

Central Lancashire Online Knowledge (CLOK)

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Lighting the way: the LANTERN system for children's autism referrals to enhance triage effectiveness and navigate frontline timely support

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ABSTRACT

Objectives To evaluate the implementation and outcomes of the Layered Assessment of Neurodevelopmental Needs, Evaluation of Referrals and Navigation of support (LANTERN) triage system developed to improve referral quality, reduce unnecessary delays and enhance support for children referred for autism diagnostic assessment.

Design Service improvement informed by action-based methodology and clinical audit, employing descriptive analysis of administrative and outcome data.

Setting A UK National Health Service community paediatric service covering 59 000 children aged 4–16.

Participants All referrals to the neurodevelopmental pathway for autism assessment from April 2019 to March 2025.

Intervention The LANTERN system incorporates senior diagnostician-led triage, expanded evidence review and detailed guidance for families and referrers.

Main outcome measures Referral volume and acceptance rates, rates per 1000 population, patient experience via friends and family test and cost-effectiveness.

Results Referral rates fell 25% over 5 years, and acceptance rates dropped from 79.6% (2019–2020) to 61% (2024–2025), compared with 92% in the wider region. LANTERN achieved a local referral rate of 4 per 1000 versus 33 system-wide. 'Good' or 'very good' family satisfaction rose from 35% to 95%. The system incurred an annual cost of £58 695 but avoided £96 025 in assessments not indicated, yielding a net saving of ~£37 330.

Conclusions The LANTERN system reduced assessments not indicated while improving family satisfaction and support for children, families and referrers. A senior-led, evidence-informed triage can enhance quality and efficiency in the autism diagnostic pathway.

BACKGROUND

Trends in autism diagnosis are clear and broadly consistent globally, with exponential increases over the last 30 years.¹ In the UK, over a 20-year period, this represents an eight-fold increase² with 1.76% prevalence among a 7 million whole sample of English school children in 2021.³ Within the USA in 2022, the

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Autism diagnostic services in the UK face unsustainable referral volumes, long waiting times and limited support for children awaiting assessment.

WHAT THIS STUDY ADDS

⇒ The 'Layered Assessment of neurodevelopmental Needs, Evaluation of Referrals and Navigation of support' (LANTERN) triage system reduced referral and acceptance rates, increased satisfaction and delivered cost savings by enhancing evidence review and support at the point of referral.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Senior clinician-led triage with structured evidence gathering may offer a scalable model to improve diagnostic efficiency and early support across neurodevelopmental pathways.

prevalence in children between 5 and 8 years old is 3%,⁴ suggesting this trend will continue to increase in the UK and other countries.

Within the UK National Health Service (NHS), waiting numbers and times have increased dramatically. The National Institute for Health and Care Excellence (NICE)⁵ and NHS England set a standard for first clinical contact (in any form by a clinician skilled in autism) on an autism waiting list within 13 weeks of referral, but this is now achieved in just 5% of patients nationally, with over 145 000 open referrals for children under 18 in December 2024.⁶ This has been caused by a sustained increase in referrals, which have trebled in children over the last 5 years.⁶

Such an increase in demand produces a barrier to diagnosis from the pure volume of children needing assessment, but there are perhaps more important barriers to consider. Research from the USA suggests the use of a correct and appropriately complex diagnostic journey itself is vital in producing positive outcomes,⁷ and this may be more important



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than the speed of accessing an assessment, but in turn further impacts the ask on services and the time taken to get a diagnosis. It may be that in some cases, delays cannot be mitigated and are related to complexity and not waiting times alone.

Public and media concerns have been raised with methods of triaging referrals that are often seen as gate-keeping based on capacity and not clinical grounds.^{8 9} More concerning is the delay in offering support that can and should be offered while waiting for a diagnostic assessment. In 2024, the English Children's commissioner produced a report¹⁰ that summarised this core issue:

“While the drivers of this increased demand for assessment and support in health services are complex and varied, this report highlights how shortcomings in the wider Special Educational Needs and Disabilities (SEND) system have contributed to creating a diagnosis-led, rather than needs-led, model of support – with health, education and social care often not prioritising the integrated, early support that children with neurodevelopmental conditions need.”

