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Mapping the impact
Exploring the payback of arthritis research
The research described in this report was prepared for and funded by the Arthritis Research Campaign (arc).

Cover Design ‘Making an Impact’:
(left) Dr George Peat, Senior Lecturer in Clinical Epidemiology at the Arthritis Research Campaign National Primary Care Centre at Keele University, who is leading a major study aimed at improving the care and treatment of osteoarthritis.

(centre) Andrew McCaskie, Professor of Orthopaedics at the University of Newcastle, prepares for surgery.

(right) Andrew Fulljames had both knees replaced in 2005 at the Nuffield Orthopaedic Hospital in Oxford. His surgery has been very successful and has enabled him to lead a normal life.

(background picture) Dr David Gould and arc Professor Yuri Chernajovsky working on gene therapy research at the University of London.

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Mapping the impact

Exploring the payback of arthritis research

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This report, prepared for and funded by the Arthritis Research Campaign (arc), describes a series of tools developed to map the arc research portfolio and catalogue the impacts of arc research. These tools were implemented as web-based surveys and were used to collect initial data from 136 grants that finished in 2002 and 2006. This initial work demonstrated that the tools were both effective and easy for researchers to complete. The data give a snapshot of arc research impacts and provide a foundation for further data collection. By developing a deeper understanding of the research that it funds, arc will be in a better position to decide its strategy for future funding to cure arthritis and alleviate the suffering of those afflicted with the disease.

This report will be of interest to arc’s trustees, senior management, staff, scientists, fundraisers, donors and people with arthritis. It will also be of interest to other research funding agencies and evaluators who are keen to measure the impacts of research.

The research was led by RAND Europe, with additional input from the Health Economics Research Group at Brunel University and the newly appointed Medical Director of arc, Professor Alan Silman. RAND Europe is an independent not-for-profit policy research organisation that aims to improve policy and decision making in the public interest, through research and analysis. RAND Europe’s clients include European governments, institutions, NGOs and firms with a need for rigorous, independent, multidisciplinary analysis. This report has been peer-reviewed in accordance with RAND’s quality assurance standards.

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Executive summary

To further its mission of curing arthritis, arc needs to develop a better understanding of its research portfolio and the impacts arising from its research. What types of research are being funded? What paybacks are being produced? And how will the advances made through research be followed up, in the short and long term? The charity also needs to be able to demonstrate the impacts and importance of the work it funds to justify its spending to donors and reform its end-of-grant reporting. Although previous end-of-grant reports have been detailed, it has been difficult to aggregate and analyse the information they collect across arc’s research portfolio.

Working with RAND Europe, arc set out to develop a new survey system that would provide an overview of the research arc funds through an information-gathering tool (survey instrument) that would be quick and easy for researchers to complete. This overview would inform arc’s future funding strategy and provide a foundation for more detailed evaluation work. The work built on earlier detailed case study research carried out for arc by RAND Europe, investigating how arc-funded research led to patient benefit. Figure S.1 details the key characteristics of an “ideal survey system” against which we could compare our designs and plans.

The survey instrument was intended to identify the diverse range of impacts arising from arc research. In addition to mapping the impacts of arc research, arc wanted a better overview of the types of research it was funding. While arc knows what types of research it funds in terms of disciplines, it has been harder to assess the stage of development of that research. The research pathway section of the instrument was developed to tackle this information gap. From an initially very rudimentary design, a complex and specific pathway emerged, through an iterative design process guided by consultation with researchers.

Over 40 arc researchers were consulted throughout the development of the system. They were involved at all stages, from initial conception of the system, through the design and testing of the final web-based questionnaire, and all appraisal areas.

The survey instrument

The new system is built around a web-based survey instrument (questionnaire) that asks about the sort of research that has been done, how it was developed and its impacts. Two major virtues of the instrument are that it is easy to use and that it

Figure S.1
The characteristics of arc’s ideal evaluation system

- Capturing the full range of benefits
  This should include benefits and impacts beyond publications and research qualifications.

- Aggregation
  The survey should allow impacts of many grants to be aggregated to provide an impression of the overall impact of a group or grants. At the same time, it had to allow for impacts of very different types to be kept apart – for example, the production of knowledge and influence on health policy. This would allow the different strengths if different types of research to be explored.

- Valuation
  The survey should provide a way of considering the differing value of different types of impacts, i.e. a method of reducing a range of impacts to a common currency.

- Low burden
  Any survey instrument always has a burden attached, whether this is the time it takes to complete a questionnaire or the administration costs involved. The burden will only be felt if it is disproportionate to the benefit of conducting or completing the survey. It is important to be disciplined about the information elicited – collect only what can be used and resist the temptation to gather extraneous information simply because you have the tools to do so.

- Wide applicability
  The instrument has to be widely applicable across all forms of research, while allowing room for some variation.

- Fairness
  The instrument should capture information fairly, allowing true comparisons of groups of research grants or types of research.

- Timeliness
  The speed with which the instrument can provide information will always be a tradeoff between the requirement for speed to support decision-making and allowing time for the outcomes of research to develop. Where possible, a monitoring system can provide early indicators of impact.
provides data that is easy to analyse. One indication of the ease of use is the speed with which researchers can complete the questionnaire: in most cases it takes less than an hour (see Figure S.2). In contrast, previous end-of-grant forms could take between half a day and a full day to complete.

There are two key sections in the questionnaire. The first asks researchers to place their work on a research pathway (see Figure S.3). This allows arc to collect and analyse information on the range of research it funds.

The second key section investigates the impacts of that research. Rather than just examining publication outputs or qualifications gained, the tool covers a broad range of research impacts, including:

- research questions addressed and experimental systems used
- the position of the research on the research pathway
- whether the research has been or will be developed since the grant
- how the grant affected future research
- how results were disseminated
- impacts of the research on health policy, training and education
- whether the work led to medical intervention of public health advice.

Most questions can be answered with Yes/No tick-boxes. Figures S.4 and S.5 show sample questions from the Future Research and Interventions/Products sections of the questionnaire.

When arc adopted the survey to replace its end-of-grant reports it added two sections of qualitative questions encompassing a scientific summary and a lay summary. The structure of the survey instrument is discussed in more detail in Chapter 4.

Figure S.2
Time to complete questionnaire (minutes)

Figure S.3
The final research pathway

Figure S.4
Example questions on research collaborations showing the Yes/No/Not Known tickbox structure
The organisation of this report

This report describes the development and final structure of the survey tool. Because many of the key issues discussed in this report are interwoven, some reiteration of information and data is unavoidable. However, we have done our best to keep this to a minimum. Chapter 1 provides some background to the Arthritis Research Campaign, its research focus and the findings from previous research reviews that led to their portfolio mapping initiative. Chapter 2 looks at general issues of research evaluation, the problems they can generate and the ways in which we dealt with them when developing the survey tools. Chapters 3 and 4 lay out in more detail the methods we selected and developed to produce the most effective questionnaire and explain how it was implemented. Chapter 5 shows results from our initial waves of surveying and discusses the potential for wider application of the survey and possible avenues for development. Appendix A is a sample of the online questionnaire completed by researchers.
Acknowledgements

The Arthritis Research Campaign commissioned this study and many people contributed to its success. Steven Wooding led the study with advice from Jonathan Grant of RAND Europe and Martin Buxton and Stephen Hanney of the Health Economic Research Group. Eddy Nason and Stijn Hoorens carried out much of the initial work on developing evaluation tools. Tony Starkey implemented the survey tool and carried out the data extraction and analysis.

We would like to thank the staff of arc who supported the work and provided input and guidance at many points – Fergus Logan, Michael Patrick, Prof Alan Silman and Lisa Croucher; Beverley Chapman for providing lists of researcher names and for chasing non-respondents; Prof Tom Ling and Prof Cy Frank for their helpful comments and suggestions; and our editor Sally Simmons of the Cambridge Editorial Partnership for her excellent drafting, and for ensuring that our report was shorter than we expected.

A special acknowledgement must go to all those scientists – over 40 in total – who provided input and feedback on our evaluation tools throughout their development. This project would have been impossible without them.
Chapter 1  The Arthritis Research Campaign

The history of arc

arc was founded in 1936 and raises funds to promote medical research into the cause, treatment and cure of arthritic conditions; educate medical students, doctors and AHPs about arthritis; and provide information to people affected by arthritis and to the general public.

The mission of arc is to improve the lives of people with arthritis. Currently, clinical and basic scientific research into arthritis is supported through a number of different strategic and response mode funding schemes. The latter cover approximately 400 project grants, programme grants and fellowships in universities and medical schools throughout the UK. Clinicians and scientists are encouraged to develop careers in musculoskeletal research through arc’s fellowship and studentship schemes. arc also provides core funding for two major research institutes, the Kennedy Institute of Rheumatology at Imperial College, London and the Epidemiology Unit (arc EU) at the University of Manchester.

arc is also dedicated to the enhancement of rheumatology teaching for medical undergraduates and the development of academic rheumatology. This has been achieved by establishing 10 chairs in rheumatology and funding clinical academic posts at lecturer or senior lecturer level in 16 medical schools in the UK.

Arthritic disease in the UK

It is challenging to estimate the burden of arthritic disease in terms of health service costs as there is no national system for monitoring the musculoskeletal health of the population and the extent of arthritis and related conditions. It is even harder to estimate the social costs of these conditions. However, it is important to have such figures to give an impression of the scale of the problem. For this reason, in May 2002 arc published two separate studies under its Arthritis: the Big Picture campaign to find out how many people are affected by arthritis. More recently, the Royal College of General Practitioners has made estimates of the scale of the incidence of arthritis in the UK.

These studies indicate that between 7 and 13 million people in the UK are affected by arthritis (see Figure 1.1). The wide range of the figures may relate to confusion over what constitutes arthritis, joint pain or musculoskeletal pain, and may also reflect the different ways in which the estimates were calculated. Nevertheless, these independent studies indicate that around one in six of the UK population has arthritis. The studies showed also that arthritis and joint pain is more prevalent in women, while the Health and Safety Executive indicates that the condition costs the economy in excess of 8.8 million working days per annum. The estimated direct annual costs to the economy are £5.7 billion in lost working days, £307 million in GP consultations, £341 million in prescription costs, and £477 million in hip replacements.

1 Arthritis Research Campaign (arc) 2002a, Arthritis: the big picture.
3 Health and Safety Executive, Table SWIT1 – 2007/08.
4 Health and Safety Executive, Musculoskeletal disorders – Why tackle them?
7 Arthritis Research Campaign (arc). UK arthritis facts – at a glance.
To mark its 65th anniversary in 2002, arc undertook a strategic review of its research activities and their impact. This resulted in the publication of a five-year strategic plan, *Research into Practice.* The review consulted arc’s stakeholders – including trustees, staff, scientists, volunteer fundraisers, donors and people with 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 response, the decision was made “to establish mechanisms to bridge this gap, and to stimulate and manage the exploitation of research and educational advances so that they translate into outcomes of practical benefit to people with arthritis”.

As a result of the strategic shift from outputs to outcome, arc needed to “instigate a system of rigorous retrospective evaluation on work which has already been completed, with a view to identifying opportunities for development”. To oversee this process, arc appointed a development committee that commissioned RAND Europe to produce a study of the most effective research activities and implementations.

