Richmond & Kingston
M.E. Group
Serving Richmond & Kingston Boroughs & the surrounding areas

Richmond & Kingston Local Area Survey 2014

SKIPTON
MY BUILDING SOCIETY

RPLC
Richmond Parish Lands Charity

Royal Kingston

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1. Background

In 2009 the Richmond & Kingston ME Group commissioned Simply Research to conduct a local area survey with generous support from Grassroots Grants in order to assess its members on a range of topics including demographics, health status, welfare and benefits and a short evaluation of the Group's activities and services. Following funding applications made by the Group's Treasurer Fernando Campo, grants were secured for a follow-up survey from Richmond Parish Lands Charity, the Royal Borough of Kingston and Skipton Building Society through their Grassroots Giving campaign for 2014. Therefore, in December 2013 Linda Webb approached Simply Research once again to provide the present report. Initially, this was to be comprised of the original quantitative items from the 2009 survey but after discussion by the Richmond & Kingston ME Group Committee it was decided that new information was required. Therefore, comparisons to the 2009 results made within this report are limited to the items repeated in 2014.

2. Methodology

The updated 2014 survey consisted of five sections: key information, health, impact on life, Richmond & Kingston ME Group membership and welfare and benefits with two qualitative items at the end[1]. It is hoped that the findings from this survey will further enable the Richmond & Kingston ME Group to communicate with government bodies, clinical commissioning groups, benefit agencies and voluntary services regarding the needs of people with ME in the local area.

The survey was once again administered online[2] and in hard-copy form for those members that requested paper questionnaires. The survey was launched on Monday October 27th 2014 and was closed on Monday 8th December 2014. A total of 148 questionnaires were administered, comprised of 124 online invitations and 24 hard copies. Fifty-nine completed surveys were returned, equating to a 39.9% response rate. This is lower than the 56.5% response rate in

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[1] The qualitative data from the online survey is presented at the end of this report but not analysed as per contractual agreement.

[2] The Survey Gizmo online tool was utilised for this project. Please see www.surveygizmo.com for more information.

2009 which would be expected; however a near-40% response rate illustrates a very good outcome for survey research[3].

3. Key Findings

- 81.4% of those who responded to this survey were members of the Richmond and Kingston ME Group.
- Respondents in this survey reported an illness duration of over 15.5 years on average, but this varied widely from 3 months to 49 years.
- Time taken to gain a diagnosis was just over 4.5 years for the sample as a whole, varying from 2 months to 27 years.
- One-third of the survey respondents resided in Kingston-upon-Thames and 18.6% were from Richmond-upon-Thames.
- Almost 40% of the respondents stated that their ME was ‘severe’ when they were at their worst.
- Over half the sample reported their condition to be ‘moderate’ at best and over the past five years (or since diagnosis if less than five years).
- Approaching one-third of respondents reported that their ME had deteriorated over the past year; 42.4% reported a fluctuating illness course.
- Extreme fatigue and exhaustion were the most troubling symptoms to the surveyed sample, followed by cognitive issues and post-exertional malaise.
- Over 90% of respondents had a diagnosis made by a NHS professional.
- Just over two-thirds of the sample had been screened for secondary conditions and co-morbidities.
- Half of the surveyed respondents received NHS treatment in the past year for ME.

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[3] In general, questionnaire-based research elicits a 20-25% response rate at best.

- 15.3% of the sample had been refused NHS tests, treatments and/or referrals in the past year.
- Over half the respondents stated that their GPs were supportive but could not help with their ME; 22% said their GP was unsupportive.
- No one in this survey reported that they'd been discharged from specialist care after sufficient improvement; 50.8% had been discharged by their consultant even though they were still symptomatic.
- 8.5% of individuals referred to an ME/CFS specialist clinic were too unwell or unable to attend; 52.5% were able to attend with the majority going to the Sutton/ St Helier clinic.
- Two-thirds of the surveyed sample did not require home care visits; 20.3% needed domiciliary care but did not receive it.
- Two-thirds of the respondents were employed when they became ill; one-third of the sample as a whole felt that work stress was a contributing factor to the development of their ME.
- Over half the sample reported they were unable to work at present due to their illness.
- Almost a quarter of the respondents had some sort of disruption to their education.
- Approaching three-quarters of the sample reported mobility problems as a result of their ME; one-third could mobilise 200m or more outside repeatedly, reliably and safely the majority of the time.
- Over 40% of the survey respondents reported that their ME affected their housing.
- More than 10% of the sample stated that they were completely unable to participate in family life due to their condition; one-third of respondents reported a severe effect on family life and responsibilities.
- 18.6% of the individuals who responded to this survey had caring responsibilities, the majority of whom had one person to care for.

- Over half of those who said they were carers reported that their ME had a considerable impact on their caring role and over one-third of the carers stated that their caring role had a serious effect on their ME, causing significant deterioration.

- More than 1in 5 of the survey sample had a carer, and were most commonly cared for by their partners or parents.

- 16.9% of the respondents could not afford home care support and 15.3% felt home care was too difficult to organise, resulting in unmet care needs.

- Benefits support was the most frequent type of support other than care reported by the sample.

- Approaching a quarter of respondents reported feeling very isolated and just over one-quarter experienced moderate isolation because of their ME.

- Within the past year the newsletter was the Group's activity that most respondents were engaged in and this was also what individuals wanted to see continue.

- Over 40% of the surveyed sample was very satisfied with the Group's work and 25.4% were completely satisfied.

- The most troublesome type of social interaction reported in this survey was going out to meet people, followed by replying to letters and holding face-to-face conversations at home.

- 16.9% of the respondents stated that their ME symptoms had worsened because of changes to the benefits system; 11.9% reported that their income level had decreased and 10.2% experienced hardship.

- Over a quarter of the sample reported that they had to appeal or apply for reconsideration 1-3 times for their benefits and approaching one-third of the survey sample had 1-3 benefits assessments and reassessments in the past five years.

- 5.1% of the respondents had been able to obtain emergency financial or hardship support locally when needed but 11.9% had not.

4. Results

4.1. Key information

4.1.1 Demographics

Within the sample of 59 participants, 78% were female and 22% male, which approximately reflects the wider ME population in the UK. Slightly more men responded to this 2014 survey as compared to the 2009 local area questionnaire (20.7% male in 2009).

The majority of the sample (96.6%) classed their ethnic origin as ‘White’; a category that included English, Welsh, Scottish, Northern Irish and British, Irish, Gypsy or Irish Traveller and any other White background. Only two (3.4%) respondents stated they were of Asian/Asian British origin (including Indian, Pakistani, Bangladeshi, Chinese and any other Asian background). No respondents identified as Mixed Multiple ethnic groups (including White and Black Caribbean, White and Black African, White and Asian and any other Mixed/Multiple ethnic background), Black/African/Caribbean/Black British (including African, Caribbean and any other Black/African /Caribbean) or any other ethnic group (including Arab and any other ethnic group). Compared to 2009, there was an increase in those that recorded their ethnicity as ‘White’ (91.2% in 2009).

The mean age of the sample respondents was 53.95 years (standard deviation (SD) = 16.66) with a range from 16 to 91 years. This average was almost identical to the 2009 survey (54.03 years in 2009); however the age range widened by 12 years (range 63 years in 2009).

The mean duration of illness was 15.66 years (SD = 9.51), which was unsurprisingly longer than reported in the 2009 survey (13.71 years in 2009). The length of time respondents had ME ranged from 3 months to 49 years. The average time taken to receive a diagnosis of ME (or CFS as one respondent recorded on her survey) was 4.57 years (SD = 6.06), ranging from 2 months[4] to

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[4] The National Institute for Health and Care Excellence state that a diagnosis of CFS/ME should be made after symptoms have persisted for four months in adults and three months in children. One respondent who reported a diagnosis after only two months stated a label of ‘post-viral fatigue syndrome’ rather than ME or CFS. There was no further information on the other respondent who reported a diagnosis after two months of ill health.

27 years. Seven respondents had additional household members with ME (11.9%).

4.1.2 Location

The largest proportion of respondents resided in the Royal Borough of Kingston-upon-Thames (19 individuals, 32.2%), followed by ‘Other’ (17 cases, 28.8%). Eleven respondents resided in the London Borough of Richmond-upon-Thames (18.6%), 10 in Surrey County Council (16.9%), three in the London Borough of Hounslow (5.1%) and two individuals were from Merton Council (3.4%). Of the ‘Other’, one respondent was based in each of following locations/boroughs: Australia; the City of Bradford Metropolitan District Council; Dorset County Council; the London Borough of Hackney; the London Borough of Southwark; Lymington and Pennington Town Council; West Dorset District Council. Four people were based in London Borough of Wandsworth and one respondent did not state a borough of residence.

