Receiving a diagnosis of young onset dementia: evidence-based statements to inform best practice

O'Malley, Mary ORCID: https://orcid.org/0000-0003-3636-6197, Parkes, Jacqueline, Campbell, Jackie, Stamou, Vasileios, La Fontaine, Jenny, Oyebode, Jan and Carter, Janet (2020) Receiving a diagnosis of young onset dementia: evidence-based statements to inform best practice. Dementia. ISSN 1471-3012

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Abstract:

Introduction: Better understanding of patient experience is an important driver for service improvements and can act as a lever for system change. In the UK, the patient experience is now a central issue for the NHS Commissioning Board, Clinical Commissioning Groups and the providers they commission from. Traditionally, dementia care in the UK has focused predominantly on the individual experience of those with late onset dementia, while the voice of those with young onset dementia has been, comparatively, unheard. This study aims to improve the understanding of the personal experience of younger people undergoing investigation for dementia.

Methods: A modified Delphi approach was undertaken with 18 younger people with dementia and 18 supporters of people with young onset dementia. Questions were informed by a scoping review of the literature (O'Malley, Carter, et al., 2019). Summary individual statements were refined over two rounds to a final list of 29 key statements.

Results: Twenty-seven of these statements were rated as absolutely essential or very important and included the (1) For the GP to identify dementia in younger people, (2) Clinicians should be compassionate, empathic and respectful during the assessment and particularly sensitive when providing information about a diagnosis, and (3) Remembering that receiving the diagnosis is a lot to absorb for a person with dementia and their supporter. Statistical analyses found no difference in the scoring patterns between younger people with dementia and supporters, suggesting similar shared experiences during the diagnostic process.

Conclusion: Understanding the uniquely personal experience of young people going through the process of diagnosis for dementia is essential to providing person-centred, needs-led, and cost-effective services. Patient's values and experiences should be used to support and guide clinical decision making.

Keywords: young onset dementia, dementia assessment, diagnosis, lived experiences, Delphi methods

Introduction:

The prominence of the ‘patient experience’ as the fourth of five domains in the NHS Outcomes Framework (NHS Digital, 2019) highlights that the patient experience has become a central issue for the NHS Commissioning Board, Clinical Commissioning Groups (CCGs) and the providers they commission from. A better understanding of patient experience can drive service improvements, and act as a lever for system change, but at an individual level it is crucial to providing healthcare which is person-centred and meets emotional and physical needs. The King’s Fund in 2011 (Robert et al., 2011) documented that providing the right care the first time around, and reducing multiple assessments improves the patient experience in the NHS and avoids unnecessary expenditure. Delivering exceptional patient experience requires the optimising of staff interactions with patients and families and support for staff through ongoing education, training and development.

People with young onset dementia (YOD) face inequity across the dementia pathway compared to those with late onset dementia. This includes taking longer to get an accurate and specific diagnosis, a lack of age appropriate services, and a lack of support to meet their unique needs (Rodda & Carter, 2016; Svanberg, Spector, & Stott, 2011; van Vliet et al., 2013). Capturing what matters to younger adults diagnosed with dementia undergoing assessment for dementia is currently lacking (O’Malley, Carter, Stamou, La Fontaine, Oyebode & Parkes, 2019). International research shows that for these young people, aged below 65, receiving a confirmed and accurate diagnosis of dementia can be a long and daunting process, taking on average up to four years in the Netherlands (van Vliet et al., 2013; Vernooij-Dassen, 2006) and 4.7 years in Australia (Draper et al., 2016). Compared with late onset dementia (dementia diagnosed over the age of 65), the presentations of YOD are likely to be of rare cause disorders, and the common dementias (such as Alzheimer’s disease) frequently present with atypical symptoms (such as visual loss as seen in Alzheimer’s disease variant of posterior cortical atrophy) rather than with memory loss as the first symptom (Harding et al., 2018; Rosness et al., 2016; Vieira et al., 2013).

The increased frequency of symptoms, other than memory loss, upon first presentation tends to result in misdiagnoses, such as psychiatric disorders, depression, or other neurological illness (Vieira et al., 2013). Even when presentations include complaints about memory loss, the lack of YOD awareness amongst some healthcare professionals can result in a late detection of red flag symptoms and an under recognition that dementia could be the underlying cause of the symptoms. This period is coupled with feelings of uncertainty for families, and a delay in accessing suitable support (Williams et al., 2001). Timely and accurate diagnoses as well as increased awareness of YOD amongst healthcare professionals would help mitigate these issues (Millenaar et al., 2016; Sansoni et al., 2016).

Qualitative studies involving younger people with dementia have illuminated how personal and individual the diagnostic journey is (Rabanal et al., 2018; Roach et al., 2016; Wawrziczny et al., 2016). A recent literature review (O'Malley, Carter, et al., 2019) has highlighted that delays in diagnosis can be attributed to the initial delays in accessing help by the younger person, and the misattribution of symptoms by the clinician. The review also illuminated how reactions to the diagnosis can range from feelings of reassurance (in that their symptoms are now explained), to shock and destabilisation. In addition, the review emphasised how unique the impact of receiving a diagnosis is to each family affected, and how vital the role of the clinician in communicating the diagnosis.

Although a body of research has emphasised qualitative aspects of the experience of diagnosis for young people with dementia (O'Malley, Carter, et al., 2019), no research to date has employed a quantitative method aimed at generating and collating the important aspects of the individual experience during the referral, assessment and diagnosis of dementia in a younger adult.

The present study forms part of the evidence for ongoing research conducted by the authors, aimed at improving the quality of diagnosis for YPD (UCL, 2016). The design of the study is a modified Delphi approach in which people living with YOD and their supporters living in England were consulted. In order to further inform this under-researched field, the Delphi process described here was modified to suit the needs of our participants. The findings will provide unique tenets for a code of best practice against which services can be benchmarked.

Method:

Study Design:

Steering group

The decision to conduct a Delphi study with people living with YOD and their family supporters came from a meeting with the Angela Project's steering group committee. The Angela Project study design originally included a Delphi study with clinicial experts in diagnosis of YOD. Re-evaluation by the research team and steering group committee about the study aims concluded that balance must be provided by additional consultation with experts by experience to understand their personal views about the experience of diagnosis . This led to the current Delphi study format, which has been appropriately adapted to accommodate the unique needs of this specific group.

Public and patient involvement group

In line with the CO-researcher INvolvement and Engagement in Dementia (COINED) Model, (Swarbrick et al., 2016), the Patient and Public involvement group (PPI) for our study was an integral part of the project. The Angela Project's PPI group was involved from the beginning through to the dissemination phase of the project (Oliver et al., 2020).

