



**University of Dundee**

### **Routinely collected infant feeding data**

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1           **1. Title**

2   **Routinely collected infant feeding data: time for global action in the era of big data**

3

4           **2. Word Count**

5   Abstract = 39 words

6   Main body of text = 1638

7   References = 21

8           **3. Authors**

9

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40           **4. Acknowledgements**

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50 research including the UK National Institute for Health Research.

#### 51 **6. Conflict of Interest Statement**

52 Catherine Chamberlain has used routinely collected perinatal data in research to improve maternal  
53 health outcomes.

54 Heather Whitford, Pat Hoddinott, and Lisa Amir have used routinely collected infant feeding data for  
55 infant feeding research.

56 Mary Renfrew has used routinely collected infant feeding data for infant feeding research and to  
57 inform policy development, and has been a collaborator on the UK Infant Feeding Survey.

58 Leanne Jones has completed a systematic review of breastfeeding outcomes reported in studies  
59 evaluating interventions used to support breastfeeding. Based on this we are preparing a global  
60 Delphi survey to reach consensus on the most appropriate and important core outcomes to women,  
61 clinicians and policy makers.

62 All authors are currently developing a recommended core-outcomes set for a Cochrane Generic  
63 Protocol for Cochrane Systematic Reviews of breastfeeding interventions.

64

65 **7. Contributor statement**

66 All authors conceived the article. HW drafted the manuscript. All authors contributed to drafts.

67

68 **Title**

69 **Routinely collected infant feeding data: time for global action in the era of big data**

70

71 **Abstract**

72 This commentary sets out how routinely collected data, sometimes referred to as *Big Data* could  
73 strengthen the global evidence and policy base, as has been demonstrated for smoking cessation.

74 An international collaborative effort is called for to progress this.

75

76 **Keywords**

77 Infant feeding; monitoring and evaluation; public health; breastfeeding

78

79 **Key Messages**

80 • International consensus on the collection and use of routine data for infant feeding is  
81 currently lacking.

82 • The use of routine data has been shown to be a powerful tool for influencing policy, practice  
83 and research in other areas of public health.

84 • The development of internationally agreed indicators and core outcomes and improved use  
85 of routinely collected infant feeding data has the potential to re-invigorate global action on  
86 breastfeeding.

87 **Main text**

88 Breastfeeding is important globally for healthy populations, with compelling evidence to support its  
89 role in preventing the deaths of up to 823 000 children and 20 000 mothers each year (Rollins et al.,

90 2016). The 2016 *Lancet* series on breastfeeding has argued that global action to support  
91 breastfeeding has stalled and identified the lack of reliable standardised indicators as hindering  
92 effective progress (Victora et al., 2016). We argue that routine data and data linkage are crucial to  
93 inform global research and policy effectiveness (Jorm, 2015), but the collection and use of such data  
94 – both breastfeeding and the use of breast milk substitutes – lags well behind other health related  
95 behaviours like smoking. We outline the key issues affecting development of reliable infant feeding  
96 indicators and use of routine data that need to be addressed.

97 The power of routine data to re-invigorate global action has been demonstrated in the evaluation of  
98 tobacco policy on infant health in high income countries (Cox, Martens, Nemery, Vangronsveld, &  
99 Nawrot, 2013) and in evaluating infectious disease programs in low-middle income countries  
100 (Harries, Zachariah, & Maher, 2013). Large scale evaluations of natural experiments using routine  
101 data are valuable and often the only practicable means of evaluating the impact of complex systems  
102 interventions (Rutter et al., 2017) and changes in policies and services on population health  
103 (Ajetunmobi et al., 2013; Jorm, 2015). The collection and use of standardised data can also facilitate  
104 international research collaboration, enable effective data synthesis, and minimise research waste  
105 (Ioannidis et al., 2014). Although non-experimental analysis of routine data cannot determine cause  
106 and effect, it can contribute to knowledge and understanding that will advance infant feeding  
107 science.