The study, published in September 2004, provided insight into the ways in which arc-funded research led to improvements for sufferers from arthritis. It showed that the impacts of arc-funded research could be helpfully classified into five categories of benefits, the so-called Payback Categories initially developed by the Health Economics Research Group at Brunel (Table 1.1): knowledge production; research targeting and capacity building; informing policy and product development; health and health sector benefits; and the wider economic benefit.

**Conclusions of the September 2004 study**

As well as identifying a series of benefits flowing from arc-funded research, the September 2004 study produced a number of observations about...
The returns from arthritis research (Wooding et al., 2004a)

<table>
<thead>
<tr>
<th>Payback category</th>
<th>Payback</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge production</td>
<td>• Peer-reviewed publications in the serial literature</td>
<td>• 302 papers receiving a total of 975 citations per year attributable to case studies</td>
</tr>
<tr>
<td>Research targeting and research capacity</td>
<td>• Postgraduate research training</td>
<td>• 28 PhD/MDs from work on the case studies</td>
</tr>
<tr>
<td></td>
<td>• Subsequent career development of PIs and research assistants</td>
<td>• Development of technological know-how in genetic mapping</td>
</tr>
<tr>
<td></td>
<td>• The transfer of technical know-how</td>
<td>• Informed &gt;£2 million Medical Research Council (MRC) randomised controlled trial</td>
</tr>
<tr>
<td></td>
<td>• Informing future research studies</td>
<td>• Use of biologicals as therapeutic targets</td>
</tr>
<tr>
<td>Informing policy and product development</td>
<td>• Informing recommendations in clinical guidelines and other policy advice</td>
<td>• Recommendation in Royal College of Obstetricians and Gynaecologists (RCOG) guideline on the use of aspirin and heparin for women with antiphospholipid syndrome (APS)</td>
</tr>
<tr>
<td></td>
<td>• Informed development of clinical tests</td>
<td>• Recommendation in Industrial Injury Advisory Council (IIAC) assessment for hip osteoarthritis (hip OA) in farmers to be a prescribed disease</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Clinical test for a rare type of systemic lupus erythematosus (SLE) and chondrodysplasia type Schmidt</td>
</tr>
<tr>
<td>Health and health sector benefits</td>
<td>• Improving the quality of life for people with rheumatoid arthritis (RA)</td>
<td>• Hundreds of thousands of patients treated with anti-TNF of whom 70% experience a significant improvement in health</td>
</tr>
<tr>
<td></td>
<td>• Reducing the likelihood of recurrent miscarriages for women with APS</td>
<td>• 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.</td>
</tr>
<tr>
<td>Wider economic benefits</td>
<td>• Unquantified economic returns resulting from a reduction in days off work and sales of licensed drugs</td>
<td></td>
</tr>
</tbody>
</table>

how impacts were generated and suggestions for how benefits might be maximised in the future.

**Individuals translate research into practice**

Research is translated into developments of practical value to patients largely due to the conviction, effort and personal networking of an individual investigator. It is not necessarily associated with the type or mode of the funding stream or the bibliometric impact of the investigator.

**Grants for short-term projects provide value for money**

The most unexpected and surprising finding shows that the payback from project grants is similar to that from 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), grants for short-term or highly focused projects provide significant value for money.

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

Allowing researchers' flexibility in how they spend their grant money was exploited to the benefit of both the researcher and the funder, for example, allowing project grant funding to be used to cover a PhD stipend or allowing money initially planned for consumables to be spent on a higher post-doctoral salary. There was no evidence that flexibility had a negative effect on scientific outputs and research outcomes; in fact, there were indications that such flexibility was used advantageously.
The payback framework could be adapted and used by arc

The study suggested that the payback framework could be adapted for arc and, given the appropriate management information, could be used prospectively to stimulate and manage the returns from arc research. The framework captured the diverse range of research outputs and outcomes, and identified cases where research had been translated to benefit people with arthritis.

arc used the conclusions of the September 2004 study to demonstrate the value of its research to donors and its Annual Review 2003–2004 (Figure 1.2) featured many of the researchers who had contributed to the RAND study.

arc also used the conclusions concerning flexibility to justify an increasingly hands-off approach to the administrative minutiae surrounding the research grants it awarded, and to resist pressure for additional auditing and overseeing of grants.

Finally, arc looked at whether scoring against the payback categories could be used to help appraise and manage grants from application through to completion and beyond. The idea was that grant applications would be scored for predicted impact in each payback category. The scores for all applications could then be reviewed to understand the characteristics of work that was being submitted to arc, and work that was funded. In addition, over time, the scores for applications could be compared to assessments of the impacts produced by the grant during its lifetime and after its completion. To implement this, arc initially tried using the payback profiles developed for the September 2004 study. However, although the profiles were an elegant way of summarising outputs, they turned out not to be an appropriate tool for capturing output data across the arc portfolio. At this point, arc turned to RAND Europe and asked us to develop the tool introduced at the start of this chapter and detailed in the remainder of this report.

Objectives of the project

The tool we developed to assess the impacts of arc grants is based on the Payback Framework.

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

There is evidence from the analysis of successful applications that referees’ contributions to review panels do not add significant scientific value to the proposals reviewed. However, it is worth noting that the primary purpose of the review process is to select suitable applications for funding, rather than to improve successful applications.

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The Arthritis Research Campaign

The Arthritis Research Campaign project aims widened. It was decided to include means for exploring the wider fate of arc research – is research being taken forward after completion? If so, how? This stemmed from a concern that some arc research was being completed then abandoned rather than being developed further.

Three main strands of enquiry were developed.

Cataloguing outputs and outcomes from arc’s research to obtain information about the range and character of what it is producing (What has been done?).

Mapping the portfolio of what arc is currently funding to understand how arc-funded research is spread across the medical research landscape from laboratory to patient (What is being done?).

Looking ahead and assessing which individual projects of arc-funded research would be most appropriate to develop for patient benefit (Next steps).

(see Figure 3.2 on page 18). The aim is to score the output of arc grants and to examine how work develops after the grant period. The scoring system:

- is applicable to all areas of arc research (although different scales might be used for different areas);
- provides an overview of arc’s grant research portfolio to inform strategy decisions about future funding;
- highlights specific grants as opportunities for future development by arc, or others;
- minimises resource use in administering and carrying out scoring.

Throughout the process, RAND liaised closely with the newly appointed Medical Director of arc, Professor Alan Silman.

The project developed in complexity and lasted longer than intended. During development, the project aims widened. It was decided to include means for exploring the wider fate of arc research – is research being taken forward after completion? If so, how? This stemmed from a concern that some arc research was being completed then abandoned rather than being developed further.

Three main strands of enquiry were developed.

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Mapping the portfolio of what arc is currently funding to understand how arc-funded research is spread across the medical research landscape from laboratory to patient (What is being done?).

Looking ahead and assessing which individual projects of arc-funded research would be most appropriate to develop for patient benefit (Next steps).
Chapter 2 Conceptualising the system

Our previous study for arc had described in detail the impacts emerging from a small selection of case studied grants; now arc wanted us to extend that work and develop a system to collate the impacts of all the grants in its portfolio. The new project had to be much less resource intensive, and would inevitably provide a cruder assessment but one that would give an overall impression of the outputs from the entire portfolio and provide a solid foundation for more detailed evaluations.

In this chapter, we describe some of the standard issues in research evaluation and how we tackled them while developing this project. Inevitably, this involves looking in some detail at the survey tools and introducing information about the final methods we used before we turn to how we made the choice of method, which is described in Chapter 3.

Research evaluation

The money that the Arthritis Research Campaign (arc) invests in research, currently over £23 million a year, is raised entirely through voluntary contributions. These are not only substantial donations from the corporate sector and endowment trusts but also organised fundraising efforts in the community, like charity shops, and the efforts of thousands of individuals who make bequests or raise money through sponsorship. Because of this arc, like government research funders, has a responsibility to demonstrate that its money is being spent effectively.

Providing this accountability has been challenging for a variety of reasons, not least the long time lag between research and patient benefit and the fact that many research discoveries may feed into one breakthrough. The development of anti-TNF (tumour necrosis factor) therapy for rheumatoid arthritis illustrates both these challenges. TNF was first reported in 1977, but a therapy based on it was not recommended in clinical guidelines until 2002. A host of discoveries relating to monoclonal antibodies was also necessary for TNF-based therapy.

Traditionally, for arc and similar funders, accountability has been provided through stringent peer review of research proposals and annual and end-of-grant reports. Neither of these is ideal: peer review examines research proposals, not outcomes, and end-of-grant reports are not normally collected in a form that allows them to be analysed systematically. Also, these reports will not capture the majority of impacts from research, as most will still be in the future when the report is written.

The recent history of UK research evaluation

Over the past 5–10 years there has been both increasing spending on scientific research and increased pressure for improved accountability. In 2004 the UK government published a 10-year Science and Innovation Investment Framework. As part of this, the research councils were required to feed into a performance management system run by the Office of Science and Innovation that was intended to demonstrate the contribution each council was making to achieving government targets. The system included delivery plans, an outputs framework of performance metrics

and a scorecard of targets and milestones. These pressures have also been felt in the charity sector: the Charities Act of 2006, in a provision that became law in 2008, introduced a more stringent definition of “public benefit” and an increased need to demonstrate this benefit to retain charitable status.

Reacting to this climate of increased scrutiny in 2006, a consortium of funders – the Wellcome Trust, the Medical Research Council and the Academy of Medical Sciences – convened the UK Evaluation Forum to examine the best approaches to evaluating research. The forum’s report *Medical Research: Assessing the Benefits to Society* (May 2006), concluded that “there is a growing need for the UK research community to develop better methods to capture, evaluate and demonstrate these benefits”. It went on to recommend that “research funders should identify and fund further research into evaluation methods with a rigour and quality equivalent to other research fields”.

**Alternative approaches to research evaluation**

The pressure for accountability has been met by two broad classes of evaluation: “broad and shallow” and “narrow and deep”. Broad and shallow evaluations aim to quantify the large-scale impact or quality of research. Narrow and deep evaluations focus on examining how research funding could be improved, and how the process of research translation could be accelerated (how findings move from discovery to application). Much broad and shallow evaluation is based on bibliometrics (examining the quality of research publications) to assess the amount and quality of knowledge produced. For example, David King’s *The Scientific Impact of Nations* compared the scientific output of the UK with that of other major economies. However, knowledge production is normally only an intermediate aim: the ultimate objective of most medical research is to improve health and prosperity. Another approach to broad and shallow evaluation is to look at the economic impact of research – taking an area of research (often cardiovascular disease), calculating the total investment in research and comparing it to the total payback in terms of monetarised health benefit and other economic effects. An early high-profile study in this area was the “exceptional returns” work carried out by the Lasker Foundation in the US. However, this work had significant methodological weaknesses, neglecting to account for such issues as the time lag between research and impact. More recent work has estimated the impact of UK medical research on the UK economy, with a methodology that seeks to apportion the relative contribution of research more accurately and takes the discovery-to-benefit time lag into account. Making very conservative assumptions, this work suggests that medical research has an internal rate of return of 9% per annum in terms of health benefit – i.e. for every £100 invested in medical research the economy benefits by £9 every year, with significant further benefits in terms of economic “spillover” effects. Although not startlingly high, this is comparable to the rates of return recommended by HM Treasury for public investments and the rates achieved by other forms of infrastructure investment in the EU. Such economic studies provide a useful assessment of whether research is worthwhile, but shed no light on whether a different arrangement of research spending would have been more, or less, effective.

