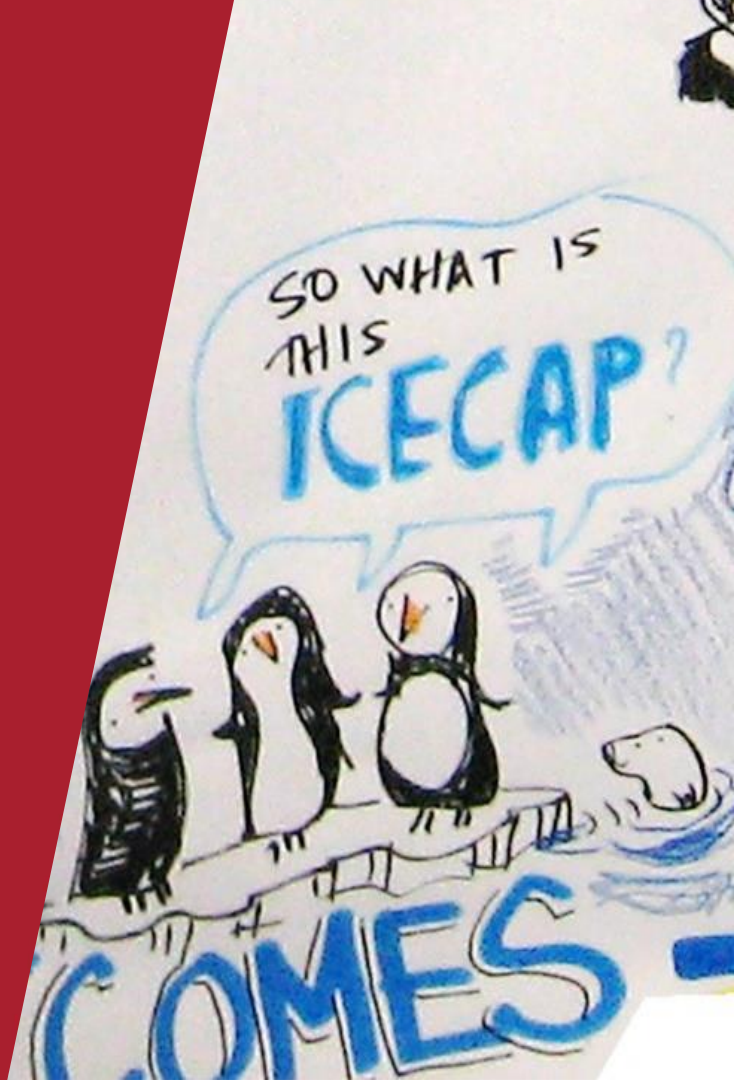
University of BRISTOL

A life-course approach to measuring capability for economic evaluation of health and social care interventions

Joanna Coast

UBC mixer, October 2020

bristol.ac.uk



Thoughts

- Focus on patient-oriented outcomes

Thoughts

- Focus on patient-oriented outcomes
  - Patient?

  OR
  - Person?

Thoughts

- Focus on patient-oriented outcomes
  - Patient?

  OR
  - Person?
- Is patient-oriented health economics primarily about PPI/co-design of research, or also about conducting research with that focus?

Outline

- Focus on person-oriented outcomes
  - So, Why capability?
- The ICECAP instruments… across the life-course
- Does a capability focus – arising from a person-oriented approach – make a difference?
- Moving forward

Why capability?

Why capability?

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

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…

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

Capturing more than health

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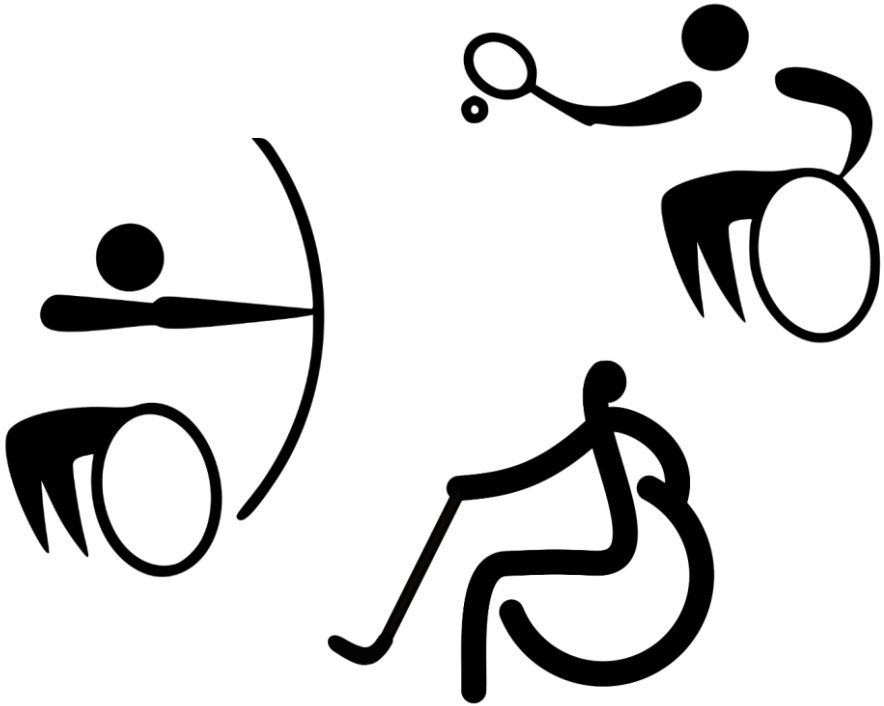
Capturing more than health



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Capabilities: an alternative evaluative space

GOOD: hospice provision

HEALTH: improvements in morbidity and mortality

UTILITY: pleasure obtained from receiving the care

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

The ICECAP instruments … across the life-course

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)

