EAPC ONLUS

European Association for Palliative Care

Non Governmental Organisation (NGO) recognised by the Council of Europe

Primary Palliative Care Research Group

http://www.cphs.mvm.ed.ac.uk/groups/ppcrg/

Primary Palliative Care Task Force

Update 4, Lancaster, Oct 2013

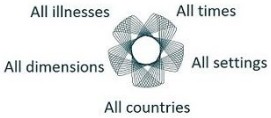
International Primary Palliative Care Research Group

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE

Primary Palliative Care Research Group

A multi-disciplinary team with strong international links researching to improve end of life care in the community.

Professor Scott Murray explains the vision of the group in a 1 minute video



Primary care is well placed to undertake palliative care for patients

- with all life-threatening illnesses
- from early in the course of the illness
- with all dimensions of need
- in all settings
- in all countries

and to support carers through the journey of illness and bereavement.

Forthcoming events:

- 3rd International Public Health and Palliative Care Conference 2013

  The International Public Health and Palliative Conference has been growing in its number of participants since the first conference was held in 2009 in Kerala, India. Up to 250 delegates will gather together for the 3rd International Public Health and Palliative Conference to be held in Limerick, Ireland between 25-27 April, 2013.

- "Palliative Care: Making a Difference Internationally" a 5-day CPD course, will run from 18th-22nd February 2013. This week will feature a keynote address by Sir Harry Burns, Scottish Chief Medical Officer on resilience at the end of life on Thursday 21st February. Please see: the lifelong learning website for more details and to register. See 'teaching' page for details of our teaching work.

News and publications:

- Jubilee Honours for Professor Scott Murray:

  Professor Scott Murray has been awarded an MBE in the Queen's birthday honours list for services to Medical Science. Congratulations Scott.

- See our 'key publications' page for recently published papers.

With thanks to all our funders, including:

Diana Princess of Wales Memorial Fund – The Work Continues
MRC Medical Research Council
We Are Macmillan. Cancer Support
E·S·R·C Economic & Social Research Council
NCRI National Cancer Research Institute
Chest Heart & Stroke Scotland
Chief Scientist Office
Marie Curie Cancer Care
NHS National Institute for Health Research
THET
The Dunhill Medical Trust
Cancer Research UK
DH Department of Health
The Robertson Trust
St Columba's Hospice
The Scottish School of Primary Care

REGISTRATION

Online registration is available from the course website:

www.lifelong.ed.ac.uk/palliativecare

Payment can be arranged by invoice or secure e-payment by credit or debit card. To register by post or fax, please contact us (details below) to request a hard-copy registration form.

Full terms and conditions on the course website.

FEES

Standard Fee £575.00 GBP

Reduced Fee* £495.00 GBP

*Academic Institution / Charitable Organisation discount

The course fee includes:

- Comprehensive course notes
- Full daytime catering
- Certificate of completion from The University of Edinburgh

Presented in partnership with the
BMJ Supportive & Palliative Care

1 year free access for course attendees

A new journal which connects many disciplines and specialties throughout the world by providing high quality, clinically relevant research, reviews, comment, information and news of international importance.

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Edinburgh, Scotland UK

VENUE

The University of Edinburgh Medical School
Teviot Place, Edinburgh EH8 9AG, Scotland UK

The Medical School is part of the University's central campus situated in the heart of Edinburgh's Old Town. The area is within a short distance of Edinburgh Castle, Royal Mile and many restaurants, shops and hotels.

An interactive map is available on the course website.

Registered attendees will be sent detailed joining instructions by email, three weeks before the course begins.

TRAVEL & ACCOMMODATION

Please note: Travel and accommodation is not included in the course registration fee and should be booked separately.

For further information and recommendations including maps, please visit the **Edinburgh** page of the course website.

18th to 22 Feb 13

EDINBURGH INSPIRING CAPITAL

www.edinburgh-inspiringcapital.com

The University of Edinburgh
Primary Palliative Care Research Group,
Centre for Population Health Sciences
& Office of Lifelong Learning

Presented in partnership with the
BMJ Supportive & Palliative Care

PALLIATIVE CARE

Making A Difference Internationally

5-day CPD course for healthcare professionals covering current research & development

20 - 24 FEBRUARY 2012 EDINBURGH, UK

www.lifelong.ed.ac.uk/palliativecare

International Primary Palliative Care Research Group

Prof Geoff Mitchell, University of Queensland, Australia
Prof Scott A Murray, University of Edinburgh, UK
Prof Fred Burge, Dalhousie University, Canada
Dr Eric van Rijswijk, UMC St Radbound University Hospital, The Netherlands
Dr Alan Barnard, University of Cape Town, South Africa

Primary Palliative Care Research Group Members

International Primary Palliative Care Research Group

Role of the group

Advocacy for pall care in the community

- Within specialist palliative care
- Within primary care and secondary care

- Support and networking
- Encouragement of palliative care research and development in the community
- Web resource http://www.uq.edu.au/primarypallcare
- Scott.Murray@ed.ac.uk

