A national ‘snapshot’ of service structure, delivery and staffing. We also sought to identify service restrictions and training needs to guide BACME advocacy and future provision of education to members.

These findings will be used to guide BACME policy and wider advocacy.
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Introduction
Specialist services that accept patients with CFS/ME are thought to see around 8000 adults and children a year in the UK\(^1\). As services are commissioned piecemeal by the NHS, no up-to-date database exists of all current services. Current national guidance\(^2\) for specialist services focuses on delivery of evidence-based interventions, and gives little guidance on the service structure, clinical leadership, staffing skill mix and training to deliver these interventions. Thus, variation in services is likely to exist, depending on local interpretation of guidance by both service providers and commissioners.

BACME is the only UK organisation that specifically supports professionals working with patients with CFS/ME. We sought to identify all current UK services delivering specialist care, and to take a national ‘snapshot’ of service structure, delivery, and staffing. We also sought to identify service restrictions and training needs to guide BACME advocacy and future provision of education to members.

Methods
A survey was developed from initial work by the East Midlands CFS/ME Network Office and refined with input from a dedicated BACME working group.

Potential services were identified from BACME records, charity service directories, trust websites, and general internet searches. Contact with the service was then attempted by email or phone. We identified 59 potential services but 2 were uncontactable.

5 services advised they could not respond and gave the following reasons - 1 service reported imminent closure, 3 no longer offered CFS/ME services, and 1 was amalgamated in another service.

The survey was emailed in December 2017, and respondents had six weeks to reply. Response rate was enhanced by further follow-up phone calls and email.

Preliminary results were published on a poster which was displayed at the ‘Changing Times’ BACME conference in Liverpool March 14\(^{th}\)-15\(^{th}\) 2018 (see Appendix).
Results Overview

Of 52 surveys emailed, 42 responded (81% response rate).

40 services were delivered by an NHS organisation, while 2 were NHS-commissioned but delivered by non-NHS organisations.

3 services were solely paediatric
9 services accepted both adults and children of varying ages.
Of the remaining 30 services, 12 accepted adolescents (aged 16 or 17 years and above).

Two-thirds of services (28) had some provision for severely affected individuals, while 3 services had some inpatient provision.

Total patients accepted during 2017 (n=40) were:
9715 adults
856 children.

Proportions of severely affected according to NICE criteria2 (n=23 services) were:
adults 7%, children 4%.

If these data are representative of other services, then NHS commissioned services could be seeing over 12,500 adults (885 severely affected) and 1000 children (43 severely affected) per year. This assumption needs to be tested further.

Since these survey results were collected, we are aware that further changes have occurred with some services including the closing down of one service and one service amalgamating with a pain service.

Maps showing services that participated in the survey

The following 2 pages contain maps of adult and paediatric services based on postcode location.
The colours represent service intensity based on the annual referral rate provided for each service.
Service size has been measured by number of referrals rather than activity delivered. This is due to the complexity of the condition and diagnostic process and the fact that up to a third of referrals may not receive a diagnosis of CFS/ME or go on to receive a therapy service following initial assessment. However, it is acknowledged that the triage and assessment of individuals is a considerable element of the service activity.

<table>
<thead>
<tr>
<th>Key to Maps</th>
<th>Annual Referrals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small</td>
<td>60</td>
</tr>
<tr>
<td>Medium</td>
<td>260</td>
</tr>
<tr>
<td>Large</td>
<td>450</td>
</tr>
</tbody>
</table>
Fig 1. Map showing Adult CFS/ME services based on annual referral data
Fig 2. Map showing Paediatric CFS/ME services based on annual referral data
Results in detail

1. **Service data**

*Fig 3. Number of adult & paediatric services*

- Adult only service: 30
- Adult and paediatric service: 9
- Paediatric only service: 3

*N=42*

*Fig 4. Size of Adult services*

- Small: 39%
- Medium: 32%
- Large: 29%

*N=38*

Adult annual referral rates range from 60 to 955
- 15 have <150 referrals/year = Small service
- 12 have between 150 and 300 referrals/year = Medium service
- 11 have >300 referrals/year = Large service

*(1 service was unable to provide referral numbers)*

*Fig 5. Size of paediatric services*

- Small: 90%
- Large: 10%

*N=10*

Paediatric annual referral rates range from 7 to 443
- 9 services have fewer than 100 referrals/year
- 1 service has over 300 referrals/year

*(1 paediatric only and 1 combined service were unable to provide referral numbers)*
Comments
There is a large variation in the number of referrals received by services, however with adult services, there is a relatively even spread across the range i.e. similar numbers of small, medium and large services.

It is beyond the remit of this survey to identify the scale of need in the general population and it is not possible to accurately define what population area a service serves.

However, the volume of referrals across the country indicates there is a definite ongoing requirement for specialist CFS/ME services and it is likely that there are areas where the patient needs are not matched by the provision of NHS services.

These findings mirror Sunniquest et al’s\textsuperscript{3} review of American resources, and Collin’s demonstration of the increased primary health care need of patients with CFS/ME\textsuperscript{4}. 
Fig 6. Where referrals are accepted from by Adult and Paediatric services

![Bar chart showing referral acceptance from different sources.](chart1)

- GP: 42 Yes, 0 No
- Other primary care: 17 Yes, 25 No
- Hospital/Secondary care: 35 Yes, 7 No
- Mental health team: 13 Yes, 29 No
- Other: 8 Yes, 34 No

Fig 7. Additional Service Information

![Bar chart showing additional service information.](chart2)

- Accept out of area referrals: 24 Yes, 18 No
- Accept referrals for patients previously seen by service: 41 Yes, 1 No
- Have access to specialist in-patient facility: 39 Yes, 3 No
Fig 8. Use of Technology by services providing therapy

One Service is a Doctor led diagnostic service and does not provide any therapy.

