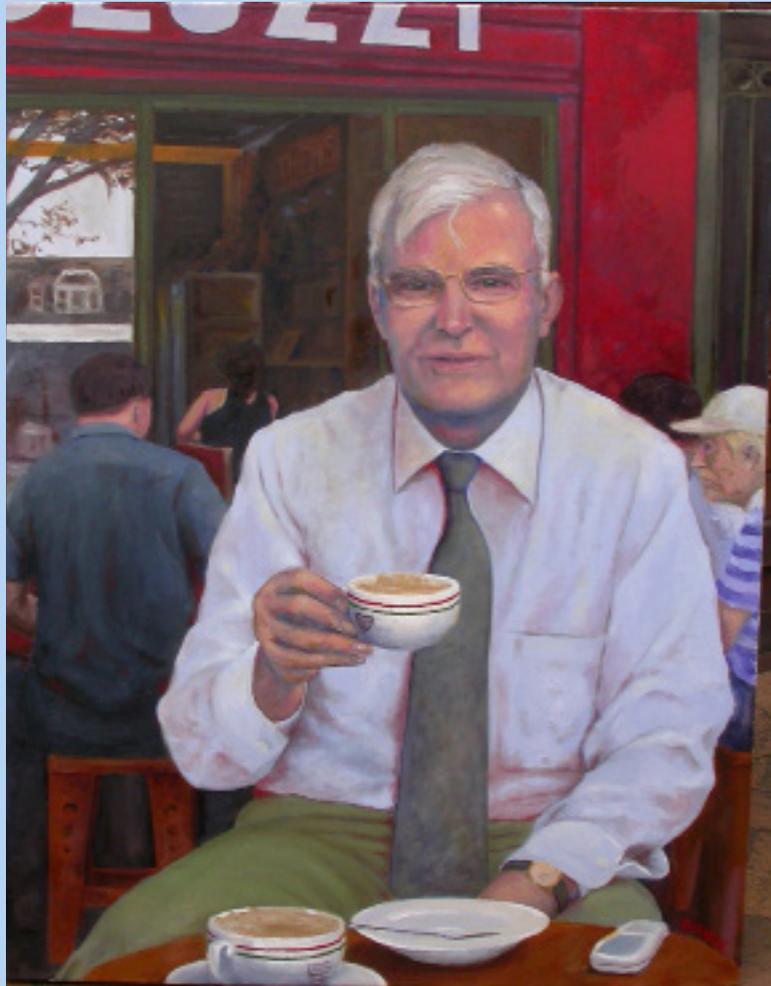




CENTRE FOR COMMUNITY-DRIVEN RESEARCH

2014-2015 ANNUAL REPORT



Our organisation was launched in February 2013 and is dedicated to the late Professor Robert L. Sutherland AO FAA. Rob was a pioneer in translational research in Australia and internationally, and a visionary who adopted a 'Bedside to Bench' approach to cancer research.

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# 1. Message from CCCR

## *A new name, a new office, but the same spirit*

It has been another productive year with a big change for us -our name. In 2012, the organisation was launched as 'Bedside to Bench' and we are now called The Centre For Community-Driven Research. Our vision however remains to facilitate meaningful connection between service providers, research organisations, the non-profit sector, practitioners, industry, government and the communities for which they provide a service or aim to benefit.

Our Bedside to Bench approach to research has led to two, newly developed programs in community engagement and patient support. Thank you so very much to all those who participated in the studies, we are so grateful for your contribution. The first new program is the result of research asking patients and family members how they would like to be involved in research decision-making, and the second is the result of research to understand the challenges patients with poor prognosis cancers face. You can read more about these new programs in this annual report.

As our organisation matures, this year has seen a focus on developing organisational policies and procedures to ensure that growth does not compromise the quality of research and services that we provide to the community. The Board have been instrumental in providing advice and guidance on a new governance system and constitution that supports the creative approach that the Centre for Community-Driven Research takes.

The last event of the year was moving into our new office at 84 Pitt St in the centre of Sydney. Moving is never fun, nor is negotiating property prices in Sydney, but we made it through and now have a home for our organisation. On a personal note, I must thank my family who took on the somewhat frustrating task of assembling an office full of Ikea furniture. Thank you!

Catherine Holliday, Chief Executive

## Centre for Community-Driven Research

### Board Members

Chair	Michael Hasenmueller
Member	Paul Hendry
Member	Ursula Hogben
Member	Tony Shaw
Member	Rebecca Sutherland
Chief Executive	Catherine Holliday (Ex officio)

### Strategic Goals

SG1 Health Education: Deliver targeted and practical health education that empowers individual decision-making

SG2 Community Engagement: Facilitate connection between health professionals, researchers, public and private sectors, and the community for more meaningful community engagement

SG3 Research: Conduct and support medical research that addresses the needs of the community

## 2. Organisational Summary

The Centre for Community-Driven Research is a non-profit organisation bringing much needed change to the way we think about, conduct, and translate medical research in Australia across all disease streams.