The narrow and deep strand of evaluation uses a series of methods such as case studies, bibliometrics and small-scale surveys to understand the impact of a small sample of research projects. Our earlier work for *ARC* was part of this strand. One of the key challenges of formative evaluation

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is making a small selection of case studies from which robust conclusions can be generalised.

What we needed for this project was a new system that was broad and shallow, rather than narrow and deep, but that still captured the full diversity of research impacts, from new collaborations to improved assays, and from influences on health policy to novel surgical interventions. Previous work in this area, notably for the North Thames Health Authority and for the UK Health Technology Assessment organisation, looked at whole portfolios of research, but took only a snapshot: there was no ongoing or routine assessment. The resource requirements of the techniques used were not conducive to repeated follow-up and tracking of research impacts. The system we were designing had to be able to answer three main questions: Which of our research grants contribute to new treatments? How long does the process take? What are the characteristics of those grants? The system also needed to provide an overview of the research impacts that would provide a solid foundation for selecting candidates for detailed, case study-based evaluation to improve further funding.

Issues in research evaluation

Previous work in this field, both by us and by others, highlighted a series of issues that had to be borne in mind when undertaking research evaluation and considering the best approaches to adopt in the new study. Additionally, researchers, physicians and patients all have their individual perspective on the value and impact of different streams of research. The system had to be constructed sensitively in order to elicit responses that could be aggregated to provide informative feedback for funders.

Minimising the burden on researchers

Principal investigators are uniquely well placed to provide information on the impacts of their grant, for two reasons: first, they can be easily and immediately identified; second, they will have seen many of the initial impacts at first hand. Unfortunately, principal investigators may not know about all the later and more distant impacts; more knowledgeable sources, however, are unlikely to have obvious links to the grant and so are impossible to identify routinely. Although they are an obvious source of information, it must be remembered that the principal investigators’ time is valuable, so we adopted two guiding principles when establishing the level of detail we would use in the questionnaire. First, that we should make the system as simple and quick for researchers to use as possible, and second, that we should avoid collecting data that we could not analyse or for which there was no specific need.

We were aware that previous end-of-grant reports had contained huge amounts of information that could not be analysed, so we resolved to ask only Yes / No / Not Known (or occasionally Yes / Not Yet / No / Not Known) questions. This meant that the survey instrument enabled us to collect only very limited additional data about specific impacts. This was clearly a compromise, but was driven by our confidence that our initial data would provide a robust basis for identifying suitable grants for more detailed analysis – for example, all grants leading to health policy change might be compared. More detailed analysis would require answers to questions that we had not anticipated. Eliciting those would mean a longer questionnaire that would take longer to fill in – and we would still have to return to the grant holder for additional information.

Timeliness

One of the complications of research evaluation is that many of impacts occur long after the research has taken place. This suggests that the survey instrument may need to be able to track research over the long term to build up a full picture of its impact. It also touches on two inter-related issues of assessing research impacts: (1) when it is theoretically best to do this; and (2) when it is best from a pragmatic basis. Theoretically, research impacts take time to develop. It has been suggested that it takes on average 15–20 years for research to develop to

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the stage where it affects patients.\textsuperscript{29} If research is evaluated too soon, many of the impacts will not have occurred. Conversely, researchers’ memories are fallible, and they will forget what impacts are related to which grants and what early impacts did occur. Because of this, we decided to trial the instrument on research grants completed two and six years before the survey date.

From a pragmatic viewpoint, there are times when researchers are more likely to complete the survey instrument. The first of these times is at the end of grant, when researchers will be expecting to complete a report anyway, and when information can be collected about actual paybacks that have resulted from the research. The second is when researchers reapply for funding from arc (our analysis suggests that over 90\% of researchers reapply within 10 years). The disadvantage of surveying at end of grant is that many impacts will not have had time to develop; nevertheless, surveying at this point provides an initial snapshot of early impacts. The disadvantage of surveying on reapplication is that the time to reapplication is not fixed, so surveys will be completed an arbitrary length of time after the original grant ends.

There are four main considerations when fixing the optimum time for completion of the questionnaire. First, it is helpful if there is an incentive for researchers to complete the questionnaire – so one excellent point would be on application for a subsequent grant.

Second, time from awarding the grant is an import factor – impacts need time to develop and there has to be something for researchers to report. The survey also has to be able to show comparability between grants, so standardisation on time lag is helpful. Third, if the survey is to capture the development of impacts it will be helpful to have information for each grant from more than one time point. Finally, the survey depends on researchers’ recall, so it cannot be administered too long after the grant has ended.

**Accuracy and completeness**

An evaluation system can never be perfectly accurate, but the level of accuracy should be appropri-ate for the purposes for which the information will be used. arc intended to use the data to assess the effectiveness of its research, justify the charitable nature of its funding and inform its strategic decision making.

Because the information would be used in an aggregated form, small inaccuracies or omissions (provided they were not systematic or biased) were acceptable.

Clearly this entire system is dependent on the knowledge, recall and honesty of the researchers completing the survey instrument, and their consistent understanding of our questions. In terms of researcher knowledge there are three concerns: there may be impacts they do not know about; there may be impacts they have forgotten; or there may be others they exaggerate or embellish. We will clearly miss impacts that our researchers are unaware of – for example, a discovery they made that was picked up and developed without their knowledge. Sadly, there is nothing we can do about this other than be aware of it when interpreting our results. Turning to memory concerns, our impression from previous work, where we have carried out detailed case studies of the development of individual research grants,\textsuperscript{30,31} is that researchers’ ability to recall particular grants and their impacts, and make judgements about the links between them, is surprisingly good, particularly given the complexities of attribution and the number of grants often held by one researcher. Finally, there is also evidence from work comparing surveys and subsequent case studies that researchers do not generally exaggerate the impact of their work, although this might change if such assessments were to be used routinely to assess the performance of researchers.\textsuperscript{32}

We tested the questionnaire intensively to ensure that researchers from across the range of disciplines that arc funds had a similar understanding of the questions. Initial drafts of the survey were reviewed by a steering group of active


\textsuperscript{32} Hanney et al., “Assessing the benefits from health research projects: can we use questionnaires instead of case studies?” Research Evaluation 8 (1999): 189.
researchers and were later tested using cognitive interviews with further researchers, whom we asked to talk us through the survey, explaining their rationale for answering questions in the way they did. As an additional check the survey was reviewed by the Medical Director of arc and an independent professional copy-editor.

To improve consistency of understanding, wherever possible we asked about concrete things or events. Rather than asking whether researchers have “interacted with industry”, we asked whether they had had an initial discussion with industry, set up an informal collaboration or signed a consultancy agreement. The intention was to make it easier for researchers to decide whether they had or had not carried out a particular activity or developed a particular impact.

Quantification
In this work we have thought of “impacts” as the individual atoms of the wider effects of a piece of research: a paper, a PhD, a patent, a new collaboration or a new diagnostic. Each of these impacts will have a range of effects, and complete quantification of those effects would be immensely challenging. An impact, such as a new therapy, will have effects on improving health and quality of life, but it may also have economic effects, for example, allowing return to work, and less tangible impacts, like improving the quality of life of relatives and carers, and increased happiness of dependents and friends. What we are attempting here is a narrower examination of the extent of each impact. This work in particular limits itself to considering the number and nature of each impact, rather than the extent of its effects. In these terms there are three principal dimensions related to quantification: the number of impacts of a certain type; the degree of dissemination of each impact; and the extent to which each impact has been developed. This is illustrated diagrammatically in Figure 2.1.

Some research grants could clearly lead to more than one of a particular type of impact; for example, a programme grant may provide training for more than one PhD student. As we had decided against trying to quantify the size or relative merit of individual impacts – attendance figures for conferences or numbers of researchers using new antibodies – we also decided not to ask researchers to count the number of particular types of impact. We felt that it would be easier for a researcher to say whether a particular impact had arisen from a grant than to attempt to count the number of those impacts. Without a way of quantifying the size of the impacts (which would add significant complexity to the survey instrument) it would be difficult to assess the relative importance of a two-impact grant and a one-impact grant. We expected that longer-term impacts would be relatively rare and that the danger of missing impacts (due to masking) would therefore be relatively low. Strictly speaking, the results of the survey instrument give a measure of the number of grants contributing to particular types of impact, rather than the number of impacts produced.

Definition also presented problems: do discussions with two different divisions of a pharmaceutical company count as two separate instances of “Informal discussions with industry”? Is this as significant as having discussions with two different companies? Whatever the subtleties of definition, the discussions themselves are important. We dealt with this complication by simplifying and refining questions to ask about the presence or absence of a particular activity or the development of a particular impact.

Figure 2.1
A diagrammatic representation of the dimensions for quantifying of impact; measures that are conceptually related are shown close together in the same colour.
12  Mapping the impact

Figure 2.2
An example question illustrating the combination of developmental stage and extent of use of research tool

### 4.5: Future Research - Tools for Research

This page explores what tools and resources your research produced, or further characterized, that could be used for future research.

1. For new or improved cell line, which stages of development were carried out during the grant or have happened since?

<table>
<thead>
<tr>
<th>Stages of Development</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
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<tr>
<td>Initial development?</td>
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<td>O</td>
<td>O</td>
</tr>
<tr>
<td>Further characterization?</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td>In use by researchers beyond the research group?</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
</tbody>
</table>

might have been shared with a few select colleagues; or it might have been adopted by the majority of researchers in the field. Furthermore, there are a number of stages through which each impact can develop – a cell line must be created and then characterised. Seminars are another example. A seminar might reach 10 or 150 people, who might be junior hospital doctors, health trust managers or CEOs of biotech companies. An objective assessment of impact in such different circumstances is extremely complex. So in terms of scale, we tried to select options that reflected qualitative differences of scale and importance, such as the split between local, national and international.

In early versions of the questionnaire, we separated these two dimensions of development, but during testing it became clear that they were generally very closely related – more well characterised reagents and techniques tended to be more widely shared. To simplify the questions, we combined the two dimensions into one scale (see Figure 2.2).

Different types of outcome follow slightly different developmental stages. Research tools may be developed, characterised and shared; a physiotherapy intervention might go through proof of concept, small-scale trial, large-scale trial and then into wider use; a pharmaceutical intervention, on the other hand, would follow the well-worn path from early clinical work through the phases of clinical trialling. Consequently we developed hierarchies of development for each type of impact.

### Attribution

Attribution is a recurring challenge for research evaluation, and we dealt with it in a particular way that combined a consideration of the theoretical issues with a healthy dose of pragmatism. Attribution is basically an examination of causality – did a particular grant lead to, or contribute to, a particular outcome? We wanted to map where the impacts of arc research were occurring and obtain an impression of the number of grants producing impacts, rather than attempting to reduce the impact of arc research to a single metric. Given the incremental nature of science and the timescales involved, it is rare for any one grant to be the sole contributor to an improvement in health. Distance between outcome and grant means that links become increasingly blurred – a conference presentation may well present the results of work done on only one grant, but a new vaccine is likely to depend on work done on many grants.

There are two ways to consider this issue (which are not mutually exclusive): the strength of the link between a piece of research and a particular impact; and the extent to which an impact relates to a portfolio of research carried out by the researcher (as opposed to findings related to a specific grant). These are illustrated diagrammatically in Figure 2.3.

Initially we sought to examine attribution in detail, asking about the significance of the link between the grant and the impact in question – was it considerable, moderate or small? However, our work with researchers suggested that this made
filling in the questionnaire more taxing. Although researchers were willing to suggest which impacts related to a specific grant, they were far less willing to try and quantify the extent of the linkage. Without additional work to examine how researchers understood the different terms it was not clear how we could compare or analyse the responses – i.e. how many “Moderate” contributions would be equivalent to a “Considerable” contribution?

