



Nutritional Profiles of Community based children with Complex Neurodisability



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OUTLINE

How this began

What we found initially (how bad things were!!)

Progress....small improvements

Where we are now...better, but more to do..

Future directions.....

Background

Enteral tube placement is beneficial to those with significant oro-motor dysfunction

Reduces stress related to feeding and risk of aspiration

Children who have enteral feeding tubes require close monitoring of growth and nutritional status



Background

Under- (and over-) nutrition hugely affect health and well-being in children with Neuro-disability

Malnutrition can affect the child's energy levels and immune system, increasing risk of infection and further delaying developmental progress

Lack of weight bearing, poor intake of Calcium and Vit D, and use of Epilepsy medications results in significant reduction in bone density at a vital stage in a child's bone growth

Experience of a peripheral “regional” hospital

PEG insertion in 1 of 3
different hospitals

Children with complex ND looked
after by many different consultants:

Neurology

Community Paediatrics

Respiratory

General Paediatrics

Neonatology

Limited access to Paediatric dietician

No onsite Gastroenterology service

Variable access to dietetics in
the community



CREST guidelines 2004:

- FBC and biochemical profile shortly after discharge and then yearly
- additional testing as required based on the patient's clinical condition

These were based on adult patients.

ESPEN 2009:

- measuring biochemistry profile, full blood count and haematinics at all visits
- measurements of trace elements and vitamins recommended at intervals of 6 months

Suggests that the typical interval between visits would be 3 months but acknowledges that may vary.

ESPGHAN 2010:Stressed the importance of monitoring nutrition

- regular review of the patient's nutritional status
- monitoring biochemical and haematological indices and the feeding tube itself

Did not specify a recommended frequency for these reviews

Monitoring in Patients on Long-Term Enteral feeds: 2017

Mc Mahon J., Griffin D., Gibson L.

Aim:

Audit the frequency of biochemical (including vitamin D) and haematological monitoring in patients on home enteral feeding.

Methods:

Patients aged 0-16 years

NG, NJ or PEG feeding tubes

Attending between 2011-2016

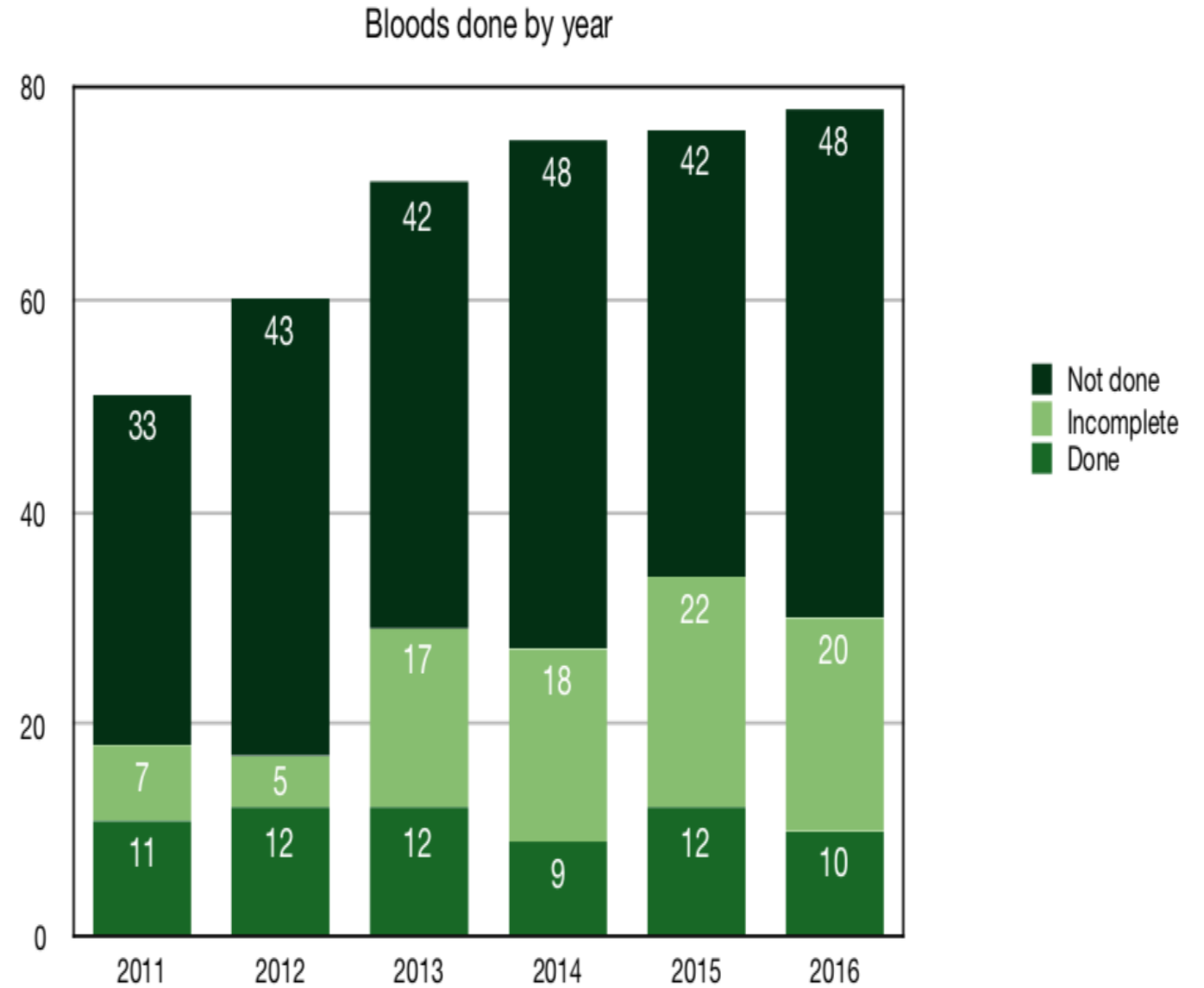
Review of biochemical and haematological markers of nutrition.

"Complete testing": Hb, Ca, Mg and PO₄⁻ tested.

"Incomplete testing": 2 to 3 of the above tests performed.

Vitamin D testing was assessed separately.

Bloods checked 2011-2016

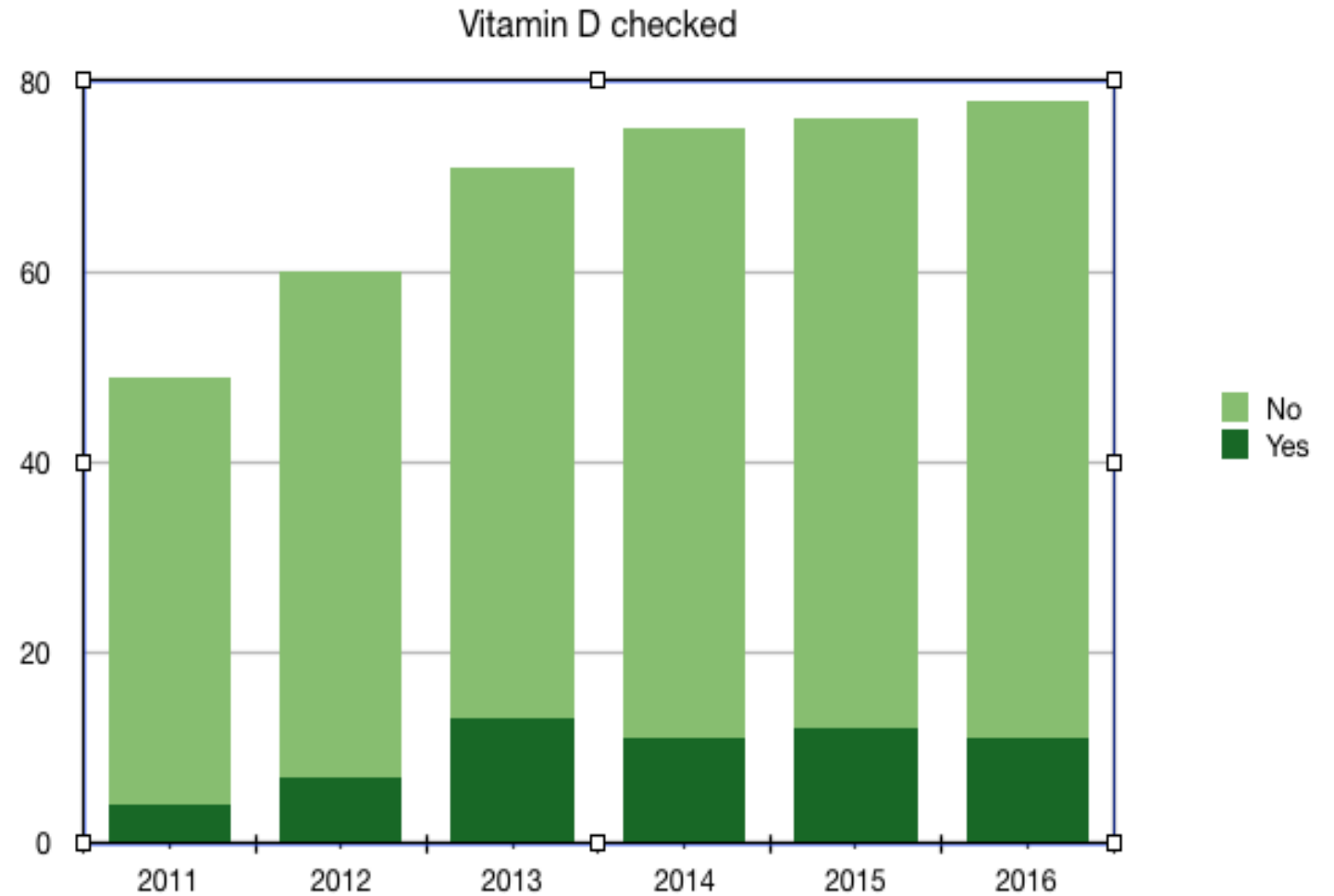


Vitamin D checked 2011-2016

12% of patients had Vit D check in 2011
(51)

18% of patients had Vit D check in 2013
(71)

14% of patients had Vit D check in 2016
(78)



Results

12% of patients
had Vit D check
in 2011

18% of patients
had Vit D check
in 2013

14% of patients
had Vit D check
in 2016

50-60% had
ANY bloods
done

<25% have
"complete"
bloods done

Conclusions

Biochemical and haematological monitoring in our patients on home enteral nutrition is ***significantly below*** the current recommendations for both Paediatric and Adult patients.

