



Rare Diseases
Ireland

***RD Care Pathways development
at Ireland's Healthcare Service Executive (HSE)***

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Vicky McGrath, CEO

Topic: Care Pathways

- Address patients' reported barriers to accessing a timely diagnosis and best quality care
- Limited (no) care pathways for RDs available in Ireland
- AIM

Document expected level of care based on validated clinical practice guidelines (CPGs) with lived experience input and mapped onto the Irish healthcare system

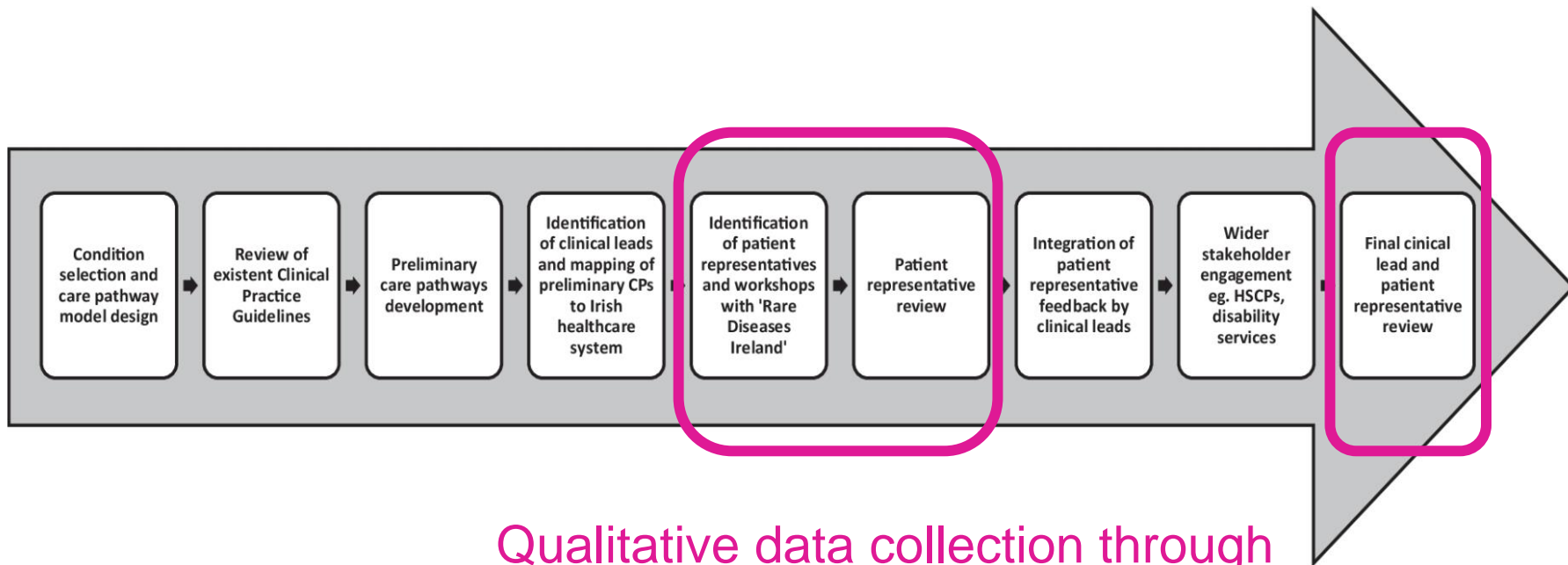
Intended outcomes

- Documented, approved & funded RD care pathways
- Improved diagnosis & care for affected patients
 - Empower PLWRD & carers to navigate health service
 - Advocacy tool for RD patient organisations
 - Support delivery of integrated multi-disciplinary care
 - Enhance links between across acute, primary and community care services
 - Increase knowledge and awareness of RDs
 - Act as educational and clinical support tools
 - Enhance clarity of roles and responsibilities

Team: Experts & PLWRD (experts by experience)

- National Rare Diseases Office – project management & guiding through HSE review/approval mechanisms
- Rare Diseases Ireland – liaison with individual patient groups
- Clinical lead – disease expert & clinical practice guidelines
- Patient groups – lived experience experts (acute & community care)
- As needed
 - Primary care, allied health & social care professionals, disability services

Process: Drafting, review & approval



Qualitative data collection through focus groups & guided questionnaires

Questions to be answered

- ‘diagnosis’ sections – anything unclear, mis-placed or missing?
- ‘care’ sections – anything unclear, mis-placed or missing?
- Other references which would be helpful to include?
- Links which would be helpful to include?
- Are there particular staff resources which you consider important to deliver this standard of care?
- Please comment on the lay-out of care-pathway?
- General comments on any aspect of care pathway?

