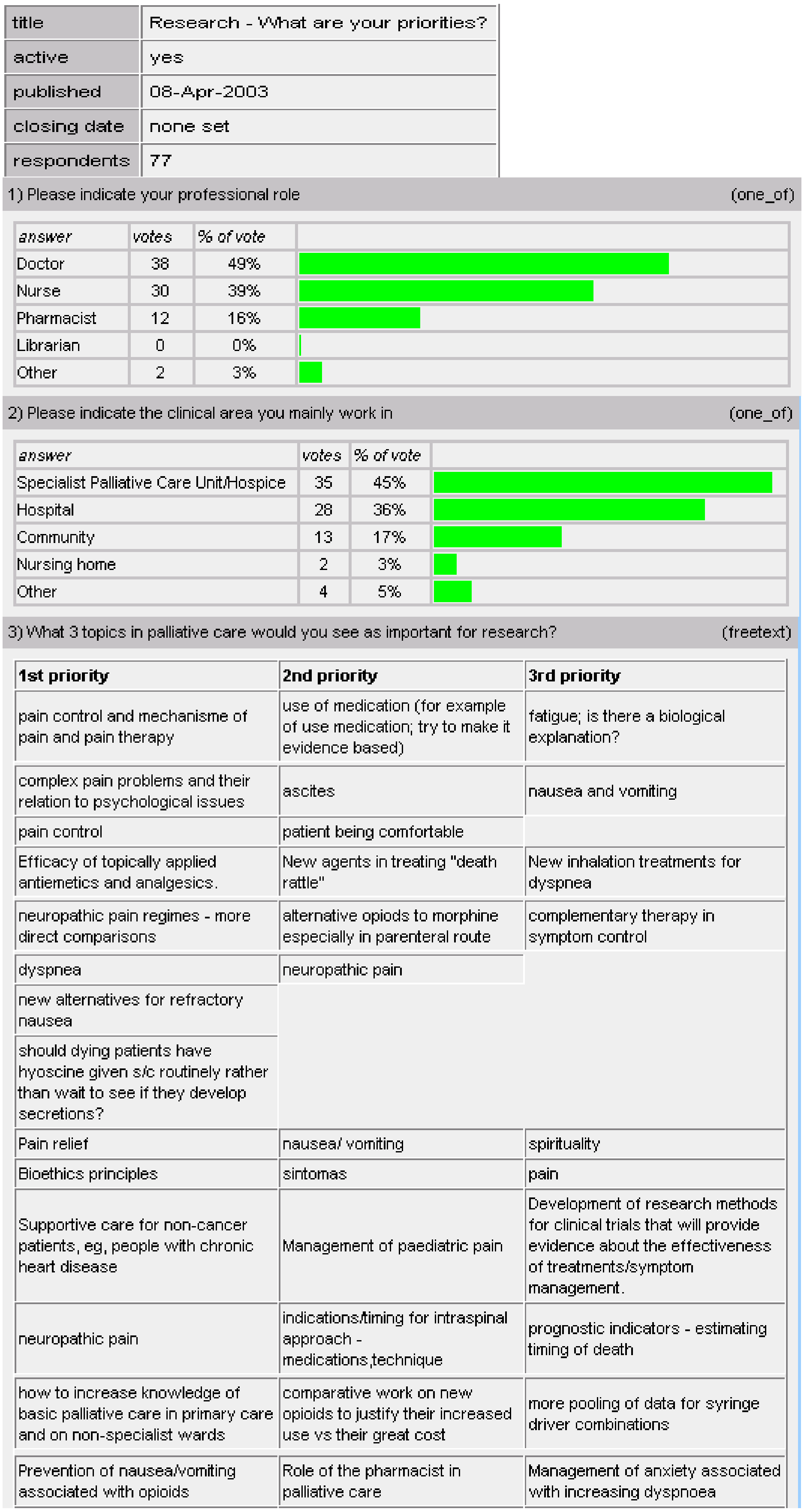


title	Research - What are your priorities?
