

Parenting Science Gang Evaluation Report

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Executive Summary

Project overview

Parenting Science Gang was a citizen science project, run by and for parents and funded by Wellcome. Parent groups, in collaboration with scientists, designed and ran their own experiments to answer questions of importance to them. These groups discussed, planned and made decisions primarily on Facebook, via Facebook groups. We also ran a number of real world events around the UK, to support the project.

Their co-produced research has included: mass spectrometry to study the composition of breastmilk for older children; surveys and interviews to study the experiences of mothers and pregnant women with healthcare providers; and laboratory tests with temperature sensors on babies being carried in slings.

In addition to their scientific achievements, the project has had significant personal impacts for many of the people involved. Participants reported an increase in their knowledge of science and their ability to find, understand and critique evidence. Their feelings about science also changed, becoming more confident in relation to science, more interested in it, that scientists were 'people like them'. They felt more empowered to use science as a tool for things that mattered to them.

Every group found a question which they thought was important, but which hadn't been studied before. These have led to eight papers in press or in preparation and seven conference presentations so far, with at least two more to come. Scientist collaborators reported that the experience gave them new insights into their work, and experimental methods, and inspired them to do more - and more ambitious - public engagement.

Project details

The project ran for just over two years, from 20th February 2017 to 19th March 2019. The groups who took part were:

Year 1

- Science-Aware Natural Parenting Science Gang (SANP PSG)
- Dumfries and Galloway Parenting Science Gang (DGBBB PSG)
- Breastfeeding Older Babies and Beyond Parenting Science Gang (BOBAB PSG)
- UK Breastfeeding and Parenting Support Parenting Science Gang (UKBAPS PSG)

Year 2

- Big Births Parenting Science Gang (BB PSG)
- Mealtime Hostage Parenting Science Gang (MH PSG)
- Let Toys Be Toys Parenting Science Gang (LTBT PSG)
- Breastfeeding and Health Care Experiences Parenting Science Gang (BF HCE PSG)

There were 2,608 members, across all the groups (total group membership was higher than this, because some people joined more than one group).

Our typical member was:

- 25 - 44 years old (>90%)
- female (>95%)
- white (~80%)
- a parent to 1 or 2 children (>80%)
- based in the UK (~90%)

Evaluation

We used a variety of different methods, to use perspective and methodological triangulation to better gauge the overall impacts of the project, and understand more fully the effect on participants. These included interviews with participants and with the partners / relatives / friends who accompanied them to events; pre and post project surveys; discussion threads in the groups; post-it notes at events; reflections and observations by project staff and evaluators; and online activity stats.

Synthesising data from all these methods, we identified the following key themes among the outcomes for participants:

Increased science skills

One of the clearest outcomes for members was an increase in their science-related skills, in several areas - information sourcing, information evaluating, knowledge of specific science findings and experimental techniques, and a greater understanding of the scientific method.

Feelings around science

Another very clear theme was a change in many participants' feelings around science, in several different (but interlinked) ways. They now felt that scientists are 'people just like them'. Their confidence discussing science, understanding science and accessing science in general increased (including small but significant numbers returning to education to study science). Members frequently reported that they now felt that science was something that they could contribute to, there was a sense of them developing a science identity, and they felt empowered to use science as a tool for things that mattered to them - this empowerment was all the stronger, for happening against a context of many of them feeling disempowered and marginalised by pregnancy and motherhood.

Self-actualisation

We included in this theme the social and emotional outcomes of the project, for members, which seemed less directly related to the science content. There was a palpable sense that many members relished the chance to have intelligent conversations with other adults, particularly other mums who were going through the same experiences, and to work together as a community to achieve something. Again, this cannot be divorced from the

context of mothers with small children feeling isolated, starved of adult interaction and as if they've lost their identity. There's obviously some overlap here with the increased confidence and empowerment subthemes of 'feelings about science'. These things all worked together and seemed interlinked for our participants too.

Impact on science and scientists

There were two main ways the project impacted on science. Firstly, finding (and starting to fill) research gaps important to parents in numerous fields of science. Secondly, they affected the scientists they interacted with - giving scientists new ideas and different perspectives on their work, feedback on their research and plans from a parent perspective, inspiration to do more public engagement, and positive affirmation from members who found their research useful.

This report

We've deliberately structured this report to provide both breadth and depth, starting with:

Introduction - explaining the background and context to this project, and giving an overview of our methodology and findings.

Methodology - exactly how we ran the project and how we evaluated it.

Key Outcomes for Participants - key over-arching themes in the outcomes we found for our participants

Our Groups and the Science They Shaped - the character and topic of each group, what research they did and what their findings were.

We then include several sections of '**Top Tips**':

- on running a project like this
- on being family friendly
- on using Facebook.

Finally, we provide more in-depth details on our main evaluation strands and findings:

- 6 **case studies** of a range of real user journeys through the project, including both heavily involved participants, and those who were more casually involved.
- Literature review and discussion on **public engagement with young families**.
- A **summary of all the questions** our groups came up with - which may be of interest to those working with families and wanting to know what research gaps they see, or producing support materials for them.
- **Online stats** describing participants' and other audiences' behaviour online.
- **Events** - details of all the events we ran, how we ran them, and outcomes for participants and project.
- Analysis of **pre and post project surveys**.
- Details and analysis of **in-depth interviews** with our participants.

- **Q&As** - detailed account of the online Q&As our volunteers had with dozens of experts, and how these worked as part of the project, including feedback from our interviewees.
- **Interviews with ‘accompanying adults’** who came to our final event with our participants, to assess the impact of the project on the wider families.
- **Citizen-led evaluation** - feedback initiated by our participants themselves.
- **Posters from our final event**, showcasing each group’s research.
- **Impact and press coverage** of the project

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Introduction

In this section you'll find an overview of the whole project including:

- *Project methodology*
- *Evaluation methodology*
- *A summary of each of the groups*
- *Mini bios of core team and evaluation team members*

In addition, a guide to finding the sections you'd like to look at next in this report.

“That's just amazing, me, actually being useful in science feels incredible.”

Becoming a parent is like an earthquake in your life. No matter how poised, competent and successful previously, you suddenly find you have no idea what you are doing, and a small person utterly dependent on you. Add in sleep deprivation, unsolicited advice in supermarkets, and often the loss of one's previous career and sense of self and it's a recipe for panic, fear and self-doubt.

Research shows that parents with newborns and in the first few months feel isolated, and like they are 'uniquely failing'. New parents can be vulnerable to anyone who offers certainty (however lacking in evidence), or to fear-based marketing – encouraging them to use antibacterial wipes on every surface, for example.

As you adjust to your new identity as parents, in many cases the fear and panic recedes somewhat. But as you get past the baby stage, new questions present themselves. What's the best way of responding to tantrums? When and how to toilet train? How do you foster independence while maintaining secure attachment? Parents are bombarded with advice. But most of it is contradictory and very little of it is based on evidence.

Parenthood is an enormous responsibility and a stressful and isolating life change. Yet the health and happiness of the next generation depends upon new parents getting it right. It's hard to imagine anything it should be a higher priority to support.

Summary of our project methodology

[Parenting Science Gang \(PSG\)](#) was a user-led citizen science project about parenting. We worked with parenting groups on Facebook. We supported each group of parents to choose their own research question, and then (in collaboration with scientists) design and run their own experiment to answer that question.

The project took place primarily on Facebook, via Facebook groups. Although we also ran a number of real world events around the UK, to support the project, to bring the project to life and to inspire and enthuse members. We also ran some events as part of the research - e.g. 130 breastfeeding mothers came to Charing Cross Hospital on the same day to express breastmilk as part of the breastmilk composition experiment.

Eight main PSG groups took part over the two years, these were the groups which chose a research question and then ran an experiment. In most cases these began as a collaboration with an existing parenting group on Facebook. We also ran a couple of smaller groups for a few weeks on topics parents were interested in.

Most activity took place in these Facebook groups – using discussion threads and sometimes polls. Working groups also sometimes met in 'pm threads' in Messenger. We also had lots of online Q&As, which would take place at a specific time, for an hour or so, in a one-off temporary group.

Q&As were usually with an invited 'expert', either to help the group to plan their research, or sometimes, just for general parenting interest. Experts would explain to the group their research and research methods and answer questions. Sometimes this worked as a kind of 'first date' between the volunteers and the scientist, and would lead to a collaboration. Sometimes Q&As had no 'expert' and were just for group members to get together and discuss a knotty problem in their research in a more immediate way than the non-contemporaneous discussions in the group.

Groups came up with a large number of questions relevant to parenting. Research and discussions with scientists would sometimes reveal that these questions had been answered by science already. But there were many left. One of our conclusions is that there are many everyday parenting questions relating to typically developing children which do not get studied. And that much parenting advice is not based on evidence, but parents would like some that is.

Every group found a question which mattered to them, but which hasn't been studied before. Several have led to papers which have been submitted to academic journals and several more papers are planned or being written.

Table 1 summarises the research each group did, their findings and outputs.

Summary of our evaluation methodology

This project was based on a much smaller, pilot project - [Nappy Science Gang \(NSG\)](#). Which was based on Facebook and used a co-production model to work with a community of mums with small children. This combination was novel, particularly in the way these elements worked together. We wanted to know how well these elements all worked and whether taking part had the positive effects on participants that we'd hoped?

NSG had of course been evaluated, but this larger scale of project meant we could go into more depth. The project aimed to change participants relationship to science, which is quite a big but subtle thing to measure, so we wanted to try to understand the effects on participants from various different angles.

Project staff worked with two evaluation consultants – Dr Karen Bultitude, Honorary Senior Research Fellow at University College London and Dr Sarah West, Deputy Director and Senior Research Associate at Stockholm Environment Institute, University of York. Together our evaluators and the project team thought through the kinds of changes they might see in

Table 1 – PSG group summaries

Year 1 Groups	Members	Research Topic	Research Method	Collaborator(s)	Outputs*	Notes
<u>SANP</u> PSG	250	Effect of babywearing on the skin and core temperature of a baby	Laboratory-based experiment using thermo-sensors, with 9 mother / baby pairs.	Dr Davide Filingeri, Loughborough University	1 paper submitted and under consideration. Presentations at 3 relevant meetings. Institute of Health Visiting (IHV) conference stall.	No previous published research on temperature of babies while worn in carriers.
<u>DGBBB</u> PSG	80	<u>Flexischooling</u> in Scotland	FOI requests to all 32 Scottish councils Surveys for parents Interviews with teachers	Dr Tara Jones, University of the West of Scotland	1 paper in 'Alternative Education' online journal. Full report published on our website. Abstract submitted to the Scottish Educational Research Association Conference	No previously published research on flexischooling in Scotland. Last publication on flexischooling in the UK from 1988.
<u>BOBAB</u> PSG jointly with <u>UKBAPS</u> PSG	900 (BOBAB PSG) and 280 (UKBAPS PSG)	What is in breastmilk produced for children over 2 years old?	Samples were analysed in a mass spectrometer (<u>REIMS</u>), and by microbiome analysis. 132 breastfeeding mothers came to Charing Cross Hospital in London and expressed breastmilk.	Dr Simon Cameron, Imperial College London and Dr Natalie Shenker, Imperial College London/Hearts Milk Bank	Presentation at UNICEF Baby Friendly Initiative Annual Conference, 2017 (Natalie) Presentation at Metabolomics 2018 (Simon) Talks by PSG staff at Breastival Belfast and NI Science Festival. Paper in preparation. Stalls at Institute of Health Visiting (IHV) conference & Primary Care & Public Health (PCPH) conference. Forthcoming <u>APPG</u> Infant Feeding presentation	"While the composition of human milk has been studied extensively in the first year of lactation, there is a paucity of data regarding human milk composition beyond one year postpartum." Perrin M. T., Fogleman A. D., Newburg D. S., and Allen J. C. (2017) A longitudinal study of human milk composition in the second year postpartum: implications for human milk banking, Maternal & Child Nutrition, 13, e12239. doi: 10.1111/mcn.12239.

*All groups, except LTBT, are attending one or more conferences or events with their results. See *Coverage and Dissemination* for more details.

Table continues on next page

Year 2 Groups	Members	Research Topic	Research Method	Collaborator(s)	Outputs*	Notes
<u>BB</u> PSG	155	What is the effect on higher- <u>BMI</u> mothers of the choices they are offered in & pregnancy labour?	Email interviews with 20 higher- <u>BMI</u> mothers about their experiences, followed by thematic analysis.	N/A	Report on our website. Paper in preparation. Primary Care & Public Health (PCPH) conference stall.	The group were unable to find research that considered the extent of effect that reduced choice in pregnancy and/or labour had on subsequent pregnancies.
<u>MH</u> PSG	327	What are the emotional behaviours (e.g. anxiety) and sensory sensitivities of children with a range of eating issues?	Questionnaire completed by 551 parents, followed by statistical analysis.	Dr Terry Dovey, Brunel University Prof Jackie Blissett, Aston University	A co-authored abstract submitted for a poster for the British Feeding & Drinking Group Conference & the International Conference on Children's Eating Behaviour. Jackie and Terry planning 3 or 4 papers (group named as author). IHV Conference stall.	<u>ARFID</u> is a recently defined condition (<u>DSM-5</u>) & poorly understood. Members' discussions of experiences made them wonder if social and sensory sensitivities contributed to the disorder. Their questionnaire has been the first research testing that hypothesis.
<u>LTBT</u> PSG	650	Effect of stereotypes in children's books on children's ideas on gender	Participants assigned one of three books (stereotype reinforcing, stereotype contradicting, and a control book with no mention of gender). Books read to their children for five weeks and a questionnaire administered on gender stereotypes to their children before and after.	Dr Lauren Spinner, University of Kent	Report on our website.	Gender stereotyping of children is of concern to both the LTBT campaign group and the PSG group. The group considered many influences and chose to investigate the influence of children's books.
<u>BF HCE</u> PSG	440	(1) Breastfeeding advice and support from healthcare providers (2) How does Personal Experience of Breastfeeding Affect the Professional Practice of Health Care Professionals?	(1) 740 narratives of mother's interactions with <u>HCPs</u> , relating to infant feeding, collected and analysed using corpus linguistics. (2) 8 HCP interviewed each other to investigate how breastfeeding experience changed their professional practice. Analysed using thematic analysis	(1) Dr Gavin Brookes, Lancaster University (2) Dr Yan-Shing Chang, King's College London	(1) Non-peer reviewed article for a biomedical journal. Research featured in Gavin's upcoming book on analysing health language data. (2) Report on our website. (1&2) Stalls at IHV conf. and PCPH conf. Forthcoming presentation at the APPG on Infant Feeding.	The idea for this group arose from members of BOBAB and UKBAPS PSG highlighting the wealth of breastfeeding and healthcare provider threads in <u>FB</u> breastfeeding groups.

participants and designed an evaluation plan to try to capture some of those changes. We 'also wanted to be alert to any unexpected but interesting outcomes. We used a mixture of methods across the two years of the project.

Methods

We used a variety of different methods, to use perspective and methodological triangulation to better gauge the overall impacts of the project, and understand more fully the effect on participants.

- Pre and post project online Google surveys for participants. These were shared in the Facebook groups, linked from the welcome post for new members kept pinned to the top of the group, and with frequent invitations to fill them in. A mix of tick boxes and open text responses. 722 pre- and 276 post-project responses were received once duplicates were removed.
- Post Q&A surveys for 'experts' sent out by email. A mix of tick boxes and open text responses.
- Various 'fill in a post-it note' activities at face-to-face events.
- 16 in-depth interviews by Ms Organ with a mix of participants from several different groups, and also with several of the scientists involved, followed by thematic analysis. Participants were deliberately chosen to include some highly engaged members and some lightly engaged members, and also those who had and had not come to 'real world' events.
- 'Focus group' threads in the groups towards the end of the project, asking them about their experiences.
- In-person semi-structured face-to-face interviews by Dr West with ten 'accompanying adults' at the final event.
- Project staff collecting 'gold dust', anecdotes or comments which seemed interesting or illuminating from all the activity in the groups, over the life of the project.
- Online activity stats from Facebook, our website and twitter.
- Project staff reflecting on their experiences running the project and collecting their thoughts, including running lists of 'what worked well' and 'what to do differently' in an online discussion space, during the project.

What do you want to find out more about now?

We've tried to bring every bit of our learning from this project together and record it in this report, so that future projects can benefit. Therefore, the report includes both our evaluation findings about the impacts on participants, and also all the nitty gritty stuff we worked out along the way. We realise that with a large and somewhat sprawling project like this, different parts of what we've learned will be useful to different audiences. Unless you want to run a project exactly like Parenting Science Gang in every respect, you probably don't want to read all of it. And let's face it, it's quite long. This section explains what is where, so you can decide which bit is useful to you.

We expect it may be of interest to three main audiences:

- Public engagement community
- Patient and public involvement in research community
- Citizen science community

We think there are three aspects to our approach which may be particularly interesting:

- Genuine co-production, led by the users
- Using Facebook extensively and in an integrated way
- Working with parents of small children

We also expect researchers/professionals in relevant areas (e.g. child development, midwifery) may be interested in what questions and concerns parents had and how we worked with parent groups. As well as the results of the individual groups' research.

We've therefore gone into a lot of detail about our methodology - HOW we actually went about things and how they worked. As well as the effects on participants. We've also written some 'top tips' (for example, on using Facebook, on being family-friendly) which are short stand-alone sections which could be useful to many audiences.

What we did

- ⇒ To read more on how the project actually worked - the nuts and bolts of how we worked with groups, took them through the process of choosing their own research question and designing and running an experiment, see *Project Methodology*
- ⇒ To read more on who each of our groups were, and what research they did, see *Our Groups and the Science They Shaped*
- ⇒ To read more about how we used Facebook read *Use of Facebook*.
- ⇒ To find out more about external publicity and links to PSG, see Coverage and Dissemination.

Understanding the context: Parents with young children

- ⇒ To read more background on the needs of mothers/parents in early parenthood, read *In-depth: Serving mothers, parents and families* and our participant questionnaire evaluation in *In-depth: Pre & post survey results*
- ⇒ To read more on what questions parents came up with and where they felt knowledge or research gaps, read *In-depth: What were parents interested in?*

User experiences

- ⇒ To read about our evaluation methodology in more detail, read *Evaluation methodology*.
- ⇒ To read about the impacts on users and the cross-cutting themes which emerged from our evaluation, read *Key Outcomes for Participants*.
- ⇒ To read individual strands of the evaluation, see
 - *In-depth: Online statistics*

- *In-depth - Events*
 - *In-depth: Investigating Participants' Experiences of an Innovative Citizen Science Project*
 - *In-depth: Q&As*
 - *In-depth: Accompanying adults' view*
 - *In-depth: User-led citizen evaluation*
 - *In-depth: Group posters from the Final Event Results Fair*
- ⇒ To get a *feel* for how participants experienced the project, read our case studies – these illustrate, in their own words, various user journeys through the project, from people who were very heavily involved and had big, transformative experiences to those who dipped in and out and were only lightly engaged. See *In-depth: Case studies*

Top tips

- ⇒ To read our top tips and lessons learned for running a project like this, see *Top Tips: Running PSG*
- ⇒ To read our top tips on using Facebook for other projects, see *Top Tips: Using Facebook*
- ⇒ To read our top tips on being family-friendly for other projects, see *Top Tips: PSG's guide to being family-friendly*

The team behind this report

Core project team

Sophia Collins (Project Director) is an award-winning public engagement with science practitioner. She's a mum of one and lives near Edinburgh.

Amy Strother (Project Manager) started her career as a pharmacist before moving in to project management in both the pharmaceutical industry and consulting. She is a mum of two and lives near London.

Tamasin Greenough Graham (Project Coordinator) decided to leave nuclear astrophysics behind when she realised she was spending all her time talking to a computer. Since then she has run science outreach programmes, written educational resources and advised professional bodies on public engagement. She's a mum of two and lives in York.

Rebecca Brueton (Project Coordinator) is a Digital Media and Marketing professional and mother of two. She is interested in the changing nature of community in the internet age and how technology can help people come together to share knowledge and ideas and to create positive social change. She lives in Eastbourne.

Evaluators

Dr Karen Bultitude (External Evaluator) is an award-winning specialist in science communication and public engagement. During the course of Parenting Science Gang, she underwent her own major lifestyle change, switching from being an academic and

professional evaluation consultant in the UK to becoming the business manager of her family's large-scale beef business back in Australia. Karen worked on Nappy Science Gang, but in this project has had a more hands-off role - she is not a member of any of the groups, nor has she attended any events - allowing her to provide an entirely external perspective on the project. Karen is a mum of two and now lives in Canberra, Australia.

Dr Sarah West (Internal Evaluator) is Deputy Director and Senior Research Associate at SEI York with expertise in citizen science. She took part in Nappy Science Gang as a participant and is the Internal Evaluator for this project. She has joined all of the groups and taken part in some of the face to face events. Sarah is a mum of two and lives in York. Sarah is currently on maternity leave and is being covered by Dr Jean McKendree also from SEI York.

Stephanie Organ has a Science Communication MSc from the University of the West of England. She is interested in empowering under-represented groups in STEM and identifying innovative ways in which to disseminate information.

Methodology

In this section you'll find:

- *Our project methodology including*
 - *Project recruitment*
 - *Use of Facebook*
 - *How we captured and chose questions*
 - *Online Q&As*
 - *Face to face events*
 - *Communication*
 - *Our 9 evaluation questions and the approaches we used to answer them*
 - *Details of our evaluators*
-

Project Methodology

Parents are responsible for raising the next generation and as such, there is strong argument for them having the best information to help them get it right. However, parents are often sleep deprived, time poor and bombarded with information from all kinds of sources (family, friends, health care professionals, online forums, parenting books), often with little or no evidence to back it up.

We wanted to run a project that put parents in charge of the science, and chose to run it through Facebook as:

1. Parents often turn to online forums for parenting advice and support.
2. It allowed us a much broader reach across the UK than a 'physical' group would for the same financial and time input.
3. It allowed parents to engage with the project at times and frequency that suited them.

Ethics

The project was subject to ethical approval by the University of York, via Dr Sarah West (our internal evaluator). This covered all aspects of the project from our use of Facebook to the surveys designed for our participants and scientists.

In addition, all group research protocols were submitted to ethics – in most cases at the University of York, but sometimes via the collaborating scientist and their own institution.

Recruitment

[Parenting Science Gang \(PSG\)](#) took place over two years, with four groups running from the start and another four running throughout the second year.

In the first year, our groups were “daughter” groups of existing Facebook groups (the “mother” groups) identified through the project director’s existing personal network or

through Nappy Science Gang (a precursor project to PSG, which has acted as a pilot for some of the methods used in this project) and invited to take part.

The “daughter” group approach was employed to reduce admin time in building a sense of community (as all members of the group are drawn from the same Facebook community), and to help with dissemination of research throughout and at the end of the project. Based on [Nappy Science Gang \(NSG\)](#), we had thought that by using existing Facebook groups, admins would spend less time on dealing with new members who didn’t understand what the project was about and were just expecting another parenting support group, and less time establishing group norms and a sense of community. However, we found that admins still spent a lot of time getting the group up to speed with the concept of PSG – we found it takes a long time for the groups to understand that we really meant user-led and not admin-led citizen science!

Two of the year one groups - Breastfeeding Older Babies and Beyond (BOBAB) and UK Breastfeeding and Parenting Support (UKBAPS) - had a very focussed area of interest – breastfeeding, while the others existed either as an online forum for those broadly interested in a scientific approach to parenting - Science-Aware Natural Parenting (SANP) - or an online forum for those in a similar locality - Dumfries and Galloway Bumps Babies and Beyond (DGBBB). We found that the groups united by a common interest found it much easier to choose a research question and work together to answer it. We therefore deliberately chose groups with a common interest in the second year.

In the second year, we used various methods to recruit four more groups:

1. An application process, advertised through our Facebook page and website, so that existing Facebook parenting groups could apply to become a PSG group, using the mother/daughter group format of Year 1 - Mealtime Hostage (MH).
2. The project team searched for under-represented groups, via existing networks, by asking PSG members for suggestions and introductions, and by approaching relevant organisations. Unfortunately, this approach yielded no groups for our second year (see *Reaching under-served audiences*).
3. Ideas for new groups were suggested based on interest from existing group members - Breastfeeding Health Care Experiences (BF HCE)
4. The project team approached potential collaborators - Let Toys Be Toys (LTBT), Big Births (BB).

Use of Facebook

Over two years, we ran 10 main Facebook groups – eight PSG groups, designing and running their own research, and two special project groups (see *Our Groups and the Science They Shaped*). In addition, we used just over 90 temporary Facebook groups for Q&As and group meetings and for the participants of PSG events.

Groups are a key Facebook structure and there is no shortage of Facebook groups on parenting-related topics.

Facebook groups are designed for communication; they are online spaces where people can come together around common interests to chat and share opinions.

Some flexibility has been designed into the structure of Facebook groups. For example, admins have some control over how public a group is, with options ranging from 'public' to 'secret' (see Table 2).

Table 2 – Facebook group privacy options

	Find the group	See who is in the group	See posts
Public	Anyone	Anyone	Anyone
Closed	Anyone	Anyone can see who runs the group; only members can see the members list	Members only
Secret	Members only	Members only	Members only

All of our groups began as 'public' groups, however, every group decided, independently, that they would prefer the group to be 'closed', meaning only members can read the members' comments and other content within the group.

Membership applications can also be easily regulated. Groups can be set so that anyone can join, or so that members can approve their friend's membership requests, or the groups can be restricted so that admins must approve membership requests. Facebook offers the option of automated questions for people wishing to join, and a group can be set to allow members of other Facebook groups immediate access, should they wish to join. Applicants to PSG groups were accepted if they met certain entry requirements which are discussed in more detail in *Our Groups and the Science They Shaped*.

Conversations on Facebook groups are organised into threads to keep different topics separate. Members of a group can visit the group and have immediate access to all threads, saved files, events and membership lists, although due to Facebook algorithms these do not necessarily appear in chronological order, but instead those with a higher degree of interaction appear closer to the top of the screen.

However, as is typical among Facebook users, most of our members interacted with group posts via their personal Facebook 'feed', meaning individual pieces of content from the Facebook group appear to them alongside content from other groups, pages and their friends.

The amount of content on Facebook is immense - and so Facebook employs algorithms to determine which content gets sent to individual users' feeds. Part of the art of admining a Facebook group is to learn to work with the algorithms so that your members see your content. There is a certain amount of educated guesswork involved in this as Facebook doesn't publish the parameters, and they seem to change every so often. See *Top Tips: Using Facebook* for more detail.

Most activity within the group took place in Facebook groups, using discussion threads and polls. Working groups also sometimes met in "PM threads" in Facebook Messenger. Polls in Facebook present a unique problem in that only the first few options can be seen when they

appear either in the group or a 'feed', and you need to click to see the remaining options. Facebook automatically updates the poll so that the most popular options appear at the top, which has the potential to skew results and requires some admin facilitation to try to mitigate this.

Questions

Groups came up with a large number of parenting-related questions (see *In-depth: What were parents interested in?* for more details). The whole purpose of this project was to put parents in charge of the research agenda, and to take parenting questions that matter to them, that have not thus far been studied by science, and design and run a research investigation to answer it.

In each group we started a questions thread which members contributed to. Due to the large number of questions in each group, there had to be a degree of voting to choose the final question. In certain groups, parents also narrowed down the research area (for example, [BOBAB](#) and [UKBAPS](#) decided that they would only choose from breastfeeding questions as there were already general parenting groups taking part in PSG, [BF HCE](#) was set up purely to look at the impact of health care practitioners on breastfeeding journeys).

Broadly the groups followed the approach below, although the influence of personal experiences (child overheating in [SANP](#), "speed dating" with a scientist over a Q&A) heavily influenced the chosen research question.

1. Questions thread - members added questions that they wanted answers to
2. Discussion - questions discussed within the group, and also Q&As with relevant experts, to identify those which had been answered by research already and to highlight ways of investigating others
3. Top 10 - questions narrowed down to a top ten which could then be discussed in more detail
4. Range voting - members voted on the top ten questions by range voting (members vote for three choices, giving three votes to their top preference, two to their second, etc). This was deliberately chosen as it is less 'first past the post' and a good system for finding the most satisfactory option for the greatest number of voters.

Once a question had been chosen, members worked together to design an experimental protocol, either in collaboration with a scientist, with advice from a scientific advisor or with ad hoc Q&As for advice on specific areas (e.g. research methodology).

The Breastfeeding and Healthcare Experiences group took a different route - they had decided their specific focus before starting the group. This group benefited greatly from online workshops with a professional facilitator to help them shape their ideas and agree on their direction.

The process for getting from a question to a research protocol varied from group to group as there was a huge variability in questions and research methods. However, it usually involved a "working group" of active members who would hammer out a lot of the details and then

bring the proposal back to the group. We found PM (Facebook Messenger) threads quite useful for this, as well as using Google Drive to share files.

Execution of the experiments also varied wildly. In some cases, the groups did almost all of it themselves (e.g. [BB](#) conducted their own email interviews and conducted their own thematic analysis of the responses). In others, the groups had to substantially hand over at this stage to the scientists (e.g. BOBAB/UKBAPS volunteered to give samples, helped to recruit others to give samples, helped with logistics on the sample day, but Imperial scientists had to run the laboratory tests and do most of the subsequent analysis).

For more information on the chosen questions and experiment details, see *Our Groups and the Science They Shaped*.

Q&As

We ran Q&As approximately weekly. Subjects and experts were suggested by the PSG team and PSG members. Usually the Q&As were open to all group members, however, some Q&As were limited to one or a few groups where it particularly applied to their research.

The Q&As were designed to encourage conversations between members and experts, enabling members to either find out more about what research has been done or to learn about specific research methods. The Q&As helped to focus research interests, develop research design and in some cases, find a scientific collaborator.

Initially we used the I'm A Scientist chat room for sessions. However, after a few technical issues, we switched to using Facebook groups temporarily. We then asked for feedback from our members about which format they preferred – there was an overwhelming preference for Facebook, so we made a permanent switch to Facebook groups for Q&As going forward.

In order to increase participation in the Q&As and to increase the quality of questioning, we advertised the Q&A sessions in advance, set up the Q&As as events (meaning those that joined got reminders on the day) as well as creating 4 or 5 Q&A-related posts (posters, lay summaries, videos, overview of research on the topic, etc).

We tried to make our Q&As as accessible as possible to our PSG members. To do this, all Q&As were:

- Held at 9pm in the evening, when the majority of our participants were free (based on experience from NSG)
- Text-based so that members could multi task (we made it clear that it was more than fine to join in while continuing to snuggle your child to sleep, breastfeed them, oversee homework, eat dinner, etc!)
- Opened in advance of the event times so that members that could not attend the event live could post questions in advance and / or could read over the session at a later time.
- Published on our website as written, with only minor editing for clarity.

For more detail on our approach to Q&As, as well as participant and scientist feedback, see *In-depth: Q&As*).

Events

At the start of the project, we proposed to run three face to face events for group members. We used events to:

1. To create buy in for the project and help to get new members up to speed with the project more quickly than can be done online
2. To inspire members about the possibilities, through sharing of experience (of NSG for the first event, and PSG for the latter two events) and through inspirational speakers (scientists, citizen science experts)
3. To up-skill and create confidence in group members
4. To provide a learning and evaluation opportunity for the project team, and,
5. For the latter event, to create a celebratory event for members to share their experiences and feel part of something big and meaningful.

Over the course of the project, we changed the format of the events so that instead of a single event one year into the project, we ran multiple single day events in various locations. For more information, see *In-depth - Events*.

Communication

Most of our communication was with participants either inside the closed groups, Q&A groups or PM threads. However, Parenting Science Gang also has a website, Facebook page, Twitter account and email newsletter.

We set up our website (www.parentingsciencegang.org.uk) at the start of the project. We used as a record of all of our Q&A content, for recruitment for PSG research and dissemination of PSG research findings.

We introduced a Facebook page (facebook.com/parentingsciencegang) in May 2017. The Facebook page is public and we used it to share content from our website. It is not possible to compare followers of the page with membership of the groups. However, being public, allowed group members to share content (e.g. study recruitment posts, interesting findings) that they could not share from a closed group, and it allowed people that were not part of PSG (or just part of a different PSG group) to access Q&A content.

PSG joined [Twitter \(@parentscigang\)](https://twitter.com/parentscigang) in November 2017, as another way to disseminate our Q&As and research. We have found that most of our interaction on Twitter is with professionals.

Our email newsletter was initially sent out to partner organisations and the distribution list has grown to just under 500 people. We sent a newsletter approximately every 2 months, which included updates on PSG and calls for contributions.

Evaluation methodology

Our evaluative methods seek to evaluate the project based around these nine questions:

1. Does taking part in the project increase parent's '[science capital](#)'
2. Does taking part in the project change where they get advice from?
3. Does taking part in the project change how they evaluate advice?
4. Does taking part in the project increase people's confidence in relation to science?
5. How is the project working in terms of numbers of people engaging, diversity of people?
6. What are people enjoying about the project, and what do they think could be done better?
7. Are there any other unexpected side effects of participating in the project?
8. Do parents taking part have higher science capital than the general UK population (i.e. is our self-selecting sample biased towards those with greater science capital?)
9. How does the project affect science and scientists?

We were also extremely interested in the project's impact on children's scientific capital. However, the majority of our participants had young children so we were unable to test this.

Table 3 shows which of the following methods we used to evaluate each of our questions:

- Questionnaires
- Online analytics
- Snap-shot feedback
- Qualitative reflections.

Table 3 – Methods used to answer our evaluation questions

Evaluation question	Questionnaires	Online analytics	Snap-shot feedback	Qualitative reflections
1	✓			
2	✓			✓
3	✓			✓
4	✓			✓
5	✓	✓		
6			✓	
7	✓			✓
8	✓			
9	✓			

Questionnaires

All participants were invited to complete a questionnaire at the start and end of the project. The questionnaires were set up in Google Forms and promoted within the Facebook groups. When we planned the project, we hoped that the post-questionnaire would be completed at the end of their participation in the project, but almost all members were still involved in the project (either active research, analysis or dissemination of research findings still ongoing). In total we had 722 pre-project responses and 276 post-project responses, once duplicate responses were removed.

The questionnaires contained both open text and check box answers. The open text responses were analysed by one of our evaluators, Dr Jean McKendree, to elicit key themes. Check box answers were compiled in a spreadsheet so that pre- and post-questionnaire responses could be compared.

We also asked all our Q&A experts to complete a survey on their experience of taking part in our online Q&As, to understand their general experience of the Q&A, any challenges and their views on PSG. Of 73 experts, we received 35 responses.

Online Analytics

Our intention was to use Facebook analytics tools to understand how engaged our members were with the project. However, a year into the project, Facebook removed access to third parties and this was no longer possible. See *In-depth: Online statistics*.

Facebook is the main tool we used to communicate with our parent participants. However, our Wordpress site, Twitter and Mailchimp newsletter are used in addition by professionals (scientists, science communication, citizen science) to follow the project.

We used the following tools to analysis engagement with each of these:

- Facebook page (<https://www.facebook.com/parentingsciencegang/>) - Facebook Insights and Sociograph (May 2017 - March 2019)
- Facebook groups: Sociograph (March 2017 - March 2019) and Grytics (Snapshot, Sept 2017)
- Website (parentingsciencegang.org.uk) - Wordpress inbuilt analytics, Google analytics (March 2017 - March 2019), Google Search Console (Jan 2019 - March 2019)
- Twitter (@parentscigang) - Twitonomy (November 2017 - February 2018)
- Mailchimp newsletter - Mailchimp campaign reports (April 2017 - December 2018)

See *In-depth: Online statistics* for more information.

Snap-shot Feedback

We used a variety of feedback methods, both online and at events.

Within Facebook we used:

- Facebook suggestions box
- #PSGTellUs posts
- Gold Dust

Both our Facebook suggestions box (an anonymous online way to feedback on the project) and our #PSGTellUs post series had a low uptake. We introduced the suggestions box at the start of the project but this only had a low response, with just a few positive comments, so we discontinued it.

Towards the end of the project, we had a series of posts in all of the Facebook groups using the hashtag #PSGTellUs, asking participants what they had enjoyed about the project, what had enabled them to take part, etc. We had a low number of responses, all of which were positive.

Project staff collected “gold dust”, that is comments, anecdotes or threads, that seemed to illustrate particular aspects or highlights of participating in the project. We broadly categorised these with reference to our nine evaluation questions and collected them on an online board in Trello.

At our events, we used a variety of post-it note activities, primarily for formative evaluation. They could be added to at any time during the event. Questions included:

- What have you enjoyed?
- What have you found interesting?
- What would you do differently if you were running this?

- Any feedback on the venue?
- What do you want out of the project?

At our Final Event, we used “Head, Heart, Hands” to find out what participants are thinking, feeling and wanted to do next. More details on the events and the feedback we received, can be found in *In-depth - Events*.

Qualitative reflections

We used a combination of observations and interviews (outlined in Table 4) at our face to face events to evaluate the project. Observations were conducted by either our internal evaluator or MSc student. Participants were aware they were being observed and permission was sought before any interviews took place.

Table 4 – Use of observations and interviews at face to face events

	Observation	Interviews	Observer / Interviewer
Residential Weekend	✓		Internal evaluator
Gangstival events	✓		MSc student
Final Event	✓	Interviews with Accompanying Adults	Internal evaluator

16 in-depth interviews were conducted with a mixture of highly engaged and less engaged individuals, as well as experts. Individuals were identified through attendance at face to face events as well as by the project team. See *In-depth: Investigating Participants' Experiences of an Innovative Citizen Science Project*.

Our MSc student also conducted eight interviews at the end of the project to serve as case studies. See *In-depth: Case studies*.

We sought to evaluate the wider impact within participants' families through a series of short interviews with ten accompanying adults at our Final Event.

Throughout the project, project staff reflected on their experiences running the project and collected their thoughts in categories such as “what worked well” and “what to do differently”. These served as formative evaluation and allowed us to adapt the way we worked on Facebook. These reflections also form the basis of our recommendations in *Top Tips: Running PSG*.

Evaluators

We worked with two main evaluators in this project. Both were involved in Nappy Science Gang.

Dr West had taken part in Nappy Science Gang as a participant and was familiar with our approach 'from the inside'. She joined all the PSG Facebook groups and joined in discussions and came to several of our real world events. She was our 'internal evaluator',

taking a more participant observation approach. Dr West took her parenting participant duties so seriously that she had a second baby towards the end of the project, so some of the later qualitative analysis was done by Dr Jean McKendree, her maternity replacement at SEI York.

Dr Bultitude had acted as our evaluation consultant to Nappy Science Gang, so was familiar with the project, but she took a more hands-off approach, wasn't involved in the groups or events. She was our 'external evaluator' and was able to have a more birds' eye view of the project.

Project staff took on some evaluation tasks like helping draft surveys, quantitative analysis of surveys, and collecting examples of behaviour during the project. We also were lucky enough to work with an MSc student from University of the West of England, Stephanie Organ, who conducted in-depth interviews with participants and wrote her dissertation on Parenting Science Gang.

Key Outcomes for Participants

In this section you'll find analysis of the outcomes for Parenting Science Gang participants and scientists. The outcomes are grouped into four main themes:

- *Science skills*
 - *Feelings around science*
 - *Self-actualisation*
 - *Impact on science*
-

We looked at all our evaluation data – analysis of pre and post project surveys, in-depth interviews with participants, and online and in-person activity – to pull out what appeared to be the key outcomes for participants and scientists taking part. We have grouped these into four main themes and provided some representative quotes.

Themes

Science skills - this included their information-sourcing strategies, the way they evaluated information, specific science knowledge, as well as an understanding of the scientific process.

Feelings around science - this included seeing scientists as 'people just like them', increased confidence in relation to science and a sense of being empowered to use science as a tool for things they need.

Self actualisation - this included social and emotional outcomes of the project that weren't specifically related to the science content, particularly intellectual stimulation and feeling part of a community.

Impact on science - this included finding (and starting to fill) research gaps important to parents in numerous fields of science. And giving scientists new ideas and different perspectives on their work, feedback on their research and plans from a parent perspective, inspiration to do more public engagement, and positive affirmation from members who found their research useful.

Science skills

One of the clearest outcomes for members was an increase in their science-related skills, in several areas - information sourcing, information evaluating, knowledge of specific science findings and experimental techniques, and a greater understanding of the scientific method.

Information sourcing

Before joining [PSG](#), interviewees sought parenting information mainly from the internet, but also from their social networks, and other parenting groups. Since taking part in PSG, they reported looking more critically and thoroughly for information, and using different strategies. Including going to primary sources.

"I'm looking for trustworthy sources...I'm much better informed and... more prepared to be cynical because I've seen the contrast between a lot of rubbish... published [in the media] ...versus much better information that you can find with a bit more attention"

"It's been good to be able to ask... 'has anyone got any...good resources?'...there's a broad mix of people...and they may have access to...papers...that the general public haven't...or...somebody will come along and 'this is what you need to search for'"

"I searched your name in the list of accepted proposals for using the ALSPAC data! And I'm really interested in the association between screen time use and anxiety in adolescents." (PSG member with no science education post A level, during a Q&A with a researcher about ALSPAC)

Evaluating information

Members also said that they evaluated information differently. They became more critical, they looked for actual scientific papers (which they now felt more qualified to read and understand, more on this later). And they would take things they found back to the group for discussion.

"I heard...some advice...and...researched it...on Google Scholar and...websites that I trusted...I listened to the advice critically...that's one of the big differences that PSG has made, not just accepting things that I'm being told"

"someone will quote something and you'll go... 'I thought that was disproved in a study in 2017' and somebody else will go 'yes, it was...let me find you the reference'"

Specific knowledge

People appreciated the access to information on parenting topics, as well as other areas of science, direct from experts.

"More factual information and less scaremongering/judgemental advice"

"I gained knowledge in areas that I didn't have previously"

"The biggest thing I've got out of it is taking part in the Q&As, which have been absolutely fascinating and I've learned a lot."

"Mostly from the Q&As. Eg I've learned that siblings experiences of their parents are no more similar than those of two unrelated children. And that children spontaneously seek out opportunities to learn about maths."

"I learned a lot about gut bacteria!"

Scientific process

Participants understood more about the scientific process, how to design experiments, significance, controls, ethics, generally, How Science Works.

“it made the scientific process...a lot more in...my grasp”

“It sounds simple to come up with a question to ask, but it isn’t always a simple matter to find ways to answer it”

“How long it takes to get a paper published! Also just how thorough the research/testing/analysis needs to be.”

“I learnt a lot about ethics.”

“the whole process has helped me understand how rigorous research is or isn't so I feel more able to trust / mistrust what I read”

Scientific methods

They also learned a lot about methods in different areas of science (which they may have known little or nothing about before) – from very physical sciences like mass spectrometry to very qualitative research methods in social science.

“I tended to think of science as just including maths, biology, chemistry, physics, but I have learned a lot about collecting social data via questionnaire, ethics, etc.”

“I learnt about how mass spectrometers work, and what it can tell us, and what it can't.”

Feelings around science

Another very clear theme was a change in participants feelings around science, in several different (but interlinked) ways. They now felt that scientists are ‘people just like them’. Their confidence discussing science, understanding science and accessing science in general increased, (including small but significant numbers returning to education to study science). Members now felt that science was something that they could contribute to, there was a sense of them developing a science identity, and they felt empowered to use science as a tool for things that mattered to them - this empowerment was all the stronger, for happening against a context of many of them feeling disempowered and marginalised by pregnancy and motherhood.

Confidence

Respondents mentioned increased confidence in multiple areas such as their own parenting choices, their contribution to science and their use of science.

“it was very empowering that feeling of...ordinary people, we can be scientists”

"Personally, increased confidence & passion for being involved in research. Also been able to make confident decisions in my parenting choices, particularly in areas where I struggled to find clear answers from existing research."

"An education. Confidence. I feel more comfortable with what information I'm capable of taking in on my own, and what my limits are. Makes speaking with a doctor so much easier!"

"I have greater confidence in finding information for myself and speaking with peers around science subjects"

"I do try to find research now if I'm worried about something impacting on my kids - it helps me to see if I should worry or forget about it."

"It lead to long discussions with my partner, so we both now base our parenting decisions on doing research and interpreting findings."

"Yes, I am much more confident in my own decisions because I know how to identify reputable sources of information."

"Shown me that there as an ordinary citizen, I can still get involved in science."

Scientists are humans

Members saw people like them being scientists and talking to them, person to person, in an informal-feeling setting.

"was nice to have those barriers broken down, they're...normal people and...talk in a language that we understand...it's been very nice to see...strong female scientists...rocking their jobs"

"Close contact with leaders in their fields through the Q&As- amazing!"

"I feel that scientists are basically normal people like the rest of us."

Science identity

People expressed feelings of developing a 'science identity'.

"This is all awakening my inner scientist. I thought that gene had passed me by."

"I've never been as interested in something like this so I think it will be plaguing my dreams (or nightmares) for some time I've been trying to figure out how I can be a scientist for my job since joining this group."

"I felt like such a fraud even commenting on discussions when I joined, and although I am SUCH a non-sciencey noob, I feel a teeny weeny bit more confident that I'm contributing and progressing our projects. That's just amazing, me, actually being useful in science feels incredible."

So much so that some members have started access courses or university courses to study science, which they attributed to their involvement in the project.

"Life changing, quite literally. I decided to go back to uni and study neuroscience (no previous science background since school). Its been amazing to help design a study around something I genuinely would like to find out. Speaking with scientists and professionals with the chance to ask them questions has been an amazing opportunity. Thankyou PSG!!"

"I'm...going to do an Access Diploma in science...and...on to...uni next year. I'm...a lot more confident...I [don't] feel like I'm going to be ridiculed or ignored...I can go into this...field...I've always felt...I wouldn't be intelligent enough"

"now I'm strongly considering applying for a PhD programme!"

Empowered

Members' experiences during the project need to be seen in the context of how women experience pregnancy and parenthood in our society. There was a clear sense here that mothers felt ignored, sidelined, patronised and not listened to, by society and by many healthcare professionals. Especially during pregnancy and birth. Against this background, being asked what they wanted to know, and given some power to find it out, felt liberating and validating. Many members felt quite passionately about the opportunity to make a difference, especially to areas of medical care where they had had bad experiences.

Context: Our members felt that a lot of the maternity care and child-rearing advice they'd experienced was not evidence-based and that in the transition to parenthood they became isolated and lost their identity. The following quotes illustrate this.

"The way women are treated when pregnant (ime) really beggars belief. It wouldn't happen in other areas of care."

"I was constantly told 'because guideline' in my first pregnancy, and never given any evidence for it by my consultant."

"The first person to talk about actual risk factors with numbers etc was the consultant Midwife who I saw around 36 weeks."

"Soooo many examples of women feeling lied to, not listened too, of maternity care not being evidence based."

There was a clear feeling that because women are the ones (in most cases) who become the primary care giver for small children, their needs and experiences are not taken seriously.

"I think medicine is still paternalistic, women's issues are ignored, I see it so frequently at work."

"I don't think there is a lack of research/evidence. I think there is a shortage of people paying the blindest bit of notice to it."

"I watched that Michael Mosley thing on the BBC about sleep and it was all about middle aged men. And about how if their sleep is disrupted how awful it is etc etc."

I was really struck by the fact no one seems to GAF¹ about women struggling to sleep in pregnancy or struggling with a baby waking a zillion times a night."

Against this background, mothers responded fervently to the chance to tell their stories, and that someone was finally listening to them.

"I've been waiting for this day for six years." (Comment from a non-member on our Facebook page post asking for people to tell us about their experiences with [HCPs](#) and breastfeeding support.)

Some of the groups (Breastfeeding and healthcare experiences, Big Birthas) specifically did research on mother's experiences and 'not feeling listened to' was a very strong theme.

For many in these groups, talking to others and sharing experiences was transformative – they could now see it wasn't just an individual experience, but a shared one.

"Mostly that I am not alone and that the way I was treated (as a big birtha) was not OK."

"Listening to others' experiences really opened my eyes."

"I've only just clicked listening to Amber Marshall's comments [in the podcast] how the negative throw away comments experienced in the Big Birthas mirrors that of many of those in the HCP/Breastfeeding study."

Group members clearly felt very energised that now they were being given the tools and a structure to work together to find evidence and do something about it.

"Proud to be part of something that's results could lead to fairer treatment of bigger mums"

"I cried reading many of the stories and then I felt angry on behalf of all the failed mothers!"

"I am so glad this [research] was happening and I could do something constructive."

"I really hope that people will listen to us about this. Reading the stories was incredibly powerful for me, but we've got to try to find a way to get that across to the people that can make changes."

¹ GAF = Give a fuck

But even in the other research projects, people clearly felt emotionally affected by being able to be part of science, and shape it to do something they thought was important.

“Feeling of having contributed to science.”

“It was GREAT to feel involved in science research.”

“Felt I made a difference, could see the full-time scientists were inspired to continue the line of research.”

“A chance to be involved in some really cool research, designed by the people it matters to, so hopefully it’ll have impact!”

“Really a feeling of being part of a community of people working for a similar cause. And that cause will have some exciting implications for other parents.”

“It’s a privilege to be involved and I feel proud of playing a little part in furthering understanding of the significant value of breastfeeding. It is currently woefully underplayed.”

“I am passionate about informed choice and the projects we are doing really will inform other parents to make whatever decision fits them.”

Self-actualisation

We’ve included in this theme the social and emotional outcomes of the project, for members, which seemed less directly related to the science content. There was a palpable sense that members loved the chance to have intelligent conversations with other adults, particularly other mums who were going through the same experiences, and to work together as a community to achieve something. Again, this can’t be divorced from the context of mothers with small children feeling isolated, starved of adult interaction and as if they’ve lost their identity. There’s obviously some overlap here with the increased confidence and empowerment subthemes of ‘feelings about science’. These things all worked together and seemed interlinked for our participants too.

Something other than being a mum...

When the accompanying adults were interviewed at the final event, three interviewees saw the group as a way their partners could do something other than parenting; two used the word “outlet”.

“feeling that she’s contributing to something more than childcare which is a big part of her life.”

“it’s a really good outlet for her, something other than being a mum.”

Members too, in survey responses, interviews with Stephanie and in comments in the groups, talked about getting to use their brains, getting to be part of something, and be something other than ‘mummy’ again.

"This was one of the most empowering things that I could have gotten involved in at a time when I was feeling vulnerable and frustrated. I was able to use my brain again, and assert my identity as both a mother and an academic and also learn loads and meet other inspiring people."

"I've made friends and had my faith in myself and abilities restored. I can still use my brain and read academic texts (and science ones at that!) and have intelligent, grown up conversations!"

"Keeping my brain alive while on mat leave."

"Recognising that while we may be Mums with baby-brain and dubious stains on our clothing, that we're still capable, intelligent beings and we have a lot to contribute!"

Community

People talked about getting to be part of something, and not just a group to 'hang out' in, but actually working together to do something, finding people in the same situation as them and feeling less isolated.

"Gave me a sense of being able to be involved in something real, even if on the fringes, while at home caring for young children."

There was a sense of a shared mission. Research in happiness science tells us that feeling part of something bigger than yourself, and working with others, makes people happy in a very meaningful sense. Looking after small children can be very isolating.

"I felt like part of a movement!!"

"Bringing like minded, motivated, but undervalued mothers together to buzz off each other and build interesting studies that matter to people."

"A sense of group passion for the topic and for making changes"

"A sense of joint purpose and community"

"It's been really lovely to be part of a very similarly minded group of parents who all understand your home situation and can make allowances for babies and toddlers, but still produce some amazing results."

"the creation of a community of people who have a similar goal and...actively working towards that...is a very different way of participating in a group"

"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!"

"it all provides a sense that you're not alone"

Taking ownership of the project

To illustrate this emotional effect of the project, we found a lot of examples of group members taking ownership of the project. Whether this was due to the large emotional and social effect it had had for them, or whether it was due to the DIY ethos we'd tried to foster (or both) is hard to say.

But, for example, members frequently posted our links to their own Facebook feed – for example, transcripts of our Q&As, requests for volunteers to donate milk, or fill in surveys.

Unasked, members asked questions on their own Facebook like, 'Does anyone know of a cheap conference venue near Manchester?' when we said we were having trouble finding a venue

When Dr Dovey told the Mealtime Hostage group that he'd got hundreds of questionnaire responses, but it would take him several days to clean the data before he could start analysing it, members asked if there was a way that they could help him clean the data. And then they went ahead and did it, using shared Google Docs.

Another member heard a phone-in on Radio 5 about gender stereotypes and phoned in to appear on the radio and tell them about our research.

As the project was coming to an end, all the groups voted to continue, and people volunteered to admin the groups. 104 members came to a Q&A to decide how to keep the groups going after the project.

Impact on science and scientists

There were two main ways the project impacted on science. Firstly, finding (and starting to fill) research gaps important to parents in numerous fields of science. Secondly, they affected the scientists they interacted with - giving scientists new ideas and different perspectives on their work, feedback on their research and plans from a parent perspective, inspiration to do more public engagement, and positive affirmation from members who found their research useful.

Finding research gaps

All groups identified a research question which hasn't been asked before, and because of their expertise from lived experience they've asked questions and designed and run experiments in a different way. These have led to eight papers in press or in preparation and seven conference presentations so far, with at least two more to come.

