

Supplementary Table 2. Patients' and clinicians' perspectives on practice patterns and self-management support in view of Chronic Illness Management

Patients' perspective			
Dimensions	Variables	Results (N = 60)	
Practice Patterns	<u>Placement of follow-up care appointments</u>		
	▪ Only at transplant center, n, %	35	58%
	▪ Also at external center, n, %	25	42%
	Cantonal Hospital Luzern, n, %	6	10%
	University Hospital Bern, n, %	16	27%
	Other, n, %	3	5%
	<u>Adherence to appointment keeping</u>		
	▪ Transplant center: Never missed, n, %	60	100%
	▪ External center: Never missed, n, %	24	96%
	○ Missed once, n, %	1	4%
<u>Time spent with the transplant team during follow-up: Transplant center</u>			
▪ Physicians, n, mean (SD)	60	23 min (±8 min.)	
▪ Nurses, n, mean (SD)	59	14 min. (±9 min.)	
▪ Psycho-oncologist, n, mean (SD)	4	49 min. (±8 min.)	
▪ Nutritionist, n, mean (SD)	3	30 min. (±0 min.)	
▪ Physiotherapist, n, mean (SD)	1	30 min.	
▪ Social worker, n, mean (SD)	1	30 min.	
<u>Time spent with the transplant team during follow-up: External centers</u>			
▪ Physicians, n, mean (SD)	25	24 min. (±11 min.)	
▪ Nurses, n, mean (SD)	23	12 min. (±7 min.)	
▪ Psycho-oncologist, n, mean (SD)	3	52 min (±8 min.)	
▪ Nutritionist, n, mean (SD)	0	0	
▪ Physiotherapist, n, mean (SD)	1	45 min.	
▪ Social worker, n, mean (SD)	0	0	
Patient's perspective of CIM implemented in their follow-up care program	Short version of the Patient Assessment of Chronic Illness Care (PACIC) instrument; mean, SD (range)	30.6	±7.8 (11 – 55)

Patients Self-Report on Self-Management and Health Behaviors	<u>Level of physical activity</u>		
	Moderate physically active, n, %	58	97%
	How long per day are you moderate active (in minutes)?, n, mean (SD)		132 min. (± 130 min.)
	Days per week moderate physical active, mean (SD)	6 days	±2 days
	<ul style="list-style-type: none"> ▪ 1 day, n (%) ▪ 2 days, n (%) ▪ 3 days, n (%) ▪ 4 days, n (%) ▪ 5 days, n (%) ▪ 6 days, n (%) ▪ 7 days, n (%) ▪ Currently not possible due to illness 	0 3 4 5 8 5 33 2	0 5% 7% 8% 13% 8% 55% 3%
Vigorous physically active, yes (%)	44	73%	
How long per day are you vigorous active (in minutes)?, mean (SD)		62 min (± 50min.)	
Days per week vigorous physical active, mean (SD)	3 days	±2 days	
<ul style="list-style-type: none"> ▪ 1 day, n (%) ▪ 2 days, n (%) ▪ 3 days, n (%) ▪ 4 days, n (%) ▪ 5 days, n (%) ▪ 6 days, n (%) ▪ 7 days, n (%) ▪ Currently not possible due to illness 	6 14 8 0 1 0 3 16	10% 24% 13% 0% 2% 0% 5% 25%	
<u>Currently smoking</u>			
<ul style="list-style-type: none"> ▪ Yes, n (%) ▪ No, stopped <one year, n (%) ▪ No, stopped > one year, n (%) ▪ No, never smoked, n (%) 	2 6 13 39	3% 10% 22% 65%	
<u>Level of alcohol consumption</u>			
<ul style="list-style-type: none"> ▪ Yes, n (%) ▪ No, stopped <one year, n (%) ▪ No, stopped > one year, n (%) ▪ No, never have drunken alcohol, n (%) 	27 13 11 9	45% 22% 18% 15%	
	If yes: Frequency of alcohol consumption		

