



**INVESTIGATION INTO THE IMPACT OF PRESCRIPTION CHARGES
FOR THOSE LIVING WITH SICKLE CELL AND THALASSAEMIA**

END THE BLOOD TAX

**AUTHORED BY
SICKLE CELL AND THALASSAEMIA ALL-PARTY PARLIAMENTARY GROUP (SCTAPPG)**

About us

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



The Sickle Cell and Thalassaemia All Party Parliamentary Group (SCTAPPG) raison d'être 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 striving to reflect the concerns of their membership and to act as a vehicle for change.

The Sickle Cell Society (SCS)

The Sickle Cell Society (SCS) is the only national charity in the UK that supports and represents people affected by sickle cell disease to improve their overall quality of life. The Society's mission is to enable and assist individuals with a sickle cell disorder to realise their full economic and social potential. The Sickle Cell Society (SCS) has been in existence since 1979 and has amassed a wealth of experience in sickle cell not only in the U.K. but through its network and association with other countries. This year marks the 40th anniversary of the Sickle Cell Society.



End the Blood Tax – Investigation into the impact of prescription charges for those living with sickle cell disorder and thalassaemia

Background

There are countless anecdotal reports from qualified nurses, doctors, other allied health care professionals and most significantly service users about the effect of prescription charges on the day-day lives of service users. This has provided an insight into the struggle and human cost that endless prescription charges present to those living with sickle cell disorder and thalassaemia. The Sickle Cell & Thalassaemia All Party Parliamentary Group (SCTAPPG) set out to research this area in the hope of shedding light on what is an effective tax on blood, and a tax on sickle cell disorder and thalassaemia. It will offer an insight into the real life experiences of those living with sickle cell disorder and thalassaemia and how prescription charges impact their daily lives.

An ongoing vehicle for the campaigning for exemption of long-term health conditions, of which the Sickle Cell Society is a member of, has been the Prescription Charges Coalition (PCC) who have sought to address the impact of prescription charges on the working-age population with long-term conditions in England. Research carried out by the Coalition has found qualitative evidence that prescription charges for working-age people with more than 40 long-term conditions can have a significant impact on medicine adherence, self-management, quality of life and health outcomes. Whilst those over the age of 60 are exempt from prescription charges, since 2010 the prescription charge has risen 26% by £1.60 to £8.80 in 2018 compared to a rise in average earnings over the same period of 16%. The impact of prescription charges on working age people has therefore been increasing.” (Hex et al, 2018, p.1) This landscape is now only bleaker with prescription charges now at £9 and real wages remaining stagnant.

“In a system that has largely upheld the principle of healthcare being free at the point of access, prescription charges have always been controversial. They were first introduced into the NHS in June 1952 for each prescription form, and then in December 1956 for each prescription item. In March 1965, charges were abolished, only to be reinstated in June 1968, which was also when the extensive exemption arrangements that remain largely in place today were introduced. Annex C provides a list of the current exemptions. Prescription pre-payment certificates were also introduced in 1968, in order to help those patients with long term conditions that were not included on the medical exemptions list. In 1975, there was a further extension to the exemption arrangements with the introduction of charge-free contraceptive drugs and appliances. The only further change to the medical exemption categories occurred earlier this year, when the new exemption for patients receiving treatment for cancer, or for the effects of cancer treatment, was introduced.” (Gilmore, 2009, p.7)

In recent years, there has been a broad political consensus that the current system is unfair as some long-term conditions qualify people free prescriptions whilst others don't. This sense of unfairness has been exacerbated since the introduction of free prescriptions for people living in Wales, Scotland and Northern Ireland.

Notwithstanding the moral argument that no person should be financially penalised for a condition that it is through no fault of their own. It is extremely apparent that there is an economic case for exemption. The PCC commissioned the York Health Economics Consortium and they found that for “working-age people with Parkinsons Disease (PD) and Inflammatory Bowel

Disease (IBD) who are not exempt from prescription charges, the economic analysis suggests that any loss in prescription revenue from removing charges would be more than offset by savings to the NHS in England. For PD this results from reduced hospital stays and A&E visits resulting from individuals' inadequate adherence to medication due to cost reasons when prescription charges are in place. For IBD, this relates to reduced levels of relapse/flare, and an associated reduction in the incidence of colorectal cancer and number of GP appointments." (Hex et al, 2018, p.2)

Consequently, successive governments failure to act decisively on this issue on the grounds of fiscal rectitude and responsibility seem hollow. Though we do not have as a rigorous evidence as mentioned we would expect this economic trend to be consistent with most longer term conditions including both SCD and thalassaemia

The objective of the research is to enable our service users to have a voice in this debate and provide a condition specific analysis of how prescription charges affect their day-day lives. We hope this report can serve to add the mounting body of evidence, which is as clear as it is vital, to exempt those with long term conditions from these charges.

Sickle Cell campaigning

There is currently an online petition on <https://petition.parliament.uk/> made by Amoafi Kwamong which calls for the government to Provide prescription payment exemption for people with Sickle Cell Anaemia. It gained 12,604 signatures surpassing the 10,000 mark which required the government to respond:

“ There are no plans to review the list of medical exemptions from NHS prescription charges. However, extensive arrangements are already in place to ensure people can access affordable prescriptions. ”

Review of Prescription Charges Review: The Gilmore Report

We believe the Gilmore review does not go nearly far enough and its approach presents a litany of potential flaws. It rallies against allowing the exemption list to be *“extended to include a much wider range of conditions that are long term in nature”* and instead *“the exemption should be based on a broad definition of a long term health condition that is based on duration (at least 6 months) and the need for some form of continuing management (which might include regular medication; periodic monitoring and review; psychological therapies).* The idea that the definition of long term health condition should be reviewed in the aforementioned way is to be welcomed, however, Gilmore's proposal for this to be a *“matter for clinical judgement and in most cases, though not always, it is likely that the patient's General Practitioner (GP) will be best placed to fulfil this role.”* We consider this to be ill-advised, though on the surface allowing the primary care give the responsibility sounds sensible, the risk of relying on the agency of GP's could give rise to a heterogeneous application of this criteria. Furthermore, Gilmore concedes *“the danger is that this system could be burdensome, with hidden costs, for example in terms of GP time, which mean that the overall costs of administration are disproportionate to the level of income raised.”* Health professionals work load is only ever increasing and to entrust them with more responsibility could take away from them administering primary care. Gilmore, goes further and in his concluding remarks urges the government should *“keep an open mind towards abolishing prescription charges altogether.”* It is clear that Gilmore recognises the difficulty of root and branch reform in prescription charging

arrangements, and does concur and empathise with the growing appetite for abolition. We believe that a simple evolutionary step would be to grant exemption to all long term health conditions, even if the definition as Gilmore states needs to be reviewed. (Hex et al, 2018, p.1-6)

