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Message from the Director

Professor James Semmens
 Director, Centre for Population Health Research

An important priority in population health research has been the increasing integration of health and health-related data to support health research, policy development and healthcare planning.

Curtin University has been a key player in the development of the highly innovative Data Linkage Project during the last decade, and is well placed to embrace important opportunities that are identified as issues for research of national and international significance.

The success of the WA data linkage effort paved the way for the development of national data linkage infrastructure, which is identified as a priority area in the National Collaborative Research Infrastructure Strategy (2008 and 2013), Super Science Initiative investments (2010), Strategic Roadmap for Australian Research Infrastructure (2011) and the National Research Investment Plan Discussion Paper (2012).

The scope and population coverage of this infrastructure supports research to explore health disparities, geographical and spatial aspects of health, and the effectiveness of health and aged care services. There is potential to expand this infrastructure to support ongoing linkages with clinical trials, registries and biological data. Such development would dramatically expand the community of researchers using the infrastructure, as well as the scope and impact of the resulting research.

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“A fundamental characteristic of our age is the rising tide of data – global, diverse, valuable and complex. In the realm of science, this is both an opportunity and a challenge.

Research infrastructure is needed to maximise research outcomes from the diverse range of data collected in the past, present and future.”

...’2011 Strategic Roadmap for Australian Research Infrastructure’ by the then Department of Industry, Innovation, Science and Research.

THE CENTRE FOR POPULATION HEALTH RESEARCH

The Centre for Population Health Research (CPHR) has established an international reputation for excellence through its research into all aspects of healthcare to improve health service design, management, delivery and outcomes.

The success of the CPHR is built on strategic research, programs for advancing technical infrastructure, and the investigation of data repositories. The prime focus is on translational research.

A key focus is on enhancing data linkage methodology to generate critical knowledge and transfer novel solutions into practice.

Key areas within the centre’s program of health services research include patient safety and health outcomes, procedural care, patient blood management, dementia, pharmaco-epidemiology and medication safety, genomics, spatial health and information systems design.

Cross-sectoral data linkage between state and Commonwealth Government departments is a developing area and will support interdisciplinary engagement with government, industry and research bodies.

The development of data linkage methodology to derive research outcomes includes collaboration with clinical, biomedical sciences and research groups. The centre is also keen to attract high-quality higher degree research students.

The strategic aim of the CPHR is to reduce inequalities in healthcare as follows:

- provide innovative solutions to improve the planning, delivery and outcomes of healthcare
- reduce healthcare inefficiencies and inpatient time
- promote best practice in surgical and procedural care
- promote clinical safety and reduce injury trauma
- improve medication safety
- advance population genomics research
- design and develop quality information systems to support health research
- contribute to the methodological developments in the linkage of state, Commonwealth and international health-related data.

The CPHR has a strong track record of high impact research, and has contributed more than 1000 scientific works including 589 scientific papers, book chapters and reports, and more than 400 presentations at national and international forums. It has also contributed to \$54 million in research funding to support its research program. This publication provides some interesting examples that reflect the centre’s research.

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DATA LINKAGE AND ITS BENEFITS TO RESEARCH POLICYMAKING AND SERVICE DELIVERY

Administrative datasets constitute a significant information resource for government and are used to manage, monitor, assess and review a range of service areas. They are also used in research to provide insight into significant health issues, to support health policy development and improve clinical practice and service delivery.

Additional value can be obtained from these administrative collections through the process of 'data linkage'. Data linkage involves bringing together and matching data from different sources, including disease registers and clinical datasets, to provide a richer information source for research and analysis. The benefits of linked data include reduced data collection costs and more detailed and extensive analysis.

DATA LINKAGE INFRASTRUCTURE DEVELOPMENTS: A WA FOCUS

Dedicated infrastructure for data linkage exists in only a handful of countries, including Canada, England, Scotland, Wales, Sweden and Australia. In Australia, purpose-built data linkage infrastructure was first established in 1995, with the Western Australia Data Linkage System (WADLS) emerging from a collaboration between The University of Western Australia's School of Population Health and the Western Australian Department of Health.

The benefits of using data linkage to support health research resulted in Curtin University being included as a core partner in the formation of Data Linkage Australia (DLA) as a WA Centre of Excellence in 2006.

Following the success of the WA data linkage system initiative and in recognition of the power of the resulting linked research data, the Centre for Health Record Linkage (CHeReL) was established in 2006 in New South Wales to undertake data linkage for NSW and the Australian Capital Territory.

Curtin University, under the leadership of Professor James Semmens, is providing ongoing support for the evolution of data linkage infrastructure in WA. It is leading a \$5.1 million project funded by Lotterywest that will see the WADLS expanding in three key areas: improving the capacity of data linkage infrastructure to support health research, targeting the needs of vulnerable Western Australians and promoting consumer participation in WA linked data health research.

POPULATION HEALTH RESEARCH NETWORK INITIATIVE: A NATIONAL FOCUS

Further investment in Australia's data linkage capability occurred in 2008 when the Australian Government identified the importance of data linkage as a strategic priority, and allocated \$20 million to develop national data linkage infrastructure under the National Collaborative Research Infrastructure Strategy (NCRIS). State and territory governments and academic partners invested a further \$32 million to support the capability. The initiative, known as the Population Health Research Network (PHRN), included the establishment of data linkage units in all other Australian states, as well as the formation of a national linkage unit – the Centre for Data Linkage (CDL) at Curtin. A further \$18 million has been provided by the Commonwealth Department of Industry, Innovation Climate Change, Science, Research and Tertiary Education to support the PHRN initiative through the Education Investment Fund (2011-

Data linkage involves bringing together and matching data from different sources, including disease registers and clinical datasets, to provide a richer information source for research and analysis.

The benefits of linked data include reduced data collection costs and more detailed and extensive analysis.

2012), the Commonwealth Research Infrastructure Strategy (2013-2014) and NCRIS2013 (2013-2015).

The purpose of the PHRN is to provide researchers in Australia with the capability to link de-identified data from a diverse and rich range of health datasets, across all jurisdictions and sectors. In turn, this will allow for nationally and internationally significant population-level research to be undertaken, to improve health and wellbeing and enhance the effectiveness and efficiency of health services.

THE CHALLENGE OF NATIONAL DATA LINKAGE

Given the federated nature of healthcare service delivery in Australia (that is, some services are delivered and administered at state level, while others are delivered and administered at a national or 'Commonwealth' level), cross-jurisdictional or national linkage is an essential but challenging component of data linkage.

Without cross-jurisdictional data linkage capabilities, research at a national level or targeting issues of common interest (health service use along border areas, for example) cannot be undertaken.

PHRN CENTRE FOR DATA LINKAGE, CURTIN UNIVERSITY

One of the first tasks of the CDL was to develop an acceptable cross-jurisdictional operational model. It also had to specify and implement a secure IT environment and strong governance arrangements to protect privacy and ensure the confidentiality of data. The CDL has also developed a sophisticated, secure production linkage system that is capable of fast, efficient, large-scale, high-quality data matching.

