

Assessing capability wellbeing at the end of life: using the ICECAP measures

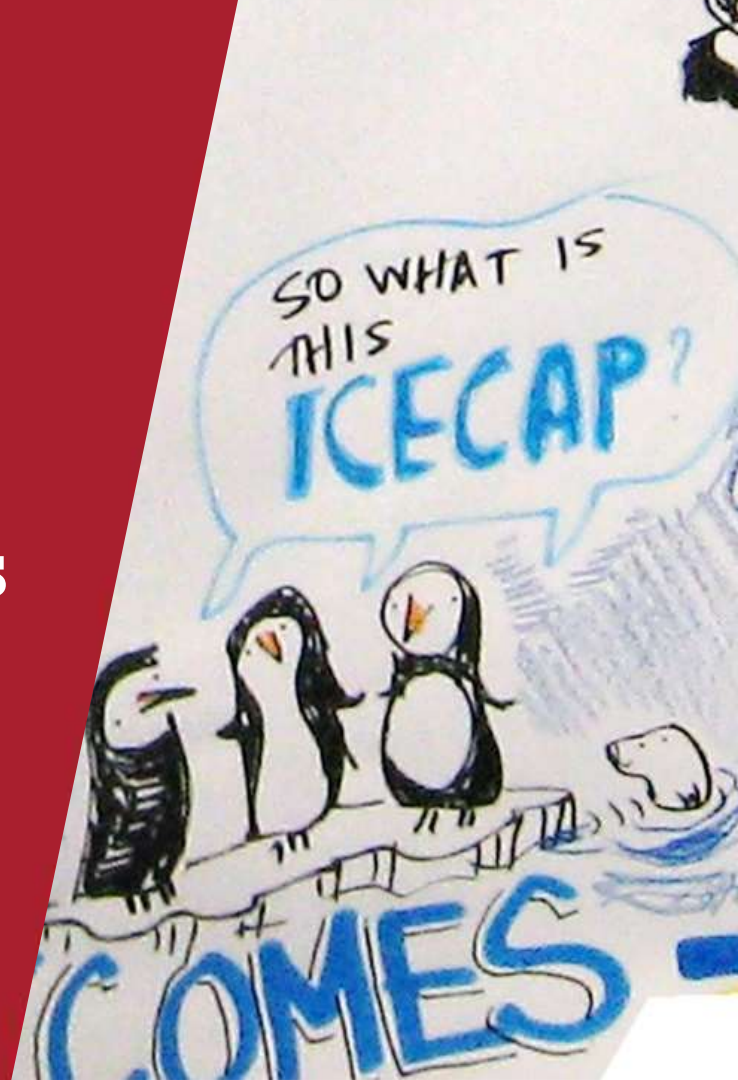
Joanna Coast

3rd Annual Research Symposium

Scholl Academic Centre, Hospice Isle of Man

Online, February 2021

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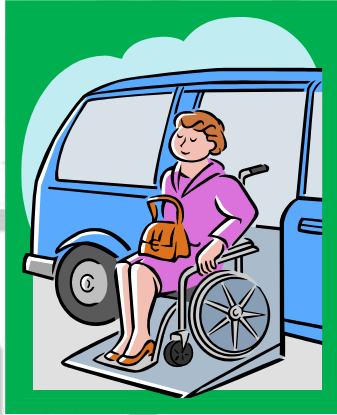


Outline

- Assessing capability for economic evaluation
- ICECAP measures for use at end of life
 - ICECAP-SCM
 - ICECAP-CPM
- Evidence for use of the ICECAP-SCM in hospice settings

Assessing capability for economic evaluation

Choices in palliative care

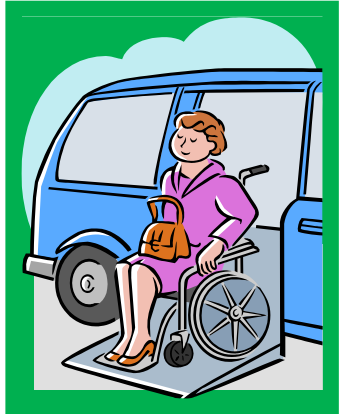


Palliative radiation
for bone metastases



Approx cost £1500

= 1 stairlift
(£1500)

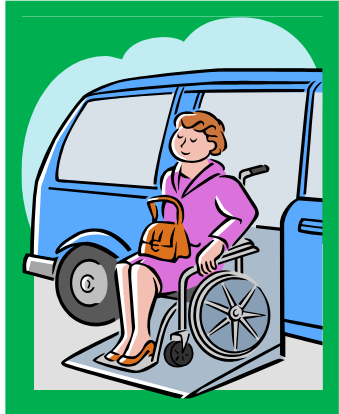


Palliative radiation
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Palliative radiation
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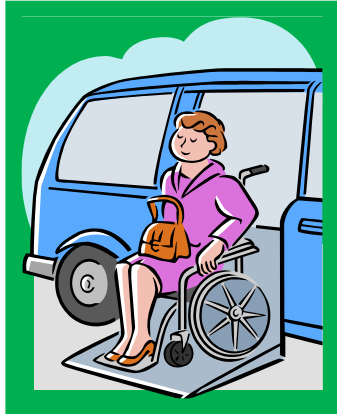


Approx cost £1500

= 1.75 weeks respite
care (£800/week)



= 1 stairlift
(£1500)



Palliative radiation
for bone metastases



Approx cost £1500

= 1.75 weeks respite
care (£800/week)



≈ 8 days of day
hospice care
(£180/day)



Making difficult choices: the UK context

NICE National Institute for
Health and Care Excellence

Making difficult choices: the UK context

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**Improving health and social
care through evidence-
based guidance**

Making difficult choices: the UK context

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Improving health and social
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Making difficult choices: the UK context

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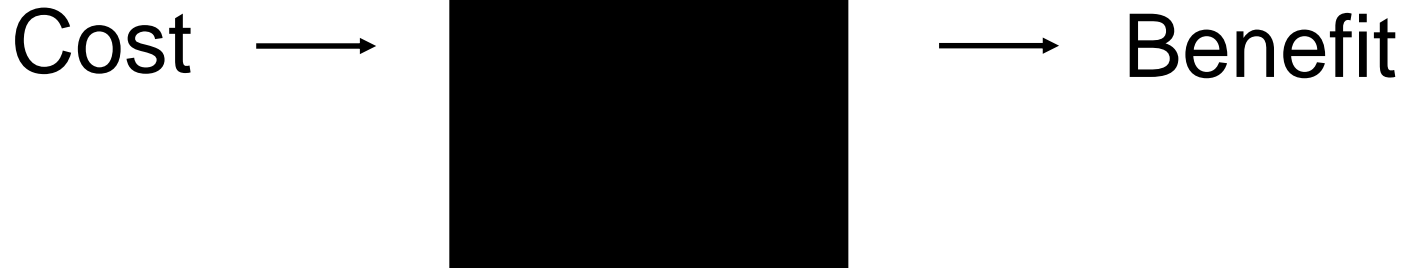
Improving health and social
care through evidence-
based guidance

&
value?

