‘A lifeline when no one else wants to give you an answer’

An evaluation of the Breastfeeding Network drugs in breastmilk service.

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The Breastfeeding Network provides independent, evidence-based information and support on infant feeding to women, parents and families. We offer support through a peer model and have over 600 trained peers across England, Scotland and Wales. A key aim is to share the evidence in infant feeding with the families we support. Our support services reach women both antenatally and after birth and many of the women we support go on and train with the charity to support others in their community. We provide the National Breastfeeding Helpline in partnership with the Association of Breastfeeding Mothers, which is funded by Public Health England and Scottish Government. Since 2008 the charity has also provided a Drugs in Breastmilk service led by Dr Wendy Jones MBE. We also work very closely with national partners including UNICEF, Baby Friendly and other charitable organisations and universities. The Breastfeeding Network is a Registered Charity No SC027007. For more details visit www.breastfeedingnetwork.org.uk

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1. Executive summary

1.1. Introduction

The Breastfeeding Network commissioned Swansea University in July 2018 to undertake an evaluation of their Drugs in Breastmilk service. This service provides information to parents, professionals and supporters about the level of risk from taking medications or having medical procedures whilst breastfeeding. The service includes a series of Factsheets about different medications on the Breastfeeding Network website, and a one to one contact service with a specialist pharmacist over email and Facebook for specific requests. At present the service is funded from the Breastfeeding Network's reserves for a period of 3 years supported by direct fund-raising appeals.

The evaluation sought to explore who is using the service, why they are accessing it, what information they are receiving and their views of the service. It also explored the impact the service upon maternal wellbeing, professional practice and decisions to continue breastfeeding.

1.2 Context

Breastfeeding rates in the UK are amongst the lowest in the world[1]. The reasons for this are complex, including multiple physiological, social, and cultural factors[2]. Many women who stop breastfeeding in the first weeks are not ready to do so, impacting on population health, the economy and maternal wellbeing[3]. Breastfeeding is important to women[4], yet often due to a lack of funding and investment, they cannot get the accurate and sufficient professional support they need[5].

One area where women often struggle to find the information they need is when it comes to being prescribed a medication or needing a medical procedure whilst they are breastfeeding their baby[6]. This is a common concern as many women are prescribed a medication, need to have a medical procedure or simply wish to take an over the counter remedy when breastfeeding[7]. However, despite the majority of medications being safe to take during

breastfeeding[8], women often report that they receive conflicting, inaccurate, or simply no advice to help them make an informed choice[9]. This is particularly stark when it comes to General Practitioner (GP) or pharmacist guidance, compounded by little formal training or updates on breastfeeding, breast milk and the breast in curriculums[10].

In 2007 in response to this need the Breastfeeding Network set up the Drugs in breastmilk information service[11]. Anecdotally, and from previous published small-scale evaluation with users of the service (n = 101)[12], the service is highly valued by those who use it. The aim of this current evaluation was to expand that evaluation, exploring who is using the service and how, reasons for use, and how the service impacts upon maternal wellbeing, professional practice, and decisions to continue breastfeeding.

1.3 Methodology

The methodology for the evaluation consisted of:

- An interview with Dr Wendy Jones who leads the service
- Interviews with 16 leads of Breastfeeding organisations or key individuals responsible for breastfeeding in their role, all based in the UK. For simplicity, these individuals are referred to as 'leads' throughout the document.
- A survey of 227 mothers, professionals and mother supporters' views of the factsheets
- A survey of 339 mothers, professionals and mother supporters' views of the contact service
- Three case study stories of mothers who used the service

1.4 Key findings

The service was held in high esteem by organisation leads, mothers, health professionals, and mother supporters. It was used by a wide variety of individuals, for a wide variety of reasons; most common usage included information regarding antibiotics, antidepressants, antihistamines, anaesthetics and surgical procedures. Most common queries for the factsheets tended to be for milder illnesses or enquiries such as cold remedies and decongestants, while

those accessing the one to one contact tended to often be for more complex cases, suggesting each arm of the service is meeting a different kind of need.

Specific highlights included:

Service delivery:

- The service was evaluated as efficient, accurate and trustworthy. It was viewed as highly evidence based and a professional source of information.

- All groups highlighted that the information was something that could not be found at the same level of accuracy elsewhere. Without the service mothers would go without this information – there would be no alternate acceptable source to pick up the slack.

- Linked to the previous point, it was clear that mothers who contacted the service were not always receiving sufficient or accurate advice from those who prescribed the medication. Women who contacted the service had frequently been told that the medication they were prescribed was unsafe to take when breastfeeding or received insufficient information to make an informed choice.

- Leads recommended the service to mothers and professionals, often referring to it in official policy and documentation as an area of good practice.

- The factsheets were highly valued as a quick and easy to use source of information available within a few clicks, around the clock. Factsheets were typically used for more day to day illnesses and remedies, and around 60% of participants found all the information they needed from them. The remainder went on to contact the one to one service with further questions, typically for more complex or multiple medications or illnesses.

- All groups valued being able to contact the service to check the information or ask specific personal questions. Speaking to a 'real life person' was reassuring, calming and supportive at a difficult time.

Impact on mothers

- All groups felt that the service enabled mothers to breastfeed for longer. It gave them the accurate knowledge, reassurance and confidence they needed to continue.
- Accurate information was important, but the right support at a difficult time from someone who listened and cared was also important to mothers. Many described the service as a lifeline after feeling listened to for the first time.
- When looking at mother's emotions and wellbeing before and after contacting the service, a highly significant improvement was seen across all aspects including feeling more confident, reassured, supported and listened to.
- Before contacting the service, mothers were frequently told by a GP that they could not continue to breastfeed when this was not the case or were given insufficient or confusing information that did not allow them to make an informed choice. Many of the mothers who continued to breastfeed expressed that they were doing so directly because of the service.
- If mothers had not received this information, many would not take their prescribed medication, rather than stop breastfeeding. GPs often assumed mothers would stop breastfeeding, but in reality, some valued breastfeeding so strongly that they would put their own health at risk in order to continue doing so.
- Being able to continue breastfeeding was protective for maternal mental health. Many mothers described the service as a lifeline.
- Amongst mothers who could not continue breastfeeding, evaluation of the service was also positive. Mothers grieved their breastfeeding relationship but were grateful to the service for its information. These mothers also saw rises in their wellbeing after using the service, predominantly as a consequence of feeling listened to and receiving accurate information.

Kate's story

I gave birth to my second child in November. I had breastfed his older brother for eighteen months and was looking forward to breastfeeding again. Breastfeeding was going well but I was not coping with looking after two children. Things were difficult with my partner and he was facing possible redundancy at work. We were all very stressed and he was working even harder than usual, and I was left to look after the boys on my own.

After a talk with my health visitor she gently suggested I had postnatal depression. She reassured me that I could go to the GP for some help and it would still be ok to breastfeed. My usual understanding GP was busy though and I ended up seeing a locum. He said that I must take antidepressants for the sake of my children but that they would not be safe to take while breastfeeding. When I queried this and said how important it was to me to continue breastfeeding, he said that it didn't matter now, I'd fed them for the first weeks which was most important and to get my husband to do some night feeds instead.

I was distraught as I believed I must take the antidepressants and wanted to feel better but didn't want to stop breastfeeding. My health visitor suggested that I contact Wendy. She was beyond amazing and told me the ones I had been prescribed were safe to take and told me to look at one of the info sheets on the website. I cannot describe the relief I felt. She was so kind to me at a time when I really was feeling at rock bottom. I took the antidepressants and started to feel better. My husband kept his job after all and we are all doing better. I am still breastfeeding and loving it.

I don't know what I would have done without Wendy and looking back it really scares me. I think I would not have taken the antidepressants and it worries me what I might have felt like or even what I might have done. Wendy is a lifeline and I can never ever thank her enough.

Impact on professional practice

- Health professionals believed that the service enabled them to provide more accurate, trusted and up to date information to mothers. This was information they often did not have in training or updates from other sources.
- Professionals believed it enabled them to be better practitioners when it came to giving advice on breastfeeding and medications.
- Professionals often shared the information that they found not only with mothers but other colleagues too.

Impact on mother supporters

- Friends, family and colleagues all expressed relief at being able to find information for a mother they cared about.
- The service enabled supporters to feel empowered in giving her the support she needed to continue breastfeeding.

Ideas for improvement

In terms of improvement, seven key elements emerged across the groups. The **absolute priority** raised by all groups was to increase funding for the service. Only with this funding would further improvements be possible. All suggestions were positive, involving additional improvements to expand the service, rather than criticism of elements that needed to change.

With further funding core ideas included:

1. Train more specialist staff to enable a wider reach. This must include succession planning.
2. Once funding and staff are in place, increase the visibility of the service. Posters in pharmacies, GP waiting rooms and places where mothers often meet such as libraries and children's centres were suggested.

3. Ensure information about the service reaches GPs and pharmacists both to support their own knowledge and to signpost mothers to the service for further information.
4. Offer further options for contact such as text, facetime, and a webpage with webchat
5. Consider whether offering different languages is viable, at least for the factsheets
6. Have a search function online for the factsheets.
7. Produce simplified versions of the factsheets, or a summary heading, for those who want a quick response or have literacy or language barriers.

1.5 Key Conclusions

The gap in service, that was identified in 2007, remains. BfN continues to fill this gap by providing a service to mothers seeking advice around breastfeeding and medications.

The service is highly valued by breastfeeding organisations, mothers, professionals, and mother supporters as giving accurate, reassuring, evidence-based information. It enables mothers to make an informed choice about continuing to breastfeed, and also look after their own health and that of their baby, as if forced to choose many women would prioritise their baby and breastfeeding rather than take prescribed medication. As well as protecting physical health, the service has an invaluable impact on maternal wellbeing.

In its present format the service is not sustainable. Further long-term funding is necessary to secure and expand the service so that more mothers can benefit.

2. Background

Breastfeeding is a topic of public health concern. Evidence reviews have indicated poorer health outcomes associated with formula feeding compared to breastfeeding across a broad spectrum of outcomes in high income country settings[1, 13, 14]. Despite policy level concern, by international standards UK breastfeeding rates are low. Survey data suggests that around four in five UK women breastfeed their babies *at least once*. However, over half of babies have received formula by the end of their first week, with a rapid tail off in breastfeeding in the early days and weeks[3].

2.1 Understanding breastfeeding in the UK

These patterns are not simply through maternal choice. Overwhelmingly UK mothers stop breastfeeding before they planned to, leading to high levels of breastfeeding 'disappointment'[15], with mothers experiencing a range of emotions including sadness, guilt, and anger, and even postnatal depression[16]. Alongside this, it is common for mothers to feel pressured by others over their feeding decisions, whether they breastfeed or use formula milk. Breastfeeding and non-breastfeeding women can experience judgement in their interactions with health professionals, with other mothers, and the general public, leading to internalised feelings of shame, failure, inadequacy and isolation, and consequently to *'perceptions of inadequate mothering'* [17].

At the heart of this is a lack of comprehensive, in depth and accurate support for breastfeeding mothers[18,19]. Marked social and geographical patterning in infant feeding rates in the UK population confirms that individual mothers' feeding journeys are not simply a matter of individual biology. Infant feeding decisions result from a complex web of influences, ranging from the experience and personal beliefs of mothers, to the influence of family and friends, community level social norms, support from health professionals and wider societal and cultural influences[20].

One area where women often experience both a lack of support and pressure to do the 'right thing' is if they are prescribed a medication while breastfeeding. Due to a lack of information or inconsistent views many women report feeling confused and anxious if they need to take a medication (which many do over the course of a breastfeeding journey). Women can end up

refusing medication that they need, or not completing a course as they are concerned about harming their baby. Others feel forced into stopping breastfeeding before they are ready[12, 21, 22].

2.2 Medicines, breastfeeding and information

Use of medication in lactation is one of the least developed areas of clinical pharmacology, and while most expectant mothers and breastfeeding women do take medication at some point, for ethical reasons only a few medications have been specifically tested for use either in pregnancy or while breastfeeding[23]. However, unlike during pregnancy, very few medications are contraindicated for breastfeeding, as the placenta and breast are very different organs and transfer through to breast milk is typically low[24]. Standard NHS advice to parents for medications that are commonly used – including antibiotics, paracetamol, ibuprofen and asthma inhalers – is that they can be taken while breastfeeding without causing harm; a few common drugs are not recommended; these include codeine phosphate, and aspirin[25].

Despite this standard NHS advice, it is common for care professionals to feel uncertain when giving advice to new mothers[9,12, 26]. Health professionals may be unduly cautious in seeking to protect the new-born baby from potential harmful effects[27,28]. Professional caution may be compounded by fears of litigation and an attitude amongst some medical professionals that there is little benefit in choosing breastfeeding over formula milk[27,29]. This over caution leads some women to stop breastfeeding earlier than planned[28] . Alternatively, in cases where women decide to discontinue medication in order to continue breastfeeding, stopping taking medicine may be linked to adverse outcomes for the mother[30].

Many breastfeeding women who are prescribed a medication or procedure report feeling that they did not get sufficient information, or that the information they received was inconsistent or confusing, leading to impossible decisions[12]. Women feel they have to choose between their own health and that of their baby, whilst balancing being a 'good mother' who protects her baby. Both breastfeeding and avoiding any risk of toxicity to the baby are seen as signifiers of "good' motherhood, while taking medication on medical advice can be a signifier of being a "good" patient[31]. As with other aspects of pregnancy and motherhood, women can feel a

strong moral obligation to manage risks and to make the 'right' decision to minimise any possible risk to the baby[32].

