Appendix A: Joanna Briggs Institute Critical Appraisal Checklist for Studies Reporting Prevalence Data

1. Was the sample frame appropriate to address the target population?
2. Were study participants sampled in an appropriate way?
3. Was the sample size adequate?
4. Were the study subjects and the setting described in detail?
5. Was the response rate adequate, and if not, was the low response rate managed appropriately?

*We have omitted four questions that were not relevant for this study.*
### Appendix B: Risk of bias assessment

| Study               | D1 | D2 | D3 | D4 | D5 | Overall |
|---------------------|----|----|----|----|----|---------|
| Bell (2017)         | +  |    | +  | +  | +  | +       |
| Corner (2018)       | +  | +  | +  | +  | ?  | +       |
| Custers (2015)      | +  | +  | +  | +  | +  | +       |
| Custers (2016)      | +  | +  | +  | +  | x  | x       |
| Custers (2017)      | +  | +  | +  | +  | x  | +       |
| Custers (2018)      | +  | x  | +  | +  | ?  | x       |
| Dixon (2019)        | +  | ?  | +  | +  | +  | +       |
| Eyrenci (2018)      | +  | ?  | +  | +  | +  | +       |
| Guimon (2019)       | +  | +  | +  | +  | +  | +       |
| Hébert (2017)       | +  | +  | +  | +  | ?  | +       |
| Jakobsen (2019)     | +  | +  | +  | +  | +  | +       |
| Jeppesen (2018)     | +  | +  | +  | +  | x  | +       |
| Kang (2019)         | ?  | ?  | ?  | ?  | ?  | ?       |
| Lane (2019)         | +  | x  | +  | +  | ?  | x       |
| Lebel (2016)        | +  | +  | +  | +  | x  | +       |
| Lim (2019)          | ?  | ?  | ?  | ?  | ?  | ?       |
| Liu (2017)          | +  | ?  | +  | +  | x  | x       |
| Mittelu (2016)      | +  | ?  | +  | +  | ?  | +       |
| Ng (2019)           | +  | +  | +  | +  | +  | +       |
| Otto (2018)         | +  | +  | +  | +  | x  | +       |
| Russell (2019)      | +  | +  | +  | +  | +  | +       |
| Shin (2017)         | +  | +  | +  | +  | +  | +       |
| Simard (2009)       | +  | +  | +  | x  | +  | +       |
| Simard (2010)       | +  | x  | +  | +  | x  | x       |
| Sukyati (2019)      | +  | ?  | +  | +  | ?  | ?       |
| van de Wal (2016)   | x  | +  | +  | +  | x  | x       |
| Van der Gucht (2017)| +  | x  | x  | +  | ?  | x       |
| van Helmondt (2017) | +  | +  | +  | +  | ?  | +       |
| van Helmondt (2020) | +  | +  | +  | +  | x  | +       |
| Vatandoust (2019)   | ?  | ?  | x  | ?  | +  | ?       |
| Wijayanti (2018)    | +  | +  | +  | x  | +  | +       |
| Zdenkowski (2018)   | ?  | +  | +  | +  | +  | +       |

**Judgement**

- **X**: No
- **Green**: Yes
- **Question Mark**: Unclear
Figure 1. Risk of bias assessment of studies that provided data and did not select on level of FCR, a) shows assessment per study, b) shows a summary of all studies. Figure created using robvis (95).

| Study                  | D1 | D2 | D3 | D4 | D5 | Overall |
|------------------------|----|----|----|----|----|---------|
| Compen (2018)          | X  | X  | +  | +  | ?  | X       |
| Dirkse (2019)          | X  | X  | +  | +  | ?  | X       |
| Fisher (2017)          | X  | X  | X  | +  | ?  | X       |
| Fisher (2019)          | X  | X  | X  | X  | ?  | X       |
| Jakobsen (2018)        | X  | +  | +  | +  | +  | +       |
| Johns (2020)           | X  | X  | +  | +  | X  | X       |
| Luigjes-Huizer (2019)  | ?  | ?  | ?  | ?  | ?  | ?       |
| Maheu (2016)           | X  | X  | +  | +  | +  | X       |
| Murphy (2019)          | X  | X  | +  | +  | ?  | X       |
| Savard (2013)          | X  | +  | +  | +  | +  | +       |
| Savard (2018)          | X  | +  | +  | +  | ?  | X       |
| Van De Wal (2017)      | X  | X  | +  | +  | X  | X       |

