The Translational Cancer Research Network (TCRN) recently celebrated four years of activities and achievements. This report has been published to highlight those achievements and to share the success of the TCRN and its members with the broader community.

As the Director of the TCRN, my vision has been to create a partnership of hospitals and universities committed to translational cancer care; a partnership that empowers staff to formulate and implement research-led improvements in patient care. To realise this vision, the TCRN has developed a unique model of translational research that draws on the strong clinical, educational and research enterprises of our partners.

After four years, the TCRN has become a highly active translational cancer research centre and continues to successfully engage with our health care and academic partners. The TCRN continues to create new initiatives and build on current ones that support the ongoing expansion of translational cancer research in NSW.

The TCRN operates on the agreed model of translational research for Cancer Institute of NSW-funded Translational Cancer Research Centres and Units. This model focuses on the translation of basic research into clinical research, but is equally applicable to the translation of population health and health services research informing programs and service delivery.

The diagram below outlines/classifies the stages of translational research as:

- **T1** - developing treatments and interventions.
- **T2** - testing the efficacy and effectiveness of these treatments and interventions.
- **T3** - dissemination and implementation research for system-wide change.

The TCRN has a particular focus on T3 research because it directly improves the efficiency of services and the way programs are provided.

The diagram below outlines the stages of translational research:

**TRANSLATION TO PATIENTS, POLICY & PRACTICE**

**TRANSLATION TO HUMANS**

**BASIC RESEARCH**

Practical studies, Clinical research, Basic health services research, Systematic reviews

**BEDSIDE**

Human Clinical Research, Controlled observational studies, Phase 3 clinical trials, & health services studies

**POLICY & PRACTICE**

Clinical Practice Across the System, Delivery of high-quality care to the right patient at the right time, Identification of new clinical questions and gaps in care

**TRANSITION TO RESEARCHERS, POLICY & PRACTICE**

Phase 3 & 4 trials, Observational studies, Survey research

With 12 months left on this current grant there is still much work to be done, but I am immensely proud of the achievements to date. I thank all who have contributed to the successes of the TCRN, and in particular the TCRN staff, past and present, who have shown great commitment to the realisation of our shared goals.

Warm regards,

**Professor Robyn Ward**

Director, Translational Cancer Research Network
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TCRN at a glance

« 2011-2015 »

344 unique members
29 research, project, operations and support staff employed or supported

Cancer Challenge of the Year
5 projects supported
$441,101 of funding awarded

HSA Biobank
1,765 biobank consent forms collected
5,819 bio-specimens available from 10 tumour streams

Translational bioinformatics
6 projects delivered

PhD Top-Up Scholarships
31 PhD students supported
$411,000 of funding awarded
20 first author publications

Conference & Professional Development Grants
92 grants awarded
$155,229 of funding awarded
20 nurses or allied health professionals supported

TCRN Projects and Operations Team
(Left to Right) Niloofar Memari, Jitendra Jonnagaddala, Toni Jue, Stella Jun, Dr Carmel Quinn, Manish Kumar, Dr Mahnaz Fanaian, Deirdre Hopkins, Dr Betty Kan, Lena Caruso

TCRN: Four Years in Review
Overview and governance

TCRN Mission Statement

To develop a sustainable translational cancer research engine and to apply it to identified areas of need, in a stepwise and focussed manner.

Launch in 2011, the Translational Cancer Research Network (TCRN) is a collaborative, interactive cancer research network that is funded by the Cancer Institute of NSW (CINSW). Based at the Lowy Cancer Research Centre at UNSW Australia, the TCRN funds research and fosters links between cancer researchers, clinicians and services in South Eastern Sydney and the Albury-Wodonga region.

The TCRN comprises the founding institutions of UNSW, Prince of Wales Hospital, the comprehensive cancer centres of St George and Sutherland hospitals, cancer services at the Royal Hospital for Women, Border Medical Oncology Research Unit (Albury-Wodonga) and the University of Technology Sydney (UTS), and operates in collaboration with the South Eastern Sydney Local Health District (SESLHD). Our network is built on a membership base of leading researchers and clinicians who share the common goal of translating cutting-edge cancer research into enhanced patient outcomes.

Objectives

The TCRN’s research agenda is guided by the objectives and themes set out by CINSW:

- Facilitate the generation of practice improving research and its more rapid adoption for improved patient outcomes.
- Facilitate evidence-into-practice research.
- Facilitate the more efficient and effective incorporation of research, clinical training, education and service delivery within a formal governance structure that supports networks and enhanced collaboration between centres of research excellence and centres of clinical excellence, which may include regional settings.
- Build capacity in research and improve the competitive advantage in securing other funds.

Leadership

The TCRN is guided by a leadership council that provides coordination and strategic direction for the network. Our council members represent the founding institutions of the TCRN and bring a diversity of disciplinary skills representing five principle domains: basic research, health systems, clinical practice, primary health care and pathology.