This detailed finding highlights the paradox of the huge impact diagnostic waiting times are having on children receiving the very support they need. However, this is not due to necessity but instead, as the report states, a cultural barrier where ‘diagnosis must come first’.¹⁰ This leaves the goal of reducing unnecessary waits a priority and speeding access to support. This paper describes an implementation research project to develop, pilot and deploy a triage system in the UK for a children's autism diagnostic service that can prevent unnecessary delays to accessing support.

METHODS

This study was a service improvement, which employed action-based approaches as an overarching method, although it was facilitated through alignment with the approaches of clinical audit to collect data to inform the changes made. Therefore, no approval was required for the service improvements, but the data collection and analysis was approved by the Audit and Effectiveness team at Blackpool Teaching Hospitals (reference number 00371).

Service improvement or quality improvement does not have a single definition and cannot be viewed as a single methodology. Rather, it describes a set of principles common to many of these definitions: a systematic continuous approach that aims to solve problems in healthcare, improve service provision and ultimately provide better outcomes for patients.¹¹ The action-based improvement process involves engagement in cycles of action and reflection as a method of driving the changes and always involves two goals: to address a real issue and to contribute to improvement through the elaboration or development of theory.¹² This included the four core

factors that form the action-based research framework: context, relationships, action process and outcomes¹³ and has been employed as a tool to facilitate service improvement in other settings¹⁴

Context

Blackpool Teaching Hospitals NHS Foundation Trust is in the North West of the UK. It is commissioned to offer school-age (4–16 years old) diagnostic assessment for autism for a catchment of 59 372 children in over 120 schools. The neurodevelopmental pathway does this, receiving referrals from any professional in health, education or social care via email or post. We are one healthcare provider in the Lancashire and South Cumbria Integrated Care Board (ICB) system, which covers 301 000 school-aged children from a total population of just under 2 million people. It must be clarified that while naming a neurodevelopmental pathway as a signal that all children referred will have neurodevelopmental traits, this is not a true all neurodevelopmental condition pathway, as such a service was not commissioned. Instead, attention deficit hyperactivity disorder (ADHD), tics and learning difficulties are assessed through other routes. However, this service can screen for such conditions at all stages from the evidence and redirect referrals appropriately.

In 2020, the service was receiving between 45 and 55 referrals per month, with 85% accepted on triage. However, on first clinical assessment by a consultant (attending) neurodevelopmental paediatrician, 50% were discharged with no further evaluation for autism being indicated. For those who continued the pathway journey, just 20% received a diagnosis of autism. This represented just 1 in 10 of those originally referred to the pathway.

Patient and public involvement and engagement

The Trust has a parent partnership forum, where interested stakeholders, often parents who have neurodiverse children, voluntarily contribute to support change in service. The trust also uses a friends and family feedback system, with a QR code for anonymous feedback given at every appointment as to whether you would suggest the service to friends and family, with reasons why invited. Both were instrumental in leading to the design of this new system, with triangulated evidence from both received. Parents wanted to know if a full pathway was supported or facilitated if the likelihood of autism as the primary cause was low. Most concerning, for all patients, including those diagnosed with autism, a common theme fed back was that no different or additional support came after a diagnosis that was not possible prior to one, and so the delays seemed avoidable. Work within the wider ICB was also reporting increases in referral rates, matching the national picture, and similar feedback to our local messaging was being received, as well as concern surrounding very long waiting times.

Action: development of LANTERN triage system

A new approach was needed to meet these various sources of concern and feedback and enhance the triage process. As the elements were developed, it became clear that all of these were interconnected and layered on top of each other. As such, the approach was named the 'Layered Assessment of Neurodevelopmental Needs, Evaluation of Referrals and Navigation of support' (LANTERN) system.

