The 25% M.E. Group

Advocacy & Support Group for Severe M.E. Sufferers
Services: Support; Newsletter; Fund Raising; Information
Charity No: SC034265
25% ME Group, PO BOX 8620, Troon, KA10 9BL
MAIN TEL: 01292 318611 ADVOCACY: 01292 822247

PATRON: Dr Byron Marshall Hyde MD
SCIENTIFIC ADVISORS: Dr Vance Spence PhD,
Prof Malcolm Hooper PhD. B.Pharm. C.Chem. MRIC

MEDICAL ADVISOR:
Dr Nigel Speight MA, MB, B Chir, FRCP, FRCPCH, DCH

Response to the Interim Delivery Plan from 25% ME Group, a national charity which supports people with severe and very severe ME/CFS- 3rd October 2023

We would like to thank all those involved, including people with ME/CFS, unpaid carers, charity representatives, clinicians, researchers, representatives from the Department of Health and Social Care (DHSC), government departments and research funding organisations for their time and commitment to working towards publication of the Delivery Plan on ME/CFS.

25% ME Group was represented on all of the working groups and the workshops. It has been a privilege to be able to share the experience we have acquired as a charity supporting people with severe and very severe ME/CFS and also providing the experiences of our members. We are pleased to see information we provided has been included in the Interim Delivery Plan (IDP).

Introduction

In the introduction we are pleased to see the four symptoms essential for diagnosis and common symptoms of ME/CFS. Included in the common symptoms we would like to see reference to the gastrointestinal symptoms people with ME/CFS, particularly severe and very severe ME/CFS can experience. Where severe and very severe ME/CFS is mentioned, we would like to see reference to the inability to speak and swallow and the need for tube feeding in some cases of very severe ME/CFS. See link Healthcare | Free Full-Text | Life-Threatening Malnutrition in Very Severe ME/CFS (mdpi.com) It is the experience of some of our members that medical professionals often seem unaware that people with very severe ME/CFS may require tube feeding.

Attitudes and Education of Professionals

We are concerned about the terms ‘functional disease’ and ‘medically unexplained’ being used and would like to see them removed from the final delivery plan, as this is misleading.

The paragraph prior to *The Economic Case* does not make reference to the difficulties people with severe and very severe ME/CFS can have just accessing healthcare and appropriate social care.

Research

We welcome the Government’s intention to increase and improve research into ME/CFS and to “continue to support researchers to better understand ME/CFS” and that priority is to be given to work understanding the disease process and into treatments. We are pleased to see the involvement of central funders of research – the NIHR and MRC – whose constructive involvement is needed to move research forward. Biomedical research holds the key to finding the underlying cause of ME/CFS and once found many of the other issues highlighted in the IDP, such as issues with health care provision would begin to resolve. However, overall, the section on research is disappointing. The IDP fails to bring anything new to the table. Previous similar calls for research from 2002 Chief Medical Officer CFS/ME Working Group, the 2006 Gibson Inquiry Report and 2008 MRC CFS/ME Expert Group failed to stimulate research into ME/CFS. We note the MRC highlight notice, in place from 2003, has failed to translate into research into ME being undertaken. We are aware of the reported stigma around research into ME/CFS so we are pleased to see a subgroup has been set up to build trust and awareness between researchers and the patient community. However, the final Delivery Plan should note that patients both support and want to be involved in good quality research, as shown by participation in DecodeME and the patients' longstanding fundraising efforts to support biomedical research.

The final delivery plan needs to set out how it will support researchers, from early career researchers upwards, this would include offering studentships, fellowships and setting up centres of excellence. It is imperative funding commitments are made to ensure researchers are not lost to other specialisms. Included in this is the need for the funding of senior academic researchers and their teams, in clinical, biomedical and pathophysiological specialities to drive the research agenda. This has been achieved successfully in other disease areas (c.f. rheumatoid arthritis). Collaboration across multiple specialisms must be encouraged.

Regarding capacity and capability, we believe there is some capacity and capability as shown in CUREME etc but such projects are being largely funded by charities; this must change in order to research at scale. Furthermore, sustainable funding streams must be made available to successful ongoing research projects. We are also aware of research proposals being turned down despite addressing areas of research highlighted by the James Lind Alliance Priority Setting Partnership.

Funding needs to be available to replicate the findings of pilot studies and to encourage the use of large sample sizes to bring credibility to research.

