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A comprehensive service re-evaluation of the UK's first NHS generic fatigue clinic four years following its inception: a mixed methods study

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Research

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CONFLICTS OF INTEREST

There are no conflicts of interest for any of the authors.

ABSTRACT

Objective: To identify if the Newcastle CRESTA (Clinics for Research in Themed Assessment) fatigue clinic continues to meet patient expectations, two years since an initial evaluation in 2015, following changes to the original service model.

Background: The CRESTA fatigue clinic was established in 2013 to fulfil the unmet needs of patients with long-term conditions and the symptom of chronic fatigue who did not have access to fatigue management support. The service was previously evaluated using a group concept mapping (GCM) approach and found to successfully meet patients' expectations. To ensure these needs continued to be met following change to

the original service model, we re-evaluated the service using a similar approach. GCM is a mixed method approach. Statements are generated from stakeholders, sorted into themed clusters, and then rated.

Method: 146 assessment tools were posted to consecutive clinic patients containing statements generated during the original study. Patients rated each statement for 'current success' on a 1-5 Likert scale and provided for free-text feedback. Unpaired t-tests were used to compare cluster success scores from both the previous evaluation and the current cohort of patients. Thematic analysis was used to evaluate the qualitative comments.

Results: 46 questionnaires were returned. Compari-

son of the cluster success scores revealed the clinic has maintained its previous success and made significant improvements in peer support ($p \geq 0.001$). The free-text comments were mainly positive and patients found the service to be invaluable.

Conclusion: The CRESTA fatigue clinic continues to successfully meet patient expectations and has made significant improvements in peer support.

INTRODUCTION

Fatigue is a perplexing and distressing symptom that affects people with a variety of health conditions including chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME)[1], rheumatological diseases[2][3] and post cancer treatment[4]. In some cases, there is no known reason for fatigue, thus it remains an ambiguous condition.[5]. The Newcastle CRESTA (Clinics for Research in Themed Assessment) fatigue clinic was established in 2013, and was the UK's first NHS generic fatigue clinic. It was set up to fulfil the unmet needs of patients with long-term conditions and the symptoms of chronic fatigue, who did not have access to symptom management support[6]. The service was subsequently evaluated, to identify and prioritise service needs of its patients. This was carried out using a group concept mapping (GCM) approach and was found to successfully meet patients' expectations[7]. This initial study confirmed that people want their fatigue and their associated symptoms to be taken seriously by clinicians and ultimately, to be 'believed'. Patients with chronic fatigue need professionals to understand and empathise with their condition or symptoms, without judgment[8].

Over the first four years the clinic has grown with increasing numbers of referrals in 2015, these numbers warranted a process review, as we were unable to sustain our one stop model. This model gave patients the opportunity to see every member of the multi-disciplinary team, throughout one clinic visit (Figure. 1a). However, this became difficult to implement, as the patient numbers increase. We therefore amended the clinic model (Figure.1b) and developed a patient information booklet 'Managing Your Energy' in partnership with the multi-disciplinary team and a group of trained patient Health Champions[9] through a series of round table discussions.. We now offer this resource booklet to new patients attending the clinic.

The Health Champions are volunteer expert patients who bring their own life experiences and skills with the broad aim of improving their health and the health of other patients accessing the clinic. A facilitator from NHS England North trained and supported the Health Champions to develop support networks, groups, and environments, which promote healthy choices and wellbeing. Evidence suggests that this method of empowerment and engagement in the community has shown significant improvement in

overall health and wellbeing[9]. The Department of Health White Paper, explains that individuals need to be empowered to make healthy choices and to address their own particular needs. Thus, the introduction of Health Champions has been a positive way to help achieve this goal[9][10].

Figure 1a: Flow diagram of patients attending CRESTA Fatigue Clinic at time of previous study[15].

