

Faculty of Computing Health and Science

Research Unit Annual Report

RESEARCH UNIT NAME: The Western Australian Centre for Cancer and Palliative Care (WACCPC)

RESEARCH UNIT LEVEL (tick):

- Level I Research Group Level II Research Centre
 Level III Research Institute Centre of Excellence

YEAR:

BRIEF OVERVIEW (1-2 paragraphs outlining major activities conducted in past year)

The Western Australian Centre for Cancer and Palliative Care (WACCPC) research programs span both the cycle of life (birth to aged care) and the cycle of healthcare (including primary, acute, and palliative care). Research projects are initiated from clinical practice and key service agencies. The expertise of our researchers covers all aspects of the chronic disease and cancer journey - including the consumer perspective - from prevention, screening and early detection to diagnosis, treatment and follow-up. The WACCPC aims to improve health outcomes at a state, national and international level by fostering collaboration between researchers, to build capacity and enable the development of a series of pre-trial studies that will lead to large-scale, multi-site studies.

The WACCPC is a multidisciplinary research centre. A variety of research skills and expertise are available within the centre which also includes researchers who have previously worked as professionals within the healthcare industry including: Nursing, Public Health, Education, Radiotherapy and Psychology. Each of the key researchers conducts programs of research in conjunction with a variety of industry partners. Some of the researchers hold either joint or honorary positions within external community organizations and health related industries including: The Cancer and Palliative Care Network research and evaluation unit, The SolarisCare Foundation, Princess Margaret Hospital, Sir Charles Gairdner Hospital, Silver Chain Hospice Care, and other associations with the community such as Rotary and NGOs (Cancer Council, Diabetes WA, Heart Foundation).

MEMBERSHIP (Full Title of Researchers, including staff, research students, adjuncts in the past year)

Director - Professor Anne Wilkinson

Adjuncts – Dr Claire Johnson

Manager - Ms Jo Hale

Administrative officer - Mrs Helen Morris

Research officers - Dr Derrick Lopez; Ms Maria Fernandez; Mr Brad Pidgeon; Ms Tanya Pidgeon; Ms Ms Natasha Long; Ms Alison Rowley; Ms Joan Braskic; Jannie Piercy; Ms Tulsi Panchani; Ms Melissa Berg; Laurence Vogler.

Students - enrolled through School of Nursing, Midwifery and Postgraduate Medicine: Laurence Vogler; Peter Wilkinson; Kesaraporn Wenajak; Jonathan Mould; Leslie Andrew; Jessie Johnson (Canada).

NEW GRANTS (Identify Funding Body, Value of grant, Years funded, Chief Investigator, collaborators, title)

A Retrospective Cohort Pilot Study of Intensity of Care, Medical Decision-Making, and Costs in an Acute Care Hospital in Western Australia. (INTENSITY 3)

Chief Investigators: Prof Anne Wilkinson, Ms Helen Walker
Funding Body: Cancer and Palliative Care Research & Evaluation Unit (CaPCREU) and the Department of Health WA Cancer and Palliative Care Network, Sir Charles Gairdner Hospital
Funding Amounts: \$34,262 [WA Cancer and Palliative Care Network]
\$16,349 [CaPCREU]
Period of Funding: September 2010 - August 2011 [DoHWA Ca & Pall Network]
December 2010 - November 2011 [CaPCREU]

There is substantial international evidence that the complexity and intensity of medical care provided to hospitalized patients at the end of life is increasing. In addition, data from the US have identified a strong negative relationship between intensity of health care services and patients' perceptions of healthcare quality and patient and carer satisfaction, with higher intensity care resulting in lower patient/carer quality of care ratings and worse quality of life reports, regardless of age or disease category. The general consensus is that providing high intensity care to those who die is a waste of resources, of poor quality, inefficient, and leads to the inappropriate use of life-sustaining interventions that may be misaligned with patient or family preferences. However, these data remain controversial and situations where more intensive therapies are related to either survival or better outcomes are often ambiguous and poorly documented. Moreover, medical decision-making about treatment for terminally ill inpatients is a complex phenomenon and not well understood. It is not clear to what extent patient/family preferences, hospital culture and/or health professional's practice patterns influence care at the end-of-life.

