

Supplementary files

Table S1. Collaborating organizations

Table S2. Outcomes assessed during Round 1 and their definition

Table S3. Round 1 means, medians and proportion (rating 7-9) of patients/caregivers and health professionals for 35 outcomes

Table S4. Suggested outcomes by participants (n=1018) in Round 1 and reasons for exclusion

Table S5. Round 2 means, medians and proportions (rating 7-9) of patients/caregivers and health professionals for 22 outcomes.

Table S6. Round 3 means, medians and proportions (rating 7-9) of patients/caregivers and health professionals for 16 outcomes.

Table S7. Mean scores of patients/caregivers by countries for outcomes rated higher by patients/caregivers.

Table S8. Mean scores by age group for Round 3 outcomes.

Figure S1. SONG-Tx Delphi process

Figure S2. Mean scores of patients/caregivers and health professionals

Figure S3. Proportion of rank scores of patients/caregivers and health professionals in Round 3 (rank 1=most important, rank 16=less important)

Table S1. Collaborating organizations.

International

Cochrane Kidney and Transplant
Dialysis Outcomes and Practice Patterns Study (DOPPS)
International Society of Nephrology (ISN)
Kidney Disease | Improving Global Outcomes (KDIGO)
PKD International
The Transplantation Society (TTS)
World Transplant Games Federation

Australia / New Zealand

Australian and New Zealand Society of Nephrology (ANZSN)
Australian Kidney Trials Network (AKTN)
Christchurch Kidney Society
Kidney Health Australia (KHA)
Kidney Health Australia – Caring for Australasians with Renal Impairment Guidelines (KHA-CARI)
Kidney Health New Zealand (KHNZ)
PKD Foundation of Australia
Renal Society of Australasia (RSA)
Transplant Australia

Canada

The Kidney Foundation of Canada (KFOC)
Canadian Society of Nephrology (CSN)
Canadian Society of Transplantation (CST)

Europe

British Kidney Patient Association
British Renal Society (BRS)
European Kidney Patients Federation (EKPF)
European Kidney Transplant Association (EKITA) | European Society of Transplantation (ESOT)
European Renal Best Practice (ERBP)
UK National Kidney Federation (NKF)
PKD Charity
Centre for Evidence in Transplantation, University of Oxford
Société Francophone de Transplantation

United States

The Renal Association
American Association of Kidney Patients
Home Dialysis Central
National Kidney Foundation Southern California

Table S2. Outcomes assessed during Round 1 and their definition.

Graft loss: <i>Losing the kidney transplant because the transplant has failed (most patients will have to go on dialysis), how long the transplant will last</i>
Acute graft rejection: <i>The extent to which the recipient's immune system is destroying the transplanted kidney, which happens suddenly, quickly, and over a short period of time. It can generally be treated and may not lead to graft loss.</i>
Chronic graft rejection: <i>Long-term damage to the graft done by the body's immune system over a long period of time, it starts slowly and can take place over many years. Chronic rejection usually happens more than 1 year after the transplant operation.</i>
Graft function: <i>How well the transplanted kidney is working (usually measured by creatinine levels in the blood or biopsy), proteinuria, includes delayed graft function (e.g. sleepy kidney)</i>
Death: <i>Number of people who die, risk of death, how long the patient will live</i>
Cardiovascular disease: <i>Disease of the heart and blood vessels e.g. heart attack, stroke</i>
Cancer – skin: <i>Any type of skin cancer that may occur after the transplant</i>
Cancer - other (not skin): <i>Any type of solid or hematologic (blood) cancers that may occur after the transplant</i>
Diabetes: <i>Diabetes that may occur after transplant, abnormally high levels of sugar in the blood because the body cannot produce enough insulin</i>
High cholesterol: <i>Abnormally high levels of cholesterol or fat in the blood (dyslipidemia)</i>
Blood pressure: <i>The number to indicate the pressure in the arteries, high (hypertension) or low (hypotension) blood pressure</i>
Infection: <i>Disease caused by bacteria, viruses, parasites (infections include cytomegalovirus [CMV], Epstein-Barr virus [EBV], hepatitis B and C, BK virus etc.)</i>
Weight gain: <i>Increased appetite, or putting on a lot of weight</i>
Bone disease: <i>Osteoporosis, breaks/fractures, weakening of the bones</i>
Impact on family/friends: <i>Ongoing impact that living with a transplant has on family, caregivers, and friends</i>
Surgical complication: <i>Complications with the kidney transplant surgery (e.g. wound infection, urine leak)</i>
Depression: <i>Strong feelings of sadness, hopelessness, despair for most of the time, over a long time</i>
Ability to work: <i>Being able to work with a kidney transplant</i>
Gastrointestinal problems: <i>Uneasy feeling in the stomach, wanting to throw up, vomiting, diarrhea, constipation</i>
Cognition: <i>Ability to think clearly, remember things, problem solve</i>
Fertility: <i>Ability to conceive and have children after kidney transplantation</i>
Fatigue: <i>Feeling tired with no energy for weeks, for most of the time</i>