Fig 9. Provision of Adult Services by Severity

N=39

Number of services

Severity

Mild

Moderate

Severe

N=39
3. **Waiting times for adult services**

**Fig 10. Waiting times for Adult services**

The waiting time to be seen in an adult service ranged from less than a month to 18 months.

Two services stated that the waiting time to see a clinician was significantly more than their therapy waiting time (3 months vs 4 weeks and 15 weeks vs 6 weeks).

**Comments**

The majority of services are managing to see patients within the NHS recommendation of 18 weeks. However, the waiting times to see clinicians are longer and a small number of services have extremely long waiting times up to 18 months. It is also possible that services are achieving these waiting times by providing initial assessment or brief group-based education sessions as the initial contact but there could then be a much longer wait to begin a therapy programme.

This is consistent with previous findings.
4. Services for patients who are severely affected

Fig 11. Services which accept severely affected patients

Fig 12. Provision of home visits in services who see severely affected patients

Comments
An audit of 49 CFS/ME services in 2013 demonstrated that 33% of services did not provide a service for housebound patients\(^6\). This survey shows that access to specialist services for patients who are severely affected has not changed since 2013.

Patients who are severely affected by CFS/ME are, by definition, rendered housebound by the severity of their illness. These patients are significantly compromised in their ability to access all medical services including primary care.

Patients with severe CFS/ME have the most complex medical needs as well as being the most vulnerable. One third of specialist CFS/ME services do not see patients who are severely affected.

Although 28 services state that they see patients who are severely affected, 12 of those do not offer home visiting. All of them do offer telephone contact and a few offer email contact. 3 offer Skype consultations and 1 also offers some web-based therapy programmes.

It can be concluded from this data that face-to-face therapy input for patients with severe CFS/ME is only provided by a small number of services. This means there will be patients across the country with significant health needs who are currently denied access to specialist care due to lack of provision of services.
5. **Paediatric CFS/ME Services**

**Service provision**
12 services see children and young people with CFS/ME.

Some specify only from age 11+ or 13+ or 14+

3 services are exclusively for children and young people – all 3 of them offer home visits but only 2 report seeing children and young people with severe CFS/ME.

**Waiting Times**
Waiting times range from 2 weeks to 4 months. The majority are achieving 1-2 months.

**Medical input**
For the 3 services that are exclusively for children and young people their medical input is:

1. 2 Paediatricians + 1 consultant Psychiatrist (443 referrals/year)
2. Pool of general Paediatricians not specific to the CFS/ME service (no referral data)
3. Diagnosis by general Paediatrician (35 referrals/year)

Of the 9 services who see both children and adults, 2 services specified having specialist Paediatrician involvement in their service.

3 of the services who see children and young people have no medical input.

**Comments**
The provision of services for children and young people is very small with only 12 services across the whole country. Only 10 of those are able to support children and young people who are most severely affected. These are the children and young people who are most vulnerable and often lose their education and all social contact, so they need the highest level of support which is currently rarely provided anywhere in the country.

There are additional complexities in managing CFS/ME in children and young people compared to adults. Beliefs about this condition can vary widely and at times can be extremely detrimental to the wellbeing of the child or young person with CFS/ME and can have a negative impact on the whole family. Good communication is required between many agencies including the parents, wider family, school, GP’s, specialists, social services etc. to ensure everyone is working together in partnership to support the child or young person. This would be best managed by clinicians with experience in the field of CFS/ME, along with skills in communicating with the wider community.

It is concerning to see that 3 services who see children and young people with CFS/ME have no medical input in their service.

The majority of services seeing children and young people who do have medical input, have either a Paediatrician or a GP. However, 2 services have medical input provided by a non-paediatric trained doctor. Some of the services only have medical input at the diagnostic stage and do not provide ongoing medical support for the care of the child or young person over time.
6. **Staffing**

**Medical Input in Adult and Paediatric CFS/ME services**

**Fig 13. Medical Provision in CFS/ME services**

Most medical input = 8 sessions/week

Least medical input = 1 session/month

**Medical input varies from:**

- a service providing initial diagnostic assessment with no therapy provision
- clinicians making a diagnosis then passing onto a therapy team
- clinicians working as part of the CFS/ME team.

16 services (38%) do not receive any medical input in their service

2 (18%) of the large services (>300 annual referrals/year) have no medical input

9 (60%) of the small services (<150 referrals/year) have no medical input

1 of the small services has 3 consultants (2x infectious diseases, 1x endocrinology)

**Comments**

Small services appear to be the most likely to be operating with no medical input, however 2 of the large services receiving more than 300 referrals a year have no medical input.

The majority of doctors work less than full-time in their CFS/ME role so are likely to have additional clinical roles outside of their CFS/ME work. This can be beneficial in that it ensures they continue to have exposure to other conditions which may overlap with CFS/ME and hence enhance their diagnostic skills. A downside of it being only a part of their clinical role is that it will reduce the time available to attend training events or network with colleagues working in the CFS/ME field. It may also make it harder for them to be involved in research.
Fig 14. Medical specialties in CFS/ME services

5 services have more than 1 medical speciality represented:

- Immunology + paediatrician
- GP with Specialist Interest + Paediatrician
- Infectious diseases + endocrinology
- Immunology + GP with Specialist Interest
- Liaison Psychiatrist + GP with Specialist Interest

Comments
Doctors from diverse backgrounds are working in this field. Currently 11 different specialities are represented by 31 doctors.

