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Post-diagnostic Support Leads Meeting

When you join the meeting please introduce yourself in the chat box:

- your name
- your role
- where you are based

Wednesday 9 March 2022
10:00 – 12:00
MS Teams

Enabling health and social care improvement

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Welcome and housekeeping

Karen Thom
Strategic Planning and Commissioning Officer - Older People
Edinburgh Health and Social Care Partnership

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Housekeeping

- Feel free to have your camera on at the start
- Mute your line – when prompted, unmute to speak
- Use the chat or raise your hand functions to ask a question (remember to lower your hand afterwards)

Focus on Dementia update: Potential new commissions

Lynn Flannigan
Senior Improvement Advisor
Healthcare Improvement Scotland

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Inverclyde Dementia Care Co-ordination Programme Update

Brenda Friel
Improvement Advisor
Inverclyde Health and Social Care Partnership

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social care improvement

#Focusoncoordination

Inverclyde HSCP
Dementia care co-ordination pathway

Stage 1	Stage 2	Stage 3	Stage 4	Stage 5
Noticing changes which prompt the person/ family to seek help.	The process of getting a diagnosis.	Learning about the condition and planning for the future.	Getting the right help at the right time. Where unavoidable, transitions to hospital will be timely and person-centred.	More complex care and support. Palliative and end of life care.

Person living with dementia

Carers and family

Visit to GP

Pre-diagnosis

Diagnosis

Accessing rehab and enablement

Carer support plan

Simple home adaptations

Self-management

Hospital admission

Community based support

Physical home adaptations and equipment

Care home admission

A change of identity and role

Leaving a Legacy

Technology and digital solutions

keeping well,
Information about dementia

Information about diagnosis,
keeping fit,
dementia register/ coding

Technology prescription,
memory aids,
cognitive stimulation/rehab,
SDS toolkit,
ACP/KIS,
keeping connected.

Purple alert,
GNSS (GPS),
Telecare,
Home care,
Day activity,
Day care support

Playlist for Life

Dementia Friendly Inverclyde

Re-establish PDS Service Recruitment; EQIA

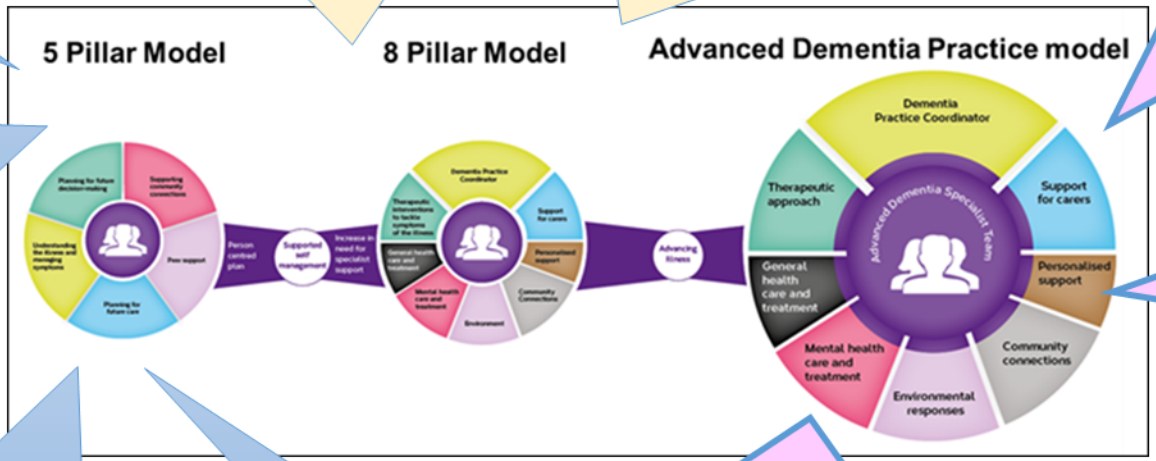
Understanding Dementia Practice Co-ordinator role

Implemented model of care co-ordinaton within Inverclyde

Applying Critical Success Factors in practice

Understanding Current Palliative & End of Life Support - District Nursing; Specialist PEOL Services; Mental Health Services

LDP Standard & Single Quality Question



PEOL identification tools - SPICT

Weekly waiting list and caseload review

Complete PDS QIF

Advanced Dementia Specialist Team & Forum

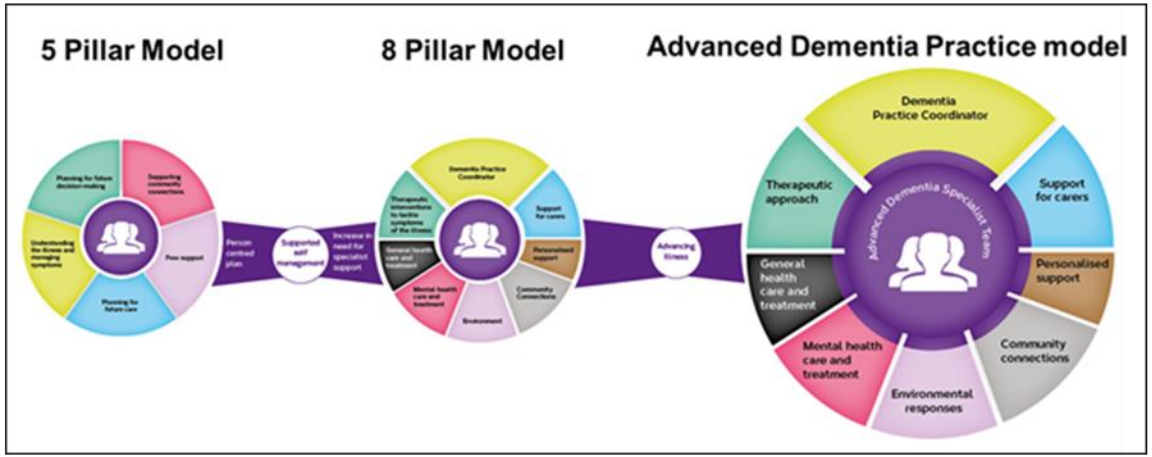
Workforce Development - TNA
Promoting Excellence Framework

Referral routes/criteria to appropriate HSCP services and community supports/Single Point of Access/self referral

