

**NCRI**

National  
Cancer  
Research  
Institute

# **NCRI**

**Operating Report 2012/13**



Partners in cancer research

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## 1. Introduction and summary

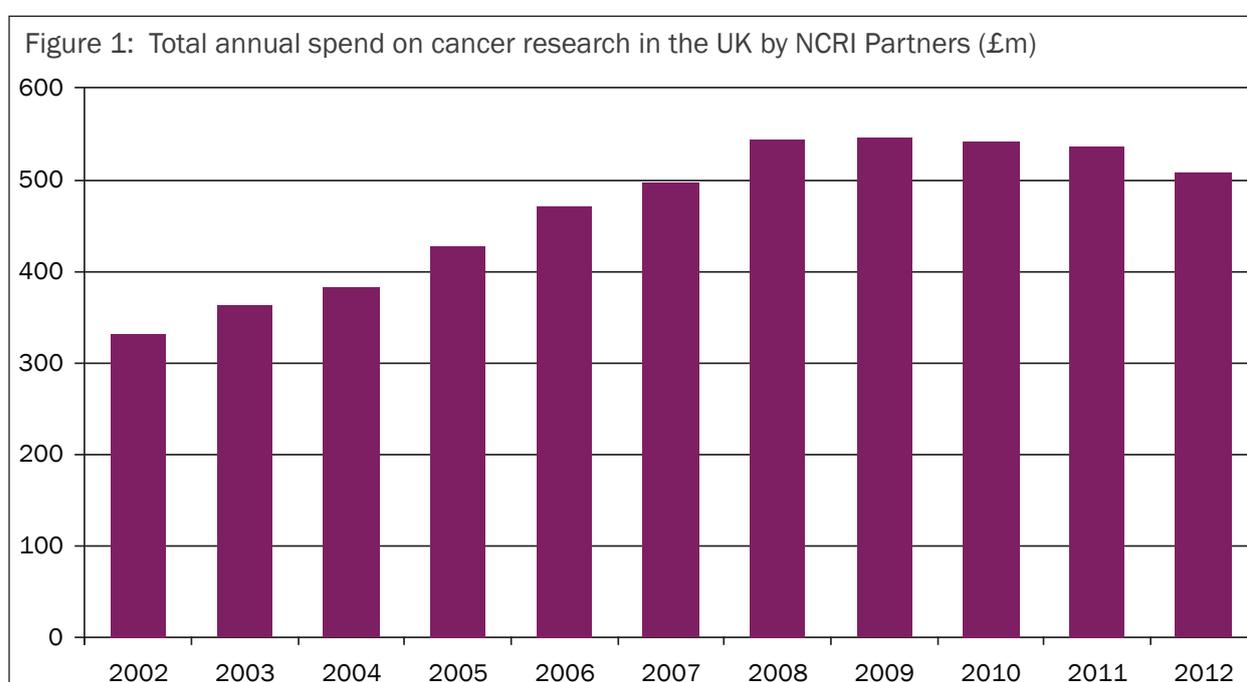
This report summarises the core activities of the NCRI Secretariat during 2012/13, and is intended to provide evidence to Partners that the work of NCRI is being taken forward in an effective and cost-effective manner on their behalf. Details of progress on individual initiatives are now reviewed and reported separately. Appendix A provides a high level summary of the main achievements/outputs during 2012/13. This report covers the first year of the Strategic Plan 2012–2017. The following objectives relating to core business have been met during the year.

- A new process for regular review of current initiatives and future priorities by the Board was successfully piloted in June 2012.
- An analysis of the first ten years of data in the Cancer Research Database was completed and will be published in 2013/14.
- Portfolio data for 2012 were collected.
- Steps were also taken towards improving the financial performance of the NCRI Cancer Conference and these are expected to bring reward in 2013/14 and beyond.

In addition, a major (and unplanned) piece of work was undertaken to plan the merger of the Clinical Studies Group Secretariat with the NCRI Secretariat, to enable it to go forward from 1 April 2013.

## 2. NCRI Cancer Research Database

Collection of the 2012 portfolio data was completed in March 2013 and the data package for the 11 years 2002–12 has been published on the NCRI website. In 2012, Partners spent £507m on cancer research in the UK which compares with a peak of £545m in 2009 (inflation adjusted figures), (see Figure 1).



Recent trends have continued with research in aetiology having dropped from 16.4% of the portfolio in 2002 to 7.5% in 2012. Among tumour types, lung cancer research now comprises 6.7% of the tumour-specific research compared with 3.4% in 2002. A fuller analysis of the first ten years of data was presented to the Partners at their meeting in October 2012, and is currently being prepared for publication.

### 3. NCRI Cancer Conference

In 2012 we piloted a new association with the Royal College of Radiologists aimed at integrating some of their regular meetings into the content of the NCRI event. It is likely that this was responsible in part for more clinicians attending in 2012 than in previous years and is planned to continue in 2013 and beyond.

Delegate feedback again suggested that the programme had achieved a good balance and high quality with over 80% giving an overall rating of 'very good' or 'excellent'. At the same time, 95% of survey respondents said they would recommend the Conference to colleagues.

Following a difficult year in 2011, the financial status of the Conference has been stabilised and some new steps are being taken for 2013 to improve sustainability: an increase in delegate fees, marketing exhibition space ourselves rather than using an agent, and more staff time invested in marketing to both sponsors and delegates. Early signs are that this will pay off.

### 4. NCRI governance and secretariat

As a result of discussions leading up to the Strategic Plan 2012–17, Board business has been streamlined with a clearer focus on decision-making. To provide more time for discussion of work-in-progress, sharing strategies, and networking, we increased the number of full Partners' meetings to two (in October 2012 and February 2013). There is now more opportunity for Partners to lead items at these meetings rather than the agenda mostly being Secretariat-led.

Discussions about the Clinical Studies Groups (CSGs) needing to be more accountable to the NCRI Board, together with developments in the National Institute for Health Research (NIHR) have led to the merger of the NCRI and CSG secretariats under the management of the NCRI Director. This is being implemented from 1 April 2013. The NIHR Cancer Research Network (NCRN) Director continues his clinical role in relation to the CSGs, and in this capacity has been designated NCRI Clinical Research Director for one year in the first instance. He will now report to the NCRI Board on this activity which is expected to take up a day a week of his time.

The process of identifying a new NCRI Director was initiated in January 2013 in anticipation of the current Director's retirement in November 2013.

### 5. Communications

Secretariat support for communication work has been increased and a redesign of the website initiated. In 2013 we published a record number of reports, including the new strategic plan, a report on surgical research and two reports relating to consumer involvement (see below). Our approach to communication generally was reviewed and approved by the Board in February 2013. It was agreed that beyond the website redesign, the next period would be one of refining and evolving the current approach rather than making radical change. In particular, we will explore how we can work through communication channels in Partner organisations, where there may be opportunities which are as yet untapped. It was also agreed that NCRI's primary focus should continue to be on communicating with all sectors of the research community including patients, carers and others affected by cancer. Wider public engagement will continue to be mainly in the domain of organisations with a broader remit than NCRI.

### 6. Involving consumers

Towards the end of 2011, consumers involved in the NCRI Board and other strategic initiatives decided to formalise their previously informal networking group and the 'Hub' was born. The Hub has consolidated its work in 2012/13. It has defined its purpose around helping consumers to see the bigger picture and contribute to wider NCRI work, making connections between different initiatives, maximising communication and strengthening the impact of the consumer voice. In a report submitted in December 2012, they

particularly highlighted their role in:

- influencing the Strategic Plan
- stakeholder mapping (still in progress)
- advice on dissemination of the NCRI PET video
- discussion of research questions in proton beam therapy
- sharing good practice on lay summaries
- general sharing of information on NCRI activities.

Two reports were published in the autumn of 2012. The first, 'Impact of Patient, Carer and Public Involvement in Cancer Research', was published jointly with NCRN. For researchers and clinicians it provides information about how patient and public involvement can contribute to studies. For patients and carers considering involvement, it shows the diversity and value of the opportunities open to them at national, regional and local levels. The second report, 'Action on access: Widening patient participation in clinical trials', was published by the NCRI Consumer Liaison Group. It records the outcome of two years of interaction between cancer patients, carers, clinicians and researchers, and recommends actions that can be taken to widen patient participation in clinical trials.

## 7. Impact of NCRI initiatives

We have agreed that during the 2012–17 Strategic Plan period we will become more proactive in evaluating partnership initiatives, using and adapting tools already available within Partner organisations. A project has been initiated to capture the benefits from the Supportive and Palliative Care (SuPaC) Collaboratives based on a questionnaire and telephone interviews. Specific aims are to understand benefits that are feeding through to patients, to help promote further application and uptake, to document benefits which have accrued to the research community and to identify any actions needed to sustain those benefits.

## 8. International activities

The International Cancer Research Partnership (ICRP), of which NCRI is a member, published its first data report in 2012 (<https://www.icrpartnership.org/publications.cfm>). This covers the period 2005–8 and includes data from all the major funders in the USA, Canada and UK as well as the Institut National du Cancer in France (some 50 organisations in total). The total spend captured during this period amounted to 19bn US dollars. The overall pattern of strengths (in biology and treatment) and relative weaknesses (prevention and cancer control, survivorship and outcomes) is similar to that in the UK, though less marked. The ICRP is expanding, with individual funders from the Netherlands, Australia and Japan now submitting data. NCRI is also participating in an EU collaboration known as TRANSCAN which includes a work package on portfolio analysis in which 16 European countries are involved. Our role is to provide training in the use of the Common Scientific Outline (CSO) and to assist in coding some projects. It is hoped that this initiative will lead to more European countries joining ICRP.

During the year, the NCRI Director has also participated in two meetings of the research workstream on the European Partnership for Action Against Cancer (EPAAC). EPAAC itself is led by the health ministries of EU countries and mainly focuses on healthcare and policy; the work package aims to join up with wider initiatives and is looking at topics such as collaboration with industry, prevention and cancer intelligence, and aiming to set up pilot collaborative projects. The UK role is mainly to pass on our experience of partnership working in these areas at national level.

## 9. Stakeholder environment

NCRI has had to keep abreast of many changes being implemented by the Westminster Government, the implications of which for research are not yet fully clear, for example:

- GP-led commissioning in the NHS in England
- a new 'outcomes framework' in which the role of the National Cancer Director has been reduced to part-time
- a restructuring of the NIHR disease-specific networks to produce integrated networks from 2014
- the formation of Public Health England and the transfer of the National Cancer Intelligence Network (NCIN) to that new organisation.

Following the CSG and NCRI Secretariat merger, some relationships within the NCRI Partnership and initiatives are also being rethought. These include whether industry contacts can be more 'joined up' across all phases of trial and the possible inclusion of phase 1 studies and experimental cancer medicine in the work of the CSGs.

## 10. Forward look

Key objectives for the year ahead and which relate to core business are:

- explore opportunities for synergy and integration between the work of the CSGs and other NCRI initiatives
- further exploration of how strategic oversight can be achieved across all phases and types of study (including those involving industry and international studies)
- set up the new Clinical and Translational Strategy Group (CTSG)
- review the role of NCRI Clinical Research Director
- consult Partners on how Partner contributions are calculated
- prepare a simple memorandum of understanding for Partners to consider
- publish the ten-year analysis from the Cancer Research Database
- improve the financial performance of the NCRI Cancer Conference whilst maintaining delegate numbers
- complete and publish the evaluation of the Supportive and Palliative Care Collaboratives
- complete recruitment and briefing of new NCRI Director.

