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Informant-based assessment instruments for dementia and their measurement properties in persons with intellectual disability: a systematic review protocol

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3 1 Title: Informant-based assessment instruments for dementia and their
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6 2 measurement properties in persons with intellectual disability: a systematic
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9 3 review protocol
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26 **ABSTRACT**

27 **Introduction**

28 Persons with intellectual disability (ID) are at a higher risk of developing dementia than
29 persons without ID, with an expected earlier onset. Assessment methods for the general
30 population cannot be applied for persons with ID due to their pre-existing intellectual and
31 functional impairments. As there is no agreed-upon measure to assess dementia in persons
32 with ID, multiple instruments for this purpose have been developed and adapted in the last
33 decades. This review aims to identify all available informant-based instruments for the
34 assessment of dementia in persons with ID and to evaluate and compare them according to
35 their measurement properties. Additionally, an overview of the amount and quality of
36 research on these instruments will be provided.

37 **Methods and analysis**

38 This review will be conducted and reported according to the PRISMA statement. We will
39 adhere to the *COnsensus-based Standards for the selection of health Measurement*
40 *INstruments* (COSMIN) guidelines, and use a set of characteristics developed for assessment
41 instruments for persons with ID, the *Characteristics of Assessment Instruments for*
42 *Psychiatric Disorders in Persons with Intellectual Developmental Disorders* (CAPs-IDD).
43 Two comprehensive, systematic literature searches will be applied in ten international
44 databases, including ASSIA, CINAHL, Cochrane Library, ERIC, MEDLINE, PsycINFO,
45 Scopus, Web of Science, OpenGrey, and ProQuest Dissertations & Theses Global. Risk of
46 bias and quality assessment will be done according to COSMIN guidelines. We will apply the
47 modified *Grading of Recommendations, Assessment, Development and Evaluation* (GRADE)
48 approach to rate the overall quality of the available evidence.

49 **Ethics and dissemination**

50 No ethics statement is needed for this study. The results will be submitted to a peer-reviewed
51 journal, and presented at international conferences.

52 **Registration details**

53 This review has been submitted for registration to PROSPERO on May 15, 2020.

54 **Keywords**

55 mental health, dementia, old age psychiatry, statistics and research methods

57 **ARTICLE SUMMARY**

58 **Strengths and limitations of this study**

- 59 • This review follows the most up-to-date standards for conducting systematic reviews
60 on assessment instruments, the PRISMA and COSMIN guidelines, and additionally
61 uses the CAPs-IDD, a system especially developed for evaluating assessment
62 instruments for psychiatric disorders in persons with ID.
- 63 • Two very comprehensive consecutive search strategies will be applied in a total of ten
64 international databases, including grey and unpublished literature.
- 65 • We use language restrictions only for abstracts of studies, not for full texts, trying to
66 minimise language bias.
- 67 • We only include informant-based instruments assessing dementia in our evaluation,
68 and exclude direct cognitive tests.
- 69 • Due to expected heterogeneity in studies, a quantitative pooling of psychometric data
70 will probably not be possible.

72 INTRODUCTION

73 Intellectual disability (ID) is characterized by limitations in intellectual functioning (IQ < 70)
74 and in adaptive behaviour originating in the developmental phase of an individual.[1] It is also
75 known as Intellectual Developmental Disorder in the *Diagnostic and Statistical Manual of*
76 *Mental Disorders 5* (DSM-5)[2] and Disorders of Intellectual Development in the *11th*
77 *Revision of the International Classification of Diseases* (ICD-11).[3] Prevalence of ID is hard
78 to establish, since in many countries no official records of persons with ID exist.[4] In large
79 meta-analysis and reviews, the worldwide prevalence of ID is estimated to range from 1% to
80 3,3%.[5–7]

81 Persons with ID are at the same or higher risk to develop dementia than persons without
82 ID.[8–10] Yet, it is often hard to recognize dementia in persons with ID, especially at an early
83 stage. Well-evaluated assessment and screening instruments for the general population, such
84 as the frequently used Mini-Mental State Examination (MMSE)[11] are not suitable for
85 persons with ID due to their pre-existing disabilities.[12,13] Diagnostic overshadowing
86 [16,17] makes it difficult to distinguish symptoms linked to the pre-existing disability from
87 symptoms caused by the onset of dementia. Additionally, the presentation of dementia in
88 persons with ID can differ from the presentation in persons without ID, with behavioural
89 symptoms and personality changes being more frequent and probably earlier in the course of
90 the illness, especially in persons with Down Syndrome.[18,19] To reliably detect dementia in
91 persons with ID, it is recommended to compare a baseline assessment with periodic re-
92 assessments.[14–16] Most dementia assessment methods for persons with ID rely on
93 informant-based measures. The respondent of these instruments should be a person who
94 knows the respective person with ID very well, for instance, a family member or care staff. In
95 contrast to direct tests of cognitive functioning, informant-based instruments can be applied
96 for all persons with ID, irrespective of their intellectual and functional capacity.

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3 97 Early recognition of dementia is particularly important to start early interventions, to plan for
4
5 98 the future, and to get adequate support for family-carers or care staff.[13–15] Not being able
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8 99 to recognize early signs of dementia constitutes a disadvantage for persons with ID, and
9
10 100 contradicts the *Convention on the Rights of Persons with Disabilities by the United Nations*
11
12 101 (UN-CRPD).[17] Article 25 and 26 of the UN-CRPD require States Parties to ensure that
13
14 102 persons with disabilities can get the “highest attainable standard of health without
15
16
17 103 discrimination on the basis of disability.”[17]

18
19
20 104 There are several tools and screening instruments in use for the early recognition of dementia
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22 105 in persons with ID.[12,20] One systematic review found 114 instruments and four test-
23
24 106 batteries that have been used to assess dementia in persons with ID. However, some of these
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26
27 107 instruments have never been designed or adapted to be used in persons with ID, or even to
28
29 108 assess dementia.[13] Although there are already some reviews summarizing tools and
30
31 109 screening instruments in use for assessing dementia in persons with ID,[13,18–20] no
32
33 110 systematic review on measurement properties using up-to-date guidelines for review
34
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36 111 conduction and psychometric evaluation has been conducted so far. Our review adds to the
37
38 112 existing body of knowledge by using a very inclusive systematic search of the literature and,
39
40 113 most importantly, by providing a systematic evaluation of informant-based dementia
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43 114 assessment instruments following up-to-date guidelines.

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45
46 115 The systematic evaluation will build on the *CO*n*SENSUS*-based *Standards for the selection of*
47
48 116 *health Measurement INstruments* (COSMIN) guidelines [21] and the *Characteristics of*
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50 117 *Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental*
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52 118 *Disorders* (CAPs-IDD).[22] The CAPs-IDD is a system especially developed for the
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54
55 119 structured collection of information and evidence-based evaluation of assessment instruments
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57 120 for persons with ID. We will not only evaluate the instruments, but also the existing body of
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59 121 research. For each instrument, we will systematically summarize the amount and quality of

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3 122 available evaluation studies, depicting which measurement properties have been evaluated to
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5 123 what extent, and which measurement properties have not or insufficiently been evaluated.
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8 124 The objectives of this systematic review are to (1) identify informant-based instruments
9
10 125 suitable for the assessment of dementia in persons ID, to (2) systematically collect and
11
12 126 evaluate information on evaluation data of these instruments, to (3) evaluate and compare the
13
14 127 instruments found according to their evaluation data, and to (4) provide a systematic overview
15
16 128 of the amount and quality of available research for each instrument and each measurement
17
18 129 property.

123 **METHODS AND ANALYSIS**

131 This review will be conducted and reported according to the *Preferred Reporting Items for*
132 *Systematic Reviews and Meta-Analyses* (PRISMA) statement.[23] The review protocol has
133 been developed using the PRISMA guidelines for protocols (PRISMA-P).[24,25] We will
134 adhere to the COSMIN guidelines,[21] and complement them with a set of characteristics
135 especially developed for assessment instruments for persons with ID, the CAPs-IDD.[22] The
136 systematic review has been submitted for registration with the *International Prospective*
137 *Register of Systematic Reviews* (PROSPERO) on May 15, 2020 (identification
138 number:181773). If amendments to the protocol are needed, we will register these in
139 PROSPERO, including date and rationale. In the final publication of our results, any
140 amendments to the protocol will be depicted and explained.

141 **Search strategy**

142 Two systematic searches will be applied consecutively, and carried out between May 2020
143 and August 2020. The first search should provide an inventory of available informant-based
144 assessment instruments for dementia in persons with ID. The goal of the second search is to
145 locate evaluation studies for each instrument found in the first search. Figure 1 and Figure 2
146 depict our search strategies using PRISMA flow charts.

147 First search

148 To identify instruments we will search in ten international electronic databases, including
 149 ASSIA, CINAHL, Cochrane Library, ERIC, MEDLINE, PsycINFO, Scopus, Web of Science,
 150 OpenGrey, and ProQuest Dissertations & Theses Global. The search string is depicted in
 151 Table 1 and will include various terms for the (1) output of interest, (2) measure of interest,
 152 and (3) the specified population. As persons with Down Syndrome are very prone to develop
 153 dementia, this subgroup of persons with ID is included in our search strategy. We will use a
 154 limit on the timespan of publication in the first search, not including publications before the
 155 year 2012. Instruments published up to the year of 2012 are summarized in a previous
 156 systematic review.[13] This review used a very inclusive search strategy and listed all
 157 assessment instruments that have been used to assess dementia in persons with ID. We will
 158 examine the total of 114 dementia assessment instruments listed in the review of 2013, and
 159 include those instruments that are in line with our inclusion criteria.

160 Table 1: Search strategy for the first search

	1: Output	2: Measure	3: Population
Search terms	Assessment instruments	Dementia	Intellectual disability
Synonyms	assessment; diagnostic; diagnosis; screening; instrument; tool; measurement; questionnaire; psychometrics; scale; interview	dementia; Alzheimer's disease	intellectual disability; learning disability; intellectual developmental disorder; trisomy 21, Down syndrome
Combined and truncated	assess* OR diagnosti* OR screen OR screening* OR	dement* OR Alzheimer*	((intellectual* OR learning) AND disab*) OR (intellectual* AND

instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*	developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)
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Example search string for SCOPUS	TITLE-ABS-KEY ((assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND (dement* OR alzheimer*) AND (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) AND PUBYEAR > 2011
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162 Inclusion criteria for the first search will be: (1) studies need to focus on assessing dementia
 163 in persons with ID, (2) include at least one informant-based instrument (development or
 164 evaluation) for the assessment of dementia, (3) this instrument has to be especially developed
 165 or adapted for persons with ID, (4) and studies need to have an English language abstract.

166 Exclusion criteria: (1) classification systems like ICD-11, DSM-5, (2) scales including
 167 dementia, but focusing on a broader spectrum of disorders for screening purposes or
 168 differential diagnosis.

169 Second search

170 Once we have identified the instruments, we will conduct a search by citation strategy using
 171 the initial publications of each instrument as a reference point. This search strategy was
 172 chosen on the assumption that a paper evaluating an instrument would surely cite the initial
 173 publication of the respective instrument. The papers used as reference points will also be
 174 included in the further appraisal of the literature. For published papers, we will use five
 175 international databases allowing a search by citation strategy, including ERIC, PsycInfo,
 176 MEDLINE, Scopus, and Web of Science. For published manuals, not listed in at least one of
 177 the five databases, we will use Google Scholar. Additionally, all records fulfilling the

1
2
3 178 inclusion and exclusion criteria of the first search will be transferred and examined in the
4
5 179 second search.

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7
8 180 The following inclusion criteria will be used in the second search: (1) studies need to describe
9
10 181 an evaluation of the respective instrument in persons with ID, and (2) have an English-
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12 182 language abstract. Exclusion criteria: (1) the respective instrument was used primarily for
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14 183 other investigations, not related to an evaluation of the instrument, (2) or the study is a review
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16 184 on assessment instruments, not providing novel information.

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20 185 To further include grey and unpublished literature in both searches, we will apply an invisible
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22 186 college approach, contacting authors in the field for information or manuscripts on this topic,
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24 187 and we will follow up on meeting abstracts. Full texts of reviews on assessment instruments
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26 188 identified in the course of the two searches will be screened for possible further studies to
27
28 189 include. References of papers meeting the inclusion criteria will be hand-searched. We will
29
30 190 re-run the search before the final analyses to include the most recent publications.

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35 191 For study selection, one reviewer will exclude duplicates. All remaining records will be
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37 192 screened and reviewed for eligibility by two team members independently, i.e. blinded to each
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39 193 other's decisions. In the case of disagreement, dissonances will be discussed until agreement
40
41 194 is reached. In the case of non-agreement, a third team member will be included in discussion.