Judgement

- X: No
- +: Yes
- ?: Unclear

Figure 2. Risk of bias assessment of studies that provided data and selected on level of FCR, a) shows assessment per study, b) shows a summary of all studies. Figure created using robvis (95).
Figure 3. Risk of bias assessment of studies that were included in the aggregate data analysis, a) shows assessment per study, b) shows a summary of all studies. Figure created using robvis (95).
### Appendix C: Main characteristics and mean FCR scores per dataset

a) Datasets that did not select participants based on their level of fear of cancer recurrence or related factors.

| Author    | Year | n  | Mean FCR severity (mean ± sd) | Mean age (yrs) | Country          | Language | Sex men (n) | Sex women (n) | Cancer type  | Patients (n) | Survivors (n) | Mean time since cancer diagnosis (yrs) |
|-----------|------|----|------------------------------|----------------|------------------|----------|-------------|---------------|--------------|-------------|--------------|--------------------------------------|
| Bell      | 2017 | 215| 15.3 (6.8)                  | 65             | Australia        | English  | 137         | 78            | melanoma     | 0           | 215          | 1.3                                   |
| Corter    | 2018 | 125| 17.2 (7.6)                  | 56             | New Zealand      | English  | 0           | 125           | breast       | 0           | 125          | 0.4                                   |
| Custers   | 2015 | 54 | 16.9 (7.7)                  | 62             | the Netherlands  | Dutch    | 29          | 25            | other        | 54          | 0            | 4.8                                   |
| Custers   | 2017 | 460| 16 (6.8)                    | 57             | the Netherlands  | Dutch    | 0           | 460           | breast       | 0           | 460          | 2.8                                   |
| Custers   | 2016 | 76 | 11.6 (7.3)                  | 67             | the Netherlands  | Dutch    | 40          | 36            | colorectal   | 0           | 76           | 5.0                                   |
| Custers   | 2018 | 150| 13.2 (6.4)                  | 68             | the Netherlands  | Dutch    | 97          | 53            | colorectal   | 150         | 0            | 0.0                                   |
| Dixon     | 2019 | 97 | 24.3 (6.8)                  | -              | USA              | English  | 33          | 64            | breast, lung | 0           | 97           | -                                     |
| Eyrenci   | 2018 | 217| 15.3 (7.4)                  | 51             | Turkey           | Turkish  | 43          | 174           | multiple     | 0           | 217          | 4.5                                   |
| Galica    | n.p. | 219| 17.3 (7.9)                  | 64             | Canada           | English  | 40          | 178           | breast, colorectal | 0           | 219          | -                                     |
| Guimond   | 2019 | 81 | 11.5 (5.8)                  | 59             | Canada           | French   | 0           | 81            | breast       | 81          | 0            | 0.3                                   |
| Hebert    | 2017 | 38 | 14.2 (6.6)                  | 69             | Canada           | French   | 0           | 38            | endometrial  | 38          | 0            | -                                     |
| Jakobsen  | 2019 | 141| 11.7 (6.3)                  | 66             | Denmark          | Danish   | 100         | 41            | colorectal   | 0           | 93           | 1.1                                   |
| Jeppesen  | 2018 | 212| 10.4 (7.1)                  | 65             | Denmark          | Danish   | 0           | 212           | endometrial  | 0           | 212          | 0.0                                   |
| Kang      | 2019 | 52 | 12.7 (6.5)                  | 63             | Canada           | English  | 52          | 0             | prostate cancer | 52          | 0            | 1.9                                   |
| Lane      | 2019 | 554| 22.8 (7)                    | 34             | Canada           | English  | 72          | 482           | multiple     | 37          | 301          | 4.9                                   |
| Lebel     | 2016 | 350| 13.8 (7.9)                  | 67             | Canada           | English  | 185         | 165           | multiple     | 2           | 295          | 5.9                                   |
| Lim       | 2019 | 125| 10.9 (6.7)                  | 59             | South Korea      | Korean   | 80          | 45            | colorectal   | 125         | 0            | -                                     |
| Liu       | 2017 | 405| 13.1 (6.7)                  | 56             | Singapore        | English  | 81          | 324           | multiple     | 0           | 405          | -                                     |
| Mititelu  | 2016 | 32 | 16.5 (6.5)                  | -              | Canada           | English  | 3           | 29            | multiple     | 4           | 13           | 2.2                                   |
| Ng        | 2019 | 293| 10.8 (7.2)                  | 60             | Hong Kong        | Cantonese| 76          | 217           | breast, colorectal | 0           | 293          | 0.0                                   |
| Otto      | 2018 | 300| 15 (7.8)                    | 62             | USA              | English  | 0           | 300           | breast       | 0           | 300          | 3.5                                   |
| Russell   | 2019 | 69 | 16.8 (7.3)                  | 53             | Australia        | English  | 32          | 37            | melanoma     | 0           | 69           | 3.9                                   |
| Shin      | 2017 | 239| 15.1 (7.2)                  | 50             | South Korea      | Korean   | 71          | 168           | multiple     | 239         | 0            | 0.0                                   |
| Simard    | 2009 | 1984| 12.9 (6.9)                  | 63             | Canada           | French   | 904         | 1080          | multiple     | 575         | 1390         | 4.2                                   |
### Table: Datasets that did select participants based on their level of fear of cancer recurrence or related factors.

