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Establishing breast feeding in babies with Down's syndrome: the FADES cohort experience

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3 **Title Page:**
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5 **Establishing breast feeding in babies with Down's syndrome: the**
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8 **FADES cohort experience**
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59 Word Count: 2551 words
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Abstract:

Objective: To describe breast feeding prevalence, and maternal experience in infants with Trisomy 21.

Design: Longitudinal cohort study

Setting: Participants from UK recruited through websites, social media and local collaborators: neonatologists, community paediatricians and research nurses.

Subjects: Babies under the age of 8 months with Down's syndrome (DS) recruited between the 1st September 2014 to 31st August 2017. Seventy participants: median age 20 weeks (Interquartile range (IQR) 13, 29 weeks) at initial questionnaire.

Main outcome measure: Breastfeeding prevalence at 6 weeks and 6 months amongst babies with DS.

Results: The prevalence of exclusive breastfeeding amongst study participants was similar to the general population (21% vs 23% at 6 weeks, 4% vs 1% at 6 months). However, the prevalence of breastfeeding (exclusive or combination feeding) amongst the study participants was higher than the general population (64% vs 55% at 6 weeks, 54% vs 34% at 6 months).

Conclusion: Although there may be challenges in establishing breastfeeding in babies with DS, our data suggest that exclusive breastfeeding is possible for some, and the prevalence of breastfeeding is comparable to the prevalence in the general population.

Trial Registration: ISRCTN 12415856

Keywords: Down's Syndrome, Trisomy 21, Feeding, Breast-feeding,

Background

Down's syndrome (DS) is caused by trisomy of chromosome 21. DS is usually diagnosed in the first few days of life by recognition of salient features (1). A number of associated conditions including congenital heart disease and gastrointestinal complications can cause additional challenges during the neonatal period. Infants with DS may have oral, anatomical and physiological abnormalities affecting their ability to feed normally: as with other features of DS there is phenotypic variability. To breastfeed effectively, a tight oral/nipple seal needs to be induced with the tongue making a groove and the lips sealing around the nipple. For a baby with DS, the flattened shape of the tongue and low tone in the oral structures means that establishing breastfeeding may be challenging. (2,3). Lewis et al reported that 40% of DS babies had been NG tube fed during the neonatal period illustrating some of the issues with feeding (4). Current World Health Organisation (WHO) recommendations are that babies should be exclusively breastfed until 6 months (5), this is based on the health benefits for mother and baby. Prolonged exclusive breastfeeding is possibly protective against some autoimmune conditions including type 1 diabetes and coeliac disease for which children with DS are at increased risk (6,7,8). Furthermore, there is evidence that breastfeeding exclusively or combined feeding to a lesser but significant extent, enhances immunity and is protective against otitis media and respiratory tract infections (9) both being more prevalent in children with DS (10).

Many countries have registers which provide data on people with DS. These have facilitated retrospective studies providing statistics on for example: birth and death rates and congenital anomalies. However longitudinal birth cohort studies of infants with DS in the UK are rare (11,12,13,14). The FADES (Feeding and Autoimmunity in Down's Syndrome Evaluation

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3 Study) was established to investigate early feeding and the development of autoimmunity.
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5 Medical and detailed feeding data are collected by mothers from birth and includes both
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7 feeding in the hospital settings and at home. A study hypothesis is that babies with DS have
8
9 difficulties with establishing breast feeding and are therefore introduced to formula feeds at
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11 an earlier age. This paper describes findings from the analysis of the feeding data collected
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13 between September 2014 and August 2017.
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19 **Methods:**

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24 FADES is an ongoing UK wide study recruiting babies with DS antenatally or in the first
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26 eight months of life. Exclusion criteria are babies born with a child protection plan, fostered
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28 or adopted, >8 months or parents do not speak English. Participants are recruited either by
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30 health professionals including neonatologists, community paediatricians and research nurses
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32 or via web recruitment through the Downs Syndrome Association, Downs Syndrome
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34 Scotland, and other websites and social media [https://www.bristolbrc.nihr.ac.uk/our-](https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/)
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36 [research/nutrition-diet-and-lifestyle/childhood/fades-study-2/](https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/). A combined feeding and
37
38 medical questionnaire is completed by families at recruitment (initial questionnaire), at six to
39
40 eight months of life (7-month questionnaire) and then at 12 months (12-month questionnaire).
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42 Feeding questions are based on those from the Infant Feeding Survey (IFS) 2010 (15),
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44 medical questions are related to conditions associated with DS, hospital admissions and
45
46 antibiotic usage. Mothers are able to provide free text answers to some questions. This paper
47
48 presents data collected in the first three years of recruitment from 1st September 2014 to 31st
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50 August 2017 when the feasibility assessment was conducted.
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3 **Statistical Analysis:** As a feasibility study, analysis of the questionnaires is descriptive as
4 numbers are too small for statistical testing. Frequencies were derived and presented as
5 percentages for categorical variables. For continuous data, means and standard deviations
6 (SDs) were presented for data that were approximately normal, and medians and interquartile
7 ranges (IQRs) for non-normal data. Analysis used STATA vs. 15.
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17 **Public involvement:** The study design including recruitment and data collection methods
18 were established following discussion with and involvement of the Downs Syndrome
19 Association. Local members (all of whom were parents of a child with DS) advised on the
20 wording and feasibility of the feeding and medical questionnaires.
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Ethics approval for FADES was given by the National Research Ethics Service (NRES)
Committee South West – Central Bristol 23rd April 2014 14/SW/0030 and it is an NIHR
Portfolio study.

Results:

Seventy participants were recruited between the 1st September 2014 and the 31st August
2017. 87% (61 of 70) completed the initial feeding and medical questionnaire at a median age
of 20 weeks (IQR 13, 29 weeks). Of these, approximately a quarter (n=15) were diagnosed
antenatally with DS. Table 1 summarises maternal characteristics and birth details. Over half
were born by normal vaginal delivery: median gestation, 38 weeks (IQR 37, 39 weeks), mean
birthweight of 3kg (SD 0.5kg). Most babies were born in hospital units, three were home
deliveries. Median hospital stay after birth was five days (IQR 3, 9 days).

Background Characteristics			
Maternal age (years) at time of completing initial questionnaire	20 to 24	8.2%	(5/61)
	25 to 29	9.8%	(6/61)
	30 to 34	24.6%	(15/61)
	35 to 39	37.7%	(23/61)
	40 or over	19.7%	(12/61)
Mother's marital status	Living together	27.9%	(17/61)
	Married or in a civil partnership	65.6%	(40/61)
	Single	4.9%	(3/61)
	Widowed, divorced, or separated	1.6%	(1/61)
Mother's ethnic group	Other	3.3%	(2/61)
	White British	86.9%	(53/61)
	White Irish	4.9%	(3/61)
	White Other	4.9%	(3/61)
Birth History			
First baby		31.2%	(19/61)
Prenatal diagnosis of DS		24.6%	(15/61)
Twin Birth		3.3%	(2/61)
Type of delivery	Normal Vaginal delivery	63.3%	(38/60)
	C-Section	28.3%	(17/60)
	Forceps	3.3%	(2/60)
	Ventouse	5.0%	(3/60)
Gestation (weeks)	Median 38 (IQR 37, 39)		
Pre-term 32-37 weeks		21.3%	(13/61)
Birthweight (kg)	Mean 3.0 (0.5 SD)		
Location of birth	At home	5.0%	(3/59)
	In hospital (consultant led)	49.2%	(29/59)
	In hospital (midwife led)	42.4%	(25/59)
	Birth centre (midwife led)	3.4%	(2/59)
Length of initial hospital stay (hours)	Median 120 (IQR 72, 216)		

Table 1: Maternal characteristics and birth details

Footnote: DS (Down's syndrome), IQR (inter quartile range), SD (standard deviation), C-section (Caesarean Section)

Over half (56%) were admitted into a special care baby unit (SCBU) with almost a third of these (29%) primarily due to poor feeding. Half of the babies for whom data were available, required naso-gastric (NG) tube feeding as shown in Table 2. All admitted to SCBU, were

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3 NG tube fed. Around 40%, primarily required NG tube feeds in SCBU due to feeding issues,
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5 the remainder due to medical co-morbidities (37% with multiple medical indications). NG
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7 tube feeds were mostly expressed breastmilk or a mixture of expressed milk and infant
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9 formula. Just over 60% required NG tube feeds for less than two weeks.
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SCBU Admission			
Admitted to SCBU		55.7%	(34/61)
Admitted to SCBU due to problems with feeding		29.4%	(10/34)
Admitted to SCBU for any other reason*		70.6%	(24/34)
Hypoxia / respiratory distress / PPHN		50.0%	(17/34)
Jaundice		20.6%	(7/34)
Cardiac / cardiac monitoring		11.8%	(4/34)
Infection		11.8%	(4/34)
Prematurity		8.8%	(3/34)
Polycythaemia		5.9%	(2/34)
Other		20.6%	(7/34)
Length of SCBU stay (weeks)		Median 2 (IQR 2, 4)	
Feeding in SCBU and NG tube Feeds			
SCBU admission affected ability of mother to feed baby as she would have liked		67.7 %	(23/34)
Shown how to express milk in SCBU		85.3 %	(29/34)
Felt supported to express milk in SCBU		90.0 %	(27/30)
Had NG tube feeds		100 %	(31/31*)
Required NG tube feeds due to problems with feeding		38.7 %	(12/31)
Medical reason for NG tube feeds**	Prematurity	10.5 %	(2/19)
	Dehydration / hydration	10.5 %	(2/19)
	Ventilation	10.5 %	(2/19)
	Respiratory problems	42.1 %	(8/19)
	Jaundice / polycythaemia	21.1 %	(4/19)
	Vomiting or surgical abdomen	21.1 %	(4/19)
Length of time NG tube fed	< 3 days	16.1 %	(5/31)
	> 3 to 7 days	19.4 %	(6/31)
	> 1 to 2 weeks	25.8 %	(8/31)
	> 2 to 4 weeks	19.4 %	(6/31)
	> 1 to 2 months	16.1 %	(5/31)
	> 2months	3.2 %	(1/31)
Type of NG tube feeds given	Only expressed breast milk	32.3 %	(10/31)
	Only infant formula	6.5 %	(2/31)
	Expressed breast milk and infant formula	61.3 %	(19/31)
Feeds stopped and IV fluids given		32.4 %	(11/34)
Length of time on IV fluids	< 3 days	22.2 %	(2/9)
	> 3 to 7 days	44.4 %	(4/9)
	> 7 days to 1 month	33.3 %	(3/9)

Table 2: Feeding in SCBU (special care baby unit) and NG (nasogastric) tube feeds

Footnote: IV fluids (Intra- venous fluids), PPHN (persistent pulmonary hypertension of the newborn),

*Due to an issue with branching of the questions at least 31 babies were NG tube fed but there may have been more. Where they were branched away, people have been counted as missing, so the denominator is 31.