active	yes
published	08-Apr-2003
closing date	none set
respondents	77

1) Please indicate your professional role (one_of)

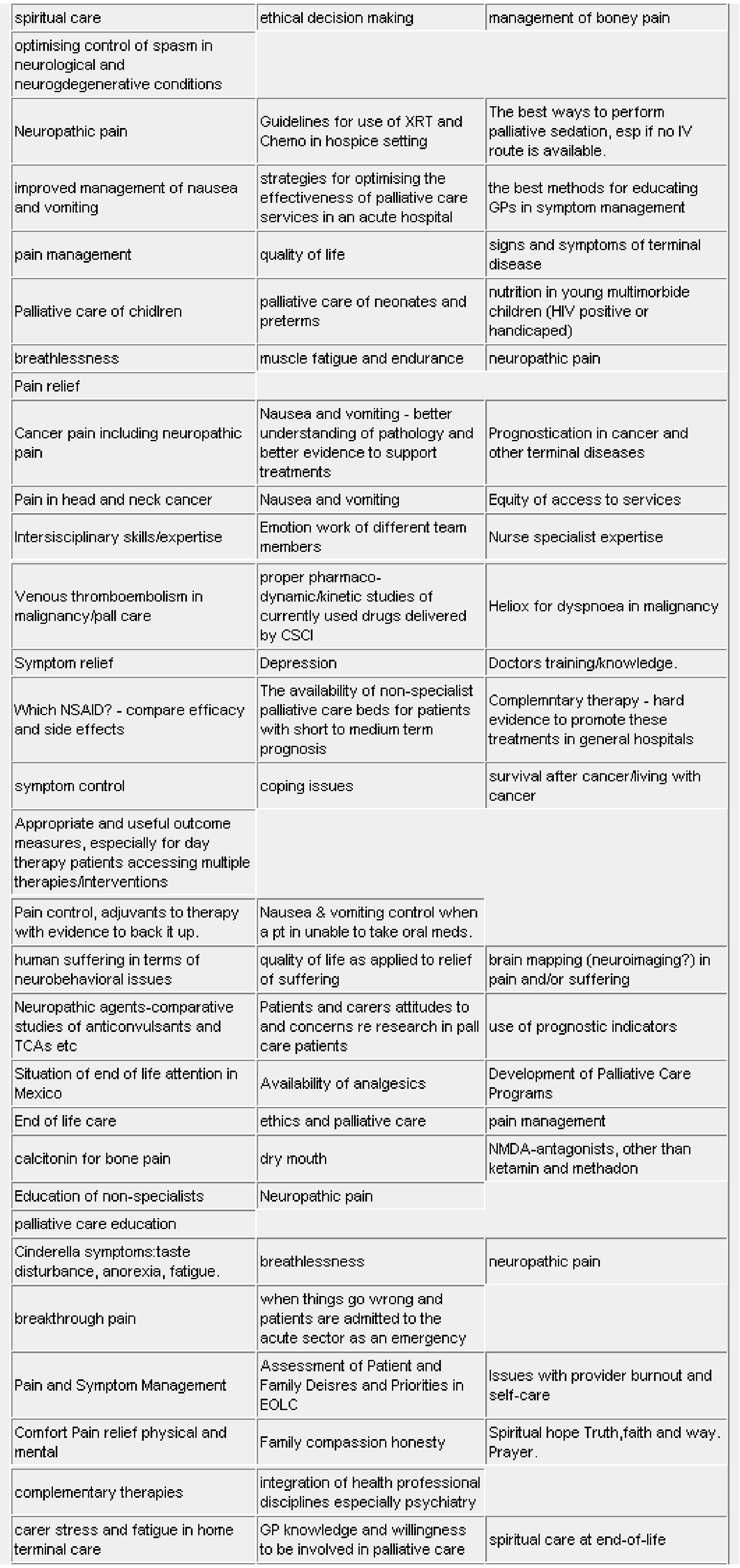
answer	*votes*	*% of vote*	
Doctor	38	49%	
Nurse	30	39%	
Pharmacist	12	16%	
Librarian	0	0%	
Other	2	3%	

