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# The returns from **arthritis research**

A report prepared by RAND Europe for the Arthritis Research Campaign (arc)



The research described in this report was prepared for and funded by the Arthritis Research Campaign (**arc**).

Cover photos illustrate some examples of Research payback:

(left) **arc**-funded research demonstrates that the use of aspirin and heparin for pregnant women with APS increases the live birth rate by 40% compared to the use of aspirin alone and by 60% compared to no treatment at all.

Photo © Paul Preacher

(right) **arc**-funded research demonstrates that OA of the hip is a condition that arises through the interaction of a predisposition to the disease, and mechanical insults to the hip. It is now accepted by the Industrial Injuries Advisory Council that hip OA in farmers is a prescribed disease, meaning that farmers have become eligible for appropriate compensation payments.

Photo © Kate Bellis

(main picture) Basic research at **arc**'s flagship Institute led to the development of a new category of drugs. Hundreds of thousands of patients worldwide have been treated, of whom 70% experience a significant improvement in their health.

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# The returns from arthritis research

Volume 1: Approach, analysis and  
recommendations

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Prepared for the Arthritis Research Campaign  
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## Executive summary

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The mission of the Arthritis Research Campaign (**arc**) is to improve the lives of people with arthritis. **arc** aims to achieve this mission by raising funds to support medical research into the cause, treatment and cure of arthritic conditions. **arc** is the UK's fourth largest medical research charity, investing £22 million a year in research into arthritis. Currently, clinical and basic scientific research is supported through approximately 400 project grants, programme grants and fellowships in universities and medical schools throughout the UK. **arc** also provides core funding for its two major research institutes, the Kennedy Institute of Rheumatology in west London, and the Epidemiology Research Unit (**arc** ERU) at the University of Manchester.

To mark its 65th anniversary in 2002 **arc** decided to undertake a strategic review that resulted in the publication of a five-year strategic plan, *Research into Practice*. The review was informed by consultations with **arc**'s stakeholders – including trustees, staff, scientists, volunteer fundraisers, donors and people who have arthritis – and concluded that “there seems to be a gap between the aspirations of people affected by arthritis and the ability of science and academia to meet those aspirations”. In order to bridge this gap, **arc** decided to “instigate a system of rigorous retrospective evaluation on work which has already been completed, with a view to identifying opportunities for development”. To inform this commitment, **arc** commissioned this study to:

- review and document the long-term outcomes of **arc** research grants awarded in the early 1990s;
- identify the factors associated with the successful translation of research;
- illustrate the strengths and weaknesses of different modes of funding; and
- identify “good news stories” that **arc** could use in its public engagement and fundraising activities.

The purpose of this volume is to report on the approach, results, conclusions and recommendations arising from an in-depth evaluation of 16 research grants funded by **arc** in the early 1990s. It is supported by a second volume, *The returns of arthritis research. Volume 2: Case studies*, that describes the output and outcomes from the grants. In this executive summary we set out what we did, reporting our key conclusions and their implications for policy.

### Evaluation purpose and approach

This evaluation is intended to improve understanding of how research is translated from “bench to bedside”. It examines the historical development of 16 case study research

grants, and assesses the extent to which different types of funding support might prevent or promote the successful translation of research.

To conduct this inquiry, the research team created a framework that breaks down the process by which research translates into practice. The framework had two elements. The first element is the five payback categories (summarised in Box S.1). The second element is the payback model (illustrated in Figure 2.2, Chapter 2 and summarised in Box S.2). The payback categories and model were adapted from the Buxton and Hanney Payback Framework following interviews with a series of key informants.

Knowledge production
Research targeting and capacity building
Informing policy and product development
Health and health sector benefits
Wider economic benefit

Box S.1: Payback categories

Stage 0:	Topic/issue identification
Interface A:	Project specification and selection (peer review)
Stage 1:	Inputs to research
Stage 2:	Research process
Stage 3:	Primary outputs from research
Interface B:	Dissemination
Stage 4:	Secondary outputs
Stage 5:	Adoption
Stage 6:	Final outcomes

Box S.2: Summary of payback model

Guided by this framework, we conducted case studies of 16 research grants. The case studies were selected from 556 possible grants awarded by arc between 1990 and 1994. In order to allow us to compare the effect of the mode of research support, the type of research and the bibliometric impact of the principal investigators (PIs), we constructed a selection matrix. With the help of the Development Committee, we chose six project grants, three programme grants, three fellowships and four institute grants for evaluation. Our collection of grants contained six basic grants, eight clinical grants and two allied health professional (AHP) grants (classified according to the qualifications of the PIs), with nine “high” impact PIs and seven “mid” impact PIs.<sup>1</sup> With 16 case studies we could

<sup>1</sup> As explained in Appendix A, impact was measured using a range of different bibliometric indicators; “high” impact was the top decile of PIs based on those indicators, and “mid” was the 45–55 percentile.

not expect them to be representative of all arc grants in a statistical sense; however, by using a selection matrix we aimed to produce a set of case studies that mirrored the diversity of arc funding in key dimensions and hence from which could be carefully generalised.

