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 1,522 researchers, and resulted in 134 peer-reviewed publications.

Discussion: Public registries of individuals interest 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.

Key words

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

1. Introduction

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

Barriers to research [2] include low trial awareness, language, logistics of attending research centres, 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 [2], and significant study partner requirements. Another barrier highlighted in some studies from healthcare staff is a lack of an effective referral network [6]. 'Gatekeepers', such as doctors or nursing staff may exclude patients from studies independently of the exclusion criteria [4],

whilst also being under pressure to balance recruitment for simultaneous trials leading to competition for participants [7].

In response to these barriers, patient registries have been used in many diseases to support research [8] and registries have evolved to support dementia research [9]. 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 [10] [11]. 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 Alzheimer Scotland), 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 [12] 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) employed 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 [13] (then called Quality Research in Dementia) played an important role in gaining support for JDR from policy makers.

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 policy makers. 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 email 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 organisational partners.

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 5,733 had dementia (Figure 2). The mean rate of total registration has been 588 volunteers per month (652 prior to start of the pandemic), with a range of 141 to 2,487 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

80% of volunteers register online, with 10% via the charity helplines and 10% via post. Table 1 summarises the source of volunteers from different channels/activities since JDR was launched. The

larger sources of all volunteers have been healthcare, including GPs, 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 2,407 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 paper). Of volunteers without dementia, 74% (32,407) are women and 26% (11,251) are men (.018% do not identify as male or female). Volunteers with a diagnosis are as likely to be men (2,880, 51%) as women (2,844, 49%).

3.4 Research portfolio

JDR has seen wide uptake across the UK dementia research community with 1,522 researchers trained to use the system across 295 research sites (75% NHS organisations, 20% Universities, 4% private research sites and 2% charitable research sites). 488 studies have used JDR; 386 (79%) studies were health care related, and 102 (21%) were social care related. 76% 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 successful recruited via the service.

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 one and thirteen separate studies (Table 3).

Most enrolment has been to large online observation studies, with the top single recruiting study accounting for 9,869 (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 [14].

3.6 Publications

Chief Investigators for the 187 closed studies to have 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 approached

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 [25]. 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 [26]. Each of these systems take 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 [15] 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 utilising all available volunteers. Furthermore, the JDR model meets the 'challenge' in so far 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 [16] [17] [18] [19].
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.
3. 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, whilst also facilitating notes and contact management – giving both the researchers and patients a real choice.
4. 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.

5. JDR conducted a significant amount of work to determine the information it would need from volunteers, to support study matching, whilst keeping the registration process quick and simple. It may be possible, like other registers, to collect additional information and to regularly collect further information. Whilst some volunteer data remains constant e.g. age, gender etc. the most important information used in matching e.g. stage of disease, 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 [16] [17] [20] [21]. These studies typically seek deeper phenotypic and genotypic characterisation of participants 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 which already have these data e.g. 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 whilst 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 resource 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 healthcare 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 organisations, training of healthcare 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 with current JDR practice where volunteers have to self-register.

An alternate 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 [22].

There are a range of external factors impacting on the success of JDR. Social factors, including perceptions and public attitudes to research, healthcare professionals and researchers. Many people believe that dementia is a normal part of ageing [1] so may not see it as an important focus of research. There are a number of existing local research recruitment mechanisms, including local

registries, which 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 reduction in diagnosis rates [23] [24]. 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 6,719 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 on their life [26].

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, that 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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Figures & tables

Figure 1: Schema of registry functions.

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.