For health professionals who need further information on medications and breastfeeding there are a number of resources. In the UK the British National Formulary[33] is the standard reference manual for health professionals. A number of further reference texts are used including Hale[34] and Jones[8]. The UK Drugs In Lactation Advisory Service (UKDILAS)[35] also provides advice for health professionals, however, this tends to be used by health professionals for complex case-specific information, for example where mothers are taking multiple medications or babies are unwell. Similarly, the US National Library of Medicine provides LactMed[36], a regularly updated site with information on drugs and other chemicals to which breastfeeding mothers may be exposed. But who do mothers turn to if they need further information?

2.3 The Breastfeeding Network Drugs in Breastmilk service.

The specialist *Drugs in Breastmilk Helpline* was set up by the Breastfeeding Network in 2007[11]. The helpline was a pharmacist-led service and was set up in response to a high frequency of calls to the National Breastfeeding Helpline relating to medication[12]. Many mothers who called were unsure whether they could safely combine their medication with breastfeeding. The service was also available to health professionals who needed more information than the British National Formulary could provide. The line itself was supplemented by detailed Factsheets covering a range of conditions and medications.

An internal evaluation of the Drugs in Breastmilk helpline surveyed 101 helpline callers from December 2010 to January 2011[12]. The survey was conducted to understand how the service was being used and how it was valued. This study found that the helpline tended to be used by highly educated women, whose experience of the service was very positive. Around two thirds of calls from women concerned medication to treat acute conditions, enquiries relating to managing minor illnesses, anti-infective medicines and pain relief medicines.

Around one in five breastfeeding women who called the line were looking for information relating to management of chronic illness; calls regarding chronic illness crossed many

conditions, including depression and Chrohn's disease. Women who called the line were often looking for reassurance, many had received conflicting information, some distrusted the advice they had been given, some reported that their health professional had not felt confident to advise. The findings showed that of 70 enquiries involving medicines, 68 women received reassurance that they could take the medications they asked about.

Health professionals also reported high rates of satisfaction. Those who called the helpline discussed medications relating to wide range of conditions. While health professionals had often already looked for another source of information (for example a pharmacist or consulting Hale) many felt that the helpline would be able to give them a definitive answer.

In 2017, the Breastfeeding Network decided to switch the service to provision via email and social media enquiry only – as the majority of enquires from parents and health professionals were coming to the service via these routes. The factsheets remained, with further additions over time. The service is very popular with estimates of 10,000+ queries from mothers, health professionals, and mother supporters for a wide range of conditions every year. However, despite this volume of contact and previous evaluations showing it is highly valued and the only real source of additional information for mothers, the service is not centrally funded and relies on charity reserves and donations and the work of one specialist pharmacist, with additional part time support from another pharmacist. Formally evaluating the service's reach, impact, and worth is therefore a vital part of understanding the future needs of the service.

2.4 Aims of this study

This study was commissioned by Breastfeeding Network to provide an updated and expanded evaluation of the Drugs in Breastfeeding service, drawing on the perspectives of mothers, health professionals, mother supporters and those who deliver the service. It explored:

1. Who is using the service, how and what for?
2. What advice are users receiving and how does this impact on feeding decisions?
3. How do users rate the service?
4. What is the impact of the service on maternal wellbeing and health professional practice?

3. Methodology

3.1 Design

The study was designed to triangulate perspectives of mothers, professionals, mother supporters and breastfeeding organisations. Data was collected in four parts:

- Part One: An interview with the lead pharmacist for the service, Dr Wendy Jones
- Part Two: A questionnaire for Breastfeeding leads
- Part Three: An evaluation of the drugs in breastmilk factsheets
- Part Four: An evaluation of the drugs in breastmilk information email and Facebook service

Data was specifically collected for a twelve-month period, running from September 2017 – August 2018 for the contact service, and October 2017 – September 2018 for the factsheets.

3.2 Participants

Participation in part one consisted of the lead pharmacist for the drugs in breastmilk service. In part two, leads from breastfeeding organisations and senior professionals with a primary responsibility for breastfeeding in their role were invited to take (referred to as a group as 'leads').

In part three, all previous readers of a Breastfeeding Network drugs in breastmilk factsheet were invited to take part.

In part four, all previous contacts to the Breastfeeding Network drugs in breastmilk contact service (via Facebook or email) were invited to take part. In both cases this included mothers, those who used the service on behalf of the mother (mother supporters), and health professionals. Participants could take part separately in both parts three and four if applicable.

All participants were aged 18+, could complete the survey in the English language, and were able to give consent. Approval for this study was granted by Swansea University College of Human and Health Sciences Research Ethics Committee. All participants gave informed consent

and all aspects of this study have been performed in accordance with the ethical standards set out in the 1964 Declaration of Helsinki.

3.3 Measures

Data were collected between August – November 2018. All data were collected via online survey link, hosted by Qualtrics UK. This method of data collection was chosen as access to the Factsheets and contact service is solely via the internet, therefore all potential participants would reasonably be expected to be able to complete the questionnaire online. An option to contact the team for a paper copy of the questionnaires was given, but no request was made.

In parts one and two, two open ended questionnaires were designed, allowing participants to write their responses as fully as possible in unlimited text boxes (see Tables one and two).

Table one: Part One open-ended questions with service lead

1. How is the service delivered?
2. How is the service funded?
3. How many queries do you estimate the service receives each year?
4. What are the most common queries?
5. How often would you estimate enquirers have been given incorrect information (or no information at all) around taking a medication and breastfeeding
6. How often would you estimate that you are able to advise a woman who has been told to stop breastfeeding that she can in fact carry on?
7. Do you believe the service enables women to carry on breastfeeding?
8. What do you think this means to women to be able to carry on breastfeeding?

Table two: Part two open-ended questions with breastfeeding leads

1. Do you think having to take a medication affects women's decision to start or continue breastfeeding? How? What might mothers worry about?
2. What is your understanding of the drugs in breastmilk service? Do you know how it is run? Who answers queries? How it is funded?
3. How many queries do you estimate the drugs in breastmilk service answer each year?
4. What impact do you think the drugs in breastmilk service has upon those who use it? e.g. mothers, professionals, family and friends who contact on her behalf?
5. Do you think the drugs in breastmilk service affects women's ability to start or continue breastfeeding? How?
6. Do you tell others about the drugs in breastmilk service? Who? Do you direct / tell others about any other source of information about medications and breastmilk?
7. If the drugs in breastmilk service no longer existed what would the impact be?
8. Do you have any suggestions about how the service could be improved?
9. Do you have any further comments about the drugs in breastmilk service?

In part three, participants responded to a questionnaire consisting of both closed and open-ended questions. Questions examined:

- Participant demographic background
- Participant identification as mother, mother supporter or health professional
- Use of specific Factsheets, including how participants found the factsheets
- Evaluation of usefulness of the factsheets
- Impact of the factsheets upon wellbeing
- Impact of the factsheets upon ability to continue breastfeeding (mothers), give support (mother supporters), or professional practice (health professionals)
- Open ended opportunity to describe what impact the factsheets had upon them

In part four, participants completed a questionnaire consisting of open and closed ended questions. Due to the different focus of some questions, three separate questionnaires were designed aimed at mothers, health professionals, and mother supporters. Questions examined:

- Participant background
- How they found out about the service and why they contacted it
- What advice they were given and what happened next
- Evaluation of the service
- Impact of the service upon wellbeing (mothers only)
- Impact of the service upon breastfeeding duration (mothers only)
- Impact of the service upon professional practice (health professionals only)
- Impact of the service upon ability to give support (mother supporters only)
- Open ended opportunity to describe what impact the service had upon them

The option to consent to be contacted to write a further detailed account of their experience of using the service was also given. Three mothers were randomly selected and contacted via email. Mothers were asked '*In as many words as you wish, tell us more about your experience of using the service e.g. why you contacted it, what information you were given, and what the service meant to you*'. All names of mothers who offered stories were changed.

3.4 Procedure

For parts one and two, a purposive sampling approach was used. Breastfeeding leads were identified, and an email sent to them explaining the study with a link to the questionnaire. For parts three and four, online adverts were placed on social media describing the aim of the evaluation and calling for participants. These adverts were initially shared by the research team, the drugs in breastmilk service and the Breastfeeding Network. Snowball sampling was used by asking others, including breastfeeding organisations to share the adverts. Over the study period, social media analytics recorded at least 500 shares of the initial post.

For each part, interested participants clicked on the questionnaire link and a study information sheet loaded, explaining the aims of the study, inclusion criteria, and study procedures, including researcher contact details for further questions. Participants were also given details on how to request a paper copy of the questions if preferred. A series of consent questions were presented, and the remainder of the questionnaire only loaded once consent items were completed. A debrief at the end of the questionnaire encouraged participants to seek advice from a healthcare provider if the survey had raised any concerns or questions.

3.5 Data analysis

Quantitative data were analysed using SPSS version 25. For the open-ended data, a thematic analysis was performed to identify themes and subthemes[37]. A simple qualitative descriptive technique was used to summarise themes that participants presented in the data[38]. A sub-sample of scripts were checked by a second coder, and discussion held if disagreement occurred. Double-coding indicated a high level of agreement between coders.

4. Results

The results are presented in four separate parts. For parts three and four, each section is split into responses from mothers, health professionals, and mother supporters.

1. Findings from interview with lead pharmacist, Dr Wendy Jones
2. Breastfeeding organisation lead views on the service
3. Evaluation of the factsheets
4. Evaluation of the drugs in breastmilk information service

4.1 Part One: Findings from interview with lead pharmacist for the service, Dr Wendy Jones

This section is designed to give an overview of the service delivery, and to set the scene for the evaluation. It describes the estimated workload of the service alongside types of query.

1. Who runs the service?

'The service is run by two pharmacists'

2. How is it funded?

'The service is funded by the Breastfeeding Network from charity reserves. Although many applications have been made for grants, to date none of them has been successful sadly'

3. How many queries do you estimate the service receives each year?

'Based on samples we believe that it is 10, 000 queries a year'.

4. What are the most common queries?

'We know that about 20% relate to mental health issues but the scope is wide from multiple drug regimes to microblading eye brows. It tends to be seasonal too so currently cough colds and flus jabs but in summer hay fever and insect bites. No two days are ever the same'.

5. How often would you estimate enquirers have been given incorrect information (or no information at all) around taking a medication and breastfeeding

'That is difficult to answer but because not all enquirers tell us immediately what they have been told but sadly it is a very high proportion because professionals do not have access to the specialist sources we use or even know they exist and almost appear to perceive that breastmilk is not important and can be turned off like a tap. Most mothers do not get information on how to maintain their supply nor a clear plan about when they can go back to feeding as normal. The hardest queries for me is when professionals refuse to acknowledge the evidence-based information which we provide and insist that mothers can't continue or refuse to prescribe/carry out a procedure leaving mums in a very difficult position.'

6. How often would you estimate that you are able to advise a woman who has been told to stop breastfeeding that she can in fact carry on?

'If I am honest at least 90% of the time if not more or that there is an alternative which would enable her to carry on'.

7. Do you believe the service enables women to carry on breastfeeding?

'Yes, I very firmly do, or I wouldn't be spending the hours I do answering questions. We provide evidence-based information and an explanation of the pharmacokinetics of the drugs in as simple a way as possible. I hope we phrase the information in a way that they can understand but backed up with the full information that they can share with professionals.'

8. What do you think this means to women to be able to carry on breastfeeding?

'I truly believe it means a lot. These are mums who are happily breastfeeding and don't want to give up. They talk about babies who have never taken a bottle of formula or expressed milk and who rely on the comfort of the breast. It isn't just about the milk!'

4.1.2. Summary

The service responds to a phenomenal number of queries per year. Two things are clear: a significant number of women who turning to a charity funded service after receiving incorrect or incomplete medical advice, and the likely impact this service has upon breastfeeding women's knowledge and confidence, and ability to continue breastfeeding. The next sections will explore the experiences and views of those who work in the field of breastfeeding, or who have used the service.

4.2 Part Two: Breastfeeding lead views on the service

Sixteen organisations and key individuals (referred to as 'leads') completed the questionnaire:

- Alison Thewliss MP, Chair of All Party Group on Infant Feeding and Inequalities
- Association of Breastfeeding Mothers (ABM) – Emma Pickett
- Better Breastfeeding (BB) – Ayala Ochert
- Dr Louise Santhanam, GP
- Dr Vicky Thomas, consultant paediatrician
- First Steps Nutrition Trust (FSNT) – Dr Helen Crawley
- Human Milk Foundation (HMF) Dr Natalie Shenker
- Institute of Health Visiting (IHV) Alison Spiro
- Jane Scattergood Maternity Adviser Public Health England (PHE)
- La Leche League GB (LLL) Justine Fieth
- Linda Wolfson, Breastfeeding Programme for Government Lead Scotland
- Local Information Infant Feeding Information Board (LIFIB) – Shel Banks
- NCT
- UK Association of Milk Banking (UKAMB) – Debbie Barnett
- UNICEF Baby Friendly (BFI) – Sue Ashmore
- World Breastfeeding Trends Initiative (WBTI) – Helen Gray

All leads had an excellent understanding of how the service was run including who offers the service and how it is funded. Estimates of number of contacts per year ranged from 1000 to tens of thousands. The service was held in high regard with all but one lead disseminating information about the service in reports, discussions and in one to one contacts. For example, the service is referred to several times in the WBTI UK report as an example of good practice. The remaining lead stated that they would be disseminating information in the future.