The goal of this pilot project are to conduct an initial examination of end-of-life care and medical decision-making for a random sample of deceased patients in one tertiary hospital in Western Australia in order to test the feasibility of the research design and data collection instruments proposed for this project; to inform and improve health service delivery to terminally ill patients not referred to palliative care in the acute care hospital setting; and to provide pilot data for a two State NHMRC intensity of care at the end of life project grant proposal by the investigators in 2011. The specific research aims of this project are to:

- 1) conduct a medical record audit of a representative sample (n=270) of inpatients not receiving Silver Chain services (e.g., palliative care in the community), who are in the hospital at least 24 hours, are 18 years of age or older, who die at SCGH between May 15, 2011 to January 15, 2012 to evaluate medical decision-making, the patterns of care, and use of healthcare resources at the end of life during the last hospitalization;
- 2) conduct short (15 minute) semi-structured, audio-taped interviews (N=90) with the health professional (e.g., Registrar/Senior Resident/Senior Nurse) most involved in the decedents care during the last hospitalization to identify the clinical factors that may influence end-of-life medical decision-making;
- 3) conduct short (20 minute) semi-structured, audio-taped telephone interviews with a subsample (N=90) of the decedent's Next-of-Kin to understand more about patient and family factors that may influence end-of-life medical decision-making, and
- 4) conduct a cost analysis of the care provided to these inpatients to describe the associated health care costs of end-of-life care using WA hospital cost data.

Evaluation Plan Development for the CoNeCT Program; part of the WA Aged Care Directorate FINE Scheme – Friends in Need-Emergency (FINE).

Chief Investigator:	Prof Anne Wilkinson
Partner organisations:	Dept of Health of WA, Aged & Continuing Care Directorate
Funding Amount:	\$20,000
Period of Funding:	Jan- June 2011

The FINE scheme is a initiative partnering the public health and community sectors that supports a range of service including non-patient acute and complex care and the Government of Western Australia which aims to improve access to health care for older people and people with chronic conditions who could be cared for in their home rather than being admitted to hospital. This framework is targeting the metropolitan complex care coordination service – now known as the “**Complex Needs Coordination Team**” (CoNeCT). CoNeCT is a new service developed collaboratively across North Metropolitan Area Health Service and South Metropolitan Area Health Service under the auspice of the Department of Health (WA). Complex Care Coordination aims to provide a quality service that targets improving outcomes for patients and their carers whose care and support needs in the community are complex.

An evaluation to assess the degree to which the CoNeCT program meets the goals of the FINE scheme is being conducted under the auspices of the WACCPC and the Dept of Health of WA, Aged & Continuing Care Directorate. The proposed research is intended to inform policy makers and compliment a larger investigation of the range of FINE funded programs, focusing on value for money including financial acquittal and the impact of the programs. The proposed project will make a significant contribution to both policy and program service delivery by conducting a rigorous assessment of the efficiency and effectiveness of the CoNeCT model of care to ensure that public funds are being optimally managed.

An 18 month, quasi-experimental quantitative and qualitative pre/post research design, will assess the degree to which the CoNeCT program demonstrates improvements in patient/carer support, assistance, and appropriateness of service utilisation. Data collected in the usual provision of the service and quality activities will be reviewed in conjunction with information available from patient hospital records, linked data sets, and formal interviews of patients/carers and referrers by external researchers. Economic analysis will analyse the average cost per patient, return on investment (LoS, bed days, admission/presentation rates and program costs) and non-financial benefits including gap analysis within the healthcare system.

Investigating the Impact of an End-Of-Life Pathway on End-of-Life Care and Costs in an Urban Acute Care Hospital [Fremantle LCP Project]

Chief Investigator:	Prof Anne Wilkinson
Administering Institution:	ECU Industry Collaborative Scheme and the Department of Health WA Cancer and Palliative Care Network,
Funding Amount:	\$29,960 (ECU) \$20,000 + \$10,000 in kind (DoHWA Ca & Pall Network)
Period of Funding:	January 2011 – December 2011