In depth interview to uncover what is important to the informant

Interview analysis

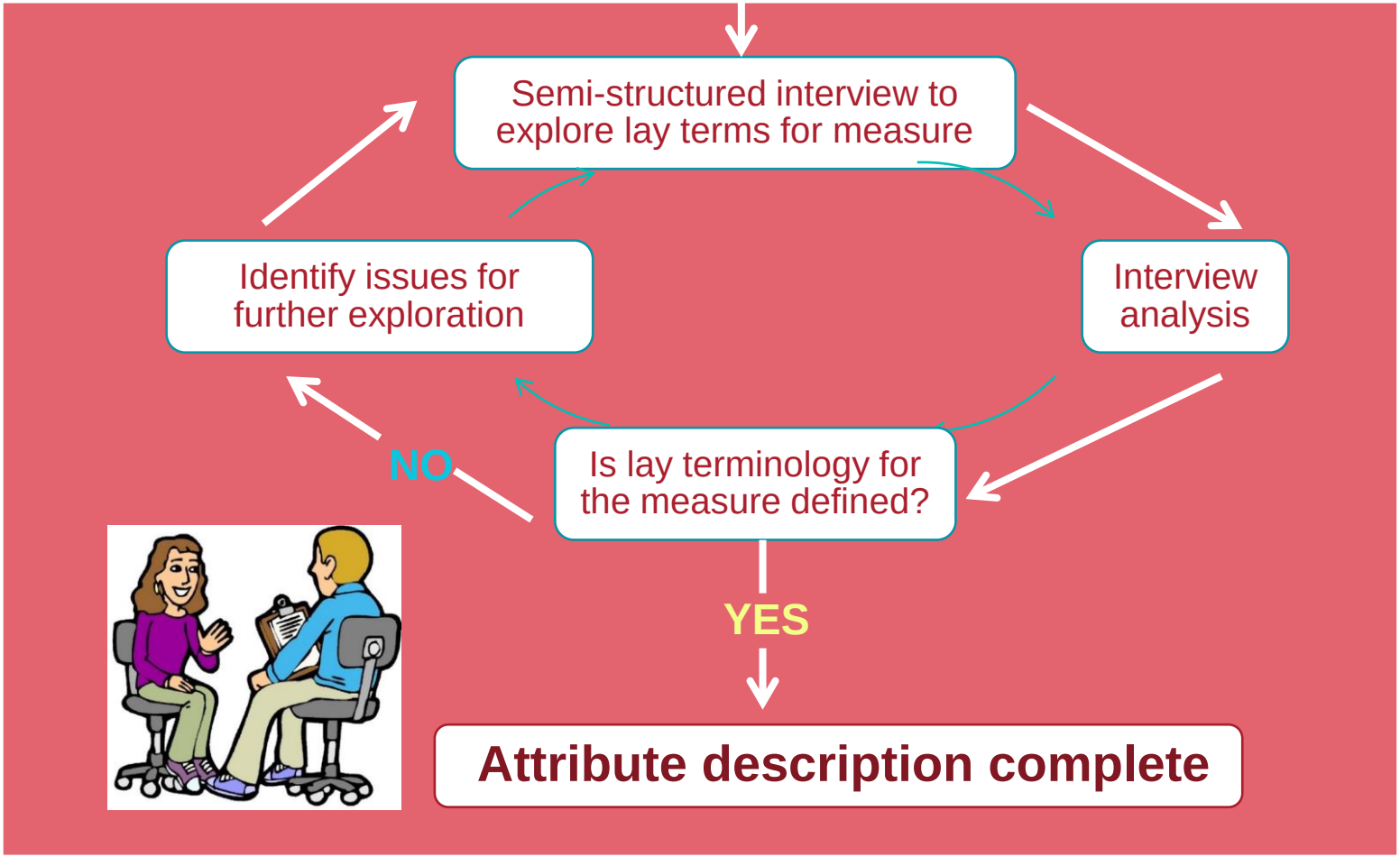
Are conceptual attributes fully defined?

NO

Identify issues for further exploration

YES

Move to stage 2


Semi-structured interview to explore lay terms for measure
Interview analysis
Is lay terminology for the measure defined?
NO
Identify issues for further exploration
YES
Attribute description complete

ICECAP-A

5 questions, each with 4 possible responses

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

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	☐	4
I am able to feel settled and secure in **many** areas of my life	☐	3
I am only able to feel settled and secure in **a few** areas of my life	☐	2
I am **unable** to feel settled and secure in **any** areas of my life	☐	1

2. Love, friendship and support

I can have **a lot** of love, friendship and support	☐	4
I can have **quite a lot** of love, friendship and support	☐	3
I can only have **a little** love, friendship and support	☐	2
I **cannot** have **any** love, friendship and support	☐	1

3. Being independent

I am able to be **completely** independent	☐	4
I am able to be independent in **many** things	☐	3
I am only able to be independent in **a few** things	☐	2
I am **unable** to be at all independent	☐	1

4. Achievement and progress

I can achieve and progress in **all** aspects of my life	☐	4
I can achieve and progress in **many** aspects of my life	☐	3
I can only achieve and progress in **a few** aspects of my life	☐	2
I **cannot** achieve and progress in **any** aspects of my life	☐	1

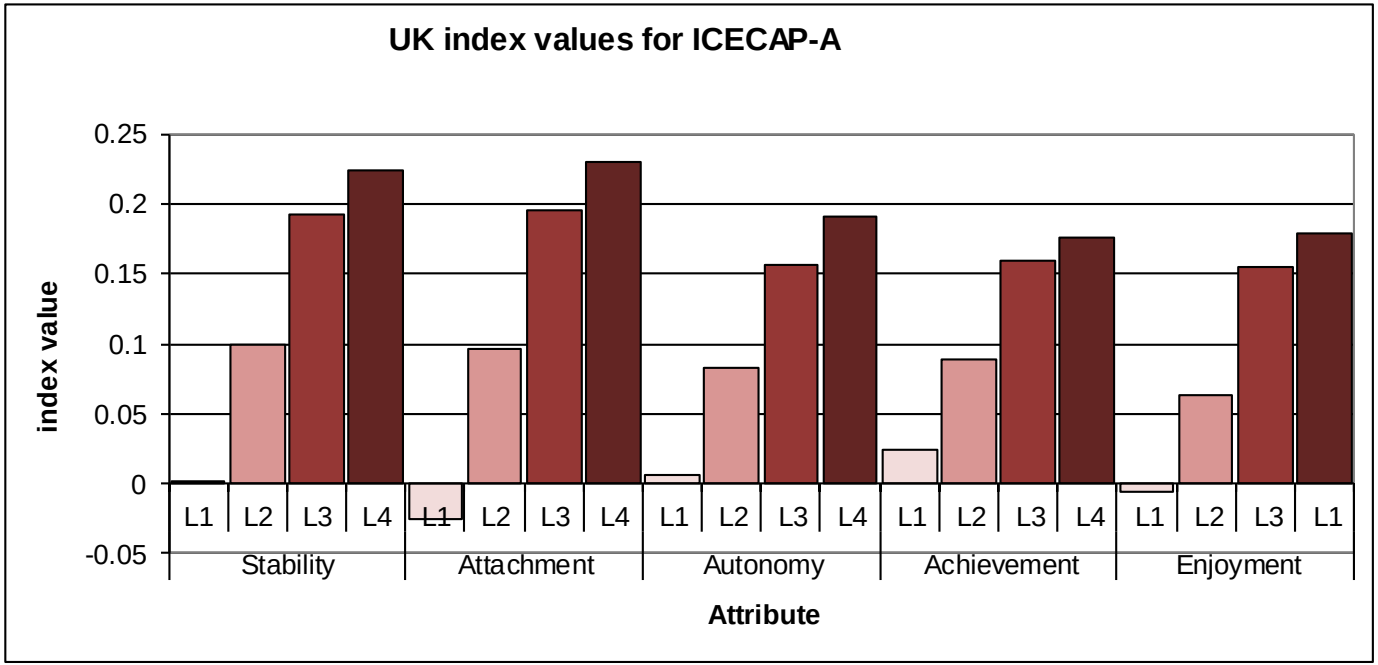
5. Enjoyment and pleasure

I can have **a lot** of enjoyment and pleasure	☐	4
I can have **quite a lot** of enjoyment and pleasure	☐	3
I can only have **a little** enjoyment and pleasure	☐	2
I **cannot** have **any** enjoyment and pleasure	☐	1