A number of PHRN proof-of-concept research projects will test the CDL data linkage capabilities. The first proof-of-concept project is already underway.



Data linkage and its benefits to research policymaking and service delivery (cont).

The study examines in-hospital mortality and investigates issues of surgical safety and quality using inpatient and mortality information at a national level. The CDL has linked over 25 million health records from NSW with 10 million records from WA. South Australian and Queensland data will soon be linked to these records.

PROOF-OF-CONCEPT: SAFETY IN HOSPITALS

Curtin's Population Health Research Network – Centre for Data Linkage (CDL) has just completed a series of linkages for a proof-of-concept project using the new national data linkage system that it has been developing at Curtin over the past three years. The proof-of-concept project – investigating hospital mortality – is the first of four projects that will run over the next year. The project aims to test the new CDL and other Population Health Research Network infrastructure linkages by examining in-hospital and 30-day mortality rates using hospital inpatient and mortality information at a national level.

Senior Research Fellow Dr Katrina Spilsbury, says that the study aims to demonstrate that national linkage has valuable benefits to gaining a rich and accurate picture of health patterns and health concerns in Australia.

"This study will give us a better picture of the rates of death in, or directly after being admitted to an Australian hospital," Dr Spilsbury says.

"Our research is able to include data not only from large public hospitals but also from private and smaller hospitals, so we will get a comprehensive picture across the nation.

"We'll also gain particularly useful data in concentrated cross-jurisdictional areas, such as along the Queensland–New South Wales border where people move frequently across state lines, receiving medical treatment in both states. Currently, there is no way of tracking this cross-border hospital use. The new system will address these issues."

To undertake the proof-of-concept project, the CDL has linked over 25 million records from New South Wales with six million records from Western Australia, as well as South Australia, with seven million records, and Queensland, with between 10 and 15 million records.

So far, Associate Professor Ferrante says that testing has gone well.

"When we linked Western Australia to New South Wales the process took just two days, matching millions of records, pair by pair," Associate Professor Ferrante says. "We were pleased that such a significant process took a relatively short amount of time."

"The proof-of-concept projects will give stakeholders – including the government agencies who are providing the data and the broader Australian community – a good sense of what can be achieved through these studies and how this can be done without compromising individual privacy.

"We are pioneering a national data linkage model in Australia, which balances the protection of privacy with the public good arising from research."

PROOF-OF-CONCEPT: GETTING THE WHOLE PICTURE

For the first time in Australia, a national linked data system will allow researchers to conduct population studies encompassing the whole country – providing unprecedented research possibilities previously limited by Australia's federated health system. While at the state level Australia has developed robust population datasets and linked data capability, to date there has been no national or cross-jurisdictional data linkage system. This has limited population health research and government understanding of national health issues and trends.

Associate Professor Anna Ferrante, from Curtin's Population Health Research Network – Centre for Data Linkage (PHRN-CDL), says that administrative datasets constitute a significant information resource for government.

"They are used to manage, monitor, assess and review a range of service areas," she says.

"In research, they are used to provide insight into significant health issues, to support health policy development and to improve clinical practice and service delivery by governments."

Without national cross-jurisdictional data linkage capabilities, however, research aimed at the national level or targeting issues of common interest – for example, health service use along border areas – cannot be undertaken. Linking different data sets – such as disease registers and clinical data sets – gives researchers and government additional important data through a richer information source for more extensive analysis.

Over the past three years, Associate Professor Ferrante has been working with Associate Professor James Boyd and colleagues from Curtin's Centre for Population Health Research to develop a national data linkage system, designed from the ground up to integrate and manage massive volumes of complex information for the whole of the Australian population.

"The system is a sophisticated, secure production linkage system that is capable of fast, efficient, large-scale and high-quality data matching," Associate Professor Ferrante explains.

"In its design, we included a number of new and innovative features and methods around the way in which multiple records relating to one person are matched. The result is much more accurate than previously achieved."

The system is also fully automated because of the need to operate it at a national level. It has extensive reporting and auditing capabilities. Secure, ongoing management of data has been a priority and has been integrated into the system.

"Because the system links records from different states for the first time, the research potential is enormous," Associate Professor Ferrante says.



The aim is to demonstrate that national linkage has valuable benefits to gaining a rich and accurate picture of health patterns and health concerns in Australia.

"Researchers will be able to ask questions previously impossible to answer and, at a national level, policymakers will have evidence based on the whole population – rather than on smaller samples.

"The system also allows for linkage between sectors. One of our proof-of-concept projects involves data from the health and education sectors.

"The potential for doing whole-of-population national research is becoming a reality. I'm not sure researchers have had time to imagine the types of research questions they could be posing. It's a real windfall for Australian researchers – not only for those working in the health domain but also for those in other related disciplines."

FUTURE

Data linkage in Australia is an evolving space. The Commonwealth Government has recently established guidelines and institutional arrangements for the linkage of Commonwealth data. With appropriate safeguards it should be possible to adapt the existing PHRN CDL cross-jurisdictional linkage model to accommodate the linkage of state-based datasets to Commonwealth-held data. The resulting infrastructure would provide a resource that can be used to create epidemiological and management information to investigate and model complexities of Australia's federated health system.

FOCUS ON SURGERY

The Western Australian Safety and Quality of Surgical Care project is looking at the rates and outcomes of surgical procedures in Western Australia, with the aim of improving clinical practice to provide better patient outcomes.

Established in 1996 by Professor James Semmens, the Western Australian Safety and Quality of Surgical Care (WASQSC) project has measured both the short- and long-term health outcomes for patients in a number of focused surgical procedures in WA hospitals.

The program has relied on data obtained from the WA Data Linkage System, which currently brings together 37 million records – comprising population-based hospital morbidity data, birth and death records, mental health services data, cancer registrations and midwives' notifications – reaching back to the 1970s.

Lead researcher Dr Katrina Spilsbury says that the 40-year archive of records makes it possible to track patients over time in an anonymous fashion, as they move through life and different healthcare services.

"It offers researchers a powerful tool for in-depth, longitudinal analysis," Dr Spilsbury says. "It also allows us to detect rare outcomes."

This was the case in their most recent study on the rates and outcomes of grommet procedures – one of the most frequently performed procedures on children.

Controversy around whether and when to resort to grommet surgery (a process of inserting a tympanostomy tube into the eardrum to release pressure build-up and excess fluid) for children still exists, although the number of procedures have declined over the years.

Many practitioners favour a watch-and-wait approach, and all would agree that minimising surgical intervention is always the ideal, especially in children.

In reviewing the records of 57,000 children over a 30-year period, Dr Spilsbury and her colleagues came up with a number of interesting findings.