Sun sensitivity: *Being more at risk of developing sunburn, redness of the skin, which can lead to skin damage*

Mood swings and anger: *Unusual changes in emotion after the kidney transplant, crying easily, feelings of anger or agitation towards others*

Sleep disturbance: *Difficulty sleeping, quality of sleep after the kidney transplant*

Muscle weakness: *Decrease in the strength in 1 or more muscles, loss of muscle tone*

Eye problems: *Blurry vision, unable to see clearly, clouding of the lens in the eye, cataracts*

Anxiety: *Intense, persistent worry and fear about everyday situations*

Changes in appearance: *Including excessive hair growth or loss, acne, overgrowth of gums, swollen or rounded face*

Anemia: *Low number of red blood cells; can make a person feel tired, cold, dizzy, and irritable; or be short of breath or have a headache*

Hand tremors: *Involuntary shaking of the hands*

Arthritis and joint pain: *Pain experienced in a joint, includes gout*

Pins and needles: *Tingling sensation in a limb*

Hospitalization: *Staying in hospital for a health problem or complication*

Pain (excluding joint pain): *Any type of pain including headache, abdominal pain, back pain, pain after surgery (Arthritis/joint pain will be rated as a separate outcome)*

Table S3. Round 1 means, medians and proportion (rating 7-9) of patients/caregivers and health professionals for 35 outcomes.

Outcome	Mean scores		Median scores		Proportion 7-9 score	
	Patients/ caregivers	Health professionals	Patients/ caregivers	Health professionals	Patients/ caregivers	Health professionals
Graft loss	8.3	8.4	9	9	88.3	91.4
Graft function	8.1	7.9	9	8	85.7	83.3
Chronic graft rejection	7.9	7.8	9	8	82.6	84.2
Acute graft rejection	7.9	7.4	9	8	81.1	73.2
Death	7.6	8.3	8	9	71.1	84.6
Infection	7.6	7.4	8	8	75.3	77.6
Cancer (non skin)	7.5	7.1	8	7	74.8	69.3
Cardiovascular diseases	7.4	7.4	8	7	73.3	77.0
Cancer (skin)	7.3	6.4	8	6	70.1	48.8
Diabetes	7.2	6.8	7	7	68.5	57.3
Blood pressure	7.2	6.5	7	7	69.6	50.1
Surgical complication	7.1	6.5	7	7	66.2	51.9
Cognition	6.9	6.3	7	6	64.0	47.2
Ability to work	6.8	6.6	7	7	59.4	54.9
Depression	6.8	6.3	7	6	58.1	48.1
Bone disease	6.7	5.8	7	6	56.0	33.9
Fatigue	6.7	5.6	7	6	56.4	29.6
Anemia	6.7	5.6	7	6	56.6	28.4
Eye problems	6.6	5.4	7	5	54.7	24.8
High cholesterol	6.5	5.6	7	6	52.1	29.1
Sun sensitivity	6.4	5.0	7	5	49.7	19.2
Hospitalization	6.3	6.6	7	7	50.8	56.0
Gastrointestinal disorders	6.4	5.7	6	6	48.2	30.9
Muscle weakness	6.4	5.3	6	5	48.8	22.6
Impact on family	6.3	6.1	6	6	47.9	40.4
Weight gain	6.3	5.8	6	6	44.9	31.2
Mood swings	6.3	5.5	6	6	47.3	26.4
Sleep disturbance	6.2	5.4	6	6	46.2	23.5
Pain	6.1	5.6	6	6	43.4	30.5
Anxiety	6.1	5.3	6	5	43.6	24.1
Arthritis	6.0	5.2	6	5	39.7	17.1
Appearance	5.8	5.4	6	6	41.2	23.3
Hand tremors	5.7	5.1	6	5	34.9	17.8
Pins and needles	5.5	4.8	6	5	30.6	14.2
Fertility	5.4	5.8	6	6	34.7	33.0