Objectives for the initiatives are itemised separately elsewhere.

## Appendix A: Highlights from NCRI initiatives during 2012/13

Topic	Outputs
Surgical research	Approval of report by the Board, publication on NCRI website and dissemination at NCRI Cancer Conference and elsewhere.
Imaging	Results of survey (n=157) analysed and report published on NCRI website. Themes for action identified: <ul style="list-style-type: none"> <li>• close collaboration and interdisciplinary working</li> <li>• making imaging data work harder.</li> </ul>
Clinical and Translational Radiotherapy Working Group (CTRad)	<ul style="list-style-type: none"> <li>• Two all-workstreams meetings for proposal development (80–100 investigators at each).</li> <li>• Workshops on biomarkers, microenvironment and signal transduction, radiotherapy in pancreatic cancer, and clinical trials for young investigators.</li> <li>• Planning for proton therapy research in four domains: physics; clinical trials; clinical methodologies; ion beams and biology.</li> <li>• Clinical Oncology Academic Think Tank meeting.</li> <li>• CTRad consumers created and shared guidance to improve lay abstracts in radiotherapy.</li> </ul>
Supportive and Palliative Care	Scholarship scheme in lung cancer launched.
End of Life Care Research Interest Group (eolcRIG)	<ul style="list-style-type: none"> <li>• Launch meeting of the UK eolcRIG May 2012 and agreement on priorities for the group.</li> <li>• Publication of UK eolcRIG members' statement of intent on the NCRI website and in BMJ Supportive and Palliative Care.</li> <li>• Circulation of regular bulletins of research-relevant projects, calls and conferences.</li> <li>• Growth of the UK eolcRIG from 24 to 29 members.</li> </ul>
PET Core Lab	<ul style="list-style-type: none"> <li>• Agreement to provide quality assurance for four new trials.</li> <li>• All the fixed PET scanning sites that desired accreditation have now achieved this.</li> <li>• The Core Lab has also accredited several international sites in Italy, Australia, Denmark, Ireland, Sweden and Norway.</li> </ul>
Confederation of Cancer Biobanks (CCB)	<ul style="list-style-type: none"> <li>• Membership increased from 24 to 28 banks.</li> <li>• Two member-hosted meetings.</li> <li>• Further development of functionality of Biosample Directory and increased listings to 30 biobanks plus 35 clinical trial collections.</li> </ul>

<p>Biobanking Harmonisation</p>	<ul style="list-style-type: none"> <li>• Enthusiasm in the community has continued to fuel the steering group and four working groups leading to:</li> <li>• A first draft of the quality standard (27 clauses).</li> <li>• Development of an accreditation scheme based on peer review.</li> <li>• Piloting of an inspection process.</li> <li>• Preliminary discussion with the UK Accreditation Service (UKAS) to explore whether they might adopt the scheme in future.</li> </ul>
<p>National Cancer Intelligence Network (NCIN)</p>	<ul style="list-style-type: none"> <li>• Assisted in the design of 25 new research studies.</li> <li>• Communication plan agreed and implementation begun.</li> <li>• Progress in linking NCIN data to research cohorts such as UK Biobank.</li> </ul>
<p>National Awareness &amp; Early Diagnosis Initiative (NAEDI)</p>	<ul style="list-style-type: none"> <li>• Research conference planned to take place in April 2013</li> <li>• Third call for proposals planned for launch in April 2013.</li> </ul>

## Appendix B: Budget outturn for NCRI Secretariat 2012/13 (excluding CSGs)

	Proposed budget 2012/13 £k	Final outturn 2012/13 £k
Staff salaries and on-costs	444	418
Service agreement with Cancer Research UK	80	61
Office consumables	8	8
Travel and subsistence for Secretariat and Chair	8	7
Meetings	15	20
Exhibition stand	9	7
Public relations	20	20
Design and print (incl website)	10	9
Training	6	3
Consultancy	2	1
IT including website and desktop support	18	13
International Cancer Research Partnership	20	20
Database maintenance	3	2
<b>Total expenditure</b>	<b>643</b>	<b>589</b>
Less carried forward funds	(19)	(19)
Less property services refund for 2011/12	0	(13)
Conference contribution	195	195
<b>Net expenditure</b>	<b>819</b>	<b>752</b>

## Appendix C: Budget outturn for Clinical Studies Groups Secretariat 2012-2013

	Budget 2012/13 £k	Outturn 2012/13 £k
Staffing costs inc pension and NI contributions	221,515	204,021
Training and development	1,727	415
Consumables, stationery, printing, photocopying , and other misc	18,405	10,274
Building, project management and IT service charges	79,115	55,877
CSG meeting costs, travel and subsistence	188,950	183,213
<b>Total</b>	<b>509,712</b>	<b>453,800</b>

## Appendix D: Risk management

### 1. Introduction

The Secretariat assesses the high level risks to NCRI as an organisation in April each year, and identifies mitigation action required. This process only includes risks over which the Secretariat has some influence or control. The research networks and initiatives have responsibility for managing their own risks.

The Secretariat continues to monitor these risks throughout the year. Any which are, at any time, identified as having a high probability will be regarded as business critical and will be reported to the Board without delay, together with a proposed mitigation plan.

The NCRI risk assessments for April 2012 and 2013 are summarised below, together with actual and planned mitigation actions. There are currently no significant causes for concern and the risk of the Conference failing to meet financial targets has been reduced from Medium to Low this year

### 2. Ongoing risks

	Risk	Assessment in 2012	Planned mitigation in 2012	Mitigation action achieved in 2012/13	Assessment in 2013	Planned Mitigation in 2013/14
1.	The Partners decide that NCRI no longer adds value.	Probability  LOW  Impact  HIGH	Pilot new more flexible approach to assessing progress and priorities in June 2012	Pilot warmly welcomed by the Board; agreed to adopt as new annual process	Probability  LOW  Impact  HIGH	No new action planned. Recruitment of new Director is evidence of Partners' ongoing commitment
3.	The NCRI Cancer Conference fails to meet its (financial) targets, with consequent damage to reputation.	Probability  MEDIUM  Impact  HIGH	2012 has been treated as an 'austerity year' and inessential costs excluded from the budget. Staff turnover has provided the opportunity to bring in additional capacity and new skills which will enable a review of the financing, and enhance the marketing of the event to both sponsors and delegates	Financial performance in 2012/13 was adequate. Steps have been taken which should lead to better performance in 2013 – already a new major sponsor has been secured. Successful alliance with RCR.	Probability  LOW  Impact  HIGH	Trade Exhibition now being organised in-house; delegate fees will be modestly increased. Potential new sponsors being courted; marketing to delegates also being beefed up

## 2. Ongoing risks (continued)

Risk	Assessment in 2012	Planned mitigation in 2012	Mitigation action achieved in 2012/13	Assessment in 2013	Planned Mitigation in 2013/14
4. Actions are agreed by the Board, but funders decline, or are unable, to provide funds to take them forward.	<p>Probability</p>  <p>MEDIUM</p> <p>Impact</p>  <p>HIGH</p>	The focus has now switched mainly to consideration of actions which can be supported through existing resource rather than needing new money, although the coordination of biobanking will need to be refinanced if it is to continue. The case for this will need meticulous preparation	Future of biobanking is still under consideration (there are dependencies beyond NCRI's control)	<p>Probability</p>  <p>MEDIUM</p> <p>Impact</p>  <p>HIGH</p>	Balance between core and non-core work to be considered as part of wider Partner consultation on how Partner financial contributions are calculated
5. NCRI fails to capture data from partners for the Cancer Research Database leading to a gap which cannot be filled retrospectively	<p>Probability</p>  <p>LOW</p> <p>Impact</p>  <p>HIGH</p>	Data collection for 2011 is in hand and ten-year trend analysis being undertaken. International analyses also to be published. The interest so generated should help to maintain motivation among Partners to supply their data	International analysis published and ten year NCRI analysis presented to Partners. 2012 data collection not completed in time for Partners' meeting in February 2012	<p>Probability</p>  <p>LOW</p> <p>Impact</p>  <p>HIGH</p>	Ten year analysis to be published. Some European data will also become available from the TRANSCAN project. Letter to Partners to remind of importance of meeting deadlines and responding to queries in a timely manner

## 3. Closed risks

Risk number 2 – that NCRI loses its identity as part of a wider UK Clinical Research Collaboration – was closed in 2009.

## Appendix E: Progress and priorities

Activity templates aim to give Board members a bird's eye view of the current catalogue of activities and to give an idea of the amount of core Secretariat resource and/or dedicated funding that is being used. Activities are divided into three categories as shown in the table below. The numbering in the table cross-refers to the activity templates.

Category 1: Exploratory activities managed by the Secretariat with core resource only	Category 2: Infrastructural activities managed mainly by the Secretariat with some dedicated resource	Category 3: Partner-led research funding initiatives
Surgical research (1)	CTRad (6)	NPRI (12)
Imaging research (2)	Survivorship after cancer (7)	NAEDI (13)
Cancer inequalities (3)	UK End of Life Care Research Interest Group (8)	
Childhood cancer research (4)	PET Research Initiative and Core Lab (9)	
Cancer 52 portfolio analysis (5)	Confederation of Cancer Biobanks (10a)	
Cancer and Diabetes (14)	Biobanking harmonisation project (10b)	
	Follow up to Funders' Vision for human tissue resources (10c)	
	Follow up to Pathology Report (10d)	
	NCIN (11)	

## **Activity templates category 1:**

### **Exploratory activites**

<b>Name of activity</b>
Surgical research: identifying challenges and opportunities for action
<b>Why are we doing it?</b>
Although surgery is central to the treatment of cancer patients, surgical research forms a very small part of the research portfolio, despite the major role of surgery in cancer. The NCRI report on the challenges and opportunities in surgical research identified areas where action could help to boost surgical research, which now need to be taken forward by Partners.
<b>Who is in the lead?</b>
NCRI Secretariat
<b>Type of activity</b>
Exploratory
<b>Is there dedicated funding?</b>
No
<b>Core secretariat resources allocated</b>
0.4 FTE Programme Manager (AF) from end of Feb 2013; 0.1 FTE Head of Programmes (JM)
<b>Overall aims at outset</b>
<ul style="list-style-type: none"> <li>To gather information on the current status of surgical research in the UK, the barriers to research, and initiatives already under way.</li> <li>To identify ways in which surgical research can be strengthened by NCRI Partners and other organisations, including those with remits beyond cancer.</li> </ul>
<b>Specific objectives at outset</b>
<ul style="list-style-type: none"> <li>Produce an NCRI report on the challenges and opportunities in surgical research, which contains areas for action agreed to by NCRI Partners.</li> <li>Agree with Partners and other organisations who will take on these actions.</li> </ul>
<b>Start date</b>
2011
<b>End date</b>
Core Secretariat support currently available until early 2014; update on progress will be presented to Board in February 2014 for consideration of whether further Secretariat-led work is needed, and its timescale.
<b>Planned outputs April 2012–March 2013 - objectives set last year</b>
<ul style="list-style-type: none"> <li>Board sign-off of report in June 2012.</li> <li>Report to be published on NCRI website and in hard copy once approved by the NCRI Board.</li> <li>Finalise actions and timescales with Partners and other stakeholders, and begin delivery.</li> </ul>
<b>Actual outputs April 2012–March 2013</b>
<ul style="list-style-type: none"> <li>Report approved by the NCRI Board.</li> <li>Report published on NCRI website and in hard copy; dissemination via and Royal College of Surgeons England (RCS), Working Group on Growing Recruitment in Surgical Trials (GRIST) and at the 2012 NCRI Cancer Conference.</li> <li>Working relationships established between NCRI Secretariat and RCS, both at a strategic level (seat on RCS Steering Committee) and an administrative link for connecting up on future activities.</li> <li>Additional activities have begun to be led from within the surgical community, often with Partner organisations taking an active role by putting forward funds or contributing to workshops. NCRI has been tracking these activities, offering input where helpful, and planning our 2013–14 outputs to complement them.</li> </ul>

