APPENDIX S1 Overview of multi-level variables, their measurement and psychometric characteristics (if applicable) of the BRIGHT study

Variable	Instrument	• Assessment method • Conceptual definition (if needed) • Number of items • Recall period • Response options • Scoring	Psychometric evidence (based on the literature or BRIGHT study analysis)
		PATIENT LEVEL	
		Integrative Model of Behavioral Prediction – factors	
Barriers to taking immunosuppressants as prescribed	*Immunosuppressive Medication Adherence Barriers scale [69]*	• BRIGHT patient self-report (written) questionnaire • Personal or environmental constraints preventing people from acting upon their intentions • 19 items • Current situation • 5-point Likert scale ranging from '1= never' to '5= always' • Average score	19 of the original 27 items retained in a unidimensional scale, with a Cronbach's alpha of 0.89
Intention to adhere to the immuno-suppressive regimen	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • Cognitive representation of a person's readiness to perform a given behavior • 3 items • Current situation • 5-point Likert scale ranging from '1= strongly disagree' to '5= strongly agree' • Average score	3 of the original 5 items retained in a unidimensional scale, with a Cronbach's alpha of 0.81
Attitudes towards immunosuppressant intake	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • Degree to which a patient has a favorable or unfavorable evaluation or appraisal of adherence behavior • 21 items; 2 dimensions: Worries (12 items) and positive aspects/looking toward to the future (9 items) • Current situation	21 of the original 22 items retained in a two-dimensional scale, with Cronbach's alpha values of 0.77 (Worries) and 0.66

		• 5-point Likert scale ranging from '1= strongly disagree' to '5= strongly agree'	(Positive aspects/looking toward the future)
		• Average score	
Perceived norms related to immunosuppressants	*Investigator developed questions based on previous transplant research [16, 70-74]*	• BRIGHT patient self-report (written) questionnaire • A patient's perception of social pressure, or relevant others' beliefs whether or not he/she should adhere to the immunosuppressants • 11 items • Current situation • 5-point Likert scale ranging from '1= strongly disagree' to '5= strongly agree' • Average score	Unidimensional scale, with a Cronbach's alpha of 0.94
Self-efficacy regarding taking immunosuppressants	*Long-Term Medication Behavior Self-Efficacy Scale (LTMBES) [75]*	• BRIGHT patient self-report (written) questionnaire • A person's perception of his/her ability to perform a given behavior in a given situation • 23 items • Current situation • 5-point Likert scale ranging from '1= not at all confident' to '5= completely confident' • Average score	23 of the original 24 items retained in a unidimensional scale, with a Cronbach's alpha of 0.98
Literature derived patient level factors			
Socio-demographic factors			
Gender	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item • Male/female • Dichotomous variable	Not applicable
Age	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item • In years • Continuous variable	Not applicable
Educational level	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item	Not applicable

Employment	*Investigator developed*	• 4 categories: less than high/ secondary school; completed high/ secondary school; completed further education/ training; completed college/ university • Ordinal variable • BRIGHT patient interview questionnaire • 1 item • 5 categories: 1 Being (self-)employed (part-time/full time paid work); 2 Looking for a job/ unemployed; 3 Unable to work (temporarily) or receiving a disability benefit /allowance; 4 Retired; 5 Other (working as a volunteer; student; housewife/househusband, …) • Categorical variable	Not applicable
Race	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item • Caucasian/white <u>vs</u> other ethnicities (Asian, African-American, Hispanic, North-African, Other) • Dichotomous variable	Not applicable
Marital status	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item • Married/living together or single or divorced/separated or widowed • Categorical variable	Not applicable
Living alone	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item • Yes/no • Dichotomous variable	Not applicable
Clinical factors			
Etiology of end-stage heart disease	*Investigator developed*	• Structured form for medical record information extraction • 1 item: ischemic cardiomyopathy, idiopathic cardiomyopathy (dilated, restrictive, hypertrophic), valvular disease, or other • Categorical variable	Not applicable
Comorbidities post-transplant	*Adapted Charlson Comorbidity Index [76]*	• Structured form for medical record information extraction • 19 items	Not applicable

