

**Assessing unmet needs in advanced cancer patients:
a systematic review of the development, content, and
quality of available instruments**

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Ben Rimmer*, Dr Lisa Crowe, Dr Adam Todd, Professor Linda Sharp

*Ben.rimmer@newcastle.ac.uk

Background

‘Survival in advanced cancer is increasing’

- Improved diagnosis and effective treatment (Arnold et al., 2019)
- Increasing availability and success of biological and precision therapies (Jackson et al., 2015)
 - Various side effects different to traditional treatments
- Prolonged and uncertain illness trajectory (Pizzoli et al., 2019)

Background

‘Advanced cancer patients have a comprehensive range of unmet needs’


- Needs have been identified for: *physical, psychological, informational, functional, social, activities of daily living (ADL), health care, spiritual, sexual, and economic* (Moghaddam et al., 2016; Wang et al., 2018)
- Needs are associated with symptoms, anxiety, and quality of life (Wang et al., 2018)
- Needs can be contextual, influenced by diagnosis, treatment, and ‘awareness of dying’ (Arantzamendi et al., 2020)

Background

What do we already know?

RESEARCH ARTICLE

Evaluation of psychometric properties of needs assessment tools in cancer patients: A systematic literature review

Lang Tian ¹*, Xiaoyi Cao²*, Xielin Feng¹

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However...

Supportive care needs change across the cancer journey (Okediji et al., 2017)

Rationale

What do we need to know?

We need to understand whether:

- Advanced cancer patients are considered in instrument development
- Needs of advanced cancer patients are captured
- Instrument performance is reliable in advanced cancer populations
- Any existing instruments are targeted to advanced cancer

Aims and objectives

What instruments are available to measure unmet needs in advanced cancer patients and what is their quality?

Objectives – to establish:

1. Available instruments
2. Instrument development
3. Instrument content
4. Clinimetric properties

Search strategy

Searched: MEDLINE, Embase, PsycINFO, CINAHL, PubMed and forward/backward citations of relevant articles – inception to January 2021

**Key
concepts:**

- Cancer
- Advanced disease
- Needs
- Instrument

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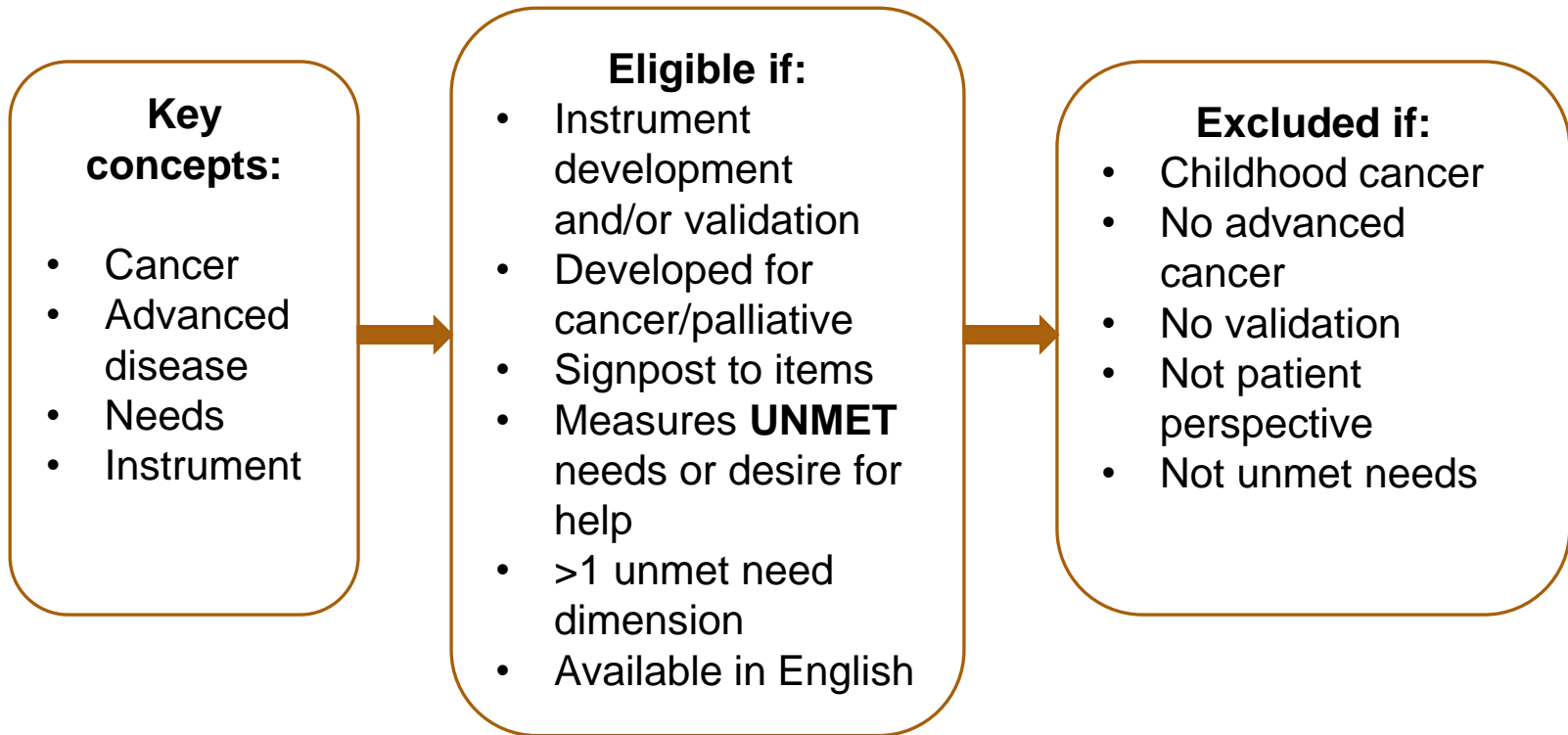


