

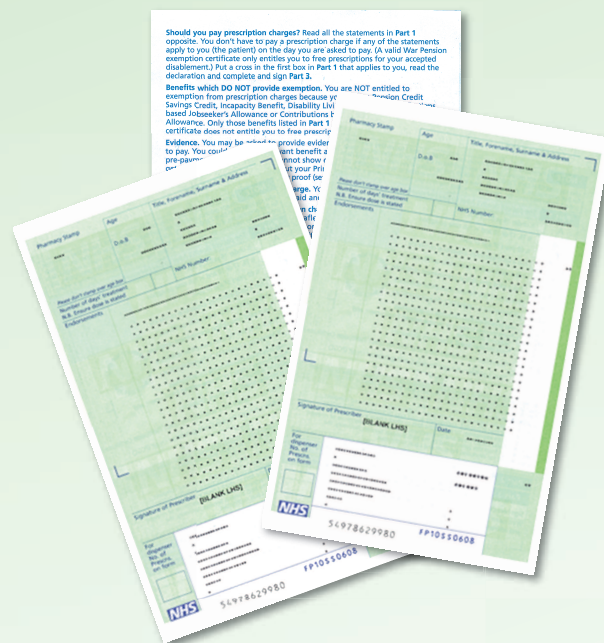
Paying the Price

Prescription Charges

and

People with Long-Term Conditions

A report by the
Prescription Charges Coalition



March 2013

Foreword

April 1st has been christened 'Fairness Day' to commemorate the arrival of free prescriptions in Scotland. I'm afraid to say that for those in England with a long-term condition, the situation is anything but.

The list of conditions that qualify for exemption from prescription charges has barely changed since its creation in 1968. Worse, the system of arbitrary exemptions is not even internally coherent, for example some people with diabetes are exempt, while others are not.

Prescriptions are not paid for by those under 16 and over 60, but this tax on the sick squeezes the incomes of working age people that develop a long term condition, such as Inflammatory Bowel Disease, which is most commonly diagnosed in the early twenties. Prescription charges impose costs on people with chronic conditions for the medicine that keeps them well or even alive, not to mention the additional costs if their illnesses flare-up.

Although we applaud the Government's prescription prepayment certificate scheme as one way of dealing with the cost of prescription charges, this is not a long-term solution. Our report highlights real issues around low awareness of the scheme and its suitability for people with conditions that fluctuate, making it impossible to know whether it is worth purchasing, as well as the current price which is a significant outlay and considered unaffordable by a proportion of our survey respondents.

In short, there is nothing fair or healthy about this 45 year old system and it's clear that the current prescriptions policy in England needs urgent reform.

Setting out the case for change, this report by the Prescription Charges Coalition highlights the personal cost of this policy, and tells the story of a society paying too great a price for prescriptions for those with long-term conditions. This is a price paid in preventable hospital admissions, missed household bills, wasted doctors' time and avoidable sick leave.

However, this report is not the end. In fact, this is only the beginning of the Prescription Charges Coalition's campaign to highlight the fundamental unfairness of the system and convince all political parties in England to deliver the reform that would be truly priceless for those with long-term conditions.



A handwritten signature in black ink that reads "D Barker". The signature is written in a cursive style and is underlined with a single horizontal line.

David Barker,
Chief Executive
Crohn's and Colitis UK



Paying the Price:

Prescription Charges and People with Long-Term Conditions

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Paying the Price:

Prescription Charges and People with Long-Term Conditions

Executive Summary

Prescription charges have been in existence for nearly as long as the NHS itself. Always controversial, there has been mounting evidence that they are presenting an unacceptable barrier to the effective use of medicines for people with long-term conditions. They also run counter to Government objectives aimed at improving outcomes for people with long-term conditions and commitment to an NHS that remains comprehensive and universal – available to all, based on clinical need and not ability to pay, as reaffirmed in the NHS Mandate and NHS Constitution.

The NHS spends £8.8bn on pharmaceuticals in primary care. £500 million is thought to be wasted due to the ineffective use of medicines. Yet numerous initiatives to reduce medicine waste and improve the use of medicines have not addressed the impact of charges. Some of the resulting policies, especially 28 day prescribing, may be costing more to both the NHS and the individual.

While some people are exempt from prescription charges on the basis of age, income and medical condition, the criteria for exemptions were set in 1968 and have remained largely unchanged since then. 45 years on, these criteria are now outdated, arbitrary and inequitable. Schemes to provide extra support with health costs, in particular the Prescription Prepayment Certificate and NHS Low Income Scheme are poorly publicised and difficult to access. The Prescription Prepayment Certificate still represents a significant outlay for people with long-term conditions. Prescription charges have now been scrapped entirely in Wales, Scotland and Northern Ireland.

The Prescription Charges Coalition brings together more than 20 organisations concerned with the detrimental impact that prescription charges are having on people in England with long-term conditions. The findings of our survey of over 3,700 people with long-term conditions illustrate the effect that charges for medicines have on adherence, self-management, health outcomes and quality of life and the knock-on impact on society as a whole in terms of employment, welfare and additional costs to the NHS.

Key Findings

- 73% of our total survey respondents are paying for their prescriptions
- 64% of respondents require more than 13 prescription items a year
- 35% of respondents who pay for each prescription have not collected at least one item due to the cost, with three quarters of this group reporting that their health got worse as a result. 10% said that they ended up in hospital as a direct consequence of not taking their medication
- 29% of respondents who paid for their prescriptions and did not have a Prescription Prepayment Certificate reported not taking their medicine as prescribed either occasionally or often. Over half of these gave the cost of the prescription as the main reason for not taking their medicine as prescribed.
- 76% of respondents had not heard of the NHS Low Income Scheme
- Only 14% of respondents found out about the Prescription Prepayment Certificate from their GP, and 5% from their consultant. Combined, this is fewer than the 23% who found out from friends and family. 30% of our survey respondents who did not have a Prescription Prepayment Certificate felt it was unaffordable:

- The majority of respondents do not claim any benefits whatsoever, with 73% of those who pay for their prescriptions reporting that they received no financial support
- Over 36% of respondents reported they are unhappy with their schedule for repeat prescriptions, citing cost and inconvenience as the main reasons for this
- Qualitative responses indicate that prescription costs are impacting detrimentally on respondents' medical conditions and quality of life and are felt to be a significant burden in addition to their lifelong illness. Respondents also highlighted lack of parity for medical exemptions across conditions and parts of the UK.

Recommendations

Key Recommendation: Extend prescription charge exemption to all those with long term conditions.

This report shows that prescription charges are a major barrier to people with long-term conditions taking their medicines effectively and have a detrimental impact on health outcomes. This carries significant cost implications for the NHS and for society as a whole.

A measured, cost-effective approach to implementation of this recommendation could be achieved through a staged reduction in the cost of the Prescription Prepayment Certificate until prescription charges for people with long-term conditions are phased out altogether. Ultimately, we would support a broad-based definition of long-term condition, with exemptions reviewed every three years, as proposed by Professor Sir Ian Gilmore's Prescription Charges Review.

Recommendation: The frequency and duration of prescriptions for people on long-term maintenance medication for a stable, long-term condition should be based on individual needs and circumstances and agreed between the prescriber and patient, not bound by rigid 28 day prescribing policies.

Reducing medicines waste will be best achieved by ensuring the most effective treatment is in place and medicines are optimised for the individual. For stable, long-term conditions, three or six monthly prescribing may be the best approach, as it enables people to get on with their life while managing their condition and reduces the cost of unnecessary appointments.

Recommendation: As long as prescription charges remain in place for people with long-term conditions, awareness of entitlements and the help available should not be left to chance. Information about prescription charge exemptions, the Prescription Prepayment Certificate and NHS Low Income Scheme should be given routinely to people with long-term conditions at the point of diagnosis, as part of care planning, where medicine is dispensed and in any relevant medicine reviews. Information leaflets should be on display in all GP surgeries and pharmacies.

Respondents to our survey found out about the Prescription Prepayment Certificate through a variety of routes. Many told us that it had taken some time before they had been informed about it. There was very low awareness of the NHS Low Income Scheme.

Recommendation: Entitlement to prescription charge exemption should be retained for all those who are currently eligible following the introduction of Universal Credit.

It is important to retain an exemption from prescription charges for those who are currently eligible. Better health outcomes as a result of taking necessary medicines, will support people to return to work. Conversely, inability to afford medicines could result in more time out of work and greater reliance on benefits in addition to worse health outcomes.

Ultimately, there will be a disproportionate impact at any income or earnings thresholds, whereby people suddenly have to start paying for medicines, especially if there is no tapering support. This will be exacerbated when other health charges and support, such as free school meals are also affected.

www.prescriptionchargescoalition.org.uk

email: prescriptionchargescoalition@crohnsandcolitis.org.uk

Paying the Price:

Prescription Charges and People with Long-Term Conditions

Introduction

The Prescription Charges Coalition is an alliance of more than 20 organisations concerned with the impact of prescription charges on people with long-term conditions. Combined, the member organisations represent millions of people with a wide range of long-term conditions, providing services, information, support, funding and conducting research, amongst other activities.

This report details the findings of an online survey which ran from 8 August – 31 October 2012 to explore the impact of prescription charges on people with long-term conditions in England in the current economic climate. Past research and experience from health professionals has identified that prescription charges have had a significant impact on medicine adherence, despite the existence of the Prescription Prepayment Certificate and exemptions for charges for those with some specific medical conditions and for those in receipt of certain state benefits. Member organisations are also contacted on a regular basis through their helplines and social media forums by individuals for whom prescription charges are an issue.