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

UK values

No capability on all attributes: value 0
A little capability on all attributes: value 0.43
A lot of capability on all attributes: value 0.86
Full capability on all attributes: value 1



ICECAP-O

5 questions, each with 4 response categories

1024 possible capability wellbeing' states

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		4
I can have **a lot** of the love and friendship that I want		3
I can have **a little** of the love and friendship that I want		2
I cannot have **any** of the love and friendship that I want		1
2. Thinking about the future		
I can think about the future **without any** concern		4
I can think about the future **with only a little** concern		3
I can only think about the future **with some** concern		2
I can only think about the future **with a lot** of concern		1
3. Doing things that make you feel valued		
I am able to do **all** of the things that make me feel valued		4
I am able to do **many** of the things that make me feel valued		3
I am able to do **a few** of the things that make me feel valued		2
I am unable to do **any** of the things that make me feel valued		1
4. Enjoyment and pleasure		
I can have **all** of the enjoyment and pleasure that I want		4
I can have **a lot** of the enjoyment and pleasure that I want		3
I can have **a little** of the enjoyment and pleasure that I want		2
I cannot have **any** of the enjoyment and pleasure that I want		1
5. Independence		
I am able to be **completely** independent		4
I am able to be independent in **many things**		3
I am able to be independent in **a few things**		2
I am **unable** to be at all independent		1

Tick one box only in each section

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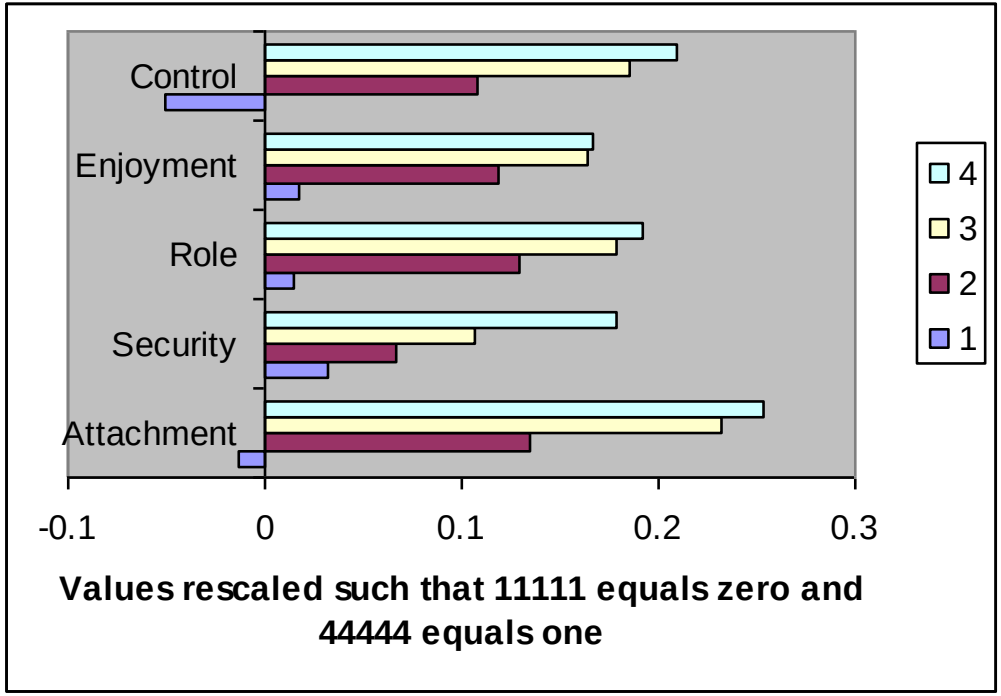
ICECAP-O index values



- No capability on all attributes: value 0
- A little capability on all attributes: value 0.556
- A lot of capability on all attributes: value 0.868
- Full capability on all attributes: value 1

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**	4
I can make decisions that I need to make about my life and care **some of the time**	3
I can make decisions that I need to make about my life and care **only a little of the time**	2
I can **never** make decisions that I need to make about my life and care	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**	4
If I want to, I can be with people who care about me **some of the time**	3
If I want to, I can be with people who care about me **only a little of the time**	2
If I want to, I can **never** be with people who care about me	1

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

I **always** experience significant physical discomfort	4
I **often** experience significant physical discomfort	3
I **sometimes** experience significant physical discomfort	2
I **rarely** experience significant physical discomfort	1

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

I **always** experience emotional suffering	4
I **often** experience emotional suffering	3
I **sometimes** experience emotional suffering	2
I **rarely** experience emotional suffering	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**	4
I can maintain my dignity and self-respect **some of the time**	3
I can maintain my dignity and self-respect **only a little of the time**	2
I can **never** maintain my dignity and self-respect	1

6) Being supported – Having help and support

I am able to have the help and support that I need **most of the time**	4
I am able to have the help and support that I need **some of the time**	3
I am able to have the help and support that I need **only a little of the time**	2
I am **never** able to have the help and support that I need	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	4
I have had the opportunity to make **some** of the preparations I want to make	3
I have **only** had the opportunity to make a **few** of the preparations I want to make	2
I have **not** had the opportunity to make **any** of the preparations I want to make	1

Thank you for your help

ICECAP-SCM

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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