Literature review

An in-depth literature review (O'Malley, Carter, et al., 2019) was conducted to provide focus for the questions and the modified delphi study design. The review identified eight qualitative research studies which highlighted the key diagnostic concerns for those with young onset dementia as a theme or finding. The review clearly indicated that there was a need for a study specifically focusing on the diagnostic journey.

Delphi Method

The Delphi method is particularly useful in situations where existing literature is incomplete and inconsistent (Hasson et al., 2000; Keeney et al., 2006). It involves a structured process of collecting information on a specific subject or problem from a panel of experts through a series of questionnaires. The approach allows anonymised individuals to freely express their opinions, reconsider them in the light of collective opinions from the whole group and initiate a narrowing of the range of opinions with each round to gain consensus. As the study focused on an under-studied area, involving a group whose voices are often not heard, we undertook a qualitative first round to capture the experiences and views of our participants (Iqbal & Pipon-Young, 2009; Van Der Steen et al., 2014). Whilst there are shared experiences across individuals and families during the diagnostic journey, receiving a diagnosis of dementia is a unique experience. With this in mind, we modified the Delphi to include all statements in the final list (including those where consensus was not reached) with their corresponding descriptive statistics to ensure all views were reported and not discarded. In addition, we also offered an e-Delphi option to enable our participants to complete the process online should this suit their personal circumstance.

In the present study, the Delphi process to determine what constitutes a good diagnostic experience for YPD involved four steps: (1) formation of the expert panels, (2) survey development informed by a literature search, (3) data collection and analysis, and (4) guidelines development.

Sample Selection:

The Delphi expert panel consisted of our participants who were younger people living with dementia and family supporters of younger people living with dementia. Previous Delphi studies have had expert panels that have ranged in size from employing five, to more than 60 people, with little evidence to suggest that sample size has any effect on validity or reliability (Powell, 2003). Thirty-six participants (18 people living with dementia, and 18 family supporters) took part in the Round 1, 24 participants (11 people living with dementia, and 13 family supporters) took part in Round 2, 10 of whom were dyads. Dropout (12 participants in total) was predominantly due to changes in personal circumstances. All participants were recruited from six National Health Service locations from across England and through national third sector organisations, including the Young Dementia Network

Survey development

Open-ended questions for Round 1 of the Delphi related to the personal experience of participants about referral, assessment and diagnosis of dementia (see Appendix 1 for the questions presented in Round 1) and were co-designed with younger people with dementia and family supporters who were members of the PPI panel.

The PPI group were asked to comment and revise the wording of open ending questions for Round 1, and provided feedback on how user-friendly and legible the questionnaires were for both Round 1 and 2.

Analysis Framework:

The primary aim-in the analysis framework was to capture the voices of people with dementia and their supporters. The analysis of Round 1 of the Delphi adopted a structured approach to collate the qualitative responses. Similar responses were therefore grouped and an overarching statement was used to represent the theme. Please see Appendix 1 for the questions asked in the first round of the Delphi and Table 2 for the analysis plan for the first round.

Round 1

The analysis framework for Round 1 consisted of 4 stages

Stage 1:

The first stage focused on the researchers' familiarisation with the qualitative responses from our participants and involved. The researchers read through all reports from the participants and where appropriate grouped the exact quotes from that reported similar topics. Quotes were revised and re-written to develop a summary short title (please see appendix 2 and appendix 3 for the short titles), and a longer detailed title, for clarity and legibility-and a second checker read through the statements and prepared feedback. Only the detailed longer titles are included in the main body of this paper. Finally, the second checker and researcher attended a 'statement workshop' where statements were grouped and collapsed as appropriate.

Following this Stage 1 process, there were 224 statements in total. One hundred statements were from people with dementia, and 124 statements were from supporters.

Stage 2

Two of the researchers collated similar statements per question across the two groups of YPD and supporters, further reducing the statements to 81 in total. These were next itemised as originating either from both people with dementia and supporters, or separately from people with dementia or supporters.

Stage 3

Similar statements were further reduced by looking at similarities across the whole data set. Doing this reduced the list of Delphi statements to a final list of 29. See Table 2 for the final list of statements and the supporting quotes from YPD and family supporters.

Stage 4

Statements were organised according to three headings; referral, assessment and diagnosis of young onset dementia. Consultation with the project PPI members, between February 2017 until December 2019, provided guidance on how best to present the statements to participants in the final round. This consultation included the presentation of the rating scale, font type and size and wording of the statements.

Round 2

In the final round (Round 2) of the Delphi, participants were asked to rate the importance of the 29 statements using a 7- point Likert scale, with points on the scale representing whether statements were: not at all important, low importance, slightly important, neutral, moderately important, very important or absolutely essential. In Round 2, we also wanted to explore whether there were any statistically significant differences in the Likert scale ratings between those with young onset dementia versus family supporters.

Ethics

The Angela Project was approved by the Health Research Authority in England and by the South Central Berkshire Research Ethics Committee (REC ref.: 17/SC/0296).

Findings:

Thirty-six participants, 18 people diagnosed with YOD and 18 family supporters were recruited between February 2018 - July 2018. See Figure 1 below which shows the geographical locations of the participants.

Location:

Figure 1: geographical spread of participants who took part in the Delphi study. This image was produced by the research team using Maptitude 2019 (Caliber Corporation).

Table 1: Participants' demographics table

	Demographics		
Person with young onset dementia		Sum	Percentage %
Gender	Female	6	33.33
	Male	12	66.67
Age at diagnosis (mean, SD and range)	61.66 years (SD = 4.02 years). Age range = 39 – 64 years		
Dementia diagnosis			
	Alzheimer's disease	7	38.89
	Posterior cortical atrophy (PCA)	3	16.67
	Frontotemporal dementia (FTD)	2	11.11

	Mixed dementia – Lewy body, Parkinson’s disease and FTD	1	5.56
	Mixed dementia - Alzheimer's and FTD	1	5.56
	Vascular dementia	1	5.56
	Primary progressive aphasia (PPA) semantic variant	1	5.56
	Lewy body dementia	1	5.56
	short term memory loss	1	5.56
Previous misdiagnosis			
	Depression	5	27.78
	Epilepsy	3	16.67
	Anxiety	2	11.11
	Stress	2	11.11
	Lifestyle changes	1	5.56
	Thyroid levels	1	5.56
	Bang on the head	1	5.56
	Another dementia diagnosis	1	5.56
	Mild cognitive impairment	1	5.56
Family supporter			
Family supporter gender	Female	14	77.78
	Male	4	22.22
Family supporter type			
	Wife	9	50.00
	Husband	5	27.78
	Partner	1	5.56
	Daughter	1	5.56

	Sister	1	5.56

Two rounds of a modified Delphi process resulted in 29 key statements related to referral, assessment and diagnosis of which 27 were rated by participants as absolutely essential or very important. Please see Table 2 for the full list of 29 of statements that were organised following the analysis framework of Round 1 of the modified Delphi**,** and the supporting raw data quote from the participants with young onset dementia and the family supporters.

