

## 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](#).

### Outcome

Using SNOMED CT, a Disabilities Terminology Set (DTS) subset was created. It was designed to embrace the range of needs experienced by disabled children and their families at different stages of their care journeys, so that these could be accurately recorded. An explanatory [glossary](#) was produced in which each term was clearly explained, to encourage consistent use of the same terms across all care settings.



A [traffic light tool](#) was designed with families and the multidisciplinary team to capture and prioritise needs on the day of each clinic review appointment. Families complete this in the waiting room and bring it to the consultation, which ensures that the needs that matter most to the family that day are addressed. Families appreciate this opportunity to gather their thoughts and find using this tool empowering. Data captured by the tool can be recorded in the electronic

patient record by the clinician at the end of the consultation, using a bespoke data capture screen that doubles up as the clinic booking out slip, reducing duplication of effort. This information is included in the clinic letter sent to the family and the child's interagency team.

## Benefits of Using SNOMED CT

More than just health conditions can be recorded e.g. body structure, function, activities, participation, personal and environmental factors, technology dependencies, need (or not) for round the clock care etc.

Different levels of detail relevant to the stage in the clinical journey can be captured. For example, at the first visit, 'impaired social interaction' may be recorded, then once the assessment is completed, 'autism spectrum disorder' may be recorded. This allows analyses at different levels.

## Benefits for the patient

The approach facilitates person-centred care by empowering the child and family to raise the issues that matter most to them, so that these can be addressed by the clinician and multidisciplinary team.

Proactive health care is encouraged rather than the passive monitoring of the natural history of the disabling health condition. This leads to improved outcomes, as needs that are properly identified in a timely way can be addressed promptly, with less risk of complications.

The outcome facilitates quantification of complexity of needs, by articulating what they all are. This improves the quality of communication with the interagency team across health, education and social care.

## Service Improvement Outcomes

Service provision improvements in Sunderland include the SNOMED CT data being used to support:

- Business cases for additional disability paediatricians and therapists
- Commissioning for Quality and Innovation framework to improve learning disability being appropriately recorded and flagged, prompting letters to GP practices to ensure appropriate inclusion on practice learning disability registers
- Service design and development, including the establishment of combined paediatric, orthopaedic and physiotherapy postural management clinics that reduce the amount of school missed by children and inconvenience for families
- Range of audits and the redesign of care pathways as well as secondary uses
- Significant improvements in equipment provision
- Clinical care improvements including prompting clinicians to consider further tests

This case study provides an overview of their achievements.

## Challenges and lessons learned

The development of a speciality terminology set like the DTS requires a collaborative effort and require maintenance and review by an expert clinical reference group from a clinical perspective. The Royal College of Paediatrics and Child Health has produced guidance to encourage other subspecialty groups to develop their own Terminology Sets.

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# Case Study Analysis

## Organisation Profile

City Hospitals Sunderland was established as an NHS Trust in April 1994 and became the first NHS Foundation Trust in the North East July 2004. The Trust provides hospital services to a local community of around 350,000 along with a range of more specialist services to a population as great as 860,000. The Trust also provides a substantial range of community-based services particularly within Family Care and Therapy Services. The specialist paediatric disability service provides health care for disabled and potentially disabled children across all settings including the paediatric emergency department, inpatient wards, out-patient clinics, outreach clinics in special schools, and care at home including end of life care.

## Background

From limited existing population data, there is evidence of variation in aspects of care for disabled children globally and in the UK. In order to address the multifaceted needs of disabled children in a local population, these must be accurately identified and described. Data are also required to measure the effectiveness of interventions and support, leading to a continuous cycle of improvement.

## Original business process

At the time, there was an imperative from the Department of Health to determine the identity, location and needs of disabled children and young people to inform appropriate commissioning arrangements. However existing national data collection did not give the required breadth or level of detail required and so an alternative approach was needed for recording multifaceted data in a consistent way.



## Approach

A new subset was created called the Disabilities Terminology Set (DTS) that describes the multifaceted needs of disabled children using 296 SNOMED CT terms along with an [explanatory glossary](#) (to make explicit the exact meaning of each term with supporting evidence and links to further information). Paediatricians worked together with therapists from the British Academy of Childhood Disability, parents from the National Network of Parent Carer Forums and Terminologists from NHS Digital. The DTS was designed to embrace the different stages of the journey, from initial presentation when terms needed to be broad through to specific terms that could accurately capture the detail resulting from a period of assessment, thought, investigation and intervention. The scope of the design went beyond merely recording health conditions, but also included body structure, function, activities, participation and personal and environmental factors. This multifaceted approach allows for comprehensive data capture at each stage of the journey so that the holistic needs of the child or young person and their families can be accurately recorded. The co-production model with parent carers was celebrated in a [report](#) published by the National Network of Parent Carer Forums.



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

stored in the hospital's electronic patient medical record.

The traffic light tool is illustrated below:



## HEALTH, FUNCTIONING AND WELLBEING SUMMARY



Name:  DoB: / /  Date completed: / /

Please fill in this information. It will help professionals to understand what is going well and what worries you most at this time.

Things to celebrate, things that are going well:

Thoughts about what might help to make it easier to join in everyday activities and make life more enjoyable:

Things that are causing concern and questions:

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## Business process after the introduction of SNOMED CT

### Data recording

To ensure all relevant issues were captured, families were invited to complete a 'traffic-light tool' in the waiting room at disability clinic review appointments. The traffic-light tool was co-produced with families and the multidisciplinary team, to capture the breadth of issues that commonly arise for disabled children, young people and their families, regardless of the primary disabling health condition. Use of the tool has been formally evaluated, with [extremely positive feedback from families](#), who reported that it assists them to gather their thoughts and prioritise their concerns prior to seeing the paediatrician, enabling them to have the issues that matter most to them at that time addressed in the consultation.

The following areas are covered: health conditions that commonly coexist regardless of diagnosis (e.g. constipation, disordered sleep, gastro-oesophageal reflux); functioning across a range of domains (e.g. mobility, personal care, vision, hearing, communication, behavioural issues); and environmental issues, including with family, school, housing, equipment, and access to leisure. This informs not only the consultation, but also the clinic letter sent to families that is

Name:  DoB: / /  Date completed: / /

For each of the following areas please indicate which traffic light colour best matches your level of concern.

