

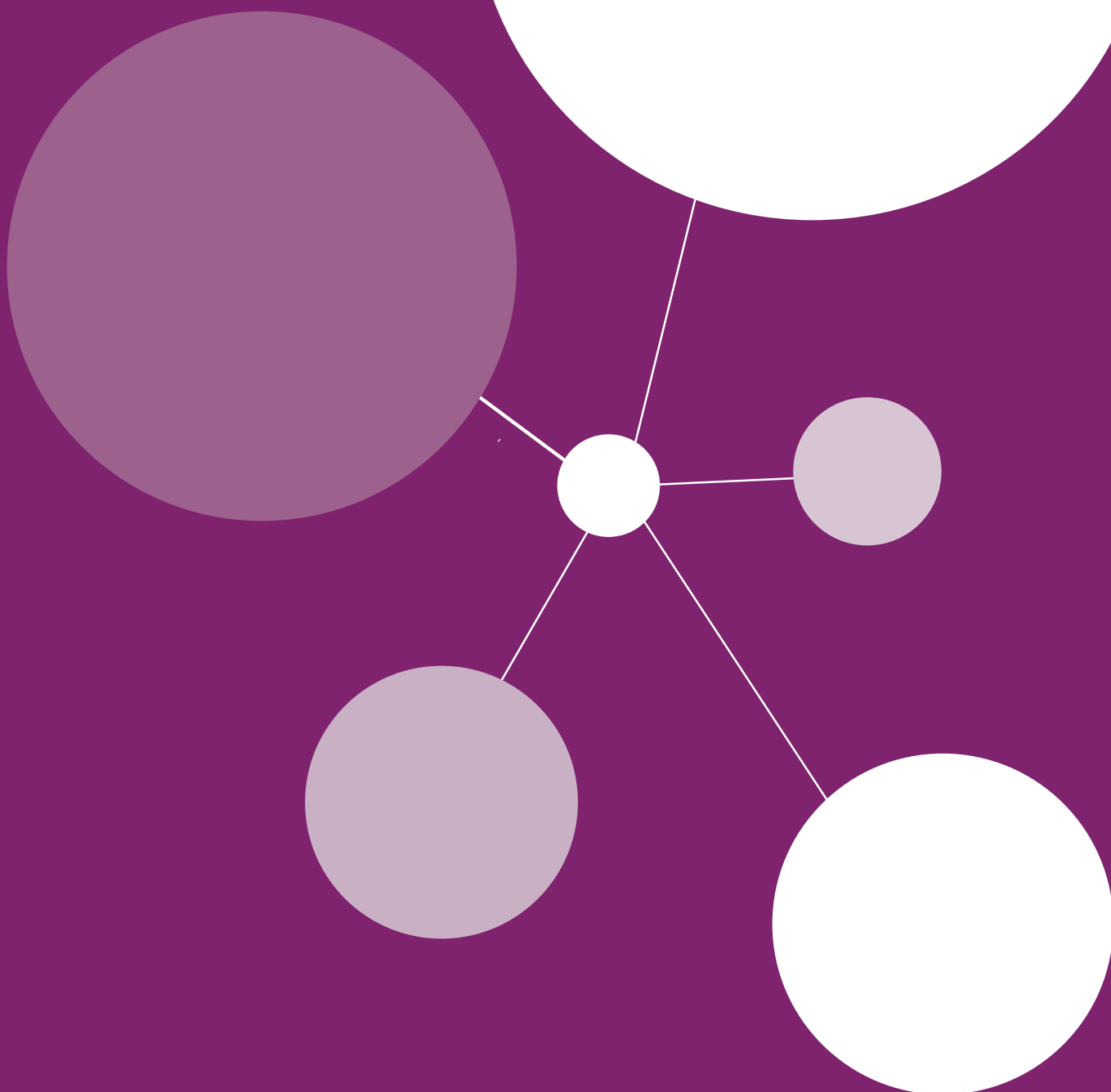


**NCRI**

National  
Cancer  
Research  
Institute

# NCRI

**Operating Report 2013/14**



Partners in cancer research

## Contents

1. Introduction and summary .....	3
2. NCRI Cancer Research Database .....	3
3. NCRI Cancer Conference .....	4
4. NCRI governance and Secretariat .....	4
5. Communications .....	4
6. Involving consumers .....	4
7. NCRI Clinical Studies Groups .....	5
8. Clinical and Translational Strategy Group (CTSG) .....	5
9. Cancer clinical trials unit (CTU) coordination .....	5
10. Impact of NCRI initiatives .....	5
11. International activities .....	6
12. Stakeholder environment .....	6
13. Forward look .....	6
Appendix A: highlights from NCRI initiatives during 2013/14 .....	8
Appendix B: budget outturn for NCRI Secretariat 2013/14 (excluding Clinical Studies Groups).....	10
Appendix C: risk management .....	13
Appendix D: progress and priorities – activity templates .....	15
Glossary of acronyms .....	60

## 1. Introduction and summary

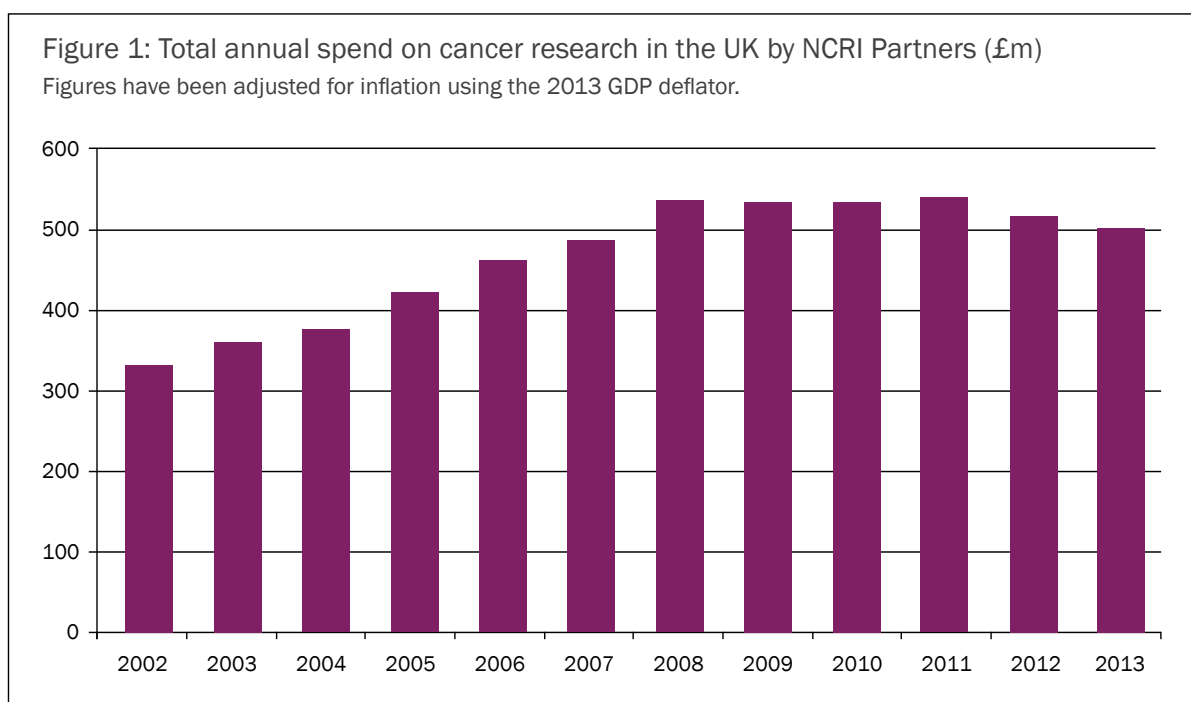
This report summarises the core activities of the NCRI Secretariat during 2013/14, and is intended to provide evidence to Partners that the work of NCRI is being taken forward in an effective and cost-effective manner on their behalf. Details of progress on individual initiatives are reviewed and reported separately; **Appendix A** provides a high level summary of the main achievements/outputs during 2013/14.

## 2. NCRI Cancer Research Database

Collection of the 2013 portfolio data was completed in March 2014 and showed that Partners spent £503m on cancer research compared to a peak of £541m in 2011 (see Figure 1). The fall in reported spend was due to transient changes in research reporting procedures within certain Partner submissions and the reappportioning of a small number of large grants to better reflect the cancer research focus.

The online data package for the 12 years 2002–2013 has been published on the NCRI website and shows a continuation of recent trends: research spend on aetiology continues to fall while spend on early detection, diagnosis and prognosis research has risen and now comprises 13.8% of total spend in 2013. In recent years there has been a slight increase in the proportion of site-specific research in the database with approximately 45% of all research spend now focussed on a specific cancer site.

The NCRI published a report ‘Cancer research spend in the UK 2002–2011 – an overview of research spend by NCRI Partners’ at the NCRI Cancer Conference in November 2013. There were two other analyses and publications in 2013: research into less common cancers: ‘An analysis of research spend by Cancer52 members and National Cancer Research Institute (NCRI) Partners in 2012’; and, ‘Funding of children’s cancer research: 2008 data from the ICRP portfolio’.



### 3. NCRI Cancer Conference

The 2013 Conference was another successful event. Delegate feedback was excellent: once again over 95% of survey respondents said that they would recommend the Conference to colleagues.

The NCRI continued its association with the Royal College of Radiologists (RCR) in 2013 and this has now been confirmed for the 2014 Conference, with a view to it being continued for 2015. The goal of this association is to integrate some of the RCR's regular meetings into the content of the NCRI event.

The Conference exhibition was managed in-house for the first time in 2013: exhibitors' satisfaction levels were as good as, or better than in the past. This move, and the fact that the sponsorship target was exceeded, led to an improved financial status for the Conference. 2014 sponsorship targets have been lowered due to changes in the external environment; it is hoped that these targets will be achieved by increasing the pool of Conference supporters.

### 4. NCRI governance and Secretariat

There have been some significant changes within the Secretariat over the last 12 months. Dr Karen Kennedy took on the NCRI Director role in November 2013, upon the retirement of Dr Jane Cope, and has been establishing links with NCRI Partners and other key stakeholders. The merger of the NCRI and Clinical Studies Groups (CSGs) Secretariats took place in April 2013 and the teams have continued to explore ways to work together more effectively. The 0.2FTE NCRI Clinical Research Director role was established to transfer clinical oversight of the CSGs from the NIHR Clinical Research Network: Cancer (NIHR CRN: Cancer), formerly NIHR Cancer Research Network (NCRN) to within NCRI, and the NIHR CRN: Cancer Director is continuing in this role.

Two major related pieces of operational work have been initiated by the Secretariat within the last year: the first piece of work is exploring the options for the future legal structure of NCRI and a second is exploring the funding model for the NCRI Secretariat with the goal of producing a simple, transparent and predictable tool to calculate Partner contributions. It is anticipated that these will be completed and implemented by March 2015.