**Coded from open response

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6 Of the mothers receiving an antenatal diagnosis for their baby, 87% were told about problems
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8 relating to feeding but only 20% received any specific antenatal advice about breastfeeding a
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10 baby with DS. Most mothers initially breastfed their baby, with 78% having skin to skin
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12 contact within 24 hours of birth (Table 3). Feeding problems that were experienced in the
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14 hospital or birthing centre by mothers, included those commonly associated with babies with
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16 DS such as poor latch and lethargy. Although hypotonia is one of the explanations frequently
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18 given as a cause for feeding difficulties, only one parent described this feature. Mothers
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20 provided responses to an open question regarding feeding their baby in the hospital, birth
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22 centre or unit as illustrated in the quotes in Table 4.
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First Feeds			
Ever breastfed or received expressed breast milk		90.2 %	(55/61)
Had skin to skin contact within 24hrs of birth		78.3 %	(47/60)
Maternal health problems after birth that affected feeding		6.6 %	(4/61)
Received help with breastfeeding within first few days		66.7 %	(40/60)
How soon after birth was baby put to the breast	within a few minutes	25.5 %	(14/55)
	<30 min	30.9 %	(17/55)
	30 min to 1 hr	16.4 %	(9/55)
	>1 hr to 8 hrs	5.5 %	(3/55)
	>8 hrs to 24 hrs	5.5 %	(3/55)
	> 24 hrs later	16.4 %	(9/55)
Experienced problems when feeding their baby in the hospital, birth centre or unit		77.5 %	(45/58*)
Common problems with feeding**	Poor latch	44.4 %	(20/45)
	Medical issue	31.1 %	(14/45)
	Jaundice	31.1 %	(14/45)
	Tired / lethargic	28.9 %	(13/45)
	Maternal reason	8.9 %	(4/45)
	Tongue size/ position	6.7 %	(3/45)
	Low tone	2.2 %	(1/45)
Reported that they received enough help with feeding in hospital / birth centre		82.8 %	(48/58)
General Feeding and feeding after discharge from hospital / birth centre			
Problems with feeding baby after discharge from hospital / birth centre		53.6%	(30/56)
Problems with feeding after discharge**			
	Lethargy	21.3%	(13/61)
	Poor weight gain / weight loss	16.4%	(10/61)
	Low tone	1.6%	(1/61)
	Latch	8.2%	(5/61)
	Medical	4.9%	(3/61)
	Jaundice	4.9%	(3/61)
	Reflux	4.9%	(3/61)
Received help or information with feeding problems after discharge		84.4%	(27/32***)

Table 3: First feeds and feeding after discharge

Footnote:* Three babies were home births ** These problems were coded from open responses

***This denominator comes from the 30 participants who experienced problems with feeding after discharge from hospital and two who experienced problems with feeding after their home birth.

Question from initial questionnaire	‘Were there any problems feeding your baby while you were in the hospital, birth centre or unit? What problems were there?’
Quotes	<p><i>“X would not take anything from the breast and was very sleepy so had an NG tube put in.”</i></p> <p><i>“A feeding tube was inserted straight away, which prevented me from breast feeding. It also prevented her from becoming hungry enough to feed from me”</i></p> <p><i>“baby continually pushing tongue out and could not latch on. Decided to try the bottle which she took immediately so did not try breast again and was not questioned by staff”</i></p>
Question from Initial, 7 month and 12 month questionnaire	‘Have you stopped breastfeeding (no longer give your baby any expressed milk or put your baby to your breast)? What were your reasons for stopping?’
Quotes	<p><i>“Significant weight loss in early days, poor latch, inadequate milk being taken by baby, readmission to hospital for tube feeding, introduction of bottle feeding in hospital, milk supply subsequently drying up due to baby being put on bottle and use of pumps further made milk supply deteriorate.”</i></p> <p><i>“Baby fell asleep too much at the breast to feed properly. It was too time consuming and stressful to keep expressing.”</i></p>
Question from initial, 7-month and 12-month questionnaires	‘What would have helped you breastfeed longer?’
Quotes	<p><i>“Knowing as I do now that it's common to have feeding problems with Down syndrome. More specific breastfeeding support.” (from initial questionnaire)</i></p> <p><i>“I feel I was forced to give Child’s name a bottle when she was only a day old as the midwife was unwilling to entertain my concerns about the bottle meaning that she would never take the breast. I had wanted to give the milk by syringe or cup to give her a chance to keep trying the breast, but I was shot down and ridiculed.” (from 7-month questionnaire)</i></p> <p><i>“I just became too sick, unwell but at the same time I fed longer than I thought I would. Thanks to the support I received.” (from 12-month questionnaire)</i></p> <p><i>“She lost 6% of her birth weight by day 9 and the NICU home midwife suggested we move onto top up.</i></p>

I think that was the pinch point. If I had said no, let's try harder to feed from the breast it might have established itself. But she had just been discharged from hospital and I was so reluctant to go back. You really have the threat of readmission hanging over you... I would have loved to feed her myself. It is my biggest sadness but there were too many other variables at play. I am pleased I was able to exclusively breast feed her though for well over 4 months." (from 12-month questionnaire)

Table 4: Quotes from free text boxes in initial, 7 month and 12 month questionnaire

Of the 61 mother/baby dyads, 64% continued some breastfeeding for over six weeks (Table 5) (including babies who received mixed infant formula and breastmilk feeds). Over the age of six months, this decreased to 54% still breastfeeding in part. These percentages are higher than in the general population, levels reported in the Infant Feeding Survey (IFS) 2010 (55% and 34% respectively) (15). The prevalence of exclusive breastfeeding in the study population at six weeks was 21% compared to 23% in the general population in the IFS 2010 (15). By six months of age, less than 4% of participants were exclusively breast fed (2/54). This compares to 1% of general population. Using data from the initial and 7-month questionnaires, the median age at which some formula milk was introduced in the whole cohort was five days (IQR 1, 21 days). Formula feeds were introduced by 52% of mothers within a week in the IFS 2010 and 75% by 6 weeks.

Types of feeds / Stopping breastfeeding			
Age stopped breastfeeding*			
6 weeks or less	40.7%	(11/27**)	
> 6 weeks to 4 months	25.9%	(7/27)	
> 4 months to 6 months	11.1%	(3/27)	
> 6 months	22.2%	(6/27)	
Age started formula feeds			
6 weeks or less	77.2%	(44/57***)	
> 6 weeks to 4 months	5.3%	(3/57)	
> 4 months to 6 months	8.8%	(5/57)	
> 6 months	8.8%	(5/57)	
Age when given a non – milk drink**** (weeks)	Median 26 (IQR 20, 28)		
Age at which first given cow’s milk (weeks)	Median 44 (IQR 28, 36)		
Stopping breastfeeding and problems with feeding	Initial Questionnaire	7 month Questionnaire	12 month Questionnaire
Maternal opinion on how long they breastfed			
Breastfed for as long as they intended	37.8% (14/37)	17.4% (4/23)	20.0% (4/20)
Breastfed for longer than they intended	8.1% (3/37)	13.0% (3/23)	15.0% (3/20)
Would have liked to breastfeed longer.	54.1% (20/37)	69.6% (16/23)	65.0% (13/20)
Reasons for stopping breastfeeding			
Inadequate breastmilk supply	30% (6/20)	13.0% (7/54)	5.0% (2/40)
Problems expressing milk	25% (5/20)	5.6% (3/54)	10.0% (4/40)
Excessive time expressing milk	25% (5/20)	1.9% (1/54)	5.0% (2/40)
Baby losing weight	20% (4/20)	3.7% (2/54)	5.0% (2/40)
Maternal medical problem	15% (3/20)	3.7% (2/54)	2.5% (1/40)
Lethargy	5% (1/20)	1.9% (1/54)	
Weaning by choice	n/a	7.4% (4/54)	7.5% (3/40)
Other		5.6% (3/54)	10.0% (4/40)

Table 5: Stopping Breastfeeding

Footnote: *including using expressed breastmilk and mixed feeding and/or were introduced to other types of milk feeds or drinks. **this denominator is the number of women who had stopped breastfeeding by the data cut off date for data analysis. Some babies would still have been receiving breastmilk at the cut-off date for data analysis. Some would also have been still mixed feeding both breastmilk and formula ***Non-milk drinks included any drink other than milk including water (which would be fine) and juices which would not be recommended.

Just over half of the participants had problems associated with feeding after discharge from hospital (Table 3). The most common problems were lethargy or faltering growth. Three mothers mentioned their babies being readmitted to hospital with poor feeding. Less than

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3 three-quarters, 72% (34/47) had the correct 'DS insert' in their Red book (the personal child
4 health record that is given to every baby). The 'DS insert' contains the appropriate growth
5 charts reflecting a tendency to 'normal', slower growth trajectory in this condition compared
6 to non-trisomy babies (16).
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14 Over half of the mothers said that they would have liked to have breastfed for longer.
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16 Reasons for stopping breastfeeding included inadequate breastmilk supply, issues with
17 expressing breast milk and their babies having faltering growth. The quotes in Table 4
18 illustrate the reasons mothers gave for stopping breastfeeding.
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26 Mothers were asked "What would have helped you breastfeed longer?" the answers included
27 not introducing bottles as early, not needing to express, being at home and having more
28 specific support. Quotes from the initial, 7-month and 12-month questionnaires in response to
29 this question are given in Table 4. Some mothers also used this question to explain that they
30 did breastfeed.
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40 **Discussion:**

