

Data Matters to make all needs visible: Development of a SNOMED CT terminologies set

Karen Horridge, Paediatrician (Disability), Sunderland

Coding to communicate



Hospital Episode Statistics

Bespoke databases



Data capture by clinicians
at point of care

Common terms used across settings – SNOMED CT coded



SNOMED CT

Internationally recognised

Independent of hardware/software

Captures multifaceted conditions, situations, technology dependencies, interventions etc.

Regular cycle of review of terms, synonyms permitted, outdated terms 'retired'



Disability Terminology Set development

122 disability terms

117 general paediatric terms

178 community paediatric terms

Discussion and debate

Final published terminologies set of 296 terms

http://www.diseasesdatabase.com/snomed/refset_metadata.aspx?id=9990017510000000105



<https://www.bacdis.org.uk/policy/documents/ExplanatoryGlossaryofTerms.pdf>

**Explanatory Glossary of Paediatric Disability Terms
to support data collection by Paediatricians at the
point of clinical care**

**Includes Guidance for considering Person-centred Outcomes
and Actions for Education, Health and Care planning**

Author:

Karen Horridge, Disability Paediatrician, Sunderland
Chair, British Academy of Childhood Disability until 2017

Editorial reviewers:

Dr Ronng Cheung, Paediatric trainee, Evelina London Children's Hospital, London
Karina Dancza, Professional Advisor, Children and Young People, College of Occupational Therapists, London
Professor Gillian Baird, Guys and St Thomas NHS Foundation Trust, London

Terminologies Set Development Group:

Karen Horridge, Jane Williams, Gabriel Whittingum, Gillian Baird, Mary Busk (parent representative), Sue Fox (therapies representative), on behalf of the British Academy of Childhood Disability
Fawzia Rahman, Anastasia Bern on behalf of British Association for Community Child Health
Ronny Cheung on behalf of general paediatrics
Max Davie, on behalf of Paediatric Mental Health Association
working with John May and Richard Mountford, terminology consultants, Health and Social Care Information Centre

July 2017



Data capture at the point of care

SCH.CHS - Scheduler Desktop - (DAGSUN/DAGSUN.LIVEN/DAGSUN.LIVEN) - Mathew Poole

Dr K Horridge Resource Group: Paed Consultant NQB
Count/% Booked: [21] 95%

Resource

March 2014

Sun	Mon	Tue	Wed	Thu	Fri	Sat
23	24	25	26	27	28	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	1	2	3	4	5

Friday 07 March, 2014

Time	Resource	Appt Type	Appt Duration	Facility	Clinician	Appt Status	Patient Type	Reason For Visit
0900	0920	Wil				NF Rev	1F	
		Kel				NF Rev	1F	
0920	0940	Mo				NF Rev	1F	
		Wa				NF Rev	1F	
0940	1000	Dra				NF Rev	1F	
		Am				NF Rev	1F	
1000	1020	For				NF Rev	1F	
		Ka				NF Rev	1F	
1020	1040	Wil				NF Rev	1F	
		Ro				NF Rev	1F	
1040	1100	Tor				NF Rev	1F	
		He				NF Rev	1F	
1100	1120	Wa				NF Rev	1F	
		Be				NF Rev	1F	
1120	1140	Be				NF Rev	1F	
		Wi				NF Rev	1F	
1140	1200	Wil				NF Rev	1F	
		Tin				NF Rev	1F	

Patient Information

Birthdate	2005
Age/Sex	8/M
Home Phone	
NHS Num	
Account Num	
Med Rec Num	

Appointment Information

Appt Type	HACJRNFNQB
Appt Duration	20
Facility	DGH
Clinician	Horridge,Karen
Appt Status	BOOKED
Patient Type	SCH CLI
Reason For Visit	KS 12MTH F/U 9AM SLOT REQ



Data capture at the point of care

Physician Care Manager - HIM Dept: CHM (DAGSUN/DAGSUN.LIVE/DAGSUN.LIVE) - Poole, Mathew [GSST]

Test, Laura PRE CLI DGMAIN Acct: D00001129409 MR: X001900003
33/F 15/03/1980 VIP NHS: 100 000 0001 EMR: S01220051
Allergy/AdvReac: ciprofloxacin, PENICILLINS

PND OPD Activity

Neurodisability Data Capt...

