






## RESEARCH ARTICLE

# A national open-access research registry to improve recruitment to clinical studies

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## Abstract

**Introduction:** Barriers to recruitment for dementia studies are well documented. As part of the UK government's Dementia 2020 strategy, a nationally consistent system to increase public engagement and participation in research was launched in February 2015.

**Methods:** We describe the development of the "Join Dementia Research" registry, including evolution of policy, involvement of people with dementia in co-production, data requirements, governance, technology, and the impact on study recruitment and what factors may have contributed to the services success.

**Results:** The UK-wide online, telephone, and postal service has registered 47,071 volunteers, with 33,139 people (67.9% of all volunteers) taking part in 378 studies, with 49,954 total study enrolments. This has taken place across 295 research sites, involved 1522 researchers, and resulted in 134 peer-reviewed publications.

**Discussion:** Public registries of individuals interested in research, with user-provided data enabling basic phenotyping, are effective at increasing public engagement with research and removing barriers to study recruitment. Deeper pheno/genotyping could be undertaken to improve matching, but how and when that information is collected will be a key factor.

## KEYWORDS

Alzheimer's disease, clinical trial recruitment, consent-for-approach, consent-for-contact, dementia, online registry, public engagement, registries, registry, research participation, research recruitment

## 1 | INTRODUCTION

Dementia is a global problem with more than 50 million people living with dementia worldwide<sup>1</sup> and yet research studies struggle to recruit participants and, in the case of pharmacological trials, retain participants.<sup>2,3,4</sup> Under-recruitment increases risks and costs of drug development<sup>5</sup> and limits the impact of research as results may not be applicable beyond the small group studied.<sup>2,4</sup>

Barriers to research<sup>2</sup> include low trial awareness, language, logistics of attending research centers, perceptions of research, and cultural factors that lead to underrepresentation of minority groups. Barriers more specifically related to dementia studies are comorbidities, lack of capacity to give informed consent,<sup>2</sup> and significant study partner requirements. Another barrier highlighted in some studies from health-care staff is a lack of an effective referral network.<sup>6</sup> "Gatekeepers," such as doctors or nursing staff, may exclude patients from studies

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**RESEARCH IN CONTEXT**

- 1. Systematic Review:** The authors reviewed the literature using traditional sources (PubMed and Google Scholar) and had personal communications with authors and conducted analysis on data held within the Join Dementia Research (JDR) registry.
- 2. Interpretation:** JDR has successfully registered more than 49,000 people, with > 33,000 going on to take part in at least one study. JDR has been widely adopted with more than 1500 researchers using the service across 295 sites to enroll to 378 studies. This demonstrates the feasibility and utility of a light phenotypic register to recruit to a wide range of clinical studies; and validates a model for a national, open-access online research register.
- 3. Future Directions:** Improving depth of phenotyping through pre-screening questionnaires, linkage to electronic health records, and inclusion of online cognitive testing should improve pre-screening capabilities, reduce screen failure rates, and increase researcher use, further increasing the benefits and impact of the register.

independently of the exclusion criteria,<sup>4</sup> while also being under pressure to balance recruitment for simultaneous trials leading to competition for participants.<sup>7</sup>

In response to these barriers, patient registries have been used in many diseases to support research<sup>8</sup> and registries have evolved to support dementia research.<sup>9</sup> We report the development, implementation, and initial outcomes of the Join Dementia Research (JDR) service, a national dementia research registry in the UK.

**2 | METHODOLOGY**

JDR was developed by the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) Coordinating Centre team at University College London.<sup>10,11</sup> JDR was delivered in partnership with the UK Clinical Research Network Coordinating Centre team at the University of Leeds and supported by two major third-sector dementia research funders, Alzheimer's Society and Alzheimer's Research UK (and subsequently ^), and the UK health research regulator, the Health Research Authority.

**2.1 | Public involvement**

People affected by dementia, both those with a diagnosis and family carers, were central to the development and delivery of JDR. An "insider" approach<sup>12</sup> was adopted, with people affected by dementia involved in the co-production of all areas of the project (consultation, champions group, design team membership, steering group

membership, and individual advocacy) used to support effective involvement depending on the requirements and, to some degree, time and resource constraints. Advocacy for the need for a registry by members of the Alzheimer's Society Research Network<sup>13</sup> (then called Quality Research in Dementia) played an important role in gaining support for JDR from policymakers.