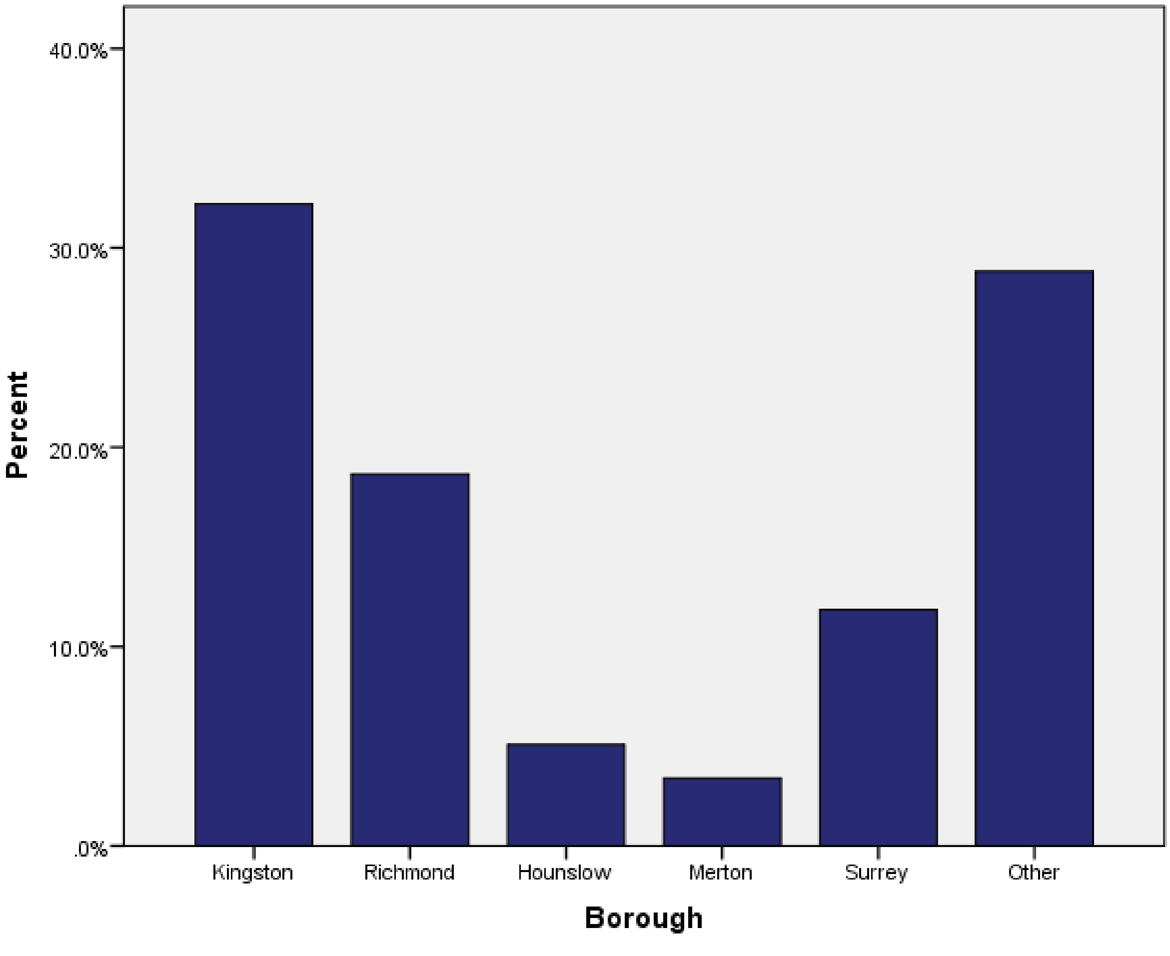

Figure 1. Borough of residence

4.2. Health

Respondents were given the following categories to rate their symptom severity level when they were at their worst, best and as an average over the past five years:

Mild = you are able to carry-on with the majority of everyday activities.

Moderate = you are able to carry-on with some daily activities but need help with others (e.g. larger tasks such as housework).

Severe = you cannot manage everyday activities without help and would consider yourself to be house-bound.

Very severe = you cannot manage everyday activities and would consider yourself to be bed-bound.

4.2.1. Illness severity

The majority of respondents (39%) categorised their symptoms as ‘severe’ when they were at their worst (see Figure 2).

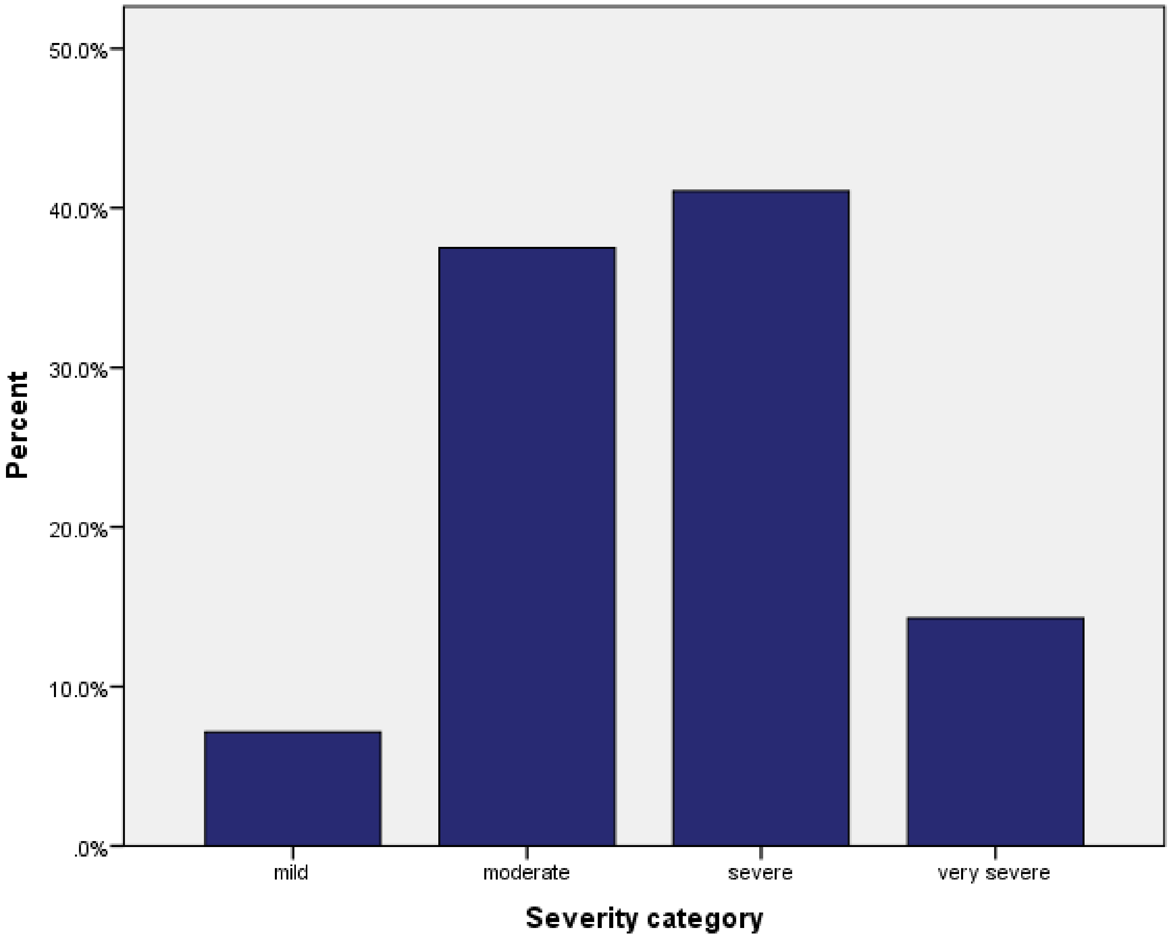

Figure 2. Self-reported illness severity when ME symptoms are at their worst

This was a reduction from 46.6% in the 2009 sample which stated ‘severe’ as the severity category when symptoms were at their worst. The next most frequent category was ‘moderate’ with 35.6% of the sample stating this level of severity when their ME was at its worst, followed by ‘very severe’ (13.6%) and ‘mild’ (6.8%).

As in the 2009 local area survey, in addition to ratings of symptoms when they are at their worst, respondents were also asked to state the severity of their symptoms when they were at their best (see Figure 3).

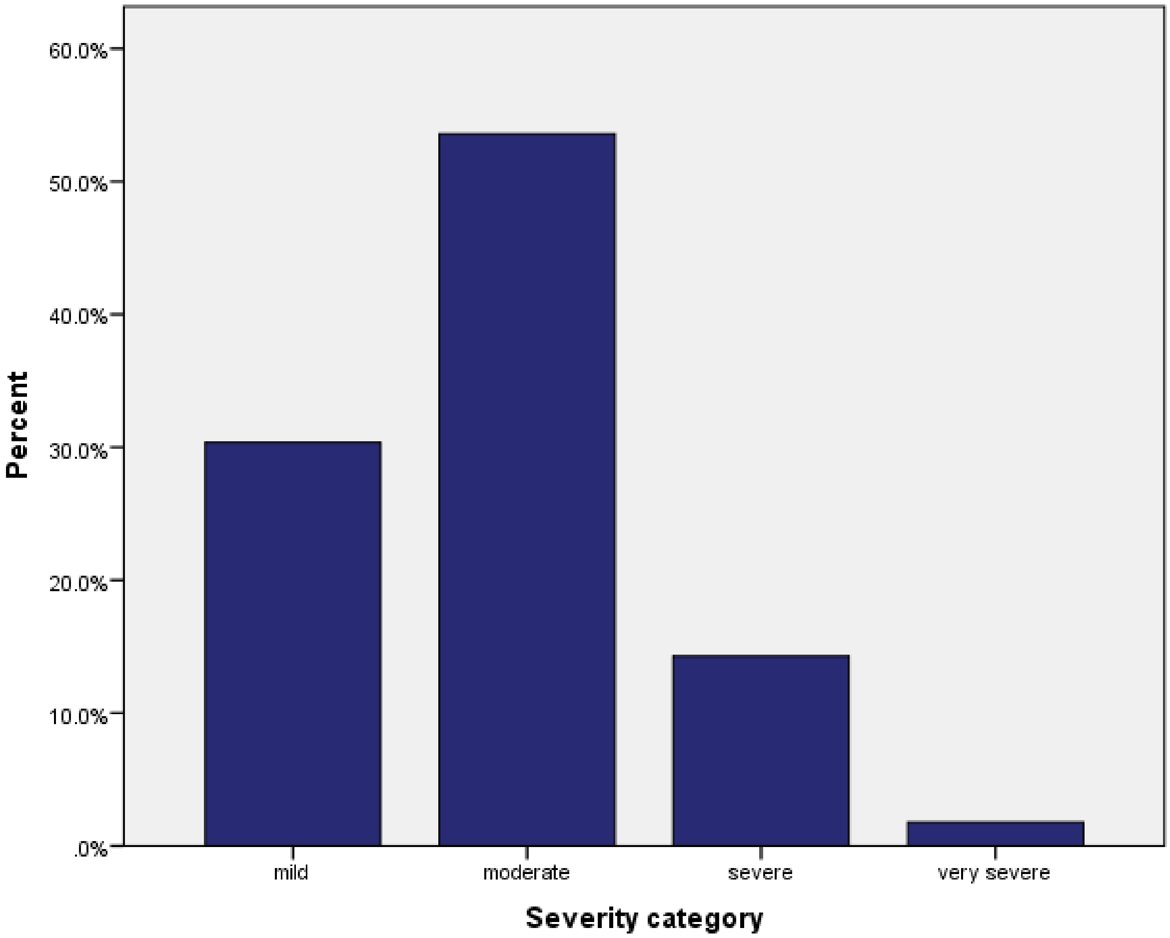

Figure 3. Self-reported illness severity when ME symptoms are at their best

The majority of respondents (50.8%) reported that they had a moderate level of ME symptomatology when they were at their best, meaning they could carry-on with some daily activities but needed help with others. Only one respondent stated that their symptoms were ‘very severe’ on this item, which equates to 1.7% and was the same as the 2009 survey.

When asked for severity estimates over the past five years, or since diagnosis if less than five years, over half the sample stated that their ME was 'moderate' (50.8%). Twenty-two percent of respondents stated their ME had been 'severe' over the past five years, 10.2% experienced 'mild' symptoms and 11.9% had very severe symptomatology (see Figure 4).