2) Please indicate the clinical area you mainly work in (one_of)

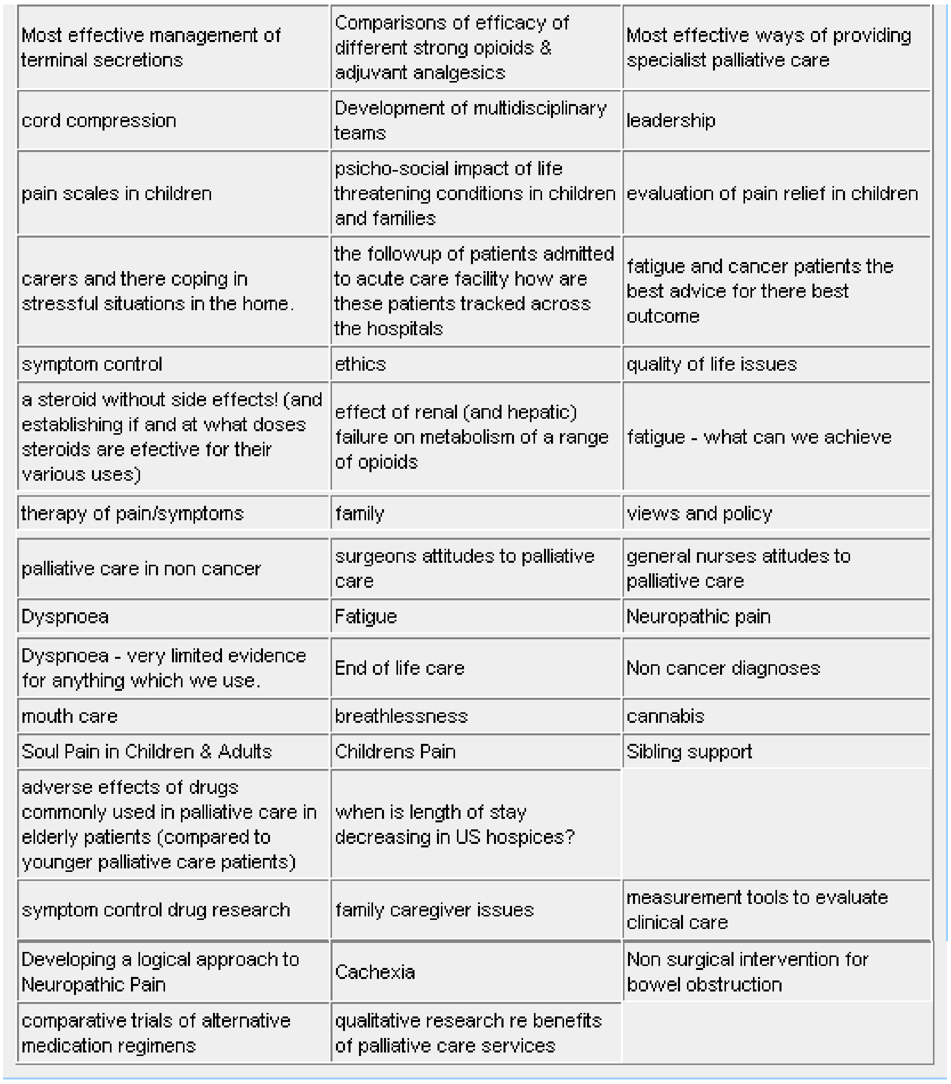
answer	*votes*	*% of vote*	
Specialist Palliative Care Unit/Hospice	35	45%	
Hospital	28	36%	
Community	13	17%	
Nursing home	2	3%	
Other	4	5%	

3) What 3 topics in palliative care would you see as important for research? (freetext)