| Author          | Year | n   | FCR severity mean (sd) | Mean age (yrs) | Country          | Language | Patients (n) | Survivors (n) | Mean time since cancer diagnosis (yrs) |
|-----------------|------|-----|------------------------|----------------|------------------|----------|--------------|--------------|---------------------------------------|
| Compen          | 2018 | 245 | 21.3 (6.5)             | 52             | the Netherlands  | Dutch    | 35           | 210          | 3.5                                   |
| Dirkse          | 2020 | 83  | 21.5 (5)               | 51             | Canada           | English  | 14           | 69           | 2.1                                   |
| Fisher          | 2019 | 27  | 25.6 (7.6)             | 51             | United Kingdom   | English  | 3            | 24           | -                                     |
| Fisher          | 2017 | 4   | 30.3 (4.9)             | NA             | United Kingdom   | English  | 0            | 4            | 2.1                                   |
| Jakobsen        | 2018 | 69  | 12.4 (7)               | 67             | Denmark          | Danish   | 39           | 30           | 1.9                                   |
| Johns           | 2020 | 91  | 19 (5.6)               | 58             | USA              | English  | 0            | 91           | 5.1                                   |
| Luigjes-Huizer  | 2019 | 58  | 17.6 (7.3)             | 64             | the Netherlands  | Dutch    | 21           | 26           | 6.9                                   |
| Maheu           | 2016 | 136 | 23.1 (5.4)             | 56             | Canada           | English  | 0            | 136          | 2.2                                   |
| Murphy          | 2020 | 114 | 22.4 (5.7)             | 53             | Australia        | English  | 13           | 101          | 4.0                                   |
| Savard          | 2013 | 962 | 14.3 (6.9)             | 57             | Canada           | French   | 343          | 619          | 0.2                                   |
| Savard          | 2018 | 38  | 21.4 (5.6)             | 57             | Canada           | French   | 2            | 36           | 1.1                                   |
| Van de Wal      | 2017 | 88  | 19.3 (7.2)             | 59             | the Netherlands  | Dutch    | 41           | 47           | 2.6                                   |
Appendix D: Characteristics of FCR severity groups, according to different cutoffs.
For these analyses, 12 additional studies were included, that had selected participants based on the severity of their FCR. The mean FCR severity score for these additional studies was 20.7.

