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# Reducing DNA Rates and Increasing Positive Contacts in an Outpatient Chronic Fatigue Service

Tumseela Masoud, Amar Shah, Shameem Joomun, Amar Shah

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## ABSTRACT

The Chronic Fatigue Service at East London NHS Foundation Trust recognised and coalesced around its major issue of engaging its service users. Using the systematic approach of quality improvement, and the infrastructure provided within East London NHS FT's quality improvement programme, it tested a number of change ideas which saw a significant reduction in non-attendance at appointments, an increase in patient cancellations when they could not attend, and an increase in positive contacts with the service. All these improvements surpassed the initial aims set within the project, and have been sustained over the course of 18 months.

## PROBLEM

Since the introduction of the Chronic Fatigue Service in East London NHS Foundation Trust (ELFT) outcome data has shown that approximately three quarters of patients with a diagnosis of Chronic Fatigue Syndrome either recovered or showed improvements in their illness from being in the clinic. A randomised trial showed that a quarter recover and half show significant life improvement.<sup>1</sup> Over recent years, it had been noticed that the level of engagement in the Chronic Fatigue Service was beginning to decline, i.e the number of patients not attending their appointments was increasing. This quality improvement (QI) project was designed by the professionals working within the service with the aim of improving engagement with the evidence based multidisciplinary service by reducing non-attendance at appointments and increasing positive contact rate. The various aspects of the service which were addressed within the project are illustrated further below.

## BACKGROUND

Chronic Fatigue Syndrome (CFS) otherwise known as myalgic encephalomyelitis represents a complex debilitating disorder with a

wide range of physical and psychological sequelae. The National Institute for Health and Clinical Excellence (NICE) released guidelines in 2007<sup>2</sup> stating a diagnosis of Chronic Fatigue Syndrome should be considered if: fatigue is present for 3 months and is of new onset, persistent or recurrent, unexplained by any other condition, substantially reduces the amount of activity an individual can do, and the person subjectively feels worse after minimal physical activity. Associated symptomatology include, insomnia, muscle or joint pains without inflammation, recurrent headaches, tender lymph nodes, sore throat, flu-like symptoms, difficulty in thinking, dizziness, nausea, and heart palpitations without cardiac morbidity.

The diagnosis must be made by a clinician and is a diagnosis of exclusion, where other conditions have been ruled out. There is currently no conclusive epidemiological data in the UK for Chronic Fatigue Syndrome, but estimates have been made from extrapolations in other countries. An estimated prevalence of between 0.2-0.4%<sup>2</sup> has been calculated, so in a clinic with 10,000 patients, up to 40 people would suffer from the illness with half requiring specialist input from a CFS clinic.<sup>2</sup> A more recent report from the MRC<sup>3</sup> suggests that the scale and impact of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) on individuals and society is significant. Around 250,000<sup>4</sup> people in the UK have ME/CFS which is at least as disabling as multiple sclerosis and congestive heart failure.<sup>5</sup> Many more people – carers, children and family members – are directly affected by the illness each year. The economic cost of ME/CFS was estimated at £6.4 billion<sup>6</sup> per year in the UK in 2006, and this figure will likely have increased since.

Research has looked at a variety of aetiologies for CFS ranging from infectious, immunological, neurological, endocrine, genetic and psychiatric but to this date, the exact



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aetiology is not fully understood.<sup>7</sup> There is a need for further detailed research in this area. The UK CFS/M.E. Research Collaborative (CMRC) announced in 2015 aims to promote high quality research into ME/CFS.

Due to its chronic and disabling nature, and impact on both patients and their families, this illness has presented itself as a significant problem to clinicians, and specialist services have thus needed to be developed for the early diagnosis and management of this complex disorder.

