



ME NORTH EAST MEMBERS SURVEY 2007

'Working to shape the future of care for people with CFS/ME'

REPORT PUBLISHED March 2008
Jennifer Elliott
Joanna Hainsworth

List of contents

Introduction to ME North East.....	page 1
Member survey outline.....	page 2
Summary of survey.....	pages 3 – 5
Conclusion to survey.....	page 6
Detailed findings (including by locality).....	pages 7 - 26
Appendix.....	pages 27 - 30

Introduction to ME North East

ME North East is a registered charity (established July 2000) to "relieve the suffering of people with ME and support research into the cause and cure of this disease."

We are the voice for ME in the North East, improving the lives of those affected with ME, their families and carers. We empower people to make informed choices and we support the implementation and development of dedicated CFS/ME services within the northern region.

We provide a dedicated telephone helpline with links to CFS/ME specialists for advice, we represent the needs of ME at every level of decision making, we provide high quality up to date information, produce regular newsletters and maintain a popular website. We inform and educate service providers and the general public on the needs of ME. We provide an advocacy and information service for young people and their families with a dedicated full-time worker. We host conferences, seminars and workshops for members and service providers with an interest in ME.

We operate from offices in Chester le Street and our work covers those areas included within the Northern CFS/ME Clinical Network: North of Tyne, South of Tyne, County Durham & Darlington, North Cumbria and Teesside. Department of Health prevalence rates suggest there are 12,000 people with ME in this region, and we have a membership of over 1250. This is increasing more rapidly since the introduction of CFS/ME clinical services.

ME affects all ages, all social classes with a 3:1 ratio of women to men. Until 2005 there were no dedicated services for this patient group and people would have to travel to Leeds or Glasgow for treatment. A small number of Consultants took an interest in this disease and patients were able to see them within the consultant specialty clinics (i.e. Immunology, Rheumatology, Infectious Diseases and Paediatrics.)

We campaigned for years to gain health services in this region, and since 2003 have been actively involved in the planning, bidding, implementation and development of dedicated CFS/ME services. Department of Health funding was secured to establish CFS/ME local multi-disciplinary teams in four of the five localities within our region, The Tees area were not successful in their bid, and despite annual presentations to Tees Commissioners to fund a local service, patients in this area are not considered a priority.

ME North East continue to work in partnership with the Northern CFS/ME clinical network and offer additional support and help to the local multi-disciplinary teams. For a second term our Chief Executive is contracted by the network via a service level agreement to provide maternity cover (one day per week) for the Programme Manager.

National Institute of Health and Clinical Excellence (NICE) guidelines on the care and treatment of CFS/ME were published in August 2007 placing a mandatory responsibility on all Primary Care Trusts to ensure the recommendations are implemented. This will provide a platform for the continued development and expansions of CFS/ME services in the four localities already operating, and to include implementation of new services in the Tees area.

ME North East member's survey 2007/8

ME North East regularly surveys our members to review the services we offer and to shape the future of service needs and aspirations. In an effort to make the best use of our limited

resources this latest survey conducted in Autumn 2007 was devised to cover a variety of topics. We wished to review the make-up of members by; age, gender, length of illness, and severity of illness. We also wished to identify the number of members who are accessing CFS/ME dedicated clinical services across the region via GP referral.

As part of our monitoring and evaluation role we also wished to identify those members accessing local CFS/ME services and seek the patient's view of services received (appendix I, page 28), we asked;

- Who they were seen by within the local team
- How helpful the services they received were
- What additional services they felt may be helpful in the multi-disciplinary team make-up

To enable us to review the services ME North East presently offer, and how we may prioritise these services, we asked members to select from the wide range of functions we deliver (appendix II, page 29)

We recognise the gap in the northern CFS/ME service delivery as the Tees Primary Care Trust's were not successful in securing Department of Health pump-prime funding, and to date have declined to fund dedicated CFS/ME services from their own budgets.

We wished to seek our Teesside members' views on the limited access to services that are available to them. We intend to use this feedback to help shape the Case of Need to support a Business Case for the Tees Commissioners (appendix III, page 30).

Additional comments were welcomed to enable the diverse views of people with CFS/ME to give an in-depth overview of the support people feel would best meet their needs and aspirations, and to help both ME North East, the local CFS/ME services and the Northern CFS/ME Clinical Network to shape the future of service delivery

For detailed results of all questions asked in the survey see pages 7-26

We would like to thank all those members who gave their time and energy to participate in this survey.

A special thank you to Joanna Hainsworth who completed this evaluation and produced all of the findings within this report. Her time, energy and particularly her patience in producing such detailed and comprehensive graphs and charts has resulted in this important document that gives us the tools to help deliver the best possible services to people with CFS/ME from ME North East, the Northern CFS/ME Clinical Network and the Local CFS/ME Multi-disciplinary teams.

Jennifer Elliott – Chief Executive ME North East.

Summary of Survey

A total of 1200 questionnaires were circulated. 191 were completed (16%)

Of the 191 (100%) respondents 77 (40%) had accessed CFS/ME services and 11 (6%) were waiting for an appointment. The number of referrals may be considered low; however in the early days of the clinics only new patients were being seen, the longer term chronic CFS/ME patient were unable to access services.

Responses were received from across all 5 localities; North of Tyne, South of Tyne, County Durham & Darlington, North Cumbria and Teesside.

Below we summarise the key findings from the 191 responses across the whole region. Full details by locality follow in the main part of this report.

Q1 Numbers responding from each locality

- North of Tyne 55
- South of Tyne 33
- Durham & D'ton 47
- North Cumbria 24
- Teesside 32

The higher number of referrals to North of Tyne and Durham & Darlington services is because these two teams were the "first wave" and commenced services almost one year ahead of South of Tyne and North Cumbria.

Q2 Gender

- 80% Female
- 20% Male

Q3 Age

- 2% Children up to age 16
- 5% Adults 17 - 25
- 26% Adults 26 - 45
- 60% Adults 46 - 65
- 7% Adults 66 +

Q4 Length of illness (in years)

- 20 People 1 - 3 years
- 32 People 4 - 6 years
- 21 People 7 - 10 years
- 118 People 10+ years

The very high number of people who have had this illness for over 7 years reflects the lack of services available in this region in the past.

Q5 Severity of illness (%)

- Mild 12
- Moderate 45
- Severe 36
- Very severe 7

Evaluation of other surveys shows this illness fluctuates and many people move between moderate and severe in cycles

Q6 Referral to CFS/ME Services

- Yes 77
- No 103
- Yes but awaiting appointment 11

Q7 Of the key CFS/ME team members who did you see? (more than one team member may have seen respondents)

- Physician 20
- Psychiatrist 3
- Psychologist 30
- Physiotherapist 45
- Occupational therapist 41
- Other 10

Only the Durham & Darlington team has designated psychiatric input. Main input is from the therapists in physiotherapy, occupational therapy and psychology, reflecting the treatment and management based on NICE recommendations.

Q8 Of those 77 seen by the CFS/ME service how helpful did you find it?

- Very Helpful 19%
- Helpful 54%
- Not Helpful 19%
- Made symptoms worse 6%

Not all our members welcome the management plans and treatments offered by the CFS/ME teams. Cognitive Behaviour Therapy, Graded Exercise Therapy and Graded Activity Therapy have had a bad press in the ME world. Research outcomes have been challenged as too small to be scientific and patients have reported being harmed by these treatments. Therefore it is unsurprising to see these results.

It is encouraging however that 73% found the service to be helpful. We will try to identify what in particular caused the 6% of members to suffer worsening of symptoms.

Q9 Members ranked the following additional services in order of importance

- | | |
|-----------------|----------------|
| 1 st | Counsellor |
| 2 nd | Nutritionalist |
| 3 rd | Dietician |
| 4 th | Social Worker |

Members were then asked to highlight any other services they found important, see pages 19-20.

Conclusion to Survey

When we undertook this survey (September – November 2007) over 600 patients had been seen across the four CFS/ME teams.

Our 77 member responses therefore reflect roughly 13% of the total.

Internal monitoring and evaluation within each team is now taking place.

The CFS/ME Network wish to centralise these findings as part of the review of regional service delivery in the future.

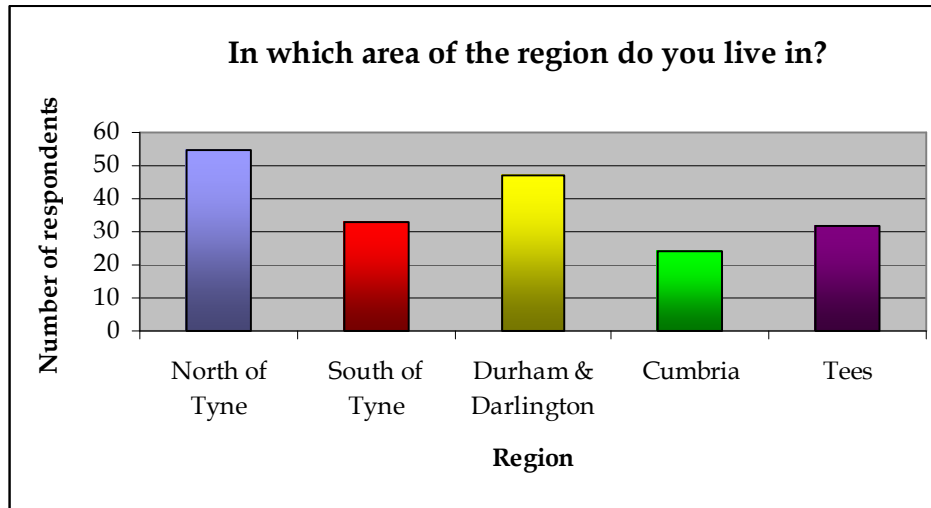
ME North East is willing to work with each team as part of local evaluation, to share our members' experience as patients and to give a comprehensive overview of services across the region.