Outcome

Consultation Outcomes **NAD** DiagNotMade NoNDevCond NoNDisCond MedUnexp

Diagnosis

Intellectual abilities	Ldiff DevAcadDis TypIAA BordIA MildIDD SigIDD ModIDD SevIDD	ProfIDD EDI/Unspec IDD unknown SpLD Dyslex Dyscal Dysgraph PIND	IEM Mitochond Down Synd FraX MECP2Dis MECP2Dupl ChromDis GenSynd
Physical/Motor/ Musculoskeletal	PD Neurolog MvtDis CP WDSynd SpCP	SpCPunIR SpCPunIL SpCPbilat DyskinCP DystonCP ChorAthCP	AtaxicCP GMFCS I GMFCS II GMFCS III GMFCS IV GMFCS V
Neuroimaging	Nireq Date NI NI Abn NI not done Maldev WhiteMatInj GreyMatInj Misc NI Normal	Neuropathy HSP NMD CongenMD DMD NMJdis Talipes DCD Clumsy	GaitAbn SkelDyspl JointLaxity CAMSK ULanomaly CDH Scoliosis DislocHip/s

Comment

My Notices
Patient Lists
Next Patient
Select Visits
Summary
Review Visit
Notices
New Results
Clinical Panels
Vital Signs
I & O
Medications
Laboratory
Microbiology
Blood Bank
Reports
Patient Care
Notes
Consultant Eps
Orders
Amb Orders
Mar
Document
Sign
Preferences

Add Section Code Visit Protocol Quick Save Cancel View/Save

Physician Care Manager - HIM Dept: CHM (DAGSUN/DAGSUN.LIVE/DAGSUN.LIVE) - Poole, Mathew [GSST]

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33/F 15/03/1980 VIP NHS: 100 000 0001 EMR: S01220051
Allergy/AdvReac: ciprofloxacin, PENICILLINS

PND OPD Activity

Head, brain, congenital anomalies & growth	SpinaBifida DevBrainAnom Hydroceph Microceph ABI TBI TBI NAI	ConHypo CongenInfect CleftPalate CAHead Craniosyn Plagioceph CongenAnom	ConHeartDis GUanom Dysmorphic ShortStature FaltGrowth
Sensory Impairments	HI SNHL BCSNHL ProfBSNHL SevSNHL ModSNHL	MildSNHL UniSNHL CondHL HearingAid/s CochlearImp VI	SevBVI SevUniVI PartVI CVI
Speech, Language, Communication, Feeding & Nutrition	SALD Speech Lang Fluency ImpSocialint	FeedingDiff RiskNutrProb LowRskMal MedRskMal HghRskMal	ARFID LiquidDiet ThickFluidDt SoftDiet WgtGainDt
Neurological	SeizDis AbsSeiz FocSeiz FebConv	DizzySpell Syncope FunnyTurn WestSyndrome	TensHeadache Migraine
Safeguarding/Child Protection	VictimSA NAI Neglect EmotAbuse	CSA Exploit SexExploit VictDomV	VictOth SuspectCA CAinFam
Behaviour, Mental Health	AnxietyDis	PTSD	Depression

Comment

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Vital Signs
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Laboratory
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Consultant Eps
Orders
Amb Orders
Mar
Document
Sign
Preferences

Add Section Code Visit Protocol Quick Save Cancel View/Save

Data capture at the point of care

Physician Care Manager - HIM Dept: CHM (DAGSUN/DAGSUN.TEST60F/DAGSUN.TEST60F) - (TEST 6.05) - Poole, Mathew [GSST]

Frog, Michigan
26/M

ADM IN DGB20 DGB20-1.1
1.77 m/84 kg/2.01 m²
Allergy/AdvReac: PENICILLINS
DNACPR Cancelled