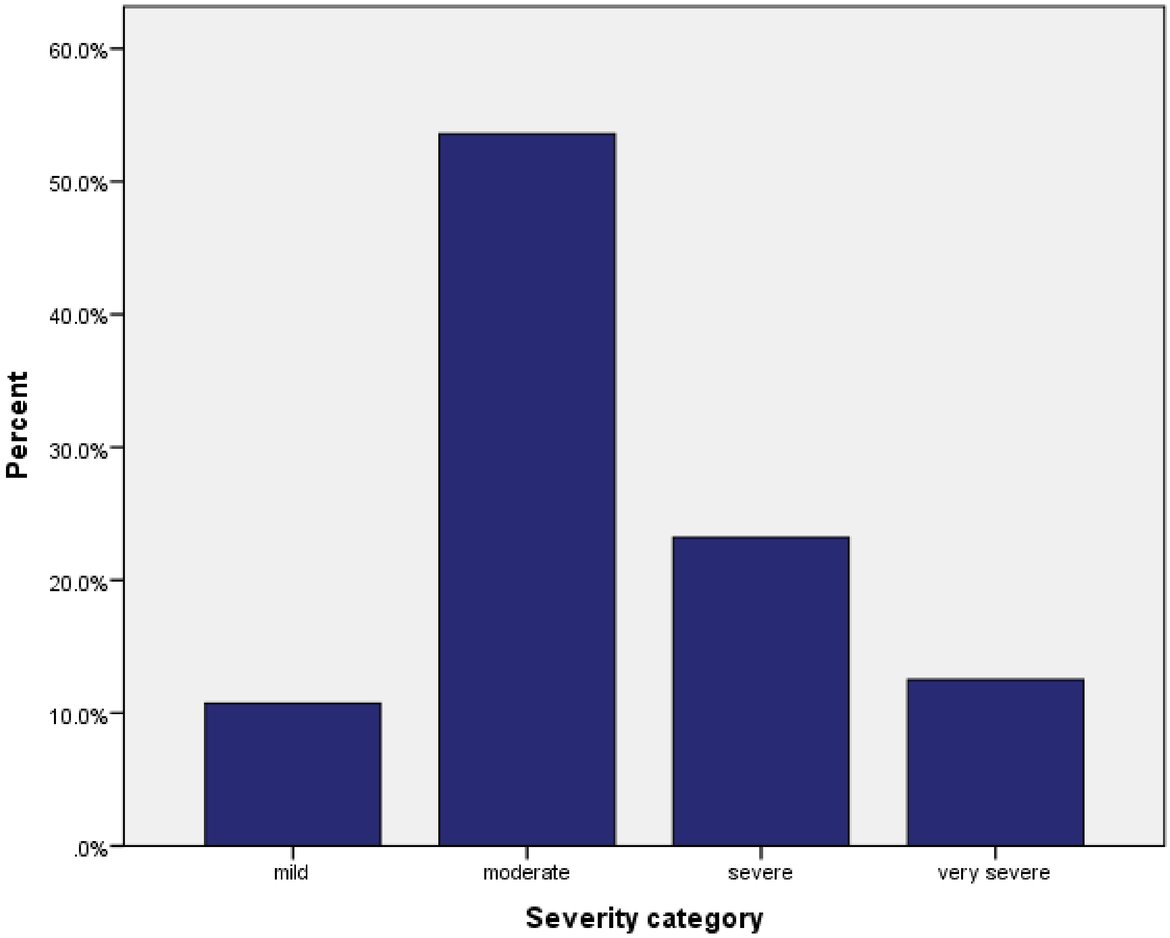

Figure 4. Self-reported illness severity of ME symptoms over the past 5 years or since diagnosis

4.2.2. Illness stability

In terms of symptom stability, 42.4% of the respondents stated that within the past 12 months their ME had fluctuated between improvement and deterioration. Almost one-third (32.2%) of respondents felt their condition had deteriorated, 15.3% believed their ME was stable and 5.1% (i.e. 3 cases) reported their symptoms to have improved over the past year [4] (Figure 5).

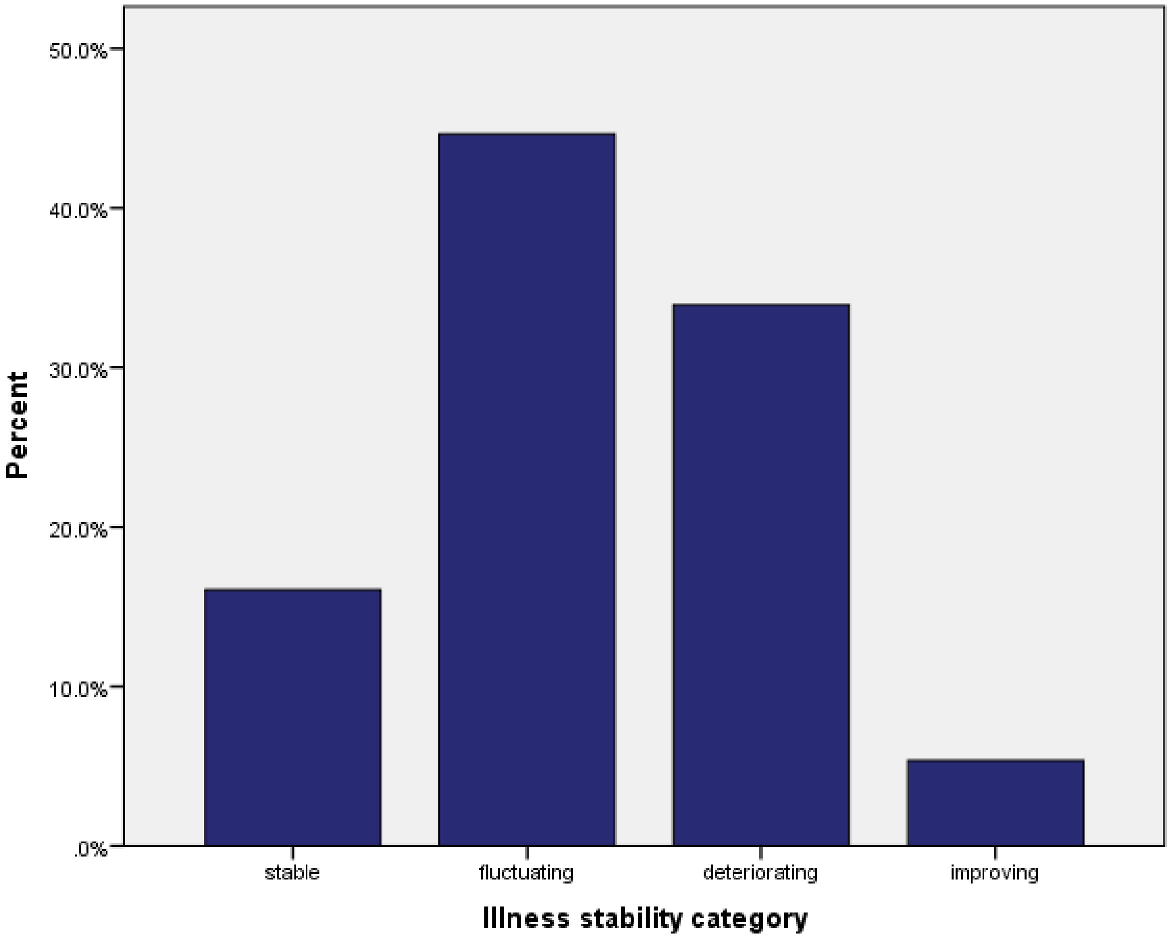

Figure 5. Self-reported illness stability

4.2.3 Most troublesome symptoms

Survey respondents were asked to indicate their three most troublesome and limiting symptoms from a list of 11 symptoms (plus an option of ‘other’).

Table 1. Most troubling symptoms

Symptom	Indicated as most troublesome (count)
Extreme fatigue/exhaustion	43
Pain	19
Dizziness	8

Symptom	Indicated as most troublesome (count)
Headache/migraine	11
Blurred vision	1
Impaired memory	8
Cognitive issues (e.g. difficulty with maintaining concentration)	30
Post-exertional malaise	24
Insomnia	11
Paralysis/inability to move	3
Sensitivity to light, sounds or touch	9
Other/s	4

Extreme fatigue/exhaustion was the most prominent symptom reported in this survey. Cognitive difficulties and post-exertional malaise (i.e. fatigue following exertion which is not consistent with the level of activity) were also particularly troublesome and limiting to this group (see Table 1).

4.2.4. Diagnosis and screening

The vast majority (91.5%) of the respondents reported a formal diagnosis of their condition by doctor or nurse (i.e. an NHS health professional). However a smaller proportion of the sample (67.8%) had been screened for secondary conditions and co-morbidities. Approximately half of the individuals surveyed (50.8%) had been given NHS medical care for their ME symptoms in the past year; although 15.3% of respondents had been refused NHS tests, treatments and/or referrals in the previous 12 months (see Table 2). This was an improvement from 72.5% to 78.0% who had not been refused treatments or referrals within the NHS from the 2009 to the current survey.

Table 2. Diagnosis, screening and care

	Formally diagnosed by a doctor or nurse	Screened for secondary co-morbidities	Had NHS medical care	Refused NHS tests, treatments or referrals
Yes	91.5%	67.8%	44.1%	15.3%
No	3.4%	22.0%	50.8%	78.0%
Did not respond	5.1%	10.2%	5.1%	6.7%

4.2.5. GP support

When asked about the support given to the respondents by their GPs, over half the sample (50.8%) stated that their GP was supportive but couldn't help with their ME. This was less than in the 2009 survey where 56.6% of respondents stated that their GP was 'supportive but cannot help'. The proportion of people who stated their GP was unsupportive increased slightly from 20.8% to 22.0% in 2014. The proportion of respondents that said their GP was supportive and informed dropped form 22.6% in 2009 to 16.9% in 2014 (the remaining 10.2% did not respond to this item in 2014).

4.2.6. Consultant referrals

Over half of the individuals surveyed (50.8%) had been referred to a consultant and were discharged even though they were still symptomatic. No respondents stated that they'd been discharged after sufficient improvement. Over a quarter of the group (28.8%) had never been referred to a specialist whereas 15.3% were currently seeing a consultant at the time of questionnaire completion (see Table 3).

