Advanced Care Planning

What, Why, How & When….

A View from General Practice & Primary Care

Dr Brendan O' Shea MD FRCGP

GP in Kildare and Assistant Professor in Public Health & Primary Care at Trinity College

THE IRISH HOSPICE FOUNDATION

Trinity College | Coláiste na Tríonóide
The University of Dublin

icgp


Vista


St. Brigid's Hospice
Kildare & West Wicklow


Tallaght Primary Care Centre

How can we improve the care for people who are dying ?

The Chronic Care Model (www.improvingchroniccare.org)

Barbara Starfield

Ed Wagner

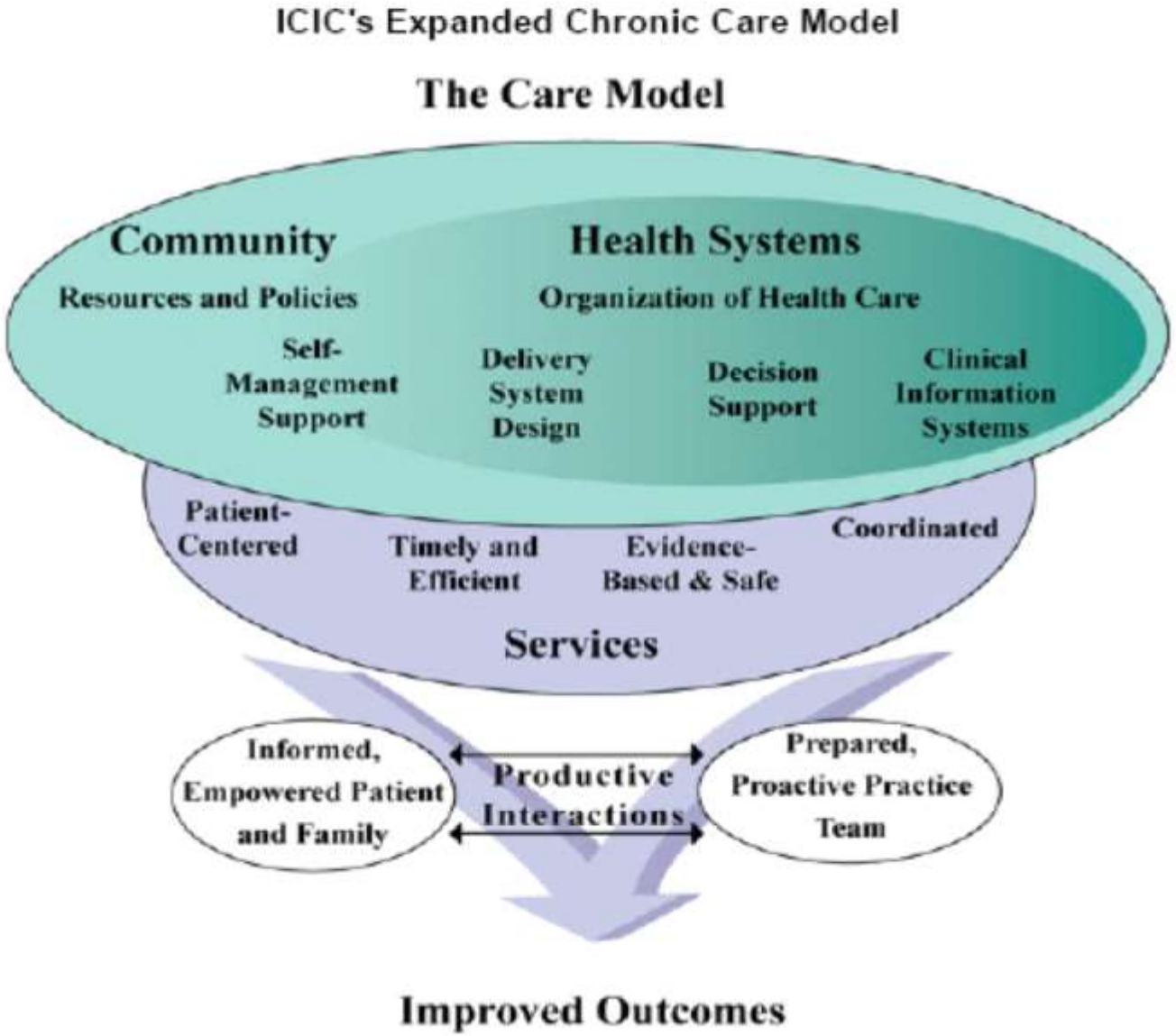
Cathy Schoen

Michael Marmot

Paul Grundy

The Patient Centered Primary Care Collaborative (www.pcpcc.org)

www.improvingchroniccare.org



What problems do we experience
in this area of care ?