4.2.1 Does information about medication impact on breastfeeding rates?

All leads except for one (who stated they were unsure of the evidence base rather than disagreeing) felt that information about medication affected mother's ability to breastfeed.

> *'There is no question that medication has a big impact on decisions around breastfeeding. Some women go through pregnancy with an assumption (sometimes false) that breastfeeding is not an option for them. These may be women for whom breastfeeding may be particularly significant in terms of health impact. They may not prepare for breastfeeding or only discover very late that it is an option'. (Emma Pickett, ABM)*

> *'The Scottish Infant and Maternal Nutrition Survey in 2017 showed that women have concerns about harming their baby if they take medications whilst breastfeeding (Linda Wolfson, Scottish Government)*

Leads indicated that they were aware that many women were receiving incorrect advice from GPs regarding whether medications were safe to take when breastfeeding. In many cases this led to women stopping breastfeeding, unnecessarily, and often before they are ready to do so.

> *'I know of mothers who have not started breastfeeding because they were told (wrongly) that the medication they were on was not compatible with breastfeeding. More often though I hear of mothers stopping breastfeeding because their GP has told them that they can't breastfeed on a particular medication'. (Ayala Ochert, BB)*

> *'Women think they cannot breastfeed when taking medication. Doctors may reinforce this'. (Alison Spiro, IHV)*

Leads also raised the issue that sometimes mothers were advised to stop temporarily while prescribed a short-term medication but not given information around how breastmilk supply could be maintained during this period, even if the breastmilk itself could not be used.

> *'Sometimes the medication is only needed for a week, but mothers aren't given information about how to maintain their supply during that time. By the time they've finished the course, it effectively means the end of breastfeeding. In almost all cases the mother could have continued breastfeeding on that medication or taken an alternative'. (Ayala Ochert, BB)*

Part of the issue was that mothers were reluctant to challenge information given by their GP, and did not feel confident in asking for an alternative. Even when given correct information they could then feel too overwhelmed to challenge figures they saw as being in authority.

> *'We hear mothers saying they are told inaccurately by their GP or pharmacist that they can't have a specific medication because they are breastfeeding. Having the confidence to challenge the information provided by their health professional, can feel overwhelming, especially at a time when the mother is feeling unwell. (Justine Fieth, LLL GB)*

> *'Better information from health care professionals would help mothers make an informed decision. They may worry that the medication will make their baby unwell, that health care professionals disagree with their decision to breastfeed if they are taking/need to take medication' (Dr Louise Santhanam, GP)*

> *'Resources healthcare professionals usually rely on to guide prescribing, such as the British National Formulary, are overcautious to the point of being unhelpful. Women are understandably anxious that the medication they use will manifest in their milk and cause harm to their baby'. (Dr Vicky Thomas, consultant paediatrician)*

Leads recognised the catastrophic impact having to stop breastfeeding due to a lack of advice had upon maternal wellbeing. Breastfeeding was not simply about milk, but also about maternal experience.

Speaking to a mother who discovers she has been advised incorrectly is a distressing experience. It can undermine her entire faith in the medical world and cause her to re-evaluate her mothering experience. Mothers who are sometimes told to abruptly end breastfeeding can find this very distressing regardless of whether the information was correct. They are not being asked to switch types of food for their baby but are being asked to be a different kind of mother (Emma Pickett, Chair of the ABM)

'I see women grieving the end of their breastfeeding journeys every day in clinic, and questioning if the reason their child is ill is because they stopped breastfeeding when they did. This is especially aggravated if a mother feels she has chosen her own health over her child's as she's taken medication' (Dr Vicky Thomas, consultant paediatrician)

However, it was clear that some health professionals could underestimate the impact of not being able to breastfeed had upon women, believing it was as simple as just stopping breastfeeding with no adverse consequences for physical or mental health.

'In my experience it is relatively common for doctors to concentrate on the mother's condition with the attitude that breastfeeding can be sacrificed in order to prescribe their preferred medication'. (Sue Ashmore, BFI)

4.2.2 What impact do you think the drugs in breastmilk service has?

All leads felt that the service played an invaluable role in supporting mothers to breastfeed, and also in protecting mothers' mental health. The service was viewed as providing mothers with information, support, and reassurance which enabled them to make informed decisions.

'The drugs in breastmilk service is a trusted source of information for prescribers and practitioners. Women and their families are able to access written information to help them navigate these conversations with their health practitioner'. (Jane Scattergood, PHE)

'It is invaluable. Accurate and clear, with a solid evidence base'. (Dr Louise Santhanam, GP)

'I know that many many women find the fact sheets invaluable tools to support informed choice, and that her personal responses to individual queries about medications and specific circumstances, are absolutely invaluable to so many families'. (Shel Banks, LIFIB)

'I don't know how many lives have been saved, how many relationships have been strengthened, how many families have better mental as well as physical health, due to Wendy Jones' dedication. Thank you for everything you've done!' (Helen Gray, WBTI)

'It is very reassuring for mothers, health professionals and families to have expert information and more mothers will breastfeed as a result'. (Alison Spiro, NCT)

Leads were clear that without the service many mothers they had had contact with would not be breastfeeding

'I have spoken to mothers who have breastfed only because Wendy gave them the confidence to do so'. (Sue Ashmore, BFI)

'It means women taking medication can be properly informed in order to reach their goals. And in many cases, women can continue and only end breastfeeding when it feels right for them WHILE getting the medical treatment they need'. (Emma Pickett, ABM)

'The service allows mothers to be informed about their own health and medications, to keep breastfeeding and to feel empowered with evidenced based information to present to their health care providers'. (Justine Fieth, LLL)

This extended to mothers donating their milk:

We use the service ourselves in the Hearts Milk Bank. Wendy is one of our expert advisors and we contact her approximately once a month with a query about recruiting a donor and medication. Through her expertise we have been able to recruit a wider population of donors, if they are taking a medication that would not be advisable for milk donation to preterm babies, for healthy full-term babies where the mothers are unable to breastfeed. This has changed outcomes for these babies and mothers and creates a wider pool of donors as milk bank services scale across the country. (Dr Natalie Shenker, HMF)

The impact on maternal wellbeing again came out strongly throughout the responses. When mothers were able to carry on breastfeeding and take their medication, the impact was significant. The concept that the service 'saved lives' was repeated throughout.

> *'I understand that those who use the service get a great deal of information and reassurance from it'. (Alison Thewliss, Chair APPGIFI)*

> *'It means women can breastfeed for longer and I have no qualms in saying it has saved lives. I'm thinking particularly of mums with mental health issues who have been able to continue appropriate treatment'. (Emma Pickett)*

> *'It literally not only saves breastfeeding for families every day, it also saves mothers' mental health'. (Helen Gray, WBTI)*

> *'Parents in crisis would have nowhere to go without Drugs in breastmilk service'. (Dr Helen Crawley, FSNT)*

The service was also identified as helping save time and resources for health professionals and peer supporters. Mothers could be signposted to the service, knowing it would provide accurate information and support whilst focussing on other elements of care themselves.

> *'It saves GP and HV time. It means breastfeeding volunteers can focus on appropriate care and signpost to the service where needed'. (Emma Pickett, ABM)*

> *'I am aware that many health professionals use the fact sheets and refer to the service'. (Shel Banks, LIFIB)*

Within this, the service was also recognised as enabling health professionals to update their own knowledge. Infant feeding professionals and supporters valued the service, often because they could not find such an accurate source of information elsewhere.

> *'I know it is very valued by professionals, particularly infant feeding specialists who use it to protect mothers' breastfeeding all the time'. (Sue Ashmore, BFI)*

'It is also enabling doctors to inform their colleagues and their own practice with better evidence other than the general training to advise against feeding and medication use, simply for lack of an evidence base'. (Dr Natalie Shenker, HMF)

'Breastfeeding supporters would find it very difficult to support mothers without the service as not everyone has access to Hale etc. This means without the service mothers would stop breastfeeding before they needed to'. (NCT)

4.2.3 What would happen if the service did not exist?

Leads envisaged a number of serious consequences if the service ceased to exist. No response referred to the idea that another service would simply pick up requests – the BfN provides a unique and invaluable service. Broadly, if the service did not exist this would cause considerable distress to new mothers left with the information to make a decision. More detailed consequences of a theoretical removal of the service included:

1. Some women would refuse medication

Women's desire to breastfeed must not be underestimated. It is often assumed that if told they cannot breastfeed and take a certain medication, women will automatically stop breastfeeding, but a key theme was that women would in fact carry on, but not take the medication, with potentially catastrophic consequences.

'Women who are unwell might delay their own treatment in order to breastfeed which could have serious effects'. (Emma Pickett, ABM)

'Women worry about the transfer of medication to their baby via their breastmilk. Worrying about medication will be a factor in feeding choices. Many women modify their use of over the counter medication when breastfeeding and hesitate to use medicines in the absence of reliable advice from a trusted source'. (Jane Scattergood, PHE)

'In my own area, a mother who was severely mentally ill was afraid to take her medication because she was worried about the impact on her baby, and was secretly discarding it. Tragically, her condition worsened and in the end she took the lives of both her children.

There were MANY factors involved, but one of them was certainly ignorance on the part of health professionals and the mother herself about the impact of her medication on breastfeeding and on her baby'. (Helen Gray, WBTI)

2. Some women would stop breastfeeding unnecessarily

Conversely, others would feel that they had to stop breastfeeding in order to take their medication, putting both their mental and physical health at risk. Many would rely on incorrect advice from pharmacists or GPs.

'I imagine we would have far more women mistakenly being advised to stop breastfeeding because doctors and other prescribers do not understand the implications of either medication is in lactation, or cessation of breastfeeding'. (Emma Pickett, ABM)

'Without a doubt it would lead to fewer women starting and continuing to breastfeed as most mothers will need to take some sort of medication at some point during the time they are breastfeeding'. (Ayala Ochert, BB)

'This would remove a vital source of expertise, for which there is no other replacement. Women would be poorly advised, and their breastfeeding experience would suffer'. (Alison Thewliss, APPGIFI)

3. Health services would be placed under more pressure

Leads highlighted that without the service, more pressure would be placed on the NHS. Many of those who use the service contact it rather than taking up GP time, or use it for quick information and guidance rather than needing to spend a lot of time searching for it themselves. The support the service provides was felt to be irreplaceable – it was not as if other services could simply take the strain.

'I think the breastfeeding support community would lose a key pillar of information provision' (Dr Helen Crawley, FSNT)

Mothers, health professionals and others would rely on local pharmacists who may not be so well informed and not have access to reliable sources (Alison Spiro, IHV)

'It would leave a very large void and many women and health professionals would lose a very much needed resource' (Debbie Barnett, UKAMB)

4.2.4. How would you like to see the service improved?

The **core area for improvement identified by leads was more funding into the service** to allow more staff to be trained, and the potential reach of the service to grow.

'I would like to see it receive the central Government funding it deserves to expand the service'. (Alison Thewliss, APPGIFI)

'I think a lot of professionals think the service is bigger and better funded than it is' (Sue Ashmore, BFI)

As part of this, the emphasis on the reliance of one individual was raised several times.

'The service is invaluable and needs to be made sustainable long term'. (Dr Vicky Thomas, Consultant Pediatrician)

'Wendy needs a successor - or a succession plan - and this might require funding to train and retain someone willing to lead this service'. (Dr Helen Crawley, FSNT)

With funding secured, leads identified a number of potential expansions for the service.

1. More publicity for the service so that more mothers are aware of the service, including working closely with GPs and pharmacists.

'Medical organisations and education bodies need to raise awareness of resources on drugs in breastmilk and include the topic on health care curricula'. (*Dr Louise Santhanam, GP)*

I'd like to see a "breastfeeding friendly" mark that pharmacies could display in their window showing that they've had training on breastfeeding-safe medications and that they consult with experts in the service. It should also like to see it incorporated into Baby Friendly training for all health professionals. (Ayala Ochert, Better Breastfeeding)

2. Train more specialist pharmacists, including in paid positions. This would also support succession planning.

'Funding to train new specialist pharmacists, and for the service, and pharmacists to be paid for their time'(Shel Banks, LIFIB)

'The volunteers should be given paid roles, professionalised, given supported time to increase their skills further and allowed to work with researchers to understand and collate open access resources for other professionals to access easily online. Like the BNF but for breastfeeding'. (Dr Natalie Shenker, HMF)

3. Further links with other organisations, including closer partnerships with other information sources, and potentially NHS links.

'It would be more universally accepted by medical professionals and pharmacists if it had an "NHS" badge/ brand'. (Helen Gray, WBTI)

'I think the DIBM helpline would benefit from NHS or Government funding support, and perhaps facilitation to work more closely with UKDILAS'. (Dr Louise Santhanam, GP)

4. Explore further delivery options such as a web contact form and sharable links

'Easy access to information on common medicines and situations would be most helpful' (Linda Wolfson, Scottish Government)

'More money would allow more support staff. Perhaps a bespoke website separate from FB with a webchat option?' (Emma Pickett, ABM)

4.2.5. Summary of Breastfeeding organisation leads

Leads of key breastfeeding organisations in the UK believed that the quality of information around medication significantly affected women's ability to breastfeed.

The drugs in breastmilk information service is seen as a vital source of information and reassurance for mothers and health professionals, filling a gap and, in many cases, counteracting poor information and guidance from prescribers.

The service is viewed as enhancing women's ability to breastfeed, take care of their own health, and maternal wellbeing. More funding for the service is seen as vital to an extended and sustainable future.