Technology
Self Management application

Self management Information Resource

Role of Allied Health Professionals
Connecting People
Connecting Support



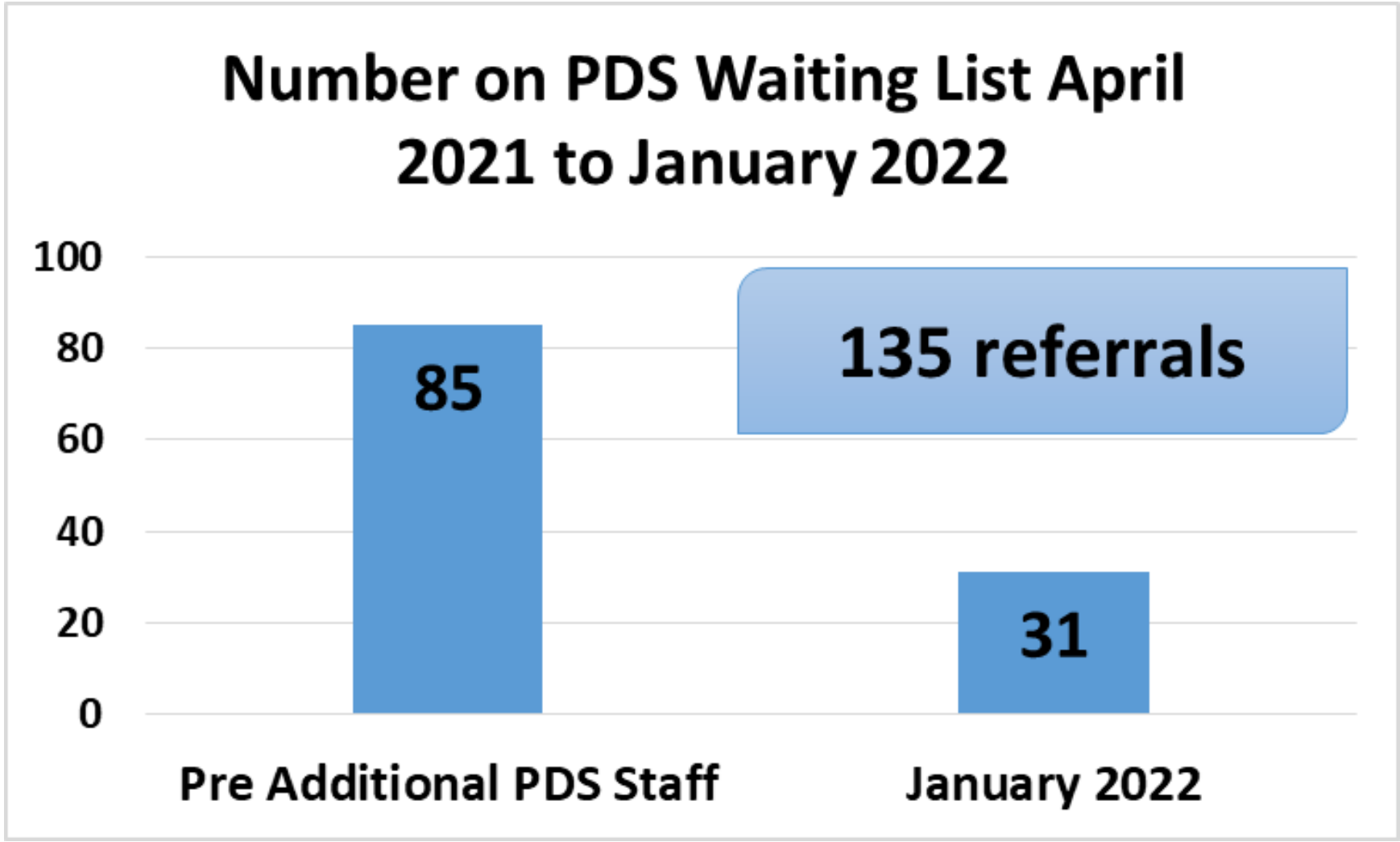
Anticipatory Care Planning & Frailty

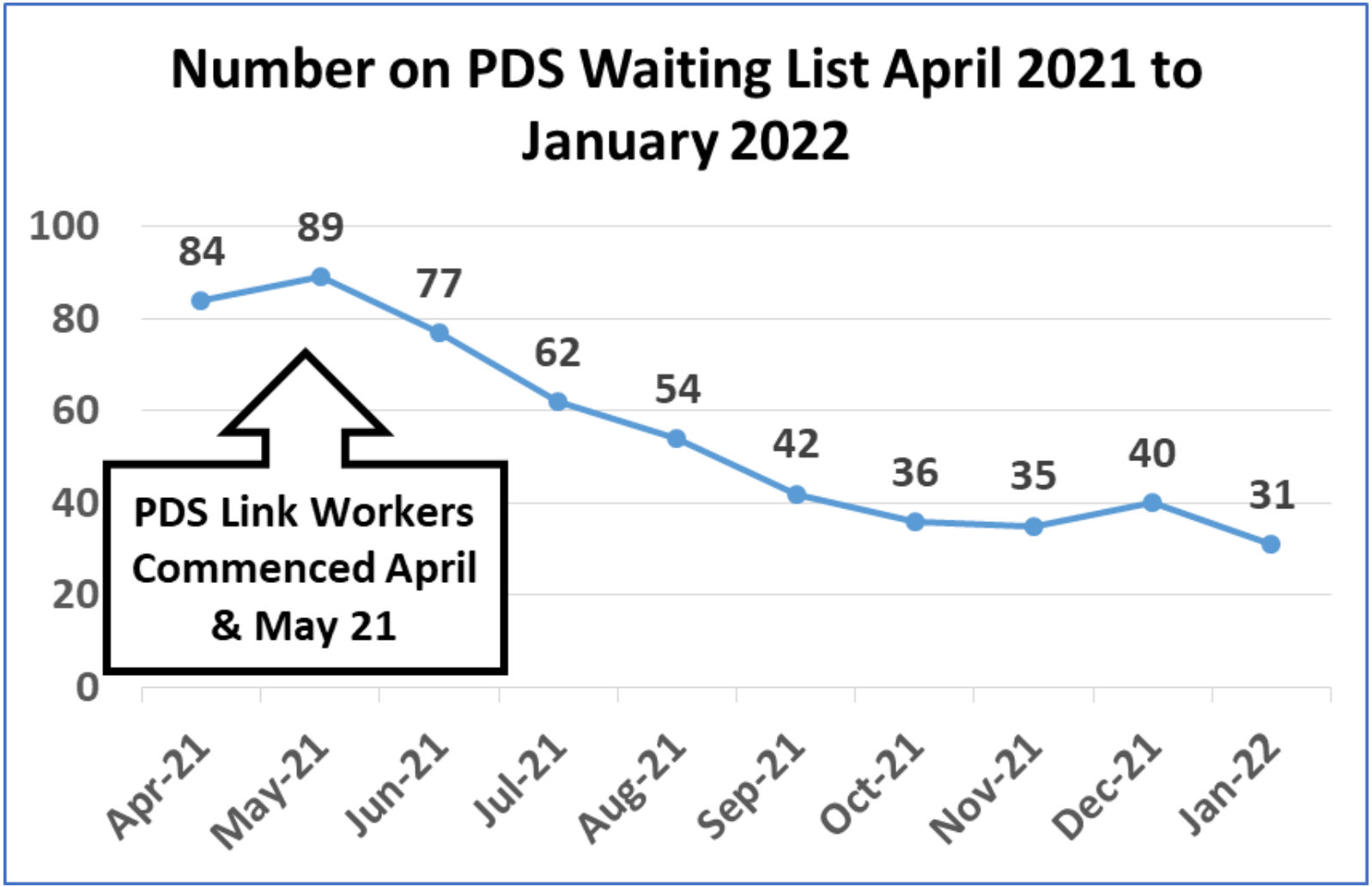
Housing & Dementia

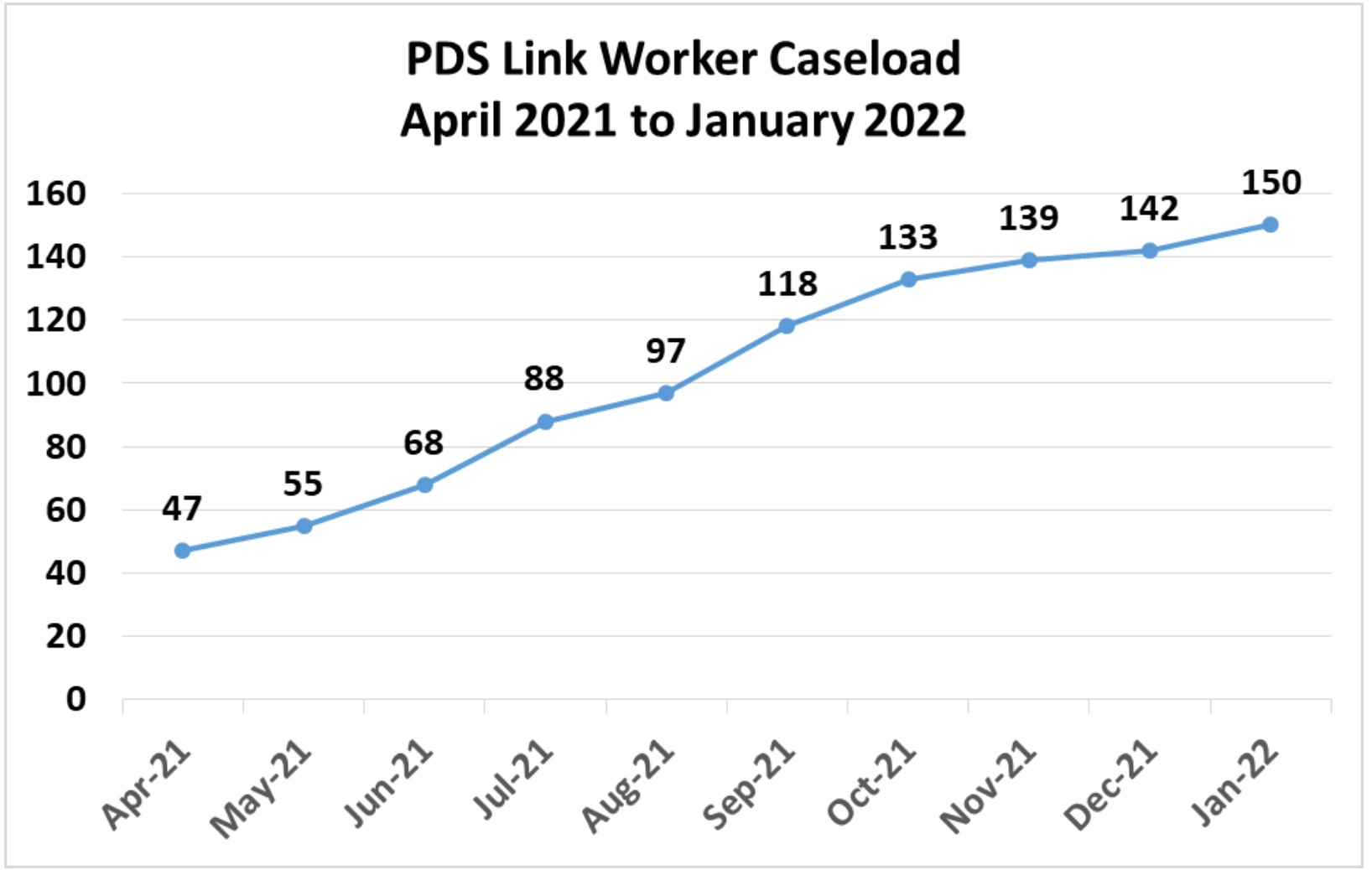
Engagement with local GP to improve dementia pathway