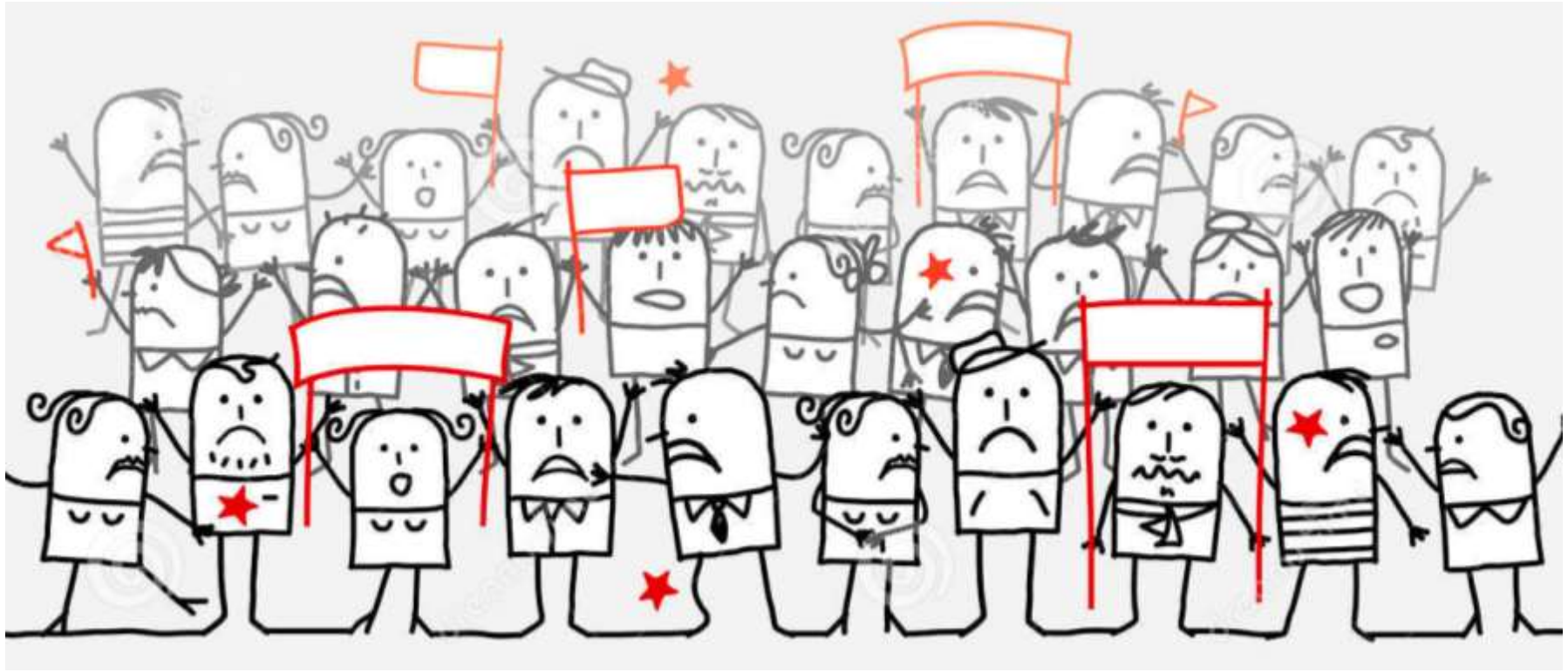
What do we find useful in this area of care ?

What can we do differently ?

Are we, as Health Care Staff, well placed to make a difference ?

What might good end of life planning look like ?

How GPs & Practice Nurses see it……



~~4000 GPs & 1800 PNs~~ ***5000 of each***

What GP Clinical Care in Ireland now feels like…….

