

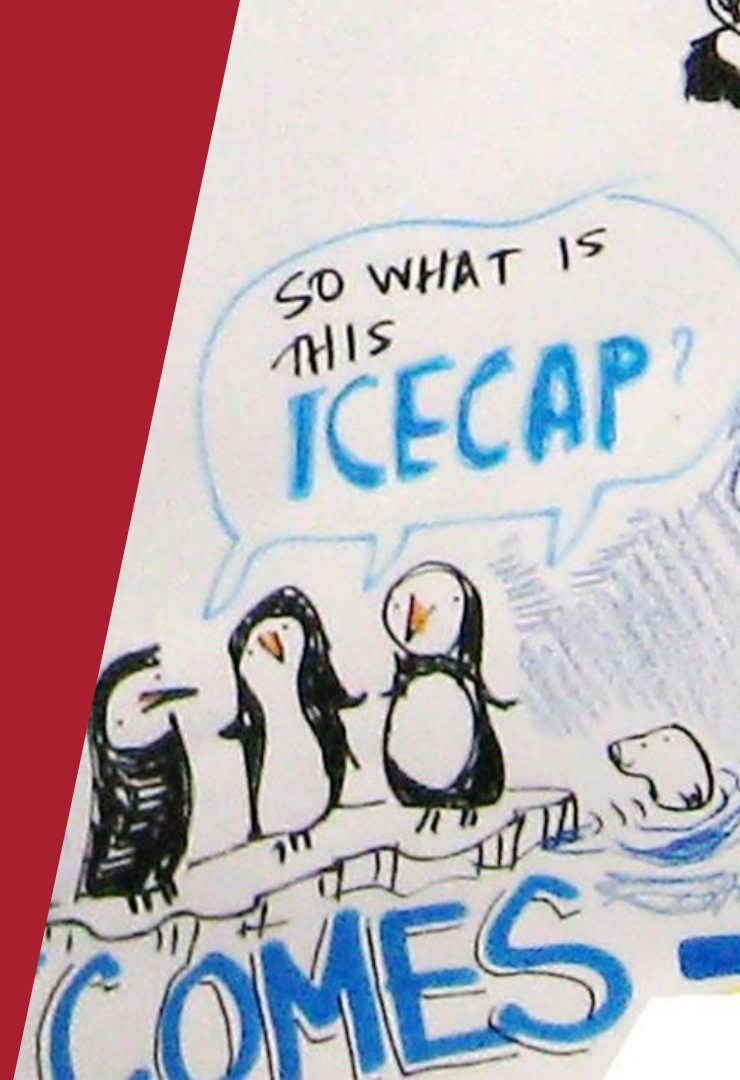
Who to treat? Allocation of health resources using the capability approach?

Joanna Coast

BMA – Justice and fairness

Online, December 2020

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Outline

- The rationing context
- The capability approach
 - Why capabilities rather than health for resource allocation?
 - What capabilities matter?
- Who to treat? Rationing, capabilities and covid-19
 - What should be prioritised for care home residents?
 - What interventions should have priority among non-covid patients?
 - Should we prioritise Christmas?

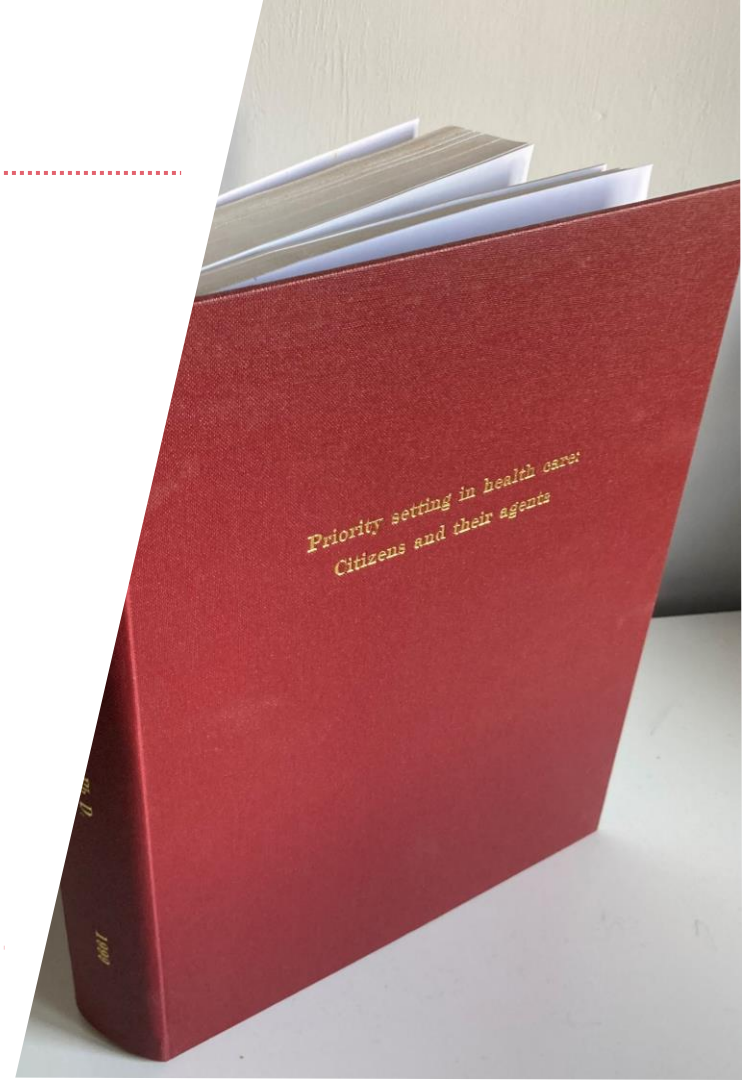
The rationing context

*Priority setting in health care:
Citizens and their agents*

More than 20 years ago

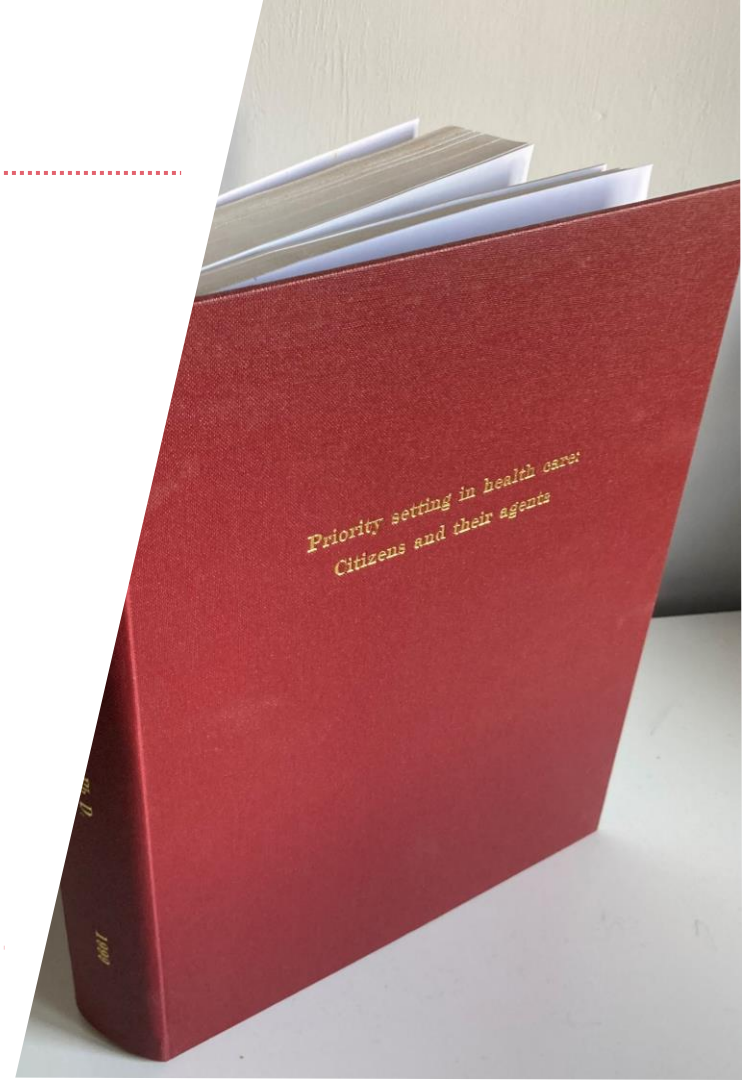
- Citizens & ‘agents’
 - ... surprisingly un-dated
 - Basic values
 - Care for all
 - Care when needed
 - Quality care
 - “free” health care is a mechanism for ensuring these
 - Constraints: reality & morality
-

