

# Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/110796/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Rebafka, Anne, Bennett, Clare ORCID: <https://orcid.org/0000-0002-5144-3894>, Jones, Jonathan, Carrier, Judith ORCID: <https://orcid.org/0000-0002-2657-2280>, Kugler, Christiane and Edwards, Deborah ORCID: <https://orcid.org/0000-0003-1885-9297> 2018. Lung transplant recipients' experiences of and attitudes towards self-management: a qualitative systematic review protocol. JBI Database of Systematic Reviews and Implementation Reports 16 (4) , pp. 831-837. 10.11124/JBISRIR-2017-003524 file

Publishers page: <http://dx.doi.org/10.11124/JBISRIR-2017-003524>  
<<http://dx.doi.org/10.11124/JBISRIR-2017-003524>>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies.

See

<http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



1 **Lung transplant recipients' experiences of and attitudes towards self-management: a**  
2 **qualitative systematic review protocol.**

3

4 **Background**

5 Lung transplantation (LuT) is an established treatment to improve the survival of patients with  
6 end-stage lung diseases and has been performed in over 40,000 patients worldwide.<sup>1,2</sup> Lung  
7 transplantation is performed in patients suffering from a variety of lung diseases such as  
8 chronic obstructive pulmonary disease, bronchiectasis, cancer, connective tissue disease,  
9 idiopathic interstitial pneumonia, interstitial lung disease, pulmonary arterial hypertension,  
10 lymphangiomyomatosis, obliterative bronchiolitis, sarcoidosis, other lung diseases or  
11 retransplant.<sup>3</sup> Eligible for transplant are patients with one of the above end-stage lung  
12 diseases who meet all of the following criteria: (1) High (>50%) risk of death from lung  
13 disease within 2 years if LuT is not performed, (2) high (>80%) likelihood of surviving at least  
14 90 days after LuT and (3) high (>80%) likelihood of 5-year post-transplant survival from a  
15 general medical perspective provided that there is adequate graft function.<sup>4</sup> There are  
16 various absolute and relative contraindications including but not limited to untreatable  
17 dysfunction of another major organ system or non-adherence to medical therapy. A recent  
18 review indicates that LuT substantially improves quality of life, especially in the domains of  
19 physical health and functioning.<sup>5</sup> Over recent years, survival time after receiving a lung  
20 transplant has improved significantly, with 79% of all lung transplant recipients surviving the  
21 first year after transplantation. The median survival of patients is now about eight years  
22 following LuT.<sup>3</sup>

23 Despite the undoubted benefits of LuT, it is not a 'cure' for end-stage lung diseases.<sup>6</sup> Similar  
24 to other solid organ transplant recipients, the focus of care for lung transplant recipients has  
25 shifted from the direct postoperative phase to one of long-term follow-up.<sup>7</sup> Lung transplant  
26 recipients are increasingly regarded as chronically ill patients<sup>6</sup> who need to adapt to and  
27 follow complex self-management tasks<sup>8</sup> to prevent complications, such as graft rejection or  
28 infections, and to enable the patient to keep the transplanted graft as long as possible.<sup>9</sup>

29 This paradigmatic shift from short to long-term care of lung transplant recipients has resulted  
30 in the application of chronic illness management strategies that aim to foster lung transplant  
31 recipients' self-management.<sup>10</sup> Self-management, in this regard, can be defined as an:

32 "individual's ability to manage the symptoms, treatment, physical and  
33 psychological consequences and life style changes inherent in living with a  
34 chronic condition".<sup>11(p178)</sup>

35 To understand self-management after LuT, a conceptual model originally developed in the  
36 context of renal transplantation may be useful.<sup>12</sup> This model reports that self-management  
37 after transplantation comprises of adherence to a life-long medical regimen including  
38 medication-taking,<sup>8,10</sup> self-monitoring of lung function and signs and symptoms of  
39 complications,<sup>10,13</sup> and maintaining a healthy lifestyle.<sup>10</sup> The latter requires lung transplant  
40 recipients to adapt to various behaviors, which may include fundamental lifestyle changes for  
41 individual patients, such as abstaining from harmful substances, keeping medical  
42 appointments, refraining from smoking, eating healthily, exercising, and protecting from the  
43 sun.<sup>10,12,14</sup> In order to follow these behaviors, lung transplant recipients need to possess and  
44 execute a set of skills including action-taking, decision making, problem solving, resource  
45 finding and utilization as well as the establishment of partnerships with healthcare  
46 providers.<sup>15</sup>