Acct: D00000017727 MR: X000001168
NHS: EMR: S00001182

Assign Clinicians

*Status ☐ Pending ☐ Draft ☒ Signed
*Enter Pin ****

My Notices
Patient Lists
Next Patient
Select Visits
Summary
Review Visit
Notices
New Results
Clinical Panels
Vital Signs
I & O
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Reports
Patient Care
Notes
Consultant Eps
Orders
Amb Orders
Mar
Document
Sign
Preferences

Required Questions

Cancel Save



Outcomes of data capture

Development of Disability Complexity Scale

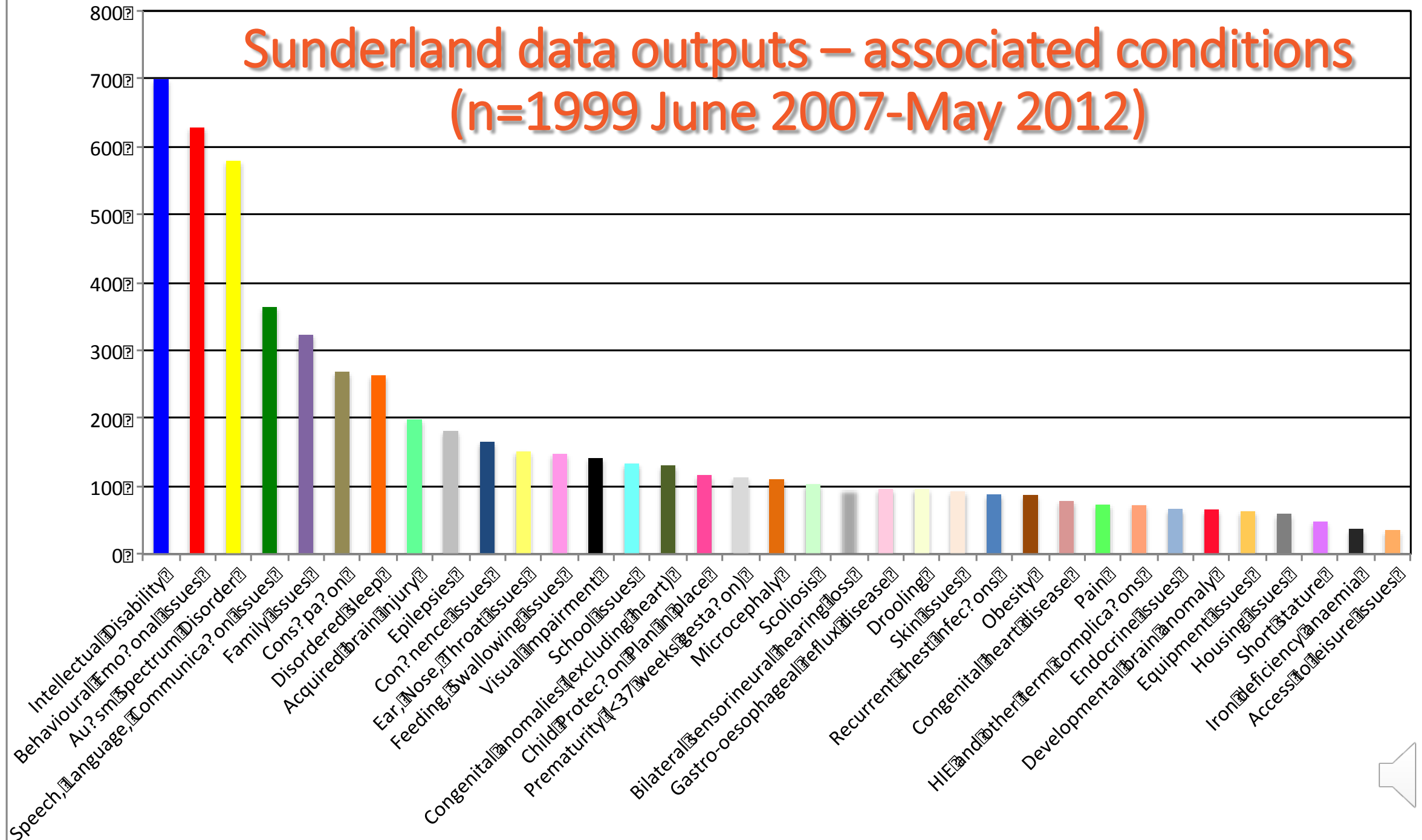
Rollout to ALL paediatric clinics in Sunderland