### 5. Communications

2013/14 was the Secretariat's first year with a communications manager in post. A rewrite and rebuild of the website has been the primary activity, with a refresh of branding and straplines in parallel. This now provides us with a strong platform that will support future activities, such as clearer presentation of news and events, and the ability to share Partners' publications and other materials centrally. Publications in 2013/14 have been mostly data analyses as detailed above. The first CSG prospectus was also produced and has been well received. We have begun to revamp the newsletter to increase its efficiency and to explore how we can work in sync with communication channels in Partner organisations, and these will be bigger features of our work next year.

### 6. Involving consumers

Responsibility for consumers on NCRI Clinical Studies Groups (CSGs) was transferred from the NIHR Clinical Research Network: Cancer to the NCRI during 2013/14. Both institutions had different reimbursement guidelines. These were reviewed and the CSG consumers were brought under the slightly modified NCRI guidelines from 1 April 2014.

Consumers are involved in all NCRI activities and it was agreed that it is timely to review these interactions. A working group has been set up to carry out this review, with the overarching aims of the review being to:

- clarify how we would like consumers to help the NCRI achieve its aims
- determine whether the NCRI and its consumers are getting the maximum benefit from current consumer involvement in NCRI activities and how best to ensure maximum impact (value) in going forward.

The working group has held its initial meeting with others scheduled during the summer, along with consultation with other key stakeholder groups. The review will also look at how NCRl consumer activity is supported and how this will be impacted by changes in the NIHR Clinical Research Network. The intention is to report to the Board at its October 2014 meeting.

## 7. NCRl Clinical Studies Groups

2013/14 was a very busy year for the CSGs with seven highly successful annual trials meetings (including the first for the Children's Cancer and Leukaemia CSG), six progress reviews and several CSGs holding strategy days in addition to the normal cycle of meetings, membership and Chair rotation and annual reporting. There are ongoing discussions regarding whether the current CSGs structure is appropriate for biomarkers and imaging, the interaction and overlap of the Primary Care CSG and the Screening, Prevention and Early Diagnosis (SPED) Advisory Group, and the metrics by which cross cutting CSGs should be judged. SPED is gaining momentum and will be reviewed in February/March 2015, three years after its establishment.

The first ever CSGs prospectus was produced in time for the 2013 NCRl Cancer Conference and has been well received. The CSG portfolio maps, which give a visual representation of a Group's portfolio of studies, with links to trial description and inclusion and exclusion criteria, have been further developed to provide information on funding, of sponsorship of a study and CSG input into that study. Results of this triaging exercise have been analysed and presented to the CSG Chairs' Forum. There have been a number of excellent workshops including the NCRl-led Mesothelioma workshop, jointly planned with the British Lung Foundation and the Department of Health, which brought together 75 leading scientists and clinical researchers in this field. Others including one on the use of biomarkers in early detection will take place later this year.

## 8. Clinical and Translational Strategy Group

The first meeting of the Clinical and Translational Strategy Group (CTSG) was held in July 2013, and four have now been convened in total. The CTSG's initial focus has been oversight of the CSGs and a process has been established for the first year of CSG annual reviews that will have oversight through NCRl rather than the NIHR CRN: Cancer. Useful discussions have also been held on how to optimise CSG cross-cutting groups and on steps to improve visibility of early phase trials within the portfolio. The CTSG's remit also includes strategic oversight of other areas of cancer research and discussions have taken place on topics such as building industry relations in cancer, ongoing needs in pathology, and the progress and future of UK radiotherapy research.

## 9. Cancer clinical trials unit coordination

As agreed by the Board in October 2013, it is now timely for NCRl to move away from 'accreditation' of clinical trials units (CTUs) to a more networking-focused approach. After discussion with heads of the currently accredited CTUs, the Secretariat has put plans for a new group to the CTSG, these will be implemented in summer 2014. CTUs who reach a certain volume of multicentre, interventional cancer studies will be eligible to join the group, with one wider open forum meeting per year for any CTU working in cancer. Up to now, NIHR CRN: Cancer has been managing and funding the activity relating to the NCRl CTU accreditation scheme. The Coordinating Centre is continuing to provide funds for the CTU meetings and the annual workshop (3 July 2014) for this year only, with meeting management and costs passing over to NCRl from July 2014 onwards.

## 10. Impact of NCRl initiatives

During 2013/14 the NCRl completed an evaluation of the NCRl Supportive and Palliative Care (SuPaC)

initiative. This initiative comprised the support of the SuPaC Collaboratives CECO and COMPASS between 2006 and 2011 and the NCRI Capacity Building Grant scheme during 2008/9. The evaluation, which was a first such project for the NCRI, was based on interviews with key members of the SuPaC Collaboratives and analysis of other relevant materials including final grant reports and peer-reviewed journal articles. The evaluation highlighted the extensive impact the initiative had on policy and practice and on the development of research capacity in the field. The Secretariat is continuing to develop tools and frameworks to support more systematic evaluation of NCRI initiatives.

## 11. International activities

The International Cancer Research Partnership (ICRP), of which NCRI is a member, have agreed upon changes to the Common Scientific Outline (CSO) guidelines which members use to classify their research. The changes have been implemented to improve accuracy and consistency of CSO usage across the partnership and will be implemented from April 2014.

The ICRP have undertaken several bespoke analyses using the ICRP dataset, which includes NCRI Partner data, including analyses of research into obesity and cancer and environmental influences on cancer. Reports based on these analyses are expected to be published during 2014.

During 2013/14 the NCRI has continued its involvement in TRANSCAN, the ERA-NET on translational cancer research. As part of TRANSCAN the NCRI has led a work package to collect and analyse the research funding portfolios of 16 organisations from across Europe. Details of over 2,000 awards have been translated, coded and verified, and combined with data from NCRI Partners, ahead of aggregate analysis. A report based on the analysis will be published, and the work package completed, during 2014/15. More recently, the NCRI has been involved in facilitating discussions between NCRI Partners and TRANSCAN regarding the participation of UK-based research funders in the next iteration of TRANSCAN, TRANSCAN-2 and the associated joint transnational calls in translational cancer research.

During the year, the NCRI Director participated in the international cancer funders meeting alongside representatives of CR-UK, National Cancer Institute and other charity and government funders of research. The UK role at the meeting was to understand NCRI's work in the context of international research priorities.

## 12. Stakeholder environment

The Secretariat continues to keep abreast of the external environment and to monitor the impact of any changes on cancer research. Two key areas are the changes within the NIHR Clinical Research Network and the impact of the transfer of the National Cancer Intelligence Network to Public Health England.

The Secretariat is also exploring opportunities to work more effectively across the NCRI Partnership, for example, on communications and policy issues, and is beginning to explore opportunities to work more effectively with industry partners.

## 13. Forward look

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

- Undertake an opinion survey of NCRI Partners.
- Capture 2014 research funding data from NCRI Partners and implementation of the new CSO coding guidelines.
- Publicise an analysis of research funded by TRANSCAN partners.
- Develop a resource bringing together information and tools on research evaluation.
- Review the options for NCRI's governance structure and implement agreed option.
- Develop and agree on a Partner contribution model for financial year 2015/16 onwards.
- Agree operational and budget planning processes for 2015 onwards.

- Review the future of the NCRI Clinical Research Director role.
- Deliver the 10<sup>th</sup> NCRI Cancer Conference with high attendance levels and improved financial performance.
- Review the NCRI Cancer Conference.
- Review consumer involvement in NCRI.
- Set up a new networking function to replace CTU accreditation and introduce new CTU networking structures.
- Maintain a watching brief with the NIHR Clinical Research Network transition.

Objectives for initiatives are detailed elsewhere.

## Appendix A: highlights from NCRI initiatives during 2013/14

Topic	Outputs
Surgical research	<ul style="list-style-type: none"> <li>• Design and delivery of a surgery-themed day at the 2013 NCRI Cancer Conference (parallel session, workshop and facilitated networking lunch).</li> <li>• Production of a research funding guide and signposting mechanism for surgeons, distributed widely via Colleges and surgical associations.</li> <li>• Contribution to GRIST and CRISC surgical working groups.</li> </ul>
Imaging	<ul style="list-style-type: none"> <li>• Imaging subgroup within Biomarkers and Imaging CSG has been established.</li> <li>• Clinical prioritisation of imaging needs piloted with three CSGs and with CSG Chairs for further action.</li> </ul>
Clinical and Translational Radiotherapy Working Group (CTRad)	<ul style="list-style-type: none"> <li>• Continuing to make progress on a wide range of projects, as detailed in a report of activities produced by the Executive Group (soon to be made available on NCRI website).</li> <li>• Highlights include:               <ul style="list-style-type: none"> <li>– Two all-workstreams meetings for proposal development (80–100 investigators at each), which continue to be a major focus for study development and critique.</li> <li>– A number of workshops, many in partnership with other organisations.</li> </ul> </li> <li>• Continued oversight of radiotherapy QA.</li> <li>• New activities on preclinical data packages for drug-radiation combinations (RaDCom), proton therapy coordination, and a biomarker support network.</li> </ul>
Supportive & Palliative Care	<ul style="list-style-type: none"> <li>• Two junior researchers granted funding through the NCRI Lung Cancer Supportive and Palliative Care Scholarship scheme.</li> </ul>
End of Life Care Research Interest Group (eolcRIG)	<ul style="list-style-type: none"> <li>• Transfer of the support and coordination of the group, which comprises 30 members, to Marie Curie Cancer Care.</li> </ul>
Database analyses	<ul style="list-style-type: none"> <li>• Publication of 'Cancer research spend in the UK 2002–2011: An overview of the research funded by NCRI Partners.</li> <li>• Publication of 'Research into less common cancers: An analysis of research spend by Cancer52 members and National Cancer Research Institute (NCRI) Partners in 2012'.</li> <li>• Publication of 'Funding of children's cancer research: 2008 data from the ICRP portfolio'.</li> </ul>



