Access to newly licensed medicines

Macmillan Cancer Support

Background

There have been considerable improvements to the system of access to newly licensed medicines in Scotland over the last few years and the Scottish Parliament has been instrumental in this. We also recognise action taken by the Scottish Government in implementing change and welcome the continuing commitment to improve access.

Although these changes have resulted in a better system, there are still groups of patients for whom the process does not work well, particularly people with rarer cancers. The proposed introduction of value-based pricing in 2014 will hopefully address many of the issues around access to medicines, but as value-based pricing will only apply to newly licensed medicines, there will be a continuing need for some years to ensure that we have the best system possible for fair and equal access to medicines in Scotland.

Continuing issues with access to cancer medicines

1. Use of the IPTR process

The IPTR process is designed for patients who can show that they are likely to gain additional benefit from a treatment compared to the general patient population and when used for this it tends to work well. However, the Government continually states that if the SMC does not recommend a treatment, the patient may be able to access it through the IPTR process which, for most people, is incorrect. This misconception has led to confusion and disappointment for patients and has also led to a lack of focus on the actual issue, which is clinically effective treatments that are not being recommended by the SMC on the grounds of cost. There should be clear communication about the role of the IPTR process and it should not be put forward as the solution to improved access to medicines.

2. People with rarer cancers

Treatments for orphan and ultra orphan diseases are more likely to be turned down by the SMC as they tend to have a higher cost per QALY because of high development costs and clinical trial evidence can be limited because the patient group is so small. The IPTR process does not work for people with rarer cancers because it is their exceptionality as a patient group, rather than as individual patients that is an issue.
3. Treatments for people at the end of life

For treatments for people nearing the end of life, improvements in quality and quantity of life tend to be incremental and can therefore attract a high cost per QALY and be less likely to be recommended by the SMC. However, the IPTR system is not appropriate as an alternative because people tend not to be ‘exceptional’ within their patient group.

Committee inquiry

The Health and Sport Committee should focus on the root causes of why medicines are not recommended by the SMC. The number of negative decisions by the SMC has been increasing and it is important to understand why.

The areas the Committee should focus on include:

- Quality of industry submissions, including poor economic modelling and uncertainty in clinical trials data.
- Whether the SMC process can be adapted to work better for certain patient groups, such as people with rarer cancers and those at the end of life.

Potential solutions

What the industry can do:

- Look at the cost of medicines which are often too high.
- Offer patient access schemes at submission stage.
- Continue to improve the quality of submission.

What the Scottish Government/Parliament/SMC can do:

- Communicate clearly over the differing purpose of the SMC and IPTR processes.
- Encourage patient access schemes and the use of modifiers.
- Review the process for orphan/ultra orphan and end of life treatments to see where main problem is and how it can be addressed.

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