KCE REPORT 395S

Federaal Kenniscentrum voor de Gezondheidszorg
Centre Fédéral d'Expertise des Soins de Santé
Belgian Health Care Knowledge Centre

YOUNG-ONSET DEMENTIA: PAVING THE WAY FOR AN INTEGRATED CARE PATHWAY IN BELGIUM

SUPPLEMENT



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HEALTH SERVICES RESEARCH

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SUPPLEMENT

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2025 www.kce.fgov.be

COLOPHON

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1. SEARCH STRATEGIES

1.1. Medline preliminary search

Date	2023-11-27		
Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily 1946 to November 17, 2023		
Strategy	1	dementia.ti,ab.	138 652
	2	Alzheimer.ti,ab.	30 945
	3	frontotemporal.ti,ab.	14 482
	4	Lewy.ti,ab.	12 112
	5	Neurocognitive disorder*.ti,ab.	3 969
	6	1 or 2 or 3 or 4 or 5	170 057
	7	young-onset.ti,ab.	1 875
	8	early onset.ti,ab.	47 281
	9	presenile.ti,ab.	1 468
	10	under 65.ti,ab.	2 032
	11	7 or 8 or 9 or 10	52 392
	12	6 and 113 984	
	13	patient*.ti,ab.	8 265 686
	14	carer*.ti,ab.	19 012
	15	caregiver*.ti,ab.	93 008
	16	child*.ti,ab.	1 654 536
	17	family.ti,ab.	954 886
	18	families.ti,ab.	296 901
	19	relative*.ti,ab.	1 687 228

	20	spouse*.ti,ab.	20 388	
	21	son*.ti,ab.	187 676	
	22	daughter*.ti,ab.	29 099	
	23	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22		11 405 255
	24	12 and 23	2 727	
	25	support.ti,ab.	1 288 765	
	26	service*.ti,ab.	661 180	
	27	care.ti,ab.	1 817 530	
	28	facilit*.ti,ab.	910 218	
	29	25 or 26 or 27 or 28		3 902 935
	30	experience*.mp.	1 392 554	
	31	satisfaction.mp.	260 416	
	32	need*.mp.	2 499 501	
	33	problem*.mp.	1 303 435	
	34	access.mp.	449 395	
	35	30 or 31 or 32 or 33 or 34		5 055 332
	36	24 and 29 and 35		247
	37	limit 36 to dt=20150101-20231120 [January 1st, 2015 to November 27, 2023]		174
Source	Millenaar et al. (2016)[1]			

1.2. Research Rabbit

Date	2023-12-08
Database	Research Rabbit (free account)
Strategy	Gold standard 1 – similar work (952) Manual selection from first 150 items (29)

1.3. Medline SH

Date	2023-12-04
Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to December 01, 2023>
Strategy	1 exp Dementia/ (209328) 2 exp Neurocognitive disorders/ (316916) 3 age of onset/ (40731) 4 Middle Aged/ (4736302) 5 Young Adult/ (1018196) 6 Caregivers/ (51330) 7 Family/ (85241) 8 Health Services Accessibility/ (86209) 9 Needs Assessment/ (32510) 10 Patient Satisfaction/ (89981) 11 "Health Services Needs and Demand"/ (55258) 12 1 or 2 (317781) 13 3 or 4 or 5 (5193256) 14 6 and 7 (6801) 15 8 or 9 or 10 or 11 (248661) 16 12 and 13 and 6 and 15 (300)

1.4. Medline TW

Date	2023-12-22
Database	Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations, Daily and Versions <1946 to December 21, 2023>
Strategy	1 (Young* adj3 dementia).mp. (747) 2 (Young* adj2 alzheimer).mp. (19) 3 (Young* adj2 huntington).mp. (1) 4 (Early adj1 dementia).mp. (950) 5 (Early adj1 alzheimer).mp. (249) 6 (Early adj1 huntington).mp. (34)

	7 1 or 2 or 3 or 4 or 5 or 6 (1985) 8 (Family adj1 care*).mp. (17086) 9 caregiv*.mp. (116040) 10 carer?.mp. (19460) 11 supporter?.mp. (4189) 12 spouse?.mp. (34899) 13 child*.mp. (2800290) 14 8 or 9 or 10 or 11 or 12 or 13 (2912258) 15 need*.mp. (2513656) 16 wish*.mp. (47935) 17 service?.mp. (1194549) 18 15 or 16 or 17 (3439561) 19 7 and 14 and 18 (201)

1.5. PsycINFO SH

Date	2024-01-05
Database	APA PsycInfo <2002 to January Week 1 2024>
Strategy	4 exp Dementia/ (75404) 5 exp Neurocognitive Disorders/ (89035) 6 exp Caregivers/ (32378) 7 exp Family/ (239885) 8 exp Health Care Services/ (245659) 9 exp Needs Assessment/ (3037) 10 exp Client Satisfaction/ (5288) 11 (early or young).mp. (574895) 12 4 or 5 (89035) 13 11 and 12 (17039) 14 6 or 7 (260390) 15 9 or 10 (8310) 16 8 and 15 (3259) 17 13 and 14 and 16 (3)

1.6. PsycINFO TW

Date	2024-01-05
Database	APA PsycInfo <2002 to January Week 1 2024>
Strategy	1 ((Young* adj3 dementia) or (Young* adj2 alzheimer) or (Young* adj2 huntington) or (Early adj1 dementia) or (Early adj1 alzheimer) or (Early adj1 huntington)).mp. (1092) 2 (need* or wish* or service?).mp. (830477) 3 1 and 2 (367)

1.7. Embase SH

Date	2024-01-05
Database	Embase (embase.com)
Strategy	#1. 'dementia'/exp 456,520 #2. 'disorders of higher cerebral function'/exp 1,026,532 #3. 'onset age'/exp 98,866 #4. 'middle aged'/exp 2,284,079 #5. 'young adult'/exp 526,479 #6. 'caregiver'/exp 117,317 #7. 'family'/exp 631,973 #8. 'health care access'/exp 108,939 #9. 'needs assessment'/exp 27,678 #10. 'patient satisfaction'/exp 172,617 #11. 'health service'/exp 7,285,642 #12. #1 OR #2 1,026,532 #13. #3 OR #4 OR #5 2,715,938 #14. #6 OR #7 723,222 #15. #9 AND #11 18,412 #16. #8 OR #10 OR #15 295,778 #17. #12 AND #13 AND #14 AND #16 163

1.8. Embase TW

Date	2024-01-05	
Database	Embase (embase.com)	
Strategy	#18. young* NEAR/3 dementia	1,099
	#19. young* NEAR/2 alzheimer	122
	#20. young* NEAR/2 huntington	7
	#21. early NEAR/1 dementia	1,471
	#22. early NEAR/1 alzheimer	2,417
	#23. early NEAR/1 huntington	215
	#24. family NEAR/1 care*	23,722
	#25. caregiv*	172,391
	#26. carer$	31,721
	#27. supporter$	5,281
	#28. spouse$	34,383
	#29. child*	4,257,003
	#30. need*	3,494,579
	#31. wish*	83,338
	#32. service$	2,810,511
	#33. #18 OR #19 OR #20 OR #21 OR #22 OR #23	5,241
	#34. #25 OR #26 OR #27 OR #28 OR #29	4,404,951
	#35. #30 OR #31 OR #32	5,863,703
	#36. #33 AND #34 AND #35	366

2. INTERVIEW GUIDES

2.1. Profile interviewee: clinician (Dutch version)

2.1.1. Introductie

Dit KCE project is er gekomen op vraag van het kabinet van Minister Vandenbroecke. De studie moet beleidsmakers helpen om de zorg voor personen met jong dementie adequaat te organiseren. In functie daarvan willen we weten wat hun noden zijn enerzijds en waar ze binnen de huidige zorgverlening tegen aan lopen anderzijds. Het is een project met een korte doorlooptijd. We moeten klaar zijn tegen april 2024, dus we hebben een aantal pragmatische keuzes moeten maken.

Binnen dit project zullen derhalve vooral focussen op een beperkte internationale vergelijking (NL, FR, UK), een literatuurstudie over unmet needs bij personen met jong dementie, een overzicht van het huidige zorgaanbod in België en waar dit zorgaanbod te kort schiet.

We hebben gesprekken gepland met een 15-tal experten (beleidsmensen, artsen, paramedici, vertegenwoordigers van patiëntenverenigingen, etc) om voornamelijk de noden en tekorten in kaart te brengen.

We zouden graag dit gesprek opnemen om de verwerking te vergemakkelijken. Uiteraard wordt wat hier gezegd wordt confidentieel behandeld en op een geaggregeerd niveau verwerkt in de conclusies van het rapport. Heeft u daar bezwaar tegen?

Alvorens echt van start te gaan, stellen we onszelf nog graag kort even voor: […]

	Vraag	Onderwerp
1	Kan u omschrijven op welk manier of in welke rol u betrokken bent bij jong dementie?	Motivatie
2	Wat is voor u jong dementie? • Hoe zou u het definiëren? • Hoe zou u het onderscheiden van dementie in het algemeen? Op basis van leeftijd of ook op basis van andere criteria zoals symptomen? • Vanaf wanneer spreken we van vergevorderde dementie?	Definitie
3	Hebben we een specifiek zorgtraject nodig voor personen met jong dementie? Of zou het beter zijn om personen met jong dementie te helpen binnen een zorgprogramma voor dementie? Waarom (niet)?	Zorgtraject
4	Bij personen met jong dementie duurt het vaak lang (verschillende jaren) eer de diagnose wordt gesteld of worden de symptomen in eerste instantie aan iets anders toegeschreven zoals depressie of burn-out. • Wat zijn daar volgens u de voornaamste redenen voor?	Diagnose

	• Hoe zouden we die diagnose kunnen versnellen?	
5	Welke zorg wordt er momenteel voorzien voor personen met jong dementie (in vergelijking met personen met dementie in het algemeen)? Wat zou er verbeterd kunnen worden?	
6	U werkt in de geheugenkliniek van Gasthuisberg. • Geheugenklinieken bieden een multidisciplinair zorgprogramma aan ten einde personen met (beginnende) dementie thuis te houden. Ook personen met jong dementie vallen binnen de doelgroep, met 35 sessies gespreid over maximaal 4 jaar. • Is dat niet genoeg? Hebben we dan nog een zorgprogramma (men denkt ook aan een conventie) specifiek voor jong dementie nodig? Indien ja, wat moet daar dan inzitten? Wat missen we nog? • Wat zou de rol zijn van de huisarts in zo'n zorgprogramma voor jong dementie? • Is 35 zittingen gespreid over 4 jaar waarvan 15 (?) het eerste jaar. Dat is minder dan 10 sessies per jaar. Is dat voldoende? • Wat na die 4 jaar? Zou dat voor personen met jong dementie zeker niet langer/onbeperkt moeten zijn? • Er zijn in België 12 geheugenklinieken. Is dat voldoende? Sommige patiënten moeten best wel een eind rijden tot de dichtst bij zijnde geheugenkliniek en wat met de wachttijden? • De tijd besteed aan de uitvoering van de conventie wordt in de overeenkomst vastgelegd, bijv. voor artsen is dan 20% of 1 dag per week. Is dat genoeg? • Hoeveel personen met (jong) dementie kan uw geheugenkliniek op die manier helpen op jaarbasis? • Geen enkele geheugenkliniek bereikt het door de conventie vooropgestelde quotum. (Heb enkel een maximum van 875 facturatieeenheden gevonden in de overeenkomst. Is er ook een minimum?) Hoe komt dat?	geheugenklinieken
6	Er wordt in de resolutie over jong dementie ook verwezen naar de conventie voor de ziekte van Huntington. Die conventie voorziet in een liaisonfunctie tussen ziekenhuizen en RVT's. Zou dat een goeie aanvulling kunnen zijn op de conventie van de geheugenklinieken? Maar dan specifiek voor personen met (jong) dementie?	Huntington
7	Wat vindt u van het systeem met de referentieartsen?	Referentieartsen
7	Welke zorg of omkadering hebben personen met jong dementie nodig? • Kan u ons uitleggen in hoeverre de verschillende soorten jong dementie ook leiden tot andere zorgnoden bij de patiënten? • In hoeverre zijn de noden verschillend naargelang het stadium (vroeg versus vergevorderd) waarin de persoon met jong dementie zich bevindt? • In welke opzichten moet deze zorg verschillen van de zorg voor personen met dementie? • Welke ervaring heeft u met bepaalde bestaande initiatieven?	Noden
8	Wat functioneert reeds goed binnen ons huidige zorgaanbod voor personen met jong dementie?	Wat werkt reeds
9	Wat missen we in het huidige gezondheidszorgsysteem om personen met jong dementie de juiste zorg te geven?	Hiaten in het systeem

	• Als we nadenken over een zorgtraject voor personen met jong dementie, wat mag er dan zeker niet ontbreken in zo'n traject?	
10	Wie zouden we volgens u zeker nog moeten spreken in het kader van dit project?	Snowballing interviewees

2.2. Profile interviewee: clinician (French version)

2.2.1. Introduction

Ce projet du KCE a été initié à la demande du cabinet du ministre Vandenbroecke. Cette étude doit aider les décideurs politiques à organiser de manière adéquate les soins pour les personnes atteintes de démence précoce, et c'est pourquoi nous souhaitons connaitre leurs besoins d'une part, et ce qu'elles rencontrent dans le cadre de l'offre de soins actuelle d'autre part. Il s'agit d'un projet à court terme : nous devons être prêts pour avril 2024 ; dès lors nous avons dû faire des choix pragmatiques.

Dans le cadre de ce projet, nous nous concentrerons principalement sur une comparaison internationale limitée (NL, FR, UK), une étude de la littérature sur les besoins non satisfaits des personnes atteintes de démence précoce, une vue d'ensemble des soins actuels en Belgique et ce qui manque dans ces soins.

Nous avons prévu de réaliser une quinzaine d'entretiens avec d'experts (décideurs politiques, médecins, personnel paramédical, représentants d'associations de patients, etc.).

Nous souhaitons enregistrer cette conversation afin d'en faciliter le traitement. Bien entendu, ce qui est dit ici sera traité de manière confidentielle et incorporé à un niveau agrégé dans le rapport. Avez-vous des objections à cela ?

Avant de commencer, nous aimerions nous présenter brièvement : [...]

	Question	Objet
1	Pouvez-vous décrire de quelle manière ou dans quelle fonction vous êtes impliqué.e auprès de patients souffrant de démence précoce ?	Motivation
2	Pour vous, qu'est-ce que la démence précoce ? • Comment la définiriez-vous ? • Comment la distingueriez-vous de la démence en général ? Sur base de l'âge ou d'autres critères tels que les symptômes ? • À partir de quand parle-t-on de démence avancée ?	Définition
2' **MG**	Quels sont les soins actuellement dispensés aux personnes atteintes de démence juvénile (par rapport aux personnes atteintes de démence en général) ? Qu'est-ce qui pourrait être amélioré ?	