Because attribution is so complex, it is often impossible to divide it up like a cake – 50% from grant A, 50% from grant B. Consider the case where two discoveries from different grants were required for an impact – if either one of the two had not happened, the impact would not have happened, so the impact is 100% due to both grants.

In early versions of the questionnaire we tried to discover whether impacts were related to a particular grant or the overall body of a researcher’s work. We trialled a system that allowed researchers to indicate whether each impact was attributable to the grant in question or to their wider portfolio of work. We also asked whether each impact was “slightly, substantially or wholly” attributable to their work. However, although this distinction is important to evaluation professionals, it was too subtle for most researchers. It became clear that researchers reviewing or filling in the questionnaire paid little attention to these distinctions and it was not obvious how such information could be analysed or used by arc. A number simply failed to pick up the distinction, or rapidly stopped applying it as they moved through the questionnaire. Because of this, we sacrificed detail (a fine-grained approach to attribution) for simplicity and used a threshold contribution level – asking researchers to mention only impacts that are “substantially” attributable to the grant. A second reason for taking a relatively simplistic approach to attribution is the danger that researchers’ level of knowledge might render subtle distinctions meaningless: even if researchers have full knowledge of their own contribution to an impact, they may not have knowledge of any other contributions, and so may not give an accurate assessment of their overall contribution.

The approach we took means that there are some differences in the significance of the links between the impacts captured by our questionnaire and the grants examined. However, as we were capturing an overview of the range and areas of impacts developing from the grant portfolio we felt this was an acceptable compromise, led by our principle that the survey instrument should be as simple for the researchers to fill in as possible and that we should avoid collecting data that we could not analyse.
Chapter 3  Developing and implementing the survey tools

This chapter describes the process we went through to design, develop and test the survey tools. We began by investigating whether a suitable tool was already available, then developed a number of potential tools and tested them with researchers before developing the best performing tools further. A full-scale electronic pilot that covered two years’ worth of grants followed initial pilot work in 2007.

Reviewing current practice

In recent years, medical research funders have become far more concerned about evaluation and examining the outcomes, as well as the outputs, of medical research. Many organisations collect information, but it is generally analysed only on an ad hoc basis. However, we were not aware of any charitable foundations or funding agencies that carry out systematic reviews of the wider impacts of their research activities. To ensure we were not reinventing the wheel, we carried out interviews with six foundations that we considered were most likely to have interesting evaluation procedures, based on our knowledge of selection procedures and ethos.33

Four of the six were interested in developing systematic methods of assessing the wider impacts of their research; however, none of these initiatives has proceeded far. The National Health and Medical Research Council of Australia (NHMRC) has the most developed initiative and this aims to develop a metric to evaluate the impact track record of researchers as one input to the peer review process. This metric will take into account a wide range of research impacts, from knowledge production through to economic benefit. All of the foundations required end-of-grant reports, and some also asked for intermediate reports, but these were restricted to research results and the immediate publications. All have carried out ad hoc evaluations to look at particular aspects of their work, or particular collections of grants.

However, our interviews revealed that none of these comparable organisations had a suitable existing tool for us to adapt for the arc project; it was clear that we would have to develop something from scratch.

Project activities

At the start of the project, it was not clear which tools would be most appropriate, so the project was structured to investigate a series of approaches and, through consultation, to focus on the most appropriate. To complicate matters, some tools addressed more than one of the aims of the project. For example, scoring scales could be used both to predict impact and to quantify the impact achieved.

Figure 3.1 outlines the structure of the development phase project and provides information about the tools tested. Short summary descriptions of the tools show how far each progressed. For more details about tools that were tried and rejected or remained unused, please see our earlier report, which describes the initial work carried out in the project.34

33 Funders interviewed were: Breakthrough Breast Cancer; The Canadian Health Services Research Foundation; The Canadian Institutes of Health Research; The Joseph Rowntree Foundation; The National Health and Medical Research Council of Australia; The Parkinson’s Disease Society.

Testing and progression of survey tools

**Project Activities**

**Key informant interviews**
A series of interviews with 10 key individuals within and outside arc to develop an understanding of the context in which the tools would be used, and the sensitivities about such methods.

**Options development**
Some tools were developed from scratch, most were taken from our previous work. To inform this work we also carried out a brief survey of the peer-reviewed literature and some telephone interviews with evaluators.

**Advisory group workshop**
A day-long workshop in which the Advisory Group was presented with the different tools we had developed, attempted to apply them to their own research, and provided feedback about the tools’ suitability.

**Revision of tools**
The most suitable tools were revised and improved, following the advisory group’s feedback, and a smaller set produced.

**Review by advisory committee**
The revised tools were then circulated to the advisory committee and telephone interviews gathered feedback.

**Review by arc (Medical Director)**
The revised tools were reviewed by the Medical Director of arc to ensure they met the requirements of arc’s data collection. Some were further simplified to reduce the burden on researchers filling in the questionnaires and to avoid the collection of data that arc did not need.

**Cognitive interviews**
An initial draft questionnaire was tested on a small sample of additional researchers, through cognitive interviews.

**Instrument piloting**
The revised questionnaire, in paper form, was piloted with 32 researchers whose grants had recently ended. In addition to examining completed questionnaires, we carried out interviews with a selection of the respondents to explore their opinions of the questionnaire.

**Project review with arc**
With the feedback from the piloting, we carried out a second review of the questionnaire with arc at which point we decided that the barriers and facilitators questions were not providing useful information. We needed to reassess how we collected forward-looking information.
Tools and approaches investigated

Mapping the portfolio
To provide arc with a view of the portfolio of research it funds we developed the research pathways.

Research pathways
Starting with a relatively simple linear research pathway we worked with researchers to refine and develop it to provide a version on which most researchers were happy to site their research, and which could also capture how that research developed towards patient benefit (or not).

Cataloguing impacts
We investigated a number of tools to summarise and catalogue the impacts produced by arc research. The first three tools aimed to capture the impacts. Ticklists aimed to capture each individual impact for later aggregation, whereas exemplar scales and calibrator scales aimed to provide a way of assessing the overall impact of a grant in a number of impact categories (e.g. knowledge production). Output valuation and two approaches to attribution concern how we dealt with impacts allocated to particular grants.

Ticklist
An exhaustive detailed listing of each type of impact – e.g. citation in policy paper, discussion with industry, new research collaboration – where the researcher simply answers Yes/No to whether each particular impact arose from the grant in question.

Exemplar scales
This approach would involve breaking the impact of a grant down into a series of dimensions, for example: knowledge production, research targeting, informing policy & product development, and health benefit and then scoring the impact of the grant on a scale of 0 to 10 against each of these dimensions. Exemplars would be used to illustrate the levels on these scales, for example, a score of 5 for knowledge production might equate to publishing 4 papers that each received more than 5 citations.

Calibrator scales
A similar approach to Exemplar scoring, breaking down the impact of the grant into a series of dimensions but illustrating the levels of the scales using examples taken from actual previous arc grants, to make the examples more concrete.

Output valuation
The idea of putting relative values on each type of impact – e.g. 5 points for a patent, 2 points for a follow-on grant – to simplify comparison of different areas of the portfolio. This technique could allow the impacts of a grant catalogued through a ticklist to be aggregated into dimensions of impact. Different stakeholders are likely to have different valuations and determining such relative valuations could potentially allow the impacts of the research portfolio to be viewed from alternative perspectives.

Fine-grained attribution
Trying to unpick issues of attribution in detail – e.g. asking whether an impact was due to a particular grant or to the overall portfolio of the researcher’s work – and providing a variety of strengths of attribution for a researcher to pick from, for example, ‘slight, moderate, substantial’.

Threshold attribution
A cruder method of dealing with attribution where researchers are asked to include a impact if they feel it exceeds a threshold, for example, ‘significantly attributable to’.

Next steps
We also attempted to develop a technique for investigating the possible future impact or next steps that ought to be carried out on the grant.

Prediction matrix and potential impact
Two techniques we tried to explore the potential impact of research, neither of which proved very successful.

Barriers and facilitators
An unsuccessful attempt to map the key aspects determining whether research is developed.

Next steps
A structured set of questions designed to provide details on the outcome of the research in terms of the next steps taken and the reason for these.
Our ticklist was developed from the five categories in the RAND/HERG Payback Framework, supplemented by items concerning dissemination (see Figure 3.2). We had hoped to examine all five categories, and in the process tried to identify the types of output for each category and ways in which we could construct questions that would be clear, unambiguous and easy to answer. Although we were successful in breaking down the first three categories, we encountered problems with the last two and did not pursue them. These problems were related to the difficulty of providing simple categories for an area as diverse as “Health and Health Sector Benefits” and concerns that laboratory researchers would not necessarily have detailed knowledge of disease burden and related issues. Because of these concerns we gave priority to devising questions that could be answered sensibly and significantly by researchers.

**Selecting the tools**

Through the consultation process, we selected a system that combined the ticklist approach to capturing impacts with research pathways to map...
Developing and implementing the survey tools

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the portfolio and an initial qualitative approach to exploring barriers and facilitators for future development. Figure 3.3 shows an alternative representation of the project’s progress with a visual representation of the development of the successful tools settled on for capturing outputs and mapping the portfolio and investigating the next steps.

Capturing and cataloguing outputs and outcomes

We devised three main tools for collecting data: the ticklist, exemplar scales and calibrator scales. One problem with calibrator and exemplar scales is that the need to score for each of five payback categories means that detail is lost when data are aggregated. The scales also have more scope for subjectivity, adding to the recognised risk of depending on researchers’ views. With our brief to provide robust data, the use of scales meant it would be necessary to collect short descriptions of projects that would have to be scored by assessors, rather than directly by the researchers themselves. This would add an additional resource requirement to the system. However, the ticklist provided more fine-grained and useful data that could be aggregated easily across subject areas, institutions or time. The ticklist also had the advantage of reducing the time it would take for researchers to fill in the questionnaire. We selected the ticklist as the most appropriate tool for the survey instrument.

Having chosen the ticklist, we investigated the option of combining it with output valuation, to put an explicit value on each type of impact. This would have allowed a total impact score for each grant to be computed. However, the difficulties of agreeing the relative valuations, even with a group of researchers, suggested this approach would require a lot of development. We decided not to pursue this aspect of the approach further.

In Chapter 2, we discussed how we dealt with generic research issues: minimising burden, timeliness, accuracy and completeness, quantification and attribution. The remainder of this chapter describes the pathway we developed to map arc’s overall research portfolio.

Research pathways

Research pathways were developed to provide an overview of the distribution of arc’s research funding, from basic research to applied research on patients (see Figure 3.4 on page 20). Researchers can select all the boxes into which they feel their research fits. By showing the relationship between different types of research, we hope to clarify the definition of each individual box. Health research is clearly more interconnected and complex than the three, largely independent, pathways we illustrate, but our pathways were a compromise between ease of understanding – so researchers could easily position themselves on it – and accuracy.

The pathway we have developed is designed to allow us to track the development from lab bench to bedside; other systems, such as Health Research Classification System developed by the UKCRC,35 although useful as classification systems, do not allow such clear tracking of the development of particular pieces of research. The research pathway gives an idea of how far research has progressed and how it might progress over the next stages. Repeated sampling (reiterations of the questionnaire) will allow development of research to be seen.