Evidence... & value

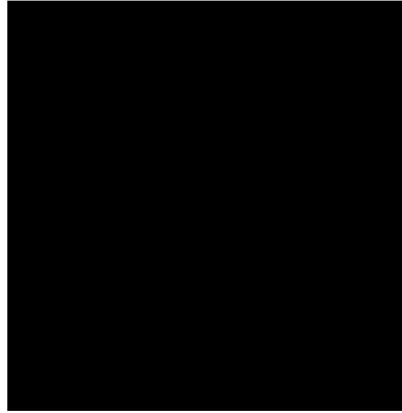


Economic analysis

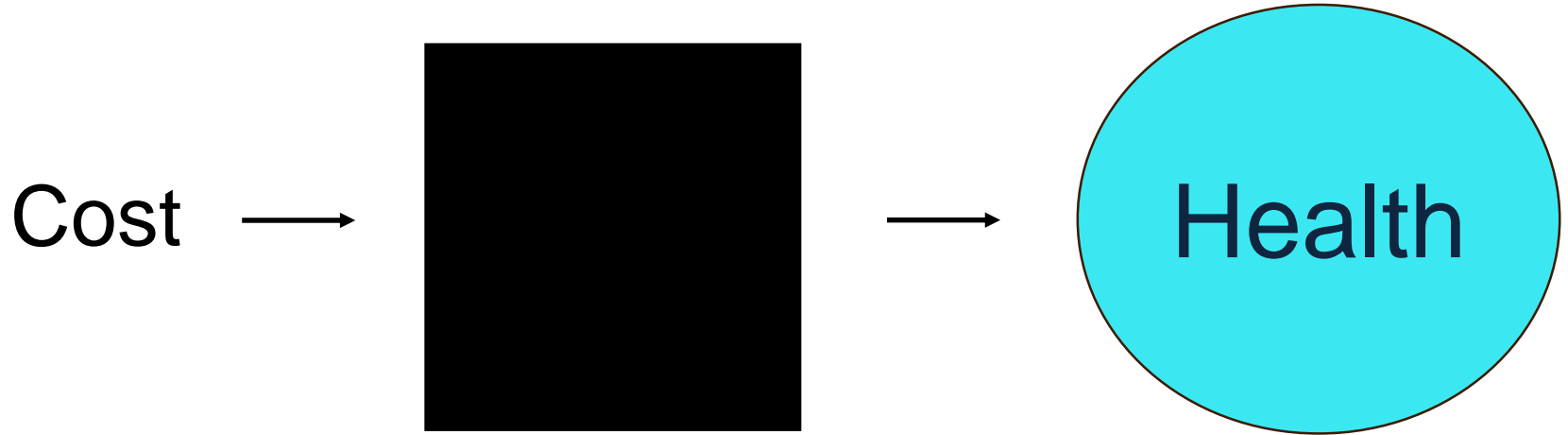


Economic analysis

Cost

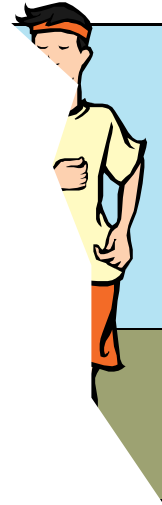
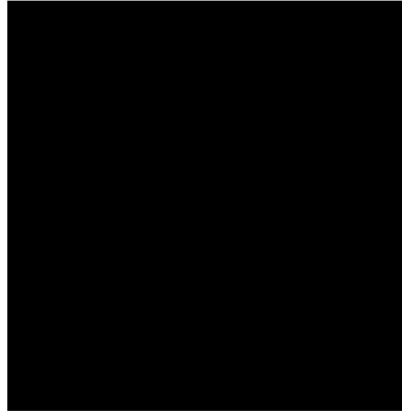


Economic analysis

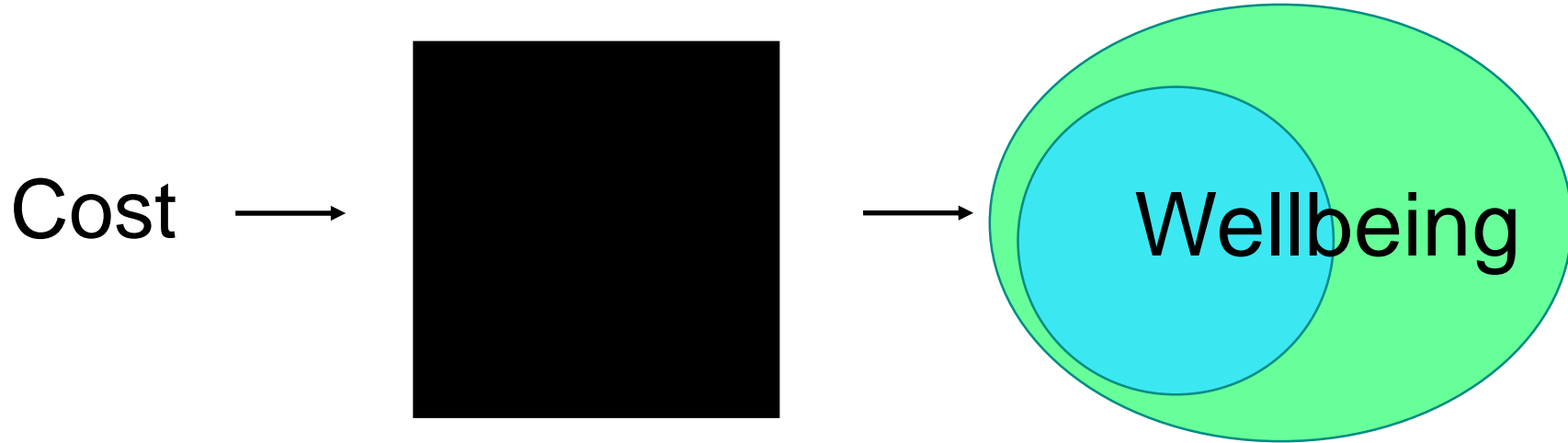


Economic analysis

Cost



Economic analysis



The Mail Online – June 9th 2014



Dying cancer patient left to
wait on trolley

The Mail Online – June 9th 2014

The value of care?



Dying cancer patient left to
wait on trolley

The Mail Online – June 9th 2014

‘conventional CEA underestimates the value
of care in the face of death’

(Menzel et al, 1999)



Dying cancer patient left to
wait on trolley



‘conventional CEA underestimates the value of care in the face of death’

(Menzel et al, 1999)

Dying cancer patient left to wait on trolley

A hospital today launched an investigation after a cancer patient was left waiting on a trolley for 16 hours shortly before she died.

Goals of end of life care

“Helps all those with advanced, progressive, incurable illness to live as well as possible until they die.

It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.

It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.”

(National Council for Palliative Care)

Focus groups on end of life decision making

6E68: ...end of life care's different from everything else in that you're not making a person better, you're just making a person comfortable and happy...

6E69: I'd argue that the guiding principle should be need... and compassion. If I were a policy maker I'd be looking at that

6C3: ... [families] haven't always got the support ... sometimes it's not enough, it's not enough at all