		• Assessing 1) post-Tx comorbidities ongoing from pre-Tx or 2) new-onset comorbidities post-Tx (myocardial infarction and heart failure were only scored if newly onset post-Tx, given that all patients underwent a heart transplantation for end-stage heart disease) • Dichotomous score Yes/no (either ongoing or newly onset) • Item scores weighted from 1 to 6 points depending on the co-morbidity *[76]. Scores were not adjusted for age.* Possible total score ranges from 0 to 37	
Number of treated rejections experienced per year in follow up	*Investigator developed*	• Structured form for medical record information extraction • 1 item • Calculation is based on information on the number of treated rejection(s) reported in the medical record until time of study enrolment, divided by the time in post-transplant follow-up (in years) • Continuous: number of rejections per year in follow-up	Not applicable
Treatment-related factors			
Number of daily doses of immunosuppressants	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item • Maximum number of daily doses of immunosuppressants taken/day • Continuous variable (1 to 3 times daily)	Not applicable
Time since transplantation	*Investigator developed*	• Structured form for medical record information extraction • 1 item • In years • Continuous variable	Not applicable
Condition related factors			
Depressive symptomatology	*Depression subscale of the Depression, Anxiety, Stress Scale 21-item version (DASS21) [77]*	• BRIGHT patient self-report (written) questionnaire • Symptoms referring to a persistent state of low mood and/or lack of interest in activity that affect the way people feel, think or behave and can lead to a variety of emotional and physical problems, including experiencing difficulty in normal day-to-day activities • 7 items • 1 week	Unidimensional scale of 7 items, with a Cronbach's alpha of 0.93

History of diabetes pre-transplant	*Investigator developed*	• 3-point Likert scale ranging from '0= did not apply to me at all' to '3= applied to me very much, or most of the time' • total score= sum of item scores times 2 (possible range from 0 to 42) • Structured form for medical record information extraction • 1 item • Yes/No • Dichotomous score	Not applicable
Body Mass Index	*Quetelet Index [78]*	• Structured form for medical record information extraction • 2 items: height (in cm or inches, depending on the country) and weight (in kg or pounds, depending on the country) • BMI= weight in kg / length in m^2 • Continuous variable	Not applicable
Patient-related factors			
Stages-of-change	*Investigator developed based on the stage-of-change model [79]*	• BRIGHT patient self-report (written) questionnaire • Pre-contemplation phase: patient finds correct medication taking not important and shows no motivation to change their non-adherence behavior in the near future; contemplation phase: patient starts thinking of changing his/her nonadherent behavior, yet lacks the confidence to do so, and experiences a lot of barriers hindering him/her to act upon his/her intentions • 2 items (importance and confidence ruler) • Current situation • 10-point Likert scales, going from not at all important to extremely important and from not at all confident to extremely confident, respectively • Pre-contemplation: score below 8 on the first item; Contemplation: score 8 or higher on first item, but score below 8 on the second item; Other: score of 8 or higher on both items. • Ordinal score with possible range from 1 to 3	No further information available
Sleep quality	*Item derived from the Kidney Disease and Quality of Life Short Form [80]*	• BRIGHT patient self-report (written) questionnaire • 1 item • 4 weeks recall	Predictive validity for mortality in dialysis patients[81]

		• 10-point Likert scale ranging from '0= very poor' to '10= very good' • Ordinal score on Likert scale	Concurrent validity with Pittsburgh Sleep Quality Index r_s=-0.822, *P*<.001)[82]
Daytime sleepiness	*Item adapted from Dialysis Outcomes and Practice Patterns Study [81] and a VAS Sleepiness Scale [83]*	• BRIGHT patient self-report (written) questionnaire • 1 item • 4 weeks recall • 10-point Likert scale ranging from '0= not at all sleepy' to '10= very sleepy' • Ordinal score on Likert scale	Concurrent validity: with Epworth Sleepiness Scale (ρ: 0.531, p< 0.01) [82, 84] Convergent validity: with Depression Anxiety and Stress scale (ρ: 0.235, p< 0.01) [84] Group difference validity: renal transplant recipients with moderate, severe, and extremely severe depressive symptom scores had a 3.4, 4.3, and 5.9 times higher odds of having daytime sleepiness [84]
Non-adherence to appointment keeping	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 1 item • Last 5 appointments recall period • 5 point Likert scale ranging from '1= never missed' to '6= all 5 appointments missed' • Continuous: number of appointments missed	No further information available
Smoking	*Item from Swiss Health survey (Swiss Federal Statistical Office 2008) [85]*	• BRIGHT patient self-report (written) questionnaire • 1 item • Response options: yes, I stopped less than 1 year ago, I stopped more than 1 year ago, I never smoked • Currently smoking or stopped less than one year ago considered as post-transplant smoking • Dichotomous score	No further validity information available