The results of this survey will be an integral part of that overall review.

Detailed findings of Members Survey

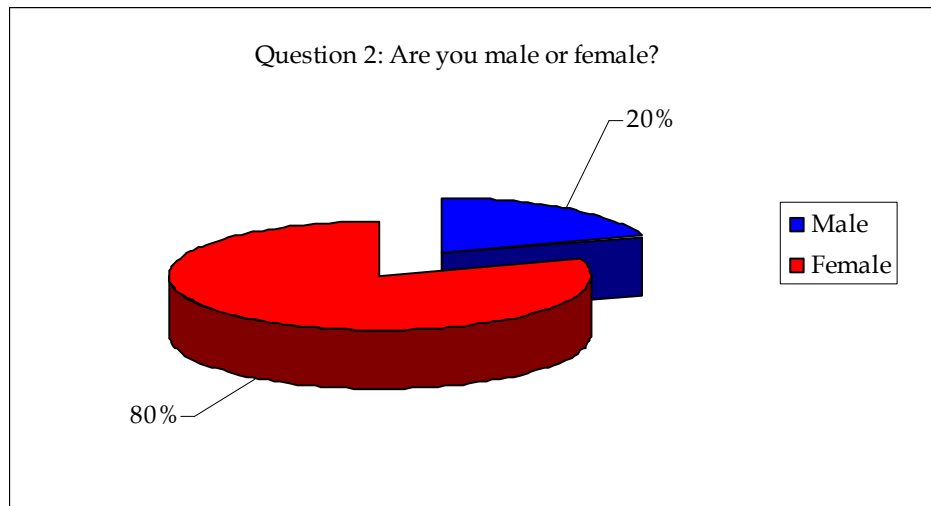
Part one - General survey

Question 1: In which area of the region do you live in?

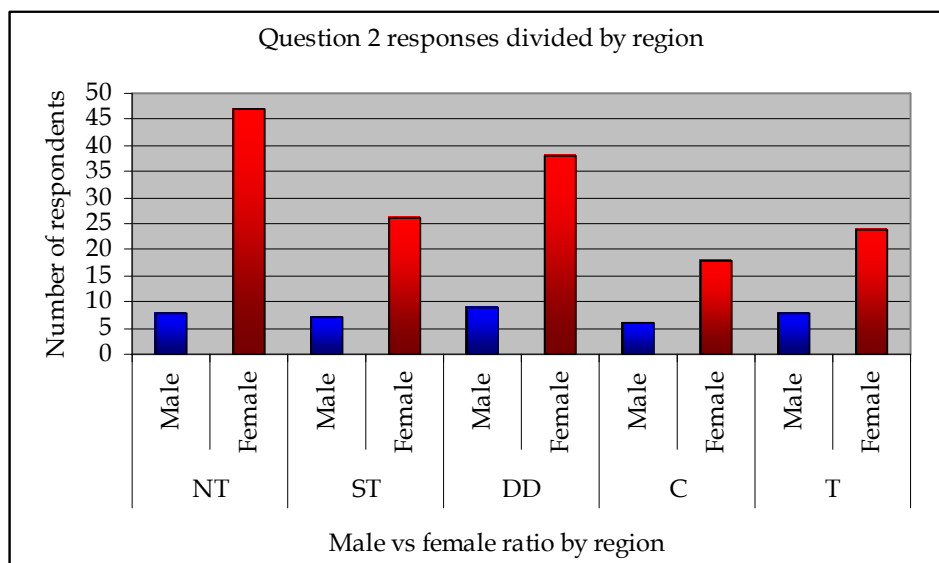


Question 2:

Are you male or female?

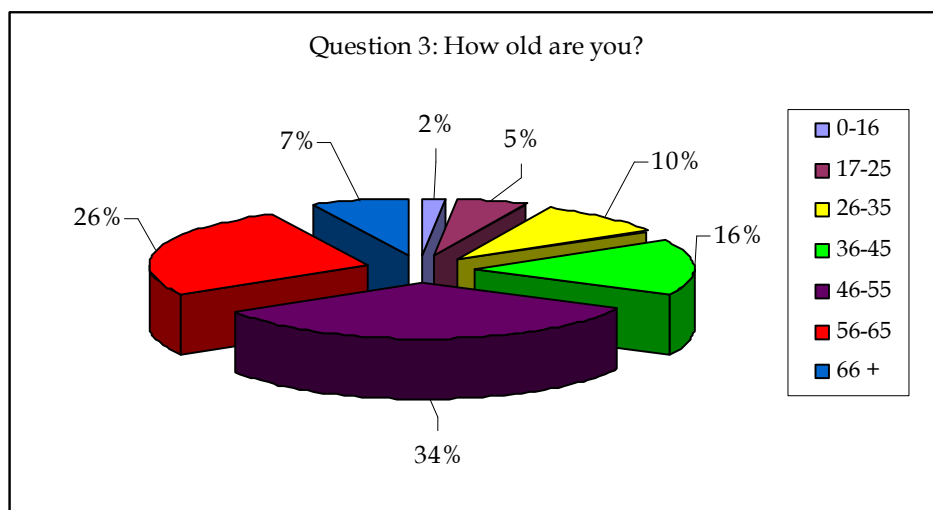


Question 2 responses divided into region:



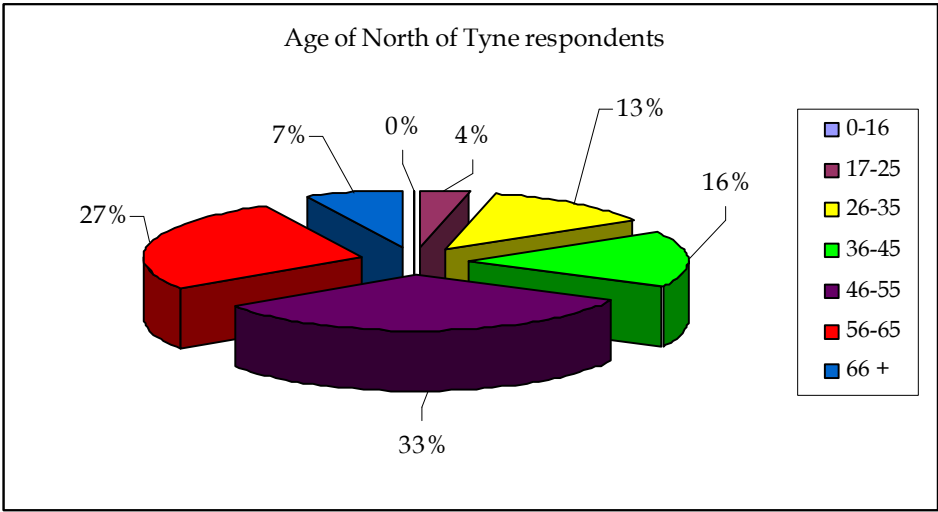
Key
North of Tyne(NT) South of Tyne (ST) Durham/Darlington (DD) Cumbria (C) Tees (T)

Question 3: How old are you?

