A QUESTION ASKED BY A MEDICAL ASSESSOR TO A 46-60, SICKLE CELL PATIENT FROM LONDON

"HOW DID YOU CONTRACT THAT?"

The Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG) Report into the institutional failures of Personal Independence Payment (PIP) for those living with sickle cell disease and thalassaemia

IN COLLABORATION WITH THE SICKLE CELL SOCIETY
& UK THALASSAEMIA SOCIETY

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Report into the institutional failures of Personal Independence Payment (PIP)
for those living with sickle cell disease and thalassaemia

Executive summary

About the Sickle Cell and Thalassaemia All-Party Parliamentary Group (SCTAPPG)

The Sickle Cell and Thalassaemia All Party Parliamentary Group (SCTAPPG) *raison d’etre* is to reduce the health inequalities that are faced by sickle cell and thalassaemia patients in the UK. The SCTAPPG secures this by influencing and lobbying policymakers to raise the profile of sickle cell disease and thalassaemia on the political agenda. These efforts are ultimately intended to improve standards of care and address other critical issues, as recommended by the key stakeholders. Members achieve this aim by engaging with parliamentary colleagues, the government, health professionals, and community and patient groups to raise awareness relating to the conditions and needs of patients. The SCTAPPG works in collaboration with The Sickle Cell Society and the UK Thalassaemia Society striving to reflect the concerns of their membership and to act as a vehicle for change.

About the Research

Initial conversations took place regarding service users mounting concerns of the Personal Independence Payment (PIP) process at the SCTAPPG meeting on November 15th 2017. Both voluntary organisations shared that it was clear that the regularity of service user concerns coming through to helplines indicated a system that was failing patients and exacerbating the difficulties they faced. Discussions centred on the strongly held sentiment that service users believed that their condition, and the lack of understanding around it, from the outset put them at a disadvantage. It was decided that the SCTAPPG go forward with this as a potential topic, and collect evidence to substantiate these claims. Furthermore, in the November meeting Baroness Thomas of Winchester echoed these concerns about the DWP and PIP failing patients with respect to access to benefits. She advocated a meeting with Sarah Newton MP, Minister of State for Disabled People. Marsha de Cordova MP, Shadow Minister for Disabled People seconded this and agreed to also attend the prospective meeting.

The SCTAPPG through this report has endeavoured to capture those recommendations made at the November meeting and the voice of the membership of both the Sickle Cell Society and the UK Thalassaemia Society.

PIP is a source of financial support designed to help disabled people and those with long-term conditions manage the extra costs of their conditions. It was introduced in 2013 to replace Disability

Living Allowance (DLA) with a view to "focus support on those with the greatest need'" (Secretary of State for Work and Pensions, Statement on not going ahead with changes to Personal Independence Payment (PIP), March 2016). The policy intent of Personal Independence Payment (PIP) was to introduce a more dynamic, fair, transparent and objective assessment compared to Disability Living Allowance (DLA), moving most people from an indefinite to a fixed term award (Government's response to the consultation on Disability Living Allowance reform, 2011). For those individuals with sickle cell and thalassaemia – this has not been the case. Attempts have been made in the form of two independent reports commissioned by the Department of Work and Pensions (DWP) in 2014 and 2017 to ameliorate concerns, however we feel Paul Gray's recommendations fall well short of what should be being done.

There remains the long standing difficulty of ensuring that those who administer PIP claims understand the consequences of what it can be like to live with a fluctuating condition, such as SCD [and thalassaemia], where impairment can be intermittent and often not immediately obvious (Standards for the clinical care of adults with sickle cell disease in the UK, 2018). We believe the PIP process fails to sufficiently recognise the significant physiological and psychological effects which sickle cell disease and thalassaemia have on a service user. We consider that this is attributable to medical assessors' lack of understanding and knowledge around the two genetic blood disorders. This institutional failure is resulting in an unfair reduction in people's standard of living; service users deserved of PIP are suffering on a daily basis because of these injustices.

To determine the prevalence of people experiencing these problems with PIP, both the Sickle Cell Society and UK Thalassaemia Society commissioned a survey which was circulated to both their respective memberships. We had an overwhelming response with 91 responses from sickle cell patients and 19 responses from thalassaemia patients (with the thalassaemia population totalling approximately 10% of sickle cell population, we deem this a similar response rate). The survey was designed to decipher where and how the process was failing to recognise that people with sickle cell and thalassaemia qualify as "those with the greatest need". We hope this report reflects the reality on the ground, that these are not merely isolated examples but that this inequity is endemic and the system as it stands is failing our service users. The current state of play is avoidable, and we hope that the legitimate grievances outlined in this report can be rectified. So ultimately the question: "How did you contract this?" will be a question that is consigned to the past.

Research findings

- The 'PIP2' Form is not fit for purpose. It's generic, rigid and inflexible criteria means that those with sickle cell and thalassaemia are scored unfairly and inconsistently.
    - Around half of sickle cell and thalassaemia members who responded believed the form failed to capture their experiences adequately.
    - Only 7.7% and 5.2% of sickle cell and thalassaemia patients respectively felt they were asked questions which were relevant to their conditions.
- The 'face-to-face' assessment is fundamentally flawed. Due to the lack of assessor's knowledge around sickle cell disease and thalassaemia, members are not guaranteed a fair process. They are from the outset at a disadvantage. Furthermore, the conduct of assessors has to be called into question as several areas have been highlighted as concerns, from failing to accurately report proceedings to intimidating behaviour.

  - 73.6% and 89.5% of respondents of sickle cell and thalassaemia patients respectively believed the assessors did not to possess the adequate knowledge of their condition.
  - A sizable 43.9% of sickle cell patients felt they were treated unfairly whilst a staggering 78.9% of thalassaemia patients also echoed these sentiments.

- Members who have attended a tribunal have been broadly more content with this stage of the process. There have been accounts where many have felt listened to for the first time and have felt confidence in the panel in being able to understand their condition. However, there have been examples of claimants having to, out of their pocket, employ their own litigation representatives to fight on behalf of them. Furthermore, this lengthy process we feel has led to the worsening of some member's conditions. We are saddened that in the pursuit of fairness, some people have had to pay the price of a deterioration in their condition.

Recommendations

'PIP2' Form

We judge that the present 'PIP2 Form' is not fit for purpose for those living with sickle cell disease and thalassaemia. As has been evident, it is designed in such a way that poses irrelevant questions; fails to capture experiences properly; reflects the hardship faced by our service users and as a result scores them inconsistently and unfairly. Though we fully endorse the Disability Benefits Consortium recommendations on the application process and evidence gathering and believe they would improve the process, we contend that they do not sufficiently accommodate the complexity, nuance and specific nature of our service users' conditions. Our membership has overwhelmingly and resolutely condemned the PIP 2 form. We see the only way to provide a fairer, more holistic and egalitarian form is to enable and empower them to present their condition in a more nuanced way. To establish fairness the SCTAPPG recommends the following changes:

- The DWP should immediately carry out a full and comprehensive Equality Impact Assessment on the criteria of the 'PIP2' Form and whether it negatively affects those from BAME backgrounds. As has been demonstrably shown through *RF v Secretary of State for Work and Pensions*, whereby the High Court judged that government policy had been "blatantly discriminatory" against people with mental health conditions, the government has revealed it hasn't and needs to do more to improve the fairness of the criteria. An example of this is at present our members can only channel their condition partially through what the Citizens Advice Bureau advises in the "what to write section" as the 'Good Day' & 'Bad Day' in which they will score you on the basis of whether "if you have bad days more often" - this is done all in the hope to give the assessor a better picture of how a claimant copes most of the time. This simplistic and crude measurement is not an appropriate substitute for 'in crisis' or 'not in crisis.' We believe it is paramount that our members are given the opportunity to express themselves in a way which is adapted for them and their condition. We believe an effective and meticulous Equality Analysis could aid our service users. There is however a precedent for the DWP; despite their own Equality Analysis in the case of MH v Secretary of State for Work and Pensions (PIP): [2016] UKUT 531, instead of acting to remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic (section 149 of the Equality Act 2010), have in fact done the opposite and spawned those very regulations that have resulted in the court ruling against the Government. Therefore, in the spirit of this conciliatory approach, we recommend an Equality Impact Assessment that fully embraces public consultation, and produces meaningful change not court battles.

- The DWP should begin to collect and request data on ‘Race’ as part of its future PIP caseload. The current protected characteristics that are collected as part of its existing PIP caseload are: Disability, Gender and Age. As a result, there is little or no analysis bar reference to ‘published studies’ and an ambiguous “commitment to monitoring the impacts of our policies and using evidence from a variety of sources to monitor experiences and outcomes for protected groups”. In particular using survey data, such as the Family Resources Survey (FRS) and Labour Force Survey (LFS) is being done. We think this would be a welcome step so we can really for the first time discover the ethnic composition of those receiving PIP, and then think about how we can ensure that the Equality Act 2010 is being complied with.

- The DWP needs to strive to foster and cultivate trust and goodwill between claimant and assessor. Hence, The DWP should look to drastically alter the dynamic between claimant and assessor. At present, the responsibility to provide medical documents and supporting evidence is very much the sole duty of the claimant without much exterior help. Furthermore, the burden to seek guidance and support also falls on the claimant; the help from the DWP is limited and scarce, and it often falls to voluntary organisations to take up the slack. This ‘us and them’ culture that is produced is detrimental to the integrity and fluidity of the process; it does not take into account the potential vulnerabilities and faculties of the claimants sufficiently enough. Consequently, the DWP should produce its own comprehensive guidance available in every format and offer pastoral support which runs parallel to the PIP process. Furthermore, we echo the DBC’s recommendation that in order to restore confidence in the process, assessors should be obligated to review all supporting evidence provided by a claimant with penalties if they do not (Supporting Those Who Need It Most?, DBC, 2017).