<p>PET Core Lab</p>	<ul style="list-style-type: none"> <li>• The number of accredited PET scanning sites remains at 31, with all sites desiring accreditation now having reached the standard required. The number of trials for which the Core Lab is coordinating QA has increased in 2013/14, with 13 trials at present.</li> <li>• Many of the key procedures involved in running the core lab, including IT, have been updated and streamlined.</li> <li>• As advised by the Board, the Core Lab has developed and implemented a mechanism for building QA costs into grants, and is now recouping part of the activity cost in this way (although underpinning funding is still needed to sustain core staffing).</li> </ul>
<p>Confederation of Cancer Biobanks (CCB)</p>	<ul style="list-style-type: none"> <li>• Biobank membership increased from 28 to 31 biobanks.</li> <li>• The CCB Secretariat organised a number of events through-out the year: <ul style="list-style-type: none"> <li>– two member-hosted workshops, one in association with the Liverpool GCLP Biobank and UK CLL Trials Biobank and another with NHS Greater Glasgow &amp; Clyde Biorepository and Tayside Tissue Bank</li> <li>– a workshop as part of the 2013 NCRI Cancer Conference and</li> <li>– a public engagement event organised in collaboration with the Royal College of Pathologists.</li> </ul> </li> </ul>
<p>Biobanking Harmonisation</p>	<ul style="list-style-type: none"> <li>• Quality Assurance and data harmonisation standards have been agreed within the UK and published.</li> <li>• Pilot peer-review audit scheme redeveloped and implemented within the UK.</li> <li>• Work begun with ISO on development of an international standard for biobanks.</li> </ul>
<p>National Cancer Intelligence Network (NCIN)</p>	<ul style="list-style-type: none"> <li>• Facilitated the linkage of UK Biobank to the most up to date cancer registration data available. Progressed work on the phase 1 pilot project on the adjudication of cancer outcomes amongst the UK Biobank and facilitated the initiation of a phase 2 pilot project on gaining access to tissue held in NHS diagnostic achieves for participants diagnosed with cancer.</li> <li>• Provided operational support to the PHE Office of Data Release, which was established in January 2014 to process data access requests for researchers and other third parties</li> </ul>
<p>National Awareness &amp; Early Diagnosis Initiative (NAEDI)</p>	<ul style="list-style-type: none"> <li>• Funding agreed for 11 project grants through third NAEDI Research Call.</li> </ul>

## Appendix B: budget outturn for NCRI Secretariat 2013/14

**Table 1. NCRI Secretariat budget (excluding Conference, CSGs and initiatives with dedicated funding)**

	Budget 2013/14 £k	Final outturn 2013/14 £k	Budget 2014/15 £K
Staff salaries	503	487	480
Director recruitment	30	32	-
Property services charges	69	53	68
Office consumables	7	5	12
Travel and subsistence	7	9	16
Meetings	19	14	32
Exhibition stand	7	8	12
Press office/PR	20	20	20
Design and print (incl. website)	15	13	10
Training	12	11	18
Consultancy & Database maintenance	4	3	7
IS service charge	15	15	18
ICRP	0	0	20
<b>Total expenditure</b>	<b>708</b>	<b>670</b>	<b>713</b>
Less carried forward funds	(67)	(67)	(38)
<b>Net expenditure</b>	<b>641</b>	<b>603</b>	<b>675</b>

Table 2. NCRl Cancer Conference budget

	Budget 2013/14 £k	Final outturn 2013/14 £k	Budget 2014/15 £K
<b>Income</b>			
Trade exhibition	200	191	190
Conference dinner	17	10	15
Registration	330	308	325
Partner Contributions	195	195	195
Session sponsorship	135	123	80
Major sponsorship	90	100	90
Misc sponsorship including comm workshops	37	52	35
VAT Return	25	24	25
Misc income	0	6	5
<b>TOTAL</b>	<b>1,029</b>	<b>1,009</b>	<b>960</b>
<b>Expenditure</b>			
Facilities	280	255	265
Administration	305	307	305
Travel & accommodation	105	100	100
Consumer bursary	22	22	20
Student bursaries	5	10	5
Trade exhibition	131	118	120
Refreshments	150	143	145
Contingency/misc	0	0	0
<b>TOTAL</b>	<b>998</b>	<b>955</b>	<b>960</b>
<b>(Surplus)/loss</b>	(31)	(54)	0
<b>Carried forward</b>	(39)	(39)	(93)
<b>Net (surplus)/loss</b>	(70)	(93)	

**Table 3. Clinical Studies Groups budget**

	<b>Budget 2013/14 £</b>	<b>Final outturn 2013/14 £</b>	<b>Budget 2014/15 £</b>
Staffing costs inc pension and NI contributions	225,945	219,744	217,736
Training and development	1,744	1,290	*
Consumables, stationery, printing, photocopying , and other misc	18,589	26,910	27,000
Building, project management and IT service charges	76,800	43,431	59,729
CSG meeting costs, travel and subsistence	190,840	216,716	200,952
<b>TOTAL</b>	<b>513,918</b>	<b>508,091</b>	<b>505,417</b>

\*Training and development is now included in the Secretariat budget.

## Appendix C: 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 2013 and 2014 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 2013	Planned mitigation in 2013	Mitigation action achieved in 2013/14	Assessment in 2014	Planned Mitigation in 2014/15
1.	The Partners decide that NCRI no longer adds value.	Probability  LOW  Impact  HIGH	No new action planned. Recruitment of new Director seen as evidence of Partners' ongoing commitment.	New Director in post since October 2013.	Probability  LOW  Impact  HIGH	Review of governance and legal structures. Partner feedback on NCRI sought through survey.
2.	The NCRI Cancer Conference fails to meet its (financial) targets, with consequent damage to reputation.	Probability  LOW  Impact  HIGH	Trade exhibition to be organised in-house; delegate fees to be modestly increased. Potential new sponsors courted; marketing to delegates increased.	Successful in-house organisation of Trade exhibition with no loss in sales to exhibition space. Delegate fees increased with no significant changes to delegate numbers. Marketing increased.	Probability  LOW  Impact  HIGH	Formal review of the Conference to take place in 2014. Increase breadth of sponsorship base.

## 2. Ongoing risks (continued)

	Risk	Assessment in 2013	Planned mitigation in 2013	Mitigation action achieved in 2013/14	Assessment in 2014	Planned Mitigation in 2014/15
3.	<p>Actions are agreed by the Board, but funders decline, or are unable, to provide funds to take them forward.</p>	<p>Probability</p>  <p>MEDIUM</p> <p>Impact</p>  <p>HIGH</p>	<p>Balance between core and non-core work to be considered as part of wider Partner consultation on how Partner financial contributions are calculated.</p>	<p>NCRI Finance Group set up to review how Partner contributions will be calculated from 2015.</p>	<p>Probability</p>  <p>MEDIUM</p> <p>Impact</p>  <p>HIGH</p>	<p>Further development of a suitable financial model for Partner contributions to be put in place by April 2015.</p>
4.	<p>NCRI fails to capture data from partners for the Cancer Research Database leading to a gap which cannot be filled retrospectively</p>	<p>Probability</p>  <p>LOW</p> <p>Impact</p>  <p>HIGH</p>	<p>Letter to Partners sent to remind of importance of meeting deadlines and responding to queries in a timely manner in order for data to be collected and analysed in time for the annual February/March Partners meetings.</p> <p>Publication of 10 year analysis will highlight the value of the data and should generate ongoing buy-in from Partners to supply their data in a timely fashion.</p>	<p>Letter to Partners and active follow up by NCRI Secretariat ensured that data was collected and analysed in time for the March 2014 Partners meeting.</p> <p>10 year analysis published in November 2013.</p>	<p>Probability</p>  <p>LOW</p> <p>Impact</p>  <p>HIGH</p>	<p>Data on research spend by TRANSCAN partners, including NCRI Partners, will highlight the broader value of the data held in the Cancer Research Database and help to support continued buy-in from Partners to supply data for the database in a timely manner.</p> <p>Publication of topic-specific analyses using the Cancer Research Database will highlight the broader value of the database.</p>

## Appendix D: progress and priorities – activity templates

### 1. Introduction to the activity templates

The activity templates aim to give Board members a bird's eye view of the current catalogue of activities, broadly grouped according to type, and to give an idea of the amount of core Secretariat resource and/or dedicated funding that is being used.

### 2. List of current activities

Activities are divided into three categories as shown in the Table below. Exploratory work is supported solely by core Secretariat resource and is at a stage when it could either lead to a specifically funded project or may be completed within a limited timeframe. Activities in the second and third categories have been established for longer, with at least some dedicated funding, and often their own governance function or steering committee. The Secretariat is responsible for driving forward the activities in the second column; the Secretariat role for the last column is that of 'watching brief'. The bracketed numbers in the table cross-refer to the activity in the activity template. It is intended that each activity will retain its number through the years to make it easy to follow an audit trail if necessary.

Category 1: exploratory activities managed by the Secretariat with core resource only	Category 2: infrastructural activities man- aged mainly by the Secretariat with some dedicated resource	Category 3: partner-led research funding initiatives
Surgical research (1)	CTRad (6)	Cancer inequalities: identification of research priorities and opportunities (3)
Imaging research (2)	Confederation of Cancer Biobanking (10a)	UK End of Life Care Research Interest Group (8)
Children's cancer research (4)	Biobanking harmonisation project (10b)	PET Core Lab (9)
Cancer52 portfolio analysis (5)	Funders' Vision for Human Tissue Resources (10c)	NPRI (12)
Survivorship (7)	Revisit the actions from the NCRI report 'Fostering the role of Pathology in Research' (2009) (10d)	NAEDI (13)
Cancer and diabetes (14)	National Cancer Intelligence Network (11)	

In the second column of the Table, and the following templates, the term 'infrastructural' is used as a broad category to include any or all of the following:

- capacity building
- promoting applications on specific topics to existing funding schemes, e.g. through workshops
- coordination among researchers and/or funders
- harmonisation of policy and/or practice
- provision of a research service, e.g. QA or accreditation.

### 3. Notes on the the activity templates

The allocation of core staff time shown is a rough guide only. In most cases it is an estimate of the amount of staff time supported by the core budget over the last year or so. Because time is also spent on core business, including general management and intelligence, the figures do not account fully for staff time.

A glossary of acronyms is provided on page 60.



**Activity templates category 1:  
exploratory activites**

<p><b>Name of activity</b> Surgical research</p>
<p><b>Why are we doing it?</b> Surgical research forms a very small part of the research portfolio, and the number of surgeons engaged with research was low. The NCRI report on surgical research identified areas that could help to boost surgical research, and a Programme Manager's time has been put to working with Partners and other stakeholders to increase activity in this area.</p>
<p><b>Who is in the lead?</b> NCRI Secretariat.</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> 0.4 FTE Programme Manager (AF); 0.1 FTE Head of Programmes (JM).</p>
<p><b>Overall aims at outset</b></p> <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 underway.</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>
<p><b>Specific objectives at outset</b></p> <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>
<p><b>Start date</b> 2011.</p>
<p><b>End date</b> Core Secretariat support currently available until early 2015.</p>
<p><b>Planned outputs April 2013–March 2014 - objectives set last year</b></p> <ul style="list-style-type: none"> <li>Organise and promote an NCRI Cancer Conference parallel session on surgery, with an accompanying surgical trainee workshop.</li> <li>Chart the activities and initiatives that are happening to capture an overall picture and determine what is proving effective.</li> <li>Compile funding opportunities for surgical research, and promote through colleges and associations, and highlight any funding scheme gaps to research funders.</li> <li>Consider a CSG workshop or similar to bring surgeons together for further ideas.</li> <li>Monitor Hisham Mehanna's scheme to introduce three trainee surgeons into Head &amp; Neck CSG subgroup for trial development experience; could be built on if successful.</li> </ul>

**Actual outputs April 2013–March 2014**

- A surgery parallel session accompanied by a workshop and educational lunch was run at the NCRI Cancer Conference and promoted as a ‘surgery-themed day’. The event was well received and identified a pool of surgeons not previously associated with NCRI.
- Funding opportunities and guidance from NCRI Partners and others for surgeons to undertake research have been compiled and hosted on the NCRI website. These have been enthusiastically received by surgeons, and Colleges and associations have promoted the document. Gaps in funding opportunities have not emerged; discussions with funders regarding the success rates of surgical applications are ongoing.
- A workshop for CSG surgeons was piloted to explore whether there are surgery research topics that people have a will to address across cancer types; there was enthusiasm for more regular cross-cutting surgery discussion/advice to address some of these. The meeting was run as a satellite at the Association of Surgeons of Great Britain and Ireland (ASGBI) annual congress, building new links with this organisation.
- The surgical trainee scheme in the Head and Neck CSG was discussed at the recent CSG surgeons’ workshop and there was considerable interest in exploring this in other CSGs to improve links with associations and encourage trainee involvement in research.

