with the world of parenting: I ran a licensed home daycare for 10 years and had no support to help my son with his phobia of choking on food. Through my own search for answers, I discovered I was not alone in the challenges I was experiencing with feeding my son.

Can you elaborate? When my son was 7 months old, he choked on a piece of pear. I grew up around community pools [and] have always been certified in some form of first aid, so delivering the Heimlich was automatic, although I never dreamed it would be something, I would use to save the life of my own child. He choked on food again when he was around 2 years old and again when he was 4 years old. There was never any explanation beyond eating too quickly and breathing at the wrong time. The experience - traumatic as it may be - was something that I could share with other parents. The event was within the range of “normal”.

When my kiddo was 4 years old and wouldn't eat what we (his parents, other adults) or his sister or friends were eating, he was “picky”, “a fussy eater”. The experts in the Parenting magazines said it was my fault - I wasn't offering enough variety, I was molly coddling, a “bad” parent. The solution was “be firm” “show him who the boss is”.

Our paediatrician told me my 4-year-old son could go up to 3 weeks without food and getting him to eat his broccoli was worth the risk. I didn't have it in me to try. His weight was already faltering - he had tumbled from the 25th percentile to the 10th between annual well checks. I was terrified that unless I could find help, I would be planning my son's funeral before his next birthday. I had no one to share this experience with. Being unable to feed your own child is “not normal.”

In 2010, Avoidant Restrictive Food Intake Disorder (ARFID) didn't exist. The Internet offered up 6 hits for “child fear of food”. Three of those were re-blogged. I decided to start a blog and add my personal experience and musings to the other 4 unique points of view available via Google.

My first indication that I wasn't an anomaly was an online group called Picky Eaters Association. It's an online group made up of over a thousand full grown adults who could list the entirety of their diet on a post-it note. They were incredibly helpful in wiping the assumptions off my lenses and translating my son's perspective. When my son was a bit older, he told me that food frightened him - to the point that eating could kill him. Again, "not normal", but now I had a group of individuals with whom I could share this experience and receive the benefit of their insight.

The blog attracted the attention of Dr Katja Rowell. I discovered her wisdom was incredibly relevant for my son, and parents appreciated the sensible and responsive approach that was nurturing a respectful feeding relationship over using force and coercion. This is ultimately what led to the creation of the current Facebook group.

Feeding struggles are incredibly isolating; the sense of feeling connected to a community who understands what you are going through is incredibly powerful.

What do you think is missing and what's needed? When ARFID was being considered for inclusion into the DSM, one of the many discussions included some history. From what I recall, the category of eating disorders prior to May 2013 included anorexia nervosa (AN), bulimia nervosa (BN), and eating disorder not otherwise specified (EDNOS). Because AN and BN had very specific diagnostic criteria, more than half of all diagnoses ended up in the catchall category of EDNOS. The result of the DSM revision expanded the eating disorder diagnostic options, including the recognition of binge eating disorder (BED) and ARFID.

The problem with ARFID is it is incredibly broad in scope and vague in definition. For example, my son's fear of choking is equivalent to a child with reflux or food allergies. It makes it very difficult to come up with a treatment protocol for such a varied range of issues. Also - the criteria for psychosocial impairment is optional. At the risk of tipping over trees in a vacant forest, if the diagnosis doesn't disrupt one's ability to function socially, is there a disorder?

For a first draft, ARFID is a welcome addition to the DSM. I just feel that there is a great potential for harm to proceed with options for treatment before understanding what ARFID is (and isn't). This is what makes me so excited about what PSG has helped to accomplish... we've added a piece of understanding.

Have there been ways in which PSG has impacted you and your world? Personally? Being involved with PSG has given me an opportunity to better understand how research works, how important it is to narrow down the question that ultimately creates the entire purpose of investigation and observation without tainting any of the process with my own ideas and opinions.