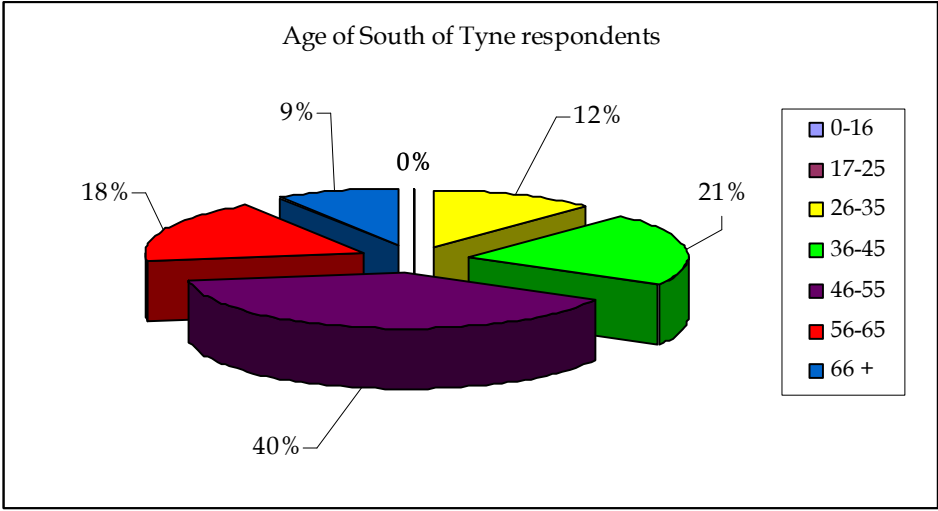


Question 3a: Respondents ages divided into regions

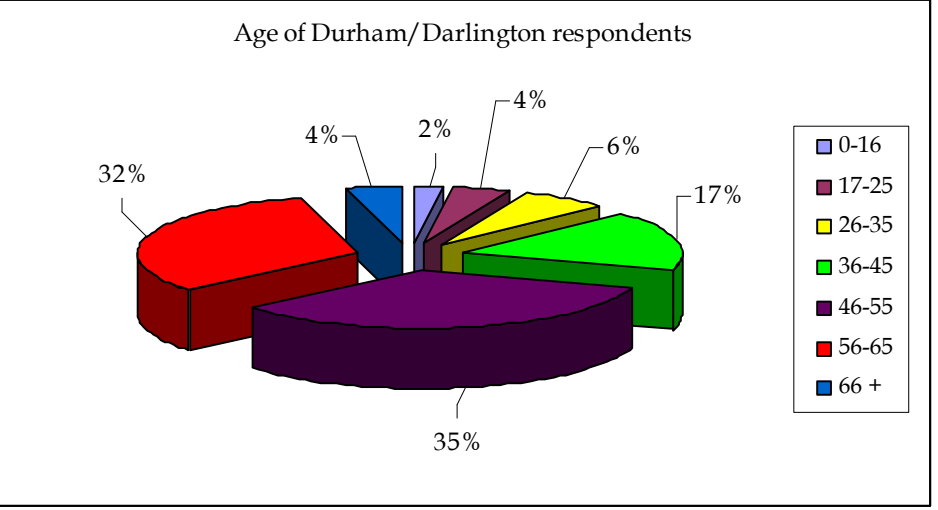
North of Tyne



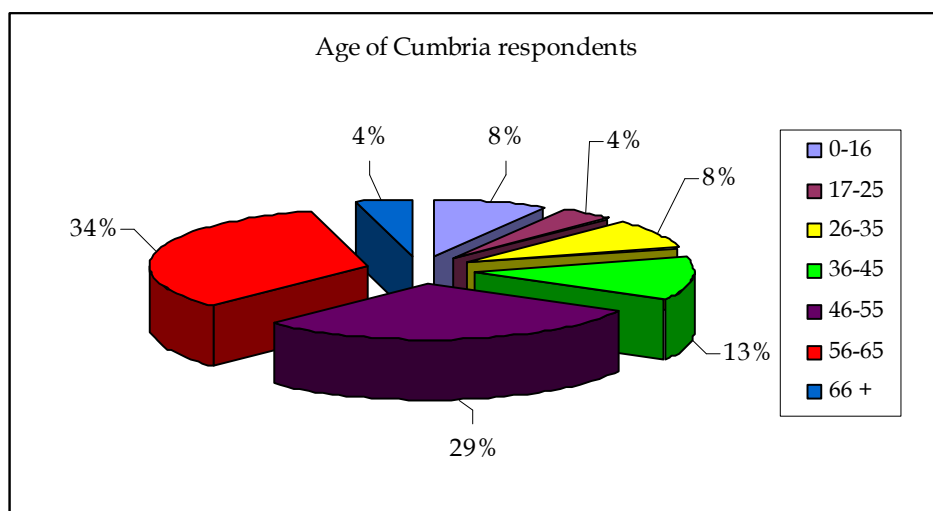
South of Tyne



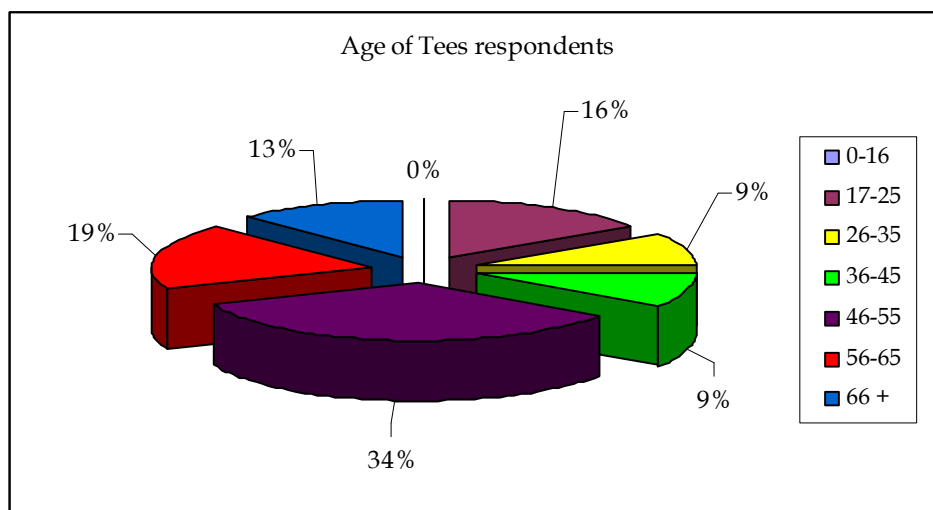
Durham/Darlington



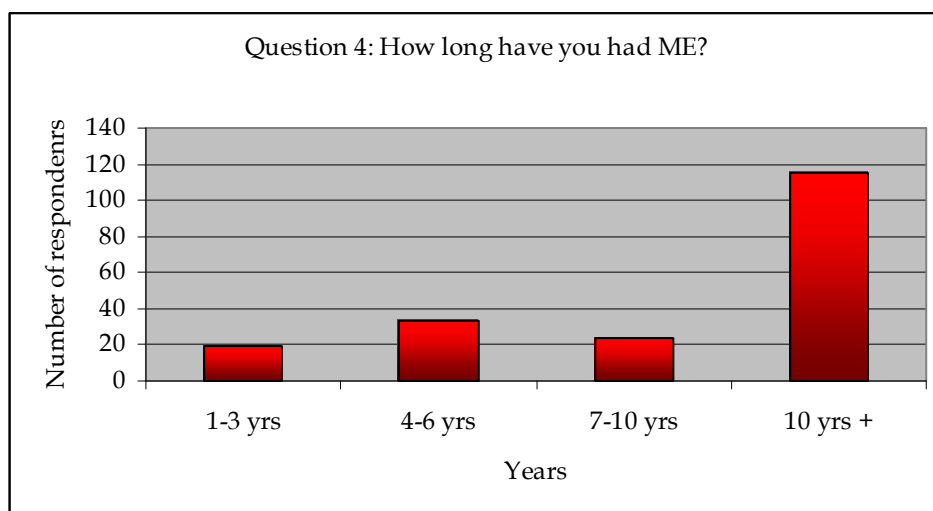
Cumbria



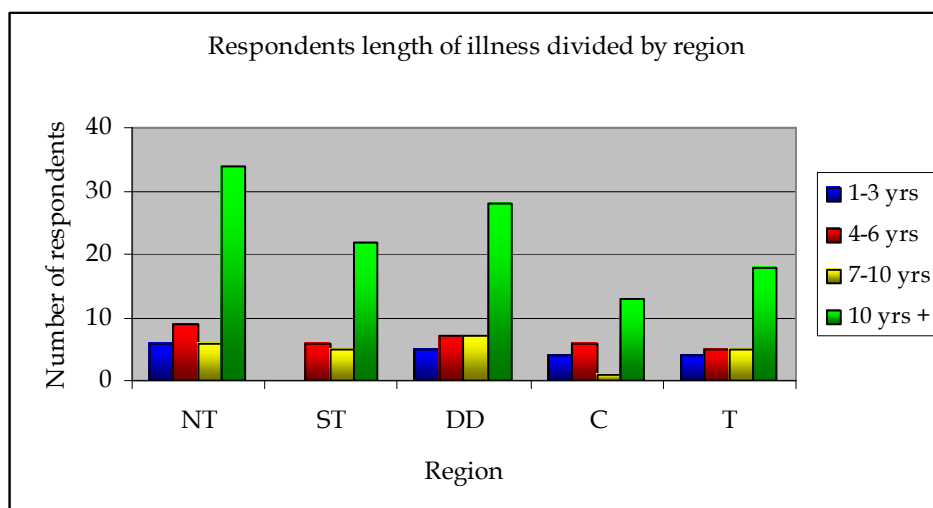
Tees



4: How long have you had ME?



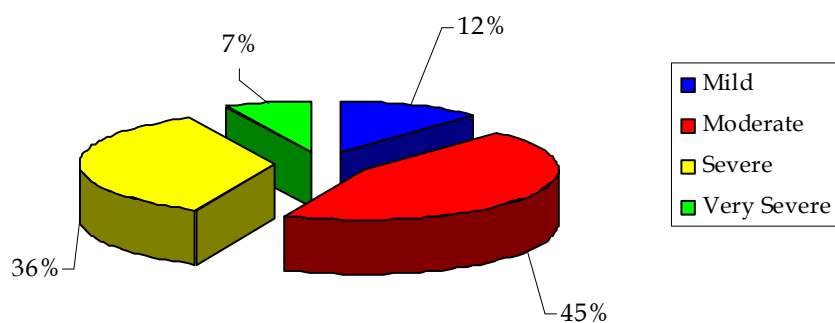
Question 4a: Respondents length of illness divided by region



Key
North of Tyne(NT) South of Tyne (ST) Durham/Darlington (DD) Cumbria (C) Tees (T)

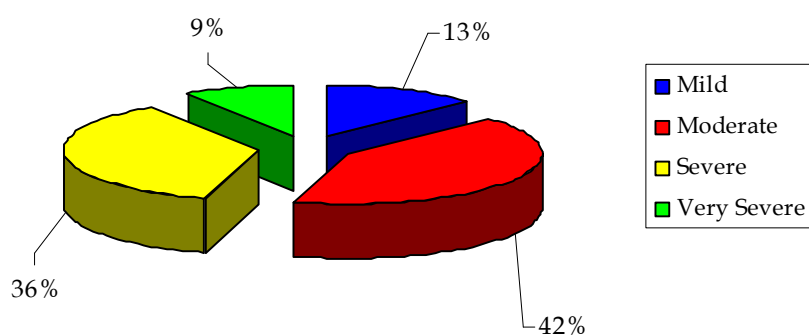
Question 5: How severe do you consider your CFS/ME?