The IDP highlights the paucity of funding given to ME/CFS research over the past decade but fails to address the disparity between research funding for ME/CFS and similar chronic diseases. Research spend into psychosocial ME/CFS projects dwarfed that invested by the MRC into biomedical research. First and foremost a commitment to a specific amount of MRC/NIHR funding is urgently needed, e.g. £100m over the next 5 years. The combined MRC & NIHR spend on ME/CFS research of £8m over the last decade is astonishingly low given the disease burden and the two funders' respective annual budgets of over £580m and £1300m respectively. Commitments to specific funding allocated to ME/CFS research are critical to make progress and make up for considerable lost time, during which patients have been without adequate treatments. Funding invested over the next 5-10 years must be a key impact metric.

We would like to see a caveat that psychiatric, psychological and biopsychosocial research is excluded from this funding stream. To resolve the lack of research into ME/CFS the government needs to make funding commitments to support biomedical research and pledge to continue this level of funding over the next 25 years to ensure retention of researchers and to bring new researchers into the field.

Funding needs to be increased in line with other chronic conditions. For example, since 2020, £50 million has been given to long COVID research. The government pledged £50m on MND research (which affects 5,000 people) and £45m over 5 years for brain tumour research (which affects 12,000 people). Ring fencing funding kick-started research into anti-microbial research.

The acknowledgement of low research capacity must be coupled with more specific actions for how to increase that capacity. It is not enough for funders to be open to responsive-mode grant applications in this area; NIHR and MRC must take a more proactive approach to encouraging grant applications, including through specific funding calls relating to ME/CFS, to mobilise researchers and research activity. Annual reports from the MRC and NIHR should be required which include unsuccessful applications and the reasons they were rejected, as well as funded projects.

The proposed landscaping review of national and international work underway in ME/CFS is an excellent idea but will only have impact if it is produced quickly and used as a platform to stimulate national and international collaboration and promote complementarity rather than duplication of efforts. The final delivery plan should set out specific, manageable, achievable, realistic, timebound (SMART) objectives including a timeline with specific targets to be met and objective measures of outcome, as well as action to be taken if the targets are not met. Likewise, the final delivery plan needs to objectively measure outcomes of funded projects; SMART or similar objectives need to be put in place to achieve this.

We are pleased to see examples of *Best Practice* will be made available to researchers. Research into severe and very severe ME/CFS is much needed and researchers need to understand the necessary reasonable adjustments required to do so. Additional funding to support engagement by people with severe and very severe ME/CFS must be provided. See Healthcare | Free Full-Text | Ensuring the Voice of the Very Severely Affected Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patient Is Heard in Research—A Research Model (mdpi.com) We would like to see a long-term commitment to research into severe and very severe ME/CFS. As part of the work of the Research Working Group’s remit workshops on severe and very severe ME should be organised.

High quality research should lead to improvement in the quality of life for people with ME/CFS and in so doing lessen the need for social care, reduce the state benefit bill and NHS costs and in turn enable people with ME/CFS and their supporters to contribute to society.

Attitudes and Education

We are pleased to see some people with ME/CFS experiencing good quality care. However, rather than the delivery plan aiming 'to ensure that more people with ME/CFS have this kind of experience' the final delivery plan must make a commitment to ensuring all people with ME/CFS have positive experiences when accessing health and social care.

The statement 'many healthcare workers are striving to follow this guidance' (NG206) is factually inaccurate- only 28% of NHS Trusts and ICBs have implemented the 2021 NICE Guideline as highlighted by a Freedom of information request made by Action for ME FOI Report reveals shocking lack of specialist care | Action for ME

In many cases public opinion and professional mindset need to change. The final delivery plan needs to commit to delivering a public information campaign to highlight ME/CFS is a physiological disease which can in some instances be fatal. See link Changing the narrative #1: exploring a new approach to strategic communications in the ME community | valerieeliotsmith

The attitudes of those sitting on funding committees has also been seen to be outdated, with some still believing ME/CFS is a psychological disorder; this is reflected in the allocation of grants. There is serious need for appropriate training of funding committee members in this disease area.