As JDR was a novel approach to public engagement and research recruitment, the development of all aspects of the service required the generation of new knowledge in partnership with a range of stakeholders, including people with dementia, family carers, researchers, clinicians, designers, developers, and policymakers. People affected by dementia were an equal component of the co-production of the business processes, governance arrangements, branding content, and technology. For the launch of JDR in February 2015, a network of public champions across the UK were media trained and supported to deliver regional and national public relations. This "Champions" network continues to play a vital role in the promotion of the service through press and social media engagement nationally.

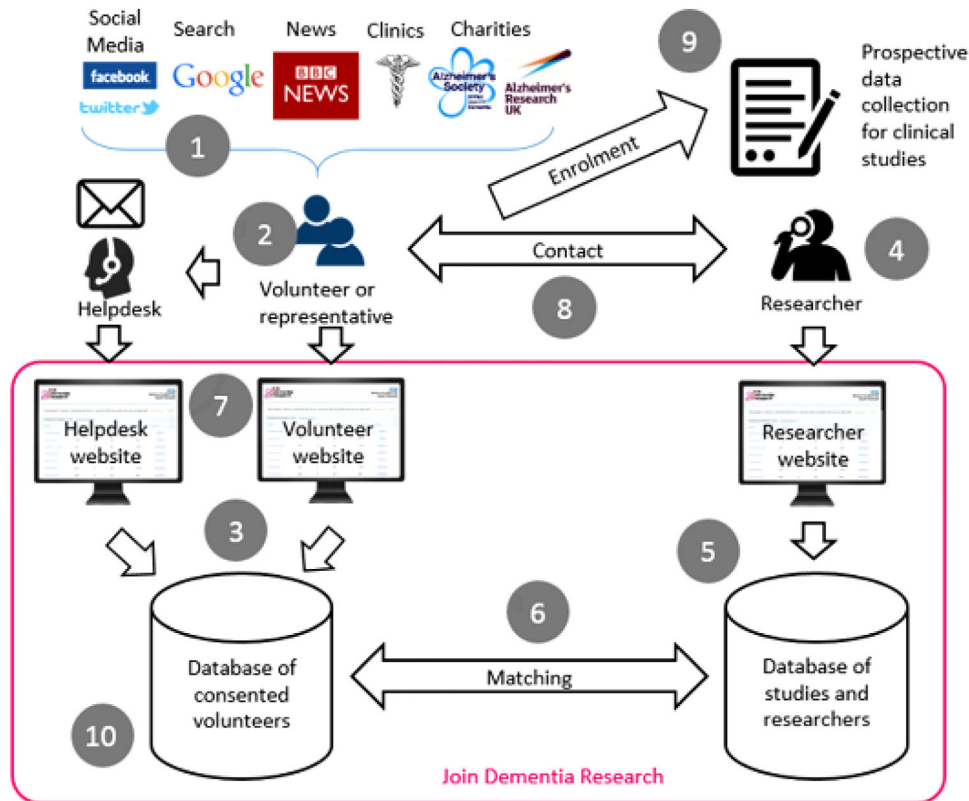
**2.2 | The registry**

JDR is a matchmaking service between people interested in participating in dementia research and researchers. It is provided through a partnership between the National Institute for Health Research (NIHR) in England, Alzheimer's Research UK, Alzheimer's Society, and Alzheimer Scotland. The service and dataset are illustrated in Figure 1.

Any member of the public aged 18 years or over, with or without dementia, is encouraged to register via the website, charity-managed telephone helplines, or a free postal application form. Registration involves providing 18 mandatory data items, and up to 30 optional items, depending on diagnosis. Data in JDR is maintained as accurate by the volunteers and by researchers who are responsible for recording any changes to a volunteer's data when they are speaking to them about a specific study. Researchers define the matching criteria for their studies based on the study protocol and volunteer-provided data fields—supporting multiple study arms and sites for the same study. The unique element of this service is the "real-time" matching, which gives researchers direct access to volunteers, who are contacted via telephone and e-mail for further screening. At any one time, 300+ studies, operating at 100+ different sites, can be simultaneously using the service, and drawing on the same volunteers. Moreover, volunteers are made aware of all studies for which they are provisionally eligible.