"We found that children treated at a younger age with grommets had less chance of needing further grommets," Dr Spilsbury says.

"In addition, children who had their adenoids removed at the same time were also less likely to need further grommet surgery."

During their data review, the team also came across potentially valuable information on a very rare condition called cholesteatoma – a destructive and invasive growth in the ear with potentially fatal outcomes if left untreated.

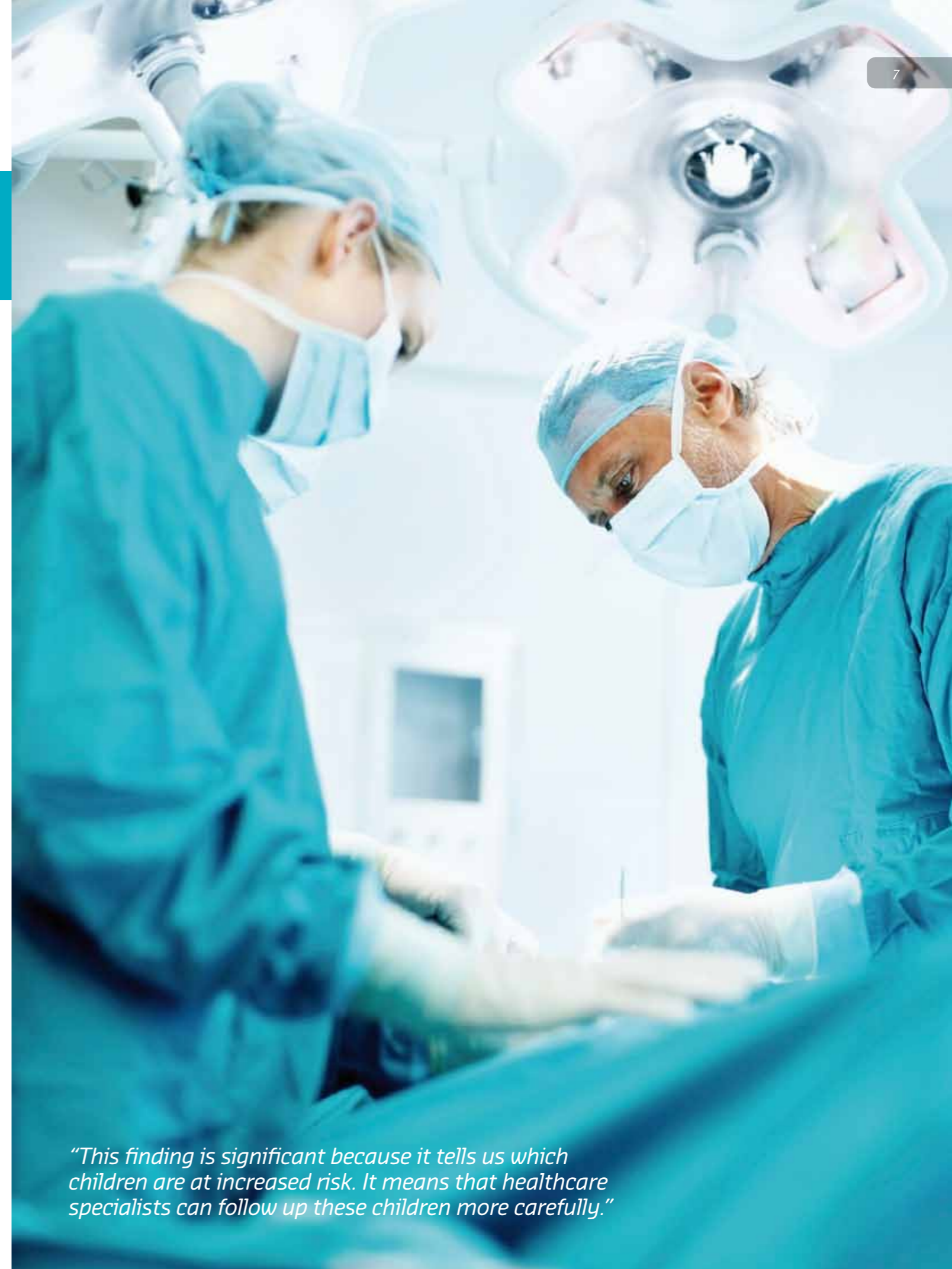
They found that children with more severe middle ear disease requiring multiple grommet insertions were more likely to develop a cholesteatoma years later. Children with cleft palates also had higher rates of the condition.

"This finding is significant because it tells us which children are at increased risk," Dr Spilsbury explains. "It means that healthcare specialists can follow up these children more carefully."

Other studies under the WASQSC project have focused on cancer treatment (breast, ovarian, colorectal, lung, pancreatic), the development and use of vascular stent technology in the treatment of aneurysmal disease, the introduction of minimally invasive surgical techniques, endoscopic procedures, cholecystectomy, tonsillectomy, hysterectomy, appendectomy and others.

In one project, a research team was able to report that women in rural areas are more likely to have a mastectomy for breast cancer, whereas women living in urban areas are more likely to have the less invasive treatment of lumpectomy with radiotherapy – due to easier access to radiotherapy in urban areas.

Yet another study showed that keyhole surgery to remove the gall bladder had worse outcomes for the patient compared to traditional open surgery. The reasons for this difference were identified and this has since led to changes in clinical practice and improved outcomes for the keyhole surgery.



"This finding is significant because it tells us which children are at increased risk. It means that healthcare specialists can follow up these children more carefully."

CALCULATING THE COST OF INJURY

Injury prevention and control is a National Health Priority Area. But despite the personal and community burdens that result from injury, and the economic impacts experienced across the healthcare system, until now there has been a lack of research into the cost of injury in Australia.

Injuries account for almost one-quarter of emergency department presentations in Western Australian hospitals. While this may reflect a population with a high participation rate in sport and manual labour occupations, falls among children and the elderly, transport crashes and intentional self-harm are major causes of hospitalisations due to injury. Moreover, about seven per cent of deaths in WA can be attributed to unintentional and intentional injuries, which include assault.

The overall problem places a substantial health, social and economic impact on individuals, families and the community. Compounding the loss of personal wellbeing, an injury may cause a temporary or permanent reduction in capacity to work.

Although it is acknowledged that for any population health problem, accurate data are necessary to assess risks, set research priorities and select interventions, health economist Dr Delia Hendrie, who is based at the Centre for Population Health Research at Curtin and who has a longstanding research interest in injury prevention and control, says the most recent study on injuries in WA – now more than eight years old – relied heavily on secondary data, including some from the US.

“The lack of recent research into injury has meant that policymakers can’t make informed decisions about resource allocation for interventions,” she explains.

“Fortunately, the availability of the WA Data Linkage System (WADLS) and other relevant datasets, such as police reports of road crashes, now provides the opportunity to produce estimates of the cost of injury using best practice methods.”

