

1 **Factors associated with participation in life situations for adults with stroke: a systematic**  
2 **review.**

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4 **Keywords** stroke, community participation, social support, activities of daily living, depression,  
5 cognitive dysfunctions, and chronic disease.

6 **Abstract**

7 **Objectives:** To identify biopsychosocial factors associated with participation outcomes for adults  
8 with stroke and to investigate factors associated with participation at different time points post  
9 stroke.

10 **Data sources:** Medline, CINAHL, AMED, PyschINFO and Web of Science were systematically  
11 searched using key words “stroke”, “participation” and “outcomes” and their synonyms on 15th  
12 May 2017.

13 **Study selection:** Observational studies reporting on biopsychosocial factors and participation  
14 outcomes for community dwelling adults with stroke were selected. Studies were eligible for  
15 inclusion if participation outcomes were measured using indices that mapped to the participation  
16 domain of the ICF. Intervention studies were excluded. A second reviewer checked all studies  
17 against eligibility criteria at each stage.

18 **Data extraction:** Data were extracted on any statistically determined association between  
19 biopsychosocial factors and participation outcomes.

20 **Data synthesis:** The proportion of studies reporting significant associations with variables were  
21 classified according to the ICF. The exact binomial test was used to determine the probability  
22 that the proportion of studies reporting significant associations was due to chance alone.  
23 Qualitative descriptive summaries of each study allowed consideration of interactions between  
24 variables and changes in participation over time points.

25 **Conclusions:** Whilst depressive symptoms, cognitive functioning and mobility were found to  
26 have the strongest associations with participation, we found that other frequently occurring  
27 factors (such as fatigue and environmental factors) were less extensively considered. The  
28 diversity of outcome measures encountered within the review highlight the need for a consensus  
29 on a core set of outcome measures to evaluate long term participation in life situations after  
30 stroke.

31 **Keywords:** stroke, participation

32 **Abbreviations:** International classification of functioning (ICF). Cumulative Index of Nursing  
33 and Allied Health Literature (CINAHL), Allied and Complimentary Medicine Database  
34 (AMED).

### 35 **Introduction**

36 Advances in the prevention and management of stroke mean that more people are surviving and  
37 living with the long-term consequences of stroke<sup>1</sup>. Moreover, the number of people experiencing  
38 stroke at a younger age is increasing<sup>2,3</sup> resulting in a considerable lifetime impact of stroke,

39 particularly around productivity and work<sup>4</sup>. These changes have been described as an  
40 epidemiological shift towards stroke becoming a long-term health condition<sup>5</sup>.

41 There is considerable evidence that those surviving stroke experience difficulties retaining  
42 previous levels of participation in social, community, work and leisure activities<sup>3</sup>. Personal,  
43 environmental and stroke related factors have been reported as potential barriers to resuming  
44 participation in life roles one year after stroke<sup>6</sup>. The resulting restrictions in social and  
45 community participation are strongly associated with lower quality of life<sup>7</sup>.

46 Many overlapping terms are used to describe social and community participation<sup>8</sup>. The  
47 International Classification of Functioning (ICF) provides a taxonomy of activities and  
48 participation: where activities reflect performance at an individual level and participation in life  
49 situations reflects performance at a societal level<sup>9-11</sup>. For the purpose of this review, participation  
50 was operationalized using the ICF chapters 6 (domestic life), 7 (interpersonal interactions and  
51 relationships), 8 (major life areas) 9 (community social and civic life)<sup>12 13</sup>.

52 Participation in life situations is potentially modifiable even when there is no further recovery in  
53 body functions and is therefore an important concept to consider for those living with long term  
54 health conditions<sup>14</sup>. Considering that participation in life situations is an important outcome of  
55 stroke rehabilitation,<sup>15</sup> there is surprisingly limited evidence of effective interventions for  
56 reducing participation restrictions in the longer term<sup>3, 16, 17</sup>. There is considerable literature  
57 investigating factors associated with participation after stroke, but this hasn't sufficiently  
58 informed the use of participation measures within intervention studies and participation  
59 outcomes remain underutilised<sup>18 19, 20</sup>. Synthesis of the available evidence could inform the

60 development of more comprehensive approaches to improve participation outcomes for stroke  
61 survivors. Therefore, the aims of this study are:

- 62 • to identify biopsychosocial factors associated with or determining participation outcomes  
63 for adults with stroke
- 64 • to investigate associations with participation at different time points post stroke.

## 65 *Methods*

66 *Search strategy and Selection criteria.* This systematic review was registered with  
67 PROSPERO<sup>21</sup> and is reported following PRISMA guidelines<sup>22</sup>.