4.3 Part three: Evaluation of the Breastfeeding Network Factsheets

4.3.1 Sample

Two hundred and twenty-seven participants evaluated the leaflets including 174 mothers, 37 health professionals and 16 mother supporters. Mean maternal age was 33.59 (SD: 4.54), with a range 22 - 44. Seventy-seven (33.9%) were first time parents, 96 (63.7%) had two or more children, 1 was pregnant for the first time (0.4%). A further two were pregnant with a second or more baby. Further demographic details are shown in Table three.

Table three: Maternal demographic background

Category	Sub category	N	%
Education	No formal qualifications	7	4.0
	GCSE or equivalent	21	12.1
	A level or equivalent	80	46.2
	Degree or equivalent	65	37.6
	Postgraduate	7	4.0
Relationship	Married / civil partnership	133	76.9
	Living with a partner	35	20.2
	Singe / divorced	5	2.2
	Widowed	0	0
Employment	Full time	61	26.9
	Part time	85	37.4
	No	27	19.0
Occupation	Higher professional and managerial occupations	46	26.4
	Lower professional and managerial	64	36.8
	Intermediate	23	13.2
	Employers in small organisations & self employed	4	2.3
	Lower supervisory and technical	1	.6
	Semi routine	7	4.0
	Routine	2	1.1

Thirty-seven professionals evaluated the leaflets with a mean duration of 10.1 years in practice (SD: 8.1), with a range from 1 to 32 years. Details of occupational group are shown in Table four:

Table four: Occupational group for health professional respondents

Occupational group	N	%
Breastfeeding Counsellor / Supporter	20	54.1
Nurse	1	2.7
Specialist medic	1	2.7
GP	2	5.4
Health Visitor	3	8.1
IBCLC	4	10.8
Infant Feeding Advisor / Coordinator	3	8.1
Midwife	3	8.1

Finally, sixteen mother supporters completed the evaluation. Eight (50%) were friends or colleagues, 4 (25%) were breastfeeding peer supporters and 4 (25%) were family members.

Looking at the sample as a whole:

- 185 (81.9%) lived in England, 20 (8.8%) in Wales, 11 (4.9%) in Scotland, 3 (1.3%) in Northern Ireland, 6 (2.7%) in ROI and 1 overseas (0.4%).
- In terms of first language, 220 (96.9%) noted English with further first languages including German, Hungarian, Scottish, Slovak and Welsh.
- For ethnicity, 220 (97.3%) were White, 1 (0.4%) mixed race, 1 Asian (0.4%), 1 Black (0.4%), 2 'Other' (0.8%) and 1 preferred not to state.

4.3.2. How are the factsheets being used?

Participants were asked whether they had used the factsheets before, and how they had found them. One hundred and thirty-nine participants (62.3%) had previously used the leaflets, whereas 84 (37.7%) had used them for the first time in the last year. Facebook was the most common place to first learn about the existence of the factsheets, followed by a breastfeeding organisation or supporter. Sources of information are shown in Table five.

Table five: Sources of information for locating the factsheets

Source	N	%
Facebook	130	58.3
Internet Search	18	8.1
BFN website	8	3.6
Breastfeeding Organisation/ Breastfeeding supporter	34	15.2
Health Professional (Midwife or Health Visitor)	4	1.8
Friend, family or word of mouth	15	6.7
Unsure or unspecified	10	4.5
International Board-Certified Lactation Consultant (IBCLC)	4	1.8

When asked how often they used the factsheets, a wide range of responses were seen. The most common usage were twice (14.6%), three times (19.5%), five times (15.2%), or ten times (12.2%), although a third of the sample simply wrote 'lots', 'loads of times' or 'too many times to remember'. The range of usage stemmed from once to over one hundred times (n = 3).

Participants reported using 106 different factsheets. Some listed a specific factsheet, whilst other listed an illness / symptom. These were coded into main illnesses / issues. The top ten most commonly accessed factsheets were: Analgesics (n = 106), Antibiotics (n = 65), Cough and cold remedies (n = 59), Antihistamines (n = 45), Antidepressants (n = 44), Anaesthetics (n = 31), Hayfever (n = 25), Flu (n = 29), Contraception (n = 19), Decongestants (n = 15).

Participants were asked whether the leaflets provided them with enough information to make a decision / pass on information about taking the medication. One hundred and ninety-one (86.0%) stated they felt fully provided with sufficient information, 28 (12.6%) partially, and 3 (1.4%) not at all. Mothers who read the leaflets were asked what they decided to do after reading them (with 148/174 providing a detailed response). The majority (n = 123, 83.1%) decided to go ahead and take the medication or go ahead with the treatment. Sixteen (10.8%) contacted their GP or other health professional for a different prescription. Two (1.4%) investigated alternate medications and seven (4.7%) decided not to take the medication for

reasons including making an informed choice, deciding the treatment was not needed, or had accidentally taken a medication as a one off).

4.3.3. Do readers use any other sources before finding the factsheets?

Participants were asked whether they used any other sources of information before finding the factsheets. Around a third did not, going straight to the factsheets. Others used a range of sources first, sometimes more than one. The most common source that led an individual to seeking out the factsheets was information from a GP, presumably after prescribing. Sources are shown in rank order in Table six.

Table six: Sources of information used prior to the factsheets

Source	N	%
A GP	77	33.9
I didn't ask anyone else	72	31.7
Community pharmacist	39	17.2
BNF (British National Formulary)	30	13.2
A health visitor or midwife	25	11.0
Drugs in breastmilk email / Facebook	16	7.0
A breastfeeding organisation e.g. La Leche League or ABM	14	6.2
Wendy Jones Breastfeeding and Medications books	12	5.3
A lactation consultant	12	5.3
National Breastfeeding helpline	10	4.4
Hospital/ Medicines Information Pharmacist	10	4.4
Hale 'Medications and Mothers milk' book	9	4.0
Manufacturer	9	4.0
UK Drugs in Lactation Advisory Service (UKDILAS)	6	2.6
Other medics e.g. dentist obstetricians, psychiatrist	3	1.3
Pharmacist	2	0.9

Those who contacted / used a difference source of information before finding the leaflets, were asked why they went on to use the leaflets. The most common response was that they trusted the leaflets more than other sources (38.3%). Other reasons included:

- They were getting mixed messages from different sources (27.8%)
- They were told by the initial source to stop breastfeeding and wanted to check (18.5%)
- They wanted as many answers as possible (16.7%)
- They were told by the initial source to carry on breastfeeding and wanted to check (11.5%)
- The source could not give me an answer (8.8%)
- The source suggested I read the leaflets (4.8%)

Participants were also asked whether they went on to contact the drugs in breastmilk service. One hundred and thirty-six participants (60.2%) found all the information they needed in the factsheets.

Of those who went on to contact the service, the main reason was that they wanted to double check the information with a 'real life' person (21.3%). Others contacted the service as they had further questions not covered by the factsheets (11.5%).

4.3.4. How do participants evaluate the factsheets?

When asked whether participants felt the factsheets helped women breastfeed for longer. Almost all (95.6%) agreed that they did, with just 2 participants (0.9%) feeling that they did not.

All participants were asked a series of questions around their experience of using the factsheets. The vast majority evaluated the factsheets extremely positively. Responses were split into those who agreed (agreed or strongly agreed) with a statement and those who disagreed (disagreed or strongly disagreed) with a statement. As can be seen in Table seven, participants were vastly positive about the factsheets, with the main criticism (albeit held by just 4% of respondents) being that they were not easy to find online.

Table seven: Participants ratings of their experience of using the factsheets

Statement	Agree		Disagree	
	N	%	N	%
Easy to find online	206	90.3	9	4.0
Easy to understand	220	98.7	1	0.4
Non-judgemental	225	99.6	0	0
Full of useful information	224	99.1	0	0
Provided information difficult to find elsewhere	221	97.8	1	0.4
Accurate	222	98.2	0	0
Written in language that can be understood	222	98.2	2	0.9
Gave clear answers	224	99.1	1	0.4
Help mothers make decisions	225	99.6	1	0.4
Evidence based	221	97.8	1	0.4
Clearly written by an expert	220	97.3	0	0
An efficient way to find information	223	98.7	0	0
It is a bonus you can access them 24/7	225	100	0	0
Have enough information in them	223	98.7	2	0.9
I found the information very useful	225	99.6	1	0.4
I felt women's choices were supported	218	96.5	0	0
I was very satisfied with the support	221	97.8	2	0.9
I would recommend them to others	225	100	0	0
I would use the factsheets again	226	100	0	0
The information was written in a respectful way	223	98.7	0	0
I found the factsheets reassuring	222	98.2	1	0.4
I trusted the information in the factsheets	224	99.1	1	0.4

Health professionals responded to a further three statements, exploring their perceptions of the factsheets upon their professional practice. All found the factsheets had a positive impact with 100% agreeing that they felt better able to support mothers, better informed in their professional role, and more confident in their professional role.

Likewise, mother supporters reflected on how the factsheets helped them in providing the support to the mother. Again, responses were all positive, with 100% of supporters agreeing that they felt better able to give support, better informed to give support, and more confident in giving support.

Finally, all participants were asked in an open-ended question how they felt about the factsheets. Responses centred around the accuracy of the information, how supportive they were to help women carry on breastfeeding:

1. Full of high quality, accurate, trusted information

Participants described the factsheets as being highly evidenced based, accurate and full of useful information, often that they could not find elsewhere. A number of mothers in particular stated that they trusted the quality of the information more than that they had received from their GP.

> *'Completely reassured. Trust them over the information I received from consultants. (Mother)*

As part of this a number of participants voiced their frustration that the information was not provided a part of standard care via GPs.

> *'I feel disappointed that primary care clinicians are not better acquainted with the availability of the factsheets and gave me poor advice on breastfeeding with medicines. (Mother)*

2. Supporting breastfeeding decisions

Many mothers talked about how the factsheets enabled them to continue breastfeeding.

> *'I felt confident in my decision to take medication knowing it would not affect my breastfeeding journey or baby'. (Mother)*

One mother specifically talked about the decision to stop now feeling like her own, rather than dictated to by someone else.

> *'Relived that the choice to stop was now mine and my baby's not external circumstances'. (Mother)*

A number of mothers referred to the fact that without the information they would have carried on breastfeeding and avoided the medication, as against stopping breastfeeding to take the medication.

> *'Without them I would have carried on breastfeeding and not taken the drugs, which ultimately would have affected my health. So the factsheets were very useful'. (Mother)*

3. Reassuring, empowering and confidence boosting

Three key emotions were raised in relation to how mothers felt once they had the information from the factsheets: reassured, empowered, and confident

> *'Made me feel confident that I had access to information whenever I need it'. (Mother)*

For professionals, the factsheets often gave them the confidence and knowledge to support mothers, and challenge those around them who held inaccurate views.

> *Confident to provide up to date information and signpost on issues outside of my personal knowledge. Always feels great when receiving feedback from mums about how useful they have found the service and how it has allowed them to continue breastfeeding (Breastfeeding counsellor)*

As shown in Table seven, a small number of participants did not find the factsheets useful. Reasons for this were expanded upon in the open-ended box. One participant described how they felt the information was not clear to them and did not help them make a decision.

> *'Didn't reassure me either way if I could breastfeed or not'. (Mother)*

A minority also felt that they contained too much information, finding them overwhelming or difficult to understand

> *'Occasionally too much information hard to digest'. (Breastfeeding counsellor)*

Another two participants described how although they found the information useful, they were then worried about actually using the information to take to her GP.

> *I love the information contained in the factsheets but it's difficult when you have a hcp telling you face to face that you are going to endanger your baby. It feels wrong to go against that purely because of a factsheets - having said that I know most hcps know nothing about this stuff. (mother)*

4.3.5. How could the factsheets be improved?

Participants were overwhelmingly positive about the factsheets but had five core ideas for improvement:

1. Enhance their visibility

A number of participants noted that they only came across the factsheets after someone told them about them, rather than knowing about them more broadly.

2. Increase their use by GPs and pharmacists

A central idea for improvement was to develop ways for more GPs and pharmacists to use them in practice. This was linked to point one – participants wished that they had been signposted to them by their medical professionals, rather than feeling that they were somehow deviating from advice.

3. Increase the number available

Others called for more of the factsheets, to cover a wider range of illnesses and medications.

4. Adapt the way they are used

Some participants called for the factsheets to be viewable without being downloaded e.g. a link that could be shared rather than the factsheet itself. Another suggestion was a search function on the website so that an illness or medication could be typed in and the relevant leaflet shown. Finally, a clear statement at the top (or a traffic light system) about whether the medication was considered to safe to take or not.

5. Simpler language versions, and in additional languages

Some participants called for a simpler version for those who found them too in depth or difficult to read. The idea of different languages was also suggested.

4.3.6. Summary of factsheet evaluation

Mothers, professionals and supporters valued the factsheets highly. Some felt they gave sufficient information on their own, but often readers wished to speak to a 'real life person' for reassurance, fact checking, or more complex questions, indicating a need for a personal service.

Many parents reached out for the factsheets after being prescribed or advised to take a medication by a GP or pharmacist, wanting to check whether the medication was safe.

Almost one in five of all parent respondents made the decision to double check with the service after they had been told, often incorrectly, that they could not continue breastfeeding.

Suggestions for improvement include a wider range that could be accessed in different formats or languages.

4.4 Part Four: Evaluation of the drugs in breastmilk service: Mothers

4.4.1. Sample

Two hundred and seventy mothers completed the questionnaire. Participants had a mean age of 33.61 [SD: 5.24, range from 21 – 46]. Further details of the participant sample are shown in Table eight.