There has been considerable focus in recent years on reducing medicine wastage and improving the use of medicines. This report makes the case that prescription charges need to be considered as a key part of this work and strongly questions the economic value of preserving prescription charges for people with long-term conditions in England.

Membership of the Prescription Charges Coalition

Androgen Insensitivity Support Group

Arthritis Care

Asthma UK

Behçets Syndrome Society

British Heart Foundation

British Liver Trust

Crohn's and Colitis UK

Cystic Fibrosis Trust

Disability Rights UK

FibroAction

Hughes Syndrome Association

Klinefelter's Syndrome Association

MS Society

Motor Neurone Disease Association

National Ankylosing Spondulitis Society

National Rheumatoid Arthritis Society

Parkinson's UK

Pernicious Anaemia Society

Raynaud's and Scleroderma Association

Rethink Mental Illness

Royal Pharmaceutical Society

Stroke Association

Terence Higgins Trust

Turner Syndrome Support Society



Policy Context

The NHS in England spends £8.8bn on prescription medicines supplied through primary care.¹ However, an estimated £500 million is wasted because patients are not taking their medicines effectively and are therefore not getting the full benefits.² A Cochrane review *Interventions for enhancing medication adherence* concluded that improving the use of medicines may have a far greater impact on clinical outcomes than an improvement in treatments.³ Five to eight per cent of hospital admissions are related to ineffective or inappropriate use of medicines.⁴ Reviews conducted across medical conditions and countries are consistent in estimating that between 30%-50% of prescribed medication is not taken as recommended.⁴

The optimal use of appropriately prescribed medicines is vital to the self-management of most chronic illnesses. Key policies that are predicted to affect medicines-taking behaviour are “the prescription tax system, deregulation of prescription only medicines and expansion of prescribing rights.”⁴

The Government has set out a variety of objectives aimed at improving outcomes for people with long-term conditions⁵ and the NHS Constitution⁶ and NHS Mandate⁷ “reaffirm the Government’s commitment to an NHS that remains comprehensive and universal – available to all, based on clinical need and not ability to pay.” There have also been numerous government-led initiatives to optimise medicines use and to reduce wastage, including the New Medicines Service, Medicine Use Reviews and the Steering Group on Improving the Use of Medicines. However, the impact of prescription charges in terms of the wider economic picture has so far not been addressed within this context and yet remains a key aspect. The cost and value of prescriptions must be considered not just at the point of prescribing but at all stages of the process. This was highlighted by recent research which found that rigid 28 day prescribing policies, designed specifically to reduce medicine wastage, may be costing the NHS more than they save, while also being counter-productive to optimal individual treatment plans.⁸

Evidence of the Impact of Prescription Charges

There is significant evidence that prescription charges present a barrier to the effective and optimal use of medicines by people with long-term conditions. The RAND health insurance experiment carried out in the US in the 1970s offered a comprehensive insight into the effect of different user charges on over 7,000 participants who took part over a number of years. The findings showed that charges reduced demand for effective treatments and impacted disproportionately on vulnerable and low income groups.⁹

Our survey also builds on past research from Citizens Advice which found in 2001 that 50% of their clients surveyed, who had paid prescription charges, reported difficulties in affording the charge and 28% had failed to get all or part of a prescription dispensed during the previous year because of the cost. People with long-term health problems were particularly affected.¹⁰ A study in 2005¹¹ found that the most common strategies for patients with problems affording medicines were to delay the dispensing of medicines, to not visit the GP and/or to lower the dose below that prescribed to extend the duration of the prescription. In

¹ Prescription Cost Analysis England 2011. <https://catalogue.ic.nhs.uk/publications/prescribing/primary/pres-cost-anal-eng-2011/pres-cost-anal-eng-2011-rep.pdf>

² The estimated opportunity cost of the health gains foregone because of incorrect or inadequate medicines taking in just five therapeutic contexts is in excess of £500 million per annum. Evaluation of the Scale, Causes and Costs of Waste Medicines, York Health Economics Consortium, University of York and The School of Pharmacy, University of London, November 2010, ISBN 978 090 293 620 1, http://eprints.pharmacy.ac.uk/2605/1/Evaluation_of_NHS_Medicines_Waste_web_publication_version.pdf

³ Haynes RB, Ackloo E, Sahota N, McDonald HP, Yao X. Interventions for enhancing medication adherence. Cochrane Database Systematic Review 2008;(CD000011)

⁴ Concordance, adherence and compliance in medicine taking. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSSDO), December 2005, http://www.medslearning.leeds.ac.uk/pages/documents/useful_docs/76-final-report%5B1%5D.pdf

⁵ The Department of Health is committed to enhancing quality of life for people with long term conditions. <http://longtermconditions.dh.gov.uk/>

⁶ <http://www.dh.gov.uk/health/category/policy-areas/nhs/constitution>

⁷ <http://mandate.dh.gov.uk/>. In November 2012 the government published the first NHS Mandate, which included an ambition to be among the best in Europe at supporting people with ongoing health problems to live healthily and independently.

⁸ Davies, J.E. and Taylor, D.G. (2012) Individualisation or standardisation: Trends in National Health Service prescription durations in England 1998-2009. *Prim Health Care Res Dev.*, Oct 3:1-11

⁹ Free for All? Lessons from the RAND Health Insurance Experiment, Joseph P Newhouse and the RAND Insurance Experiment Group

¹⁰ Unhealthy Charges, Citizens Advice, 2001, <http://www.citizensadvice.org.uk/unhealthy-charges.htm>

¹¹ Atella V, Schafheutle E, Noyce P, Hassell K. Affordability of medicines and patients’ cost-reducing behaviour: empirical evidence based on SUR estimates from Italy and the UK. *Appl Health Econ Health Policy* 2005; 4(1):23-35.



2007, MORI research found that 800,000 people in England had failed to collect a prescription because of the cost involved.¹² Research by Rethink Mental Illness in 2008¹³ showed that 38 per cent of people surveyed with severe mental illnesses such as schizophrenia had to choose between paying household bills and paying prescription charges. Similarly, in 2009, the British Heart Foundation found that 35% of respondents had foregone something else in order to meet the costs of prescribed medicines. In many cases, this included food, despite the importance of a healthy diet to cardiovascular health and 30% had not taken prescribed medicines due to costs.¹⁴

A poll by Doctor in 2001¹⁵, a specialist newspaper for GPs, found that eight out of ten doctors said that they had patients who had not collected medicines that had been prescribed because they could not afford to pay for their prescriptions. The Royal Pharmaceutical Society also receives reports from pharmacists who say that they are regularly asked to help people choose which of their prescription items are most important and which could be left uncollected.

In their 2006 Inquiry into NHS Charges¹⁶, the House of Commons Health Select Committee highlighted international research which has shown that health charges have a negative effect on health, in particular for patients with long-term illnesses.

“The system of health charges in England is a mess. Charges for prescriptions and dentistry have been in place for over 50 years and sight tests for almost 20 years. They have not been introduced following detailed analysis of their likely consequences; rather they have come about piecemeal, often in response to the need to raise money. There are no comprehensible underlying principles. The charges remain largely for ‘historical’ reasons”.

Health Select Committee, NHS Charges, July 2006

The History of Prescription Charges

Prescription charges were first introduced in 1952 and resulted in the resignation of Aneurin Bevan and other ministers, including later Prime Minister Harold Wilson, on the basis that they undermine the fundamental principles of the NHS as being provided free at the point of delivery on the basis of need rather than ability to pay. They were initially set at one shilling per prescription form, rising to one shilling per item in 1956 and then two shillings in 1959. Prescription charges remained controversial being later abolished by Harold Wilson in 1965, but then subsequently reintroduced in 1968 with a system of exemptions on the basis of age, income and for some medical conditions. Charges were static at 20p between 1971 and 1979, but then increased to 45p and then twice to 70p and then £1 in 1980 and subsequently rose each year thereafter. Since 1979, prescription charges have risen considerably faster than inflation, and are now eight times higher in real terms than they were 30 years ago. For example, if prescription charge increases had been limited to the rate of inflation since 1979, then by 2012 they would have been 96p per item rather than £7.65.¹⁷ At the time of compiling this report, the prescription charge stands at £7.65 per item (from 1st April 2012) having risen by 25p from £7.40 in 2011 and this is set to rise once again to £7.85 on 1st April 2013.

“I consider the imposition of charges on any part of the health service (an issue) ... I could never agree to. If the government impose them my resignation would automatically follow”

Aneurin Bevan, Minister for Health responsible for establishing the NHS in 1948

¹² Prescription Costs A Barrier to Healthcare, Ipsos MORI for Citizens Advice, February 2008,

<http://www.ipsos-mori.com/researchpublications/researcharchive/151/Prescription-Costs-A-Barrier-To-Healthcare.aspx>

¹³ Your Treatment, Your Choice Survey, Rethink Mental Illness, 2008

¹⁴ BHF Prescription Charges Survey, August 2009

¹⁵ Doctor, 5 April, 2001

¹⁶ House of Commons Health Select Committee: NHS Charges. July 2006, <http://www.publications.parliament.uk/pa/cm200506/cmselect/cmhealth/815/815-i.pdf>

¹⁷ Calculated using the Bank of England inflation calculator

In September 2008, the then Prime Minister Gordon Brown pledged to exempt people with long-term conditions from prescription charges and commissioned an independent review into implementation. However, the pledge was never fulfilled and the Prescription Charges Review¹⁸, led by Professor Sir Ian Gilmore, the then President of the Royal College of Physicians, remained unpublished for six months until finally released in May 2010 by the incoming Coalition Government. Subsequently, in the October 2010 Spending Review, they stated that “some programmes announced by the previous Government [will] not be implemented - including proposals to extend free prescriptions to all those with long term conditions. The Government will continue to look at options for creating a fairer system of prescription charges and exemptions, which takes into account the overall NHS financial context and introduction of Universal Credit.” This has remained their position to date.