68 We searched for and included studies involving stroke patients that met the following criteria:

- 69 • community dwelling stroke survivors (all strokes) aged 18 and over. Studies with mixed  
70 populations were included if 90% of participants had stroke
- 71 • observational studies
- 72 • investigated biopsychosocial factors associated with participation outcomes
- 73 • written in English.

74 Intervention studies were excluded.

75 We searched Medline, CINAHL, AMED, Psych INFO and Web of Science on 1<sup>st</sup> January 2015  
76 (updated on 17<sup>th</sup> May 2017). The literature search was not limited by date; results dated back to  
77 1946. We used keywords ‘stroke’, ‘participation’, ‘measures’ and their associated synonyms and  
78 terms (please see supplementary appendix I). We hand searched three most cited journals from  
79 our eligible studies between May 2016 and May 2017. Additional studies were located through  
80 reference lists of eligible studies.

81 The primary outcome of interest was participation in life situations. An initial list of measures  
82 relevant to stroke was collated from literature that had evaluated psychometric properties and  
83 mapped participation instruments to the ICF <sup>23-26</sup> .

84 Two reviewers then independently mapped the content of each measure to chapters six to nine of  
85 the activity and participation domain of the ICF (domestic life, interpersonal interactions and  
86 relationships, major life areas, community social and civic life). Learning and applying  
87 knowledge, general tasks and demands, communication, self-care and mobility were not included  
88 <sup>27</sup>. This was to ensure that participation was the primary focus of each measure. Participation  
89 outcomes were included if fifty percent or more of the questions in the measure mapped to  
90 chapters six to nine. Differences in reviewers' assessments were discussed until agreement was  
91 reached.

92 A total of 24 measures were reviewed and 14 were eligible for inclusion (table 1). Interrater  
93 agreement was very good (Cohens kappa 0.81, 95% CI. 0.47-0.69). All included measures were  
94 standardized questionnaires. It is beyond the scope of this review to report on psychometric  
95 properties.

96 ***Study selection process.*** Figure 1 summarises the selection process. A second reviewer (LF)  
97 independently reviewed all studies against eligibility criteria at each stage. Any disagreements  
98 were resolved through discussion between reviewers. Agreement was assessed using Cohen's  
99 kappa. Inter-rater agreement of eligibility by abstracts was moderate (kappa 0.65, 95% CI.,0.58  
100 to 0.73) <sup>28</sup>. Inter-rater agreement of eligibility by full text was also moderate (kappa 0.58 95% CI.  
101 0.47 to 0.69).

102 **Data extraction.** Data were extracted on any statistically determined association between  
103 participation outcomes and biopsychosocial variables under study. Where studies were reported  
104 in more than one paper, data was extracted, pooled and treated as one study.

105 **Risk of bias in individual studies.** Risk of bias was assessed using the Quality Assessment Tool  
106 for Observational and Cross-sectional studies<sup>29,30</sup>. The tool provides a rating for low, fair or high  
107 risk of bias. A second researcher reviewed (LP) ten per cent of the risk of bias assessments,  
108 interrater agreement of risk of bias was moderate (kappa 0.56, 95% CI 0.02-1). Risk of bias  
109 assessments informed the interpretation of our findings, particularly where studies reported  
110 anomalous results.

111 **Analysis.** Variables investigated were grouped (by LE) according to the ICF classification<sup>31</sup>:  
112 contextual factors (personal or environmental factors), health condition (type of stroke, time  
113 since stroke), stroke related impairments in body functions and structures (e.g. cognitive deficits,  
114 movement deficits) and activity limitations (i.e. limitations in mobility or in daily activities)<sup>9</sup>.  
115 For example, Fugl Meyer assessment of lower limb function was labelled as “control of  
116 voluntary movement” from the ICF chapter “neuromusculoskeletal and movement functions”,  
117 whereas the six-meter timed walk test was labelled as “walking and moving” from the ICF  
118 chapter “mobility”. As the presence of depressive symptoms was determined by depression  
119 scales, it was mapped to “emotional functions” within the ICF chapter “mental functions”, rather  
120 than assuming the presence of depression as a health condition<sup>31</sup>.

121 For each study, we determined which factors had a significant association ( $p < 0.05$ ) with  
122 participation outcomes. In longitudinal studies with multiple data time points, we counted each  
123 association once. We then used an exact binomial test to calculate the probability that the

124 observed proportion of studies reporting associations deviated from the expected proportion by  
125 chance alone (assuming that there was no association and no publication bias)<sup>32,33</sup>. The expected  
126 proportion of studies finding an association with  $p < 0.05$ , would be 0.05<sup>34</sup>. We also determined  
127 whether studies were adequately powered to detect a weak association (correlation of 0.2), alpha  
128 at 0.05 (two tailed), and power of 0.8. Factors which were investigated once only were not  
129 included in the binomial test analysis (please see supplementary appendix IV).

