#### CLAHRC NWC FEBRUARY 2019

# **NHS** National Institute for Health Research

# **CLAHRC**BITE

Brokering Innovation Through Evidence

## TITLE: Wigan Later Life and Memory Service (LLAMS):

Improving Young Onset Dementia (YOD) Services



## Background

The purpose of the evaluation was to ask whether the care provided by Wigan Later Life and Memory Service (LLAMS) is acceptable to people living with young onset dementia (YOD) and the people who support them. The evaluation also aimed to identify gaps in how services are provided and how services could be improved.

People who are diagnosed with dementia before they are 65 often have different needs to people diagnosed later in life. They may have financial and work commitments, care for children and be physically fit and well. However dementia services are generally designed for and attended by older people and so services may not meet the needs of younger people.

In Wigan, it is estimated that 130 people are living with YOD. They are offered the same diagnostic and post-diagnostic support as people with late onset dementia, which raised the question of whether the service is meeting their needs.

#### What did we do?

• Questionnaires were sent to people living with YOD who were registered with the local Alzheimer's Society Dementia Adviser service and people who were open to LLAMS.

• The questionnaires included an invitation to take part in an interview to discuss their experiences in more detail.

• Two discussion groups were held with staff from LLAMS so that they could share their experiences of working with people with YOD and their perspective on services.

#### What we found and what does this mean?

Staff and people who had used the service felt that the process of diagnosis dementia worked well. People value the support given by their key worker as they were getting used to their diagnosis. However, there were gaps in the service after diagnosis and a lack of suitable activities and support in the community after people had been discharged from LLAMS.

People living with YOD and their families want to meet with other people in the same situation. They are not using dementia services and activities in the community because they feel out of place or believe that they will not be right for them. It is a challenge to include people with YOD in developing services after they are discharged from LLAMS. People often become involved with this work because they attend dementia support in the community and this is not being accessed by people with YOD.

#### What next?

• Working with other agencies in Wigan to set up a support group for people with YOD and their families and friends.

• Identifying how LLAMS can give more support to people with YOD and their carers after they are diagnosed.

• Identifying how training and information can be used to improve staff knowledge and skills in working with people with YOD.

• Supporting people with dementia and their carers to take part in patient engagement and involvement work.

#### What is NIHR CLAHRC NWC?

The mission of the NIHR CLAHRC NWC is to work collaboratively with Partner organisations and other stakeholders including members of the public to coproduce and conduct high-quality, leadership enhancing, applied research designed to decrease health inequalities and improve the health of the population of the North West Coast.

#### Find out more

http://www.clahrc-nwc.nihr.ac.uk/index.php

info-clahrc-nwc@nihr.ac.uk / 0151 795 5342



Partners / Stakeholders