

Matrix of measures and questions in HORIZONS

(* denotes changes in measure – e.g. module(s)/items/questions/sub-scales added or removed)

Measure / Question name		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo
Quality of Life in Adult Cancer Survivors¹ <ul style="list-style-type: none"> QLACS part 1 QLACS part 2 	QLACS	X	X	X	X	X*	X*	X*	X*
		X	X	X	X	X	X	X	X
						X	X	X	X
Body Image Scale ² (for further details, see page 11)	BIS	X	X	X	X	X		X	X
Brief Illness Perception Questionnaire ³	B-IPQ; IPQ-B					X		X	X
Caring responsibilities (for <18 y.o., others, yourself)		X		X			X		
Collective Efficacy of Networks Questionnaire ⁴	CENS								X
Co-morbidities (List and impact on day-to-day tasks)		X		X				X	X
Connor-Davidson Resilience Scale (2-item) ⁵	CD-RISC2	X	X	X	X	X		X	X
European Organisation for Research and Treatment (EORTC) Quality of Life Questionnaire Core 30 items ⁶	QLQ-C30	X	X	X	X	X	X	X	X
Items from the EORTC QLQ Spiritual Well-being module ⁷ : 22, 31 & 32	QLQ-SWB32	X		X					
EORTC-QLQ Breast cancer module ⁸	QLQ-BR23	X	X	X	X	X	X	X	X

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EORTC-QLQ Breast Reconstruction module ⁹	QLQ-BRR24						X		
EORTC-QLQ Cervical cancer module ¹⁰	QLQ-CX24	X	X	X	X	X	X	X	X
EORTC-QLQ Endometrial cancer module ¹¹	QLQ-EN24	X	X	X	X	X	X	X	X
EORTC-QLQ Non-Hodgkin's lymphoma high grade module ¹²	QLQ-NHL-HG29	X	X	X	X	X	X	X	X
EORTC-QLQ Ovarian cancer module ¹³	QLQ-OV28	X	X	X	X	X	X	X	X
EORTC-QLQ Vulval cancer module ¹⁴	EORTC-QLQ-VU34			X	X	X	X	X	X
EuroQoL 5 Dimensions 5 Levels & Visual Analogue Scale ^{15,16}	EQ-5D-5L & VAS	X	X	X	X	X	X	X	X
Family history of cancer		X							
Family history of cardiac health							X		
Genetic testing for cancer		X							
Health literacy screening questions ¹⁷		X		X					
Health service use (Brief version)		X		X					
Health service use (Full version), travel costs & other expenses			X		X	X		X	X
Hobbies, Interests & Supporting Others question [Social engagement]				X		X		X	X
Hospital Anxiety and Depression Scale ¹⁸	HADS	X	X	X	X	X	X	X	X
Health Education Impact Questionnaire ¹⁹	heiQ™	X	X	X	X			X	
Medical Outcomes Study (MOS) – Social Support Survey ²⁰	MOS-SSS	X	X	X	X	X	X	X	X

Measure / Question name		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo
Menopause status				X			X		
Number of close friends & family		X	X	X	X	X		X	X
Patient Activation Measure ²¹	PAM-13								X
Patient Experience with Treatment & Self-Management ²²	PETS		X		X	X	X	X*	X*
Patient Roles and Responsibilities Scale ²³	PRRS								X
Personal Wellbeing Index (Adult) ²⁴	PWI-A	X	X						
Posttraumatic Growth Inventory: Short Form ²⁵	PTG-SF								X
Program on Research for Integrating Services for the Maintenance of Autonomy ²⁶	PRISMA-7						X		
Scale of Chemotherapy-Induced Neurotoxicity ²⁷	SCIN						X		X
Self-Efficacy for Managing Chronic Diseases ²⁸ & Cancer Survivors Self-Efficacy Scale ²⁹	SEMCD	X	X	X	X	X	X	X	X
	CS-SES		X		X	X	X	X	X
The General Health Survey Questionnaire, Short Form 12 Ver 2.0 ³⁰	SF-12v2					X		X	X
Supportive Care Needs Survey ³¹	SCNS-SF34					X		X	X
Work and Social Adjustment Scale ³²	WSAS		X		X	X	X		X
Worry of Cancer Scale – Revised ³³	WoC-R					X	X	X	X