130 Descriptive summaries of the results of each study were coded and analyzed for evidence of  
131 interactions between biopsychosocial factors within each study<sup>35</sup>. Findings from cohort studies  
132 were summarized by time points to provide a descriptive summary of how factors associated  
133 with participation outcomes changed over time.

#### 134 ***Results***

135 In total, 92 papers (reporting on 81 studies) were eligible for inclusion (figure 1).

136 ***Study Characteristics.*** Thirty-three of the studies in the review were cross-sectional and  
137 collected data from participants who were from three months to 31 years post stroke. Forty-two  
138 were prospective cohort studies and seven were retrospective cohort studies. Of the cohort  
139 studies, 11 studies assessed participants' outcomes at multiple time points, ranging from three  
140 months<sup>36</sup> to six years post stroke<sup>37</sup>. The total number of study participants was 11,815. Studies  
141 included people from 18 to 99 years old and stroke severity from minor to severe, residing at  
142 home or in a care facility (please see supplementary appendix II). Fourteen participation  
143 measures assessed aspects of participation in life situations (table 1). Studies employed a range  
144 of statistical analyses including correlation, univariate and regression analysis.

145 **Table 1:** Outcomes measures mapped to Activity Participation domain of ICF.

146

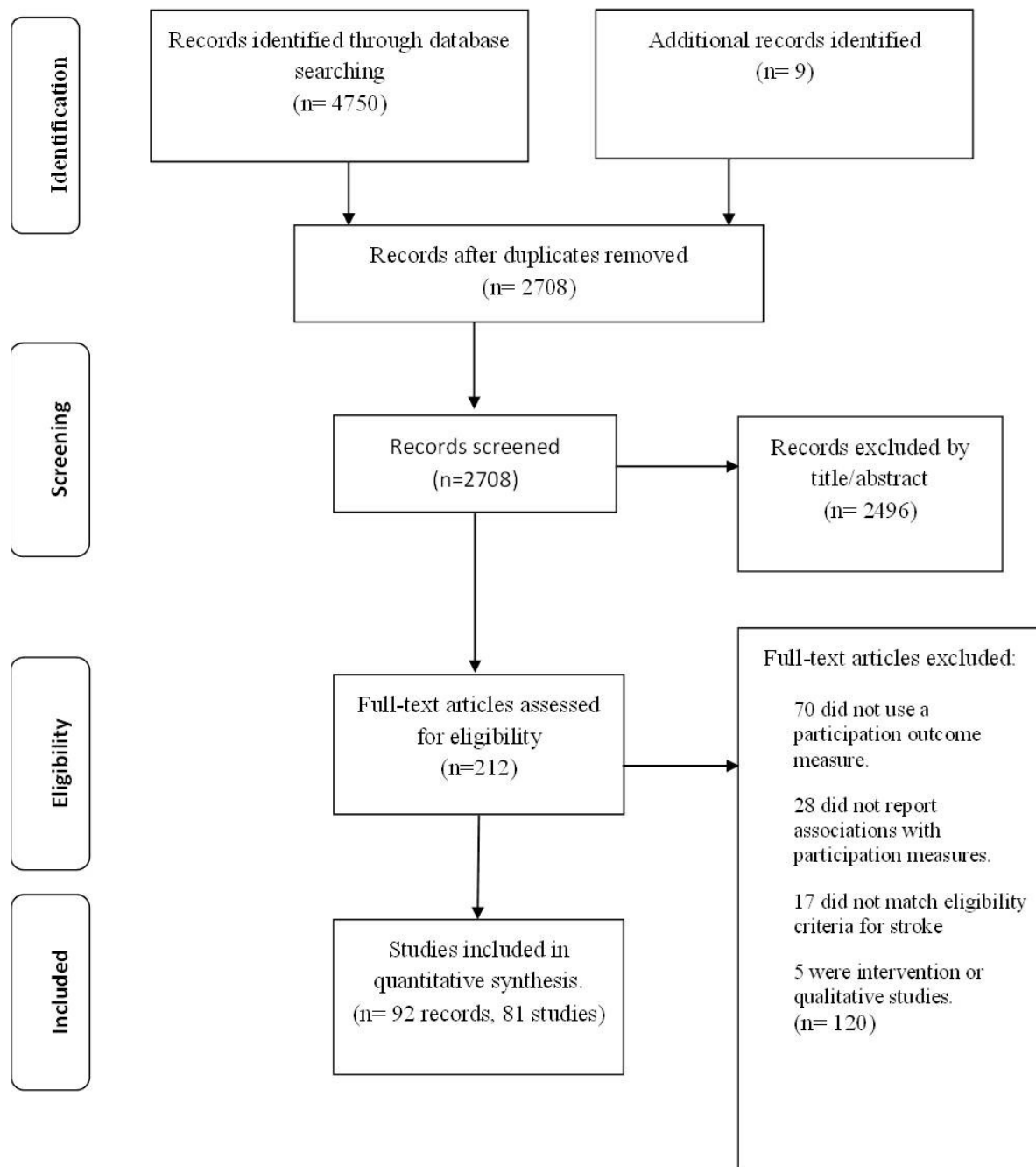
Outcome measures	Activity and Participation chapters ICF								
	Learning & knowledge	General tasks	Communication	Mobility	Self-care	Domestic life	Interpersonal relationships	Major life areas	Community, social and civic life
Activity Card Sort (ACS) <sup>*1</sup>	✓		✓	✓	✓	✓	✓	✓	✓
Community Integration questionnaire <sup>2</sup>		✓		✓		✓	✓	✓	✓
Frenchay Activities Index <sup>3</sup>				✓		✓		✓	✓
IMPACT-S (participation subscale) <sup>4</sup>					✓	✓	✓	✓	✓
Impact on Participation & Autonomy Questionnaire (IPAQ) <sup>5</sup>					✓	✓	✓	✓	✓
LIFE-H (assessment of life habits) <sup>6</sup>			✓	✓	✓	✓	✓	✓	✓
London Handicap Scale <sup>7</sup>			✓	✓	✓	✓	✓	✓	✓
PAR- Pro <sup>8</sup>				✓		✓	✓	✓	✓
Re-integration to normal living index <sup>9</sup>							✓	✓	✓
Short Form 36 (social role functioning subscale only) <sup>10</sup>									✓
Sickness Impact Profile			✓	✓	✓				



