

# Hybrid Decentralized Recruitment Approach to a Rare Disease Registry for Pediatric Patients With Narcolepsy: The CATNAP® Registry

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## Introduction

- Limited information is available on the natural history, initial presentation, and subsequent management of pediatric narcolepsy
- Children, Adolescents, and Their providers: the Narcolepsy Assessment Partnership (CATNAP®) is a retrospective and prospective, longitudinal, multicenter, web-based pediatric registry with a decentralized site (NCT04899947)
- The CATNAP registry collects relevant real-world clinical information from patients, caregivers, and clinicians, leveraging both a site-based and a decentralized enrollment option for participants

## Objective

- The primary objectives of CATNAP are to improve understanding of the natural history of pediatric narcolepsy, describe the initial symptom presentation and diagnosis, and characterize treatment practices and outcomes
- After registry initiation, an innovative decentralized approach was added to adapt to the post-COVID-19 environment and reach additional participants via social media

## Methods

- Since registry initiation in September 2020, 17 sites have been activated, including a virtual site launched in August 2022
  - Hybrid decentralized recruitment required a new web interface, Institutional Review Board submissions, and a 7-week social media campaign (1 press release, 5 targeted posts) to accompany the virtual site launch
- Eligibility criteria included children/adolescents (<18 years of age) with narcolepsy; participants at physical sites had a physician-confirmed diagnosis
- Using web-based portals, patients and caregivers (and clinicians at physical sites) completed an initial survey on sociodemographic characteristics; diagnostic, medical, and treatment history; comorbidities; and disease progression
  - Participants continue to answer follow-up questions annually until they reach 25 years of age or decline to participate

