



Rare Disease Support Report Q3 2023

Part 4 of the Evidence for Change Research Series





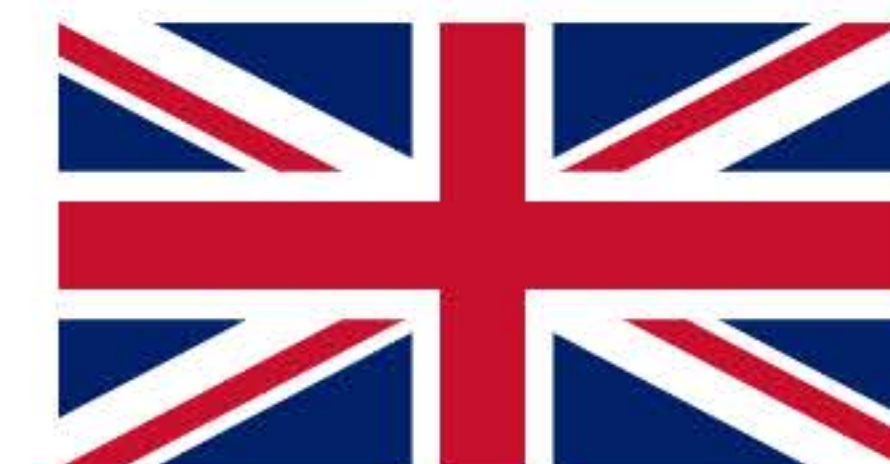
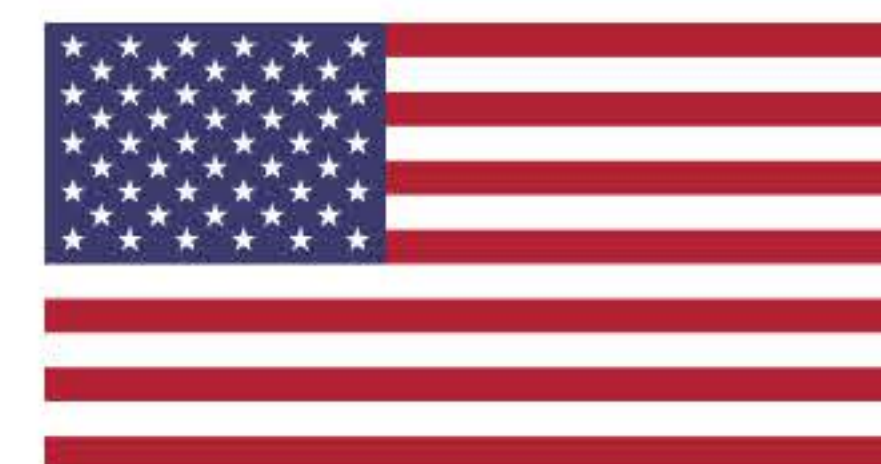
Introduction

Support comes in many forms, whether sharing information, giving reminders, lending a helping hand, or listening. Some support is organized. For example, groups and organizations may exist to help patients or caregivers with any problems or challenges they experience. Other support can include healthcare staff who are not part of the main healthcare team or groups where people share their experiences and feel heard and validated.



Methodology

To understand what services are used and to recognize opportunities for further support, we asked 72 patients with rare diseases and 45 caregivers about their experiences. The 117 respondents were from the United States (USA), the United Kingdom (UK), Germany and Australia. A wide range of rare diseases were represented in the patient and caregiver samples, including both genetic and non-genetic conditions, cancers and autoimmune conditions.