Question 5: How severe do you consider your ME?



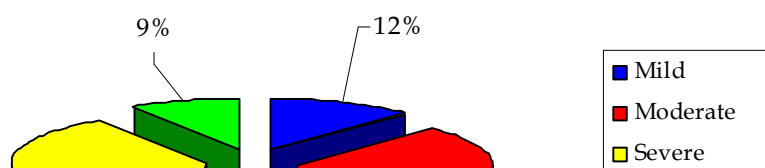
Question 5a:

Question 5a: North of Tyne respondents severity of ME

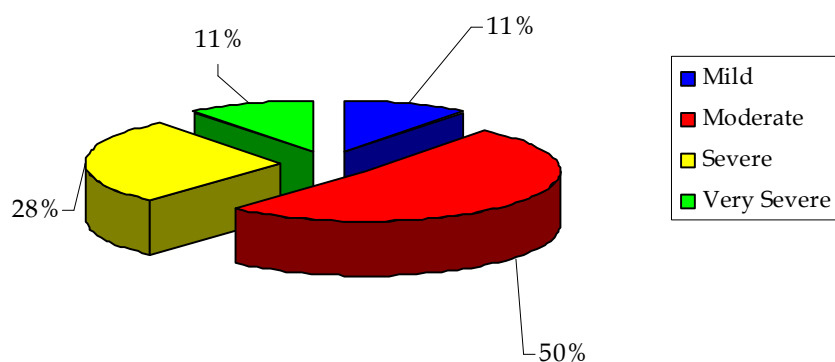


Question 5b:

Question 5b: South of Tyne respondents severity of ME

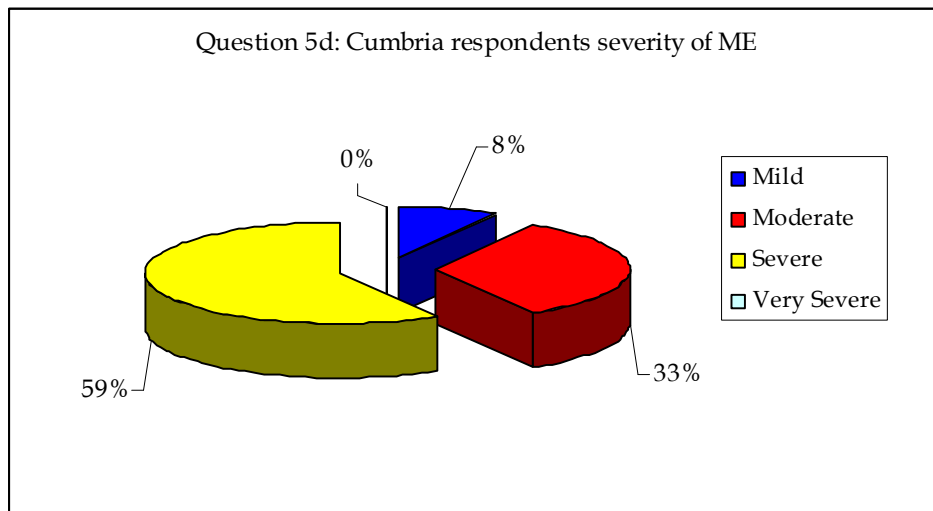


Question 5c: Durham/Darlington respondents severity of ME

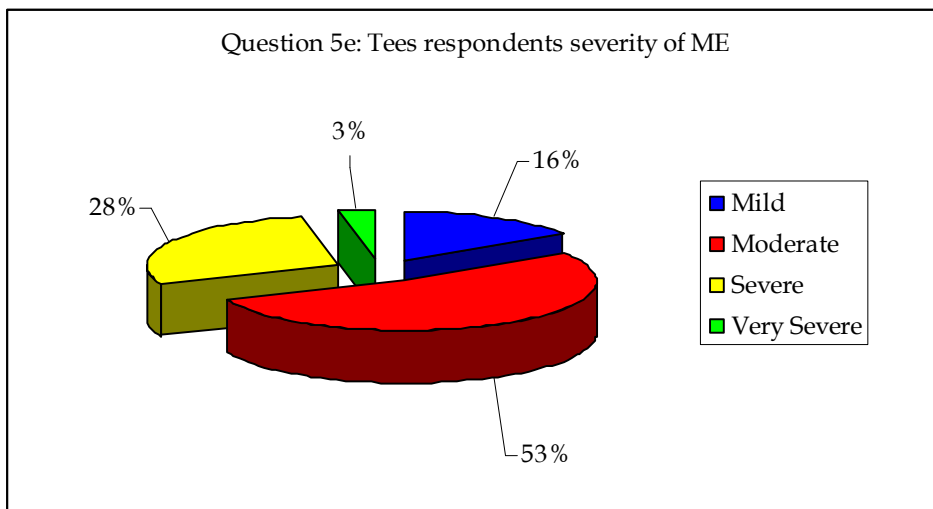


Question 5c:

Question 5d:



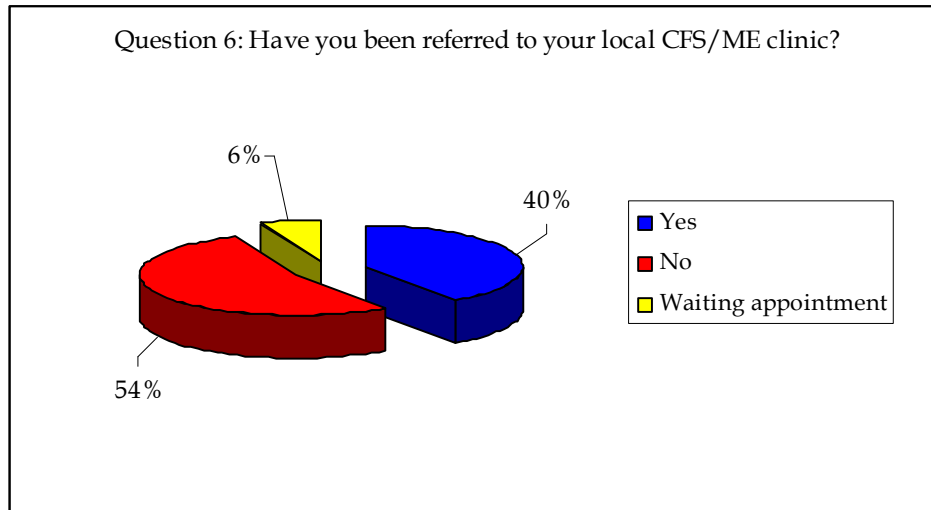
Question 5e:



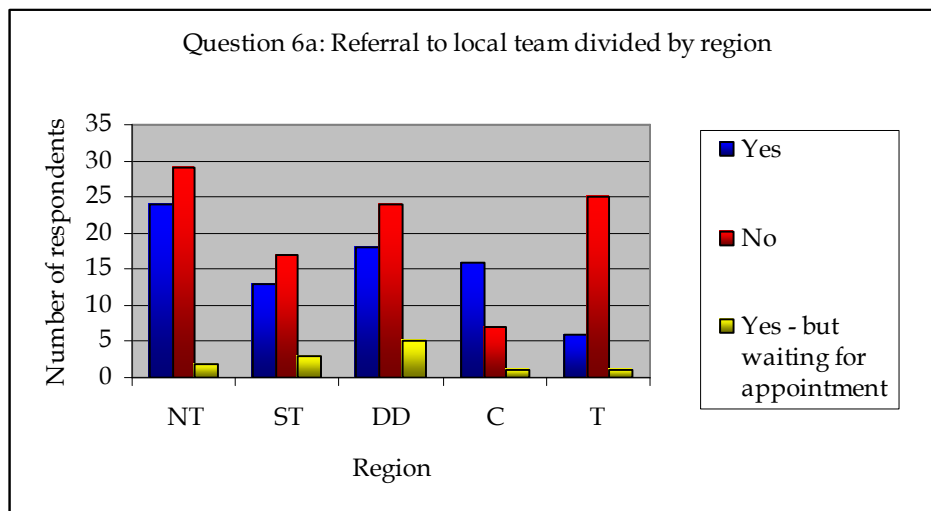
Question 6:
Four
CFS/ME

clinics operate across the North East - have you been referred to your local team?

In total 77 out of 191 respondents had been referred to the CFS/ME service. The graph below shows the percentage breakdown.