Table 2: Full list of statements, and the supporting raw data quote from the participants with young onset dementia and the family supporters, following Round 1 of the Delphi, and in preparation for Round 2

Diagnostic Phase	**Statement**	**Person with dementia Quotes**	**Supporters Quotes**
Referral Process	For the GP to identify dementia in younger people	*GP reluctant to take seriously as a younger person (115).*	
	Ensure there is enough notice between appointment letters being issued and the appointment	*To ensure there is enough time between appointment letters being issued, and the appointment (107).*	
	Making appointments convenient for working adults	*The fact that I had the brain scan on a Saturday was very helpful. (129)*	*as we were both still working, evening appointments would have been better (229).* *It's important to be supported by your employer who can support you to take time off to accompany your partner to appointments (201).* *To be mindful that supporters of people with YOD are still in full-time work, and require time off for appointments (214).* *Being mindful that supporters of people with YOD are still in full-time work, and some can only come to appointments on certain days of the week which can prolong delays (226).*
	Being kept in the loop and feeling involved in the assessment	*I felt that the communication was good that everyone I had seen was in the loop (103).* *I felt involved during the assessment and diagnosis (125).*	*I was pleased information was being shared between health professionals - gave me a form of confidence (207).* *Making sure the person and their family are kept in the loop (202).*

			It's important to keep the person with dementia and their family in the loop (207) *Fully explaining each of the processes in the diagnosis. (205)*
	Healthcare professionals should make contact with family supporters if unable to get through to the person with dementia directly regarding appointments.		*It would have been better if my number had been given to the clinic and not my husbands. After all, he was suspected of having a memory problem - would he remember that they had called or what the clinic had said to him (222).*
	The clinicians should listen to the person with dementia and their family as a whole	*Being believed and listened to (130).* *Believing me that something was wrong and not saying it was all down to stress (133).* *I would have liked to have been just listened to (102).* *if the doctors took into account the families worries and not just the person with dementia as well all know depending on how they are feeling on any given day, the answers, and how they present can be very different. (202)*	*In case of dementia, where patients have little or no awareness of their symptoms their carer/partner experiences extreme distress because they cannot get the sufferer to be assessed by the GP. NB It would be so much better if a concerned relative could request a GP to do an assessment in the house. With frontotemporal dementia/behavioural variant the sufferer has no idea that anything is wrong! This creates emotional anguish and distress for the family as their hands are tied!!! (204)* *I feel that if we were listened to as a family who know my husband inside out, he might have got his diagnosis earlier and started medication earlier (202).* *listen to the family as a whole (202).* *if the doctors took into account the families worries and not just the person with dementia as well all know depending on how they are feeling on any given day, the answers, and how they present can be very different. (202)*

	Having an identified key person as a single point of contact throughout the whole diagnostic process	*Having someone to contact when you have a specific question (203).* *Having someone, who was involved in your diagnosis, who you can call and speak to when necessary (112).*	*It's important to have a point of contact between appointments when appointments are several months apart (203).* *Consultations speeded up instead of months in between. (205).* *For referrals to be made to specialist units. Better awareness and training in Mental Health Trusts on the issues faced by younger people with dementia (224).*
	Communication with clinicians should ideally be in person.	*Speak with specialists in person rather than on the phone. (105)* *Face to face interactions were good (115).* *Very respectful service. Good communication. (124).* *Communication by Neurologist was good. (125).*	
	Avoid the same questions being asked by the separate clinicians where possible	*Avoid the same questions being asked by the separate clinicians (107)*	*It felt like we kept repeating the same things over and over again. (201).*
Assessment Process	The referral process from GP to first assessment needs to be shorter.	*GP making a quick referral to the neurology unit (124).* *Not wait 3 months to see the neurologist (125).*	*Making a quick referral to the most appropriate specialist. (214)* *Having timely appointments. A friendly welcome. (205)* *Referral to a specialist centre straight away this would of save months of upset and distress and unbearable waiting. (224)* *A much earlier referral ... in view of presentation of symptoms (230).*

		Being sign-posted to the correct department earlier (130). Not having to go around in circles would have been helpful. It was also very exhausting and confusion having a big black cloud after us. (112).	*Not having to go around in circles - it was also very exhausting and confusing having a black cloud after us. (212).*
	Referrals should ideally be made to specialist YOD clinicians and services	*Making sure referrals to specialist services are made, who can provide helpful information. (124)*	*I would of preferred not to of been seen in older persons MH (224)* *For referrals to be made to specialist units. Better awareness and training in Mental Health Trusts on the issues faced by younger people with dementia (224)* *To only make referrals to specialist services (224)* *By Direct referral to specialists who know what they are doing and are equipped to advise and support you (224).*
	Clinicians should be compassionate, empathic and respectful during the assessment and particularly sensitive when providing information about a diagnosis.	*Being aware that people may be anxious about receiving their results. (115)*	*The first assessment (local neurologist looking at MRI scans) was extremely blunt and distressing. "sorry my dear, this is going to destroy you". (204)* *More sensitive handling of devastating news/emotional support. (204)* *sympathetic ears are always welcoming. (227)* *Delivering the diagnosis with compassion and respect (204)*

		Questions were answered using clear language, not jargon. (115). *Questions were answered truthfully. (102)*	*It is so important to that you feel people understand what you are going through (otherwise you feel isolated and fending for yourself) (204).* *The diagnosis was handled sympathetically and very re-assuring (227)* *Being tactful and careful when discussing how quickly the person's dementia may deteriorate (201).*
	To be seen at home for assessments and post-diagnostic support where appropriate	*Felt relaxed and comfortable with neuropsychology - seen at home. (115)* *Being seen in own surroundings, made me feel more relaxed (115).* *Being seen at home was helpful. (114).* *Since diagnosis they have all been very helpful, especially the admiral nurse that comes to our home to see us (102).*	*A neuropsychologist came out from the XXX memory assessment service. Seen at home, reassuring, pleasant. (215)* *Being seen at home. More relaxed and informal. (214)* *Maybe a home visit would have been more appropriate rather than the NHS clinic. Seeing other people with different health problems could have a stigma effect. (227)*
	Giving the person with dementia and their family enough opportunities to ask questions.	*Giving the patient and their family enough opportunities to ask questions. (105)*	*The consultant really took their time to explain things and answer any questions (204).*
	Clinicians should be calm, approachable and easy to talk to.	*Staff being easy to speak to make you feel more welcome in the memory centre. (105).*	*Having a relaxed approach. (215). Support from the nurses at the memory clinic - never feeling "alone" or that it was "my problem" - Feeling like I can call at anytime (205). A good and sympathetic opinion (219).*