"it's parents asking questions other people aren't"

"Almost single handedly you have opened up a new area of research"

"This is an awesome data set. I have never seen in my career to date a data set like this. This is massive... brilliant... I don't know anyone in science who has this."

Affecting scientists

Giving scientists new perspectives on their research, new ideas of research questions or approaches.

"It was great to be able to have a multi-way conversation and get other people's perspectives on my work."

"[Some of the] questions that were being asked potentially would make good research questions, as the field is very under-researched."

"Being part of PSG informs the way I want to conduct science, but also the way I engage with information outside of my own subject area."

Giving scientists useful feedback or comments on their plans.

For example, during a Q&A about the effects of computer games, Dr Pete Etchells (Bath Spa) invited PSG to contribute to an interdisciplinary meeting looking at screen time research. We were asked to talk about parents' interests, priorities and concerns about this research. A short-term group was created to share opinions and bring together material for our contribution. PSG representatives then went to the meeting and gave 'the parent perspective'.

"I cannot state strongly enough how important it was to have your voices there at the meeting. This is an issue that acutely affects parental worries about the effects that technology is having on their kids behaviour, and having people from PSG there with the experience and knowledge of these concerns was crucial to the success of the day. A lot of people mentioned to me that Tamasin's talk was the most insightful and useful one they went to that day, and it's really made me think how I can best include parent groups in future academic conferences and workshops." Dr Pete Etchells

Baby Biome researchers asked PSG to help with shaping the design of their proposed cohort study. Members quizzed the researchers in three Q&As, and discussed the research for two weeks in a special temporary group, giving feedback on draft surveys, recruitment and retention plans, and sharing the questions they'd want the research to be answering.

"You know, for a clinical trial you're not going really change it after you've got [the grant approved], because that's what the trial is funded and they expect to see the outcomes...So the PPI input needs to go in beforehand."

Inspiring more public engagement

It gave scientists new ideas of how to communicate their work and encouragement to do more public engagement.

"Really like this initiative, as I am a big believer that real impact from research comes from engaging with the primary users of the knowledge produced."

“The importance of public engagement has been emphasised to me and I am trying to incorporate this further into my work day.”

Scientists came for us for ideas on how to work with mothers with small children. Prof Amy Brown (Swansea University) contacted us asking for details of how we organised our residential weekend as a funding body turned down a proposal, saying that it wasn't feasible to get breastfeeding mothers to come to an event.

Feeling appreciated

And scientists got a warm fuzzy feeling, after hearing directly from members how their work had affected them. For example, Dr Maryanne Perrin (University of North Carolina) did a Q&A with us about the composition of breastmilk up to 18 months pp. One member afterwards printed out her journal paper and took it to a GP appointment. “I went in armed with a copy of Perrin et al!” And then emailed Maryanne afterwards to thank her. Maryanne replied, “Thanks, that made my day! It's slow in academia to see the impact of your work (often measured in the number of other papers citing your work). It's really awesome to know your work is being used at the family level! Thanks for sharing this. :)”

Conclusion

The outcomes of this project clearly involved an increase in [science capital](#) for members - their science knowledge and understanding increased and they developed a sense of themselves as having a science identity and confidence in relation to science. But the '[extreme citizen science](#)' approach had outcomes that clearly went beyond that. This wasn't a project in a traditional 'science communication' mould, which just equipped them with some useful knowledge.

Members felt emotionally and intellectually engaged, they felt empowered. Science became a tool for them to assert themselves in the world and, in many cases, to right wrongs on behalf of themselves and others.

This project is indivisible from the experiences of becoming a mother, and primary care-giver for a small child. To engage this audience in the way that we have, we had to shape the project around the practicalities of motherhood, and around the pressing needs for information about pregnancy, birth and childrearing that women have at this life stage.

This is an audience who are often overlooked (other than as the people who might bring, e.g. a small child to a child-orientated event at a science centre). But they are an audience with emotional and social needs, and informational needs which biomedicine (broadly constituted) should be answering. By consciously basing the project around the needs of mothers, we have been able to empower them to help shape future health research. This benefits both them personally and directly (in feeling listened to and self-actualised) and health research, by spotting missed opportunities, making it more informed about the needs of its publics, and creating more inclusive and people-centred research practice.

Our Groups and the Science They Shaped

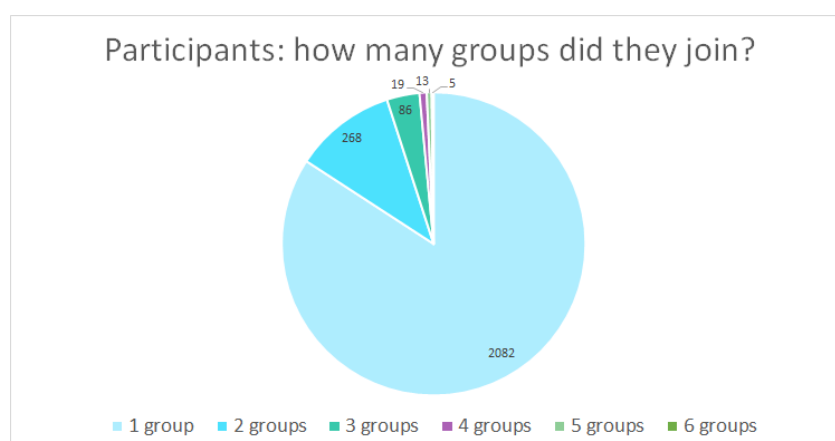
In this section you'll find:

- Details on each of our eight groups including
 - Members
 - How we recruited each group
 - The character of the group
 - Their research, findings and dissemination plans
 - An overview of our two special projects (“mini-PSGs”)
-

Group statistics

We currently have 2,608 members over 10 groups (8 main [PSG](#) groups, plus two short-term, special groups)

Figure 1 – How many groups did our participants join?



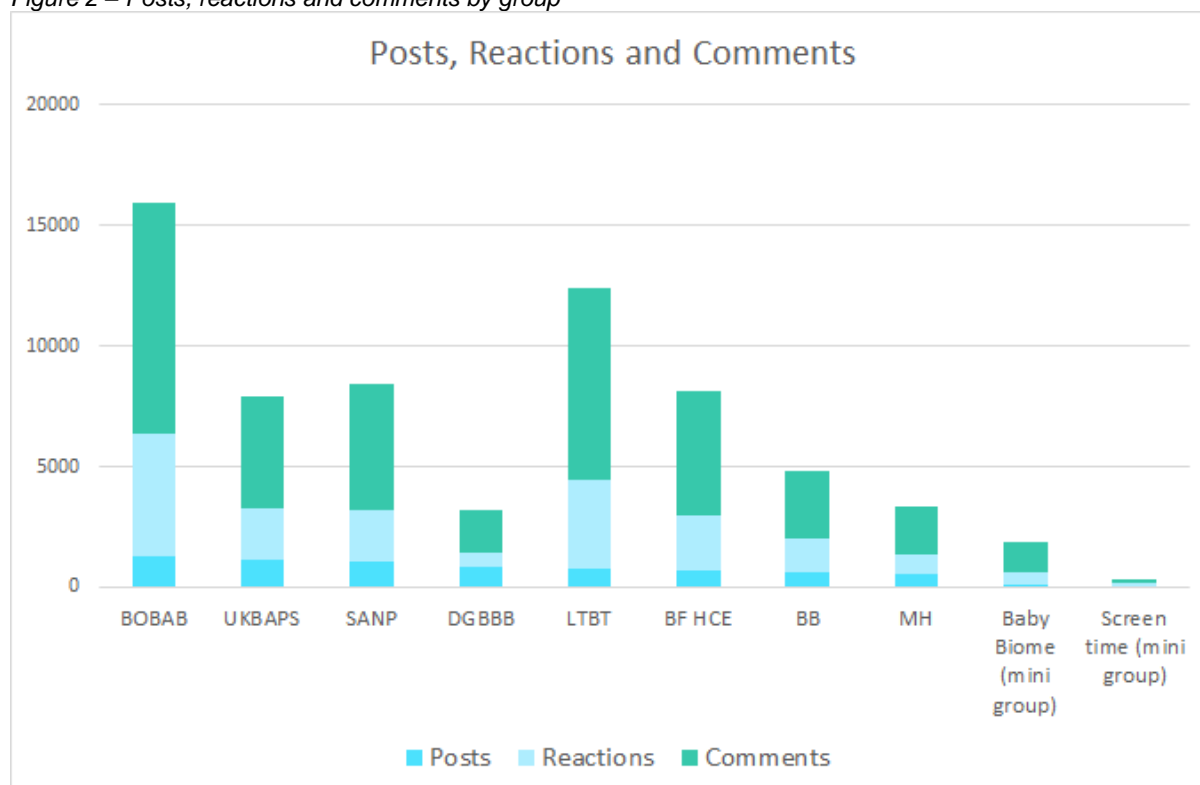
Of these:

- 391 members are in more than one group
- 2083 members are in just one group
- 129 members are just in the Baby Biome special group

For the most part, members were only heavily involved in one group, even if they were members of more than one.

Although all groups completed research projects, the Facebook groups showed quite a variation in activity, with the larger groups (Breastfeeding Older Babies and Beyond PSG and Let Toys Be Toys PSG) commenting and reacting in greater numbers than the smaller groups. In all the groups, the majority of posts were initiated by PSG team members despite members being encouraged to create their own posts. Over the course of the two years, our groups posted over 61,000 comments, though these were spread unequally over the time, increasing with our membership and with more complex tasks.

Figure 2 – Posts, reactions and comments by group



The Groups

Over the two-year project we ran 10 main Facebook groups – 8 PSG groups (4 for each year), designing and running their own research; and 2 special project groups. In addition, we used just over 90 temporary Facebook groups for Q&As and group meetings and for the participants of PSG events.

Groups are a key Facebook structure. While Facebook Pages are typically used by businesses and organisations to represent their “brand”, Facebook groups are designed for communication; they are online spaces where people can come together around common interests to chat and share opinions. There is no shortage of Facebook groups on parenting-related topics.

Some flexibility has been designed into the structure of Facebook groups. For example, admins have some control over how public a group is, with options ranging from ‘public’ to ‘secret’.

All of our groups began as “public” groups- meaning all posts are visible, but only members can post or comment. However, every group decided independently that they would prefer the group to be “closed”, meaning only members can read the members’ comments and other content within the group.

Membership applications can be easily regulated. Groups can be set so that anyone can join, so that members can approve their friend’s membership requests, or groups can be restricted so that admins must approve membership requests. Admins can set automated questions for people who request membership, and a group can be set to allow members of

other Facebook groups immediate access, on application. Applicants to PSG groups were accepted if they met certain entry requirements - e.g. membership of the “mother” group (see individual groups for details).

Members can visit the group Facebook page and have immediate access to all threads, saved files, events and membership lists. However, as is typical among Facebook users, most of our members interacted with group posts their personal Facebook ‘feed’, meaning individual pieces of content from the Facebook group appear to them alongside content from other groups, pages and their friends.

The quantity of content on Facebook is immense, and so Facebook uses algorithms to determine which content gets sent to individual users’ feeds. Part of the art of admining a Facebook group is learning to work with the algorithms so that your members see your content. There is a certain amount of educated guesswork involved in this as Facebook doesn’t publish the parameters, and they seem to change every so often.

Recruitment

In the first year, our groups were “daughter” groups of existing Facebook groups, identified during Nappy Science Gang and invited to take part in PSG. During the nappy project, admins had to dedicate an unexpected amount of time to dealing with new members who didn’t understand what the project was about and were just expecting another parenting support group, and to dealing with friction with some other cloth nappy groups, whose admins disliked the results of our experiments. The daughter group model enabled gatekeeping duties to stay with the mother group, and us to build on established group norms and sense of community. It also meant that we had a relationship with the mother groups, for gathering research ideas, helping with our experiments (e.g. distributing questionnaires, recruiting participants) and disseminating our outputs such as Q&A write-ups, and research findings.

In the second year, these methods were used for recruitment:

1. An application process was made available to groups so that they could apply to become a PSG group, in the mother / daughter group format (Mealtime Hostage)
2. The project team searched for under-represented groups, via existing networks, by asking PSG members for suggestions and introductions, and by approaching relevant organisations.
3. Ideas for new groups were suggested based on interest from existing group members (Breastfeeding and Healthcare Experiences)
4. The project team approached potential collaborators (Let Toys be Toys, Big Birthas).

Science-Aware Natural Parenting Science Gang

Table 5 -SANP PSG summary

Science Aware Natural Parenting PSG (SANP PSG)	
Members:	250
Recruited from:	Science Aware Natural Parenting (Facebook community)
Chosen topic:	Effect of babywearing* on the skin and core temperature of a baby
Type of study:	Experiment in a university lab
Collaborated with:	Dr Davide Filingeri, Loughborough University
Q&As & other Facebook events:	50

*The term 'babywearing' means to use a sling or wrap to carry an infant.

“This is a project that we are really excited about. We love collaborating with you guys - it’s clear route for real-world impact. If we can be the first ones to find good data, we could really influence NHS policy”

Dr Davide Filingeri, Loughborough University

Mother group: Science-Aware Natural Parenting is a secret Facebook group (i.e. it does not appear in searches) for parents who subscribe to natural/gentle/attachment parenting methods but also place value on evidence-based decisions. The membership is maintained at around 1000. General interests are similar to most parenting groups but lean towards intersectional feminism and ongoing active support for a few members’ personal situations.

SANP PSG Character: The group has a stable membership of around 250 with members with children ranging from newborns to teenagers. The group is not very chatty as members already have an established community group for discussing science and parenting in their mother group. Some members have been quite vocal about their opinion that the PSG group should remain tightly focussed on their research.

Interests: Wide and unfocussed. There was a great interest in practices strongly supported in attachment parenting communities such as breastfeeding, co-sleeping and babywearing, but also in less mainstream parenting choices such as home education/[flexischooling](#)/delayed school starting, unregulated screen time, and baby-led weaning.

Research: A personal experience by a member of a baby going floppy while in a sling led to a last minute change of plan to investigate the temperature of babies during babywearing (being carried in a sling or structured carrier).

Babywearing is rapidly increasing in popularity, with a wide range of slings and carriers on the market, and peer-led sling libraries appearing across the country. However, there is very little evidence-based guidance on safe babywearing beyond the [TICKS](#) advice which focusses on the baby’s breathing rather than temperature gain. Many parents refer to NHS guidance of dressing a baby in one extra layer than yourself, but we were unable to find any research that provided evidence for the accuracy this advice while babywearing. As many of the group carry (or have carried) their children regularly, they were keen to find out more and

increase the quality of information that is available to parents, hopefully reassuring them (and health care professionals) that babywearing is a safe practice.

Initially the group wanted to investigate the conditions where babywearing might lead to overheating, but as it became apparent that there was no research on the subject at all, they decided to cover the basics - how does the combination of the body heat of the carrying adult (in this case, the mother) and the extra layers of a carrier or sling, affect the baby's temperature while the adult is at rest or moving around the house?

Following a Q&A on infant thermoregulation, an offer of collaboration and lab space was made by Dr Davide Filingeri of Loughborough University, and the group devised an experiment to investigate the core and skin temperature differences of a baby during babywearing. The temperature of a baby was monitored before and while in a sling, before and after the mother undertook light exercise, and with and without wearing the NHS recommended one extra layer than the adult.

9 mother-baby dyads took part in the experiment at Loughborough University. 3 were members of the group, but due to the need to have babies of the correct age and ability to travel to the lab the others were recruited locally.

Findings: Details are currently under a publishing embargo. Preliminary results suggest that the baby's skin temperature rises during babywearing, though not uniformly over the body. The core temperature did not vary much during the duration of this study, and in fact reduced slightly. The addition of an extra layer of clothing did not affect the baby's temperature.

Dissemination:

- A paper authored by PSG, Davide and two Loughborough colleagues is currently under consideration by a major journal.
- Group members presented their work to the Midlands Baby Carrying Convention (October 2018).
- Davide presented the work to the International Conference on the Physiology and Pharmacology of Temperature (October 2018)
- Davide and group members presented their work at a meeting of the Institute of Physics and Engineering in Medicine Physiological Measurements Special Interest Group (March 2019).

Dumfries and Galloway Parenting Science Gang

Table 6 – DGBBB PSG summary

Dumfries and Galloway Bumps, Babies, Beyond PSG (DGBBB PSG)	
Members:	80
Recruited from:	Mummies United and other Facebook groups under the DGBBB banner
Chosen topic:	Flexischooling
Type of study:	Collection of basic data through FOI requests Qualitative analysis of interviews
Collaborated with:	Dr Tara Jones, University of the West of Scotland
Q&As & other Facebook events:	28

***“We're using your freedom of information research to argue our case with Glasgow!”
Mother of flexischooled children***

Mother group: Dumfries and Galloway Bumps, Babies and Beyond is a charity that aims to support parents across the Dumfries and Galloway region. Established originally to promote breastfeeding and run breastfeeding support sessions, the group now runs sessions on many themes (including sling and nappy libraries, forest school) across the county. It coordinates several Facebook groups, the largest being Mummies United which provides information about parent and child activities and member requests for recommendations for, for example, camp sites, baby equipment, days out. The group has approximately 1000 members and is relatively quiet – it isn't used for discussion so much as for seeking local information.

DGBBB PSG Character: The group grew slowly to a membership of around 70, bolstered by PSG Director, Sophia attending local groups and publicising the group. Similarly, to the mother group, the group is quiet, without much chat. In order to maximise the involvement of the local flexischooling community, who by and large do not Facebook, this group moved to operating almost entirely on Facebook messenger, and instant messaging service where messages are displayed chronologically and cannot be grouped by thread. In the platform move we lost some active members, but gained other members with a specific interest in flexischooling.

Interests: As the group is geographically selected, the range of interests are wide. A large proportion of the questions suggested looked at parenting styles, for example, the effects of structure vs unstructured play, how parenting can affect a child's ability to make and maintain relationships. There were a few questions that could be seen to relate specifically to the rural and disparate locations in which members are based, for example what is the effect on children of spending a lot of time in the car, what difference does playing outside have on children, what is the effect of the area of space in which a child is free to roam?

Research: The group found it difficult to choose a research question as there were no clearly unifying interests, and the leading topics after voting on potential areas for investigation were well covered by existing research (limiting sugar, potty training, co-sleeping). A face-to-face meeting, with childcare and cake laid on, was held locally to

encourage more in depth discussion, during which the idea of investigating flexischooling, a little-researched topic but key to many rural communities, was suggested.

There is increasing discontent with the UK education system amongst parents. Many are unhappy with school start age of 4-5. Many believe that structured education at this age is ineffective and not developmentally appropriate and point to European norms of starting school at age 6 or 7 as more desirable. Some parents consider current education policy to be overly pressured and exam-driven and feel that the curriculum has been squeezed so tightly that children are no longer being provided with a balanced education including the arts, sciences and sufficient physical exercise. In addition, children with special educational needs are not always well catered for, and schools are often unable to provide the range of interventions that parents feel are necessary for their child to access education effectively.

Increasing numbers of parents choose to home educate, but some families want to make the most of both education options for their children - to attend school part-time and spend the rest of the time home educating. This is known as flexischooling.

Some schools, such as Hollinsclough Church of England Academy² in Staffordshire, now offer flexible attendance as standard, but figures are not collected centrally (either for the UK, or for Scotland), so no-one knows how many children at other schools are flexischooling in total.

Communities of parents who wish to flexischool have developed on Facebook, and it appears that the majority of schools and local authorities are not keen to entertain flexischooling and suggest that it is not in the best interests of the children, teachers or school. However, despite much interest from parents, there has been extremely little research into flexischooling, most of which has been carried out by master's-level students, and the group was unable to find any research at all about flexischooling in Scotland. This discovery was confirmed by experts during Q&A sessions. The subject is almost entirely unresearched.

With committed flexischooling families within the group, it was an area that clearly required our attention.

With the support of Dr Tara Jones from the University of the West of Scotland, the group decided to survey the extent of support for, and numbers of families registered as, flexischooling across Scotland using Freedom of Information Requests to all 32 local authorities. Additionally, the group decided to investigate the motivations for, and experiences of flexischooling among parents using a questionnaire distributed within Dumfries and Galloway, and the experiences of teachers who encounter flexischooling by conducting interviews.

Responses from 31 of the 32 FOI requests were received. 23 parent questionnaires were returned. 4 interviews were conducted with local teachers.

² <https://hollinsclough.staffs.sch.uk/>

Findings: Findings include:

- an estimation of flexischooling numbers in Scotland;
- the over-representation of Additional Support for Learning pupils in flexischooling numbers;
- the motivating factors for why parents choose to flexischool their children;
- the surprisingly positive experiences of teachers with experience of teaching flexischooling pupils.

The full report can be found <http://parentingsciencegang.org.uk/wp-content/uploads/2019/03/PSG-Flexischooling-in-Scotland-research-final-report.pdf>

Dissemination:

- The group have authored a paper based on their research for Other Education (in press, 2019) www.othereducation.org, issue 8, vol 1.
- Our work is highly regarded by educational academic experts, such that feedback comments provided by us to academics also researching and writing about flexischooling in Scotland were considered extremely helpful for ensuring rigour and validity in academic publications.
- A group member and PSG Director, Sophia spoke about our research on *Mornings with Kaye Adams* on BBC Radio Scotland on 21 March 2019.
- An abstract has been submitted to the Scottish Educational Research Association Conference.

Breastfeeding Older Babies and Beyond Parenting Science Gang

Table 7 – BOBAB PSG summary

Breastfeeding Older Babies & Beyond Parenting Science Gang (BOBAB PSG)	
Members	900
Recruited from:	Breastfeeding Older Babies & Beyond (Facebook community)
Chosen topic:	The Constituents of Breast Milk from Mothers Breastfeeding Older Infants (joint with UKBAPS - PSG)
Type of study:	Samples analysed by mass spectroscopy and for microbiology and fat percentage
Collaborated with:	Dr Natalie Shenker and Dr Simon Cameron, Imperial College, London
Q&As & other Facebook events:	54

Mother Group: Breastfeeding Older Babies and Beyond (BOBAB) is a fast-growing Facebook group (growing from 18,000 to 30,000 members during this project) providing community support to mothers who breastfeed (or feed with human milk via another method) a child of a year or over.

Research: See *BOBAB PSG and UKBAPS PSG collaboration*.

UK Breastfeeding and Parenting Support Parenting Science Gang

Table 8 – UKBAPS PSG summary

UK Breastfeeding and Parenting Support Parenting Science Gang (UKBAPS PSG)	
Members:	280
Recruited from:	Recruited from: UK Breastfeeding and Parenting Support (Facebook community)
Chosen topic:	The Constituents of Breast Milk from Mothers Breastfeeding Older Infants (joint with BOBAB - PSG)
Type of study:	Samples analysed by mass spectroscopy and for microbiology and fat percentage
Collaborated with:	Dr Natalie Shenker and Dr Simon Cameron Imperial College, London
Q&As & other Facebook events:	54

“We’d investigated mastitis in cows, but we’d never thought about using this technique on breastmilk. None of our team is a mother”

Dr Simon Cameron, Imperial College

Mother Group: UK Breastfeeding and Parenting Support has a strong community of 14k members. The group offers parent-to-parent help, support and guidance for breastfeeding and other areas of parenting. UKBAPS members tend to join the group with young babies rather than older children.

Research: See *BOBAB PSG and UKBAPS PSG collaboration*.

BOBAB PSG and UKBAPS PSG collaboration

BOBAB and UKBAPS PSG Character: PSG offered these huge groups a different kind of community - one with a similar character to the mother groups, but with a focus on science within a group small enough to be able to get to know other members better. The culture is supportive and members are respectful of each other's opinions.

They are used to looking for scientific evidence to back up their views and will share information freely such as in the example below. This member took research by Professor Maryanne Perrin on human milk composition for 1-year-olds, as protection against anticipated negative comments from [HCPs](#) and recommends it here to other group members.

"I went armed with a print out of Perrin et al. to the paediatrician today with my 33 mth old. The appointment was to see if there is any medical reason for his diddiness [small size] so I couldn't leave out the fact he's breastfed. I'd prepared what I would say when asked why he's still breastfed... ...Attached link to Perrin et al below if you haven't seen it" (BOBAB member)

Members have said they appreciate that no one is made to feel stupid for asking questions.

The feeling of being united against an unjust world likely does a lot for community spirit and purpose: BOBAB and UKBAPS groups are motivated to fight injustice which they experience as breastfeeding mothers, or which they see others endure and as a consequence it's arguably easier for such a group to recognise ways in which research could make a real impact on parenting.

Interests: A common discussion in both mother groups is the pressure to stop breastfeeding from friends, family, colleagues and HCPs before the mother feels the child is ready. Despite WHO and NHS advice (that breastfeeding should continue to age 2), there is not a culture of breastfeeding in the UK, especially past the newborn stage and this creates a vicious circle, where people don't commonly see breastfeeding, so it doesn't seem normal, and so they don't do it, reinforcing the norm.

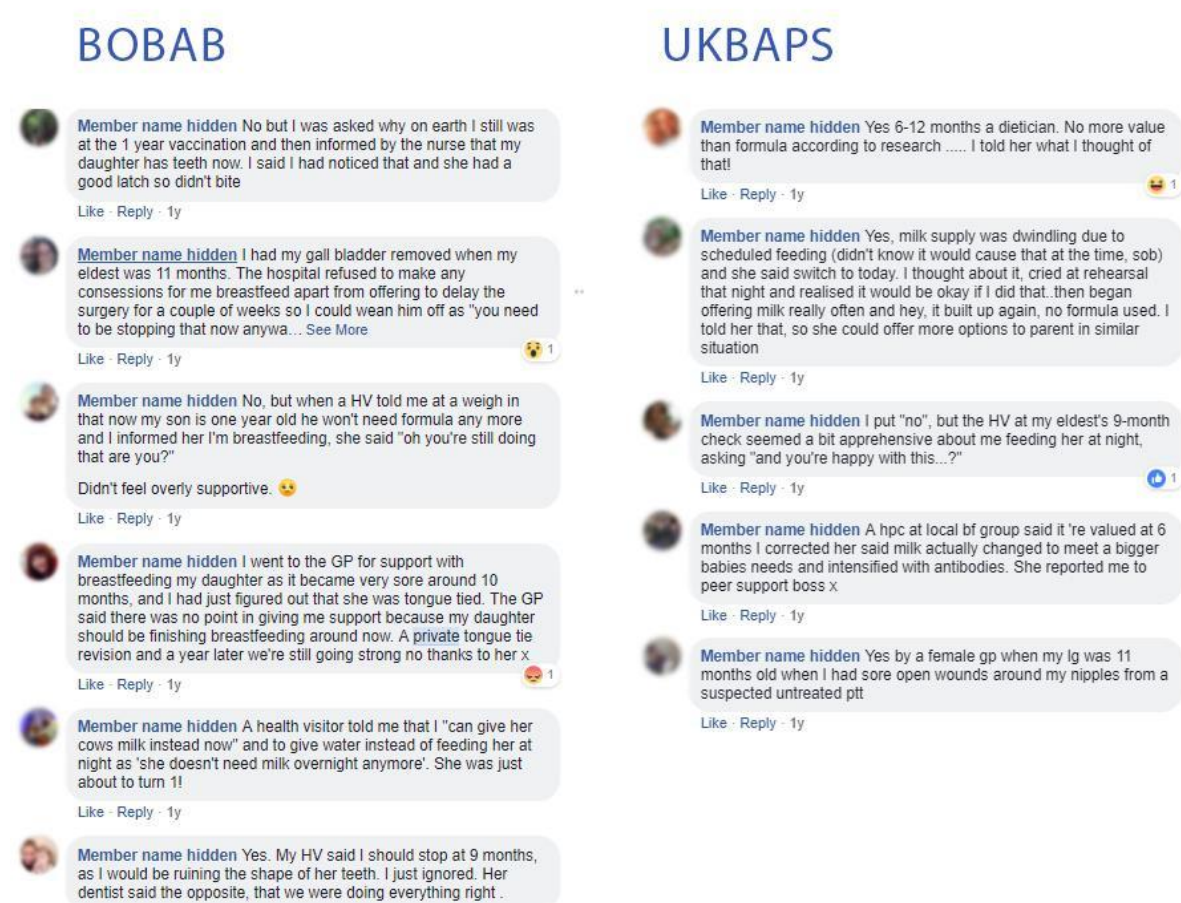
Many members of both groups related experiences of being told that breastfeeding has no benefit beyond 6 months or 1 year (see Figure 3 – Members recounting their experiences of being told breastmilk has no benefit beyond 6 months/1 year), and in a poll on both groups, around 45% of respondents in each group reported that they had been told by a HCP at some point that they should stop breastfeeding or that their milk had no value.

There is little research on the composition of breastmilk for children above six months and no research focussing on milk for over 18 months. Given that the biological norm is breastfeeding until between 4 and 7 years, this represents a clear research gap. Group members wanted to find out what was in breastmilk for older children, and hopefully start to understand what role it might play for the older child.

A Q&A with Hearts Milk Bank founder Dr Natalie Shenker on the composition of breastmilk led to the offer of collaboration with Natalie and Dr Simon Cameron (Imperial College) who were considering using a newly developed mass spectroscopy technique to investigate

breast milk composition. Both groups were excited by this offer and decided to combine efforts and work together on one research project.

Figure 3 – Members recounting their experiences of being told breastmilk has no benefit beyond 6 months/1 year



Research: In collaboration with Natalie and Simon the groups decide to investigate the question, *How does the composition of breast milk change as children get older?* using a [rapid evaporative ionization mass spectrometry technique \(REIMS\)](#) developed by Simon's lab.

The process of setting up the study was simplified as it aligned closely with Natalie Shenker's research interests and was able to take advantage of existing ethical approval for her Breastmilk Epigenetics Cohort Study (BECS) - Health Research study, an ambitious large scale study of breast milk, planning to recruit some 18,000 mothers. Using this approval saved considerable time as the project did not need to seek ethical approval for a new study involving breast milk - classified as human tissue. However, this meant that the groups' freedom to design questionnaires according to their specific interests and stylistic conventions was limited, as questions had to be selected from the bank of pre-approved survey questions.

130 mothers with over 130 children travelled from all over London (and some from further afield) for a one-day event at Charing Cross Hospital in London to donate breast milk. Usable samples were obtained from 117 mothers with children aged from 6 weeks to 6 years

and then analysed in Simon's lab using REIMS, an examination of the fat content and microbiology analysis.



Figure 4 – UKBAPS PSG member Mo Ade created this image, after asking experiment participants for three words each, to describe their experience of the experiment day.

Initial findings:

Simon's lab is still working on analysis, and we cannot report details of the initial findings as we hope to publish them in the near future. However, preliminary findings suggest:

Fat analysis

- Fat content of breast milk appears consistent across age range
- Fat content of breast milk is not affected by method of expression

REIMS analysis

- The *overall* content of human breast milk analysed using REIMS does not appear to change based on age of nursling, however...
- REIMS detected approximately 150 metabolites (out of 6,900 identified) which appear to vary systematically across age groups. More work is needed to identify what these are and in what way they are different.
- All storage methods have significant effect on chemical content of milk.
- Storage at either -20 or -80 is preferred.

Dissemination:

- Findings will be published in a peer-reviewed journal by Dr Simon Cameron and Dr Natalie Shenker.
- Simon presented preliminary results at Metabolomics (June 2018).
- Group members to distribute via their personal and professional networks.
- Results shared on PSG website.

- Members had stalls at the Institute of Health Visiting Conference (May 2019) and the Primary Care and Public Health Conference (May 2019).
- Members invited to present at the All-Party Parliamentary Group on Infant Feeding (July 2019).
- Poster submitted to UNICEF Baby Friendly Initiative Conference.

Big Birthas Parenting Science Gang

Table 9 – Big Birthas PSG summary

Big Birthas Parenting Science Gang (BB PSG)	
Members:	155
Recruited from:	Followers of Amber Marshall's blog: Big Birthas Existing PSG groups, and by word of mouth
Chosen topic:	The effect of choice during pregnancy and labour for mothers with a high BMI
Study type	Qualitative study - thematic analysis
Q&As & other Facebook events:	32

“It's interesting that there is increasing preoccupation with maternal mental health but no-one seems to have any problems with essentially telling women with higher BMIs that they are putting themselves and their babies at risk.”

Clare Murphy, BPAS

Mother group: Big Birthas PSG arose from discussions with Amber Marshall, who runs www.bigbirthas.co.uk, a website providing information and support during pregnancy and birth to mothers with a high body mass index (BMI). After two high-BMI pregnancies, Amber was fed up with the discrimination and misinformation that she came up against, and realised that it was up to her to provide health care professionals with evidence to demonstrate that her pregnancies were not unduly dangerous or required such a battery of tests and interventions.

Amber joined us for a Q&A about her work, and such was the excitement and interest from members, that we decided to run a year 2 group for mothers with this interest.

The group was advertised on existing PSG groups, on Amber's website and on other parenting Facebook groups within members' networks. Prospective members had to answer two questions confirming that they supported women with high BMI to access health care with equity and without judgement, and that they understood the purpose of the group. The “risk” of this more open recruitment process has paid off - there has only been one difficult moment where one member felt that the group was insufficiently realistic about the risks of high BMI, and that was resolved quickly and amicably by group members.

BB PSG Character: Big Birthas PSG has always been characterised by an easy-going humour despite the experiences that have led members to join. The vast majority of active members have a high BMI and many experienced undesirable care during pregnancy and labour due to their weight. As there are no other well known Facebook groups catering for this community, the group has been chatty and active, regularly linking articles from elsewhere on the internet, sharing experiences and seeking advice.

Interests: Medically, high-BMI pregnancies and births are well researched and so the group concentrated on the experiences and feelings of mothers and the choices that they had been denied. We found that it takes a long time for research to affect clinical decisions and so

many mothers are being given advice that is not informed by the most recent findings. The group narrowed down their choice of research topic to water births or the choices offered to mothers during labour. Voting was split very evenly between the two, but eventually, motivated by many members' ongoing dissatisfaction with the ways that they had been treated and the effects of their labour and early motherhood, the group decided to look into the effect of choice during pregnancy and labour.

Research: A qualitative study was designed using email interviews with women with a high BMI to explore the effects of the choices that they were, or weren't offered during pregnancy and labour. 8 interview questions were asked, followed up by one email asking for additional details where necessary. The interviews were examined using thematic analysis.

There were 60 responses to our request for volunteers to be interviewed and 20 interviews completed.

Findings: As would be expected from qualitative research, the findings were not simple but encompassed a wide range of unsatisfactory (and some positive) experiences.

Many mothers felt that they were treated simply as a high BMI problem leading to HCPs expecting certain medical situations (e.g. GTT, high blood pressure, c-sections), and being disbelieving if they didn't appear. Even if there were no other risk factors, mothers found that their choices in where and how to give birth were immediately reduced. They experienced highly variable levels of expertise (and hence advice) across different HCPs, often receiving conflicting information. Over and over, mobility issues were used as a "reason" for reduced choice particularly in birth location and birth position, without supporting research evidence.

Many experienced unsatisfactory personal treatment by HCPs. The language used was often blaming, lecturing, patronising and mothers received repeated warnings about potential issues irrespective of their personal risk factors. Some mothers felt that options weren't fully presented, they were just told what would happen without choices, and if they questioned this, guilt used to "persuade" them. Sadly, many mothers felt that their feelings were neither consulted or valued, and worryingly, several reported that interventions were administered without their consent.

Most mothers didn't realise what choices they could have made during their first pregnancy eg refusing inductions, and many suffered extreme levels of stress and anxiety during pregnancy and labour.

During their second pregnancy, most mothers made an effort to equip themselves with increased relevant knowledge of risk factors and guidelines and were more confident to assert their views. Most acknowledged that they planned to fight for their right to make their own choices. Most made an active choice to use or avoid specific HCPs, with many seeking private midwives or doulas, but worryingly, some distanced themselves from health care altogether e.g. declining appointments and tests entirely.

Dissemination:

- Members shared results at a stall at the Primary Care and Public Health Conference (May 2019).
- Paper in preparation, co-authored with Dr Zoe Darwin.
- The group intends to continue as a support group and repository of relevant research and will continue their discussions about dissemination beyond the end of the project.

Mealtime Hostage Parenting Science Gang

Table 10 – Mealtime Hostage PSG summary

Mealtime Hostage Parenting Science Gang (MH PSG)	
Members:	327
Recruited from:	Mealtime Hostage (Facebook community)
Chosen topic:	ARFID (Avoidant / Restrictive Food Intake Disorder)
Study type:	Questionnaire followed by university-based analysis
Collaborated with:	Dr Terry Dovey (Brunel University) Prof Jackie Blissett (Aston University)
Q&As & other Facebook events:	26

“You guys have a great data set. It’s very, very good. Best one I have seen in a very long time. Better than my PhD students, but don’t tell them.”

Dr Terry Dovey, Brunel University

Mother Group: Mealtime Hostage-The Group is a 10k member-strong, international group of parents who have children who exhibit extreme selective or avoidant eating behaviours. A number of these children may well be typically developing and are in a food neophobic stage. Some children have received a diagnosis of the recently defined condition Avoidant/Restrictive Food Intake Disorder ([ARFID](#)).

The group is highly moderated – members support a [division of responsibility \(DOR\)](#) method (recommended by the large majority of experts) and questioning this method is not accepted within the group. The majority of posts are mothers asking for advice for their own specific situation, and posting successes, both minor and major. It is a very supportive group, and extremely topic-specific. There are no general or community-building posts. Members appear to post extensively for a period and then become lurker, sometimes commenting with advice or encouragement.

MH PSG Character: Similarly, to the mother group, the PSG group is extremely supportive but not chatty. Members tend to be extremely research-aware due to their own needs, and are confident in critically evaluating information. Members are highly attuned to the differences between developmental food neophobia and ARFID-like behaviour and have great attention to detail and nuance. The group is very focussed and members will take tasks away and complete them to the highest quality when their home life affords them the time.

Interests: The overriding desire of the group as a whole is to find effective interventions that will help children with ARFID and similar conditions, and to establish early and accurate identification of these children. However, our discussions with experts quickly showed that research into these conditions was still in its infancy and that intervention research couldn’t be carried out until the conditions themselves were better understood. The group were offered support by Dr Terry Dovey (Brunel University) and Prof Jackie Blissett (Aston University) in devising research that investigated aspects of interest of the characterisation of ARFID and similar conditions.

Research: As the group shared their experiences, they noticed that many of their children disliked touching new textures and the feel of certain clothes. Many were quite anxious about non-food situations and were more nervous than their friends about new places or situations. The group wondered whether this was typical of children with eating issues and how the two behaviours interacted - which one came first and could understanding the link between the behaviours enable early detection and more effective interventions?

With Terry and Jackie's help, the group decided to investigate the emotional behaviour (eg anxiety) and sensory sensitivity of children with a range of eating issues. Terry and Jackie worked with the group to select several validated measures that could be combined to create a questionnaire. The group publicised the questionnaire and then volunteered to help clean the data. Terry has performed the first interrogations of the data and the group were encouraged to suggest questions that we might be able to answer.

The questionnaire was viewed by 1238 people resulting in 551 usable submissions. Both Jackie and Terry have commented positively on the breadth of responses, including a notable number from parents of children with diagnoses of ARFID. This good response rate is likely to be because the group shared links to the questionnaire widely amongst informal networks of parents with personal interests in the condition; groups in which researchers (though a good number of clinical practitioners) are rarely present. In addition, Mealtime Hostage appears to be fairly representative of other similar support groups in that members are keen to engage with research. Many parents read widely and already have some knowledge of the gaps. This may have influenced their willingness to get involved.

Findings: The data is still being analysed, and a complete analysis will continue beyond the end of the project. Both Terry and Jackie were impressed with the scale of data acquired, which unlike many other studies by researchers in the field, includes a wide range of severity of eating issues including a good number with ARFID diagnoses.

“Great sample size – that gives us plenty of power for our analyses.” - Jackie

“The most useful bit is that you managed to get so many people with clinical issues. They are hard to see.” - Terry

It may be the first to include a large number of children who have also suffered from reflux.

“I don't know if there is ever been this amount of reflux kids measured before. Seems like it's [our data] a first” - Terry

The initial analysis indicates that ARFID and selective eating are likely to be on a spectrum with similar behaviours being displayed by children to different extents. There seems to be a clear link with Autism Spectrum Disorder. However, where children with ASD exhibit issues with externalising behaviours (eg disruptive behaviours), children with just ARFID and similar conditions exhibit more issues with anxiety and other internalising behaviours. Children with ARFID and similar conditions appear to have environmental sensory sensitivities but not social sensitivities. They are more likely to have visual and tactile sensitivities than auditory issues. A summary of the initial findings can be found here:

<http://parentingsciencegang.org.uk/experiments/first-findings-of-the-mealtime-hostage-research/>

Dissemination:

- A co-authored poster has been presented at the British Feeding and Drinking Group Conference (<http://venueswales.com/bfdg2019/>) and the International Conference on Children's Eating Behaviour (<https://www.munchiesuk.com/>).
- Members shared results at a stall at the Institute of Health Visiting Conference (May 2019)
- Jackie and Terry are planning 3 or 4 papers (and will name the group as an author) based on
 - Comparing children with ARFID to other children
 - Comparing children with ARFID to those with ASD and Neurodevelopmental disabilities
 - Examining the links between reflux and eating issues
 - An evaluation of the use of the validated measures used in our questionnaire

Let Toys Be Toys Parenting Science Gang

Table 11 – LTBT PSG summary

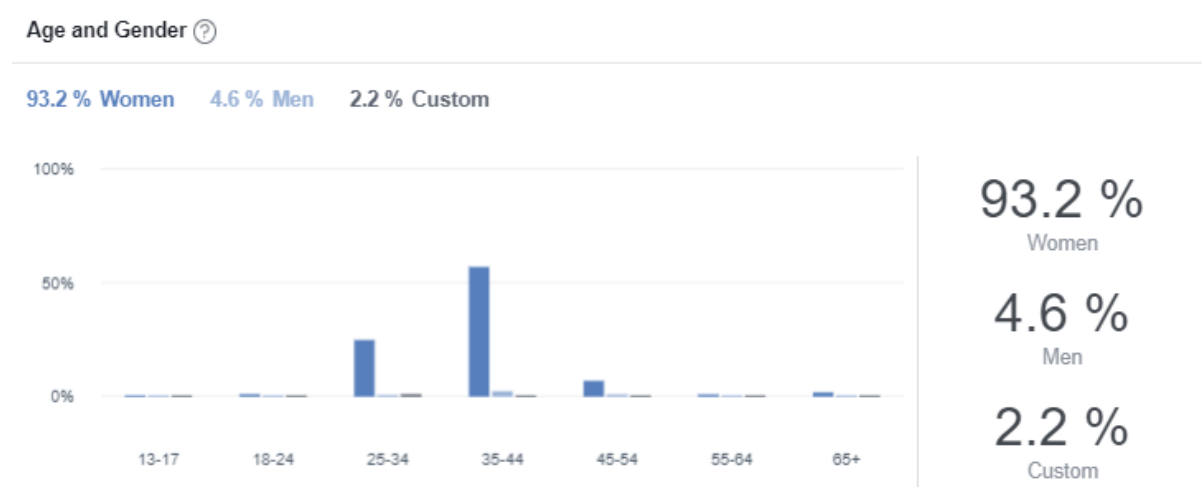
Let Toys Be Toys Parenting Science Gang (LTBT PSG)	
Members:	650
Recruited from:	Open recruitment for LTBT supporters, advertised on social media and to PSG members
Chosen topic:	Gender stereotypes in children's books
Type of study:	Intervention: children aged 3-7 read a book several times over 5 weeks, completing surveys before and afterwards.
Collaborated with:	Dr Lauren Spinner, University of Kent
Q&As & other Facebook events:	37

Recruitment: Let Toys Be Toys is an influential grass roots consumer campaign set up by a group of parents in 2012. It does not have a group; supporters typically follow the campaign on social media - the campaign has over 30,000 supporters following its Facebook page and 35,000 Twitter followers.: Let Toys Be Toys were approached by the project team and invited to participate. All Let Toys Be Toys supporters were welcome to join LTBT PSG after confirming that they understood the purpose of the group.

LTBT PSG Character: This was one of our larger groups - with 650 members at the end of the project. The group was active over the course of the project with members sharing articles and their own thoughts and experiences of gender stereotyping and children.

This was one of the few PSG groups where we had male members. However, under 5% of members were male (according to Facebook) and none were among the most active members.

Figure 5 – Members of LTBT PSG by age and gender



Interests: The parents of this group are all concerned with the effect of gender stereotyping in childhood. They wanted to know - can the books we read influence our children's attitudes to gender?

Research: Gender socialisation refers to the process of children being taught by agents (such as the family) about their gender role and the ways in which they are expected to behave according to their gender. Children's ideas of gender can be shaped by agents such as peers, siblings, and the media too.

Parents who are concerned about the effects of gender stereotyping on children are keen to know how much the books children read affect them - or not.

The group collaborated with Dr Lauren Spinner of the University of Kent in a study looking at the effect of gender stereotypes in books on 3-7 year olds.

This study was designed to examine the effect of exposure to gender stereotypic storybooks on young children's (3-7 years) gender-related attitudes and stereotypes. The study also aimed to explore the relationship between children and parents' gender-related attitudes.

The group identified three picture books: a gender-stereotypic book (Charlie Cook's Favourite Book by Julia Donaldson and Axel Scheffler), a gender-counterstereotypic book (Interstellar Cinderella by Deborah Underwood and Meg Hunt) and a gender-neutral book (The Book with No Pictures by B.J. Novak). The first 185 participants who successfully completed both the child and parent questionnaires were then sent a book and instructed to read it with their child three times per week for five weeks. The book participants received (i.e. the experimental condition which they were in) was randomly allocated

Children completed a gender-contentedness measure, an adapted version of the [Gender-Stereotyped Attitudes Scale \(GASC\)](#), and children aged 6 years+ also completed a measure which examined their attitudes toward gender-normative and –deviant boys and girls.

Parents completed two scales: The Modern Sexism Scale (MSS) and the New Modern Sexism Scale (NMSS). Parents also answered questions in relation to family demographics.

Following the five-week intervention, all participants were then asked to complete the same questionnaires for a second time. This allowed us to examine whether there had been a change in participants' attitudes following the intervention, and if this differed according to which book the participants had read.

Participants: A total of 131 participants completed the second parent questionnaire (129 female) and 84 of these also completed the child questionnaire, thus completing all the stages of the study.

Findings: The study didn't show the effect we were expecting.

Surprisingly, the girls in the stereotypic book condition showed an increase in "gender contedness" after reading the book as measured by the Gender-Stereotyped Attitudes Scale (GASC). No effects seen in the other 2 conditions. This sparked discussion within the group as to what could have caused this result. Members questioned whether the chosen book was stereotypical enough, for example, as it is generally the male characters involved in stereotypical roles - perhaps the presence of many female characters was the cause of this positive effect. See the PSG website for the report and the group's many theories.

- The storybooks had very little effect on children's or parents' gender-related attitudes.
- Children's gender flexibility on the GASC measure was not affected by condition.
- Children's age was positively correlated with gender flexibility
- Children (especially boys) more flexible about feminine- than masculine-typed activities. This is somewhat surprising and contradicts previous research which shows children tend to be more flexible about masculine-typed activities as these are linked to the higher-status group.
- Girls in the stereotypical condition reported greater gender-contentedness after reading the stereotypical book.
- Participant numbers were too low to perform statistical tests on children's attitudes towards gender-normative and -deviant characters, but descriptively, looking at the means, the Normative Boy was rated highest (indicating greatest approval) and the Deviant Boy was rated lowest, following previous research findings.
- Parents scored significantly higher on the NMSS than the MSS, indicating fewer egalitarian attitudes towards men than women. There was no effect of condition on parents' scores on either scale.
- Parents' scores on the MSS were negatively correlated with children's ratings of both the Normative and Deviant Girl characters.

Dissemination: Results report and discussion published PSG website

Breastfeeding and Health Care Experiences Parenting Science Gang

Table 12 – BF HCE PSG summary

Breastfeeding and Health Care Awareness Parenting Science Gang (BF HCE PSG)	
Members:	440
Recruited from:	PSG groups, particularly BOBAB PSG and UKBAPS PSG initially Then, members were welcome to join if they were part of the wider breastfeeding community on Facebook
Chosen topic:	Breastfeeding and healthcare experiences
Type of study:	Interviews with HCPs - qualitative - thematic analysis Also, survey for mothers - free text and quantitative questions - free text to be analysed by corpus linguistics
Collaborated with:	Dr Yan-Shing Chang, King's College, London Dr Gavin Brookes, Lancaster University
Q&As & other Facebook events:	39

“PSG has at its disposal what promises to be a rich and insightful collection of breastfeeding stories which give voice to the perspectives of mothers across the UK. In any other circumstance, it would be possible to write an entire PhD (and perhaps even a book!) based on this exciting and wonderful resource.”

Dr Gavin Brookes, Lancaster University

Recruitment: The idea for this group arose from discussions on breastfeeding and healthcare within year one groups BOBAB PSG and UKBAPS PSG. Members were initially drawn from BOBAB and UKBAPS. Once the group was well-established, group members decided to accept new members from a range of breastfeeding Facebook groups across the wider breastfeeding community. This differed to the mother-group model of other PSG groups in that there was no direct relationship with the groups, other than BOBAB and UKBAPS.

Group Interest: The Breastfeeding and Healthcare Experiences group are interested in the vital role that health professionals play in supporting mothers to breastfeed successfully.

UK breastfeeding rates are poor. In their 2017 Position Statement on Breastfeeding, the Royal College of Paediatrics and Child Health (RCPCH) note that:

The UK has one of the lowest rates of breastfeeding in Europe. An analysis of global breastfeeding prevalence found that in the UK only 34% of babies are receiving some breast milk at 6 months compared with 71% in Norway.³

One of RCPCH's key recommendations from the same report:

³ RCPCH (2017). Position statement: breastfeeding in the UK | RCPCH. [online] Rcpch.ac.uk. Available at: <https://www.rcpch.ac.uk/resources/position-statement-breastfeeding-uk> .

Breastfeeding is a natural process. However mothers may require support, knowledge and education. With such support, the expectation is that most women will be able to breastfeed.

However, the World Breastfeeding Trends Initiative shows that the level of training that UK health professionals receive on breastfeeding as part of their pre-registration training varies widely between professions, with few relevant professions meeting the WHO standards.⁴

The mothers in this group are keenly aware of the practical implications of this lack of training on the ground; all are members of breastfeeding communities on Facebook, where it is common to read stories from mothers about sub-standard advice given to them by HCPs.

BF HCE PSG Character: This group had a unique mix of breastfeeding mothers from a range of backgrounds including several breastfeeding mothers currently working as HCPs; approximately 50% of the group were HCPs or peer supporters breastfeeding their own children. Thus the group were focused not only exploring the - often negative - experiences of mothers, but also on how to communicate their results to HCPs in such a way that supports improvements to their professional practice, rather than undermining them.

Research: The group ran two complementary studies:

1. Breastfeeding and Health Care Experiences
2. How does Personal Experience of Breastfeeding Affect the Professional Practice of Health Care Professionals?

Study 1: Breastfeeding and Health Care Experiences

The group collaborated with Dr Gavin Brookes of the Lancaster University to explore the effect of interactions with HCPs on the infant feeding journeys of mothers who breastfeed or who wanted to breastfeed.

In total 741 breastfeeding narratives (257,319 words) were collected, along with survey data. These written narratives were then text analysed by a team of group members using corpus linguistics techniques.

Preliminary results: Preliminary findings identified the following issues and solutions across the breastfeeding journey narratives.

Table 13 – BF HCE study 1 preliminary results

Issues	What worked / what mothers wanted
<ul style="list-style-type: none">• The early days are crucial.• “Throw away” comments can make or break breastfeeding for many mums.• Lack of time for staff is a major factor.	<ul style="list-style-type: none">• HCPs listening to the mother is important.• HCPs need to be ready to listen to what mothers want/need before offering any advice.

⁴ WBTi Steering and Core Groups (2016). World Breastfeeding Trends Initiative UK 2016. Part 1 [online] pp.30,31. Available at: <https://ukbreastfeeding.org/wbtiuk2016>

<ul style="list-style-type: none"> • Tongue tie seems to be commonly missed or down-played. • Problematic latches and the effective transfer of milk were a significant issue but often the focus was on treating weight loss, thrush, mastitis or nipple damage rather than the underlying problem. 	<ul style="list-style-type: none"> • Success stories often occurred when one person listened to the mother about the whole situation and worked through everything step by step. • HCPs working with mothers should be prepared to admit they don't always know the answer to mothers' questions and be willing to look in to it.
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Study 2: How does Personal Experience of Breastfeeding Affect the Professional Practice of Health Care Professionals?

The second study investigated the effect of their own breastfeeding experiences on the support that healthcare professionals offered breastfeeding mothers. It was devised and run with support from Dr Yan-Shing Chang of King's College, London and after workshops facilitated by Petra Boynton. The group recruited from within their membership HCPs who were involved in breastfeeding support at work. In pairs, they interviewed each other and a team examined the interviews using thematic analysis. 8 HCP interviews were conducted.