This is implemented at the point a school-aged child is actively referred to the pathway to assess for autism. It is not used on screening or broad assessment pathways, such as those that may occur in mental health, general practitioner or general/community paediatric assessments, but at the time that either those services or a direct school-initiated request for autism assessment is made. LANTERN has no role once the pathway has begun and an assessment journey is ongoing.

This is a distinct departure from the current national framework for developing autistic pathways, which focuses on support after acceptance on a pathway, instead of offering this at the time of triage, and is not specific on mandating a full range of evidence to be gathered.¹⁵ It also deviates from other high-quality approaches developed specifically for children,^{16 17} as it mandates senior active assessors and decision makers in autism and other neurodevelopmental conditions, as well as neurodisability and learning disability, who form part of the NICE-mandated core autism team⁵ and are the joint decision makers. This

LANTERN was designed by layering three key pillars of the process:

1. Detailed evidence gathering—in the past and among wider regional providers, referrals were sent on a pro-forma referral form, but additional evidence was not requested or encouraged. This led to many key gaps. With LANTERN, details of cognitive progress, the direct evidence on which referrals were based and detailed parental observation are all core requests with a referral. More importantly, many supporting forms of evidence exist, and now submission is encouraged. This includes community health records, with entries from health visitors in preschool and school nurses at school age, and hospital records of other medical appointments, assessments and inpatient episodes. This has the potential to add illumination regarding key related medical problems (such as epilepsy or genetic conditions), other neurodevelopmental disorders (such as ADHD, tics or Tourette's) and mental health history that referrers may simply not be aware of or, in the case of non-medical referrers, may not be well placed to assess and include as relevant.
2. Senior diagnostician review of all referrals—while pathway staff had done broad checks in the past, the increased volume and complexity of evidence needed a change in the staff receiving and actioning referrals. The role was clarified as one to be completed by a paediatric diagnostician who is actively involved in the di-

agnostic assessment and decision-making for autism in children, is ADOS-2 trained, and is actively completing such assessments. Key to this role was awareness of other key differential diagnoses, an expert knowledge of the Diagnostic Service Manual (DSM V) criteria¹⁸ for autism and the thresholds for these criteria in practice. This allowed a sensitive and specific screening to occur that was also safe, allowing risk to be understood and managed, particularly when related to wider areas than neurodevelopment, such as mental health or child protection issues. The other key item to be considered is related to other neurodevelopmental conditions. Examples of commonly considered conditions include ADHD, learning difficulties or disability and foetal alcohol syndrome (now known as ND-PAE, Neurobehavioural disorder associated with pre-natal alcohol exposure).

3. Identification of all differences and highlighting support—this was the most novel element of the system. This was not possible without the two other elements on which the system was built. The increased and highly detailed individual evidence allowed an increased consideration of the specific problems and differences that often were at the heart of new referrals. The addition of a clinician with significant neurodevelopmental and mental health skills completing the assessment allowed local knowledge of systems, support structures, commissioning rules, third sector sources of support and relevant legislation to be used. This happens at the point of LANTERN triage which is at the time of referral and therefore prior to any assessment process. This also occurs whether a child is accepted for assessment or not, as it is relevant to all children.

The system is graphically summarised in the infographic in [figure 1](#).

Outcomes

All referrals received are recorded using the trust's EMIS computer system, which contains a module specifically for the neurodevelopmental pathway.

The following summary data have been recorded on a continuous basis:

- ▶ Referral date and outcome.
- ▶ Complaints related to triage.
- ▶ Time taken for referral decisions.
- ▶ Any repeated referrals for the same patient, and if so, whether new evidence or the same evidence was presented.
- ▶ Time taken to complete referrals by the clinician.
- ▶ Diagnostic rate in the decision-making panel.
- ▶ Rate of autism diagnoses per 1000 childhood population.
- ▶ Friends and family test feedback data,¹⁹ collected prior to pathway diagnosis to remove bias related to diagnostic outcome.

Descriptive analysis was completed using reports requested from the EMIS system.