**2.3 | Promotion**

The primary responsibility for national promotion of JDR sits with the NIHR Clinical Research Network Coordinating Centre (CRNCC), three charity partners, and the National Health Service (NHS). A network of public JDR Champions is supported by the CRNCC and supports communications locally and nationally. Promotional activities aimed at volunteers have three core audiences: the general public including people with dementia, health service staff, and organizational partners.



**FIGURE 1** Schema of registry functions

## 3 | RESULTS

### 3.1 | Volunteer numbers

Since its national launch in February 2015 (including an earlier testing phase), the total number of volunteers by end of June 2021 was 49,474, of whom 5733 had dementia (Figure 2). The mean rate of total registration has been 588 volunteers per month (652 prior to start of the COVID-19 pandemic), with a range of 141 to 2487 per month (Figure 3). Prior to the pandemic, the rolling average number of registrations per month has seen a downward trend for people without a diagnosis of dementia, while slightly increasing for people with a diagnosis. There has been a corresponding rise in the proportion of volunteers with dementia from an average of 7.1% across the first year to 11.5% in June 2021. The COVID-19 pandemic has had a dramatic effect on volunteering rates, primarily due to NHS services moving to online or closing during periods of national lockdown.

### 3.2 | Source of volunteers

Eighty percent of volunteers register online, with 10% via the charity helplines and 10% via post. Table 1 summarizes the source of volunteers from different channels/activities since JDR was launched. The larger sources of all volunteers have been health-care, including general practitioners, provider trusts, and pharmacies (23%); the charity partners (22%); and news items from public relations activities (18%;

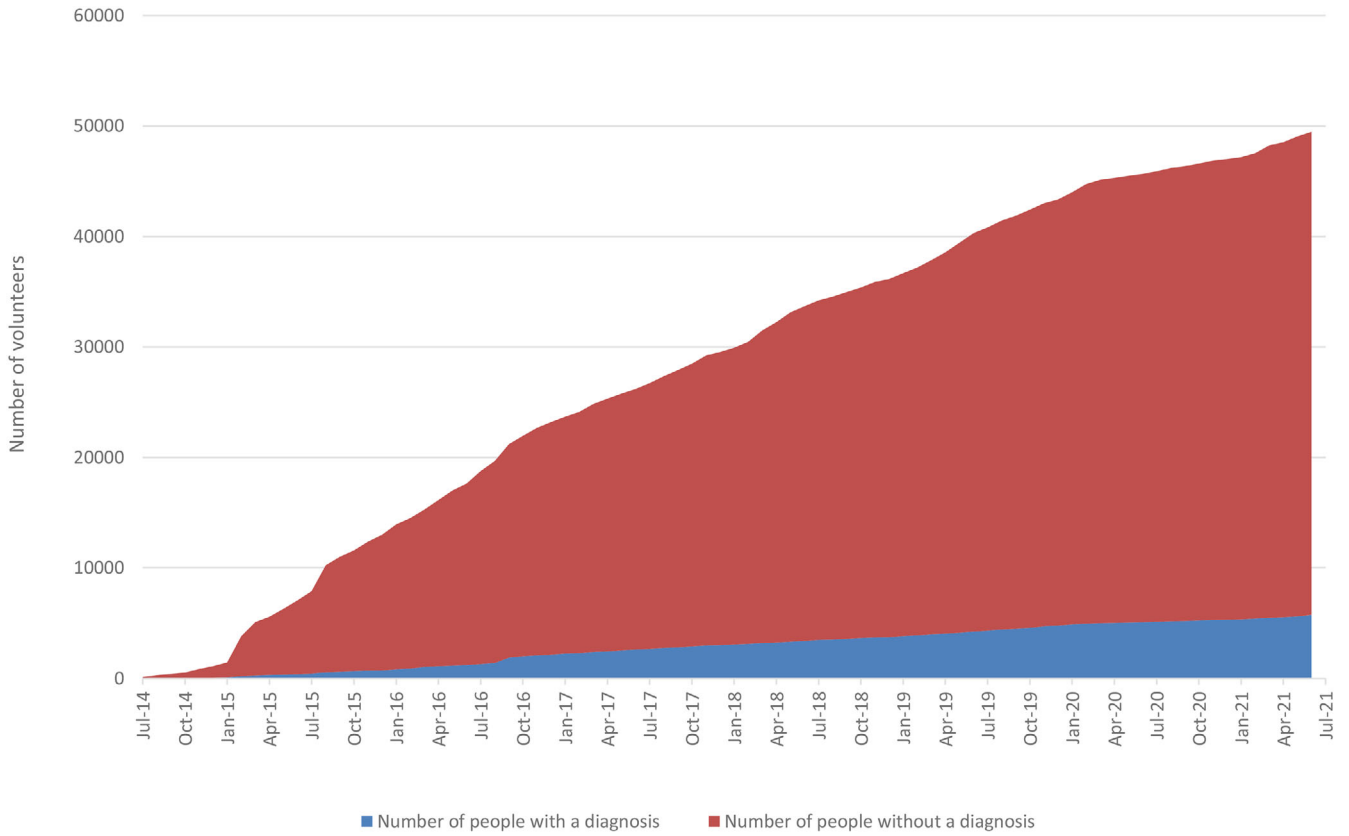
Table 1). These data are self-reported by volunteers when they register, and the source categories are not necessarily mutually exclusive. As such, they provide an indication of source rather than an absolute measurement.