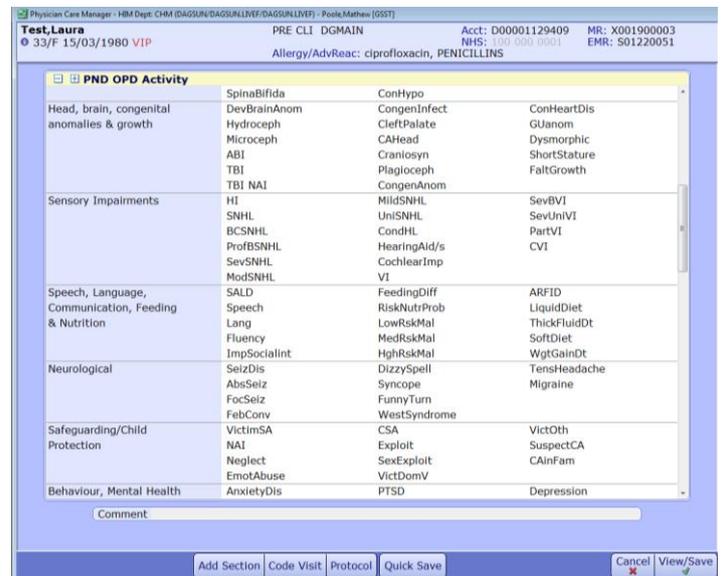
- No Concerns** Does not limit joining in every day activities or enjoying life.
- Some Concerns** Regularly but intermittently limits joining in every day activities or impacts on ability to enjoy life.
- Serious Concerns** Frequently or daily limits joining in every day activities or impacts on ability to enjoy life.

	No Concerns	Some Concerns	Serious Concerns
General physical health			
Alway & breathing issues			
Recurrent chest infections			
Pain			
Seizures (fits, faints, funny turns)			
Eating, drinking, swallowing issues			
Drooling			
Acid reflux (acid, smelly burps), vomiting			
Constipation (infrequent stools, hard to pass)			
Soiling			
Day time wetting			
Night time wetting			
Period issues			
Ear, nose or throat issues			
Skin issues			
Faltering weight gain			
Overweight issues			
Mobility, moving around			
Hand function			
Personal care (self feeding, washing, dressing, soiling, etc.)			
Vision (eyesight)			
Hearing			
Speech, language, communication			
Friendships and relationships, social communication			
Disruptive behaviour			
Emotional issues (mood, anxiety)			
Self injury			
Sensory sensitivities (e.g. to sounds, textures etc.)			
Pica (eats inappropriate things e.g. soil, metal etc.)			
Learning			
Sleep			
Family issues			
School issues			
Equipment issues			
Housing issues			
Access to leisure activity issues			
Are you well enough supported?			
Do you have enough information about your child's condition and services?			
Other (please specify):			

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This also informs the data captured at the point of care into the Paediatric Outpatient Activity document, built into Sunderland's electronic medical record (Meditech Version 6), which doubles up as a clinic booking out slip. The paediatrician clicks on all the abbreviated DTS terms that apply for the patient on that day and at that time, then completes the 'Referral To Treatment' outputs and next actions in terms of any follow up or onwards referrals required. These data, captured at the point of care, can then flow behind the scenes for the CSDS.

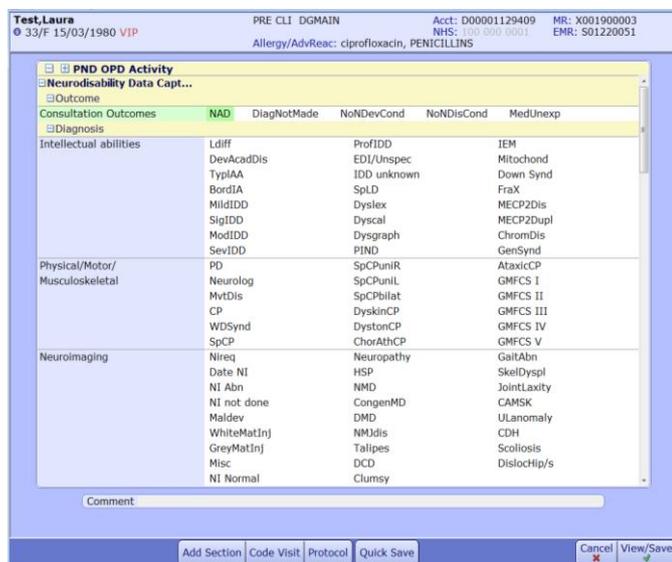
Data recording is quickest and most efficient when it is captured electronically at the time of the consultation by the paediatrician and takes less than a minute once the clinician is familiar with the terms and the layout on the screen. Also, the burden of duplicate data entry into additional tools for audit and secondary uses was reduced by extracting structured data directly from the electronic patient record. The Sunderland data capture interface is illustrated below.



## Data analysis

A retrospective analysis was completed and [published](#) based on 8329 consultations with 1999 Children and Young People (CYP) in Sunderland paediatric disability clinics between June 2007 and May 2012. A Disabilities Complexity Scale was developed, based on the sum of overall needs that was calculated for each child from the sum of health conditions, technology dependencies, family-reported issues, and need (or not) for round-the-clock care.

The needs of children with the most common disabling conditions: autism spectrum conditions, cerebral palsies, epilepsies, and chromosomal/genetic syndromic conditions were compared. Similarly, the needs of children who were born preterm were compared to those who were born at term but requiring neonatal intensive care. To quantify the additional burden for families when IDD were present, children with and without IDD were compared for a range of common disabling conditions. Finally, children who died during the 5-year time window were compared to the other groups.



