The M.E. Trust Office

Inspection report

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Date of inspection visit: 29/08/2019
Date of publication: 31/10/2019

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?	**Outstanding** ☆
Are services responsive?	**Outstanding** ☆
Are services well-led?	**Outstanding** ☆

Overall summary

This provider is rated as Outstanding **overall.**

The key questions are rated as:

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

We carried out an announced comprehensive inspection at The M.E. Trust Office as part of our inspection programme.

The ME Trust is a charity dedicated to funding and providing individual patient treatment for people with myalgic encephalomyelitis (ME) also called Chronic Fatigue syndrome (CFS) usually described as ME/CFS.

The provider has a registered manager. A registered manager is a person who is registered with the Care Quality Commission 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 and associated Regulations about how the service is run.

We received six comment cards from patients and spoke with four patients. They were all positive about the service. In particular patients commented that the medical staff were caring and responsive.

Our key findings were :

- The care provided was safe. There were systems for reporting, investigating and learning from incidents. Staff were trained to the correct level in safeguarding.
- All the patient feedback stressed that the staff were caring. Patients said that staff went the extra mile; their care and support exceeded patients' expectations.
- Patients and their carers were active partners in their own care. The patients and carers directed their appointments and staff responded to the needs and capacity that patients presented. In this way individual preferences and needs were always reflected in how care was delivered.
- There was strong feedback from patients that the provider was responsive, each patient was an individual whose symptoms and history were listened to and acted on. Some patients reported that, in the M.E. Trust, they had found the first organisation that believed in their symptoms unequivocally.
- The M.E. Trust recognised the need to understand that each patient with ME/CFS displayed symptoms differently and that individual needs and preferences were central to the delivery of tailored services. As such almost all the people involved in the Trust, as clinicians, volunteers or trustees had experience of ME/CFS either as an individual or through a family experience.
- There was innovation such as video conferencing and email consultations. Patients whose condition meant that they needed long appointments had them.
- The provider was using medicines outside the terms of the licence for that medicine. However, this was only in case where there was valid special clinical need for that patient and where there was no suitable licensed medicine available.

We saw the following outstanding practice:

- Any letters about the patient, such as to their GP, were sent to the patient first so that they could check the content.
- After each consultation the patient was sent an email report of the discussion and any agreed treatment plan. The provider had found that patients suffering with me/cfs needed a written record to help them manage the decisions.
- Almost all staff, including volunteers and trustees, had direct experience of the impact of me/cfs. This gave them a true empathy for the outcomes of the patients.

Overall summary

Dr Rosie Benneyworth BM BS BMedSci MRCGP
Chief Inspector of Primary Medical Services and Integrated Care

Our inspection team

Our inspection team was led by a CQC lead inspector. The team included a GP specialist adviser.

Background to The M.E. Trust Office

The M.E. Trust Office is located at:

12 William Street

Windsor

SL4 1BA

This is the administrative centre and no patients are seen here.

The M.E Trust (the trust) has an outpatient's clinic at:

Crowborough War Memorial Hospital

Southview Road,

Crowborough

East Sussex

TN6 1HB.

The outpatients' clinic takes place on the afternoon of the third Friday of the month. The inspectors did not visit the outpatients' clinic.

The ME Trust is a charity dedicated to funding and providing individual patient treatment for people with myalgic encephalomyelitis (ME) also called Chronic Fatigue syndrome (CFS), usually described together as ME/CFS. Approximately 250,000 people in the UK suffer from ME/CFS. It is an umbrella term for neurological conditions or spectrum of diseases that may cause extreme exhaustion, muscle and joint pain, noise and light sensitivities, cognitive impairment, digestive problems and other symptoms. There is currently no cure. The trust provides treatment where this is possible. It provides advice, physiotherapy and emotional support for those living with ME/CFS. The emotional and physiotherapy service fall outside the scope of registration and are therefore not covered by CQC registration.

How we inspected this service

We reviewed information from the provider including evidence of staffing levels and training, audit, policies and the statement of purpose.

We interviewed the GP in charge of treatment, the receptionist/secretary, the physiotherapist, the Registered Manager, and a trustee of the charity. We reviewed documents, inspected the facilities and the building. We also asked for CQC comment cards to be completed by patients prior to our inspection. We received six comment cards. We talked with four patients.