Key Findings

- **70.1% of respondents informed us that they had used either savings, an overdraft facility or a payday loan to be able to afford their prescription.** This illustrates that the current situation is not sustainable, all three of these solutions have drawbacks. The use of savings acts as a penalty and fosters financial insecurity. Pay day loans possess extra exorbitant charges which only serve to rise indebtedness. It should not be the case that anyone shouldn't be able to meet their most basic health needs, however currently this is how the system exists.
- **Awareness of the prescription prepayment certificate (PPC) is quite high with 71.4% of those surveyed being familiar with its existence, however this still isn't high enough. The 29.6% who aren't aware are paying much greater prices they have to over the counter in the long term.** The barometer of success of the PPC is only as good as how many people are aware of it and currently the NHS is falling short within the sickle cell and thalassaemia communities.
- Despite awareness being moderately high, the questionnaire showed that take up was sluggish in comparison. **63.5% of respondents did not use the PPC which suggests that even in spite of our respondents being aware of them they weren't utilising the facility. Moreover 44% of the cohort said they couldn't afford the cost of the PPC and 17% said that the PPC wouldn't actually save them money.** Clearly the PPC isn't the magic bullet many believe it to be.
- **88% of respondents asserted that they either always or sometimes had difficulty with their prescription payment.** This exists for both those who purchase the PPC and pay the £9 charge and illustrates that the system systematically causes stress and difficulty to those with sickle cell and thalassaemia. Furthermore, the consequence of it being difficult leads to people making cutbacks. For example, **87.7% of the cohort said they had to sacrifice leisure time in order to afford the prescription.** This decrease in leisure activity can have negative effects on wellbeing and is directly caused by the burden of prescription payments. Even more worryingly around half of those who were questioned for the survey also disclosed that they'd been forced to cut back on essentials for living such as bills and food. **Finally, 16.7% of respondents had even delayed or cutback on rent payments to be able to afford medicine.**
- **Over half of the cohort (52%) revealed that they had infrequently or sparingly taken their medicine due to the cost.** This is in direct contradiction of doctors' orders who have clear advice on the most effective amounts of medicine. This illustrates the impact of burgeoning prescription costs and how people are being forced to choose between their health and their economic security. Moreover, people not being sufficiently medicated leads to strain on primary care services, therefore making this an economic as well as moral tragedy.

- Participants were invited to articulate what their thoughts were on prescription charges and how it affected them via short text responses, below are a small sample:

“When I was a student, paying the yearly prepayment cost was more difficult and would affect how I spend money on other things” remarked a 30-39 female from Yorkshire.

“I have been on the same medication for the last 22 years and since the age of 16 I've had to pay for them and I know I am on this medication for life, I have used credit cards to make the payments for prescription so I can pay a month later, I feel that as a tax and NI payer I should not have to pay for my medication when my condition can be life threatening” commented a 30-39 male from East Midlands.

“It is unfair that SCAT patients should have to pay for their regular prescriptions seeing as it is a long term health condition. It can be difficult to pay especially if you are a student like myself and then you have to cut back which affects your health” stated 19-29 year old from West Midlands.

Courteney’s Story

My name is Courteney and I’m 21 years old and I live with sickle cell anemia. This is a long term health condition that can & does effect most areas of my life. The condition itself is genetic and some of its symptoms can include chronic pain, fatigue and mobility issues.

Sickle cell is a very unpredictable condition, pain can be brought on by elements such as the weather, change in temperature, stress, or something like a simple cold, and many people living with sickle cell will at some point in their lives have one or more complications which will require ongoing treatment & care.

I only truly learnt about these charges in the last year or so. I personally rely on 5 main tablets to help maintain control over my condition, Paracetamol, Neurofen & Codeine, Folic acid & Penicillin these are tablets I need topping up every month.

My 1st experience with this issue was, as usual, I went to the pharmacy counter and was thoroughly shocked to see my bill came to nearly £45, this amount every month is £540 a year on medication alone.

Now I’m lucky to have just gotten my first real job after graduating which allows me to be able to keep up with these prices, but for those that don't, for those young people who have such chronic pain that they don't have the opportunity to work or parents who have to stay at home with their children because of the impact of sickle cell, £540 or more a year is an impossible figure.

But this is based on only five medications, imagine those that on 7-15 and have to pay for each. So now one can see how sickle cell can have devastating socio-economic effects on individuals & their families.

Not to take away from their struggles but those with conditions like cancer or diabetes don’t have to pay for their medication and why... because it's understood and perceived as a true disability, and of course it would appear inconsiderate to charge someone, whose life is deeply affected by something they have no control over, to then add an additional burden with prices like these for medication that is needed for manageable pain control. The issue lies in the fact that sickle cell is not viewed as a true disability, which would entitle us to free prescriptions.

Sickle cell is a life threatening condition, it’s unpredictable, requires long term treatment and regular pain relief medication. It can cause organ & bone damage, strokes, cardiovascular issues and so on.

So why are we different, why is someone who's born with sickle cell, something that affects us every day and is incurable, any different to others who are entitled to free prescriptions, the truth is we aren't.

To stop this issue becoming a greater problem, like sicklers no longer purchasing much needed medications and having to go to the hospital more often, which in itself is a greater expense.

See Appendix 1 for full data set & methodology

Recommendations

In view of the outcome of this survey, SCTAPPG make the following recommendations:

- SCTAPPG would echo the Prescription Charges Coalition's recommendation and petition the Department of Health and Social Care (DHSC) to immediately grant exemption to sickle cell disorder and thalassaemia along with all other long-term health conditions.
- DHSC should honour the Gilmore review's recommendation to shift to a definition "*based on a broad definition of a long term health condition*", it however is ill-advised to endow the primary care giver the responsibility to cast judgment on whether exemption should be granted. As the risk of relying on the agency of GP's could give rise to a heterogeneous application of this criteria. DHSC should launch an independent review with service user engagement at the heart of its decision making to establish which conditions qualify as long term conditions and hence qualify for exemption. Subsequently, an annual review to widen and hence grant new exemption should take place.
- DHSC should be more far more ambitious than the Gilmore review's recommendations, and commit to the abolishment of prescription charges in the long term.
- In the meantime, NHS England should announce a new information campaign to raise awareness of the Prescription Payment Certificate (PPC). It is abundantly clear, however, that this is not the magic bullet as advocated as those who do know about it are still not in a position to afford it. It is described as a 'season ticket' but if your cash flow means you can't afford a 'weekly return' then it serves no purpose. Consequently, it is imperative for an information campaign to be carried out in conjunction with a move to make PPC more affordable.
- The NHS Business Services Authority (NHSBS) offers a Direct Debit for a 12 month PPC - this is a commitment to pay all 12 payments without a break clause. This inflexible arrangement should be made to have a holistic exit clause.

Conclusion

The data suggests that the current system is not fit for purpose, our members are effectively being taxed for the blood they have and were born with. We are calling for an end to the blood tax. It is evident from the key findings that prescription charges are having a seismic impact on the financial security of many. This in turn is having a discernible and verifiable effect on the wellbeing of service users. The dire and dangerous health consequences due to a lack of medicine adherence is in solitude enough of a reason to end this tax. A choice between financial security and quality of life should not be mutually exclusive. In effect the current prescription charge is a Hobson's choice with no real choice but to pay this tax and hence for our members to be left in a precarious pecuniary state. The PPC does not offer enough of an avenue for service users to navigate their way through this dilemma. Ultimately, the economic analysis carried out on other long term conditions have added credence that an end to this regressive tax would ironically raise funds for the exchequer

effectively paying for itself. A healthier workforce would mean increased productivity and decreased reliance on benefits, this in tandem with less additional treatment and fewer hospital admissions would translate into lower public spending. Prescription charges for sickle cell and thalassaemia patients are crucially significant as they tend to struggle to qualify for benefits as the requirements don't seem to cater to disabilities that include intermittent asymptomatic states. As many patients are unable to work, this is an extra financial burden that enhances stress and anxiety which can only serve to worsen service users condition. If this burden can be lifted, it will aid our service users quality of life and ease the financial strain on those who may not be able to provide for themselves. We urge to the government to heed the calls of so many in a dire need of a helping hand, and end the blood tax.