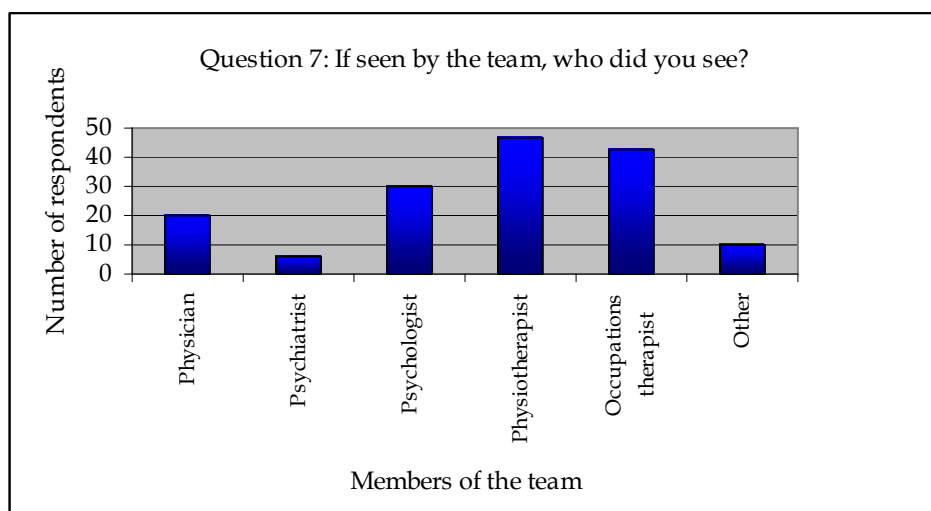


Question 6a:

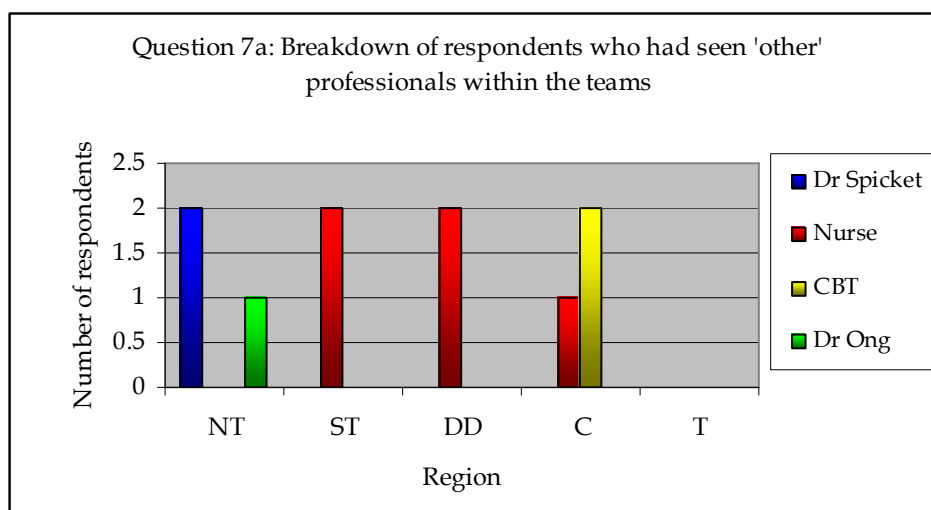


Key
North of Tyne(NT) South of Tyne (ST) Durham/Darlington (DD) Cumbria (C) Tees (T)

Question 7: If seen by the team who did you see?

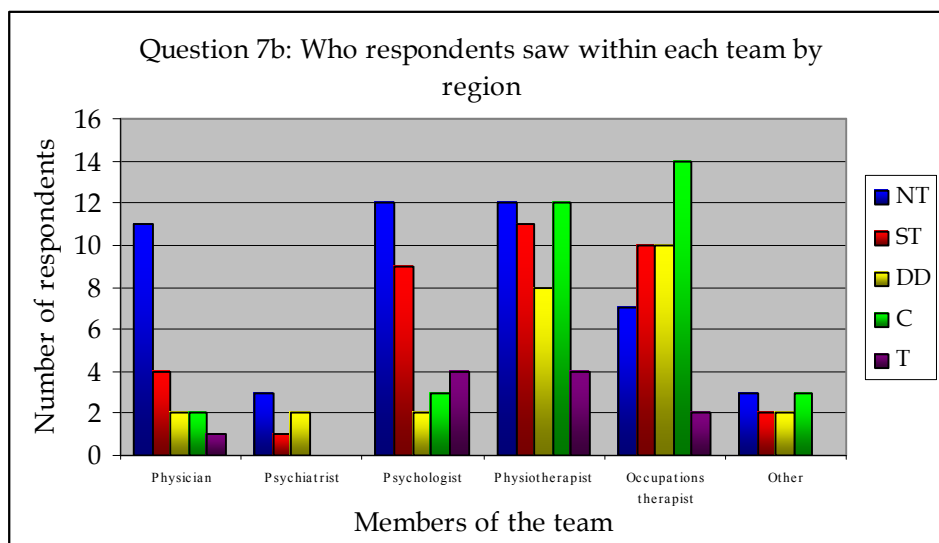


Question 7a: 10 respondents highlighted they had seen 'other' professionals within the teams, see the graph below

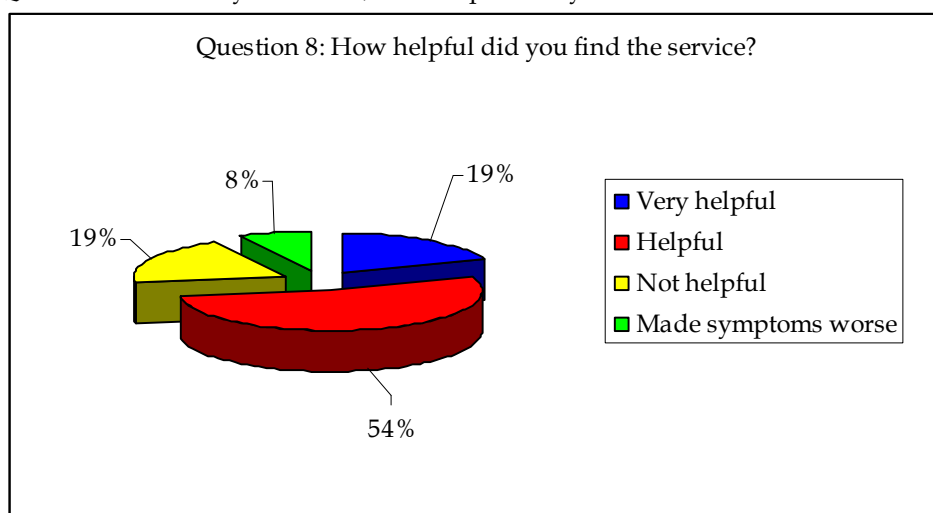


Key
North of Tyne(NT) South of Tyne (ST) Durham/Darlington (DD) Cumbria (C) Tees (T)

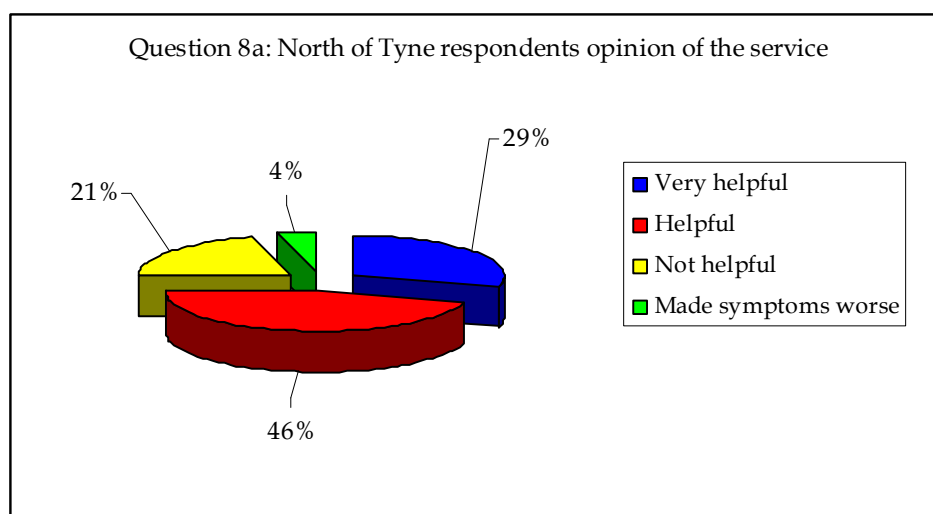
Question 7b: Who respondents saw within each team and by region



Question 8: If seen by the teams, how helpful did you find the service?



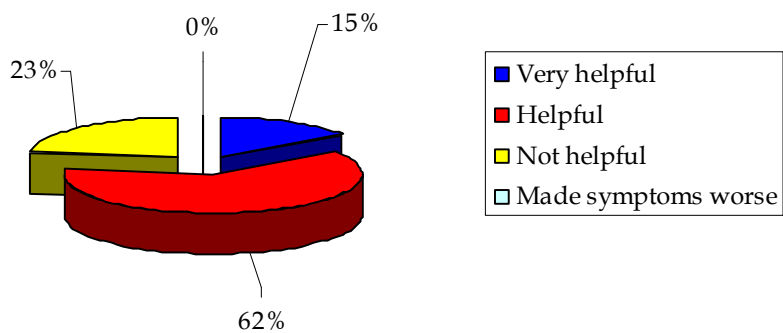
Question 8a: Respondents from North of Tyne opinion of the service



opinion of the service

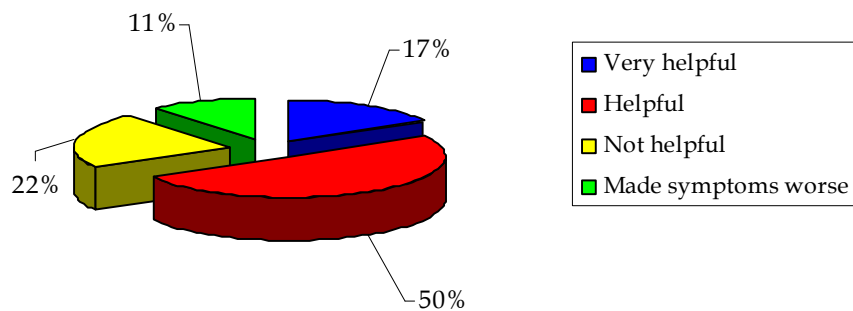
Question 8b:
Respondents
from South
of Tyne