A decision to refer to a specialist Chronic Fatigue Service care is usually based on the patient's needs, the type, duration, complexity and severity of symptoms, and the presence of comorbidities. The decision to refer to a specialist service needs to be patient centred, and involve both the health care professional and the patient jointly. Referrals are usually within 6 months for those with mild symptoms, 3 months for those with moderate symptoms and immediately for those with symptoms at the severe end of the spectrum.<sup>2</sup>

The Chronic Fatigue Services provides a specialist comprehensive, multidisciplinary outpatient service for patients with Chronic Fatigue Syndrome. The service consists of professionals such as doctor physicians, liaison psychiatrists, psychologists, physiotherapists, and occupational therapists, who are supported by an overall manager and administrative staff. The multidisciplinary approach places emphasis on rehabilitation, and offers expert medical assessment and therapeutic interventions based on best models of care and evidence base, showing an enhanced patient care and satisfaction. The Chronic Fatigue Service in East London NHS Foundation Trust is one such service that provides the multidisciplinary input mentioned. The Chronic Fatigue Service in East London NHS Foundation Trust is provided jointly with Barts Hospital. It is one of the largest in the UK. The service is delivered by 10 clinicians similar to those mentioned above. The service also additionally provides domiciliary assessments, and sometimes treatments, for bed bound patients. The service was established 30 years ago.

The primary goal of the quality improvement project was to improve the engagement to evidence-based therapy in the Chronic Fatigue Service. As a result there were three main aims to the project. These were:

- To reduce non-attendance/DNA rates to 7 per cent for all appointments by 31st December 2015.
- To reduce cancellation rates to 12 per cent for all appointments by 31st December 2015.
- To increase percentage of positive contacts to at least 75 per cent for all appointments by 31st December 2015.

## BASELINE MEASUREMENT

The measures used to demonstrate improvement were:

- proportion of non-attendance at appointments. At baseline, the percentages were 8.47 per cent.

- proportion of appointments cancelled by the patients. At baseline, the cancellations were 16 per cent.
- positive contacts as a proportion of total contacts. At baseline this was 66.69 per cent.

Data was recorded from August 2015 to February 2016 to look at the period post study as well. Baseline data was collected prior to any changes being introduced, and then monthly throughout the life of the project. All data was obtained from the performance reporting system. The CFS team reviewed and reflected on the data throughout the project, making adjustments to the process and tests along the way.

## DESIGN

Prior to the quality improvement project, it was evident from the increasing DNA numbers, that patients were not attending their appointments regularly and kept being offered more appointments.

The initial step was to send out to all patients registered with the service the Engagement and Disengagement Policy. In this policy, patients were offered up to a maximum of 25 sessions, based on the principle that if they did not attend an appointment they lost a session. It was clarified that if they cancelled an appointment, however, it did not count as a lost session. The theory behind this change idea was that making the boundaries clear regarding the duration of therapy, and clarifying the consequences of not attending an appointment, would lead to patients valuing their sessions more and attending more often.

Another intervention tested was to offer telephone sessions more routinely. If the patient was too unwell to attend or had childcare or work commitments, in order to maintain engagement, telephone contact was made by the relevant clinician and this counted as a positive patient encounter. The theory here was that by maintaining engagement with the patient and offering alternative modes of therapy to fit around the patient's needs, the service was more likely to see sustained engagement over the course of therapy.

Prior to the start of the project, the team utilised a paper diary to record all appointments, cancellations, rebookings and schedules. A change idea was to move to a centralised booking system that everybody could access electronically, making it easier to book and reschedule an appointment.

Referrals within the Chronic Fatigue Service were made to other disciplines such as Physiotherapy, Psychology, and Occupational Therapists by the medics and other professionals. This process normally followed a session, and this internal referral system meant that the patient received an appointment letter 3-4 weeks later for an appointment with physiotherapy, psychology, etc. This led to the time from the initial medical assessment to the first therapy appointment being longer than necessary. A change idea tested within the project was to give the patient a referral slip at their first appointment,

which was taken to the reception where he/she was given the relevant appointment immediately.

