BEAT CKD

BETTER EVIDENCE AND TRANSLATION IN CHRONIC KIDNEY DISEASE

Systematic review of research priority setting in kidney disease

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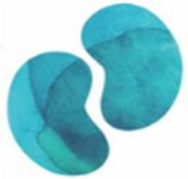
Background

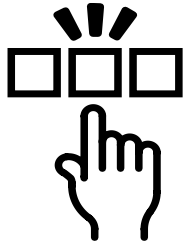
Why is research prioritisation important?

- Kidney disease affects millions of people worldwide with rising prevalence.
- Research prioritisation is crucial for directing limited resources to pressing issues.
- Incorporating diverse stakeholder perspectives is essential to align research with real-world needs



Methods

Selection criteria:

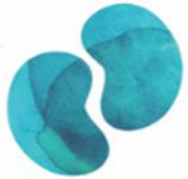


- Studies explicitly aiming to identify kidney disease research priorities.
- Focusing on AKI and all CKD stages (1-5, 5D, 5T).
- Databases: MEDLINE, EMBASE, PsycINFO, CINAHL, Google Scholar, JLA.

Synthesis:

- Categorisation by disease type/stage and **research domains***.

**Etiology, diagnosis, primary prevention, secondary prevention, treatment, prognosis, health services, psychosocial and education, and economic considerations.*



Methods

All included studies were independently appraised using REPRISE.

Reporting Guideline for Priority Setting of Health Research (REPRISE)

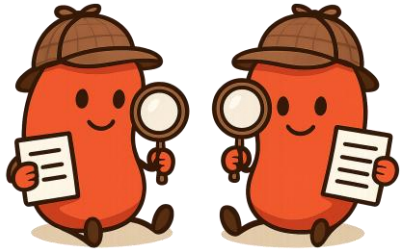
Reporting guideline provided for? (i.e. exactly what the authors state in the paper)	Reporting research priority setting studies.

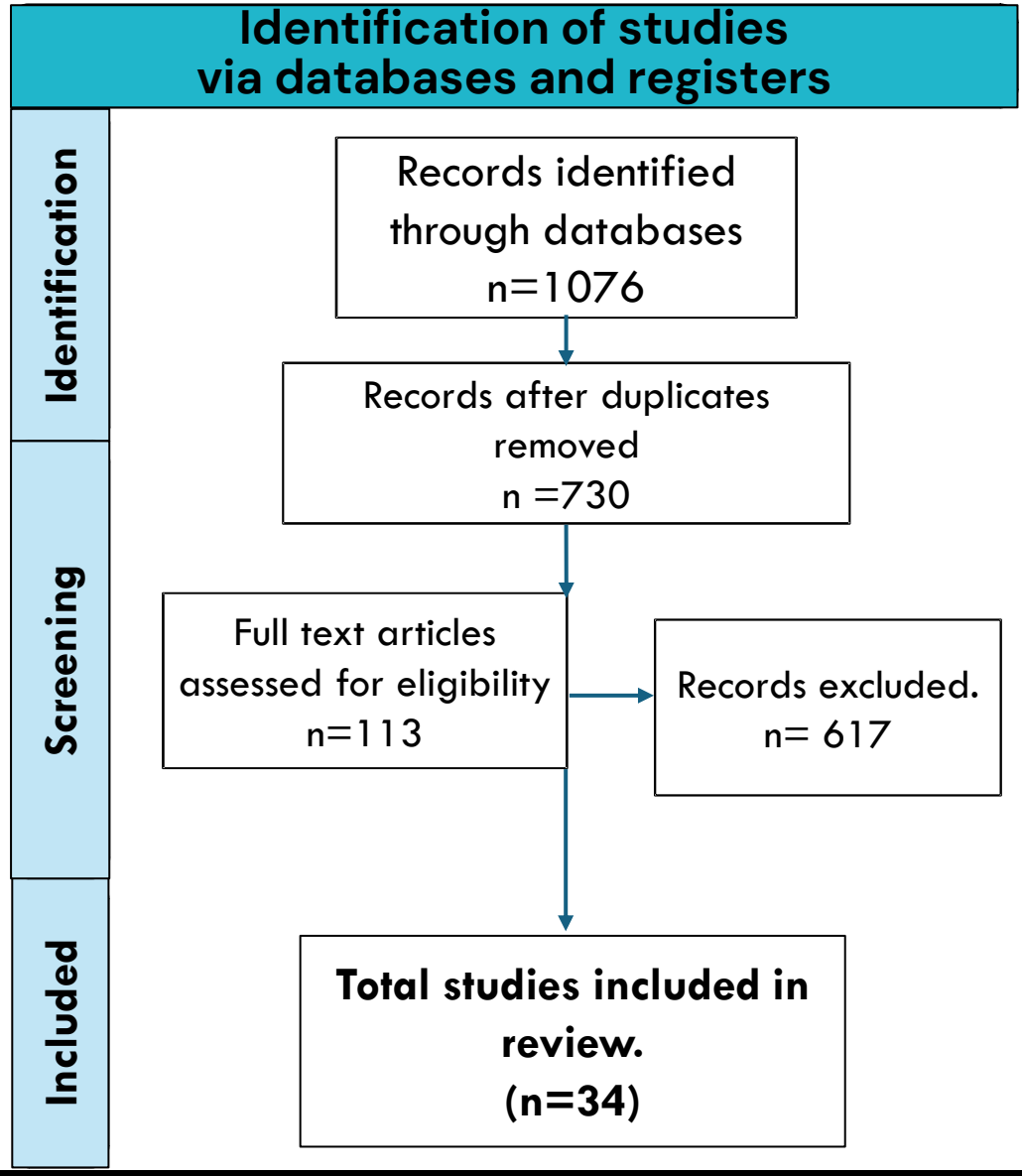
REPRISE contains 10 domains of good practice in research priority setting studies, with 31 total items evaluating the comprehensiveness and quality of reporting.