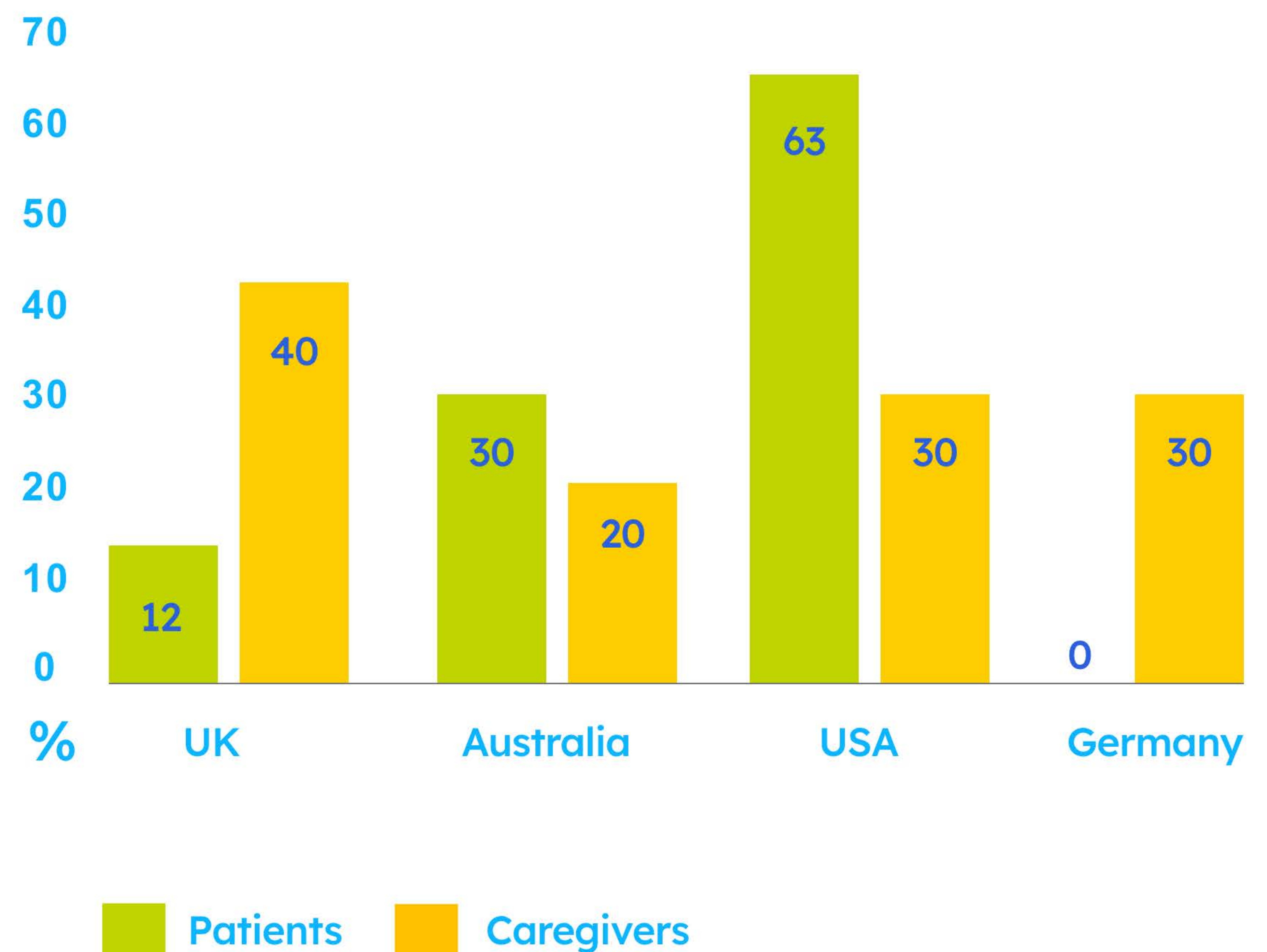


Key Finding: Low Awareness Of Pharma-Sponsored Programs Or Services

Only 33% of patients were aware of any pharma-sponsored programs or services which can offer practical, emotional or reminder support. However, of those who were aware of services, just 54% were enrolled in them. Of the caregivers, 31% were aware of pharma-sponsored programs or services to help with the practical and emotional impacts of caregiving. Of these, 71% were enrolled in that type of program or service.

Patient awareness was much higher among the respondents from the USA, with 63% aware of the programs. Awareness was lowest in the German patients, as none of the respondents knew of any programs or services. This was different among caregivers, with respondents from the UK being the most aware (40%) and Australian respondents being the least aware (20%).