### 3.3 | Volunteer characteristics

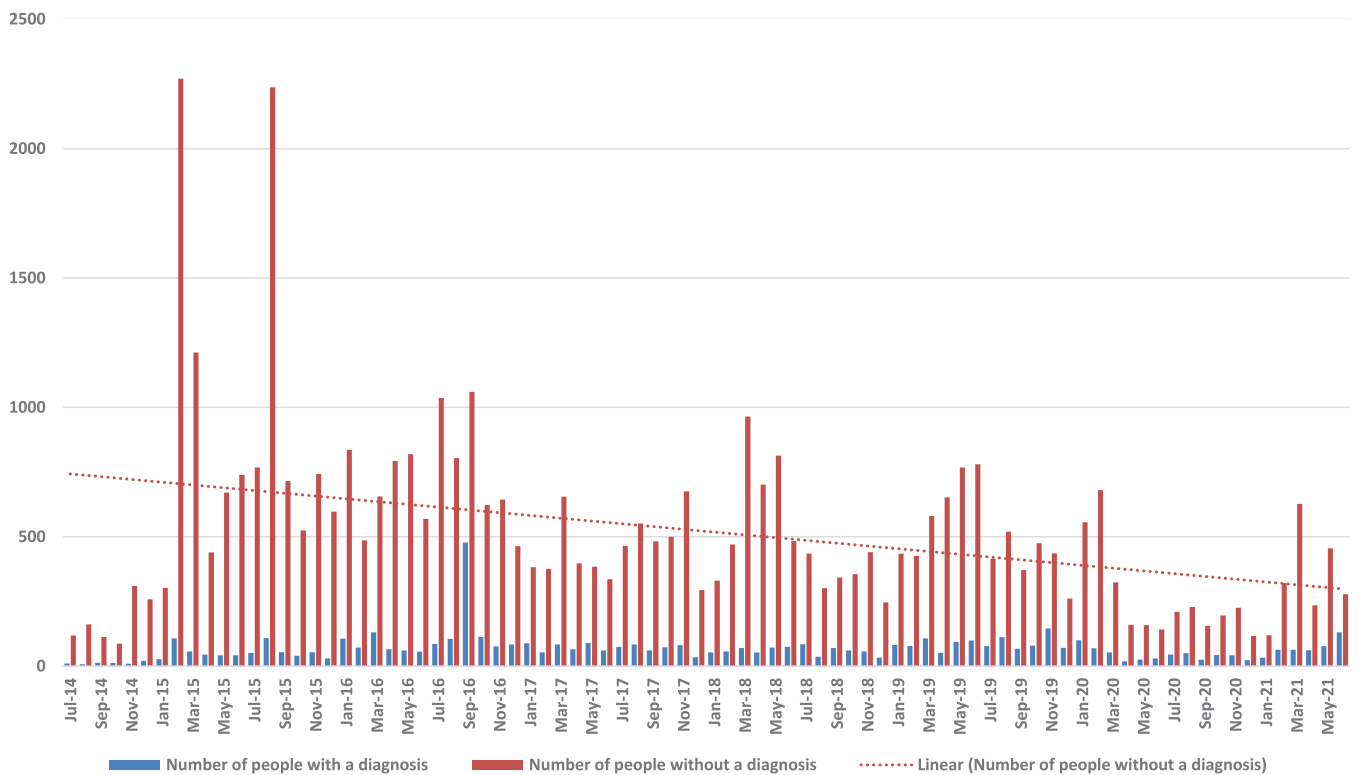
Volunteers can select multiple diagnoses from a pre-defined list when registering. Table 2 shows the breakdown of diagnoses recorded. These diagnoses are self-reported and non-verified through clinical data or further investigation; however, diagnoses will be confirmed by the researcher for a specific study. A further 2407 volunteers have registered as having dementia but not being aware of their specific diagnosis (not included as “people with dementia” in the data reported in this article). Of volunteers without dementia, 74% (32,407) are women and 26% (11,251) are men (0.018% do not identify as male or female). Volunteers with a diagnosis are as likely to be men (2880, 51%) as women (2844, 49%).