References

Hex et al, 2009, Economic Evaluation of the Benefits of Extending Free Prescriptions to People with Long-Term Conditions. 2018,
www.prescriptionchargescoalition.org.uk/uploads/1/2/7/5/12754304/economic_evaluation_report.pdf.

Gilmore, 2009, Prescription Charges Review Implementing Exemption from Prescription Charges for People with Long Term Conditions
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213884/dh_116367.pdf

Appendix 1

Survey Process and Outcome

Methodology

In order to determine the impact that prescription charges were having the SCTAPPG commissioned a survey which was then distributed to sickle cell and thalassaemia service users. In order to increase the reliability of results the survey was distributed widely throughout communities to get as many responses as possible, the use of convenience sampling made this possible. We had a response of 80 people, primarily through accessing the networks of patients groups and encourage them to share the questionnaire

The design of the survey was built upon the work that Asthma UK had done in this area and sought to apply these issues to the sickle cell and thalassaemia communities. The survey looks at both the impact of the Prescription Payment Certificate and that of over the counter charges and seeks to look at how these effect people economically and in terms of their wellbeing

The survey report is authored by Adam Lloyd

The data collected was secure, protected, and covered by the privacy statement outlined on the Sickle Cell Society website, which adheres to the latest GDPR regulations. All respondents' information is confidential and hence they will not be made identifiable in the analysis that follows.

Results of Survey

Participant Population

Pie chart 1, 2 and 3 below illustrates the composition of the participants that made up the data set. The respondents as discernible from the evidence are regionally diverse. The data size allows us to be sure the sample size is adequately representative of the national picture. Unsurprisingly a large section of the cohort was based in London, this was presumably due to the high prevalence of those with both sickle cell and thalassaemia in the capital. Further expansion of the cohort will seek to get more representation from all regions of the United Kingdom We presume that the data would look much bleaker if we'd had engagement from rural areas where the prevalence of SCD and thalassaemia would be much lower due to the smaller minority ethnic population in those areas.

Chart 1 – Gender of participants

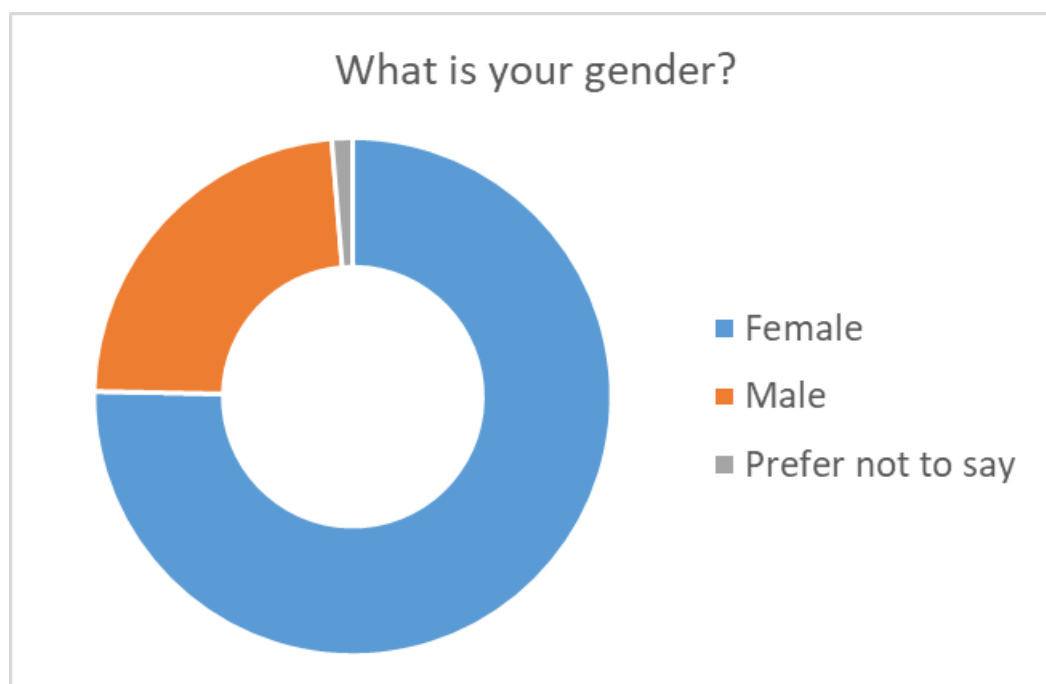


Chart 2 – Age of participants

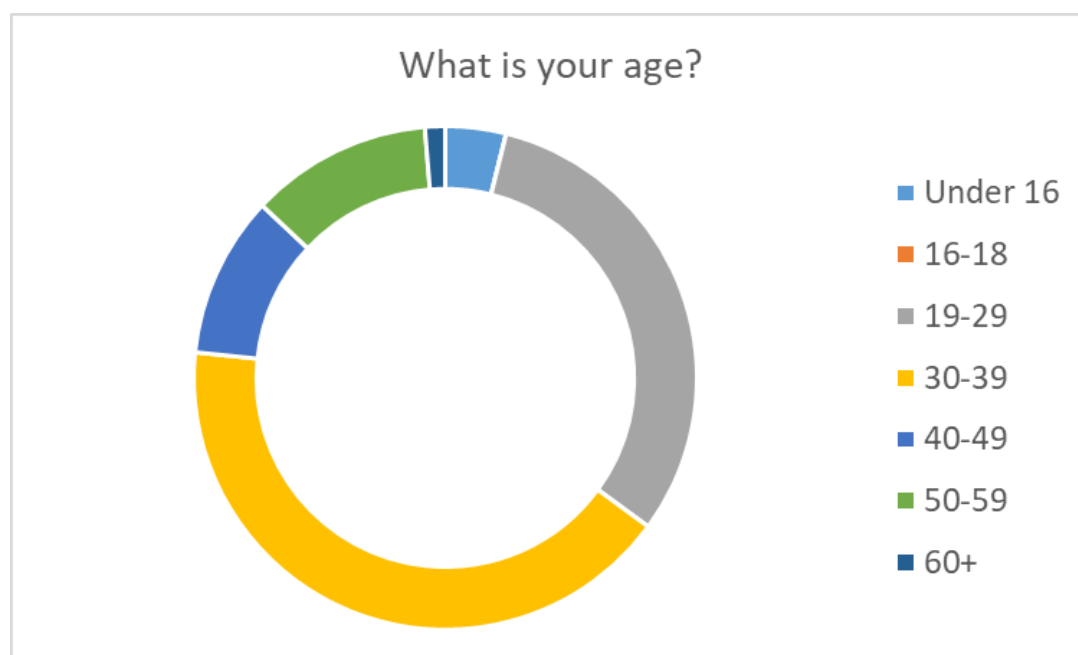


Chart 3 – What region of UK participants are from?