Eligible if:

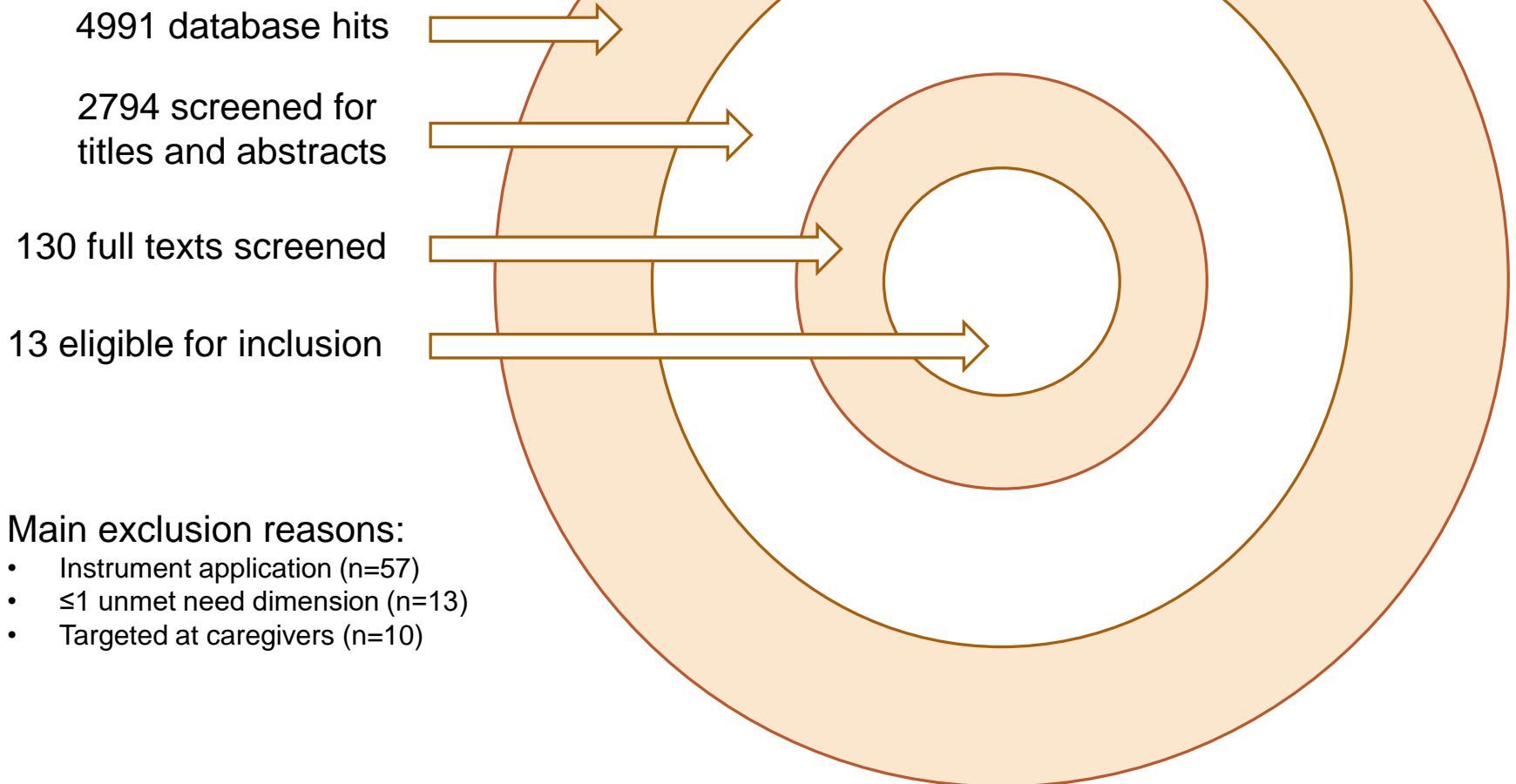
- Instrument development and/or validation
- Developed for cancer/palliative
- Signpost to items
- Measures **UNMET** needs or desire for help
- >1 unmet need dimension
- Available in English