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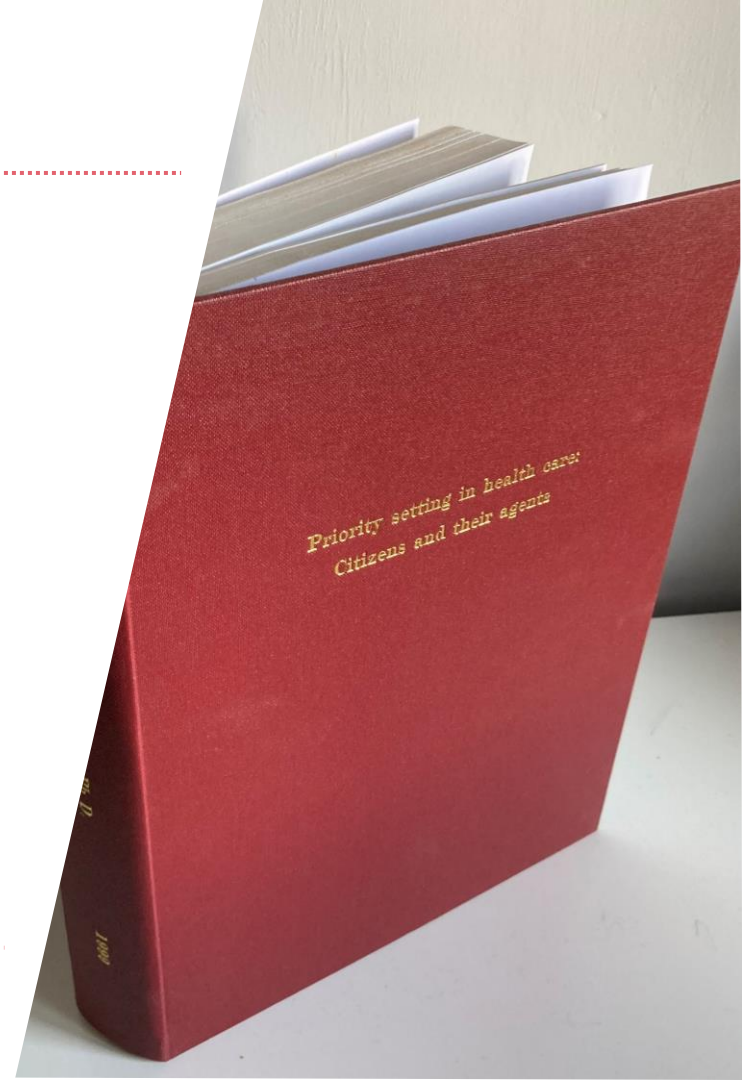
Reality & morality?

“If there was a war
tomorrow, you’d find the
money”



Reality & morality?

“If there was a **pandemic** tomorrow, you’d find the money”



The capability approach

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DEVELOPMENT AS FREEDOM

AMARTYA
SEN

OXFORD

Humanism and beyond

EDITED BY AMARTYA SEN
& BERNARD WILLIAMS

CAMBRIDGE

Idea of Justice AMARTYA SEN



NUSSBAUM AND SEN

THE QUALITY OF LIFE



ON ETHICS & ECONOMICS SEN

IDRC

An Introduction to
the Human Development
and Capability Approach

Edited by
Séverine Deneulin
with Lila Shahani

earthscan

CHOICE, WELFARE

RVARD

The capability approach

- Equity of what? An alternative evaluative space
 - Functionings – what an individual does or is e.g. well-nourished, healthy, socially respected,
 - Capability – what an individual is ABLE to do or be, whether or not they then choose to do or be that
 - Opportunities are important, even if individuals choose not to pursue them

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Amartya Sen: capability as evaluative space

- Starving family?
 - Unable to eat because there is no food



- Fasting family?
 - Choose not to eat for religious reasons
 - Food is freely available

Capability is about opportunity, without requiring us to take that opportunity

The capability approach: why capabilities rather than health for resource allocation?

Why capability rather than health?

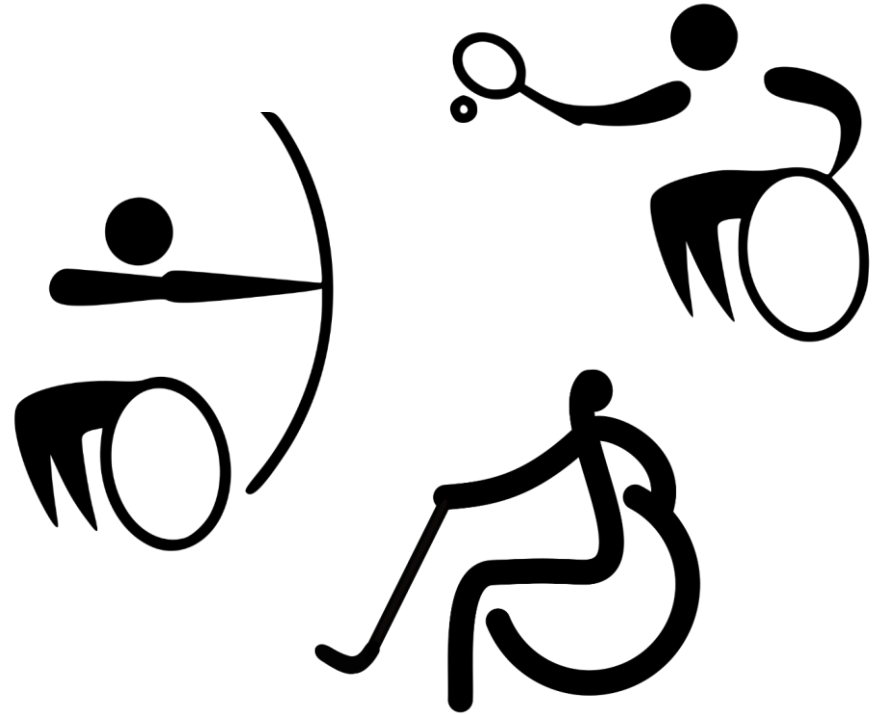


philipmartin.info

Why capability rather than health?



philipmartin.info



Why capability? Data from earlier work

I lost all my friends when I couldn't go out – for seven years I was looking after both my husband and my mother who was beginning to go senile

I can choose what I want to do, I can choose my friends, I can choose who I want to do things with

For the first time in my life I am dependent, which is not very pleasant...I can't go out as I did a few years ago - take the car and go swimming

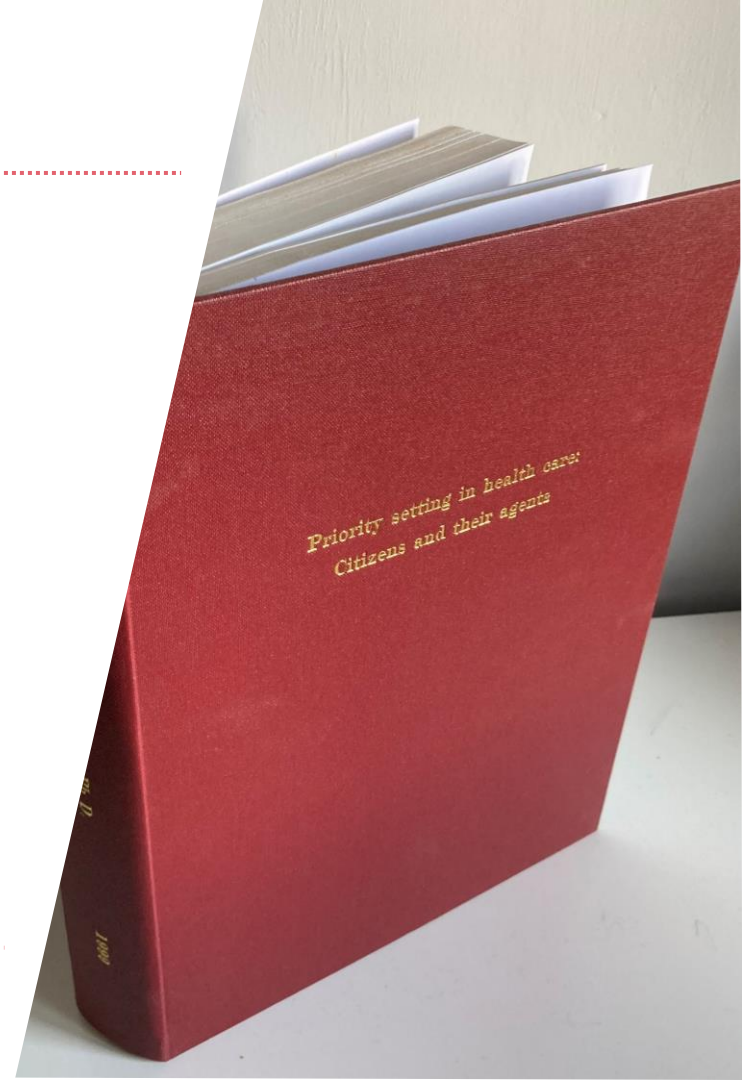
Fortunate in so far as that we've got the two pensions we're able to go off... we grabbed a cheapie flight at the end of April...