Improved understanding of multifaceted needs of children

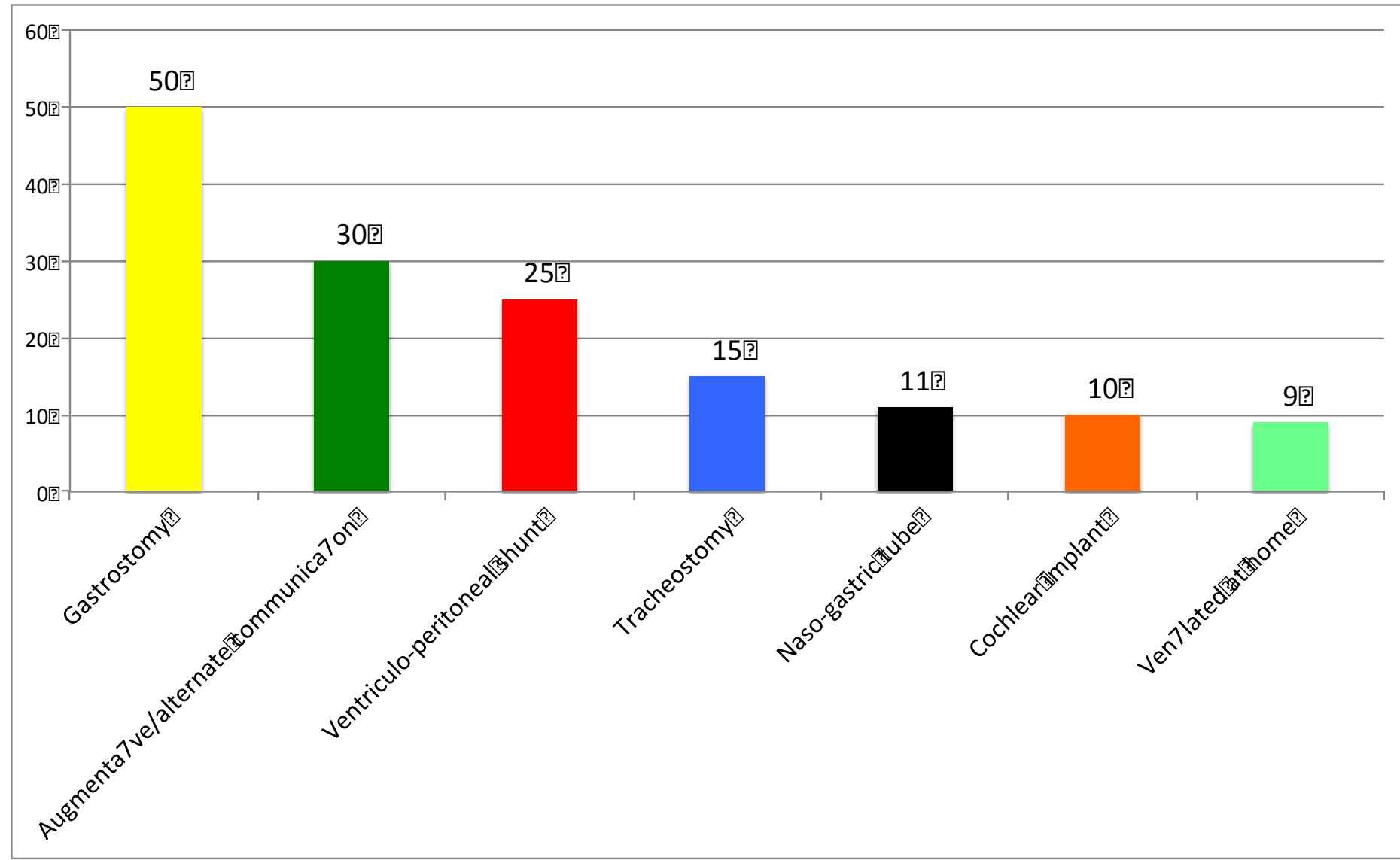
Development of NHS England currency model based on complexity of needs and ultimately to underpin tariffs



