

End of Life Care — a Geriatrician's view

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Disclosures

I have no conflict of interest or disclosure in relation to this presentation

Learning Objectives



DEFINITIONS



CASE VIGNETTE



PROGNOSTICATION



ADVANCE CARE
PLANNING

Cardiff and Vale University health

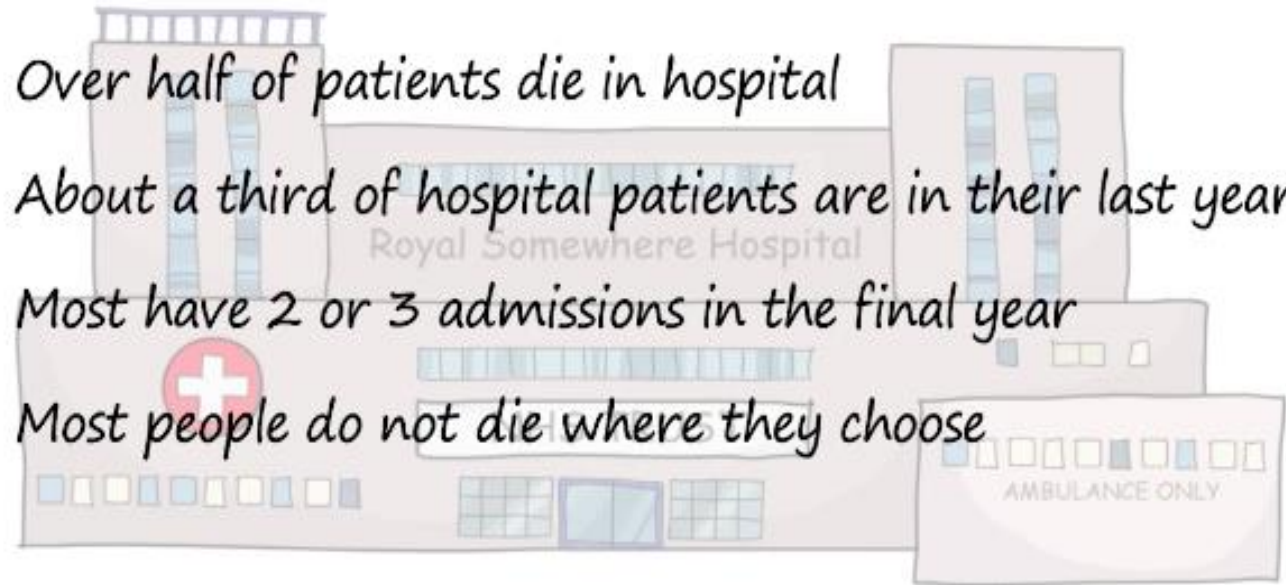
End Of Life (EoL) care vs Palliative Care

End of Life Care -People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent

Palliative Care - an approach that improves the quality of life of patients and their families caring for a loved one associated with life threatening illness

End of life care may be delivered by disease-specific specialists and their associated teams; by generalists such as primary care teams or hospital-based generalists (for example, elderly care); or by palliative care specialists in hospices, hospitals and community settings

End of life care for adults
NICE guideline [NG142] Published date: October 2019



Gold standards framework, UK

Cardiff -

Can hospital admissions predict mortality in Parkinson's?

Biju Mohamed, FRCP, MSc, MBBS, Nicola Leopold, MRCP MB Bch, Chris Thomas, FRCP, MSc, MB BCh Cardiff Parkinson's and Movement Disorder Clinic, Department of Gerontology and Medicine, Cardiff and Vale University Health Board, UK.

Background

People with Parkinson's (PwP) are more likely to have unscheduled admissions to hospital, tend to have longer length of stay and experience higher inpatient mortality than their non-PD peers. There is a scarcity of data relating to hospital admissions and subsequent impact on mortality in this frail cohort of patients.^{1,2}

Objectives

- Profile patients with Parkinson's who experience inpatient care
- Evaluate re-admissions and mortality rates
- Determine if there is a correlation between frailty, co-morbidity and subsequent re-admission and death

Methods

We conducted an 18 month follow-up of all People with Parkinson's admitted to hospital in order to audit their routine care. All PwP admitted within a 2-month period (December 2013 - January 2014) were identified for follow-up. Clinical notes, prescription charts and electronic health records were reviewed. Reason for admission, frailty scores, co-morbidities, length of stay, re-admissions within one month of discharge and deaths were recorded.

Results

Results

Frailty carried a relative risk of death of 3.2 with the average frailty index of those who died being 6 compared to 4.84 for those who did not die. 15 patients died during a year of admission with 3 deaths occurring during the index admission. There was no correlation between sex and likelihood of death.

	Patients who died within 1 year	Patients still alive at 1 year
Number of admissions	3.61	1.15

There was no significant difference between readmission rates in frailer and less frail patients but length of stay was longer in the frailest cohort. For patients readmitted twice or more in the 18 months following index admission the relative risk of death was 1.4.

Conclusion and discussion

In chronic conditions such as Parkinson's it can be difficult to identify when patients are approaching the end of life. This study has shown a correlation between death and the number of admissions over the preceding 18 months in people with Parkinson's. 37% of our cohort died within a year of index admission, the rate of death for general medical patients in the same time period is 28.8%.

Mohamed B et al, Can hospital admissions predict mortality in Parkinson's? [abstract]. *Mov Disord.* 2016; 31 (suppl 2).

Survival in multimorbid patients



Dementia – CASCADE STUDY – 55% died within 18 months; median life expectancy - 13 months



