

# Building on Strengths and Abilities: Update on the National Dementia Post-diagnostic Supports Programme

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National Dementia Office

**Engaging Dementia Conference, Croke Park 2019**

# National **Dementia** Office

Leadership, Integration  
and Innovation

Our vision is that people with dementia and their family carers receive the supports and services they need to fulfil their potential and to maintain their identity, resilience and dignity as valued and active citizens in society.

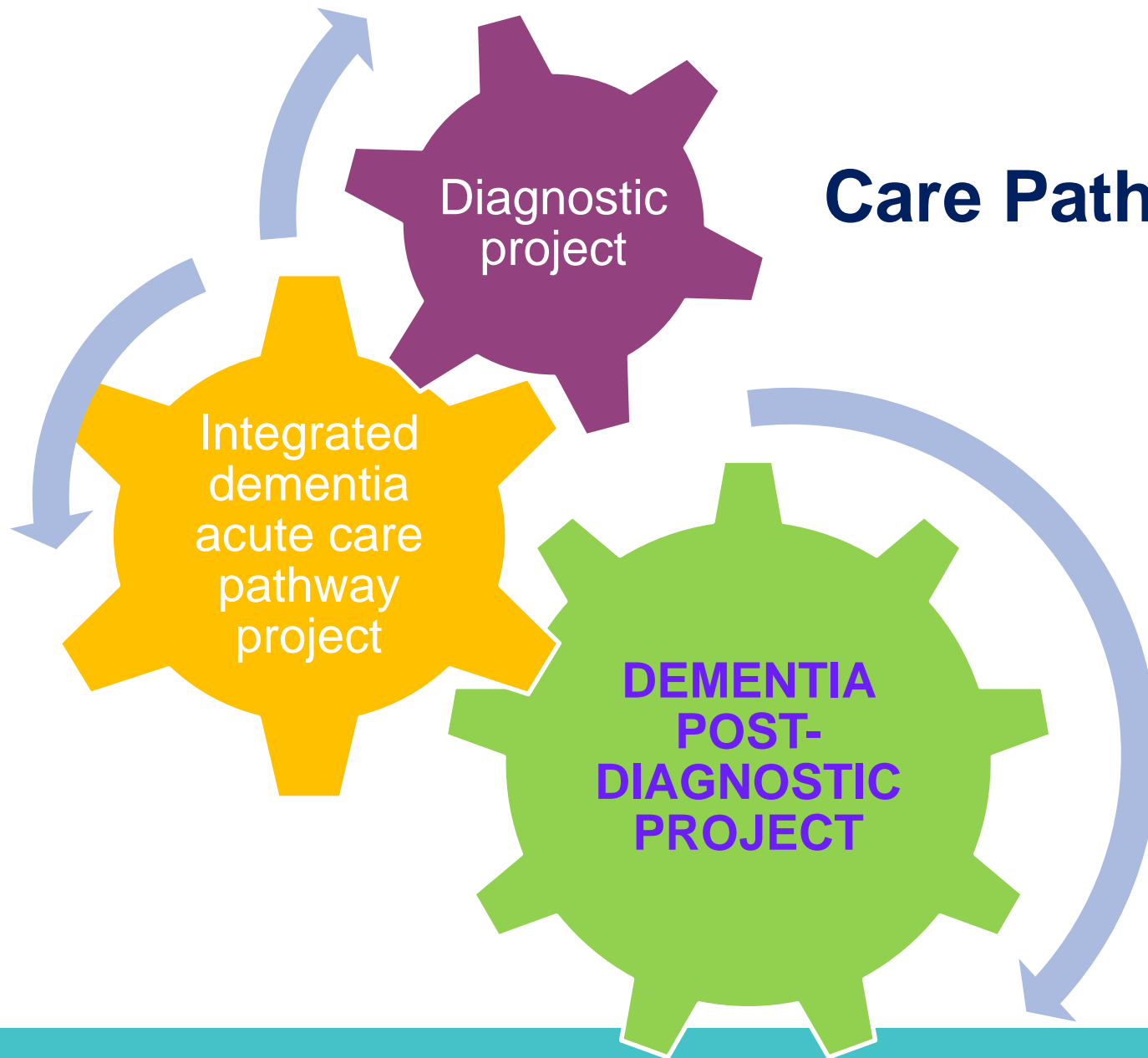
# Objectives:

- To oversee the National Dementia Strategy's implementation.
- Integrate different elements of the strategy into the wider health and social care system.
- To inform policy and practice on dementia care.
- Work in partnership and collaboration with key stakeholders, including people living with dementia and family carers.

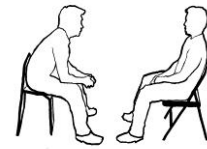
## Priority Area in National Dementia Strategy

The Health Service Executive will develop a National and Local Dementia Care Pathway to describe and clearly signpost the optimal journey through the system from initial presentation with worrying symptoms, through to diagnosis, including levels of intervention appropriate to need at any given time.

