

Prescription Charges for People with Long-Term Conditions: Report of the Deliberative Event Hosted by National Voices

National Voices

National Voices is a new umbrella organisation established by and for the voluntary sector, bringing together organisations representing users of health and social care services to give them a stronger voice in policy-making. We work with the policy-making community to ensure that the voices of service users are heard and that their diverse needs and preferences are genuinely placed at the heart of policy development.

Background

National Voices hosted a deliberative event for service users and representatives of its member organisations on Wednesday 4 March 2009 in London. The event was funded by the Department of Health. The agenda and participant list for the event are in the Appendix of this report.

The participants were provided with written information on the Prescription Charges Review in advance, and further information was presented by Dilip Chauhan (Department of Health) at the opening of the event. During the event the participants were divided into groups and their discussions were guided by facilitators.

This report is a summary of all the arguments that were made during the event. It records the diversity of opinion at the event rather than a consensus, and not all arguments recorded are the views of all participants or all member organisations that were present.

1) The effects of prescription charges and free prescriptions for people with long-term conditions

The effects of the current prescription charging system on people with long-term conditions

The participants raised several concerns about the effect of the current prescription charging system on people with long-term conditions who are not exempt. These were that:

- People do not make medical appointments they need because they know that they will be prescribed medication that they cannot afford to have dispensed.
- People do not have their prescriptions dispensed.
- People do not take the prescribed dosage of their medication to reduce the frequency with which they need to have prescriptions dispensed.

The participants suggested that the effects of these behaviours might be that:

- People with long-term conditions have poor health outcomes.
- There is an increased financial burden on health services as a result of these poor health outcomes.
- This increased financial burden might exceed the income from prescription charges.

The other concerns participants raised about the current prescription charging system on people with long-term conditions were:

- People feel penalised for having a long-term condition because they have to pay prescription charges.
- There is low awareness of the current exemptions system, and people do not understand the logic of it.
- It is iniquitous that people with some long-term conditions are currently exempt from prescription charges whilst people with others are not.

- There is a “mythology” that people on incapacity benefit are exempt from prescription charges.
- It penalises young people during their transition to adulthood.

The potential benefits of introducing free prescriptions for people with long-term conditions

The participants suggested that introducing free prescriptions for people with long-term conditions might have the benefits of:

- Incentivising compliance with medication.
- Improving health outcomes.
- Preventing the symptoms of long-term conditions being exacerbated.
- Preventing long-term conditions from causing related poor health outcomes.
- Reducing the financial burden on health services.
- Reducing the financial burden on society as whole, e.g. by reducing the number of people with long-term conditions who are unemployed for health reasons.

The potential disadvantages of introducing free prescriptions for people with long-term conditions

The participants suggested that introducing free prescriptions for people with long-term conditions might have some disadvantages. These were that:

- The policy might cause people with long-term conditions and prescribers to choose medication when other available treatments may be more appropriate. Medication may be perceived as a panacea and other treatments may be marginalised.
- People with long-term conditions may request prescriptions for medication they do not need or will not take.
- The introduction of free prescriptions for people with long-term conditions might make the system an

administrative nightmare. It might become more complex and more expensive to operate.

2) The extension of the list of medical exemptions

The potential benefits of introducing an extended list of medical exemptions

The participants suggested that introducing free prescriptions for people with long-term conditions by producing an extended list of medical exemptions might have the benefit of being:

- The most objective method.
- The most transparent method.
- Simple to administer and to identify those conditions classed exempt.
- Good for people with long-term conditions that make it onto the list.

The potential disadvantages of introducing an extended list of medical exemptions

The participants suggested that introducing free prescriptions for people with long-term conditions by producing an extended list of medical exemptions might have some disadvantages. These were that:

- The list would be impracticably long. It was suggested that there were enough genetic conditions alone to render the list unworkable.
- The list would be continuously increasing in length as medical advances allow people to live with more conditions in the long-term. It would be poorly suited to take account of the emergence of new diseases, e.g. those that might emerge in a similar way to HIV.
- The list would always be discriminatory because some long-term conditions would always be excluded. It would not be perceived as fair by the public because it would be considered as a list of “haves” and “have nots”. The public would also not understand why some conditions were on the list whilst others were not.
- The list would not be well placed to take account of rare conditions or conditions

affecting seldom-heard groups in society.