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44 We have shown that exclusive breastfeeding amongst the babies with DS at six months is
45 comparable to the general population (4% vs 1%). Apart from exclusive breastfeeding at six
46 weeks when prevalence was similar (21% of babies with DS versus 23% in the general
47 population), breastfeeding (exclusive or combination feeding) amongst the study participants
48 was higher at all time points than levels reported in the general population (15). This was
49 surprising and does not support the hypothesis that hypotonia and oro-motor issues associated
50 with DS significantly alters ability to breastfeed. This is an important and encouraging
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3 message for mothers and should inspire midwives and health professionals to support breast
4 feeding. These findings suggest that the frequently heard mantra, that babies with DS
5 probably will not breastfeed successfully, needs to be changed.
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12 Formula was introduced very early at a median of five days with 77% having started by the
13 age of six weeks. Overall, over half of the mothers were still breastfeeding beyond the age of
14 six months (including babies who combination fed with breastmilk and infant formula) which
15 is a very positive message for families. This is higher than the 34% at six months within the
16 general population. Due to the wording of the questionnaire, it was not possible to distinguish
17 between those who directly breastfed or those who gave expressed breastmilk, and this would
18 be useful to include in future questionnaires.
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31 Over half of FADES babies were admitted to SCBU, all being NG tube fed. In around 40%,
32 issues with feeding were responsible for NG placement and for most of these participants,
33 this was also the reason for SCBU admission. Almost 70% of the mothers said that having
34 their baby in SCBU had affected their ability to feed the way they would have liked. This is
35 possibly open to intervention as some admissions might be prevented with more
36 specialised/tailored support on the postnatal wards. Some hospitals will only have one or two
37 babies born a year with DS, possibly leading to automatic SCBU admissions with increased
38 levels of anxiety around potential complications and associated conditions. In terms of oro-
39 motor skill development, it is important that babies have the chance to feed orally early on.
40 This is postulated to be important for the development of oral skills, tolerance of tastes and
41 textures and is also important for social development (17). Most babies in our cohort required
42 NG tube feeds for less than two weeks but a third also required feeds to be stopped altogether
43 at some point and were put onto intravenous fluids.
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5 NG tube feeding was required for some babies due to dehydration, jaundice, polycythaemia
6 and vomiting. Although classified as a 'medical' reason, inability to feed may have
7
8 contributed or caused these issues. Other 'medical' reasons, were are all standard causes for
9
10 any neonate to receive NG tube feeds including prematurity, ventilation or surgical abdomen.
11
12 Prevalence of NG tube feeding in the general population and in the typical DS population are
13
14 poorly reported. A third of those NG fed babies continued to receive exclusively expressed
15
16 breastmilk. Many of the babies were fed using expressed breastmilk either for NG tube feeds
17
18 or for top up feeds via alternative feeding methods including bottle.
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26 Lethargy was the most commonly reported problem with feeding after discharge with far
27
28 fewer citing poor latch than during the initial admission. Importantly 16% of the mothers said
29
30 that poor weight gain or weight loss was an issue. It is of concern that over a quarter of the
31
32 mothers reported that they were not given the correct 'DS insert' in their Personal Child
33
34 Health Record ('Red' book) (16). Healthy babies with DS gain weight more slowly than
35
36 other babies and it is important to account for this when assessing feeding and growth. If a
37
38 baby with DS is plotted on a standard growth chart they will appear to be failing to thrive and
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40 a mother who is successfully feeding her baby, may be told that she needs to supplement
41
42 feeds, start formula feeds if she is breastfeeding or even that her baby needs admission to
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44 hospital.
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51 The higher levels of breastfeeding in the study compared to the general population may in
52
53 part, be due to selection bias. Mothers who have chosen to take part in the study may already
54
55 have a specific interest in infant feeding. In the UK, higher breastfeeding frequency is
56
57 described in mothers over 30 years of age (87%) (15) which may also explain the higher level
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3 of initial breastfeeding in FADES. The karyotype for the babies in the cohort was not
4 requested which might be considered a weakness of the study. FADES potentially might
5 include children with mosaic Down's syndrome who can be phenotypically milder although
6 this is rare: Only one to three percent of DS children have Mosaicism (18).
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15 Reasons for stopping breastfeeding were similar to the IFS 2010 (15) with inadequate
16 breastmilk supply and faltering growth being common. However, a large proportion
17 mentioned issues surrounding expressing milk. This highlights the need for mothers who are
18 expressing to receive tailored support. Mothers were asked "What would have helped you
19 breastfeed longer" the responses indicated that mothers understandably wanted 'normality',
20 they wanted their babies to be well, to not require bottle or expressed milk and to be at home.
21 Although it is not possible to change these factors for many, every effort should be made to
22 listen to maternal wishes and assist where possible. Some mothers used this questionnaire to
23 voice their frustration at alternative feeding methods being introduced 'too early' or 'against
24 their wishes'.
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40 It is a strength of the study that the families recruited were representative of the general
41 population of children with DS, with similar numbers of children having associated
42 conditions including cardiac abnormalities as reported in other studies (19). The eligibility
43 criteria were broad and did not exclude any medical conditions. A further strength is that the
44 study was UK wide reducing selection bias. Those who could not speak English were
45 excluded and this may have had altered feeding results with cultural differences in early
46 feeding (20). Translating all study documentation however was not possible for the multiple
47 languages now represented in UK population.
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3 These results raise some important questions and highlight potential opportunities for
4 interventions in relation to feeding support for mothers of babies with DS. Any advice given
5 to mothers on feeding a baby with DS based on this study should include the message that
6 babies with DS can be exclusively breastfed or receive a combination of breast and formula
7 feeds. However, some may need to include expressed breastmilk and alternative feeding
8 methods. Providing mothers with access to tailored support and advice specifically around
9 expressing should be included, as should information on NG tube feeding.
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21 **Conclusion:**

22 It is clear that some babies with DS can breastfeed exclusively for six months as per WHO
23 guidelines. This may require significant perseverance from the mother and supportive
24 professionals, as establishing breastfeeding can be challenging. Oro-motor difficulties and
25 significant medical needs may underlie some challenges, but overall, mothers who wish to
26 breastfeed should be encouraged and supported to do so as success is possible.
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38 Boxes – What is already known on this topic (bullet points)

- 39 • Babies with DS have anatomical and physiological features that may affect their
40 ability to feed but this is phenotypically variable.
 - 41 • Babies with DS have associated medical conditions including congenital heart disease
42 and gastro-intestinal abnormalities which may impact on early feeding.
 - 43 • Prevalence of NG Tube feeding in babies with DS has previously been reported as up
44 to 40%.
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57 What this study adds
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- Breastfeeding prevalence amongst babies with DS are equivalent to the general population at 6 months.
- Babies with DS can receive exclusive breast-milk feeds for over 6 months.
- Early and extra post-natal support for breast feeding may be beneficial.
- At least half of babies with DS in this UK wide cohort study receive nasogastric feeds.

How this Study might affect research, practice or policy

- This study seeks to promote an increase in tailored feeding support for mother's of babies with DS.
- Key findings from this study may contribute to positive changes in breastfeeding advice and support for mother's of babies with DS.
- The high prevalence of babies receiving naso-gastric tube feeds warrants further research and potentially change in policy within neonatal units.

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Authors Contribution: Georgina M.G. Williams was the chief investigator and PhD student, wrote the protocol, completed the data collection, data analysis and drafts of the manuscript. Sam Leary was the lead statistician on the study and PhD supervisor. She contributed to the protocol and study design, data analysis and draft manuscripts of the paper. Sofia Leadbetter provided the administrative support and coordination for the study, she was involved in participant recruitment and data collection. Stu Toms contributed to the study design, online questionnaires and managed the study database. Georgina Mortimer contributed to the data

collection and coordinates sample collection for the FADES study. Tim Scorrer recruited participants for the study and reviewed draft manuscripts of the paper. Kathleen Gillespie (PhD supervisor) contributed to the study protocol, study design and reviewed draft manuscripts of the article. Julian Hamilton Shield (PhD supervisor) contributed to the study protocol, study design and reviewed draft manuscripts of the articles.

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Establishing breast feeding in Infants with Down syndrome: the FADES cohort experience

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3 **1 Title Page:**
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5 **2 Establishing breast feeding in infants with Down syndrome: the**
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8 **3 FADES cohort experience**
9

10
11 4 Georgina M.G. Williams^{1,2,3,4}, Sam Leary¹, Sofia Leadbetter¹, Stu Toms¹, Georgina
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13 5 Mortimer², Tim Scorrer⁵, Kathleen Gillespie², Julian Hamilton Shield^{1,2,3}
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54 24 Bristol, Bristol, England
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45 28 **Abstract:**

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8 29 Objective: To describe breast feeding prevalence, and maternal experience in infants with
9
10 30 Trisomy 21.

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12 31 Design: Longitudinal cohort study

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14 32 Setting: Participants from UK recruited through websites, social media and local
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16 33 collaborators: neonatologists, community paediatricians and research nurses.

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18 34 Subjects: Infants under the age of 8 months with Down syndrome (DS) recruited to the
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20 35 FADES (Feeding and Autoimmunity in Down Syndrome Evaluation Study) between the 1st
21
22 36 September 2014 to 31st August 2017. Seventy participants: median age 20 weeks
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24 37 (Interquartile range (IQR) 13, 29 weeks) at initial questionnaire.

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26 38 Main outcome measure: Breastfeeding prevalence at 6 weeks and 6 months amongst infants
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28 39 with DS.

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30 40 Results: The prevalence of exclusive breastfeeding amongst study participants was similar to
31
32 41 the general population (13/61 21% vs 23% at 6 weeks, 2/54 4% vs 1% at 6 months).

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34 42 However, the prevalence of breastfeeding (exclusive or combination feeding) amongst the
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36 43 study participants was higher than the general population (39/61 64% vs 55% at 6 weeks,
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38 44 32/59 54% vs 34% at 6 months).

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40 45 Conclusion: Although there may be challenges in establishing breastfeeding in infants with
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42 46 DS, our data suggest that exclusive breastfeeding is possible for some, and the prevalence of
43
44 47 breastfeeding is comparable to the prevalence in the general population.

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46 48 Trial Registration: ISRCTN 12415856
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50 51 **Keywords: Down Syndrome, Trisomy 21, Feeding, Breast-feeding,**
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53 **Background**

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55 Down syndrome (DS) is caused by trisomy of chromosome 21. DS is usually diagnosed
56 antenatally or in the first few days of life by recognition of salient features (1). A number of
57 associated conditions including congenital heart disease and gastrointestinal complications
58 can cause additional challenges during the neonatal period.

59

60 Current World Health Organisation (WHO) recommendations are that infants should be
61 exclusively breastfed until 6 months (5), this is based on the health benefits for mother and
62 baby. Prolonged exclusive breastfeeding is possibly protective against some autoimmune
63 conditions including type 1 diabetes and coeliac disease for which children with DS are at
64 increased risk (6,7,8). Furthermore, there is evidence that breastfeeding exclusively or
65 combined feeding to a lesser but significant extent, enhances immunity and is protective
66 against otitis media and respiratory tract infections (9) both being more prevalent in children
67 with DS (10).

68

69 Infants with DS may have oral, anatomical and physiological abnormalities affecting their
70 ability to feed normally: as with other features of DS there is phenotypic variability. To
71 breastfeed effectively, a tight oral/nipple seal needs to be induced with the tongue making a
72 groove and the lips sealing around the nipple. For a baby with DS, the flattened shape of the
73 tongue and low tone in the oral structures means that establishing breastfeeding may be
74 challenging. (2,3). Lewis et al reported that 40% of DS infants had been naso-gastric (NG)
75 tube fed during the neonatal period illustrating some of the issues with feeding (4).

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3 77 Many countries have registers which provide data on people with DS. These have facilitated
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5 78 retrospective studies providing statistics on for example: birth and death rates and congenital
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7 79 anomalies. However longitudinal birth cohort studies of infants with DS in the UK are rare
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10 80 (11,12,13,14). The FADES (Feeding and Autoimmunity in Down Syndrome Evaluation
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12 81 Study) was established to investigate early feeding and the development of autoimmunity.
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14 82 Medical and detailed feeding data are collected by mothers from birth and includes both
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16 83 feeding in the hospital settings and at home. A study hypothesis is that infants with DS have
17
18 84 difficulties with establishing breast feeding and are therefore introduced to formula feeds at
19
20 85 an earlier age. The aim of this paper is to describe breastfeeding prevalence and experiences
21
22 86 among infants with DS and their mothers, in the first six months of life. This paper describes
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24 87 findings from the analysis of the feeding data collected between September 2014 and August
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26 88 2017, to explore this and compare to breastfeeding prevalence in the general population.
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33 **Methods:**

