

Appendix 2: Matrix of validated measures and study-specific questions used in HORIZONS

Conceptual Framework Domain	Measure / Question	Assessed pre-treatment (Baseline)	Assessed 3 months after	Assessed 12 months after	Assessed 18 months after	Assessed 24 months after
Pre-existing factors	Co-morbidities (list and impact on day-to-day tasks)	X				X
	Caring responsibilities (for <18 years old, others, yourself)	X			X	
	Menopause status	X			X	
Lifestyle	Alcohol intake self-assessment	X	X	X		X
	Body Mass Index (height and weight)	BMI	X	X	X	X
	Diet (open ended question)		X	X	X	X
	e-Cigarette use self-assessment		X	X	X	X
	Fruit and vegetable screening log		X	X	X	X
	Godin-Shephard Leisure-Time Exercise Questionnaire ¹	LTEQ	X	X	X	X
	Receipt of lifestyle advice or information			X	X	X
	Strength and resistance exercise measure		X	X	X	X
	Tobacco smoking self-assessment		X	X	X	X
Sociodemographic information	Accommodation type ²		X			X
	Age		X			
	Domestic (marital) status ²		X		X	
	Car access or ownership		X			
	Ethnicity ²		X			
	Gender		X			
	Highest level of education attained ²		X			X
	Household composition ²		X			X
	Number of children (<18 years old)		X			X
Relationship status					X	
Sexual orientation ³		X				

Conceptual Framework Domain	Measure / Question		Assessed pre-treatment (Baseline)	Assessed 3 months after	Assessed 12 months after	Assessed 18 months after	Assessed 24 months after
<i>Socioeconomic information</i>	Employment status ²		X		X		X
	Income (gross salary) ⁴		X		X		X
	Number of hours worked per week ⁵		X		X		X
	Receipt of benefits ⁶		X		X		X
	Receipt of pension ⁶		X		X		X
	Sickness leave (number of days taken)		X		X		X
Consequences of cancer diagnosis and treatment	Hospital Anxiety and Depression Scale ⁷	HADS	X	X	X	X	X
	EORTC Core Quality of Life Questionnaire ⁸	EORTC-QLQ-C30	X	X	X	X	X
	EORTC Site-specific modules: Breast cancer ⁹ Cervical cancer ¹⁰ Endometrial cancer ¹¹ High grade NHL ¹² Ovarian cancer ¹³ Vulval cancer ¹⁴	EORTC-QLQ-BR23 CX24 EN24 NHL-HG29 OV28 VU34	X	X	X	X	X
	Additional items from the EORTC item bank ¹⁵		X	X	X	X	X
	Body Image Scale ¹⁶	BIS	X	X	X		X
	Patient Experience with Treatment and Self-Management ¹⁷	PETS		X	X	X	X
	Program on Research for Integrating Services for the Maintenance of Autonomy ¹⁸	PRISMA-7				X	
	Scale of Chemotherapy-Induced Neurotoxicity ¹⁹	SCIN				X	

Conceptual Framework Domain	Measure / Question		Assessed pre-treatment (Baseline)	Assessed 3 months after	Assessed 12 months after	Assessed 18 months after	Assessed 24 months after
	Supportive Care Needs Survey Short Form ²⁰	SCNS-SF34			X		X
	Use of complementary and alternative medicines (CAMs)			X	X		X
	Work and Social Adjustment Scale ²¹	WSAS		X	X	X	
	Worry of Cancer Scale – Revised ²²	WOC-R			X	X	X
Self-management of and responses to consequences and aftercare	Health Education Impact Questionnaire ²³	heiQ	X	X			X
	Experiences of self-management (open-ended question)				X	X	X
Personal factors	Self-efficacy for Managing Chronic Disease scale ²⁴	SEMCD	X	X	X	X	X
	Cancer Survivors’ Self-Efficacy Scale ²⁵	CS-SES		X	X	X	X
	Brief Illness Perception Questionnaire ²⁶	BIPQ			X		X
	Connor-Davidson Resilience Scale 2-items ²⁷	CD-RISC2	X	X	X		X
	EORTC QLQ Spiritual Well-being module ²⁸ Items 22, 31 & 32	EORTC-QLQ-SWB32	X				
	Health literacy screening questions ²⁹		X				
Environmental factors	Medical Outcome Study Social Support Survey ³⁶	MOS-SSS	X	X	X	X	X
	Health service use (including social care and third sector services)		X	X	X		X
	Travel costs and other expenses			X	X		X
	Hobbies, Interests and Supporting Others question		X		X		X
	Number of close friends and family		X	X	X		X
	Social network assessment tool ^{30,31}		X	X	X		X
	Use of the internet		X				

