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## **The ANGELA Project: Improving diagnosis and post-diagnostic support for younger people with dementia and their families/supporters**

### **Dr. Vasileios Stamou<sup>a</sup>**

<sup>a</sup>School of Dementia Studies, Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, email: V.Stamou@bradford.ac.uk

### **Dr. Jenny La Fontaine<sup>a</sup>**

<sup>a</sup>School of Dementia Studies, Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, email: J.Lafontaine@bradford.ac.uk

### **Prof. Jan Oyebode<sup>a</sup>**

<sup>a</sup>School of Dementia Studies, Centre for Applied Dementia Studies, Faculty of Health Studies, University of Bradford, email: J.Oyebode@bradford.ac.uk

### **Dr. Bridget Jones<sup>b</sup>**

<sup>b</sup>Surrey Health Economics Centre, Department of Economics, University of Surrey, email: b.e.jones@surrey.ac.uk

### **Prof. Heather Gage<sup>b</sup>**

<sup>b</sup>Surrey Health Economics Centre, Department of Economics, University of Surrey, email: h.gage@surrey.ac.uk

### **Dr. Mary O'Malley<sup>c</sup>**

<sup>c</sup>Centre for Applied Mental Health Research, Faculty of Health and Society, University of Northampton, email: Mary.O'Malley@northampton.ac.uk

### **Prof. Jacqueline Parkes<sup>c</sup>**

<sup>c</sup>Centre for Applied Mental Health Research, Faculty of Health and Society, University of Northampton, email: jacqueline.parkes@northampton.ac.uk

### **Dr. Janet Carter<sup>d</sup>**

<sup>d</sup>Division of Psychiatry, Faculty of Brain Sciences, University College London, email: j.carter@ucl.ac.uk

## **Abstract**

**Objectives:** Younger people with dementia face significant challenges in gaining access to age- and needs-appropriate support. In this paper, we tell the story so far, of the ANGELA Research Project, which seeks to develop guidance to improve the ‘dementia journey’ for younger people with dementia and their families/supporters.

**Design:** Our story is one of a research group aiming to conduct clinically relevant research to achieve positive changes for younger people with dementia. Our research journey will last 3 years and is now almost one year in. In this article, we aim to convey some of the decisions we have made to date, and what lies ahead for a successful implementation.

**Methods:** So far, we have been forming as a research group and turning our initial ideas into plans that will work in the real world. Our methods for ensuring all elements of the project work well have involved internal and external aspects and processes. These have included involvement with and feedback from experts-by-experience and an advisory panel.

**Results:** To date we have generated a protocol for all the key elements and have launched the Improving Support and Service Use Survey; a national survey gathering evidence from younger people with dementia and their supporters. In this article, we present how we aim to move forward to bring positive real-life changes to the lives of those affected by young onset dementia.

**Conclusions:** There is a cautiously happy ending to this first phase, as we are now collecting data. However, the judgement of whether the Angela Project is a success overall will depend on whether it makes a difference at its conclusion to younger people with dementia and their supporters.

## 1. Introduction

Younger people living with dementia (YPD) have been at the forefront of the growing campaign to challenge society's attitude to dementia. Currently, there are an estimated 42,325 people with young onset dementia (YOD) (onset < 65 years) in the UK, with numbers expected to rise by 20% over the next 38 years (Alzheimer's Society, 2014). However, despite their increased visibility, receiving a timely and accurate diagnosis and gaining access to appropriate support remain challenging processes for younger people with dementia and their supporters.

Traditionally, the allocation of responsibility for YPD has been inconsistent across the country and has led many service users to 'fall through the net' of services. A characteristic example of how problematic this situation may be is the average time from symptom onset to diagnosis, which is approximately 4 years compared to 2 years in older people. Contributing factors to this delay appear to be lack of awareness among general practitioners and other key professionals that dementia can occur in younger people and lack of recognition of unusual presenting symptoms (Van Vliet et al, 2012). These factors often lead to insufficient investigation, misdiagnosis and multiple or misdirected referrals into care pathways (Fadil et al, 2009; Harris & Keady, 2004; McMurtry et al, 2006) that further delay diagnosis and post-diagnostic help (Van Vliet et al., 2013).

