

Willingness to Trade Off Life Years or Accept Risk of Dying in Time Trade-Off and Standard Gamble Exercises to Restore the Life of a Non-Healthy Family Member: Considerations for Measurement of Non-Patient Utilities

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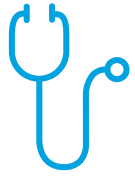
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Background & Objectives

A family member's health substantially impacts the rest of the family (Drummond et al., 2015), yet these impacts are currently not included in cost-utility analyses (CUA)



Given all health effects should be considered in health economic evaluations, this study explored the impacts of living with a non-healthy family member for inclusion of non-patient utilities in CUA



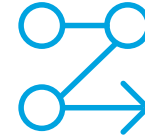
Quality of Life & Well-being

Explored the effects of ill-health of a loved one on a family member's overall happiness, quality of life & well-being



Work Productivity

Explored the effects of ill-health of a loved one on a family member's work productivity



Health State Valuations

Explored the impacts of ill-health of a loved one on a family member in terms of utilities through health state valuations using time trade-off (TTO) and standard gamble (SG) exercises

Focus of today's discussion

Methods

Data were collected using a cross-sectional survey designed for online self-completion, with a total of 500 completes



- Data were collected through an online survey vendor (Dynata) in the UK
- 500 respondents were aimed to be recruited from the UK general population
- Respondents were eligible to participate if:
 - Living-with a non-healthy family member with an acute or chronic disease
 - Aged between 18 – 80 years old
- Sample aimed to be representative for age, gender, educational level and geographical location across the UK

Health valuations were captured using time trade-off (TTO) and standard gamble (SG) exercises, where family members imagined hypothetical situations to restore their family members' health

	Health state value (UK EQ-5D TTO value set, or VAS)	Health state description in questionnaire
Health State 1	0.447 (UK EQ-5D TTO value set)	• Your family member has severe problems in walking about • Your family member has moderate problems with washing or dressing oneself • Your family member has severe problems doing his/her usual activities (e.g., work, study, housework, family or leisure activities) • Your family member has no pain or discomfort • Your family member is moderately anxious or depressed • Your family member will be in this health state for the rest of his/her life
Health State 2	0.753 (UK EQ-5D TTO value set)	• Your family member has no problems in walking about • Your family member has moderate problems with washing or dressing oneself • Your family member has moderate problems with performing his/her usual activities (e.g. work, study, housework, family or leisure activities) • Your family member has no pain or discomfort • Your family member is moderately anxious or depressed • Your family member will be in this health state for the rest of his/her life
Non-healthy family member health status	43.9 (VAS as completed by respondent, scale 0-100)	• Now, keep in mind the actual current health state of your non-healthy family member • Think about how the actual current health state of your non-healthy family member influences their mobility, self-care, usual activities, pain/discomfort and anxiety/depression

Example time trade-off (TTO) exercise (Health State 1)

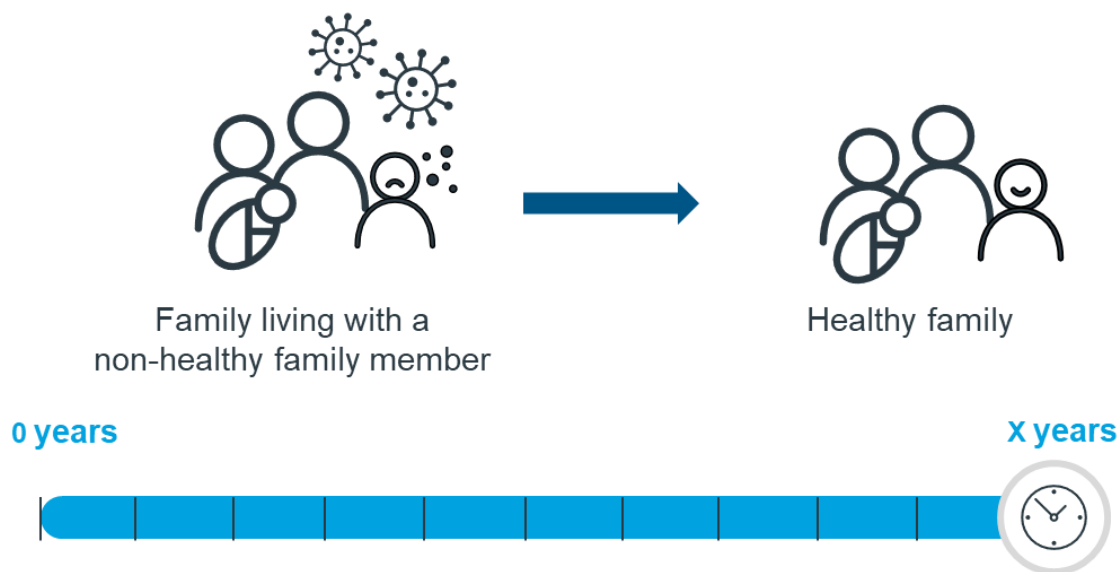
Imagine that the health state of your non-healthy family member has the following description:

- Your family member has **severe problems** in walking about.
- Your family member has **moderate problems** with washing or dressing oneself.
- Your family member has **severe problems** doing his/her usual activities. (e.g. work, study, housework, family or leisure activities)
- Your family member has **no pain** or discomfort.
- Your family member is **moderately** anxious or depressed.
- Your family member will be in this health state for the rest of his/her life.

Imagine that a new treatment is available to restore your family member's health. In this case, you will need to donate an organ to restore your family member's health.

The organ donation will not affect your overall health, but it will potentially shorten your life expectancy. Please assume that you would live another X years.

How much time of your remaining life span would you be willing to sacrifice for your non-healthy family member to be fully healthy again?



Example standard gamble (SG) exercise (Health State 1)

Imagine that the health state of your non-healthy family member has the following description:

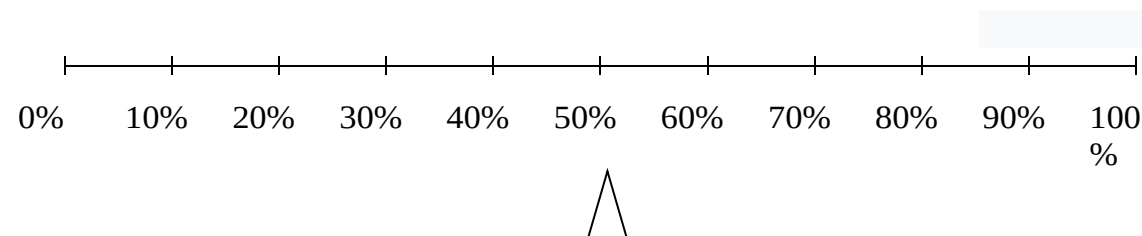
- Your family member has **severe problems** in walking about.
- Your family member has **moderate problems** with washing or dressing oneself.
- Your family member has **severe problems** doing his/her usual activities. (e.g. work, study, housework, family or leisure activities)
- Your family member has **no pain** or discomfort.
- Your family member is **moderately** anxious or depressed.
- Your family member will be in this health state for the rest of his/her life.

Imagine a new treatment is available to restore your family member's health. The treatment consists of you donating your own bone marrow. After receiving this treatment, your family member would be fully healthy.

However, there is some risk that you would develop a deadly complication while donating your own bone marrow.

How much risk of developing a deadly complication are you maximally willing to accept to still donate your own bone marrow for your family member?

