



6 April 2009

Professor Ian Gilmore
Review of prescription charges for those with long-term conditions
Department of Health
Skipton House
80 London Road
London SE1 6LH
Email: eleanorshenton@dh.gsi.gov.uk

Dear Professor Gilmore

Re: Reforming prescription charges

With sincere apologies, our submission to your review is late. Because patients with adrenal failure are exempt from the prescription charge, we were not invited to make a submission and have only just found out about your review. However, as patients with life-long medication dependencies, we have a view on prescription charging, a view which encompasses equitable access to essential medication and security of supply. We therefore hope that you may take our suggestions into consideration.

Summary of main points

1. Prescription charges and length of repeat prescriptions for patients with long-term medication dependencies are two issues that must be reformed in tandem, because of inevitable concerns over the potential for increased medicines wastage where medication is a “free good” and because restricting patients to just 28-days’ supply at a time unnecessarily and artificially limits the medical benefit.
2. The current main mechanism for wastage prevention, 28-day rationing, is inefficient when applied to drugs with a stable, long-term dependency. It is costing the NHS hundreds of millions of pounds in additional expenditure in pharmacy costs.
3. Our estimates suggest it would be possible to phase out prescription charges for the entire UK population on a cost-neutral basis, through a one-third reduction of the current spending on pharmacy dispensing fees and associated charges. The prescription charge brings in around £450 million pounds in revenue, which is about one-third of the £1.36 billion spent on pharmacy costs. A cost-neutral phasing out of the prescription charge could be achieved by extending the length of repeat prescriptions for patients with a stable, long-term medication dependency from the current 28 days to between three and six months, as appropriate.

Further remarks

- One possible option to address the concern for potential medicines wastage arising from phasing out the current prescription charge is described in Appendix B. Appendix A sets out the recent guidance from the National Prescribing Centre for determining where repeat prescriptions of more than 28 days are appropriate. We ask you to note that this



guidance is, from widespread evidence across patient support groups, widely ignored by Primary Care Trusts in the mistaken belief that 28-day rationing saves them money.

- The evidence cited in our submission has been prepared from statistics compiled by the NHS information centre for health and social care, with particular reference to the Prescription Cost Analysis 2007.¹ We wish to acknowledge the comprehensive resources and support provided by the information centre.

1. What are the guiding principles to bear in mind when seeking to extend prescription charge exemption to people with long term conditions?

Concern for human dignity is an important aspect of the way the NHS operates. It is played out in simple, practical ways – such as mixed wards versus single sex wards in crowded hospitals. For people with long-term conditions, human dignity is inevitably a factor in gaining access to the medications on which they depend.

28-day rationing is a constant, disempowering reminder that the patient has a long-term medication dependency. It causes considerable anxiety when patients realise they are running low and are likely to run out over a weekend. It constrains the ability to travel on business or for holidays. And it incurs unnecessary pharmacy charges that are costing the NHS hundreds of millions of pounds.

This is of particular concern to members of the Addison's Disease Self-Help Group, who have an acutely life-threatening dependency on their essential steroid medication. Steroid-dependent patients will feel unwell within hours of a missed dose and will be extremely unwell within a few days of running out of medication. They are unlikely to survive more than seven days without their essential steroid medication.

Therefore, prescription charges and length of repeat prescriptions for patients with long-term medication dependencies are two issues that must be reformed in tandem.

2. How can these principles be applied to define the basis for exempting people with long term conditions from prescription charges? How do we ensure that the approach is fair, transparent and, as far as possible, based on objectivity?

Recognising that human dignity is a fundamental aspect of access to essential medication and medical appliances should be part of the way Primary Care Trusts manage their pharmacy operations and budgets. This means ending the 28-day restriction currently enforced in many Primary Care Trusts on repeat prescription items and replacing by a more effective mechanism to discourage potential medicines wastage.

Total prescription charge income came to around £450 million in 2007/8. Pharmacy costs in the same year were roughly three times that amount – £1.36 billion.