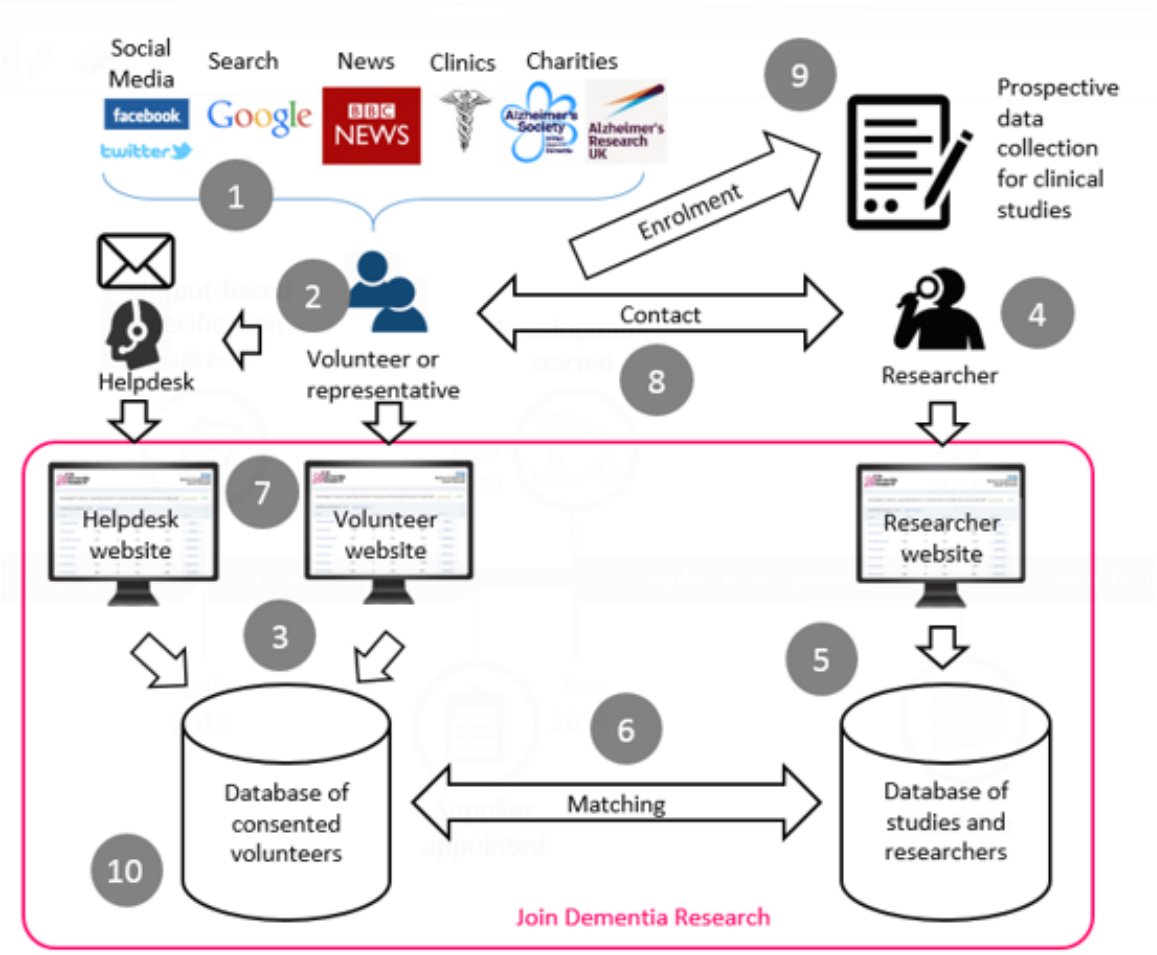
Table 1: Source of volunteers July 2014 to June 2021, showing number and percentage of volunteers with dementia and without dementia recruited through different channels (healthcare providers, charity partners, news article / PR, other / unknown, internet searches, recommendations from a friend, events / exhibitions, social media, dementia friends, and local dementia groups).

Table 2: Diagnosis of volunteers with dementia, showing the number and percentage of volunteers by diagnosis (Alzheimer's Disease, Vascular Dementia, Mild Cognitive Impairment (MCI), Mixed Dementia, Dementia With Lewy Bodies, Frontotemporal Dementia (FTD), Alcohol related Dementia (including Wernicke-Korsakoff Syndrome), Dementia in Parkinson's Disease, Other Dementias, and Dementia in Huntington's Disease).

Table 3: Enrolment from JDR into studies broken down by enrolments and individual participation and study count. From July 2014 to June 2021.

Figure 1

Figure 1: schema of how the registry works



1. Anyone over 18, with or without dementia, who is resident in the UK can register via a website provided by the NIHR, telephone helplines of the three voluntary sector partners, or by postal application form. Registration can either be completed by someone registering themselves or by a carer or relative of someone with dementia, provided they have their consent or hold lasting power of attorney on health and welfare grounds.
2. The use of JDR by researchers is managed by the NIHR Clinical Research Network. The national JDR team is responsible for managing the inclusion of studies, assigning accounts to Regional Administrators. Only a validated, trained research user associated to a specific study site is able to access the results of a study site match, and from there they are able to access the details of volunteers matching that study at that site.
3. The criteria for inclusion of a study on JDR is simply that it is a dementia relevant study and has ethical approval to use JDR to recruit. For studies which have their ethics approval prior to applying to use JDR, the Health Research Authority requires the use of JDR as a recruitment channel to be recorded as a non-substantial, non-notifiable amendment. The main route for studies coming onto JDR is via the NIHR portfolio. The national JDR portfolio team will be notified about new studies coming onto the portfolio and automatically assess them for suitability for inclusion on JDR. For non-NIHR portfolio studies, chief investigators can apply to have their study included on JDR by completing a simple form. These studies are then assessed against the same criteria as the portfolio studies. This is an important

aspect of JDR as it is intended to be a 'one stop shop' through which those registering can access a spectrum of research.