Figure 1. CATNAP Study Flow

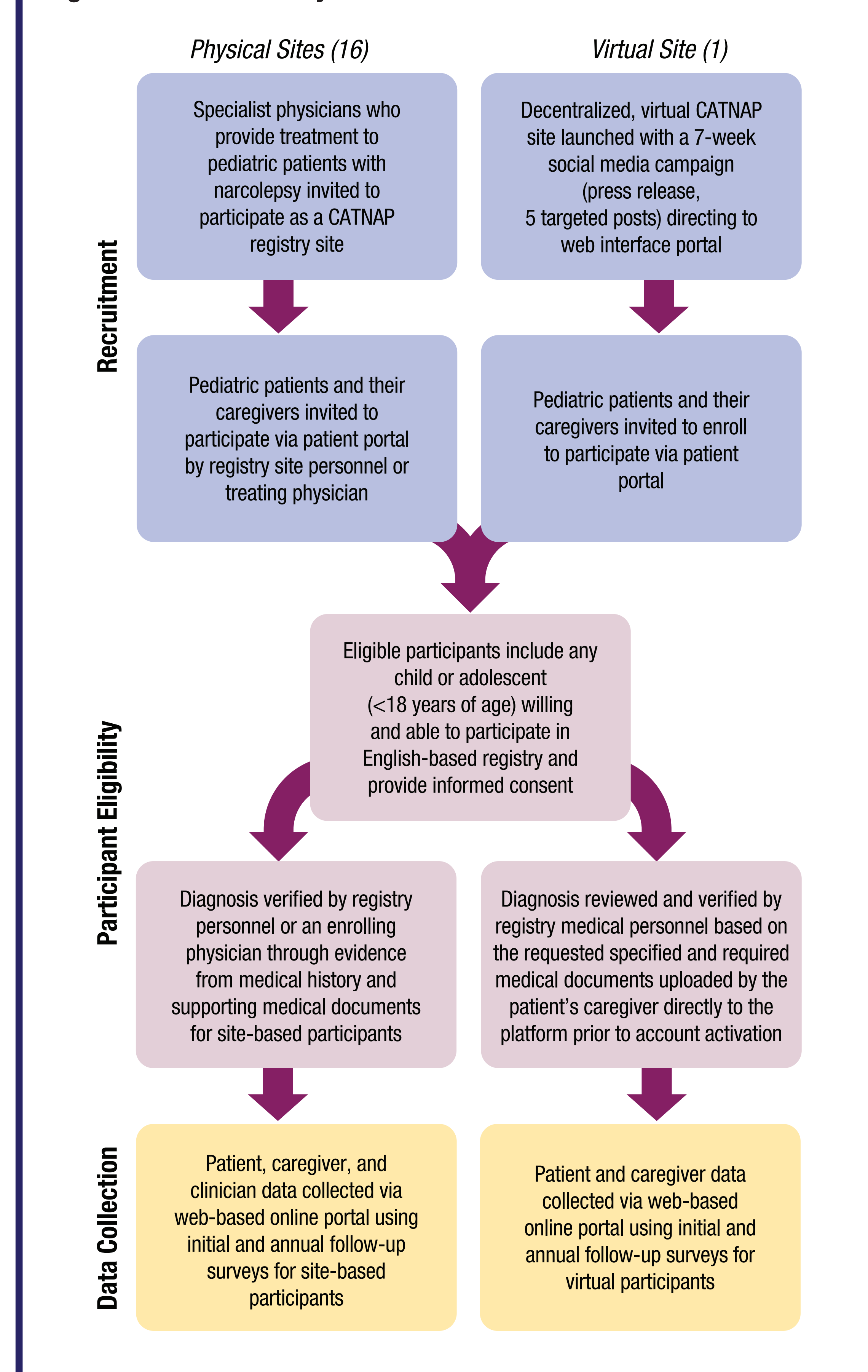


Figure 2. CATNAP Social Media Campaign and Website

### Social Media Campaign

#### Campaign Timeline

- Week 1
  - Virtual site launched
  - Social media post #1 (all channels)
  - Newsletter post and summary
- Week 2
  - Press release
  - Social media post #2 (all channels)
  - Newsletter post and summary
- Week 3
  - Social media post #3 (all channels)
  - Newsletter feature and posts
- Week 4
  - Social media post #4 (all channels)
  - Newsletter post and summary
- Week 5
  - Social media post #5 (all channels)
  - Newsletter summary
- Week 6
  - Newsletter summary
- Week 7
  - Newsletter posts

#### Press Releases

##### Parents of Children with Narcolepsy Invited to Participate in Registry

Members Participating Must Allow People to Enroll from Almost Anywhere in the World

August 16th 2022, London, Ontario, Canada—Children with pediatric narcolepsy and their caregivers can now take part in a patient registry to help researchers and clinicians better understand the condition. This information, which specialists in parent registries for rare diseases, launched the registry in 2020 and has 10 active clinical sites. Today, the study is expanding into the real world. A flexible model that allows participation and allows you to participate and complete an online form from anywhere in the world at their convenience.

"The patient registry called 'Children Adolescents and Their providers: the Narcolepsy Assessment Partnership' (CATNAP) is the first to use active recruiting and to ask writing patients and their providers to share information in different areas of their lives related to narcolepsy. This includes diagnosis, medical and treatment history, other conditions, and how a parent's narcolepsy progresses.

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Pediatric narcolepsy has detrimental effects on all areas of a child's life, including school, social circles, extra-curricular activities, and self-esteem. Taking part in a patient registry empowers the condition and helps pediatric patients and caregivers, where clinical research and potentially contribute to the development of new treatment strategies with a better understanding of patient impact. To learn more about participating in this registry, visit <https://bit.ly/CATNAP-Registry>

#### About Jazz Healthcare

Jazz Healthcare is a real-world evidence generation, health informatics and insight company that provides technology and services platform designed to extract, curate, analyze and disseminate evidence-based insights that improve the quality of people's lives. Jazz Healthcare provides full studies in registries, clinical trials studies and a range of other observational and regulatory grade studies. With proven relationships by patient access, Pulse Inframe ensures that insight, evidence and publication results are disseminated across the ecosystem, including oncology organizations, key opinion leaders, researchers, and sponsors. Learn more at [www.jazzpharm.com](https://www.jazzpharm.com)

#### Jazz Pharmaceuticals Debuts CATNAP™ Pediatric Narcolepsy Registry

Narcolepsy is still a widely misunderstood and understudied disorder. Safety, in children and adolescents, narcolepsy can often be mistaken for anxiety, depression, attention deficit hyperactivity disorder, or other conditions. This means many children living with the condition may experience feelings of loneliness and isolation. Low disease awareness, data collection and limited info-sharing have made facing this life-altering condition all the more challenging for young patients and their families.

"@JazzPharma understands that sleep disorders can impact every facet of someone's life

@JazzPharma are inviting Parents/caregivers of children aged 0-18 years who live with narcolepsy in the USA to take part in their patient registry

#### Focus attention with hashtags

#Narcolepsy  
#PediatricNarcolepsy  
#SleepDisorders  
#Sleep

### Website

Welcome!

This web-based pediatric narcolepsy registry is an organized collection of data focused on health and quality of life information for children under the age of 18 and their caregivers. The data collected will be used to help researchers and providers improve treatments and outcomes as well better inform the management of this condition for patients and their families.

## CATNAP® Pediatric Narcolepsy Registry

children, adolescents, and their providers: the narcolepsy assessment partnership

**ENROLL**

- About Pediatric Narcolepsy
  - Narcolepsy is a chronic condition where the brain is not able to control sleep-wake cycles normally. The symptoms can make it hard to do everyday tasks and may impact home, school, or work.
- About CATNAP® Registry
  - This CATNAP® registry is designed to collect and store health data from children/adolescents with narcolepsy as well as information from their caregivers.
- How to Enroll
  - To register and join the CATNAP® Pediatric Narcolepsy Registry select Enroll.