**Planned outputs April 2013 – March 2014**

- Organise and promote an NCRI Cancer Conference parallel session on surgery, with an accompanying surgical trainee workshop.
- Chart the activities and initiatives that are happening to capture an overall picture and determine what is proving effective.
- Compile funding opportunities for surgical research, and promote through colleges and associations. To include quotes from surgeons on funding boards and individuals funded by schemes currently, to provide additional guidance. This will also highlight any gaps to research funders
- Consider a CSG workshop or similar to bring surgeons together for further ideas.
- Monitor Hisham Mehanna’s scheme to introduce three trainee surgeons into Head & Neck CSG subgroup for trial development experience; could be built on if successful.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- Increased activity within surgical oncology research in the UK (which in due course can be captured in the NCRN portfolio, trials recruitment numbers and NCRI Cancer Research Database)
- Influence among the wider community of surgeons, surgical researchers and research funders, where the issues are not specific to cancer.

**Sustainability plan**

Not applicable to exploratory work.

**Issues and risks**

- A small number of enthusiastic surgeons have been very resourceful with securing funds for workshops and working groups over the past year or two, from a range of sources. A centrally funded NCRI initiative does not appear to be needed, but there does need to be a willingness from funders to support standalone activities if this work is to achieve success.
- NCRI Secretariat input has been welcomed by the surgical groups and has allowed sharing of experience from capacity building initiatives like CTRad, as well as a chance to give cancer a share of voice. It would be useful to keep these links active after an end date for the project is set.

**External profile**

- NCRI has formed strong links at RCS England and at GRIST; although neither route has independent funding for taking forward initiatives, this offers channels for cascading information to surgeons.

**Links to other NCRI or related activities**

- NCRI Secretariat staff participate in the GRIST working group and on the Steering Committee of RCS England Surgical Research Institute (CRISC).
- A number of NCRI partners have investments or activities of some kind in surgical research, but at this exploratory stage there are no other formal links.

<b>Name of activity</b>
Imaging research in cancer: is there a continuing role for NCRI?
<b>Why are we doing it?</b>
Imaging is used at all stages in the cancer treatment pathway, including diagnosis, screening and follow-up. In anticipation of the conclusion of the PET initiative in 2012, the Board questioned whether there was a need to coordinate imaging research more broadly, looking across modalities and disciplines, and whether there was a niche for NCRI in this.
<b>Who is in the lead?</b>
NCRI Secretariat, with advice from Professor Dame Janet Husband.
<b>Type of activity</b>
Exploratory
<b>Is there dedicated funding?</b>
No
<b>Core secretariat resources allocated</b>
0.4 FTE Programme Manager (AF) from end of Feb 2013; 0.1 FTE Head of Programmes (JM).
<b>Overall aim</b>
To identify whether NCRI should play a role in coordination of, or infrastructure provision for, any wider aspects of imaging research in the UK, beyond the existing work on PET.
<b>Specific objectives</b>
To gather more information on what is working well and what may need further collaborative support to succeed in this diverse, multidisciplinary field of research.
<b>Start date</b>
2011
<b>End date</b>
Core resource allocated until early 2014.
<b>Planned outputs April 2012–March 2013 – objectives agreed last year</b>
<ul style="list-style-type: none"> <li>• Report of imaging survey results to be published on NCRI website.</li> <li>• Structured roundtable meeting held in April 2012 to discuss community feedback on current status, strengths, weaknesses, opportunities and barriers in UK imaging research and identify priorities for action.</li> <li>• Discussions to be held with Partners about opportunities for collaborative working – informally and at Partners’ meeting in October 2012.</li> </ul>
<b>Actual outputs from April 2012–March 2013</b>
<ul style="list-style-type: none"> <li>• Results from imaging survey (n=157 responses) analysed and report published on NCRI website.</li> <li>• Roundtable meeting held in April 2012, with two possible themes for action identified: <ul style="list-style-type: none"> <li>– Closer collaboration and interdisciplinary working in clinical imaging research</li> <li>– Making imaging data work harder.</li> </ul> </li> <li>• Discussion at Partners’ meeting in October 2012 and encouragement to continue, in so far as core resource permits, with further scoping across these two themes to determine whether NCRI can add value.</li> </ul>

**Planned outputs April 2013–March 2014**

- Mapping exercise to document what groups and organisations are present in imaging to identify strengths and weaknesses, and areas where more coordination or collaboration ('joining up') is required. Further scoping across the two themes above to determine whether the NCRI can add value.
- Support NCRI Biomarkers & Imaging CSG with the setup of its new Imaging subgroup, and with their aim to support imaging work across CSGs.
- Pilot of a clinician-led prioritisation of imaging topics in 1-2 CSGs, to identify areas where research could have the greatest patient impact; could be expanded if deemed useful.
- Continue the search within the research community for a champion and focus for NCRI coordination work.
- Explore whether there is a business case for a Core Lab for MRI.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

A clear understanding of whether and how NCRI can add value, by early 2014.

**Sustainability plan**

Not applicable to exploratory work.

**Issues and risks**

- This work needs a champion currently in the field to drive it forward, and such a person has not yet emerged. In the meantime, the NCRI Biomarkers and Imaging CSG and ECMC Imaging Network Group are the main foci of interaction.
- Some researchers are still having problems in accessing NHS funding for scans in trials and such concerns have made many sceptical about the value of taking on more innovative projects unless this becomes easier.
- The community is concerned about fragmentation of effort but the field is so large and diverse that it may not be possible to define something of appropriate scale that NCRI can do to help overcome this. However, the concept of QA initiatives akin to the PET Core Lab for other modalities is frequently raised as a necessary next step to advance research.

**External profile**

None at present, though some imaging groups (e.g. Biomarkers & Imaging CSG, ECMC Imaging Network Group) are aware that NCRI has been exploring this topic.

**Links to other NCRI or related activities**

- Builds on the work started in the NCRI PET Research Initiative; ongoing NCRI PET Core Lab may be a model for other similar activities.
- Has some shared goals with CTRad, in respect of both image guidance and radiotherapy planning.

<p><b>Name of activity</b> Cancer inequalities: identification of research priorities and opportunities</p>
<p><b>Why are we doing it?</b></p> <ul style="list-style-type: none"> <li>• In response to a request from Sir Mike Richards to respond to needs identified in the National Cancer Equality Initiative (NCEI) in England.</li> <li>• In recognition of known inequalities across all parts of the UK, some highlighted in reports prepared by NCIN</li> </ul>
<p><b>Who is in the lead?</b> NCRI Secretariat in conjunction with NCEI and NCIN.</p>
<p><b>Type of activity</b> Exploratory</p>
<p><b>Is there dedicated funding?</b> No</p>
<p><b>Core secretariat resources allocated</b> 0.1 FTE Head of Programmes (KG)</p>
<p><b>Overall aims</b></p> <ul style="list-style-type: none"> <li>• To explore how to: <ul style="list-style-type: none"> <li>– build a community of researchers focussed on identifying cancer inequalities and how to overcome them</li> <li>– encourage and empower this community to identify research gaps and opportunities, to take forward ideas and get them funded via the existing funding streams.</li> </ul> </li> <li>• To promote research relating to inequalities in respect of older age, gender and socioeconomic deprivation in particular.</li> </ul>
<p><b>Specific objectives</b></p> <p>To hold a workshop/conference of researchers to:</p> <ul style="list-style-type: none"> <li>• discuss research in progress and needs and opportunities for further research: specifically focusing on research to determine the causes of specific cancer inequalities and/or to develop and test interventions to prevent or overcome them.</li> <li>• bring together researchers from the multiple and varied research disciplines required to carry out high quality research aimed at resolving cancer inequalities.</li> </ul>
<p><b>Start date</b> March 2011 at the NCRI Partners' meeting.</p>
<p><b>End date</b> Exploratory work came to an end during the last year</p>
<p><b>Planned outputs April 2012–March 2013 – objectives agreed last year</b></p> <ul style="list-style-type: none"> <li>• Prepare meeting proposal for review by a planning group</li> <li>• Determine budget requirements for the meeting and seek external contributions if required.</li> <li>• Organise the researcher meeting to take place by March 2013 according to recommendations of the meeting planning group.</li> </ul>

**Actual outputs April 2012 – March 2013**

It did not prove feasible to organise the research meeting/conference as it was not possible to agree with community or the NCEI on what the focus of such an event should be: The cancer inequalities agenda cuts across the cancer pathway from prevention to end of life care and has many dimensions (age, gender etc). Without a clear focus or leadership from the community, the NCRI's impact in this area would be limited. There was also a need for the NCRI not to duplicate effort where other stakeholders were leading on activities relevant to cancer inequalities, for example the Men's Health Forum on men and cancer.

**Planned outputs April 2013–March 2014**

It is currently not feasible for the NCRI to achieve significant outputs in cancer inequality. The NCRI will maintain a 'watching brief' in this area looking out for new opportunities for action. NCRI will continue to engage with:

- Joanne Rule, as co-Chair of the NCEI
- The Men's Health Forum, following their hosting of a The Men and Cancer Expert Roundtable, 29 Jan 2013
- Macmillan Cancer Support, as they undertake a scoping exercise on older people and cancer which will include a research prioritisation component in which the NCRI will participate.
- NAEDI initiative and inequalities relating to cancer awareness and early diagnosis, which may be addressed through NAEDI Research Call 3.
- The NPRI initiative, which funds a number of awards addressing inequalities and health behaviours. The area of prevention will undergo a review during 2013 (see summary on NPRI) which will inform what, if any, further work in this area should follow.

**Looked-for outcomes and success factors by end date or as ultimate legacy – may not now be delivered**

- Development of new links between those with an interest in cancer research, behavioural research, epidemiology and health inequalities.
- Generation of greater awareness of cancer inequalities and the research opportunities in the field.
- Funding, through existing research funding streams, of an increased number of high quality research proposals to understand or address cancer inequalities.

**Sustainability plan**

Not applicable to watching brief

**Issues and risks**

Not applicable to watching brief

**External profile**

More information about NCEI (which stemmed from the 2007 Cancer Reform Strategy for England) can be found at [www.cancerinfo.nhs.uk/healthcare-professional/ncei](http://www.cancerinfo.nhs.uk/healthcare-professional/ncei).

