



International Niemann-Pick Disease Registry

# A GLOBAL GATEWAY TO A LASTING LEGACY - HARNESSING DIGITAL COMMUNICATIONS TO EMPOWER PATIENTS TO SHARE THEIR EXPERIENCES TO PROGRESS RESEARCH AND TREATMENT

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## BACKGROUND

The International Niemann-Pick Disease Registry (INPDR) was created through global collaboration between patient organisations, clinicians and scientists with appropriate support from industry.

The INPDR is a web-based, anonymised Clinician Reported Database (CRD) and a Patient Reported Database (PRD), where patients self-enrol online and complete a disease impact assessment, health economics and quality of life questions.

### PATIENT REPORTED DATA



## PATIENT EXPERIENCE

- The PRD circumvents the need for Clinician Reported Data where there is little or no infrastructure for rare diseases.
- Patients are a powerful force of advocacy and influence.
- Patients or their family members from 9 countries have self-enrolled and are entering data into the PRD.

## DIGITAL TECHNOLOGY

- Digital technology opens a global gateway by enabling patients from non-UK countries to access the Registry.
- Use of social media raises profile and encourages two-way communication.
- Redeveloped systems and a website with translation offers industry standard user experience.

## NEXT STEPS

- Encourage more patients in more countries to sign up
- Link Clinician Reported Data (CRD) to Patient Reported Data (PRD)

## DISCUSSION

The INPDR monitors recruitment figures, website activity and social media to inform strategy and the Communications Plan.

Collective patient reporting over time combined with data from clinicians can create a better understanding of the disease and its impact.

The same technology that helps rare patients find and support each other can also be used to progress research, treatment and care, and enable patients and their families contribute to a lasting legacy.