We feel this highlights the need to improve our care pathways for these patients to ensure optimal growth and nutrition.

(.....how bad things were!!)

ESPGHAN guidelines 2017



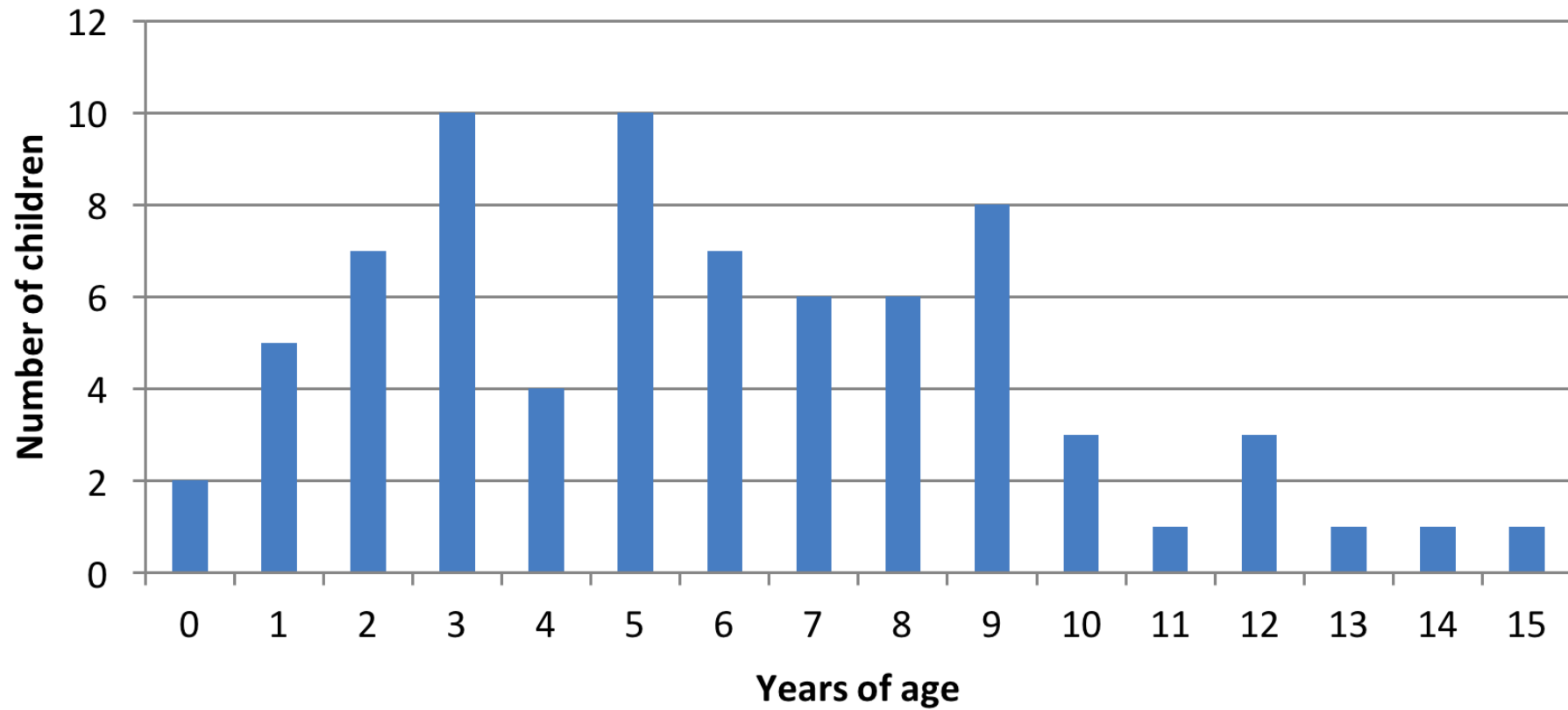
HOW OFTEN SHOULD NUTRITIONAL STATUS BE MONITORED?

For infants, it is recommended to assess growth every 1 to 3 months and in older children the frequency of assessment may vary depending on their nutritional and health status⁽⁵⁰⁾. There are no data on the optimal follow-up schedule for body composition assessment and this should be individually depending on risk factors and initial assessment. It is, however, important to use same methods to have comparable values. For the assessment of growth velocity, the use of calculated heights based on segmental measures may be unreliable⁽¹⁰⁾. There is no consensus on the appropriate laboratory indices to be measured or on how frequent this should occur.

4: ESPGHAN WG suggests that children with NI have anthropometry at least every 6 months and micronutrients checked annually.

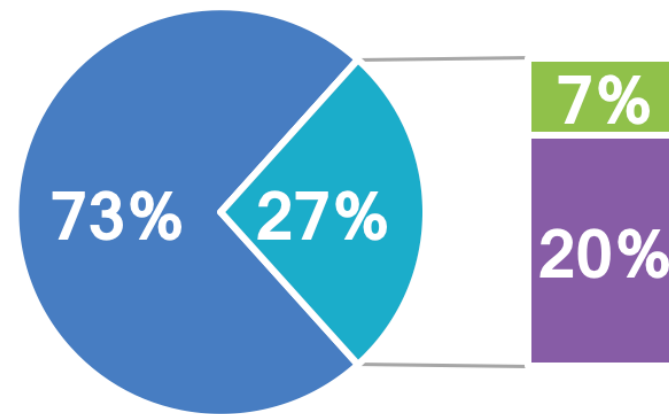
Progress: Re-audit 2018 (N=75)

Harvey S., Gibson L., Griffin D,



Re-audit 2018

Bloods done within the last year



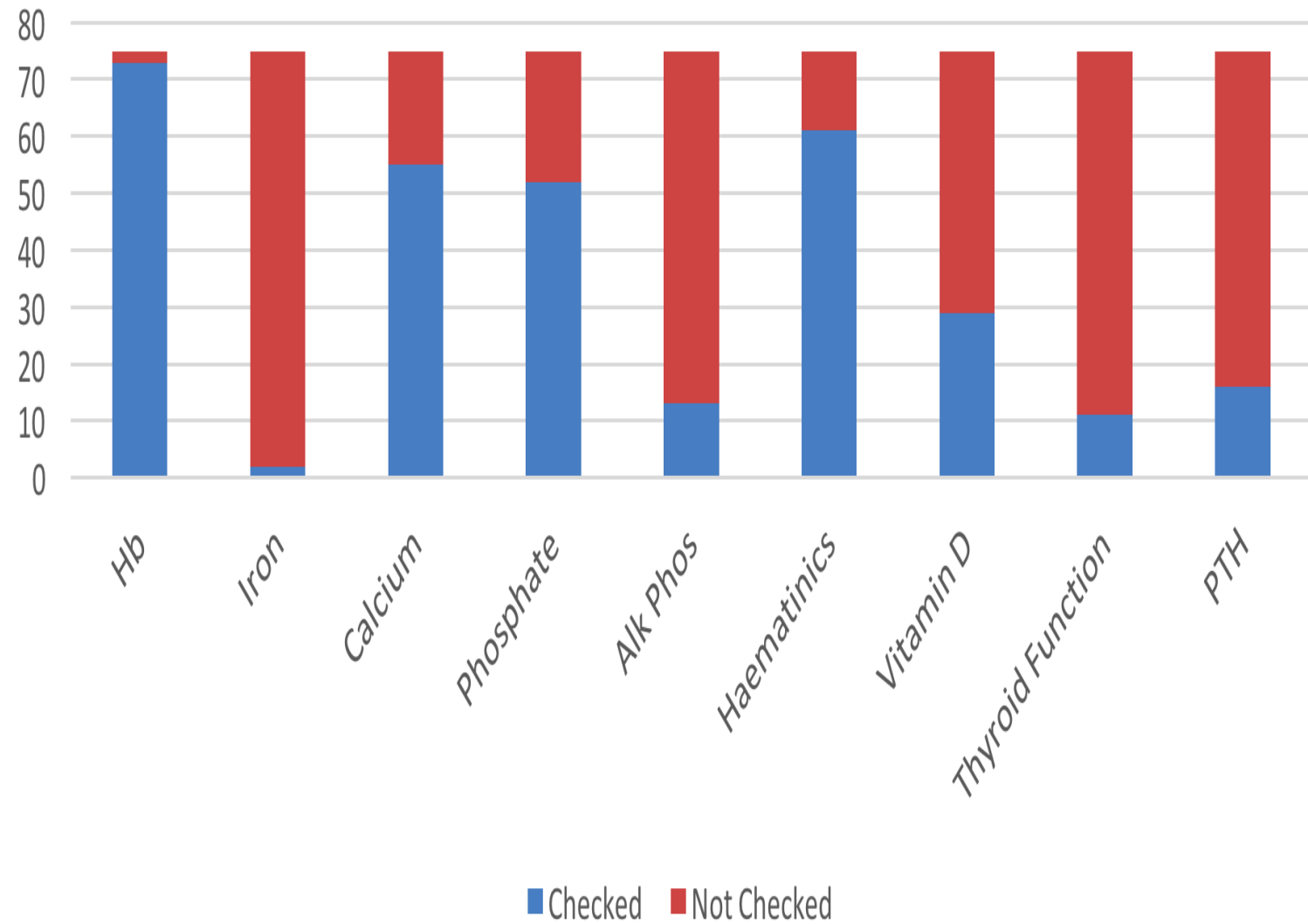
■ Bloods done

■ Bloods not done - NG Fed



■ Bloods not done - PEG Fed

Bloods
checked in
re-audit
2018



Progress: Results of re-audit 2018 (...small improvements)

Haemoglobin checked in >90%

Calcium /Phosphate checked in > 50%

Vitamin D checked in 30 %

PTH /Alk Phos checked in 15%

Re-audit 2019: How are we doing now??

