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

Karen Horridge, Paediatrician (Disability), Sunderland

City Hospitals | 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Regular cycle of review of terms, synonyms permitted, outdated terms 'retired'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=999001751000000105

https://www.bacdis.org.uk/policy/documents/Explanatory GlossaryofTerms.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 Whitlingum, 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

Data capture at the point of care

Data capture at the point of care

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)
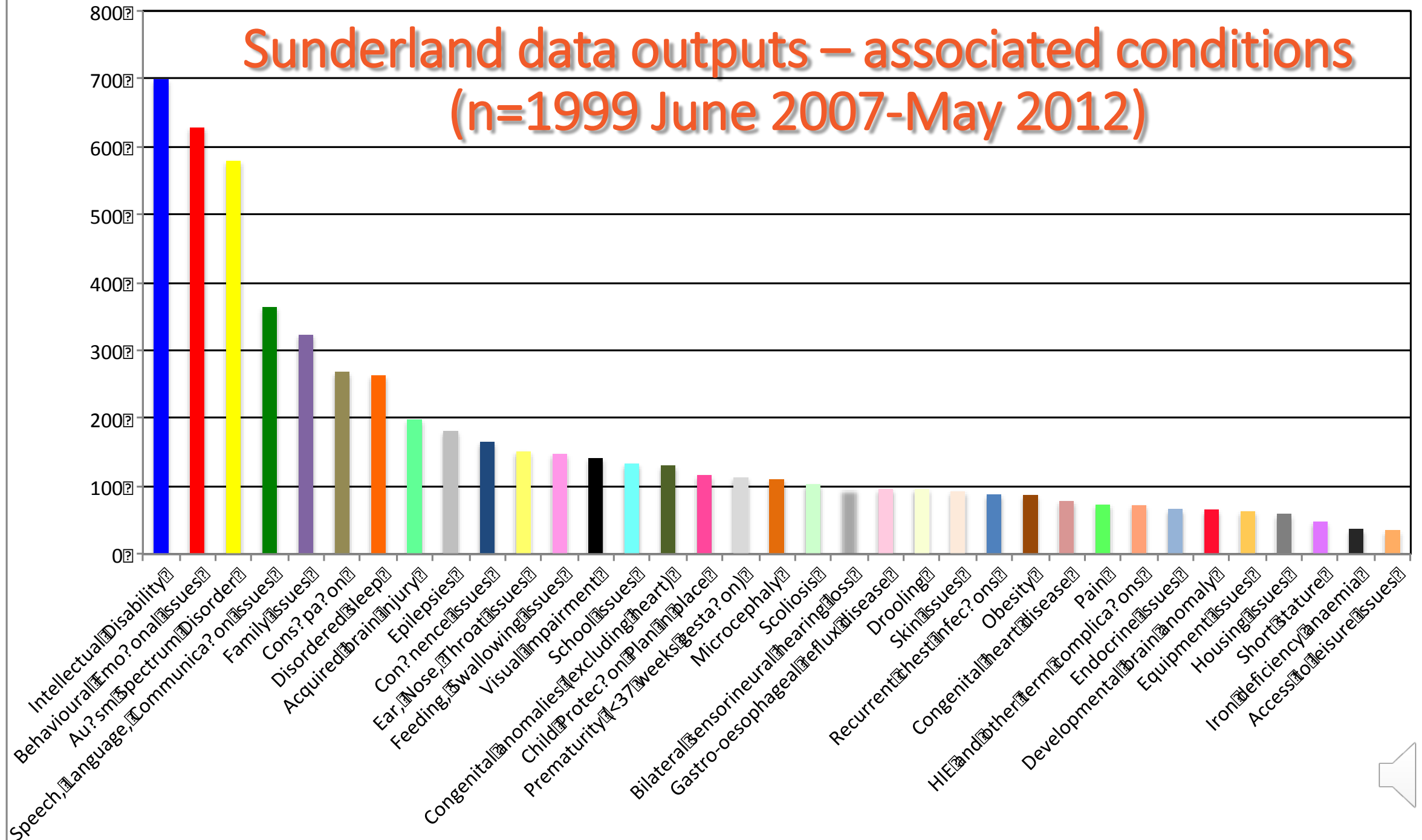
Sunderland data outputs – technology dependencies (n=1999 June 2007-May 2012)
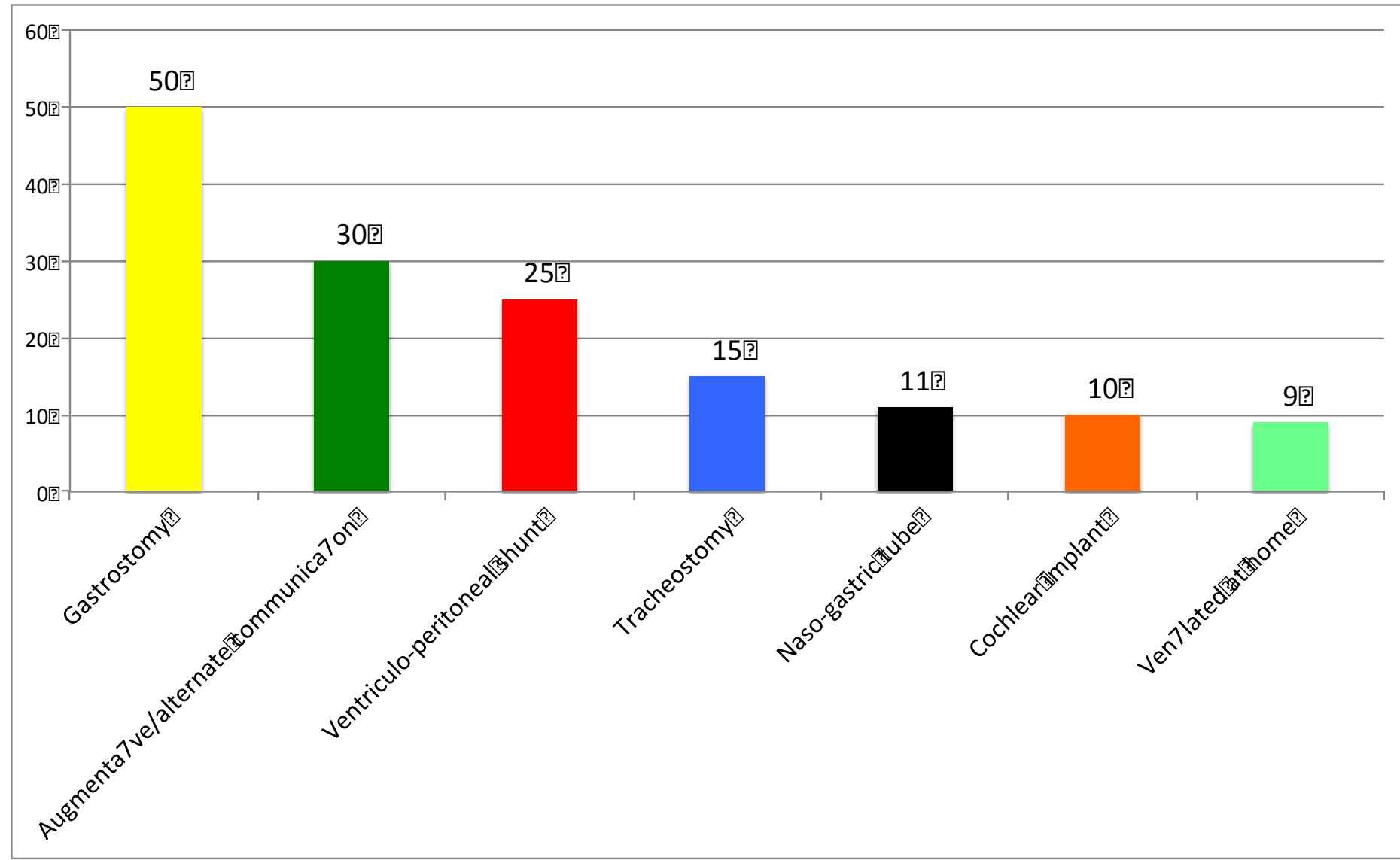
Sunderland data outputs – number of needs per child (n=1999 June 2007-May 2012)
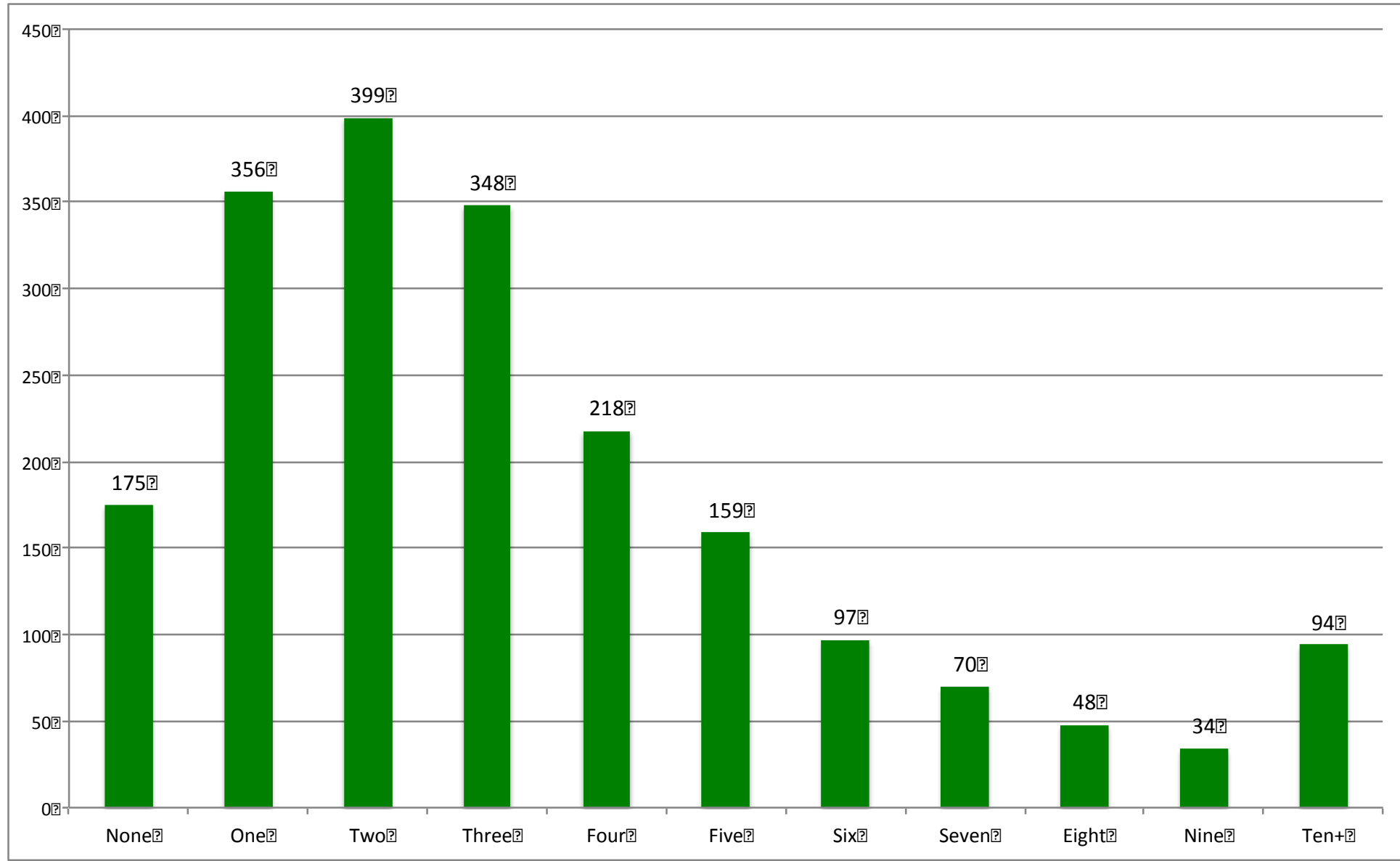
Sunderland data outputs – number of paediatric disability clinic visits by number of needs per child (Pearson's correlation R=0.97)
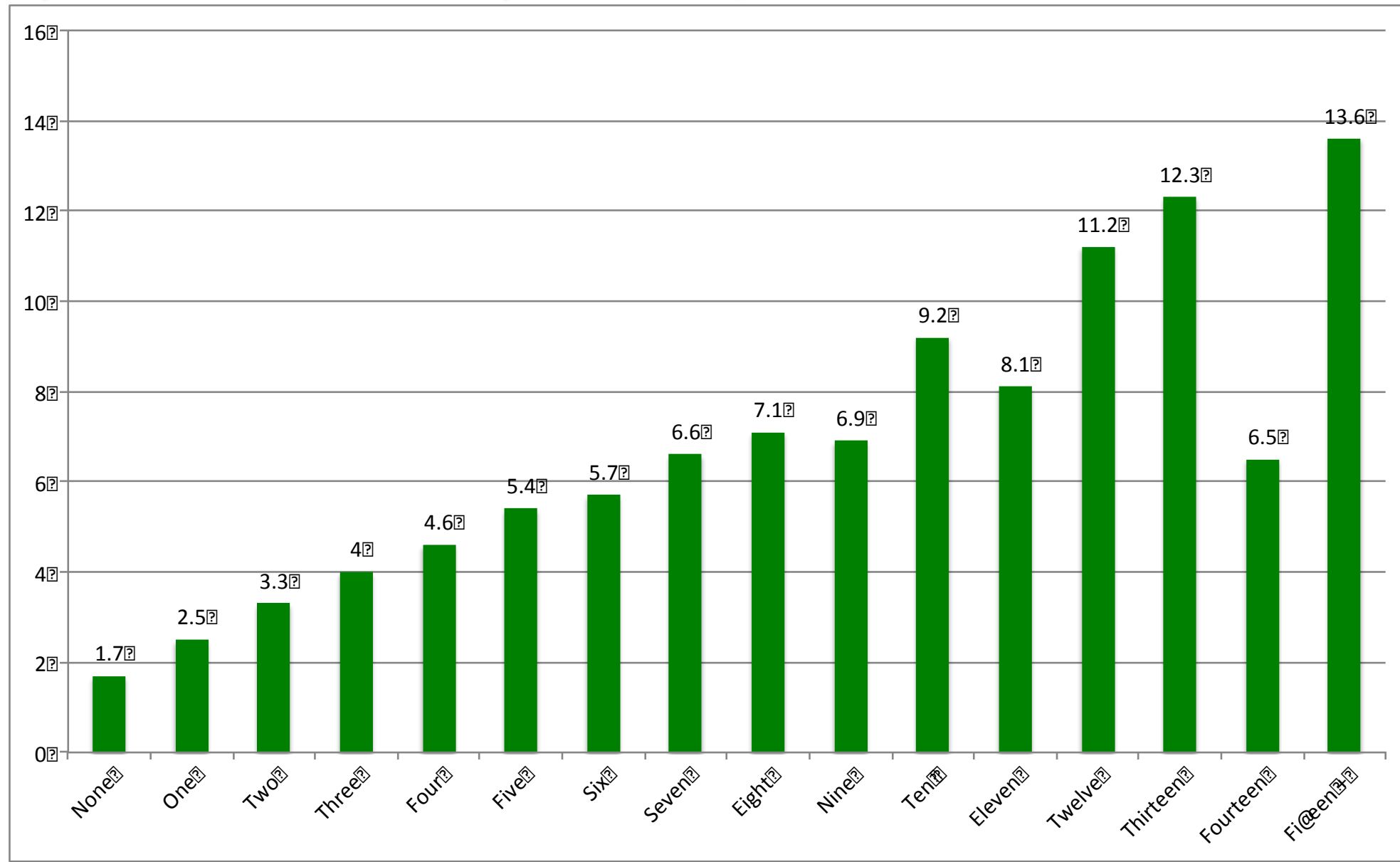
Disabilities Complexity Scale

Health conditions (C)

+

Family-reported issues (F)

Technology dependencies (T)

Round the clock care (or not) (R)

+

+

Leading article

Empowering clinical data collection at the point of care

Andy Spencer,[1] Karen Horridge,[2] Denise Downs[3]

SNOMED CT has a structure that is designed to reduce ambiguity and to facilitate subsequent data analysis. Online tutorials and webinars[11] explain the 19 different SNOMED CT hierarchies and the 'IS-A' parent–child relationships. Each unique SNOMED CT concept (equivalent to a clinical thought) has a Concept ID

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

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 HORRIDGE[1] | CARL HARVEY[1] | KENNETH MCGARRY[2] | JANE WILLIAMS[3] | GABRIEL WHITLINGUM[4] | MARY BUSK[5] | SUZANNE FOX[6] | GILLIAN BAIRD[7] | ANDY SPENCER[8]

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

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 HORRIDGE[1] | KENNETH MCGARRY[2] | JANE WILLIAMS[3] | GABRIEL WHITLINGUM[4] | ON BEHALF OF THE BRITISH ACADEMY OF CHILDHOOD DISABILITY

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

Parent carer engagement

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

NHS Digital case study: Data capture in Sunderland

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

NHS Digital

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