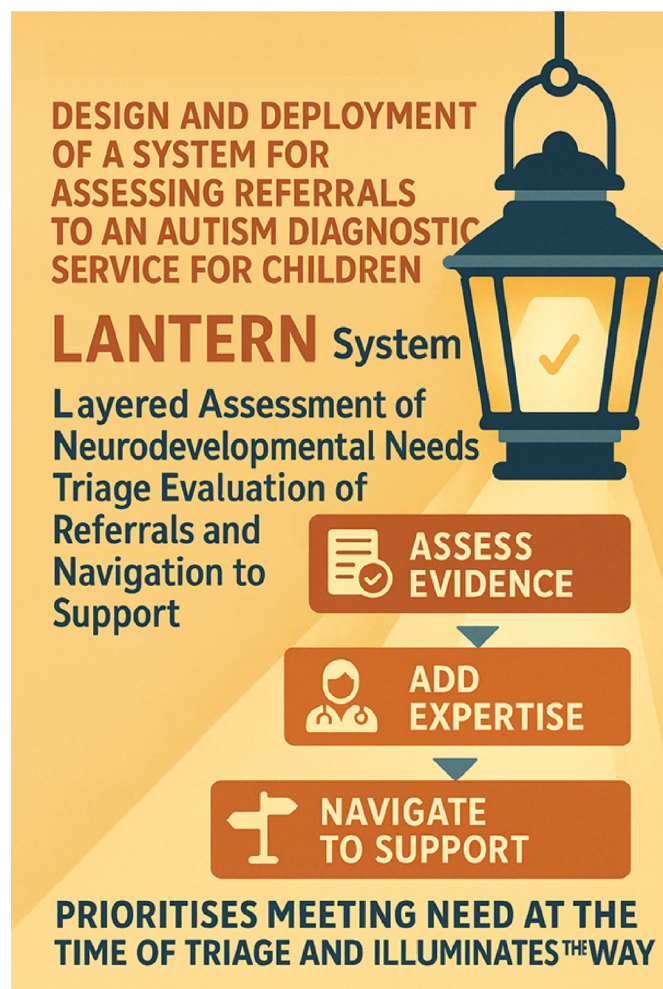


Figure 1 Infographic describing the LANTERN system and the layered approach to its design.

Initially, this manuscript was to be prepared with data for the 2 years after the introduction of the new system. However, with the onset of the global pandemic, referral patterns were heavily impacted and capricious. As such, the data from the 1 year prior to the pandemic, ending in March 2020 and then the 2 years of data from April 2023 to March 2024 and April 2024 to March 2025 have been included.

Data from regional comparators have also been collected from the last 12 months to allow comparison.

Costing data were calculated based on prospective recording of hours worked and using the unit costs of health and social care manual.²⁰ Using such data, a 2024

audit calculated that the mean cost for an entire journey of assessment on our diagnostic pathway was £835 per child.

This article was written in line with the Standards for Quality Improvement Reporting Excellence reporting guidelines.²¹

Patient and public involvement was achieved as described above. The LANTERN system described was primarily based on patient feedback, so they conceived the intervention. Feedback was also used to amend the system.

RESULTS

The LANTERN system was deployed in May 2020 to the school-aged ND autism pathway team within our hospital. This works within the child health department and not Child and Adolescent Mental Health Services who offer this service in some areas of the country.

During its first year of operation, the mean time taken per triage (including the formulation and writing of a response letter) was 16 min (SD 5.5 min).

Performance data and regional comparators

Table 1 includes the total number of children referred, accepted and rejected in the 1 year prior to the launch of the LANTERN system and the last 2 years during which the LANTERN system has been operating.

The overall number of referrals has dropped by 25% in the 5 years. The rate of acceptance is also lower than prior to the system, dropping from 79.6% to 61% in the last year. In the most recent year of 2024–2025, the wider health system received 8168 referrals and accepted 7541, an acceptance rate of 92%. This equates to a referral rate of 33 per 1000 and acceptance of 30 per 1000 children versus 4 per 1000 children in our area using LANTERN. These data are shown in figure 2. All wider outcomes are displayed in the infographic in figure 3.

In the year 2019–2020, the friends and family test ratings were very good or good for 35% of families. In the last 6 months of 2024–2025, the responses were very good or good in 95% of responses (65 of 68).