**Planned outputs April 2014–March 2015**

- Produce short report summarising the CSG surgeons’ meeting, and work with the surgical community to explore ways of supporting potential cross cutting work, seeking funding to support group working if deemed of value.
- A follow-up report on cancer surgery research will be produced for the October 2014 Board, examining changes in infrastructure and activity since the NCRI surgery report in 2012. This will also highlight any challenges still remaining.
- Continue to build relationships with surgical organisations, and facilitate collaboration wherever possible. This includes working with BASO to encourage abstract submissions for their poster prize at the NCRI Cancer Conference, and encouraging surgeon attendance.

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

- Increased activity in surgical cancer research in the UK (which in due course can be captured in the NIHR Clinical Research Networks).
- 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**

The group GRIST is considering the future of its national coordination activity; it currently provides a useful surgical cross-specialty forum but is unfunded and has minimal support. If downsized or changed substantially, this could impact on the level of role that any CSG-wide surgical grouping might take.

**External profile**

- NCRI's work on surgery has a profile at RCS England and at GRIST; although neither route has funding to take forward initiatives, they cascade our information to surgeons and provide a valuable liaison channel.
- Partnership links have been built between the NCRI and the surgical associations ASGBI and BASO. BASO will be sponsoring a poster prize at the 2014 NCRI Conference. These associations also offer channels for wider engagement with 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 Initiative (CRISC).
- A number of NCRI Partners have investments or activities of some kind in surgical research, which NCRI Secretariat members contribute to on request.

<b>Name of activity</b>
Imaging research in cancer
<b>Why are we doing it?</b>
With the NCRI PET Research Network having ended 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 role 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>
0.3 FTE Programme Manager (AF); 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 Secretariat time currently available until early 2015, if required.
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b>
<ul style="list-style-type: none"> <li>• 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 data and clinical imaging to determine whether the NCRI can add value.</li> <li>• Support the CSG imaging subgroup in setup and with their aim to support imaging work across CSGs.</li> <li>• 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.</li> <li>• Continue the search within the research community for a champion and focus for NCRI coordination work.</li> <li>• Explore whether there is a business case for a Core Lab for MRI.</li> </ul>

**Actual outputs from April 2013–March 2014**

- Clinical imaging groups/organisations and their activities have been collated, though it has been challenging to translate this information into a ‘map’, as organisations and areas of focus remain disparate. Despite further scoping with the imaging community, it has not been possible to distil wider aims for clinical imaging into a series of smaller actionable steps. Data aspects have not been possible to explore within current resource, although the CSG Imaging subgroup has expressed interest in these areas.
- The CSG Imaging subgroup has been established and core Secretariat resource used to give initial momentum to projects/agenda setting (until Sep 2014).
- A clinician-led prioritisation of imaging topics was carried out in three CSGs, generating a list of suggestions for research topics which could have the greatest patient impact. It has been difficult to persuade the imaging community to pursue these suggestions as potential research topics, suggesting a gap between the interests of imaging researchers and clinical needs for imaging. As such, it has been challenging to bring imaging researchers and clinicians using imaging into closer alignment.
- Despite efforts, no champions willing to lead a wider strategic effort have been found.
- The desire for an MRI Core Lab has been discussed by the CSG Imaging subgroup, but a clear need/business case for this has not yet been outlined by the imaging community.

**Planned outputs April 2014–March 2015**

- Following wider discussions on the advisory role of cross-cutting CSGs, support the imaging subgroup in any transition agreed (until Sep 2014).
- Make funders aware of the CSG suggestions for imaging research, so that any studies addressing these questions are prioritised, and the gap between some currently funded research and clinical need for imaging is recognised.
- Make information gathered to date (including the imaging groups/organisations and their activities) available on the NCRI website for public use.

**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**

- Lack of an ‘imaging champion’ with breadth of view of the field has limited any wider collaborative potential beyond the CSG subgroup, and the distinct nature of imaging modalities and specialties suggests that such a person individual will be difficult to find.
- A gap exists between some funded imaging research and clinical needs for imaging, making it challenging to bring individuals working in these two areas into closer alignment.

**External profile**

Imaging groups (e.g. ECMC Imaging Network Group and CR-UK imaging centres secretariat) have interacted with NCRI on its exploration of the topic.

**Links to other NCRI or related activities**

- Follows on from the work started in the NCRI PET Research Initiative; ongoing NCRI PET Core Lab is a coveted model for other modalities.
- Has some shared goals with CTRad, in both image guidance and radiotherapy planning.

<b>Name of activity</b>
Children's cancer research
<b>Why are we doing it?</b>
<ul style="list-style-type: none"> <li>Community request for review of academic paediatric oncology thought by the Board in March 2010 to be untimely in aftermath of restructuring.</li> <li>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.</li> </ul>
<b>Who is in the lead?</b>
NCRI Secretariat.
<b>Type of activity</b>
Analysis from the NCRI Cancer Research Database (CaRD) and International Cancer Research Partnership (ICRP) Database.
<b>Is there dedicated funding?</b>
No.
<b>Core secretariat resources allocated</b>
0.1 FTE Research Analyst (TW), <0.1 FTE Head of Programmes (JM).
<b>Overall aim</b>
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.
<b>Specific objectives</b>
<ul style="list-style-type: none"> <li>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.</li> <li>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.</li> </ul>
<b>Start date</b>
2012.
<b>End date</b>
2014.
<b>Planned outputs April 2013–March 2014</b>
<ul style="list-style-type: none"> <li>Discussion of the data outputs, interpretation and implications with the children's cancer Chairs' forum. Final approval of report to be sought from ICRP.</li> <li>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.</li> </ul>
<b>Actual outputs from April 2013–March 2014</b>
<ul style="list-style-type: none"> <li>Teleconference held with representatives from Children's Cancer and Leukaemia (CCL) CSG in Jan 2014, and clarifications made to the report and data set description.</li> <li>Input and signoff received from ICRP Partners on the data report.</li> <li>Report published on NCRI website in Jan 2014, and shared by CCL CSG Chair at meeting in Feb 2014.</li> </ul>
<b>Planned outputs April 2014–March 2015</b>
<ul style="list-style-type: none"> <li>No further outputs, as this activity is now complete.</li> <li>No formal evaluation planned, but have requested feedback from the CCL CSG as to how the document is used.</li> </ul>

**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 is now complete following report publication.

**Issues and risks**

A previously identified risk was that one or more ICRP partners may choose not to allow their data to be used in the published analysis; this was not realised, although several ICRP partners (as well as NCRI Partners for the UK components) required footnotes or other explanatory text to clarify understanding of their own data.

**External profile**

The report is now on the NCRI website, has been publicised via newsletter, and put forward to CCL CSG via the Chair, for use within their strategy and planning.

**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 UK 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. The majority of Cancer52's members do not reach the £1m threshold for membership of the NCRl however they are keen to engage with us and therefore the NCRl agreed to undertake an analysis of their research portfolio to understand how research active as a group Cancer52 are.
<b>Who is in the lead?</b>
NCRl Secretariat.
<b>Type of activity</b>
Data collection and analysis.
<b>Is there dedicated funding?</b>
No.
<b>Core secretariat resources allocated</b>
During 2013/14 the work was 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 NCRl portfolio analysis.
<b>Specific objectives</b>
Collect abstract and financial data from Cancer52 members and code it using the Common Scientific Outline with a view to publication during 2013/14.
<b>Start date</b>
Feasibility work started: Summer 2011.
<b>End date</b>
Analysis of the portfolio completed November 2013.
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b>
<ul style="list-style-type: none"> <li>• Successful bid for an intern for a 12 week placement.</li> <li>• Re-establish contact with the Cancer52 Secretariat and the Cancer52 membership to establish which organisations fund research, what they fund and their funding mechanisms.</li> <li>• Produce a final report by September 2013.</li> </ul>
<b>Actual outputs from April 2013–March 2014</b>
<ul style="list-style-type: none"> <li>• Data collected from 25 Cancer52 members who together funded over £7m of research in 2012.</li> <li>• Report of the data including a comparison with the NCRl Partner portfolio published in November 2013.</li> </ul>
<b>Planned outputs April 2014–March 2015</b>
None as activity to revert to 'watching brief' following completion of the portfolio analysis.
<b>Looked-for outcomes and success factors by end date or as ultimate legacy</b>
Publication of the analysis report to act as a platform for ongoing working relationship with Cancer52 and its members.
<b>Sustainability plan</b>
Portfolio analysis was a one-off project. Going forward NCRl will maintain a watching brief on Cancer52's activities and research on rarer cancer more generally while Cancer52 will continue to disseminate the report of the analysis.

**Issues and risks**

Not applicable to watching briefs.

**External profile**

- Information about Cancer52 can be found at [www.cancer52.org.uk/](http://www.cancer52.org.uk/).

**Links to other NCRI or related activities**

- NCRI Cancer Research Database.