Capabilities & rationing

“... everybody should have an equal opportunity and equal chances, and that’s what we should be striving towards” (agent)

“...lots of cases of old people who are obviously incapable of looking after themselves, or financially unable to make ends meet. Obviously in any civilised community, you’re going to look after people like that” (citizen)

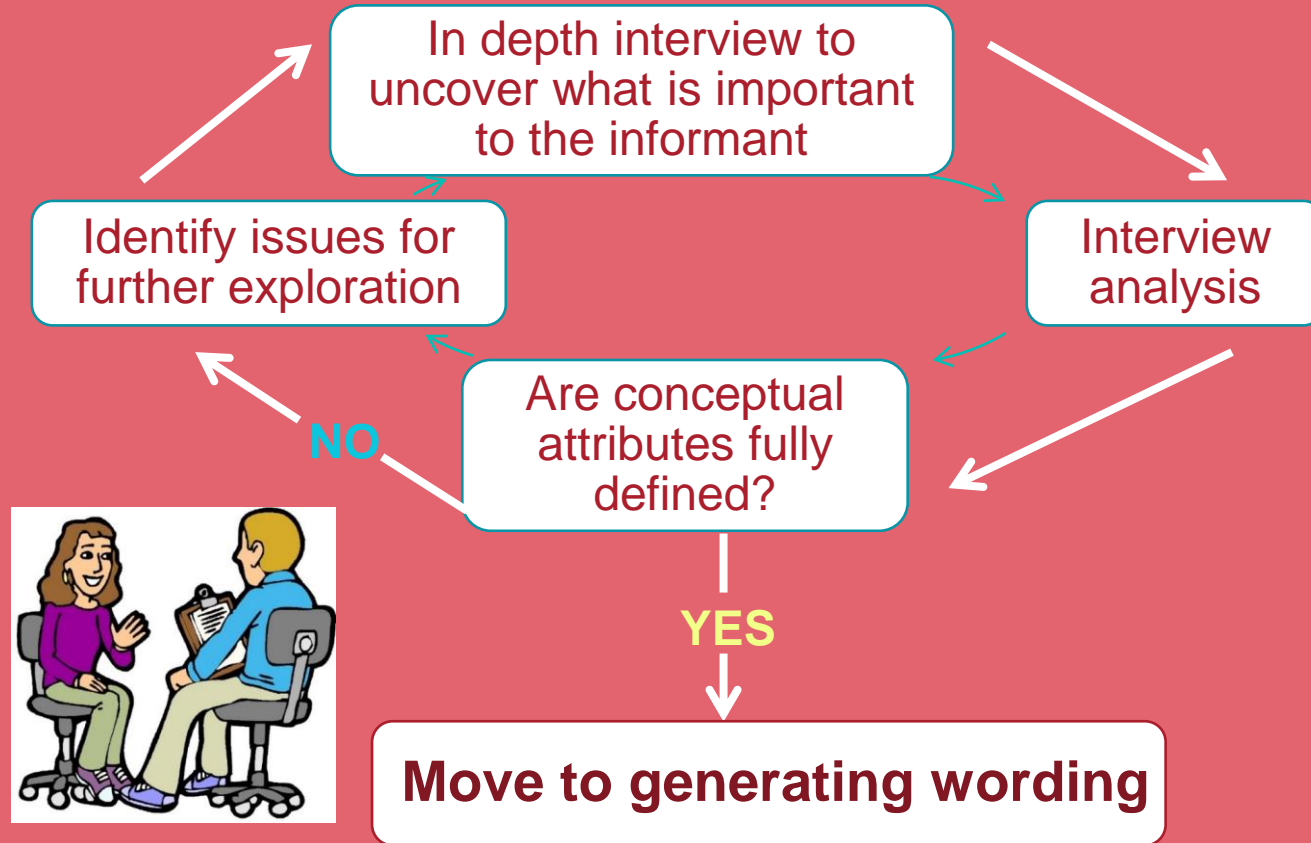
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A large, solid red triangle pointing downwards, located on the right side of the slide.

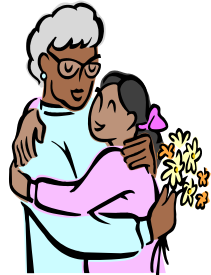
The capability approach:
what capabilities matter?

... and do the same
capabilities matter across
the life-course?



An example: family & other relationships

- “I look forward to hearing from them. I look forward to seeing them... And also hearing about their lives and what they’re up to” (F, 69)
- “They’re always there, if I want anything, need anything...” (M, 69)
- “He and I are very close...he lost his wife last year... and I’m just trying to help him” (M, 69)
- “I’ve got a friend... we go into the football club and play bingo...” (F, 80)



An example: family & other relationships

- “I look forward to hearing from them. I look forward to seeing them... And also hearing about their lives and what they’re up to” (F, 69) **ATTACHMENT**
- “They’re always there, if I want anything, need anything...” (M, 69) **SECURITY**
- “He and I are very close...he lost his wife last year... and I’m just trying to help him” (M, 69) **ROLE**
- “I’ve got a friend... we go into the football club and play bingo...” (F, 80) **ENJOYMENT**



Also for standard of health

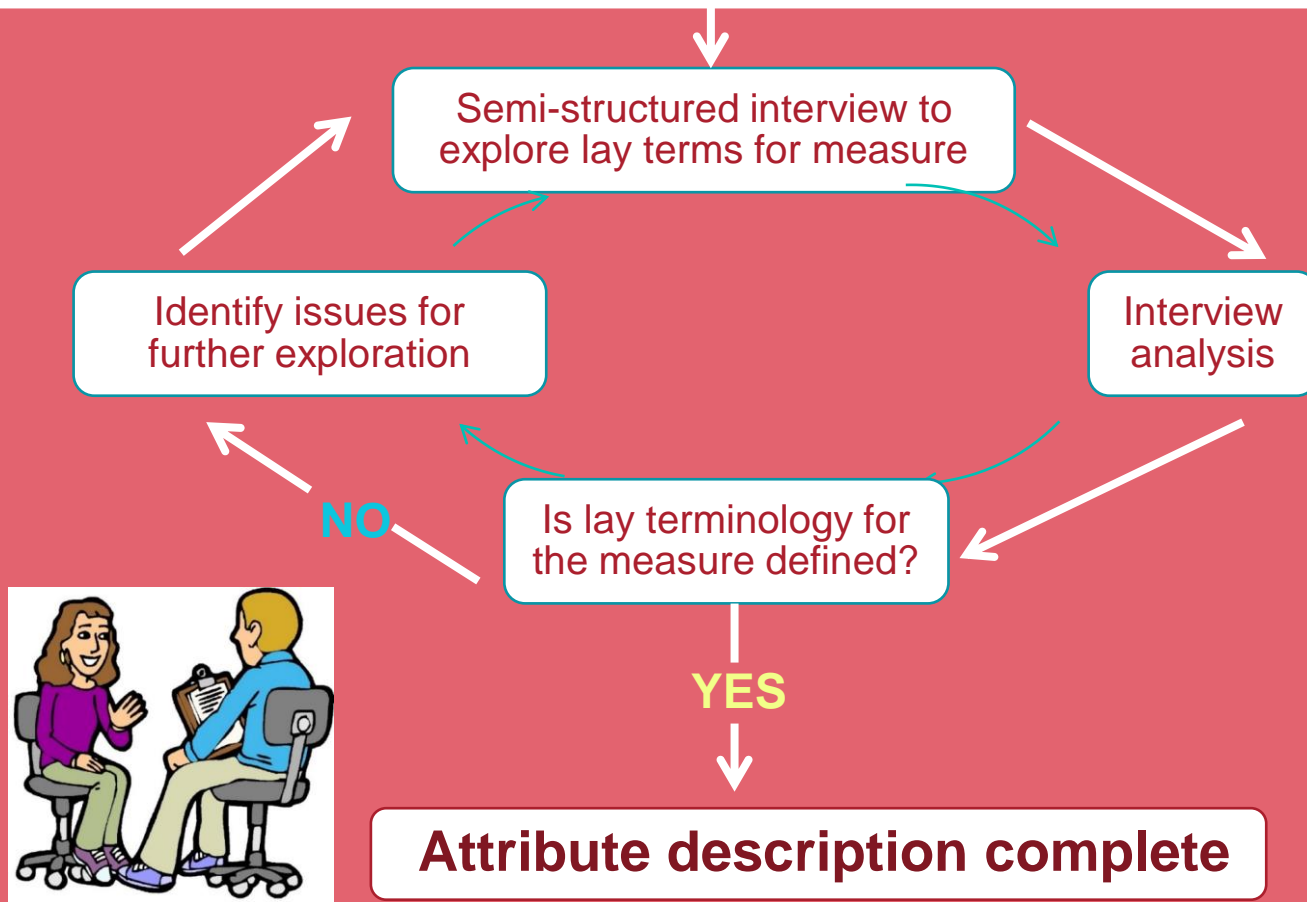
- “... I wouldn’t want to have to rely on other people...” (M, 69)
- “I wouldn’t be able to ramble if I didn’t enjoy good health...” (M, 77)
- “My family found it hard to believe their dad had Alzheimers... I said ‘you heard what he called me – make me a cup of coffee, Nurse.’ How do you think that makes me feel” (F, 85)



Also for standard of health

- “... I wouldn’t want to have to rely on other people...” (M, 69)
CONTROL
- “I wouldn’t be able to ramble if I didn’t enjoy good health...” (M, 77) **ENJOYMENT**
- “My family found it hard to believe their dad had Alzheimers... I said ‘you heard what he called me – make me a cup of coffee, Nurse.’ How do you think that makes me feel” (F, 85)
ATTACHMENT





ICECAP measures

- Measures of capability wellbeing
 - Focus on what people are able to do and be in their lives
- Draw on some lessons from the QALY approach
 - Based on a number of dimensions
 - Valued in a meaningful way
- Differ in important ways
 - Based on what people themselves feel is important
 - Anchored based on full capability and no capability (not death)



ICECAP-A

5 questions, each with 4 possible responses

Aims to tap into what is important to the general adult population

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ABOUT YOUR OVERALL QUALITY OF LIFE

Please indicate which statements best describe your overall quality of life at the moment by placing a tick (✓) in **ONE** box for each of the five groups below.