47 Research has indicated that lung transplant recipients realize the importance of following  
48 multi-dimensional self-management behaviors.<sup>16,17</sup> However, research has also shown that  
49 self-management is insufficient in many aspects.<sup>9,10,18-21</sup> Of these self-management aspects,  
50 medication adherence has been studied most extensively with up to 72% of lung transplant  
51 recipients displaying some extent of medication non-adherence at some time.<sup>10,22</sup> Suboptimal  
52 implementation of transplant-related self-management is also reported in other self-  
53 management tasks including infrequent use of self-monitoring of lung function.<sup>16,19,20,23</sup>  
54 Likewise, smoking cessation proves difficult in some lung transplant recipients.<sup>24,25</sup>  
55 Consequently, there is a gap between patients' awareness of the need and importance of  
56 self-management and individual health-related behavior.

57 Research in solid organ transplant recipients has shown that adherence to self-management  
58 tasks depends on patients' personal experiences and attitudes rather than on non-modifiable  
59 factors such as gender, age or ethnicity.<sup>26-28</sup> Qualitative research in renal transplant  
60 recipients, for example, has demonstrated that a major driver for medication adherence is  
61 experience of dialysis treatment.<sup>29-31</sup> Likewise, lung transplant recipients with cystic fibrosis  
62 with prior experience of home spirometry displayed better adherence to home spirometry  
63 than other lung transplant patients.<sup>16</sup> Attitudes also play an important role in the self-  
64 management of many conditions. In 2003, the World Health Organization<sup>32</sup> identified  
65 patients' attitudes as one of several patient-related factors which affected adherence to self-  
66 management in patients with HIV<sup>33</sup>, epilepsy,<sup>34</sup> and diabetes.<sup>35</sup> In renal transplant recipients,  
67 skepticism or medication-related concerns were shown to be associated with inadequate  
68 medication adherence.<sup>36,37</sup> A positive, optimistic attitude to life and illness in general was also  
69 shown to be an important part of managing ones' everyday life after lung and heart  
70 transplantation.<sup>38,39</sup>

71 Experiences and attitudes, defined as a “tendency that is expressed by evaluating a  
72 particular entity with some degree of favor or disfavor”<sup>13(p666)</sup>, as well as values, beliefs or  
73 knowledge can best be explored using qualitative research methods.<sup>40-42</sup> In the case of solid  
74 organ transplant recipients, this has been performed to some extent, however, research has  
75 primarily focused on isolated self-management tasks such as medication-taking<sup>28</sup>, social  
76 adaptation<sup>17</sup>, alcohol abstinence<sup>43</sup>, smoking cessation<sup>44</sup> or physical activity<sup>45</sup>, neglecting the  
77 multidimensionality of self-management after solid organ transplantation.<sup>46</sup> Synthesizing  
78 qualitative evidence by conducting systematic reviews may deepen our comprehension of  
79 how patients perceive and execute self-management. A systematic review on renal  
80 transplant recipients’ motivations, challenges and attitudes to self-management has been  
81 performed recently.<sup>27</sup> However, no qualitative systematic review on any aspect of LuT or on  
82 lung transplant recipients’ experiences of and attitudes towards self-management could be  
83 found in the Joanna Briggs Institute (JBI) Database of Systematic Reviews and  
84 Implementation Reports, the Cochrane database of systematic reviews or the PROSPERO  
85 international prospective register of systematic reviews.