Table 3. Consultant referrals

Have you been referred to a consultant?	Count (%)
Yes, I am currently seeing a consultant about ME	9 (15.3%)
I was referred but I've been discharged although I'm still ill	30 (50.8%)
I was referred but discharged when sufficiently improved	0 (0%)
No, I've never been referred to a consultant	17 (28.8%)
Did not respond	3 (5.1%)

4.2.7. Referrals to specialist NHS ME/CFS clinics

Over half of those respondents whose GP had referred them to a specialist NHS ME/CFS clinic were able to attend (52.5%, which was almost identical to the 51.9% referred in 2009), although 8.5% of individuals who had received a referral were too unwell or unable to attend their appointments (see Table 4). Approximately one-third of the surveyed sample had not asked for such a referral (32.2%); however one respondent requested a referral to a specialist clinic but did not receive one.

Table 4. NHS ME/CFS clinics referrals

Have you been referred to a specialist NHS ME/CFS clinic?	Count (%)
Yes, and I was able to attend	31 (52.5%)
Yes, but I was unable/too ill to attend	5 (8.5%)
No, although I have asked for a referral	1 (1.7%)
No, and I haven't asked for a referral	19 (32.2%)
Did not respond	3 (5.1%)

Twenty-three of the referrals were to Sutton/St Helier Hospitals and two individuals were referred to the Maudsley CFS Unit (no one in this survey was referred to Kingston Hospital). One respondent was referred to each of the following clinics: St. Bartholomew's Hospital CFS/ME Service, Great Ormond Street Hospital, Kings' College Hospital CFS Unit, Leeds & West Yorkshire CFS/ME Service, M.E. Centre in Romford, Hospital of Integrated Medicine and Wareham Hospital in Dorset.

One respondent was referred to a London clinic but didn't recall its name and one individual refused to attend the Sutton/ St Helier clinics.

Of those referred to the Sutton/St Helier Hospitals clinics, the journey prevented attendance at some of the sessions for 20.3% of those referred and 11.9% could not attend the clinics at all due to the journey; although 18.6% were caused no problems by the journey.

4.2.8. Home visits

Only a small proportion of the surveyed sample were offered and received the medical care they needed at home (6.8%). Although the majority of the respondents did not need a home visit, and were not offered one (66.1%), over a fifth of the individuals who needed a home visit for their medical needs were not offered domiciliary care and did not receive the input they needed (20.3%).

Table 5. Home visit option and care

Were you given the option of a home visit?	Count (%)
Yes, and I received the medical care I needed at home	4 (6.8%)
Yes, but I didn't need any medical care at home	0 (0%)
No, and I didn't receive the medical care I needed at home	12 (20.3%)
No, but I didn't need any medical care at home	39 (66.1%)
I received some but not all of the medical care I needed at home	1 (1.7%)
Did not respond	3 (5.1%)

4.3. Impact on Life

4.3.1. Employment status at illness onset

The majority of the survey respondents were in employment when they became ill with ME (64.4%). Over half of this group felt that work stress was a factor in the development of ME (33.9%) (see Table 6).

Table 6. Employment status at illness onset

Were you in employment when you became ill with ME?	Count (%)
N/A	5 (8.5%)
No	11 (18.6%)
Yes, and I think work stress was a factor in making me susceptible to ME	20 (33.9%)
Yes, and I think work stress was not relevant to me getting ME	18 (30.5%)
Did not respond	5 (8.5%)

4.3.2 Effect of ME on employment status

When asked what effect their ME had on the respondents' current employment status, the majority of the sample reported that they were unable to work (55.9%). Only one individual stated that ME had no effect on employment in this survey. Two respondents were able to work from home full-time (3.4%) and work from home part-time for 16 hours or more (3.4%). Almost a quarter of the surveyed respondents were retired (23.7%). Those who stated 'other' (5.1%) were engaged in voluntary work or trying to get back to work. No one in this survey said they worked part-time but less than 16 hours, worked occasional hours (less than £20 per week), worked from home part-time (less than 16 hours), worked from home occasional hours (less than £20 per week) (see Figure 6).

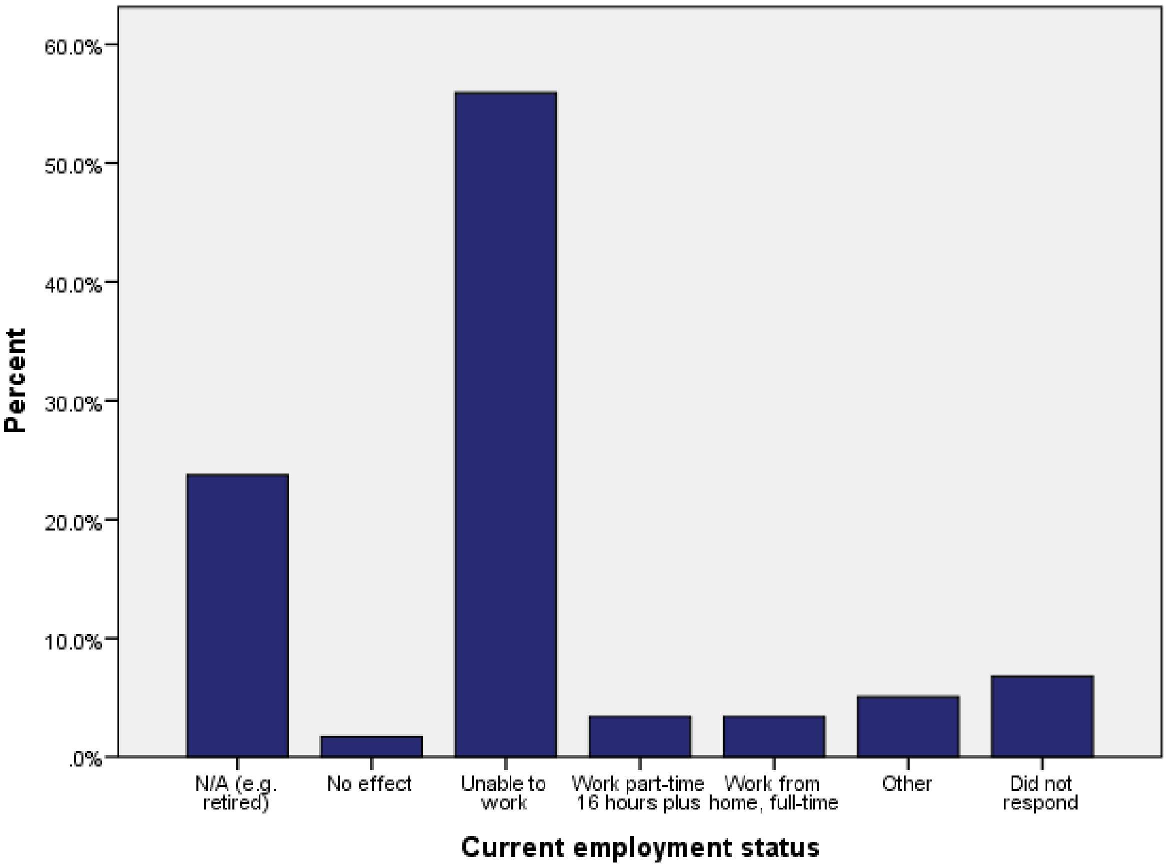

Figure 6. Effect of ME on current employment status

4.3.3. Effect of ME on education

The majority of the sample did not feel this question was applicable to them (57.6%). Of the remaining respondents, five individuals stated that their ME had no effect on their education (8.5%), two were currently in engaged in education (3.4%), one completed their education using distance learning (1.7%), three completed with reduced hours, with delays, gaps or over a longer period (5.1%) and two completed with other adjustments (3.4%). One respondent was unable to complete school sixth form/further education/vocational apprenticeship study to age 18+ (1.7%), five individuals were not able to complete higher education or higher level vocational training (e.g. university, nursing training, etc.) (8.5%) and one person was unable to complete post-graduate education (1.7%). No one in this sample was prevented from completing school to age 16 or completed school with home school tuition (see Table 7).

Table 7. Effect of ME on education

What effect has ME had on your education?	Count (%)
N/A	34 (57.6%)
No effect	5 (8.5%)
Unable to complete school to age 16+	0 (0%)
Unable to complete school sixth form/further education/vocational apprenticeship study to age 18+	1 (1.7%)
Unable to complete higher education or higher level vocational training (e.g. university, nursing training, etc.)	5 (8.5%)
Unable to complete post-graduate education	1 (1.7%)
Completed using home schooling	0 (0%)
Completed using distance learning	1 (1.7%)
Completed with reduced hours, with delays, gaps or over a longer period	3 (5.1%)
Completed with other adjustments	2 (3.4%)
In progress	2 (3.4%)
Did not respond	5 (8.5%)

4.3.4. Effect of ME on mobility

Almost three-quarters of the surveyed respondents stated that their ME had an effect on their mobility (72.9%; no 18.6%; did not respond 8.5%).

One-third of respondents were able to mobilise 200m or more outside repeatedly, reliably and safely the majority of the time (walking or unaided using a self-propelled manual wheelchair) (33.9%). In terms of mobilising 50m but less than 200m, 20.3% of the sample could do this; 13.6% of respondents could mobilise 20m but less than 50m and 15.3% could mobilise less than 20m. Three individuals were unable to mobilise outside at all (5.1%) and two respondents were unable to mobilise either inside or outside (3.4%) (see Figure 7).