What might good EoLP look like ?

GPs & Practice Nurses are trusted, available, and good at discussion of difficult issues…
They use electronic medical records…

Continuity

Conflicted
Frustrated
Sad
Uncertain
Pressurised

Why ***we don't*** Think Ahead

- Cultural / Societal
- Avoidance
- Busyness
- Complex and Fragmented Care
- Legal uncertainties – fear of women and men in black !
- **End of Life Care is not a professional value....**
- Professional inexperience / unease

Don't know when to....***procrastination***

Why ***do we need*** to Think Ahead ?

Katharine Sleeman

- Avoid additional uncertainties
- Reduce costs
- Alleviate suffering

- ***It often feels good to !***

When....How to...Where.....

FORUM on END of LIFE IN IRELAND

Think ahead
Speak for Yourself

When to Think Ahead ?

- **Today !**
- At 50 years of age
- At 6-8 weeks after a new/significant diagnosis
- Over 65's – perhaps biannually
- On admission to a Nursing Home

Many right answers

Two wrong ones.... 'Never' and 'Later'

When to Think Ahead ?

Shift the conversation from

Acutely unwell / Pre arrest / Ventilated patient

to several years earlier.....

……***in the Community***

The conversations work best for a clinically stable, autonomous patient

Think Ahead

Presenting it to patients….

Are we ready to ‘Think Ahead’ ? Acceptability study using an innovative end of life planning tool.

O Shea B, Brennan B, Martin D, Bailey O, McElwee O, Darker C, 2014, IMJ Vol 107, No 5.

N=100 stable patients, aged 40 to 70 yrs, in the General Practice Setting

Study supported by The IHF

Was 'Think Ahead' difficult to understand ?

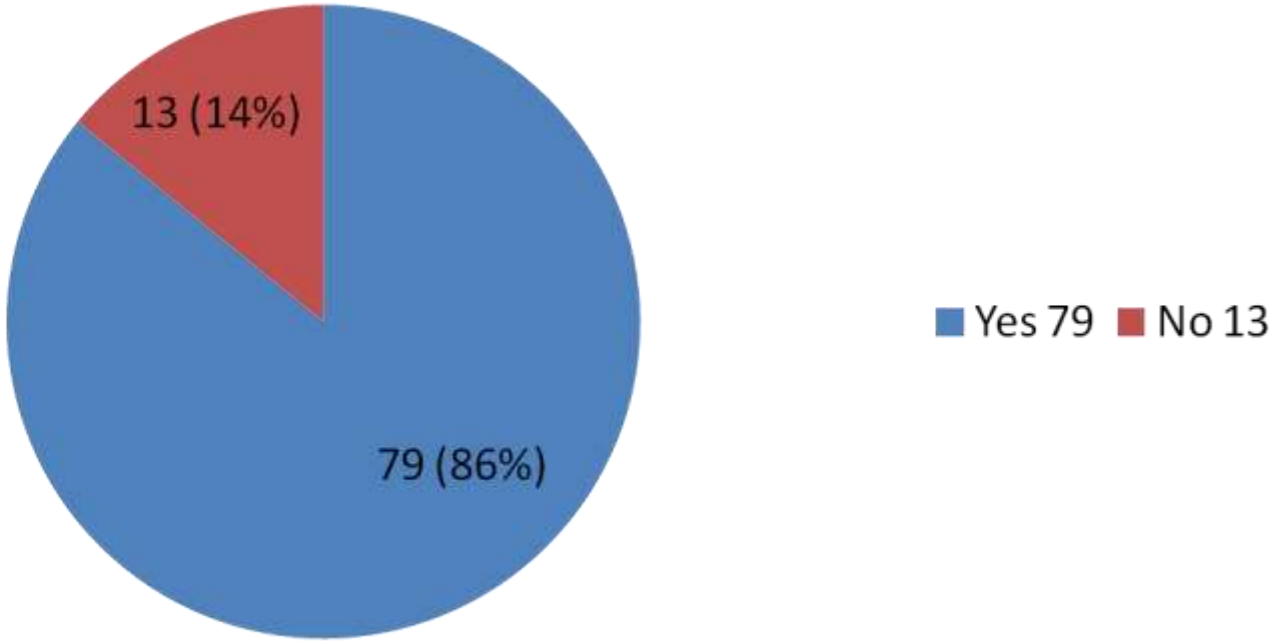
- 63% reported 'no difficulty' in filling in the folder.
  - Areas that caused difficulty for some were "Care Preferences".
    "I don't understand the issues around CPR and ventilation".
  - Some difficulty completing parts of the document in the "Legal" and "Key Information" sections.

