

**Y Pwyllgor Iechyd a Gofal Cymdeithasol
Health and Social Care Committee**

Cynulliad
Cenedlaethol
Cymru
National
Assembly for
Wales



**William Powell AM
Chair of the Petitions Committee**

15 January 2015

Dear William,

P-04-570 Inequitable access to treatments that have not been national appraised in Wales

Thank you for your letter of December 2014, received on 9 January 2015, about the above petition.

In the light of the Health and Social Care Committee's existing policy and legislative scrutiny commitments, it is unlikely that it will have capacity to undertake a specific inquiry into the use of the 'exceptionality rule' in the Individual Patient Funding Request ("IPFR") process. However, the petitioners may be interested to note the following recent work undertaken by the Committee.

Inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan

The Committee took evidence in relation to the IPFR process during its inquiry into progress made to date on implementing the Welsh Government's Cancer Delivery Plan. In its [report](#), published in October 2014, the Committee noted that it shared the concerns of many of those who gave evidence to the inquiry about varying interpretations of 'exceptionality', the lack of flexibility to respond to cohorts of patients seeking to access new treatments, inconsistencies in clinicians' willingness to engage with and access the IPFR process, and inconsistencies in the decisions made by local panels. The

Bae Caerdydd
Cardiff Bay
CF99 1NA

Ffôn / Tel: 0300 200 6354

E-bost / Email: Seneddlechyd@Cynulliad.Cymru/
SeneddHealth@Assembly.Wales

Trydar / Twitter: [@seneddiechyd](https://twitter.com/seneddiechyd) / [@seneddhealth](https://twitter.com/seneddhealth)

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Committee indicated in its report that it believed that to ensure equity of access to novel and innovative treatments, a national panel should be established for the purpose of considering and making decisions about individual patient funding requests. To this end, recommendation 8 of that report recommends that:

“to ensure that there is consistency and equity across Wales, the Minister for Health and Social Services establishes a national panel to consider and make decisions about Individual Patient Funding Requests”.

The Welsh Government indicated in its [response to the Committee’s report](#) that it did not accept the Committee’s recommendation. The Minister for Health and Social Services said that the review of the IPFR process, commissioned by the Minister in October 2013, had concluded that:

“the IPFR process supports rational, evidence based decision making to access medicine and non–medicine technologies that are not routinely available in Wales”.

He went on to say that the Review Group had made a number of recommendations to strengthen the process, improve transparency and inter–panel consistency. He said that once the revised arrangements had bedded in, he intended that the IPFR process would be reviewed again.

During the [Plenary debate on the Committee’s report](#) on 10 December 2014, I noted the Committee’s disappointment that the Welsh Government had not been able to accept the Committee’s recommendation. I reiterated the Committee’s concerns, including the interpretation of ‘exceptionality’, and asked the Deputy Minister for Health to ensure that the review of the revised IPFR arrangements would take them into account.

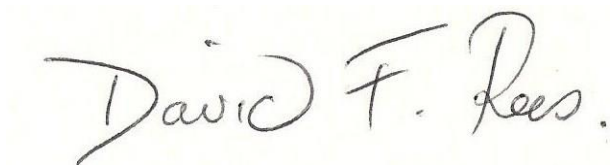
Inquiry into access to medical technologies

During its [inquiry into access to medical technologies](#), the Committee heard concerns about the operation of the IPFR process in relation to new medical technologies, with witnesses referring to the difficulties associated with assessing exceptionality. The Committee did not make an explicit

recommendation about the IPFR process as it had already done so as part of its work on the implementation of the Cancer Delivery Plan, however its [report](#) did make a number of recommendations to address what it concluded was variable service provision across health services in Wales. The Welsh Government's response to the report is due in February 2015 and is expected to be debated by the Assembly shortly thereafter.

I hope that this information is of interest to you and the petitioners.

Yours sincerely,

A handwritten signature in black ink on a light yellow background. The signature reads "David F. Rees." with a period at the end. The letters are cursive and fluid.

David Rees AM

Chair, Health and Social Care Committee