We are pleased to see a commitment from NHS England to develop an e-learning module on ME/CFS. However, an online Continuing Professional Development module on ME/CFS has had very poor uptake by professionals. Therefore, on education, the final delivery plan needs to commit to providing mandatory training to all allied healthcare professionals and social care professionals. It is imperative this starts at undergraduate level and continues throughout a person's career with additional training on severe and very severe ME/CFS. We are pleased to see that 'The Royal College of Physicians will ensure their training on ME/CFS will keep pace with research and guidance in the core post graduate training for primary and secondary care physicians.' Mandatory Continuing Professional Development modules, which must be updated in line with new research, need to be developed to ensure this happens. Funding streams need to be made available to facilitate this. The final delivery plan should specify actions to be taken and SMARTS need to be put in place to ensure high quality training is being provided. Objective measures must be put in place to monitor the quality and quantity of the education on ME/CFS in medical schools.

There is no co-ordinated attempt to understand or research best practice for people with severe and very severe ME/CFS. Nurses need appropriate training to be able to recognise the reasonable adjustments needed and appropriately support people with severe and very severe ME/CFS as inpatients in hospital. Specific training is also required around the nutritional requirements of people with ME/CFS including in relation to severe and very severe ME/CFS and the potential need for tube feeding. Home Enteral Nutrition Service (HENS) dietitians with expertise in ME/CFS are vital to prevent life-threatening malnutrition and dehydration in people with severe and very severe ME/CFS. The final delivery plan also needs to set out a commitment to providing mandatory education for people who may encounter people with ME/CFS in their working lives, including care workers, DWP staff and those in the teaching profession.

Again, the IDP fails to provide an impact framework and this is essential.

Living with ME/CFS

Quality of Life

This section understates the effect on ME/CFS on quality of life. Mean EQ-5D 2L score (0.47) was lowest of 20 conditions, including MS (0.67), rheumatoid arthritis (0.69), and stroke (0.71) (Hvidberg et al PLoS One 2015 10.1371/journal.pone.0132421). Multiple sources including published papers indicate that people with severe and very severe ME/CFS are very sick indeed. This can be demonstrated in respect of physical suffering, level of function, and other aspects of quality of life. On reviewing Anderson & Ferrans and Schwietzer papers, together with the published findings of four other studies, Carruthers et al. conclude: "The quality of life (QOL) of ME/CFS patients shows marked diminution that is more severe than in many other chronic illnesses." Carruthers, B. et al. Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols Journal of Chronic Fatigue Syndrome, Vol. 11 (1) 2003, pp7-115 (page 29)

Quality of Life can be improved for people with ME/CFS by improving the benefits system- both in terms of assessment and the financial support available. The stress associated with benefit claims and financial worries only serve to worsen the quality of life for people with ME/CFS. In the case of people with severe and very severe ME/CFS provision of appropriate health and social care can improve their quality of life.

It must be noted that for many people with severe and very severe ME/CFS just living day to day is all they can manage. For them engaging in activities 'that are important and satisfying to them' will be very small activities which they may only be able to do sporadically. Their condition does not fluctuate, it remains largely unchanged on a day to day basis. The IDP lacks detail about how seriously ME/CFS can impact people's lives and needs to add detail about this including the fact that people with very severe ME/CFS are bedbound, require around the clock care and that some will require tube feeding.

Support for Children and Young People with ME/CFS

We are encouraged to see that as part of *Best Practice* the child or young person and their family will be recognised as experts in their condition. We are also pleased to see 'medical evidence should not be required by schools or colleges in order to record absence' and that 'the local authority will not follow an inflexible policy of requiring medical evidence before making their decisions about alternative education.' These are positive steps. However, we are concerned about phrases such as 'maximising attendance' and 'most appropriate full time education provision.' We note that it is followed by 'taking into account the impact of each individual's medical condition including their capacity to expend energy'; perhaps it could be worded such that it is less open to interpretation. The IDP does not acknowledge that some students with ME/CFS are too ill to participate in education in any form. For these students it is imperative their health needs are prioritised. Within this section of the IDP the onus is placed on the education setting to put a plan of action in place for the child/young person. The final delivery plan needs to set out how centres of learning will be held accountable for supporting a child/ young person in education.

Children's Social care

We are pleased to see the voice of the child will be heard. The proposed Family Help reforms may lead to better support for families of children with ME/CFS by putting some focus back onto the support they need rather than being entirely safeguarding oriented. However, it will not of itself overcome the major problem of children with ME/CFS being subjected to safeguarding investigations and inappropriate plans as a result of their condition and needs being misunderstood. Until the education of all professionals is accomplished, the NICE guideline points, (NG 206 1.7.1., 1.7.2, 1.7.4,) that all safeguarding investigations should include an expert in ME/CFS must be followed.