Search strategy

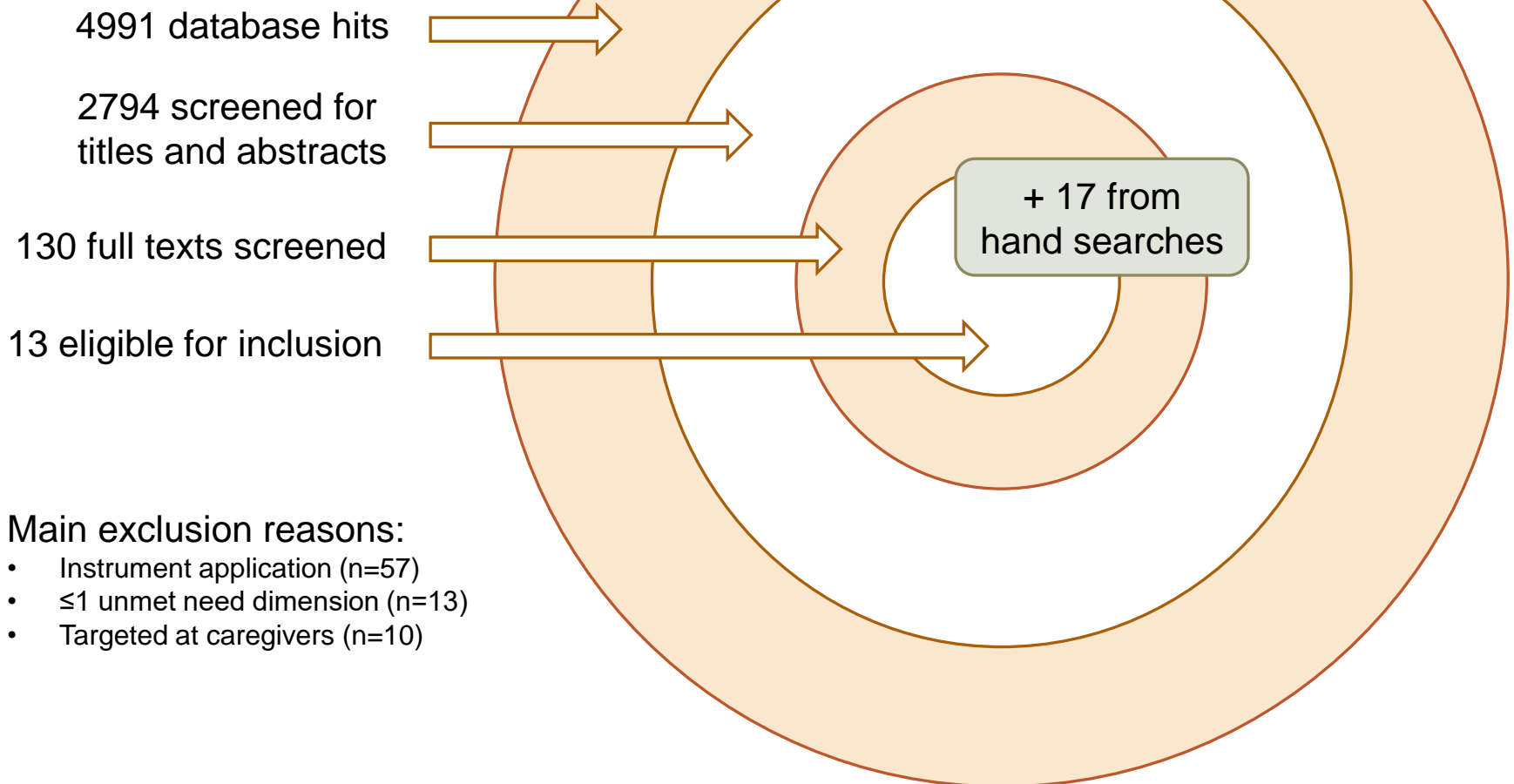
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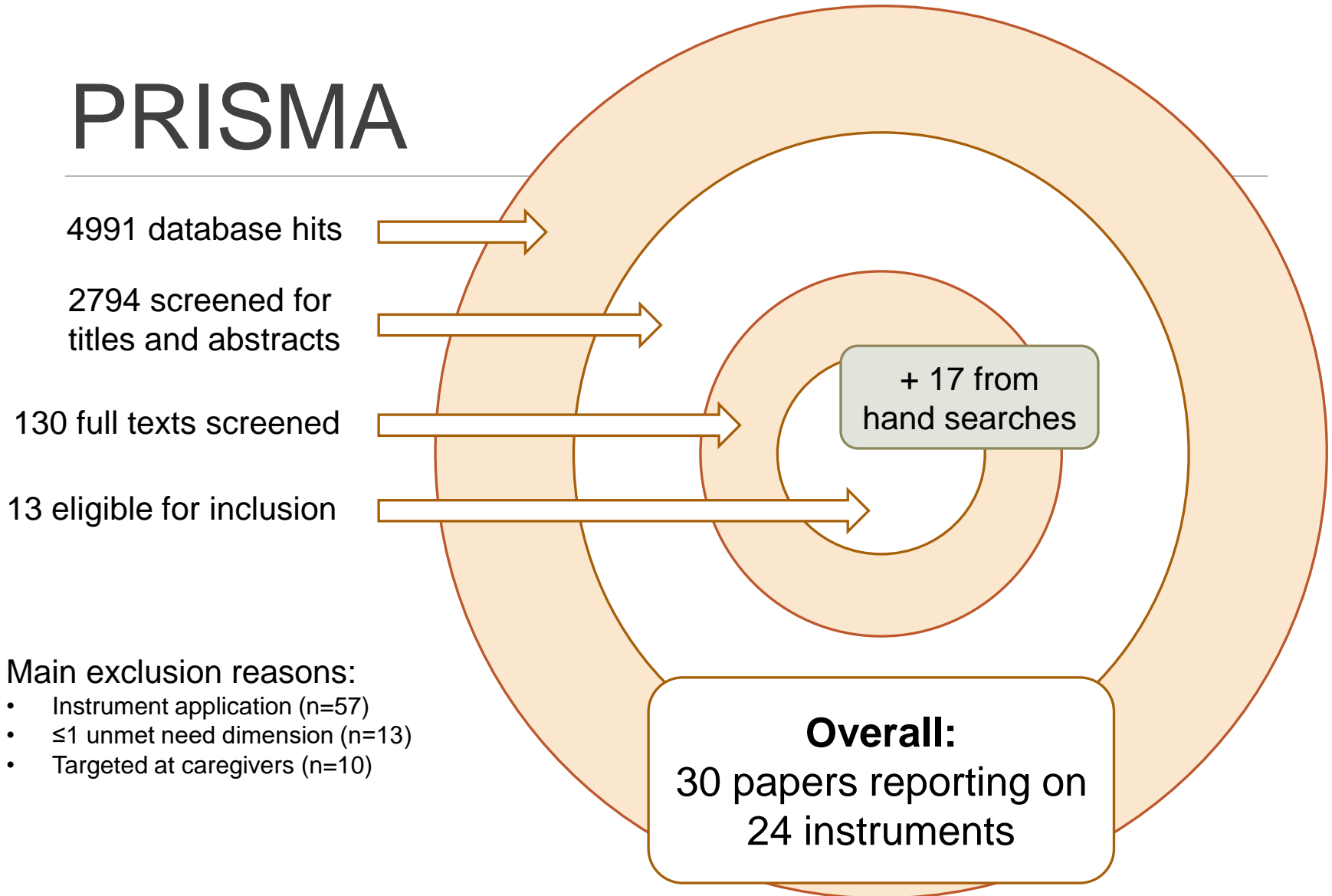
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PRISMA



