



# Patient and Public Involvement in Shaping Health Policy and Services in Ireland North and South

## **A FOCUS ON RARE DISEASES**

Philip Watt: Rare Disease Task Force (Republic of Ireland)  
Fiona McLaughlin: Northern Ireland Rare Disease Partnership

# What is PPI?

## **World Health Organisation (1978)**

'People have the right of duty to participate individually and collectively in the planning and implementation of their healthcare'

## **Irish Health Research Forum (2015)**

'By involvement we mean a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives and implementing policies, in planning, developing and delivering services and taking action to achieve change'

## **John Saddler, NHS Confederation (2015)**

'Sharing decision-making with patients and the wider community can improve care, help internal NHS collaboration and engage vulnerable people'

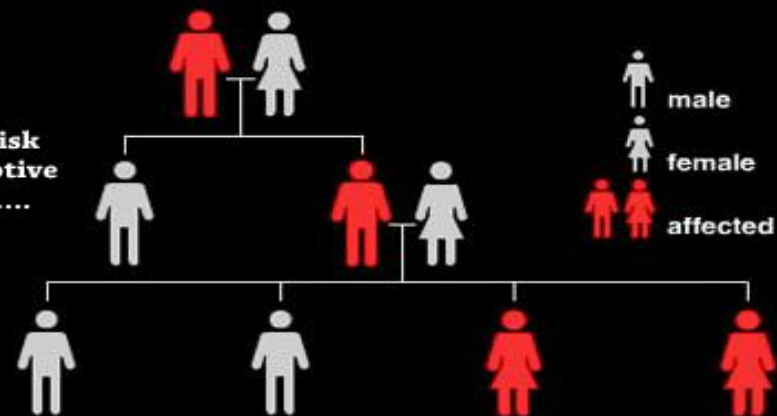
## **Terry McGeeney MD (2012)**

'The lack of patient engagement is the Achilles' Heel of health care delivery in the US'



## Inheritance

Family planning for those living at risk of inheriting HD can be a highly emotive and divisive issue within the family.....





# Patient and Public Involvement (PPI)



# The Journey of Patient Groups

1. Development of Effective networks
  - ❑ Northern Ireland Rare Disease Partnership
  - ❑ Rare Disease Task Force
2. The National Rare Disease Plans in the UK (2013) and NI Implementation Plan (2015)
3. The National Rare Disease Plan in Ireland (2014)
4. Joint commitments in both plans to N/S cooperation
5. Increased cooperation of civil servants on a North/South basis



[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)



# Agency Patient and Client Council

## Your voice in health and social care



# Launch of NI Rare Disease Implementation Plan, 2015





# Rare Disease: Progress



Emergence of patient groups concerned with rare diseases



1988: Genetic and Rare Disorders Organisation



1994: National Centre for Medical Genetics, Crumlin



2014: National Clinical Programme



2014: National Rare Disease Plan Published



2012 Rare Disease Task Force Established  
GRDO  
IPPOSI  
MRCG



2015: National Rare Disease Office Opened



Key questions  
Access to new and innovative drugs???



Future of Clinical Genetic Services??

*A health service that fully meets the needs of those with a rare disease*



# Rare Disease Day, 29 February

## SAVE THE DATE!

RARE DISEASE DAY 2016

'The Patient Voice'

Feb 29, 2016 - Dublin Castle



### WHAT IS HAPPENING?

- Rare Disease Day 2016, Main Hall, Dublin Castle
- Registration 9am
- Speakers 9.30-1pm

### WHY YOU SHOULD GO

- United voice for Rare Diseases (RD)
- Key speakers update on RD policy implementation
- Networking

### HOW TO PREPARE

- Read the National Plan
- Read the EUCERD guidelines
- Read 'The story so far' by Philip Watt



# North/South Rare Disease Conferences



# The Impact of Cross Border PPI on Rare Diseases

Exchange of information and good practice (for example North-South conferences on rare diseases alternately held in Belfast and Dublin)

Awareness raising - Rare diseases now 'on the agenda'.

Identification of best potential for increased co-operation, for example:

- Health Research (very advanced in some areas)
- Transplant services (lung and Kidney programmes)
- Clinical genetic services (diagnosis and counselling)
- Clinical trials for new and innovative therapies



# What now?

- ▶ Implementation plans
- ▶ Personal & public involvement
- ▶ Brexit?
- ▶ Funding