Mapping the portfolio

Although arc has details of all the research it funds, and can classify it according to disease area and funding type, it currently does not classify it by its position on the research pathway. As a result, it is difficult for arc to gauge how much of its research is early stage research and how much is research providing direct insights into improving patient care. To help arc understand how its research is distributed, we developed a chart laying out the main types of research and their links and relationships. This pathway was amended and refined through discussions with the advisory group and subsequent piloting and cognitive interviewing. The pathways can be seen clearly in Figure 3.4, overleaf, which provides a schematic picture of the whole system. In this part of the questionnaire, researchers plot their research position on the pathway.

35 UK Clinical Research Collaboration.
Mapping the impact

Of these approaches, the first three suffered from a range of disadvantages including imprecision, requiring information that the researchers were unlikely to know, and/or being hard for the researchers to understand and use or respond to. We decided to follow the fourth option and devise a very basic classification of the next steps for each project, allied to open questions eliciting a description of the next steps to be taken, and who would be appropriate to carry them out. This section of the questionnaire was developed by arc’s Medical Director, Professor Alan Silman.

Next steps

An important element of the survey system was that it should provide a clear picture of what opportunities there are for arc in the current research it funds. We investigated various approaches to quantifying estimates of the possible, or likely, impact of the research on patient health.

- Assessing (a) the extent of health impact if the research was successful and (b) the likelihood that it would be successful.
- A more qualitative assessment of the likely time to impact and the magnitude of that impact, using impact matrices.
- Asking about the barriers and facilitators to development of the grant.
- Classifying the next steps to be taken for a particular project and exploring them through open questions.

Of these approaches, the first three suffered from a range of disadvantages including imprecision, requiring information that the researchers were unlikely to know, and/or being hard for the researchers to understand and use or respond to. We decided to follow the fourth option and devise a very basic classification of the next steps for each project, allied to open questions eliciting a description of the next steps to be taken, and who would be appropriate to carry them out. This section of the questionnaire was developed by arc’s Medical Director, Professor Alan Silman.

Prediction

There has been much discussion about how accurately the impacts of research findings can be predicted. There are examples both where impact has been easy to predict and others where prediction would have been impossible.
We had intended to cover prediction through the new survey system, asking researchers to hypothesise about the directions in which current and future research was likely to move. We had to let this strand of enquiry go as we moved through the development process. Feedback on prediction matrices we piloted was unfavourable and the steering group felt it was an unreasonable extra step to ask researchers to make.

Because science is seen as fundamentally unpredictable, practitioners are wary of prediction. Nevertheless, the instrument could be adapted to capture prediction as well as results. While we felt that prediction was worth trying, the time was not right and we decided to concentrate on mapping the research that had already been done.

Our priority was to determine the current status of ARC-funded projects rather than to predict future events. We also felt that the questionnaire was sufficiently complicated without introducing something as immeasurable as prediction. However, we suggest that if predicting future impact is to be an important function of such a survey, then the most effective way to address this question is to test whether the predictions of researchers (or others) are accurate or not.
This chapter describes the assessment tool we developed, provides a brief description of the rationale for each section and details the rationale of our IT implementation.

**The structure of the ticklist questionnaire**

The two-part introduction to the questionnaire states its purpose explicitly and provides clear guidance to how it is to be completed. For example, it addresses possible ambiguity about the principal format of responses (Yes / No / Not Known) and explains that the researcher will not have to fill in every question – users have first to navigate the survey and identify the areas pertinent to their work. Researchers are advised that completing the survey will take around an hour and that they can complete it in stages and revisit their responses before submitting their data.

**Research type and research pathway**

The questions in this section ask about the type of research questions that were addressed by grant holders and the experimental systems they used. This section also provides a generic research pathway in which to place research. In turn, this gives an understanding of how ARC research is distributed and where different types of impact arise.

**Next steps**

The data elicited from this section will help arc to understand how their research has (or has not) been developed after end of grant and whether there are barriers to be addressed.

**Future research**

Has the research grant led to further funding and/or new collaborations? How has it contributed to researchers’ careers? Researchers are asked whether they developed any new tools and to identify any tools not mentioned in the list.

**Dissemination**

The section on dissemination looks for information about research results beyond academic publications, for example, seminars, websites, leaflets and media coverage. Respondents have the opportunity to add any that are not mentioned in the list.

**Health policy**

The questions in this section ask for information about healthcare impacts, for example, citations in clinical guidelines, contributions to guideline committees and discussions of health policy.

**Training**

What impact did individual grants have on the training of undergraduates and health professionals?

**Interventions/Products**

The section on interventions and products asks about long-term impacts of research (new treatments, public health advice, etc.) in areas such as drug development, diagnostics, medical devices, physiotherapy and public health advice.

**Comments**

Respondents are encouraged to record their personal comments on the questionnaire, including its ease of use, and especially to suggest categories that might be considered for inclusion in future surveys.

**Implementation**

The initial pilot questionnaire was a paper version and only a small number were sent out. However, testing coincided with three postal strikes, so
mapping the impact

Low burden
The questionnaire had to be presented in a form that minimised demands on grant holders’ time and goodwill. This was achieved by a function that allowed non-applicable questions to be skipped, either manually or by electronic routing.

Ease of interaction
Some of the questions contained graphics and grant holders were asked to position the grant on the image. Some means had to be found to allow for easy insertion of a visual position on a diagram.

Ease of data extraction
The extraction of data from the survey questionnaire had to be quick and simple to allow analysis to begin while the data were being collected.

Data pre-loading
To help researchers recall specific aspects of their grant, the survey had to be personalised to each grant in arc’s portfolio.

Control of responses
Individual grant holders should generate only one response to the questionnaire. A tracking system was needed to monitor who was completing it.

Table 4.1
Pros and cons of various means of implementation

<table>
<thead>
<tr>
<th>Means</th>
<th>1 Emailed Microsoft Office Word document</th>
<th>2 Emailed Adobe pdf</th>
<th>3 Online</th>
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<td>Researcher can respond by email more than once; data unavailable until researcher mails a reply.</td>
<td>Responses logged on the survey server in real time. Access to server controlled by personalised logons and password. Researchers cannot make more than one response.</td>
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<td>Routing at page level; allows for routing on the page currently displayed.</td>
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<td>No easy way to select a visual position on the Research Pathway graphic.</td>
<td>No easy way to select a visual position on the Research Pathway graphic.</td>
</tr>
<tr>
<td>Ease of data extraction</td>
<td>Time-consuming manipulation of individual files to extract data.</td>
<td>Manipulation of groups of files in a group using Adobe Acrobat 8 Professional; easy extraction of data.</td>
<td>Easy extraction of data; some simple analysis possible within the software.</td>
</tr>
<tr>
<td>Other comment</td>
<td>A commercial software package that cannot be acquired gratis. Grant holders need access to Word.</td>
<td>Adobe Reader 7.0 or 8.0, available free; researchers do not need access to specific commercial software.</td>
<td>Online accessibility; can be completed on numerous freely available web browsers.</td>
</tr>
</tbody>
</table>
Means of implementation

Three independent approaches were considered for the implementation of the survey: an emailed Microsoft Office Word document, an emailed Adobe pdf and an online document. The advantages and disadvantages of each are detailed in Table 4.1.

Given the superior flexibility of online surveys over Word and Adobe, we decided to use the former.

RAND Europe already has in-house access to ClassApps.com SelectSurvey.NET 2.8.6.36 This is a commercially available tool written in C# using the Microsoft .NET v2.0 web application framework that has been used extensively in previous online surveys that RAND Europe has administered.37 The arc survey was implemented using SelectSurvey.NET 2.8.6.

Data collection and analysis

Personalised email invitations to complete the survey were sent out to researchers across arc’s portfolio, including basic scientists, research clinicians and health service researchers. Hyperlinks in these email messages took them straight to their individual questionnaire. Completion was monitored online and late respondents were chased through email, telephone calls and personal follow-up from arc. Appendix A contains a copy of the questionnaire that was sent out in 2007, to capture information about arc research grants that finished in 2002 and 2006.

The data were extracted from the online responses and transferred to spreadsheets for analysis using Excel 2007 and the statistical package R.38

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36 Classapps. SelectSurvey.NET Overview.
37 Microsoft Developer Network. .NET Framework Developer Center.
Because we have only surveyed two years of grants it is still early to be drawing substantial conclusions from the dataset. However, to illustrate the potential of the technique this chapter provides some examples of the data collected in the survey. We then summarise the limitations of the approach and consider future uses and developments of the tools.

**Pilot sample, response rates and burden**

Earlier in this report (page ix) we touched on the results from our initial full-scale pilot, in which we surveyed all arc grants that finished in 2006 or 2002. By choosing a delay of two or six years from the end of the grant, we hoped to have allowed sufficient time for many impacts to have developed, and by examining two different years we hoped to be able to see changes over time (although as they were different sets of grants, rather than the same grant followed up at two and six years, it was not a genuine longitudinal sample). Because arc awards grants of differing length we could not select a full variety of grants that both started and finished in the same years; instead, we decided to select grants that finished in the same year. The distribution of start dates of the grants is shown in Figure 5.1.

Our initial sample consisted of 158 grants. We removed from this a few grant types that arc no longer awarded or that posed particular challenges for evaluation because they were not standard “research activity” grants, e.g. equipment grants, travel grants and grants that provided secretarial support. We also removed grants where arc had no contact details for the principal investigator. This left us with 136 grants. After a series of follow-ups from the project team and arc management, we achieved a response rate from the shorter list of 87% (75% of the initial list). Response rates for each year were similar and are broken down in Table 5.1.

The survey instrument we used in the full-scale pilot (included in Appendix A) contained

<table>
<thead>
<tr>
<th>Survey response rates broken down by year</th>
</tr>
</thead>
<tbody>
<tr>
<td>From short list of grants approached</td>
</tr>
<tr>
<td>Overall</td>
</tr>
<tr>
<td>118/136 = 87%</td>
</tr>
<tr>
<td>2002</td>
</tr>
<tr>
<td>66/90 = 73%</td>
</tr>
<tr>
<td>2006</td>
</tr>
<tr>
<td>52/68 = 76%</td>
</tr>
</tbody>
</table>

**Figure 5.1**
The distribution for start dates for the sampled grants

**Figure 5.2**
The time taken by researchers to complete the full scale pilot questionnaire
The impact array illustrates the range of impacts generated by each grant. The impacts assessed include levels of collaboration, additional funding, career progression, publications, citations, policy outcomes and and generation of tools for future research (see impact categories along the top of the array).

Each impact is represented by a coloured block in the graphic – from pink to blue, with pink representing early stages or local effect, and dark blue being developed or international impact. In the pull out below we show a small section of the array in greater detail to show exactly how the grants are represented. The pull out shows the ‘Collaborations’ subsection of the array for two grants. Blocks indicate a ‘Yes’ response to the various questions. Both grants led to new academic collaborations and co-publications, although only Grant Q lead to a successful co-application for funding. Grant Q also led to collaborations with industry. Each grant is represented by a single row of pink to blue blocks, one for each each type of impact. The grants are sorted by total number of impacts, as indicated by the arrows, and as the chart lets you identify those with the highest number of impacts (the grants details are not shown here, just their impacts).

