# Evaluation of the Healthcare Burden of Idiopathic Pulmonary Fibrosis (IPF) in Fife, Scotland

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## RATIONALE

- IPF is considered a rare lung disease, a progressive fibrotic disease with a median survival of 3 years. Disease has been associated with numerous factors including age, cigarette smoking, dust exposures and mutations[1,2].
- The region of Fife borders Edinburgh and Lothian in south-east Scotland, with an estimated population of 367,260. Fife has high rates of cigarette smoking, occupational exposures through industry such as mining (coal, stone), and significant numbers of lower socio-economic classes[3].
- IPF has anecdotally posed a significant problem in Fife, and we were keen to explore the extent of the problem and the extent of resource required to support this locally. Prevalence data in IPF globally has been notoriously difficult to obtain[1].

- **OBJECTIVES**
- To estimate the prevalence of IPF in Fife, Scotland
- To estimate healthcare related costs, predominantly related to secondary care, and examine the impact upon the acute hospital admissions
- To provide information to inform regional and national health care policy

## METHODS

- Retrospective study of patient records, imaging, primary and secondary care databases. Data obtained for the period, Jan 1st – Dec 31st 2014

- ***Prevalence data in Primary Care***
- Codes related to IPF through the 'EMIS' and 'Vision' primary care coding systems were requested from all 58 General Practices in Fife.
- H563 codes below given to patients in primary care were interrogated further using available records to check validity.

| GP CODE | DEFINITION |
|---|---|
| H563-1 | Diffuse Pulmonary Fibrosis (DPF) |
| H563-2 | Pulmonary Fibrosis (PF) |
| H563-3 | Idiopathic Pulmonary Fibrosis (IPF) |
| H563-4 | Idiopathic Fibrosing Alveolitis |

- ***Costs of Secondary healthcare***
- Data collected through the 'Health Informatics Centre' (HIC), a research support unit[4], local hospital coding data. Bed-costs obtained from NHS Fife health board documents – 'direct costs' (staffing, labs, theatres) combined with 'allocated costs' (estates, domestic, catering).
- Cases searched according to ICD-10 diagnosis, J84.1
- Indeterminate cases were given a consensus diagnosis of either 'Definite/Probable IPF', 'Possible IPF', or 'Low risk IPF'.
- 'Caldicott approval' through local guardians of patient sensitive information was obtained, and this study was approved as 'service evaluation'.

## RESULTS

- ***Prevalence data from Primary care***
- 145 IPF cases from 37 GPs (64% response) in population of 241,216
- 145/241,216 = 0.06%, or 1 per 1664 cases, or 60/100,000 population
- Majority dual coded; 18/37 (49%) GPs entering 2nd code - typically 'IPF/DPF'

- *Identification of IPF through search of CT reports (age >50, 'honeycomb')*
  - 198 CT reports identified, then multiple cases excluded - Rheumatoid arthritis (15), significant asbestos exposure (21), or inconsistent other imaging features (15).
  - Final 147 cases considered likely to be IPF

- ***Costs of Secondary Healthcare*** *(see Figures 2, 3)*
- Where IPF was the *primary diagnosis*, the number of admission events related to 'Definite/Probable IPF' was 12 (9 patients), extending to 16 (13 patients) where 'Possible IPF' was included
- Where this was a *non-primary diagnosis*, the figures were 69 admissions (47 patients) related to Definite/Probable IPF, 98 admissions (71 patients) to include 'Possible IPF'.
- Approximately 30% of IPF-assigned diagnoses had 'Definite/Probable IPF'
- Approximately 60% were unlikely to have IPF ('Low risk IPF').