What impact has PSG had on the rest of 'parenting world'? PSG was instrumental in helping to create an impressive database of paediatric eating problems. Much of the research on ARFID tends to focus on intervention. Sadly, there is little emphasis on understanding the problem.

Is there anything else you would like to tell us or that you feel is important that we should know? I can't say enough good things about Tamasin - she is wonderfully gifted at encouraging conversation and keeping the group on task. I am so grateful for her experience and expertise.

Case study: Jo, the one from the smaller PSG group

“[PSG has] built my confidence and developed my skills”

Name: Jo

Age: 37

Location: Dumfries and Galloway

Occupation: Support Mental Health Worker

Highest science qualification: Higher Physics (like Scottish A-Levels), MA (SocSci) [in] Sociology (not sure if social sciences count).

Involvement with the world of breastfeeding/healthcare: I've received support and advice from healthcare professionals and breastfeeding supporters.

My PSG journey: I first joined thinking it was about learning how to teach kids science. [I] then joined the Breastfeeding Older Babies group as I was feeding a 2-year-old. I got quite involved in the Q&A's and [the] design stage but kinda lost interest when I couldn't join the sampling in London.

Meantime I'd also joined the Dumfries and Galloway Baby Bumps and Beyond group and again was very involved in the Q&A's and design. We got together in person for some of this which was a good way to meet new folk and strengthen bonds I already had. Once we selected our topic we steadily lost interested members so became a tiny group, meaning a lot of work on few shoulders.

It's been a great project to be involved in. [PSG has] built my confidence and developed my skills in collaboration and in designing and carrying out research.

PSG's effect: I've been utterly blown away by the interest in our flexischooling study. I hope it can affect others. The topics of other PSG studies have come up repeatedly in conversation with other parent friends, so it seems really relevant. It's early days to see if it's had any larger impact though.

Was there much research about flexischooling out there already? As far as we are aware (after some searching) there was no research on Flexischooling whatsoever before we started. Since then there has been a very small-scale research done with around 4 respondents.

What was your experience like of the final meet-up in York? I got a huge amount from the final event. It opened my eyes to the impact of PSG on science in general, and on its effect on the women who have taken part. It also gave me insight into the interest around our study and motivated me more in terms of how to write up our report.

Case study: Vic, the consultant paediatrician looking to bridge the gap

“the exact opposite of an ivory tower – [PSG] values lived experience and asks the questions parents really want answered”

Name: Victoria

Age: 38

Location: Newcastle upon Tyne

Occupation: Consultant Paediatrician

Highest science qualification: Member of the Royal College of Paediatrics and Child Health (MRCPCH)

Involvement with the parenting world: [I am a] consultant paediatrician with special interest in growth and nutrition, [and a] La Leche League professional advisor. [I] work with several third sector organisations in the field of infant health [and] have two children.

What was the driving factor behind you becoming involved in PSG? I have been interested in the clash between what I was taught as a doctor and what I learned from being a parent. PSG feels like a way to bridge that gap.

Can you elaborate? For me there is the key message I hear from colleagues when they or their partners have breastfed 'I didn't know what I didn't know.' I admin a group of 2000 breastfeeding doctor mothers and last year asked our group for their thoughts on how well or otherwise their medical training prepared them for breastfeeding their own children. The recurring theme was 'everything I know about breastfeeding I learned from doing it myself' and that medical education was focused on the idea that breastfeeding is a good thing rather than how to do it.

My PSG journey: I've found it useful to see other perspectives on child health and research. It's fascinating to watch a project take shape and be formed by the passions and interests of the group taking part.

The PSG effect: PSG puts the control and agency into the hands of the people who will be living the research outcomes. It is the exact opposite of an ivory tower - it values lived experience and asks the questions parents really want answered.

Case study: Georgie, the home educator

“[!] was amazed that I could take part in researching something that was so important to me”

Name: Georgie

Age: 33

Location: Oxfordshire

Occupation: Home Ed parent

Highest science qualification: GCSE science, unless you count psychology A-Level.