Vatca A., Griffin D., Gibson L.,

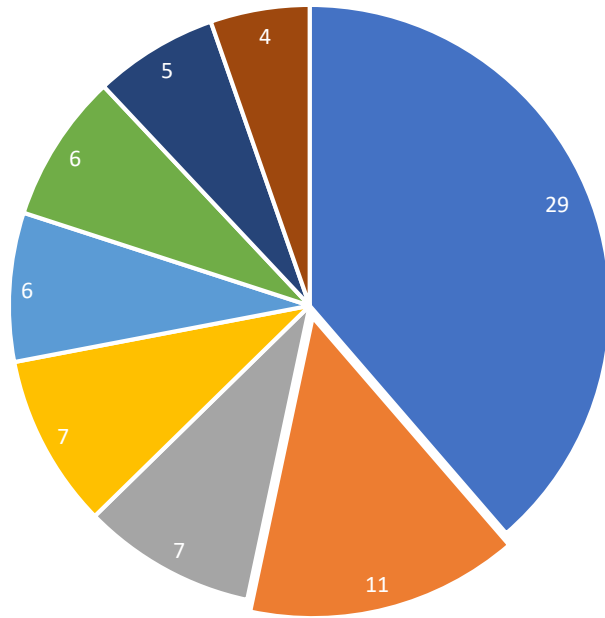
Next review sought to identify
not just biochemical and
haematological parameters,

but

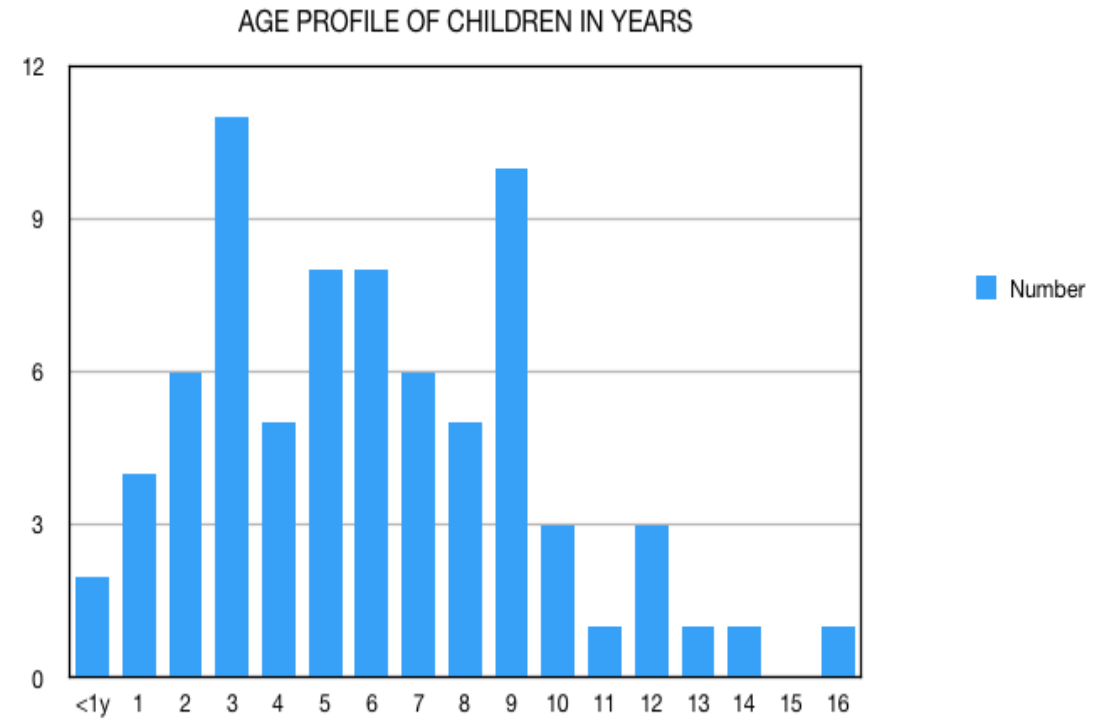
anthropometric data, in line
with the new ESPGHAN
recommendations.....



Profile of children: Audit 2019

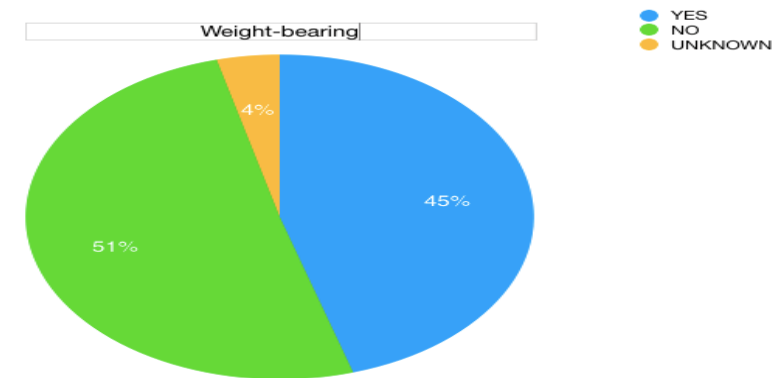
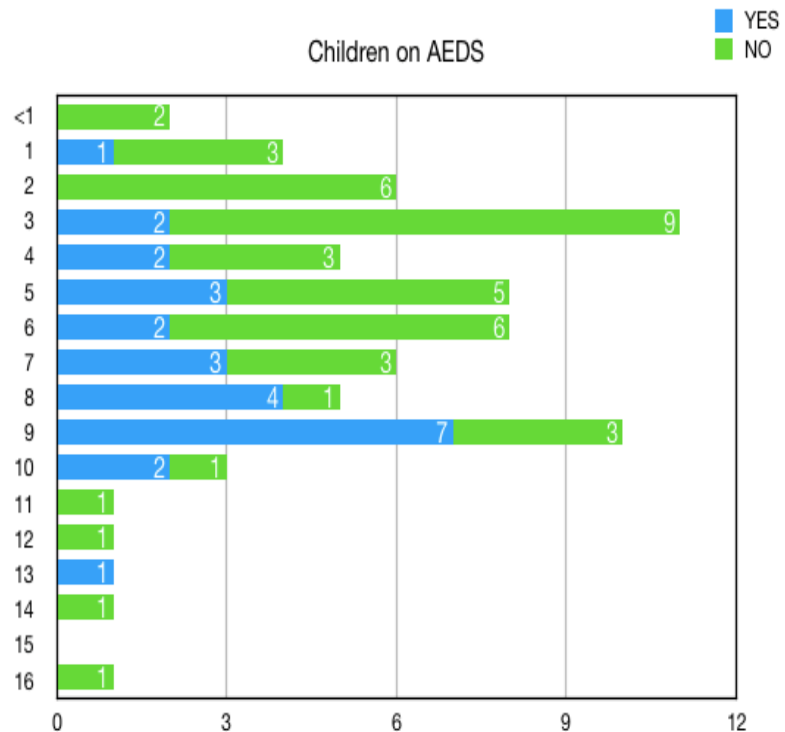


- Genetic mutation
- Congenital Brain Malformation
- Neuromuscular
- Respiratory disease
- Congenital Malformation
- Cerebral Palsy
- Ex=preterm/oral aversion/GORD
- Mitochondrial/Neurodegenerative