Resource implications and costs

The administrative burden has remained stable, based on monitoring by the administrative team of the time taken to complete the processing of referrals between the start

Table 1 Comparison of referral data from 1 year prior to the LANTERN system and the last 2 years it was in use

Time period (each 12 months)	Referrals received	Referrals per 1000 population 4–16 years old	Referrals accepted	Referrals accepted per 1000 population 4–16 years old	Referrals rejected	Percentage referrals accepted
April 2019–March 2020	587	10 per 1000	467	8 per 1000	120	79.6%
April 2023–March 2024	549	9 per 1000	269	4 per 1000	280	49.0%
April 2024–March 2025	472	8 per 1000	288	4 per 1000	184	61.0%

LANTERN, Layered Assessment of Neurodevelopmental Needs, Evaluation of Referrals and Navigation of support.

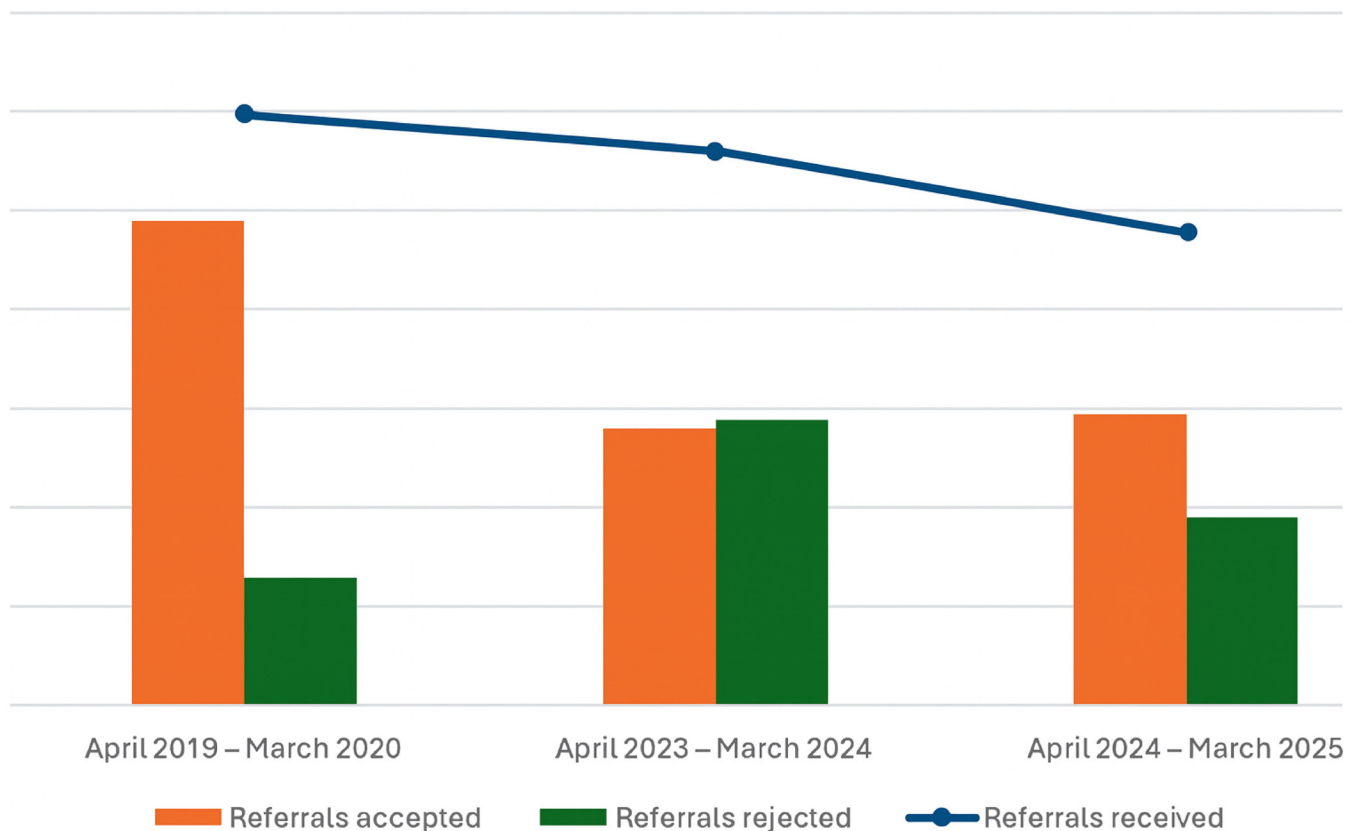


Figure 2 Change in referral data over time.

and the end of the periods described. To process referrals, including uploading to a secure drive to allow triage review, typing and then processing of outcome letters has not changed with the LANTERN system. The senior diagnostician's time has shifted. In the first year of the LANTERN system, the mean time for triage and then dictating or typing of an outcome letter took 10 min per

patient. This has increased substantially as the complexity of referrals, amount of evidence currently in the year April 2024–March 2025 and the mean time per week for triage being 15.5 hours for the diagnosticians. This represents an additional cost burden of £58 695 per annum or £124 per LANTERN triage per child. By calculating the annual costs of the 115 extra children triaged by LANTERN and not accepted in 2024 when compared with 2019, the overall cost impact of the LANTERN system is an additional direct saving of £37 330 per annum in 2024–2025.

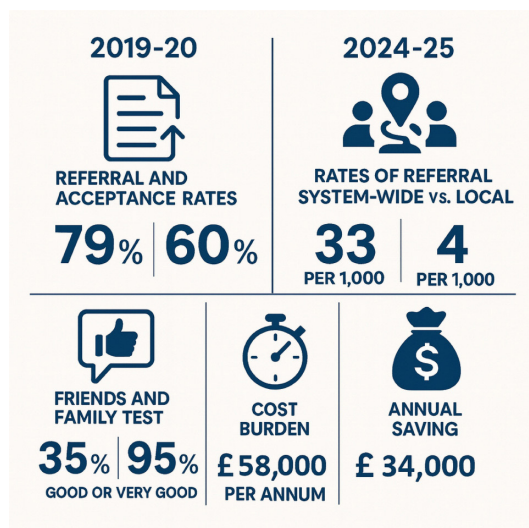


Figure 3 Summary of key outcomes of the LANTERN system.

Challenges and solutions

