

The Children's e-Hospital

Inspection report

Prospect House
High Street, Bramham
Wetherby
LS23 6QQ
Tel: 07568 758540
Website: www.e-hospital.co.uk






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This report describes our judgement of the quality of care at this service. It is based on a combination of what we found when we inspected, information from our ongoing monitoring of data about services and information given to us from the provider, patients, the public and other organisations.

Ratings

Overall rating for this location

Outstanding 

Are services safe?	Good 
Are services effective?	Good 
Are services caring?	Good 
Are services responsive?	Outstanding 
Are services well-led?	Outstanding 

Overall summary

Letter from the Chief Inspector of General Practice

We rated this service as Outstanding overall. (The previous inspection on 26 February 2019 rated the service as being compliant.)

The key questions are rated as:

Are services safe? – Good

Are services effective? – Good

Are services caring? – Good

Are services responsive? – Outstanding

Are services well-led? – Outstanding

We carried out an announced comprehensive inspection at The Children's e-Hospital on the 19 and 24 September 2019, as part of our inspection programme to rate independent health providers. We carried out this inspection under Section 60 of the Health and Social Care Act (HSCA) 2008 (Regulated Activities) Regulations 2014, as part of our regulatory functions. This inspection was planned to check whether the service was meeting the legal requirements and regulations.

The Children's e-Hospital is a digital service which provides advice for parents along with care and treatment for children aged from birth to 18 years who have a paediatric medical condition; particularly for the parents of children who experience Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) and Paediatric Autoimmune Neuropsychiatric Syndrome (PANS). The service is accessible via the website. Video consultations are available for parents and their children with either a consultant paediatrician or a paediatric dietician as appropriate. At the time of our inspection, the service was commencing face-to-face consultations with the consultant paediatrician, as an alternative option for parents. We visited the location where video consultations are carried out and the location where face-to-face consultations were going to be undertaken as an additional part of service provision.

The clinical director is the registered manager. A registered manager is a person who is registered with the Care Quality Commission (CQC) to manage the service. Like registered providers, they are registered persons. Registered persons have legal responsibility for meeting the requirements in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014, about how the service is run.

At this inspection our key findings across all the areas we inspected were as follows:

- There were clearly defined and embedded systems and processes in place to support safeguarding and risk management.
- Medicines were prescribed in line with appropriate guidance and evidence-based practice.
- Parents of the children who accessed the service were provided with information to support the delivery of safe care and treatment.
- The service routinely reviewed the effectiveness and appropriateness of the care it provided. It ensured that care and treatment was delivered according to evidence-based guidelines.
- Parents and children were supported and treated with dignity and respect and involved as partners in their care.
- Satisfaction rates from parents was consistently high.
- The leadership, governance and culture of the service were used to drive and improve delivery of high-quality, person-centre care.
- There was evidence of strong collaboration with other colleagues, agencies and service users to improve services for children and their parents.
- There was a strong focus on continuous learning and improvement.
- The service was committed to finding innovative ways and improvements to deliver care, treatment and support for parents, whilst also raising awareness with other health care professionals, including GPs.

We saw areas of outstanding practice:

- The provider had used their knowledge, skills and experience to develop the service, in order to meet the individual needs of patients due to a perceived lack of service provision relating to PANDAS and PANS.
- Patients, via the Parent Steering Group, were pivotal in the development of the service.
- The service worked with other organisations to develop national pathways relating to PANDAS and PANS.
- There was compassionate, inclusive and effective leadership, with the clinical director demonstrating the high levels of experience, capacity and capability needed to deliver excellent and sustainable care.
- The service invested in innovative and best practice information to support service delivery and raise awareness in other clinicians and health care agencies.

Overall summary

Dr Rosie Benneyworth BM BS BMedSci MRCGP

Chief Inspector of Primary Medical Services and Integrated Care

Our inspection team

The inspection team consisted of a CQC lead inspector and a CQC GP specialist advisor. A shadow CQC GP specialist advisor was also in attendance.