Care Co-ordination - Post Diagnostic Support Service

- Additional PDS Link Worker investment – significant impact
- Weekly meetings
- Quality Improvement Framework
- PDS Service Standard Operating Procedure – including data requirements


Number on PDS Waiting List April 2021 to January 2022
100
80
60
40
20
0
85
135 referrals
31
Pre Additional PDS Staff
January 2022


Number on PDS Waiting List April 2021 to January 2022
100
80
60
40
20
0
84
89
77
62
54
42
36
35
40
31
PDS Link Workers Commenced April & May 21
Apr-21
May-21
Jun-21
Jul-21
Aug-21
Sep-21
Oct-21
Nov-21
Dec-21
Jan-22


PDS Link Worker Caseload
April 2021 to January 2022
160
140
120
100
80
60
40
20
0
47
55
68
88
97
118
133
139
142
150
Apr-21
May-21
Jun-21
Jul-21
Aug-21
Sep-21
Oct-21
Nov-21
Dec-21
Jan-22

Care co-ordination - 8 Pillar Model of Community Support

- Defining the care co-ordinator role in Inverclyde
- Collating services document
- Reviewing Inverclyde against 12 critical success factors for Care Co-ordination

Inverclyde Dementia Care Co-ordination Programme
Application of Alzheimer Scotland 8 Pillar Model of Community Support

INVERCLYDE HSCP
Health and Social Care Partnership

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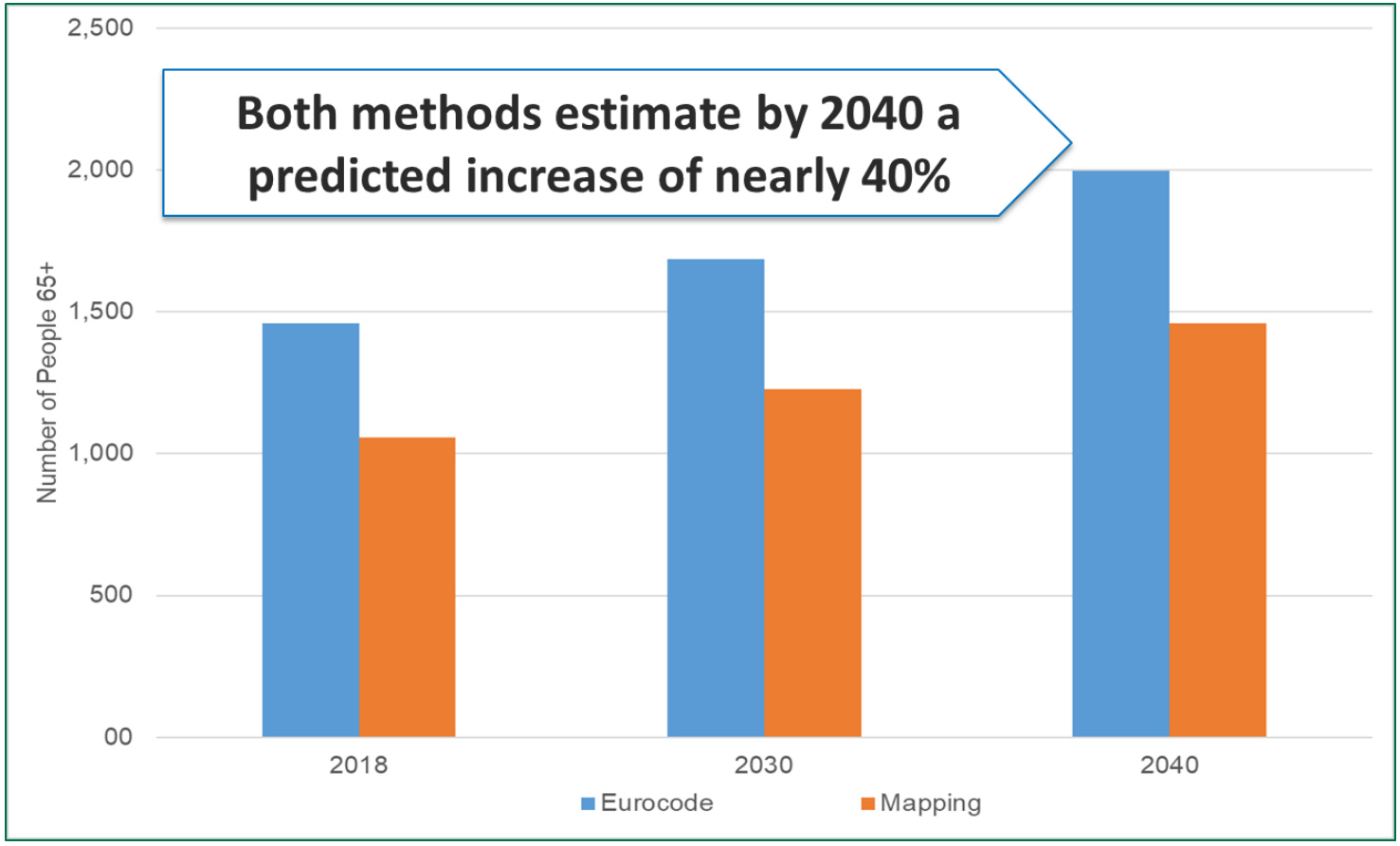
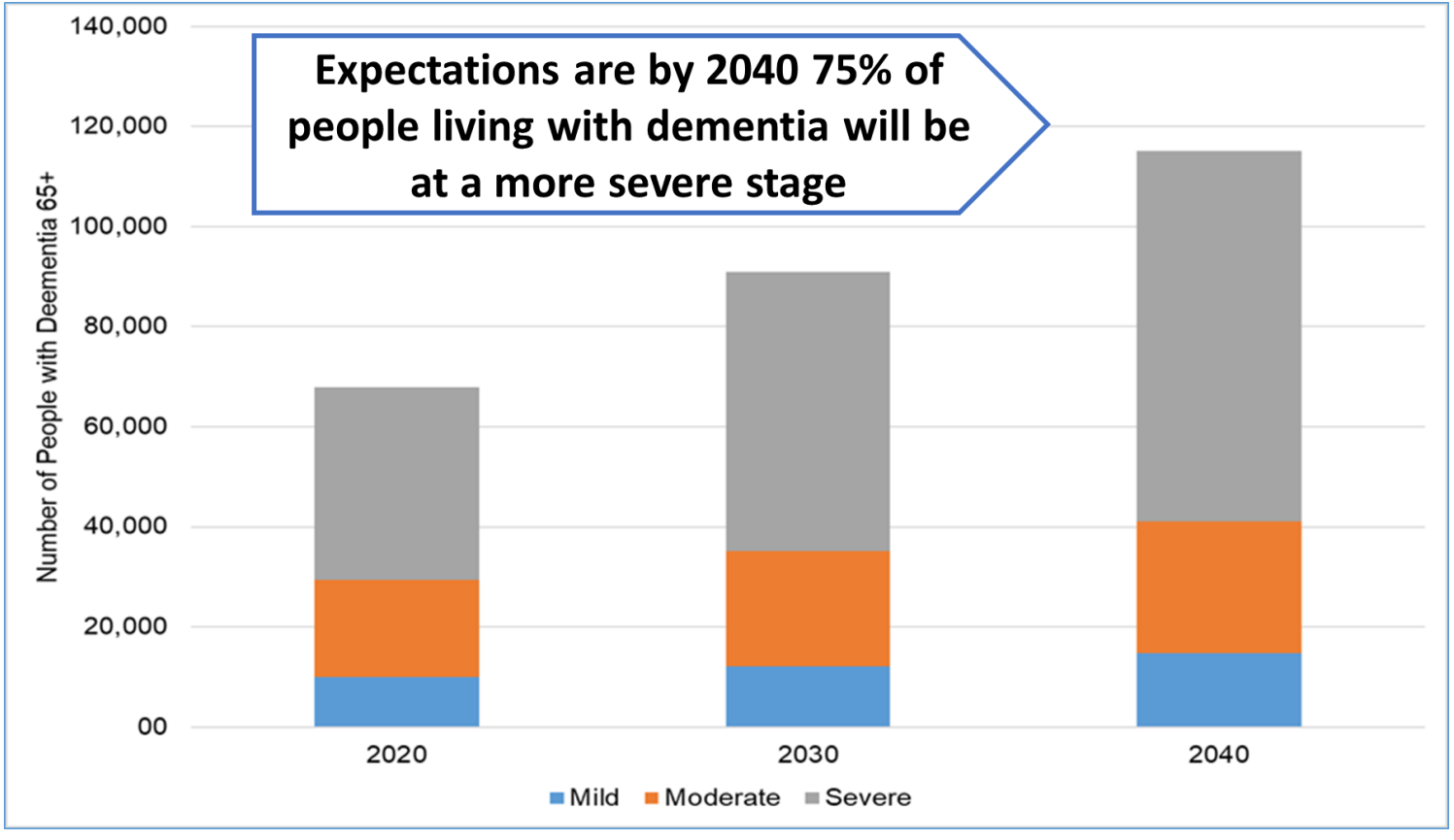
Alzheimer Scotland Advanced Dementia Practice Model