1. Feeling settled and secure

- I am able to feel settled and secure in **all** areas of my life
- I am able to feel settled and secure in **many** areas of my life
- I am only able to feel settled and secure in **a few** areas of my life
- I am **unable** to feel settled and secure in **any** areas of my life

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

2. Love, friendship and support

- I can have **a lot** of love, friendship and support
- I can have **quite a lot** of love, friendship and support
- I can only have **a little** love, friendship and support
- I **cannot** have **any** love, friendship and support

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

3. Being independent

- I am able to be **completely** independent
- I am able to be independent in **many** things
- I am only able to be independent in **a few** things
- I am **unable** to be at all independent

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

4. Achievement and progress

- I can achieve and progress in **all** aspects of my life
- I can achieve and progress in **many** aspects of my life
- I can only achieve and progress in **a few** aspects of my life
- I **cannot** achieve and progress in **any** aspects of my life

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

5. Enjoyment and pleasure

- I can have **a lot** of enjoyment and pleasure
- I can have **quite a lot** of enjoyment and pleasure
- I can only have **a little** enjoyment and pleasure
- I **cannot** have **any** enjoyment and pleasure

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

Please ensure you have only ticked **ONE** box for each of the five groups.

ICECAP-O

Measuring capability wellbeing for older people

- 5 questions, each with 4 response categories
- 1024 possible capability wellbeing states

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ABOUT YOUR QUALITY OF LIFE

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

1. Love and Friendship

- I can have all of the love and friendship that I want
I can have a lot of the love and friendship that I want
I can have a little of the love and friendship that I want
I cannot have any of the love and friendship that I want

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

2. Thinking about the future

- I can think about the future without any concern
I can think about the future with only a little concern
I can only think about the future with some concern
I can only think about the future with a lot of concern

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

3. Doing things that make you feel valued

- I am able to do all of the things that make me feel valued
I am able to do many of the things that make me feel valued
I am able to do a few of the things that make me feel valued
I am unable to do any of the things that make me feel valued

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

4. Enjoyment and pleasure

- I can have all of the enjoyment and pleasure that I want
I can have a lot of the enjoyment and pleasure that I want
I can have a little of the enjoyment and pleasure that I want
I cannot have any of the enjoyment and pleasure that I want

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

5. Independence

- I am able to be completely independent
I am able to be independent in many things
I am able to be independent in a few things
I am unable to be at all independent

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

Tick
one
box
only in
each
section

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**

I can make decisions that I need to make about my life and care **some of the time**

I can make decisions that I need to make about my life and care **only a little of the time**

I can **never** make decisions that I need to make about my life and care

4
3
2
1

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**

If I want to, I can be with people who care about me **some of the time**

If I want to, I can be with people who care about me **only a little of the time**

If I want to, I can **never** be with people who care about me

4
3
2
1

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

I **always** experience significant physical discomfort

I **often** experience significant physical discomfort

I **sometimes** experience significant physical discomfort

I **rarely** experience significant physical discomfort

4
3
2
1

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

I **always** experience emotional suffering

I **often** experience emotional suffering

I **sometimes** experience emotional suffering

I **rarely** experience emotional suffering

4
3
2
1

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**

I can maintain my dignity and self-respect **some of the time**

I can maintain my dignity and self-respect **only a little of the time**

I can **never** maintain my dignity and self-respect

4
3
2
1

6) Being supported – Having help and support

I am able to have the help and support that I need **most of the time**

I am able to have the help and support that I need **some of the time**

I am able to have the help and support that I need **only a little of the time**

I am **never** able to have the help and support that I need

4
3
2
1

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

I have had the opportunity to make **some** of the preparations I want to make

I have **only** had the opportunity to make a **few** of the preparations I want to make

I have **not** had the opportunity to make **any** of the preparations I want to make

4
3
2
1

Thank you for your help

ICECAP-SCM – varying focus for capability

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 – varying focus for capability

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5. **Dignity** (Being yourself, being clean, having privacy, being treated with respect, being spoken to with respect, having your religious or spiritual beliefs respected)
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ICECAP-SCM – varying focus for capability

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)
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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 – varying concepts

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)
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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)

Who to treat? Rationing, capabilities and covid-19

Known unknowns?



Topic

COVID 19: Known Unknowns (Facing up to scientific uncertainty during a pandemic)

Description

Join Dr Anna Godlee of The BMJ and Professor George Davey Smith of Bristol University and the MRC, plus their invited guests from leading institutions in the US, UK, Germany, Norway, Sweden, India, Hong Kong, Gabon and New Zealand, as they discuss many aspects of the covid pandemic. This is a day-long event (with regular breaks), and you are welcome to join for the whole day or to join us only for those topic sessions that most interest you or which you can accommodate in your schedule. Topics covered will include:

Can capability thinking help?

- Three exemplars:
 - What should be prioritised for care home residents/those at end of life?
 - Who should have priority among non-covid patients?
 - Should we prioritise Christmas? (or, covid v non-covid public health?)

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What should be prioritised
for care home residents/those
at the end of life?

Can capabilities be traded?

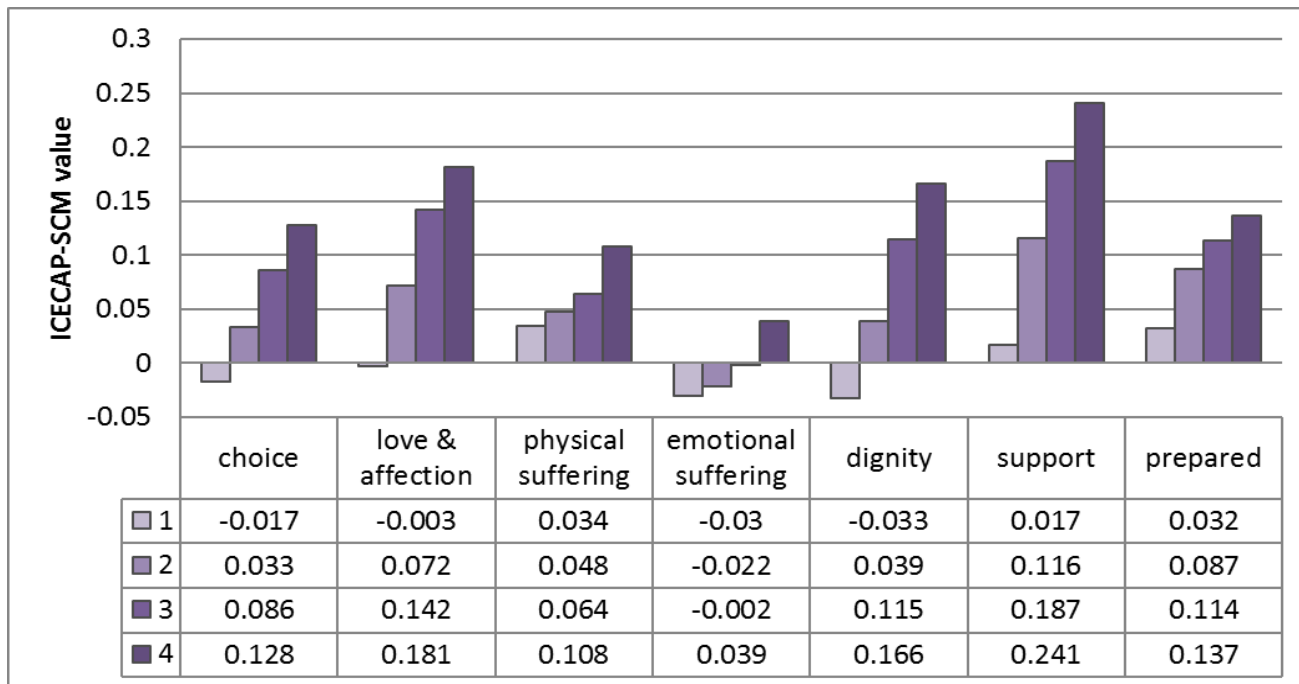
Difficult trade-offs for this group...