Conceptual Framework Domain	Measure / Question		Assessed pre-treatment (Baseline)	Assessed 3 months after	Assessed 12 months after	Assessed 18 months after	Assessed 24 months after
Health and well-being	Quality of Life in Adult Cancer Survivors ³¹	QLACS	X	X	X	X	X
	EuroQoL EQ-5D & Visual Analogue Scale ^{33,24}	EQ-5D-5L & VAS	X	X	X	X	X
	The General Health Survey Questionnaire, Short Form 12 Ver 2.0 ³⁵	SF-12v2			X		X
Life events	Life events (open-ended question)		X	X	X	X	X

References

1. Godin G, Shephard, R. J. Godin Leisure-Time Exercise Questionnaire. *Medicine and Science in Sports and Exercise*, 29 June Supplement: S36-S38. 1997.
2. Office for National Statistics 2011. Census 2011: Household Questionnaire England https://census.ukdataservice.ac.uk/media/50966/2011_england_household.pdf
3. Haseldon L, Joloza, T. and Labour Market Household. *Measuring sexual identity: A guide for researchers*. Newport (UK): Office for National Statistics. 2009.
4. Office for National Statistics (2015). *Harmonised Concepts and Questions for Social Data Sources Secondary Principles: Income*. London: Crown Copyright.
5. Office for National Statistics [ONS] (2014). *Labour Force Survey: User Guide Volume 2 – LFS Questionnaire – Version 4*. Newport (UK): Office for National Statistics. <http://www.ons.gov.uk/ons/guide-method/method-quality/specific/labour-market/labour-market-statistics/volume-2---2013-questionnaire.pdf>
6. University of Essex. Institute for Social and Economic Research and NatCen Social Research, *Understanding Society: Waves 1-5, 2009-2014 [computer file]*. 7th Edition. Colchester, Essex: UK Data Archive [distributor], November 2015. SN: 6614. https://www.understandingsociety.ac.uk/documentation/mainstage/dataset-documentation/wave/1/questionnaire-module/benefits_w1
7. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(6):361-70.
8. Aaronson NK, Ahmedzai S, Bergman B, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst* 1993;85(5):365-76.
9. van de Poll-Franse L, Oerlemans S, Bredart A, et al. International development of four EORTC disease-specific quality of life questionnaires for patients with Hodgkin lymphoma, high- and low-grade non-Hodgkin lymphoma and chronic lymphocytic leukaemia. *Qual Life Res* 2018;27(2):333-45.
10. prangers MA, Groenvold M, Arraras JI, et al. The European Organization for Research and Treatment of Cancer breast cancer-specific quality-of-life questionnaire module: first results from a three-country field study. *J Clin Oncol* 1996;14(10):2756-68.