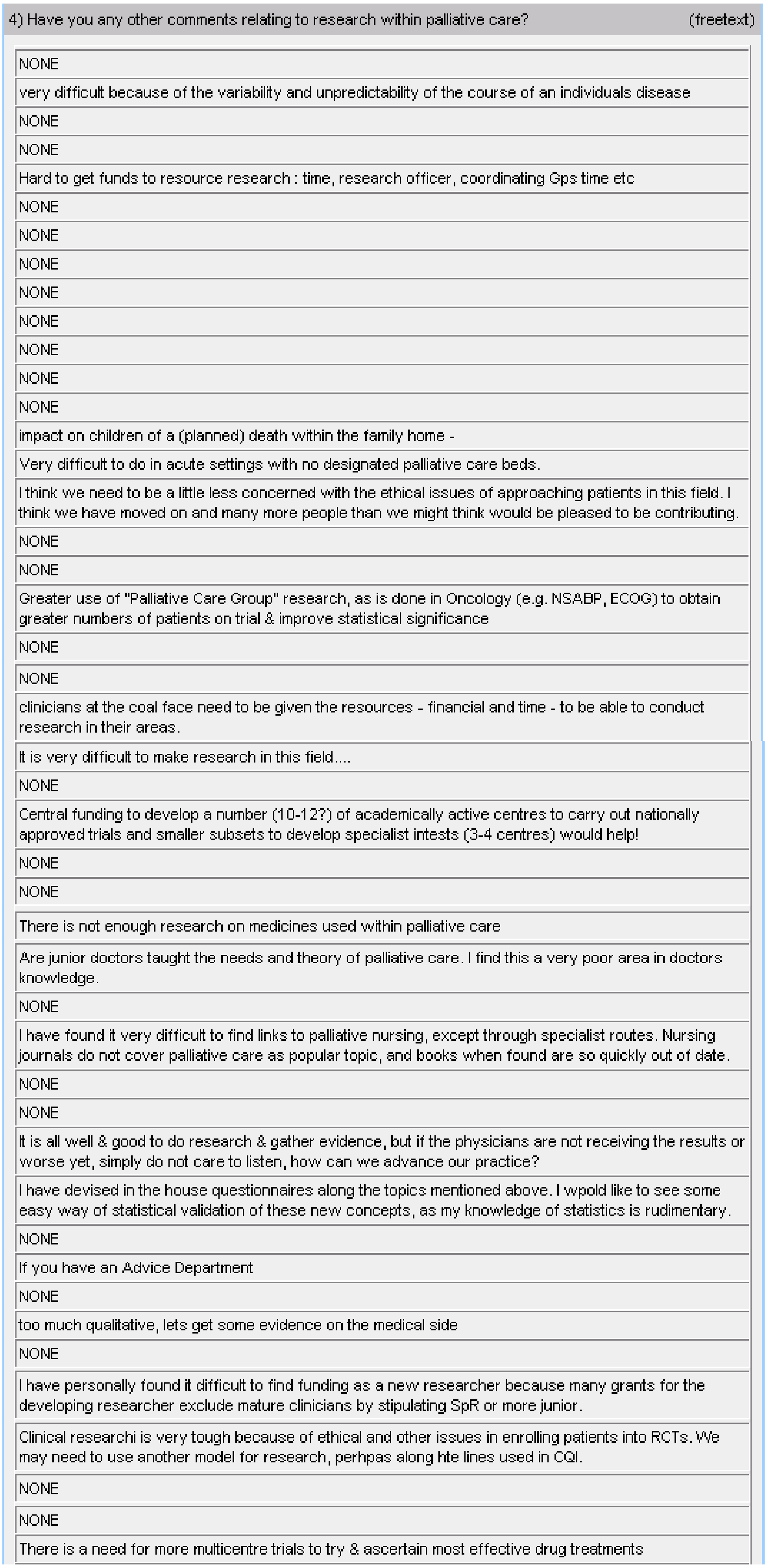
1st priority	**2nd priority**	**3rd priority**
pain control and mechanisme of pain and pain therapy	use of medication (for example of use medication; try to make it evidence based)	fatigue; is there a biological explanation?