Preliminary Results

Table 14 – BF HCE study 2 preliminary results

Before breastfeeding experience	After breastfeeding experience
<ul style="list-style-type: none"> • Little formal training on breastfeeding • Lack of knowledge of breastfeeding norms • Familiar with myths on when to wean e.g. when the child gets teeth, or can talk, or is just "too old" • Feelings of discomfort around breastfeeding mothers 	<ul style="list-style-type: none"> • Positive experiences of breastfeeding to sleep conflicted with between baby sleep advice • Keeping mothering practices (cosleeping, natural term breastfeeding) secret from colleagues for fear of disapproval: • HCPs' work environment not breastfeeding friendly for mothers who return to work while breastfeeding • Informal training: Knowledge gained from own experience, support groups, online communities and observing other mothers • Participants became 'breastfeeding champions' <ul style="list-style-type: none"> ◦ Participants used as informal breastfeeding experts by colleagues ◦ Used knowledge of normal breastfeeding and sleep behaviour to support mothers ◦ Able to recognise and confidently challenge breastfeeding unfriendly practice

Dissemination of results of both studies:

- Media aimed at busy HCPs e.g. infographic and leaflets.
- Group members to distribute via their personal and professional networks.

- Discussion of results published on PSG website.
- Non-peer reviewed article in preparation for a biomedical journal.
- Dr Gavin Brookes is writing a book on analysing health language data; this project will be featured in one of the chapters.
- Members manned stalls at the Institute of Health Visiting Conference (May 2019) and the Primary Care and Public Health Conference (May 2019).
- Members invited to present at the All-Party Parliamentary Group on Infant Feeding (July 2019).

Special Projects

Baby Biome Cohort Study PSG

Table 15 – Baby Biome Cohort Study PSG summary

Baby Biome Cohort Study - PSG	
Members:	320
Recruited from:	All Parenting Science Gang groups (Facebook community)
Collaborated with:	Prof Peter Brocklehurst (Birmingham) and Dr Nigel Field (UCL)
Topic specific Q&As	3

We were approached by Dr Peter Brocklehurst (Birmingham) and Dr Nigel Field (UCL) who were looking for input into their grant proposal for a cohort study looking at the microbiome of infants and children. A pilot study had had difficulties with recruiting and retaining sufficient participants who would provide samples and so Peter and Nigel were keen to explore what motivates parents to get involved in research and what aspects of the microbiome particularly interested our members. They used their findings from this group in writing a new research proposal.

A two week project was designed where Peter and Nigel would be our guests for 3 Q&A sessions, exploring the microbiome in general, discussing their research interests and starting conversations about how to maximise participation. This was true dialogue – our members were keen to find out more about research in the area and the researchers were keen to hear members' opinions and ideas about participation.

PSG thinks about Screen Time

Table 16 – PSG thinks about screen time summary

PSG thinks about Screen Time	
Members:	47
Recruited from:	Y1 PSG groups
Collaborated with:	Dr Pete Etchells (Bath Spa)

“I cannot state strongly enough how important it was to have your voices there at the meeting.”

Dr Pete Etchells, Bath Spa University

During a Q&A about the effects of computer games, Dr Pete Etchells (Bath Spa University) invited PSG to contribute to an interdisciplinary meeting looking at screen time research. We were asked to talk about parents' interests, priorities and concerns about this research. A short-term group was created to share opinions and bring together material for our contribution.

On 17th January 2018, a team member and a PSG member (plus her 1 year-old) presented at the meeting at the Wellcome Collection, and sat on a panel for the final plenary sharing

the stage with Professor Andy Przybylski and Professor Dorothy Bishop (both University of Oxford). The 1 year-old played quietly on the floor at the front of the lecture theatre, was doted on during breaks and was breastfed on stage during the plenary session. We were all made very welcome.

Dr Pete Etchells told us: “I cannot state strongly enough how important it was to have your voices there at the meeting. This is an issue that acutely affects parental worries about the effects that technology is having on their kids behaviour, and having people from PSG there with the experience and knowledge of these concerns was crucial to the success of the day. A lot of people mentioned to me that Tamasin's talk was the most insightful and useful one they went to that day, and it's really made me think how I can best include parent groups in future academic conferences and workshops.”

We were subsequently approached in November 2018 by the Royal College of Paediatrics and Child Health to review and comment on their first public guidance on screen time. The group is still occasionally used by members to post links to articles of interest.

“Thanks for your really great feedback, including several points that all the paediatricians missed!”

Dr Max Davie, RCPCH

Top Tips: Running PSG

In this section you'll find reflections from the PSG core team on what worked well and what we'd do differently if we were running a similar project again.

[Parenting Science Gang \(PSG\)](#), while based on a similar premise to [Nappy Science Gang \(NSG\)](#), was much larger in scale and reach than that earlier project. Reflecting on our experience, we (the core team of four staff) have reflected on our experience and produced the following notes to serve as a guide for those thinking of running a similar project.

Staffing

- This kind of project is time-consuming. Each group is different and they need a lot of support (reminders, scaffolding, etc). In this project, actual staff time worked was significantly more than the “official” hours. For a future project, plan and budget for a lot more staff time.
- Team time – one of the fantastic things about this project was that as well as putting parents (mostly mums) in charge of the research agenda, it also offered part time and flexible working to all its staff. All staff were mums with small children and worked from home for the most part and part time. However, working remotely can be hard sometimes. We had a couple of face to face meet ups, but mostly we only got together when running the events for participants. Face to face meetings to bond as a team and to brainstorm future aspects of the project would have been valuable.

Advisors

The research areas that our parents chose were wide ranging as were the techniques they chose to use. Often these were outwith the expertise of the team. Having scientific advisors, separate to the collaborating experts, would have been useful for understanding and perspective.

“I would have really appreciated a friendly scientist who the project team members could go to for advice throughout the project (e.g. questions about writing surveys / ethics applications or whatever) in addition to the experts we were working with. Someone who understood citizen science and our aims and who supported us throughout the project and who we could bounce ideas off.” Core Project Team Member

The difficulty with this of course is knowing who to have available from the outset. As we didn't know what areas the groups would choose, we couldn't predict this in advance. We had partner organisations (although, other than [NCT](#), they were mainly interested in our work rather than involved) and some friendly scientists that gave their time. Budgeting for scientific advisors in a range of areas might have been useful.

Tools

Online project tools help remote working enormously. However, choose your tools carefully; as an example, Slack is great for quick chats/exchange of ideas, but a nightmare to find anything again!

We found the tools we used changed as the project developed and our needs and priorities changed. Because of our limited budget, we predominantly used free tools.

Tools we used included:

- Slack - mainly for exchanging ideas on a day to day basis; the free version has limited storage, so it is not a place to store important information as you will lose it.
- Trello - an online project management tool which we found useful to begin with, but the more we progressed with the project, the more we utilised Google Drive.
- Google Drive - we stored all our important documentation here; the file management system is familiar and you can limit the visibility at the document and folder level.

As our project was conducted on Facebook, we had a lot of posts. Many of these need to be personalised, but many are repetitive in nature, therefore we tried various social media management tools.

We tried several free/fremium tools, before deciding it was worthwhile paying for one:

- Facebook
- Publer
- Slack social
- Grytics
- Tweet deck
- Coschedule (we paid for this)

We would definitely recommend budgeting for social media management tools rather than trying to get by with the free ones. But recognise the limitations of these tools – most packages have limited users (social profiles) unless you have a very large budget.

Events

We all agreed that events are often the most transformative experiences. It is real human experiences that make the most difference, no matter how great the internet is. It doesn't need to be online OR offline, they can work together. The feedback we received from attendees at our events was almost unanimously positive. However, they are a lot of work – they take up a lot of time and headspace, which interrupts from work on the day-to-day of the project. Given the paucity of staff time, this had a big impact on keeping the groups on track with project timelines.

We don't have the perfect solution to this, however, in a future project we would seriously consider hiring an events manager to do the bulk of the event organisation e.g. scoping venues, liaising with attendees re. requirements and focus on the event timeline. We still

think events would require attendance and work from the other team members, but the time spent involved in planning, and the impact on our focus on other parts of the project would be massively reduced.

Choosing Groups

In our first year, the four groups were all groups that our Director, Sophia, had links with, or who approached us off the back of Nappy Science Gang. We found that the two breastfeeding groups found it much easier to choose a final question because they had a unifying interest and focus. Whereas the other two groups did not - one group was interested in all aspects of evidence-based parenting, the other group was based around geographical area rather than shared interests.

In year 2, for the most part we chose groups that had shared area of interest. In a future project, we would recommend taking this approach. There will still be a lot of questions but selecting which questions to focus on and choosing a final question will be more streamlined, and less likely to put off a proportion of the group who are not interested in it.

Managing Groups

If we were to run a similar project, there are a few changes that we would make to the way we managed the groups:

- Allow more time at the start for each group to explore the idea of how science approaches parenting issues and how to use what you find out. When this process is rushed, groups do not necessarily choose the most powerful questions.
- Lessons from one group cannot necessarily be carried over to another group as each group has its own distinct culture. In a future project, we would stagger the start of new groups by a few months, to allow admins to get to know the new group, increase the groups understanding and to avoid clashing deadlines across multiple groups.
 - The disadvantage to this is that by having 2 cohorts of groups we were able to have shared Q&As on general topics, and this would be difficult to do if the groups were staggered. However, by having a panel of advisors (see Advisors section), this risk may be mitigated.
- Emphasise the timeline and limitations of the project to the group from the start and keep repeating the information (we had many instances where group members thought that PSG would continue indefinitely even though we thought we had made the timelines clear).
- Allow plenty of time to help the groups work through their dissemination plans and their “after PSG” plans (i.e. will the group close or transition to self-management) as this takes quite a lot of support.

Co-production and working with scientists

Our Q&As functioned not just as a way for groups to learn more about areas of science they were interested in, from experts in the field. But, as the groups honed in on their research

questions, they also worked as a low-stakes ‘first date’ between the groups and scientists working in the area. Sometimes ideas for collaborations came out of these chats.

In the main, we have enjoyed mutually productive relationships with the scientists our groups have collaborated with. The scientists got access to research subjects, or help recruiting research subjects, and the ‘expertise from lived experience’ of our parents in working together to design a novel research study. Our groups got access to scientific equipment and expertise and guidance through the steps they needed to take to make their research plan happen. However, we have sometimes had misunderstandings and a mismatch of expectations. There is a growing literature on co-production and patient involvement in research (see some useful resources below). This identifies several obstacles to effective co-production, including the need for roles to be shared and a lack of hierarchy, ‘experts’ needing to recognise and value the expertise-from-lived-experience that publics can bring, and the time and energy needed from experts to explain things at far more length than they would to their peers, in order to give the lay volunteers the chance to truly be part of decision-making.

The literature linked to below generally assumes that ‘experts’ and institutions have purposefully decided to do something on a co-production model. So, it enjoins experts to recognise their privilege and relative power at the start of the process. Our project was kind of ‘extreme co-production’ model, where it wasn’t led by an institution, but by the lay publics. Experts weren’t putting themselves forward for a co-production adventure. WE asked THEM out. And while most were sensitive, self-reflective and supportive, they didn’t really have a chance to prepare themselves or know quite what they were letting themselves in for.

When WE had approached THEM, it may not be fair to them expect them to go and seek out and familiarise themselves with the emerging literature on social and ethical issues in co-production and start adjusting their worldviews. And, particularly given the well-documented issues of over-work and lack of time experience by many academics, it may not be realistic to demand they spend an afternoon playing a ‘Purposeful Partnerships’ card game with us before agreeing to work together

Our only advice would be for similar projects to read the literature below, be mindful of the kind of issues that might occur, try to be clear in your expectations, and sound out the expectations of your scientific collaborator(s). And be willing to choose a different collaborator if your expectations don’t align.

“The many shades of co-produced evidence”, by Pippa Coutts

<https://www.carnegieuktrust.org.uk/publications/the-many-shades-of-co-produced-evidence/>

Being Inclusive in Public Involvement (PI) in Health Research <https://www.invo.org.uk/wp-content/uploads/2019/02/Being-Inclusive-Health-Research.pdf>

“Purposeful Partnerships card game” <https://www.publicengagement.ac.uk/whats-new/news/new-partnership-building-resources-launched>

A framework for public involvement at the design stage of NHS health and social care research: time to develop ethically conscious standards. Raksha Pandya-Wood, Duncan S. Barron, Jim Elliott

Res Involv Engagem. 2017; 3: 6. Published online 2017 Apr 4. doi: 10.1186/s40900-017-0058-y <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5611655/>

Reaching under-served audiences

Under-represented groups are hard to find! We had our first four groups planned as part of our application process, but for our Year 2 groups we tried to increase diversity with little success. To make this work, we think we would have needed a lot more time and also funded staff that are part of other communities.

For example, we found it worked really well where the admins in a group were already part of that community (for example, mothers / breastfed our own children / lived in the same region). It was possible to admin when we weren't part of that community, and we did, but it was easier and quicker to get started when we already understood the "culture" of the community. For a future project, some thought about recruiting additional team members who are part of an existing group or recruiting someone who has experience of working with under-served audiences.

Our attempts to reach a more diverse set of groups in Year 2 included reaching out to personal contacts of the PSG team, asking existing PSG members to put us in touch with groups that they were members of / aware of and reaching out to various support organisations. We were explicit in a lot of our posts in that we wanted to recruit a more diverse mix of parents for year 2 (example text below from one of our blog posts, as well as example memes in *Picture 1*)

"The whole point of this project is democratising science and changing the balance of power. We'd especially love to hear from groups of young parents, black and ethnic minority parents, parent carers, and anyone whose voice is not usually well represented in science. Normally a bunch of middle-class white guys decide what gets funded in science. They may not have the same view as you about what's important."

We had arranged to run a face to face PSG group working with an NCT-funded project for refugee mothers in Leeds. However, in the end this group had to pull out as budget cuts and local circumstances meant that staff were over-stretched. We offered to run the sessions ourselves, but staff locally would still have needed to do some additional admin (booking rooms, publicising sessions, etc) and as staff were only paid for contact time (and working well over their hours already), they eventually decided they couldn't go ahead. Even though they had been very positive about what this opportunity could offer for their client group.

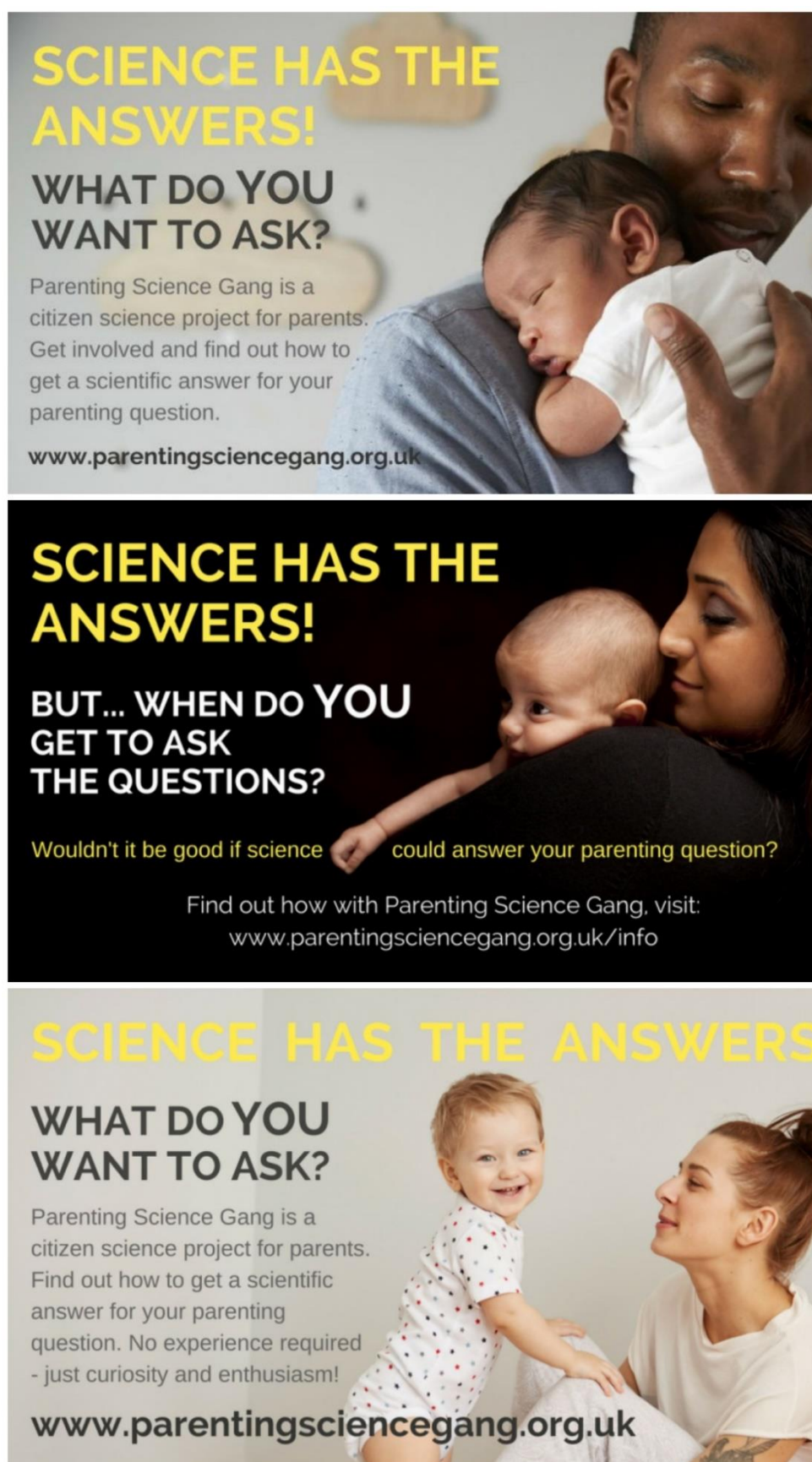
This was very disappointing both for us and them. If we had better understood the situation much earlier in the process, we could have built extra money into the budget to pay their staff to support the collaboration. One learning point for us has been that small, local organisations working with the most under-served audiences are likely to be very over-stretched, and don't have the slack to provide any staff time to support a partnership, even

when it aligns completely with their organisational aims and they really want to do it. We should have built in extra budget and would do in future.

However, while we were not as successful as we'd hoped, we did engage various audiences who were marginalised in some way:

- Mothers with a higher [BMI](#) (over 30) at the start of pregnancy – see *Big Birthas Parenting Science Gang*
- Mothers who live in rural Scotland – see *Dumfries and Galloway Parenting Science Gang*
- Mothers of children are extremely restricted or selective eaters – see *Mealtime Hostage Parenting Science Gang*
- Mothers who are are breastfeeding past one year (only 0.5% of the UK population) – see *Breastfeeding Older Babies and Beyond Parenting Science Gang*.

Picture 1 – Examples of Year 2 recruitment memes



Living with uncertainty

This has been tangentially touched on in other sections, but it's worth stressing. The radical user-led design of the project meant that we had to live with a lot of uncertainty. We didn't know what topics the groups would choose to research, what kind of experiment they'd want to do, or how long it would take. This made planning ahead hard. We couldn't (in most cases) book Q&A experts months in advance, because we didn't know what they'd want to be talking about. Things like the (considerable) logistics for the breastmilk experiment - getting 130 nursing mothers plus children to the same hospital in London, on the same day, with all the equipment and paperwork needed - couldn't even be begun until the groups had decided on their protocol. We couldn't front-load our planning much.

We had to be willing to live with uncertainty if we wanted to truly give our participants power. It is not for the fainthearted.

Top Tips: PSG's guide to being family-friendly

In this section you'll find our top tips on engaging parents online and at face-to-face events.

The golden rule of public engagement is to know your audience, and if you want to get parents involved, then you need to cater for the whole family.

Online

Regular engagement requires minimising the effort of getting involved. **Going to where your participants are, not making them come to you is essential.** Facebook is great for that, it's where many mums hang out for their downtime, in the evening, while breastfeeding for hours, while kids are playing etc and can be used on a phone (doesn't need computer).

"It being on Facebook made it really accessible"

The advantages of Facebook extended beyond familiarity.

- **Privacy settings of groups enables discussion to be private** so that members discussing more sensitive subjects can be confident that their comments can't be viewed by their wider social networks or the public.
- **Members can interact non-simultaneously** - a comment made in the morning by one person can be interacted with throughout the day by others.

However, as Facebook doesn't show users all content, **schedule regular reminders about everything.** This also supports those with extremely busy home and work lives, for whom an extra reminder means one less thing to have to remember!

Text-based activities are important to members with small children as they can engage with tasks while feeding or while sitting with a child as they fell asleep without disturbing the child or the need for headphones.

Keep posts short. These display well on phones and, busy parents can read them quickly when they have a few minutes to spare. **Break down complex processes into small, simple to understand chunks**, so that members can respond quickly and fit tasks in between work and family commitments.

Don't hop between online platforms. By and large, we kept the whole project on Facebook, very occasionally using other platforms (e.g. Google Drive for documents), when it was unavoidable. We found that pretty much any extra clicks - especially moving to an unfamiliar platform - reduced engagement. Initially we trialled Q&As in a chat room on another site, but members overwhelming voted for the familiarity of Facebook.

Timing

9pm is a great time for parents (though some might be drifting off to sleep!). We decided to run our Q&A sessions live so that members thoughts could bounce off each other and

natural conversations could develop with the expert. We discussed the timing of these sessions with our members and concluded that despite families' very different schedules, 9pm was the best time, after most children had gone to bed. In general, experts were happy to join us in the evenings and the only major problems we encountered were with experts from Australasia, for whom it was a pretty early start (7am).

Face-to-face events

Designing events that fit in with parents' busy lives is a real challenge. We quickly recognised that mothers are often bottom of the pecking order in a household - a child's party can trump a previously arranged mother-centred activity. **Stay as flexible as possible about people dropping out and adding new people fairly close to the deadline.**

Make your event rank highly in a family's calendar by providing something exciting for everyone. Our events that included organised science activities for kids were better attended than those that just provided child care. Kids were excited about coming and so parents were more able to prioritise getting there.

Choose your venues carefully to cater for families rather than conferences. As well as the usual accessibility considerations think about

- Acoustics (lots of kids equals lots of noise)
- Distance to bedrooms (little kids need naps)
- Baby changing facilities (some kids need quiet for a mess-free change)
- Space for storing buggies (they are massive and often muddy/wet)
- Flooring in eating areas (kids make a mess)
- Flexibility in food content and timings (kids will often sleep through a meal time)

Don't underestimate the impact of food allergies. Make sure your catering company provides accurate information well in advance and can work with specific needs. Have really clear communication with parents who are affected by this.

Make it easy for busy parents to access detailed information about the whole event and venue. Post regularly on Facebook with the most important pieces of information and provide a full info pack really early on with detailed agendas and travel info. **Provide excessively detailed travel info** - busy parents don't have time to spend looking for bus services or working out what stop to get off at. Our participants thanked us for providing photos of bus stops, car parks and the route to venues.

In online projects, members have often never met each other and may feel apprehensive about meeting up in real life. **Set up Facebook groups for them to chat informally** about the event so that they have an idea of people that they are going to meet. Nervous people don't like surprises – make sure the agenda is clear about the sort of activities that might occur. An idle comment about bringing wellies (just in case it rains and you want to keep your feet wet while walking between buildings), can result in panic to those who fear crazy team-building activities!

Construct your agenda so that it is really flexible and can cope with participants being absent for sessions (while they calm an upset child, or stay with a sleeping child).

Make an effort to include accompanying adults to look after members' children and give them lots of information about what is happening. Be aware that some accompanying adults may not be used to having to look after kids without support of their parent and may be surprised not to be involved in the "work" of the event. They need to feel that their contribution as a carer is valued and essential to the project. Information pack about the event, venue and things to do nearby (for those who don't want to hang out with other families) are always well received.

Provide free, high-quality childcare at all events for those who can't bring an additional adult to care for children. But be prepared for the numbers of children to vary dramatically and keep updating the childcare providers so that they are prepared for the group's different needs.

Always welcome children into the working area so that mothers can feed them, but make sure something more interesting is happening elsewhere so that mobile children are keen to get back to the fun. **Regular, kid-friendly snacks** mean that children are less likely to need input from a parent.

Have your child-care and kids' activities close enough to the main activity so that the child can visit the parent quickly if necessary and so that breastfed children can access their mother. But don't have them too close! If kids can see their parent, then they will want to come and play with them. Avoid windows between the two areas.

Most importantly, keep everything really informal and model that it's okay for your kids to have disrupted your sleep/morning/life and that you can still be respected as an intelligent person. Acknowledge caring for kids as integral to the lives of your participants. It is just as normal as needing toilet facilities or regular meals.

Top Tips: Using Facebook

In this section you'll find:

- *Why we think using Facebook for this kind of project works*
 - *Our tips on how to make the most of Facebook and how to get around some of the challenges.*
-

Why Use Facebook?

It's huge. It's accessible. It's familiar. We know it works.

It's huge

Facebook has a vast reach. In the UK, according to OfCom, in 2018:

- More than three-quarters of UK internet users (77%) had a profile or account on a social media or messaging site. (Bearing in mind 99% of UK adults aged 18-44 have used the internet in the last three months, this is huge!)
- Facebook was the most-visited social media platform, reaching 41 million UK internet users aged 13+, or 90% of the UK internet audience.
- Facebook visitors spent on average 27 minutes per day on Facebook sites and apps

It's accessible

Facebook is hugely accessible. People are not excluded due to location, disability, financial status or any other reason. The map below shows the location of respondents to our pre-project survey. We would not have been able to run a project with this geographical reach face to face on a similar budget.

Figure 6 - Geographical location of UK-based respondents to our pre-project questionnaire



It's familiar

People are on Facebook anyway, and know how it works. UKOM research in 2017 showed that mothers spend over 2 hours a month more on social media sites and more time on Facebook than non-mothers. Facebook uses push notifications so your group members do not have to actively search out your project in order to stumble across your content, it appears in their feed while they are browsing for other reasons.

We know it works

We used Facebook for Nappy Science Gang and know it works well for engaging parents of young children. There are a wealth of parenting-related groups on Facebook so parents are here already.

Our tips for using Facebook

We have talked about how we used Facebook earlier in this report (see *Use of Facebook* and *The Groups*) , so here we will focus on our top tips for using Facebook, and how to manage some difficulties.

Firstly, Facebook algorithms decide what gets shown in newsfeeds and what doesn't, and these are changing all the time and Facebook does not share them. However, a general principle is that the more people interact with your group, the more likely they are to see posts from your group in their newsfeed.

Unless people deliberately visit your group, it is possible for group members to see no posts from your group appearing in their newsfeed. Active posts (posts that look popular to Facebook) are more like to make it on to newsfeeds. You can also encourage group members to change their notification setting for the group to 'all posts'.

Below are some tips which we found helpful across the lifespan of the project.

1. Use Facebook like a person, not a corporation
2. ... But invest in a social media tool
3. Remind and repeat
4. Polls
5. Tagging
6. Keep it short and simple
7. Consider privacy

Use Facebook like a person

We used Facebook like a person – all posts were made by a member of the [PSG](#) team, not an anonymous PSG account. As Facebook is about conversations, not one-way communication, we felt this was a better approach as members knew who they were 'speaking' to. We used relaxed, informal language and many groups had in-jokes. As we became more familiar with each group, language changed subtly as we got to know what worked well with group members.

Possibly the biggest thing about using Facebook like a person is that people hang out on Facebook in their downtime – often evenings and weekends. But corporate pages usually post Monday to Friday, 9-5, which isn't when most people are around to notice or reply. You will need to think about this when staffing your project. Using scheduling tools to line up posts and publish them at a time you set can help. But often someone needs to be around to reply to your first few comments from members, to get conversations going.

Invest in a social media tool

We came late to using social media tools, largely down to cost. We tried various free tools, but none of them really met our needs. We concluded that social media tools are not really designed for the running of multiple social profiles (groups) by multiple people, unless you have a very large budget. Eventually, we chose to pay for a monthly plan on CoSchedule. This allowed us to schedule posts for each of our groups, but only from one project team member, rather than any of the project team.

Co-schedule worked well for scheduling non-specific posts such as upcoming Q&As, new blog posts, reminders to sign up for an event. And it had the advantage of being able to schedule posts many weeks in advance e.g. reminders about signing up for the newsletter, our #ThrowbackThursday posts.

Group specific posts still needed to be posted by individual team members. Facebook scheduler (a free tool) allowed posts to be staggered throughout the day but it is limited in how far in advance these posts can be made.

Remind and repeat

Facebook does not show all content, unless people actively access the group (rather than through their newsfeed), and even for those that do go direct to the group, Facebook puts the most popular posts at the top, not the most recent. So people miss stuff. Add in busy home and work lives and lots of your information and threads can get lost.

So remind and repeat important information. Ask people to bump important posts (by commenting or adding a GIF) which will keep the posts active. We found the scheduler very useful for regular reminders that did not need a really personal post.

Polls

Polls work well for asking volunteers to sign up for things. Ideally you need at least two options. We also found that adding a "I can't do this but please tag me in future" option works well as:

- It makes people who cannot volunteer for that task still feel involved
- It helps to keep the poll active (more likely to appear in people's newsfeeds)

Polls are not ideal for voting if you are using it as a decision-making tool. Facebook reorders polls with the most popular option at the top, and it hides any options greater than five in number – you must click to see them. This means the poll is often heavily biased towards

the options that were ticked first as these appear in the top five. We tried making it really clear in poll posts that this happens, but it does not completely mitigate the effect (as people are scrolling through Facebook, they are not necessarily reading the detail).

To encourage engagement and help keep the poll active, ask members to comment when they have voted. Asking members to post their favourite GIF worked well in several of our groups.

Tagging

Tagging people is very effective when you need their attention. However, some people find it spammy, so take note if people ask not to be tagged. Facebook will also bar you from tagging if it feels you are using it too often. We often asked members to help with tagging – a handful of members would tag others in the group to circumvent this.

In general, we found tagging an effective tool for PSG, either tagging groups members to get engagement on a thread or tagging people who have shown an interest or volunteered on the same subject.

Keep it short and simple

A lot of our members access Facebook primarily on their phone, so short posts work better, as you need to click to read the full text in longer posts. It also means that busy parents can read them quickly when they have a few minutes to spare.

The same is true for tasks. We found that we had a lot of willing volunteers, but mums are generally not time rich. Therefore, breaking down complex tasks into smaller, simpler tasks makes them easier to understand and to fit in between other responsibilities.

Difficult questions need to be approached with a mixture of open and closed formats. Most groups found open questions difficult to start with, but would comment on a poll (i.e. a closed question leading to free text).

Consider privacy

Facebook is a great place for online conversation and accessibility. However, the fact that it is open to everyone can be a disadvantage when members are discussing more sensitive subjects. All of our groups started as public groups, but we allowed members to choose privacy settings early on and all groups chose to switch to a closed group. This means that members can be confident that their comments cannot be viewed by their wider social networks or the public.

There are some further, detailed tips on using Facebook and other online platforms in *In-depth: Online statistics*.

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

“[I] 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 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!

In-depth: Serving mothers, parents and families

In this section you'll find:

- *Why we think public engagement with parents is needed*
 - *A literature review on the needs of mothers during the early years, and online support.*
-

The early years are a crucial time in a child's life and strongly influence whole life outcomes. Maternal health, including mental health, is particularly vital during this period. But parents (mums) feel unsupported and isolated at this time. They find it hard to find evidence-based information on a lot of parenting topics. For many, online spaces such as Facebook and Mumsnet provide crucial support, handholding and access to advice and information.

So these are the conversations we need to be in if we want to help. Health Visitors, and other services are great, but often mums are looking for an answer at 2am, and their next meeting with the health visitor isn't until next week.

Few public engagement projects focus on this period in parents' lives, perhaps partly for practical reasons. As mothers with young children ourselves, we are well aware that it's a time when:

1. It is practically very difficult to take on anything extra, or do anything that involves leaving the house at a particular time or going somewhere.
2. If you do leave the house, you usually need to take your kids with you, so you spend the whole time wiping noses and bums or running around after kids and it's hard to do much or focus on anything.
3. Your world contracts to be all about keeping the small human(s) alive. You don't have a lot of headspace for thinking about the wonders of gravity, or pursuing other interests.

Therefore, to engage parents at this stage in their lives public engagement projects need to:-

1. Fit around the restrictions on their time and movements. We found doing it on Facebook (and using facebook the way humans use facebook, rather than just broadcasting during office hours from an institutional facebook page) was perfect for this. As it's where a lot of your audience are hanging out anyway.
2. Be extremely family-friendly if you organise any real world events.
3. Take parenting - the thing parents are actually thinking and worrying about all day long - as your topic.

Why we need public engagement with science that engages with parenting

We ran several 'focus group' threads in the groups, as a different way to draw out some of their feelings about the project. One of the busiest responses was to 'Do you think science studies parenting enough? Where do you think the gaps are?'

Frequently brought up was the lack of evidence for lots of advice, or the way things we know from research don't sufficiently influence policy.

"I don't think there is a lack of research/evidence. I think there is a shortage of people paying the blindest bit of notice to it."

Also frequently mentioned was the lack of evidence for long term effect of mainstream Western parenting practices (e.g. sleep training). And discussion of how things that affect primarily women and children are sidelined or not taken seriously.

"I watched that Michael Mosley thing on the BBC about sleep and it was all about middle aged men. And about how if their sleep is disrupted how awful it is etc etc."

I was really struck by the fact no one seems to GAF⁵ about women struggling to sleep in pregnancy or struggling with a baby waking a zillion times a night."

Members also discussed how findings that apply to parenting get reported in the press in a sensationalised way, and how this can be used as a stick to beat mothers with. The press don't seem to be 'honest brokers', bringing us parenting-relevant information in a useful way. They discussed reports about how parent-facing buggies may help language development. "Mummy two might not have the money for a more expensive buggy (or mummy one's car). But mummy two is now being taken apart on mumsnet because she is clearly going to cause her baby massive long term harm - one of those articles mentions prison."

In short, parents (in practice mothers) are deluged with judgements but not with helpful information, or often consulted about what information they need.

A note about parents vs mothers

We have attempted to be welcoming of all parents, and use inclusive language. The project is called Parenting Science Gang. But in practice almost all of our members and the followers of our page are mothers. This is similar in all the facebook parenting groups we have encountered. We even deliberately hunted for facebook groups for dads, as we would have loved to involve them in the project, but we couldn't find any active UK-based ones.

Even though there are now a small but significant number of stay-at-home-dads, and average time spent by fathers on childcare has increased every decade since the 1970s*, it seems that parenting spaces online are still predominantly female. The reasons for that are probably multi-faceted and complex, and outwith the scope of this project to explore. But it appears that much of the 'work' of seeking out and evaluating parenting information still falls to women.

* Altintas, A. (2016). Are British Parents Investing Less in Children? Oxford: Centre for Social

⁵ GAF = Give a fuck

Literature review on key issues in early parenthood and motherhood and online behaviour

The transition to parenthood can be a stressful and anxious time (Barrett et al., 2018; Amin et al., 2018; Gilmer et al., 2016; Knowles and Wilkinson, 2015; McCourt, 2006) with parents feeling unprepared for their new roles (Entsieh and Hallström, 2016). Previously this transition was considered to start from pregnancy, ending a few months post-birth. However, it is now believed to start from the time a couple decides to become pregnant through to the child reaching between the ages of two and three years (Entsieh and Hallström, 2016). This transition has been highlighted as one of the most challenging 'life transitions' resulting in major changes to the lives of parents (Amin et al., 2018; Piquart and Teubert, 2010; Madge and O'Connor, 2006) and is important due to the impact it has on parental well-being, parenting quality and subsequently infant development (Amin et al., 2018; Yokoyama et al., 2018; Whittle et al., 2014; Milgrom et al., 2011; Ammerman et al., 2010; Trough et al., 2010). Additionally, feelings of isolation and lack of support can be detrimental to the mother, child and family generally (Hanna et al., 2002).

A child's experiences in early life are widely acknowledged to have the potential to affect their development (Amin et al., 2018; Whittle et al., 2014; Trough et al., 2010). Just as the first three years of parenthood are considered a challenging transition for parents, the first three years of life for children are deemed as crucial (RCPCH, 2018). For example, Rodriguez and colleagues (2009) outline that the first three years of a child's life is a dynamic time of cognitive growth and early language acquisition and can be impacted by their environment, including maternal quality of engagement. Additionally, Simmons and colleagues (2017) suggest parenting behaviour can be a significant contributor to brain development and subsequently to psychological adjustment later during adolescence, and that these parenting behaviours may be more important earlier in life, although important development still occurs throughout childhood and adolescence.

A decrease of 'in real-life' support networks, possibly in part due to the increased mobilisation seen in our present culture, can increase the risk of further isolation and shrinking life-world of mothers (Madge and O'Connor, 2006; O'Connor and Madge, 2004). Parenting groups can provide opportunities for peer socialisation, help to diminish feelings of isolation and benefit parental mental well-being (Strange et al., 2015). Parents are increasingly turning to more easily accessible virtual communities to seek information and support (Entsieh and Hallström, 2016; Plantin and Daneback, 2015; Bernhardt and Felter, 2004). This online support can improve parents' ability to cope with parenting, negate feelings of isolation, increase wellbeing and allow the sharing of experiences, important in developing identity and therefore supporting the transition to parenthood (Suarez et al., 2016a; Plantin and Daneback, 2015; Doty and Dworkin, 2014; Dworkin et al., 2013; Madge and O'Connor, 2006). Additionally, mothers participating in Internet-based discussion boards found that the online support encouraged them to take more responsibility in parenting and these websites enabled them to recognise their own expertise and knowledge (Dworkin et al., 2013). Social support has been seen to provide information, encourage information-seeking behaviours (Guillory et al., 2014) and has protective effects against negative health consequences and stressful life events, something known as 'stress buffering', with a lack of social support being associated with anxiety, depression and having a negative impact upon

the immune system (Amin et al., 2018; Biaggi et al., 2016; Guillory et al., 2014). Higher levels of maternal cortisol, the stress hormone, can also cross the placenta and affect the developing foetus (Biaggi et al., 2016).

Women are active seekers of online information especially in the areas of health which increases with the transition to parenthood (Plantin and Daneback, 2009; Sarkadi and Bremberg, 2005; Bernhart and Felter, 2004). Online information-seeking behaviour amongst women during pre- and post-natal stages is high (Sayakhot and Carolan-Olah, 2016; Bernhardt and Felter, 2004) with women twice as likely to look for information online regarding their children compared to men (Plantin and Daneback, 2009). The Internet as a resource is advantageous, providing immediate, anytime and anywhere support and information, tailored to the specific needs of the user (Suarez et al., 2016b; Largan et al., 2011). This is an important and increasingly common reservoir of informational and social support versus more traditional avenues of face-to-face contact with healthcare professionals with parents finding more traditional means insufficient in contact time, information provision and emotional support (Amin et al., 2018, Entsieh and Hallström, 2016; RCM, 2015; RCM, 2014; Guillory et al., 2014; Largan et al., 2011; Singh et al., 2002). However, it would be erroneous to believe that women were relying on the Internet exclusively. The Internet is purported to be used to gather new and supplementary material to inform decision-making and improve parents' ability and confidence in speaking to healthcare professionals and provide reassurance and support to parents between healthcare appointments (Guillory et al., 2014; Largan et al., 2011; Bouche and Migeot, 2008). This is mutually beneficial to healthcare services and parents, since mothers desire more support from healthcare professionals and healthcare professionals are increasingly constrained regarding time and other resources (Amin et al., 2018; Das, 2018; Entsieh and Hallström, 2016; Harvey, 2016; Largan et al., 2011), thus unable to provide the necessary time and support parents require (RCM, 2015; RCM, 2014). Disseminating parenting information via the Internet has previously been deemed beneficial by health professionals (Madge and O'Connor, 2006). Additionally, supplementing information provided by healthcare professionals can provide a better understanding of choices available to parents and aid decision-making (Largan et al., 2011), something which needs sufficient and appropriate information and fulfils a patient's legal entitlement to be informed, and subsequently be able to contribute to decision-making, regarding their own healthcare (Kamali et al., 2017).

As part of the Internet's offerings, interactive platforms, such social media and parenting forums, can provide important social support to parents (Kimmerdale et al., 2017; Sarkadi and Bremberg, 2005) who are becoming more accustomed to finding companionship and communication online (Plantin and Daneback, 2015). These platforms can also provide readily accessible information, facilitating the formation of support networks and be accessible day and night (Knowles and Wilkinson, 2015; Plantin and Daneback, 2009; Bouche and Migeot, 2008; Sarkadi and Bremberg, 2004). Online platforms have the ability to empower parents and improve self-efficacy (Stavrositu and Sundar, 2012), which can influence behaviour towards one's infant, parenting quality and subsequently their development (Amin et al., 2018). Self-efficacy also plays a role in empowerment (Dahl et al., 2015; Stavrositu and Sundar, 2012) and can impact on information seeking and the decision-making process (Armstrong-Heimsoth et al., 2017).

Women need evidence-based material to be able to make informed decisions and worldwide recommendations support decision-making as an essential part of maternal care, something which the Internet can support as an important reservoir of information (Largan et al., 2011). Although mothers search online for evidence-based information supported by research (Largan et al., 2011) parents can sometimes find it difficult to find as highlighted by Suarez and colleagues (2016b) where approximately half of participants stated that they hardly find relevant information when searching online. However, it has been shown that informational support, together with instrumental and emotional support, is important for parents (Biaggi et al., 2016; Guillory et al., 2014). In addition, the Internet gives parents a greater understanding of the choices available to them and can support the decision-making process (Largan et al., 2011).

Parents need informational, social and emotional support to improve self-efficacy, information-seeking behaviours, the decision-making process and the well-being of parents and infants, yet the current healthcare provision is not fully meeting these needs. Online resources may act as a supplementary resource for parents, helping to empower them in their parenting roles. Therefore, conversations need to be had to discover how best to aid parents with such a resource which is accessible and supports them during this critical time, not only benefiting parents but potentially aiding primary care services and the long-term wellbeing and development of children and the family generally.

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Whittle, S., Simmons, J. G., Dennison, M., Vijayakumar, N., Schwartz, O., Yap, M. B. H., Sheeber, L. and Allen, N. B. (2014). Positive parenting predicts the development of adolescent brain structure: A longitudinal study. *Developmental Cognitive Neuroscience*. 8, pp.7-17.

Yokoyama, Y., Hakulinen, T., Sugimoto, M., Silventoinen, K. and Kalland, M. (2018). Maternal subjective well-being and preventive health care system in Japan and Finland. *European Journal of Public Health*. 28 (4), pp.652-657.

In-depth: What were parents interested in?

In this section you'll find examples of the wealth of questions submitted by parents divided into 11 categories.

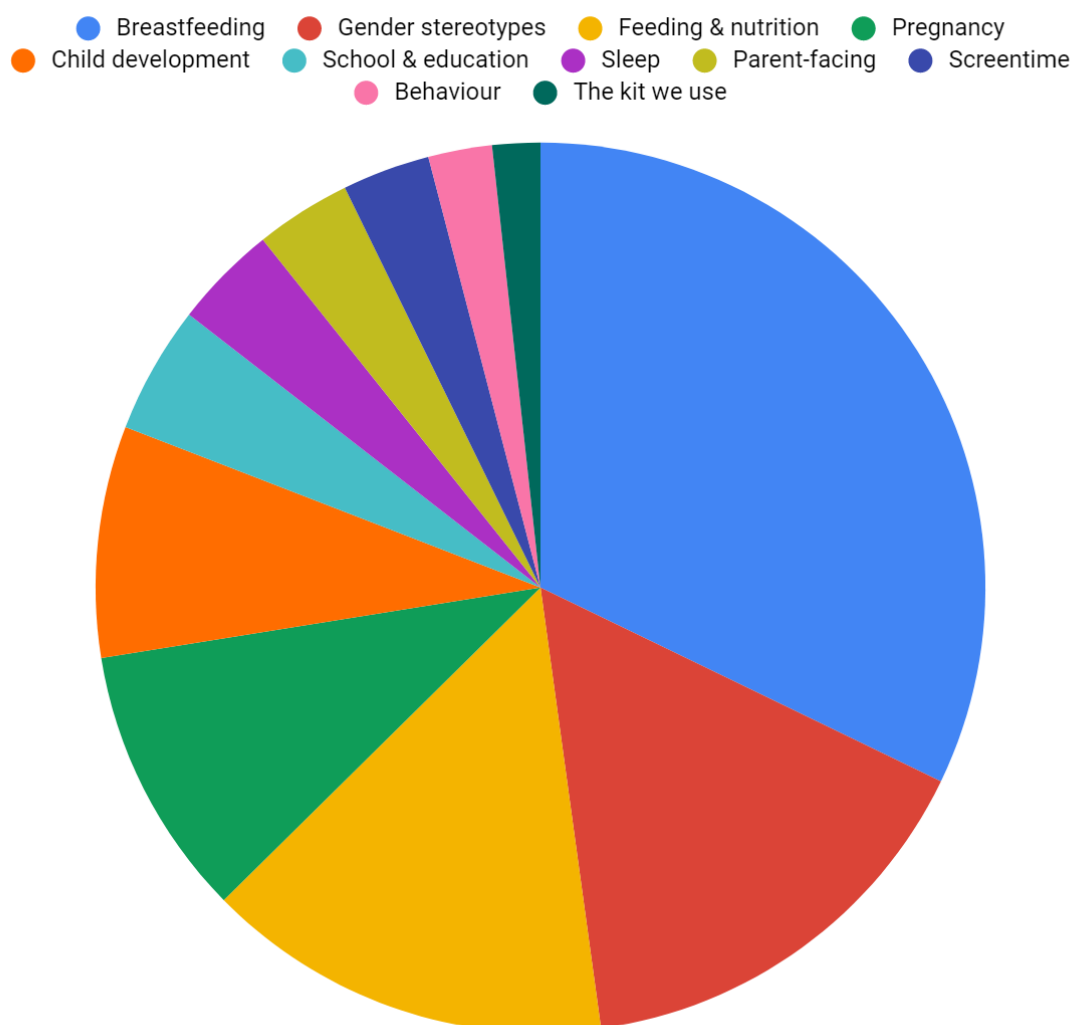
At the start of each group, we asked parents what questions they wanted evidence-based answers for. One of the reasons for [Parenting Science Gang \(PSG\)](#) was that parents are given lots of (often conflicting) advice about parenting, but very little of this is evidence-based.



Picture 2 – Word clouds based on questions by parents in [UKBAPS](#), [BOBAB](#), [SANP](#) and [DGBBB](#)

Across our 8 groups we had hundreds of questions submitted. These span all sorts of topics with very time-specific questions (e.g. toilet training, baby wearing) being just as interesting to parents as big-picture questions such as parenting style.

Figure 7 – Proportion of questions by category



The top five categories - breastfeeding, gender stereotypes, feeding and nutrition, pregnancy, and child development - make up around 80% of the questions submitted, so we have broken these down in a little more detail.

Breastfeeding

Unsurprisingly, as three of our groups had a breastfeeding focus, we had more questions on breastfeeding than any other topic. Within this category, around 60% of questions related to breastfeeding rates, child health, health care professionals and health care provision, and qualities of breast milk - some examples of the questions are given below. Other areas of interest included the effects of breastfeeding on dads and partners, use of formula, mothers' health, older children, tandem feeding and sex/fertility.

Breastfeeding Rates

- *"Why are breastfeeding rates lower for women with higher [BMIs](#)? Is there a link to insulin resistance and supply? Is specific advice for larger women needed/available?"*

- *“If you know other mothers are feeding older children, does this affect how long you feed for?”*
- *“How does the attitude towards breastfeeding within a family and the community as a whole contribute to mothers successfully breastfeeding?”*

Child health

- *“When leaving you to enter the world of nursery, what difference is there between the 'emotional' brain of a breastfed child and that of one who isn't breastfed anymore.”*
- *“Are there any IQ differences between teens or adults who were breastfed until 3,4,5, or 5 and those who weren't? Do these kids stand out somehow?”*
- *“Regarding health and immunological perspective, is there a difference later in life compared to others who were breastfed for a shorter period or not at all or combi fed?”*
- *“Breastmilk as a cure for conjunctivitis/eczema/soothing chicken pox - is there anything in this or is it placebo - or as good as any other moisturising fluid?”*

Health care professionals and health care provision

- *“I'm really interested in the variation between hospital trusts- some are brilliant at encouraging breastfeeding and supporting mums and some seem to be terrible. There are nice guidelines but they are just guidelines. Is there any evidence that those who follow the guidelines have better outcomes? Is there any way we can measure how good or sensitive different trusts are to women with high BMIs and map them to outcomes?”*
- *“Do GPs and other Health Care Professionals actually give evidence-based advice about breastfeeding? And if they don't, why not?”*
- *“What are mothers' experiences of interactions with [HCPs](#) regarding long-term BF (possibly from 6 months and up?).”*
- *“What are BFing mothers' experiences of sleep and BFing in the first few months? Does the advice given by HCPs about normal infant sleep and how to cope with night wakings/feedings affect mothers' experiences of sleep and BFing?”*

Qualities of breast milk

- *“What immune factors are in breastmilk made for older children? Do immune they vary depending on the health / illness of the toddler?”*
- *“What is the content of breastmilk for those feeding to natural term? What does breastmilk for a 2/3/4/5/6 year old consist of? How big a part of their diet is it making up?”*
- *“How does breastmilk change depending on the needs of your child?”*

Gender Stereotypes

Gender stereotyping was of huge interest to parents in our [LTBT](#) PSG in particular. They were interested in gender bias, marketing and messages, and toys and play; examples in each of these categories are given below.

Gender bias

- *“Observational study on unconscious gender bias in schools/nurseries. Getting care-givers to acknowledge that it exists is the first step to getting them engaged in changing.”*
- *“Do adults show a gender bias in how they judge children’s behaviour? E.g. do girls daydream and boys ignore, are girls fidgeting and boys being disruptive. Are boys just playing rough and girls being nasty? Girls picking up a smaller child are being caring, boys are being dangerous.”*

Marketing and messages

- *“How do adult shoppers respond to the removal of gender labelling for toys and clothes?”*
- *“Can we stereotype-proof our children, so they can withstand later efforts at gender-policing their choice of toys and books?”*
- *“Which messages matter the most? I’d be interested to know where children get their ideas of gender stereotypes from (e.g. peers, parents, school, extended family, advertising, etc.). If we knew which sources had the most influence then we would have evidence about where to target our effort.”*
- *“Would exposure to a non-gender-conforming adult reinforce stereotypes or give children more freedom to try new things? E.g. a male makeup arts or caregiver or female truck driver. Could that impact children’s attitudes or toy choices?”*

Toys and play

- *“Does a child’s choice of toys limit their abilities as they get older? E.g., if a child consistently chooses a care-giving or role play toy rather than a construction toy, does that definitely limit their potential abilities as engineers (or vice versa).”*
- *“If you give girls and boys the same set of basic equipment with which to construct their own play items - e.g. sticks, blocks, fabric, paper, tape, and no instructions, do girls and boys choose/evolve different styles of play? What about mixed groups? Does it depend on the age of the children involved?”*
- *“Grown ups’ play: What differences are there in how men / women play with boys / girls when no toys available (e.g. rough & tumble / imaginative play)”*

Feeding and Nutrition

Feeding and nutrition is of particular interest to one of our groups, Mealtime Hostage PSG, a group of parents to selective eaters or children diagnosed with Avoidant Restrictive Food Intake Disorder ([ARFID](#)). Therefore, the majority of questions in this area pertain to picky eating, selective eating or ARFID. Most members of the group follow a [Division of Responsibility \(DOR\)](#) style of feeding their children and feeding style was the second most common area of questioning.

Picky eating / selective eating / ARFID

- *“To what extent is typical eating in the eye of the beholder? If ten different people observed the same child’s eating behaviour (list of safe foods, attitude to new foods,*

behaviour at meal times etc.), how many would agree about whether the child was a typical eater, picky eater, selective eater, or something else?"

- *"What is the link between anxiety and selective eating?"*
- *"What are the long term health issues that might affect selective children who eat very few and specific foods for a long time eg salami? Does a highly restricted diet result in malnutrition?"*

Feeding style

- *"Does sending children with feeding issues to nursery helps them to eat more? For the children it doesn't help, why doesn't it?"*
- *"What happens if you apply DOR to a family who don't feel that they have any issues surrounding food. What happens to their habits? What does this tell us about "standard" practices?"*

From the other groups, questions were commonly around weaning and diet:

- *"Evidence for and against weaning between 4 and 6 months"*
- *"Is BLW as effective in achieving adequate feeding & nutrition? Does it help with childhood obesity?"*
- *"Does limiting sugar have long term benefits?"*

Pregnancy

Our Big Birthas PSG were very interested in the evidence base for pregnancy options for women with a high BMI - around 80% of pregnancy related questions related to pregnancy for women with a high BMI. The biggest topic within this was complications and interventions:

- *"Are the barriers around birth choices related to inherent increased risk or it being more difficult in some way for HCPs to do their job? I'm think particularly of intermittent monitoring where higher BMI makes it harder to find a foetal heartbeat so there may be a preference for Continuous foetal monitoring not because there is likely to be foetal distress but because it saves time, or alternative birthing positions"*
- *"Birthing pools. Is there evidence to suggest there is a greater risk for mothers purely on the basis of BMI (no other risks)? If used, is there any evidence to show benefits (eg in a reduction in complications) at either a greater or lesser rate than for women in the 'normal' weight range."*

"In the absence of any complications is there any clinical need for continuous foetal monitoring during the labours of women with higher BMI?"