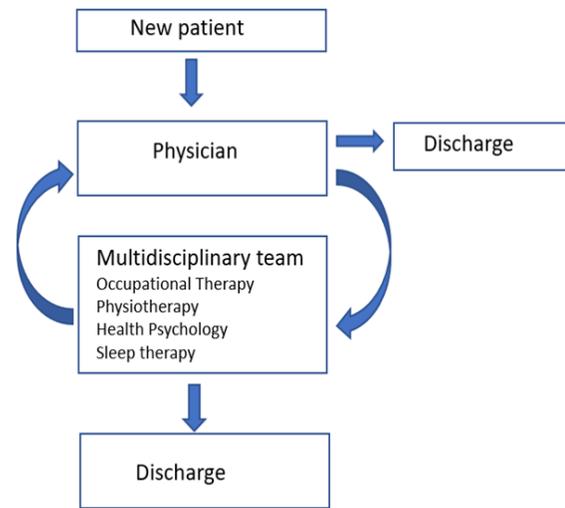
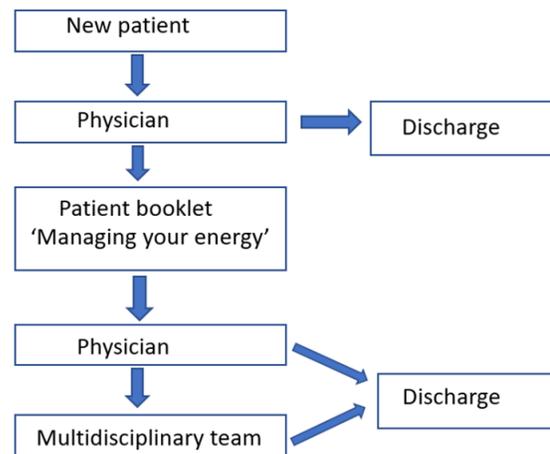


Figure 1b: Flow diagram of the amended CRESTA Fatigue Clinic model.



Furthermore, following the initial clinic evaluation, demand for the service has increased, placing an unsustainable demand on individual therapy appointments. Subsequently, following an individual assessment, most physiotherapy treatments are offered in groups of 6-8 patients over a six-week programme.

To ensure we continue to meet the needs of clinic patients and in light of the recently implemented changes, we believed it was important to re-evaluate the service using the same factors identified by patients and referrers as part of the original study[7]. These factors, or ideas, were identified through a brainstorming exercise involving clinic patients and clinician referrers. A cohort of patients in 2014 subsequently sorted these individual ideas into themed clusters of statements. Patients then applied a success rating score to each statement, from which themed cluster success scores were calculated.

Our primary objective was to compare the clinic's current success scores for each of the themed clusters with the original 2014 success scores, following the implementation of the service changes. This would enable us to determine whether the service continues to meet the needs of its patients. Our secondary objective was to capture further qualitative feedback from a recent cohort of clinic patients exposed to the recent service changes.

METHOD

Eligibility criteria

We invited patients who had attended the CRESTA Fatigue clinic, for a minimum of two occasions, within a 6-month period, to complete a questionnaire to rate the clinic's success. The 6-month period, allowed us, to capture our most current patients who had been exposed to recent clinic changes following the previous service evaluation. 146 patients were deemed eligible to receive the anonymous postal invitation pack, containing a covering letter explaining about the clinic re-evaluation and a questionnaire, which included demographic questions capturing; age, gender, diagnosis, travel time to clinic and which team members patients had seen, on their visits to the clinic.

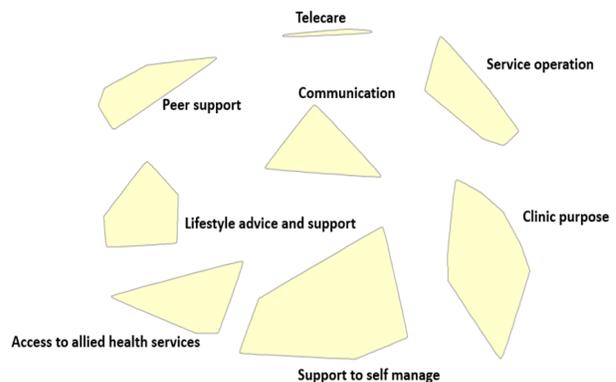
Concept mapping

Group concept mapping methodology (GCM), developed by[11] was used in this evaluation. It is a mixed-methods participatory approach, which uses a combination of group processes (brainstorming, sorting, rating, and interpretation) and a sequence of multivariate statistical analysis steps (multidimensional scaling and hierarchical cluster analysis) that result in concept maps. Concept maps are visual representations of how participants conceptualize the relationship between ideas which they have generated on a particular topic and include themed clusters containing similar meaning statements (Figure 2). Priority values are added by participants to the qualitative statements gathered during a brainstorming phase. These rated statements can be interpreted in pattern matches (which compare rating values of the themed clusters) and value plots (comparing rating values of individual statements) and used in planning or evaluation studies[12].

The rating questionnaire

A 'success rating' questionnaire was compiled from a list of statements which were generated from stakeholders in the original clinic evaluation concept mapping study [7]. The list of statements can be seen in Table 1. The rating questionnaire allowed recent patients to identify, how successful they perceived the clinic to be at meeting their needs. They were asked to apply a value judgement to each statement on a Likert scale (1-5). The instructions for the current success rating questionnaire were; 'rate each statement below according to how the CRESTA fatigue clinic is at meeting each need' and to circle a number between one and five. One on the rating scale represented the need as 'not being met' and a five represented 'need successfully met'. Finally, each questionnaire invited respondents to provide free-text feedback (positive or negative) about the clinic following the rating questions.