			As a clinician, being easy to talk too, and having a calming approach (201).
	Clinicians should offer opportunities for the person with dementia and their supporters to speak separately about any issues they wish to discuss.	*My partner would have liked to ask the questions without me being there (130)*	*Taking both the person with dementia's and the family supporters views separately as these views can be quite different (202).* *Offering to speak to the person with dementia and the carer individually, should they have any questions they would like to ask in private. (230).*
	To have a multi-disciplinary team involved in diagnosis to provide appropriate support.	*Having a supportive team of specialists to address questions and fears is important (119)*	*Having an OT who specialises in dementia to be allocated to us to help us understand and to give us advice (233)* *The opportunity to see other professionals besides neurologists. (230)* *Provide better explanations of processes rather than recommending booklets alone. (207) Better information and support through the process (225)*
	More awareness and training on rarer dementia types as well as the issues faced by younger people with dementia in Mental Health Trusts.		*For referrals to be made to specialist units. Better awareness and training in Mental Health Trusts on the issues faced by younger people with dementia (224)* *More awareness of PCA amongst medical professionals*

	Being understanding during the assessments, especially visual tests for people with PCA.	*Being understanding during the visual tests, especially for people with PCA. (130)*	*More understanding of PCA and the problems it presents (230)*
	Assessments should be conducted in a quiet and private room.		*To have privacy, and a quiet, private room during the assessments (227)*
	Having more information on what the SPECT scanning was all about.	*Having more information on what the SPECT scanning was all about (133)*	*A better explanation of why certain tests need to be done (207)*
	Better access to sleep and anger clinics.		*Having better access to sleep and anger clinics. Having referrals made to units more local. (212).*
	The MRI experience should provide blankets, ear protectors to reduce noise and allow supporters to be in the room if the person wishes.	*Reducing noise during the MRI scan (125)* *Providing an option for supporters to come into the MRI room for support. (105)* *Providing blankets during MRI scanning is important (125)*	*Provide ear protectors and a blanket during MRI (225)* *Provide ear protectors and a blanket during MRI (225)*
	Results to be given in clinic more quickly.	*Perhaps results to be given in clinic more quickly (124).*	
	The time taken to achieve a formal diagnosis needs to be shortened if possible.	*A time span of 6 months to diagnosis is acceptable (103).* *Shorter time from start to finish of the diagnosis. (125)* *The process could have been improved if it could have been diagnosed quicker and again if they listened to us as a family.*	*Needed to be quicker overall, from GP visit initially to the diagnoses (233)*

		(102). Shortening the time to diagnosis (125).	
	Providing the people with dementia and their families with information about their diagnosis and prognosis if they wish it.	*Being told the potential life expectancy was helpful. (133)*	*Being told what could happen as we progress down the time-line is helpful (233)* *The doctor should fully explain the type of dementia that's been diagnosed and prognosis (225).*
Diagnosis Process	Clinicians should explain medical terms, and what they mean in a simplified manner.	*He used the medical terms but fully explained what this meant (103). No but then my wife has always been very good at explaining things to me and others in lay terms (129)* *To explain that possibility of being on a placebo rather than drug when participating in research projects. (112)*	*All reference to the diagnosis has difficult terminology but this was explained and having the follow up letter I was able to research and look up the reference (203).* *The doctor was very honest and explained everything in a language we could understand. (202)*
	Remembering that receiving the diagnosis is a lot to take in for the person with dementia and supporter.	*Remembering that it is a lot to take in for the person with dementia (114)*	*Going online, I've come to understand the diagnosis a lot better (202). Being given some websites to visit with people's experiences of dementia is helpful (203).*
	Providing the person with dementia and their supporters with a letter which details the diagnosis.	*Delivering the diagnosis face-to-face, face and providing a subsequent letter (102)*	*ll sp reference to the diagnosis has difficult terminology but this was explained and having the follow up letter I was able to research and look up the reference (203)*

Statisical analyses: In addition to the rich qualitative data to support the formation of each statement, we wanted to explore whether there were any significant differences in the ratings given by those with young onset dementia versus family supporters following Round 2. The distributions of the ratings for all 29 statements were non-normal, therefore a non-parametric test (Mann-Whitney test) was used for the analysis. Statistical significance was tested at the 5% level throughout.

Table 3 consists of the full list of the statements, inter-quartile range, median score, and results of Mann-Whitney test. The two statements highlighted denoted ** have averages which are moderately important.

Table 3: the full list of the statements, inter-quartile range, median score, and results of Mann-Whitney test that compared ratings between people with dementia (PWD) and family supporters.

Diagnostic Phase	Statement	Respondent	Rating			Mann-Whitney test	
			Lower quartile	Median	Upper quartile	U	p
Referral Process	For the GP to identify dementia in younger people	PWD	6.00	7.00	7.00	59.00	.39
		Supporter	6.00	7.00	7.00		
	Ensure there is enough notice between appointment letters being issued and the appointment **	PWD	5.00	5.00	6.50	65.50	.71
		Supporter	5.00	6.00	6.00		
	Making appointments convenient for working adults	PWD	5.00	6.00	6.00	53.50	.26
		Supporter	6.00	6.00	7.00		
	Being kept in the loop and feeling involved in the assessment	PWD	6.00	7.00	7.00	62.50	.55
		Supporter	6.00	6.00	7.00		
	Healthcare professionals should make contact with family supporters if unable to get through to the person with dementia directly regarding appointments.	PWD	6.00	7.00	7.00	67.50	.78
		Supporter	6.00	7.00	7.00		
	The clinicians should listen to the person with dementia and their family as a whole	PWD	6.00	7.00	7.00	66.00	.72
		Supporter	6.00	7.00	7.00		
	Having an identified key person as a single point of contact	PWD	6.00	6.00	7.00	66.00	.71
		Supporter	6.00	6.00	7.00		

	throughout the whole diagnostic process						
	Communication with clinicians should ideally be in person.	PWD	6.00	6.00	7.00	71.00	.97
		Supporter	6.00	6.00	7.00		
	Avoid the same questions being asked by the separate clinicians where possible	PWD	5.50	6.00	7.00	60.50	.50
		Supporter	5.00	6.00	7.00		
Assessment Process	The referral process from GP to first assessment needs to be shorter.	PWD	6.00	6.00	7.00	63.00	.56
		Supporter	6.00	7.00	7.00		
	Referrals should ideally be made to specialist YOD clinicians and services.	PWD	6.00	7.00	7.00	59.00	.39
		Supporter	6.00	7.00	7.00		
	Clinicians should be compassionate, empathic and respectful during the assessment and particularly sensitive when providing information about a diagnosis.	PWD	6.00	6.00	7.00	52.00	.18
		Supporter	7.00	7.00	7.00		
	To be seen at home for assessments and post-diagnostic support where appropriate **	PWD	5.00	5.00	6.00	71.00	.98
		Supporter	5.00	5.00	6.00		
	Giving the person with dementia and their family enough opportunities to ask questions.	PWD	6.00	7.00	7.00	61.50	.52
		Supporter	6.00	6.00	7.00		
	Clinicians should be calm, approachable and easy to talk to.	PWD	6.00	7.00	7.00	66.00	.72
		Supporter	6.00	7.00	7.00		