Health literacy	*Subjective Health Literacy Screener [86]*	• BRIGHT patient self-report (written) questionnaire • 1 item: How confident are you filling out medical forms by yourself • Current situation • 5-point Likert scale ranging from '1= none of the time' to '5= all of the time' • Score between 0 and 2 considered as low health literacy • Dichotomous score	Concurrent validity: with the Short Test of Functional Health Literacy in (AUC=.72-.74; with the Rapid Estimate of Adult Literacy in Medicine (AUC=.81-.84) [87]
Non-adherence to physical activity recommendations	*Brief Physical Activity Assessment tool [88]*	• BRIGHT patient self-report (written) questionnaire • 2 items • current situation • Nonadherent vs. Adherent (Sufficiently active: ≥ 3x/week 20 minutes of vigorous AND/OR ≥ 5x/week 30 minutes of moderate physical activity) • Dichotomous score	Criterion validity of self-report against electronic monitoring gold standard measurement: κ statistic 0.14-0.40 [88]
Level of alcohol consumption	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 2 items (whether the patient is using alcohol (yes/no); if yes, number of alcoholic drinks consumed per week) • 1 week recall period • Ordinal scoring: non-drinker; moderate drinker (1 drink/day (women), 2 drinks/day (men)), or heavy drinker (>1 drink/day (women), >2 drinks/day (men)[89])	No further information available
Adherence to sun protection measures	*Swiss study on health of people with cancer, leukemia, tumor in childhood (Swiss Childhood Cancer Registry) [90] and Cambridge University Hospitals' perception of skin cancer in transplant recipients scale [91]*	• BRIGHT patient self-report (written) questionnaire • 4 items assessing consistency of protection against the sun • No recall period specified • 5-point Likert scales: never, seldom, sometimes, often, always • Average score	Unidimensional scale, with a Cronbach's alpha of 0.59
Non- adherence to dietary guidelines	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire	No further information available

- 5 items, measuring adherence to low salt, respectively low calorie, low saturated fat, low sugar or other kind of diet reported as applicable
- No recall period specified
- 5-point Likert scales: never, seldom, sometimes, often, always
- Scoring: adherent = yes if scored "often" or „always" to any of the 5 listed diets
- Dichotomous score

		MICRO LEVEL	
Social support	*Social Support Questionnaire [48]*	• BRIGHT patient self-report (written) questionnaire • 11 items, 2 dimensions, i.e. practical support (6 items) & emotional support (5 items) • 4 weeks recall period • 5-point Likert scale ranging from '1= never' to '5= always' • Average score per dimension	Two-dimensional scale, with a Cronbach's α values of 0.87 (Practical) and 0.88 (Emotional)
Being a member of a patient organization	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 1 item • Current status • Answering options: 'Yes/no' • Dichotomous score	No further information available
Who is responsible for preparing the immunosuppressants	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 1 item • Current status • 4 Answering options: myself, together with my partner/family member; my partner/family member, a nurse • Categorical variable	No further information available
Frequency of having someone helping them to read health-related materials*	*Subjective Health Literacy Screener [86]*	• BRIGHT patient self-report (written) questionnaire • 1 item: how often do you have someone help you read health related materials? • Current situation • 5-point Likert scale ranging from '1= none of the time' to '5= all of the time'	No further information available

Fluency with language spoken at the transplant center	*Investigator developed*	• Ordinal score • BRIGHT patient interview questionnaire • 1 item • Current situation • 10-point Likert scale ranging from 0= not at all fluent to 10= very fluent • Ordinal score	No further information available
Does the Tx team communicate in the mother tongue of the patient or a language the patient masters fluently	*Investigator developed*	• BRIGHT patient interview questionnaire • 1 item • Current situation • answering option: No/yes (either via interpreter or directly) • Dichotomous variable	No further information available
Trust in the Tx team	*Adapted form of the Wake Forest University Trust scale [92]*	• BRIGHT patient self-report (written) questionnaire • Measures interpersonal trust, and refers to fidelity (caring and advocating for the patient's welfare); competence; honesty, confidentiality, as well as global trust (93) • 10 items • Current situation • 5-point Likert scale ranging from '1= strongly disagree' (low trust) to '5= strongly agree' (high trust) • Average score	Unidimensional scale, with a Cronbach's alpha of 0.80
Patient satisfaction with the interpersonal dimension of care	*Westaway Patient Satisfaction scale [93]*	• BRIGHT patient self-report (written) questionnaire • Refers to the degree of support, consideration, friendliness, and encouragement received from the team • 12 items • Current situation • 5-point Likert scale ranging from '1= very dissatisfied' to '5= very satisfied' • Average score	Unidimensional scale, with a Cronbach's alpha of 0.98