Using the information collected from document and literature reviews, semi-structured key informant interviews and bibliometric analysis, each of the 16 cases was written up as a narrative organised according to the structure provided by the payback framework (Box S.2). Using a common structure facilitates comparative analysis, allowing us, for example, to identify the factors associated with the successful translation of research. We employed two approaches to our cross-case analysis. The first was based on a qualitative assessment of the case studies based on a discussion within the project team of the key observations made by each member of the team. The second involved a novel method of scoring the case studies on the five payback categories.

## Conclusions and implications for policy

The study reached six main conclusions, which we discuss below. However, there are several limitations to our approach, the key issues being:

- whether it is reasonable to use a largely linear framework to structure analysis of the scientific process;
- whether the use of, and generalisation from, case studies, is appropriate;
- biases in the process of selecting our case study grants;
- how to determine whether a specific outcome can be attributed to a particular grant or investigator;
- how to pick a suitable time window for the start of study: a compromise between allowing outcomes to come to fruition and ensuring that records are available and investigators' recall are suitably detailed.

Each of these issues is discussed in more detail in Chapter 4 (section 4.2). By discussing them we do not wish to undermine our conclusions, but to illustrate some of the challenges of evaluating research.

### There is a diversity of research payback

There is strong evidence from our analysis that there is a considerable range of research paybacks and that these would not have been identified without the structured, case study approach employed in this evaluation. The highlights of these paybacks are listed in Table S.1.

Table S.1: Summary of research paybacks

<b>Payback category</b>	<b>Payback</b>	<b>Example</b>
Knowledge production	<ul style="list-style-type: none"> <li>Peer-reviewed publications in the serial literature</li> </ul>	<ul style="list-style-type: none"> <li>302 papers receiving a total of 975 citations per year attributable to case studies</li> </ul>
Research targeting and research capacity	<ul style="list-style-type: none"> <li>Postgraduate research training</li> <li>Subsequent career development of PIs and research assistants</li> <li>The transfer of technical know-how</li> <li>Informing future research studies</li> </ul>	<ul style="list-style-type: none"> <li>28 PhD/MDs from work on the case studies</li> <li>Development of technological know-how in genetic mapping</li> <li>Informed &gt;£2 million Medical Research Council (MRC) randomised controlled trial</li> <li>Use of biologicals as therapeutic targets</li> </ul>
Informing policy and product development	<ul style="list-style-type: none"> <li>Informing recommendations in clinical guidelines and other policy advice</li> <li>Informed development of clinical tests</li> </ul>	<ul style="list-style-type: none"> <li>Recommendation in Royal College of Obstetricians and Gynaecologists (RCOG) guideline on the use of aspirin and heparin for women with antiphospholipid syndrome (APS)</li> <li>Recommendation in Industrial Injury Advisory Council (IIAC) assessment for hip osteoarthritis (hip OA) in farmers to be a prescribed disease</li> <li>Clinical test for a rare type of systemic lupus erythematosus (SLE) and chondrodysplasia type Schmidt</li> </ul>
Health and health sector benefits	<ul style="list-style-type: none"> <li>Improving the quality of life for people with rheumatoid arthritis (RA)</li> <li>Reducing the likelihood of recurrent miscarriages for women with APS</li> </ul>	<ul style="list-style-type: none"> <li>Hundreds of thousands of patients treated with anti-TNF of whom 70% experience a significant improvement in health</li> <li>Use of aspirin and heparin for women with APS increases live birth rate by 40% compared to the use of aspirin alone and by 60% compared to no treatment at all.</li> </ul>
Wider economic benefits	<ul style="list-style-type: none"> <li>Unquantified economic returns resulting from a reduction in days off work and sales of licensed drugs</li> </ul>	

### Individuals translate research

There is good evidence from our 16 case studies that when translation of research into developments of practical value to patients occurs it is largely due to the conviction, effort

and personal networks of a particular investigator, and is not associated with the type or mode of the funding stream or the bibliometric impact of the investigator. This complements previous studies that have shown that encouraging partnership between researchers, practitioners, policymakers and industrialists promotes successful translation.

Therefore, we propose that **arc** introduces two new types of award. “Translation awards” would be topic-focused and directly linked to the translation of a previous piece of **arc**-funded research. “Partnership awards” would be people-focused and provide resources to **arc**-funded researchers to develop networks with potential users of research. This could include supporting secondments to or from commercial and non-commercial laboratories, and participation in policymaking networks. Criteria for translation and partnership would focus on the potential return or payback from translation, the stated route or plan of translation, relevance to **arc**’s strategic aims and, in the case of translation awards, evidence of existing networks.