42 43 44 195 **Data extraction**

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47 196 The first search will result in a list of instruments. Data extracted will be the names of the
48
49 197 instruments and information on their initial publication(s). In the second search, we will
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51 198 extract evaluation data of instruments, i.e. measurement properties and characteristics as listed
52
53 199 in the COSMIN checklist and the CAPs-IDD. For each characteristic/property extracted, we
54
55 200 will record the study design and sample characteristics, including sample size, gender
56
57 201 distribution, age distribution, and aetiology of ID. We will include all studies, irrespective of
58
59 202 their design, but apply the COSMIN quality rating.

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3 203 The extraction of all relevant data will be done via standardised and piloted excel
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5 204 spreadsheets by two team members independently. In the case of disagreement, dissonances
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7 205 will be discussed until agreement is reached. In the case of non-agreement, a third team
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9 206 member will be included in discussion. If we find important data missing in a study, we will
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11 207 contact study authors for this information.
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15 208 **Risk of bias and quality assessment**

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17 209 Quality and risk of bias will be assessed on study level, on single outcome level, and on an
18
19 210 aggregated outcome level, i.e. for each study, each measurement property, and each
20
21 211 assessment instrument. We will combine the COSMIN checklists [26–28] with the CAPs-IDD
22
23 212 [22], a comprehensive tool especially developed for the evaluation of assessment instruments
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25 213 for psychiatric disorders in persons with ID.
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30 214 All ratings will be done by two reviewers independently. In the case of disagreement,
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32 215 dissonances will be discussed until agreement is reached. In the case of non-agreement, a
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34 216 third team member will be included in the discussion. Initial interrater agreement will be
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36 217 determined using Cohen's Kappa, calculated in R.[29] The quality rating of the studies will
37
38 218 go into the final appraisal of the quality of available evaluation data for each instrument.
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42 219 As to publication bias, we assume that evaluation results not in favour of the respective
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44 220 instruments are likely to be underreported. This may be partly due to evaluations being
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46 221 frequently done and published by the author(s) of the respective instrument. We will address
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48 222 this by including grey literature and by discussing this aspect in the interpretation of our
49
50 223 results.
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54 224 **Strategy for data synthesis**

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56 225 A narrative synthesis will be conducted. Assessment instruments will be presented in a table
57
58 226 along with their measurement properties and quality ratings according to CAPs-IDD and the
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60 227 COSMIN checklists. Data pooling will probably not be possible. This is due to an expected

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3 228 limited number of studies evaluating the same property (e.g. internal consistency) for an
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5 229 instrument, and an expected heterogeneity in the population studied (e.g. severity of ID,
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7 230 persons with Down syndrome vs. persons with ID of other aetiology). However, if applicable,
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9 231 we will calculate pooled estimates and 95% confidence intervals using R.[29]
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13 232 **Analysis of subgroups**

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15 233 We define persons with Down syndrome/trisomy 21 (DS) as a special subgroup, as they are
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17 234 more often affected by Alzheimer's dementia, with a suspected earlier onset.[30] We will
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19 235 group instruments according to their intended use, and studies according to their participants
20
21 236 in four clusters: (1) persons with ID, including persons with DS, (2) only persons with DS, (3)
22
23 237 only persons with ID, not including DS, (4) aetiology of ID not specified. For the fourth
24
25 238 cluster, we will contact study authors to determine aetiology of ID in the respective sample or
26
27 239 for the respective instrument. We will then allocate each study or instrument to the first three
28
29 240 clusters according to the information provided by the authors. If no information is provided,
30
31 241 the respective study or instrument remains in cluster four.
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36 242 **Confidence in cumulative evidence**

37
38 243 The modified *Grading of Recommendations, Assessment, Development and Evaluation*
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40 244 (GRADE) approach as suggested by the COSMIN guidelines[21] will be applied to grade the
41
42 245 quality of the evidence.
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46 246 **Data management**

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48 247 We will use ZOTERO for saving records and managing and storing literature. For extracting
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50 248 data and recording decisions on quality ratings we will use standardised and piloted excel
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52 249 spreadsheets.
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56 250 **Patient and public involvement**

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58 251 This research was done without patient involvement due to limited resources.
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252 **DISCUSSION**

253 This review will summarize measurement properties of available informant-based assessment
254 instruments for persons with ID and give an overview of the quality of each instrument and
255 the quality of available evaluation studies. For each instrument we will depict which
256 psychometric properties are evaluated to what extent, and which properties need further
257 evaluation in future research. This will be the first systematic review of dementia assessment
258 instruments for persons with ID using the PRISMA and COSMIN guidelines as well as
259 applying ID-specific criteria of the CAPs-IDD.

260 Our work will highlight gaps in research on these instruments, thus setting the ground for
261 more effective research in the future. The results of this review will inform researchers and
262 clinicians of the quality of available instruments to assess dementia in persons with ID, and
263 guide them in choosing an adequate instrument. This will hopefully contribute to an
264 improvement of dementia assessment in persons with ID and a better, earlier, and more
265 adequate provision of healthcare services, as demanded by the UN-CRPD.[17]

266 **Ethics and dissemination**

267 No ethics statement is needed for this study. The results of this systematic review will be
268 submitted for publication to a leading peer-reviewed journal, and presented at international
269 conferences and congresses in the fields of ID, ageing, and dementia.

270

271 **Author contributions**

272 ELZ conceived the study, drafted the protocol, and is the guarantor of the review. SK, IZ and
273 FF contributed to study design and drafting the protocol. ELZ, SK, and KW designed and
274 tested the search strategy. FF and IZ tested quality rating tools and software options. All
275 authors read and approved the final protocol.

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14
15

16 281 **Patient and public involvement**
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18 282 This research was done without patient involvement.
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21 283 **Competing interests**
22

23 284 The authors have no competing nor potential conflict interests to declare.
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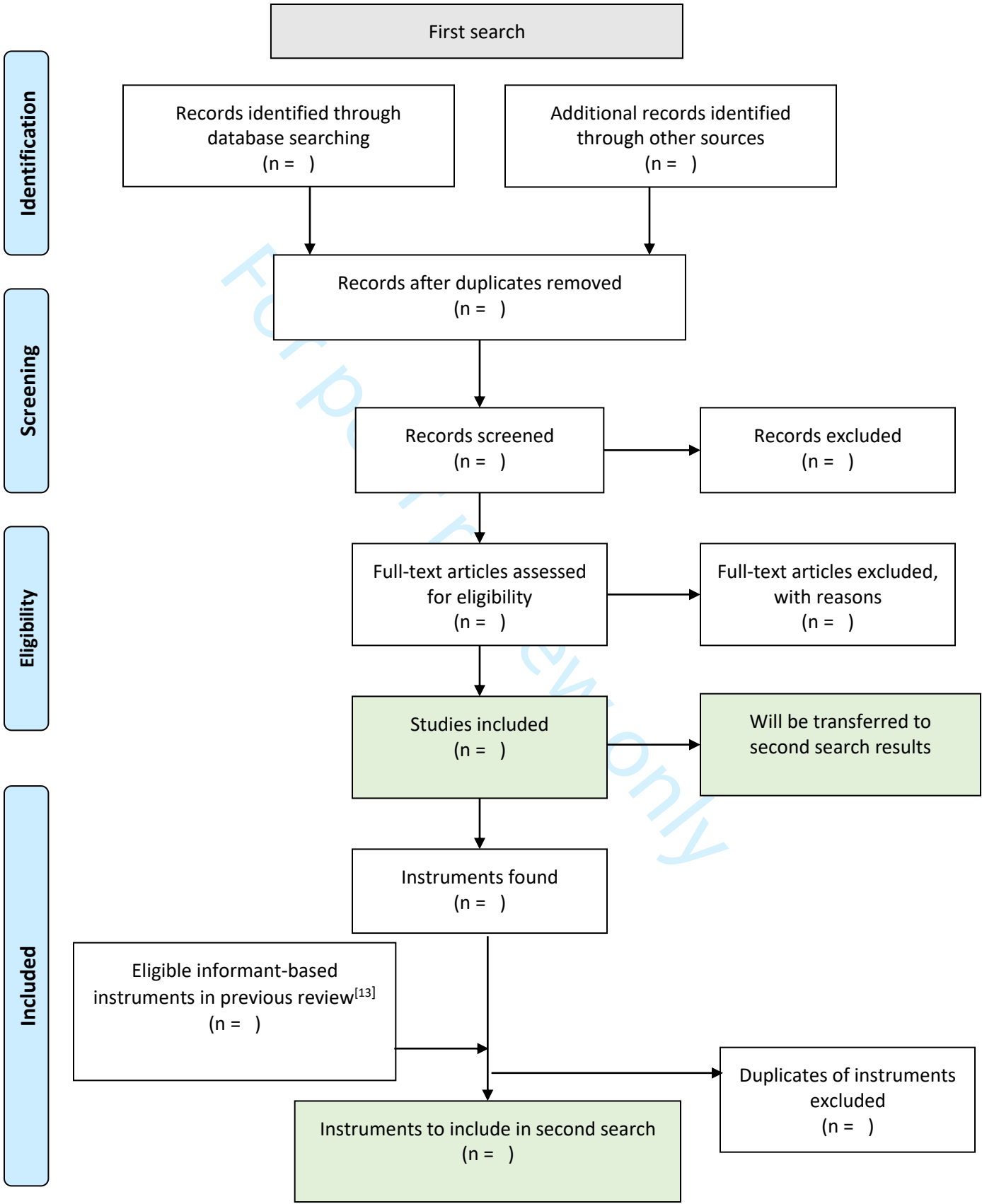
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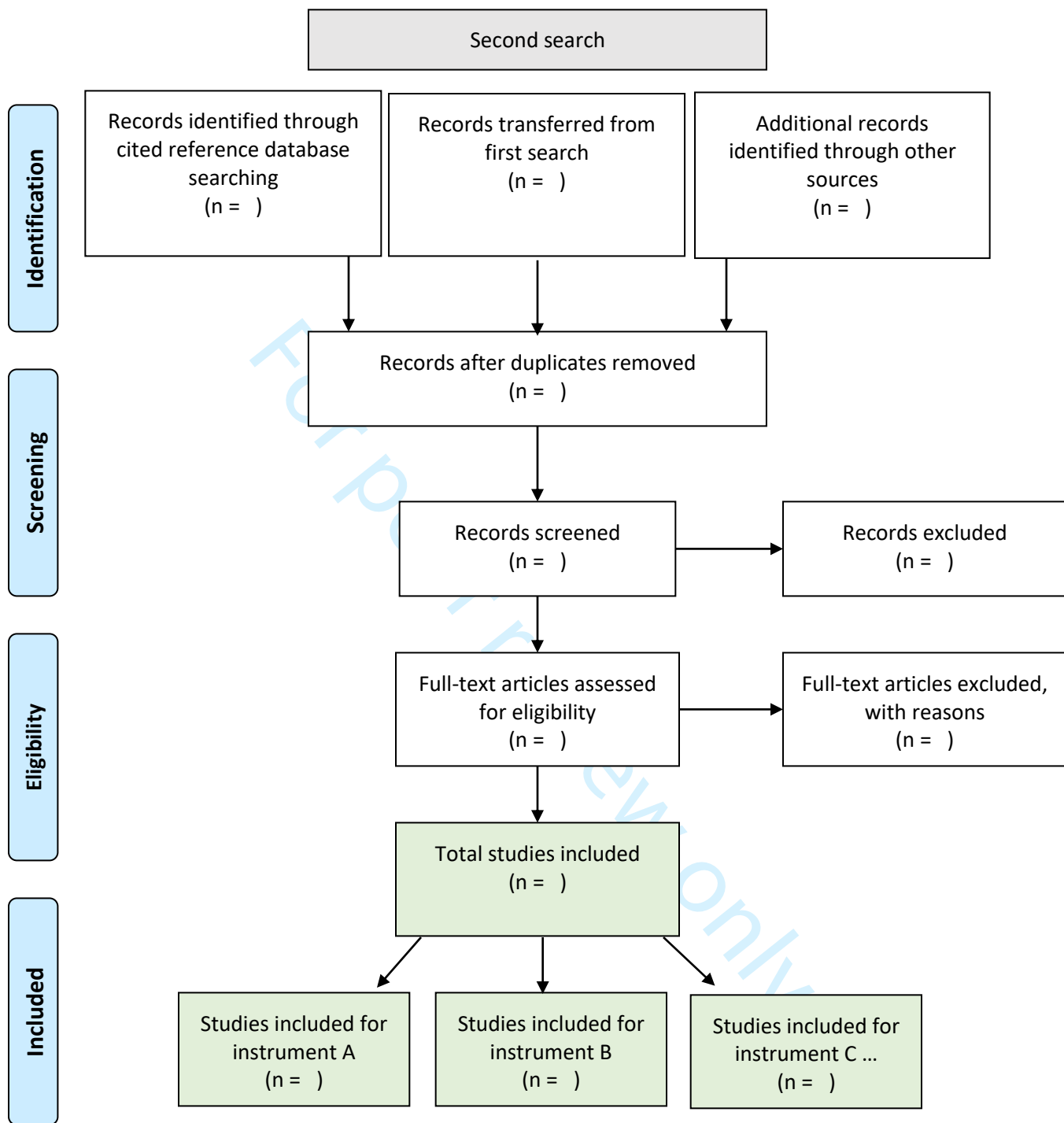
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29 375 **Figure legends**

30
31
32 376 Figure 1: PRISMA flow chart of first search
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35 377 Figure 2: PRISMA flow chart of second search
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Reporting checklist for protocol of a systematic review.