Medical Assessment

- It is paramount that all assessors have a sufficient level of knowledge and understanding of sickle cell disease and thalassaemia. Time and time again, we hear of members denouncing the astonishing lack of understanding of their condition. Without an adequate level of knowledge it is 'nigh-on-impossible' for a member to have access to a thorough and meticulous process that is grounded in expertise. All assessors should receive training and education to make this the case, and the Sickle Cell Society and UK Thalassaemia Society are both willing to provide this. This we believe is crucial to our members receiving the optimum opportunity to have a fair and just process. Where this is not possible, it is paramount that at the minimum an assessor must have access and be well versed with the latest clinical guidelines.

- The DWP should order both ATOS and Capita to video-record and log all face to face assessments, and these should be available on request to all parties concerned. At the tribunal stage it can act as supporting evidence to determine whether the initial outcome should be overturned. It is alarming to hear our members express trepidation experienced during these assessments. This countermeasure will mean a definitive record of events which provides security for both the assessor and the claimant. What’s more, is this will not only improve transparency and accountability amongst assessors it will foster trust in the process as a whole. Ultimately, this will enable for the first time an extensive review into the agency factor of assessors, whether their delivery, style and tone has a material impact on the outcome of cases.

- All assessors irrespective of the extent of their medical proficiency should have professional experience at dealing with vulnerable people. In lieu of this, they should be required to embark on some form of pastoral training. Too many respondents have detailed experiences of assessors whom lack an appropriate level of compassion towards their circumstances which is fuelling distrust and disdain in the process. If it was mandatory for all assessors to have a minimum level of aptitude in pastoral care, this problem would soon be ameliorated.

Tribunal

- The judge should allow the appellant (claimant) to nominate a proxy to make the case for appeal against the respondent (DWP). Though we realise that at present members are allowed to have family and friends accompany them and make a short statement, we feel this still falls short. Too often have we been informed of members who have difficulty effectively communicating feeling that they have been mistreated by the panel. Hence, they consider that they have not been able to offer a true reflection of the reality of their condition. By permitting close family and friends to act on their behalf, their experiences and hardship can be conveyed in an articulate manner.

- We feel as with the face-to-face assessment, all on the panel should receive training and education in sickle cell disease and thalassaemia. In addition, at the very minimum those on the panel must have access and be well versed with the latest clinical guidelines. Hence, tribunal proceedings will possess critique that is based on specialised knowledge. This will maintain continuity which translates into a consistently high level of scrutiny. Furthermore, members *en masse* have informed us of sustained questioning on their knowledge of their condition. The level of understanding that a claimant has of their condition should have no bearing on the outcome of their case. This worrying trend of a seemingly irrelevant line of questioning, if not to ‘test’ the claimant, we fear is to educate the panel themselves. Either way this practice is unnecessary and deeply concerning. One questions whether the same line of questioning would be levelled at a cancer patient?

- We recommend a compensation scheme to reimburse the costs of the tribunal process. Members have told us that they have had to employ litigation reps due to the convoluted, complex and exhaustive process and this requires full recompense. Moreover, members have at great length informed us the emotional toll they have been subject to because of the process. Therefore, the scheme has to account for the psychological trauma, stress and anxiety the tribunal has caused which in some cases has led to the worsening of people’s conditions. We would expect a judgement be made case by case on the amount of compensation warranted. The compensation would only be applicable if the appeal was successful.

Survey findings

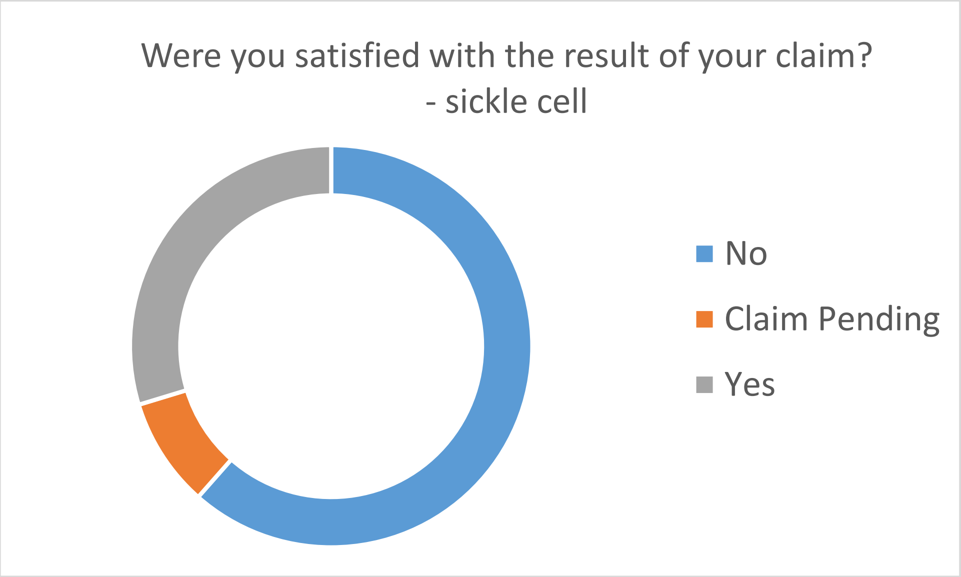
Methodology

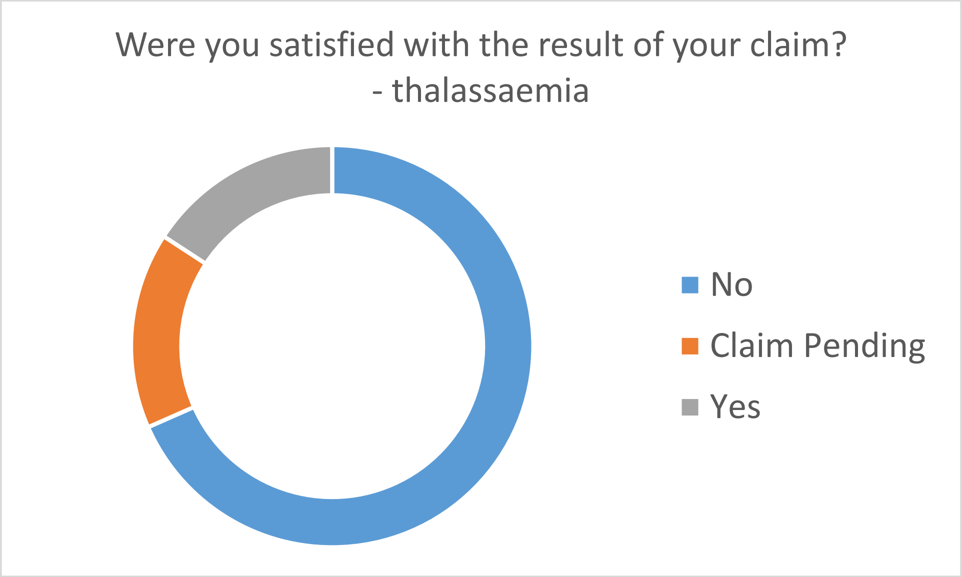
The Sickle Cell Society and UK Thalassaemia Society in unison have sought to determine the prevalence of issues within their memberships by commissioning a survey. The Sickle Cell Society launched its "Experience of Personal Independence Payment (PIP) claim Survey" on 20th October 2017, collecting 47 responses until it closed on 11th November 2017. However, the decision was made in early January that both voluntary organisations, under the banner of the SCTAPPG, would collaborate on the project. The aim of this was to demonstrate the common struggle that existed between both those individuals living with SCD and thalassaemia. Another aim being that both were stalwart in their determination to correct these injustices. Hence, on 2nd February 2018, UKTS (for the first time) and SCS (for the second time) opened up the aforementioned survey to their respective memberships. On 15th March the survey closed with UKTS receiving 19 responses, and SCS acquiring another 44 responses meaning their total amount was at 91 responses. Consequently, we have managed to gain an insight into the lives of 110 people who have strived to acquire PIP. We consider this to be a healthy figure which is representative of the community as a whole and will provide us with a true and fair reflection of the process.

Members were encouraged to offer anecdotal evidence to serve as case studies; these would help to contextualise the survey's findings. The recommendations you see here stem from the breadth and depth of sources made available to us by members.

Results

The majority of questionnaire respondents answered **no** when asked if they were satisfied with result of their claim. The pie charts below show that 61.5% and 68.4% of sickle cell and thalassaemia respondents respectively were not satisfied. What's more, as both still had a percentage of respondents whose claims were pending (8.8 & 15.8), it is safe to assume that if they were consistent and remained proportionate with what came before, then the final picture would look much bleaker.





The overwhelming dissatisfaction present amongst both membership bases was clear and expected by all agents concerned within both voluntary organisations. Hence, this report has been authored to delve deeper into why exactly the process has generated such discontent. The survey was devised to tackle the PIP process in three ways: PIP2 Form, face-to-face assessment and the tribunal.