TCRN governance structure

Randwick Health and Medical Research Institute (Ltd)

Director and leadership council

Representing founding institutions

TCRN operations and projects team

TCRN Leadership Council

<table>
<thead>
<tr>
<th>Member</th>
<th>Domain</th>
<th>Founding institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prof Robyn Ward</td>
<td>Director &amp; Clinical Practice</td>
<td>Prince of Wales Hospital (POWH)</td>
</tr>
<tr>
<td>Prof Neville Hacker</td>
<td>Clinical Practice (Surgeon)</td>
<td>Royal Hospital for Women</td>
</tr>
<tr>
<td>Prof Mark Harris</td>
<td>Primary Health Care</td>
<td>UNSW</td>
</tr>
<tr>
<td>Prof Jeffrey Brathwaite</td>
<td>Health Systems</td>
<td>UNSW</td>
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<tr>
<td>Prof Phil Hogg</td>
<td>Basic Science</td>
<td>UNSW</td>
</tr>
<tr>
<td>Associate Prof Rob Lindeman</td>
<td>Pathology/Administration</td>
<td>South Eastern Area Laboratory Services (SEALS Pathology)</td>
</tr>
<tr>
<td>Prof Marion Haas</td>
<td>Health Economics</td>
<td>UNSW</td>
</tr>
<tr>
<td>Prof Nick Hawkins</td>
<td>Pathology/Education</td>
<td>UNSW</td>
</tr>
<tr>
<td>Dr Craig Underhill</td>
<td>Clinical Practice (Clinical Trials)</td>
<td>Border Medical Oncology Research Unit (Regional)</td>
</tr>
<tr>
<td>Prof David Goldstein</td>
<td>Clinical Practice (Medical Oncology)</td>
<td>POWH</td>
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<tr>
<td>Ms Elizabeth Browne</td>
<td>Clinical Practice (Nursing)</td>
<td>UNWS</td>
</tr>
<tr>
<td>Associate Prof Winston Liew</td>
<td>Clinical Practice (DCIS)</td>
<td>St George Hospital/SESLHD</td>
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</tbody>
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The HSA Biobank

The first T3 flagship initiative of the TCRN, the Health Science Alliance (HSA) Biobank is a collaborative, multi-use resource established by the TCRN and supported by numerous academic (UNSW) and health care (SEALS Pathology, Prince of Wales Hospital, St George Hospital, Royal Hospital for Women and Border Medical Oncology) partners.

Housed in the Lowy Biorepository at UNSW, the biobank is built on a unique model in which processes for patient consent and tumour collection are embedded within patient care workflows, leading to significant changes in practice for hospital-based research in NSW.

The HSA Biobank is built on a novel approach to biobanking processes into routine hospital workflows. Clinicians at participating hospitals seek informed patient consent for biobanking during routine pre-operative consultations, while SEALS Pathology staff allocate appropriate tissue blocks to the biobank as part of their standard diagnostic work-ups. This integrated tissue collection process has been key to the success of the HSA Biobank thus far. Once a patient has given informed consent during their pre-operative consultation, their tissue is collected during their scheduled surgery. Tissue samples are sent to the hospital’s anatomical pathology team, as per standard hospital processes, where routine diagnostic procedures are completed. Additional tissue blocks are then allocated for storage in the Lowy Biorepository where suitable.

The Lowy Biorepository is a purpose-built, state-of-the-art biorepository facility for the reception and processing of human biospecimens. The HSA Biobank is one of a number of biobanks housed there. The biorepository team provides expertise in the management and secure storage of biospecimens and patient health data and the processing of derivatives (such as RNA and DNA) and manages researcher requests for access to the biospecimens and data in the HSA Biobank.

Since 2012, the TCRN, SEALS Pathology and UNSW’s Lowy Biorepository have worked together to develop an integrated tissue collection model as part of standard diagnostic work-ups.

This integrated tissue collection process has been extremely successful in developing the HSA Biobank as a multi-use resource that supports a wide variety of translational research projects into the diagnosis and treatment of multiple cancers. As at July 2015, there were 5189 biospecimens from 10 tumour types stored in the biobank.

Consent project: key outcomes

- Development of a single A4 biobanking information pamphlet to replace the existing 16-page document.
- Development of a single 16-page consent form to replace the existing eight-page document.
- Approval from the Human Research Ethics Committee, the SESLHD Forms Committee and the Commonwealth Department of Human Services for the consent form to become a formal hospital document that is stored within a patient’s file.

The results of this project have been extremely positive, with over 1700 patients (94 per cent) consenting to their tissue and linked health data being stored in the biobank and associated databases.

Tissue collection and storage

Hospital diagnostic services are central to tissue and data collection processes, and forging strong relationships with participating pathology and haematology teams, who identify suitable tissue blocks for biobanking, has been key to the success of the HSA Biobank thus far. Once a patient has given informed consent during their pre-operative consultation, their tissue is collected during their scheduled surgery. Tissue samples are sent to the hospital’s anatomical pathology team, as per standard hospital processes, where routine diagnostic procedures are completed. Additional tissue blocks are then allocated for storage in the Lowy Biorepository where suitable.