- Requirement of this commission
- Working Group to agree Inverclyde's application
- Identification tools PEOLC
- Advanced Dementia Specialist Team (ADST)
- Advanced Dementia Specialist Forum (ADSF)

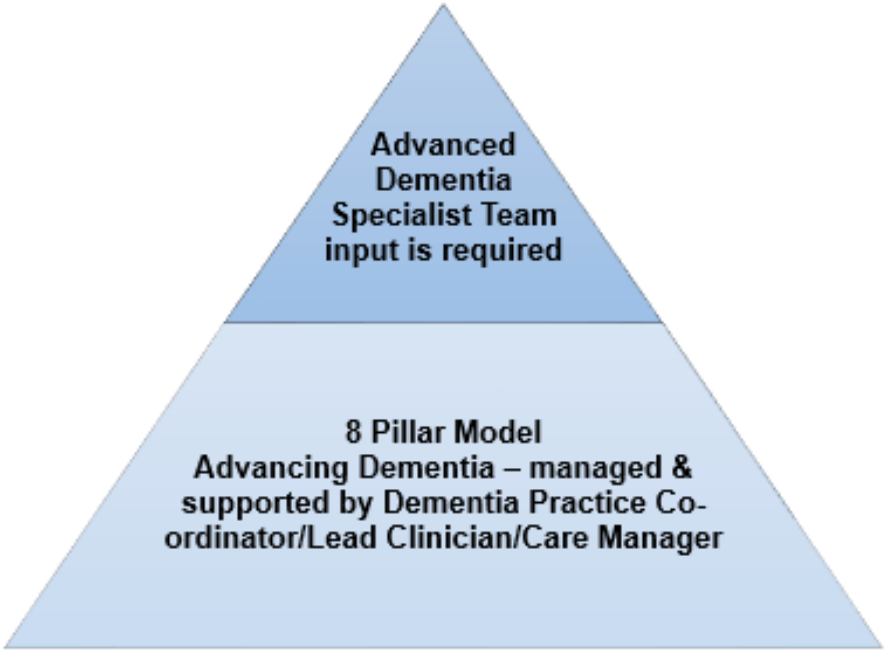
Estimated projected number of people with Dementia - Inverclyde



Projected number of people with dementia and severity of dementia in Scotland



A Needs Based Approach to Advanced Dementia Care and Support in Inverclyde



Advanced needs not being met by current care & support arrangements

Individual with advancing dementia, who is being supported by their care co-ordinator, has unmet needs that are not responding to current supports. This may include - stress and distress, symptom management and carer stress and distress.

Advanced needs being met by current care & support arrangements

Care co-ordination role, person centred support planning aligned to the 8 pillars of community support. Support continues as dementia becomes more advanced. Co-ordinator will recognise advancing dementia, support palliative and end of life care needs and connect to appropriate services.

Identifying Advancing Dementia

- Identified gap – many identification tools – not necessarily for dementia
- Progression of dementia is varied, over longer period of time
- Often not picked up till end of life
- Short life working group to agree identification tool/s - clinical & non-clinical background
- Conclusion – possible to determine that one tool is preferable to others – depends on role & reason – e.g. identification of symptoms and concerns, early warning, rate of change.
- Await recommendations of the forthcoming SIGN guidelines

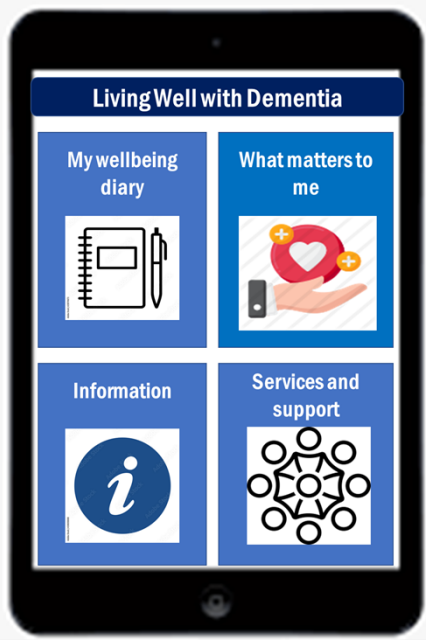
Test and evaluate Inverclyde Advanced Dementia Specialist Forum

- Standard Operating Procedure & Advanced Dementia Specialist Team agreed for 6 month test
- Identifying cases was difficult
- Evaluation – Forum valued, multi-agency input valued, better understanding of roles and responsibilities, services & supports, learning opportunity
- Did make a difference – for individual with dementia & person presenting the case

- Psychiatrist
- Psychologist
- Geriatrician
- Community Psychiatric Nurse
- Social worker
- District Nurses
- Specialist PEOL
- Alzheimer Scotland
- Carers Centre
- Inpatient charge nurse
- Pharmacist
- Allied Health Professional - OT

Care co-ordination - overarching actions across whole pathway

Dementia Training Co-ordinator now in post

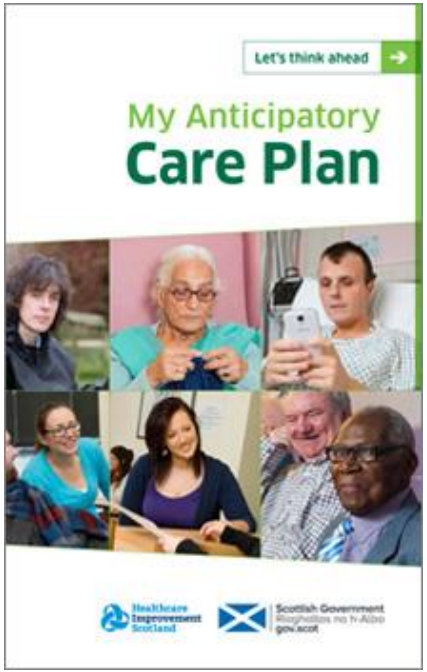


Care co-ordination - overarching actions across whole pathway continued

Care co-ordination - overarching actions across whole pathway continued…

Occupational Therapy interventions Journeying Through Dementia and Home Based Memory Rehabilitation are being delivered and evaluated.

Engagement with GPs



Next steps

- Programme ends March 2022
- End of Programme events - March
- Evaluation – capture learning
- Share learning
- Sustainability beyond March 2022 – re-establish Inverclyde Dementia Strategy Group

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Focus on Dementia update: Post-diagnostic Support

Julie Miller
Improvement Advisor
Healthcare Improvement Scotland

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social care improvement

PDS in Primary Care activity

Evaluation report status – to publish this month.

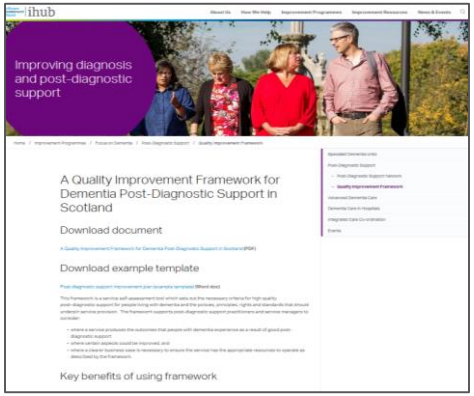
Webinar 20 April to share key messages.

East Edinburgh

- HSCP funding until March 2023
- Project Management (under pilot) ends March 2022. Dementia Support Facilitator (DSF) to join, and be line managed by, the OPMHT
- Virtual groupwork courses successfully undertaken.