Should 'Think Ahead' be changed ?

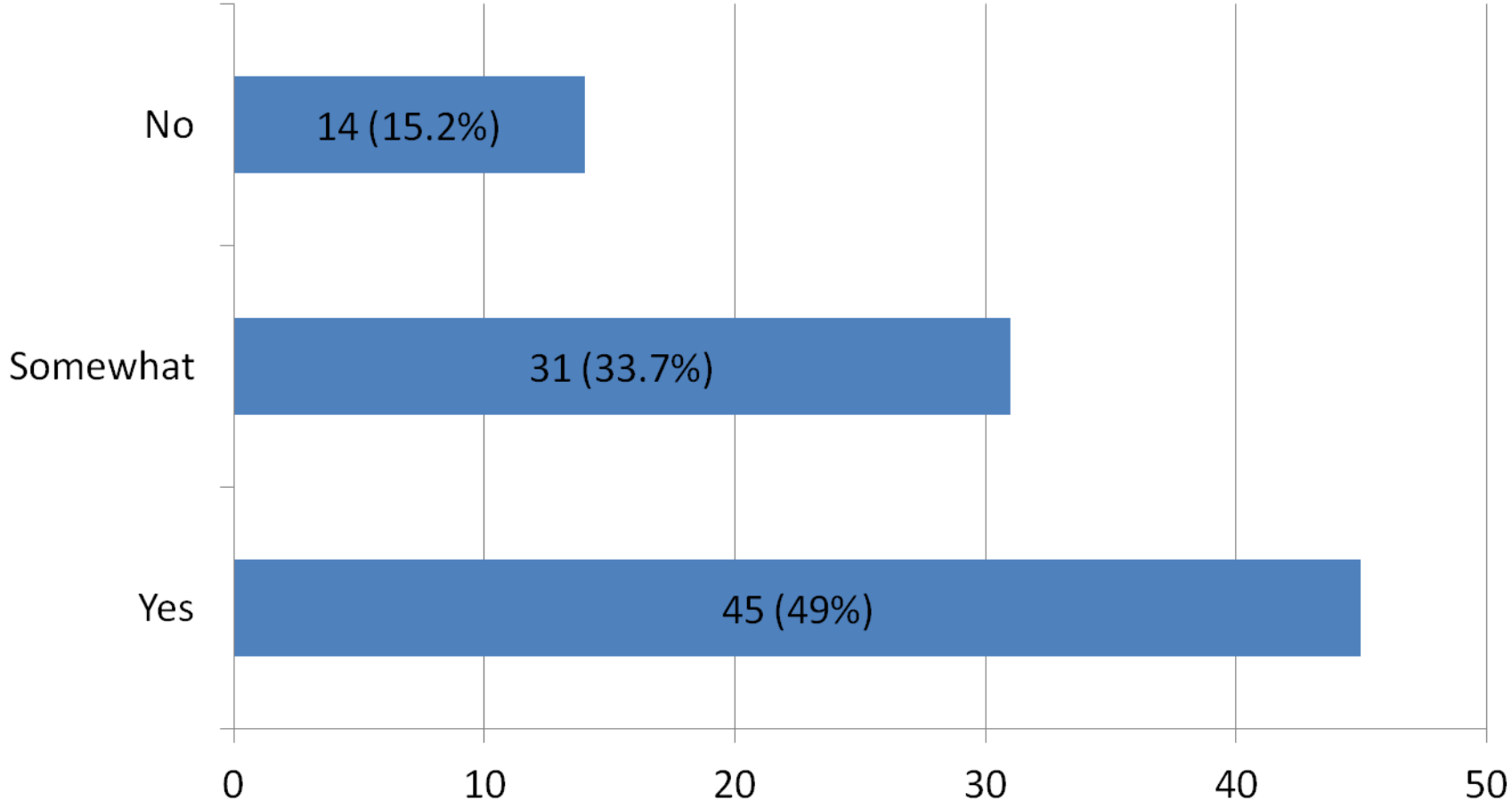
NO - 83.7%

- Suggestions for additional information
  - People or groups that should be contacted at the time of a person's death ?
  - How often the Think Ahead document should be reviewed ?
  - Church or religious organisations to be notified ?