Background to The Children's e-Hospital

The Children's e-Hospital is a digital service which operates from Prospect House, High Street, Bramham, Wetherby LS23 6QQ. The service was founded in 2015 and registered with CQC in August 2018, to deliver the regulated activity of treatment of disease, disorder or injury.

The service predominantly provides remote clinical advice and support to parents of children from birth to 18 years, who have a paediatric medical condition. Parents can access the service by telephoning or emailing using details provided on the website. Appointments can also be booked via the website or by speaking with the patient coordinator.

Support and advice are provided particularly for the parents of children who experience Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) and Paediatric Autoimmune Neuropsychiatric Syndrome (PANS).

PANDAS is a condition with symptoms such as tics, obsessive compulsive disorder (OCD), deterioration in handwriting, eating disorders and behaviour regression, which are exacerbated or brought on by a common bacterial infection called Group A streptococcus. PANS is a clinical syndrome which may be caused by non-infectious or infectious triggers. Symptoms can appear suddenly with a rapid shift in a child's behaviour relating to OCD or severely restricted food intake and can include anxiety, aggression, sensory or motor abnormalities, sleep disturbance or incontinence.

In addition, the service provides information and support for parents of children who have a cow's milk protein allergy. Via the service website, parents can access information regarding a range of childhood conditions, such as eczema, colic, bedwetting, seizures, self-harm and provides first aid advice.

The clinical director provides the service and is supported by the patient treatment coordinator. The provider also contracts the services of an additional consultant paediatrician and allergy specialist and other paediatric health professionals. To support governance, development and delivery of the service, there is a Medical Advisory Group (MAG), a parents' steering group and a board of trustees. The consultant paediatrician has close working links with other paediatric clinicians, the UK PANDAS Physicians Network and PANS PANDAS UK.

How we inspected this service

Before the inspection, we reviewed information from the provider, their website and other information received by CQC.

On the 19 September we visited the premises at Prospect House, High Street, Bramham, Wetherby LS23 6QQ, where the online service is operated from. On the 24 September we visited the premises at 10 Harley Street, London W1G 9PF, where face-to-face consultations were commencing that same day.

During the inspection we reviewed documents and observed both environments from where the service was delivered. We also spoke with the registered manager/clinical director and the parent of a child with PANDAS.

To get to the heart of patients' experiences of care and treatment, we ask the following five questions:

- Is it safe?
- Is it effective?
- Is it caring?
- Is it responsive to people's needs?
- Is it well-led?

Are services safe?

We rated safe as Good because:

- There were clearly defined and embedded systems and processes in place to support safeguarding and risk management.
- Medicines were prescribed in line with appropriate guidance and evidence-based practice.
- Parents of the children who accessed the service were provided with information to support the delivery of safe care and treatment.

Keeping people safe and safeguarded from abuse

The service treated children aged from birth to 18 years of age, through consultation with their parent or guardian. There were systems in place to check the date of birth and address of the patient, including proof of parental authority or guardianship. Parents/guardians were asked to provide photographic ID in the form of a passport or driving licence at the first consultation. The identity of the child was confirmed via their birth certificate and passport (where applicable). Each patient was allocated a unique identification number when they initially accessed the service.

The clinical director we spoke with had a good understanding of what safeguarding was and how to deal with any concerns appropriately. Staff had received the appropriate level of safeguarding training for their role. For example, clinicians had completed level three children's safeguarding. There was a safeguarding policy in place and a flowchart available for staff, which clearly highlighted the procedure to follow when a safeguarding concern was identified. Details were available for staff to contact local safeguarding authorities relevant to the area in which the patient resided.

Monitoring health & safety and responding to risks

The online service was operated from the registered premises. An office was used solely for service delivery. Patients were not physically treated on the premises, as online consultations were carried out remotely via a secure, password encrypted computer system. Consultations were conducted via private video calls. We were assured that confidentiality was always maintained.