Roughly 15% of total community prescription spending went on pharmacy dispensing fees and associated charges for the 796 million prescription items dispensed in the community in

¹ See <http://www.ic.nhs.uk/statistics-and-data-collections/primary-care/prescriptions>



2007.² Pharmacy costs to issue a prescription averaged £1.71 per item within England in the same year. Total NHS spending on pharmacy costs has risen rapidly in recent years due to the adoption of 28-day repeat prescribing in many Primary Care Trusts³.

Where patients with long-term conditions are stable on their existing medication, it should be possible to achieve significant savings on pharmacy costs by extending their repeat prescription from the current 28 days to three - six months. This would allow spending on pharmacy costs to be reduced – potentially by around one-third – so that prescription charges could be phased out for the entire UK population on a cost-neutral basis.

Primary Care Trusts who adopt a 28-day restriction on repeat prescriptions argue that this prevents medicines wastage and saves them money. However, this is costing the NHS hundreds of millions of pounds in additional expenditure on pharmacy costs, and is therefore an inefficient means of achieving this goal. For patients with long-term medication dependencies, levels of medicine wastage are likely to be low in any case.

The £7.30 prescription charge is an uncomfortable hybrid of means-tested exemptions and 'severity of illness' exemptions that has failed to keep pace with advances in medical technology, prompting the government to initiate the current Gilmore review.

3. Taking account of your views on questions 1 and 2, which conditions do you think should definitely qualify for exemption, and which conditions do you consider should not qualify?

As explained above, it is our view that all patients throughout the UK should be exempt from the £7.30 prescription charge. This is set at an inequitable level that penalises the working poor. It also hinders a genuine understanding among patients of the value of their medication, since it hides the true cost of both cheap and expensive drugs and perpetuates the misguided assumption that all drugs must be expensive.

In practice, many of the drugs consumed by those with long-term conditions are relatively cheap. The ten most frequently prescribed items of medication in 2007 – accounting for more than one-third of all prescriptions – had an average Net Ingredient Cost of £6.47.⁴

Thus, at £7.30, the level of the prescription charge is set above the real cost of many community-dispensed prescription items, so that a large number of those patients who do

² Dispensing fee, processing charges and associated claims.
See <http://www.ic.nhs.uk/statistics-and-data-collections/primary-care/prescriptions>

³ Dispensing fee spending rose by 5% per annum in each year from 2003 to 2007. See *Prescriptions dispensed in the community 2007*. <http://www.ic.nhs.uk/pubs/presdisp97-07>
The average pharmacy charge per prescription item of £1.71 for England now stands at more than one-third of the Net Ingredient Cost of £4.62 for all class 1 generics. Class 1 generics accounted for 64% of all prescription items dispensed in 2007.

⁴ See <http://www.ic.nhs.uk/statistics-and-data-collections/primary-care/prescriptions>
The ten most-frequently prescribed drug items and their Net Ingredient Costs are: Angiotensin-Converting Enzyme Inhibitors (£5.34), Antiplatelet Drugs (£5.91), Beta-Adrenoceptor Blocking Drugs (£3.63), Calcium-Channel Blockers (£6.66), Lipid-Regulating Drugs (£12.52), Non-Opioid Analgesics (£4.95), Proton Pump Inhibitors (£8.02), Selective Beta(2)-Agonists (£7.92), Thiazides And Related Diuretics (£1.87), Thyroid Hormones (£2.22). These items together have an average Net Ingredient Cost of £6.47.



pay for their prescriptions are being charged more than the actual cost of their medication to the NHS. Only those patients on the less frequently prescribed and more expensive drugs are benefiting from the current system.

There are now a number of prescription items where paying patients would be better off asking their GP to write them a private prescription for a 3 or 6 month supply, rather than accept a 28-day repeat on the NHS.⁵ Although only a small proportion of patients are yet in the habit of verifying the true cost of their medicines, this information is now freely available to the public on the British National Formulary website.⁶ Thus, over time, a growing number of paying patients are likely to become disenchanted as they realise they are being effectively over-charged by the NHS. A flat-rate prescription charge also acts as a regressive form of taxation that disproportionately affects those employed in lower-income occupations.

