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Mind the gap : explanations for the differences in utilities between respondent groups

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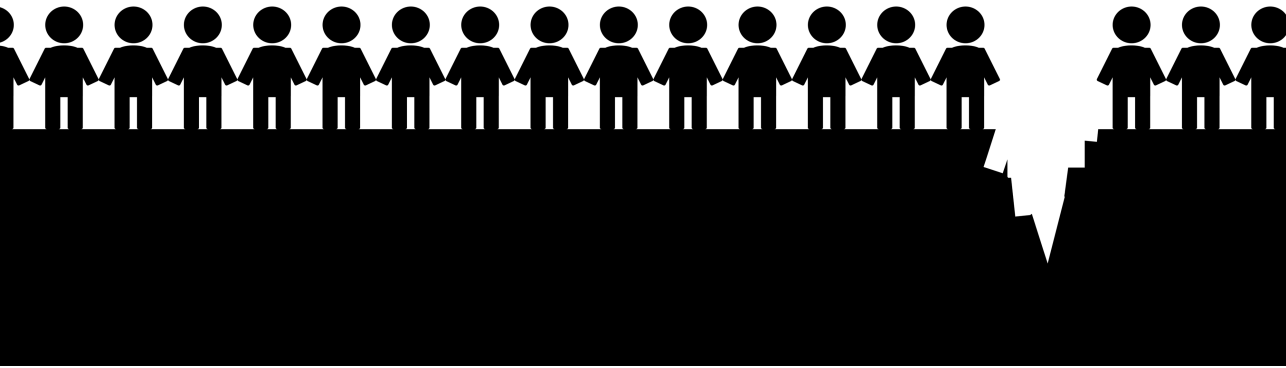
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Appendix A - D



Appendix A

Study characteristics of the 30 included studies(Chapter 2)

Source	#patients	#non-patients	Unstandardized difference	Elicitation method	Kind Patients	Kind non-patients
Ashby & O'Hanlon (1994)	18	59	0.15 ^f	TTO	Women with breast cancer	Professionals
Badia et al. (1996)	103	360*	0.13 ^f	VAS	Critical medical & surgical patients	General public
Badia et al.(1998)	120	360*	0.09 ^f	VAS	Chronically ill	General public patients
Boyd et al. (1990)	40	99	0.09(NR)	VAS	Patients with colostomy	Professionals
			0.01(NR)	SG		
			0.23(NR)	VAS		General public
			0.09(NR)	SG		
Calhoun et al. (2004)	40	50	-0.01(NR)	TTO	Ovarian cancer patients	Professionals
			0.03(NR)	TTO		General public
Cappelli et al.(2001)	57	46	0.08 ^{II}	VAS	Women with breast cancer	General public
			0.11 ^{II}	SG		
Chen et al. (1998)	14	41	-0.10 [†]	VAS	Patients with psoriasis	Professionals
			-0.02(NR)	VAS		General public

Appendix

Source	Kind scenario	Illness label	Country
Ashby & O'Hanlon (1994)	6 breast cancer health state scenario's	Yes	UK
Bardia et al. (1996)	15 EQ-5D health states	No	Spain
Bardia et al. (1998)	15 EQ-5D health state scenario's	No	Spain
Boyd et al. (1990)	Scenario living with a colostomy	Yes	Canada
Calloun et al. (2004)	6 chemotherapeutic-induced toxicity health states	Yes	USA
Cappelli et al. (2001)	6 health state descriptions related to breast cancer	Yes	Canada
Chen et al. (1998)	3 psoriasis health state descriptions	Yes	USA
Clarke et al. (1997)	3 Gaucher Disease scenario's	Yes	Canada & USA

Source	#patients	#non-patients	Unstandardized difference	Elicitation method	Kind Patients	Kind non-patients
Clarke et al. (1997)	50	39	-0.03 [†] -0.04 [†] -0.02 [†] -0.01 [†]	TTO SG TTO SG	Chronic ill patients Gaucher disease patients	General public General public
Cunningham et al. (2000)	40	55	-0.05(NS) 0.05(NS) -0.06(NS)	TTO VAS SG	Orthognathic patients	General public
De Wit et al.(2000)	152	103	0.19 [†] 0.04 [†]	TTO SG	Dialysis patients	General public
Gabriel et al. (1999)	44	199	0.39 [†]	TTO	Women with osteoporotic fractures	General public
Goldberg (2006)	173	128	0.00(NR) -0.03 NR	SG SG	Prostate cancer Diabetes	General public General public
Grann et al. (1999)	20	125	0.04(NR) 0.12(NR) 0.01(NR) 0.06(NR)	TTO VAS TTO VAS	Breast cancer patients	Professionals
Hallan et al. (1999)	41	117	0.15(NR)	SG	Stroke survivors	General public
Happich & Lengerke (2005)	105	66	0.06 [†] 0.19 [†] 0.08 [†]	TTO VAS SG	Patients affected with tinnitus	General public
Hayman (1997)	97	20	0.02(NR)	SG	Early-stage breast cancer	Professionals