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37 92 FADES is an ongoing UK wide study recruiting infants with DS antenatally or in the first
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39 93 eight months of life. Exclusion criteria are infants born with a child protection plan, fostered
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41 94 or adopted, >8 months or parents do not speak English. Participants are recruited either by
42
43 95 health professionals including neonatologists, community paediatricians and research nurses
44
45 96 or via web recruitment through the Downs Syndrome Association, Downs Syndrome
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47 97 Scotland, and other websites and social media [https://www.bristolbrc.nihr.ac.uk/our-](https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/)
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49 98 [research/nutrition-diet-and-lifestyle/childhood/fades-study-2/](https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/). A combined feeding and
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51 99 medical questionnaire is completed by families at recruitment (initial questionnaire), at six to
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53 100 eight months of life (7-month questionnaire) and then at 12 months (12-month questionnaire).
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56 101 Feeding questions are based on those from the Infant Feeding Survey (IFS) 2010 (15),
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3 102 medical questions are related to conditions associated with DS, hospital admissions and
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5 103 antibiotic usage. Mothers are able to provide free text answers to some questions and quotes
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8 104 from these have been used to illustrate key points. A full qualitative study and analysis has
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10 105 not been completed as part of this feasibility study. This paper presents data collected in the
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12 106 first three years of recruitment from 1st September 2014 to 31st August 2017 when the
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14 107 feasibility assessment was conducted.
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19 109 **Statistical Analysis:** As a feasibility study, analysis of the questionnaires is descriptive as
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21 110 there is not enough power to statistically test for associations. Frequencies were derived and
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23 111 presented as percentages for categorical variables. For continuous data, means and standard
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25 112 deviations (SDs) were presented for data that were approximately normal, and medians and
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27 113 interquartile ranges (IQRs) for non-normal data. Analysis used STATA vs. 15. Comparisons
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29 114 are made with the general population from the results reported by the IFS 2010 (15).
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35 116 **Public involvement:** The study design including recruitment and data collection methods
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37 117 were established following discussion with and involvement of the Downs Syndrome
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39 118 Association. Local members (all of whom were parents of a child with DS) advised on the
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41 119 wording and feasibility of the feeding and medical questionnaires.
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47 121 Ethics approval for FADES was given by the National Research Ethics Service (NRES)
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49 122 Committee South West – Central Bristol 23rd April 2014 14/SW/0030 and it is an NIHR
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51 123 Portfolio study.
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3 127 **Results:**
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8 129 Seventy participants were recruited between the 1st September 2014 and the 31st August
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10 130 2017. 61 out of the 70 participants (87%) completed the initial feeding and medical
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12 131 questionnaire at a median age of 20 weeks (IQR 13, 29 weeks). Of these, approximately a
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14 132 quarter (n=15) were diagnosed antenatally with DS. Table 1 summarises maternal
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16 133 characteristics and birth details. Over half were born by normal vaginal delivery: median
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19 134 gestation, 38 weeks (IQR 37, 39 weeks), mean birthweight of 3kg (SD 0.5kg). Most infants
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21 135 were born in hospital units, three were home deliveries. Median hospital stay after birth was
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23 136 five days (IQR 3, 9 days).
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Background Characteristics		
Maternal age (years) at time of completing initial questionnaire	20 to 24	5/61 (8.2%)
	25 to 29	6/61 (9.8%)
	30 to 34	15/61 (24.6%)
	35 to 39	23/61 (37.7%)
	40 or over	12/61 (19.7%)
Mother's marital status	Living together	17/61 (27.9%)
	Married or in a civil partnership	40/61 (65.6%)
	Single	3/61 (4.9%)
	Widowed, divorced, or separated	1/61 (1.6%)
Mother's ethnic group	Other	2/61 (3.3%)
	White British	53/61 (86.9%)
	White Irish	3/61 (4.9%)
	White Other	3/61 (4.9%)
Birth History		
First baby		19/61 (31.2%)
Prenatal diagnosis of DS		15/61 (24.6%)
Twin Birth		2/61 (3.3%)
Type of delivery	Normal Vaginal delivery	38/60 (63.3%)
	C-Section	17/60 (28.3%)
	Forceps	2/60 (3.3%)
	Ventouse	3/60 (5.0%)
Gestation (weeks)	Median 38 (IQR 37, 39)	
Pre-term 32-37 weeks		13/61 (21.3%)
Birthweight (kg)	Mean 3.0 (0.5 SD)	
Location of birth	At home	3/59 (5.0%)
	In hospital (consultant led)	29/59 (49.2%)
	In hospital (midwife led)	25/59 (42.4%)
	Birth centre (midwife led)	2/59 (3.4%)
Length of initial hospital stay (hours)	Median 120 (IQR 72, 216)	

152

153 Table 1: Maternal characteristics and birth details

154 Footnote: DS (Down syndrome), IQR (inter quartile range), SD (standard deviation), C-section (Caesarean
155 Section)

156

157 Over half (34/61, 56%) were admitted into a special care baby unit (SCBU) with almost a
158 third of these (10/34, 29%) primarily due to poor feeding. Half of the infants for whom data
159 were available, required NG tube feeding as shown in Table 2. All admitted to SCBU, were
160 NG tube fed. Of the 31 infants who were fed via NG tube, 12/31 (40%), primarily required

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3 161 NG tube feeds in SCBU due to feeding issues, the remainder due to medical co-morbidities
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5 162 (37% with multiple medical indications). NG tube feeds were mostly expressed breastmilk
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8 163 or a mixture of expressed milk and infant formula. NG tube feeds were required in 19/31
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10 164 (60%) participants for less than two weeks.
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SCBU Admission		
Admitted to SCBU		34/61 (55.7%)
Admitted to SCBU due to problems with feeding		10/34 (29.4%)
Admitted to SCBU for any other reason*		24/34 (70.6%)
Hypoxia / respiratory distress / PPHN		17/34 (50.0%)
Jaundice		7/34 (20.6%)
Cardiac / cardiac monitoring		4/34 (11.8%)
Infection		4/34 (11.8%)
Prematurity		3/34 (8.8%)
Polycythaemia		2/34 (5.9%)
Other		7/34 (20.6%)
Length of SCBU stay (weeks)		Median 2 (IQR 2, 4)
Feeding in SCBU and NG tube Feeds		
SCBU admission affected ability of mother to feed baby as she would have liked		23/34 (67.7 %)
Shown how to express milk in SCBU		29/34 (85.3 %)
Felt supported to express milk in SCBU		27/30 (90.0 %)
Had NG tube feeds		31/31* (100 %)
Required NG tube feeds due to problems with feeding		12/31 (38.7 %)
Medical reason for NG tube feeds**	Prematurity	2/19 (10.5 %)
	Dehydration / hydration	2/19 (10.5 %)
	Ventilation	2/19 (10.5 %)
	Respiratory problems	8/19 (42.1 %)
	Jaundice / polycythaemia	4/19 (21.1 %)
	Vomiting or surgical abdomen	4/19 (21.1 %)
Length of time NG tube fed	< 3 days	5/31 (16.1 %)
	> 3 to 7 days	6/31 (19.4 %)
	> 1 to 2 weeks	8/31 (25.8 %)
	> 2 to 4 weeks	6/31 (19.4 %)
	> 1 to 2 months	5/31 (16.1 %)
	> 2months	1/31 (3.2 %)
Type of NG tube feeds given	Only expressed breast milk	10/31 (32.3 %)
	Only infant formula	2/31 (6.5 %)
	Expressed breast milk and infant formula	19/31 (61.3 %)
Feeds stopped and IV fluids given		11/34 (32.4 %)
Length of time on IV fluids	< 3 days	2/9 (22.2 %)
	> 3 to 7 days	4/9 (44.4 %)
	> 7 days to 1 month	3/9 (33.3 %)

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187 Table 2: Feeding in SCBU (special care baby unit) and NG (nasogastric) tube feeds

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189 Footnote: IV fluids (Intra- venous fluids), PPHN (persistent pulmonary hypertension of the newborn),

190 *Due to an issue with branching of the questions at least 31 infants were NG tube fed but there may have been

191 more. Where they were branched away, people have been counted as missing, so the denominator is 31.

192 **Coded from open response

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3 193 Of the mothers receiving an antenatal diagnosis for their baby, 13/15 (87%) were told about
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5 194 problems relating to feeding but only three (3/15, (20%)) received any specific antenatal
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7 195 advice about breastfeeding a baby with DS. Most mothers initially breastfed their baby, with
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10 196 47/60 (78%) having skin to skin contact within 24 hours of birth (Table 3). Feeding problems
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12 197 that were experienced in the hospital or birthing centre by mothers, included those commonly
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14 198 associated with infants with DS such as poor latch and lethargy. Although hypotonia is one of
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16 199 the explanations frequently given as a cause for feeding difficulties, only one parent
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18 200 described this feature. Mothers provided responses to an open question regarding feeding
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20 201 their baby in the hospital, birth centre or unit as illustrated in the quotes in Table 4.
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First Feeds		
Ever breastfed or received expressed breast milk		55/61 (90.2 %)
Had skin to skin contact within 24hrs of birth		47/60 (78.3 %)
Maternal health problems after birth that affected feeding		4/61 (6.6 %)
Received help with breastfeeding within first few days		40/60 (66.7 %)
How soon after birth was baby put to the breast	within a few minutes	14/55 (25.5 %)
	<30 min	17/55 (30.9 %)
	30 min to 1 hr	9/55 (16.4 %)
	>1 hr to 8 hrs	3/55 (5.5 %)
	>8 hrs to 24 hrs	3/55 (5.5 %)
	> 24 hrs later	9/55 (16.4 %)
Experienced problems when feeding their baby in the hospital, birth centre or unit		45/58* (77.5 %)
Common problems with feeding**	Poor latch	20/45 (44.4 %)
	Medical issue	14/45 (31.1 %)
	Jaundice	14/45 (31.1 %)
	Tired / lethargic	13/45 (28.9 %)
	Maternal reason	4/45 (8.9 %)
	Tongue size/ position	3/45 (6.7 %)
	Low tone	1/45 (2.2 %)
Reported that they received enough help with feeding in hospital / birth centre		48/58 (82.8 %)
General Feeding and feeding after discharge from hospital / birth centre		
Problems with feeding baby after discharge from hospital / birth centre		30/56 (53.6%)
Problems with feeding after discharge**		
	Lethargy	13/61 (21.3%)
	Poor weight gain / weight loss	10/61 (16.4%)
	Low tone	1/61 (1.6%)
	Latch	5/61 (8.2%)
	Medical	3/61 (4.9%)
	Jaundice	3/61 (4.9%)
	Reflux	3/61 (4.9%)
Received help or information with feeding problems after discharge		27/32*** (84.4%)

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219 Table 3: First feeds and feeding after discharge

220 Footnote:* Three infants were home births ** These problems were coded from open responses

221 ***This denominator comes from the 30 participants who experienced problems with feeding after discharge

222 from hospital and two who experienced problems with feeding after their home birth.

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Question from initial questionnaire	‘Were there any problems feeding your baby while you were in the hospital, birth centre or unit? What problems were there?’
Quotes	<p><i>“X would not take anything from the breast and was very sleepy so had an NG tube put in.”</i></p> <p><i>“A feeding tube was inserted straight away, which prevented me from breast feeding. It also prevented her from becoming hungry enough to feed from me”</i></p> <p><i>“baby continually pushing tongue out and could not latch on. Decided to try the bottle which she took immediately so did not try breast again and was not questioned by staff”</i></p>
Question from Initial, 7 month and 12 month questionnaire	‘Have you stopped breastfeeding (no longer give your baby any expressed milk or put your baby to your breast)? What were your reasons for stopping?’
Quotes	<p><i>“Significant weight loss in early days, poor latch, inadequate milk being taken by baby, readmission to hospital for tube feeding, introduction of bottle feeding in hospital, milk supply subsequently drying up due to baby being put on bottle and use of pumps further made milk supply deteriorate.”</i></p> <p><i>“Baby fell asleep too much at the breast to feed properly. It was too time consuming and stressful to keep expressing.”</i></p>
Question from initial, 7-month and 12-month questionnaires	“What would have helped you breastfeed longer?”
Quotes	<p><i>“Knowing as I do now that it's common to have feeding problems with Down syndrome. More specific breastfeeding support.” (from initial questionnaire)</i></p> <p><i>“I feel I was forced to give Child’s name a bottle when she was only a day old as the midwife was unwilling to entertain my concerns about the bottle meaning that she would never take the breast. I had wanted to give the milk by syringe or cup to give her a chance to keep trying the breast, but I was shot down and ridiculed.” (from 7-month questionnaire)</i></p> <p><i>“I just became too sick, unwell but at the same time I fed longer than I thought I would. Thanks to the support I received.” (from 12-month questionnaire)</i></p> <p><i>“She lost 6% of her birth weight by day 9 and the NICU home midwife suggested we move onto top up. I think that was the pinch point. If I had said no, let’s try harder to feed from the breast it might have established itself. But</i></p>

she had just been discharged from hospital and I was so reluctant to go back. You really have the threat of readmission hanging over you... I would have loved to feed her myself. It is my biggest sadness but there were too many other variables at play. I am pleased I was able to exclusively breast feed her though for well over 4 months.” (from 12-month questionnaire)

Table 4: Quotes from free text boxes in initial, 7 month and 12 month questionnaire

Of the 61 mother/baby dyads, 39 (64%) continued some breastfeeding for over six weeks (Table 5) (including infants who received mixed infant formula and breastmilk feeds). Over the age of six months, this decreased to 32 (32/59 (54%)) still breastfeeding in part. These percentages are higher than in the general population, levels reported in the Infant Feeding Survey (IFS) 2010 (55% and 34% respectively) (15). The prevalence of exclusive breastfeeding in the study population at six weeks was 13/61 (21%) compared to 23% in the general population in the IFS 2010 (15). By six months of age, two (2/54 (4%)) participants were exclusively breast fed. This compares to 1% of general population. Using data from the initial and 7-month questionnaires, the median age at which some formula milk was introduced in the whole cohort was five days (IQR 1, 21 days). Formula feeds were introduced by 52% of mothers within a week in the IFS 2010 and 75% by 6 weeks.