Quality Improvement Framework for PDS

https://ihub.scot/media/8976/a-quality-improvement-framework-for-pds-in-scotland-2nd-edition.pdf



- 2nd Edition on FoD webpages
- SG PDS Governance Group – want to know about quality & are committed to QIF's use across IJBs and the use of the SQQ
- FoD supporting increased uptake.

Testing the feasibility and usability of a post-diagnostic support single quality question

June 2021

Summary

For the full report or to ask questions contact:
his.focusondementia@nhs.scot

About this report

This summary provides key findings from a test to ask people with dementia and carers a single quality question (SQQ) to determine the difference post-diagnostic support (PDS) has made to them. This was a collaboration between Focus on Dementia, Sheila Inglis (ihub Associate), Alzheimer Scotland, Inverclyde Health and Social Care Partnership and Inverclyde Dementia Reference Group. The summary includes next steps for the PDS SQQ.

Background

The PDS SQQ was designed to provide important national information about how helpful PDS has been to people with dementia and their carers with the vision of it becoming a universal question that all PDS services build into their evaluation methods. If all services can ask the same question then we have the potential to complement the national PDS data, collected by Public Health Scotland, to demonstrate the difference PDS makes to people.

The PDS SQQ test project aimed to:

- assess the feasibility and usability of a PDS SQQ to establish the experience of the service and the difference it has made to the individual

In total, 28 people were interviewed by phone over the course of 2 weeks in February 2021

Overall the test project found that the PDS SQQ and the follow-on open-ended question “did its job”, it provides the qualitative feedback that is needed. Following adoption of the recommendations, no further testing of the question is required and its use can be promoted widely.

Next steps - call to action!

We are now asking for all PDS practitioners and PDS services to adopt the following updated question and the follow on open-ended question into their evaluation methods:

Please tell us, overall, how helpful or unhelpful the support has been to you? (Tick box)

Helpful	Neither helpful nor unhelpful	Unhelpful

Please tell us a bit more about the option you chose: If the support from your Link Worker made a difference to you, please tell us about the difference. If the support from your Link Worker did NOT make a difference, please tell us a bit more.

We will keep the SQQ and its use on the PDS Leads agenda and in our network newsletter to:

- Maintain momentum of its implementation
- Continue to promote its use
- Gauge its uptake
- Gather further feedback on the outcomes of asking it, and
- Consider how the qualitative data it yields can be captured and presented nationally.

Please let Focus on Dementia know if you will adopt the question and/or if you have any queries: his.focusondementia@nhs.scot

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Diagnosis and diagnostic models

Julie Miller

Vivek Pattan
Clinical Lead Psychiatry
NHS Forth Valley

Enabling health and
social care improvement

Models of Diagnosis survey

- HIS moratorium on surveys in January
- Great feedback on survey content 
- Information Governance to consider
- Will inform our proposed new commission to conduct proper exploration of this area
- Aim to get survey out from April 2022.

1. Please enter the name and email address of the person completing this survey

Enter your answer

2. Please enter the designation of the person completing this survey

Enter your answer

3. Please enter the name of your service and geographical area

Enter your answer

4. Please enter the Health and Social Care Partnership of your service

Enter your answer

5. Who contributes to the diagnostic assessments in the memory clinic/ diagnostic service? (consider the following health care professions when responding to this question, tick all that apply)

- [ ] Community Mental Health Nurse
- [ ] Occupational Therapist
- [ ] Healthcare Assistant
- [ ] Consultant Psychiatrist
- [ ] Psychiatrist (other grades)
- [ ] Psychologist/ Neuropsychologist
- [ ] Link Worker
- [ ] Specialist Nurse
- [ ] Advanced Nurse Practitioner
- [ ] Speech and Language Therapist
- [ ] Other

6. Please tell us which professionals make the diagnosis in your area?

	Never	Rarely	Sometimes	Often	Always
Psychiatrist	○	○	○	○	○
Psychologist	○	○	○	○	○
Neurologist	○	○	○	○	○
Geriatrician	○	○	○	○	○
General Practitioner	○	○	○	○	○

7. In your memory clinic or similar setting, who is involved in delivering the diagnosis?

- ☐ Psychiatrist exclusively
- ☐ Psychologist/ neuropsychologist
- ☐ Community Mental Health Nurse
- ☐ Occupational Therapist
- ☐ Other

8. On average where do most referrals come from?

	Never	Rarely	Sometimes	Often	Always
Acute hospital	○	○	○	○	○
GP Practice/ primary care	○	○	○	○	○
Care home	○	○	○	○	○
Adult mental health service	○	○	○	○	○
Learning disability service	○	○	○	○	○
Self referral	○	○	○	○	○
Social services	○	○	○	○	○

9. Please provide more details in relation to question 8 if necessary.

Enter your answer

10. How often do you think people are diagnosed in other set ups?

	Never	Rarely	Sometimes	Often	Always
Acute hospital	○	○	○	○	○
GP Practice/ primary care	○	○	○	○	○
Care Home	○	○	○	○	○
Adult mental health service	○	○	○	○	○
Learning disability service	○	○	○	○	○

11. Please provide more details in relation to question 10 if necessary.

Enter your answer

12. Please tell us what training the person assessing and/or diagnosing has completed if it is not psychiatrist/neurologist (please tick all that apply).

	Formal training for example Promoting Excellence Framework, CPD	Experience of working/ shadowing in the team	Don't know
Person carrying out the assessment	◯	◯	◯
Person arriving at the diagnosis	◯	◯	◯

13. Please provide more details about the training if selected above.

Enter your answer

14. What cognitive assessment tools are used in your area?

Enter your answer

15. How are new referrals allocated?
Please use the 'other' box to provide more details if a different system is used.

- [ ] All new referrals are allocated to different members of the MDT team based on the complexity or needs
- [ ] All new referrals are seen by psychiatrist in the memory clinic
- [ ] All new referrals are seen by members assisting memory clinic followed by psychiatrist
- [ ] Other

16. How do you decide if a case is complex and the psychiatrist should carry out the assessing and diagnosing?

Enter your answer

17. How is the diagnosis arrived at? (please consider the following models when answering this question, tick all that apply)

- [ ] Diagnosis made by psychiatrist after undertaking full assessment of the patient at the clinic/ visit.
- [ ] Diagnosis made by psychiatrist after reviewing the diagnostic information from staff assisting the memory clinic followed by meeting the patient.
- [ ] Diagnosis made at virtual MDT based on assessment information from Community Mental Health Nurse/Occupational Therapist and results of investigations.
- [ ] Diagnosis made in Primary Care by General Practitioner.
- [ ] Diagnosis made by neurologists/ geriatrician
- [ ] Diagnosis made by psychologist/ neuropsychologist
- [ ] Other

18. If psychiatrist time is involved to corroborate diagnosis how much time is allocated for each case?

Enter your answer

18. If psychiatrist time is involved to corroborate diagnosis how much time is allocated for each case?

Enter your answer

19. On average how many contacts (face to face or virtual) are made prior to diagnosis?

1	2	3	4	5	6	7	8	9	10
○	○	○	○	○	○	○	○	○	○

20. Do you run a one stop to diagnosis model? (i.e. all the diagnostic assessments, collateral history taking, investigations including bloods/ ECG, CT scans taking place in a single session)

- ○ Yes
- ○ No
- ○ Other

21. Can you give us an anonymised example of the typical process of memory clinic referral to assessment?

Enter your answer

22. Please tell us about strengths / potential risks with the current model in operation

Enter your answer

23. Please use this space to tell us anything else that is relevant to this topic. For example

- are any other models of diagnosis that have been tried previously and the outcome of this
- how do you engage with families and carers engaged in the diagnostic process?

Enter your answer

Submit

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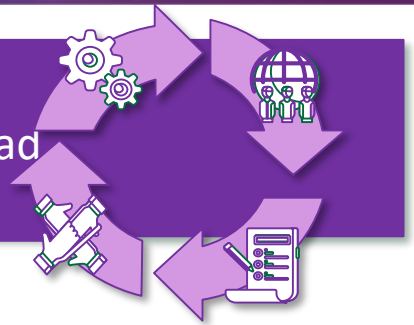
Focus on Dementia Learning System

Julie Miller

Improvement Advisor

Learning System Activity

The Focus on Dementia Portfolio is underpinned by a **National Learning System** which aims to rapidly capture and share learning to support spread at pace and scale. We do this in a number of ways:



Hosting webinars

Sharing evidence summaries

Flexible learning opportunities

Supporting networks

Producing case studies

Develop toolkits and measurement plans

Learning System Activity

- Spring Newsletter due end March – content to Marina!
- Sharing the learning from the PDS in Primary Care Programme (Webinar 20 April & further webpage development)
- Animation in progress (re PDS in PC)
- Possible webinar on virtual PDS groupwork (July)
- Combining/sharing the learning from community programmes to inform our work after March – new commission proposals.

