Institution: University of Sunderland

Unit of Assessment: 11 Computer Science and Informatics

Title of case study: The Disabilities Complexity Scale resulted in new clinical posts, improved service design, and ensures disabled teens receive timely palliative care

Period when the underpinning research was undertaken: 2014-16

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Kenneth McGarry	Associate Professor in Computer Science	1996-present

Period when the claimed impact occurred: 2015-December 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact (indicative maximum 100 words)

A study of disability complexity by the University of Sunderland in collaboration with Sunderland and South Tyneside NHS Trust produced a Disabilities Complexity Scale (DCS) which quantifies, for the first time, the complexity of disabled children's needs. The DCS has been used in Sunderland's paediatric disability service since 2015 and was rolled out across the Paediatric department in 2016. The DCS informs NHS decision making, resulting in a doubling of senior clinical staffing in the paediatric disability service, as well as improved clinical care and service design. The DCS is used by clinicians supporting disabled teenagers to identify appropriate pathways to transition from paediatric to adult care, and by GPs to ensure disabled teenagers receive timely palliative care.

2. Underpinning research (indicative maximum 500 words)

This case study describes the impact of McGarry's research in data mining and knowledge discovery. Specifically, the impact arises from a statistical model of disability complexity created by McGarry as part of a collaborative project on the multifaceted needs of disabled children and young people, led by Sunderland and South Tyneside NHS Trust (then City Hospitals Sunderland NHS Trust). This work, presented in **R1** and **R2**, builds upon the foundations of a body of work, led by McGarry, that explores medical and biostatistical information using computational techniques including machine learning, clustering and inferential statistics to construct statistical models for prediction and interpretation.

Understanding of the multifaceted needs of disabled children has been hampered by the absence of quality patient data. Without such data, service planning and resource allocation lack accuracy, an issue that must be overcome to meet needs and reduce inequalities in access to best outcomes. The project aimed to produce a tool that could be used to measure multifaceted needs by (1) creating a Disability Terminology Set (DTS) that incorporates both clinical symptoms such as seizures, and environmental factors such as housing issues **[R2]**, (2), by assessing the feasibility of prospective data capture in paediatric clinics using the DTS **[R1],** and (3) using the DTS to create a complexity scale that can inform planning and resource allocation **[R2].** In this project, McGarry, as Co-Investigator, performed all statistical modelling work and designed the Disabilities Complexity Scale (DCS). He found that complexity could be measured based on the sum of overall needs calculated for each child, from the sum of health conditions, technology dependencies, family-reported issues, and the need for round-the-clock care. McGarry tested the validity of the DCS against existing validated scales of functioning, including the Gross Motor Function Classification System, levels of epilepsy severity defined in NICE guidance, and levels of intellectual development defined in ICD-10 **[R1]**. The DCS, being linked to a ring-fenced terminology set, is location-agnostic and can therefore both facilitate comparisons across populations, and document changes over time for individual children even if they relocate and receive treatment elsewhere. Fundamentally, the DCS means that the multifaceted needs of disabled children in the population are better understood, and that planning and resource allocation decisions can be based on this understanding.

3. References to the research (indicative maximum of six references)
R1 Horridge, Karen, **McGarry, Kenneth**, Williams, Jane and Whittlingum, Gabriel (2016) Prospective pilots of routine data captures by paediatricians in clinics and validation of the disability complexity scale. *Developmental Medicine and Child Neurology*, 58 (6). pp. 12-19. ISSN 1469-8749.
R2 Horridge, Karen, Harvey, Carl, **McGarry, Kenneth**, Williams, Jane, Whittlingum, Gabriel, Busk, Mary, Fox, Suzanne, Baird, Gillian and Spencer, Andy (2016) Quantifying multi-facted needs in a district disability clinic population: analysis of data captured at point of care and development of a disabilities terminology set and disabilities complexity scale. *Developmental Medicine and Child Neurology*, 58 (6). pp. 570-580. ISSN 1469-8749

Quality indicators
Both references are peer-reviewed articles in a Q1 journal in the field. Both received positive reviews in a commentary in *Developmental Medicine and Child Neurology*, noting that the tool presents "a very promising approach." **R2** was selected as Editor's Choice in the issue.

Details of the impact (indicative maximum 750 words)
This research, and in particular McGarry's expertise in creating medical statistical models, has had conceptual, capacity-building and instrumental impacts that benefit disabled children and young people, their families, and clinicians who treat them. This has been achieved through the creation of the Disabilities Complexity Scale (DCS), a statistical model designed by McGarry **[R1, R2]** that enables clinicians to quantify, for the first time, the complexity of disabled children's needs, based on data gathered using the Disabilities Terminology Set **[R2]**. Since 2015 the DCS has been used by providers and users of the South Tyneside and Sunderland NHS Trust specialist paediatric disability service **[S1]**, which serves a population of approximately 70,350 children aged 0-19 years across Sunderland, South Tyneside and County Durham. Within this population, all-cause mortality rates, life expectancy, and the proportion of children living in poverty are all significantly worse than average for England **[R2]**. The tools were rolled out across the entire paediatric department in 2016. Since 2019 the DCS has been used by GPs and Learning Disability clinicians to ensure disabled teenagers transition to appropriate adult services, and receive timely palliative care **[S2, S3]**.