The WA Department of Health has responded to this new research capability, and in 2012 funded a project to examine the cost of injury in WA. Using the WADLS, and led by Dr Hendrie, the study examines key cost components, determines the longer-term costs of injury and explores risk factors associated with high-cost injuries.

“We’ll deliver an analysis of costs by demographic factors, injury type and severity, socio-economic status and Aboriginal status,” Dr Hendrie says.

“We will also have an accurate means of estimating injury severity, which is essential to meaningful evaluations of patient outcomes and an understanding of the impact of interventions.”

The outcomes will deliver policymakers and numerous stakeholder agencies, at both state and national level, a valuable tool for making decisions about future resource allocation.

“It will also provide useful cost data for the range of stakeholders involved in injury prevention and control – including researchers, policy and emergency services, healthcare services, welfare groups and child protection agencies, to name a few,” Dr Hendrie says.

The overall problem places a substantial health, social and economic impact on individuals, families and the community.

THE HIDDEN EFFECTS OF ALCOHOL

It is well recognised that harmful maternal alcohol use impacts on a range of child health and developmental outcomes, including morbidity, mental health, disability and education.

Alarming, however, a high proportion of women in Australia drink heavily during pregnancy.

Dr Colleen O’Leary, from the Centre of Population Health Research says children can be harmed through prenatal alcohol exposure, and through exposure to risk factors associated with maternal alcohol-use disorder during a child’s early years.

“Half of all Australian women drink during pregnancy, but we’ve yet to determine how many children are damaged by the alcohol use,” Dr O’Leary said.

Part of the issue, she explains, is that among the conditions collectively known as Foetal Alcohol Spectrum Disorders (FASD), only one – Foetal Alcohol Syndrome – is more readily attributable to prenatal alcohol exposure, due to characteristic facial features that aid diagnosis.

“Estimates of FASDs vary considerably because most of the conditions – including alcohol-related neurodevelopmental disorder and alcohol-related birth defects – can’t be easily attributed to in-utero alcohol exposure,” Dr O’Leary says.

“Linking a child’s developmental, behavioural, and learning problems to maternal alcohol use during pregnancy is challenging when the classic facial features of Foetal Alcohol Syndrome are absent, since it is difficult to rule out other causes of these problems.”

To address the knowledge gap, Dr O’Leary is using de-identified data from the WA Data Linkage System to examine the effect of maternal alcohol-use disorder on the mental and physical health and developmental outcomes of the children exposed to it.

The project will provide the first population measure of alcohol-related harm in Australian children.

The four-year longitudinal study, which is funded by the National Health and Medical Research Council, is providing the first population measure of alcohol-related harm in Australian children.

“We are examining a range of child health and social outcomes, such as justice, education and child protection, for a cohort of children whose mothers have been diagnosed by a health professional as having an alcohol-related problem. We are then comparing those results with children whose mothers have not been diagnosed with alcohol-related problems,” she says.

“Already we’ve uncovered new information, including the risk of cerebral palsy, intellectual disability, birth defects, and foetal and child death.”

The project has confirmed the link between heavy prenatal alcohol exposure and stillbirth, revealing that almost eight per cent of Aboriginal stillbirths and about one per cent of non-Aboriginal stillbirths are the result of heavy alcohol consumption. These results were discussed in a 2012 paper by Dr O’Leary and her research colleagues, published in the *British Journal of Obstetrics and Gynaecology*.

In another paper published online in the specialist journal *Developmental Medicine and Child Neurology*, Dr O’Leary and colleagues demonstrated that maternal alcohol-use disorder increases the risk of pre- and post-neonatally acquired cerebral palsy, and provided the first population-based data confirming that prenatal alcohol exposure is the leading cause of non-genetic intellectual disability overall.

Dr O’Leary anticipates the project will lead to further research regarding health and mental health outcomes, educational achievement, and the risk of contact with the justice system, for example, for the children whose mothers drink alcohol at harmful levels. The outcomes of this research provide important new observations that are being used to inform health policy in Australia.

DIAGNOSTIC TECHNOLOGY: TOO MUCH OF A GOOD THING?

A Curtin-led project is investigating the surge in diagnostic imaging, and the impacts on the provision and cost of healthcare.

Like all states, Western Australia's population is ageing. While it has long been known this demographic shift will intensify the demand on the national health system, it is also evident that raised expectations of personal health status, caused partly by increased healthcare capabilities, are also impacting on the health system and state health budget.

Associate Professor Rachael Moorin, from the Centre for Population Health Research, says people's eagerness to take advantage of new technologies reflects the higher expectations Western Australian's have of healthcare and the health system.

"Community expectations about what is normal and what is abnormal with ageing have changed: people are more attentive to chronic disease management than in the past, and there is a tendency to 'medicalise' symptoms of ageing," Associate Professor Moorin says.

This phenomenon presents major challenges for policymakers, who are looking to researchers such as Moorin to help inform future population health policies.

Associate Professor Moorin's particular research focus is health policy relevant to the utilisation and outcomes of health services. She is currently leading a three-year project that is assessing the escalation in diagnostic imaging and, in particular, computed tomography (CT) scanning – one of the highest radiation dose medical imaging procedures.

"While medical innovations offer many benefits, there are valid concerns about unrestricted use of technologies such as scanning for routine examinations."

"While medical innovations offer many benefits, there are valid concerns about unrestricted use of technologies such as scanning for routine examinations," she says.

"For example, CT scans are now performed routinely in a wide range of non-cancer related diagnoses, such as sporting injuries. This, together with technological advances, means that CT scanning is used more often than in the past."

The project is funded by the National Health and Medical Research Council, and follows a previous study funded by the Cancer Council of WA that was completed in 2011.

The previous project provided a snapshot of CT scanning practice in the state, and revealed the variation in technique and radiation dose across service providers for similar examinations. For the same clinical indication and diagnostic benefit, the radiation dose from a scan varied greatly, depending upon the provider and technical factors.

"The technology has changed, but there is yet to be a consensus on application, or diagnostic reference levels of radiation from CT scanning," Associate Professor Moorin says.

"This has implications for patient safety, policy decisions and health resource allocation."

With assistance from hospital imaging departments and assessing data provided by the WA Data Linkage System, Associate Professor Moorin's research team is determining the changes in utilisation of CT scanning over a 20-year period from 1990 to 2009. The current project will also include a radiation dosimetry assessment of protocols followed in WA.

"Changes in demographics and community expectations mean that policies associated with healthcare delivery need to be informed by investigations of the underlying population health dynamics and changes in healthcare demand," she says.

DELIVERING MORE KNOWLEDGE ABOUT DEMENTIA

Nobody knows exactly how many Australians have dementia; however, the population is ageing, and the prevalence of dementia doubles every five years from the age of 65.