There may be advantages to having specialists from different fields involved in CFS/ME services given that it is a heterogeneous condition that overlaps with conditions from many different specialities. The potential differential diagnoses for patients referred to CFS/ME services is extensive and crosses over many specialities.

However, having a small number of clinicians spread across such diverse fields means it is more challenging to establish common approaches. Some clinicians are only providing a diagnostic service and have no ongoing role in the management of patients after diagnosis. This results in a loss of learning opportunities to see the outcome of their decisions in terms of which patients benefit from therapy input and which patients may subsequently turn out to have alternative diagnoses. It also means patients are left without ongoing specialist medical input to help manage their condition which commonly causes ongoing concern and distress.
Doctors who work as part of the therapy team can support the team when complex medical issues arise and advise on appropriate strategies for symptom management which may include prescribing. It can also mean the team are better placed to identify when patients have symptoms which require further investigation ensuring that treatable conditions are not missed (e.g. sleep apnoea).

In a field which is complex and subjective, networking amongst clinicians is essential to share expertise and promote best practice in all services. The fact that clinicians working in this field often do CFS/ME jobs as a small part of their work, along with the fact they are from such diverse backgrounds, means the networking opportunities are significantly reduced.

Only one service listed doctors in training positions as part of their CFS/ME team (SHO and SpR). This demonstrates the lack of exposure to this condition during medical training and is likely to be a significant contributor to why doctors lack the confidence or skills required to assess patients with complex presentations. This will also impact on recruitment into CFS/ME posts which is of considerable concern.

**Diagnostic data**

Some services had audited their diagnostic rate and gave the following examples:

- An audit April to September 2016 showed 267 referrals, 173 assessed, 92 CFS/ME - 34% of those referred = CFS/ME 53% of those assessed = CFS/ME
- 57% of assessed patients were taken on for therapy. 23% not chronic fatigue, 19% other fatigue types
- Medical assessment service identifies alternate diagnosis in 49%
- 142 were assessed, 81 were taken on for treatment. Others received diagnosis other fatigue types 27, non chronic fatigue 33. Number or % severely affected 0%

**Comments**

The information from services which have audited their diagnostic process shows high numbers of patients being referred to CFS/ME services who do not have CFS/ME. This is consistent with previously published data².

This demonstrates that it is a difficult diagnosis to make and cannot be done to a high level of accuracy in primary care⁸. It demonstrates a clear need for doctors to have specialist knowledge of this condition and the appropriate time to properly assess patients in order to be able to make accurate diagnoses. It also demonstrates the need for improved education and training in this field.
Therapy Input in Adult and Paediatric CFS/ME services

The following list is all of the different types of therapist and multi-professional involvement currently working in the CFS/ME services surveyed:

Occupational therapist
Physiotherapist
Paediatric physiotherapist
Specialist nurse practitioner
Advanced practitioner
Specialist nurse
Senior rehab assistant
Psychologist
Neuropsychologist
Psychotherapist
Health psychologist
Cognitive behavioural therapist
Mental health nurse
Health and wellbeing facilitators
Counsellor
Dietitian

Fig 15. Number of different types of therapists in CFS/ME services

All the services which have only 1 type of therapist are staffed by Occupational Therapists.
Comments
The majority of services have therapists from more than one field. Presumably this is because they have found benefit from having a variety of therapy skills available as part of multidisciplinary teams. It would also appear that practitioners from a wide variety of backgrounds can effectively treat and support patients with CFS/ME.

This could be seen as an advantage with regard to recruitment issues as staff can be sourced from many different fields.

However, it also demonstrates that there will be a lot of diversity in the type of therapy programmes being delivered. It also means that training for therapists in this field will need to take into account that practitioners may have very different levels of background knowledge.

As there are no formal training programmes or qualifications in managing CFS/ME, the majority of learning is done from peers with experience working in the field. Small teams with less diversity may find it harder to access this kind of learning. Teams which have staff attending CFS/ME specific conferences have the potential for greater learning. When doctors have regular contact with therapy staff there are greater opportunities for two way learning about the condition, what approaches help patients and how new research is adding to our understanding of the condition.

Teamwork and the potential for collaborative learning can be greatly influenced by the environment in which the team is working. Having the time, opportunity and appropriate setting for team meetings to occur are all important considerations to improve collaborative learning. This is essential in a field that does not yet have a secure evidence base and hence relies on the professional expertise of practitioners working in the field to provide best practice.

Only two services listed a Dietitian as part of their CFS/ME team

Eating challenges that lead to an increased risk of inadequate nutritional intake can occur in CFS/ME. Gastrointestinal symptoms and food intolerances are also commonly reported, yet only 2 services report having a dietitian as part of their specialist team. This means that people with CFS/ME are likely to have no dietetic input or to be seen by a dietitian with little experience in, or understanding of, the illness. They may also self-treat from online and social media sources with unproven diets or access help from independent nutritionists who do not have recognised qualifications.

This is a very under-researched and under-resourced area in this field and improvement in this area has the potential to bring large benefits to patients both in terms of helping them manage their symptoms but also potentially for more positive recovery outcomes.
Therapy staffing levels in CFS/ME services

With regard to the provision of all therapy staff in services, the Full Time Equivalent (FTE) ranges from 0.4 to 9.81.

