

Patient, family/caregiver and other knowledge user engagement in Learning Health Systems: A scoping review

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Background/Rationale

- Holland Bloorview is implementing a Learning Health System (LHS)
- The engagement of patients, families/caregivers and other knowledge users (KUs) is a key principle of LHSs^{1,2,3}
- KU engagement in LHSs is inconsistently described and poorly understood^{2,4}



Objective

To map and describe the literature on LHSs that have engaged patients, families/caregivers, and other KUs.

Method

We are conducting a scoping review, in line with JBI guidance.

Six databases were searched: MEDLINE, Embase, CINAHL, PsycINFO, Healthstar, and Web of Science. Backward searching of key sources was performed.

Sources were screened independently and in duplicate by five team members against the criteria:

✓

Describes the engagement of patients, families, or other KUs in an LHS across any healthcare setting

✓

Empirical studies, case studies, program descriptions, reports, and commentaries with concrete examples

✓

Published 2006 or later

LHSs can use **best practices and approaches** identified in the review to inform **meaningful engagement of patients, families/caregivers, and other knowledge users** across the LHS cycle.

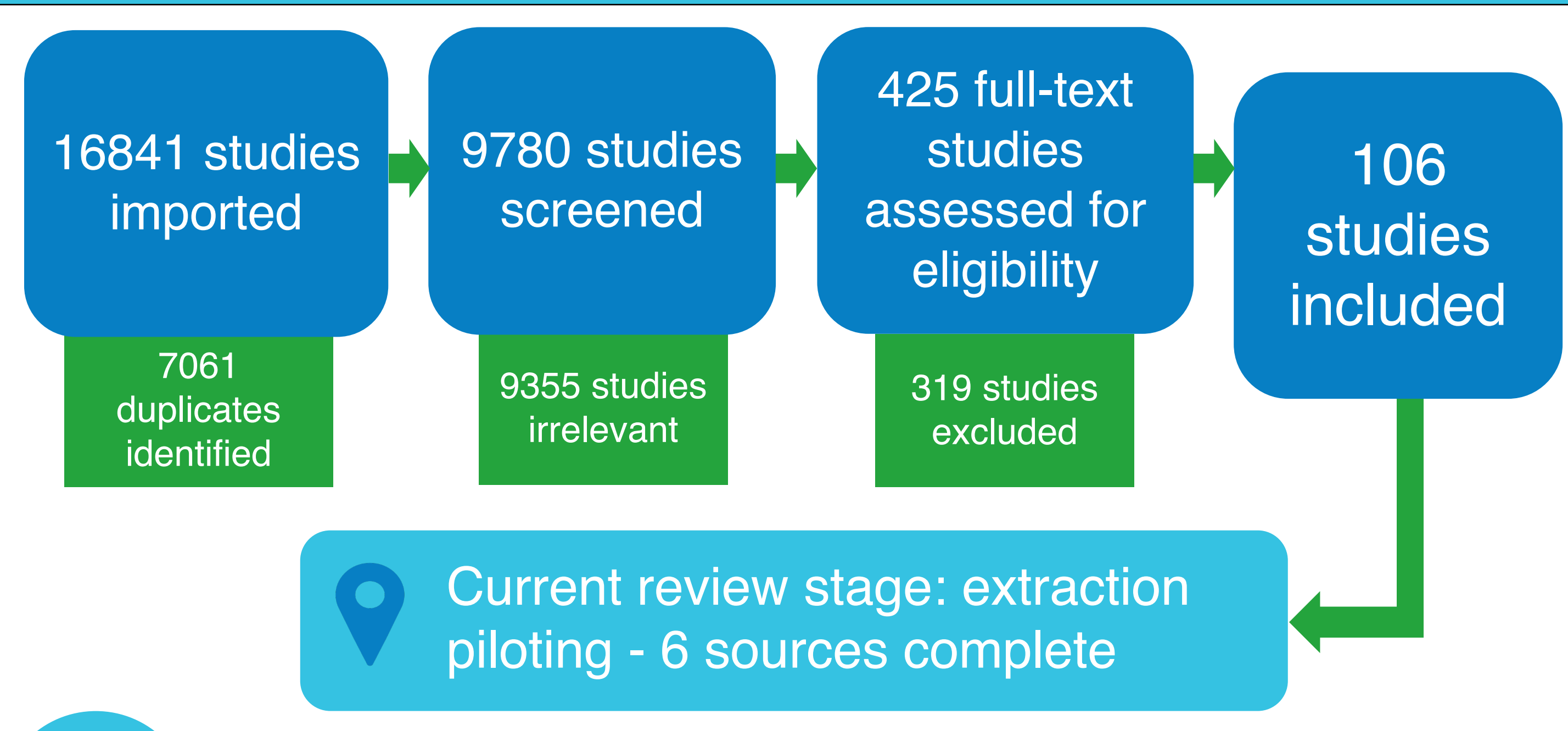


At **Holland Bloorview**, this could help ensure that all LHS efforts are led by children and youth with disabilities and their families.