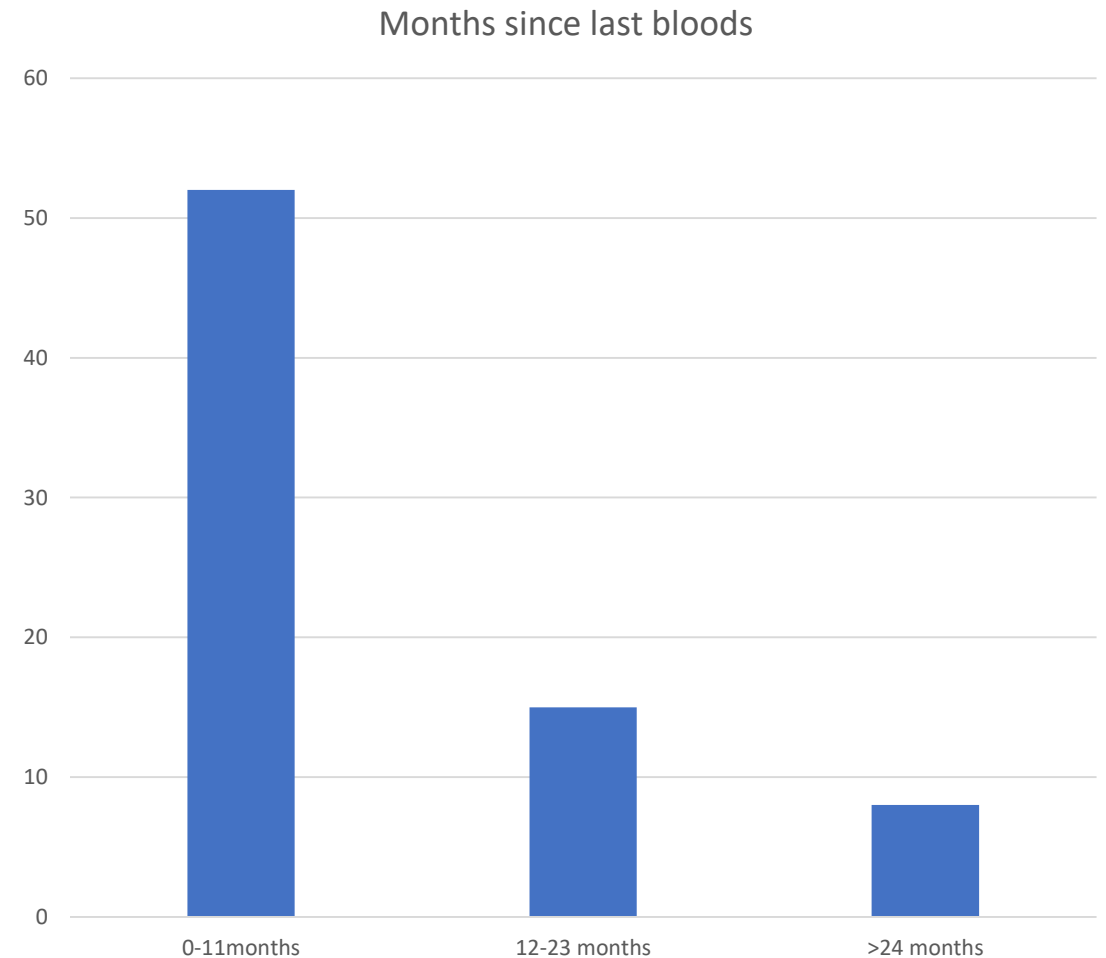
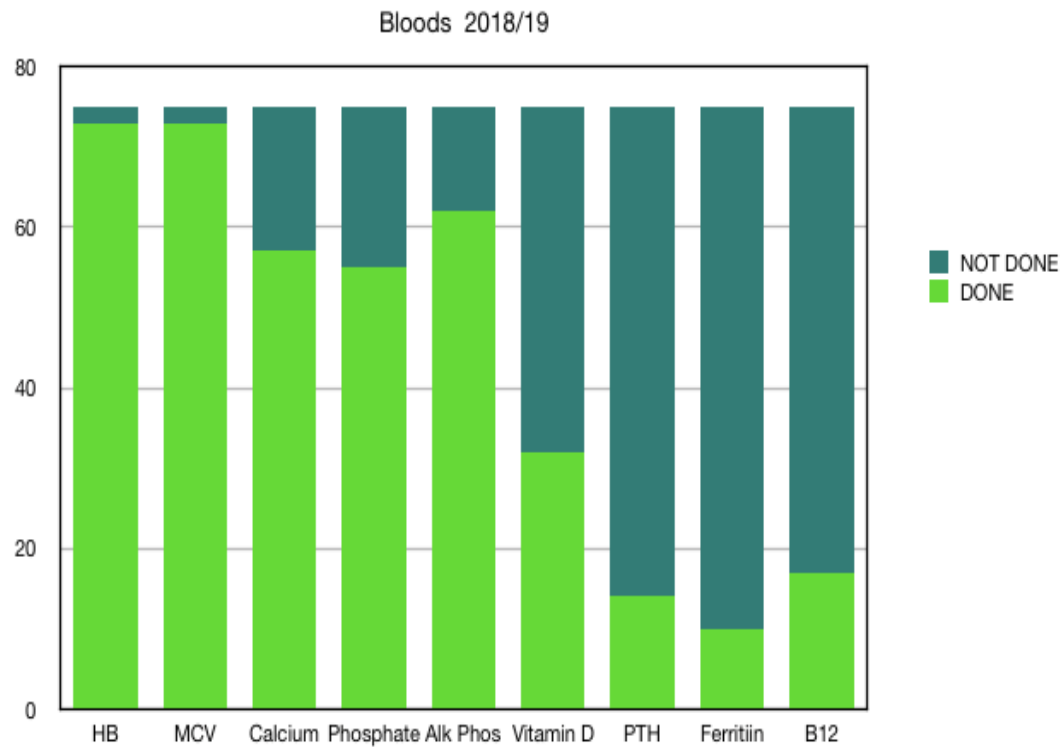