MESO LEVEL			
Structural characteristics			
Type of HTx center	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item • Current situation • 2 response options: 1) University or 2) regional, community or other hospital • Dichotomous variable	No further information available
Location of the transplant program	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item • Current situation • 2 Options: 1) urban, or 2) suburban or rural • Dichotomous variable	No further information available
Years since the start of the transplant program	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item: in what year did your program start • Time in years between start date of the transplant program and the date of the start of the BRIGHT data collection in a given center • Continuous variable	No further information available
Number of patients who are at least 1 year post-tx that are followed up regularly at the HTx center	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item: How many adult HTx recipients who are at least 1 year post-Tx are followed up on a regular basis by your HTx program (total number currently followed)? • Current situation • Number of patients regularly being followed up • Continuous variable	No further information available
Center size	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item: how many adult heart transplants did your center perform in 2007, 2008, 2009, 2010, and 2011 • Past 5 years • Total number over the last 5 years • Categories based on total number: Small (< 75), Medium (75-100), or Large (> 100) center	No further information available

Practice patterns			
Length of hospital stay after HTx surgery in the transplant program	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item: average length of stay after HTx • In days • Continuous variable	No further information available
Total number of yearly visits scheduled for patients who are at least 1 year post-tx	*Investigator developed*	• BRIGHT transplant director questionnaire • 3 items (number of visits between 1 and 2 years; between 2 and 3 years and beyond 3 years post-transplant) • Current situation • Sum of normally scheduled outpatient visits after 1 year post-transplant • Continuous variable	No further information available
Time spent with the transplant team during a follow-up visit	*Investigator developed*	<u>*Patient's perspective*</u> • BRIGHT patient self-report (written) questionnaire • 1 item • Current situation • 5-point scale ranging from '1= < 5 minutes' to '5= > 30 minutes' • Ordinal variable <u>*Clinician's perspective*</u> • BRIGHT clinician questionnaire • 1 item: • Current situation • average time per patient in minutes • Continuous variable	No further information available
Formal mental health or psychological evaluation performed before Tx	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item • Current situation • Response options: Yes/No • Dichotomous score	No further information available
Formal financial-social evaluation performed before Tx	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item • Current situation	No further information available

Adherence to immunosuppressants is routinely being assessed as part of post-transplant follow-up care	*Investigator developed*	• Response option: Yes/No • Dichotomous score • BRIGHT clinician questionnaire • 1 item • Current situation • Response option: Yes/no • Dichotomous score	No further information available
Does the Tx team discuss immuno-suppressive medication intake in daily life	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 1 item • current • response option: Yes/No • Dichotomous score	No further information available
Clinicians reporting that non-adherent patients are targeted with adherence interventions	*Investigator developed*	• BRIGHT clinician questionnaire • 1 item • Current situation • 4-point Likert scale ranging from '1= never' to '4= always' • Ordinal item	No further information available
Are patients followed up by the same healthcare worker when they visit the outpatient clinic	*Investigator developed*	• BRIGHT transplant director questionnaire • 1 item • Current situation • 3-point Likert scale ranging from '1= always or nearly always' to '3 rarely or never' • Ordinal variable	No further information available
Who is the initial contact in case of after hour questions or emergencies	*Investigator developed*	• BRIGHT transplant director questionnaire • 2 items: 1 item registered nurse & 1 item advanced practice nurse • Current situation • Response options: Yes/no for both items • Dichotomous score per item	No further information available
Team composition			
Multidisciplinarity of the team	*Investigator developed*	• BRIGHT transplant director questionnaire	No further information available