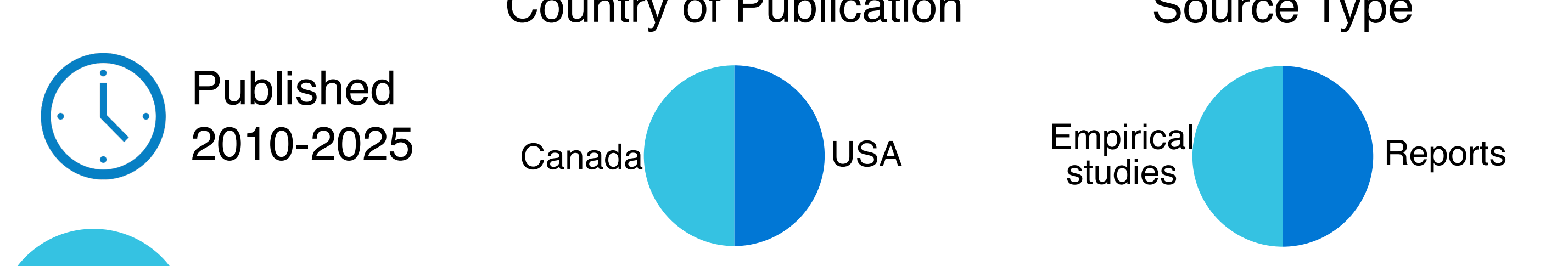


Scan for references & strategic report

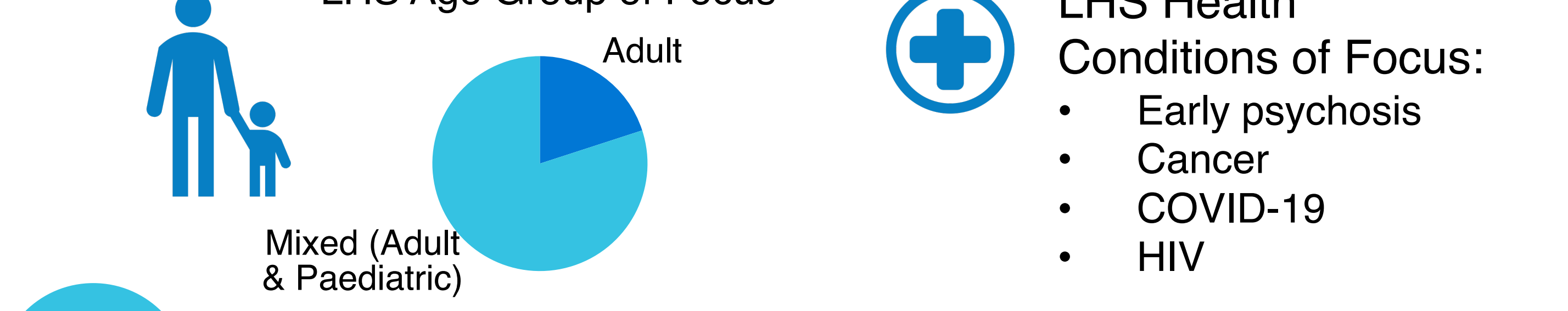
Preliminary Results



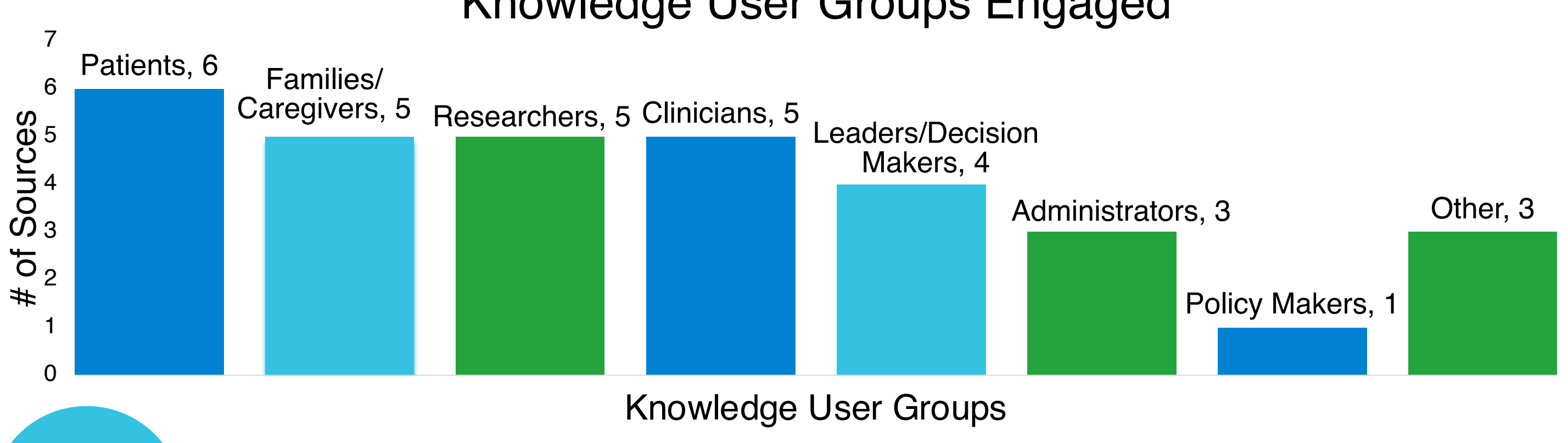
What types of sources were included?



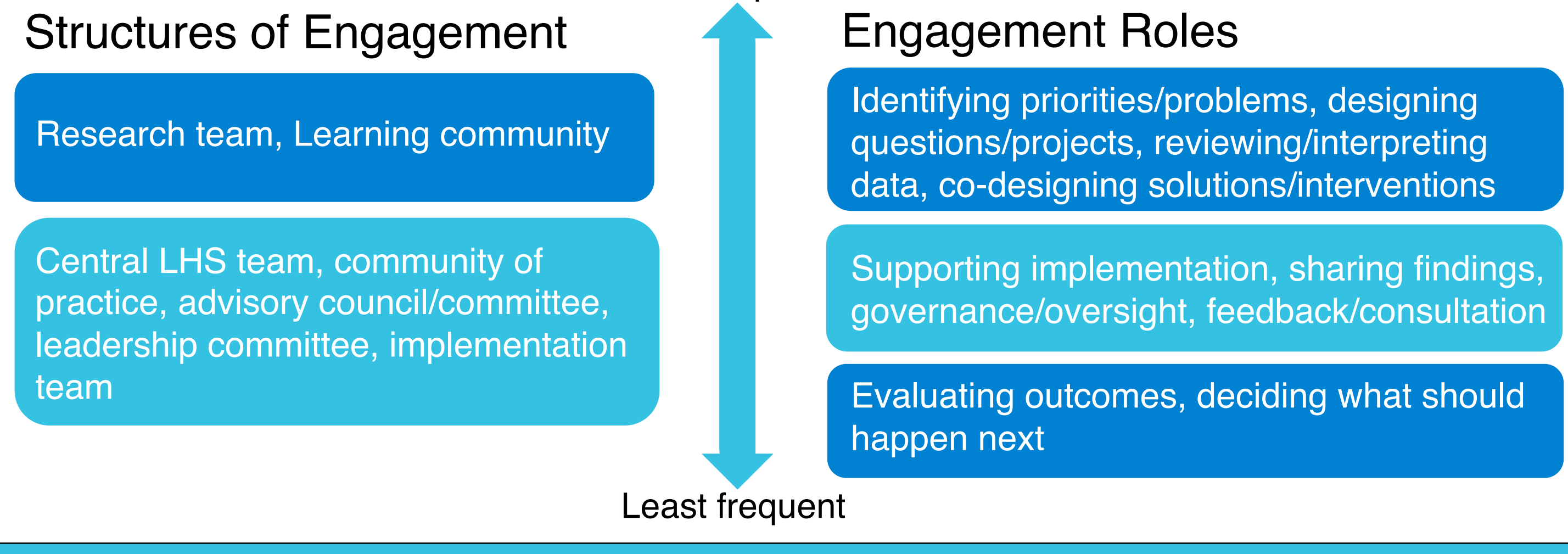
What LHS contexts reported engagement?



Who was engaged?



What did engagement look like?



Discussion

Results can help identify:

- Best practices for engagement in LHSs
- Gaps that persist in LHS engagement

Acknowledgements

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