	Quel est le rôle du médecin généraliste ? • Dans le diagnostic • Dans le suivi à long terme (en tant que médecin de famille) À qui les médecins généralistes adressent-ils les patients chez qui l'on soupçonne une démence précoce ? Le médecin généraliste est-il correctement formé à ce rôle ? Le médecin généraliste dispose-t-il des outils nécessaires pour remplir ce rôle (lignes directrices, aides à la décision, etc.) ?	
3	Faut-il un parcours de soins spécifique pour les personnes atteintes de démence précoce ? Les personnes atteintes de démence précoce peuvent-elles être aidées dans le cadre de l'offre de soins existant pour les personnes atteintes de démence ? Pourquoi ?	Trajet de soin
4	Les personnes atteintes de démence précoce mettent souvent beaucoup de temps (plusieurs années) à être diagnostiquées, leurs symptômes étant d'abord attribués à autre chose, comme la dépression ou l'épuisement professionnel. • Quelles en sont, selon vous, les principales raisons ? • Comment la pose du diagnostic pourrait-elle être accélérée ?	Diagnostic
5	Quels soins sont dispensés actuellement aux personnes atteintes de démence précoce (par rapport aux personnes atteintes de démence en général) ? Qu'est-ce qui pourrait être amélioré ?	Suivi à long terme
6	Quelles sont les difficultés rencontrées par les personnes atteintes de démence précoce ? • Avant ou après le diagnostic ? • À un stade précoce ou à un stade avancé de la maladie ? • Dans quelle mesure cette situation diffère-t-elle de celle des personnes atteintes de démence ?	Problèmes
7	De quelle prise en charge ou de quel cadre les personnes atteintes de démence précoce ont-elles besoin ? • Pouvez-vous expliquer dans quelle mesure les différents types de démence précoce entraînent également des besoins de soins différents chez les patients ? • Dans quelle mesure les besoins diffèrent-ils selon le stade (précoce ou avancé) auquel se trouve la personne atteinte de démence précoce ? • En quoi ces soins devraient-ils différer de ceux prodigués aux personnes atteintes de démence ? • Quelle expérience (connaissance) avez-vous d'initiatives existantes ? (et avec quelles conclusions/résultats ?)	Besoins
8	Qu'est-ce qui fonctionne dans l'offre actuelle de soins aux personnes atteintes de démence précoce ?	Ce qui fonctionne
9	Que manque-t-il dans le système de santé actuel pour que les personnes atteintes de démence précoce reçoivent les soins appropriés ? • Lorsque l'on envisage un parcours de soins pour les personnes atteintes de démence à un stade précoce, quels sont les éléments qui ne devraient absolument pas manquer dans ce parcours ? • (est-ce qu'il faut un parcours de soins ?)	Lacunes dans le système
	Génétique ? Nouveaux traitements ?	

	Biomarqueurs ?	
10	Selon vous, à qui d'autre devrions-nous nous adresser dans le cadre de ce projet ?	Snowballing interviews

2.3. Profile interviewee: expertise centrum in Flanders (Dutch version)

2.3.1. Introductie

Dit KCE project is er gekomen op vraag van het kabinet van Minister Vandenbroucke. De studie moet beleidsmakers helpen om de zorg voor personen met jong dementie te organiseren.

Binnen dit project zullen we derhalve vooral focussen op een beperkte internationale vergelijking (NL, FR, UK) van initiatieven in het buitenland, een literatuurstudie over unmet needs bij personen met jong dementie, een overzicht van het huidige zorgaanbod in België en waar dit zorgaanbod te kort schiet.

We hebben ook gesprekken gepland met een 15-tal experten (beleidsmensen, artsen, paramedici, vertegenwoordigers van patiëntenverenigingen, etc).

! We zouden graag dit gesprek opnemen om de verwerking te vergemakkelijken. Uiteraard wordt wat hier gezegd confidentieel behandeld en op een geaggregeerd niveau verwerkt in de conclusies van het rapport. Heeft u daar bezwaar tegen?

Alvorens echt van start te gaan, stellen we onszelf nog graag kort even voor: […]

	Vraag	Onderwerp
Intro	In dit interview zullen we ons voornamelijk richten op de huidige initiatieven en tekortkomingen van de dementiezorg in Vlaanderen en meer specifiek jongdementie. Maar als startpunt voor dit interview zullen we vertrekken vanuit jullie organisatie waarna we het huidige beleid zullen bespreken nl. de voorgestelde resolutie en het Vlaams dementieplan (2021-2025)	Scope gesprek
1	Als expertisecentrum dementie Vlaanderen hebben jullie een belangrijk rol in de educatie, het verschaffen van informatie, het ondersteunen, in onderzoek, het bewustzijn verhogen en een signaalfunctie naar de overheid. Deze doelen streven jullie na via een nationaal expertisecentrum waaronder regionale centra functioneren, deze regionale centra zetten tal van lokale initiatieven op en zorgen voor een meer lokale samenwerkingen en sensibiliseringsacties: - Wat zijn de belangrijkste **doelstellingen** die het expertisecentrum beoogd op korte en lange termijn - Op welke **drempels** stuiten jullie als organisatie om deze doelstellingen te bewerkstelligen? - Specifiek voor jongdementie, zien we dat er enkele initiatieven uitgerold zijn in regionale centra (bv. Familiegroepen jongdementie), zijn deze initiatieven lokaal geïnitieerd door bv. aanwezige expertise of hoe komen deze tot stand? - Hoe is de samenwerking met partnerorganisaties in Franstalig België?	Missie Expertisecentrum
2	In de resolutie (2020) wordt er gepleit voor een zorgtraject specifiek voor personen met jong dementie in een matig-gevorderd stadium. Er wordt meer specifiek gepleit voor een conventie voor jongdementie.	Visie op de resolutie

	Dat brengt mij tot een aantal vragen: A) Waarom hebben we een conventie nodig voor personen met jong dementie? Waarom geen conventie voor personen met dementie in het algemeen, inclusief jongdementie? Hoe staat u daar tegenover? B) Waarom in een matig-gevorderd stadium? Komen we dan niet te laat volgens u? C) De focus ligt in de resolutie voornamelijk op residentiële zorg. Is dat een terechte keuze volgens u?	
3	In het huidige **Vlaamse dementieplan** ligt de focus voornamelijk op preventie, het verbeteren van de kwaliteit van de zorg en het ondersteunen van mantelzorgers. - Bent u tevreden over het Vlaamse dementieplan? Waarom wel/niet? Wat ontbreekt er nog? - Hoe moeten we jongdementie situeren binnen het Vlaamse dementieplan? In welke zin of in welke mate komt de zorg voor personen met jong dementie aan bod in dit dementieplan? Is dat voldoende? - Welke handvaten biedt het huidige dementieplan aan om de kwaliteit van de zorg te verbeteren tegen 2025? - Worden de verschillende sectoren, daarmee bedoel ik, residentiële zorg, thuiszorg en dagcentra, en ziekenhuiszorg, voldoende ondersteund? Of tegen welke specifieke problemen lopen zij aan? - Hoe loopt de samenwerking tussen deze sectoren en de eerste lijn? - Zou het Vlaamse dementieplan nationaal uitgerold kunnen/moeten worden?	Vlaams dementieplan
4	Welke andere maatregelen zouden kunnen helpen om de huidige zorg in Vlaanderen te verbeteren? Enkele voorbeelden: • Initiatieven die informele zorgverleners beter ondersteunen • Verder uitrollen van referentiepersonen in woonzorgcentra en de thuiszorg? • Initiatieven van de regionale centra verder uitrollen zodat ze minder regio gebonden zijn (toegankelijkere zorg) • Wat zou er veranderen mocht jongdementie erkend worden als een beperking? • Hoe expertisedeling en informatie verder stimuleren onder professionele en informele zorgverleners? Algemene bevolking? • Impact van preventie intiatieven?	Andere initiatieven
5	Waaraan zouden beleidsmakers volgens u prioriteit moeten geven als het aan komt op zorg voor personen met jong dementie?	Prioriteiten
6	Zou u graag nog iets willen toevoegen dat nog niet aanbod is gekomen?	
7	Wie zouden we volgens u zeker nog moeten spreken in het kader van dit project?	Snowballing interviewees

2.4. Profile interviewee: patient organisation (French version)

2.4.1. Introduction

Ce projet du KCE a été initié à la demande du cabinet du ministre Vandenbroecke. Cette étude doit aider les décideurs politiques à organiser de manière adéquate les soins pour les personnes atteintes de démence précoce, et c'est pourquoi nous souhaitons connaitre leurs besoins d'une part, et ce qu'elles rencontrent dans le cadre de l'offre de soins actuelle d'autre part. Il s'agit d'un projet à court terme : nous devons être prêts pour avril 2024 ; dès lors nous avons dû faire des choix pragmatiques.

Dans le cadre de ce projet, nous nous concentrerons principalement sur une comparaison internationale limitée (NL, FR, UK), une étude de la littérature sur les besoins non satisfaits des personnes atteintes de démence précoce, une vue d'ensemble des soins actuels en Belgique et ce qui manque dans ces soins.

Nous avons prévu de réaliser une quinzaine d'entretiens avec d'experts (décideurs politiques, médecins, personnel paramédical, représentants d'associations de patients, etc.).

Nous souhaitons enregistrer cette conversation afin d'en faciliter le traitement. Bien entendu, ce qui est dit ici sera traité de manière confidentielle et incorporé à un niveau agrégé dans le rapport. Avez-vous des objections à cela ?

Avant de commencer, nous aimerions nous présenter brièvement : [...]

	Question	Objet
1	Pouvez-vous décrire de quelle manière vous êtes impliqué.e auprès de patients souffrant de démence précoce ?	Motivation
2	Pour votre association/collectif, qu'est-ce que la démence précoce ? • Comment la définiriez-vous ? • Comment la distingueriez-vous de la démence en général ? Sur base de l'âge ou d'autres critères tels que les symptômes ? • À partir de quand parle-t-on de démence avancée ?	Définition
3	Les personnes atteintes de démence précoce mettent souvent beaucoup de temps (plusieurs années) à être diagnostiquées, leurs symptômes étant d'abord attribués à autre chose, comme la dépression ou l'épuisement professionnel. • Quelles en sont, selon vous, les principales raisons ? • Comment la pose du diagnostic pourrait-elle être accélérée ?	Diagnostic
4	D'après votre expérience, comment s'organisent les soins pour les personnes atteintes de démence précoce ? / Quels soins sont dispensés actuellement aux personnes atteintes de démence précoce (par rapport aux personnes atteintes de démence en général) ? • Selon les stades de la maladies: phase pré-diagnostique, diagnostique, post-diagnostique • Spécifiquement pour les patients jeunes/par comparaison à la démence en générale Les personnes atteintes de démence précoce peuvent-elles être aidées dans le cadre de l'offre de soins existant pour les personnes atteintes de démence ? Pourquoi ?	Suivi à long terme
5	De façon générale dans le parcours de soins, quelles sont les difficultés rencontrées par les personnes atteintes de démence précoce ? • Avant ou après le diagnostic ? • À un stade précoce ou à un stade avancé de la maladie ? • Dans quelle mesure cette situation diffère-t-elle de celle des personnes atteintes de démence ?	Problèmes
6	De quelle prise en charge les personnes atteintes de démence précoce ont-elles besoin ?	Besoins

	• Dans quelle mesure les différents types de démence précoce entraînent des besoins de soins différents chez les patients ? • Dans quelle mesure les besoins diffèrent-ils selon le stade (précoce ou avancé) auquel se trouve la personne atteinte de démence précoce ? • En quoi ces soins doivent-ils différer de ceux prodigués aux personnes atteintes de démence ? • Quelle expérience (ou connaissance) avez-vous d'initiatives existantes ? (avec quelles conclusions/résultats ?) ○ Quels retours avez-vous sur les initiatives mises en place en Flandre, pour les patients avec une démence précoce ?	

	Quel serait l'intérêt d'instaurer un trajet de soins pour le personnes souffrant de démence précoce ?
	• Que faudrait-il inclure dans ce trajet de soins ?
	• Quels professionnels devraient être impliqués ?
	  ○ Rôle de la 1ère ligne de soins ?
	  ○ Rôle de la médecine spécialisée ?
	  ○ Rôle de la coordination des soins et des intervenants ?
	• Quand ce trajet de soins devrait-il commencer dans l'histoire de la maladie (dès le diagnostic ? à un stade avancé de la maladie ? autre ?)
	• Ce trajet de soins devrait-il être spécifique pour les personnes atteintes de démence précoce ? Pourquoi ?
		Trajet de soin

7	Qu'est-ce qui pourrait être amélioré dans l'offre de soins actuellement disponible ? Lorsque l'on envisage un parcours de soins pour les personnes atteintes de démence à un stade précoce, quels sont les éléments qui ne devraient absolument pas manquer dans ce parcours ?	Offre de soins
8	Qu'est-ce qui fonctionne dans l'offre actuelle de soins aux personnes atteintes de démence précoce ?	Ce qui fonctionne
9	Que pensez-vous de la demande de certains groupes de considérer la démence précoce comme un handicap ?	
10	Selon vous, à qui d'autre devrions-nous nous adresser dans le cadre de ce projet ?	Snowballing interviews

2.5. Profile interviewee: policy maker (Dutch version)

2.5.1. Introductie

U kent de ontstaansgeschiedenis van dit KCE project wellicht zeer goed. Dit KCE project is er gekomen op vraag van het kabinet van Minister Vandenbroucke. De studie moet beleidsmakers helpen om de zorg voor personen met jong dementie adequaat te organiseren.

Binnen dit project zullen derhalve vooral focussen op een beperkte internationale vergelijking (NL, FR, UK) van initiatieven in het buitenland, een literatuurstudie over unmet needs bij personen met jong dementie, een overzicht van het huidige zorgaanbod in België en waar dit zorgaanbod te kort schiet.

We hebben gesprekken gepland met een 15-tal experten (beleidsmensen, artsen, paramedici, vertegenwoordigers van patiëntenverenigingen, etc).

! We zouden graag dit gesprek opnemen om de verwerking te vergemakkelijken. Uiteraard wordt wat hier gezegd confidentieel behandeld en op een geaggregeerd niveau verwerkt in de conclusies van het rapport. Heeft u daar bezwaar tegen?

