



## Faculty of Computing Health and Science

### Research Group, Research Centre or Research Institute Report

**RESEARCH UNIT NAME:** The Western Australian Centre for Cancer and Palliative Care

**RESEARCH UNIT LEVEL (tick):**

Level I Research Group:

Level II Research Centre:

Level III Research Institute:

Centre of Excellence:

**REPORT TYPE: ANNUAL REPORT**

**YEAR: 2009**

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**BRIEF OVERVIEW** (1 – 2 paragraphs):

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):

The WACCPC consists of 6 researchers, 40 research staff, and 14 post-graduate students, who are supported by a vast team of over 60 associate members.

ECU staff include:

Director - Professor Anne Wilkinson

Manager - Ms Jo Hale

Administrative officer - Mrs Helen Morris

Research officers - Dr Derrick Lopez; Dr Caroline Bulsara; Dr Judith Pugh; Ms Maria Fernandez; Mr Brad Pidgeon; Ms Jannie Piercy.

The research they are conducting is focused in the area of health, which directly aligns with the University's strategic plan. The collaborators in the WACCPC have well established relationships with key national and international research leaders, as illustrated by their impressive project and publication record.

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

**The WACCPC ECU team have been able to secure approximately \$407,000.00 in grants, contracts, and income in 2009. Through these grants and contracts we have been able to start to rebuild the research capacity within the WACCPC and the ECU School of Nursing and to provide numerous research opportunities and support for recently degreed and current higher degree students.**

**ECU projects**

- **An Outcome Evaluation of the Liverpool Care Pathway for Care of the Terminally Ill in Rural Western Australia. Chief Investigators: Professor Anne Wilkinson, Primary CI, Edith Cowan University. Co-CI's 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 Giardner Hospital. State Health Research Advisory Council (SHRAC), Department of Health, Government of WA: Research Translation Projects 2009/2010 - \$154,000.**

**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.**

- **A Baseline Evaluation of the Liverpool Care Pathway for Care of the Terminally Ill in Rural Western Australia.** Chief Investigators: Professor Anne Wilkinson, Primary CI, Edith Cowan University. Co-PI's 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. Cancer and Palliative Care Network, Department of Health, Government of WA. 2009/2010 - \$108,501.

**Description:** Formative/Process evaluation of the pre-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, Primary CI, Edith Cowan University. Co-PI's: A/Prof Anne Williams, 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. WA Cancer and Palliative Care Network, Research and Evaluation Unit, Department of Health, Government of Western Australia. 2009/2010 - \$11,756.

**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 Investigators: Professor Anne Wilkinson, Primary CI, Edith Cowan University. Co-PI's: Dr Ruth McConigley, WA Centre for Cancer and Palliative Care, Curtin University; Dr Jane Phillips, Cancer Australia. WA Cancer and Palliative Care Network, Research and Evaluation Unit, Department of Health, Government of Western Australia 2009/2010 - \$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. PI's: Ms. Toni Wain, Edith Cowan University. Dr Eric Kong, BreastScreen WA, Dr. Roger Clarnette, Consultant Geriatrician for the McCusker Foundation for Alzheimer's Disease Research; Professor Cobie Rudd, Edith Cowan University. WA Department of Health \$18,000.

**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.

#### **Other Projects**

- **The Home Heart Walk Study.** Chief Investigators: Professor Patricia Davidson, Primary CI, Curtin University. Co-CI's: Yenna Salamonsen and Bronwyn Everett, Univ. of Western Sydney; Phillip Newton & Hui Yn Du, Curtin University. AP's: Professor Anne Wilkinson, Edith Cowan University; David Currow, Flinders University; Peter Macdonald, St. Vincent's Hospital. National Health and Medical Research Council (NHMRC), Commonwealth of Australia. 2009/2011 - \$180,000.

**Description:** An RCT assessing the reliability and viability of the Home-Heart-Walk test, adapted from a standardised 6-minute walk test protocol for self-administration.

- **Palliative Care for Cancer Patients Living at Home: Palliative Care Community Medications Project.** Chief Investigators by State: Western Australia: Professor Moyez Jiwa; Professor Anne Wilkinson; Dr Moira O'Connor; Dr Georgia Halkett; Dr Colleen Fisher. New South Wales: Professor Afaf Girgis; A/Professor Tim Shaw; Professor Patricia Davidson. Victoria: Professor Roger Nation; Professor Michael Dooley. Queensland: Professor Michael Roberts; A/Professor Geoff Mitchell; Dr Julie Stokes. Pharmacy Guild Australia. 2008/ 2010 - \$673,233 .