Patients who contribute to the HSA biobank give informed consent to providing a sample of resected tissue/bone marrow sample and a blood/buccal swab, clinical information and Medicare Australia data for storage in the biobank and associated biobank systems. All patient data is anonymised in order to protect patient privacy. Patients are provided with information about biobanking during a pre-operative appointment with their surgeon, which takes place up to two weeks before surgery. Surgical staff explain the purpose of the biobank, the process involved in the acquisition of tissue samples and patient health data, and the benefits and implications of consenting to participate. Patients are also advised that they can withdraw their consent at any time.

Developing this patient consent process was the first step in establishing the HSA Biobank. With funding from the CINSW Biobank Stakeholders Network, the TCRN launched a universal consent project at Prince of Wales Hospital and the Royal Hospital for Women in 2012, and at St George Hospital the following year. This project sought to establish and test the biobank’s processes in a hospital setting. As a hospital-based research initiative, the biobank and its associated processes needed to be acceptable to both patients and staff and deliver useful outcomes for researchers; from the outset, the aim of the consent project was to achieve high rates of clinical staff engagement, as well as high numbers of patients giving consent to the use of their tissue and health data, thereby resulting in significant quantities of tumour samples being collected for storage.

One of the major achievements of this project was the development of a customised SESLHD patient research consent form that became part of the patient’s permanent record. An existing eight-page consent form was revised into a single page accompanied by a patient information brochure, with input from the TCRN’s Consumer Advisory Committee, and was approved by the Human Research Ethics and SESLHD Forms Committees and Commonwealth Department of Human Services (DHS) as a formal hospital document to be stored with each patient’s permanent hospital file. The new form simplified the patient consent process while simultaneously upholding research ethics and governance requirements.

Finally, the TCRN has a patient consent project that began in 2011, which aimed to replace the existing 16-page consent document with a single-page SESLHD-approved consent form. The project has also resulted in a single A4 biobanking information pamphlet to replace the existing 16-page document.

Consent

The purpose of the HSA Biobank is to:

- give every patient admitted to a NSW hospital the opportunity to consent to their tissue and data being made available for research.
- make the biobank’s tissue and data collection available for research anywhere, provided that researchers have appropriate ethics clearance.

The results of this project have been extremely positive, with over 1700 patients (94 per cent) consenting to their tissue and linked health data being stored in the biobank and associated databases.
Traditional biobanks focus on the collection of bio-specimens and associated pathology data. However, the consent process developed for the HSA Biobank also captures patients’ clinical data from a variety of hospital-based databases.

In a NSW first, the Department of Human Services approved the TCRN to access the de-identified Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) records of patients who have consented to having their tissue and clinical health data stored in the biobank. This access has been granted for future unspecified research over a period of 30 years, giving the TCRN a unique opportunity to do cancer research that is both broad and deep, using tissue and health data resources that will continue to grow in richness over time.

The TCRN has commenced four research projects to determine the utility of this unique opportunity, the first, is a collaboration with Prof Anna deFazio and the Sydney West TCRC: “Essential clinical annotation for NSW Biobanks through data integration using State and Commonwealth datasets.”

The TCRN also secured additional funding from CINSW to undertake three American Society of Clinical Oncology (ASCO) Audit Grants to assess Clinical Practice Guidelines:
- Utilising the HSA Biobank resource: an audit of inappropriate use of imaging in early breast cancer
- Utilising the HSA Biobank resource: an audit of inappropriate use of anti-emetic drugs
- Utilising the HSA Biobank resource: an audit use of PET-CT as routine surveillance after cancer treatment with curative intent.

The results of all four projects will be available in December 2015.

HSA Biobank publications


Ovarian cancer project seeks answer to metastasis riddle

A UNSW research team with an interest in ovarian cancer is using tissue samples from the HSA Biobank to investigate the mechanisms of cancer metastasis.

Led by TCRN member Dr Caroline Ford of the Lowy Cancer Research Centre, this project is focused on what’s known as epithelial to mesenchymal transition (EMT), or the ability of a cancer cell to change shape in order to move through the body; and the Wnt pathway, a network of genes responsible for controlling specific aspects of cell behaviour.

“The big picture question we’re trying to understand is around cancer metastasis, or cancer spread. We’re really trying to figure out why, if you have two patients with cancer, one of the cancers will progress very rapidly and the other one won’t,” Ford says.

“We’re looking at two levels – at the very early changes that transform a cell into a cancer cell, and then at the late changes that allow a cancer cell to change its expressions of genes, its shape and its ability to move to other parts of the body.”

The research team received 33 tumour samples from the HSA Biobank at the beginning of this year. These samples are representative of five different sub-types of ovarian cancer; Ford and her team will use the samples to test a series of hypotheses about a receptor named ROR2 and its role in how these cancers spread.

“We suspect that ROR2 will be over-expressed and up-regulated in ovarian cancer tissue, and we think that’s exciting because this particular gene is not expressed in normal adult tissue – it’s completely absent in healthy adults,” Ford says.

The researchers are also interested in ROR2’s location on the surface of the cancer cells, which has the potential to make it an easily accessible target for therapeutic treatments.

In order to complete their work, the research team is hoping to acquire another 200 ovarian tumour samples, which they are currently sourcing from the HSA Biobank and a number of other biobanks in Australia and overseas.