4. The data about volunteers and studies are used to match volunteers to research study sites based on inclusion and exclusion criteria defined by research teams when entering studies onto JDR. Volunteers who match the criteria set for the study are allocated to one of the study sites, depending on the criteria used for geographical matching, as set by the research teams.
5. By logging into the volunteer website or via the helpdesk, volunteers can see information about studies they match to and express their interest in particular studies. Volunteers can set alerts so that they are sent notifications of new matches.
6. When registering for the service, volunteers provide their consent for the data they provide to be used to match them to studies, and for researchers working on those studies to contact them. It is research teams who are responsible for initiating the contact with volunteers who match to their studies.
7. If a volunteer decides to take part in a study, the outcome of the recruitment is recorded in JDR but the data collection and study management for any specific study are independent of JDR.

Figure 2

Figure 2: Cumulative number of volunteers registered from July 2014 to June 2021

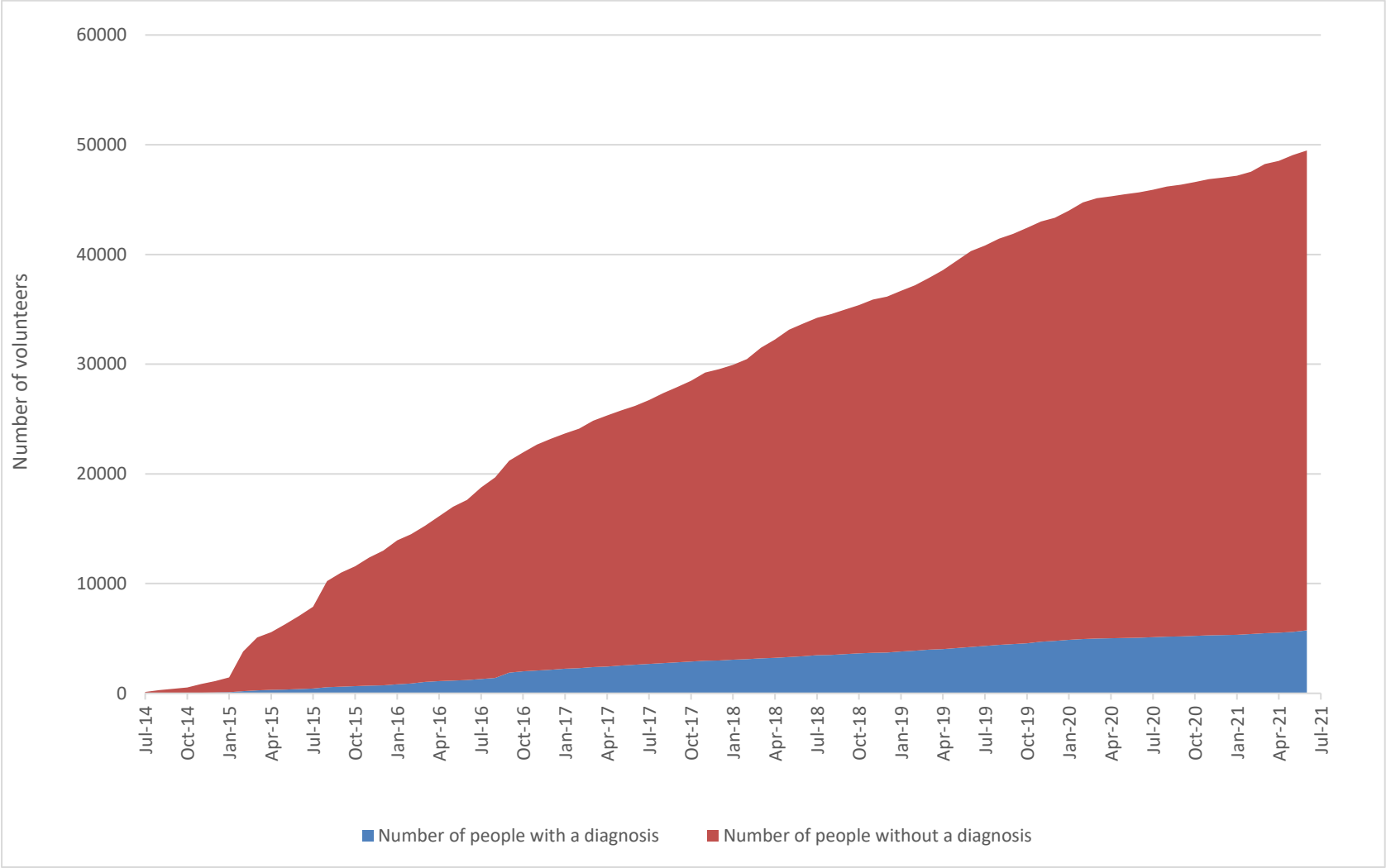
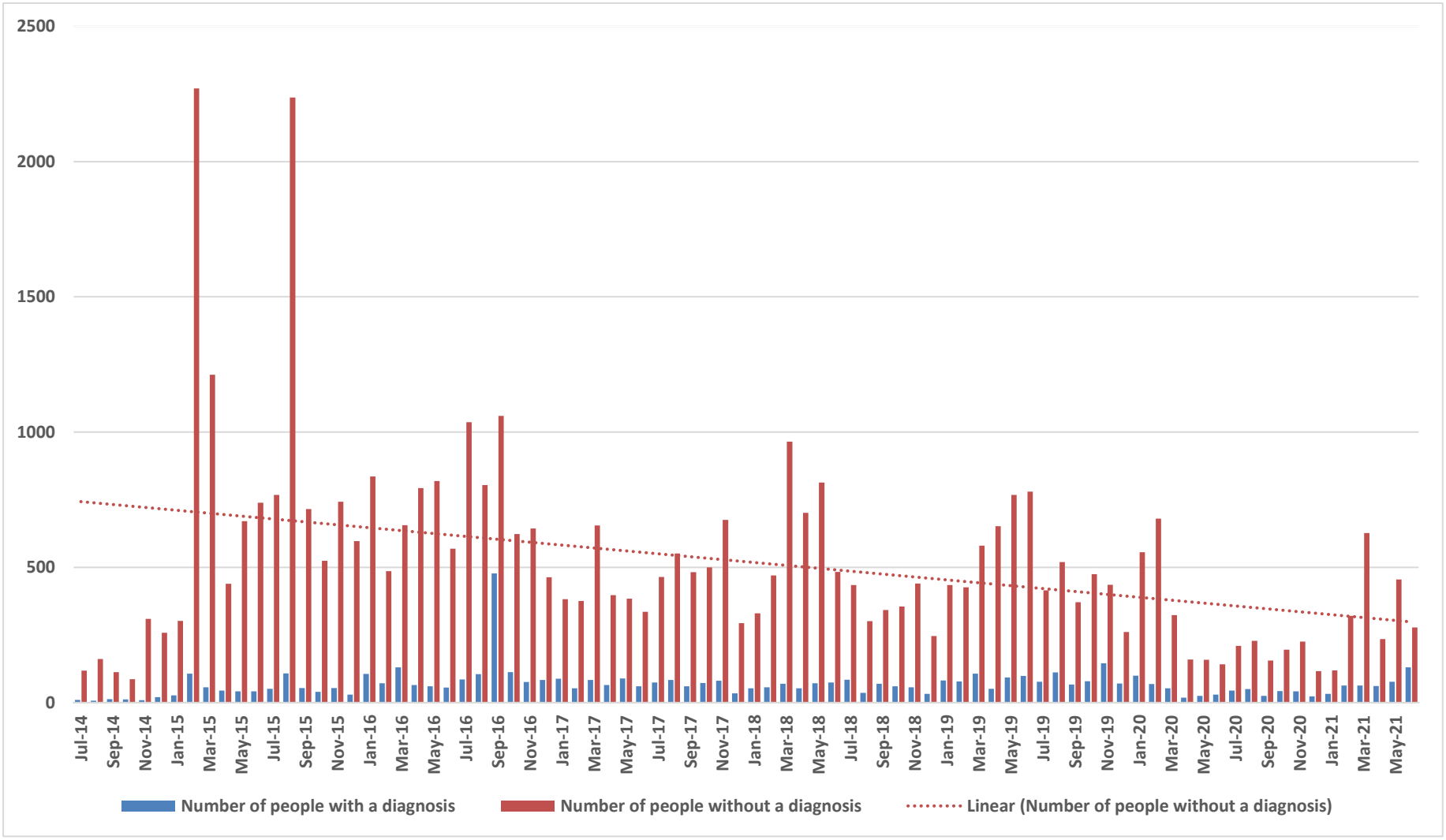


Figure 3: Monthly volunteer registration from July 2014 to June 2021



Tables

Table 1: Source of volunteers July 2014 to June 2021

	With dementia		Without dementia		Total	%
Healthcare 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 snap shot 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 diagnosis e.g. Alzheimer's Disease + Vascular Dementia*

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%												