Possible evaluative spaces

**GOOD:
hospice
provision**



Possible evaluative spaces

**GOOD:
hospice
provision**

**UTILITY:
pleasure
obtained from
receiving the
care**



Possible evaluative spaces

**GOOD:
hospice
provision**

**UTILITY:
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**HEALTH:
improvements in
morbidity and mortality**

Possible evaluative spaces

GOOD:
hospice
provision

UTILITY:
pleasure
obtained from
receiving the
care



HEALTH:
improvements in
morbidity and mortality

CAPABILITY:
what you are able to do or be
e.g. ability to make
preparations

ICECAP measures for use at end of life

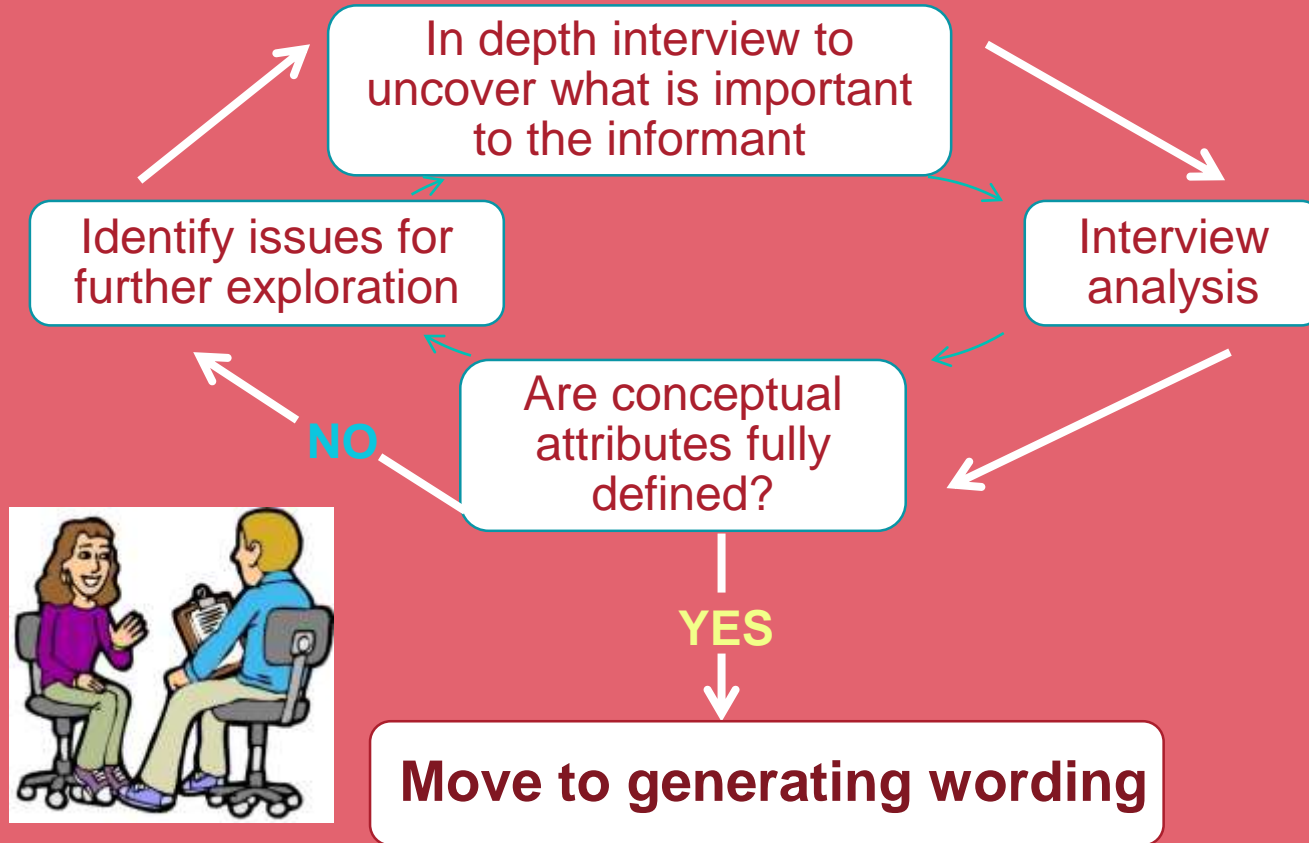
Economic analysis for palliative care

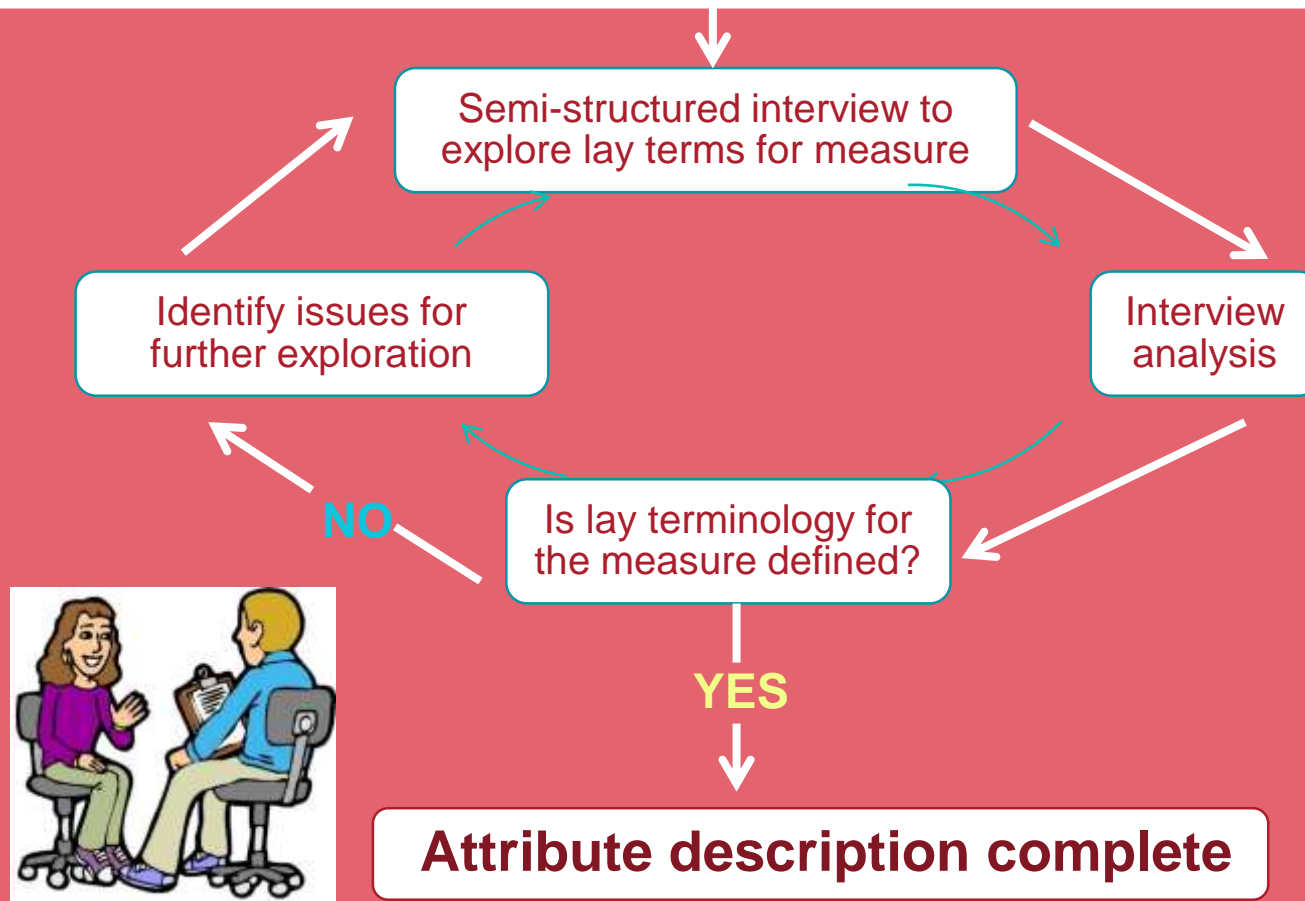
- Capability as a broad evaluative space that captures all the consequences that are relevant
 - ICECAP Supportive Care Measure (ICECAP-SCM)
 - ICECAP Close Person Measure (ICECAP-CPM)



ICECAP development – all versions

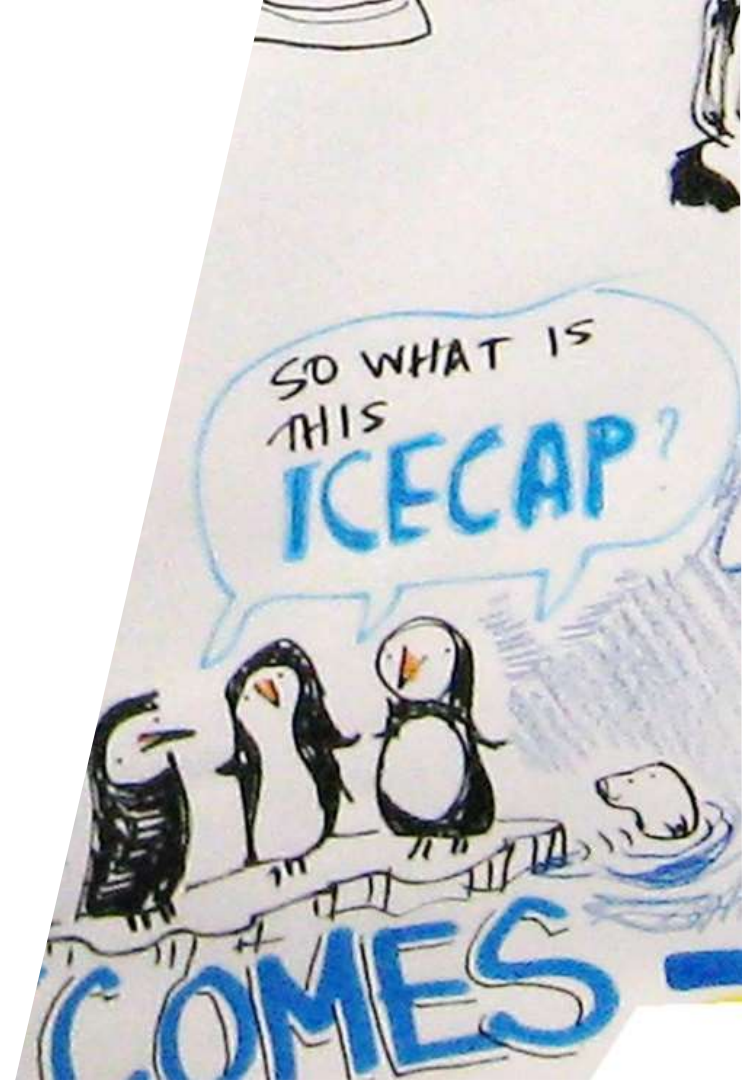
- **Phase 1:** in-depth interviews to generate conceptual attributes for measures, analysed using constant comparative methods
- **Phase 2:** semi-structured interviews to check attributes and develop meaningful wording for measures
- **Phase 3:** valuation using best-worst scaling amongst general population
- **Phase 4:** assessment of feasibility, validity, reliability, sensitivity to change





ICECAP Supportive Care Measure (ICECAP-SCM)

