

Palliative Care Studies

NISCHR CRC

November 2011



Table of Contents

1 RECRUITMENT.....	3
1.1 SUMMARY OF RECRUITMENT IN WALES INTO UK APPROVED PALLIATIVE CARE STUDIES.....	3
1.2 ALL WALES NCRN REPORTED PALLIATIVE CARE STUDIES RECRUITMENT BY STUDY AND HOSPITAL (FINANCIAL YEAR 2010/11).....	3
1.3 COMPARISON OF PALLIATIVE CARE STUDIES RECRUITMENT WITH NETWORKS IN ENGLAND 2010/11.....	5
2 APPENDICES	6
2.1 APPENDIX 1: NCRN PORTFOLIO – OPEN STUDIES AUGUST 2011.....	6
2.2 APPENDIX 2: ALL WALES NCRN REPORTED PALLIATIVE CARE RECRUITMENT BY STUDY AND MONTH (FINANCIAL YEAR 2010/11) BY REGIONAL NETWORK.....	7
2.3 APPENDIX 3: NCRN PALLIATIVE CARE PORTFOLIO – UK & WALES.....	7
2.4 APPENDIX 4: CONTACTS.....	10

Recruitment

1.1 Summary of Recruitment in Wales into UK Approved Palliative Care Studies

	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11
N Wales	0	0	0	0	0	0	1
SE Wales	0	0	0	2	3	43	64
SW Wales	0	0	0	0	0	0	5
TOTAL	0	0	0	2	3	43	70

1.2 All Wales NCRN Reported Palliative Care Studies Recruitment by Study and Hospital (Financial Year 2010/11)

North Wales	BANG	GCHR	WREX							Total
QUARTZ	0	1	0							1
Total	0	1	0							1

North Wales hospital codes:

BANG Bangor Hospital

GCHR Glan Clywd Hospital, Rhyl

WREX Wrexham Hospital

South East Wales	POW	CHW	UHWC	VEL	LLAN	NEVH	PCMT	RGH	RGL	Total
EPAT© (Jun-11)	0	0	0	57	0	0	0	0	0	57
Modafinil for Fatigue in Lung Cancer*	0	0	0	0	2	0	0	0	0	2
Pregabalin study (Apr-11)	0	0	0	2	0	0	0	0	0	2
QUARTZ	0	0	0	1	0	0	0	0	0	1
SCORAD	0	0	0	1	0	0	0	0	0	1
SCORAD III	0	0	0	1	0	0	0	0	0	1
Total	0	0	0	62	2	0	0	0	0	64

South East Wales hospital codes:

POW Princess of Wales, Bridgend

RGL Royal Glamorgan, Pontypridd

UHWC University Hospital of Wales, Cardiff

LLAN Llandough, Cardiff

RGH Royal Gwent Hospital, Newport

PCMT Prince Charles, Merthyr Tydfil

CHW Children's Hospital, Cardiff

VEL Velindre Hospital, Cardiff

NEVH Nevill Hall, Abergavenny

*Please note that this recruitment data is also reported in the Lung CSCG report

South West Wales	PPHL	WWGH	BRON	MOR	SING	WYBH				Total
NCRN177 - ACE: At home Compression Evaluation	0	0	0	0	5	0				5
Total	0	0	0	0	5	0				5

South West Wales hospital codes:

SING Singleton, Swansea

PPHL Prince Phillip, Llanelli

WYBH Witybush, Haverfordwest

BRON Bronglais, Aberystwyth

WWGH West Wales, Carmarthen

1.3 Comparison of Palliative Care Studies Recruitment with Networks in England 2010/11

Region	Network	Population (M)	Recruitment into Palliative Studies
England	Anglia - East NCRN	1	0
	Arden NCRN	1	27
	Avon, Somerset & Wiltshire NCRN	1.66	18
	Black Country NCRN	1	0
	Central South Coast NCRN	2.3	93
	Derby/Burton NCRN	0.8	18
	Dorset NCRN	0.7	0
	Essex NCRN	1.3	0
	Greater Manchester & Cheshire NCRN	3	119
	Greater Midlands NCRN	2.2	0
	Humber and Yorkshire Coast NCRN	1	29
	Kent & Medway NCRN	1.6	401
	Lancashire and South Cumbria NCRN	1.45	177
	Leics, Northants & Rutland NCRN	1.4	9
	Merseyside & Cheshire NCRN	2.4	0
	Mid Anglia NCRN	0.9	0
	Mid Trent NCRN	1.7	48
	Mount Vernon NCRN	1.6	70
	Norfolk and Waveney NCRN	0.7	0
	North East London NCRN	1.5	0
	North London NCRN	1.625	0
	North of England – North NCRN	2	57
	North of England - South NCRN	1	0
	North Trent NCRN	1.8	447
	North West Midlands NCRN	1.2	0
	Pan Birmingham NCRN	1.8	11
	Peninsula NCRN	1.5	68
	South East London NCRN	1.5	52
	South Essex NCRN	0.7	0
	South West London NCRN	1.75	92
	Surrey, W Sussex & Hampshire NCRN	1.1	0
	Sussex NCRN	1	0
	Thames Valley NCRN	2.5	126
Three Counties NCRN	1.1	76	
Unknown NCRN	-	31	
West Anglia NCRN	1.375	80	
West London NCRN	2.1	0	
Yorkshire NCRN	2.5	16	
England Total		55.76	2065
Wales	Wales - North	0.7	1
	Wales - South East	1.5	64
	Wales - South West	0.8	5
Wales Total		3	70

*= Greater Midlands and Essex populations excluded from England population total for duplication reasons as these have been recently formed and are made up of other NCRNs listed in the table.

2 Appendices

2.1 Appendix 1: NCRN Portfolio – open studies November 2011

UK

Cancer Site	Number of Trials	Percentage
Brain	12	2%
Breast	100	18%
CCLG	29	5%
Colorectal	48	9%
Gynaecological	34	6%
Haematological	57	10%
Head & Neck	21	4%
Lung	47	8%
Lymphoma	37	7%
Palliative Care	31	6%
Sarcoma	16	3%
Skin	18	3%
Upper GI	45	8%
Urology	59	11%

Wales

Cancer Site	Number of Studies	Percentage
Brain	2	1%
Breast	20	14%
CCLG	10	7%
Colorectal	10	7%
Gynaecological	6	4%
Haematological	20	14%
Head & Neck	6	4%
Lung	14	10%
Lymphoma	7	5%
Palliative Care	8	6%
Sarcoma	3	2%
Skin	3	2%
Upper GI	15	11%
Urology	18	13%

2.2 Appendix 2: All Wales NCRN Reported Palliative Care Recruitment by Study and Month (Financial Year 2010/11) by Regional Network

North Wales	2010									2011			Total
	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	
QUARTZ	0	0	0	0	0	0	0	1	0	0	0	0	1
Total	0	0	0	0	0	0	0	1	0	0	0	0	1
South East Wales	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Total
Diagnosis and Management of venous thromboembolism (VTE)	0	0	0	0	0	0	0	0	0	0	0	0	0
EPAT© (Jun-11)	1	6	1	10	4	9	7	5	3	5	2	4	57
Modafinil for Fatigue in Lung Cancer	0	0	0	0	0	0	0	1	1	0	0	0	2
Pregabalin study (Apr-11)	0	0	0	0	0	0	0	0	0	0	2	0	2
QUARTZ	0	0	0	1	0	0	0	0	0	0	0	0	1
SCORAD	0	1	0	0	0	0	0	0	0	0	0	0	1
SCORAD III	0	0	0	0	0	0	0	0	0	1	0	0	1
Total	1	7	1	11	4	9	7	6	4	6	4	4	64
South West Wales	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Total
NCRN177 - ACE: At home Compression Evaluation	0	0	0	0	0	0	0	0	0	0	2	3	5
Total	0	0	0	0	0	0	0	0	0	0	2	3	5
GRAND TOTAL	1	7	1	11	4	9	7	7	4	6	6	7	70

