

Appendix 3: Summary of studies

Lead Author	Location	Indication (disease)	Intervention	Samples compared	Attributes Tested	Design of Attributes	Generated in all groups?	Piloting of studies	Piloted in all groups?	Framing of choice tasks	Choice same in all groups?
Bishop et al. 2004	United Kingdom	Down's Syndrome	Screening	253 pregnant women/ 94 HCPs	Time at screening; Detection rate; Risk of miscarriage	Pilot study with 21 women	No	Yes; methods not reported	Not known	Women chose for themselves; HCPs chose for their patients (opt-out and indifference option provided)	No
Lee et al. 2005	China	Postoperative period (1 st DCE) and Postoperative nausea/ vomiting(2 nd DCE)	Preferred symptoms (1 st DCE) and drug treatment (2 nd DCE)	200 women undergoing elective surgery/ 52 HCPs	DCE #1: Risk of PONV; Level of Pain; Level of Sedation DCE #2: Type of regimen; Efficacy of antiemetic; Extra cost to patient	Not reported	Not known	Not reported	Not known	DCE #1: Patients chose for themselves; Framing not reported for HCPs. DCE #2: Patients and HCPs randomized into low, moderate, high risk of PONV versions of DCE	No
Mantovani et al. 2005	Italy	Hemophilia	Drug treatment	178 patients/ 137 HCPs	Perceived viral safety; Risk of inhibitor development; Pharmaceutical dosage form; Distribution mode; Frequency of infusion for prophylaxis; Cost	Generation with physicians, pharmacists and economists; piloting in patients, hematologists and pharmacists. Levels corresponded to available medications.	Yes	Yes: 5 patients, 5 physicians and 5 pharmacists	Yes	Respondents invited to choose one of the two pairs presented	Not reported
Espelid et al. 2006	Norway and Denmark	Dental restoration	Materials used	306 patients/ 107 HCPs	Duration; Appearance; Adverse reaction;	Generated by a general survey of patients and dentists in Great Britain, France, Germany, Italy and Sweden in 1998. Piloted in Norwegian dental students	No	Not reported	Not known	Patients chose for themselves; Dentists chose recommendation for an included patient case; dental assistants chose the best-suited option for the same patient case. Indifference option also.	No
Lewis et al. 2006	Australia	Down's Syndrome	Prenatal screening	113 pregnant women/ 175 HCPs	Timing (weeks); Accuracy (%); Risk (%)	Same method as described in Bishop et al. 2004	No	See Bishop et al. 2004	See Bishop et al. 2004	Patients chose for themselves; HCPs chose what they would offer women	No

Gidman et al. 2007	United Kingdom	Child daycase surgery	Provision of services	280 parents of children undergoing daycase surgery/ 193 HCPs	Parental involvement in medical decisionmaking; Parental presence at the induction of anesthesia;	Generated from systematic literature search and analysis of interviews with parents.	No	Yes: in parents of children aged 3-11 years	No	Participants asked to choose the option they thought was preferable.	Yes
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					Staff attitude; Postoperative pain; Quality of recovery from anesthesia; Cost to parents						
de BekkerGrob et al. 2009	The Netherlands	Osteoporosis	Preventative drug treatment	117 patients/ 39 HCPs	Effectiveness of treatment; Nausea as an adverse effect; Total treatment duration; Route of drug administration; Cost	Generated by literature review, expert interviews, and a study in communitydwelling women over 60yo with and without osteoporosis.	Yes	Yes: 2 GPs and 8 patients	Yes	Patients asked to choose for themselves; GPs asked to choose treatments for a standardized female patient over 60yo. 'No-drug' treatment option provided.	No

Fiebig et al. 2009	Australia	Cervical Cancer	Screening	167 women who had Pap tests previously/ 215 HCPs	<p><u>Women's Survey:</u> Recommended screening interval; Familiarity of GP; Sex of GP*; Time since last cervical screening test; Doctor's recommendations*; Doctor's incentive; Cost of test*; Chance of false negative*; Chance of false positive*</p> <p><u>GP Survey:</u> Reason for consultation*; Recommended screening interval; Familiarity with patient; Patient's last screening; Age*; Perception of patient's income/ socioeconomic status*; Payment to practice for test</p>	Generated by literature review, current Australian policy context and a pilot test (Fiebig et al 2005).	Reported in Fiebig & Hall 2005	Not reported	Not known	Women asked whether they would choose a cervical Pap and which test; GPs asked whether they would recommend a cervical Pap and which test. Opt-out option provided.	No
Marshall et al. 2009	United States, Canada	Colorectal Cancer	Screening	501 Canadians; 1087 Americans/ 100 HCPs in	Test process; Test frequency; Requirement for follow-up if initial test is positive;	Generated by a literature review, focus groups and the results of a Canadian-based	Not reported	Yes: patients and physicians attending clinics in California	Yes† †Piloted in American	Participants asked to choose between two treatments, then between the same two or no	No