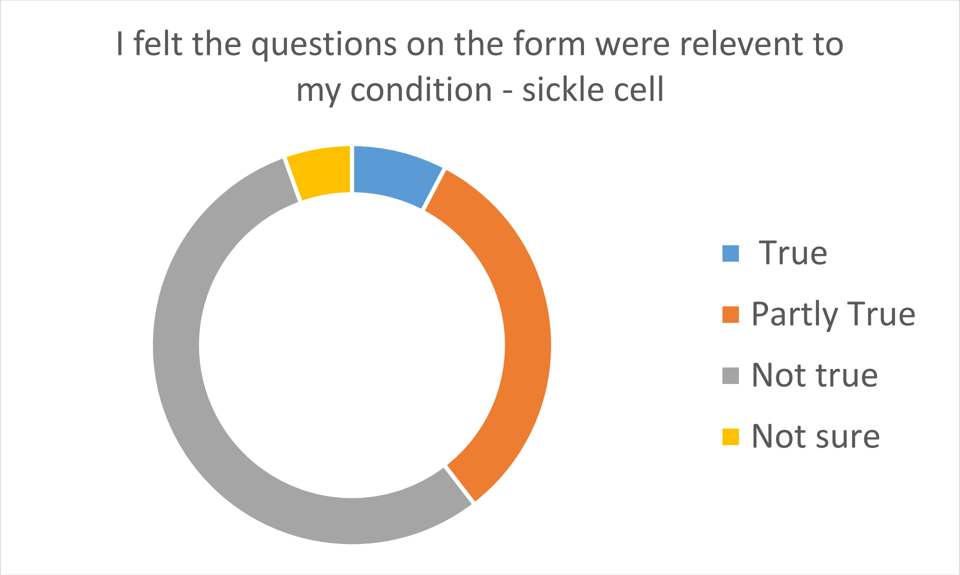
PIP2 Form

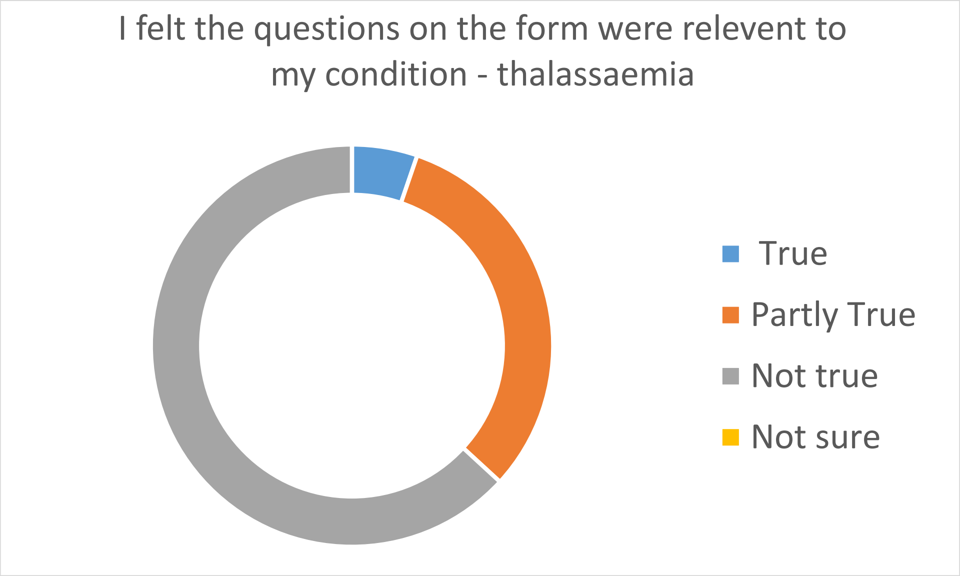
To apply for PIP, claimants must undergo a two-stage process. A person must make an initial telephone call, where they provide basic details about themselves. They are then posted an application form – known as the ‘PIP2’ form, which has their key details prepopulated and a unique barcode. They must complete the form, which asks detailed questions about a person’s condition and how it affects their ability to undertake daily activities and get around, within four weeks (Supporting Those Who Need It Most?, DBC, 2017).

Whilst some members were happy with the opportunity to attach medical information and valued the space given in which they could articulate at length about their condition, it is clear that members deeply lamented the structure, rigidity and inflexibility of the ‘PIP 2 form,’ so much so that they felt that it failed to appreciate their condition (sickle cell disease and thalassaemia).

The majority of survey respondents found the PIP2 asked questions which weren’t relevant to their conditions.

We found that 54.9% of sickle cell respondents and 63.2% of thalassaemia respondents didn’t agree that the questions asked were relevant to their condition. Moreover only 7.7% and 5.2% of sickle cell and thalassaemia patients fully agreed with the statements. This illustrates a broad consensus that the questions didn’t adequately grasp sickle cell disease and thalassaemia as conditions.





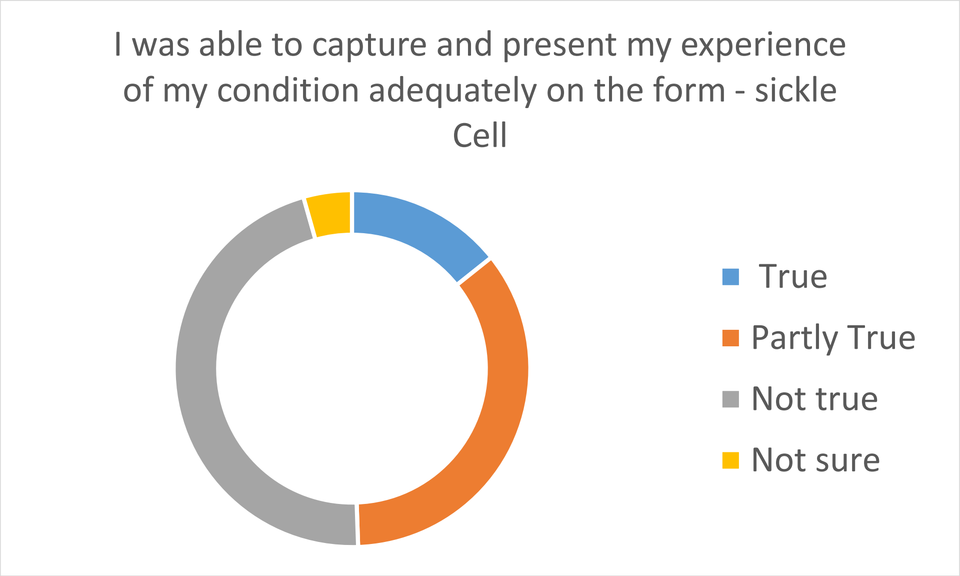
In free text responses, members expressed disappointment at the extraneous nature of the questions that they felt failed to encapsulate their condition:

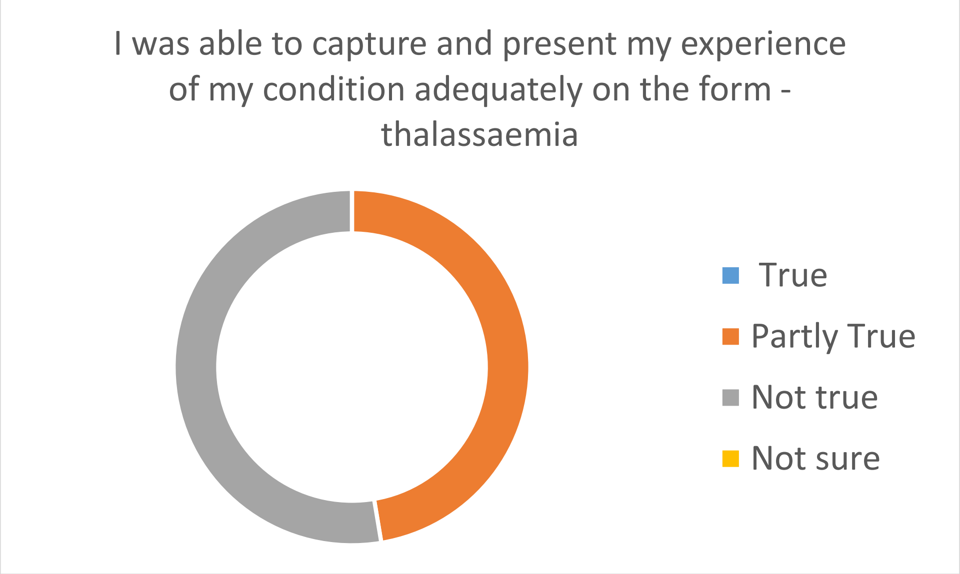
“The questions asked should be more relevant to my condition.” 16- 25, thalassaemia patient from the West Midlands

“[There were] too many irrelevant questions that didn’t have anything to do with my condition. The form also fails to put into consideration that sickle cell disease is quite different from so many medical conditions, the pain/crises are very unpredictable and the assessors fail to realise this.” 36-45, sickle cell patient from London.

“Questions not relevant to people with haemoglobinopathies (sickle cell disease), common sense should prevail [in that] if someone has a medical condition that states that their joints (shoulders and hips) have avascular necrosis [than] obviously there is to be limited or restricted movement and constant pain. Yet the form does not have anywhere to express this.” 26-35, sickle cell patient from the West Midlands.

Furthermore, respondents felt the form was unsuccessful in capturing their experiences sufficiently; those who administer claims neglect to understand the consequences of what it can be like to live with a fluctuating condition, such as SCD and thalassaemia, where impairment can be intermittent and often not immediately obvious (SCD/thalassaemia Standards). Respondents believed that the form wanted answers that conformed to unyielding and unbending criteria which allowed no room for nuance, which is what those with sickle cell disease and thalassaemia exactly need. In essence, the form is looking for answers our members with their condition simply can’t give but hence they are being inadvertently penalised for it. It is abundantly clear that the form discriminates against such a variable intermittent condition.


I was able to capture and present my experience of my condition adequately on the form - sickle Cell


I was able to capture and present my experience of my condition adequately on the form - thalassaemia

In response to whether the condition adequately captured experiences the majority answered either not true or only partly true. Specifically 46.2% and 52.6% of sickle cell and thalassaemia members did not believe the form did so. In addition, no thalassaemia patients fully agreed with the statements which indicates a lack of understanding on the complexities of the conditions:

In free text responses, members elaborated on their issues with how the PIP2 form failed to capture their experiences.