A number of early concerns were raised by professional stakeholders regarding the requirements from them and what the advantages of the new system were. In response, two actions were taken. First, education sessions were run with school SEND staff, educational psychologists, mental health practitioners and paediatricians focusing on thresholds for diagnosis and alternative routes to receive support. A total of six sessions were run during the year via online video sessions. Second, individual consultations were offered on an ad hoc basis for referrers who were unsure as to whether a referral was needed or wanted support and advice. During the year, 136 one-to-one sessions were offered by diagnosticians, averaging 30 min each.

Both of these initiatives were continued and run in parallel with the LANTERN system. Requests for individual consultations have dropped, as system familiarity with thresholds and broad upskilling on the support offer and alternative routes have increased. In April 2024–March 2025, there were 64 individual requests for professional-to-professional consultation (compared with 136 in year one).

Initially, there was an increase in complaints related to rejected referrals, with six formal complaints made in the first 2 years. An independent review followed the formal and statutory complaints process offered by the trust in line with NHS policy and included at least one senior clinical leader in the team, other ND assessors and broader leadership from the senior team within the organisation. None were upheld as clinically of concern, and the decision was not overturned. The complaints then dropped, and in the latest clinical year, no complaints on the basis of referral triage alone have been received.

Also, initially, some physician groups raised concerns with the thresholds being employed for triage decisions. A system of second checking, independently of all rejected referrals, was initiated in 2022 for a period of 6 months. During that time, the agreement was over 95%. This process was changed to a system of random independent checks of rejections by a second diagnostician for 10% of cases and all cases where any concerns are raised or the first LANTERN triage staff member.