Available instruments

24 unmet needs instruments

General palliative:

- *PNAP*
- *SPARC*

Advanced cancer:

- *NA-ACP*
- *NA-ALCP*
- *PNPC*
- *PNPC-sv*
- *SPEED*
- *3LNQ*
- *Ndiok*
- *PCNA-EAV*

All stages of cancer:

- *CaNDI*
- *CNAT*
- *PNI*
- *eHNA*
- *SCNS-SF34; LF-59; ST-9*
- *SCNAT-IP*
- *NEQ*
- *CNQ-sf*
- *CSS-25*
- *BCNAS-32*
- *PCNQ V2*
- *YYFcore03*

Characteristics

- **Length:** 9 to 138 items instrument length
- **Mode of administration:** self (17), interviewer (6)
- **Completion time:** 5 to 76 minutes
- **Recall period:** Last month (7), week (2), present day (2)
- **Scores:** Subscales (14), individual items (12), total (6), >1 (8)
- **Response formats:** Continuous (14) and dichotomous (4) scales used to indicate problem and need for help; combination of the two (6)

8 instruments available in languages other than English, mostly Chinese

Mainly developed in Australia (8), USA (5), UK (3) and Netherlands (2)

Development

Item generation (>1 : $n=16$)

- Existing instrument ($n=11$)
- Literature ($n=10$)
- Review of content of existing instruments ($n=6$)
- Health professional interviews ($n=5$)

- Patient discussions ($n=11$)
- Expert review ($n=9$)