Advocacy in meetings

Quebec 2005

Cape Town 2010: 13th -14th September 2010

Palliative care: Family physicians can research and treat

1. All diseases

2. All times
-earlier rather than later

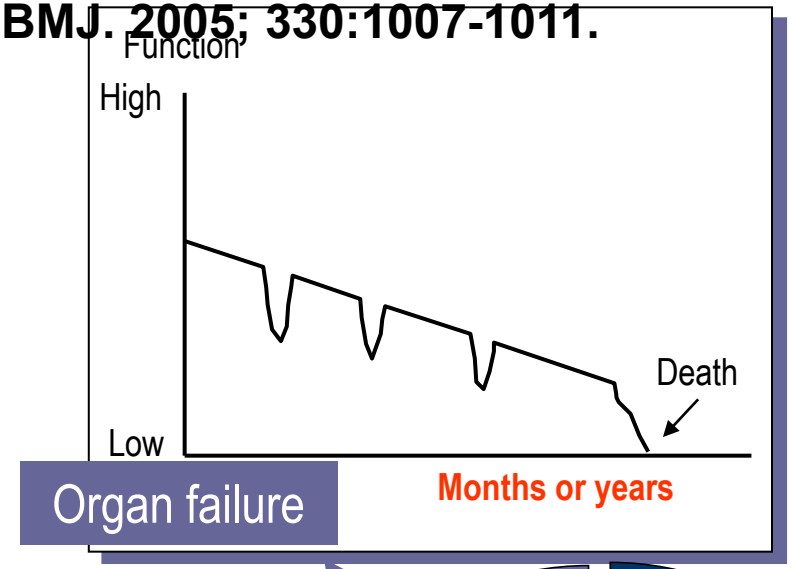
3. All dimensions

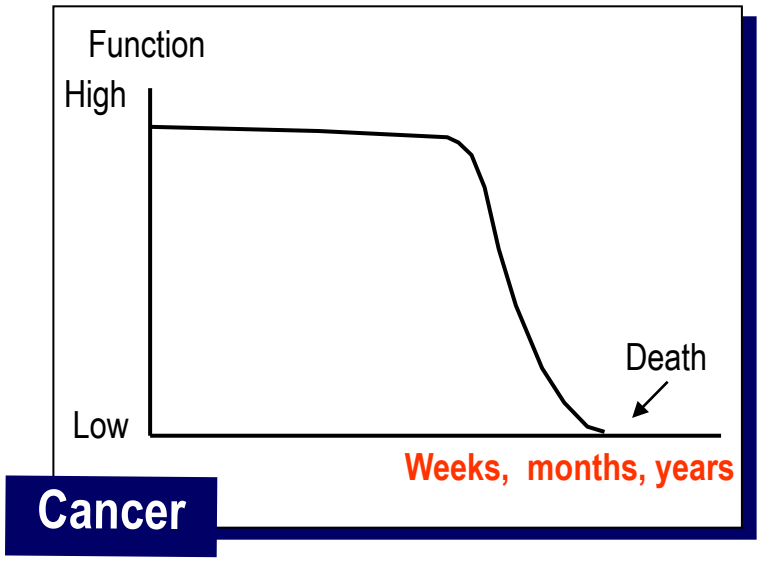
5. All nations

4. All settings

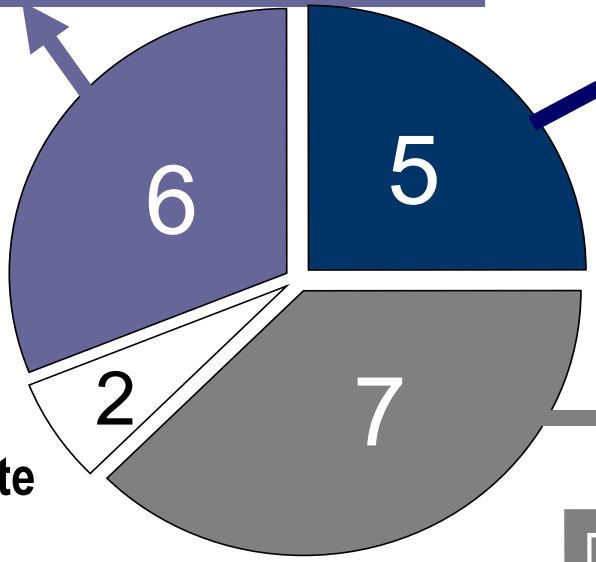
Opportunity 1 : cancer and beyond

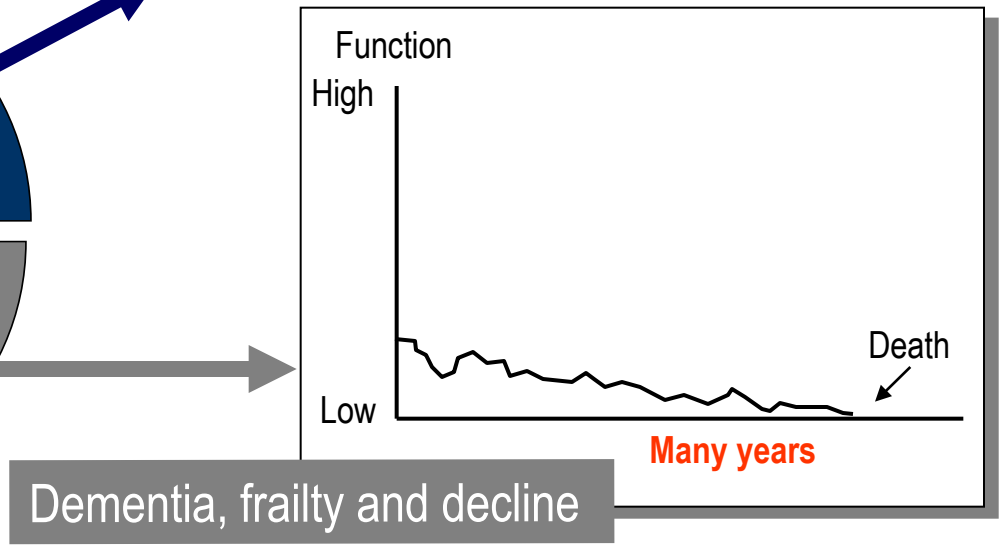
Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005; 330:1007-1011.