Alvorens echt van start te gaan, stellen we onszelf nog graag kort even voor: […]

	Vraag	Onderwerp
Intro	We kennen u uiteraard voornamelijk als indiener van de resolutie. We zouden het met u graag hebben over wat in de resolutie wordt voorgesteld, maar tegelijk willen we het gesprek niet daartoe beperken en ook breder kijken.	Scope gesprek
1	Kan u ons kort even toelichten hoe is de resolutie tot stand is gekomen?	Geschiedenis
2	In de resolutie wordt er gepleit voor een zorgtraject specifiek voor personen met jong dementie in een matig-gevorderd stadium. Er meer specifiek gepleit voor een conventie voor jongdementie. Dat brengt mij tot een drietal vragen: A) Waarom hebben we een conventie nodig voor personen met jong dementie? Waarom geen conventie voor personen met dementie in het algemeen, inclusief jongdementie? B) Waarom in een matig-gevorderd stadium? Wat verstaat u daar onder en komen we dan niet te laat? C) Waarom wordt er gekozen voor een conventie als financieringsvorm?	Scope van de resolutie
3	Vervolgens wil ik even met u stilstaan bij de inhoud van de conventie. In de resolutie worden drie doelgroepen beschreven: mensen die thuis verzorgd worden, personen die gebruik maken van dagcentra, en tenslotte de residentiële zorg. Als we kijken naar de residentiële zorg, in Vlaanderen werden extra middelen toegekend aan woonzorgcentra die gespecialiseerd zijn in de zorg voor personen met jongdementie. Het gaat om een 23-tal woonzorgcentra met 200 wooneenheden. Moeten we daar verder op inzetten (want het overgrote deel van de personen met jong dementie woont thuis)? Is het genoeg? Maar er zijn ook noden stroomopwaarts qua medische zorg: bijv. wachttijden voor consulten bij specialisten, de ontoegankelijkheid van diagnostische tests, nood aan multidisciplinaire zorgteams, gebrek aan ondersteuning en opvolging op lange termijn etc. Moeten we die dingen niet meenemen?	Inhoud van de conventie

4	Ik zou met u een aantal probleemgebieden willen van naderbij bekijken: A) Een eerste probleem is de **late diagnose**. Hoe zouden we dit kunnen oplossen? B) Ten tweede horen we bij clinici dat de **wachttijden** oplopen tot een jaar voor een intake consultatie bij een neuroloog. Voor een opvolgingsconsult zijn er ook wachttijden van 6 tot 9 maanden. Daardoor kan er niet kort op de bal gespeeld worden en gaat er veel tijd verloren. Heeft u daar suggesties voor? Kan opvolging op lange termijn door een neuropsycholoog een oplossing zijn? C) Ten derde is de **toegang tot diagnostische testen** beperkt doordat ze niet terugbetaald worden (uitgezonderd een eenmalig bilan), nochtans zijn die testen en het kunnen herhalen over de tijd, belangrijk om de voortgang van de aandoening op te volgen en de veranderende noden te evalueren. Hoe kijkt u daarnaar? D) Ten vierde worden clinici betaald voor een **consult van 20 minuten** wat niet volstaat. Consulten duren minstens dubbel zo lang. Ziekenhuizen investeren niet in zorgdomeinen die hen meer kosten dan opbrengen. Is er daar ruimte voor verbetering?	Problemen
5	We wonen ook in een land met verschillende snelheden in Vl, BXL, Wall. In Vlaanderen staan we structureel wat verder, o.a. met het expertisecentrum dementie Vlaanderen. Er zit dus een communautair kantje aan dit verhaal wat het ook politiek gevoelig maakt. Hoe kijkt u hiernaar? Wat kunnen mogelijke oplossingen zijn? Is dat opgelost met een conventie?	Verschillende snelheden in Vl, Bxl, Wall
6	Ruimer denken dan een conventie. Welke andere maatregelen zouden kunnen helpen? • Bijv. is er een rol weg gelegd voor psychiatrische thuisverpleegkundigen? • Idem voor referentie artsen en – verpleegkundigen. • Bijv. hospitalisatieverzekeringen ook toepassen voor psychologische en psychiatrische zorg, wat nu buiten de regeling voor de verzekeringsproducten valt. • Wat zou er veranderen mocht jongdementie erkend worden als een beperking? Is dat een goeie denkpiste? • Hoe expertisedeling stimuleren? • Wat is de rol van de huisartsen?	Ruimer dan de conventie
7	Zou u graag nog zaken willen toevoegen, onderwerpen die nog niet aan bod gekomen zijn?	
8	Wie zouden we volgens u zeker nog moeten spreken in het kader van dit project?	Snowballing interviewees

3. INTERNATIONAL COMPARISON: ORGANISATION OF CARE AND SUPPORT IN FOUR COUNTRIES

3.1. England

Dementia care, as part of health care, strategies, implementation and funding is devolved to Scotland, Wales, Northern Ireland by the United Kingdom (UK) government's Department of Health and Social Care (DHSC). The DHSC is directly responsible for government policy on health and social care in England. The National Health Service (NHS) England is responsible to the DHSC for implementation and commissioning of health services and, from mid-2022, supports a new structure of 42 Integrated Care Systems (ICS) which have replaced the clinical commissioning groups (CCG). This reflects the implementation of the Health and Social Care Act 2022 promoting integration. The ICS seek to integrate health (NHS), social care (local authority) and the voluntary sector to provide the services their populations need, and are allocated funding including from NHS and other sources. The NHS mandates and policies and guidelines are used by the ICS. Care for people of all ages with dementia will be included in their plans, but it may or may not be a priority and young-onset dementia may or may not be explicitly included in these plans.

In recent years, various documents have been published in England by different institutions, organisations or groups in the form of plans, strategies, quality standards or recommendations. They aim to **organise and support improvements in the provision and quality of care** and **support for people living with (young-onset) dementia and their families/carers**.

In 2020, it has been announced that a new 10-year plan to tackle dementia will be published. Finally, a strategy for six major groups of conditions[a], including dementia, will be published by the DHSC in 2024. This strategy is still under construction, but an initial draft policy paper states that the "vision is to improve the lives of people living with dementia and their carers now, as well as the lives of those who may be affected in the future. We must create a society where every person with dementia, their families and carers, receive high-quality, compassionate care, from diagnosis through to end of life".[1] Operational planning guidance is also expected be published. It is not yet known how and to what extent young-onset dementia will be included in this new comprehensive strategy on these six major conditions. An effort has been made to involve people with dementia and their families in a participatory process to revise this strategy. (Personal communication Dementia UK) As the Major Conditions Strategy has not yet been published in its final version, we have extracted information from this document, as well as from the previous ones.

In addition to these plans or strategies, the Angela Project was carried out: it is the largest study on young-onset dementia in England. This three-year study ended in 2019 and provides the most comprehensive findings on diagnosis, support and living well for people with young-onset dementia and their families. The research team conducted a Delphi with international experts to develop guidance for clinicians on essential elements to support clinical decision-making in the diagnosis of young-onset dementia: 48 statements were rated at a high level for a comprehensive assessment, covering questions from pre-assessment to end of life and including neuroimaging, for example.[2] As this research is outside the national plan, it is not included in the table below.

[a] It covers cancer, heart disease, musculoskeletal disorders, mental ill-health, dementia and respiratory diseases.

The English national plan does not include anything specific about maintaining **employment** for people with young-onset dementia. Patient' organisations such as Alzheimer's Society or Dementia UK provide information to workers about their rights and options.

Table 1 – The national plan on (young-onset) dementia in England

Topic	
General information on dementia strategy	
• **Name**	- **The Major Conditions Strategy: Case for change our strategic framework** (the final document is expected to be published in 2024)[1] *We have also consulted previous national dementia strategies to set the context for dementia care[b]:* - ***The dementia care pathway: Full implementation guidance*** *(published by the National Collaborating Centre for Mental Health (NCCMH), 2018)[3]* - ***Prime Minister's Challenge on Dementia 2020: Implementation plan*** *(from the Department of Health, 2016)[4]* - The **Well Pathway for Dementia** (from NHS England, 2016)[5] - ***Living well with dementia: A National Dementia strategy. Best practice guidance*** *(from the Department of Health, 2009)[6]*
• **Country/Region**	England
• **Funding**	Funding for NHS England to implement dementia plans comes from the government through the Department of Health and Social Care (DHSC). As there is no specific national plan for young-onset dementia, there no specific funding for people with young-onset dementia. In addition, it is difficult to obtain figures on funding for dementia (all ages). (Personal communication Dementia UK)
• **Institution**	Department of Health and Social Care (DHSC) In England, care is provided by the NHS England (and Integrated Care Boards (ICB)).
• **Date**	Expected in 2024: **The Major Conditions Strategy**, that includes care for people with dementia.[1] It's been more than 15 years since strategies, plans, actions or recommendations for the care of people with (young-onset) dementia have been published and updated.
• **Aim**	The **Major Conditions Strategy**, which is broader than dementia, aims to improve health outcomes, increase healthy life expectancy and reduce ill-health related labour market inactivity.[1] In 2016, the **Prime Minister's Challenge on Dementia 2020** was published with a clear and unambiguous aim: to be the best country in the world for dementia care, support, research and awareness by 2020.[4] *We also retrieved some other documents, having specific aims, such as setting quality standards for services or quality outcomes or recommending care pathways.*

[b] In this table, we have included health policy documents on dementia, such as national plans or strategies, as well as recommendations and standards of care from national institutions or organisations.

Organisation and initiatives	
• **Target group of the national strategy**	All national strategies focus on people with dementia and their informal carers (with the exception of the Major Conditions Strategy, which will be published in 2024 and will cover the whole population). **People with young-onset dementia are included as a subgroup and, where appropriate, are specifically addressed due to their specific needs**. Only documents published by the **Young Dementia Network** focus on young people (*they are recommendations, and not national strategies*).
• **Public awareness and prevention**	The **Major Conditions Strategy** looks at primary and secondary prevention, with the aim of tackling the wider determinants of health and stopping or delaying the progression of conditions. Determinants are broad and can include air quality, healthy habits (diet, exercise). According to this document, "twelve risk factors account for approximately 40% of dementias globally, meaning that 40% of cases could potentially be prevented if action is taken on these risk factors across the life course" (Chapter 2).[1] In previous national plans: The **Prime Minister's Challenge on Dementia 2020** focuses on risk reduction, and more precisely on preventing/delaying the onset and progression of the disease, based on National Institute for Health and Care Excellence (NICE) guidelines. Awareness and social action are also part of the Challenge, through Dementia Friendly Communities.[4] The **Well Pathway for Dementia** (2016) consists of five stages. The first stage is "Preventing well" and includes prevention, risk reduction, health information. The standards for: - prevention were based on NICE guidelines, - risk reduction and research support were based on the OECD dementia pathway, - health information were based on the NICE pathway.[5]
• **Screening and diagnosis**	There are no national guidelines for screening and treatment (for people with young-onset dementia and of all ages). Diagnosis of people with suspected types of young-onset dementia varies across England in terms of timeliness, assessments and imaging carried out, and the service managing the diagnosis. The first point of contact is the GP, from there it depends on local arrangements and the pathway may be to Older Adults Mental Health Teams, Memory Assessment Services (sometimes known as memory clinics) run by Mental Health Foundation Trusts or Cognitive Disorders or Neurology clinics, usually in acute hospitals. Follow-up support also varies. In addition, much of the post-diagnosis support and some of the pre-diagnosis support is provided by the voluntary/third sector (e.g. Dementia UK), which provides face-to-face, virtual and helpline support to families affected by (young-onset) dementia.(Personal communication Dementia UK) The **Major Conditions Strategy** has a chapter on early diagnosis (Chapter 3) which mentions that "not enough people have an accurate and timely diagnosis".[1] In a previous national document:

	In the **Well Pathway for Dementia** (2016), the second stage (out of five) is "Diagnosing well" and it has aimed to achieve a timely and accurate diagnosis, care plan and review within the first year. The standards for diagnosis, memory assessment[c], discussion of concerns, investigation, provision of information, and integrated and advanced care planning are based on the NICE guidelines, the NICE quality standards 2010, the NICE quality standards 2013, the NICE pathway, and the OECD dementia pathway.[5] In a recommendation document from a patient organisation: The **Young Dementia Network**, a patient organisation, has published (2022) a set of recommendations for the care of people with young-onset dementia in its document "Young Onset Dementia Pathway, Supporting implementation of the NICE guideline for people with young onset dementia".[8] It brings together the experience and expertise of people with young-onset dementia and those who work with and support them. It also highlights the unique needs of people with young-onset dementia that require a tailored approach to support and care. The recommended pathway includes: 1) Positive contact with the GP, reducing the time taken to get the right diagnosis, including i) GP awareness of young-onset dementia and appropriate local referral routes ii) Access to pre-assessment counselling iii) Provision of information 2) A clear collaborative and specialist diagnostic process i) Diagnosis in specialised services (team with expertise in young-onset dementia and specialist investigations (imaging, neuropsychology, molecular biomarkers, genetic testing) (including some elements that should be carried out during the diagnostic assessment) ii) Feedback of diagnosis iii) Referral to key worker (e.g. "dementia advisor", to support the patient and his/her family in the care pathway)
• **Management and treatment**	In the UK, there are specialist dementia nurses called "Admiral Nurses", supported by Dementia UK (around 430 Admiral Nurses in the UK): they support patients and their informal carers, helping them to manage their complex needs; they help people living with dementia to stay independent for longer. Admiral Nurses work in local community services, GP practices and NHS hospitals, care homes, and hospices. They also run a Dementia Helpline and virtual and face-to-face clinic appointments. They can be contacted by any patient or family member of a person with dementia and support patients at their request and provide services to people with dementia of all ages.(Personal communication Dementia UK) The **Major Conditions Strategy** states that a "formal diagnosis unlocks access to care and support for the person with dementia, as well as their families and unpaid carers and empowers people to manage their condition and plan for the future" (Chapter 3).[1] It is also about living with major conditions, including supporting person-centred care, empowering people and end of life care (Chapter 4). For people with dementia, it highlights that targeted cognitive rehabilitation can reduce the functional impact of the condition on their daily lives. The strategy states that "the national ambition is for at least two-thirds of people with dementia to have a formal diagnosis, but the pandemic has delayed progress. In March 2020, the dementia diagnosis rate dropped below

[c] The usual UK model is a specialist-led service, often associated with psychogeriatric services, requiring a referral by a general practitioner to access. There are 222 memory clinics in England.[7]

the national ambition for the first time in almost 4 years, with current rates around 63%. This is why the NHS has committed to recover dementia diagnosis rates in the priorities and operational planning guidance for 2023 to 2024." (Chapter 3) They also mention "several actions to improve dementia diagnosis rates, including:

- providing £17 million of government funding to address dementia waiting lists and increase the number of diagnoses
- piloting the Diagnosing Advanced Dementia Mandate tool to improve diagnosis in care homes
- working with GP IT system providers to improve identification of people who may have dementia."[1]

In previous national plans:

The **Prime Minister's Challenge on Dementia 2020** has expected to see joined-up plans for health and care support in every area and personalised care plans for every person with dementia.[4]

The final three stages of the **Well Pathway for Dementia** (2016) are "Supporting well", "Living well", and "Dying well". The standards for :

- "Supporting well" relates to choice, Behavioural and Psychological Symptoms of Dementia (BPSD), liaison, advocates, housing, hospital treatment, technology, health and social services, and hard to reach groups;
- "Living well" relates to integrated services, carer support, carer respite, coordinated care, promoting independence, relationships, leisure and safe communities;
- "Dying well" refers to palliative care and pain, end of life and, preferred place of death.