The organisation was registered in November 2012 and launched in February 2013, and is dedicated to the late Professor Robert L. Sutherland AO FAA. Rob was a pioneer in translational research in Australia and internationally, and a visionary who adopted a 'Bedside to Bench' approach to cancer research. As his daughter Rebecca Sutherland explains,

"Dad thought that by listening to patients and clinicians at the bedside, scientists could identify the most important research questions to answer at the bench. The importance of working to achieve this ideal was reinforced throughout Dad's own cancer treatment. It is this *bedside to bench* approach that we continue through the organisation in a number of ways, so that in the end, patients receive the benefits of research, sooner"

The Centre for Community-Driven Research implements community engagement in research programs, helping researchers and industry to connect with the community, so that projects being developed address the most pressing and important clinical problems currently facing patients and their carers – research that has a better chance of making a difference to patients, sooner rather than later, and all the while helping patients to have their voice heard.

This is the Bedside to Bench approach.

Vision: Our vision is to facilitate meaningful connection between health service providers, research organisations, industry and the communities for which they provide a service or aim to benefit.

Services and programs: Our services and programs are aligned with our five strategic goals across Capacity Building, Health Education and Health Promotion, Community Engagement, Anecdotal Evidence, and Research. We also have a fee-for-service program to support the implementation of research, into the clinic.

Outcome: The outcome will be that we will accelerate research through developing projects that have a better chance of being translated into the clinic; we will have a closer connection between the community, clinicians, researchers and industry; and as a nation, we have a better understanding of the value of research.

Unique value proposition: Previous attempts to involve the community in research have been over-politicised, and driven from the perspective of engaging patients without meaningful thought to the reason why the community needs to be engaged or how each stakeholder group can benefit from engaging the community.

The Centre for Community-Driven Research is an independent and unaffiliated organisation with one level of governance. We were established to be responsive to stakeholder needs, and deliver services that advance translational and clinical research through community engagement, in a timely and effective

# 3. Report on Strategic Goals

## SG 1 Health Education

Our health education campaigns are based around mother's day and father's day. These are times of the year when individuals are often looking for a meaningful way to celebrate the occasion. The focus of our Mother's Day campaign is the importance of knowing your family medical history. For some, the 'Listen to your mother' campaign provides families with an opportunity to talk with their mother about their family history and for others it is a way to remember their mother and talk with their family to develop their medical history together. A tool is provided which individuals are then able take to discuss with their family doctor.

This was the second year for our father's day campaign which reached just over 35,000 people. The health education message attached to this campaign is that when it comes to your health, it's ok to get a second opinion - even if it is just for piece of mind.

Our message focused on explaining to the community that healthcare providers often encourage second opinions, in fact this is an important sign of a good physician as they know that consulting with another doctor can help patients sort through their treatment options, answer questions and shed new light on how an illness or condition is affecting them. We also talk about when patients are diagnosed with a disease or illness, and how a second opinion can be important to confirm diagnosis and treatment options. At the very least, they may walk away with a renewed sense of confidence in their existing physician and in the choices they are making, or they may decide it is necessary to change physicians.

## SG 2 Community Engagement

In 2014 we conducted a research study to simply ask patients how they would like to be involved in the research process. The results suggested that patients and their families want to be involved in research, particularly at the beginning of the process when researchers are developing their ideas, however they felt that researchers needed more support to do this in a meaningful way.

This year we designed and tested a program that we call our "Bedside to Bench Program" – which included an education session for patient representatives to understand the research environment and how they can provide feedback to researchers, and a research feedback workshop for researchers to listen to the experience of patients and also gain feedback from patient representatives on their research projects. We will now develop the Bedside to Bench program into an online portal so that more people can access information to support more meaningful community engagement.

## SG 3: Research

The Centre for Community-Driven Research conducted a series of structured interviews and focus groups to understand the needs of patients with poor prognosis cancers. The most commonly cited challenge described by patients and family members was understanding how to access services within the health system.

As a result of our research, we developed our Support Service and Nurse Network Program. In 2015 we will pilot this program for pancreatic cancer patients in Australia, with the view to conduct future programs in other disease streams. The Program builds research and clinical care capacity in Australia. It has the potential to provide coordination of care to patients, improve quality of life through timely referral to services, and increase access to new or re-purposed therapeutics through recruitment to available clinical trials. This is the first network of its kind for pancreatic cancer patients and will mean that every pancreatic cancer patient in Australia has access to a specialist pancreatic cancer nurse to answer questions and help them navigate the health system.