Appendix

Source	Kind scenario	Illness label	Country
Cunningham et al. (2000)	One description with pictures of dental problems	Yes	UK
De Wit et al.(2000)	3 EQ-5D scenario's	No	The Netherlands
Gabriel et al. (1999)	3 health state descriptions, disabling hip fracture,established osteoporosis and multiple vertebral fractures	Yes	USA
Goldberg (2006)	4 Erectile dysfunction descriptions	Yes	USA
Gram et al. (1999)	8 Cancer-related health states	Yes	USA
Hallan et al. (1999)	2 scenario's describing functional outcomes after stroke	Yes	Norway
Hapich & Langerke (2005)	Description of Timitus	Yes	Germany
Hayman (1997)	5 Breast-cancer related health states	Yes	USA

Source	#patients	#non-patients	Unstandardized difference	Elicitation method	Kind Patients	Kind non-patients
Hayman (2005)	120	210	-0.01 †	SG	Women with ductal carcinoma-in-situ	General public
Korfage et al. (2007)	53	52	-0.02(NS) 0.02 ^l	TTO VAS	Men with prostate cancer	General public
Molzahn (1997)	215	49	0.07 [‡]	TTO	End stage renal disease	Professionals
Naraine et al. (2002)	28	30	0.02 [†]	SG	Patients with haemophilia	General public
Postularat & Adang (2000)	22	54	0.25 [‡]	VAS	Insulin-dependent diabetes mellitus with end-stage renal disease	General public
Prosser et al. (2003)	29	33	0.07 [‡]	SG	MS patients	General public
Smith et al.2006	95	567	0.21 [‡]	TTO	Colostomy patients	General public
Souchek et al. (2005)	66	64	0.02(NS) 0.00(NS) -0.07(NS)	TTO VAS SG	Patients with osteoarthritis	General public
Sackett & Torrance (1978)	29	246	0.132 ^u	TTO	Dialysis patients	General public
Stewart (2005)	84	78	0.03(NR) 0.01(NR) 0.05(NR)	TTO VAS SG	Men with prostate cancer	General public
Suarez -Almazor & Conner-	50	147	0.02(NR) -0.00(NR) -0.05(NR)	TTO VAS SG	Patients with rheumatoid	Professionals

Appendix

Source	Kind scenario	Illness label	Country
Hayman (2005)	8 breast cancer related health states	Yes	USA
Molzahn (1997)	Life on dialysis	Yes	Canada
Naraine et al. (2002)	7 haemophilia A health state descriptions	Yes	Canada
Postularat & Adang (2000)	Self vs. Description of Insulin-dependent diabetes mellitus and end-stage renal disease	Yes	The Netherlands
Prosser et al. (2003)	6 MS health state descriptions	No	USA
Smith et al. (2006)	Colostomy health state description	Yes	USA
Souchek et al. (2005)	2 EQ-5D health states	Yes	USA
Sackett & Torrance (1978)	5 Dialysis health state descriptions	Yes	Canada

Source	#patients	#non-patients	Unstandardized difference	Elicitation method	Kind Patients	Kind non-patients
Spady (2001)			-0.00 (NR)	TTO		General public
			-0.02 (NR)	VAS		
			0.07 (NR)	SG		
Suarez-Almazor (2001a)	105	5	-0.16 [†]	VAS	Musculoskeletal diseases	Professionals
			-0.19 [†]	SG		
Van der Donk et al. (1995)	20	20	-0.11 (NR)	TTO	Laryngeal cancer	Professionals
			-0.08 (NR)	VAS		
			-0.23 (NR)	SG		
Wells et al. (2004)	114	83	-0.11 (NR)	TTO	Laryngeal cancer	General public
			-0.03 (NR)	VAS		
			-0.13 (NR)	SG		
			-0.12 (NR)	TTO	Floor of the mouth cancer	
			-0.05 (NR)	VAS		
			-0.18 (NR)	SG		
-0.12 (NR)	TTO	Floor of the mouth cancer				
			0.04 (NR)	VAS		General public
			-0.07 (NR)	SG		
			0.14 [†]	TTO	Cirrhotics	Professionals

