



Integration of ERNs into National Health Systems

Best Practice – Care Pathways [2]

BEST PRACTICE

CARE PATHWAYS

ORGANISATION

NATIONAL RARE DISEASES OFFICE, IN THE REPUBLIC OF IRELAND

Summary

The Republic of Ireland has a population of 5 million, of whom an estimated 300,000 people live with a rare disease. Affected individuals have reported that they experience delays in diagnosis and a fragmented care journey, which can be more challenging than in larger Member States due to the capacity of the healthcare system. Therefore, integrated diagnostic, care pathways and cooperation with other countries for highly specialised healthcare under the European Reference Networks (ERNs) is critical to help build the capacity of the system. The Department of Health's initiative for healthcare reform in Ireland (Slaintecare Reform Programme), promotes the development of a universal single-tier health and social care system through which everyone has equal access to services based on need and delivery of care as close to home as possible.

In the context of this initiative, the rare disease patient community highlighted the development of care pathways as a priority area in order to address 3 top unmet needs: i. better care co-ordination between health care professionals (HCPs), ii. improved access to specialists, and iii. enhanced treatment opportunities.

To respond to this demand, the Irish National Rare Diseases Office developed and piloted a cooperative methodology to develop integrated diagnostic and care pathways in the Irish healthcare system, as there is no single recommended best practice methodology for the development of care pathways for rare diseases in health systems.

References & Links

[National Rare Disease Plan for Ireland, 2014-2018](#)

[Model of care for Rare Diseases](#)

[National Rare Diseases Office - HSE.ie](#) provides the following core functions: supporting centres of expertise, supporting and developing ERN integration into the health system, hosting 'Orphanet Ireland' and the delivery of the National Rare Diseases Information Service

Approach

The Irish National Rare Disease Office engaged with experts and patient groups to develop 'integrated diagnostic and care pathways' for rare diseases and subsequently developed and piloted a methodology for developing these care pathways in the Irish healthcare system, focussing on care pathways for chronic, multi-system conditions that needed



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multidisciplinary care. 29 rare diseases were selected based on prevalence, the existence of Irish clinical expertise and representation across 18 ERNs. As cancer care has a separate governance system from rare diseases in the Republic of Ireland, none of the 29 rare diseases were oncology conditions.

The template developed to illustrate the care pathways was structured from diagnosis through to hospital-based care, community care and primary care. Under each of these key categories the HCP disciplines and interventions were detailed. Other core information included a section for patient organisations, the relevant Orphanet information, Orphacodes, ERN links, references and a resources section where the optimum staff resources needed to deliver care along the pathway were detailed. The care pathways were developed to be live reference documents that are digitally accessible, so that they can serve as interactive tools for GPs, experts, patients, and health and social care professionals (HSCPs) who wish to navigate the care journey.

The process for developing the care pathways began with an audit of the clinical practice guidelines available on the ERNs' websites, PubMed and Orphanet. The results formed the basis for the first draft of the pathways, which were reviewed by a clinical lead and then by patient representatives. The final revision was approved by the clinical leads with overall clinical responsibility for their respective pathway. The pathways are now in the process of review by other stakeholders in the Irish health and social care system.

One of the main goals of this pilot was to address patients' reported barriers to accessing a timely diagnosis and best quality care, to ultimately improve patient outcomes. Patient representatives identified four common needs that needed to be addressed in all the care pathways: 1. Co-ordinated care; 2. Holistic care in the community; 3. Psychological support at key points – diagnosis, transition, and major milestones; 4. more timely access to HSCPs in the community.

A cross-analysis of the 29 care pathways served to identify core roles that were relevant for all pathways, including a nurse specialist, psychologist, medical social worker and database manager (all essential); health and social care professionals – physiotherapy, occupational therapy and speech & language therapy were key for >75%, genetic counselling for >90% and dietetics for 45% of the pathways.

Enablers/success factors or lessons learnt

Early and systematic patient involvement in the development of the care pathways enhanced the relevance and practicality of the pathways and highlighted key gaps in current care arrangements.

Why is this a good practice?

Patient involvement in care pathway development is central to ensure that the pathways meet the patients' needs, allowing their perspective to complement the experience of clinical leads, and be mapped against the infrastructure of the national healthcare system, as well as the published evidence.

The Irish integrated diagnostic and care pathways have successfully translated the evidence, experience and knowledge from the ERN system into a clinical decision support tool accessible in digital format for local services to access. Enabling the expertise to travel and not the patient!