Population child health: understanding and addressing complex health needs

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ABSTRACT

Advances in paediatric care mean that more children with complex medical problems (heart disease, neurodevelopmental problems and so on) are surviving their early years. This has important implications for the design and delivery of healthcare given their extensive multidisciplinary requirements and susceptibility to poor outcomes when not optimally managed. Importantly, their medical needs must also be understood and addressed within the context of the child and family's life circumstances. There is growing recognition that many other factors contribute to a child's complex health needs (CHNs), for example, family problems, fragmentation of health and care provision, psychological difficulties or social issues.

To facilitate proactive care for these patients, we must develop accurate ways to identify them. Whole Systems Integrated Care—an online platform that integrates routinely collected data from primary and secondary care—offers an example of how to do this. An algorithm applied to this data identifies children with CHNs from the entire patient population. When tested in a large inner-city GP practice, this analysis shows good concordance with clinical opinion and identifies complex children in the population to a much higher proportion than expected. Ongoing refinement of these data-driven processes will allow accurate quantification and identification of need in local populations, thus aiding the development of tailored services.

INTRODUCTION

Demands on child health services have changed dramatically in recent decades, challenging healthcare to adapt.[1] Given reduced mortality rates, many children and young people (CYP) live longer with conditions previously fatal in childhood.[2] Subsequently, a greater proportion of the childhood population have complex health needs (CHNs).[2–4] The Royal College of Paediatrics and Child Health 2040 Project and National Health Service (NHS) Long Term Plan acknowledge the challenges of improving care for these patients and stress the need to develop new, innovative systems that improve coordination and focus on personalised, preventative medicine.[5 6]

New models of integrated care are already being developed and are particularly suited to CYP with CHNs, who require multiple-specialty inputs and new technologies and who find access challenging.[7] Integrated care tries to tackle these issues, offering increased contact, proactive support and holistic care rather than fragmented episodic encounters.[8] However, unless we can accurately identify these children in the local population, these services cannot be used. Here we consider what complexity really means, discuss one possible way of seeking out these children and look at next steps for adopting similar approaches at scale.

WHAT ARE COMPLEX HEALTH NEEDS?

Various terms exist to define complexity: 'medically complex children',[3] 'special healthcare needs',[9] 'complex chronic conditions'[10 11] and more. Complexity can also be considered from numerous endpoints: economic,[10] clinical[11] or family impact,[3] with the current NHS definition concentrating predominantly on medical criteria.[12] However, these isolated definitions risk too narrow an approach. Experience has shown that CYP themselves and many clinicians often view complexity as an interplay of medical, psychological, emotional, social and environmental factors. Thus, there is a need to develop a broader, universally accepted definition.

One way of achieving this is by considering the overall consequences for these children of their illness or social circumstances, in combination with the input they require from healthcare and allied services. The US Maternal and Child Health Bureau define this cohort as 'those with increased risk of chronic physical, developmental, behavioural or emotional conditions, requiring healthcare and related services of a type or amount beyond that required by children generally'.[13] Cohen *et al*[4] state that these children 'require extra time, expertise and resource to achieve optimal health outcomes', also highlighting the importance of non-diagnostic factors, including family service need, healthcare usage data and children's functional limitations.

IDENTIFYING THESE CHILDREN

To implement change, both individually and on service level, these children first need to be identified. Linked data sets, for example, Whole Systems Integrated Care (WSIC)—an online platform collating routinely collected data from primary and secondary care, mental health and community services—can facilitate this.[14] WSIC used iterative, structured design sessions with a multiprofessional team to create a logic sequence that identifies CYP with complex health needs from the overall WSIC data lake (figure 1).