Based on the PRISMA-P guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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			Page	Line
Reporting Item			Number	Number
Title				
Identification	#1a	Identify the report as a protocol of a systematic review	1	2-3

1	Update	#1b	If the protocol is for an update of a previous	n.a.	
2			systematic review, identify as such		
3					
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5					
6	Registration				
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10		#2	If registered, provide the name of the registry	6	137-138
11			(such as PROSPERO) and registration number		
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15	Authors				
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18	Contact	#3a	Provide name, institutional affiliation, e-mail	1	5-20
19			address of all protocol authors; provide physical		
20			mailing address of corresponding author		
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26	Contribution	#3b	Describe contributions of protocol authors and	12	271-275
27			identify the guarantor of the review		
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31	Amendments				
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34		#4	If the protocol represents an amendment of a	6	138-140
35			previously completed or published protocol,		
36			identify as such and list changes; otherwise,		
37			state plan for documenting important protocol		
38			amendments		
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46	Support				
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49	Sources	#5a	Indicate sources of financial or other support for	13	276-278
50			the review		
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55	Sponsor	#5b	Provide name for the review funder and / or	n.a.	
56			sponsor		
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1	Role of sponsor	#5c	Describe roles of funder(s), sponsor(s), and / or	n.a.
2				
3	or funder		institution(s), if any, in developing the protocol	
4				
5				
6	Introduction			
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9				
10	Rationale	#6	Describe the rationale for the review in the	5 104-114
11			context of what is already known	
12				
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15	Objectives	#7	Provide an explicit statement of the question(s)	6 124-129
16			the review will address with reference to	
17			participants, interventions, comparators, and	
18			outcomes (PICO)	
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25	Methods			
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28	Eligibility criteria	#8	Specify the study characteristics (such as PICO,	7-8, 9 153-168,
29			study design, setting, time frame) and report	180-184
30			characteristics (such as years considered,	
31			language, publication status) to be used as	
32			criteria for eligibility for the review	
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40	Information	#9	Describe all intended information sources (such	7, 8, 9 148-150,
41			as electronic databases, contact with study	174-177,
42	sources		authors, trial registers or other grey literature	185-190
43			sources) with planned dates of coverage	
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50	Search strategy	#10	Present draft of search strategy to be used for at	8 160-161
51			least one electronic database, including planned	
52			limits, such that it could be repeated	
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1	Study records -	#11a	Describe the mechanism(s) that will be used to	11	246-249
2					
3	data		manage records and data throughout the review		
4					
5	management				
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8					
9	Study records -	#11b	State the process that will be used for selecting	9	191-194
10					
11	selection		studies (such as two independent reviewers)		
12					
13	process		through each phase of the review (that is,		
14					
15			screening, eligibility and inclusion in meta-		
16			analysis)		
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21	Study records -	#11c	Describe planned method of extracting data from	10	203-207
22					
23	data collection		reports (such as piloting forms, done		
24					
25	process		independently, in duplicate), any processes for		
26					
27			obtaining and confirming data from investigators		
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30					
31	Data items	#12	List and define all variables for which data will be	9	195-202
32					
33			sought (such as PICO items, funding sources),		
34					
35			any pre-planned data assumptions and		
36					
37			simplifications		
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41	Outcomes and	#13	List and define all outcomes for which data will	n.a.	
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43	prioritization		be sought, including prioritization of main and		
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45			additional outcomes, with rationale		
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48	Risk of bias in	#14	Describe anticipated methods for assessing risk	10	208-223
49					
50	individual studies		of bias of individual studies, including whether		
51					
52			this will be done at the outcome or study level, or		
53					
54			both; state how this information will be used in		
55					
56			data synthesis		
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1	Data synthesis	#15a	Describe criteria under which study data will be	10-11	227-231
2			quantitatively synthesised		
3					
4					
5					
6	Data synthesis	#15b	If data are appropriate for quantitative synthesis,	n.a.	
7			describe planned summary measures, methods		
8			of handling data and methods of combining data		
9			from studies, including any planned exploration		
10			of consistency (such as I ² , Kendall's τ)		
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19	Data synthesis	#15c	Describe any proposed additional analyses	n.a.	
20			(such as sensitivity or subgroup analyses, meta-		
21			regression)		
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26	Data synthesis	#15d	If quantitative synthesis is not appropriate,	10	224-227
27			describe the type of summary planned		
28					
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32	Meta-bias(es)	#16	Specify any planned assessment of meta-	10	219-223
33			bias(es) (such as publication bias across		
34			studies, selective reporting within studies)		
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39	Confidence in	#17	Describe how the strength of the body of	11	242-245
40	cumulative		evidence will be assessed (such as GRADE)		
41	evidence				
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BMJ Open

Informant-based assessment instruments for dementia and their measurement properties in persons with intellectual disability: a systematic review protocol

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-040920.R1
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Date Submitted by the Author:	30-Sep-2020
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Primary Subject Heading:	Ophthalmology
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Keywords:	MENTAL HEALTH, Old age psychiatry < PSYCHIATRY, STATISTICS & RESEARCH METHODS, Dementia < NEUROLOGY

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3 1 Title: Informant-based assessment instruments for dementia and their
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6 2 measurement properties in persons with intellectual disability: a systematic
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9 3 review protocol
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26 **ABSTRACT**

27 **Introduction**

28 Persons with intellectual disability (ID) are at a higher risk of developing dementia than
29 persons without ID, with an expected earlier onset. Assessment methods for the general
30 population cannot be applied for persons with ID due to their pre-existing intellectual and
31 functional impairments. As there is no agreed-upon measure to assess dementia in persons
32 with ID, multiple instruments for this purpose have been developed and adapted in the last
33 decades. This review aims to identify all available informant-based instruments for the
34 assessment of dementia in persons with ID and to evaluate and compare them according to
35 their measurement properties. Additionally, an overview of the amount and quality of
36 research on these instruments will be provided.

37 **Methods and analysis**

38 This review will be conducted and reported according to the PRISMA statement. We will
39 adhere to the *COnsensus-based Standards for the selection of health Measurement*
40 *INstruments* (COSMIN) guidelines, and use a set of characteristics developed for assessment
41 instruments for persons with ID, the *Characteristics of Assessment Instruments for*
42 *Psychiatric Disorders in Persons with Intellectual Developmental Disorders* (CAPs-IDD).
43 Two comprehensive, systematic literature searches will be applied in ten international
44 databases, including ASSIA, CINAHL, Cochrane Library, ERIC, MEDLINE, PsycINFO,
45 Scopus, Web of Science, OpenGrey, and ProQuest Dissertations & Theses Global. Risk of
46 bias and quality assessment will be done according to COSMIN guidelines. We will apply the
47 modified *Grading of Recommendations, Assessment, Development and Evaluation* (GRADE)
48 approach to rate the overall quality of the available evidence.

49 **Ethics and dissemination**

50 No ethics statement is needed for this study. The results will be submitted to a peer-reviewed
51 journal, and presented at international conferences.

52 **Registration details**

53 PROSPERO registration number: CRD42020181773

54 **Keywords**

55 mental health, dementia, old age psychiatry, statistics and research methods

57 **ARTICLE SUMMARY**

58 **Strengths and limitations of this study**

- 59 • This review follows the most up-to-date standards for conducting systematic reviews
60 on assessment instruments, the PRISMA and COSMIN guidelines, and additionally
61 uses the CAPs-IDD, a system especially developed for evaluating assessment
62 instruments for psychiatric disorders in persons with ID.
- 63 • Two very comprehensive consecutive search strategies will be applied in a total of ten
64 international databases, including grey and unpublished literature.
- 65 • We use no language restrictions to minimise language bias.
- 66 • We only include informant-based instruments assessing dementia in our evaluation,
67 and exclude direct cognitive tests.
- 68 • Due to expected heterogeneity in studies, a quantitative pooling of psychometric data
69 will probably not be possible.

72 INTRODUCTION

73 Intellectual disability (ID) is characterized by limitations in intellectual functioning (IQ < 70)
74 and in adaptive behaviour originating in the developmental phase of an individual.[1] It is also
75 known as Intellectual Developmental Disorder in the *Diagnostic and Statistical Manual of*
76 *Mental Disorders 5* (DSM-5)[2] and Disorders of Intellectual Development in the *11th*
77 *Revision of the International Classification of Diseases* (ICD-11).[3] Prevalence of ID is hard
78 to establish, since in many countries no official records of persons with ID exist.[4] In large
79 meta-analysis and reviews, the worldwide prevalence of ID is estimated to range from 1% to
80 3,3%.[5–7]

81 Persons with ID are at the same or higher risk to develop dementia than persons without
82 ID.[8–10] Yet, due to their limitations in intellectual functioning, it is often hard to recognize
83 dementia in this population, especially at an early stage. Well-evaluated assessment and
84 screening instruments for the general population, such as the frequently used Mini-Mental
85 State Examination (MMSE)[11] are not suitable for persons with ID due to their pre-existing
86 disabilities.[12,13] Diagnostic overshadowing[14,15] makes it difficult to distinguish
87 symptoms linked to the pre-existing disability from symptoms caused by the onset of
88 dementia. Additionally, the presentation of dementia in persons with ID can differ from the
89 presentation in persons without ID, with behavioural symptoms and personality changes being
90 more frequent and probably earlier in the course of the illness, especially in persons with
91 Down Syndrome.[16,17] To reliably detect dementia in persons with ID, it is recommended to
92 compare a baseline assessment with periodic re-assessments.[18–20] Most dementia
93 assessment methods for persons with ID rely on informant-based measures. The respondent of
94 these instruments should be a person who knows the respective person with ID very well, for
95 instance, a family member or care staff. In contrast to direct tests of cognitive functioning,

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3 96 informant-based instruments can be applied for all persons with ID, irrespective of their
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5 97 intellectual and functional capacity.
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8 98 Early recognition of dementia is particularly important to start early interventions, to plan for
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10 99 the future, and to get adequate support for family-carers or care staff.[21–23] Not being able
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12 100 to recognize early signs of dementia constitutes a disadvantage for persons with ID, and
13
14 101 contradicts the *Convention on the Rights of Persons with Disabilities by the United Nations*
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16 102 (UN-CRPD).[24] Article 25 and 26 of the UN-CRPD require States Parties to ensure that
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18 103 persons with disabilities can get the “highest attainable standard of health without
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20 104 discrimination on the basis of disability.”[24]
21
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25 105 There are several tools and screening instruments in use for the early recognition of dementia
26
27 106 in persons with ID.[13,25] These instruments can be distinguished in three categories:
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29 107 medical test (e.g. fMRI, gene-markers), direct cognitive tests, and informant-based scales,
30
31 108 which are also called observer-rated scales. In this review we focus solely on informant-based
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33 109 scales, which include observer-reported outcome measures (ObsROM), as well as clinician-
34
35 110 reported outcome measures (ClinROM). [26]
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40 111 One systematic review found 114 instruments and four test-batteries that have been used to
41
42 112 assess dementia in persons with ID. However, some of these instruments have never been
43
44 113 designed or adapted to be used in persons with ID, or even to assess dementia.[13] Although
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46 114 there are already some reviews summarising tools and screening instruments in use for
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48 115 assessing dementia in persons with ID,[13,25,27,28] no systematic review on measurement
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50 116 properties using up-to-date guidelines for review conduction and psychometric evaluation has
51
52 117 been conducted so far. We want to provide an inventory of available informant-based
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54 118 instruments and their measurement properties. This should help clinicians and researches in
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56 119 choosing the adequate instrument for their respective purpose. Our review adds to the existing
57
58 120 body of knowledge by using a very inclusive systematic search of the literature and, most
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3 121 importantly, by providing a systematic evaluation of informant-based dementia assessment
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5 122 instruments following up-to-date guidelines.
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8 123 For each instrument, we will systematically summarise the amount and quality of available
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10 124 evaluation studies, depicting which measurement properties have been evaluated to what
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12 125 extent, and which measurement properties have not or insufficiently been evaluated.
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15
16 126 The objectives of this systematic review are to (1) identify informant-based instruments
17
18 127 suitable for the assessment of dementia in persons with ID, to (2) provide a systematic
19
20 128 overview of descriptive aspects for each instrument (e.g. respondent requirements, response
21
22 129 format), to (3) provide a systematic overview of the amount and quality of available research
23
24 130 for each instrument and each measurement property, and to (4) provide a recommendation for
25
26 131 the most suitable instrument(s) based on all information collected.
27
28