There was a policy in place identifying that all staff, such as the dietitian and allergy specialist, would conduct consultations in private and maintain patient confidentiality. Each clinician used an encrypted, password

secure computer to log into the operating system, which was a secure programme. Non-clinical staff also had systems in place to manage confidentiality. All home-workers were required to complete a risk assessment to ensure their working environment was safe.

There were appropriate health and safety risk assessments in place at the premises where face-to-face consultations were to be undertaken. For example, those relating to fire, infection prevention and control and clinical waste management.

There were processes in place to manage any emerging medical issues during a consultation and for managing test results and referrals. The service was not intended for use by patients with either long-term conditions or as an emergency service. In the event an emergency did occur, the provider had systems in place to ensure the location of the patient at the beginning of the consultation was known, so emergency services could be directed should the need arise.

Staffing and Recruitment

At the time of our inspection there was enough staff to meet the demands for the service. The clinical director provided the service, supported by a patient treatment co-ordinator, a paediatric dietician and an additional consultant paediatrician; who was a specialist in cows' milk protein allergies. Staff were employed on a sessional basis via zero hours contracts.

There was a recruitment policy and process in place, along with an employee checklist the provider completed upon recruiting additional staff as the service developed. There were a number of checks which were required to be completed prior to employment, such as references, photographic ID, Disclosure and Barring Service (DBS) checks and confirmation of qualifications. (DBS checks identify whether a person has a criminal record or is on an official list of people barred from working in roles where they may have contact with children or adults who may be vulnerable.) All clinical staff had produced evidence of their professional qualification, registration with an appropriate professional body and had indemnity cover (to include cover for video consultations).

Prescribing safety

At the time of our inspection, there was a limited range of medicines prescribed, due to the limited number of

Are services safe?

conditions the service treated. All medicines were prescribed in line with the British National Formulary for Children. Evidence-based guidance was used, particularly treatment guidelines for Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) and Paediatric Autoimmune Neuropsychiatric Syndrome (PANS). For other paediatric conditions, disease management pathways in line with the National Institute for Health and Care Excellence (NICE) were used.

There was a medicines management policy in place. We saw evidence to support clear prescribing, which included dosage and frequency. All parents were given instructions regarding when and how their child should take the medicine, the purpose of it, advised of any potential side effects and what they should do if their child became unwell. The clinical director was aware of the 'Yellow Card' adverse drug reaction reporting scheme. A review of all prescriptions and medicines prescribed was undertaken periodically.

The patient's GP was always informed, via letter, of the treatment plan and medicines prescribed. This information supported the GP to continue with the provision of treatment in line with the patient's individual plan.

Since the previous inspection, the provider had reviewed their provision of prescriptions to patients. They had introduced a system that avoided any potential for duplication. Patients had the option to receive their prescription direct through the post to themselves, through a registered online pharmacy or via a request sent to their own NHS GP.

Information to deliver safe care and treatment

On registering with the service, and at each consultation, patient identity was verified. A comprehensive medical history was obtained from the child's parent to support decisions regarding treatment plans. We were informed that parents had often sought other medical advice on multiple occasions regarding their child's condition, regarding PANDAS and PANS, prior to accessing this service.

The clinicians had access to the patient's previous records held by the service to support delivery of safe care and treatment. Information was sent to the patient's own GP to support continuity of treatment and raise awareness relating to PANDAS and PANS.

Management and learning from safety incidents and alerts

There were systems in place for identifying, investigating and learning from incidents relating to the safety of patients and staff members.

At the time of our inspection there had not been any reported or recorded incidents. We were informed that in the event of an incident, it would be managed in line with the policy and procedures. Any incidents would be shared with the patient steering group to support learning and development of the service.

The clinical director received patient safety alerts and ensured other staff were aware of them. Any that were relevant to the service were acted upon accordingly.

Are services effective?

We rated effective as Good because:

- There was a holistic approach to assessing, planning and delivering care and treatment to patients, which included an assessment of their quality of life.
- The service was committed to finding innovative ways and improvements to deliver care, treatment and support for parents, whilst also raising awareness with other health care professionals, including GPs.