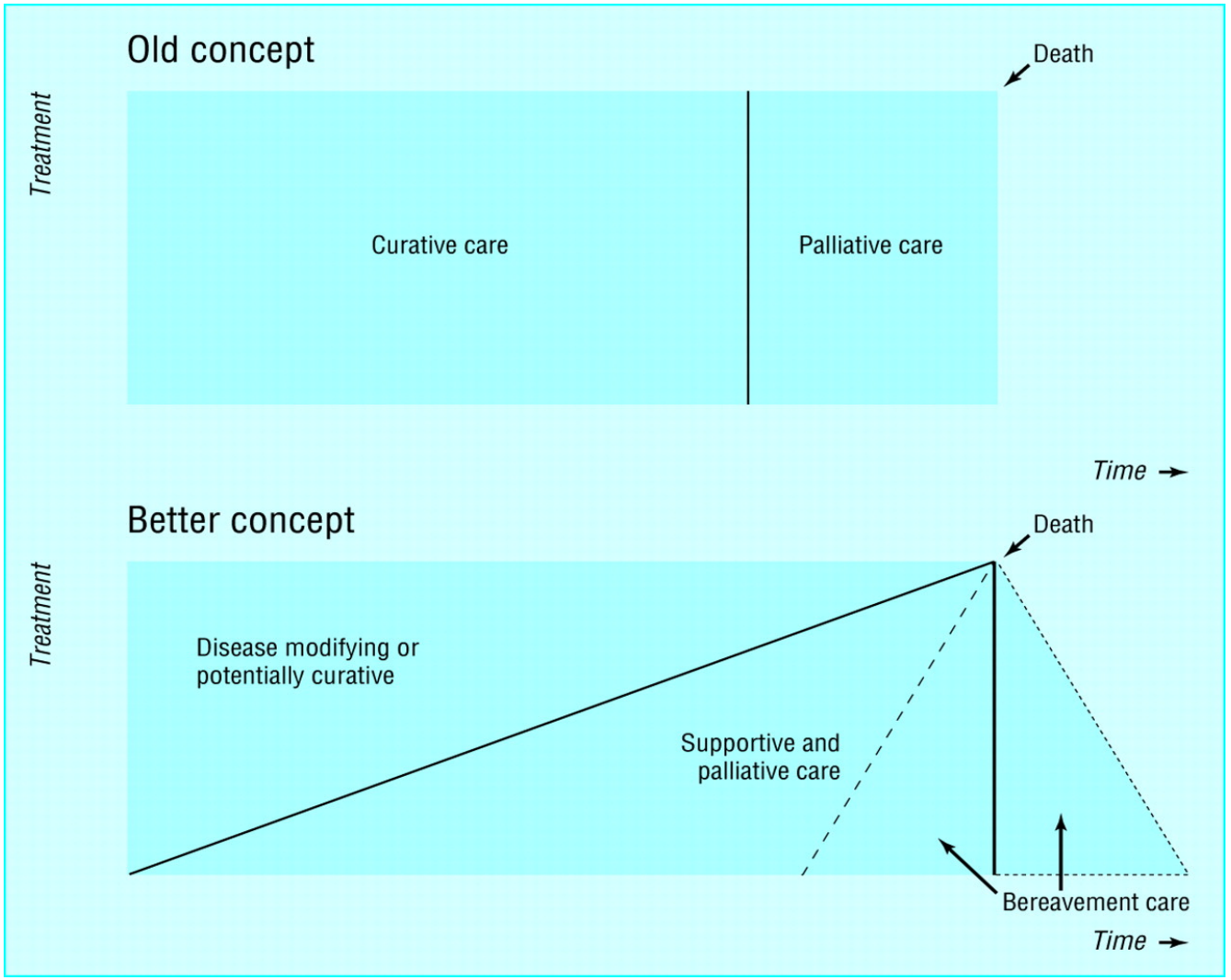


GP has 20 deaths per list of 2000 patients per year

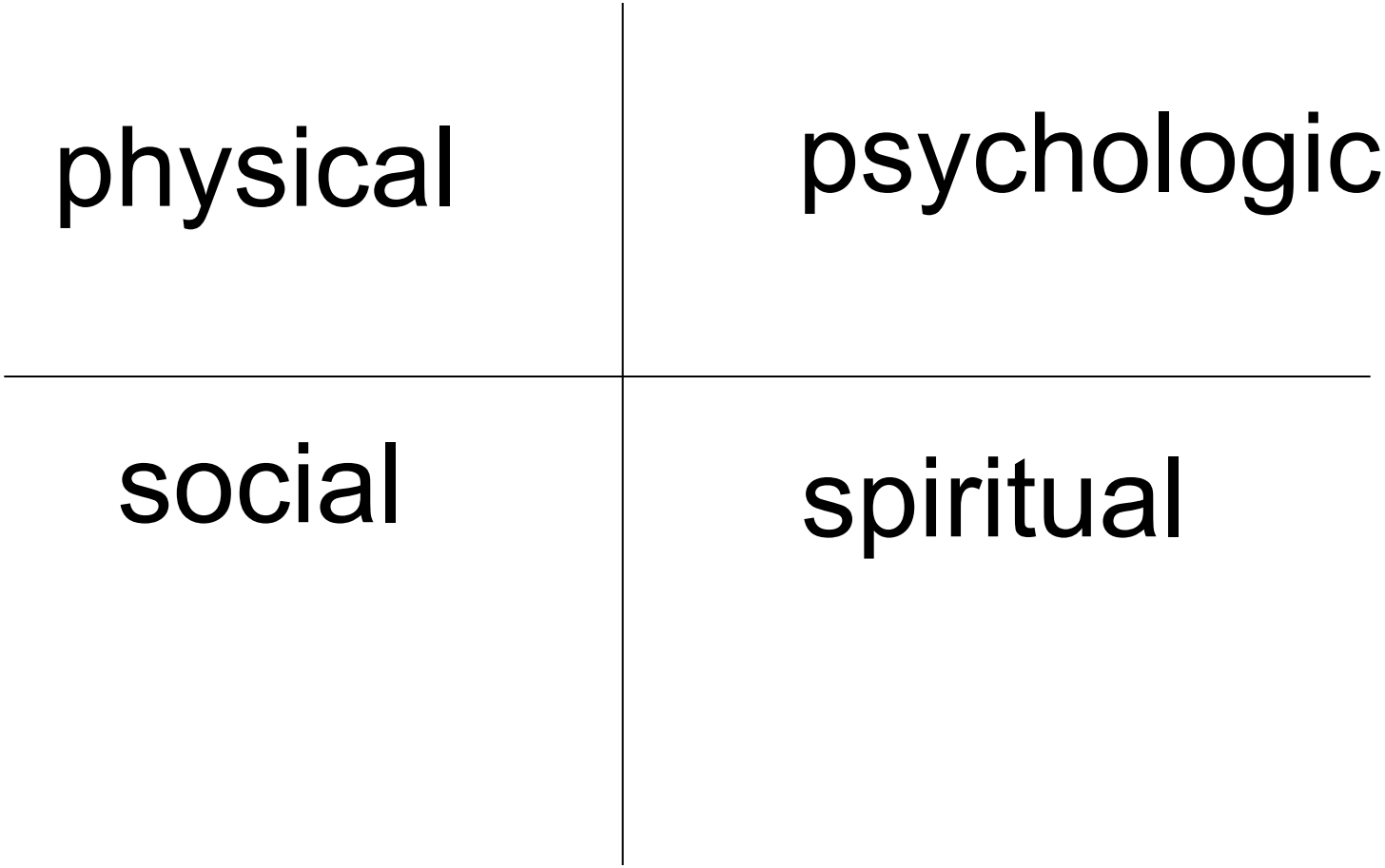




Opportunity 2 Palliate early, at diagnosis of life-threatening illness.



Opportunity 3: impacting on all dimensions



4 Community based: care frameworks

3. Plan

2. Assess

1. Identify

+ communicate

Strengthening and Integrating Palliative Care into national health systems in Kenya, Uganda, Rwanda and Zambia

Supported by British Government

2102-15 £1.5M

Palliative care in the community can treat and research

1. Cancer and life-threatening illnesses

2. Earlier rather than later

3. Holistic care – all dimensions

5. All nations

4. All settings

Vision

Scotland should be a society in which dealing with death, dying, bereavement and loss in a healthy and constructive way is seen as part of ordinary life and where members of the public and health and social care professionals and volunteers have awareness of these issues and the many ways in which communities and individuals can support each other

Scott.murray@ed.ac.uk

- Health Promoting Palliative Care
- Carers

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Primary Palliative Care Task Force

Update 4, Lancaster, Oct 2013

International Primary Palliative Care Research Group

INTERNATIONAL ASSOCIATION FOR HOSPICE & PALLIATIVE CARE

Taskforce Members

- Scott Murray, Scotland
- Eric van Rijswijk, Holland
- Nils Schneider, Germany
- Bart Van den Eynden, Belgium
- Xavier Gomez, Spain
- Trine Brogaard, Denmark
- Tiago Villanueva, Portugal
- Jurgen Abela, Malta
- Steffan Echmüller, Switzerland
- Geoff Mitchell, Australia
- Julia Downing, Serbia
- Libby Sullnow, England

Background

- Primary care is uniquely placed in the community to provide palliative care
- It is already providing much of the care for long term conditions
- Ongoing relationships facilitate physical, social, psychological and spiritual support
- Primary care teams require training and support to realise this potential
- Countries have variable primary care

Aims and Objectives

- Aim:
  - To help maximise the potential of primary care to provide quality last year of life care
- Objectives
  - To help develop the practice of palliative care in primary care
  - To develop guidelines for early palliative care for all trajectories and in the community
  - To develop links between specialist and primary palliative care and public health

Year 1 activity: 2012

Year 1: case studies from 20 European countries, and analysis of what factors promote and hinder primary palliative care in these countires.

Literature review as to components of good palliative care in the community. Scoping of any tools and ways patients are identified for palliative approach, and vocabulary used.

