

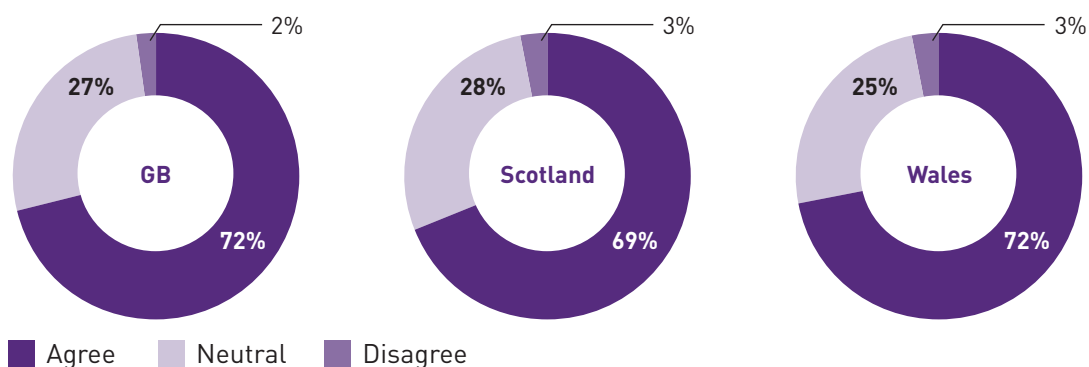
Strong Public Support for Equal Access to Treatment for Patients with Very Rare Diseases

A summary of public opinion in Great Britain towards access to therapy for very rare diseases*

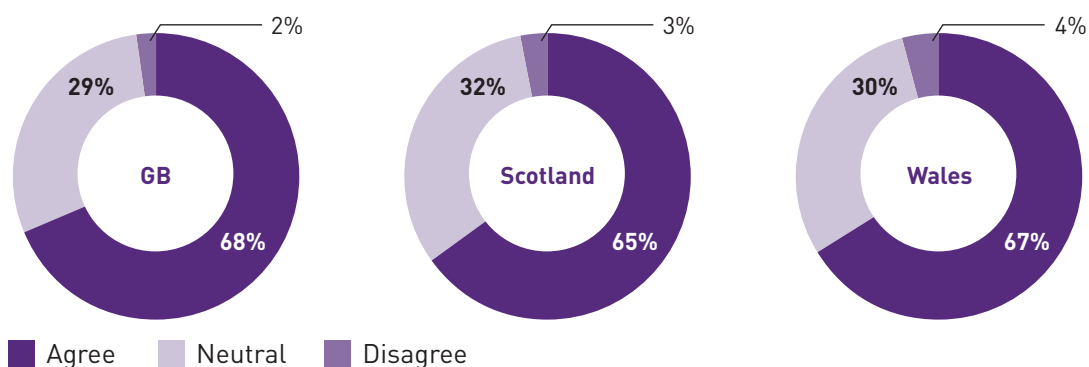
Summary of key data

New polling data reveals the following key findings regarding public opinion towards access to therapy for very rare diseases.

- Almost three quarters of the public agrees that patients with a very rare disease should have the same access to treatment as patients with common diseases
- Patients should have access to a treatment based on clinical need, even if this would be individually costly to the NHS because of the rarity of the disease:



- A large majority of the public supports equal access to treatments for very rare diseases even if savings have to be made elsewhere in the NHS
- The NHS should ensure patients with very rare diseases have the same access to treatment as patients with common diseases, even if it means savings have to be made elsewhere in the NHS:



Data and methodology

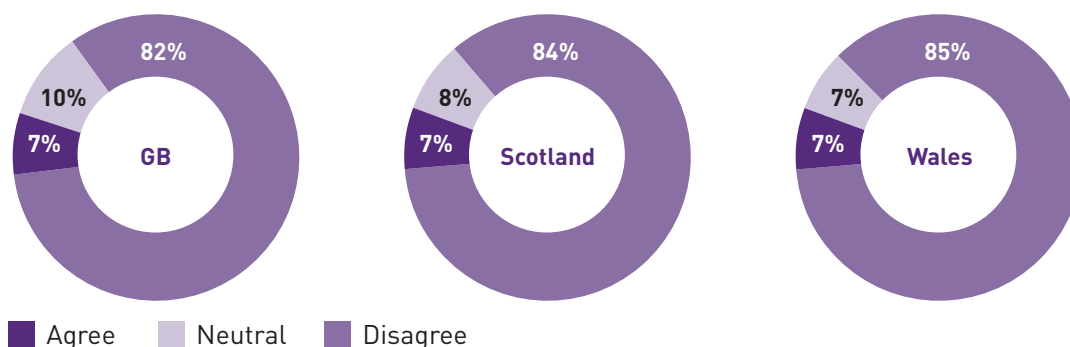
*This document provides an overview of polling undertaken across Great Britain, as well as separate data for Scotland and Wales on attitudes towards patient access to treatments for very rare diseases. The polling was conducted by Populus and commissioned by Genzyme Therapeutics Limited and is available at:

<http://www.populus.co.uk/Poll/Genzyme-Reasonable-Access-Profits-Survey/>
<http://www.populus.co.uk/Poll/Genzyme-Devolved-Nations-Survey/>

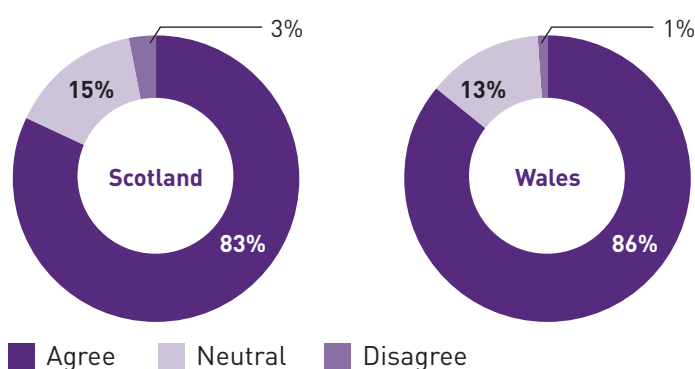
Populus interviewed 2,011 GB adults online between 26 and 27 February 2014. Results have been weighted to be representative of all GB adults. In a follow-up survey, Populus interviewed 1,002 adults in Wales and 1,001 in Scotland online between 28 April and 6 May 2014. Results within each nation have been weighted to be representative of the adults who live there. Where results do not sum to 100% this is due to rounding.

Populus is a member of the British Polling Council and abides by its rules. For more information see www.populus.co.uk

- Against a backdrop of the NHS facing a potential £30 billion funding gap, the public strongly agrees that the NHS should not ration access to expensive medication to create cost savings
 - Given the state of NHS finances, the NHS might decide that medicine, which it has been buying for years at the same price is now 'too expensive' to be provided by the NHS. The patients who have been taking the medicine would have no alternative treatment available. Should this be allowed?:



- The public in Scotland and Wales strongly agrees that patients in devolved nations should have the same access to treatment as patients in England
 - People with very rare diseases in Scotland/Wales should have the same access to treatments and services as people in England:



BIA recommendations

This new data underlines the importance of access to treatments for patients with very rare diseases. The BioIndustry Association (BIA) continues to call for:

- Equal access to treatment for patients with very rare diseases across the NHS
- A fit for purpose evaluation framework for ultra-orphan medicines
- A system where the incentives for the research and development of orphan and ultra-orphan medicines are aligned with the broader development and regulatory process

The BIA report *Very rare diseases, complex issues* can be found at:

<http://bia.me/VeryRareDiseases>

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