Questions from other groups covered a wide variety of pregnancy-related topics, from alcohol, labour advice and diet:

- *"The more subtle effects of drug and alcohol exposure in pregnancy - not profound disruption, which most understand, but the impact of "moderated" intake on the gestated infant."*

- *“How have the NHS come up with their guidance about when in labour you should come into hospital? Is it based on any evidence? My kids were almost born in a car park!”*
- *“Are the expensive pregnancy vitamins with added omega 3 worth it?”*

Child Development

Child development is a vast category and we had all sorts of questions from toilet training, the effects of birth order, teething and temperature control. The top two categories were play and social / emotional development.

Examples of play-based questions included:

- *“How do different toys impact on kids’ imagination?”*
- *“How much difference does it make if children spend time playing outside?”*
- *“Benefit of structured vs unstructured play”*

Questions around social and emotional development included:

- *“How can parenting affect a child's ability to make and keep good relationships?”*
- *“Socialisation of infants - do children in nursery environments engage / play with other children earlier / better?”*
- *“Does carrying/ cuddling/ wearing babies lead to a lack of independence and/or a rod for your own back?”*

Other areas of interest

The remaining six areas accounted for around 20% of our questions; below are some examples.

School & education

- *“What effect do alternative vs mainstream education have on children? Is [flexischooling](#) beneficial? (These were two separate questions, from different people, but the group decided to put them together)”*
- *“I would like to see a study of summer born adults, to determine to what extent they felt it affected them. How does it affect them in the teenage years? Are they more susceptible to peer pressure if they are the youngest in the group?”*

Sleep

- *“Do co-sleepers get more sleep, parents and babies?”*
- *“Are some children naturally “bad” sleepers or whether sleeping habits are down to parent?”*

Parenting-facing

- *“If online “villages” can successfully replace the support networks older generations had when parenting. I know if I have a question, I can ask any number of online groups, but I*

have no-one to watch the kids if I need to go to the doctor during the day, whereas my mum had people to help out physically, but a smaller knowledge base to consult"

- *"How do various parenting choices influence each other?"*

Screen time

- *"Is there a difference in effect on kids who use screens for solitary activities (such as single-player games or watching TV) or social activities (such as multi-player games or social media)?"*
- *"Is there evidence to suggest that self-regulation of screen time is a good or bad strategy?"*
- *"I would be interested in finding out if there is actually an issue with too much screen time (as opposed to not enough activity which often goes hand in hand) - particularly in neurodiverse children with known sleep issues."*

Behaviour

- *"What works best to manage difficult behaviour beyond toddler years: rewards, praise and intrinsic/extrinsic motivation?"*
- *"Are some babies just genuinely more "sensitive"? What is the science of "fussiness" that is not linked to medical factors?"*

The kit we use

- *"Do amber teething necklaces work? Do they do anything at all? I'd like to see a study on that, but linked to socio-economic factors. Who buys amber teething necklaces?"*
- *"Babywearing - what are benefits? What is the relationship with temperature regulation, calming effect, effect on breastmilk supply, Oxytocin levels, better sleep quality, help with reflux, premature babies, PND etc etc?"*

In-depth: Online statistics

In this section you'll find:

- Statistics for our Facebook groups, Facebook page, website, Twitter and newsletter
- How people found PSG online

Table 17 – Headline statistics

	Content	People	Activity	Notes
Facebook groups	10,085 posts	2608 members	61,400 comments	The PSG Facebook groups, Q&As and meeting groups formed the core of the project
Facebook page	1,064 posts	1,462 followers	425 comments / 1082 shares	Used effectively to share study invites. 72% followers not PSG members.
Website	157 blog posts	46,700 visitors	99,300 page views / 65,700 sessions	Most PSG website traffic from social media with $\frac{1}{5}$ from search. $\frac{1}{4}$ visitors view at least two pages.
Twitter	584 tweets	700 followers	Reach: 2,260,200	Quality over quantity! Followers include many relevant blue tick accounts, academics & significant third sector orgs.
Newsletter	11 newsletters	400 subscribers	45% average open rate / 8.5% click through	Mostly professionals but also several group members. Excellent open & click through rates

Facebook groups

Activity across all groups

The majority of Facebook group activity took place in the main groups, with just over 70% of comments, for example, shared there rather than Q&As or meeting groups. As *Figure 10* (a snapshot of comment activity in BOBAB PSG in June 2017) shows, the majority of comments are made outside of normal office hours.

Figure 8 – Number of posts, comments and reactions by group

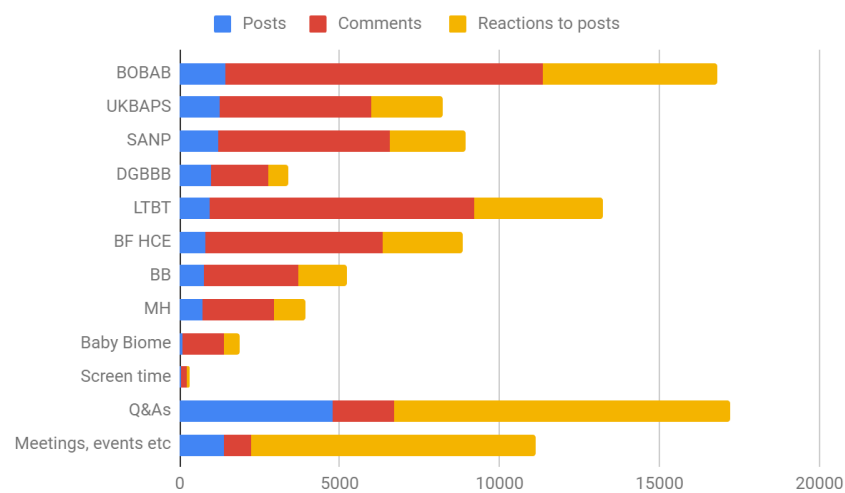


Figure 9 – Proportion of comments by Facebook group type

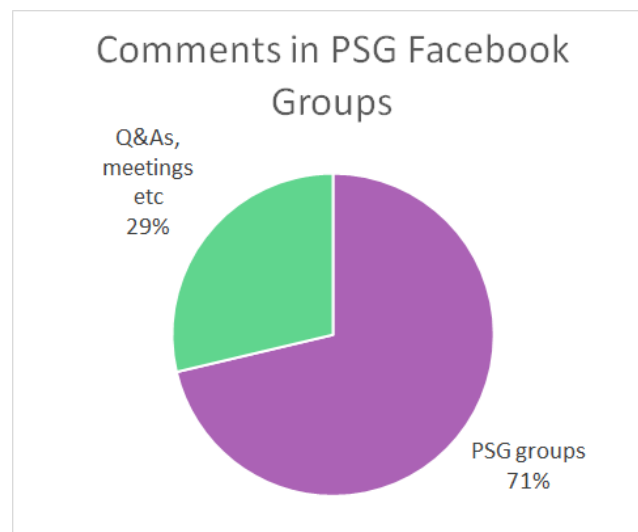
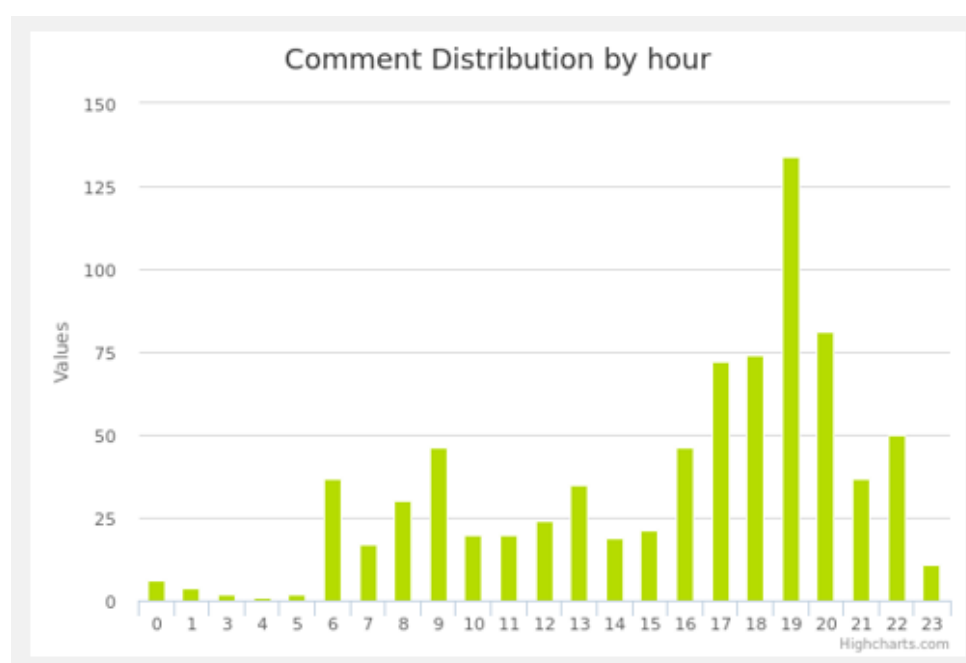


Figure 10 – Comment distribution by hour, BOBAB PSG, June 2017



Group interaction, a snapshot

[BOBAB](#) PSG welcomed its 700th member on September 28th 2017. In this month:

- 46% of members interacted with the group in some way (i.e. posted, commented, or reacted to - eg “liked” - content)
- 30% contributed at least one comment or post
- A small minority of the group members were very engaged; eg 50% of the comments were made by just under 3.5% of members⁶.

A small number of members creating a large proportion of the content is typical for online groups and has long been observed.

A rule of thumb for online groups is the 90-9-1 rule, observing that typically:

- 1% are Super-users - creating the vast majority of new content.
- 9% are Contributors - contributing sparingly
- 90% are lurkers⁷ - observing but not participating

BOBAB PSG are more engaged than this; continuing to use the snapshot of data from September 2017 - if we name those who contributed at least 5 posts or comments as Super-

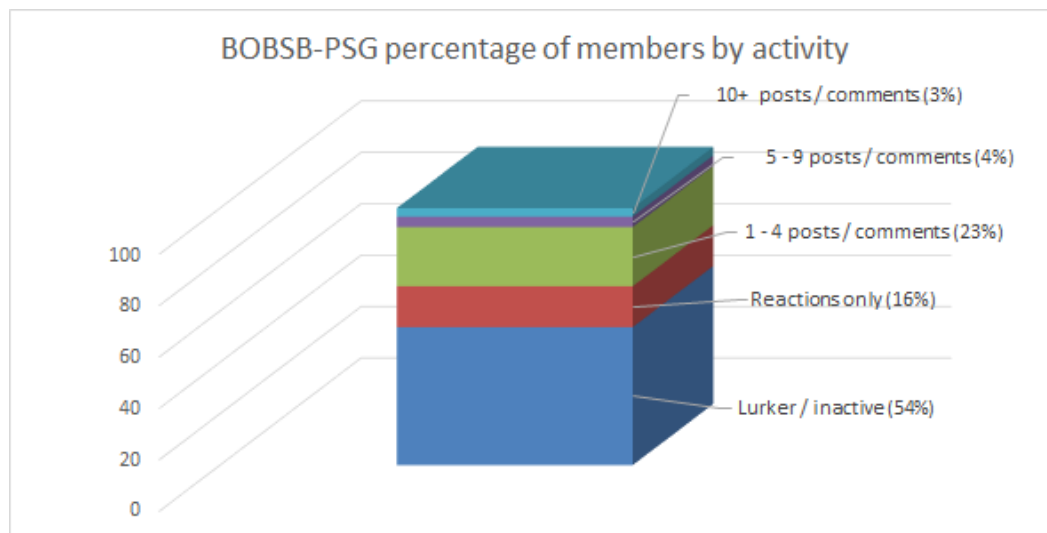
⁶ Admins have been excluded from this data.

⁷ The 1% Rule in Four Digital Health Social Networks: An Observational Study
<https://www.jmir.org/2014/2/e33/> - also see Nielsen <https://www.nngroup.com/articles/participation-inequality/>

users; those with fewer than 5 comments or only reactions as Contributors, and those who do not participate as lurkers, then the BOBAB PSG breakdown is:

- 7% Super-users
- 39% Contributors
- 54% Lurkers

Figure 11 – BOBAB PSG snapshot



Ideally, engagement across the project would be evaluated, but this is not possible with current data tools; therefore snapshots of data from earlier in the project have been used.

When PSG began, it was possible to get detailed data on group members. The data tool Grytics, for example, supplied engagement statistics per member such as number of posts and comments. This was useful in aggregate to see how engaged the groups were, and also by individual to be able to easily identify the members who were most engaged with the project.

However, in April 2018, Facebook removed access to individual data from its API without warning - both because of GDPR and also in response to the Cambridge Analytics revelations in the news.

Facebook page

The public-facing PSG page has:

- 205 posts
- 1,400+ followers

Followers:

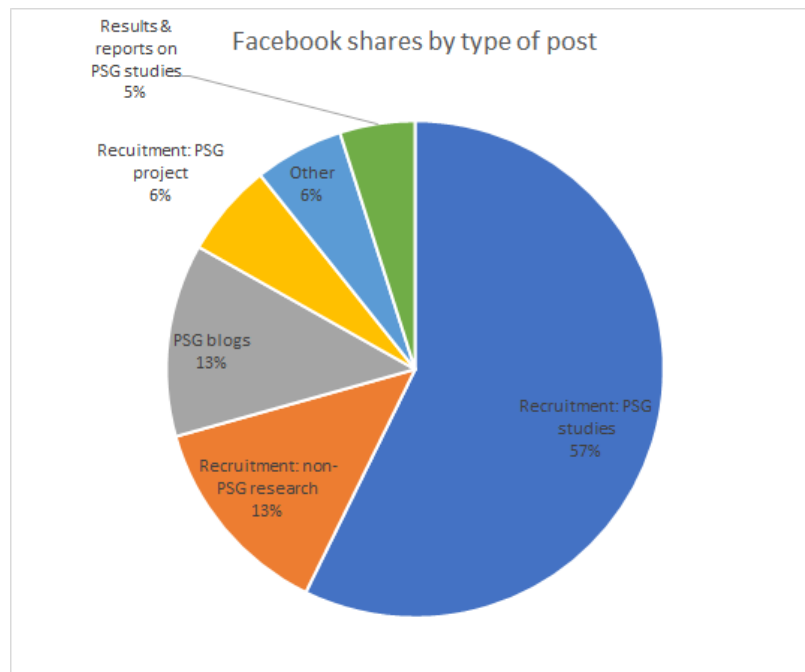
- 50% between 35 and 44
- 32% between 25 and 34
- 72% not PSG group members

- 93% of followers are female

It's interesting that the vast majority of followers of the Facebook page are female - similar to the groups - despite 72% not being members of any of the PSG groups.

Blog posts and other PSG web content were shared via the PSG Facebook page just over 1,000 times. The most popular posts were invitations to take part in research (see chart below).

Figure 12 – Facebook shares by type of post



Recruitment for PSG studies on Facebook

PSG's primary public means of recruitment our studies was Facebook: both from within the closed PSG groups and from PSG Facebook page with their networks.

The recruitment advert for the Breastfeeding and Health Care Experience study was the most popular invitation: posted to Facebook 5 times, resulting in 365 shares and a reach of 50,300. The survey was also shared within the PSG groups and members posted it on local Facebook pages.

Posts inviting participation in PSG studies were the most popular type: despite making up only 5% of posts in the Facebook page, invitations to join PSG studies account for 57% of shares.

Posts inviting participation in external, non-PSG research were the second most popular type, accounting for 13% of shares generated from 5% of posts.

The large number of shares for PSG research will no doubt be in large part due to a concerted effort by group members to promote their research. However, that non-PSG posts

- which were not promoted by group members - were also popular, suggests that this audience are particularly interested in research participation opportunities.

PSG Website⁸

The website received over 63,000 visits from 45,000 users over the course of the project, generating nearly 84,000 unique page views.

Visitors

Most PSG web visitors arrive after following a link from Facebook, typically using their mobile phones to read a Q&A.

The average time spent on the popular Q&As⁹ is 6:46 minutes, suggesting the Q&As are well read. About a quarter of users go on to look at at least one more page on the site.

Requests for participants for PSG studies were met with enthusiasm and a short term spike in traffic to those pages, which are consequently well represented in the top landing pages.

Nearly three quarters of sessions are via mobile phone; a fifth are on desktop and only 1 in 20 on a tablet (Figure 13).

Our desktop users tend to be more engaged; they look at more pages and stay for longer; the fifth of PSG's users who are on a desktop generate nearly two fifths of the overall user time spent on the website.

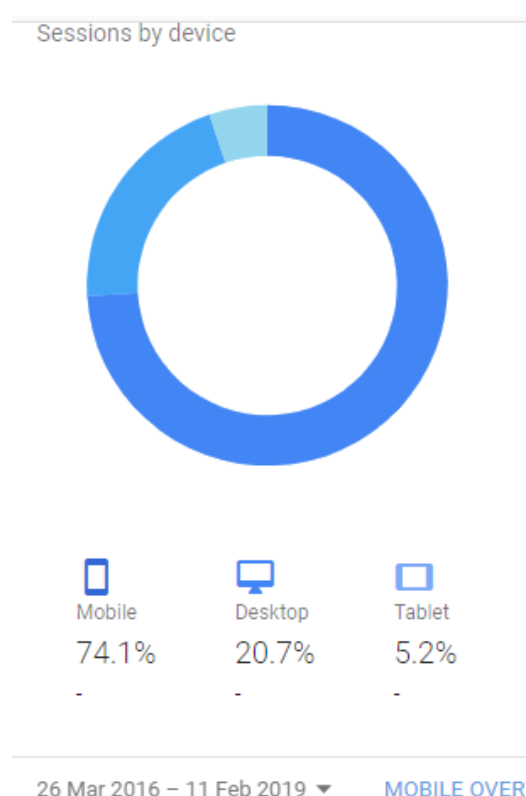
Tip for similar projects: If many of your web site visitors are likely to be using mobile, check your web pages work well on a small screen.

⁸ All data from:

- *Google Analytics, based on a period 23 months, from the web site launch in March 2017, to February 2019 - unless otherwise stated.*
- *or Google Search Console, based on the maximum available period: 3 months to the beginning of February, unless otherwise stated*

⁹ Average time spent reading one of the top 10 most visited Q&As.

Figure 13 – Proportion of sessions by device

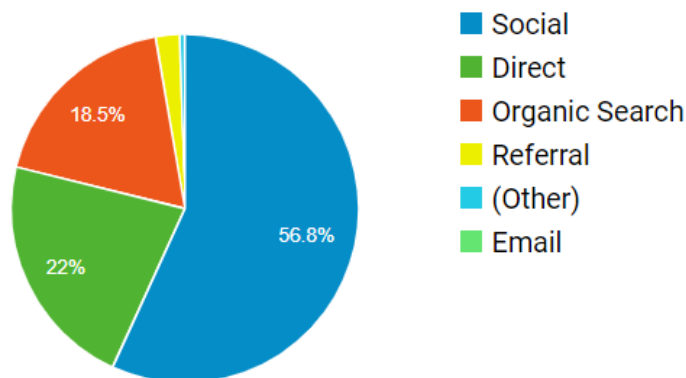


Channels (i.e. how did the visitors find the website?)

Table 18 – Top content by channel

	Most popular page	Most popular Q&A
Facebook	Invitation to participate in the Breastfeeding & Healthcare study	What's in breast milk? A Q&A with Dr Natalie Shenker
Twitter	Invitation to take part in the Let Toys Be Toys - PSG group	What's in breast milk? A Q&A with Dr Natalie Shenker
Search	Evidence-based parenting - A Q&A with Emily Oster	Evidence-based parenting - A Q&A with Emily Oster
Direct	Invitation to take part in the breast milk experiment at Imperial	What's in breast milk? A Q&A with Dr Natalie Shenker

Figure 14 – Top channels



Top Channels

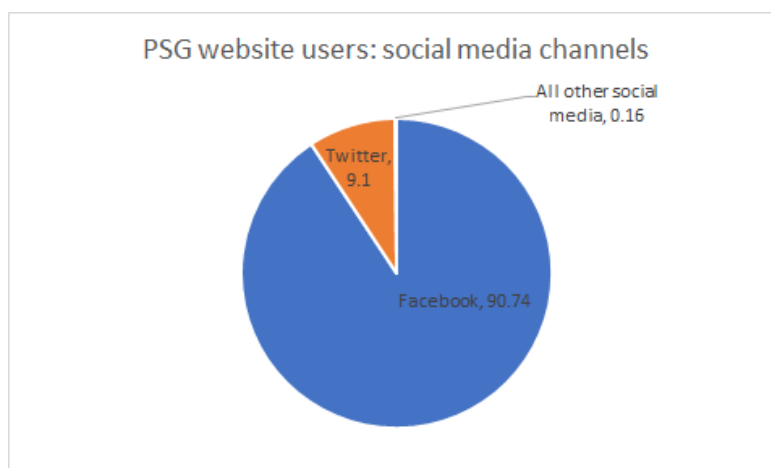
Social media: 57%

The majority of the users arrived via social media: nearly 57% in total.

Considering the project is Facebook-based, it's not surprising that the vast majority of the social media traffic - nearly 91% - comes from Facebook. 9% comes from Twitter with negligible traffic from other social media channels.

Most of the traffic to the Q&As is generated in direct response to promotion of the Q&A when first published, on "Throwback Thursdays" where we shared Q&As from our archives some time later.

Figure 15 – Website traffic by social media channel



Tip for similar projects: Don't forget, you can reuse your content over time. Our members were interested in revisiting Q&As some time later, with newer members visiting for the first time. Members didn't tend to explore the website much beyond the link they clicked on, but they did respond reasonably well to links to individual pages being publicised to them on Facebook.

Direct traffic: 22%

Direct is Google's way of saying "I don't really know where this traffic came from".

It includes not only direct access (where people type the URL into the address bar) but also bookmarked pages and - increasingly - visitors who have come into an HTTP site from an HTTPS site.

Tip for similar projects: Get an SSL certificate for your website, then traffic from HTTPS sites will show up under referrals.

Organic Search: 18.5%

Nearly a fifth of users found the PSG website through search, representing 13,600 visits across the project. 98% of search traffic was from Google.

These users were more engaged, staying just over double the amount of time on the PSG website on average, than users arriving from Facebook.

The proportion of traffic coming to the site through search will almost certainly rise significantly once the project is finished and new Q&As are no longer being generated or promoted.

Tip for similar projects: Sign up for Google Search Console (in addition to Google Analytics) to discover the search terms people are using to find your website. (Both are free services provided by Google) .

Tip for similar projects: Google prioritises mobile-friendly websites in the search results. PSG ensured our website is mobile friendly by using a "responsive" theme with our WordPress website.

Unsurprisingly PSG ranks at the top of the Google Search results for the search term "Parenting Science Gang". This isn't the term that brings us the most traffic however, nor is the home page the page that most search traffic ends up on.

PSG received a steady traffic for two types of search result through Google:

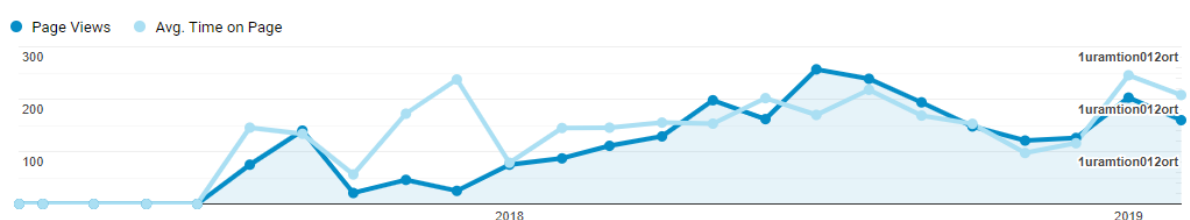
- Keywords (such as [flexischooling](#), AFRID) where there is not a lot of online content on the subject, and the PSG material is a significant contribution
- Keywords (such as “Emily Oster”) where there is a lot of traffic - and so despite receiving only a tiny percentage of that traffic, the numbers reaching the PSG website at significant

Most popular PSG content found via search¹⁰

1. **Q&A: Evidence based parenting. A Q&A with Dr Emily Oster**¹¹

The Q&A with Professor Oster is the most visited web page accessed through search results. It is working well in terms of bringing a new, engaged audience into the website; the lighter blue line represents time spent on the site (average 8:17 minutes).

Figure 16 – Dr Emily Oster Q&A page views over time



Most visitors leave after reading this Q&A, but about 12% explore the site a little further. Emily Oster writes on evidence-based parenting in general, so it's reasonable to assume that these users may well be interested in other PSG Q&As. This write up is continuing to bring new people to PSG long after the Q&A event.

Tip for similar projects: Use plain English that describes your page well and include keywords that people may search on, in your blog/page titles and URLs to attract traffic. Where the URLs and titles contained a popular search term, a steady trickle of traffic came into the site over time.

Link to similar content within your site.

Tip for similar projects: Writing up content from a contributor with popular appeal can bring new audiences to the project over time.

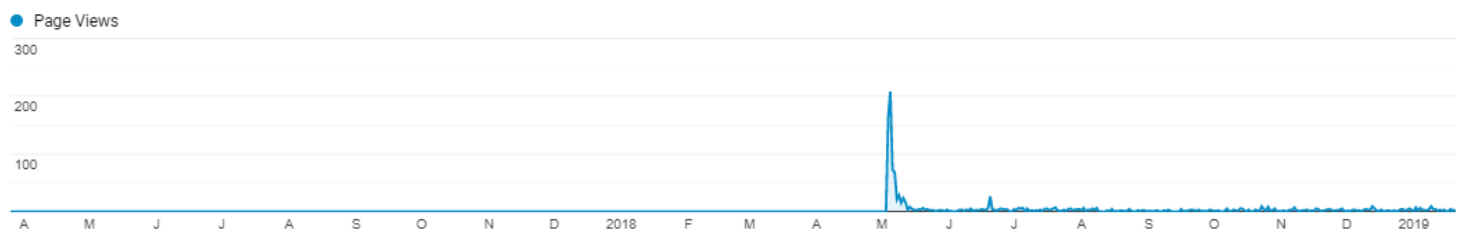
¹⁰ Excluding the home page, which is the third most popular page found by search.

¹¹ www.parentingsciencegang.org.uk/web-chats/evidence-based-parenting-a-qa-with-emily-oster/

2. Researching Avoidant/Restrictive Food Intake Disorder ([ARFID](#)) – A Q&A with Dr Terry Dovey¹²

Another page with a steady trickle of web traffic - 70% of the traffic to this page in recent months is from Google search on a range of ARFID key words. This page is working well in terms of bringing a niche audience to this well targeted, relevant content.

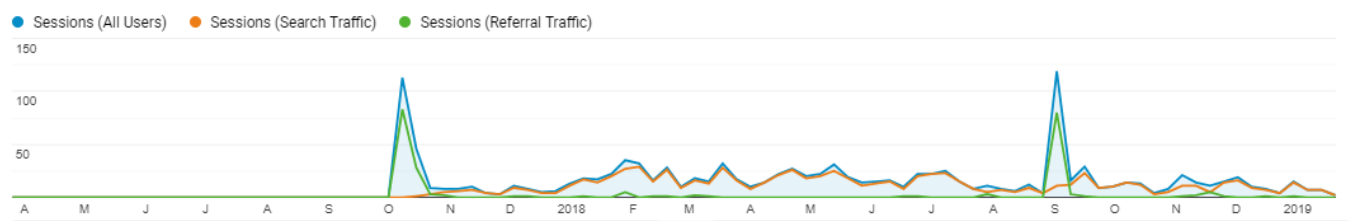
Figure 17 – Dr Terry Dovey page views over time



3. What's the Alternative? A Q&A on Flexischooling with Dr Helen Lees¹³

This flexischooling Q&A has a steady stream of traffic from Google.

Figure 18 – Dr Helen Lees page views over time



This page ranks second in Google search for the term "Flexi schooling scotland". Second place is hugely significant.

There's a small amount of traffic coming through this link, however but it's a very niche subject and one that our Q&A can potentially have an impact on. (The top result is the Scottish Government guidance on home schooling and the result just under PSG is the flexischooling section of a home ed forum.)

This page also receives a small amount of traffic from numerous related search terms such as "flexi schooling" "flexi schooling UK" "flexi learning" etc.

¹² www.parentingsciencegang.org.uk/web-chats/researching-arfid/

¹³ www.parentingsciencegang.org.uk/web-chats/flexischoolingqna/

These visitors are engaged; they spend nearly 7 minutes reading this Flexi schooling Q&A, on average. Nearly a quarter go on to look at at least one more page on the website.

Twitter

Headline stats:

- Followers 681
- Mentions 749
- Mentions per day 1.6
- Replies to @parentscigang 10%
- Retweets 942
- Active users 245
- Potential Reach 2,260,236

PSG is followed on Twitter by a modest number of followers, but the quality of the followers is excellent; several “blue tick” accounts, academic institutions and well respected third sector organisations follow the account.

Most popular tweets

All of the most popular tweets related to our breastfeeding groups, with the Breast Milk Experiment Results Day featuring in seven of them.

Our most popular Q&A on Twitter was with Breastfeeding expert pharmacist Wendy Jones.

Our best engagement happened when we were tweeting from events - both PSG and external - eg the APPG on Infant Feeding.

Top Followers

If Facebook is where PSG communicates with parents, Twitter is where PSG speaks - mostly - with professionals.

Our following is modest - 681 followers, but many of the accounts following and mentioning us are influential.

Our top ten followers have nearly 290,000 followers between them. They are:

1. Vaughan Bell: Neuropsychologist and associate professor at UCL. Clinical psychologist in the NHS.
2. British Science Association
3. Science Grrl
4. Let Toys Be Toys
5. Chris van Tulleken, BBC presenter, Infectious Diseases Doctor at UCLH
6. Alison Thewliss, MP for Glasgow Central, Chair, APPG on Infant Feeding
7. Andrew Maynard, Professor and author
8. I'm a Scientist Team

9. Graham Andre, of Channel 4's No More Boys and Girls documentary fame
10. Jules Daulby, National lead @WomenEd @WomenEd_tech

Mentions

So, who is engaging with us?

The accounts who've mentioned us with the most influence are (in terms of Twitter influence) are the following:¹⁴

Between them they have a reach of over 410,000 followers.

1. Wellcome
2. British Psychological Society's magazine
3. Sense About Science
4. Science Grrl
5. Let Toys Be Toys
6. [NCT](#)
7. Dr Jess Wade, Physics Post Doc, Imperial
8. Women Ed

It's arguably not a surprise, therefore, that the activity on the Twitter account more closely resembles a working week.

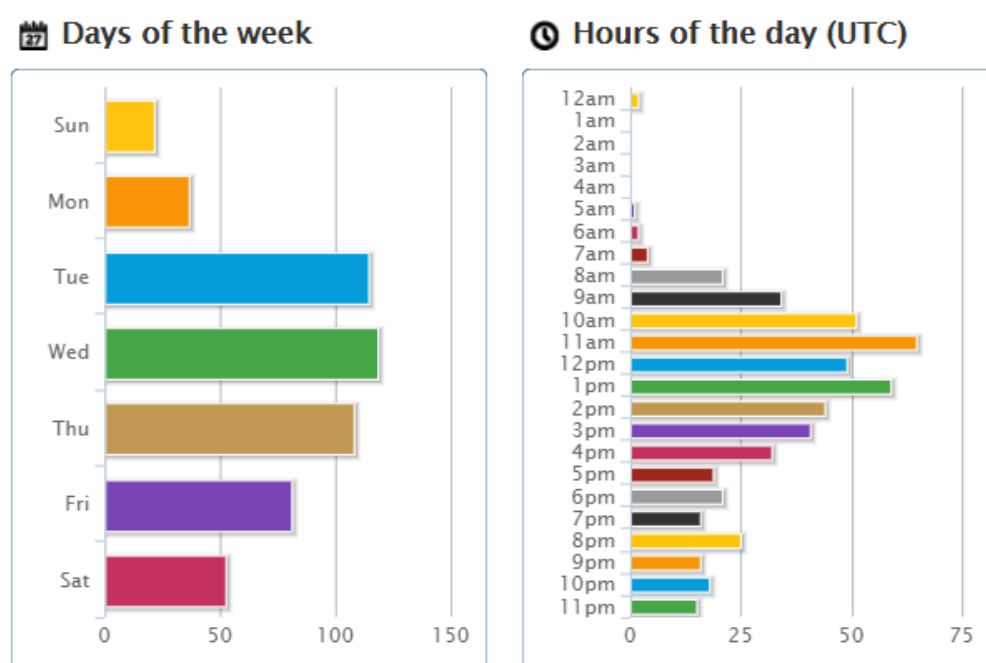


Figure 19 – Twitter activity

¹⁴ The top ten included two marketing-driven accounts with no relevance to PSG content. These have not been included.

Newsletter

The PSG newsletter has 400 - mostly professional - subscribers. It has excellent open & click through rates:

- 45% average open rate
- 8.5% click through

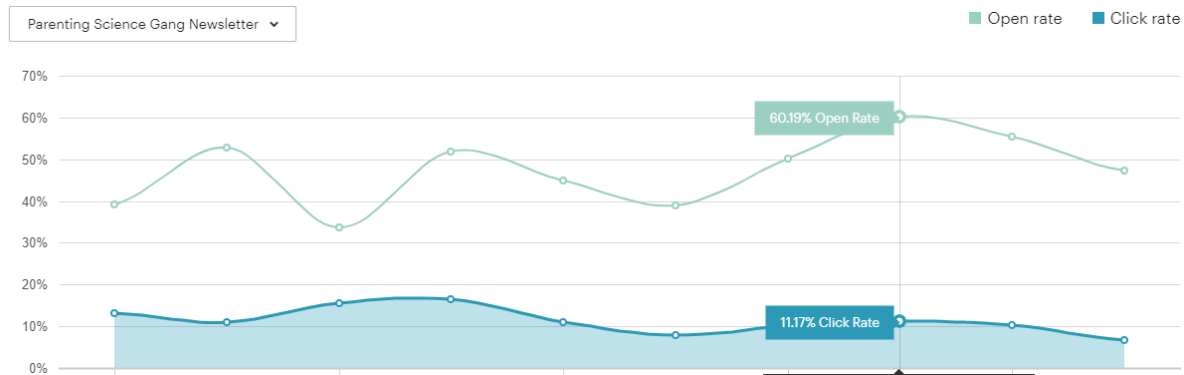


Figure 20 – PSG newsletter open rate and click rate

In-depth - Events

In this section you'll find:

- *Details of the face-to-face events we ran over the two-year project:*
 - *Why we ran them*
 - *How we ran them*
 - *Participants' experiences of the events*
 - *What we learned from running the events*
-

Tips for similar projects

- Face-to-face events can be great for fostering enthusiasm, ideas and engagement - however it's not a given that this will transfer back to the group. Consider how you might help to make this happen.
- There may be people within the group who feel anxious about meeting new people or travelling to new places. Some of our group members told us that having detailed information including directions, information about on-site facilities and details about the structure and timings of the day helped reduce anxiety and made it easier for them to attend face-to-face events.
- Events are resource-intensive to organise, and sometimes only get fairly modest attendance, despite online enthusiasm and your best efforts.

Over the course of the project we ran three sets of events (spending £19,000), plus two events for the [BOBAB](#) and [UKBAPS](#) breastmilk experiment (costing £2500).

1. Residential weekend, June 2017, for members of the Year 1 groups
 - a. Small one day event in Dumfries as no members from [DGBBB](#) were able to attend the residential weekend.
2. Gangstival (4 separate afternoon events in different locations), February to March 2018, for members of Year 1 and Year 2 groups
3. Final Event, November 2018, for members of Year 1 and Year 2 groups
4. Breastmilk Experiment Day and Results Day

We made a concerted effort to ensure all of our events were family friendly. Our main take-aways were:

- Having family friendly events made it possible for our group members to take part
- Mothers' priorities are often low on the list of family priorities.
- Face to face events are really appreciated by group members and they inspire and empower
- It can be hard to transfer enthusiasm, ideas and engagement from the event back to the Facebook groups

Residential Weekend



Picture 3 – PSG residential weekend

“I feel empowered to do science!”

Our first event was held at Mount Cook Adventure Centre in Matlock. We had

- 14 [PSG](#) participants
- 12 accompanying adults
- 24 children
- 3 speakers - Dr Alice Jones Bartoli (Goldsmiths), Alice Sheppard (University College London) and Rachel Plachcinski ([NCT](#))
- 5 PSG staff
- 2 nannies
- 1 storyteller for adults and children.

The event ran from Friday evening to Sunday lunchtime. Accompanying adults, nannies and the storyteller entertained the children during the day either indoors or in the surrounding grounds. The participants (all mothers) took part in the PSG activities all day Saturday and Sunday morning. All accommodation, food and nannies were paid for by PSG. Travel was self-funded by participants, although we offered bursaries on a self-declared basis. Total costs was £6500.

“And there was so much cool stuff to do! For the kids, there were activities going on from the moment we arrived. PSG hired a storyteller, which was brilliant – my five year old was enthralled. “

The PSG activities ranged from a workshop on what makes us happy, to child development, and a workshop analysing a journal article. We chose to run a face to face event early on in the project for several reasons:

- To help form soft ties within the group
- To create buy-in for the PSG
- To up-skill and give confidence to group members

One day event in Dumfries

“I was surprised I had so many questions [about parenting] when I started thinking about it.”

None of the DGBBB members volunteered to come to the residential weekend in Derbyshire. Partly as it was a long way for them to come, and as it clashed with the date of a popular local festival. As this group was inactive and hard to get going, and geographically based, we decided to run a small event locally to try to get more people engaged and make some progress. We had:

- 9 parents
- 12 children
- 2 nannies
- 1 forest school teacher to entertain the children

We provided toys, lunch, snacks, cake and hot and cold drinks. The total cost was £500.

Aims were similar to the main Residential Weekend - create buy-in with the project, create soft-ties within the group, up-skill members. But as everyone was from the same group we were able to focus more on what question they wanted to study. The group came up with loads of possible questions they were interested in, on similar topics to other groups. But one topic which hadn't been mentioned in any other groups got a lot of interest - [flexischooling](#).

It turned out that several parents in the group had children flexischooling (i.e. in school for part of the week, but home educated for part of the week.) We discussed whether this was more common in rural areas, where undersubscribed schools mean parents have more bargaining power with the school, and whether teachers welcome or are distrustful of requests to flexischool. This coalesced into an idea for a possible research project which several members of the group felt very enthusiastic about.

Gangstivals



Picture 4 – Images from PSG Gangstival events

We ran 4 Gangstival events on Saturday afternoons between February and April 2018. Again, the events were family friendly and participants could bring their children if they wished. We provided nannies for those that did not have an accompanying adult, and a play leader at the Manchester and Birmingham events. Gangstivals were free to attend, but participants self-funded travel, with bursaries available on a self-declared basis. Total cost of all 4 Gangstival events was £3500. We were fortunate to be given free venue hire at both our London and Edinburgh events, otherwise this figure would have been much higher.

At the start of the project, the event(s) at this point in the project were intended to provide an opportunity for Year 1 groups to present the findings of their research, an introduction to the project for Year 2 group participants and an opportunity for Year 1 participants to transfer their knowledge of PSG to the Year 2 groups. However, in early 2018 the Year 1 groups had mostly not completed their experiments, so we had overlap of year 1 and year 2 groups for the whole of 2018. In addition, many Year 1 participants are also members of the year 2 groups. Therefore, we decided these sessions would be open to members of all groups. We also chose to run multiple small events around the country rather than one larger event in the hopes of attracting larger numbers of group members. While this limited the amount that we could achieve within the individual event, it opened up the events to those that were less able to travel long distances or free up a whole weekend for an event.

Table 19 – Gangstival summary

Where	Dana Centre, London	Edinburgh University, Edinburgh	Ziferblat, Manchester	Trefoil House, Birmingham
Who	7 participants, 3 staff	6 participants, 2 staff	5 participants, 2 staff	10 participants, 2 staff
Speakers	Katherine Mathieson (BSA), Dr Simon Cameron (Imperial), Dr Alice Jones Bartoli (Goldsmiths)	Dr Barbora Skarabela (Edinburgh)	Rachel Plachcinski (NCT)	Prof Carrie Paechter (Nottingham Trent), Dr Simon Cameron (Imperial)

Final Event



Picture 5 – PSG final event weekend

“Never been in discussions with so many passionate, balshy women. I can’t get a word in for once! I love it!”

Our Final Event, held at Stableside in York saw 30 participants from Year 1 and Year 2 groups, 13 accompanying adults, 30 children, 7 guests/speakers - Katherine Mathieson (BSA), Dr Lauren Spinner (Kent), Dr Simon Cameron (Imperial), Dr Alice Jones Bartoli

(Goldsmiths), Dr Zoe Darwin (Leeds), and Rachel Plachcinski (NCT) - 5 PSG staff, 4 nannies, 1 play leader, 1 children's storyteller, our MSc student and Hannah. Total cost for this event was £8500.

As this was the final face to face event, we wanted it to be a celebration of what the groups had achieved as well as an opportunity for the groups to look forward and consider what they can continue to do once PSG has finished.

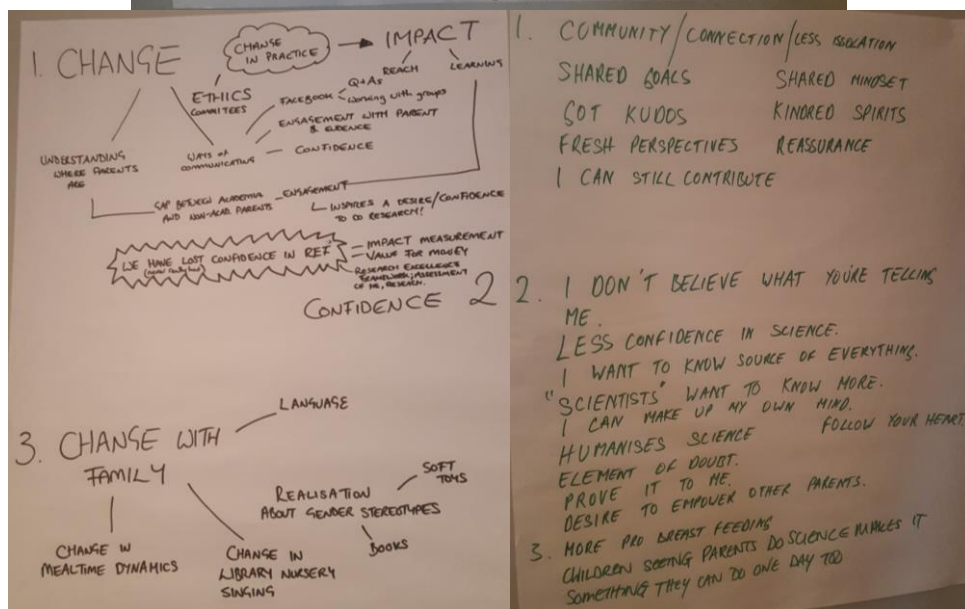
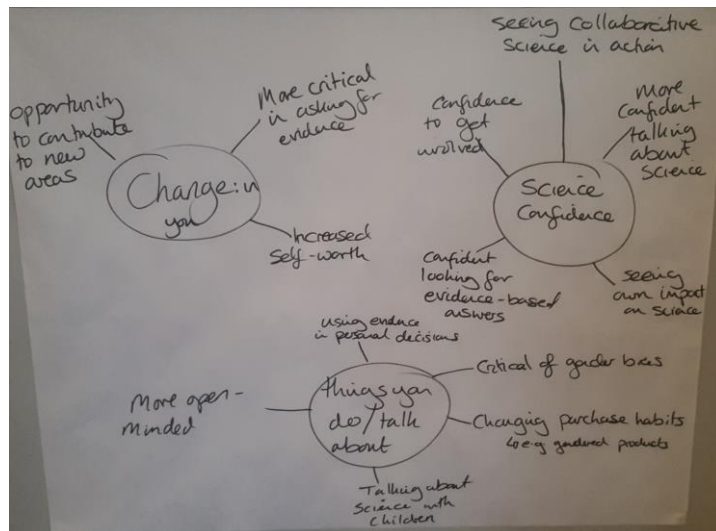
The event ran from Saturday lunchtime to Sunday lunchtime. On the Saturday, we held a results fair poster session (see *In-depth: Group posters from the Final Event Results Fair*). On the Sunday morning, the groups were more reflective and brainstormed how they could disseminate their results as well as whether the groups could continue to exist once PSG is complete. As previously, the event, catering and accommodation was free, but travel was self-funded by participants, although we offered bursaries on a self-declared basis.

Our intentions for the Final Event were:

- To give group members and scientists the opportunity to reflect on their personal experience of PSG
- To allow participants to share their experiences and make sense of their experience
- To create confidence and a willingness to share outputs of the project
- To generate ideas for group experiment dissemination
- To celebrate the achievements of the groups

We asked participants to reflect on their PSG experience in small groups using the following three questions:

1. Do you think taking part in PSG has changed you in any way?
2. Do you think your confidence with about science has changed in any way?
3. (For those who are parents:) Has it changed what you do with your kids or as a family?



⊛ CHALLENGE + INNOVATE ACROSS THE WIDER SOCIETY/WORLD!
 ⊛ FAITH IN YOUR BELIEFS - PUT THEM INTO ACTION IN YOUR PARENTING
 ⊛ FUELLED A HIDDEN/PASSION IN SCIENCE SUPPRESSED
 ⊛ JUST BECAUSE WE'RE NOT SCIENTISTS DOESN'T MEAN WE CAN'T SCIENCE
 ⊛ CONFIDENT TO DO MORE IN THE COMMUNITY TO SHARE KNOWLEDGE/BELIEFS
 ⊛ IT MADE US MORE CONSIDERED IN OUR PARENTING DECISIONS
 ⊛ GENERATED SELF-REFLECTION/REFLEXIVITY

1) Going on to higher education / change in job
 → Increased knowledge & evaluating quality of information
 2) Overall confidence has increased in feeling what we are doing as parents is validated e.g. 'extended' breastfeeding
 → Confidence to research & question validity of information
 → Reinforced desire to be debated & involve children in science, make it everyday knowledge
 3) Confidence in ourselves as parents & our decisions → able to 'stand up' for ourselves, our choices & our children saying their research is validated - we have been involved in research projects

Picture 6 – Reflections on PSG at the Final Event

Throughout the event, participants had the opportunity to reflect on their PSG experience using “Head, Heart, Hands”. Participants could add comments at any time throughout the event by sticking post it notes on the relevant poster. The questions were:

- Head - What are you thinking?
- Heart - How do you feel?
- Hands - What do you want to do now?

Key themes for “Head” were the future, enjoying meeting other PSGers and the benefits of citizen science:

- *“This has been great! How do we use what we found to change practice?”*
- *“Never been in discussions with so many passionate bolshy women I can’t get a word in for once! I love it!”*
- *“How can we get more scientists involved with citizen scientist as contributors not just data collectors?”*

On the heart poster, there was a lot of excitement and enthusiasm for the project, as well as a sense of sadness that the project was drawing to a close:

- *“I feel privileged to be part this unique group – it is rare to be this involved in citizen science and I love it!”*
- *“I feel empowered to continue asking questions”*
- *“I’m sad that this will end. I want to carry on learning and contributing. PSG makes this possible.”*

When asked what do you want to do now on the Hands poster, some people voiced their ideas for where they’d like to do research, others thoughts were about the future of PSG, however, just over half of the comments reflected a desire to do more citizen science:

- *“Research some of the questions that our results have given”*
- *“More PSG! We now have even more questions and keen professionals”*
- *“More! PSG, Research, Science, Study”*



Picture 7 – “Head, heart, hands” reflection posters at the Final Event

We also talked to accompanying adults to try to understand the wider impact of PSG. See *In-depth: Accompanying adults’ view*.

The Breastmilk Experiment Day and Breastmilk Results Day

"I am incredibly passionate (about breastmilk research) now. For me it's one of the few areas of research that affects everyone everywhere anytime"

Dr Simon Cameron

Table 20 – Breastmilk Experiment event summary

What	Breastmilk Experiment Day	Breastmilk Results Day
Where	Charing Cross Hospital, London	St Mary's Hospital, London and Facebook Live (accessible by PSG group members only)
When	21 February 2018	10 July 2018
Who	<ul style="list-style-type: none"> • 130 volunteers • 117 successful expressions • 4 PSG staff • 2 Hearts Milk Bank staff • 5 Imperial staff • 12 lactation consultants and peer supporters • Nurslings ranging from 6 weeks to 6 years • 2 nannies 	<ul style="list-style-type: none"> • 31 delegates • 10 children and babies • 5 nannies • 4 staff

Our breastmilk experiment events totalled £2500 which came from the experimental budgets assigned to BOBAB and UKBAPS.

Breastmilk Experiment Day



Picture 8 – Images from the Breastmilk Experiment day in February 2017

In February 2018, our participants travelled to London from all over the country to express milk for the BOBAB and UKBAPS Breastmilk Experiment, the furthest travelling 372 miles from Galloway, Scotland, and the longest journey time being 6 hours and 20 minutes. *“It’s amazing to see the lengths people are going to today to be involved in this thing we all feel so passionately about. I’m lucky though as only got about an hour journey.”* Travel and time were self-funded, although we offered to reimburse travel costs up to the cost of a London zone 6 travel card for those that requested it.

We took over 7 rooms in the hospital’s university campus, so that mothers had the option of a private room to express or a shared room. We also had 2 nannies to help to entertain little ones while their mum expressed. But in many cases mothers helped mothers with expressing and child entertainment! Imperial staff printed posters with inspiring images to encourage mums while they expressed and we had 10 lactation consultants and peer supporters on hand as many mothers had never expressed before or not expressed in a while.

The excitement and enthusiasm of the mums on the day were palpable:

“So proud to be part of such a groundbreaking study. Also super chuffed I was able to express, as I’ve not done so in years! Thank you to everyone organising.”

“What a lovely day! So much oxytocin and love around. Such support and a palpable excitement in the air.”

“I just wanted to say I think women are amazing! From the organisers/ helpers to all the women that schlepped from outside of London, kids and lunches and pumps in tow, to donate their milk! ++ inspiring!”

“Thanks for letting me take part! And thank-you to the people who looked after my baby while I pumped.”

Breastmilk Results Day



Picture 9 – (left) Dr Simon Cameron presenting at the Results Day. He told mothers “Almost single-handedly you have opened up a new area of research.” (right) A tweet from Dr Alice Jones while at the results day.

In July, we held another event so that members could hear the preliminary results in person. 31 mothers attended with 3 nannies looking after children. As with all our events, we have found that nannies have been important to making our events work for mothers, while leaving the option for children to be in the meeting room with the mother should they wish to be. Travel was self-funded, although we offered bursaries on a self-declared basis.

Given the interest and enthusiasm about this experiment, we also streamed the event on Facebook Live, accessible to members of BOBAB and UKBAPS PSG. This allowed mothers to follow along in real time or to watch it back at a later date. We also used #breastmilkexperiment to collate tweets from staff and participants on the day so that people could follow along on Twitter.

What we learned

Having family friendly events were really important to our participants

"I found the accommodation of the children really important in my being able to attend. I usually say no to everything these days, even though they're 8 and 6 and can certainly live without me, I don't want to be selfish to them or my husband by abandoning them to pursue my interests! This way, it was a family outing.

Knowing they were going to be entertained with science activities while I was busy made coming to the event a no-brainer and well worth the drive - they were happy to come! And it wasn't just pointless keeping them entertained and out of my hair activities either, but edutainment!

Lovely to see so many breastfeeding mums feeding on demand - again without such a family friendly event, with the children near enough if needed but far enough when needed, I know I would have turned down the opportunity when mine were nurslings if the baby couldn't come too.

The accommodation was perfect for us - fully functional and equipped, but not posh like a hotel so that I was concerned if the kids dropped anything. Sharing our tables with others at mealtimes was lovely too."

Family friendly means not only that children are welcome but that activities are laid on for the children so that mothers feel it is a valuable use of their child's time and they are not just being made to come because it is something the mother wants to do.

At our residential weekend we provided nannies for those that brought children but not an [accompanying adult \(AA\)](#). We provided toys, dressing up and a storyteller for part of the weekend, as well as choosing a venue with large grounds to explore. However, we found that many of the accompanying adults found this difficult as they did not have a specific role or purpose to the weekend other than as child carer.

It also means including the AAs in some of the activities, rather than their sole role being childcare. While the feedback from participants (mothers) was overwhelmingly positive, feedback from AAs was more mixed at our residential weekend:

"I still have no idea what it was about and hated that dads were segregated throughout the process."

"A focus on mothers attending the workshop. It seemed men's views or opinions did not matter in the slightest. No official summaries to the dads as to what the day actually covered. Kids roaming around with no adult looking after them, meaning responsibility fell to a few dads, some didn't seem to care."

While we had tried to explain that the event was for PSG participants and that families and AAs were welcome, we tried to take these feelings on board at our future events. For our Gangstival events, we made an effort to come up with suggested activities in the local area so that AAs could take the children out while the mother attended the event. At two of the events, we also had a play leader. At the Final Event, we invited AAs to join the event Facebook group ahead of time with threads on suggested activities in the local area, we had nannies and play leader. We also invited the whole family to visit the Results Fair.

"I think it was nice for my kids to see Mummy working for once - usually it's Daddy leaving the house with a shirt and tie whereas I work at home and my efforts are less tangible and identifiable to them. Them being able to come and look around the room at the posters and such helped demystify what we'd been up to when we were apart."