Young onset dementia has a vast differential diagnosis. It includes less commonly occurring forms of dementia such as fronto-temporal dementia, dementia with Lewy bodies and posterior cortical atrophy, as well as rare sporadic or hereditary diseases (Ridha & Josephs, 2006; Sampson et al, 2004) which present particular diagnostic challenges (Bakker et al, 2013). As a result, it may not be clear where to refer a person for specialist assessment since the GP may think an old age service is not the right place, but an adult mental health service may not know about YOD either. Furthermore, prominent changes in mood, or cognitive functions such word-finding or visual perception, that present more commonly in YOD, can often be misdiagnosed as depression or anxiety (Mendez, 2006; Woolley et al, 2011). Indicative of the extent of this dysfunctionality in diagnostic services are the findings of a systematic blind case note review which included 252 younger people eventually diagnosed with dementia, and revealed that 30% had previously received an incorrect psychiatric diagnosis when presenting to a memory clinic (Bakker et al, 2013), highlighting the need for specialist expertise in YOD diagnosis. Consistent with this view, a recent survey of key healthcare professionals across the UK showed that only a minority of services provided access to a consultant with specialist expertise in the diagnosis of YOD (Rodda & Carter, 2016). Opportunities for case discussions with other professionals such as neurologists, psychologists and neuro-radiologists appeared to be limited or non-existent in most services, underscoring the need to integrate specialist knowledge of YOD diagnosis in secondary care, in order to ensure consideration of all the clinical features that are required for diagnosis (Rossor et al, 2010). Considering the complexity and multifactorial nature of the various subtypes of YOD and the absence of well-established standardised instruments and processes for YOD diagnosis, it becomes evident that diagnosing YOD poses a significant challenge for all who are involved.

The guidelines of the National Institute for Health and Care Excellence (NICE) clearly recognise that YPD have special requirements, and specialist multidisciplinary services should be developed - allied to existing dementia services - to meet the needs for assessment, diagnosis and post-diagnostic care (National Institute for Health and Clinical Excellence, 2006). The Alzheimer's Society has advocated the appointment of a dementia lead in Clinical Commissioning Groups with responsibility for identifying and assessing the specific needs of YPD when planning and commissioning services (Alzheimer's Society, 2014). Despite increasing focus upon needs-led services, the available evidence suggests that this model of good practice is not currently reflected in the majority of post-diagnostic services provided in the UK and numerous gaps exist in the provision of care for YPD.

The essential elements of service provision for YPD include clear pathways into care, increased availability of more meaningful occupational and social activities, and age-appropriate short-stay and long-term care (Alzheimer's Society, 2014; National Institute for Health and Clinical Excellence, 2006). For example, younger people with dementia may prefer to retain a physically active lifestyle or may have a strong wish to remain in work. They may have dependent children or ageing parents who they need to care for or have significant financial commitments. As a consequence, the transition to living with dementia after diagnosis requires access to age-appropriate services and specific types of support. However, the national survey cited earlier highlighted that there is limited or no availability of post-diagnostic support that meets the specific life-stage and age-related needs of YPD, nor sufficient short-stay or long-term care in most regions (Rodda & Carter, 2016). Almost a third of the professionals responding to the survey reported that no post-diagnostic support was available to YPD; 43% reported no access to cognitive stimulation therapy even though it is recommended in NICE guidelines (Spector et al, 2010); and under a third reported that age-specific occupational or social groups were available in their area (Rodda & Carter, 2016). The lack of dedicated age-appropriate services often places YPD in significant distress and undermines their quality of life. Of note, international studies of YOD have identified that family members and friends, rather than formal services, provide most of the care needed. For example, a community-based prospective longitudinal study of 215 YPD and their informal caregivers in the Netherlands (Allen et al, 2009) examined the use of formal and informal support networks and demonstrated that informal care had a 3:1 ratio with formal care. The amount of informal care was directly associated with disease severity, whereas the amount of formal care was related to high levels of distress and increased difficulty with activities of daily living (Allen et al, 2009).

