

Are patients being told about research opportunities?: An Audit

Tees, Esk and Wear Valleys Miss **NHS Foundation Trust**

Kavindu Appuhamy (FY2 Doctor)¹ Amanda Leigh (Psychiatric Cons) ¹

Chris Clarke (Cons Clinical Psychologist) ¹

Sarah Morris (Clinical Research Practitioner)¹

¹Tees, Esk and Wear Valley (TEWV) NHS Foundation Trust, UK

Background:

- Dementia is a huge contributor to disability and health burden in the UK with over 850,000 people currently living with it. [1]
- Research in dementia continues to be vital as we aim to find out more about prevention, diagnosis and treatment of this devastating disease.[2]

Evidence base	Criterion	Standard
Dementia Care Pathway – Clinical Standard 2	Newly diagnosed dementia patients should be signposted about research opportunities e.g. Join Dementia Research (JDR)	100%
Dementia Care Pathway – Clinical Standard 4	Written information about JDR is given to the patient post-diagnosis	100%
Dementia Care Pathway – Clinical Standard 4	Patients who express interest in partaking in research should be referred to the R&D department	100%

Aims:

To identify if dementia patients were being adequately signposted towards the research opportunities available to them during their diagnostic appointment

Methods:



10 patients from each service were included in the sample (n=30) with data collection over a period of one month

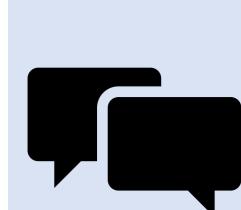


Keyword search was used in PARIS casenotes to identify documentation of conversations of research opportunities



Relevant information about research discussion and JDR referrals was gathered in a pre-defined data collection tool

Results:



Discussion regarding research opportunities had only been documented in 23% of diagnostic appointments (nearly all of these were in the clinic setting).

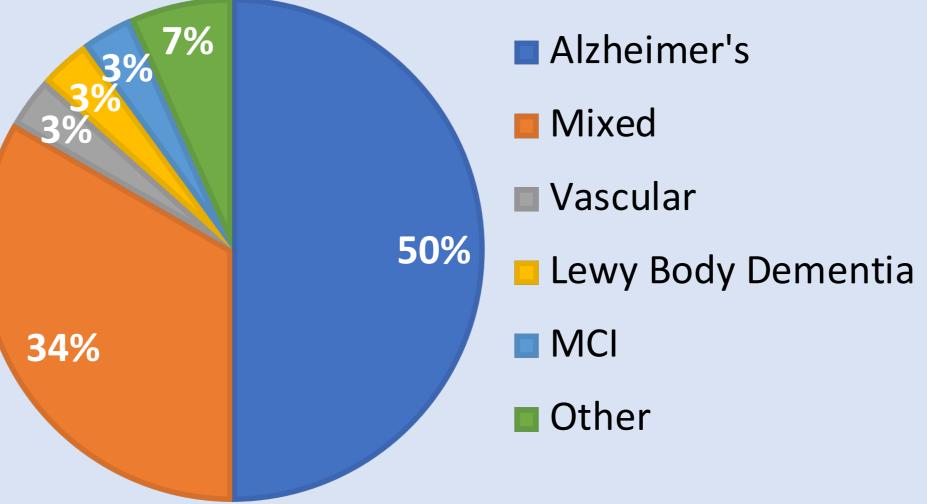


5/7 patients who had discussions, consented to their details being shared with R&D, of which 4 were referred to JDR

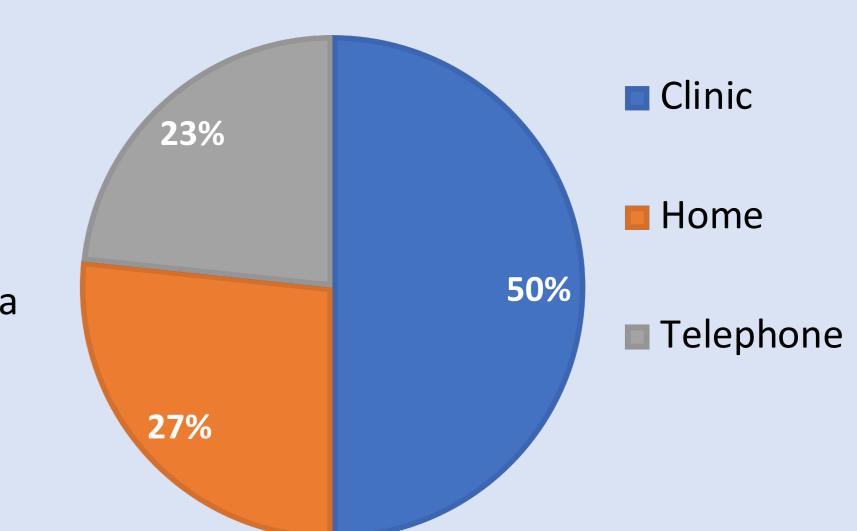


Only 10% of patients received written information about R&D before referral had been made (more received information after consenting to referral)

DIAGNOSIS



SETTING OF APPOINTMENT



Conclusion:

The number of appointments where research is being discussed falls well below the 100% compliance that is expected from the DCP.

More efforts therefore need to be made to encourage and remind clinicians of the importance of signposting, especially given that there proves to be a high likelihood that when the topic is broached, patients will consent to referral, which will significantly improve recruitment rates across the trust.

Recommendations:



Lack of documentation across all teams - difficult to know if discussions have been had or not without clear notes if not, why not?



Need to ensure patients are informed about research opportunities and briefly outline of what this could entail



Ensure clinics are well stocked with JDR leaflets to provide to all patients, post-diagnosis

References:

- [1] https://www.dementiastatistics.org/statistics/numbers-of-people-in-the-uk/
- [2] https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/dementia-research