Figure 2: An example of a concept map made up of themed clusters.



Analysing the data

We took completed questionnaires as patients' consent, to use their individual data in the re-evaluation. We analysed the data in two parts. Firstly, we examined the 2016 'current success' rating scores in software designed for concept mapping projects (Concept Systems Global Max™) and calculated mean success rating scores for each statement and cluster. Next, we compared the mean cluster current success scores with the 2014 initial success scores using independent t-tests and generated a pattern match to provide a visual representation of these scores. Secondly, we analysed the qualitative free text feedback using thematic analysis [13]. We made comparisons between age and gender of the both cohorts using independent t-test and fisher's exact test respectively in Minitab 17.

RESULTS

Quantitative data

46 out of 146 questionnaires were fully completed and returned by patients who had attended the CRESTA clinic two or more times, within the previous 6 months (March 2016 - Sep 2016). There was a significant difference in age between the 2014 patient respondents (M=43.1 SD17.1) and the 2016 group (M=52.2 SD 17.8); $t(88) = -2.49$, $p=0.015$ with the 2014 patients being younger than 2016 cohort. However, the gender distribution was similar in the two cohorts with a male prevalence of 15.22% (7/46) in the 2014 group and 13.04% (6/46) in the 2016 group ($p=1.0$).

The pattern match [Fig. 3] and t-test comparisons between the initial success in 2014 vs Current success in 2016 revealed no significant differences between success scores for each cluster, with the exception of 'Peer Support', where the success ratings had significantly improved ($p=0.001$).

Qualitative free text comments

The themes emerging from the free-text qualitative feedback included; 'Understanding my condition', 'Improve quality of life', 'Peer support', 'Resources', 'Technology' and more. Table 2 illustrates all the organising and high order themes. Common higher themes emerging, through the various narrative/comments of the patients, were their implicit

and explicit references to the following:

'Condition management'

Patients felt the clinic was able to understand and help them manage their condition "The clinic helped me understand my condition and accept my difficulties and find ways to improve quality of life", and provide them with strategies to help increase their quality of life: "The service certainly provided me with strategies I needed to improve my quality of life". The nature of fatigue can restrict the patient's ability to fulfil their usual roles, thus condition management is one of the key elements of the clinics success.

'Excellent Service'

Most of the patients felt the service and treatment offered, on their visits to the clinic were excellent: "They offer a holistic, practical and useful service that has certainly helped and still helps me" and the clinic offers a warm, welcoming, and friendly environment: "An Excellent service, everyone was very friendly and informative from entering reception to consultations". The patients have high regard for the health professionals they see in the clinic: "The staff are brilliant they understand when you are having an off day and don't think it's 'put on'" and for the service overall: "The CRESTA clinic has changed my life!"

Figure 3: Pattern match demonstrating success rating results at cluster level. Mean success scores for the statements falling within each cluster are presented and clusters that were given comparatively higher scores are positioned nearer the top of the pattern match.