The "Protocol" button at the bottom of the screen opens up the explanatory glossary of terms, including supporting information:

Disabilities Complexity Scale illustrated below:

## Disabilities Complexity Scale

Health conditions (C)



Family-reported issues (F)



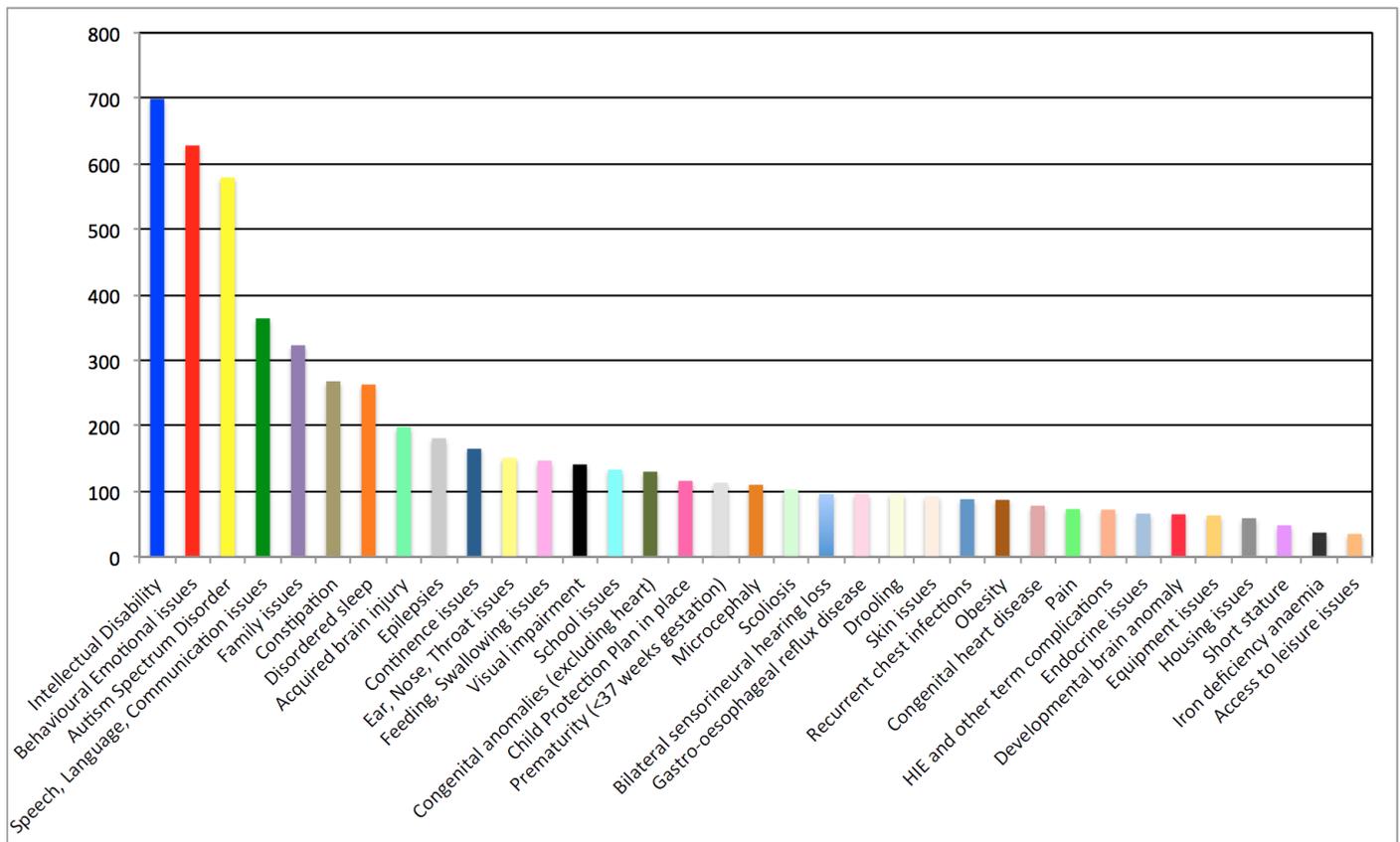
Technology dependencies (T)



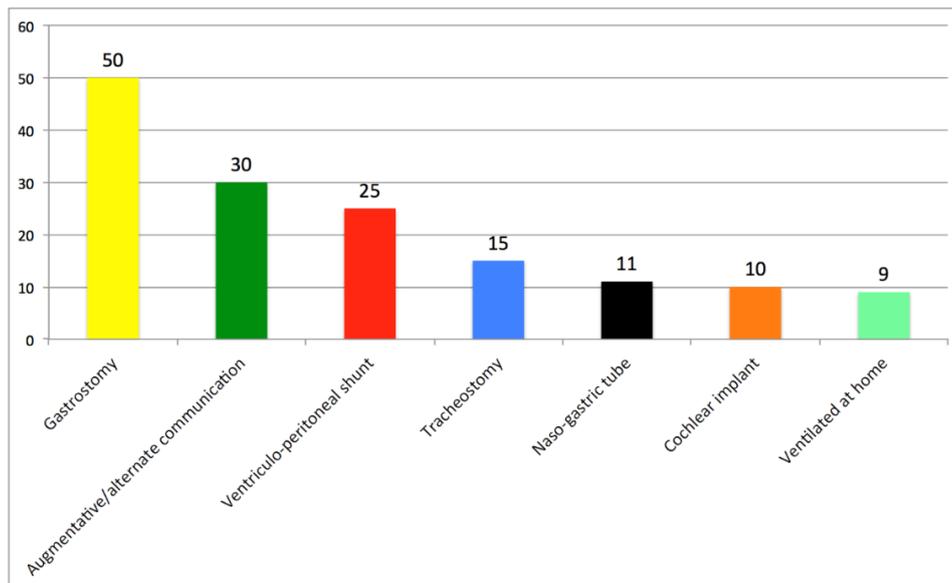
Round the clock care (or not) (R)



The 'headline' health conditions are illustrated below (based on Sunderland data 2007-2012):