Clinicians should offer opportunities for the person with dementia and their supporters to speak separately about any issues they wish to discuss.	PWD	6.00	6.00	7.00	49.50	.15
	Supporter	6.00	7.00	7.00		
To have a multi-disciplinary team involved in diagnosis to provide appropriate support.	PWD	6.00	6.00	6.50	68.00	.81
	Supporter	6.00	6.00	7.00		
More awareness and training on rarer dementia types as well as the issues faced by younger people with dementia in Mental Health Trusts.	PWD	6.00	7.00	7.00	62.50	.51
	Supporter	7.00	7.00	7.00		
Being understanding during the assessments, especially visual tests for people with PCA.	PWD	6.00	6.00	7.00	57.50	.36
	Supporter	6.00	7.00	7.00		
Assessments should be conducted in a quiet and private room.	PWD	6.00	6.00	7.00	55.50	.29
	Supporter	6.00	7.00	7.00		
Having more information on what the SPECT scanning was all about	PWD	5.00	7.00	7.00	61.50	.49
	Supporter	6.00	7.00	7.00		
Better access to sleep and anger clinics	PWD	5.00	6.00	6.00	68.50	.86
	Supporter	4.00	6.00	6.00		
The MRI experience should provide blankets,	PWD	5.50	6.00	7.00	68.00	.83
	Supporter	5.00	6.00	7.00		

	ear protectors to reduce noise and allow supporters to be in the room if the person wishes.						
	Results to be given in clinic more quickly	PWD	6.00	6.00	7.00	67.50	.80
		Supporter	6.00	6.00	7.00		
	The time taken to achieve a formal diagnosis needs to be shortened if possible	PWD	6.00	7.00	7.00	64.00	.62
		Supporter	6.00	7.00	7.00		
	Providing the people with dementia and their families with information about their diagnosis and prognosis if they wish it.	PWD	6.00	7.00	7.00	63.50	.59
		Supporter	6.00	7.00	7.00		
Diagnosis Process	Clinicians should explain medical terms, and what they mean in a simplified manner.	PWD	6.00	7.00	7.00	66.50	.74
		Supporter	6.00	7.00	7.00		
	Remembering that receiving the diagnosis is a lot to take in for the person with dementia and supporter.	PWD	6.00	7.00	7.00	58.00	.34
		Supporter	7.00	7.00	7.00		
	Providing the person with dementia and their supporters with a letter which details the diagnosis.	PWD	6.00	7.00	7.00	58.00	.34
		Supporter	7.00	7.00	7.00		

The statement ‘Ensure there is enough notice between appointment letters being issued and the appointment’ only reached a moderate importance consensus level for people with dementia (PWD) and ‘To be seen at home for assessments and post-diagnostic support where appropriate' only reached moderate importance consensus level for both PWD and family supporters.

Statistics: There were no statistically significant differences between statements expressed by the people with dementia and their supporters. There was a ceiling effect which effectively decreased the sensitivity of the scale since most of the median ratings were 7 (Absolutely essential), with the lowest median rating being 5 (Moderately important). However, this does shows a high degree of agreement that the statements extracted were considered important to all participants. Paired analysis of the ratings of PWD and their supporter also did not show any statistically significant differences in ratings for any of the statements.

Agreement between those diagnosed with dementia and supporters

Following the ratings made for each statement in Round 2, scores were available for 10 dyads who participated in this round. Paired tests (Wilcoxon tests) on data from PWD/supporter dyads also showed no statistically significant differences between the scores of YPD and their supporters on statements, with the exception of the statement "Making appointments convenient for working adults" where there was a statistically significant difference between the responses of PWD compared to their supporters, with the supporters generally reporting this as having higher importance (related-samples Wilcoxon test, test statistic=15, n=10, p=0.038) .

Percentage agreement

When comparing agreement in scoring for all 10 dyads, we found a difference in scoring patterns on aspects of the referral, assessment and diagnosis. Please see Table 4 below for the percentage agreement per statement.

Table 4: Level of agreement (percentage) on statements between the 10 dyads that completed all rounds of the Delphi.

Diagnostic Phase	**Statement**	**% agreement**
Referral Process	For the GP to identify dementia in younger people	90

	Ensure there is enough notice between appointment letters being issued and the appointment	40
	Making appointments convenient for working adults	50
	Being kept in the loop and feeling involved in the assessment	70
	Healthcare professionals should make contact with family supporters if unable to get through to the person with dementia directly regarding appointments.	50
	The clinicians should listen to the person with dementia and their family as a whole	60
	Having an identified key person as a single point of contact throughout the whole diagnostic process	70
	Communication with clinicians should ideally be in person.	80
	Avoid the same questions being asked by the separate clinicians where possible	30
Assessment Process	The referral process from GP to first assessment needs to be shorter.	40
	Referrals should ideally be made to specialist YOD clinicians and services.	60
	Clinicians should be compassionate, empathic and respectful during the assessment and particularly sensitive when providing information about a diagnosis.	60
	To be seen at home for assessments and post-diagnostic support where appropriate	60
	Giving the person with dementia and their family enough opportunities to ask questions.	70
	Clinicians should be calm, approachable and easy to talk to.	60
	Clinicians should offer opportunities for the person with dementia and their supporters to speak separately about any issues they wish to discuss.	50
	To have a multi-disciplinary team involved in diagnosis to provide appropriate support.	40
	More awareness and training on rarer dementia types as well as the issues faced by younger people with dementia in Mental Health Trusts.	80
	Being understanding during the assessments, especially visual tests for people with PCA.	80
	Assessments should be conducted in a quiet and private room.	70

	Having more information on what the SPECT scanning was all about	60
	Better access to sleep and anger clinics	30
	The MRI experience should provide blankets, ear protectors to reduce noise and allow supporters to be in the room if the person wishes.	50
	Results to be given in clinic more quickly	70
	The time taken to achieve a formal diagnosis needs to be shortened if possible	90
	Providing the people with dementia and their families with information about their diagnosis and prognosis if they wish it.	70
Diagnosis Process	Clinicians should explain medical terms, and what they mean in a simplified manner.	70
	Remembering that receiving the diagnosis is a lot to take in for the person with dementia and supporter.	70
	Providing the person with dementia and their supporters with a letter which details the diagnosis.	40

It is important to note that the percentage agreement between dyads findings do not take into account the agreement that would be expected purely by chance. High levels of agreement do not mean high levels of importance of that statement (just that most pairs of PWD gave the same score for that statement as their supporter). Note that there were no statistical differences between the paired scores for all but one of the statements, so low percentages do not suggest that PWD scored differently overall to their supporters (the differences were in both directions - sometimes PWD scored higher than supporters, sometimes the other way round).

