



**Genetic Alliance UK**  
Supporting. Campaigning. Uniting.

## Pharmacy dispensing models and displaying prices on medicines consultation

### Prices of medicines on dispensing labels

Department of Health and Medicines and Healthcare products Regulatory Agency

Response from Genetic Alliance UK, 17<sup>th</sup> May 2016

### Introduction

1. Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by all types of genetic conditions. We are an alliance of over 180 patient organisations. Our aim is to ensure that high quality services, information and support are provided to all. We actively support research and innovation across the field of genetic medicine.
2. Rare Disease UK (RDUK) is a campaign initiative run by Genetic Alliance UK. It is the national alliance for people with rare diseases and all who support them. RDUK is a stakeholder coalition brought together to work with Government to develop a UK Strategy for Rare Diseases, which was published by the Department of Health in November 2013. RDUK continues to campaign for the implementation of the Strategy across all four home nations of the UK.
3. SWAN UK (Syndromes Without A Name) is a patient and family support initiative run by Genetic Alliance UK. It is a UK-wide network providing information and support to families of children without a diagnosis. It works to support the development of high quality information and services for families of children affected by undiagnosed genetic conditions and raise public and professional awareness of undiagnosed genetic conditions and the unique challenges faced by affected families.
4. Genetic Alliance UK speaks from the perspective of families affected by genetic and rare conditions who look toward innovation and research as a means to deliver effective therapies for currently untreatable conditions. These innovative treatments can often be high cost medicines, and we recognise the broad support that exists for ensuring the NHS-wide commissioning of such medicines from the public, patients and government, particularly when the medicine is required by children. We welcome the opportunity to respond to this consultation.

**Question 8: Before changes can be made for the price to be displayed on NHS dispensed medicines, enabling amendments need to be made to the Human Medicines Regulation 2012. Do you agree with these amendments to the Human Medicines Regulations 2012?**

5. No. While we acknowledge that the proposed changes to the Regulation only permit the display of pricing rather than require it, we still question the reasoning of the proposal (see questions 9 and 10), and so consider the changes to be unnecessary.

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**Question 9: Are you aware of any other evidence that supports the impact of patients' understanding of the prices of health services on their behaviour, including from local initiatives? If so, please give details?**

6. No. We are very concerned about this proposal, which is likely to be very difficult to implement and also to not have the intended effect. At least within the field of rare and genetic conditions, patients tend to already be aware whether they are taking a high cost medicine.
7. NHS England has not presented any evidence to support the claim that printing the prices of high cost medicines on the packaging will increase adherence. On the contrary, this proposal is may have a negative impact. We are concerned that vulnerable patients may stop taking their medicines, or reduce their dosage, without consulting their doctor, due to guilt or other feelings regarding the cost of the medicine.
8. This measure should not be implemented without significantly more research into the likely consequences.

**Question 10: Do you have any views on the proposed implementation in the NHS in England? If so, please give details?**

9. We are deeply concerned that this proposal will not have the intended effect of increasing medicines adherence, and is likely to have unintended negative effects on patients, as discussed in our response to question 9. We would urge the Department of Health wait until the likely impact of this proposal has been evaluated through substantial research before taking any steps to implement package pricing.

A handwritten signature in blue ink that reads "Alastair Kent".

Alastair Kent OBE, Director