CCDR Facebook campaign to encourage community engagement in research



Father's day campaign



A new office complete with new art



## 4. Organisation Structure and Management

The Centre for Community-Driven Research was registered in November 2012 and is a public company limited by guarantee, holding full charity status in Australia.

We operate under a constitution that includes a governance structure where the role of the Members is to elect the Core Directors. The process for electing members to the Board is outlined in our Constitution.

The names of each person who has been a board director during the year are: Paul Hendry (appointed 11.7.14); Ursula Hogben (appointed 5.12.13) Michael Hasenmueller; Tony Shaw (appointed 11.7.14); Rebecca Sutherland (appointed 11.7.14).

In 2014, the Centre for Community-Driven Research developed a series of new policies, that were adopted by the Board on 14 July 2014, to support the governance and operational aspects of the organisation.

To ensure that the internal controls are successful, systems were implemented to ensure that all staff and, where appropriate, volunteers are aware of their responsibility to ensure internal controls are operating properly and complied with.

The control environment has been created by setting policies and procedures that embrace the overall objectives of the organisation. Policies and procedures that have been developed to support the growth of the organisation and ensure good governance include the following areas:

- Human resources
- Financial Control and Financial Management
- Communication
- Governance

## 5. Financial Summary

The Centre for Community-Driven Research deliver services and operations on a limited budget. In-kind human resources including the CEO and interns were provided to the value of \$342,000.

INCOME	
Grants and service fees received	31,446
Donations received	100,064
<b>TOTAL INCOME</b>	<b>131,510</b>
LESS EXPENDITURE	
Accounting fees and bank charges	4,117
ASIC and business fees	3,469
Communication and awareness	1,742
General expenses	880
Health education	5,480
IT costs	1,810
Office rent	3,275
Office equipment and running costs	1,456
Research costs	19,357
Staff costs	36,051
Travel and accommodation	2,406
<b>TOTAL EXPENDITURE</b>	<b>77,290</b>
<b>NET OPERATING PROFIT (LOSS)</b>	<b>0</b>
Retained profits at the beginning of the financial year	2,488
<b>TOTAL AVAILABLE FOR APPROPRIATION</b>	<b>54,219</b>
<b>RETAINED PROFITS AT THE END OF THE FINANCIAL YEAR</b>	<b>54,219</b>
2015 - 2016 Projected Income	300,000

## 6. New program for FY 2015-16

### Support Service and Nurse Network for pancreatic cancer

The Support Service and Nurse Network Program builds research and clinical care capacity in Australia. It provides coordination of care to patients, improves overall survival through timely referral to services, and increases access to new or re-purposed therapeutics through recruitment to clinical trials. It can be implemented in any disease stream, but we would like to start with pancreatic cancer. The reason for this is that it is the most lethal type of cancer. Only 4% of patients survive more than 5 years, and the average length of life after diagnosis is only 180 days. We won't be able to cure the disease, but for those 180 days, we want to make it easier for patients and their families.

For patients, the Network will mean that every patient will have access to a nurse that has expertise in their specific disease. The nurse will be networked with community services and support systems, so that patients and their families have access to care when they have completed treatment and after they are discharged from hospital. When at home, patients can also access a dedicated nurse via a telephone service, for those times when extra advice or support is needed. For the first time, there will not be any patients that fall through gaps.

The nurse network will be dedicated to Erica Ruck and Margaret Lees, a mother and daughter who both sadly died from pancreatic cancer. Erica was so supportive of the network approach and an advocate for more pancreatic cancer support. For nurses, we will provide training and support. Training will help to up skill a dedicated pool of nurses in specific disease streams, and build capacity in health care in Australia. Support will be in the form of peer support, where nurses will be able to learn from each other, and support each other in their roles.

The Network is held together by a coordinator that works closely with clinical trials groups, making sure that where trials are available, patients are made aware of them and provided with the opportunity to discuss participation. The Coordinator is also the point of contact for patients and nurses. This makes it easier for everyone to know that there is one person that they can go to, when they don't know who to turn to.

Key program components:

1. Nurse Network providing nurses with access to quarterly in-service professional development and peer support opportunities in the context of clinical research and access to services. This also includes an annual retreat.
2. In-Service Program for study sites to increase awareness of the role of the Network and how to access nurses working in coordination roles.
3. Evaluation of the Network and the impact of nurses working in coordination roles on patient outcomes, overall survival, referral to clinical trials.
4. Telephone Service – support for patients and their families to navigate the health system and ensure they have a documented care plan.