**Links to other NCRI or related activities**

- NCIN have published a number of reports that are relevant: [www.ncin.org.uk/publications/reports/default.aspx](http://www.ncin.org.uk/publications/reports/default.aspx)
- NPRI and NAEDI initiatives have some relevant projects
- Men's Health Forum: [www.menshealthforum.org.uk/](http://www.menshealthforum.org.uk/)
- Macmillan Health and Social pages on Older People pilots: [www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/Improvingervicesforolderpeople/ProjectImprovingcancertreatment,assessmentandsupportforolderpeople.aspx](http://www.macmillan.org.uk/Aboutus/Healthandsocialcareprofessionals/Macmillansprogrammesandservices/Improvingervicesforolderpeople/ProjectImprovingcancertreatment,assessmentandsupportforolderpeople.aspx)

**Name of activity**

Childhood cancer research

**Why are we doing it?**

- Community request for review of academic paediatric oncology thought by the Board in March 2010 to be disproportionate and untimely in aftermath of restructuring.
- Community organised a workshop and analysed strengths and weaknesses themselves, as reported to the NCRI Board in June 2011. Board agreed that NCRI would contribute an analysis from the NCRI and ICRP portfolio databases to help understand the portfolio.

**Who is in the lead?**

NCRI Secretariat

**Type of activity**

Analysis from the NCRI Cancer Research Database (CaRD) and International Cancer Research Partnership (ICRP) Database

**Is there dedicated funding?**

No

**Core secretariat resources allocated**

0.1 FTE Research Analyst (TW), < 0.1 FTE Head of Programmes (JM).

**Overall aim**

To give children's cancer researchers an overview of what activity is funded and by whom, to allow them to benchmark the UK situation against activity elsewhere and inform future research planning.

**Specific objectives**

- To analyse childhood cancer research funding in the UK, France and North America, using the NCRI CaRD and data from members of the ICRP, using the 2008 ICRP dataset as this was the most recent year available at time of analysis.
- To go through the process of performing this type of international portfolio analysis for the first time, determining the feasibility and usefulness of doing so, and enabling refinement of processes.

**Start date**

2012.

**End date if known**

- Originally expected to be concluded in late 2012, but there were some data compatibility/integrity issues to deal with in using the international data set for the first time, and the planning input from the paediatric community was slow to materialise.
- Now expected to be completed in summer 2013. Wider sharing/publication will depend on approval from international partners.

**Planned outputs April 2012–March 2013 – objectives agreed last year**

- Analysis to be undertaken and report created.
- Short report of data analysis to go on NCRI website once complete, and be circulated to key members of the children’s cancer research community.
- Discussion of the analysis, interpretation and implications with the children’s cancer Chair’s forum, followed by further report to the Board.

**Actual outputs April 2012–March 2013**

Methodology planned, dataset compatibility worked out, and initial analysis undertaken. Other actions delayed as indicated above

**Planned outputs April 2013–March 2014**

- Discussion of the data outputs, interpretation and implications with the children’s cancer Chairs’ forum. Final approval of report to be sought from ICRP.
- Short report of data analysis to go on NCRI and ICRP websites once complete, and be circulated to key members of the children’s cancer research community.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- Improved strategic planning by the children’s cancer research community in the UK.
- Growing confidence in the data capture and access processes, willingness to share information, and better understanding of the resource required to undertake this type of funding analysis amongst international partners.

**Sustainability plan**

Not applicable: a one-off project that will conclude upon report publication.

**Issues and risks**

Small risk that one or more ICR Partners may choose not to allow their data to be used in the published analysis.

**External profile**

None as yet.

**Links to other NCRI or related activities**

- Draws on data within the NCRI Cancer Research Database and International Cancer Research Partners’ database.
- Children with Cancer are doing a separate analysis of children’s cancer funding using NCRI CaRD data, for their own strategic planning; NCRI’s international analysis will complement this.

<b>Name of activity</b>
Working with the Cancer52 group of charities
<b>Why are we doing it?</b>
There is increasing awareness of the need to consider research in respect of the less common cancers as well as ‘the big four’. Cancer52 acts as a focus for such interests in the charity sector. They feel that the £1m threshold for membership of NCRI unfairly excludes their members, and are looking for other means to engage with us.
<b>Who is in the lead?</b>
NCRI Secretariat
<b>Type of activity</b>
Exploratory including portfolio analysis
<b>Is there dedicated funding?</b>
No
<b>Core secretariat resources allocated</b>
None were allocated during 2012/13. Work will now be undertaken by an intern (12 week placement) under the supervision of the Research Analyst (0.1 FTE).
<b>Overall aim</b>
To compile and analyse data on the research undertaken by Cancer52 members (a minority of their 60+ members), using the methods used for NCRI portfolio analysis.
<b>Specific objectives</b>
<ul style="list-style-type: none"> <li>• Collect abstract and financial data from Cancer52 members and (where appropriate) code using the Common Scientific Outline (expected to exceed £5m pa in total)</li> <li>• Discuss with the relevant charities with a view to publication and/or inclusion in the NCRI database (although status of peer review may be a factor in the latter).</li> </ul>
<b>Start date</b>
Feasibility work started: Summer 2011
<b>End date</b>
Analysis of the portfolio to be completed September 2013.
<b>Planned outputs April 2012–March 2013 – objectives agreed last year</b>
<ul style="list-style-type: none"> <li>• Collection and analysis of portfolio data in comparable format to NCRI portfolio data</li> <li>• Publication and/or inclusion in NCRI portfolio database</li> </ul>

**Actual outputs April 2012–March 2013**

- Due to changes in the NCRI Secretariat this project received less priority than initially planned.
- Latterly the CR-UK internship scheme was identified as a route through which to undertake the Cancer52 data collection and analysis project.

**Planned outputs April 2013–March 2014**

- Successful bid for an intern for a 12 week placement.
- Re-establish contact with the Cancer52 Secretariat and the Cancer52 membership to establish which organisations fund research, what they fund and their funding mechanisms.
- Produce a final report by September 2013.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

Platform for ongoing working relationship with Cancer52.

**Sustainability plan**

Not applicable to exploratory work.

**Issues**

- If no suitable interns are identified the project may be further delayed.
- Ability to provide data in necessary format may be an issue for some charities.
- Only about half of the dozen or so research-active members of Cancer52 are members of AMRC – we will wish to look at the peer review processes in the other cases before inclusion in any aggregate dataset.

**External profile**

None as yet for the NCRI work. Information about Cancer52 can be found at <http://www.cancer52.org.uk/>

**Links to other NCRI or related activities**

Cancer Research Database (CaRD)

<b>Name of activity</b>	Diabetes and cancer
<b>Who is in the lead?</b>	NCRI Secretariat
<b>Type of activity</b>	Exploratory work – idea brought to NCRI during NCRI Strategic Plan consultation process by Sir Mike Richards on behalf of himself and the National Clinical Director for Diabetes, Dr Rowan Hillson.
<b>Is there dedicated funding? If so how much and from whom?</b>	No. Support currently from the NCRI Secretariat core budget. The format and scale of the final activity will determine if more funds will need to be sought from NCRI Partners or others outside the NCRI, for example the Diabetes Research Network or Diabetes Research UK.
<b>Core secretariat resources allocated</b>	0.1 FTE
<b>Overall aim</b>	To highlight the opportunities for research in diabetes and cancer.
<b>Specific objectives</b>	To engage with researchers and research funding managers involved in diabetes and cancer research to identify areas for synergy.
<b>Start date</b>	Project initiated within the NCRI in December 2012.
<b>End date if known</b>	Exploratory
<b>Outputs April 2012–March 2013</b>	<ul style="list-style-type: none"> <li>• Preliminary interactions with researchers with an interest in diabetes and cancer research to understand the intersections between these two conditions.</li> <li>• Brief analysis of the 2008-2013 ICRP database of studies, which include a focus on diabetes and cancer to understand what research has been funded in the area.</li> </ul>
<b>Planned outputs for April 2013–March 2014</b>	<ul style="list-style-type: none"> <li>• Further engagement with relevant stakeholders including Diabetes Research UK</li> <li>• To establish the key players in this field.</li> <li>• To hold a ‘diabetes and cancer research’ stakeholder workshop from which to generate a consensus on research opportunities and priorities and generate momentum for the research community to take forward the ideas.</li> </ul>
<b>Looked-for outcomes and success factors by end date or as ultimate legacy</b>	To bring together researchers with an interest in diabetes and cancer, clarify the research priorities and give the research community the information needed to establish new and relevant research in this area.
<b>Sustainability plan</b>	Not applicable to exploratory work.
<b>Issues and risks</b>	<ul style="list-style-type: none"> <li>• Minimal in relation to development of ideas.</li> <li>• The researcher workshop may generate research ideas but researchers may not have the capacity to develop research proposals.</li> </ul>

**External profile**

None.

**Links to other NCRI or related activities**

None.

## **Activity templates category 2:**

### **Infrastructural activities**

<b>Name of activity</b>	Clinical and Translational Radiotherapy Research Working Group (CTRad)
<b>Why are we doing it?</b>	To implement the 10-point plan from the Rapid Review published in 2008 and build a portfolio of practice-changing trials
<b>Who is in the lead?</b>	NCRI Secretariat
<b>Type of activity</b>	Infrastructural
<b>Is there dedicated funding? If so how much and from whom?</b>	<ul style="list-style-type: none"> <li>• Now in second phase of funding, £180k per annum from 1 April 2012 to 31 March 2015.</li> <li>• Funded by CR-UK, MRC and all four UK Health Departments</li> <li>• Funds provide staff within Secretariat (1 FTE Programme Manager [CC], 0.5 FTE Administrator [RD]), sessional costs for Chair and Deputy, and activity/event costs for the Executive Group and workstreams.</li> </ul>
<b>Core secretariat resources allocated</b>	0.2 FTE Head of Programmes (JM).
<b>Overall aim</b>	To ensure coordination across all aspects of radiobiology and radiotherapy research, develop an ambitious portfolio of practice-changing trials and actively promote translation of new discoveries into practice.
<b>Specific objectives</b>	<ul style="list-style-type: none"> <li>• Provide ongoing leadership and continuing development of UK radiotherapy research.</li> <li>• Support proposal development and review, to ensure UK trials are innovative, relevant and of the highest possible quality.</li> <li>• Support the development of relevant academic departments.</li> <li>• Oversee and develop national radiotherapy trials quality assurance (RTTQA) programme.</li> <li>• Enhance pharma connections and improve relationships with radiotherapy equipment manufacturers; ensure evaluation of new technologies and improved data collection/use.</li> <li>• Work closely with the radiobiology community to improve the use of imaging biomarkers in assessment of treatment response and associated translational research.</li> <li>• Promote methodological development and the use of appropriate methods.</li> <li>• Work with research funders to ensure funding opportunities are accessible and fit for purpose, and take up further central discussions where shortfalls are noted.</li> </ul>
<b>Start date</b>	First Chair appointed 1 Nov 2008; CTRad launched on 1 Jul 2009.
<b>End date</b>	Current funding runs until 31 Mar 2015.