Measure / Question name		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo
Social Network Mapping Tool ^{34,35} ("Your Social Network" question)		X	X	X	X	X		X	X
Alcohol intake self-assessment		X	X	X	X	X		X	X
Body Mass Index	BMI	X	X*	X	X*	X*		X*	X*
• Height (cm)		X		X					
• Weight (kg)		X	X	X	X	X		X	X
Diet		X	X	X	X	X		X	X
e-Cigarette use self-assessment		X	X	X	X	X		X	X
Fruit & vegetable screening log		X	X	X	X	X		X	X
Godin-Shephard Leisure-Time Exercise Questionnaire ³⁶	LTEQ	X	X	X	X	X		X	X
Information Needs Assessment (including lifestyle and other)			X		X	X		X	X
Smoking self-assessment		X	X	X	X	X		X	X
Strength & Resistance Exercise Measure		X	X	X	X	X		X	X
Accommodation type ³⁷		X		X				X	X
Age		X		X					
Car use/ownership		X		X					
Domestic/Marital Status ³⁷		X		X			X		X
Employment status ³⁷		X		X		X		X	X
Ethnicity ³⁷		X		X					
Gender		X		X					

Measure / Question name		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo
Highest level of education attained ³⁷		X		X				X	
Household composition ³⁷		X		X			X		
Internet / Online use		X		X					
Number of children (<18 years old) caring for				X			X		
Pre-tax (gross) salary / Income				X		X		X	X
Receipt of benefits & pension				X		X		X	X
Relationship status (supplement to Domestic status)							X		X
Sexual orientation ³⁸				X					
Sickness leave (number of days taken)				X		X		X	X
Weekly hours worked				X		X		X	X
Use of Complementary and Alternative Medicines (CAMs)			X		X	X		X	X
Changes to lifestyle: alcohol intake, diet, smoking/e-Cigarettes, physical activity			X		X	X	X	X	X
Experiences of self-management						X	X	X	X
Changes to jobs and careers									X
Life events		X	X	X	X	X	X	X	X
Anything else we ought to know?		X	X	X	X	X	X	X	X
Participant study feedback question		X	X					X	
Follow-up mode of completion		X	X	X	X	X	X	X	X

Measure / Question name		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo
Opinions on collection of saliva and blood samples		X							
EORTC additional items (for further details see pages 8-10)									
Aches & pains ³⁹				X	X	X	X	X	X
Burden of disease ³⁹			X	X	X	X	X	X	X
Burden of treatment ³⁹					X	X	X		
Concern for fertility ³⁹			X	X	X	X	X	X	X
Changes in bowel habit (NHL specific) ³⁹									X
Changes in urinary habit: Frequency (NHL specific) ³⁹									X
Changes in urinary habit: urgency (NHL specific) ³⁹									X
Headaches ³⁹				X	X	X	X	X	X
Impact on work & education: Disruption ³⁹			X	X	X	X	X	X	X
Impact on work & education: Problems ³⁹			X	X	X	X	X	X	X
Leg lymphoedema (Ovarian specific) ³⁹									X
Peripheral Neuropathy ³⁹				X	X	X	X	X	X
Radiotherapy-specific adverse effects: Skin problems ³⁹					X	X	X	X	X
Symptoms of the menopause: Hot flushes ³⁹				X	X	X	X	X	X
Symptoms of the menopause: Night sweats ³⁹				X	X	X	X	X	X

Measure / Question name		Pilot Baseline	Pilot 3mo	Baseline	3mo	12mo	18mo	24mo	36mo
Worry about future health ³⁹			X	X	X	X	X	X	X
Sexual function: Sexual activity ³⁹				X	X	X	X	X	X
Sexual function: Sexual enjoyment ³⁹				X	X	X	X	X	X
Sexual function: Sexual interest ³⁹				X	X	X	X	X	X
Sexual function: Sexual pain ³⁹				X	X	X	X	X	X
Sexual function: Vaginal dryness ³⁹				X	X	X	X	X	X
Sexual function: Vaginal shortening / stenosis ³⁹				X	X	X	X	X	X
Sexual function: Ejaculation problems ³⁹				X	X	X	X	X	X
Sexual function: Erectile dysfunction ³⁹				X	X	X	X	X	X
Sexual function: Ability to reach orgasm ³⁹							X	X	X