Co-morbidities

- Less than half are weight bearing
- Over 1/3 are on anti-epileptic medication

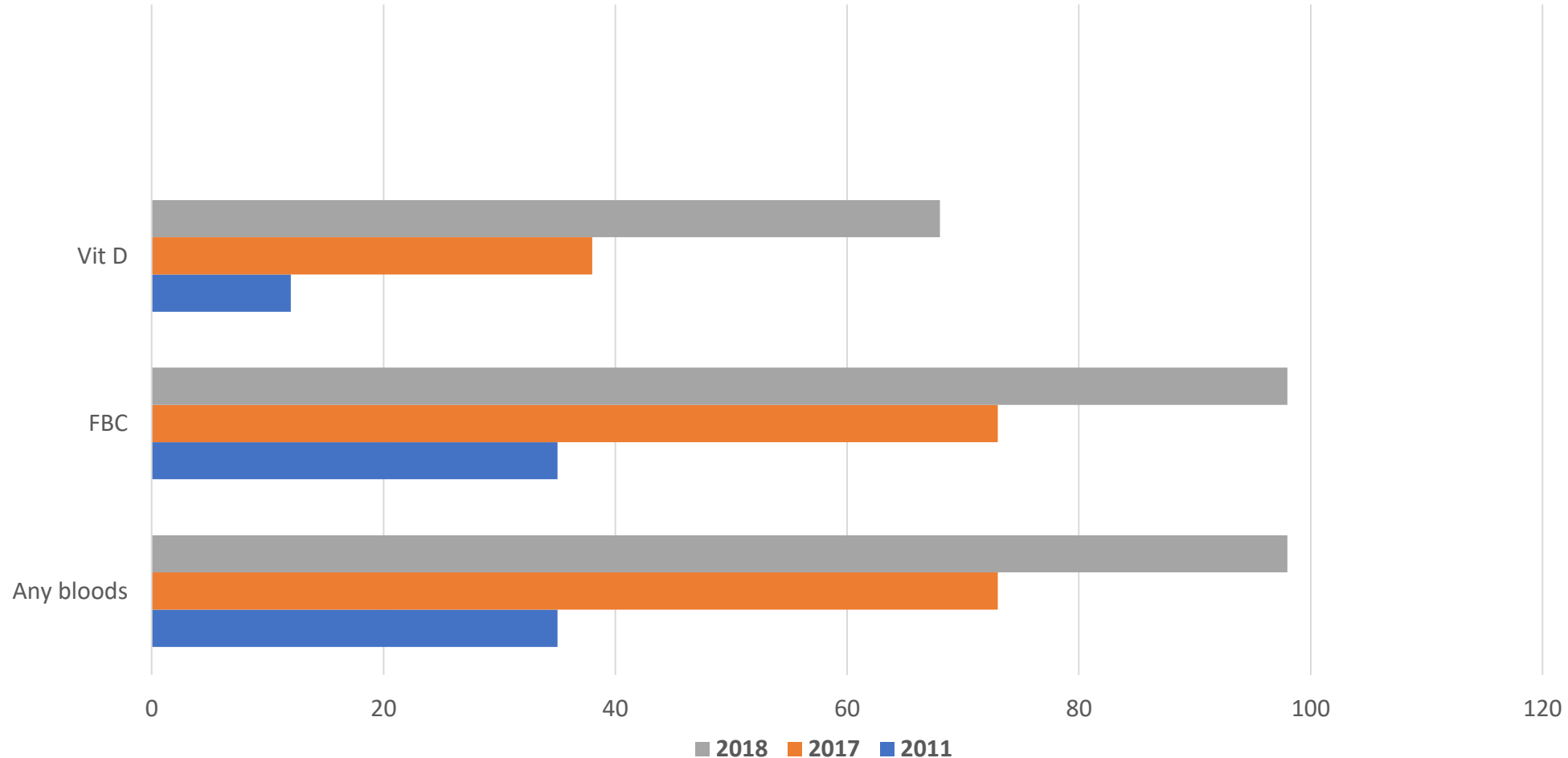


Results: Re-audit 2019

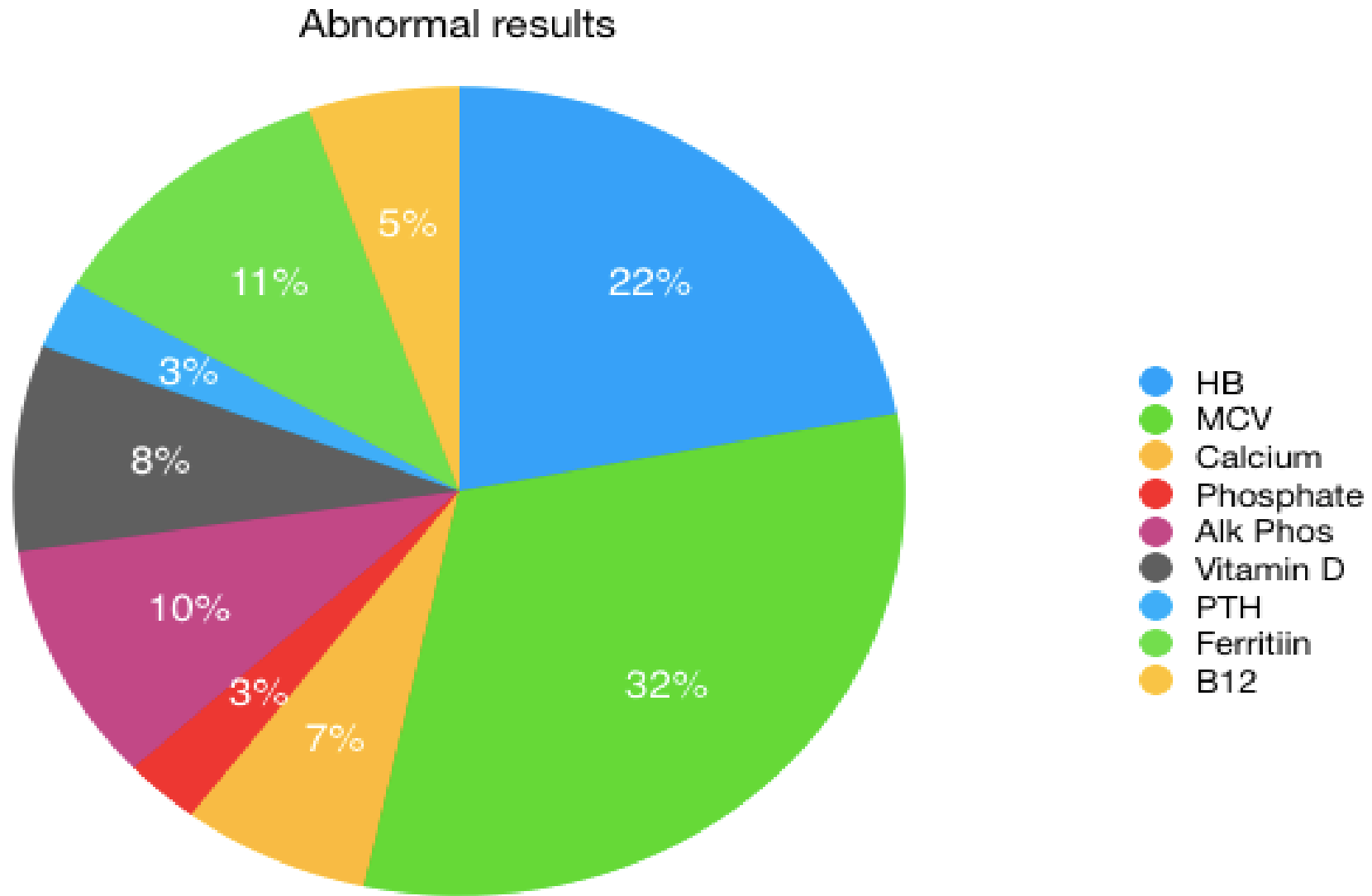


Results 2018/19 (..better but more to do!)

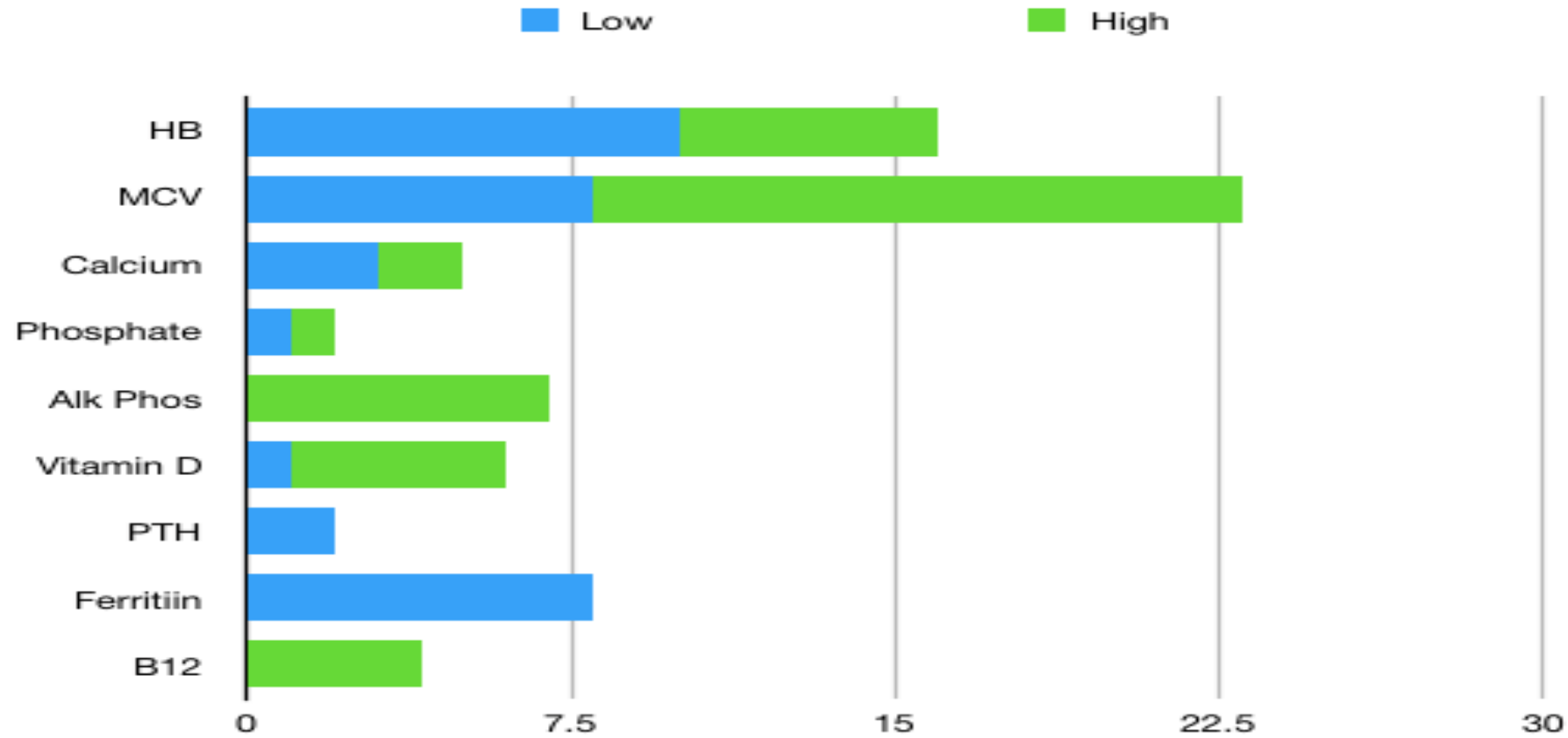
Bloods checked by year



Which parameters were abnormal?

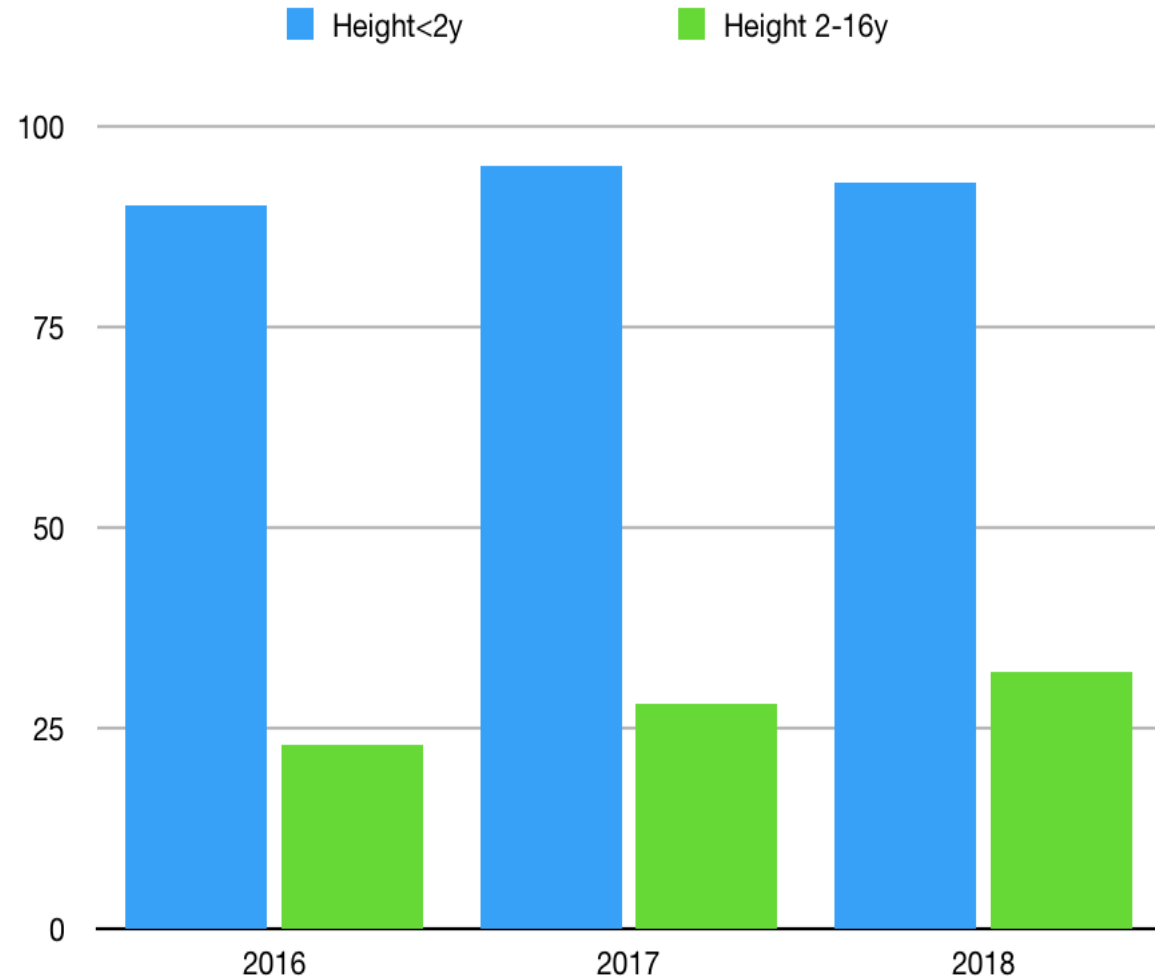


Abnormal results



Anthropometrics: Height measurement

- Standing heights not possible in many children >2y
- Method of measurement NOT DOCUMENTED
- Knee lengths performed more recently by dietician
- No evidence of adjustment for lengths in children >2y