This grants which finished in 2002 and in 2006 have been grouped separately to allow comparison. The red histogram along the central part of the chart shows the total number of each type of impacts for all the grants in each section. It allows us to compare 2002 and 2006 impacts.
initial sections classifying the research questions addressed and the experimental system used. It then asked researchers to map their research onto a research pathway and identify the next stage to which their research might have progressed. The bulk of the survey was the impacts ticklist section. Even with these additional sections at the start, the vast majority of researchers said it had taken them less than an hour to complete the entire questionnaire; the distribution of times taken is included in Figure 5.2.

**Cataloguing outputs and outcomes**

To show the range of impacts from the research we developed a way to display sets of full answers that we term “impact arrays”. Figure 5.3 shows an impact array comparing the grants from 2002 and 2006. Impact arrays show all the impacts of each grant, allowing detailed exploration of data as well as providing an overall impression of the range and number of impacts. Each row of blocks is one grant; each column represents the answers to a question about one type of impact. Hence each coloured block shows one impact, while a white space shows the absence of that type of impact.

The grants are sorted vertically by the number of impacts they produced; grants with more impacts are closer to the middle of the page. This arrangement produces a fish-tail effect, suggesting that there is a correlation between successful production of impacts of one type and the production of other types of impact. Two reflected histograms along the centre of the page show the total number of impacts in each category for the 2002 and 2006 grants respectively.

Looking at the matrix, it can clearly be seen that certain impacts are more common than others: there is a concentration of colour around the early part of the “Collaborations” subsection indicating further academic collaboration and a river of colour under “Academic seminars”; the prevalence of dark blue there shows that much of the work is being presented internationally. Between these, the “Tools for Research” section shows a well-distributed sprinkling of blocks, suggesting that a wide range of grants produce new research tools. There are plainly other forms of dissemination, as indicated by the blocks in the “Other seminars”, “Other dissemination” and “News media coverage” subsections. Notably fewer blocks are seen in the “Health Policy” section. Finally, there is then a sprinkling of blocks showing up in the last section, which shows interventions and products.

Figure 5.3 suggests that the number and distribution of impacts produced by the 2002 and 2006 grants is similar for all but the final categories of impact. This was a surprise, as we expected more impacts to develop over time. There are a number of possible explanations for this, including recall bias (perhaps researchers are better at remembering impacts of recent grants) and rapid impact accumulation (perhaps most impacts have occurred within two years of the grant), or it may be that another factor, such as the personality of the researcher, is a more significant factor than the time lapse since end of grant. It is also possible that the grants finishing in 2002 were of a different character from those finishing in 2006, and there is some evidence that this is the case (see Mapping the portfolio on page 31). However, analysis we have done where we try to match the types of research examined still shows a similar number and distribution of impacts for grants ending in 2002 and 2006.

In order to resolve these questions we need additional data, and genuine longitudinal samples. Given the low burden of the survey tool we have developed it should, over time, be practical to collect such data.

**Unanswered questions and “Not Known” responses**

During the course of the project we wrestled with ways of treating questions that were either left unanswered, or answered as “Not Known”. However, in the pilot this problem proved to be less significant than expected.

To reduce the number of questions the researchers have to work through we use routing questions. For example, when researchers are asked whether their research produced a new animal model, only if they answer “Yes” are they asked to what stage this work was developed. This means there are two ways a question may remain unanswered: because the researcher simply does not answer it or because the researcher never sees it, having answered “No” to the relevant routing question. This proved a very effective technique with, on average, researchers seeing only 40% of the ques-
In the case of “Not Known” answers, we have erred on the side of caution and generally treated them as “No”. Overall 2% of questions were answered “Not Known” and the distribution of these answers is shown as an “Impact array” in Figure 5.4.

Mapping the portfolio

The second strand of the project was to develop a method of mapping the arc research portfolio to supplement the current classification system using key words. As described in Chapter 3, we developed a research pathway on which arc researchers were asked to place their research. In the full-scale pilot, researchers were allowed to choose up to five boxes on the pathway into which their research fell. Most researchers used fewer than four boxes; Figure 5.5 shows the numbers of boxes used.

This mapping allows us to visualise the spread of arc research across the research pathway and...
the distribution for two years of grants is shown in Figure 5.6. For each box there are two bars showing the number of grants sited in that box: for each box a blue bar on the left, for the 2002 grants; and a red bar on the right, for the 2006 grants. The bars height is proportional to the number grants. If there are no grants from a particular year in a particular box no bar is shown.

The figure shows a slight shift towards more clinical and AHP work from 2002 to 2006, although the majority of work is still around “Basic Biological Understanding”. Comparing the two years, it is not clear whether this is a trend or just a difference; this will become evident as further data are collected.

**Relationships and trends**

In addition to visualising the full dataset using impact arrays, we also carried out a series of visualisations combining the research pathway and the impacts information. Alongside this we carried out a preliminary exploration through cross tabs and regressions.

**Pathway and impact visualisation**

We combined the research pathway and impact data to explore which types of research gave rise to particular types of output. Using the impact data, we selected grants that had produced particular classes of impacts, for example grants that had had an impact on health policy. We then showed only these grants on the research pathway as coloured blocks (note different scaling for individual grants).

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**Figure 5.5**
The number of boxes on the research pathway selected by each researcher

**Figure 5.6**
The distribution of ARC grants ending in 2002 and 2006 across the research pathway
On to this we added pie charts that showed the fraction of grants from that box that generated the type of impact in question. Figure 5.7 illustrates this with the grants producing impacts in health policy and those producing either interventions or products. For example, consider the top panel and Box 1 “Epidemiology: Prevalence and Risk Factors”: there were four grants classified in this box (shown by the purple bar) of which one (25%) led to an impact on health policy (shown in the blue pie chart). The impression from the pathways is that a larger fraction of the grants that are positioned later on the pathways have produced impacts, which confirms our expectations.

Caveats and limitations
In contrast to previous studies, where we have looked in great detail at individual cases, the challenge of this project was to develop a system that could be used across a portfolio of work. As a result, a series of trade-offs have had to be made;

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**Box 5.1**

**Relationships examined**

<table>
<thead>
<tr>
<th>Relationships examined using R</th>
<th>Relationships examined visually using Excel graphs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Number of impacts v grant value</td>
<td>• Sort by grant type (fellowship and projects)</td>
</tr>
<tr>
<td>• Number of impacts v grant value separating top and bottom 10%</td>
<td>• Sort by grant value</td>
</tr>
<tr>
<td>• Number of impacts v grant value for separate grant types (fellowships and projects)</td>
<td>• Grouped sort by grant value</td>
</tr>
<tr>
<td>• Number of impacts v grant value for separate research types (basic, clinical, early translational, late translational)</td>
<td>• Sort by interventions/products (Yes, No, Likely to be in the future)</td>
</tr>
<tr>
<td>• For “Biological system understanding” grants on the research pathway, number of impacts v start date</td>
<td>• Grouped sort by lay keyword</td>
</tr>
<tr>
<td>• For “Biological system understanding” grants on the research pathway, number of impacts v end date</td>
<td>• Grouped sort by start date</td>
</tr>
<tr>
<td>• Number of impacts v start date</td>
<td>• Grouped sort by end date</td>
</tr>
<tr>
<td>• Number of impacts v end date</td>
<td>• Sort by number of impacts</td>
</tr>
<tr>
<td>• Number of impacts in 14 different groupings of questions, based on the questionnaire sections v grant value</td>
<td>• Number of impacts in 14 different groupings of questions, based on the questionnaire sections v start date</td>
</tr>
<tr>
<td>• Tools shared v interventions/products</td>
<td></td>
</tr>
</tbody>
</table>

39 The comprehensive R archive network.
Figure 5.7
The distribution of grants producing particular classes of impact

Key: Bar height represents number of grants in box, a single grant is represented as: 

Fraction of grants from box producing health policy impact shown in light blue pie charts.

Key: Bar height represents number of grants in box, a single grant is represented as: 

Fraction of grants from box producing interventions/products impact shown in light blue pie charts.
these have been discussed in detail in Chapter 2 but we summarise them here.

There are three broad categories of limitation: those around timeliness, accuracy and completeness; those concerning quantifying the extent of the impact, which have implications for the level of detail we collected about each impact; and those around attribution and the link between research and impact.

**Quantification**

To minimise the burden of completing the questionnaire we made a very pragmatic decision to collect only simple tickbox answers. This meant that we could collect very little information about each impact. If there is more than one of each type of impact for a particular grant, the overall impact of the grant will be underestimated. We felt that this trade-off was worth making for two reasons. First, we were more interested in mapping the spread of impacts than estimating the net impact. Second, because of the fine granularity of our questions, the chances of there being two or more impacts associated with a particular grant are relatively small. The data from our full-scale pilot backs up this assumption. This issue is most acute when comparing grants of very different sizes.

**Attribution**

Issues around attribution fall into two areas: the extent of the link from the grant to the impact, and whether that link flows from a particular grant or the overall portfolio of work done by the researcher. The researchers we worked with when developing the survey steered us firmly towards a very pragmatic decision to use a threshold approach to attribution. While this minimises misunderstanding and the burden on respondents, there is some loss of subtlety with regard to attribution and linkages. A more important aspect may be that impacts that are linked to the body of work carried out by a researcher, and only peripherally linked to any particular grant, will be missed by this approach.

**Future possibilities**

This work has demonstrated the effectiveness of the impact ticklist and research pathway tools, and they have already been incorporated into a revised end-of-grant reporting system for arc. This is completed six months after the end of grants and will provide a snapshot of the early impacts of the grant. arc is also considering building on the survey of 2002 grants to build up a wave of surveys for grants six years after completion (see Figure 5.8). Each year’s grants are shown on the timeline in the year that they end. The first block on the left represents grants finishing in 2002. (The grey section represents grant types that were not surveyed.) Grants surveyed in 2008 (i.e. those that finished in 2002 and 2006, and each month’s

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Mapping the impact needed to answer such questions. Responses to these types of questions (e.g. Does the research benefit large numbers of patients to a small extent or small numbers of patients to a large extent? What social and economic backgrounds do those patients have?) might allow us to address questions of health equity. Currently, the distribution of research impacts can be examined by type of research or by subject area, using keywords supplied on the grant applications; but it cannot be examined against the extent and nature of disease suffered by patients.

So far the work has concentrated exclusively on cataloguing impacts and mapping research that have already occurred. It would be relatively simple to extend the mapping work to grant applications, rather than completed grants, giving an improved understanding of the grant applications it is receiving and funding.

Moving further into the controversial area of predication, a modified form of the impact ticklist could be used to collect researchers’ predictions of the likely impacts of a grants and potentially their predications of the timescales to these impacts. As we mentioned previously, there are examples of both successful and unsuccessful prediction in science – but prediction, to our knowledge, has not been systematically tested in a grant application context. Clearly reviewers’ opinions could also be canvassed in a similar way. Because of the relatively low burden of the survey, it is an ideal tool to allow the follow-up of such predications. In fact the survey already flirts with prediction – in the final section on products and interventions we added the option “Likely to be in the future” to the standard responses. We did this in response to researchers’ concerns that they could only tick very few boxes in the later stages of the questionnaire. However, these responses could provide an ideal stepping-off point to start to test the accuracy of prediction.

If the tool is to be used for longer-term follow-up, perhaps 10 or 15 years from end of grant, it may be helpful to allow researchers to name their impacts with a short description. This would not need to be highly detailed, or necessarily immediately comprehensible to an outsider, but it could be

Accuracy is a key concern with regard to this method of data collection. It would be useful to carry out additional qualitative research to examine a small sample of the responses in more detail by collecting more information about the grants both from researchers themselves (through interviews) and by methods such as bibliometric tracking, to try and identify impacts of which the researchers may be unaware.