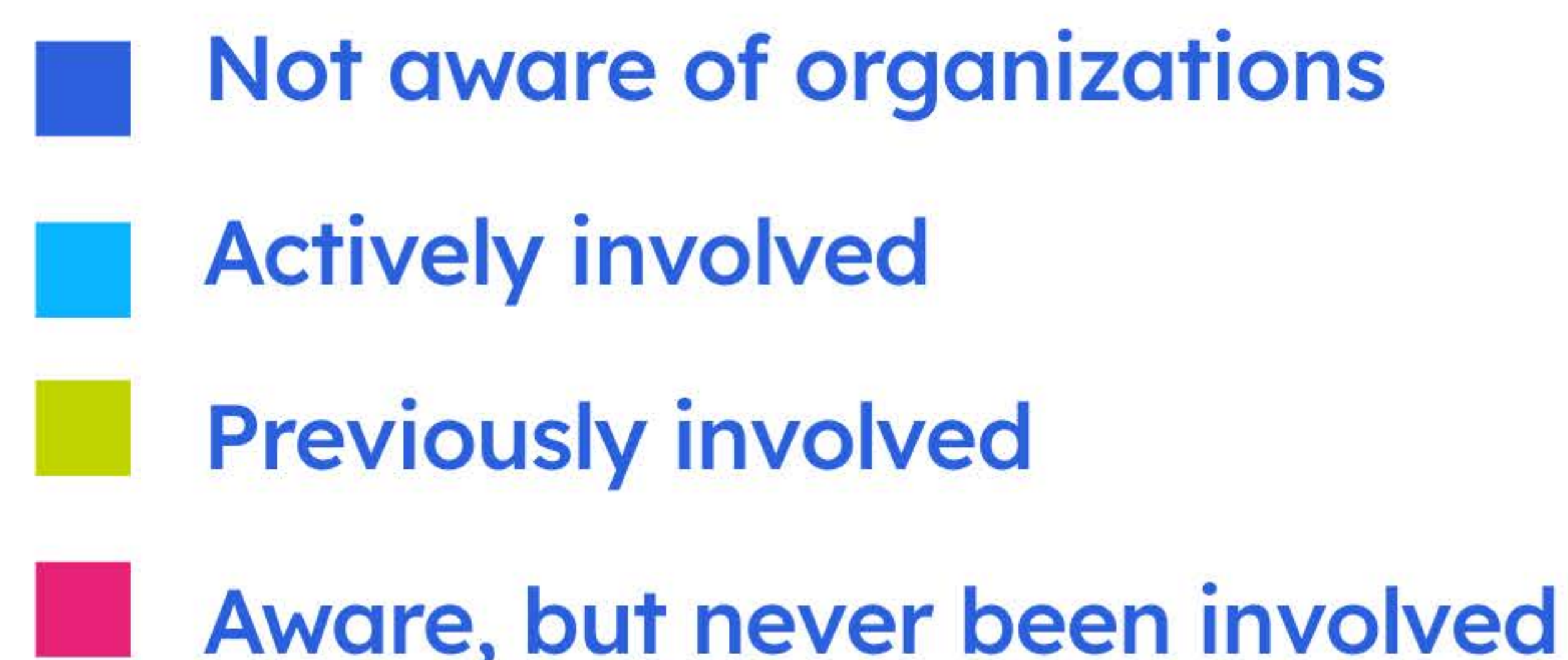
Respondents Who Were Aware Of Pharma-Sponsored Programs Or Services



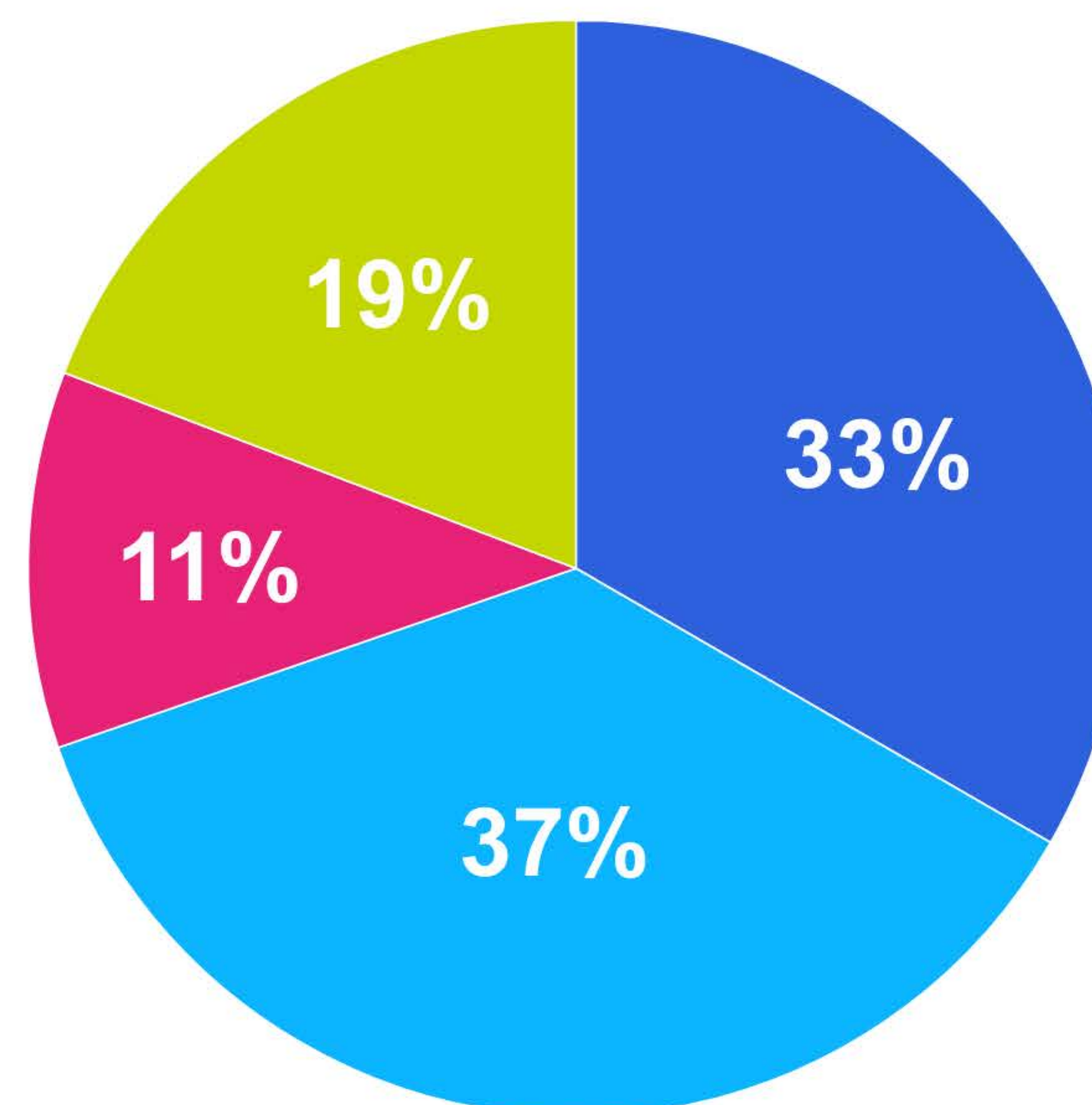
Key Finding: Awareness But Limited Engagement With Support Organizations