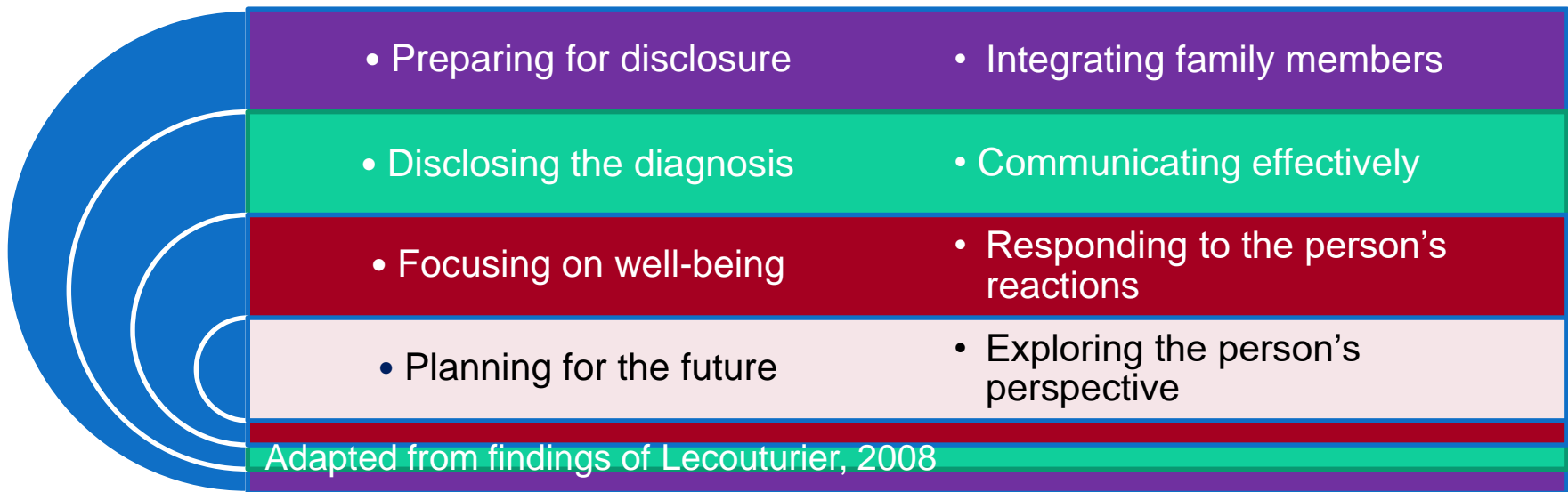
# Care Pathways



# Telling the person (Revez et al, 2018)



- Most people want to know their diagnosis;
- Experiences of diagnosis disclosure can be complex and emotional;
- Many healthcare professionals simply avoid disclosure altogether (at least to the person);
- The pathway of diagnosis-disclosure can be long and fraught ;
- How the person is told has a significant impact on their experience of the condition;
- Tailoring information to the individual.



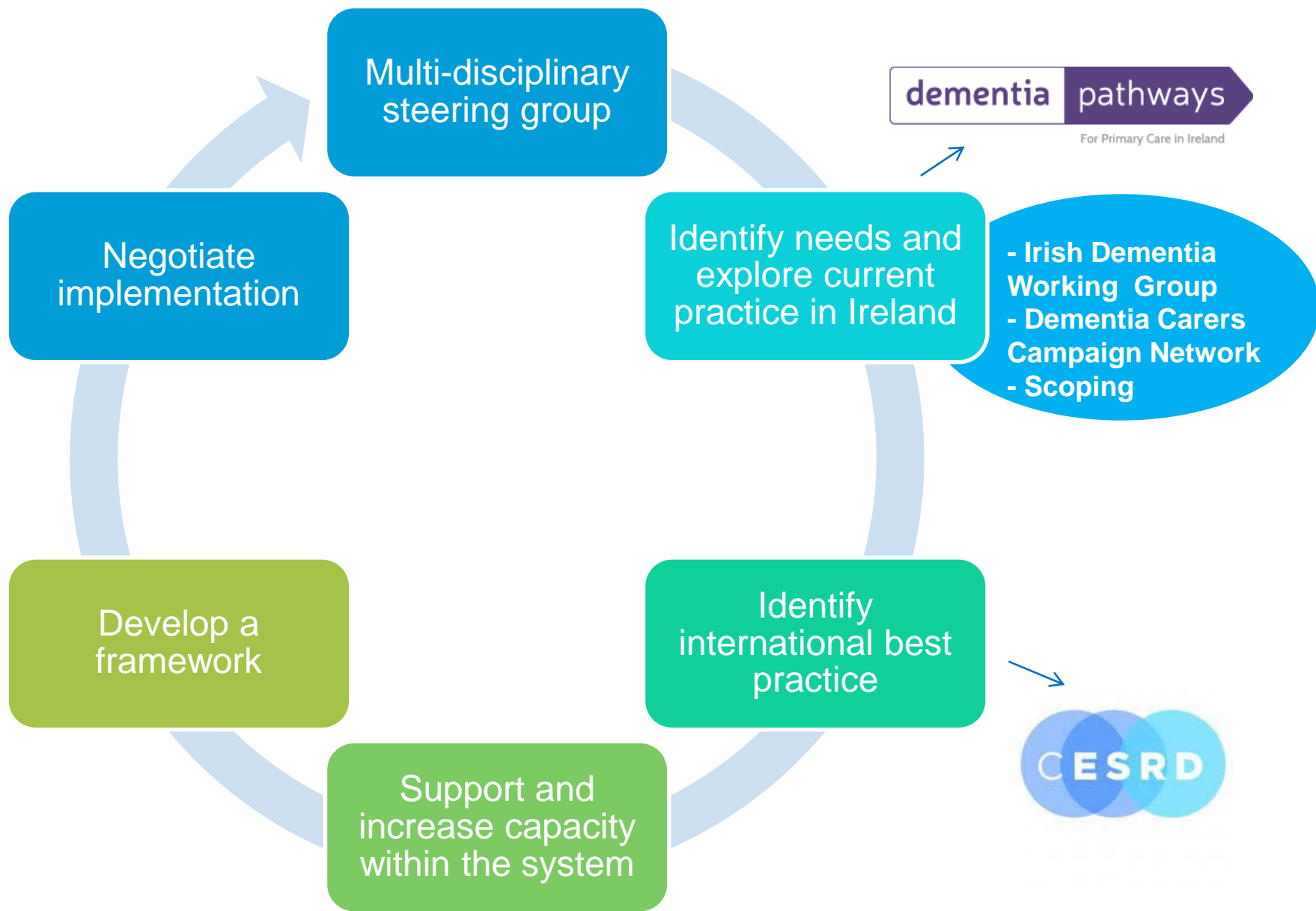
# An Identified Care Gap following a Diagnosis