This logic was tested in a large inner-city GP practice for concordance with the clinical opinion that the child identified would benefit from proactive

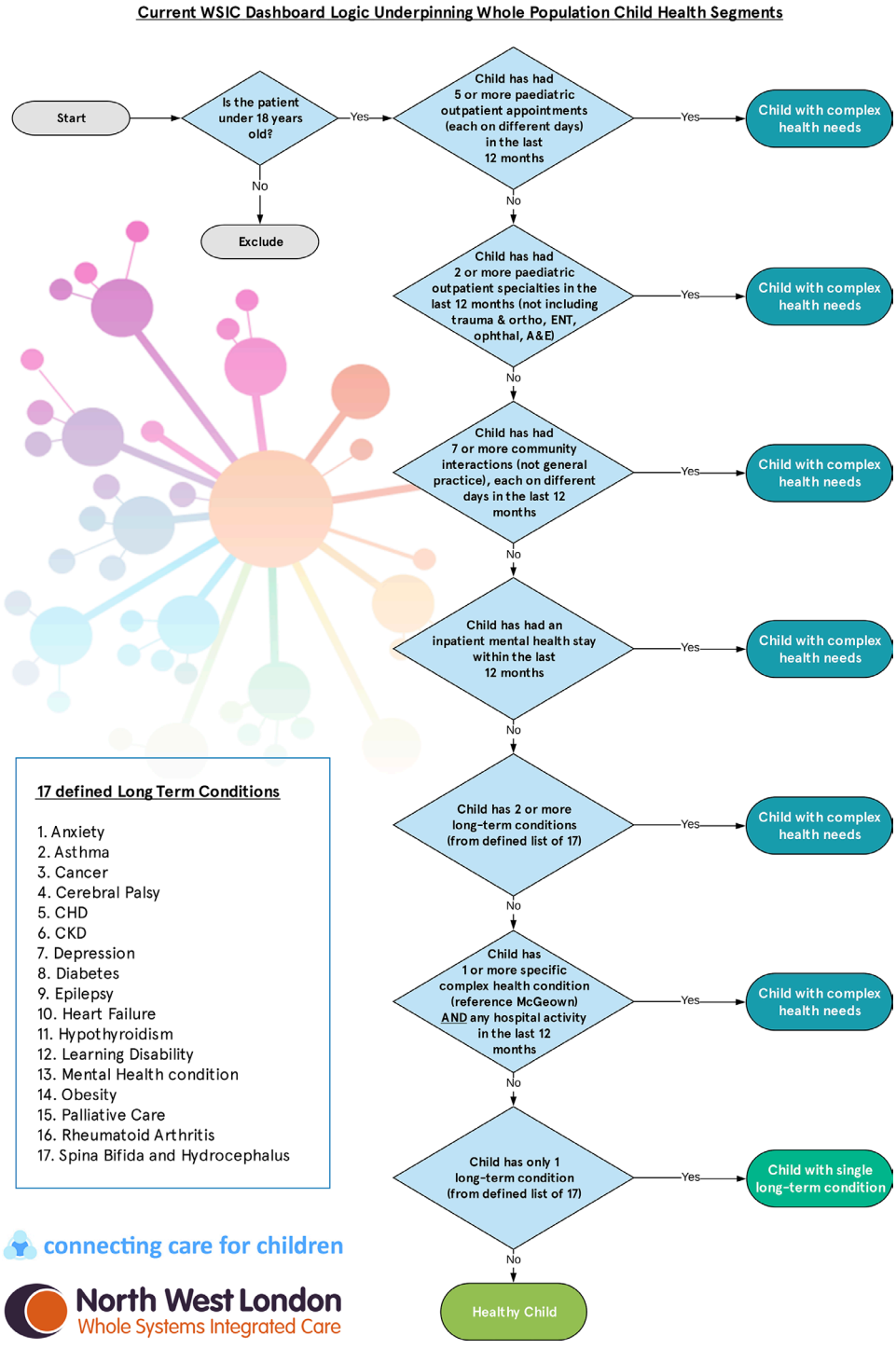

Figure 1 WSIC logic sequence used to identify children with complex health needs (CHNs). WSIC, Whole Systems Integrated Care.

multidisciplinary team (MDT) care (figure 2). This showed good agreement between WSIC-identified children and clinicians (65%) and confirmed ease of use. Additionally, it revealed pertinent insights for the practice (figure 3) showing that:

- 77.1% of registered children were mostly healthy.
- 5.6% had a single long-term condition (LTC).
- 17.2% had CHNs.