The £7.30 prescription charge applies to around 50% of the UK population. However, in practice only around 12% of prescription items are paid for, as those in the existing exempt categories receive more medication for long-term conditions than those eligible to pay. The elderly consume more than 60% of exempt medications; their exempt medications represented a Net Ingredient Cost of £4.48 billion in 2007.

At present, the UK has a regressive and inequitable flat rate prescription charge that levies a surplus charge above the true cost of the drug on many of those paying it. This is unsustainable, if only because around 88% of prescription items evade it. As described above, concern about prescription wastage has seen an inefficient and expensive form of rationing bolted on to the prescription charge, in the form of the 28-day limit on repeat prescriptions.

4. What could be the anticipated health benefits of extending exemption to patients with long term conditions? What other potential benefits could be achieved by extending prescription charge exemption?

Allowing patients with long-term medication dependencies to receive an extended three – six month supply would have appreciable health benefits. Most importantly, it would reduce the potential for adverse outcomes from missed doses, where the patient runs low on their essential medication. Longer prescription lengths would reduce the likelihood of preventable patient deaths in the event of national drug shortages, such as are predicted to occur during pandemic flu.

Even during normal, stable conditions, the 28-day limit causes major difficulties for patients with an acutely life-threatening dependency on steroid medication, because they are frequently only days away from running out of their essential medication. The Addison's Disease Self-Help Group can document numerous instances where its members have come close to or have, in fact, run out of one of their essential steroid medications, despite their best efforts. This has occurred through circumstances such as manufacturing breakdowns or

⁵ Even allowing for a 100% mark-up by pharmacy retailers.

⁶ See www.bnf.org



production shortages, disruption to wholesaler and retail supplier chains, order and delivery delays at a retailer level, or even just the intervention of a long weekend in the process of ordering the repeat.

Despite the real risks to patient safety in a 28-day limit, many PCTs have imposed this across the board, in the belief that it prevents medicines wastage and saves them money.

A recent survey by the British Thyroid Foundation found that around one-third of all thyroid patients are affected by the 28-day limit and that this 28-day limit has caused around 17% of all thyroid patients to run out of their essential levothyroxine medication at some stage.⁷ The average prescription length on levothyroxine is now 6.5 weeks.

Across the UK, the NHS spent **£31.9 million** on pharmacy charges for levothyroxine prescriptions, and **£38.4 million** on Net Ingredient Costs for these same levothyroxine prescriptions in 2007. In other words, for the standard 100mcg levothyroxine tablet, the Net Ingredient Cost per prescription item was just **£1.78**, compared to pharmacy costs averaging **£1.71** per item in England.

Similarly, for England in 2007, the Net Ingredient Cost per prescription item for 10mg hydrocortisone tablets was **£1.92**, compared to **£1.71** for pharmacy costs per prescription item. The average prescription length for hydrocortisone 10mg tablets was four - six weeks.⁸

Yet levothyroxine and hydrocortisone endocrine therapies are a life-long dependency with no switching costs, ie there are no substitute therapies that patients could be switched to. They are among the cheapest drugs on the market: a tablet costs just three or four pence.

The current "one-size fits all" approach adopted by many PCTs, with a universal 28-day limit on repeat prescriptions that assumes all drugs are expensive and may be wasted, is clearly absurd when applied to endocrine medications such as thyroxine and hydrocortisone.

Therefore, reform of the prescription charge and reform of the 28-day limit on repeat prescriptions must be carried out in tandem. They are two sides of the same coin and cannot be tackled in isolation.

In extending prescriptions to three - six months for patients with long-term medication dependencies, the length of the repeat could be determined with reference to the factors outlined in recent advice by the National Prescribing Centre.⁹ These factors are:

- The stability of the patient's condition and how often their clinical management is to be reviewed

⁷ See <http://www.endocrine-abstracts.org/ea/0019/ea0019p345.htm>.

⁸ Hydrocortisone doses are weight-related and can vary from 15mg - >40mg per day. All patients should receive an allowance for illness, as episodes of fever or other infection require double or triple the normal dose.