**Figure 2. IPF-related admission length of stay, Jan 1st - Dec 31st, 2014**

| *Primary diagnosis* | Admissions | Total bed days | Average bed stay | Median bed stay |
|---|---|---|---|---|
| Definite/Probable IPF | 12 | 197 | 16.4 | 4.0 |
| Low risk IPF | 4 | 35 | 8.8 | 5.0 |
| Combined IPF | 16 | 232 | 15.0 | 4.5 |
| *Non-primary diagnosis* | Admissions | Total bed days | Average bed stay | Median bed stay |
| Definite/Probable IPF | 69 | 605 | 8.8 | 4.0 |
| Low risk IPF | 29 | 284 | 9.8 | 5.0 |
| Combined IPF | 98 | 889 | 9.1 | 4.5 |

*diagnosis from study of records, and consensus of Respiratory physician and 2 thoracic radiologists, as necessary

**Figure 3. IPF admission-related bed-cost analyses, Jan 1st - Dec 31st, 2014**

| | Definite / Probable* | Possible* | Low risk* |
|---|---|---|---|
| IPF coded as primary diagnosis | 12 (£32,832) | 4 | 16 |
| IPF coded as non-primary diagnosis | 69 (£188,784) | 29 | 134 |
| Admissions outwith Fife | 1 | 2 | 15 |
| Combined primary/non-primary admissions | 82 (£224,352) | 35 | 165 |
| Total no of admissions in original search result | 283 | 283 | 283 |
| % of primary/non-primary admissions | 29.1% | 12.4% | 58.3% |
| ***82 admissions of definite/probable IPF as primary or other diagnosis in 2014*** | | | |

- Majority of admissions through 'Medical Admissions Unit' (MAU); typically 1-2d in MAU followed by 2-3d in a respiratory or general medical ward.
- 14/16 (88%) admissions in 'Definite/Probable/Possible' IPF group were dead by January 2015, one month after the end of the year in study

## DISCUSSION

1. **IPF coding is inconsistent** across mechanisms in primary and secondary care, and probably reflects from a poor understanding of the condition, and inconsistencies in clinical practice.

2. **Prevalence of 60/100,000 is probably above 'rare'** – however, this may represent over-diagnosis in primary care and under-diagnosis in secondary care

*- Extrapolated from Fife to the UK implies 36,000 cases (BLF data, 35,000[5]).*
*- Compare CF prevalence in UK of 1/2,500, and TB in London 40/100,000*

3. **Secondary healthcare costs are significant**, and typically involve a 3-5 day admission on medical wards, at an estimated annual bed-cost of £200,000.

*- Estimate typical admission bed-cost = £3040.00 ($4,381.00)*
*- Short median stay 4d suggests transient destabilisation, and potential for support in community and admission avoidance*
*- Admission to hospital is associated with a short life expectancy thereafter, with the majority of cases dead within 1 month of the end of the year in study.*

4. **'Honeycombing' is a sensitive tool for searching cases with IPF**, with further significant exclusions possible through careful use of additional terms such as 'asbestos', 'Rheumatoid arthritis' and 'connective tissue disease'.

- CT imaging forms an integral part of diagnosis, and offers a further strategy in accurate monitoring and coding.

**RECOMMENDATIONS**

There is a need to improve upon the current understanding of IPF in primary and secondary care sectors, and thereby provide for robust healthcare assessments.

We are now able to discuss ILD service requirements with our local health board. Key areas include early identification in the MAU, facilitated early discharge, close liaison with Palliative Care, transfers direct to the Respiratory ward to an 'Assessment Room' to enable admission avoidance.

Improved reporting of CT scans has the potential to significantly enhance identification and surveillance in IPF; a formal 'Structured Reporting Form' is in development to improve recognition, quality & consistency in reporting.

## CONCLUSIONS

- IPF is poorly recognised, poorly understood both in primary and in secondary care, and current coding practice is frequently incorrect.
- IPF is not a rare cause of admission, utilises significant secondary care resources, and may signify advanced disease, so suggesting an emphasis on a palliative care approach and admission avoidance.
- These data will inform the prevalence and secondary care resource use, and will also increase awareness of the burden of IPF in Fife, Scotland.

**References**

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