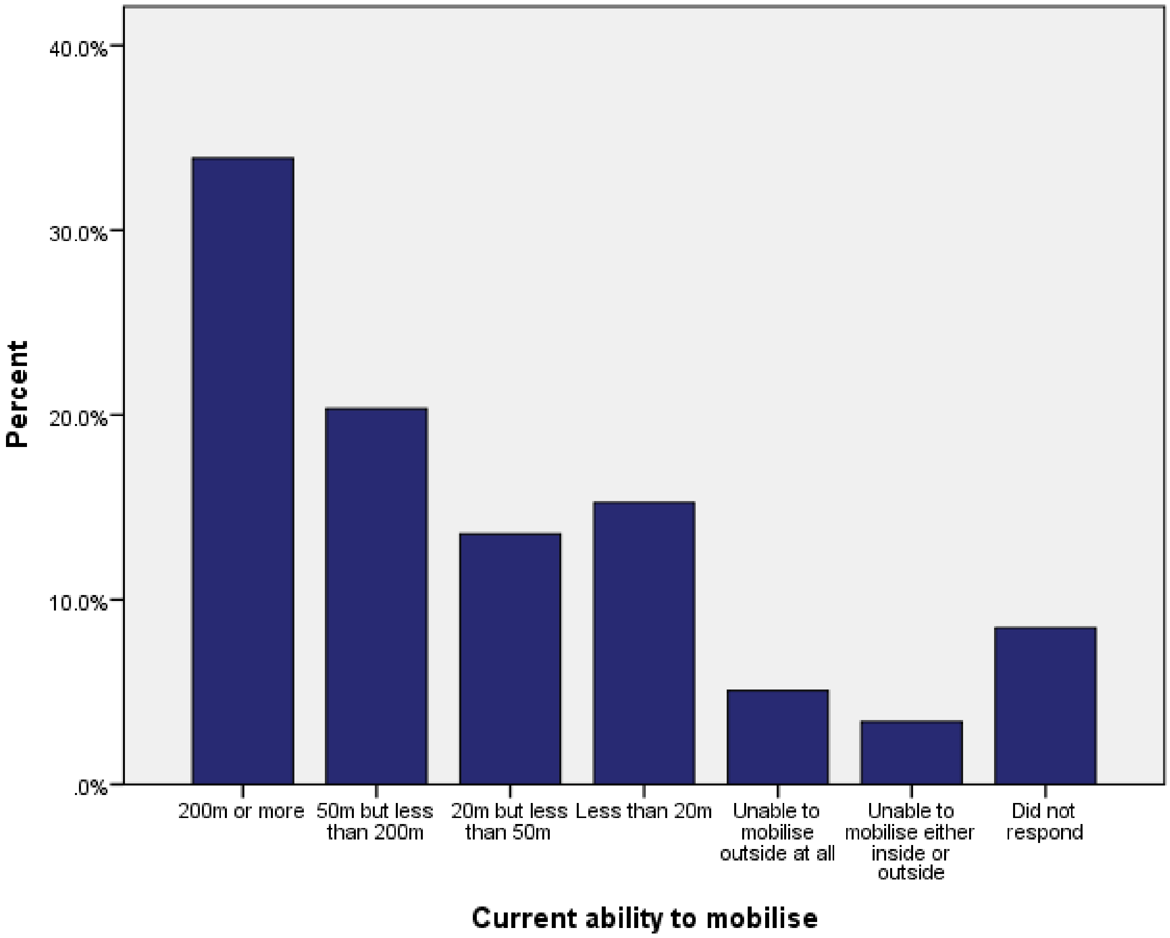

Figure 7. Ability to mobilise repeatedly, reliably and safely

4.3.5. Mobility aids

Thirty-three respondents reported that they could mobilise without the use of aids. Seven individuals surveyed stated that they used walking sticks or frames, two individuals used a shopper with a seat or similar and three respondents used a wheelchair. One person used a mobility scooter and one used splints or supports. Six respondents used other types of aids and four people were not able to mobilise at all (see Table 8[i]).

Table 8. Mobility aids used

Mobility aids used most of the time	Count
Walking stick(s)/frame or similar	7
Shopper with seat or other similar mobility aid	2
Wheelchair	3
Mobility scooter	1
Splints or supports	1
Other	6
Mobilise without aids	33
Unable to mobilise	4

4.3.6. Effect of ME on housing

Nearly half of the respondents in this survey stated that their ME had no effect on their housing (47.5%). Just over 30% stated ‘other’ (30.5%); some examples given were parents’ downsizing their housing in order to care for young people with ME and the need to move due to care needs but not being able to access support to do this. Four individuals did indeed move due to care needs (6.8%), two respondents moved because of withdrawal of housing-related benefits such as spare room subsidy, Housing benefit, Council tax benefit, etc. (3.4%) and one individual had to move due to reduced income (1.7%) (see Figure 8).

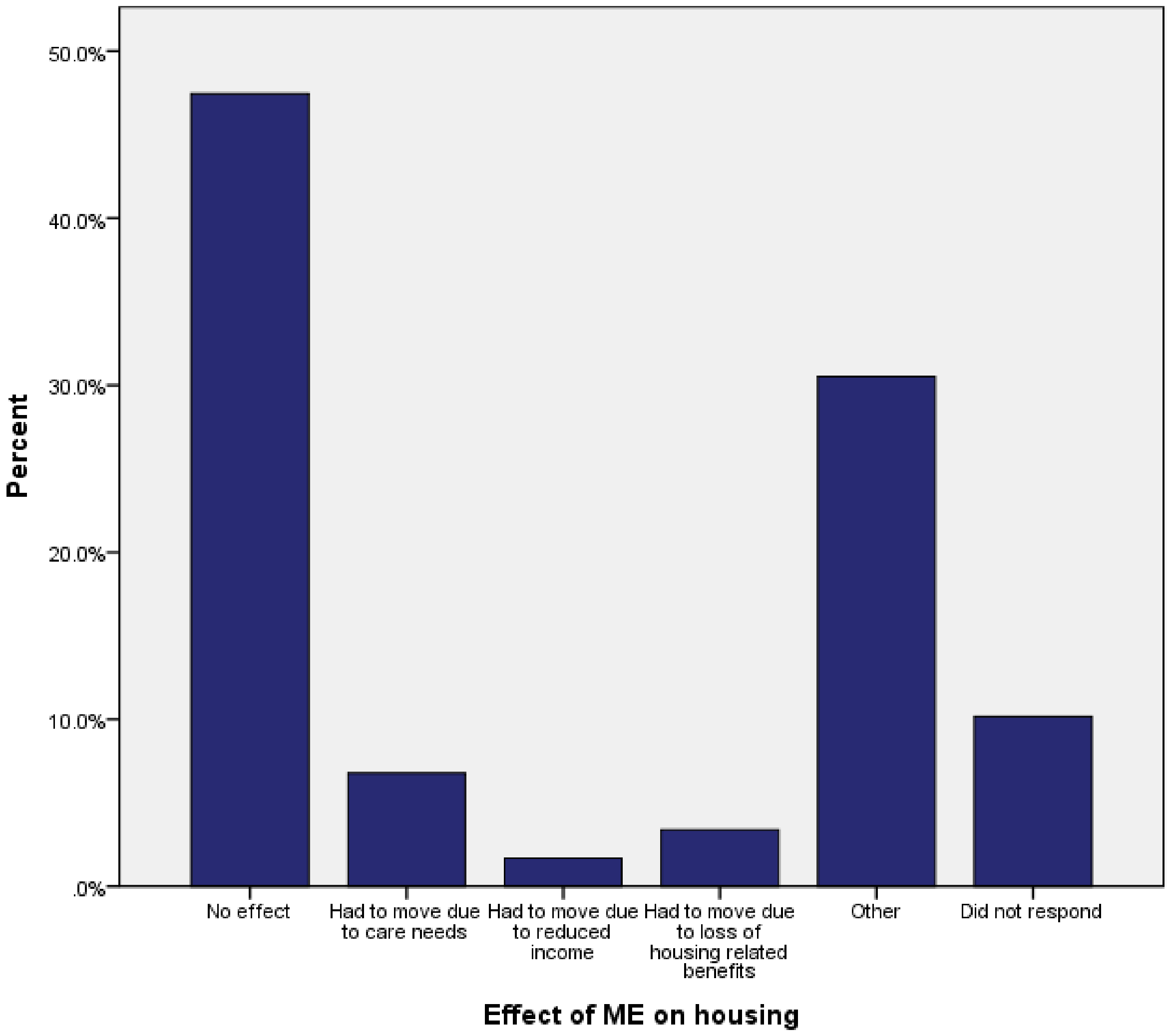

Figure 8. Effect of ME on housing

4.3.7. Effect of ME on family life and responsibilities

Most of the respondents in this survey stated that their ME had a moderate (40.7%) or severe (33.9%) effect on their family life and responsibilities (see Figure 9). Three individuals felt that their ME had a mild impact on their family life (5.1%) and two respondents did not feel this question was applicable to them (3.4%). Six people reported that they were completely unable to participate in family life due to their ME (10.2%).

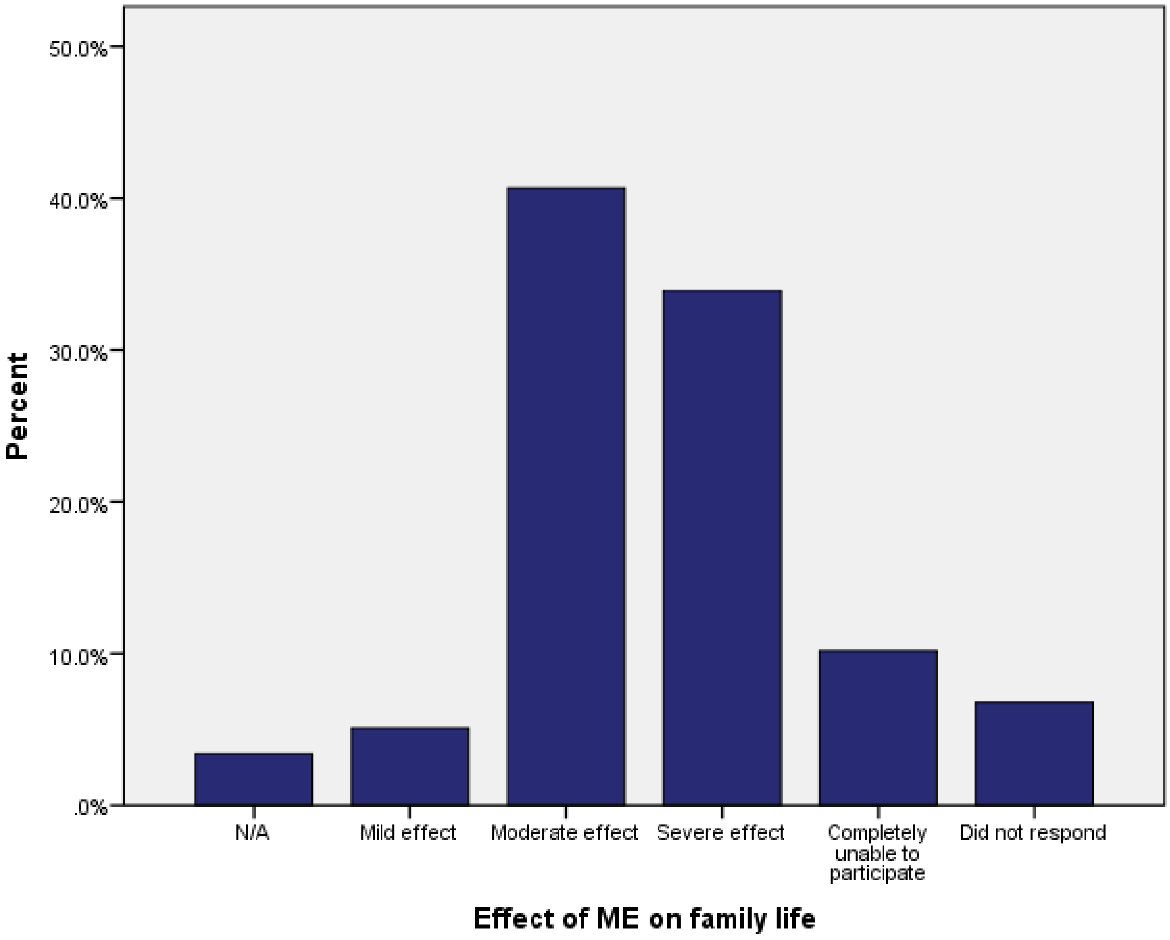

Figure 9. Effect of ME on family life and responsibilities

4.3.8. Carer status

Eleven of the respondents (18.6%) had caring responsibilities (72.9% did not and 8.5% did not respond). Eight of these individuals had one person to care for, two respondents were caring for two family members and one person had care responsibilities for three loved ones (see Table 9).