- The groups who shouted the loudest would have their condition included on the list at the expense of others.
- The list would not be objective, because diagnosis is a subjective process. There would be a need to identify the criteria that would be used to add diagnoses to the list, and this would be a subjective process.
- The list would also penalise people who had symptoms but not a diagnosis. However, it was argued that this problem could be overcome by allowing people who had been given a “working diagnosis” to qualify for exemption.
- There might be problems of poor diagnosis or misdiagnosis.
- The list would ignore the severity of the condition.
- The list would need to be reviewed on a regular basis. This would be bureaucratic and expensive.
- The list would be difficult for prescribers to operate.
- It would be difficult to adjudicate if a diagnosis was contested by a patient or by clinicians.

Other comments on introducing an extended list of medical exemptions

The participants made other suggestions relating to introducing an extended list of medical exemptions.

The suggestions relating to producing and reviewing the list were:

- The list should be produced by an accountable and independent organisation.
- The public, people with long-term conditions and campaigning groups should be consulted on producing and reviewing the list.
- The decisions to include or exclude long-term conditions should be evidence-based.

- The list should be reviewed annually.
- The review process should be transparent and well publicised.

The other suggestions that were made were:

- It would be simpler to introduce a list of short-term conditions than a list of long-term conditions.
- The exemption certificate should continue to last for five years.
- The implementation of the list will rely on I.T. systems and these should be improved.
- The prescription form should be amended to record the diagnosis in order to make pharmacists aware that the person is exempt.

3) The criteria that could be used to define a long-term condition

The criteria that could be used to define the long-term conditions that should be exempt

The participants suggested that exempt long-term conditions should include:

- All life-long or non-curable conditions.
- All terminal conditions.
- All conditions requiring medication for the same symptoms or related symptoms for a prolonged period of time.
- All conditions where the level of need for prescriptions fluctuates.
- Mental as well as physical health problems.
- All conditions that have a significant effect on quality of life.

It was also suggested that:

- Exemption should begin from the point of diagnosis.
- A clinician should assess whether a person has a long-term condition that meets the criteria listed above.
- Preventative medication for people at risk of developing a long-term condition should be exempt. However, other participants suggested that this should not be exempt. They suggested that preventative medication was not a priority, and that preventative medicine should only be included if there was sufficient evidence and guidance for prescribers.
- The length of time a condition needs to last to be classified as long-term was suggested to be 3, 6, 9, or 12 months. Some participants felt strongly that 3 months was too short and that 12 months was too long.
- The exemption certificate should continue to last for five years. This would help maintain the health of people with long-term conditions for a prolonged period of time, and would be useful

for people with long-term conditions with a fluctuating need for prescriptions.

- There should be an appeals process for people who disagree with a clinician's assessment of their condition, and people should have a right to appeal.
- If a clinician does not assess a person's condition as likely to be long-term, but the condition subsequently lasts for a prolonged period of time, the person should be able to reclaim the cost of prescription charges from the point of diagnosis.
- There should be no moral judgements or judgements about deservedness in defining which long-term conditions should be exempt.

The potential benefits of using these criteria to define the long-term conditions that should be exempt

The participants suggested that the potential benefits of using these principles to define the long-term conditions that should be exempt were:

- It would be more flexible than extending the list of medical exemptions.
- It would only require people to have symptoms, not a diagnosis.
- It would be perceived as more fair and equitable than a list.
- It would be shorter and simpler than a list.

The potential disadvantages of using these criteria to define the long-term conditions that should be exempt

The participants suggested that the potential disadvantages of using these principles to define the long-term conditions that should be exempt were:

- It is too subjective.
- The principles would never be exhaustive or definitive.
- The implementation would not be consistent between prescribers and this would be unfair.

- There would be a need to train clinicians in assessing people based on these criteria and this would take time and be expensive.
- The system would not be regarded as transparent by patients and the public.
- Patients and the public might disagree with the principles used to define long-term conditions that should be exempt.