### 3.4 | Research portfolio

JDR has seen wide uptake across the UK dementia research community with 1522 researchers trained to use the system across 295 research sites (75% NHS organizations, 20% universities, 4% private research sites, and 2% charitable research sites). A total of 488 studies



**FIGURE 2** Cumulative number of volunteers registered from July 2014 to June 2021, showing those with a diagnosis and those without



**FIGURE 3** Monthly volunteer registration from July 2014 to June 2021, broken down to volunteers with a dementia diagnosis and those without a diagnosis

**TABLE 1** Source of volunteers July 2014 to June 2021

	With dementia		Without dementia		Total	%
Health-care provider	2371	41%	9004	21%	11375	23%
Charity partner	1196	21%	9583	22%	10779	22%
News article/PR	685	12%	7226	17%	7911	16%
Other/unknown	507	9%	5307	12%	5814	12%
Internet search	509	9%	4263	10%	4772	10%
Friend recommendation	178	3%	2695	6%	2873	6%
Event/exhibition	119	2%	2163	5%	2282	5%
Social media	115	2%	2196	5%	2311	5%
Dementia friends	31	1%	1168	3%	1199	2%
Local dementia groups	22	0%	136	0%	158	0%
Total	5733	100%	43741	100%	49474	100%

Note: This is a snapshot of volunteer registration source at the time of creation—volunteers who have joined and left during the period covered would not be represented in these figures.

**TABLE 2** Diagnosis of volunteers with dementia

Diagnosis	Total	Total
Alzheimer's disease	3190	50%
Vascular dementia	932	15%
Mild cognitive impairment (MCI)	888	14%
Mixed dementia	616	10%
Dementia with Lewy bodies	188	3%
Frontotemporal dementia (FTD)	287	5%
Alcohol-related dementia (including Wernicke-Korsakoff Syndrome)	30	0%
Dementia in Parkinson's disease	67	1%
Other dementias	174	3%
Dementia in Huntington's disease	3	0%
	6375	100%

Note: Volunteers may indicate multiple diagnoses, for example, Alzheimer's disease + vascular dementia.

have used JDR; 386 (79%) studies were health-care related, and 102 (21%) were social-care related. Seventy-six percent of studies include people with a diagnosis of dementia, 23% include carers, and 46% include people without a diagnosis of dementia.

### 3.5 | Study recruitment via JDR

JDR supports recruitment to all ethically approved dementia studies, from PhD projects to large surveys, and academic studies to commercial pharmaceutical trials. Of the 478 studies added to JDR, 378 (79%) have successfully recruited via the service.