The lack of knowledge about the prevalence of Alzheimer's disease and other types of dementia is an increasing challenge for Australia's healthcare sector. In the absence of a national register of dementia sufferers, statistics for dementia in Australia are currently based largely on European prevalence estimates.

At Curtin's Centre for Population Health Research, Dr Renate Zilkens is addressing this knowledge gap through the analysis of linked administrative data to study population-based estimates of healthcare services and health outcomes for Western Australians living with Alzheimer's disease.

Funded by the National Health and Medical Research Council, the project will provide significant new knowledge about the national epidemiology of dementia.

"Australia is heading towards an epidemic of Alzheimer's disease. It accounts for up to 70 per cent of all dementia types, and the healthcare costs directly attributable to this disease are increasing," Dr Zilkens says.

"We urgently need to increase our understanding of how many Australians are living with dementia."

The study has evolved from previous research supported by Alzheimer's Australia. The project, which also includes researchers from Fremantle Hospital and the School of Medicine and Pharmacology at The University of Western Australia, is utilising the Western Australian Data Linkage System to undertake a longitudinal population-based study of Alzheimer's disease.

"We can determine patterns of care, drug treatment regimens and survival outcomes for Western Australians with Alzheimer's disease," Dr Zilkens says.

"Although we lack a national dementia register we can study Alzheimer's disease at a population level because the Pharmaceutical Benefits Scheme records all cholinesterase inhibitor medication that is prescribed only for people with Alzheimer's disease."

An important responsibility of the study will be to ascertain, from death records, how long people live with dementia after starting treatment with this medication. This knowledge is considered essential for planning healthcare service provision, yet is currently not available at a population level.

The study will provide this and other information critical for the development of dementia-specific healthcare.

"We'll also determine any differences in access to health resources, for example. This is very relevant in WA, where more than one-quarter of the population is dispersed across rural and remote areas," Dr Zilkens says.

"Any findings that reveal inequity in access to treatment must translate into healthcare policy that ensures all persons with Alzheimer's disease, regardless of socio-economic status or geographic location, can be treated."

Dr Zilkens expects that data linkage as a research method will become increasingly important for healthcare planners.

"The healthcare sector needs research that uses data linkage methods, to prepare for the healthcare needs of the growing population that is Australians with dementia," Dr Zilkens says.



The incidence of dementia in Australia may be underestimated considerably – which has major implications for healthcare planning, policy and resource allocation.

IN GOOD SUPPLY

A new patient blood management system is addressing previous concerns about inappropriate blood transfusion. Patient outcomes can be improved by effectively targeting blood management strategies.

In certain clinical situations where there is major blood loss, the use of blood products has life-saving potential. However, inappropriate blood transfusions come at enormous cost to the health system, and they may add risks of health complications or mortality for patients.

In 2008, researchers from Curtin’s Centre for Population Health Research (CPHR) identified that there was no routine system in Western Australia for monitoring where and why blood was used. The impact of inappropriate blood transfusions was, therefore, exposing patients to excessive risks of adverse outcomes.

With a grant from the WA Department of Health, the CPHR team collaborated with a group of leading haematologists and other clinicians with the goal of designing and implementing a patient blood management (PBM) program.

The team established a pilot study in 2009 at Fremantle Hospital to set up a data system that could monitor the use of blood products. Curtin Research Fellow Aqif Mukhtar assembled an electronic database to link and analyse data on current patterns of blood use.

“We connected pathology laboratory results with admission data of patient records,” Mr Mukhtar says.

“This enabled existing transfusion data to be linked with other key clinical data, such as haemoglobin levels before surgery and the type of surgery being performed.”

Mr Mukhtar says that the first three years of the pilot study also focused on making more effective use of preoperative clinics to better identify and manage perioperative anaemia, improve perioperative haemostasis, reduce the volume of blood sampling, educate staff about more restrictive transfusion triggers, and to implement a single unit transfusion policy.

The system is now active at Fremantle Hospital, with the other three major public hospitals – Royal Perth, Sir Charles Gairdner and King Edward Memorial hospitals – having all commenced using the PBM linked data system.

Mr Mukhtar says that data gathered during the three-year Fremantle pilot have been important in that they have revealed that significant change in practice needed to occur.

“Using the new system we identified that during 2010, 17 per cent of total transfusions in all Western Australian metropolitan public hospitals were inappropriate, according to Australian national guidelines,” he says.

“Furthermore, we found that large cost savings can be made by avoiding inappropriate transfusions. With a direct cost of \$350 per RBC [red blood cells] unit, the savings roughly come to \$2.8 million. The total cost of one unit of RBC including indirect costs such as blood testing and nursing hours can be as high as \$800.”

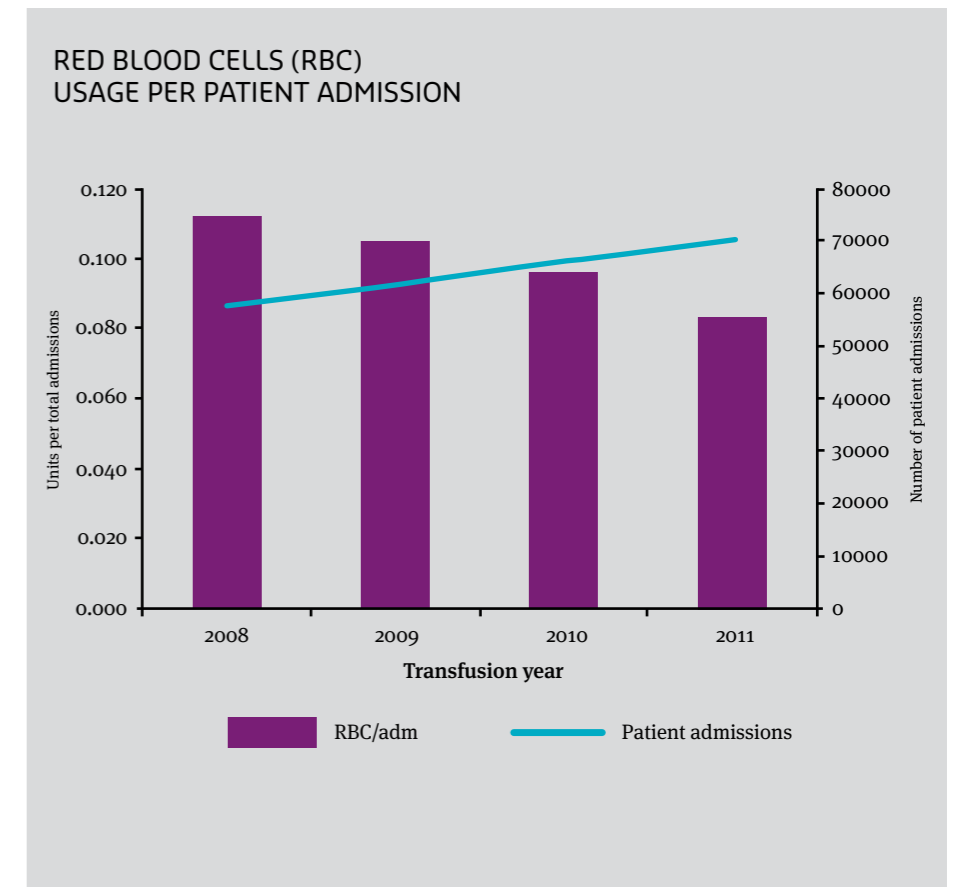
Using 2008 as a reference year, the mean RBC units per admission declined by 26 per cent by 2011. The leading decline in the RBC transfusion rate was seen in cardiothoracic surgery – from 27.5 per cent to 12.8 per cent.