**Who Can Join?**

Anyone who is younger than 18 years with a diagnosis of narcolepsy. Child/Caregivers eligible to be compensated for completing surveys.

**Contact Information**

E. [catnap@pulseinframe.com](mailto:catnap@pulseinframe.com)

Disclaimer: The content on this site is not meant to replace a conversation with a sleep specialist. A sleep specialist can evaluate your symptoms and make a diagnosis.

## Results

Table 1. Baseline Demographics and Disease Characteristics

Characteristic	Physical Sites (n=74)	Virtual Site (n=51)	Total Participants (N=125)
<b>Age at enrollment, years</b>			
Mean (SD)	14.7 (3.13)	9.9 (2.01)	12.7 (3.59)
Median (Q1, Q3)	16 (13, 17)	9 (8, 11)	12.7 (3.59)
Min, max	4, 19	7, 16	4, 19
<b>Sex, n (%)</b>			
Male	20 (27.0)	24 (47.1)	44 (35.2)
Female	25 (33.8)	18 (35.3)	43 (34.4)
Not available	29 (39.2)	9 (17.6)	38 (30.4)
<b>Race, n (%)</b>			
Asian	0 (0)	1 (2.0)	1 (0.8)
Black or African American	21 (28.4)	0 (0)	21 (16.8)
Native Hawaiian or Other Pacific Islander	1 (1.4)	0 (0)	1 (0.8)
White	23 (31.1)	41 (80.4)	64 (51.2)
Not available	29 (39.2)	9 (17.6)	38 (30.4)
<b>Ethnicity, n (%)</b>			
Not Hispanic or Latino	37 (50.0)	42 (82.4)	79 (63.2)
Hispanic or Latino	8 (10.8)	0 (0)	8 (6.4)
Not available	29 (39.2)	9 (17.6)	38 (30.4)
<b>Narcolepsy type, n (%)</b>			
Type 1 (with cataplexy)	52 (70.3)	14 (27.5)	66 (52.8)
Type 2 (without cataplexy)	11 (14.9)	1 (2.0)	12 (9.6)
Unsure	11 (14.9)	36 (70.6)	47 (37.6)
<b>Region, n (%)</b>			
South	18 (24.3)	12 (23.5)	30 (24.0)
Northeast	14 (18.9)	11 (21.6)	25 (20.0)
West	3 (4.1)	10 (19.6)	13 (10.4)
Midwest	10 (13.5)	9 (17.6)	19 (15.2)
Not available	29 (39.2)	9 (17.6)	38 (30.4)

Q1, first quartile; Q3, third quartile; SD, standard deviation.

- Patient/caregiver-reported interim baseline data are included for 125 participants