Table 9. Caring responsibilities

Responsible for the care of:	Count
Parent(s)	4
Secondary school age child(ren) under 18	2

Responsible for the care of:	Count
Primary school age child(ren)	1
Pre-school age child(ren)	0
Adult child(ren)	4
Spouse or partner	2
Other family member or friend	0

4.3.9. Effect of ME on caring role

Of the eleven respondents who had caring responsibilities, six stated that their ME had a considerable effect on their caring roles (i.e. could not carry out most of their care roles), three individuals reported a moderate effect (i.e. could only carry out about half of their previous care roles), one person reported a small effect (i.e. could still carry out most of their care roles) and one person said that the impact varied from moderate to considerable.

4.3.10. Effect of caring role on ME

Conversely, when asked whether their caring role had an impact on their ME, two respondents reported a mild effect, deteriorating their condition somewhat and four individuals stated that their caring role had a moderate effect, deteriorating their condition markedly. Four respondents said that their caring role had a serious effect on their ME, significantly deteriorating their condition and one person reported a very severe impact on health.

4.3.11. Care requirements

Thirteen of the respondents stated that they had a carer (22.0%); 71.2% did not and 6.8% did not respond. This was down from 62.3% of the 2009 survey respondents who reported that they had a carer; over half of which stated that their partner acted as a carer.

Of the 13 individuals in the current survey, five were cared for by their parents, five were cared for by their partners, two people had paid carers and one individual had support from a friend.

For those that did not have a carer but need one, 10 gave up on the process to obtain care and two were refused care.

4.3.12. Unmet care needs

Almost half of the respondents did not feel that they had an unmet need for home care support (45.8%). Of those that did have an unmet care need, 16.9% could not afford home care support and 15.3% felt home care was too difficult to organise. Just over 5% (5.1%) of the sample did not want this type of support and 6.9% said they had an unmet care need for reasons other than those listed in the survey (see Figure 10). No one who responded to the survey was being assessed for home care support at the time of questionnaire administration and no one was having home care organised at that time.

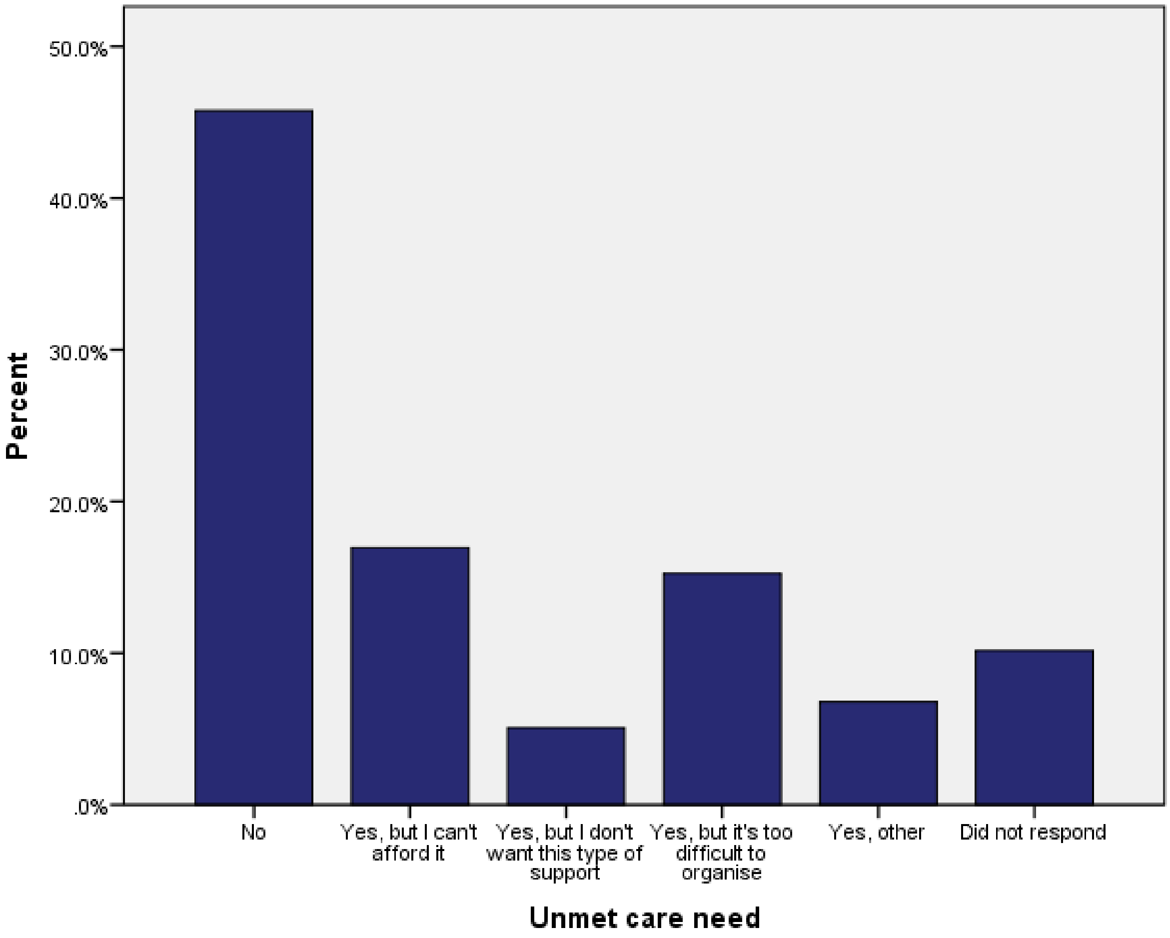

Figure 10. Unmet need for home care support

4.3.13. Other sources of support

The most common type of support other than care reported by the survey respondents was benefits support. Advocacy and other voluntary services support were also used by the individuals in this survey but befriending services were not utilised (see Table 10).

Table 10. Other sources of support

Other sources of support	Count
Advocacy	5
Befriending service	0
Benefits support	12
Other voluntary service support	6

4.3.14. Isolation

A quarter of the survey sample felt ‘moderately isolated’ because of their ME (25.4%) and almost a quarter reported feeling ‘very isolated’ (23.7%). The same proportion of the sample, 16.9%, felt ‘slightly isolated’ or ‘extremely isolated’ due to their symptoms and limitations. Only 8.5% of respondents (5 individuals) did not experience feelings of isolation (see Figure 11).

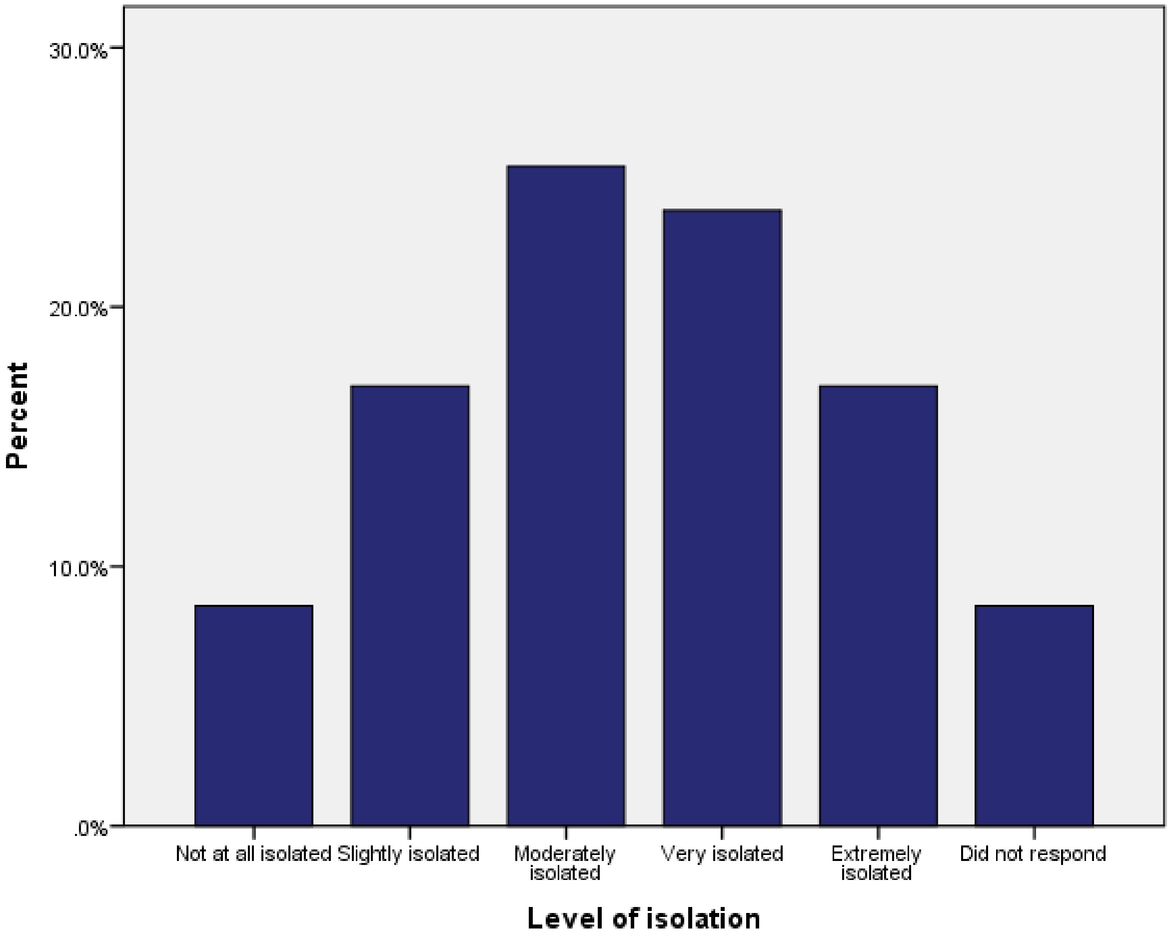

Figure 11. Isolation due to ME

4.4. Richmond and Kingston ME Group Membership

The proportion of completed questionnaires by members increased in the 2014 local area survey from 77.2% to 81.4% (8.5% were not members and 10.2% did not respond to this question).