It has been estimated that 80% of those between the ages of 16 and 60 pay for their prescriptions.¹⁹ 83% of respondents to a British Heart Foundation survey in 2009 paid for their prescriptions.¹⁴

Prescription Charge Exemptions

As stated above, a range of exemptions from prescription charges were introduced in 1968 and have remained largely unchanged since this time, despite significant changes in treatments and medical conditions.²⁰

The list of medical conditions for which prescription charges are not payable is limited and apparently arbitrary in current times, including insulin-controlled diabetes and underactive thyroid, but not asthma, inflammatory bowel disease, heart conditions, inflammatory arthritis auto-immune disease, HIV or Parkinson's, amongst many others.

“The system of medical exemptions to the prescription charge is particularly confusing. The list of exemptions was compiled in 1968... Given the vast improvements in medical science since that time, this is unacceptable. People with cystic fibrosis who would have died of their illness during childhood in the 1960s now reach adulthood. Diseases such as HIV/AIDS did not exist in 1968. The original list could not have taken these conditions into account.”

Health Select Committee, July 2006

Currently, those under 16, 16-18 in full-time education and over 60 are exempt from prescription charges. Receipt of some benefits, such as Income Support and income-based Jobseeker's Allowance currently entitle recipients to exemption from prescription charges, while others such as Disability Living Allowance and contribution-based Employment and Support Allowance do not. However, this is set to change with the introduction of Universal Credit as these benefits will be subsumed within the new system. The Government has stated that it intends roughly the same number to be exempt from charges as is currently the case, through the application of income or earnings thresholds. However there has been some indication that a proportion of those who would be eligible under the present rules are likely to lose their entitlement to exemption from prescription charges.

“Income-related exemption can involve a complex application process and must be renewed annually. Charges also create a harsh poverty trap for those just above the threshold. More fundamentally, no easily understood principle underlies the complex set of exemptions.”

Health Select Committee, July 2006

¹⁸ Prescription Charges Review: Implementing Exemption from Prescription Charges for People with Long Term Conditions, November 2009, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/@sta/@perf/documents/digitalasset/dh_116367.pdf

¹⁹ Hansard 2.7.2001, col 571

²⁰ See Appendix for details of exemptions

“The present system of exemption for prescription charges is not logical, nor rooted in the principles of the NHS.”

Derek Wanless, Securing our future health: taking a long-term view: final report, April 2002,

The NHS Low Income Scheme

The NHS Low Income Scheme (LIS) was established to provide financial assistance for those who are not eligible for exemption from charges. As well as prescriptions, it covers dental and optical services, travel expenses, wigs and fabric supports. The capital threshold for the LIS is £23,250 for those permanently in a care home and £16,000 for all other patients.

To apply to the scheme, patients must complete a lengthy HC1 form which is sent to the NHS Business Services Authority (NHS BSA). The certificate usually lasts for 12 months and must be renewed each year. There is very low awareness of the scheme and it is very difficult to establish eligibility before starting the process. The LIS also has high administration costs. The NHS BSA has estimated that the overall cost of administering the LIS in England, Wales and Scotland in 2010/11 was £5 million.²¹

Prescription Prepayment Certificate

It is also possible to purchase a Prescription Prepayment Certificate (PPC), which is effectively a type of season ticket for prescription medicines, for a period of either three months or 12 months and covers all prescriptions over that period. At the time of compiling this report, the cost is £29.10 for a three month certificate and £104 for a 12 month certificate. This means that it is worthwhile for somebody who requires four or more prescription items over three months or 14 prescription items over one year. The 12 month PPC can be paid for by direct debit over 10 monthly instalments if purchased from the NHS BSA, but only at total cost from pharmacies and for the three month certificate.

Pharmacies and GP surgeries are not required to hold or display leaflets about the PPC, although they are encouraged to do so by the Department of Health. There is currently no specific responsibility for GPs or pharmacists to highlight the PPC to those with long-term conditions.

“While they said that there was a good deal of information about the benefits available to assist patients to pay charges, Ministers admitted that patients often do not claim the benefits to which they are entitled. Many do not know about the assistance that is open to them. GP surgeries, chemists, opticians and dentists [are encouraged but not obliged] to hold copies of relevant information leaflets“

Health Select Committee, July 2006.

The authors of a 2009 study found that only 23% of respondents had PPCs despite 81% requiring more than two prescriptions a month, with many stating cost as a major obstacle²². They concluded that *“The problem may stem from the fact that advising patients about the PPC and the Low Income Scheme is not embedded in any part of either the prescription giving or the prescription dispensing process and there are no departmental targets around take-up of either scheme.”*

The Prescription Charges Review also found strong consensus for an increased role for health professionals in making patients aware about the PPC, during routine medication reviews, for example. In a 2011 survey by the Prescription Charges Coalition, 58% of respondents referred to a need for healthcare professionals

²¹ Hansard 19.7.2011, col 276

²² Northumberland Citizens Advice Bureau: What the Doctor ordered – but at what cost? November 2009 <http://www.lpc-online.org.uk/bkpage/files/175/Northumberland%20CAB%20report.pdf>



to inform people routinely about the PPC at the point of diagnosis, check-up, prescription-writing or dispensing and a number highlighted the time it had taken before they had become aware of the PPC. For example, “When diagnosed it would be helpful if when first prescribed you were told. It was several years before I realised – I could have saved a lot of money.”

“There was support for the process of care planning to include a discussion about prescription charges.”

Prescription Charges Review, November 2009

Additionally, it is not always possible to determine if it will be worthwhile to purchase a PPC, particularly for those with a fluctuating condition, who cannot predict how their condition will affect them in the future and therefore cannot plan ahead. The application process can be off-putting and the outlay is still significant, especially for people with lower incomes and when considered over a number of years, potentially until age 60.

For conditions diagnosed at a young age, this represents the best part of a lifetime paying for medication in addition to the other costs associated with the condition or multiple conditions, such as travel to hospital appointments, aids and equipment. In the current economic climate, this impact is likely to be even more acutely felt by many.

Thus, the Prescription Charges Review stated, following extensive research and consultation with a wide range of stakeholders, “There is universal support for reform of the current system of prescription charges and for extending the exemption criteria” and that “Any reform of the system should be based on principles of equity and fairness; clarity, consistency, simplicity.”

Wales, Scotland and Northern Ireland

Prescription charges were abolished for all in Wales in 2007, in Northern Ireland in 2010 and in Scotland in 2011, in all three cases after a phasing-in period whereby charges were decreased in stages.

In Wales, which has the longest experience of this policy, there has not been a significant overall increase in prescriptions dispensed since its introduction. There has also been no notable effect on the amount of over-the-counter medicines such as cold remedies that are dispensed, which may otherwise have been purchased directly.²³

“Three years on from their introduction, they are making a real difference to thousands of people’s lives and remain one of the Assembly Government’s most popular and recognised policies.”

Welsh Assembly Government, March 2010

In Scotland and Northern Ireland, the policy has met with greater political opposition and a consultation on reintroducing prescription charges, either with categories of exemption or a lower across-the-board rate is expected soon in Northern Ireland. In Scotland, the commitment to free prescriptions has recently been restated strongly.

²³ Helping to Improve Wales’s Health: Free Prescriptions Three Years On. <http://www.wales.nhs.uk/documents/prescriptions-report-three-years.pdf>



“The phasing out of prescription charges benefits all individuals in Scotland, but in particular those who are the most vulnerable. Those with low incomes and those with long-term conditions will clearly benefit most each and every time they have their prescribed medicines dispensed. Enabling access to necessary prescribed medicines is an essential component in ensuring patients’ compliance with the management of their health without reference to their income. Patients no longer face making choices between which medicines to take based on affordability.

The Scottish Government is clear that the extension of free prescriptions to all removed the inequalities embedded in the previous charges regime caused by the existence of an income threshold and approved list of conditions.”

Alex Neil, Health and Wellbeing Secretary, Scotland, November 2012

“Prescription charges have been called a tax on illness. The fact is that within our community there are ill people who do not have enough money to pay for their prescriptions. They are being forced to choose between their medicine and food, which is totally unacceptable. Why should the health service fund the cost of operations, outpatient appointments and diagnostic tests and expect people with asthma, diabetes and other long-term conditions to pay for the medication they desperately need? I believe that full abolition of charges is right for Northern Ireland.

It’s an economic investment, as people will be able to get back to work earlier if they have the right medication. It’s also an investment in people, at a time when they need it most.”

Michael McGimpsey, Northern Ireland Health Minister, 31 March 2010

Survey Findings

Methodology

The survey ran online for 12 weeks from 8th August to 31st October. It was advertised through the websites, Facebook pages and newsletters of organisations representing people with long-term conditions. As respondents were self-selecting, it is not a representative sample. However, there was a normal distribution across all age groups and a wide range of long-term conditions were represented.

3,748 individuals responded to the survey. Of these, 1,316 were discounted as they did not live in England, did not have a long-term condition or were exempt from paying charges. This left a sample size of 2,432 respondents who provided both quantitative and qualitative responses to questions.