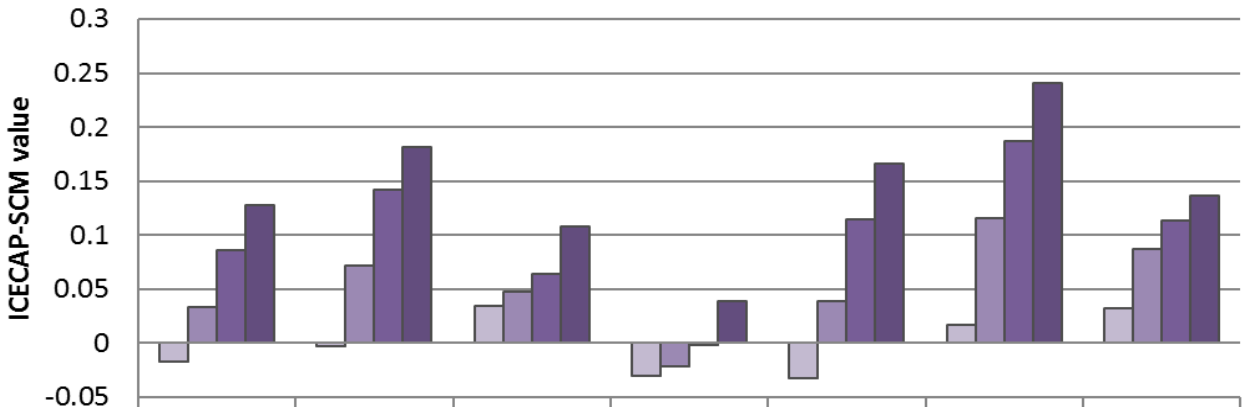
1. **Having a say** (Your ability to influence where you would like to live or be cared for, the kind of treatment you receive, the people who care for you)
2. **Being with people who care about you** (Being with family, friends or caring professionals
3. **Physical suffering** (Experiencing pain or 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)

UK BWS values

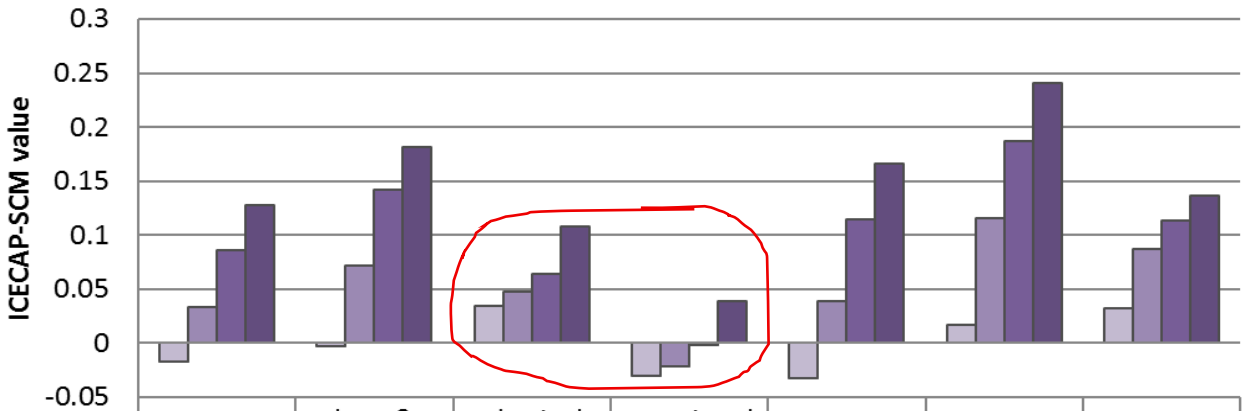
No capability on all attributes: value 0
A little capability on all attributes: value 0.373
A lot of capability on all attributes: value 0.706
Full capability on all attributes: value 1



	choice	love & affection	physical suffering	emotional suffering	dignity	support	prepared
1	-0.017	-0.003	0.034	-0.03	-0.033	0.017	0.032
2	0.033	0.072	0.048	-0.022	0.039	0.116	0.087
3	0.086	0.142	0.064	-0.002	0.115	0.187	0.114
4	0.128	0.181	0.108	0.039	0.166	0.241	0.137

UK BWS values

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



	choice	love & affection	physical suffering	emotional suffering	dignity	support	prepared
1	-0.017	-0.003	0.034	-0.03	-0.033	0.017	0.032
2	0.033	0.072	0.048	-0.022	0.039	0.116	0.087
3	0.086	0.142	0.064	-0.002	0.115	0.187	0.114
4	0.128	0.181	0.108	0.039	0.166	0.241	0.137

UK BWS values

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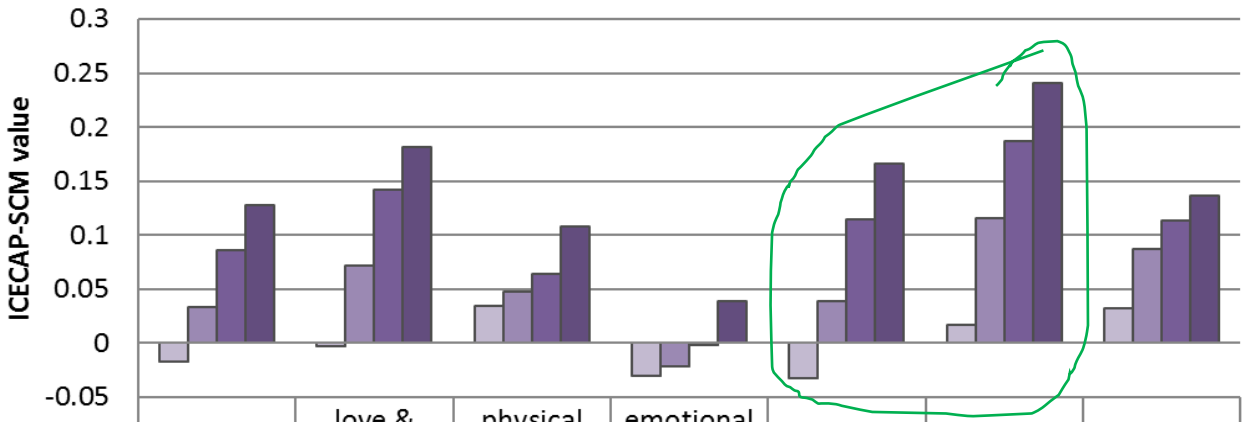
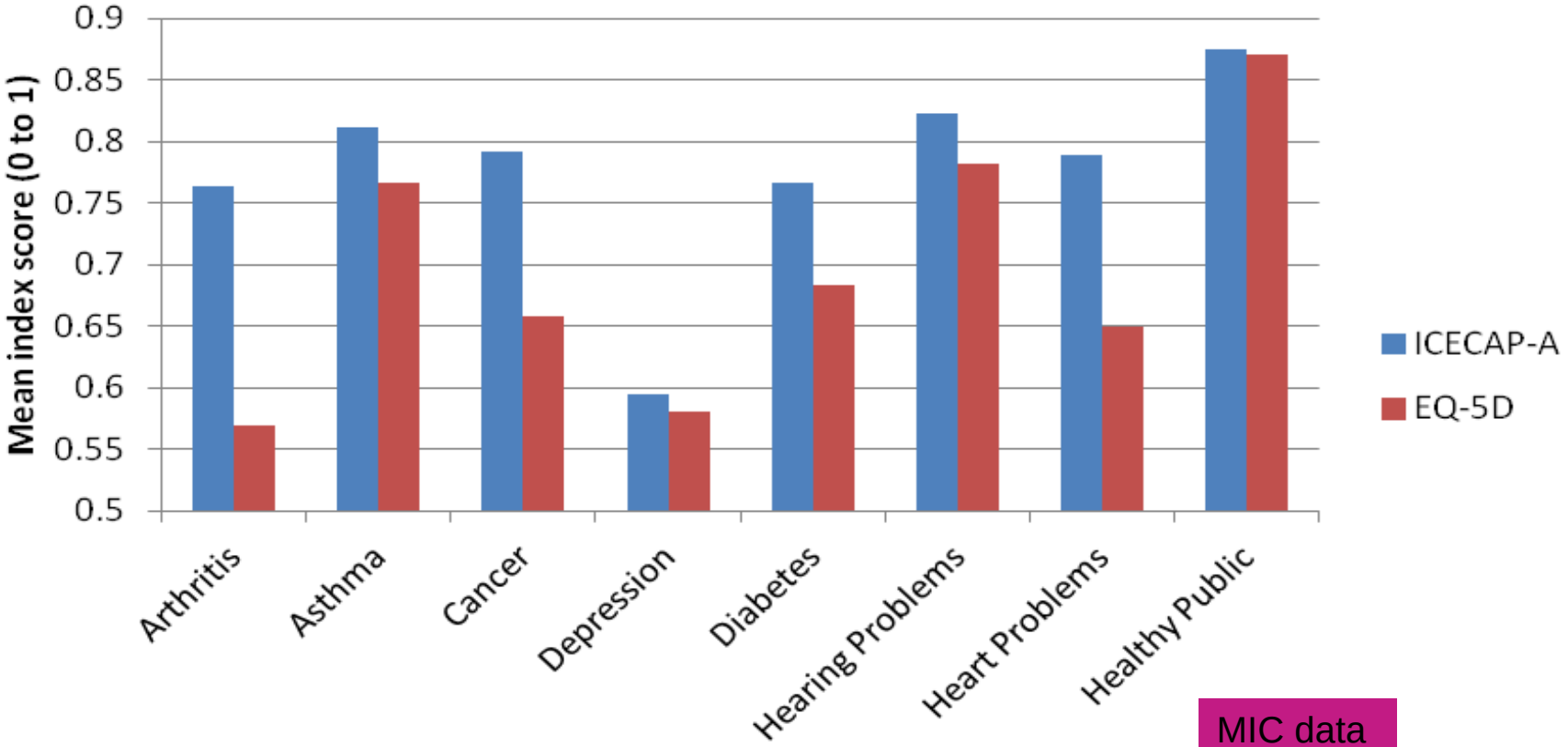
A lot of capability on all attributes: value 0.706
Full capability on all attributes: value 1