Types of feeds / Stopping breastfeeding			
Age stopped breastfeeding*			
6 weeks or less	11/27** (40.7%)		
> 6 weeks to 4 months	7/27 (25.9%)		
> 4 months to 6 months	3/27 (11.1%)		
> 6 months	6/27 (22.2%)		
Age started formula feeds			
6 weeks or less	44/57*** (77.2%)		
> 6 weeks to 4 months	3/57 (5.3%)		
> 4 months to 6 months	5/57 (8.8%)		
> 6 months	5/57 (8.8%)		
Age when given a non – milk drink**** (weeks)	Median 26 (IQR 20, 28)		
Age at which first given cow’s milk (weeks)	Median 44 (IQR 28, 48)		
Stopping breastfeeding and problems with feeding	Initial Questionnaire	7 month Questionnaire	12 month Questionnaire
Maternal opinion on how long they breastfed			
Breastfed for as long as they intended	14/37(37.8%)	4/23 (17.4%)	4/20 (20.0%)
Breastfed for longer than they intended	3/37 (8.1%)	3/23 (13.0%)	3/20 (15.0%)
Would have liked to breastfeed longer.	20/37 (54.1%)	16/23 (69.6%)	13/20 (65.0%)
Reasons for stopping breastfeeding			
Inadequate breastmilk supply	6/20 (30%)	7/54 (13.0%)	2/40 (5.0%)
Problems expressing milk	5/20 (25%)	3/54 (5.6%)	4/40 (10.0%)
Excessive time expressing milk	5/20 (25%)	1/54 (1.9%)	2/40 (5.0%)
Baby losing weight	4/20 (20%)	2/54 (3.7%)	2/40 (5.0%)
Maternal medical problem	3/20 (15%)	2/54 (3.7%)	1/40 (2.5%)
Lethargy	1/20 (5%)	1/54 (1.9%)	
Weaning by choice	n/a	4/54 (7.4%)	3/40 (7.5%)
Other		3/54 (5.6%)	4/40 (10.0%)

Table 5: Stopping Breastfeeding

Footnote: *including using expressed breastmilk and mixed feeding and/or were introduced to other types of milk feeds or drinks. **this denominator is the number of women who had stopped breastfeeding by the data cut off date for data analysis. Some infants would still have been receiving breastmilk at the cut-off date for data analysis. Some would also have been still mixed feeding both breastmilk and formula ***Non-milk drinks included any drink other than milk including water (which would be fine) and juices which would not be recommended.

Just over half of the participants had problems associated with feeding after discharge from hospital (Table 3). The most common problems were lethargy or faltering growth. Three mothers mentioned their infants being readmitted to hospital with poor feeding. Less than

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2
3 270 three-quarters, 34/47 (72%) had the correct 'DS insert' in their Red book (the personal child
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5 271 health record that is given to every baby). The 'DS insert' contains the appropriate growth
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7 272 charts reflecting a tendency to 'normal', slower growth trajectory in this condition compared
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9 273 to non-trisomy infants (16).

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14 275 Over half of the mothers said that they would have liked to have breastfed for longer (20/37,
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16 276 (54%)). Reasons for stopping breastfeeding included inadequate breastmilk supply, issues
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18 277 with expressing breast milk and their infants having faltering growth. The quotes in Table 4
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20 278 illustrate the reasons mothers gave for stopping breastfeeding.

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25 280 Mothers were asked "What would have helped you breastfeed longer?" the answers included
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27 281 not introducing bottles as early, not needing to express, being at home and having more
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29 282 specific support. Quotes from the initial, 7-month and 12-month questionnaires in response to
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31 283 this question are given in Table 4. Some mothers also used this question to explain that they
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33 284 did breastfeed.

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40 286 **Discussion:**

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44 288 We have shown that exclusive breastfeeding amongst the infants with DS at six months is
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46 289 comparable to the general population (4% vs 1%). Apart from exclusive breastfeeding at six
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48 290 weeks when prevalence was similar (21% of infants with DS versus 23% in the general
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50 291 population), breastfeeding (exclusive or combination feeding) amongst the study participants
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52 292 was higher at all time points than levels reported in the general population (15). This was
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54 293 surprising and does not support the hypothesis that hypotonia and oro-motor issues associated
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56 294 with DS significantly alters ability to breastfeed. This is an important and encouraging
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3 295 message for mothers and should inspire midwives and health professionals to support breast
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5 296 feeding. These findings suggest that the frequently heard mantra, that infants with DS
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7 297 probably will not breastfeed successfully, needs to be changed.
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12 299 Formula was introduced very early at a median of five days with 77% having started by the
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14 300 age of six weeks. Overall, over half of the mothers were still breastfeeding beyond the age of
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16 301 six months (including infants who combination fed with breastmilk and infant formula)
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18 302 which is a very positive message for families. This is higher than the 34% at six months
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20 303 within the general population. Due to the wording of the questionnaire, it was not possible to
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22 304 distinguish between those who directly breastfed or those who gave expressed breastmilk,
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24 305 and this would be useful to include in future questionnaires.
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30 306
31 307 Over half of FADES infants were admitted to SCBU, all being NG tube fed. In around 40%,
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33 308 issues with feeding were responsible for NG placement and for most of these participants,
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35 309 this was also the reason for SCBU admission. Almost 70% of the mothers said that having
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37 310 their baby in SCBU had affected their ability to feed the way they would have liked. This is
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39 311 possibly open to intervention as some admissions might be prevented with more
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41 312 specialised/tailored support on the postnatal wards. Some hospitals will only have one or two
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43 313 infants born a year with DS, possibly leading to automatic SCBU admissions with increased
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45 314 levels of anxiety around potential complications and associated conditions. In terms of oro-
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47 315 motor skill development, it is important that infants have the chance to feed orally early on.
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49 316 This is postulated to be important for the development of oral skills, tolerance of tastes and
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51 317 textures and is also important for social development (17). Most infants in our cohort
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53 318 required NG tube feeds for less than two weeks but a third also required feeds to be stopped
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55 319 altogether at some point and were put onto intravenous fluids.
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5 321 NG tube feeding was required for some infants due to dehydration, jaundice, polycythaemia
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7 322 and vomiting. Although classified as a 'medical' reason, inability to feed may have
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9 323 contributed or caused these issues. Other 'medical' reasons included prematurity, ventilation
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11 324 or surgical abdomen. Prevalence of NG tube feeding in the general population and in the
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13 325 typical DS population are poorly reported. A third of those NG fed infants continued to
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15 326 receive exclusively expressed breastmilk. Many of the infants were fed using expressed
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17 327 breastmilk either for NG tube feeds or for top up feeds via alternative feeding methods
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19 328 including bottle.
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26 330 Lethargy was the most commonly reported problem with feeding after discharge with far
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28 331 fewer citing poor latch than during the initial admission. Importantly 16% of the mothers said
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30 332 that poor weight gain or weight loss was an issue. It is of concern that over a quarter of the
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32 333 mothers reported that they were not given the correct 'DS insert' in their Personal Child
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34 334 Health Record ('Red' book) (16). Healthy infants with DS gain weight more slowly than
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36 335 other infants and it is important to account for this when assessing feeding and growth. If an
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38 336 infant with DS is plotted on a standard growth chart they will appear to be failing to thrive
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40 337 and a mother who is successfully feeding her baby, may be told that she needs to supplement
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42 338 feeds, start formula feeds if she is breastfeeding or even that her baby needs admission to
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44 339 hospital.
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51 341 Although the number of participants is relatively high compared to other cohorts of infants
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53 342 with DS, the small number in this paper means that caution needs to be used when drawing
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55 343 conclusions. Those infants born with a child protection plan, fostered, or adopted, and parents
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57 344 who do not speak English did not meet the inclusion criteria. Therefore, we are likely to have
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3 345 excluded some of the most disadvantaged of our population. The higher levels of
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5 346 breastfeeding in the study compared to the general population may in part, be due to selection
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7 347 bias. Mothers who have chosen to take part in the study may already have a specific interest
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9 348 in infant feeding. In the UK, higher breastfeeding frequency is described in mothers over 30
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11 349 years of age (87%) (15) which may also explain the higher level of initial breastfeeding in
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13 350 FADES. The karyotype for the infants in the cohort was not requested which might be
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15 351 considered a weakness of the study. FADES potentially might include children with mosaic
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17 352 Down syndrome who can be phenotypically milder although this is rare: Only one to three
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19 353 percent of DS children have Mosaicism (18).
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26 355 Reasons for stopping breastfeeding were similar to the IFS 2010 (15) with inadequate
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28 356 breastmilk supply and faltering growth being common. However, a large proportion
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30 357 mentioned issues surrounding expressing milk. This highlights the need for mothers who are
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32 358 expressing to receive tailored support. Mothers were asked “What would have helped you
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34 359 breastfeed longer” the responses indicated that mothers understandably wanted ‘normality’,
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36 360 they wanted their infants to be well, to not require bottle or expressed milk and to be at home.
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38 361 Although it is not possible to change these factors for many, every effort should be made to
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40 362 listen to maternal wishes and assist where possible. Some mothers used this questionnaire to
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42 363 voice their frustration at alternative feeding methods being introduced ‘too early’ or ‘against
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44 364 their wishes’.
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51 366 It is a strength of the study that the families recruited were representative of the general
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53 367 population of children with DS, with similar numbers of children having associated
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55 368 conditions including cardiac abnormalities as reported in other studies (19). The eligibility
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57 369 criteria were broad and did not exclude any medical conditions. A further strength is that the
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3 370 study was UK wide reducing selection bias. Those who could not speak English were
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5 371 excluded and this may have had altered feeding results with cultural differences in early
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7 372 feeding (20). Translating all study documentation however was not possible for the multiple
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9 373 languages now represented in UK population.
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14 375 These results raise some important questions and highlight potential opportunities for
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16 376 interventions in relation to feeding support for mothers of infants with DS. Any advice given
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18 377 to mothers on feeding a baby with DS based on this study should include the message that
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20 378 infants with DS can be exclusively breastfed or receive a combination of breast and formula
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22 379 feeds. However, some may need to include expressed breastmilk and alternative feeding
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24 380 methods. Providing mothers with access to tailored support and advice specifically around
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26 381 expressing should be included, as should information on NG tube feeding.
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33 **Conclusion:**

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35 384 This paper provides critical understanding of the early breastfeeding practices and
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37 385 experiences of mothers with infants. It is clear that many infants with DS can breastfeed
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39 386 exclusively for six months as per WHO guidelines. Our study shows that almost two-thirds of
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41 387 babies with DS were being breast fed at 6 months. This may require significant perseverance
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43 388 from the mother and supportive professionals, as establishing breastfeeding can be
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45 389 challenging. Oro-motor difficulties and significant medical needs may underlie some
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47 390 challenges, but overall, mothers who wish to breastfeed should be encouraged and supported
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49 391 to do so as success is possible.
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3 395 Boxes – What is already known on this topic (bullet points)
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- 5 396 • Infants with DS have anatomical and physiological features that may affect their
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8 397 ability to feed but this is phenotypically variable.
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10 398 • Infants with DS have associated medical conditions including congenital heart
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13 399 disease and gastro-intestinal abnormalities which may impact on early feeding.
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15 400 • Prevalence of NG Tube feeding in infants with DS has previously been reported as up
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18 401 to 40%.