Question 8b: South of Tyne respondents opinion of the service



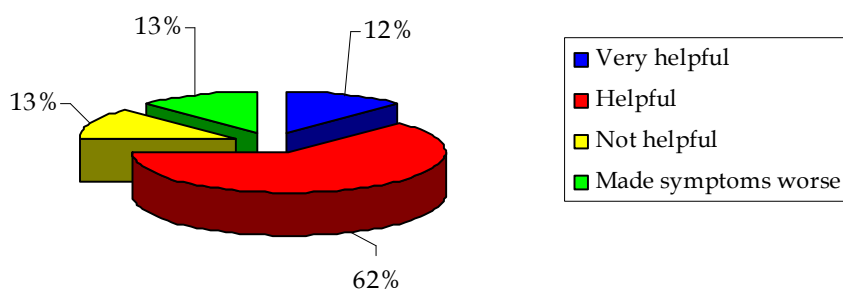
Question 8c: Respondents from Durham/Darlington opinion of the service

Question 8c: Durham/Darlington respondents opinion of the service



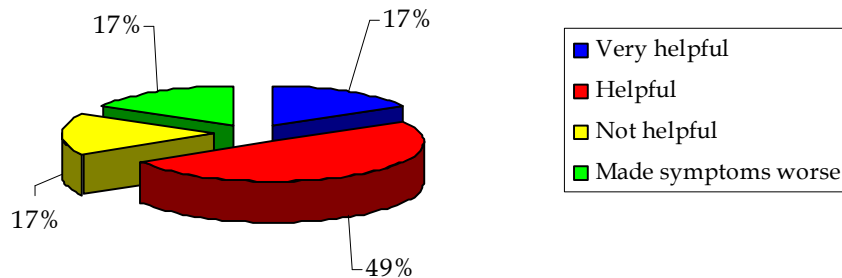
Question 8d: Respondents from Cumbria opinion of the service

Question 8d: Cumbria respondents opinion of the service



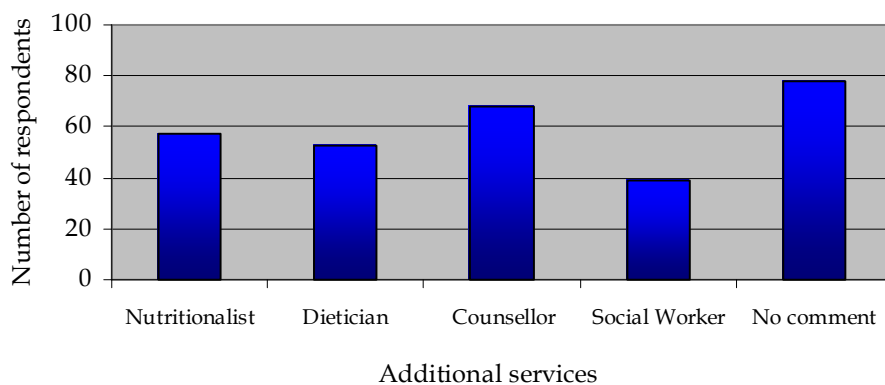
Question 8e: Respondents from Tees opinion of the service

Question 8e: Tees respondents opinion of the service

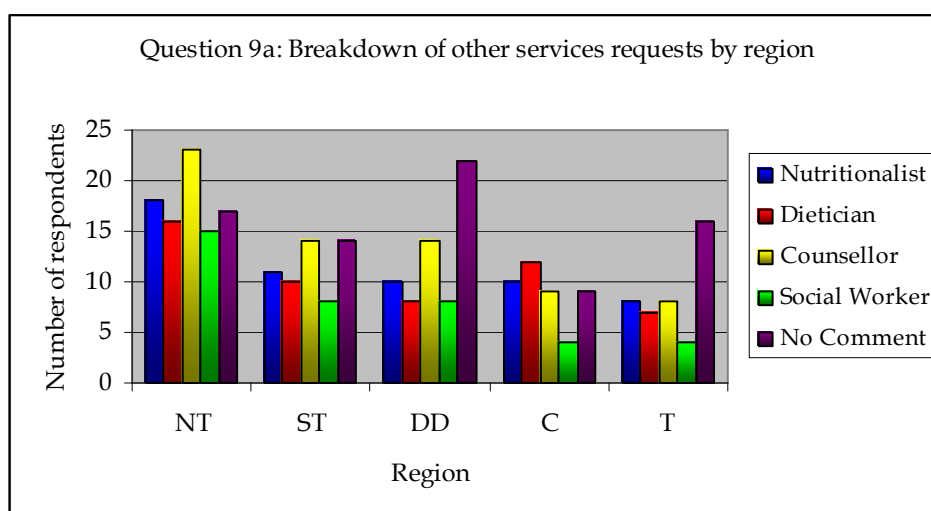


Question 9: Most teams only have the services of those listed in Question 7. What other services do you think should be available?

Question 9: What other services do you think should be on offer?



Question 9a: Breakdown of what other services respondents would like by region



Key
North of Tyne(NT) South of Tyne (ST) Durham/Darlington (DD) Cumbria (C) Tees (T)

Respondents were also asked what other services would be beneficial. See the comments below

➤ North of Tyne

Aromatherapist
Complementary Therapist
Legal Welfare advisor
Homecare worker
Pain Management Clinic
Alternative Therapist
Benefits advisor
Exercise Physiologist
Endocrinologist
Complimentary Therapist
Mediator for DHSS
Advocate
Dental Treatment for Bedbound
Patient Liaison
Acupuncturist
Social Services Officer

➤ South of Tyne

➤ Advocacy

➤	Someone who has ME/CFS who has completed the programme
➤	Medical Doctor
➤	Relaxation Techniques
➤	Immunologist
➤	Infectious diseases expert
➤	Neurologist

- Durham/Darlington

➤	Emergency Counsellor (for crisis periods)
➤	Benefits advisor
➤	Home visits by specialist ME Nurse for housebound
➤	Perrin Technique
➤	Welfare rights Advisor
➤	Reflexology
➤	Relaxation Techniques
➤	Holistic Therapies
➤	Phone Appointments for housebound
➤	Regular tests by Physician
➤	Supply of Procaine Infusion

- Cumbria

➤	A General practitioner who is supportive
➤	Interviewers should be properly trained medical personnel
➤	Pain Management Clinic
➤	Proper Consultation
➤	Diagnostic Centre

- Tees

➤	Respite care
➤	Allergy and Food Intolerance Tests
➤	Complimentary Therapies

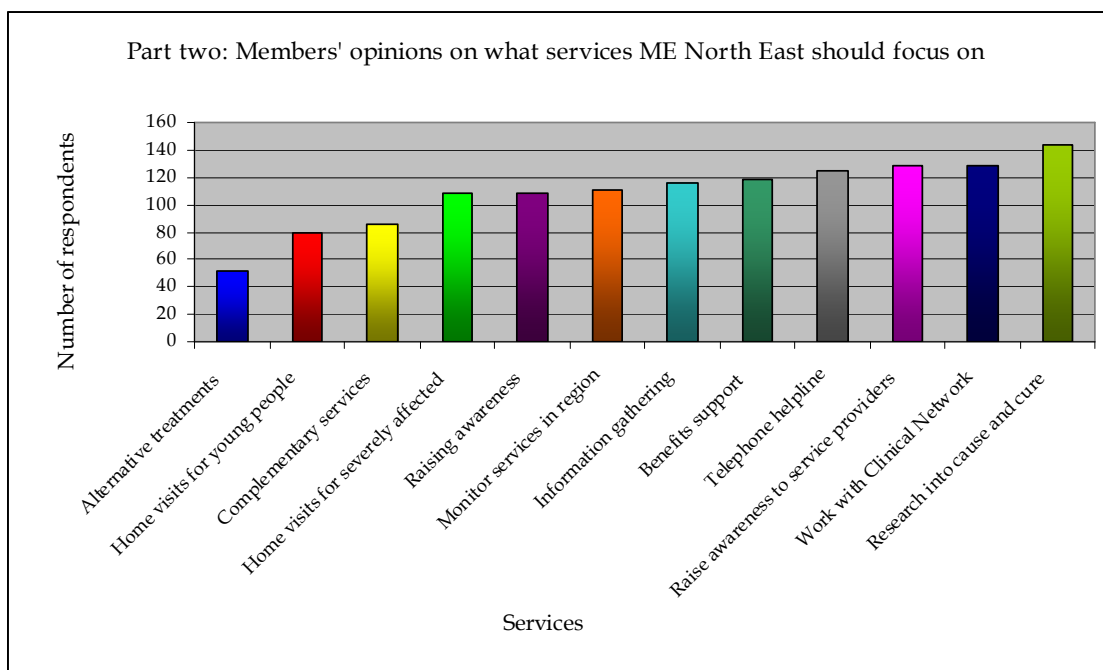
Part Two: Review of services ME North East currently deliver

ME North East asked members to think about the following question and provide answers.