⁹ The full advice is given in Appendix A.



- The risk of important side effects and hence the need for more frequent monitoring (taking into account the patient's clinical history)
- How likely it is that the patient will take the medicine as they intended
- Safety considerations associated with storing the particular medicine in the home
- Patient convenience including, where relevant, cost in prescription charges

Certain drugs – notably those open to substance abuse – may be best kept on short repeats. As outlined above, we suggest that important additional factor determining prescription length should be to recognise where the patient's medication dependency is acutely life-threatening.

5. What impact could the widening of prescription charge exemption for people with long-term conditions have on

(a) prescribing practice

(b) medicines usage/wastage?

(c) wider initiatives for people with long term conditions – such as care planning?

How can potentially positive aspects be maximised and adverse impacts be mitigated?

The Department of Health currently estimates medicines wastage by patients – in the form of prescription items that are dispensed but not consumed – to have a value of **£100 million** per annum or more. This is around **1.2%** of the total Net Ingredient Cost of all 796 million prescription items dispensed in 2007, or **7.3%** of the amount spent on pharmacy costs in the same year, or roughly three times (**314%**) the amount that was spent in pharmacy costs on levothyroxine prescriptions alone.

If repeat prescription lengths for patients with long-term conditions were generally extended to three – six months (as appropriate to the patient) then spending on pharmacy costs could reduce by around one-third, representing a saving of around £450 million. So we can estimate that unnecessary pharmacy costs currently outweigh patient wastage by a factor of three or more.

Policy-makers may feel that it is advisable to require patients to make some part-payment towards the cost of their medication, so that they value their treatment and are not inclined to waste medicines. The current system of prescription charges and exemptions is a poor mechanism to achieve this, since the groups who consume the most medication are exempt from charges. A 'communication device' that encourages patients to comply with their therapeutic regime and to value their medication should, of course, be relevant to all patients.

If a new pharmaceutical part-payment were to be introduced, to encourage patients to value their medication and comply with treatment, it should be set at such a level that the elderly and unwaged could also contribute it, and it should indicate the true cost of the prescription item to the NHS.



A charge set between 5% and 10% of the Net Ingredient Cost would be one possibility. This would be a genuine part-payment towards the real cost of the drug or medical appliance, on the same basis as VAT, rather than an arbitrary co-payment. Medicines wastage would be more effectively discouraged than at present, because all prescription items would bear the levy.

For the UK, spending on Net Ingredient Costs in 2007 amounted to £8.372 billion. Thus, a 5% to 10% NIC levy might raise somewhere between £400 and £800 million. In other words, the amount raised by an NIC levy might be of roughly the same magnitude as the current prescription charge, but it would be borne by a much broader group of consumers and so would function as a more effective mechanism to prevent medicines wastage.

Such an approach would obviously need to be costed in full, so that its impacts on the elderly or those with multiple long-term conditions – for example asthma and diabetes – were fully understood. Detailed analysis might suggest that NIC part-payments should be capped in some way for the most expensive drugs dispensed in the community or for those patients with multiple, long-term conditions.

The benefits would be a more equitable and transparent system, so that all patients were aware of the true value of their medication. At the same time, patients with long-term conditions would be less at risk of running out of essential medications, either because they could not afford prescription charges, or because their prescriptions were restricted to a 28-day supply.

6. Taking into account your responses to the previous question, what will be the key practical considerations that determine how policy changes can be phased in?

As explained above, reform of the prescription charge and reform of the 28-day limit on repeat prescriptions must be synchronised. Reform of the 28-day limit on repeat prescriptions should see pharmacy costs reduce by around one-third, which will inevitably see a rationalisation of the retail pharmacy sector and some business mergers or closures over time. The role of dispensing doctors may therefore need to be extended, especially in rural areas.

7. What other issues would you wish to raise about exempting people from long term charges?

We would be happy to provide further information on any of the issues outlined in our submission.

Yours sincerely,

A handwritten signature in blue ink, appearing to read "Katherine G White", is written over a light blue rectangular background.