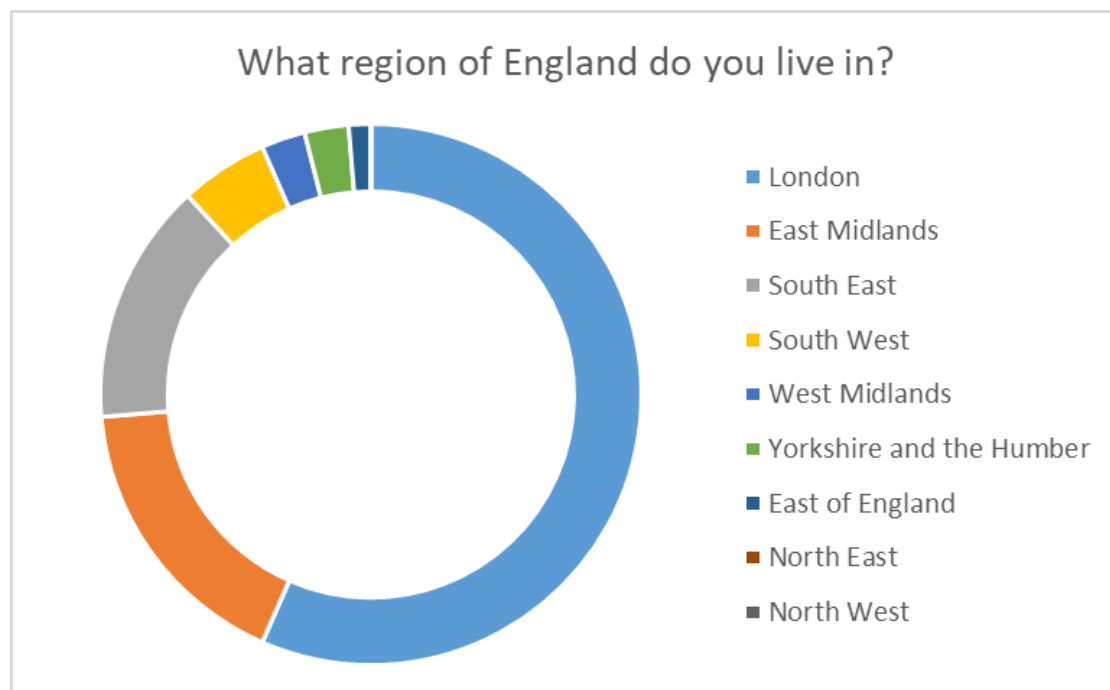


Chart 4 - Annual income of participants

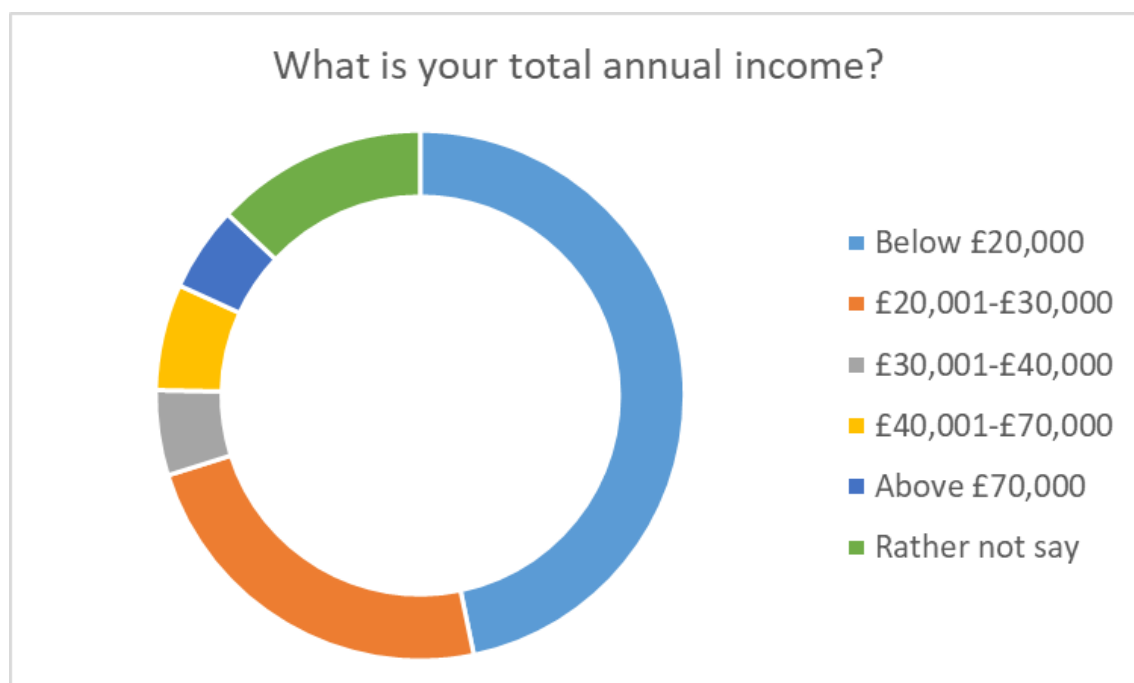
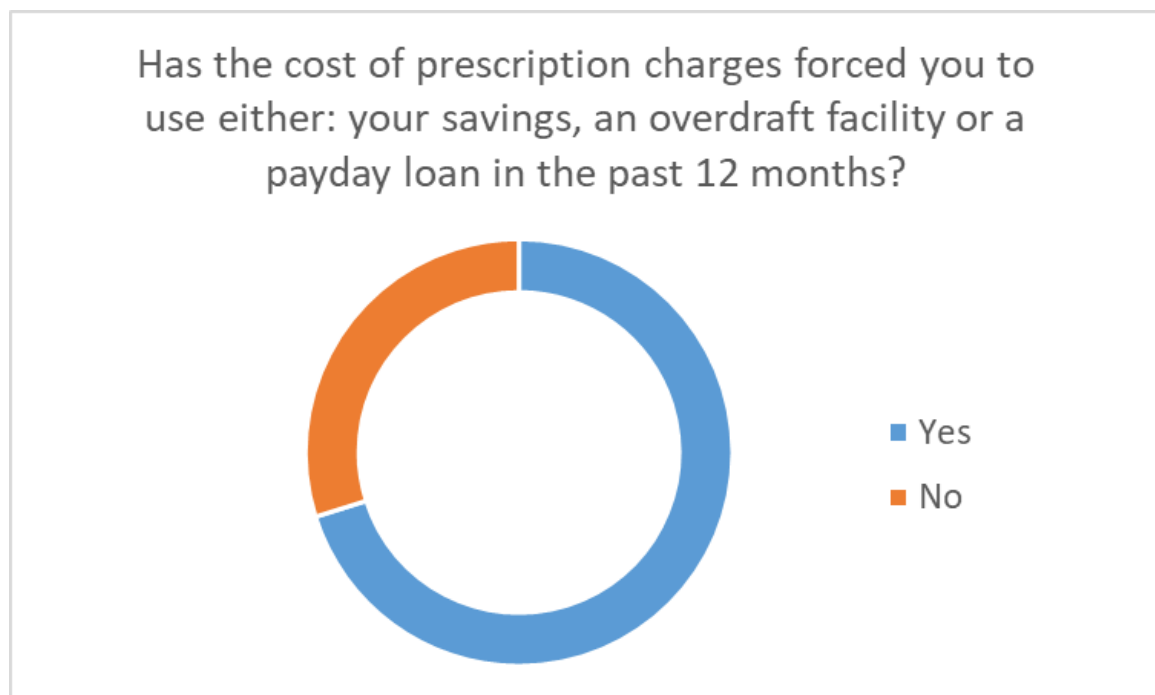