Another issue was the recording of accurate outcomes in the electronic clinical record system following appointments. The clinicians were given a crib sheet with a list of outcomes that were numbered (i.e. attended, cancelled, etc). If clinicians failed to outcome following an appointment, they recorded the relevant number from the crib sheet on their electronic calendar, and thus enabled the admin team to input the outcome correctly themselves.

Speaking further to why patients were not attending appointments, it became clear that they often simply forgot, confused their date or turned up on the wrong day for their appointments. Understanding this led to the team introducing the change idea of text message reminders for appointments in order to provide up to date reminders with key details close to the date of the appointment.

Please see Driver Diagram attached to describe the change theory, Figure 1.

## STRATEGY

Four change ideas were tested using PDSA cycles, as described below. The PDSA cycles were all implemented at the same time. However, the text message reminder (most effective change idea) required four further cycles of PDSA:

1. To develop and distribute a local engagement and disengagement policy.
2. To switch to a centralised booking system for appointments
3. To develop a team therapy waiting list (where new referrals were added and where clinicians could check regularly).

4. To manually send electronic text message reminders for appointments

Predictions:

1. That attendance will improve.
2. Cancellation rate and non attendance/DNA rate will decrease.
3. Overall positive contact will increase.

The testing and implementation of text message reminders required four further cycles of PDSA testing:

Cycle 1: Introducing text message reminders for all new medical assessments for 1 month.

Cycle 2: Introducing text message reminders for all medical appointments for 1 month.

Cycle 3: Introduce text message reminders for all appointments for 1 month.

Cycle 4: Continue text message reminders for all appointments.

Each PDSA cycle learnt by looking at the project level measures (tracked throughout the lifetime of the project) together with PDSA-level measures (for eg: asking patients in the clinic whether they received the text message reminders, the engagement policy, and what they thought of it).

## RESULTS

Through the PDSA cycles of testing, the team found that clinicians had to be prompted to remind patients of the Engagement and Disengagement policy.

By updating patients on the Engagement and Disengagement policy, the percentage of cancellations in the clinic went from 21.92% to 11.76% between December 2014 to January 2015. This reduction was sustained throughout the project with cancellations fluctuating between 10-14%. The baseline average

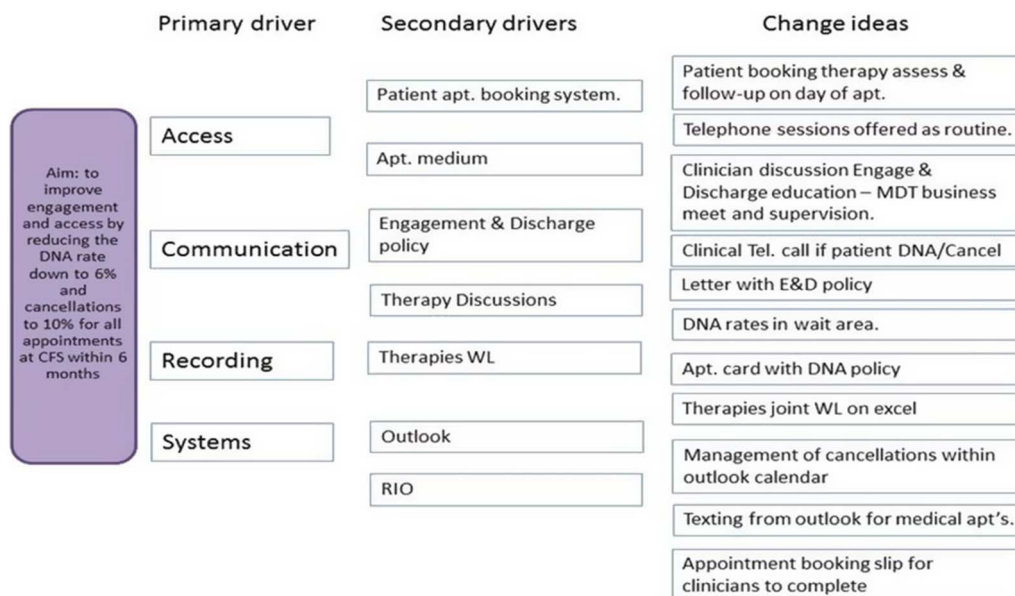


Figure 1 CFS driver diagram

cancellation proportion was 16.0% and this reduced to a new average of 9.6%. The lowest cancellation proportion within a month was 6.5% in March 2015 (please see Figure 2). It was felt that reminding the patients of this policy actually emphasised that their cancellations were followed with consequences and failure to engage would result in a discharge from the service. It encouraged patients to be more proactive about their own care, which is reflected in the results.