A total of 33,139 individuals have been recruited into studies via the service (66.9% of all volunteers), and there have been a total of 49,954

study enrolments—with volunteers having participated in between 1 and 13 separate studies (Table 3).

Most enrolment has been to large online observation studies, with the top single recruiting study accounting for 9869 (19%) of all enrolment, the top 5 studies 23,500 (47%), and top 10 studies 33,458 (66%). Previous analysis of JDR's impact on interventional clinical trials found that in its first 3 years, JDR enrolled 19% of all participants into commercial contract trials in the UK.<sup>14</sup>

### 3.6 | Publications

Chief Investigators for the 187 closed studies having used JDR were contacted about their publications from those studies. A total of 55 Chief Investigators responded to the request and reported that of the 55 studies, 134 publications have been published in peer-reviewed journals, all of which recruited through JDR.

### 3.7 | International context and approaches

JDR is not unique. In the United States the Alzheimer's Association "Trial Match" service launched in 2010, and since then numerous other registers have been developed by governments, charities, and research institutions.<sup>25</sup> In 2020, the Trial Match service reported that it has supported recruitment to 460 studies, the Brain Health Register 25 studies, and the Alzheimer's Prevention Registry 80 studies.<sup>26</sup> Each of these systems takes a slightly different approach, with some also acting as longitudinal studies with data capture, or recruiting via passive distribution of study information.

## 4 | DISCUSSION

JDR was established in response to the call in the UK Prime Minister's challenge on dementia<sup>15</sup> for a nationally consistent system to enable people, if they wish to do so, to participate in research. It has proven to be highly successful in supporting study recruitment, and is effective at using all available volunteers. Furthermore, the JDR model meets the "challenge" insofar as it provides free, open access to both researchers and volunteers nationally. There are a number of factors that have contributed to its success.

1. The JDR model for inclusion of studies and access by researchers provides the minimum possible barrier to access for researchers while retaining appropriate governance. There has been wide uptake by researchers as well as a larger number and broader range of studies being supported than in other published examples of similar registries.<sup>16,17,18,19</sup>
2. From a participant perspective, JDR provides information about all the ways in which a volunteer can contribute to research, and about all relevant research opportunities open to them.

**TABLE 3** Recruitment to studies by volunteers by study count

Number of studies	1	2	3	4	5	6	7	8	9	10	11	12	13
Number of volunteers having participated	22806	6605	2243	809	367	175	66	27	18	11	9	0	3
%	45.65	13.22	4.49	1.62	0.73	0.35	0.13	0.054	0.032	0.021	0.016	0	0.0054
Total volunteers enrolled into 1 or more studies	33139												
Total number of studies enrolments	49954												
Total number of JDR volunteers	49474												
% of volunteers recruited into 1 or more studies	66.9%												

- JDR offers researchers real-time matching to potential study participants. This achieves more than simple sign posting and provides increased choice for the participants. This “live” matching means that hundreds of researchers, working on single or multi-site studies, across hundreds of research sites can simultaneously access the system and the same pool of volunteers. JDR manages volunteer exposure to these research teams, while also facilitating notes and contact management—giving both the researchers and patients a real choice.
- JDR has attracted a relevant population to support current dementia research needs: both people with and without a diagnosis. For volunteers that recorded one or more specific diagnoses, the relative prevalence of diagnoses is approximately what might be expected from the prevalence in the general population, although there is under-representation of people with dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), and Parkinson's disease dementia (PDD). One reason for this may be that the largest source of volunteers with dementia is NHS memory clinics, which are mainly old-age psychiatry-led services. A significant proportion of people with DLB, FTD, and PDD may be diagnosed in neurology-led clinics provided in acute hospital trusts, in which there has been less work to promote JDR.
- JDR conducted a significant amount of work to determine the information it would need from volunteers, to support study matching, while keeping the registration process quick and simple. It may be possible, like other registers, to collect additional information and to regularly collect further information. While some volunteer data remain constant, for example, age, sex, etc., the most important information used in matching, for example, stage of disease or other health conditions, is constantly changing. The JDR approach is to only collect the information needed for matching at the point it is actually required. This ensures only essential data are collected, and reduces duplication of effort, as most studies will conduct additional data gathering and screening once a potential volunteer is identified—even if the data are available from JDR.