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Methods

- First phase
 - 23 Interviews with those at various stages along dying trajectory
 - explored what informants felt was important about end of life care, dying and death
- Second phase
 - repeat interviews with 12 informants
 - checked attributes & generated wording
- Third Phase
 - Best-worst scaling with 6020 members of general public
 - 10% suffering from a life-limiting illness
 - 40% had experienced a close bereavement in previous two years

ICECAP-SCM – example attributes

- **Dignity** – maintaining your dignity and self-respect

I've got my self-respect, she [carer] doesn't stand there if I'm having a shower and all that, she just makes sure the windows are covered ... we all want our self-respect no matter who we are (Female, 68, PC)

- **Choice** – having a say in decisions that affect your life and care

I don't want to be kept alive if I'm not fit enough to enjoy it (Female, 81, RC)

ICECAP-SCM – opportunity for a good death

1. **Having a say** (Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you)
 2. **Being with people who care about you** (Being with family, friends or caring professionals)
 3. **Physical suffering** (Experiencing pain or physical discomfort which interferes with your daily activities)
 4. **Emotional suffering** (Experiencing worry or distress, feeling like a burden)
 5. **Dignity** (Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected)
 6. **Being supported** (Having help and support)
 7. **Being prepared** (Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will)
-

ICECAP-SCM – health

1. **Having a say** (Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you)
 2. **Being with people who care about you** (Being with family, friends or caring professionals)
 3. **Physical suffering** (Experiencing pain or physical discomfort which interferes with your daily activities)
 4. **Emotional suffering** (Experiencing worry or distress, feeling like a burden)
 5. **Dignity** (Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected)
 6. **Being supported** (Having help and support)
 7. **Being prepared** (Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will)
-

ICECAP-SCM – care

1. **Having a say** (Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you)
 2. **Being with people who care about you** (Being with family, friends or caring professionals)
 3. **Physical suffering** (Experiencing pain or physical discomfort which interferes with your daily activities)
 4. **Emotional suffering** (Experiencing worry or distress, feeling like a burden)
 5. **Dignity** (Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected)
 6. **Being supported** (Having help and support)
 7. **Being prepared** (Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will)
-

ICECAP-SCM – broader capabilities

1. **Having a say** (Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you)
2. **Being with people who care about you** (Being with family, friends or caring professionals)
3. **Physical suffering** (Experiencing pain or physical discomfort which interferes with your daily activities)
4. **Emotional suffering** (Experiencing worry or distress, feeling like a burden)
5. **Dignity** (Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected)
6. **Being supported** (Having help and support)
7. **Being prepared** (Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will)

ICECAP-SCM

ABOUT YOUR WELL-BEING

Please place a tick (✓) in ONE box in EACH group below, to indicate which statement best describes your situation at the moment. **For each group please tick one box only.**

1) Having a say – Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you

I can make decisions that I need to make about my life and care most of the time	<input type="checkbox"/>
I can make decisions that I need to make about my life and care some of the time	<input type="checkbox"/>
I can make decisions that I need to make about my life and care only a little of the time	<input type="checkbox"/>
I can never make decisions that I need to make about my life and care	<input type="checkbox"/>

2) Being with people who care about you – Being with family, friends or caring professionals

If I want to, I can be with people who care about me most of the time	<input type="checkbox"/>
If I want to, I can be with people who care about me some of the time	<input type="checkbox"/>
If I want to, I can be with people who care about me only a little of the time	<input type="checkbox"/>
If I want to, I can never be with people who care about me	<input type="checkbox"/>

3) Physical suffering – Experiencing pain or physical discomfort which interferes with your daily activities

I always experience significant physical discomfort	<input type="checkbox"/>
I often experience significant physical discomfort	<input type="checkbox"/>
I sometimes experience significant physical discomfort	<input type="checkbox"/>
I rarely experience significant physical discomfort	<input type="checkbox"/>

4) Emotional suffering – Experiencing worry or distress, feeling like a burden

I always experience emotional suffering	<input type="checkbox"/>
I often experience emotional suffering	<input type="checkbox"/>
I sometimes experience emotional suffering	<input type="checkbox"/>
I rarely experience emotional suffering	<input type="checkbox"/>

Please remember to tick one box only.

5) Dignity – Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected

I can maintain my dignity and self-respect most of the time	<input type="checkbox"/>
I can maintain my dignity and self-respect some of the time	<input type="checkbox"/>
I can maintain my dignity and self-respect only a little of the time	<input type="checkbox"/>
I can never maintain my dignity and self-respect	<input type="checkbox"/>

6) Being supported – Having help and support

I am able to have the help and support that I need most of the time	<input type="checkbox"/>
I am able to have the help and support that I need some of the time	<input type="checkbox"/>
I am able to have the help and support that I need only a little of the time	<input type="checkbox"/>
I am never able to have the help and support that I need	<input type="checkbox"/>

7) Being prepared – Having financial affairs in order, having your funeral planned, saying goodbye to family and friends, resolving things that are important to you, having treatment preferences in writing or making a living will

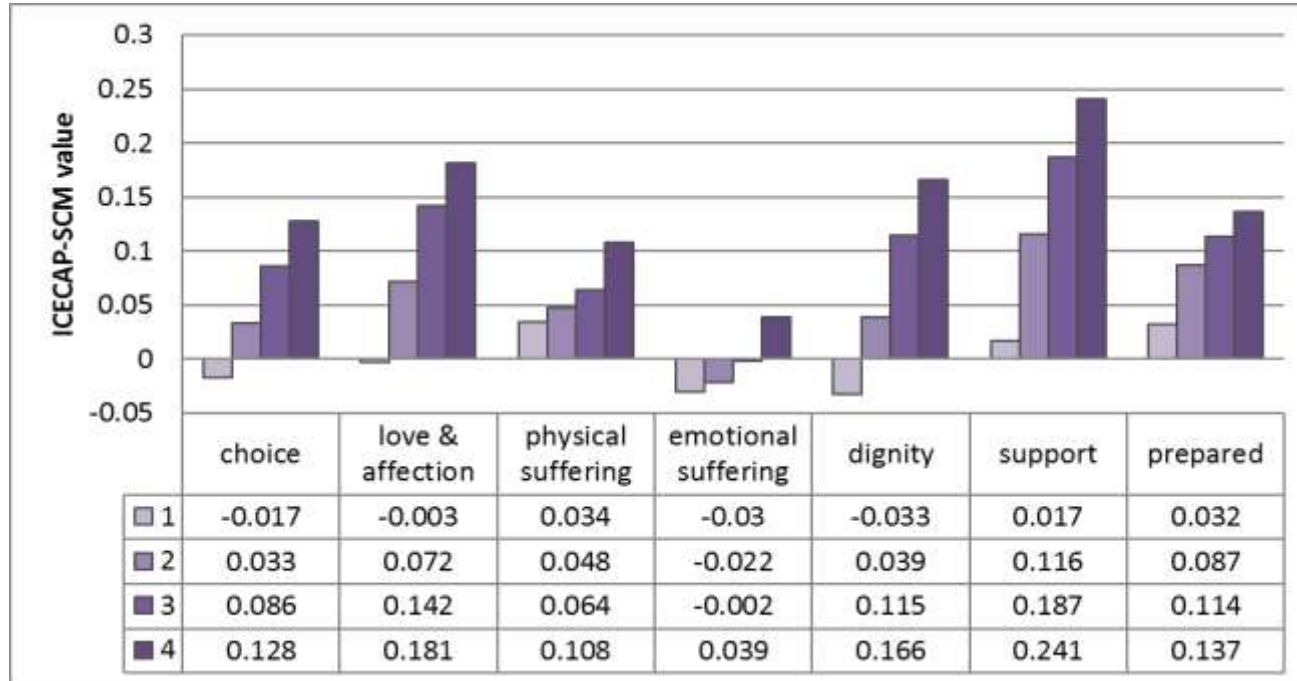
I have had the opportunity to make most of the preparations I want to make	<input type="checkbox"/>
I have had the opportunity to make some of the preparations I want to make	<input type="checkbox"/>
I have only had the opportunity to make a few of the preparations I want to make	<input type="checkbox"/>
I have not had the opportunity to make any of the preparations I want to make	<input type="checkbox"/>

Thank you for your help

Sutton & Coast, Palliative Medicine, 2014; 28:151-157.

