

9 February 2024

The Senate  
Standing Committee on Community Affairs  
Reference Committee  
Australian Parliament House

Dear Senator Rice, Senator Askew, Senator Pratt & Senator Kovacic

**Inquiry into the Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer.**

**Respectfully please find below the responses to the Questions on notice and additional information**

Please see **page 10** of the transcript regarding Senator Pratt's request below, noting other relevant discussion on **pages 8-10**:

**Senator PRATT:** Could you take on notice any detail around My Health Record if you get a further chance to reflect on some of those issues.

**Response:** There needs to be a system that results are not put into the patient's My Health record unless they have been reviewed / authorised by the Clinician. By doing this, patients are then not subjected to misinterpreting results causing addition stress by seeing results without having a Clinician to explain the results to them.

There needs to be better interface between facilities including public and private to ensure access to all health information. There are so many different platforms it is not easy for clinicians to click between tabs to chase results etc in the limited consultation time. As mentioned in the Hearing the majority of hospitals' electronic records and systems in Australia to do communicate between each other. Another issue is many patients have opted out of My Health record, so it is a non-event with regards to provision of health information.

In addition, please also see later on **pages 10-11**, for the following question on notice from Senator Pratt and Senator Rice:

**Senator PRATT:** I'm keen to see where the inequities are. You're doing a great job in the places you're going. Who's got nothing and where do you see the data that people aren't getting the appropriate treatment?

**CHAIR:** Perhaps you could take that on notice. We had the Cancer Atlas present to us yesterday regarding the inequities. Is specific data available for NETs?



**Ms Cummins:** I don't think there is because there's a lot of people out there who we don't know have NETs.

**Prof. Hicks:** We know there are people who are missing out, because it takes five to seven years to get a diagnosis. Even when they've got a diagnosis, it often takes them a year or two to get into the right care pathway because their clinicians aren't aware of the availability of specialised services, and they hang on to patients for too long.

**Response:** As per Prof Hicks' answered question during the hearing at the Inquiry Hearing regarding patients missing out on appropriate treatment – the timeframe for the delay in diagnosis (misdiagnosis) and the stage at diagnosis (stage 4 which means it has spread to other organs) indicates the lack of appropriate treatment.

The Cancer Atlas does not report neuroendocrine cancer again highlighting the inequity of access to valuable data.

Also discussed in the Hearing was the inadequacy of AIHW data with respect to NETs. By collecting data on "body parts/ organs" NETs are being predominantly ignored and the importance of knowing the numbers /data is not being respected. NETs need to be counted and the data needs to be easily available, including it's ranking amongst all cancers.

Should you require any further information please do not hesitate to contact me or my mobile

Yours Sincerely,

Meredith Cummins  
CEO NeuroEndocrine Cancer Australia