The unexpected finding of having over three times more children with CHNs than with single LTCs highlights that children with complexity are not always clinically apparent. Even clinicians who set out to have a broad overview (GPs, mental health professionals or general paediatricians) can miss the complete picture. Worryingly, this means that some CYP with CHNs are unintentionally overlooked. Unbiased systems like WSIC will minimise this cohort. While clinicians may underidentify complexity, the WSIC logic is deliberately designed to be broad; it flags children who *may* have complex needs, to be determined by further clinical scrutiny.

NEXT STEPS AND FUTURE IMPLICATIONS

The current WSIC logic takes a holistic approach to complexity, built largely around activity and not outcome data. Insights from activity data can vary depending on country or healthcare system;

Methods

After identifying the GP practice of choice, appropriate filters were applied on WSIC to present the breakdown of registered children at the practice (based on the decision-tree model demonstrated in Figure 1). Every other child included on the WSIC complex health needs (CHNs) 'watch-lists' was selected (regular in-patient users/recent did not attends/regular A&E visits/care plans out of data). These children had their primary care records examined and they were subsequently categorised as 'Yes', 'Maybe' or 'No' with regard to demonstrating clinically apparent CHNs. This was done firstly by a paediatric trainee (KA), then reviewed with a consultant paediatrician (MW). Any discordance was discussed until agreement was reached. Given the lack of consensus definition for CHNs, and the setting in which this work was conducted, a child with CHNs was clinically defined as:

- One with needs beyond those that a GP and single paediatric consultant would feel comfortable managing in partnership OR
- CYP with significant co-ordination and/or wider needs in addition to purely medical ones who would benefit from broader MDT care

Results

1541 children were registered at the time. WSIC group segmentation showed (Figure 3):

- 1188 (77%) were mostly healthy
- 87 (5.6%) had a single LTC
- 266 (17.2%) were considered children with CHNs

Of the 23 children whose records were reviewed, 15 received either a 'Yes' or 'Maybe' (65%) and 8 (35%) received a 'No'. Examples of each:

Clearly complex – 'Yes'	Possibly complex – 'Maybe'	Not obviously complex – 'No'
Severe eosinophilic asthma under care of specialist cardiothoracic hospital, on medolizumab	Congenital cataracts and knee swelling. Juvenile idiopathic arthritis has been considered but no formal diagnosis	Mild speech and language issue. Coded as complex due to >7 community interactions in last 12 months (Figure 1)

Interpretation

There was a reasonable level of agreement between WSIC-identified children and clinical opinion (65%). If this were extrapolated to the entire 266 children in the CHNs group, it suggests that within one large GP practice there may be over 170 children with CHNs. When considering the 35% of children who were described as complex by WSIC but not by clinical review, it is pertinent to note that there was deliberate intention to make the WSIC logic sequence as sensitive as possible. The ultimate aim of this approach is to use the system as a possible marker of CHNs, thus prompting further clinical scrutiny and minimising the chance of children being missed. Specificity was not assessed here however a crude way of achieving this would be asking GPs to raise complex cases that WSIC did not pick up. Formal specificity testing would likely require analysis of all childrens' case notes at the practice, which was outside the scope of this exploratory work. Formal analysis of this system is warranted with larger numbers and in a variety of settings.

Figure 2 WSIC case study. WSIC, Whole Systems Integrated Care.

however, in European settings, children with poorer health have increased contact with health services, making activity an appropriate, helpful marker of need.[15 16] Nevertheless, the current approach does not include all contributing factors to complexity, including education, social care, family networks and household elements. Including these, plus a greater outcomes focus, would improve the impact these linked data sets have on population health.