We found that taking into account the needs of the children and AAs improves the enjoyment of the whole family as the mothers were able to take part more fully in the PSG activities and the AAs felt more empowered to take responsibility for the child(ren).

Our spending on childcare has been significantly higher than we planned when applying for funding, but we think it has been worthwhile as it has made the events accessible to many more mothers.

Mothers' priorities are often low on the list of family priorities.

Not only in terms of time, but in use of family money, so we needed to make our events as low costs as possible. At our events, all accommodation, catering and childcare, where needed, were paid for. Travel was self-funded, although we offered self-declared bursaries. We were not inundated with requests and most requests were very tentative, with people making an effort to minimise how much they asked for. We know that some people decided not to come because of the costs but they didn't feel that they were low enough income to "deserve" a bursary.

"Everyone at PSG were very accommodating of all needs – because they're parents too!"

Face to face events are really appreciated by group members and they inspire and empower

For those that could make the events we had really positive feedback, with many saying that they felt inspired and wish they had longer (although recognising that practically, they would not have been able to attend if the event were longer).

"It re-engaged me into science. Allowed me time to use my curious and inquisitive mind."

"A chance to think about parenting in a new way - what would we like to know, what is currently known, how could we explore those questions. Plus the sheer level of enthusiasm in the room was inspiring, and infectious - I know we went over time, and you had trouble moving things on, as we all were intrigued by some of the ideas, wanted to know more, discuss more, explore more!"

"It felt like our days were jam-packed with interesting sessions... The only drawback was the small amount of time we had – we were all so passionate about what we were discussing that sessions often overran and had to be cut short."

"It was laid back but real science. Being able to critique a paper and have other people value what I said was really confidence building."

They help to validate the project: *"It was good to know everyone is very serious about it. It's not just some people who made a Facebook group - it's a proper project with dedicated members."*

"it was great to hear from and fire questions at a pro scientist."

It can be hard to transfer enthusiasm, ideas and engagement from the event back to the Facebook groups.

"Since we have been back, I've kind of lost my way a bit. Work has been hectic and I haven't jumped on the project like I thought I would. I really want to be a part of something awesome and I believe that the 'gangs' are where it's at!"

We have found it difficult to transfer the energy from the events back to the Facebook groups. People that actively contributed to discussions at events did not contribute to Facebook conversations on the same topics.

We found it hard to find a role for the people who came to the events. We really wanted them to take back their project understanding and enthusiasm to the groups, but at the same time we decided not to elevate them to a visible role in order to keep the group democratic, rather than those that could attend being "super users" or similar. This might be something that could be tried differently in future projects.

In-depth: Pre & post survey results

In this section you'll find

- A profile of a typical [PSG](#) member
 - Quantitative and qualitative analysis of our pre- (722 unique responses) and post-(276 unique responses) surveys.
-

Our typical member was

- 25 - 44 years old (>90%),
- female (>95%),
- white (~80%),
- a parent to 1 or 2 children (>80%),
- and based in the UK (~90%).

Typically, our members had a high level of science qualification compared with the general public - 63% of pre-project respondents and 72% of post-project respondents had a science qualification at undergraduate degree level or higher. Although only around 30% worked as a scientist or had a science-related job, they were typically highly engaged with science in their everyday lives:

- <20% of respondents knew no one that had a science-related job
- None of our respondents had no one to talk about science with; over half talked about science with friends and online
- The vast majority felt confident in their understanding of science stories in the news and felt confident discussing these stories with friends
- Over half responded that they trust advice more if it appeared to be based on scientific evidence and almost none trusted celebrities as a source of parenting advice.
- Over 70% of respondents that completed both pre and post surveys mentioned evidence or research in both responses as a primary reason they would trust a source.

Given the relatively high awareness of science and interest in evidence-based information, we didn't see significant changes in behaviour related to [science capital](#) in our survey responses (e.g. consumption of science-related media) because of the relatively high starting point of participants. However, changes did occur in more discrete ways which were not teased out by the quantitative questions in this survey.

When asked what they had gained from the project, the four most common responses were around sense of community, opportunity to add to knowledge/change practice, knowledge, and increased confidence.

Sense of community – respondents said this was to do with feeling part of something bigger or being part of a like-minded group.

- *"It's been really lovely to be part of a very similarly minded group of parents who all understand your home situation and can make allowances for babies and toddlers, but still produce some amazing results."*

- *“It was good to talk to people about the different issues when designing the experiments. Without the PSG I would never have had these conversations. I also feel like I have been part of something I enjoy.”*

Opportunity to add to knowledge / change practice – respondents felt proud to contribute to and spread scientific knowledge

- *“The happy feeling you get from contributing to science”*
- *“Answer to a question I was really interested in and part of a spreading of science in parenting (which I believe is really important)”*

Contributing to research / knowledge was the second most common motivation for joining PSG in the pre-project survey.

- *“I’d like to be part of improving the quality of evidence-based parenting advice.”*

Knowledge – respondents mentioned gaining knowledge in areas they didn’t have before as well as knowing more about where to look for existing evidence.

- *“I gained knowledge in areas that I didn’t have previously”*
- *“Knowledge about where to start looking for existing research. Many scientists seem very approachable”*

Gaining knowledge was the most frequent motivator for joining PSG in the pre-project survey. It seems clear that there is a desire for evidence-based parenting information, but that it is not always easy to come by.

- *“More factual information and less scaremongering/judgemental advice”*

Increased confidence – respondents mentioned increased confidence in multiple areas such as their own parenting choices, their contribution to science and their use of science.

- *“...the chance to be part of things that I passionately believe in (breastfeeding-related). Which has increased my confidence in speaking out about breastfeeding views & issues.”*
- *“Personally, increased confidence & passion for being involved in research. Also been able to make confident decisions in my parenting choices, particularly in areas where I struggled to find clear answers from existing research.”*

In terms of changing participants attitude to science, almost half indicated that they had changed their attitudes. Of those that elaborated, most said that they now found science more approachable or accessible or that they had gained confidence in their ability to contribute and understand science.

A small number of respondents (7), said that PSG had influenced their career direction, ranging from embarking on further study to returning to a science career or re-focussing their science career.

- “As a researcher you often end up in a niche research area and this has given me the confidence that actually I do have the skills to research something a bit different. I've recently written a grant for something outside my field, and I'm not sure I would have done that if I hadn't been involved in the science gang.”
- “I found new areas of interest and reawoke old ones. I've made friends and had my faith in myself and abilities restored. I can still use my brain and read academic texts (and science ones at that!) and have intelligent, grown up conversations! I've been waffling about returning to work and what I could do, I suddenly have more ideas and enthusiasm thanks to working with PSG and meeting the others involved.”

Many of our respondents told us that they learned more about the project (individual group) research topics and about how scientific research works.

- “I tended to think of science as just including maths, biology, chemistry, physics, but I have learned a lot about collecting social data via questionnaire, ethics, etc.”
- “It sounds simple to come up with a question to ask, but it isn't always a simple matter to find ways to answer it”

Quantitative Analysis

For the analysis below, where participants had completed more than one feedback questionnaire:

- The earliest dated responses were used for the pre-project questions
- The latest dated responses were used for the post-project questions

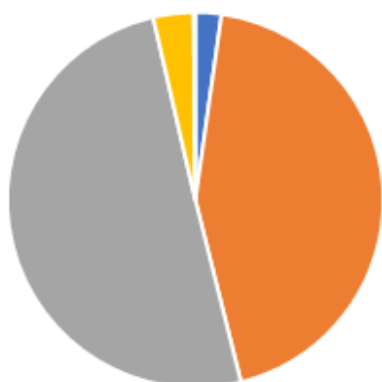
After doing this, we had 722 responses to the pre-project survey and 276 responses to the post-project survey.

Age

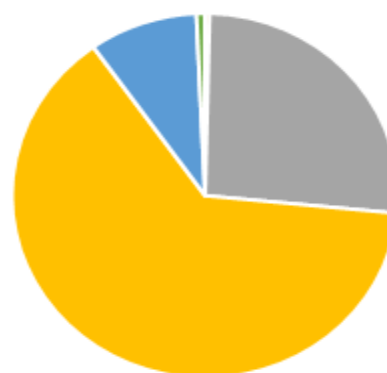
Most of our participants were in the 25 - 44 years age range (94% of respondents in the pre-survey, 90% of respondents in the post-survey). This is not surprising as this project was predominantly aimed at parents of young children. The average age of first-time mothers (in England & Wales) is 28.8 years.¹⁵

¹⁵Office for National Statistics: Birth characteristics in England and Wales: 2017 <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2017>

Pre-project: Age of participants



Post-project: Age of participants



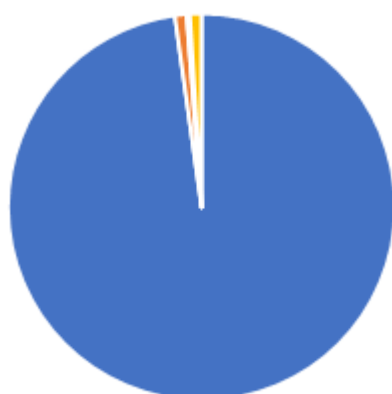
■ 18-24 ■ 25-34 ■ 35-44 ■ 45-54 ■ 55 or over ■ under 18 ■ 18-24 ■ 25-34 ■ 35-44 ■ 45-54 ■ 55 or over

Figure 21 – Age of pre- and post-survey participants

Gender

The vast majority of our participants were female. While this project was aimed at all parents, and despite a concerted effort on behalf of the project team ahead of the recruitment of Year 2 groups to look for groups which included fathers, the groups that our PSG groups were drawn from were predominantly female.

Pre-project: Gender



Post-project: Gender



■ Female ■ Male ■ Trans* ■ Prefer not to say ■ Female ■ Male ■ Trans* ■ Prefer not to say

Figure 22- Gender of pre- and post-survey participants

Ethnicity

We had trouble categorising the ethnic groups present in PSG, as many people did not wish to choose from the 2011 standardised ethnic categories provided by the Office of National Statistics. Many people chose to write in the free text box, and with a wide range of styles of entries, it was difficult for us to categorise. For these charts we have used Wellcome's reporting structure to define ethnic groups and only categorised individuals who positively identified themselves as being in these groups.

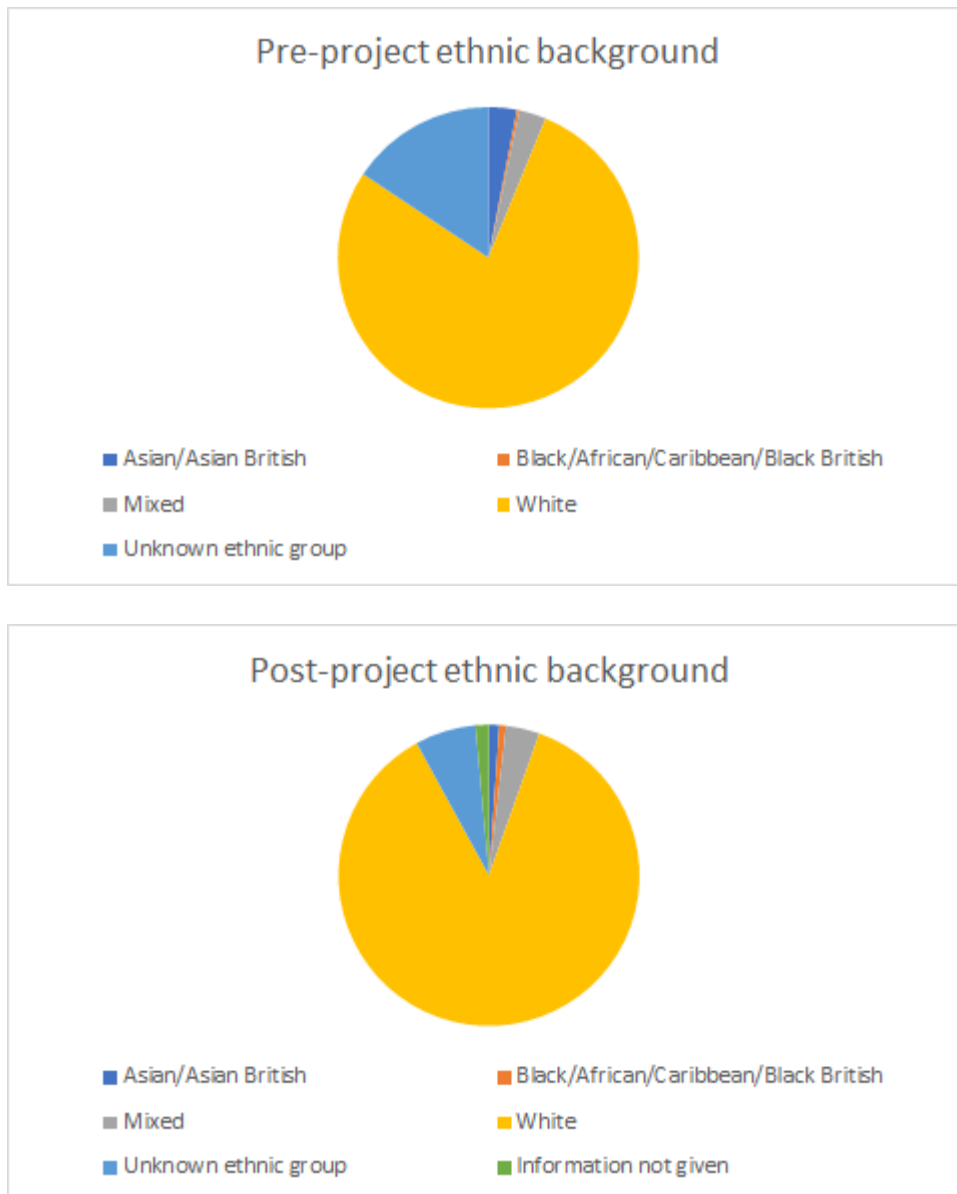


Figure 23 – Ethnicity of pre- and post-survey respondents

Number of Children

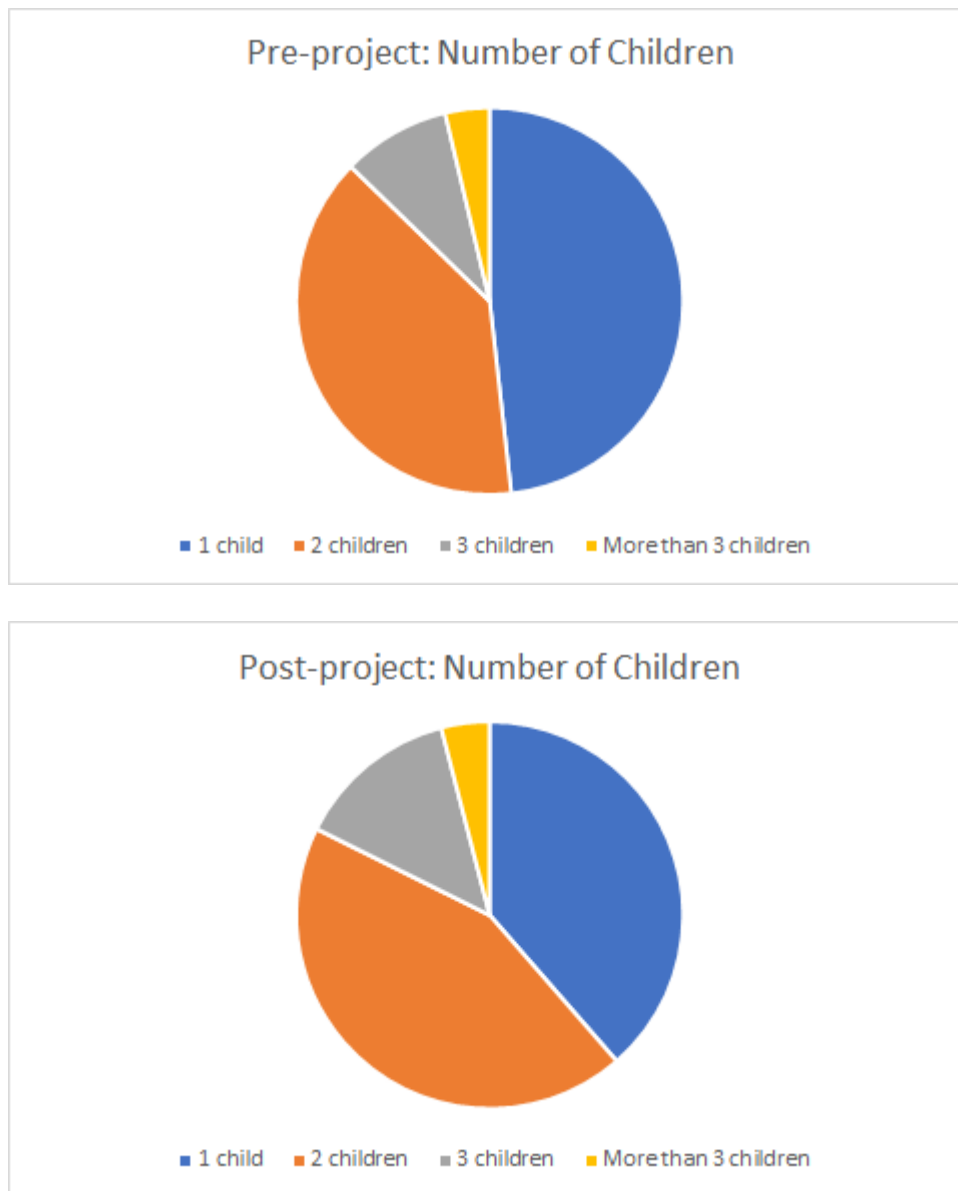


Figure 24 – Number of children of pre- and post-survey participants

Highest Level of Science Qualification

Our participants had a high level of science qualification: 63% of pre-project respondents and 72% of post-project respondents had a science qualification at undergraduate degree level or higher. This may indicate that the project appealed more to those with a higher level of scientific education.

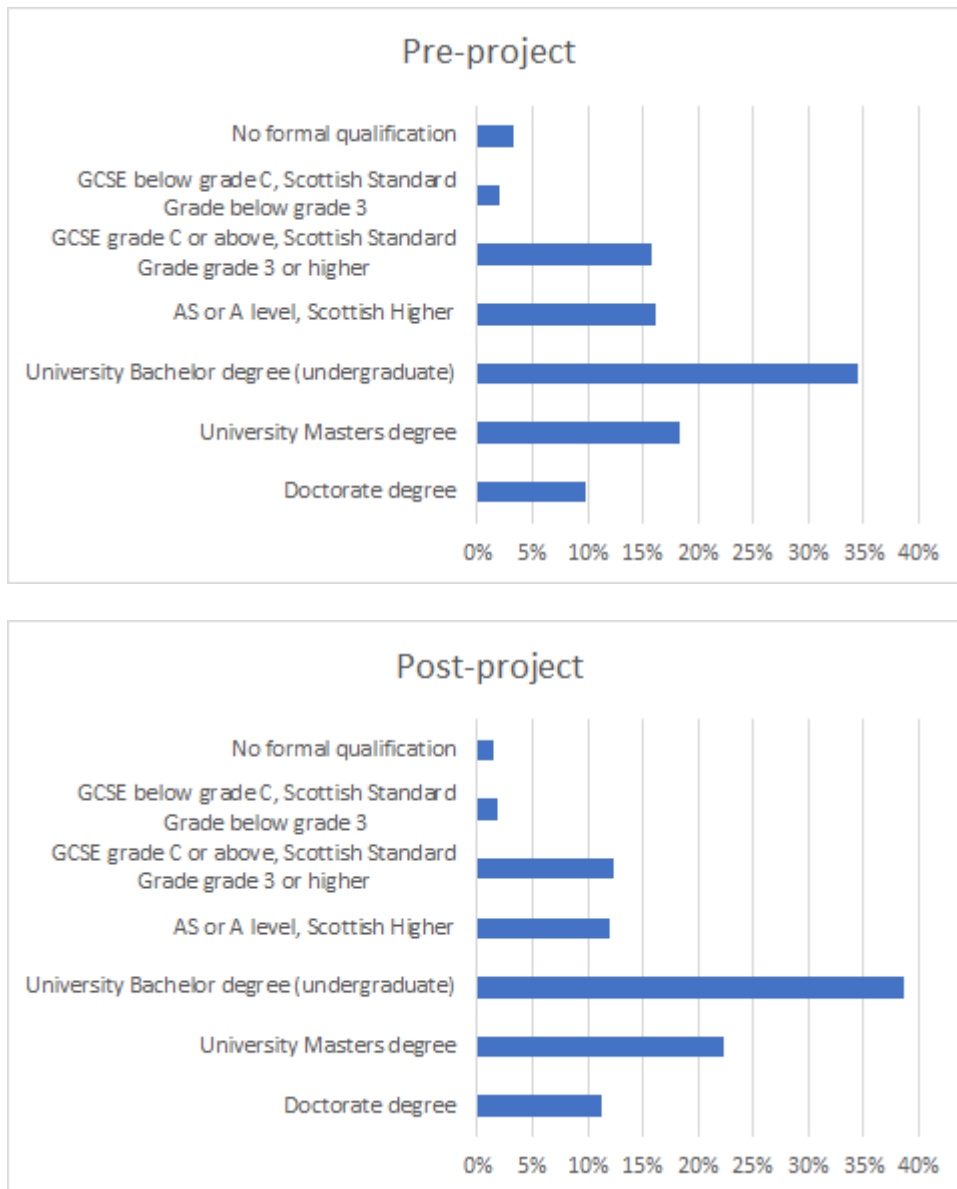


Figure 25 – Highest science qualification of pre- and post-survey participants

Location



Figure 26 – Location of pre-project survey participants



Figure 27 – Location of post-project survey participants

Non-UK participants locations (where given)

Although our project was aimed at UK-based participants, using Facebook means we had a small proportion of participants based outside the UK - 12% of respondents in the pre-survey and 8% of respondents in the post-survey. The majority of non-UK based participants were from the USA.

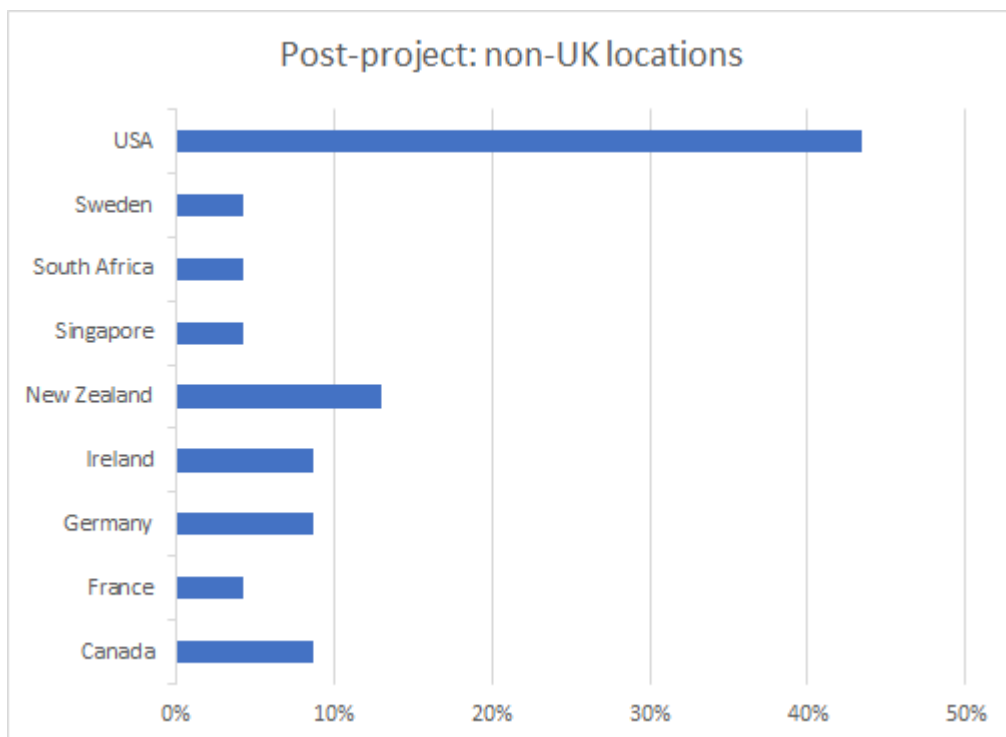
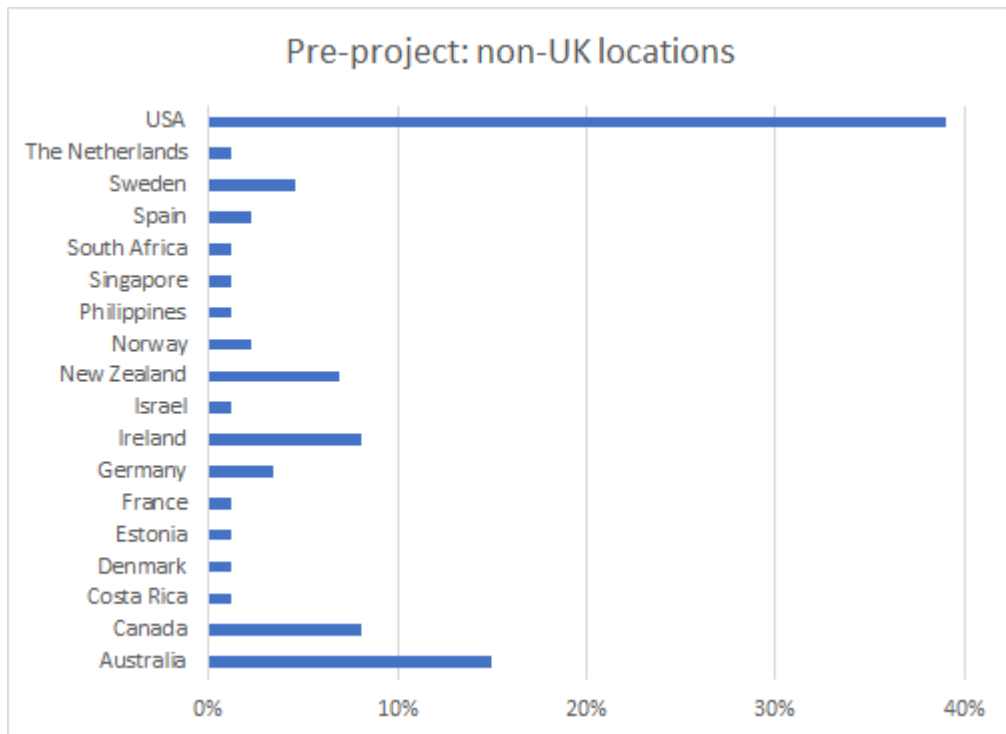


Figure 28 – Pre- and post-project survey participants locations (non-UK)

Where do you go to for parenting advice?

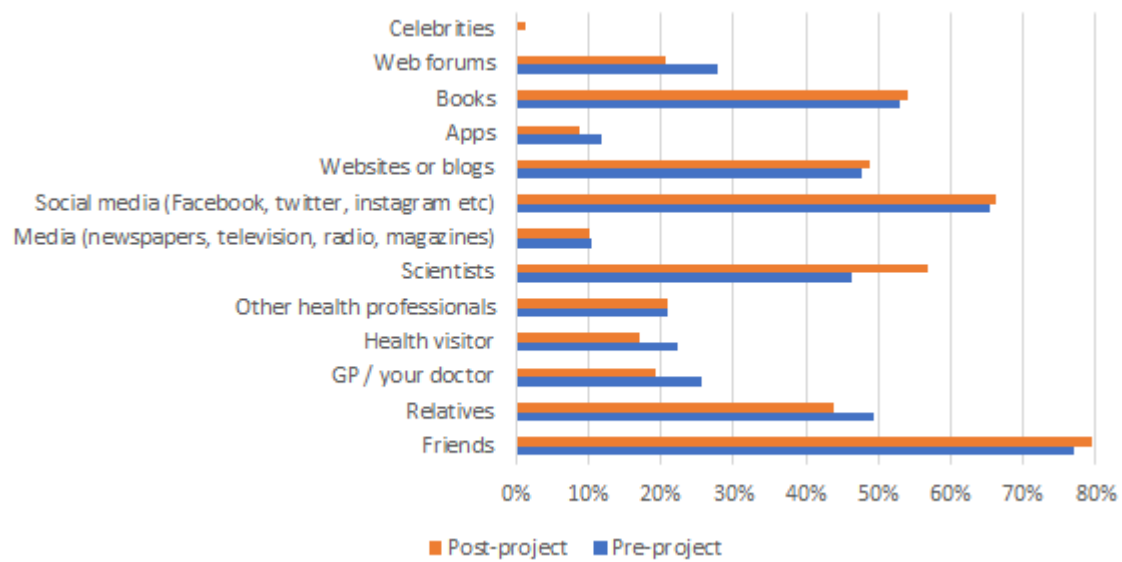


Figure 29 – Where do you go to for parenting advice?

Which parenting advice sources do you trust most / distrust?

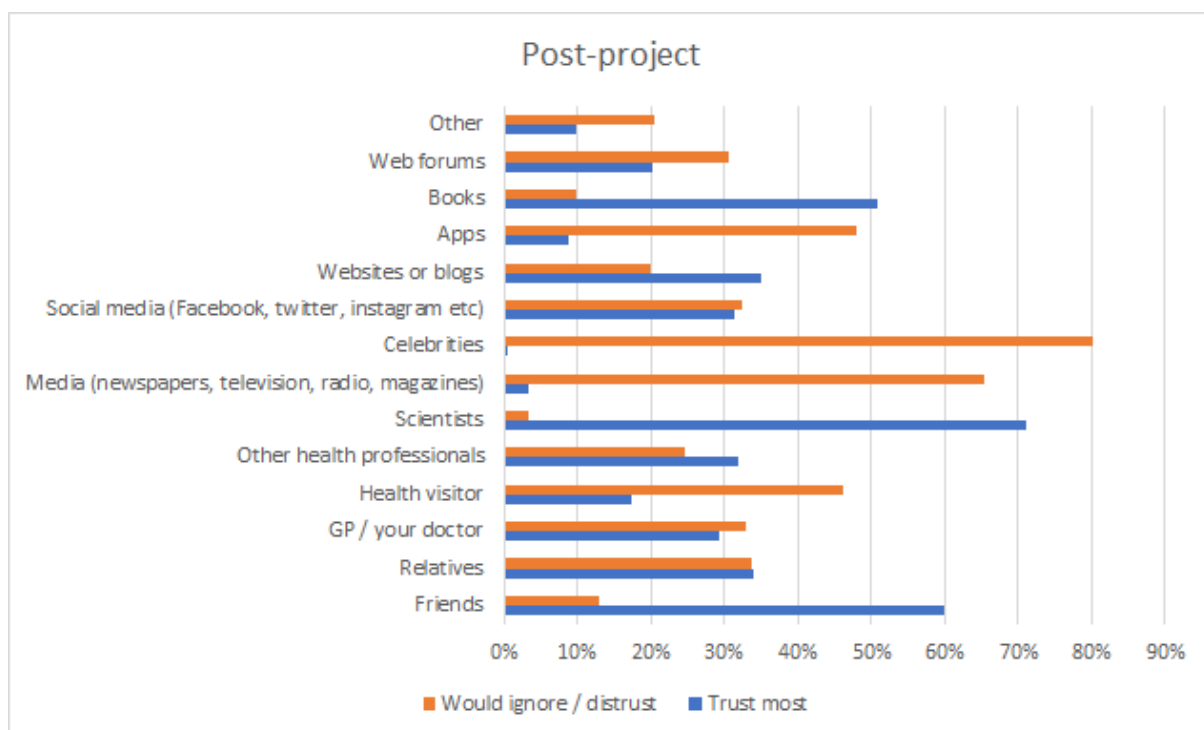
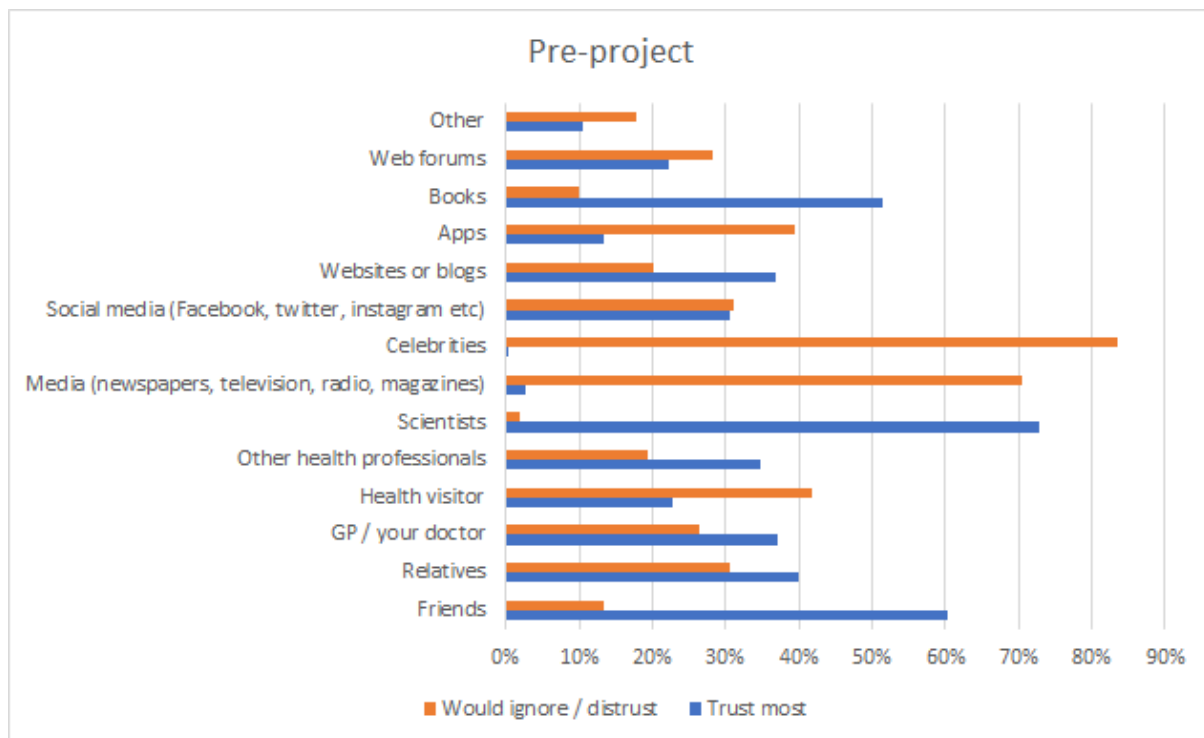


Figure 30 – Most trusted / distrusted sources pre- and post-survey

Science connections

Most respondents both pre- and post-project, talked about science with friends and online/social media contacts. Around 40% spoke to immediate family members (children, siblings and parents), and around 20% to wider family members.

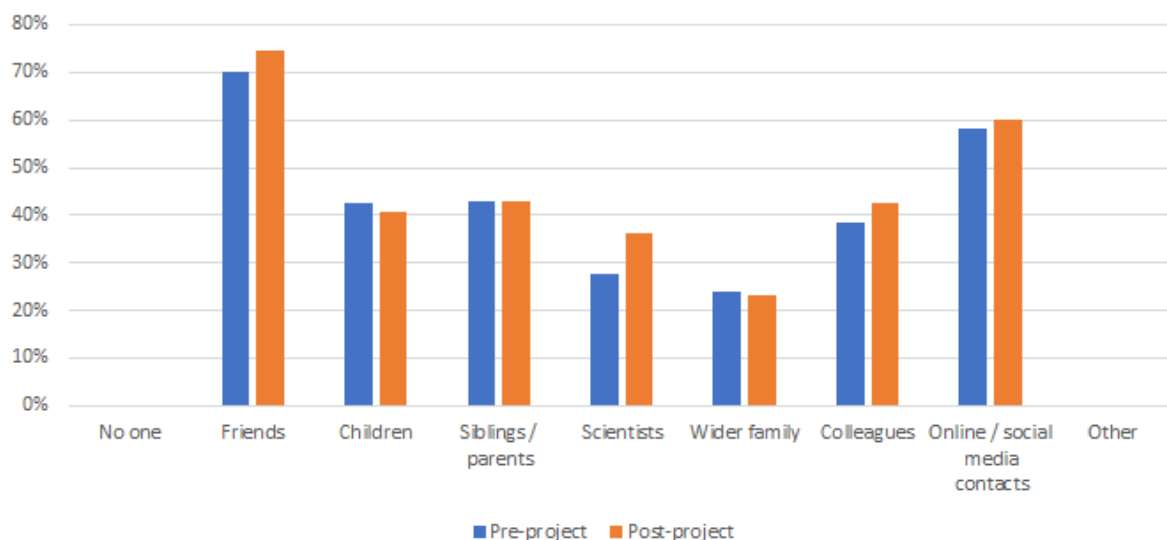


Figure 31 – Who do you get a chance to talk about science with?

Both at the start and end of PSG, less than 20% of respondents did not know anyone that worked as a scientist or in a job that uses science.

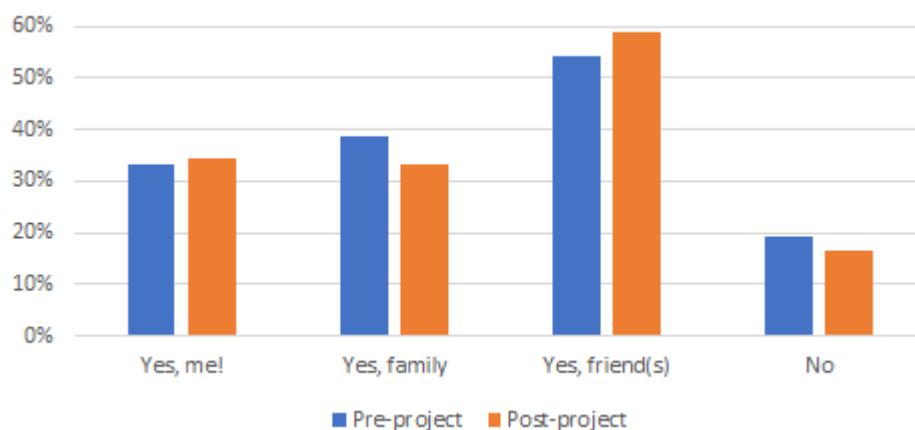


Figure 32 – Do you know anyone (family or friends) who works as a scientist or in a job that uses science?

Science capital

Overall, our participants had relatively high science capital and we saw little change in their confidence with science stories in the media or the frequency with which they undertook science-related activities.

In general, our participants were fairly confident when reading science stories in the news.

70% or more respondents in both the pre- and post-surveys felt they usually understand what the stories they read are about. And the vast majority in both surveys felt either fairly confident or very confident discussing these stories with other people.

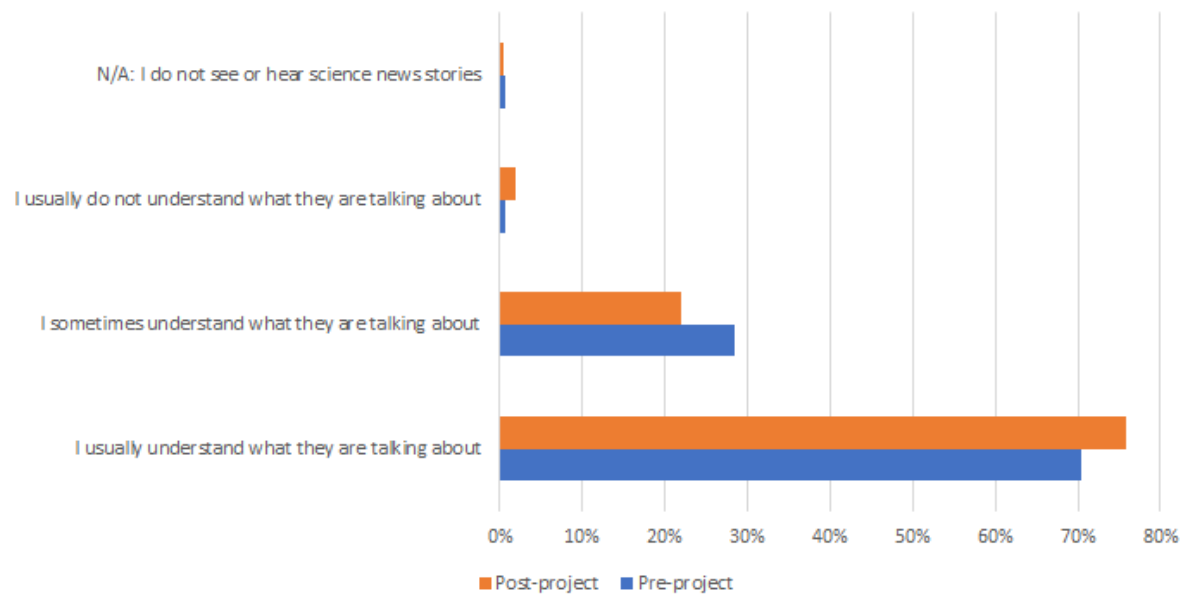


Figure 33 – Thinking of the news stories about science you see or hear in the news, which of the statements would you say best describes you?

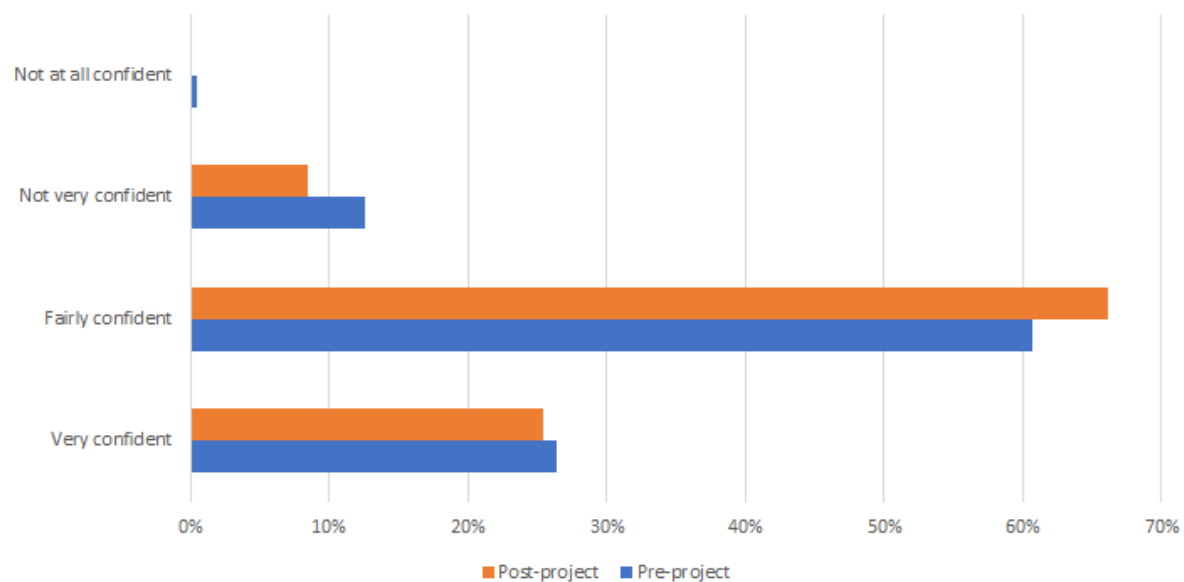


Figure 34 – In general, how confident would you say you feel discussing these news stories about science with other people?

Figure 35 – Pre- and post- project: how much do you agree or disagree with the following statements?

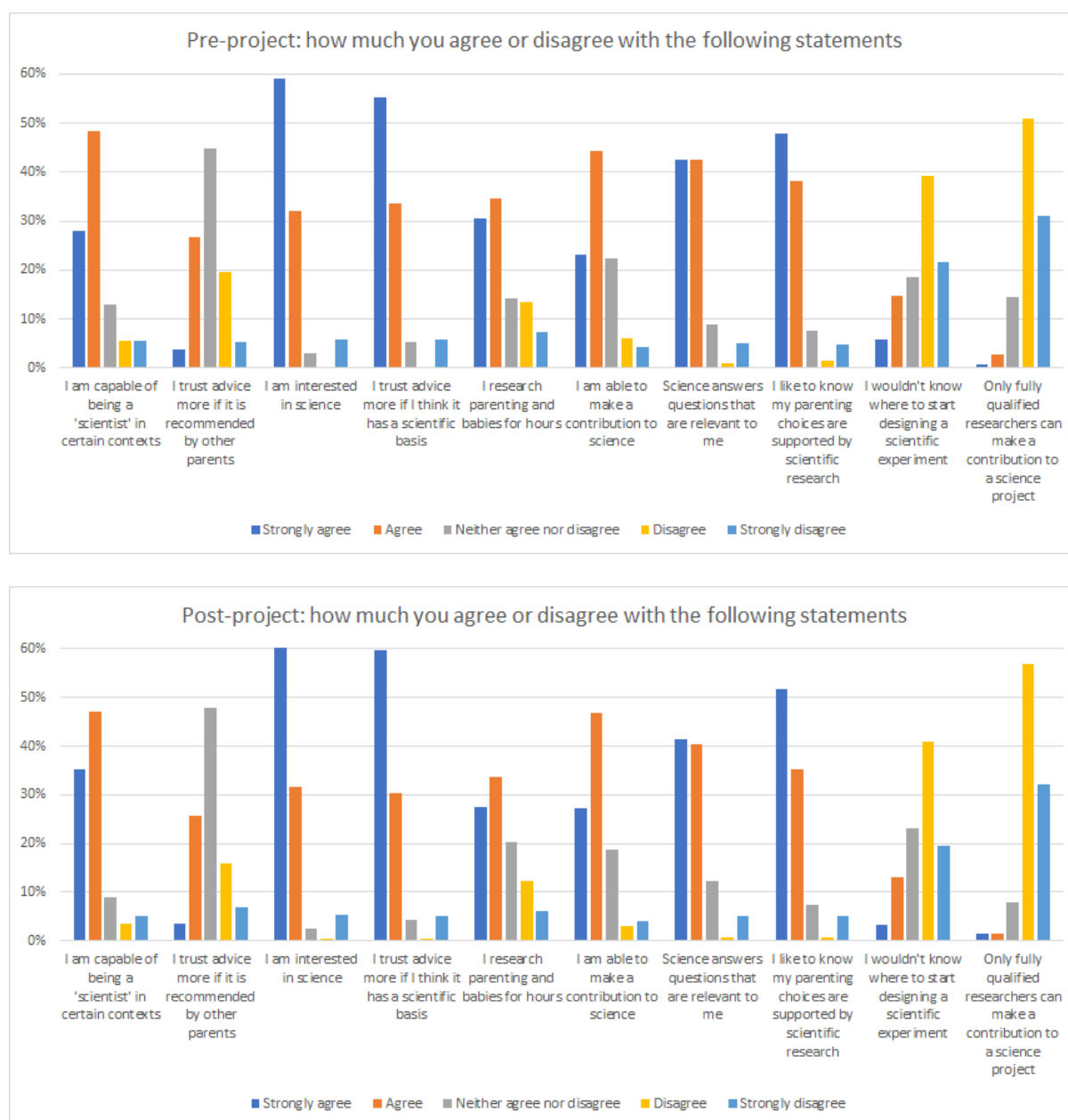
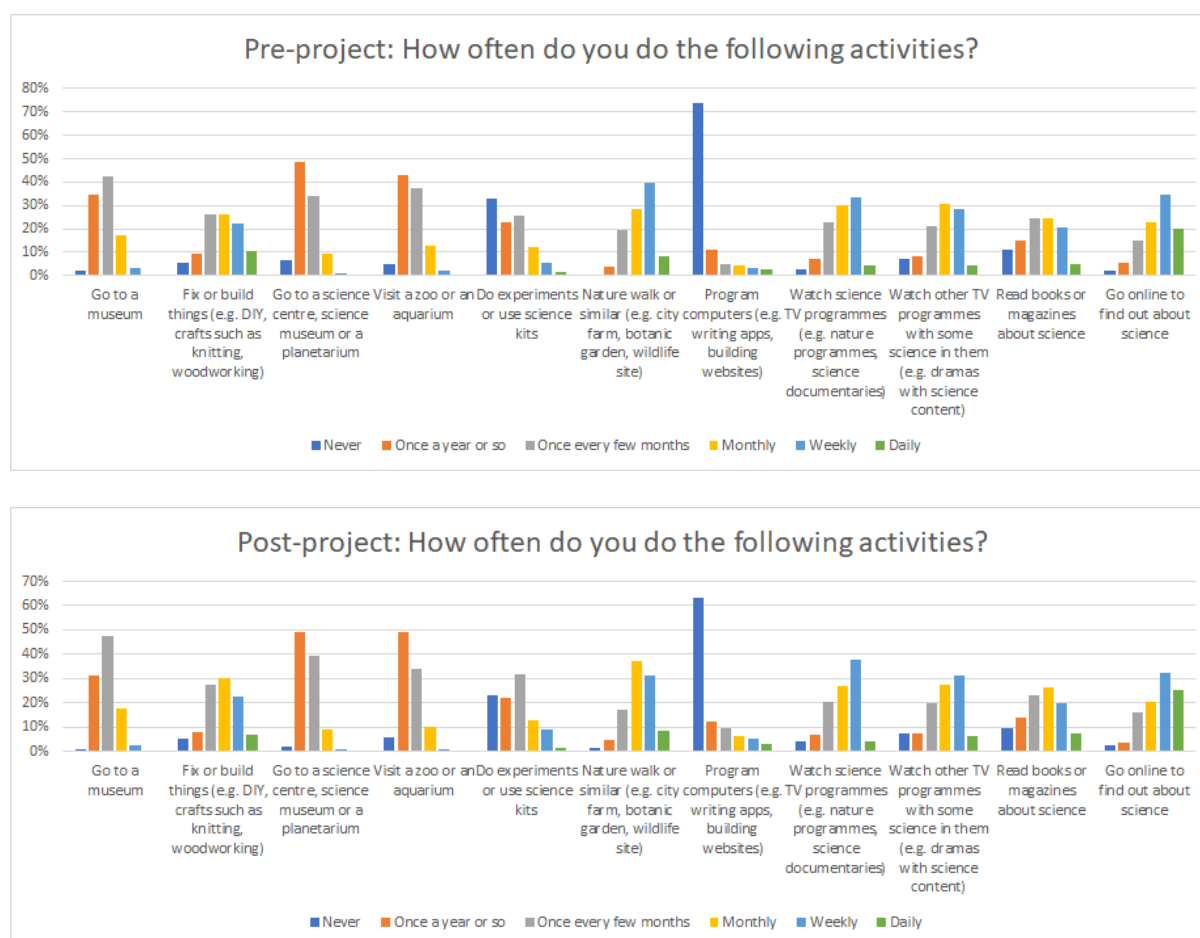


Figure 36 – Pre- and post- project, how often do you do the following activities?



Qualitative Analysis

Qualitative analysis was carried out on a smaller number of post-project surveys than the quantitative analysis due to staff time.

Pre-Project Hopes

Some participants filled in a questionnaire more than once; sometimes this was a matter of submitting the same responses multiple times in a short period of time, though a few were responses months apart and some people submitted more than once because they joined more than one project at different times. If the responses were identical and submitted closely in time, the duplicates were deleted. If a second response was submitted after several months or for a different project, the text responses were kept. Therefore, the total number of responses indicated may include multiple responses from the same person. For the pre-project questionnaire, no one had more than four responses and no more than two on any one project. A large majority of participants had only one response.

For the pre-project questionnaire, there were 768 questionnaire submissions of which 616 filled in the free text question:

“Q16. What do you hope to get out of being involved in Parenting Science Gang?”

The responses to this question were analysed to summarise the hopes of people for getting involved in the projects. Of the 616 responses, three were removed because they were incomplete (e.g. “I’d like to”) or didn’t really address the question (e.g. “can i have a coffee?”). The remaining 613 were grouped into types of responses for what the participants hoped to get out of the project. Some people listed more than one hope, generally no more than two, but for the analysis, only the first motivation that was mentioned was coded. 33 people contributed twice, usually because they were on two projects. These were counted as separate responses.

The resulting type of motivation and the number mentioning it are listed in Table 21. Examples of the range of responses within some of those categories are given as well, following the table.

Table 21 – Pre-survey “what I hope to gain” responses

What I hope to gain	Number of responses
Gain knowledge about topic	289
Contribute to research/knowledge	170
Discussion with others	43
Interested/mental stimulation	32
Confidence in parenting choices	30
Not sure	19
Encourage/involve my children in science	9
Positive change in advice/parenting experience	9
Learn more about citizen science	2
Links with people with similar interests	2
Other	8
Total	613

Some examples of the range of answers given for the more common response types are given below.

Gain knowledge

Many of the comments in this category mentioned learning more about research or evidence in general and some mentioned the specific topic of the project they were involved in.

- *“A clearer understanding of actual facts as opposed to opinions. I like to think although my parenting style is fairly intuitive that I can back up my reasons for certain things with science...or debunk others.”*
- *“Lots of useful information hopefully. Open to anything that may come of it.”*
- *“More factual information and less scaremongering/judgemental advice”*
- *“Learning more about breastmilk and having more info to educate people around me about it!”*
- *“I’m particularly interested in how gender bias develops and how I’m likely to be influencing my child. I’m also interested in how the landscape can be changed. Part of what I’d like to get out of the group is a sense of where the literature is at when science questions do come up (e.g. behaviour issues and gender in children, how gender stereotypes influence this, toy preference development, etc.) More generally with gender*

bias, things like how stereotypes affect e.g. accessing mental health support etc - topics that are current in the literature but where summaries and reviews can be hard to find. I'd definitely be interested in starting some FAQ or summary pages if anyone else is."