2.3 Appendix 3: NCRN Palliative Care Portfolio – UK & Wales

Open Palliative Care Studies

Acronym	Description	Open in Wales	Patient/s recruited to date in Wales
A pilot psycho-educational intervention for cancer carers	Development and Piloting of a Brief, Short-Term Psycho-Educational Intervention for Informal Carers of Patients at the End of Life		
Care in the last days of life: aspects of decision making	Care in the last days of life for people with cancer: aspects of decision making. A qualitative study of the perspectives of clinical staff and bereaved relatives		
Communication pathways surrounding people with cancer	Communication pathways surrounding people with cancer: who is involved, how do they communicate, and how do patients understand and manage this?		
Comparing GP and family experiences of palliative and bereavement care	Comparing general practitioners' experiences of providing palliative and bereavement care following the death of child with cancer, with the experience of the family.		
Developing a model of best practice for Cutaneous T cell lymphoma	Developing a model of best practice for people with Cutaneous T cell lymphoma (CTCL) and those of their caregivers: an investigation of multidimensional supportive and palliative care needs		
Development of KCH breathlessness service	Development, effectiveness and cost-effectiveness of a new respiratory and palliative care out-patient breathlessness support service		
EPAT©	Edinburgh Pain Assessment Tool - Does the institutionalisation of pain assessment using the EPAT© package reduce pain in cancer unit inpatients more than usual care: A cluster randomised trial	✓	✓
EURECA Version 1.2	Exploring, Understanding And Reducing Emergency Cancer Admissions		
Evaluation of Pilgrims Hospices Rapid Response Service	Evaluation of Pilgrims Hospices Rapid Response Community End of Life Service in East Kent		

KPS	Ketamine in Pain Study - A randomised double-blind controlled trial of ketamine versus placebo in conjunction with best pain management in neuropathic pain in cancer patients		
Modafinil for Fatigue in Lung Cancer	Modafinil for the treatment of fatigue in lung cancer: a multicentre, randomised, double-blinded, placebo controlled trial	✓	✓
Multifrequency Bioimpedance in the Early Detection of Lymphoedema	Multifrequency Bioimpedance in the Early Detection of Lymphoedema after Axillary Surgery		
NCRN137 - Sativex in relieving pain in patients with advanced cancer	A double blind, randomized, placebo-controlled, parallel group study of Sativex oromucosal spray (Sativex®; Nabiximols) in relieving pain in patients with advanced cancer, who experience inadequate analgesia during optimized chronic opioid therapy.		
NCRN154 - long term safety of Sativex in patients with cancer related pain.	A Multicenter, non-comparative, follow on study to assess the long term safety of Sativex oromucosal spray (Sativex ®; Nabiximols) therapy in patients with cancer related pain.		
NCRN177 - ACE: At home Compression Evaluation	At Home Evaluation of Two Pneumatic Compression Devices in the Treatment of Lower Extremity Lymphoedema (ACE: At home Compression Evaluation)	✓	✓
NCRN197 - Sativex in advanced cancer	A double blind, randomized, placebo-controlled, parallel group study of Sativex oromucosal spray (Sativex®; Nabiximols) in relieving pain in patients with advanced cancer, who experience inadequate analgesia during optimized chronic opioid therapy.		
NCRN294-APD515 xerostomia in patients with cancer	Randomised, double-blind, placebo-controlled Phase II proof-of-concept study of APD515 solution for oromucosal and oral administration for relief of xerostomia in patients with cancer		
NMES trial	Is neuromuscular electrical stimulation an acceptable and feasible supportive therapy for patients with non-small cell lung cancer receiving palliative chemotherapy?		
NOURISH - Pilot study 1	NOURISH - comparing Nutritional Outcomes Using Routine care v Interventional Support v beta-Hydroxy-beta-methylbutyrate / arginine/ glutamine		
PACE: Plans and Care Expectations. Version 1	PACE: Plans and Care Expectations of patients with incurable lung cancer and advanced Chronic Obstructive Pulmonary Disease (COPD), their lay supporters and health professionals.		
Patient and carers views of quality in end of life primary care	An exploratory study into patient and family carers constructions of quality in supportive and palliative district nursing care		
Phase III RCT BIS	Phase III randomised controlled trial of a breathlessness intervention service for intractable breathlessness.		
Pregabalin study	Double-blind randomised controlled trial of pregabalin versus placebo in conjunction with palliative radiotherapy for malignant bone pain	✓	✓
Prevention of Lymphoedema after Clearance by External Compression (PLACE)	Prevention of Lymphoedema after axillary clearance by early external compression		
Quality of life in multiple myeloma and follicular lymphoma	Quality of life in multiple myeloma and follicular lymphoma		
QUARTZ	A phase III multicentre randomised controlled trial to assess whether optimal supportive care (including dexamethasone) alone is as effective as optimal supportive care (including dexamethasone) and whole brain radiotherapy (WBRT) in the treatment of patients with inoperable brain metastases from non-small cell lung cancer (NSCLC).	✓	✓
RECC	The role of exercise in patients with cancer cachexia: a study of preferences, motivation and outcomes of importance in patients with cancer	✓	✓
Receiving end of life care at home	Receiving end of life care at home: experiences of the bereaved carers of cancer patients cared for by health care assistants		
SCORAD III	A randomised phase III trial of single fraction radiotherapy compared to multifraction radiotherapy in patients with metastatic spinal cord compression	✓	✓
SOBLC II: Shortness of Breath in Lung Cancer	A randomised trial of high versus low intensity training in breathing techniques for breathlessness in patients with malignant lung disease: early intervention	✓	✓