30 132 **METHODS AND ANALYSIS**

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32
33 133 This review will be conducted and reported according to the *Preferred Reporting Items for*
34
35 134 *Systematic Reviews and Meta-Analyses* (PRISMA) statement,[29] and the review protocol has
36
37 135 been developed using the PRISMA guidelines for protocols (PRISMA-P).[30,31] We will
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39 136 adhere to the *COnsensus-based Standards for the selection of health Measurement*
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41 137 *INstruments* (COSMIN) guidelines,[32] and complement them with a set of characteristics
42
43 138 especially developed for assessment instruments for persons with ID, the *Characteristics of*
44
45 139 *Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental*
46
47 140 *Disorders* (CAPs-IDD).[33] The systematic review has been registered with the *International*
48
49 141 *Prospective Register of Systematic Reviews* (PROSPERO) with registration number
50
51 142 CRD42020181773. If amendments to the protocol are needed, we will register these in
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53 143 PROSPERO, including date and rationale. In the final publication of our results, any
54
55 144 amendments to the protocol will be depicted and explained.
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3 145 **Search strategy**
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5 146 Two systematic searches will be applied consecutively, and carried out between May 2020
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7 147 and August 2020. The first search should provide an inventory of available informant-based
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9 148 assessment instruments for dementia in persons with ID. The goal of the second search is to
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11 149 locate evaluation studies for each instrument found in the first search. Figure 1 and Figure 2
12
13 150 depict our search strategies using PRISMA flow charts.
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16
17 151 **First search**
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19
20 152 To identify instruments we will search in ten international electronic databases, including
21
22 153 ASSIA, CINAHL, Cochrane Library, ERIC, MEDLINE, PsycINFO, Scopus, Web of Science,
23
24 154 OpenGrey, and ProQuest Dissertations & Theses Global. The search string is depicted in
25
26 155 Table 1 and will include various terms for the (1) output of interest, (2) construct of interest,
27
28 156 and (3) the specified population. As persons with Down Syndrome are very prone to develop
29
30 157 dementia, this subgroup of persons with ID is included in our search strategy. We will use a
31
32 158 limit on the timespan of publication in the first search, not including publications before the
33
34 159 year 2012. Instruments published up to the year of 2012 are summarised in a previous
35
36 160 systematic review.[13] This review used a very inclusive search strategy and listed all
37
38 161 assessment instruments that have been used to assess dementia in persons with ID. We will
39
40 162 examine the total of 114 dementia assessment instruments listed in the review of 2013, and
41
42 163 include those instruments that are in line with our inclusion criteria.
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47

48 164 Table 1: Search strategy for the first search
49

	1: Output	2: Construct	3: Population
Search terms	Assessment instruments	Dementia	Intellectual disability
Synonyms	assessment; diagnostic; diagnosis; screening;	dementia; Alzheimer's disease	intellectual disability; learning disability;

	instrument; tool;		intellectual
	measurement;		developmental disorder;
	questionnaire;		trisomy 21, Down
	psychometrics; scale;		syndrome
	interview		
Combined and truncated	assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*	dement* OR Alzheimer*	((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)
Example search string for SCOPUS	TITLE-ABS-KEY ((assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND (dement* OR alzheimer*) AND (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) AND PUBYEAR > 2011		

165

166 Inclusion criteria for the first search will be: (1) studies need to focus on assessing dementia
 167 in persons with ID, (2) describe the development or evaluation of an informant-based
 168 instrument for the assessment of dementia, (3) and this instrument has to be especially
 169 developed or adapted for persons with ID. Exclusion criteria: (1) classification systems like
 170 ICD-11, DSM-5, (2) scales including dementia, but focusing on a broader spectrum of
 171 disorders for screening purposes or differential diagnosis, such as the *Psychiatric Assessment*
 172 *Schedule for Adult with Developmental Disability* (PAS-ADD).[34]

173 Second search

174 Once we have identified the instruments, we will conduct a search by citation strategy using
 175 the initial publications of each instrument as a reference point. This search strategy was

1
2
3 176 chosen on the assumption that a paper evaluating an instrument would surely cite the initial
4
5 177 publication of the respective instrument. The papers used as reference points will also be
6
7 178 included in the further appraisal of the literature. For published papers, we will use five
8
9
10 179 international databases allowing a search by citation strategy, including ERIC, PsycInfo,
11
12 180 MEDLINE, Scopus, and Web of Science. For published manuals, not listed in at least one of
13
14 181 the five databases, we will use Google Scholar. Additionally, all records fulfilling the
15
16 182 inclusion and exclusion criteria of the first search will be transferred and examined in the
17
18 183 second search.

19
20
21
22 184 The following inclusion criterion will be used in the second search: (1) studies need to
23
24 185 describe an evaluation of the respective instrument in persons with ID. Exclusion criteria
25
26 186 comprise: (1) the respective instrument was used primarily for other investigations, not related
27
28 187 to an evaluation of the instrument, (2) or the study is a review on assessment instruments, not
29
30 188 providing novel information.

31
32
33
34 189 To further include grey and unpublished literature in both searches, we will apply an invisible
35
36 190 college approach, contacting authors in the field for information or manuscripts on this topic,
37
38 191 and we will follow up on meeting abstracts. Full texts of reviews on assessment instruments
39
40 192 identified in the course of the two searches will be screened for possible further studies to
41
42 193 include. References of papers meeting the inclusion criteria will be hand-searched. We will
43
44 194 re-run both searches before the final analyses to include the most recent publications.

45
46
47
48 195 For study selection, one reviewer will exclude duplicates. All remaining records will be
49
50 196 screened and reviewed for eligibility by two team members independently, i.e. blinded to each
51
52 197 other's decisions. In the case of disagreement, dissonances will be discussed until agreement
53
54 198 is reached. In the case of non-agreement, a third team member will be included in discussion.

199 **Data extraction**

200 The first search will result in a list of instruments. Data extracted will be the names of the

1
2
3 201 instruments and information on their initial publication(s). In the second search, we will
4
5 202 extract evaluation data of instruments, i.e. measurement properties and characteristics as listed
6
7 203 in the COSMIN checklists and the CAPs-IDD. For each characteristic/property extracted, we
8
9 204 will record the study design and sample characteristics, including sample size, gender
10
11 205 distribution, age distribution, aetiology of ID, and country (language) in which the instrument
12
13 206 was evaluated. We will include all studies, irrespective of their design.
14
15
16

17 207 The extraction of all relevant data will be done via standardised and piloted excel
18
19 208 spreadsheets by two team members independently. In the case of disagreement, dissonances
20
21 209 will be discussed until agreement is reached. In the case of non-agreement, a third team
22
23 210 member will be included in discussion. If data necessary for coding is missing in a study, we
24
25 211 will contact the respective study authors for this information.
26
27
28

29 212 **Risk of bias and quality assessment**

30
31 213 Quality and risk of bias will be assessed on study level (for each measurement property), on
32
33 214 outcome level (for each assessment instrument), and on an aggregated outcome level,
34
35 215 applying the *Grading of Recommendations, Assessment, Development and Evaluation*
36
37 216 (GRADE) approach. We will combine the COSMIN checklists [35–37] with the CAPs-IDD
38
39 217 [33], a comprehensive tool specifically developed for the evaluation of assessment
40
41 218 instruments for psychiatric disorders in persons with ID. The CAPs-IDD consists of two parts:
42
43 219 (1) conceptual and measurement model (including descriptive aspects of instruments, e.g.
44
45 220 respondent requirements, theoretical foundation), and (2) psychometric properties. We will
46
47 221 only use the first part, as the second part is more comprehensively covered by the COSMIN
48
49 222 checklists.
50
51
52
53

54
55 223 All ratings will be done by two reviewers independently. In the case of disagreement,
56
57 224 dissonances will be discussed until agreement is reached. In the case of non-agreement, a
58
59
60

1
2
3 225 third team member will be included in the discussion. Initial interrater agreement will be
4
5 226 determined using percentage agreement, calculated in R.[38]
6
7

8 227 As to publication bias, we assume that evaluation results not in favour of the respective
9
10 228 instruments are likely to be underreported. This may be partly due to evaluations being
11
12 229 frequently done and published by the developer(s) of the respective instrument. We will
13
14 230 address this by including grey literature and by discussing this aspect in the interpretation of
15
16 231 our results.
17
18

19 20 232 **Strategy for data synthesis**

21
22 233 A narrative synthesis will be conducted. Assessment instruments will be presented in a table
23
24 234 along with descriptive aspects according to CAPs-IDD, and their measurement properties and
25
26 235 quality ratings according to the COSMIN checklists. Quantitative data pooling will probably
27
28 236 not be possible. This is due to an expected limited number of studies evaluating the same
29
30 237 property (e.g. internal consistency) for an instrument, and an expected heterogeneity in the
31
32 238 population studied (e.g. severity of ID, persons with Down Syndrome vs. persons with ID of
33
34 239 other aetiology). However, if applicable, we will calculate pooled estimates and 95%
35
36 240 confidence intervals using R.[38]
37
38
39
40
41

42 241 **Analysis of subgroups**

43
44 242 We define persons with Down Syndrome/trisomy 21 (DS) as a special subgroup, as they are
45
46 243 more often affected by Alzheimer's dementia, with a suspected earlier onset.[16] We will
47
48 244 group instruments according to their intended use, and studies according to their participants
49
50 245 in four clusters: (1) persons with ID, including persons with DS, (2) only persons with DS, (3)
51
52 246 only persons with ID, not including DS, (4) aetiology of ID not specified. For the fourth
53
54 247 cluster, we will contact study authors to determine aetiology of ID in the respective sample or
55
56 248 for the respective instrument. We will then allocate each study or instrument to the first three
57
58
59
60

1
2
3 249 clusters according to the information provided by the authors. If no information is provided,
4
5 250 the respective study or instrument remains in cluster four.
6
7

8 251 **Confidence in cumulative evidence**

9
10 252 The modified GRADE approach as suggested by the COSMIN guidelines[32] will be applied
11
12
13 253 to grade the quality of the evidence.
14
15

16 254 **Data management**

17
18 255 We will use ZOTERO for saving records and managing and storing literature, including
19
20 256 managing duplicates. For extracting data and recording decisions on quality ratings we will
21
22
23 257 use standardised and piloted excel spreadsheets.
24
25

26 258 **Patient and public involvement**

27
28 259 This research was done without patient involvement due to limited resources.
29
30

31 260 **DISCUSSION**

32
33 261 This review will summarise measurement properties of available informant-based assessment
34
35 262 instruments for persons with ID and give an overview of the quality of each instrument and
36
37
38 263 the quality of available evaluation studies. For each instrument we will depict which
39
40 264 psychometric properties are evaluated to what extent, and which properties need further
41
42 265 evaluation in future research. This will be the first systematic review of dementia assessment
43
44 266 instruments for persons with ID using PRISMA and COSMIN guidelines as well as applying
45
46
47 267 the ID-specific criteria of the CAPs-IDD.
48
49

50 268 Our work will highlight gaps in research on these instruments, thus setting the ground for
51
52 269 more effective research in the future. The results of this review will inform researchers and
53
54 270 clinicians of the quality of available instruments to assess dementia in persons with ID, and
55
56
57 271 guide them in choosing an adequate instrument. This will hopefully contribute to an
58
59
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1
2
3 272 improvement of dementia assessment in persons with ID and a better, earlier, and more
4
5 273 adequate provision of healthcare services, as demanded by the UN-CRPD.[24]
6
7

8 274 **Ethics and dissemination**

9
10 275 No ethics statement is needed for this study. The results of this systematic review will be
11
12 276 submitted for publication to a leading peer-reviewed journal, and presented at international
13
14 277 conferences and congresses in the fields of ID, ageing, and dementia.
15
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17