- *"To gain exposure to scientific research, that is verified by members of the group that have more experience and knowledge than I do, and that I would not know how to look for myself."*

Contribute to research

The second largest category of responses all had to do with hoping to contribute to knowledge or research in some way. A number of the respondents had some background in science or evidence-based areas such as health professions and wanted to share this experience to help contribute to the projects.

- *"Maybe help to get some answers or at least support other members. I am passionate about BF and would love to see more scientific answers to questions about breastmilk. Nature is amazing and should be researched more and appreciated."*
- *"I just like the idea of being part of some research and feel that I might be able to contribute. I'm interested to see the results of this particular experiment."*
- *"I'd like to be part of improving the quality of evidence-based parenting advice. I am aware of a lack of studies into breastfeeding beyond 2 years as it is relatively rare in western society. It would be great to change that for the next generation."*
- *"... my son has been part of a babylab and I think large data pools are beneficial and it's a good way to contribute without getting off the sofa!"*
- *"The satisfaction of contributing positively to the body of evidence (rather than just moaning!)"*
- *"This subject area is close to my heart as a new mum with a scientific background. I have been questioning topics such as breastfeeding, sleeping, teething etc a lot recently."*

Discussion with others

Responses about discussion of evidence, research or experiences that could inform their parenting practices or feed into better knowledge about parenting were also a relatively common category. A number of the responses mentioned interacting with "like minded" people to share ideas and learning.

- *"Discussing with others who practice evidence based parenting, new insights and information"*
- *"I look forward to interacting with like-minded people. Keep up to date with new parenting information and share knowledge I already have"*
- *"Science based parenting advice. Chat to like-minded people, not just about the science stuff."*
- *"Speak with other parents with a scientific approach. Learn about recent research on various aspects of parenting"*
- *"Getting support for science based parenting and exchanging knowledge and experiences. All the while not equating scientific with artificial/processed. No ideological*

approach. Critical thinking also re scientific findings. Getting input for stimulating scientific interest in children. Ideas, recommendations for trips, crafts etc. A group of friendly, tolerant, supportive, sensible people.”

Confidence in parenting choices

Another interesting category was the subset of those who hoped to gain confidence in the choices they were making as parents by being involved in the projects and to be able to justify those choices if challenged.

- *“Confidence and understanding of my role as a parent to do my job without prejudice.”*
- *“I am interested in the science behind parenting advice and being able to feel confident in my choices”*
- *“Scientific evidence to confirm my parenting choices and help me to defend myself against negative attitudes to my choices.”*
- *“I'd like confirmation that my parenting practices are *okay* and I'm not messing my kids up.”*
- *“More informed decisions, help to broaden my outlook, research to support my decision making and defend my choices when challenged.”*

Pre-post project comparison of trusted sources

One free-text question was present on both pre and post questionnaire:

Q3b. Please could you briefly explain why you do / do not trust the sources you ticked above?

134 participants filled out the post-questionnaire; of those, 85 participants also filled in a pre-project questionnaire. 14 answered the free text question once only, either pre or post project, so responses could not be compared for any changes. Responses from the 71 participants who answered both times were analysed to assess whether there were changes in the reasons for trusting or distrusting sources from the beginning of the project in spring/early summer 2017 to the end of 2018 as reflected in written comments.

50 of the 71 responses were consistent across the time of the projects. Of these, 31 explicitly mentioned evidence, facts or science as a reason to trust a source or lack of evidence as a reason to distrust them at both times. Some examples of these responses are presented in the table below.

Table 22 – Comparison of pre- and post-project responses to question 3b (1)

Pre-project response	Post-project response
They're often hearsay rather than factual. If it's something that isn't of importance such as clothing etc then I will seek advice that way. Otherwise I'd rather go factual.	Fact vs fiction. I said on the first one [trusted sources] that I use social media - but that is just to help narrow down a search. I don't trust all websites but would trust some e.g. NHS
I am very cautious of claims made without link to clear peer reviewed evidence from a source I already trust; or appears reputable (e.g. a university).	I prefer evidence based advice.

I trust sources I feel would take an evidence based approach and would prefer someone to say we don't know than guess. Don't trust sources that 'go with their gut' or don't provide evidence for their claims.	Hope scientists have facts behind their answers, very picky about Facebook sources in that they need to be from science based groups. Don't trust family, etc because they rarely have any evidence for their claims.
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Of those that gave consistent answers both times, but didn't explicitly mention evidence or science, 16 mentioned issues such as a lack of specific training in parenting issues, outdated knowledge or advice that might be biased or agenda-driven rather than fact-driven as reasons not to trust sources and many mentioned facts or evidence in at least one of the responses. Some examples of these are given in the table below.

Table 23 – Comparison of pre- and post-project responses to question 3b (2)

Pre-project response	Post-project response
Medical professionals are not qualified to give parenting advice, only medical advice (unless they are e.g a child psychologist).	I wouldn't trust or ask health professionals on parenting advice as they have no or minimal training on parenting - their training is on medical issues. (apart from child psychologists or others with specific relevant education). I trust friends/websites/blogs depending on what the advice is.
Health Professionals and family members tend to have an old-fashioned one-size-fits-all approach to parenting, which is fine for basic stuff that you would know anyway, but when it comes to specific problems where your child is different then their advice is rarely helpful. I would prefer to find like-minded people through social media, listen to their experiences of or similar problems and make up my own mind using that information	Don't think celebrities have more clue than me, and health visitors and doctors usually give old fashioned advice that's not scientifically based and doesn't fit with my sense of ethics.
Wide range of opinions from friends, family and peers on social media to take what I want from the advice given. Celebs/media views can be false to promote certain products or force single points of view.	Celebrities, newspapers as they may be swayed by advertising revenue.
Media and celebrities always have a their own agenda and are often trying to sell something.	[Celebrities are] usually doing it to promote themselves.

The remaining three responses which were consistent in the two questionnaires emphasised trusting family or friends with parenting experience and whose values matched theirs.

Of the 21 participants whose answers were different in the pre and post questions, 12 did not mention evidence or research in their pre-project responses, but mentioned those as reasons to trust a source in the post-project response. Of the other 9, 3 mentioned evidence in the pre-project response, but not in the post-project reasons. The other 6 mentioned trusting those with experience or distrusting sources with different agendas to theirs with different reasons on the two questionnaires.

Table 24 - Comparison of pre- and post-project responses to question 3b (2)

Pre-project response	Post-project response
I find a lot of articles social media follow trends in all things, even parenting techniques. My child is not a fad.	HCP seem to have opinionated and dated approaches and advice and support regardless of families situation or needs. Books, science seems more reliable in terms of facts and family/friends are a source of emotional support and understand family make up.
Other mums that have done their research I trust the most. Media least trust as they have adverts and sometimes it's difficult to see which is fact and which is just advertisement.	Relatives are older and do not have up to date advice. Science is up to date and fact based on research. All the other it depends on the individual, for example some health professionals are great and up to date training other are completely uneducated in new research and ways of parenting for example breastfeeding and co sleeping. I tend to trust my friends and articles and books I read as they have the same parenting techniques as me.
Anything which could be biased with ulterior motives	Generally trust people who have evidence, ie through own experience or research

Post-project responses

Three free text questions were asked on the post-project questionnaire that give some insight into what people felt they had gained from being in the projects. 143 responses to the post-project questionnaire were submitted up to end of December 2018. Seven people submitted two responses. All responses have been included in the analysis of free text.

Q24. What (if anything) do you feel YOU got out of being involved in Parenting Science Gang?

There were 116 responses submitted to this question. A number of them mentioned several things that they felt they had gained. All of these were categorised so the total number of gains mentioned is 172. The types of gains mentioned are shown in the following Table 25.

The gain that people mentioned most (28 times) was a *Sense of community* which was about feeling a part of something bigger and/or being a part of a group of people with the same aims. The second most mentioned categories were *Opportunity to add to knowledge/change practice* and *Knowledge* with 23 mentions each. The fourth most common was *Increased confidence*. Several responses simply said "Confidence" but a number of longer responses were either about confidence in their own parenting choices or about being able to understand and contribute to research and to explain it to others who might question their decisions. The rest of the responses were mentioned from 11 to 1 times. As might be expected, many responses were specific to the person, such as the two experienced scientists who said they had learned about how to better communicate science to other people. Examples of the most common types of responses are given below Table 25.

Most responses were very positive, but there were a few negative ones. Five people felt that they couldn't contribute because they didn't have time, four said they didn't get much out of the projects and two said they didn't feel included because the group was "clique-y" or the

conversation went into a Messenger group to which they were not privy. The eleven “Other” contributions were single comments which included: liking the “democratic process”, seeing how scientists can work with a community group, feeling much more informed about issues facing women in the NHS, doing research outside academia, having time set aside to think, a lack of feedback, insufficient project time overall, and feeling guilty for not contributing.

Table 25 – What I got out of the project

What I got out of the project	Number of responses
Sense of community	28
Opportunity to add to knowledge/change practice	23
Knowledge	23
Increased confidence	20
Renewed interest	11
Appreciation of citizen science	7
Career	7
Enjoyment	6
Achievement	6
Time constraints	5
Pursue interests	4
Use my brain	4
Not much	4
Contact with experts	3
Understanding process of science	3
How to better communicate science to others	2
Different experience of science than before	2
Use existing skills	2
Interesting discussions	2
Felt excluded	2
Other	6
Total	172

Sense of community

Many of the respondents mentioned a fulfilment in being a part of a like-minded group who were working and discussing issues of importance to them. Some examples are given below.

- *“It’s been really lovely to be part of a very similarly minded group of parents who all understand your home situation and can make allowances for babies and toddlers, but still produce some amazing results.”*
- *“A lot of fun & enjoyment! But more importantly, the chance to be part of things that I passionately believe in (breastfeeding-related).”*
- *“Be part of something bigger with like minded people where you’re not the one in the minority”*
- *“Really a feeling of being part of a community of people working for a similar cause.”*
- *“It was good to talk to people about the different issues when designing the experiment. Without the PSG I would never have had these conversations. I also feel like I have been part of something that I enjoy”*

- *“... a community of like minded people, happiness”*

Opportunity to add to knowledge/change practice

A number of participants mentioned that they felt proud or felt they had gained most from the opportunity to add to scientific knowledge or potentially to change practice for the better.

Examples of these contributions include:

- *“The happy feeling you get from contributing to science!”*
- *“Got to be on the cusp of new science! That was cool!”*
- *“Answer to a question I was really interested in and part of a spreading of science in parenting (we I believe is really important)”*
- *“Really a feeling of being part of a community of people working for a similar cause. And that cause will have some exciting implications for other parents”*
- *“Proud to be part of something thats results could lead to fairer treatment of bigger mums”*

Knowledge

The same number mentioned gaining knowledge about how science works or about the topic they were researching.

- *“Getting more scientific knowledge about something which people love to give unhelpful random advice on”*
- *“The biggest thing I’ve got out of it is taking part in the Q&As, which have been absolutely fascinating and I’ve learned a lot.”*
- *“Knowledge about where to start looking for existing research. Many scientists seem very approachable. “*
- *“Useful info on babywearing, often useful info”*
- *“I learnt some things about breastfeeding I didn't know”*
- *“I gained knowledge in areas that i didn't have previously”*

Increased confidence

Other participants mentioned a number of ways that they had gained confidence – in their parenting choices, in understanding or using science or in their ability to contribute to a new area.

- *“... the chance to be part of things that I passionately believe in (breastfeeding-related). Which has increased my confidence in speaking out about breastfeeding views & issues. It's so great to be able to respond to negative/uninformed comments with "Well I was part of an experiment & we found this result..." & have an air of confidence and authority, rather than just mumbling "Well I've read an article on Facebook..."!”*
- *“Personally as a mum feeding a 3 year old. Explaining to my parents why I’m still feeding her and ‘defending’ my choice had started to become depressing and annoying. I even started to doubt the choice I had made when I was vulnerable! But having the science (particularly the radio 2 interview) really shut them up. It seems hearing it from Amy on radio 2 made them realise maybe I wasn’t talking nonsense after all!”*

- *“Personally, increased confidence & passion for being involved in research. Also been able to make confident decisions in my parenting choices, particularly in areas where I struggled to find clear answers from existing research.”*
- *“I’ve ... gained confidence in my ability to contribute to scientific and academic work.”*
- *“More confidence that I (we) can play a role to change the status quo.”*
- *“It helped me to feel better about myself”*

Renewed interest

Some participants mentioned a renewed interest in science.

- *“A renewed love of science, and a reminder about how important that being scientifically minded can be”*
- *“It reminded me how much I love science. Reminded me how much I’ve forgotten!”*
- *“...being able to continue an interest in science which would be hard if not impossible to get elsewhere”*
- *“I found new areas of interest and reawoke old ones.”*
- *“Using my brain to process more challenging information... reawakening my interest in research.”*
- *“Refocus science career on why I started in first place”*
- *“A renewed passion “*

Appreciation of citizen science

Another subset of responses was from seven people who mentioned gaining an appreciation of social science, participatory research or citizen science.

- *“Learned a lot about genuine co-produced science which has already informed my professional life and will continue to do so.”*
- *“I gained knowledge in areas that i didn't have previously, and professionally - I've gained a great appreciation of the importance and methods of making citizen science projects work well.”*
- *“I have no professional experience of social science data. This has opened my eyes to what is involved in formulating questions, etc.”*
- *“It's been very interesting learning more about citizen science.”*
- *“Learning about participatory action research”*
- *“Interesting to work on a different side of science”*
- *“User led science”*

Career

An interesting group of responses were the seven people for which the project had influenced them enough that they were either planning to return to a science career with new energy and ideas or to embark on a new career that involved science.

- *“As a researcher you often end up in a niche research area and this has given me the confidence that actually I do have the skills to research something a bit different. I've*

recently written a grant for something outside my field, and I'm not sure I would have done that if I hadn't been involved in the science gang."

- *"I found new areas of interest and reawoke old ones. I've made friends and had my faith in myself and abilities restored. I can still use my brain and read academic texts (and science ones at that!) and have intelligent, grown up conversations! I've been waffling about returning to work and what I could do, I suddenly have more ideas and enthusiasm thanks to working with PSG and meeting the others involved."*
- *"...I'm strongly considering applying for a PhD programme!"*
- *"The courage to re-apply for my masters and begin a career in science"*
- *"The drive and confidence to pursue education and a scientific career"*
- *"Refocus science career on why I started in first place"*
- *"It has also shaped my current career direction! "*

Enjoyment

Several participants mentioned simply enjoying or being excited about the experience!

- *"A lot of fun & enjoyment!"*
- *"Some fun!"*
- *"It has been exciting!"*

Achievement

Some participants mentioned their biggest gain being pride and a sense of achievement.

- *"It was amazing to watch what a group of mums achieved"*
- *"I felt very proud and grateful to be a part of it."*
- *"A sense of achievement and feeling like I am at the forefront of parenting research."*

The second question that was asked on the post-project questionnaire that gives some insight into gains in science understanding or science capital was:

Q26. Do you think your attitude towards science has changed in any way as a result of this project?

116 participants filled in answers to this question. Of those, 50 said *No/not really*, 11 said *A little/Maybe/Slightly/Not sure* and 6 said *"Neutral"*. Of the ones who said *No/not really*, 10 elaborated saying that they already loved science or that they worked as scientists. One of those said that they didn't think they had changed their attitude, but it had renewed their interest. Two others responded that they were still as interested as they had been.

Of the 57 remaining responses that indicated they had changed their attitudes, 18 simply answered *Yes*. The remaining 39 gave some elaboration. Of those, 18 mentioned feeling that science was more approachable, accessible or that they had gained confidence in their ability to understand and contribute to science. As one participant put it:

- *“Yes, I definitely feel that I can contribute to science, in places where research isn't even being done yet, or no one has thought to do it. Also, finding things that make researchers excited about makes you realise that everyone can be involved.”*

The other 21 responses were quite varied. 6 mentioned a better understanding of how science or citizen science works. Two examples are:

- *“Yes, it feels more dynamic than I expected- moving from first questions to the experiment to the results. It was much quicker than I expected even as a researcher.”*
- *“Greater insight into the degree of humility that many researchers have, who say “we don't have all the answers, there's still so much to learn”. This isn't the science that gets most noise in the news or in our wider cultural setting.”*

Four mentioned being excited, more positive, or having renewed interests in science. One scientist in the group said:

- *“Yes, actually - might seem strange because I am a scientist, but the enthusiasm of everyone involved has helped rekindle my enthusiasm for science in general, when my day-to-day work has lots of slog, often followed by rejection and disappointment, with bright spots of cool results or something being accepted seeming few and far between: being able to see real science being done, and people actually getting to do something they designed and being so excited about it all, has helped me look more positively towards my job.”*

Four more responses mentioned aspects of changed attitudes toward involving “real people” in scientific studies and that grassroots efforts can make a difference. Examples include:

- *“My attitude to online questionnaires and user support groups/forums working with a professional researcher. “*
- *“Made me realise more can be done at grassroots level that has a signi[ficant] impact nationally/internationally “*

The remaining seven mentioned wanting to encourage children to do science, the importance of science in decision-making, not having thought that something she felt so positive about would actually be proved, opening new lines of enquiry for her own research, that there is science in the “everyday”, and being aware of how much research still needs to be done in the project area. The final response mentioned science still feeling “as distant as before in my understanding as I still don't know how to read bias”, but that it was reassuring that real people could be involved in finding answers.

The final question asking about the personal experiences and gains from the project was:

Q28. Do you think you learned anything new from the project? Please explain your answer.

Participants responded to the first part of the question by choosing answers from a menu. Of those, 50 said *Yes, lots of things*, 59 chose *Yes, a few things*, 19 were *Neutral* and 5 chose *No*. Of these 133 participants, 82 wrote responses to the second half of the question. Of

these, 37 had answers *Yes, lots of things*, 38 chose *Yes, a few things*, 4 were *Neutral* and 3 chose *No*.

Of those who answered *Yes, lots of things* and *Yes, a little*, some people gave more than one answer, so the total is more than 75. The type and number of answers for each of the two responses is shown in the table below.

Table 26 – Did you learn anything new?

Did you learn anything new?	Number of responses Yes, lots/Yes, a little
Knowledge of how (citizen) science works	20/15
Knowledge of project areas	17/11
Learned from articles/Q&A	4/5
Other	4/3
People can make a difference	1/1
Don't know/not sure/not specific	0/4

Many respondents mentioned learning about the project topics and about how scientific investigations in work, either in general or for social/citizen science projects. Some examples of the latter category are:

- “*Yes I have learnt lots about how scientific experiments are put together and the work behind it. Methods and collecting samples etc. Also how different results could be depending on the focus of the experiment.*”
- “*I tended to think of science as just including maths, biology, chemistry, physics, but I have learned a lot about collecting social data via questionnaire, ethics etc.*”
- “*It sounds simple to come up with a question to ask, but it isn't always a simple matter to find ways to answer it*”
- “*I learnt more about how to actually 'do' various qualitative and textual analysis methods taking part in PSG than I did academically (which included a social sciences methods MA, and a qualitative methods based PhD).*”
- “*Didn't really appreciate that a qualitative study was research before! Didn't know it existed!*”
- “*that my own experience of applying for ethical approval was normal (i.e. thoughtful, considered, painstaking, slow!).*”
- “*The amount of work and funding required to pilot a study*”

The “other” answers ranged from finding that it is possible to be involved but also to step back when necessary without feeling guilty, that it was interesting to hear from experts, how to influence influencers (e.g. health visitors), learning about themselves, having their choices confirmed, and remembering “the continuing power of words and how healthcare professionals continue to wield power”. A few answers were not specific, saying that they knew they learned things but didn't remember.

Of the seven participants who said they were *Neutral* or *No – didn't learn anything* and wrote responses, four said that they were not really involved, one said they were already familiar with science, one said they were only helping with admin and one said “Results”.

Discussion

A relatively high percentage of the participants who filled in the questionnaires have some formal science qualification, from GCSE up to PhD. Of the 616 responses on the pre-project questionnaire, only 20 of the responses said they had no formal science qualification. In comparison, 63 had a doctoral degree in a science subject. This is undoubtedly one factor influencing the content of the responses. For instance, almost 70% of the participants who filled in pre- and post-project questionnaires mentioned evidence or research in both responses as a primary reason they would trust a source. Most of the others mentioned evidence or research in one or the other questionnaire and mentioned distrusting sources that did not have specialist training, a personal agenda that could influence the information, a lack of up-to-date knowledge or biased information as reasons to distrust sources. This indicates a high awareness of and interest in evidence-based, current information as desirable sources of information on parenting for most of the participants from the start of the project. This is also borne out by the fact that on the pre-project questionnaire, only 91 individuals out of 720 said that they were “not at all confident” (3 responses) or “not very confident” (95 responses) discussing news stories about science with other people. All the rest said they were “fairly confident” or “very confident”.

A variety of motivations and hopes were given for joining the various projects. 75% of participants mentioned as their first motivation that what they wanted to get out of the project was to either gain knowledge of evidence, science or their topic area (47%) or they wanted to contribute to research (28%). These hopes reflect a strong interest in science, again indicating at least some level of comfort in engaging with scientific processes and information for a large number of the participants.

One participant who started in Dec 2017 and submitted two responses first said “I’m just along for the ride at this point!”; then, in Feb 2018, “Ability to influence topics researched and get the answers to questions”. After three months, it seems she was clearer about how projects worked and was interested in influencing the topics that were being researched.

The post-project questionnaire asked what people felt they had gained from being involved in the projects. Many of the responses matched with the hopes in the pre-project questionnaire about gaining knowledge and contributing to science but there was a variety of other benefits mentioned. Many participants mentioned excitement, achievement, new confidence, a chance to use their brain and their skills, and/or a sense of being part of something bigger.

An interesting outcome was reflected in the very inspirational contributions about being motivated to renew an existing science career or embark on a new area or career in science. There were also several mentions from experienced scientists about understanding or appreciating participatory science or citizen science in ways that they hadn’t before.

In terms of changing attitudes, of the 116 who responded, 57 said Yes and 59 said No/not really. Given the high percentage of participants who already felt they were knowledgeable or comfortable with science before the projects, this is encouraging, particularly since a number of those giving a negative response noted that they already loved science or were scientists. The largest number of positive responses to this question mentioned feeling that

science was more accessible and that they could understand and participate in creating new knowledge. Other responses discussed feeling more excited or positive about science even if they were already scientists, wanting to encourage their children in science, and that the importance of science in helping make decisions. These responses indicate that for at least a percentage of participants, there were gains in science capital, feeling more comfortable with science and feeling more ownership or confidence in knowledge creation and use.

In terms of whether people said they had learned something, the ones who said they had were much more likely to say what they had learned, which is no surprise. The main responses here, again, were learning about topic areas and learning about science or citizen science.

Strengths / weaknesses

Here is the brief summary of having looked through the 143 records for the strengths and weaknesses in case it is of use to you. I haven't included it in the discussion above.

88 people gave a strength with one saying "Everything so far!". Of the other 87, 50 mentioned aspects of citizen science such as inclusivity and having a variety of people involved in setting questions, letting parents decide the questions, and the collaborative nature with scientists and community working together. Examples of these responses include:

- *"Connecting citizen scientists with professional scientists, and bringing science to the feet of parents to answer their questions."*
- *"How it seems to appeal to so many people. The central team is fantastic, and have done such a great job at getting both parents and experts on board and excited about what they can do together."*
- *"Involving ordinary people in the extraordinary I guess!"*
- *"Lack of hierarchy. Having relevant 'experts' prepped and provided for us to question. Bringing like-minded, motivated, but undervalued mothers together to buzz off each other and build interesting studies that matter to people."*
- *"Parents! Parents asking the questions we want the answers to but no-one thought to ask! Recognising that while we may be Mums with baby-brain and dubious stains on our clothing, that we're still capable, intelligent beings and we have a lot to contribute!"*
- *"The collaborative nature and support (both for the projects and those of us who took part. At no point have I been made to feel 'stupid' for asking questions)."*

12 mentioned the skill and effort of the facilitators and organisers.

- *"[B]eing led by people with a real passion and asking the right questions to elicit honest responses"*
- *"The enthusiasm of Rebecca and Tamasin in all the projects and the inclusion of AI who wanted to help."*
- *"The staff keeping things current, keeping us engaged and on track, and giving us gentle pushes when needed, without taking too much of a leadership role. Their skills in this have been very much appreciated."*

- *“The team overseeing the project have been amazing in prompting along the projects so they get completed, without taking control of them. It's a very difficult balancing act for them, but they've nailed it.”*
- *“Great moderation of the Facebook groups”*
- *“The organisation - they worked their arses off”*

5 mentioned that the topics and discussions were interesting. 3 mentioned the ability to be involved but not having to commit large amounts of time.

- *“[B]uilds on ability to be engaged at own pace, in own time, as a parent that is so vital as time is so short and demands of family life (and work in conjunction with that) are BIG”*

Other comments covered topics such as the use of Facebook groups so many people could be involved, the passion and support of everyone, the need to get stuck in, the robustness of the science, the large number of people answering the survey, and how many women were involved.

Areas for improvement

84 wrote a response to what the project could do better. Of those, 17 said *Nothing* or *Not sure*. One was not an improvement as they said, “The PSG group were awesome! Tamasin and Rebecca and Sophie are aces!!”

Of the remaining 66, 12 mentioned improved communication, mostly to do with updates on projects, including whether there were any results, but two mentioned better explanation at the beginning of what the project entailed and how to get involved. Two of these suggested a visual timeline to help keep people up to speed with timelines and a way to check in on progress if someone has been gone for a while.

6 mentioned needing more guidance about tasks and deadlines including perhaps a more focused strategy for deciding questions because so much time was taken up by that aspect. However, three others said that they wanted more time and input into the questions or at the later stages because they felt the project was a bit hijacked by the experts.

4 mentioned more funding for projects, including thinking about how people continue to participate after the projects. One of these said, “I think there are still lots of good ideas, and developing relationships - funding is limited, and all projects need to close at some point - but I think some more focus about legacy projects might be helpful. How do these parents maintain their involvement?” 4 said more time on the projects would be good, either overall or for planning stages.

5 people mentioned that they wished they could have posted breastmilk since they would have liked to donate but couldn't get to London. 3 said they didn't have enough time to contribute fully. Of these, one said “I wanted to be involved in several of the groups, but this was hard due to time constraints of family life. Having the projects run in a staggered fashion, rather than potentially being at the same place at the same time, might work better. But I totally understand that this is very difficult to do!”

5 mentioned wishing more people were actively involved.

3 mentioned wanting more publicity and exposure both at beginning and end. One said “I would very much have liked to see us publish our results, in peer reviewed journals, with us as the named authors.”

2 mentioned Facebook not being the best place for discussion once the project got going. 2 mentioned being involved in more than one project was hard. 2 people mentioned wanting more face to face options, but two others mentioned not being able to go and feeling left out.

There were a small number of other comments including:

- *“At some points it felt to me like the project was being designed to prove previously held beliefs about Healthcare attitudes and approaches to breastfeeding, so clarity around hypotheses and study design and the communication of those aspects could be improved to reduce potential bias.”*
- *“Been a bit quicker to decide on books and get them out there to parents”*
- *“Waiting is frustrating!”*
- *“The information day at Imperial was a bit of a shamozzle but not a huge deal.”*
- *“Our group was quiet but don't know why”*
- *“Introduced sustainability earlier on in project”*
- *“I wish people could be more sensitive with the way they put stuff across online. I backed away from being more involved after someone got Very Offended by one of my suggested research questions. It was heavily implied that I was being unethical, but without any deeper explanation as to how. Ive been trying to stay more detached from stuff online, but that still stung a bit -- I'm certainly not setting out to hurt anyone when I brainstorm a research question. Maybe if there had been a way to discuss whether questions could be problematic or cause harm before the big vote on whether to look into them, it could be less of an issue on future projects.”*
- *“The other PSG's seemed really cool, but were limited in joining due to the way things were set up; I wonder if there could be some sharing of expertise between groups in some way, like one group looks at another's experimental design or results and provides advice or something?”*

In-depth: Investigating Participants' Experiences of an Innovative Citizen Science Project

In this section you'll find Stephanie Organ's dissertation submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Master of Science.

The report aims to examine if [PSG](#) increases parents' confidence in relation to science, has an effect on information sourcing and parents' evaluation of this information. It includes:

- *Review of the pertinent literature*
 - *Observations and interviews with participants*
 - *Analysis of the key themes.*
-

Summary

Stephanie's research found that:

- Participation in PSG led to members changing the way that they sourced and evaluated parenting information.
 - members used the community to share high-quality information and skills that enabled critical evaluation; those with more experience and better access to papers supporting others.
- Members reported an increase in confidence over a range of areas including confidence to be female and interested in science, do science, understand experts, speak to experts, healthcare professionals and/or other parents, and self-confidence in own knowledge and decision-making.
 - This confidence gain was seen in members who reported only low levels of engagement.
 - This is unusual amongst citizen science projects which rarely increase confidence in multiple areas.
- Members gained understanding of, and developed trust in, the scientific process. This is not common in citizen science projects and results from the full-cycle involvement necessary in user-led projects.
- The shared purpose of the members resulted in a strong community that provided effective social support.
- Researchers benefitted from their interactions with PSG. They;
 - valued the range of questions asked, prompting them to look at their research subject differently and see new avenues for exploration
 - learnt from members where passionate individuals had highly specific scientific knowledge
 - discovered the areas of their work that have relevance to parents, and which aspects had potential for greatest impact on societal need.

Investigating Participants' Experiences of an Innovative Citizen Science Project – in collaboration with the Parenting Science Gang

Abstract

Parental insecurities and anxieties, conflicting information, and a feeling of isolation are problems which have been observed with the shift in seeking information and support online. [Citizen science \(CS\)](#) is a rapidly increasing field reported to be useful for research, yet its benefits to participants are less distinct. This research adopts a qualitative approach, using observations from three events, 16 semi-structured interviews (11 members, 4 experts and one member-expert hybrid) and secondary survey data, with collected data analysed thematically in order to discover whether CS can change parents' information-seeking behaviour, evaluation of information found, confidence regarding science and unexpected outcomes. Data revealed that CS can be a useful tool when it comes to improving information-seeking and evaluating information quality, increasing participants' confidence to engage with science, and can build social support networks and communities which help drive changes and negate feelings of isolation. An increase in understanding the scientific process was also recorded as were impacts on experts including their research and future collaboration plans. CS can be used to empower parents to engage with science in order to answer questions pertinent to their communities. It can also improve the seeking of higher-quality information and help parents see science as relevant to them and their lives. Further, it can help experts develop more socially robust research which addresses problems at the societal level.

1.0 Introduction

Concerns and uncertainty regarding parenting and infant care can elicit tensions such as anxiety for parents (Knowles and Wilkinson, 2015). Conflicting information from different sources further confuses parents (Castell *et al.*, 2014; Serpell and Green, 2006), and feeling unprepared for parenthood is common (Entsieh and Hallström, 2016). Increasingly, the Internet, online forums and social media provide readily accessible information for parents (Plantin and Daneback, 2009; Bouche and Migeot, 2008). Forums such as 'Mumsnet' enable parents to interact online, form diffuse communities and develop support networks (Knowles and Wilkinson, 2015; Sarkadi and Bremberg, 2004). However, some emphasise that such support networks are lacking in a real-world context, creating an increased sense of isolation due to the reduction of real-world support (Entsieh and Hallström, 2016; Plantin and Daneback, 2009).

The importance of lay knowledge has been previously elucidated (Epstein, 2000; Wynne, 1992) and the public's active participation in science may contribute to the production of knowledge to address real-world problems (Dickel and Franzen, 2016). Such contributions could be facilitated by citizen science (CS). CS, usually referring to the public's involvement in various stages of the scientific process (Land-Zandstra *et al.*, 2016a), is part of a wider reconfiguration of the science-society relationship where knowledge production and reception are becoming more socially inclusive (Dickel and Franzen, 2016). The Parenting

Science Gang (PSG) is one such user-led CS project started in 2017 and funded by the Wellcome Trust. PSG is run by parents, aimed at answering science-related concerns raised by parents, grounded in empirical evidence (PSG, 2018).

2.0 Literature Review

2.1 Background

PSG's precursor study was the [Nappy Science Gang \(NSG\)](#). Participants submitted and voted for science-related questions they wanted answering, undertook experiments at home with guidance from experts, and interacted via Facebook (NSG, 2016). Member interactions, weekly live chats with experts, and questions raised by NSG led to a change in NHS advice regarding washing powder for baby items (NSG, 2016). CS volunteers want to know their project data has an impact and the assimilation of the research into such guidance can be an important participation driver for online projects (Curtis 2015; Land-Zandstra *et al.*, 2016b; Weitkamp, 2016).

PSG followed NSG in 2017 with subgroup (Table 27) covering parenting topics such as [flexischooling](#), breastmilk composition, and the effects of storybooks on children's gender-related attitudes. Non-parenting topics have included mass spectrometry and qualitative research which have tied into their research projects.

Table 27 - PSG groups, numbers of members per group and research project investigated by each group. Interviewees belonged to groups highlighted in blue ([BOBAB](#), [SANP](#) and [BB](#)). Groups in italics were temporary PSG groups with projects which started outside PSG but asked PSG members to help with their projects.

Project year established (one/two)	Group	Research project	Number of members (as of 5/11/2018)
One	Breastfeeding Older Babies and Beyond (BOBAB)	Changes in breast milk composition for nurslings over the age of 2.	872
	UK Breastfeeding and Parenting Support (UKBAPS)		276
	Science Aware Natural Parenting (SANP)	Babywearing and baby core temperature.	254
	Dumfries and Galloway Baby Bumps and Beyond (DGBBB)	Flexischooling in Scotland.	80
Two	Breastfeeding and Healthcare Experiences (BF HCE)	Helpful and unhelpful advice breastfeeding mothers receive from healthcare providers. Potentially an additional project looking at how advice from healthcare professionals changes once healthcare professionals become breastfeeding mothers themselves.	428
	Big Birthas (BB)	Labour choices for women with higher BMI .	144
	Let Toys Be Toys (LTBT)	The effect bedtime stories have on children's gender stereotyping.	625
	Mealtime Hostage (MH)	Examine mealtime experiences of families with children with a range of feeding disorders, ranging from typical food neophobia to Avoidant/Restrictive Food Intake Disorder (ARFID).	294
Temporary	<i>Baby Biome</i>	Baby Biome Cohort Study (collaboration with existing research which aims to understand more about how babies are first colonised by microorganisms and the effects on long-term health).	328
	<i>Screen Time</i>	Involved in the planning and doing of an existing project. PSG were invited to and spoke at a conference as part of this.	48

2.2 Citizen science

CS projects are increasing (Baker, 2016) in part due to technological advances (Land-Zandstra *et al.*, 2016b), fostering a culture of 'science for all' (Metz, 2015). These projects involve the public (Den Broeder *et al.*, 2017), facilitated by groups of volunteers primarily collecting and/or analysing "vast amounts of data to support research" (Baker, 2016, p.921). Bonney *et al.* (2009) categorise CS projects depending on level of engagement – contributory, collaborative, and co-created. Most CS projects fall under the first, where the public contributes to data, such as collection and analysis, and engagement in science is minimal. Collaborative projects have more involvement, the public refines the design, contributes and analyses data or disseminates results. Co-created projects appear scant in

the literature. These are co-designed by scientists and lay participants in order to address questions specific to the needs of a community and, as a result, are more likely to attract participants without a pre-existing scientific interest (Bonney *et al.*, 2009). In general, CS projects can be realised on a global scale leading “to discoveries that no single scientist – or even groups of scientists could ever achieve on their own” (Metz, 2015, p.6). Further, projects can facilitate democratic interaction with science including catalysing discussions between participants and researchers (Ruiz-Mallén *et al.*, 2016; Weitkamp, 2016).

CS projects include diverse topics and are of interest due to their ability to engage communities and help to understand differing viewpoints within society (Baker, 2016). Examples include *Foldit* to progress knowledge of protein structures (Memarsadeghi, 2015), *Galaxy Zoo* to identify images of galaxies (Baker, 2016), and *BioBlitz*, a biological survey of living species (Roger and Klistorner, 2016). Despite the proliferation of CS projects (Baker, 2016), gaps remain in our understanding, such as what motivates participation (Weitkamp, 2016).

2.3 Impact on participants

In the limited research conducted, a study by Brossard *et al.* (2005) found no change in attitudes towards science or the environment following participation in a CS project, or in participants’ understanding of the scientific process, although there were changes in topic knowledge. Crall *et al.* (2012) recorded self-reported behavioural changes, for example participants felt empowered to make post-engagement changes but found attitudes towards science and the environment remained unchanged pre- to post-study. They suggested attitude changes depended on participation levels and participants had more positive attitudes towards topics than the general public due to self-selection. This may relate to many CS studies being confined to offline, environmentally-based subjects, involving a bigger commitment of time and resources (Domroese and Johnson, 2017; Jennett *et al.*, 2016; Crall *et al.*, 2012), thus attracting those with a higher scientific interest. Online CS projects allow for greater flexibility of time and input (Land-Zandstra *et al.*, 2016a; Masters *et al.*, 2016) known as “microvolunteerism” (Curtis, 2015), and may afford an added advantage of accumulated project information online increasing learning impact (Land-Zandstra *et al.*, 2016b).

Although there is debate around the extent CS can impact participants, it is generally believed that participation affects learning regarding the project’s topic (Jennett *et al.*, 2016; Bonney *et al.*, 2009), but additional benefits are mentioned, including improved social skills and web literacy (Jennett *et al.*, 2016; Ruiz-Mallén *et al.*, 2016). However, opinions vary over what drives change, including engagement level (Masters *et al.*, 2016), participant interest (Brossard *et al.*, 2005), and interaction with a community, supporting social learning (Jennett *et al.*, 2016).

Although underexplored, benefits of CS involvement extend beyond public participants. Aside from the benefit of having large amounts of data collected and/or analysed (Brossard *et al.*, 2005), there are other tangible benefits for experts engaged with CS. This includes satisfying funder conditions for public engagement (Silvertown, 2009), improving the public’s understanding of science (Rotman *et al.*, 2012), valuable participant feedback (Jennett *et al.*, 2016) which can help to develop new research avenues (Stilgoe and Wilsdon, 2009), and

thinking about their research and their approach to it in a different way (Ruiz-Mallén *et al.*, 2016; Wilkinson *et al.*, 2011).

The term 'expert' can be applicable to people in different contexts, although generally it suggests someone who has learnt from experience (Ericsson *et al.*, 2006). However, 'experts' and 'expertise' are contested terms (Kerr, *et al.*, 2007). Here 'experts' are considered as professionals with science being a reference system for professional knowledge (Ericsson *et al.*, 2006), and 'expertise' as an exclusive form of knowledge and competence in a particular field acquired through training and experience (Schickltanz *et al.*, 2012). There are arguments for and against the inclusion of public expertise in the production of knowledge (Dickel and Franzen, 2016; Braun *et al.*, 2015; Collins and Evans, 2002). However, lay knowledge can be an important facet to driving necessary change to knowledge (Epstein, 2000) and participant input can help improve research (Dickel and Franzen 2016; Stilgoe and Wilsdon, 2009), make research more relevant to society (Alander, 2016) and be adjunct to, not a substitute for expert knowledge (Kerr *et al.*, 2007).

2.4 Confidence in science

UK public attitudes to science are positive (Bowater and Yeoman, 2013). The Public Attitudes to Science Survey (PAS) found that 64% of UK citizens felt the public should be involved in decision-making about science, with women feeling more strongly about this than men (Castell *et al.*, 2014), although the report does not make it clear what this would entail other than dialogue. PAS found that, although there is the "overwhelming desire for the public to be involved...most people do not feel that the public are sufficiently involved in decisions about science" and "confidence in getting involved may be linked to their level of education" (Castell *et al.*, 2014, p.104-105), with women feeling less confident to engage than men. Amongst young age groups, the ASPIRES report shows, whilst respondents liked science, perceived ability to participate is determined by their '[Science Capital](#)' and a major contributor to this is a family's 'Science Capital' (Archer *et al.*, 2013). Furthermore, women play an important role in informal science learning, with people more likely to attend science-based activities with their mother than their father (Castell *et al.*, 2014). By engaging parents in CS projects such as PSG, opportunities to build families' 'Science Capital' may be provided.

Building confidence through different science-related interventions has been observed previously (Kearns *et al.*, 2016; McDonald *et al.*, 2012) and CS projects can be useful when it comes to engagement, dialogue and empowerment (Roger and Klistorner, 2016; Ruiz-Mallén *et al.*, 2016). Using social media to create community groups may empower participants further, as seen in blogging which contributes to a sense of agency, community, self-efficacy, and inner-strength to make sound decisions (Stavrositu and Sundar, 2012). Confidence and self-efficacy regarding science is important, notably when it comes to the ability to source high-quality, trustworthy information and make informed decisions based thereon (Armstrong-Heimsoth *et al.*, 2017).

2.5 Information sourcing and evaluation of information quality

Most decisions are automatic and, for decisions needing further investigation, available information is incomplete and of variable quality (Serpell and Green, 2006). Many variables contribute to parental decision-making including personal attitudes, social and subjective

norms, level of trust in information sources and where parents source information to make decisions (Gesser-Edelsburg *et al.*, 2017; Brunsden, 2013; Brown *et al.*, 2012). Additionally, people actively seek information aligned with their worldviews (Shäfer, 2017; Kenski, 2017; Xenos *et al.*, 2011).

The risk of misinformation from unregulated and unsubstantiated claims online (Li *et al.*, 2015; Khoo *et al.*, 2008), alongside people seeking information which reaffirms their opinions (Bernhardt and Felter, 2004; Xenos *et al.*, 2011) and high levels of trust placed in online health information (Knowles and Wilkinson, 2015) can cause people to make ill-informed decisions (Dahl and Eagle, 2016). Informed decision-making relies on parents' ability to use sources to retrieve relevant information and assess its quality (Morahan-Martin and Anderson, 2000). Health studies across different populations and contexts have found people lack the ability to do this and may overestimate information trustworthiness (Austvoll-Dahlgren *et al.*, 2016). Although people report searching for credible information online, in practice, this is not always implemented (Eysenbach and Köhler, 2002) and those lacking confidence using online information may have trouble determining its quality (Armstrong-Heimsoth *et al.*, 2017).

With conflicting information and uncertainty, people use heuristics to make decisions (Austvoll-Dahlgren *et al.*, 2016). This can include information such as personal experience, experiences of others, and the media (Gesser-Edelsburg *et al.*, 2017; Serpell and Green, 2006). Evidence from other parents is more trusted than official figures since parents are perceived to have no agenda and to be accessible and experienced in parenting (Brown *et al.*, 2010; Bernhardt and Felter, 2004).

2.6 Aim

Given PSG's interest in helping parents answer their science-related concerns, this research aimed to examine if PSG meets its purpose of increasing parents' confidence in relation to science, has an effect on information sourcing and parents' evaluation of this information.

2.7 Objectives

1. Explore and critically evaluate current literature of relevance to CS and information sourcing.
2. Develop a suitable methodology, using observations and interviews, to collect empirical data regarding participation in PSG, concerning any changes to (a) information sourcing, (b) evaluating that information, (c) confidence in relation to science and (d) unexpected outcomes.
3. Analyse the gathered data using NVivo within the context of existing literature.
4. Form conclusions regarding changes brought about by participating in PSG, and CS in general.

3.0 Research Methodology

3.1 Introduction

This research adopted a qualitative approach, predominantly thematic analysis from semi-structured interviews and descriptive analysis of observations from three PSG events. Secondary data was used to supplement primary data. Using multiple data collection methods permits triangulation which 'can provide a more accurate and complete account than either could alone' (Maxwell, 2005, p.94). Thematic analysis is a common approach to qualitative data (Bryman, 2008), which is accessible and theoretically flexible (Braun and Clarke, 2006).

3.2 Philosophical Assumptions

The interpretivist paradigm frames this research. Interpretivism recognises the distinctive and complex nature of the social world (Hammersley, 2013) with 'social reality regarded as a product of its inhabitants requiring interpretation of the meanings individuals produce as part of their everyday activities' (Blaikie, 2010, p.99). The aim of this research is to access the interviewees' world meaning, itself open to interpretation by the researcher, with formation of categories and theories creating a tertiary level of interpretation (Bryman, 2008). Since PSG asks questions pertinent to participants' everyday activities, coupled with this aim, interpretivism fits well.

The concept for this research comes from the Hermeneutic Tradition where the concepts used to describe and understand social phenomena are based in everyday language of the social actors investigated, with the researcher eventually able to mediate between this and technical language to produce concepts relevant to the topic (Blaikie, 2010). This study is well suited to this since the Hermeneutic Tradition allows research to work from the bottom up, a key facet of the PSG project. Interpretivism evolved from the Hermeneutic Tradition where it is argued that the interpreter's own biases can colour their understanding (Blaikie, 2010), and in Interpretivism it is questioned whose meanings are used to construct understanding, the observer or the social actors. Thus, an element of Reflexivity was needed.

Reflexivity has many different meanings (Bryman, 2008; May, 2002) but here it is taken to mean to go beyond the literal understanding of what is observed and reflect upon one's role, the impact one may have on the situation and how one may be perceived by the interviewee or observed (Blaikie, 2010). As a research strategy, reflexivity can address the issue of power in the researcher-researchee relationship (Haney, 2002). Reflexivity also incorporates the recognition that there is fluidity of meanings of what is witnessed, with meanings identified by different people in different ways (Bryman, 2008). Sensitivity to and awareness of the ways in which the researcher as an individual, including age, gender and background, may impact upon what is revealed is also necessary (Bryman, 2008).

An abductive research strategy compliments interpretivism since it is based in the subjects' social world – their construction of reality and their way of conceptualising and giving meaning to that world, the researcher entering that world to discover meanings attached to social activities. Similar to the Hermeneutic Tradition, translation of social actors' language to

technical discourse is required. The strategy is derived from lay concepts through abstraction during the research process (Blaikie, 2010) and is used so theory can be shaped in tandem with data collection and analysis (Davies, 2007). The relationship between these theoretical elements is summarised below (Figure 37).

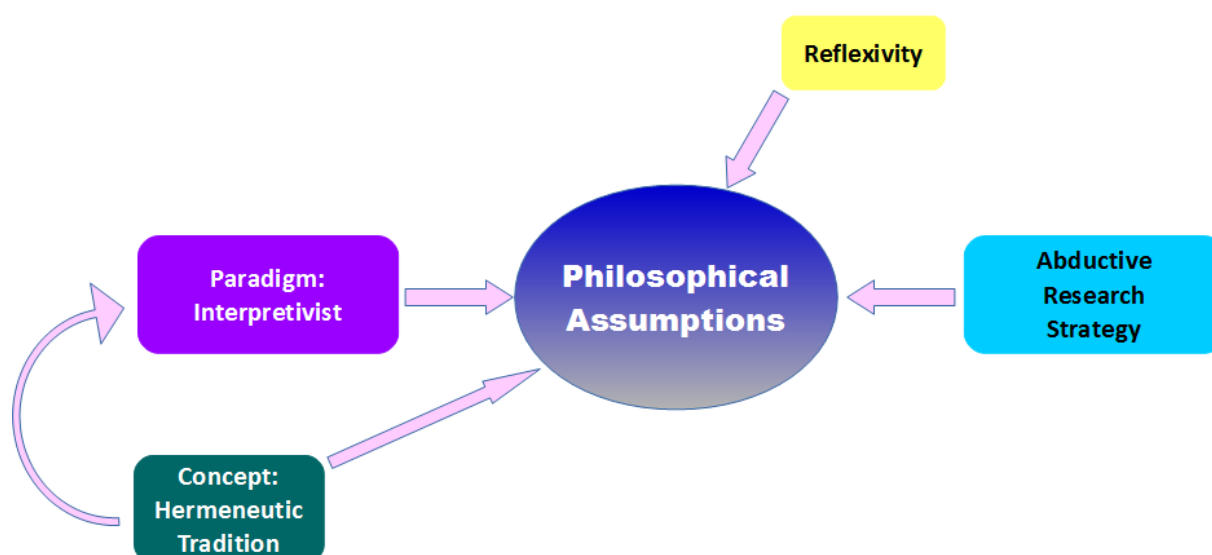


Figure 37 – The relationship between theoretical elements utilised in this project

3.3 Research Strategy

3.3.1 Observations

Observations, conducted ‘ad libitum’ (Bryman, 2008), were undertaken on two half-days (‘Gangstivals’) and a results day (Table 28), identifying participants’ reactions and reflecting on the researcher’s own experiences of the events (Bowater and Yeoman, 2013) using an observation schedule and field notes (Bryman, 2008). A message introducing the researcher was posted on the Facebook event page and information and observation sheets were displayed at the events.

Table 28 – PSG events observed

Event	Location	Numbers attending
Gangstival - London	The Dana Centre, The Science Museum, London	8 members, 4 experts, 3 PSG team members
Gangstival - Birmingham	Trefoil House, Birmingham	9 members, 2 experts, 2 member-expert hybrids, 2 PSG team members
Results Day	Queen Elizabeth Queen Mother wing, St Mary's Hospital, Paddington, London	27 members, one expert, 4 PSG team members

Although Bryman (2008) suggests observations are used to negate the problem of meaning, question threat and interviewer characteristics, for the present research, observations were chosen to observe how members behaved at meet-ups, their interactivity with experts, how readily they interacted with science, and any changes during the event.

3.3.2 Interviews

Interviewees were identified by the PSG Project Managers who had in-depth knowledge about PSG groups and individual members, and at the two 'Gangstivals'. Due to the General Data Protection Regulation (GDPR), interviewees were initially contacted by PSG to ask whether the researcher could contact them. After acquiescence, PSG Project Managers introduced interviewees and the researcher via a private Facebook message. An information sheet and consent form were sent to the potential interviewees and returned prior to interview.

Semi-structured interviews were conducted via telephone and Facebook Calling. Interviews followed a topic guide where the researcher could vary the sequence of questions (Bryman, 2008) and probe interviewees using standardised prompts for consistency to better elicit their meanings and interpretations of their social world (Davies, 2007). Since interpretivism aims to understand social actors' world meanings and how PSG has impacted this world, semi-structured interviews were needed to elicit richer data and gain deeper understanding of the way interviewees constructed their reality (Greeff, 2015).

The interview schedules for members and experts were designed in consultation with the PSG Project Managers. The member-expert interview had a combination of questions taken from each schedule. Interviews were conducted between 26th June 2018 and 28th August 2018.

3.3.3 Secondary Data

Data was used from the PSG member starter questionnaires to obtain demographic information. Secondary data is suggested to be advantageous regarding cost, time, quality and the opportunity for research covering a longer period than the present study (Bryman, 2008). Additionally, it allowed the researcher to use interviews for more in-depth questions.

3.3.4 Sampling

Purposive and theoretical sampling was used. Purposive sampling is where the researcher identifies 'cases for in-depth investigation' (Blaikie, 2010, p.178). Theoretical sampling is where 'decisions about sample size are made progressively' (Blaikie, 2010, p.179), leading to data saturation where no new research themes are discovered. This has been shown to occur around seven interviews, but subsequent interviews were conducted to ensure nothing important was missed (Galvin and Sunikka-Blank, 2014).

Individuals were selected from three groups – two nearing completion of their projects to sufficiently record their full project journey, Breastfeeding Older Babies and Beyond (BOBAB) and Science Aware Natural Parenting (SANP), and one starting their experiments to capture their thoughts including expectations at the outset, Big Birthas (BB). Using prospective and retrospective interviews aimed to minimise consistency bias where thoughts which were part of the process but do not fit with the final decision are removed from memory (Brown *et al.*, 2012).

A purposive sampling frame was used to select parents ranging in participation level (Brown *et al.*, 2012) (Table 29). Since one group was recently established, not enough time had

lapsed for members to fall into all activity level categories, resulting in no interviewee for 'less active + meet-up'. However, due to the member-expert hybrid fitting into this group, there were still four interviewees, two categorised as 'active + meet-up', giving a total of 12 interviewees, coded as per Table 30. Interviewee were selected per selection criteria (Table 31).

Table 29 - Purposive sampling frame for interview selection based on activity levels.

Activity Level Categories
One active member + attended a meet-up
One active member + not attended a meet-up
One less active member + attended a meet-up
One less active member + not attended a meet-up

Table 30 - Interviewee activity level category coding. Group initials act as a prefix to these numbers to identify interviewee group, for example BOBAB-1.1 would be an active BOBAB member who had attended a meet-up.

	Meet-up	Non-meet-up
Active	1.1	1.2
Less Active	2.1	2.2

Table 31 – Sample selection criteria

Criterion	Essential/Desirable
Be a member of PSG	Essential
Have children under 18 years old	Essential
Completed a PSG joining questionnaire	Desirable

3.3.5 Experts

Some experts involved with PSG activities were also observed and interviewed. They had a variety of academic backgrounds and differing levels of involvement with PSG (Table 32) and public engagement and CS projects. There was a member-expert hybrid who had some involvement as an expert and some as a member and fit criteria for both. This gave five interviews.