To get to the heart of patients' experiences of care and treatment, we always 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?

These questions therefore formed the framework for the areas we looked at during the inspection.

Good ●

Are services safe?

We rated safe as Good because:

Safety systems and processes

The provider had clear systems to keep people safe and safeguarded from abuse.

- The provider conducted safety risk assessments. It had appropriate safety policies, which were regularly reviewed and communicated to staff. The policies outlined clearly who to go to for further guidance. Staff received safety information from the M.E. Trust (the trust) as part of their induction and refresher training. The provider had systems to safeguard children and vulnerable adults from abuse.
- The provider had systems to assure that an adult accompanying a child had parental authority.
- The provider worked with other agencies to support patients and protect them from neglect and abuse. Staff took steps to protect patients from abuse, neglect, harassment, discrimination and breaches of their dignity and respect. We saw evidence that the safeguarding lead and clinical staff discussed, in clinical meetings, different safeguarding scenarios and how they would respond to them.
- The provider carried out staff checks at the time of recruitment and on an ongoing basis where appropriate. All staff had received a Disclosure and Barring Service (DBS) check. (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 staff received up-to-date safeguarding and safety training appropriate to their role. They knew how to identify and report concerns. Staff who acted as chaperones were trained for the role and had received a DBS check.
- There was an effective system to manage infection prevention and control. There were few physical examinations and little need for infection prevention and control beyond universal precautions. No clinical waste was generated. Where a need had been identified, for example, a legionella risk assessment, the provider had either conducted, as at the Windsor office, or had recorded that it had been conducted, as at the outpatients' clinic.
- The provider ensured that equipment was safe and that equipment was maintained according to manufacturers' instructions.

Risks to patients

There were systems to assess, monitor and manage risks to patient safety.

- There were arrangements for planning and monitoring the number and mix of staff needed.
- There was an effective induction system for new staff, no agency staff were deployed.
- The GP understood their responsibility to manage emergencies and to recognise those in need of urgent medical attention. They knew how to identify and manage patients with severe infections, for example sepsis.
- There were suitable medicines and equipment to deal with medical emergencies which were stored appropriately and checked regularly. The provider had ensured that suitable equipment was held at the outpatients' site. The provider had their own medical oxygen and a defibrillator available at the outpatients' site.
- The provider had reviewed the staffs' indemnity arrangements which were appropriate.

Information to deliver safe care and treatment

Staff had the information they needed to deliver safe care and treatment to patients.

- Individual care records were written and managed in a way that kept patients safe. The care records we saw showed that information needed to deliver safe care and treatment was available to relevant staff in an accessible way.
- The provider had systems for sharing information with staff and other agencies to enable them to deliver safe care and treatment.
- The provider had a system in place to retain medical records in line with Department of Health and Social Care (DHSC) guidance in the event that they cease trading.
- Clinicians made appropriate and timely referrals in line with protocols and up to date evidence-based guidance.

Safe and appropriate use of medicines

The provider had reliable systems for appropriate and safe handling of medicines.

Good ●

Are services safe?

- The provider did not hold any medicines. The provider kept prescription stationery secure and monitored its use.
- The provider used a medicine, outside the terms of the license for the medicine. The use of the medicine was supported by academic journals and it was authorised for use in the treatment of ME/CFS in some other medical jurisdictions. The dosages used were very low about one quarter of a standard tablet as a starting dose. There were a very small number of patients to whom the provider prescribed the medicine. There were some patients where the medicine had been prescribed by the patients' GP, following a consultation with the provider. Other patients were prescribed the medicine by the provider. Patients were made aware of that the low dose use of the medicine was outside the terms of the medicine's license. The provider had produced a comprehensive leaflet, for patients, explaining the use of the medicine. The patient's consent was recorded. The impact of the medicine was reviewed for each patient using it, and this was recorded in the patients' notes.
- Staff prescribed medicines to patients and gave advice on medicines in line with legal requirements and current national guidance. Where there was a different approach taken from national guidance there was a clear rationale for this that protected patient safety.

Track record on safety and incidents

The provider had a good safety record.

- There were comprehensive risk assessments in relation to safety issues.
- The provider monitored and reviewed activity. This helped it to understand risks and gave a clear, accurate and current picture.