Table eight: Maternal demographic background

Category	Sub category	N	%
Education	No formal qualifications	1	0.4
	GCSE or equivalent	20	7.5
	A level or equivalent	57	21.3
	Degree or equivalent	100	37.3
	Postgraduate	90	33.3
Relationship	Married / civil partnership	195	72.8
	Living with a partner	61	22.8
	Singe / divorced	12	4.5
	Widowed	0	0.0
Employment	Full time	70	26.1
	Part time	120	44.8
	No	78	29.1
Occupation	Higher professional and managerial occupations	40	20.8
	Lower professional and managerial	92	34.1
	Intermediate	38	14.1
	Employers in small organisations and self employed	5	1.9
	Lower supervisory and technical	2	0.7
	Semi routine	13	14.8
	Routine	2	0.7
Ethnic group	White	254	94.1
	Mixed	7	2.6
	Asian or Asian British	3	1.1
	Black or Black British	2	.7
	Other	4	1.5

One hundred and twenty-seven were first time mothers (47.0%) and 143 (57.0%) had more than one child. Three (1.1%) were currently also pregnant. In terms of location, 207 (76.7%) participants lived in England, 15 (5.6%) in Wales, 25 (9.3%) in Scotland, 13 (4.8%) in Northern Ireland, 9 (3.3%) in ROI, and 1 (.4%) from overseas in Ukraine. Two hundred and fifty-seven spoke English as their first language (95.2%), with 13 speaking another (4.8%) including Welsh, English, Polish, Hungarian, German, Shona and Afrikaans.

Participants were asked about the baby they contacted the service about. One hundred and forty-four participants were male (53.3%) and 126 (46.7%) female. The mean age of the baby was 31.53 weeks (SD: 34.47) with the youngest baby less than a week old and the oldest baby 208 weeks old (approximately 3 years old).

4.4.2. How did mothers use the service?

Participants were asked a series of questions around when, how, and why they contacted the service. The majority of participants contacted the service once (n = 157, 58.1%) or twice (n = 50, 18.5%) but some contacted it up to seven times over the 12-month period. Others (n = 7) gave a descriptive rather than numerical answer, simply stating ‘lots’, ‘several’ or even ‘too many times to remember’. One hundred and five (38.9%) were previous service users, while 161 (61.1%) were new to the service.

Two hundred and twenty-five participants (83.4%) contacted the service using Facebook, whilst 45 (16.7%) used email. In terms of who responded, 164 (60.7%) stated their query was answered by a pharmacist, 19 (7.0%) said it was answered by a non-pharmacist, and 87 (32.3%) were unsure. In terms of speed of response, half (n = 136, 50.4%) had their query answered in less than one hour, rising to 84.8% within three hours, 89.2% within six hours, 92.9% within twelve hours, and 97.3% within twelve hours. Two respondents stated they did not get a response (0.7%).

Participants were asked where they found out about the service, citing a wide range of sources. Facebook, breastfeeding organisations and friends and family were the most common sources,

making up 85% of responses. These are shown in rank order from most common to least in Table nine.

Table nine: Where did participants find out about the service?

Source	N	%
Facebook	151	55.9
Breastfeeding organisation	50	18.5
Family or friend	29	10.7
Internet search	17	6.3
BFN website	7	2.6
Midwife of health visitor	6	2.2
Unsure	5	1.9
GP	2	0.7
Pharmacist	1	0.4
IBCLC	1	0.4
Mumsnet	1	0.3

4.4.3. Why do mothers contact the service?

When asked why they contacted the service, 89 (33.1%) gave a broad answer stating that they wanted to check the safety of a medication whilst breastfeeding including checking it was safe to take alongside others. More specific reasons were also identified. The most common of these related to hospital procedures (8.5%), analgesics (8.1%), antidepressants (7.4%), antibiotics (7.0%). A full list of query topics is shown in Appendix one.

Participants were asked what advice they were given in relation to taking the drug and breastfeeding. These were coded into broad groups and are shown in Table ten. Over half (58.5%) directly gave the answer that their medication was fine to take, with a further 80 (29.6%) stated they were given information to make an informed decision. Only two mothers (0.7%) were taking a medication that required permanently stopping breastfeeding, and two participants received advice to temporarily stop breastfeeding (0.7%).

Table ten: Advice received by participants in response to query

Advice given	N	%
Fine to continue breastfeeding	157	58.5
Given information, factsheets etc to make informed decision	80	29.6
Continue breastfeeding and watch milk supply / effects on baby	12	4.4
Fine to continue breastfeeding, with advice regarding dosage	7	2.6
Switch to an alternative medication while breastfeeding	3	1.1
Cannot take this medication with breastfeeding	2	.7
To temporarily stop breastfeeding after taking medication	2	.7
No response from BFN	2	.7
Limited research for BFN to give advice on this medical situation	2	.7
Fine to breastfeed, as time limited for one month	1	.4

When asked how fully the response answered their query, 258 (95.6%) felt the information given fully answered their query, whilst 7 (2.6%) felt it partially answered their query, and 5 (1.9%) felt it did not answer their query. After receiving the information 211 (78.1%) took the medication or treatment, 8 (3.0%) altered the dose or frequency, 23 (8.6%) contacted their GP for a different medication, 4 (1.5%) temporarily stopped breastfeeding in order to take it, 2 (0.7%) chose to not take the medication, 19 (7.0%) didn't take the medication as it was no longer needed, and just 1 (0.4%) decided to stop breastfeeding altogether.

Participants were asked whether they knew the Breastfeeding Network had a range of leaflets that could be used. Only 29 participants (10.7%) didn't know they were available:

- 17 (6.3%) knew the factsheets were available, but didn't look at them
- 97 (35.9%) looked at the factsheets but couldn't find a relevant one
- 111 (41.1%) found a relevant factsheet but still wanted to speak to someone directly
- 44 (16.3%) were asking about multiple medications
- 4 (1.5%) looked at the factsheets but found them hard to understand

4.4.4. Who else do mothers contact for advice?

Participants were asked whether they had contacted or used any other sources of information before contacting the service. A quarter of participants (n = 68, 25.2%) stated they contacted the service as their first option. Other (often multiple) sources are shown in Table eleven:

Table eleven: Initial sources of information used before contacting the service

Source	N	%
A GP	94	34.8
Breastfeeding Network website	85	31.5
Community pharmacist	44	16.3
BNF (British National Formulary)	29	10.7
Hospital/ Medicines Information Pharmacist	24	8.9
A health visitor or midwife	22	8.1
A breastfeeding organisation e.g. La Leche League or ABM	18	6.7
Other medics e.g. paediatrician, psychiatrist , oncologist	14	5.2
A lactation consultant	14	5.2
Manufacturer	10	3.7
National Breastfeeding helpline	7	2.6
Wendy Jones Breastfeeding and Medications books	6	2.2
Other online databases e.g. LactMed, E lactancia	4	1.5
Hale 'Medications and Mothers milk' book	4	1.5
UK Drugs in Lactation Advisory Service (UKDILAS)	2	0.7

Participants were asked why they went on to contact the service. Reasons included:

- 126 (46.7%) they trusted the service more than other options.
- 82 (30.4%) they were getting mixed messages from different sources
- 57 (21.1%) were told to stop breastfeeding by the first source
- 38 (14.1%) the source could not give them an answer
- 31 (11.5%) they wanted as many answers as possible
- 30 (11.1%) were told they could continue but wanted to check

Responses from participants who were told they could not breastfeed and take a medication, or who could not get an informed response from their GP were examined in relation to what information they were given from the service. All participants except for one were given incorrect information. After contacting the service, participants made decisions to take the medication or a different medication and continued breastfeeding. Of those who stopped breastfeeding by the time of the survey, all had done so for reasons not related to the medication.

4.4.5. How do mothers evaluate the service?

Participants were asked to respond how strongly they agreed to a series of statements around their experience of using the service. Responses were collated into those who agreed or strongly agreed, and those who disagreed or strongly disagreed. The responses were overwhelmingly positive and are shown in Table twelve.

Table twelve: Mothers ratings of their experiences of using the service

Statement	**Agree**		**Disagree**	
	N	%	N	%
I found the information I received very useful	264	97.8	1	.4
I felt listened to	264	97.8	1	.4
I felt that it improved my wellbeing	254	94.1	3	1.1
I felt respected	261	96.7	2	0.7
I felt my choices were supported	256	94.8	1	0.4
I did not feel pressured to do any particular thing	265	98.1	2	0.8
I felt that someone cared about my experience	258	95.6	4	1.4
I felt comforted by the service	257	95.2	3	1.1
The service felt like a lifeline to good information	264	97.8	2	0.8
I felt connected to a supportive community	248	91.9	3	1.1

These experiences – of efficiency, reliability and accurate knowledge - were reflected in mothers' open-ended responses:

> *'The service is incredible, quick and efficient. Most breastfeeding Mums know of Wendy, she is always my first port of call and I have multiple health conditions. Many GPs told me to stop breastfeeding without any evidence. Wendy takes the time to investigate fully. I wouldn't have fed my son without her and am still feeding now at 2yrs 3m.'*

> *'I was very impressed with how quickly I received a response as I was in so much pain I just wanted to start the meds straight away'.*

Mothers expressed how much they trusted and valued the information that they received from the service, which was immensely important to them. A core theme throughout mothers responses was the frustration that they felt at receiving information, particularly from GP's that they would not be able to breastfeed on the medication. Women reported feeling let down, angry and distraught at this, expressing how the service made an enormous difference both to their knowledge and wellbeing.

> *'I felt very let down by my GP and local pharmacist who were not supportive of my decision to continue breastfeeding and were not informed about the doses that would allow me to continue*

Mothers described how the information they received helped them at a time in their life when they were already struggling. This ranged from simply feeling unwell and distraught at worrying they couldn't take a painkiller or medication, through to those dealing with serious illnesses. The service provided comfort to them, in helping them to continue feeding.

> *'The service was a lifeline for me at an extremely terrifying and difficult period in my life and made it slightly easier in dealing with my diagnosis.'*

4.4.6. How does accessing the service make mothers feel?

Participants reflected on a series of questions asking how mothers felt about their experience of contacting the service.

Rachel's story

I had been diagnosed with a degenerative condition and my symptoms were becoming more severe. I contacted the helpline because my GP had told me it was time to start taking medication, but it was not compatible with breastfeeding. He had told me I had no choice and must take it or would end up even more disabled (with the implication that this would also be all my own fault). I contacted Wendy in despair. I was not prepared to stop breastfeeding yet and would have never been able to forgive myself as a mother. It was too important to me, and selfishly I really wanted to continue.

Wendy explained the risks of my prescribed medication and told me there was less risk in taking a different one. I was initially very scared about taking this information back to my GP but to my surprise he agreed to change (although he was a bit reluctant).

The end story is that my symptoms are much improved, my child is still breastfed and I am being the mother I want to be. I cannot praise the service enough. They changed my life and made a very difficult situation so much easier. Thank you.

Next, participants were asked to reflect on a series of emotions around how they felt about needing to take their medication and breastfeeding both before and after contacting the service. Table twelve shows the proportion of respondents who strongly agreed or agreed they felt each emotion, before and after.

Table twelve: How mothers felt about breastfeeding and their medication, before and after contacting the service (showing mothers who agree they felt each emotion)

Emotion	Before		After	
	N	%	N	%
Understood	34	12.6	245	90.7
Cared for	54	20.1	240	88.9
Relaxed	29	10.7	223	82.6
Happy	30	11.2	225	83.3
That I had enough information	43	15.9	253	93.7
Confident	25	9.3	234	86.7
Informed	38	14.2	244	90.4
Conflicted	203	75.2	26	9.6
Isolated	132	49.1	9	3.3
Worried about making the right decision	250	92.6	26	9.6
Anxious about harming my baby	256	94.8	24	8.9
Distressed	188	69.9	18	6.7
Anxious	221	81.6	25	9.3
Unsure	245	91.1	27	10
Confused	205	76.5	21	7.8

It is clear that contacting the service has a large impact on how mothers felt about taking a medication and breastfeeding. Before and after data was compared statistically using paired samples t tests (that compare whether two average scores are significantly different to each other). Every single emotion was significantly improved after contacting the service. For details of the analysis see Appendix two.

Mothers open ended responses strongly reflected these emotions. When asked whether they wished to reflect on how the service made them feel, two core emotions emerged: relief and reassured.

> *'The service is amazing, the relief to know an expert has given me their information on the safety of the meds'.*

> *'It is so reassuring to know there is somewhere to ask questions and receive information without judgement'.*

Notably, even when mothers were given the information that they could not breastfeed and take a suitable medication, their evaluation was positive. Comments from mothers who were told medications were incompatible or little information was known noted:

> *'I received a lot of good information about different drugs.'*

> *'I felt like there was someone I could ask no matter what'.*

> *'It made me feel like I have made the right decision for myself and my baby'*

Qualitative negative responses were sparse. One mother, who stated that she did not get a response noted she was 'disappointed'. Another noted 'It is an hugely important service, I just don't seem to have had a very good experience of it!'. These two responses were in a tiny minority, against the backdrop of positive comments.

4.4.7. Does the service enable women to carry on breastfeeding?

The majority of mothers in the study were told that they could continue taking either their prescribed or a different medication. At the time of contacting the service, 230 (85.2%) had

breastmilk only for their milk feeds, 11 (4.1%) a mix of breast and formula milk, 24 (8.9%) a mix of breast and other milks. Five participants (1.9%) did not provide data.