When looking at the size of services based on referral numbers and their FTE therapy provision, there is very wide variation in therapy provision. However, the data collected does not identify how many referrals are rejected without the patients being seen and how many patients are discharged after initial assessment. Medical time has not been included and it may differ greatly between services that employ doctors as to how many patients are seen by doctors and whether they are seen only once for assessment or whether they also provide ongoing medical follow-up.

We therefore do not have data on therapy case-loads for individual services.

Small services (<150 referrals/year) have therapy FTE ranging from 0.7 to 4.2
Medium services (150-300 referrals/year) have therapy FTE ranging from 0.4 to 4.1
Large services (>300 referrals /year) have therapy FTE ranging from 1.64 to 9.81
Fig 16. Service Leads in CFS/ME services

- OT, 14
- Psychologist, 11
- Physiotherapist, 6
- Physician, 5
- Psychiatrist, 2
- Paediatrician, 1
- Nurse, 1
- Manager, 1
- Speech and Language therapist, 1

Fig 17. Clinical Leads in CFS/ME services when different to Service Leads

- OT, 4
- Psychologist, 1
- Physiotherapist, 2
- Physician, 3
- Paediatrician, 1
- Nurse, 1
- Advanced Practitioner, 1
- Paediatric nurse, 1
Comments

This demonstrates that there is significant variation in the structure of services. Not all services have both a service and clinical lead and, in some services, both roles are carried out by the same person. Teams are often so small they function as a multidisciplinary team rather than one person being seen as a clinical lead.

Leadership positions are being fulfilled by practitioners from a wide variety of occupations.

The majority of services are therapy led with a third being led by an occupational therapist, and a quarter being psychology led.

Historically, clinical champions were sought to secure funding for local services. These tended to be clinicians working with existing CFS/ME patients, mostly in the community or in rehabilitation services. The ownership came from clinicians who were struggling to support these patients who were considered untreatable in the medical arena. The lack of medical leadership and input for this previously unrecognised condition is reflected in how the services have evolved and continued to try to survive over time. Medical time in services is often limited, either with funding only agreed for initiation of a service and then not continued, or with ongoing medical input only being a small fraction of the clinical provision within the service.
7. **Diagnostic Criteria**

36 services (83%) stated that their service used published criteria to make a diagnosis of CFS/ME.

6 services commented that they do not offer a diagnostic service or that they require the diagnosis to be made prior to referral to their service.

30 Services indicated that they use NICE criteria for diagnosis. 9 of them use it exclusively.

27 Services indicated they use a CFS specific tool such as Fukuda or Canadian criteria.

3 Services indicated that they use other criteria such as the Oxford Criteria.

22 services indicated that they use more than one diagnostic criteria.

**Comments**

The decision over which diagnostic criteria to use continues to be an area with differing beliefs.

The role of diagnostic criteria in clinical practice is different to the research field. Research requires much stricter criteria to ensure uniformity in the group being studied and this could mean certain factors would be considered an exclusion for entry into a study. For example, if a patient has a very low or very high Body Mass Index (BMI) this could indicate an additional health problem that is contributing to their symptoms and could mean they will have a different response to a therapy being trialled. Hence the diagnostic criteria for entry into a study would exclude patients with a low or high BMI. However, in clinical practice, an experienced diagnostician would be able to evaluate the whole clinical picture and make an informed assessment as to whether the symptom profile is suggestive of CFS/ME and ensure that other factors have been accounted for when making a diagnostic decision.

The ‘milestone’ of being given a diagnosis is an extremely important component in the management of CFS/ME. It results in the patient feeling validated and leads on to them being able to access appropriate information and support to manage their condition. It also acts as a catalyst for the patient to make changes in their life to adapt to having an illness and allows them to ask others in their life, such as employers, to do the same.

Services may differ in their criteria for therapy provision dependent on their service capacity, the skills available within the team, local funding agreements and locally identified need.

This has the potential to result in variation across the country as to which patients can access specialist services.
8. Types of Core Therapy Provided

34 Services indicated that they provide Activity Management Strategies, 5 services do not and 3 were left blank

34 Services indicated that they provide Cognitive Behaviour Therapy (CBT), 5 services do not and 3 were left blank

34 Services indicated that they provide Graded Exercise Therapy (GET), 5 services do not and 3 were left blank

21 Services indicated they provide symptom control with medication

(Although the numbers for activity management, CBT and GET are the same it is not due to the same response from each service for each modality)

Although some services stated they do not use CBT or GET, or left the responses blank, they commented that they use aspects of these approaches in their therapy programme. If these comments are taken into account, there are 38 services who are incorporating CBT and/or GET principles into the programmes they offer.

Many services commented that these types of therapy are provided as part of an integrated approach with comments including:

“Part of a holistic therapy package or group programme”

“Most of our sessions are a combination of Activity Management, CBT and GET although a small number of patients are offered specific CBT sessions.”

“Flexible toolkit approach means we have no finite number of sessions around each topic and have both 1:1 and workshop sessions available as needed”

“Provide a combined approach that includes elements of CBT, GET and Activity Management. No maximum number of sessions but usual package is 10 individual or group programme. Severe patients will commonly have more”

“Most patients would receive approximately 6 - 8 sessions of treatment over all, including GET, activity and lifestyle management as appropriate to the individual patient”
Where services set a maximum number of sessions for a specific therapy programme the range was from 1 session to 16 sessions.