<u>Discussion:</u>

In this study, young people with dementia and their supporters have highlighted key components of the referral, assessment and diagnosis, that they deem to be absolutely essential or very important for informing best practice based on their own personal experience.

People with young onset dementia expressed concern about inequity in waiting times in receiving a diagnosis and access to necessary investigations, as highlighted in the present study’s final list of 29 statements. Research has shown people with young onset dementia can wait four years (D van Vliet et al., 2013) for diagnosis, and that **in England, only 45.9% of those predicted to have a diagnosis of YOD have a recorded diagnosis compared to those over 65 where the recorded diagnosis rate is 68% (Public Health England, 2020).**

In general practice, delays may be due to GPs not considering the possibility of dementia in younger people, and because the rarer types of dementia that are more common in younger people are harder to recognise and have symptoms that overlap with those of common psychiatric disorders such as depression. This explanation is consistent with the reports of misdiagnosis by the participants in the current study, whereby 15 of the 18 individuals reported a diagnosis of another condition before receiving a confirmed diagnosis of dementia. Once someone is referred to a specialist setting, there can be further delays due to a lack of specialist clinicians and limited access to the often, complex investigations required to diagnose young onset dementia. This means a longer period of having to cope with unexplained symptoms and no support, for both the person with dementia and their family.

Health care research has established that involving individuals in shared decision-making by encouraging active participation and enhanced communication, can provide individuals with more control over their care, improves the ability to make informed choices and allows them to participate knowledgeably in treatment decisions (de Wilde et al., 2017; Elwyn et al., 2010). Shared decision-making in dementia care is a relatively new concept (Mariani, 2017), and has more often been implemented in terms of care planning and end-of-life care (Gjerberg et al., 2015), though more recently research is exploring shared decision-making during the diagnostic process (de Wilde et al., 2017) . As captured in our statements, patient-clinician conversations during the workup require sensitivity, and care should be taken when delivering updates on ongoing assessments and when delivering diagnoses.

Evidence suggests that improving the patient experience is linked to improvement in performance and systems **within clinical practice** (Schlesinger et al., 2015) but, equally as important it increases individual autonomy and empowerment to maintain independence (Stamou et al., 2020). The results presented here support this view by clearly demonstrating that while both the efficiency and practicalities of the diagnostic process were important, participants equally valued feeling listened to, informed and supported.

Of note, rapid referral to specialists, early identification of presenting symptoms by GPs, convenient appointment times especially for working adults are in-line with known 'pinch points' in current care pathways for YPD which result in delays in referral (O'Malley et al., 2019; Van Vliet et al., 2011). Clinicians taking time to gather the views of important informants and listening to the whole family, overlaps with good practice guidance for clinicians in assessment and history taking, particularly where the person with dementia may lack insight into their difficulties or the presentation is non-amnestic and harder to recognise (Harding et al., 2018; O'Malley, Parkes, et al., 2019). Younger people with dementia (YPD) endorsed the value of having an identified key person as a single point of contact throughout the whole diagnostic process. Although, this approach to case management is enshrined in the National Institute for Clinical Excellence (NICE) dementia guideline (National Institute for Health and Clinical Excellence, 2018), the necessity for specialist skills in the case management role specifically relevant to YPD are usually not acknowledged. For example, having skills and knowledge to facilitate access to information about young onset dementia and rare forms of dementia, to communicate the diagnosis to young children, to facilitate access to specialist advice and support about young onset specific needs e.g. employment, mortgage and financial obligations and future financial planning. Guidance on this role is available (Hussey & Hayo, 2019).

The communication skills of the clinician and the feeling of being listened to and heard by those with expertise in diagnosis formed the focus of most statements in relation to the assessment stage of the process. Sensitivity about the impact of the information because of the 'lack of narrative' for dementia at a young age and making time for questions with follow-up summary information were particularly valued in terms of the way diagnosis was relayed. **Getting a diagnosis in working age can significantly disrupt the normal life events, particularly when the person faces increasing disability, dependency and mortality (Clemerson et al., 2013; Pipon-Young et al., 2012). At the point of diagnosis, there would be an opportunity for the clinician to have a conversation with the person about the impact of the diagnosis on the changes they may be faced with, and how they might adjust** (Roach et al., 2008)**. However, these conversations would need to be considered in a person-centred and individual way as they may not be appropriate for some individuals.**

The clinician's use of language, avoiding the use of medical jargon, and adopting a calm manner in a private environment were all also valued. This mirrors findings in a recently published scoping review that highlighted how the impact of a diagnosis on the patient and their supporter was heavily influenced by the language used by the clinicians (O'Malley et al., 2019).

Several generic frameworks have attempted to capture what matters most to patients (Robert, Cornwell, & Brearley, 2011) in terms of improving individual experience, and the statements identified here show significant overlap with their core tenets, often identified as relational and functional aspects. Most research in the field of patient experience has focused upon the relational aspects of care (feeling informed, listened to) but interestingly in our study, the majority of statements preferentially related to functional aspects of care (i.e. the process). This may reflect previous research which demonstrates that those with YOD often see up to five different consultants before diagnosis and care pathways can be chaotic (Carter et al., 2018). Our own research which identifies the core features of YOD services which are perceived positively (Stamou et al., 2020) demonstrates that positive post-diagnostic services may collectively create an enabling-protective circle that supports YPD to re-establish and maintain a positive identity in the face of YOD.

It could be argued that many of the individual statements reported by YPD and family member/supporters simply represent good practice in all-age dementia assessment. However, statements related to knowledge base of rare dementias, GP recognition of early symptoms, shortening the time to diagnosis and explanation of specialist investigations, arguably reflect the reality of current shortfalls in services for those with YOD (Murrells et al., 2013). Additionally, the value of the statements here is that they provide insight into the multidimensional aspects of individual experience ranging from 'relational' aspects of care such as feeling informed, listened to, communication styles, to, 'functional' aspects of care such as the practicalities of the process, and how this can guide shared decision-making, deliver a more person-centered experience and increase individual autonomy.