Estimating a score: SCM

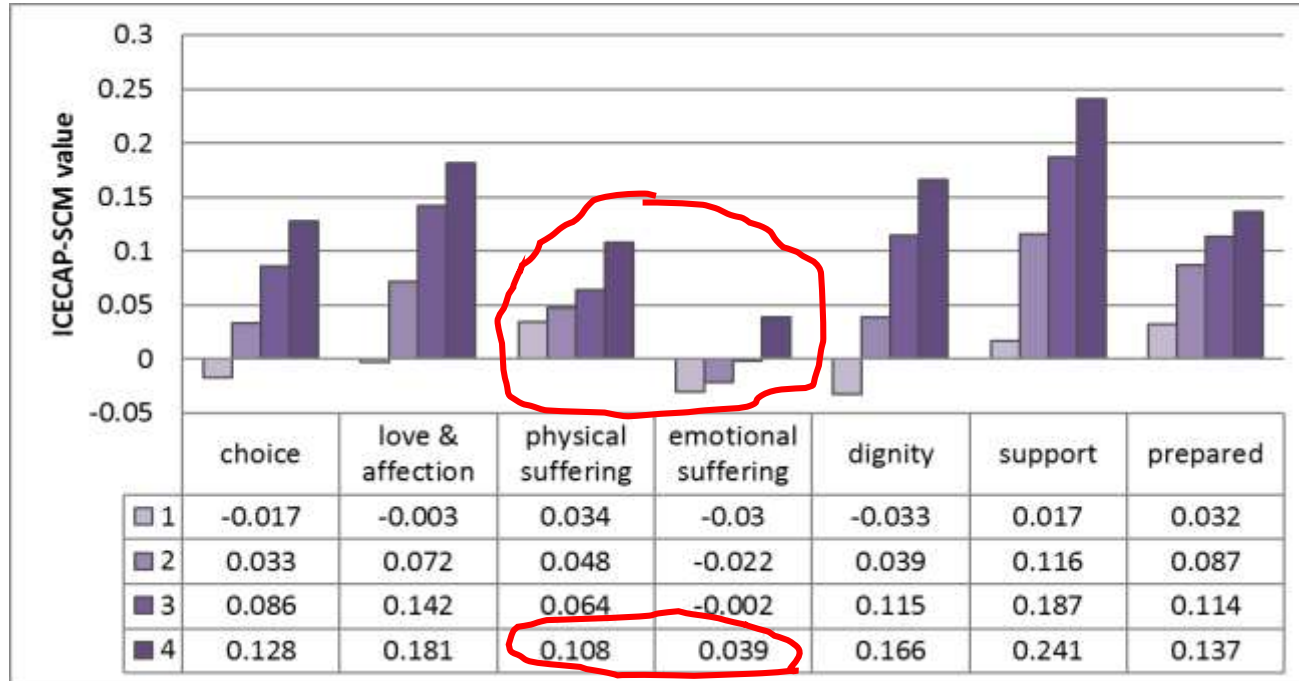
No capability on all attributes: value 0
A little capability on all attributes: value 0.373
A lot of capability on all attributes: value 0.706
Full capability on all attributes: value 1



*Huynh et al, Soc
Sci Med, 2017;
189:114-128.*

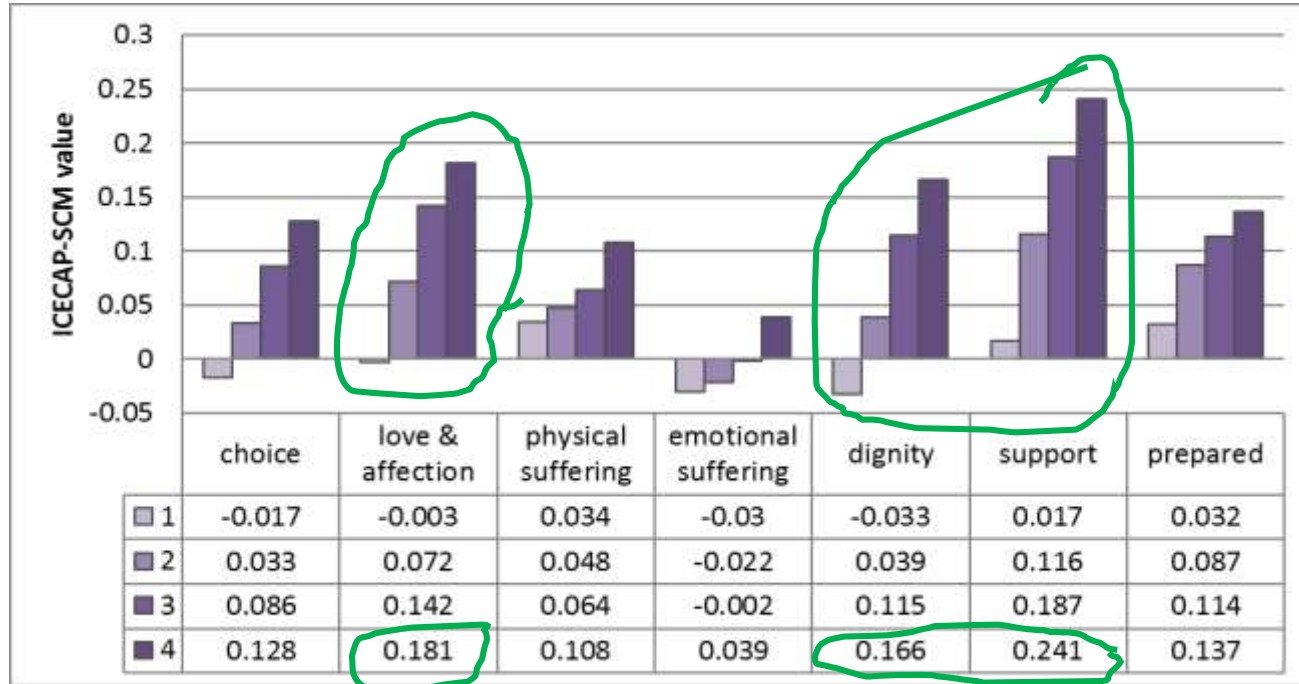
Health importance

No capability on all attributes: value 0
A little capability on all attributes: value 0.373
A lot of capability on all attributes: value 0.706
Full capability on all attributes: value 1



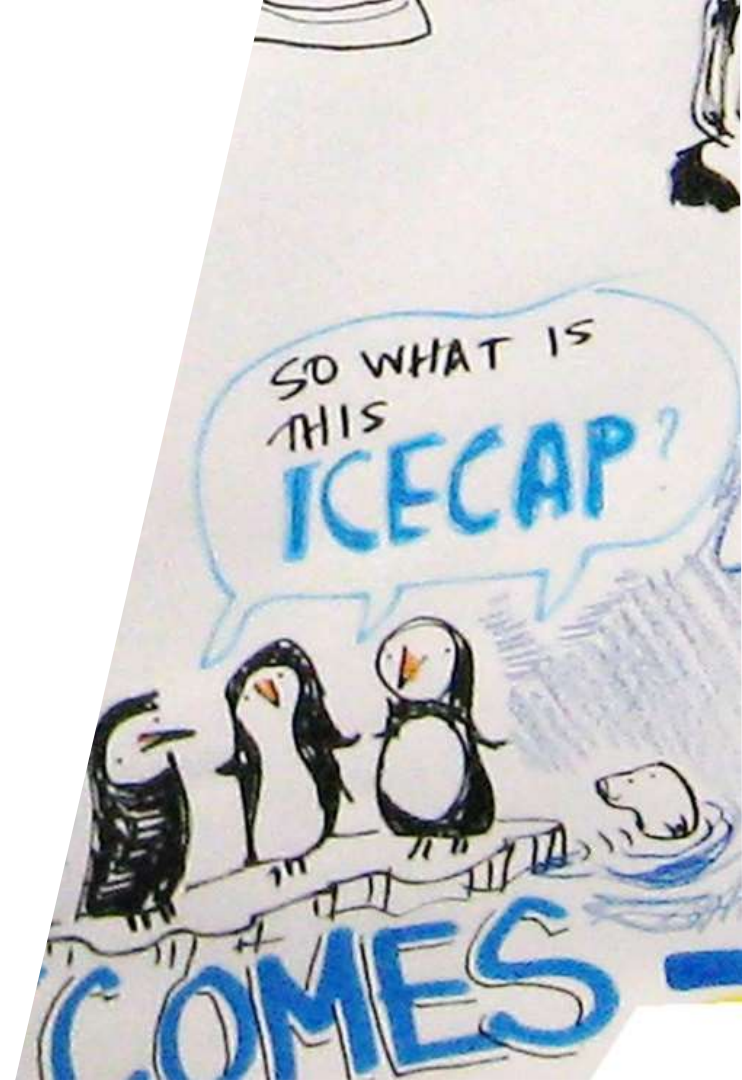
Most important...

