

Current Practices in Sinus Rinse/Nasal Irrigation for Patients with Primary Ciliary Dyskinesia (PCD) at PCD Foundation Clinical and Research Centers Network Sites

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Background

Sinus rinse (SR) may help mobilize thick, dehydrated secretions, reduce postnasal drip, prevent or reduce sinus infections, and improve patient comfort.

The PCD Foundation (PCDF) recommends nasal irrigation (NI), or sinus rinse (SR) for patients with PCD, and this recommendation is supported by limited data in PCD suggesting symptom relief and improved health-related quality of life (HrQOL) ^(1, 2). Sinonasal symptoms negatively impact HrQOL and chronic rhinosinusitis (CRS) is common in patients with PCD⁽³⁻⁵⁾.

Our center observed that patients who began SR/NI in adolescence struggled with SR/NI adherence more than patients who started at a younger age. Our goal was to determine how other Primary Ciliary Dyskinesia Foundation Clinical and Research Centers Network (PCDF-CRCN) programs were approaching teaching and recommending SR/NI to PCD patients.

Methods

Survey of PCDF-CRCN Centers

A REDCap survey was distributed to PCDF-CRCN centers to evaluate current practices for teaching and recommending nasal irrigation/sinus rinse (SR/NI) for patients with primary ciliary dyskinesia (PCD).

Survey topics included:

- Frequency and timing of SR/NI education during clinic visits
- Clinical team members responsible for SR/NI education
- Availability of standardized protocols for:
 - o SR/NI administration
 - o Equipment cleaning
 - o Disinfection procedures

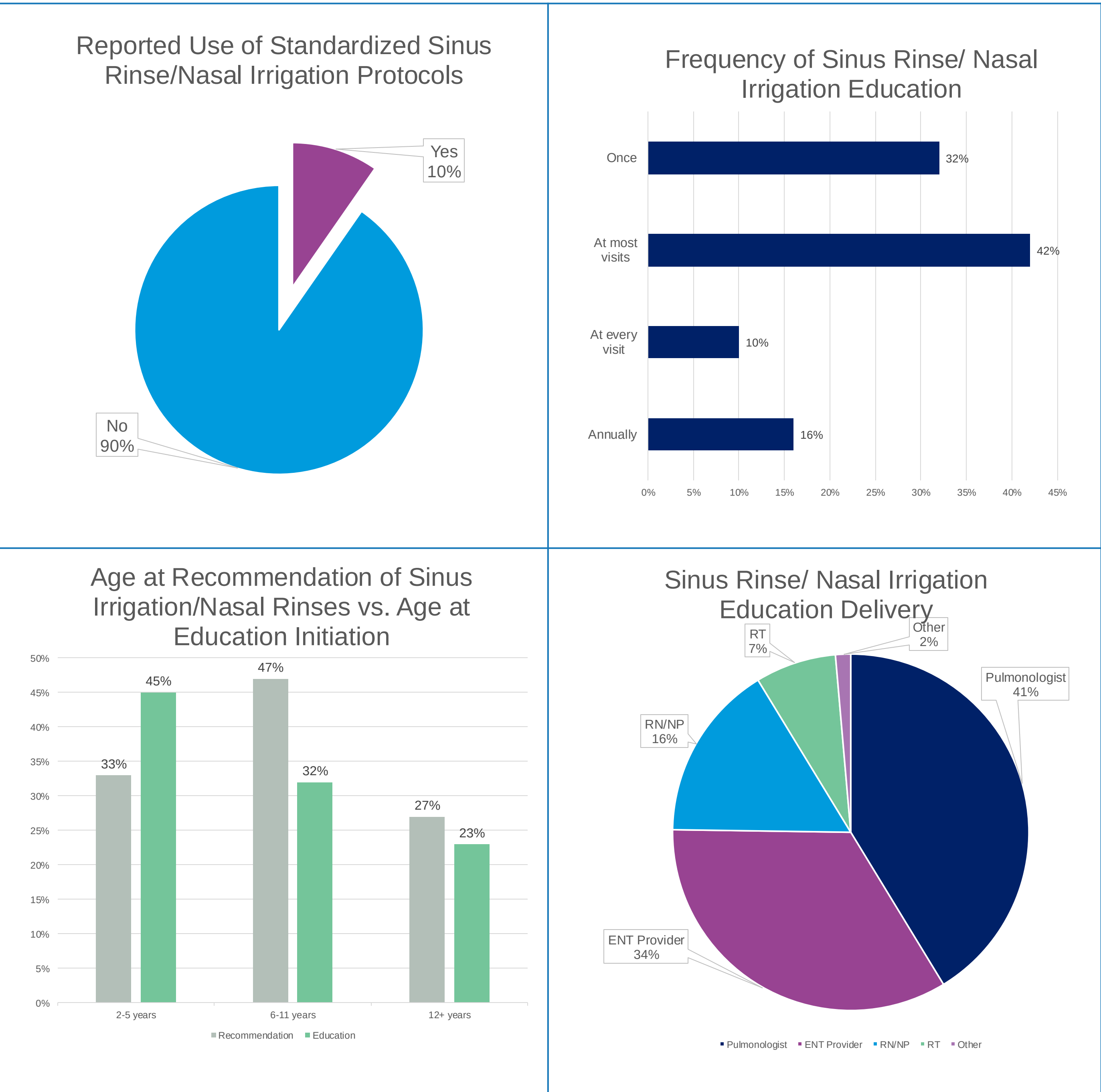
Incomplete or duplicate responses were clarified when possible or excluded from analysis. Adult and pediatric centers were analyzed together.

Results

40 of 44 PCDF-CRCN centers were successfully contacted. 36 centers completed the survey.

Key Findings:

- 86% of centers report routinely recommending SR/NI.
- Notably, 90% of centers do not have a SR/NI standard protocol in place.
- Of the centers that recommend SR/NI, 42% provide education at most clinic visits.
- Education is primarily delivered by pulmonologists (90%), followed by otolaryngologists (74%) nurses or nurse practitioners (RN/NP) (35%), and RTs (16%).



Conclusions

Therapies are limited for patients with PCD. SR/NI are an important recommended therapy for PCD patients, yet education varies between PCDF-CRCN centers. 86% of centers routinely recommend SR, while 90% of centers do not have a protocol in place. These findings highlight the need for standardized instruction across centers.

As CRS symptoms are frequent and burdensome for patients with PCD, educating and teaching sinus rinses and nasal irrigation to patients and families may help improve symptom control.

Interpretation of these findings is limited by a few survey design factors:

- The survey did not assess other aspects of sinus management, such as steroid use, which limits the ability to contextualize SR/NI practices within broader care approaches.
- Age categories were weighted toward pediatric populations, with no distinct adult (≥18 years) option.
- Options for SR/NI education frequency did not include "never" or "not at all."

Poster and References can be viewed by scanning the QR Code below:



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Disclosure: Children's Minnesota IRB determined this protocol meets the definition of research not involving human subjects. The authors received no specific internal or external grant funding for this project.

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