1. **BACKGROUND**

Join Dementia Research is an IT platform that allows people interested in participating in research into dementia to be matched to suitable research studies. The service is aimed at people with dementia and their carers, but anyone with and without dementia over the age of 18 can register their interest on the website. Join Dementia Research (JDR) aims to increase the extent of research into Alzheimer’s Disease, vascular dementia and other types of dementia. It is delivered in partnership with the National Institute for Health Research, Alzheimer Scotland, Alzheimer’s Research UK and Alzheimer’s Society.

The service aims to enable a greater number of patients to access research more quickly, thereby increasing the speed of research and reducing the cost of recruiting participants. This is thought to lead to more rapid implementation of research findings, increased awareness of dementia, improved diagnosis rates, and consequent improvements in treatment and care for patients. Research that can improve outcomes for people with dementia and carers may also generate cost-effectiveness gains for the health and social care system and for society more generally.

The activity numbers for the service as of June 2017 are as follows:

- 27,946 volunteers registered;
- 7,371 volunteers enrolled in dementia studies;
- 171 NHS, university and commercial research organisations using the system;
- 816 trained researchers using the service;
- 98 research studies currently open to recruitment.

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1. [https://www.joindementiaresearch.nihr.ac.uk/content/howitworks](https://www.joindementiaresearch.nihr.ac.uk/content/howitworks), Accessed 1 June 2017.
3. [https://www.joindementiaresearch.nihr.ac.uk](https://www.joindementiaresearch.nihr.ac.uk), Accessed 9 June 2017.
A new IT platform has been developed for JDR, with improved functionality and user experience for both researchers and participants.\(^4\) This also enables the registration of people with a diagnosis of dementia directly from NHS electronic health records, into the JDR system.

This case study describes a cost-consequence analysis for JDR, which identifies the potential consequences arising from adoption of the innovation, based on the theory of change and assumptions stated. The analysis was developed in spring 2017 and was based on the information and evidence available at the time. The limitations of the analysis were that there were no quantifiable outcome data available in order to conduct a return on investment analysis.

2. **INPUT COSTS**

The development of the new IT platform for JDR cost approximately £1m, funded via an SBRI\(^5\) Healthcare Phase 2 Grant. The estimated cost to implement the new IT platform for the live national JDR service is £500,000. There is an additional cost of £50,000 for each NHS trust that is added to the network and integrated with the JDR platform.

There will be an annual Software as a Service (SaaS) fee for the JDR platform. Estimated SaaS licence costs are approximately £150,000, if JDR is centrally funded through the NIHR.\(^6\) The estimated annual SaaS fee if implemented per trust is £20,000.

3. **OUTCOMES**

There are a number of outcomes of JDR, some of which have the potential to generate economic benefits. By assisting trusts in matching patients with research, the costs of recruitment to research may be reduced. Furthermore, increased participation in research generates income for trusts, and also covers some of the costs of healthcare, in some cases.\(^7\)

A report into the importance of research and the impact and value of the NIHR Clinical Research Network found that, for commercial studies, NHS trusts receive an average of £6,658 in revenue from sponsor companies, and a pharmaceutical cost saving of £5,250 per patient recruited to each clinical study.\(^8\) The report also identified productivity benefits in terms of Gross Value Added (GVA),\(^9\) to the value of £701 per patient per study from academic research activity and £3,914 GVA per patient from commercial research activity.

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\(^5\) SBRI: Small Business Research Initiative.

\(^6\) NIHR: National Institute for Health Research


\(^8\) Ibid.

\(^9\) GVA: a measure of an individual investment, producer, industry or sector contribution to GDP - defined as output minus intermediate consumption.
There are further, intangible benefits which may arise from JDR. Increased awareness of dementia can lead to improved diagnosis and earlier access to treatment and care. Furthermore, staff involved in clinical research often benefit from training offered by the research network or sponsor company. There are also benefits from the process of participation in research, with people affected by dementia reporting that getting involved in research has been an important and valuable experience for them.\(^{10}\) In a recent survey of JDR registrants, two out of three people responding said that JDR had improved their access to research, which equates to approximately 18,000 people to date.\(^{11}\)

The outcome metrics that may be observed from JDR and their proxy values are shown in Table 3.1.

<table>
<thead>
<tr>
<th>Impact</th>
<th>Metric</th>
<th>Proxy value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced cost of research</td>
<td>Cost of recruiting patients into trials: £200 saving per patient recruited</td>
<td>£200</td>
</tr>
<tr>
<td>Economic value from academic research activity</td>
<td>Gross Value Added: £701 per patient per study.(^{12})</td>
<td>£701</td>
</tr>
<tr>
<td>Economic value from commercial research activity</td>
<td>Gross Value Added: £3,914 per patient per study.(^{13})</td>
<td>£3,914</td>
</tr>
<tr>
<td>Increased commercial research income</td>
<td>Research income: estimated as £8,500 per patient per trial.(^{14}) Assuming 10% surplus on trial income (i.e. £850/recruit).(^{15})</td>
<td>£850</td>
</tr>
<tr>
<td>Increased drug offset costs</td>
<td>Drug offset value: £5,250 per patient per commercial trial.(^{16})</td>
<td>£5,250</td>
</tr>
</tbody>
</table>

4. **ECONOMIC ANALYSIS**

The potential costs and consequences from JDR are summarised in Table 4.1. This includes assumptions proposed by the Fellow regarding the proportion of patients registered with JDR that have the potential to accrue the benefits stated. Across trusts providing memory clinic diagnostic services, on average 2,000 people receive a dementia diagnosis per trust per year. It is estimated from the pilot and feasibility work that implementation of the new platform will yield 50% of people with a diagnosis of dementia signing up to JDR.\(^{17}\)

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\(^{10}\) [www.handouthope.today](http://www.handouthope.today) Accessed 2 June 2017


\(^{13}\) KPMG. Ibid.