**Outputs April 2012–March 2013 (delivered as planned)**

- Two all-workstreams meetings for proposal development held (Jun [18 proposals] and Nov [12 proposals]). Both meetings attended by 80–100 people.
- Biomarkers workshop (Apr 2012), microenvironment and signal transduction workshop (May 2012), and radiotherapy in pancreatic cancer workshop (Jul 2012) – these workshops brought together experts to review the current field and discuss future trials and collaboration opportunities; a clinical trials workshop (Feb 2013) was held to educate attendees, especially young investigators, components of a good clinical trial proposal and understand different roles.
- Proton therapy experts met to begin planning how research can/should be supported within the two confirmed proton beam centres. First meeting in Sep 2012, identified four domains of work to be carried forward in 2013, namely physics, clinical trials, clinical methodologies, and ion beams and biology.
- Clinical Oncology Academic Think Tank meeting (Mar 2013) brought together centres to share successes, progress made, and discussed current barriers including funding and ill-informed academic requirements limiting publication avenues.
- CTRad consumers created and shared guidance to improve lay abstracts in radiotherapy.
- Met with equipment manufacturer (Dec 2012) to stimulate joint working but without success. Manufacturer engagement is being de-prioritised as other avenues appear more promising.
- New Deputy Chair (Prof. Anthony Chalmers) successfully recruited for Apr 2013 start, with Prof. Neil Burnet stepping up to Chair.

**Planned outputs April 2013–March 2014**

- All-workstreams meetings for proposal development planned for Jun & Nov.
- ‘Radiotherapy-Drug Combinations Consortium’ being set up to facilitate collaborative preclinical research; the project manager role will be funded by CR-UK.
- Academic development for physicists (pursuing funding opportunities with relevant funders and setting up support for funding applications) and radiographers (organising a first academic think tank meeting in collaboration with the Society and College of Radiographers).
- Proton group due to arrange workshops to discuss direction in collecting outcome data (July 2013) and clinical trials.
- Imaging in radiotherapy: with aim to enhance collaboration and the use of imaging in radiotherapy treatment planning and dose escalation, starting with a working meeting (Jun 2013) meeting to bring together EPSRC/CR-UK imaging centres with radiotherapy themes.
- Biomarker ‘Champions’ network to be established to support translational research.
- Consumer working meeting at the Gray Institute (Jun 2013) to discuss preclinical research.
- Stereotactic Body Radiotherapy (SABR) workshop (Sep 2013); other events to support education/collaborative working to be planned.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- Increase in the capacity for radiotherapy/radiobiology research in the UK, with at least five centres of excellence.
- More practice-changing trials involving radiotherapy.
- Metrics agreed: Patient accrual in radiotherapy trials; proportion of radiotherapy applications awarded by CR-UK and MRC; number of radiotherapy programme grants awarded by NCRI Partners; number of new outline proposals reviewed at CTRad all-workstream meetings; publications from CTRad members.

**Sustainability plan**

- Discussions with funders in 2013–14 about what happens after the current funding period. CTRad leaders are very keen to retain the current, effective setup and continue momentum.
- The technical workstream (workstream 4) in particular has been developing an increasing number of work packages and oversees the RTTQA work, so it is likely a standalone group will remain necessary beyond 2015.

**Issues and risks**

- Future of the Radiotherapy Trials Quality Assurance (RTTQA) team is insecure as centralised DH funding currently committed only until early 2014.

**External profile**

- CTRad activities publicised via news bulletin and website.
- CTRad provides meetings/workshops for researchers as described above (publicised via CSGs, ECMCs, RCR and others).
- Sessions at NCRI and other conferences (e.g. Association for Radiation Research).

**Links to other NCRI or related activities**

- Relevant CSGs have nominated CTRad link members.
- CTRad RTTQA team interacts regularly with NCRI PET Core Lab.
- The use of imaging for treatment planning/response links to the exploratory work on imaging.
- CTRad working with RCR on radiotherapy programme at NCRI Cancer Conference.

<b>Name of activity</b>	Survivorship after cancer
<b>Why are we doing it?</b>	To implement Action 1 from the Rapid Review of Survivorship and End of Life Care 2010
<b>Who is in the lead?</b>	NCRI Secretariat
<b>Type of activity</b>	Infrastructural
<b>Is there dedicated funding?</b>	Some of the funds remaining from the Lung SuPaC budget and a contribution of £13k from the National End of Life Care Programme for England (NEOLCP), now part of NHS Improving Quality, have enabled the appointment of a Research Officer (Survivorship & End of Life Care) for 12 months from August 2012. (Resource shared with activity 8).
<b>Core secretariat resources allocated</b>	0.15 FTE Head of Programmes (KG).
<b>Overall aim</b>	To promote investigator-led research through existing funding streams.
<b>Specific objectives</b>	<ul style="list-style-type: none"> <li>To promote the development of large scale interventional studies focussed on the needs of cancer survivors, their carers or their families.</li> <li>To seek to maintain the inter-disciplinary and cross-institutional collaboration achieved by the NCRI SuPaC Collaboratives.</li> <li>To identify survivorship research champions: individuals who can promote survivorship research nationally, and act as a focus point for survivorship research in their area.</li> </ul>
<b>Start date</b>	2010 (on completion of review)
<b>End date</b>	Q3 2013
<b>Planned outputs April 2012–March 2013 – objectives agreed last year</b>	<ul style="list-style-type: none"> <li>Run competition for lung cancer SuPaC scholarships (using funds left over from the NCRI Lung Cancer SuPaC project grant call).</li> <li>Explore feasibility of designating ‘hubs’ of high quality peer-reviewed survivorship research.</li> </ul>
<b>Actual outputs April 2012–March 2013</b>	<ul style="list-style-type: none"> <li>Developed paperwork for NCRI Lung Cancer SuPaC scholarship scheme and launched call 7 March 2013.</li> <li>Met with Sir Mike Richards (Sep 2012) to discuss opportunities to further encourage survivorship research. Agreed to continue to seek a champion for survivorship research and to promote the ideas stemming from the October 2011 NCRI research proposal development meeting.</li> </ul>

**Planned outputs April 2013–March 2014**

- Scholarship call to close 2 May 2013. Applications to be reviewed by scientific review panel 4 June 2013.
- A champion has not emerged, and the community has not shown the necessary motivation to move forward the workshop ideas, so it is proposed that ‘survivorship’ reverts to a watching brief rather than a specific initiative. The Secretariat will maintain contact with such activities as the Cancer Population Evidence Programme, which include the Routes from Diagnosis project, which operates through NCIN and Macmillan Cancer Support, and the work of relevant CSGs including the Psychosocial Oncology CSG.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- To have sustained and possibly enhanced the research capacity built via the SuPaC Collaboratives.
- To attract research-naive individuals into the supportive and palliative care research field by way of the Scholarship Scheme.
- At least one (ideally more) grant proposal arising from the workshop held in October 2011.

**Sustainability plan**

The SuPaC evaluation project (see Operating Report) will be looking at the outcomes above and assessing their sustainability to some extent.

**Issues and risks**

Not applicable to a watching brief.

**External profile**

NCRI Grantsmanship Gateway [www.ncri.org.uk/grantsmanship/](http://www.ncri.org.uk/grantsmanship/)

**Links to other NCRI or related activities**

Details of the Department of Health (England) and Macmillan Cancer Support National Cancer Survivorship Initiative (NCSI) can be found at [www.ncsi.org.uk/](http://www.ncsi.org.uk/).

<b>Name of activity</b>	UK end of life care Research Interest Group (eolcRIG)
<b>Why are we doing it?</b>	NCRI was asked to pick up on the research needs identified in the End of Life Care Strategy for England, published in 2008. This was carried forward as Action 2.1 in the Rapid Review of Survivorship After Cancer and End of Life Care).
<b>Who is in the lead?</b>	NCRI Secretariat
<b>Type of activity</b>	Infrastructural
<b>Is there dedicated funding?</b>	Some of the funds remaining from the Lung SuPaC budget and a contribution of £13k from the National End of Life Care Programme for England (NEOLCP), now part of NHS Improving Quality, have enabled the appointment of a Research Officer (Survivorship & End of Life Care) for 12 months from August 2012. (Resource shared with activity 7.)
<b>Core secretariat resources allocated</b>	0.25 FTE Head of Programmes (KG).
<b>Overall aim</b>	To bring end of life care more into the mainstream of health and social care research raising the awareness of both funders and researchers to the needs and opportunities for research in the field. The aim is not limited to patients with cancer, and a number of charities relating to other diseases and conditions are members of the group.
<b>Specific objectives</b>	<ul style="list-style-type: none"> <li>• To create a forum for research funders (and a peer group of research funding managers) with an interest in funding research in end of life care.</li> <li>• To set up one or more working groups or meetings to address specific barriers to research in this area.</li> <li>• To communicate to researchers the breadth of research funders with an interest in end of life care.</li> </ul>
<b>Start date</b>	First informal meeting held May 2010.
<b>End date if known</b>	The aim is for coordination and support of the UK eolcRIG to pass to Marie Curie Cancer Care during 2014.
<b>Planned outputs April 2012–March 2013 – objectives agreed last year</b>	<ul style="list-style-type: none"> <li>• Third meeting and soft launch of UK eolcRIG as an entity to be publicised and given a profile.</li> <li>• Set up website and publish the statement of intent online and in specialist journals.</li> <li>• A report/action list highlighting the priorities of the UK eolcRIG and its members and how these will be pursued going forward.</li> </ul>
<b>Actual outputs April 2012–March 2013</b>	<ul style="list-style-type: none"> <li>• Launch meeting of the UK eolcRIG May 2012 held and agreement on priorities for the group reached.</li> <li>• Publication of UK eolcRIG members' statement of intent (see <a href="http://www.ncri.org.uk/UKeolcRIG">www.ncri.org.uk/UKeolcRIG</a>) and the Sep 2012 issue of BMJ Supportive and Palliative Care).</li> <li>• Circulation on regular bulletins of research-relevant projects, calls and conferences.</li> <li>• Growth of the UK eolcRIG from 24 to 29 members.</li> </ul>

**Planned outputs April 2013–March 2014**

- Hold second formal meeting of the UK eolcRIG to discuss progress since May 2012 and agree the next priorities for action.
- Collect information on the palliative and end of life care research spend of eolcRIG full members.
- Generate interest and support for an end of life care research prioritisation exercise via the James Lind Alliance.
- Subject to eolcRIG member agreement, begin transition of running of the eolcRIG to Marie Curie Cancer Care.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- The Group continues to meet annually and to spawn working groups as required, generally making it more acceptable to talk about research involving death and dying.
- Publicity for successful research projects.
- Greater awareness amongst researchers of research needs and funding opportunities.
- More research on end of life care funded by NCRI Partners and other eolcRIG members.

**Sustainability plan**

- Explore whether Marie Curie Cancer Care can take over the organisation and (modest) support of the annual eolcRIG meetings (to be confirmed). Consideration could be given to membership becoming subscription-led.
- eolcRIG members to take the lead on specific projects or working groups as needed.

**Issues and risks**

Low cost activity with very low risk and potentially significant impact over a period of years if commitment amongst the members is sustained.

**External profile**

Statement of intent and list of full and associate members available at [www.ncri.org.uk/UKeolcRIG](http://www.ncri.org.uk/UKeolcRIG).