18 278

21 279 **Author's contributions**

22
23 280 ELZ conceived the study, drafted the protocol, and is the guarantor of the review. SK, IZ and
24
25 281 FF contributed to study design and drafting the protocol. ELZ, SK, and KW designed and
26
27 282 tested the search strategy. FF and IZ tested quality rating tools and software options. All
28
29 283 authors read and approved the final protocol.
30
31
32

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38
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40

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42
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44
45

46 289 **Patient and public involvement**

47
48 290 This research was done without patient involvement.
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51 291 **Competing interests**

52
53 292 The authors have no competing nor potential conflict interests to declare.
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56 293 **Word Count:** 2,548 words.
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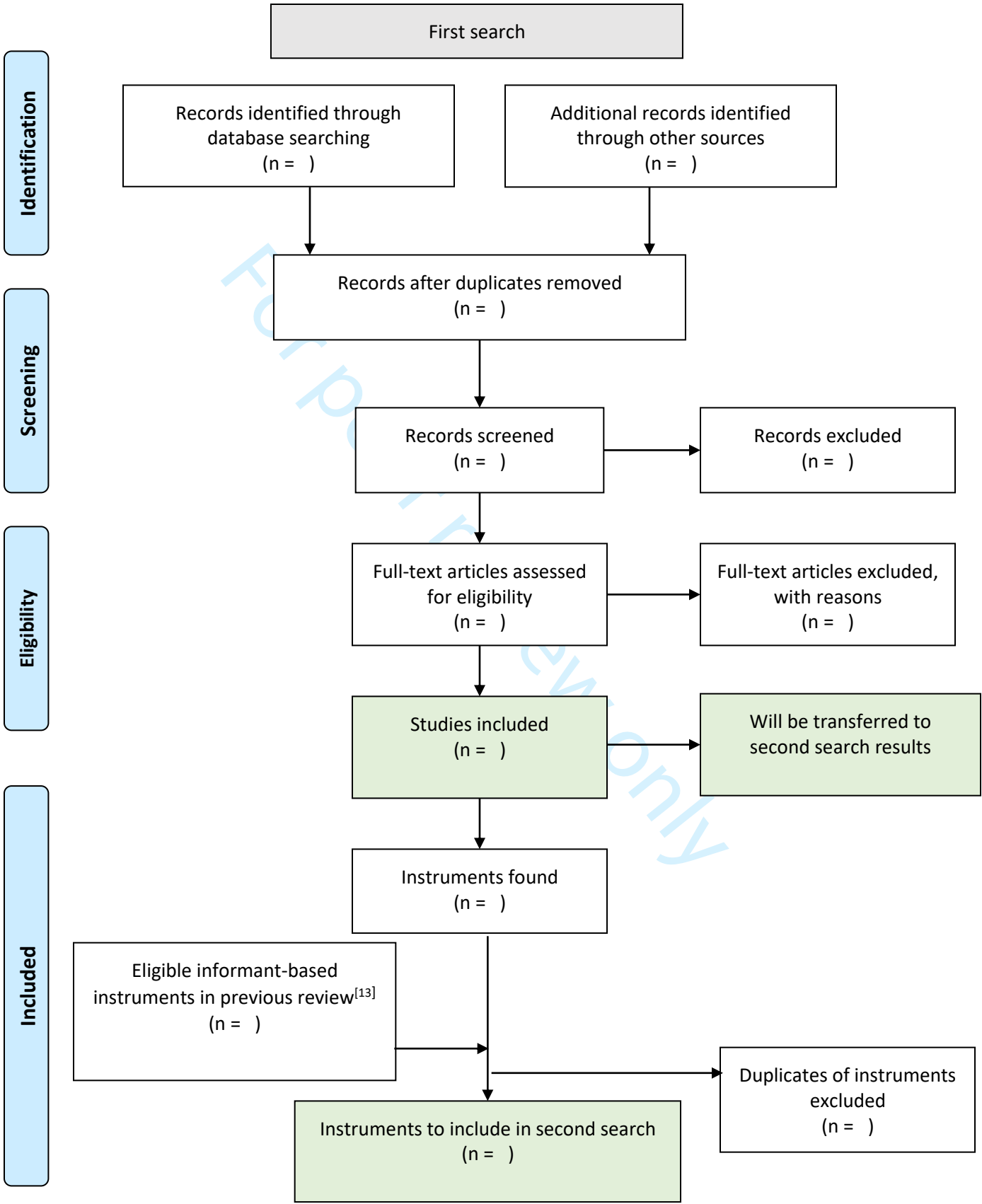
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3 408 **Figure legends**
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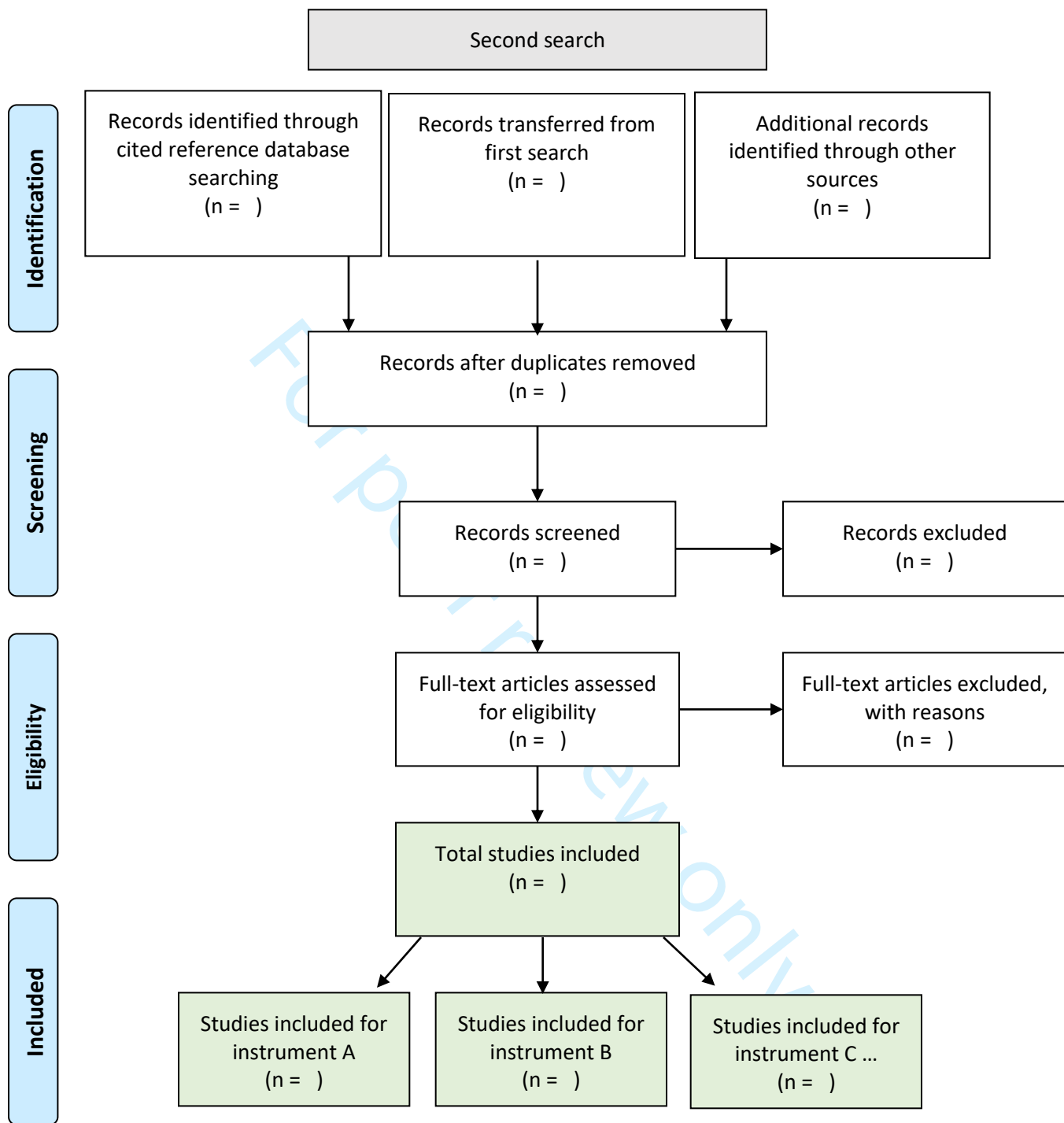
6 409 Figure 1: PRISMA flow chart of first search
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9 410 Figure 2: PRISMA flow chart of second search
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Supplementary information

Informant-based assessment instruments for dementia and their measurement properties in persons with intellectual disability: a systematic review protocol

Detailed search strategy in electronic databases

ASSIA

(via ProQuest)

noft(Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND noft(Dement* OR Alzheimer*) AND noft(((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))

Additional limits: Date: From 2012 to 2020

CINAHL

(via EBSCOhost) (MEDLINE records excluded, since they are already in the MEDLINE Search):

(AB (Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND AB (Dement* OR Alzheimer*) AND AB (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) OR (TI (Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND TI (Dement* OR Alzheimer*) AND TI (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) OR (SU (Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND SU (Dement* OR Alzheimer*) AND SU (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))))

Limiters - Published Date: 20120101-20201231; Exclude MEDLINE records

Cochrane Library

(Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*):ti,ab,kw AND (Dement* OR Alzheimer*):ti,ab,kw AND (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)):ti,ab,kw

with Cochrane Library publication date from Jan 2012 to Dec 2020

ERIC, MEDLINE, and PsycInfo

(via Ovid) [mp=ab, ti, hw, id, tc, ot, tm, mh]

((Assess* or diagnosti* or screen or screening* or instrument* or tool* or measure* or questionnaire* or psychometr* or scale* or interview*) and (Dement* or Alzheimer*) and (((intellectual* or learning) and disab*) or (intellectual* and developmental* and disorder*) or trisom* 21 or (down* and syndrom*))).mp

limit to yr="2012 - 2020"

SCOPUS

TITLE-ABS-KEY ((assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND (dement* OR alzheimer*) AND (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) AND PUBYEAR > 2011

Web of Science Core Collection:

TOPIC:(Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND

TOPIC:(Dement* OR Alzheimer*) AND

TOPIC:((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)

Timespan: 2012-2020. **Indexes:** SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC.

OpenGrey

(Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND

(Dement* OR Alzheimer*) AND

((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)

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noft(Dement* OR Alzheimer*) AND noft(((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))

Additional limits: Date: From 2012 to 2020

Reporting checklist for protocol of a systematic review.

Based on the PRISMA-P guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

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In your methods section, say that you used the PRISMA-Reporting guidelines, and cite them as:

Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. Syst Rev. 2015;4(1):1.

			Page	Line
		Reporting Item	Number	Number
Title				
Identification	#1a	Identify the report as a protocol of a systematic review	1	2-3