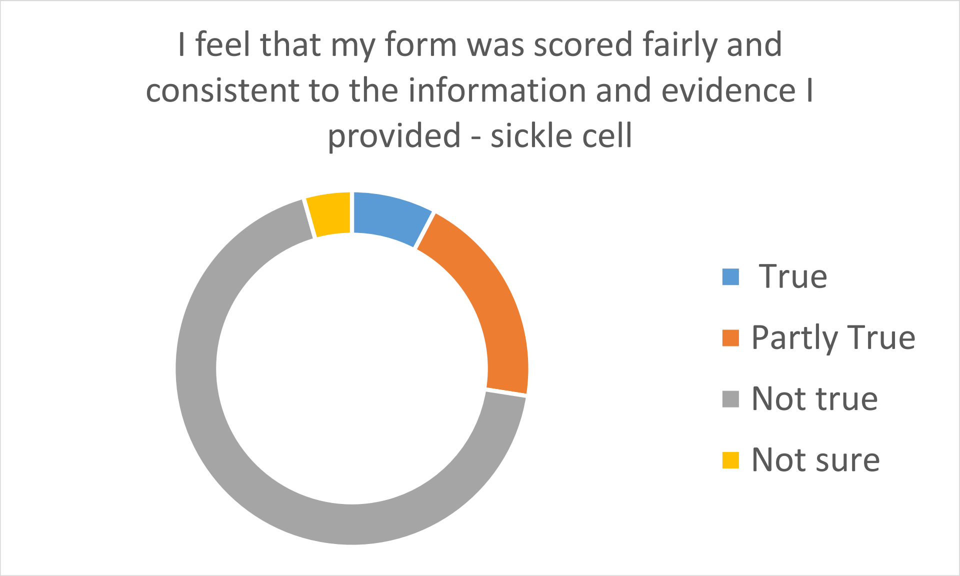
“I feel that it would be more beneficial if it could also consider past and continual difficulties of coping/living with the condition of thalassaemia”. 46-60, thalassaemia patient from the South West.

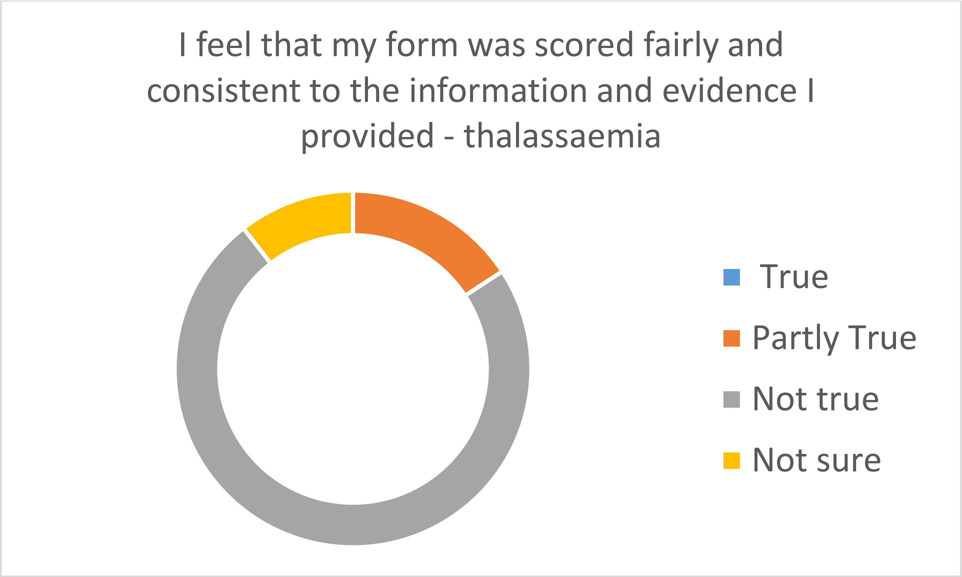
“As my condition is unpredictable I was unable to talk about problems which are not present but often occur.” 16- 25, thalassaemia patient from Yorkshire.

“The form is not designed to capture the real limitations that sickle cell sufferers face as SCD is not a visible disability that can be seen instantly, some days a SCD sufferer can be okay and the next they will be in agony and yet this can’t be explained in a concise way as per the PIP2 form.” 46-60, sickle cell patient from the North West.

“It has a construct of questions that leads you to a choice of answers. These answers are not likely to describe my experience of sickle cell anaemia crisis. The choices of answers either leads the assessor to believe that you are both extremely well and enabled or you are extremely unwell. It does not take into account your recovery, or effects of your illness on your general health e.g. days of extreme fatigue, days of sudden crisis that affect your mobility etc.” 46-60, sickle cell patient from London.

What’s more, members deemed that the ‘PIP2’ form meant they were scored unfairly and inconsistently. Members indicated that although there was space to write at length about their condition, there was deep lying sentiment that because of the issues mentioned they felt the nature of the form meant they were scored unfairly.





Members went into detail about how they felt form did not appreciate their condition for example, the seasonal impact (Winter) was not taken into consideration:

"The mobility section of the form need[s] to be reviewed because it does not reflect how SCD affects ones mobility especially in the winter months. No consideration is given to the effects the cold have on people with SCD as this deters them from using public transport." 46-60, sickle cell patient from London.

"[They need an] Understanding of the physiological affects a long term illness can have on a person, realising that you (assessor) want me to seem weak and frail and illness does not have that effect on everyone, that looking strong and healthy one day and hardly move and in consistent pain the next. Also, there was an insinuation that because you are not walking with an aid I was alright, you have to be mentally strong to deal with the pain that you suffer, so just because you cannot see it does not mean it is not there in this circumstance." 36-45, sickle cell patient from the East of England.

Recommendations

We judge that the present 'PIP2 Form' is not fit for purpose for those living with sickle cell disease and thalassaemia. As has been evident, it is designed in such a way that poses irrelevant questions; fails to capture experiences properly; fails to reflect the hardship faced by our service users and as a result scores them inconsistently and unfairly. Though we fully endorse the Disability Benefits Consortium recommendations on the application process and evidence gathering and believe they would improve the process, we contend that they do not sufficiently accommodate the complexity, nuance and specific nature of our service user's conditions. To establish fairness the SCTAPPG recommends the following changes:

- The DWP should immediately carry out a full and comprehensive Equality Impact Assessment on the criteria of the 'PIP2' Form, and whether it negatively affects those from BAME backgrounds. As has been demonstrably shown through *RF v Secretary of State for Work and Pensions*, whereby the High Court judged government policy had been "blatantly discriminatory" against people with mental health conditions, the government has revealed it hasn't and needs to do more to improve the fairness of the criteria. An example of this is at present our members can only channel their condition partially through what the Citizens Advice Bureau advise in the “what to write section” as the ‘Good Day’ & ‘Bad Day’ in which they will score you on the basis of whether “you have bad days more often.” This done all in the hope to give the assessor a better picture of how a claimant copes most of the time. This simplistic and crude measurement is not an appropriate substitute for ‘in crisis’ or ‘not in crisis,’ we believe it is paramount that our members are given the opportunity to express themselves in a way which is adapted for them and their condition. We believe an effective and meticulous Equality Analysis could aid our service users. There is however a precedent for the DWP despite their own Equality Analysis in the case of MH v Secretary of State for Work and Pensions (PIP): [2016] UKUT 531. Instead of aiding to remove or minimise disadvantages suffered by persons who share a relevant protected characteristic that are connected to that characteristic (section 149 of the Equality Act 2010), the DWP have in fact done the opposite and spawned those very regulations that have resulted in the court ruling against the Government. Therefore, in the spirit of this conciliatory approach, we recommend an Equality Impact Assessment that fully embraces public consultation and produces meaningful change not court battles.

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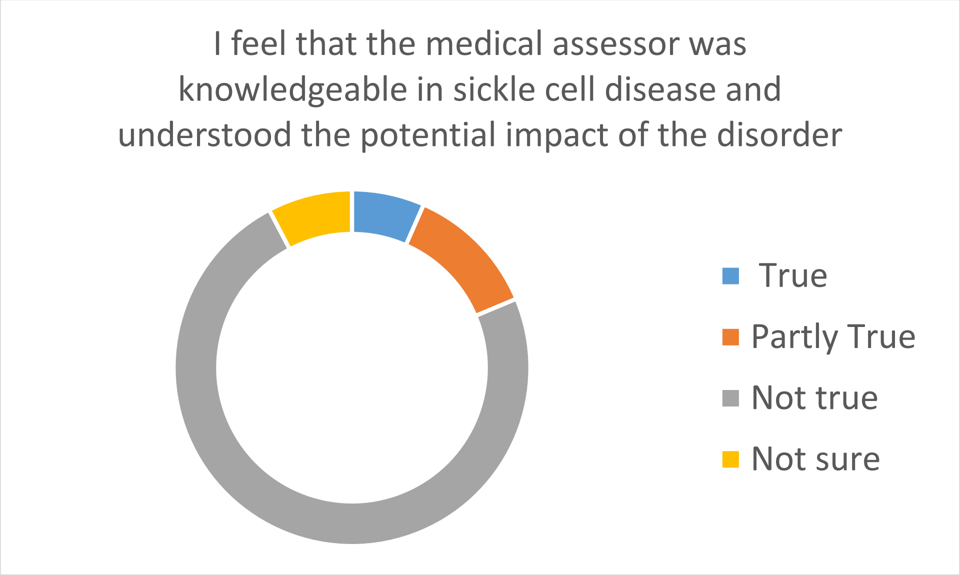
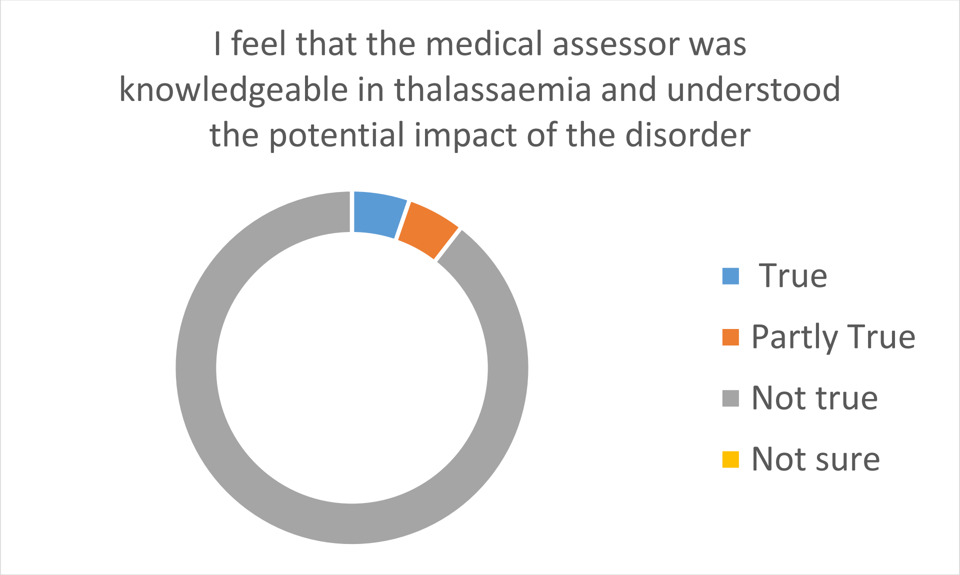
- The DWP needs to strive to foster and cultivate trust and goodwill between claimant and assessor. Hence, The DWP should look to drastically alter the dynamic between claimant and assessor. At present, the responsibility to provide medical documents and supporting evidence is very much the sole duty of the claimant without much exterior help. What’s more, the burden to seek guidance and support also falls on the claimant; the help from the DWP is limited and scarce and it often falls to voluntary organisations to take up the slack. This ‘us and them’ culture that is produced is detrimental to the integrity and fluidity of the process, it does not take into account the potential vulnerabilities and faculties of the claimants sufficiently enough. Consequently, the DWP should produce its own comprehensive guidance available in every format and offer pastoral support which runs parallel to the PIP process. Furthermore, we echo the DBC’s recommendation that in order to restore confidence in the process, assessors should be obligated to review all supporting evidence provided by a claimant, with penalties if they do not (Supporting Those Who Need It Most?, DBC, 2017).