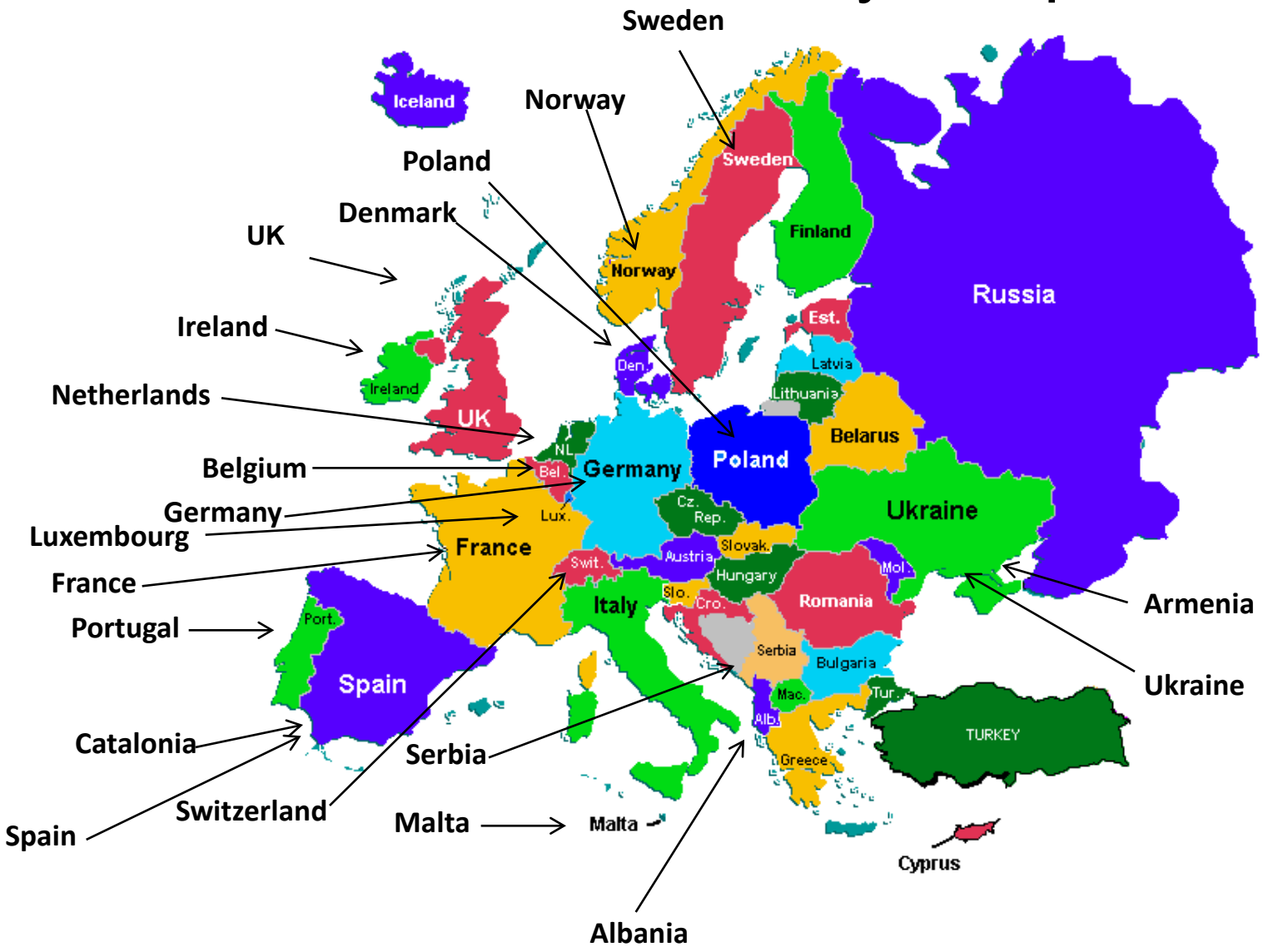
Produce a holding statement of the importance of primary palliative care.

Year 2 activity: 2013

Further international consultation process with Primary Care and Palliative care to produce

- guidelines for fast-forwarding palliative care in the community in European countries.
- Advocacy document for use at national level to promote palliative care in primary care

Countries with survey completed



Results – number of services

Country	Hospice	IP other	Hospital teams	Home care serv	Day service	Palliative care beds
Albania	0	0	1	5	1	0
Armenia	5	1	10	8	5	59
Belgium	0	45	150	28	6	379
Catalonia	0	61	49	76	50	650
Denmark	17	3	28	28	1	33
France	0	78	309	84	0	1615
Germany	185	238	56	1500	No valid data	1707
Ireland	8	2	30	34	8	171
Luxembourg	1	2	1	2	0	28
Malta	0	1	1	1	0	10
Netherlands	84	4	50	Not known	Not known	716
Norway	2	12	16	1	3	220
Poland	?	3	321	11	145	1675
Portugal	1	3	1	3	1	53
Spain	0	106	51	167	32	1186
Serbia	0	0	2	3	0	Not known
Sweden	0	0	2	3	0	Not known
Switzerland	5	28	13	18	0	276
UK	158	63	305	356	257	2515
Ukraine	7	55	0	6	0	985

Teaching

- Undergraduate: 15/20 countries have some form of undergraduate teaching

- All countries reported postgraduate training opportunities
  - Ranging from PhD/MSc/diploma to 2 day sensitisation programmes

Place of Death

Country	Hospital	Home	Hospice	Care Home	Other
Albania *(ca)*	5	93	0	0	2
Armenia	14	86	0	0.4	n/a
Belgium	50	23	0	24	4
Catalonia	52	Variable	Variable	10	15 s-h cen
Denmark	55	26	n/a	18	1
France	70-80	20-30	n/a	Unknown	Unknown
Germany	42	27	1-2	20	5
Ireland	48	25	4	20	3
Luxembourg	60	21	0	17	3
Malta	57	15	0	13	3
Netherlands	-	-	-	-	-
Norway	35	15	-	44	6
Poland	50	38	6	?	6
Portugal	61	30	-	(included in home figures)	9
Serbia	33 (cancer)	-	-	-	-
Spain	40	50	-	11	-
Sweden	38	6	5	45	6
Switzerland	34	15	<1	51	-
UK	58	18	4	17	3
Ukraine	70	26	4	2	1