All standards are based on the following references: NICE guidelines, NICE quality standards 2010, NICE quality standards 2013, NICE pathway, OECD dementia pathway, and Behavioural and Psychological Symptoms of Dementia (BPSD).[5]

Recommendations were also made on diagnostic services and a care pathway for young-onset dementia:

- The **NICE recommendations** about assessment, management and support for people living with dementia and their carers (2018) have included a specific chapter on the needs of younger people with dementia. These needs "include, but are not limited to, loss of employment (and hence income and status), reduced ability to care for elderly parents or dependent children, a need to reconsider plans for retirement, and stigma from having an illness more typically associated with later life". The NICE recommendations also specify the special needs of carers of people living with young-onset dementia. According to NICE, "it is incumbent on professionals working with people affected by young-onset dementia to be mindful of the additional challenges faced by this group, and to respond to these in a personalised way", e.g. some people may be able to continue working with appropriate support. (Chapter 17 is dedicated to the needs of younger people living with dementia.)[9]
  The conclusion of the NICE recommendations reported that "the overall quality of the evidence was low or very low, because of the paucity of studies in this area and the low numbers of study participants. However, the Committee agreed that the findings of the review did match their experience and therefore were confident they would be replicated in larger studies. They agreed that, due to the relatively low quality of the evidence available, it was more appropriate to make modifications to recommendations made in other sections with stronger evidence bases to ensure they

appropriately considered the needs of younger people, rather than writing a separate set of recommendations to cover younger people."[9]
As a result, the section on "Involving people with dementia in decisions about care" noted that many subgroups of people living with dementia, such as younger people, "may have very different information needs" and that "it was important that the information provided be tailored to these different circumstances, rather than only general information about dementia being provided."[9] The recommendations also include care planning, review and coordination, and also staff training sessions to review the evidence on the specific needs of younger people with dementia.

- Approximately 80% of people with young-onset dementia are diagnosed within older adult mental health services, and young-onset services (when they exist) are most often part of Older Adult Mental Health services.(Personal communication Dementia UK) The **Royal College of Psychiatrists** made the following key recommendations for young-onset dementia in mental health services:

1) Access to a specialised service with expertise in assessment and treatment to facilitate support
   a. Putting the patient and their family at the centre
   b. Clinical leadership and expertise
   c. Developing partnership and commissioning
   d. Optimising diagnostic and evidence-based practice
   e. Developing links with other medical and psychiatric specialties
2) Workforce planning for psychiatrists
3) Continuing professional development for consultants and trainees
4) Future research and strategic development.[10]

- The **Young Dementia Network** has recommended a "Young Onset Dementia Pathway" which includes:

1) Specialist support and information to meet changing needs
   i) Key worker engaging with the individual and their family/friends to understand their needs
2) Living with young-onset dementia
   i) Regular contact with joint reviews with a core team
   ii) Key worker (e.g. case manager, admiral nurse) works with the person and their family to develop a plan appropriate to their stage of life
3) Towards the end of life
   i) Regular reviews are agreed as the person approaches the end of their life and support is tailored to provide
      a. access to short term care to give family members a break from caring (including day and residential care)
      b. acute care in dementia friendly wards, compliant with John's Campaign, so that a family member can stay with the person during their stay
      c. age-appropriate long-term residential care within a reasonable distance from home
      d. support to stay in the home if this is what the person wants
      e. age-appropriate palliative and end of life care
      f. bereavement support for families and carers.[11]

• **Identified gaps**	- Variability depending on locality. - Gaps relating to young-onset dementia may include low awareness of potential symptoms in the younger person by the GP; some areas may not have specific clearly identified pathway for diagnosis from the GP onwards. - It may be lack of young-onset dementia expertise within clinicians in some diagnostic services, lengthy waiting lists for different types of scans (imaging) required to determine subtype of dementia, insufficient supported access to genetic testing. - There may not be support available through diagnosis process.(Personal communication Dementia UK)
Assessment	
• **Timing**	The **Major Conditions Strategy** does not currently have an evaluation plan. ***This section reports on what was planned in previous national strategies.*** At the end of the **National dementia strategy**, some attempts were made to review the progress. However, for various reasons (including COVID-19), this review was not comprehensive. As a result, it is difficult to assess the state of young-onset dementia within the big picture and across England. Since 2020, there has been a lot of activity/investment in dementia to restore the 66.7% dementia diagnosis rate target and to try to reduce waiting times for dementia related appointments/scans/assessments, care and support (the dementia diagnosis rate reports focus on the patients over 65 years).(Personal communication Dementia UK) The **Prime Minister's Challenge on Dementia 2020**: annual assessment. Initial assessment of all Clinical Commissioning Groups (CCG – recently replaced by the ICB) in summer 2016; formal annual summative assessment of all CCG for 2016/17: published in summer 2017.[4]
• **Type of assessment**	Outcome and process measures were planned in the **Dementia Plans** (see indicators below). Document other than the national strategy: Quality standards have also been developed by the **Memory Services National Accreditation Programme** (MSNAP): the standards are aspirational (according to the MSNAP, "it is unlikely that any service would meet all of them"[12]), and the services are categorised against each standard according to 3 levels: i) failure to meet the standards would result in a significant threat to patient safety, rights or dignity and/or would breach the law (provision of evidence-based care and treatment; they must be met for a service to be accredited), ii) expected to be met by an accredited service, iii) aspirational standards or not the direct responsibility of the service[d]. The MSNAP helps memory services to evaluate themselves against agreed standards and awards accreditation to services that meet the required level of performance. The accreditation is on a voluntary basis (not automatic and not mandatory).[12]

[d] 'Accredited', means that teams meet 100% of type 1 standards, 80% of type 2 standards, and 60% of type 3 standards.

- **Indicators**

Dementia data and analysis: data on dementia are gathered by the Office for Health Improvement and Disparities (OHID) from across the health and care system; it covers the following topics: understanding dementia locally, dementia and comorbidities, end of life care, and use of hospital services, but are not specific to young patients.[13]

The following section reports on the indicators reported in previous national strategies[e]. They cover indicators for patients of all ages, except when mentioned differently.

The implementation plan for the **Prime Minister's Challenge on Dementia 2020** set out more than 50 commitments that aim to make England the world-leader in dementia care, research and awareness by 2020 (here below the commitments identified in the plan itself as the crucial enablers). The implementation plan sets out how these commitments will be met, and it sets out priority actions, and the organisation responsible, across 4 themes: i) risk reduction, ii) health and care, iii) awareness and social action, and iv) research. No more details are given on the methods to assess the commitments. *These indicators (reported in the Implementation plan) should be seen as a target to make England a world-leader in dementia care, research and awareness, and the document clearly sets out the actions to be taken to address each of them.*[4]

Risk reduction:

- Commitment: Improved **public awareness** and understanding of the factors which increase the risk of developing dementia and how people can reduce their risk by living more healthily.
  Success: if by 2020 people at risk of dementia and their families/carers will have a clear idea about why they are at risk, how they can best reduce their risk of dementia and have the knowledge and know-how to get the support they need.

Health and care:

- Commitment: In every part of the country people with dementia having **equal access** to diagnosis as for other conditions, with an expectation that the national average for an initial specialist assessment should be six weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.
  Success: if national dementia diagnosis rate maintained at two-thirds prevalence, and reduced local variation between CCG following agreement and implementation of an appropriate and affordable plan to bring services into line within the national framework for treatment and care.
- Commitment: Every person diagnosed with dementia having **meaningful care** following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published NICE Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to made publicly available.
  Success: if people with dementia and their carers are able to access quality dementia care and support, enabling them to say "I have support that helps me live my life", "I know that services are designed around me and my needs", and "I have personal choice and control or influence over decisions about me".
- Commitment: **GPs playing a leading role** in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.

[e] Not necessarily on what was assessed/how it was assessed (in case it was actually carried out).

Success: if GPs ensuring everyone diagnosed with dementia has a personalised care plan that covers both health and care and includes their carer. This will enable people to say "I know that services are designed around me and my needs", and "I have personal choice and control or influence over decisions about me".

- Commitment: All hospitals and care homes meeting agreed criteria to becoming a **dementia-friendly health and care setting**.
  Success: if hospitals and care homes to become and stay dementia-friendly.
- Commitment: **All NHS staff having received training on dementia appropriate to their role**. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.
  Success: if people with dementia and their carers will be supported by health and care staff in all types of service that will have the appropriate level of dementia awareness and training.

Dementia awareness and social action:

- Commitment: Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement including sharing its learning across the world and learning from others.
  Success: There will be 4 million Dementia Friends in England covering all aspects of society, business and community, and connected to a global network of Dementia Friends and Dementia Friendly Communities. This movement will **normalise dementia awareness, care and support**, and people affected by dementia will be able to say 'I have support that helps me live my life'.
- Commitment: Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer's Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.
  Success: There will be dementia-friendly communities across the country which means that people affected by dementia will be able to say 'I have a sense of belonging and of being a valued part of family, community and civic life'.
- Commitment: **All businesses encouraged and supported to become dementia friendly**, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programs.
  Success: Increasing numbers of businesses will be involved in dementia-friendly practices which means people affected by dementia will be able to say 'I live in an enabling and supportive environment where I feel valued and understood'.
- Commitment: National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.

Success: Local and national government will be involved in dementia-friendly communities across the country which means that people affected by dementia will be able to say 'I have a sense of belonging and use of being a valued part of family, community and civic life'.

An "Implementation guide and resource pack for dementia care" has also been published by NHS England (2017) to support the delivery of a number of objectives in the Prime Minister's challenge on dementia 2020. It's based on key-statements (such as ""I was diagnosed in a timely way" → We know that if I am referred for an assessment for dementia, I will receive a timely diagnosis and agree on an initial care plan) and on access and quality benchmarks for the dementia care pathway (some are based on the NICE recommendations).[14]

The **Dementia Care Pathway** outlines the care pathway and associated benchmarks to support improvements in the delivery and quality of care and support, for people living with dementia and their families and carers.[3]

Other document of interest report the following:

Quality statements from the NICE Dementia quality standards[9]

Diagnosing well:

Support in Health and Social Care NICE quality standard:

- People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

Independence and Wellbeing NICE quality standard:

- People worried about possible dementia in themselves or someone they know can discuss their concerns, and the option of seeking a diagnosis, with someone with knowledge and expertise.

Living well:

Support in Health and Social Care NICE quality standard:

- People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local areas.
- People with dementia who develop non-cognitive symptoms that cause them significant distress, or develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
- People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

Care planning and review:

- People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator* and addresses their individual needs.
- Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

Joint decision-making:

- People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:
  - advance statements
  - advance decisions to refuse treatment
  - Lasting Power of Attorney
  - Preferred Priorities of Care.

Appropriately trained staff :

- People with dementia receive care from staff appropriately trained in dementia care.

Independence and Wellbeing NICE quality standard:

- People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

Care planning and review:

- People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.

Joint decision-making:

- People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
- People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

Involvement in research:

- People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

Supporting well:

Support in Health and Social Care NICE quality standard:

- Carers of people with dementia have access to a comprehensive range of **respite/short-break services** that meet the needs of both the carer and the person with dementia.

Independence and Wellbeing NICE quality standard:

- People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.
- People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
- People with dementia live in housing that meets their specific needs.
- People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

Dying well:

Support in Health and Social Care NICE quality standard:

- People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

Benchmarks are the following:

- Benchmark 1: Achieve and maintain a diagnosis rate of at least two-thirds.
- Benchmark 2: Increase the number of people being diagnosed with dementia, and starting treatment, within six weeks of referral.
- Benchmark 3: Improve the quality of post-diagnostic treatment and support for people with dementia and their carers.[3]

The **Memory Services National Accreditation Programme** has been established (eighth edition) to support local service improvement of memory services in the UK. These standards have been developed from key documents and expert consensus and have been subject to extensive consultation with professional groups involved in the provision of memory services, and with people who have used these services and their families/carers. It works such a quality improvement and accreditation network.[12]

Standards specific to young-onset dementia:

Assessment and referrals:

- The service has access to in-depth assessment of occupational functioning and neuropsychological assessment as required (e.g. for young-onset dementia, complex or abnormal presentations).

Resources and staffing:

- There is a named lead within the service for people with young-onset dementia.

Psychological interventions:

- The team signposts younger people with dementia to structured activities such as vocational rehab, employment support and workplace adjustments.

Joint working and liaison:

- Specialist advice is taken when interpreting investigations/assessments/scans in people with complex needs, such as learning disabilities and those with young-onset or rare dementias.
- Health and Social Care funders, in consultation with local partners, people with memory problems/dementia/suspected dementia and carers, have a local integrated care pathway based on best practice, which includes referral to national or regional specialist centres and exit from the service, where appropriate. (This includes specifically a pathway for young-onset dementia, people with learning disabilities and people with rarer types of dementia where diagnosis is more complex and likely to be delayed).
- The service can refer on to specialist services for rare or young-onset dementia and/or complex care needs (e.g. regional/tertiary neurology/neuropsychiatry services, learning disability services).

The **Young Dementia Network**, in its document “Supporting implementation of the NICE guideline for people with young onset dementia”, highlights on some important quality standards from the NICE guidelines that should be met in patient care and has made the following recommendations[8]:

Diagnosis

	- People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated Care coordination - People with dementia have a single named practitioner to coordinate their care. Interventions to promote cognition, independence and wellbeing - People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences. Supporting family members/carers - Carers of people with dementia are offered education and skills training.
• **Who**	***This section reports on what was planned.*** The **Dementia Plan** (through Public Health England Dementia Intelligence (DIN)) aims to collect new and existing data on dementia at both ICB and local authority level, covering the whole dementia pathway (prevalence, preventing well, diagnosing well, living well, supporting well, and dying well); it is included in NHS England and dementia data is extracted from GP patient records (limited data is collected on diagnosis only for patients under 65 years).(Personal communication Dementia UK) It aims to improve monitoring of improvements in dementia care and support.