Highest qualification: BA [in] design

Involvement with the world of breastfeeding and parenting: I'm a parent who is involved in many breastfeeding support groups and birth support groups on Facebook, I do go to a playgroup but there's no discussions around [parenting] info really. I like to refer to good and accurate resources as well as give opinion, if it's asked for, and I think it's useful having knowledgeable resources to back [things] up.

PSG involvement gave me a push to try learning more [and I've] just completed the Association of Breastfeeding Mothers (ABM) Mother Supporter [training] which is basically their first level of support in the realm of normal breastfeeding. Complex things get referred to breastfeeding counsellors who have 2 years training, twins or medical things for example, [are] not my remit. I got used to being able to say 'you know what, you don't need to wean your child to eating 3 meals a day by the time they're one', it's meant to be mostly milk to one and [then] food after.

Have you used any of your PSG experiences in your ABM role? I've discussed the study that PSG were investing time and money in and people were relieved because they knew that there would be something to refer to support their actions. The preliminary results were even better for this!

Sometimes we dismiss 'it feels right' especially in a world where women and mothers aren't respected and a lot of knowledge has been lost, it's almost like this study is a weird culture way of confirming what we used to know!

My PSG journey: I came across PSG in the Breastfeeding Older Babies and Beyond group and was amazed that I could take part in researching something that was so important to me. I was astonished that it wasn't just taking part but [that] the people managing the project were just normal parents like me, not scientists. I didn't know that so much research is people based, it made numbers I see in studies more real. I learned so much about how a study is put together and again realised how usually it's just a few people working on something.

The PSG effect: Being part of PSG [has] meant that I could support people questioning things that are important to me and to many people I talk to. Future effects: with the BF HCE study, knowing that sharing valuable info is only as good as the method of sharing it.

I am so pleased to be able to discuss projects, and I often refer to the post-12-month-old study and really hope it's published this year because it is so relevant to many people that need a boost for their choices. I realised so often that people were saying there must be more to it [breastfeeding] than just comfort, it feels like it and it makes sense, but we need something reliable to refer to so people don't just think we're making it up for our own benefit.

Is there anything else you would like to tell us or that you feel is important that we should know? It has made a massive confidence difference being able to say to people that I 'do' science and is such a good thing for my children to see!

I was so disappointed that I couldn't take part in any analysis because I was overseas, I feel that was a very important part of understanding how data comes together and is presented.

Whilst studies often make little sense, I can appreciate how much work goes into them [since PSG]. I notice a lot more when there are queries too whereas before I'd have just taken one person's article about the study to be absolute. [I've] learnt about interpretation when before I would have just scrolled past anything about study workings.

Case study: Amber, the UK-based group founder of Big Birthas

“I've rarely come into contact with anyone willing to rock the boat on this topic before”

Name: Amber Marshall

Age: 42

Location: Birmingham

Occupation: Formerly Addiction Counsellor, currently mum and admin.

Highest science qualification: A-Levels in Economics and Maths if you consider those sciences, if not, GCSE.

Highest qualification (if different from above): Law degree

Involvement with the world of parenting: I started the Big Birthas website when I discovered a lack of info available for UK bigger mums. Nothing formal in this field.

Could you elaborate? I started the Big Birthas website just after my first pregnancy. I'd been trying to find out as much as I could about high BMI pregnancies in the UK - guidance, research, policy etc. and realised that there was no central point for resources, no community, no support network in the UK at all. I decided to set up a website to collect together any research I found. I tried to set up a forum for women to support each other, but there was never much interaction, so I shut that part of the website down. Over the next few years I did get many messages of support and thanks from the women who'd found the site useful, but aside from that, it was very isolated. Then PSG came along! It was lovely to find other women who wanted to get involved.