At the time of completing the questionnaire 234 (86.7%) were still breastfeeding, whilst 36 (13.3%) were not. Of those who stopped, mean age of stopping was 71.69 weeks (SD: 36.80) with a range from 13 – 156 weeks).

Two questions specifically asked mothers about the impact of using the service on their breastfeeding experience. The first asked whether '*Contacting the service made a positive impact on the experience of feeding my baby*' – of which 244 (90.4%) agreed it did, with just 2 (0.8%) disagreeing.

The second statement asked whether they felt that '*Without the service I would not have known whether to carry on breastfeeding or not*'. One hundred and ninety three (71.5%) agreed with this, with 28 (10.4%) disagreeing.

However, notably, a number of mothers added further comments that the service did not impact upon whether they continued breastfeeding, as without the service they would have continued breastfeeding but *not take their medication*. Therefore, the service would not technically have enabled these mothers to carry on breastfeeding as they felt that was non-negotiable, but the service would most likely have improved their health.

> *'I would have cancelled my operation if I hadn't used the service when I did which would have led me to be even more poorly than I was. I will be forever grateful for the service.'*
>
> *'If I had been told medication I needed would harm my child I wouldn't of taken it, breastfeeding was very important to me, it seems in most cases there's an alternative tho which I would never of known if it wasn't for Wendy and the page so thank you'.*
>
> *'I would have carried on breastfeeding regardless, I would have chosen not to take the medication rather than stop'.*

Of those who were able to continue breastfeeding, 83.7% (n = 206) agreed that the information they received from the service helped them to breastfeed for longer. This was strongly reflected in mothers' responses about the effect the service had on their feeding experience:

> *'Being able to find out which medication is safe and best means that I don't need to stop feeding my baby in order to recover from an illness.'*
>
> *'Had it not been for this service I would have seriously considered stopping feeding earlier, as who wants to just put up with being ill and not take anything for it?! Especially while sleep deprived with a small baby'.*

One mother noted that the advice she received at a tough point enabled her to continue breastfeeding, increasing her milk supply until she was exclusively breastfeeding:

> *'So happy I could continue to feed as I soon after managed to go from mixed feeding to exclusively breastfeeding.'*

Importantly, the service often enabled mothers who were told by others *that they had to stop* breastfeeding, to continue

> '*I have contacted the service 3 times and each time have been supported to continue feeding my baby, even during one particularly severe illness in 2016 which I had been advised would end my breastfeeding relationship'.*
>
> *'My specialist was unable to recommend my drug whilst breastfeeding so if it was not for the information, I received I would of been unable to continue. I could not find information on the internet nor at a pharmacy. If it had not been for your advice I would of stopped all together. I have been breastfeeding 11 months! Thank you for your advice, it may of been a 5 minute email to you but it has given me & my daughter to share a bond I wouldn't of been able to have.'*

4.4.8. The impact of being able to carry on breastfeeding upon mental health

Mothers frequently raised how invaluable the service was for their mental health. Breastfeeding was so important to them, and the service provided the information these mothers so desperately needed to carry on safely made an important difference to their lives.

> *'Thank you for the chance to feed my firstborn to 2 years old and allowing me that privilege'.*

> *'No one can imagine how it feels to have someone understand this desperate need to feed your child, even if it means a bit more suffering for mum'.*

> *'As mentioned before, without your reply to my email my breastfeeding journey would of been over. Thank you so much for enabling me to carry on & have an unbreakable bond with my daughter!'*

Mothers often discussed how being ill, and needing medication left them feeling distraught, but being able to receive accurate information helped them feel more positive

> *'It meant a huge amount to me. I'd tried to cope for weeks on just paracetamol as I was so intent on continuing to breastfeed. The pain I was in was getting so bad that I felt as if I 'gave in' and took the medication my breastfeeding g journey would be over. With Wendy's advice and the support of a fabulous physiotherapist I managed to get back to breastfeeding (after a very short break) and we are still going strong 2 months later. I'm so glad I reached out as things could've been very different for me and my son'.*

Many referred directly to the mental health, labelling the service as a lifeline at a time of distress. The service 'saved' mothers, from a difficult and unnecessary choice of their own health, or that of having to stop breastfeeding before they were ready.

> *'It saved my mental health and made me a better mom to my children'.*

'The service is a lifeline for mothers. It has saved me in a time of my life dealing with a difficult diagnosis. If I had had to stop feeding my baby due to medications to treat my disease I am certain I would be depressed. Breastfeeding gives me a purpose beyond normal routines and it has kept me going when otherwise I think I would have crumbled'.

Sara's Story

My breastfeeding journey has not been an easy one. I had a difficult birth and he lost a lot of weight. I was threatened with having to supplement with formula and even though he regained enough, he continued to struggle to gain much weight. I had lots of difficulty latching and pain. My partner suggested we stop several times, but it was too important to me despite me frequently crying over the pain and frustration of trying to get him to take a good feed. It turned out he had a tongue tie which we eventually got snipped and things got a lot easier. We turned a real corner and then I got a throat infection and was prescribed high strength antibiotics. The locum told me there was no way I could continue and to think of my baby. I was thinking of my baby!!! He needed breastmilk!!! He needed me!!!

When a friend suggested I contact Wendy I was feeling really distressed. Just in a few messages she gave me the confidence (and evidence) to ignore the locum and to take the antibiotics. They worked, and we are still breastfeeding which I am over the moon with. We didn't go through all of that in the early days to be defeated by a locum who hadn't been properly trained. I hate to think where I would be now if I'd had to stop. It feels a bit dramatic bit I feel like Wendy saved my life.

4.4.9. What about mothers who needed to stop breastfeeding?

One aim of the survey was to explore the experiences of mothers who were given the advice to stop breastfeeding in order to take the medication. However only two respondents in the survey were given this advice. The experiences of these two mothers were very different. One

mother felt that she had been given permission to stop, felt at peace with her decision, relieved she had received good information, felt confident she had received the correct response, felt happy with her decision, supported, informed, understood, grateful, and reassured.

Conversely the other mother did not feel these emotions instead feeling conflicted, upset, anxious, distraught, disappointed, let down, angry, heartbroken and devastated she had to stop. These emotions were not directed at the service – but at the trauma she personally felt at having to stop breastfeeding before she was ready, in order to take much needed medication.

However, although only small numbers were involved, and statistical significance cannot be drawn, all mothers who were advised they could not continue had an increase in their wellbeing scores after contacting the service. Their anxiety and distress reduced, and they felt more listened to.

4.4.10. Summary

Mothers found the service a highly useful source of information, reassurance and support. It was trusted, accurate and evidence based. The majority of mothers found the service fully answered their query, often enabling them to carry on breastfeeding when told previously they could not or were not given sufficient information to make an informed choice.

Many mothers viewed the service as saving their breastfeeding journey, their health and their wellbeing – seeing the three as tied. Women had often felt forced to choose between breastfeeding *or* taking their medication, and between either their physical *or* mental health. The service, often in just a couple of contacts, enabled many women to maintain all three.

4.5 Evaluation of the drugs in breastmilk service: Professionals

4.5.1. Sample

Fifty-three professionals completed the survey. Participants had a mean 12.21 years in practice (SD: 7.60) with a range from 1 – 31 years. Breakdown of roles is shown in Table thirteen.

Table thirteen: Professionals roles

Role	N	%
Breastfeeding Counsellor / Supporter	6	11.5
Nurse (Specialist)	4	7.7
Paediatrician	1	1.9
Doctor (Emergency Medicine)	1	1.9
GP	8	15.4
Health Visitor	6	11.5
IBCLC	6	11.5
Infant Feeding Advisor / Coordinator	9	17.3
Midwife	8	15.4
Pharmacist	2	3.8
Public Health Practitioner	1	1.9

Participants were based in England (n = 40, 75.5%), 3 from Wales (5.7%), 5 from Scotland (9.4%), 3 from Northern Ireland (1.9%) 1 from ROI (1.9%) and 1 from overseas (1.9%). Forty (97.6%) of those who completed ethnicity data identified as White, and one from an Asian background (2.4%). Twelve declined this information. All spoke English as their first language.

4.5.2. How are professionals using the service?

Participants reported that they had used the service a mean 2.52 times in the past year (SD: 2.31) with a range from 1 – 13. Half had accessed it via Facebook and half via email. The majority (n = 46, 86.8%) had used the service before but 7 were new users in the last year (13.2%). For response time, 19 (37.3%) stated they had a response within one hour, rising to 39 (76.5%) within three hours and 45 (88.3%) within six hours. All had a response within 24 – 48

hours. In terms of where participants found out about the service, Facebook and word of mouth were the top sources. Further sources are shown in Table fourteen.

Table fourteen: Sources of recommendation to contact the service

Source	N	%
Facebook group	13	24.5
Word of mouth or recommendation	9	17.0
Wendy Jones (conference, talk, book)	8	15.1
Online search	7	13.2
BFN (membership, website, course)	6	11.3
Unspecified or Uncertain	6	11.3
Breastfeeding Support Training / Study	3	5.7
GP Infant Feeding Network	1	1.9

When asked why they contacted the service, 33 (62.3%) gave a general answer of checking the safety of a medication for a breastfeeding mother. The main specific reasons included antidepressants (9.4%), hospital procedures (7.5%), and antibiotics (3.8%). Other issues included pain relief, psychiatric medications, galactagogues, methadone, and infections.

In terms of the response they were given, 31 (58.4%) responded they were advised the medication was safe, whilst 21 (41.6%) were given alternate solutions. Forty-nine (94.2%) felt the service fully answered their query, 2 (3.8%) partially, and 1 (1.9%) did not feel it answered their query. When asked if they knew who responded to their question, 47 (88.7%) responded pharmacist, 2 (3.8%) responded no, and 4 (7.5%) were unsure.

4.5.3. Who else do professionals contact for advice?

Professionals were also asked whether they had contacted anyone else, or used any other source of information before contacting the service. Around half (49.1%) had contacted the service as their first option. The different sources approached or accessed are show in Table fifteen.

Table fifteen: Sources of information used before contacting the service

Source	N	%
BNF (British National Formulary)	13	24.5
Hale 'Medications and Mothers milk' book	7	13.2
Wendy Jones Breastfeeding and Medications books	13	24.5
Breastfeeding Network website	22	41.5
A lactation consultant	3	5.7
A breastfeeding organisation e.g. La Leche League or ABM	2	3.8
National Breastfeeding helpline	1	1.9
Community pharmacist	2	3.8
Hospital/ Medicines Information Pharmacist	3	5.7
Manufacturer	1	1.9
UK Drugs in Lactation Advisory Service (UKDILAS)	5	9.4
A midwife or health visitor	4	7.5
Another database e.g. Lactmed	4	7.5

When asked why they went on to contact the service, the most common response was that they trusted the service more than other sources (53.4%), not being able to find a clear answer from other sources (22.6%), or wanting to double check the answer with the service (18.9%).

Professionals were also asked whether they knew about the factsheets available online. All knew about the factsheets, but the majority wanted to speak directly to someone at the service too (37.7%). A further third (37.7%) could not find a relevant factsheet, with others having often multiple queries and wanting more specific information (22.6%). Only one participant (1.9%) went straight to the service without looking at them.

4.5.6. How do professionals evaluate the service?

Professionals were asked how strongly they agreed with a series of statements around the service and their experience of it. These were grouped into those who agreed (strongly agree and agree) and those who disagreed (strongly disagreed and disagree). The results were

overwhelmingly positive, with only one respondent occasionally disagreeing with positive statements. The responses are shown in Table sixteen.

Table sixteen: Professionals evaluation of the service

	Agree		Disagree	
	N	%	N	%
I found the information very useful	52	98.1	1	1.9
I felt the service I received was very professional	51	96.2	1	1.9
I though the service I received was efficient	52	98.1	0	0
I felt the service I received was non-judgemental	50	94.3	0	0
I felt the service welcomed my enquiring as a professional	51	96.2	0	0
I would recommend the service to mothers	52	98.1	0	0
I would recommend the service to other professionals	52	98.1	1	1.9
I felt the service improved my knowledge	52	98.1	1	1.9
I felt the service enabled me to give better information to mothers	52	98.1	1	1.9
I felt that it improved my ability to support mothers	52	98.1	1	1.9
I felt I could contact the service again if I needed to	52	98.1	1	1.9
I felt listened to	51	96.2	0	0
I felt respected	51	96.2	0	0
I feel the service is a vital source of advice for parents	52	98.1	1	1.9
I would not have been able to give such informed support if the service did not exist	52	98.1	0	0
I feel like the service is an excellent source of advice for professionals to use	52	98.1	1	1.9
I feel like the service fills a gap for professionals who need specific advice	52	98.1	0	0
I think the service provides good information for mothers who need to stop breastfeeding	39	73.6	1	1.9
I think the service has a positive impact on maternal wellbeing	51	96.2	0	0
I would contact the service again if I needed to in the future	52	98.1	1	1.9

In the open-ended responses professionals raised a number of key elements that they valued about the service. Professionals repeatedly stated that the service was unique and invaluable and that they would be lost without it.

> *'This service is so essential for so many women and professionals. Having the correct, reliable information to base decisions on is hugely important, and there is no other service as tailored and knowledgeable'. (Breastfeeding counsellor)*

> *'It's been brilliant and helped me to support mums to make informed choices and continue breastfeeding where they thought they could not' (Health visitor)*

> *'Excellent online service and fills gap left by other resources'. (GP)*

In particular professionals described how the service improved their professional practice, giving them the knowledge, they needed, but also provided a useful place that could be trusted to signpost mothers to.