The maximum risk of a deathly complication I would accept when donating my own bone marrow for my family member:



Results



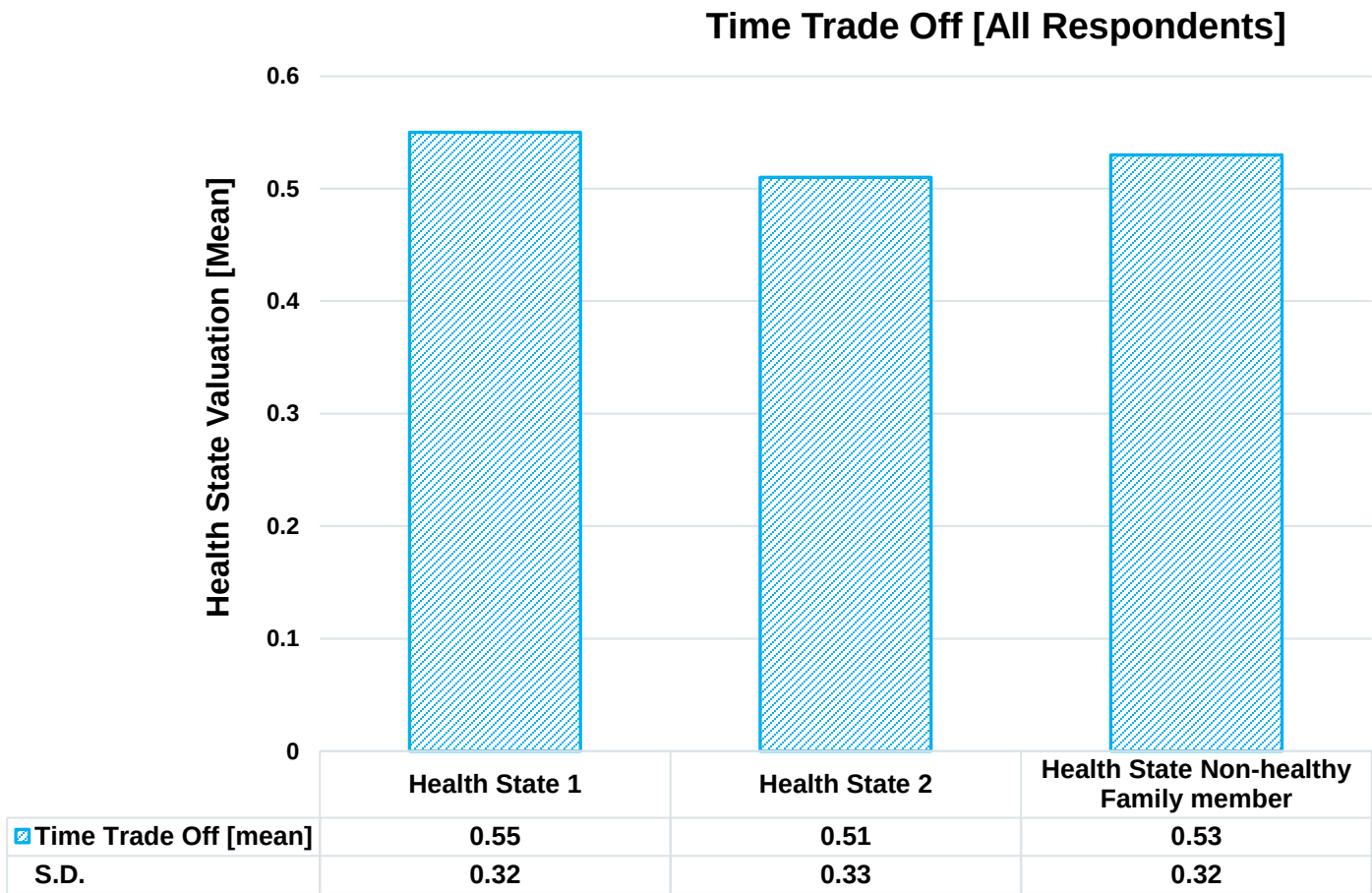
Majority of respondents reported their family member to be in poor (30.6%) or fair health (41.2%), and their own average perceived health state score was 64.5 (lower than the UK general population)