11. Greimel ER, Kuljanic Vlastic K, Waldenstrom AC, et al. The European Organization for Research and Treatment of Cancer (EORTC) Quality-of-Life questionnaire cervical cancer module: EORTC QLQ-CX24. *Cancer* 2006;107(8):1812-22.
12. Greimel E, Nordin A, Lanceley A, et al. Psychometric validation of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-Endometrial Cancer Module (EORTC QLQ-EN24). *Eur J Cancer* 2011;47(2):183-90.
13. Greimel E, Bottomley A, Cull A, et al. An international field study of the reliability and validity of a disease-specific questionnaire module (the QLQ-OV28) in assessing the quality of life of patients with ovarian cancer. *Eur J Cancer* 2003;39(10):1402-8.
14. Jensen P, Froeding, L., Greimel, E., Lanceley, A., Nordin, A., Oberguggenberger, A. and Vistad, I. . Development and pre-testing of the EORTC quality of life questionnaire for vulva cancer patients – the significance of patient involvement. *International Journal of Gynaecological Cancer* 2017;27((S4)):1770-70.
15. EORTC Item Library [ONLINE] <https://www.eortc.be/itemlibrary/>
16. Hopwood P, Fletcher I, Lee A, et al. A body image scale for use with cancer patients. *European Journal of Cancer* 2001;37(2):189-97.
17. Eton DT, Yost KJ, Lai JS, et al. Development and validation of the Patient Experience with Treatment and Self-management (PETS): a patient-reported measure of treatment burden. *Qual Life Res* 2017;26(2):489-503.
18. Raïche M, Hébert, R. and Dubois, M.F. PRISMA-7: a case-finding tool to identify older adults with moderate to severe disabilities. *Archives of gerontology and geriatrics* 2008;47(1):9-18.
19. Oldenburg J, Fossa SD, Dahl AA. Scale for chemotherapy-induced long-term neurotoxicity (SCIN): psychometrics, validation, and findings in a large sample of testicular cancer survivors. *Qual Life Res* 2006;15(5):791-800.
20. Centre for Health Research & Psycho-oncology (2003) Supportive Care Needs Survey. (SCNS-SF34). *Journal of Evaluation in Clinical Practice* 2009; 15(4):602-606.
21. Mundt JC, Marks IM, Shear MK, et al. The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *Br J Psychiatry* 2002;180(5):461-4.
22. Hodges LJ, Humphris GM. Fear of recurrence and psychological distress in head and neck cancer patients and their carers. *Psychooncology* 2009;18(8):841-8.

23. Osborne RH, Elsworth GR, Whitfield K. The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient Educ Couns* 2007;66(2):192-201.
24. Lorig KR, Ritter P, Stewart AL, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Med Care* 2001;39(11):1217-23.
25. Foster C, Breckons M, Hankins M, et al. Developing a scale to measure self-efficacy to SELF-manage problems following cancer treatment. *Psycho-Oncology* 2013;22(16-16):16-16.
26. Broadbent E, Petrie KJ, Main J, et al. The brief illness perception questionnaire. *J Psychosom Res* 2006;60(6):631-7.
27. Vaishnavi S, Connor K, Davidson JR. An abbreviated version of the Connor-Davidson Resilience Scale (CD-RISC), the CD-RISC2: psychometric properties and applications in psychopharmacological trials. *Psychiatry Res* 2007;152(2-3):293-7.
28. Vivat B, Young, T.E., Winstanley, J., Arraras, J.I., Black, K., Boyle, F., Brédart, A., Costantini, A., Guo, J., Irarrazaval, M.E. and Kobayashi, K. The international phase 4 validation study of the EORTC QLQ-SWB 32: A stand-alone measure of spiritual well-being for people receiving palliative care for cancer. *European Journal of Cancer Care* 2017;26(6):p.e.12697.
29. Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. *J Gen Intern Med* 2008;23(5):561-6.
30. Koetsenruijter J, van Lieshout J, Vassilev I, et al. Social support systems as determinants of self-management and quality of life of people with diabetes across Europe: study protocol for an observational study. *Health and Quality of Life Outcomes* 2014;12(1):29.
31. Koetsenruijter J, van Lieshout J, Lionis C, et al. Social Support and Health in Diabetes Patients: An Observational Study in Six European Countries in an Era of Austerity. *PLoS ONE* 2015;10(8):e0135079.
32. Avis NE, Smith KW, McGraw S, et al. Assessing quality of life in adult cancer survivors (QLACS). *Qual Life Res* 2005;14(4):1007-23.
33. EuroQol. EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16(3):199-208.
34. Herdman M, Gudex C, Lloyd A, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Qual Life Res* 2011;20(10):1727-36.

35. Ware J, Jr., Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. *Med Care* 1996;34(3):220-33.