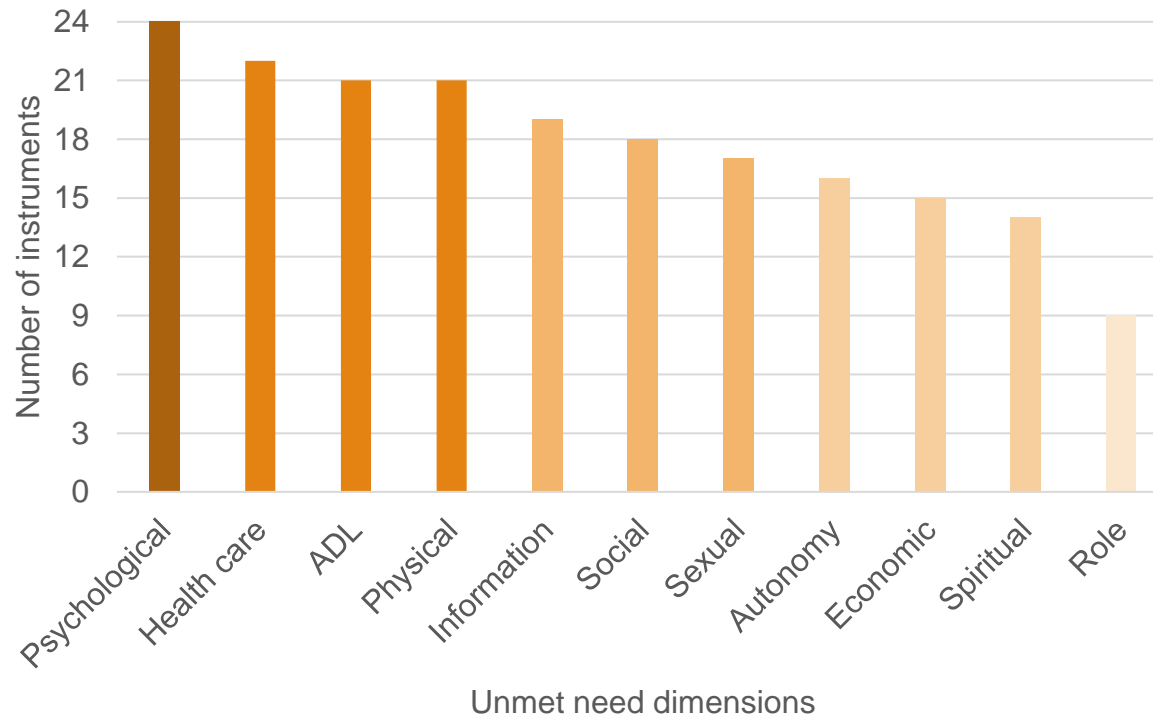
Item reduction ($n=17$; >1 : $n=11$)

- Factor analysis ($n=8$)
- Item-response frequencies ($n=6$)
- Test-retest reliability ($n=2$)

Content

Most comprehensive: *PNPC, PNI (11 dimensions), CaNDI (10 dimensions)*

Least comprehensive: *SPEED (5 dimensions), SCNS ST-9, BCNAS-32, PCNQ V2 (6 dimensions)*



COSMIN

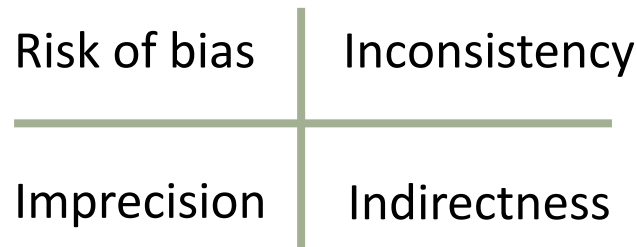
COnsensus-based Standards for the selection of health Measurement Instruments (COSMIN)

- We assessed seven clinimetric properties using the COSMIN checklist (Mokkink et al., 2018) and **GRADE** (Prinsen et al., 2018).
- 3-35 items for each property, worst score counts.