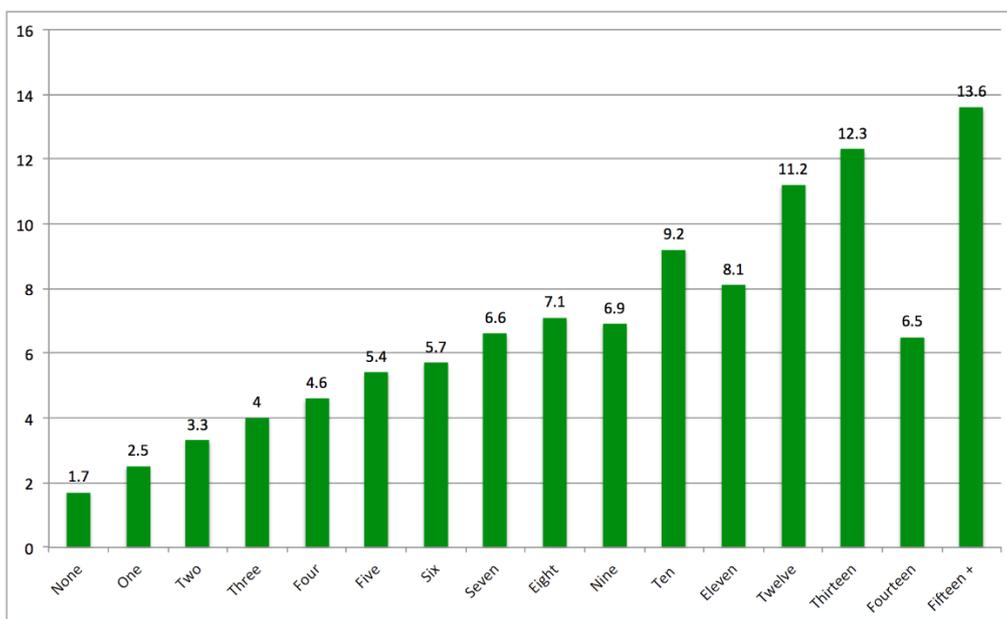


The numbers of children and young people with technology dependencies from the same cohort are represented below:



These data evidenced that the overall number of needs of a child or young person correlated strongly with the number of clinic appointments attended during the five-year time window, with a Pearson's rank correlation  $r=0.97$  ( $df=9$ ,  $p=7.224e-07$ ). Thus, simply counting up the number of needs can be used as an accurate proxy of complexity of needs, which otherwise can be a rather nebulous phenomenon.

The graph below represents the number of needs per patient along the x axis, with the number of paediatric clinic appointments in the five-year time window on the y axis:



The mean number of needs was markedly highest at 15 amongst the 21 children and young people who died during the five years, compared to other groups for whom the mean number of needs ranged from 4.4 to 9.4. This was statistically significant using the Kruskal–Wallis test ( $\chi^2=17.642$ ,  $df=6$ ,  $p=0.007$ ). Adding Intellectual Developmental Disability (IDD) to the mix of needs was found to significantly increase complexity of needs, for all groups other than those with autism spectrum conditions. Family-reported issues were more prevalent in all conditions where IDD was present, this being statistically significant for children and young people with epilepsies ( $p=0.04$ ).

## Benefits

SNOMED CT was chosen for many reasons including: it is the national standard terminology for the future in the NHS, it allows capture of much more than just diagnosis and health conditions e.g. it allows recording of all aspects relevant to person-centred care in tune with the World Health Organisation's International Classification of Functioning, Disability and Health conceptual framework (the 'ICF'). This embraces family-reported issues, technology dependencies, round-the-clock care needs, as well as affording the opportunity to capture interventions. As SNOMED CT has a structured hierarchy, that removes the burden of always having to record higher-level terms and allows analysis at different levels. Outdated terms can be 'retired' and up to date content/synonyms can be added as required within a six-month time frame (the terminology must continually develop to accommodate advances in healthcare such as genomics, stratified medicines and rare diseases).

## Standardised approach to data recording across clinical and geographical settings

Using SNOMED CT as the vocabulary ensures consistency, so data from different settings may be accurately compared. Data collection by paediatricians at the point of care in a range of clinical settings using the DTS has been conducted and [published](#). Hospital trusts and community clinics in England (Newcastle upon Tyne, Sunderland, Durham, Blackpool, Leeds, Bolton, Wigan, Liverpool, Sutton-in-Ashfield, Nottingham, Sandwell, Harrow, Winchester, and Brighton) have participated in a wider study. This was to enable subgroup comparison of children and young people with the same or different conditions across different geographical areas and to validate the Disabilities Complexity Scale against other tools, including the Gross Motor Function Classification System, levels of epilepsy

severity defined in NICE guidance and levels of intellectual developmental disability defined in ICD-10. The number of health conditions, family-reported issues, technology dependencies, and need for round-the-clock care were thus compared with respect to: gross motor function for children with cerebral palsies; severity level for those with epilepsies or intellectual developmental disabilities respectively. The study demonstrated that counting numbers of needs per child or young person is a useful method for quantifying complexity that correlates accurately with other validated scales of functioning.

Most paediatricians reported that data collection did not affect the running or flow of clinics. The benefits of comprehensive data collection and defining complexity at a population level were reported as quality assurance, facilitation of audit, definition of workload, accurate local service planning and resource allocation as well as to inform commissioning. It was noted that careful quality assurance of data recording and reporting over time will mitigate against over-reporting as a means of attracting more resources. Clinicians also reported that the data collection process often prompted them to consider further tests and ensure they used current accepted terms. For example, some children with a diagnosis of Down's syndrome were recorded as having 'learning difficulty' rather than intellectual developmental disability or learning disability, whilst others were not recorded as having any learning difficulty or intellectual disability at all. It may be possible in future, with bigger data sets, to use such under-reporting to quality check the validity of data from districts or clinicians.

Because the DTS is small, it is possible to use it with a rudimentary EPR or even to collect the data on paper. There is an urgent need for developers of all electronic medical record systems to link with the clinicians who

will be using them, to ensure that easy-to-use interfaces are developed, to make data capture just as easy to manage as has proven possible in Sunderland. They are already provided with the system specification required, but it will only be by direct conversations that the technology-savvy developers will fully understand what is needed by the busy clinician who cannot afford time-consuming data entry processes that require screen hopping or multiple password entries.

Evidence provided from this work has influenced the design of the new Community Services Data Set. Where data is collected in England, NHS providers are mandated to report data to NHS Digital. This will allow comparisons between different areas, resulting in atlases of variation of needs and health care.

## Service provision improvements

In Sunderland, where data has been collected by the disability paediatricians for some time, it has already been used to support business cases for additional disability paediatricians and therapists. Knowing the numbers of children and young people presenting to the service with possible autism diagnoses acted as a driver to expand the number of specialist speech and language therapists in the autism diagnostic team, which resulted in achieving timely throughput to diagnosis (or not), in line with NICE guidance.