WHO guidance: Measuring children who cannot stand

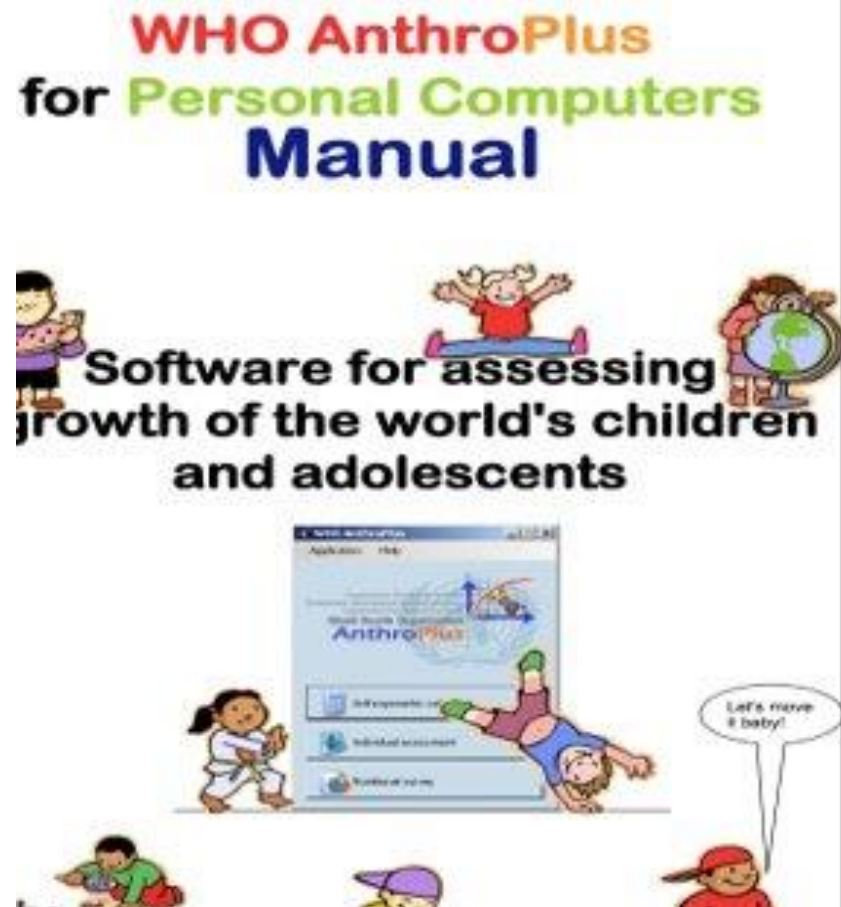
For children 0-60 months it is important to specify how the child was measured, ie. recumbent or standing. According to that information and the child's age the calculation is adjusted if necessary.

Length/height-for-age

Sex	Age group (months)	Type of measurement (l/h) ¹	Conversion	Data tables
Boys and girls	<24	l		Length-for-age
	<24	h	$h + 0.7 \text{ cm}$	Length-for-age
	≥24 & <61	l	$l - 0.7 \text{ cm}$	Height-for-age
	≥24 & <61	h		Height-for-age

¹ l = length; h = height

Guidance for anthropometry



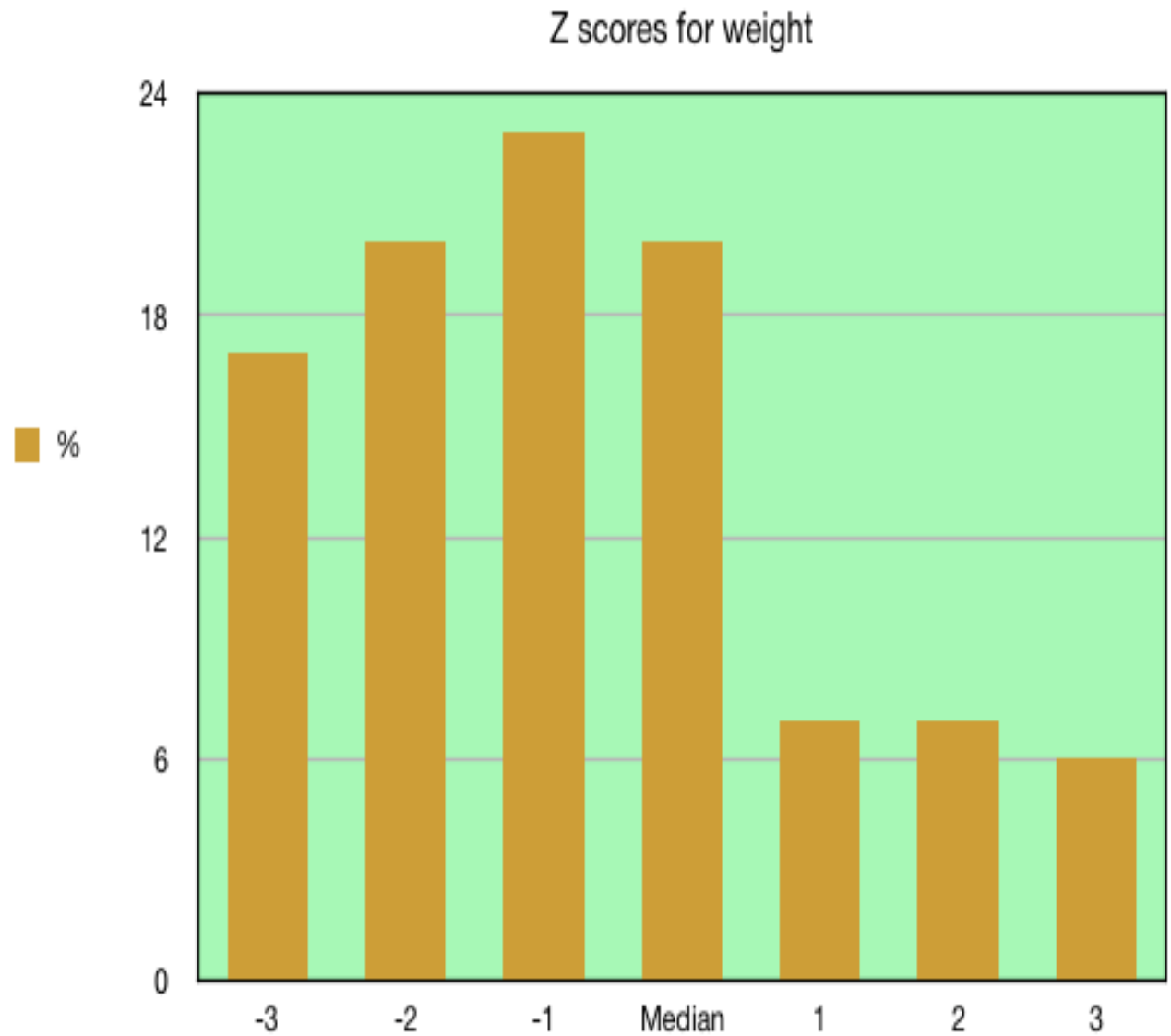
ANTHROPOMETRIC MEASUREMENT	METHOD	NI CHALLENGE	ESPGHAN RECOMMENDATION
Weight	Wheelchair scales Sitting scales Hoist scales	Weight for height (WFH) is a poor indicator of fat stores in children with cerebral palsy. Low body mass index can also imply a low muscle mass but high fat mass	Assessment of nutritional status in children with NI should not be based solely on weight and height measurements
Height	Stadiometers – for those who can stand Supine length – good alternative for children able to lie straight Segmental length, such as knee-heel, tibia and ulnar using sliding calipers – reliable for monitoring growth for those unable to stand or lie straight	Many children with NI are not able to stand and have joint contractions, spasticity and/or scoliosis	Measurements of knee height or tibial length in children with NI should be performed routinely to assess linear growth, when height cannot be measured
Skinfolds and limb circumferences	Body fat estimated by using skinfold measurement usually at biceps and triceps region using a caliper	Interpretation challenging as children with NI tend to store fat around their abdomen rather than in skinfolds	Measurement of fat mass by skinfold thickness should be a routine component of the nutritional assessment in children with NI
Body composition	Whole-body dual-energy x-ray absorptiometry (DXA) is the best way to assess a child's fat stores	Nutritional status of children with NI more accurate using measures of body composition, including fat, water, protein and bone	Whole-body dual-energy x-ray absorptiometry (DXA) is the 'criterion standard' for body composition measurement
Bone status	Bone mineral density (BMD) assessment by DXA is limited to lumbar spine and hip	Due to hip flexion contractures, in children with severe NI, only lumbar DXA measurements are mostly performed	DXA scans should be used to measure bone mineral density