Initially, LANTERN triage was relatively quick. As stakeholders engaged with the system, analysed feedback and changed practice, this has led to an increase in the complexity of referrals. In particular, the volume of evidence has increased. In 2019, most referrals included our pro forma form. In the most recent year, the mean referral included four different documents or reports at a length of over 10 000 words. This has increased the staff resource needed, as demonstrated above. Operationally, this was met through additional overtime and allowed upskilling of the team to share LANTERN duties more widely.

DISCUSSION

Diagnostic rates of autism in children have been incrementally increasing globally for the last three decades.¹ However, over the last 5 years, the rates of diagnostic interest and, in turn, referrals have exponentially grown. In England, a 5-year 300% increase in referral rates has led to there currently being 1.6% of all under 18-year-olds on a waiting list for autism assessment,⁶ yet the current prevalence is 1.8%. As the month-on-month referral rates show no signs of slowing despite this objective prevalence data, it can be inferred that some children are not being referred to the correct pathway for the correct reasons. Our own local data from this project, as well as the qualitative stakeholder evidence that informed its inception, suggested this was the case. Some families did not just want a pathway to assess for autism, but they wanted

frontline guiding to support and an indication as to whether autism was likely from experts, even if this did not need a pathway to achieve.

The LANTERN system was produced to offer an expert evaluation of detailed evidence and offer guidance to support and mitigate these issues while supporting children and families. When considered by its constituent parts, it is not novel. Additionally, given the increased demand and subsequent resource pressures on the system for neurodevelopmental assessment, it could appear counterintuitive to increase the time spent by senior staff on such activities.

The data presented within this study demonstrate that the LANTERN system deployment has reduced overall triage acceptance, but this has in turn led to reduced overall primary referral numbers, likely related to increased knowledge in the system. This is at the same time that the national referral rate has trebled and within our wider ICB system covering a sizeable population, our rate of referral is now significantly lower than all other providers. When considering this, we are mindful that readers may question whether this is simple gatekeeping.

We propose that this is not the case for a number of reasons related to the evidence within our results. The first is the rate of re-referral. The team monitors how many patients are re-referred within 18 months of a rejection to the pathway. As we know in other services, such as mental health, it is common for this to occur, as the users and stakeholders are not satisfied and cannot meet needs. In the case of this service, this occurs in less than 5% of cases, suggesting the LANTERN guidance directs them to the support needed. Second, complaint and 'Friends and family' data suggest satisfaction with the system. Finally, when considering the empirical rates of referral, the team still has 0.8% of the local school-aged population referred per annum and 0.4% accepted for assessment of autism, a condition that occurs in between 1.8% and 3% of people globally. If this is extrapolated over a 12-year period of childhood served by the team, it will assess 4.8% of the population during childhood, and current diagnostic data suggest we confirm autism in half of these children. These data are consistent with the USA prevalence data and, if anything, much higher than the current UK data.

The national data present a contrasting picture. With 0.15% of English children referred per month and no signs of this slowing, over the same 12-year childhood period, this suggests over 20% of all children would be assessed for autism to diagnose the 1.8%–3% who are affected. We would propose that purely from first principles and inductive reasoning, this suggests many children referred do not have this condition. Apart from the cost of inappropriate pathways to the system, our main concern is the delay in support, the frustration to families and the risk of missing other diagnoses this poses.

LANTERN seeks to address this at the 'front door'. It does not impact or redesign the wider assessment journey, but the findings of this action-based research project

suggest that it can prevent the exponential growth in referrals and even reduce overall referrals, while offering support to the most appropriate diagnostic and management journey. The system does this within existing training envelopes, and while it does incur increased ‘front door’ costs, these are more than mitigated by savings, and this does not factor in the increased quality for children and families. Subjectively, we have seen one of the great strengths of LANTERN is to layer the expertise and embed it in the system. We have therefore found the types of referrals have shifted. Prior to LANTERN, those with the most stereotypical and perhaps obvious symptoms would get priority, even though many of these were not caused by autism. Conversely, those who have a less obvious presentation would often be missed. Our feedback through LANTERN over time has shifted the needle, and in turn, we believe the appropriateness of referrals has improved, and now a greater proportion of the total children referred have autism. We have seen in the subset of teenage girls that our diagnostic rate has increased over 300% in the 5 years, suggesting we are now better screening, selecting and diagnosing this complex subset of autistic young people. We believe LANTERN has been key in supporting this shift and is the greatest strength of such a system.

