

Case Study Education and Support for Caregivers: Building a 'Digital-First' Programme in Rare Disease

To support caregivers of children with a rare brain disease, a biopharma company and IQVIA created a digital-first program. This program provided educational resources, emotional support, and training for daily injections. By using a personalized platform, it improved treatment adherence and caregiver confidence, enhancing patient outcomes.



Situation

An emerging biopharma company aimed to develop a comprehensive, digital-first support program for caregivers responsible for administering daily subcutaneous injections to children with a rare pediatric brain disease. These patients often begin treatment at a very young age, sometimes as early as two or three years old, and continue with daily injections until they reach 18 years of age. The caregivers, who are frequently family members, face numerous challenges, including the need for educational resources, emotional support, and specific training on how to properly administer the injections.

Solution

To address these needs, IQVIA implemented a caregiver-facing platform designed to provide personalized and engaging support. The platform included several key features:

1. **Educational tools:** Comprehensive resources to educate caregivers about the disease, treatment process, and best practices for administering injections.
2. **Injection training:** Step-by-step guides and video tutorials to ensure caregivers are confident and competent in giving the injections.
3. **Tailored action plans:** Customized plans to help caregivers build confidence and self-efficacy, addressing their unique needs and concerns.
4. **Adherence support:** Tools and reminders to help ensure that patients adhere to their treatment regimen consistently.
5. **Nursing application:** An application that allows caregivers and patients to make calls for face-to-face or remote support from nursing professionals, providing immediate assistance and reassurance when needed.

Program objectives

Equip with educational tools | Build confidence | Drive long-term adherence

Support provided



Journey
personalization



Education



Injection
training



Behaviour
change



Adherence
support

IQVIA capabilities deployed



Behavioural science
informed design



IQVIA patient
engagement technology



IQVIA measurement
framework



IQVIA HCP
network

Outcomes

The implementation of this program resulted in an impressive average compliance rate of **95%**. Initially launched in two countries, the program's success led to its expansion into an additional six countries. This solution not only supported patient uptake and adherence but also provided a centralized, flexible, and scalable approach that could be tailored to meet the specific needs of local markets.

In summary, the digital-first support program significantly enhanced the caregiving experience by offering a robust, multifaceted support system that addressed both the practical and emotional challenges faced by caregivers. This holistic approach ensured that young patients received consistent and effective treatment, ultimately improving their health outcomes.

Putting patients first

At IQVIA, we partner with you to deliver comprehensive patient engagement and support services focused on safety, quality, and compliance. **[IQVIA Patient Engagement and Support](#)** services aim to improve awareness, access, affordability, and adherence to treatments through our insights-driven, personalized solutions, which enhance the patient experience and ultimately help people live happier, healthier lives.

With over four decades of expertise serving health systems and patients, IQVIA's teams are prepared to be your trusted partner in ensuring comprehensive care from start to finish and improving patient health outcomes.

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Support provided to Meike



Journey
personalization



Identify behavioral
barriers and
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interventions



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Support provided to Meike



Journey personalization

Identify behavioral barriers and personalize interventions



Education

Articles, learning modules and videos through caregiver-facing App



Injection training

Injection training video through caregiver-facing App and F2F nurse visit



Behaviour change



Adherence support

IQVIA capabilities deployed



Behavioural science informed design



IQVIA patient engagement technology



IQVIA measurement framework



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Behaviour change

Tailored action plan to build caregiver self-efficacy



Adherence support

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IQVIA patient engagement technology



IQVIA measurement framework



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Injection
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Injection training
video through
caregiver-facing App
and F2F nurse visit

Behaviour
change

Tailored action plan
to build caregiver
self-efficacy

Adherence
support

Injection tracker
and reminders

IQVIA capabilities deployed



Behavioural science
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