

2024.04.30

3.4 Deputy G.P. Southern of the Minister for Health and Social Services regarding cystic fibrosis treatment (OQ.76/2024)

I will do my best on brevity, Sir. Further to his response to Written Question 30/2024, will the Minister advise what “value for money” assessment has been undertaken, compared to alternative treatments, in relation to the medicine Kaftrio, used to treat patients who have cystic fibrosis?”

Deputy T. Binet of St. Saviour (The Minister for Health and Social Services):

I had a formal response to this question prepared by the appropriate person at H.C.S. (Health and Community Services) and it is rather long and rather complicated. So I have done my best to summarise it. In relation to the use of Kaftrio, the value-for-money assessment has not taken place yet because N.I.C.E. (National Institute for Health and Care Excellence) guidelines have not yet approved in this particular case to which the Deputy refers. It is my understanding that the value-for-money assessment will take place when the case is reviewed during the course of the impending independent patient funding requests.

The Bailiff:

Yes, you certainly summarised it.

3.4.1 Deputy G.P. Southern:

I am just wondering where to go after that response. Does the Minister accept that there have been a number of trials of this particular treatment covering countries such as France, Scotland, Israel and even Guernsey, where it has proved to be very successful at improving lung function? Will the Minister ensure that this assessment does come to the fore in terms of how valid this is?

Deputy T. Binet:

Yes, I am very comfortable with that. I think the Deputy knows that I am privately supportive of this, and I shall do what I can. Obviously there are limitations as to what I can do, but I do keep in touch with the Deputy on this particular matter.

3.4.2 Deputy T.A. Coles:

The Minister mentions N.I.C.E. guidelines but, as we see from our proposition coming forward, that we do not always follow N.I.C.E. guidelines. Are there any other opportunities and deviations from N.I.C.E. guidelines that he has used previously and approved medications?

The Bailiff:

I am sorry, I think that goes far too far outside. You are asking questions about medication generally and the Minister is asked specifically about this particular medication. I think that takes it outside what is permissible.