# 'A lifeline when no one else wants to give you an answer'

# An evaluation of the Breastfeeding Network drugs in breastmilk service [Executive summary]

Professor Amy Brown, Professor of Child Public Health, Swansea University
Dr Gretel Finch, Research officer, Swansea University
Dr Heather Trickey, Research Fellow, DECIPHer, Cardiff University
Dr Ruth Hopkins, Lecturer in Public Health, Swansea University









Commissioned by the Breastfeeding Network

**March 2019** 

This report was funded in part by a research grant from the Breastfeeding Network and by an anonymous donation from a BfN Supporter.

Data collection and analysis was carried out independently by the research team.

Views expressed in this report are those of the researcher and not necessarily those of the Breastfeeding Network.

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

For further information about this report please contact: Professor Amy Brown Department of Public Health, Policy and Social Sciences Swansea University, UK

Tel: +44 1792 518672

Email: a.e.brown@swansea.ac.uk

#### To cite this document:

Brown, A., Finch, G., Trickey, H., Hopkins, R. (2019) 'A lifeline when no one else wants to give you an answer: an evaluation of the Breastfeeding Network drugs in breastmilk service'. Breastfeeding Network: Scotland

#### 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.

#### **Context**

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

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<sup>6</sup>. 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<sup>7</sup>. However, despite the majority of medications being safe to take during breastfeeding<sup>8</sup>, women often report that they receive conflicting, inaccurate, or simply no advice to help them make an informed choice<sup>9</sup>. 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<sup>10</sup>.

In 2007 in response to this need the Breastfeeding Network set up the Drugs in breastmilk information service<sup>11</sup>. Anecdotally, and from previous published small-scale evaluation with users of the service (n = 101)<sup>12</sup>, 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.

# 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

# **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.

# References

- 1. Victora CG, Bahl R, Barros AJ, França GV, Horton S, Krasevec J, Murch S, Sankar MJ, Walker N, Rollins NC, Group TL. Breastfeeding in the 21st century: epidemiology, mechanisms, and lifelong effect. The Lancet. 2016 Jan 30;387(10017):475-90.
- 2. Brown A. Breastfeeding as a public health responsibility: a review of the evidence. Journal of Human Nutrition and Dietetics. 2017 Dec;30(6):759-70.
- 3. McAndrew F, Thompson J, Fellows L, Large A, Speed M, Renfrew MJ. Infant feeding survey 2010. Leeds: Health and Social Care Information Centre. 2012 Nov 20.
- 4. Brown A. What do women really want? Lessons for breastfeeding promotion and education. Breastfeeding medicine. 2016 Apr 1;11(3):102-10.
- 5. Fox R, McMullen S, Newburn M. UK women's experiences of breastfeeding and additional breastfeeding support: a qualitative study of Baby Café services. BMC pregnancy and childbirth. 2015 Dec;15(1):147.
- 6. Saha MR, Ryan K, Amir LH. Postpartum women's use of medicines and breastfeeding practices: a systematic review. International breastfeeding journal. 2015 Dec;10(1):28.
- 7. Schirm E, Schwagermann M, Tobi H, de Jong-van den Berg LT: Drug use during breastfeeding: A survey from the Netherlands. Eur J Clin Nutr. 2004, 58 (2): 386-90. 10.1038/si.ejcn.1601799.
- 8. Jones W. Breastfeeding and Medication. Routledge; 2018 May 11.
- 9. Hussainy SY, Dermele N. Knowledge, attitudes and practices of health professionals and women towards medication use in breastfeeding: A review. International breastfeeding journal. 2011 Dec;6(1):11.
- 10. Amir LH, Raval M, Hussainy SY. Breastfeeding information in pharmacology textbooks: a content analysis. Breastfeeding Review. 2013 Aug;21(2):31.
- 11. <a href="https://www.breastfeedingnetwork.org.uk/detailed-information/drugs-in-breastmilk/">https://www.breastfeedingnetwork.org.uk/detailed-information/drugs-in-breastmilk/</a>
- 12. Rutter PM, Jones W. Enquiry analysis and user opinion of the Drugs in Breastmilk Helpline: a prospective study. International breastfeeding journal. 2012 May;7(1):6.