No capability on all attributes: value 0
A little capability on all attributes: value 0.373
A lot of capability on all attributes: value 0.706
Full capability on all attributes: value 1



ICECAP Close Person Measure (ICECAP-CPM)

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Methods

- First and second phases combined
 - 27 interviews with those bereaved for between 7 and 24 months OR currently caring for a person at the end of life
 - questions about the participant and their relationship to the decedent
 - experiences of end of life care and bereavement
 - Later interviews checked coverage of the attributes, explored possible wording and tested drafts of the measure with participants
- Third Phase
 - Preliminary values: deliberative methods with 38 members of public

Communication: illustrative quotes

CDX5: *“but what I feel end of life care should be is firstly: communication with family and telling you what’s going on and telling you what can be done”*

CDX7: *“no, nobody talked, nobody said anything clearly...but maybe we should have gone to ask, but trying to find people sometimes is a nightmare, trying to find people to talk to, of any sort of seniority that knows the...you know I’m not being rude about more ancillary staff but who know, you know how ill she is or what’s going on.”*

ICECAP-CPM

- Communication with those providing care services.
- Privacy and space
- Practical support
- Emotional support
- Preparing and coping
- Emotional distress



*Canaway et al, Palliative Medicine, 2017;
31(1):53-62.*

End of Life Impact

THINKING ABOUT YOUR EXPERIENCE, PLEASE TICK (✓) ONE BOX FOR EACH GROUP WHICH BEST DESCRIBES YOUR SITUATION

1. Communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- being able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being able to have rapport with those providing care.

- A. I have been able to have good communication all of the time..... ☐
- B. I have been able to have good communication most of the time..... ☐
- C. I have been able to have good communication some of the time..... ☐
- D. I have been able to have good communication a little of the time..... ☐
- E. I have been able to have good communication none of the time..... ☐

End of Life Impact

THINKING ABOUT YOUR EXPERIENCE, PLEASE TICK (✓) ONE BOX FOR EACH GROUP WHICH BEST DESCRIBES YOUR SITUATION

1. Communication with those providing care services (e.g. doctors, nurses and carers). This includes things like:

- being able to get information about the person's health and care;
- having been able to have a say in the care that the person receives;
- being able to ask questions, have them answered and have views respected;
- being at ease with those providing care.

- A. I have been able to have good communication **all** of the time..... 5
 B. I have been able to have good communication **most** of the time..... 4
 C. I have been able to have good communication **some** of the time..... 3
 D. I have been able to have good communication **a little** of the time..... 2
 E. I have been able to have good communication **none** of the time..... 1

2. Privacy and Space. This includes things like:

- having been able to have time with the person in private (e.g. a private room in hospital);
- having been able to be in a peaceful location with pleasant facilities;
- having been able to be with the dying person at the end of their life.

- A. I have been able to have privacy and space **all** of the time..... 5
 B. I have been able to have privacy and space **most** of the time..... 4
 C. I have been able to have privacy and space **some** of the time..... 3
 D. I have been able to have privacy and space **a little** of the time..... 2
 E. I have been able to have privacy and space **none** of the time..... 1

3. Practical Support. This includes things like:

- having been able to get practical support and help with the care of the person, such as nursing help, help from social services or help from family;
- being able to get practical support from employers such as time off when needed;
- being able to get practical support with bereavement processes and dealing with the person's affairs.

- A. I have been **fully able** to get practical support..... 5
 B. I have been **mostly able** to get practical support..... 4
 C. I have been **somewhat able** to get practical support..... 3
 D. I have been **mostly unable** to get practical support..... 2
 E. I have been **completely unable** to get practical support..... 1

4. Emotional Support. This includes things like:

- being able to get emotional support through family, friends or colleagues;
- being able to get emotional support through other services including charities and religion if applicable.

- A. I have been **fully able** to get emotional support..... 5
 B. I have been **mostly able** to get emotional support..... 4
 C. I have been **somewhat able** to get emotional support..... 3
 D. I have been **mostly unable** to get emotional support..... 2
 E. I have been **completely unable** to get emotional support..... 1

5. Preparing and Coping. This includes things like:

- being prepared for the person's death;
- having the person's post-bereavement affairs and funeral arrangements in order;
- being free from guilt and regrets.

- A. I have been **fully able** to prepare for and cope with, the person's death..... 5
 B. I have been **mostly able** to prepare for, and cope with, the person's death..... 4
 C. I have been **somewhat able** to prepare for, and cope with, the person's death..... 3
 D. I have been **mostly unable** to prepare for, and cope with, the person's death..... 2
 E. I have been **completely unable** to prepare for, and cope with, the person's death..... 1

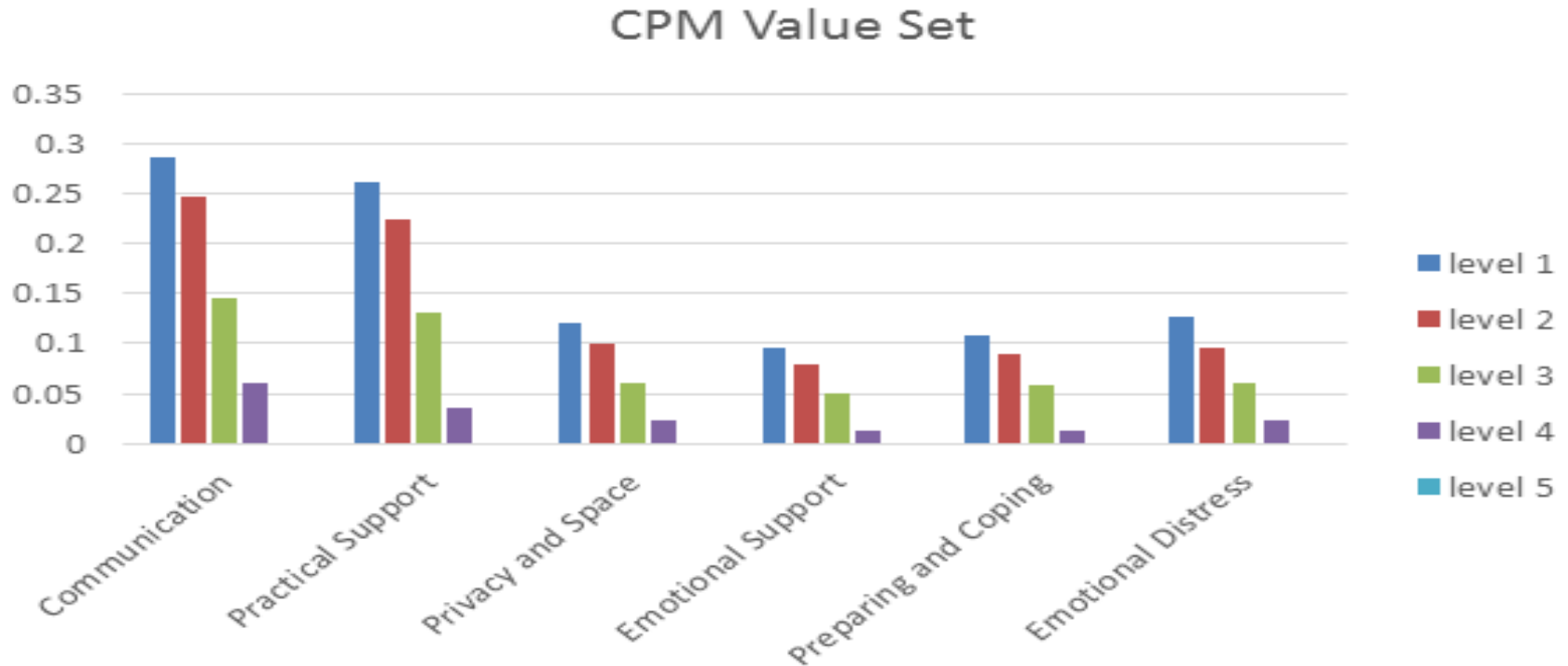
6. Emotional Distress to you, related to the condition of the person. This includes things like being free from emotional distress resulting from:

- seeing the person in pain and discomfort;
- seeing the loss of dignity, or a lack of respect given to the person;
- seeing a lack of care and attention given to the person.