	choice	love & affection	physical suffering	emotional suffering	dignity	support	prepared
1	-0.017	-0.003	0.034	-0.03	-0.033	0.017	0.032
2	0.033	0.072	0.048	-0.022	0.039	0.116	0.087
3	0.086	0.142	0.064	-0.002	0.115	0.187	0.114
4	0.128	0.181	0.108	0.039	0.166	0.241	0.137

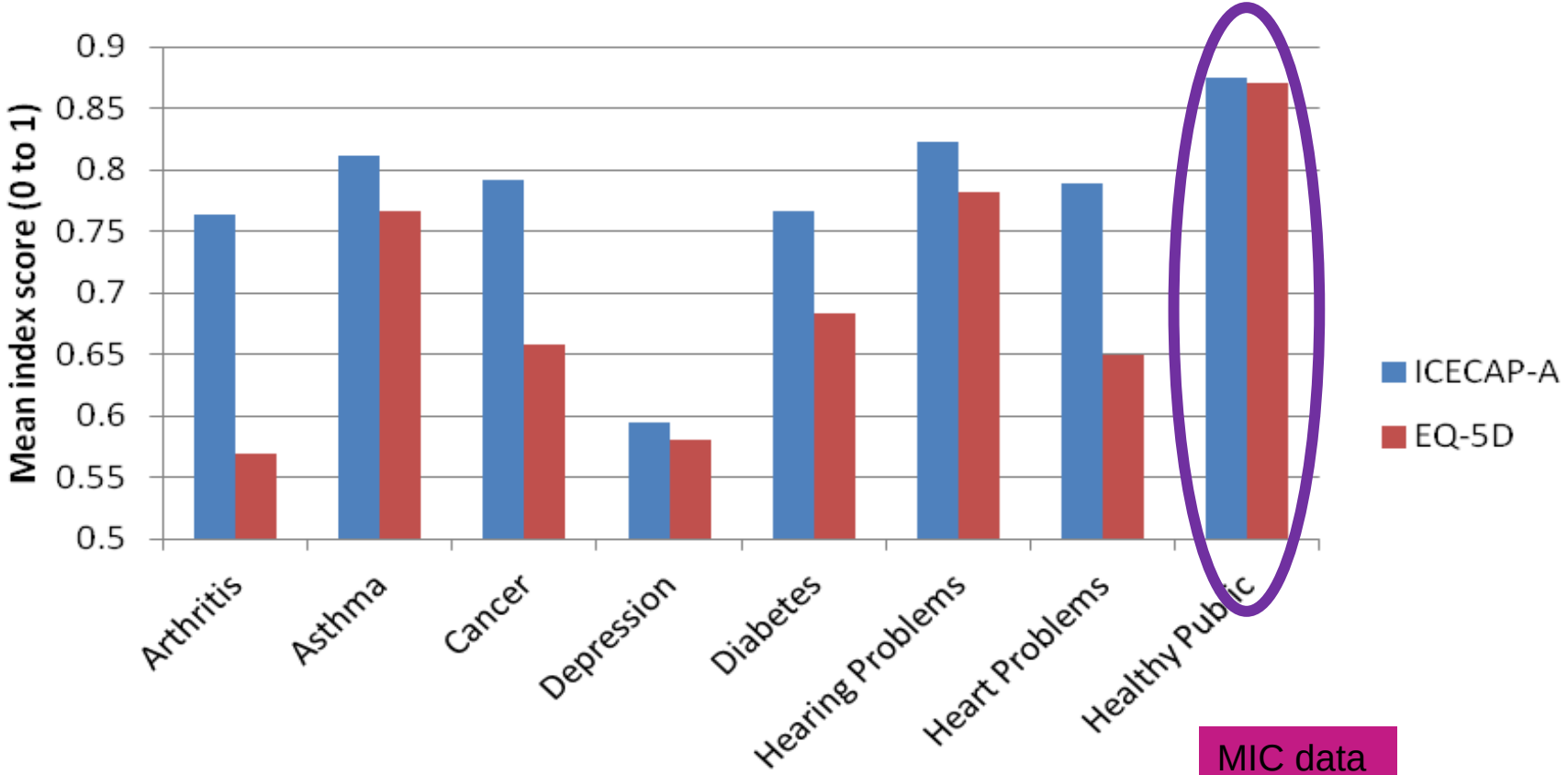
Does a capability focus – arising from a person-oriented approach – make a difference?

