

20 December 2017

Our Ref: RFI 22086

Dear

**Freedom of Information Act 2000
Information in Relation to Idiopathic Pulmonary Fibrosis**

I am writing to confirm that the South Eastern Health & Social Care Trust (the Trust) has now completed its search for the information relating to the above which you requested on 24 November 2017.

A response to each of the questions raised has been provided by the Hospital Services Directorate and is attached in Appendix A.

Under the terms of the legislation, if you are unhappy with this response you have the right to seek a review within the Trust in the first instance. If you wish to do so, please write to me at the address below.

If after such a review you are still unhappy with the response, you have the right to appeal to the Information Commissioner who will undertake an independent review. The Information Commissioner can be contacted at The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, SK9 5AF.

If you have any queries about this letter, please do not hesitate to contact me. Please remember to quote the reference number above in any future communications.

Yours sincerely,

**L McAree (Miss)
Head of Information Governance &
Directorate Support**

Does your Trust manage/treat patients with Idiopathic Pulmonary Fibrosis (IPF) (ICD-10 J840, J841, J848, J849)?

Yes No If No, please go to "IPF Patient Referrals"

If yes, how many patients within your Trust received a diagnosis of IPF (ICD-10 J840, J841, J848, J849) within the last 6 months:

Table 1

Number of patients diagnosed with IPF within the last <u>6</u> months	Unknown
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Please indicate the number of unique IPF patients managed by your Trust treated with the following:

Table 2

Therapy	Number of IPF patients treated within the last <u>30</u> days	Number of IPF patients treated within the last <u>3</u> months
Esbriet (pirfenidone)	11	12
Ofev (nintedanib)	11	11
Any treatment <u>other than</u> Ofev or Esbriet ¹	Unknown	Unknown

If information is held in a sufficient way within your Trust systems, please indicate the total number of current/active IPF patients managed by your Trust, that is, patients that could have received a diagnosis of IPF at any time and are currently receiving anti-fibrotic, other or no treatment for IPF by your Trust. If you do not hold information in this way, please indicate accordingly and proceed to the referrals question:

¹ Any treatment other than Ofev or Esbriet i.e. patient is not treated with Ofev or Esbriet, but is/has received IPF treated with one or multiple of the following treatments: **Corticosteroids** (prednisone); **Immunosuppressants**, **Cyclophosphamide** (Cytoxan®); **Azathioprine** (Imuran®); **Mycophenolate mofetil** (Cellcept®, Myfortic®); **N-acetylcysteine** (NAC); **Proton pump inhibitors** (Prilsec OTC®, Nexium®, others); **Supplemental Oxygen Therapy**; **Other** (anti-cough, vaccines etc); **Palliative Care** (morphine)

Table 3

	Number of <u>current/active</u> IPF patients	Data not held/accessible by Trust
Total number managed by Trust		✓
Treated with anti-fibrotics (Esbriet/Ofev)	22	
Treated with any other treatment <u>excluding</u> Ofev/Esbriet ²		✓
Not currently treated ³		✓

Please note that the figures provided in Table 3 are likely to be an underestimate due to the ambiguities of clinical diagnosis and coding.

IPF Patient Referrals

Table 4

Does your Trust refer IPF patients to other Trusts?	Select all that apply	Trusts to which patients are referred
Yes, all IPF patients referred upon diagnosis		Not applicable
Yes, when they need treatment with an anti-fibrotic (Esbriet/Ofev)		
No		

² As footnote 1

³ Not currently treated – this could be mild IPF patients that do not currently require treatment