Characteristics	Sample (n = 500)
In paid employment (%)	317 (63.4)
Age (Mean, SD)	46.06 (16.3)
Gender	
• Female (%)	251 (50.2)
• Male (%)	247 (49.4)
• Other (%)	2 (0.4)
Living with a partner (%)	380 (76)
Having children (%)	387 (77.4)
Education	
• Low (%)	104 (20.8)
• Medium (%)	186 (37.2)
• High (%)	184 (36.8)
• No information provided (%)	26 (5.2)
Non-healthy family member	
• Child (%)	120 (24.0)
• Spouse (%)	226 (45.2)
• Parent (%)	92 (18.4)
• Cousin (%)	4 (0.8)
• Sibling (%)	14 (28)
• Grandparent (%)	29 (5.8)
• Other (%)	15 (3.0)
Health state of non-healthy family member	
• Excellent (%)	15 (3.0)
• Very good (%)	30 (6.0)
• Good (%)	96 (19.2)
• Fair (%)	206 (41.2)
• Poor (%)	153 (30.6)
Perceived stress level of respondent related to family members health: EQ-VAS (Mean, SD)	67.7 (19.6)
Health status non-healthy family member according to respondent: EQ-VAS (Mean, SD)	43.9 (21.8)
Perceived health state respondent: EQ-VAS (Mean, SD)	64.5 (21.6)
Self-reported happiness: EQ-VAS (Mean, SD)	63.49 (22.7)
EQ-5D value health state respondent (Mean, SD)	0.753 (0.242)

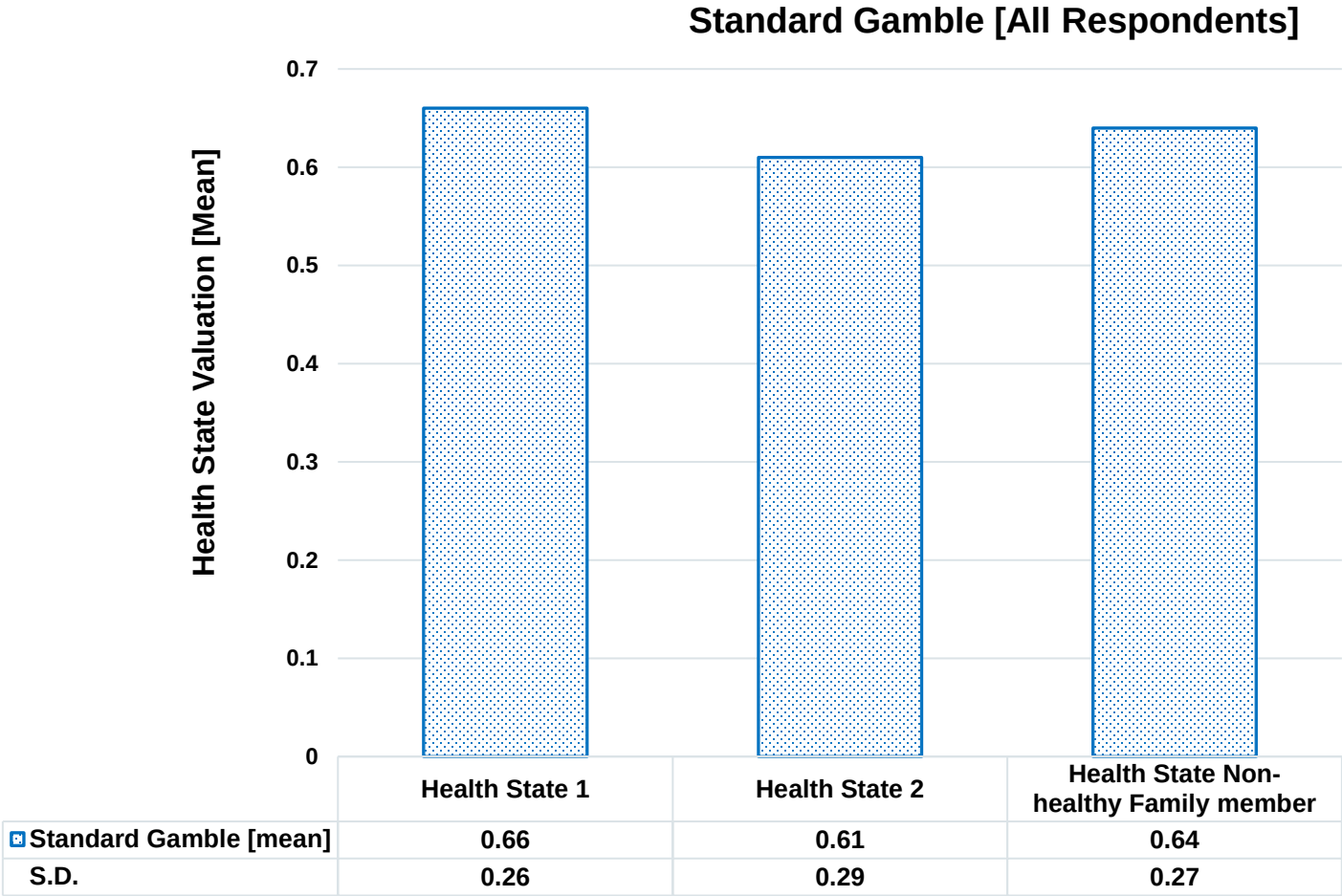
The majority of respondents perceived the impact of their non-healthy family member's health status as (somewhat) negative, particularly for leisure time, overall happiness, social activities, well-being and sense of control