complex pain problems and their relation to psychological issues	ascites	nausea and vomiting
pain control	patient being comfortable	
Efficacy of topically applied antiemetics and analgesics.	New agents in treating "death rattle"	New inhalation treatments for dyspnea
neuropathic pain regimes - more direct comparisons	alternative opiods to morphine especially in parenteral route	complementary therapy in symptom control
dyspnea	neuropathic pain	
new alternatives for refractory nausea		
should dying patients have hyoscine given s/c routinely rather than wait to see if they develop secretions?		
Pain relief	nausea/ vomiting	spirituality
Bioethics principles	sintomas	pain
Supportive care for non-cancer patients, eg, people with chronic heart disease	Management of paediatric pain	Development of research methods for clinical trials that will provide evidence about the effectiveness of treatments/symptom management.
neuropathic pain	indications/timing for intraspinal approach - medications,technique	prognostic indicators - estimating timing of death
how to increase knowledge of basic palliative care in primary care and on non-specialist wards	comparative work on new opioids to justify their increased use vs their great cost	more pooling of data for syringe driver combinations
Prevention of nausea/vomiting associated with opioids	Role of the pharmacist in palliative care	Management of anxiety associated with increasing dyspnoea



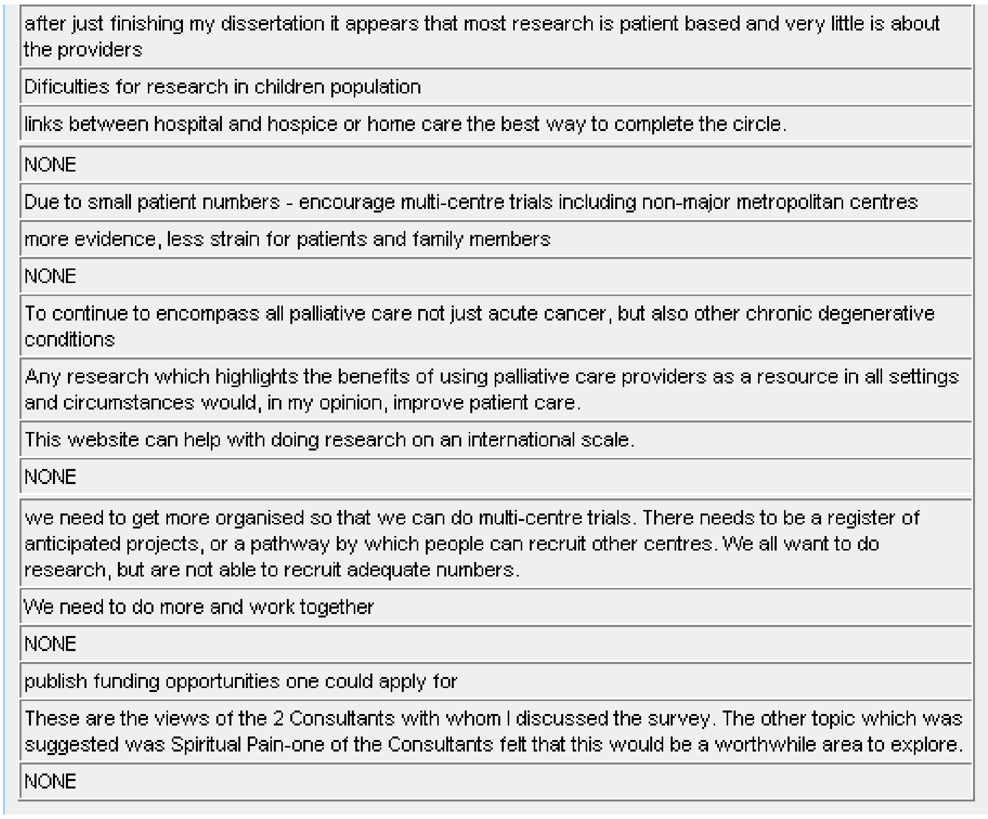
spiritual care	ethical decision making	management of boney pain
optimising control of spasm in neurological and neurogdegenerative conditions		
Neuropathic pain	Guidelines for use of XRT and Chemo in hospice setting	The best ways to perform palliative sedation, esp if no IV route is available.