Table 32 – PSG activities experts interviewed were involved with

Activity	Number Interviewed
Experiment, Gangstival, Q+A	1
Gangstival, Q+A	1 (+1 member-expert hybrid)
Gangstival, Residential	2

3.3.6 Data Analysis Methods

Interviews were audio-recorded, transcribed verbatim, and analysed via thematic analysis (Bryman, 2008). A framework of themes and subthemes was identified manually using the qualitative software, NVivo (Davies, 2007). The emphasis of thematic analysis is to work flexibly (Braun and Clarke, 2008). Nodes were generated by reviewing all transcriptions to find common themes. This was then repeated to check for coding consistency and ensure nothing was missed (Bryman, 2008).

Despite being commonly used, there is little guidance on thematic analysis methodology (Braun and Clarke, 2008). However, Braun and Clarke (2008) have broken the process into six steps which is the process used in this study (Table 33).

Table 33 – Thematic analysis stages adapted from Braun and Clarke (2008).

Step	Description
1	Researcher's familiarisation with the data - transcribing, reading and re-reading, notation.
2	Generate initial codes – systematically code interesting features of the data.
3	Search for themes - organise codes into potential themes.
4	Review themes - check if themes work in relation to coded extracts and data set.
5	Define and name themes - refine specifics of each theme, generate clear definitions and names for each.
6	Produce the report - final analysis involving the selection of extracts and relating them back to the research questions.

It was decided analysing word frequency and word linkages could be misleading since they may appear more frequently in the speech of some interviewees for reasons including greater willingness to talk about a subject (Vaismoradi *et al.*, 2013), which does not necessarily determine value. Thus nodes produced in NVivo were processed manually. This was beneficial to gain deeper understanding of the data and determine whether any single comments held more weight than recurrently expressed ones (Braun and Clarke, 2008).

Observations were written up from field notes and observation schedules, read, and re-read making memos (Maxwell, 2005). Data was used to give context, highlighting both similarities and contrasts with behaviour reported in interviews (Bryman, 2008). Secondary data regarding interviewee demographics was extracted to gain background understanding.

To improve the integrity of this research (Bryman, 2008), validity was addressed as outlined in Table 34. Additionally, reflexivity can improve the validity of data (Maxwell, 2005).

Table 34 – Validation type and how achieved

Validity	Description	How met
Construct	Identify effective methods for concepts studied (Yin, 2014) to avoid subjectivity within the research and data (Fielding and Warnes, 2009)	Methodology reviewed by supervisor
Internal	Whether a conclusion incorporating a causal relationship between variables is reasonable (Bryman, 2008)	Rival explanations
Ecological	Findings applicable to social actors' everyday, natural and social settings (Bryman, 2008)	Methodology – data collected in subjects' natural and social environments.

3.3.7 Ethical Considerations

Ethics approval was obtained through the University of the West of England, Bristol (UWE) as the research was deemed 'high risk'. The researcher was included on the PSG ethics approval obtained through York University to access the secondary data. A risk assessment was also conducted. Participants at observations were made aware that they were being observed for research and evaluation purposes, an information sheet was provided and participants could opt-out. The information sheet and consent form covered anonymity. Since approximately half of interviewees wanted to remain anonymous, all interviewees were anonymised.

4.0 Results

4.1 Participant Demographics

Member interviewees were all female, aged between 25 and 44 years. They had one to four children, averaging two, and children's ages ranged from zero (pre-natal) to 24 years old.

Educational levels amongst interviewees ranged from GCSE to Doctoral level. According to secondary data, the majority had either AS/A-Levels or a bachelor's degree and seven out of 12 members had studied at university. Only one interviewee had not studied A-levels or their equivalent, though there did appear to be discrepancies between primary and secondary data, with the number of postgraduate qualifications reported amongst interviewees increasing from three to five, although only two were science-based.

Interviewees were spread across the UK. Eight identified as white British, with other interviewees recorded as white other, half white British and half other, and black Caribbean.

4.2 Observations

Two 'Gangstivals' and a results day were observed (Table 28). Observations intended to support and contrast reported behaviour in interviews and were integrated with the interview data to give context and elaborate on findings overall.

4.3 Member Interviews

Interview data was extensive and covering it all here was beyond the scope of this project. However, themes (Figure 38) pertaining to Objective 2 are examined below.

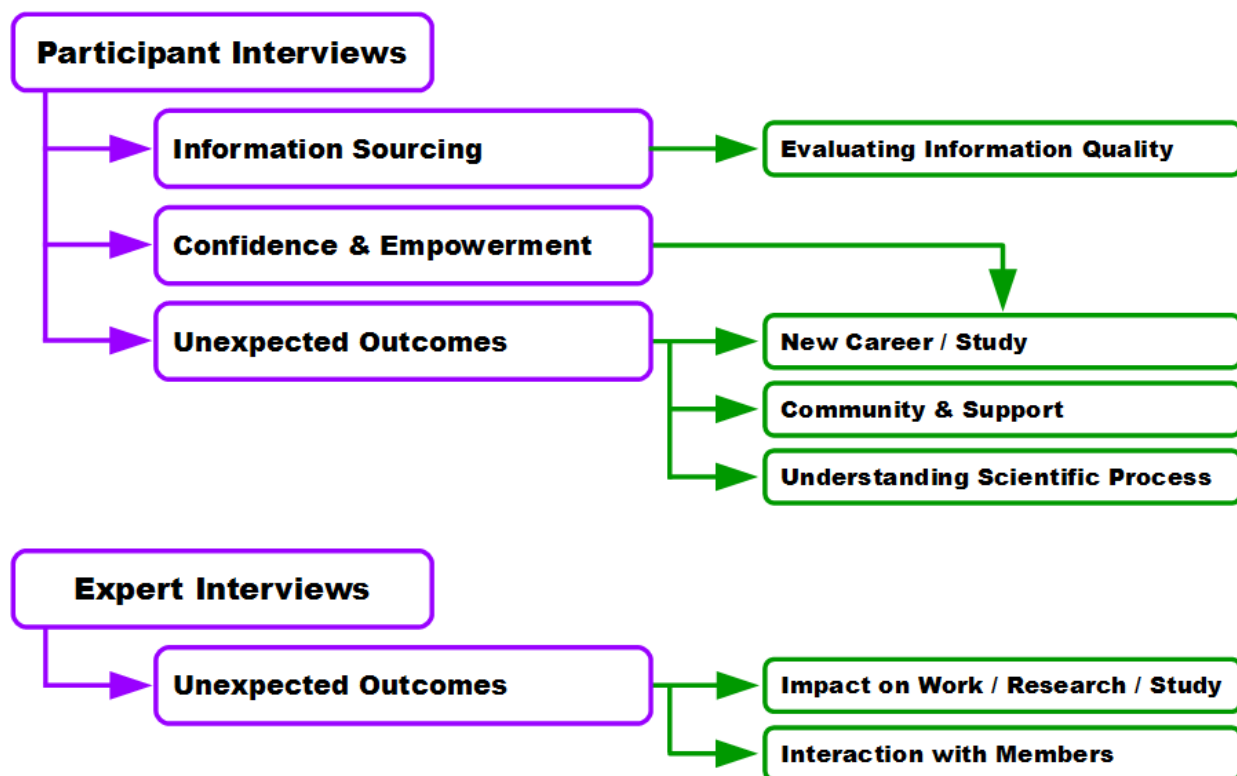


Figure 38 – The main themes (purple) and subthemes (green) identified from member and expert interviews pertaining to the research objectives in this project.

4.3.1 Theme 1: Information-Sourcing

Before joining PSG, interviewees sought parenting information mainly from the Internet, but also from their social networks, and other parenting groups: “*mostly from...Googling things*” (Florence, SANP 2.2), “*probably the Internet. I mean, kinda family and friends*” (Clare, SANP 1.2), “*mostly...through...Facebook groups*” (Isabelle, BOBAB 1.1). Some interviewees who had studied at university said they would still source information online: “*I’d go on the Internet...but I guess because of the...training...you tend to know if what you’re looking at is sensible or not*” (Olivia, BB 1.2).

They would rarely seek information from healthcare professionals, feeling the information was not relevant: “*I don’t think their information is taking [my baby] into account or me, or the things that we do*” (Isabelle, BOBAB 1.1), or due to negative experiences: “*I still have a massive issue with healthcare professionals...because of the ordeal...we’ve been through*” (Astrid, BOBAB 1.2). Such experiences were discussed at the Birmingham Gangstival with people providing stories around poorly-informed consent processes and treatments.

Changes post-joining were recorded. Interviewees explained how PSG represented a community composed of people with different skills and backgrounds, from which they could now source information they may not have had access to before:

“It’s been good to be able to ask...‘has anyone got any...good resources?’...there’s a broad mix of people...and they may have access to...papers...that the general public

haven't...or...somebody will come along and 'this is what you need to search for'" (Elizabeth, SANP 1.1).

Members stated they were now able to access more reliable, trustworthy information:

"I'm looking for trustworthy sources...I'm much better informed and...more prepared to be cynical because I've seen the contrast between a lot of rubbish...published [in the media]...versus much better information that you can find with a bit more attention" (Amelia, BOBAB 2.2).

Some members felt they trusted themselves more to look for higher-quality information sources, linking to changes in confidence and self-efficacy: *"I feel more able to trust myself and...to look for things myself" (Isabelle, BOBAB 1.1).*

There was some indication that groups may play a part in driving this change: *"The general response is 'have you got your references for that?'...if it comes from...dailymail.com, that doesn't count"* (Clare, SANP 1.2). Level of change seemed partially dependant on pre-existing level of science education: *"I wouldn't say I've changed massively, I'm still having to Google and try to find multiple sources" (Florence, SANP 2.2 – Scientific PhD), "it's given me more resources to...check information" (Astrid, BOBAB 1.2 – A-levels).*

There were occasions where members felt unsure whether changes were entirely attributable to PSG: *"I don't know if it was all PSG, but my life has changed completely...since I started...there's definitely elements of Parenting Science Gang in there" (Isabelle, BOBAB 1.1).*

Event observations demonstrated that experts also signposted members towards resources. At Gangstival, Birmingham one expert gave a book recommendation, whilst in London an expert explained that parenting books did not utilise necessary academic information on the discussed topic, so members should seek academic literature. At all three events members photographed presentation slides and took notes to varying degrees, corroborating interviewees' described behaviour of recording information of interest: *"I'd screenshotted loads...[in Q&As]...and researched them...coz I was reading one of [them yesterday] going...I remember that paper" (Isabelle, BOBAB 1.1).*

4.3.2 Subtheme 1a: Evaluating information quality

Members observed that, before PSG, they relied on instincts or used confirmation bias: *"I...double check...if it doesn't sound right...if it feels ok, then I'll...go with the flow" (Clare, SANP 1.2), "I do that thing where you find the research that...backs up your ideas" (Emma, BB 2.2).*

Some interviewees mentioned they would 'try' to check and were sceptical of information: *"I've always been quite sceptical...if I'm looking for information...I wouldn't necessarily just go to the top one on Google" (Elizabeth, SANP 1.1).* Some with university training said they were drawn towards sources with referencing, believing these to be non-opinion based: *"makes me think...they've got a proper reference list...[they] may have...done their own...reading and research...not just giving...opinions" (Alex, SANP 2.1).*

After joining, members found they were more likely to check information themselves, or take it back to the PSG community for critical analysis:

“someone will quote something and you’ll go...‘I thought that was disproved in a study in 2017’ and somebody else will go ‘yes, it was...let me find you the reference” (Juliet, BB 1.1),

“I heard...some advice...and...researched it...on Google Scholar and...websites that I trusted...I listened to the advice critically...that’s one of the big differences that PSG has made, not just accepting things that I’m being told” (Isabelle, BOBAB 1.1).

Analytical skills may have been supported by training at the PSG Residential, specifically on how to look at journal articles which some referred to: *“they...arranged...[a] talk...about how to look at journal articles, and what research was out there about parenting”* (Alex, SANP 2.1).

Even those with doctoral-level education admitted there had been changes: *“I...look...harder for the original source or hope that somebody else has...because...if you don’t have time to do it, chances are somebody else will”* (Clare, SANP 1.2). This is an important factor since many members are time poor, an issue that was referred to by seven interviewees: *“my child was...doing XYZ which meant...I couldn’t...take part...life gets in the way”* (Juliet, BB 1.1).

A member who worked in healthcare said since joining PSG she reads research that contradicts her own beliefs: *“I’m learning...to...read the research that negates what...[you] believe...to find out, actually, is there some...good evidence the other way”* (Emma, BB 2.2).

4.3.3 Theme 2: Unexpected Outcomes

There were several unexpected outcomes recorded for members since joining PSG. These were divided into subthemes: Confidence and Empowerment; New Career or Study; Community and Support; and Changes to Understanding the scientific process.

4.3.4 Subtheme 2a: Confidence and Empowerment

Participating in PSG was seen as empowering: *“[PSG] gives...parents a platform...It empowers us”* (Astrid, BOBAB 1.2), *“it was very empowering that feeling of...ordinary people, we can be scientists”* (Alex, SANP 2.1).

Participation also saw an increase in confidence to be female and interested in science, do science, be part of it, and understand experts: *“empowered, like I was more part of this world”* (Isabelle, BOBAB 1.1), *“I was surprised...I did know what was being talked about”* (Astrid, BOBAB 1.2). There was an increase in self-confidence regarding their own knowledge and decisions: *“these are experts and I know more about this specific thing...maybe I do have a say”* (Isabelle, BOBAB 1.1), *“giving me...confidence...[to know] what I’m doing is right”* (Elizabeth, SANP 1.1). Additionally, confidence increased to question or refute information or advice:

“the group has given me confidence...it’s...helped me...stand up...to the midwife...[and] a very...senior...gynaecologist...who was really taken aback...but I

just asserted myself...I might have felt...downhearted if I hadn't had that background [from BOBAB]" (Amelia, BOBAB 2.2).

Although some members' backgrounds made them confident talking to academics, they still saw changes post-joining: *"it's...increased my confidence...talking to parents...[and] healthcare professionals"* (Clare, SANP 1.2).

A confidence change was observed at PSG events. Discussions at both Gangstivals were initially dominated by a vocal few. Those who were quieter and admitted to being less active in PSG, asked questions and participated in discussions later in the event. Discussions became fast-paced when they were most relevant to members, for example talking about breastmilk and the best way to store it. At the Results Day, attendees remained passive until the expert talked about specific findings which was a catalyst for vocalising questions and thoughts. The most vocal attendees opened questioning, with contributions from others gradually increasing. Queries ranged from asking about the results' statistical significance to 'is it better to refrigerate or freeze breastmilk'. Later, there was a shift in dynamic, with a member answering a question before the expert, followed by other members joining the discussion.

4.3.5 Subtheme 2b: New Career or Study

Confidence went further to include some members changing their profession or embarking on further and higher education: *"I have a new job...I am a project coordinator for [parent-baby service volunteers]"* (Isabelle, BOBAB 1.1), *"I'm...going to do an Access Diploma in science...and...on to...uni next year"* (Astrid, BOBAB 1.2). PSG was cited as giving them confidence to know they could do this:

"it's really helped me in my new job...I'm suddenly going to meetings with...important people in the NHS...drawing on PSG experience and feeling...more comfortable with how to talk about it" (Isabelle, BOBAB 1.1)

"I'm...a lot more confident...I [don't] feel like I'm going to be ridiculed or ignored...I can go into this...field...I've always felt...I wouldn't be intelligent enough" (Astrid, BOBAB 1.2).

Others used information learnt through PSG in their current roles: *"it's been quite helpful with...[my] project...[it's]informed...my understanding and...knowledge"* (Clare, SANP 1.2), *"I can use it...for my practice"* (Emma, BB 2.2).

4.3.6 Subtheme 2c: Community and Support

Despite not having specific questions in the interview schedule, all interviewees mentioned this subtheme. Members generally spoke about feeling isolated or lacking support before PSG: *"I'm quite isolated in this topic"* (Juliet, BB 1.1), *"there is not enough support out there"* (Astrid, BOBAB 1.2), *"I don't see other children that age being breastfed...you wouldn't know about if it wasn't for the online support...because [it] isn't...in wider society"* (Amelia, BOBAB 2.2).

This changed post-joining:

“[the most important element was] the interaction...with other parents...there’s...learning new things, but...it’s that discussion with people which I don’t have in the same way” (Olivia, BB 1.2),

“it all provides a sense that you’re not alone” (Amelia, BOBAB 2.2).

Finding a group of like-minded people who were all working towards a specific goal helped create this sense of community and support: *“the creation of a community of people who have a similar goal and...actively working towards that...is a very different way of participating in a group”* (Marie, BB 1.1).

Members felt they could drive change and contribute to knowledge: “what can we do to change [how bigger women are treated]” (Marie, BB 1.1), “[can] pull together meaningful advances...by...networking people together” (Amelia, BOBAB 2.2).

Gangstivals observably related to community and support. In London, the value of meeting people face-to-face was cited, and, in Birmingham, discussing healthcare experiences lent itself to providing support to other attendees, group bonding and finding common ground.

4.3.7 Subtheme 2d: Changes to Understanding the Scientific Process

Changes in understanding the scientific process were seen. Interviewees said that, post-joining, the scientific process was more relevant, less disconnected from them, and they had a better understanding of what was involved: *“it’s become more involved instead of something abstract that people do in universities”* (Marie, BB 1.1), *“it made the scientific process...a lot more in...my grasp”* (Alex, SANP 2.1), *“I think of science as more of an art now...it’s really flexible...helpful, and relevant”* (Isabelle, BOBAB 1.1).

Interviewees with a scientific background still mentioned changes, not to the traditional process, but how it could be made more accessible to the public: *“I find it heartening that there are people within the academic world...willing to make science, and the process, more open and...accessible”* (Clare, SANP 1.2).

Some were now “more trusting of the process” (Kate, BOBAB 2.1) in which interaction with experts may have a role: *“[Interacting with experts has been] very positive...I find it easier to trust them”* (Alex, SANP 2.1). This interaction may contribute to changes in confidence and understanding the scientific process: *“access to the experts...[is] really important for the people who didn’t have the...confidence...talking to experts...helps to de-mystify the scientific process”* (Clare, SANP 1.2), and information seeking: *“talking to the expert...I was pointed to a number of other studies...on the topic”* (Kate, BOBAB 2.1). This interaction was not viewed as one-sided. Members explained how the interaction was valuable for all involved and experts were normal people who could be role models: *“without our input...the questions wouldn’t be the same”* (Kate, BOBAB 2.1), *“was nice to have those barriers broken down, they’re...normal people and...talk in a language that we understand...it’s been very nice to see...strong female scientists...rocking their jobs”* (Elizabeth, SANP 1.1).

The research process was discussed at events, for example what could and could not be done and how long it takes to publish a paper. Although details of the scientific process were

covered at the Results Day, it was not the main topic, but queries still arose, including anomalies and how the equipment used affects the sample.

4.4 Expert Interviews

Experts were interviewed to gain understanding of their PSG experience, with themes identified pertaining to Objective 2(d), divided into subthemes: member-expert interactions and impact on research, work or study.

4.4.1 Theme 3: Unexpected Outcomes

4.4.2 Subtheme 3a: Member-Expert Interactions

Experts were positive about their interactions with members. They were “happy” (E2) and “excited” (E4) to speak with members and discussions were “informal” (E3) and “open” (E2), with questions being “interesting” (E2, E4), “insightful” (E1) and “sophisticated” (E4). Additionally, two experts mentioned that questions were different from those they would receive from academics:

“questions...I...wouldn’t have expected from a scientific audience...it was...refreshing to have people who had never...been exposed to how research is conducted” (E1),

“the interest the parents have are on a...fine-grained level of what does this mean for me and my kid...which is good...science should be able to answer those questions” (E2).

Although the questions could be seen at times as less scientific, there were comments which suggested that this was not always the case:

“[The questions] were really varied...[and] interesting...some of them were quite sophisticated” (E4),

“a couple of times I got...an impression that there were members of the group that were pro-science, but maybe anti-scientist...on the whole it was very scientifically interested” (E1).

Observations supported positive member-expert experiences, experts seemed relaxed interacting with members and surprised by some of the exchanges. They also corroborated the mix of questions experts received, some more personal, for example ‘what age does gender conditioning start’, some more scientific ‘were the numbers recruited for each group high enough’. Additionally, there were times when experts learnt from the members, for example whether breastmilk had been split into hind and fore milk. This helped members see their knowledge and opinions as valuable and helped the experts understand areas where they lacked experience, for example lipase in breastmilk causing faster degeneration of milk.

4.4.3 Subtheme 3b: Impact on Research, Work and Study

As in member interviews, experts discussed outcomes of PSG involvement. There was reference to members feeling confident to embark on scientific study:

“one [member]...has a...degree in theatre, so...isn’t the kind of person most likely to start doing a master’s in neuroscience...This experience...crystallised for her that this is what she wanted...there wasn’t a barrier because she hadn’t done science before” (E2).

Additionally, experts found PSG impacted them and their work:

“I’ve started a piece of work...that really did come out of the...discussions we had while we were at the residential...It made me think about it in a different way...[and] I got an acceptance...to display...the research...at [a] conference” (E2).

Working partnerships were formed through PSG involvement as well as changes to public participation in future research:

“this has kicked off...a long-lasting collaboration with myself and [named expert]...[it’s] got the potential to answer...very interesting questions...the involvement of the public in that will be...very important” (E1).

Impact was not all research-based. Some used their PSG experience to promote CS: *“I write about...citizen science projects...Parenting Science Gang was one” (E3).*

Observations reinforced the impact PSG had on experts. One expert reiterated to members how their research was a result of their interaction. Another asked members to brainstorm ideas including the best way to present results to different audiences, what stood out from the PSG research, and how best to recruit participants for longitudinal studies. Additionally, there were ideas proposed by members which had not been considered in research and the scientific process which were well received by the expert.

5.0 Discussion

The findings of this study have demonstrated a range of changes across the participating groups. This discussion positions these findings within the context of the literature.

5.1 Discussion of Findings:

5.1.1 Changes to information sourcing

Analyses provide evidence of participant changes to sourcing information and advice. Behavioural changes have been seen across different CS projects, albeit it inconsistently and at differing levels (Van Brussel and Huyse, 2018; Den Broeder *et al.*, 2017; Crall *et al.*, 2012). In this project, members initially used the Internet as an easy, accessible source of knowledge, corroborating others’ findings on Internet usage (Brossard and Scheufele, 2013; Plantin and Daneback, 2009; Bouche and Migeot, 2008). This may be due, in part, to all member interviewees being female, where online CS projects are normally dominated by

highly educated men with a STEM-based qualification (Land-Zandstra *et al.*, 2016a; Curtis, 2015; Raddick *et al.*, 2013). Although a high proportion of PSG interviewees had studied at university, this was not necessarily a STEM-based subject.

Online information and support-seeking behaviour is high amongst women (Plantin and Daneback, 2009), especially during pre- and post-natal phases with women being twice as likely as men to seek parenting information online (Bernhardt and Felter, 2004). Findings differ from Khoo and colleagues (2008) who found that, regarding health, although parents cite the Internet as an information source, they mostly use traditional sources such as healthcare professionals. Results may differ here as negative experiences with healthcare professionals and perceived lack of relevance to members and their situation emerged, deterring the use of professionals.

In the context of health information-seeking, it has been suggested that the community acts as a bank of information and support (Basu and Dutta, 2008), supporting the findings in this project that the PSG community is a readily available knowledge resource. The PSG community was cited as interviewees' primary information reservoir after joining. Using parents as an information source, either in person or online, is consistent with the literature, with other parents' advice perceived as more trustworthy compared to authoritative figures (Brown *et al.*, 2010; Plantin and Daneback, 2009). Platforms such as forums can provide an online space for learning collaboratively, which has been linked to deeper learning, better knowledge retention and higher-level critical thinking skills (Saqr *et al.*, 2018), with social media purported to promote positive behaviour changes (Scanfield *et al.*, 2010). Price and Lee (2013) found that social components in CS were highly valuable since participants used online forums to source information and news. Social interaction is not fundamental to all CS projects (Raddick *et al.*, 2013; Nov *et al.*, 2011). However, previous research has shown that participants' engagement with online communication tools, such as social media, drives the link between active participation and learning (Masters *et al.*, 2016) with learning evolving through community participation (DeVries Hassman, *et al.*, 2013). This might explain the observation that PSG groups play a role in changes to information-seeking and evaluating information quality with more experienced members or those with better access to higher-quality information supporting others.

One reason for citing the PSG community as a primary source of information after joining could be its accessibility. Benefits of accessibility have been noted in studies of information-seeking on parenting websites (Plantin and Daneback, 2009; Bernhardt and Felter, 2004). Facebook is a widely-used social media platform (Office for National Statistics, 2018; IPSOS mori, 2018; Lomanowska and Guitton, 2016), familiar to members and allows access anytime (Liberatore *et al.*, 2018), going further by sending members notifications and having a smartphone application.

5.1.2 Changes to evaluating information quality

The data suggests that prior to joining PSG members relied on instincts and whether information sounded 'right' to assess information quality. This supports literature on confirmation bias where individuals actively seek information aligning with their world-views (Shäfer, 2017; Kenski, 2017; Xenos *et al.*, 2011). Algorithmic echo chambers and filter bubbles can compound this further by displaying information online which fits an individual's

predilections (Adee, 2016), contributing to the perception of social norms, a factor in decision-making (Serpell and Green, 2006). Identifying repeated information across different online sources as a strategy for evaluating information quality, already less effective than using multiple source types (Bernhardt and Felter, 2004), could be nullified by echo chambers.

Trying to check or being sceptical of information quality corroborates previous studies that parents mistrust online information (Khoo *et al.*, 2008; Morahan-Martin and Anderson, 2000), and despite best efforts, may not be able to distinguish between high- and low-quality information (Armstrong-Heimsoth *et al.*, 2017; Bernhardt and Felter, 2004) or put assessment strategies into practice (Eysenbach and Köhler, 2002). This may be attributable to a lack of confidence determining information quality, as seen in health information-seeking (Armstrong-Heimsoth *et al.*, 2017) with some suggesting those with higher levels of health literacy may not be immune to this effect (Aharon *et al.*, 2017).

A community can help increase a member's self-confidence and ability to do a task, and subsequently help others (Jennett *et al.*, 2016). This may explain changes to evaluating information quality after joining PSG where interviewees used the community to critically analyse information. Whilst changes in confidence in finding and assessing high-quality information have been observed in a health literacy programme (Armstrong-Heimsoth *et al.*, 2017), in PSG, specific training outside the community was not undertaken by all so community impact may be more applicable here, alongside others' findings that parents feel the quality of the information increases if it is verified by other parents (Plantin and Daneback, 2009). Furthermore, members were time-poor, a barrier for parents enrolling and engaging in interventions (Swindle *et al.*, 2017), potentially facilitating using the community as a more time-efficient resource.

5.1.3 Changes to confidence regarding science

Changes to empowerment and confidence seen as a result of PSG participation are not unique amongst CS or other science interventions, although only mentioned in a handful of CS studies.

Empowering participants to feel they could be scientists or participate in science was also seen by Jennett and colleagues (2016) who found 'feeling like a scientist' became an element of participant identity. They also suggested repeated practice in project tasks increased participants' skills and confidence. Additionally, Ruiz-Mallén *et al.* (2016) saw an increase in empowerment after involvement in CS, suggesting that empowerment comes from confidence and collaboration. However, the PSG project found that participants who were less actively engaged still acquired confidence and felt empowered, suggesting more complex factors are involved.

Having a platform to communicate was empowering in PSG, supporting other studies on empowering women through blogging and social media (McDaniel *et al.*, 2012; Stavrositu and Sundar, 2012; Amichai-Hamburger *et al.*, 2008). Whilst virtual tools are purported not to provide a platform for those inclined to remain unvocal (Pew Research Centre, 2014), PSG findings indicate that more passively-engaged members still felt empowered.

An increase in confidence was seen across a range of areas for PSG interviewees, including confidence to be female and interested in science, do science, understand experts, speak to experts, healthcare professionals and/or other parents, and self-confidence in own knowledge and decision-making. Increases in confidence have been highlighted in CS and health-related literature but are not all found within a single study, unlike the present study. Changes in confidence to be able to do science (Jennett *et al.*, 2016; Ruiz-Mallén *et al.*, 2016), in communication skills (Den Broeder *et al.*, 2017), and self-confidence regarding knowledge, ability and decision-making can be seen in CS and health-related programmes (Dahl and Eagle, 2016; Rodger and Klistorner, 2016; McDonald *et al.*, 2012) and can result in positive actions relating to a project (Toomey and Domroese, 2013).

Changes to confidence may be influenced by positive interactions with PSG experts. This is supported by other studies which say parents' confidence and decision-making are affected by communication with healthcare professionals (Aarthun and Akerjordet, 2014) and effective science communication can empower a community in decision-making (Roger and Klistorner, 2016).

Findings in PSG show that information and knowledge were shared via symmetrical member-expert communication throughout, with members acknowledging experts as comprehensible. The development of member-expert relationships has been shown to improve self-confidence and self-efficacy in another CS project which led to participants feeling more motivated to study STEM-based careers (Ruiz-Mallén *et al.*, 2016). Although this study analysed a small group of school students, many of whom were considering STEM-based study before the project, there are comparable findings in PSG where interviewees identified that, as a result of confidence gained from PSG membership, they were now embarking on further and higher education in STEM, or changed career to a STEM-related job. Most experts who interacted with PSG members were female, potentially serving as role models which has been seen to impact female uptake of STEM (Breda *et al.*, 2018; Horn, 2011), as well as promoting academic and career aspirations, increasing sense of belonging, improving attitudes towards STEM, helping women identify actions needed for attaining a desired identity, negating feelings of failure and contributing to the psychological reframing of self-narrative leading to behavioural changes (Herrmann *et al.*, 2016). Alongside the influence of role models, other factors exist, such as a sense of belonging produced by interaction in a community (Jennett *et al.*, 2016), a change in perception of social norms (Breda *et al.*, 2016; Basu and Dutta, 2008), an increase in self-efficacy (Dahl and Eagle, 2016; Roger and Klistorner, 2016), and changes to behaviour and attitude towards science (Ruiz-Mallén *et al.*, 2016).

Changes to behaviours and attitudes brought about by CS have been debated in the literature, some seeing changes in behaviour (Den Broeder *et al.*, 2017; Toomey and Domroese, 2013), attitude (Ruiz-Mallén *et al.*, 2016; Price and Lee, 2013), or both (Van Brussel and Huyse, 2018; Roetman and Daniels, 2011, Bonney *et al.*, 2009) generally at low levels. Greater levels of change were seen in PSG, for example a change in information-seeking behaviour, possibly due to its co-created nature, numerous interactions with experts, strong community and differing backgrounds of the members.

5.1.4 Unexpected outcomes of PSG

Community and Support:

The community and support networks created through PSG were unexpected. As seen in previous sections, its influence was felt throughout, including changing how members looked for and evaluated information, increasing confidence, promoting social interaction, connection and support. This has been seen in other studies from healthcare, parenting and in some, but not universally, CS.

Before PSG, interviewees said they felt isolated and lacked support in real life. This agreed with parenting literature that attributed it to decreasing real-life support alongside increasing social mobilisation (Entsieh and Hallström, 2016; Plantin and Daneback, 2009). Previous studies propose that social support from other mothers can negate feelings of isolation (Madge and O'Connor, 2006), which has been observed in PSG. Furthermore, virtual social support can increase parents' ability to cope with parenthood and allows sharing of experiences, important in developing identity (Plantin and Daneback, 2009). Sharing of experiences was witnessed at PSG events, cited previously as an important resource for social support (Doty and Dworkin, 2014) and community building (Cooke, 2016).

Interactive platforms are noted as providing important social support to women (Kimmerdale *et al.*, 2017; Sarkadi and Bremberg, 2005), helping parents feel more secure in their roles, and are accessible day or night (Plantin and Daneback, 2009). As seen by Jennett and colleagues (2016), an online, interactive space provides a tool for members to share information, improve self-confidence, extend social networks, identify with the project community and develop a sense of belonging. PSG groups were able to move beyond this social support by working towards shared goals, thus creating social bonds and building a stronger community (Hoyle and Moseley, 2012).

This sense of social support and community is not ubiquitous amongst all CS projects, some finding it to be the least important element (Land-Zandstra *et al.*, 2016a; Raddick *et al.*, 2013), possibly attributable to the types of CS projects available. Co-created and collaborative CS projects can better facilitate a sense of community by moving beyond the role of data collector or analyser (Price and Lee, 2013; Bonney *et al.*, 2009). Co-created projects are also designed to address specific community needs, so are more likely to attract people interested in those needs (Crall *et al.*, 2012). PSG facilitates co-creation of projects pertinent to members' lives, with member-member and member-expert collaborations needed to conduct research to address specific needs. By its very nature, PSG encourages community and support network development.

Understanding the Scientific Process

Analyses highlighted changes in participants' understanding of the scientific process pre- to post-joining PSG. This covered a range of areas from a better understanding of what was involved, being more trusting of the process, and feeling science is more relevant and less disconnected from participants' lives. These last two elements overlap with a change in attitude towards science which is an inconsistent outcome of CS projects, discussed earlier.

Improving understanding of the scientific process has been mixed in CS, although it is purported to have potential in this area (Masters *et al.*, 2016). Many CS projects have been unable to demonstrate significant changes, such as in environmental, contributory-type projects (Crall *et al.*, 2012; Brossard *et al.*, 2005). Some show glimmers of change but conclude that scientific process skills did not change overall (Jordan *et al.*, 2011). There is suggestion that more involvement in all aspects of the scientific process is more likely to impact understanding (Bonney *et al.*, 2009). However, all PSG activity categories demonstrated changes to scientific process understanding which may be attributable to the involvement of participants at more levels of the scientific process, which is seen in more collaborative and co-created CS projects (Bonney *et al.*, 2009). Experience of the research process has been seen to provide a better understanding of what science does, how scientists work, and the complexity of the scientific process (Jennett *et al.*, 2016; Ruiz-Mallén *et al.*, 2016). This supports the results with PSG interviewees having a better understanding of science and the scientific process, and feeling less disconnected from it.

Being more trusting of the scientific process was also recorded during the PSG project, perhaps influenced by member-expert interactions which can engender trust and reduce power differences (Ruiz-Mallén *et al.*, 2016; Jordan *et al.*, 2011; Evans *et al.*, 2005). Communication can facilitate trust and, alongside an increased understanding of the scientific process and more established member-expert relationships, participants can feel more empowered to engage with science beyond a particular project (Vann-Sander *et al.*, 2016). This may be a factor with interviewees' sense of empowerment due to PSG participation. Although it is suggested that for CS to change understanding of the scientific process, direct interaction in the scientific study, interaction with scientists and the use of educational materials are needed (Brossard *et al.*, 2005), this was not necessarily applicable to PSG. However, the use of live chats with experts, available online as transcripts afterwards, and the availability of the community as a knowledge resource may be contributory factors to the observed changes.

Outcomes for Experts

Although the voice of experts regarding CS is largely absent (Riesch and Potter, 2013), this project has highlighted ways in which PSG has impacted experts involved. Outcomes include learning from members, positive and exciting interactions, resulting in new research and work.

Excitement around interaction with and contribution of ideas from participants has been seen by others (Riesch and Potter, 2013; Rotman *et al.*, 2012). Discussion regarding how questions differed from those asked by other academics and how refreshing it was speaking to non-researchers aligns with previous research which suggests interactions outside the academic community can be rewarding (Curtis, 2015) and novel approaches, improvements and tools can be identified (Jennett *et al.*, 2016; Curtis, 2014). Additionally, it has been suggested that working with the public can help experts produce socially relevant research, confounding claims of science being removed from societal needs, which may otherwise not be addressed, challenging traditional research approaches (Ruiz-Mallén *et al.*, 2016; Crall *et al.*, 2012) and taking advantage of different problem-solving techniques and skills (Curtis, 2014). This helps experts see their research in different ways (Wilkinson *et al.*, 2011), a key outcome in PSG, alongside identifying necessary, socially relevant research.

Researchers were observed learning from their interactions with PSG members, also seen in participant-expert interactions in CS and public engagement (Ruiz-Mallén *et al.*, 2016; Wilkinson *et al.*, 2011). However, since public engagement is not a goal of all CS projects (Riesch and Potter, 2013), this may not be applicable, especially to projects which focus on data collection and analysis with minimal scope for participant-expert interactions.

Interestingly, a high proportion of literature cites collection and analysis of vast amounts of data in CS as a key benefit for experts (Land-Zandstra *et al.*, 2016b; Curtis, 2015; Rotman *et al.*, 2012) but was not identified as a benefit of PSG, possibly due to the collaborative nature of the project. Similarly, participants were not seen as a free source of labour (Silvertown, 2009) nor their participation questioned as unethical regarding taking paid jobs from researchers which has caused concern (Riesch and Potter, 2013).

5.2 Recommendations

Recommendations based on PSG findings include ensuring community support is embedded into CS projects, potentially supporting participants, and ensuring scientists are visible, relatable and relevant, so members can see science as accessible and normal. These findings can encourage scientist-public collaborations to better inform research pertinent to the public and their daily lives. Outside CS, this study is useful for those wanting to increase confidence and public involvement regarding science and science decision-making.

Further research could investigate changes to information sourcing and evaluating, and confidence with science within other CS projects to see whether the findings apply outside parenting communities, and longitudinal studies exploring whether there is an impact on families' Science Capital. Since social learning became prominent during this project and has links to the literature, it warrants further investigation. Additionally, with current interest surrounding mental health alongside research from other disciplines suggesting event attendance (Ballantyne *et al.*, 2014) and online support networks (McDaniel *et al.*, 2012) can improve well-being, further research into how participation in PSG contributes to this is needed.

5.3 Limitations

Limitations do exist within this study, although the methodology sought to minimise this, including addressing construct, internal and ecological validity (Table 34), but was limited regarding testing external validity due to time constraints (Yin, 2014).

The data collected is not statistically generalisable as it is based on PSG groups, however it is analytically generalisable (Blaikie, 2007; Bryman, 2008). There were specific caregivers in PSG, so we know less about other primary caregivers such as fathers and grandparents. Also, by the project's online and English-language nature, participants needed a level of computer and general literacy to be able to participate.

The researcher was not involved at the outset of PSG or able to conduct interviews before members joined, meaning interviewees had to retrospectively describe their experiences (Brown *et al.*, 2012). This weakness was minimised by including a group in the early stages

of its PSG journey. Additionally, more interviews with experts, time permitting, would have been beneficial to ensure saturation of themes.

Observations were restricted to three events. Not all members attended these, potentially skewing results since those who participate are most likely to be highly engaged (Crall *et al.*, 2012), although this was mitigated by using selection criteria (Davies, 2007). To prevent intra-coder error the researcher returned to previously coded transcripts to ensure rules of assignment to themes were consistent (Bryman, 2008).

The presence of the researcher and the potential role of 'power' could have impacted interviewee response (Creswell, 2007; Bryman, 2008). Eliminating researcher influence is impossible (Maxwell, 2005). However, the researcher was the same gender and of similar age to almost all those involved (Alex and Hammarström, 2008), dressing to blend in, in clean, inoffensive attire aiming to soothe any potential 'power' relationship. Additionally, interviews were conducted remotely so the interviewee could be in familiar surroundings. The language used in the interview schedule was checked with the PSG Project Managers to identify anything which would not be used by interviewees in the PSG setting. This attempted to ameliorate the power dynamic being influenced by the interviewer's 'habitus' (Alex and Hammarström, 2008), in this case, language.

6.0 Conclusion

Parents have apprehensions around parenting and infant care, further confounded by the glut of conflicting information, especially online, and feel unprepared and isolated (Knowles and Wilkinson, 2015; Serpell and Green, 2006; Entsieh and Hallström, 2016). CS has the potential to address these problems. However, the existing literature regarding the impact of CS on participants is mixed. Through evaluating PSG using observations from events, interviews with members and experts, and secondary data from PSG surveys, this project investigated whether changes in several areas could be brought about by participating in this user-led CS project through collaborating with experts to ask real-world questions important to the parenting community and wider society.

The findings demonstrate that participation, no matter the level, can effect changes to participant behaviour, in this case information sourcing and evaluating quality, attitudes to science including a change in confidence, and unexpected outcomes such as increasing understanding of the scientific process, creating a sense of belonging and reducing isolation, and impacting experts' research, knowledge, and future plans.

These results have implications for research. They refute previous findings which suggest for change to happen, participants need to be high engagers (Crall *et al.*, 2012), and support the idea that CS can facilitate democratic interaction with science and scientists (Ruiz-Mallén *et al.*, 2016; Weitkamp, 2016). Such collaborations can better inform research through a symbiotic relationship, with real-world impact by answering questions pertinent to the public and their daily lives. Results illustrate that collaboration with other participants, not just experts, within a community can be integral to any changes seen and reduce feelings of isolation. Findings also support the idea that, by improving parents' confidence, their ability to source high-quality information is enhanced and, as such, their ability to make well-informed decisions (Armstrong-Heimsoth *et al.*, 2017). Furthermore, project findings tie into

the PAS Survey where those polled felt the public should be involved with decision-making regarding science (Castell *et al.*, 2014) thus having implications for policy.

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In-depth: Q&As

In this section you'll find details of our online, text-based Q&As, including:

- *The aims of the Q&As*
 - *Experts feedback on their experience including any challenges*
 - *Experts views of [PSG](#) following their Q&A experience*
-

Key take-aways

- Parents and scientists both really enjoy the opportunity to chat and will make time to do so.
- Preparation is key - parents are very willing to read a bit in advance and this gives better quality questions.
- 100% of experts would take part again, and would recommend it to a colleague. Found it stimulating and enjoyable
- Stimulated ideas about their own research and possible research projects.
- The invisible nature of online sessions helps to level the playing field - the expert is not on a stage, not dressed differently, can't see their qualifications on the wall.
 - This can be challenging for experts used to getting immediate visual feedback from their audience
- Direct. Immediate. Informal. Takes up little time from experts compared to going to a meeting or giving a lecture (no travel, etc).
- Establishing a culture is important - informal language, not talking about your own kids all the time, admitting when you are wrong etc.

"I was terribly nervous before each session, but I really rather enjoyed it, and that first time, that first night I went to bed afterwards and I couldn't sleep for about half an hour, it was all buzzing around in my head."

Prof Peter Brocklehurst, University of Birmingham

"It's a surprisingly efficient and effective way of doing things"

Anonymous expert

We ran 73 Q&As over the project, most of which were open to all members. Some were for specific groups and explored topics relevant to their research interests such as particular research techniques. Numbers of participants varied dramatically, ranging from 8 or 9 for our initial few sessions to 120 for a session looking at research into different parenting styles and averaging 50 signed up to each session.

Subjects for the Q&As were suggested by the PSG members and by the PSG team. Experts were found by searching through recent, highly regarded papers on the subject, by recommendation from previous experts and by general internet searches. They were invited by email or by phoning them up for a conversation. When we spoke directly to an expert, 100% agreed to join us for a Q&A. We prioritised experts with a long record of research in the area so that they were able to answer a wide range of questions, so of which might be

tangential to the advertised subject. Where possible we invited female experts (81% of total Q&As), and looked for individuals from under-represented groups in science.

Sessions took place approximately weekly, at 9pm in the evening, when the majority of members were free from child care and work commitments. However, we know that a large number of infants and toddlers were breastfed during the sessions, and quite a few parents participated on their phones while sitting on the floor near a child who wanted company as they went to sleep! Using a text-based format was essential to ensure that members were able to multi-task involvement with the session with supporting their children.

After initially using the I'm A Scientist, Get Me Out Of Here¹⁶ (IAS) chat room for sessions, the groups overwhelmingly supported using Facebook groups, one for each session. This format enables members to scroll through the conversation easily and keep different topics in different threads which resulted in a more coherent conversation that everyone could keep track of. It also meant that we avoided any technical difficulties of a new and unfamiliar platform and kept all our work on Facebook, easily linked from the main PSG groups. This suited our members much better:

"IAS feels like a teacher addressing the class, FB feels like chatting in the playground" BOBAB member

"On IAS I feel that I have to consider my phrasing and make sure there are no typos. On FB I can write naturally" UKBAPS member

Sessions were advertised on the PSG groups in advance, and Facebook events were set up for members to join. This meant that Facebook sent automatic reminders of the event. Members had to join the appropriate Q&A Facebook group (linked from posts on the groups and event listings), and the groups were set to automatically accept requests from PSG group members. We scheduled reminders on the main PSG groups as well as the Q&A group about the events, and the former tended to result in new members for the Q&A.

The total number of 'bums of seats' across all Q&As, was 3,419, but many of those will be the same person attending more than one Q&A. This number refers to the number of members who joined the event group, but we have no way of knowing how many actually turned up to the live event. Some lurked and some used Facebook reactions during sessions. Some members missed the session and read up later, posting their own responses to the conversation. Some academics, alerted by automatic Facebook notifications of these late responses, chose to come back and reply

The number of comments for each session varied dramatically over the project, ranging from 57 during a Q&A on water births to 307 on a session on gender differences. This was also affected by the experts' and members' Facebook style - whether they used multiple posts/comments with short sentences or wrote long paragraphs in each post/comment.

Our aims for the sessions were:

¹⁶ <https://imascientist.org.uk/>

- To enable members to find out more about what research has been done and it's findings
- To learn about specific research methods so that members could assess their suitability for PSG research and develop skills in the methods that were chosen
- To start meaningful conversations, minimising external reminders of the differences between experts and members.

The first Q&As were dominated by members asking questions about their personal situations, often hoping for advice eg to Prof Helen Ball, expert in infant sleep: "My nearly 2 year old wakes hourly no matter what we try." PSG team members modelled examples of how to ask about research findings and ensured that all Q&A included the questions

- What research gaps do you see?
- If you could have unlimited funding, what research would you do?

Apart from these questions, the conversation was left to follow the interests of the members, even if it strayed from the area of the researcher's specific expertise.

As the project progressed, questions became more research focussed, eg "Can you tell us more about this research that shows children need to taste food lots of times before they like it? What do you actually do?", and group members started asking the questions above themselves. It would be really interesting to analyse more carefully how the members' questioning developed during the project.

In order to develop the maturity and depth of questions, and encourage members to Q&As outside their immediate interests, we prompted members to think about the Q&A subjects within the PSG groups in advance of the session. We posted 4 or 5 Q&A-related posts over the preceding days sharing posters or lay summaries of the expert's research, videos from their research or providing an insight in the topic, inviting members to share their own experiences, or providing polls to stimulate thought on the subject. These worked extremely well, and members shared and discussed their own knowledge in advance, leading to more complex questions and far fewer incidences of sharing tangential personal stories during the Q&A. We also know that members did come to sessions with an aim of simply increasing their general knowledge rather than as a result of having problems that they wanted to solve. We had comments such as this one during a co-sleeping Q&A:

"Just interested in being a passenger on this q&a. I didn't co-sleep with either of mine, due to my own need for being alone. I think I'm here for insight" [SANP](#) member

After each Q&A, the session was transcribed, anonymised, and published on our website so the conversation could be shared widely. We regularly needed to contact members to get permission to publish their comments, as although anonymised, they contained sufficient details to identify them. In some situations we suggested slight edits, but all members were happy for us to publish their posts.

Our Facebook posts about the published Q&As were widely shared from the public PSG page, and within the groups, were regularly reacted to with "likes" and "loves". An unexpected audience for the sessions were students and other academics who used them to

develop their own knowledge either in a less familiar field, or to understand more about parent's driving interests, questions and motivations.

"I recommend your Q&As to my student midwives - they are great introductions to areas of research and help me in delivering research-led teaching" Dr Zoe Darwin,
University of Leeds.

The majority of experts who joined us for Q&As had no further interaction with PSG after their sessions apart from receiving our newsletter (one only did not request being put on our mailing list). However, five sessions resulted in collaborations (eg Dr Davide Filingeri, who joined us for a session on infant thermoregulation and ended up offering us support and lab space), and other experts offered support in other ways such as putting us in touch with other relevant scientists, advising us on research methods or sending us relevant research papers.

Expert Feedback

After each Q&A, the expert was asked for feedback on their experience using five evaluation questions. We received 28 responses and they were almost all effusively enthusiastic, with 100% of respondents saying that they would take part again or recommend the activity to a colleague. We were in close contact with guests during and immediately after the Q&As, chatting on a PM thread, and have no indication that those who didn't return our evaluation questions were dissatisfied with the experience.

General Experience

Most importantly, **100% of respondents said that they would have part in a session again**, and that they would recommend the experience to a colleague. There were, however, some caveats to the latter, two comments expressed concern that some "less tech-savvy" colleagues might find using Facebook challenging. Another felt that this format wasn't for everyone:

"I would recommend, but usually I find academics can struggle with this kind of format where they are asked to do things and answer rapid fire questions."

The vast majority of respondents told us how much they **enjoyed the experience**:

"Thoroughly enjoyable - the hour flew by! (In fact, a 90 minute session might have worked fine too.)"

"Loved it!"

"It went so quickly! It was really fun and engaging and went by in a flash"

And most could see a **clear benefit of being involved**, either to themselves to to the group members.

"It was great to be able to have a multi-way conversation and get other people's perspectives on my work."

“Really like this initiative, as I am a big believer that real impact from research comes from engaging with the primary users of the knowledge produced.”

“[Some of the] questions that were being asked potentially would make good research questions, as the field is very under-researched.”

Many respondents were **positively surprised about the members’ questions** - their depth, breadth and enthusiasm (8 comments in total);

“Positively surprised by the number of questions and by how detailed some were.”

“[I was surprised by] the level of technicality of some of the questions - quite impressive!

“In a good way – just how engaged those who participated in the group were. I know that only those interested would be likely to take part, but even so, I felt there was some great questions raised.”

And some mentioned that they had enjoyed the informality of the session;

“[I was surprised by] the ease of the conversation.”

Challenges for experts

All guests received information in advance of the session giving some background to the project and an indication of what we wanted out of the session. This preparation worked well - approximately half our responding reported that they had not been surprised by any aspect of their session. The document also included clear instructions describing how Q&As worked and how to use Facebook features to support the session (eg tagging, notifications). These were well received;

“As a non-Facebook user I felt the support before, during and after the session was very helpful and supportive.”

However, the session wasn’t necessarily easy for our experts, and several reported personal challenges, ranging from keeping up with the number of questions, to overcoming their own nerves;

“I did find the parallel firing of comments/observations a bit of a challenge, to be honest.”

“I was terribly nervous before each session, but I really rather enjoyed it.”

Interestingly, the experts who were willing to report that they had been nervous, tended to be the more well-known of our guests. Could it be that they are more used than others to attending events where there are frequent reminders of their stature, for example standing on a stage, in front of a highly responsive and attentive audience, dressed to impress? There is very little feedback to experts apart from verbal thanks and the continuous onslaught of questions, and without being able to see nodding heads, and attentive faces, some people might find it difficult to assess how well they are being received.

Some respondents felt that the rapid fire of questions had led to a lower quality of answer than they would have liked. It is definitely a skill that not everyone feels confident in.

“The need for quick-fire answers was quite challenging and sometimes a bit unsatisfying (but probably a good discipline).”

“They were great questions but given the number of them - and the fact that several conversations were going on at once - I did not feel that I had time for very considered or detailed answers.”

“A chance to edit my responses afterwards before being put onto the blog would have been nice.”

The sheer number of questions, and their personal nature provided a challenge for experts who would like to have been able to provide more individual support.

“I was a bit surprised at...the posts asking for individual advice – I think I could have anticipated this if I’d thought about it! So thank you for stepping in during the session to try to nip this in the bud. There’s clearly a lot of un-met need out there...”

“It is always compelling for parents (and for me!!) to ask (answer) questions about real/ongoing experiences, and here staying with research was tricky in the chat. And yet I couldn’t fully help parents either because I was trying to stay away from those questions -- I was a little frustrated about that and was almost tempted to follow-up with some parents!”

Getting the science across

Our primary aim for these sessions was for PSG members to find out more about findings of research in areas of interest. But did the experts feel that they had been able to explain their knowledge effectively? 87% of respondents felt that they had managed to communicate their work at least in the most part. But clearly you cannot cover a whole topic and all the relevant background in an hour.

“Yes I explained my expertise, but just at the tip of the iceberg!”

“I think so – it’s hard to explain nuances/subtleties in this kind of forum – easy to come across as more certain than you really are.”

“Sometimes soundbites feel a little lacking in scope and I would perhaps have answered a couple of the questions in a slightly different way.”

One highly reflective guest noted that the questions deepened during the session, starting with simple queries on a subject that the members were highly conversant in, but increased in complexity as their respect for the guest increased.

“Often I find I get a lot of testing questions first but the better ones come out much later when I can be trusted.”

In some of our groups, members were used to treating experts with a degree of caution due to previous experiences of discrimination, misinformation or underestimation of the severity of the situation, and so in these sessions, it was important for the expert to gain the trust of the members before we could have meaningful conversation.

Facebook as a platform for discussion

The platform itself was relatively stable, and the only guests who reported technical difficulties attributed them to their own inexperience (4 comments) or locally slow internet (2 comments).

Mostly our guests felt that Facebook was a useful platform;

"I was really impressed at the software functionality of facebook. Against my better judgement, I came away thinking, whatever else facebook is, they've really nailed.. ..how to manage a complex conversation between a large number of people with multiple threads and somehow make it work."

Experts' views of PSG

Finally, some experts used this opportunity to comment on the project as a whole, many commenting on the value of dialogue with parents.

"I really like this initiative, as I am a big believer that real impact from research comes from engaging with the primary users of the knowledge produced."