- Important attributes relating to residents being able to be with people who care about them
- as well as in relation to potential physical suffering and/or death from infection



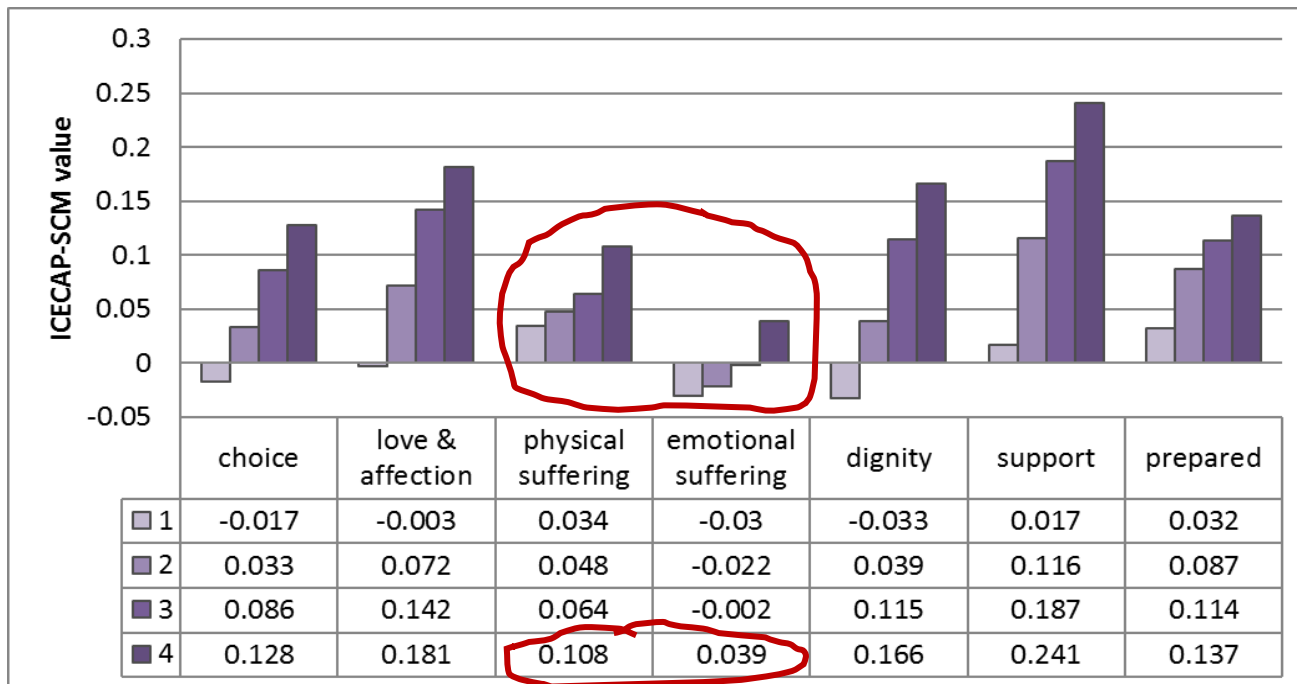
Value of capabilities?

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



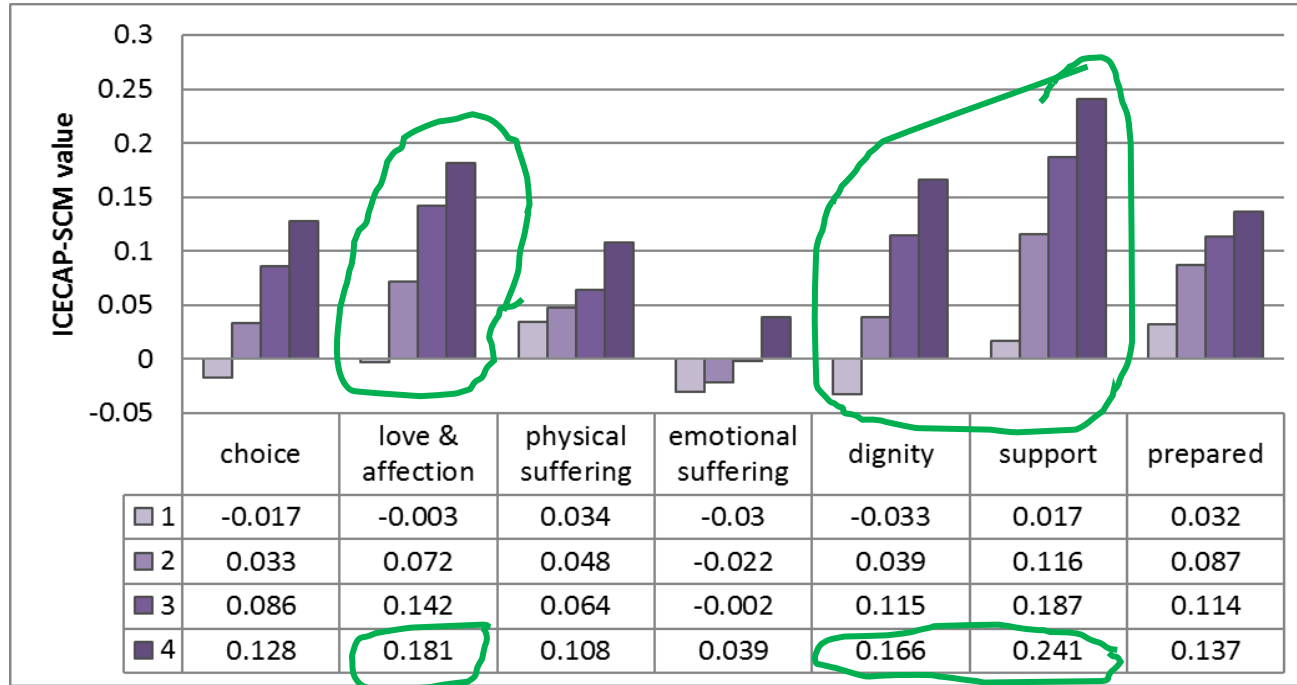
Health?

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...

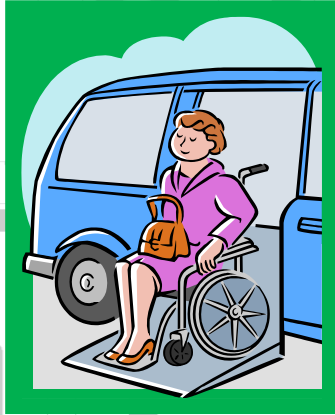
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Full capability on all attributes: value 1



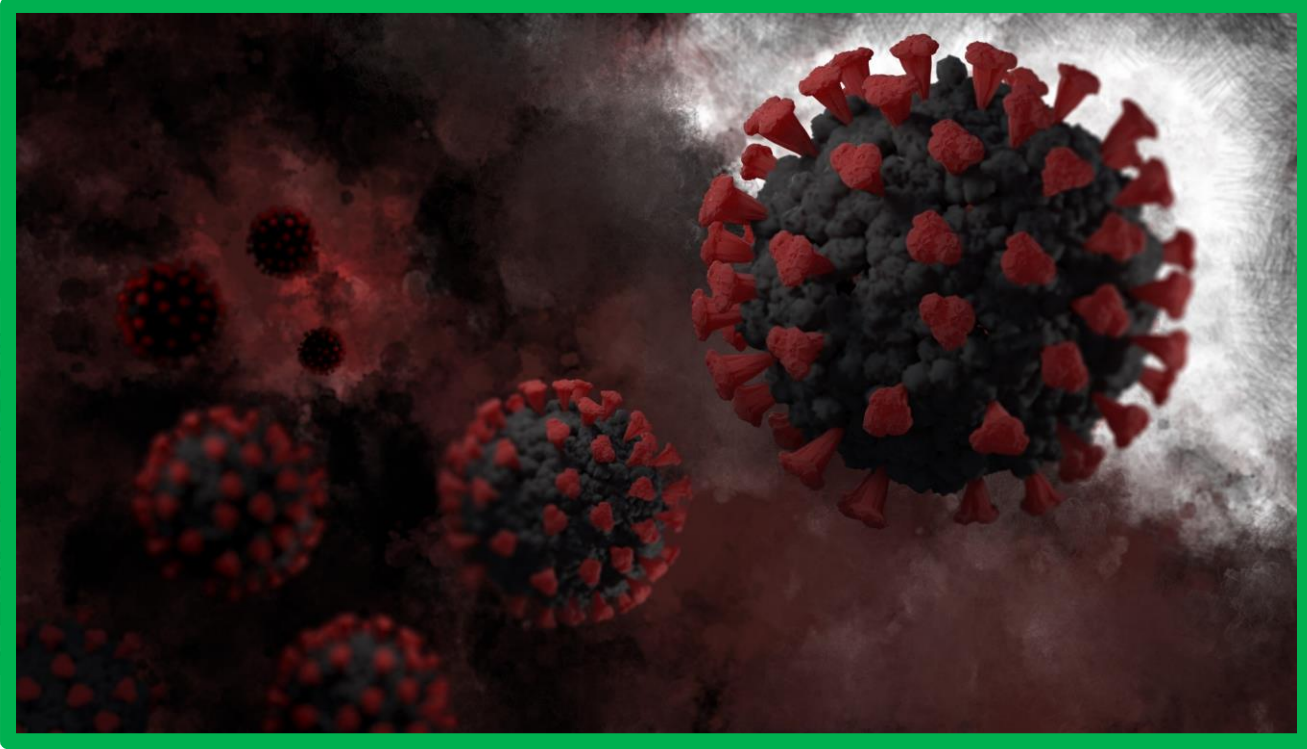
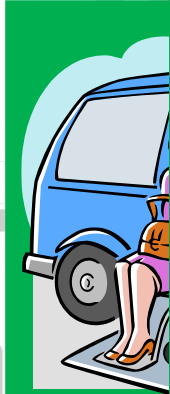
What interventions should
have priority among non-
covid patients?