Heart failure - 1 year mortality rate 52% for NYHA III/IV, 81% hospitalisation



HR2.05 in frail men; studies show a 2-5 times higher mortality for frailer men

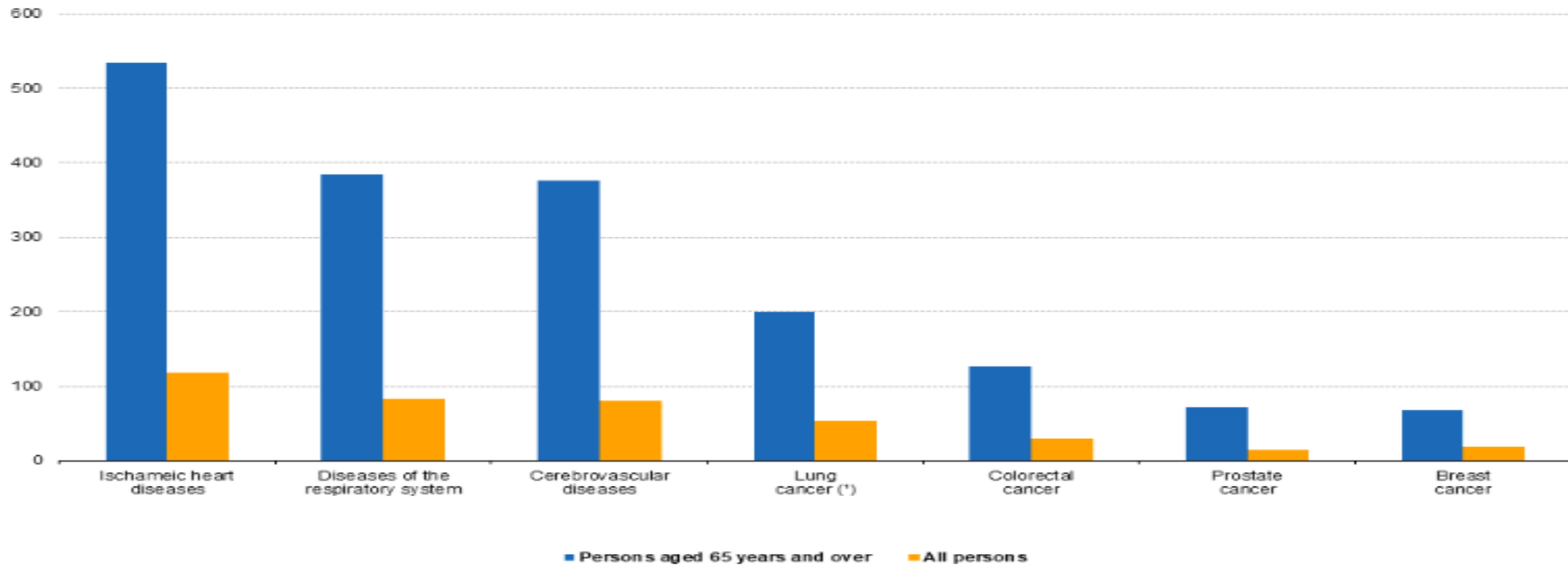
Jones NR, Roalfe AK, Adoki I, Richard Hobbs FD, Taylor CJ. Survival of patients with chronic heart failure in the community: a systematic review and meta-analysis protocol. *Syst Rev.* 2018;7(1):151.

Peggy M Cawthon;Lynn M Marshall;Yvonne Michael;Thuy-Tien Dam;Kristine E Ensrud;Elizabeth Barrett-Connor;Eric S Orwoll; *Journal of the American Geriatrics Society.* , 2007, Vol.55(8), p.1216-1223

Susan L Mitchell;Joan M Teno;Dan K Kiely;Michele L Shaffer;Richard N Jones;Holly G Prigerson;Ladislav Volicer;Jane L Givens;Mary Beth Hamel; *The New England journal of medicine.* , 2009, Vol.361(16), p.1529-1538

What do older people die from?

Major causes of death, EU-28, 2016
(standardised death rates per 100 000 inhabitants)



Societal change?

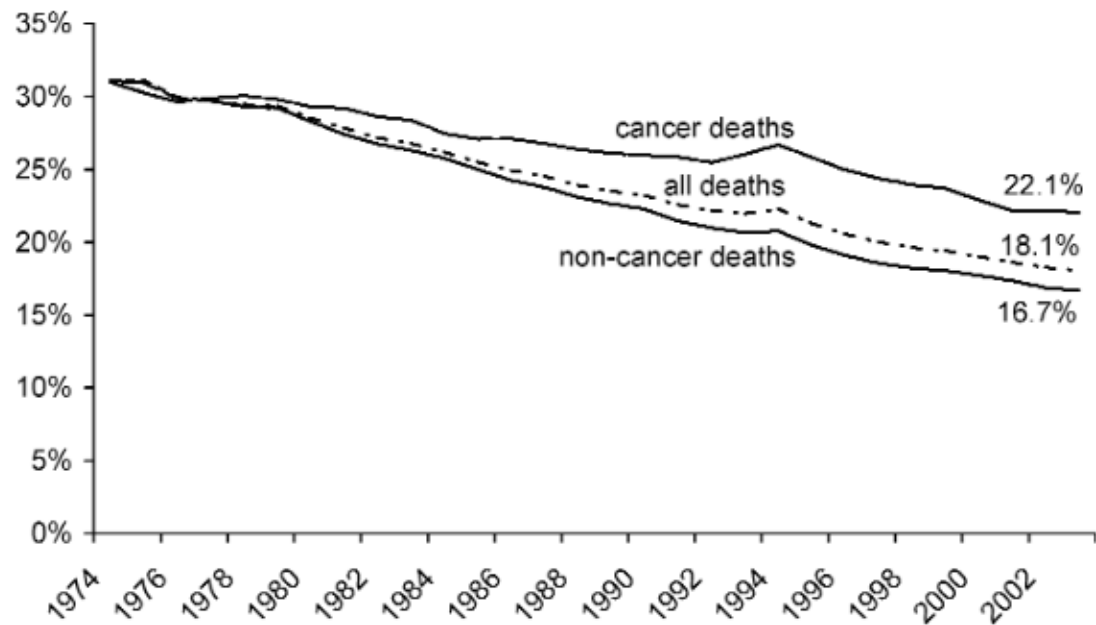
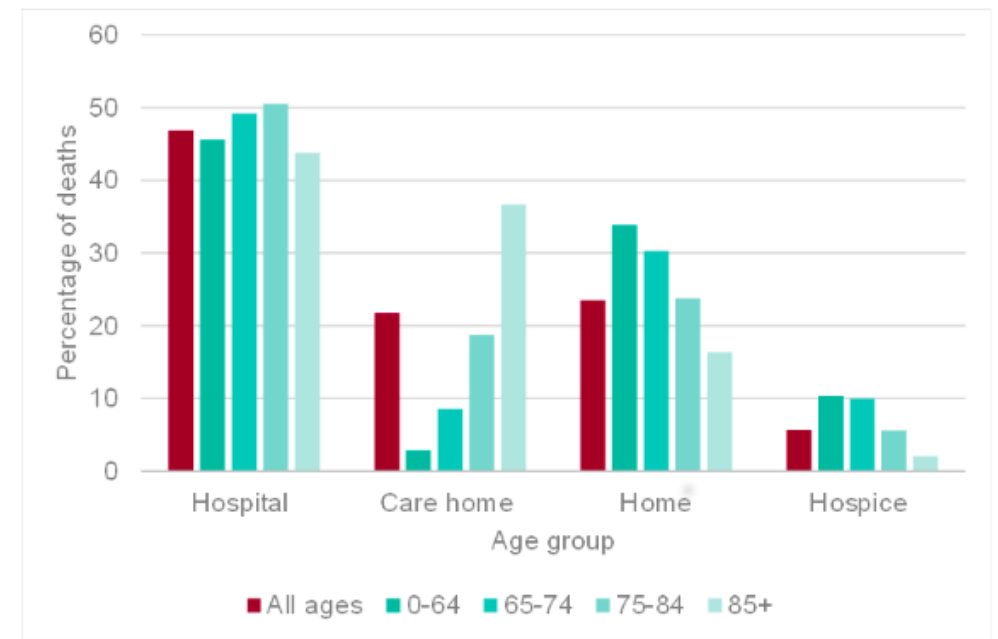
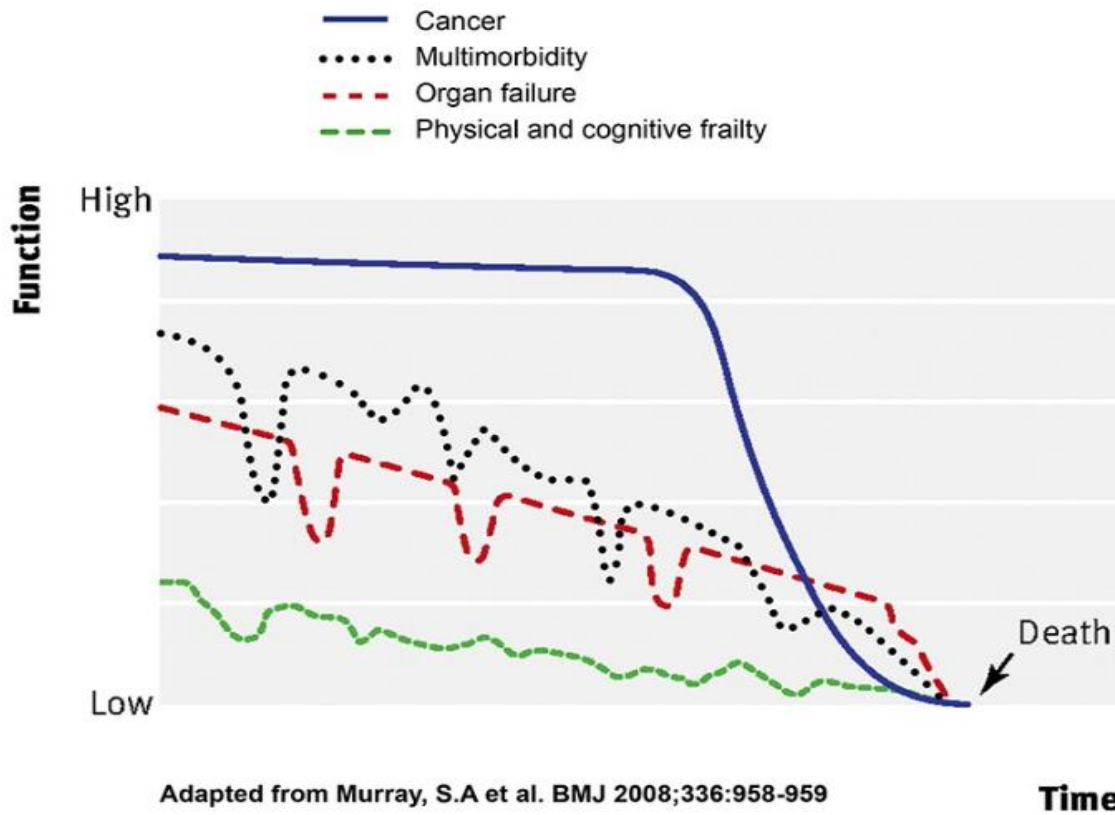


