**PATIENT or CARER QUESTIONNAIRE**

**We would like to understand what it’s like to have a disease or condition, or to care for someone who has it. Anything you tell us about your experience of the disease or condition will be very helpful.**

Telling us about the effects of a living with a disease or condition will help members of the All Wales Medicines Strategy Group (AWMSG) to decide whether a new medicine might significantly improve the lives of patients and carers. We also ask clinical experts about the disease or condition, to give us their views and the medical facts.

**At AWMSG’s assessment meetings, a lay member will summarise all comments received from patients, carers and patient organisations.**

We don’t need to know who individual patients or carers are. So please don’t give us any personal details that might identify you or someone else (such as full names, dates of birth, addresses). If you do include any personal details on this form, we will remove them before the members of AWMSG’s medicines assessment groups read it.

We won’t put any completed forms on a website or in the public domain.

**Please fill in this form and email it to us at the All Wales Therapeutics & Toxicology Centre (AWTTC) at** [**AWTTC@wales.nhs.uk**](mailto:AWTTC@wales.nhs.uk)**, or post it to us at the address below.**

See our website for the deadline to return this form.

If you have any questions or if you find it difficult to fill in the form, please contact we and we’ll try to help. You might also find our [Involving Patients and Carers FAQ](http://www.awmsg.org/awmsgonline/patient_questions.html) document useful.

**Patient organisations:**

If you’re filling in this form on behalf of a patient organisation or support group, please fill in sections 1 **and** 2. Information entered in section 2 relates to the organisation and may be used again if you fill in other questionnaires for us in the future.

**Section 1: General information and medicine details**

**I am a** (please tick as appropriate):

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| --- | --- |
|  | **patient**  **carer**  **Patient organisation** (name): …………………………………………………………….. |
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| **Disease or condition:**  **Medicine being assessed:** |

**Experience of the disease or condition and any treatments for it**

**Q1 How does the disease or condition affect your daily life?**

***[For example, you could include: what it stops you from doing; how it affects your ability to work, your mental health, your social life, and your relations with your family and friends.]***

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**Q2 Have you had any previous treatments for this condition? Please describe your experiences, including any advantages or disadvantages.**

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**Q3 Which aspects of living with this condition are NOT met by the treatments currently available?**

***[For example, what do patients need the most help with?]***

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| **The new medicine** |

**Q1 Have you heard of this medicine, or have you been treated with it? If so, please describe your experience.**

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**Q2 What do you think its advantages or benefits are?**

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**Q3 What do you think its disadvantages or risks are?**

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**Q4 What effect might this new medicine have on your life?**

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**Section 2: Patient organisation details**

**ONLY complete this section if you are submitting information on behalf of a patient organisation or support group.**

Notes:

It is important that individual patients are not identifiable. The information you give us will be kept confidential and will not be put on the All Wales Medicines Strategy Group website. The All Wales Medicines Strategy Group meetings are held in public and it is usual practice for members to refer to information in the patient organisation questionnaire. Organisations are reminded of the [Data Protection Act](http://www.legislation.gov.uk/ukpga/1998/29/contents), the [Freedom of Information Act 2000](http://www.legislation.gov.uk/ukpga/2000/36/contents) and [Human Rights Act](http://www.legislation.gov.uk/ukpga/1998/42/contents).

If you would prefer your organisation not to be named in our report, please tick this box

**Information about your organisation**

**Q1 Please provide an overview of your organisation**

It would be helpful to include its aims and an outline of membership.

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**Q2 Please list any pharmaceutical companies that are corporate members of your organisation**

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**Q3 Please list all funding received from pharmaceutical companies in the last TWO years**

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| --- | --- | --- |
| **Pharmaceutical company** | **Amount received** | **Reason** |
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**Q4 For all people who played a significant role in completing this questionnaire, please provide the following information:**

* Is the person a shareholder or director of the pharmaceutical company that makes this medicine?
* Has the person, or the organisation to which they belong, been given support in cash or kind from the company, but not related to this specific medicine?
* Has the person, or the organisation to which they belong, been given support in cash or kind in respect to this specific medicine?
* Has the person taken part in a clinical trial or study for this specific medicine?

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