<b>(psychosocial subscale only) <sup>11</sup></b>									
<b>Stroke Impact Scale (social subscale) <sup>12</sup></b>						✓	✓	✓	✓

147

Figure 1: PRISMA 2009 Flow Diagram <sup>21</sup>



148

149

150 *Analysis of factors associated with participation outcomes.* Participation outcomes  
 151 were associated with sociodemographic factors, health conditions, body function impairments  
 152 and activity limitations (please see supplementary appendix III). Type of stroke was the only  
 153 factor where the proportion of studies finding associations with participation was likely to be a  
 154 chance occurrence. The direction of the associations was mostly consistent across the studies  
 155 with sex being the only exception. Poorer participation outcomes were associated with older age,  
 156 increased stroke severity, more comorbidity, greater degree of stroke related impairment and  
 157 more activity limitations (Table 2).

158 **Table 2:** Results of exact binomial test.

159 Associations with biopsychosocial factors and participation in all studies compared to those  
 160 found in sufficiently powered studies ( $n > 194$  for a correlation size of 0.2). Effect sizes are  
 161 categorised by Cohens rule of thumb were  $d = 0.2$  small, 0.5 medium, 0.8 large or  $r < 0.3$  small,  
 162  $0.31 < r < 0.5$  medium,  $r > 0.5$  large<sup>15</sup>. NR (not reported).

	Total number of studies.	No. of studies with a significant association	Binomial test, significance at $p < 0.05$	Association found in (n) studies with sufficient power*.	Effect size	No association found in (n) studies with sufficient power	Effect size
<b>Contextual Factors</b>							
Age	58	33	$p < 0.001$	9	small – medium.	3	small
Sex	35	10	$p < 0.001$	2	small	2	NR
years of education	22	8	$p < 0.001$	3	small	3	Small
Employment	9	3	$p = 0.001$	2	small	0	
Social support	7	4	$p < 0.001$	0		0	
<b>Health condition</b>							
comorbidities	11	7	$p < 0.001$	2	small	2	small
Type of stroke (haemorrhagic or ischemic)	14	2	$p = 0.12$	2	small	2	NR
Stroke severity	22	21	$p < 0.001$	7	medium-large	2	NR

	<b>Total number of studies.</b>	<b>No. of studies with a significant association</b>	<b>Binomial test, significance at p&lt; 0.05</b>	<b>Association found in (n) studies with sufficient power*.</b>	<b>Effect size</b>	<b>No association found in (n)studies with sufficient power</b>	<b>Effect size</b>
Number of strokes	5	3	<b>p=0.001</b>	3	small-large	1	NR
Time since stroke	13	4	<b>p=0.003</b>	0		1	NR
<b>Body functions.</b>							
Impairment in movement related functions	14	14	<b>p&lt;0.001</b>	3	small-large	0	
Involuntary movement reaction functions: balance	6	6	<b>p&lt;0.001</b>	0		0	
Impairment in movement related functions: arm	7	5	<b>p&lt;0.001</b>	1	NR	1	NR
Impairment in specific mental functions (cognition)	30	24	<b>p&lt;0.001</b>	6	medium-large	2	NR

163

164 **Contextual Factors.** Older age was associated with worse participation outcomes. Whilst  
165 there was inconsistency in study results, we found a small effect size for associations between  
166 age and participation in sufficiently powered studies with a fair to low risk of bias.