Figure 2 Proportions of home deaths, 1974–2003. Results

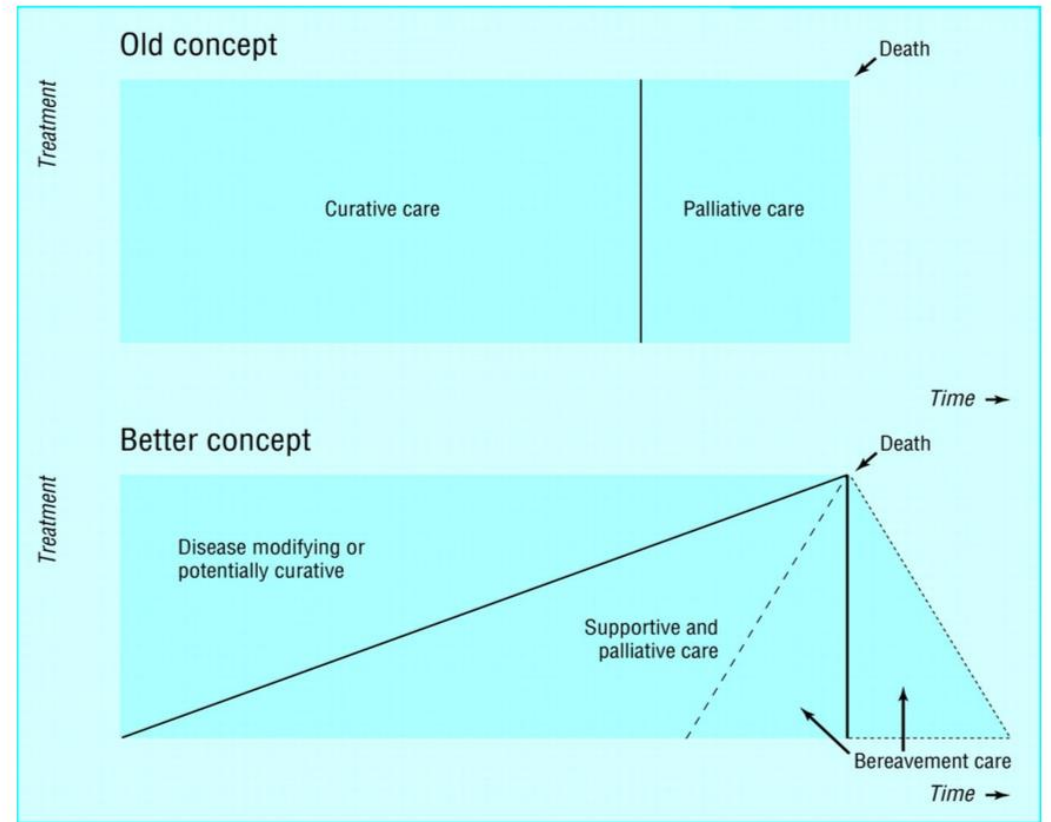


Trajectories

Trajectories of decline at the end of life



Va



Supporting a good death

- Identifying adults approaching EOL
- Assessing holistic needs
- Supporting carers
- Providing information
- Reviewing current treatment
- Advance care planning
- Sharing and communicating information
- Provide multipractitioner care

Comprehensive Geriatric Assessment

Cardiff and Vale University health Board

What do we admire in our palliative care colleagues?