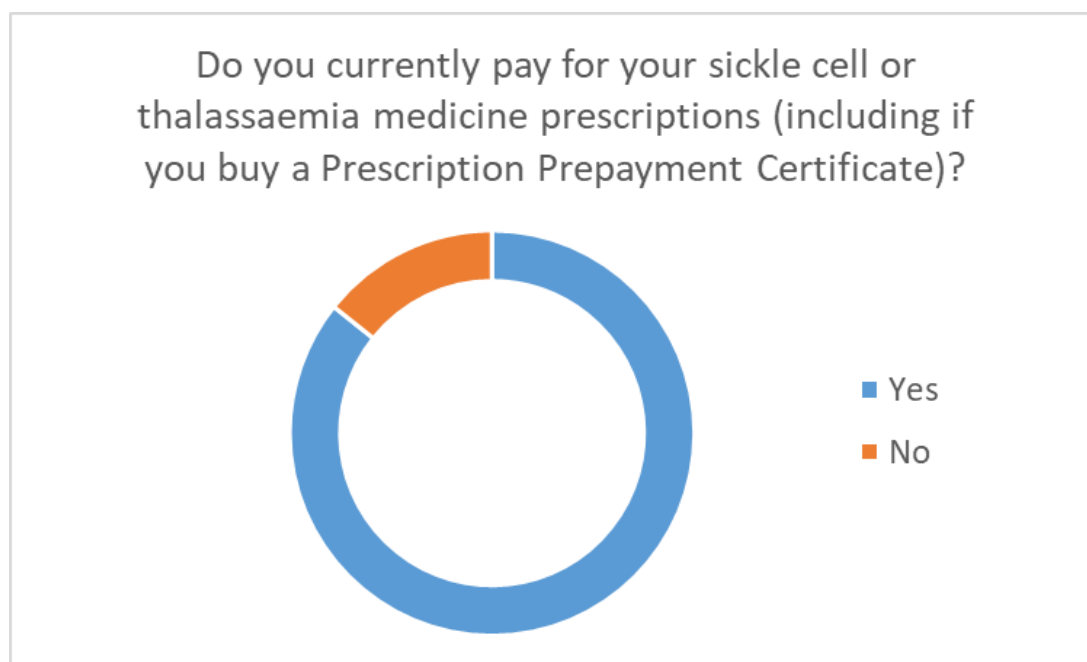
Chart 4 above shows the income distribution of the cohort. It shows that 46.8% of those surveyed have a total annual income of less than £20,000. Those earning an income of this level are likely to be living pay-cheque to pay-cheque and often precariously. Therefore, the presence of a flat £9 prescription fee is likely to have an impact on the finances of sickle cell and thalassaemia sufferers. These fees are regressive as they cost the same regardless of one's income and as a percentage of income cost more for the poorest.

Chart 5 - Impact of prescription charges on the need to use overdrafts, savings or payday loans



70.1% of respondents informed us that they had used either savings, an overdraft facility or a payday loan to be able to afford their prescription. This illustrates that the current situation is not sustainable, all three of these solutions have drawbacks. The use of savings mean they can't be contributed to other goods and both overdrafts and payday loans have extra charges which indebt the users more. It should not be the case that anyone shouldn't be able to meet there most basic health needs, however currently this is how the system exists. Moreover, the cost of these prescriptions clearly makes sickle cell and thalassaemia users financially vulnerable but this often feeds into stress about their economic wellbeing which has impacts on mental health

Chart 6 - Amount of participants paying for prescriptions



A slim minority of those who responded (14.3%) didn't have to pay for their prescriptions, this is positive and means the burden of prescriptions isn't on them, however it does leave a large majority beholden to the cost of these prescriptions. Those who do not have to are exempt for a plethora of reasons, which include: pregnancy and being either below 18 or over 65. It is the aim of this report to extend this benefit to everybody with sickle cell and thalassaemia.

Chart 7 - Participants awareness of Payment Prescription Certificates (PPC's)

Awareness of the PPC is quite high with 71.4% of those surveyed being familiar with its existence. This then suggests that therefore the issue isn't the communication of this service and its success or failure for patients relies on its own merits. However, there is still more that can be done given that 29.6% weren't aware

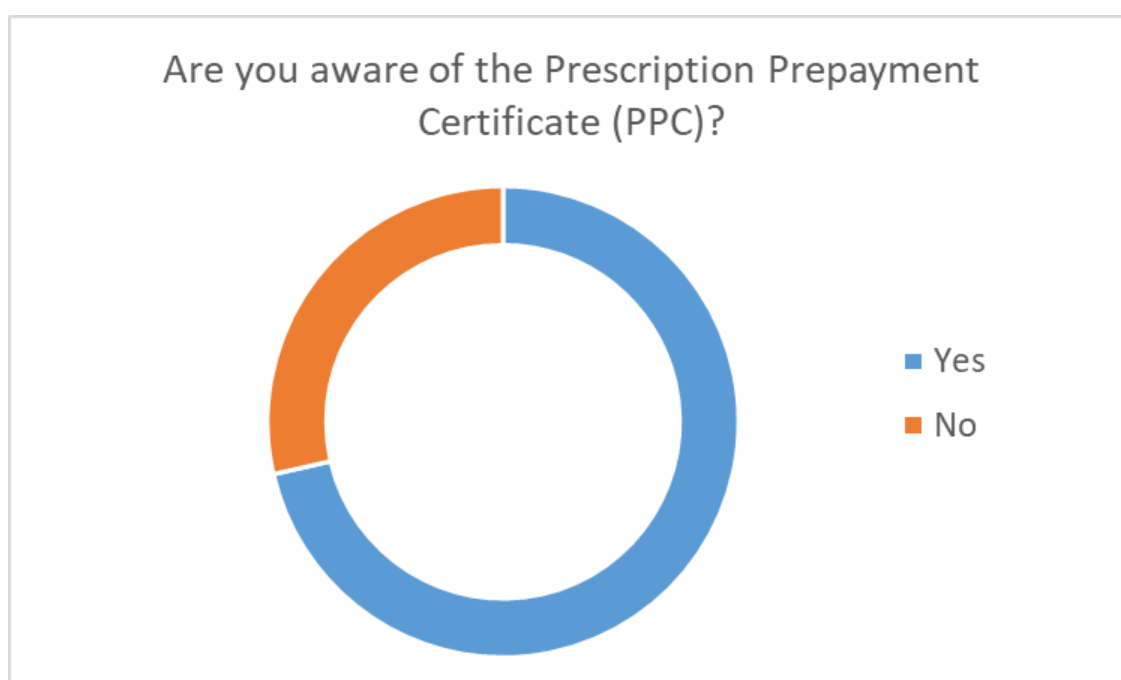
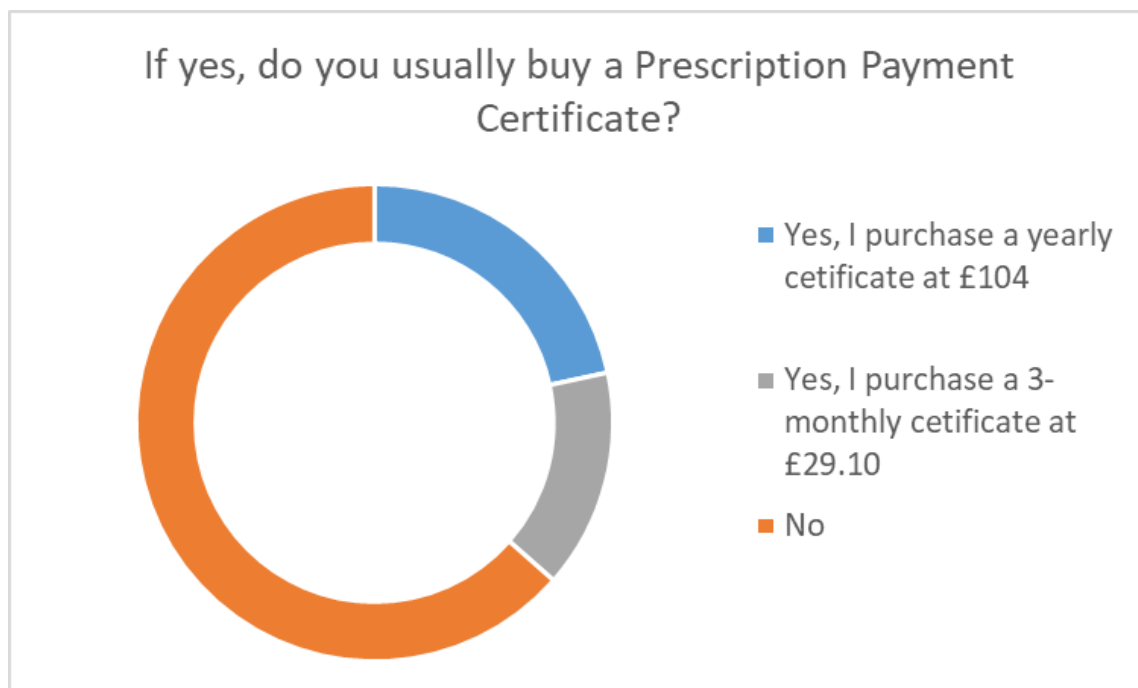