<p><b>Name of activity</b> Survivorship after cancer</p>
<p><b>Why are we doing it?</b> To implement Action 1 from the Rapid Review of Survivorship and End of Life Care 2010.</p>
<p><b>Who is in the lead?</b> NCRI Secretariat.</p>
<p><b>Type of activity</b> Watching brief.</p>
<p><b>Is there dedicated funding?</b> Some of the funds remaining from the Lung SuPaC budget and contributions from the PHE's NEOLCIN and NISCHR provided resource for a Research Officer post up to August 2013.</p>
<p><b>Core secretariat resources allocated</b> &lt;0.1 FTE Head of Programmes &amp; Evaluation.</p>
<p><b>Overall aim</b> To promote investigator-led research through existing funding streams.</p>
<p><b>Specific objectives</b></p> <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>
<p><b>Start date</b> 2010 (on completion of review).</p>
<p><b>End date</b> Q3 2013.</p>
<p><b>Planned outputs April 2013–March 2014</b></p> <ul style="list-style-type: none"> <li>• NCRI Lung Cancer Supportive and Palliative Care Scholarship call to close 2 May 2013. Applications to be reviewed by scientific review panel 4 June 2013.</li> <li>• A champion has not emerged, and the community has not shown the necessary motivation to move forward the December 2011 workshop ideas, so it is proposed that 'survivorship' reverts to a watching brief rather than a specific initiative.</li> </ul>
<p><b>Actual outputs from April 2013–March 2014</b></p> <ul style="list-style-type: none"> <li>• Two scholarships were funded following scientific review during 2013. Projects have since gained ethical approval and commenced in 2013/14.</li> <li>• NCRI Grantsmanship Gateway website, produced as part of the Rapid Review to support junior researchers in making the best use of available funding opportunities, has been updated and revised.</li> </ul>
<p><b>Planned outputs April 2014–March 2015</b></p> <ul style="list-style-type: none"> <li>• Follow up on successful scholarships once completed.</li> <li>• Maintaining watching brief through engagement with specific CSGs and NCRI Partners and in future to identify new opportunities for NCRI to support research in cancer survivorship if appropriate.</li> </ul>
<p><b>Looked-for outcomes and success factors by end date or as ultimate legacy</b> To attract research-naive individuals into the supportive and palliative care research field by way of the Scholarship Scheme.</p>

<p><b>Sustainability plan</b></p> <p>Not applicable to watching brief.</p>
<p><b>Issues and risks</b></p> <p>Not applicable to a watching brief.</p>
<p><b>External profile</b></p> <p>NCRI Grantsmanship Gateway: <a href="http://grantsmanship.ncri.org.uk/">http://grantsmanship.ncri.org.uk/</a>.</p>
<p><b>Links to other NCRI or related activities</b></p> <p>Details of the Department of Health (England) and Macmillan Cancer Support National Cancer Survivorship Initiative (NCSI) can be found at <a href="http://www.ncsi.org.uk/">www.ncsi.org.uk/</a>.</p>

<b>Name of activity</b>	Cancer and diabetes
<b>Why are we doing it?</b>	Following discussions in late 2011 between the then National Clinical Directors for Cancer and Diabetes and feedback received as part of the NCRI Strategic Plan consultation process.
<b>Who is in the lead?</b>	NCRI.
<b>Type of activity</b>	Exploratory.
<b>Is there dedicated funding?</b>	No.
<b>Core secretariat resources allocated</b>	0.2 FTE Head of Programmes & Evaluation.
<b>Overall aim</b>	To scope the needs and opportunities for research to investigate the potential interaction between cancer and diabetes.
<b>Specific objectives</b>	To consider what value the NCRI could add to research in diabetes and cancer.
<b>Start date</b>	December 2012.
<b>End date</b>	To be determined.
<b>Planned outputs April 2013–March 2014</b> – objectives agreed last year	<ul style="list-style-type: none"> <li>Further engagement with relevant stakeholders including Diabetes Research UK to identify the key players in this field.</li> <li>To determine the potential for a ‘diabetes and cancer research’ stakeholder workshop from which to identify and discuss research opportunities and priorities and generate momentum for the research community to take the ideas forward.</li> </ul>
<b>Actual outputs from April 2013–March 2014</b>	<ul style="list-style-type: none"> <li>Engagement with researchers and representatives of research funding organisations to understand what research is underway in this area and what collaborations are already established.</li> <li>To consider the feasibility of undertaking a research gap analysis to identify areas in which further research may be appropriate.</li> </ul>
<b>Planned outputs April 2014–March 2015</b>	To work closely with the Diabetes Research Network’s writing group to determine whether NCRI’s work in diabetes and cancer should progress to become an initiative or whether there is already sufficient research being carried out in this area such that specific NCRI support in this area is not necessary.
<b>Looked-for outcomes and success factors by end date or as ultimate legacy</b>	Not applicable to exploratory work.
<b>Sustainability plan</b>	Not applicable to exploratory work.
<b>Issues and risks</b>	Not applicable to exploratory work.
<b>External profile</b>	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 ten-point plan from the Rapid Review published in 2008.
<b>Who is in the lead?</b>	NCRI Secretariat.
<b>Type of activity</b>	Infrastructural.
<b>Is there dedicated funding?</b>	<ul style="list-style-type: none"> <li>• Collaborative funding of £191k p.a. (CR-UK, MRC, DH, CSO, NISCHR and HSC) from 1 Apr 2012 to 31 Mar 2015.</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.
<b>Specific objectives</b>	<p>As CTRad's work has evolved and priorities and structures have evolved, the core objectives have been redefined into three main areas:</p> <ol style="list-style-type: none"> <li>1. Developing high-quality research: RT study development and delivery, facilitating efficient translational research, patient and public involvement.</li> <li>2. Developing infrastructure: Leadership in RT quality assurance, developing centres of excellence, supporting the research workforce, promoting networking and collaboration.</li> <li>3. Exploiting opportunities: Engaging with research funders, engaging with industry, driving the research agenda for advanced technologies.</li> </ol>
<b>Start date</b>	First Chair appointed 1 Nov 2008; CTRad launched on 1 Jul 2009.
<b>End date</b>	Current funding ends 31 Mar 2015.



**Planned outputs April 2013–March 2014**

- All-workstreams meetings for proposal development planned for Jun and 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 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 [SCoR]).
- Proton group due to arrange workshops to discuss direction in collecting outcome data (Jul 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/CRUK 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.

**Actual outputs from April 2013–March 2014**

- Two all-workstreams meetings for proposal development held (Jun [12 proposals] and Nov [13 proposals]). Both meetings attended by 80-100 people.
- Radiotherapy-Drug Combinations Consortium (RaDCom) up and running. First collaborative preclinical project between three centres funded by CRUK New Agents Committee; discussion meetings with various pharma companies being arranged (first one in May 2014).
- Imaging in RT workshop (Jun 2013), SABR research workshop joint with the SABR Consortium looked at translational opportunities (Feb 2014); Consumers meeting at the Gray Institute (Jun 2013); Proton research group workshop to discuss collecting outcome data (July 2013).
- CTRad senior leaders presented to CRUK’s SEB to discuss and support their RT research strategy (Aug 2013).
- Radiographers think tank meeting in collaboration with Society and College of Radiographers (SCoR) to identify research priorities, unmet needs and emerging research areas (Sep 2013).
- CTRad and RTTQA presented at European data collection meeting (Nov 2013).
- Biomarker Support Network established to advise researchers (Nov 2013); editorial published in *Clin Oncol* (Jan 2014) to promote this network.
- Senior leaders’ letter to NHS England in support of SABR trials over CtE (Mar 2014).

**Planned outputs April 2014–March 2015**

- These include: All-workstream meetings for proposal development planned for May and Nov 2014; working with CRUK/ECMC Radiopharmacy Taskforce (CERT) on barriers to molecular RT research; protons research meeting to discuss national agenda and clinical trial ideas (Jun 2014).
- CTRad presentation to NCRI CTSG reporting CTRad’s achievements and vision (May 2014), following which Exec Group will be seeking further CTRad funding (summer 2014).
- RT Physics grants educational workshop to explore getting successful collaborative physics grants (Jul 2014); route to registration workshop inviting pharma to explore barriers to drug-radiation studies (Autumn 2014); CTRad/RCR clinical trials training workshop (Oct 2014); Radiographers think tank follow-up meeting (Nov 2014); ‘Project sandpit’ interactive workshop to help early researchers develop studies (Spring 2015).

**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 and more practice-changing trials involving radiotherapy.
- Metrics collected: 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.

**Sustainability plan**

- CTRad Executive Group sees a longer-term role for CTRad in its current structure, with a good start made but much still to achieve over the coming years. They are seeking funding at a similar level for the next three years.

**Issues and risks**

Funds currently only committed until March 2015.

**External profile**

- CTRad quarterly news bulletin and website with resources and events listings.
- Many meetings/workshops also open to non-CTRAd members (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**

CTRAd is highly interconnected with other organisations, including RCR (proton therapy; workforce; NCRI Cancer Conference); CSGs (nominated CTRAd link members); the CRUK/MRC Oxford Institute for Radiation Oncology (workshops, leadership); professional bodies such as Society and College of Radiographers, National Physical Laboratory; members on national funding committees; and connections with other national collaborative initiatives such as the PET Core Lab, Radiotherapy Board and the National Radiotherapy Awareness Initiative.

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>	<ul style="list-style-type: none"> <li>The funds that were transferred from onCore UK to the NCRI Secretariat in early 2011, when it closed down, supported 1.8 FTE posts (net) within the NCRI office, which were shared across activities 10a–10d, plus external pathology expertise. These funds were depleted at the end of 2013.</li> <li>Since January 2014, the resource required for the CCB-related activities has been supported from within other existing NCRI funds and posts.</li> </ul>
<b>Core secretariat resources allocated</b>	0.2 FTE Head of Cancer Intelligence (EB) split across activities 10a, 10c and 10d and 0.1 FTE NCIN Research Officer (RB).
<b>Overall aims</b>	<p>To become the representative body for cancer biobanking in the UK:</p> <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.
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b>	<ul style="list-style-type: none"> <li>Expansion of biobank membership to include all major holders of samples if possible.</li> <li>Two further member-hosted meetings delivered successfully (high attendance and positive feedback levels) and commitment from members to host further meetings.</li> <li>Significant expansion of clinical trial collections listings on Cancer Biosample Directory.</li> <li>Active involvement in planning of broader biosample directory.</li> </ul>

**Actual outputs April 2013–March 2014**

- Biobank membership increased from 28 to 31 biobanks.
- Two member-hosted meetings delivered successfully: 60+ attendees at each meeting with very positive feedback received.
- Supported the CCB Executive Group and organised two meetings for this group.
- CCB website is ready for migration to a new microsite within the main NCRI website.
- Produced two newsletters that were widely distributed.
- Explored with the UKCRC funders how to progress with a sustainable model for UK-wide tissue coordination.

**Planned outputs for April 2014–March 2015**

- Expansion of biobank membership to include all major holders of samples if possible.
- Two further member-hosted meetings delivered successfully (high attendance and positive feedback levels) and commitment from members to host further meetings.
- Produce two newsletters.
- Recruit new Chair for the CCB Executive Group; revise Terms of Reference and membership of this group.
- Run a survey across the CCB members to evaluate current activities and identify future strategic priorities.

**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). To this end, the UKCRC joint funders announced a call for applications for a national Tissue Directory and Coordination Centre in March 2014.
- The CCB would need to link with the national Coordination Centre and identify synergies to avoid duplication of effort. However, until the national Tissue Directory and Coordination Centre are up and running, it may make sense for CCB to continue to run from within the NCRI and for this to be supported from core NCRI resource.

**Issues and risks**

Need to avoid potential duplication of effort with the UKCRC-funded, national Tissue Directory and Coordination Centre.

**External profile**

- Communications include the website; <http://www.ncri.org.uk/ccb/>, newsletters, presence at conferences including NCRI Cancer Conference, technical meetings.
- NCRI Pathology lead and CCB Secretariat 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.
- Regular liaison with the PHE National Cancer Registration Service.
- Biomarkers and Imaging CSG.

