## Supplementary File: Tables of Empirical Studies Included in Literature Review

## **Qualitative**

| Study |                                       | Population  | Methods   |
|-------|---------------------------------------|---|---|
| 1.    | Bajwah <i>et</i><br><i>al.</i> (2012) | 8 patients with ILD, 4 informal carers and 6 HCPs from<br>two specialist ILD clinics in London. The HCPs were a<br>mixture of generalist and specialist palliative care<br>providers and specialist respiratory care providers. | Semi-structured interviews.   |
| 2.    | Bajwah <i>et</i><br><i>al.</i> (2013) | 8 patients with ILD, 4 informal carers and 6 HCPs from<br>two specialist ILD clinics in London. The HCPs were a<br>mixture of generalist and specialist palliative care<br>providers and specialist respiratory care providers. | Semi-structured interviews.   |
| 3.    | Cawley <i>et al.</i> (2014)           | 21 patients with COPD, 13 family carers and 18 HCPs (generalists and respiratory professionals). Primary and secondary care setting of three regions of Scotland.   | Longitudinal in-<br>depth interviews (4<br>time points)   |
| 4.    | Crawford <i>et al.</i> (2013a)        | 15 patients with severe COPD, their carer and healthcare professionals in Australia   | Focus groups with<br>HCPs and semi-<br>structured<br>interviews with<br>patients and carers           |
| 5.    | Crawford<br>(2010)                    | 7 respiratory healthcare professionals in London.   | Phenomenological<br>approach, semi-<br>structured<br>interviews                                       |
| 6.    | Curtis <i>et al.</i><br>(2008)        | Patients with COPD (n=24), cancer (n=30), COPD and cancer (n=1), their family (n=36) and HCPs (n=56) in the USA.  | Interviews  |
| 7.    | Ek <i>et al.</i> (2015)               | 13 bereaved carers of patients with COPD in Sweden.<br>Recruited from a pulmonary clinic.   | Semi-structured interviews  |
| 8.    | Ek and<br>Ternestedt<br>(2008)        | 8 patients with advanced COPD. Recruited from two<br>pulmonary clinics in Sweden.   | Semi-structured<br>interviews.<br>Phenomenological<br>approach.                                       |
| 9.    | Epiphaniou<br>et al. (2014)           | 7 patients with advanced COPD, 9 patients with lung<br>cancer and 2 patients with COPD and lung cancer were<br>recruited from 3 respiratory outpatient clinics at a large<br>UK hospital.                                       | A qualitative<br>longitudinal study<br>involving in-depth<br>serial semi-<br>structured<br>interviews |
| 10.   | Fitzsimons<br>et al. (2007)           | 6 patients with respiratory failure, 6 patients with renal<br>failure and 6 patients with heart failure. 17 significant<br>others and a focus group with 18 HCPs. Set in a regional<br>hospital in Northern Ireland.            | Semi-structured<br>interviews and<br>focus groups were<br>employed.                                   |
| 11.   | Gardiner <i>et al.</i> (2009)         | 21 patients with moderate or severe COPD. From 3 GP practices across two areas in the UK.   | Semi-structured interviews  |
| 12.   | Gott <i>et al.</i><br>2009            | Five focus groups with 39 healthcare professionals<br>involved in care of patients with COPD. 3 focus groups<br>at GP surgeries and 2 at large hospitals. All in the UK.  | Focus Groups  |
| 13.   | Gysels and<br>Higginson<br>(2008)     | 18 patients with advanced COPD from a large hospital<br>in the UK. Experiencing problems with breathlessness.   | Semi-structured<br>interviews   |