Katherine G White

Chair, Addison's Disease Self-Help Group



Appendix A:

National Prescribing Centre Guidance on prescription length

Balancing the patient perspective against the need to reduce drugs wastage

The Parliamentary Accounts Committee in its 2008 report *Prescribing costs in primary care*, estimated that unused and wasted drugs cost the NHS at least £100 million a year. The Department of Health has commissioned research into medicines waste and the complex and varied reasons why people don't take their medicines as intended, a report will be released in 2009. Meanwhile the Department is keen to minimise the losses due to medicines waste because they represent a direct loss to patient care.

The NHS has adopted a range of measures, involving prescribing and dispensing practice, to meet this objective. However, it is also important to ensure that the patient's perspective is considered when making decisions about prescription duration. Many prescribers, as a matter of policy, now routinely write prescriptions for 28 days. However, where patients have stable long-term conditions, and can manage their stocks of medicines effectively, prescriptions for longer periods may be more suitable and more convenient for patients. In determining how much of a medicine to prescribe, prescribers should first ensure that the prescription meets the clinical needs of the patient.

However, it is important that the views and circumstances of the patient are considered when decisions are taken about their clinical management. Factors to take into account when considering prescription duration for individual patients as exceptions to the usual prescribing policy include:

- stability of the patient's condition and how often their clinical management is to be reviewed
- the risk of important side effects and hence the need for more frequent monitoring (taking into account the patient's clinical history)
- how likely it is that the patient will take the medicine as they intended
- safety considerations associated with storing the particular medicine in the home
- patient convenience including, where relevant, cost in prescription charges

Medicines, Pharmacy & Industry Group

Department of Health

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Appendix B: Proposed Net Ingredient Cost prescription levy

If a new pharmaceutical part-payment were to be introduced, as a 'communication device' to encourage patients to value their medication and comply with treatment, it should be set at such a level that the elderly and unwaged could also contribute it, and it should indicate the true cost of the prescription item to the NHS.

A charge set between 5% and 10% of the Net Ingredient Cost would be one possibility. For the elderly, low-waged or unwaged to contribute this charge, it would require a cap, perhaps set at £5 per item. A full examination of the cost burden on those with multiple long-term conditions – for example asthma and diabetes – might further suggest that an overall cap of, say, £100 per annum unwaged and £200 per annum waged could be appropriate. This would be less than working age asthmatics currently pay for their multiple prescriptions, but would require diabetics to begin paying towards the cost of their drugs.

Elderly patients averaged 42 prescription items per head in 2007.¹⁰ So a 10% NIC levy, applied to an average prescription NIC of £10.51, could hypothetically cost the elderly patient around £44 per annum, on average.

For members of the Addison's Disease Self-Help Group with simple adrenal insufficiency, a 10% levy on the Net Ingredient Cost of their medication would mean the following annual charges:

Medication	Average requirement	Annual Net Ingredient Cost	10% levy
Hydrocortisone 10mg	30mg per day	£25.55	£2.55
Fludrocortisone	0.15mg per day	£29.35	£2.94
Efcortisol	One 5-vial packet per annum	£4.48	£0.45

However, many of our members have multiple autoimmune conditions and we are not immune to the normal complications of ageing, such as osteoarthritis, degenerative eye or heart diseases. A small proportion of our members have insulin-dependent diabetes and severe asthma in addition to adrenal insufficiency.¹¹ These conditions require some of the more expensive drugs routinely dispensed in the community. The impact of a 10% NIC levy on these patients would have to be carefully costed; an equitable 'cap' on total NIC contributions per patient may be required.

¹⁰ See <http://www.ic.nhs.uk/webfiles/publications/PCA%20publication/Final%20version%20210708.pdf>

¹¹ The 2003 UK membership survey (N=495) found the following rates of associated autoimmune conditions: thyroid condition 45%; asthma 14%; psoriatic, rheumatoid or spondylitic arthritis 9%; B12 deficiency 6%; insulin-dependent diabetes 5%; type 2 diabetes 4%; coeliac 3%; Crohn's and ulcerative colitis 2%