Ford herself is a champion of biobanking, which she describes as a ‘crucial’ component of effective translational research, and says that as the HSA Biobank matures, its value to researchers will only continue to increase.

“I really think that with medical research, it’s absolutely essential to have clinical patient samples to complement the molecular biology that’s done in wet labs. If you want to be looking at eventual translation of your research, then you absolutely need to explore and validate laboratory findings in patient material.”
Translational bioinformatics

What is translational bioinformatics?

Translational bioinformatics refers to multidisciplinary research that brings biomedical research, informatics and clinical research fields together. It is the development of storage, analytic, and interpretive methods used to optimise the transformation of increasingly large biomedical and genomic data. Its focus is on applying informatics methodology to this data to formulate knowledge and medical tools, which can be utilised by scientists, clinicians, and patients.

Program highlights

- Over 7000 electronic pathology reports processed using the automated pipeline developed by the TCRN Bioinformatics team (Phase I)
- Hosted Biobanking Informatics in NSW, a 1-day workshop with 3 international speakers (2013)

Funding leveraged
- $70,000 from UNSW Australia Major Research Equipment and Infrastructure Grant for OpenClinica (Phase II)
- $85,000 under the Major Open Data Collections Project, by the Australian National Data Service (ANDS) for Phase III (tranSMART)

- Phase I – Development

The result was a secure data transmission pathway that enabled the safe transfer of information between:

1) the SEALS Pathology database, which holds pathology information on the patients whose tissue is stored in the HSA Biobank
2) the Lowy Biorepository OpenSpecimen database, which contains patient health data about the banked biospecimens
3) the UNSW Aperio database, which contains whole slide images of the tissue specimens themselves.

- Phase II – Increasing capacity

The second phase of the translational bioinformatics work was to continue increasing the TCRN’s translational bioinformatics capacity by adding new data sources to the data linkage platform. OpenClinica, an open source software program used for managing clinical data, was successfully integrated in 2013. OpenClinica currently houses research information from six different research projects. This work was funded by a UNSW Major Research Equipment & Infrastructure Grant, and was completed in 2014.

- Phase III – Integration

The final phase of the project was the implementation of a web-based query tool called tranSMART, which brings together all the datasets collected and linked by the TCRN, many of which are based on data collated from HSA Biobank consented patients.

A pilot project was commenced in July 2014 to test the utility of tranSMART by giving researchers access to the Molecular and Cellular Oncology (MCO) database, a colorectal cancer collection and one of UNSW’s most valuable datasets. The MCO database holds a wealth of whole slide images, tissue samples and patient health data, including clinical follow-up data, for over 1500 patients with colorectal cancer. The data was collected between 1993 and 2010, and its depth and richness makes it an exciting resource that can potentially support a range of translational cancer research projects looking at colorectal and other cancers.

Prior to the implementation of tranSMART, access to the MCO collection was extremely limited, with no simple way to search and organise the content. A funding arrangement between the TCRN and the Australian National Data Service (ANDS) enabled the TCRN to bring biocuration expertise in house with the secondment of a UNSW data librarian who took a lead role in making the information in the MCO datasets more easily searchable. The project was completed in 2015, and the MCO database is now accessible to the broader international translational research community.

tcrn.edu.au/tranSMART

“One of our major aims is to support current and future research, and that can be achieved with stronger data management practices and stronger discovery capacity. [The UNSW tranSMART project] is a good example of that.”

– Ingrid Mason, ANDS

TCRN translational bioinformatics platform

UNSW health grade secure infrastructure

Key

Phase I

Phase II

Phase III

Future

Query and analysis tools

Research systems

Clinical systems

OpenSpecimen

OpenClinica

Bioimaging

Experimental results data

Omics data

MCO Access Database

Omnilab

Mosaix

Other data sources

Phase III – Integration

UNSW Aperio database, which contains whole slide images of the tissue specimens themselves.

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TCRN translational bioinformatics platform

UNSW health grade secure infrastructure

Key

Phase I

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Future

Query and analysis tools

Research systems

Clinical systems

OpenSpecimen

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Bioimaging

Experimental results data

Omics data

MCO Access Database

Omnilab

Mosaix

Other data sources
Social network theory

Social network theory underpins a body of research conducted by PhD student Janet Long between 2012-2013, and a third study commissioned by the TCRN in 2015. These studies sought to understand the TCRN’s extensive network of professional relationships, with the research team asked to determine how those relationships were formed, where relationship gaps existed, and how connectivity between partner institutions could be influenced to drive further positive outcomes.

A rigorous analysis of the TCRN’s social networks in 2012 demonstrated that the TCRN is the hub of an extensive and complex web of professional relationships. It closes gaps between professional groups and increases connectivity between partner institutions, with key players within the TCRN, such as the program manager, forging key linkages between people and resources. Geographic location was also found to influence strategic partnerships, with members demonstrating a strong preference for working with other local network participants.

In 2013, a second round of research showed that many members had experienced significant and positive outcomes as a result of their membership with the TCRN, with some making changes to their professional practice and others claiming to have benefitted personally from their participation.

The third study, completed in June 2015, found that while membership numbers have grown, the TCRN’s core membership has remained largely constant, resulting in a strong foundation on which the network can continue to build.