Commitment to psychological and emotional care

Engagement with family/carers

Time and resources

Continuity of care

Communication skills

Working across boundaries

What we do very well

Managing acute medical problems including delirium

Rational prescribing

Multidisciplinary working

Dealing with uncertainty

Volume and scale of work

Rehabilitation and functional assessments

Ethics and shared decision making

'There's always something more we can do'

Cardiff experience

OPTCARE
Neuro

KING'S
College
LONDON

OPTCARE Neuro - Design

Quantitative

OPTCARE Neuro Trial
randomized, double-blind, multi-centre

Mapping

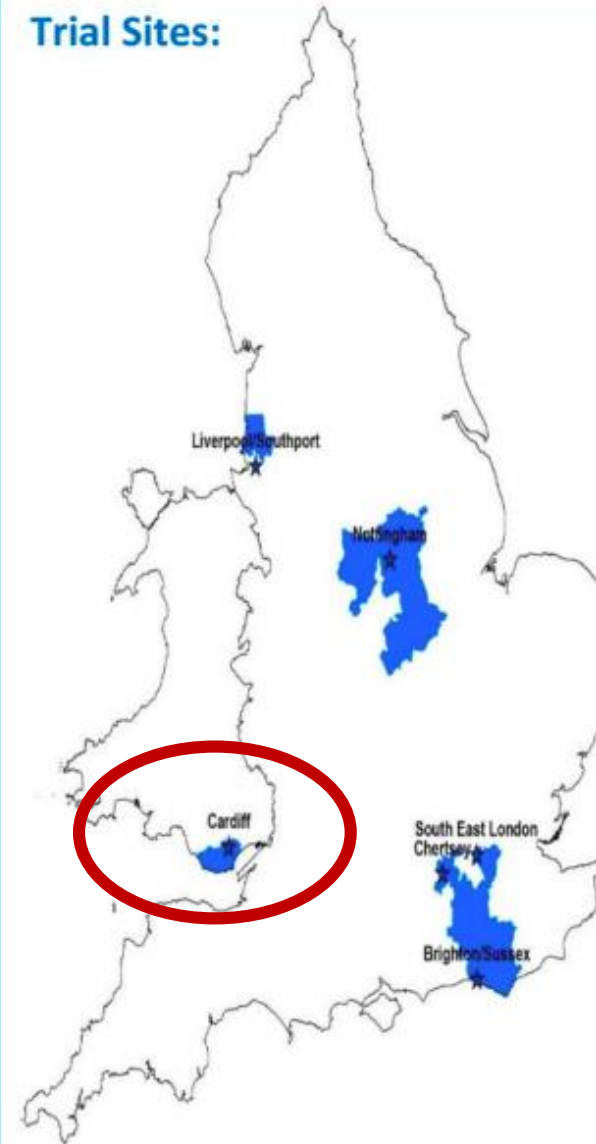
Survey 1

Qualitative

Survey 2

Cardiff

Trial Sites:



Key Publications:

Hepgul N et al. **Integrating palliative care into neurology services: what do the professionals say?** BMJ Supportive & Palliative Care [In press]

Gao W, et al. **Psychometric Properties of a Generic, Patient-Centred Palliative Care Outcome Measure of Symptom Burden for People with Progressive Long Term Neurological Conditions.** PLoS One. 2016

van Vliet LM, et al. **How integrated are neurology and palliative care services? Results of a multicentre mapping exercise.** BMC Neurology. 2016

Reflection

Mr P

- 78, gent Parkinson's for 19 years
- Admitted over a 3 day holiday period with aspiration pneumonia
 - Initial plan was naso-gastric tube feeding
 - 3 failed attempts and left on iv fluids
- Day 5, doctors discussion with family that Mr. P is dying and nothing more can be done

Family: What about feeding?

- Indicates he wants to eat and drink
- Patient difficulty communicating
- Day 10, Family keen for a peg and referral sent but too weak

EOL Care

- Identifying adults approaching EOL
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<https://www.nice.org.uk/guidance/ng142/chapter/Recommendations#providing-end-of-life-care-coordination>

EOL Care

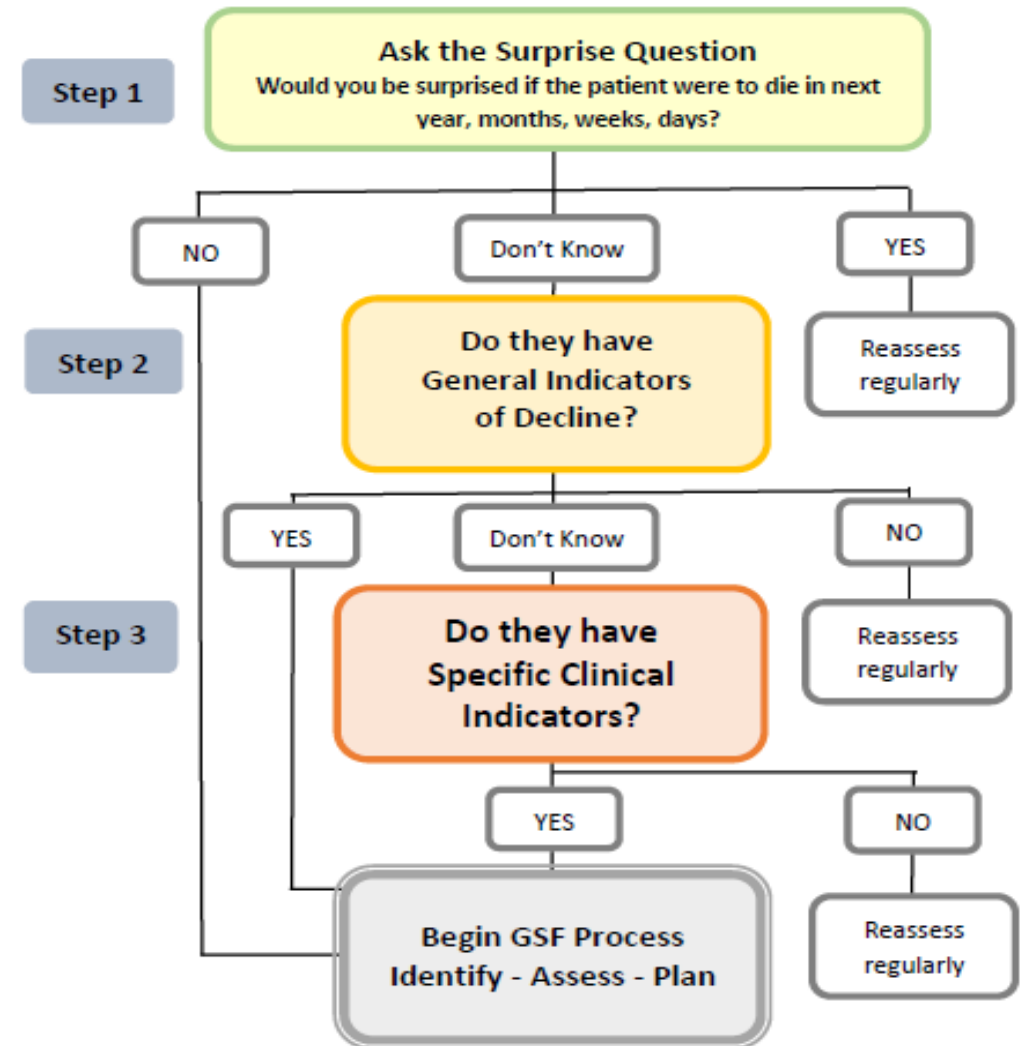
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Identification & Prognostication