*“Emotionally it is a hammer blow. It is a serious, it is a depressing thing, it just knocks you sideways. All I was left with was the sickening sense of loss” (person with dementia, PDS needs analysis)*

*“Services offered may be fragmented, poorly coordinated, inflexible and inequitable” (Foley and Swannick, 2014)*

*“Following a diagnosis, the person with dementia will need considerable emotional and practical support. Local, well-coordinated support services are needed to assist people and their families to cope with the choices and dilemmas confronting them at this often distressing and challenging time” (National Dementia Strategy, 2014)*





## Definition of Post-diagnostic Support

“To enable and assist people with dementia and their families to live a life of their choosing throughout the continuum of dementia. Post-diagnostic supports include interventions, therapeutic treatments and activities that build on strengths and abilities; helping to maintain and enhance quality of life”

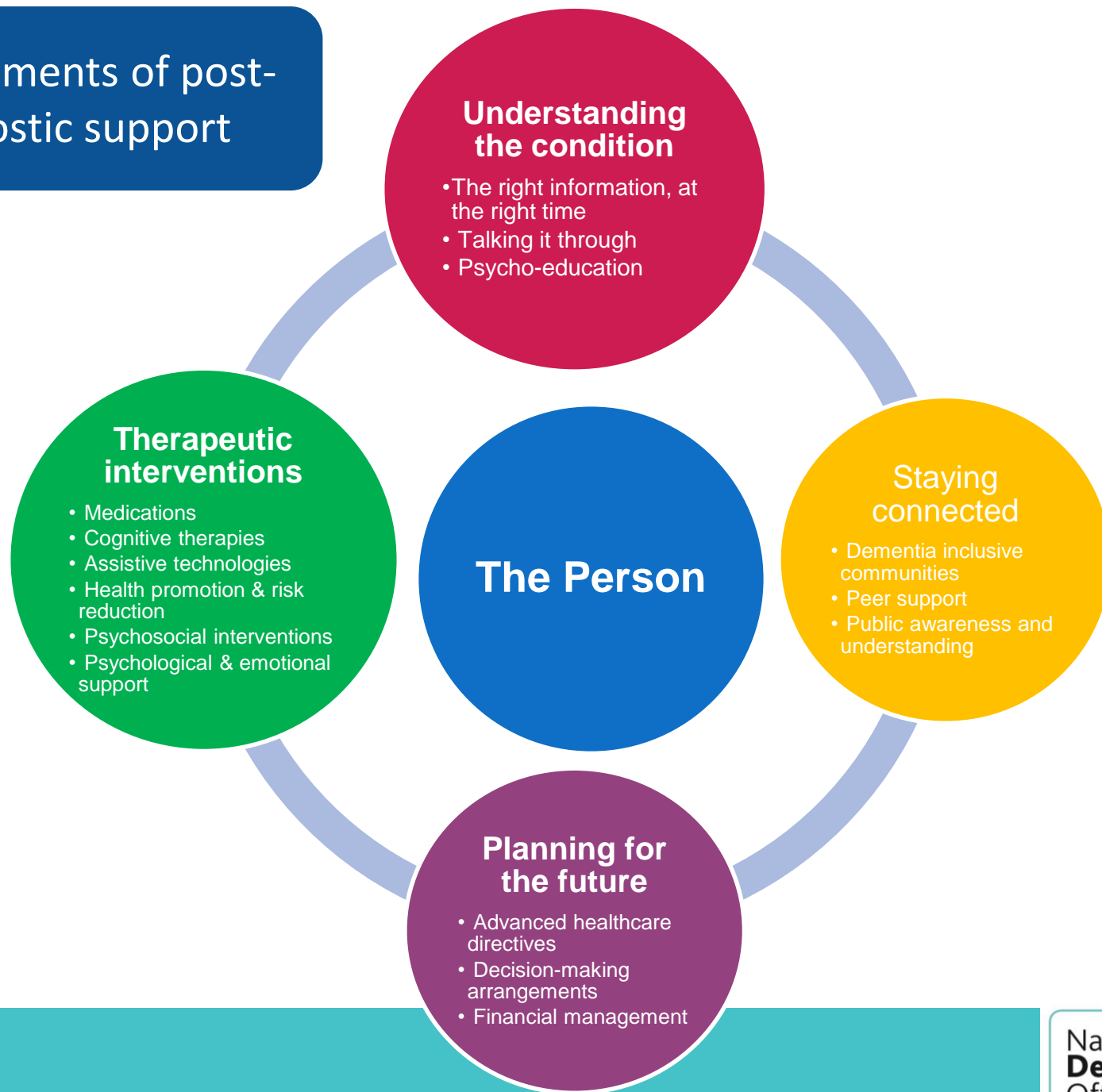
*(Dementia Post-diagnostic Steering Group, 2018)*

# Dementia Post-diagnostic Literature Review

(O'Shea, Keogh and Heneghan, 2018)

- PDS is crucial for contemporary and future decision-making;
- Can reduce anxiety and isolation; helping the person to work through the diagnosis and supports adjusting and coping;
- Can enable the person to plan for a life beyond diagnosis;
- Can reduce home-care placement (targeted carer programmes);
- Approaches can enhance self-efficacy, management of symptoms and maintaining independence;
- Timing of the intervention matters;
- Tiered approach to information provision;
- Responses tailored to the individual;
- Responses should address the needs of both the person with dementia and their supporters;
- Staying connected is very important.