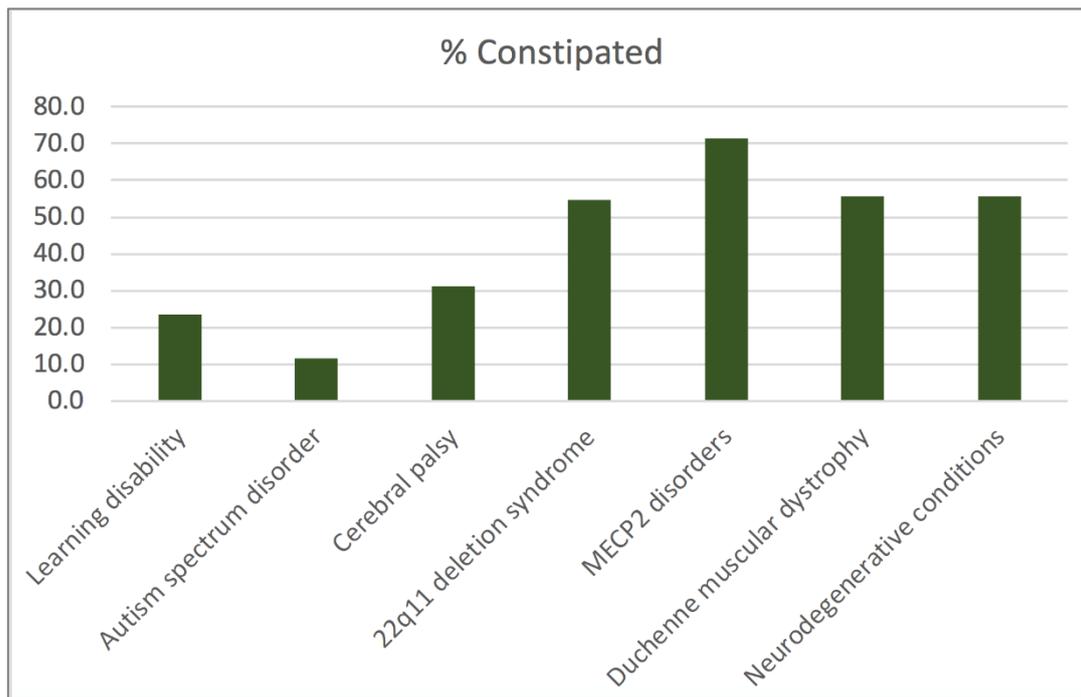
Understanding the importance of identifying children and young people with intellectual developmental disability or learning disability acted as a driver to improve this further, using the Commissioning for Quality and Innovation (CQIN) framework to increase the numbers of children and young people's electronic medical records that were appropriately flagged to indicate their IDD. A templated letter simultaneously sent to the patient's general practitioner acted as a prompt for

those with IDD to be added to practice learning disability registers, in order to underpin access to the enhanced service of annual learning disability health checks from 14 years onwards, as well as annual influenza immunisations. Between January 2015 and May 2018, 711 children and young people have had their electronic medical records flagged and their GPs have been informed about their identified learning disability. In future when other areas are doing the same, the uptake of GP learning disability enhanced service health checks from 14 years onwards could be used as an outcome measure of a quality service.

Quantification of the correlation of the burden of barriers to participation and quality of life reported by families to level of complexity of children's and young people's needs and issues has proven useful for service design and development, including the establishment of combined paediatric, orthopaedic and physiotherapy postural management clinics that reduce the amount of school missed by offering a one-stop shop service rather than multiple different clinic appointments.

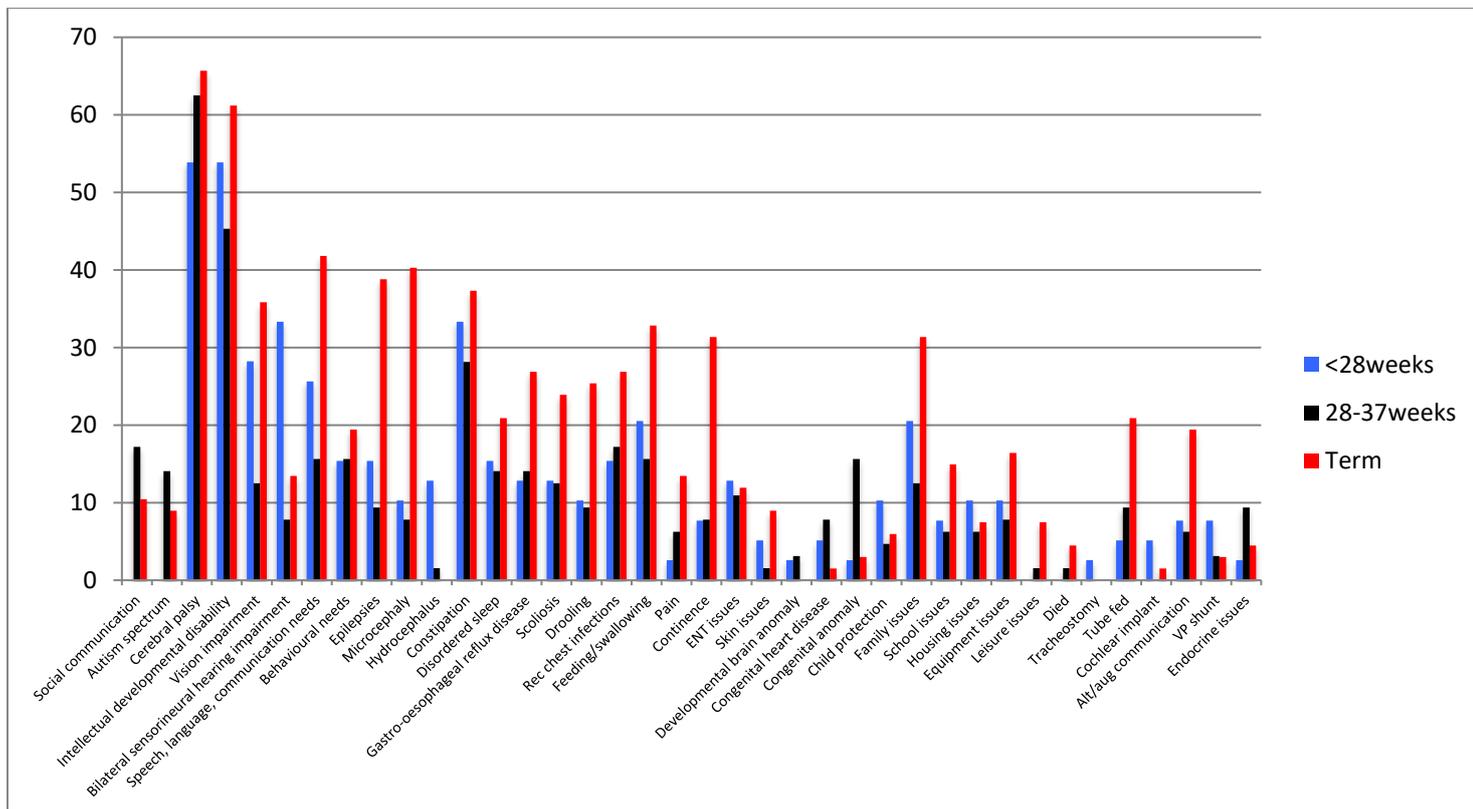
Data-driven, evidence-based information is also being used to underpin a range of audits and the redesign of care pathways. From November 2016, the whole paediatric department have been capturing data using the same DTS. This provides a rich dataset for secondary uses, including reporting to the CSDS, also for various audit projects as well as to inform Sunderland's Joint Strategic Needs Assessment. The latter had previously been based on data extrapolated from limited national data projections, now informed by real data from the local population. A number of Student-Selected Component medical students have undertaken projects that would not have been possible without these data, including: 'Constipation: are we managing it NICEly?', which was presented as a poster at the European Academy of Childhood Disability meeting in 2013.