				Canada and the United States	Pain/discomfort from the test; Preparation needed for the test; Risk of complications; Test sensitivity; Test specificity; Cost of test	DCE completed in 2007. Further refined through clinical and methodological input.			respondents only	treatment. Physicians asked the same, but for a patient aged 50, no history of colorectal cancer	
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Neuman & Neuman 2009	Israel	Labour and Hospitalization following birth	Provision of services	323 women who recently gave birth/ 30 HCPs	Number of beds in hospital room; Attitude of staff towards patient; Professionalism of medical staff; Information given from personnel to patient Travel time from residence to hospital	Generated by literature survey, in-depth interviews with women who recently gave birth, and a pilot study	Not reported	Not reported	Not known	Women asked which maternity ward they would prefer; hospital staff asked to make choices that reproduce and represent the choices made by hospitalized women	Yes
Scalone et al. 2009	Italy	Hemophilia with inhibitors	Drug treatment	37 patients with hemophilia with inhibitors and caregivers/ 64 HCPs	Risk of Infection; Risk of Anamnestic Response; Number of Infusions to stop bleeding; Time to stop bleeding; Time to pain recovery; Number of infusions/week for prophylaxis; Possibility of undergoing major surgery; Increase in healthcare taxes (cost)	Generated by 1 focus group with physicians, pharmacists and health economists; pilot study in 35 patients, pediatric caregivers, physicians and pharmacists; focus groups in physicians to determine levels	Yes	Not reported	Not known	Patients and HCPs asked to choose the option with the maximum global benefit from their point of view	Yes
Davison et al. 2010	Canada	Chronic Kidney Disease (CKD)	Organ procurement, allocation, end-of-life care and organisation of care	169 patients with Chronic Kidney Disease / 150 HCPs	Who provides comprehensive, day-to-day care; How deceased donor kidneys should be allocated; How live donor kidneys should be obtained; When should end-of-life care discussions begin; How much information should be provided on prognosis	Generated by review of the literature on aspects of CKD management that are substantial ethical challenges to the nephrology community	No	Not reported	Not known	Participants asked to choose between hypothetical Chronic Kidney Disease programs	Yes

					and end-of-life care issues; How should decisions to stop dialysis be made						
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Johnson et al. 2010	United States	Crohn's disease	Drug treatment	580 patients/ 315 HCPs	Severity of symptoms; Effect on serious complications; Time between flareups; Treatment requires taking oral steroids; Chance of dying from a serious infection within 10 years; Chance of dying or severe disability from PML within 10 years; Chance of dying from lymphoma in 10 years	Generated by review of the literature, consultations with 10 gastroenterologists to finalize hypothetical patient profiles, and interviews with 10 Crohn's disease patients.	Yes	Yes: 51 Crohn's disease patients recruited by a market research company.	No	Participants asked which treatment they would choose; Gastroenterologists evaluated for 3 hypothetical patients	No
Bijlenga et al. 2011	The Netherlands	Pregnancy and delivery with complications	Valuation of health states	24 patients+27 laypersons/ 30 HCPs	Maternal health ante partum; Time between diagnosis and delivery; Process of delivery; Maternal outcome; Neonatal outcome	In-depth interviews with 10 patients with gestational diabetes, preeclampsia, and/or intrauterine growth retardation as well as 10 obstetrical care professionals. Attribute levels assigned from these interviews, a literature search and results from the HYPITAT and DIGITAT trials	Yes	Not reported	Not known	Participants asked to choose between pairs of health states	Yes
van Empel et al. 2011	The Netherlands, Belgium	Infertility	Treatment provision	925 patients/ 227 HCPs	Travel time to clinic; Physician's attitude to patients; Information on treatments; Continuity of physicians; Clinic's mean ongoing pregnancy rate	Attributes and levels generated from a literature search, focus groups with 82 Belgian and Dutch fertility clinic patients, expert panel of 5 fertility experts.	Yes	Yes: 8 couples during 4 rounds of cognitive interviewing.	No	Patients asked which fertility clinic they would choose. HCPs asked which clinic they would recommend to their patients	No
Faggioli et al. 2011	Italy	Abdominal aortic aneurysm	Drug treatment	160 patients + 102 relatives / 30 HCPs	Type of anesthesia; Time necessary to recover (defined as returning to normal activities);	Attributes and levels generated by review of the literature plus discussion with experienced staff	Yes	Not reported	Not known	Participants asked which treatment would they choose – cost attribute was framed as out-of-pocket cost for	No [†] Cost attribute framed differently