3.2. France

In France, the first Alzheimer's plans were for 2001-2003 and 2004-2007 and did not include anything specific for young patients. The 2008-2012 plan was more ambitious for young patients, with the creation of a **reference centre**. This was followed by the 2014-2019 plan for neurodegenerative diseases and, finally, the 2021-2024 national plan for neurodegenerative diseases. An update of the national plan for the period 2024-2028 and a corresponding roadmap are expected to be published shortly (the 2021-2022 roadmap for neurodegenerative disorders has not been updated). (Personal communication)

The plans and roadmaps do not focus exclusively on young patients with dementia: they refer to patients of all ages with neurodegenerative diseases (all forms). Certain criteria for evaluation are mentioned in the roadmaps and/or plans, but we were not able to access the documents with the results.

We were also told about some local initiatives, such as a clinic dedicated to young patients with Alzheimer's or related diseases. For example, there is an initiative supported by a 'departmental coordination cell' located in a university hospital: the role of the multidisciplinary team is to support the patients and their families throughout the care pathway, but also to train health professionals and build a network.[15] There are other local initiatives to support patients and professionals (e.g. facility for people with young-onset dementia (https://www.aede.fr/etablissement/residence-le-chemin). These local initiatives are outside the scope of this international comparison and are therefore not included in the table below.

In terms of **occupational activity**, there are no specific national programmes or initiatives in France to help people with young-onset dementia return to work or maintain of their occupational activity. However, some principles apply to all workers in France, whether they have young-onset dementia or another condition, and the occupational physician can be involved to get some support, such as adapting the working post or reassessing the work project.[16]

Table 2 – The national plan on (young-onset) dementia in France

Topic	
General information on dementia strategy	
• **Name**	**Roadmap for Neurodegenerative Diseases 2021-2022** (called P-MND for "*Plan Maladies neuro-dégénératives*"). The axis 3/sheet 6 of this roadmap is on "Design and implementation of a response adapted to the specific needs of young Alzheimer's patients"[f].[17, 18] The National Reference Centre for Young Alzheimer's Patients (*Centre National de Référence – Malades Alzheimer Jeunes* (*CNR-MAJ*)) is part of this roadmap.[19] Note: The roadmap 2021-2022 was due to be updated ("enhanced roadmap 2023-2024"), but this was never done due to a change of government. The National Neurodegenerative Diseases Plan 2024-2028 is still expected.
• **Country/Region**	The roadmap has a national scope.
• **Funding**	Activities are financed separately. (Personal communication CNR-MAJ) - The budget for the care of young Alzheimer's patients is to be defined as part of the GAA (*"Grand âge et autonomie"*) reform - no information retrieved on the amount of funding.

[f] I*n French: Feuille de route maladies neurodégénératives 2021-2022 (P-MND): Axe 3/Fiche 6: Concevoir une réponse adaptée aux besoins spécifiques des malades jeunes Alzheimer et la déployer*

	- The activities of the Reference Centres are mainly financed by activity-based pricing and by funds allocated by the General Directorate for Healthcare Services (*Direction générale de l'offre de soins* (*DGOS*)) to the Regional Health Agencies (*Agences Régionales de Santé* (*ARS*)), which then redistribute them to the Reference Centers. - Users' healthcare costs are fully covered by health insurance and mutual or supplementary health insurance. (*Note: In the context of their neurodegenerative pathology, patients are declared on ALD 15, which means 100% reimbursement for all care related to their neurodegenerative pathology, such as consultations, hospitalisation, speech therapy, cognitive rehabilitation sessions or treatments, provided they are reimbursed by the health insurance.*)
• **Institution**	The roadmap comes from the Ministry of Health and Prevention[g]; certain actions are implemented at the regional level (*ARS*). The CNR-MAJ is granted by the General Directorate for Healthcare Services (*DGOS*).
• **Date**	*Updated 2024-2028 roadmap expected in 2024*. This table presents the **2021-2022 Roadmap for Neurodegenerative Diseases** (P-MND) (which follows 3 successive Alzheimer's plans between 2000 and 2013 and the 2014-2019 National Plan for Neurodegenerative Diseases. The 2008-2012 Alzheimer's plan recognised the need for specific support for people diagnosed before the age of 65[h], and consequently the creation of this CNR-MAJ).[17]
• **Aim**	The aim of this Roadmap is to maintain a set of essential actions to strengthen the collective response to the challenges of P-MND, and in particular the care and support of patients and their informal carers.[17] As mentioned above, the Axis 3/Sheet 6 concerns young patients, and one of the sub-themes is dementia. Its objectives are: - To propose, in each region, a network adapted to the care of young patients, taking into account the specific needs of their care and the need to limit the geographical distance from their families and relatives; - To improve the care of young patients in institutions by creating multidisciplinary teams, better training of teams and appropriate units, in order to improve their quality of life and autonomy, reduce their psycho-behavioural problems and improve their end of life. The Axis 3/Sheet 6 highlights the necessity to maintain the CNR-MAJ: since 2009, three centres have been selected for their expertise to form the CNR-MAJ (i.e. one national centre located in 3 sites: Lille-Bailleul, Rouen and Paris-Salpetrière). The CNR-MAJ provides expert multi-professional care for young patients with Alzheimer's disease or related disorders; patients can access the CNR-MAJ provided that they are young (<65 years) at the onset of their symptoms. They may be referred by a GP, neurologist or other specialist or they (or a carer) can contact directly the centre.[19] The CNR-MAJ aims to: - improve diagnosis and reduce diagnosis times; - improve genetic diagnosis in rare familial forms; - improve the follow-up of young patients according to their needs throughout the course of their disease (e.g. raising awareness of the support to which patients are entitled, providing psychological support to patients and their families,

[g] It is now called the "Ministry of Labour, Health and Solidarity" (*Ministère du Travail, de la Santé et des Solidarités*)

[h] Both thresholds (60 and 65 years) are mentioned, depending on the documents.

	helping them to cope with periods of crisis, especially behavioural crises, helping them to find accommodation if necessary, providing support until the end of life, enabling brain sampling if the family so wishes for diagnostic certainty); - promote access to clinical and pharmacological protocols.[20] The CNR-MAJ also carries out teaching, training and research activities for patients and health professionals, as well as public information and awareness activities (see below).
Organisation and initiatives	
• **Target group of the national strategy**	The parts of the 2021-2022 roadmap for neurodegenerative diseases relating to young people are aimed at people with Alzheimer's disease or related disorders whose onset of the disease occurred before the age of 65.
• **Public awareness and prevention**	Prevention or awareness raising activities are not explicitly covered in the national dementia roadmap.
• **Screening and diagnosis**	There is no national screening programme, or official national guidelines for the screening, diagnosis, and treatment of people with young-onset dementia. However, due to the network developed by the CNR-MAJ, patients with young-onset dementia tend to receive similar care throughout France; the Centre for Rare or Young onset Dementias (for patients with one of four specific neurological disorders[i]) also aims to provide standardised care throughout France. Entry into the care pathway occurs with diagnosis, usually initiated by complaints or symptoms (patients or relatives). The CNR-MAJ website provides information on the disease (young-onset dementia), care, support and rights, as well as a list of contacts.[19] For example, the Centre in Rouen has created a website on genetic questions and they analyse the genetic samples for all young patients with suspected dementia. (Personal communication CNR-MAJ) The High Authority of Health (*Haute Autorité de Santé*) has recommended (2018) that patients with a neurocognitive disorder related to Alzheimer's disease or a related disease should be referred to a specialised centre (National Reference Centre for Young Alzheimer's Patients or National Reference Centre for Rare or Young onset Dementias available in each territory). Patients will undergo clinical, cognitive and medico-social assessment, imaging (IRM, PET), biological markers and genetic evaluation. Neurogenetic consultation is recommended in patients with symptoms before the age of 50 or with a family history of the disease.[21]
• **Management and treatment**	Axis 3 of the P-MND concerns young patients, specifically the Sheet 6 "Design and implementation of a response adapted to the specific needs of young people with Alzheimer's disease". According to this document, the situation is as follows: - Approximately 55,200 people under the age of 65 have Alzheimer's or related diseases. They do not have the same needs as older people, and current institutional provision, apart from a few experiments, does not meet these needs. The limited number of patients makes it impossible to envisage specialised/dedicated local structures. A pragmatic solution would be to train the staff of nursing facilities and set up a "young patients" unit in each region. The system would consist of a network of institutions with a dedicated unit and staff trained in the care of young patients (these institutions would have a "label" so that they could be identified).[17] Different types of centres coexist to provide care: some specialised centres are dedicated to young Alzheimer's patients (CNR-MAJ) or to people with rare dementia (FTD, PNFA/SD, PSP or CBD) (the Reference Centre for Rare or Young onset dementias);

[i] Any of the following neurological disorders caused by the degeneration of nerve cells in the frontal and temporal cortex: frontotemporal degeneration (FTD), progressive non-fluent aphasia and semantic dementia (PNFA/SD), progressive supranuclear palsy (PSP) and cortico-basal degeneration (CBD)

	other centres are not specific to young patients (memory centres or memory resources and research centres).[22] They have their own missions and activities (some missions may overlap). - The CNR-MAJ[20] organises a wide range of activities for patients and health professionals, based on its expertise in diagnosis, announcement and feedback, and in multidisciplinary care and follow-up (medical, paramedical, psychological and social). Some activities are related to management and treatment, such as: o Therapeutic patient education programmes; o Organisation of multidisciplinary consultation meetings; o Coordination of networks of health and medical-social correspondents; o Supporting health professionals in the management of complex situations; o Training of health professionals; o Teaching and research activities; o Harmonisation and dissemination of good practice. The expertise available at the CNR-MAJ includes neurologists and neurology coordinators, neuropsychologists, speech therapists, psychologists, health educators, social workers, genetic diagnosticians, clinical research associates.[19] The centre also has research missions, care missions (helping to raise awareness of the specific needs of young patients) and public health missions; the website provides information and contacts by region, for patients and their families. - The Reference Centres for Rare or Young Onset Dementias (accredited by the French Ministry of Health – 1 reference centre and 17 regional centres), which form a national network whose aim is to provide care throughout France for patients with FTD, PNFA/SD, PSP or CBD.[23] - The Memory Resource and Research Centres ("C*entres Mémoire de Ressources et de Recherche*" – CM2R), which act as a local network for patient care. Each CM2R has a designated referral person who is the point of contact for health professionals, nursing homes and families. Patients should be referred to the regional correspondent of the CNR-MAJ.[24] - the Memory Centres[25, 26], which act as a local network for patient care. The High Authority of Health (*Haute Autorité de Santé*) has also published a synthesis to guide the care pathway of patients with Alzheimer's disease (or related diseases). In complex situations such as young patients (<60 years), it has recommended to look for resources.[21, 27]
• **Milestones**	The old age and autonomy actions (*"Grand âge et autonomie"*) should include measures to adapt serivces to specific populations (young patients). The milestones to be set will depend on what is included in the reform of the GAA (*"Grand âge et autonomie"*). Key milestones: Project defined for the relay as part of the GAA roadmap: June 2021.
Assessment[j]	
• **Timing**	This section reports on what was planned.

[j] The 2014-2019 Neurodegenerative diseases Plan has been evaluated and is available online. See main results below in the table.

	A pilot responsible for implementation will be identified for each measure. Every six months, he or she will be responsible for producing a progress report with comments and updated monitoring indicators, which will be discussed by a monitoring committee responsible for proposing adjustments to the proposed actions. A Steering Committee will meet once a year and will approve the annual report to the Minister. A report will be sent to the Minister (and to the P-MND evaluators) at the end of each year. Deadlines: Semi-annual monitoring, semi-annual monitoring committee, annual Steering Committee, annual report. Dissemination: The network (Regional health agencies (*agences régionales de santé – ARS*), centres of expertise, learned societies, etc.) will be encouraged to consolidate and promote positive experiences in the field, which will be disseminated nationally in the form of a fact sheet and through thematic seminars. Representatives of patient organisations will be members of the Editorial Board.[17]
• **Type of assessment**	Monitoring indicators, economic evaluation
• **Indicators**	The following indicators are proposed in the roadmap for the Axis 3/Sheet 6.[17] - Outcome and patient impact indicators: o Behaviour rating scale (anxiety, depression, aggression, motor instability, delusions, hallucinations): NPI-ES; o Autonomy scales: AGGIR, DAD 6, IADL; o Dementia Severity Scale, Reisberg scale; o Walking test: Get up and walk test; o Number and dosage of psychotropic drugs, hypnotics, antidepressants; o Quality of life scale: Qualidem10, EVIBE; - Caregiver satisfaction indicators : o Caregiver burnout assessment scale (Lourel's BMS 1015), absenteeism and turnover of caregivers; o Workload; time spent on care, meals and medication; - Caregiver satisfaction indicators: number of visits, caregiver stress assessment scale and depression score, Caregiver Burden Scale (Zarit); - Process and resource indicators (financial, human, etc.), economic evaluation: o Number of hospital admissions and consultations in a given period and in the previous year; o adverse events; number of falls, inhalation pneumonitis, hospitalisations; o programme costs; o cost of treatments; antipsychotic, anxiolytic, antidepressant, hypnotic; o cost of transport avoided and generated.
• **Interim assessment**	Axis 3 of the P-MND (on young patients): over time, surveys have identified some residential centres that welcome young patients, but depending on their experience and internal organisation, they may decide that they don't want to accept young patients anymore (permanently or temporarily). Under these circumstances, it is difficult to create a "label". (Personal communication CNR-MAJ)
• **Who**	The evaluators of the new plan are not yet know.
• **Results**	The evaluation of the 2014-2019 Neurodegenerative Diseases Plan (previous plan) was carried out by two experts and consists of two parts (the evaluation is not specific to young patients or patients with dementia)[28]: - The evaluation of the plan itself, based on 3 strategic areas: o Providing care and support throughout life and throughout the country

	○ Helping society adapt to the challenges of neurodegenerative diseases and mitigating their personal and social impact on daily life ○ Developing and coordinating research into neurodegenerative diseases. - Perspectives and recommendations, including reflections on the follow-up of the 2014-2019 Neurodegenerative Diseases Plan and governance questions: ○ An integrative approach in the form of a plan/roadmap ○ Guiding principles for a Plan/Roadmap on Dementia and Neurodegenerative Diseases ○ A balanced research component As the plan was part of a series of successive plans (Alzheimer's, Parkinson's, rare diseases, etc.), it is difficult to identify the specific impact of the 2014-2019 Neurodegenerative Diseases Plan. The degree of achievement of the objectives of the 96 measures is very variable: it can be close to 100% for some specific measures and zero for others, which was to be expected given the large number of measures and the excessive ambition of some of them, which went beyond health and medico-social issues (for example, measures providing for societal adaptations that were impossible to achieve in the short duration of the plan); in other cases, the funding initially expected was not granted. The second part sets out the perspectives for a future plan. The first point concerns the governance of the plan and its positioning in relation to the health system, and recommends the creation of a governance mechanism for "neurodegenerative diseases". The second point concerns the diseases (“neurodegenerative diseases”) and recommends that the commonalities and needs be more clearly highlighted, from a functional health perspective and by rehabilitating the term "dementia", which has a negative connotation in France. The third point is to include the future plan in international discussions. The other recommendations are of a more operational nature, such as the involvement of all stakeholders in drawing up the future plan, the role of front-line structures and specialised services, the training of professionals in early diagnosis and management in care structures, the social involvement of people suffering from neurodegenerative diseases and the pursuit of research.