Lessons learned and improvements made

The provider learned and made improvements when things went wrong.

- There was a system for recording and acting on significant events. Staff understood their duty to raise concerns and report incidents and near misses. Leaders and managers supported them when they did so.
- There were adequate systems for reviewing and investigating when things went wrong. The provider learned, and shared lessons, identified themes and took action to improve safety in the service. For example, the providers' service was available to children from the age of 13 years. The provider maintained a tracking system that recorded the patients' age. On reviewing the system, it was noted that two patients under 13 had been seen. The provider carried out an investigation and identified that the tracking system was incomplete, in some respects and there was a need to ensure staff understood the age limit. The age limit had been introduced following CQC registration and some staff did not understand this. At the time of the inspection we saw that that the changes to the tracking system had been carried out and all staff had been made aware of the aged limitations.

The provider was aware of the requirements of the Duty of Candour. There had been no unexpected or unintended safety incidents, since the provider had registered with the Care Quality Commission since June 2018, however the provider had arrangements to:

- Give affected people reasonable support, truthful information and a verbal and written apology and

- Keep written records of verbal interactions as well as written correspondence.

The provider had a system to act on external safety events as well as patient and medicine safety alerts.

Good ●

Are services effective?

We rated effective as Good because:

Effective needs assessment, care and treatment

The provider had systems to keep clinicians up to date with current evidence based practice. We saw evidence that clinicians assessed needs and delivered care and treatment in line with current legislation, standards and guidance (relevant to their service)

- The provider assessed needs and delivered care in line with relevant and current evidence based guidance and standards such as the National Institute for Health and Care Excellence (NICE) best practice guidelines. However, in 2017 NICE acknowledged that the clinical assessment and treatment recommendations in the guidelines were not meeting the needs of people with ME/CFS and a new guideline was required. Some patients were treated outside of NICE guidance, their treatment options were explained to them and the provider used evidenced- based options.
- Patients' immediate and ongoing needs were fully assessed. Where appropriate this included their clinical needs and their mental and physical wellbeing.
- We saw no evidence of discrimination when making care and treatment decisions.
- Staff assessed and managed patients' pain where appropriate.
- The provider used telecommunications applications to provide video, messaging and voice calls between computers, tablets and mobile devices to help patients, such as those who were bedbound, communicate with the services.

Monitoring care and treatment

The provider was actively involved in quality improvement activity.

The provider used information about care and treatment to make improvements. For example, recording the degree of disability experienced by a patient is an important clinical measure. The M.E. Trust (the trust) aimed to have this recorded for 90% of patients. This had been audited twice, in November 2018 89% of patients had their degree of disability recorded, in May 2019 88%. The findings had been discussed at clinical governance meetings and a further audit was planned.

The provider planned to respond to patients' requests for clinical contact within two working days 90% of the time. The provider had audited this across the period October, November and December 2018. In 92% of cases the patients had been contacted within the two working days.

Effective staffing

Staff had the skills, knowledge and experience to carry out their roles.

- All staff were appropriately qualified. The provider had an induction programme for all newly appointed staff.
- Relevant professionals (medical and nursing) were registered with the General Medical Council (GMC)/ Nursing and Midwifery Council and were up to date with revalidation and appraisal.
- The provider understood the learning needs of staff and provided protected time and training to meet them. Up to date records of skills, qualifications and training were maintained. Staff were encouraged and given opportunities to develop.

Coordinating patient care and information sharing

Staff worked together, and worked well with other organisations, to deliver effective care and treatment.

- Patients received coordinated and person-centred care. Staff referred to, and communicated effectively with, other services when appropriate. All patients were asked for consent to share details of their consultation and any medicines prescribed with their registered GP on each occasion they used the provider. Where patients agreed to share their information, we saw evidence of letters sent to their registered GP in line with GMC guidance. We saw that the patients' GP were regularly updated following a consultation with the provider's GP. After each consultation, whether with the GP or physiotherapist the patients received an email reporting what had been discussed and any actions agreed. The provider saw that it was difficult for patients with severe ME/CFS to retain information and manage care plans without such detailed reports.
- Before providing treatment, the doctors at the provider ensured they had adequate knowledge of the patient's health, any relevant test results and their medicines history.
- The provider had risk assessed the treatments they offered.