					Need to repeat intervention within 5 years; Type of periodical exams and medical visits on follow-up; Risk of severe complications including death; Additional cost	surgeons and health economists with experience in outcomes research. Piloted in 6 patients and 7 experienced staff vascular surgeons				patients and additional hospital cost for HCPs	
Muhlbacher & Nubling 2011	Germany	Multiple Myeloma	Drug treatment	282 patients/ 213 HCPs	Life expectancy/ effectiveness; Adverse effects; Therapy-free intervals; Physical quality of life; Emotional quality of life; Social quality of life; Therapy application; Further treatment options	Reported in Muhlbacher et al. 2008	No	Yes [†]	Yes [†]	Physicians asked to select their patients' preferences; patients' preferences elicited in Muhlbacher et al. 2008	Yes
Payne et al. 2011	United Kingdom	Azathioprine-induced neutropenia	Pharmacogenetic testing services for predicting the risk of azathioprine-induced neutropenia	159 patients prescribed azathioprine/ 138 HCPs	Level of information given; Predictive ability of test; How the sample is collected; Turnaround time for a result; Who explains the test result	Generated by review of the literature; qualitative study described in Fargher et al. using focus groups with HCPs and interviews with patients; expert review of attributes	Yes	Yes: 20 clinic patients and 30 staff	Yes	Participants asked to indicate which test they would choose.	Yes [†] [†] From picture of DCE included
Shafey et al. 2011	Canada	Relapsed follicular lymphoma	Drug treatment	81 patients/ 48 HCPs	Administration of treatment; Toxicity; Remission length; Healthcare cost	Attribute levels were determined by literature review, existing administration protocols and toxicities of each regimen	No	Yes: 2 members of the Calgary Hematology Group, 5 lymphoma patients and 5 medical oncologists	Yes	DCE asked which treatment would participants choose	Yes
Thrumurthy et al 2011	United Kingdom	Esophagogastric cancer	Surgical treatment	81 patients/ 90 HCPs	Mortality; Morbidity; Quality of Life; Cure rate; Hospital type; Reputation of surgeon	Attributes elicited by review of the literature, expert opinion and pilot test	Not known [†]	Yes: patients	No	Participants chose between two hypothetical surgeries	Yes [†] [†] From picture of DCE included

Chancellor et al. 2012	France, Germany, Italy, Spain,	Chronic Pain	Drug treatment	186 patients/ 310 HCPs	<u>Patient DCE:</u> Effectiveness for pain;	Attributes elicited by review of the literature; focus groups with 44	Yes	Yes: piloted among research colleagues and	Yes	Participants asked to choose between two profiles; optout option provided	Yes
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	United Kingdom				Constipation and bowel problems;* Nausea and vomiting;* Alertness;* Energy* <u>Physician DCE:</u> Range of dosage forms;* Proportion of patients with 50% pain reduction; Side effects (constipation, NV, CNS)*	osteoarthritis/low back pain patients and 40 cancer pain patients; semi structured telephone interviews with 9 physicians.		then soft launched before actual release			
Clark et al. 2012	United Kingdom	Kidney Transplant	Prioritization preferences	908 patients + 41 carers + 48 donors / 113 HCPs	Time spent awaiting transplant; Tissue type matching; Number of child or adult dependents the recipient has; Recipient age; Diseases predominantly affecting life expectancy; Diseases predominantly affecting quality of life	Attributes and level selection mainly informed by discussion with clinicians; piloted in 60 respondents (41 patients, 16 healthcare practitioners, 1 donor, 1 carer, 1 renal consultant's secretary) and analysed using random effects probit	Yes	Yes: 60 respondents (41 patients, 16 healthcare practitioners, 1 donor, 1 carer, 1 renal consultant's secretary); confirmed attributes and survey	Yes	Participants asked to express a stated preference for which one of two transplant recipients should receive a kidney.	Yes
Hill et al. 2012	United Kingdom	Down's Syndrome	Prenatal screening	335 women/ 181 HCPs	Accuracy; Time of results; Risk of miscarriage; Information gained from the test	Attributes selected by literature review	No	Yes: 17 midwives and 20 women	Yes	Patients asked which test they preferred to have; HCPs asked which test they preferred to offer patients. Option to choose neither test provided.	No