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



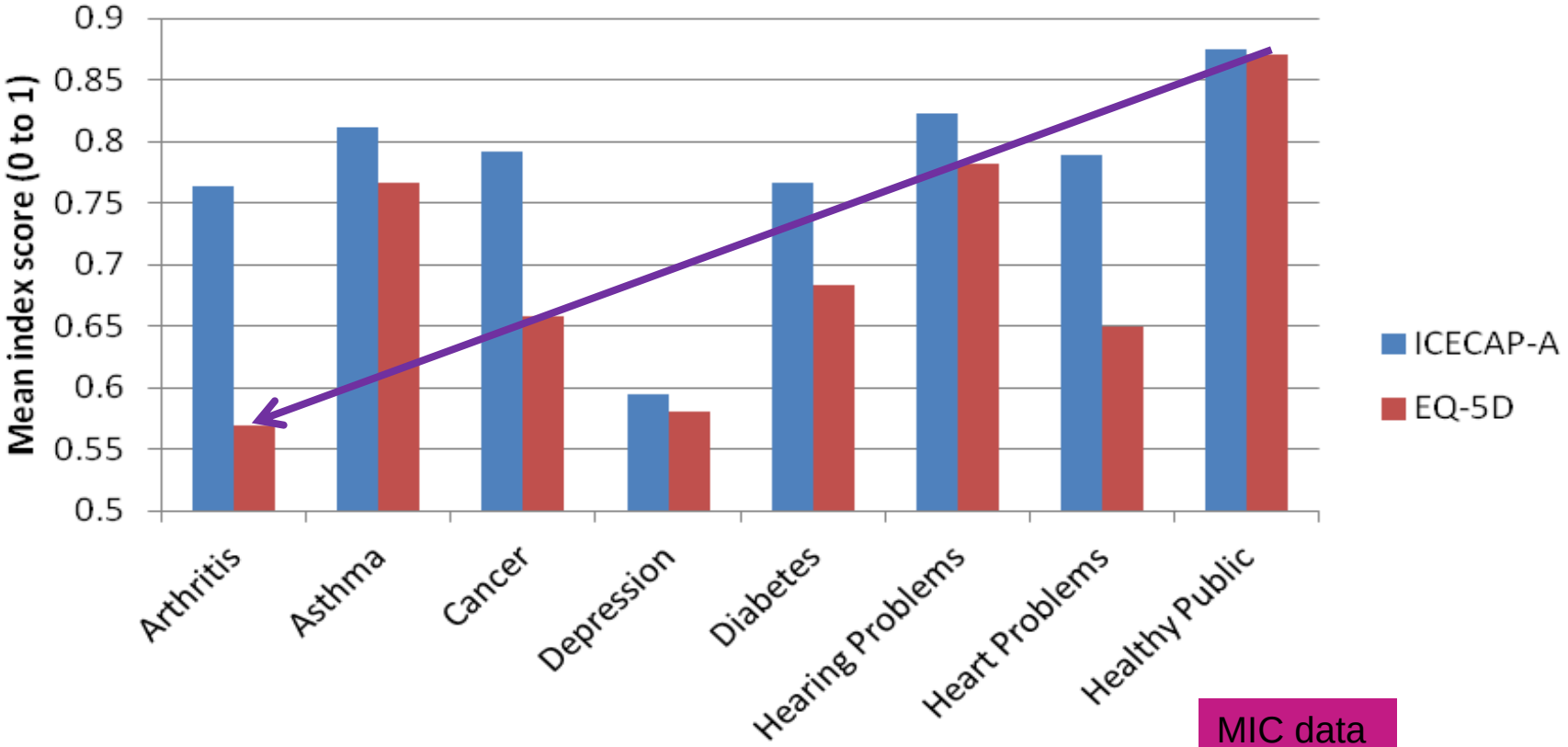
MIC data

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



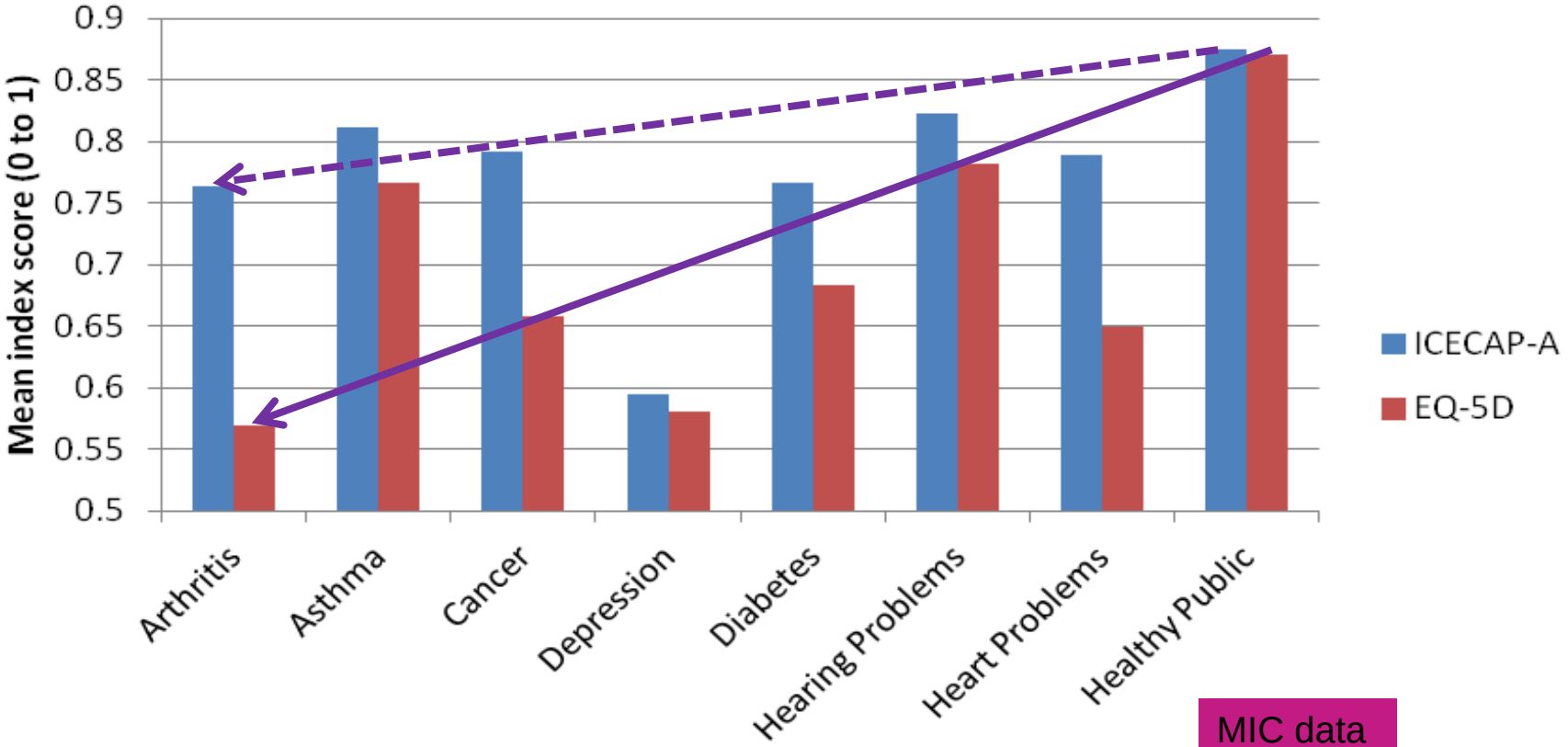
MIC data

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



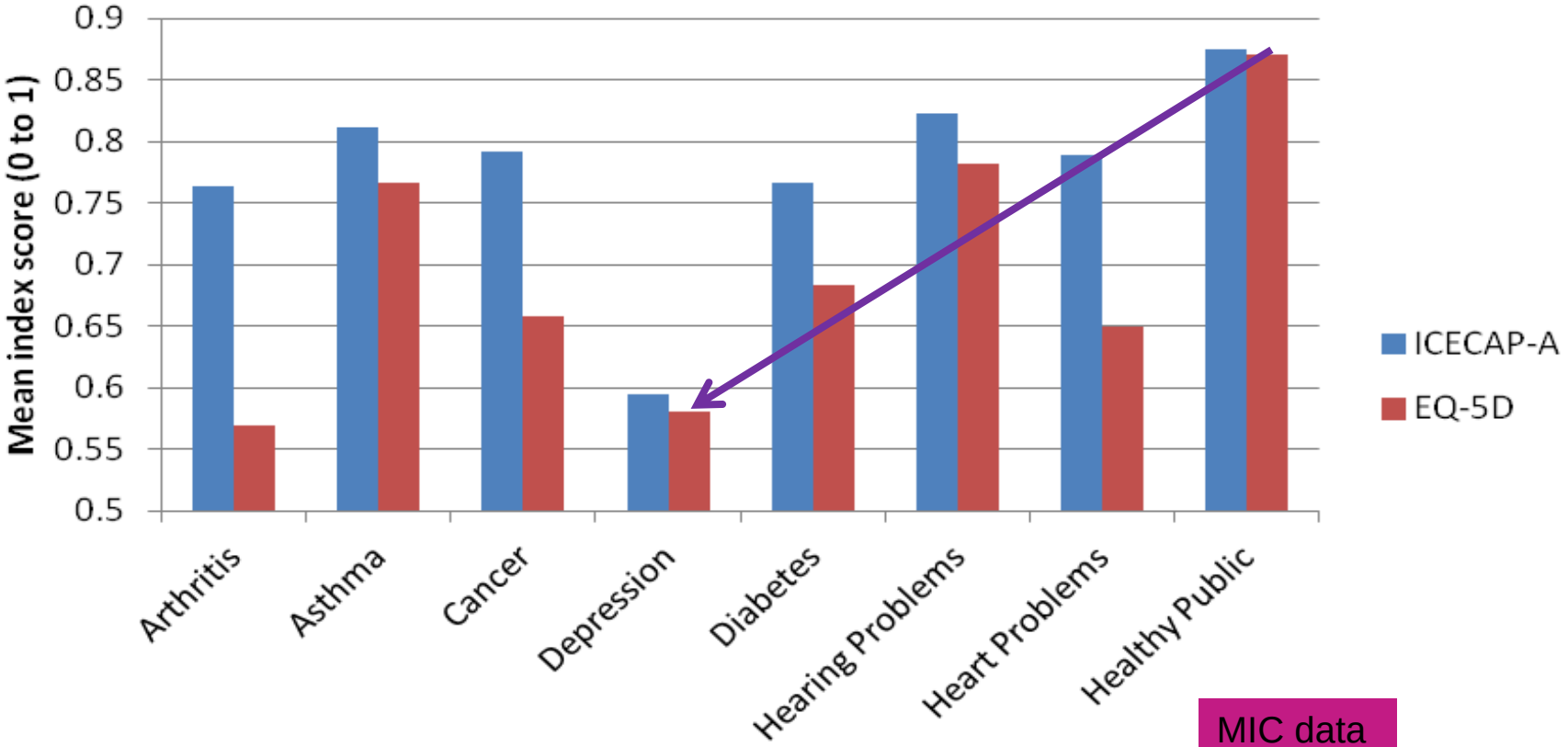
MIC data

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



MIC data

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



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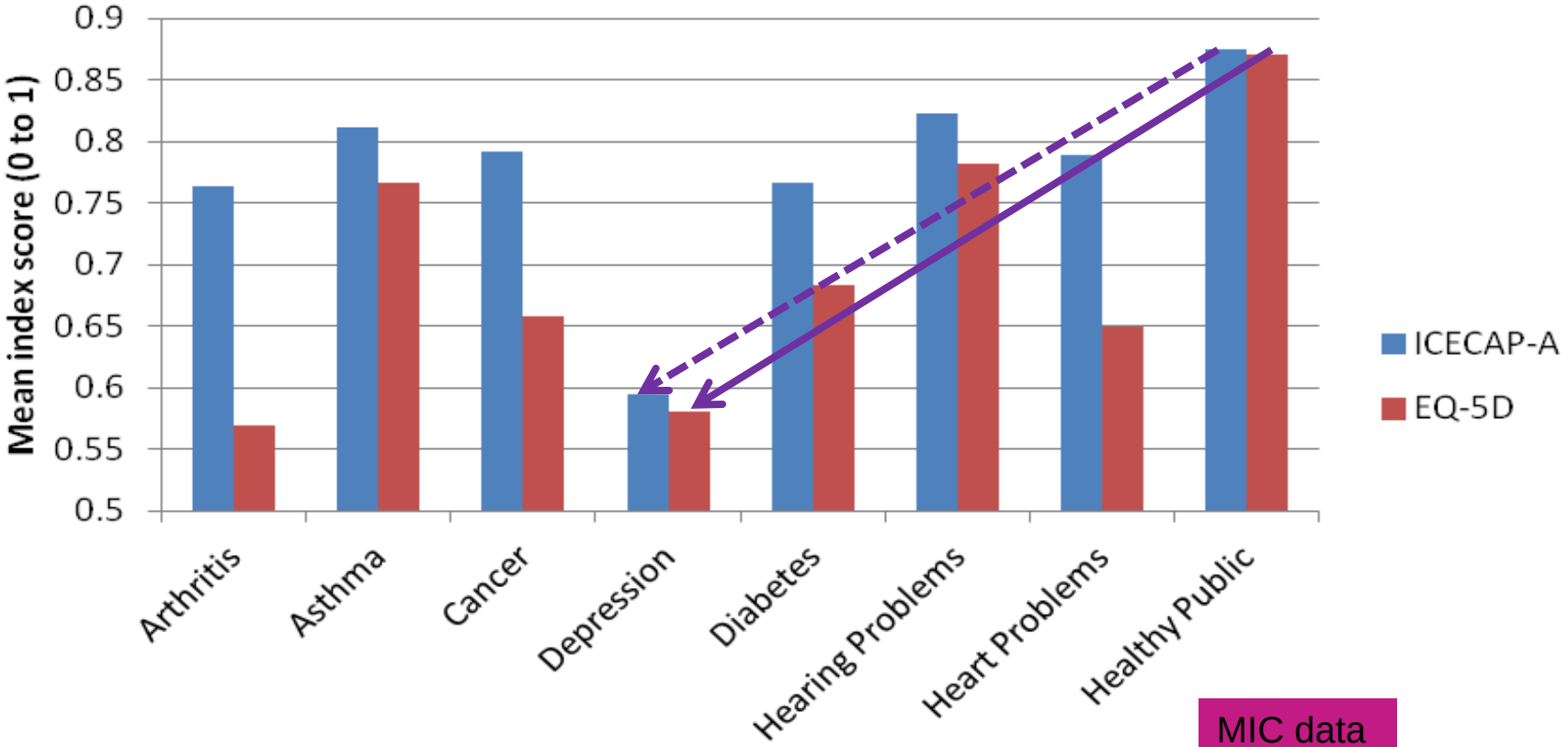
ICECAP-A and EQ-5D mean scores for different conditions (UK)



MIC data

Covid-19

The value of broader outcomes in a pandemic?

My health hasn't changed but my capabilities have

- Capabilities will also change for those who suffer from covid, particularly dying or with long-term sequalea
- But also those who lose livelihoods
- Or those who miss out on treatment for other conditions

Can capabilities provide a useful analytic framework for decision making?

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	4	4 → 2
I am able to feel settled and secure in **many** areas of my life	3	
I am only able to feel settled and secure in **a few** areas of my life	2	
I am **unable** to feel settled and secure in **any** areas of my life	1	
2. Love, friendship and support		
I can have **a lot** of love, friendship and support	4	4 → 3
I can have **quite a lot** of love, friendship and support	3	
I can only have **a little** love, friendship and support	2	
I **cannot** have **any** love, friendship and support	1	
3. Being independent		
I am able to be **completely** independent	4	4 → 4
I am able to be independent in **many** things	3	
I am only able to be independent in **a few** things	2	
I am **unable** to be at all independent	1	
4. Achievement and progress		
I can achieve and progress in **all** aspects of my life	4	3 → 3
I can achieve and progress in **many** aspects of my life	3	
I can only achieve and progress in **a few** aspects of my life	2	
I **cannot** achieve and progress in **any** aspects of my life	1	
