

Down's Syndrome Service Provision Audit



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Children with Down Syndrome grow differently

- Prenatal - Birth weight mean 2.9 kg (- 0.9sd)
- Infancy - most marked growth deficiency (- 2.5sd by 3 yrs)
- Childhood - slow velocity periods of no growth (3-6/12)
- Adolescence - pubertal growth spurt does occur
- Adult height
 - male - 157 cm (5'1")
 - female - 146cm (4'9")

Guidance on weight monitoring



GIRLS BOYS Down syndrome 0-18 years

Down Syndrome Medical Interest Group

RCPCH Royal College of Paediatrics and Child Health
Leading the way in Children's Health

Basic Medical Surveillance Essentials for people with Down syndrome
Growth revision 11.02.2012

GROWTH
(Revised 2012)

One of a set of guidelines drawn up by the Down Syndrome Medical Interest Group (DSMIGS)

Short stature is a recognised characteristic of most people with Down syndrome.^{1,2} Average height at most ages is around the 2nd centile for the general population. Some children however also have additional medical conditions which may further impede growth. These include congenital heart disease,^{3,4} sleep related upper airway obstruction,⁵ celiac disease,^{6,7} nutritional deficiency due to feeding problems,⁸ and thyroid hormone deficiency^{9,10} which all occur more frequently among those with the syndrome. Regular surveillance of growth, general health, nutritional and thyroid status should aid in early identification of pathological causes of poor growth.

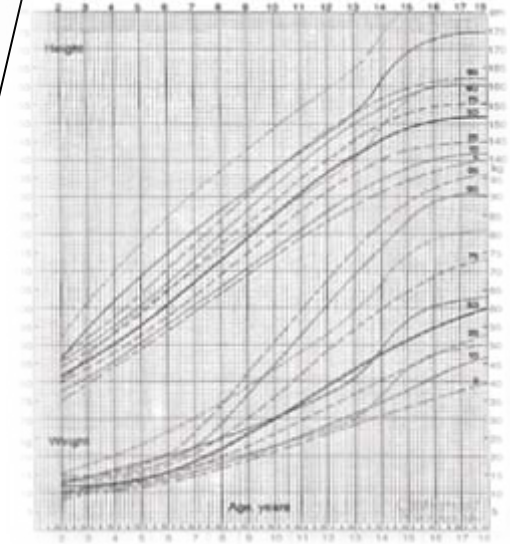
UK Specific of Ireland growth charts for healthy children with Down syndrome from birth to 18 years are available and have been revised in 2011.^{11,12} These reference values are essential for assessing linear growth. However as many older children and adults with the syndrome are overweight^{13,14} the reference values for weight should not be used as a standard that children should aim to achieve. Body Mass Index (BMI) information is included on the charts particularly to aid the assessment of those who may be overweight.

Recommendations:

1. We suggest that it is good practice to record and chart height and weight frequently in the first two years using the 2011 revised Down syndrome specific charts.¹¹ Thereafter measurements should be made at least annually throughout childhood and at regular intervals in adult life. Regular measurements of this sort are likely to be sensitive early indicators of the many medical problems that are over represented in this population.
2. As in all children growth spurts and plateaux occur but among those with Down syndrome those tend to be more prolonged. They are not reflected in the smoothed curves of a reference chart.
3. As with all children head circumference should be measured at birth and 6 weeks and charted on the Down syndrome charts. Subsequent measurements can be made as clinically indicated.
4. Preterm babies
There are...

Weight charts for preterm babies with Down syndrome who and infant close monitoring (NICAM) chart may be used. Thereafter the Down syndrome charts should be used at chronologically corrected age for at least a year.

11.02.2012



personal child health record

Guidance on monitoring

The UK Healthy Child Programme recommends

- Weight must be measured within the first 2 weeks to ensure birth weight is regained and that no more than 10% weight loss has occurred.
- Weighing at routine contacts only
 - i.e. birth, 2 weeks etc.
- Babies should be weighed more frequently if there is concern about poor or excessive weight gain





Guidance on monitoring

DSMIG Guidelines for essential medical surveillance

- good practice to record and chart height and weight frequently in the first two years using the 2011 revised Down syndrome specific charts
- head circumference should be measured at birth and 6 weeks and charted on the Down syndrome charts. Subsequent measurements as clinically indicated.

What do we know about early weight gain in babies without Down syndrome?

- “Babies should regain their birth weight by 10-14 days”
- Weight loss of up to 10% in first few days accepted as norm
- Limited data on neonatal weight loss /subsequent gain to support above
- Wright and Parkinson (2004) Arch Dis Child Fetal Neonatal Ed
 - 961 healthy term infants
 - Only 3% lost more than 10% birth weight
 - 80% regained birth weight by 12 days
 - Lighter babies lost less
 - Growth charts misleading in first 2 weeks as make no allowance for neonatal loss

And what do we know about early weight gain in babies with Down syndrome?