Medical Assessment

Unless a claimant has a terminal illness, they will usually have to have an assessment to complete their Personal Independence Payment (PIP) application. It's an opportunity for a claimant to talk about how their condition affects them (Citizensadvice.org.uk, 2018).

A recurring theme we encountered was members felt from the outset that because of the condition they had, they were at a disadvantage. They protested that the system inadvertently penalised them due to the assessors not having the adequate level of knowledge to be able to carry out a fair assessment. Respondents were asked whether they agreed with the following statement: **I feel that the medical assessor was knowledgeable in SCD and understood the potential impacts of the disorder**





Again a vast majority of respondents believed that the assessors were not knowledgeable in either sickle cell or thalassaemia. We found that 73.6% and 89.5% of respondents respectively believed the assessors did not possess the adequate knowledge. Given the unique nature of the conditions, this provides a worrying picture as knowledge of the specifics of the conditions is a necessary safeguard to a fair assessment.

These findings were only strengthened when members were afforded the opportunity to describe the lack of understanding apparent:

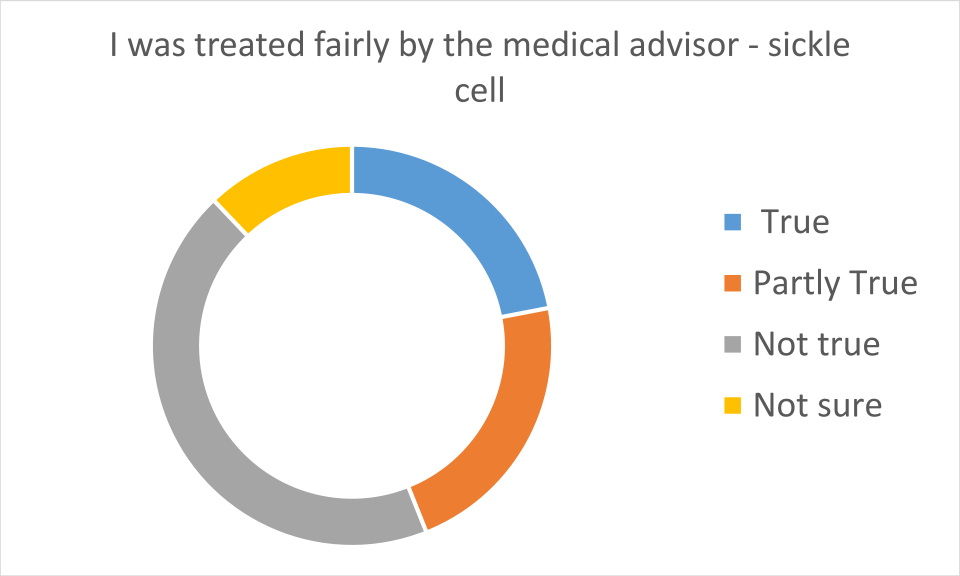
“The first time I applied the medical assessment was not good [as] she did not know about thalassaemia and all the complications that go with it. She had no patients and no understanding of the complication.” 46-60, thalassaemia patient from the East of England

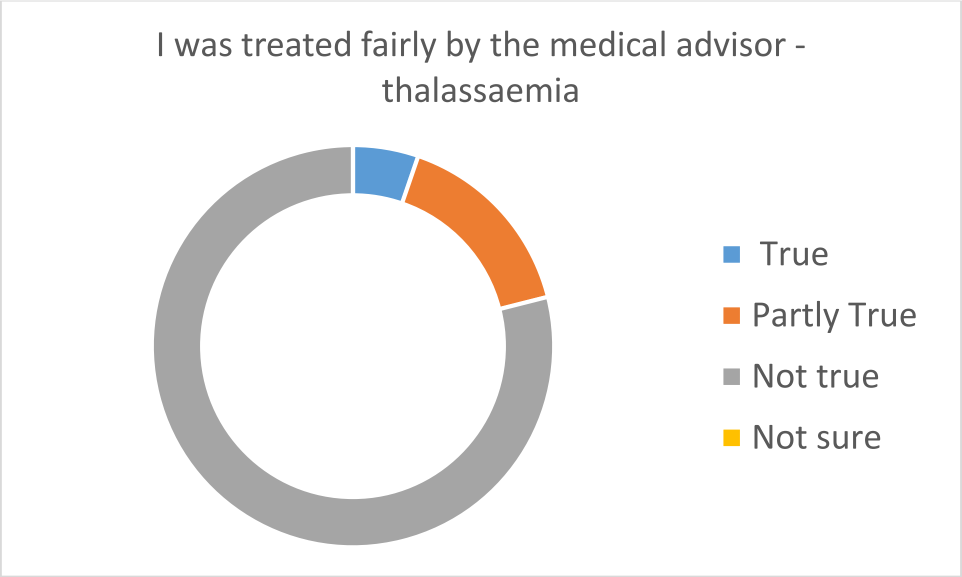
“She did not have any idea about the complications living with thalassaemia and what other illnesses come with it.” 46-60, thalassaemia patient from London

“The assessor told me that she has no knowledge of my condition. Her profession is a physio-therapist which led me to agree that she has no qualifications to assess someone of my medical condition. The assessment was based on a few minutes of one's whole life medical condition. I was not seen on my worst day when I'm in tears incapable of functioning or when my whole body is in a vegetative extreme[ly] painful condition. The assessor gave a description of a very enabled person that was full of gust and energy. The questions were very leading to enable you discuss your positive experience. Hence, the assessor (in my experience) would prefer to write about the PIP applicant as a healthy capable person that is well at most times. It does not take into account that my condition is permanent with sporadic crisis that could occur for many varying lengths of period.” 46-60, sickle cell patient from London

“Appalling! She asked me how I contracted SCD. I advised her it is an inherited disease.” 46-60, sickle cell patient from London

An alarming trend we faced, which members have provided evidence for, is the behaviour and professionalism of assessors. We are deeply concerned at reports of intimidation and bullying that respondents have detailed. Irrespective of the outcome of a case we consider it a prerequisite that people are given the respect they are entitled to and that they feel safe. This has not been the case. Respondents were asked whether **they felt they were treated fairly by the medical assessor.**





A sizable 43.9% of sickle cell patients disagreed with statement “they felt they were treated fairly” whilst a staggering 78.9% of thalassaemia patients also contended the same. This concerning trend is made worse by the details of such events:

“Yes; asking the applicant to repeat the list of medication/illness is unfair when this is listed on the application form itself. This can bring back painful memory of difficult treatment that they have undergone.” 46-60, sickle cell disease patient from London.