Many services stated that the number of sessions was judged on an individual need basis.

Services vary in their provision of exclusively group programmes or a combination of individual options and group programmes.

“Plans vary from 1x2hour first assess / intervention only, to this 8 x2.5hr group & 5x2 2.5 hr FU session +/- individual input”

Services indicated that they provide a variety of additional therapy options, these included:

**Additional Therapeutic Interventions or Delivery Techniques/Modalities:**

- Acceptance Commitment Therapy (ACT)
- Clinical Hypnotherapy
- Mindfulness
- Brainwork recursive therapy for trauma
- Qi Gong
- Eye Movement Desensitisation and Reprocessing (EMDR)
- Neuro Linguistic Programming techniques (NLP)
- Counselling
- Dietitian group education
- Clinical Hypnotherapy

**Social Interventions:**

- Employment support
- Family support liaison
- “As therapists we offer lots of other interventions, sensory approaches, compassion-based interventions, mindfulness, cognitive rehab, balance and vestibular exercises depending on patient needs”

**Comments**

This demonstrates that there are some shared therapy approaches across services and also that individual services have creatively developed additional therapeutic strategies by adapting them to apply to patients with CFS/ME.

It is essential that services are supported and encouraged to continue developing new approaches and that they have sufficient resources to audit and measure outcomes to ensure they are providing clinically effective treatments. It would also be beneficial for the whole patient community if these ideas can be shared and developed across many services working in collaboration which requires time and funds available to facilitate it.
9. **Outcome Measures**

Services were asked to list what outcome measures they are currently using:

- 3 Services did not respond
- 3 Services said they were not currently collecting outcome data (one cited this was due to lack of capacity)

Of the 36 services who indicated they are collecting outcome data, all are collecting multiple types of data.

**Common outcome measures used by CFS/ME services**

- SF36
- Chalder Fatigue Scale
- HADs
- Analogue Pain Scale
- Global Impression Scale
- Epworth Sleep Scale
- Self-efficacy

**Other outcome measures used:**

- PROMS (Patient Reported Outcome Measures) - Revised childhood and anxiety scale - parent and child
- TOMS (Therapist Reported Outcome Measures) - Functional disability scale - parent and child
- EQ5D - Self-report school attendance
- FIS - W7 SA scale
- Local Measure - Jenkins sleep scale
- GAD-7 - CORE
- PHQ-9 - GIS
- Wellbeing - WEMWBS - BDI-FS Nijmegen
- Perceived health VAS
Comments

Devlin and Appleby\(^{15}\) confirm measuring and benchmarking the performance of health care providers is necessary for patient safety. This report demonstrates that there is a vast array of different measures in use. Some of this may reflect the different skill mixes within the teams. CFS/ME cannot be defined by biological markers and hence there are no clear markers of illness progression or improvement. For many services the aim of therapy provision will be to educate and facilitate, support and guide changes in self-care and self-management with the patient.

Questionnaires which focus on unrealistic illness improvement could be detrimental to the patient\(^{16}\). Consideration also needs to be given to the burden on the patient of completing multiple questionnaires. Patient support groups report that patients find questionnaires difficult to complete and often cannot see the value of them\(^{17}\). This is an area where more patient involvement could inform services as to which outcome measures are meaningful for them\(^{18}\).

Questionnaires need to be given to patients with explanation and clear purpose in order to ensure engagement. Patients also need to be given feedback on their completed questionnaires with opportunity to discuss any comments based on the outcomes. All of this requires time and facilities which are not available in all services without them compromising the provision of therapy.

Services need to be supported to collect this data in a standardised manner and for this to be collated nationally, in order to support research into service and treatment provision\(^{19}\).
10. Involvement in Audit and Research

Fig 18. Number of services involved in Audit and Research

Comments

Services are not specifically funded or supported at a local level or nationally to conduct audit or research work.

Staff are often stretched to their maximum clinically and managerially, allowing no time for research, audit or development of services. Ensuring service provision for patients has been their main priority.

Staff remain willing and motivated to be involved in audit and research but require additional support in terms of time, money and administrative input in order to achieve this.
11. Patient Involvement

38 (90%) of CFS/ME services have some provision for patient and/or carer involvement, while 35 (83%) of CFS/ME services conducted a patient survey during 2017.

Ways that services report involvement of patients
(Numbers in brackets indicate the number of comments relating to that theme)

- Contact with local patient support group (7)
- Relatives and friends’ sessions provided (4)
- Past patients invited to share experiences with current patients (2)
- Patient focus group (1)
- Expert patients (1)
- Patients involved in staff interviews (1)
- Patient representatives at CCG meetings (1)
- Patients co-facilitate training workshops for trainee therapists (1)
- Research team advisory group (1)
- Self-care co-ordinator (1)
- Service user volunteers (1)
- Social events (1)

Comments

Healthcare providers’ responsiveness to peoples’ emotional and practical experience of illness and care is crucial\(^{20}\) and there are positive associations between acting on patient reports and increased clinical effectiveness\(^{21}\). Such approaches ensure accountability by and to patients and communities\(^{22}\). Patients have an important role in improving patient safety by becoming actively involved in their health care.