Profile of Primary Care

Country	Range GPs per practice	Average no. GPs	Community nurses?	Size of registered list	Pay for consultations?
Albania	1-12	4	No	2500	No
Armenia	-	1 rural, 25 urb	Yes	2000	No
Belgium	1-3	2 (median1)	Yes – practice		No not for pc
Catalonia	5-20	10	Yes to group	1800	No
Denmark	1-9	2	Yes	1600	No
France	2-3	Unknown	No	No reg. list	Yes
Germany	1-3	2	Few	No reg. lists	Yes
Ireland	1 -6	2	No	800	Yes
Luxembourg	NK	NK	No	No	Yes (36E)
Malta	Solo paid grps	-	-	-	-
Netherlands	18% single, 54% group	-	No	2400	No
Norway	-	-	No formal link	-	Free up to age of 16
Poland	1-12	2	Yes	1800	No
Portugal	4-50	20	Yes	1478	Yes
Serbia	-	1 dr, 4 nurses for 25,000	No	2000	No
Spain	-	-	Yes	870	No
Sweden	3->20	Unkown	Yes	2000	Yes
Switzerland	-	1.5	Yes	Yes but ?	Yes
UK	1-12	4	Yes	1800	No
Ukraine	2-6	4	Yes	Regional	No

Development of Primary Palliative Care

- Do GPs keep a register of “palliative care patients”? Only 3/20
- Are any frameworks used? 4/20
- How are patients identified: usually not: if identified it is by hospital and primary care
- Percentage of cancer patients: average 80% but ranged from 19-95%
- All countries had specialist advice by phone, most via outpatient service or in the home and about half in a day centre

Terminology used

- No locally accepted European-wide terminology: some stigma of the term palliative care but few know it's meaning
- Current term used translates as 'relief care'
- Taboo with the term 'palliative' but this is diminshing
- Increasingly, the term 'care of the critically ill and dying' is used
- Hospice care, palliative care, terminal care, supportive care and end of life care all used.
- Stigma exists around 'hospice care' as it is seen as somewhere people are abandoned and rejected and die
- The terms palliative and hospice are not frequently used with pateints as they are not understood

Policy Developments

- Range including
  - Production of national standards (Albania, Armenia)
  - Action plan by Ministry of Health (Albania)
  - New identification tools in Belgium, Holland, Catalonia
  - Development of out of hours specialist advice (Denmark)
  - Legal right to palliative care in statute and ‘Charter for the critically ill and the dying’ (Germany)
  - National steering committee in Primary Palliative Care (Ireland)
  - National Plan for Palliative Care (Portugal)
  - National strategy for palliative care (Serbia)
  - National strategy for palliative care moving to community care (Switzerland)
  - End of Life initiative in UK gives financial incentives in primary care (UK) and specific incentives in Scotland