- **Data from NDSCR 2000-2009**
 - 4296 Live births
 - 38 weeks most common gestational age at birth ($1053/4296 = 25\%$)
 - Mean BW all gestations 2824 gram
 - Mean BW 36 – 42 weeks 2979 g (3063 g – general population)
- Babies with Down syndrome often appear puffy
- Weight loss may be greater than in the general population (no evidence)

Time for children with Down syndrome to regain Birth weight

Mark Chilvers, DSMIG presentation, Sept 1997

- Retrospective audit. Nottingham Down syndrome clinic
 - 38 children. 15 with cardiac lesions.
 - Average gestation 37 weeks.
 - Average birth weight 2840 g (NDSCR 2824g)
 - NG fed 35%. Breast 43%. Bottle 27%
- Mean time to regain BW: 23 days

Objectives

- To evaluate the service provision for growth monitoring in children with Down Syndrome accessing the Nottingham Down Syndrome clinic
- Documentation and evaluation of growth parameters, feeding pattern and co-morbidities

Method

- Retrospective with informed parental consent
- Review of “red books” and medical notes for growth measurements, feeding pattern and medical information within 8 weeks following birth
- Included children born between 01/2006 and 05/2011

Focus of this data

- Frequency and type of growth measurements
- Evaluation of growth pattern by ascertaining number of days until regain of birth weight
- Additional information sought on associated feeding regimes and co-morbidities