Hospitals are by far the biggest user of financial resources in health, consuming almost 4 in every 10 dollars (39%) of recurrent health expenditure (which, in turn, makes up 95% of total health expenditures).[1] In Australia, 67 per cent of people die in hospital but only a small minority of them (11%) die in a designated palliative care bed. The majority of deaths today are neither sudden nor unexpected, yet the care provided to these patients is often poor.[2,7-13] Patients who die in a hospital or ICU have worse quality of life than those dying at home and their bereaved carers are at increased risk for developing psychiatric illness.[14-15] Nonetheless, improving end-of-life care in the acute care hospital has been shown to be extremely challenging, due to the availability of high-technology care and the authority wielded by local practice patterns on treatment intensity.[16-27] It has been suggested that high healthcare costs might be reduced

by decreasing the need and demand for medical services, particularly among terminally ill patients whose deaths are seemingly imminent and which could be anticipated. Efforts to improve both the quality and cost of health care generally have focused on fostering physician adherence to evidence-based clinical practice guidelines and reducing medical errors.[54]

The aim of this study is to determine whether the implementation of the Liverpool Care Pathway (LCP) in an urban, tertiary care hospital results in cost savings to the Department of Health WA. **The research questions to be addressed are:**

- 1) Does the implementation of the Liverpool Care Pathway (LCP) achieve cost savings in an urban, tertiary care hospital with its curative hospital culture?
- 2) Does the implementation of the LCP influence end-of-life multidisciplinary team decision-making for seriously ill patients? and
- 3) 3) Does the implementation of the LCP result in next-of-kin being more involved in end-of-life decision-making and more satisfied with end-of-life care?

This project will involve: 1) A retrospective medical record audit of a consecutive sample of 270 inpatient deaths in Fremantle hospital (135 pre LCP and 135 post LCP) to describe the patterns and costs of end-of-life care *before and after* the implementation of the LCP; 2) A retrospective survey of one member of the health care team (N=140; 70 pre/70 post) most involved in the deceased patient's end-of-life care to identify barriers/facilitators to the adoption of the LCP and the clinical and hospital-related factors associated with the healthcare Team's communication and medical decision-making *before and after* the implementation of the LCP; and 3) A retrospective interview with the deceased patients' next-of-kin to identify patient and family factors that may influence the acceptance of the LCP, reports of quality and satisfaction with end-of-life care *before and after* the implementation of the LCP. Potential cost savings can be estimated based on the results of the previous rural study. The number of deaths in the adult population aged 15 years and above in WA in 2008 was 12,593 (ABS, 2010). Assuming (i) 67% of people die in hospital and 11% die in a designated palliative care bed (Palliative Care Australia 2009) and (ii) similar cost savings are achieved from implementing the LCP in metropolitan hospitals as was achieved in rural hospitals, the potential cost savings from implementing the LCP throughout WA would be \$3.1 million.

Projects completed during 2010

An Outcome Evaluation of the Liverpool Care Pathway for Care of the Terminally Ill in Rural Western Australia.

Chief Investigators:

Co-CI's:

Professor Anne Wilkinson, Edith Cowan University.

Ms. Helen Walker, WA Palliative Care Program Coordinator, WA Palliative Care network; Dr. Claire Johnson, Ph.D., Research Fellow, Research and Evaluation Unit, WA Cancer and Palliative Care Network; Dr. David Dunwoodie, Palliative Care Consultant, Sir Charles Gairdner Hospital.

Funding organisation:

State Health Research Advisory Council (SHRAC), Department of Health, Government of WA: Research Translation Projects 2009/10

Funding Amount:

\$154,000.00

Description: Outcome, including costs, evaluation of the implementation of the Liverpool Care Pathway for the dying clinical guidelines implementation in 3 rural regions in WA.

Pilot Project Testing the Feasibility of Measuring Quality of Life in Dying Patients in the Acute Care Hospital.

Chief Investigators: Professor Anne Wilkinson, Edith Cowan University.
Co-CI's: A/Prof Anne Williams, WACCPC, Curtin University & Sir Charles Gairdner Hospital; Dr. Doug Bridge, Palliative Care Consultant, Royal Perth Hospital; Ms Helen Walker, Palliative Care Program Coordinator at the WA Dept. Of Health; Sir Charles Gairdner Hospital.