Chart 8 - Number of participants using PPC's



Despite the high awareness of the PPC's as illustrated in Chart 7, Chart 8 sheds more light on the amount that choose to utilise the facility. In answering this question 63.5% of respondents did not use the PPC which suggests that even in spite of our respondents being aware of them they were not suitable for them. Moreover, there was split in those who did purchase them with 21.6% of respondents purchasing the yearly certificate and only 14.9% opting for the 3-monthly option. This is presumably accounted for by the yearly option being available at a cheaper monthly rate.

Chart 9 - Participants explanations for not purchasing a PPC

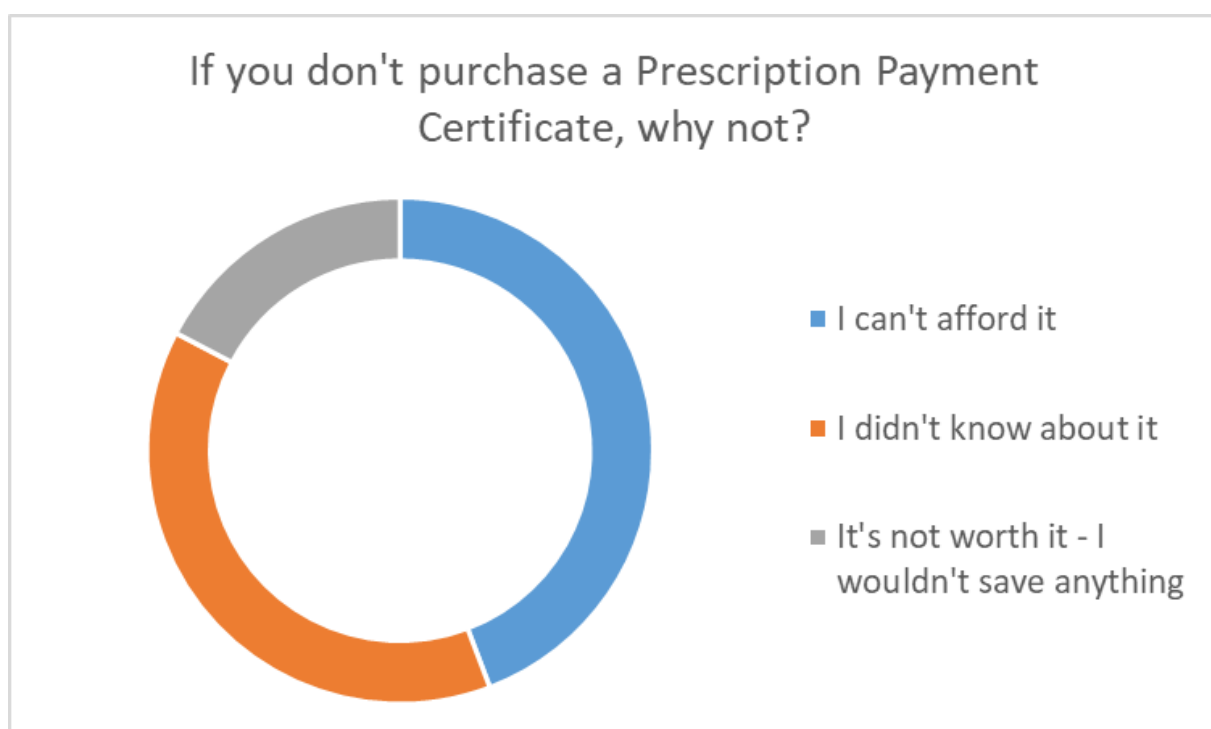
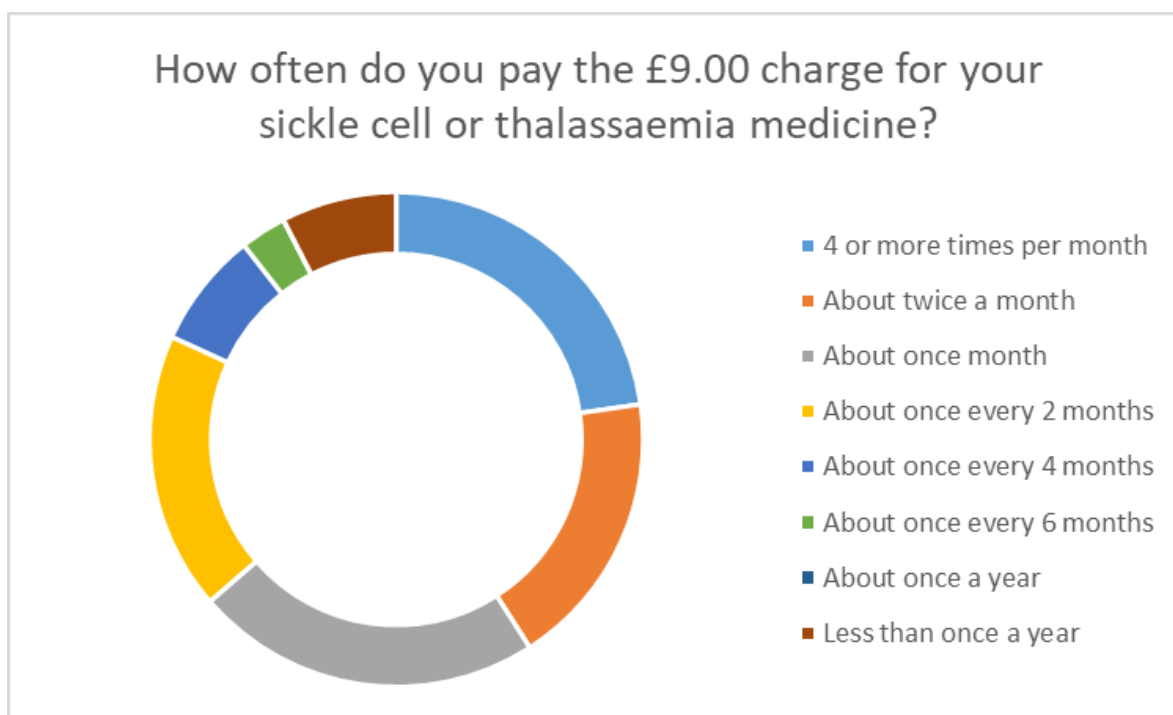