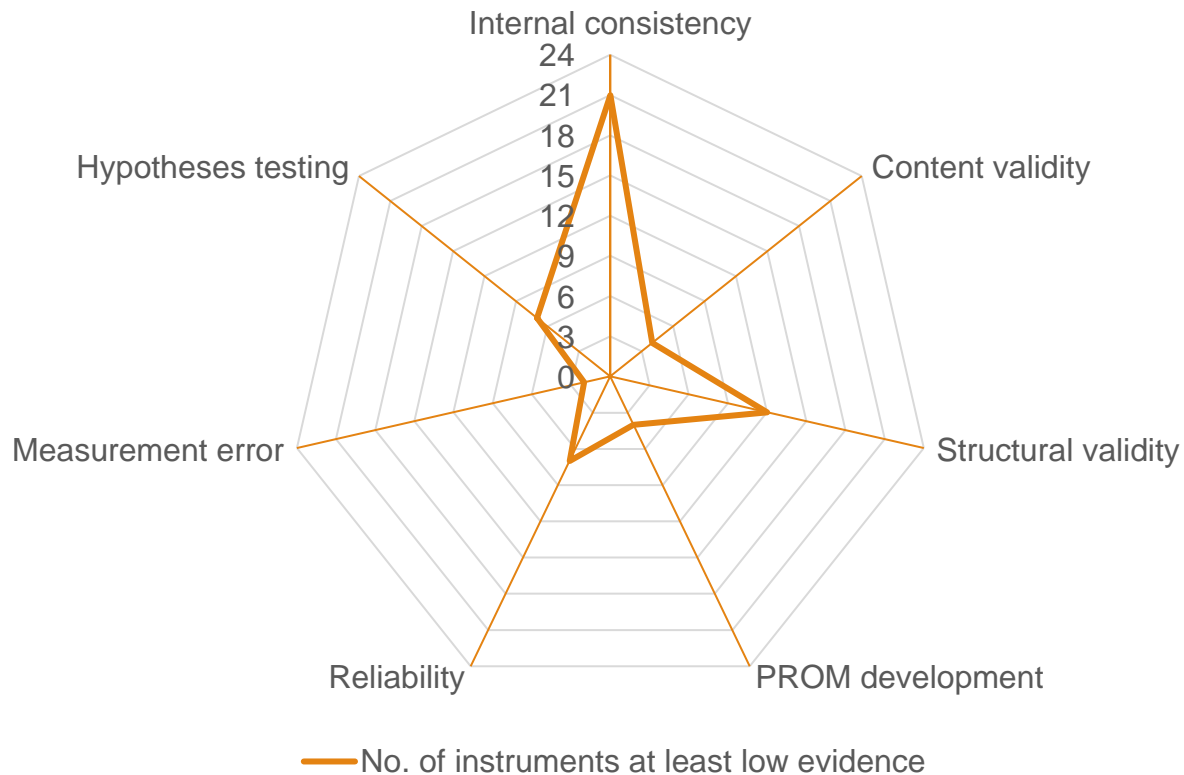
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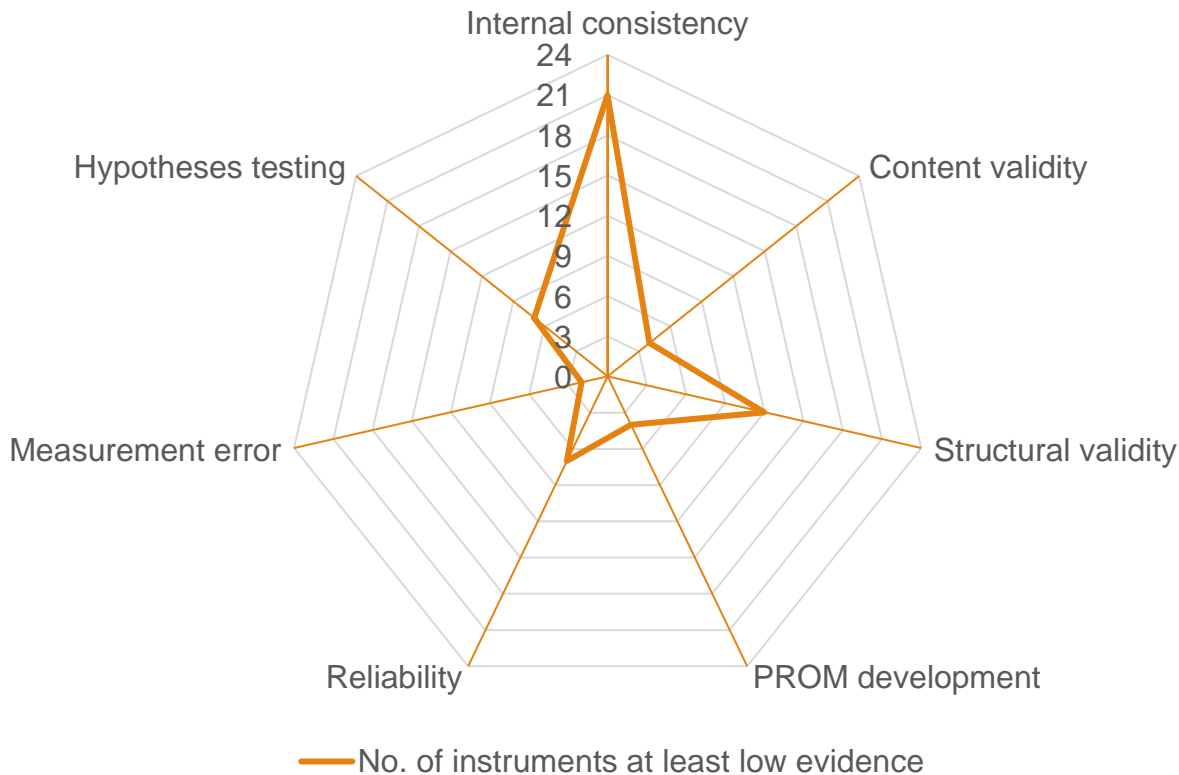
- We assessed seven clinimetric properties using the COSMIN checklist (Mokkink et al., 2018) and GRADE (Prinsen et al., 2018).
- 3-35 items for each property, worst score counts.
- Evidence is downgraded in accordance with the four aspects of GRADE:



Clinimetric properties



Clinimetric properties

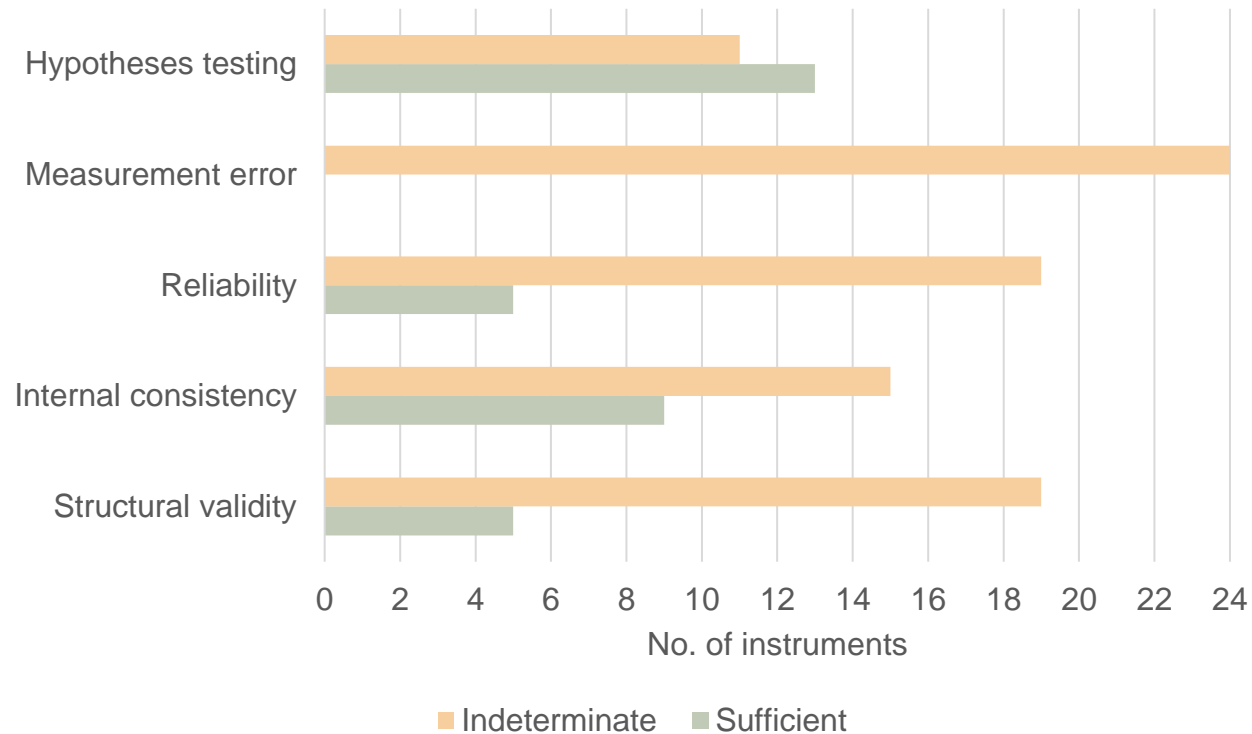


Methodological quality highlights

- High evidence on any property: *NA-ACP* and *NA-ALCP* (*internal consistency*)
- Strongest overall: *CSS-25* (*4 moderate evidence properties*)
- Runners up: *SCNS-SF34* and *CNAT* (*3 moderate evidence properties*)

Clinimetric properties

Quality was assessed for five properties, using the criteria in the COSMIN manual (Mokkink et al., 2018).



Feasibility

- **Patient comprehensibility:** Varying favourable levels (n=12)
- **Standardisation:** Formula available (n=4)
- **Access:** In paper (n=11), appendices (n=6), or downloadable online (n=3)
- **Cost:** Free to access (n=10)
- **Equipment:** Pen and paper (n=19) or touchscreen computer (n=7); available in multiple formats (n=5)
- **Setting:** Clinical (n=24), research (n=16)

Interpretability

- **Distribution of scores in the study population:** Through mean (SD), frequencies, median and range (n=16)
- **Percentage of missing items:** Through each individual item or sample that missed ≥ 1 item (n=9)
- **Floor and ceiling effects:** not observed or were addressed (n=4), both effects (CNAT)
- **Scores available for relevant subgroups:** Such as gender, age, treatment and cancer type (n=8)

Summary of findings

Development

- 10 instruments included patients in their item development.
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- Psychological, healthcare, ADL, and physical dimensions were most commonly measured.