Respondents were asked about their active involvement with a patient organization that offers support. Two-thirds (67%) of the responding patients and caregivers were aware of a relevant patient group or organization, but less than half were actively engaged or enrolled at the time.

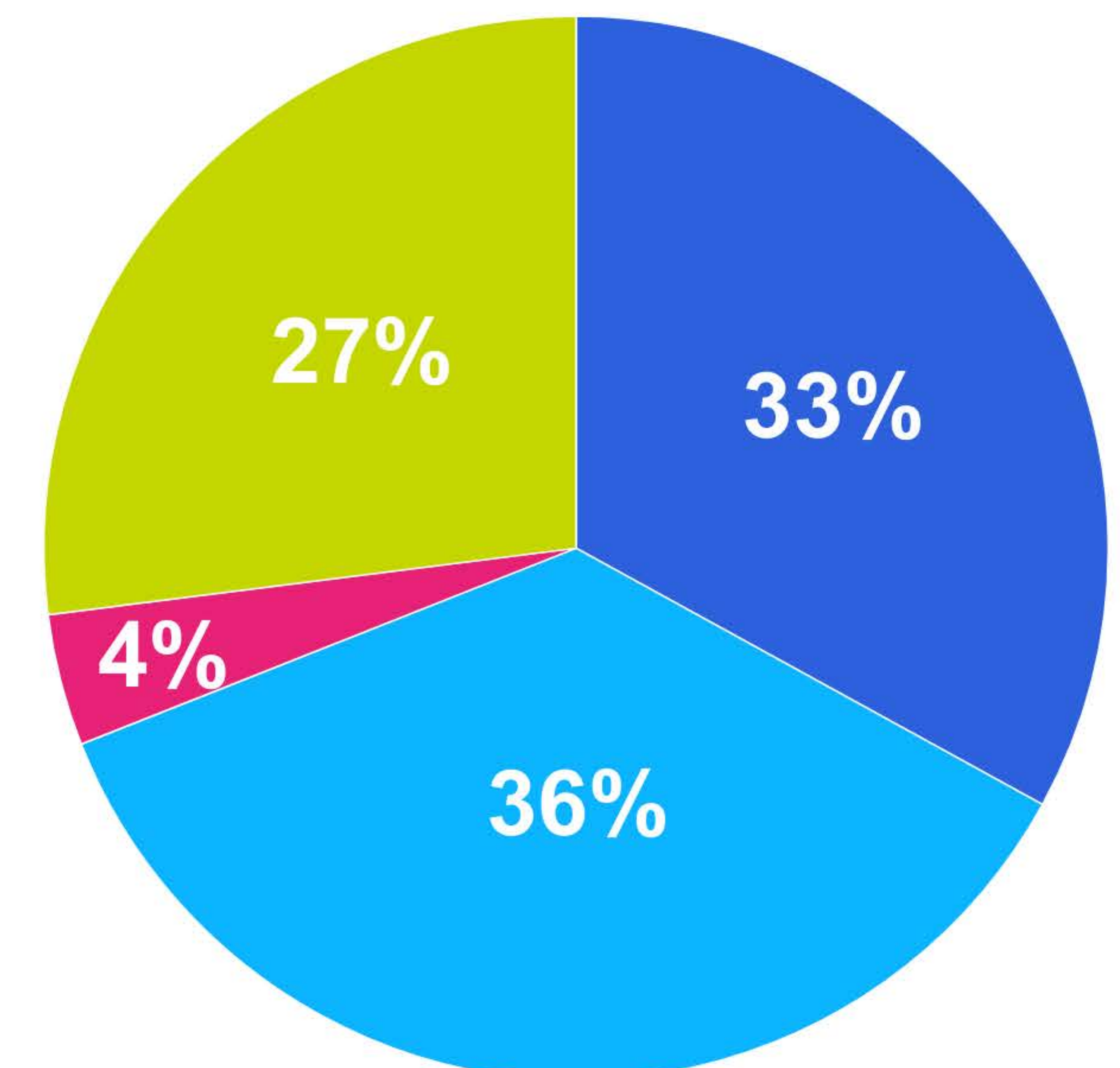
Awareness and engagement were highest among the US patients, with 87% aware of an organization and half actively engaged or enrolled. For the other responding patients, awareness ranged from 40-80%, and active involvement ranged from 20-36%. This differed in caregivers, as the UK respondents had the highest level of awareness (90%) and active engagement (80%). For the other caregivers, awareness ranged from 55-80%, and active engagement ranged from 0-40%.