The consideration that should be given to severity, the amount of treatment required, and the potential to improve health outcomes

The participants suggested that these criteria would not be satisfactory. It was suggested that:

- They are all too subjective.
- Severity should not be used as a criterion because it might be perceived differently by the person experiencing it than it is by a clinician.
- Severity should not be used as a criterion because it might penalise people with well managed long-term conditions and act as a disincentive for preventative care.
- Severity should not be used as a criterion because it might cause iniquity between people with the same diagnosis, as some people with the diagnosis would be exempt whilst others would not.
- The potential to improve health should not be used as a criterion because for many people with long-term conditions medication maintains health rather than improving health.
- The amount of medication required should not be used because it might penalise people with a condition for which not much medication is required, even if this medication is essential.

4) Alternative ways to introduce free prescriptions for people with long-term conditions

The participants suggested other ways of introducing free prescriptions for people with long-term conditions. These were:

- Linking exemption to incapacity benefit. However, other participants suggested that exemption should not be linked to benefits.
- Producing a list of exempt medications rather than a list of exempt long-term conditions. However, it was suggested that this would not be suitable as it would require people to pay prescription charges for medication for the acute health problems that can directly result from a long-term condition.

5) Case studies

The case studies that provoked debate amongst participants were those for hay fever, sporadic asthma, and vascular heart disease. In general the participants suggested that the other case studies should be exempt.

It was suggested that the **hay fever** case study (Clayton) should not be exempt because:

- The symptoms do not last for long enough to qualify as a long-term condition.
- The symptoms do not occur regularly enough to qualify as a long-term condition.

The participants suggesting that he should be exempt argued that:

- The exemption should not be dependent on having symptoms.
- The allergy to pollen is life-long and non-curable, even if there is no pollen in the air.
- The symptoms do occur regularly enough for it to qualify as a long-term condition.
- If he visited other countries he might need medication more regularly.

It was suggested that the **sporadic asthma** case study (Barbara) should not be exempt because:

- Her condition did not last for a prolonged period of time.
- Her condition only affects her once every four or five years.
- Her condition does not require continuous medication.
- If somebody with her condition was exempt, everybody would be exempt.

The participants suggesting that she should be exempt argued that:

- The list of exempt diagnoses should include asthma, so she should be exempt regardless of the nature of her symptoms.

- The length of her recovery period should make her exempt.
- She should not be penalised for having a fluctuating condition.

It was suggested that the **vascular heart disease** case study (Salim) should not be exempt because:

- Preventative medication should not be exempt.

The participants suggesting that he should be exempt argued that:

- He is at risk of developing a long-term condition and preventative medication should be exempt.

6) Implementing free prescriptions for people with long-term conditions

The participants suggested several ways of introducing free prescriptions for people with long-term conditions. These were:

- Introducing free prescriptions for people with long-term conditions in a “big bang”.
- Gradually reducing the cost of prescription charges for people with long-term conditions over a longer period of time.
- Using means-testing to introduce free prescriptions for people with long-term conditions who are least able to pay first.

The participants expressed concern that if the policy is not implemented soon then it will not be implemented at all. It was suggested that the Government should be encouraged to implement the policy before the next general election.

The other comments made by participants were:

- The exemption should be implemented in a way that makes people with long-term conditions feel that the system is on their side.
- The implementation should be the same across the country and not dependent on which Strategic Health Authority or Primary Care Trust a person lives within.
- The implementation should not be means-tested. However, other participants suggested that socio-economic circumstances should be taken into account.
- The implementation of the policy is an opportunity to reduce health inequality.
- The implementation of the policy is an opportunity to improve public health and prevent poor health outcomes.

The Pre-Payment Certificate

The participants suggested that there was a need to improve awareness and uptake of the Pre-Payment Certificate.

It was suggested that the Pre-Payment Certificate requires people with long-term conditions to calculate in advance whether the certificate will be cost-effective or not. In practice this can result in people paying more than is necessary for their prescriptions. The participants suggested improving the Pre-Payment Certificate by:

- Making the cost of the Pre-Payment Certificate the maximum a person with a long-term condition would be required to pay, regardless of whether a Pre-Payment Certificate is purchased in advance.
- Allowing people who purchase a Pre-Payment Certificate to reclaim its cost if they have not used a sufficient number of prescriptions to make it cost-effective.

Medicine use reviews

The participants suggested that the awareness, availability, and uptake of medicine use reviews should be improved. It was suggested that medicine use reviews are not simply tick-box exercises. They should be holistic assessments of medicine use and the role of medication in the care of a person with a long-term condition.