Should 'Think Ahead' be introduced more widely?



Has reading 'Think Ahead' caused you to discuss it with your family?



Was 'Think Ahead' upsetting ?

74% reported they did not find 'Think Ahead' upsetting.

26% reported some parts caused upset.

- Two main areas were identified: "When I Die" and "Care Preferences"
- Sample responses include
  - "the idea of organ donation and switching off the life support machines"
  - "when you are sick you may feel differently about the choices you have made compared to when you are well".

Think ahead
Speak for Yourself

‘Think Ahead’ is very effective at

- having the work done,
- often, with the family,
- outside of the consultation……

Research

Eoin J Dunphy, Sarah C Conlon, Sarah A O'Brien, Emer Loughrey and Brendan J O'Shea

End-of-life planning with frail patients attending general practice:

an exploratory prospective cross-sectional study

Study supported by The IHF

BJGP 2016

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating and dying. Assess for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating with limited reversibility; is in bed or a chair for 50% or more of the day.
- Dependent on others for most care needs.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more 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; swallowing difficulties; difficulties with nutrition.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; 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.

Review supportive and palliative care needs and care planning

- 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, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate care plan.

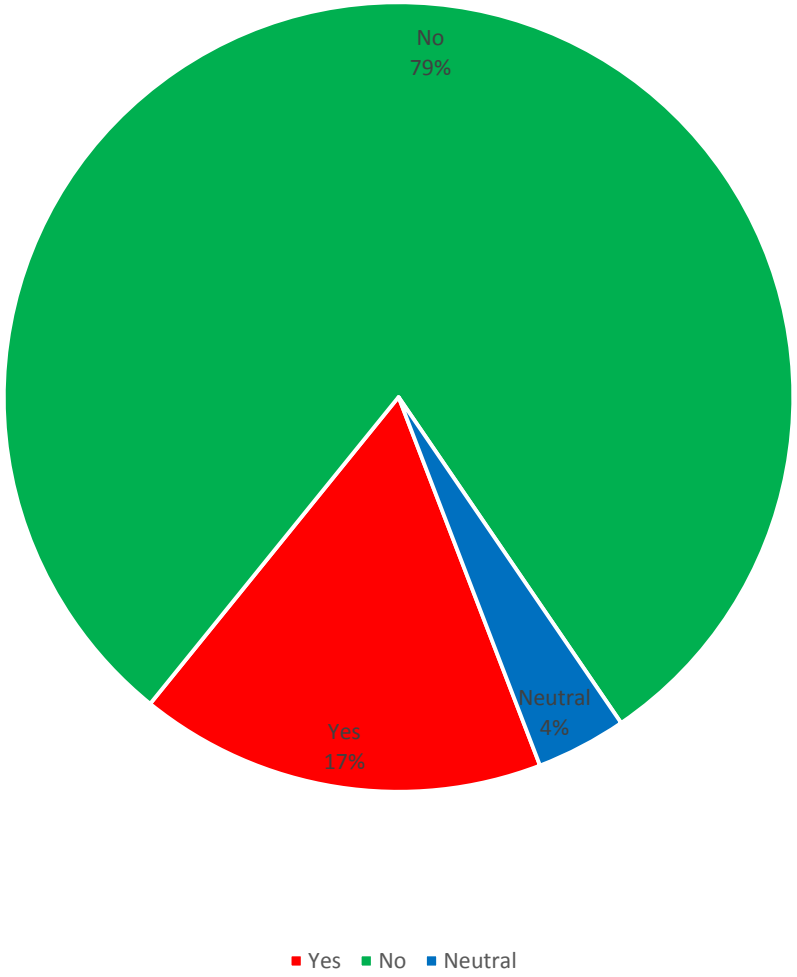
Please register on the SPICT website (www.spict.org.uk) for information and updates