“The patient blood management program has given us the impetus for national or state-wide benchmarking of practice,” Mr Mukhtar says.

“It has also allowed an exploration of the drivers leading to transfusion and a better understanding of the impact of population demographic and clinical service changes upon the supply and demand for blood products.”



Inappropriate blood transfusions come at an enormous cost to the health system and may add risks of health complications or mortality for patients.



THE CONCEALED LINK BETWEEN BURN INJURY AND CANCER

Over the past two decades, better management of major burn injuries in Western Australian hospitals has led to increased survival rates of burn patients. Consequently, there is now a pressing need for information about subsequent health problems – particularly the risk of cancer – that may be related to major burn injury.

With lead investigator Associate Professor Janine Duke at The University of Western Australia's Burn Injury Research Unit, Associate Professor James Boyd, from Curtin's Centre for Population Health Research, is participating in a unique collaboration to deliver knowledge about the little-known relationship between major burn injury and cancer risk.

"This study will give us a better picture of the changes in health following major burn injury and build links for better research," Associate Professor Boyd explains.

Depending on injury severity, a major burn can lead to significant impairment of the immune system – and people whose immune systems are suppressed for a prolonged period have an increased risk of developing a malignancy. Therefore, it is important to identify if certain sub-groups amongst burn patients should be monitored for subsequent development of cancer.

Associate Professor Boyd is a population health researcher with particular expertise in statistical analysis and data linkage. He was recruited to Curtin's Centre for Population Health Research in 2009 from the Scottish Government.

The project – in addition to benefiting from the highly valued and internationally envied Western Australian Data Linkage System – involves a unique partnership with the National Health Service (NHS) in Scotland, which has agreed to contribute NHS health data for the research.

"We'll use de-identified health data, such as hospital morbidity, cancer and death records, to investigate the subsequent incidence of cancer in people hospitalised with major burns between 1983 and 2008 in WA and in Scotland," Associate Professor Boyd says.

"The results will then be compared with the cancer incidence of the two general populations for the 25-year period."

The study, which is funded by the Fiona Wood Foundation, follows a longitudinal analysis by research teams from Curtin's Centre for Population

Health Research and the Fiona Wood Foundation that was funded by the National Health and Medical Research Council.

One of the unexpected findings of that study was the higher incidence of subsequent cancer in females than males who survived a major burn injury. However, although a state-wide study, the population base wasn't large enough to deliver statistically significant results. "Combining WA and Scottish data sets significantly extends the population-base – to more than 7.5 million – and increases the statistical power of the new study," Associate Professor Boyd says.

"The end goal is to be able to identify those burn patients that have a greater risk of developing cancer."

"The end goal is to be able to identify those burn patients that have a greater risk of developing cancer."

RESEARCH FOCUS ON BLINDNESS

How many people in Western Australia are blind?

The prevalence of blinding eye conditions is now being revealed by new research.

"Half of all the people living with blindness in WA have never accessed support services for the blind or vision-impaired."

Until recently, the extent of blinding eye conditions in Western Australia was unknown, and could only be estimated through very large population-wide studies or from incomplete voluntary registers.

Now, at the Centre for Population Health Research, a team specialising in studies of blinding eye disease has determined that almost 3,400 people in WA are living with blindness, and with an ageing population and the rising incidence of diabetes, the number is increasing.

Research fellow Julie Crewe and the Epidemiology of Blinding Eye Disease (EBED) study group are investigating how people who are blind utilise the healthcare system.

"Half of the people living with blindness in WA have never accessed support services for the blind or vision-impaired," Ms Crewe says.

"These services include rehabilitation training to maintain mobility and to develop skills with assistive technologies to ensure social connectivity."

Commencing in 2008, with the support of the Eye Surgery Foundation, the research team has been examining the extent and causes of blinding eye diseases, and issues such as co-morbidities, health service utilisation, and access to rehabilitation and support services.

The group has found that half of all the blindness in WA is caused by age-related macular degeneration – for which there is no treatment, excepting a small proportion with the 'wet' form of the disease. A further fifteen per cent is due to glaucoma, and eight per cent due to the damaging effects of diabetes on the eye.

The EBED team is now examining the health and wellbeing of people living with blinding eye conditions by analysing how they utilise WA's healthcare system.

An important finding of this current research is that children who are blind have four times as many hospital admissions and stay for periods six times longer than normal-sighted children.

"Surprisingly, a third of children who are blind are hospitalised with respiratory infections, and spend ten times more days in hospital than normal-sighted children for these infections," Ms Crewe says.

"Further studies are necessary to understand why children who are blind would experience such severe and potentially life-threatening respiratory infections."

The study showed a similar picture for adults who are blind: they have 30 per cent more hospital admissions and stay one-third longer than normal-sighted people of a similar age.

"Our understanding, treatment and provision of support services would be greatly enhanced if there were an 'active' database of those people living with severe vision loss," Ms Crewe explains.

"A register of those living with blindness is the hard endpoint for evaluating disease treatment outcomes – because if we can monitor changes in disease incidence and prevalence we can better understand the impact of targeted programs and treatments in the future."

MAPPING HEALTH AND WELLBEING MORE ACCURATELY

Sophisticated evaluation of geo-coding software to allow more accurate mapping of demographic health patterns will better support health planning and policy development.

Spatial information is increasingly being used to better understand the geographic distribution of health, wellbeing and the associated risk factors for different diseases across Australia. By geographically tagging a state's administrative records to a higher level of accuracy, more appropriate information about the population and the environment will be available for planners and policymakers.

The process of 'geo-coding' relies on three factors: a detailed description of each residential or service location captured in administrative health records; reference data, such as the property street address, containing the GPS location and managed by Landgate; and matching software, which matches the residential address with a property address in the reference data.

One challenge for accurate matching is that components of any address entry – such as street names, suburb names and postcodes – may be written or recorded differently each time someone reports their address. These differences result in imperfect matches when reconciling against the official land records containing standardised addresses.

Current software packages are available that can compensate for these anomalies. The need, therefore, to check, compare and contrast different software products before investing significantly in any new and costly system is an important one for state health departments. As new software becomes available, it is likely to include additional features and increased capacity.

