

## Registry Partnership Request

### Introduction

The National and International Skin Registry (NISR) Solutions company (CLG) is a not-for-profit organisation established 2015 (Company Registration no. 567600) and became a registered charity in 2020 (CRN 20205667 & CHY22573) based out of the UCD Charles Institute of Dermatology. NISR was established to focus on the development and support of dermatology registries.

The challenges to developing registries are substantial, however NISR has developed core competencies and technologies that can assist and support the establishment of a disease specific registry. NISR can assist with Governance, Ethical Approval, Patient Consent, Patient information booklets, GDPR and preparation of DPIA's, technology platform and operations.

NISR is open to receiving requests for assistance from any dermatological disease anywhere in Ireland. These requests must be accompanied by a short proposal that demonstrate an understanding of the aims and objectives of the registry. NISR will consider each application and engage with the applicants on how NISR can assist. A Registry Funding Application Form is provided to assist with your proposal preparation.

### Proposal requirements

Before preparing your proposal we recommend reading "Developing a Patient Registry: A Practical Guide" that can be downloaded from the HRCI (Health Research Charities Ireland) website <https://hrci.ie/category/publications/latest/>.

The proposal (maximum of 4 pages) to be submitted should demonstrate an understanding of what is required to develop a registry and guarantee its sustainability.

Please present your proposal under the following headings:

1. List your registry's aims and objectives
2. Define the dataset, what is the minimum dataset required. Is it a National dataset?
3. How and by whom will data be collected? Are you looking for assistance with this?
4. What funding can you bring to the project and is it sustainable?

Email your proposal to [registry@nisrsolutions.com](mailto:registry@nisrsolutions.com)