|                  | <13 Survivors | <13 Patients | 13-15 Survivors | 13-15 Patients | 16-21 Survivors | 16-21 Patients | 22+ Survivors | 22+ Patients |
|------------------|---------------|--------------|-----------------|---------------|-----------------|----------------|--------------|-------------|
| **Sex**          |               |              |                 |               |                 |                 |              |             |
| Men              | 1150 (39)     | 512 (40)     | 279 (28)        | 168 (34)      | 475 (23)        | 216 (27)       | 302 (17)     | 133 (23)    |
| Women            | 1817 (61)     | 778 (60)     | 702 (72)        | 332 (66)      | 1581 (77)       | 575 (73)       | 1484 (83)    | 455 (77)    |
| **Age groups**   |               |              |                 |               |                 |                 |              |             |
| 18-29 years      | 19 (1)        | 9 (1)        | 12 (1)          | 4 (1)         | 55 (3)          | 10 (1)         | 84 (5)       | 17 (3)      |
| 30-44 years      | 157 (5)       | 100 (8)      | 108 (11)        | 57 (11)       | 274 (14)        | 94 (12)        | 431 (25)     | 110 (19)    |
| 45-59 years      | 753 (26)      | 468 (36)     | 367 (38)        | 218 (44)      | 793 (40)        | 365 (46)       | 628 (37)     | 262 (45)    |
| 60-74 years      | 1505 (52)     | 600 (47)     | 384 (40)        | 200 (40)      | 733 (37)        | 282 (36)       | 481 (28)     | 178 (30)    |
| ≥75 years        | 474 (16)      | 113 (9)      | 92 (10)         | 20 (4)        | 127 (6)         | 36 (5)         | 71 (4)       | 20 (3)      |
| **Cancer type**  |               |              |                 |               |                 |                 |              |             |
| Breast cancer    | 1368 (47)     | 534 (41)     | 536 (57)        | 223 (44)      | 1148 (60)       | 385 (49)       | 1025 (61)    | 263 (45)    |
| Colon and rectal | 373 (13)      | 235 (18)     | 102 (11)        | 56 (11)       | 171 (9)         | 112 (14)       | 133 (8)      | 61 (11)     |
| Endometrial cancer | 123 (4)   | 59 (5)       | 25 (3)          | 32 (6)        | 38 (2)          | 33 (4)         | 33 (2)       | 28 (5)      |
| Leukemia & non- |               |              |                 |               |                 |                 |              |             |
| hodgkin lymphoma | 19 (1)        | 1 (0)        | 13 (1)          | 1 (0)         | 34 (2)          | 3 (0)          | 42 (2)       | 9 (2)       |
| Lung cancer      | 57 (2)        | 35 (3)       | 16 (2)          | 18 (4)        | 36 (2)          | 39 (5)         | 73 (4)       | 23 (4)      |
| Melanoma         | 89 (3)        | 0 (0)        | 42 (4)          | 0 (0)         | 91 (5)          | 0 (0)          | 71 (4)       | 3 (0)       |
| Prostate cancer  | 754 (26)      | 289 (22)     | 151 (16)        | 105 (21)      | 218 (11)        | 99 (13)        | 101 (6)      | 65 (11)     |
| Thyroid cancer   | 4 (0)         | 0 (0)        | 8 (1)           | 0 (0)         | 9 (0)           | 3 (0)          | 25 (1)       | 5 (1)       |
| Other cancer types | 123 (4) | 137 (11)     | 46 (5)          | 64 (13)       | 165 (9)         | 117 (15)       | 177 (11)     | 131 (22)    |
| **Time since diagnosis** | |              |                 |               |                 |                 |              |             |
| 0-1 years        | 779 (33)      | 764 (69)     | 262 (35)        | 290 (67)      | 514 (35)        | 440 (65)       | 486 (37)     | 304 (60)    |
| 2-5 years        | 1098 (47)     | 246 (22)     | 347 (46)        | 107 (25)      | 686 (46)        | 160 (24)       | 581 (44)     | 142 (28)    |
| 6-10 years       | 328 (14)      | 69 (6)       | 100 (13)        | 23 (5)        | 203 (14)        | 50 (7)         | 174 (13)     | 41 (8)      |
| >10 years        | 153 (6)       | 26 (2)       | 40 (3)          | 12 (3)        | 83 (6)          | 26 (4)         | 76 (6)       | 16 (3)      |

A partially imputed dataset was used: the variables FCR severity, age, cancer type and time since cancer diagnosis were not imputed, since the imputation did not converge.