5. Enjoyment and pleasure		
I can have **a lot** of enjoyment and pleasure	4	4 → 2
I can have **quite a lot** of enjoyment and pleasure	3	
I can only have **a little** enjoyment and pleasure	2	
I **cannot** have **any** enjoyment and pleasure	1	

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

Similar issues at the end of the life course

Difficult trade-offs in care homes between important attributes relating to residents being able to be with people who care about them and e.g. physical suffering

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**	4
I can make decisions that I need to make about my life and care **some of the time**	3
I can make decisions that I need to make about my life and care **only a little of the time**	2
I can **never** make decisions that I need to make about my life and care	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**	4
If I want to, I can be with people who care about me **some of the time**	3
If I want to, I can be with people who care about me **only a little of the time**	2
If I want to, I can **never** be with people who care about me	1

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

I **always** experience significant physical discomfort	4
I **often** experience significant physical discomfort	3
I **sometimes** experience significant physical discomfort	2
I **rarely** experience significant physical discomfort	1

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

I **always** experience emotional suffering	4
I **often** experience emotional suffering	3
I **sometimes** experience emotional suffering	2
I **rarely** experience emotional suffering	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**	4
I can maintain my dignity and self-respect **some of the time**	3
I can maintain my dignity and self-respect **only a little of the time**	2
I can **never** maintain my dignity and self-respect	1

6) Being supported – Having help and support

I am able to have the help and support that I need **most of the time**	4