3.3. Germany

In Germany, a national dementia strategy has been developed since 2018 and launched in July 2020 by the Federal Ministry for Family, Seniors, Women and Youth, the Federal Ministry of Health and the German Alzheimer Society in cooperation with stakeholders from states, municipalities, the scientific community and healthcare associations.

This strategy does not solely focus on young patients with dementia, but they refer to patients of all ages with dementia. Four fields of action where defined by the German dementia strategy, of which:

- Developing and establishing **dementia-inclusive communities to enable people** with dementia to participate in society
- **Supporting** people with dementia and their relatives
- Advancing health- and long-term care services for people with dementia
- Promoting excellent research on dementia

Within these fields of action 27 more specific goals and 162 concrete measures were drawn up to be implemented between 2020 and 2026, progress on reaching these goals is annually monitored and reviewed.

In Germany, the outpatient dementia care is predominantly fragmented, and dementia networks (DNs) represent an integrated care concept to overcome this problem. Furthermore, memory clinics exists but the offered care is very heterogenous and the term memory clinic is often used as an umbrella term.

Table 3 – The national plan on (young-onset) dementia in Germany

Topic	What we are looking for
General information on dementia strategy	
• **Name**	Nationale Demenzstrategie[29]
• **Institution**	The strategy was developed by the Federal Ministry for Family, Seniors, Women and Youth (BMFSFJ), the German Alzheimer Society or Deutsche Alzheimer Gesellschaft (DAlzG) and the Federal Ministry of Health (BMG), among other stakeholders from states and municipalities, healthcare associations and the scientific community, in cooperation with 74 stakeholders from relevant fields. *500 local alliances have been established before the launching of the National Dementia Strategy; they are implementing measures but they were not initially involved in the design of the strategy.*
• **Date**	*January 2019*: Launch of the National Dementia Strategy and start of development process *January - September 2019*: Development of goals and measures with the strategy's stakeholders *September 2019 - June 2020:* Establishment and agreement of the National Dementia Strategy *July 2020:* Adoption of the National Dementia Strategy by the Federal Government

	September 2020 - December 2026 - Implementation of the National Dementia Strategy
• **Aim**	The national dementia strategy is focused on 4 key fields of actions: • Developing and establishing **dementia-inclusive communities to enable people** with dementia to participate in society *(leadership: BMFSFJ and the German Association of Towns and Municipalities)* • **Supporting** people with dementia and their relatives (*leadership: BMFSFJ and the German Alzheimer Society)* o Low-threshold information services as well as comprehensive and high-quality counselling services for people with dementia will be made available and expanded. One of the target groups will be people with young-onset dementia. o Extending counselling and support structures for people with dementia ((including young-onset dementia))and their families (e.g. empowerment to adapt workplace,…) o Extending counselling, further education and support structures for volunteers to accompany people with dementia and their relatives after their first diagnosis • Advancing health- and long-term care services for people with dementia *(leadership: BMG and the Federal Association of Non-statutory Welfare)* • Promoting excellent research on dementia *(leadership:* Federal Ministry of Education and Research *(BMBF) and the German Centre for Neurodegenerative Diseases)* **Within those four fields of action, 27 more specific goals and 162 concrete measures were drawn up to be implemented between 2020 and 2026.*
• **Supplementary (or previous) reports**	Some federal states have an own dementia strategy[30] and the experience of these plans has led to the current nationwide dementia strategy: - **Bayerische Demenzstrategie** (2013) o Ten action points, mostly focused on raising awareness and enabling patients to live in society - **Demenzstrategie Rheinland Pfalz** (2003) o Raising awareness, removing taboos, training and qualification for GP/home nursing/nursing homes/…, regional networking - **Demenzplan Saarland** (2015 and updated version in 2021) o Saarland has 6 local networks in the district, as well as a Saarland Dementia centre o In 2019, a “state doctor for people suffering from dementia” was appointed - **Demenzplan Schleswig-Holstein** (2013) o 80 recommendations in 3 overarching themes o Practical implementation of the dementia plan commisionned to “*Dementia competence centre*” (state-wide specialist centre of dementia) ▪ Funded by insurance funds and Ministry of social affairs and equality of the state of Schleswig-Holstein

	- **Sächsische Demenzstrategie and Landesdemezplan Sachsen** (2024) {Sächsisches Staatsministerium für Soziales und Gesellschaftlichen Zusammenhalt, 2024 #147}
	  o Dementia strategy: describes the initial situation in Saxony, key objectives and fields of action as well as the development process of the strategy
	  o Dementia Plan: Four fields of action and a total of 12 measures to improve the situation of people with dementia and their relatives (e.g. Support for relatives and young-onset dementia)
	
	In general, it is considered the task of the German municipalities to design the space and local structures (e.g. supporting structures, local networks) for people with dementia and their relatives, therefore the participation of local authorities is of utmost importance for the implementation of the National Dementia Strategy.

Organisation and initiatives	
• **Target group of the national strategy**	The national dementia strategy is primarily focused on overall dementia care.
• **Prevalence - Incidence**	**Prevalence – incidence :** It is estimated that as of 31 December 2021, 1 798 00 persons were affected by dementia in Germany of which 102 000 persons were 64 years or younger.[31] The prevalence and incidence of dementia in Germany has been declining in recent years, especially among older age groups, according to several studies.[31, 32]
• **Public awareness and prevention**	**Public awareness – dementia friendly community:** The dementia plan states that the *"German Association of Towns and Municipalities*" [Deutscher Städte- und Gemeindebund] needs to ensure a favourable environment for people with dementia (village development concepts, planning of care, dementia-sensitive public meeting place,…) and enable people with dementia to maintain their daily lives and to participate in social life.[29] In this regard, *"Local alliances for people with dementia"* and other dementia networks are being established and expanded nationwide. Currently, these local networks that support dementia care are principally sustained by voluntary engagement, which is to be further promoted. The German ageing survey (2020-2021) showed that many people in Germany are unfamiliar with dementia, while few are afraid of people with dementia. Almost half of respondents (45.5%) say they are unfamiliar with dementia, while about one third of respondents (32.6%) are familiar with dementia.[33] **Prevention:** In Europe, prevention measures are being continuously developed into an international dementia prevention network, in which Germany also participates with a multi-component prevention trial (e.g. AgeWell.de).[34, 35] This trial found no beneficial effects of a multi-domain intervention on cognitive performance in older adults at-risk in Germany, despite general studies on the subject suggesting otherwise {Mukadam, 2024 #146}. However, the intervention benefitted health-related quality of life in the total sample.[36] In Germany, fewer cases of dementia are attributable to lower levels of education because of the high educational level of the population at large. Instead, the metabolic syndrome plays a greater role, with a relatively high number of cases

	being attributable to hypertension and obesity. Local risk constellations should be considered in the further development of preventive approaches in Germany (and elsewhere).[31] A telephone survey among the German population (n= 1 002) showed that more than half of the respondents (55%) belief that dementia can be prevented. Respondents mostly indicated psychosocial prevention options. [37] This shows that dementia awareness campaigns may be employed to carefully inform the public about the prevention options currently available and their efficacy.[37]
• **Screening and diagnosis**	In agreement with international guidelines, the national guidelines in Germany (S3 Leitlinie Demenzen) on dementia care recommend using the clinical history, medical and neurological examinations, and assessments of cognitive functions (e.g., Mini-Mental State Examination (MMSE), DemTect, Clock Drawing Test) as well as assessment tools that consider cultural and linguistic aspects. Additionally, if dementia is detected/suspected, further investigations include blood sampling and cranial computer tomography (CT) or magnetic resonance imaging (MRI) can take place. In specific circumstances, biomarker-based diagnosis is recommended (e.g. cerebrospinal fluid puncture (CSF), positron emission tomography (PET)). These more specialised diagnostic procedures are often only available in specialised clinics (e.g. Memory clinics). Furthermore, the German guideline recommends considering **additional tests** in people with young-onset dementia: human immunodeficiency virus, syphilis, and drug screening, which are not recommended for assessment of dementia in people over the age of 60.[38]

• **Management and treatment**	One of the main objectives of management and treatment of persons with young-onset dementia and their families, described in the national strategy, is the extension of **counselling and support structures.** The following measures have been agreed upon to achieve this:
	- Information, advice and continued education for those affected and their relatives, as well as employers, to improve opportunities of remaining in gainful employment.
	- People should be empowered to adapt workplaces to the specific needs of people with young-onset dementia (e.g. Integration offices which provide advice and financial support).
	  ○ Patient organisations and regional specialist dementia centres can play an important advisory role
	- Support groups can help people to feel less isolated and reduce feelings of depression or anxiety (e.g. small support groups, online options).
	
	Another objective outlined in the national strategy is **information and education** for relevant bodies/officers in companies.
	- The BMFSFJ is developing a *handbook* about dementia:
	  ○ For companies providing information about dementia and outlining the needs of people with young-onset dementia.
	  ○ Discusses opportunities for developing in-house measures to support people with young-onset dementia and employees with dementia.

- By the end of 2024, the Alzheimer's *telephone service*, which offers counselling services to companies provided by the DAIzG, will have been extended and the effectiveness of calls made via companies evaluated on an annual basis.
- The *Dementia Friends training programme* will implemented for employees within the framework of company health management to address the subject of dementia and employment.

Between 2012 and 2016, 500 local networks were selected as part of a support program "**Local alliances for People with Dementia**" *("integrational measures to support the early-affected*"), which is a *key measure of the Federal government*.[39, 40] Funding is provided for help and support networks with services for people with dementia and their relatives, which help them, for example, to continue living in their own homes for as long as possible. These networks can be a collaboration of interdisciplinary medical, care and social services that offer the following, for example:

- Counselling and support services close their homes (relieve burden on carers)
- Awareness initiatives
- Recruit volunteers in the neighbourhood to aid support services (therapeutic and/or social support)
- Support local authorities by coordinating and networking with local stakeholders

"Rhapsody"-project is an online program aimed at informal caregivers to improve the lives of people with young-onset dementia. The program was set up in six European countries (UK, Germany, France, Sweden, Portugal and Netherlands). The program offers information on care facilities for persons with young-onset dementia.[41]

The DAIzG has developed a regular, moderated online self-help group for people with young-onset dementia with the involvement of the 'Living with dementia' advisory committee. There are currently no plans to expand the model in the originally intended way.

- **Identified gaps**

Memory clinics[42-44]

In Germany, they have a variety of different organizational forms, "memory clinics" is not a protected term. Additionally, the reimbursement for a diagnostic process is not standardised nor adjusted for different diagnosis, the financing of memory clinics could therefore differ tremendously.

Due to the growing diagnostic options in neurodegenerative diseases, the increasing demand for early detection and prediction as well as foreseeable new diagnostic procedures and disease-modifying treatment, it is important to standardize the structural prerequisites and areas of responsibility of MC. In most cases, reimbursement is based on flat-rate payments or special agreements with health insurers, and the financial means provided by those insurers can be insufficient to fully cover the cost of the diagnostic process of each patient. Therefore, most clinics use additional funds for compensation, such as donations. However, reimbursement is not based on procedures that are necessary to reach a final diagnosis.[44]

Outpatient dementia healthcare is predominantly fragmented, and dementia networks (DNs) represent an integrated care concept to overcome this problem.[45]

Assessment	
• **Timing**	Outcome of the strategy and the necessity for further development will be reviewed after 2026. ** The national dementia strategy is defined as a long-term process by the federal government, providing the possibility to change priorities, challenges and their impact on the lives of people with dementia and their (family) caregivers.*
• **Type of assessment**	In December 2017, a scientific impact analysis was launched to investigate the extent to which dementia structures in Germany have improved and which effects have been achieved through the federal pilot programme Dementia care network services patients may help to maintain quality of life for patients remaining in the community, regardless of their specific organisation (organisation, stakeholder, hybrid, mission).[46] Furthermore, research has indicated that different governance structures of DCNs also seem to contribute to reducing caregiver burden.[47] DN were primarily financed by membership fees, earnings of services provided, public funds and payments by municipalities or health care providers, 63% of the DN reported a financial sustainability and a minimum funding of 50 000€/year for human resources coordinating the DN.[48]
• **Indicators**	Not retrieved
• **Interim assessment**	Annual monitoring of the national dementia strategy in order to document the status of the implementation of the measures defined by the national dementia strategy (reports exist from 2021, 2022, 2023, 2024). This report provides an extensive overview of each measure, the appointed actor and its status.
• **Who**	Not retrieved
• **Results**	Not retrieved
Note about evidence: assess whether screening for YOD adds any benefit, or whether early diagnosis affects quality of life	

3.4. The Netherlands

In the Netherlands a national dementia strategy is implemented by the ministry of Health, Welfare and Sports. The ministry of health, welfare and sports has been publishing dementia strategies since 2004, with the current dementia strategy launched in 2021 and running until 2030. The strategy is aimed at keeping people with dementia at home and empower them as a valuable member of society by offering good supportive measures and qualitative care. To attain this goal three overarching themes are defined: promote dementia research, empower persons with dementia and improve the support for the patient and their relatives. Within each of these themes, persons with YOD are specifically mentioned.

The organisation of care and support for people with young-onset dementia in the Netherlands can be summarised as follows: a national centre responsible for developing and disseminating knowledge, affiliated regional centres that coordinate and provide care and support at the regional level. The local level is responsible for the continuity of care, including case management, multidisciplinary YOD teams, respite options, psychological support, day care centres and residential care facilities.[49]

Currently, the care for persons with dementia in the Netherlands is focused on keeping people at home for as long as possible, with case management as the key to ensuring high-quality and person-centred care (e.g. facilitate transition to day care and/or intramural care, improving the continuity of care). Approximately 40 care organisations provide care to persons with young-onset dementia in the Netherlands, most of them in cooperation with other care partners (e.g. support groups, day care, palliative care) to provide care across the whole care trajectory of the patient.