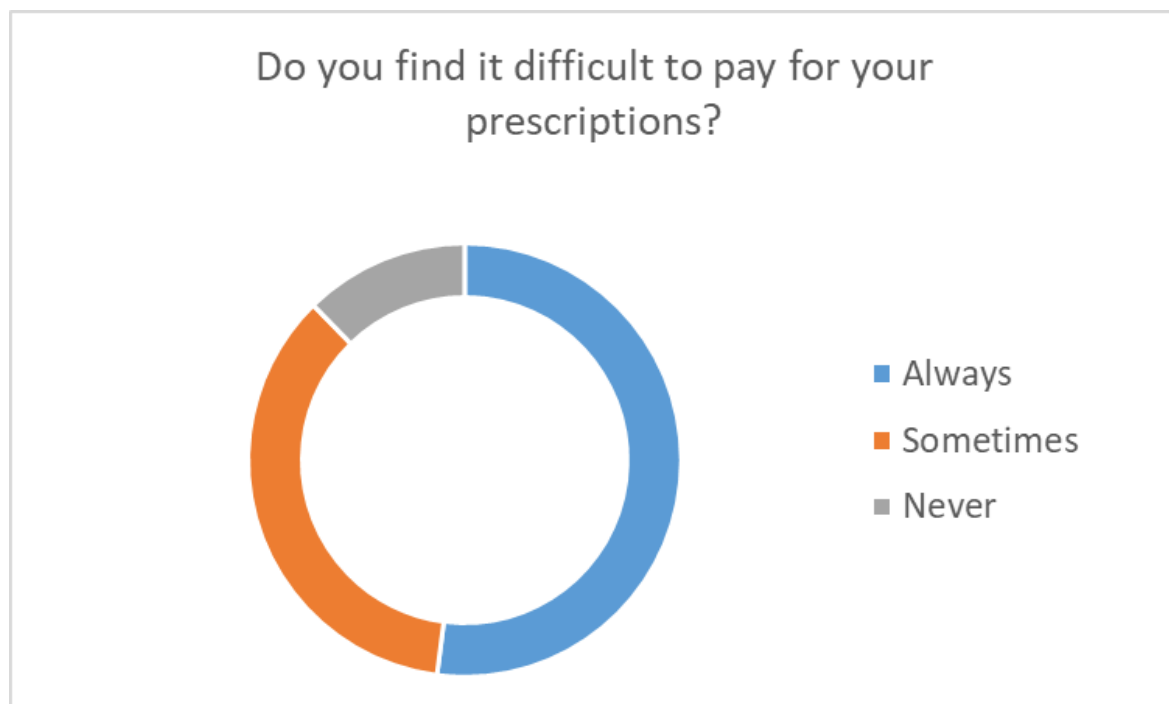
Chart 9 outlines the reasoning behind why some respondents chose not to purchase the PPC, there was an obvious proportion (38%) who didn't know about it and didn't purchase it, but there were also two other reasons for lack of uptake. Firstly 44% didn't because they couldn't afford it, this outlines the burden that a lump sum of £104 can have on people's cash flow, secondly 17% didn't as they didn't believe it would actually save them money in the long term. This second reason undermines the whole purpose of the PPC, bringing its effectiveness into question

Chart 10 - How often participants purchase prescriptions over the counter



The alternative to the PPC's for those with sickle cell and thalassaemia is to pay the £9 over the counter prescription charge and many of the cohort were having to do this more than once per month (41%). This represents a large monetary outlay for those with sickle cell and thalassaemia and will amount to more cost than the PPC.

Chart 11 - Participants difficulty in paying for prescriptions



88% of respondents asserted that they either always or sometimes had difficulty with their prescription payment. This exists for both those who purchase the PPC and pay the £9 charge and illustrates that the system systematically causes stress and difficulty to those with sickle cell and thalassaemia. Bewildered