I am able to have the help and support that I need **some of the time**	3
I am able to have the help and support that I need **only a little of the time**	2
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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

I have had the opportunity to make **most** of the preparations I want to make	4
I have had the opportunity to make **some** of the preparations I want to make	3
I have **only** had the opportunity to make a **few** of the preparations I want to make	2
I have **not** had the opportunity to make **any** of the preparations I want to make	1

ICECAP-SCM

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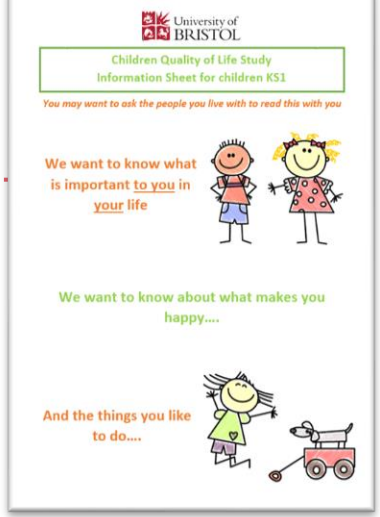
Moving forward

ICECAP measures: ongoing assessment

- included in more than 300 studies globally

Children & Young People QoL study

- Data collection working well; creative approach helping with engagement
  - 48 interviews to date
    - CYP aged 5-18: 33 (interviews ranging from 20-59 minutes)
    - Parents/guardians of CYP aged 0-18: 15
  - Impacted by covid-19
    - Feasibilty of recruitment and data collection
    - Possible changes in attributes? Still to be determined
  - Hoping to re-start recruitment in near future
  - ***Preliminary analysis is suggesting the importance of well-becoming as well as wellbeing***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Children Quality of Life Study
Information Sheet for children KS1

You may want to ask the people you live with to read this with you

We want to know what is important to you in your life

We want to know about what makes you happy....

And the things you like to do....

Impacts of covid-19 & policies on capability

- World Universities Network funding
  - ICECAP-A in UK, Netherlands, Australia
- CONTRAST study led by Birmingham
  - Including questions about capability impacts for CYP

www.birmingham.ac.uk/icecap

ICECAP capability measures

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Acknowledgements:

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