Using capabilities in
decision-making

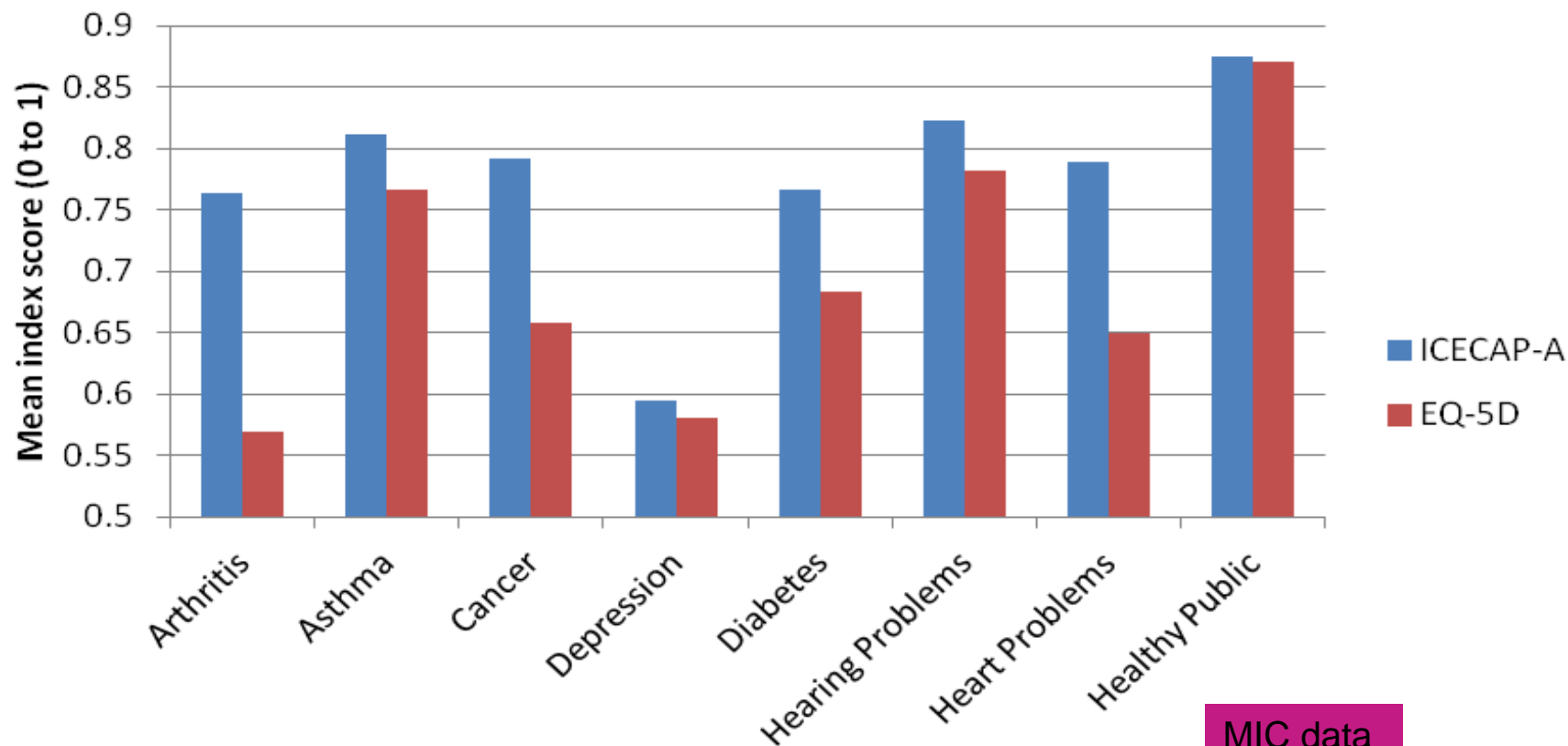
Who to treat?



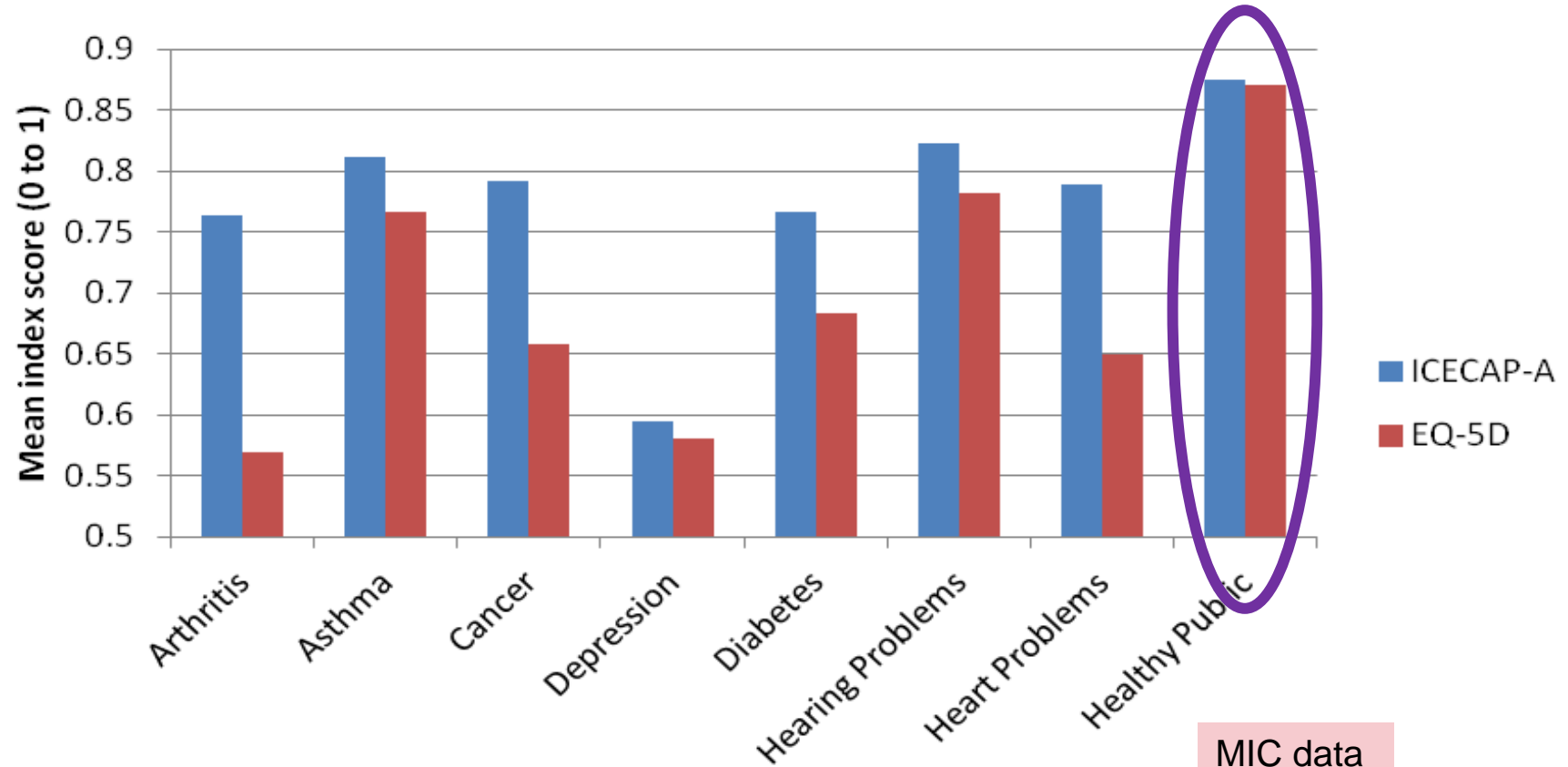
Who to treat with squeezed resources?