The figure below illustrates how rates of constipation can be presented by primary diagnosis, based on Sunderland data.



“Timely diagnosis of disabling conditions in graduates of Sunderland’s Neonatal Intensive Care Unit”, undertaken in 2018, compares our local practice to NICE guideline 72. The latter project is acting as a catalyst for discussions with the neonatologists in Sunderland, about how in future it will be possible to generate outcome data in terms of the needs profiles of graduates of the neonatal intensive care unit.

The figure below is based on data collected at the point of care 2007-2012.



## Informing clinical care

Defining and recording the complexity of an individual child's needs at a point in time using SNOMED CT terms allows changes in complexity over time to be documented in a consistent way. One aspect may improve with time, for example 'constipation' may change from an 'active concern' to 'quiet on treatment', while another aspect may become symptomatic, for example epilepsy or pain.

Profiling subsets of children with specific conditions informs clinical care, by prompting families and clinicians to proactively seek out known associations, identify them early, and manage them in a timely way, to achieve better outcomes. Where there are family-reported issues, the paediatrician can advocate on behalf of the family, for example with supportive letters about housing or timely provision of appropriate equipment.

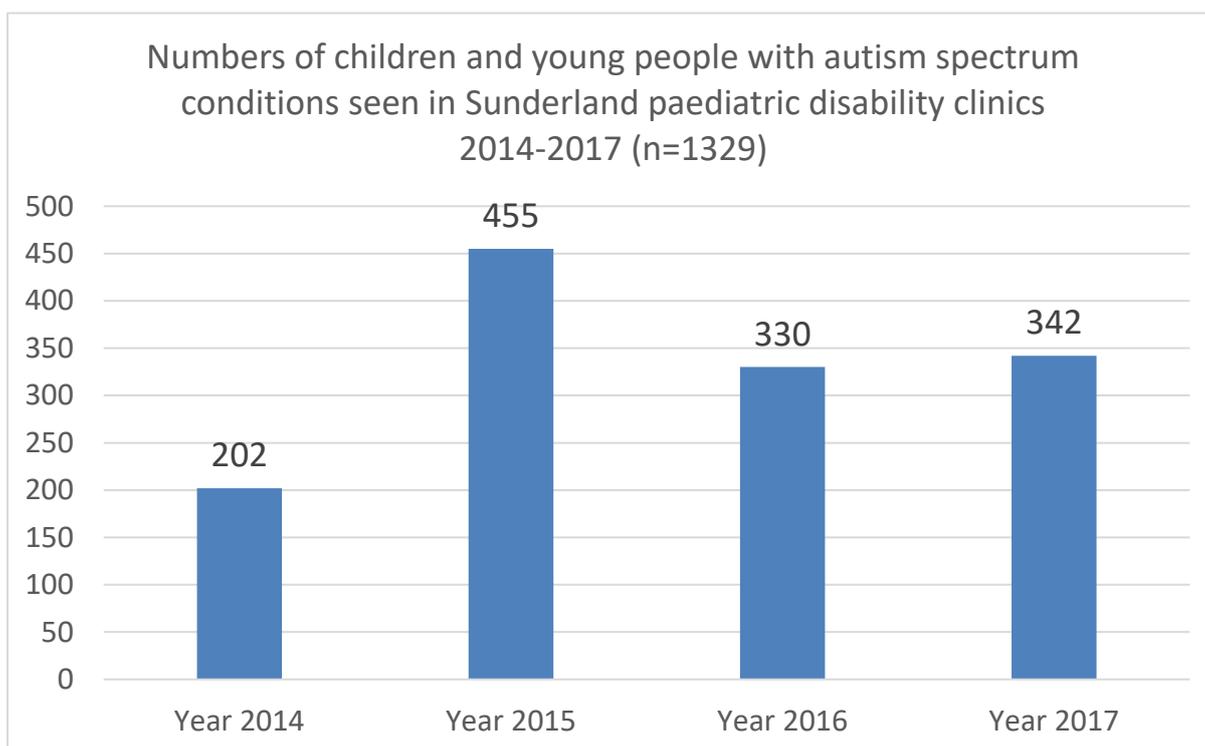
How many children do you see?' and, 'What clinical and other issues do they and their families face?' These data informed the

creation of sufficient capacity in the joint postural management clinics (disability paediatrician, orthopaedic surgeon, and physiotherapist) and expansion of the specialist speech and language therapy service to meet the needs of those referred on the autism assessment pathway.