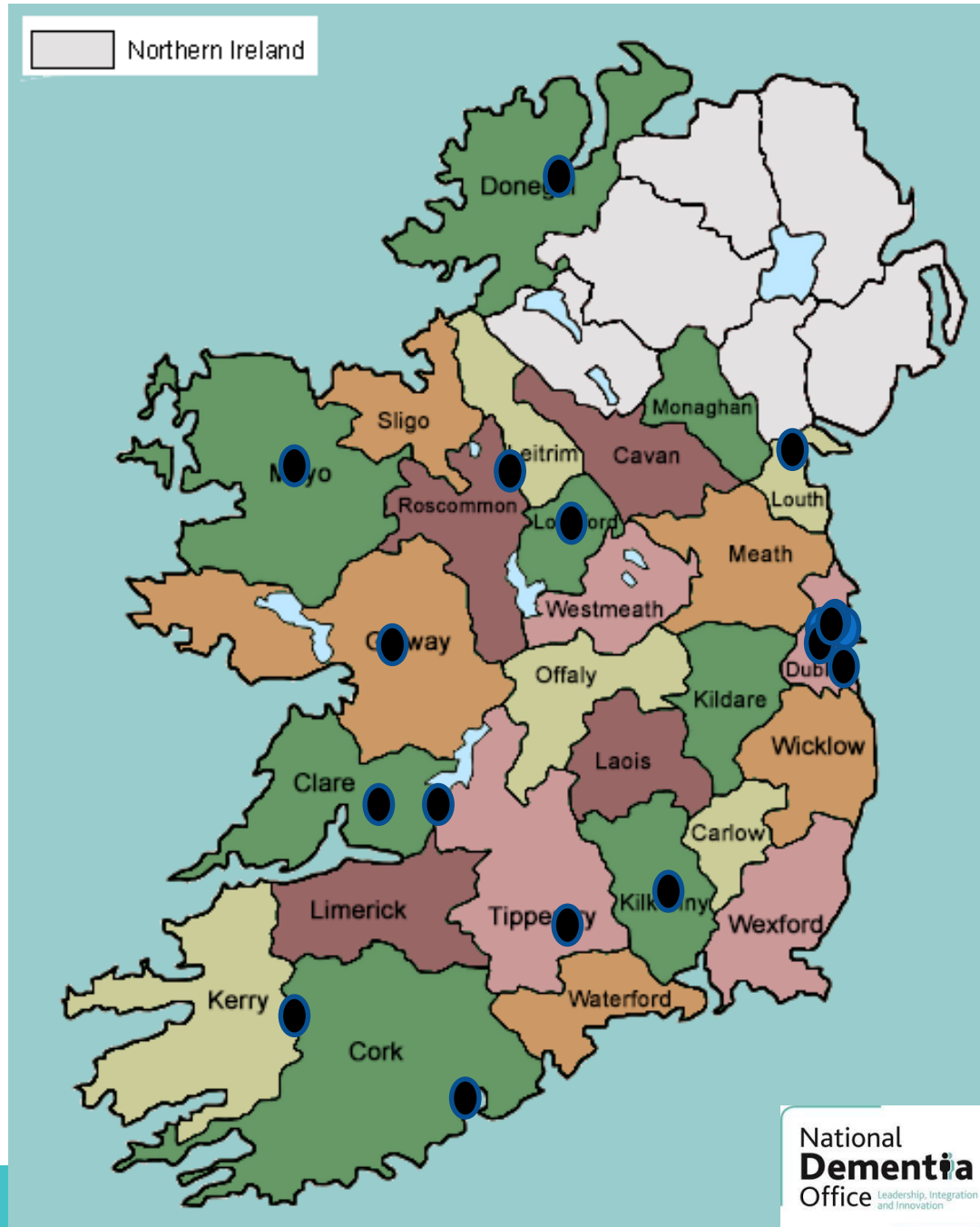
## 4 key elements of post-diagnostic support