A recent research paper[50] on people suffering from YOD in the Netherlands, based some recommendations on three general themes: knowledge and information (e.g. knowledge infrastructure), personalised/integrated care (e.g. case management) and work (e.g. adopt WIA/IVA legislation).

Table 4 – The national plan on (young-onset) dementia in The Netherlands

Topic	
General information on dementia strategy	
• **Name**	Nationale dementiestrategie 2021-2030[51]
• **Country/Region**	The Netherlands
• **Institution**	Ministry of Health, Welfare and Sport's
• **Date**	November 2020
• **Aim**[51]	The general aim of the national dementia strategy is to focus on keeping people with dementia **at home** and **empower** them as a valuable member of society by offering good **supportive measures** and **qualitative care**. To attain this goal **three overarching themes** are defined in the current national dementia strategy (2021-2030): 1) To promote the cooperation in dementia research, through (long-term) funding of top clinical dementia centers and/or multidisciplinary consortia.[52, 53] This to ensure that dementia research will continue to accelerate in the coming 10 years ("*ZonMw's Dementia Research programme*"). ○ Lessons learned from previous research program *("Memorabel"* by ZonMw), that was a part of the *Deltaplan dementie* (2013-2020)[54]

	○ Long-term funding of such research consortia creates a knowledge, research and development infrastructure that is broad-based and long lasting. ○ Proposed amount of funds allocated to dementia research in the current plan is: 140 million euros over 10 years. One of those research themes, but not the only theme, is young-onset dementia. The call for proposals on this theme has led to the development and financing of a research infrastructure - "Young people with dementia" ("*YOD INCLUDED*")[55] 2) Empower persons with dementia to remain valuable part of the society. This can be attained by improving how the general public looks at people with dementia and offer (alternative) valuable roles in society to them. 3) Improve the support for patients with dementia and their relatives People with YOD are **specifically mentioned**, to be a separate subject within each of the abovementioned overarching themes *("doorsnijdende thema's").* However, the current dementia strategy is **a first step** that needs further clarification. The ministry of Health wants to take these next steps together with the regional dementia networks, health carers, insurers and patient organisations.
• **Supplementary (or previous) reports**	The ministry of health has published dementia programs since 2004, of which in chronological order: 1) Landelijk Dementieprogramma (2004 – 2007) 2) Programma Ketenzorg Dementie (2008 – 2012) 3) Deltaplan Dementie (2013 – 2020) In 2018, a report was published describing the current state and organisation of dementia care in the Netherlands.[56] Specifically for YOD the following aspects are mentioned: - There are around 254 000 – 270 000 persons with dementia in the Netherlands, of whom 5-10% younger than 65 years - Little is known about the care needs and experiences of persons with dementia, more is known about the needs of their informal caregivers - The current care options/services are not aligned with the care needs of people with YOD ○ This is seen in day care and (day care) activities - Information and care services are not always accessible - Informal caregivers report ▪ The need for case management • In some regions long waiting lists for such case management ▪ An increasing (care) burden on them, because persons with YOD are staying at home longer and longer - There is a need for more health care workers/professionals with education and affinity with dementia care - There is a need for more crisis units

	○ Acute/temporary admissions in hospitals/nursing homes, this is possibly in relation with the fact that people are staying at home longer Furthermore a care standard for people with young onset dementia (*2015; "Kenniscentrum dementia op jonge leeftijd")* was published[57]: - Specification following on the care standard for people with Dementia - Description of the necessary services/care from a multi-disciplinary perspective - In addition to this care standard several standards for quality of care are developed focused on specific themes such as: case management, day care, (adapted) activities,… A quality mark/certification for quality of care has been developed for care facilities that offer care to people with young-onset dementia ("*PREZO keurmerk*").[58]
Organisation and initiatives	
• **Target group of the national strategy**	General dementia plan, with some specific attention for young-onset dementia
• **Public awareness and prevention**	Not all people with dementia, their relatives or people in society know what dementia entails and what its consequences are. Several initiatives focus on providing information after diagnosis, raise social awareness and focus on education (starting in school). Research has shown that in the Netherlands, 98% knows dementia and even 60% knows somebody who suffers from dementia. However only 13% of the general public indicates that they know how to handle someone with dementia.[56] Young-onset dementia has been included as an overarching theme in the Dutch Dementia Strategy, and specific recommendations to improve diagnosis and post diagnostic support have been included in the national dementia standard. These developments have enabled: - promote awareness of young-onset dementia in the community, - provide guidance on key requirements to improve diagnosis and service provision for young-onset dementia, - increase opportunities for funding not only to develop but also to maintain the existing dedicated care infrastructure for young-onset dementia, - provide funding for scientific research into young-onset dementia.[49] Information and awareness initiatives could be spread by the national Knowledge Centre* *("Kenniscentrum Dementie op jonge leeftijd"),* which should play a central role, and in collaboration with the regional dementia networks (60-65 networks). This national Knowledge Centre aims to raise awareness about young-onset dementia and advocate for the specific needs of young people living with dementia and their families. The centre also ensures that the voices of people with young-onset dementia and their families are heard and used to guide policy and service development.[49] Dementie.nl (Alzheimer Netherlands platform) offers a specific training focused on young-onset dementia, this was developed during the European RHAPSODY-project and was translated to Dutch, which was then made available for the public. The

	programme is called 'Online training young-onset dementia' and evaluation showed that the training is in line with the needs of informal carers.[59] ** acknowledged by the Dutch government as centre of preference regarding matters in young-onset dementia*
• **Screening and diagnosis**	The period between the first symptoms/changes and the diagnosis is overall longer for young persons (<65 years; 4.4 years) in comparison to elderly persons (>65 years; 1.6 years).[60] - **How does diagnosing dementia work?**[61] GP does anamnesis, tests behaviour, memory, language ability and concentration, when there is a suspicion the MME-test can be done. When necessary the GP will refer the person to a specialist at a memory clinic ("Dutch Memory Clinic Network"; www.geheugenpoliklinieken.nl), in case of suspicion of young-onset dementia patients will always be referred to a memory clinic specialized in young-onset dementia. At the memory clinic further testing can be done: neurophysiological tests, blood tests, brain scans and/or possibly lumbar punction. This allows the physician to give a more conclusive assessment. The Dutch guideline recommends considering additional tests including cerebrospinal fluid or positron emission tomography scans (the Netherlands), which are not recommended for assessment of dementia in people over the age of 60.[38] - **Improving and streamlining current diagnostic processes**[61] Currently, multiple ways are used to reach a diagnosis and each Dutch memory clinic has its own preference. To harmonise this process, the TAP (*Tijdige, Accurate en gePersonaliseerde*) Dementia Consortium of the Dementia Research Programme is going to devise a single test and implement it nationally. This is part of the ZonMw-programme *"Memorable"*. - **Research on the cause, diagnosis, care and treatment of YOD**[59, 61] A research consortium focused on young dementia ("*YOD INCLUDED*") will study the cause, diagnosis, care and treatment of young-onset dementia. They hope to gain an understanding of the dementia stage before the onset of symptoms and thus improve early diagnostics and diagnostics in general. The researchers also wish to contribute to better care and support for people with dementia and their loved ones.'
• **Management and treatment**	According to the national dementia strategy, every health professional should work following the standard of care (*"zorgstandaard dementie")* from 2025. - This is being implemented since 2023 (over a period of 3,5 years) by monthly (learning) meetings withing the regional networks, supervised by "*Dementie netwerk Nederland*" - Importantly, these meetings are more focused on general dementia care, but some regional initiatives also discuss the theme of young-onset dementia within their clinical network and some regional working groups on the subject exist. - These are accredited meetings/education sessions for health professionals. The national Knowledge Centre's role is to develop standards of care for young-onset dementia care and to facilitate the development of interventions and services that meet the needs of the families; to establish a scientific research agenda for

	young-onset dementia; and to promote and support scientific research to improve diagnosis and post diagnostic care and support.[49] The national strategy has established accredited training programmes for nurses and case managers in young-onset dementia and an interprofessional training programme for geriatricians, psychologists, specialist nurses and physician assistants. Close collaboration between general practitioners and case managers (national initiative, discussed in the national dementia strategy) is expected: - they should be very involved at the end of the diagnostic process in the memory clinics - facilitate transition to day care and/or intramural care, thereby improving the continuity of care Approximately 40 care organisations provide care to persons with young-onset dementia in the Netherlands, most of them in cooperation with care partners (e.g. support groups, day care, palliative care) to provide care across the whole care trajectory of the patient. A package with meaningful daytime activities has been developed aimed at younger people with dementia (e.g. *SPANkracht*). This package focuses on the person with dementia, with the informal carer or healthcare professional being available for support. Thanks to follow-up funding, modules have been developed to also teach case managers to think in terms of possibilities and to make the care for people with dementia and their loved ones more person-centred.[59] Other interventions focus more on the informal caregiver, such as *"partner in balans"* or the children of persons with dementia *("Breinspoken kamp voor kinderen")*[k]
• **Outlines**	Focus on keeping people at home for as long as possible, with case management as the key to ensuring high-quality and person-centred care.
• **Research**	Several research aims are proposed: - Initiating a national cohort of patients with Young-onset dementia, this cohort will be an important aspect of future research (e.g. causes – biopsychosocial, biomedical,…) ○ The Dutch dementia strategy commits to the development of a specific database with evidence-based recommendations and information for professionals on how people with dementia may continue to live longer and more safely at home, with online resources available and professionals able to share good practice examples. - Early recognition of symptoms - Improvement of the clinical trajectory and post-diagnostic care of YOD patients - Develop and evaluate instruments to support and facilitate work reintegration To find an answer to these questions, research consortiums have been assembled such as YOD-INCLUDED, YOD-MOLECULAR, WERKDEM and more recently FOCUSSEN.

[k] Non-exhaustive list of some initiatives in the Netherlands

• **Identified gaps**	The current dementia plan is **not a specific plan**, it is more a program outline from which a more specific national (action) plan can be developed. The national dementia strategy should therefore be seen together with *other national plans* such as: - *"één tegen eenzaamheid"* - takes into account dementia - *"Agenda mantelzorg"* - support measures for informal carers - *"Alliantie Jonge Mantelzorgers*" – support measures for informal carers - *"Werken in de zorg"* – continuity of quality of care A recent research paper has focused on solutions and recommendations for people suffering from YOD in the Netherlands, see section *"Interim assessment"*.[50]
Assessment	
• **Type of assessment**	There is data collection in the Netherlands in the form of a registry on **general** dementia care and support (https://www.dementiezorgvoorelkaar.nl/register/). This is a public accessible register ("*Register Dementiezorg & ondersteuning*") that collects data about the received care of patients with dementia and their relatives/carers. This data can be used by policymakers or coordinators of (regional) dementia networks to organize care within their region. The registry is a part of the program "*Dementizorg voor Elkaar*" , founded by Nivel ("*Nederlands instituut voor onderzoek van de gezondheidszorg*") in cooperation with the ministry of health and Alzheimer Nederland. (Initiative from previous national plan - "*Deltaplan dementie*" – but no specific data on young dementia reported) A national database on the characteristics of patients in memory clinics with YOD (< 70 years) is started, to improve diagnosis and care for this underrepresented and vulnerable patient group.[62] Inventory of the operational structure, characteristics and working methods of memory clinics ("Geheugenpoliklinieken") in the Netherlands [63, 64] - Type of professional disciplines present (multidisciplinary team) and who is coordinating the memory clinic, most frequently neurologists, clinical geriatrics, and (neuro) psychology are part of the team. - Type of professional health care workers deemed necessary for each memory clinic - Increased number of MC leading to an increased capacity (more patients seen, but huge variability in patients seen from centre to centre) - Great variability in diagnostic tools - More patients diagnosed with milder cognitive problems (people with cognitive problems attend the memory clinic in an earlier disease stage and at a younger age) - Better embedded in regional care chains and organisations, leading to more psychosocial interventions

• **Indicators**	The standard of care on dementia speaks about indicators but to our knowledge, no reports are found evaluating these indicators. There is a lack of indicators for young-onset dementia patients, most focus on (elderly) dementia. Proposition of a set of quality indicators for Memory clinics in the Netherlands.[65] Proposition and validation of quality indicators for diagnosis and management of dementia in primary care.[66] This set of quality indicators is complementary to the existing quality indicators for memory clinics and may improve primary dementia care, aiding guideline implementation and primary care workers.
• **Interim assessment**	Research paper [50] on solutions and recommendations for people suffering from YOD in the Netherlands, the recommendations were based on three general themes: 1) Knowledge and information ○ A more professional and structural knowledge infrastructure to promote and disseminate information and knowledge among HC professionals and the general public ○ Recommendation to further develop the national knowledge centre and its partner regional centres *(e.g. "Alzheimer Nederland")* and dementia networks (60-65 networks) 2) Personalised and integrated care (with adequate financing) ○ E.g. case manager 3) Work and income ○ To adopt WIA/IVA legislation ○ Make it appealing for employers to keep patients with young-onset dementia involved in their company

REFERENCES

1. Department of Health and Social Care. Major conditions strategy: case for change and our strategic framework (Policy paper, updated 21 Aug. 2023) [Web page].2023 [cited 5/04/20242024]. Available from: https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework--2#foreword
2. O'Malley M, Parkes J, Stamou V, LaFontaine J, Oyebode J, Carter J. International consensus on quality indicators for comprehensive assessment of dementia in young adults using a modified e-Delphi approach. Int J Geriatr Psychiatry. 2020;35(11):1309-21.
3. National Collaborating Centre for Mental Health. The dementia care pathway: Full implementation guidance 2018. Available from: https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf
4. Department of Health. Prime Minister's Challenge on Dementia 2020: Implementation Plan. 2016. Available from: https://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan#:~:text=The%20Prime%20Minister's%20challenge%20on%20dementia%202020%20set%20out%20more,these%20commitments%20will%20be%20met.
5. NHS England. The Well Pathway for dementia [Web page].2016 [cited 5/04/2024]. Available from: https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf
6. Department of Health. Living well with dementia: A National Dementia Strategy. 2009. Available from: https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy
7. Hayhoe B, Majeed A, Perneczky R. General practitioner referrals to memory clinics: are referral criteria delaying the diagnosis of dementia? Journal of the Royal Society of Medicine. 2016;109(11):410-5.
8. Young Dementia Network. Supporting implementation of the NICE guideline for people with young onset dementia [Web page].2022. Available from: https://www.youngdementianetwork.org/wp-content/uploads/2023/11/Supporting-implementation-of-the-NICE-guideline-for-people-with-young-FINAL-June-2022-amend.pdf
9. Excellence NIfHaC. Dementia: Assessment, management and support for people living with dementia and their carers. London: National Institute for Health and Care Excellence (NICE); 2018. NICE Guideline 97
10. The Royal College of Psychiatrists. Young-onset dementia in mental health services: Recommendations for service provision (CR217). 2018. Available from: https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr217.pdf
11. Young Dementia Network. Young onset dementia pathway: Diagnosis and support for people with young onset dementia and their families. Recommendations from the Young Dementia Network Steering Group [Web page].2022. Available from: https://www.youngdementianetwork.org/wp-content/uploads/2022/03/Young-onset-dementia-pathway-03-2022-FINAL.pdf