<p><b>Name of activity</b> Biobanking Harmonisation: Quality Management</p>
<p><b>Why are we doing it?</b></p> <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 specialist technical leadership which is available through one of the former employees of onCore UK.</p> <p>The work is being sustained through the NCRI Secretariat pending a decision on the role and activities of the proposed UKCRC Joint Funders Tissue Directory and Coordination Centre, which may take over this work since it is applicable to the broader biobanking community.</p>
<p><b>Who is in the lead?</b> NCRI Secretariat.</p>
<p><b>Type of activity</b> Infrastructural.</p>
<p><b>Is there dedicated funding?</b></p> <p>The work related to biobanking is spread across activities 10a-10d. Although these activities are interrelated, the harmonisation and quality assurance work has a specialist technical focus which occupies approx. 0.6 FTE senior staff time. This activity was funded, until 31 December 2013, with funds transferred from onCore UK. It is funded by MRC from 1 January 2014 until 31 August 2014.</p>
<p><b>Core secretariat resources allocated</b> Minimal.</p>
<p><b>Overall aim</b></p> <ul style="list-style-type: none"> <li>• To increase the availability and interoperability of biological samples and data held in biobanks for use in research. Initially this was developed in collaboration with cancer biobanks although it is expected to have broader applicability.</li> <li>• To maintain momentum of the project pending implementation of the UKCRC Joint Funders' plans.</li> </ul>
<p><b>Specific objectives</b></p> <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> <li>• Maintain momentum of the project pending implementation of the UKCRC Joint Funders' plans.</li> </ul>
<p><b>Start date</b> October 2011.</p>
<p><b>End date</b> August 2014.</p>

**Planned outputs April 2013–March 2014 – objectives agreed last year**

- Develop written standards in consultation with the biobanking community.
- Develop strategy and publicise the standards.
- Develop “quality mark” scheme.
- Investigate option for United Kingdom Accreditation Service (UKAS) operating an accreditation scheme based on the CCB’s standards.
- Maintain awareness of external developments and assess their impact on this work.

**Actual outputs from April 2013–March 2014**

- Standards published following broad consultation and with input from cancer and non-cancer biobanks, patients, donors, researchers, regulators and funders.
- Strategy for dissemination developed. Standards announced at biobanking workshop at the NCRI conference in November, information about their publication has been disseminated through NCRI and CCB contact lists and newsletters, and through presentations at meetings and conferences.
- Pilot of peer-review audit scheme implemented; scheme improved based on experience in the first few audits.
- UKAS option proved to be too expensive at this time and would take too long; interactions discontinued.
- UKCRC Joint Funders call will have the biggest impact in this area but the development of BBMRI-ERIC and a formal ISO standard for biobanks will be important.

**Planned outputs April 2014–August 2014**

- Disseminate the outputs from the harmonisation project more fully, especially outside of the cancer biobanking community.
- Continue to pilot the peer-review audit scheme, focussing on biobanks outside of the cancer field.
- Work with groups seeking to respond to the UKCRC Joint Funders call to ensure that the harmonisation project is represented in some of the proposals put forward.
- Work with the British Standards Institute and ISO in the development of an international standard for human tissue biobanks.

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

- Publish written quality standard that has received broad approval from the cancer biobanking community and stakeholders.
- Publish a data standard, approved by the cancer biobanking community and stakeholders, which can be used to harmonise the data collected by biobanks and will allow comparisons to be made between the contents of the biobanks.
- Pilot a peer-review audit process, based on the published standards, to demonstrate that the standards can be used as the basis for an accreditation scheme and that the biobanking community is interested in such a scheme.

**Sustainability plan**

The project will be passed to the UKCRC Joint Funders for incorporation into their plans.

**Issues and risks**

The successful proposal to host the UKCRC Joint Funders Tissue Directory and Coordination Centre does not include continuation of the harmonisation project.

**External profile**

Maintained on the CCB website.

**Links to other NCRI or related activities**

- The harmonisation and quality management activity links to the CCB and NCRI's other biobanking activities.
- This activity links also to harmonisation, standardisation and quality management activities undertaken by the Biobanking and BioMolecular Resources Research Infrastructure (BBMRI-ERIC) and the International Organisation for Standardisation (ISO).



10c

<b>Name of activity</b>	Funders' Vision for Human Tissue Resources
<b>Why are we doing it?</b>	The 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>	The MRC on behalf of the UKCRC Experimental Medicine Funders Group (EMFG).
<b>Type of activity</b>	Infrastructural.
<b>Is there dedicated funding?</b>	<ul style="list-style-type: none"> <li>The funds that were transferred from onCore UK to the NCRI Secretariat in early 2011, when it closed down, supported 1.8 FTE posts (net) within the NCRI office, which were shared across activities 10a–10d, plus external pathology expertise. These funds were depleted at the end of 2013.</li> <li>Since January 2014, the resource required for activities related to the implementation of the Vision has been supported from within other existing NCRI funds and posts.</li> </ul>
<b>Core secretariat resources allocated</b>	0.2 FTE Head of Cancer Intelligence (EB) split across activities 10a, 10c and 10d.
<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>	<p>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:</p> <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).
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b>	Funders to review current policies against Funders' Vision and work to close gaps and harmonise approaches where required.

**Actual outputs April 2013–March 2014**

The UKCRC joint funders announced a call for applications for a national Tissue Directory and Coordination Centre in March 2014 with the aim to:

- develop a prototype and deliver a functional Resource Finder/Directory to enable researchers to discover, search across and contact multiple human tissue and biosample collections via a unified interface (taking account of existing systems) in order to facilitate sample access. The Centre will be expected to provide an evaluation of the system, in terms of usability, effectiveness in providing the ability to locate relevant samples, a demonstration of the benefits of the chosen approach, and an appraisal of potential options for a second phase of development, for example with increased metadata content and functionality;
- provide coordination and guidance to increase harmonisation of standards across the entire biosample lifecycle;
- build and manage engagement between researchers, biosample collections, the public, regulators and policy makers supporting evidence-based approaches to best practice.

**Planned outputs April 2014–March 2015**

- The funding decision for a national Tissue Directory and Coordination Centre is expected to be made at the end of July 2014. A maximum of £900k will be available to the successful bid over three years.
- 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 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/research-infrastructure/experimental-medicine/funders-vision-for-human-tissue-resources/>.

**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 of 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>	The funds that were transferred from onCore UK to the NCRI Secretariat in early 2011, when it closed down, supported 1.8 FTE posts (net) within the NCRI office, which were shared across activities 10a–10d, plus external pathology expertise. These funds were depleted at the end of 2013. The NCRI Secretariat was no longer able to support Dr Bridget Wilkins who is now the ECMC Pathology Lead (funded through the ECMC Secretariat). Professor Andy Hall still remains as NCRI Pathology Lead and provides his expertise free of charge. Since January 2014, the resource required for the pathology-related activities has been supported from within other existing NCRI funds and posts.
<b>Core secretariat resources allocated</b>	0.2 FTE Head of Cancer Intelligence (EB) split across activities 10a, 10c and 10d.
<b>Overall aim</b>	To keep pathology on the agenda and ensure agreed actions are taken forward.
<b>Specific objectives</b>	Review actions from the report and publish a report on progress Consider the need for renewed impetus where progress has been lacking and take further action accordingly.
<b>Start date</b>	January 2012.
<b>End date</b>	No end-date has been set.
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b>	Report (with proposal if appropriate) to NCRI Board in October 2013.
<b>Actual outputs April 2013–March 2014</b>	<ul style="list-style-type: none"> <li>Report to Board postponed until October 2014.</li> <li>Dr Bridget Wilkins created a NCRI pathology trainees' forum for discussion and mutually beneficial activities. With support from the RCPATH and the APC, the trainees had an exhibition stand at the 2013 NCRI Conference through which they promoted pathology to the rest of the research community and the public.</li> </ul>
<b>Planned outputs April 2014–March 2015</b>	<ul style="list-style-type: none"> <li>Prepare a paper on the status review of actions from the "Fostering the Role of Pathology in Research" 2009 NCRI report to be presented at the NCRI CTSG meeting in May 2014.</li> <li>In collaboration with Dr Bridget Wilkins, continue to perform a top-level assessment of the progress to date against the actions set out in 2009 with the aim of putting together a report and recommendations for the NCRI Board.</li> </ul>

**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 funds, leadership and coordination if this is to progress.

**External profile**

An [executive summary](#) and the [full report](#) on 'Fostering the role of pathology in research' (2009) are available on the NCRI website.

**Links to other NCRI or related activities**

- Close links to other NCRI biobanking activities.
- Regular liaison with the ECMC Secretariat.

<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 Cancer Outcomes and Services 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 PHE.
<b>Who is in the lead?</b>	NCIN Coordinating 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>	There is joint funding by NCIN and NCRI (Cancer Research UK, Macmillan Cancer Support and onCore UK) for one FTE split over two posts at senior and junior level. These two posts also support the NCRI biobanking activities (10a, 10c and 10d). The rest of the funding for these two posts is provided by NCIN, which is now funded by the Department of Health via PHE with additional resource provided by other Partners including Macmillan Cancer Support and Cancer Research UK.
<b>Core secretariat resources allocated</b>	0.3 FTE Head of Cancer Intelligence (EB) and 0.4 FTE NCIN Research Officer (RB) (the rest of the FTE for these two posts supports the NCRI biobanking-related activities including the 2009 pathology review).
<b>Overall aim</b>	To promote the use of data collected by the PHE for investigator-led cancer research and to promote UK-wide harmonisation and linkage of data, capitalising on new data capabilities as they are introduced.
<b>Specific objectives</b>	<ul style="list-style-type: none"> <li>Supporting research access to PHE 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>Enabling the routine linkage of PHE data to research datasets. This involves work to supplement data collected in clinical trials, cohort studies or biobanks with data held by PHE and the National Cancer Registration Service (NCRS).</li> <li>Supporting strategic national initiatives such as UK Biobank. In particular, ensuring that the required data flows between cancer registries and these initiatives are in place.</li> <li>Working across the UK nations. Joining up data linkage activities across the UK to support research.</li> </ul>
<b>Start date</b>	November 2008 (current funding from Nov 2011).
<b>End date</b>	Current NCRI funding ends in 2016.

**Planned Outputs April 2013–March 2014 – objectives agreed last year**

- Ensuring that research continues to be facilitated in the new environment of PHE, and especially that data governance arrangements for access are as streamlined as possible.
- Supporting research access to data held by PHE as the English cancer registries move to a single national database.
- Better communication of the opportunities for research presented by data held by PHE.
- 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.
- Supporting the work on the linkage of UK Biobank data to cancer registration records and provide an initial analysis of incident and prevalent cases for the England registered cohort.
- Managing the abstract submissions and poster presentations at the 2013 NCIN Cancer Outcomes Conference.
- Leading the organisation of the 2014 NCIN Cancer Outcomes Conference.