- A. I have been **fully able** to be free from emotional distress..... 5
 B. I have been **mostly able** to be free from emotional distress..... 4
 C. I have been **somewhat able** to be free from emotional distress..... 3
 D. I have been **mostly unable** to be free from emotional distress..... 2
 E. I have been **completely unable** to be free from emotional distress..... 1

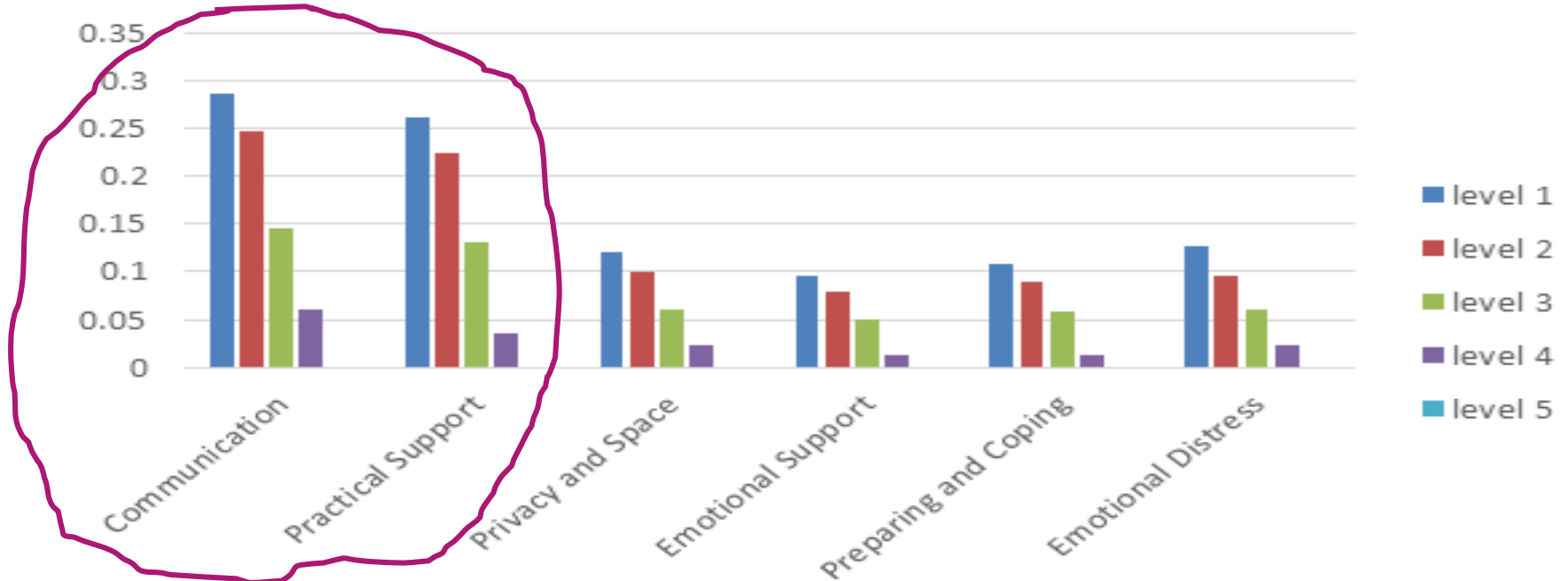
Thank you for your help with this research

ICECAP-CPM preliminary value set

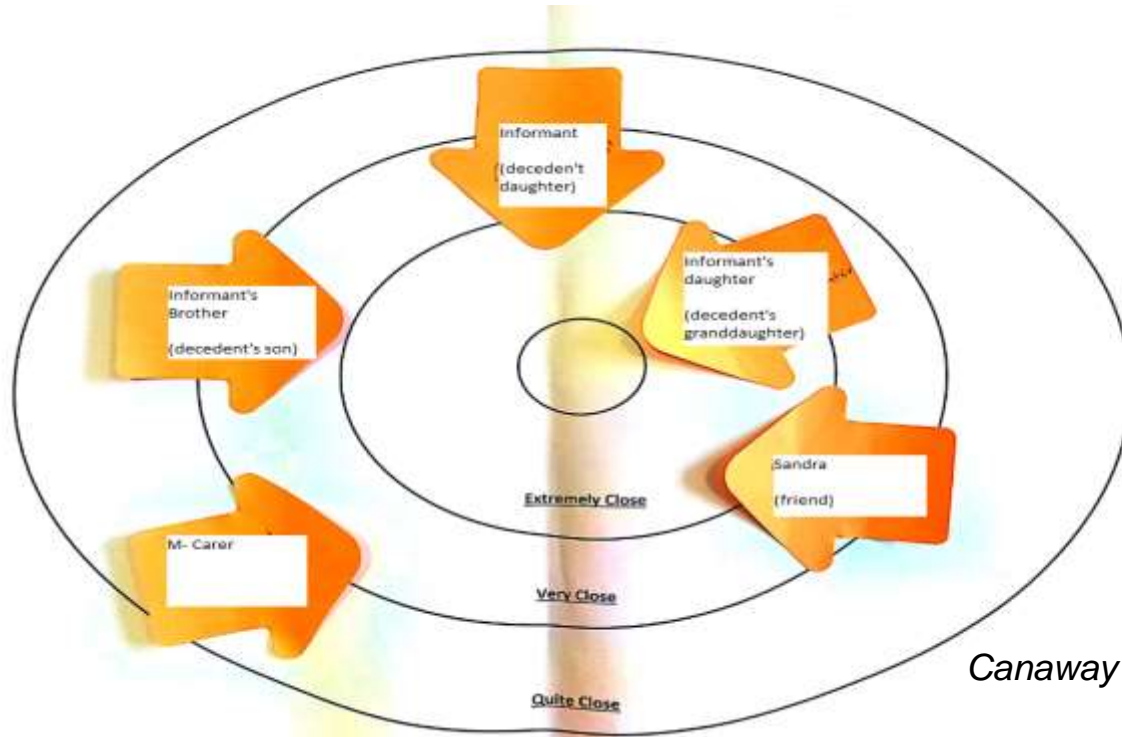


ICECAP-CPM preliminary value set

CPM Value Set

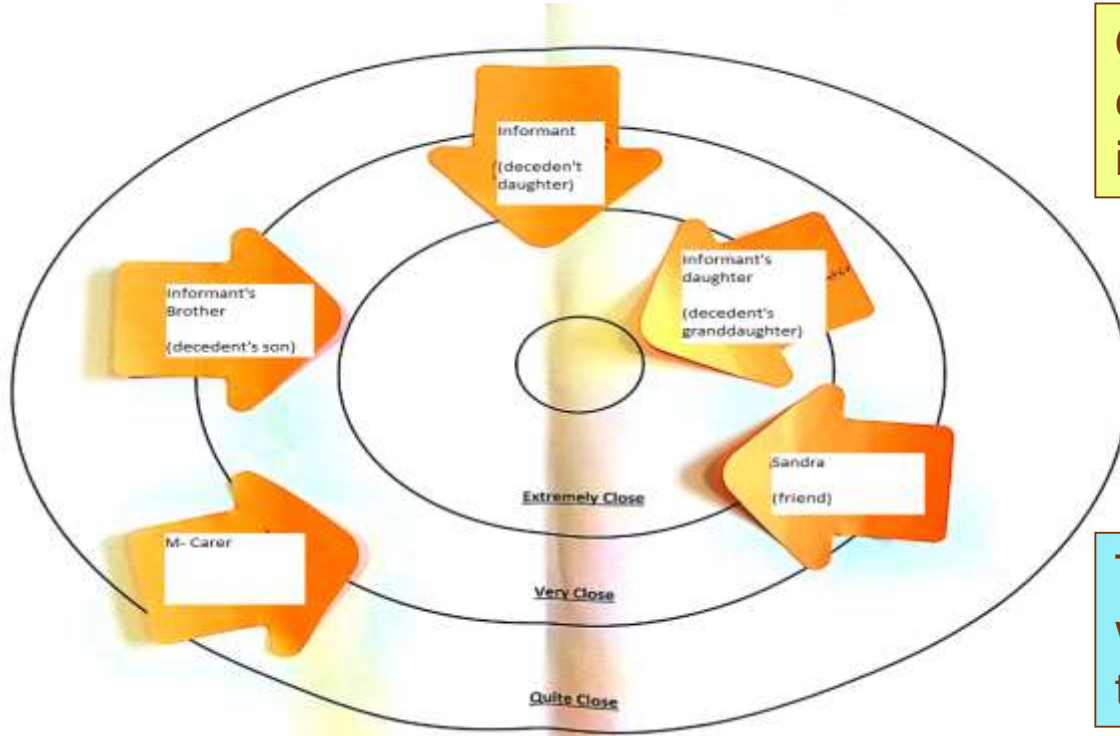


Who/how many close persons?