Good ●

Are services effective?

- Care and treatment for patients in vulnerable circumstances was coordinated with other services. We saw reports to government departments such as, Work and Pensions, concerning patient's fitness to work.
- Patient information was shared appropriately (this included when patients moved to other professional services), and the information needed to plan and deliver care and treatment was available to relevant staff in a timely and accessible way.

Supporting patients to live healthier lives

Staff were consistent and proactive in empowering patients, and supporting them to manage their own health and maximise their independence.

- Where appropriate, staff gave people advice so they could self-care.
- Risk factors were identified, highlighted to patients and where appropriate highlighted to their normal care provider for additional support. Staff regularly advised patients on how to effectively manage their condition, for example, the most effective postures to sit or rest. Staff ensured that patients and carers understood the reasons behind the advice.

Consent to care and treatment

The provider obtained consent to care and treatment in line with legislation and guidance .

- Staff understood the requirements of legislation and guidance when considering consent and decision making.
- Staff supported patients to make decisions. Where appropriate, they assessed and recorded a patient's mental capacity to make a decision.

The provider monitored the process for seeking consent appropriately. For example, where medicines were used outside of the terms of their licence there was substantial guidance to help ensure patients understood the risks and possible benefits. Consent to the use of such medicines was closely monitored.

Outstanding ☆

Are services caring?

We rated caring as Outstanding because:

People were truly respected and valued as individuals and are empowered as partners in their care, practically and emotionally, by an exceptional and distinctive service.

There was a strong person centred culture. Staff were highly motivated and inspired to offer care that is kind and promotes people's dignity.

Relationships between people who use the service, those close to them and staff were strong, caring, respectful and supportive. These relationships were highly valued by the patients and the staff we spoke with.

Staff recognised and respected the totality of people's needs. They always took people's personal, cultural, social and religious needs into account, and found innovative ways to meet them.

People's emotional and social needs were seen as being as important as their physical needs.

People were always treated with dignity by all those involved in their care, treatment and support. Consideration of people's privacy and dignity was consistently embedded in everything that staff did, including awareness of any specific needs as these are recorded and communicated.

Kindness, respect and compassion

Staff treated patients with kindness, respect and compassion.

- The provider sought feedback on the quality of clinical care patients received. Feedback from patients was positive about the way staff treat people. Feedback from patients, both to The M.E. Trust (the trust) and to the CQC was wholly positive. In all we viewed about 55 items of feedback. The CQC website had received ten feedback reviews. During the inspection we received six comment cards and spoke to four patients. All the patients' comments mentioned the caring or compassionate attitude of staff. The comments emphasised the strong, supportive yet professional relationship between patients and staff. Staff we spoke with highly valued the relationship which they said was at the heart of a successful approach to treatment of the condition.
- Staff understood patients' personal, cultural, social and religious needs. They displayed an understanding and non-judgmental attitude. Emotional, social and spiritual welfare was given as high a priority as patients physical needs. There was counselling and chaplaincy support. The two chaplains provided support on a non-denominational basis and this approach was embedded into their training. The non-denominational nature of this support had been mentioned by patients and families of those who did not share the chaplain's' faith, or indeed any faith.
- Chaplaincy and counselling were offered to all the patients at the provider. At the time of the inspection approximately 36 patients were on the chaplaincy list and 45 patients on the counselling list. Over the previous year there had been 72 chaplaincy consultations and 138 counsellor consultations. Both services were available to patients in a variety of media, for example, by telephone, by video link and by email. The services were available to suit the patients' needs or abilities. If patients were not able to sustain a lengthy session with either counselling or chaplaincy then the sessions were cut short and resumed when the patients were able to cope.
- There had been a survey of the effectiveness of the chaplaincy service. All the participants reported an increased sense of hope, from "a little" to "greatly". All the participants reported a lessened sense of social isolation again from "a little" to "greatly". One patient reported that the impact of speaking with chaplaincy had been "transformational"
- The provider gave patients timely support and information. We saw one case where a patient with ME/CFS had been admitted to hospital for an unrelated condition. The patient contacted the provider because they felt that hospital staff lacked an understanding of their needs. The provider's GP went to the hospital to explain to hospital staff how they could better support this patient. The patient reported that the care they received had been transformed for the better. The hospital contacted the GP and asked them to deliver training to staff on the needs of ME/CFS patients.