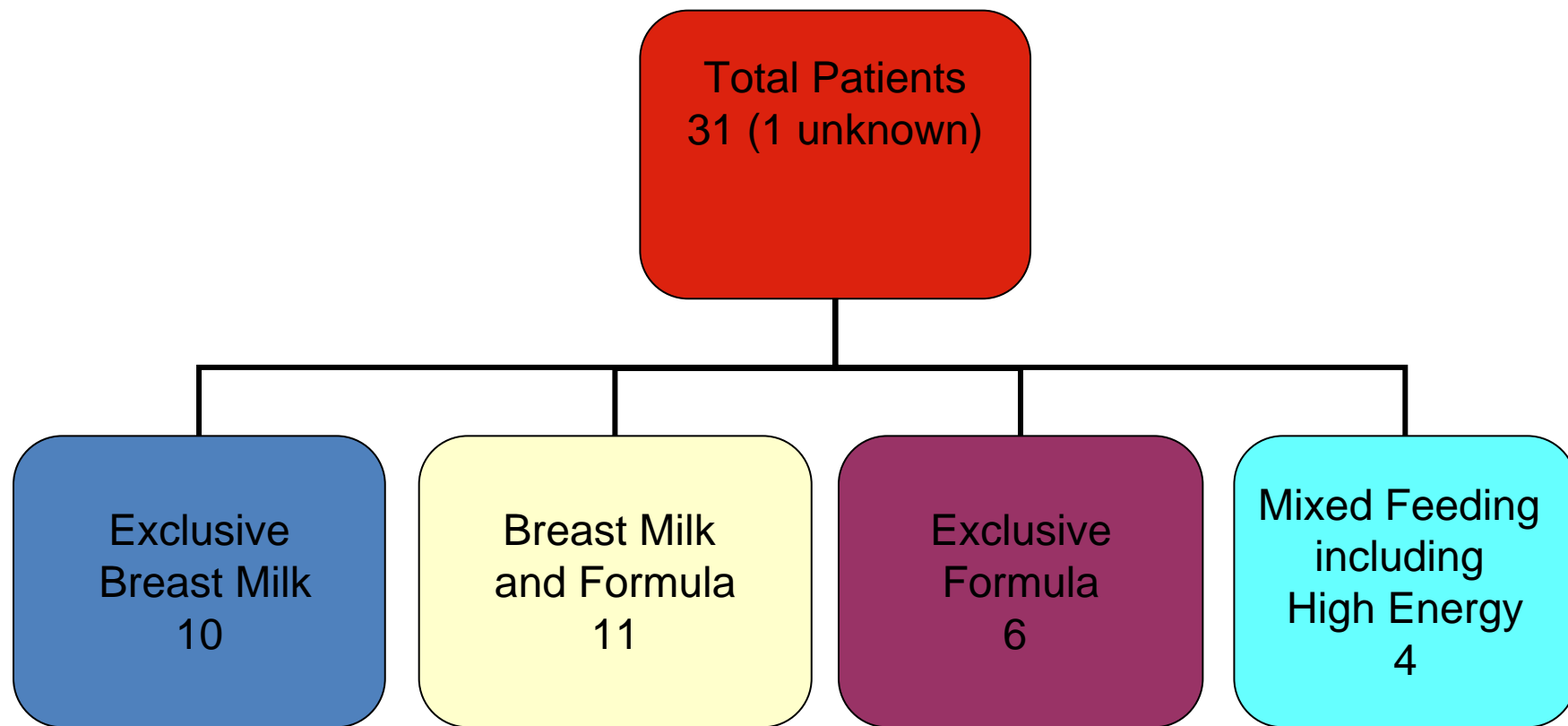
RESULTS

66 patients eligible

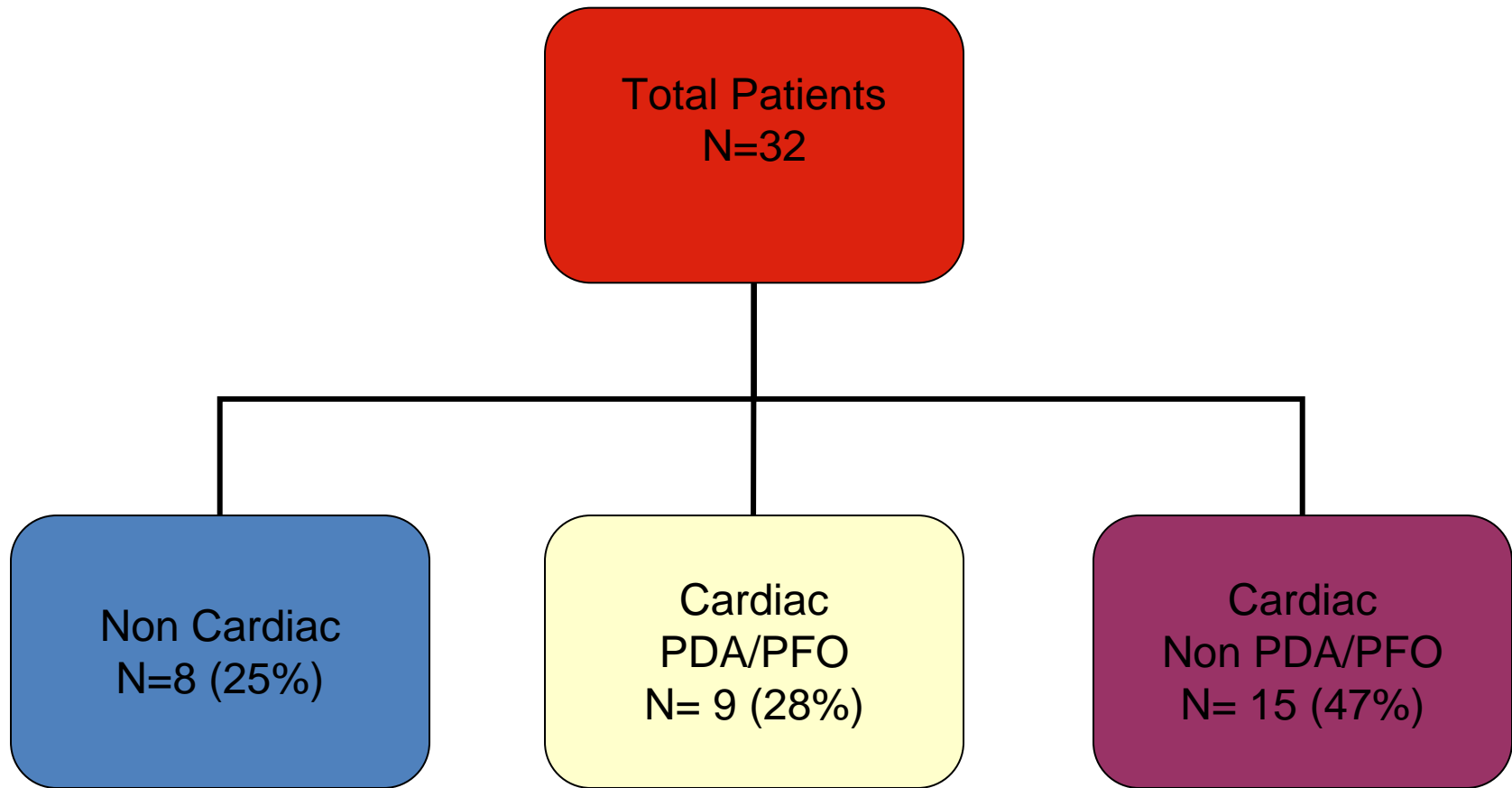
4 moved out of area
1 no contact details
2 deceased
1 unable to contact – maternal ill health
25 unable to contact despite multiple attempts
1 excluded as first weight available at 228 days

