

Supplementary file 2: DEVELOPMENT OF 14 ORVERARCHING RESEARCH THEMES

| Initial themes identified as part of Stage 1 (N=196) [listed alphabetically] | Number of respondents | % of total | Corresponding overarching theme number |
|---|-----------------------|------------|--|
| Access to services (e.g. pulmonary rehabilitation, lung transplant) | 5 | 3% | 11 |
| Adjustment to life with PF | 10 | 5% | 6 |
| Better access to diagnosis and care in regional areas and interstate | 6 | 3% | 11 |
| Better informed GPs | 15 | 8% | 3 |
| Better treatments to prolong life/reduce disease progression | 51 | 26% | 12 |
| Blood markers | 3 | 2% | 1 |
| Cause | 65 | 33% | 2 |
| Complementary and alternative therapies | 3 | 2% | 7 |
| Cost of treatment | 2 | 1% | 14 |
| Cure | 47 | 24% | 5 |
| Drug treatments with fewer side effects | 18 | 9% | 12 |
| Early detection | 19 | 10% | 1 |
| Education of HCP | 9 | 5% | 3 |
| Effects of repeated testing | 1 | 1% | 8 |
| End of life care | 6 | 3% | 7 |
| HCP Informing patients of what to expect with PF | 2 | 1% | 13 |
| Holistic care | 2 | 1% | 8 |
| Impact of specialist visits on patient and carers | 2 | 1% | 6 |
| improve prognosis after transplant | 3 | 2% | 12 |
| Improve QOL for carers | 1 | 1% | 9 |
| Improve QOL for patients | 14 | 7% | 9 |
| Information /education for patients | 18 | 9% | 3 |
| Information on clinical trials/research developments | 6 | 3% | 10 |
| Isolation due to PF | 3 | 2% | 6 |
| Lung transplant eligibility | 2 | 1% | 12 |

14 Overarching research themes

1. Quicker/better/more certain **diagnosis** – *early detection, better prognosis*
2. Understand the **cause** of PF – *family history, occupation, exposures, mechanisms*
3. Improve **education / information / awareness** – *reduce stigma, understand experience of living with PF*
4. Relieve **symptoms** – *breathlessness, cough, fatigue*
5. Find a **cure** for PF – *provide hope for those with disease*
6. **Psychosocial support** for patients & carers– *awareness of support groups and where to seek assistance*
7. Better **supportive care** – *optimal exercise and rehab programs, oxygen therapy, diet, end of life planning and care*
8. Improve **self-management** – *empower individual to deal with disease*
9. Improve **quality of life** for patients & carers – *ability to perform basic tasks, dependency on carers*
10. Access to **research and clinical trials** – *access to trials, information on research*
11. Better **access to care**, especially in rural/regional areas – *need to travel long distances for care, impact on patient and carers*
12. **Better treatments** – *fewer side effects, reduce disease progression, prolong life, lung transplant eligibility and post-transplant medications*
13. Understand my **prognosis** – *stages of progression, life expectancy, what to expect*
14. Decrease **costs** of care – *long-term use of oxygen expensive*

| | | | |
|---|------------|-----|----|
| Manage side effects of meds | 10 | 5% | 8 |
| Managing acute exacerbations | 1 | 1% | 8 |
| More research | 5 | 3% | 5 |
| More support groups for people with PF | 1 | 1% | 6 |
| Non-lung effects of PF | 5 | 3% | 13 |
| Optimal exercise/ pulmonary rehab program | 11 | 6% | 7 |
| Optimising lung transplant | 4 | 2% | 12 |
| Oxygen therapy | 7 | 4% | 7 |
| Post lung transplant meds with fewer side effects | 1 | 1% | 12 |
| Prevention | 11 | 6% | 5 |
| Psychosocial support and counselling for patients | 8 | 4% | 6 |
| Public awareness of condition | 11 | 6% | 3 |
| Quicker/better/ more definite diagnosis | 37 | 19% | 1 |
| Recovery from acute exacerbations | 1 | 1% | 12 |
| Relieve breathlessness | 24 | 12% | 4 |
| Relieve cough | 21 | 11% | 4 |
| Relieve discomfort | 2 | 1% | 4 |
| Relieve fatigue | 8 | 4% | 4 |
| Relieve phlegm | 1 | 1% | 4 |
| Role of diet | 3 | 2% | 7 |
| Self-management /optimise living with PF | 10 | 5% | 8 |
| Support/education for caregivers and families | 7 | 4% | 6 |
| Treatments to improve ex capacity | 8 | 4% | 7 |
| Understand disease mechanisms | 2 | 1% | 2 |
| Understand prognosis | 28 | 14% | 1 |
| Understand what research is happening | 4 | 2% | 10 |
| Understanding experience of living with PF | 16 | 8% | 3 |
| TOTAL | 560 | | |

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