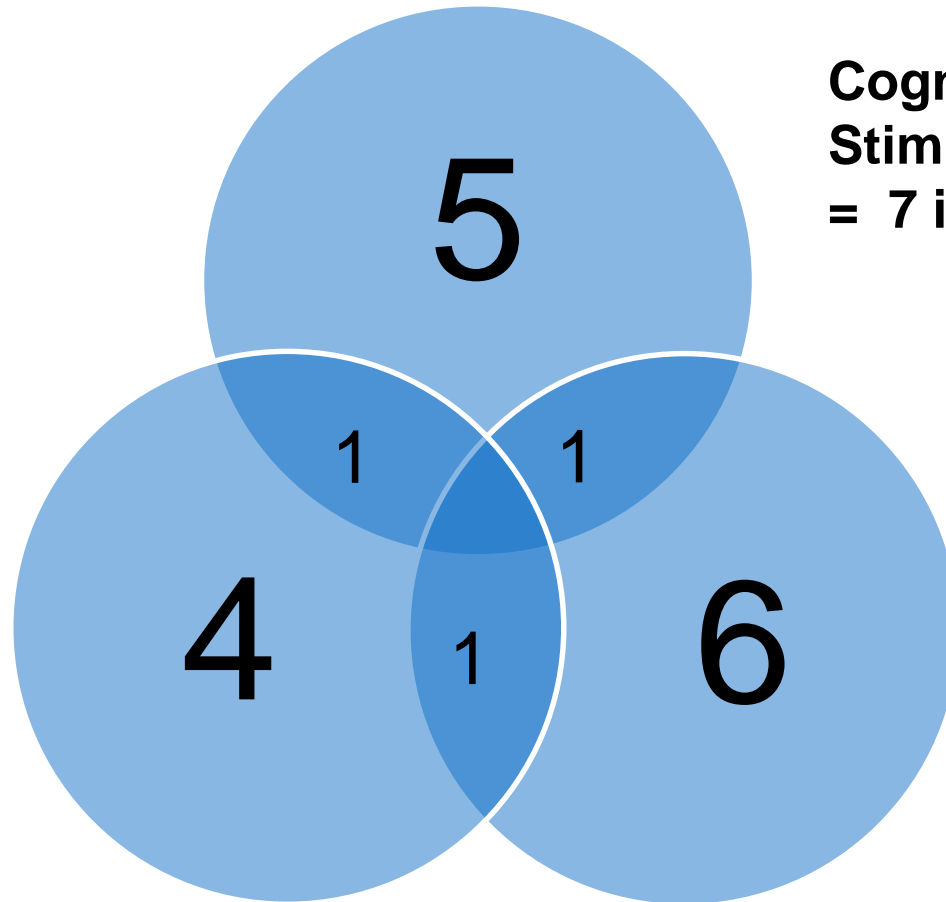
# **Initiative: Dementia Post-diagnostic Grant Scheme**

- Focus on cognitive rehabilitation, cognitive stimulation and psycho-education programmes
- Call for applications April 2018
- €25,000 per grant to cover staff costs
- Open competition across Health Service Executive and section 38 and 39 organisation
- 18 sites
- Two per Community Health Organisation area
- 50+ applications received
- Independently reviewed
- Grants awarded in September 2018.

# Grant Distribution



# Intervention and Programme Areas



**Cognitive  
Rehabilitation  
= 6 in total**

**Cognitive  
Stimulation Therapy  
= 7 in total**

**Psycho-  
educational  
Programmes  
= 8 in total**



# PDS Grant Evaluation

Tender process:  
Awarded to Dr. Maria  
Pierce (independent  
researcher); Dr. Fiona  
Keogh and Prof. Eamon  
O'Shea (CESRD, NUI  
Galway).

## WELLBEING FRAMEWORK



### Purpose:

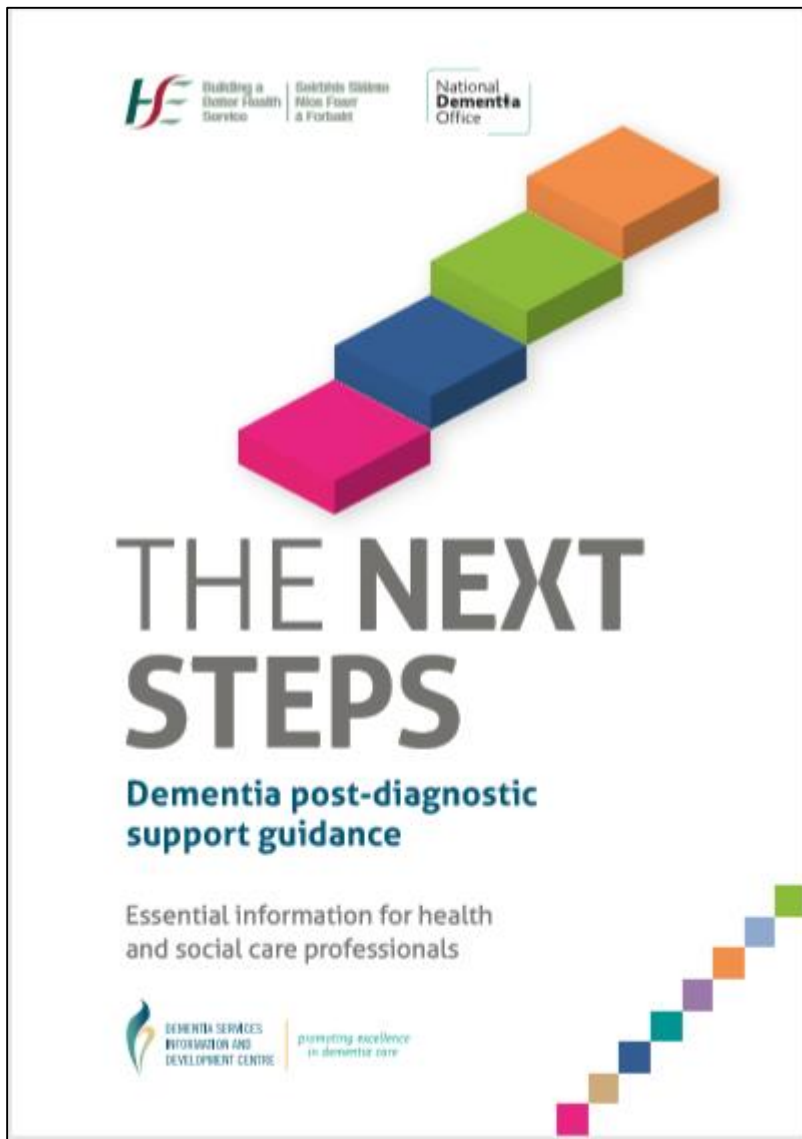
Assess the impact / effectiveness of interventions.