This survey found that 38 (90%) CFS/ME services have some provision for patient and/or carer involvement. We found several examples of good practice – e.g. patients who have successfully completed therapy who then attend new patient groups and share their experiences. Some services have patient forums that review services and patient information. Only one service currently uses social media. Four reported no patient involvement.
12. **Education and Training**

**Opportunities being provided currently for and by staff of CFS/ME services:**
(Numbers in brackets indicate the number of comments relating to that theme)

- BACME conference (15)
- In-house education events (12)
- External courses e.g. CBT, ACT, motivational interviewing, hypermobility, coaching (12)
- Peer support/supervision (9)
- Providing medical presentations to medical students and GPs (5)
- Regional networks/meetings (4)
- Local mandatory training (3)
- BACME webinars (3)
- CMRC conference (1)
- Clinical trial training (1)
- GET training (1)
- Providing student placements (medical, OT and work experience placement) (1)

Access to funding for staff training varies between services from, to

"No funding is available for staff to pursue training or attend conferences"

"all staff attend the BACME conference, have two weeks study leave, and have additional £500 per head per year to spend on courses. All members of staff are encouraged to perform an audit"
Training needs identified by services:
(Numbers in brackets indicate the number of comments relating to that theme)

- Information about research advances (7)
- Medical aspects e.g. bloods, autonomic dysfunction, differential diagnoses, prescribing (6)
- Training in other therapeutic approaches e.g. ACT, mindfulness, motivational interviewing (6)
- Specialist clinical supervision (4)
- Networking with other CFS/ME therapists (4)
- Webinars/on-line training (4)
- Sharing information on different services and treatment pathways (3)
- Use of technology/digital tools to provide care (3)
- BACME conference (3)
- More local MDT training days (2)
- GET (2)
- CFS/ME specific CBT (2)
- Non-NHS treatments on offer e.g. diet/nutrition, lightening process (1)
- More national CFS/ME specialist training (1)

Comments
The main themes from these suggestions are:

- The need to remain informed of research advances
- How to be educated about the medical aspects of diagnosing and managing CFS/ME
- Maintaining good clinical networks both locally and nationally to share expertise
- The need for specialist supervision
- Having national conferences and training days
- Using webinars and digital technology to make training easily accessible and affordable
- More training on specific therapeutic approaches applied in a CFS/ME setting

Ways that BACME has already made progress meeting these needs:

- National conference held every 18 months with research updates and workshops on medical and therapy-based subjects
- Webinar programme which has included medical and therapy topics some full presentation and some more small group discussion based
- Regular research update newsletters
- Members only website with discussion forums to aid networking and peer support
13. **Service Constraints**

33 services (79%) reported issues with service constraints, the majority reporting more than one issue.

**Fig 19. CFS/ME service constraints**

The common themes and a selection of comments are:
(Numbers in brackets indicate the number of comments relating to that theme)

**Workforce:**
- Insufficient therapy capacity (7)
- Poor admin support (6)
- Lack of medical input (4)
- Staff not replaced (3)
- Lack of MDT e.g. CBT, physio, psychology (3)
- Delayed recruitment (2)

“Lost 2 medics and psychology, unable to recruit physio”

“No longer have medical input, seeking medical input for complex cases”

“No replacement of previous Paediatric specialist consultant, hours now undertaken by generalist paediatricians with subsequent variations in pathway and management”

“CNS replaced GPwSI several years ago and now CNS has moved to management bar 1 clinical session and not been replaced like for like”
Service provision:
- Lack of or poor access for severely affected patients (5)
- Lack of or poor access to children's service (3)
- Demand for PIP reports (1)

Accommodation:
- Lack of facilities or not suitable (7)
- Challenges of covering large geographical areas (6)
- IT restrictions e.g. for Skype (2)
- Parking (1)

Training:
- Lack of time/money for staff training or research (4)
- Lack of GP knowledge (2)

Budget:
- Financial constraints (15)
- Future uncertainty (2)
- Lack of clarity at national level compromising local negotiations (1)

“Not commissioned to deliver home visits so difficult access for severely affected patients”

“Major waits in children's services”

“Unable to provide safe effective treatment for severely affected”

“Staff located in different trusts and locations”

“Technology would help maximise resource e.g. face time”

“No research funding but staff able and willing to partake”

“No funding is available for staff to pursue training or attend conferences”

“Funding restricting sessions”

“Lack of resource to deal with demand”

“CCG finances limiting referral rates and length of treatment episodes”

“Could do more for patients but commissioners do not wish to increase budgets”

“Significant under resourcing resulting in longer waits for CBT and some assessments”

“Service in upheaval as …CCG has commissioned service from private provider… who do not run CFS service anywhere else and do not have staff to run it.”

“Unable to provide safe effective treatment for severely affected”

“Major waits in children's services”
Comments

There is clearly a wide array of difficulties encountered by CFS/ME services across the country. Funding constraints are not surprisingly the commonest cause of restrictions on the quality of care that can be provided. The comments reflect how lack of money affects patient waiting times, how many therapy sessions can be provided and even the number of referrals that can be accepted. Poor funding can also result in patients and carers doubting the usefulness and efficacy of services and can also reduce the likelihood of GP's making referrals to services. The uncertainty regarding future funding of services can cause significant stress for the staff and is likely to be a factor in recruitment difficulties.

Many services report difficulties caused by inappropriate accommodation which can have a big impact on how teams operate as well as causing significant difficulties for patients in terms of long travel times and difficulties accessing the services. This is especially true for severely affected patients and clearly several services are aware that they are compromised in the quality of care they can provide to this group due to the constraints on how they can deliver their service and the capacity within the service.