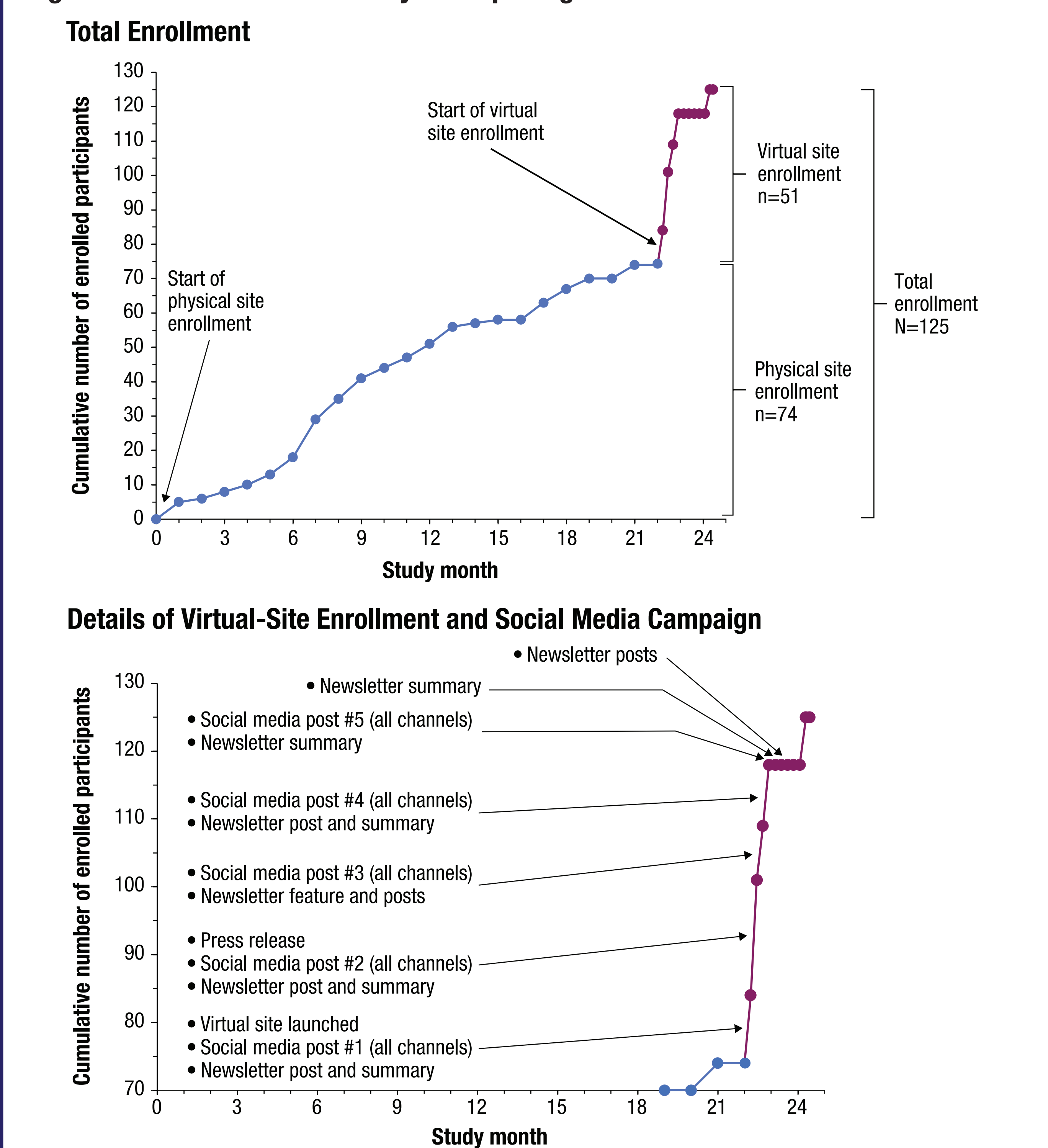
Table 2. Social Media Engagement Rates

	Facebook (organic)	Facebook (sponsored)	Instagram	LinkedIn	Twitter	Total
Engagements	13	29	45	54	26	167
Impressions	1076	12,551	1406	748	1094	16,875
Engagement rate	1.2%	0.2%	3.2%	7.2%	2.4%	2.8%
Clicks	10	29	N/A	4	7	50
Number of posts in period	6	1	6	6	6	25

Note: Good engagement rates were considered 3%, 2%, 2%, and 1% for Instagram, Facebook, LinkedIn, and Twitter, respectively.

- Rates of engagement (eg, clicks, likes, and shares) for Instagram (3.2%), LinkedIn (7.2%), and Twitter (2.4%) exceeded "good engagement rate" benchmarks for these platforms
- Although the engagement rate for Facebook was below benchmarks (<2%), the absolute number of "clicks" (29) was the largest among social media platforms in the campaign

Figure 3. Enrollment After Study Site Opening



## Conclusions

- A hybrid recruitment approach for CATNAP supports patient choice by opening another avenue for patient enrollment into this real-world registry, which is especially important for research in rare diseases
- A targeted social media campaign raises awareness, drives traffic to the registry portal, and results in registry enrollments
- Decentralization can contribute to enrollment in real-world data registries and studies; however, new approaches to encourage ethnic and racial diversity need further exploration
- A successful implementation of a hybrid approach with both physical and virtual opportunities for enrollment may inform designs of future registries and clinical studies

**Support and Acknowledgments:** The authors thank the participants in the CATNAP registry study. This study was supported by Jazz Pharmaceuticals. Under the direction of the authors, Shawn Jaramillo, PharmD of Peloton Advantage, LLC, an OPEN Health company, provided medical writing and editorial support for this poster, which was funded by Jazz Pharmaceuticals. Analysis and data supported by the Data Science Team at Pulse Inframe, Inc.

**Disclosures:** DA Nichols and W Macfadden are full-time employees of Jazz Pharmaceuticals who, in the course of this employment, have received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. EB Leary is a former full-time employee of Jazz Pharmaceuticals who, in the course of this employment, received stock options exercisable for, and other stock awards of, ordinary shares of Jazz Pharmaceuticals, plc. F Gwadry-Sridhar is the founder and CEO of Pulse Inframe, Inc., the platform technology company that built the CATNAP registry. J Owens has received consultancy fees from Jazz Pharmaceuticals, Harmony Biosciences, Idorsia, Citrine, Clair Labs, and Sleep Number, and receives royalties from WebMD, Wolters Kluwer, and Taylor & Francis.

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