1	Update	#1b	If the protocol is for an update of a previous	n.a.	
2			systematic review, identify as such		
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6	Registration				
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10		#2	If registered, provide the name of the registry	6	141-142
11			(such as PROSPERO) and registration		
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20	Contact	#3a	Provide name, institutional affiliation, e-mail	1	5-20
21			address of all protocol authors; provide		
22			physical mailing address of corresponding		
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30	Contribution	#3b	Describe contributions of protocol authors and	13	279-283
31			identify the guarantor of the review		
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39		#4	If the protocol represents an amendment of a	6	142-144
40			previously completed or published protocol,		
41			identify as such and list changes; otherwise,		
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51	Support				
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54	Sources	#5a	Indicate sources of financial or other support	13	284-286
55			for the review		
56					
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1	Sponsor	#5b	Provide name for the review funder and / or	n.a.	
2			sponsor		
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6	Role of sponsor	#5c	Describe roles of funder(s), sponsor(s), and /	n.a.	
7			or institution(s), if any, in developing the		
8	or funder		protocol		
9					
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13					
14	Introduction				
15					
16					
17	Rationale	#6	Describe the rationale for the review in the	5-6	105-122
18			context of what is already known		
19					
20					
21					
22	Objectives	#7	Provide an explicit statement of the	6	126-131
23			question(s) the review will address with		
24			reference to participants, interventions,		
25			comparators, and outcomes (PICO)		
26					
27					
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31					
32	Methods				
33					
34					
35	Eligibility criteria	#8	Specify the study characteristics (such as	7-8, 9	157-172,
36			PICO, study design, setting, time frame) and		180-188
37			report characteristics (such as years		
38			considered, language, publication status) to		
39			be used as criteria for eligibility for the review		
40					
41					
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48	Information	#9	Describe all intended information sources	7, 9	152-154,
49			(such as electronic databases, contact with		178-181,
50	sources		study authors, trial registers or other grey		189-194
51			literature sources) with planned dates of		
52			coverage		
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1	Search strategy	#10	Present draft of search strategy to be used for	8;	164-165
2					
3					
4			at least one electronic database, including	supplement	
5					
6			planned limits, such that it could be repeated		
7					
8					
9	Study records -	#11a	Describe the mechanism(s) that will be used	12	254-257
10					
11	data		to manage records and data throughout the		
12					
13	management		review		
14					
15					
16	Study records -	#11b	State the process that will be used for	9	195-198
17					
18	selection		selecting studies (such as two independent		
19					
20	process		reviewers) through each phase of the review		
21					
22			(that is, screening, eligibility and inclusion in		
23					
24			meta-analysis)		
25					
26					
27					
28	Study records -	#11c	Describe planned method of extracting data	10	207-211
29					
30	data collection		from reports (such as piloting forms, done		
31					
32	process		independently, in duplicate), any processes		
33					
34			for obtaining and confirming data from		
35					
36			investigators		
37					
38					
39					
40	Data items	#12	List and define all variables for which data will	9-10	199-206
41					
42			be sought (such as PICO items, funding		
43					
44			sources), any pre-planned data assumptions		
45					
46			and simplifications		
47					
48					
49					
50	Outcomes and	#13	List and define all outcomes for which data will	n.a.	
51					
52	prioritization		be sought, including prioritization of main and		
53					
54			additional outcomes, with rationale		
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1	Risk of bias in	#14	Describe anticipated methods for assessing	10-11	212-231
2					
3	individual		risk of bias of individual studies, including		
4					
5	studies		whether this will be done at the outcome or		
6					
7			study level, or both; state how this information		
8					
9			will be used in data synthesis		
10					
11					
12					
13	Data synthesis	#15a	Describe criteria under which study data will	11	235-240
14					
15			be quantitatively synthesised		
16					
17					
18	Data synthesis	#15b	If data are appropriate for quantitative	n.a.	
19					
20			synthesis, describe planned summary		
21					
22			measures, methods of handling data and		
23					
24			methods of combining data from studies,		
25					
26			including any planned exploration of		
27					
28			consistency (such as I ² , Kendall's τ)		
29					
30					
31					
32					
33	Data synthesis	#15c	Describe any proposed additional analyses	n.a.	
34					
35			(such as sensitivity or subgroup analyses,		
36					
37			meta-regression)		
38					
39					
40					
41	Data synthesis	#15d	If quantitative synthesis is not appropriate,	11	232-235
42					
43			describe the type of summary planned		
44					
45					
46	Meta-bias(es)	#16	Specify any planned assessment of meta-	11	227-231
47					
48			bias(es) (such as publication bias across		
49					
50			studies, selective reporting within studies)		
51					
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1 Confidence in [#17](#) Describe how the strength of the body of 12 251-253
2
3 cumulative evidence will be assessed (such as GRADE)
4
5 evidence
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7

8
9 None The PRISMA-P checklist is distributed under the terms of the Creative Commons Attribution
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12 made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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Informant-based assessment instruments for dementia and their measurement properties in persons with intellectual disability: a systematic review protocol

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3 1 Title: Informant-based assessment instruments for dementia and their
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6 2 measurement properties in persons with intellectual disability: a systematic
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9 3 review protocol
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12 4

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26 **ABSTRACT**

27 **Introduction**

28 Persons with intellectual disability (ID) are at a higher risk of developing dementia than
29 persons without ID, with an expected earlier onset. Assessment methods for the general
30 population cannot be applied for persons with ID due to their pre-existing intellectual and
31 functional impairments. As there is no agreed-upon measure to assess dementia in persons
32 with ID, multiple instruments for this purpose have been developed and adapted in the last
33 decades. This review aims to identify all available informant-based instruments for the
34 assessment of dementia in persons with ID, to evaluate and compare them according to their
35 measurement properties, and to provide a recommendation for the most suitable instrument(s).
36 Additionally, an overview of the amount and quality of research on these instruments will be
37 provided.

38 **Methods and analysis**

39 This review will be conducted and reported according to the PRISMA statement. We will
40 adhere to the *COnsensus-based Standards for the selection of health Measurement*
41 *INstruments* (COSMIN) guidelines, and use a set of characteristics developed for assessment
42 instruments for persons with ID, the *Characteristics of Assessment Instruments for*
43 *Psychiatric Disorders in Persons with Intellectual Developmental Disorders* (CAPs-IDD).
44 Two comprehensive, systematic literature searches will be applied in ten international
45 databases, including ASSIA, CINAHL, Cochrane Library, ERIC, MEDLINE, PsycINFO,
46 Scopus, Web of Science, OpenGrey, and ProQuest Dissertations & Theses Global. Risk of
47 bias and quality assessment will be done according to COSMIN guidelines. We will apply the
48 modified *Grading of Recommendations, Assessment, Development and Evaluation* (GRADE)
49 approach to rate the overall quality of the available evidence.

50 **Ethics and dissemination**

51 No ethics statement is needed for this study. The results will be submitted to a peer-reviewed
52 journal, and presented at international conferences.

53 **Registration details**

54 PROSPERO registration number: CRD42020181773

55 **Keywords**

56 mental health, dementia, old age psychiatry, statistics and research methods

58 **ARTICLE SUMMARY**

59 **Strengths and limitations of this study**

- 60 • This review follows the most up-to-date standards for conducting systematic reviews
61 on assessment instruments, the PRISMA and COSMIN guidelines, and additionally
62 uses the CAPs-IDD, a system especially developed for evaluating assessment
63 instruments for psychiatric disorders in persons with ID.
- 64 • Two very comprehensive consecutive search strategies will be applied in a total of ten
65 international databases, including grey and unpublished literature.
- 66 • We use no language restrictions to minimise language bias.
- 67 • We only include informant-based instruments assessing dementia in our evaluation,
68 and exclude direct cognitive tests.
- 69 • Due to expected heterogeneity in studies, a quantitative pooling of psychometric data
70 will probably not be possible.

73 INTRODUCTION

74 Intellectual disability (ID) is characterized by limitations in intellectual functioning (IQ < 70)
75 and in adaptive behaviour originating in the developmental phase of an individual.[1] It is also
76 known as Intellectual Developmental Disorder in the *Diagnostic and Statistical Manual of*
77 *Mental Disorders 5* (DSM-5)[2] and Disorders of Intellectual Development in the *11th*
78 *Revision of the International Classification of Diseases* (ICD-11).[3] Prevalence of ID is hard
79 to establish, since in many countries no official records of persons with ID exist.[4] In large
80 meta-analysis and reviews, the worldwide prevalence of ID is estimated to range from 1% to
81 3,3%.[5–7]

82 Persons with ID are at the same or higher risk to develop dementia than persons without
83 ID.[8–10] Yet, due to their limitations in intellectual functioning, it is often hard to recognize
84 dementia in this population, especially at an early stage. Well-evaluated assessment and
85 screening instruments for the general population, such as the frequently used Mini-Mental
86 State Examination (MMSE)[11] are not suitable for persons with ID due to their pre-existing
87 disabilities.[12,13] Diagnostic overshadowing[14,15] makes it difficult to distinguish
88 symptoms linked to the pre-existing disability from symptoms caused by the onset of
89 dementia. Additionally, the presentation of dementia in persons with ID can differ from the
90 presentation in persons without ID, with behavioural symptoms and personality changes being
91 more frequent and probably earlier in the course of the illness, especially in persons with
92 Down Syndrome.[16,17] To reliably detect dementia in persons with ID, it is recommended to
93 compare a baseline assessment with periodic re-assessments.[18–20] Most dementia
94 assessment methods for persons with ID rely on informant-based measures. The respondent of
95 these instruments should be a person who knows the respective person with ID very well, for
96 instance, a family member or care staff. In contrast to direct tests of cognitive functioning,

1
2
3 97 informant-based instruments can be applied for all persons with ID, irrespective of their
4
5 98 intellectual and functional capacity.
6
7

8 99 Early recognition of dementia is particularly important to start early interventions, to plan for
9
10 100 the future, and to get adequate support for family-carers or care staff.[21–23] Not being able
11
12 101 to recognize early signs of dementia constitutes a disadvantage for persons with ID, and
13
14 102 contradicts the *Convention on the Rights of Persons with Disabilities by the United Nations*
15
16 103 (UN-CRPD).[24] Article 25 and 26 of the UN-CRPD require States Parties to ensure that
17
18 104 persons with disabilities can get the “highest attainable standard of health without
19
20 105 discrimination on the basis of disability.”[24]
21
22
23
24

25 106 There are several tools and screening instruments in use for the early recognition of dementia
26
27 107 in persons with ID.[13,25] These instruments can be placed into one of three categories:
28
29 108 medical test (e.g. fMRI, gene-markers), direct cognitive tests, and informant-based scales,
30
31 109 which are also called observer-rated scales. In this review we focus solely on informant-based
32
33 110 scales, which include observer-reported outcome measures (ObsROM), as well as clinician-
34
35 111 reported outcome measures (ClinROM). [26]
36
37
38
39

40 112 One systematic review found 114 instruments and four test-batteries that have been used to
41
42 113 assess dementia in persons with ID. However, some of these instruments have never been
43
44 114 designed or adapted to be used in persons with ID, or even to assess dementia.[13] Although
45
46 115 there are already some reviews summarising tools and screening instruments in use for
47
48 116 assessing dementia in persons with ID,[13,25,27,28] no systematic review on measurement
49
50 117 properties using up-to-date guidelines for review conduction and psychometric evaluation has
51
52 118 been conducted so far. We want to provide an inventory of available informant-based
53
54 119 instruments and their measurement properties. This should help clinicians and researches in
55
56 120 choosing the adequate instrument for their respective purpose. Our review adds to the existing
57
58 121 body of knowledge by using a very inclusive systematic search of the literature and, most
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1
2
3 122 importantly, by providing a systematic evaluation of informant-based dementia assessment
4
5 123 instruments following up-to-date guidelines.
6
7

8 124 For each instrument, we will systematically summarise the amount and quality of available
9
10 125 evaluation studies, depicting which measurement properties have been evaluated to what
11
12 126 extent, and which measurement properties have not or insufficiently been evaluated.
13
14

15
16 127 The objectives of this systematic review are to (1) identify informant-based instruments
17
18 128 suitable for the assessment of dementia in persons with ID, to (2) provide a systematic
19
20 129 overview of descriptive aspects for each instrument (e.g. respondent requirements, response
21
22 130 format), to (3) provide a systematic overview of the amount and quality of available research
23
24 131 for each instrument and each measurement property, and to (4) provide a recommendation for
25
26 132 the most suitable instrument(s) based on all information collected.
27
28
29

30 133 **METHODS AND ANALYSIS**

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32
33 134 This review will be conducted and reported according to the *Preferred Reporting Items for*
34
35 135 *Systematic Reviews and Meta-Analyses* (PRISMA) statement.[29] The review protocol has
36
37 136 been developed using the PRISMA guidelines for protocols (PRISMA-P).[30,31] We will
38
39 137 adhere to the *COnsensus-based Standards for the selection of health Measurement*
40
41 138 *INstruments* (COSMIN) guidelines,[32] and complement them with a set of characteristics
42
43 139 especially developed for assessment instruments for persons with ID, the *Characteristics of*
44
45 140 *Assessment Instruments for Psychiatric Disorders in Persons with Intellectual Developmental*
46
47 141 *Disorders* (CAPs-IDD).[33] The systematic review has been registered with the *International*
48
49 142 *Prospective Register of Systematic Reviews* (PROSPERO) with registration number
50
51 143 CRD42020181773. If amendments to the protocol are needed, we will register these in
52
53 144 PROSPERO, including date and rationale. In the final publication of our results, any
54
55 145 amendments to the protocol will be depicted and explained.
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1
2
3 **146 Search strategy**
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5 147 Two systematic searches will be applied consecutively, and carried out between May 2020
6
7 148 and August 2020. The first search should provide an inventory of available informant-based
8
9 149 assessment instruments for dementia in persons with ID. The goal of the second search is to
10
11 150 locate evaluation studies for each instrument found in the first search. Figure 1 and Figure 2
12
13 151 depict our search strategies using PRISMA flow charts.
14