- The 'surprise question'
- Gold standards framework – proactive identification guidance
- Clinician estimate
- Prognostic scoring systems



Mr P

- 78, gent **Parkinson's for 19 years**
- Admitted over a 3 day holiday period with **aspiration pneumonia**
 - Initial plan was naso-gastric tube feeding
 - 3 failed attempts and left on iv fluids
- Day 5, doctors discussion with family that Mr. P is dying and **nothing more can be done**

Identifying patients for supportive, palliative and advance care planning

1 ASK - Would it be a surprise if this patient died in the next 6 months?
If NO go to section 4

2 If unsure consider the following: look for two or more general clinical indicators

- Performance status poor (limited self care; in bed or chair over 50% of the day) or deteriorating.
- Progressive weight loss (>10%) over the past 6 months.
- Two or more unplanned admissions in the past 6 months.
- A new diagnosis of a progressive, life limiting illness.
- Two or more advanced or complex conditions (multi-morbidity).
- Patient is in a nursing care home or NHS continuing care unit; or needs more care at home.

3 Now look for two or more disease related indicators - If YES go to section 4

Heart Disease	Kidney Disease	Respiratory Disease	Liver Disease	Cancer	Neurological Disease	Dementia
<p>NYHA Class III/IV heart failure, severe valve or coronary artery disease.</p> <p>Breathless or chest pain at rest or on minimal exertion.</p> <p>Persistent symptoms despite optimal tolerated therapy.</p> <p>Systolic blood pressure <100mmHg and /or pulse > 100.</p> <p>Renal impairment (eGFR < 30 ml/min).</p> <p>Cardiac cachexia.</p> <p>>1 acute episodes needing IV therapy in past 6 months.</p>	<p>Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min).</p> <p>Conservative renal management due to multi-morbidity.</p> <p>Deteriorating on renal replacement therapy with persistent symptoms and/or increasing dependency.</p> <p>Not starting dialysis following failure of a renal transplant.</p> <p>New life limiting condition or kidney failure as a complication of another condition</p>	<p>Severe airways obstruction (FEV1 < 30%) or restrictive deficit (vital capacity < 60%, transfer factor < 40%).</p> <p>Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).</p> <p>Breathless at rest or on minimal exertion between exacerbations.</p> <p>Persistent severe symptoms despite optimal tolerated therapy.</p> <p>Symptomatic right heart failure.</p> <p>Low body mass index (< 21).</p> <p>> 3 emergency admissions for infective exacerbations or respiratory failure in past year.</p>	<p>Advanced cirrhosis with one or more complications:</p> <ul style="list-style-type: none"> • intractable ascites • hepatic encephalopathy • hepatorenal syndrome • bacterial peritonitis • recurrent variceal bleeds <p>Serum albumin < 25g/l and prothrombin time raised or INR prolonged (INR > 2).</p> <p>Hepatocellular carcinoma.</p> <p>Not fit for liver transplant.</p>	<p>Performance status deteriorating due to metastatic cancer and/or co-morbidities.</p> <p>Persistent symptoms despite optimal palliative oncology treatment or too frail for treatment.</p>	<p>Progressive deterioration in physical and/or cognitive function despite optimal therapy.</p> <p>Symptoms which are complex and difficult to control.</p> <p>Progressive speech problems difficulty communicating and/or progressive dysphagia.</p> <p>Recurrent aspiration pneumonia; breathless or respiratory failure.</p>	<p>Unable to dress, walk or eat without assistance; unable to communicate meaningfully.</p> <p>Worsening eating problems (dysphagia or dementia related) needing pureed/ soft diet or supplements.</p> <p>Recurrent febrile episodes or infections; aspiration pneumonia.</p> <p>Urinary and faecal incontinence.</p>

4 If patient condition fits these criteria:

- Assess patient, family and dependents, including children, for supportive & palliative care needs.
- Review treatment and medication priorities.
- Consider patient for general practice palliative care register.
- Consider advance care plan discussions with patient and family.

EOL Care

- Identifying adults approaching EOL
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- Advance care planning
- Sharing and communicating information
- Provide multipractitioner care

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Mr P Progress

- Established good lines of communication
- Multiple capacity assessments, deemed to have capacity to make decision to eat and drink
- Formal 2nd opinion sought, PEG cancelled
- Medications optimised
- Home day 40 with Palliative care support & escalation plan

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Advance Care Planning (ACP) can be defined as:

Advance care planning enables individuals who have decisional capacity to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family/carers and healthcare professionals, and to record these preferences.

European Consensus Definition (2017)

A process of discussions between an individual and their care provider(s)... irrespective of discipline... usually in the context of an anticipated deterioration in condition, with attendant loss of capacity to make decisions and/or to communicate their wishes to others.

(DH 2008)

It is a voluntary process and can be amended over time.

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Triggers for ACP

- Triggers for healthcare professionals to initiate Advance Care Planning may include:
- At diagnosis, or shift of treatment focus, in a 'terminal illness' e.g. metastatic cancer, severe COPD, Grade IV heart failure, MND
- Multiple hospital admissions
- "Would not be surprised if patient died in next 6-12 months"
- At any health care setting
- GP pal care register



Name:	NHS no:
Address:	Date of birth:
Postcode:	Hospital no:
GP and practice:	

This form is to record the advance care wishes of a patient with mental capacity. The decisions recorded here are not legally binding, but should inform any clinical decisions made on behalf of the patient.

Date:

1 INVOLVING OTHERS IN DECISION MAKING

Have you appointed a Lasting Power of Attorney? Yes No

Is it for health matters , or financial matters , or both?

Name:

Tel no:

If not, is there someone you would like to be consulted if the doctors ever have to make treatment decisions on your behalf?

Name:

Tel no:

2 DEPENDENTS

Do you have anyone **dependent** on you for their care (e.g. children, partner or elderly relatives)?
Record who, what relationship, and age:

If so, have you made any plans for their care if you are unable to look after them?
Record brief details:

3 TREATMENT & CARE PREFERENCES / PLACE OF CARE

Have you ever made a "Living Will" - either an **Advance Decision to Refuse Treatment (ADRT)** or a **written statement of your wishes about medical treatment?**

If so, what does it say and where is it kept? (Is a copy available in the medical records?)

If not already covered by the above -
Do you have a **preference about where you would like to be cared for** if you become less well, including when you are nearing the end of your life?

3 TREATMENT & CARE PREFERENCES (contd.)

*Some people wish to set a limit, or ceiling, to their treatment. Are there any **treatments or interventions** you would **not** want in some circumstances? (⇒ optionally use next page)*

Is there anything you are worrying may happen in the future? (e.g. difficulty breathing, being left alone)?