**Actual outputs April 2013–March 2014**

- Received 58 of data access queries and processed 47 new research data requests.
- Provided operational support to the PHE Office of Data Release, which was established in January 2014 to process data access requests for researchers and other third parties.
- Facilitated the linkage of UK Biobank to the most up-to-date cancer registration data available (NCDRv2011). Progressed work on the phase 1 pilot project on the adjudication of cancer outcomes amongst the UK Biobank participants and delivered initial report on incident and prevent cases. Helped to initiate a phase 2 pilot project on gaining access to tissue held in NHS diagnostic achieves for participants diagnosed with cancer.
- The 2014 NCIN Cancer Outcomes Conference will take place on 9 and 10 June at Birmingham. A full programme has been developed involving 86 speakers and 132 poster presentations. 485 delegates have registered to date (May 2014).

**Planned outputs April 2014–March 2015**

- Continue to provide operational support to the PHE Office of Data Release for processing data access requests for the cancer research community and advice on the use, linkage and appropriateness of existing routinely collected health services data for investigator-led research projects.
- Better communication of the opportunities for research presented by data held by PHE.
- Provide a report detailing descriptive analyses of cancer cases in UK Biobank after one-year follow-up and an overall proposal for the on-going adjudication and phenotyping of cancer outcomes in this cohort. Also, continue to support a feasibility study between UK Biobank and the Newcastle Hospitals NHS Foundation Trust on gaining access to tissue held in the NHS diagnostic archives for participants' diagnoses with cancer.
- In collaboration with NCRS, support and promote a service to securely link biosamples held in biobanks (or investigator-led research study biosample collections) to national cancer registration records.
- In collaboration with NCRS, explore the possibility of setting-up a flagging service to provide long-term follow-up information for clinical trial patients through cancer registration records.
- Provide the secretariat for the NCIN Scientific Advisory Group.
- Enable better cross-fertilisation of knowledge and ideas between the NCRI Clinical Study Groups (CSGs) and NCIN Site-Specific Reference Groups (SSCRGs).
- Deliver the 2014 NCIN Cancer Outcomes Conference.

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

Routine use of high quality, linked data collected by the NCRS 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 2015.

**Issues and risks**

On April 1 2013, the central NCIN coordinating team was transferred into PHE within the Chief Knowledge Officer's Directorate. At the same time the cancer registration functions of the English cancer registries were transferred to the NCRS and the analytical functions were transferred from the cancer registries to eight new Knowledge and Intelligence teams. All these organisational changes led to delays in access to cancer registration data from researchers and wider third parties for the best part of 2013.

Although, PHE has an interest in supporting research and to this end, it has established the Office for Data Release to service PHE data access requests from researchers (and other third parties), currently, there is a lack of adequate resource for the timely processing of these requests and subsequent release of the data. This would need to be resolved soon and a sustainable service to be put in place.

**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. These receive regular press attention.
- An annual conference is now in its sixth year with a target attendance of over 400 delegates.

**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).
- NIHR CRN: Cancer 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 template category 3:  
partner-led funding initiatives**

<b>Name of activity</b>
Cancer inequalities: identification of research priorities and opportunities
<b>Why are we doing it?</b>
<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>
<b>Who is in the lead?</b>
NCEI with support from NCRI and NCIN.
<b>Type of activity</b>
Watching brief.
<b>Is there dedicated funding?</b>
No.
<b>Core secretariat resources allocated</b>
<0.1 FTE Head of Programmes & Evaluation.
<b>Overall aims</b>
To maintain awareness of research activities relating to cancer inequality and support work, currently led by NCEI, focussed on building a community of researchers focussed on research to identify cancer inequalities and how to overcome them.
<b>Specific objectives</b>
To support NCEI to hold workshops to: <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 addressing cancer inequalities.</li> </ul>
<b>Start date</b>
The NCEI came out of the 2007 Cancer Reform Strategy. Cancer inequality research needs and opportunities were first discussed by the NCRI Partners at their March 2011 meeting.
<b>End date</b>
Ongoing 'watching brief'.
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b>
The NCRI will maintain a 'watching brief' in this area looking out for new opportunities for action through engagement with the NCEI, including its co-Chair Joanne Rule, the Men's Health Forum and Macmillan Cancer Support.
<b>Actual outputs from April 2013–March 2014</b>
<ul style="list-style-type: none"> <li>• Contributions to the newly established NCEI Advisory Group including summary of inequalities research supported, during 2012, by NCRI Partners and other research-related activities.</li> <li>• Discussions with NCEI Secretariat, provided by Macmillan Cancer Support, on next steps to support the development of research in relation to older age, in the first instance.</li> </ul>
<b>Planned outputs April 2014–March 2015</b>
To support the NCEI Secretariat to develop a stream of work to develop research addressing inequalities relating to older age and from there develop research into other equality domains.

<p><b>Looked-for outcomes and success factors by end date or as ultimate legacy</b></p> <p>Through the work of the NCEI the:</p> <ul style="list-style-type: none"> <li>• Development of new links between those with an interest in cancer research, behavioural research, health services research, epidemiology and health inequalities.</li> <li>• Generation of greater awareness of cancer inequalities and the research opportunities in the field.</li> <li>• Funding, through existing research funding streams, of an increased number of high quality research proposals to understand or address cancer inequalities.</li> </ul>
<p><b>Sustainability plan</b></p> <p>Not applicable to watching brief.</p>
<p><b>Issues and risks</b></p> <p>None.</p>
<p><b>External profile</b></p> <p>None.</p>
<p><b>Links to other NCRI or related activities</b></p> <ul style="list-style-type: none"> <li>• NCIN have published a number of reports that are relevant: <a href="http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/equality">www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/equality</a></li> <li>• NPRI and NAEDI initiatives have some relevant projects.</li> <li>• Men's Health Forum: <a href="http://www.menshealthforum.org.uk/">www.menshealthforum.org.uk/</a>.</li> </ul>

<p><b>Name of activity</b> UK end of life care Research Interest Group (UK eolcRIG)</p>
<p><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 (2008). This was carried forward as Action 2.1 of the Rapid Review of Survivorship after Cancer and End of Life Care (2010).</p>
<p><b>Who is in the lead?</b> NCRI Secretariat.</p>
<p><b>Type of activity</b> Partner-led infrastructural activity.</p>
<p><b>Is there dedicated funding?</b> Some of the funds remaining from the Lung SuPaC budget and contributions from the PHE's NEOLCIN and NISCHR provided resource for a Research Officer post up to August 2013.</p>
<p><b>Core secretariat resources allocated</b> 0.2 FTE Head of Programmes &amp; Evaluation.</p>
<p><b>Overall aim</b> To bring end of life care for all diseases and conditions 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.</p>
<p><b>Specific objectives</b></p> <ul style="list-style-type: none"> <li>• To create a forum for research funders with an interest in funding research in end of life care.</li> <li>• To set up one of more working groups 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>
<p><b>Start date</b> First informal meeting held May 2010.</p>
<p><b>End date</b> Ongoing.</p>
<p><b>Planned outputs April 2013–March 2014 – objectives agreed last year</b></p> <ul style="list-style-type: none"> <li>• Hold second formal meeting of the UK eolcRIG to discuss progress since May 2012 and agree the next priorities for action.</li> <li>• Collect information on the palliative and end of life care research spend of eolcRIG full members.</li> <li>• Generate interest and support for an end of life care research prioritisation exercise via the James Lind Alliance.</li> <li>• Subject to eolcRIG member agreement, begin transition of running of the eolcRIG to Marie Curie Cancer Care.</li> </ul>
<p><b>Actual outputs from April 2013–March 2014</b></p> <ul style="list-style-type: none"> <li>• Second UK eolcRIG meeting held and information on the palliative and end of life care research spend of UK eolcRIG full members presented.</li> <li>• Establishment of the Palliative and end of life care Priority Setting Partnership (PeolcPSP) by Marie Curie Cancer Care, supported and guided by the James Lind Alliance and with contributions from a further nine research funders and organisations.</li> <li>• December 2014 transition of running of the UK eolcRIG to Marie Curie Cancer Care.</li> </ul>

**Planned outputs April 2014–March 2015**

- Hold third meeting of the UK eolcRIG to discuss progress since May 2013 and agree the next priorities for action.
- Publication of the research priorities identified through the PeolcPSP in January 2015.
- Publication of summary of analysis of palliative and end of life care funding, based on data from the NCRI Cancer Research Database, jointly by NCRI and 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 generate working groups as required.
- 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.
- More patients, carers and health and social care professionals are given the opportunity to take part in palliative and end of life care research studies / trials.
- Clarification of research governance for research carried out in hospices and increased clinical network support for end of life care studies.

**Sustainability plan**

- Ongoing support for the UK eolcRIG to be provided by Marie Curie Cancer Care.
- UK 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**

<http://www.ncri.org.uk/initiatives/eolc>.

**Links to other NCRI or related activities**

There are some links with the Palliative and Supportive Care CSG and the PeolcPSP ([www.palliativecarepsp.org.uk/](http://www.palliativecarepsp.org.uk/)).

<b>Name of activity</b> 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 funding to work on the Board's request to transition to being financially independent.
<b>Who is in the lead?</b> PET Core Lab team at St Thomas' Hospital.
<b>Type of activity</b> Infrastructural.
<b>Is there dedicated funding?</b> CR-UK, DH, CSO, NISCHR and MRC have committed three years of interim funding (tapered, from £110k in year 1 to £83k in each of years 2 and 3) to allow time for the Core Lab to work out 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 (UK and overseas).
<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 date</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 date</b> The additional funding runs until 31 Jul 2015.
<b>Planned outputs April 2013–March 2014</b> <ul style="list-style-type: none"> <li>• To work up a costing model, with proposed costings to be tested out with funders and researchers for feasibility.</li> <li>• Ongoing delivery of QA for the 10 trials that are open/planned to open.</li> <li>• 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.</li> </ul>

**Actual outputs from April 2013–March 2014**

- Four studies being coordinated prior to the start of the current grant (RAPID; R-CHOP; RATHL; PET-Panc) have completed recruitment and are in follow up. Three trials have closed early due to poor recruitment (ReACH; TITAN; POETIC); one study is ongoing (PAIReD); and a further twelve have opened (MAPPING; CHEMO-T; FGFR; SPuTNIK; BACCHUS; IELSG37; STO-3; ABLE; BREVITY; LEGEND; REASURE; BIOPROP).
- Developing the necessary procedures for studies using non-FDG 18F-labelled radiopharmaceuticals (18F-FEC for the MAPPING study and 18F-FLT for the POETIC PET sub-study).
- Development of new accreditation/QC procedures for handling complex dynamic studies (POETIC being the first study requiring dynamic imaging).
- The resources and funds required to run the service have been looked at in detail, and a mechanism has been developed whereby costs are now being recouped from trials. However, the total is still far short of that needed to run the service, and the small and unpredictable inflow of funds means the 1.5FTE posts central to the Core Lab cannot be retained on contracts in the absence of some core funding. Remaining costs would then be built in to grants by the mechanism that the team is using at present. This was put forward to the CTSG in Feb 2014 (paper CTSG 14/02).

