

11 March 2021

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Re: Official Information Act request – Cystic Fibrosis Costs

I refer to your Official Information Act request dated 22 February 2021 requesting the following information:

My name is Edward Lee, I am involved in the effort to get Trikafta funded in NZ as this drug presents the best chance for a normal life for sufferers of Cystic Fibrosis like myself. I am trying to gather some data for this purpose.

Can you please provide me with the following information or the closest available information you have if the specifics cannot be provided.

- 1. The lifetime cost, to the DHB, of a lung transplant assuming a person who is 20 years old and has no other significant health issues. Please include the costs of any expected procedures, medicine, follow up care, hospital stays, etc)**
- 2. The lifetime cost, to an individual, of a lung transplant if they were to pursue this through private care. Would this be likely to differ if provided in a different region?**
- 3. The lifetime cost, to the DHB, for the care of a person with Cystic Fibrosis assuming they lived till 40 years of age. Please include all expected costs of medication, treatments, hospital visits, medics scans etc).**
- 4. The lifetime cost, to the DHB, for the care of a person without Cystic Fibrosis assuming they lived till 40 years of age.**

Auckland DHB does not collect cost or activity data from outside of its own hospital. This response does not include:

- Primary care costs
- Pharmacy costs for drugs dispensed outside of the hospital system
- Any contact with private hospitals or other health care providers.
- Any contact with other publicly funded hospitals.

Therefore, we cannot provide a true lifetime cost for patient treatment. We are only able to provide costs related to patients who have had direct contact with Auckland DHB services.

1. The lifetime cost, to the DHB, of a lung transplant assuming a person who is 20 years old and has no other significant health issues. Please include the costs of any expected procedures, medicine, follow up care, hospital stays, etc)

The estimated lifetime cost of associated hospital treatments for a person aged 20 who also received a lung transplant has been calculated as follows:

- Non lung transplant hospital related costs for cystic fibrosis patients - the cost has been split into age bands as the input required differs by age. The average cost is based on the cost per patient rather than cost per event.

Table 1 - Estimated Cost of a Cystic Fibrosis Patient Up to 20 Years Old For Hospital Care only excluding Transplant

Age Band	Inpatient Average Cost	Outpatient Average Cost	Average Total Cost by Age Band	Total Cost (by year by age band)
under 1	15,903	2,144	18,047	18,047
1-4	4,892	2,746	7,638	30,551
5-9	14,557	2,079	16,637	83,184
10-14	40,881	3,171	44,052	220,259
15-19	34,746	4,582	39,328	196,641
Cost - Up to 20 years				548,683

- Lung transplant hospital related costs for cystic fibrosis patients - The inpatient cost of a lung transplant is for the transplant event only. If a patient has multiple admissions before or after the transplant, those costs are contained above. The average cost of a lung transplant (based on financial years 1617-1920) is \$288k

However, they are highly variable in cost depending on complications during treatment.

Table 2 – Lung Transplant Cost 1617-1920

Average	287,958
Min	158,153
Max	872,336
Median	190,375

The total estimated hospital cost for a cystic fibrosis patient aged 20 with a lung transplant, using an age weighted average cost for normal hospital care and an average cost for the lung transplant is \$837k.

Note cystic fibrosis patients may also require other organ transplants. These costs have not been included.

2. The lifetime cost, to an individual, of a lung transplant if they were to pursue this through private care. Would this be likely to differ if provided in a different region?

The private sector does not provide transplantation. Patients may be managed by the private sector for other aspects of their care, but we do not have any data on that. Auckland DHB is the only DHB in the country that provides transplantation. We are unable to provide any information on the other aspects of care provided in other parts of the country.

3. The lifetime cost, to the DHB, for the care of a person with Cystic Fibrosis assuming they lived till 40 years of age. Please include all expected costs of medication, treatments, hospital visits, medics scans etc).

Table 3 - Estimated Cost of a Cystic Fibrosis Patient Up to 40 Years Old For Hospital Care only excluding Transplant

Age Band	Inpatient Average Cost	Outpatient Average Cost	Average Total Cost by Age Band	Total Cost (by year by age band)
0-20				548,683
20-24	49,456	2,720	52,176	260,880
25-29	32,619	2,590	35,209	176,047
30-34	41,803	1,793	43,595	217,976
35-39	24,164	1,957	26,121	130,605
Cost - 20 to 40 years				785,509
Total Cost - Up to 40 years				1,334,191

The combined estimated hospital cost of a person with cystic fibrosis *without* a lung transplant up to the age of 40 is \$1.334m.

4. The lifetime cost, to the DHB, for the care of a person without Cystic Fibrosis assuming they lived till 40 years of age.

Auckland DHB does not collect this sort of data. However, a study by Otago University Medical School published in the New Zealand Medical Journal in 2013 estimated the cost of care for a person up to the age of 40 was \$36k (in \$2011). This is a population based cost and so would

include a portion of cystic fibrosis patients. This impact would be minimal across the total population noting the small number of patients in New Zealand. It includes primary care, hospital care, pharmaceutical and laboratory costs etc.

You are entitled to seek a review of the response by the Ombudsman under section 28(3) of the Official Information Act. Information about how to make a complaint is available at www.ombudsman.parliament.nz or freephone 0800 802 602.

Please note that this response, or an edited version of this response, may be published on the Auckland DHB website.

Yours faithfully



Ailsa Claire, OBE
Chief Executive of Te Toka Tumai (Auckland District Health Board)