Funding organisation: WA Cancer and Palliative Care Network, Research and Evaluation Unit, Department of Health, Government of Western Australia

Funding Amount: \$11,756.00

Description: At present there is no baseline information concerning the quality of care being delivered to end-of-life patients in Western Australia. This project examines the feasibility of administering a patient-based QoL questionnaire at Royal Perth Hospital (RPH) and Sir Charles Gairdner Hospital (SCGH) in terminally ill patients.

Mapping Cancer Prevalence in Residential Aged Care Facilities in WA

Chief Investigator: Professor Anne Wilkinson, Edith Cowan University.
Co-CI's: Dr Ruth McConigley, WACCPC, Curtin University; Dr Jane Phillips, Cancer Australia.

Funding organisation: WA Cancer and Palliative Care Network, Research and Evaluation Unit, Department of Health, Government of Western Australia

Funding Amount: \$14,622.55

Description: There is little information currently available about the problem of cancer in the frail elderly RACF population. The aim of this project is to quantify the incidence and prevalence of cancer in residents living in RACFs in Western Australia. This project will use data from the WA Cancer Registry (Department of Health Western Australia) to determine the number of people living in RACF who have cancer and to a knowledge base that will be used to plan and implement programs to improve cancer care in this setting.

Consent to Medical Treatment Education Project.

Chief Investigators: Professor Anne Wilkinson, Dr. Moira Sim, Edith Cowan University.

AP's: Ms. Toni Wain, Edith Cowan University. Dr Eric Kong, BreastScreen WA, Dr. Roger Clarnette, Consultant Geriatrician for the McCuster Foundation for Alzheimer's Disease Research; Professor Cobie Rudd, Edith Cowan University.

Funding organisation: WA Department of Health

Funding Amount: \$18,000.00

Description: The Acts Amendment (Consent to Medical Treatment Act) 2008 will be fully proclaimed in 2009/2010. A range of health professionals will have an important role to play in implementing the Act in WA. This project will develop DVD based education materials for health care providers (primarily GPs), who will be tasked with implementing this legislation in WA.

PUBLICATIONS, REFERRED BOOKS, CHAPTERS, JOURNAL ARTICLES, CONFERENCE PAPERS, REPORTS

Prof Wilkinson has published two chapters in Advance Care Planning in End of Life Care; edited by Keri Thomas and Ben Lobo, and published by Oxford University Press in January, 2011. These book chapters focused on the state of the science around advance care planning and advance directives as well highlighting action research in the implementation of advance care planning in the US and Western Europe, which I believe is a major contribution to the advance care planning literature. As a result of this work, Prof Wilkinson have received international recognition as an expert on advance care planning and have been invited to be a Conference Ambassador to the second *International Society of Advance Care Planning and End of Life Care Conference*, chaired by Dr. Keri Thomas, the internationally known developer of the Gold Standards, to be held in London, UK on June 22-24, 2011 (See [acpelsociety.pdf](#) attachment).

ECU and the Cancer Council WA received also national attention with the publication of Prof Wilkinson's article on cancer caregiving at the end of life in a special issue of the journal Cancer Forum, published by Cancer Australia (pdf of article attached). This article was selected from among the 10 articles in the special issue to be highlighted in a media release by Cancer Australia. As a result of the media release, prof Wilkinson was asked to appear on the ABC News Breakfast program on July 8, 2010, where she was interviewed on national television about issues facing cancer caregivers. In addition, the media release was also summarized in three articles written for the West Australian (July 12, 2010), the Australian Doctor (July 14, 2010), and a second media release for Media Monitors, which has a circulation of almost 200,000 individuals in the Perth metropolitan area (See PR attachments).

Conferences Attended and Papers Presented 2010	
The Gerontological Society of America's 63rd Annual Scientific Meeting, Hilton Hotel, New Orleans, LA, USA; November 19-23, 2010	2 Paper Presentations and 2 Session organizer
Clinical Oncology Society of Australia Annual Scientific Meeting, Melbourne Convention and Exhibition Centre, November 9-11, 2010.	Poster Presentation
Public Health Association Australia (WA Branch), State Conference, East Fremantle, WA, November 18-19, 2010.	Paper Presentation
Public Health Association of Australia Annual Meeting, Fremantle, WA, November 18-19, 2010.	Oral Paper Presentation
ECU Research Week, Joondalup Campus, August 16-20, 2010.	Invited Oral Presentation
Inaugural International Advance Care Planning Conference, Melbourne Convention and Exhibition Centre, April 22-24, 2010.	Paper Presentation and Seminar Organizer

HIGHER DEGREE BY RESEARCH LOAD (list name of candidate and degree type)

Professor Anne Wilkinson is now Principle or Co-Supervisor to four higher degree students, with one Ph.D. student set to graduate within the next year.