86 The reasons for the gap between lung transplant recipients’ awareness of the need for self-  
87 management and their self-management behavior remain unclear. This review aims to  
88 identify lung transplant recipients’ experiences of and attitudes towards self-management.  
89 The findings of this review will help healthcare practitioners to better understand the  
90 challenges their patients face, potentially resulting in more patient-centered education and an  
91 increase in lung transplant recipients’ self-management abilities.

## 92 **Keywords**

93 lung transplantation; self-management; attitude; experience

## 94 **Review Question**

95 What are lung transplant recipients’ experiences of and attitudes towards self-management?

## 96 **Methods**

### 97 **Inclusion Criteria**

#### 98 **Participants**

99 This review will consider studies that include persons over 18 years who have received a  
100 lung transplant. No restrictions on underlying diseases, gender, ethnicity or length of time  
101 since transplant will be imposed. Studies including participants with mixed types of solid  
102 organ transplantations will be included where it is possible to accurately identify data on  
103 aspects of lung transplant-related self-management separately. Data on self-management

104 related to other conditions will be excluded. Only studies on participants who are able to  
105 perform their self-management tasks independently will be included.

106 ***Phenomena of Interest***

107 This review will consider studies on the experiences and attitudes of lung transplant  
108 recipients towards self-management.

109 ***Context***

110 This review will consider all available evidence on lung transplant recipients worldwide. If this  
111 review reveals regional and/or cultural differences in lung transplant recipients' experiences  
112 and attitudes towards self-management, these will be explicated in the review.

113 ***Study Types***

114 This review will consider studies that focus on qualitative data including, but not limited to,  
115 designs such as phenomenology, grounded theory, ethnography, action research, and  
116 feminist research. Mixed-methods studies will be included only when qualitative data can be  
117 extracted separately.

118 Studies published in English or German will be considered for inclusion in this review,  
119 however studies found in any other languages will be mentioned in the review. No date  
120 restrictions will be imposed for inclusion in this review.

121 ***Search Strategy***

122 The search strategy will aim to find both published and unpublished studies. An initial limited  
123 search of MEDLINE and CINAHL has been undertaken using the terms "lung  
124 transplantation", AND "self-management", AND ("attitude" OR "experience"). This was  
125 followed by analysis of the text words contained in the title and abstract, and of the index  
126 terms used to describe the article. This informed the development of a search strategy which  
127 will be tailored for each information source. A full search strategy for MEDLINE is detailed in  
128 Appendix 1. The reference list of all studies selected for critical appraisal will be screened for  
129 additional studies.

130 The databases to be searched from their inception will include:

131 MEDLINE, CINAHL, PsycINFO, EMBASE, Web of Science, British Nursing Index

132 The search for unpublished studies will include:

133 Proquest Dissertation & Theses Database, EThOS, Open Grey (Sigle)

134 ***Study Selection***

135 Following the search, all identified citations will be collated and uploaded into Endnote and  
136 duplicates removed. Titles and abstracts will then be screened by two independent reviewers

137 for assessment against the inclusion criteria for the review. Studies that may meet the  
138 inclusion criteria will be retrieved in full and their details imported into JBI SUMARI. The full  
139 text of selected studies will be retrieved and assessed in detail against the inclusion criteria.  
140 Full text studies that do not meet the inclusion criteria will be excluded and reasons for  
141 exclusion will be provided in an appendix in the final systematic review report. Included  
142 studies will undergo a process of critical appraisal. The results of the search will be reported  
143 in full in the final report and presented in a PRISMA flow diagram.<sup>47</sup> Any disagreements that  
144 arise between the reviewers will be resolved through discussion, or with a third reviewer.

### 145 **Critical Appraisal**

146 Selected studies will be critically appraised by two independent reviewers for methodological  
147 quality in the review using the JBI Qualitative Assessment and Review Instrument.<sup>48</sup> Any  
148 disagreements that arise between the reviewers will be resolved through discussion, or with  
149 a third reviewer. The results of critical appraisal will be reported in narrative form and in a  
150 table.

151 All studies, regardless of the results of their methodological quality, will undergo data  
152 extraction and synthesis. Studies rated as “unclear” or “no” in seven or more QARI items will  
153 be specified.