**Links to other NCRI or related activities**

There are some links with the work of the NEOLCP (now NHS Improving Quality), National End of Life Care Intelligence Network (now within Public Health England), NCRI SuPaC Collaboratives, the Palliative and Supportive Care CSG, the Association for Palliative Medicine (APM) and others.

<b>Name of activity</b>
NCRI PET Core Lab
<b>Why are we doing it?</b>
The PET Core Lab for QA and network of accredited sites was established during the NCRI PET Research Network grant, and while other project-based workstreams have now closed, the Core Lab required additional interim funding to work towards financial independence.
<b>Who is in the lead?</b>
Core Lab team at St Thomas', with low-level support from NCRI Secretariat.
<b>Type of activity</b>
Infrastructural
<b>Is there dedicated funding?</b>
CR-UK, DH, CSO, NISCHR, Northern Ireland HSC and MRC have committed interim funding (up to £280k over 3 years) to allow time for the Core Lab to develop and introduce a cost recovery plan for QA costs.
<b>Core secretariat resources allocated</b>
<0.1 FTE Head of Programmes (JM).
<b>Overall aim</b>
To provide QA for multicentre PET trials, and contribute to standard setting and harmonisation.
<b>Specific objectives</b>
<ul style="list-style-type: none"> <li>• Promote harmonization with relevant international standards</li> <li>• Implement Good Clinical Practice (GCP)</li> <li>• Formalise contact lists of PIs experienced in the use of PET</li> <li>• Develop standards that will allow multi-site mechanistic and early phase studies</li> <li>• Explore ways to implement centralised data analysis</li> <li>• Set up a data archiving service on a per trial basis</li> <li>• Website maintenance.</li> </ul>
<b>Start dates</b>
<ul style="list-style-type: none"> <li>• This workstream of the original PET Research network began in Aug 2009</li> <li>• The extended funding for the Core Lab began on 1 Aug 2012.</li> </ul>
<b>End dates</b>
<ul style="list-style-type: none"> <li>• The additional funding runs until 31 Jul 2015.</li> </ul>
<b>Planned outputs April 2012–March 2013 – objectives agreed last year</b>
<ul style="list-style-type: none"> <li>• Complete and publicise patient video on PET in clinical trials</li> <li>• Final report to NCRI Board on initial grant</li> </ul>

### Outputs April 2012–March 2013

- Patient video completed and actively promoted (>3,800 views on YouTube in 9 months)
- Report considered by the Board in Oct 2012
- Trial progress (at January 2013):
  - Several of the trials for which the Core Lab delivered QA during the previous PET Research Network grant have closed (RAPID, RCHOP), others were winding down (RATHL – closed recruitment because recruited ahead of time; PETPANC – almost finished recruitment), 2 were being combined and reviewed due to low recruitment (PAIReD and ReACH) and 1 was still ongoing (TITAN).
  - The core lab had 6 trials that were open and scanning (including MAPPING, their first non-FDG trial) and 4 trials due to open in the next few weeks (including POETIC, their first full quantitative study).
- All the fixed PET scanning sites that desired accreditation have now achieved this.
- Having worked actively with mobile scanning units to improve QA, 4 mobile units (serving 12 sites) have now been accredited for participation in trials.
- The Core Lab has also accredited several international sites in Italy, Australia, Denmark, Ireland, Sweden and Norway.
- A group of ‘critical friends’ has been identified to provide guidance to the Core Lab team as needed.

### Planned outputs April 2013–March 2014

- The Core Lab team is working out a costing model at present, with proposed costings to be tested out with funders and researchers for feasibility.
- Ongoing delivery of QA for the 10 trials that are open/planned to open.
- As at January 2013, eight additional trials had put forward requests for costings from the Core Lab, and if funded, will start to have QA delivered by the Core Lab.

### Looked-for outcomes and success factors by end date or as ultimate legacy

- Network of centres accredited by the Core Lab for participation in multicentre PET trials and a growing portfolio of trials involving PET using the core lab for QA.

### Sustainability plan

- The vision is for full financial independence by 31 July 2015, with the model in place by 2014; there is concern within the Core Lab team about how achievable this is (see issues and risks below).

### Issues and risks

Clarity has yet to be achieved on how far it will ultimately be feasible for the Core Lab to be fully self-sustaining through charging to trial grants, so the future beyond 2015 is currently uncertain. NCRI has urged St Thomas’s to identify the true cost of the QA service on a per scan basis. Once this has been done, discussions will be held with Partners on the future business model, i.e. whether there should be full-cost charging or a continuing element of central support.

### External profile

- Documentation and outputs hosted on dedicated website, [www.ncri-pet.org.uk](http://www.ncri-pet.org.uk)
- Presentations at meetings and conferences to promote Core Lab.

### Links to other NCRI or related activities

- PET Core Lab liaises with CTRad radiotherapy trials quality assurance group.
- Representation of Core Lab team on ECMC Imaging Network Group and CTRad workstream 2.

## 10a

<b>Name of activity</b>
Confederation of Cancer Biobanks (CCB)
<b>Why are we doing it?</b>
To foster coordination among cancer biobanks, including the development and adoption of best practice
<b>Who is in the lead?</b>
NCRI Secretariat
<b>Type of activity</b>
Infrastructural
<b>Is there dedicated funding?</b>
£5m was provided originally for the charity onCore UK by DH, CR-UK and MRC. When the charity closed in early 2011, remaining funds were transferred to the NCRI Secretariat where they are currently used to support 1.4 FTE posts within the NCRI office, plus external pathology expertise. This resource is shared across activities 10a–10d and will last until early 2014. Although the four activities are interrelated, they are not necessary co-dependent and have been listed separately.  This activity currently occupies approx 0.6 FTE senior staff time.
<b>Core secretariat resources allocated</b>
Minimal
<b>Overall aims</b>
To become the representative body for cancer biobanking in the UK: <ul style="list-style-type: none"> <li>• Promoting best practices for biobanks</li> <li>• Providing guidance</li> <li>• Promoting transfer of knowledge and experiences between banks.</li> </ul>
<b>Specific objectives</b>
<ul style="list-style-type: none"> <li>• To grow the membership to include as many biobanks and collections holding samples from cancer patients as possible.</li> <li>• To demonstrate knowledge-sharing between banks to improve quality and embed best practice. This is done, for example, through member-hosted meetings on technical subjects and participation in the Harmonisation project (see 10b).</li> </ul>
<b>Start date</b>
The CCB was started by onCore UK in 2006.
<b>End date</b>
Ongoing network so no end date, subject to the availability of funds.

**Planned outputs April 2012–March 2013 – objectives agreed last year**

- Active expansion of membership to include all major holders of samples if possible.
- At least 3 member-hosted meetings delivered successfully (high attendance and positive feedback levels).
- Increase in number of sample collections listed on Cancer Biosample Directory.
- Inter-bank IT pilot project delivered and plan for further roll-out developed.

**Actual outputs April 2012–March 2013**

- Membership increased from 24 to 28 biobanks:
  - Membership categories redefined and registered collection status developed
  - Active partnership with ECMC secretariat to encourage centre-associated biobanks to join
- Two member-hosted meetings delivered successfully:
  - 60+ attendees at each meeting with very positive feedback received, including application of learnings locally
- Listings on Cancer Biosample Directory increased to 65 (30 biobanks and 35 clinical trial collections):
  - User functionality added to allow users to manage their own listing.

**Planned outputs for April 2013–March 2014**

- Rollout of registered collection membership category (gain at least 10 members).
- Two further member-hosted meetings delivered successfully (high attendance and positive feedback levels) and commitment from members to host further meetings.
- Significant expansion of clinical trial collections listings on Cancer Biosample Directory.
- Active involvement in planning of broader biosample directory.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- Examples of best-practice sharing across the member banks.
- Greater collaboration between banks.
- Potential creation of one-stop-shop for researchers in accessing samples from multiple biobanks.
- Ultimate concept: a single virtual national biobank for cancer researchers.

**Sustainability plan**

The UKCRC Experimental Medicine Funders' Group is planning a broadly-based coordination function for biobanking to implement some of the actions from the Funders' Vision (template 10c). The CCB, along with other disease-specific initiatives such as the UK brain-banking network will need to link in to this. At the same time it may make sense for CCB to be run from within NCRI and for this to be supported from core NCRI resource from 2014–15 onwards.

**Issues and risks**

The CCB as currently set up will not function without some dedicated part-time secretariat resource.

**External profile**

- Communications include the website; <http://www.ncri.org.uk/ccb/>, newsletters, presence at conferences including NCRI Cancer Conference, technical meetings.
- NCRI Pathology Leads engaging the biobanking community.

**Links to other NCRI or related activities**

- Close links to the other NCRI biobanking activities.
- Regular liaison with the ECMC secretariat.
- Biomarkers and Imaging CSG.

## 10b

<b>Name of activity</b>
Biobanking Harmonisation: Quality Management
<b>Why are we doing it?</b>
<ul style="list-style-type: none"> <li>• None of the statutory regulation (through the Human Tissue Act etc) covers the fitness of samples for the purpose of research.</li> <li>• There are currently no agreed national or international quality standards for research samples in operation in the UK.</li> <li>• If samples are not of appropriate quality then the quality of research that uses them is compromised, and there is a risk that resources are wasted.</li> <li>• Ideally researchers should be able to draw samples from different banks and know that they are of comparable quality.</li> </ul> <p>This project fits within the overall remit of the Confederation of Cancer Biobanks (activity 10a) but is a self-contained piece of work requiring <u>specialist technical leadership</u> which is available through one of the former employees of onCore UK.</p>
<b>Who is in the lead?</b>
NCRI Secretariat
<b>Type of activity:</b>
Infrastructural
<b>Is there dedicated funding?</b>
<p>£5m was provided originally for the charity onCore UK by DH, CR-UK and MRC. When the charity closed in early 2011, remaining funds were transferred to the NCRI Secretariat where they are used to support approx 1.8 FTE posts (net) within the NCRI office, plus external pathology expertise. This resource is shared across activities 10a-10d and will last until early 2014. Although the four activities are interrelated, they are not necessarily co-dependent and have been listed separately.</p> <p>This activity continues to occupy approx 0.6 FTE senior staff time.</p>
<b>Core secretariat resources allocated</b>
Minimal
<b>Overall aim</b>
To increase the availability and interoperability of biological samples and data held in biobanks for use in research. Initially this is being developed in collaboration with cancer biobanks although it is expected to have broader applicability.
<b>Specific objectives</b>
<ul style="list-style-type: none"> <li>• Engage the interest of the biobanking community through the CCB in the first instance.</li> <li>• Through such engagement, devise and agree standards and best practice guidelines for biobanks.</li> <li>• Set up an accreditation scheme whereby biobanks which comply with the standards can be awarded a "quality mark".</li> <li>• Seek an independent body to operate the accreditation scheme.</li> </ul>
<b>Start date</b>
October 2011
<b>End date</b>
No clear end date yet identified. Funding is currently available until the end of 2013.

**Planned outputs April 2012–March 2013 – objectives agreed last year**

- First eight standards documented (subsequently changed to a single multi-part standard)
- Procedures for accreditation scheme drafted and trialled at two CCB member sites.