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PDS and inequalities

Julie Miller

Improvement Advisor

Evidence review of inequalities in accessing PDS services

- Search of recent literature specific to access to PDS
- Key findings against protected characteristics.

NB. useful HIS resource on using the right terminology and inclusive language (in chat box).

Post-diagnostic dementia support and inequalities: initial search

Literature search conducted

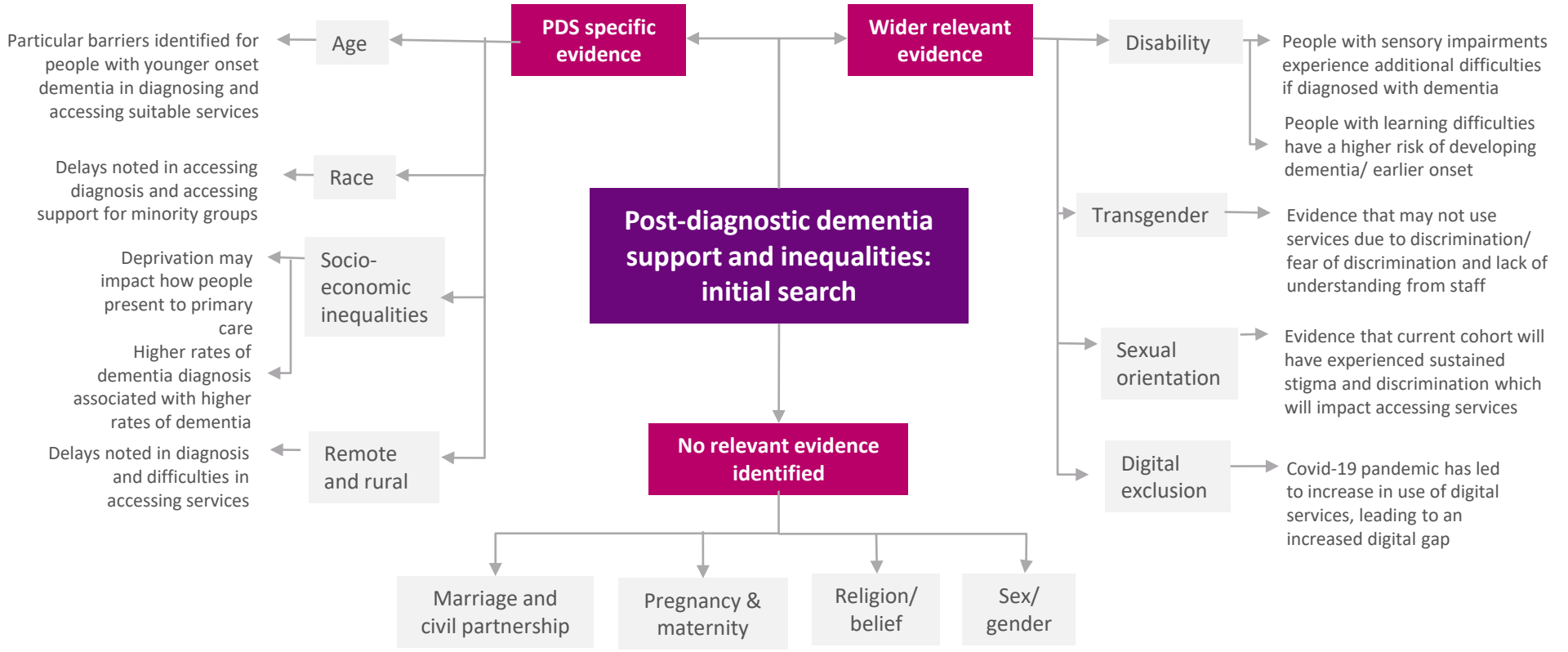
- Seven studies identified related to PDS and inequalities
- Further two studies reviewed for context information

Literature reviewed to identify relevant points to relevant characteristics

- Nine protected characteristics set out in the Equality Act, and
- Other relevant characteristics as noted within SG EQIA

Production of knowledge map

Knowledge map



PDS specific evidence

- **Age**
  - **Diagnosis** – misdiagnosis is more common for people with younger-onset dementia (NHS Health Scotland 2016)
  - **PDS** – some services including PDS not suitable/ perceived to be suitable for younger-onset dementia (Giebel et al 2021)
- **Race**
  - **Diagnosis** - some evidence regarding difficulties/ delays obtaining diagnosis (Arblaster 2021a)
  - **Barriers** – accessing diagnosis and PDS including community-led issues and cultural accessibility (Arblaster 2021a)
- **Socio-economic**
  - **Diagnosis** - higher levels of deprivation associated with higher diagnosis rate (Arblaster 2021b)
  - **Accessing services** – costs of day centres, support groups (including travel and food) could be an issue for those who do not meet criteria for a funded place (Giebel et al 2021)
- **Remote/ rural**
  - **Prevalence** - evidence that prevalence of dementia is higher in rural communities (Russ et al 2012)
  - **Barriers** - evidence that people in rural services access diagnosis services later in the progression of their condition – barriers include harder to identify symptoms in rural communities (eg fewer social activities), and lack of access to services (Arblaster 2021b)

Wider relevant evidence

- **Disability**
  - **Prevalence** – people with learning difficulties have a greater risk of developing dementia, people with learning disabilities have a greater risk of developing younger-onset dementia (NHS Health Scotland 2016)
  - **Barriers**– people with sensory disabilities and dementia can experience additional challenges including difficulties accessing services due to communication needs (NHS Health Scotland 2016)
- **Transgender**
  - **Accessing healthcare** - evidence that transgender people may not use health and social carer services due to discrimination, fear of discrimination and previous poor experiences of healthcare (Scottish Government 2021)
- **Sexual orientation**
  - **Accessing healthcare** - evidence that LGB people will have experienced sustained stigma and discrimination which will impact accessing services, they may also feel out of place in traditional services – for example, they may not feel comfortable discussing their partner or family of choice (Scottish Government 2021, NHS Health Scotland 2016)
- **Digital exclusion**
  - **Accessing healthcare** - the pandemic has made accessing services digitally necessary and has meant a greater risk of those who are digitally excluded may be left behind including many older person – the Scottish Government highlights in their EQIA that accessing digital services may not be suitable for all people with dementia and their carers (Scottish Government 2021)

No relevant evidence

- **Marriage and civil partnership**
- **Pregnancy and maternity**
- **Religion and belief**
  - In their EQIA, the Scottish Government observe that religion can be closely associated to race and ethnicity, particularly when considering community approaches to dementia (Scottish Government 2021).
- **Sex and gender** (new report just out from Alzheimer Europe, link on next slide)

Useful links

Overall

- NHS Health Scotland. Dementia and equality – meeting the challenge in Scotland. Recommendations of the National Advisory Group on Dementia and Equality. 2016 [cited 2022 Feb 28]; Available from: http://www.healthscotland.scot/media/1226/27797-dementia-and-equality_aug16_english.pdf.
- Scottish Government. Coronavirus (COVID-19) dementia action plan: equality impact assessment. 2021 [cited 2022 Mar 08]; Available from: https://www.gov.scot/publications/equality-impact-assessment-dementia-covid-19-national-action-plan-continue-support-recovery-people-dementia-carers/documents/.
- Giebel C, Hanna K, Tetlow H, Ward K, Shenton J, Cannon J, et al. "A piece of paper is not the same as having someone to talk to": accessing post-diagnostic dementia care before and since COVID-19 and associated inequalities. International journal for equity in health. 2021;20(1):76.

Gender, LGBT

- Alzheimer Europe. 2021 Alzheimer Europe Report: Sex, gender and sexuality in the context of dementia: a discussion paper. 2022 [cited 2022 Mar 08]; Available from: https://www.alzheimer-europe.org/reports-publication/2021-alzheimer-europe-report-sex-gender-and-sexuality-context-dementia

Race

- Arblaster K. Ethnic minority communities Increasing access to a dementia diagnosis. 2021 [cited 2022 Mar 08]; Available from: https://www.alzheimers.org.uk/sites/default/files/2021-09/ethinic_minorities_increasing_access_to_diagnosis.pdf.

Rural/ socio-economic issues

- Arblaster K. Regional variation Increasing access to a dementia diagnosis. 2021 [cited 2022 Mar 03]; Available from: https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf.

Questions for discussion:

- Does this feel accurate in relation to your experience?
- Is there information which could be added to this? E.g. additional characteristics to consider/other published information?

- Who has experience/practice to share around reducing inequalities in accessing PDS?