4.4.1. The Group's activities

The most popular activity in terms of engagement in the preceding 12 months reported by the survey respondents was the newsletter (indicated 21 times or by 35.6% of the sample). Again regarding engagement, the private email chat group was used by 18 of the respondents of this survey (30.5%) and the social mornings and afternoons were attended by 16 individuals (27.1%). There was awareness of the website from approximately half of those who completed the survey (49.2%). Approaching 60% (59.3%) of the sample would like to see the newsletter continue. Overall, awareness of campaigning activities was good with around one-third or more of the respondents aware of these efforts and wanting to see them continue (see Table 11).

Table 11. Activities (within last 12 months)

Group activity	Aware of	Engaged in	Would like to see continue
Newsletter	21	21	35
Website	23	16	24
Facebook page	29	13	15
Twitter	23	5	11
Private (closed) email chat group	14	18	17
Social mornings and afternoons	24	16	19
Private members contact list	24	4	12
Meditation meet-ups	23	8	16
One off evening socials	18	4	14

Group activity	Aware of	Engaged in	Would like to see continue
(e.g. pub)			
Telephone helpline	26	1	16
Benefits support and signposting	19	7	20
Signposting to local services	19	6	17
Signposting to national services	18	3	16
Library	25	8	17
Fund/awareness raising events	22	11	19
Tradespersons list	21	2	14
Training on ME for local providers	22	3	18
Talks on aspects of ME	22	6	15
Campaigning for better local services	23	4	22
Supporting biomedical research into ME	25	11	20
Improving services for children/young people	21	6	21
Improving services for the severely affected	22	7	22

4.4.2. Satisfaction with the Group's work

The majority of the survey respondents were either 'very satisfied' with the work of the Group (40.7%) or 'completely satisfied' (25.4%); 11.9% were 'moderately satisfied' and 6.8% of respondents were 'quite satisfied' with the Group's work. Only 3.4% (which equates to two individuals) stated that they were 'not at all satisfied' with the Group's work (see Figure 12).

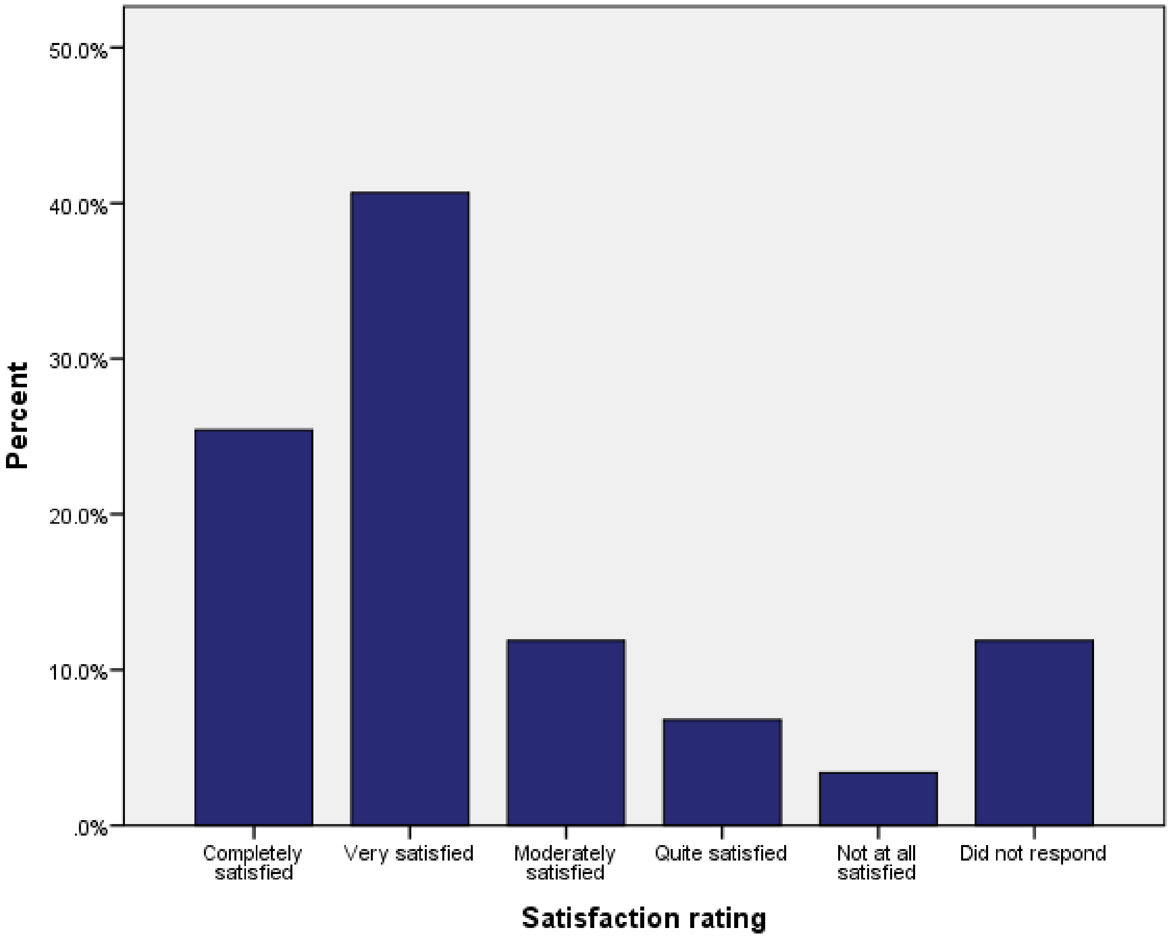

Figure 12. Satisfaction with the Group's work

4.4.3. Communication difficulties

The most troublesome type of social interaction reported in this survey was going out to meet people (40 respondents). Replying to letters (20) and holding face-to-face conversations at home (17) were also difficult for the respondents. Using the telephone was troublesome for 16 people and, similarly, recording a video message was difficult for 15 of the survey respondents. Thirteen people had difficulty in writing emails and twelve individuals found Skyping and video calling trying. Texting appeared to be the easiest method of communication in this sample (see Table 12).

Table 12. Types of communication difficulties

Difficulties reported with the following:	Count
Reply to a letter	20
Write an email	13
Use the telephone	16
Text	8
Skype or video call	12
Record a video message	15
Hold a face-to-face conversation in your home	17
Go out and meet people	40

4.5. Welfare and Benefits

4.5.1. Effect of changes in the benefits system

In terms of those affected by benefit changes (including migration from Incapacity Benefit to Employment Support Allowance, migration from Disability Living Allowance to Personal Independence Payment, the spare room subsidy (bedroom tax), Universal credit, the benefit cap and changes to Housing benefit together with repeated assessments, mandatory reconsiderations and sanctions), 10 individuals stated that their ME symptoms had worsened because of these changes. Seven respondents reported that their income level had decreased and six people experienced hardship due to the changes in the benefit system. Seven respondents gave up with the process; although one person said their ME symptoms had improved due to these changes (see Table 13).

Table 13. Effects of changes in the benefits system

Effect of benefits system changes	Count
N/A	25
Not affected	11
Income level has decreased	7
Income level has increased	0
ME symptoms have worsened	10
ME symptoms have improved	1
Gave up on the process	7
Led to hardship (e.g. Lack of food/fuel)	6

4.5.2. Benefit appeals, repeated assessments and emergency funds

Over a quarter of the respondents in this survey stated that they had to appeal or apply for reconsideration for their benefits 1-3 times in the past five years (28.8%). Two individuals had to appeal or apply for reconsideration 4-6 times

(3.4%) and one person appealed/reapplied more than six times (1.7%). Approaching one-third of the survey sample had 1-3 benefits assessments and reassessments in the past five years (30.5%). Four respondents had 4-6 repeated assessments (6.8%) and two individuals had six or more benefits reassessments in the preceding five years from the point of survey administration (3.4%) (see Table 14).

Table 14. Benefits appeals and assessments

	Number of appeals in last 5 years	Number of repeated assessments in last 5 years
N/A	24 (40.7%)	29 (49.2%)
None	9 (15.3%)	
1-3	17 (28.8%)	18 (30.5%)
4-6	2 (3.4%)	4 (6.8%)
More than 6	1 (1.7%)	2 (3.4%)
Did not respond	6 (10.2%)	6 (10.2%)

Three respondents had been able to obtain emergency financial or hardship support locally when needed (5.1%), although seven individuals had not been able to obtain such support (11.9%). Of the remaining respondents, 74.5% did not feel this type of support was applicable to them and 5.1% of the sample did not reply to this question.

4.6 Additional comments

Two qualitative items were included in the 2014 survey. Firstly, respondents were asked “Apart from a cure or advance in treatment, thinking about services provided locally by the NHS, your Council and other agencies and volunteer services, what three things would most help you cope with your illness and daily life challenges?”