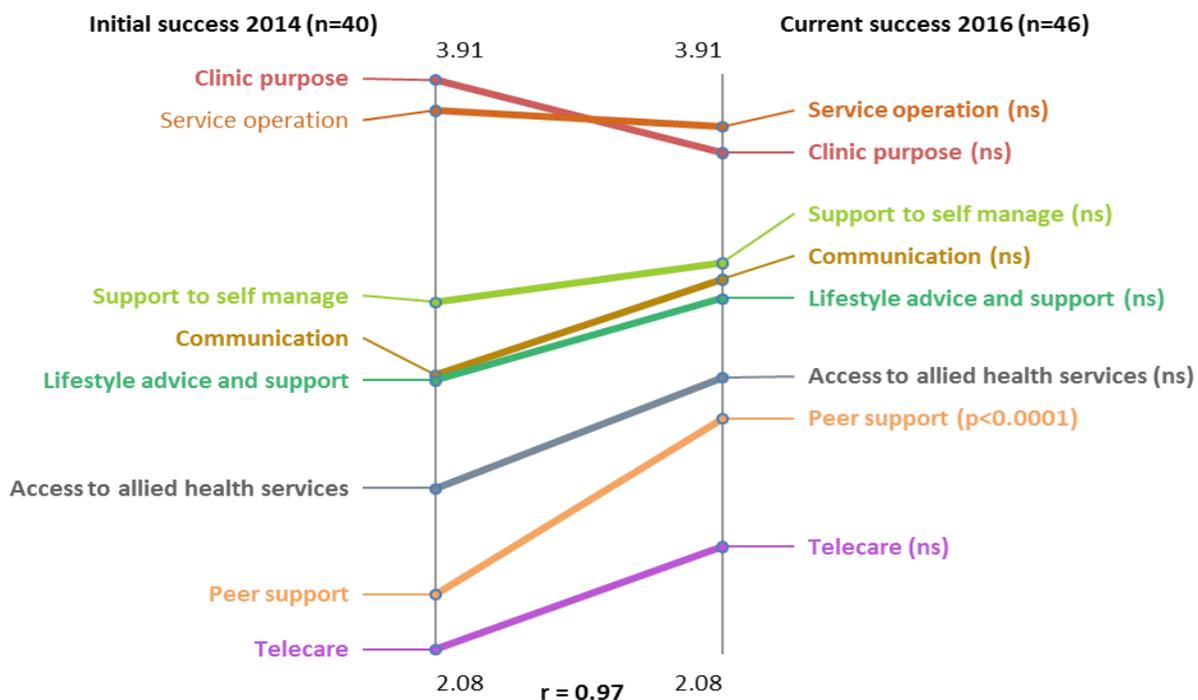


Table 1: Shows a refined statement set generated from stakeholders in the original clinic evaluation.

Improve my health	Clinic staff to liaise with other clinicians and agencies (when appropriate)
Inform me of my test results	Believing my symptoms
Provide up to date advice	Deliver an endurance exercise training programme
Make it possible for me to be in touch with others who have fatigue	Provide access to a dedicated team of professionals
Provide me with a diagnosis	Provide access to a dedicated team of professionals
Support with managing work and/or education	Provide me with exercises
Advice about outside support/support groups	Offer telephone appointments
Take my fatigue seriously	Provide new ways to help me cope with the fatigue
Inform me how I could make beneficial changes to some of my behaviours	An opportunity to discuss my symptoms
Give me hope	Provide a clinic close to where I live
Provide a culture of understanding which leaves patients understood and less isolated	Access to occupational therapy
Support me to better manage my symptoms	Help to distinguish which symptoms are due to which condition
Inform me of relaxation and meditation techniques	Help me cope with brain fog
Access to a telephone or email helpline for advice and support when required	Guidance on how best to take my medication
Co-ordinate appointments with different members of the clinic team on the same day	Help with my sleeping
Copy of letters to GPs to be sent to patients	A group session for patients to be able to meet up with each other every few months
Help me to explain my symptoms to others to help them to better understand	Help to reduce my isolation
Deliver a personalised treatment programme	Time in appointments to express my feelings
Have medical students in clinic so they can learn about fatigue	Help me improve my balance
Being able to talk to someone about anything	Help me overcome my dizziness
Opportunities for me to be involved in research studies	Provide an online drop in clinic
Support me to manage life events such as change in working patterns or temporary lifestyle changes	Cure my problem
Provide information to referring doctors about the clinic and the referral criteria	Provide written information about my condition,
Access to physiotherapy	Provide letters giving information on my health and abilities for benefit claims
Meet other people with similar problems and learn how they manage	Start a class to promote exercise
Help me to understand my symptoms	Help to manage pain
Support me to manage my daily activities	Have the option for skype (or similar) appointments
Provide massage and hydrotherapy sessions	Being offered a physical assessment
Provide support, encouragement and reassurance	Advice about diet
Investigate potential causes of my fatigue and offer treatments for them	Online forums and/or discussion board for CRESTA patients to share stories
Offer one to one counselling	Advice on balancing activities and rest
Appointments to review my progress periodically	Face to face contact
Provide a leaflet which explains about the clinic prior to my first appointment	Advice on how to increase activity/exercise levels without reaching burn-out

Assist me in reaching my unique goals	Access to psychological therapy
Provide a leaflet which explains about the clinic prior to my first appointment	Provide access to an expert patient
Assist me in reaching my unique goals	Look at all my symptoms as a whole
Offer a range of appointment times	Advice about financial support
Provide letters giving information on my health	Keep the clinic going
Offer follow up appointments	Keep me informed of new research findings
Being able to talk to someone who is not a patient or a doctor	Help me manage anxiety and stress

Table 2: Illustrates all the organising and high order themes.