167 Associations between sex and participation outcomes were also inconsistent. Ten studies  
168 reported significant associations, with women being at greater risk of poor participation  
169 outcomes than men. However, the effect size was small ( $r = 0.1 - 0.27$ )<sup>38, 39</sup> and two adequately  
170 powered studies found no association between the persons sex and participation<sup>40, 41</sup>. One study  
171 reported better participation outcomes for women<sup>42</sup> and one study reported a differential effect of  
172 marriage on participation according to sex<sup>43</sup>.

173 Four studies found positive associations between social support and participation. These studies  
174 were underpowered but nevertheless reported small to medium effect sizes ( $r= 0.21- 0.41$ )<sup>44, 45</sup>.

175 ***Stroke factors.*** Stroke severity and increased number of comorbidities were consistently, and  
176 moderately associated with worse participation outcomes. The type of stroke (ischemic or  
177 hemorrhagic) was not found to be associated.

178 ***Stroke related impairments.*** Cognitive functioning and presence of depressive symptoms  
179 were the factors most frequently investigated. Most studies investigating depressive symptoms  
180 found significant associations with participation outcomes; the effect size range from small to  
181 large. One sufficiently powered study did not find an association with depressive symptoms (as  
182 measured by the Centre for Epidemiological studies depression scale<sup>46</sup>) but did find a significant  
183 association between positive affect and better participation outcomes.<sup>47</sup> Depressive symptoms  
184 were determined through the administration of depression scales (for example Geriatric  
185 Depression scale<sup>46, 48</sup>); mean scores on the depression scales reflected the presence of mild  
186 depressive symptoms with only two studies reporting mean scores indicating moderate to severe  
187 depression <sup>49, 50</sup>.

188 Cognitive functioning was determined through cognitive screening tools and assessment of  
189 specific cognitive functions. Most studies found significant relationships of impaired cognitive  
190 functions with participation, with effect sizes ranging from small to large.

191 Movement related functions and balance were consistently associated with poorer participation  
192 outcomes. Associations between hand and arm function and participation tended to be weaker  
193 than associations with impaired lower limb function or balance.

194 Nine out of ten studies reported significant associations between aphasia and participation  
195 outcomes. Effect sizes range from small to large.

196 Fatigue and pain were less frequently investigated but were consistently significantly associated  
197 with poorer participation outcomes.

198 ***Activity limitations.*** Limitations in activities of daily living and mobility were strongly  
199 associated with poor participation with studies reporting medium to large effect sizes. Only one  
200 investigated frequency of falls and found a moderate association between participation outcomes  
201 and the number of falls or fear of falling<sup>51</sup>.

202 ***Factors associated with participation at different time points post stroke.***

203 Participation scores for most stroke survivors were stable at one year or more post stroke<sup>52,53,54</sup>.  
204 There seems to be improvement in participation outcomes when comparing mean participation  
205 scores at three months to six months<sup>55</sup> but little variation in participation scores overall from 1  
206 year on<sup>52,53,56,57,58</sup>. However, this does not reflect changes in participation at an individual level.  
207 Jansen et al<sup>57</sup> found that participation deteriorated in 11% and increased for 12% of participants.  
208 Lo et al<sup>40</sup> found that 17.8% of participant's participation scores deteriorated from three months  
209 to one-year post stroke. Egan<sup>42</sup> found improvement in participation scores over time but only for  
210 participants with higher incomes. Older age was associated with deterioration in participation<sup>40</sup>  
211 <sup>37</sup>. Nevertheless, participation outcomes remained significantly different from matched controls<sup>59</sup>  
212 <sup>60</sup> and poor participation outcomes at one year were strongly associated with poor outcomes three  
213 years post stroke<sup>57</sup>.

214 **Table 3:** Biopsychosocial factors associated with participation outcomes at different time points  
 215 in longitudinal studies.