Perceived impact of the health status of the non-healthy family member on...	Positive n (%)	Somewhat positive n (%)	Neutral n (%)	Somewhat negative n (%)	Negative n (%)
Overall happiness	41 (8.2)	76 (15.2)	131 (26.2)	207 (41.4)	45 (9.0)
Sleep	30 (6.0)	73 (14.6)	160 (32.0)	170 (34.0)	67 (13.4)
Well-being	30 (6.0)	73 (14.6)	166 (33.2)	193 (38.6)	38 (7.6)
Social activities	29 (5.8)	64 (12.8)	144 (28.8)	164 (32.8)	99 (19.8)
Social relationships	31 (6.2)	76 (15.2)	188 (37.6)	136 (27.2)	69 (13.8)
Work productivity	27 (5.4)	74 (14.8)	212 (42.4)	135 (27.0)	52 (10.4)
The relationship with other family members	53 (10.6)	108 (21.6)	204 (40.8)	105 (21.0)	30 (6.0)
Self-care	44 (8.8)	83 (16.6)	229 (45.8)	111 (22.2)	33 (6.6)
Having a sense of control over life	38 (7.6)	71 (14.2)	151 (30.2)	184 (36.8)	56 (11.2)
Leisure time	33 (6.6)	72 (14.4)	127 (25.4)	192 (38.4)	76 (15.2)
Psychological health	38 (7.6)	59 (11.8)	165 (33.0)	172 (34.4)	66 (13.2)