32 studied
17 Female 15 Male

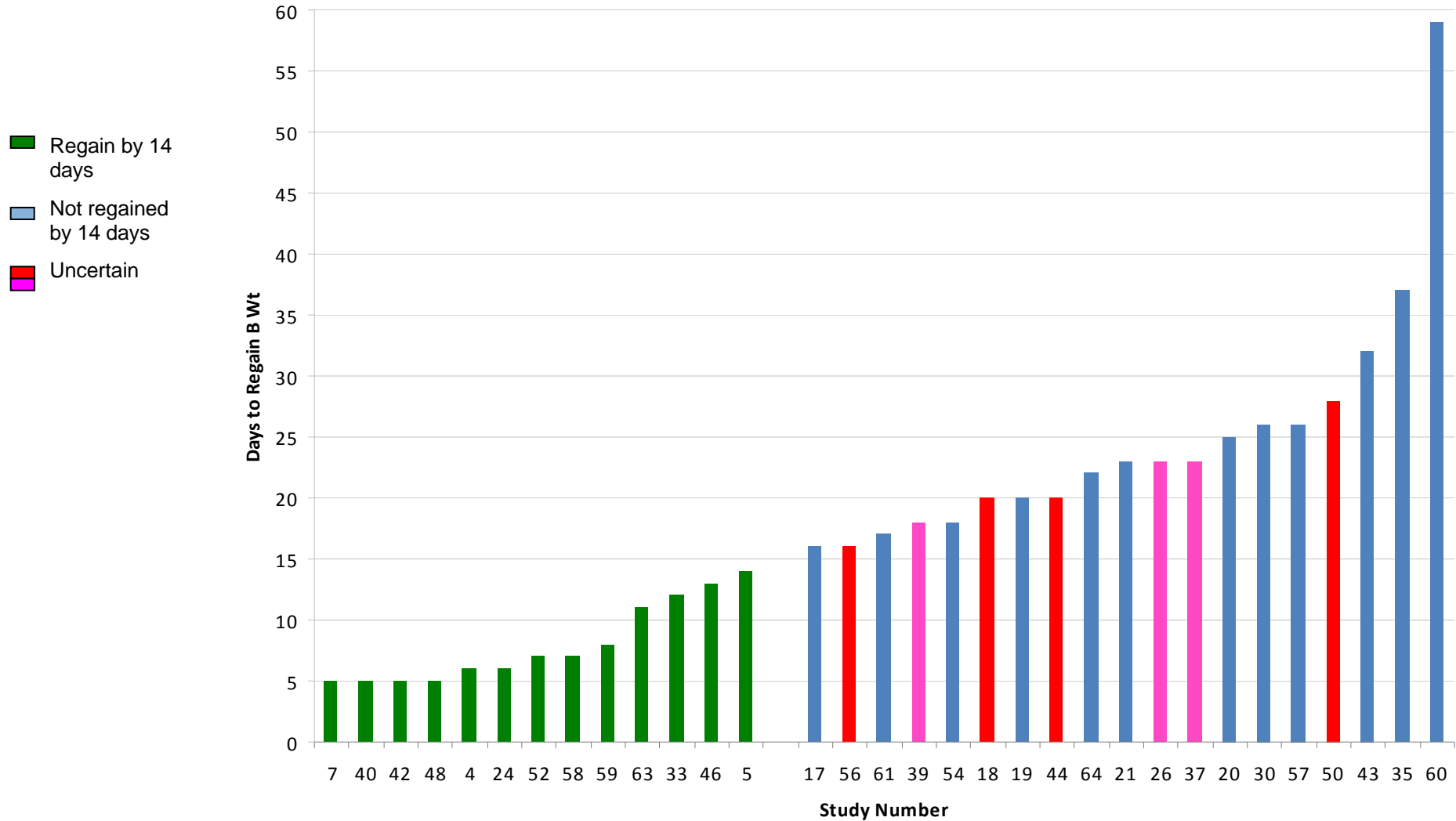
Feeding Pattern



Associated Cardiac Disease



Regain of birth weight in days



No. of babies reaching their birth weight by 14 days

- Only 14 /32 recorded as reaching birth weight by 14 days
- 7 more may have but recorded weights did not allow us to be sure what day weight was regained
- 12/32 had not regained birth weight by 14 days