In light of the current evidence on delayed diagnosis, lack of age- and needs-appropriate post-diagnostic support, and the grave impact these have upon the lives of those living with YOD and their families, the aims of the study presented in this article focus on improving diagnostic accuracy and post-diagnostic support for younger people with dementia and their families/supporters.

## **2. Aims and Objectives**

The ANGELA Project is composed of two work-streams which have two specific aims. Work-

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stream 1 aims to provide guidance for improving the accuracy of clinical diagnosis in YOD, and work-stream 2 aims to provide guidance that will enable commissioners and service providers to facilitate improvements in post-diagnostic care and support.

The objectives of work-stream 1 are to develop specific quality indicators that will act as a guide for clinicians during YOD diagnosis and to understand how the process of receiving a diagnosis can be improved for YPD and their supporters.

The objective of work-stream 2 is to facilitate the improvement of post-diagnostic services and support by developing guidance on best practice across the care pathway.

### **3. Methods**

The ANGELA project has been approved by the South Central - Berkshire Research Ethics Committee and by the Health Research Authority. It is taking place at a national level in England and includes eight key designated NHS sites in the North, Midlands, and South of the country that reflect the breadth of diagnostic arrangements for YPD (i.e. dedicated YOD diagnostic services, age-generic dementia diagnosis services and neurology services), as well as a range of other sites which will take part in selected aspects of the study.

#### **3.1 Design**

Two Delphi studies (see figure 1) will be carried out by work-stream 1 with a group of 40 international and national experts and stakeholders (Delphi-PRO) and with 40 purposively selected YPD and supporters (Delphi-EXP) including representatives from Black and Minority Ethnic communities, to establish a consensus view on quality indicators for accurate diagnosis and a consensus view on the optimum diagnostic experience from the users' perspective. A case note audit of current UK clinical practice will then be conducted for comparison with the quality standards developed during the two Delphi studies.

Work-stream 2 involves three different stages (see figure 1). In the current first stage, a cross-sectional semi-structured national survey is being conducted to identify examples of positive post-diagnostic services across the care pathway and gain an overview of current service use, costs and satisfaction with care, and care patterns (formal vs. informal) within England. The survey is entitled the Improving Support and Service Use Survey (ISS) with the aim of gathering a minimum of 200 responses. During this stage, focus groups will also take place in the 8 key sites and in other purposively selected sites to include participants who may otherwise not be consulted, such as those attending groups organized by BME communities or younger people with dementia who live alone and may not have access to others who can help them to complete the survey. In the second stage, follow up interviews will take place with 50 YPD and 50 supporters who will also be purposively selected to provide further depth concerning the characteristics of positive services and to identify the needs that these services address. In the third stage, 45 interviews with service providers and commissioners will allow the

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investigation of potential barriers and facilitators to commissioning or providing needs-based positive care for YPD and their supporters.