Involvement in decisions about care and treatment

Staff helped patients to be involved in decisions about care and treatment.

Are services caring?

- Interpretation services were available for patients who did not have English as a first language. Information leaflets were available in easy read formats, to help patients be involved in decisions about their care.
- Patients told us through comment cards, that they felt listened to and supported by staff and had sufficient time during consultations to make an informed decision about the choice of treatment available to them. There was a partnership approach to care. This partnership included the carers, where the patient wanted this. Carers were frequently involved in the discussions about care. Patients severely affected by ME/CFS often have communication difficulties. Staff used creative methods to overcome this, for example, taking with patients and carers on video links and, because patients were unable to respond easily, waiting for a typed response. Clinical staff shared the patients' needs with other staff. Therefore, counselling and chaplaincy, for example, were aware of patients' limitations, such as the time of day or the time span for which they might be available.
- For patients with learning disabilities or complex social needs family, carers or social workers were appropriately involved. We spoke with patients where ME/CFS had an impact on the entire family. They told us that the provider took a whole family, as well as a whole patient, approach to helping the patient manage their own health and care when practicable and to maintain independence as much as possible. Patients we spoke with talked of the provider being the lifeline that enabled them to have any degree of independence. They reported that the advice, from the GP and physiotherapist, about incremental exercise and the importance of structured rest had enabled them to go from being bedbound to getting out of the house once or twice a week. Family members told us how the provider's support had given them a belief that they could change the outcomes for the better. For example, by providing strategies to cope with living with chronic pain, becoming more mobile, and more connected to the local community.
- Staff communicated with people in a way that they could understand, for example, communication aids and easy read materials were available.

Privacy and Dignity

The service respected patients' privacy and dignity.

- Staff recognised the importance of people's dignity and respect. Consideration of patient's privacy and dignity was consistently embedded in the provider's approach. For example, prior to sending a letter to the patient's GP, or other healthcare professional, consent was obtained, and a copy of the letter was sent to the patient so that the patient could check the content.

Outstanding ☆

Are services responsive to people's needs?

We rated responsive as Outstanding because:

Services were tailored to meet the needs of individual people and were delivered in a way to ensure flexibility, choice and continuity of care.

People's individual needs and preferences were central to the delivery of tailored services.

There was a proactive approach to understanding the needs and preferences of people and to delivering care in a way that met these needs, which was accessible and promotes equality.

People could access services and appointments in a way and at a time that suited them.

Responding to and meeting people's needs

The provider organised and delivered services to meet patients' needs. It took account of patient needs and preferences.

- The provider understood the needs of their patients and improved services in response to those needs. The M.E. Trust (the trust) was set up to meet an unmet need. The provision of services for patients with ME/CFS across the country is inconsistent. In 2017 NHS organisations reported that only 27% of NHS organisations have data on how many people have ME/CFS in their locality and only 44% of all UK NHS organisations commissioned a specialist service for M.E. Some such services were only available who could get to a clinic so were not suitable for patients with severe ME/CFS. Services were sometimes delivered solely by Mental Health Trusts, where patients may be reluctant to accept a referral.
- The provider has some 450 patients most of whom have severe or very severe symptoms and who might struggle to find appropriate support elsewhere.
- Many patients who consulted with the provider's staff were vulnerable and/or had complex needs. For example, being bedbound, unable to sustain a conversation for very long or being hypersensitive to light or sound. Staff approached each one as an individual to help them access services and appointments in a way and at a time that suited them. Appointments could be by video link alone, video link accompanied by a typed response, by telephone or by email. With patients having limited powers of concentration staff would wait, perhaps for several minutes before receiving a response during a consultation. For those who needed it, and could not get to the outpatients' clinic, there were home visits. The range of appointments was designed to help ensure that no patient was unable to access care due to the severity of the illness.
- Services had been tailored to meet patients' needs. For example, patients reported to the provider that the traditional counselling approach, focused on depression or anxiety, with treatments such as Cognitive Behavioural Therapy was not always helpful. As a result, in early 2019, the provider moved to an Emotional Support Model where the emphasis was on counsellors building long-term relationships based on empathy, compassion, and concern for, and acceptance of, the patient's condition. Patient feedback has provided support for the change but as yet there have been no formal audits of the new approach.
- The facilities and premises were appropriate for the services delivered. Patients often arrived at the outpatients' clinic tired. There were refreshments available and sun lounger for patients to rest before their appointment. The length of appointments at the outpatients' clinic reflected the patients' needs. They were from 60 to 90 minutes to provide time for the clinical staff to listen carefully.