Healthcare Services for people with ME/CFS

We welcome the initiatives featured in the *Best Practice* section. Accessing healthcare for other health needs are covered well within the IDP. However, a clinical pathway for ME/CFS needs to be developed. In order to address health inequalities, domiciliary care must be provided to people with severe and very severe ME/CFS from allied health care professionals based in both primary and secondary care and this must be recognised by the Integrated Care Boards (ICBs).

There needs to be a commitment to ensure that ME/CFS clinics are consultant physician led with funding available for the provision of domiciliary visits to people with severe and very severe ME/CFS. All people with ME/CFS must have a care and support plan in place and a named point of contact in both primary and secondary care. Objective measures need to be put in place to ensure all specialist ME/CFS services are following NICE guidance. Specialist ME/CFS services must keep a patient on their list regardless of whether they are making progress. Where shown to be beneficial, the prescribing of off label drugs such as low dose naltrexone, nimodipine and analgesics used in palliative care is to be encouraged. ME/CFS needs to be recognised by the providers of Palliative Care Services. We know of members who have benefitted greatly from input from palliative care teams.

A commitment to improving the coding of ME/CFS, eg SNOMED-CT, across both primary and secondary care is necessary. This in turn would allow researchers to work with electronic health data, where consent has been given, thus improving understanding of ME/CFS.

Allied healthcare professionals need to recognise the reasonable adjustments people with ME/CFS require when attending hospital in either an inpatient or outpatient setting. This includes proximity to toileting facilities, being able to lie down in a quiet, dark environment if visiting outpatients and for a person with severe ME/CFS who is an inpatient, a single room and family or home care workers staying with the person when requested by the patient etc. The final delivery plan needs to state these reasonable adjustments are a clinical need rather than a ‘want’ and identify measurable ways to ensure their provision becomes a reality for people with ME/CFS.

Exceptions also need to be made where a person with ME/CFS has multiple hospital appointments to enable them to have all the appointments in one visit. There could also be a cost and resources benefit to the NHS; where people with severe and very severe ME/CFS are travelling by ambulance it would save on multiple journeys. Similarly, some people with ME/CFS are too ill to cope with the day patient experience and need to be able to stay in a suitable environment in hospital before their procedure. Failure to provide a suitable environment leads to people declining procedures which in turn can have an impact on their overall health or puts them off reporting symptoms leading to late presentation.

Patients with severe and very severe ME/CFS need to be monitored for signs of malnutrition in the community and receive prompt intervention if clinically assisted nutrition and hydration (CANH) is required following NICE Clinical Guideline 32 *Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition*. ME/CFS needs to be recognised as a disease risk for malnutrition.

The section does lack objective measures of outcomes. A national ME/CFS audit is required which collects data from both hospital settings and patients akin to the National Diabetes Audit.

Provision of Adult Social Care

We are pleased to see government funding reforms in the social care system.

We are pleased the IDP acknowledges the need for people with severe and very severe ME/CFS to have a prompt assessment for NHS Continuing Health Care, home aids/adaptations and respite care and the need for advanced and emergency planning. We are pleased to see ‘third party support to manage a direct payment’ in *Best Practice*. As a charity we are aware of a high demand for this service and that it is not provided country wide. Social care staff should follow NICE guidance and take advice from the multi-disciplinary team. We are pleased to see recognition of the support unpaid carers provide. However, not all people have family or partners whose help they can draw on. We are pleased to see a need for more flexibility in the delivery of Community Care Assessments (CCA) is recognised. The IDP does not address the support that parents with ME/CFS need to enable them to continue to care for their children.

We raised concerns about self-funders whose needs require more of a safety net than a CCA and the local authority sending them a list of local agencies, so we request the final delivery plan includes signposting and more details about how brokerage services (a local authority obligation) work, how they differ in their delivery, for example are they inhouse or outsourced services, are the duties undertaken by key workers, independent advocates, social work assistants or direct payment staff? If brokerage services could assist self-funders with recruitment this would advantageous as it would make the person less vulnerable.

If the brokerage services are the third party for those needing help with running their care and support packages it may help to increase education about ME/CFS within the locality and assist in building up resilience in the local workforce.