The current study points to a well-functioning network which has retained its focus on the original goals of the TCRN and has created greater levels of collaboration between researchers, clinicians, managers and TCRN operational staff than previously shown... the TCRN’s impact goes well beyond outcomes from formal TCRN-funded projects."

– Excerpt from Social Network Survey #3

The TCRN has facilitated 1658 collaborative ties between members, and over 40 per cent of those ties have been forged with people who were otherwise unknown to TCRN participants before they joined the network. Awareness of the TCRN’s activities remained high among members, with one-third able to list projects and research initiatives that were linked to TCRN activities.

These studies demonstrate the ‘network’ component of the Translational Cancer Research Network. Importantly, this extensive investigation into social network theory is unique to the TCRN and will be useful to evaluate the growth and effectiveness of the TCRN over the long term.

Primary health care project

The TCRN is currently conducting a research project titled Attitudes to cancer follow up care in general practice: a qualitative study. Led by Professor Mark Harris, the study explores the feasibility and acceptability of transferring cancer patients with no current evidence of cancer recurrence into the care of general practitioners (GPs) once their hospital-based treatment is complete.

The study responds to the growing concept of survivorship, in many cases seeing cancer as a chronic illness rather than a terminal disease. Advances in medical treatment coupled with longer life expectancy mean that many cancer patients live for many years after their initial diagnosis, leading to a need for change in the way that the health system addresses post-treatment cancer care.

This research is focused on understanding the views of specialists, GPs and patients when it comes to transferring aspects of the management of breast and colorectal cancer survivors to a primary care setting. Existing models of care can see cancer survivors continuing to attend hospital-based follow-up appointments for many years, despite not necessarily requiring the expertise of a specialist oncology team. This approach is challenging an already stretched health care system and increasing costs.

The TCRN Social Network in 2012

Primary health care project

Oncology specialists from a major teaching hospital in Sydney nominate patients who in turn nominate their GPs, with all three parties providing linked feedback on what they perceive to be the benefits and risks, facilitators and barriers to follow-up cancer care occurring in the general practice setting.

Initial findings suggest that patients and GPs welcome the prospect of GPs becoming more involved in their cancer follow-up care if adequate training, support and protocols are in place.

It appears that a staged, shared care team arrangement with both GPs and specialists flexibly providing continuing care would be acceptable for most.

This is the first step in a proposed series of research projects that investigate primary care’s role in the ongoing care of cancer survivors. The qualitative study is due to be completed at the end of 2015.
Cancer Challenge of the Year

The Cancer Challenge of the Year is a flagship TCRN funding scheme that provides up to $100,000 per year to support research that responds to cancer’s most pressing challenges. The focus of this initiative is to support research led by TCRN members that results in improvements in cancer diagnosis, treatment and prognosis, and that delivers positive outcomes in cancer patient care.

Since its launch in 2012, the Cancer Challenge of the Year scheme has been delivering significant impact in the field of translational cancer research. Projects have resulted in substantial gains along the length of the translational pipeline, with a focus on evidence into practice that informs the way that researchers and clinicians interact with common cancer scenarios.

Achieving behaviour change for detection and management of Lynch syndrome (2015)

Lynch syndrome is a hereditary condition caused by a gene mutation that vastly increases a carrier’s chances of being diagnosed with bowel and other cancers. Like other hereditary cancers, Lynch syndrome typically diagnosed via referral to a genetic counsellor. In partnership with a genetic counselling team, patients who test positive to Lynch syndrome can reduce their cancer risk by monitoring their health on a regular basis. However, various barriers to referral mean that a large number of suspected Lynch syndrome cases are not being passed on to appropriate genetic counselling services, resulting in missed diagnosis opportunities and increased potential for negative health outcomes for patients and their relatives.

Led by Dr Natalie Taylor of the Institute of Health Innovation at Macquarie University, the Achieving behaviour change for detection and management of Lynch syndrome project seeks to improve referral pathways by identifying existing psycho-social and environmental barriers to referral; developing a strategy to assist clinicians to overcome them and implementing co-designed interventions using evidence-based behaviour change techniques. Dr Taylor is an international expert in the field of health-care-specific behavioural change research. Prior to her arrival in Australia, she implemented similar projects in hospitals across the UK.

This project was launched in 2015. Dr Taylor and her team are about to commence recruitment of clinical stakeholders prior to commencing the first stage of the project.

“If we can identify the Lynch syndrome mutation in high-risk individuals, they can be closely monitored for the development of subsequent cancers. Importantly, this information can be shared with family members who may also choose to be screened,” says Dr Taylor.

“We want to develop and implement ways of breaching the barriers that prevent health care professionals from referring patients for genetic testing. We have successfully used an approach using behaviour change theory and implementation science in UK hospitals, and we will use this same approach in this project with the aim of promoting changes in referral behavior.”

What we’d be hoping to see as a result of the project is improvement in patient outcomes— to increase patient knowledge about radiotherapy, particularly around the management of side effects, and help patients to feel more prepared for treatment. We’re also hoping to reduce patient anxiety before treatment by giving them this information.”