Note: "Unsure" responses omitted from the sample, therefore the total sample size varies with each outcome. The 13 outcomes in grey were excluded in round 2.

Table S4. Suggested outcomes by participants (n=1018) in round 1 and reasons for exclusion.

Cause for noninclusion	N (%)
Outcome described as an intervention	31 (8.1)
Outcome related to living kidney donors	19 (3.0)
Outcome related to children	13 (1.9)
Outcome related to caregivers	3 (0.3)
Outcome already included in the survey	183 (18.0)
Outcome suggested by less than 10% of participants	
- Adherence	28 (2.8)
- Global quality of life	25 (2.5)
- Burden of treatment	21 (2.1)
- Sexual function	18 (1.8)
- Cost (patient)	13 (1.3)
- Cost (global)	10 (1.0)
- DSA	9 (0.9)
- Global adverse effects of medication	7 (0.7)
- Recurrence of original disease	6 (0.6)
- Psychological impact	5 (0.5)
- Delayed graft function	4 (0.4)
- Drug interactions	4 (0.4)
- Relationship impact	4 (0.4)
- Antibody mediated rejection	3 (0.3)
- Diet impact	3 (0.3)
- Frailty	3 (0.3)
- Mental health	3 (0.3)
- Proteinuria	3 (0.3)
- Tolerance	3 (0.3)
- Polyomavirus infection	3 (0.3)
- Ability to exercise	2 (0.2)
- Edema	2 (0.2)
- Hearing disturbance	2 (0.2)
- Self esteem	2 (0.2)
- Urinary tract infection	2 (0.2)
- Weight gain	1 (0.1)
- Ability to obtain travel insurance	1 (0.1)
- Ability to take holidays	1 (0.1)
- Ability to travel	1 (0.1)
- Awareness	1 (0.1)
- Burning chest when doing sport	1 (0.1)
- Cellular rejection	1 (0.1)
- Chronic antibody mediated rejection	1 (0.1)
- Chronic allograft nephropathy	1 (0.1)
- Chronic dehydration	1 (0.1)
- Chronic infection	1 (0.1)
- Compliance on food intake	1 (0.1)
- Cultural and social acceptance of transplantation	1 (0.1)
- Damaged foot bones	1 (0.1)
- Dependence	1 (0.1)
- Developmental progress	1 (0.1)
- Estimated glomerular filtration rate	1 (0.1)
- Electrolyte disturbances (Na, K, Mg, Ca)	1 (0.1)
- Fear of Graft Failure	1 (0.1)
- Functional status	1 (0.1)
- Guilt	1 (0.1)
- Hair loss or thinning	1 (0.1)
- Health behaviours	1 (0.1)
- Humoral rejection	1 (0.1)
- Malnutrition	1 (0.1)
- Measured GFR	1 (0.1)
- Multi-morbidities	1 (0.1)
- Polycythemia	1 (0.1)
- Pregnancy	1 (0.1)
- Posttransplant diabetes mellitus	1 (0.1)
- Posttransplant lymphoproliferative disorder	1 (0.1)
- Rejection	1 (0.1)

- Renal biopsy complications	1 (0.1)
- Resiliency	1 (0.1)
- Restless legs	1 (0.1)
- Satisfaction	1 (0.1)
- Self-efficacy	1 (0.1)
- Sense disturbances	1 (0.1)
- Skin sensitivity	1 (0.1)
- Social work care for siblings	1 (0.1)
- Vascular rejection	1 (0.1)
- Vascular stiffness	1 (0.1)
- Weakness of tendons	1 (0.1)
- Weight loss	1 (0.1)

Table S5. Round 2 means, medians and proportions (rating 7-9) of patients/caregivers and health professionals for 22 outcomes.