### 154 **Data Extraction**

155 Qualitative data will be extracted from papers included in the review using the standardized  
156 data extraction tool<sup>49</sup> from JBI SUMARI by two reviewers. The data extracted will include  
157 specific details about the populations, context, culture, geographical location, study methods  
158 and the phenomena of interest relevant to the review question and specific objectives.  
159 Findings, and their illustrations, will be extracted and assigned a level of credibility. Authors  
160 of primary studies will be contacted for clarification or missing information when necessary.

### 161 **Data Synthesis**

162 Qualitative research findings will, where possible be pooled using JBI SUMARI with the  
163 meta-aggregation approach.<sup>48</sup> This will involve the aggregation or synthesis of findings to  
164 generate a set of statements that represent that aggregation, through assembling the  
165 findings and categorizing these findings on the basis of similarity in meaning. These  
166 categories are then subjected to a synthesis in order to produce a single comprehensive set  
167 of synthesized findings that can be used as a basis for evidence-based practice. Where  
168 textual pooling is not possible the findings will be presented in narrative form.

### 169 **Assessing Confidence**

170 The final synthesized findings will be graded according to the ConQual approach for  
171 establishing confidence in the output of qualitative research synthesis and presented in a

172 Summary of Findings table.<sup>50</sup> The Summary of Findings table includes the major elements of  
173 the review and details how the ConQual score is developed. Included in the table is the title,  
174 population, phenomena of interest and context for the specific review. Each synthesized  
175 finding from the review is then presented along with the type of research informing it, a score  
176 for dependability, credibility, and the overall ConQual score.