Appointments were more easily accessible by the admin team by the centralised booking process. Appointments could be cancelled and rescheduled quicker. When qualitative data was gathered from both staff and service users regarding the change ideas, which demonstrated that service users were more aware of the number of sessions they would receive, this led to them informing the service when they could not attend an appointment.

After implementing the change idea of electronic text messages in May 2015, there was a significant reduction in non-attendance at appointments. The average percentage reduced from 8.47% to 3.58%.

Through the combination of change ideas being tested, the service observed an increase in percentage positive contact from an average of 66.69% during the baseline period to a new average of 79.88% which was sustained through the project.

## LESSONS AND LIMITATIONS

The project generated many learning points. By streamlining processes and with enough flexibility on appointments days and times, patients were able to choose a more suitable appointment for themselves, which had a positive impact on their engagement with the service and led to a reduction in their non-attendance and cancellation rate.

Adequate training on how to use the patient electronic system was also a necessity for clinicians as they had to record outcomes using an appropriate code, which led to more reliable and accurate recording of outcomes.

Constant reminders to the wider multidisciplinary team members in team and QI meetings of what this project is trying to achieve, and the roles of clinicians, helped drive the project further towards completion and better involvement of all those involved. Constant motivation of team members was central towards the successful completion of this project.

Given the effort put into motivating the workforce to achieve the aims of the project and the impact of that on the results achieved, it was clearly evident that this needs continued attention in order to be sustainable and effectively implemented into the way the team functions. To ensure these changes are sustained in the future, the service meets regularly to look at the data,