Canaway et al, *PharmacoEconomics*, 2019;37(4):573–583..

Who/how many close persons?



On average, eight close-persons included

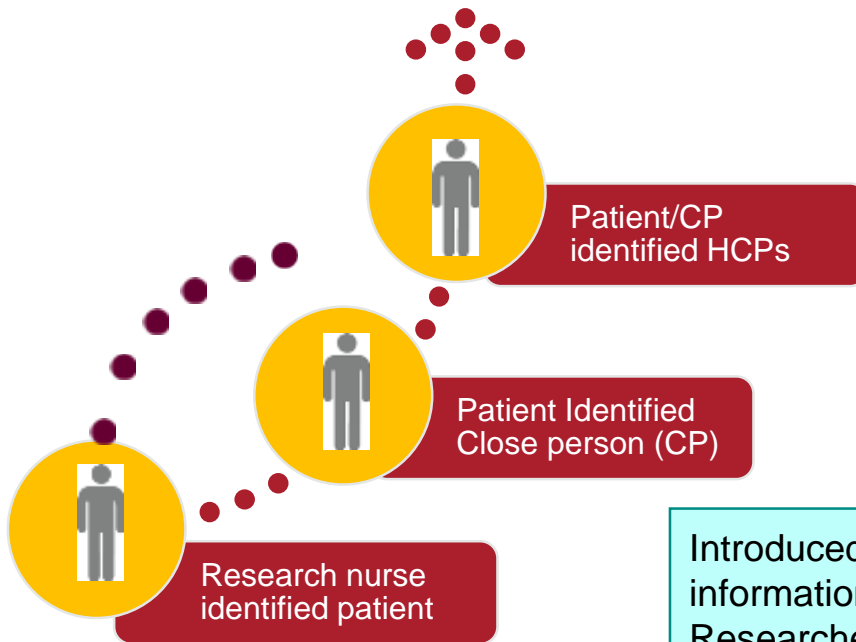
Typically, there were four within the inner circle

Evidence for use of the ICECAP-SCM in hospice settings

Qualitative/thinkaloud study of feasibility

- ❖ Receiving care through the hospice
- ❖ Sufficiently well to be able to provide informed consent & participate
- ❖ Wishing to participate
- ❖ Able to communicate in the English language

Hospice Inpatient Unit
Hospice Day Case
Community



Introduced study and provided information sheet.
Researcher contact and consent.

Think aloud

Introductory demographic questions

- Age
- Marital status
- Family circumstances
- Religion

Warm-up to 'think aloud'

- How many windows are in your house?
- Who have you seen today?
- Satisfaction with life question

Randomly allocated 3 scales for think aloud

- ICECAP-SCM
- ICECAP-A
- EQ5D-5L
- Prompted to 'think aloud'

Semi-structured Interview

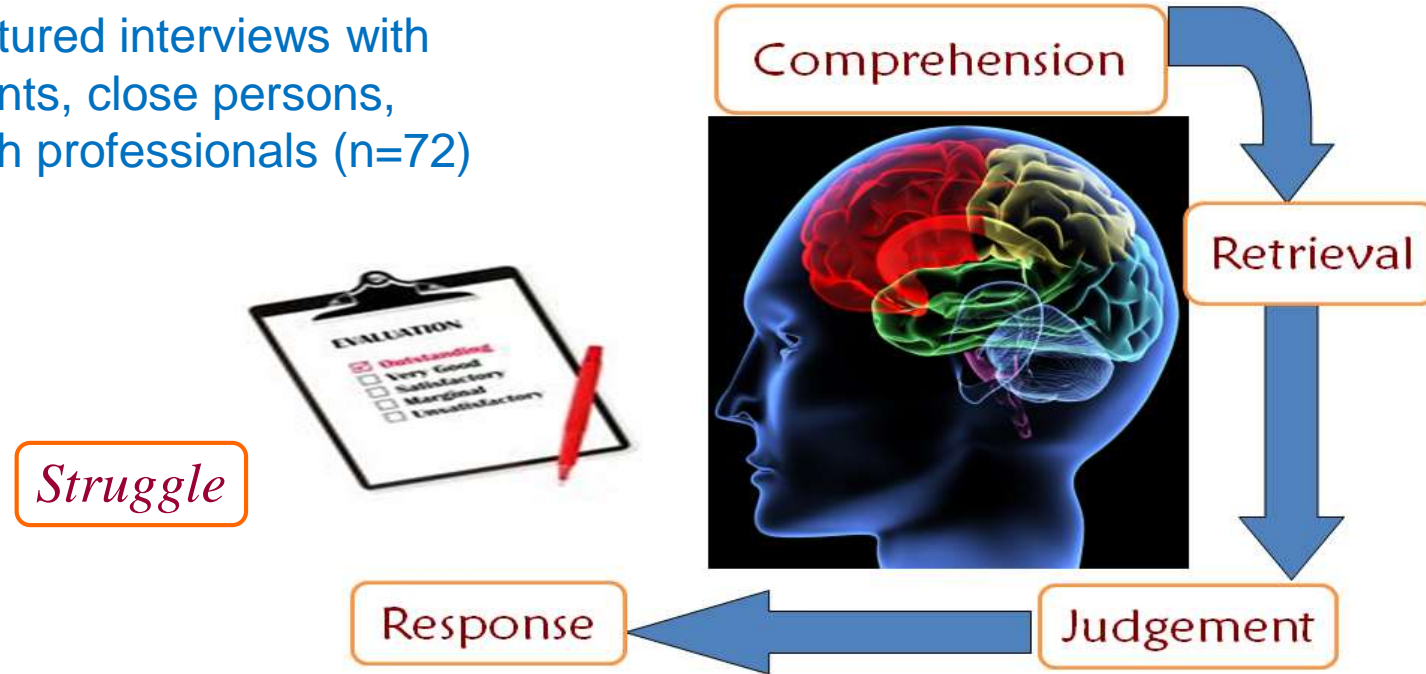
- Errors/struggles
- Scale completion
- Preference
- Aftercare

Interviews audio-recorded - lasted approx. 30 mins



Methods: Think aloud

'Think aloud' with semi-structured interviews with patients, close persons, health professionals (n=72)



Error scoring

- Few errors in ICECAP-SCM completion (n=10), compared to ICECAP-A (n=12) and EQ5D-5L (n=16), despite having more attributes
- ICECAP-SCM:
 - 'Support' error free
 - 'Preparation' had most errors (n=4)

“That’s a difficult one... We haven’t got the funeral planned, because my wife won’t talk about it. She won’t talk about how she’ll manage with the money... She don’t want to know” (PT27)

Support	Preparation
0	0
0	0
0	1
0	1
0	2
0	4

Positive perceptions of ICECAP-SCM

“I think they were all pretty straightforward... I think [the ICECAP-SCM] with me everything was applicable to my situation” (PT02)

“It seems like a better choice than the other two, because, it’s more about me, what I’m really like (PT26)

“That [ICECAP-SCM] tells you more about what I’m going through, that does” (PT27)

“I suppose that one really [ICECAP-SCM], I found easier” (PT22)



Using in practice: Day Hospice Study

- Capability approach: ICECAP-SCM
 - Choice
 - Love & affection
 - Physical suffering
 - Emotional suffering
 - Dignity
 - Support
 - Preparation
- Standard 'health' approach: EQ-5D-5L
 - Mobility
 - Self-care
 - Usual activities
 - Anxiety/depression
 - Pain/discomfort

*Mitchell et al. BMC Palliative Care
(2020) 19:119*

Little change in outcome at 4 weeks

- Centre 3 had largest numbers included (n=22)
 - Health change -0.03
 - Capability change $+0.03$
 - Very small numbers...
- But shows that different perspectives on outcome can give different answers



To conclude...

- Interventions at the end of life need to be evaluated to aid decision making about what should be done
 - Capability provides one option for evaluating the benefits of intervention
 - going beyond health
 - ICECAP measures can be used to capture impacts on those at end of life, and those close to them
 - Good evidence on feasibility of use
 - Limited evidence as yet on validity, reliability, responsiveness to change
-



Acknowledgements:

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Samantha Husbands
Tom Keeley
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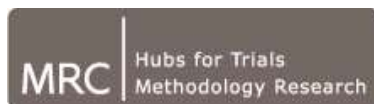
Advisory Groups

ICEPOP
ICECAP-A
EconEndLife
LifeCourseCap



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