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22 403 What this study adds

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25 404 • Breastfeeding prevalence amongst infants with DS are equivalent to the general
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27 405 population at 6 months.
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30 406 • Infants with DS can receive exclusive breast-milk feeds for over 6 months.
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32 407 • Early and extra post-natal support for breast feeding may be beneficial.
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35 408 • At least half of infants with DS in this UK wide cohort study receive nasogastric feeds.
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40 410 How this Study might affect research, practice or policy

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42 411 • This study seeks to promote an increase in tailored feeding support for mother's of
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44 412 infants with DS.
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47 413 • Key findings from this study may contribute to positive changes in breastfeeding
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49 414 advice and support for mother's of infants with DS.
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52 415 • The high prevalence of infants receiving naso-gastric tube feeds warrants further
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54 416 research and potentially change in policy within neonatal units.
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2
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5 419 Centre Nutrition Theme.

6
7 420 **Competing interests:** No competing interests

8
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10
11 422 wrote the protocol, completed the data collection, data analysis and drafts of the manuscript.
12
13 423 Sam Leary was the lead statistician on the study and PhD supervisor. She contributed to the
14
15 424 protocol and study design, data analysis and draft manuscripts of the paper. Sofia Leadbetter
16
17 425 provided the administrative support and coordination for the study, she was involved in
18
19 426 participant recruitment and data collection. Stu Toms contributed to the study design, online
20
21 427 questionnaires and managed the study database. Georgina Mortimer contributed to the data
22
23 428 collection and coordinates sample collection for the FADES study. Tim Scorrer recruited
24
25 429 participants for the study and reviewed draft manuscripts of the paper. Kathleen Gillespie
26
27 430 (PhD supervisor) contributed to the study protocol, study design and reviewed draft
28
29 431 manuscripts of the article. Julian Hamilton Shield (PhD supervisor) contributed to the study
30
31 432 protocol, study design and reviewed draft manuscripts of the articles.
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37 433 **Data Sharing:** Data sets may only be available by individual request to the Corresponding
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39 434 Author.
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42 435

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3 1 **Title Page:**
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6 2 **Establishing breast feeding in infants with Down syndrome: the**
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9 3 **FADES cohort experience**
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6 28 **Abstract:**
7
8 29 Objective: To describe breast feeding prevalence, and maternal experience in infants with
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10 30 Trisomy 21.
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12 31 Design: Longitudinal cohort study
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14 32 Setting: Participants from UK recruited through websites, social media and local
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16 33 collaborators: neonatologists, community paediatricians and research nurses.
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18 34 Subjects: Infants under the age of 8 months with Down syndrome (DS) recruited to the
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20 35 FADES (Feeding and Autoimmunity in Down Syndrome Evaluation Study) between the 1st
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22 36 September 2014 to 31st August 2017. Seventy participants: median age 20 weeks
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24 37 (Interquartile range (IQR) 13, 29 weeks) at initial questionnaire.
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26 38 Main outcome measure: Breastfeeding prevalence at 6 weeks and 6 months amongst infants
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28 39 with DS.
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30 40 Results: The prevalence of exclusive breastfeeding amongst study participants was similar to
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32 41 the general population (13/61 21% vs 23% at 6 weeks, 2/54 4% vs 1% at 6 months).
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34 42 However, the prevalence of breastfeeding (exclusive or combination feeding) amongst the
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36 43 study participants was higher than the general population (39/61 64% vs 55% at 6 weeks,
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38 44 32/59 54% vs 34% at 6 months).
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40 45 Conclusion: Although there may be challenges in establishing breastfeeding in infants with
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42 46 DS, our data suggest that exclusive breastfeeding is possible for some, and the prevalence of
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44 47 breastfeeding is comparable to the prevalence in the general population.
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46 48 Trial Registration: ISRCTN 12415856
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52 51 **Keywords: Down Syndrome, Trisomy 21, Feeding, Breast-feeding,**
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53 **Background**

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55 Down syndrome (DS) is caused by trisomy of chromosome 21. DS is usually diagnosed
56 antenatally or in the first few days of life by recognition of salient features (1). A number of
57 associated conditions including congenital heart disease and gastrointestinal complications
58 can cause additional challenges during the neonatal period.

59

60 Current World Health Organisation (WHO) recommendations are that infants should be
61 exclusively breastfed until 6 months (5), this is based on the health benefits for mother and
62 baby. Prolonged exclusive breastfeeding is possibly protective against some autoimmune
63 conditions including type 1 diabetes and coeliac disease for which children with DS are at
64 increased risk (6,7,8). Furthermore, there is evidence that breastfeeding exclusively or
65 combined feeding to a lesser but significant extent, enhances immunity and is protective
66 against otitis media and respiratory tract infections (9) both being more prevalent in children
67 with DS (10).

68

69 Infants with DS may have oral, anatomical and physiological abnormalities affecting their
70 ability to feed normally: as with other features of DS there is phenotypic variability. To
71 breastfeed effectively, a tight oral/nipple seal needs to be induced with the tongue making a
72 groove and the lips sealing around the nipple. For a baby with DS, the flattened shape of the
73 tongue and low tone in the oral structures means that establishing breastfeeding may be
74 challenging. (2,3). Lewis et al reported that 40% of DS infants had been naso-gastric (NG)
75 tube fed during the neonatal period illustrating some of the issues with feeding (4).

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3 77 Many countries have registers which provide data on people with DS. These have facilitated
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5 78 retrospective studies providing statistics on for example: birth and death rates and congenital
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7 79 anomalies. However longitudinal birth cohort studies of infants with DS in the UK are rare
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10 80 (11,12,13,14). The FADES (Feeding and Autoimmunity in Down Syndrome Evaluation
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12 81 Study) was established to investigate early feeding and the development of autoimmunity.
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14 82 Medical and detailed feeding data are collected by mothers from birth and includes both
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16 83 feeding in the hospital settings and at home. A study hypothesis is that infants with DS have
17
18 84 difficulties with establishing breast feeding and are therefore introduced to formula feeds at
19
20 85 an earlier age. The aim of this paper is to describe breastfeeding prevalence and experiences
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22 86 among infants with DS and their mothers, in the first six months of life. This paper describes
23
24 87 findings from the analysis of the feeding data collected between September 2014 and August
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26 88 2017, to explore this and compare to breastfeeding prevalence in the general population.
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33 **Methods:**

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37 92 FADES is an ongoing UK wide study recruiting infants with DS antenatally or in the first
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39 93 eight months of life. Exclusion criteria are infants born with a child protection plan, fostered
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41 94 or adopted, >8 months or parents do not speak English. Participants are recruited either by
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43 95 health professionals including neonatologists, community paediatricians and research nurses
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45 96 or via web recruitment through the Downs Syndrome Association, Downs Syndrome
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47 97 Scotland, and other websites and social media [https://www.bristolbrc.nihr.ac.uk/our-](https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/)
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49 98 [research/nutrition-diet-and-lifestyle/childhood/fades-study-2/](https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/). A combined feeding and
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51 99 medical questionnaire is completed by families at recruitment (initial questionnaire), at six to
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53 100 eight months of life (7-month questionnaire) and then at 12 months (12-month questionnaire).
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56 101 Feeding questions are based on those from the Infant Feeding Survey (IFS) 2010 (15),
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3 102 medical questions are related to conditions associated with DS, hospital admissions and
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5 103 antibiotic usage. Mothers are able to provide free text answers to some questions and quotes
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7
8 104 from these have been used to illustrate key points. A full qualitative study and analysis has
9
10 105 not been completed as part of this feasibility study. This paper presents data collected in the
11
12 106 first three years of recruitment from 1st September 2014 to 31st August 2017 when the
13
14 107 feasibility assessment was conducted.
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19 109 **Statistical Analysis:** As a feasibility study, analysis of the questionnaires is descriptive as
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21 110 there is not enough power to statistically test for associations. Frequencies were derived and
22
23 111 presented as percentages for categorical variables. For continuous data, means and standard
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25 112 deviations (SDs) were presented for data that were approximately normal, and medians and
26
27 113 interquartile ranges (IQRs) for non-normal data. Analysis used STATA vs. 15. Comparisons
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29 114 are made with the general population from the results reported by the IFS 2010 (15).
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35 116 **Public involvement:** The study design including recruitment and data collection methods
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37 117 were established following discussion with and involvement of the Downs Syndrome
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39 118 Association. Local members (all of whom were parents of a child with DS) advised on the
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41 119 wording and feasibility of the feeding and medical questionnaires.
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47 121 Ethics approval for FADES was given by the National Research Ethics Service (NRES)
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49 122 Committee South West – Central Bristol 23rd April 2014 14/SW/0030 and it is an NIHR
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51 123 Portfolio study.
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3 127 **Results:**
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8 129 Seventy participants were recruited between the 1st September 2014 and the 31st August
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10 130 2017. 61 out of the 70 participants (87%) completed the initial feeding and medical
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12 131 questionnaire at a median age of 20 weeks (IQR 13, 29 weeks). Of these, approximately a
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14 132 quarter (n=15) were diagnosed antenatally with DS. Table 1 summarises maternal
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16 133 characteristics and birth details. Over half were born by normal vaginal delivery: median
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19 134 gestation, 38 weeks (IQR 37, 39 weeks), mean birthweight of 3kg (SD 0.5kg). Most infants
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21 135 were born in hospital units, three were home deliveries. Median hospital stay after birth was
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23 136 five days (IQR 3, 9 days).
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Background Characteristics		
Maternal age (years) at time of completing initial questionnaire	20 to 24	5/61 (8%)
	25 to 29	6/61 (10%)
	30 to 34	15/61 (25%)
	35 to 39	23/61 (38%)
	40 or over	12/61 (20%)
Mother's marital status	Living together	17/61 (28%)
	Married or in a civil partnership	40/61 (66%)
	Single	3/61 (5%)
	Widowed, divorced, or separated	1/61 (2%)
Mother's ethnic group	Other	2/61 (3%)
	White British	53/61 (87%)
	White Irish	3/61 (5%)
	White Other	3/61 (5%)
Birth History		
First baby		19/61 (31%)
Prenatal diagnosis of DS		15/61 (25%)
Twin Birth		2/61 (3%)
Type of delivery	Normal Vaginal delivery	38/60 (63%)
	C-Section	17/60 (28%)
	Forceps	2/60 (3%)
	Ventouse	3/60 (5%)
Gestation (weeks)	Median 38 (IQR 37, 39)	
Pre-term 32-37 weeks		13/61 (21%)
Birthweight (kg)	Mean 3.0 (0.5 SD)	
Location of birth	At home	3/59 (5%)
	In hospital (consultant led)	29/59 (50%)
	In hospital (midwife led)	25/59 (42%)
	Birth centre (midwife led)	2/59 (3%)
Length of initial hospital stay (hours)	Median 120 (IQR 72, 216)	