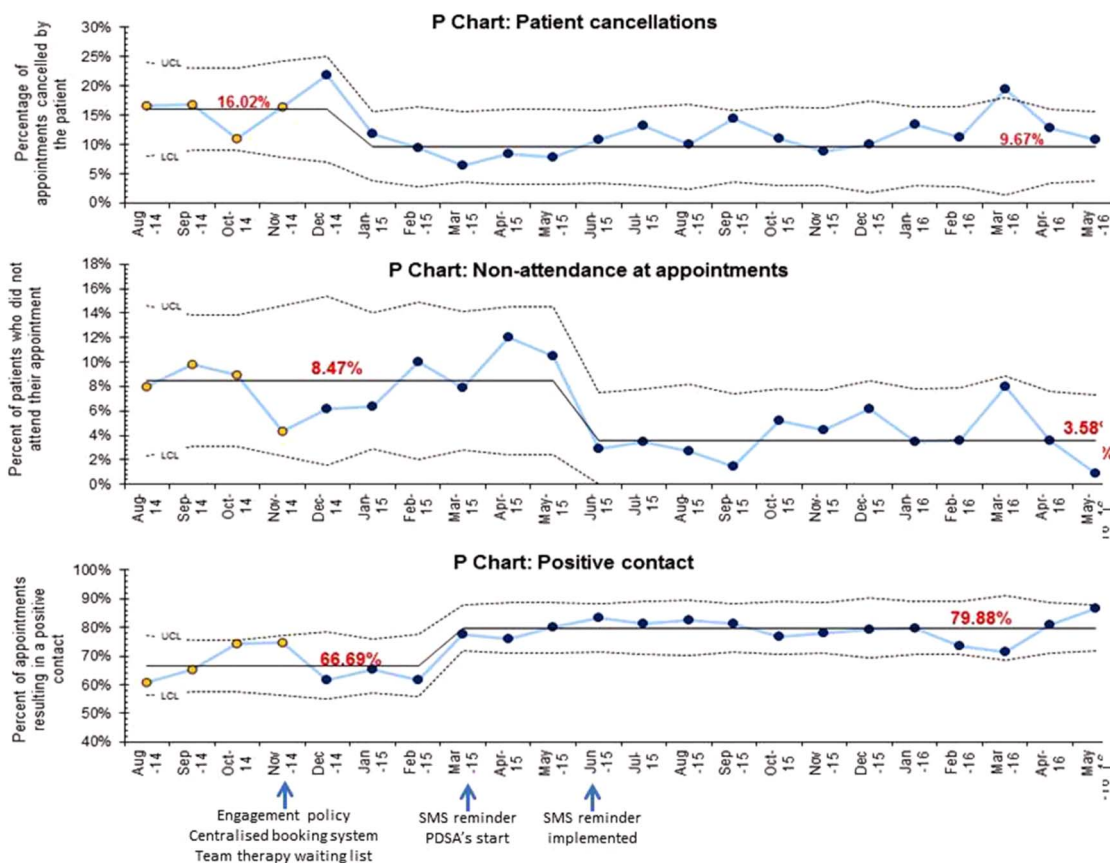


Figure 2 CFS charts

and there are plans for regular 3 monthly audit of their data. In this way, the team has switched from intense effort through quality improvement leading to a step-change in performance, to move into assurance and control mode (with periodic checks to make sure the gains are sustained).

There were also limitations to the project. These were related to patient factors. Firstly, the most effective change idea seemed to be the introduction of text message reminders. However, there were some patients that wanted to keep their numbers confidential and therefore could not have been informed with up to date reminders of their appointment date and times. All patients were asked for their consent prior to this change idea. Had they been willing to receive text messages, the reduction in non-attendance could have been even greater.

Coupled with that, due to the inherent nature of the illness, some patients, despite all the change ideas implemented remained unable to attend or forgot to call in to inform of their non-attendance to appointments.

Overall, the team felt that the project generated robust change ideas and results that can be applied in similar clinic settings to achieve similar results.

## CONCLUSION

The initial problem encountered in the Chronic Fatigue Service over the years was one of climbing DNA rates and falling positive contact. There was felt a need to increase positive engagement with the service as outcome measures showed significant clinical improvement following engagement with the service historically. The quality improvement project with its change ideas (centralised appointment booking system, Engagement and Disengagement Policy, tele-therapy, telephone follow up calls to patients, text message reminders, therapy waiting list, patients booking therapy assess and follow up on day of appointment) helped achieve and far exceed the aims of the project, namely a reduction of non-attendance to below 7%, reduction in cancellation rate to below 12% and increase in positive contact to above 75%.

The project has been a success due to several factors, without which this would not have been possible. Initially, it was hard to get people on board but with time and perseverance, we managed to overcome that barrier and with a motivated team, it was easier to steer the project towards completion. The administrative team played a crucial role in this project by ensuring data was recorded in an accurate and timely manner. Clinicians were fully involved and agreed to adopt the new processes being tested. Another team who played an important role in the success of this project was the Informatics

team who provided the data required for analysis on a monthly basis. Having regular reflective discussions about the success or failure of change ideas was key to the success of this project. After more than 18 months of quality improvement work, the Chronic Fatigue Service continues to sustain the gains demonstrated here, which is testament to everyone involved directly or indirectly in this project.

This proves that the outcomes that were achieved have been sustainable following the period of the quality improvement project and have introduced new and more efficient ways of working into the team. There were no financial costs of this project, however, changing the way the team worked and reducing DNA rates/increasing positive contacts has made it a more cost effective service in the long run. The cost of the extra time and human resources invested has contributed to this longer term gain.

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**Declaration of interests** No conflicts of interest to declare.

**Ethical approval** According to East London NHS Foundation Trust's policies on ethical approval, research and quality improvement, this work met criteria for operational improvement activities exempt from ethics review.

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