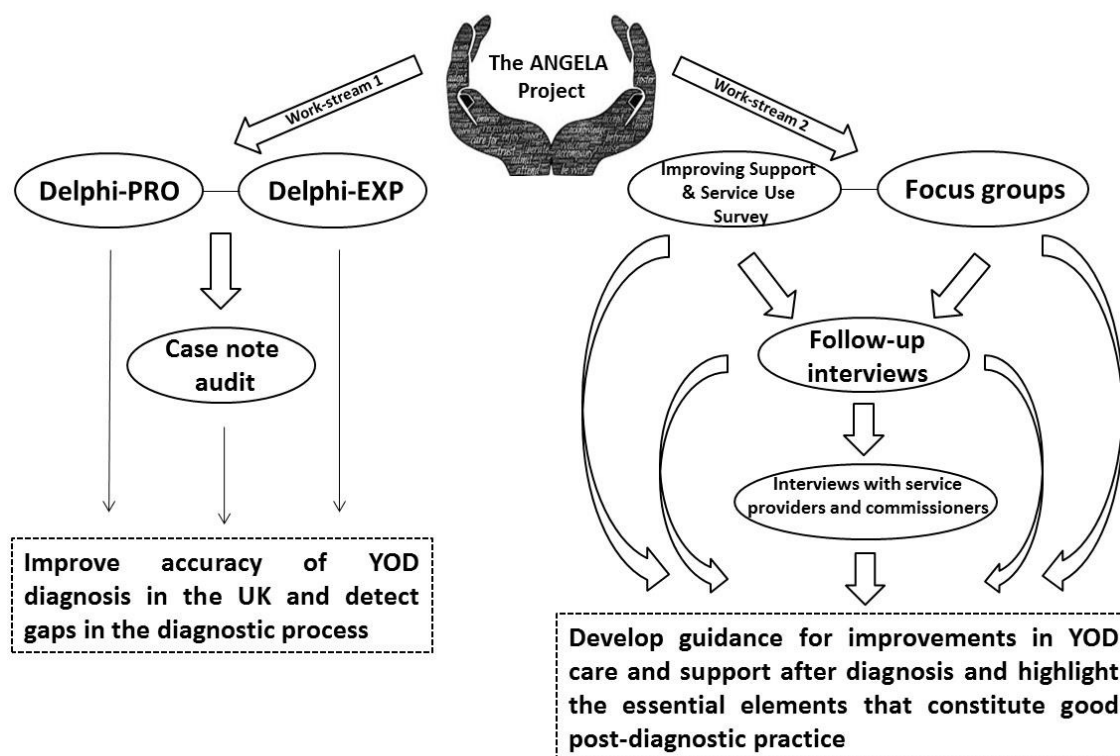


Fig. 1. Flowchart presenting the research activities of the two work-streams of the ANGELA Project.

### 3.2 Participants

Participants are people with a diagnosis of dementia given before their 65th birthday, primary carers of YPD, and other family members or supporters who are affected by the diagnosis of YOD. We are not including younger people diagnosed with dementia related to HIV, traumatic brain injury, Huntington's chorea, alcohol misuse, or Down's syndrome as they usually have different needs and access different services.

## 4. Results

Following completion of work-stream 1, we anticipate producing specific Guidelines for Best Practice in Diagnosis for YOD, highlighting the key quality indicators that screen for typical causes of cognitive and behavioural dysfunction and a rational approach to additional testing that is based on selected features of the history and examination, to achieve faster and more accurate diagnosis. The guidelines are further expected to underscore key elements of the lived experience of receiving a YOD diagnosis and represent a balanced view that is based on the expertise of both clinicians and YPD and their supporters.

Similarly, the completion of work-stream 2 is expected to result in Good Practice Guidance for Post-diagnostic Services and Support for younger people with dementia and their families/supporters. This will include practical examples of services that illustrate this guidance and meet specific needs of service users, as well as important information concerning barriers and facilitators to providing and commissioning such services and support, in order to highlight the route towards service provision that meets the full range of needs across the experience of young onset dementia.

## **5. Summary and Conclusions**

The judgement of whether the Angela Project is a success overall will depend on whether it brings positive real-life changes to younger people with dementia and their supporters at its conclusion. The solid research design of the study combined with the positive rate of participation observed so far seem to be promising for the potential future impact of the project on the services and support offered to YPD and their families as well as on raising awareness about young onset dementia in the public. This impact is expected to be enhanced by the project dissemination plans which will target professional and lay audiences composed of health and social care professionals, researchers and academics, clinicians, people from the young onset dementia community and the general public.

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