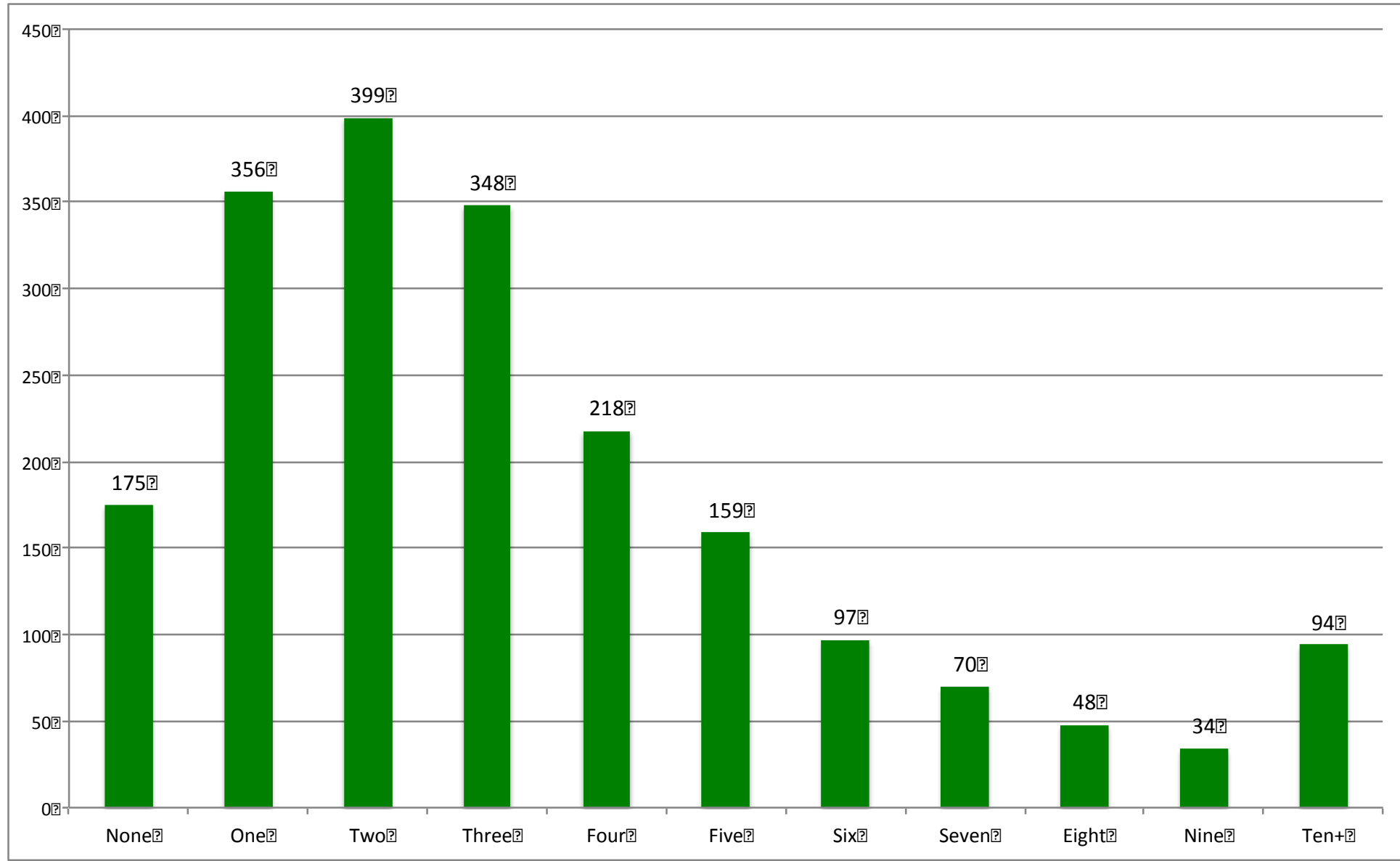
Sunderland data outputs – associated conditions (n=1999 June 2007-May 2012)