We are pleased to see mention that 'the lack of understanding of ME/CFS has led to negative consequences for people and families in relation to safeguarding decisions'. As a charity delivering advocacy services, we are very aware this does happen. This can be improved by providing the necessary education to professionals. However, until the education of all professionals is accomplished the NICE guideline point (NG 206 1.7.1., 1.7.2) that all safeguarding investigation should include an expert in ME/CFS must be followed. Regarding reablement we welcome the *Best Practice* statement, bullet point 3 'local authorities should not automatically require people with ME/CFS to engage with reablement prior to assessment, due to the risk of a harmful effect.' The risk of a harmful effect from reablement or rehabilitation style interventions exists at any time. People with ME/CFS are unlikely to benefit from reablement as increasing their activity level is likely to cause post exertional malaise (PEM) and may cause a relapse and a long-term worsening of their condition. See NICE NG 206 1.11.2, 1.11.9 and 1.11.14. Thus, undertaking reablement would contradict NICE guidance.

Training will be required within social service departments and reablement providers about the risks of people with ME/CFS (and possibly long COVID patients) undertaking reablement. See NG 206 1.16 Furthermore, all those working in social care must understand the need to 'risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risks.' NG 206 1.17.4

We are pleased to see the inclusion of the link to the 25% ME Group information on social care in the IDP, it serves as a good education resource for professionals and patients and their families.

People with severe and very severe ME/CFS need help attending outpatient appointments; they need their home care worker/PA to go with them. This provision needs to be built into CCA and to be included in training for social service departments.

We raised the issue of the current lack of respite beds in either hospice, residential or nursing care home settings that would meet patients' clinical needs i.e., single rooms, low light and low noise and proximity to toilets in our feedback to the Quality of Life workshop. Please see below:-

- 'We agree in principle that respite facilities should be available, but with the current poor level of understanding of severe and very severe ME, admission to a residential care environment as they presently exist will almost certainly be counterproductive. Pressing ahead with this at present would be fraught with difficulty. Access to suitable residential care is nonetheless an important issue to address for those for whom it cannot be avoided.
- In the present circumstances, when family carers need respite, this is best provided by home care workers **in own home** with staff who are well briefed in severe ME

> particular needs. To do otherwise could do more harm than good with family carers returning to an even worse scenario. Feedback from a family carer - "Residential respite is simply not available for the severe. If it was, the journey would likely be lengthy and result in major setback. Respite in our own home is more feasible but would require carers to come in who really understood ME otherwise the person with ME would likely deteriorate and regular carers return from their break would face a worse situation. If the person with ME is just surviving trying to impose something on them could be disastrous."'

We request an Agreed Action is added. Home care worker and PA staff must undertake Food and Hygiene Training so that they can be employed to shop and cook for food being prepared from scratch when specialist diets needed. The charity is aware of cases where home care staff (or the employing agency) refuse to cook from scratch or refuse to cook protein where it is fish and meat.

There was consensus at the workshop that adult social care services were all too often failing to meet people's most basic care needs ie to maintaining hydration, nutrition and toileting. We strongly urge that these gaps in the delivery of care and the reasons for the gaps occurring are addressed as a priority.

Welfare support

People with ME/CFS, but particularly those with severe and very severe ME/CFS find the benefit claiming process daunting - they are concerned they will not be believed by DWP staff (this is not without justification), and about completion of the relevant documents in the timeframe allowed. They have difficulty completing the forms; the majority need someone else to complete them for them. The time allowed to complete the form is insufficient for them and they are very worried about the prospect of having a benefit assessor in their home and justifying their need for this, particularly as they feel the assessor will not have any appropriate prior knowledge of ME/CFS. The emphasis during assessments is on specific activities which do not encapsulate the effect of ME/CFS on physical activity, with no recognition of the limitations on how long an activity can be done before the individual needs to stop, their inability to repeat activities, or PEM. The assessments also rely too much on the individual's ability to communicate their difficulties.

Benefit forms need to continue to be available as paper copies. DWP staff need to undertake mandatory training about ME/CFS; this would make people with ME/CFS less fearful of benefit assessments. People with severe and very severe ME/CFS find heath assessments for benefits exhausting, even when they are undertaken in their home. Where a condition is chronic, as in the case of ME/CFS, long-term benefits awards must be made to avoid the need for repeated reassessment and this needs to be acknowledged in the final delivery plan. A commitment needs to be made to ensure that the decision about the benefit claim of a person with severe or very severe ME/CFS is made based on the written evidence submitted. Unpaid carers also need to be made aware of the financial support they are entitled to.