improved management of nausea and vomiting	strategies for optimising the effectiveness of palliative care services in an acute hospital	the best methods for educating GPs in symptom management
pain management	quality of life	signs and symptoms of terminal disease
Palliative care of chidlren	palliative care of neonates and preterms	nutrition in young multimorbide children (HIV positive or handicaped)
breathlessness	muscle fatigue and endurance	neuropathic pain
Pain relief		
Cancer pain including neuropathic pain	Nausea and vomiting - better understanding of pathology and better evidence to support treatments	Prognostication in cancer and other terminal diseases
Pain in head and neck cancer	Nausea and vomiting	Equity of access to services
Intersisciplinary skills/expertise	Emotion work of different team members	Nurse specialist expertise
Venous thromboembolism in malignancy/pall care	proper pharmaco-dynamic/kinetic studies of currently used drugs delivered by CSCI	Heliox for dyspnoea in malignancy
Symptom relief	Depression	Doctors training/knowledge.
Which NSAID? - compare efficacy and side effects	The availability of non-specialist palliative care beds for patients with short to medium term prognosis	Complemntary therapy - hard evidence to promote these treatments in general hospitals
symptom control	coping issues	survival after cancer/living with cancer
Appropriate and useful outcome measures, especially for day therapy patients accessing multiple therapies/interventions		
Pain control, adjuvants to therapy with evidence to back it up.	Nausea & vomiting control when a pt in unable to take oral meds.	
human suffering in terms of neurobehavioral issues	quality of life as applied to relief of suffering	brain mapping (neuroimaging?) in pain and/or suffering
Neuropathic agents-comparative studies of anticonvulsants and TCAs etc	Patients and carers attitudes to and concerns re research in pall care patients	use of prognostic indicators
Situation of end of life attention in Mexico	Availability of analgesics	Development of Palliative Care Programs
End of life care	ethics and palliative care	pain management
calcitonin for bone pain	dry mouth	NMDA-antagonists, other than ketamin and methadon
Education of non-specialists	Neuropathic pain	
palliative care education		
Cinderella symptoms:taste disturbance, anorexia, fatigue.	breathlessness	neuropathic pain
breakthrough pain	when things go wrong and patients are admitted to the acute sector as an emergency	
Pain and Symptom Management	Assessment of Patient and Family Deisres and Priorities in EOLC	Issues with provider burnout and self-care
Comfort Pain relief physical and mental	Family compassion honesty	Spiritual hope Truth,faith and way. Prayer.
complementary therapies	integration of health professional disciplines especially psychiatry	
carer stress and fatigue in home terminal care	GP knowledge and willingness to be involved in palliative care	spiritual care at end-of-life



Most effective management of terminal secretions	Comparisons of efficacy of different strong opioids & adjuvant analgesics	Most effective ways of providing specialist palliative care
cord compression	Development of multidisciplinary teams	leadership
pain scales in children	psicho-social impact of life threatening conditions in children and families	evaluation of pain relief in children
carers and there coping in stressful situations in the home.	the followup of patients admitted to acute care facility how are these patients tracked across the hospitals	fatigue and cancer patients the best advice for there best outcome
symptom control	ethics	quality of life issues
a steroid without side effects! (and establishing if and at what doses steroids are efective for their various uses)	effect of renal (and hepatic) failure on metabolism of a range of opioids	fatigue - what can we achieve
therapy of pain/symptoms	family	views and policy
palliative care in non cancer	surgeons attitudes to palliative care	general nurses atitudes to palliative care
Dyspnoea	Fatigue	Neuropathic pain
Dyspnoea - very limited evidence for anything which we use.	End of life care	Non cancer diagnoses
mouth care	breathlessness	cannabis
Soul Pain in Children & Adults	Childrens Pain	Sibling support
adverse effects of drugs commonly used in palliative care in elderly patients (compared to younger palliative care patients)	when is length of stay decreasing in US hospices?	