216

<b>Factors associated with participation at time points post stroke</b>					
	<b>&lt;3 months</b>	<b>4-6months</b>	<b>7-11 months</b>	<b>12-23 months</b>	<b>&gt;24 months</b>
<b>Clarke et al (1999)<sup>16</sup></b>	Stroke severity, depressive symptoms, cognition, limitations in adls			Stroke severity, depressive symptoms, cognition, limitations in adls, sex	
<b>Egan et al (2015)<sup>17</sup></b>		Mobility, female, low income	Mobility, female, low income, emotional well being	Mobility, female, emotional well being	Female, emotional well being
<b>Harwood et al (1997)<sup>18</sup></b>				Depressive symptoms, stroke severity, limitations in adls, age, sex	Depressive symptoms, stroke severity, limitations in adls,
<b>Mercer et al (2009)<sup>19</sup></b>	Motor function	Not significant			
<b>Patel &amp; Tilling (2006)<sup>20</sup></b>				Depressive symptoms, mobility, pain	Depressive symptoms, mobility, energy functions
<b>Sturm et al (2002)<sup>21</sup></b>	Limitations in adls			Limitations in adls	
<b>Tse et al (2017b)<sup>22</sup></b>	Limitations in adls, cognition, depressions, mobility	Limitations in adls.			

217 Seven studies compared biopsychosocial factors associated at different time points after stroke  
218 (time points from three months to three years). No single factor was consistently associated with  
219 participation at all time points (table 3).

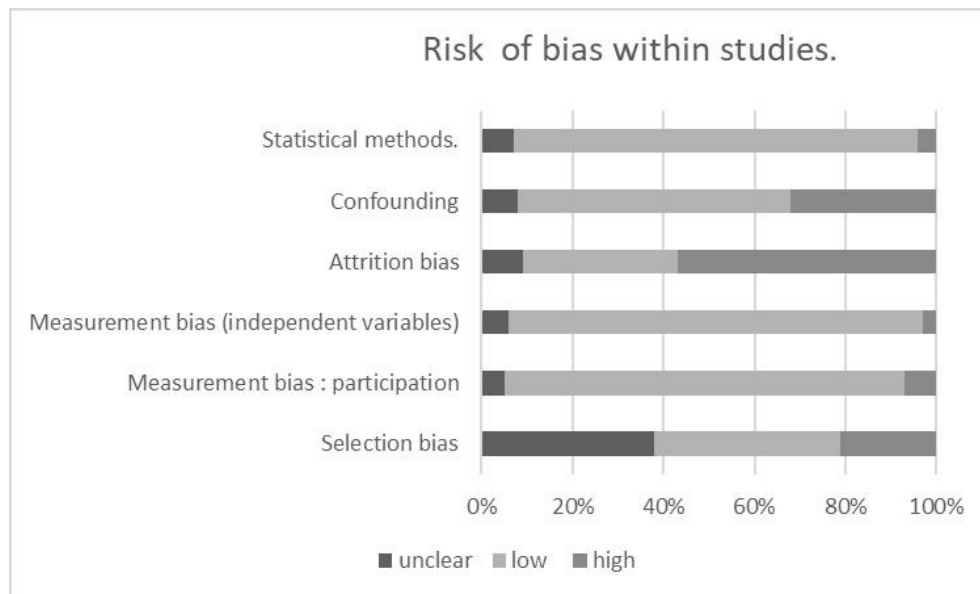
220  
221 ***Descriptive analysis findings.*** From the narrative descriptive analysis, the presence of cognitive  
222 impairments was reported as an independent predictor of participation but was also found to  
223 predict depression and were associated with limitations in activities of daily living<sup>52, 61, 62</sup>.

224 Four studies reported associations with subdomains of participation and found depression to be  
225 strongly associated with social functioning domains<sup>60, 63</sup>. One study found that participation  
226 outcomes at six months post stroke predicted emotional wellbeing up to two years post stroke<sup>64</sup>.

227 ***Risk of bias within studies.*** Forty-six studies were assessed as being low to fair for risk of bias,  
228 35 as high risk of bias and 11 studies where risk of bias was unclear. The main sources of bias  
229 were selection bias and attrition bias (figure 2). Death and deterioration in health were the main  
230 causes of attrition in longitudinal studies with 57 % of studies losing 20% or more participants.<sup>30</sup>



231 **Figure 2:** Percentage of studies with risk of bias for each domain.



232

233

## 234 **Discussion**

235 To our knowledge, this is the first comprehensive synthesis of research exploring factors  
236 associated with participation outcomes after stroke. We found that participation in life situations  
237 was associated with a wide range of biopsychosocial factors and remained limited in the longer  
238 term after stroke with most improvement occurring in the first six months. Furthermore, this  
239 review exposes that associations between participation outcomes and factors other than body  
240 functions are rarely considered.