Park et al. 2012	South Korea	Metastatic renal cell carcinoma	Drug treatment	140 patients + 60 family members/ 295 HCPs	Progression-free survival; Bone marrow suppression (neutropenia/ thrombocytopenia); Hand-foot skin reaction; GI perforation Bleeding; Administration	Attributes selected by comprehensive literature review and expert opinions.	No	Yes: 20 persons before launch.	Not known	Participants asked which treatment they would choose	No
Pedersen et al. 2012	Denmark	Primary Care	Provision of services	698 members of the general	Typical waiting time on telephone;	Attributes generated by	Yes	Yes: cognitive interviews and	Yes	Respondents asked to choose their	Yes

				public/ 969 HCPs	Opening hours; Typical waiting time to appointment; Distance to practice; Typical wait time in waiting room; Average consultation time; Who performs routine tasks	literature review, interviews with GPs, interviews with patients, and discussions with the Organization of General Practitioners of Denmark		pilot studies in general population and GPs		preferred alternative from a set; one set of forced choices and one set of unforced choices	
Regier et al. 2012	Canada	Antimicrobial prophylaxis in pediatric oncology	Provision or nonprovision of drug treatment for prophylaxis	102 parents of pediatric oncology patients/ 60 HCPs	Risk of infection; Risk of death; Risk of nausea, vomiting, diarrhea or headache; Route of administration; Cost (out of pocket) Two DCE versions: one for antifungal prophylaxis and one for antibacterial	Attributes and levels informed by literature review, qualitative interviews with 3 experienced pediatric oncology physicians	No	Yes: parents and health care professionals	Yes	Parents asked to imagine that their child were a candidate for antimicrobial prophylaxis; HCPs asked to imagine their patients were candidates for prophylaxis. Optout option provided.	Yes
de Bekker-Grob 2013	The Netherlands	Early prostate cancer	Drug treatment	110 patients with + PSA results but no biopsy results yet/ 50 HCPs	Risk of urinary incontinence due to treatment; Risk of erection problems due to treatment; Risk of other permanent side effects due to treatment; Main aim is to cure; Frequency of PSA testing with a risk of new biopsies; Type of treatment	Attributes and levels informed by literature review, interviews with urologists and senior researchers in the field of prostate cancer research.	No	Yes: 11 patients and urologists before launch.	Yes	Participants asked to consider both treatment alternatives as realistic and forced to choose from among them	Yes

Boone et al. 2013	United Kingdom	Colorectal cancer	Screening by CT Colonography	75 patients/ 50 HCPs	Number of additional true positive detections; Number of additional false positive detections	Not reported	Not known	Yes: 10 volunteers	No	Participants asked to choose between a hypothetical "enhanced" test or the standard test	Yes
Laver et al. 2013	Australia	Rehabilitation/ Occupational therapy	Provision of services	100 rehabilitation patients/ 114 HCPs	Mode of therapy; Dose of therapy (per day); Team providing therapy; Amount of recovery made; Cost	Attributes and levels informed by literature search and qualitative interviews with 10 rehabilitation patients.	No	Not reported	Not known	Patients asked to identify their preferred rehabilitation program; HCPs asked to choose what they would recommend for one of their 'typical	No

										rehabilitation clients'.	
Muhlbacher et al. 2013	Germany	HIV/AIDs	Drug treatment	218 patients (from Muhlbacher et al. 2013)/ 131 HCPs	Life expectancy; Long-term side effects; Flexibility of dosing; Physical quality of life; Emotional quality of life; Social quality of life	Attributes and levels informed by literature search and 4 patient focus groups;	No	Yes: 28 patients prior to launch	No	Patients asked to choose between two treatments; HCPs asked to choose how they thought their patients would rate or what they would choose	Yes

