Basic Results Summary

Fig 1. Participant Flow Diagram

Recruitment events and snowballing

Expressed an interest in participating in the study (n = 41)

Excluded (n = 10)
- Declined to participate (n = 9)
- Other reasons (n = 1)

Assigned to Participant Groups (n = 31)

Person Living with Lung Disease (PLD) (n = 13)

Caregivers (n = 9)

Healthcare Practitioners (HCP) (n = 9)

Semi-structured interview (n = 13)

Semi-structured interview (n = 9)

Semi-structured interview (n = 9)

Data Analysed (n = 13)
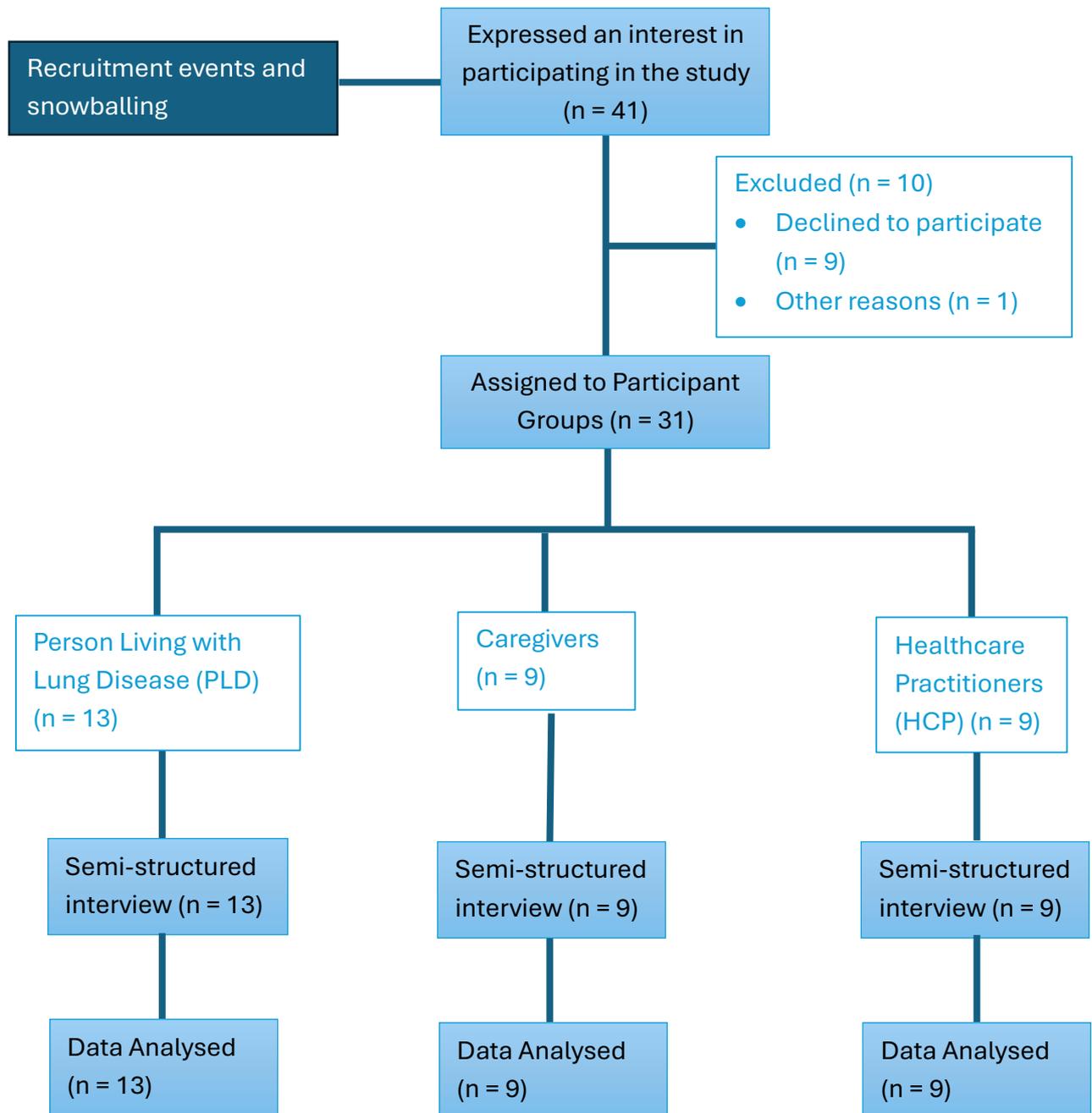
Data Analysed (n = 9)

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Fig 2: Participant Baseline Demographic and Clinical Characteristics

Age, Gender, Relationship Status and Time since Diagnosis of People Living with Lung Disease Participants

	Mean (years)	Standard Deviation (years)	Range (years)
Age (total)	70	6	59-82
Age of those in spousal relationships n:6 (1 female: 5 male)	69	7.5	59-82
Age of those living alone n:7 (6 female: 1 male)	70	5	64-78
Time with known lung disease (total)	13.5	5.5	5-25
Time with known lung disease of those in spousal relationships n:6 (1 female: 5 male)	12	7	5-25
Time with known lung disease of those living alone n:7 (6 female: 1 male)	15	3.5	11-23

Age, Gender and Relationship Status of the Caregiver Participants

	Mean (years)	Standard deviation (years)	Range (years)
Age (total)	70	6	61-82
Age of those in spousal relationship n: (5 female: 1 male)	67	4	61-72
Age of those living alone n: (1 female, 2 male)	76	5	70-82

Age and Years of Respiratory Nursing Experience

	Mean (years)	Standard deviation (years)	Range (years)
Age	51	3.5	47 - 59
Nursing Experience (total)	30	3.5	27 – 38
Respiratory Nursing Experience	17	7.5	8 - 27

Outcome Measures

The participants' experiences of the management of long term, progressive, non-malignant respiratory disease, measured using a qualitative interview with each participant at least 5 years post the commencement of their involvement with this condition.

The data from these interviews was analysed using reflexive thematic analysis including interrogation of the data, coding and development of themes. Themes were developed from each participant group and then compared. A resultant twelve themes were developed and ranked by perceived impact and affinity using the K-J Method with the symbol size demonstrating the impact or perceived affinity (Hannington & Martin 2019).

Fig 3: Themes Ordered in Relation to Groups, Affinity (Hannington & Martin 2019) and Perceived Impact

Note: P: People with lung disease Group. C: Caregiver Group, H: Healthcare practitioner Group

Adverse Events

Although physical adverse events were not anticipated, plans were put in place for additional emotional support should the discussions and topics cause distress to any participants. This included referral on for additional psychological therapeutic support as required.

Although this was in place for all participants, it was not required.