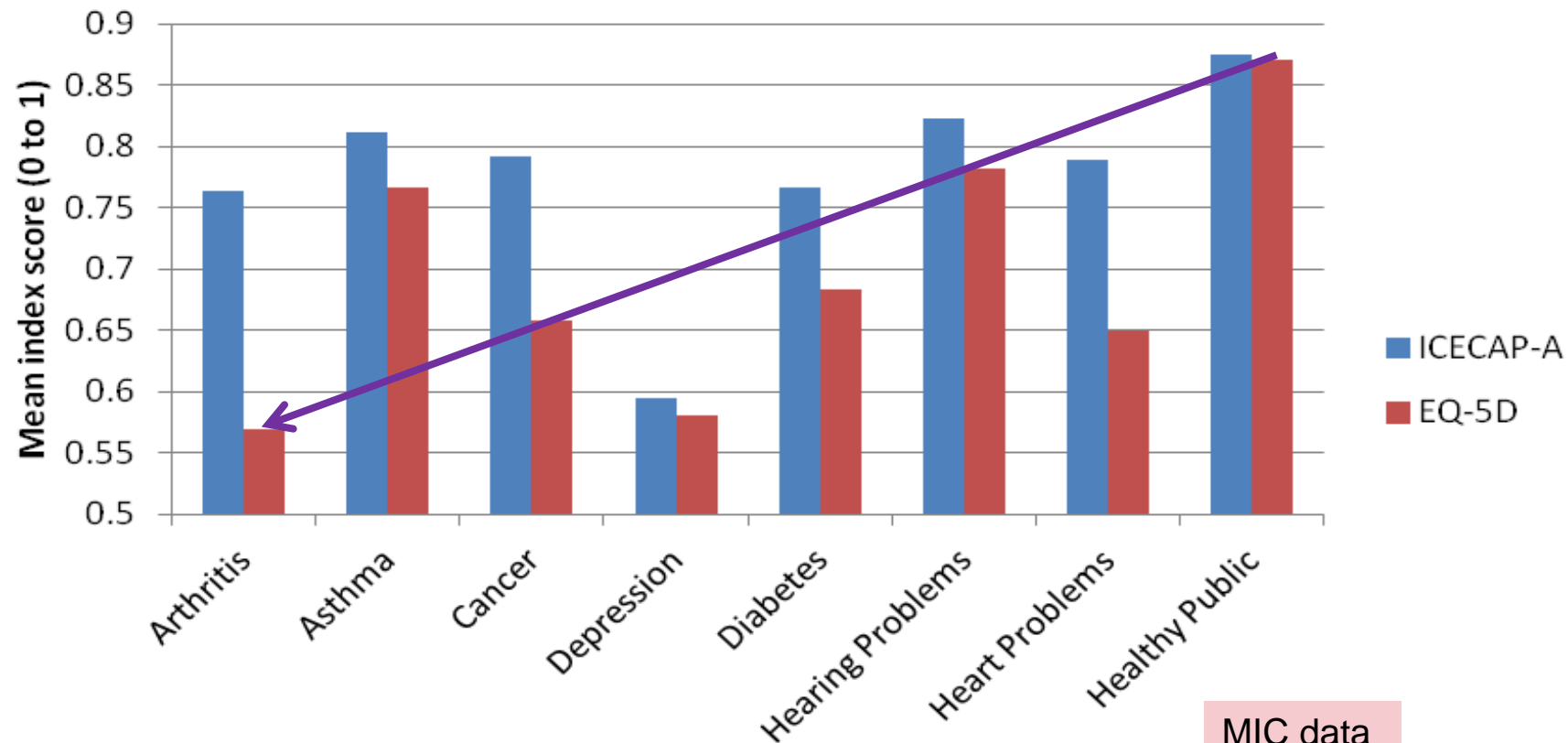
ICECAP-A and EQ-5D mean scores for different conditions (UK)



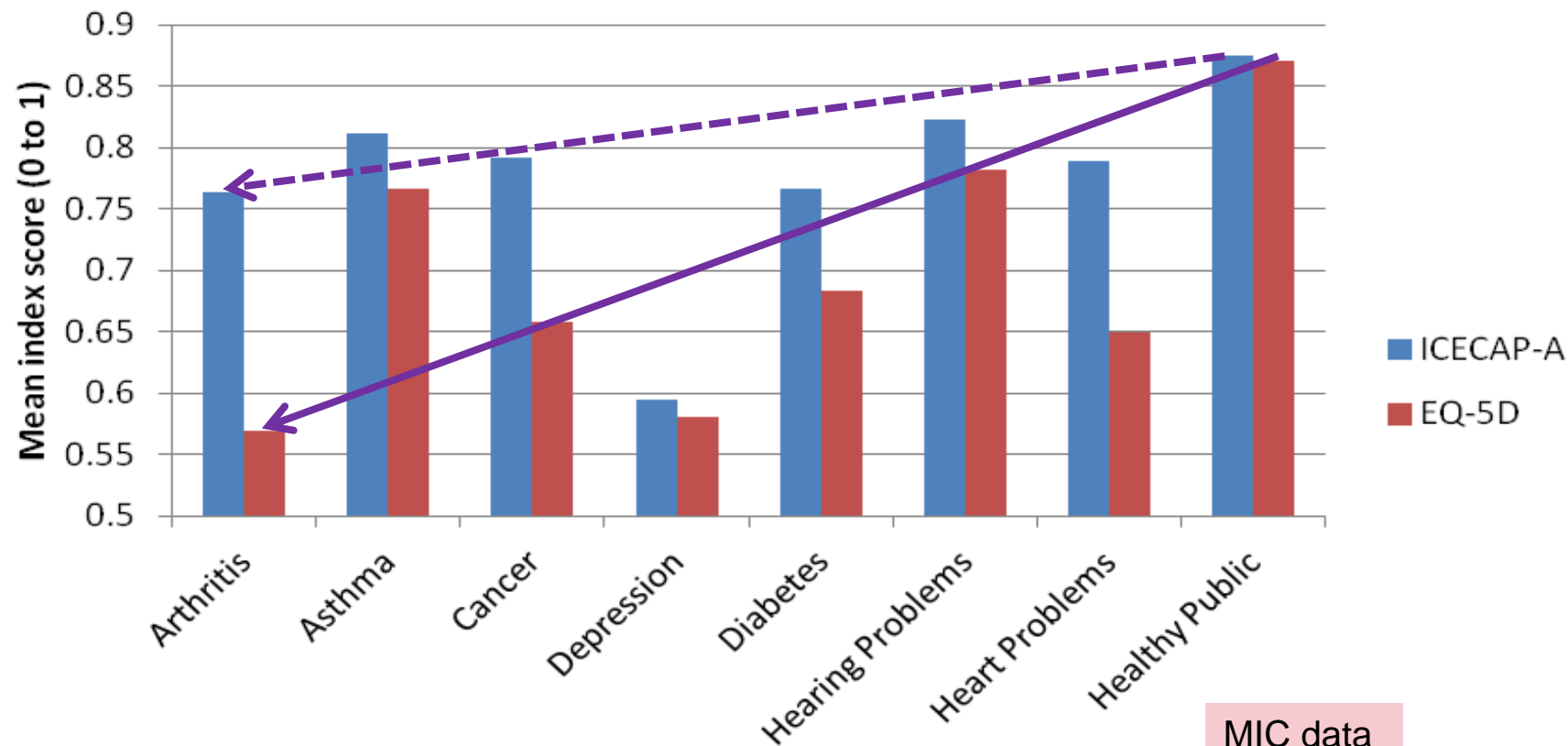
ICECAP-A and EQ-5D mean scores for different conditions (UK)



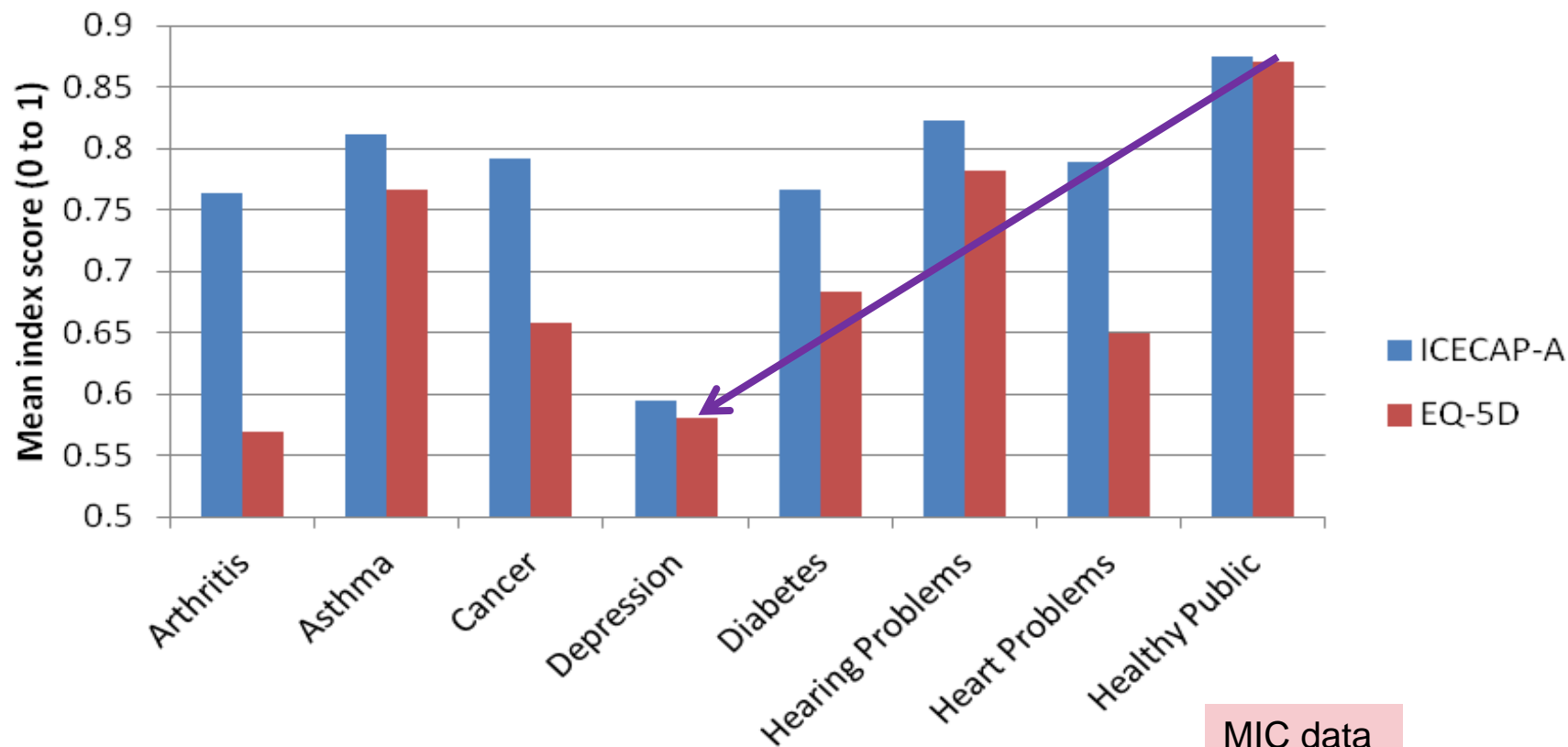
ICECAP-A and EQ-5D mean scores for different conditions (UK)