**Actual outputs April 2012–March 2013**

- Enthusiasm for the project has been maintained in the biobanking community leading to volunteers continuing to participate in the Steering Group and four Working Groups.
- First draft of a quality standard, containing 27 clauses, prepared and reviewed by the Steering and Working Groups.
- Accreditation scheme involving peer review further developed.
- Inspection process piloted at one biobank with the inclusion of a lay inspector.
- Preliminary discussions with the United Kingdom Accreditation Service (UKAS) to investigate requirements for handing over operation of the accreditation scheme.

**Planned outputs April 2013–March 2014**

- Preparation of publication-ready standard, with input from the wider biobanking community and UKAS.
- Alignment of the standard with international (ISO) quality standards.
- Inspection process trialled at two further biobank sites.
- Agreement with UKAS for work leading to their adoption of the accreditation scheme.
- Report to Board on progress and future costs October 2013.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- Interoperability of samples from accredited banks.
- Researchers using samples from more than one bank.
- Voluntary take-up of accreditation by 90% of CCB member biobanks.
- Take-up of standards and expansion of accreditation scheme to non-cancer biobanks.
- Confidence among funders that the research they support uses samples of appropriate quality.

**Sustainability plan**

Under consideration. Funding will be required until the accreditation scheme can be operated by UKAS at which time biobanks will need to pay a fee for accreditation. Costs will be lower if the community accepts that it provides human resource for the peer review on a non-reimbursed (i.e. contribution in kind) basis. The standard devised will be applicable beyond cancer research and will need to be “owned” by the biobanking community. There will be an ongoing need for maintenance and updating of the standard; this will require technical input from the biobanking community.

**Issues and risks**

Risks to successful completion include the following:

- Biobanking community does not continue to support project or it proves impossible to agree on level at which to set standards
- Unable to reach agreement with UKAS for their adoption of the accreditation scheme
- Unable to find a “home” for the standard
- International biobank initiatives create alternative, incompatible standards
- Funding dries up before project is complete.

**External profile**

- Articles on project published in CCB and NCRI newsletters.
- Talks at biobanking and research meetings.
- International awareness of the project through the Marble Arch Working Group on International Biobanking.
- Members of Steering and Working Groups are representative of the wider biobanking community and the scheme is well-supported by the community.

**Links to other NCRI or related activities**

- Close links to the other NCRI biobanking activities.
- Links maintained with ECMCs, CR-UK's Stratified Medicines team and the STRATUM project (Strategic Tissue Repository Alliance Through Unified Methods).

## 10c

<b>Name of activity</b>
Funders' Vision for Human Tissue Resources
<b>Why are we doing it?</b>
MRC identified a need for coordination of biobanking at the level of funders and research funding policy. The resulting Vision provides a top-down complement to the bottom-up work of activities 10a and 10b.
<b>Who is in the lead?</b>
MRC on behalf of the UKCRC Experimental Medicine Funders Group (EMFG).
<b>Type of activity</b>
Infrastructural
<b>Is there dedicated funding?</b>
£5m was provided originally for the charity onCore UK by DH, CR-UK and MRC. When the charity closed in early 2011, remaining funds were transferred to the NCRI Secretariat where they are used to support approx 1.7 FTE posts (net) within the NCRI office, plus external pathology expertise This resource is shared across activities 10a–10d and will last until early 2014. Although the four activities are interrelated, they are not necessarily co-dependent and have been listed separately.
<b>Core secretariat resources allocated</b>
Minimal
<b>Overall aim</b>
To maximise the value for research of human tissue samples and resources while minimising duplication of effort through harmonisation of policy and practice among funders of medical research (i.e. not limited to cancer research).
<b>Specific objectives</b>
In the course of preparing the Vision the following emerged as requirements which could be tackled, at least in part, from a funding policy perspective:
<ul style="list-style-type: none"> <li>• better characterisation of tissue samples</li> <li>• that researchers ask for generic consent when collecting samples</li> <li>• increased linkage of samples to accurate clinical data</li> <li>• that sample collections are more easily discoverable and accessible for use in high quality, ethical research.</li> </ul>
<b>Start date</b>
June 2010 for preparation of Funders' Vision. 2011 for publication and implementation.
<b>End date</b>
No end date has been set (see risks and issues below).

**Planned outputs April 2012–March 2013 – objectives agreed last year**

Funders to review current policies against Funders' Vision and work to close gaps and harmonise approaches where required.

**Actual outputs April 2012–March 2013**

While the Funders' Vision was being compiled, it came to light that a piece of work being funded by the Technology Strategy Board named STRATUM (Strategic Tissue Repository Alliance Through Unified Methods) was planning to cover some similar ground, risking unnecessary duplication. STRATUM has been led by AstraZeneca with contributions from other organisations, both commercial and academic; it has included work packages comprising public engagement, biobanking policy, technical standards, directory/catalogue, sample characterisation datasets, cost model and consent.

Implementation of the Funders' Vision through EMFG has been delayed pending the outputs from STRATUM which has now come to an end (in May 2013). In summary it appears that STRATUM has come to similar conclusions about what the issues are and the need for national coordination. They are also recommending that this be funded by the public sector.

**Planned outputs April 2013–March 2014**

The way appears to be clear for the EMFG to pick up on this again and a business case for a coordination function is being prepared. The NCRI Secretariat will work with the EMFG to work out how cancer biobanking activities can best be configured in future to fit in with the wider plans.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

Wide and routine acceptance by funders and investigators of the principles set out in the Funders' Vision: that tissue samples are collected with generic consent, well characterised and linked to accurate clinical data, and that, once any primary study is complete, sample collections are easily discoverable and accessible for use in additional high quality, ethical research.

**Sustainability plan**

Many elements of the Funders' Vision will be implemented through harmonisation of funders' approaches and so should be largely self-sustaining. Long-term ownership of infrastructure such as sample directories will need to be agreed with relevant funders. Sustainability for coordination of cancer biobanking will depend on defining the appropriate link with the new wider activity.

**External profile**

The Funders' Vision is on the UKCRC website and accessible via the NCRI and relevant Partners' websites <http://www.ukcrc.org/infrastructure/expmed/fundersvisionforhumantissuesresources/>

**Links to other NCRI or related activities**

Close links to the other NCRI biobanking activities.

## 10d

<b>Name of activity</b>	Revisit the actions from the NCRI report 'Fostering the role Pathology in Research' (2009)
<b>Why are we doing it?</b>	Because the most important action, relating to the need to rejuvenate academic pathology, has not been taken forward in spite of some prompting from the Secretariat, and continuing calls from the academic community and pharma.
<b>Who is in the lead?</b>	NCRI Secretariat and Pathology Leads
<b>Type of activity</b>	Infrastructural
<b>Is there dedicated funding?</b>	<p>£5m was provided originally for the charity onCore UK by DH, CR-UK and MRC. When the charity closed in early 2011, remaining funds were transferred to the NCRI Secretariat where they are used to support approx 1.8 FTE posts (net) within the NCRI office, plus external pathology expertise. This resource is shared across activities 10a-10d and will last until early 2014. Although the four activities are interrelated, they are not necessarily co-dependent and have been listed separately.</p> <p>This activity draws mainly on the expertise of the Pathology Leads.</p>
<b>Core secretariat resources allocated</b>	Minimal
<b>Overall aim</b>	To keep pathology on the agenda and ensure agreed actions are taken forward.
<b>Specific objectives</b>	<ul style="list-style-type: none"> <li>• Review actions from the report and publish a report on progress</li> <li>• Consider the need for renewed impetus where progress has been lacking and take further action accordingly</li> </ul>
<b>Start date</b>	January 2012
<b>End date</b>	Next milestone is October 2013 (report to Board)
<b>Planned outputs April 2012–March 2013 – objectives agreed last year</b>	Report (with proposal if appropriate) to NCRI Board March 2013

**Actual outputs April 2012–March 2013**

Report to Board delayed until October 2013.

Discussion held with Royal College of Pathologists.

Pathology trainees forum being set up.

**Planned outputs April 2013 – March 2014**

Report to Board in October 2013.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- Action plan to address issues in Academic Pathology.
- Adoption of toolkits and increase in access to pathology archives for research.
- Increased engagement by key stakeholders in addressing the issues.

**Sustainability plan**

To be included in report to Board.

**Issues and risks**

Issue has been lack of commitment/engagement from key stakeholders and there remains a high risk that this will persist. Requires leadership if this is to progress.

**External profile**

None at present.

**Links to other NCRI or related activities**

Close links to other NCRI biobanking activities.

<b>Name of activity</b>	National Cancer Intelligence Network (NCIN) – promotion of investigator-led research.
<b>Why are we doing it?</b>	To capitalise on the growing research opportunities provided by the National Cancer Dataset in England and to promote a UK-wide approach to cancer intelligence and data-linkage. There is also a useful spin-off in giving NCRI a closer link with part of the NHS than had previously been enjoyed.
<b>Who is in the lead?</b>	NCIN Co-ordinating Team for core work of NCIN and NCRI Secretariat for promotion of research.
<b>Type of activity</b>	NCRI component is Infrastructural.
<b>Is there dedicated funding?</b>	Funding is provided for one FTE based primarily in the NCIN core team but also spending time with NCRI. Scientific direction to this resource is provided from NCRI. Funds are provided by CR-UK and Macmillan Cancer Support with a small portion (0.2 FTE) coming from the former onCoreUK budget for work related to the Funders' Vision and other issues relating to data governance and access to biosamples and associated data.
<b>Core secretariat resources allocated</b>	Minimal
<b>Overall aim</b>	To promote the use of data held by NCIN for investigator-led research and to promote UK-wide harmonisation and linkage of data, capitalising on new data capabilities as they are introduced.
<b>Specific objectives</b>	<ol style="list-style-type: none"> <li>1. Managing and improving research access to NCIN data and related resources (This requires day-to-day assistance with applications to use data and longer term work to improve the processes for access.)</li> <li>2. Increasing the value of the information available from NCIN (This includes expanding the range of data available and ensuring that NCIN is linked into national infrastructure (e.g. the Clinical Practice Research Datalink).)</li> <li>3. Enabling the routine linkage of NHS information to research datasets (This involves work to supplement data collected in clinical trials, cohort studies or biobanks with data held by NCIN or elsewhere in the NHS.)</li> <li>4. Supporting strategic national initiatives such as Cancer Research UK's Stratified Medicines Initiative and UK Biobank (In particular ensuring that the required data flows between cancer registries and these initiatives are in place.)</li> <li>5. Working across the UK nations (Joining up data linkage activities across the UK to support research.)</li> </ol>
<b>Start date</b>	November 2008 (current funding from Nov 2011).
<b>End date</b>	Current NCRI funding ends in 2015.

**Planned Outputs April 2012–March 2013 – objectives agreed last year**

- Improved research access to data held by NCIN as the English cancer registries move to a single national database.
- Better communication of the opportunities for research presented by data held by NCIN.
- Making cancer data an integral part of emerging UK research infrastructure (especially CPRD) and ensuring this meets the needs of cancer research.
- Preparing an overview of the evidence base for use of routine data to support trials (and other studies) and beginning work to further enable this.

**Actual outputs April 2012–March 2013**

- Assisted in the design of 25 new research studies.
- Communication plan agreed and implementation begun.
- Progress on linking NHS and registry data to research cohorts, e.g. UK Biobank and the BRIGHTLIGHT study.