4 CARE AROUND LAST DAYS OF LIFE - PREFERENCES OR WISHES / PLACE OF DEATH

*Would you like to go on and discuss your **care around the last days of your life**?*

*Do you wish to express a **preference about where you would like to be cared for when you are dying**?*

*Do you have any **religious or spiritual needs** for care around the time of death?*

*Have you **made a will**?*

*Would you like your organs or tissues to be considered for **donation**?*

Have you considered your "digital legacy" e.g. on-line content on Facebook

(Further information on this is available at: www.deadsocial.org)

OPTIONAL: Use this page to record more details of patient preferences about specific medical treatments or interventions.

- * Consider adding possible treatments specific to the patient's condition e.g. dialysis for advanced kidney disease
- * If the patient has a clear understanding of his/her preferences, and wishes to refuse treatments under specific conditions, you should advise that completing an Advance Decision to Refuse Treatment (ADRT) could make such decisions legally-binding.

"Some people wish to set a limit, or ceiling, to the care they receive.

If the following treatments were medically appropriate, how would you feel about these interventions?"

Treatments	Would want	May want it if it were primarily to maintain dignity or comfort	Not under any circumstances	Comments
Antibiotics for a serious (life-threatening) infection				
Intravenous hydration (a 'drip')				
Admission to hospital				
Admission to an Intensive Care Unit				
A mechanical ventilator (to help with breathing)				
An endo-tracheal tube used in order to perform the above				
Nasogastric, gastrostomy, or other enteral feeding tubes introduced to feed				
Attempted Cardio-pulmonary resuscitation (CPR)			(Complete a DNA-CPR form)	


Emergency situations


“Although life-threatening emergencies are very uncommon, you may wish to consider how you would like others to respond if a sudden life-threatening event should occur at home, for example a large haemorrhage/bleed. Which would be your priorities?”


	Comments
To get to hospital a.s.a.p. to receive active treatment i.e. a 999 emergency ambulance.	
To control pain or other symptoms as quickly and effectively as possible, wherever that may be.	
To stay at home if at all possible.	
To put the wishes or needs of partner/carer first.	
Other priority...	


ADDITIONAL INFORMATION


*Would you like to record **any other preferences or choices** about your healthcare?*

If appropriate, has a DNA-CPR form been completed? 

Does the patient consent to share this information with other healthcare professionals? 

Does the patient consent to record this information in their computerised healthcare record? 

Has the patient discussed this information with their next-of-kin/family? 

Permission to discuss this information with next-of-kin/family if appropriate? 

Please record (by ticking) all who have been informed:

GP

District Nurses

Out-of-Hours primary care service

Hospital team(s)

Specialist Palliative Care Team

Ambulance Service (WAST)

Others:

Where is this document kept?

e.g. where in the house

If the information on this form needs to be updated or changed, please strike through all pages of this form, and ensure that you inform all those listed above.

Signature of patient (optional)	Print Full Name & Contact Information	Date
Signature of care professional helping with form	Name & Contact	Date

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Changing Hospital Systems

The screenshot displays a patient information system interface. At the top, there is a navigation bar with a menu icon, a home icon, a person icon, and an envelope icon, followed by the text "Patient Search Patient Lists". Below this, a red box highlights the text "ACP information" with a red arrow pointing to it. To the right of this box is a large empty rectangular field. Further right, the text "Date of Birth", "Sex", and "Address:" is visible. Below the navigation bar, a blue banner contains the text "Highly Sensitive information is DISPLAYED. HIDE for this patient. * 1 active user(s) Show * Add to watch list: ". Below the banner are several tabs: "Demographics", "Documents" (which is selected), "Tests", "Medicines", "GP Record", "Events", and "Access Log". The main content area is divided into a left sidebar and a main panel. The sidebar, titled "Current search", shows a search filter "x Excluded: Pharmacy Order" and a "Clear all applied filters" link. It lists "Document type" and "Speciality" filters. Under "Document type", there are "Clinic Attendance [18]", "Referral Letter [3]", "Discharge Advice Letter [2]", and "Discharge Advice Letter CAV [2]". Under "Speciality", there are "Orthopaedics [8]", "TRAUMA & ORTHOPAEDICS [3]", "Cardiology [2]", "Ophthalmology [2]", "Podiatry [2]", "[1]", "Diagnostics [1]", and "General Surgery [1]". The main panel shows "Showing 27 of 27 documents" and a document titled "Referral Letter (v2)". The document details are: "Document Date: 09 Oct 2019", "Specialty: REHABILITATION (REHAB)", "Consultant: B MOHAMED (MOHB)", "Author: WAP", "Site:", "Date Received: 08 Oct 2019", "Priority: Urgent", and "Prioritise". Below the document details is a large empty rectangular field. At the bottom of the main panel, the text "Specialty: Orthopaedics" and "Consultant: Davies, Jonathan P" is visible.

Communication

- Issues to be communicated between primary & secondary care
- GP Palliative Care Register
- Ongoing review e.g. curative to palliative, patient decision not to start dialysis
- Change in expected prognosis group (months, weeks or days cf. [Traffic lights](#))
- Likely complications e.g. PEG tube for MND, de-activation of ICD



Communication

Summary of Advance Care Plans and Preferences

Patient Details

Name: _____ DOB: ____ / ____ / ____

NHS/Hospital Number: _____

Address: _____

Family/Carer contact: _____

Diagnosis: _____

Is patient aware of diagnosis: Yes / No

Is next of Kin/Carer aware of Diagnosis: Yes / No

Advance Care Plan Summary

Has the patient nominated an Emergency Contact/Proxy: Yes / No

Contact 1: _____ Tel: _____

Contact 2: _____ Tel: _____

Preferred Place of Care:

1st choice: _____

2nd choice: _____

Preferred Place of Death (if different): _____

Resuscitation Status: _____

Summary of wishes regarding treatment/future care:

<https://wales.pallcare.info/>

Multiprofessional care



Additional important information/Religion/Culture:

Organ Donation:

Lasting Power of Attorney (LPOA): Yes / No **Advance Decision to Refuse Treatment (ADRT):** Yes / No
If yes, please give details including where copies are kept:

Professionals involved and contact details

GP – _____ DN – _____

Palliative Care Nurse – _____ Hospital Consultants – _____

Others (e.g. Social Services) – _____

Completed by

Signature: _____ Print Name: _____

Position: _____ Date: ____ / ____ / ____

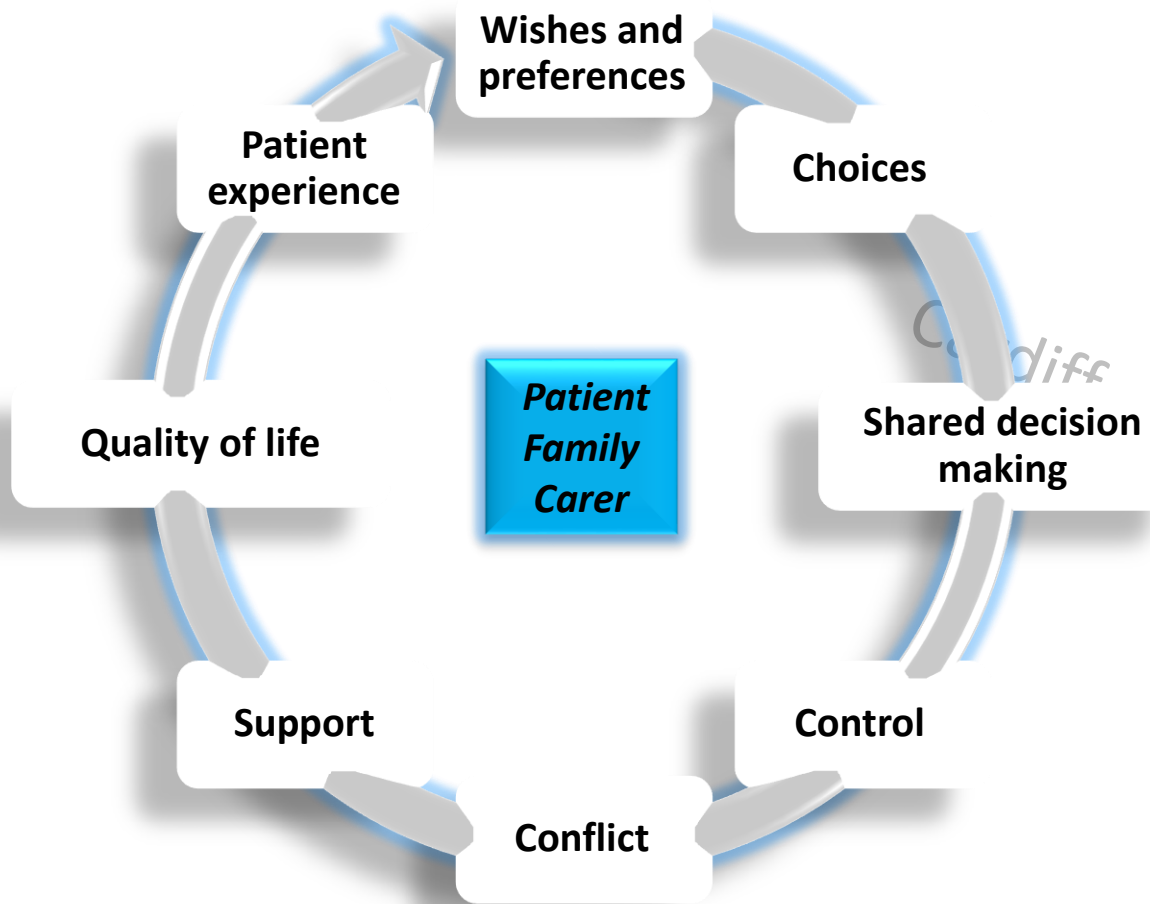
Copies of this form have been sent to:

GP Out of Hours GP Other

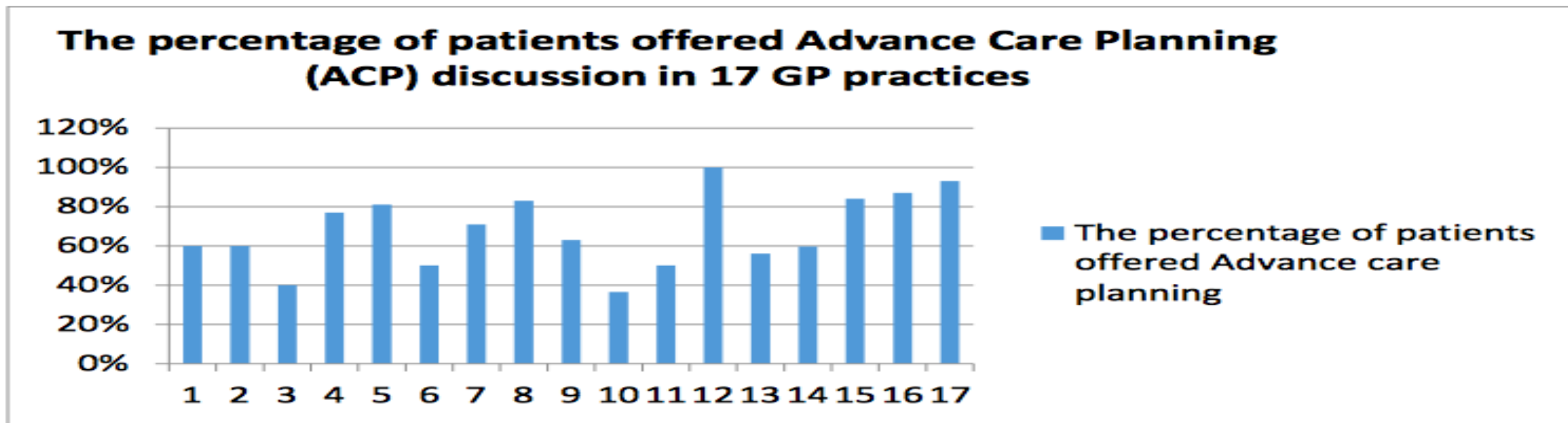


<https://wales.pallcare.info/>

Benefits of ACP



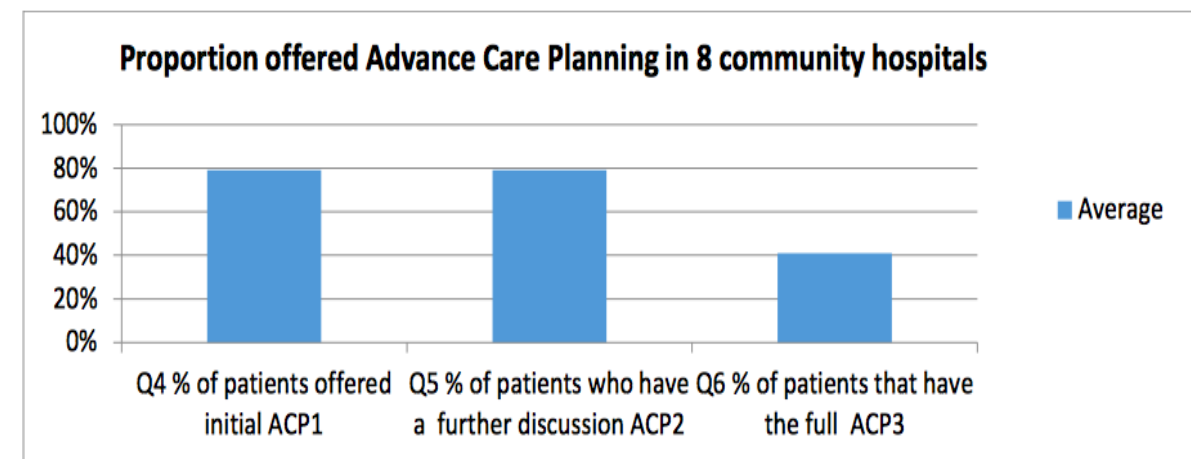
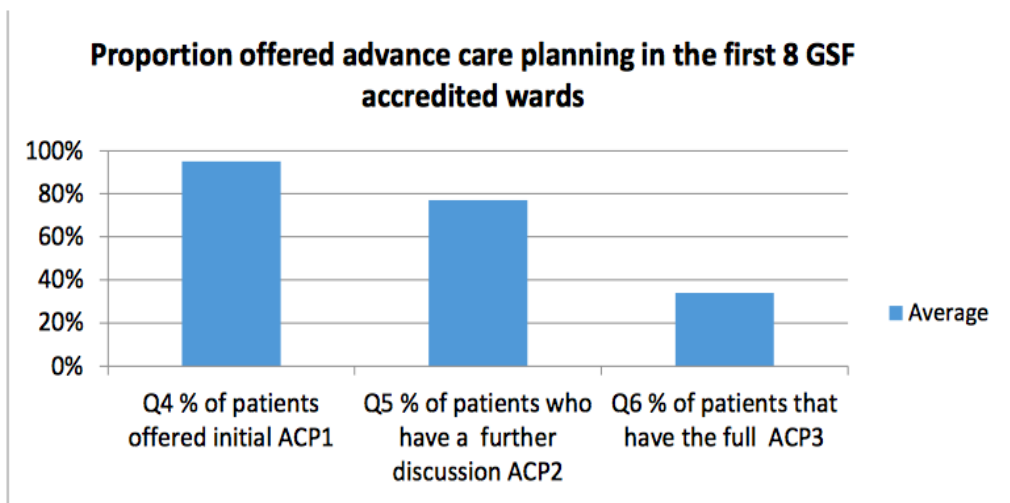
Primary care – 68% identified patients offered ACP discussions (range 37%-100%).



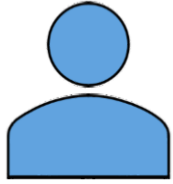
Acute hospital wards - average 95% offered Levels 1, 75% both Levels 1 and 2 ACP discussions

video

Community Hospitals – average 79% offered ACP discussions (range 38% - 100%).



Barriers of ACP



Patient



Family



Culture



**Health Care
Professional**



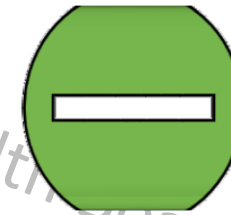
Competence



Confidence



**Personal
Experience**



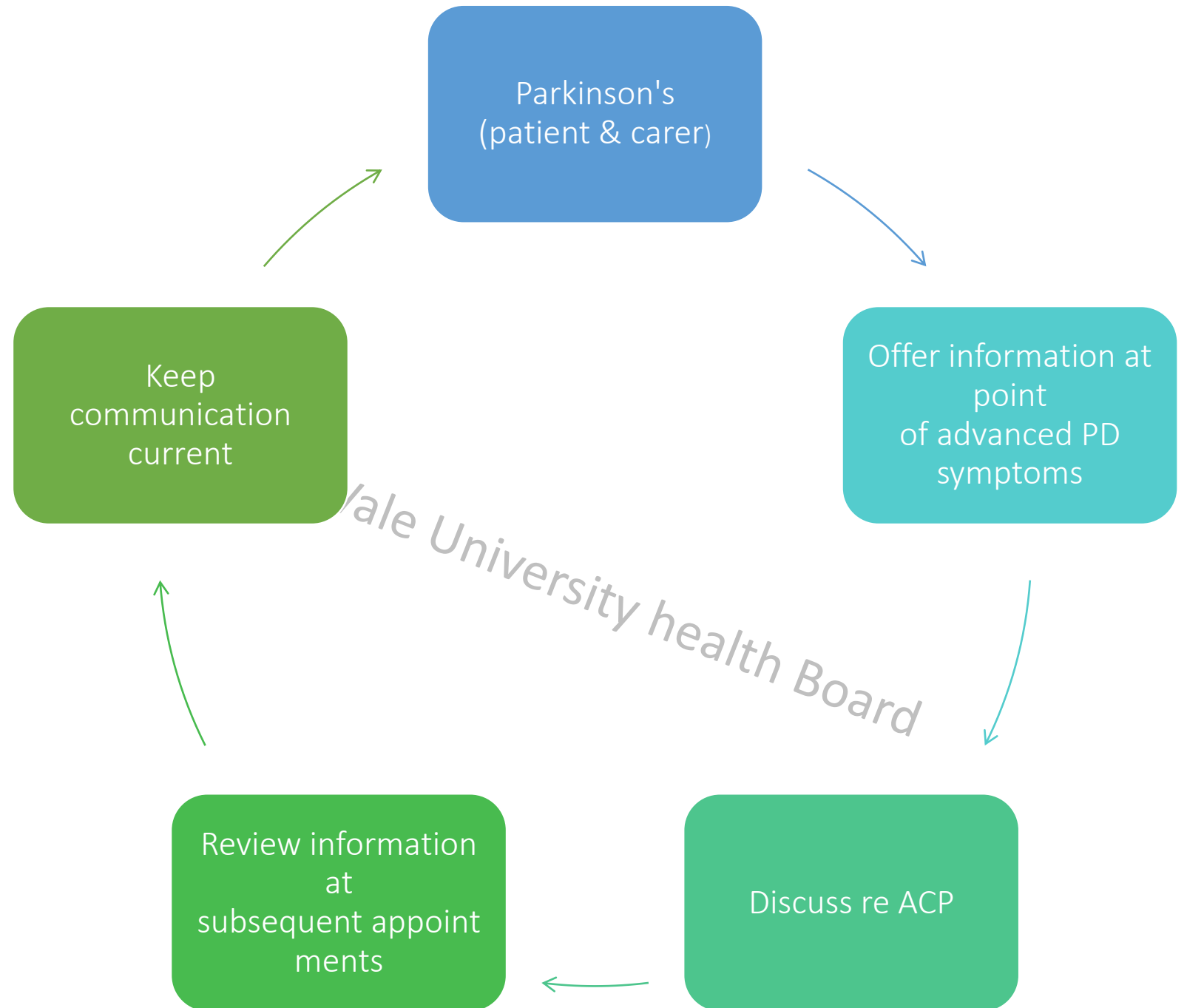
Taboo



The best outcome...

Cardiff and Vale University health Board

Cardiff Palliative model for Parkinson's



Summary



Prognostication tools
helpful in planning



Timely prompt for ACP



EoL care planning
dependent on health care
systems working together



Cultural and religious
considerations



Significant opportunity to
improve both patients and
carers quality of life

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“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being.”

– Atul Gawande, Being Mortal: Illness, Medicine and What Matters in the End

Health Board