Assessment and treatment

When an appointment request was made, the parent of the patient was sent a request for information form, which included past medical history, current symptoms, any previous investigations and medication. This was made available to the clinician to support assessment and the development of a treatment plan. We saw evidence that any information was reviewed, understood or clarified before care planning and treatment commenced.

At the time of the consultation a comprehensive holistic assessment was undertaken, which included the impact of symptoms on the child's quality of life. If a child required any blood tests to support a diagnosis, a pack could be sent direct to the parent for them to access phlebotomy services, such as at the child's GP. All test results were then returned direct to the service and reviewed by the clinician. The results were used to confirm a diagnosis and formulate a treatment plan.

We were informed how parents may have accessed other clinicians/health care professionals on multiple occasions due to their child's behaviour. PANDAS and PANS arise from a streptococcal infection, particularly in the upper respiratory tract, which provokes a response from the immune system, causing extreme symptoms to rapidly (within 24 to 48 hours) occur in a child. As a result of the correct diagnosis, treatment provided to the child can show improvements quickly (within days or weeks). Treatment is generally through anti-microbial therapy (prescribing of specific antibiotics).

We were provided with evidence which showed that 72% of patients that had been prescribed treatment, had a good response to and 28% had some response. We were informed that some of these children may have had other conditions, such as autism, or needed to have further investigations to support an alternative or supplementary

diagnosis of their condition. The clinician could refer a patient to a range of paediatric consultants or specialists as appropriate. Both the parent and the child's GP would receive information should this occur.

Parents reported high satisfaction rates regarding the improvement in their child's behaviour and symptoms in respect of the care and treatment they received from the service. We saw evidence to show the significant impact on a child's life within four days of receiving treatment via The Children's e-Hospital. This included a significant reduction in symptoms and clear improvements in writing and drawing skills.

We reviewed five random medical records that demonstrated that the clinician had assessed patients' needs and delivered care and treatment, in line with relevant and current evidence-based guidance. These included NICE and treatment guidelines for PANDAS and PANS.

Quality improvement

The clinical director collected and monitored information on patients' care and treatment outcomes and used these to support quality improvement.

Information was collected by the provider to further understand the impact of symptoms and the types of symptoms children experienced. For example, 85% of patients experienced obsessive compulsive disorders (OCDs), 70% tics, 21% eating disturbances, 43% urinary disturbance.

Audits were undertaken to review timescales for patients having access to a diagnosis and treatment from NHS services, such as their own GP and the response of the patient to treatment prescribed. These audits were used to improve service delivery and patient outcomes.

Staff training

All staff had completed mandatory training appropriate for their role, which included safeguarding and information governance.

There was an induction process for new starters to the service. At the time of our inspection, the service was in the process of recruiting to an administration post. We saw evidence of appropriate recruitment checks and the plan for that member of staff's induction programme.

Coordinating patient care and information sharing

Are services effective?

Before providing treatment, clinicians ensured they had adequate knowledge of the patient's health, any relevant test results and their medicines history.

The service had clear guidelines regarding consent. It was the policy to always share information with the patient's GP to support quality care, treatment and awareness of the conditions. If parents refused consent to share information with their GP, further discussion would be had with the parent to understand the rationale behind their decision. However, at the time of inspection 100% of parents had given consent to share information with their GP. If a child needed to be referred elsewhere, information would be shared with that service, in line with parental consent.

Due to the complexity of their child's symptoms, some parents had accessed care and treatment from the United States of America. The clinical director was aware of this and subsequently liaised with parents to gain a better understanding of why they had gone outside the UK and to discuss treatment options available within the UK. In order to connect parents with UK services, such as the NHS and their GP, the clinical director (along with other health professionals) had developed the UK Physicians Network Guidelines to support safe treatment. This was intended to give health professionals and parents guidance regarding what to do in the initial stages of the condition, such as investigations, treatment and long-term plans.