Results

Systematic search results:

- **34** studies were included
  (inception to Jan 20th 2025).
  - **18** (53%) of studies were published in the last 10 years.





Results

Research topics across stages

Acute kidney injury (n=**7**).
Chronic kidney disease (n=**20**).
Dialysis (n=**12**).
Transplantation (n=**9**).

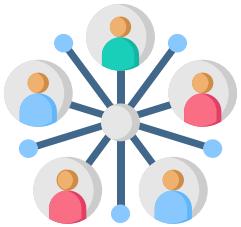
**Nine studies had mixed kidney disease priorities(included in numbers above)*

Participants

3,659 participants across 25 studies^.

^Nine studies did not report numbers.

Results

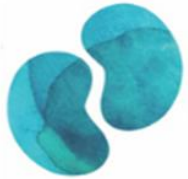


Twenty studies (59%) reported patient and/or caregiver involvement.

- 752 consumers identified across all studies.
  - *(504 patients, 82 caregivers, 166 not clearly specified/other category).*

Most studies provided a balance between professional expertise and lived experience perspectives.

- Trend toward increased consumer involvement between 2015-2025.
- Limited reporting on consumer compensation (only 15% of studies mentioned reimbursement).



Results

(Research Priority Matrix)

Research Domain	CKD (n =20)	Dialysis (n=12)	Transplantation (n=9)
Etiology	6+5 (11)	2+2 (4)	1+1 (2)
Diagnosis	3+6 (9)	0+3 (3)	2+2 (4)
Primary prevention	2+5 (7)	1+2 (3)	0+2 (2)
Secondary Prevention	7+7 (14)	0+3 (3)	0+3 (3)
Treatment	6+8 (14)	4+4 (8)	4+3 (7)
Prognosis	1+5 (6)	0+3 (3)	0+2 (2)
Health Services	2+9 (11)	2+6 (8)	3+4 (7)
Psychosocial and education	2+9 (11)	1+3 (4)	1+4 (5)
Economic	1+3 (4)	0+2(2)	0+1 (1)

= Increased priority domain (<10 years)

= Consistent priority domain (all years)

Results
(REPRISE Appraisal)

Strengths across studies:

- 82% detailed the priority-setting process methodology.
- 62% described methods for identifying and engaging stakeholders.

Common gaps:

- Only 15% outlined implementation/ plans for priorities.
- 41% explicitly stated using a recognized framework (e.g., JLA-PSP, CHNRI, COHRED).

Conclusion

- Treatment and health services are high priorities across all disease modalities.
    - *A recent shift toward patient-centered outcomes and psychosocial and education aspects*.
- Patient and caregiver engagement has increased but remains inconsistent (and often without remuneration).

Future Recommendations

- Increase transparency in methodology and reporting.
- Ensure diverse representation, especially underserved populations.
- Establish feedback loops to assess impact on patient outcomes.
- Connect priorities directly to funding mechanisms.

THANK YOU

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References

- Tong, A., Synnot, A., Crowe, S., Hill, S., et al. (2019). Reporting guideline for priority setting of health research (REPRISE). BMC Medical Research Methodology, 19, 243. https://doi.org/10.1186/s12874-019-0889-3
- National Institute for Health and Care Research, James Lind Alliance. (2021, March). The James Lind Alliance Guidebook (Version 10). https://www.jla.nihr.ac.uk/jla-guidebook/
- Barnieh, L., Jun, M., Laupacis, A., Manns, B. J., & Hemmelgarn, B. R. (2017). Determining the research priorities for patients with chronic kidney disease not on dialysis: A James Lind Alliance partnership. Nephrology Dialysis Transplantation, 32(5), 847–854. https://doi.org/10.1093/ndt/gfw065
- Bello, A. K., Abu-Alfa, A. K., et al. (2024). [The Lancet Global Health, 12(3), e382–e395. https://doi.org/10.1016/S2214-109X(23)00570-3Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. Annals of Internal Medicine, 151(4), 264–269. https://doi.org/10.7326/0003-4819-151-4-200908180-00135
- Graves, R. S. (2002). Users' guides to the medical literature: A manual for evidence-based clinical practice [Review of the book Users' guides to the medical literature: A manual for evidence-based clinical practice, by G. Guyatt & D. Rennie (Eds.)]. Journal of the Medical Library Association, 90(4), 483.
- Tong, A., Chando, S., Crowe, S., et al. (2015). Research priority setting in kidney disease: A systematic review. American Journal of Kidney Diseases, 65(5), 674–683. https://doi.org/10.1053/j.ajkd.2014.11.01
- Manns, B. J., Hemmelgarn, B. R., Lillie, E., Crowe, S., Cyr, A., Gladish, M., et al. (2014). Setting research priorities for patients on or nearing dialysis. Clinical Journal of the American Society of Nephrology, 9(10), 1813–1821. https://doi.org/10.2215/CJN.01610214