One benefit of WSIC is that linked data on all aspects of healthcare usage can be made readily available to clinicians and policy makers (see online supplementary file 1 for examples of how WSIC presents these data). This will improve understanding of the exact needs of complex children and their families, helping guide proactive, preventative and cost-effective interventions. Examples may include:

- Better quality child care plans or 'patient passports'.
- Multiprofessional 'team around the child' annual reviews.
- Dedicated MDT time to discuss issues and interventions.
- Care coordinators/GP leads within practices.

Regardless of the intervention, the broader aims should also include opportunities to support patients and their families in managing their own complexity.

A more practical illustration is using a system like WSIC to ensure all CYP with CHNs receive the seasonal influenza vaccine. These children are more susceptible to getting influenza and more likely to warrant consequent intensive care admission.[17 18] Despite this, Public Health England data show that in 2018/2019 fewer than half of children in one or more at-risk groups received the vaccine.[19] A means of accurately highlighting at-risk children enables them to be actively sought out

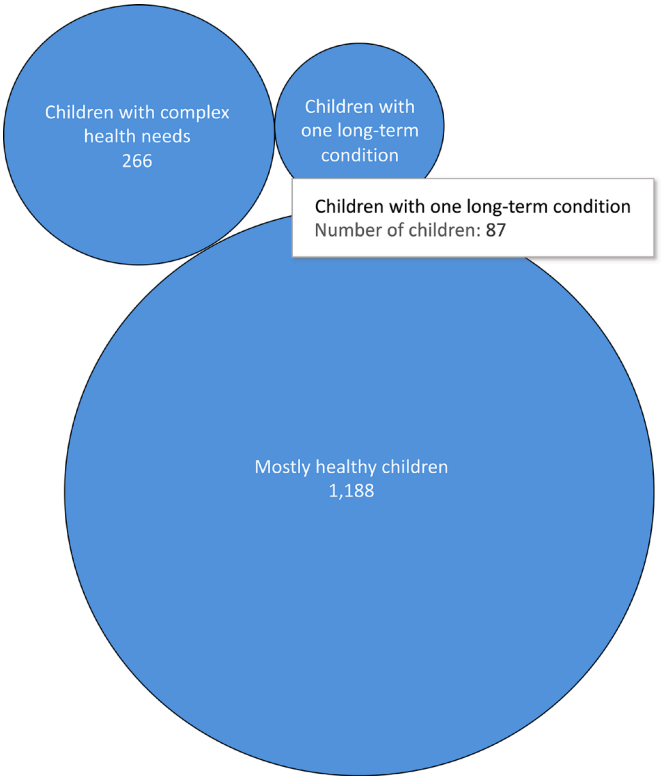

Figure 3 Breakdown of registered children at one GP practice.

for immunisation, with benefits including fewer admissions and reduced healthcare costs.

Integrated care services are attracting greater attention, with growing recognition of the benefits they can offer particular patient groups. Promising examples include ChenMed in the USA, which focuses on complex elderly patients.[20] Additionally, a successful Australian paediatric integrated care system focusing on complex children has seen reduced hospital encounters, emergency department visits and resultant cost savings.[21] The CC4C integrated care programme in London uses WSIC to target interventions for particular patient groups, for example, asthma.[22 23] These same processes are easily replicable in other settings.

Linked data sets have numerous advantages but are limited by the records from which they extract data. Horridge *et al*[24] have demonstrated tangible benefits of high-quality data recording. By interrogating historical child disability clinic letters, they have shown how diligent data coding provides accurate and up-to-date indications of local population need. Despite being based on manual records Horridge *et al*'s[24] work highlights how high-quality data can facilitate service development that is fit for purpose.

CONCLUSION

We have discussed the importance of identifying CYP with CHNs in the local population, demonstrated how database services can facilitate this and considered the challenges and benefits of using similar approaches nationwide. Understanding complexity in children and developing services that meet their needs is a growing healthcare and population challenge, but we believe this work is an important step towards achieving this. Development of these approaches has vast potential for informing service planning decisions, not least within the setting of emergent primary care networks, and could significantly impact the overall management of CYP with CHNs.

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