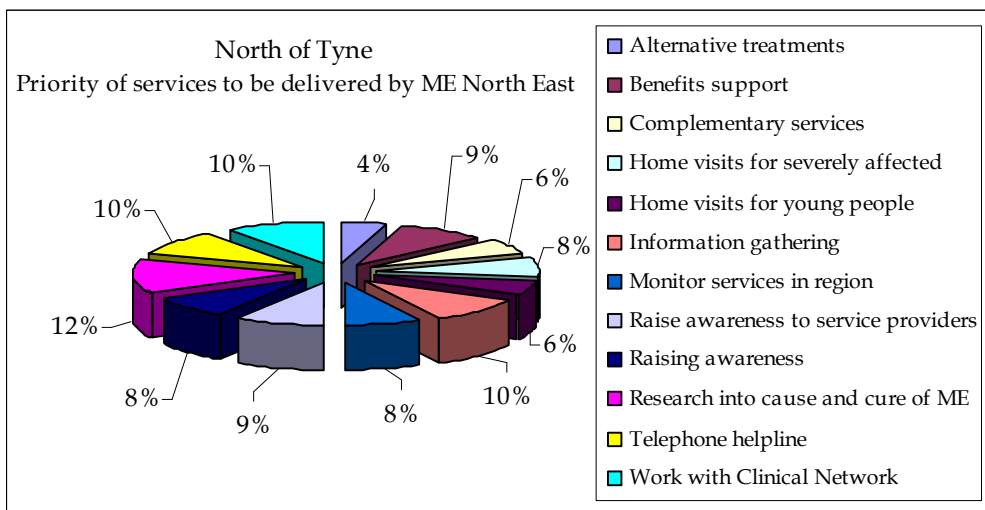
As funding our work is becoming harder – we may need to review the range of services we presently offer. In your opinion what key areas should ME North East focus on?

The following options were outlined:

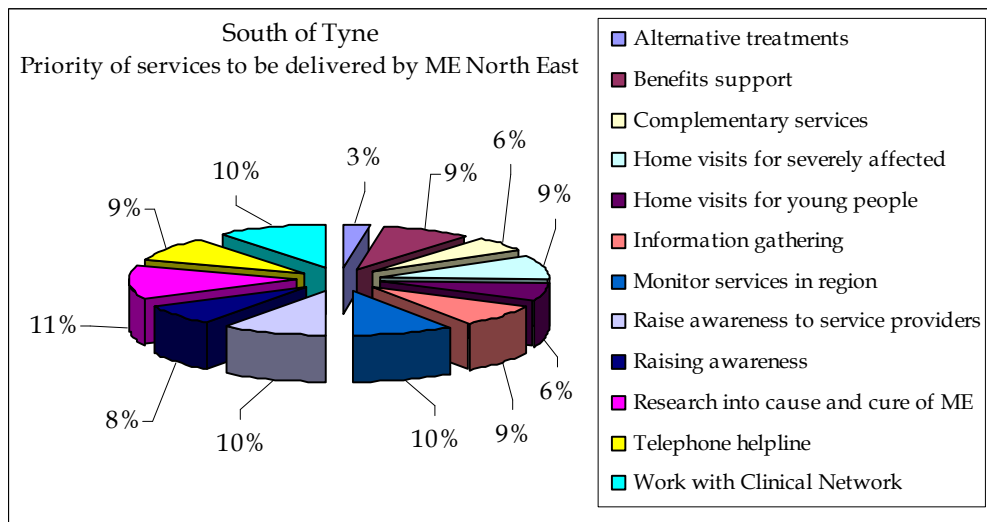
➤	Facilitate speakers and demonstrators for alternative treatments
➤	Home visits and advocacy for young people and families
➤	Provide access to complementary services (i.e. Counselling and stress relief)
➤	Home visits and advocacy for the severely affected
➤	Raising awareness with the general public
➤	Monitor and evaluate the CFS/ME services in our region
➤	Information gathering and circulation (via newsletters and internet)
➤	Provide benefits advocacy and support
➤	Telephone help-line for support, understanding, help and information
➤	Raising awareness and delivering training on the needs of ME to service providers
➤	Working with the Northern CFS/ME Clinical Network and local clinical teams to improve and increase services to patients
➤	Support and enable research into the cause and cure of ME