**Description:** The need for this project has been identified within Western Australia. A state palliative care review in 2005 culminated in "The Palliative Care in WA. Final Report December 2005," which made 48 recommendations to improve palliative care across the state. The purpose of this project is to: Develop and implement medication protocols that are specific to palliative care across Western Australia, Standardise availability of palliative care medications, Establish links between regional community pharmacies and palliative care teams with additional support available from metropolitan specialists, Develop and implement strategies for medication management by terminally ill people and their family living in the community.

- **Low Literacy Spousal Caregiver Support Call Centers.** Chief Investigators: Dennis V. Ary, Ph.D. and Amy Birney, Senior Fellow, Primary CIs; Oregon Research Center Center for Applied Science, University of Oregon, Eugene, Oregon, USA. AP's: Professor Anne Wilkinson, Edith Cowan University. Administration on Aging (AoA), US Department of Health and Human Services (HHS). 2008/2009 - \$350,000.

**Description:** Call centers for private sector disease management organizations are moving into a care coordination role with the Medicare population. Materials are needed to help coaches assist senior spousal caregivers in fulfilling and maintaining their roles as adherence facilitators for the patient. This project will develop CG education

materials and staff modules needed for call center coaches, including training, surveys, talking points, VHS, DVD-video, print, and support materials.

- **Prospective Study of Medical Emergency Team (MET) Calls to Define Issues of End of Life Decision-Making, Symptoms and Transition in Goals of Care.** Chief Investigators: Dr.s Meera Agar, Braeside Hospital and Professor Ken Hillman, University of New South Wales and Liverpool Hospital. Co-CP's: Dr. Louise Elliott, Dr. Jennifer Wiltshire, Dr. Jack Chen, Jayne Stevenson, Dr. Rebecca Strutt, Liverpool Hospital, Jeneane Harlum, Braeside Hospital; Dr. David Currow, Flinders University, A/Prof Liz Lobb, Calvary Health Care; Anne Wilkinson, Edith Cowan University. AI's: Dr. Amanda Walker, SSWAHS Area Palliative Care Services, NSW. National Health and Medical Research Council (NHMRC), Commonwealth of Australia: NHMRC Palliative Care Research Development Grant. 2009/ 2010 - \$85,000.

**Description:** This study aims to explore the interface between the roles of the MET and palliative care teams and expand the outcomes of the medical emergencies to include symptom control and improved communication in persons with life limiting illness.

#### **PUBLICATIONS, REFEREED BOOKS, CHAPTERS, JOURNAL ARTICLES, CONFERENCE PAPERS, REPORTS:**

- **Advance Care Planning: The US Experience.** In Keri Thomas and Ben Lobo (Eds.), *Advance Care Planning*. Oxford University Press. (In Press). London, England. Expected Publication: December 2009. Author: Professor Anne M. Wilkinson, Ph.D., M.S. Book Chapter

and

- **A Common Sense Guide to Improving Advanced Care Planning - From Theory to Practice.** In Keri Thomas and Ben Lobo (Eds.), *Advance Care Planning*. Oxford University Press M.S. London, England. (In Press). Expected Publication: December 2009. Author: Professor Anne M. Wilkinson, Ph.D.,

A practical but comprehensive text and guidebook on advance care planning, including pragmatic guidance and worked examples, presentation of sound evidence, and experiential learning to enable the extensive adoption of best practice.

- **Decision-Making at the End-of-Life.** In Deborah Carr (Ed.), *Encyclopedia of the Life Course and Human Development*, Vol. 3. pp. 134-137. Authors: Anne M. Wilkinson and Moira Sim. ISBN: 978-0-02-866162-9. Book Chapter Gale Publishing, part of Cengage Learning. Framing Hills, MI, USA. January 2009. Compendium in 3 volumes examining three key life stages from a sociological perspective, exploring how enduring experiences, as well as transitions and events such as childcare, education, stress, marriage, career, addiction, friendship, parenthood, disease, spirituality, retirement and death influence the individual's life course.