### Primary objectives:

- Describe the programmes delivered and processes around their delivery.
- Assess the impact of the interventions for the person with dementia and their family members.

### Secondary objective:

Assess if the PDS interventions have succeeded in addressing post-diagnostic support and care gaps.



## Dementia Psycho-education Guidance Document (2019)

- Offers suggestions on how to organise a programme;
- Outlines suggested content;
- Offers resource suggestions;
- It is not prescriptive;
- It is adaptable to suit local context

Available as an interactive pdf on

[www.dementia.ie](http://www.dementia.ie)  
[www.understandtogether.ie](http://www.understandtogether.ie)

NDO commissioned the Dementia Services Information and Development Centre to develop this psycho-education guidance; supported by a national multi-disciplinary group

# **Initiative: Memory Technology Resource Rooms (MTRRs)**

# Memory Technology Resource Rooms

A network of MTRR established which aim to support independence and safety for people living with dementia and those with memory difficulties through the use of Assistive Technologies.

- Assistive technology libraries – Genio funded Community Consortia Projects;
- Older Persons Services applied for DoH Dormant Account funding.

# **Initiative: Cognitive Therapy Masterclasses**

**Cognitive Rehabilitation Therapy**, where people with dementia and their supporters work together with a health professional over a number of sessions to identify **personally relevant goals** and devise and implement strategies for achieving them.

It generally refers to an individual approach to improving functioning in the everyday context rather than enhancing performance on general cognitive tasks (Baher-Fuchs et al, 2013)

- Four masterclasses held in November and December 2018.
- NDO partnered with Engaging Dementia.
- Mary McGrath, Advanced Specialist OT facilitated the workshops.
- **111 health and social care professionals** from across the Ireland attended.

# **Initiative: National Intellectual Disability Memory Service**

# National Intellectual Disability Memory Service

Centre of Excellence in proactive dementia assessment and diagnosis for people with an intellectual disability.

The service is led by Prof. Mary McCarron will:

- Operate a central coordinating national memory clinic, with a number of satellite clinics distributed nationally.
- Provide expert consultation which will include person-centred recommendations following a diagnosis of dementia to ensure that the person is in a position to live well and to die with comfort and dignity.



# dementia

understand together

[www.understandtogether.ie](http://www.understandtogether.ie)



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive



THE ALZHEIMER  
SOCIETY OF IRELAND



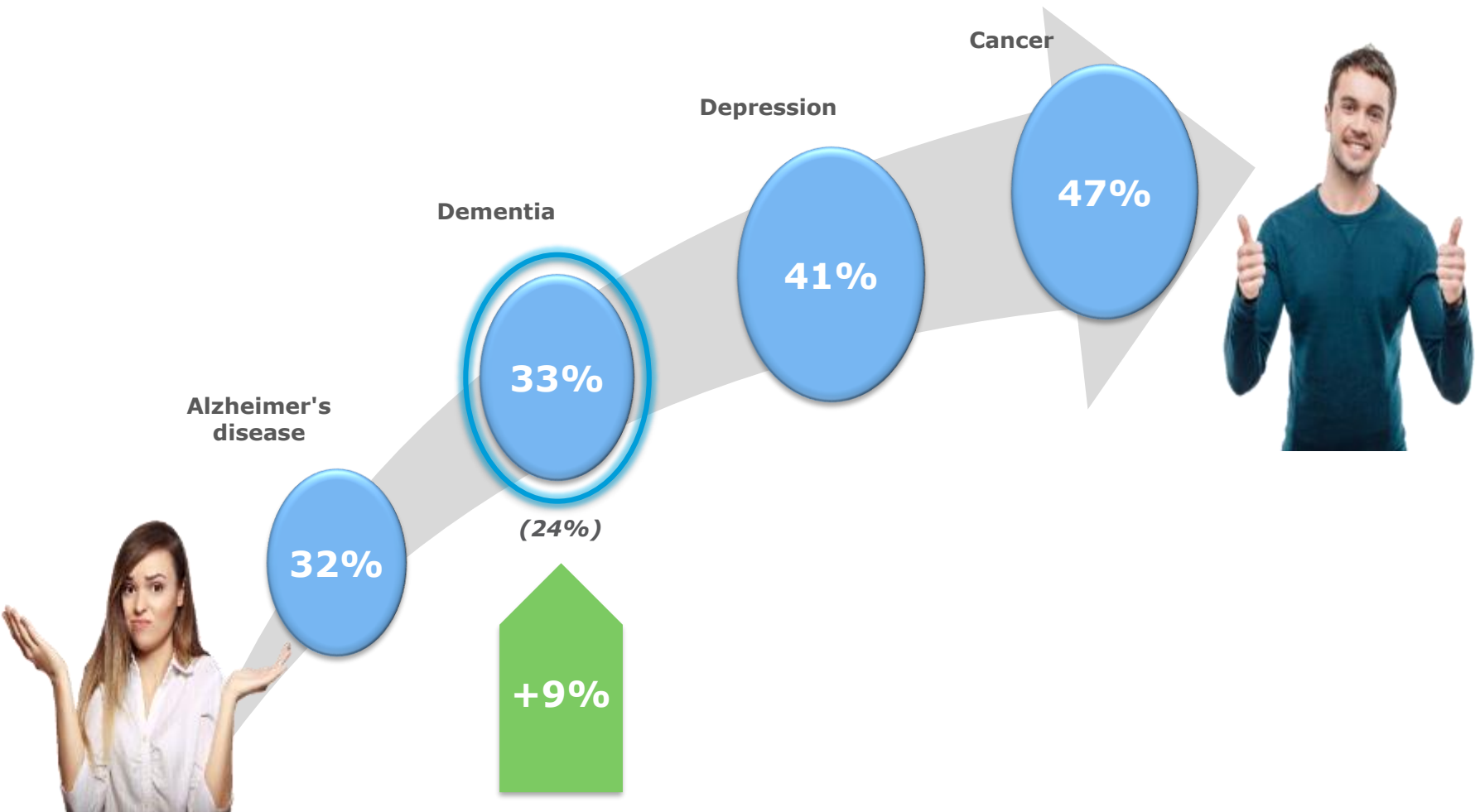
# Dementia: Understand Together campaign