> *'This service has enabled me to support mothers with confidence when they have been advised by others they have to stop feeding because of medications they have been prescribed which was not actually the case. It is vital to have someone with some authority and expertise to give advice when as professionals we are often having to challenge advice given by GP's and consultants'. (Infant feeding lead)*

> *'Wendy makes me a better midwife. She helps me to support women in a way I could not if she wasn't there. Without Wendy I think there would be many many women who stop breastfeeding before they are ready and many babies who would not benefit from being breastfed. She is a star'. (Midwife)*

4.5.7. Does the service help mothers to breastfeed for longer?

Professionals were asked whether they felt the service enabled mothers to breastfeed for longer. One hundred per cent of professionals agreed that the service did so. Professionals

described how they were able to give mothers information from the service, or direct them to the service themselves, which in turn gave mothers the confidence and knowledge to carry on.

> *'Without Wendy and the service I would see so many more mums stop breastfeeding when they didn't want to'. (Health Visitor)*
>
> *'The service in my opinion is one of the most valuable good practice tools we have out there supporting women to breastfeed day to day' (Midwife)*
>
> *'I see mums every week who I know would have stopped breastfeeding if it wasn't for Wendy and that I'd be picking up the pieces not watching them and their babies thrive. (Health visitor)*

4.5.8. How could the service be improved?

All respondents were asked how they felt the service could be improved. Four key themes were raised. Again, increased funding was central, which in turn affected all other elements.

1. More funding to enable a sustained service into the future

The most commonly raised idea was increased and long-term funding to enable the service to support more mothers. Succession planning was again raised.

2. Greater publicity

Professionals wanted more mothers to know about the service, so that more mothers could benefit. Advertising in GP surgeries, pharmacies and in libraries was suggested.

3. Greater knowledge of the service amongst medical professionals

Increased knowledge was desired for all professionals who would prescribe medication, including pharmacists.

4. Extend the service

Professionals suggested a number of ideas of extending the service such as using Facetime, web chats or a text service.

4.5.9. Summary

Professionals highly valued the service for the support it enabled them to give mothers. They viewed it as an accurate and trusted source of evidence-based advice and used it both in their own practice and directed colleagues to it. The majority felt it made them better practitioners, improving the information they could give or signpost mothers to, and without it they would not be able to provide the same level of service. Many believed that, through the service, mothers were enabled to breastfeed for longer and have more confidence in doing so.

4.6 Evaluation of the drugs in breastmilk service: Mother supporters

4.6.1 Sample

Twenty-six mother supporters completed the questionnaire: 22 female and 4 male. Supporters had a mean age of 35.46 (SD: 7.91) with a range from 24 to 62. Sixteen (61.5%) lived in England, 6 (23.1%) in Wales, 1 (3.8%) in Scotland, 2 (7.7%) in Northern Ireland and 1 (3.8%) in ROI. All but three participants (11.5%) spoke English as their first language: the first language was of remaining were Lithuanian (1) or Polish (2). All participants identified as White British. Further details of the sample are shown in Table seventeen.

Table seventeen: Demographic background of mother supporters

Category	Sub category	N	%
Education	No formal qualifications	1	3.8
	GCSE or equivalent	6	23.1
	A level or equivalent	12	46.2
	Degree or equivalent	7	26.9
	Postgraduate	7	4.0
Relationship	Married / civil partnership	26	100
	Living with a partner	0	0
	Singe / divorced	0	0
	Widowed	0	0
Employment	Full time	19	73.1
	Part time	6	23.1
	No	1	3.8

4.6.2 Who did mother supporters contact the service for?

Four of the mother supporters (15.4%) contacted the service for a partner, 16 (61.5%) for a friend, 3 (11.5%) for a family member and 3 (11.5%) for another such as a colleague. The mean age of the baby for which the question was based 26.28 weeks (SD: 35.40) with a range from 1 – 104 weeks. One enquiry was on behalf of a pregnant woman. At the time of contact, 23 infants (88.5%) were exclusively breastfed for milk feeds, whilst 2 (7.7%) were mixed fed (and one infant had not been born yet). At the time of questionnaire completion, 22 infants (84.6%) were still receiving breastmilk.

4.6.3. How did supporters contact the service?

Twenty-four (92.3%) contacted the service via Facebook and two (6.7%) via email. The majority (n = 19, 73.0%) had not used the service before. Twenty (76.9%) stated their query was answered by a pharmacist. Three quarters contacted the service once, and a quarter contacted

the service twice. Nineteen participants (73%) received a response in less than one hour, rising to 25 (23.1%) within three hours and all within six hours. In terms of where supporters found out about the service, the most common response was Facebook (n = 10, 38.5%), following by word of mouth (n = 5, 20.0%), a breastfeeding organisation (n = 5, 20.0%), the BFN website (n = 3, 12.0%), and from a health professional (n = 2, 7.6%)

4.6.4. Why did supporters contact the service?

For reason for contacting the service, 8 (30.8%) gave a general response of checking the safety of a medication. For specific medications the most common reasons were antidepressants (n = 4, 15.4%), hospital procedures (n = 3, 11.5%), antihistamines (n = 2, 7.7%), analgesics (n = 2, 7.7%), antibiotics (n = 1, 3.8%) and cough and cold medications (n = 1, 3.8%). Other medications included steroid injections, miscarriage, thrush, and thyroid medications.

Twenty (76.9%) were given the advice that it was fine to continue breastfeeding, 3 (11.5%) to continue but watch out for any effect on the baby, and 3 (11.5%) directed to factsheets to make an informed decision. Twenty-one (81.6%) went ahead with the medication/ procedure and continue breastfeeding. One (3.8%) temporarily stopped breastfeeding to take the medication, 1 (3.8%) didn't take the medication, 2 (7.7%) no longer needed the medication, and 1 (3.8%) stopped breastfeeding.

The majority of supporters went straight to the service as their first point of contact (n = 21, 80.0%). The remainder accessed the service through reading the BFN website (n = 5, 19.2%). However, a number of supporters started their search after discussion with a GP (n = 2, 7.4%) or pharmacist (n = 2, 7.4%). Of those, one supporter contacted the service because they were told breastfeeding must stop, one because they were told breastfeeding could continue but wanted to check, two because they could not get an informed response, and four because they were getting mixed messages. One supporter was told to contact the service. Altogether, all respondents chose to go on to contact the service as they trusted it more than other sources.

4.6.5. How do supporters evaluate the service?

Supporters were also asked about their use of the service and their experience of it. These were grouped into those who agreed (strongly agree and agree) and those who disagreed (strongly disagreed and disagree). The results were overwhelmingly positive, with only one respondent occasionally disagreeing with positive statements. The responses are shown in Table eighteen.

Table eighteen: Supporters evaluation of the service

	Agree		Disagree	
	N	%	N	%
I found the information very useful	26	100	0	0
I felt the service I received was very professional	25	96.5	0	0
I though the service I received was efficient	26	100	0	0
I felt the service I received was non-judgemental	26	100	0	0
I felt listened to	25	96.5	0	0
I felt that it improved my wellbeing	23	95.2	0	0
I felt respected	25	96.5	0	0
I felt that my choices were supported	25	96.5	0	0
I did not feel pressured to do any particular thing	26	100	0	0
I felt that someone cared about my experience	26	100	0	0
I felt I could contact the service again if I needed to	26	100	0	0
The service felt like a lifeline to good information	26	100	0	0
I felt relieved I could pass this information back to the mother I was supporting	26	100	0	0
I felt that the information I received helped the mother I was supporting make a decision	25	96.5	0	0
I felt connected to a supportive community	26	100	0	0
I think the service helped the mother I was supporting breastfeed for longer	26	100	0	0
I would contact the service again if I needed to	26	100	0	0
I would recommend the service to others	26	100	0	0
I am very satisfied by the service I received	26	100	0	0

Exploring participants open ended responses, themes again reflected key words of reassurance, support, and confidence. Responses were viewed as quick, and the source very much trusted. The service was viewed as enabling women to continue breastfeeding for longer.

'Wendy was so calm and reassuring which is half the battle when you are worried about your baby and your partner' (partner)

'I can't believe how quickly I got a response' (friend)

'The service is invaluable' (friend)

'I don't think she would be breastfeeding without access to this information' (friend)

4.6.6 Summary

Mother supporters felt comfortable contacting the service and that their query was handled sensitively and non-judgementally. The service enabled them to support a partner or friend at a difficult time, and they valued being able to give this support, especially when they could see the mother could then continue breastfeeding.

5. Discussion

5.1 Overview of the evaluation

This evaluation explored the impact of the Breastfeeding Network's Drugs in breastmilk information service on maternal ability to continue breastfeeding after being prescribed a medication. It explored how breastfeeding organisations, mothers, professionals, and mother supporters used the service, what information they received, and how they evaluated the impact of the service on their knowledge and emotional wellbeing (or ability to practice for health professionals).

Overall it showed that the service was highly valued by breastfeeding organisations, mothers, professionals and mother supporters. It provided trusted, accurate, evidence-based information at a time when mothers felt vulnerable, enabling them to breastfeed for longer and protecting their health and wellbeing.

The service was perceived as unique, valuable and providing a service that was irreplaceable. Specifically, it enabled a significant number of women who had been told they could not breastfeed whilst taking a medication (or who received little information) to make an informed and evidence-based decision to continue. This had multiple positive influences on mothers' physical and mental health.

Alongside this the service, despite the volume of calls and reliance predominantly on one individual, scored highly across all items in terms of being respectful, welcoming, and non-judgemental. Responses were often made within a few hours, fully providing the vast majority of respondents with full information about their query. All felt welcome in contacting the service – mothers, health professionals, and mother supporters alike.

5.2 Key findings

The findings and quotes are detailed and to some extent speak for themselves. However, four main points must be highlighted here:

1. The service enables many women to breastfeed for longer

2. The service meets gaps in professional care

3. The service protects maternal mental health

4. The service protects mothers from forced 'choices' between their own physical health (e.g. take a medication) and wellbeing (e.g. continue breastfeeding), and between managing what they perceived to be a choice between their own health (e.g. take a medication) and the health and wellbeing of their baby (e.g. continue breastfeeding).

5.2.1. The service enables women to breastfeed for longer

The majority of women who responded to the evaluation were still breastfeeding their baby after contacting the service, with only two being told they could not breastfeed and take a suitable medication. We know that many women's experience was that their breastfeeding journey had been saved by the service. Almost all women who were told by a GP or pharmacist they could not breastfeed and take their medication but contacted the service for a second opinion were given further information and were still breastfeeding at the time of completion. On top of this, a large number were also given inconsistent, confusing, or absent advice, and correct information from the service enabled this group to also continue breastfeeding.

The service was accredited by all groups of participants as playing a role in helping women to feel more confident to make an informed decision. All groups were deeply concerned at any hypothetical possibility of the service not being sustained in the future, stating there was no comparable replacement.

It could well be that women who receive positive news and support to enable them to continue breastfeeding are more likely to respond to the evaluation. However, in the initial interview with the lead pharmacist, she estimated that over 90% of women who contact the service could continue breastfeeding alongside their medication. Therefore, we would expect to see low numbers of women responding who had to stop breastfeeding.

Also, as part of their responses, breastfeeding organisations, women, health professionals, and mother supporters all described how the service enables continued breastfeeding by offering not only useful information but reassuring them and helping women feel more confident. The majority of mothers who responded credited the support they received in enabling them to continue breastfeeding for longer. Those who were advised that they did need to stop breastfeeding still evaluated the professionalism and approach of the service as valuable.

5.2.2. The service meets gaps in professional care

As noted, many women received inconsistent, incomplete or incorrect advice from a GP or other health professional which led them to the service. Some went straight to the service, often after reading unclear information on manufacturer leaflets. What is stark is that although some women were diagnosed with complex cases or rarer illnesses, the most common queries to the service were for relatively common medications such as antibiotics, antihistamines, analgesics, antidepressants and hospital procedures. Given the frequency that mothers may require medications in this category, it could have been expected for all health professionals to know which are suitable for breastfeeding, and to explain this clearly to mothers.

However, receiving incorrect information from health professionals regarding breastfeeding and medication is unfortunately not uncommon. In one Australian study, 10% of women who developed mastitis were told by their GP to stop breastfeeding, or were prescribed inappropriate antibiotics, despite knowledge that continued breastfeeding is recommended to prevent more serious infection[39]. And those statistics are for a relatively common disorder affecting breastfeeding women. In another study, only 47% of physicians knew that most women can take antiepileptic medicines and safely breastfeed[40]. And when it comes to simple

over the counter medications, in another study 55% of pharmacists said that they wouldn't recommend any medications at all for OTC illnesses such as cough, cold, analgesia, constipation, diarrhoea, insomnia and heartburn[41]. In another study with GPs, less than a third knew that common medications such as ibuprofen could be used when breastfeeding[42]. And this information matters. Women who are told by their GP to stop breastfeeding in order to take a medication are more likely to stop[43].

Conversely, some health professionals do not even ask women if they are breastfeeding when prescribing a medication, leaving women unsure whether it is safe. One study suggested over half of pharmacists didn't routinely ask a woman if she was breastfeeding[44]. In another, just 9% regularly asked[45]. This also changes with age. In one study whilst 93% of GPs stated they would ask a woman with a baby if she was breastfeeding, only 22% they regularly would for a toddler[22]. This means many women are left confused, or unable to make evidence-based decisions.

