

Top 10 Research Priorities for People Living with Pulmonary Fibrosis, their Caregivers, Healthcare Professionals and Researchers

Tikellis et al. (2020)

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For which topic were research priorities identified?

pulmonary fibrosis

In which location was the research priority setting conducted?

Australia - Australia

Why was it conducted at all?

People with pulmonary fibrosis (PF) experience a high symptom burden, reduced quality of life and a shortened lifespan. Treatment options are limited and little is known about what patients, caregivers and healthcare professionals (HCPs)/ researchers consider as the most important research priorities

What was the objective?

to identify the research questions that are most important to people living with pulmonary fibrosis, their caregivers, healthcare professionals and researchers, so as to better align stakeholder priorities to research efforts

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: setting up PSP: stakeholders and partner organizations were identified. Step 2: collecting research questions: participants were asked: What are the two most important problems for people with pulmonary fibrosis that you feel should be addressed by research?, 560 questions were submitted along 14 research topics. Step 3: interim ranking: via workshop: to develop more specific research questions within each theme, small group discussions resulted in 53 indicative questions, each participant used colored adhesive dots to indicate the three most important questions, 39 indicative questions moved forward. Step 4: final prioritization: via survey: participants were asked to rank their top 10 questions

Which stakeholders took part?

People with PF, caregivers, healthcare professionals (allied health professionals, nurse, respiratory physicians, specialist ild physicians), researchers involved with PF. Survey: 196 participants (78% people with PF). Workshop: 32 participants: 63% (n=20) people with PF, 15% (n=5) caregivers, 22% (n=7) HCPs and researchers. Prioritization survey: 261 participants: 51% people with PF, 34% HCPs/researchers, 15% were caregivers.

How were stakeholders recruited?

People with PF and their caregivers were identified through the Australian Idiopathic Pulmonary Fibrosis Registry (AIPFR) and Lung Foundation Australia's (LFA) website and electronic direct mail (EDM) database. Healthcare professionals with experience in PF were identified through the Australian IPF Network (AUS IPF-net), a special interest group for HCPs also managed by LFA. For the workshop, people with PF, caregivers, HCPs and researchers were invited to participate.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.