

1. Introduction

- 1.1 The Rarer Cancers Foundation (RCF) offers advice and information to people with rare or less common cancers and to their families and friends. The charity facilitates supportive networking, raises awareness of rare and less common cancers and works to ensure that people with rarer cancers have access to the best possible services.
- 1.2 The RCF welcomes the opportunity to contribute to the Health and Social Care Committee's Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan. The RCF has conducted in-depth research into a variety of issues affecting cancer care and treatment in Wales over the last few years and many of the findings are relevant to the Committee's inquiry.
- 1.3 We believe that our research findings are particularly relevant to two of the areas being considered by the Committee:
- Whether patients across Wales can access the care required (for example, access to diagnostic testing or out-of-hours care) in an appropriate setting and in a timely manner
 - Whether the current level of funding for cancer services is appropriate, used effectively and provides value for money.

2. Access to required care

- 2.1 The Cancer Delivery Plan set an ambition for Wales to be "*amongst the best in Europe for cancer treatment*". However, there is currently a wide disparity in access to cancer treatments between Wales and England, with patients in Wales unable to routinely access many treatments that are available to patients elsewhere. This means that currently Wales is not even amongst the best in the UK for cancer treatment.

Disparities with England and Scotland

- 2.2 In both England and Scotland mechanisms have been put in place to enable patients to routinely access cancer treatments that have been rejected by NICE. In England, patients can get access to 32 treatments indications rejected by NICE through the Cancer Drugs Fund. In Scotland, the Scottish Medicines Consortium has approved ten cancer treatments that have been rejected by NICE and have announced plans to further expand access¹. However, no such alternative mechanisms for access to NICE rejected medicines currently exist in Wales, meaning that it is now the only nation in the UK where a negative NICE decision is fully enforced.

Inadequate processes

- 2.3 In Wales, patients have to rely on the Individual Patient Funding Request (IPFR) process to gain access to treatments which their doctors feel could benefit them, but which have not been approved by NICE or the All-Wales Medicines Strategy

Group (AWMSG). However the IPFR process is wholly inappropriate for determining fair access to cancer treatments.

2.4 The test for approving an IPFR is whether a patient can demonstrate clinical exceptionality. This – by definition – prevents the majority of patients from gaining access to treatment. Clinical exceptionality is only an appropriate test when an intervention is of variable clinical benefit. For example, a tattoo removal would – in normal circumstances – be of little clinical benefit. However, if a tattoo was causing clinical depression then removing it could give an individual a disproportionate benefit. It is difficult to assess whether a cancer patient could gain a disproportionate benefit from a treatment that has already undergone extensive clinical trials ahead of commencing that treatment.

2.5 The IPFR process is failing to enable patients to gain access to the treatments that their clinicians wish to prescribe. Recent research conducted by the RCF found that²:

- At least 230 patients have been denied funding since 2010 for cancer treatments they would have received in England
- Rejections for IPFR for cancer treatments by the NHS in Wales more than trebled between 2010 and 2013
- Patients in Wales are now more likely to have their IPFR rejected than approved

2.6 Many clinicians in Wales are being deterred from making IPFRs on behalf of their patients due to the poor chances of success. In addition, evidence from England shows that making decisions on an individual basis is an expensive, inefficient and inequitable approach to funding treatments³.

Improving access to treatments

2.7 Delivering cancer outcomes amongst the best in Europe will only be possible if the best interventions are delivered at each stage of the pathway, including making available the most clinically effective treatments. This is not currently the case. There are a range of ways in which this could be addressed, with the approaches adopted in Scotland and England offering two potential models. **The committee may wish to recommend that, irrespective of the model adopted, the Welsh Government should set an explicit goal to improve access to cancer treatments.**

2.8 The RCF is encouraged by the AWMSG's recent announcement concerning changes to its appraisal process that are intended to "*address some of the issues relating to equity of access in relation to new medicines for patients in Wales*"⁴. The RCF hopes that these proposals will translate into increased access to the latest cancer treatments in Wales, however it is unclear how the process will work in practice.

2.9 **The committee may wish to recommend that the Welsh Government should ensure that additional resources are provided to enable the AWMSG to resource new appraisals and to enable Health Boards to fund additional**

treatments in the event that the changes result in more treatments being approved by the AWMSG.