It is perhaps unsurprising that one study found that only 28% of women were satisfied with advice from a GP or pharmacist about medicines and breastfeeding[22]. The drugs in breastmilk service is clearly combatting this lack of knowledge and support for breastfeeding women. It is recognised that medical professionals today would have to do a large amount of reading every week in order to keep up to date on every medication[46]. Many have insufficient training in the first place[47]. Breastfeeding women may even be a minority group in their care. This isn't helped by a lack of manufacturer data, complicated by the issues of conducting randomised controlled trials with mothers and babies[8].

Legal concerns do arise. In Australian research exploring the experiences of GPs in prescribing medication for breastfeeding women, 76% stated how legal concerns affected their decision making, leading them to err on the sign of caution[42]. This in itself is an interesting consideration for how breast milk is viewed and valued – why is it not a risk to tell a mother she needs to stop breastfeeding, despite the vast literature showing the increased risks to her own health and that of her baby? This will in part be influenced by some medics not thinking there is any real

difference between breast and formula feeding and it is a simple equal choice[29].

This is despite very little published evidence that medications during breastfeeding will harm the infant. Many medications cannot physiologically enter breastmilk, whilst others will enter in very small amounts, too small to have an impact. Many medics appear to translate some known risks of potential harm from pregnancy through to breastfeeding – but the placenta and breast are different organs[48].

One review of studies published up to 2003 found that just 100 cases of reaction were identified, but none of these were definite. Around half were 'probable' with the other half 'possible'. Two thirds of cases were for neonates with only 4% of cases for babies over 6 months old. Three babies in the sample died, all of whom were exposed to drugs that depressed the central nervous system but all had extenuating circumstances. The authors conclude '*By taking a few simple precautions in drug selection and considering the infant's age, breastfeeding rarely needs to be discouraged or discontinued when a mother needs drug therapy*'[28]. Other authors agree that the majority of medications will be safe for breastfeeding mothers[21, 30, 49].

Of course, not all GPs and pharmacists will be giving poor information and some participated in this evaluation after using the service themselves. We cannot know from this evaluation how many women received positive support, from passionate and knowledgeable professionals, and therefore did not need to contact the service. We can only know that a significant number – based on the volume of queries to the service – are not. One recommendation would be that more medics work closely with the service, referring to it themselves, or referring their patients where relevant. Much of the information is available in textbooks written by the lead pharmacist, yet it is unknown how many health professionals use these resources. One option that could be explored going forward is a potential collaboration with UKDILAS, to strengthen and connect both organisations and service users.

Additionally, breastfeeding education and update training should be an established part of the curriculum and CPD training requirements for medics. It should not be acceptable for medical knowledge of a major part of the body to be absent, or for a charity funded service to need to

provide information on its function. Research shows that GPs and paediatricians would welcome further training on infant feeding[50]. One useful step for GPs would be for them to join and read the resources of the UK GP Infant Feeding Network (GPIFN) on their website and social media pages. However, again this group is voluntary based, bringing us back to an overreliance on volunteers and charity funding across the field of infant feeding. Central, sustainable funding is needed.

5.2.3. The service protects maternal mental health

One of the key findings that mothers in particular raised was the protective impact the service was felt to have upon wellbeing. The service is not simply something that helps mothers breastfeed for longer – it is a form of reassurance and care for mothers, provided often at a vulnerable point in their lives. The data that compared mothers' emotions before and after using the service was stark –significant positive changes were made for every emotion listed. Even where mothers were advised to stop breastfeeding women still saw a rise in wellbeing, just from being able to get an evidence-based response from a trusted and supportive expert.

A positive breastfeeding experience can be protective for maternal wellbeing both psychologically in terms of meeting her own infant feeding goals[4] and physically through the protective effect of oxytocin upon stress and exhaustion[51]. However, when women are unable to meet their breastfeeding goals, especially if they feel forced to stop before they are ready due to factors outside of their control, they can feel a whole host of emotions from grief, to anger, through to guilt and sadness. Their risk of postnatal depression also increases[16]. Telling a woman to simply take a medication and stop breastfeeding is therefore not the end of the story – it is likely that it could have serious consequences for her wellbeing. This must be part of any consideration when suggesting a woman stops breastfeeding in order to take a medication.

5.2.4. The service protects mothers from a forced 'choice' between their physical health and their emotional wellbeing

A further critical finding is the extent to which women will go in order to breastfeed their baby. We know how much breastfeeding means to many women, but this evaluation has shown that many will value breastfeeding over and above other things, including their own physical health. Going into this evaluation we expected to see that women would value being able to continue breastfeeding if possible. However, we did not expect to see the strength of the reaction that if made to choose, it would be the medication that was stopped, rather than breastfeeding. This reflects previous findings suggesting that around 20% of women prescribed antibiotics when breastfeeding do not start or finish the course because of breastfeeding concerns[52].

This is a serious issue. Some women noted the medication they hoped to take was not critical, but many would be left in unnecessary discomfort or pain if they choose to not take an over the counter medication that they would otherwise have taken. Other women are placed in more serious situations. The media all too sadly alerts us to cases where women have decided not to take medication in order to breastfeed with catastrophic consequences.

5.3 Limitations

It is recognised that this evaluation provides a specific snapshot from those who chose to participate in the research. It may well be that those who received high quality information were more likely to come forward to participate. Those who are still breastfeeding, or more invested in supporting breastfeeding, may have also been more likely to see the survey advert, albeit it was shared widely across social media (with at least 500 shares of the original study advert). Moreover, any evaluation of a service that offers women important information when they request it, free of cost, is likely to be rated positively. However, in the authors' view, the scale of positivity in responses exceeded this potential effect.

It could also be that those who were told they needed to stop breastfeeding avoided any memory of breastfeeding or the service, for reasons not related to the support they received but the grief they experienced at having to stop breastfeeding. However, information from the lead pharmacist confirms that the majority of women who contact the service received advice that they could continue breastfeeding, so these data are unlikely to be heavily skewed.

In terms of demographic background, participants spanned a fairly wide diversity for maternal age, education, and occupational background. However, it is notable that the majority of respondents were of White British background, falling below expected random participation numbers based upon UK demography (approximately 95% of respondents were White British compared to a population rate of 85%). Understanding whether this is a lower level of access to the service (and whether this is through choice or a lack of reach) or a lower participation in research (or both) is important. In the UK mothers from non-White backgrounds have a longer breastfeeding duration[3], coupled with an increased level of health issues[53], highlighting a likely increased need for the service. Ensuring support reaches all population groups is important.

Limitations aside, the evaluation identified how positively the service was viewed across groups, from breastfeeding organisations to mother supporters. All groups described a service that was accurate, trusted, and evidence based, and that of one which filled a gap in knowledge, or acted as a safety net against incorrect or inconsistent advice from other health professionals. The service not only reassures women at a vulnerable time but enables many to breastfeed for longer whilst also maintaining their health, with impact on their emotional wellbeing.

6. Conclusions

The service is filling a gap, that is rightly or wrongly not provided by the clinical skills of at least some prescribers in the UK. The gap in service identified in 2007 remains, this may be due to a combination of factors such as lack of professional training and professional beliefs shaped by prevailing culture where stopping breastfeeding is seen as unproblematic. These factors are amenable to change but would require resourcing over several years.

For over a decade the Drugs in Breastmilk service has provided an information service and factsheets. The service is highly valued by breastfeeding organisations, mothers, health professionals and mother supporters, and recognised as a unique source of reliable, accurate evidence-based information that leaves mothers and professionals alike reassured and empowered. The vast majority of mothers and those supporting them come into the service confused and unsure, and leave it feeling their query has been fully answered, and their wellbeing improved; regardless of whether they are able to continue breastfeeding.

The service is viewed by breastfeeding organisations, mothers, health professionals, and mother supporters as supporting women to breastfeed for longer, both through providing them with accurate information, and confidence to continue. This, in turn, not only protects the physical health of mothers and babies, but also the *wellbeing* of mothers. The service was referred to as 'saving lives', indicating that, without it, many mothers would feel a deep loss.

Without the service, many women would be forced to make the choice between either stopping breastfeeding before they are ready, therefore risking their emotional health, or risking their physical health because they want to prioritise breastfeeding their baby. No mother should have to make that decision unduly, and neither option puts infant and maternal health first – a baby needs breastmilk, but they also need a healthy mother.

In its current format the drugs in breastmilk service is not sustainable long term, either in terms of finance or personnel. Participants called for the service to be sustained and expanded in the future. Four key recommendations arose across the groups. Central to this was the need for an increase in sustained funding, in order to enable further recommendations, which if not

followed risk sustainability of the service will be in question, and expansion impossible. Central government funding for the service is an obvious solution. Short and long term health benefits of both breastfeeding and of taking prescribed medication, have the potential to provide economic cost savings [54]. The number of women in this survey alone who stated that they continued breastfeeding because of the information they received from the service, suggests an expanded service could be important in reducing burden of disease and in the long term.

6.1. With funding in place, the following key proposed improvements arose:

1. Train more specialist staff to enable a wider reach. Review consultancy costs, create job descriptions and roles. This must include succession planning.
2. Once funding and staff are in place, increase the visibility of the service. Posters in pharmacies, clinics, and venues such as libraries and children's centres were suggested.
3. Ensure the service and information reaches GPs and pharmacists. It is recognised that keeping up to date is time consuming, but at the very least they should signpost to the service, if not use it themselves when prescribing.
4. Offer further options for contact such as text, facetime, and a webpage with webchat
5. Consider whether offering different languages is viable, at least for the factsheets
6. Have a search function online for the factsheets.
7. Produce simplified versions of the factsheets, or a summary heading, for those who want a quick response or have literacy or language barriers.

In final reflection, this evaluation has shown the strength of positive regard that the drugs in breastmilk service has amongst breastfeeding organisations, mothers, those that support mothers, and health professionals. Investment in this service would most likely enable more women to breastfeed for longer, to protect and prioritise both their physical and emotional health, and ultimately make a real difference to the lives of new families in the UK today.

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8.1 Appendix One: Mothers specific reasons for contacting the drugs in breastmilk service

Reason	N	%
Antivirals (chicken pox & shingles	5	1.9
Antihistamine / allergy	10	3.7
Antidepressants	20	7.4
Antibiotics	19	7.0
Vaccinations	2	.7
Analgesics	22	8.1
Epilepsy drugs	1	.4
Asthma medications	1	.4
Herbal remedies	8	3.0
Cholesterol lowering medication	1	.4
Blood pressure treatment	3	1.1
Coughs and colds	2	.7
Contraceptives & hormonal medications	6	2.2
Dermatological conditions & treatments	6	2.2
Medication to treat or prevent blood loss	3	1.1
Steroid injections	2	.7
Travel medications & treatment	4	1.5
Ear, nose & throat conditions	4	1.5
Digestive conditions	4	1.5
Musculoskeletal conditions	6	2.2
Hospital, surgical & dental procedures & related treatment	23	8.5
Anaesthetics (local & general)	4	1.5
Morning Sickness & Hyperemesis	3	1.1
Miscarriage	3	1.1
Induction of birth	1	.4
Termination of birth	1	.4
Mastitis	2	.7
Thrush	7	2.6
Migraines	7	2.6

8.2 Appendix Two: Mothers' before and after contacting the service emotions

Appendix two shows the mean scores (and standard deviation) for each emotion before and after contacting the service. The paired samples t test examines whether these two mean scores are significantly different to each other. A significance level of $p < 0.05$ is considered a significant difference, with the smaller the number the greater the significance.

	Before you contacted the service, how strongly did you feel the following emotions around feeding your baby whilst being recommended to take a medication? [Five-point scale 1 = strongly agree to 5 = strongly disagree].	**After you contacted the service**, how strongly did you feel the following emotions around feeding your baby whilst being recommended to take a medication? [Five-point scale 1 = strongly agree to 5 = strongly disagree].	Paired samples t-test (Before vs After contacting the BFN service)
Understood	3.53 (1.02)	1.50 (0.77)	$t(269) = 26.32$, $p < 0.001$
Cared For	3.28 (0.07)	1.54 (0.05)	$t(267) = 21.55$, $p < 0.001$
Relaxed	3.81 (1.05)	1.76 (0.92)	$t(269) = 24.75$, $p < 0.001$
Happy	3.75 (1.04)	1.72 (0.90)	$t(267) = 23.70$, $p < 0.001$
Conflicted	1.98 (0.99)	4.17 (0.99)	$t(269) = -24.14$, $p < 0.001$
Isolated	2.54 (1.17)	4.29 (0.83)	$t(267) = -19.96$, $p < 0.001$
Worried about making the 'right' decision	1.38 (0.71)	4.11 (1.04)	$t(269) = -35.42$, $p < 0.001$
Anxious about harming my baby	1.33 (0.63)	4.14 (0.06)	$t(269) = -39.10$, $p < 0.001$
That I had enough information	3.81 (1.19)	1.58 (0.80)	$t(269) = 23.79$, $p < 0.001$
Distressed	2.10 (1.09)	4.28 (0.95)	$t(269) = -24.81$, $p < 0.001$
Anxious	1.76 (0.93)	4.17 (1.04)	$t(269) = -29.43$, $p < 0.001$
Unsure	1.54 (0.77)	4.23 (1.03)	$t(268) = -33.52$, $p < 0.001$
Confident	3.81 (1.01)	1.74 (0.94)	$t(268) = 24.30$, $p < 0.001$
Informed	3.79 (1.06)	1.52 (0.84)	$t(267) = 26.66$, $p < 0.001$
Confused	1.98 (0.96)	4.23 (0.99)	$t(266) = -25.91$, $p < 0.001$