177 ***Conflicts of Interest***

178 No conflict of interest.

179 ***Acknowledgements***

180 None

181

**182 References**

- 183 1. DeVito Dabbs A, Terhorst L, Song MK, Shellmer DA, Aubrecht J, Connolly M, et al. Quality of  
184 recipient-caregiver relationship and psychological distress are correlates of self-care agency after lung  
185 transplantation. *Clin Transplant* 2013; 27(1): 113-120.
- 186 2. Yusen RD, Christie JD, Edwards LB, Kucheryavaya AY, Benden C, Dipchand AI, et al. The Registry  
187 of the International Society for Heart and Lung Transplantation: Thirtieth Adult Lung and Heart-Lung  
188 Transplant Report—2013; Focus Theme: Age. *J Heart Lung Transplant* 2013; 32(10): 965-978.
- 189 3. Yusen RD, Edwards LB, Dipchand AI, Goldfarb SB, Kucheryavaya AY, Levvey BJ, et al. The  
190 Registry of the International Society for Heart and Lung Transplantation: Thirty-third Adult Lung and  
191 Heart-Lung Transplant Report—2016; Focus Theme: Primary Diagnostic Indications for Transplant. *J*  
192 *Heart Lung Transplant* 2016; 35(10): 1170-1184.
- 193 4. Weill D, Benden C, Corris PA, Dark JH, Davis RD, Keshavjee S, et al. A consensus document for  
194 the selection of lung transplant candidates: 2014—An update from the Pulmonary Transplantation  
195 Council of the International Society for Heart and Lung Transplantation. *J Heart Lung Transplant* 2015;  
196 34(1): 1-15.
- 197 5. Singer J, Chen J, Blanc PD, Leard LE, Kukreja J, Chen H. A thematic analysis of quality of life in  
198 lung transplant: the existing evidence and implications for future directions. *Am J Transplant* 2013;  
199 13(4): 839-850.
- 200 6. Schaevers V, Schoonis A, Frickx G, Verleden G, Jans C, Rosseel C, et al. Implementing a  
201 standardized, evidence-based education program using the patient's electronic file for lung transplant  
202 recipients. *Prog Transplant* 2012; 22(3): 264-270.
- 203 7. Dobbels F, Vanhaecke J, Dupont L, Nevens F, Verleden G, Pirenne J, et al. Pretransplant  
204 predictors of posttransplant adherence and clinical outcome: an evidence base for pretransplant  
205 psychosocial screening. *Transplantation* 2009; 87(10): 1497-1504.
- 206 8. Rosenberger EM, DeVito Dabbs AJ, DiMartini AF, Landsittel DP, Pilewski JM, Dew MA. Long-Term  
207 Follow-up of a Randomized Controlled Trial Evaluating a Mobile Health Intervention for Self-  
208 Management in Lung Transplant Recipients. *Am J Transplant* 2017; 17(5): 1286-1293.
- 209 9. Zaldonis J, Alrawashdeh M, Atman KS, Fatigati A, Dabbs AD, Bermudez CA. Predictors and  
210 influence of goal orientation on self-management and health-related quality of life after lung transplant.  
211 *Prog Transplant* 2015; 25(3): 230-242.
- 212 10. Hu L, Lingler JH, Sereika SM, Burke LE, Malchano DK, Dabbs AD, et al. Nonadherence to the  
213 medical regimen after lung transplantation: A systematic review. *Heart Lung* 2017.
- 214 11. Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people  
215 with chronic conditions: a review. *Patient Educ Couns* 2002; 48(2): 177-187.
- 216 12. Schäfer-Keller P, Dickenmann M, Berry DL, Steiger J, Bock A, De Geest S. Computerized patient  
217 education in kidney transplantation: Testing the content validity and usability of the Organ Transplant  
218 Information System (OTIS™). *Patient Educ Couns* 2009; 74(1): 110-117.
- 219 13. Kilpatrick K, Kaasalainen S, Donald F, Reid K, Carter N, Bryant-Lukosius D, et al. The  
220 effectiveness and cost-effectiveness of clinical nurse specialists in outpatient roles: a systematic  
221 review. *J Eval Clin Pract* 2014; 20: 1106-1123.
- 222 14. Kowalski C, Diener S, Steffen P, Wuerstlein R, Harbeck N, Pfaff H. Associations between hospital  
223 and patient characteristics and breast cancer patients' satisfaction with nursing staff. *Cancer Nurs*  
224 2012; 35(221-228).
- 225 15. Lorig KR, Holman H. Self-management education: history, definition, outcomes, and mechanisms.  
226 *Ann Behav Med* 2003; 26(1): 1-7.
- 227 16. Teichman BJ, Burkner EJ, Weiner M, Egan TM. Factors associated with adherence to treatment  
228 regimens after lung transplantation. *Prog Transplant* 2000; 10(2): 113-121.
- 229 17. Forsberg A, Karlsson V, Cavallini J, Lennerling A. The meaning of social adaptation after solid  
230 organ transplantation. *Nordic J Nurs* 2015; 36(2): 62-67.