This Curtin research project – a component of the Cooperative Research Centre for Spatial Information initiative – will assist organisations in selecting the best product for their needs.

Project leader Associate Professor James Boyd, from Curtin's Population Health Research Network –Centre for Data Linkage, says that choosing the 'right' software is one of the essential elements to supporting effective geographic analysis of data – and, ultimately, better population-based health outcomes.

"Our goal is to develop methodology to allow comparisons of different geo-coding software packages," Associate Professor Boyd says.

"In particular, we are interested in how well the software resolves data anomalies, but we will also evaluate other factors such as the speed with which each processes data. We are talking about millions of addresses in a dataset, so it's vital to have software that can process data quickly and accurately."

The research group – which includes Western Australia's Department of Health data linkage staff and US expert Professor Dan Goldberg – is developing an evaluation methodology that will use a set of key criteria and metrics for measuring quality and cost across several software packages.

"We short-listed four packages – of the many that are available on the market," Associate Professor Boyd says.

"And have assessed them in conjunction with address reference data and real-life data to assess key criteria such as the algorithms used for address standardisation and matching, the functions and features within the software, and the precision of the output.

"The results will help define the geo-coding research challenges facing the Australian health sector, including the issue of geo-referencing of individuals over time. They will also address the increasing demand for information at the localised level, focusing on smaller geographic areas for more targeted health policy approaches."

The evaluation framework and results from the case study evaluation are published internationally, enabling the approach to be used by other key health organisations.



Choosing the 'right' software is one of the essential elements to supporting effective geographic analysis of data – and, ultimately, better population-based health outcomes.



TAKING COMFORT IN PALLIATIVE CARE

A comprehensive body of research has informed palliative care support systems and education both in the community and among healthcare professionals. For the past 10 years, Curtin researchers have been investigating the provision of palliative care in Western Australia.

Professors Lorna Rosenwax and Beverley McNamara, both of Curtin's School of Occupational Therapy and Social Work, have completed more than 10 consecutive and inter-related studies about the provision of palliative care in WA, with four of the studies funded by prestigious National Health and Medical Research Council (NHMRC) grants. In their latest study, they turn their attention to the use of hospital emergency departments (ED) by people in their last year of life, with particular interest in people who would benefit from palliative care.

Early research results revealed alarming levels of unmet need, with barely half of those considered by experts as needing palliative care actually receiving the care.

In collaboration with an expert interdisciplinary group of health professionals, Professors Rosenwax and McNamara developed a model that captured an accurate profile of the population potentially needing palliative care. They then used information in the WA Data Linkage System to determine which groups were missing out on much needed services.

"This meant that those needing palliative care were not only more clearly identified as a group, but were identified through the state's key patient data linkage system," Professor McNamara says.

"Based on that, we were then able to evaluate the care they were receiving as a group and to compare those who were receiving community-based and hospital-based palliative care with those who were not receiving these services."

Results from this early work drew attention to population-based palliative care planning in Australia. Palliative care practitioners and policymakers were now armed with credible data to advocate for increased services.

More recently, Professors Rosenwax and McNamara are completing work on a project which involves collecting information from a range of sources – including hospital service data and hospital notes – to identify critical points in the last year of patients' lives where something could have made a difference to their care.

Initial findings from this work show an exponential rise in hospital services in the last three months of life. Their work has been featured in the Medical Journal of Australia.

In another project, the 4 are collaborating with researchers from the Centre of Population Health Research reviewing the use of ED services by those identified as having been in their last year of life. Their efforts aim both to increase quality of end-of-life care for patients and to decrease the demand on EDs by this group, if unnecessary. One focus will be on people with dementia.

"We need to better understand how people in their last years of life navigate the healthcare system in order to achieve a comfortable death," Professor McNamara says.

"During the data collection stage, we are asking questions such as: How often does this group use the ED? Which sub-groups come in more often than others? Are they then admitted to hospital? What occurs once they are admitted? Who goes home and who remains in hospital, and for how long, and receiving what types of care?"

The study will help policymakers and health professionals to determine more appropriate resourcing and processes around delivering the best possible care to palliative care patients.



The project involves collecting information from a range of sources – including hospital service data and hospital notes – to identify critical points in the last year of patients' lives where something could have made a difference to their care.

"Depending on what we find, it may be that funds are better spent on enhanced community support through groups such as Silver Chain," Professor Rosenwax explains.

"Currently, the vast majority of people who do not access community-based palliative care services die in hospital. For many people, this is not ideal.

"Our research has enabled us to provide the 'big picture' of health service use for this vulnerable group. Our results will hopefully make a difference to the lives of dying people, their families and their friends by ensuring that independent, current and rigorous research informs resource allocation."

Professors Rosenwax and McNamara's work has been adopted nationally and internationally. Their model for deciding which disease groups most need palliative care has been taken up nationally in Australia as well as by Kings College in London, the World Health Organization, and other organisations in Belgium, Spain and New Zealand.

POPULATION GENETIC SCREENING

Researchers at the Centre for Population Health Research are working to ensure that doctors, patients and healthcare systems can make informed decisions about the use of new genetic screening tests.

Rapid advances in genetic knowledge and technologies are being applied to identify increasing numbers of medical disorders. They provide early detection of genetic defects during pregnancy or in newborns, as well as susceptibility to genetic diseases such as familial cancers or hypercholesterolaemia. Early diagnosis can be vital in enabling individuals to maximise treatment options and improve health outcomes. However, introducing new tests into the public health system is a complex process, requiring extensive evaluation prior to selecting and implementing a particular test.

“The decision to introduce a new test for each genetic condition is based on the incidence and natural history of the condition, the accuracy of the screening test and the number of individuals who will be prevented from developing serious disability,” says Professor Peter O’Leary, Deputy Director of the Curtin-based Centre for Population Health Research.

“Several additional issues must be addressed, including the need for counselling, issues around informed consent, and the costs and resources required. Ongoing assessment of the screening program performance is then also required.”

Research programs led by Professor O’Leary have shown the benefits of population genetic screening. For example, they have demonstrated that screening for inherited chromosomal disorders during pregnancy and metabolic defects in newborns are worthwhile. The current newborn screening program has also been considered a success in terms of health improvements and economic benefits. However, there are challenges for the health system in expanding newborn screening to identify additional conditions.

“Currently, there is discussion around the expansion of the screening program,” says Professor O’Leary.

“But questions remain unresolved: things like whether screening should be used only for the benefit of the child or for the benefit of the whole family, and whether screening should identify late-onset conditions, or those for which we have no current treatment.”

Through the Australian Better Health Initiative, Professor O’Leary and research colleagues developed and implemented a comprehensive model of care for familial hypercholesterolaemia in Western Australia. Their research has shown that genetic screening to identify familial hypercholesterolaemia was accepted by almost all family members and cholesterol-lowering therapies resulted in a 50 per cent reduction from pre-treatment values.