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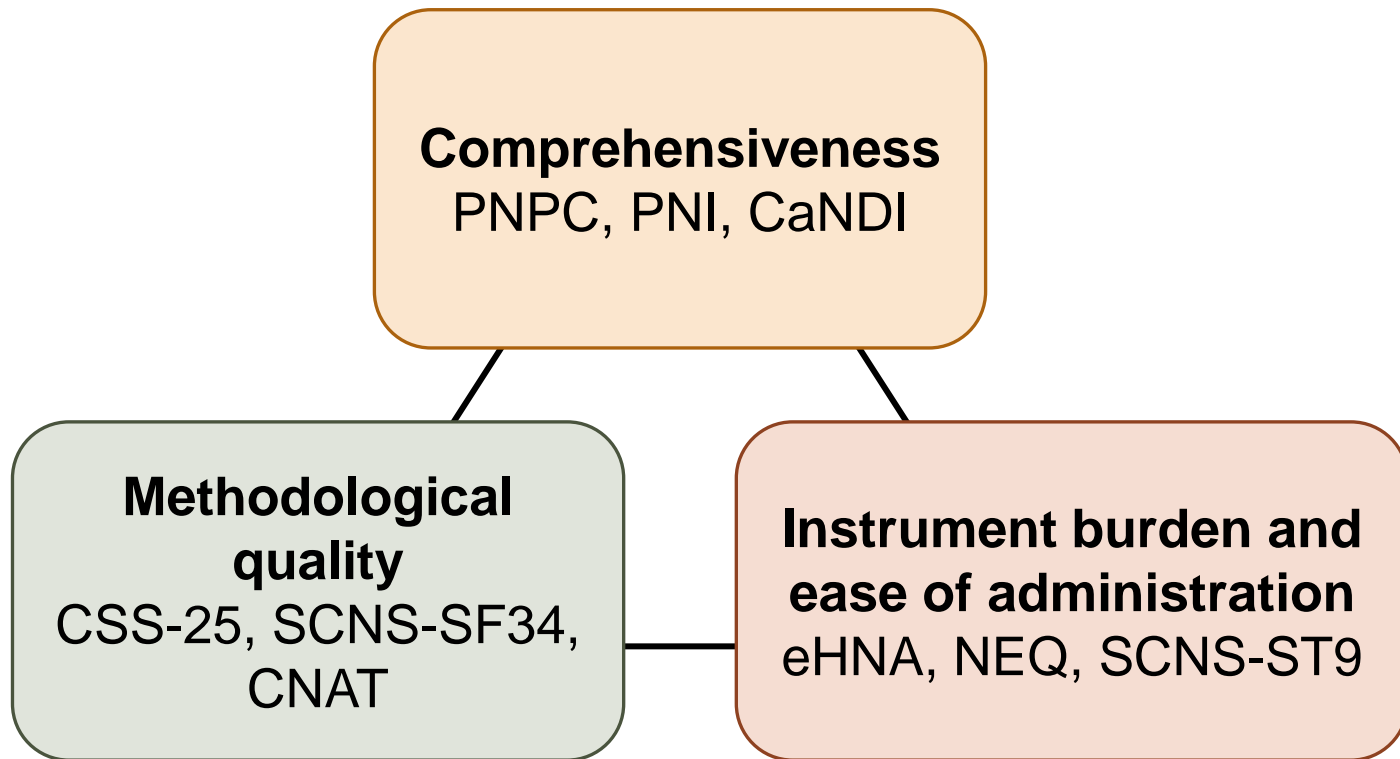
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- Psychological, healthcare, ADL, and physical dimensions were most commonly measured.

Quality

- Only CSS-25, CNAT, SCNS-SF34 had at least moderate evidence for ≥ 3 properties.
- Strongest evidence for internal consistency; other properties generally poor.

Recommendations



Clinical implications

‘Appropriate instrument selection is essential for effective supportive care’

- Clinicians and researchers must consider what is important:

Comprehensiveness

Instrument burden

Methodological quality

Ease of administration

- More robust instrument are needed - selection should be based on instrument characteristics, without sacrificing methodological quality
- Needs assessments should lead to supportive care that is consistent with patient needs (Ahmed et al., 2015)

Future research

How do instruments perform in patients treated by biological and precision therapies?

- Are the needs of those treated by these therapies captured?
- Given different symptom burden, this needs explored

Future research

Improved reporting in accordance with COSMIN

- Insufficient methodological detail – word limits and deemed importance
- Use supplementary material to provide additional detail
- A COSMIN study design checklist has been established (Mokkink et al., 2019)

Strengths and limitations

Strengths:

- Thorough search, inclusive of advanced disease palliative literature
 - *Included 11 instruments omitted by Tian et al. (2019)*
- Evaluation of instrument development and content
 - *Detailed understanding of variability between instruments*

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Limitations:

- We did not translate
 - *May have missed a study not published in English*
- Only assessed English versions of instruments
 - *Additional language validations may have influenced GRADE*

Conclusions

- 24 instruments available to measure unmet needs in advanced cancer patients
- Extensive heterogeneity in their development, content, and quality
- Most not developed specifically for advanced cancer
- Changing approach to advanced cancer – are these instruments an accurate assessment?

Thank you for listening

Any questions, please contact: ben.rimmer@newcastle.ac.uk

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