SPICT™, March 2015

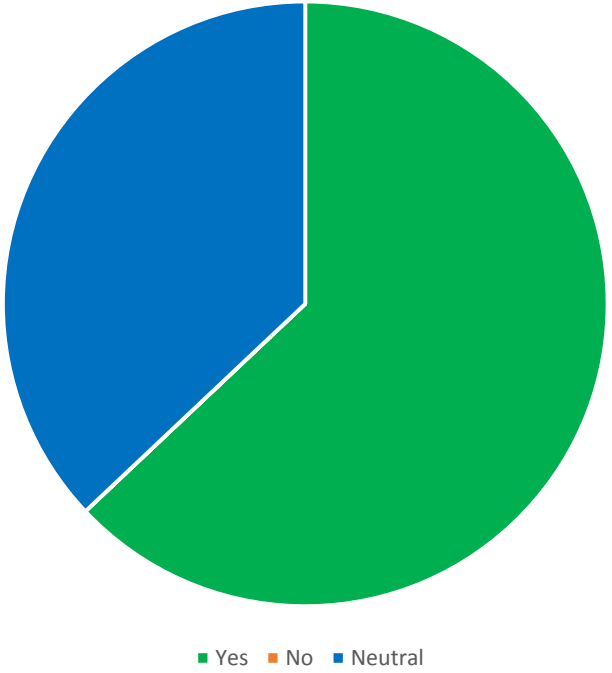
"Found it very helpful. This area is like a list of jobs I need to sort but never got around to"

Results

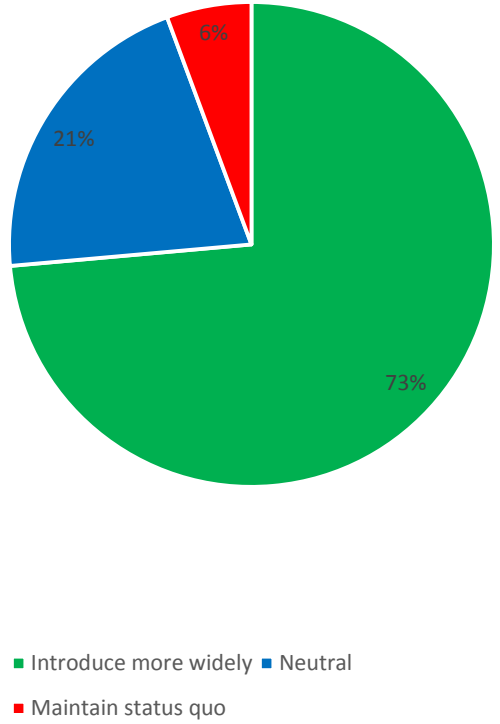
Did you find any part upsetting?



Do you feel this document would be of interest to people generally?



Do you feel it would be better to introduce the document more widely?



Comments from SPICT Survey …..

'Makes you think positively about things, puts things into perspective…'

'Found it very helpful. This area is like a list of jobs I need to sort but never got around to…'

'A lot of people won't go and get it, a GP should bring it up….'

'Opened a door allowing the family to start talks….'

Improving Practice at The ICGP

Think Ahead - Quick Reference Guides (Dementia & Nursing Home Medicine)
Integrated Care Guidelines (COPD, Diabetes, Heart Failure)
ICGP SIG for Nursing and Care Homes

ICGP Blended Learning Module www.icgp.ie (IHF Supported)

- Background material
- Videoed consultations with people / families / GPs
- Suitable for use by The Practice Team
- Focus on experience and consultation skills

How ?

Back at the Practice

What can we do in Just a Minute ?

1. People have a right & a need to know if they are at risk of dying in the intermediate term……..

2. A practical approach, delivered with sensitivity may be best…

3. The risks of silence are much greater than risks of discussion

Key Principles

All clinicians require to be skilled in the practice of brief interventions….

No engagement

Thinking about it

Planning to do something about it

Actually doing something about it

Simple clear communications, reflexively tailored to the individual….

What we say…..