Display options

- All disciplines
- References
- Resources required
- Clinical leads
- Orphanet information
- CLEAR ALL**



- Diagnostic criteria
- Clinical presentation (including common signs & symptoms)
- Red flags for GPs
- Laboratory tests
- Genetic tests
- Investigations eg. ECG
- Scans eg. CT
- Disciplines involved in diagnosis



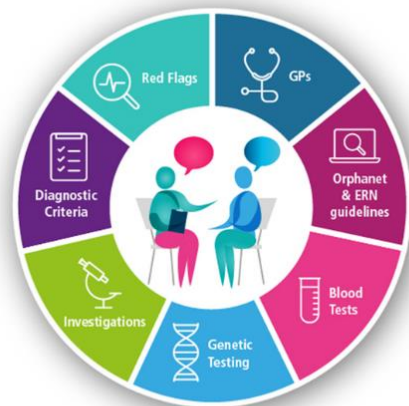
- Core medical disciplines required for routine management
- 'As required' medical disciplines for complex clinical needs
- Co-ordinating clinical speciality eg. Developmental Paediatrician for NF1
- Surveillance ie. asymptomatic screening including at what stage, how often
- Symptomatic screening - triggered by what, who to screen & refer on?
- Treatment for symptoms
- Prophylactic treatment
- Follow-up for at-risk family members
- Specific advice / management for pregnancy, anaesthetic, sick days
- GP role
- Database manager
- Health and social care professionals role
- Psychosocial supports eg. medical social work, psychology and social care information links
- Validated national and international patient organisation links
- Care delivery location



- Orphacode(s)
- Orphanet definition of the condition
- Orphanet link for each condition
- Clinical Practice Guidelines and medical references used to inform the care pathway
- Links to relevant European Reference Networks websites
- Links to ERN endorsed disease-specific resources
- Staff resources (including linked services) required to deliver the care outlined in the care pathway eg. for 50 patients
- Clinical Lead names and Centres of Expertise

Results/Outcomes to date

- 9 care pathways signed off
- 20 care pathways under review



TIMELY DIAGNOSIS



INTEGRATED CARE



POSITIVE OUTCOMES

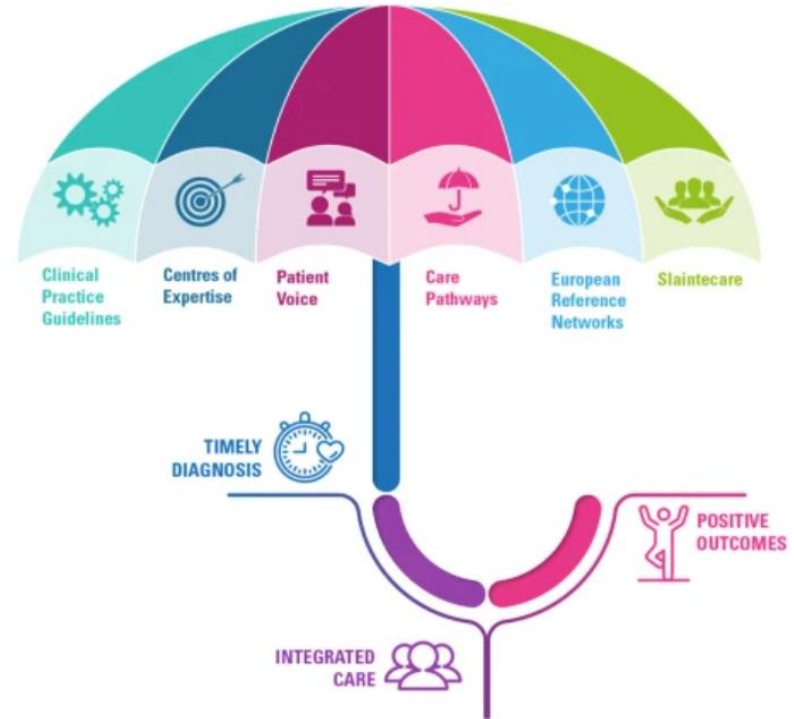
Additional learning

Common needs of all the care pathways:

- Co-ordinated care
- Holistic care in the community
- Psychological support at key points
 - diagnosis, transition, major milestones
- Timely access to HSCPs in the community

Core roles across all pathways:

- nurse specialist
- psychologist
- medical social worker
- database manager
- health and social care professionals
 - physio, OT & SLT for >75%,
 - genetic counselling for >90%
 - dietetics for 45% of the pathways.



Dissemination

- Pathways shared with patient groups, expert clinicians, HSCPs, etc.
- Available online, shared on social media
- Process and stakeholder roles published in peer reviewed publication

Designing rare disease care pathways in the Republic of Ireland: a co-operative model 2022 Ward et al OJRD



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THANK YOU!
Questions???

Vicky McGrath, CEO
vicky.mcgrath@rdi.ie