symptom control drug research	family caregiver issues	measurement tools to evaluate clinical care
Developing a logical approach to Neuropathic Pain	Cachexia	Non surgical intervention for bowel obstruction
comparative trials of alternative medication regimens	qualitative research re benefits of palliative care services	



4) Have you any other comments relating to research within palliative care? (freetext)
NONE
very difficult because of the variability and unpredictability of the course of an individuals disease
NONE
NONE
Hard to get funds to resource research : time, research officer, coordinating Gps time etc
NONE
NONE
NONE
NONE
NONE
NONE
NONE
NONE
impact on children of a (planned) death within the family home -
Very difficult to do in acute settings with no designated palliative care beds.
I think we need to be a little less concerned with the ethical issues of approaching patients in this field. I think we have moved on and many more people than we might think would be pleased to be contributing.
NONE
NONE
Greater use of "Palliative Care Group" research, as is done in Oncology (e.g. NSABP, ECOG) to obtain greater numbers of patients on trial & improve statistical significance
NONE
NONE
clinicians at the coal face need to be given the resources - financial and time - to be able to conduct research in their areas.
It is very difficult to make research in this field....
NONE
Central funding to develop a number (10-12?) of academically active centres to carry out nationally approved trials and smaller subsets to develop specialist intests (3-4 centres) would help!
NONE
NONE
There is not enough research on medicines used within palliative care
Are junior doctors taught the needs and theory of palliative care. I find this a very poor area in doctors knowledge.
NONE
I have found it very difficult to find links to palliative nursing, except through specialist routes. Nursing journals do not cover palliative care as popular topic, and books when found are so quickly out of date.
NONE
NONE
It is all well & good to do research & gather evidence, but if the physicians are not receiving the results or worse yet, simply do not care to listen, how can we advance our practice?
I have devised in the house questionnaires along the topics mentioned above. I wpold like to see some easy way of statistical validation of these new concepts, as my knowledge of statistics is rudimentary.
NONE
If you have an Advice Department
NONE
too much qualitative, lets get some evidence on the medical side
NONE
I have personally found it difficult to find funding as a new researcher because many grants for the developing researcher exclude mature clinicians by stipulating SpR or more junior.
Clinical researchi is very tough because of ethical and other issues in enrolling patients into RCTs. We may need to use another model for research, perhpas along hte lines used in CQI.
NONE
NONE
There is a need for more multicentre trials to try & ascertain most effective drug treatments



after just finishing my dissertation it appears that most research is patient based and very little is about the providers
Dificulties for research in children population
links between hospital and hospice or home care the best way to complete the circle.
NONE
Due to small patient numbers - encourage multi-centre trials including non-major metropolitan centres
more evidence, less strain for patients and family members
NONE
To continue to encompass all palliative care not just acute cancer, but also other chronic degenerative conditions
Any research which highlights the benefits of using palliative care providers as a resource in all settings and circumstances would, in my opinion, improve patient care.
This website can help with doing research on an international scale.
NONE
we need to get more organised so that we can do multi-centre trials. There needs to be a register of anticipated projects, or a pathway by which people can recruit other centres. We all want to do research, but are not able to recruit adequate numbers.
We need to do more and work together
NONE
publish funding opportunities one could apply for
These are the views of the 2 Consultants with whom I discussed the survey. The other topic which was suggested was Spiritual Pain-one of the Consultants felt that this would be a worthwhile area to explore.
NONE