‘Time is short’

‘It is getting rather difficult, but we should be able to do something about it’

‘Comfort Care’

‘Prepare for the worst’

‘We will all look after you’

What we say…	***What we mean***
‘Time is short’	**‘You’re Dying’**
‘Comfort Care’	**‘You’re Dying’**
‘Prepare for the worst’	**‘You’re Dying’**

Doctors & Nurses find it extremely difficult to mention / discuss death & dying

(But we can and are getting better at it….)

What ***do you*** say ?

We’re in a very difficult situation with this…

Is there anything you want to ask me about ?

Is there anything you’d like to discuss ?

Is there anything that you’re particularly worried about ?

Is there anything that you’re bothered or afraid about ?

Use of silence, touch and body language…….

This is a new situation for you / us to be in….

This is different for everyone…

Things are getting very complicated…… ?

We're in a very difficult situation with this…

Is there anything you want to ask about ?

Is there anything you'd like to discuss ?

Is there anything that you're worried about ?

Is there anything that you are bothered or afraid about ?

If you become very unwell again, how would you like your medical care organised ?

Use of silence, touch and body language…….

Think Ahead

Think ahead
Speak for Yourself


Think
ahead
My form
Think
Talk
Tell
Record
Review

comments

EOLP Monica EPAtt. Not for aggressive measures if long term prognosis very limited. TA given and d/w Monica. B

- Complete ‘Think Ahead’ for yourself
- Communicate EoLP as core professional value
- Challenge / advise all Clinical Staff
- **Survey those under your care now – what is on file ?**

Think ahead
Speak for Yourself

FORUM on END of LIFE IN IRELAND

- Express EoLP as core professional value
- Challenge / advise all Clinical Staff
- **Survey those under your care now – what is on their file ?**
- **1-2 documented consultations regarding EoLP**
- **Ensure you initiate an informed discussion with all who can engage**
- **Involve their Social Carers**

……and Yes….this takes a little time…

……..but not as much as you might think !

Think ahead

Speak for Yourself

Preserving the voice of the individual….

- Shift EoLP to an earlier time, with well people….
- Have EoLP reflected in Integrated Care Guidelines (HSE, ICGP, RCPI)
- Single GP EoLP Consult at outset of CD, NH Admission, or at 70 years
- Better management at care transitions – Electronic Medical Records
- More GPs, and a lot more Practice Nurses….(Slaintecare)
- Continue to apply and develop evidence based care
- Engage more directly with People, and with Voluntary Sector
- EoLP in the social and clinical domain, rather than the legal domain
- Understand - We will improve care…

The Senior Clinical Decision Maker Covid 19

- Who is this ? GP / MO at NH / PC Consultant /ED Consultant /Service Consultant
- What is their duty in this regard ?
- What is their duty in the context of Covid 19

Good Anticipatory Care (EoLP / Anticipatory Meds)

Safer and more rational Transitions

Communication

2020 Dying and Death in Ireland

- Pre Covid 19 Sample of Carers of people dying 2019-2020
- Sampling in 5 East Leinster Practices

- 84 cases, 64 completed responses, 74% Response Rate
- Only 25% had an AHD in Place
- Only 39% had an identified EPOA
- As many as 56% felt to have had no opportunity to discuss medical care

THE IRISH HOSPICE FOUNDATION

Trinity College | Coláiste na Tríonóide
The University of Dublin

Knowledge and circumstances surrounding death

”Large gap in care between diagnosis and assignment of oncology team” “At one point we had to go to 5 hospitals… in a 24 hour period”

"I had to wait several weeks for the death certificate and nobody was available to explain. I was very distressed”

“Even though he was hospitalised four times over Christmas, nobody ever implied he was dangerously ill”

"I feel the system is very disjointed" "My dad’s GP never called him once but my own GP took my calls and said she could help" "There seemed to be a lot of obstacles for every request, eg trying to get a hospital bed at home, home help and to get a medical card for a cancer patient"

2019 – 2020 Pre Covid 19

Acknowledgements

Colleagues at The ICGP, The IHF & The HSE
The Team at The Bridge Medical Centre, and The People who attend us
Larry, and everyone with the guts to go on his show

Apologies

To people hurt or neglected in their interaction with our services….

Commitment

For all of us, to be better at this…….together.


Dying in Ireland 2020…..
Can we do better for ourselves ?