Young onset dementia - update

Jill Carson

Consultant Public Policy, Policy and Practice

Alzheimer Scotland

Young Onset Dementia

- Round table event held October 2021, chaired by Maureen Taggart
- Presentations from four services across Scotland
- Lived experience
- Alzheimer Scotland to consider proposals for the way forward

Alzheimer Scotland

Key Points

- Small numbers
- Diverse services (funding, personnel, breadth of service offered, case management)
- Mix of public sector & third sector involvement
- Recognition that the needs of people with YOD are different, but that developing appropriate services for the relatively small number affected in a local area is challenging

Alzheimer Scotland

Issues

- Access to appropriate respite
- Access to SDS
- Equal access to diagnosis and post diagnostic support
- Timely diagnosis
- Consistency (postcode lottery)
- No clear picture of services across Scotland

Alzheimer Scotland

Opportunities

- Develop principles of service delivery to promote equity
- Benchmark current services
- Consider what (and who) is needed to support a positive impact on quality for people with young onset dementia (AHPs, social care)
- Cross-boundary approach
- Short term working group to consider issues and opportunities in greater depth
- Resurrection of the Scottish Young Onset Dementia conference
- Further round table session

Alzheimer Scotland

Next Steps

- Further engagement with Alzheimer Scotland to look at feasibility of supporting SLWG and next round table session
- Identify avenue of support for planning & delivering YOD conference
- Explore synergies with Brain Health Scotland
- Support from PDS Leads?

Alzheimer Scotland

Actions by Alzheimer Scotland

- Initiated contact with Brain Health Scotland to explore synergies
- Exploring potential to create digital support for people with young onset dementia
- Agreed to support a short life working group
- Proposed terms of reference

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Draft Terms of Reference

1. Background

It is acknowledged that people with young onset dementia (YOD) are often at a different life stage compared to people who are diagnosed later in life. They are also more likely to have received their diagnosis through a different pathway, and as such may be less connected to post diagnostic support services. Estimates of the relative percentage of people with YOD compared to older adults with dementia are varied; however the Alzheimer's Society suggests that around 4.5% of people with dementia in the UK receive a diagnosis before the age of 65.

2. Role & Remit

This short life working group (SLWG) has been established to explore service delivery for people with YOD in Scotland, and to identify 'best practice' with the aim of improving access to appropriate services for people under the age of 65 who are living with dementia.

3. Scope

All elements of the pathway can be considered by the SLWG to be in scope: diagnosis, immediate (first year) post diagnostic support and ongoing specialist under 65s community/other support.

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4. Membership

Members will be invited from the PDS Leads Group, with representation from across a number of Health & Social Care Partnerships (HSCPs).
PDS Leads may also suggest additional members with YOD experience who would be active contributors to the work.
People with lived experience will be invited to be part of the SLWG.

5. Meetings & Administration

Meetings will be held monthly for between one and two hours over a six month period. Alzheimer Scotland will provide a Chair for the meetings as well as admin support. The agenda will be circulated no later than one week in advance of the meeting, and a brief action note will be recorded.

6. Output

In taking forward the actions identified at the YOD round table discussion held on 26th October 2021, it is anticipated that the SLWG will:
• Consider conducting a survey of service delivery to people with YOD;
• Explore equity of access to services;
• Gather the views of people with lived experience;
• Organise a second round table session;
• Support planning for a Scottish YOD conference.

7. Accountability

The SLWG will report back to the PDS Leads Group and to Alzheimer Scotland's Senior Management Team

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What do we want from PDS Leads?

- Agreement to the proposal for SLWG
- Suggestions for members
- Agreement to Alzheimer Scotland and PDS Leads Group Chair considering possible members and inviting representatives to join the SLWG, ensuring appropriate spread (geography, experience, expertise)
- Ongoing support for the SLWG, including commitment to respond to requests for information

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Comfort break – be back at 11:35

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social care improvement

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Scottish Government update

David Berry
Scottish Government Policy

Enabling health and
social care improvement

Dementia Post Diagnostic Support: PHS Update

9 March 2022

Lisa Reedie

Public Health Scotland

Latest data submission: as at 31 December 2021

- Data submissions up to 31 December 2021 received from all Health Boards; resubmissions received from 12 HBs

Year of Diagnosis	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22
Number of records submitted	7,865	7,656	8,356	8,205	6,529	5,982

- Error rate across all years is 5.5% (HB error rates range from 0 – 22%)

Year of Diagnosis	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	All years
Scotland	3.4%	1.8%	3.2%	6.4%	10.5%	9.4%	5.5%

- Latest management reports were issued 2 March 2022

LDP standard methodology

- PDS referrals with a termination reason of “07 Service user has moved in to care” within 12 months of diagnosis are currently assigned as “not meeting” the LDP standard
- One area has raised this and provided examples to demonstrate that, in these cases, individuals have continued their PDS in the care home however this is not reflected in their PDS return as the individual is removed from their system
- PHS assessing impact of assigning these records as “exempt” from the LDP standard

Year	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	Total
Scotland	202	270	453	551	434	75	1985

- Affects some areas more than others – feedback required around local data recording of this termination reason

Further analysis – what would be useful locally?

- Demographics
  - Age at diagnosis
  - Deprivation
  - Accommodation type
  - Living alone

- Referral information (for diagnoses from 1 April 2019 onwards)
  - Clinical Impression of Stage of Illness
  - Model of Care
  - Subtype of Dementia
  - Termination / Transition Reason
  - PDS uptake decision
  - PDS referral source
  - PDS status

- Data quality
- Presentation of output

Future work

- Next annual release of LDP standard is 29 March 2022 presenting figures up to 2019/20
  - 2018/19 – finalised
  - 2019/20 - provisional
- Refinement of LDP standard methodology
- Using routinely provided information to additional outputs
- Changes to PHS team

Contact details: phs.dementiapds@phs.scot

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AHPs contribution to diagnosis and Post-diagnostic Support

Elaine Hunter
Alzheimer Scotland

Carrie Hill
NHS Highland

Alison McKean
Alzheimer Scotland

Enabling health and
social care improvement

Connecting you to support by the allied health professionals

Carrie Hill

carrie.hill@nhs.scot @carriehill1

Alison McKean

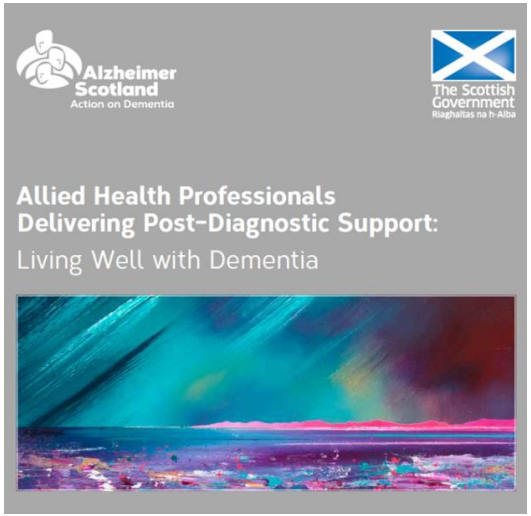
Amckean@alzscot.org @AliAHPDem

@AHPDementia

AHPDementia@alzscot.org

Making sure nobody faces dementia alone.

In the beginning



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Dementia & Rehabilitation.

An emerging debate

- Four approaches to rehabilitation & dementia, sharing new ideas and research and the positive outcomes of rehabilitation (Marshall 2005)

- Range of evidence based interventions are shared 16 years later such as occupational therapy, exercise programmes, psychological therapies & working with families to optimise independence (Low & Laver 2021)

“Despite a significant body of evidence, health-care providers have continued to ignore rehabilitation for people with dementia…We need a new pathway of diagnostic support”

(Swaffer in Low & Laver 2021)

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The Allied Health Profession Contribution to post diagnostic support

Rehabilitation

"a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment".

World Health Organisation, 2020

"rehabilitation applies to anyone, no matter what they've got."

"it's learning new ways to cope with having dementia"

(SDWG, 2021)

Film:
https://youtu.be/x1d9X7SmHBU

what does this look like in practice?

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The Allied Health Profession contribution to post diagnostic support

Dietitians Promote good nutrition and hydration, provide advice on conditions which can be managed by nutrition such as coeliac disease or diabetes, during rehabilitation, following illness or injury or to manage symptoms which impact on quality of life or stress/distress such as constipation.

https://www.malnutritionselfscreening.org/

Occupational Therapy equipment and adaptions in the home, adapting every day activities including dressing and shopping; rehabilitation, meaningful activity; support diagnosis.

Physiotherapy provide education on physical changes in dementia and top tips on how to manage these. Reduce fear, reduce falls, promote and enhance movement and mobility.