- 231 18. DeVito Dabbs A, Song MK, Myers BA, Li R, Hawkins RP, Pilewski JM, et al. A Randomized  
232 Controlled Trial of a Mobile Health Intervention to Promote Self-Management After Lung  
233 Transplantation. *Am J Transplant* 2016; 16(7): 2172-2180.
- 234 19. Dew MA, DiMartini AF, Dabbs ADV, Zomak R, De Geest S, Dobbels F, et al. Adherence to the  
235 medical regimen during the first two years after lung transplantation. *Transplantation* 2008; 85(2): 193.
- 236 20. Kugler C, Gottlieb J, Dierich M, Haverich A, Strueber M, Welte T, et al. Significance of patient self-  
237 monitoring for long-term outcomes after lung transplantation. *Clin Transplant* 2010; 24(5): 709-716.
- 238 21. Bosma OH, Vermeulen KM, Verschuuren EA, Erasmus ME, van der Bij W. Adherence to  
239 immunosuppression in adult lung transplant recipients: Prevalence and risk factors. *J Heart Lung*  
240 *Transplant* 2011; 30(11): 1275-1280.
- 241 22. Kugler C, Fischer S, Gottlieb J, Tegtbur U, Welte T, Goerler H, et al. Symptom experience after  
242 lung transplantation: impact on quality of life and adherence. *Clin Transplant* 2007; 21(5): 590-596.
- 243 23. Lindgren BR, Snyder M, Sabati N, Adam T, Pieczkiewicz D, Finkelstein SM. Health Locus of  
244 Control and Adherence with Home Spirometry Use in Lung Transplant Recipients. *Prog Transplant*  
245 2002; 12(1): 24-29.
- 246 24. DeVito Dabbs A, Hoffman LA, Iacono AT, Wells CL, Grgurich W, Zullo TG, et al. Pattern and  
247 predictors of early rejection after lung transplantation. *Am J Crit Care* 2003; 12(6): 497-507.
- 248 25. Ruttens D, Verleden SE, Goeminne PC, Poels K, Vandermeulen E, Godderis L, et al. Smoking  
249 resumption after lung transplantation: standardised screening and importance for long-term outcome.  
250 *Eur Respir J* 2013; 43(1): 300.
- 251 26. Rebaafka A. Medication adherence after renal transplantation - a review of the literature. *J Ren*  
252 *Care* 2016; 42(4): 239-256.
- 253 27. Jamieson NJ, Hanson CS, Josephson MA, Gordon EJ, Craig JC, Halleck F, et al. Motivations,  
254 Challenges, and Attitudes to Self-management in Kidney Transplant Recipients: A Systematic Review  
255 of Qualitative Studies. *Am J Kidney Dis* 2015; 67(3): 461-478.
- 256 28. Tong A, Howell M, Wong G, Webster AC, Howard K, Craig JC. The perspectives of kidney  
257 transplant recipients on medicine taking: a systematic review of qualitative studies. *Nephrol Dial*  
258 *Transplant* 2011; 26(1): 344-354.
- 259 29. Russell CL, Kilburn E, Conn VS, Libbus MK, Ashbaugh C. Medication-taking beliefs of adult renal  
260 transplant recipients. *Clin Nurse Spec* 2003; 17(4): 200-210.
- 261 30. Orr A, Orr D, Willis S, Holmes M, Britton P. Patient perceptions of factors influencing adherence to  
262 medication following kidney transplant. *Psychol Health Med* 2007; 12(4): 509-517.
- 263 31. Tong A, Sainsbury P, Chadban S, Walker RG, Harris DC, Carter SM, et al. Patients' experiences  
264 and perspectives of living with CKD. *Am J Kidney Dis* 2009; 53(4): 689-700.
- 265 32. Sabaté E (ed). *Adherence to Long-Term Therapies. Evidence for Action*. Geneva: WHO; 2003.
- 266 33. Siegel K, Karus D, Schrimshaw EW. Racial differences in attitudes toward protease inhibitors  
267 among older HIV-infected men. *AIDS Care* 2000; 12(4): 423-434.
- 268 34. Desai P, Padma MV, Jain S, Maheshwari MC. Knowledge, attitudes and practice of epilepsy:  
269 experience at a comprehensive rural health services project. *Seizure* 1998; 7(2): 133-138.
- 270 35. Johnson SB. Knowledge, attitudes, and behavior: Correlates of health in childhood diabetes. *Clin*  
271 *Psychol Rev* 1984; 4(5): 503-524.
- 272 36. Griva K, Davenport A, Harrison M, Newman SP. Non-adherence to immunosuppressive  
273 medications in kidney transplantation: intent vs. forgetfulness and clinical markers of medication  
274 intake. *Ann Behav Med* 2012; 44: 85-93.
- 275 37. Goetzmann L, Klaghofer R, Spindler A, Wagner-Huber R, Scheuer E, Buddeberg C. Die  
276 Medikamenten-Erfahrungs-Skala für Immunsuppressiva“ (MESI): erste Ergebnisse zu einem neuen  
277 Screeninginstrument in der Transplantationsmedizin. *Psychother Psychosom Med Psychol* 2006;  
278 56(2): 49-55.