Timely access to the service

Patients were able to access care and treatment from the provider within an appropriate timescale for their needs.

- Waiting times, delays and cancellations were minimal and managed appropriately. The provider aimed to respond to requests for clinical appointments, either by phone or through the provider's website, within two days. This was audited in 2019 and had been achieved over 90% of the time. The provider was concerned that increased demand for their service was putting pressure on their ability to manage each patient as an individual. To prevent this they had stopped taking new referrals. Although they had managed to maintain outpatients' appointments for new patients who could travel. The provider had recruited additional staff to meet the demand and expected them to be in place in the autumn.
- Patients with the most urgent needs had their care and treatment prioritised.

Listening and learning from concerns and complaints

Outstanding ☆

Are services responsive to people's needs?

The provider took complaints and concerns seriously and responded/did not respond to them appropriately to improve the quality of care.

Information about how to make a complaint or raise concerns was available. The provider had a complaint's policy and procedures. There had been no complaints since the provider registered with the Care Quality Commission. The provider's procedures allowed for lessons to be learned from complaints.

Outstanding ☆

Are services well-led?

We rated well-led as Outstanding because:

There was compassionate, inclusive and effective leadership at all levels.

The provider developed its vision, values and strategy jointly with staff and external partners.

Staff were proud of the organisation as a place to work and spoke highly of the culture.

Leaders had an inspiring shared sense of purpose.

There were consistently high levels of constructive engagement with staff and patients.

Leadership capacity and capability;

Leaders had the capacity and skills to deliver high-quality, sustainable care.

- Leaders were knowledgeable about issues and priorities relating to the quality and future of services. They understood the challenges and were addressing them. For example, demand for services had outstripped supply. The M.E. Trust (the trust) had assessed the demand and considered innovative approaches to the problem. They had recruited nursing support staff, for the first time, and had recruited an additional GP to help meet the demand.
- Leaders at all levels were visible and approachable. They worked closely with staff and others to make sure they prioritised compassionate and inclusive leadership.
- The provider had effective processes to develop leadership capacity and skills, including planning for the future leadership of the provider.

Vision and strategy

The provider had a clear vision and credible strategy to deliver high quality care and promote good outcomes for patients.

- There was a clear vision and set of values. One of the key issues reported by ME/CFS patients was that they felt their symptoms were not believed and they were not listened to. The core values of the provider were designed to address this. The core values were choice, empowering patients to make decisions; dignity, valuing people for what they are; and respect, honouring each person's story and building trust. The provider had a realistic strategy and supporting business plans to achieve priorities.
- The provider developed its vision, values and strategy jointly with staff and external partners. The vision, values and strategy were developed during an "away day" attended by people within and outside the organisation. Attendees included trustees, administrators, clinical staff people with ME/CFS and family members, volunteers and contracted staff. From this a three-year strategy was developed and the provider had supporting business plans to achieve priorities which were monitored.
- Staff were aware of and understood the vision, values and strategy and their role in achieving them

Culture

The provider had a culture of high-quality sustainable care.

- Staff felt respected, supported and valued. They were proud to work for the provider.
- The provider focused on the needs of patients.
- Leaders and managers acted on behaviour and performance inconsistent with the vision and values. There was a strong ethos of recruiting leaders and staff who had had experience of ME/CFS. Therefore, the people working in the provider had an empathy with the problems faced by the patients and their families.
- Openness, honesty and transparency were demonstrated when responding to incidents and complaints. There had been two occasions when patients had been seen outside of the terms of the M.E. Trust's registration. The provider carried out an investigation, it identified that no harm had occurred, the provider spoke with the families concerned and report the matter to the Care Quality Commission. The provider was aware of and had systems to ensure compliance with the requirements of the duty of candour.
- Staff told us they could raise concerns and were encouraged to do so. They had confidence that these would be addressed.