Staffing issues were a very common theme with many services reporting reductions in staffing over time, leaving the remaining workforce under pressure to try to maintain the same quality of service. Several services reported loss of medical input to the team which was compromising their ability to deal with complex patients.

Lack of administrative support was also mentioned by several services. This will impact on communication with patients and other clinicians and result in poor use of clinical time sorting out issues which could have been dealt with by adequately trained administration staff. In addition, this can also compromise a service's ability to collate data to evaluate their work and look at how to make improvements in the care they provide.
Conclusion

The response to our survey was high and responses were comprehensive.

Previously, McDermott et al identified 49 services in the UK, with 27 offering services to the severely affected. Given recent and anticipated losses reported here, we have identified only a slightly higher number of ongoing services (52). However, free text responses within the survey indicate that further services or service delivery are at risk due to funding cuts, specialist retirement, recruitment difficulties, lack of skill mix/training, together with other concerns.

Compared with estimates by Collin et al, specialist services are accepting higher numbers of patients than 5 years ago. However, this falls significantly short of the estimated need. Moreover, provision for the severely affected has not increased greatly, despite repeated calls for improvements. We have identified substantial variation in service provision according to location, and in all aspects of service delivery, including waiting times, diagnostic process, structure of intervention, and patient involvement. However, this variation does represent an opportunity to learn from different approaches and disseminate examples of good practice.
Visions for the Future

This survey demonstrates that over 10,000 patients each year are accessing NHS specialist CFS/ME care. It is clear that there is an ongoing requirement for specialist CFS/ME services and it would be beneficial to build on the good work that is already being carried out by services across the country. It is essential that we protect what is already being provided and aim to increase the provision to those populations that are currently excluded either by geography, age, disease severity or local funding arrangements.

As this is an area of medicine that does not yet have the advantage of an accepted evidence base for diagnosis or treatment, the expertise of clinicians working in this field becomes more important. It is encouraging to know that many patients are accessing this expertise and that staff working in CFS/ME services are motivated to provide high quality care and are enthusiastic about sharing knowledge between services and look at ways to improve care provision. However, it is clear that there are many barriers to the aspiration to increase the provision of care in this field and many services feel under threat rather than being supported and encouraged to develop.

These are BACME’s thoughts on how positive progress could be made in the field of CFS/ME medical care:

Funding

Barriers:

- NHS budget always stretched
- Business model of the NHS results in competition that can result in cheaper services being chosen over good quality services
- Individual CCGs being responsible for commissioning services resulting in a significantly uneven spread across the country
- Lack of national guidance on what a CFS/ME service should look like

Solutions:

- Continue to keep the patient voice heard by politicians
- Create a minimum standard for service provision based on population served and include expected provision for children, young people and severely affected patients
Recruitment

Medical staff

Barriers:

- Lack of knowledge about the condition
- Lack of exposure to it at medical school and in working practice
- No formal training programme or qualifications
- Negative perceptions about patients with CFS/ME
- CFS/ME commonly misdiagnosed as a psychiatric condition or a behavioural problem

Solutions:

- Ensure detailed information on CFS/ME is on all medical school curriculums
- Teach skills in history taking for complex presentations including exploring fatigue symptoms
- More students and doctors in training posts working in CFS/ME services
- Provide formal training in primary fatigue conditions
- Educate doctors about the condition and use patients as education resource to promote empathy
- Promote membership of BACME
- Provide professional support, networking opportunities and education for doctors working in the field

Therapy staff

Barriers:

- Lack of knowledge about the condition
- Lack of training
- Negative perceptions about working in the field
- CFS/ME commonly misdiagnosed as a primary mental health condition

Solutions:

- Provide training suitable for therapists from different backgrounds
- Encourage student placements in CFS/ME teams
- Consider options for diversity in the team – recruit from areas outside usual scope or consider alternative roles when unable to fill a post
- Increase provision of dietitian input in services
- Promote membership of BACME
- Provide appropriate supervision and support for therapists working in the field
Paediatric and adolescent provision

Barriers:

- Delay in diagnosis due to lack of awareness of condition in children and young people
- Therapy may be provided by non-CFS services e.g. paediatric services or CAMHS
- Unhelpful attitudes/beliefs can result in children being misdiagnosed with behavioural problems

Solutions:

- Improved education at medical school level, in primary care and paediatric training
- Ensure general paediatricians are kept up-to-date with research advances – promote membership of BACME and use of discussion forums as a way of networking
- Provide education on the condition to schools and social workers
- Develop a partnership model between the child/young person, parents, clinicians, therapists and teachers recognising everybody’s knowledge and skills

Severely affected provision

Barriers:

- Complex presentations can obscure a diagnosis
- Co-morbidities may mean focus is on managing other conditions and neglecting fatigue management
- Housebound – restricts access to all medical care
- Difficulties with benefits service resulting in lack of money and support to engage in medical assessments and treatment

Solutions:

- Better training for doctors to identify CFS/ME
- More medical provision in specialist services including home visits by doctors
- Access to home visiting for therapy staff along with offering telephone, skype or web-based options for patients able to utilise them
- Education for benefits assessors

Premises

Barriers:

- Lack of choice of where services are delivered
- Low priority given to office space for staff and importance of team working
- Geographical challenges when providing a service to a large area

Solutions:

- Explore flexible working options such as outreach clinics, renting rooms in GP surgeries
- Ensure managers are aware of the importance of multidisciplinary team working, collaborative learning and the need for time and space for staff to interact regularly
- Look for local options for improving access through use of Skype and web-based therapy programmes
How to involve patients more in service provision

