

Current Practices in Mental Health Screening for Patients with Primary Ciliary Dyskinesia (PCD) Among the PCD Foundation Clinical and Research Centers Network

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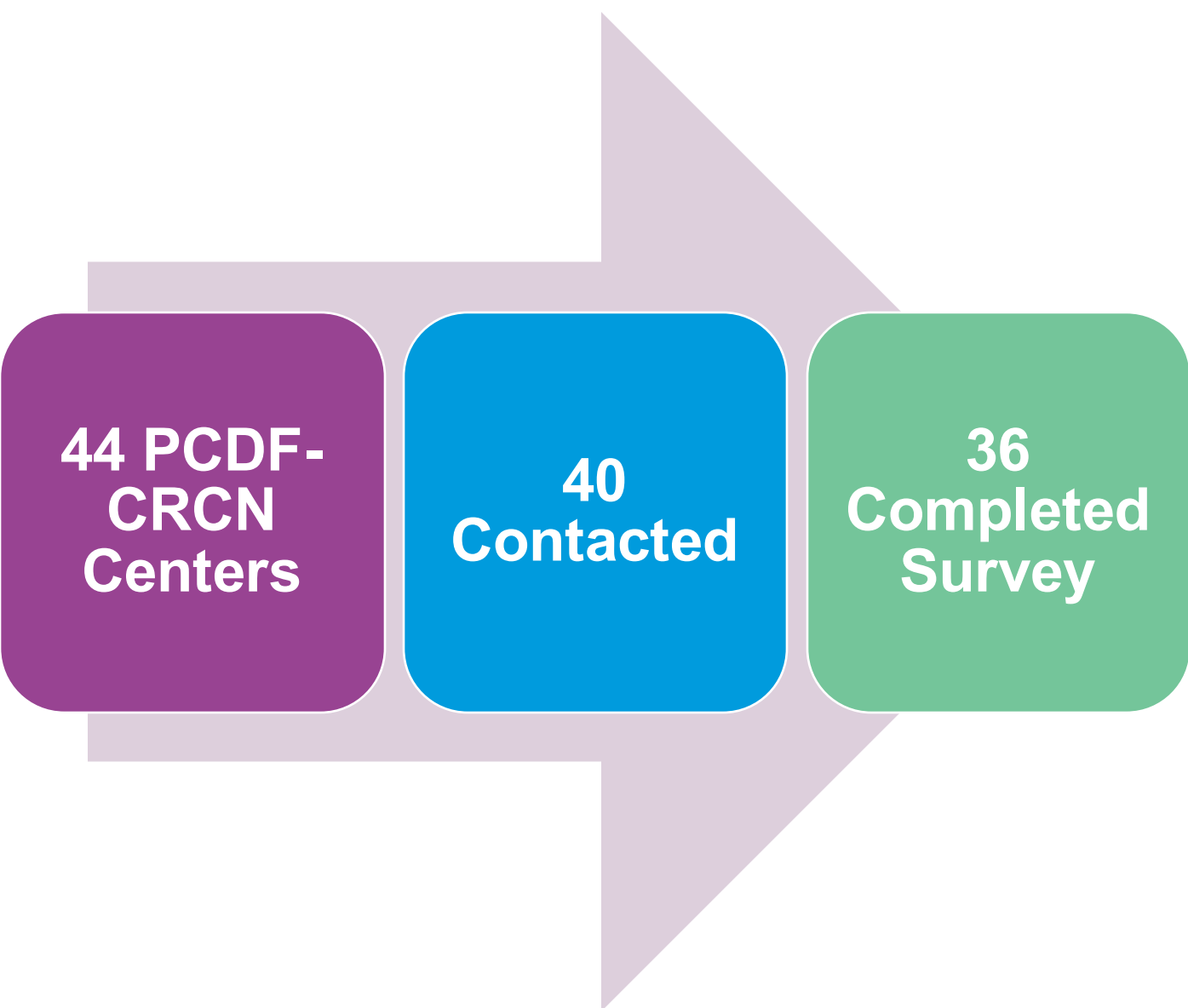
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Background