- 2.10 **The committee may wish to recommend that the AWMSG should be asked to report to the Welsh Assembly on its progress in improving access to cancer treatments in Wales no later than May 2015.**
- 2.11 Changes to the AWMSG process can only deliver benefits to patients if manufacturers participate fully in the process. **The committee may wish to recommend that manufacturers should be encouraged to submit evidence to the AWMSG.**

3. Access to care in the appropriate setting

- 3.1 Figures recently disclosed in the House of Commons show that the number of patients resident in Wales who are being referred for cancer treatment in England has increased significantly in recent years⁵.
- 3.2 The RCF believes that it is important that cancer patients – and particularly patients with rare cancers – should be able to access appropriate specialist expertise. Given the size of the Welsh population, it will not be feasible for Welsh hospitals to develop appropriate levels of expertise for all treatments for all cancers. In these circumstances, it is vitally important that restrictions are not placed on patients being referred to non-Welsh hospitals.
- 3.3 However, we are aware that some patients are having difficulty in securing referrals for treatment outside Wales. **The committee may wish to recommend that the Welsh Government should make clear that restrictions on out-of-Wales referrals are inappropriate and should be stopped.**
- 3.4 Some commentators have asserted that out-of-Wales referrals have been necessitated due to unacceptable waits for diagnostic scans and treatment. **The committee may wish to recommend that the Welsh Government should audit out-of-Wales referrals to establish the reasons for them. Where capacity issues are identified, an action plan should be developed to address them.**

4. The current level of funding for cancer services

- 4.1 The quality of cancer services will always to some extent be contingent on the level of funding available to support them. In order for the Welsh Government to deliver on the ambition set out in the Cancer Delivery Plan for Wales to be “amongst the best in Europe for cancer treatment and outcomes” funding levels for cancer services should be closer to funding levels in countries that currently deliver the best treatment and outcomes in Europe.

4.2 The Welsh Government currently devotes 6.6% of its health budget to spending on cancer services⁶. Although this is a greater proportion of the health budget than is spent on cancer services in England, demand in Wales is also greater due to higher levels of cancer incidence. Wales actually spends £1000 less per cancer patient than England⁷.

4.3 Given that spending on cancer services in England is considerably lower than in countries such as France and Germany⁸, this demonstrates the level of underinvestment in Wales. **The committee may wish to recommend that the Welsh Government should consider whether the level of expenditure on cancer services in Wales is consistent with the ambition of delivering services amongst the best in Europe.**

4.4 It is, however, worth noting that the cost of improving different elements of services is relatively modest. For example, we have estimated that it would cost approximately £10 million to increase access to cancer treatment in Wales to a level comparable with that in England⁹.

5. Conclusion

5.1 Some aspects of Welsh cancer services are to be applauded. The experience reported by patients of their treatment and care is largely good and patients benefit from high levels of expertise at hospitals such as Velindre with a deserved reputation for clinical quality.

5.2 Nonetheless, there are aspects of cancer care where services in Wales have fallen behind those in other UK nations and elsewhere. In relation to access to cancer medicines, there is now a clear and growing disparity. Put simply, patients in Wales are not able to benefit from a number of clinically effective cancer treatments that are routinely available in England and Scotland.

5.3 The current IPFR arrangements in Wales are inadequate and will not address this disparity. Nonetheless, there are opportunities to take affordable steps to increase access to life-extending treatments, providing the political will exists to do so. This is an issue on which political action could make a significant difference.

¹ Scottish Government, [Improving access to new medicines](#), 2013

² Rarer Cancers Foundation, [Hundreds of Welsh patients denied access to life extending medicines](#), 2014

³ Department of Health, [Improving access to medicines for NHS patients](#), November 2008

⁴ AWSMG, [AWMSG in relation to NICE](#), 2014

⁵ HC Deb, 5 March 2014, c873W

⁶ StatsWales, [NHS expenditure by budget category and year](#), March 2013

⁷ Rarer Cancers Foundation, [Hundreds of Welsh patients denied access to life extending medicines](#), 2014

⁸ Department of Health, [Cancer Reform Strategy](#), December 2007

⁹ Rarer Cancers Foundation, [Exceptional Cymru](#), 2011