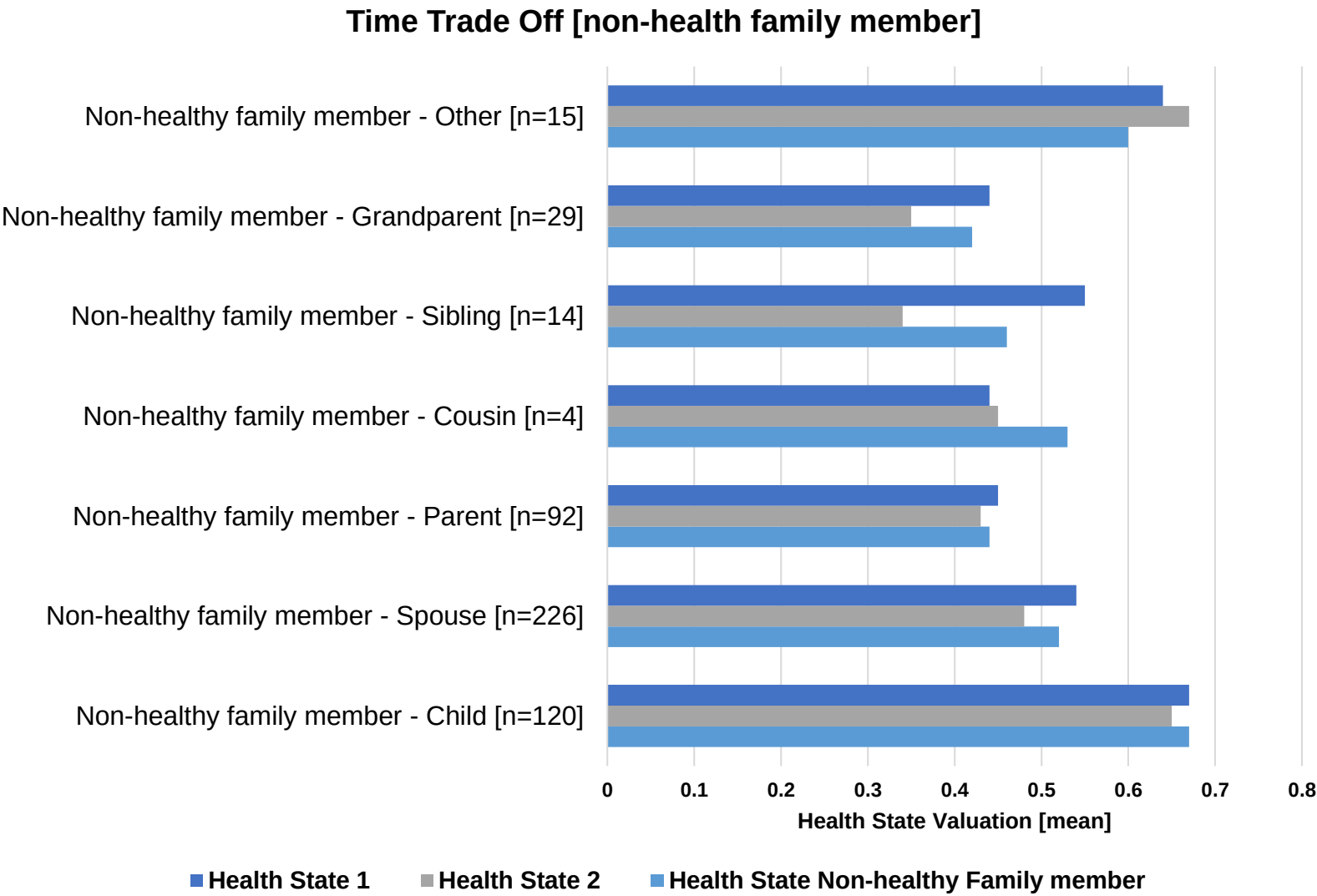
In the time trade-off exercise, respondents, on average would give up 51 to 55% of their remaining life expectancy to restore their family member’s health