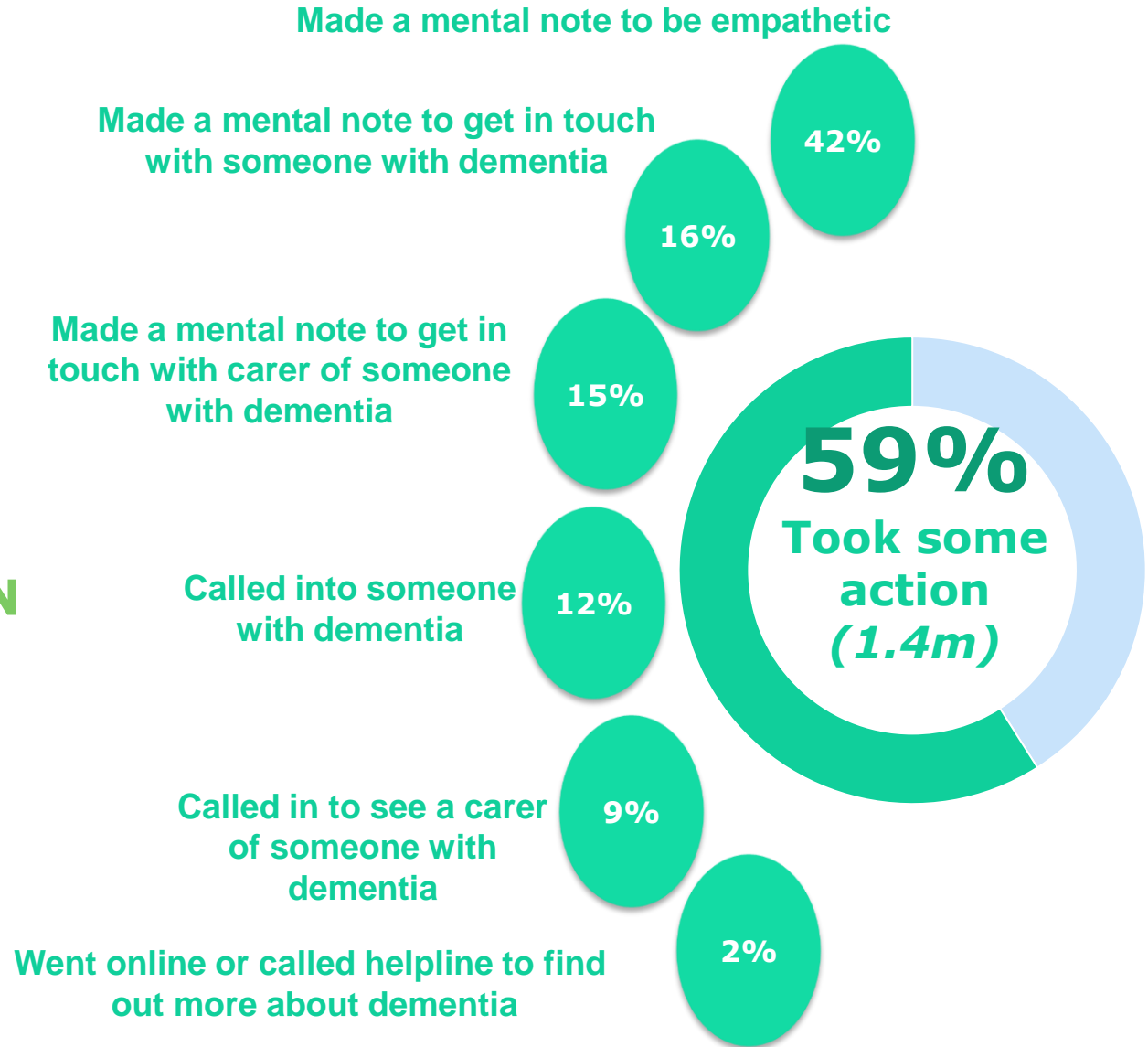
## Survey results



# A third of adults believe they have a reasonable understanding of dementia



**63%**  
Saw  
**TV CAMPAIGN**  
(2.3 million)

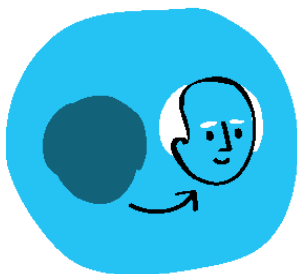


We are growing a **movement** of  
**people taking action**

to create **understanding and inclusive  
communities**

where people with dementia and their families are  
**respected, supported and connected.**