List of students

Laurence Vogler	Ph.D. research	principal supervisor
Peter Wilkinson	Ph.D. research	principal supervisor
Kesaraporn Wenajak	Ph.D. research	2nd supervisor
Jonathan Mould	Ph.D. research	2nd supervisor
Leslie Andrew	Ph.D. research	2nd supervisor
Jessie Johnson	Ph.D. research	principal supervisor (Canada).

HIGHER DEGREE BY RESEARCH COMPLETIONS (List name, degree, title of thesis)

nil

VISITORS AND COLLABORATIONS (List the organisation's name and short summary of the nature of the collaboration. Separate into local, national and international)

Local

The largest of our new projects involve combined funding from the State Health Research Advisory Council (SHRAC) Research Translation Project funding and monies from the Cancer and Palliative Care Network to conduct a formative and substantive program evaluation of the implementation of the Liverpool Care Pathway clinical guidelines for the last few days of life in three rural regions in WA. This work is a result of the robust community engagement and collaboration activities we have pursued with the WA Cancer and Palliative Care Network and the WA Department of Health as well as the assembling of a highly competent collaborative research team. In addition, we have secured three smaller grants and contracts that will serve as pilot projects for larger research projects in the future. **Helen Walker**, Program Coordinator, WA Cancer and Palliative Care Network, WA Department of Health, Perth, Australia;

Dr. Delia Hendrie, Associate Professor, Centre for Population Research, University of Western Australia;
Dr. Claire Johnson, Research Fellow, Research and Evaluation Unit, WA Cancer and Palliative Care Network, WA Department of Health;

Dr. Tapan Rai, Statistician, Faculty of Computing, Health and Science, ECU; Associate Professor David Preen, Director, Centre for Health Services Research, School of Population Health, The University of Western Australia;

Dr Margherita Nicoletti palliative care consultant and director Murdoch Community Hospice

Dr. David Dunwoodie, Palliative Care Consultant, Sir Charles Gairdner Hospital.

Ms Deborah Murphy, the Associate Director Marie Curie Palliative Care Institute Liverpool (MCPCIL), Lead Nurse - Liverpool Care Pathway, UK.

WA Government; Department of Health, Aged Care Policy Directorate, Innovation and Health System Reform. Research and program development consulting/advice on development of the Friend In Need – Emergency (FINE) scheme. The FINE scheme supports a system wide program to develop and enhance the capacity of non in-patient acute and complex care in the community by applying \$84 million over four years to strengthening and establishing community based services across metropolitan Perth. This initiative aims to build on the current framework and network of service provision, and is to be subject to a rigorous evaluation of effectiveness (June, 2008 – present).

Ms Noellene Foster, Acting Policy Officer, Aged and Continuing Care Directorate; Department of Health WA;

Mr Brian Piercy, Aged and Continuing Care Directorate, Department of Health WA;

Ms Gail Miller, Aged and Continuing Care Directorate, Department of Health WA.

Executive Committee Member, Research and Evaluation Unit, WA Cancer and Palliative Care Network, WA Department of Health.

Dr. Claire Johnson, Research Fellow, Research and Evaluation Unit, WA Cancer and Palliative Care Network, WA Department of Health;

Professor Samar Aoun, Co-Director with me of the Western Australia Centre for Cancer and Palliative Care Research, Curtin University of Technology;

Other collaborations

Associate Professor David Preen, Director, Centre for Health Services Research, School of Population Health, The University of Western Australia;

Dr. Anil Tandon, Palliative Care Physician, Palliative Care Consult Team, Sir Charles Gairdner Hospital, Perth, Australia;

Dr. Doug Bridge, Palliative Care Physician, Palliative Care Consult Team, Royal Perth Hospital, Perth, Australia;

Professor Jane Ingham, MB BS FRACP FACHPM, Academic Chair in Palliative Medicine at the University of NSW and Director, Cunningham Centre for Palliative Care, Sacred Heart Centre, St Vincent's Hospital, Sydney, Australia;