TIME3	Adjuvant Urokinase in the Treatment of Malignant Pleural Effusion: The Third Therapeutic Intervention in Malignant Effusion Trial (TIME3-UK). (A Randomised Controlled Trial to evaluate whether use of intrapleural Urokinase aids the drainage of multi-septated pleural effusion compared to placebo)		
-------	--	--	--

Studies in set up

Acronym	Description
CanTalk V3	CanTalk: the clinical and cost effectiveness of CBT plus treatment as usual for the treatment of depression in advanced cancer: a randomised controlled trial
Development of a HRQOL questionnaire for cancer patients with cachexia	Development of a health related quality of life questionnaire module to supplement the EORTC QLQC30 questionnaire for cancer patients with cachexia
NOURISH PHASE II TRIAL	Improving the management of cachexia in patients with advanced lung cancer: Does the introduction of betahydroxy betamethylbutyrate/ arginine / glutamine (HMB/ARG/GLN) supplementation maintain lean body mass and quality of life?
Nurses decisions to use anticipatory prescriptions	Understanding the role of nurses in decisions to use anticipatory prescriptions to manage symptoms and distress in the last days of life: a prospective community based case study using mixed methods

2.4 Appendix 4: Contacts

Research Network Managers and Clinical Leads

Position	Contact Name	E-Mail	Telephone
South East Wales Network Manager & NISCHR CRC Lead for Cancer	Sara Shankland	Sara.Shankland@wales.nhs.uk	029 2019 6193
South East Wales Clinical Lead	Vacant	Vacant	Vacant
North Wales Network Manager	Jackie Morris	Jackie.Morris2@wales.nhs.uk	01745 448681
North Wales Clinical Lead	Dr Simon Gollins	Simon.Gollins@wales.nhs.uk	01745 445161
South West Wales Network Manager	Jayne Caparros	Jayne.Caparros@wales.nhs.uk	01792 285200
South West Wales Clinical Lead	Dr Gian Filippo Bertelli	Gianfilippo.Bertelli@wales.nhs.uk	01792 205666 ext. 6412

Clinical Research Centre contact details

Position	Contact Name	E-Mail	Telephone
NISCHR CRC Deputy Clinical Director (Cancer)	Professor John Wagstaff	John.Wagstaff@wales.nhs.uk	01792 285299
NISCHR CRC Acting Director of Operations	Sue Figueirido	Susan.Figueirido@wales.nhs.uk	029 2031 6241
NISCHR CRC Lead for Cancer	Sara Shankland	Sara.Shankland@wales.nhs.uk	029 2019 6193
Information Manager	Ben Toth	Ben.Toth@wales.nhs.uk	029 2019 6853
Information Officer	Jennifer Keyte	Jennifer.Keyte@wales.nhs.uk	029 2019 6803
Training & Development Manager	Zoe Whale	Zoe.Whale@wales.nhs.uk	029 2019 6816

Website: www.wcrn.wales.nhs.uk

Please send feedback on this report to Jennifer Keyte, Information Officer (NISCHR CRC)