15
16
17 152 **First search**
18

19
20 153 To identify instruments we will search in ten international electronic databases, including
21
22 154 ASSIA, CINAHL, Cochrane Library, ERIC, MEDLINE, PsycINFO, Scopus, Web of Science,
23
24 155 OpenGrey, and ProQuest Dissertations & Theses Global. The search strategy is described in
25
26 156 Table 1 and depicted in detail in the supplementary file. It will include various terms for the
27
28 157 (1) output of interest, (2) construct of interest, and (3) the specified population. As persons
29
30 158 with Down Syndrome are very prone to develop dementia, this subgroup of persons with ID is
31
32 159 included in our search strategy. We will use a limit on the timespan of publication in the first
33
34 160 search, not including publications before the year 2012. Instruments published up to the year
35
36 161 of 2012 are summarised in a previous systematic review.[13] This review used a very
37
38 162 inclusive search strategy and listed all assessment instruments that have been used to assess
39
40 163 dementia in persons with ID. We will examine the total of 114 dementia assessment
41
42 164 instruments listed in the review of 2013, and include those instruments that are in line with
43
44 165 our inclusion criteria.
45
46
47
48
49

50 166 **Table 1: Search strategy for the first search**
51

	1: Output	2: Construct	3: Population
Search terms	Assessment instruments	Dementia	Intellectual disability

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	Synonyms	assessment; diagnostic; diagnosis; screening; instrument; tool; measurement; questionnaire; psychometrics; scale; interview	dementia; Alzheimer's disease	intellectual disability; learning disability; intellectual developmental disorder; trisomy 21, Down syndrome
16 17 18 19 20 21 22 23 24 25 26 27 28 29	Combined and truncated	assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*	dement* OR Alzheimer*	((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)
30 31 32 33 34 35 36 37 38	Example search string for SCOPUS	TITLE-ABS-KEY ((assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND (dement* OR alzheimer*) AND (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) AND PUBYEAR > 2011		

167

168 Inclusion criteria for the first search will be: (1) studies need to focus on assessing dementia
169 in persons with ID, (2) describe the development or evaluation of an informant-based
170 instrument for the assessment of dementia, (3) and this instrument has to be especially
171 developed or adapted for persons with ID. Exclusion criteria: (1) classification systems like
172 ICD-11, DSM-5, (2) scales including dementia, but focusing on a broader spectrum of
173 disorders for screening purposes or differential diagnosis, such as the *Psychiatric Assessment*
174 *Schedule for Adult with Developmental Disability* (PAS-ADD).[34]

175 Second search

176 Once we have identified the instruments, we will conduct a search by citation strategy using

1
2
3 177 the initial publications of each instrument as a reference point. This search strategy was
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5 178 chosen on the assumption that a paper evaluating an instrument would surely cite the initial
6
7 179 publication of the respective instrument. The papers used as reference points will also be
8
9 180 included in the further appraisal of the literature. For published papers, we will use five
10
11 181 international databases allowing a search by citation strategy, including ERIC, PsycInfo,
12
13 182 MEDLINE, Scopus, and Web of Science. For published manuals, not listed in at least one of
14
15 183 the five databases, we will use Google Scholar. Additionally, all records fulfilling the
16
17 184 inclusion and exclusion criteria of the first search will be transferred and examined in the
18
19 185 second search.
20
21
22
23

24 186 The following inclusion criterion will be used in the second search: (1) studies need to
25
26 187 describe an evaluation of the respective instrument in persons with ID. Exclusion criteria
27
28 188 comprise: (1) the respective instrument was used primarily for other investigations, not related
29
30 189 to an evaluation of the instrument, (2) or the study is a review on assessment instruments, not
31
32 190 providing novel information.
33
34
35

36 191 To further include grey and unpublished literature in both searches, we will apply an invisible
37
38 192 college approach, contacting authors in the field for information or manuscripts on this topic,
39
40 193 and we will follow up on meeting abstracts. Full texts of reviews on assessment instruments
41
42 194 identified in the course of the two searches will be screened for possible further studies to
43
44 195 include. References of papers meeting the inclusion criteria will be hand-searched. We will
45
46 196 re-run both searches before the final analyses to include the most recent publications.
47
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51 197 For study selection, one reviewer will exclude duplicates. All remaining records will be
52
53 198 screened and reviewed for eligibility by two team members independently, i.e. blinded to each
54
55 199 other's decisions. In the case of disagreement, dissonances will be discussed until agreement
56
57 200 is reached. In the case of non-agreement, a third team member will be included in discussion.
58
59
60

201 **Data extraction**

202 The first search will result in a list of instruments. Data extracted will be the names of the
203 instruments and information on their initial publication(s). In the second search, we will
204 extract evaluation data of instruments, i.e. measurement properties and characteristics as listed
205 in the COSMIN checklists and the CAPs-IDD. For each characteristic/property extracted, we
206 will record the study design and sample characteristics, including sample size, gender
207 distribution, age distribution, aetiology of ID, and country (language) in which the instrument
208 was evaluated. We will include all studies, irrespective of their design.

209 The extraction of all relevant data will be done via standardised and piloted excel
210 spreadsheets by two team members independently. In the case of disagreement, dissonances
211 will be discussed until agreement is reached. In the case of non-agreement, a third team
212 member will be included in discussion. If data necessary for coding is missing in a study, we
213 will contact the respective study authors for this information.

214 **Risk of bias and quality assessment**

215 Quality and risk of bias will be assessed on study level (for each measurement property), on
216 outcome level (for each assessment instrument), and on an aggregated outcome level,
217 applying the *Grading of Recommendations, Assessment, Development and Evaluation*
218 (GRADE) approach. We will combine the COSMIN checklists [35–37] with the CAPs-IDD
219 [33], a comprehensive tool specifically developed for the evaluation of assessment
220 instruments for psychiatric disorders in persons with ID. The CAPs-IDD consists of two parts:
221 (1) conceptual and measurement model (including descriptive aspects of instruments, e.g.
222 respondent requirements, theoretical foundation), and (2) psychometric properties. We will
223 only use the first part, as the second part is more comprehensively covered by the COSMIN
224 checklists.

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2
3 225 All ratings will be done by two reviewers independently. In the case of disagreement,
4
5 226 dissonances will be discussed until agreement is reached. In the case of non-agreement, a
6
7 227 third team member will be included in the discussion. Initial interrater agreement will be
8
9 228 determined using percentage agreement, calculated in R.[38]
10
11
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13 229 As to publication bias, we assume that evaluation results not in favour of the respective
14
15 230 instruments are likely to be underreported. This may be partly due to evaluations being
16
17 231 frequently done and published by the developer(s) of the respective instrument. We will
18
19 232 address this by including grey literature and by discussing this aspect in the interpretation of
20
21 233 our results.
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25 234 **Strategy for data synthesis**

26
27 235 A narrative synthesis will be conducted. Assessment instruments will be presented in a table
28
29 236 along with descriptive aspects according to CAPs-IDD, and their measurement properties and
30
31 237 quality ratings according to the COSMIN checklists. Quantitative data pooling will probably
32
33 238 not be possible. This is due to an expected limited number of studies evaluating the same
34
35 239 property (e.g. internal consistency) for an instrument, and an expected heterogeneity in the
36
37 240 population studied (e.g. severity of ID, persons with Down Syndrome vs. persons with ID of
38
39 241 other aetiology). However, if applicable, we will calculate pooled estimates and 95%
40
41 242 confidence intervals using R.[38]
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45

46 243 **Analysis of subgroups**

47
48 244 We define persons with Down Syndrome/trisomy 21 (DS) as a special subgroup, as they are
49
50 245 more often affected by Alzheimer's dementia, with a suspected earlier onset.[16] We will
51
52 246 group instruments according to their intended use, and studies according to their participants
53
54 247 in four clusters: (1) persons with ID, including persons with DS, (2) only persons with DS, (3)
55
56 248 only persons with ID, not including DS, (4) aetiology of ID not specified. For the fourth
57
58 249 cluster, we will contact study authors to determine aetiology of ID in the respective sample or
59
60

1
2
3 250 for the respective instrument. We will then allocate each study or instrument to the first three
4
5 251 clusters according to the information provided by the authors. If no information is provided,
6
7 252 the respective study or instrument remains in cluster four.
8
9

10 253 **Confidence in cumulative evidence**

11
12
13 254 The modified GRADE approach as suggested by the COSMIN guidelines[32] will be applied
14
15 255 to grade the quality of the evidence.
16
17

18 256 **Data management**

19
20 257 We will use ZOTERO for saving records and managing and storing literature, including
21
22
23 258 managing duplicates. For extracting data and recording decisions on quality ratings we will
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25 259 use standardised and piloted excel spreadsheets.
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28 260 **Patient and public involvement**

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30 261 This research was done without patient involvement due to limited resources.
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33 262 **DISCUSSION**

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35 263 This review will summarise measurement properties of available informant-based assessment
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38 264 instruments for persons with ID and give an overview of the quality of each instrument and
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40 265 the quality of available evaluation studies. For each instrument we will depict which
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42 266 psychometric properties are evaluated to what extent, and which properties need further
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44 267 evaluation in future research. This will be the first systematic review of dementia assessment
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46 268 instruments for persons with ID using PRISMA and COSMIN guidelines as well as applying
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48 269 the ID-specific criteria of the CAPs-IDD.
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52 270 Our work will highlight gaps in research on these instruments, thus setting the ground for
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54 271 more effective research in the future. The results of this review will inform researchers and
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56 272 clinicians of the quality of available instruments to assess dementia in persons with ID, and
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58 273 guide them in choosing an adequate instrument. This will hopefully contribute to an
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3 274 improvement of dementia assessment in persons with ID and a better, earlier, and more
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5 275 adequate provision of healthcare services, as demanded by the UN-CRPD.[24]
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8 **276 Ethics and dissemination**
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10 277 No ethics statement is needed for this study. The results of this systematic review will be
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12 278 submitted for publication to a leading peer-reviewed journal, and presented at international
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14 279 conferences and congresses in the fields of ID, ageing, and dementia.
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21 **281 Author's contributions**
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23 282 ELZ conceived the study, drafted the protocol, and is the guarantor of the review. SK, IZ and
24
25 283 FF contributed to study design and drafting the protocol. ELZ, SK, and KW designed and
26
27 284 tested the search strategy. FF and IZ tested quality rating tools and software options. All
28
29 285 authors read and approved the final protocol.
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32