| 14. Habraken <i>et</i><br><i>al.</i> (2008)  | 11 patients with advanced COPD from 5 hospitals in the Netherlands.  | Semi-structured interviews   |
|--|--|--|
| 15. Hasson <i>et al.</i>                     | 9 carers who had been bereaved 6 to 24 months from   | Semi-structured  |
| (2009)                                       | caring for a patient with COPD in Northern Ireland   | interviews   |
| 16. Hasson <i>et al.</i> (2008)              | 13 patients with advanced COPD from Northern Ireland   | Semi-structured interviews   |
| 17. Hayle <i>et al.</i><br>(2013)            | 8 patients with advanced COPD who were accessing specialist palliative care from one area in the UK.   | Semi-structured<br>interviews.<br>Phenomenological<br>approach   |
| 18. Hynes <i>et al.</i><br>(2012)            | 11 family caregivers of people with advanced COPD in<br>the Republic of Ireland  | Semi-structured<br>interviews  |
| 19. Janssen <i>et</i><br><i>al.</i> (2010)   | 2 case studies of patients with advanced COPD and 1<br>with a patient with pulmonary fibrosis in the<br>Netherlands.   | Case studies of<br>patients part of an<br>interdisciplinary<br>palliative care<br>program  |
| 20. Kanervisto<br>et al. (2007)              | 5 people with severe COPD and 4 of their spouses in Finland.   | Semi-structured<br>interviews  |
| 21. Lowey <i>et al.</i>                      | 10 patients with advanced COPD and 10 patients with  | Semi-structured  |
| (2013)                                       | advanced heart failure in a primary care setting in New<br>York  | interviews   |
| 22. Mc Veigh <i>et</i><br><i>al.</i> (2017a) | 17 bereaved family carers of patients with ILD,<br>bronchiectasis or COPD, and 18 HCPs involved in the<br>care of patients with NMRD in rural and urban areas of<br>the North and Republic of Ireland. | Semi-structured<br>interviews and<br>focus groups  |
| 23. Mc Veigh <i>et al.</i> (2017b)           | 17 bereaved family carers of patients with ILD,<br>bronchiectasis or COPD, and 18 HCPs involved in the<br>care of patients with NMRD in rural and urban areas of<br>the North and Republic of Ireland. | Semi-structured<br>interviews and<br>focus groups  |
| 24. Mac Pherson<br><i>et al.</i> (2013)      | 10 patients with severe COPD from the primary and secondary care setting in the UK.  | Semi-structured<br>interviews.<br>Grounded theory<br>approach.   |
| 25. Nguygen <i>et</i><br><i>al.</i> (2013)   | 12 people with moderate to severe COPD from an outpatient clinic in Canada.  | Semi-structured<br>interviews and<br>participants<br>watched a DVD<br>within the<br>interview that<br>covered end of life<br>care topics |
| 26. Philip <i>et al.</i><br>(2012)           | 10 patients with advanced COPD and 31 HCPs (18 nurses, 7 doctors and 6 AHPs) in Australia  | Semi-structured<br>interviews with<br>patients and 5 focus<br>groups with HCPs   |
| 27. Philip <i>et al.</i> (2014)              | 9 active and 10 bereaved carers of patients with severe COPD in Australia  | Semi-structured<br>interviews  |
| 28. Pinnock <i>et</i><br><i>al.</i> (2011)   | 21 patients with severe COPD, 13 informal carers<br>and 18 professional carers, from primary and secondary<br>care setting in Scotland   | Longitudinal multi-<br>perspective<br>qualitative study<br>(18 month period<br>up to 4 interview)  |

| 29. Reinke <i>et al.</i><br>(2008)          | Physicians $(n=31)$ Nurses $(n=25)$ Patients with<br>advanced COPD $(n=24)$ , advanced lung cancer $(n=30)$ ,<br>COPD and cancer $(n=1)$ and their family members $(n=36)$ conducted in the USA | Semi-structured<br>interviews,<br>grounded theory  |
|---|---|--|
| 30. Reinke <i>et al.</i> (2011)             | 7 patients with advanced COPD in the USA  | Semi-structured interviews   |
| 31. Reticker <i>et</i><br><i>al.</i> (2012) | 2 patients with advanced COPD in the USA  | Case study based approach  |
| 32. Sampson <i>et</i><br><i>al.</i> (2015)  | 27 patients with IPF and 21 family carers in the UK   | Semi-structured interviews   |
| 33. Schroedl <i>et</i><br><i>al.</i> (2014) | 20 patients with severe COPD in America   | Semi-structured interviews   |
| 34. Simpson <i>et</i><br><i>al.</i> (2010)  | 14 active family carers of patients with advance COPD in Canada   | Semi-structured interviews   |
| 35. Spence <i>et al.</i> (2008)             | 7 active carers of patients with severe COPD in Northern Ireland  | Semi-structured interviews   |
| 36. Spence <i>et al.</i> (2009)             | 23 healthcare professionals involved in care of COPD in<br>Northern Ireland   | Semi-structured<br>interviews with 17<br>HCPs and 6 semi<br>structured<br>interviews with<br>GPs |

## <u>Quantitative</u>

| Study |   | Population   | Methods   |
|-------|---|--|---|
| 1.    | Au <i>et al.</i><br>(2012)              | 306 patients with advanced COPD in America.<br>Outpatient setting.                               | Randomised<br>controlled trial to<br>assess impact of<br>patient specific<br>feedback form<br>regarding end of<br>life conversations. |
| 2.    | Bajwah <i>et</i><br><i>al.</i> (2012)   | 45 patients with interstitial lung disease (pulmonary fibrosis) from the UK                      | Retrospective<br>documentary<br>analysis of patients<br>hospital notes  |
| 3.    | Batzlaff <i>et</i><br><i>al.</i> (2014) | 591 patients with COPD from an ICU in America  | Retrospective<br>documentary<br>analysis of patients<br>hospital notes over<br>a 14 year period                                       |
| 4.    | Bausewein et al. (2010)                 | 49 patients with lung cancer and 60 patients with advanced COPD in Germany                       | Cross sectional questionnaire study   |
| 5.    | Beernaert <i>et al.</i> (2013)          | 111 patients with COPD, 88 with heart failure, 325 with dementia and 673 with cancer in Belgium. | Population-based<br>retrospective<br>survey studying  |