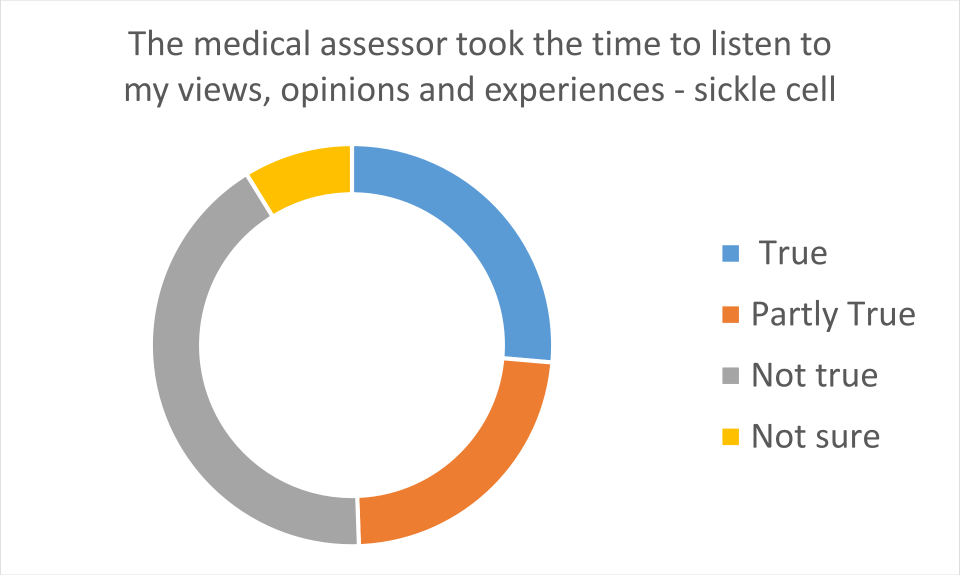
“He bullied me and order[ed] me to do what he want[ed] even if it was difficult for me to do.” 46-60, sickle cell disease from London

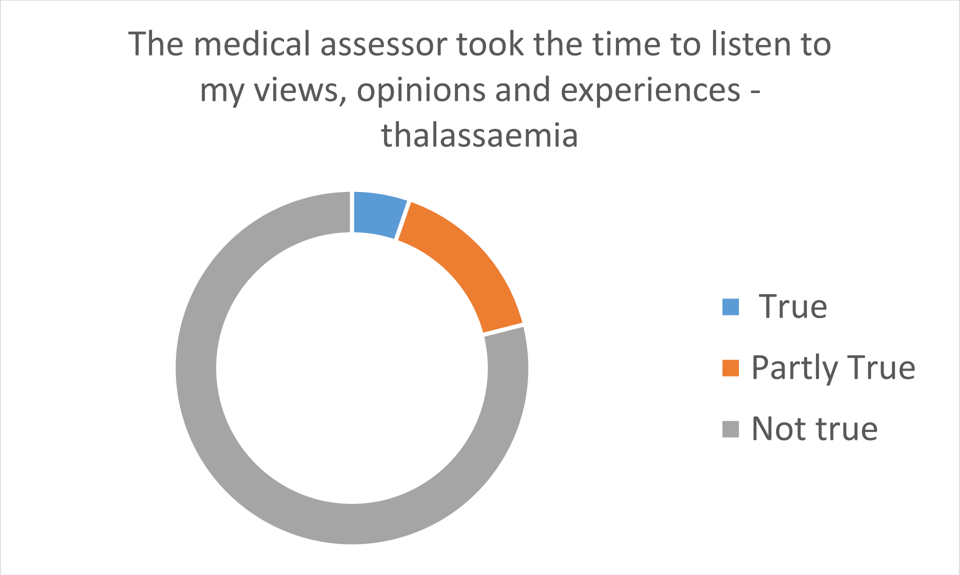
“The assessor was unfriendly, appeared to be trying to catch me out and did not even ask me to try to stand. Her outcomes completely disregarded medical evidence provided. When I could not remember the three items she asked me to, she said “oh I will let you have that one!!”, I was unable to do the sum she gave me and she put in her findings that I could complete complicated finances. She totally ignored that I am dyslexic and basically lied on the form. I felt so ill after meeting that I was in bed for over a week. I appealed which was a waste of time, I then felt too ill to take it to tribunal.” 26-35, sickle cell patient from the South East.

“Nothing as it felt like they had made up their mind before even listening to me at the assessment.” 26-35, thalassaemia patient from London.

“There were two assessors. I was initially told the other person in the room was observing the person interviewing me however, he was questioning me with the same things and sat behind me which meant I had to twist and sit uncomfortably to answer him. This was very intimidating.” 16- 25, thalassaemia from London.

Members have consistently complained about that they “were not being heard” so hence we asked respondents **whether the medical assessor took the time to listen to my views, opinions and experiences.**





In response to whether medical assessors took the time to listen to members views, opinions and experiences it is clear that the majority felt was not true or partly true. A substantial 57.8% of thalassaemia patients felt it was not true whilst 41.7% of sickle cell patients thought the same. Respondents went on to explain these sentiments:

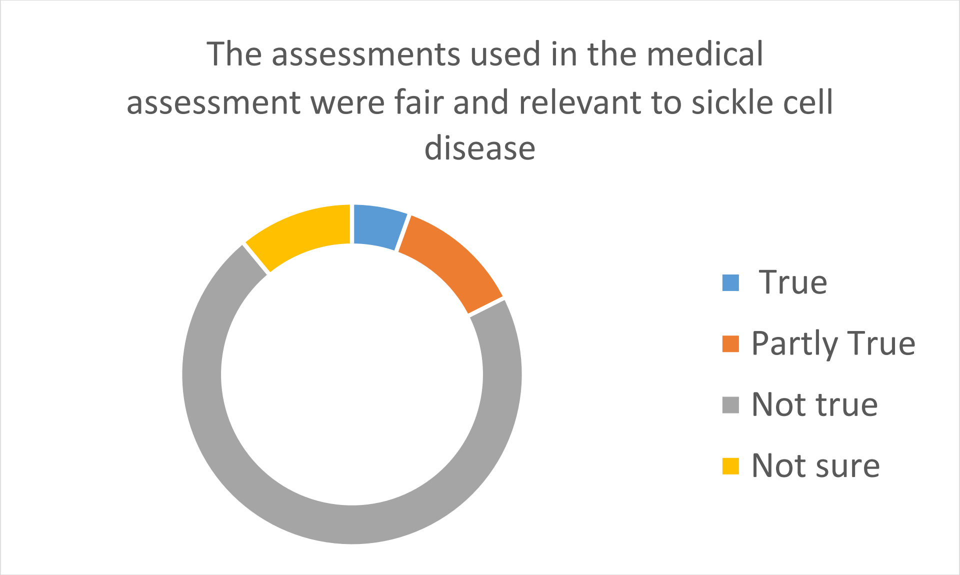
“She said she knew about SCD, told me to tell her about my other issues. I felt she dismissed my main problem which is SCD.” 36-45, sickle cell patient from London

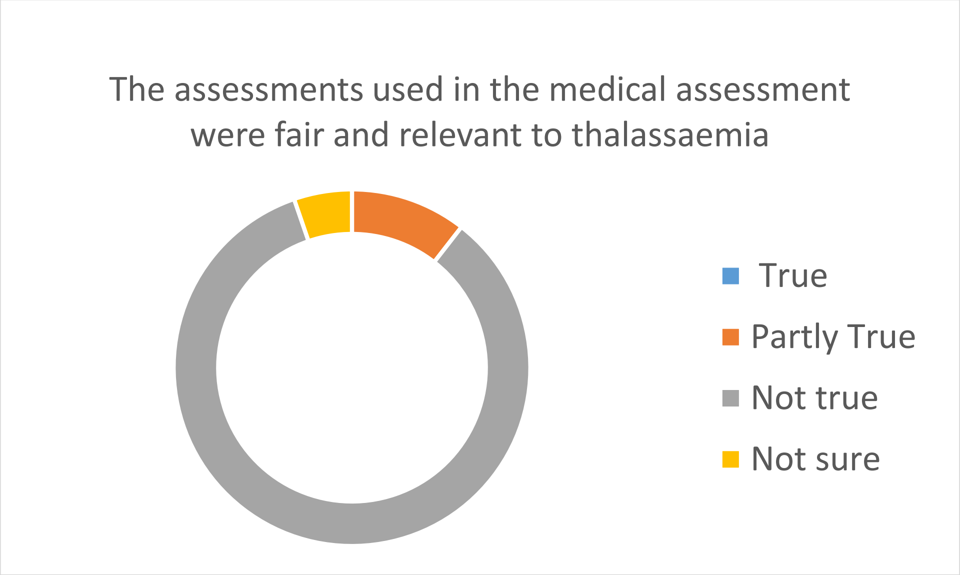
“More time to talk.” 36-45, thalassaemia from the East Midlands

“I feel that the pip medical assessment does not totally cater for or understand the mental and physical implications of day to day living with thalassaemia.” 46-60 thalassaemia patient from the South West.

“My assessor pretended to listen but only heard what she wanted to hear hence she denied my PIP claim despite her saying my situation was scary and I could have died SCD.” 46-60, sickle cell disease from the North West.

As with the ‘PIP2 form,’ members have protested that the assessment is tailored in such a way that their condition cannot be appreciated or factored in. The question of whether **the assessments used in the medical assessment were fair and relevant** was put to them.





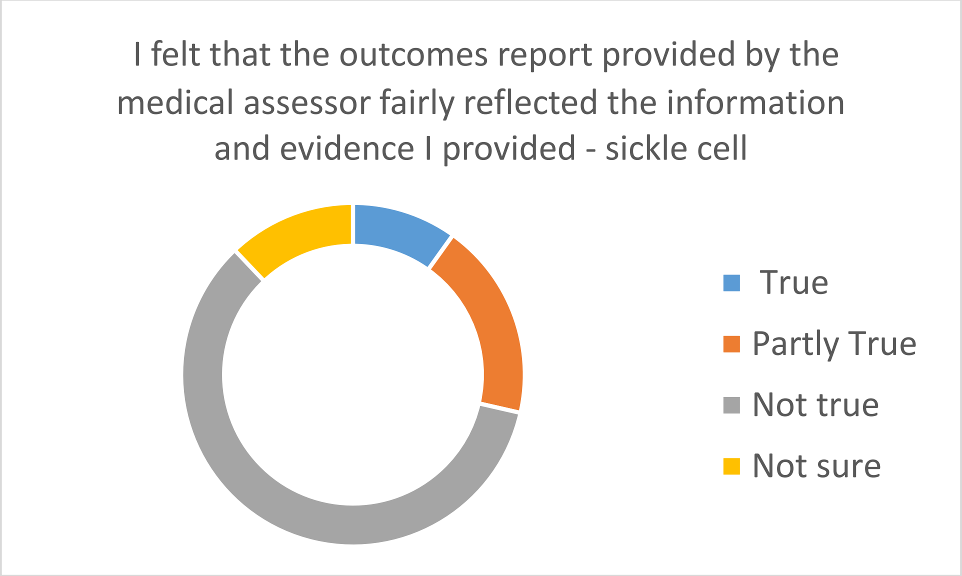
In an incredibly revealing result with 71.4% and 84.2% of sickle cell and thalassaemia patients respectively answering “not true”, members by a considerable margin do not feel that the face-to-face assessments allow them to adequately represent their condition. Members go onto elaborate why is it they feel the face-to-face assessment are by virtue unfair and irrelevant:

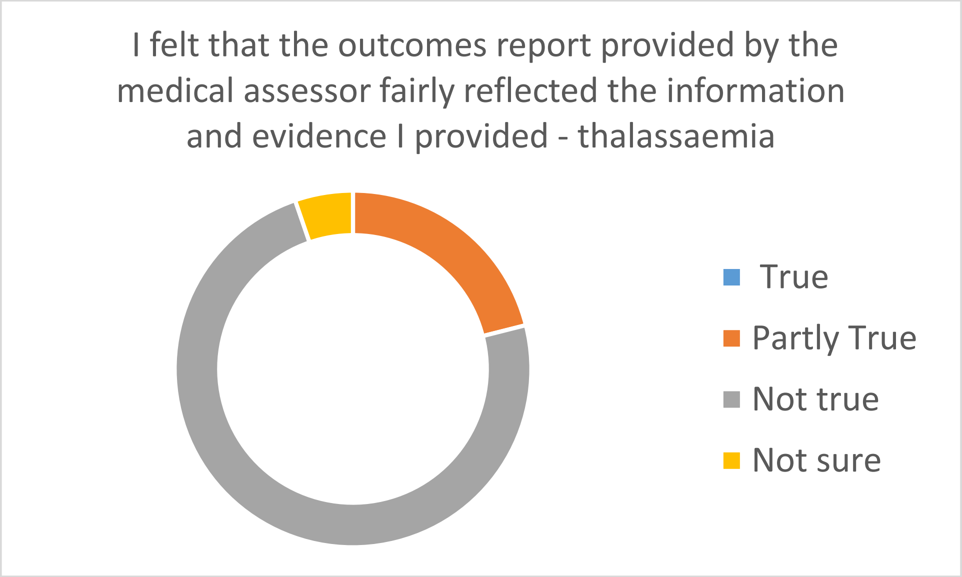
“Criteria too vague and assessor is just doing a box ticking exercise.” 26-35, thalassaemia from the West Midlands.

“Everything. The assessment does not reflect my difficulties as a sickler. The assessment was too generalised and unsuitable for a sickler. 46-60, sickle cell disease patient from London.

“Everything. Stupid questions like 'can you reach your toes' is highly irrelevant to sickle cell.” 26-35, sickle cell disease patient from London.

Members have roundly criticised the medical assessors of inaccurately representing and portraying the assessment; they believe that the record is not a true and fair reflection of proceedings. Hence, respondents were asked whether they agreed with the followings statement: **I felt that the outcomes report provided by the medical assessor fairly reflected the information and evidence I provided**





Again we see a clear verdict with respondents lamenting the accuracy of output from medical assessors. 59.4% of sickle cell patients and 73.6% of thalassaemia patients declared this was the case:

“Nothing or very little of the discussion on the day was reflected in the assessment. It was as if the assessor wrote the report based on someone else or a generic template. It most definitely had no similarities to the conversation we had. The assessment was not a true account of the discussion.

The assessor was honest and acknowledged she had no experience of Sickle Cell Disease."26-35, sickle cell patient from the West Midlands.

"The Mandatory Reconsideration did not re-assess the forms or process. It did not take account of any of the supporting evidence either from Consultants, Sickle cell Society or support from [my] main carer my mother. None of these were given equal weighting they were all overridden by the Assessors views. This is not fair. The report was very biased, discriminatory and based on stereotypes of how someone should look or behave. The process almost penalised me for trying to hold down a job and also trying to use diversional therapy to distract from my pain." 26-35, sickle cell patient from the West Midlands.

"In the declined report after the assessment the assessor had written things that weren't even true & irrelevant e.g. being able to push a door, being able to hold a pen, being able to see with glasses/contacts, was able to study until college!" 26-35, thalassaemia patient from London.

Recommendations

- It is paramount that all assessors have a sufficient level of knowledge and understanding of sickle cell disease and thalassaemia. Time and time again, we hear of members denouncing the astonishing lack of understanding of their condition. Without an adequate level of knowledge, it is 'nigh-on-impossible' for a member to have access to a thorough and meticulous process that is grounded in expertise. All assessors should receive training and education to make this the case, and the Sickle Cell Society and UK Thalassaemia Society are both willing to provide this. This we believe is crucial that our members receive the optimum opportunity to have a fair and just process. Where or not this is possible, it is paramount that at the minimum an assessor must have access and be well versed with the latest clinical guidelines.

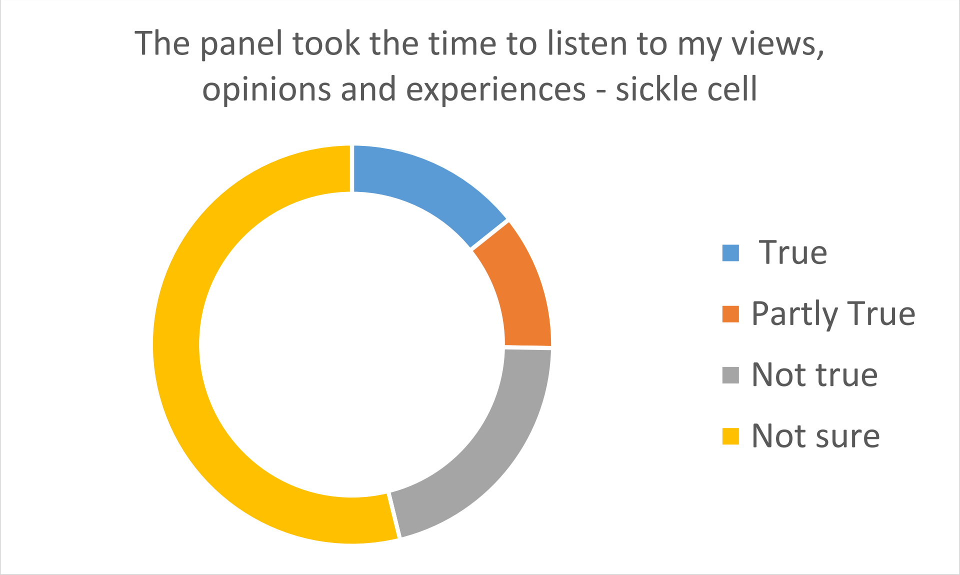
- The DWP should order both ATOS and Capita to video-record and log all face to face assessments and these should be available on request to all parties concerned. At the tribunal stage it can act as supporting evidence to determine whether the initial outcome should be overturned. It is alarming to hear our members express trepidation experienced during these assessments. This countermeasure will mean a definitive record of events which provides security for both the assessor and the claimant. What's more is this will not only improve transparency and accountability amongst assessors it will foster trust in the process as a whole. Ultimately, this will enable for the first time an extensive review into the agency factor of assessors including whether their delivery, style and tone has a material impact on the outcome of cases.

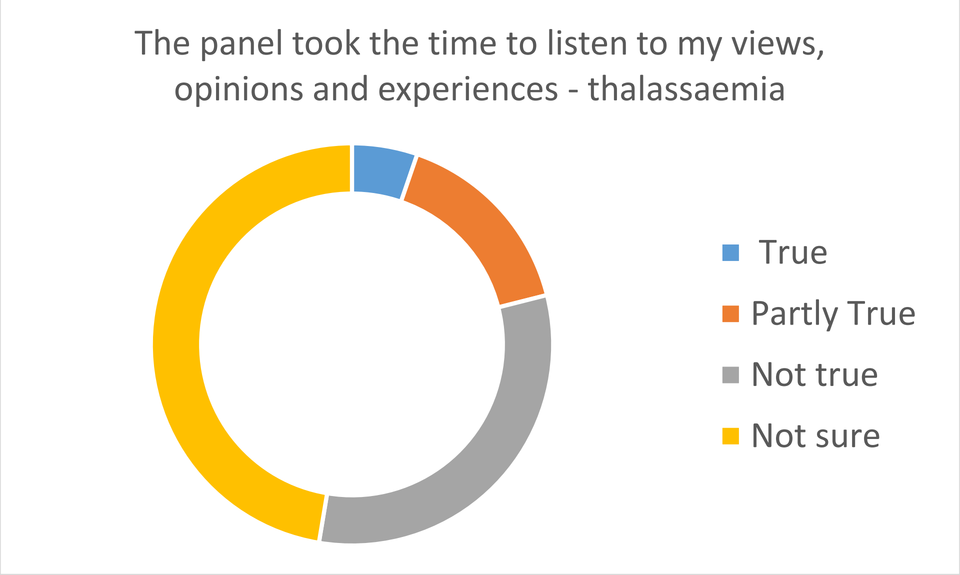
- All assessors irrespective of the extent of their medical proficiency should have professional experience in dealing with vulnerable people. In lieu of this, they should be required to embark on some form of pastoral training. Too many respondents have detailed experiences of assessors whom lack an appropriate level of compassion towards their circumstances, fuelling distrust and disdain in the process. If it was mandatory for all assessors to have a minimum level of aptitude in pastoral care this problem would soon be ameliorated.

Tribunal

Members if not pleased with the result of their mandatory reconsideration can then opt to progress their case to a tribunal. The hearing panel will be a legally qualified judge and up to 2 other independent people, including a doctor. They're called the tribunal board. Someone from the DWP might attend too but only to make their case - they won't be involved in the final decision (Citizensadvice.org.uk, 2018).