Barriers:

- Lack of time and resources in services with low staffing levels
- The nature of the illness restricts what patients can offer
- Reticence in staff to ask patients who are unwell to give their time voluntarily

Solutions:

- Support patients to engage by providing funding for travel expenses
- Ensure patient needs are met regarding the environment, timing and availability of rest areas
- Create an ethos of valuing the knowledge and skills that patients can provide to improve services for others
- Ensure CFS/ME patient involvement in commissioning and NHS England Patient and Public Involvement forums

Improving access to services

Barriers:

- GP’s lack of awareness of specialist services
- GP’s not believing it is a real illness
- GP’s underestimating the value of specialist therapy input
- Patients too ill to travel to where services are located
- Patients having negative perceptions regarding what is offered in specialist services

Solutions:

- Improve GP education about the condition
- Create GP register of patients with CFS/ME to enable identification, management and follow-up
- Improve collaboration between specialist services and primary care
- Increase provision of services including providing care in more locations to reduce the burden of travelling for the patient
- Services require appropriate funding to allow both group and individual programmes to be provided to suit the varying patient needs
- Support services to collect standardised outcome data which is meaningful to patients which can be publicised to help promote patient engagement
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References


Appendix


Introduction

Specialist services that accept patients with CFS/ME are thought to accept around 6000 adults and children a year in the UK. As services are commissioned piecemeal by the NHS, no up-to-date database exists of all current services. Current national guidance for specialist services focuses on delivery of evidence-based interventions, and gives little guidance on the service structure, clinical leadership, staffing skill mix, and training to deliver these interventions. Thus, variation in services is likely to exist, depending on local interpretation of guidance by both service providers and commissioners.

BACME is the only UK organisation that specifically supports professionals working with patients with CFS/ME. We sought to identify all current UK services delivering specialist care, and to take a national ‘snapshot’ of service structure, delivery, and staffing. We also sought to identify service restrictions and training needs to guide BACME advocacy and future provision of education to members.

Methods

A survey was developed from initial work by the East Midlands CFS/ME Network Office and refined with input from a dedicated BACME working group.

Potential services were identified from BACME records, charity service directories, trust websites, and general internet searches. Contact with the service was then attempted by email or phone. We identified 38 potential services but two were uncontactable. Three services achieved they could not respond to our survey with response rates of 83%.

The survey was emailed in Dec. 2017, and respondents had 4 weeks to reply. Response rate was enhanced by further follow-up phone calls and email.

Results

Of 43 services emailed, 42 responded (98% response rate). All 42 services were delivered by an NHS organisation, while two were NHS-commissioned but delivered by non-NHS organisations.

Three services were solely pediatrics, while 11 services accepted both adults and children of varying ages. Of the remaining 26 services, 13 accepted adolescents aged 12-17 years and above. Twenty-two of 31 services (71%) had some provision for severely affected individuals, while three had some special provision.

Total patients accepted during 2017 (n=449) were 897 adults and 806 children. Proportion of severely affected according to NICE criteria (≤23) were: adults 7%, children 4%. If these data are representative of other services, the 14% commissioned services could be seeing over 12,500 adults (800 severely affected) and 1000 children (80 severely affected) per year. This assumption needs to be tested further.

38 services offered OT, or GDT or both in their own service. One or both interventions were delivered within a combined or separate approach. One service offered activity/skill management (no needfulness), and two offered activity management alone. One service offered medical assessment only. Walking times, maximum session number, and delivery of interventions varied greatly.

Discussion

This response to our survey was high, particularly given the short time frame, and responses were comprehensive. Previously, McDermott et al identified 40 services in the UK, with 27 offering services to the severely affected. Other recent and anticipated services reported here, we identified only a slightly higher number of ongoing services (26). However, free text responses within the survey indicate that further services or service delivery are at risk due to funding cuts, specialist retirement, recruitment difficulties, lack of staff motivating, together with other concerns.

Compared with estimates by Collin et al., specialist services are accepting higher numbers of patients than 5 years ago. However, this remains a fraction of the estimated need. Moreover, provision for the severely affected has not increased greatly, despite repeated calls for improvements. We have identified substantial variation in service provision according to location, and in all aspects of service delivery, including waiting times, diagnostic process, structure of intervention, and patient involvement. However, this variation does represent an opportunity to learn from different approaches and disseminate examples of good practice.

Full analysis and publication of these findings will follow and will be used to guide BACME policy and wider advocacy.

Harpinder Aujla, Kelly Morris, Christine Oliver, and the Services Working Group, on behalf of BACME.

References


Figure 1: Profession of clinical leads

Figure 2: Making a diagnosis

Figure 3: Patient / carer involvement

Location of respondents

Your Concerns

GP - knowledge funding care - high
NHS - health
Diagnosis support
diagnosis
medical
psychology

Figure 1: shows the proportion of different professions in the clinical lead role. The majority of services are therapy led with over a third (38%) led by an occupational therapist, and almost a quarter being psychology led.

Figure 3: Patients can play an important role in improving patient safety by becoming actively involved in their healthcare. The National Patient Safety Foundation is very clear on the need. It states “Involves patients in their care and the design of services.

Our survey found that 38 (90%) CFS/ME services had some provision for patient-based care involvement. We found several examples of good practice – eg, patients who attend following referral for therapy who then attend new patient groups and share their experience. Some services have patient forums that review services and patient information. Only one service currently uses social media. Few reported no patient involvement.