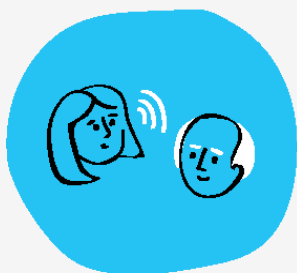
**See the person,  
not the dementia**



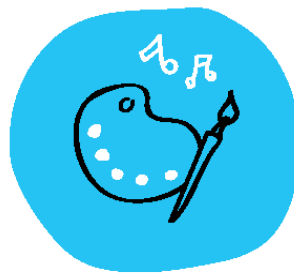
**Talk about  
dementia**



**Ask how you  
can help**



**Stay in  
touch**



**Support the person  
to keep up hobbies  
and interests**



**Make sure your  
service/space  
is easy to use**



# Partners

dementia pathways

For Primary Care in Ireland

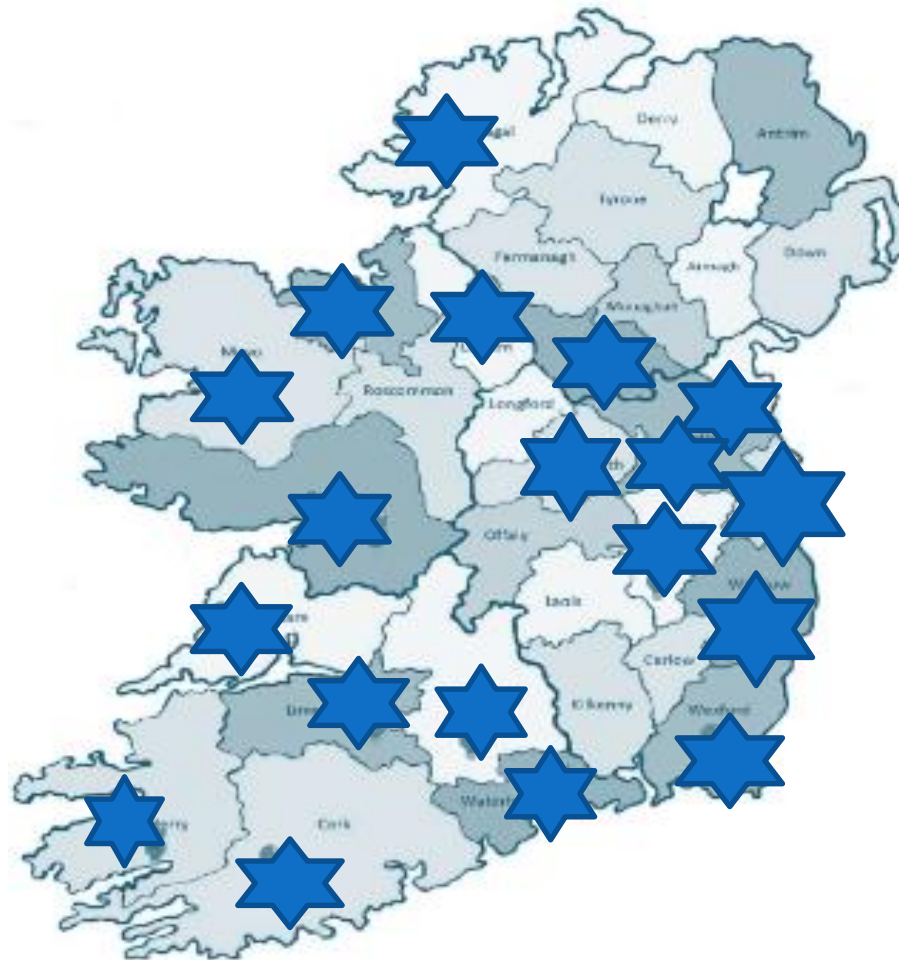


dementia

under stand together



# Growing community of Champions





## **Initiative: Diagnostic and Post-diagnostic Framework**

## Post-Diagnostic Support Project

Identify  
Current  
Practice in  
Ireland

Steering  
Group  
Established

Identify  
International  
Best  
Practice

Support &  
Increase  
Capacity in  
the System



Develop Dementia  
Diagnostic and Post-  
Diagnostic Support  
Framework

## Dementia Diagnostic Project

Steering  
Group  
Established

Identify  
International  
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Identify  
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Support &  
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the System



# Considerations

- **Stigma** may prevent people seeking support;
- Existing services may suit some more than others;
- Flexible, **individualised approaches** needed;
- What is a timely diagnosis?
- Different needs depending on where the person is in their dementia journey;
- **Evidence on the effectiveness** of various PDS interventions is weak;
- Different **local context** in which services are provided e.g. age-related care; mental health; neurology; primary care; secondary care etc.

# Thanks to:

- National Dementia Post-diagnostic Support Steering Group;
- Mary Manning, Anna de Siun and Suzanne Timmons of the National Dementia Office;
- Fiona Foley, Roisin Guiry and the Understand Together Community Activation Working Group

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[www.understandtogether.ie](http://www.understandtogether.ie)

[www.hse.ie/dementia](http://www.hse.ie/dementia)

[@dementia\\_office](https://twitter.com/dementia_office)

Get in  
touch