JDR has attracted large numbers of volunteers without a dementia diagnosis in an age range that makes them valuable for screening for high risk and pre-clinical studies. There are several ongoing initiatives globally to create cohorts in a similar population to support prevention and early intervention research.<sup>16,17,20,21,27</sup> These studies typically seek deeper phenotypic and genotypic characterization of par-

ticipants than is available on JDR. However, to date, collection of additional data has not resulted in increased recruitment to trials. A next step for JDR is to consider the value of collecting additional data, or integrating with other systems that already have these data, for example, NHS Records, Dementias Platform UK. However, the aim will be to do this digitally through tools such as online cognitive assessments, specific to each study through the form of pre-screening assessments.

The number of people registering with mild cognitive impairment (MCI) is particularly low, and while the number of volunteers with dementia has been sufficient in some parts of the country, more are needed to meet demands of the latest studies. The low number of registrants identifying as having MCI could be due to the varied use of this diagnosis in the UK, and/or public perception of whom the service is for, due to it being called Join *Dementia* Research.

Despite investment in developing social media channels and using those of the charity partners, registrations via social media have not increased, nor have other sources that social media might impact indirectly, such as registrations via internet searches. Social media channels are highly competitive and may require increasing resources in both volume and expertise to deliver the same impact over time. It is noted, however, that the highest spike in registration of those with a diagnosis was in September 2016 related to media coverage of the aducanumab trial. By contrast, registration via health-care providers has grown year on year as a source of volunteers. This may be explained by the time it takes to penetrate this channel, with implementation through regional and local organizations, training of health-care staff, and development of supporting tools and materials all taking time to develop and build.

In initial pilot work prior to the development of JDR, rate of registration of people with a diagnosis was 30%, although this was a two-stage consent process and was recorded directly into a local clinical system, which may be a key facilitator compared to current JDR practice in which volunteers have to self-register.

An alternative way to increase rates of registration of people with dementia is to integrate a simple one-stage consent process into core clinical pathways, with consent recorded electronically in electronic health records and shared with JDR. Rates of consent have been shown to be as high as 73% for patients consenting to register in mental health trusts in England.<sup>22</sup>

There are a range of external factors impacting the success of JDR, such as social factors, including perceptions and public attitudes to research, health-care professionals, and researchers. Many



people believe that dementia is a normal part of aging<sup>1</sup> so may not see it as an important focus of research. There are several existing local research recruitment mechanisms, including local registries, that may act as a barrier to uptake of JDR. While these support recruitment to local studies, they do not provide the breadth of access and choice to patients. Researchers may also take a “study-centric” approach, using local mechanisms to recruit to a study, which also limits patient access to research and choice.

Registrations of people with and without diagnosis have reduced significantly as a result of the COVID-19 pandemic. One reason for this, particularly relating to registration of people with dementia, is memory clinics being conducted virtually during the initial UK lockdown and the resulting reduction in diagnosis rates.<sup>23,24</sup> The refocus on delivery of COVID-19 research across the NIHR has also likely reduced the volume of marketing activity reducing the number of all registrations (see Figure 3). However, JDR has contributed to COVID-19 research, recruiting 6719 into COVID-19-related dementia studies. Additionally, in the long term, the perceived importance of research and its value has improved in the last 18 months; the Wellcome Trust Monitor report from 2020 shows that two in three people now feel health research has positively impacted their life.<sup>26</sup>

JDR is a live service that has had a sizeable impact on the dementia research landscape in the UK when judged by the scale of uptake (number of people registering and use by researchers), and the level of impact (number of people enrolled into studies and the proportion of overall enrolment delivered by JDR). However, it has some limitations such as richness of phenotypic data, which will need to be addressed if it is to continue to meet the needs of dementia research and be sustainable in the future.

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## CONFLICTS OF INTEREST

The authors report no conflicts, other than the NIHR infrastructure grant to create the JDR system.

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