Supporting patients to live healthier lives

There was a range of information available on The Children's e-Hospital website. Parents could access information about a range of paediatric conditions, such as eczema, colic, mumps, jaundice in new-born babies, croup,

bedwetting, seizures, choking child and slapped cheek syndrome. Information regarding symptoms, care and treatment, was available in written and visual formats. Parents could also access information via the service's social media site and PANDAS UK social media site.

The Children's e-Hospital had developed a Child Health Assessment Kit, which parents could purchase and use in conjunction with a free App. (It was advised it was suitable for children aged two years and above.) The kit contained the necessary equipment for parents to record the temperature, heart rate and oxygen levels of their child, should they be concerned about their health. Information could be inputted via the App, which measured against normal ranges. There were clear instructions on how to use the kit, perform the checks and what to do next. For example, whether they needed to seek clinical input. We were informed that the kit was useful in determining the possibility of sepsis and had been endorsed by the UK Sepsis Trust.

The clinical director was currently working with an NHS Trust to undertake research and evaluation of the kit and App, to ensure they were not being used inappropriately or were detrimental to the health of a child. They were also linking with the NHS England Director of Children's Services to provide evidence of impact on patient outcomes and safe models of care.

The service had developed a First Aid Kit for parents to purchase through the website. This included a range of equipment suitable for dealing with minor injuries, along with reference flash cards for resuscitation, choking and sepsis.

Are services caring?

We rated caring as Good

- Parents and children were supported and treated with dignity and respect and involved as partners in their care.
- Satisfaction rates from parents were consistently high.

Compassion, dignity and respect

We were informed that the clinicians undertook video consultations in a private room and were not to be disturbed during their working time. We saw the room where the consultations by the clinical director took place and noted that it was suitable for the purpose.

We also visited the location at Harley Street, London and saw that this was also appropriate for face-to-face consultations to take place. It was a welcoming environment. Parents were collected from the reception/waiting area by the clinician and escorted to the private room where the consultations took place. Confidentiality was maintained at all times.

We were informed that parents and their children were treated with compassion, dignity and respect. This was demonstrated by the manner in which the Clinical Director spoke with us and upon observation of how they greeted a parent and child.

All parents were asked to complete a satisfaction survey after their consultation. We saw that the survey evidenced a high satisfaction rate. For example, 100% would recommend the service to other parents. On a scale of one to ten (with 10 being the highest), 80% rated it as ten and 20% rated it as nine.

On the day of the visit to the Harley Street, London, location we spoke with a parent and a child. They informed us, in complimentary terms, of how they have been treated by both the clinical director and patient care coordinator and that they would recommend the service to others.

Involvement in decisions about care and treatment

Through The Children's e-Hospital website, potential service users could access information and photographs regarding the clinicians and other staff who worked for the service.

Parents were involved in decisions about their child's care and treatment. Information was given to them in a way they could understand. Parents were asked for consent to share information with their GP to support treatment of their child. This also enabled awareness to be raised with that clinician regarding PANDAS and PANS as appropriate.

Are services responsive to people's needs?

We rated responsive as Outstanding because:

- The provider had used their knowledge, skills and experience to develop the service, in order to meet the individual needs of patients, due to a perceived lack of service provision relating to PANDAS and PANS.
- Patients, via the Parent Steering Group, were pivotal in the development of the service.
- The service worked with other organisations to develop national pathways relating to PANDAS and PANS.

Responding to and meeting patients' needs

The provider, through their working experience as a consultant paediatrician, had identified that there was a gap in the provision of services for parents of children who have PANDAS or PANS. The service had been established by the clinical director in recognition of a need nationally to provide advice, treatment and parental support for children who may be experiencing symptoms indicative of PANDAS or PANS. Due to the nature of the symptoms, they may be mistaken for other disorders, such as obsessive-compulsive disorder (OCD), autism, Tourette syndrome, bipolar or anorexia nervosa, which could result in a child being diagnosed inappropriately.