**Planned outputs April 2013–March 2014**

- Resolve payment issues with the Clinical Practice Research Datalink (CPRD).
- Further develop the link with UK Biobank.
- Ensure that research continues to be facilitated in the new environment of PHE and the National Cancer Registration Service, and especially that data governance arrangements for access are as streamlined as possible.
- Review and if necessary update the Template for Access Policy Development.
- Prepare a plan for the use of NCIN data in long-term follow-up of clinical trial patients.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

Routine use of high quality, linked data collected by the NHS for epidemiological and health services research, as well as use of these data to supplement those collected directly by research studies (e.g. for long term follow up of clinical trials and cohort studies).

**Sustainability plan**

To be considered by the Secretariat during 2013–14.

**Issues and risks**

As part of NHS reforms, the NCIN and cancer registries have moved into Public Health England from 1 April 2013. There is a risk that this will reduce the focus on research and make UK-wide working less likely. The NCIN Co-ordinating Team and NCRI Secretariat will monitor this and report any concerns to the Board.

**External profile**

- Main public face is website [www.ncin.org.uk](http://www.ncin.org.uk) which receives over 5,000 unique visitors per month. A monthly email update is distributed.
- The NCIN produces a variety of publications including analytical reports, shorter data briefings and peer reviewed papers (13 peer reviewed papers in 2011).
- An annual conference is now in its fifth year. 150 abstracts were submitted for 2012 conference and the target attendance is over 400 delegates (450 at 2011 conference).
- NCIN's reports receive regular press attention, featuring in 282 articles in 2011.

**Links to other NCRI or related activities**

The NCIN links to a range of other NCRI and related activities through the provision of data either on the need for activities (e.g. identifying inequalities) or to directly support research and other work. In particular, the NCIN links to activities in:

- NAEDI (through provision of data for ICBP, research evidence supporting the need for early diagnosis, evaluation of awareness campaigns, etc)
- NCRN and CSGs (for work on long term follow up of trials)
- Survivorship (in particular through work with Macmillan Cancer Support)
- End of life care (through links to National End of Life Care Intelligence Network)
- CCB and Funders' Vision for Human Tissue Resources (through opportunities to supplement data held by tissue banks)
- CTRad (via shared interest in national radiotherapy dataset).

## **Activity templates category 3:**

### **Partner-led funding initiatives**

<p><b>Name of activity</b></p> <p>National Prevention Research Initiative (NPRI)</p>
<p><b>Why are we doing it?</b></p> <p>To increase the amount of prevention research in the national research portfolio (in cancer and beyond) in response to the NCRI Strategic Analysis (2002) and the subsequent report 'Prevention and Risk Research in the UK' (2004).</p>
<p><b>Who is in the lead?</b></p> <p>Medical Research Council (MRC).</p>
<p><b>Type of activity</b></p> <p>Research projects funded through calls for proposals.</p>
<p><b>Is there dedicated funding?</b></p> <p>Funding was pledged by NCRI Partners and other research funding organisations for each of the 4 phases of the initiative. Phases 1 &amp; 2 shared a funding pot of £11m, Phase 3 a pot of £12m and Phase 4 attracted a further £10m. The Phase 4 funding partners are:</p> <ul style="list-style-type: none"> <li>• Alzheimer's Research Trust</li> <li>• Alzheimer's Society</li> <li>• Biotechnology and Biological Sciences Research Council</li> <li>• British Heart Foundation</li> <li>• Cancer Research UK</li> <li>• Chief Scientist Office, Scottish Government Health Directorate</li> <li>• Department of Health</li> <li>• Diabetes UK</li> <li>• Economic and Social Research Council</li> <li>• Engineering and Physical Sciences Research Council</li> <li>• Health and Social Care Research Division, Public Health Agency, Northern Ireland</li> <li>• Medical Research Council</li> <li>• Stroke Association</li> <li>• Wellcome Trust</li> <li>• Welsh Government</li> <li>• World Cancer Research Fund</li> </ul>
<p><b>NCRI secretariat role and resources allocated</b></p> <p>&lt;0.1 FTE, 'watching brief'.</p>
<p><b>Overall aim</b></p> <p>To develop and implement successful, cost-effective interventions that reduce people's risk of developing major diseases by influencing their health behaviours and the environmental factors that influence those behaviours.</p>

**Specific objectives**

- To provide additional funds and infrastructure support to increase the amount of high quality research aimed at improving health and preventing diseases or conditions such as cancer, heart and circulatory diseases, diabetes, obesity, stroke and dementia.
- To encourage and facilitate cross-disciplinary collaborations in UK prevention research.
- To encourage research aimed at risk reduction in communities/social groups with a high incidence of cancer, coronary heart disease and diabetes, and exploring approaches that will reduce the inequalities in incidence from these diseases.

**Start date**

2004

**End date**

Existing grants will run until at least 2015. MRC plans to undertake a review of the prevention research field, the outcomes of which will advise future funding rounds.

**Planned outputs April 2012–March 2013 – objectives agreed last year**

The MRC will be conducting an evaluation of prevention research, including but not restricted to, NPRI, with a view to assessing future funding needs.

**Actual outputs April 2012–March 2013**

The 8<sup>th</sup> UK Society for Behavioural Medicine Annual Scientific Meeting (ASM) incorporating the NPRI ASM was held in Manchester, 10-11 December 2012.

**Planned outputs April 2013–March 2014**

The MRC have to now not been able to prioritise the evaluation of the NPRI. It is intended that the evaluation process will start during 2013.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

By end date:

- Increased funding for prevention research; the NCRI Cancer Research Database has recorded an increase in spend over and above that invested in NPRI.
- Increased capacity for research in this area and multi-disciplinarily working.
- Increased number of high quality interventional studies funded that have the potential to have a major impact on population health.

Ultimate legacy:

- To have a strong research workforce able to compete with other research disciplines for funds from the existing funding streams and thus maintain the level of research funding in this area.
- The implementation of interventions that have been shown to be effective through the work of NPRI funded researchers.

**Sustainability plan**

To be considered in 2013–14 following the MRC review.

**Issues and risks**

- If the initiative is discontinued there is a risk that it will be interpreted that funders now think prevention risk is less important.

**External profile**

Information on NPRI awards can be found at [www.mrc.ac.uk/Ourresearch/ResearchInitiatives/NPRI/index.htm](http://www.mrc.ac.uk/Ourresearch/ResearchInitiatives/NPRI/index.htm).

**Links to other NCRI or related activities**

The 5 UKCRC Centres for Public Health Research Excellence, which were set up in 2008, have been awarded a further 5 years of funding which is to commence in 2013–14. MRC is managing this second round of funding.

<b>Name of activity</b>
National Awareness and Early Diagnosis Initiative (NAEDI): research workstream
<b>Why are we doing it?</b>
To undertake peer-reviewed research which furthers the goals of NAEDI.
<b>Who is in the lead?</b>
NAEDI as a whole: DH and CR-UK Research workstream: CR-UK
<b>Type of activity</b>
Research projects funded through calls for proposals.
<b>Is there dedicated funding?</b>
Cancer Research UK, all 4 health departments, and Economic and Social Research Council, together pledged £7.5m over 5 years to support research.
<b>Core secretariat resources allocated</b>
<0.1 FTE, 'watching brief'.
<b>Overall aim</b>
<ul style="list-style-type: none"> <li>• The overarching goal of NAEDI is to achieve earlier diagnosis, leading to detection of cancers at a less advanced stage, thus improving cure rates, survival and mortality.</li> <li>• The NAEDI Research Calls have sought to support research that leads to better understanding of diagnostic delays or behavioural interventions (directed at patients or professionals) which may lead to less delay.</li> </ul>
<b>Specific objectives</b>
The two calls so far have targeted: <ul style="list-style-type: none"> <li>• Higher risk populations</li> <li>• Public awareness of cancer symptoms and reasons for late presentation</li> <li>• Health services</li> <li>• Methodology for, and evaluation of, early detection and awareness research.</li> </ul> <p>In addition, in Call 2 the funders strongly encouraged the submission of proposals on development and evaluation of:</p> <ul style="list-style-type: none"> <li>• Computer-based decision support systems</li> <li>• Models, tools and approaches to improve cervical and bowel cancer screening uptake.</li> </ul>
<b>Start date</b>
NAEDI was announced in the Cancer Reform Strategy in 2007. The first NAEDI Research Call came out in late 2009.
<b>End date</b>
To be determined.
A third Research Call to be launched in April 2013. Grants to start during 2014 and continue through to 2016.

**Planned outputs April 2012–March 2013 – objectives agreed last year**

- Evaluation, led by Cancer Research UK (with input from NCRI Secretariat), on the impact of the projects funded through Calls 1 and 2.
- Planning for a NAEDI research conference in association with the Cancer and Primary Care Research International Network (CaPRI) in summer 2013.

**Actual outputs April 2012–March 2013**

- Evaluation meeting held October 2012 involving NCRI Secretariat, funding partners and members of the scientific review committee.
- Outcomes from the evaluation meeting fed into the preparation of NAEDI Research Call 3.

**Planned outputs April 2013–March 2014**

- Joint NAEDI-CaPRI meeting held 16 April in Cambridge, UK with a NAEDI conference following on 17 April.
- Release of NAEDI Research Call 3 on 17 April 2013. Call 3 welcomes applications addressing early diagnosis across the NAEDI pathway and is particularly keen to support research to understand the significance of symptoms across different cancer types and making use of available data.
- CR-UK to run NAEDI workshop for potential applicants (advice and networking) in association with the scientific review committee and the NCRI Screening, Prevention and Early Diagnosis (SPED) group.
- Development of a Project Officer role to act as a central point of contact for all NAEDI related queries, supporting the community to develop further research proposals and disseminating research outcomes.

**Looked-for outcomes and success factors by end date or as ultimate legacy**

- In the short term: funding high quality research to promote the earlier diagnosis of cancer and for this research to be underway.
- In the longer term: to have developed interventions to increase awareness of cancer symptoms, promote early presentation and in other ways promote earlier diagnosis of cancer.

**Sustainability plan**

- Development of a Project Officer role to develop the research community further – strengthening research skills and building research capacity.
- The SPED group, which was set up in late 2012, will continue to be available to advise researchers planning trials in the area of screening, prevention and early diagnosis.
- At present there are no plans for a further NAEDI funding round therefore further progress is expected through the NAEDI Project Officer role and SPED.

**Issues and risks**

- There may be limited capacity to fund high quality research if the applications received are again of variable quality. The NAEDI workshop and development of the Project Officer role will mitigate against this.
- The length of time between awarding funding and the end dates of some projects means that outcomes may not be available for up to 5 years in some instances.

**External profile**

- Components of NAEDI are described at <http://info.cancerresearchuk.org/spotcancerearly/naedi/>.
- Details of the NAEDI Research Calls can be found at <http://science.cancerresearchuk.org/funding/find-grant/all-funding-schemes/naedi-research-workstream/>.

**Links to other NCRI or related activities**

The International Cancer Benchmarking Partnership is a programme of work which sits alongside NAEDI. It aims to identify the root causes of survival differences between countries/jurisdictions with comparable health care systems and high quality cancer data and to generate actionable insights which will help all partners improve cancer survival outcomes. More information can be found at <http://info.cancerresearchuk.org/spotcancerearly/ICBP/>.

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