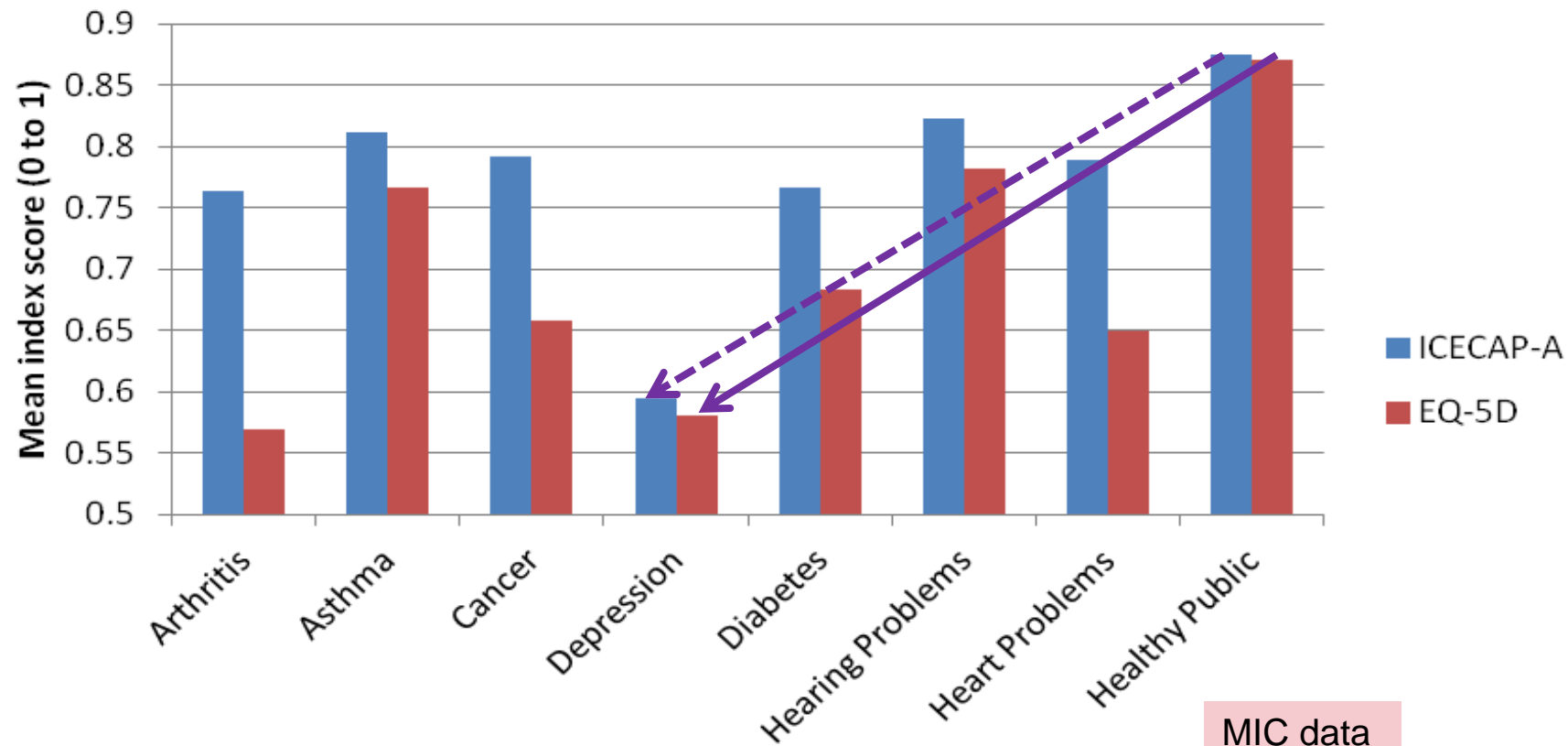
ICECAP-A and EQ-5D mean scores for different conditions (UK)



ICECAP-A and EQ-5D mean scores for different conditions (UK)



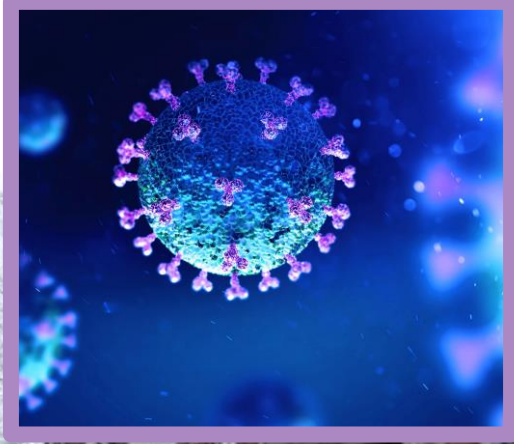
ICECAP-A and EQ-5D mean scores for different conditions (UK)



Should we prioritise Christmas?

Using capabilities in broader
public health decision
making

Policy making & evaluation



Prioritising some degree of social interaction and sense of stability for a large number in the population?

Broader outcomes?

The value of broader outcomes in a pandemic/syndemic?

Health might not change but many people's capabilities have

- Accounting for broader capability impacts on the whole population? Some being health
- Relative to the direct impacts on those catching covid, particularly those who die or have long-term effects

Can capabilities provide a useful analytic framework for broader decision making?

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ABOUT YOUR OVERALL QUALITY OF LIFE

Please indicate which statements best describe your overall quality of life at the moment by placing a tick (✓) in **ONE** box for each of the five groups below.

1. Feeling settled and secure

- I am able to feel settled and secure in **all** areas of my life
- I am able to feel settled and secure in **many** areas of my life
- I am only able to feel settled and secure in **a few** areas of my life
- I am **unable** to feel settled and secure in **any** areas of my life

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

4 → 2

2. Love, friendship and support

- I can have **a lot** of love, friendship and support
- I can have **quite a lot** of love, friendship and support
- I can only have **a little** love, friendship and support
- I **cannot** have **any** love, friendship and support

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

4 → 3

3. Being independent

- I am able to be **completely** independent
- I am able to be independent in **many** things
- I am only able to be independent in **a few** things
- I am **unable** to be at all independent

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

4 → 3

4. Achievement and progress

- I can achieve and progress in **all** aspects of my life
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<input type="checkbox"/>	4
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3 → 3

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- I can only have **a little** enjoyment and pleasure
- I **cannot** have **any** enjoyment and pleasure

<input type="checkbox"/>	4
<input type="checkbox"/>	3
<input type="checkbox"/>	2
<input type="checkbox"/>	1

4 → 2

Please ensure you have only ticked **ONE** box for each of the five groups.

Final thoughts

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No easy answers

- Resource allocation decision making/rationing was there before the pandemic...
 - ... is continuing through the pandemic...
 - ...& will be there when the pandemic ends
- Have thought here about 'evaluative spaces' but not about decision rules:
 - Getting the most capability from our resources? (efficiency)
 - Providing resources to those whose capability is lowest? (equity)



Acknowledgements:

ICECAP Research teams

Hareth Al-Janabi
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Terry Flynn
Phil Kinghorn
Sam Husbands
Tom Keeley
Paul Mitchell
Rosanna Orlando



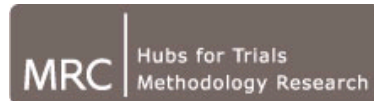
Advisory Groups

ICEPOP
ICECAP-A
EconEndLife
LifeCourseCap



Collaborators

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Ini Grewal, Elizabeth Hunyh, Louise Jones, Jane Lewis, Alison Moody,
Lucy Natarajan, Tim Peters, Jeff Round, Kerry Sproston





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Developing attributes for a generic quality of life measure for older people: Preferences or capabilities?

Ini Grewal^a, Jane Lewis^a, Terry Flynn^a, Jackie Brown^a, John Board^a, Joanna Coast^{a,*}

Original Article



Development of a supportive care measure for economic evaluation of end-of-life care using qualitative methods

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Development of a self-report measure of capability wellbeing for adults: the ICECAP-A

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Pharmacoeconomics
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ORIGINAL RESEARCH ARTICLE

Complex Valuation: Applying Ideas from the Complex Intervention Framework to Valuation of a New Measure for End-of-Life Care

Joanna Coast^a, Elizabeth Reynolds^a, Philip Kinghorn^a, Terry Flynn^a

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SCORING THE ICECAP-A CAPABILITY INSTRUMENT: ESTIMATION OF A UK GENERAL POPULATION TARIFF¹

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Valuing the ICECAP-A capability index for older people^a

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Original Article

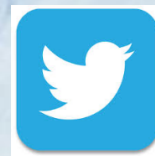


'The ICECAP-SCM tells you more about what I'm going through': A think-aloud study measuring quality of life among patients receiving supportive and palliative care

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