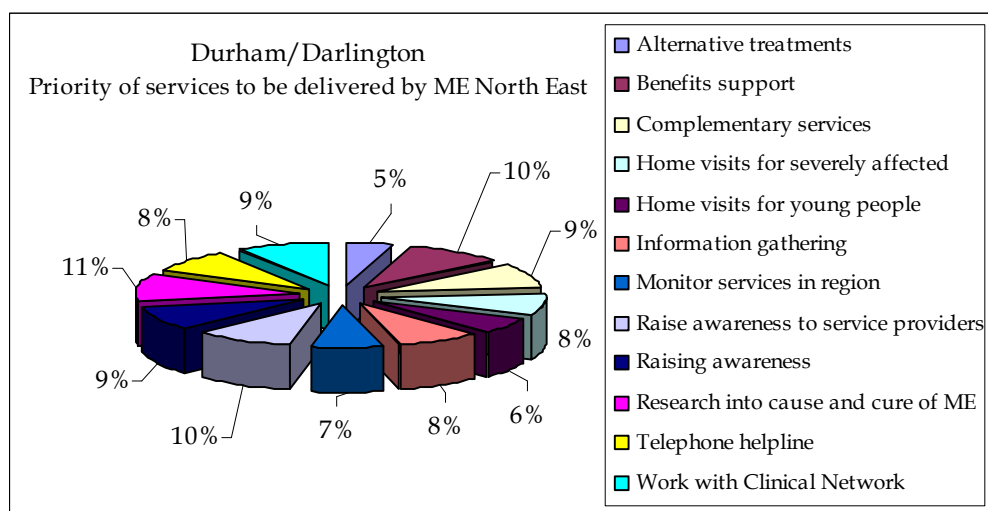
North of Tyne feedback



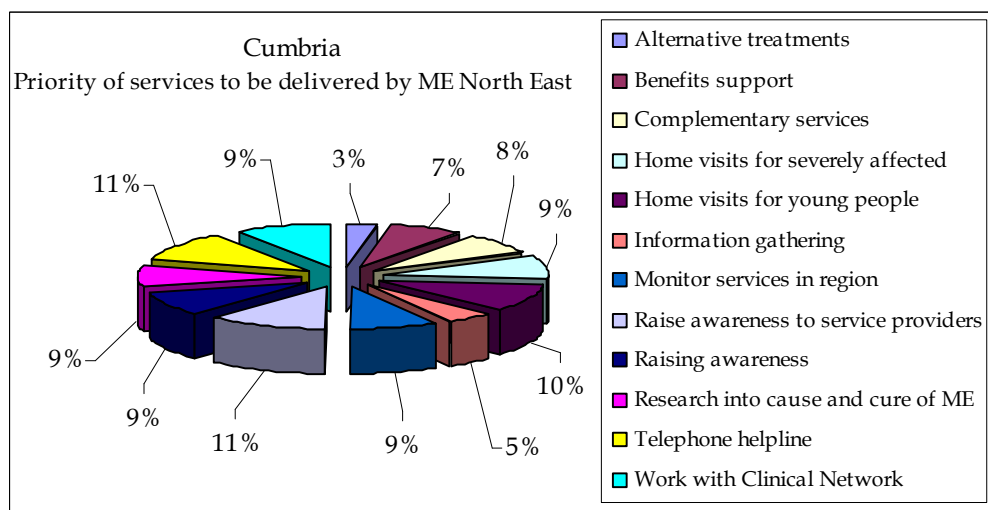
South of Tyne feedback



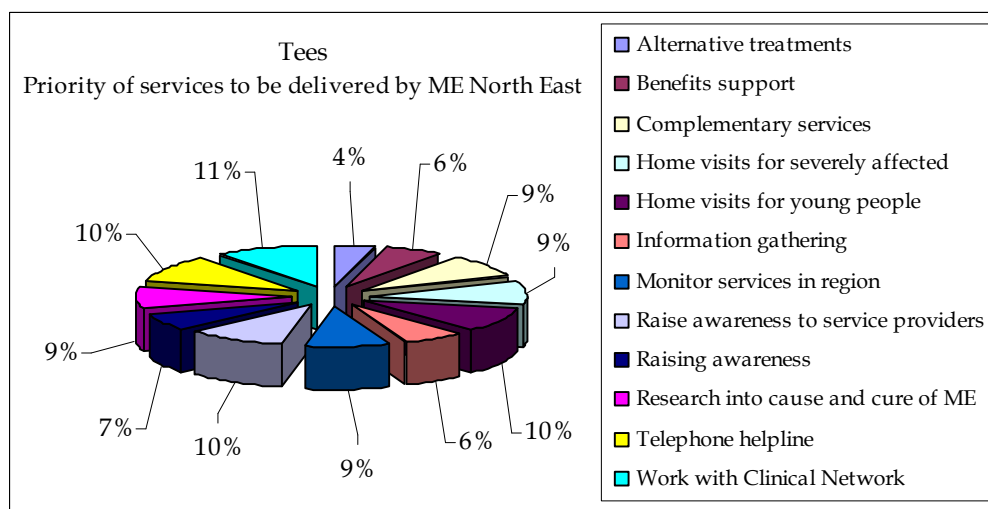
Durham/Darlington feedback



Cumbria feedback



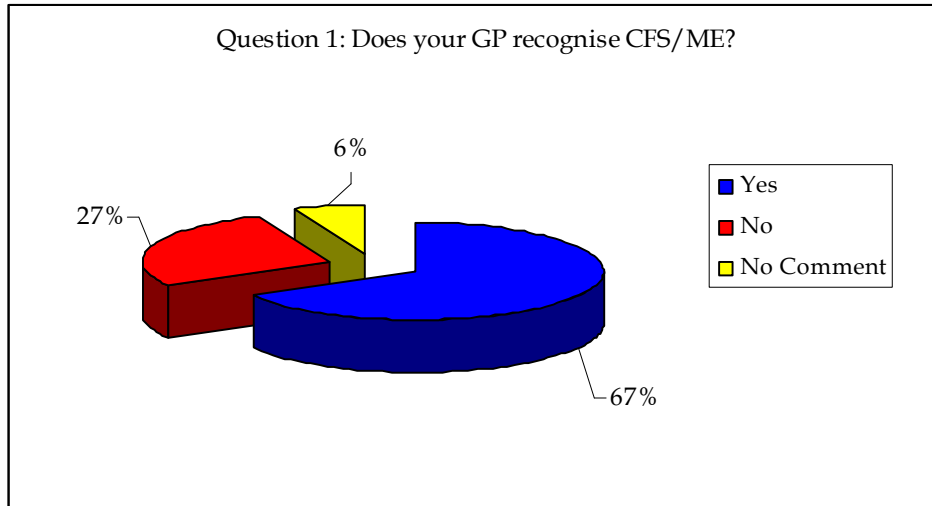
Tees feedback



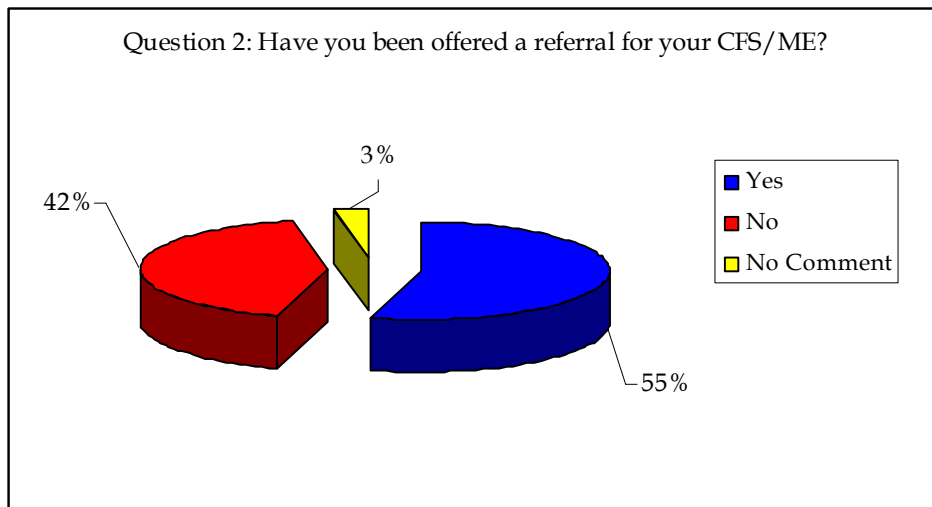
Part Three - Teesside members only survey

Introduction: In total 33 individuals responded to this section of the survey.

Question 1: Does your GP recognise CFS/ME



Question 2: Have you been offered a referral for your CFS/ME?

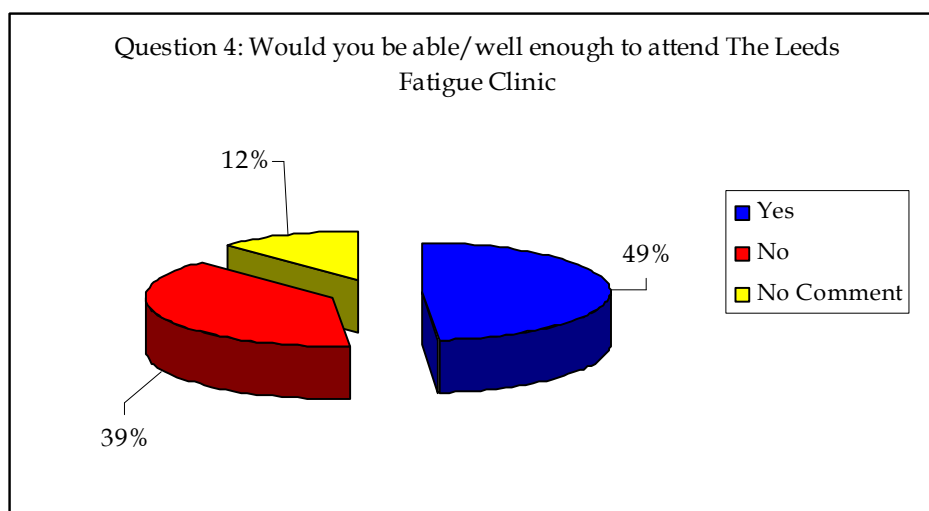


Question 3: If you were offered a referral where were you referred to?

In total 18 respondents had been referred and these were their comments

➤	Dr McCarron
➤	Hartlepool - 6 years ago to a doctor
➤	Sunderland Clinic
➤	North Tees - Psychiatric Department
➤	Friarage Hospital and Nursing Staff - 10 years ago to a psychiatrist
➤	Sunderland - Dr Richardson and Ryhope Hospital - Prof Daymond
➤	Sunderland
➤	Ashwood Mental Health Centre, Guisborough
➤	Stanhope - 15 years ago
➤	North Tees - Physiotherapy department
➤	James Cook University Hospital
➤	Northallerton and James Cook Hospital - Cognitive Therapist
➤	Leeds Fatigue Clinic
➤	Dr McCarron
➤	Sunderland Chronic Fatigue Centre
➤	Sedgefield Community Hospital
➤	No Comment x 2

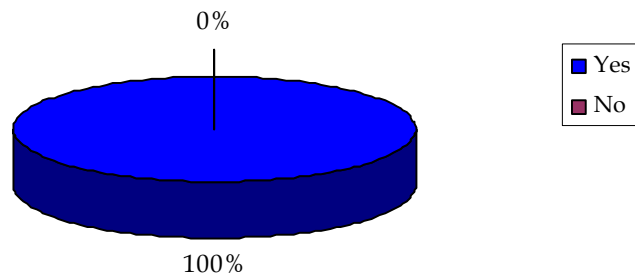
Question 4: If you were offered a referral to The Leeds Fatigue Clinic would you be able/well enough to attend?



Question 5: In your opinion should there be a local CFS/ME clinic in Teesside?

As shown in the graph below, a 100% of the respondents agreed there should be a service in Teesside

Question 5: Should there be a local CFS/ME Clinic service in Teesside?



Appendix

Appendix I

Members Survey

ME North East services are shaped by what you our members tell us. It is a while since we asked you for an update via a survey – and we feel the time is right now to help us to focus on our priorities that will bring you the greatest benefit and to identify possible funding streams to achieve our goals. We have restricted this to just one sheet – to keep it easy and simple for you to complete – but also because of postage costs.

The last few questions are especially for Teesside members – to help us to put together a case of need to support the bid for dedicated funds for local services – this evidence is crucial. Please circle your answers:

Part One

Q1 In which area of the region do you live?

North of Tyne South of Tyne Durham/Darlington Cumbria Tees

Q2 Are you:

Male

Female

Q3 How old are you?

0-16

17-25

26-35

36-45

46-55

56-65

66+

Q4 How long have you had ME?

1-3 yrs

4-6yrs

7-10years

10yrs+

Q5 How severe do you consider your ME?

Mild

Moderate

Severe

Very Severe

Q6 Four CFS/ME clinics operate across the North East - have you been referred to your local team?

YES

NO

Yes - but waiting for appointment

Q7 If seen by the team, who did you see? (circle all that apply)

Physician

Psychiatrist

Psychologist

Physiotherapist

Occupations therapist

Other (please specify)

Q8 If seen, how helpful did you find the service?

Very Helpful

Helpful

Not Helpful

Made symptoms worse

Q9 Most teams only have the services of those listed in Q7.

What other services do you think should be available?

Nutrition

Dietician

Counsellor

Social Worker

Any other services please specify:

Any additional comments would be very

helpful.....

.....

.....

Appendix II

Members Survey

Part Two

As funding our work is becoming harder - we may need to review the range of services we presently deliver. In your opinion what key areas should ME North East focus on? (Please mark all those that apply - prioritise if you wish)

Facilitate speakers and demonstrations for alternative treatments

Home visits and advocacy for young people and families

Home visits and advocacy for the severely affected

Information gathering and circulation (via newsletters and internet)

Monitor and evaluate the CFS/ME services delivered across the region

Provide access to complimentary services (ie; counselling and stress relief)

Provide benefits advocacy and support

Raising awareness and delivering training on the needs of ME to service providers (in health, education and social services)
Raising awareness with the general public via media coverage, fundraising events, and activities
Support and enable research into the cause and cure of ME
Telephone help-line for support, understanding, help and information
Working with the Northern CFS/ME Clinical Network and local clinical teams to improve and increase services to patients

Appendix III

Members Survey

Part Three

For members in the Teesside Area ONLY

Q1 Does your GP recognise CFS/ME? YES NO

Q2 Have you been offered a referral for your ME? YES NO

Q3 If Yes – where were you referred to? – please give details

.....
.....
.....

Q4 If you were offered a referral to The Leeds Fatigue Clinic would you be able/well enough to attend? YES NO

Q5 In your opinion why should there be a local CFS/ME service in Teesside?
YES NO

If YES, please give reason:

.....
.....

Any additional comments would be very helpful.....

.....
.....