Dr Sian Smith

Development and pilot-testing of a talking book to facilitate communication between radiation therapists & cancer patients with low health literacy (2014)

Health literacy levels play an important role in how well patients understand their medical condition and treatment, and impact the likelihood that patients will adhere to treatment and medication regimens and achieve positive health outcomes as a result. In a cancer context, increasing patient understanding of their cancer treatment and side effects is an important component of guiding patients through their illness. Up to 60 per cent of cancer patients receive radiation therapy as part of their treatment, but limited patient knowledge of the treatment process and its potential side effects means that many patients undergo radiation therapy with limited knowledge of how it works.

The Development and pilot testing of a talking book to facilitate communication between radiation therapists & cancer patients with low health literacy project aims to help patients improve their understanding of radiation therapy and reduce their concerns before treatment. Led by Dr Sian Smith from the Psychosocial Research Group at Prince of Wales Clinical School, the project team has created a ‘talking book’ to help cancer patients increase their understanding of the radiotherapy process. The talking book is essentially a plain language written booklet with accompanying audio-recording and illustrations that targets individuals who experience difficulties accessing and understanding information relating to their treatment, as well as navigating the broader health system.

This project is currently in its final phase, with the research team actively recruiting patients at Prince of Wales and St George hospitals to pilot-test the book and supplementary resources.

Project  Year funded  Chief investigator

Achieving behaviour change for detection and management of Lynch syndrome  2015  Dr Natalie Taylor, Institute of Health Innovation, Macquarie University

Development of a talking book to facilitate communication between radiation therapists & cancer patients with low health literacy  2014  Dr Sian Smith, Psychosocial Research Group, Prince of Wales Clinical School, UNSW Australia

Family Matters? Dissemination of genetic information about breast and ovarian cancer genes within families to prevent cancers  2013  Dr Kathy Tucker, Hereditary Cancer Clinic, Prince of Wales Hospital, Randwick, NSW

Screening for Lynch syndrome using antibodies alone  2013  Professor Nicholas Hawkins, School of Medical Sciences, UNSW Australia

Shared Education: a tool to translate pain assessment and management evidence into practice  2012  Professor Jane Phillips, University of Notre Dame

Cancer Challenge of the Year: What is it?

The Cancer Challenge of the Year scheme funds one or two projects per year, and aims to support research initiatives that:

• address an important and unmet need in cancer care
• provide solutions in a short timeframe (12-15 months)
• have broad engagement across disciplines or geographic sectors.
Screening for Lynch syndrome using antibodies alone (2013)

This project was the foundation for an ongoing body of work into Lynch syndrome, a hereditary gene mutation that increases the risk of bowel cancer. Led by UNSW Professor Nicholas Hawkins, this project aimed to help pathologists improve their ability to identify bowel cancer patients needing referral for Lynch syndrome testing.

Lynch syndrome is a genetic condition that predisposes patients and their relatives to developing bowel and other cancers. Patients suspected of having Lynch syndrome are referred to specialists in family cancer clinics for accurate diagnosis. However, it can be hard for doctors to know who to refer, because of a lack of specificity in tests performed on patients. The project results in large numbers of referrals for patients who have a low risk of Lynch syndrome, leaving genetic counselling services struggling to cope with demand.

The Cancer Challenge of the Year project was largely focused on the use of a newly developed assay and its implementation in pathology laboratories. Hawkins and his team worked with four independent pathology groups, standardising processes for the use of the assay and helping them interpret the test results effectively. The results of this research showed that when performed correctly, the process could reduce the need for genetic testing of suspected Lynch syndrome cases by up to 85%, while still effectively identifying patients at significant risk for Lynch syndrome.

The success of this project has resulted in additional funding from the TCRN to begin building a culture of routine testing for Lynch syndrome, an important step in the development of a systematic and cost-effective approach to bowel cancer screening. It also forms part of a larger body of work being produced by TCRN members around the diagnosis and treatment of a range of genetic cancers.

Family Matters! Dissemination of genetic information about breast and ovarian cancer genes within families to prevent cancers (2013)

Carriers of BRCA1 &2 mutations live with a significantly increased risk of breast and ovarian cancers. Identifying the gene mutation in individual patients allows clinicians to monitor cancer risk more effectively, and to present patients with opportunities to take preventative action, such as mastectomy and oophorectomy, if and when appropriate.

A well-established genetic link means that relatives of patients diagnosed with a BRCA1 gene mutation may also be carriers; however, communicating the resultant implications to at-risk family members remains a challenge for genetic counselling services.

The Family Matters! project, led by Dr Kathy Tucker, was devised to address the challenges of communicating BRCA1 mutation status among families. Using a family communication tool that was modelled on similar tools already being used by the Hunter Family Cancer Service and the NSW and ACT Hereditary Cancer Registry, the project team tracked the progress of each patient and their efforts to communicate their BRCA carrier status to family members, including whether a family member had been informed of the patient’s mutation status and whether they had undergone genetic testing for the gene mutation themselves.