My PSG Journey: I joined PSG after being approached by Sophia to set up a specific Big Birthas PSG group. It was really exciting to think that we could get a little group together, and maybe do some research on the issues that mattered to us. What I didn't expect was the number of people who joined our little clan, and joined in with gusto!

What PSG has meant to you? PSG has been really lovely; a chance to connect with other similar minded people who see the statistics and hear the scaremongering and think 'hang on a minute, what's the truth behind this?' I've rarely come into contact with anyone willing to rock the boat on this topic before and PSG made this happen both online and in real life in a way I never previously believed possible!

The PSG effect: It was really clear from the emails I received [through my website], and then from the stories of other PSG group participants, how many women had been really traumatised by the way they'd been treated by health care professionals, and how frustrated they were when they could see information they were given misrepresented the truth or guidance was not based on any more than professional guesswork. They were also very frustrated at having to be 'difficult' to get the same options as everyone else, and sometimes

not even then, or when treatment options are withheld because of things like 'you might have high blood pressure', but when you don't, that option is still not unlocked.

I'm hopeful that results from many of the [PSG] studies will have a real impact on their [research] areas. The Q&As have been brilliant in their ability to both be informed by and also inform researchers.

The conference in York was an amazing example of how a child & family friendly conferences can function and engage, bringing together people, particularly mothers with young children who would most likely normally have to pass up such an opportunity in preference to disrupting their families. The York conference proved this to be unnecessary!

I've always enjoyed science, and not been scared of it, but for some people, I believe it has been really powerful at helping them realise that science is and can be accessible, and that we can all be scientists!

Is there anything else you would like to tell us? My only regret is that I didn't push harder to study what I wanted to. Other people in greater numbers pushed for other angles on the topic and methodologies I was unfamiliar with, and as they seemed to be the 'sciencey' people, we deferred to them. Trouble was, when it came to carrying out and analysing research those people were nowhere to be seen, and I think the methods they'd wanted put less sciencey people off as we felt out of our depth and so it floundered a bit. In hindsight, I think we should have kept it simpler, and given that I knew I'd be in it for the long haul, been more persuasive about my preference!

Case study: Jennifer, the stay at home mum with selective eaters

“I’m a lot less worried...now having been part of some of the discussions that we had [through PSG]”

Name: Jennifer

Age: 45

Location: Dublin Ireland

Occupation: Currently a stay at home mum studying early care and education.

Highest science qualification: I suppose the last time I did any formal science was for my leaving certificate as it is here. [The] leaving certificate is the last exam you take typically around 16-17 before going to college or work.

Highest qualification: BA (Ord.) in Law. I worked in law for a little bit before my first pregnancy and didn’t enjoy it much so decided to be a stay at home mum and it made sense financially for us.

Involvement with the world of parenting: I currently help admin a pro-science parents’ Facebook page [and] I have two boys aged 10 and almost 6.

I got involved with the pro-science group as an offshoot from another parenting group before PSG. The world of parenting is fraught with pseudoscience and misinformation so we felt there was a need for an evidence-based group regarding all things parenting.

How does PSG fit into that? I think any pro-science evidence-based parenting is going to help to combat the “woo” that is out there. It can often be the first port of call that some parents go to when experiencing problems with their children.

My PSG journey: I got involved [in PSG] because I'm a mum of two very selective eaters [and] joined when the Mealttime Hostage gang were looking for people to be involved in research regarding selective eating. We've been doing Division of Responsibility (DOR) for a while and there's been some small improvement but my main concern, I suppose, was whether or not there would be any long-term detrimental health effects for them with such a limited nutritional intake and also was there something that I had done wrong in my parenting to have such selective eaters.

I am happy to say that I’m a lot less worried about it now having been part of some of the discussions that we had [through PSG], especially with Terry [Dovey], and I can see and recognise a pattern of selective eating within my own family, some who have "grown out of it". Unfortunately, it seems that even among childcare professionals a lot of them have either not heard of DOR and how to implement it, or have much of an idea of how to manage selective eating. This is something that I would like to see more awareness about.