\(^{14}\) KPMG. Ibid.

\(^{15}\) KPMG. Ibid.

\(^{16}\) NIA Fellow, August 2017

Table 4.1: Costs and consequences of implementing the new platform for Join Dementia Research

<table>
<thead>
<tr>
<th>Costs</th>
<th>Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost to implement the new IT platform:</td>
<td></td>
</tr>
<tr>
<td>i) National JDR service, £500,000;</td>
<td>Recruitment of research participants: estimated £200 saving per patient recruited. Recruiting 20% of patients registering with JDR per trust implementing the system (approx. 200 patients) would deliver savings in recruitment costs of approximately £40,000 per trust per year.</td>
</tr>
<tr>
<td>ii) £50,000 per trust added to the network</td>
<td></td>
</tr>
<tr>
<td>Annual SaaS fee:</td>
<td></td>
</tr>
<tr>
<td>i) £150,000 when centrally funded, or;</td>
<td>Commercial research income: £850 surplus income per patient per trial. Recruiting 5% of patients registering per trust implementing the system (approx. 50 patients), would deliver approximately £42,500 commercial research income per trust per year.</td>
</tr>
<tr>
<td>ii) £20,000 per trust.</td>
<td></td>
</tr>
<tr>
<td>Patient &amp; family outcomes</td>
<td>Drug offset value: £5,250 per patient per commercial trial. Recruiting 5% of patients registering per trust implementing the system (approx. 50 patients), would deliver approximately £263,000 in drug cost offset per trust per year.</td>
</tr>
<tr>
<td>Productivity</td>
<td>Intangible benefits from participation in research. Improved wellbeing due to earlier access to dementia treatments.</td>
</tr>
<tr>
<td>Productivity</td>
<td>Gross value Added: £701 per patient per academic study. Recruiting 20% of patients registering per trust implementing the system (approx. 200 patients) would deliver GVA of approximately £140,200 per trust per year.</td>
</tr>
<tr>
<td>Productivity</td>
<td>Gross value Added: £3,914 per patient per commercial trial. Recruiting 5% of patients registering per trust implementing the system (approx. 50 patients) would deliver GVA of approximately £195,700 per trust per year.</td>
</tr>
</tbody>
</table>

As there are no specific data on the size of the impacts available, it is not currently possible to calculate a return on investment for JDR or conclude whether it is a cost effective or cost saving innovation. It does, however, have the potential to be cost saving from an NHS perspective, bringing both cost savings and potential income for trusts registering with the system.

Using the costs of JDR, it is possible to conduct a threshold analysis, to calculate the extent of healthcare ‘savings’ that would be required to recoup the network cost and the annual SaaS fee incurred by an NHS trust registering with the network. In the first year, there is a cost of £50,000 to add a trust to the JDR network. Thereafter, there is an annual SaaS fee per trust of £20,000.

At a cost of £70,000 in year one, a trust would need to achieve one, or a combination of, the following outcomes:

- Either: 350 participants recruited into research (assuming realisable cost savings per recruit);
- Or: 12 patients enrolled in commercial trials (assuming 10% surplus from trial income of £850 and drug offset value of £5,250);
- Or: 5 patients attracting commercial research income of £8,500 plus drug offset costs.
At a cost of £20,000 per year for year two onwards, a trust would need to achieve one, or a combination of, the following outcomes:

- Either: 100 participants recruited into research;
- Or: 3 patients enrolled in commercial trials (assuming 10% surplus from trial income of £850 and drug offset value of £5,250).

5. **IMPACT ON EMPLOYMENT**

The development of the JDR service has resulted in the employment of approximately 15 people. These posts are involved in the running of the service across its central team, charity helpdesks and in local networks and trusts supporting delivery. The development of the new system resulted in the employment of four people in 2016. Implementation of the new system into the live JDR service will result in the employment of a further five people.

Furthermore, as the aim of JDR is to increase research activity, there is the possibility that there may be increased employment in health research if more trials are undertaken.

6. **CONCLUSION**

The analysis of JDR is currently inconclusive due to a lack of quantifiable outcome data. However, there is potential for sizeable cost savings to the NHS, with evidence that increased research activity brings benefits to NHS organisations in terms of commercial research income and drug offset value, plus additional intangible savings from benefits to patients by their participation in research.

The evidence for these impacts is drawn from good quality evidence in the form of a comprehensive report into the impact and value of clinical research, plus experience from the implementation of the service. It is anticipated that further data on the economic impacts of JDR will be available in the future, as a health economic evaluation is currently being conducted on the service.

The scale of engagement with the service would suggest that the outcomes required to cover the costs of the service (as shown in the threshold analysis), are realistically achievable. A 17% increase in commercial research activity is thought to be immediately feasible, with a potential for £850,000 savings via drug cost offset and £1.38m in commercial research income.\(^\text{18}\)

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\(^\text{18}\) NIA Fellow. April 2017