108 Data on infant feeding practices and country specific policies are already gathered in over 70  
109 countries worldwide (WBTi, 2017) as called for in the World Health Organization (WHO) Framework  
110 to increase breastfeeding (WHO/UNICEF, 2003). The World Breastfeeding Trends initiative (WBTi)  
111 compiles country-level data on national policies and indicators of infant feeding, including  
112 breastfeeding initiation and duration. National groups and/or core partners collect data within each  
113 country. This potentially offers global and national benchmarks for policy makers and enables inter-  
114 country comparisons on key indicators of practice, protection, support and promotion of

115 breastfeeding (WBTi, 2017). However, there are wide disparities in the types and methods of routine  
116 infant feeding data collected between countries (Rollins et al., 2016). There are also barriers for  
117 countries to overcome to set up systems, achieve effective access and use data to its full potential.  
118 Financial constraints and the relative priority given to WBTi data collection has affected the rigor or  
119 completeness. Most data are collected at routine health service attendances, thus the timing will be  
120 pragmatically chosen. Routine health care contact points differ between and within countries  
121 according to purpose, such as hospital discharge, child development checks, immunisation  
122 schedules, registration with a paediatrician, or collection of vitamins. Some countries only collect  
123 infant feeding data from periodic surveys – such as the National Health and Demographic Surveys in  
124 South East Asia (Dibley, Senarath, & Agho, 2010). Other countries have very limited systems in place  
125 for collecting routine infant feeding data, such as China and Russia (UNICEF, 2016).

126 Effective data use is affected by the level of detail collected. Understanding the differential impact  
127 of various infant feeding behaviours on health outcomes requires detailed measures including  
128 initiation and exclusivity of breastfeeding; whether the baby is breastfed or receives expressed  
129 breast milk by bottle/cup or other method; and whether expressed breast milk is fresh or frozen,  
130 mother's own or donor. However this detail is rarely recorded. Furthermore, data on the use of  
131 breast milk substitutes, such as infant formula brand, other liquids, and type, timing, and amount of  
132 solids used, are particularly poorly collected. The type of formula used is rarely if ever recorded,  
133 despite the fact that products differ across brand and over time, with differential impact on  
134 outcomes such as atopic disease (Renfrew et al., 2012). This seriously hinders the ability to answer  
135 important questions, such as the impact of not breastfeeding on the microbiome in different care  
136 contexts, the impact of breast milk substitute use on infectious diseases, the occurrence of cancer in  
137 women, or the effect on especially vulnerable infants such as those born preterm (Renfrew et al.,  
138 2012).



139 While some countries have relatively robust systems for the collection and analysis of routine infant  
140 feeding data, these can be adversely affected by policy changes or funding cuts. For example,  
141 Scotland was routinely collecting breastfeeding outcome data at six to eight weeks and eight  
142 months, at the start of the 'Breastfeeding in Groups (BIG)' trial (Hoddinott et al., 2009). However,  
143 halfway through the trial, the collection of eight-month routine data ceased, and a potentially  
144 important trial outcome – breastfeeding duration - could therefore not be reported. Systems and  
145 resources for storing, linking and analysing data are also variable. A recent Australian trial,  
146 Supporting breastfeeding In Local Communities (SILC), found that using routine infant feeding data  
147 as the primary outcome required time-consuming work to extract the data from individual council  
148 databases (McLachlan et al., 2016). Relevant data may be stored in the mother's maternity database  
149 (such as gestation at birth, or pregnancy complications) or the child's record, however the ability to  
150 link these datasets may be lacking. Requirements to collect core data in a standardised format and  
151 enable linkage would strengthen analyses of the relationships between infant feeding exposures and  
152 outcomes. One example might be the question of whether prematurity or the method of feeding  
153 affects infant health outcomes.

154 While the World Health Organization/UNICEF have suggested standardised methods of collecting  
155 infant feeding information, not all countries gather data in the same way. Published analyses are  
156 therefore "...based on a limited number countries, for a limited number of indicators, and a limited  
157 number of background characteristics" (UNICEF, 2016, p. 101). Analyses are generally not available  
158 for high-income countries, where breastfeeding rates are particularly low (Victora et al., 2016).  
159 Some indicators may need to be tailored to reflect the different epidemiological patterns of  
160 breastfeeding in different countries, for example measuring sales of formula in countries with very  
161 low breastfeeding rates (Baker et al., 2016).