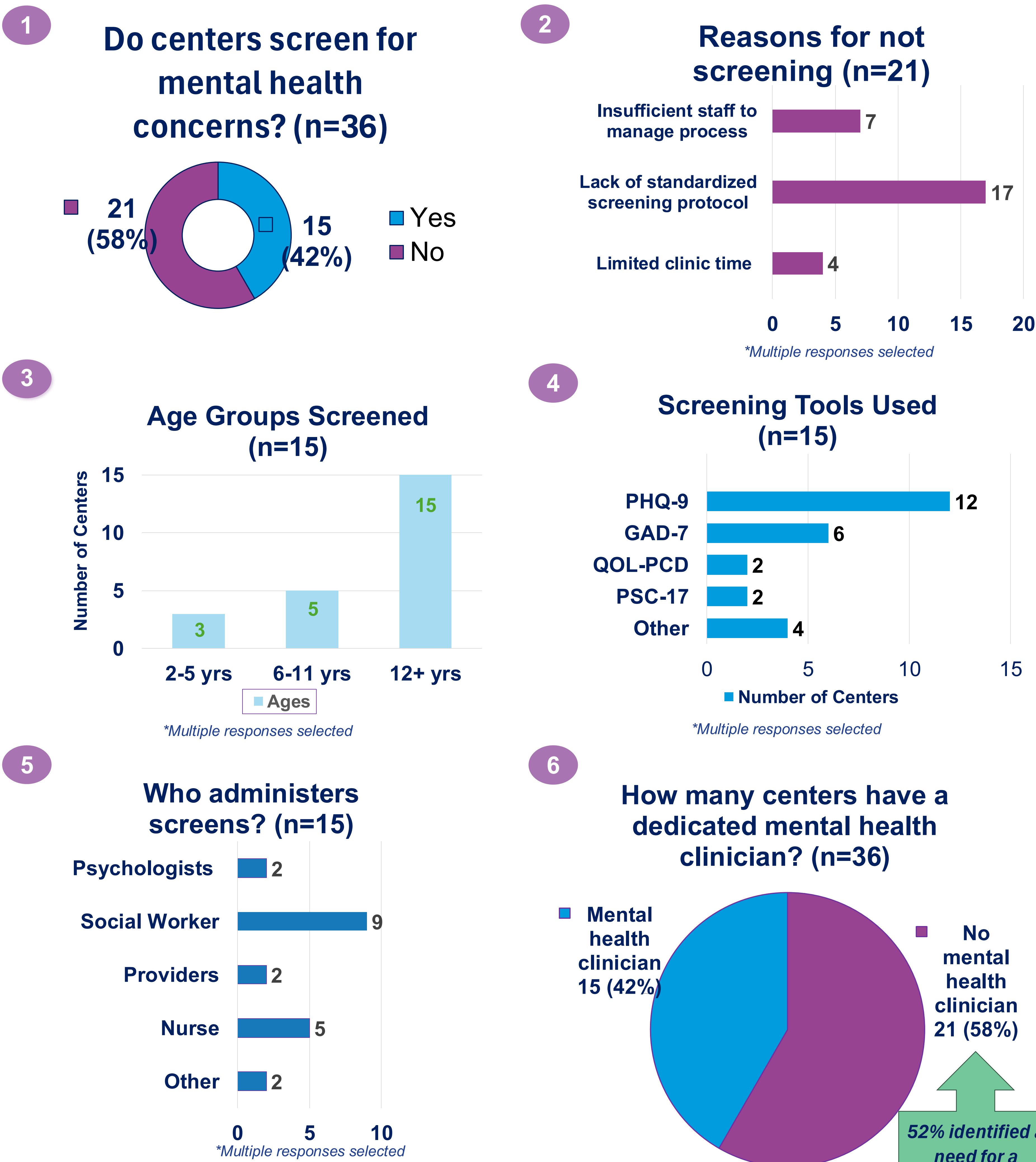
- Primary ciliary dyskinesia (PCD) is a chronic, respiratory condition with psychological comorbidity.
- Previous research has identified elevated levels of anxiety and depression among individuals with PCD and their caregivers, which are negatively associated with health-related quality of life (HRQoL)¹⁻³.
- Among the PCD Foundation Clinical and Research Centers Network (PCDF-CRCN), there is no standardized guideline for the screening, evaluation, and treatment of mental health in individuals with PCD and their caregivers.⁴
- To better understand current mental health screening practices occurring at PCDF-CRCN sites, a survey was distributed to all centers.

Methods

- PCDF-CRCN centers were invited to complete a survey regarding mental health screening practices of people with PCD.
- Of the 44 centers in the PCDF-CRCN, 40 were successfully contacted, with 36 (90%) centers completing the survey.



Results



Figures 1–6. Summary of mental health screening practices among PCDF-CRCN centers.

Conclusions

- The survey results revealed variability in mental health practices among PCDF-CRCN centers with only 15 of the 36 respondents screening for mental health, largely in part due to no standardized screening protocol, lack of mental health clinician to manage process, and limited clinic time.
- Current practices reveal gaps in screening children under 12 with PCD, particularly for anxiety, potentially delaying early intervention and increasing the risk of progression to depression.
- Standardization of mental health screening and assessment guidelines across the PCDF-CRCN could improve overall HRQoL and disease outcomes.

Future Directions

- Future directions should include standardized mental health screening and assessment guidelines for the treatment of PCD.

References

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