Deal et al. 2014	Canada	Cardiovascular disease	Electronic management	74 patients/ 70 HCPs	<p><u>Patient DCE:</u> Fee/month; Speed of new info added to vascular tracker; Individual patient tracker values displayed; Nurse coordinator tasks /duties; Access to nurse coordinator;* Vascular visits to physician/year</p> <p><u>Physician DCE:</u> Fee/month; Speed of revised information in the vascular tracker; Tracker values displayed; Nurse coordinator tasks; Nurse coordinator payment/month;* Efficiency in seeing patients;* Billing incentives from government (pay for performance)*</p>	Attributes and levels informed by focus groups conducted with 29 physicians and 21 patients	Yes	Not reported	Not known	Participants considered 18 choice screens including 2 fixed tasks and selected their most preferred out of 3 randomly selected C3CVT program alternatives	Yes
Hill et al. 2014	United Kingdom	Cystic fibrosis	Prenatal screening	92 adult patients with CF + 50 carriers of CF/ 70 HCPs	Accuracy; Time of results; Miscarriage risk	Attributes and levels informed by a series of focus groups with carriers of single gene disorders.	No	Yes: 20 carriers of cystic fibrosis	No	Patients and carriers chose for themselves; HCPs chose the test they would prefer to offer. Opt-out (neither test) option provided.	No
Huppel-schoten et al. 2014	The Netherlands	Infertility	Treatment provision	550 patients/ 45 HCPs	Clinic's mean ongoing pregnancy rate; Information provision; Patient involvement; Continuity of physicians; Additional costs per IVF cycle	Attributes and levels informed by literature review and an interview with the chief of the healthcare purchasing department in a large Dutch health insurer company.	No	Yes: 13 infertile couples and a health insurer	Yes	Participants asked which clinic they would choose	Yes

Mol et al. 2014	The Netherlands	Diabetes	Drug treatment	226 patients with Type 2 diabetes/ 227 HCPs	Glycated hemoglobin; Cardiovascular disease risk; Effect on body weight; Mild nausea, vomiting or diarrhea; Hypoglycemia; Risk of cancer	Attributes and levels informed by informal literature review, regulatory requirements and product labelling of oral antidiabetic drugs, and 22 indepth interviews with patients, nurses, regulators and pharmacists.	Yes	Not reported	Not known	Standard patient case presented to all participants. Regulators: treatment they felt appropriate. HCPs: treatment they would recommend. Patients: imagine they were that patient to choose	Yes [†] [†] Based on figure of DCE provided
Beulen et al. 2015	The Netherlands	Infant genetic abnormalities	Prenatal screening	507 pregnant women/ 283 HCPs	Minimal gestational age; Time to wait for results; Level of information; Detection rate; False positive rate; Miscarriage risk; Cost	Attributes and levels informed by systematic literature review, semi-structured interviews with pregnant women, and expert panel discussion.	Yes	Yes: 54 participants [†] [†] Type of participant not reported	Not known	Patients asked which test they would prefer to have; healthcare practitioners asked which test they would prefer for their patients. Optout (no test) option provided.	No
Gatta et al 2015	Turkey	Bone metastases	Drug treatment	91 patients/ 99 HCPs	Months to first skeletal-related event/ complication of bone metastases; Months until worsening of pain; Annual risk of Osteonecrosis of the Jaw; Annual risk of renal impairment; Administration regimen	Attributes and levels informed by review of prescribing information, literature review, and consultation with clinical experts	No	Yes: opened interviews with 8 physicians and 15 patients in the United States	Yes	Patients asked to choose the treatment based on their key attributes and the level to which each option fulfilled them; HCPs given two patient cases for this choice	No
Okumura et al. 2015	Japan, United States	Atrial fibrillation	Anticoagulation treatment	Japan: 152 patients/ 164 HCPs United States: 185 patients/107 HCPs	Risk of minor stroke (non disabling); Risk of major stroke (disabling); Risk of blood clot in the leg (non-CNS, systemic embolism); Risk of heart attack;	Attributes and levels informed by review of clinical trials of anticoagulants, consultation with experts, and semi-structured interviews with 8	Yes	Not reported	Not known	Patients asked to choose between treatments as if choosing for themselves; Physicians asked to choose treatments	No

					Risk of moderate bleeding (clinically relevant, non-major); Risk of nonfatal major bleeding (extracranial major bleed); Risk of all-cause death	patients and 9 physicians in the United States				for 4 virtual patients	
Whitty et al. 2015	Australia	Chronic conditions	Community pharmacy service provision	602 patients or carers / 297 HCPs	Continued medicines supply; Management of ongoing condition; Pharmacy location; Method of getting medicines; Medicine reviews or advice; Average cost per month	Attributes and levels informed by qualitative methods: 97 consumer and carer interviews and 26 focus groups with consumers, carers and health professionals.	Yes	Yes: convenience sample of all target populations, then in 36 adults with chronic conditions before launch.	Yes	Patients and carers asked if they would choose the new service, or remain at their current pharmacy. HCPs asked to choose the pharmacy service they thought consumers would prefer.	No