Outcome	Mean scores		Median scores		Proportion 7-9 score	
	Patients/ caregivers	Health professionals	Patients/ caregivers	Health professionals	Patients/ caregivers	Health professionals
Graft loss	8.6	8.8	9	9	97.7	99.6
Chronic graft rejection	8.5	8.3	9	9	94.8	96.5
Graft function	8.5	8.4	9	9	95.1	95.6
Acute graft rejection	8.2	7.9	9	8	90.2	83.8
Death	8.1	8.7	9	9	87.8	96.9
Infection	8.0	7.8	8	8	89.9	90.8
Cancer (non skin)	7.7	7.4	8	7	84.5	82.4
Cardiovascular diseases	7.6	7.7	8	8	83.6	90.8
Cancer (skin)	7.4	6.6	8	7	75.4	54.5
Ability to work	7.3	6.8	8	7	73.1	60.8
Surgical complication	7.3	6.6	7	7	72.5	58.6
Diabetes	7.2	7.0	7	7	74.0	65.4
Cognition	7.2	6.5	7	7	73.4	51.9
Blood pressure	7.2	6.5	7	7	70.2	50.5
Depression	6.9	6.4	7	7	61.3	53.2
Hospitalisation	6.5	6.7	7	7	53.0	61.5
Fatigue	6.8	5.7	7	6	56.2	24.9
Anemia	6.7	5.6	7	6	59.7	24.3
Bone diseases	6.7	5.8	7	6	54.1	25.7
Eye problems	6.6	5.3	7	5	52.3	17.3
Sun sensitivity	6.3	5.1	6	5	43..7	16.0
High cholesterol	6.2	5.4	6	6	42.6	19.5

Note: “unsure” responses were omitted from the sample, therefore the total sample size varies with each outcome. The 13 outcomes in grey were excluded in round 3.

Table S6. Round 3 means, medians and proportions (rating 7-9) of patients/caregivers and health professionals for 16 outcomes.

Outcome	Mean scores		Median scores		Proportion 7-9 score	
	Patients/ caregivers	Health professionals	Patients/ caregivers	Health professionals	Patients/ caregivers	Health professionals
Graft loss	8.8	8.9	9	9	98.6	99.5
Graft function	8.6	8.6	9	9	97.2	97.6
Chronic graft rejection	8.6	8.5	9	9	96.7	98.1
Infection	8.1	7.9	8	8	93.9	94.0
Acute graft rejection	8.3	8.1	9	8	92.2	87.4
Death	8.3	8.8	9	9	91.3	98.6
Cardiovascular disease	7.8	7.8	8	8	86.4	94.5
Cancer - other	7.8	7.5	8	8	85.7	89.3
Cancer - skin	7.5	6.6	8	7	78.6	57.0
Surgical complications	7.3	6.6	7	7	77.8	59.9
Diabetes	7.3	7.1	7	7	76.4	72.3
Cognition	7.3	6.6	7	7	76.2	58.0
Ability to work	7.5	7.0	8	7	75.8	66.1
Blood pressure	7.1	6.5	7	6	71.0	49.6
Depression	7.0	6.5	7	7	66.4	58.5
Hospitalization	6.6	6.8	7	7	58.1	67.3

Note: “unsure” responses were omitted from the sample, therefore the total sample size varies with each outcome.

Table S7. Mean scores of patients/caregivers by countries for outcomes rated higher by patients/caregivers.

Outcome domain	Countries							p-value
	Australia (n=167)	Canada (n=20)	Denmark (n=17)	New Zealand (n=26)	South Africa (n=20)	United Kingdom (n=55)	United States (n=23)	
Skin cancer	7.6	7.9	7.1	7.1	7.9	7.2	7.7	0.057
Ability to work	7.5	8.1	7.3	7.2	7.6	7.4	7.9	0.335
Blood pressure	7.3	7.6	6.8	6.8	7.0	6.7	7.4	0.108
Surgical complications	7.5	7.6	7.2	7.5	6.9	6.9	7.3	0.120
Depression	7.3	7.5	6.5	6.4	6.8	6.7	7.0	0.011
Cognition	7.3	7.7	7.8	7.0	7.6	6.7	7.7	0.006

Table S8. Mean scores by age group for Round 3 outcomes.