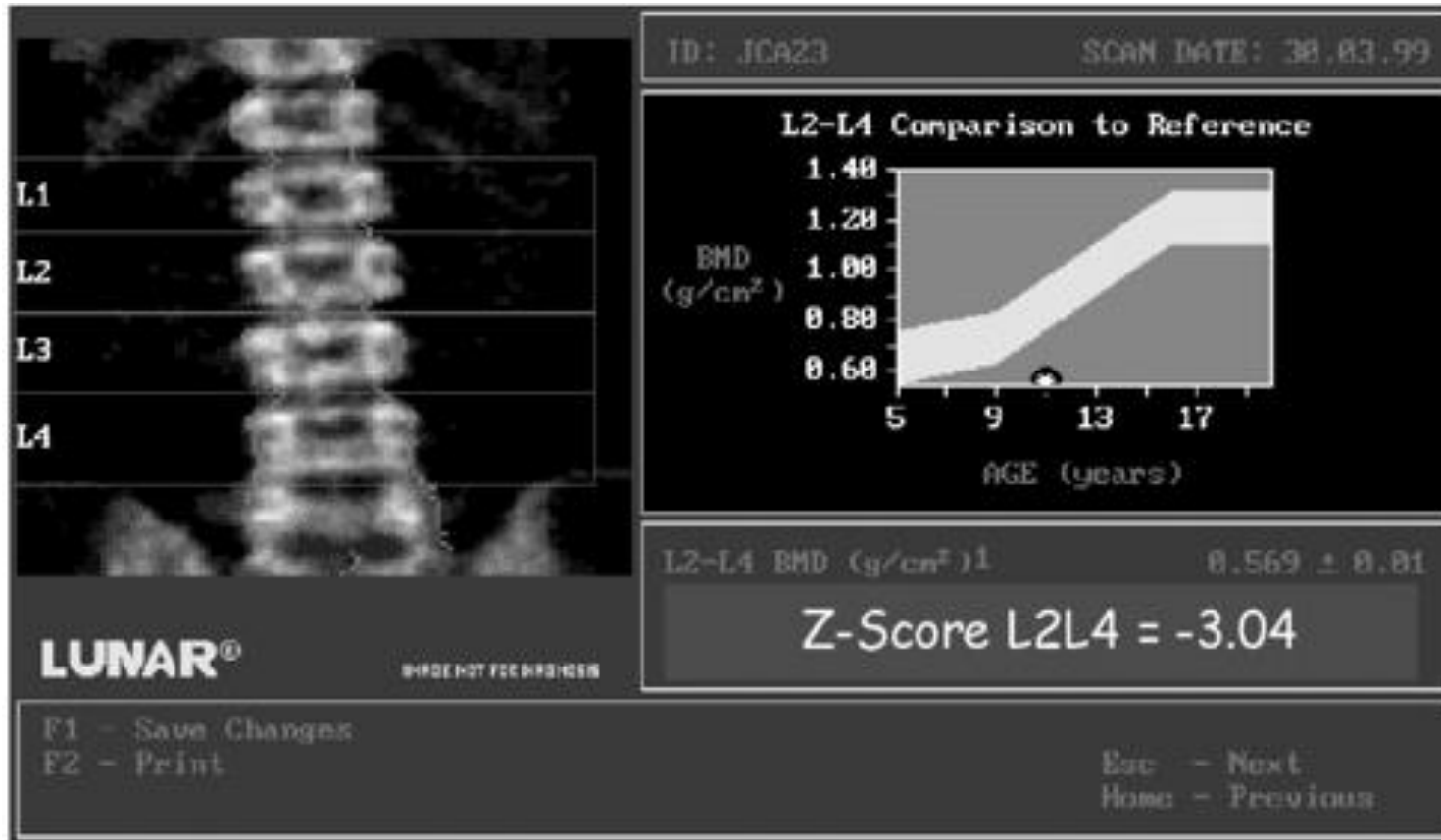
Weight by Z scores

Weight not normally distributed

60% are below median weight for age

13% are 2 or more SD above median





1 child (10 years) z score -2.3

2 children documented fractures

No other children had DEXA scans !!

Bone densitometry

Progress....

We have established a MD feeding clinic with rostered regular reviews of those most in need

We have just commenced use of Knee-Height as a surrogate for standing height

Measuring MUAC and planning to start using skinfold calipers

Now have access to DEXA with Paediatric software

What next?

BETTER ANTHROPOMETRY

-WHEELCHAIR SCALES

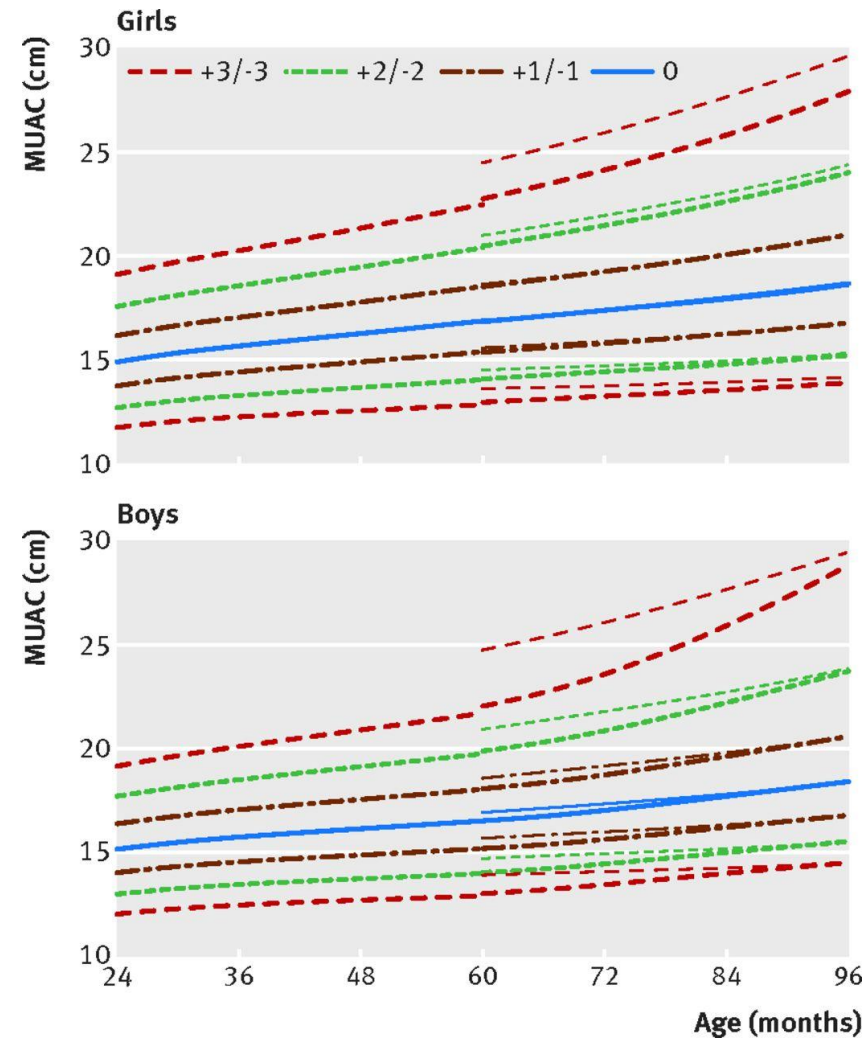
-SKINFOLD THICKNESS

-KNEE HEIGHT OR ULNA LENGTH

*MUST RECORD METHOD OF MEASUREMENT AND
ADJUST IF SUPINE*



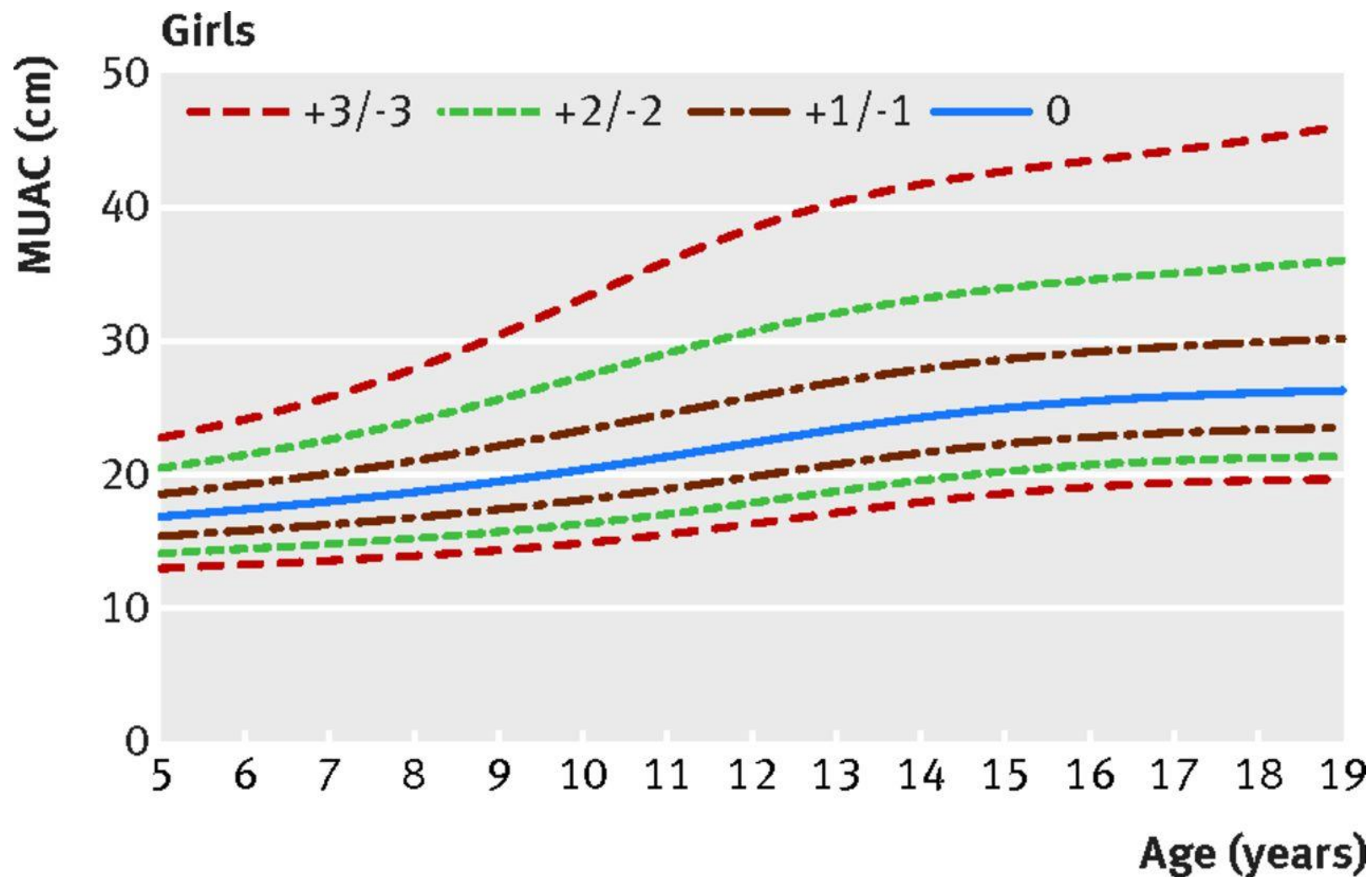
Fig 3 Transition from World Health Organization (2006) standards for under 5s to mid upper arm circumference (MUAC)-for-age z scores for 5 to 19 year olds.