**Planned outputs April 2014–March 2015**

- Additional accreditation/QC procedures are being developed for radiotherapy studies (BIOPROP; FIGARO) in collaboration with the RTTQA group.
- Delivery of QC on the 13 open trials, and others that come through.
- Continued work against other objectives including harmonisation.

**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 Board's vision that the Core Lab was working towards was for full financial independence by 31 July 2015. This does not appear feasible as outlined above, and the Core Lab team is now working towards a mixed model with minimal underpinning staff funding and the remainder of costs built into individual grants.

**Issues and risks**

Underpinning funding from the ECMCs is agreed in principle but remains to be confirmed.

**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, the CSG Imaging subgroup and CTRad workstream 2.

<b>Name of activity</b> National Prevention Research Initiative (NPRI)	
<b>Why are we doing it?</b> 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).	
<b>Who is in the lead?</b> Medical Research Council (MRC).	
<b>Type of activity</b> Research projects funded through calls for proposals.	
<b>Is there dedicated funding?</b> Funding was pledged by NCRI Partners and other research funding organisations for each of the 4 phases of the initiative. Phases 1 & 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:	
Alzheimer's Research Trust	ESRC
Alzheimer's Society	EPSRC
BBSRC	Health and Social Care Research Division, Public Health Agency, Northern Ireland
British Heart Foundation	Medical Research Council
Cancer Research UK	Stroke Association
Chief Scientist Office, Scottish Government Health Directorate	Wellcome Trust
Department of Health	Welsh Government
Diabetes UK	World Cancer Research Fund
<b>Core secretariat resources allocated</b> <0.1 FTE Head of Programmes & Evaluation.	
<b>Overall aim</b> <ul style="list-style-type: none"> <li>To develop 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; and identify the health-related behaviours that predispose to public health that might inform future interventions.</li> <li>NPRI aims to provide evidence from research that might inform the evidence base for public health practice and policy.</li> </ul>	
<b>Specific objectives</b> To support multidisciplinary and innovative research aimed at improving health and preventing diseases or conditions such as cancer, heart and circulatory diseases, diabetes, obesity, stroke and dementia.	
<b>Start date</b> 2004.	
<b>End date</b> Existing grants will run until at least 2018. With 65% of all awards now finished MRC are undertaking a review of the NPRI that will generate recommendations for next steps in prevention research.	
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b> To commence the NPRI review in February 2014.	



**Actual outputs from April 2013–March 2014**

- The scope of the review agreed amongst funders. Review will assess;
  - impact of individual grants both scientifically and on policy and practice
  - impact of the initiative overall and its legacy
  - future opportunities
- Scientific Review Group established. Chair: Prof. Phil Hannaford. First meeting July 2015.
- 10 qualitative interviews undertaken, successfully piloted questionnaire and now in pilot analysis phase
- Data on outcomes and outputs of NPRI grants drawn from Researchfish.

**Planned outputs April 2014–March 2015**

- Qualitative analysis of outputs focussing on enablement and strengths and weaknesses of funding model and quantitative analysis of outputs focussing on publications, policy impacts and capacity building.
- Scoping of themes for further support of the area with stakeholder consultation on these themes.
- Publish report of outputs and recommendations for future support of the area.

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

By end date:

- Increased funding for prevention research, increased capacity for research in this area and multi-disciplinarily working.
- Increased number of high quality interventional and observational studies funded that have the potential to have a major impact on population health.
- Development of innovative and translatable methodology.

Ultimate legacy:

- To have built a strong research workforce able to compete with other research disciplines for funds from the existing funding streams and who are in a position to contribute to and influence policy and practice and thereby improve public health in key areas.

**Sustainability plan**

To be considered in 2014/15 following the MRC review.

**Issues and risks**

If NPRI is discontinued there is a risk that there is a failure to capitalise on the momentum for high quality and influential public health research generated through the initiative.

**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 UKCRC Centres for Public Health Research Excellence which were awarded a further 5 years of funding in January 2013.

<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 whole: CR-UK and DH England. Research workstream: CR-UK
<b>Type of activity</b>	Research projects funded through calls for proposals.
<b>Is there dedicated funding?</b>	CRUK, all four health departments and the ESRC together pledged £7.5m over five years to support research. The majority of the funds have been used in NAEDI Research Calls 1-3.
<b>Core secretariat resources allocated</b>	<0.1 FTE Head of Programmes & Evaluation.
<b>Overall aim</b>	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. The NAEDI calls have sought to support research that leads to better understanding of diagnostic delays or behavioural interventions which may lead to less delay and to develop a strong and multi-disciplinary research community focussed on cancer awareness and early diagnosis.
<b>Specific objectives</b>	The first two calls focussed on higher risk populations, public awareness of cancer symptoms and reasons for late presentation, health services and methodology for, and evaluation of, early detection and awareness research. The 3rd call strongly encouraged applications: <ul style="list-style-type: none"> <li>• Investigating reasons for late presentation and low uptake of screening.</li> <li>• Developing effective interventions to prompt change to reduce late presentation and low uptake of screening.</li> <li>• Investigating reasons for delays occurring within primary care and onward referral.</li> <li>• It also encouraged research to understand the significance of symptoms across different cancer types and research making use of available data.</li> </ul>
<b>Start date</b>	NAEDI as a whole 2007 with the 1st NAEDI call released in 2009.
<b>End date</b>	To be determined. Projects from the 3rd call will continue through to 2017
<b>Planned outputs April 2013–March 2014 – objectives agreed last year</b>	NAEDI-CaPRI and NAEDI conference to be held April 2013 and 3rd NAEDI call released. CRUK to run workshop for potential applicants in association with the scientific review committee and the NCRI SPED group. Development of a Project Officer (PO) 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.
<b>Actual outputs from April 2013–March 2014</b>	NAEDI-CaPRI and NAEDI meetings held April 2013. PO role created and workshop for potential NAEDI applicants held. NAEDI Research Call 3 released with 11 projects approved for funding in February 2014.

<p><b>Planned outputs April 2014–March 2015</b></p> <p>Activities to continue to support and highlight NAEDI research including NAEDI conference (March 2015), research methodology workshop (July 2014) and publication of NAEDI newsletters.</p> <p>Current contributors to NAEDI to consider options for the continuation of the research funding component of NAEDI and to explore potential of bringing in new funding partners. If future funding is confirmed, the scientific community will be involved (e.g. via workshops) in helping shape future remits of the calls.</p>
<p><b>Looked-for outcomes and success factors by end date or as ultimate legacy</b></p> <p>In the longer term to have developed interventions promote earlier diagnosis of cancer and to have strengthened the research community in this area such that it becomes self-sufficient.</p>
<p><b>Sustainability plan</b></p> <p>Through the PO, SPED and potentially further calls to strengthen research skills, increase collaboration and build research capacity in this area.</p>
<p><b>Issues and risks</b></p> <p>There may be limited capacity to develop research in this area if applications for funding from junior researchers remain methodologically weak. The methodology workshop and the work of the PO role will mitigate against this.</p> <p>If research funding component of NAEDI is not refunded there is a risk that the momentum which has been building within the community is lost.</p> <p>The length of research projects means that there may be significant delay in generating results which are implementable.</p>
<p><b>External profile</b></p> <p>NAEDI (<a href="http://info.cancerresearchuk.org/spotcancerearly/naedi/">http://info.cancerresearchuk.org/spotcancerearly/naedi/</a>) and NAEDI calls (<a href="http://www.cancerresearchuk.org/funding-for-researchers/our-funding-schemes/national-awareness-and-early-diagnosis-initiative-naedi-research-call">http://www.cancerresearchuk.org/funding-for-researchers/our-funding-schemes/national-awareness-and-early-diagnosis-initiative-naedi-research-call</a>).</p>
<p><b>Links to other NCRI or related activities</b></p> <ul style="list-style-type: none"> <li>• The ICBP which aims to identify the root causes of survival differences between countries/jurisdictions to generate actionable insights which will help all partners improve cancer survival outcomes.</li> <li>• The CRUK Early Diagnosis Advisory Group (EDAG) which acts as a small grants funding, advisory and policy setting committee.</li> </ul>

## Glossary of acronyms

While most acronyms are explained at first usage, the following glossary may be useful. The most familiar names, e.g. those of most Partners, NCRl and NHS are excluded.

AMRC	Association of Medical Research Charities
ASGBI	Association of Surgeons of Great Britain and Ireland
BASO	British Association of Surgical Oncology
CaPRI	Cancer and Primary Care Research International Network
CaRD	NCRl Cancer Research Database
CCB	Confederation of Cancer Biobanks
CLRNs	Comprehensive Local Research Networks (in the NHS in England)
CPRD	Clinical Practice Research Datalink
CSG(s)	Clinical Studies Group(s)
CSO	Chief Scientist Office (Scotland)
CTAAC	Cancer Research UK Clinical Trials Advisory and Awards Committee
CTRad	Clinical and Translational Radiotherapy Research Working Group
ECMCs	Experimental Cancer Medicine Centres
EMFG	Experimental Medicine Funders' Group
FTE	Full-time equivalent
GRIST	Working Group on Growing Recruitment to Interventional Surgical Trials
ICBP	International Cancer Benchmarking Partnership
ICRP	International Cancer Research Partnership
MHRA	Medicines and Healthcare products Regulatory Agency
NAEDI	National Awareness and Early Diagnosis Initiative
NCEI	National Cancer Equality Initiative
NCIN	National Cancer Intelligence Network
NCSI	National Cancer Survivorship Initiative
NEOLCP	National End of Life Care Programme (in England)
NIHR	National Institute for Health Research (in England)
NIHR CRN: Cancer	National Institute for Health Research Clinical Research Network: Cancer
NISCHR	National Institute for Social Care & Health Research (Wales)
NPRI	National Prevention Research Initiative
PET	Positron Emission Tomography
PET-CT	Positron Emission Tomography-Computed Tomography
QA	Quality Assurance
RCR	Royal College of Radiologists
RCS Eng	Royal College of Surgeons of England
SPED	Screening, Prevention and Early Diagnosis
RTTQA	Radiotherapy trials quality assurance
STRATUM	Strategic Tissue Repository Alliance Through Unified Methods
SuPaC	Supportive and Palliative Care
UKAS	UK Accreditation Service
UKCRC	UK Clinical Research Collaboration
WS	Workstream







**National Cancer Research Institute**  
**Angel Building**  
**407 St John Street**  
**London EC1V 4AD**  
**UK**

T: +44 (0)20 3469 8460

F: +44 (0)20 3014 7658

[info@ncri.org.uk](mailto:info@ncri.org.uk)

[www.ncri.org.uk](http://www.ncri.org.uk)