The project resulted in more than 100 new individuals, or 37 per cent of study participants, being informed of their genetic risk. More than 60 relatives of a BRCA carrier, or 25 per cent, underwent genetic testing. Based on current statistics relating to BRCA status and the resultant health outcomes, it is estimated that this project alone prevented seven cases of ovarian cancer and 14 cases of breast cancer. The tool is now being rolled out across genetic counselling services at Wollongong, St George, Canberra and Prince of Wales hospitals.

As well as playing an important role in the management of BRCA-related cancer risk, the family communication tool has the potential to facilitate communication among families impacted by other cancer-causing gene mutations, such as Lynch syndrome and familial adenomatous polyposis.

Spaced Education: a tool to translate pain assessment and management evidence into practice (Now QStream) (2012)

The TCRN awarded its first Cancer Challenge of the Year project to Professor Jane Phillips and her project team in July 2012. The aim of this project was to test the impact of an online spaced learning module on the ability of inpatient nurses to assess and manage cancer pain.

Spaced learning is a pedagogy that is delivered via the QStream online platform. Spaced learning provides participants with short bursts of concentrated learning over a set period of time, making it a highly accessible and relevant tool for time-poor clinicians.

The online spaced learning modules provided tailored case-based information on pain assessment, and were combined with tools for pain assessment audit and feedback.

Professor Phillips and her interdisciplinary team developed a series of 11 case studies, each containing a short lesson on a particular aspect of cancer pain assessment. The cases were randomly distributed to participants via the QStream platform to participants email.

Participants were directed to read each case study and then answer a multiple choice question to test their understanding of the content. The outcomes of the research demonstrated that the online spaced learning case-based pain assessment module increased cancer nurses’ pain assessment knowledge and confidence, and that these benefits were maintained up to 10 weeks after completing the online learning content. The positive changes in the quality of nurses’ pain assessment capabilities as well as a significant increase in the proportion of documented pain assessments in patients chart at the end of the project.

As a direct result of this project, Albury Base Hospital has adopted the Australian Cancer Pain Guidelines to assess and manage patient pain.

The results of this Cancer Challenge of the Year project have significant implications for clinicians seeking ongoing educational opportunities in a variety of health care disciplines, and for harnessing time and resource efficiency through the online platform coupled with the residual impact of its learning outcomes enabled large numbers of clinicians over wide geographical areas to be reached.

“Often, when we identify new cases of gene mutations within a family, the information that needs to be passed along to at-risk relatives often doesn’t get through, or when it does get through, it’s not acted upon. The public health benefit for cancer prevention depends on disseminating appropriate information to those at risk.

Given evidence that survival to age 70 can be improved from 53 per cent to 79 per cent for BRCA1 mutation carriers who are appropriately managed, this is a significant public health issue.”

Dr Kathy Tucker
Consumer engagement

Consumer engagement is an important component of translational research. In 2012, the TCRN Consumer Advisory Committee (CAC) was established to provide consumer input into TCRN research and to ensure that consumer interests are represented on all TCRN issues relating to the cancer experience.

“We have become more aware of the need to involve consumer advocates/representatives in our grant proposals. Hearing about how [consumers] think about issues of relevance has been an eye-opener.”

Researcher, Lowy Cancer Research Centre

Genomics and hereditary cancer

Hereditary cancer is a key area of interest for the TCRN, with research into Lynch syndrome and BRCA 1&2 gene mutations occupying the research of high-level TCRN-led academic teams. This body of work was expanded in 2013-2014 with a capacity building initiative to enable the delivery of Next Generation Sequencing (NGS), a high-throughput screening process to detect BRCA 1&2 mutations, at Prince of Wales Hospital.

A co-investment by the TCRN and the SEALS Pathology team at Prince of Wales Hospital resulted in the support of a Genomics Senior Scientist position and the purchase of associated equipment to support NGS processes. A SEALS Pathology team, led by Dr Scott Mead, Dr Michael Buckley and Ms Glenda Mullan, was tasked with achieving accreditation from the National Association of Testing Authorities (NATA) prior to commencing NGS activities. The team was required to validate the NGS process by undertaking a proof of principle study to demonstrate how a particular assay would be used to detect BRCA mutations effectively, and by demonstrating validation against the gold standard Sanger sequencing by showcasing successful use of the assay in the laboratory.

NATA accreditation was granted in November 2014, with the SEALS Pathology commencing NGS service provision at Prince of Wales Hospital that same year. By December 2014, 20 patients had undergone NGS screening, with five found to be carrying a BRCA gene mutation.

These outcomes are good news, not only for the SEALS Pathology team and the local health district which bear the cost of these testing procedures, but also for patients and their families who previously faced a long and anxious for critical health information. The next phase of work is to complete the design of several NGS-based familial cancer multi-gene panels.

NGS outcomes

This highly efficient, low-cost screening tool has significantly impacted both the speed and cost of already achieved a 12-fold increase in resource utilisation at Prince of Wales Hospital that includes:

- a 50 per cent reduction in BRCA testing costs (from $1950 to $1000 per test)
- a 400 per cent increase in BRCA testing throughput (from 50-70 patients a year to 200-240 patients per year)
- a 66 per cent reduction in testing turnaround time (from three months to one month for receipt of results).

