

Access to newly licensed medicines

Prostate Cancer UK

Prostate Cancer UK (formerly The Prostate Cancer Charity Scotland) welcomes the opportunity to submit evidence to the Health and Sport Committee on newly licensed medicines and Individual Patient Treatment Requests (IPTRs).

Prostate Cancer UK is the leading charity for men with prostate cancer. We fight to help more men survive and enjoy a better quality of life. We support men and provide vital information. We find answers by funding research. And we lead change, raising awareness and improving care. We believe that men deserve better.

Prostate cancer is the most common cancer in men in Scotland. 2,700 men are diagnosed with prostate cancer every year, and 19,000 men in Scotland are currently living with the disease. 790 men die of prostate cancer every year in Scotland.¹

We are committed to delivering a range of services tailored to the specific needs of men, their partners and families in communities across Scotland. A series of pilot services are currently in operation with plans to further develop these services across regions and communities.

The current approval process for new medicines

Prostate Cancer UK believes that the Scottish Medicines Consortium (SMC) currently provides very limited patient and public involvement when assessing new medicines and technologies. Patient and public involvement is limited to one submission from patient organisations, such as Prostate Cancer UK, who submit evidence to the appraisal of new drugs but do not receive any feedback from their submissions. This can cause much upset as people affected by prostate cancer want to feel their voice is being heard. From our experience, the recent SMC evaluation of abiraterone highlighted the lack of patient and public engagement offered by the SMC.

We believe the SMC could adopt better models of patient engagement. From the beginning of the assessment process the SMC should have mechanisms in place which enable meaningful engagement with patients and patient groups. For example, the SMC could ask patient organisations to nominate patients with an experience of a disease and other clinical experts to provide their view on what an appraisal should cover. This would ensure the 'patient voice' is represented from the beginning.

Furthermore, we believe there should be opportunities for patient representatives to provide oral evidence to the SMC when they are considering the evidence in committee. To enable better scrutiny and transparency we also believe the SMC should consider whether it may be

possible to publish a draft decision, after which there would be a further opportunity for patient organisations and individuals to comment on that decision. The National Institute for Health and Clinical Excellence (NICE) in England and Wales, for example, has produced some measures on patient and public involvement during their technology appraisal process.

We are disappointed that the Committee Oral Session on 18th September 2012 has not invited any patient organisations to give evidence on their experiences on the process around newly licensed medicines, the assessment of, and access via Individual Patient Treatment Requests (IPTRs). We believe that without input from those affected by conditions, it devalues the process.

Value-based Pricing

Value-based Pricing is a new way of pricing new medicines from April 2014. Discussions between the Department of Health in England and the Association of British Pharmaceutical Industry (ABPI) are about to begin in next month, but it is expected that a settlement will be UK-wide. Whilst we understand that the Health and Sport Committee will be working hard over the next twelve months to understand how Value-based Pricing will be implemented in Scotland, we wish to feed in the patient perspective.

We think every person with cancer should have access to any treatment their doctor recommends for them. Prostate Cancer UK recently saw abiraterone approved for men with advanced prostate cancer and the difference this has made to men in Scotland. Unfortunately, we do not think enough has been done to involve people with cancer, or any disease, in the development of the new approach to pricing drugs. This approach will be based on the views of general public rather than specifically the views of people with diseases or long term conditions, such as people with cancer. This is a problem because healthy people and people with diseases and long term conditions often value the benefits of new drugs in very different ways.

Prostate Cancer UK want to make sure that cost-effective drugs which make the biggest difference to people with cancer are approved for use on the NHS. This is why we want to ensure that the views of people with cancer are put at the heart of the new approach to pricing drugs. Understanding key priorities for people with cancer in defining 'value' of new drugs is key. We have therefore commissioned a research project which aims to find out what people affected by cancer think the most important issues are when it comes to defining the value of new drugs. These findings will be presented to the Department of Health and ABPI in October. We would be very happy to share our findings with the Health and Sport Committee.

IPTRs

When SMC rejects a drug being made available on the NHS, the only option is to apply for funding via an Individual Patient Treatment Request (IPTR). However, there is no duty for the local Health Board to routinely fund drugs

which have been rejected by the SMC. An IPTR must be completed by the clinician responsible for the patient for whom the medicine is being sought.ⁱⁱ

Before abiraterone was finally approved by the SMC, IPTRs were the only option for men with advanced prostate cancer to receive abiraterone on the NHS. This meant that there was a real possibility of a 'post code' lottery existing between those health boards who agreed to IPTRs and those who did not. Prostate Cancer UK views this arrangement grossly unfair.

Prostate Cancer UK generally views IPTRs as a good option for men to access new medicines which have been licensed, but not yet considered by the SMC. However, we question the subjectivity of each request and the associated bureaucracy involved in trying to access medicines which many men could potentially benefit from. Furthermore, there is an unfairness of some men being able to access new medicines in some areas of Scotland but not in others.

We welcome the opportunity to provide an overview of our experiences and recommendations and provide case studies. We will watch with interest what next steps are agreed in terms of newly licensed medicines in Scotland going forward.

ⁱ ISD Scotland

ⁱⁱ http://www.sehd.scot.nhs.uk/mels/CEL2010_17.pdf

Prostate Cancer UK
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