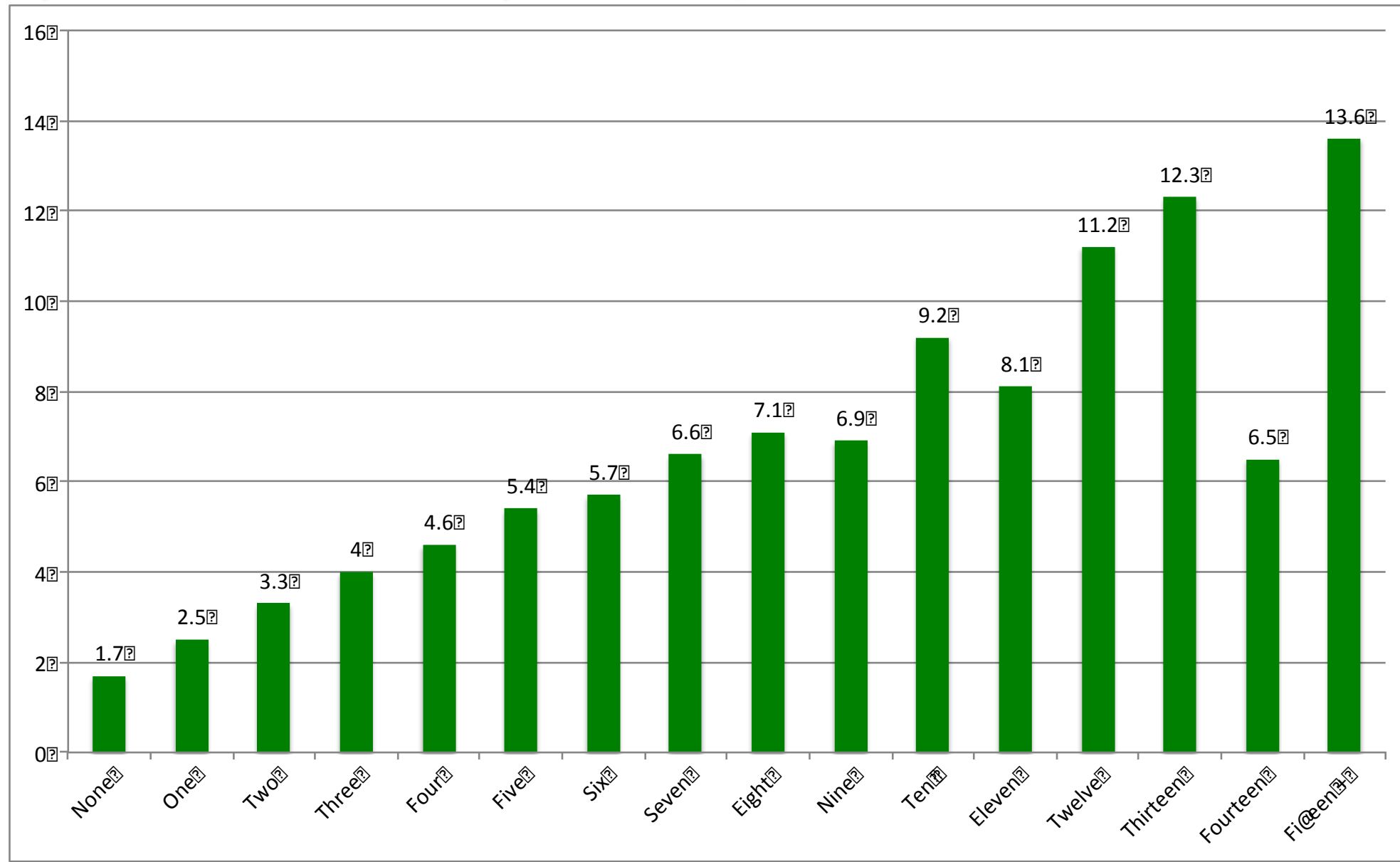
Sunderland data outputs – technology dependencies (n=1999 June 2007-May 2012)