Organising Themes	Higher Order Themes	Global themes
Understand my condition Accept my difficulties Improve quality of life Understanding PTs condition Provide me with strategies Acceptance	1. Condition management	
Comments about staff Supporting patients Peers and support Comments about the service Friendly Informative Feelings Appreciation Resources	2. Excellent service	Positive and valuable service
Technology Appointments Travel	3. Recommendations	

‘Recommendations’

Patients freely offered recommendations for the service they felt would benefit them and others: *“Afternoon appointments need to be available at the CRESTA clinic”*. Patients felt that a wider range of appointment times should be available and technology should be utilised, to make the service and its resources more accessible to all: *“It would be very useful for me if skype appointments and online drop in clinic were available”*.

Patient narratives were largely positive and demonstrated appreciation and gratitude for the clinic, indicating its continued success. Patients offered their suggestions for improving the service, through ‘recommendations’. Other comments highlighted the clinic’s stretched resources and the need for expansion; *‘No choice of time for appointments’*, *‘Letters from the clinic can be slow’* and *‘Shame the resources are so*

stretched, but ‘I’m so happy to have access to it’. However, the consensus was, that the fatigue clinic offered a positive and valuable service; *‘I really appreciate having access to the clinic.’*

DISCUSSION

The Newcastle CRESTA fatigue clinic continues to maintain patient satisfaction with the current success ratings demonstrating that the service continues to meet the majority of its patient’s needs. This is despite an increase in referrals and a required change in the service delivery model. Patient narratives demonstrate an appreciation for the service. Patients clearly want a service which shows understanding for the unique challenges their fatigue may bring. The clinic continues to successfully meet this expectation. This is understandable, when patients want to improve their quality of life and engage in the world, as others do, who are

well. The need to ration their energy and manage symptoms is a challenge in its self. Therefore, to have a team, who can advise and support patients with appropriate guidance in how best to do this, is invaluable. Patients demonstrate their motivation and drive for answers and support, merely by their attendance at clinic. This can be a mammoth task for some patients and this effort means many patients risk an exacerbation of their symptoms. However, their desire to function and feel 'normal' is a powerful intrinsic driver.

There are questions that must be considered when patients do come to the clinic. Are patient's expectations too high? Do they expect more than the clinic can offer? What are the cost implications for the service? There are limited services available and resources are stretched, meaning their issues may not be adequately addressed or some of their questions may remain unanswered by health professionals. The clinic appears to be equipped at dealing with these sensitive issues and helping patients with their understanding, even when there is no definitive diagnosis.

Peer support received one of the lower cluster success ratings in the original study. The significant improvement in peer support demonstrated in this re-evaluation, is a clear indicator that clinic improvements have contributed towards meeting this important patient need. As we have implemented a range of service improvements, it is not possible to pinpoint whether one specific improvement is directly responsible, or whether several have had a combined effect. However, we assume that the reasons for improvement in this cluster are multi-factorial. We believe the peer support provided by Health Champions' initiatives (including a social media group and social events in the community), as well as the provision of exercise interventions in groups have supported this improvement. With the physiotherapy interventions taking place in groups over a six-week block, patients have the opportunity to meet others with long-term conditions who have the symptom of fatigue. Furthermore, at the completion of the physiotherapy group programme, some patients are encouraged to join appropriate classes in the community. This support means that they are less likely to feel less socially isolated. A previous scoping review of the literature has demonstrated improvements in health and well-being of those with long-term conditions who are linked with appropriate community resources by a facilitator[14].

Although the clinic remains successful at meeting the needs of its patients, we are mindful of patients who are too unwell to access the clinic or are unable to travel. It can be especially difficult for patients that live a great distance away from the clinic. For some attendance at the clinic can involve an overnight stay. The clinic runs one morning each week only, which is problematic for patients, finding it difficult to function earlier in the day. Limited clinic times and increasing re-

ferral numbers mean that the clinic is in high demand and there is limited flexibility with appointment times. This can be frustrating for staff and patients and cause disappointment at times.

To conclude, it is clear from both the quantitative elements of this study and qualitative narratives, that patients value the service, but feel it needs to be enhanced. We will therefore take their suggestions of telephone or online consultations and the addition of afternoon appointments seriously, and develop our clinic informed by this research.

Strengths and limitations:

The study showed that the CRESTA clinic is still maintaining its current success considering the recent changes to its service model. It reinforces the fact, that the changes have been positive and allows more patients to be seen in the clinic.

It is clear from both the quantitative elements of this study and qualitative narratives, that patients still value the service and are keen for it to continue, the need for some enhancements were highlighted, which will be addressed and help us develop our clinic further, informed by this research.

The questionnaire return rate was 31.5% therefore was not fully represented of all CRESTA patients. However, the sample size was similar to that of the original study, thus was comparable for the purpose of this evaluation.

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