Source	Kind scenario	Illness label	Country
Stewart (2005)	21 prostate cancer related health states	Yes	USA
Suarez -Almazor & Conner - Spady	2 scenario's of arthritis	Yes	Canada
Suarez-Almazor (2001)	Own experienced health of patients seen by Rheumatologist	Yes	Canada
Van der Donk et al. (1995)	4 health states after T3-laryngeal cancer	Yes	The Netherlands
Wells et al. (2004)	6 scenarios of cirrhosis	Yes	USA

*Original sample size, in analyses the sample sizes were divided by two since in both studies valuations of one group of non-patients were used.

NR Significance of the difference between respondent groups not reported

NS Difference between respondent groups is not significant

† Difference between respondent groups $p < 0.05$

‡ Difference between respondent groups $p < 0.01$

ℓ Difference between respondent groups varied for the different health states between not significant and $p < 0.05$

ℎ Difference between respondent groups varied for the different health states between not significant and $p < 0.01$

ℓ Difference between respondent groups varied for the different health states between $p < 0.05$ and $p < 0.01$

Appendix B

Description of the five additional EQ-5D scenarios and RA-patients' valuations(Chapter 3)

EQ-5D dimension	Scenario A	Scenario B	Scenario C	Scenario D	Scenario F
Mobility	Some problems	Some problems	Some problems	Some problems	Some problems
Self-care	No problems	Some problems	No problems	No problems	No problems
Usual activities	Some problems	Unable to perform	Unable to perform	Some problems	No problems
Pain/discomfort	Extreme pain	Some pain	Some pain	Some pain	No pain
Anxiety / depression	or other discomfort Moderately anxious /depressed	or other discomfort Moderately anxious /depressed	or other discomfort Not anxious /depressed	or other discomfort Moderately anxious /depressed	or other discomfort Not anxious /depressed
N	124	126	127	120	126
Mean (SD)	0.53 (0.30)	0.57 (0.30)	0.69 (0.25)	0.76 (0.24)	0.91 (0.14)

Appedix C

RA health state description

Imagine that your have been diagnosed with rheumatoid arthritis. This means that:

- some of your joints in your fingers and feet are swollen
- you have pain due to mild inflation in your tendons
- you have difficulty performing fine motor skills with your hands
- you have sore feet after walking more than half an hour
- you have some problems with your self-care, such as brushing hair, tying knots, washing your back, opening certain packages, and with cooking, e.g. with peeling potatoes
- you have some difficulty in using a computer mouse or keyboard, and with lifting items onto a shelf above your head at work
- you are not being able to run as a form of sports

Appendix D

Coding system chapter 4

Physical (in)convenience RA-related

Physical inconvenience that is obviously related to RA such as stiffness, medication or pain. Taking a rest, physical state, and fatigue were also included as well as undesirable effects of medication. Other aspects included were; the RA was improved, that momentarily the RA did not give problems, constraints or pain, or that it is possible to find solutions.

Illness/inconvenience not RA-related

Illness or inconvenience that is not RA-related, such as headache or kidney problems. Losing weight and medication or undesirable effects of medication are also included if these were not RA-related.

Family

Family or activities in which family was important, such as (grand)children or party of a son. Family members who are ill are also included.

Other social contacts

Social contacts such as friends, colleagues or acquaintances excluding family members.

Emotions/Worries

All emotions and worries and aspects in which the emotion or worry was most important. Emotions due to social contacts like conflict with a child and insomnia due to emotions, are included; as well as worries due to medication, the future or growing old. Hope, satisfaction, contentment, and rejoicing also belong to this category.

Sports/Mobility

Sport activities and mobility, such as playing soccer, swimming, sitting inside, constraints in walking and cycling around. Participants sometimes named aspects as walking or cycling as their sport, sometimes as (limitation) in their

mobility and sometimes without referring to one of both. All aspects were included in this domain, therefore no distinction could be made between sports & mobility.

Leisure activities

Leisure activities, such as sewing or reading. When bicycling is named as a pleasant, relaxing and social activity it is included as leisure activity instead of a sport.

Work

All work related aspects. Housekeeping is also included.

Broad every day life

Performance of activities of daily living, such as I am able to do what I want, I only need to adjust my tempo and am able to do the things someone does in every day life.

Others

Dimensions that could not be included in any of the categories or that can be included in more than one category.