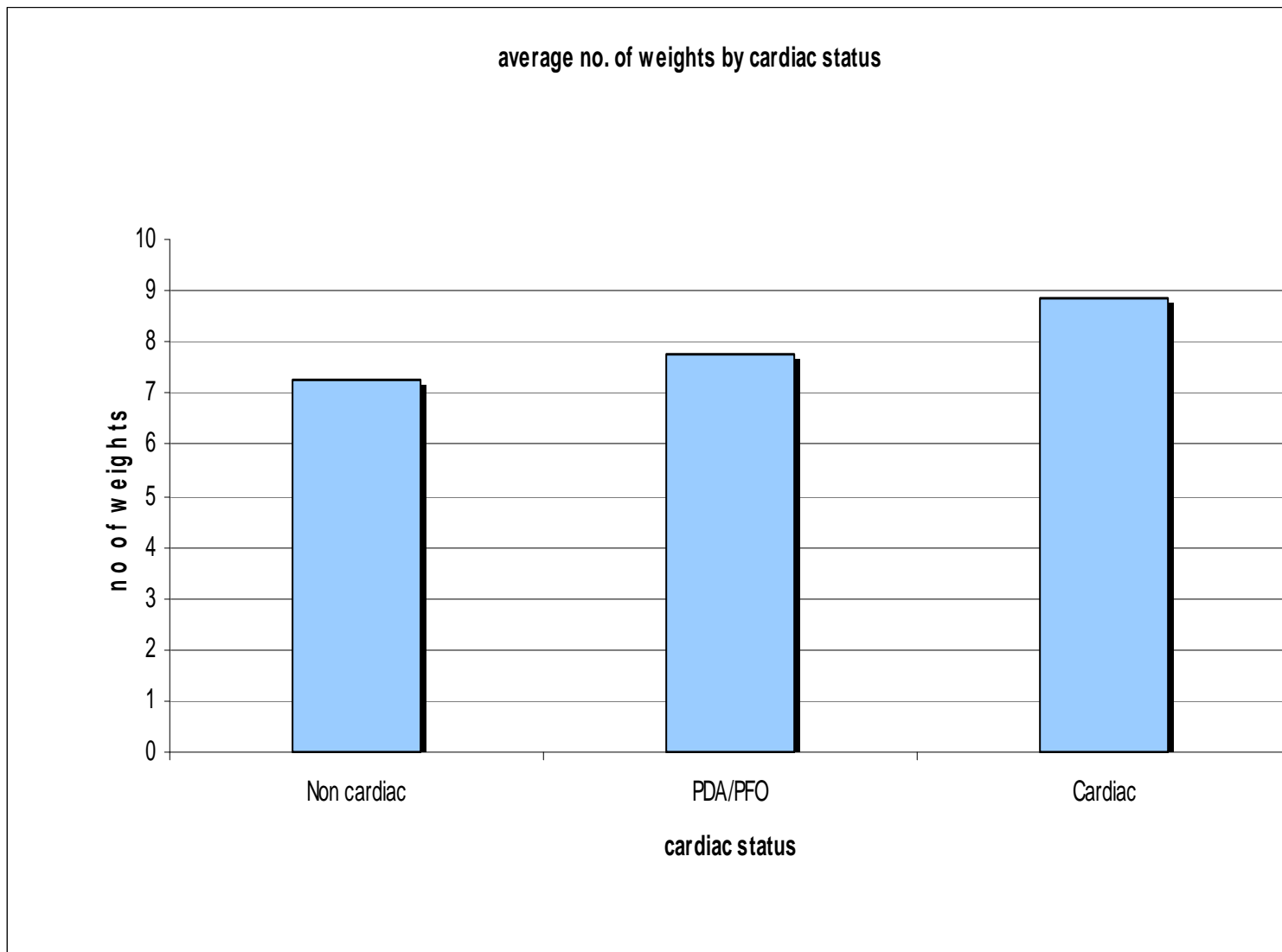
Average No. of Days to Birth Weight Regain

N=32

| | |
|---------|------|
| Max | 59 |
| Min | 5 |
| Average | 17.9 |
| Median | 17.5 |

Frequency of growth measurements in first 8 weeks

| | Weight | HC | Height |
|---------|--------|-----|--------|
| Max | 14 | 4 | 4 |
| Min | 3 | 0 | 0 |
| Average | 8.2 | 1.8 | 0.8 |
| Median | 7.5 | 2 | 1 |

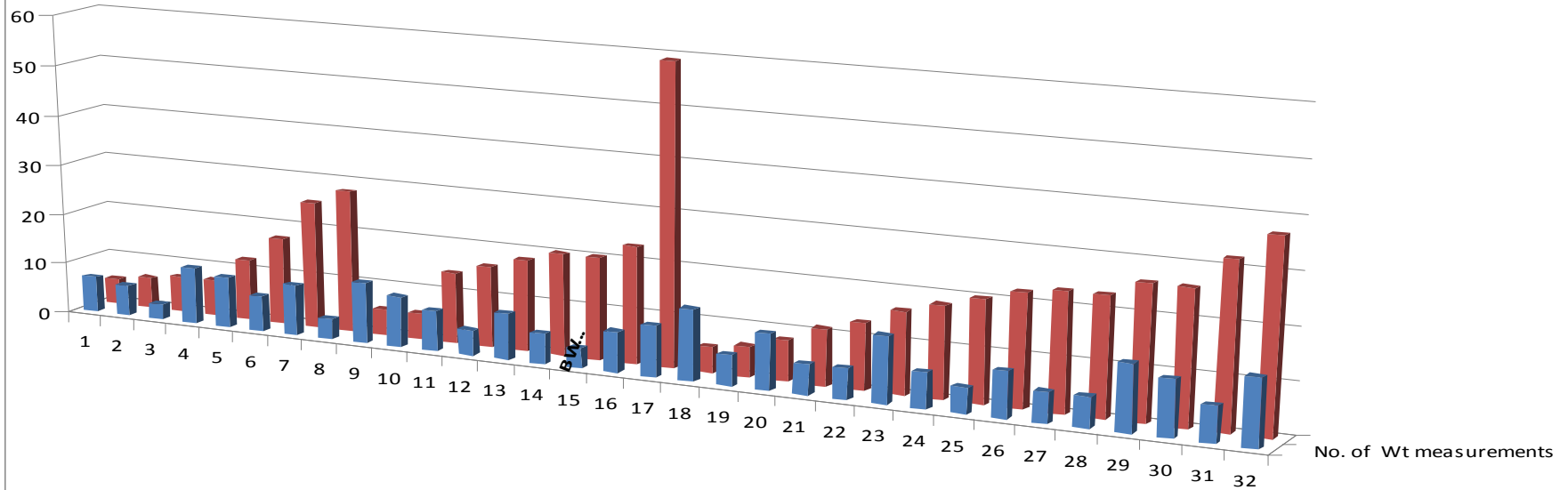
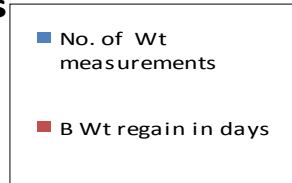