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153 Table 1: Maternal characteristics and birth details

154 Footnote: DS (Down syndrome), IQR (inter quartile range), SD (standard deviation), C-section (Caesarean
155 Section)

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157 Over half (34/61, 56%) were admitted into a special care baby unit (SCBU) with almost a
158 third of these (10/34, 29%) primarily due to poor feeding. Half of the infants for whom data
159 were available, required NG tube feeding as shown in Table 2. All admitted to SCBU, were
160 NG tube fed. Of the 31 infants who were fed via NG tube, 12/31 (39%), primarily required

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3 161 NG tube feeds in SCBU due to feeding issues, the remainder due to medical co-morbidities
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5 162 (37% with multiple medical indications). NG tube feeds were mostly expressed breastmilk
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8 163 or a mixture of expressed milk and infant formula. NG tube feeds were required in 19/31
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10 164 (61%) participants for less than two weeks.
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SCBU Admission		
Admitted to SCBU		34/61 (56%)
Admitted to SCBU due to problems with feeding		10/34 (29%)
Admitted to SCBU for any other reason*		24/34 (71%)
Hypoxia / respiratory distress / PPHN		17/34 (50%)
Jaundice		7/34 (21%)
Cardiac / cardiac monitoring		4/34 (12%)
Infection		4/34 (12%)
Prematurity		3/34 (9%)
Polycythaemia		2/34 (6%)
Other		7/34 (21%)
Length of SCBU stay (weeks)		Median 2 (IQR 2, 4)
Feeding in SCBU and NG tube Feeds		
SCBU admission affected ability of mother to feed baby as she would have liked		23/34 (68%)
Shown how to express milk in SCBU		29/34 (85%)
Felt supported to express milk in SCBU		27/30 (90%)
Had NG tube feeds		31/31* (100%)
Required NG tube feeds due to problems with feeding		12/31 (39%)
Medical reason for NG tube feeds**	Prematurity	2/19 (11%)
	Dehydration / hydration	2/19 (11%)
	Ventilation	2/19 (11%)
	Respiratory problems	8/19 (42%)
	Jaundice / polycythaemia	4/19 (21%)
	Vomiting or surgical abdomen	4/19 (21%)
Length of time NG tube fed	< 3 days	5/31 (16%)
	> 3 to 7 days	6/31 (19%)
	> 1 to 2 weeks	8/31 (26%)
	> 2 to 4 weeks	6/31 (19%)
	> 1 to 2 months	5/31 (16%)
	> 2months	1/31 (3%)
Type of NG tube feeds given	Only expressed breast milk	10/31 (32%)
	Only infant formula	2/31 (7%)
	Expressed breast milk and infant formula	19/31 (61%)
Feeds stopped and IV fluids given		11/34 (32%)
Length of time on IV fluids	< 3 days	2/9 (22%)
	> 3 to 7 days	4/9 (44%)
	> 7 days to 1 month	3/9 (33%)

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187 Table 2: Feeding in SCBU (special care baby unit) and NG (nasogastric) tube feeds

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189 Footnote: IV fluids (Intra- venous fluids), PPHN (persistent pulmonary hypertension of the newborn),

190 *Due to an issue with branching of the questions at least 31 infants were NG tube fed but there may have been

191 more. Where they were branched away, people have been counted as missing, so the denominator is 31.

192 **Coded from open response

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3 193 Of the mothers receiving an antenatal diagnosis for their baby, 13/15 (87%) were told about
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5 194 problems relating to feeding but only three (3/15, (20%)) received any specific antenatal
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7 195 advice about breastfeeding a baby with DS. Most mothers initially breastfed their baby, with
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10 196 47/60 (78%) having skin to skin contact within 24 hours of birth (Table 3). Feeding problems
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12 197 that were experienced in the hospital or birthing centre by mothers, included those commonly
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14 198 associated with infants with DS such as poor latch and lethargy. Although hypotonia is one of
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16 199 the explanations frequently given as a cause for feeding difficulties, only one parent
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18 200 described this feature. Mothers provided responses to an open question regarding feeding
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20 201 their baby in the hospital, birth centre or unit as illustrated in the quotes in Table 4.
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First Feeds		
Ever breastfed or received expressed breast milk		55/61 (90%)
Had skin to skin contact within 24hrs of birth		47/60 (78%)
Maternal health problems after birth that affected feeding		4/61 (7%)
Received help with breastfeeding within first few days		40/60 (67%)
How soon after birth was baby put to the breast	within a few minutes	14/55 (26%)
	<30 min	17/55 (31%)
	30 min to 1 hr	9/55 (16%)
	>1 hr to 8 hrs	3/55 (6%)
	>8 hrs to 24 hrs	3/55 (6%)
	> 24 hrs later	9/55 (16%)
Experienced problems when feeding their baby in the hospital, birth centre or unit		45/58* (78%)
Common problems with feeding**	Poor latch	20/45 (44%)
	Medical issue	14/45 (31%)
	Jaundice	14/45 (31%)
	Tired / lethargic	13/45 (29%)
	Maternal reason	4/45 (9%)
	Tongue size/ position	3/45 (7%)
	Low tone	1/45 (2%)
Reported that they received enough help with feeding in hospital / birth centre		48/58 (83%)
General Feeding and feeding after discharge from hospital / birth centre		
Problems with feeding baby after discharge from hospital / birth centre		30/56 (54%)
Problems with feeding after discharge**		
	Lethargy	13/61 (21%)
	Poor weight gain / weight loss	10/61 (16%)
	Low tone	1/61 (2%)
	Latch	5/61 (8%)
	Medical	3/61 (5%)
	Jaundice	3/61 (5%)
	Reflux	3/61 (5%)
Received help or information with feeding problems after discharge		27/32*** (84%)

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219 Table 3: First feeds and feeding after discharge

220 Footnote:* Three infants were home births ** These problems were coded from open responses

221 ***This denominator comes from the 30 participants who experienced problems with feeding after discharge

222 from hospital and two who experienced problems with feeding after their home birth.

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Question from initial questionnaire	‘Were there any problems feeding your baby while you were in the hospital, birth centre or unit? What problems were there?’
Quotes	<p><i>“X would not take anything from the breast and was very sleepy so had an NG tube put in.”</i></p> <p><i>“A feeding tube was inserted straight away, which prevented me from breast feeding. It also prevented her from becoming hungry enough to feed from me”</i></p> <p><i>“baby continually pushing tongue out and could not latch on. Decided to try the bottle which she took immediately so did not try breast again and was not questioned by staff”</i></p>
Question from Initial, 7 month and 12 month questionnaire	‘Have you stopped breastfeeding (no longer give your baby any expressed milk or put your baby to your breast)? What were your reasons for stopping?’
Quotes	<p><i>“Significant weight loss in early days, poor latch, inadequate milk being taken by baby, readmission to hospital for tube feeding, introduction of bottle feeding in hospital, milk supply subsequently drying up due to baby being put on bottle and use of pumps further made milk supply deteriorate.”</i></p> <p><i>“Baby fell asleep too much at the breast to feed properly. It was too time consuming and stressful to keep expressing.”</i></p>
Question from initial, 7-month and 12-month questionnaires	“What would have helped you breastfeed longer?”
Quotes	<p><i>“Knowing as I do now that it's common to have feeding problems with Down syndrome. More specific breastfeeding support.” (from initial questionnaire)</i></p> <p><i>“I feel I was forced to give Child’s name a bottle when she was only a day old as the midwife was unwilling to entertain my concerns about the bottle meaning that she would never take the breast. I had wanted to give the milk by syringe or cup to give her a chance to keep trying the breast, but I was shot down and ridiculed.” (from 7-month questionnaire)</i></p> <p><i>“I just became too sick, unwell but at the same time I fed longer than I thought I would. Thanks to the support I received.” (from 12-month questionnaire)</i></p> <p><i>“She lost 6% of her birth weight by day 9 and the NICU home midwife suggested we move onto top up. I think that was the pinch point. If I had said no, let’s try harder to feed from the breast it might have established itself. But</i></p>

she had just been discharged from hospital and I was so reluctant to go back. You really have the threat of readmission hanging over you... I would have loved to feed her myself. It is my biggest sadness but there were too many other variables at play. I am pleased I was able to exclusively breast feed her though for well over 4 months.” (from 12-month questionnaire)

Table 4: Quotes from free text boxes in initial, 7 month and 12 month questionnaire

Of the 61 mother/baby dyads, 39 (64%) continued some breastfeeding for over six weeks (Table 5) (including infants who received mixed infant formula and breastmilk feeds). Over the age of six months, this decreased to 32 (32/59 (54%)) still breastfeeding in part. These percentages are higher than in the general population, levels reported in the Infant Feeding Survey (IFS) 2010 (55% and 34% respectively) (15). The prevalence of exclusive breastfeeding in the study population at six weeks was 13/61 (21%) compared to 23% in the general population in the IFS 2010 (15). By six months of age, two (2/54 (4%)) participants were exclusively breast fed. This compares to 1% of general population. Using data from the initial and 7-month questionnaires, the median age at which some formula milk was introduced in the whole cohort was five days (IQR 1, 21 days). Formula feeds were introduced by 52% of mothers within a week in the IFS 2010 and 75% by 6 weeks.

Types of feeds / Stopping breastfeeding			
Age stopped breastfeeding*			
6 weeks or less	11/27** (41%)		
> 6 weeks to 4 months	7/27 (26%)		
> 4 months to 6 months	3/27 (11%)		
> 6 months	6/27 (22%)		
Age started formula feeds			
6 weeks or less	44/57*** (77%)		
> 6 weeks to 4 months	3/57 (5%)		
> 4 months to 6 months	5/57 (9%)		
> 6 months	5/57 (9%)		
Age when given a non – milk drink**** (weeks)	Median 26 (IQR 20, 28)		
Age at which first given cow’s milk (weeks)	Median 44 (IQR 28, 48)		
Stopping breastfeeding and problems with feeding	Initial Questionnaire	7 month Questionnaire	12 month Questionnaire
Maternal opinion on how long they breastfed			
Breastfed for as long as they intended	14/37(38%)	4/23 (17%)	4/20 (20%)
Breastfed for longer than they intended	3/37 (8%)	3/23 (13%)	3/20 (15%)
Would have liked to breastfeed longer.	20/37 (54%)	16/23 (70%)	13/20 (65%)
Reasons for stopping breastfeeding			
Inadequate breastmilk supply	6/20 (30%)	7/54 (13%)	2/40 (5%)
Problems expressing milk	5/20 (25%)	3/54 (6%)	4/40 (10%)
Excessive time expressing milk	5/20 (25%)	1/54 (2%)	2/40 (5%)
Baby losing weight	4/20 (20%)	2/54 (4%)	2/40 (5%)
Maternal medical problem	3/20 (15%)	2/54 (4%)	1/40 (3%)
Lethargy	1/20 (5%)	1/54 (2%)	
Weaning by choice	n/a	4/54 (7%)	3/40 (8%)
Other		3/54 (6%)	4/40 (10%)

Table 5: Stopping Breastfeeding

Footnote: *including using expressed breastmilk and mixed feeding and/or were introduced to other types of milk feeds or drinks. **this denominator is the number of women who had stopped breastfeeding by the data cut off date for data analysis. Some infants would still have been receiving breastmilk at the cut-off date for data analysis. Some would also have been still mixed feeding both breastmilk and formula ****Non-milk drinks included any drink other than milk including water (which would be fine) and juices which would not be recommended.