Sunderland data outputs – number of needs per child (n=1999 June 2007-May 2012)



Sunderland data outputs – number of paediatric disability clinic visits by number of needs per child (Pearson's correlation R=0.97)



Disabilities Complexity Scale

Health conditions (C)



+

Family-reported issues (F)



+

Technology dependencies (T)



+

Round the clock care (or not) (R)



Empowering clinical data collection at the point of care

Andy Spencer,¹ Karen Horridge,² Denise Downs³

SNOMED CT has a structure that is designed to reduce ambiguity and to facilitate subsequent data analysis. Online tutorials and webinars¹¹ explain the 19 different SNOMED CT hierarchies and the 'IS-A' parent-child relationships. Each unique SNOMED CT concept (equivalent to a clinical diagnosis) has a Concept ID

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

ORIGINAL ARTICLE

Quantifying multifaceted needs captured at the point of care. Development of a Disabilities Terminology Set and Disabilities Complexity Scale

KAREN A HORRIDGE¹ | CARL HARVEY¹ | KENNETH MCGARRY² | JANE WILLIAMS³ | GABRIEL WHITLINGUM⁴ | MARY BUSK⁵ | SUZANNE FOX⁶ | GILLIAN BAIRD⁷ | ANDY SPENCER⁸

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

ORIGINAL ARTICLE

Prospective pilots of routine data capture by paediatricians in clinics and validation of the Disabilities Complexity Scale

KAREN A HORRIDGE¹ | KENNETH MCGARRY² | JANE WILLIAMS³ | GABRIEL WHITLINGUM⁴ | ON BEHALF OF THE BRITISH ACADEMY OF CHILDHOOD DISABILITY

<https://adc.bmj.com/content/100/9/815>

<https://onlinelibrary.wiley.com/doi/full/10.1111/dmcn.13102>

<https://onlinelibrary.wiley.com/doi/10.1111/dmcn.13101>



Parent carer engagement

www.nnpcof.org.uk/wp-content/uploads/2014/03/NNPCF-Paediatric-Disability-Data-Project-parent-carer-and-family-perspective-May-2014.pdf




National Network of Parent Carer Forums

HOME WHO WE ARE GET INVOLVED USEFUL INFORMATION NEWS CONTACT US




Paediatric Disability Data Project

My best from: @ @CQCPr @rt_sen were you /t9bg11C November Ofsted n local are inspectio <http://www.nnpcof.org.uk>



National Network of Parent Carer Forums
'Our Strength Is Our Shared Experience'

**Paediatric Disability Data Project
Parent Carer and Family perspective**



NNPCF Steering Group
May 2014



NHS Digital case study: Data capture in Sunderland

https://hscic.kahootz.com/connect.ti/t_c_home/viewcontent?contentid=301171&done=CONCreated



SNOMED CT Case Study

“Each and every need of all disabled children must be accurately identified and described using consistent language if the best outcomes are to be achieved”

Dr Karen Horridge

Summary

Dr Karen Horridge is a Consultant Paediatrician (Disability) in Sunderland and immediate past Chair of the British Academy of Childhood Disability. In this case study she explains how each and every need for disabled children and their families require accurate identification and description, using a common language. Making every need visible is the first step towards these being addressed.

Background

There is vast variation in outcomes for disabled children. There are no national data about who or where disabled children are in the UK or what their multi-faceted needs are. This is evidenced in the 2018 National Confidential Enquiry into Patient Outcome and Death report: [Each and Every Need](#).



A traffic light tool was designed with families



Other resources

RCPCH guide to SNOMED CT coding:

<https://www.rcpch.ac.uk/resources/how-guide-clinicians-interested-developing-snomed-ct-concepts>

RCPCH SNOMED CT workshop 14 Nov 2018



Benefits of SNOMED CT coding

Clinicians decide which terms to use consistently

Coding allows data flow across systems

Data captured about all needs makes needs visible

Visible needs are more likely to be met

Population data highlight variations



Improved outcomes that can be evidenced and measured