Key Findings

- Although there is a perception that the majority of people do not pay for their prescriptions, 73% of our total survey respondents do pay for their prescriptions
- 64% of respondents require more than 13 prescription items a year
- Around 35% of respondents who pay for each prescription have not collected at least one item due to the cost, with three quarters of this group reporting that their health got worse as a result. 10% said that they ended up in hospital as a direct consequence of not taking their medication

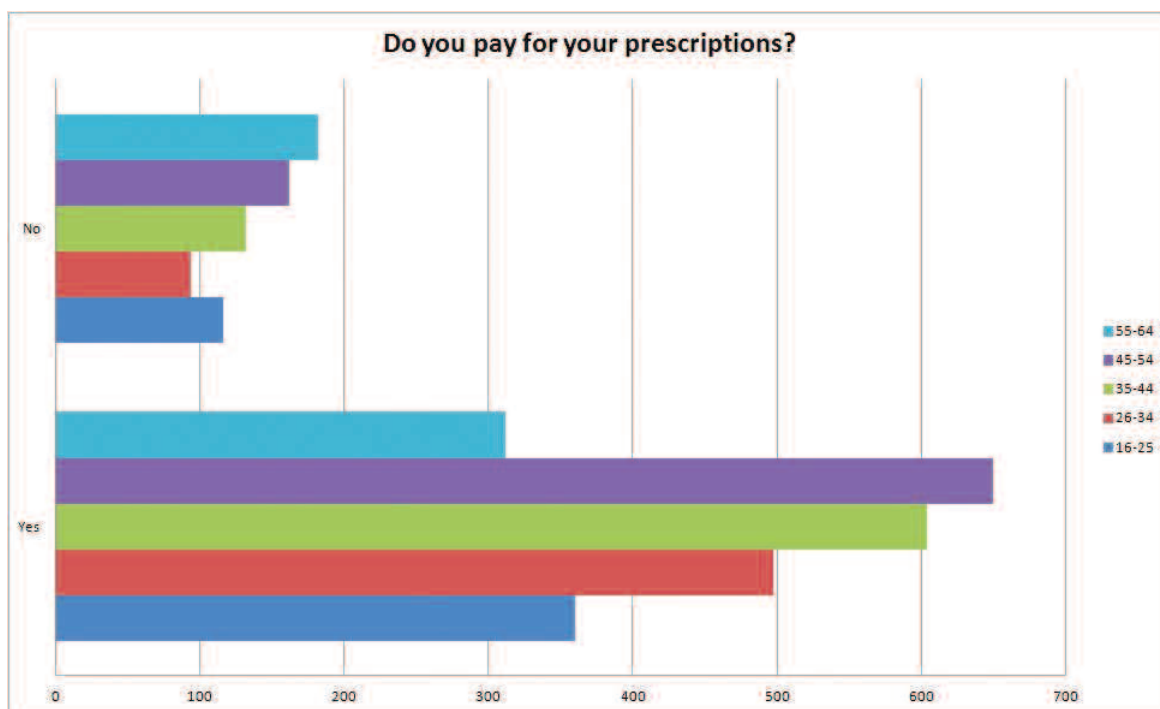
- 29% of respondents who did not have a Prescription Prepayment Certificate but were paying for their prescriptions reported not taking their medicine as prescribed either occasionally or often, with over half of this group giving the cost of the prescription as the main reason for this.
- 76% of respondents had not heard of the NHS Low Income Scheme
- Only 14% of respondents found out about the Prescription Prepayment Certificate, which can save significant amounts of money where a larger number of prescription items are required, from their GP, 5% from their consultant. Combined, this is fewer than the 23% who found out from friends and family
- The majority of respondents do not claim any benefits whatsoever, with 73% of those who pay for their prescriptions reporting that they received no financial support.
- Over 36% of respondents who answered questions about the number and frequency of their prescriptions, report they are unhappy with their schedule for repeat prescriptions, citing cost and inconvenience as the main reasons for this
- Qualitative responses indicate that prescription costs are impacting detrimentally on respondents' medical conditions and quality of life and are felt to be a significant burden in addition to their lifelong illness. Respondents also highlighted lack of parity for medical exemptions across conditions and parts of the UK.

Paying for Prescriptions

How Many People Are Paying For Prescriptions?

There are no national statistics available on this, although it has been estimated that 80% of those between 16 and 60 pay for their prescriptions.²⁴

73.2% (2,432) of respondents to this survey said they were paying for their prescriptions, with only 27% (890) exempt.

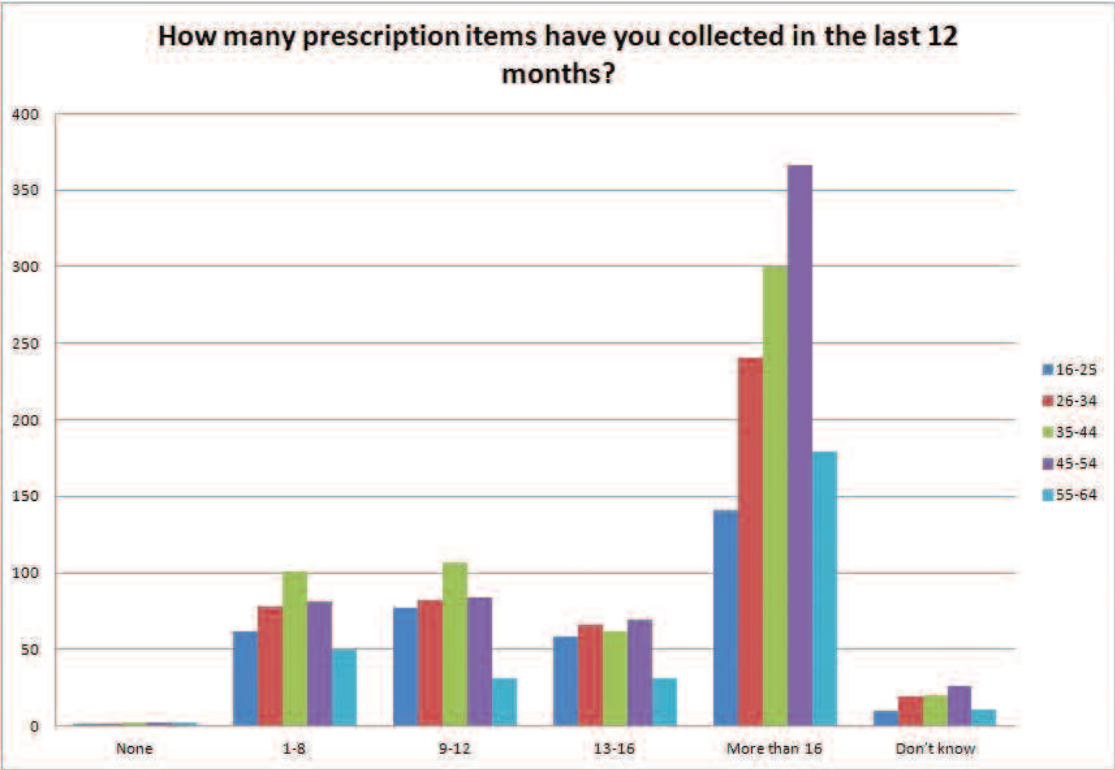


²⁴ Hansard, 7.2.2001, col 571

People with long-term conditions often rely on medication to manage their condition and some have multiple conditions and therefore require a number of medicines on a regular and ongoing basis. Some have fluctuating conditions and may require more medicines at some periods than others which provides a different set of challenges for them as will be illustrated in later sections of the report.

How Many Prescriptions?

In terms of the volume of prescriptions required by our survey respondents, 51.9% (1,229) collected more than 16 prescription items in the last 12 months and a further 12.1% collected 13-16 (287).



Our survey showed that people with long term conditions generally required prescriptions monthly or more frequently and spent over £100 a year on prescribed medicines.

The cost of prescriptions can represent an additional “challenge” for the management of long-term conditions. Our survey found that this was the case across all age groups and long-term conditions

Prescription Prepayment Certificate (PPC)

PPC Awareness

Only 14.4% (178) of respondents found out about the Prescription Prepayment Certificate, which can save significant amounts of money where a larger number of prescription items are required, from their GP, and 4.5% (56) from their consultant. This is fewer combined than the 23.2% (287) who found out from friends and family.

To improve awareness of the PPC, the Prescription Charges Coalition has worked with the Department of Health to develop a new poster and leaflet which clearly explains to the public the benefits of a PPC.

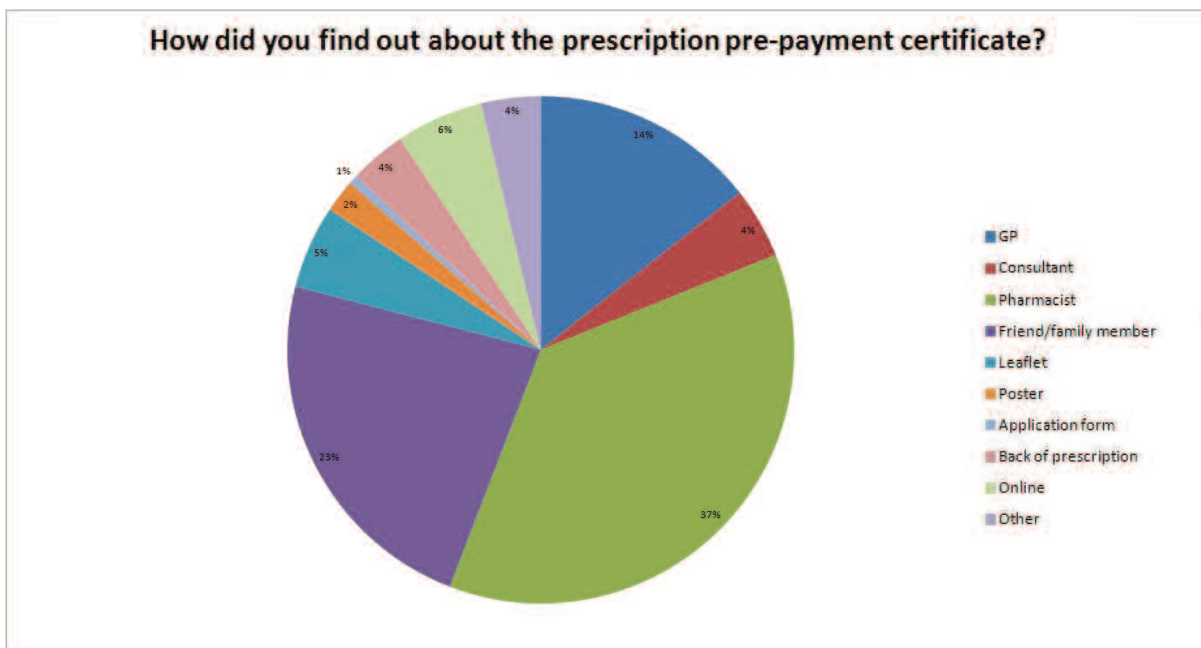
Qualitative responses illustrate that people who could benefit from a PPC may not find out about this for some time after they have been diagnosed with a condition and incurred considerable expenditure.