Just over half of the participants had problems associated with feeding after discharge from hospital (Table 3). The most common problems were lethargy or faltering growth. Three mothers mentioned their infants being readmitted to hospital with poor feeding. Less than

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3 270 three-quarters, 34/47 (72%) had the correct 'DS insert' in their Red book (the personal child
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5 271 health record that is given to every baby). The 'DS insert' contains the appropriate growth
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7 272 charts reflecting a tendency to 'normal', slower growth trajectory in this condition compared
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9 273 to non-trisomy infants (16).

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14 275 Over half of the mothers said that they would have liked to have breastfed for longer (20/37,
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16 276 (54%)). Reasons for stopping breastfeeding included inadequate breastmilk supply, issues
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18 277 with expressing breast milk and their infants having faltering growth. The quotes in Table 4
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20 278 illustrate the reasons mothers gave for stopping breastfeeding.

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25 280 Mothers were asked "What would have helped you breastfeed longer?" the answers included
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27 281 not introducing bottles as early, not needing to express, being at home and having more
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29 282 specific support. Quotes from the initial, 7-month and 12-month questionnaires in response to
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31 283 this question are given in Table 4. Some mothers also used this question to explain that they
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33 284 did breastfeed.

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37 38 39 286 **Discussion:**

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44 288 In our cohort exclusive breastfeeding amongst the infants with DS at six months is
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46 289 comparable to the general population (4% vs 1%). Apart from exclusive breastfeeding at six
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48 290 weeks when prevalence was similar (21% of infants with DS versus 23% in the general
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50 291 population), breastfeeding (exclusive or combination feeding) amongst the study participants
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52 292 was higher at all time points than levels reported in the general population (15). This was
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54 293 surprising and does not support the hypothesis that hypotonia and oro-motor issues associated
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56 294 with DS significantly alters ability to breastfeed. This is an important and encouraging

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3 295 message for mothers and should inspire midwives and health professionals to support breast
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5 296 feeding. These findings suggest that the frequently heard mantra, that infants with DS
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7 297 probably will not breastfeed successfully, needs to be changed.
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12 299 Formula was introduced very early at a median of five days with 77% having started by the
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14 300 age of six weeks. Overall, over half of the mothers were still breastfeeding beyond the age of
15
16 301 six months (including infants who combination fed with breastmilk and infant formula)
17
18 302 which is a very positive message for families. This is higher than the 34% at six months
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20 303 within the general population. Due to the wording of the questionnaire, it was not possible to
21
22 304 distinguish between those who directly breastfed or those who gave expressed breastmilk,
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24 305 and this would be useful to include in future questionnaires.
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31 307 Over half of FADES infants were admitted to SCBU, all being NG tube fed. In around 40%,
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33 308 issues with feeding were responsible for NG placement and for most of these participants,
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35 309 this was also the reason for SCBU admission. Almost 70% of the mothers said that having
36
37 310 their baby in SCBU had affected their ability to feed the way they would have liked. This is
38
39 311 possibly open to intervention as some admissions might be prevented with more
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41 312 specialised/tailored support on the postnatal wards. Some hospitals will only have one or two
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43 313 infants born a year with DS, possibly leading to automatic SCBU admissions with increased
44
45 314 levels of anxiety around potential complications and associated conditions. In terms of oro-
46
47 315 motor skill development, it is important that infants have the chance to feed orally early on.
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49 316 This is postulated to be important for the development of oral skills, tolerance of tastes and
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51 317 textures and is also important for social development (17). Most infants in our cohort
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53 318 required NG tube feeds for less than two weeks but a third also required feeds to be stopped
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55 319 altogether at some point and were put onto intravenous fluids.
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5 321 NG tube feeding was required for some infants due to dehydration, jaundice, polycythaemia
6
7 322 and vomiting. Although classified as a 'medical' reason, inability to feed may have
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9 323 contributed or caused these issues. Other 'medical' reasons included prematurity, ventilation
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11 324 or surgical abdomen. Prevalence of NG tube feeding in the general population and in the
12
13 325 typical DS population are poorly reported. A third of those NG fed infants continued to
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15 326 receive exclusively expressed breastmilk. Many of the infants were fed using expressed
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17 327 breastmilk either for NG tube feeds or for top up feeds via alternative feeding methods
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19 328 including bottle.
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26 330 Lethargy was the most commonly reported problem with feeding after discharge with far
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28 331 fewer citing poor latch than during the initial admission. Importantly 16% of the mothers said
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30 332 that poor weight gain or weight loss was an issue. It is of concern that over a quarter of the
31
32 333 mothers reported that they were not given the correct 'DS insert' in their Personal Child
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34 334 Health Record ('Red' book) (16). Healthy infants with DS gain weight more slowly than
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36 335 other infants and it is important to account for this when assessing feeding and growth. If an
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38 336 infant with DS is plotted on a standard growth chart they will appear to be failing to thrive
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40 337 and a mother who is successfully feeding her baby, may be told that she needs to supplement
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42 338 feeds, start formula feeds if she is breastfeeding or even that her baby needs admission to
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44 339 hospital.
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51 341 Although the number of participants is relatively high compared to other cohorts of infants
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53 342 with DS, the small number in this paper means that caution needs to be used when drawing
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55 343 conclusions. Those infants born with a child protection plan, fostered, or adopted, and parents
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57 344 who do not speak English did not meet the inclusion criteria. Therefore, we are likely to have
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3 345 excluded some of the most disadvantaged of our population. The higher levels of
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5 346 breastfeeding in the study compared to the general population may in part, be due to selection
6
7 347 bias. Mothers who have chosen to take part in the study may already have a specific interest
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9 348 in infant feeding. In the UK, higher breastfeeding frequency is described in mothers over 30
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11 349 years of age (87%) (15) which may also explain the higher level of initial breastfeeding in
12
13 350 FADES. The karyotype for the infants in the cohort was not requested which might be
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15 351 considered a weakness of the study. FADES potentially might include children with mosaic
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17 352 Down syndrome who can be phenotypically milder although this is rare: Only one to three
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19 353 percent of DS children have Mosaicism (18).
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26 355 Reasons for stopping breastfeeding were similar to the IFS 2010 (15) with inadequate
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28 356 breastmilk supply and faltering growth being common. However, a large proportion
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30 357 mentioned issues surrounding expressing milk. This highlights the need for mothers who are
31
32 358 expressing to receive tailored support. Mothers were asked “What would have helped you
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34 359 breastfeed longer” the responses indicated that mothers understandably wanted ‘normality’,
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36 360 they wanted their infants to be well, to not require bottle or expressed milk and to be at home.
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38 361 Although it is not possible to change these factors for many, every effort should be made to
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40 362 listen to maternal wishes and assist where possible. Some mothers used this questionnaire to
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42 363 voice their frustration at alternative feeding methods being introduced ‘too early’ or ‘against
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44 364 their wishes’.
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51 366 It is a strength of the study that the families recruited were representative of the general
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53 367 population of children with DS, with similar numbers of children having associated
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55 368 conditions including cardiac abnormalities as reported in other studies (19). The eligibility
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57 369 criteria were broad and did not exclude any medical conditions. A further strength is that the
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3 370 study was UK wide reducing selection bias. Those who could not speak English were
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5 371 excluded and this may have had altered feeding results with cultural differences in early
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7 372 feeding (20). Translating all study documentation however was not possible for the multiple
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9 373 languages now represented in UK population.
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14 375 These results raise some important questions and highlight potential opportunities for
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16 376 interventions in relation to feeding support for mothers of infants with DS. Any advice given
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18 377 to mothers on feeding a baby with DS based on this study should include the message that
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20 378 infants with DS can be exclusively breastfed or receive a combination of breast and formula
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22 379 feeds. However, some may need to include expressed breastmilk and alternative feeding
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24 380 methods. Providing mothers with access to tailored support and advice specifically around
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26 381 expressing should be included, as should information on NG tube feeding.
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33 **Conclusion:**

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35 384 It is clear that many infants with DS in our cohort can breastfeed exclusively for six months
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37 385 as per WHO guidelines. Our study shows that almost two-thirds of babies with DS were
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39 386 being breast fed at 6 months. This may require significant perseverance from the mother and
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41 387 supportive professionals, as establishing breastfeeding can be challenging. Oro-motor
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43 388 difficulties and significant medical needs may underlie some challenges, but overall, mothers
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45 389 who wish to breastfeed should be encouraged and supported to do so as success is possible.
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56 393 Boxes – What is already known on this topic (bullet points)
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3 394 • Infants with DS have anatomical and physiological features that may affect their
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5 ability to feed but this is phenotypically variable.
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8 396 • Infants with DS have associated medical conditions including congenital heart
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10 disease and gastro-intestinal abnormalities which may impact on early feeding.
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13 398 • Prevalence of NG Tube feeding in infants with DS has previously been reported as up
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15 to 40%.
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401 What this study adds

- 22 402 • Breastfeeding prevalence amongst infants with DS are equivalent to the general
23
24 population at 6 months.
25 403
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27 404 • Infants with DS can receive exclusive breast-milk feeds for over 6 months.
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30 405 • Early and extra post-natal support for breast feeding may be beneficial.
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32
33 406 • At least half of infants with DS in this UK wide cohort study receive nasogastric feeds.
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408 How this Study might affect research, practice or policy

- 39 409 • This study seeks to promote an increase in tailored feeding support for mother's of
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41 infants with DS.
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44 411 • Key findings from this study may contribute to positive changes in breastfeeding
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46 advice and support for mother's of infants with DS.
47 412
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49 413 • The high prevalence of infants receiving naso-gastric tube feeds warrants further
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51 research and potentially change in policy within neonatal units.
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415

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5 419 **Authors Contribution:** Georgina M.G. Williams was the chief investigator and PhD student,
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7
8 420 wrote the protocol, completed the data collection, data analysis and drafts of the manuscript.
9
10 421 Sam Leary was the lead statistician on the study and PhD supervisor. She contributed to the
11
12 422 protocol and study design, data analysis and draft manuscripts of the paper. Sofia Leadbetter
13
14 423 provided the administrative support and coordination for the study, she was involved in
15
16 424 participant recruitment and data collection. Stu Toms contributed to the study design, online
17
18 425 questionnaires and managed the study database. Georgina Mortimer contributed to the data
19
20 426 collection and coordinates sample collection for the FADES study. Tim Scorrer recruited
21
22 427 participants for the study and reviewed draft manuscripts of the paper. Kathleen Gillespie
23
24 428 (PhD supervisor) contributed to the study protocol, study design and reviewed draft
25
26 429 manuscripts of the article. Julian Hamilton Shield (PhD supervisor) contributed to the study
27
28 430 protocol, study design and reviewed draft manuscripts of the articles.
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33 431 **Data Sharing:** Data sets may only be available by individual request to the Corresponding
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35 432 Author.
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40 434 **References**

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