Interestingly, there were no significant differences in the opinions expressed by YPD or family/supporters, although it is recognised that this may often not be the case. This might be explained in the current study by the low number of participants with dementia subtypes more commonly associated with reduced insight such as fronto-temporal dementias.

The statements derived from this Delphi study offer the potential to identify shortfalls in current services and improve the quality of services to better meet the needs of YPD and families.

Strengths and Limitations

Although we recruited a broad geographical spread of participants, only individuals living in England took part in the study. Diagnostic experiences from the rest of the UK were therefore not captured and were beyond the scope of the current study. Future research should aim to include those living in Wales, Scotland and Northern Ireland to explore whether the statements and key reports are consistent with the experiences of those living in the rest of the UK, and whether additional statements should be considered for other regions.

A modified Delphi methodology was adopted to refine the statements viewed as being crucial during the diagnostic period. Consensus was not the prime aim of this paper, rather it was to capture absolutely essential and very important aspects of the process of diagnosis for young people with dementia. We have presented the full list of statements to ensure that all views are captured, and statements were not excluded because they represented a minority view. The limited number of participants means that the study may have missed important lived experiences of younger people undergoing assessment for dementia and may not be truly representative. It was also a small sample for statistical analysis and may have not had sufficient power to identify small to moderate differences. However, the population of individuals who participated, came from across the whole of England (see Figure 1 for the geographical spread), and were recruited through both NHS services for younger people with dementia, as well as third sector organisations and therefore could be considered representative.

How people with dementia experience their condition depends on their own complex biographies and relationships as well as the behaviour of those they encounter during the diagnostic process. Everyone's experience of receiving a diagnosis of dementia is unique, so practitioners and clinicians should use our findings as guidance but continue to listen to the views of their own patients in their specific setting and be alert to expressed differences.

Implications and Implementation:

The qualitatively rich reports made by our participants highlighted key aspects of the referral, assessment and diagnosis of dementia, that should be considered by healthcare organisations as important to the individual experience and hence delivery of good care. Good experience is generally considered a multidimensional concept dependent on functional (process), transactional (‘being care for’) and relational (‘being care about’) aspects of care. Several approaches to measurement of these aspects of care are available and future work is necessary to assess how these can inform a strategic approach to improving the experience for young people with dementia and their families/supporters.

Conclusion:

In this paper, we have presented the findings from a unique and innovative modified delphi deliberately designed to capture the perspectives of younger people with dementia and their carers as ‘experts’ of their experiences. The study provides insight into the complex interpersonal aspects of care that matter to YPD, along- side transactional and functional aspects that are necessary to improve individual experience.

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Appendix 1: Questions Round 1 of the Delphi

The Angela Project: Delphi-EXPERIENCE Questionnaire

Thank you very much for agreeing to act as a “Delphi expert” panel member for our study which aims to improve the diagnostic process for people living with young onset dementia. The study will consist of a minimum of three rounds. This is round one.

In this questionnaire we hope to learn more about your experiences of when **you** received a diagnosis of dementia. Our goal is to understand what worked well in the service(s) you received resulting in your diagnosis and what could be improved.

We would welcome your views as a younger person living with dementia, and if you prefer, we encourage you to involve your supporter/family carer to assist you with answering some of the questions.

What will I have to do?

There will be a series of questions about the referral, assessment and diagnostic processes of your diagnosis. Please answer and reflect on your own experiences. You can write as little or as much as you wish.

Please respond to all questions as this means that we can compare results in a consistent way. This should take approximately 30-45 minutes to complete depending on how detailed your responses are.

Thank you for your valuable assistance in completing this questionnaire. If you would like any support in completing the questionnaire, please contact the researcher before starting the questionnaire and she will provide you with the relevant support.

Please insert the participant code number the researcher gave you: …………

Initial questions:

1. What is your current age?

   ………………………………

2. What was your age when you were diagnosed with dementia?

   ………………………………

3. Please could you state the official diagnosis you were given:
   ……
   ……

4. Before you were given a diagnosis of dementia, were you given other diagnoses as a possible reason for your symptoms?

   (Please circle your response) Yes No

   a. If yes, please state these below:
   ……
   ……
   ……
   ……

5. In which town or county of the UK do you live?
   ……
   ……
   ……
   ……

Section 1. The Referral Process

6. Please tell us about your experience of the referral from your GP:

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a. Which aspects were handled well?

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b. How could your experience could have been improved?

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7. How did the health professionals communicate between each other during your assessment/diagnosis?

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……

a. Did this have any effect on you?

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8. How might the various appointments with dementia specialists have been better managed to suit you? (i.e. location, time of appointment, form of contact).

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Section 2. The Dementia Assessment Process

9. Please tell us about the assessment you received from the dementia specialist(s)?
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a. Can you comment on what was helpful?
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10. Based on your experience, is there anything else you would have liked to happen during this assessment process?
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11. How helpful were the staff you met during the assessment process?

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12. How long did it take from being referred onto a dementia specialist by the GP to receiving your diagnosis of dementia? Please circle the corresponding time-frame:

- **0-6 months**
- **6-12 months**
- **12 months – 18 months**
- **18 months -2 years**
- **2 - 3 years**
- **3 - 4 years**
- **4 - 5 years**
- **5+ years**

a. What was handled well over this time?

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b. How could your experience have been improved?

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13. Were there any assessments (e.g. neuroimaging, blood tests, cognitive tests) that you felt uncomfortable with?

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a. If so, how could these have been improved?

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14. How did you feel after each consultation with your dementia specialist(s)?

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15. Did you feel any questions you had were addressed during the assessment and diagnosis?
(Please circle your response) Yes No

a. If yes, what helped you to feel this way?

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b. If no, how could the experience have been improved?

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Section 3. The Diagnosis Process

16. How was the information about the diagnosis delivered to you?

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a. How did the process make you feel?

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17. How well did the dementia specialist(s) help you understand the diagnosis?

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a. Could this have been improved? (i.e. was there anything that the specialists could have said or done to better support/inform or reassure you)____

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18. Did the dementia specialist(s) use any medical terms that you felt:

Were really well explained? Yes/No If yes, please state these.	**b. Were poorly explain? Yes/No – If yes, please state these.**

19. How could your overall experience of receiving a diagnosis have been improved?

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Thank you very much for completing the first round of our Delphi study on improving the diagnosis of young onset dementia. We will now spend some time analysing your responses and will create a new questionnaire based on all the responses we receive.

When you are ready, if you could return the two questionnaires in the pre-paid envelope that would be much appreciated.

Many thanks again and we will be in touch again soon.

