deciphEHR™
connecting the dots of rare disease

Rare disease patients may be falling through the cracks[1]

USE YOUR EHR SYSTEM TO HELP TRIAGE SUSPECT PATIENTS

Rare diseases may pose unique challenges in the recognition of affected patients. As a result, critical diagnoses can be delayed or missed.[1,2] deciphEHR™ provides educational resources to help health systems, hospitals, and specialty practices leverage their electronic health record (EHR) systems to help triage suspect patients for further clinician evaluation and employ diagnostic best practices.

ALEXION®
AstraZeneca Rare Disease

UNDERSTANDING THE PATIENT BURDEN

Rare diseases may not be as rare as they sound[3]

It is estimated that there are more than **7000 rare diseases** affecting about **30 million people**.* Currently, approved treatments are available for ~5% of rare diseases.[3]

Individuals with rare diseases have **higher medical needs**, often **miss work**, **retire early**, and **require the assistance** of a caregiver.[4]

Specialists generally consider their knowledge of rare diseases to be **relatively high compared with primary care physicians**, who consider their knowledge level to be lower.[2][†]

According to NORD, individuals with a rare disease may experience **feelings of isolation and of having been abandoned** or **"orphaned"** by our healthcare system.[6]

NORD=National Organization for Rare Disorders.

*In the United States, a rare disease is defined as a condition that affects fewer than 200,000 people.[5]

[†] According to an online survey conducted between August 2012 and August 2013. Data was evaluated for 367 healthcare providers from 13 countries.[2]

The diagnostic journey in rare diseases is often inefficient[1,2]

Patients with a rare disease have reported that it takes them, on average, **4.8 years** and more than **7 physicians** to get an **accurate diagnosis**, potentially resulting in[2]:

- Delayed treatment
- Negative impact on condition

Misdiagnoses and delayed diagnoses of rare diseases can lead to **inappropriate** or **ineffective management** and an **unnecessary burden** on the healthcare system.[1,2,7]

Rare disease patients have a greater risk of **increased lengths of stay** and discharge costs across all age groups compared with patients with more common conditions.[1]

It is difficult for many clinicians to stay up to date with rare diseases.[7] *This fuels the demand for tools that integrate new information into decision-making.*[8,*]

Rare diseases and their diagnostic pathways may not be universally understood by HCPs.[9]

Missed diagnoses contribute to increases in **readmissions**, **morbidity**, and **healthcare utilization**.[1,7]

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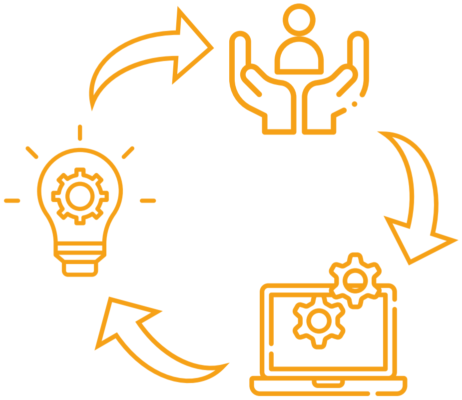
*Based upon the findings of a 2021 report that resulted from a workshop that brought together leaders from across the healthcare spectrum, including patient advocacy, clinical research, personalized medicine, venture capitalism, and payer organizations. The workshop elicited the opinions of participants; it was not a scientific study.[8]

HCP=healthcare provider

Rare diseases pose unique challenges to clinicians[1]



Leveraging EHR systems may improve care and mitigate inefficiencies[10-13]

A healthcare organization's use of EHR systems may help HCPs[10-13]:

- Efficiently triage patients
- Enable resource prioritization
- Provide more coordinated care

Leveraging EHR systems, including **best practice alerts** and **suspect patient lists**, may contribute to improved patient care and outcomes, as well as increased efficiency.[14]

Further reading: rare disease websites

Genetic and Rare Diseases Information Center (GARD),
National Institutes of Health (NIH)
https://rarediseases.info.nih.gov

National Organization for Rare Disorders (NORD)
https://rarediseases.org

Orphanet: The Portal for Rare Diseases and Orphan Drugs
https://www.orpha.net/consor/cgi-bin/index.php

Rare Diseases International
https://www.rarediseasesinternational.org

Global Genes: Allies in Rare Disease
https://globalgenes.org

Children's National Rare Disease Institute (CNRDI)
https://childrensnational.org/departments/rare-disease-institute

Rare Diseases Europe (EURORDIS)
https://www.eurordis.org

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VISIT **deciphEHRrare.com** FOR ACCESS

How can Alexion help?

Alexion provides educational resources to help you leverage your EHR system to help triage patients suspected of having a rare disease for further clinician evaluation through the use of relevant patient history data, best practice alerts, and suspect patient lists.

EHR diagnostic toolkits will be available for selected rare diseases.

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