- There were processes for providing all staff with the development they need. This included appraisal and career development conversations. All staff had received annual appraisals in the last year. Staff were supported to meet the requirements of professional revalidation where necessary. Clinical staff, including nurses, were considered valued members of the team.
- There was a strong emphasis on the safety and well-being of all staff.
- The provider actively promoted equality and diversity. It identified and addressed the causes of any workforce inequality. Staff had received equality and diversity training. Staff felt they were treated equally.

Governance arrangements

There were clear responsibilities, roles and systems of accountability to support good governance and management.

- Structures, processes and systems to support good governance and management were clearly set out, understood and effective. The governance and management of joint working arrangements and shared services promoted interactive and co-ordinated person-centred care. There was a meeting of core staff, the director, administrator and clinical governance lead weekly. There were clinical team meeting every six weeks, this meeting includes counsellors and chaplaincy as it seeks to address the wholistic needs of the patient. The trustees met quarterly. There were effective processes for communication. For example, the director and clinical lead attended for part of the clinical meeting. The clinical team were invited to a trustee meeting once a year. There was an "away day" for all staff once a year where concerns could be raised and improvements suggested.
- Staff were clear on their roles and accountabilities
- Leaders had established proper policies, procedures and activities to ensure safety and assured themselves that they were operating as intended.

Managing risks, issues and performance

There were clear and effective processes for managing risks, issues and performance.

- There was an effective, process to identify, understand, monitor and address current and future risks including risks to patient safety.
- The provider had processes to manage current and future performance. Performance of clinical staff could be demonstrated through audit of their consultations, prescribing and referral decisions. Leaders had oversight of safety alerts, incidents, and complaints.
- Clinical audit had a positive impact on quality of care and outcomes for patients.

Appropriate and accurate information

The provider acted on appropriate and accurate information.

- Quality and operational information was used to ensure and improve performance. Performance information was combined with the views of patients.
- Quality and sustainability were discussed in relevant meetings where all staff had sufficient access to information.
- The provider used performance information which was reported and monitored, and management and staff were held to account
- The information used to monitor performance and the delivery of quality care was accurate and useful. There were plans to address any identified weaknesses.
- The provider submitted data or notifications to external organisations as required.
- There were robust arrangements in line with data security standards for the availability, integrity and confidentiality of patient identifiable data, records and data management systems.

Engagement with patients, the public, staff and external partners

The provider involved patients, the public, staff and external partners to support high-quality sustainable services.

- The provider encouraged and heard views and concerns from the public, patients, staff and external partners and acted on them to shape services and culture. For example, the provider had changed its model for providing counselling from a traditional to an emotional support model as a result of patients' feedback. The provider was planning a patient participation group (PPG), the first planning meeting was scheduled for September 2019. The structure of the PPG was to include a carers' discussion group. Given that many patients were bedbound and with communication problems this had been a difficult exercise. There was regular feedback from patients and carers on the services they received. We saw for example, feedback from a chaplaincy survey which evidenced that the service was effective in supporting patients.

- A staff member undertook a charity marathon the raise money for M.E. Trust 75 people posted “thank you” responses on the marathon’s website. Most of these responses were from people or carers of people with ME/CFS. Many comments thought that the charity run had helped to raise the profile of patients with ME/CFS.
- Staff could describe to us the systems in place to give feedback. We saw evidence of feedback opportunities for staff and how the findings were fed back to staff. We also saw staff engagement in responding to these findings.
- The provider was transparent, collaborative and open with stakeholders about performance.

Continuous improvement and innovation

There was evidence of systems and processes for learning, continuous improvement and innovation.

- There was a focus on continuous learning and improvement. The provider clinicians were familiar with the latest guidance and research of treatment of ME/CFS. The provider’s GP have been asked to speak to clinical commissions groups and health boards across the United Kingdom to raise awareness of the effects of severe ME/CFS.
- National Institute for Health and Care Excellence (NICE) best practice guidelines are in the process of revision. The provider, as part of “ME forward”, an umbrella organisation, are contributing to that process.
- Managers encouraged staff to take time out to review individual and team objectives, processes and performance.