|  |   | deaths registered in<br>Belgium by GPs  |
|--|---|---|
| 6. Benzo <i>et al.</i><br>(2013)             | 1218 patients with severe COPD in the USA   | Clinical data and<br>patient self-report<br>surveys   |
| 7. Blinderman<br>et al. (2009)               | 100 patients in the USA with advanced COPD  | Longitudinal<br>Prospective survey<br>study   |
| 8. Boland <i>et al.</i> (2013)               | 16 patients with severe COPD in the UK  | Survey and<br>documentary<br>analysis   |
| 9. Buxton <i>et al.</i> (2010)               | 239 acute hospital units admitting patients with COPD in the UK   | National<br>survey/audit  |
| 10. Chandra and<br>Chandran<br>(2014)        | COPD inpatient admissions with exacerbations in<br>America  | Retrospectively<br>reviewed inpatient<br>data over an 8 year<br>period for over<br>3000 admissions.<br>Linear regression<br>analysis was<br>conducted |
| 11. Chou <i>et al.</i> (2013)                | 103 patients with COPD and 43 with lung cancer in Taiwan  | Retrospective<br>hospital data  |
| 12. Fahim and<br>Kastelik<br>(2014)          | 30 patients with advanced COPD in the UK  | Questionnaire stud  |
| 13. Farquhar <i>et</i><br><i>al.</i> (2016)  | 87 patients with NMRD in the UK   | Randomised controlled trial   |
| 14. Gaspar <i>et al.</i><br>(2014)           | 136 pulmonologists in Portugal involved in care of patients with advanced COPD  | Online<br>questionnaire   |
| 15. Goodridge <i>et al.</i> (2008)           | 433 patients who had died with a diagnosis of lung<br>cancer and 602 patients who had died with a diagnosis<br>of COPD. In Canada | Retrospective cohort study  |
| 16. Goodridge <i>et</i><br><i>al.</i> (2010) | 1098 patients who died from respiratory illness in<br>Canada  | Cohort study<br>retrospectively<br>investigating<br>healthcare data   |
| 17. Habraken <i>et</i><br><i>al.</i> (2009)  | COPD (n=82) compared to patients with advanced lung cancer (n=19) in the USA  | Questionnaires  |
| 18. Higginson <i>et</i><br><i>al.</i> (2014) | 57 patients with COPD, 19 ILD, 21 cancer, 5 Heart failure and 3 other. From the UK  | Randomised<br>Controlled Trial  |
| 19. Janssen <i>et</i><br><i>al.</i> (2011)   | 105 outpatients with severe COPD  | Observational stud<br>– using visual<br>analogue scales   |
| 20. Leung <i>et al.</i><br>(2012)            | 376 patients with moderate to severe COPD in America  | Cross-sectional<br>study using<br>validated self-<br>reporting<br>questionnaires  |
| 21. Lindell <i>et al.</i> (2015)             | 277 patients with ILD in the USA  | Retrospective data  |

| 22. Maric <i>et al.</i> (2016)               | 100 patients with advanced lung cancer and 100 patients with advanced COPD in Serbia | Cross sectional<br>cohort study  |
|--|--|--|
| 23. Matsunuma<br>et al. (2016)               | 23 patients with ILD and 59 patients with lung cancer in India                       | Retrospective data   |
| 24. Partridge <i>et</i><br><i>al.</i> (2009) | 107 respiratory physicians across England, Ireland and Wales                         | Questionnaire  |
| 25. Philip <i>et al.</i><br>(2012)           | 22019 Patients with COPD from an ICU in Australia                                    | Retrospective<br>cohort study of<br>patients data  |
| 26. Roberts <i>et</i><br><i>al.</i> (2008)   | 100 acute NHS hospitals across the UK  | Survey<br>investigating<br>existing care and<br>quality of care for<br>patients with<br>COPD |
| 27. Rush <i>et al.</i><br>(2017)             | 181,689 patients with COPD in the USA  | Retrospective<br>nationwide cohort<br>analysis   |
| 28. Slatore <i>et al.</i> (2010)             | 342 veterans with COPD in the USA  | Randomised<br>Controlled Trial   |
| 29. Smith <i>et al.</i><br>(2014)            | 17 respiratory physicians in Australia   | Pilot –<br>questionnaire   |
| 30. Strang <i>et al.</i> (2013)              | 93 respiratory physicians in Sweden  | Online<br>questionnaire  |
| 31. Tsim and<br>Davidson<br>(2014)           | Patients with COPD and Lung Cancer in Scotland                                       | Retrospective<br>cohort study of<br>patients data  |
| 32. Weingaertne<br>r <i>et al.</i><br>(2014) | Patients with lung cancer (n=32) and advanced COPD (n=50) in the UK                  | Prospective<br>longitudinal cohort<br>study  |
| 33. White <i>et al.</i> (2011)               | 163 patients with severe COPD in the UK  | Cross- sectional<br>study using HADS   |
| 34. Wysham <i>et al.</i> (2015)              | 152 patients with Lung Cancer and 86 patients with a<br>Chronic Lung Disease         | Retrospective<br>cohort study of<br>patients data  |