Professor Dianne O'Connell, biostatistician/epidemiologist, Cancer Council NSW;

Professor Patricia Davidson, RN BA Med PhD, Director, Centre for Cardiovascular and Chronic, Curtin University of Technology, Sydney Campus. She is Co-Chair of the NSW Clinical Expert Group for Cardiovascular Disease and a Co-Chair of the NSW Health Chronic Care Implementation Advisory Group;

Professor Afaf Girgis, Director, Centre for Health Research & Psycho-oncology (CHERP), the behavioural research unit of the Cancer Council NSW, Sydney, Australia and a conjoint Professor in the Faculty of Health, University of Newcastle;

David Goldsbury, MPH, BSc (Hons), statistician/data analyst, Cancer Council NSW, Sydney, Australia;

Professor Jane Phillips, RN, PhD Inaugural Chair of Palliative Nursing at The Cunningham Centre for Palliative Care and The University of Notre Dame, Australia at the Sydney Campus. She is the co-chair of the Cancer Institute, NSW EviQ Palliative Care Committee, St. Vincent's Hospital, Sydney, Australia;

Melissa Pigot BSc (Hons), research development, implementation, statistical evaluation and dissemination at the Cancer Council NSW, Sydney, Australia;

Associate Professor Deborah Parker, Acting Director of Blue Care Research & Practice Development Centre and Director, Australian Centre for Evidence Based Community Care, School of Nursing and Midwifery, The University of Queensland, Queensland;

Dr. Peter Hudson, Professor and Director, Director, Centre for Palliative Care Education & Research, St. Vincent's Hospital and the University of Melbourne, Victoria; and Director, International Palliative Care Family Carer Research Collaboration, International Palliative Care Family Carer Research Collaboration.

Dr. Karl Lorenz, MD MSHS VA Greater Los Angeles Healthcare System Director, VA Palliative Care Quality Improvement Resource Center (QuIRC) 11301 Wilshire Blvd, Code 111-G Los Angeles, CA

Dr. Joanne Lynn Palliative Care Physician and Quality Improvement Consultant 2134 Ashbury Rd. Chevy Chase Md.

Member/peer reviewer/ Mentor/Supervisor

Member, Cancer and Palliative Care Network, Department of Health, WA Government advisory body.

Member, Research and Higher Degrees Committee; Faculty of Computing, Health and Science, Edith Cowan University.

Peer Review, RIBG ECU funding applications (2008- present).

Peer Reviewer, Research Australia Philanthropy, Suite 2, Mezzanine, 257 Collins Street, Melbourne VIC 3000, (June, 2007 – present).

Peer Reviewer, Collegian, Royal College of Nursing publication, a national nursing journal (June 2007 – present).

Peer Reviewer, Nurse Education Today (2008-present).

Peer Reviewer, Prostate Cancer Foundation of Australia, (2008-present).

Mentor/Supervisor; Interprofessional Leadership Certificate Program, School of Nursing, Midwifery, and Postgraduate Medicine, Faculty of Computing, Health and Science, Edith Cowan University.

COMMUNITY ENGAGEMENT ACTIVITIES AND LINKAGES (Provide a brief overview of any significant activity)

A notable characteristic of the Centre is its commitment to collaborative research with clinical partners and government organisations. Our researchers work closely with clinical colleagues to ensure that the research undertaken is relevant to practice. The majority of the Centre's projects have been developed in collaboration with The WA Cancer and Palliative Care Network and the Research and Evaluation Unit, and the majority of our data collection for projects is carried out in major public and private hospitals in WA, for example the centre recruited from 16 WACHS sites in WA (Midwest, Southwest, and Great Southern areas) for the Liverpool Care Pathway projects in 2010.

FUTURE PLANS AND DIRECTION (Provide an overview)

As Director of the WA Centre for Cancer and Palliative Care, a joint research centre with the Curtin University of Technology, the combined researchers from both sites have worked collaboratively to ensure that the Centre can function effectively and have created enhanced opportunities for collaboration within Western Australia.

