Linking data to build a bigger picture of paediatric referral pathways

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Urgent short stay admissions in children and young people make an important contribution to the burden on the National Health Service (NHS), and have become more common over recent decades, representing almost half of all emergency admissions for this age group.[1] These short stay admissions occur when an individual is admitted and discharged on the same day and are often related to minor conditions, particularly minor infections, asthma, epilepsy and acute tonsilitis, which could be treated outside hospital. Whilst some short stay admissions are appropriate and should be seen as a positive, especially for those who have complex conditions, avoiding unnecessary admissions not only reduces the burden on healthcare services and costs for hospitals, but could help reduce emotional distress and disruption for families, and the spread of infectious disease.

Potential drivers of the increase in short stay admissions in the UK have historically included reduced access to GP services, lack of trained paediatricians in emergency departments, and wait time targets that incentivise admission rather than longer observation times in A&E.[2, 3] More recently, the immense pressures on services following the COVID-19 pandemic have exacerbated these issues. Understanding the paediatric referral pathway is therefore key to identifying opportunities to intervene, and this was one of the aims of the FLAMINGO study, which reports findings on the proportion of short stay admissions referred by primary care, emergency departments, and out of hours services in this issue.

The paper by Dick et al highlights a major challenge for studies aiming to understand how different part of the health service work together: the lack of routinely linked up data. Whilst patients may expect that their health data are linked together to support the delivery of their direct care, the reality is very different. Processes to obtain approval for linkages are often extremely lengthy and can result in long time lags for research.[4] The data used in this study, for example, are already 5 years out of date (2015-2017). Even when approvals have been granted, data completeness and quality issues provide a number of further barriers to generating meaningful evidence.

First, data from different parts of the healthcare system may simply not be available. Between 15-20% of General Practices (GPs) in Scotland agree to share data with researchers, and Dick et al could not identify a referral source in 43% of the admissions in their study. This limits the usefulness of their analysis, as the admissions for which data were available may not be representative of the target study population. As the authors note, their findings should be interpreted with caution. The issue of missing GP data is not limited to Scotland – in England, GP data available through the Clinical Practice Research Datalink (CPRD) covers around 25% of the population, and is not all linked with secondary care data. Nor is the problem limited to GPs – consistently recorded data on health visiting contacts are also lacking.[5] This is a particularly important part of the picture given the contribution of feeding problems to short stay admissions for infants. Such conditions may be appropriately resolved outside of hospital, but may be prevented from being treated in the community due to the increasing pressure on health visiting services from increasing caseloads and reductions in workforce.[6]

Second, the processes of linking data from different parts of the healthcare system, and beyond, can provide further challenges. In this study, hospital data were linked deterministically (i.e., using a rules-based approach) based on date of admission and Community Health Index number (the CHI

number uniquely identifies patients within the NHS in Scotland). Linkage errors, where records for different patients are erroneously linked together, or where records belonging to the same patient are left unlinked, are likely to be infrequent in this setting. However, the authors note that linkage to non-health data would also have provided a fuller picture of care pathways. In settings in which unique identifiers are not available, e.g. for linkage between data from health and education or children's social care, linkage errors are concentrated in specific subgroups including those from minority ethnic groups or from more deprived areas.[7] This means that researchers need to consider the possibility of bias arising from errors in the linkage process which might impact on analysis and interpretation of results.[8]

Third, data that are available and that have been linked may be missing important details. For example, Dick et al note that information on timings of admissions and GP contacts would have provided useful context for understanding the sequence of referrals. In Scotland and England, information on diagnoses made in emergency departments is of variable quality but is critical for understanding which conditions are most likely to result in a short stay admission. Accurate information in these areas could help identify which short start admissions are appropriate, and which could be avoided.

Fourth, data that are available may not capture the relevant population for a specific research question. In order to better understand how to reduce short stay admissions, we need to determine why some children are admitted while others are not. This means we need to identify the denominator population of children who have a condition that needs to be treated (rather than the population of children with admissions), and then to explore the differences between those who ended up with a short stay admission and those who did not. Identifying this population is challenging as they may not appear in any of the available data sources.

Finally, linked data can only tell us one side of the story and do not capture patient voices and preferences. The FLAMINGO study, of which the Dick et al article was one element, also involved stakeholder engagement and qualitative interviews with parents and health professionals. This valuable work highlighted that outcomes of importance to health professionals and parents are safety, relieving anxiety, and resolving uncertainty.[9] Any interventions to reduce short stay admissions must also ensure that these priorities are being met.

Whilst data linkage studies are associated with a number of challenges, they do hold great potential for generating evidence to inform development of interventions and to inform policy and practice, and progress in opening up a wider range of linked data is being made. For example, linked GP and secondary data for the whole population in England have been made available for research into covid-19, and have been used for a range of studies on cardiovascular disease.[10] This data resource will become more valuable over time as longitudinal data are created, and would benefit the research community more widely if purposes were extended beyond COVID-19. Similarly, the ECHILD database links data from secondary care, education and social care services for all children in England and has been used to understand the complex relationships between education and health.[11] In Scotland, it has been possible to link GP data and education records to understand how engagement in schools is related to missed GP appointments.[12]

In order to fully realise the value of data linkage studies for improving services for children and families, more needs to be done to understand how best to incentivise GPs, health visitors and other services to collect and contribute high quality data, to ensure that linked data are inclusive of the whole population of interest, to establish the most effective ways of making real time linked data

available in order to overcome lags in data availability and publication, and to supplement routinely collected data with additional information that addresses the priorities of patients.

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