Patient respondents actively engaged with organizations



Caregiver respondents actively engaged with organizations



Key Finding: Additional Nursing Services Accessed For Practical And Emotional Support



Support may be provided by other healthcare staff, such as nurses. Forty-four percent of responding patients from the US, the UK and Germany received additional support services from a nurse separate from their primary healthcare provider. None of the responding patients from Australia received additional support.

Additional nursing support was related to mental and physical/medical wellbeing support, such as emotional support, monitoring wellness and blood, and general tasks, like help with showering and changing dressings. The breadth of support accessed indicates the varied support needs of people living with rare disease, and also demonstrates the wide-ranging impact that rare disease can have on an individual's health and wellbeing.

Of those patients who accessed additional nursing, this was accessed through a multitude of channels, including online, over the phone, in person, and at home. Government funded organizations (e.g., the NHS in the UK) organized the care, but one participant also had a caregiver nurse. Many nurses were specialists in rheumatology, kidneys, multiple sclerosis, neurology, diabetes, occupational therapy, or anticoagulation.

Only 20% of the responding caregivers received support from nurses separate from their primary healthcare provider. Responses were consistent across the four countries. Two caregivers cited support for home health activities and hospice care. All others responded that the nursing support was medical, including physiotherapy, asthma checks, ventilation monitoring, injection support or psychiatric care. As was observed among the patient sample, caregivers accessed nursing support to address both their practical and emotional support needs.

Implications For Support



Living with a rare disease can place significant demands on both the patient and the caregiver. Our research demonstrates that patients and caregivers are seeking additional support to help manage these demands – whether medical, practical, or emotional. This support is often accessed through additional nurse support, outside of what is offered to patients and caregivers as part of standard care.

Atlantis Health recognizes the important role that nurses play in supporting patient and caregivers living with a rare disease. Nurse telephone calls are a foundational component of our Patient Engagement Platform. Through this platform, nurses are supported to build long-term collaborative coaching relationships with patients and caregivers to help them navigate the changing demands of living with a rare disease.

Enrollment into Pharma provided support programs can often be low. However this research indicates one of the most likely contributing factors is the low level of patient and caregiver awareness. This highlights the importance of program promotion and the need to offer a range of enrollment approaches that invite participation, rather than put up barriers to enrollment. At Atlantis Health, our support programs are co-designed with rare disease stakeholders, including patients, caregivers, and specialist healthcare professionals. Part of the co-design process is to look for where the program can integrate and support existing care workflows and activities. While this helps to ensure the effectiveness of our support programs, it also supports program acceptance, uptake and retention.



No matter the support need, we can support patients and caregivers to better manage the demands of living with a rare disease.

Our personalized support programs can help patients and caregivers living with rare disease to:

- Enroll and engage in support services
- Cope with uncertainty
- Build resiliency
- Be empowered to manage, practically and emotionally

Contact us to learn more regarding this research and how we can help you provide personalized support to people living with rare diseases, including case examples and research insights we have successfully implemented globally.

[Schedule a Free 30-Minute Consultation](#)