No. of Weight measurements and B Wt regain in days

1-8 No cardiac disease

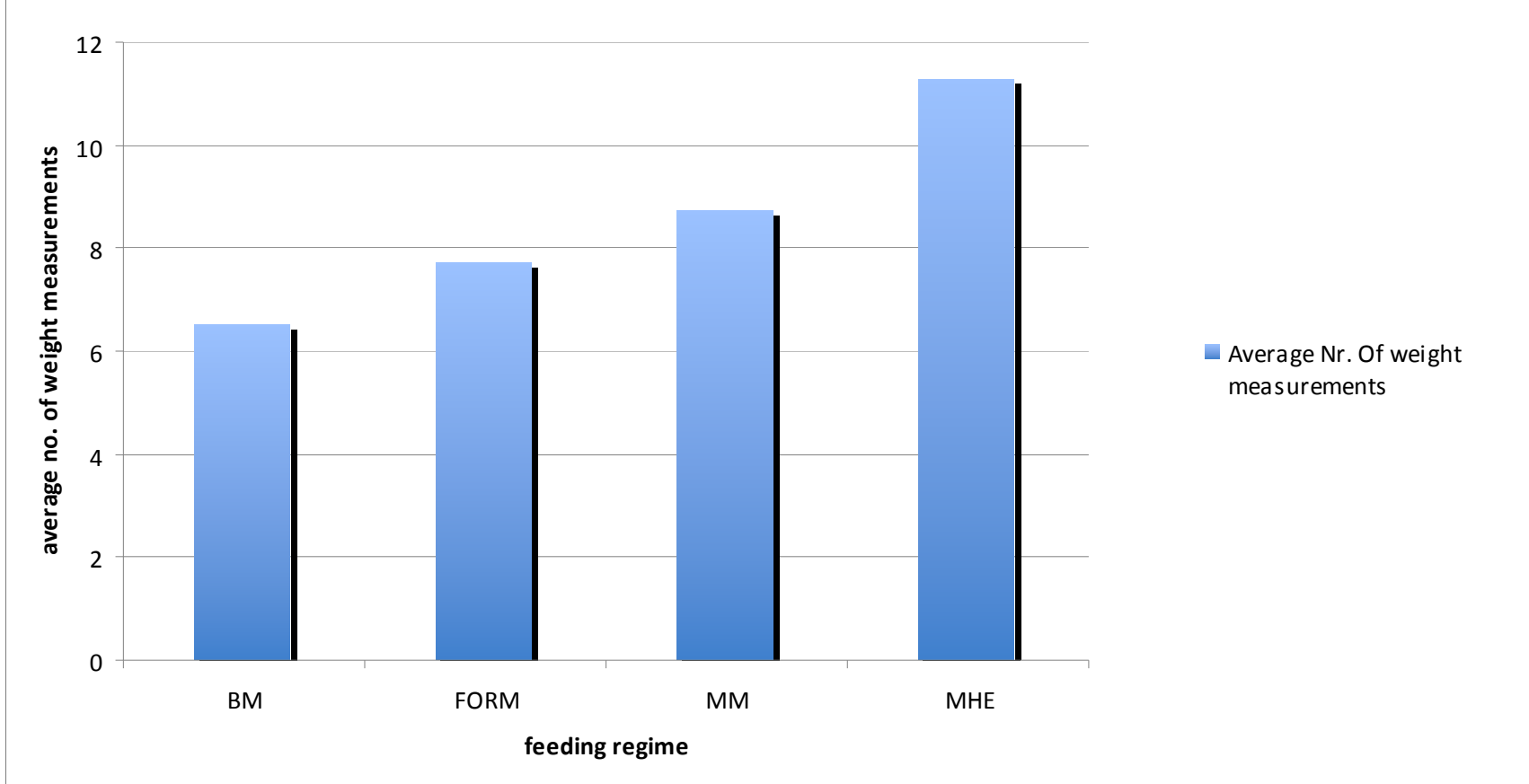
9-17 PDA/PFO only

18-32 Non-PDA/PFO cardiac disease

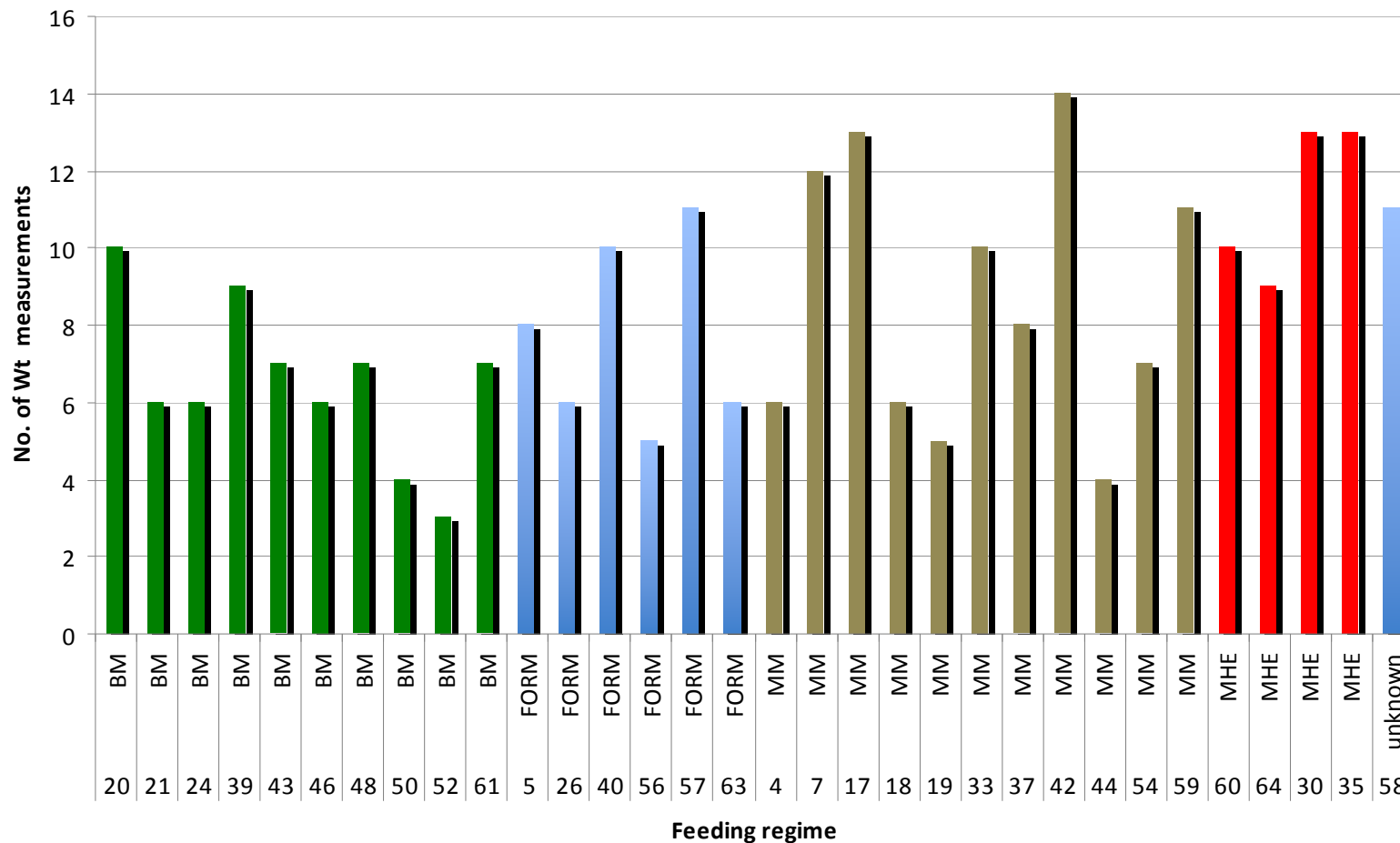


| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | 32 |
|------------------------|---|---|---|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|
| No. of Wt measurements | 7 | 6 | 3 | 11 | 10 | 7 | 10 | 4 | 12 | 10 | 8 | 5 | 9 | 6 | 4 | 8 | 10 | 14 | 6 | 11 | 6 | 6 | 13 | 7 | 5 | 9 | 6 | 6 | 13 | 11 | 7 | 13 |
| B Wt regain in days | 5 | 6 | 7 | 7 | 12 | 17 | 25 | 28 | 5 | 5 | 14 | 16 | 18 | 20 | 20 | 23 | 59 | 5 | 6 | 8 | 11 | 13 | 16 | 18 | 20 | 22 | 23 | 23 | 26 | 26 | 32 | 37 |