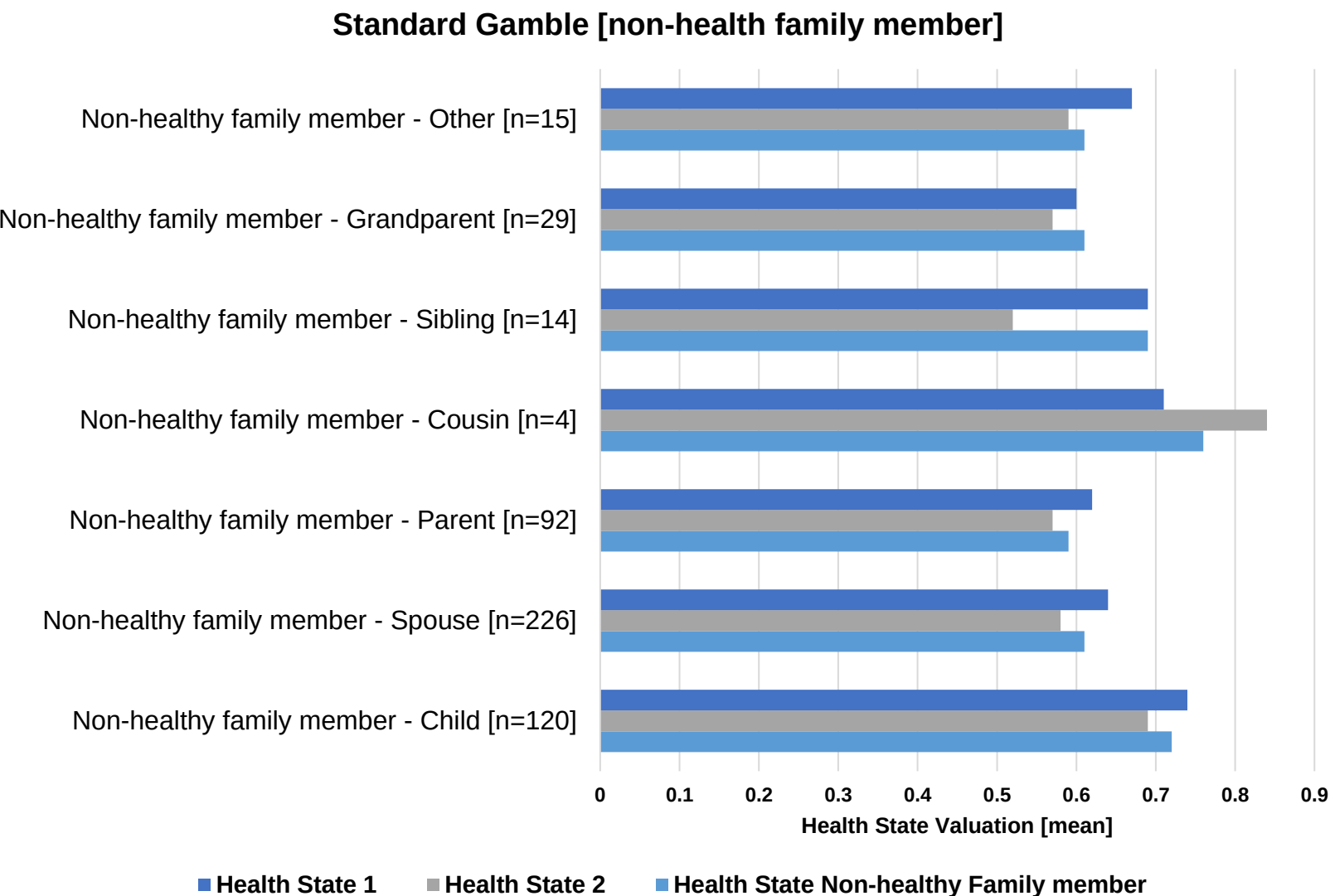
In the standard gamble, respondents were willing to accept a high risk of dying (61-66%) to restore their family member's health



Respondents, on average, were willing to give up a larger remaining life expectancy for their children (65 – 67%)



A large risk of dying was accepted by respondents for restoring their child's health (69 – 74%)



Discussion & Conclusions

Findings showed a very high impact of living with non-healthy family members

- The ill-health of a loved one **had negative impacts on many domains of the respondent's life**, with the overall happiness, leisure time, social activities, well-being and sense of control being particularly affected
- Respondents were willing to **accept risk of dying of 61 to 66%** to restore their family member's health
- Respondents were willing to **give up 51 to 55% of their remaining life expectancy** to restore their family member's health
- The greatest risk was accepted **(69 - 74%) for children**, and respondents were willing to give up a larger remaining life expectancy for their children **(65 – 67%)**



Discussion and follow up research needed to further test this approach for CUAs and to interpret the findings

- The current findings can facilitate a discussion about the inclusion of family member effects in health economic evaluations.
 - Such effects should be included and current health economic guidelines, in most countries would not prevent including such effects. However, as far as we know these effects are not (yet) included in practice.

Follow-up research needed

- If these estimates are included as disutilities, the impact on cost-effectiveness outcomes are very large. But can the outcomes be interpreted as disutility?
- Before being able to use this methodology, we need to better understand the answers the participants gave during the different exercises, to better interpret the outcomes (e.g., to understand 'the why').
- This research needs to be replicated in the general population, as utility values are typically based on general population studies > **next steps to replicate these findings in the general population + cognitive debriefing interviews**





Thank you!