Multi-faceted needs are now systematically identified at point of care
At the time of the research, 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, as the National Confidential Enquiry into Patient Outcomes and Deaths revealed, existing data collection did not provide the necessary breadth or depth of detail, resulting in a dearth of data about disabled children and young people and their multifaceted needs. As recording tools, the DTS and DCS allow clinical commissioning groups to both understand local needs, and meet the Department of Health's imperative, for the first time **[S1]**.

NHS funding is more accurately calculated and better allocated
This absence of data and meaningful measures of disability complexity has meant that NHS funding for care is based on inappropriate proxies. The precursor scale, based on the Rehabilitation Complexity Scale, reflects the number of professionals in an individual's multidisciplinary team. The model is flawed because financial pressures, such as those that were imposed by austerity measures, may mean that the size of a team reflects those pressures rather than the needs of a given patient. In this way, financial imperatives mean that team size may no longer act as a reliable proxy for disability complexity, and result in miscalculation and misallocation of NHS funding. Since patient needs are not determined by economic pressures, a patient-focused measure like the DCS means that complexity is an independent variable that can be used to calculate what resources are needed **[R2]**.

The specialist paediatric disability service has greater capacity

Evidence of the complexity of patients' needs, quantified using the DCS, supported a business case to create posts for a paediatric neurodisability consultant and an orthopaedic surgeon, thereby doubling service staffing, from 2 to 4 senior clinicians **[R2, S1]**. The same evidence underpinned investment to expand speech and language therapy provision for autism diagnosis. This has resulted in achieving timely throughput to diagnosis (or not) in line with NICE guidance, and accelerated access to appropriate support **[S1]**.

Clinical care and service design has improved
The research has changed clinical care processes, prompting families and clinicians to proactively seek out and identify known associations between needs at an early stage, to allow prompt management and better outcomes **[S1]**. Patients and their families now complete a traffic light summary of health, functioning and wellbeing issues in the waiting room, and clinicians record this and any other information arising in the appointment in the patient's electronic medical record. Patients and their families welcome this person-centred approach, saying it helps them to prioritise concerns ahead of seeing the clinician, enabling them to ensure the issues that matter most are addressed. Clinicians have reported that recording data as part of the point of care has prompted them to consider further tests and ensure they use currently accepted terms.

The DCS has enabled the service to understand the relationship between barriers to participation and quality of life, and complexity of children's needs. As a result, the service now provides a combined paediatric orthopaedic and physiotherapy postural management clinic. This 'one-stop shop' model removes the need for children to attend multiple different clinic appointments, thereby reducing the amount of school missed by children and young people. The Consultant Paediatrician who led the project says "*families really value this person-centred and family-centred approach*" **[S4]**.

Transition between paediatric and adult services has improved
The DCS is used to improve disabled teenagers' transition between paediatric and adult services in two ways:
1. GPs in Sunderland and South Tyneside use the DCS to ensure teenagers with neurodisabilities receive palliative care at the right time. Advances in medicine mean that teenagers increasingly transition from paediatric to adult services, which are managed by the GP; however, each year between 4 and 8 teenagers die during transition in this area. During this time, it may not be obvious to the GP that a patient requires palliative care. To overcome this, GPs input patients' symptoms into a DCS calculator to establish whether they may need to refer the patient to a hospice, or otherwise initiate preparations with the patient and their parents **[S3]**.
2. The Northumberland and Tyne and Wear Learning Disabilities (LD) team use the DCS to ensure that teenagers transition to appropriate services. Teenagers' needs are quantified using the scale, and those with the most complex needs are transitioned in a shared pathway with palliative care consultants and the LD team (typically 5 teenagers per year). Teenagers with less complex needs (approximately 20 teenagers per year) are transitioned to neuro-rehabilitation services, overseen by the LD team. Those with least complex needs transition to GP-led service with oversight by the LD team **[S2]**.

5. Sources to corroborate the impact (indicative maximum of ten references)
S1 NHS Digital Case study on use of SNOMED CT in Paediatric Disability Service, City Hospitals Sunderland
S2 Blog post by Associate Specialist in Palliative Medicine for Together for Short Lives https://www.togetherforshortlives.org.uk/teenagers-matter
S3 Contact details for Divisional Director, South Tyneside and Sunderland NHS Foundation Trust
S4 Written statement of support from Consultant Paediatrician (Disability), City Hospitals Sunderland