“Before I knew about the PPC, I was spending over £100 per month on medication after my heart operation.”

“Before I was made aware of the pre-payment card I would make decisions about which medication I felt was most important and only get those, therefore my health suffered, my family life suffered as I often felt too ill to care for my children and I did little socially with my family or friends.”

“I manage okay now with the Prescription Prepayment Scheme, but a lot of people are unaware of or uncomfortable signing up for this scheme. I think people with long term conditions should automatically be offered/told of this option at the very least. If I had to pay for my prescriptions individually I would not be able to afford it, quite simply. I would go without & become a total burden on my family who would have to care for me as I would be unable to function.”



Understanding of the PPC

57.8% (1,252) of respondents who were aware of the PPC, had one, while 42.2% (914) did not.

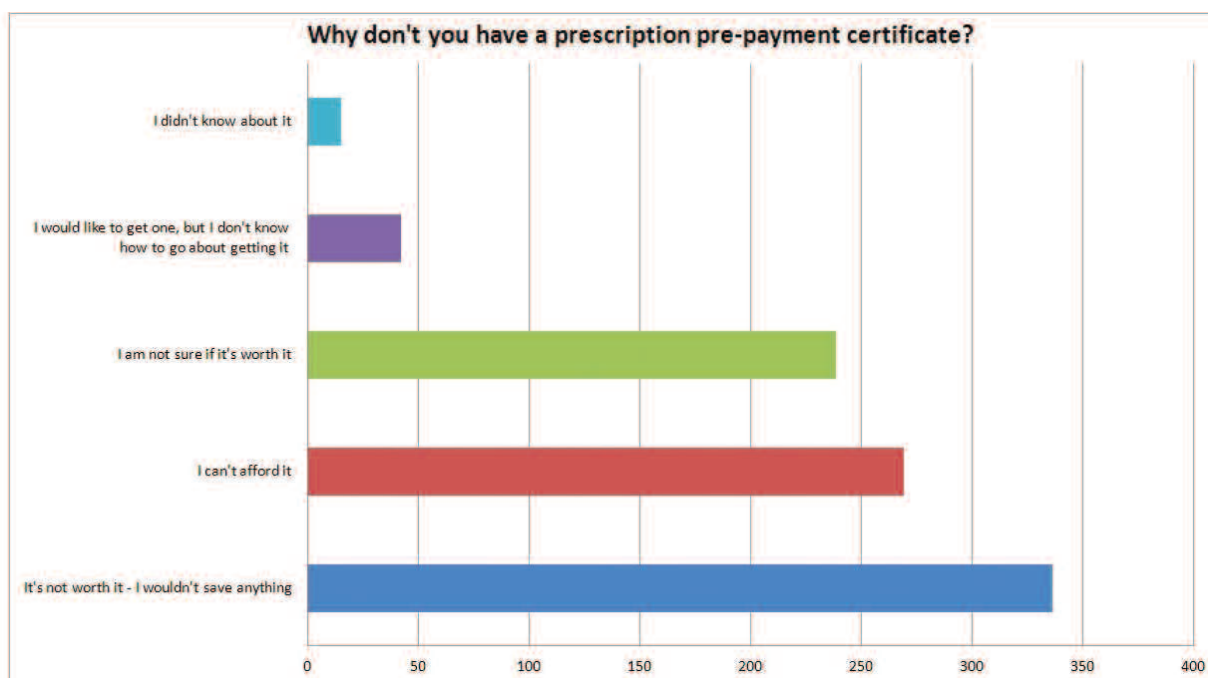
Of those who did not currently have a PPC, 37.5% (336) of respondents felt they would not save anything, while almost 30% (268) said they could not afford it and 26% (237) were not sure if it was worth it.

However, 22% (74) of those who felt they would not save anything reported they collected 13 or more prescriptions a year (enough to indicate they will save, or are likely to save, with a PPC).

Of those who were not sure if they would save anything with a PPC, an additional 37.5% (86) collected enough prescriptions to possibly benefit.

This indicates that understanding of the PPC and the point at which it can provide a saving for those with long-term conditions, remains low. This may in part be because conditions and medication needs can vary over time and it can therefore be difficult to predict if it will be worthwhile to pay for a PPC.

51.9% (1,226) of all respondents collected 16 or more prescription items in the last 12 months, and 12.1% (287) had collected 13-16. It becomes worthwhile to purchase a PPC at 14.



PPC Affordability

While the PPC makes a substantial difference for a number of respondents, it still represents a significant expense. 29.6% (268) of our survey respondents who did not have a PPC felt it was unaffordable:

"I have only one wage coming in. I work full time but have been on a four day week due to the company not doing well for a long time. I buy a 3 month card but can't afford a year one, it's just too much. I have to always make sure there's money which is very tight at moment."

"I only work part time on a self-employed basis due to my health, I receive no benefits but I do find it hard to find the current £104.00 per year to pay for my pre-payment certificate, I am wary of taking out a direct debit as I cannot guarantee that I will earn enough every month for this to be taken out my account, some months I earn more than others"

"Sometimes I cannot afford to renew the Prepayment Certificate and have to go without medication as a result"

"I have £5.00 a month more than the government says I need to live on so I can get no help with prescription charges. There is a choice between basic essentials or prescriptions. Then I have to forgo the prescription as there are the other costs to find of transport to appointments so there is no room for £10 a month direct debit for a pre-payment certificate and I certainly don't have enough for a lump sum up front for it."

"This month I cannot pay for a prepayment certificate - and I will not be able to get my medicines at all. I take 15 different tablets and inhalers."

Many survey respondents explained that they do not purchase a prepayment certificate due to the difficulty in planning financially for an unpredictable long-term condition:

“I haven't got a PPC as all of my conditions are fluctuating and the GPs all differ in how much of each medicine they will prescribe in one go, I could find myself having spent a lot of money for nothing.”

“It doesn't work out cheaper for regular medication but it does if I fall ill and need additional medication, but I never know when that is!”

“It's not worth paying for if I have my regular repeat prescriptions. If I ever need a prescription for something else it would be. Why can't it be like an Oyster Card and calculate the cheapest option retrospectively?”

“When I have flare ups I need more prescriptions but when in remission not as many. As I don't know when a flare up is going to occur having the pre-payment cert can be a waste of money”

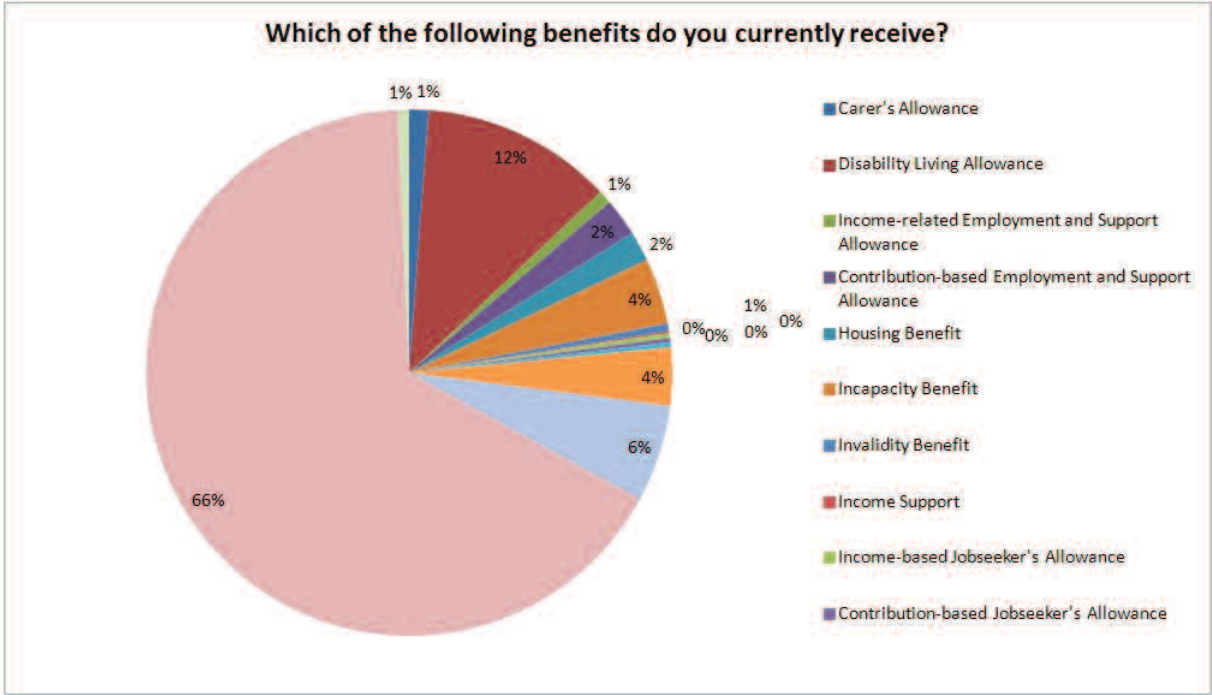
“When in remission, with a 2-monthly script it is more cost effective just to pay for the individual scripts. However, when the condition flares up I can require several items - two of which don't even last for one month.”

