

Appendix 5: Preliminary interview guides
Pre/Post Opioid Clinical Trial (G. Rocker)

Pre Opioids

- Thinking back over the past few months, what has life like for you living with this illness?
 - How would you describe your quality of life—why, what changed over the course of your illness? What was most difficult for you about this? What was your breathing like? Were there things you could not do? Why/what stopped you?
 - What about relationships, e.g., with spouse, family members, friends—do you think your illness has affected any of these; how?
 - What about formal care—how satisfactory has it been for you? (doctors, nurses, respiratory therapists, clinic visits, hospitals, home support)
 - Other effects?
 - Greatest fears? (exacerbations; getting help; burden to loved ones)
 - Hopes?

- What bothers you most right now? What would you most like to change if you could?
 - Quality of life (factors mentioned in #1), breathing
 - Relationships (as above)
 - Formal care (as above)
 - Other things
 - Fears (as above)
 - Hopes

- What were your thoughts when your doctor first talked to you about starting morphine? (fears, concerns, hopes, understandings)
 - Did you talk about any of these things with your doctor, then or since?
 - How did your doctor explain it to you? (what did s/he say)
 - Have your thoughts changed since being on the morphine?

- Is there anything else you think might be helpful for other COPD patients, doctors, or families to know about this illness?

Post Opioids

- What was life like for you before you began taking the morphine?
- How would you describe your quality of life—why, what changed over the course of your illness? What was most difficult for you about this? What was your breathing like? Were there things you could not do? Why/what stopped you?
 - What about relationships, e.g., with spouse, family members, friends—do you think your illness has affected any of these; how?
 - What about formal care—how satisfactory has it been for you? (doctors, nurses, respiratory therapists, clinic visits, hospitals, home support)
 - Other effects?
 - Greatest fears? (exacerbations; getting help; burden to loved ones)
 - Hopes?
- Since you started the morphine has anything changed? What and how?
 - Quality of life (factors mentioned in #1), breathing
 - Relationships (as above)
 - Formal care (as above)
 - Other things
 - Fears (as above)
 - Hopes
- Have your thoughts about taking morphine changed since the time your doctor first talked to you about starting you on this drug? (fears, concerns, hopes, understandings)
- Did you talk about any of these things with your doctor, then or since?
 - What do you think has made the difference (if there is one)
 - Is there anything that might change your mind about these drugs (if no change has occurred and fears/concerns persist)?
- Is there anything else you think other COPD patients, families, doctors, or the research team should know about this morphine experience?

Summary

The interview guide is designed to elicit patients' stories about their experiences both pre and post opioid therapy. The semi-structured open-ended questions will be the basis of a conversation (45-60 minutes with the patient alone) concerning changes patients have noticed in their quality of life, dyspnea/other symptoms, significant relationships, satisfaction with and type of formal care (has being on morphine enabled conversations with formal caregivers that might not otherwise have taken place—or at least had not taken place prior to beginning the morphine intervention?), fears/concerns, and hope(s). Part of the focus of the analysis of this data will be on the balance of benefits:harms (positives, negatives, neutrals) as assessed by the patients themselves and the role this plays in how they rate the formal care they have experienced.

As well, it should provide some insight into how particular patients interpret this option and how that may or may not affect their experience with it (and/or their compliance), i.e., what beginning a morphine intervention signals to them, how they fit it into their understanding of the illness, its severity (worsening, ?dying), cultural, familial, and historical views of morphine (and/or narcotics use more generally, i.e., addiction risk, association with cancer pain, etc.).