Members who have attended a tribunal have been broadly more content with this stage of the process. There have been accounts where many have felt listened to for the first time and had confidence in the panel in being able to understand their condition. However, there have been examples of claimants having to pay out of their own pocket to employ their own litigation reps to fight on behalf of them. What's more, this lengthy process we feel has led to the worsening of some member's conditions. We are saddened that in the pursuit of fairness some people have had to pay the price of deterioration in their condition.





The respondents in line with our thinking asserted that the tribunal stage is an experience which has caused mixed emotions and members echo these sentiments:

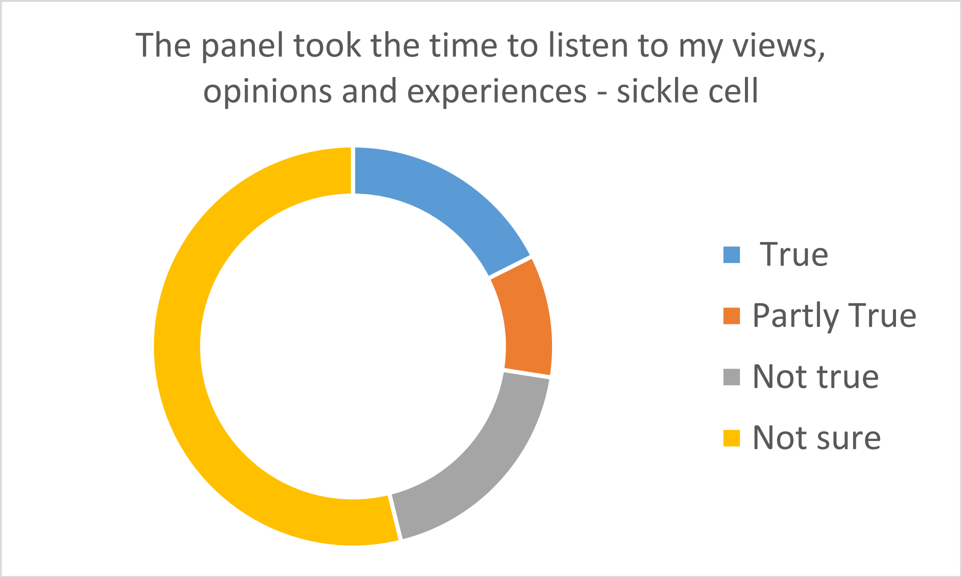
“They talked about other people who have different conditions & how they managed which isn’t helpful. E.g. we have some people who can’t verbally communicate at all. I am not them & that doesn’t mean I don’t have trouble communicating.” 26-35, sickle cell patient from the East Midlands.

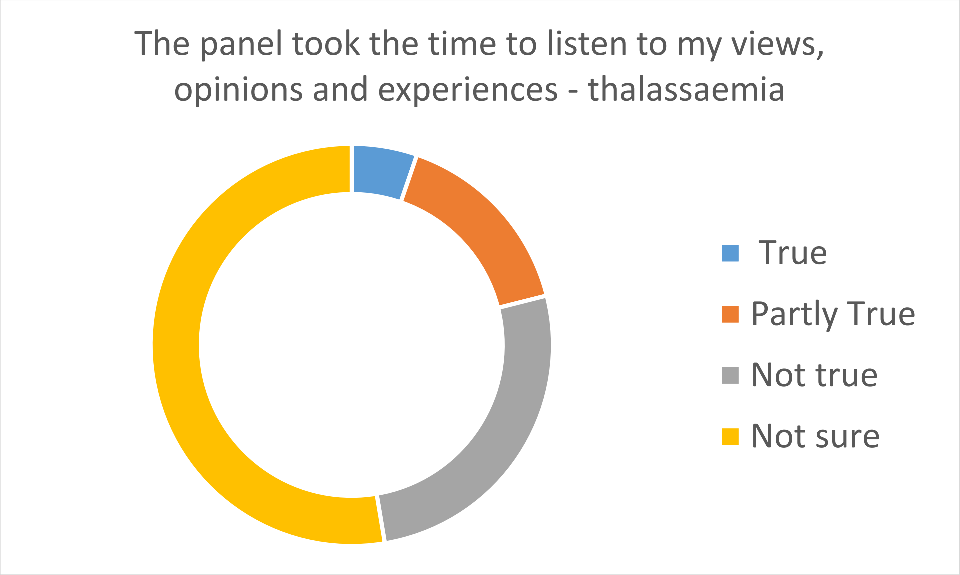
“Nothing was good because they make you feel that you’re cheating the system. How can a patient with a lifetime illness who is dependent on regular blood transfusions and other medications want to lie about their condition?” 46-60, thalassaemia patient from London.

“It gives a fair hearing and based on one’s knowledge you can convince the panel. This should not be the case though because the condition is inherited and I am sure it’s not the case for other chronic health conditions.” 16- 25, sickle cell disease patient from London.

“Yes I was as the panel listened. But, I had to employ a litigation rep to fight the case on my behalf as I didn't know how to fight this system. Obviously, my legal rep. had to be paid from my win backlog. It disrupted my whole life and caused me more crisis incidences including depression. I was turning into a social recluse as I was unable to leave my home. My health deteriorated that crisis were re-occurring and due to lower immune, I had more crisis that were triggered by infection and anxiety respectively. However, this independent tribunal had to put things back in place despite the disruption.” 46-60, sickle cell disease patient from London.

Respondents were asked if they agreed with the following statement: **The panel took the time to listen to my views, opinions and experiences:**





Again we see a picture which points to a varied of experience of the tribunal, but what has become clear is that there is a positive correlation between expertise of the agents carrying out the process and member's approval of the process. Members have highlighted these opinions in more detail in free text responses:

“I'm not sure if the 'Disabled' expert was knowledgeable of my SCD condition. It was a stressful process that it exacerbated my condition that 2 days later my body went into a panic crisis attack. You are in front of a panel to justify why you were born with a disease that you have no control or no choice when the crisis shuts the body down due to extreme pain and side-effects of illness and drugs.” 46-60, sickle cell disease patient from London.

“My husband was treated like a child and was not allowed to give evidence. I have severe anxiety and they made me answer all the questions without help even though I was crying.” 16- 25, sickle cell patient from Wales.

“The Doctor on the panel really listened to me and how sickle cell affects me he was understanding and empathetic.” 16- 25, sickle cell disease patient from the West Midlands.

“I was eventually heard.” 26-35, thalassaemia patient from the East Midlands.

“The Panel gave me time to explain my condition. They didn't lead my questions. It gave me the independence to explain my condition rather than the assessment that is set to lead or trap your answers to a 'Yes' or 'No' conclusion. There was a medical Doctor on the panel and a 'so-called' disability expert. I'm not sure if that was good.” 46-60, sickle cell disease from London.

Recommendations

- The judge should allow the appellant (claimant) to nominate a proxy to make the case for appeal against the respondent (DWP). Though we realise that at present members are allowed to have family and friends accompany them and make a short statement, we feel this still falls short. Too often have we been informed of members who have difficulty effectively communicating feeling that they have been mistreated by the panel. Hence, they believe that they have not been able to offer a true reflection of the reality of their condition. By permitting close family and friends to act on their behalf, their experiences and hardship can be conveyed in an articulate manner.

- We feel as with the face-to-face assessment, all on the panel should receive training and education in sickle cell disease and thalassaemia. In addition, at the very minimum those on the panel must have access and be well versed with the latest clinical guidelines. Hence, tribunal proceedings will possess critique that is based on specialised knowledge; this will maintain continuity which translates into a consistently high level of scrutiny. Furthermore, members *en masse* have informed us of sustained questioning on their knowledge of their condition; the level of understanding that a claimant has of their condition should have no bearing on the outcome of their case. This worrying trend of a seemingly irrelevant line of questioning, if not to 'test' the claimant, we fear is to educate the panel themselves. Either way this practice is unnecessary and deeply concerning. One questions whether the same line of questioning would be levelled at a cancer patient.

- A compensation scheme to reimburse the costs of the tribunal process. Members have told us that they have had to employ litigation reps due to the convoluted, complex and exhaustive process and this requires full recompense. Moreover, members have at great length informed us of the emotional toll they have been subject to because of the process. Therefore, the scheme has to account for the psychological trauma, stress and anxiety the tribunal has caused which in some cases has led to the worsening of people's conditions. We would expect a judgement be made case by case on the amount of compensation warranted. The compensation would only be applicable if the appeal was successful.

Conclusion

We do hope this report has comprehensively provided the evidence that the current system is failing our service users and highlights the next steps which ought to be taken to ensure everyone receives a fair and just process. The current state of play is avoidable and we strongly urge that the recommendations made are fully embraced so that those who deserve help are given it.

Queries

For any queries about the report or to find out more information please contact the author Adam Lloyd at adam.lloyd@sicklecellsociety.org

Bibliography

Citizensadvice.org.uk. (2018). *Challenging a PIP decision - the tribunal hearing*. [online] Available at: https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/appeals/your-hearing/

Government's response to the consultation on Disability Living Allowance (2018) [online] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/181637/dla-reform

Standards for the clinical care of adults with sickle cell disease in the UK. (2018). London: Sickle Cell Society.

Disabilitybenefitsconsortium.files.wordpress.com. (2018). [online] Available at: https://disabilitybenefitsconsortium.files.wordpress.com/2017/09/supporting-those-who-need-it-most-full-report.pdf [Accessed 21 May 2018].

Legislation.gov.uk. (2010). Equality Act 2010. [online] Available at: http://www.legislation.gov.uk/ukpga/2010/15/contents [Accessed 11 Jan. 2015].

(Secretary of State for Work and Pensions, Statement on not going ahead with changes to Personal Independence Payment (PIP), March 2016). www.gov.uk/government/uploads/system/uploads/attachment_data/file/516954/ secretary-of-state-for-work-and-pensions-statement-on-not-going-ahead-with-changes-to-pip-21-march-2016.pdf