

## **Interview guide**

### **Health care professionals' telephone or in person interview**

1. Oral consent documentation:
2. Occupation/years in practice
3. What is the single biggest frustration with ACP/EOL or Palliative care delivery in your own practice?
4. What can be done to make this better?
5. Do you think patients are satisfied with the level of information they are given about advance care planning (ACP) including end of life (EOL) issues?
6. How well would you say patients understand the need for EOL/ACP?
7. Who should lead this discussion (MD/RN/others) and where should it occur?
8. Do you book a separate visit to address these issues?
9. When do you do ACP/EOL discussion in your practice and when do you think it should ideally start?
10. Do you feel confident about addressing patient questions on EOL or leading the ACP discussion in clinic? (not at all confident/somewhat confident/confident/very confident)
11. In your experience where do you have majority of these discussions- clinics or hospitals?
12. Do you think having an education booklet on ACP will help you and your patients in initiating and documenting this discussion more effectively?
13. What topics do you think should be included in a tool kit/patient education document for ILD/IPF?

14. Do you think some topics should not be addressed?
15. Given the heterogeneous nature, evolution and treatment options of ILDs, how do you think tailored educational information should be delivered to groups of patients in clinics/rehab groups?
16. How to measure dyspnea in your practice? Scale? (MRC/NYHA/others)
17. How do you treat dyspnea? Non pharm/pharmacological (opioids). What route do you most commonly use?
18. Do you provide action plans to your patients for self-management?

**ILD patient and caregiver focus group/interview if needed**

1. Are you satisfied with the level of information you were given about ACP/EOL issues when you received the diagnosis of pulmonary fibrosis or interstitial lung disease?
2. Did you look for information elsewhere?
3. Did you look on the Internet to get additional information?
4. How well would you say you understand these issues?
5. What topics do you think should be included in an educational booklet to address this need?
6. How would you want this information to be delivered (group discussion, written material, online resources, formal education program)?
7. Who should lead this discussion in clinic and who should be involved?  
MD/RN/respiratory therapist/family doctor/others
8. Do you think some topics should not be addressed?
9. How can the clinic help you around end of life issues?

10. How can the healthcare system help you navigate the end of life issues in the hospitals?

At home?

11. As patient/caregiver what additional resources do you need?

12. How can you prepare better for what the future holds?

13. Did your physicians ever give you self- management action plans?

14. Did your physicians ever give you the option of being care for at home without going to

ER/hospitals and passing away at home?