"Everything I do research wise has to be directed, supported and informed by those who use the services, so the newsletter would be great to have."

"The idea of engaging with citizens in this way, making research more accessible, encouraging them to think critically about evidence and supporting them to do their own research seems an excellent idea"

And we were pleased that some were moved to take these ideas forwards themselves,

"You have inspired me to follow your example and do some Q&As for our facebook page, to take our supporters through our complicated report one indicator at a time."

"The participants were super interesting, I enjoyed our exchanges, and I'd love to be involved in this project and/or potential spin-offs from my conversations."

In-depth: Accompanying adults' view

We wanted to gauge whether the effects of [PSG](#) had gone beyond the person involved by asking three simple questions of accompanying adults at our Final Event. In this section, you'll find a summary of the answers to each of the questions, followed by the interviews in full.

At our Final Event, participants were encouraged to bring another adult (which we referred to as accompanying adult, or [AA](#)), if possible, to supervise their children during the activities and throughout the event, when they were engaged in workshops and other PSG business. (Nannies were available for those who were not able to bring an accompanying adult). Most of the accompanying adults at our events were partners or spouses, although friends and parents also fulfilled this role.

Our evaluator, Dr Sarah West, conducted brief interviews with ten of the accompanying adults at our Final Event – asking three simple questions:

1. Could you describe Parenting Science Gang to me?
2. What effect do you think participating in the project has had on the person you are accompanying?
3. Has the project had any knock-on impacts on you or your family?

Could you describe Parenting Science Gang to me?



Figure 39 – Word cloud of responses to “Could you describe PSG to me?”

Most of the accompanying adults knew that the project to do with parents doing their own research, based on their partners' or the wider group's interests.

"From what I've learned from what she's said - it's parents asking questions other people aren't - working in collaborative groups to do research. This event is about finding out what groups found and celebrating that."

"It's collaboration essentially of people interested in that particular topic, parenting, and making it a bit more evidence-based."

"it's parents asking questions other people aren't"

Some apologised for their lack of knowledge, and then gave a fairly accurate description in a nutshell.

"My understanding is probably quite limited. It's a more flexible approach to gathering data and research. It's an accessible way of engaging people in the process of developing research."

One had an excellent appreciation of many aspects of the project and had reflected on the nature of the project e.g.:

"I was thinking on the way up here, it's not just getting parents involved in science but with female-led and focus, and female presence, it makes me think about family-friendliness."

Three had little idea, although two knew it was something to do with their partner's interest in breastfeeding.

What effect do you think participating in the project has had on the person you are accompanying?



Figure 40— Word cloud of responses to “What effect do you think participating in the project has had on the person you are accompanying?”

The enjoyment their partners got from community aspect was a common theme: half of the interviewees mentioned this. Two used the phrase “like-minded people” although one cautioned that the similarities meant the group wasn’t very diverse. Many used positive words such as “enthusiastic” and “excited”.

Three interviewees saw the group as a way their partners could do something other than parenting; two used the word “outlet”

“feeling that she’s contributing to something more than childcare which is a big part of her life.”

"it's a really good outlet for her, something other than being a mum."

Three suggested the project helped their partners in their professional life, and one said it had given his partner new ideas on how to approach her analysing data more creatively:

“she has talked about in this project learning more ways of analysing data than in her PHD. More creative than perhaps academic. Not that this isn’t academic, but it has broadened her horizons”

"the project has helped her network, link with professionals, keep her in the loop."

Half of the interviewees mentioned the project meeting their partner's need to research / find information on a topic.

Three mentioned the project positively influencing family discussions and information sharing e.g.

"It generates some discussion in the family, and it's nice to talk about things apart from just child-care related issues"

"We are getting lots of information here today. I think it will have lots of impacts on us. At home, everyday life, just getting on with things...today we are getting lots of information and ideas here."

And two mentioned their children enjoying the events:

"it's got support for children - our older child can play with others, is able to get far more involved with crafts, experiments etc, they will probably take away some of this"

"the kids loved going to the Birmingham thing like this, they were excited to come"

Some offered further impacts on their partner they hadn't mentioned in the previous answer., for example two mentioned the project giving their partner confidence in her parenting decisions and one of them included himself in that confidence:

"It has made us more confident, that this is good, hearing this makes us more confident that what we are doing is right"

"Well I think it's helped my wife feel a lot more confident about feeding our older child, as there is still a lot of stigma about it. Or at least, if she is confronted, she has got a comeback"

Full interviews

AA1

SW Could you describe Parenting Science Gang to me?

It seems like a public / community research project where people do research on anything they like, not academics. There are lots of different groups, they work out what they want to do, what interests them.

SW What effect do you think participating in the project has had on the person you are accompanying?

She is very enthusiastic about it, the Q&As, coming into contact with lots of like-minded people (sometimes not a good thing as it's not very diverse). Pleased to be engaging with educated people with science backgrounds. She is involved with Big Birthas. It has all been good, until maybe 2 days ago - why has nobody done what they were meant to? So until the actual doing, it was all very positive. I guess that's not very surprising, but maybe a better way of managing the volunteers would be helpful.

SW Has the project had any knock-on impacts on you or your family?

Not really, the kids loved going to the Birmingham thing like this, they were excited to come to this. It took some time up for her, the Q&As, but not outrageous, and she was all enthusiastic afterwards so it is all good.

AA2

SW Could you describe Parenting Science Gang to me?

A research project trying to get parents looking...a parent-led look at parent-focused science. Not just getting adults into science, getting parents who aren't into science in science. What science initiatives that are of relevance to parents. My wife is involved in overseeing it - i'm here to help with the kids. It is interesting to see the effect of trying to get the families involved with it, seeing the stuff, the service provided, the support of other parents, making it possible to bring relevant people here. A few years ago, before the kids, my wife might have attended for work, but i'd not come, so it is interesting. It is a female-led project. That's not a criticism, but it is interesting and speaks of issues of women in science, what relevance science has in day to day life. I was thinking on the way up here, it's not just getting parents involved in science but with female-led and focus, and female presence, it makes me think about family-friendliness, it's an interesting initiative of keeping women professionally interested in science. When my wife has been off work, there is a slow down in her research interests, Parenting Science Gang is something that keeps her in touch with work professionally, so she is not out of the loop. But her academic research is social / family side, something that has worked well, kept the ball rolling, helped make her less isolated. So it's not just that it gets parents in science who wouldn't before, but it keeps women involved in science once they are on maternity leave, can still keep the ball rolling, give confidence, research ideas.

SW What effect do you think participating in the project has had on the person you are accompanying?

It has been a very positive thing for her. It's a way of supporting her, keeping in the loop, when she's had concerns, the project has helped her network, link with professionals, keep her in the loop.

SW Has the project had any knock-on impacts on you or your family?

The family that we are, we'd have been likely to be involved in work-trips anyway. Not this work. But because it's got support for children - our older child can play with others, is able to get far more involved with crafts, experiments etc, they will probably take away some of this - they pick things up from nursery for example. For the family, I will discuss with my wife how things like this could work for events she's organising, and what impacts her research might have. And offshoot discussions about how people parent, and how social issues can affect parents.

AA3

SW Could you describe Parenting Science Gang to me?

It's collaboration essentially of people interested in that particular topic, parenting, and making it a bit more evidence-based, which we are all for. People don't have any particular training in that field, but obviously there is oversight from people in that field.

SW What effect do you think participating in the project has had on the person you are accompanying?

It has certainly given her a much-needed outlet for her interest in the subject and her...finding a community of like-minded people and feeling that she's contributing to something more than childcare which is a big part of her life. She is involved with Let Toys Be Toys

SW Has the project had any knock-on impacts on you or your family?

No. From a negative point of view, definite no. It generates some discussion in the family, and it's nice to talk about things apart from just child-care related issues. Because it's made her go out and do some background reading, she'll go and find an article and we'll do some critical analysis of articles - you can tell we are a bit of a geeky family. It's mainly journal articles, sometimes magazines but it's easier to slag those off.

AA4

SW Could you describe Parenting Science Gang to me?

Not really. I know my wife went down to London to donate a sample of breastmilk as they were interested in the constitution of older child milk.

SW What effect do you think participating in the project has had on the person you are accompanying?

She does quite a lot of work related to breastfeeding, some maternity partnership thing, sorry I don't know the name, as well as that she does this, and it's a really good outlet for her, something other than being a mum. She'll find articles and pass them onto me. Before we had a child and before doing any research, everyone said 'sleep every 4 hours etc' - we've learned a lot. Or rather, she has, and passed it on to me.

SW Has the project had any knock-on impacts on you or your family?

I don't think so at all. Well i think it's helped my wife feel a lot more confident about feeding our older child, as there is still a lot of stigma about it. Or at least, if she is confronted, she has got a come back.

{Note from SW, this father later came up to me and said that he hadn't realised when we were talking that he does actually know a lot more about the project than he had said, he just handed realised that the activities his wife has been involved in were all part of PSG}.

AA5

SW Could you describe Parenting Science Gang to me?

Not really no. sorry.

SW What effect do you think participating in the project has had on the person you are accompanying?

I think it has fed the natural inclinations she already had for investigating things in detail.

SW Has the project had any knock-on impacts on you or your family?

Not that I am aware of, no.

AA6

SW Could you describe Parenting Science Gang to me?

I think with the children in here, with the babies and the children, it is a good get together. And lots of things, lots of information, I've never been in this type of event before, it is good information for me.

SW What effect do you think participating in the project has had on the person you are accompanying?

I really don't know about this one, sorry.

SW Has the project had any knock-on impacts on you or your family?

On my nany and me, the very best thing is this {points around the room with all the children playing in}. We are getting lots of information here today. I think it will have lots of impacts on us. At home, everyday life, just getting on with things...today we are getting lots of information and ideas here. This type of event should be....so not having people just in everyday life, come and give new knowledge and experience, especially for the children, they understand this type of event, but I'm really enjoying it too.

AA7

SW Could you describe Parenting Science Gang to me?

I've got to be honest, I'm the other half, she's a breastfeeding advocate and has been invited as part of that, I'm entertaining our child, rather selfishly I went to the National Railway Museum.

SW What effect do you think participating in the project has had on the person you are accompanying?

I think she's basically spreading what she's learnt as a mother to others. She struggled with breastfeeding so is supporting others. And she is getting support from others.

SW Has the project had any knock-on impacts on you or your family?

That's to be discovered in the future. I'll see what she says. We are both older parents, for us, our child is a real blessing. She's passionate about breastfeeding and rear-facing child seats in particular, those are her things, and that's rubbed off on me. She works in the NHS.

AA8

SW Could you describe Parenting Science Gang to me?

My understanding is probably quite limited. It's a more flexible approach to gathering data and research. It's an accessible way of engaging people in the process of developing research.

SW What effect do you think participating in the project has had on the person you are accompanying?

She comes from an academic background anyway, she's just finished her PhD so she's immersed in a very academic world, but she has talked about in this project learning more ways of analysing data than in her PHD. More creative than perhaps academic. Not that this isn't academic, but it has broadened her horizons

SW Has the project had any knock-on impacts on you or your family?

I'm here. This is my weekend. Urm. I don't think it has, because she's done a PhD, the maternity experience, we've been living this for the past 4 years so it is not any different really.

AA9

SW Could you describe Parenting Science Gang to me?

What have I picked up from my wife? I suppose you are doing research into parenting issues, or thoughts that aren't being done by anyone else. Answering questions of interests to parents.

SW What effect do you think participating in the project has had on the person you are accompanying?

I think it has made her quite excited about things she has already been interested in. She is in breastfeeding older babies and beyond - they have already been doing research and she is excited to do more., they went down to Imperial, she was excited about that. It has also been good that she has met others with a similar passion.

SW Has the project had any knock-on impacts on you or your family?

Erm. Probably it has made my wife more confident in some things she knew already. It has also given her people she's going to keep in contact with after this has finished.

SW: Has this impacted you?

It has made us more confident, that this is good, hearing this makes us more confident that what we are doing is right.

AA10

SW Could you describe Parenting Science Gang to me?

From what I've learned from what she's said - it's parents asking questions other people aren't - working in collaborative groups to do research. This event is about finding out what groups found and celebrating that.

SW What effect do you think participating in the project has had on the person you are accompanying?

We've not spoken much about it, but when she talks about it I can see the effect on her. She flexischools her oldest and so just getting more evidence on that.

SW Has the project had any knock-on impacts on the family?

At the moment she has lots going on in her personal life, so lots of plates to spin - this is just one thing amongst lots of other things.

In-depth: User-led citizen evaluation

In this section, you'll find participant-initiated feedback on our #breastmilkexperiment day.

"I wanted to document aspects of the essence of what happened... a snapshot of our breastfeeding voices and hearts"

117 breastfeeding mothers came to Imperial College in February 2018 to express and donate milk for the [BOBAB](#) / [UKBAPS PSG](#) breast milk experiment.

One of the mums - Lyato - was inspired to capture people's experiences of the day. "I'm a creative mother writer in England, who is tandem breastfeeding a school age child and toddler. I am also a citizen scientist, who takes a philosophical approach to life. I am passionate about learning and I enjoy thinking. Time poor and ideas rich, I spread my wings as far as they can go, reaching for much more beyond."

Of her motivation to capture the day she said "I was / am very enthused, encouraged and inspired by the experiment development, execution, and potential findings and this got my creative juices flowing. I particularly felt that we were / are part of something ground-breaking and history making; and as such, I wanted to document aspects of the essence of what happened. In this, it was important to me to capture something from the core feelings and thoughts of mothers who participated in the experiment. Why? So that then, now, and in the future, a snapshot of our breastfeeding voices and hearts will reflect how we felt about the contribution we were making."

She asked mothers to comment with 1 to 3 words that summed up their participation in the experiment.

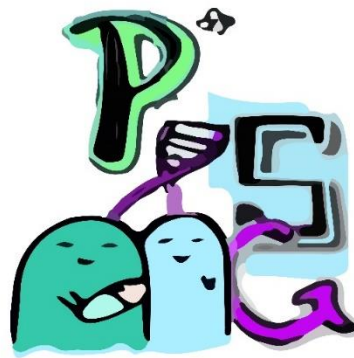
Another participant, Kayley Linares, a graphic designer, helped to create the feeding mother and child graphic. Members of the group then voted for the designs then commented to select their favourite designs (see Figure 42). The most frequently used words are larger than those used less often.

In-depth: Group posters from the Final Event Results Fair

In this section, you'll find the posters that each group created for the Final Event Results Fair. You can also listen to participants talking about the Fair in our podcast from the event: <http://parentingsciencegang.org.uk/events/psg-podcast-2-final-event-results-fair/>

PSG

Parenting Science Gang



- Working with existing parenting groups on Facebook
- Each group chose a research question
- Designed and ran their own experiment to find the answer
- In collaboration with scientists
- Eight groups
- Almost 3,000 members



Academic Collaborators

"This is an awesome data set. I have never seen in my career to date a data set like this. This is massive... brilliant... I don't know anyone in science who has this!"

Terry Dovey, Brunel University, London
Collaborating with Mealtime Hostage Parenting Science Gang group

"Almost single handedly you have opened up a new area of research"

Simon Cameron, Imperial College London
Collaborating with Breastfeeding Older Babies and Beyond and UK Breastfeeding and Parenting Support groups

"Loved it too, crazy but great way to spend an hour!"

Dr Sarah Rose, Staffordshire University, on doing an online Q & A with our volunteers

Participants

Information Sourcing

Before Joining

Google/internet / Social networks / Other parenting groups

After Joining

- Other PSG members
- Better access to more reliable information sources, look for more trustworthy information
- Better informed and pay more attention
- Trust themselves more to look for things
- Have got references for that?

Evaluating Information

Before Joining

'Instinctive'

After Joining

- Community knowledge pool/resources
- More likely to check information and listen to advice critically
- More likely to look harder for original source or find someone (in PSG) who has
- Training on how to look at journal articles



Picture 10 – PSG project poster

Breastfeeding Older Babies and Beyond PSG and UK Breastfeeding and Parenting Support PSG

Breastfeeding Older Babies and Beyond (Bobab) & UK Breastfeeding and Parenting Support (UKbaps)



#BreastMilkExperiment

3 words to describe the experiment day



Our older babies on our milk

"Mummy milk is my favourite thing; it tastes nice - I like drinking it. It tastes of carrots"
~3.5

"It's yummy. I love it. You drink it at bedtime."
Cerys, 5

"Mumma's pips can read if you are poorly and make milk to make it better."

Your blood has guard dogs (*antibodies*) that go around keeping you well, they look for baddies. But they will only get baddies that they know are baddies because they've already met them before. Your pips are like a computer and can find baddies that the baby's dogs don't recognise so if the baby hasn't got the right dogs the pips will make the right dogs to fight the new baddies the baby hasn't got."

~ Ruben, 6

"Mum, can I have some mummy milk so that it will remind me of you while I'm sleeping and so that I dream of you? Also so that there will be an invisible mummy walking in my room."
~ 4.5

"Milkie's are my best friend. They taste of love."
Aishah, 3

"You need something to eat so you can make my mumma milk for bed."
~ Cassius 3



Imperial College
London

Picture 11 – #breastmilkexperiment posters (1 of 3) by BOBAB & UKBAPS PSG



#BreastMilkExperiment

Why?

To analyse how the composition of breast milk changes as children get older

When?

21 February 2018

Who?

Parenting Science Gang (BOBAB and UKBAPS)
Dr Natalie Shenker, Hearts Milk Bank and Imperial College and Dr Simon Cameron, Imperial College

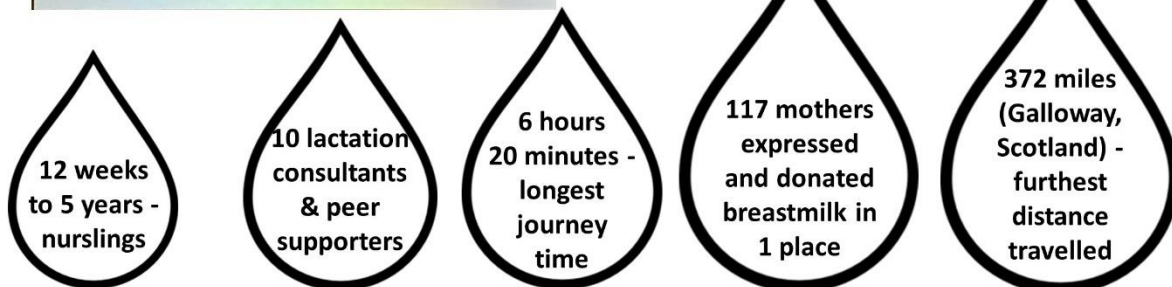
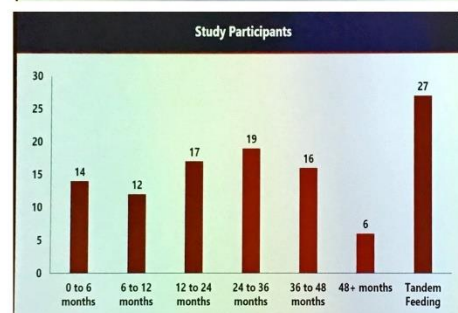
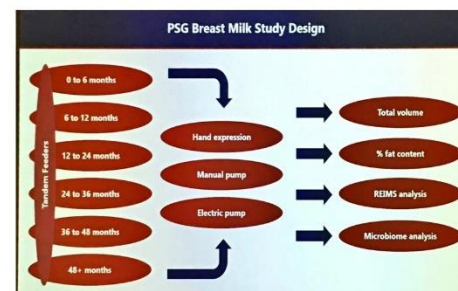
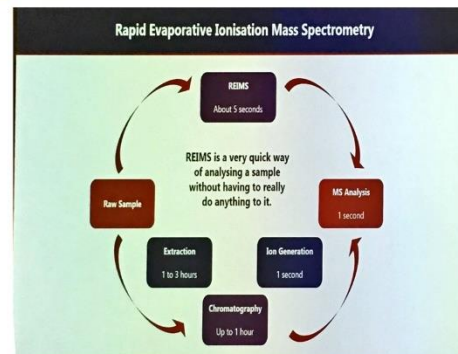
How?

Analysis of breast milk composition, including fat content and microorganisms, using the rapid evaporative ionization mass spectrometry (REIMS)

Preliminary Results

Take Home Message from Preliminary Results

- Nutritional content does not change over age of nursing
- Nutritional content does not change depending on expression method
- Volume of expression significantly changed by age of nursing and expression
- All storage methods have significant effect on chemical content of milk
- Storage at -20°C or -80°C preferred



Imperial College
London

Picture 12 - #breastmilkexperiment posters (2 of 3) by BOBAB & UKBAPS PSG

#BreastMilkExperiment



Imperial College
London

Picture 13 - #breastmilkexperiment posters (3 of 3) by BOBAB & UKBAPS PSG

One Layer, or Two? The effects of baby-wearing upon the skin and core temperature of a baby

THE PROBLEM

- Babies cannot regulate their own **core** temperature
- Babies in lots of clothes cannot sweat
- Babies can overheat, become sleepy, danger of SIDS
- Parents become hot during movement transferring additional heat to the baby
- Current information not clear

AUDIENCE

- Parents and guardians
- Care-givers
- Media and manufacturers
- Health care professionals (midwives, health visitors)
- Institute of Physics and Engineering in Medicine

EXPERIMENT



9 Mothers and babies
10 minutes playing
10 minutes carrying
10-15 minute stepping exercise (sub 70% HR)

RESULTS


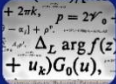
- Joy and Joe stretchy provided 3 layers of bamboo/cotton/elastane
- Temperature measured using skin electrodes and readings from the ear
- Mothers asked to rate temperature of baby subjectively
- **Small** increase in skin temperature with 2 layers
- Continued increase over course of the experiment
- Mothers **perception** tracked temperature
- **Little change in core temperature** (small drop with extra layer)

More details will be available after publishing embargo.

ACKNOWLEDGEMENTS



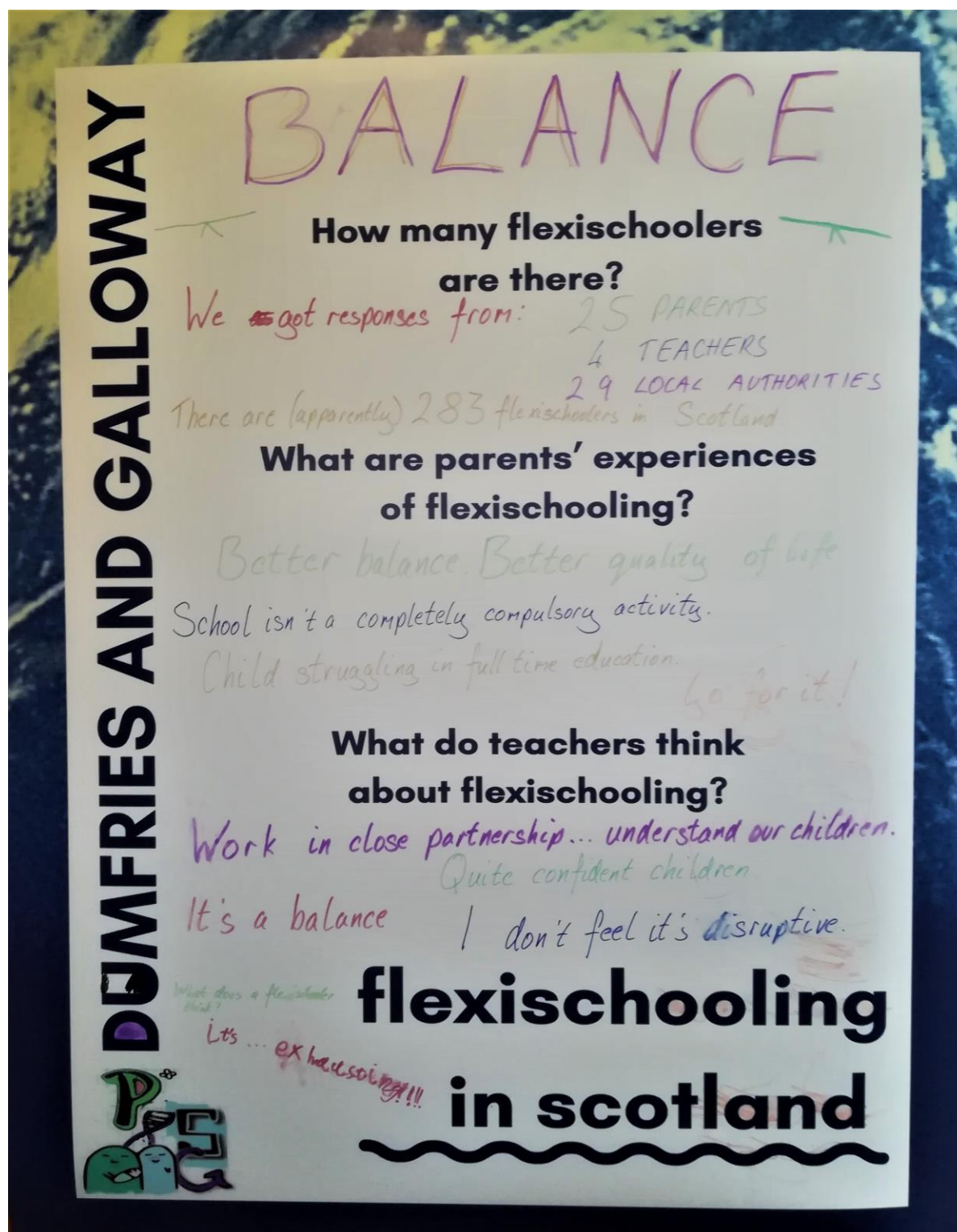
Dr Davide Filingeri
Environmental Physiology,
Loughborough University



Parenting Science Gang is funded by
Wellcome

Picture 14 – SANP PSG research poster

Dumfries & Galloway Bumps Babies & Beyond PSG



Picture 15 – DGBBB PSG research poster

Let Toys Be Toys PSG



Picture 16 - LTBT PSG research poster

Breastfeeding and Health Care Experiences PSG

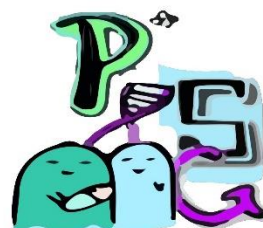
Parenting Science Gang
Breastfeeding and Healthcare Experiences

Breastfeeding and Healthcare Experiences - What have we been up to?

Introduction and Background

The Breastfeeding and Healthcare Experiences Parenting Science Gang has 400+ members. About half of the group are breastfeeding mothers from a wide variety of backgrounds and about half are healthcare or breastfeeding professionals (also breastfeeding mothers themselves)

Our group has designed not one, but two (!) social science studies. The group was started to explore the advice that breastfeeding mums encounter from their healthcare providers and reflects the members own experiences in breastfeeding facebook support groups.



What have we learned so far?

That our healthcare providers have little to no breastfeeding training! See World Breastfeeding Trends chart on separate poster. That mothers' experiences are a rich source of data. We hope we can use our experiences to help other professionals better support breastfeeding mothers.

Study 1: Healthcare Practitioners' Own Breastfeeding Experiences

Research Question

How does the experience of breastfeeding affect healthcare practitioners professional practice?

Collaborator

Dr Yan-Shing Chang, King's College London

Method

Semi-structured peer-to-peer interviews, ie healthcare practitioners interviewing other healthcare practitioners

Analysis

Thematic analysis, an analyst-focused method of looking across a qualitative dataset for shared 'stories'

Stage

Interviews are underway. See box below for an interview excerpt*.

Study 2: Breastfeeding Mothers' Healthcare Experiences

Research Question

How do breastfeeding mothers characterise the infant feeding advice and treatment they've received from their healthcare providers?

Collaborator

Dr Gavin Brookes, Lancaster University

Method

Electronic survey with a free-text box for their healthcare experiences followed by quantitative questions

Analysis

Corpus linguistics, a computer-assisted method of analysing word patterns in large quantities of text

Stage

Ethical approval has recently been granted, recruitment will start soon, **you can help!**

Interview Excerpt from Study 1*

Has your breastfeeding changed the way you approach breastfeeding mothers in a professional context?

A&E Nurse: "With CT scans, I've had a couple of mums who've had CT scans and then suddenly, after the CT scan, someone has said, 'Oh, by the way, the baby that you've got with you, you can't feed now.' And they've suddenly gone 'what?' And I'm like, nope, stop right there, it's fine, it's fine."

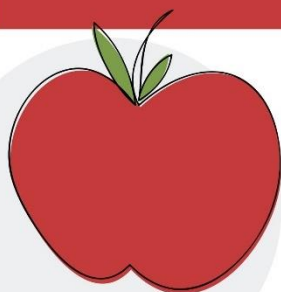
A&E Nurse: "Admitting patients to wards when I was in A&E I was very, very fierce with the bed managers about this patient being admitted with a four-month old baby. And I was like, 'She will be admitted with this child, it's never taken a bottle before, it's an emergency admission, you cannot leave this child without its mother. You find her somewhere.'"

*all excerpts used with permission

Picture 17 – BF HCE PSG research poster

MEALTIME HOSTAGE PSG

Avoidant/Restrictive Food Intake Disorder



WE ARE PARENTS OF EXTREME PICKY EATERS INCLUDING DIAGNOSES OF ARFID

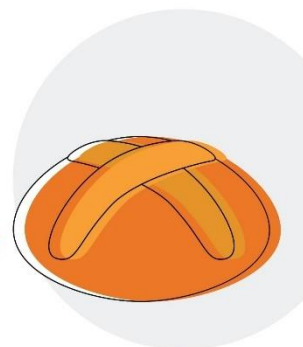
Many of our research ideas were too complex and too far ahead of current knowledge! We decided to focus on getting exploratory data. We devised a questionnaire to investigate children's eating, sensory sensitivities and anxious behaviours.

WE GATHERED 670 COMPLETED QUESTIONNAIRES OVER 3 WEEKS

Of these 42 were about children with diagnosed ARFID, and 158 with eating issues. We don't know of any researchers with this scale of data relating to diagnosed ARFID cases and patterns in picky eaters.

Dr Terry Dovey says *"You guys have a great data set. It's very, very good. Best one I have seen in a very long time. Better than my PhD students', but don't tell them."*

We are cleaning the data, ready for Prof Jackie Blissett and Dr Terry Dovey to analyse. Meanwhile we are putting together a long list of questions to ask of the data.



WE HAVE ALREADY FOUND THAT:

- Children with ARFID tend to have reported sensitivities with lights, tactile textures and food, but not with water or loud noises. Sensory issues seem to be specific rather than general.
- Children with ARFID don't tend to have reported issues with socialising. When they do it is usually comorbid with Autistic Spectrum Disorder (ASD)
- Our data includes a large sample of children who suffer from reflux. There is a lack of recent studies that examine the link between reflux and picky eating, so this has great potential!

WE HAVE FOUR POTENTIALLY PUBLISHABLE PAPERS!

1. Comparing the characteristics of children with ARFID to the picky eaters (ie less severe issues) and the typically developing children.
2. Looking at the differences and similarities between children with ARFID, ASD and other neurodevelopmental conditions.
3. What does this data tell us about the link between reflux and ARFID/picky eating?
4. Comparing the data acquired from the two different validated measures; Child Eating Behaviour Questionnaire and Behavioural Paediatrics Feeding Assessment Scale.



With loads of thanks to Dr Terry Dovey (Brunel) and Prof Jackie Blissett (Aston) without whom this research could not have happened

Picture 18 – MH PSG research poster

Big Birthas Parenting Science Gang

"I was told it was a consultant led birth but not what that meant."

"I had to be very stubborn and refuse [to be monitored.] to be free and mobile."

"I refused so many scans, appointments etc because I felt it contributed greatly to my antenatal depression."

"I was going to end up with a C section, that was it, they had chosen."

"when I was weighed and measured, the midwife changed completely"

"They all said that I'd have a big baby - over 9lb. she was 7lb 6."

"midwife told me I was being silly"

"I wanted a water birth and was told no because I was too fat."

"I felt I had no choice"

"I was lectured about my weight"

"I wasn't treated with respect or like the educated individual that I am."

"Yes I am overweight but they don't consider the wider picture."

"the focus was on how unhealthy I MUST be, just really negative. No support, no guidance, just critical finger pointing."

"It made me really angry."

"They were more concerned with measuring my physical attributes than managing my mental health."



Picture 19 – BB PSG research poster

PSG thinks about screentime

Picture 20 shows the two posters created for PSG thinks about screentime. As they are hard to read when reduced in size, the text is provided below.

What constitutes screentime?

- Watching/streaming
- Gaming
- Computers
- Smartphones

Concerns:

- Past – effects of violent video games on aggressive behaviour
- Current – overall use of “screens” and possible effects of use or over-use on behaviour

The BIG question?

Q. What are parents interested in knowing and what are their concerns?

A. The general consensus was to debunk myths rather than provide a policy or guidelines

Ethics:

- Not possible to test aggression in relation to screen use

Observations:

- Gender & uses
 - Boys were reported as more likely to play on consoles e.g. Xbox/Playstation
 - Girls tend to use smartphones and social media e.g. Facebook
- A high number of teenagers use screentime through these platforms for emotional support from friends made online developing supportive social networks

Positives:

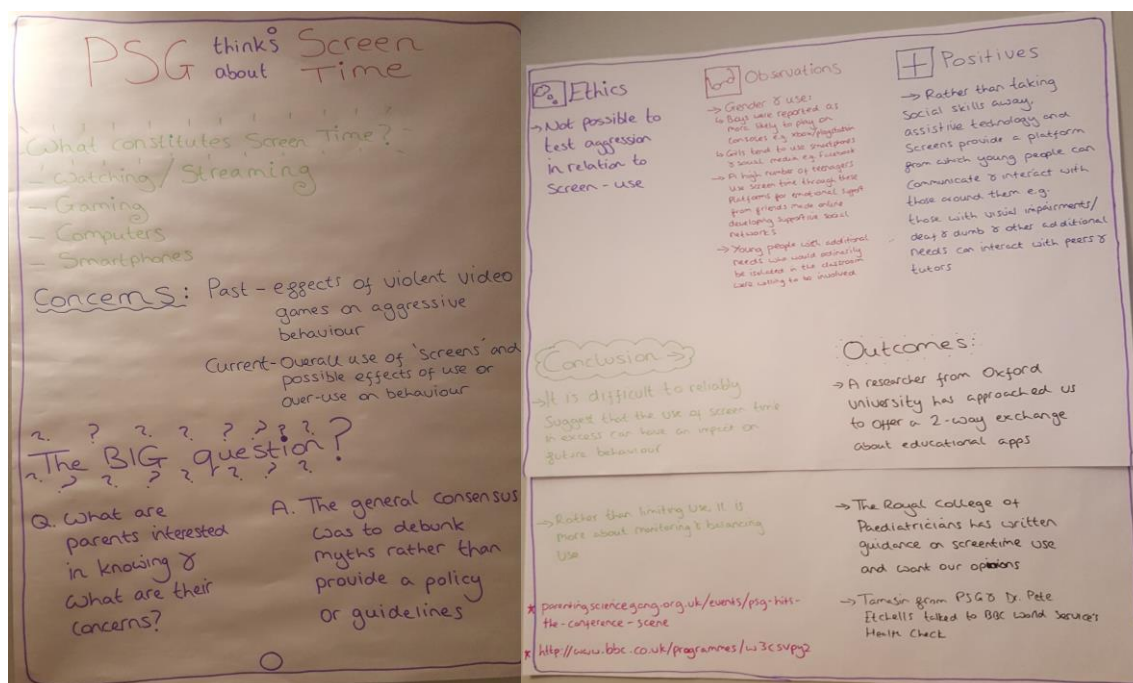
- Rather than taking social skills away, assistive technology and screens provide a platform from which young people can communicate and interact with those around them e.g. those with visual impairments, deaf and dumb and other additional needs can interact with peers / tutors

Conclusions:

- It is difficult to reliably suggest that the use of screen time in excess can have an impact on future behaviour.
- Rather than limiting use, it is more about monitoring and balancing use.

Outcomes:

- A researcher from Oxford University has approached us to offer a 2-way exchange about educational apps
- The Royal College of Paediatricians has written guidance on screentime use and wants our opinions
- Tamasin from PSG and Dr Pete Etchells talked to BBC World Service's Health Check.



Picture 20 – PSG thinks about screentime poster

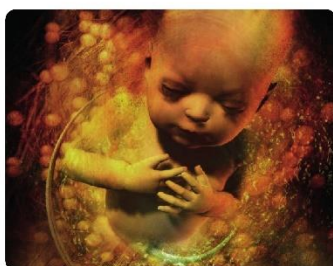
Baby Biome



Parents, science and baby poo: researchers and citizen scientists working together to shape a birth cohort study proposal

Truly meaningful user involvement in research starts early, before the project details are finalised. We brought together researchers and citizen scientists in a two-week temporary Facebook group in order to inform a proposal for the next UK birth cohort study.

- Our citizen scientists came from Parenting Science Gang, a Wellcome Trust-funded citizen science project which supports parents to identify relevant research questions and investigate them. It is run via Facebook groups, plus a blog and yearly face-to-face events.
- Our researchers came from the Baby Biome Study group which is developing a proposal for a large-scale UK birth cohort study. Baby Biome aims to investigate the impact of mode of birth, and antibiotics given in pregnancy or labour, on the acquisition of bacteria in a baby's gut and the implications of this for childhood conditions such as asthma and obesity.



Our goals

To get a sense of how interested parents were likely to be in the Baby Biome study, and also how likely they were to sign up their babies to take part.

To gather suggestions from PSG members on how to improve communications to parents about the study.

What we did

PSG facilitators set up the Facebook group and advertised it to their existing groups. We also advertised it via the regular monthly mailing to NCT volunteers and practitioners. Some 328 people signed up to take part.

We funded five places for PSG members and facilitators to attend a conference on the UK cohort studies, run by the Centre for Longitudinal Studies at UCL.

The facilitators established the conversation and group relationship by sharing information about the gut microbiome (the communities of bacteria that inhabit the gut) and cohort studies, and asking questions of the participants. We also scheduled three evening slots where Baby Biome's principal investigators, Prof Peter Brocklehurst and Dr Nigel Field, were available to ask and answer questions about the microbiome and study methodology. These chats were written up and feature on the Parenting Science Gang blog: www.parentingsciencegang.org.uk/blog

At the end of the two-week period we opened an evaluation survey for participants. Fifty one people (15.6%) responded. We also conducted semi-structured interviews with the PSG facilitators and the Baby Biome researchers.

What we learned

The importance of building local networks and knowledge into our study.

The range of information we will need on the website to meet different parents' needs and interests.

The types of information parents are likely to find helpful at different stages, such as information for women on how to poo comfortably after giving birth.

About using hospital TV to reach parents during pregnancy.

That parents have many, many questions about health conditions which could be linked to the microbiome!

We need to have a really good think about how (if) we can collect data on birth in water, home birth and maternal request caesareans.

Dr Nigel Field: "At the end of the first live session I thought, '***', that was incredible!"

"I was terribly nervous before each live session but I really rather enjoyed it. It was good being challenged, having those questions and having to justify your thinking"

Prof Peter Brocklehurst

What it was like for PSG members

More than half of the people who responded to our evaluation survey had shared information they learned in the group with friends.

"Was really nice to feel listened to when we brought up different questions about the research approach."

"I love the combination of science and real world, real families concerns!"

"It didn't assume previous knowledge but treated us as intelligent people."

"Different viewpoints and thoughts really made me think about my own family's microbiology and whether we were doing anything harmful to it, or could help it."

"The scientists had come to us."

"I thought the scientists wanted their thoughts and procedures simply confirmed, but it turned out there were a lot of things they hadn't thought of that we the non-scientists suggested."

Many of those who responded said they would have liked the group to run for longer, or to set up a separate PSG group about the microbiome.

Next steps

In October we submitted an outline application to the Medical Research Council cohort strategic review group. If this is accepted, we will produce a full application for our three potential funders: the Medical Research Council, the Wellcome Trust and the Biotechnology and Biological Sciences Research Council.

Our proposal includes a programme of parent and public involvement (PPI) activities. We want to run a citizen science project alongside the academic science to study aspects of baby poo. We will invite all the parents recruited to the study to join in, as well as other interested parents. We also plan to set up four groups around the UK where parent representatives can work with researchers to guide the Baby Biome project.

We hope to have the go-ahead to begin the study in 2019.



www.nct.org.uk



Picture 21 – Baby Biome poster created by Rachel Plachcinski of NCT based on the 2 week mini project with PSG

Coverage and Dissemination

Over the course of the project, we have

- *appeared at 19 events / conferences*
- *published 4 print articles*
- *appeared or been mentioned on national radio 4 times, and*
- *featured in 5 online blogs (with many more links).*

Our members continue to attend conferences now that the project has finished to disseminate their results.

Events

British Pregnancy Advisory Service

September 2017

“Pregnancy science, risk and communication” workshop and roundtable

Sophia Collins

UNICEF Baby Friendly Initiative Conference, Glasgow

22 November 2017

Presentation

Dr Natalie Shenker

Screen Time Meeting, Wellcome Collection

16 January 2018

Presentation and panellists

Tamasin Greenough Graham, Luna Lyall ([UKBAPS](#), [LTBT](#))

Knowledge Quarter Conference, British Museum

12 February 2018

Panel discussion

Sophia Collins

Forest Hill / Sydenham family festival

24 February 2018

Panel discussion on how parents can best assess evidence

Dr Alice Jones Bartoli ([SANP](#)) and Gabrielle Nwaordu ([BOBAB](#))

NCCPE Social Innovation Skill Share

31 May 2018

Tamasin Greenough Graham

Metabolomics 2018, Seattle, USA

June 2018

Presentation

Dr Simon Cameron

Breastival Belfast, Belfast Museum

4 August 2018

“Parenting Science Gang: What’s in Your Toddler’s Milk?” <http://breastivalbelfast.co.uk/psg-toddler-milk>

Sophia Collins

Midlands Baby Carrying Convention

12 October 2018

Presentation

Claire Lucas, Anne Crook and El Malloy (all SANP)

Engage 2018, Edinburgh

13 – 14 November 2018

Poster presented

Sophia Collins and Tamasin Greenough Graham

Imperial College Science Communication Unit Silver Jubilee Event

27 September 2018

Keynote speech (audience of science communication professionals and allied professions)

Sophia Collins

International Conference on the Physiology and Pharmacology of Temperature Regulation

10 October 2018

Presentation “Thermoregulatory responses to babywearing in babies under 12 months old”

Dr Davide Filingeri

Northern Ireland Science Festival, Belfast

16 February 2019

‘Science of breastfeeding’ day, hosted by Breastival. Ticketed, general popular science audience.

Sophia Collins

The International Conference on Children’s Eating Behaviour

22 – 22 March 2019

Poster presented

Prof Jackie Blissett and Dr Terry Dovey

IPEM Meeting of the Physiological Measurements group

23 March 2019

SANP research presentation

Dr Davide Filingeri, Tamasin Greenough Graham and Amy Wilkins (SANP)

European Science Association Doing It Together Science (DITOs) project final event, Brussels.

3 April 2019

Stall at ‘market place’.

Sophia Collins

The British Feeding and Drinking Group Annual Meeting 2019

16 – 17 April 2019

Poster presented

Prof Jackie Blissett and Dr Terry Dovey

Association for Academic Outreach (AFAO), Warwick University.

27 April 2019

Presentation “Parents in Control – the Extreme Citizen Science of Parenting Science Gang”

Tamasin Greenough Graham, Claire Lucas (SANP, LTBT), Sophia Payne-Gifford ([BF HCE](#))

Institute of Health Visiting Conference, Manchester

9 May 2019

Presentation “Power to the Parents - Co-producing science research with parents”

Sophia Collins

Stall representing BF HCE, BOBAB/UKBAPS, SANP and [MH](#) research

Kate Raine, Rachel Walker, Alex Duxbury and Samantha Thompson

Primary Care and Public Health Conference, Birmingham.

15 – 16 May 2019

Stand representing [BB](#), BOBAB/UKBAPS and BF HCE research

Amber Marshall, Serena Gilzean-Hughes, Mawgen Baber, Danielle Jayne Phillipson and Eleanor Molloy

Forthcoming events

All-Party Parliamentary Group on Infant Feeding

July 2019

Presentation of BOBAB/UKBAPS and BF HCE research results

Volunteers from BOBAB, UKBAPS and BF HCE

Science in Public, Manchester

10 July 2019

Panel discussion “Power to the parents – research driven by societal need using user-led citizen science”

Sophia Collins, Dr Davide Filingeri (Loughborough University), Amber Marshall (BB), Katie Bebb (MH)

Scottish Educational Research Association Conference, Edinburgh

20 – 22 November 2019

Abstract submitted

Sophia Collins and 2 volunteers ([DGBBB](#))

UNICEF Baby Friendly Initiative Conference, Glasgow

28-29 November 2019

Poster submitted

Volunteers from BOBAB, UKBAPS and BF HCE

Engage 2019, Bristol

4 December 2019

Presentation submitted
Sophia Collins

In print

The Microbiologist (magazine for the Society for Applied Microbiology).

Sept 2018, vol 19 no 3.

Special themed edition on pregnancy, birth and infancy. 1,500 article by SC about [NSG](#) and [PSG](#).

Science Magazine (American Association for the Advancement of Science).

Feb 2018

U.K. moms are turning parenting into an experiment. Tania Rabesandratana

(<https://www.sciencemag.org/news/2018/02/uk-moms-are-turning-parenting-experiment>)

Annandale Herald & Moffat News

Thursday, October 12, 2017

Could part time schooling for children be the way forward? Fiona Reid.

Doing It Together Science (DITOs)

Featured as one of the examples in the 'DITOs' (<http://www.togetherscience.eu/>) report on business models in citizen science, part of their outputs from this EU-wide project.

Radio

BBC World Service, Health Check

17 January 2018

Kids' Screen Time: What Are the Risks?

(Clip: <http://www.bbc.co.uk/programmes/p05v9q3r>; Whole programme:

<http://www.bbc.co.uk/programmes/w3csvpy2>)

BBC Radio 2, Jeremy Vine show "Milk and Cakes"

11 October 2018

PSG mentioned by Dr Natalie Shenker and Dr Amy Brown during a piece on the magic and science of breastmilk.

BBC Five 5, Breakfast

14 December 2018

Phone in: Liz Blackshaw (member of SANP) talks about PSG with host, Nicky Campbell.

BBC Radio Scotland, Mornings with Kaye Adams

21 March 2019

Sophia Collins and Demi Powell (member of [DGBBB](#)) talk about PSG [flexischooling](#) research.

Online

Goldsmiths College Department of Psychology blog, article about first residential event

20 July 2017

<https://goldsmithspsychologyblog.wordpress.com/2017/07/20/parenting-science-gang-citizen-science-takes-to-the-hills/>

Project of the Week for DITOs blog

7 December 2017

<https://www.togetherscience.eu/blog/project-of-the-week-15-parenting-science-gang>

Frontline Genomics, article about breastmilk experiment

15 February 2018

<http://www.frontlinegenomics.com/news/19552/project-bring-science-new-mothers/>

Imperial College podcast about the breastmilk experiment

<https://wwwf.imperial.ac.uk/imedia/content/view/6119/the-parenting-science-gang/>

University of Staffordshire report of TV and Creativity Q&A

6 July 2017

<http://blogs.staffs.ac.uk/inpsych/2017/07/06/dr-sarah-rose-featured-in-a-ga-with-the-parenting-science-gang-on-childrens-tv-viewing-and-creativity/>

Forthcoming

Case study as example of including new audiences, ASDC call for Phase 4 Explore your Universe

<https://www.sciencecentres.org.uk/projects/explore-your-universe/>

Foreign language articles

Wie wäscht man Windeln?

Translation: *How do you wash nappies?* Neue Zürcher Zeitung

5th March 2018

Article on PSG breast milk experiment day and pilot project Nappy Science Gang.

<https://www.nzz.ch/wissenschaft/windeln-mit-exoskelett-ld.1358718>

No cal ser Einstein ni Marie Curie

Translation: *You do not have to be Einstein or Marie Curie.* Gemma Marfany

17 February 2018.

Article including PSG breast milk experiment day and pilot project Nappy Science Gang.

https://www.elnacional.cat/ca/opinio/gemma-marfany-einstein-marie-curie_239946_102.html

Links to PSG

Steven Hill Blog

15th December 2018

Open science and public engagement

Link anchor text: “Examples that truly bring citizens into the shaping of research questions are much rarer. That’s not to say projects that do this don’t exist, with the Parenting Science Gang being an excellent example, but citizen science is often framed from as a narrower activity.”

<http://stevenhill.org.uk/open-science-public-engagement/>

Jisc scholarly communications

19th December 2018

Public engagement and open science. Neil Jacobs

Link anchor text: “Less obviously political, but another example of activist citizen science is the [parenting science gang](#), supported by Wellcome”

<https://scholarlycommunications.jiscinvolve.org/wp/2018/12/19/public-engagement-and-open-science/>

The Psychologist (The British Psychological Society monthly publication)

March 2018, Vol. 31

Seeing screen time differently. Joe Sutton

Link anchor text: “What do parents want from us as psychologists? Tamasin Greenough Graham represented the Parenting Science Gang, 2000 parents united by a desire to have scientific evidence to drive parenting... “

<https://thepsychologist.bps.org.uk/seeing-screen-time-differently>

Healthline (US Health website)

31 May 2018

Parents May Mistake Picky Eating for a More Serious Eating Disorder

Link anchor text: “those who have dealt with [ARFID](#) are passionate about raising awareness. So, details of this disorder are starting to find their way into various mommy blogs, online publications, and treatment center pages.”

<https://www.healthline.com/health-news/parents-may-mistake-picky-eating-for-a-more-serious-eating-disorder#1>

Mumsnet (UK parenting forum)

15 November 2017

Part time homeschooling - is it allowed?

Link anchor text: “Parenting Science Gang had a Q&A about flexischooling the other week - some useful info here”

<https://www.mumsnet.com/Talk/primary/3087969-Part-time-homeschooling-is-it-allowed?messages=100&pg=1>

Foreign language links

Wissenschafts Kommunikation

26 April 2018

<https://www.wissenschaftskommunikation.de/panoptikum-18-09-communicatorpreis-aquarien-flamechallenge-15119/>

Other impact

PSG used as a teaching example, on:

- Imperial College, London, Science Communication MSc.
- Exeter University, “Public Environmental Politics” course (undergrad) and “Knowledge Exchange” (Masters)
- University College London, Science and Technology Studies B.Sc.
- Edinburgh University, Science Communication and Public Engagement MSc.

PSG approached by a parent in Aberdeenshire who’d found our flexischooling research online. The council due to debate allowing flexischooling and the introducing councillor wanted ‘as much evidence as possible’. Of course, there’s almost no evidence, except for our research so we sent her a copy of our report.

Glossary of Abbreviations and Terms

AA	Accompanying adult - another adult (partner, family member or friend), brought by the PSG member to events, to supervise their children during the activities and throughout the event, when they were engaged in workshops and other PSG business.
ALSPAC	Avon Longitudinal Study of Parents and Children (http://www.bristol.ac.uk/alspac/)
APPG	All-Party Parliamentary Group
ARFID	Avoidant/Restrictive Food Intake Disorder
BB	Big Births
BF HCE	Breastfeeding and Health Care Experiences
BMI	Body Mass Index – calculated by dividing weight in kilograms by the square of height in metres
BOBAB	Breastfeeding Older Babies and Beyond
CS	Citizen Science – scientific research conducted, at least in part, by nonprofessional scientists.
DGBBB	Dumfries and Galloway Bumps Babies and Beyond
DOR	Division of Responsibility method, see https://www.ellynsatterinstitute.org/wp-content/uploads/2016/11/handout-dor-tasks-cap-2016.pdf
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5 th Edition – definition and classification of mental disorders. See https://www.psychiatry.org/psychiatrists/practice/dsm
Extreme Citizen Science	Enabling communities / groups to identify and solve their own problems or conduct their own research in an area that interests them. See https://www.geog.ucl.ac.uk/research/research-centres/excites .
FB	Facebook
Flexischooling	Part-time school and part-time home educating.
GASC	Gender-Stereotyped Attitudes Scale – see http://www.personal.psu.edu/sdq/articles/gasc.html
HCP(s)	Health care professional(s)
La Leche League	A non-profit organisation for breastfeeding advocacy, education, training and support (https://www.laleche.org.uk/)
LTBT	Let Toys Be Toys
MH	Mealtime Hostage
NCT	National Childbirth Trust (www.nct.org.uk/)
NSG	Nappy Science Gang (nappysciencegang.wordpress.com)
PSG	Parenting Science Gang (parentingsciencegang.org.uk)
REIMS	Rapid Evaporative Ionization Mass Spectrometry, see http://parentingsciencegang.org.uk/experiments/introduction-to-mass-spectrometry-reims-a-qa-with-dr-simon-cameron/
SANP	Science-Aware Natural Parenting
Science Capital	Science capital refers to science-related qualifications, understanding, knowledge (about science and 'how it works'), interest and social contacts (e.g. knowing someone who works in a science-related job). See https://www.kcl.ac.uk/ecs/research/research-centres/cppr/research/currentpro/enterprising-science/01science-capital and https://www.youtube.com/watch?v=A0t70bwPD6Y
TICKS	Acronym for rules for safe babywearing – see babyslingsafety.co.uk
UKBAPS	UK Breastfeeding and Parenting Support