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46 **291 Patient and public involvement**
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48 292 This research was done without patient involvement.
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51 **293 Competing interests**
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53 294 The authors have no competing nor potential conflict interests to declare.
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56 **295 Word Count:** 2,566 words.
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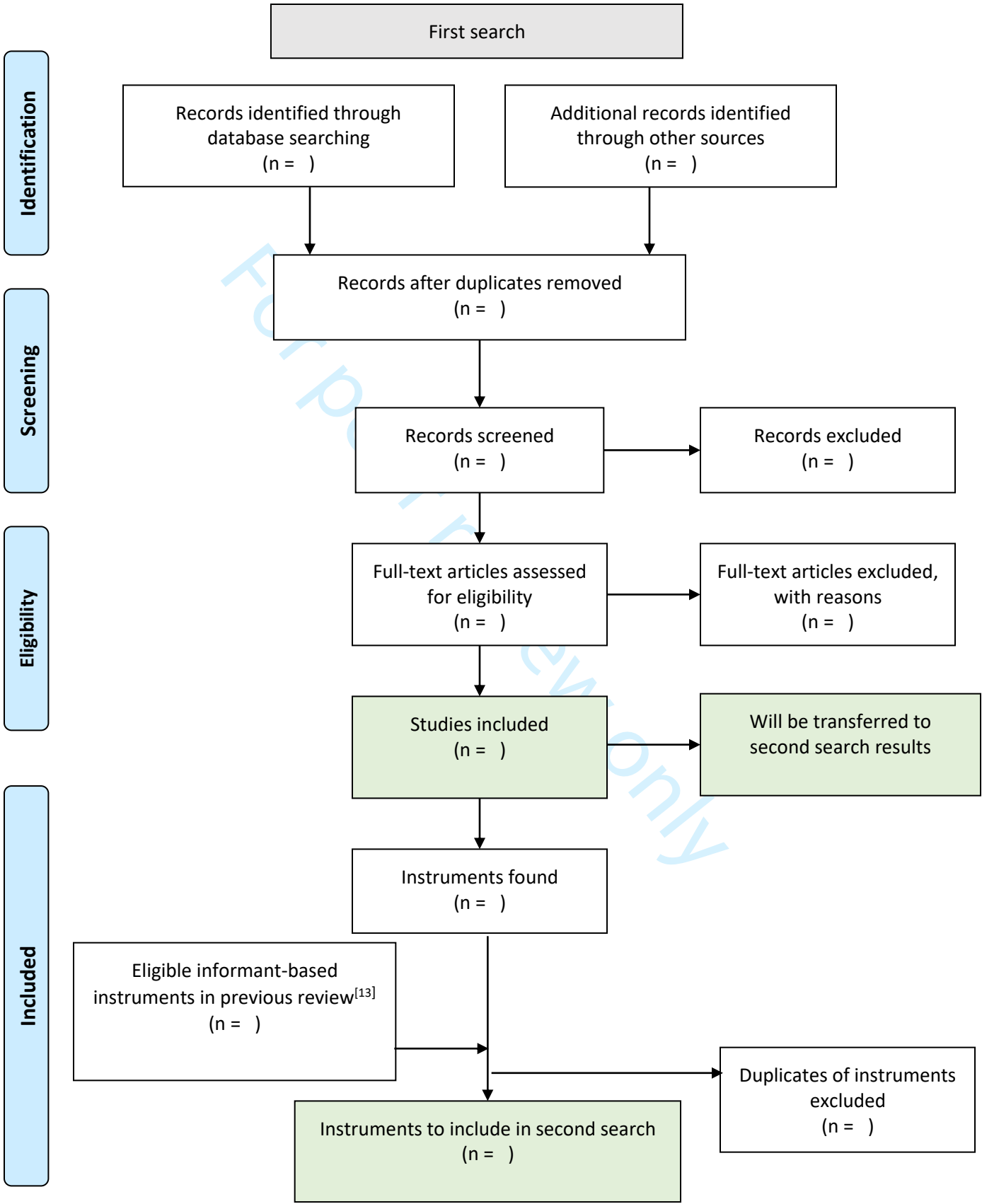
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3 410 **Figure legends**
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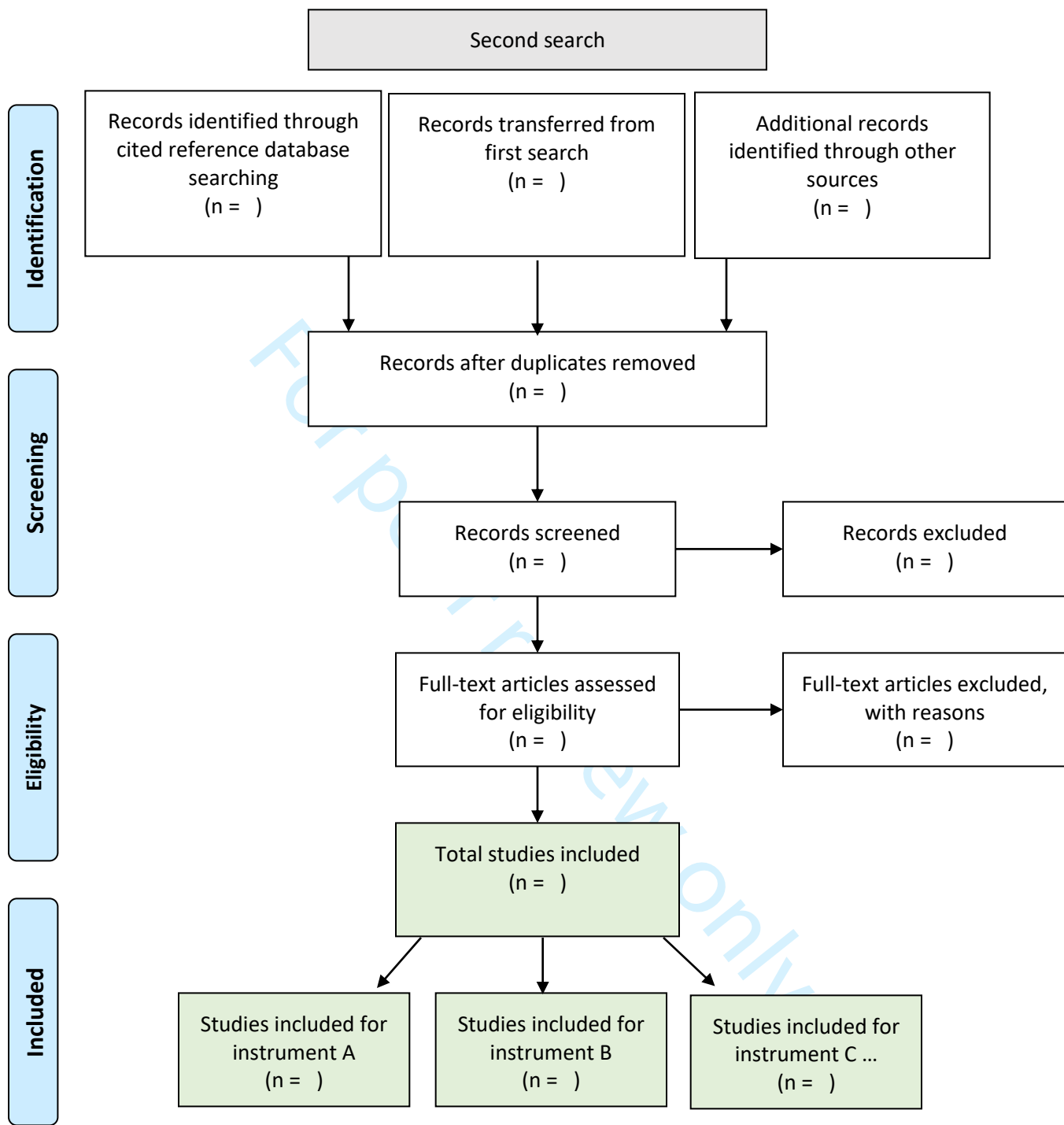
6 411 Figure 1: PRISMA flow chart of first search
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9 412 Figure 2: PRISMA flow chart of second search
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Supplementary information

Informant-based assessment instruments for dementia and their measurement properties in persons with intellectual disability: a systematic review protocol

Detailed search strategy in electronic databases

ASSIA

(via ProQuest)

noft(Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND noft(Dement* OR Alzheimer*) AND noft(((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))

Additional limits: Date: From 2012 to 2020

CINAHL

(via EBSCOhost) (MEDLINE records excluded, since they are already in the MEDLINE Search):

(AB (Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND AB (Dement* OR Alzheimer*) AND AB (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) OR (TI (Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND TI (Dement* OR Alzheimer*) AND TI (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) OR (SU (Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND SU (Dement* OR Alzheimer*) AND SU (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))))

Limiters - Published Date: 20120101-20201231; Exclude MEDLINE records

Cochrane Library

(Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*):ti,ab,kw AND (Dement* OR Alzheimer*):ti,ab,kw AND (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)):ti,ab,kw

with Cochrane Library publication date from Jan 2012 to Dec 2020

ERIC, MEDLINE, and PsycInfo

(via Ovid) [mp=ab, ti, hw, id, tc, ot, tm, mh]

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limit to yr="2012 - 2020"

SCOPUS

TITLE-ABS-KEY ((assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND (dement* OR alzheimer*) AND (((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))) AND PUBYEAR > 2011

Web of Science Core Collection:

TOPIC:(Assess* OR diagnosti* OR screen OR screening* OR instrument* OR tool* OR measure* OR questionnaire* OR psychometr* OR scale* OR interview*) AND

TOPIC:(Dement* OR Alzheimer*) AND

TOPIC:((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)

Timespan: 2012-2020. **Indexes:** SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC.

OpenGrey

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(Dement* OR Alzheimer*) AND

((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*)

ProQuest Dissertations & Theses

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noft(Dement* OR Alzheimer*) AND noft(((intellectual* OR learning) AND disab*) OR (intellectual* AND developmental* AND disorder*) OR trisom* 21 OR (down* AND syndrom*))

Additional limits: Date: From 2012 to 2020

Reporting checklist for protocol of a systematic review.

Based on the PRISMA-P guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the PRISMA-Reporting guidelines, and cite them as:

Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA-P) 2015 statement. Syst Rev. 2015;4(1):1.

			Page	Line
		Reporting Item	Number	Number
Title				
Identification	#1a	Identify the report as a protocol of a systematic review	1	2-3

1	Update	#1b	If the protocol is for an update of a previous	n.a.	
2			systematic review, identify as such		
3					
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6	Registration				
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10		#2	If registered, provide the name of the registry	6	141-142
11			(such as PROSPERO) and registration		
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17	Authors				
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20	Contact	#3a	Provide name, institutional affiliation, e-mail	1	5-20
21			address of all protocol authors; provide		
22			physical mailing address of corresponding		
23			author		
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30	Contribution	#3b	Describe contributions of protocol authors and	13	279-283
31			identify the guarantor of the review		
32					
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35	Amendments				
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39		#4	If the protocol represents an amendment of a	6	142-144
40			previously completed or published protocol,		
41			identify as such and list changes; otherwise,		
42			state plan for documenting important protocol		
43			amendments		
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51	Support				
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54	Sources	#5a	Indicate sources of financial or other support	13	284-286
55			for the review		
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1	Sponsor	#5b	Provide name for the review funder and / or	n.a.	
2			sponsor		
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6	Role of sponsor	#5c	Describe roles of funder(s), sponsor(s), and /	n.a.	
7	or funder		or institution(s), if any, in developing the		
8			protocol		
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14	Introduction				
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17	Rationale	#6	Describe the rationale for the review in the	5-6	105-122
18			context of what is already known		
19					
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21					
22	Objectives	#7	Provide an explicit statement of the	6	126-131
23			question(s) the review will address with		
24			reference to participants, interventions,		
25			comparators, and outcomes (PICO)		
26					
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32	Methods				
33					
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35	Eligibility criteria	#8	Specify the study characteristics (such as	7-8, 9	157-172,
36			PICO, study design, setting, time frame) and		180-188
37			report characteristics (such as years		
38			considered, language, publication status) to		
39			be used as criteria for eligibility for the review		
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48	Information	#9	Describe all intended information sources	7, 9	152-154,
49	sources		(such as electronic databases, contact with		178-181,
50			study authors, trial registers or other grey		189-194
51			literature sources) with planned dates of		
52			coverage		
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1	Search strategy	#10	Present draft of search strategy to be used for	8;	164-165
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4			at least one electronic database, including	supplement	
5					
6			planned limits, such that it could be repeated		
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9	Study records -	#11a	Describe the mechanism(s) that will be used	12	254-257
10					
11	data		to manage records and data throughout the		
12					
13	management		review		
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16	Study records -	#11b	State the process that will be used for	9	195-198
17					
18	selection		selecting studies (such as two independent		
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20	process		reviewers) through each phase of the review		
21					
22			(that is, screening, eligibility and inclusion in		
23					
24			meta-analysis)		
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28	Study records -	#11c	Describe planned method of extracting data	10	207-211
29					
30	data collection		from reports (such as piloting forms, done		
31					
32	process		independently, in duplicate), any processes		
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34			for obtaining and confirming data from		
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41	Data items	#12	List and define all variables for which data will	9-10	199-206
42					
43			be sought (such as PICO items, funding		
44					
45			sources), any pre-planned data assumptions		
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47			and simplifications		
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50	Outcomes and	#13	List and define all outcomes for which data will	n.a.	
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52	prioritization		be sought, including prioritization of main and		
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54			additional outcomes, with rationale		
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1	Risk of bias in	#14	Describe anticipated methods for assessing	10-11	212-231
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3	individual		risk of bias of individual studies, including		
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5	studies		whether this will be done at the outcome or		
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7			study level, or both; state how this information		
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9			will be used in data synthesis		
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13	Data synthesis	#15a	Describe criteria under which study data will	11	235-240
14					
15			be quantitatively synthesised		
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18	Data synthesis	#15b	If data are appropriate for quantitative	n.a.	
19					
20			synthesis, describe planned summary		
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22			measures, methods of handling data and		
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24			methods of combining data from studies,		
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26			including any planned exploration of		
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28			consistency (such as I ² , Kendall's τ)		
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33	Data synthesis	#15c	Describe any proposed additional analyses	n.a.	
34					
35			(such as sensitivity or subgroup analyses,		
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37			meta-regression)		
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41	Data synthesis	#15d	If quantitative synthesis is not appropriate,	11	232-235
42					
43			describe the type of summary planned		
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46	Meta-bias(es)	#16	Specify any planned assessment of meta-	11	227-231
47					
48			bias(es) (such as publication bias across		
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50			studies, selective reporting within studies)		
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1 Confidence in [#17](#) Describe how the strength of the body of 12 251-253
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3 cumulative evidence will be assessed (such as GRADE)
4
5 evidence
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9 None The PRISMA-P checklist is distributed under the terms of the Creative Commons Attribution
10 License CC-BY 4.0. This checklist can be completed online using <https://www.goodreports.org/>, a tool
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12 made by the [EQUATOR Network](#) in collaboration with [Penelope.ai](#)
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