

RARE REALITY - LIVING WITH A RARE DISEASE IN IRELAND HEALTHCARE EXPERIENCES



1 in 17

People live with a rare disease; there are **300,000 people in Ireland** living with a rare disease



There are approximately

6,000 to 8,000 known rare diseases

A disease that affects less

than **1 in 2,000** people in Europe is considered rare

On average **5 areas of health** affected by rare condition



Attend **4 or more different specialist hospital clinics** for regular on-going care

34%

31% no medical expertise for the rare condition in Ireland

31%

Multi-disciplinary care, available

to **44%**, enables coordination and takes account of the whole person.

77%

Genetic testing provided a **diagnosis for 77%** who had access. Newborn screening identifies rare conditions early, often before symptom onset

73%

Saw **3 or more consultants with different specialisms** on diagnostic journey

53%

Investigated and treated for **3 or more rare conditions** before final diagnosis

37%

Spent over **5-years** seeking a diagnosis

RARE DISEASES ARE COMMON

DIAGNOSTIC JOURNEY IS CONVOLUTED

INTEGRATED PERSON-CENTERED CARE REQUIRED

SPECIFIC TRAINING AND RESEARCH REQUIRED

80%

want more opportunity to get involved in research

38%

Max 38% satisfied with the disease specific information provided by healthcare provider involved in their care

People living with rare conditions are **experts by experience**. Listen to and learn from them

Lack of awareness and knowledge of rare conditions among healthcare providers undermines trust and delays access to appropriate care