Meditation Massage Dietary advice.
1 A more sympathetic and informed GP who believed in the illness and was prepared to try alternative treatment options, including those advised by a consultant. 2 Free help with household and garden chores I can't manage, especially paperwork that's never ending. 3 Someone to drive me when I need to go longer distances outside the immediate local area.
Home visits - a friendly chat from time to time would alleviate the boredom of living on one's own.
Home care for severely affected. Proper understanding of ME by professionals. Not being able to afford adaptations or carer services.
Support with medical evidence to acquire the benefits that I know I'm entitled to, but find it very stressful and exhausting to apply for. Support with Access to work, which I have tried to get help accessing several times, but that has remained elusive to me. A reduction in the unnecessary paperwork involved in re applying for a taxi card, why don't they let you sign to say that your situation remains unchanged and that you would like to continue to have one, instead of having to apply again from scratch completing the whole process again. This is so much extra unnecessary and expensive bureaucracy.
M.E. awareness campaign for the public M.E. training for GPs NHS funded research.
Specialized Advocacy. Specialized Welfare Officer. Local ME Support Group to meet with socially.
More recognition that ME does seriously affect how you live your life no matter how well you look. Kill the myth that it's 'All in your mind'.
Some sleep. More money and some support befriending for my son.
Change in benefit regulations reinstatement of benefits Blue badge.
1. Proper understanding of the suffering and limitations imposed by this illness instead of ticking boxes with M.E. where nothing is taken on board 2. More practical information/exchange of information on managing the illness e.g. on pacing (I have no carer, receive no benefits, have no family and live on my own - local groups have a focus on benefits, which I fully understand the need for, but it is not my need) 3. Maybe asking the

impossible - talks/information on the medical/research side of the illness for the lay-person. I attend and am interested in talks by experts/researchers but find them well above my head.
1. Increase in benefits. 2. More financial help with heating home. 3. Tests with someone like Dr Myhill so that I can understand what is happening to my body and then address those issues. 4. I cannot digest sugar and have a restricted diet without nutrients, supplements are critical but these have quadrupled so I am starving to death, very slowly and painfully.
More rigorous testing. More joined up approaches. More individualised management & rehabilitation protocols.
Someone to help fill in welfare claims.
Better understanding from my GP, support in helping me find alternative treatments instead of being made aware of costs and so easily dismissed, told that there are no others, anything new and as had attended Sutton hosp ME clinic it would all be the same. I have only been offered B12 injections/counselling/pain relief. I need to find the confidence to find a better support network, and ask for help in the home etc when really need it but by someone that really understands my situation.
Joined up care service for better info sharing Upgrade from Fax to Email option for NHS communication - not just offer phone. More default large print documents.
Being believed On line schooling A GP that understands ME
Educating public, family, work places and doctors so that there is less negative prejudice for people with ME. Natural therapies that might help ME to be on the NHS. Meditation to ease the stress and frustration of the illness.
Single point of contact to get practical help in a relapse NHS and Council staff to be named, with contact details Provision of local free therapeutic yoga/meditation classes.
1. Help with home visits by a doctor/specialist and benefits advisor. 2. A comprehensive service of physiotherapy, massage and treatment locally or at home. 3. More support as a disabled and isolated person.
Better understanding of ME by medical profession. Better understanding of ME by local authority personnel. Can't think of anything else - my income is not affected by my ME.
Home visits so I don't have to visit GP.
Severe ME people are left to rot in silence and darkness. We are the most ill and yet get no proper support whatsoever. In any other illness the illest people get most help. In ME the illest get completely ignored by the bastard NHS, and the ones least affected get most of the help. The psychiatrists need to go to hell as well.
Continual support rather than a pre-defined quota of clinic appointments paid for by the

CCG. Home visits by a befriending service. Advocacy for using other NHS services to explain difficulties and needs when fatigue and cognitive symptoms are too bad for me to explain myself.
Help with cooking, housework and shopping. Transport to social functions.
Alternative medicine on the NHS.
1. Additional help for my Mum 2. Ongoing support from a consultant who is more local than Sutton 3. Reliable benefits advice - experience with RAID was disappointing.
Home visits of physio to help with exercise. Regular appointments with specialist M E doctor nurse/just to discuss progress or deterioration even if by telephone and new research, etc. Home visits by nurse/welfare person to help with organising stuff which gets left undone.
1. Closer consultants (Sutton is a bit of a journey). 2. Greater understanding of the condition amongst GPs.
1. Home care provided by local social services (have been refused as an M.E. patient). 2. A GP who would acknowledge my illness and its consequences (I was diagnosed by Dr Weir at The Royal Free yet I'm still ignored by all available GPs). 3. Tests and treatments for secondary/treatable illnesses which complicate my overall situation but are ignored.
GP who is well informed about ME and supportive. To have proper screening to eliminate causes. GPs only test T4 levels. I spent thousands over the years to eliminate causes as I knew something was wrong physiologically. To have disability support/buddy so is less painful to engage in work I can do.

Finally, respondents were asked to provide any additional comments or experiences regarding any aspects of ME.

I have care responsibilities for an elderly mother who lives a distance away and also for one adult child who has severe ME and lives with me and another adult child who has anxiety and depression and is currently at university, so this care is also 'long distance'. This second child still suffers low energy after contracting glandular fever and receiving a diagnosis of CFS 4 years ago. I am separated from my husband, have no siblings and have almost no external support, either financial or practical and this absence of free support for matters that are not specifically to do with personal care cause me the most stress and difficulty. I survive financially through having lodgers but there is no spare fund for a break or anything similar and I am unable to visit relatives who live a distance away. I have recently had to give up counselling I relied upon as I can no longer afford it, even at a very reduced rate. The local carer's centre are now saying they won't recognise the emotional and POA support I give to my mother (which is very stressful as she has schizophrenia and dementia) as she lives 'out of

area'. Although my daughter who lives with me receives a care package from Richmond Social Services, it is not sufficient to cater for all her care needs and we therefore muddle through with a patchwork of care in which I do what I can only as and when I can manage it, so we can't follow a normal predictable life timetable healthy people take for granted, like being able to eat when hungry, for example. I find this a considerable strain and drain on my energy and health. We are having to cut back on heating even though we are at home all day and can't go to a warmer location like the library or similar. We find this difficult as keeping warm uses precious energy and getting cold makes our symptoms worse. We had very difficult experiences with the education system and local secondary schools and feel this is a very important priority for raising awareness. It's very important attendance officers and schools allow children adequate time to recuperate from illness and adequate home tuition is provided. School should not be treated as a form of graded exercise as this just makes things worse.
Especially isolating for a single person. I have a small garden at present which I cannot look after. The house is sold, theoretically, and I'm supposed to be buying something more manageable.
11.My ME has had a severe impact on my working hours, 9 years ago, prior to having ME I was working 40-50 hours per week, mainly standing and that included rushing up and down stairs numerous times every day. I couldn't work at all when I first became ill and was off work completely for six months. After a year I went back to 25 hours per week. (5hrs/day, 5days/wk). This was way too much, and so I cut down to 10 hours per week. (2hrs/day, 5days/wk). In Feb this year I had to go off sick and don't know how long my job will be kept open for me, at the moment I'm not well enough to go back. 16. Luckily for myself and my husband my parents have bought out the banks share of our house so we are currently not paying anything towards our housing, without this amazing help, I really don't know where we would be now.
Re. Within the system re. applying for benefits:- After a period of time (years) passes by and diagnosis are made, and the ME Clinic has discharged you and there are barely (if any) visits made to the GP, Surgery, benefits are based on measuring your condition with medications taken and does not take your word on how your condition affects you, this is a difficult one to have up-to-date medical support, especially if not taking medications and initial treatment has drawn to a close, struggling with moderate symptoms and not unwell enough to receive care or other forms of support. Transportation: we need transportation to be available to us particularly if there is no support around and we are unable to drive. Note, can I suggest on the Survey Question related to Impact on Life that N/A is and added response? Thanks so much for being there and the support.
My son has had ME for twenty years now, still at home with me. He has seen none other than the odd visit with the GP in a great many years. We find ourselves in a bit of a situation as he has severe ME and the iller I have become has meant he has had to do some things for himself and this has lead to him becoming more exhausted and m ore isolated. I am so sick of

everything, I appear to be getting iller especial made worse by insomnia. My GP tells me "he is sorry I am so ill and he wishes there was something he could do for me on the NHS" Repeated ESA forms, one a year for the last three years and not one response as to whether I have passed. Have just had to do a renewal form for my son.
27. I was a full-time PhD student before becoming ill. I reduced hours/struggled on before taking a year's full time sick leave, and returned part-time on very reduced hours (<12hours/week currently), working from home. 34. I ticked 'no' as I have no official carer, but I get help on a daily basis mainly from my partner but also from other members of our families, without which I would need outside help.
I think we should be prepared to share information about alternative routes of recovery that others have found helpful, without necessarily endorsing them.
30 Mobility - I use my car to get from A to B as far as possible, cost and parking allow. Otherwise would be more housebound than I am. 31 I need to move from my 3 bed house with garden to a flat and spent some months looking this year. It was exhausting and difficult trying to find somewhere near shops and transport, but not on a main road, so I'm having to stay in my house with cleaner and gardener 36 carer - I have employed a carer privately, but it's hard to get the kind of support I need to manage my life - a PA would probably be best!
I would be happy to offer my services on an awareness campaign to raise money to help with peoples need today. I have drafted a leaflet and would be happy to run this past you if you are interested. Please contact me if you are.
Still living with parents aged 30 due to the illness (mostly for indirect, financial reasons).
Symptoms I struggle with. Sensitivity to food, chemicals, light, noise.
I am 16. I live at home with my parents. My school fund on line education and last year I managed to gain 2 GCSEs but have not been able to access any education in recent months because my illness has got worse. I have a lot of difficulty maintaining friendships. My sleep pattern is 'upside' down which doesn't help. It would be good to have a group that is more local to Epsom. This group is good but its focus is on Richmond and Kingston.
I was diagnosed with Post Viral Fatigue my a neurologist 2 months after I came down with a bad long lasting virus, and it has been just over 3 months now. However, I think I had mild ME before as I was getting very tired at work nearly falling asleep at my computer, and when I went back home I would lay in bed tired early, and on weekends I would spend more time in bed and didn't have the motivation to exercise anymore as I felt too tired to. My housing has been effected as in I have lost some of my independence since I fell ill 3 months ago and have had to move in with my family so that they can help me when I need it and I have company, I may lose my job and my rented room in a flat if I don't get well enough soon.
Question 31: I was going to buy a house when I fell ill and now I have lost my savings for

paying a deposit.
I do wish the medical establishment would listen more to people who have ME. We are the real experts in living with it.
Fuel bills are crippling. Also financial hardship due to no help with housing costs such as mortgage interest. Just because I am a home owner does not mean I am loaded with money. I am Â£300 worse off a month then someone renting that gets housing benefit. Also waiting for PIP assessment for months. Even if I was well enough to get out and about more often I couldn't afford to anyway. I am living on Â£10 a week for food and travel costs. The future looks very bleak because of this. I feel suicidal regularly.
Better education of medical staff. More publicity about the difficulties of living with ME available to public and medical staff. More free care help available.
I have found recently managing to see main GP at my surgery, he is more aware of ME (but not hugely informed) but is now treating me for Fibromyalgia with newer drugs than previously been offered so I feel more hopeful than before when my illness was ignored basically.
Three years ago through my own research and confirmed by Kingston Hosp endocrinologist - I lack the gene to convert T4 to T3. In 9o's. I saw a thyroid specialist privately but he neglected to test my T3 levels.

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[i] Tables that only included a count, not a percentage, did so as respondents were asked to tick all the options that applied; i.e. numbers may be larger than the sample size.

Percentages may equal more than 100 due to rounding-up.

The qualitative data included in this report was from the online survey only.