Benefits

Despite the high proportion of respondents who do not claim benefits, our report shows that people are still struggling to afford their prescriptions.

The majority of survey respondents do not claim any benefits whatsoever, with 73% (1,736) of those who pay for their prescriptions reporting that they received no financial support.

63% of those who said they could not afford a PPC were not receiving any benefits.



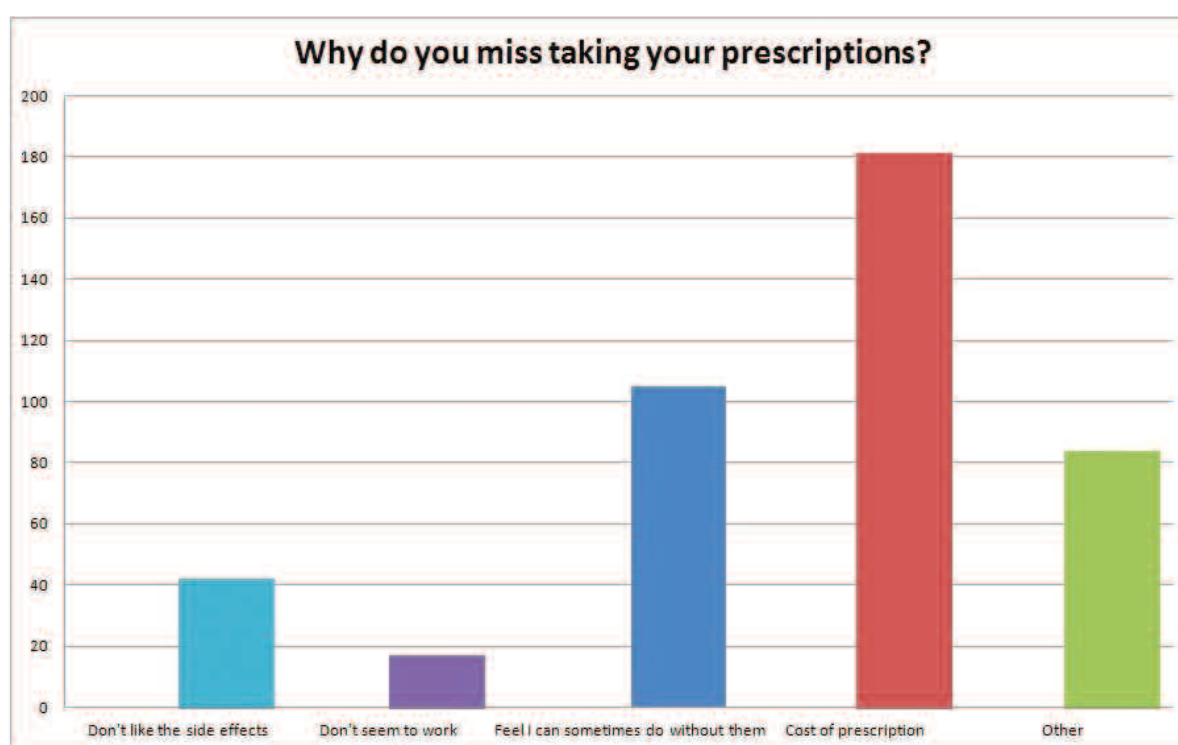
NHS Low Income Scheme

The NHS Low Income Scheme provides help with a range of health costs on a means-tested basis. This includes free prescriptions for those who are found to be eligible. Individuals need to make an application to the NHS Business Services Authority to be considered by completing a form detailing their circumstances.

Our survey found a low awareness of the NHS Low Income Scheme. 76.4% of respondents (1,806) had not heard of the scheme.

Of the 23.6% (558) that had heard of the NHS Low Income Scheme, 87.3% (489) had not applied, with 78.4% (381) responding that this was because they were ineligible for the scheme.

Medicine Adherence and Prescription Charges



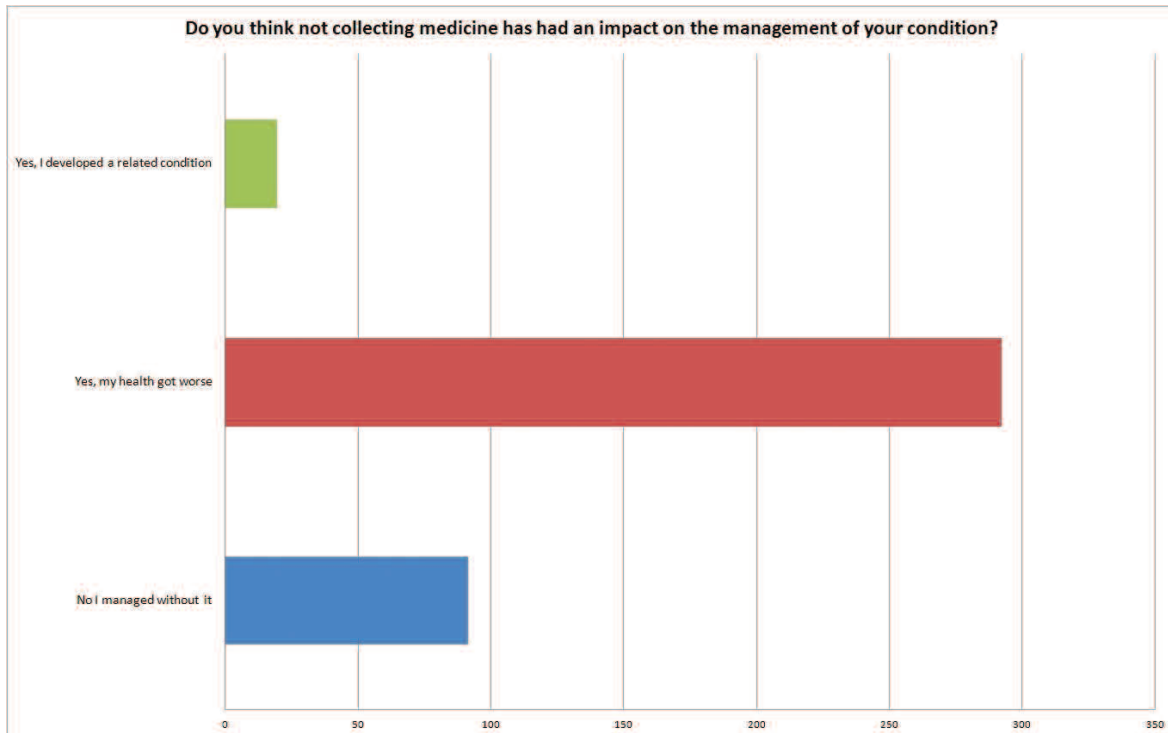
28.9% (333) of respondents who paid for their prescriptions but did not have a PPC reported not taking their medication as prescribed occasionally or often.

Over half (54.8%) of these respondents (181) reported that the cost of prescriptions was the reason for them not taking their medicine as prescribed.

35.2% (406) of respondents who paid for their prescriptions but did not have a PPC told us that they had been issued a prescription for their condition but had not collected it from the pharmacy because of the cost.

72.6% (292) of this group reported that their health got worse as a result of failing to take medicine as prescribed.

Among those reporting that they had not collected medicines from the pharmacy due to cost and who felt their health got worse as a result, 37.8% (152) had to go back to their doctor, and 10.4% (42) said that they ended up in hospital as a result of not taking their medication.



Respondents told us about the impact that an inability to pay for prescription medication had on their long-term health conditions:

“I could not afford the prescribed medication for anxiety, so thought I'd try and go without, ended up having panic attacks and losing my job,”

“I ended up being hospitalised for two weeks because I missed five days of medication. I think that my hospitalisation probably cost the NHS more than giving me a free prescription in the first place.”

“I had to go without medication due to the need to pay food and rent costs, I ended up in hospital, all because money was tight, now my parents pay for my pre-payment card because otherwise I still wouldn't be able to afford them”

“I go without pills for my depression and end up getting in a bit of a state. I had an asthma attack last week and I had no inhalers in the house because I hadn't bought more. I ended up at the doctors on the nebuliser with a peak flow of 60.”

“I couldn't afford to get my medication one month and as a direct result of me not having my medication I was rushed into hospital and put on oxygen.”

Many have reported taking less of their prescription, choosing between prescribed medicines and replacing prescriptions with a cheap over-the-counter painkiller because of cost:

“I cannot take the risk of being without an inhaler so sometimes I will not take it as prescribed so that I am not using too much.

“I sometimes reduce the dose - cut pills in half to save money. I am also paying for my son's prescriptions - he is a 21 year old full time student.”

“Had to borrow the pills from my mum or just try coping on cheap painkillers”

“I cannot afford my medication at the moment as I am looking for permanent work. Instead I use Ibuprofen which I buy cheaply from the supermarket. The relief is often very slight and does not last for long”



Respondents also told us that by not collecting an initial prescription because of the cost, this had exacerbated their condition. thus requiring further prescriptions and incurring higher costs:

“I needed an additional prescription as I needed an even longer course of medication than originally prescribed, this might not have happened if I hadn't had to delay starting the medication”.