#### **Short focused projects grants seem to provide value for money**

There is good evidence from our analysis that the payback arising from projects grants is similar to that arising from the other modes of funding. Given that the median value of a project grant is £90,000 (compared to £250,000 for fellowships, £480,000 for programmes and £450,000 for institutes) this indicates that they provide significant value for money. Of all the observations that we have made from our analysis, this was the most unexpected and surprising and illustrates the importance of maintaining a funding mechanism for short-term, focused research of this nature.

#### **Intended or unintended flexibility in funding is used advantageously**

There is some evidence from our case studies that investigators successfully exploit flexibility in the scientific and administrative management of grants. In none of the case studies was there any evidence that this flexibility had a negative effect on the scientific outputs and outcomes of the research, and in some cases there were indications that such flexibility was used advantageously. This observation therefore supports the continuation of **arc**’s current policy of flexibility in funding.

#### **Referees’ contributions to the peer-review process are of variable benefit**

There is some evidence from analysis of successful applications that referees’ contributions to review panels do not add significant scientific value to the reviewed proposals. However, it is worth noting that the primary purpose of the review process was to select suitable applications for funding, rather than to improve those successful applications. For nine of the case study proposals, even where the referees’ comments were fed back to the PI, they had little or no impact. For four of the case studies, the peer-review process did have an impact on the design of the study. For a further two cases (which had the highest payback), if the referees’ comments had been taken at face value and not overruled by the assessing panel, the proposed research would not have been funded.

#### **The payback framework could be operationalised and embedded by **arc****

There is good evidence from this study that the payback framework adapted for **arc** works and, given the appropriate management information, could be operationalised prospectively to stimulate and manage the returns from **arc** research. The payback framework proved to be effective in capturing the diverse range of research outputs and outcomes, and in identifying cases where research had been translated to benefit people with arthritis. If applied prospectively, the framework could be used to inform the granting of the recommended translation and partnership awards. (In Chapter 4 we

describe how arc could operationalise and embed the payback framework, and identify a number of issues that would need to be resolved prior to implementation.)

## Recommendations

On the basis of these conclusions we make six recommendations, which are intended to help arc develop a system to ensure the successful translation of the research that it funds. These are outlined below, along with the aim and context of each recommendation.

Recommendation	Context	Aim
<p>1. <b>arc</b> should survey all forms of payback when monitoring and evaluating the returns from arthritis research.</p>	<p>There is strong evidence from our case studies that all types of grant produce a range of research outputs and outcomes, beyond the usually assessed publications in the peer-reviewed literature.</p>	<p>To ensure that the returns from <b>arc</b>-funded research are fully recorded and recognised.</p>
<p>2. <b>arc</b> should selectively support investigators in translating their research. This might include:</p> <ul style="list-style-type: none"> <li>• translation awards to promote the successful transfer of knowledge with potential health benefit;</li> <li>• interaction awards to develop productive relationships between researchers and policymakers or industry.</li> </ul> <p>These awards could be made in both reactive and directed modes.</p>	<p>There is good evidence from our case studies that when translation occurs, it is largely down to the individuals' conviction, effort and personal networks, although individuals currently have little or no support for these activities.</p>	<p>To recognise the importance of personal networks in the translation of research, and to ensure that translation opportunities are resourced fully and realised.</p>
<p>3. <b>arc</b> should continue to support short focused project grants as part of its funding portfolio.</p>	<p>There is good evidence from our case studies that project grants provide value for money when compared to programme grants, fellowships and institutes.</p>	<p>To acknowledge the importance of project grants in funding research.</p>
<p>4. <b>arc</b> should maintain its flexible approach to the funding and administration of research grants. In addition we suggest that <b>arc</b> considers the costs and benefits of fixed budget funding.</p>	<p>There is some evidence from our case studies that investigators successfully exploit flexibility in the scientific and administrative management of grants.</p>	<p>To confirm that <b>arc</b> should maintain its current policy of being flexible in the award and administration of grants.</p>
<p>5. <b>arc</b> should review its peer-review processes to maximise their efficiency and effectiveness.</p>	<p>There is some evidence from our case studies that for successful applications referees' contributions to review panels are of variable benefit.</p>	<p>To challenge <b>arc</b> into assessing the costs and benefits of its peer-review system, with a view to improving its value to applicants.</p>
<p>6. <b>arc</b> should consider developing systems for the ongoing and prospective monitoring and evaluation of its funded research.</p>	<p>There is good evidence from this study that the payback framework developed for <b>arc</b> works and, given the appropriate management information, could be operationalised to prospectively monitor the returns of <b>arc</b>-funded research.</p>	<p>To develop an approach whereby <b>arc</b> will be in a position to "stimulate and manage the exploitation of research ... into outcomes of practical benefit to people with arthritis".</p>