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The TCRN is an active participant in the development of the cancer workforce of the future, known as the 2020 cancer workforce. Our activities in this area have delivered broad impact to students, TCRN members, the health professions and the general public, and will continue to do so in coming years.

> **PhD top-up scholarship scheme**

Supporting the ongoing education and professional development of PhD students and increasing their translational awareness is a longstanding commitment of the TCRN. Since 2012, we have provided PhD top-up scholarships that provide students with funding to further support their research endeavours. In exchange, students are required to participate in a TCRN-designed education program that enhances their understanding of translational research; they attend cancer grand rounds, participate in an annual translational skills workshop, and actively engage with the TCRN’s consumer representatives. To date, the TCRN has provided $411,000 in funding to 31 students at both UNSW and UTS.

> **Postgraduate education initiatives**

Postgraduate education is a key platform in the TCRN’s 2020 cancer workforce toolkit. The TCRN has provided funding to support the development of two postgraduate courses to be delivered as part of the Masters of Pharmaceutical Medicine at UNSW. The first, Cancer Therapeutics, was delivered for the first time in Semester 2 2015, while the second, Translational Biometrics (TBI), will be rolled out in early 2016. The Cancer Therapeutics course addresses the development of drug-based therapeutic options across a range of common cancers, and looks at best treatment options for patients with different types of cancers and at varying stages of the disease. The TBI course, which will be delivered predominantly online, looks at the use of bioinformatics as a tool to support translational cancer research, with a specific focus on the use of big data application to increase the speed at which translational research can be conducted.

> **BEST Network**

The TCRN has partnered with the Biomedical Education Skills and Training (BEST) Network, a community of biomedical experts who are committed to driving quality in health care education. Through this partnership, the TCRN has provided high quality, annotatable, de-identified whole slide images from the HSA Biobank that have been uploaded to the cloud and made accessible to undergraduate and postgraduate pathology students undertaking health care degree qualifications across Australia.

Part of the TCRN’s commitment to the education and professional development of translational cancer professionals is the provision of Conference and Professional Development Grant funding for TCRN members. These grants cover the cost of travel and conference registration for TCRN members who are presenting an oral or poster presentation at an Australian or international conference. All conferences must have a clear link to translational cancer theory or practice.

Over the last four years, the TCRN has distributed nearly $156,000 in Conference and Professional Development Grant funding, supporting 92 researchers and clinicians to attend leading conferences in their discipline areas. As well as gaining conference presentation experience, TCRN members have the opportunity to build their professional networks, access the latest international research in their field, and engage with leading researchers and clinicians who are making groundbreaking discoveries in a range of health care disciplines.

For a complete list of funding recipients, please visit tcrn.unsw.edu.au/pggrants

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**Conference and Professional Development Grant Recipient: Dr Jeremy Henson**

Dr Henson and his team have demonstrated that a cancer cell’s telomeres produce circles of DNA called ‘C-Circles’ when the ALT mechanism is present and used this discovery to invent the first method for measuring ALT activity. Being able to measure ALT activity has helped researchers to further their understanding of the ALT mechanism and is an important step on the road toward developing new therapeutics that specifically target cancer cell immortality.

**For Dr Jeremy Henson, head of the Cancer Cell Immortality Group in the Prince of Wales Clinical School, attending the Telomeres and Telomerase 2015 Conference was an opportunity to find out about the latest research from US and Europe.**

Dr Henson’s research group is focused on the ALT mechanism, which allows cancer cells to achieve immortality. Unlike regular cells, which can only divide a finite number of times before dying, cancer can activate an immortality mechanism that allows them to continue growing indefinitely. The ALT mechanism is often seen in cancers that are typically hard to treat, such as brain, bone and lung cancer.

“We try to use our discovery to do basic science and find out more about the cancer immortality mechanism, and to develop diagnostics and therapeutics that target this mechanism to allow better management and treatment of cancer,” Dr Henson said.

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**The Telomeres and Telomerase 2015 Conference provided an important opportunity for Dr Henson to share his work with some of the leading researchers in the international cancer immortality field. He said that the conference allowed him to explore new collaboration opportunities and to meet with existing research partners, broaden his understanding of new compounds and new techniques that are being developed to combat cancer cell immortality, and speak with researchers whose work provided new insights into his own.**

“There was quite a major paper that recently came out, and I got to speak to the head of the group that wrote it. He provided me with additional unpublished information that allowed me to understand the data in that paper, which could hold a key for me to able to complete the project that I’ve been trying to complete for several years,” Dr Henson said.

Now back in Sydney, Dr Henson plans to continue his membership with the TCRN. His current focus is on accessing the HSA Biobank and engaging with the Consumer Advisory Committee to facilitate existing and future research projects.

“The HSA Biobank is an exceptional biobank in terms of the resources that it provides, and I’ve also had some communication with the TCRN about making contact with the CAC to get cancer consumers involved in my work,” he said.

“Being part of the TCRN is important for our group. The TCRN is necessary for our group’s ability to undertake our research and translate our discoveries towards improving patient outcome.”

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**For a complete list of funding recipients, please visit tcrn.unsw.edu.au/pggrants**
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