241 The initial gains in participation after stroke maybe explained by the recovery of body functions  
242 but we found that participation outcomes stabilised for most stroke survivors after six months  
243 post stroke <sup>52, 53, 56 57, 58</sup>. This finding is explained by qualitative literature on life after stroke. Wood  
244 et al<sup>65</sup> reveals how stroke survivors adjust their lives to match changes in their abilities once their  
245 recovery from stroke has slowed. Furthermore, Salter <sup>66</sup> describes a process of relinquishing roles

246 and meaningful activities because of a loss of ability and this is likely to be reflected in  
247 participation outcomes. However, the relative stability of participation from one-year post stroke  
248 could also be affected by long term stroke survivors being younger with less severe stroke <sup>56</sup> .  
249 Over half of the cohort studies in this review were at risk of attrition bias, with death and  
250 worsening health being cited as the main reasons for high attrition rates.

251 The ICF framework explains participation as arising from the dynamic, non-linear and multiple  
252 interactions between health conditions, the person and their given context<sup>14</sup>. Hence the wide  
253 range of biopsychosocial associated with changes in participation after stroke found in this  
254 review are illustrative of the ICF framework and suggest the need for an interactionist  
255 perspective to intervention studies<sup>67</sup>. Further research is needed to investigate how participation  
256 outcomes are influenced by the interrelationships of factors, rather than by any one single factor.

257 The studies included in the review tended to reflect a biomedical focus with relatively few  
258 studies investigating environmental factors. Nevertheless, we found social support to be  
259 positively associated with participation after stroke. Other studies have found satisfactory social  
260 support to be protective of well-being and health related quality of life <sup>68</sup> and may enable  
261 successful return to social and community activities<sup>6</sup>. We propose that knowledge of social  
262 support, along with considering the presence of other factors such older age and comorbidities  
263 helps to identify those at greater risk of poor participation outcomes.

264 There was insufficient evidence to draw conclusions about associations between other  
265 environmental factors and participation considered in the review: for example, type of residence,  
266 whether the person lives alone, quality of physical and social environments and societal attitudes.  
267 This may reflect a historical focus on recovery of body functions and personal care activities

268 within stroke research, as well as the difficulties encountered in developing meaningful and  
269 reliable measures of environmental factors<sup>3,69</sup>. Further research utilising validated environmental  
270 measures is needed to develop our understanding of how the environment enables or restricts  
271 stroke survivors' participation.

272 Of the other contextual factors investigated, we found age and sex are most likely to be  
273 associated with participation. In line with others findings,<sup>70,71</sup> we found that participation  
274 outcomes for older stroke survivors were worse than those for sociodemographic and  
275 comorbidity matched peers.<sup>59</sup> The relationship between age and participation is complex, with  
276 older people experiencing more comorbidities and activity limitations prior to their stroke, as  
277 well increased likelihood of severe stroke<sup>72</sup>. Whilst, sex was less consistently associated with  
278 participation amongst studies, there was a small effect size for women to experience worse  
279 participation outcomes than men. However, Dehelendorf<sup>73</sup> found that women experience more  
280 severe stroke and have better survival rates than men, thus explaining this finding.

281 All the investigated impairments in body functions were associated with participation, with  
282 depressive symptoms and cognitive impairment being most frequently investigated and  
283 consistently associated. It is probable that there are confounding relationships between different  
284 body function impairments, however the narrow focus of studies in the review and the statistical  
285 methods employed meant it was not possible for us to explore confounding relationships  
286 between different stroke related impairments. Indeed, the studies within the review tended to  
287 reflect a split between more physically focused factors and those related to cognition and mood.  
288 Only four studies within the review considered problems with movement functions as well as  
289 depression and cognitive functioning<sup>44, 63, 74, 75</sup>.

290 Limitations in mobility, self-care and activity were consistently associated with poor  
291 participation outcomes. This may be due in part to overlapping constructs within activity and  
292 participation measures. We minimised this by including only participation measures with a focus  
293 on domestic, social and community life. However, the strong associations between mobility,  
294 activity limitations and participation outcomes may also indicate a potential area amenable to  
295 interventions focused on adaptation and modifications of environmental factors and activities.  
296 Participation is theoretically modifiable and achievable even in the presence of disability<sup>76</sup>.  
297 The review also identified factors that are likely influential but underrepresented in the literature.  
298 For example, fatigue is highly prevalent after stroke (incidence of fatigue has been reported as  
299 between 35% and 92%<sup>77</sup>), yet was investigated by only six studies within this review.