We were informed that there had been a lack of national pathways relating to PANDAS and PANS and that parents had expressed difficulty in accessing the right diagnosis, care and treatment for their child. At the time of our inspection, there were few known services in the UK providing extensive clinical support for children with PANDAS or PANS. The provider was working with the PANS Physicians' Network (PPN UK) and Royal College of Paediatricians to improve awareness and access to services for children.

Information about all the services provided, including costs, was available on The Children's e-Hospital website. Parents could speak with the patient service coordinator via telephone or email, to obtain further information about the service or to discuss any concerns. The service also had a social media account and app, where parents could find further information.

Parents could either book an appointment online or contact the service by telephone. Consultations were undertaken in the form of a video call. The initial

consultation was approximately 45 minutes in length and a follow-up was planned for two weeks. After the consultation the parent was provided with an individualised care and treatment plan for their child.

The service was not intended for emergency consultations and the provider made it clear to users what the limitations of the service were.

At the time of our inspection, parents could access a consultation within two weeks. They could also access a clinician within 48 hours, depending on whether it was a weekend or bank holiday.

The service used comments from parents, service users and staff to improve how the service was delivered. Consequently, the clinical director had developed a face-to-face consultation service in London, which parents could access after initially undertaking a video consultation. A parent we spoke with informed us they were happy to attend the location to discuss further treatment and long-term plans for their child.

The provider developed the service in line with gaps in service provision relating to specific needs. As a result, they had developed the service to include cow's milk protein allergy. There was a questionnaire on the service's website, which parents could undertake to determine how quickly they should access clinical intervention.

We were informed by a parent how they had initially been made aware of The Children's e-Hospital through a social media site for PANDAS and PANS. Parents on that site had spoken positively about the service, the clinician and the improvements in their child's health and well-being, as a result of receiving a correct diagnosis and treatment.

The clinical director was very passionate about ensuring children had access to care and treatment in a timely way to prevent further distress to the child and parent.

Tackling inequity and promoting equality

The provider did not discriminate against any client group. However, the service was only available for children aged birth to 18 years of age, in conjunction with their parent/guardian.

Are services responsive to people's needs?

To support inequity and equality regarding PANDAS and PANS awareness in the medical field, particularly with primary care clinicians such as GPs, the clinical director was working with PANDAS UK to develop and deliver a training course for clinicians and health care professionals.

Managing complaints

There was a complaints policy and mechanisms in place should parents wish to make a complaint. Parents could complain either by email or writing to the service. We were informed that all complaints would be reviewed and investigated by the clinical director and shared with the Medical Advisory Group and Parent Steering Group as appropriate. However, at the time of our inspection the service had not received any complaints. We were assured that complaints would be taken seriously and actioned appropriately.

Consent to care and treatment

There was a clear consent process and staff were aware of the need to obtain consent in line with guidance and mental capacity.

Upon receiving a booking for a consultation, a consent form was emailed to the parent/guardian of the child, who then completed and returned it via email. After the consent form had been received, this was documented on the patient's record.

Parents of children aged 14 years and over were asked if their child was aware that the consultation was taking place and had agreed to the parent/guardian talking with the clinician on the child's behalf. This was also documented.

Parents were also asked for the details of the child's GP and consent to share information with that clinician. An audit of consent had been undertaken and found to be 100%.

Are services well-led?

We rated well-led as Outstanding because:

- The leadership, governance and culture of the service were used to drive and improve delivery of high-quality, person-centre care.
- There was compassionate, inclusive and effective leadership, with the clinical director demonstrating the high levels of experience, capacity and capability needed to deliver excellent and sustainable care.
- There was evidence of strong collaboration with other colleagues, agencies and service users to improve services for children and their parents.
- The service invested in innovative and best practice information to support service delivery and raise awareness in other clinicians and health care agencies.

Business Strategy and Governance arrangements

The service had a Medical Advisory Group (MAG), which included the clinical director, a consultant paediatrician, a paediatrician, a child nutrition and functional medicine practitioner, advanced paediatric nurse practitioner and paediatric dieticians. This group met quarterly to review clinical performance and service delivery. In addition, there was a Parent Steering Group, consisting of a school nurse lead and parents. This group helped to put patients at the centre of service delivery. Both these groups supported the governance and direction of the service.