“I ended up getting another prescription for the same item a few weeks later but initially I thought I could manage without it and didn't want to pay the cost - it was two courses of different treatment and so two prescription charges”

The Impact of Prescription Charges

1,800 respondents provided comments in response to an open question about their experience of prescription charges.

Written responses from 16-25 year olds and 45-54 year olds indicate that the cost of prescription charges remain challenging for those of all ages.

Responses from 16-25 year olds:

“I have to get my partner and family members to help me out with my prescription costs as I am a student with no income but live in a household for which the income excludes me from the Low Income Scheme”

“It is a huge expense on my part especially as a student, I have about 5 prescriptions every month sometimes more, I have often gone without medication as I cannot afford it but I am not entitled to any benefits even though I have two chronic illnesses”

“I am in a gap year saving my money for university and find that my money gets eaten up by prescriptions”

“As a student I don't have any disposable income, it's all from my student loan, which I have to be careful what I spend on.”

Responses from 45-54 year olds:

“As both me and my husband have an assortment of illnesses between us we do now find it a struggle. I think we have in the region of about 10-12 items per month”

“I need to budget to pay for the Prescription Prepayment Certificate”

“For the last 10 years my parents have paid for this; otherwise, yes, I would have financial problems”

Written responses identify that the cost of prescriptions has a significant impact on general wellbeing, with many reporting doing without essentials such as food, clothing, rent and utility bills:

“I have used money allocated for gas and electricity and put these on emergency credit so that I could have my prescriptions”

“I have been unable to afford petrol to see my family and friends because of it, this has made my mental health worse”

“I have had a couple of days off work to save the cost of petrol as I could not afford both.”

“I cut down on food in order to get medicines. I've also not paid some bills e.g. utilities so got into arrears.”

Written responses from people completing the survey identified a connection between the cost of a prescription and mental stress and anxiety which can exacerbate chronic conditions:

“It is a constant worry which can exacerbate my illness which then leads to more time off work and extra visits to my GP/hospital.”

“I can become more stressed when I am experiencing a flare up and problems with my condition, knowing that the doctors will prescribe me more medication and I have to spend more money on 'trying' to get better”

“It increases my anxiety when I realise I need to pay for one or two prescriptions and I realise I will not have enough money for food later in the week.

“I worry that I will soon retire but not qualify for free prescriptions yet and not qualify for my state pension for several more years.”

“I constantly worry over money especially having two small children to care for, we never have new clothes or any treats, I struggle to pay for little things for my child’s school even the £2 school disco.

“I am worried I will not be able to afford my prescription since losing my tax credits... I am also worried my health may deteriorate if I fail to purchase my prescription.”

People also report taking out loans, or even getting parents to pay for their prescriptions despite being adults:

“I have emptied a penny jar to pay for a prescription before today.

“I have had to borrow money to get them”

“Although I am 32 years old, I have to rely on my family to pay for my prescriptions. This is not a nice situation to be in”

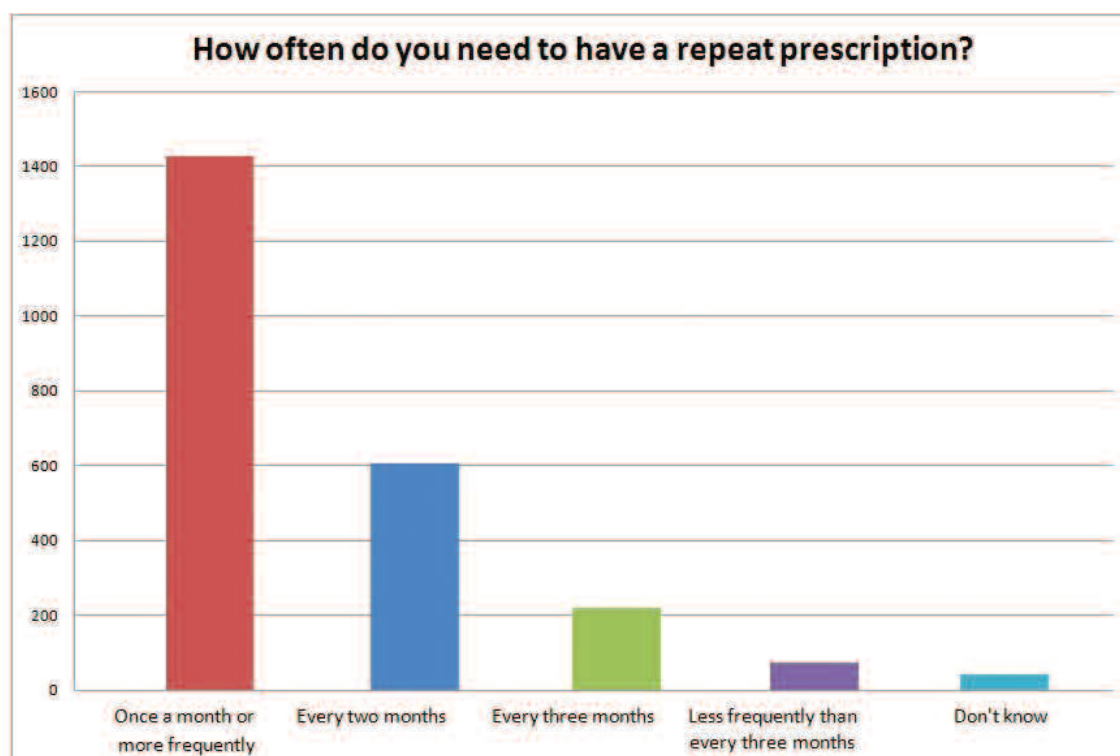
“On one occasion the chemist agreed to give me a prescription and I went back the following week to pay”

Repeat Prescriptions

60% (1,426) of respondents told us they required a repeat prescription once a month or more frequently.

Over 36% (851) of respondents who answered questions about the number and frequency of their prescriptions, report they are unhappy with their schedule for repeat prescriptions.

52.4% (446) of those telling us they were unhappy with their prescription schedule required more than 16 prescriptions a year, which adds further complexity to the management of repeat prescriptions.



Some respondents highlighted the difficulty and inconvenience involved in managing frequent repeat prescriptions, especially fitting this around work

“I think once every three months would be better - I have to remember to order the prescription every month, and collect it, and allow for holidays, mine and public.”

“Too frequent, with a blood test required before each renewal, it makes scheduling both the blood test and repeat request (giving at least 48 hours notice, not at weekends but no more than a week in advance, allowing time for pick up) difficult.”

“The current system is very time consuming; having to drop my repeat prescription forms off every few weeks and then collect a few days later from my GP surgery. On top of this, I have to visit a pharmacy during my lunch hour to pick the medication up. I cannot visit the pharmacy attached to my GP surgery as they are not open when I leave for work. I appreciate that issuing smaller amounts is usually more cost effective when prescriptions are paid for individually but given that I have pre-paid, it would seem more cost-effective for the NHS to be able to issue my medication in quantities covering more than 28 days, when I have already paid for the entire year.”

“I would like it to be longer as this would cut the cost (I will be taking prescribed medicine for 2-5 years)”

For some respondents, the difficulty in managing this planning process and fitting it into their lives means they miss some of their medication or it causes anxiety that they may do so.

“The need to plan ahead and remember to ask for and pick up a repeat prescription stops me from getting medication when I've run out - I sometimes wait until symptoms reappear before being motivated enough to get further prescriptions.”

“I haven't always got the time to go to get my prescription every month.”

“I'd prefer to be able to get my medication for up to six months at a time. I get very anxious when it's getting low and I have to go through the rigmarole of ordering more and collecting it.”

A number of respondents made the point that, as they had been taking the same medication regularly for a number of years and their condition was stable, a longer supply would be more convenient and cost-effective and could be coordinated with their regular reviews

“As I am stable on my medication, it would be of benefit to have a 6 month prescription as I see my GP every 6 months for a check-up. It is sometimes difficult to get a repeat prescription, then collect it and take it to the pharmacy - a month goes past so quickly a longer time would be better.”

“As the medication I am on is for long term, incurable illnesses why can I only order one months worth of pills at a time? Why not make it three months worth to coincide with when I have to visit the surgery for my routine blood tests?”

“My basic medication varies very little, and it takes four visits each month to get a replacement - one to request the prescription, one to collect it, one to take it to the pharmacy and one to collect it again. It would be very helpful if I could get prescriptions every two or three months instead.”

Some respondents were on a number of different medicines, which ran out at different times, adding further complexity to arrangements for collecting repeat medication

“The quantities of each prescription item that I am given at one time vary, so it is sometimes difficult to keep track of when each item needs ordering.”

“Some pills last 15 days, some pills 25 and some 30 days.”



Inequality

Inequality and fairness were key themes emerging from respondents' general comments.

Perception that it's unfair that other long-term conditions are exempt from prescription charges:

"Other long term illnesses seem to have been exempted but there is no reasoning behind the choices"

"It seems very unfair that I have to pay when other conditions are excluded and I pay my taxes too!"

"As I have to take Warfarin for the rest of my life due to having a metal heart valve then exemption should be brought in the same as other health conditions"

"I've managed, but sometimes it has been tough. I work in the NHS in a GP surgery and the whole system needs an overhaul"

"It's upsetting that those with thyroid conditions get prescriptions free as their conditions are considered "for life" and mine (transplant) is not"

Perception of unfairness that the diagnosis of a long term health condition means a lifetime of prescriptions for maintenance medication:

"It is through no fault of my own that I have this disease and I have always paid my National Insurance since starting work at 18 years old"

"It's been a long term drain of thousands of pounds - what do I pay taxes for if not to help people in my situation with long term conditions"

Respondents were also sharply critical of the perceived "unfairness" of free prescriptions in Scotland, Wales and Northern Ireland:

"Assuming I live until I am least 65 my total expenditure based on what I'm currently taking at the current costs will be £5590. If I lived in Wales or Scotland it would be £0. Please tell me how this is fair."