“Research using advanced genetic technology is rapidly changing the landscape of genetic testing and diagnosis,” says Professor O’Leary. “It is poised to revolutionise how our public health system approaches medical diagnoses and treatments.

Genetic population screening programs that demonstrate shared inherited genetic susceptibilities will raise ethical issues and require careful assessment of the impact on individuals.”

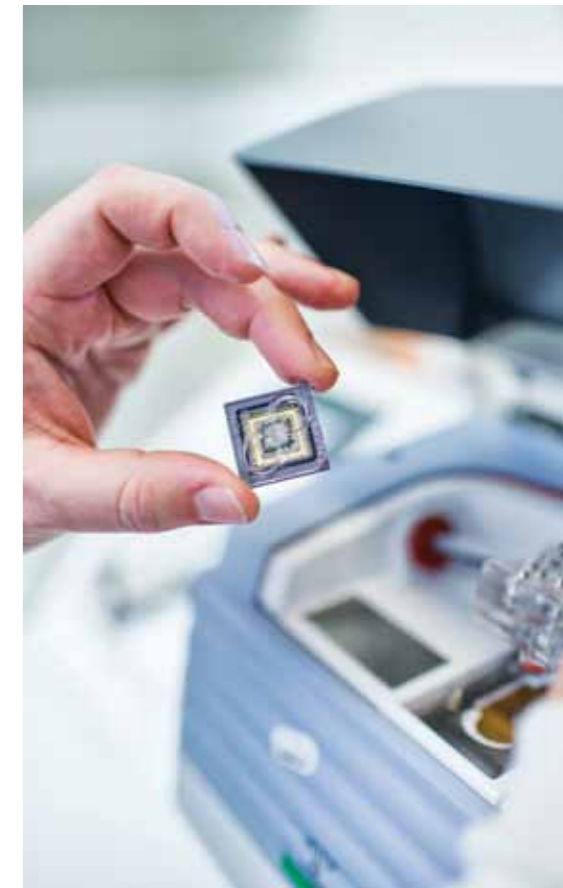
Increased community knowledge about genetic testing will also increase expectations and demands on the health services, with Professor O’Leary’s research helping to inform decisions concerning the health priorities and funding required to provide equitable access to health services.

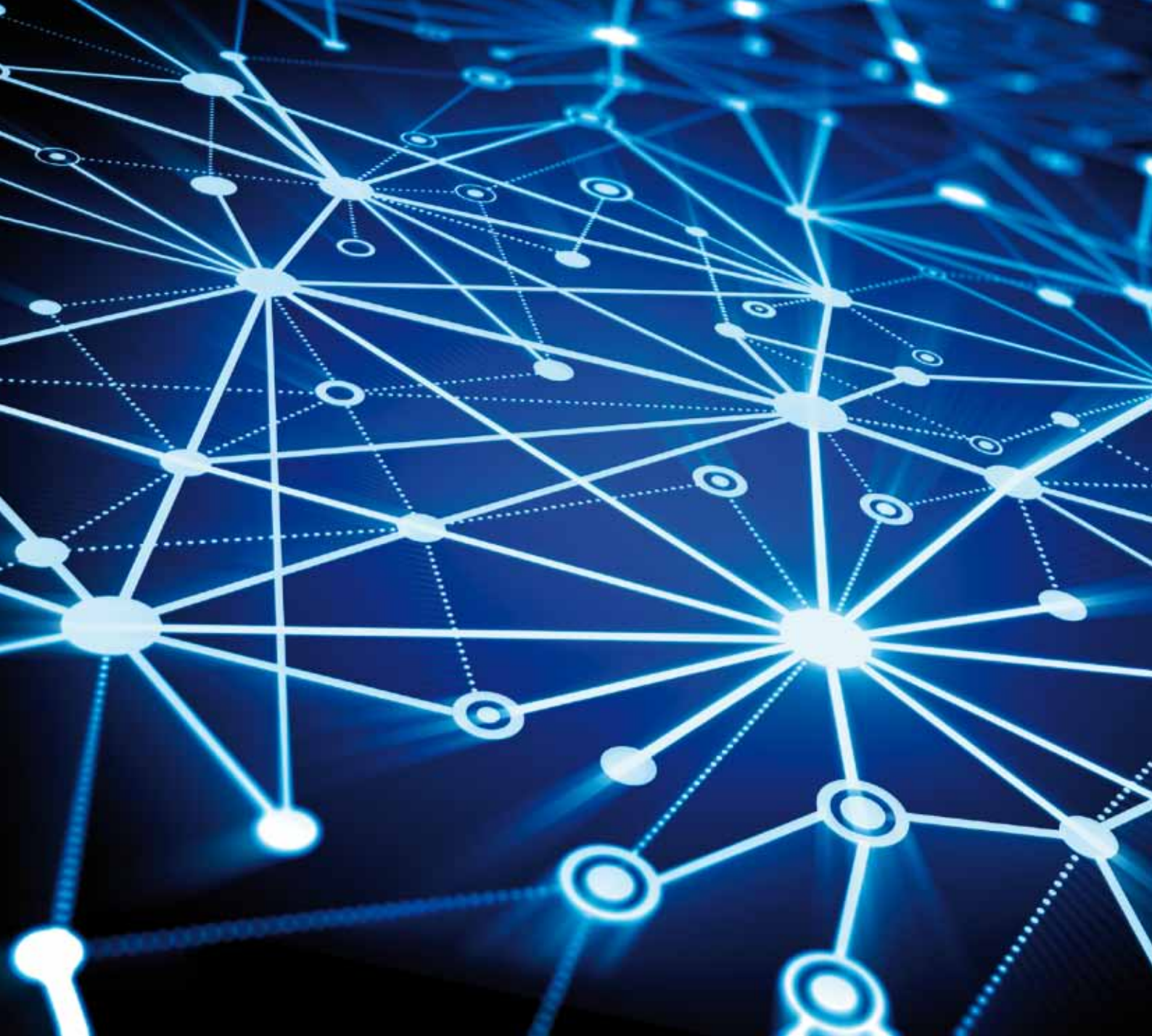
“Implementation and sustainability of new population genetics screening programs are real challenges for the public health system,” he says.

“We need to collaborate closely with clinical, policy and political champions to translate the clinical evidence into long-term government programs.

“Ultimately, our goal as a research team is to help policymakers navigate this important but complex terrain by undertaking the rigorous scrutiny of data that will be used to determine the relative risks, merits and priorities for implementing these programs.”

Research using advanced genetic technology is rapidly changing the landscape of genetic testing and diagnosis.





For more information contact

**Centre for Population
Health Research
Faculty of Health Sciences**

Curtin University

Kent Street Bentley WA 6102

GPO Box U1987 Perth WA 6845

Tel: + 61 8 9266 4583

Email: healthresearch@curtin.edu.au

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