Chart 12 - Prevalence of cutbacks being necessitated by cost of prescriptions

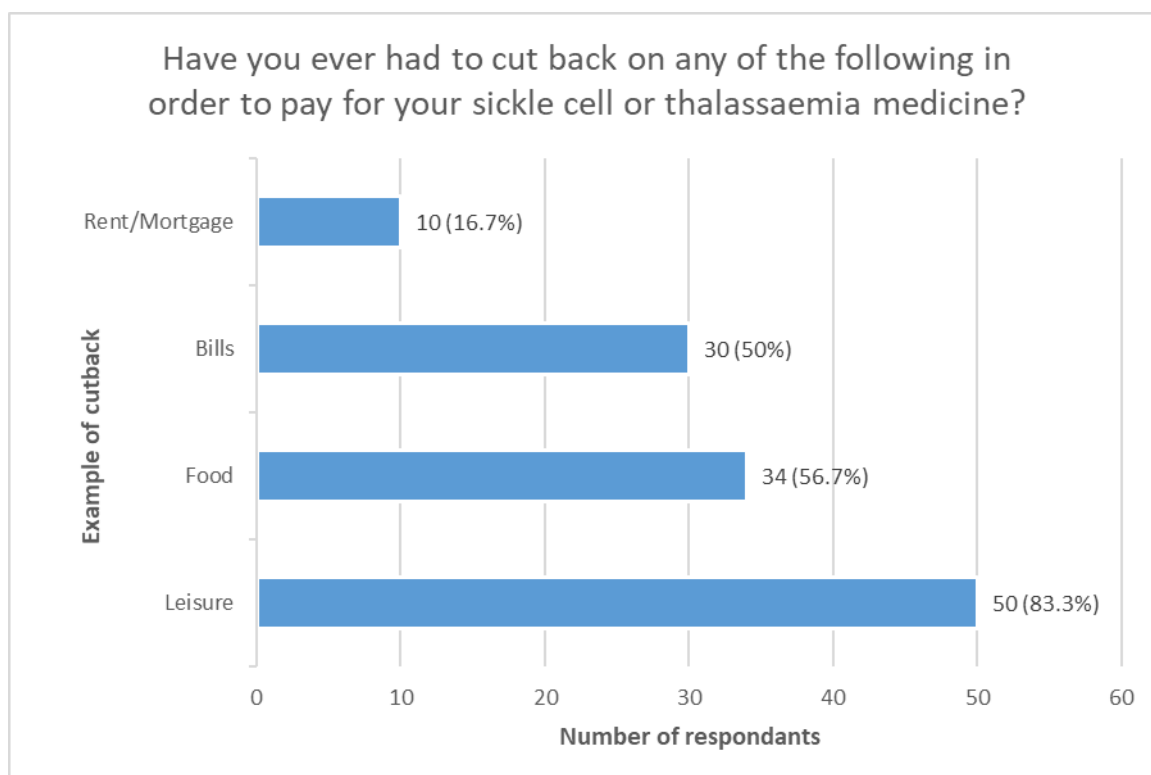
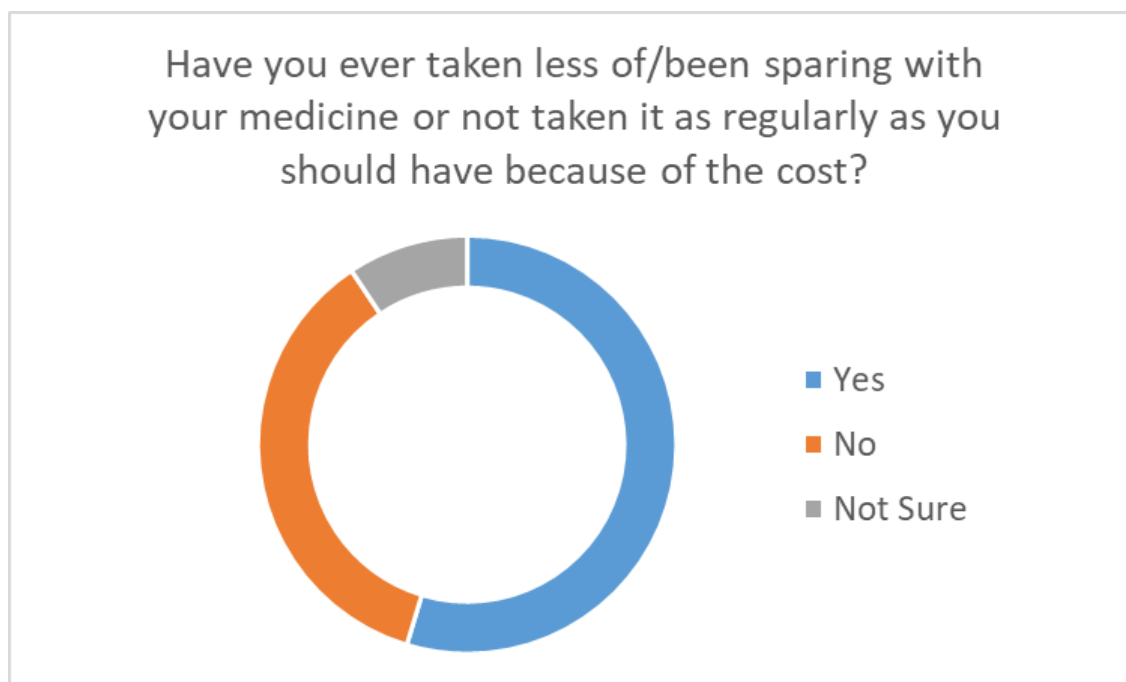


Chart 12 highlights the different aspects of life that those with sickle cell and thalassaemia have had to cut back on in order to afford their prescription. The most common of these cut backs was leisure

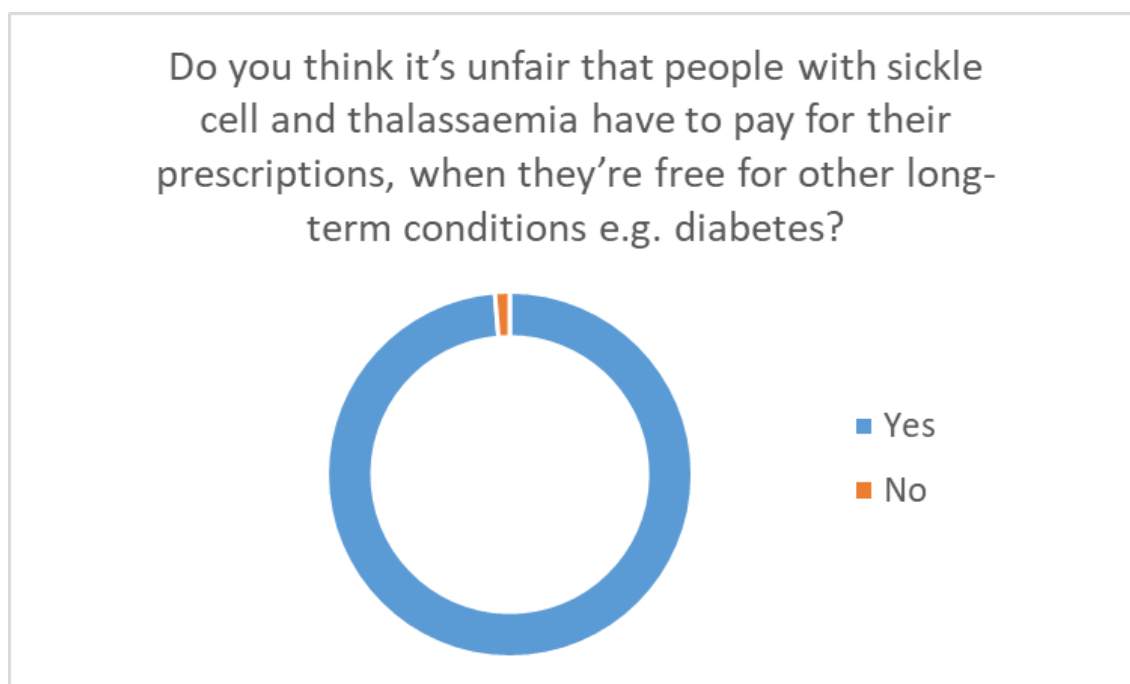
activities which 87.7% of the cohort said they had to sacrifice. This decrease in leisure activity can have negative effects on wellbeing and is directly caused by the burden of prescription payments. Even more worryingly around half of those who were questioned for the survey also disclosed that they'd been force to cut back on essentials for living such as bills and food. Finally, 16.7% of respondents had even delayed or cutback on rent payments to be able to afford medicine.

Chart 13: Prevalence of participants having to cut down amount or frequency of prescription usage due to cost



Over half of the cohort (52%) revealed that they had infrequently or sparingly taken their medicine due to the cost. This is in direct contradiction of doctors' orders who have clear advice on the most effective amounts of medicine. This illustrates the impact of burgeoning prescription costs and how people are being forced to choose between their health and their economic security

Chart 14: Participants opinions on whether it's unfair that Sickle Cell and Thalassaemia users have to pay for prescriptions



An overwhelming 99% of respondents agree with the sentiment that the lack of parity with other long term conditions is unfair. People with other conditions such as diabetes are given free prescription chargers, however sickle cell and thalassaemia which are both lifelong illnesses which are no fault of the person are penalised. The cohort believes there is a clear injustice that this generosity is not passed onto the sickle cell and thalassaemia communities

Chart 15 - Participants opinions on whether prescriptions should be free for Sickle Cell and Thalassaemia users