"It goes up each year and I think it is ridiculous the amount it costs, especially when people in Scotland are getting it free!"

"I think it's wrong that people in England have to pay but the Welsh and Scots do not"



Conclusion and Recommendations

History shows that prescription charges have always been controversial and this survey highlights the detrimental effect that they continue to have on people with long term conditions. In current economic times, this impact is likely to be even greater.

The £8.8bn spent on pharmaceuticals in primary care and the additional costs of health professionals' time will only be well spent if the medicines have been used appropriately to ensure the best possible health outcomes. This also has the knock-on effect of enabling those being treated to be more productive members of society, to take up or remain in employment and to reduce the pressure on the benefits system.

As our survey shows, where patients are not taking their medicines as prescribed, health can deteriorate, additional conditions can develop, visits to GPs and other health care professionals and costly hospital admissions can follow. This builds on past research which demonstrates that a high proportion of medicines are not being taken to optimal effect and that, while a number of factors are involved in this, prescription charges are a key element.

However, they have not yet been addressed as part of the raft of initiatives we have seen over the past few years focusing on optimising medicines use and reducing medicine waste or the wider context of an NHS which is based on clinical need and not ability to pay.

The cost barrier

Prescription charges have risen at levels far higher than inflation over the years and now represent a significant expense per item. This can quickly become unaffordable for those with long-term conditions, of working age, who are affected disproportionately by prescription charges. They may also have lower than average incomes due to the impact of their condition on employment and the range of extra costs that can be associated with the management of a long-term condition.

Impact on health outcomes

Difficulties finding the money to pay for medicines have been shown to force a proportion of people with long-term conditions to make decisions over whether to compromise their healthcare or other basic necessities. Our survey results demonstrate that many people with long-term conditions are not collecting their medicines or are delaying, reducing or missing doses or substituting cheaper, but possibly inappropriate alternatives, leading to worsening health, the necessity for additional treatment and/or costly hospital admissions. Where they are taking their medicines appropriately, people facing these financial challenges often have to cut back in other critical areas that will also have an impact on their health condition and outcomes.

The fear of not being able to afford the medicines required for their condition has been shown to cause substantial stress and anxiety, which also has an impact on health and the individual's ability to cope in society.

Nearly three quarters of our survey respondents were not receiving benefits and many were in employment, yet were still struggling to afford prescription charges and some expressed the belief that they were worse off than if they were not working and receiving support.

Making information and support part of the system

The Prescription Prepayment Certificate makes a big difference to some people with long-term conditions, but awareness of this is to a large degree left to chance. Similarly, awareness of the NHS Low Income Scheme was extremely low, suggesting that many who may be able to benefit from this scheme are being prevented from doing so as a result.

Building in flexibility for best outcomes

With many primary care trusts adopting rigid 28 day prescribing policies, there is a clear impact on people with long-term conditions. For those who are on regular medication, which they may have been taking for

a number of years, a longer supply, which fits in with regular reviews, would be much more convenient and cost-effective for all concerned. The Electronic Prescription Service, which should reduce some of the inconvenience of multiple visits to request and collect repeat prescriptions is to be welcomed.

Making it fair and relevant

There is a strong consensus that the criteria for medical exemption from prescription charges are outdated, arbitrary and inequitable.

There is a strong perception of inequality from our survey respondents, in terms of having to pay for a lifetime of medication, given they have worked and paid National Insurance and taxes, especially when those with different but equally serious medical conditions are exempt from charges, and those who live in Wales, Scotland or Northern Ireland no longer have to pay.

Key Recommendation:

Extend prescription charge exemption to all those with long term conditions.

Prescription charges have been demonstrated to be a major barrier to people with long-term conditions taking the medicines they have been prescribed effectively and to impact negatively on health outcomes. This carries significant cost implications for the NHS in terms of the value of health professionals' time, including for additional consultations and treatment required as a result of not taking the medicines appropriately, potential unnecessary or premature hospital admissions, the pharmaceuticals themselves, administration of the prescription charge and exemption system and the cost of lost work days and subsequent benefits that may be required.

Exemption for people with long-term conditions could be achieved in a measured, cost-effective way through a staged reduction in the cost of the Prescription Prepayment Certificate until charges are phased out altogether. Combined with greater promotion, the Prescription Prepayment Certificate would incrementally become cost-effective for more and more people with long-term conditions who require fewer than 14 prescribed medicines a year.

While the Prescription Prepayment Certificate is a significant help for some people with long-term conditions, the cost is still a substantial outlay and it can be difficult to predict if it will be worthwhile, especially for those with fluctuating conditions. For 30% of our survey respondents who paid for their medicines, but did not have a Prescription Prepayment Certificate, the cost was felt to be unaffordable, even where savings would have been made overall.

It is clear that the medical exemption criteria for prescription charges are arbitrary and out-of-date in current times. As our survey respondents pointed out, some long-term conditions which also require regular and essential medicine but are not included, are just as serious, if not more so, than some in the list. The Prescription Charges Review put forward proposals for a broad-based definition of long-term condition and review after three years and we would support this approach.

Recommendation: The frequency and duration of prescriptions for people with stable, long-term conditions on long-term maintenance medication should be based on individual needs and circumstances and agreed between the prescriber and patient, not bound by rigid 28-day prescribing policies.

Reducing medicines waste will be best achieved by ensuring the most effective treatment is in place and medicines are optimised for the individual patient. In the early stages of identifying what works for the individual and for some conditions and medicines, shorter prescribing periods may be advisable. For stable, long-term conditions, three or six monthly prescribing may be the best approach, as it enables people to get on with their life while managing their condition and reduces the cost of unnecessary appointments, including health professionals' time, time off work, petrol and parking costs.

Recommendation: As long as prescription charges remain in place for people with long-term conditions, awareness of entitlements and the help available should not be left to chance. Information should be given routinely to people with long-term conditions about prescription charge exemptions, the Prescription Prepayment Certificate and NHS Low Income Scheme at the point of diagnosis, as part of care planning and supported self-management and when medicines are dispensed and reviewed. Information leaflets and posters should be on display in all GP surgeries and pharmacies in addition to appropriate online platforms.

While awareness of the Prescription Prepayment Certificate (PPC) was found to be high amongst our survey respondents, it may be that they are particularly well-informed as they are already in contact with organisations giving information, advice and support to people with long-term conditions. Nevertheless, it was clear from qualitative responses that it had sometimes taken a significant period of time, and years of huge financial outlay on medicines, before they had discovered it.

The majority were informed by a pharmacist, far fewer by their GP or consultant, an extremely small number through information leaflets and posters – despite the fact that the Department of Health supplies these free of charges to all pharmacies and GP surgeries on an ongoing basis – and many were fortunate to find out through friends and family.

Recommendation: Entitlement to prescription charge exemption should be retained for all those who are currently eligible following the introduction of Universal Credit.

Universal Credit is set to replace benefits which currently “passport” or automatically entitle people in receipt of those benefits to exemption from prescription charges.

It is important to retain an exemption from prescription charges for these people. Better health outcomes as a result of taking necessary medicines, will support people to return to work. Conversely, inability to afford medicines could result in more time out of work and greater reliance on benefits in addition to worse health outcomes.

Ultimately, there will be a disproportionate impact at any income or earnings thresholds, whereby people suddenly have to start paying for medicines, especially if there is no tapering support. This will be exacerbated when other health charges and support, such as free school meals, are also affected.



Appendix

Prescription Charge Exemptions

Entitlement to exemption from NHS prescription charges:

- Aged 60 or over
 - Under 16
 - 16-18 and in full-time education
 - Pregnant or have had a baby in the previous 12 months and have a valid maternity exemption certificate
 - Have a specified medical condition (see below for full list) and have a valid medical exemption certificate
 - Have a continuing physical disability that prevents you from going out without help from another person and have a valid medical exemption certificate
 - Hold a valid war pension exemption certificate and the prescription is for your accepted disability
 - Are an NHS inpatient
-

Medical Exemptions

Although there are many conditions requiring regular medication, only the following qualify for an exemption certificate:

- Treatment for cancer; note this includes treatment for the effects of cancer, or treatment for the effects of a current or previous cancer treatment
 - A permanent fistula requiring dressing
 - Forms of hypoadrenalism such as Addison's disease
 - Diabetes insipidus and other forms of hypopituitarism.
 - Diabetes mellitus except where treatment is by diet alone.
 - Hypoparathyroidism.
 - Myxoedema (underactive thyroid) or other conditions where thyroid hormone replacement is necessary.
 - Myasthenia gravis
 - Epilepsy requiring continuous anticonvulsive medication.
 - A continuing physical disability which means you cannot go out without help from another person.
-

Income-Based Exemptions

Additionally, if a claimant or partner (including civil partners) are named on, or are entitled to, an NHS tax credit exemption certificate or a valid HC2 certificate (full help with health costs), or claim the following:

- Income Support
 - Income-based Jobseeker's Allowance
 - Income-related Employment and Support Allowance, or
 - Pension Credit Guarantee Credit
-

Acknowledgements

As the organisation leading the Prescription Charges Coalition, Crohn's and Colitis UK would like to thank Jackie Glatter and Philip Reynolds for writing this report.

We would also like to thank Prescription Charges Coalition members for their invaluable contributions to the survey and the final report, and for disseminating these to their networks of members and supporters.

Finally, thank you to all those who participated in our prescription charges survey; this report would not have been possible without your input.