The Centre benefits the School of Nursing, Midwifery, and Postgraduate Medicine by: establishing a sustainable pattern of research income to support Centre activities, playing an active role in the promotion, organization, and support of postgraduate teaching activities and collaborative research projects; performing research and consultancy functions supported at the Faculty level and attracting external resources; establishing a nexus between teaching and research while enhancing the School's capacity for research training and education at the graduate and undergraduate levels resulting in improvement in RAI returns, obtaining ongoing financial support and recognition from the Cancer Council of WA, national, regional, and local community recognition for the support and leadership provided to the Centre, the development of collaborative research projects among the research staff within the School.

In addition, the Centre benefits the Edith Cowan University community by: raising the public profile of the Centre's research activity locally, regionally, and nationally; enhancing the role of the University in the local and regional community by responding to community needs and the development of joint research and demonstration projects addressing local and regional community needs, by creating integrated and sustainable University/Community engagement initiatives that build both the organizational and community capacity around palliative and supportive care, and through the development of collaborative research projects among the research staff within the University and other national and international academic institutions.

Areas of research activity that the WACCPC is pursuing include

- 1) the initiation of a new line of inquiry concerning the role of palliative care in natural and man-made disasters and mass casualty events (MCE's); The initiation of new work concerning the role of palliative care in mass casualty events is the result of pilot work conducted in the US and was part of a larger effort supported by the Agency for Healthcare Research and Quality (AHRQ), DHHS, to define and plan for the "altered standards of care" considered inevitable during a mass casualty event. professor Wilkinson and colleagues developed a major chapter in a community planning guide and recently published this work in a major national security journal (e.g., Bioterrorism and Biosecurity). This work is of international import, describes a new area of policy/research and applied work in palliative care and disaster management, and has led to the generation of collaborative work here in Australia, including Andrew Johnson, EDMS at TTH, Chair of the Emergency Planning Committee; Peter Aitkin and Nick Tonte-Filipinni, Queensland University of Technology; Paul Arbon, Head, School of Nursing, Flinders University; Dr. Kelly Kline, Maimonides Medical Centre, New York, New York, USA.
- 2) systematic review and applied research in advance care planning and advance directives; The initiation of new work concerning advance care planning and advance directives is a result of recent work Prof Wilkinson have done in the US systematically reviewing the evidence base supporting the application of advance directives in Western societies. While advance directives are an important legal tool for patients to state their treatment preferences and to name a surrogate decision-maker, research conducted on the impact of advance directives has generally concluded that ADs have not been very effective in reducing unwanted aggressive medical treatments or costs at the end of life. There is a need to consolidate the existing evidence, garner insights from experts, advocates, providers, consumers and their families in order to generate consensus on the "best practices" in AD/ACP, applicability in special populations (e.g., intellectually/ physically disabled), identify ethical, legal, racial, ethnic and multicultural issues and define methodologies concerning the broader social acceptance and promotion of ADs and ACP. In particular this expertise will prove valuable as Western Australia implements its new Living Will legislation.
- 3) exploration of the issues generated for caregivers to patients with advanced chronic illness. The initiation of a new line of inquiry exploring the issues for caregivers to patients with advanced chronic illness also

arises from previous work conducted in the US. Given Prof Wilkinson's gerontological expertise, we believe there is a window of opportunity to greatly expand that arm of the Centre's research agenda based at ECU. This is an established national priority area and looks to be an area poised to receive additional funding from the Commonwealth, given the ageing of Australia's population and of many other populations around the world. Prof Wilkinson and colleagues in Australia and the US have a global network of research collaborators in this area (e.g., in the US and UK specifically) that can support international projects. This expertise will assist ECU in building on its current strength in dementia research by further developing the capacity so that it becomes recognized as unique within Australia and a recognized global contributor. Collaborators include Chris Toye, Curtin University of Technology; Ralph Martins, ECU, Sandy Berry, MS, Senior Behavioral and Social Scientist, The RAND Corporation, Santa Monica, CA, USA ; Dr. Kate Burns, Ph.D., and David Currow, Department of Palliative and Supportive Services, Flinders Centre for Clinical Change, Flinders University; Trish Davidson, Ph.D., RN, Professor and Director, the Centre for Cardiovascular and Chronic Care, School of Nursing and Midwifery, Curtin University of Technology, New South Wales.

DATE OF NEXT FORMAL REVIEW

12 months