OUTCOME	Age group (years)						p value
	18-30	31-40	41-50	51-60	61-70	>70	
Graft loss	8.9	8.8	8.8	8.8	8.7	8.8	0.39
Graft function	8.6	8.7	8.6	8.6	8.5	8.7	0.95
Chronic graft rejection	8.9	8.6	8.7	8.7	8.5	8.4	0.19
Acute graft rejection	8.9	8.3	8.4	8.4	8.1	8.6	0.04
Death	9.0	8.1	8.5	8.4	8.2	7.8	0.11
Infection	8.0	7.8	8.2	8.1	8.1	8.7	0.08
Cancer (nonskin)	7.5	7.2	7.9	7.7	7.9	8.5	0.07
Cardiovascular disease	7.9	7.2	7.8	7.7	7.8	8.0	0.23
Cancer (skin)	7.1	7.4	7.6	7.5	7.5	8.0	0.53
Diabetes	7.1	7.3	7.4	7.3	7.1	7.8	0.56
Blood pressure	7.4	6.8	7.0	7.2	7.2	7.5	0.27
Surgical complications	7.7	7.2	7.3	7.2	7.4	8.0	0.27
Cognition	7.2	7.4	7.3	7.3	7.1	7.4	0.94
Ability to work	7.3	7.7	7.5	7.7	7.1	7.7	0.12
Depression	6.8	7.2	7.1	7.0	6.9	7.3	0.94
Hospitalization	6.9	6.7	6.7	6.5	6.5	6.7	0.94

Figure S1. SONG-Tx Delphi process.