	<ul style="list-style-type: none"> ▪ One to three times/month, n (%) ▪ Several times weekly, n (%) ▪ Once or twice per week, n (%) ▪ Three times a day or more, n (%) <p>If yes: Amount of alcohol consumption</p> <ul style="list-style-type: none"> ▪ Up to 1dl, n (%) ▪ 2 dl, n (%) ▪ 3 to 4 dl, n (%) 	<p>9 3 15 1</p> <p>4 18 5</p>	<p>32% 11% 54% 4%</p> <p>14% 64% 18%</p>
	<p><u>Sun protection measures</u></p> <p>Sun exposure on weekdays (10:00am – 4:00pm) yes, n (%)</p> <p>How many hours do you spend outside on a weekday? mean (hours), SD</p> <ul style="list-style-type: none"> ▪ 30min or less, n (%) ▪ 31min up to 1hour, n (%) ▪ 2 hours, n (%) ▪ 3 hours, n (%) ▪ 4 hours, n (%) <p>Sun exposure on weekends (10:00am – 4:00pm) yes, n (%)</p> <p>How many hours do you spend outside on weekends? mean (hours), SD</p> <ul style="list-style-type: none"> ▪ 30min or less, n (%) ▪ 31min up to 1hour, n (%) ▪ 2 hours, n (%) ▪ 3 hours, n (%) ▪ 4 hours, n (%) ▪ 5 hours, n (%) 	<p>58</p> <p>57</p>	<p>97% 2 hours (±1 hour)</p> <p>33% 38% 21% 3% 5%</p> <p>95% 3 hours (±1,5 hours)</p> <p>23% 14% 26% 25% 11% 2%</p>
Patient's perspective of CIM implemented in their follow-up care program	Short version of the Patient Assessment of Chronic Illness Care (PACIC) instrument mean, SD (range)	30.6	±7.8 (11 – 55)
EHealth openness	<p>Patients' technology openness on Self-Management support</p> <p>Patients' technology openness on Delivery System Design</p> <p>Patients' technology openness on Clinical Information System</p> <p>Would you agree to input your wellbeing, your vital signs and symptoms?</p> <ul style="list-style-type: none"> ▪ no, I wouldn't agree, n (%) ▪ yes, once a week, n (%) 	<p>See supplementary Figure 4a.-4b</p> <p>See supplementary Figure 4a.-4b</p> <p>See Table 4</p> <p>10 23</p>	<p>17% 38%</p>

▪ yes, every third day, n (%)	12	20%
▪ yes, daily, n (%)	15	25%
If there was a reminder function, which one would you prefer?		
▪ no, I don't want a reminder at all, n (%)	13	22%
▪ no, I don't want a daily reminder, n (%)	21	36%
▪ yes, but just once a day for all values, n (%)	22	38%
▪ yes, for every single value, n (%)	2	3%
If there was a reminder function, which one would you prefer?		
▪ I don't want a reminder function, n (%)	12	21%
▪ individually, e.g., chosen picture, n (%)	15	26%
▪ acoustic sound which has to be turned off, n (%)	4	7%
▪ written, with pop-up message, n (%)	27	47%
Would you like to have an updated electrical medication plan?		
▪ yes	30	50%
Would you feel confident to input your medication plan and to update it after appointments by yourself?		
▪ no, this would be too much effort	31	54%
▪ no, I don't feel confident	1	2%
▪ yes, but only if checked by professional	6	11%
▪ yes, I could do by myself	19	33%
Would you agree to mark your medication intake electronically?		
▪ no, this would be too much effort	34	58%
▪ no, I'm not feeling confident	1	2%
▪ yes, once a day	16	2%
▪ yes, after every intake	8	14%
Would you consider using a robot which can support you with the housekeeping?		
▪ no	35	59%
▪ I don't know	5	9%
▪ maybe	11	19%
▪ yes	8	14%
Would you consider using a robot to keep you company at home?		
▪ no	51	85%
▪ I don't know	0	0%
▪ maybe	6	10%

	▪ yes	3	5%
Clinicians' perspective			
Dimensions	Variables	Results (N = 5)	
Self-Management Support		n	Yes, n (%)
	1. Healthcare workers have enough time to assess, educate and support patients in self-management (e.g., medication taking, smoking, physical activity, sun protection, diet)	5	2 (40%)
	2. The transplant team routinely works with patients to identify clear, measurable and workable self-management goals	4	0 (0%)
	3. The transplant team helps all patients set up action plans for medication adherence	4	3 (75%)
	4. Before making or changing a treatment plan, the transplant team discusses the alternatives with the patient and asks them about their preferences	5	4 (80%)
	5. The transplant team lets patients decide on the treatment options they prefer	4	1 (25%)
	6. The transplant team lets patients decide on self-management goal(s)	4	1 (25%)
	7. We always ask patients if they agree with their treatment plans	4	4 (100%)
	8. The transplant team routinely assesses obstacles patients believe prevent them from following their treatment plans	4	2 (50%)
	9. The transplant team routinely assesses each patients' ability to follow the agreed treatment plan	4	1 (25%)
	10. The transplant team checks during follow-up if patient is dealing effectively with the treatment plan	4	2 (50%)
	11. The transplant team gives each patient a copy of the agreed treatment plan, including information on self-management	4	1 (25%)
	12. The transplant team routinely asks patients to report on their self-management efforts	5	0 (0%)
	13. The transplant team routinely uses interpreters for foreign language patients	5	3 (60%)
	14. During follow-up visits, the transplant team routinely reviews, together with the patient, data on self-management	4	1 (25%)
	15. The transplant team routinely conducts follow-up contacts within 2 weeks for all patients who have set a new self-management goal	4	0 (0%)
16. The transplant team routinely follows up with the patient within 2 weeks on all patients who have started a new medication regimen or who have set a new self-management goal.	4	0 (0%)	