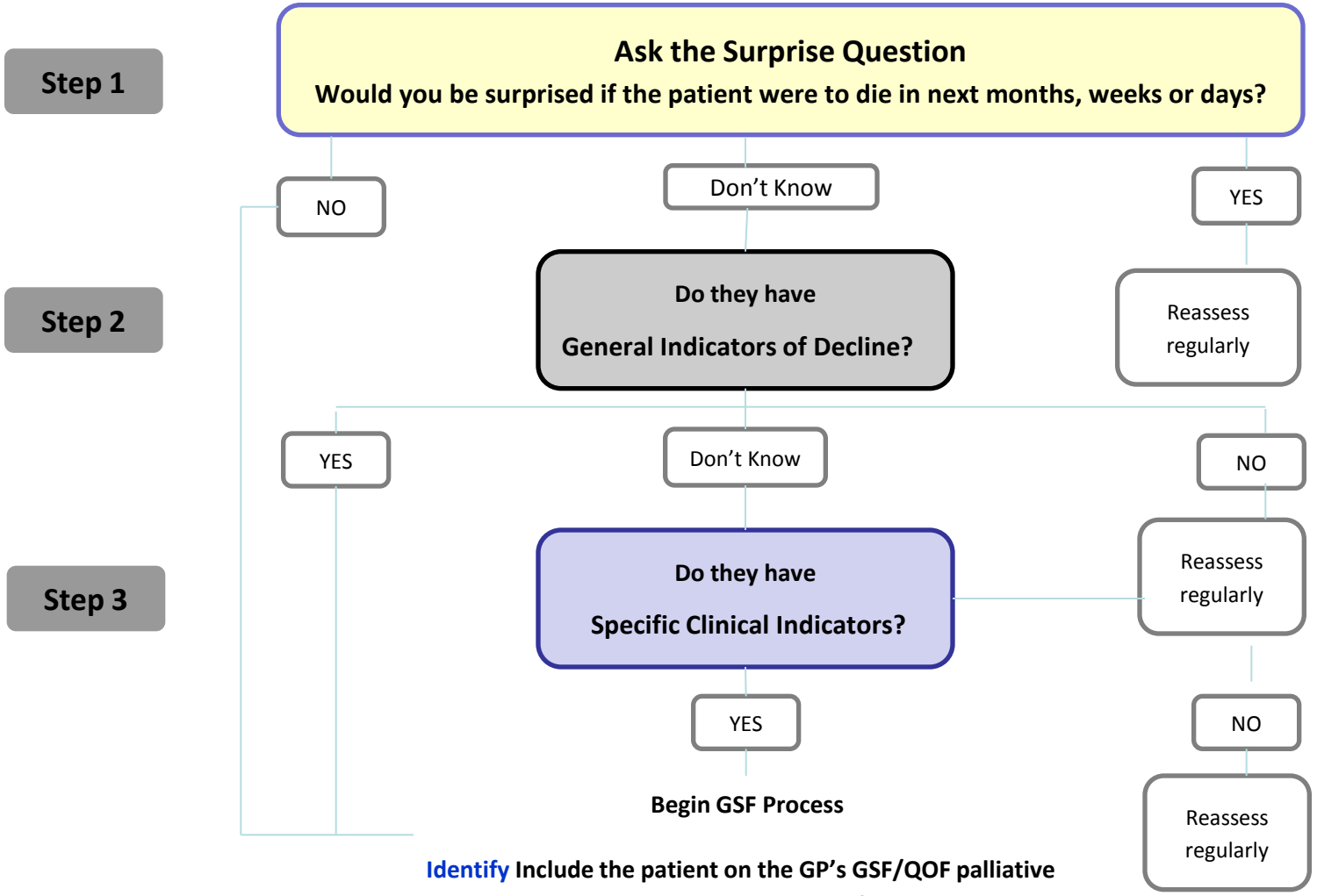
Some Barriers

- Lack of training, funding, resources and time
- Issues of bureaucracy, including around opiates
- Task distribution between specialist and primary care
- No reimbursement yet for palliative care services by insurance companies
- Poor handover out of hours
- Part of the population not yet covered by a GP
- Limitations of community nurse support
- Payment structure for GPs favours hypertension etc. over palliative care

Some Opportunities

- Increasing awareness of public, politicians and healthcare professionals of palliative care
- GPs could work to identify palliative care patients
- GPs well situated to provide good care
- National frameworks being developed
- Educational opportunities being developed
- Possibility of developing better working with community nurse services

Summary of suggested three steps for earlier identification

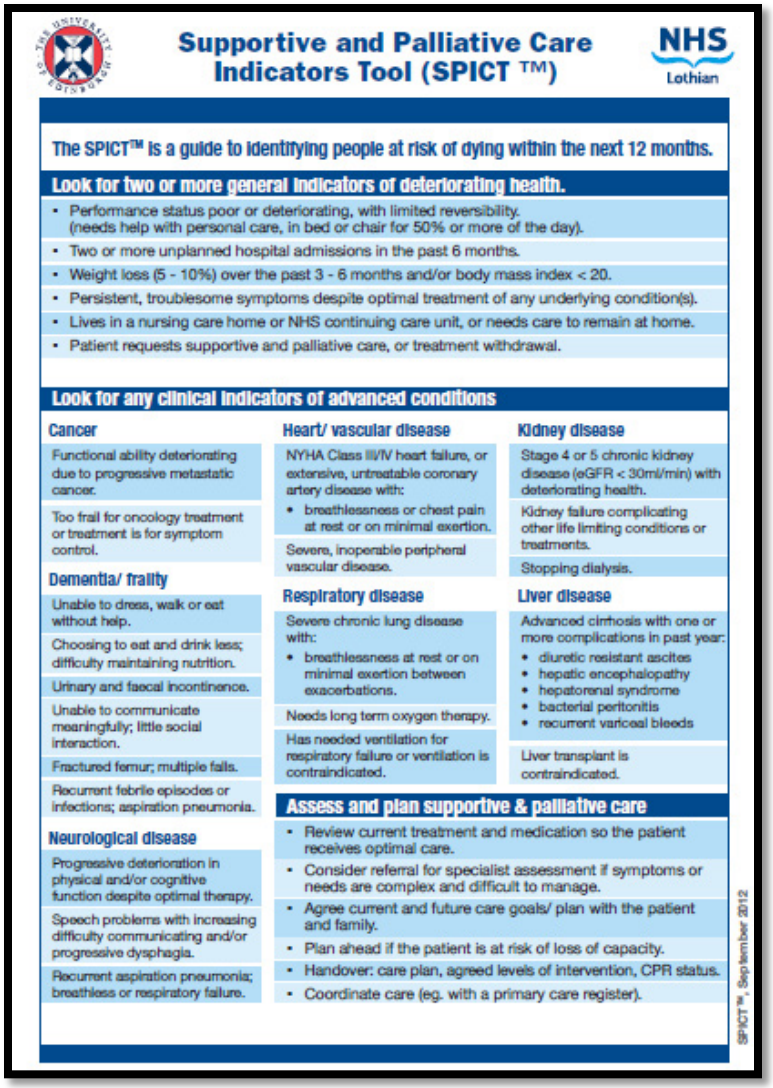


Identify Include the patient on the GP's GSF/QOF palliative care register or locality register if agreed. Discuss at team meeting.

Assess Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.

Plan Plan and provide proactive care to improve coordination and communication.

SPICT ™



Supportive and Palliative Care Indicators Tool (SPICT ™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of dying within the next 12 months.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

Unable to communicate meaningfully; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Assess and plan supportive & palliative care

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

SPICT™, September 2012

NECPAL CCOMS-ICO©

Surprise question	Would you be surprised if this patient dies within 1 year?	
Need, demand and choice	Any request to limit the treatments or palliative care from patient, family, or team members?	
• General clinical indicators (sustained, not related to acute intercurrent process) • Combined Severity AND Progression • Conditions > Individual diseases	Nutritional decline	Weight / albumin
	Functional decline	KPS or Barthel
	Severe psychological adjustment difficulties	Numerical Verbal Scale / HADS test.
	- Multi-morbidity - ≥ 3 chronic diseases - Severe Frailty & Geriatric syndromes	- Charlson test - Pressure ulcers, Severe frailty, infections, dysphagia, delirium, falls
Use of resources	- >3 urgent admissions in 6 months - Increase of demand of care	
Specific-disease indicators	Cancer, COPD, Heart, Hepatic or Renal Failure, Neurological, Stroke, Dementia, AIDS, other	