- 279 38. Thomsen D, Jensen BO. Patients' experiences of everyday life after lung transplantation. *J Clin*  
280 *Nurs* 2009; 18(24): 3472-3479.
- 281 39. Mauthner O, De Luca E, Poole J, Gewarges M, Abbey SE, Shildrick M, et al. Preparation and  
282 Support of Patients through the Transplant Process: Understanding the Recipients' Perspectives. *Nurs*  
283 *Res Pract* 2012; 2012: 9.
- 284 40. Tong A, Chapman JR, Israni A, Gordon EJ, Craig JC. Qualitative Research in Organ  
285 Transplantation: Recent Contributions to Clinical Care and Policy. *Am J Transplant* 2013; 13(6): 1390-  
286 1399.
- 287 41. Polit DF, Beck CT. *Essentials of Nursing Research. Methods, Appraisal, and Utilization*,  
288 Philadelphia: Lippincott Williams & Wilkins, 2006.
- 289 42. Dew MA, DeVito Dabbs AJ. Harnessing the Power of Qualitative Research in Transplantation. *Am*  
290 *J Kidney Dis* 2016; 67(3): 357-359.
- 291 43. Heyes CM, Schofield T, Gribble R, Day CA, Haber PS. Reluctance to Accept Alcohol Treatment by  
292 Alcoholic Liver Disease Transplant Patients: A Qualitative Study. *Transplantation direct* 2016; 2(10):  
293 e104.
- 294 44. Duerinckx N, Burkhalter H, Engberg SJ, Kirsch M, Klem ML, Sereika SM, et al. Correlates and  
295 Outcomes of Posttransplant Smoking in Solid Organ Transplant Recipients: A Systematic Literature  
296 Review and Meta-Analysis. *Transplantation* 2016; 100(11): 2252-2263.
- 297 45. van Adrichem EJ, van de Zande SC, Dekker R, Verschuuren EA, Dijkstra PU, van der Schans CP.  
298 Perceived Barriers to and Facilitators of Physical Activity in Recipients of Solid Organ Transplantation,  
299 a Qualitative Study. *PLoS ONE* 2016; 11(9): e0162725.
- 300 46. Taylor S, Pinnock H, Epiphaniou E, Pearce G, Parke H, Schwappach A, et al. A rapid synthesis of  
301 the evidence on interventions supporting self-management for people with long-term conditions:  
302 PRISMS - Practical systematic Review of Self-Management Support for long-term conditions. .  
303 *HS&DR* 2014; 2(53).
- 304 47. Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group. Preferred Reporting Items for  
305 Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 2009; 6(6).
- 306 48. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for  
307 systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc* 2015; 13(3): 179-187.
- 308 49. Joanna Briggs Institute. *Joanna Briggs Institute Reviewers' Manual: 2014 edition*, Adelaide,  
309 Australia: University of Adelaide, 2014.
- 310 50. Munn Z, Porritt K, Lockwood C, Aromataris E, Pearson A. Establishing confidence in the output of  
311 qualitative research synthesis: the ConQual approach. *BMC Med Res Methodol* 2014; 14(1): 108.  
312

313 **Appendix I: Initial Search Strategy (Medline via Ovid)**

314

Question part	Question term	Search terms
Population	Lung transplant recipients	lung transpl*[title, abstract] OR "Lung Transplantation"[Mesh]
AND		
Phenomena of Interest	Self-management	self managemen*[title, abstract] OR self car*[title, abstract] OR "Self Care"[Mesh] OR "chronic disease"[Mesh] OR chronic illness management[title, abstract] OR chronic illness[title, abstract] OR Decision making[title, abstract] OR "decision making"[Mesh] OR Illness behavior?[title, abstract] OR "illness behavior"[Mesh] OR Health behavior?[title, abstract] OR "health behavior"[Mesh] OR Health knowledge[title, abstract] OR "health knowledge, attitudes, practice"[Mesh] OR Adherence[title, abstract] OR "medication adherence"[Mesh] OR compliance[title, abstract]
	AND	
	Attitude Experience	attitude[title, abstract] OR "Attitude"[Mesh] OR "attitude to health"[Mesh] OR percept*[title, abstract] OR "Perception"[Mesh] OR experience[title, abstract] OR "social support"[Mesh] OR "self concept"[Mesh])
Context	Internationally	n/a

315