Lazarus Mramba et al. BMJ 2017;358:bmj.j3423



Fig 1 Mid upper arm circumference (MUAC)-for-age z score reference curves for girls aged 5 to 19 years.



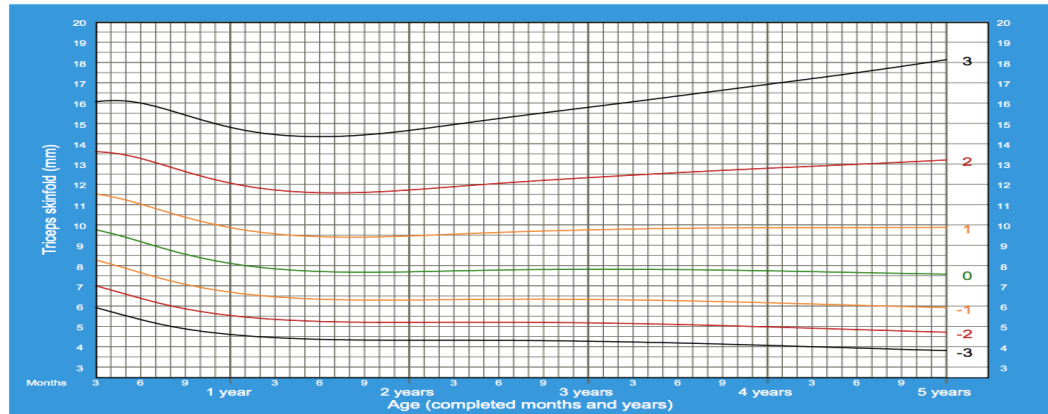
Lazarus Mramba et al. BMJ 2017;358:bmj.j3423



Use of Triceps Skinfold Thickness

Triceps skinfold-for-age BOYS

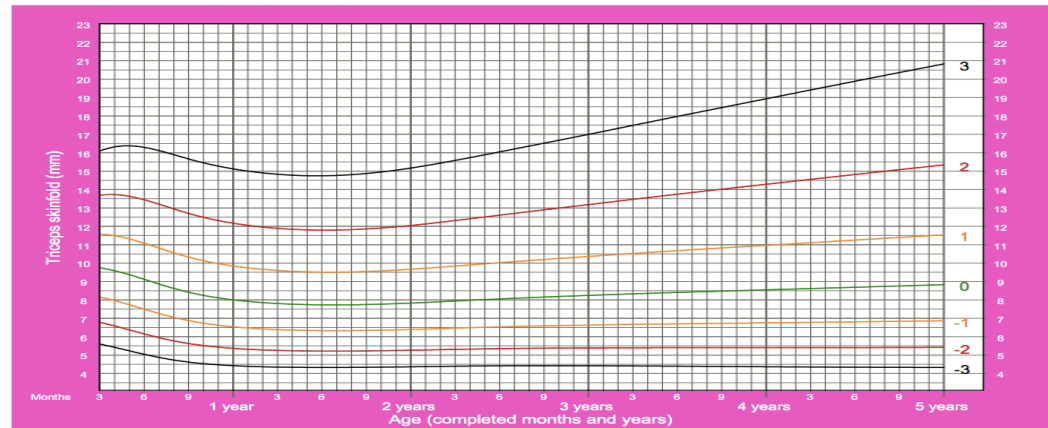
3 months to 5 years (z-scores)



WHO Child Growth Standards

Triceps skinfold-for-age GIRLS

3 months to 5 years (z-scores)



WHO Child Growth Standards



Measuring the biceps skinfold

What next ?

Written information for parents:

"Birthday bloods"

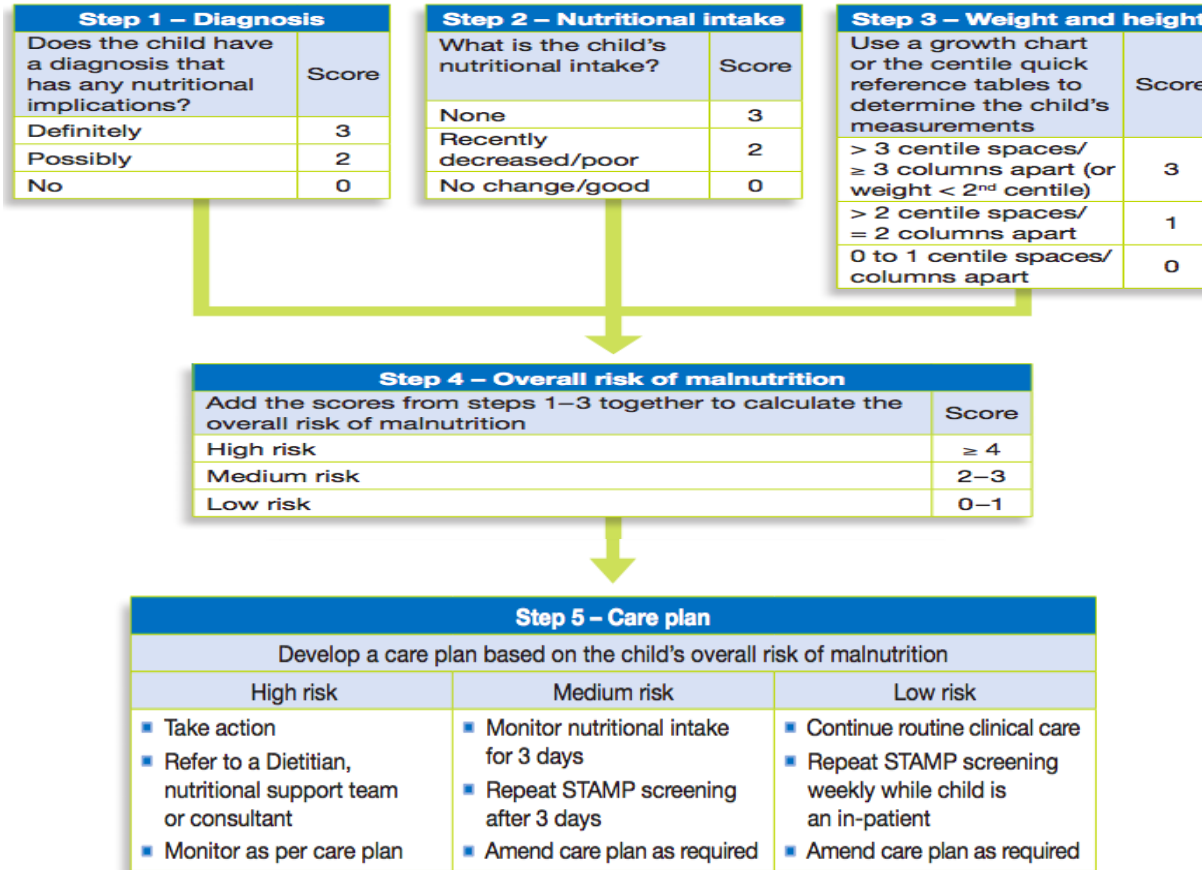
Improved Vit D and trace mineral monitoring to include zinc, selenium, vit C

Ensure BMD and lean body mass are monitored using DEXA

Develop nutritional care plan for each patient documenting serial measurements and bloods taken



A step-by-step guide to using STAMP



Other progress: encourage earlier identification of those at risk of undernutrition/malnutrition



Supported by an educational grant from **Abbott Nutrition**

Central Manchester University Hospitals **NHS** Foundation Trust

Conclusions

Monitoring levels of FBC, Ca, PO4 much improved

Vitamin D monitoring must improve further

Other micronutrients should be checked annually as deficiencies in micronutrients can occur in addition eg Vit C, Vit A, Zinc

More accurate anthropometry is vital

Better *documentation* of anthropometric methods



Acrodermatitis enteropathica

Thank you

NUTRICIA

Deborah Griffin, Senior Dietician, CUH

Dr Adela Vatca, Paediatric Registrar, CUH

Dr Jayne Mc Mahon, Paediatric SpR

Dr Susan Harvey, Paediatric SpR

The Paediatric Nursing and SLT staff at CUH

...The children and families