	17. The transplant team routinely assesses patients for their individual concerns or goals	4	4 (100%)
	18. The transplant team routinely refers patients to community services that can help them self-manage their care after leaving the hospital	4	1 (25%)
	19. If the transplant team refers patients the team routinely works directly with these agencies to coordinate care for individual patients	4	3 (75%)
	20. If the transplant team refers patients, we routinely follow up with patients to assess their progress	4	2 (50%)
Delivery System Design	21. Inpatient and outpatient services are coordinated	5	4 (80%)
	22. Services are coordinated across different healthcare providers	5	1 (20%)
	23. Services are coordinated over time	5	0 (0%)
	24. There is a specific long-term care coordinator	5	0 (0%)
	25. Patients are strongly encouraged to see the same healthcare workers over time	5	2 (40%)
	26. Patients are assessed when they have concerns/questions beside appointments	4	4 (100%)
	27. Outpatient follow-up appointments are scheduled with patients at the end of visit	5	5 (100%)
	28. Patients who cancel their follow-up visits are contacted to reschedule	4	4 (100%)
	29. Patients who cancel their follow-up visit are contacted to identify & solve problems that prevent them from their visits	4	4 (100%)
	30. Healthcare workers are given incentives for effective processes or improved outcomes	4	1 (25%)
	31. Patients are given incentives for effective self-management and improved outcomes	5	1 (20%)
	32. Senior and other influential leaders clearly help improve the quality of care	5	5 (100%)
	33. The transplant program has a system for routinely monitoring the quality of care	4	4 (100%)
	34. The transplant program has a highly organized quality improvement process	5	4 (80%)
	35. All members of the transplant program's team routinely take part in quality improvement	5	2 (40%)
	36. The achievements of quality improvement processes are reported to the public	4	2 (50%)
	37. The transplant program is based on a system of interdisciplinary team care	5	5 (100%)
	38. Team members are given roles and responsibilities for tasks according to their professional strengths and abilities	5	5 (100%)
	39. Clinicians' time is freed by shifting routine jobs to clinical assistants	4	1 (20%)
	40. Each member of the healthcare team is respected for his/her unique areas of expertise and contributions to overall patient care	5	5 (100%)

Clinical Decision Support System	41. Written guidelines for care are easily available	4	4 (100%)
	42. Written guidelines for care are supported by education/courses	5	5 (100%)
	43. Written guidelines for care are built into care through prompts/reminders	4	2 (50%)
	44. Care guidelines are built into the information system through computerized prompts/reminders	4	1 (25%)
	45. The transplant team's information system automatically gives healthcare workers specific guidance for individual patient care (e.g., reminders for visit, blood test)	4	1 (25%)
	46. The transplant team's information system automatically flags patients who are overdue for routine follow-up	4	0 (0%)
	47. The transplant team's information system is used to give feedback to individual healthcare workers	4	1 (25%)
	48. The transplant team's information system is used to give feedback to the transplant team about the quality of care they are delivering and identify areas for improvement	4	0 (0%)
	49. The transplant team's information system is used to give information about trends in the transplant population	4	2 (50%)
Clinical Information Systems	50. Patients have access to their medical records or personal health records	4	2 (50%)
	51. Electronic medical records are available to all members of the transplant team	5	3 (60%)
	52. Electronic medical records are used by all members of the transplant team	5	2 (40%)
	53. The same information about individual patients is accessible in- and outpatient	5	2 (40%)
	54. The transplant team uses information systems to monitor patients at home	5	0 (0%)
	55. The transplant team uses information systems for research purposes	4	2 (50%)
Level of CIM	BRIGHT Clinicians' Questionnaire; CIMI-BRIGHT; mean, SD (range)	2.92	± 0.58 (2.49 – 3.87)
Preparedness of the Tx team in view of CIM	BRIGHT clinician questionnaire, mean, SD (range)	3.14	± 0.40 (2.80 – 3.70)
Competencies of the Tx team in view of CIM	BRIGHT clinician questionnaire, mean, SD (range)	3.00	± 0.59 (2.42 – 3.67)

Note. Assessment of Chronic Illness Management (CIM) level from patients' and clinicians' perspectives by completing the adapted BRIGHT patient survey (N = 60), respectively the investigator-developed CIMI-BRIGHT clinician questionnaire (N = 5). Values highlighted in bold were agreed by less than 50% of clinicians. Abbreviations. min. = minutes, SD = standard deviation.