It is also important to highlight the direct impact on cost. Given the higher seniority and staff cost with triage in LANTERN, it is very reassuring to see overall direct costs down due to its impact. What cannot be estimated is the indirect costs. Giving the right support and guidance to patients and families promptly can prevent attendances at primary and secondary care, promote enhanced mental health, school attendance and achievement and support adult employment. All these are identified as factors that are impacted by lengthy assessment waiting times.¹⁰

The differences with other systems and frameworks to LANTERN have been highlighted,^{15–17} but there is a distinct similarity with a group of new tools, known as profiling tools.²² These aim to prioritise a problem-based formulation and, in doing so, can give advice and guidance to the first steps of the local offer. Such a concept is being explored locally by the ICB. However, our proposal is to combine the two systems into possibly one seamless continuum. The advice and guidance from profiling can be revisited with feedback and then, if this indicates a referral, this will direct to the correct ND condition and pathway, without the need to repeat information gathering. This, perhaps, is one of the most pragmatic and yet innovative applications for the transfer of the LANTERN system.

There are a number of limitations to this study. As with all service improvement works, the questions of both generalisability of the system as it stands or transferability, with local changes, are key. We would propose that the system we present would be transferable. However, it is recognised that without further empirical enquiry, it is difficult to comment on the accuracy of this assertion

and the broad generalisability until it has been used within different contexts and similar findings demonstrated. It is also of note that the wider environment and context of the health economy have changed massively over the study period. The global pandemic hit at the start of our improvement journey and therefore led to delays in the full implementation and the uptake of the system. Additionally, the changes in the wider referral data locally and nationally were not expected when we deployed LANTERN. While we have presented the data as transparently as possible, these confounding factors are important when considering our conclusions. Finally, as those patients who are not accepted can only complain as a route of feedback, it is possible their full views are not seen. Informal sources, such as parent and carer forums and community paediatrics, where many families are seen instead, do not suggest this for the majority, but this is a limitation of the current data presented.

Future research is vital in a few key areas. We would suggest that even without LANTERN, an urgent review of referrals in the UK and indeed other areas where referrals for ASD are exponentially growing is needed, using appropriate incidence and prevalence benchmarking data. This should seek to objectively consider referrals and ensure that if unmet needs exist that do not require an autism diagnosis to begin support, this is identified and actioned and whether other neurodevelopmental or wider conditions are being overlooked. We would clearly propose the use of LANTERN in other contexts, and it is vital that users report their findings, as well as details of their local context to support generalisability judgements. Finally, work to identify the fuller cost and care savings of this system through prompt support and enhanced outcomes is also needed.

CONCLUSIONS

The LANTERN system for triaging children’s autism referrals can reduce inappropriate assessment pathways, while ensuring support and meeting of needs is prioritised. Effective use of the LANTERN system can also help provide a base of knowledge to those who are key figures in implementing such support. This system can reduce overall rates of referrals and support high satisfaction in care. Future research to disseminate and replicate this work is key to confirming its generalisable utility.

Contributors MG conceived and led the writing and participated in data collection, analysis and manuscript write-up. He is the guarantor. AA participated in data collection and manuscript editing. AR participated in data collection, extraction and manuscript editing. The whole text of the manuscript is a completely original work of the authors, with all references appropriately cited. ChatGPT was employed to aid the summarising for the abstract and summary by reducing word count, but it was instructed to not add any new or different material not contained within the main text. The result has been approved by the authors. Additionally, it was employed to help design the infographics using the data inputted by the authors.

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Patient consent for publication Not applicable.

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Data availability statement Data are available on reasonable request. Data are available on reasonable request. Please contact the corresponding author for data requests.

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