Information Prescriptions

The participants suggested that there might be a possibility to use Information Prescriptions to inform people of the need to comply with their medication and of their exemption from prescription charges.

Care plans and care planning

The participants suggested that the awareness, availability, and uptake of care plans and the care planning process should be improved. They suggested that this process should include a detailed discussion of a person's medication needs and usage.

However, it was suggested that people with long-term conditions should not be required to have a care plan to qualify for exemption for prescription charges.

Communication

The participants suggested that good communication with people with long-term conditions and prescribers is essential. It was suggested that:

- The emphasis should be on clinicians and pharmacists to inform people.
- There should be advertising in GP surgeries and pharmacies.
- The third sector has a role in informing people, e.g. through websites and newsletters. The third sector should be funded to do this.
- The information should be put on a simple website.

It was also suggested that both medical and non-medical prescribers will need to be made aware of the exemptions.

7) Other comments about prescription charges

The participants suggested that free prescriptions should be introduced for everyone, because:

- This would be the fairest solution.
- It is iniquitous that prescription charges are not being abolished in England, given that they have been abolished in Wales and are due to be abolished in Scotland and Northern Ireland.
- Prescription charges are a co-payment that should not be required by the NHS.
- Free prescriptions would improve public health.

The participants also suggested that:

- It is unfair that the prescription charge does not relate to the cost of the medication being dispensed.
- It is unfair that the prescription charge does not relate to the amount of medication that is dispensed.
- Many prescription medications are available over the counter at a lower price than the prescription charge, but people rely on pharmacists to tell them about this cheaper option.
- The current age exemptions are irrational.
- The introduction of free prescriptions for people with cancer was not evidence-based and introduced more iniquity into the system.

Appendix I: Agenda

Prescription Charges for People with Long-Term Conditions

Wednesday 4 March, 10.30 – 16.00

The Royal National Hotel, Bedford Way, London WC1H 0DG

10:30 – 11:00: Registration

11:00 – 11:15: Welcome from David Pink

11:15 – 11:45: Introduction to the Prescription Charges Review by Dilip Chauhan (Department of Health)

11:45 – 12:30: Table Discussion 1: Introduction

12:30 – 13:15: Lunch

13:15 – 14:00: Table Discussion 2: A List of Medical Exemptions?

14:00 – 14:15: Break

14:15 – 15:00: Table Discussion 3: A Definition of Long-Term Conditions?

15:00 – 15:50: Table Discussion 4: Case Studies

15:50 – 16:00: Closing

Appendix II: List of Participants

Vicky Backhurst	National Rheumatoid Arthritis Society
Steve Benveniste	Stroke Association
Margaret Bowler	Myotonic Dystrophy Support Group
David Congdon	Mencap
Jan Curtis	Patients on Intravenous & Naso-Gastric Nutrition Therapy
Phil Cutler	Bradford Alliance on Community Care
Tom Gentry	Arthritis Care
Kail Gunaratnam	Croydon LINK
Alan Hartley	Royal Pharmaceutical Society of Great Britain
Mariam Kemple	Mind
Robin Kenworthy	Kent LINK
Helen Kirrane	Parkinson's Disease Society
Andrew Langford	Skin Care Campaign
Peter Lyne	Disabled Motorist Federation
Laura Meehan	Children's Liver Disease Foundation
Maribel Mendoza	Children's Liver Disease Foundation
Irene Oakley	Myositis Support Group
Alison Railton	Motor Neurone Disease Association
Elizabeth Rang	Ileostomy and Internal Pouch Support Group
Martin Rathfelder	Socialist Health Association
Kate Ravenscroft	Asthma UK
Dana Richardson	Essex & Southend LINK
Jo Rooney	Barnardos
Jane Skerrett	NASS
Richard Smith	Leicester LINK
Caroline Snoch	Klinefelter's Syndrome Association
Ian Stuart	Cavernoma Alliance UK
Monty Taylor	Colostomy Association
Lynn Tourle	Patients on Intravenous & Naso-Gastric Nutrition Therapy
Stella Valerkou	Diabetes UK
Heather Walker	Sarcoidosis and Interstitial Lung Association
Gillian Watt	British Heart Foundation
Russell Young	IGA