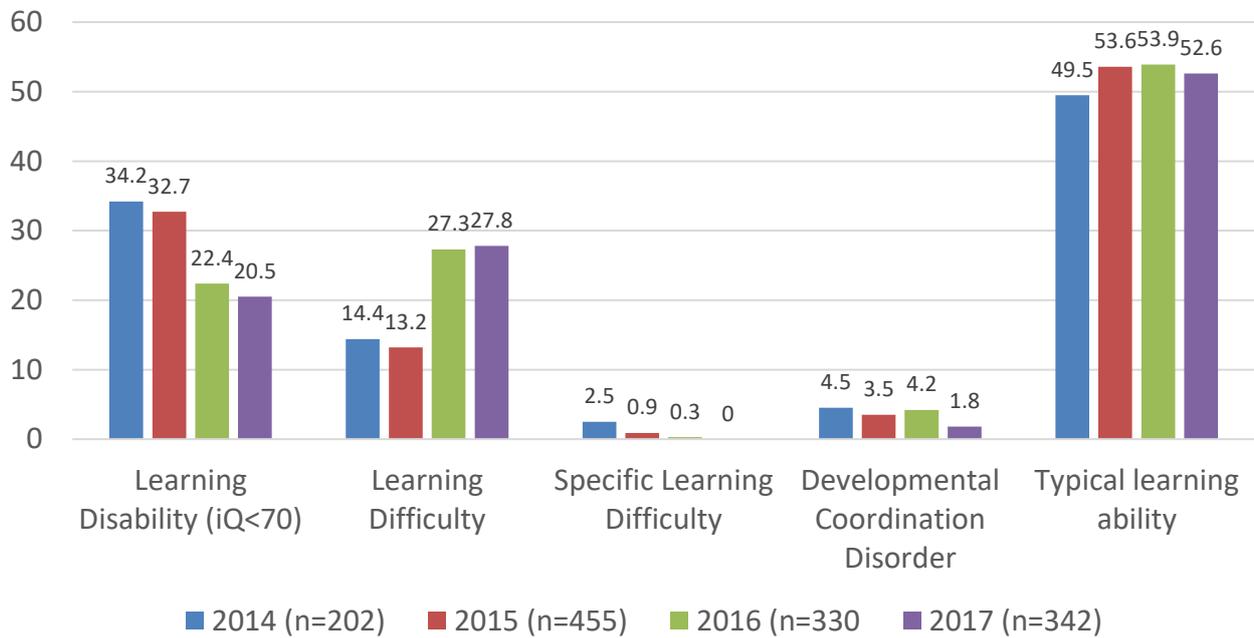
Equipment issues were frequently highlighted as concerns by families. This information was shared with Sunderland's Interagency Strategic Partnership for Disabled Children and Young People, who initiated a review with subsequent significant improvements.

Prospective data collection for a clinic population over time will allow mapping of needs including those of specific subpopulations. Knowing how many children are dependent on specific technologies or have specific needs in the preschool population will, permit planning for their needs to be met in early years, educational settings and subsequently on transition to adult services.

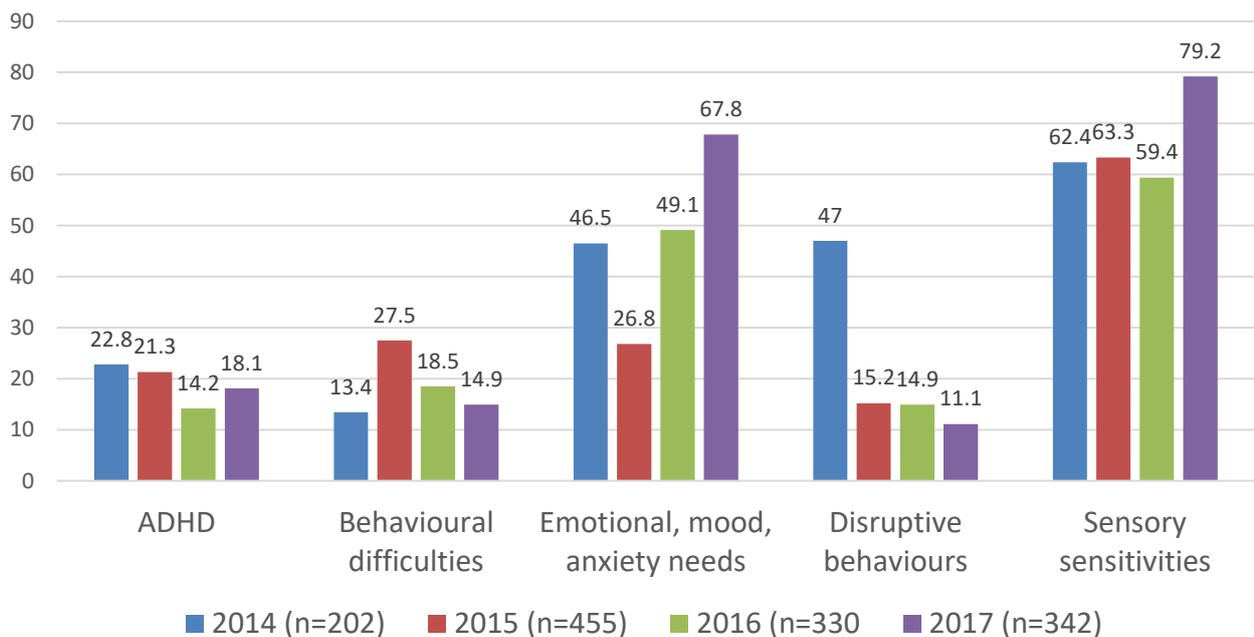
Data outputs from the routinely collected data in Sunderland are below, using children and young people with autism spectrum conditions as examples:



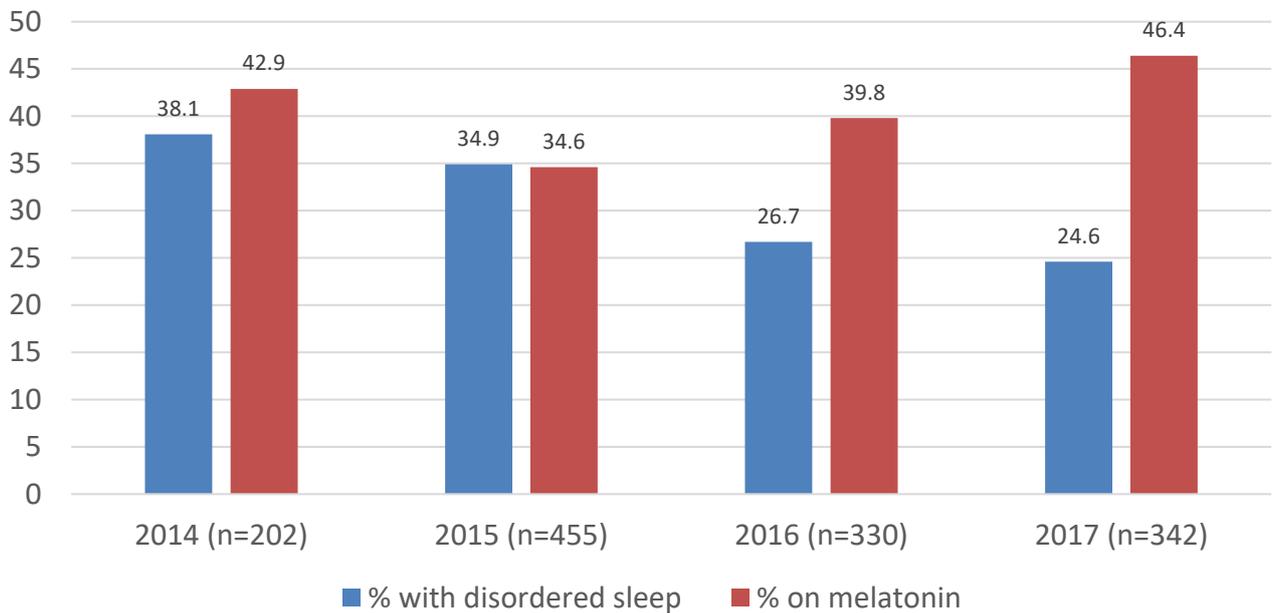
Learning needs (percentages) of children and young people with autism spectrum conditions seen in paediatric disability clinics 2014-2017



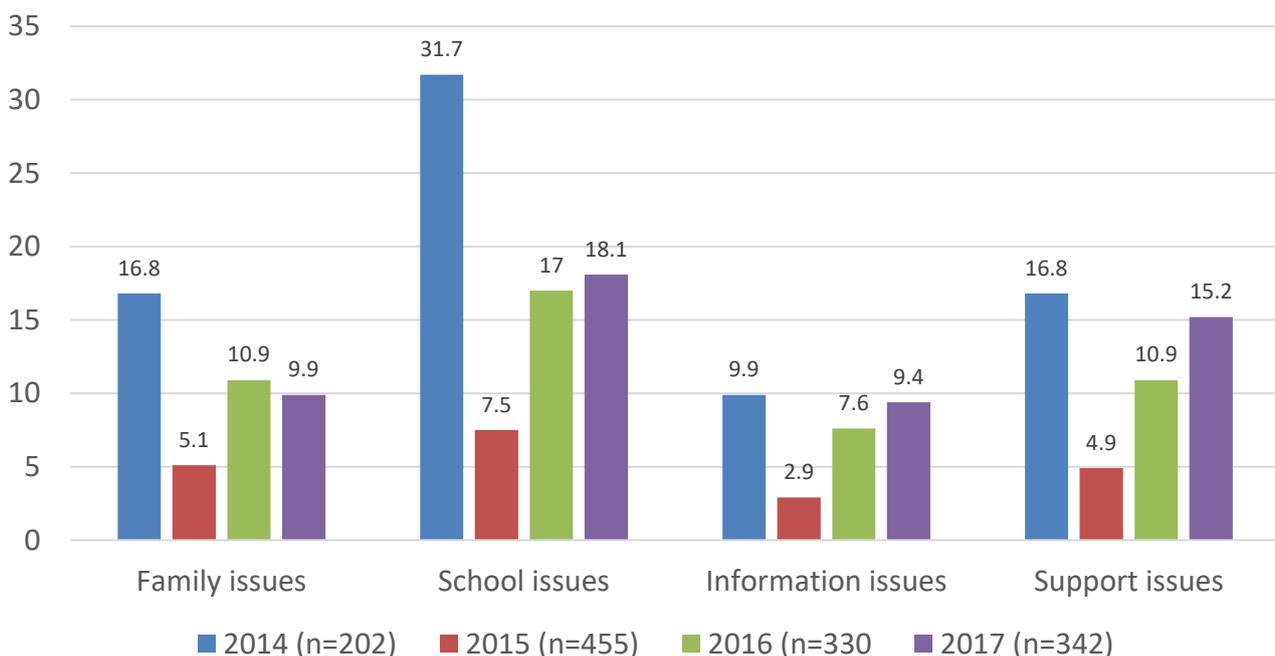
Emotional and Behavioural needs (percentages) of children and young people with autism spectrum conditions seen in Sunderland paediatric disability clinics 2014-2017



Percentage of children and young people with autism spectrum conditions and disordered sleep, including percentage prescribed melatonin, Paediatric disability clinics 2014-2017



Percentage of family-reported issues. Children and young people with autism spectrum conditions seen in Sunderland paediatric disability clinics 2014-2017



## A new approach to community healthcare funding

The SNOMED-CT subset that represents the paediatric disability terminology set and associated complexity scale is now the basis of a community healthcare currency model. The model was designed by a group of clinicians, chaired by Claire Lemer Associate National Clinical Director for CYP in 2017-18. The work is led by NHS England and supported by the National Casemix Office at NHS Digital and NHS Improvement. The currency model forms part of a wider programme to establish new approaches to payment for community services. The aims of model are to present a person-centred approach that encourages the delivery of better outcomes and experiences for patients their families and carers and the professional staff that support them, leading to outcome-based commissioning. Testing of the

currency model begins 2018 and will use the nationally mandated Community Services Data Set to collect relevant data. Further information is available from NHS England [england.communitycurrencies@nhs.net](mailto:england.communitycurrencies@nhs.net)

## Challenges and lessons learned

The development of a speciality terminology set like the DTS requires a collaborative effort from professional colleges, clinicians, allied health professionals, patient representatives and the guidance and support from a professional clinical terminologist. Sets require maintenance and review by an expert clinical reference group from a clinical perspective on an annual basis. The Royal College of Paediatrics and Child Health has produced guidance to encourage other subspecialty groups to develop their own Terminology Sets.

*Case study produced by NHS Digital in conjunction with the City Hospitals Sunderland NHS Trust and NHS England*

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