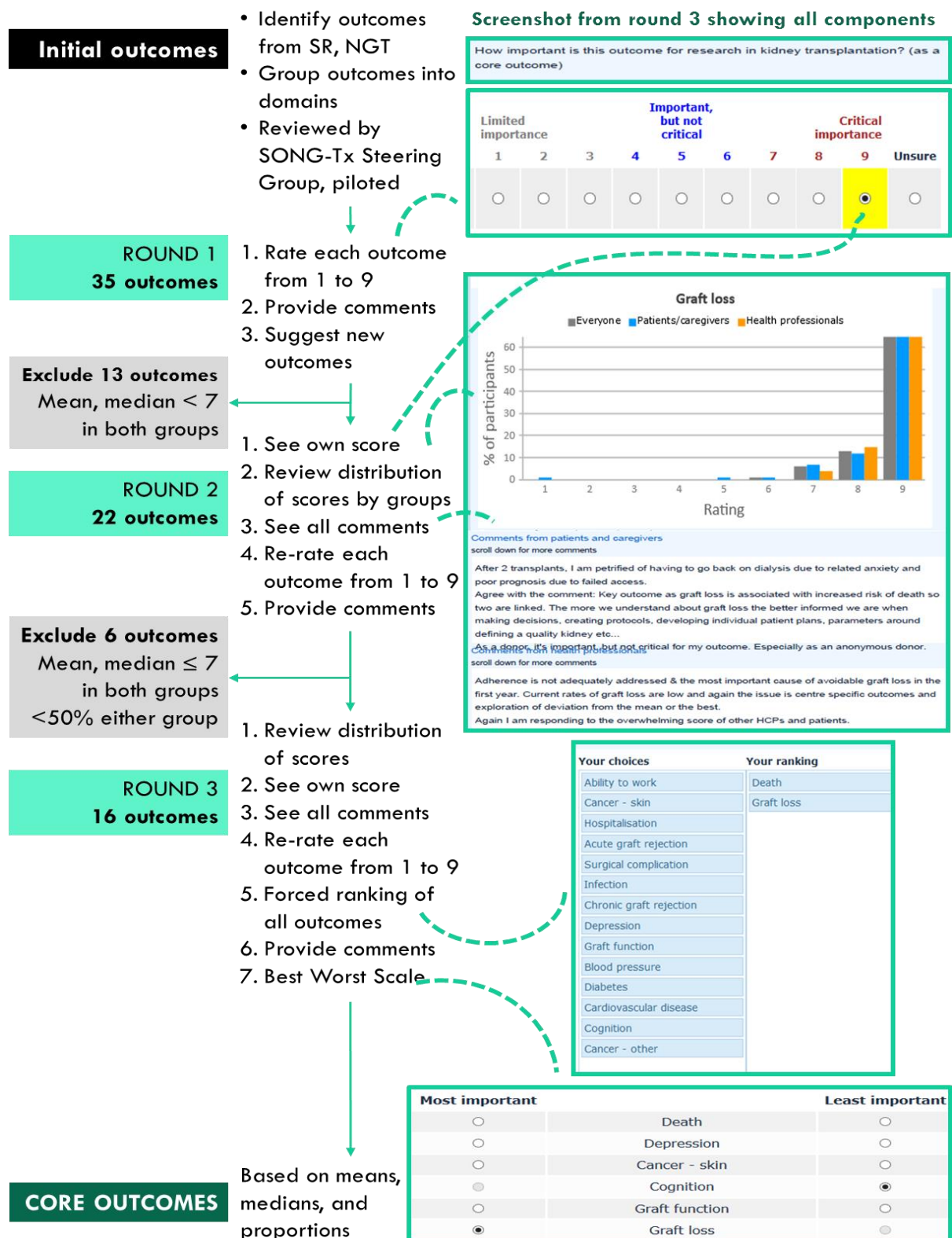


Figure S2. Mean scores of patients/caregivers and health professionals in round 3