- **The Carer Experience in End -Of -Life Cancer Caregiving: A discussion of the Literature.** Cancer Forum (In Press) Author: Anne M. Wilkinson
- **Palliative Care Considerations for Mass Casualty Events with Scarce Resources.** Authors: Marianne Matzo, Anne M. Wilkinson, Joanne Lynn, maria Gatto M., Sally Phillips. *Biosecurity and Bioterrorism: Bio-defense Strategy, Practice and Science*, 2009, Volume 7( 2): 199-210. This work is part of a larger effort supported by the Agency for Healthcare Research and Quality (AHRQ) to define and plan for the “altered standards of care” considered inevitable during a mass casualty event. This publication 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. This article is based on solicited and funded work by the Agency for Healthcare Research and Quality (AHRQ), US Department of Health and Human Services, US Government.

**Reviewers Comments:** Matzo and colleagues introduce the roles of palliative care in the response to catastrophic mass casualty events. These are valuable suggestions to planners at all jurisdictional tiers of response.

- **Caregiving to Advanced Chronic Illness Patients.** The abstract of this presentation was published in the *Journal of Nutrition, Health and Aging* in the proceedings of the 19th IAGG World Congress of Gerontology & Geriatrics, 2009, 13(Suppl 1): S672. Paper presented to the 19th International Congress of Gerontology and Geriatrics, Paris, France 5<sup>th</sup> – 9<sup>th</sup> July 2009.
- **Palliative Care for Mass Casualty Events with Scarce Resources.** Paper presented to the 16th World Congress of Disaster and Emergency Medicine, Victoria, BC, Canada 11<sup>th</sup>-15<sup>th</sup> May 2009.
- **Keynote Speaker: Advance Care Planning: What Does the Evidence Say?Dying at Home in Residential Aged Care,** Armandale Health Services, Palliative Care Division, 17<sup>th</sup> March 2009.

**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

**Professor Anne Wilkinson has also been able to attract junior researchers on my funded projects and am working with them to develop their own lines of inquiry and research agendas (Dr. Derek Lopez and Dr. Caroline Bulsara).**

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

N/A

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

The WA Centre for Cancer and Palliative Care researchers from both sites (ECU and Curtin) 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.

Example of New Strategic Partnerships: The WA Centre for Cancer and Palliative Care, with the support the Deputy Vice Chancellor (Research) have established concerted research relationships with colleagues across the country to form a "virtual" research alliance focused on developing and conducting the highest quality cancer and palliative care research. This new alliance will allow the ECU WACPCC to improve the research capabilities, research competitiveness and the ability to attract infrastructure funding for palliative and supportive care research in Australia by expanding its current partnership arrangements with Curtin University of Technology by establishing a virtual palliative care research collaborative that, initially, will include:

- Department of Palliative and Supportive Services, Flinders University, headed by Dr. David Currow and his clinical research team.
- The WA Centre for Cancer and Palliative Care at Edith Cowan University and Curtin University of Technology, headed by Professor Anne Wilkinson and Associate Professor Samar Aoun, and
- The Centre for Cardiovascular and Chronic Care, Curtin University of Technology, Sydney Australia, headed by Professor Patricia Davidson.

This partnership is designed to foster current areas of excellence that include health service evaluation and delivery, clinical trials and population-based planning in primary cancer care, supportive care, and palliative care. The longer term aim of the partnership is to establish a viable and sustained cancer and palliative care research presence between the partners in a way that will attract long-term funding to ultimately improve the quality of care offered to all Australians facing the last phase of life. The research expertise of all the parties is complementary and will allow for the development of a strong and comprehensive program of research focused on primary cancer care, population health issues related to cancer and palliative care, clinical trials related to advanced disease management, family-centered care, symptom management, quality of life, and family and caregiver issues. The alliance will provide a strong platform to foster the development of the next generation of researchers affiliated with this collaboration.

#### **COMMUNITY ENGAGEMENT ACTIVITIES AND LINKAGES** (Provide an overview)

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.

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).

Scientific Committee and Planning Committee Member, Together 2009! Cultural Connections for Quality Care at the End of Life, Palliative Care Australia International Conference, Perth, WA, 24-27 September, 2009.

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

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).

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

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).

#### **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**