The Children's e-Hospital was also part of the PANDAS national network and had been key in developing the national treatment protocol for PANDAS. The service was heavily involved in the strategy and direction of how to develop services and raise awareness.

The service had a five-year strategy in place which identified areas for development. These included development of other services for children, such as those for constipation and enuresis (particularly bed-wetting). The clinical director had engaged with the chief executive of a hospital trust regarding the development of child psychiatric services to support children getting the care and treatment they require more quickly. The service also planned to have a more comprehensive child health service to support the parents of children who are discharged from hospital but may still require advice and support.

The service also had a group of charity trustees, who supported The Children's e-Hospital to provide medical and humanitarian aid worldwide as appropriate.

Leadership, values and culture

The clinical director had overall day-to-day leadership and responsibility. However, they also had access to the MAG and Patient Steering Group and liaised with them as appropriate.

The service had an open and transparent culture. We were told that if there were unexpected or unintended safety incidents, the service would give affected patients reasonable support, truthful information and a verbal and written apology. This was supported by an operational policy.

The values of the service were to provide high-quality care, treatment and support for their patients. This was clearly evidenced by the overwhelmingly positive responses from parents of children who had accessed the service, the majority of whom had previously accessed alternative health care services.

The clinical director was passionate about ensuring children received the appropriate care and treatment. This had also been pivotal in them providing medical assistance elsewhere. For example, they had attended a Syrian refugee camp in Greece to provide medical support for the children based there. They had coordinated over 100 volunteers over an 18-month period (between 2017 and 2018), during which they provided food, clothing and specialist paediatric care to the children. The clinical director had engaged with the media to raise awareness of the plight of these children. They also engaged with local social services to look at how children were being treated and accommodated when coming into the UK. Subsequently, the service has developed the "Pop-up Children's Hospital" project to deliver care to children in disaster zones.

Safety and Security of Patient Information

Systems were in place to ensure that all patient information was stored and kept confidential.

There were policies and IT systems in place to protect the storage and use of all patient information. The service could provide a clear audit trail of who had access to records and from where and when. The service was registered with the Information Commissioner's Office (ICO). There were business contingency plans in place to minimise the risk of losing patient data.

Are services well-led?

Seeking and acting on feedback from patients and staff

Parents of children using the service could provide feedback via the request sent to them after a consultation, via the service website or by contacting the service direct. Additionally, feedback and comments about the service were also posted on the service's social media site. Comments from parents stated that the service was invaluable. A parent we had contact with, spoke about the clinician and the service extremely positively.

We saw minutes from meetings which evidenced engagement and discussion with the various groups of staff and parents. The service held discussions regarding the charges to service users. Previously, patients accessing the cow's milk protein allergy service had not been charged. However, members of the Parent Steering Group had suggested that a fee should be in place. It was decided that the monies would go into a charity pot to support charitable work. Members were asked for ideas and agreed on how the money would be used.

Continuous Improvement

We were informed of the developments to support continuous improvement, particularly regarding raising awareness of PANDAS and PANS.

The clinical director has presented at several national and international events regarding PANDA and PANS. For example, a Neuro-Immunology study day for paediatric doctors, GPs and the medical community in Glasgow and at a PANS conference in Sweden. They had, together with a group of four other doctors, formed the UK Pans Pandas Physicians Network to raise awareness of the conditions in the NHS. As part of this network, they had been liaising with the Royal College of Paediatricians and Royal College of Psychiatrists, to work towards improving access to paediatric psychiatry services. The service was also participating in UK based research.

The clinical director had a strong background in medical education. As a result, they had developed a Virtual Medical School, for clinicians to access via The Children's e-Hospital website. It was intended that resources would be available to postgraduate/undergraduate students to provide training on various paediatric conditions. There would also be access to protocols, PANDAS and PANS treatment guidelines and other guidelines with links to other appropriate resources.