Average No. of weight measurements by feeding regime

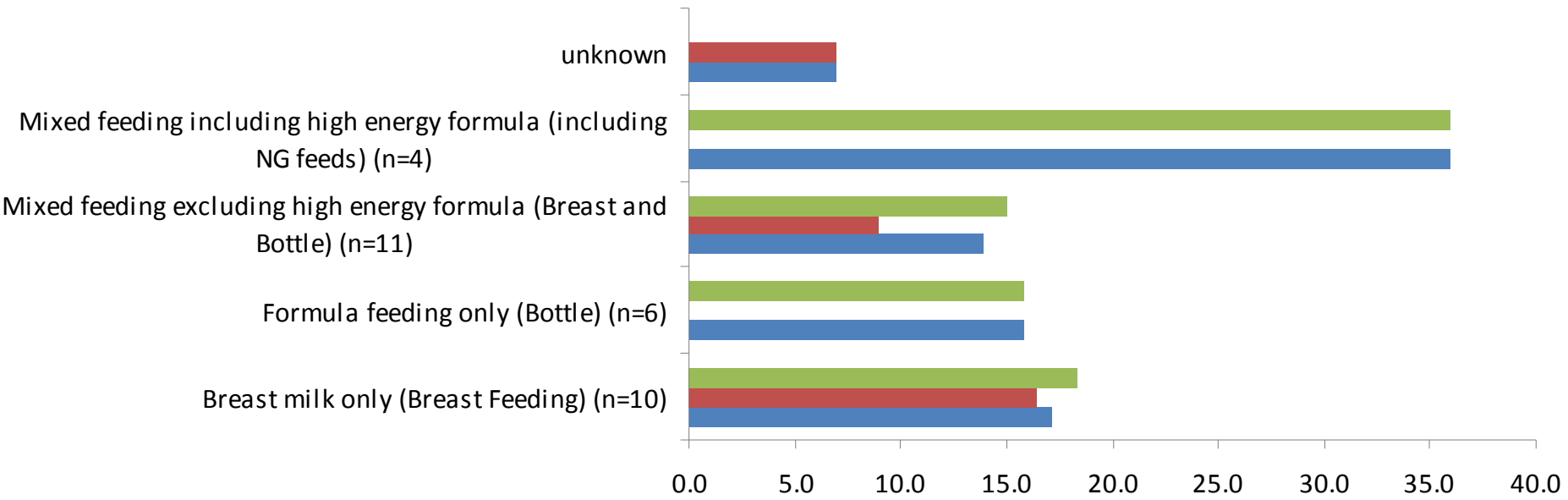


No. of Wt Measurements. vs feeding regime



Average Days to Birth Weight Regain

Milk type and Cardiac Disease



| | Breast milk only (Breast Feeding) | Formula feeding only (Bottle) (n=6) | Mixed feeding excluding | Mixed feeding including | unknown |
|---------------|-----------------------------------|-------------------------------------|-------------------------|-------------------------|---------|
| ■ Cardiac | 18.3 | 15.8 | 15.0 | 36.0 | 0.0 |
| ■ Non Cardiac | 16.4 | 0.0 | 9.0 | 0.0 | 7.0 |
| ■ Total | 17.1 | 15.8 | 13.9 | 36.0 | 7.0 |

Summary

- Average time to regain birth weight was longer than 14 days. (17.8 days)
- There was wide variability in how long it took to regain birth weight (range 5-59 days)
- Variability in length of time to regain occurred within each subgroup
- Those who were slowest to regain their birth weight were in general those who required mixed feeding including HE feeding.

Summary

- Most babies in Nottingham were weighed frequently, probably more so than routine for other babies
- Other measurements were done less frequently
- The no. of times babies were weighed did not seem to be clearly related to cardiac status, type of feed or time to regain birth weight except for those on high energy feeds who were weighed more often
- There was no standardised protocol for weight measurement which may have led to artificial differences in birth weight regain

Conclusion

- This evaluation confirms that babies with Down syndrome regain birth weight more slowly than unaffected babies
- Possible reasons include
 - different feeding patterns
 - co-morbidities
 - greater initial weight loss
 - different normal growth pattern
 - any combination of above

Conclusion

- Service provision for growth assessment with the first 8 weeks of life appears to be adequate for weight measurements
- There was lack of consistency in frequency of measurements, and/ or recording thereof.
- Decisions on offering nutritional support based on early growth patterns for the general population MAY not be applicable to babies with Down syndrome.

Future studies

- Prospective study of early growth patterns in children with Down Syndrome to establish early normal growth data
- Do babies with Down syndrome have greater neonatal weight loss than other babies?
- Is the nutritional intake for new born babies comparable with other babies?
- Or is slower weight gain just due to less calories?

Better understanding of early growth patterns in babies with Down Syndrome will help to

- Identify babies whose weight gain is a significant concern
- Reassure about those whose weight gain is appropriate for a baby with Down Syndrome
- Reduce unnecessary feeding interventions
- Ensure appropriate feeding advice by health care professionals