The dataset also raises other interesting questions about the impacts of research and provides a good foundation for selecting cases to investigate issues such as the sharing of research tools or the characteristics of grants producing interventions and products. This work could be carried out alongside work to investigate the accuracy and comprehensiveness of the tool.

Although the tools used for cataloguing impact and to map research have been shown to be effective, further work is needed to perfect survey questions designed to explore the next steps for research projects. This work is ongoing. Another area that could be developed further is quantifying the health benefits attributable to the research, where these have occurred or where they might occur. We carried out some initial work in this area, but felt that researchers would be unlikely to have

Figure 5.8 arc’s plans for further data collection

![Figure 5.8 arc’s plans for further data collection](image)

Each year’s grants are shown on the timeline in the year that they finish. The first block on the left represents grants finishing in 2002. The grey section represents grant types that were not surveyed. Grants surveyed in 2008 are shown in blue (i.e. those that finished in 2002 and 2006, and each month’s ending grants from the first six months of 2008), those that will be surveyed in 2009, 2010 and 2011 are shown in red, orange and green respectively.

Figure 5.8 arc’s plans for further data collection

![Figure 5.8 arc’s plans for further data collection](image)

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the expertise needed to answer such questions. Responses to these types of questions (e.g. Does the research benefit large numbers of patients to a small extent or small numbers of patients to a large extent? What social and economic backgrounds do those patients have?) might allow us to address questions of health equity. Currently, the distribution of research impacts can be examined by type of research or by subject area, using keywords supplied on the grant applications; but it cannot be examined against the extent and nature of disease suffered by patients.

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If the tool is to be used for longer-term follow-up, perhaps 10 or 15 years from end of grant, it may be helpful to allow researchers to name their impacts with a short description. This would not need to be highly detailed, or necessarily immediately comprehensible to an outsider, but it could be

played back to the researchers at the next follow-up point (maybe 5 years later) to jog their memory about the particular impacts they had in mind when completing the questionnaire.

During the early stages of the project we attempted to value different research outputs in common terms – if a PhD is worth 10 points, how many points is a new assay technique worth? There were clearly many challenges with this approach that put it outside the scope of this project. However, such a system would allow overall aggregation of the impacts of each grant. Alternatively, if different stakeholder groups were allowed to devise their own valuation schemes, differences between those groups could be explored.

Conclusions

The survey tool allows us to show the full range and distribution of arc research and its impacts for the first time. Collecting and analysing the data was a relatively light burden on researchers and, when integrated into end-of-grant reporting, it will allow a lower burden in terms of time and cost than previous arrangements, by allowing a reduction in the quantity of narrative data required.

The data revealed that there is a diversity of outcome from arc’s research portfolio and that the tool can capture this. The data collected in the full-scale pilot work will provide benchmarks for comparison when measuring the payback on outcomes from current and future grants.

In terms of impacts affecting patients, 2.5% of arc research has lead to diagnostics, therapeutics or public health advice that is in or nearing use, and 7.6% has generated intellectual property that has been protected or is the process of being so. However, there are no benchmarks for these figures. Despite having results for 118 grants, we have a relatively small total number of each type of patient impact – generally one or two examples – so the true potential of this approach has not yet been realised.

We have developed a robust and effective framework for assessing research impacts and mapping research portfolios that clearly has possibilities for extension. Given arc’s willingness to share the tool, there is also the tantalising possibility that it could form a standard core of impact questions that could be assessed by a range of funders, allowing comparisons and an opportunity for trans-organisational learning. In fact a number of funders, including the MRC, have already used this work as the starting point to develop their own evaluation tools, holding out the possibility that such comparisons may soon be achievable.
References

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The comprehensive R archive network. http://cran.r-project.org/ [Date accessed: 17 February 2009]


Appendix A

Screen shots of the complete arc Research Impacts Questionnaire.

Introduction - 1

Welcome to the arc impacts questionnaire. As we outlined in the invitation email, the questionnaire aims to help arc better understand the diverse range of impacts that have arisen from the research it has funded.

Our testing suggests that the questionnaire should take around 40 minutes to fill in, and you may complete it in more than one go if necessary. There is a second introductory page which explains the structure of the questionnaire.

The questionnaire is split into nine sections. The first two sections ask you to classify your research in terms of the type of questions you are addressing, the experimental systems you were using and in terms of its location on a generic research pathway. The third section asks you what the next stages for the research might be. The main part of the questionnaire then asks you about the wider impacts that have arisen from the work, and a final section gives you an opportunity to provide feedback on the questionnaire itself.

The main part of the questionnaire lists possible impacts of research and asks you which of these have arisen from your grant, primarily as a series of yes/no questions. The first section asks what further research arose (eg new collaborations) and what tools for future research were developed (eg new algorithms). The next section explains how your research has been disseminated, and then asks about any efforts on health policy or education. The final section asks about any new treatments, or health advice, that grew out of the research.

Most of the impact questions ask whether a particular type of impact has arisen and have the following options:

Yes: this impact has arisen, and the arc grant made a substantial contribution to the impact
No: this impact has not arisen, although it might arise in the future, or it has arisen but the arc grant did not make a significant contribution to the impact
Not Known: you are unsure whether this impact occurred

The focus of this questionnaire is on impacts where the arc grant made a substantial contribution, immediate outcomes of the grant and impacts of subsequent work that developed from the grant. Hence some impacts will have been contributed to by more than one grant – for example a new model of disease that was developed through a series of grants. We appreciate that longer-term impacts may be harder to link to individual grants. If in doubt, please include such impacts.

Introduction - 2

Since arc have a wide-ranging funding portfolio (from basic biomedical research through to health services research), there is a huge range of potential outputs and impacts. This means that many will not be applicable to your research, or any particular individual’s research. However, as it is difficult to know which impacts may arise from which research, we need to allow you to review all the possible impacts, although you are likely to look at only a few.

By their very nature some impacts are difficult to describe exactly, so we would encourage you to skim through the questionnaire to allow you to identify the most appropriate places to indicate the impacts of your grant.

Your answers will be automatically saved each time you move to the next page, so you can complete the questionnaire in more than one sitting. When you return to the questionnaire, you will need to skip through your previously completed pages.

To give you an idea where impacts are likely to fail we have provided a brief summary of what is in each section:

1: Research Type and 2: Research Pathway

This section asks about the type of research questions that were addressed, the experimental systems used and provides a generic research pathway in which to allocate your research. The idea is that it will provide a better understanding of how arc research is distributed and what different types of impact arise.

3: Next Steps

This section asks about how the research was developed (or not) after the grant finished. We want to understand more about how arc research develops at the end of a grant and whether there are particular barriers that need to be addressed to encourage this.

4: Future Research

This section asks whether the research grant led to further funding, new collaborations, and how it contributed to researchers’ careers. It also asks whether any new tools that could be useful in further research were developed – such as a new data analysis technique or new reagents. There is also the opportunity to mention any tools that we have not included in our list.

5: Dissemination

This section asks about dissemination of your research results that occurred in addition to academic publications (which have already been collected through your end-of-grant report). It asks about seminars for academic audiences and those aimed at health professionals, as well as other forms of dissemination such as websites, bulletins and media reports.

In addition, there is the opportunity to add other dissemination activities that we have not included.

6: Health Policy

This section asks about impacts healthcare such as if you work was cited in clinical guidelines or if you contributed to guideline committees or other discussions around Health policy.

7: Training

This brief section asks about impacts on the training of undergraduates and health professionals.

8: Interventions/Products

This section asks about long-term impacts such as the development of new treatments or public health advice. It covers such areas as drug development, diagnostics, medical devices, physiotherapy interventions and public health advice.

9: Comments

In this section we would like to gather your comments on the questionnaire so we can improve subsequent versions.

1.1: Research Type - Type of Knowledge

Which of the following areas did your research contribute to an understanding of?

Tick each area you feel constitutes a significant portion of the work. You may tick as many boxes on this page as you like.

1. The work concentrated on the normal/non-pathological state

2. The work concentrated on the condition/disease

   Identification of the condition/disease

   Mechanism/pathology/pathway of condition/disease

   Prevalence of condition/disease

   Risk factors

3. The work concentrated on developing or testing novel interventions into the disease state

   O Yes
   O No
4. The work concentrated on understanding current interventions into the disease state
   - Yes  No

5. The work concentrated on how patients experience the condition/disease
   - Yes  No

6. The work concentrated on how health professionals perceive/consider the disease
   - Yes  No

1.2: Research Type - Experimental System
Which of the following systems did your research make substantial use of? Tick all that apply.

7. used existing data sets
   - Yes  No

8. used in vitro models
   - Yes  No

9. used animal models
   - Yes  No

10. involved healthy volunteers or the public
    - Yes  No

11. involved patients
    - Yes  No

12. examined the operation of healthcare systems
    - Yes  No

1.3: Research Type - Research Design
Which of the following groups had significant input into the design of the research?

13. Clinicians/health professionals
    - Yes  No  Not Known

14. Patients or public
    - Yes  No  Not Known

15. Industrial scientists or industry policymakers
    - Yes  No  Not Known

16. Health policymakers/managers
    - Yes  No  Not Known

17. Non-clinical academic scientists
    - Yes  No  Not Known

18. If other groups were involved in the discussions about the design, please list below

2.1: Research Pathway
An understanding of how the research is distributed across subject areas, but would like to understand how it is spread across different stages/fields of research. The diagram below is an attempt to visualise those areas of research in which the work was conducted and the phase of the cycle the work was conducted in. This is not an exhaustive list nor is the order of the stages that follow the diagram. If the work has developed in a different stage since the completion of the diagram, please indicate this in the second column of the table. Then adjust the stages between listed and shown for illustration. Not all possible boxes are included.

2.2: Research Pathway
If the work based on this grant has developed since the grant ended, please use the following five rows below to indicate which boxes best describe the stage to which the work has now moved. Each box may be used more than once. If more than five boxes are required, please list them below.

Page 4

Page 5

Page 6

Page 7
Appendix A

3: Next Steps
This section asks about how the research was developed (or not) after the grant finished. We want to understand more about how and research develops at the end of a grant and whether there are persistent barriers that need to be addressed to encourage its development. We will need a brief explanation of your answers.

32. The results raise new questions which should be addressed and can be addressed by the same group of investigators.
   ○ Yes  ○ No

33. The results produced require replication in an identical or similar study.
   ○ Yes  ○ No

34. The results raise new questions which require addressing, but these questions need to be addressed by different investigators.
   ○ Yes  ○ No

35. The results produced provide the answer required and there is no obvious new question raised.
   ○ Yes  ○ No

36. The results were mainly negative (or study unable to answer questions) and this line of work is probably at an end.
   ○ Yes  ○ No

37. The results raise new questions which require addressing, but are unlikely to be addressed by any investigators.
   ○ Yes  ○ No

3.1: Next Steps
You suggested that the results from this specific grant raise new questions which should be addressed and can be addressed by the same group of investigators. Please make use of as many or as few boxes as required, continuing in the open text box if necessary.

38. Briefly explain why you feel this option is appropriate.

39. Do you plan to do the further work yourself?
   ○ Yes  ○ No

40. If no, please briefly explain why not.

3.2: Next Steps
You suggested that the results produced from this specific grant require replication in an identical or similar study. If possible please restrict your answers to fewer than 300 words (abstract length).