		• Interdisciplinary= at least one physician, one nurse and one other discipline [94] • 1 item: describe the members of your team (routinely involved or consult only) • Various disciplines listed; check box to be ticked if discipline is part of the team • Dichotomous score (multidisciplinarity yes/no)	
Transplant clinic has a care coordinator	*Investigator developed*	• BRIGHT clinician questionnaire • Care coordinator can be an advanced practice nurse, a transplant coordinator or a social worker • 1 item • Current situation • Response option: yes/no • Dichotomous score	No further information available
Having an Advanced Practice Nurse with a certificate or other advanced specialization in transplantation	*Investigator developed*	• BRIGHT clinician questionnaire • 1 item • Current situation • Response option: Yes/No • Dichotomous score	No further information available
Level of chronic illness management			
Patient's perspective of chronic illness management implemented in their HTx program	*Short version of the Patient Assessment of Chronic Illness Care (PACIC) instrument [95]*	• BRIGHT patient self-report (written) questionnaire • measures specific actions or qualities of care, congruent with the chronic care model, that patients report they have experienced in the delivery system • 11 items • 6 months recall period • 5-point Likert scale ranging from '1= almost never' to '5= almost always' • Total score ranging from 11 to 55	Unidimensional scale, with a Cronbach's alpha of 0.88
Healthcare worker's perspective of chronic illness management	*CIMI-BRIGHT [96]*	• BRIGHT clinician questionnaire • 52 items covering the 5 building blocks of the Innovative Care for Chronic Conditions framework (unidimensional)	52 of originally 55 items retained in a unidimensional

implemented in their HTx program		• Current status • 4-point Likert scale ranging from '1= strongly disagree' to '4= strongly agree' (5=don't know; set to missing) • Average score, with higher scores corresponding with higher level of chronic illness management implemented	scale, with a Cronbach's alpha of 0.94
Competencies of the Tx team in view of chronic illness management	*Investigator developed [97]*	• BRIGHT clinician questionnaire • 24 items to assess core competencies • Current situation • 4-point Likert scale ranging from '1= strongly disagree' to '4= strongly agree' (5=don't know; set to missing) • Average score, with higher scores reflecting a higher degree of core competencies	Unidimensional scale, with a Cronbach's alpha of 0.96
Preparedness of the Tx team in view of chronic illness management	*Investigator developed [97]*	• BRIGHT clinician questionnaire • Refers to the skills and availability of equipment or tools to facilitate chronic care • 5 items • Current situation • 4-point Likert scale ranging from '1= strongly disagree' to '4= strongly agree' (5=don't know; set to missing) • Average score, with higher scores reflecting higher level of preparedness	5 of the original 10 items retained in a unidimensional scale, with a Cronbach's alpha of 0.82
Opportunities for patients pre-Tx to meet or interact with post-Tx patients	*Investigator developed*	• BRIGHT clinician questionnaire • 1 item • Current situation • Respondent options: Yes/no • Dichotomous score	No further information available
Provision of self-management support interventions in view of medication taking during long-term follow up	*Investigator developed*	• BRIGHT clinician questionnaire • 1 item • Current situation • Response option: Yes/no • Dichotomous score	No further information available

Immunosuppressants refill mechanism	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 6 items (local pharmacy, hospital pharmacy, physician office, ordered online, telephone ordered, other) • Current situation • Response option: Yes/no per item • Dichotomous score per item	No further information available
MACRO LEVEL			
Coverage of immunosuppressants by health insurance	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 1 item • Current status • 3-point Likert scale ranging from '1 = Yes, fully' to '3 = No' • Ordinal score	No further information available
Monthly out-of-pocket expenses for immunosuppressants	*Investigator developed*	• BRIGHT patient self-report (written) questionnaire • 1 item • Current status • 4-point Likert scale ranging from '1= 0 USD' to '4= > 110 USD' (adapted to national currency) • Ordinal score	No further information available
Finding it hard to take their immuno-suppressive medication because patient cannot afford them	*Item from the Immunosuppressive Medication Adherence Barriers scale [69]*	• BRIGHT patient self-report (written) questionnaire • 1 item • Current situation • 5-point Likert scale ranging from '1= never' to '5= always' • Ordinal score	No further information available
Having enough money to pay for their immunosuppressants	*Item from the Supporting Medication Adherence in Renal Transplantation (SMART) study[98]*	• BRIGHT patient self-report (written) questionnaire • 1 item • Current situation • 4-point Likert scale ranging from '1= not enough' to '4= more than enough' • Ordinal score	No further information available

AUC=area under the receiver operating curve; Side effects of immunosuppressives and their possible impact on adherence were assessed by adding side-effects-related items to the barriers, attitudes and self-efficacy questionnaires

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