Podiatrists maintain mobility, improve independence and quality of life through good foot health. Help people remain physically active and participate in activities they enjoy.

Speech & Language Therapy help with strategies and confidence to support communication. Advise on how to compensate for difficulties eating, drinking and swallowing; support diagnosis.

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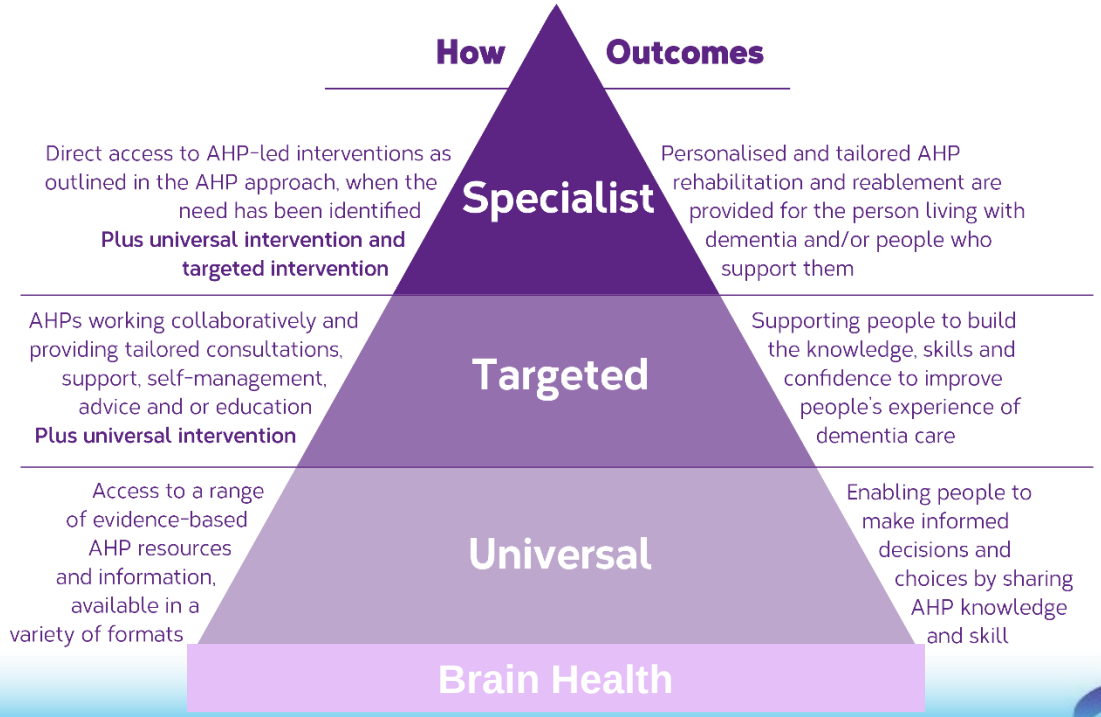
Transforming the AHP contribution to post diagnostic support



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Delivering a strategic & co-ordinated AHP approach to dementia rehabilitation

Specialist Individual

Home Based Memory Rehab

Journeying Through Dementia

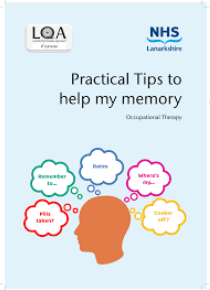
Targeted

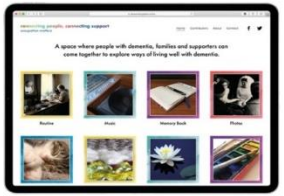
AHP webinars found at www.alzscot.org/ahpinnovation

Making Sense Together

Universal

@AHPDementia





Connecting People Connecting Support Online

Universal resources found at www.alzscot.org/ahpresources

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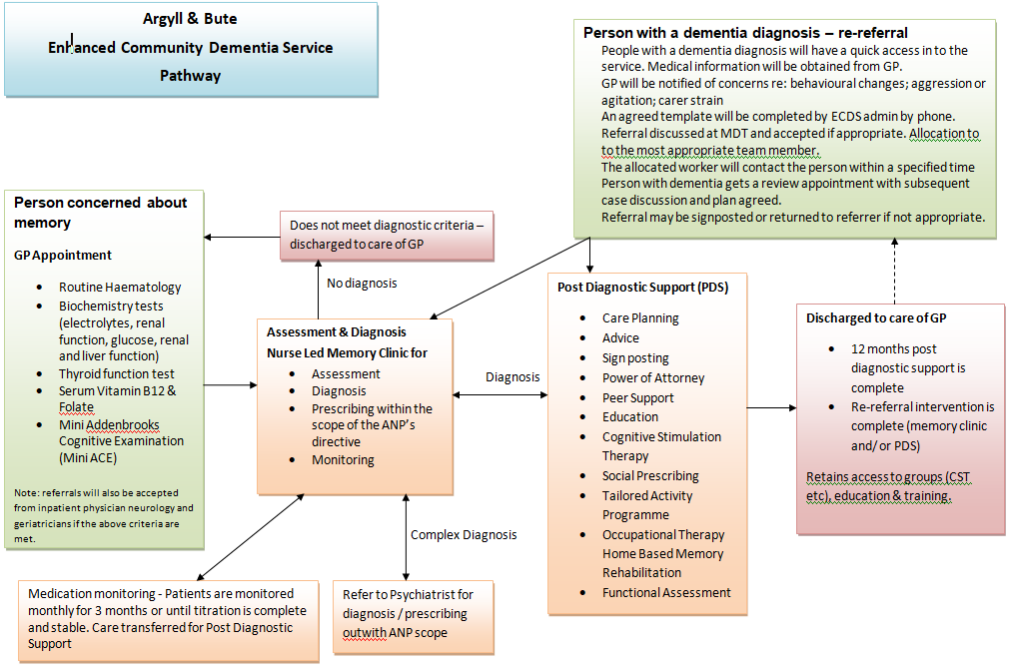
The Allied Health Profession Contribution to post diagnostic support – Argyll & Bute HSCP



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The unique OT offer to Assessment and PDS

- Cognitive assessments – as well as ACE III, Mini ACE we can use MOCA, Allen's Cognitive Level Screen (LACLS), AMPS
- Functional Assessments looking at Personal and Domestic Activities of Daily Living
- Rookwood Driving Assessments
- OT Home Based Memory Rehabilitation program
- Tailored Activity Program
- Ability to assist in Cognitive Stimulation and Rehabilitation programs
- Vocational Assessments and ability to use AHP Fit Note to inform reasonable adjustments for those still in employment
- Awareness of Risk Enablement approach where risk is measured in terms of severity and probability to ensure people's human rights are not removed unnecessarily
- Awareness of the importance that engaging in meaningful activity has on health and well-being
- Awareness of other AHP roles to allow for appropriate signposting

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Argyll & Bute HSCP Example – next stage

– Introduce **Speech and Language Therapist** post into the Post Diagnostic Team to enhance:

- ***Understanding illness and managing symptoms***
- assessment to inform differential diagnosis to allow targeted information around speech and language
- ***Supporting Community Connections***
- identification of communication networks (including people and places) to maximise communication opportunities
- Contribution to post-diagnostic services for people with dementia and their carers; for example, sessions on communication within information and support groups
- Supporting Group intervention to maximise retained communication skills and provide a supportive environment for socialisation; for example, Sonas groups, cognitive stimulation therapy, and reminiscence
- ***Planning for future decision making***
- Provide advice on changes necessary to reduce the increased risks identified for the person with communication impairment, so they are able to function as safely and independently as possible within their community
- Facilitating people with dementia to have equal access to services promoting rehabilitation and enablement ensuring information is provided in an accessible format to ensure individuals are involved in every aspect of decision making
- ***Peer Support***
- Support to individuals, their conversational partners and the wider community in adopting a fully person centred approach to care by developing peoples knowledge and skills in communication strategies
- ***Planning for future care***
- Equality of access to communication support
- Longer living at home (avoiding moving to specialist costly settings) by reducing social isolation, reducing challenging behaviour, increased confidence in social situation

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A way forward together & in partnership

AHP Dementia Networks exist in most HSCPs – opportunities to link?

Shared education opportunities to ensure all agencies work together to optimise support and rehabilitation given to those living with dementia?

Working with you all to review access to AHPs when a person has been diagnosed

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Next steps and requests for future agenda items

Karen Thom

Enabling health and
social care improvement

Thank you – keep in touch

Focus on Dementia Team	his.focusondementia@nhs.scot

Date	Time	Venue
08 June 2022	10am-12pm	MS Teams
07 September 2022	10am-12pm	MS Teams
07 December 2022	10am-12pm	MS Teams