### 300 *Measuring participation outcomes.*

301 Defining and measuring participation continues to be problematic with a lack of consensus as to  
302 the operationalisation of participation<sup>15</sup> and blurring of participation and activity within the  
303 ICF<sup>78</sup>. Older participation measures frequently include constructs outside of the activity and  
304 participation domain as they are not underpinned by the ICF framework<sup>24</sup>. Furthermore,  
305 measures included in this review captured different aspects of participation such as participation  
306 restriction, frequency or satisfaction<sup>79</sup>. The included measures all relied on self-report which  
307 compounds issues of unreliability<sup>15</sup> and is particularly problematic for this group because of the  
308 frequency of language, vision and cognitive deficits.

309 As a result of these issues, we have been cautious in our interpretation of the reviews results,  
310 particularly where findings are less consistent across the studies or where factors have been

311 infrequently investigated. However, we suggest that factors such as depressive symptoms,  
312 cognitive functioning and limitations in mobility (which were frequently investigated and found  
313 to have strong associations with participation outcomes) are likely to be associated with poor  
314 participation outcomes. Further research is needed to explore potential causative relationships  
315 between these factors and participation.

316 Participation in life situations is widely recognised as an important outcome of stroke  
317 rehabilitation yet participation outcomes remain underutilised in intervention studies<sup>18,19,20</sup>.  
318 Whilst the measurement of participation outcomes remains limited, we would urge more routine  
319 and judicious use of participation outcome measures in intervention studies and suggest wider  
320 use of the ICF to develop causative explanatory models, thereby enabling a better fit between  
321 research aims, concepts of participation and measurement of outcomes.

322 Thus, whilst a consensus is needed on a core set of outcome measures after stroke, our findings  
323 do not support a focus only measuring participation at 90 days post stroke as recently proposed<sup>81</sup>.

324  
325 **Limitations.** The broad scope of this review is both a strength and a limitation. Whilst primary  
326 research has focused on selected key areas, this review enabled examination of a wide range of  
327 factors to explore associations and potential risks for poor participation after stroke.

328 Interrater agreements for eligibility and risk of bias judgements were moderate and reflect the  
329 diversity of methodologies and participation outcome measures used by studies included in the  
330 review. However, differences between two reviewers were resolved through discussion without  
331 need for recourse.

332 Nevertheless, the heterogeneity of participation measures and inconsistency in the reporting of  
333 statistical findings meant meta-analysis was not viable. Therefore we determined proportions of  
334 studies with significant associations<sup>32</sup>. This approach is limited as it gives higher relative  
335 weighting to small studies and does not account for publication bias<sup>32</sup>. Consequently, we reported  
336 the number of insufficiently powered studies to aid interpretation.

337 Selection and attrition bias means that the studies in this review reflects outcomes for those with  
338 mild to moderate stroke. Further targeted research is needed to establish participation outcomes  
339 and restrictions for those living with more severe stroke and disability.

340 Problems with defining and operationalising participation in life situations are well-  
341 documented<sup>15, 82</sup> and the lack of a clear delineation between activity and participation has already  
342 been discussed. Furthermore, the psychometric properties of commonly used participation  
343 measures within stroke research are limited<sup>80</sup> thereby introducing measurement bias in our  
344 findings.

345 We examined associations between biopsychosocial factors and participation outcomes with the  
346 participation measures reflecting different aspects of participation. Hence, we viewed  
347 participation outcomes in the broadest terms and did not delineate between satisfaction with  
348 participation or restrictions in participation.

## 349 **Conclusion**

350 In summary, our findings suggest that there are multiple factors impacting on participation  
351 outcomes and underscore that stroke survivors may experience participation restrictions long  
352 term, particularly when they have impairments across a range of body functions. As such,

353 interventions to improve participation outcomes should be person centred, deliver gains across a  
354 range of body functions and focus on the resolution of community participation restrictions<sup>17</sup>.

355 This review identified that older people with more severe stroke and stroke related impairments  
356 are most at risk of poor participation. There is little change in participation outcomes from one-  
357 year post stroke for most stroke survivors and variability as to the factors associated with  
358 participation at different time points after stroke. The presence of depressive symptoms,  
359 problems in cognitive functioning, mobility and activity limitations were most frequently and  
360 consistently associated with poor participation outcome but how these factors impact on  
361 participation remains unclear and is inconsistent over time since stroke. The results of this  
362 review also reflect a biomedical focus of research in this area and we suggest further research is  
363 needed to understand the potential role of environmental factors in mitigating poor participation  
364 outcomes.

365 The considerable variability in how participation is operationalized is a barrier to measuring this  
366 important outcome after stroke interventions. With this in mind, a consensus is needed on  
367 defining and measuring participation outcomes relevant to stroke survivors, along with wider use  
368 of participation outcomes in research to build a body of evidence for effective interventions.

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