162 The lack of an internationally agreed core outcome set for infant feeding limits opportunities to  
163 compare, contrast and combine data (WBTi, 2017; Williamson, Altman, Blazeby, Clarke, & Gargon,

164 2011). This deficiency poses a considerable challenge in finding reliable and complete data for  
165 international comparisons (Victora et al., 2016). Standardised routinely collected infant feeding data  
166 by country would require internationally agreed definitions and consistent timing of data collection.  
167 It could be used by researchers and policy-makers to guide selection of primary or secondary infant  
168 feeding outcomes for trials of new and complex interventions to improve breastfeeding outcomes,  
169 improve monitoring of usual care, or support the evaluation of policy and systems level changes (for  
170 example Hoddinott et al., 2009; Nickel et al., 2017; Relton et al., 2018). This alignment would enable  
171 the use of more practicable and sophisticated strategies to evaluate complex breastfeeding  
172 interventions, for example comparing infant feeding rates and outcomes between populations over  
173 time. Nesting trials within large cohorts with linked data offers opportunities for efficiency. Evolving  
174 synthesis methods such as network meta-analysis offer increased opportunities to demonstrate  
175 relative benefits in the future. However these opportunities can only be realised if the data are  
176 available and accurate.

177 There are relevant lessons from the successes in other fields of public health such as smoking. For  
178 example fluctuating daily smoking and e-cigarette behaviours present similar data collection  
179 challenges to variations in mixed feeding with breast milk, formula and other liquids. In the 1990s,  
180 Professor Lumley demonstrated the value of strong health outcome data for leveraging commitment  
181 to reduce smoking during pregnancy (Lumley, Oliver, & Waters, 1999). Observational evidence of  
182 infant health outcomes among women who smoke is limited due to very serious concerns about  
183 confounding. Lumley et al (1999) conducted a meta-analysis of maternal and infant health  
184 outcomes from trials enrolling women who smoked during pregnancy, who had been randomised to  
185 a smoking cessation intervention or control. The findings clearly illustrated not only a reduction in  
186 smoking in late pregnancy but importantly, a significant reduction in preterm births and low birth  
187 weight among infants of women receiving smoking cessation interventions (Lumley et al., 1999). This  
188 seminal Cochrane systematic review, and its subsequent updates, have been fundamental in  
189 demonstrating the health benefits and direct health system cost savings from investments in

190 smoking cessation interventions, estimated to be in excess of 500 million pounds per annum in the  
191 UK alone (Taylor, 2009). It did not answer every question about outcomes of smoking in pregnancy,  
192 but established a platform for further refinement and exploration of the data.

193 We argue that international agreement to develop reliable indicators and improved use of routinely  
194 collected infant feeding data are needed to re-invigorate and evaluate global action on  
195 breastfeeding. There is an urgent need to reach consensus on recognised, standardised definitions in  
196 every country. As a preliminary step, development of a core outcome set for a Cochrane Generic  
197 Protocol for Cochrane Systematic Reviews of breastfeeding interventions is in progress. Our team  
198 has completed a scoping review of breastfeeding outcomes reported in studies evaluating  
199 interventions used to support breastfeeding (publication pending). This is informing a global Delphi  
200 survey to reach consensus on the most appropriate and important core outcomes identified and  
201 prioritised by parents, clinicians, experts and policy makers. In addition, strategic investment is  
202 needed to develop robust and reliable data collection methods, governance policies to protect  
203 individual privacy, and secure electronic linkage systems to improve overall efficiency.

204 We call on governments, global and national decision makers and researchers for genuine  
205 commitment to engage in efforts to develop reliable and agreed core infant feeding indicators and  
206 harness the power of large routinely-collected data. This has the potential to reinvigorate  
207 coordinated global action on breastfeeding so that the important public health benefits can be  
208 realised.

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