This section lacks the impact and best practice sections present under other headings, and there are no deliverables with regard to helping people with ME /CFS to apply for benefits. SMARTS need to be put in place to ensure people with ME are successful with their benefit claims. There are no actions for people with ME/CFS in the DWP section (21). This is a major oversight.

Employment Support

The IDP discusses returning to work; where a person feels able to return to work, permitted work must be allowed without fear of losing income and all necessary adaptations and adjustments must be made and funded by the Access to Work Scheme. However, it must be recognised that people with severe and very severe ME/CFS are too ill to work.

The final delivery plan also needs to address support for people either reducing their hours or working a less demanding job. It needs to set out provision for people who are no longer able to work to access long-term benefits. People with ME/CFS are harmed by trying to continue working at the level they did prior to developing ME/CFS; it can lead to a long-term worsening of their ME as we have seen in our members.

Agreed Actions

We are pleased to see commitments to moving research forward by identifying evidence gaps in the landscaping review and a commitment to educating health and social care professionals. We are particularly pleased to see that the British Association of Social Workers will ‘support and promote …..raising awareness of the needs of people with severe and very severe ME/CFS’.

With regard to education, we welcome that guidance ‘to make clear the role that home schools play in delivering education to pupils with health needs’ however, there isn’t specific guidance for teaching professionals around supporting children with ME/CFS.

There are no actions for people with ME/CFS in the DWP section (21). This is a major oversight which needs addressing in the final delivery plan.

Accessibility of the Document

At 25% ME Group we are aware of the difficulties members face, due to the severity their ME/CFS and associated cognitive difficulties, when attempting to read a document such as the IDP. Many of our members do not have access to the internet or computer equipment either because they are unable to tolerate the sensory stimulus from a screen or because they cannot afford it.

We were pleased to see paper copies being made available on request. However, it was not clear in the IDP FAQs as to whether this was only the feedback document or both the IDP and the feedback document. Furthermore, people have typically experienced delays of at least two weeks from when they request a paper copy to receiving it.

The DHSC emailed the consultation links for the IDP to charities. Given the timescale, it was not possible for charities to post out written information that the IDP was out for consultation and what to do if a paper copy was required. Our advocacy worker found instances where family members of people with severe ME/CFS who did have computer access, but were not active on social media, were not aware the IDP was out for consultation.

For many people with severe and very severe ME/CFS the document was too lengthy and detailed for them to be able to read and understand, despite a keenness to be involved, as evidenced on the 25% ME Group members only Facebook page. Often neither their homecare workers nor family had time to read the IDP and complete the document on their behalf. There wasn't any notification that the Easy Read version would be made available and when it was members felt it had been oversimplified to the extent that many of the points were lost but it remained lengthy. A further issue was that a major explainer of the disease was 'feeling tired' when it is a much more complex illness.

Recognising the difficulty and the frustration members were experiencing, the charity set up a poll on the 25% ME Group members only Facebook page, which ran from 19th -25th September 2023, asking how many people had read the IDP and completed the feedback form. Of those who took part in the poll (n=69) one person had been able to partially read the IDP; the remaining 68 had been neither able to read it nor respond to it.

Below are some anonymised quotes members left on the Facebook page.

'I wanted to do this but it's beyond me which I find very frustrating. My husband is my carer and is fully occupied looking after me- he hadn't spare capacity.'

'There is absolutely zero % chance of my daughter being able to read, comprehend or respond to this. She is just too severe. I need to do this on her behalf but having the time and energy to dedicate to giving a full and meaningful response is challenging when you are a full-time carer. I worry that the severe and very severe patients - who need radical change the most - are not able to reply themselves or do not have carers able to do so. Many, won't even know of it's existence because they are so far removed from what is happening in the world around them. I wish there was a way for their voices to be heard.'

'I tried but far too much for me and I don't have someone who can do for me.'

This IDP has largely failed to capture the views of people with severe and very severe ME via this consultation.

Next Steps

The charity was able to provide extensive feedback about severe and very severe ME, via case studies, its attendance at workshops and in written feedback after the workshops which we were pleased to see reflected in the IDP.

We are pleased to see a keenness to 'monitor and capitalise on opportunities to work together' and we would very much like to be part of this as we feel we are well positioned to provide the experiences of people with severe and very severe ME/CFS.

25% ME Group