The Angela Project: Delphi-EXPERIENCE Questionnaire

Family Members/Supporters version

Thank you very much for agreeing to act as a Delphi Expert panel member for our study which aims to improve the diagnostic process for people living with young onset dementia and their family members/supporters. The study will consist of a minimum of three rounds. This is round one.

We would welcome your views as a family member/supporter to someone with a diagnosis of young onset dementia. In this questionnaire we hope to learn more about your experiences during the dementia diagnosis period. Our goal is to understand what worked well in the service(s) your relative/friend received during the diagnostic process and what could be improved.

What will I have to do?

There will be a series of questions about the referral, assessment and diagnostic processes of your relative's/friend's dementia diagnosis. Please answer and reflect on your own experiences. You can write as little or as much as you wish.

Please respond to all questions as this means that we can compare results in a consistent way. This should take approximately 30-45 minutes to complete depending on how detailed your responses are.

Thank you for your valuable assistance in completing this questionnaire. If you would like any support in completing the questionnaire, please contact the researcher before starting the questionnaire and she will provide you with the relevant support.

Please insert the participant code number the researcher gave you: …………

Initial questions:

1. What is your relation to the person who received the diagnosis of young onset dementia?

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2. What is your current age?

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3. How old was your relative/friend when they received their diagnosis?

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4. When did your relative/friend receive their diagnosis?

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5. Please state the official diagnosis they were given:
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6. Before your relative/friend was given a diagnosis of dementia, were they given other diagnoses as a possible reason for their symptoms? (Please circle) Yes No

   If yes, please state these below:

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7. In which town or county of the UK do you live?
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Section 1. The Referral Process

8. Please tell us about the experience of the referral from your GP:

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c. Which aspects were handled well?

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d. How could your experience could have been improved?

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9. **How did the health professionals communicate between each other during your relative's/friend's assessment/diagnosis?**
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10. How might the various appointments with dementia specialists have been better managed to suit you? (i.e. location, time of appointment, form of contact).
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Section 2. The Dementia Assessment Process

11. Please tell us about the assessment your relative/friend received from a dementia specialist(s)?

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b. Can you comment on what was helpful?

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12. Based on your experience, is there anything else you would have liked to happen during this assessment process?

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13. How helpful were the staff you met during the assessment process?

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14. How long did it take from being referred onto a dementia specialist by the GP to receiving the diagnosis of dementia? Please circle the corresponding time-frame:

- **0-6 months**
- **6-12 months**
- **12months – 18months**
- **18 months-2 years**
- **2-3 years**
- **3-4 years**
- **4-5 years**
- **5+ years**

c. What was handled well over this time?

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d. How could the experience have been improved?

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15. Were there any assessments (e.g. neuroimaging, blood tests, cognitive tests) that you felt uncomfortable with?

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b. If so, how could these have been improved?

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16. How did you feel after each consultation with the dementia specialist(s)?

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17. Did you feel any questions you had were addressed during the assessment and diagnosis?
(Please circle your response) Yes No

b. If yes, what helped you to feel this way?

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b. If no, how could the experience have been improved?

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Section 3. The Diagnosis Process

18. How was the information about the diagnosis delivered to you?

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b. How did the process make you feel?

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19. How well did the dementia specialist(s) help you understand the diagnosis?

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a. Could this have been improved? (i.e. was there anything that the specialists could have said or done to better support/inform or reassure you)____

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20. Did the dementia specialist(s) use any medical terms that you felt:

a. Were really well explained? Yes/No If yes, please state these.	**b. Were poorly explained? Yes/No – If yes, please state these.**

21. How could your overall experience of receiving a diagnosis have been improved?

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Thank you very much for completing the first round of our Delphi study on improving the diagnosis of young onset dementia. We will now spend some time analysing your responses and will create a new questionnaire based on all the responses we receive.

When you are ready, if you could return the two questionnaires in the pre-paid envelope that would be much appreciated.

Many thanks again and we will be in touch again soon.

Appendix 2: Delphi statements organised by diagnostic group, with their short titles and long titles.

Diagnostic Phase	**Short title**	**Longer title**
Referral Process	GP recognition of YOD	For the GP to identify dementia in younger people.
	Appointment notice period	Ensure there is enough notice between appointment letters being issued and the appointment.
	Convenience	Making appointments convenient for working adults.
	Being involved	Being kept in the loop and feeling involved in the assessment.
	Contact family supporters as well	Healthcare professionals should make contact with family supporters if unable to get through to the person with dementia directly regarding appointments.
	Active listening	The clinicians should listen to the person with dementia and their family as a whole.

	Single point of contact	Having an identified key person as a single point of contact throughout the whole diagnostic process.
	Meeting in person	Communication with clinicians should ideally be in person.
	Avoid repetition	Avoid the same questions being asked by the separate clinicians where possible.
Assessment Process	Quick Referral	The referral process from GP to first assessment needs to be shorter.
	Referrals to specialist services	Referrals should ideally be made to specialist YOD clinicians and services.
	Considerate use of language	Clinicians should be compassionate, empathic and respectful during the assessment and particularly sensitive when providing information about a diagnosis.
	Home visits	To be seen at home for assessments and post-diagnostic support where appropriate.
	Time to ask questions	Giving the person with dementia and their family enough opportunities to ask questions.
	Calm approach	Clinicians should be calm, approachable and easy to talk to.
	Private discussions	Clinicians should offer opportunities for the person with dementia and their supporters to speak separately about any issues they wish to discuss.
	Multi-disciplinary team	To have a multi-disciplinary team involved in diagnosis to provide appropriate support.
	Enhanced awareness of YOD	More awareness and training on rarer dementia types as well as the issues faced by younger people with dementia in Mental Health Trusts.
	Understanding all forms of dementia	Being understanding during the assessments, especially visual tests for people with PCA.
	Private location	Assessments should be conducted in a quiet and private room.
	Explanation of assessments	Having more information on what the SPECT scanning was all about.
	Improved access to clinics	Better access to sleep and anger clinics.
	Improve MRI experience	The MRI experience should provide blankets, ear protectors to reduce noise and allow supporters to be in the room if the person wishes.
	Results issued more quickly	Results to be given in clinic more quickly.
	Shorter time to diagnosis	The time taken to achieve a formal diagnosis needs to be shortened if possible.
	Diagnosis explained	Providing the people with dementia and their families with information about their diagnosis and prognosis if they wish it.
Diagnosis Process	Using lay terms	Clinicians should explain medical terms, and what they mean in a simplified manner.
	Reaction to diagnosis	Remembering that receiving the diagnosis is a lot to take in for the person with dementia and supporter.
	Follow-up letter	Providing the person with dementia and their supporters with a letter which details the diagnosis.

Appendix 3: Evidence-based statements (short titles) in receiving a diagnosis of young onset dementia.