12. The Royal College of Psychiatrists. Quality Standards for Memory Services (Eighth Edition). 2022. Available from: https://www.rcpsych.ac.uk/docs/default-source/improving-care/ccqi/quality-networks/memory-clinics-msnap/msnap-standards---8th-edition-(2022).pdf?sfvrsn=d8341549_2.
13. Office for Health Improvement and Disparities. Dementia data and analysis: a guide for health professionals. Explains how commissioners and health professionals can use data and analysis for decisions about dementia services and interventions. [Web page].2023 [cited 5/04/2024]. Available from: https://www.gov.uk/guidance/dementia-data-and-analysis-a-guide-for-health-professionals
14. NHS England. Implementation guide and resource pack for dementia care. 2017. Available from: https://www.england.nhs.uk/wp-content/uploads/2018/01/implementation-guide-and-resource-pack-dementia-guide.pdf
15. CHU Rennes. La consultation multidisciplinaire CLUEDO [Web page].2019 [cited 5/04/2024]. Available from: https://www.neuro-bretagne.com/la-consultation-multidisciplinaire-cluedo.php
16. Pôle Santé Travail - Métropole Nord. Maladie d'Alzheimer : le monde du travail est aussi concerné [Web page].2023 [cited 5/04/2024]. Available from: https://www.polesantetravail.fr/maladie-dalzheimer-le-monde-du-travail-est-aussi-concerne/
17. Ministère des Solidarités et de la Santé. Feuille de route maladies neuro-dégénératives 2021-2022. 2021 Available from: https://sante.gouv.fr/IMG/pdf/plan_pmnd_version_longue.pdf
18. Ministère des Solidarités et de la Santé. Feuille de route maladies neuro-dégénératives 2021-2022 (version courte). 2021 Available from: https://sante.gouv.fr/IMG/pdf/plan_pmnd.pdf
19. Centre national de référence pour les malades Alzheimer jeunes (CNR-MAJ). Centre national de référence pour les malades Alzheimer jeunes (CNR-MAJ) [Web page].2024 [cited 5/04/2024]. Available from: https://www.centre-alzheimer-jeunes.fr/
20. Pôle Cap Neuro. Centre national de référence malades Alzheimer jeunes (CNR-MAJ) [Web page].2023 [cited 5/04/2024]. Available from: https://polecapneuro.sante-idf.fr/files/live/sites/poleCapNeuro/files/ACTEURS%20DU%20HANDICAP/Documents/FicheCNRMAJ.pdf
21. Haute Autorité de Santé. Parcours de soins des patients présentant un trouble neurocognitif associé à la maladie d'Alzheimer ou à une maladie apparentée: MA2 avant 65 ans « adulte jeune ». 2018. Available from: https://www.has-sante.fr/upload/docs/application/pdf/2018-05/fiche_3_ma_avant_65_ans_2018-05-24_11-36-42_498.pdf
22. Ministère de la Santé et de la Prévention. Instruction n° DGOS/R4/2022/217 du 10 octobre 2022 relative au nouveau cahier des charges des consultations mémoire et des centres mémoire ressources et recherche. 2022
23. Brain-Team. Centre de référence Démences Rares ou Précoce [Web page]. [cited 5/04/2024]. Available from: https://brain-team.fr/les-membres/les-centres-de-reference/demences-rares/
24. Ministère des Solidarités et de la Santé. Instruction n° DGOS/R4/2022/217 du 10 octobre 2022 relative au nouveau cahier des charges des consultations mémoire et des centres mémoire ressources et recherche. 2022 Available from: https://www.bourgogne-franche-comte.ars.sante.fr/media/113919/download?inline

25. Ministère du Travail, de l'Emploi et de la Santé, Ministère des Solidarités et de la Cohésion sociale. Circulaire DGOS/DGS/DSS/R4/MC3 no 2011-394 du 20 octobre 2011 relative à l'organisation de l'offre diagnostique et de suivi pour les personnes atteintes de la maladie d'Alzheimer ou de maladies apparentées. 2011 Available from: https://sante.gouv.fr/fichiers/bo/2011/11-11/ste_20110011_0100_0053.pdf

26. Fédération des Centres Mémoire. Centres Mémoire [Web page].2024 [cited 5/04/2024]. Available from: https://www.centres-memoire.fr/cartographie-centres-memoire/

27. Haute Autorité de Santé. Synthèse du guide du parcours de soins de la maladie d'Alzheimer ou d'une maladie apparentée (MA2). 2018. Available from: https://www.has-sante.fr/upload/docs/application/pdf/2018-05/app_180_synthese_alzheimer_vf.pdf

28. Grand A, Joanette Y. Plan Maladies neurodégénératives 2014-2019: évaluation (version 17). 2020 Available from: https://sante.gouv.fr/IMG/pdf/pmnd-rapport-evaluation.pdf

29. Health FMo. Nationale Demenzstrategie. 2020 Available from: https://www.nationale-demenzstrategie.de/fileadmin/nds/pdf/2021-01-05_Nationale_Demenzstrategie_EN.pdf

30. Health FMo. Nationale Demenzstrategie - Länder und Kommunen [Web page]. [cited 12/02/2024]. Available from: https://www.nationale-demenzstrategie.de/die-strategie/akteure/laender-und-kommunen

31. Blotenberg I, Hoffmann W, Thyrian JR. Dementia in Germany: Epidemiology and Prevention Potential. Dtsch Arztebl Int. 2023;120(27-28):470-6.

32. Bohlken J, Riedel-Heller S, Steininger G, Kostev K, Michalowsky B. Trends in Dementia and Mild Cognitive Impairment Prevalence and Incidence in German General and Specialist Practices Between 2015 and 2019. J Alzheimers Dis. 2021;79(4):1683-90.

33. M. W, A. L, B. B, C. T-R. Attitudes towards people with dementia in Germany. DZA Aktuell 03/2022 German Centre of Gerontology; 2022. Available from: https://www.dza.de/fileadmin/dza/Dokumente/DZA_Aktuell/DZA-Aktuell_03_2022_engl.__Attitudes_towards_people_with_dementia_in_Germany.pdf

34. Zülke A, Luck T, Pabst A, Hoffmann W, Thyrian JR, Gensichen J, et al. AgeWell.de - study protocol of a pragmatic multi-center cluster-randomized controlled prevention trial against cognitive decline in older primary care patients. BMC Geriatr. 2019;19(1):203.

35. Kivipelto M, Mangialasche F, Ngandu T. Lifestyle interventions to prevent cognitive impairment, dementia and Alzheimer disease. Nat Rev Neurol. 2018;14(11):653-66.

36. Zülke AE, Pabst A, Luppa M, Roehr S, Seidling H, Oey A, et al. A multidomain intervention against cognitive decline in an at-risk-population in Germany: Results from the cluster-randomized AgeWell.de trial. Alzheimers Dement. 2024;20(1):615-28.

37. Luck T, Luppa M, Sieber J, Schomerus G, Werner P, König HH, et al. Attitudes of the German general population toward early diagnosis of dementia--results of a representative telephone survey. PLoS One. 2012;7(11):e50792.

38. James T, Mukadam N, Sommerlad A, Pour HR, Knowles M, Azocar I, et al. Protection against discrimination in national dementia guideline recommendations: A systematic review. PLoS Med. 2022;19(1):e1003860.

39. Wolf-Ostermann K, Meyer S, Schmidt A, Schritz A, Holle B, Wübbeler M, et al. [Users of regional dementia care networks in Germany : First results of the evaluation study DemNet-D]. Z Gerontol Geriatr. 2017;50(1):21-7.

40. Köhler L, Meinke-Franze C, Hein J, Fendrich K, Heymann R, Thyrian JR, et al. Does an interdisciplinary network improve dementia care? Results from the IDemUck-study. Curr Alzheimer Res. 2014;11(6):538-48.

41. Kurz A, Bakker C, Böhm M, Diehl-Schmid J, Dubois B, Ferreira C, et al. RHAPSODY - Internet-based support for caregivers of people with young onset dementia: program design and methods of a pilot study. Int Psychogeriatr. 2016;28(12):2091-9.

42. Hausner L, Frölich L, von Arnim CAF, Bohlken J, Dodel R, Otto M, et al. [Memory clinics in Germany-structural requirements and areas of responsibility]. Nervenarzt. 2021;92(7):708-15.

43. Meiberth D, Rapp MA, Jessen F. [Memory Clinics in Germany - Results of a Hospital Survey]. Psychiatr Prax. 2019;46(4):213-6.

44. Michalowsky B, Flessa S, Hertel J, Goetz O, Hoffmann W, Teipel S, et al. Cost of diagnosing dementia in a German memory clinic. Alzheimer's Research & Therapy. 2017;9(1):65.

45. Wübbeler M, Thyrian JR, Michalowsky B, Erdmann P, Hertel J, Holle B, et al. How do people with dementia utilise primary care physicians and specialists within dementia networks? Results of the Dementia Networks in Germany (DemNet-D) study. Health Soc Care Community. 2017;25(1):285-94.

46. Gräske J, Schmidt A, Schmidt S, Laporte Uribe F, Thyrian JR, Michalowsky B, et al. Quality of life in persons with dementia using regional dementia care network services in Germany: a one-year follow-up study. Health Qual Life Outcomes. 2018;16(1):181.

47. Laporte Uribe F, Gräske J, Grill S, Heinrich S, Schäfer-Walkmann S, Thyrian JR, et al. Regional dementia care networks in Germany: changes in caregiver burden at one-year follow-up and associated factors. Int Psychogeriatr. 2017;29(6):991-1004.

48. Michalowsky B, Wübbeler M, Thyrian JR, Holle B, Gräske J, Schäfer-Walkmann S, et al. [Financing Regional Dementia Networks in Germany: Determinants of Sustainable Healthcare Networks]. Gesundheitswesen. 2017;79(12):1031-5.

49. Bakker C, Verboom M, Koopmans R. Reimagining Postdiagnostic Care and Support in Young-Onset Dementia. J Am Med Dir Assoc. 2022;23(2):261-5.

50. Castelijns E, Blokzijl L, Kersten B, Fransen L. Positie jonge mensen met dementie - Een onderzoek naar knelpunten, behoeften en passende ondersteuning. 2023 Available from: https://open.overheid.nl/documenten/ronl-17d7a46415429d076f72219707e10330f5b08c25/pdf

51. Ministerie van Volksgezondheid WeS. Nationale Dementiestrategie 2021 - 2030. 2020 Available from: https://open.overheid.nl/documenten/ronl-b1d5f609-f1ff-4ff0-95a1-460714d9f953/pdf

52. ZonMw. Dementia Research Programme [Web page].2020 [cited 21 December 2023]. Available from: https://www.zonmw.nl/en/program/dementia-research-programme#:~:text=By%202025%2C%20every%20person%20with,years%20(2021%2D2030)

53. ZonMw. Largest pooling of resources in dementia research [Web page].2022 [cited 21 December 2023]. Available from: https://www.zonmw.nl/en/article/largest-pooling-resources-dementia-research

54. ZonMw. Memorable [Web page].2020 [cited 21 December 2023]. Available from: https://www.zonmw.nl/en/program/memorable

55. Bakker C. Wetenschapsagenda Dementie op Jonge Leeftijd. UKON, Kenniscentrum Dementie op Jonge Leeftijd; 2020. Available from: https://www.ukonnetwerk.nl/media/1369/wetenschapsagenda-jongdementie-2020.pdf

56. Francke A, Heide Ivd, Bruin Sd, Gijsen R, Poos R, Veerbeek M, et al. Een samenhangend beeld van dementie en dementiezorg. 2018 Available from: https://www.nivel.nl/sites/default/files/bestanden/Thema_rapportage_dementie_beveiligd.pdf

57. Janssen B, Pelzer D, Pors W, Prins E, Tol Mv, Sturme T, et al. Zorgstandaard dementie op jonge leeftijd - Verbijzondering van de zorgstandaard dementie. 2015

58. Perspekt S. PREZO Dementie op jonge leeftijd [Web page].2024. Available from: https://perspekt.nu/keurmerken/prezo-dementie-op-jonge-leeftijd

59. ZonMw. Betere diagnostiek en zorg voor jonge mensen met dementie [Web page].2023 [cited 21 December 2023]. Available from: https://www.zonmw.nl/nl/artikel/betere-diagnostiek-en-zorg-voor-jonge-mensen-met-dementie

60. van Vliet D, de Vugt ME, Bakker C, Pijnenburg YA, Vernooij-Dassen MJ, Koopmans RT, et al. Time to diagnosis in young-onset dementia as compared with late-onset dementia. Psychol Med. 2013;43(2):423-32.

61. ZonMw. A reliable and timely diagnosis for people with dementia [Web page].2020 [cited 21 December 2023]. Available from: https://www.zonmw.nl/en/reliable-and-timely-diagnosis-people-dementia

62. van Gils AM, Rhodius-Meester HFM, Leeuwis AE, Handgraaf D, Bakker C, Peetoom K, et al. Young-onset dementia in memory clinics in the Netherlands: Study design and description of PRECODE-GP. Alzheimers Dement (Amst). 2023;15(3):e12471.

63. Zuizewind C, Hofman C, Bouwman F, Lemstra E. Inventarisatie werkwijzen geheugenpoli's. 2019. Available from: https://www.geheugenpoliklinieken.nl/kennis/inventarisatie-werkwijzen-geheugenpoli-s

64. Gruters AAA, Ramakers I, Kessels RPC, Bouwman FH, Olde Rikkert MGM, Blom MM, et al. Development of memory clinics in the Netherlands over the last 20 years. Int J Geriatr Psychiatry. 2019;34(8):1267-74.

65. Drasković I, Vernooij-Dassen M, Verhey F, Scheltens P, Rikkert MO. Development of quality indicators for memory clinics. Int J Geriatr Psychiatry. 2008;23(2):119-28.

66. Perry M, Drašković I, van Achterberg T, van Eijken M, Lucassen P, Vernooij-Dassen M, et al. Development and Validation of Quality Indicators for Dementia Diagnosis and Management in a Primary Care Setting. Journal of the American Geriatrics Society. 2010;58(3):557-63.