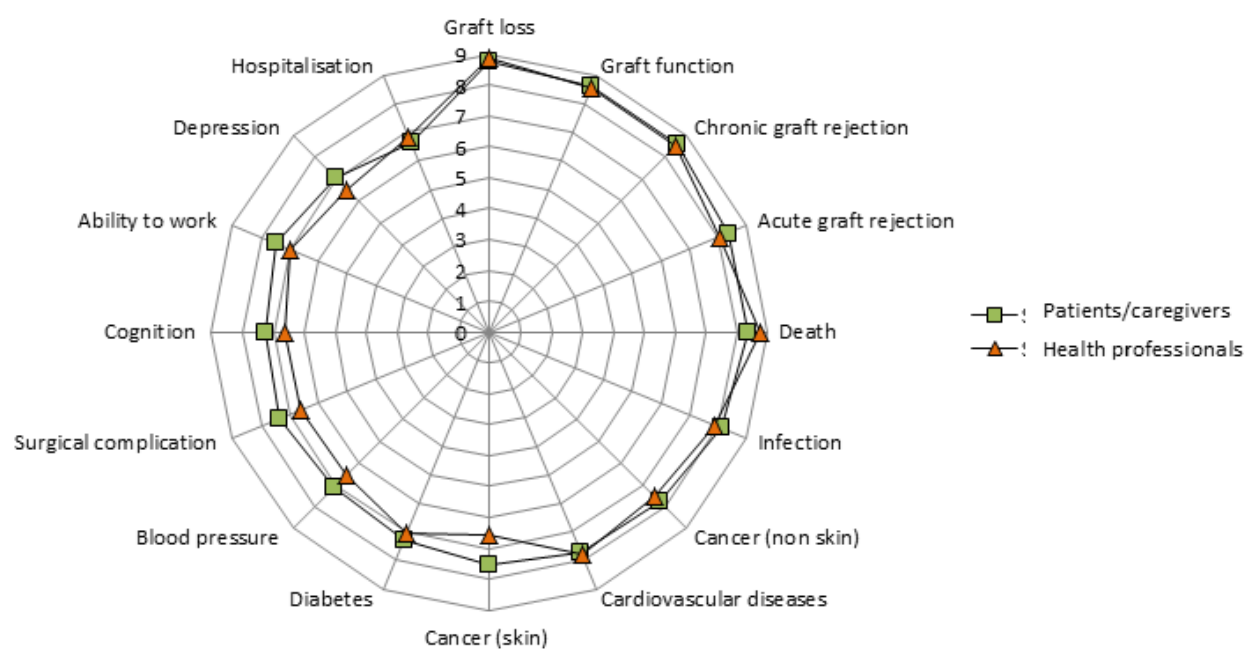
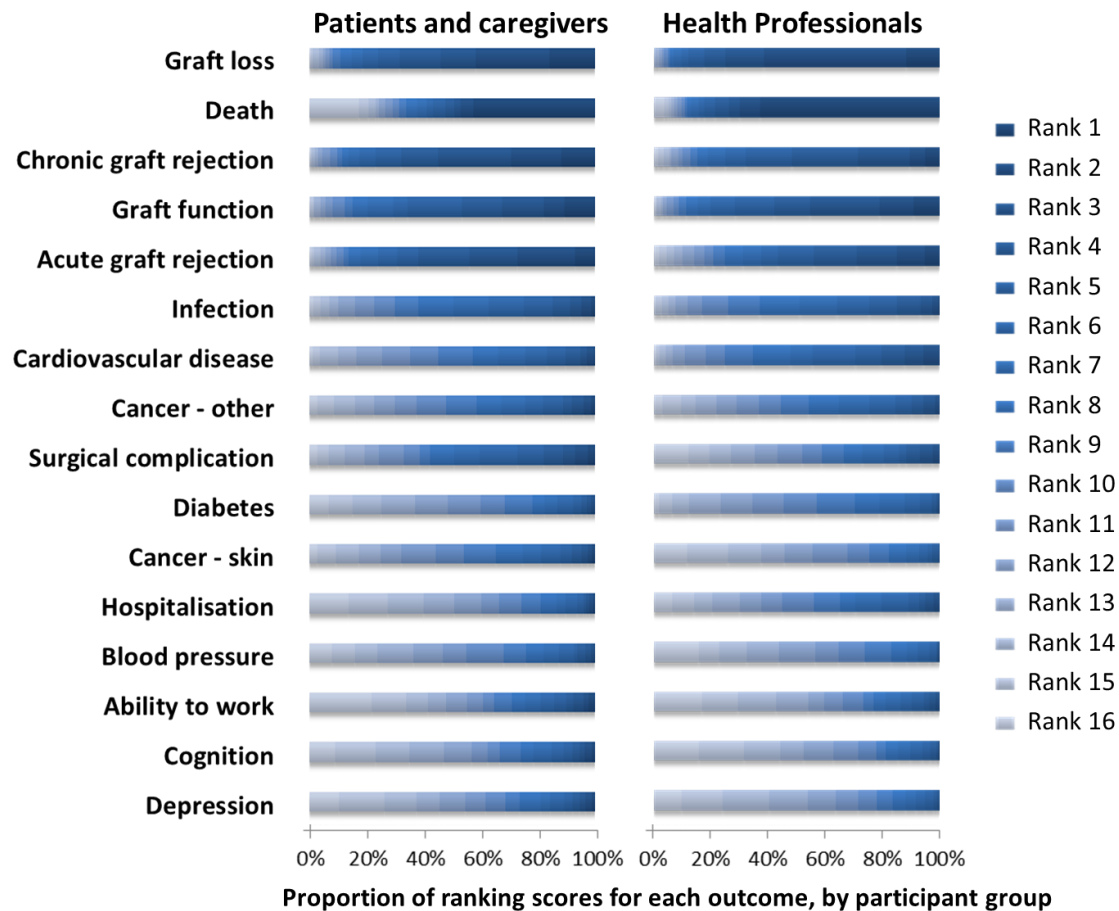


Figure S3. Proportion of rank scores of patients/caregivers and health professionals in round 3 (rank 1=most important, rank 16=less important).



Darker blue indicates a higher rank of importance. The X axis refers to the proportion of ranking scores ranked for each outcome. For example, for patients/caregivers, graft loss was ranked number 1 by 16%, number 2 by 26%, number 3 by 14% and so on. The outcomes domains are ordered by mean rank scores weighted by participant groups.