41. Briefly explain why you feel this option is appropriate.

42. Do you plan to do the further work yourself?
   ○ Yes  ○ No

43. If no, please briefly explain why not.

3.3: Next Steps
You suggested that the results from this specific grant raise new questions which require addressing, but these questions need to be addressed by different investigators. If possible please restrict your answers to fewer than 300 words (abstract length).

44. Briefly explain why you feel this option is appropriate.

45. Briefly outline how important it is that others do this work. Why is this the case?

46. Briefly indicate what could be done to encourage these developments.

3.4: Next Steps
You suggested that the results produced from this specific grant provide the answer required and there is no obvious new question raised. If possible please restrict your answers to fewer than 300 words (abstract length).

47. Briefly explain why you feel this option is appropriate.

48. Briefly outline the significance of this result.

3.5: Next Steps
You suggested that the results from this specific grant were mainly negative (or study unable to answer questions) and this line of work is probably at an end. If possible please restrict your answers to fewer than 300 words (abstract length).

49. Briefly explain why you feel this option is appropriate.

50. Briefly outline the significance of this result.
4.3: Future Research - Research Training
Has the research work on this grant played a key role in any qualifications gained by researchers?
58. Undergraduate research projects
   Yes ☐ No ☐ Not Known ☐
59. Masters
   Yes ☐ No ☐ Not Known ☐
60. MDs
   Yes ☐ No ☐ Not Known ☐
61. PHDs
   Yes ☐ No ☐ Not Known ☐

4.4: Future Research - Research Careers
Has this research made a significant contribution to the career advancement of members of the research team? If so, which of the following were gained?
62. Promotions either from gaining the grant or from work conducted on the grant
   Yes ☐ No ☐ Not Known ☐
   Did you receive a promotion substantially based on winning this grant? ☐ ☐ ☐
   Did you receive a promotion substantially based on your work on this grant? ☐ ☐ ☐
   Did any other member of the research team receive a promotion substantially based on winning the grant? ☐ ☐ ☐
   Did any other member of the research team receive a promotion substantially based on their work on the grant? ☐ ☐ ☐

63. Research group development
   Yes ☐ No ☐ Not Known ☐
   Did this research grant help you establish a new research group? ☐ ☐ ☐
   Did it help sustain the research group? ☐ ☐ ☐
   Did it increase the size of the research group? ☐ ☐ ☐

4.5: Future Research - Tools for Research
This and the following pages explore what tools and resources your research produced, or further characterized, that could be used for future research.
64. Did your research produce a database or collection of data such as digital images, epidemiological or sequence data?
   Yes ☐ No ☐
65. Did your research produce a new quantitative or qualitative data analysis technique, such as an informatics technique, economic model, or statistical model?
   Yes ☐ No ☐
66. Did your research produce a new or significantly improved animal model?
   Yes ☐ No ☐
67. Did your research produce a new or significantly improved cell line?
   Yes ☐ No ☐
68. Did your research produce a new or improved technology or technique, for example, a new method of isolating cells or producing antibodies?
   Yes ☐ No ☐
69. Did your research produce a new or significantly improved physiological or biochemical marker (bio-marker) that was identified and characterized?
   Yes ☐ No ☐
70. Did your research produce a new or significantly improved assay, such as a new antibody or reagent?
   Yes ☐ No ☐
71. Did your research produce a new or significantly improved model of disease?
   Yes ☐ No ☐
72. Did your research produce a new or significantly improved physiological assessment or outcome measure, such as gait analysis?
   Yes ☐ No ☐
73. Were improvements made to the research infrastructure that will contribute to future research, such as new equipment or the establishment of a survey group?
   ○ Yes ○ No

74. Did your research lead to any other contributions not mentioned above?
   ○ Yes ○ No

### Appendix A

**4.5: Future Research - Tools for Research**

This page explores what tools and resources your research produced, or further characterized, that could be used for future research.

#### Page 20

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<tr>
<td>Made available to other researchers?</td>
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<tr>
<td>And/or deposited in a public database or archive?</td>
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#### Page 21

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### 5.1: Dissemination - Academic Seminars

87. Have you, or a member of the group working on this grant, been involved in any of the following presentations to other academics? (See section 2 for definitions. These are not covered in this questionnaire.)

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<td>European/International</td>
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88. Keynote/spoken at a conference, where your expenses were paid? Please tick all that apply. If yes, go to question 3.

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<tr>
<td>European/International</td>
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89. Presented a paper at a conference? Please tick all that apply. If no, go to question 4.

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<thead>
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90. Poster presentation at a conference? Please tick all that apply.

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### 5.2: Dissemination - Non-academic

91. Did you, or a member of the group working on this grant, present the findings of the research to health professionals/policymakers or the public? Was it included in seminars, presentations, open-days or laboratory tours chiefly for/aimed at the public?

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<tr>
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92. Has this research been disseminated to non-academic audiences, such as health professionals/policymakers or the public? Including feedback to human subjects involved in the research?

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93. Has this research been published or covered in the news media?

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94. Has your research been the subject of other dissemination activities?

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### 5.3: Dissemination - Other Seminars

95. Seminars chiefly for/aimed at health professionals? Please tick all that apply. If no, go to question 2.

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96. Seminars chiefly for/aimed at health policymakers (health policymakers could be in government, local administration or trust administration etc.) or commissioners? Please tick all that apply. If no, go to question 3.

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97. Seminars, presentations, open-days or laboratory tours chiefly for/aimed at the public?

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### 5.4: Dissemination - Other Dissemination

98. Dissemination to health professionals?

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99. Websites for health professionals?

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100. Printed material (such as booklets) for health professionals?

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<tr>
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101. If yes, what was the distribution of this printed material? If no, go to question 5.

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102. Dissemination to patients/public?

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103. If yes, was this included (If no, go to question 9):

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104. Printed material (such as booklets) for patients/public?

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### 5.5: Dissemination - News Media Coverage

106. Has this research been the subject of a press release?

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107. Has this research been covered in the media?

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108. Have you been interviewed by the media about this research?

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109. If yes, what type of media interviewed you? If no, go to question 5.

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110. If yes, what was the subject of the press conference?

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5.6: Dissemination - Other Activities

113. For the other dissemination activities, please describe them below.

6: Health Policy

114. Was your research cited by a clinical guideline or other health policy document or in a systematic review?
   - Yes
   - No
   - Do not know

115. Did your grant lead to other impacts on health policy?
   - Yes
   - No
   - Do not know

6.1: Health Policy - Citations

116. Citation in clinical guidelines?
   - Yes
   - No
   - Not known

117. If yes, at what level? If no, go to question 3.

118. Citations in clinical reviews such as those published in the BMJ or Cochrane?
   - Yes
   - No
   - Not known

119. Citations in other policy documents at any level?
   - Yes
   - No
   - Not known

120. Citations in systematic reviews, such as Cochrane reviews?
   - Yes
   - No
   - Not known

6.2: Health Policy - Involvement in Health Policy

121. Did your grant lead to any of the following impacts:

122. If yes, at what level? If no, go to question 3.

7.1: Training - Uptake of research

In your judgment has this research influenced the training of health practitioners or researchers?

123. Has your research fed into training for healthcare practitioners?
   - Yes
   - No
   - Not known

124. If yes, at what level has this occurred? If no, go to question 3.

8. Interventions/Products

Very few pieces of are research will be developed to the stage of providing interventions of products, but some is interested in cases where this has happened. In this section we are interested in whether your research has led to development of health interventions, pharmaceuticals, or otherwise. Please include impacts that can be followed back to your research, not just ones that you were personally responsible for. For example, if a company has developed a drug based on your research which has reached phase 2 clinical trials this would count as an impact.

135. Did your research involve, or lead to, the development or trialing of an intervention delivered by nurses or allied health professionals?
   - Yes
   - Likely to be in future
   - No

136. Did your research involve, or lead to, the development or trialing of a surgical intervention?
   - Yes
   - Likely to be in future
   - No

137. Did your research involve, or lead to, the development or trialing of an improvements in health service delivery, such as improved allocation of operating theatres?
   - Yes
   - Likely to be in future
   - No

138. Has your research led to the development of new, or revised, public health advice?
   - Yes
   - Likely to be in future
   - No

139. Did your research involve, or lead to, the development of a health intervention not described above?
   - Yes
   - Likely to be in future
   - No
### 8.1: Interventions/Products - IP

140. For the research cited by patients, or intellectual property protection, which stages were carried out during the grant, or have happened since?

<table>
<thead>
<tr>
<th>Stage</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chord in a patent</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patent applied for R&amp;D</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patent granted</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patent licensed</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 8.2: Interventions/Products - Pharmaceutical

141. For the therapeutic pharmaceutical product, which stages were carried out during the grant, or have happened since?

<table>
<thead>
<tr>
<th>Stage</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td>Animal tests</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase 1 clinical trial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase 2 clinical trial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Phase 3 clinical trial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On the market</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treating a current pharmaceutical for a new indication or with a new regime</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 8.3: Interventions/Products - Diagnostics

142. For the diagnostic test, which stages were carried out during the grant, or have happened since?

<table>
<thead>
<tr>
<th>Stage</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td>Test development</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proof of concept</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Proof of efficacy</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Regulatory approval</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On the market</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treating a current diagnostic in a new environment or context</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 8.4: Interventions/Products - Medical Devices

143. For the medical device, such as a prosthetic hip, which stages were carried out during the grant, or have happened since?

<table>
<thead>
<tr>
<th>Stage</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prototype development</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial testing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Regulatory approval</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>On the market</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treating a current medical device in a new environment or context</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 8.5: Interventions/Products - AHP

144. For the intervention delivered by nurses or allied health professionals, what type of intervention is it? (Tick all that apply)

<table>
<thead>
<tr>
<th>Type</th>
<th>Yes</th>
<th>No</th>
<th>Not Known</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Podiatry</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Physiotherapy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosocial</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

145. If other, please specify
9.1: Comments

151. If your research has had impacts not captured in this questionnaire, please provide a brief description here:

152. If you have any comments on how we could improve this questionnaire, please provide a brief description here:

153. How long did it take you to complete this questionnaire?
   - Fewer than 30 minutes
   - 30 to 60 minutes
   - 1 to 2 hours
   - 2 to 4 hours
   - Greater than 4 hours
There is increasing pressure for research funders to understand the payback of the research they fund – both to justify their spending and assist in fundraising, and to learn how to spend their money most effectively. This report, prepared for and funded by the Arthritis Research Campaign (arc), describes a series of tools developed to map the arc research portfolio and catalogue the impacts of arc research. These tools were implemented as a web-based questionnaire and this was used to collect initial data from 136 grants that finished in 2002 and 2006. This initial work demonstrated that the questionnaire:

- Provided a unique, visual, mapping of both arc’s research portfolio and the impacts arising from it
- Was acceptable to researchers from basic science, clinical science and the allied health professions, with an 87% response rate
- Was easy for the researchers to complete, taking most researchers less than 1 hour

The data give a snapshot of arc research impacts and provide a foundation for further data collection. By developing a deeper understanding of the research that it funds, arc will be in a better position to decide its strategy for future funding to cure arthritis and alleviate the suffering of those afflicted with the disease.

This product is part of the RAND Corporation monograph series. RAND monographs present major research findings that address the challenges facing public and private sectors. All RAND monographs undergo rigorous peer review to ensure high standards for research quality and objectivity.