Most importantly though I think that being part of the PSG group has given me a better perspective about sensory issues that my children might be encountering when they are faced with new foods. There will be some foods that they may never like and that's ok. I'm happy if they enjoy the foods that they do like.

The PSG effect: I would hope that, like myself, there is now a greater awareness among parents regarding the sensory issues that children with picky eating experience.

Case study: Serena, the GP receptionist changing things in practice

“PSG has opened my mind into being more critical about information given”

Name: Serena

Location: Derby

Occupation: Business owner/GP receptionist

Highest science qualification: GCSE

Highest qualification (if different from above): BA (honours) degree in Design Management

Involvement with the world of breastfeeding/healthcare: Breast feeder to two children

My PSG journey: PSG has opened my mind into being more critical about information given around children/parenting/the world in general and finding evidence to support claims.

You mentioned that you work in a GP surgery, have you used your experiences through PSG in any way in your role? I've told a few of the doctors about the project and it's been met with interest especially when we start talking journals. Some have mentioned that it can be a trigger for many to look into things further.

PSG has run alongside my project submission but has given me confidence in presenting and that my contribution is valid as a non-clinical member of staff. It's also given me confidence in interactions with parents in my role to challenge clinicians more in their interactions with them, for example the effects drugs/methods may have on them or family especially in terms of breastfeeding and recommendations they are given. There have been a few examples where parents have been referred to the surgery and I have asked the question 'how do you feel about this?' There have been many occasions where a health visitor has referred parents to practice and actually, they didn't think there was a problem. Being able to give GPs the heads-up on patients' situations has meant that the parents have had a better experience because they [GPs] are looking more at the family as a whole and not just the patient, the parents have felt listened to and have been given more explanation as to why they have been referred and feel they are being worked with rather than having something 'done' to them.

There was a combi feeding (breastfeeding and formula feeding) case where parents started with combi then felt confident to fully breastfeed but because they hadn't put on weight during that week, the health visitor referred them to the GP. The parents were happy that baby was still thriving, but were now concerned. Being able to relay this to the clinician gave a bigger picture and resulted in a monitoring approach rather than a quick fix. The parents felt really supported and, although they felt the initial contact with the health visitor was upsetting, they felt that the GP listened to their feeding plan and supported them rather than contradicting it. The baby is still exclusively breastfeeding as planned and they feel it's

because the GP looked at the whole situation rather than the charts and the initial 'concern'. This was a direct result of being able to disseminate to the clinician before the actual consultation which I feel would have overridden the parents' wishes.

You mentioned your own project submission, can you elaborate? I put a proposal forward to help the surgery be more infant feeding friendly. It aims to be a wraparound service in terms of not just providing a private area but having drugsheet links available to GPs during consultations, marking every patient who is currently breastfeeding to aid consultations, a breastfeeding 'triage' service so patients can check whether they actually need to see someone. And training for the non-clinical and clinical staff for understanding about infant feeding and the needs of their families and being aware of language we use.

Was that something you did before joining PSG? It was something I had started but PSG validated and made me believe it was the right thing to do.

It was the human milk project that started it all for me. Until then, I had no idea about the issues that were faced as my support network was strong and at no point put me in a position of questioning my parenting goals and dreams. Sounds lame but both projects [Human Milk Project and PSG] have really opened my eyes to how so many people are failed and it's my mission for peeps to realise that the most important thing is to demand what you want and need and that you need your 'crew' that will always be on your team.

The PSG effect: [I] feel like PSG has enabled parents to think more about decisions they make around parenting and be more confident in challenging others and sources making those claims.

I think the PSG groups have done well in spreading the word about being more science-based and encouraging those around them, friends, family and the wider community both online and physically to do the same.

Is there anything else you would like to tell us? These types of groups make people realise what can be achieved when we work together with a common purpose. [It's] amazing the work done from so many varied backgrounds and pretty much all online too!