FIGURE 1: The NECPAL-WHOCC Tool

(In red, additions to the PIG/SPCIT tools)

RADPAC

The RADboud indicators of PAlliative Care needs (RADPAC)

Congestive Heart Failure	**1. The patient has severe limitations, experiences symptoms even while at rest. Mostly bedbound patients. *(NYHA IV)*** **2. There were frequent hospital admissions *(> 3 per year)*** **3. The patient has frequent exacerbations of severe heart failure *(> 3 per year)*** **4. The patient is moderately disabled; dependent. Requires considerable assistance and frequent care** ***(Karnofsky-score ≤ 50%)*** **5. The patient increases in weight what is not responding to increased dose of diuretics** **6. A general deterioration of the clinical situation (oedema, orthopnoe, nycturie, dyspnoea)** **7. The patient mentions 'end of life approaching'**
Chronic Obstructive Pulmonary Disease	1. The patient is moderately disabled; dependent. Requires considerable assistance and frequent care *(Karnofsky-score ≤ 50%)* 2. The patient has substantial weight loss (± 10% loss of bodyweight in six months) 3. The presence of congestive heart failure 4. The patient has orthopnoe 5. The patient mentions 'end of life approaching' 6. There are objective signs of serious dyspnoea (decreased dyspnoea d' effort, dyspnoea with speaking, use of respiratory assistant muscles and orthopnoe)
Cancer	1. Patient has a primary tumour with a poor prognosis 2. Patient is moderately disabled; dependent. Requires considerable assistance and frequent care *(Karnofsky-score ≤ 50%)* 3. There is a progressive decline in physical functioning 4. The patient is progressively bedridden 5. The patient has a diminished food intake 6. The presence of progressive weight loss 7. The presence of the anorexie-cachexie syndrome (lack of appetite, general weakness, emaciating, muscular atrophy) 8. The patient has a diminished 'drive to live'

Next steps

- Holding statement
- Circulate GPs in European countries thru WONCA Europe

- Produce Guidance /advocacy for use by Primary care and Palliative care organisations to advocate, plan and develop primary palliative care

- WHO model: advocacy, training, services, medication

Statement: The potential of palliative care in the community.

More patients can receive palliative and end-of-life care if it is delivered in the community by Primary Healthcare Teams. For this to happen GPs and nurses working in the community will need training and support by specialist palliative care teams. They will also need adequate time and financial and practical resources.

Primary Care has a great potential to deliver effective palliative care. It can

- Reach patients with all life-threatening illnesses [1]
- Start at diagnosis of life threatening illness [2]
- Meet all dimensions of need: physical, social, psychological and spiritual [3]
- Provide care in clinics, care homes and at home, and prevent unnecessary hospital admissions [4]
- Support family carers and provide bereavement care [5]

Policy

- Palliative care part of national health plan, policies, related regulations
- Funding / service delivery models support palliative care delivery
- Essential medicines

(Policy makers, regulators, WHO, NGOs)

Drug Availability

- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration

(Pharmacists, drug regulators, law enforcement agents)

Implementation

- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures

(Community & clinical leaders, administrators)

Education

- Media & public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Family caregiver training & support

(Media & public, healthcare providers & trainees, palliative care experts, family caregivers)

(Stjernsward, 2007)

Barriers	**Frequency of reporting**	**WHO Model**
Lack of resources	3	Policy
Lack of time	2	Policy
Private medical system	1	Policy
A law regulating palliative care with euthanasia and assisted suicide	1	Policy
No national coordination	1	Policy
Opportunities		
Good infrastructure of primary health care	6	Policy
National strategy	6	Policy
Increased political pressure	2	Policy
Reform of the way palliative care is financed	1	Policy
Reform of the management structures of GPs	1	Policy

Barriers	**Frequency of reporting**	**WHO Model**
Lack of knowledge and skills among GPs	9	Education
Poor identification of patients requiring palliative care	4	Education
Poor public awareness	1	Education
Limited understanding of the English language	1	Education
GPs reluctant to talk about palliative care or death and dying with their patients	1	Education
GPs see only a small number of palliative care patients each year	2	Education
Opportunities		
Increased training opportunities available	5	Education
GPs are available to provide care	4	Education
90% of the last year of life is spent at home	1	Education
Increased awareness of importance of palliative care	1	Education
Conversations about euthanasia can be used to introduce palliative care	1	Education

Barriers	**Frequency of reporting**	**WHO Model**
Poor handover to out of hours services	2	Implementation
Financial systems not permitting reimbursements	9	Implementation
Lack of professional or specialist support	5	Implementation
Poor structures of primary healthcare teams	4	Implementation
GPs bypassed by hospital and palliative care teams	2	Implementation
Part of the population not yet covered by a GP service	1	Implementation
Opportunities		
GPs know the family well	5	Implementation
The majority of patients want to die at home	1	Implementation
Availability of out of hours specialist advice for GPs	1	Implementation
Registered lists of palliative care patients	1	Implementation
New pathways for palliative care patients	1	Implementation
Development of a palliative care network	1	Implementation

Barriers	Frequency of reporting	WHO Model
Issues with opiate prescribing	6	Prescribing

Developing palliative care in primary care: a handbook

- Rationale and purpose
- Advocacy within government, GP, pall care,
- Need for education UG, PG, how to support generalists, pub health
- Structures that help: financial, large multi-disciplinary teams, time, continuity of care, OOH care
- Prescribing