Supplemental matrices of HORIZONS measures

EORTC additional items taken from the item bank/library

(‘+’ denotes item included as part of cancer specific module, blank denotes equivalent item contained in the cancer specific module)

EORTC item	Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Item Library Question Number
Aches & pains	Have you had aches or pains in your muscles or joints?	+	+				+	Q289 - aches pains muscles joints
Burden of disease	How much has your disease been a burden to you?	+	+	+	+		+	Q46 - burden disease patient
Burden of treatment	How much has your treatment been a burden to you?	+	+	+	+		+	Q47 - burden treatment patient
Changes in bowel habit (NHL specific)	Did you experience change in bowel habit as a result of your disease or treatment?	N/A	N/A	N/A	+		N/A	Q282 - change bowel habit
Changes in urinary habit: Frequency (NHL specific)	Have you passed urine frequently?	N/A			+	N/A		Q293 - urinate frequently
Changes in urinary habit: urgency (NHL specific)	When you felt the urge to pass urine, did you have to hurry to get to the toilet?	N/A	N/A		+	N/A		Q48 - hurry to toilet
Concern for fertility	If applicable: Have you been concerned about your ability to have children?	+	+	+		+	+	Q155 - worry fertility
Headaches	Did you have headaches?		+	+	+	+	+	Q127 - headaches
Impact on work & education: Problems	If applicable: Have you had problems at your work or place of study due to the disease?	+	+	+		+	+	Q369 - problem work/study

EORTC item	Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Item Library Question Number
Impact on work & education: Disruption	If applicable: Have you worried about not being able to continue working or your education?	+	+	+		+	+	Q370 - worry continue work education
Leg lymphoedema (Ovarian specific)	Have you had swelling in one or both legs?	N/A			N/A	+		Q454 - swelling legs
Peripheral neuropathy	Have you had tingling or numbness in your hands or feet?	+					+	Q141 - tingling numbness fingers toes
Radiotherapy-specific adverse effects: Skin problems	Have you had skin problems (e.g. itchy, dry)?		+	+	N/A		+	Q142 - skin problems
Symptoms of the menopause: Hot flushes	Have you had hot flushes?			+	+		+	Q63 - hot flushes
Symptoms of the menopause: Night sweats	Did you have night sweats?	+		+	+		+	Q295 - night sweats
Worry about future health	Have you worried about your health in the future?		+	+			+	Q41 - worry health in future
Sexual function: Sexual activity	To what extent were you sexually active? (with or without intercourse)				+			Q74 – sexually active
Sexual function: Sexual enjoyment	To what extent was sex enjoyable for you?				+			Q84 – sexual activity enjoyable
Sexual function: Sexual interest / desire	To what extent were you interested in sex?				+		+	Q72 - interest in sex
Sexual function: Sexual pain	Have you had pain during sexual intercourse or other sexual activity?	+			+	+		Q89 – pain sexual activity

EORTC item	Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Item Library Question Number
Sexual function: Vaginal dryness	Has your vagina felt dry during sexual activity?	+			+			Q472 – vagina dry sex
Sexual function: Vaginal shortening / stenosis	Has your vagina felt short and / or tight?	+			+	+		Q497 - vagina short tight
Sexual function: Ejaculation problems	Did you have ejaculation problems (e.g. dry ejaculation)	N/A	N/A	N/A	+	N/A	N/A	Q77 - problem erection
Sexual function: Erectile dysfunction	Did you have difficulty gaining or maintaining an erection?	N/A	N/A	N/A	+	N/A	N/A	Q78 - problem ejaculation
Sexual function: Ability to reach orgasm	Have you had a change in the ability to reach an orgasm since you received treatment for cancer?	+	+	+	+	+	+	Q85 - satisfaction reach orgasm

Body Image Scale (BIS) – Item appearance

(‘+’ denotes BIS item included, blank denotes equivalent item contained in the cancer specific module)

Question	Breast	Cervical	Endometrial	NHL	Ovarian	Vulval	Equivalent EORTC item
Have you been feeling self-conscious about your appearance?	+	+	+	+	+	+	
Have you felt less physically attractive as a result of your disease or treatment?				+			BR23 item 9 CX24 item 15 EN24 item 17 OV28 item 20 VU34 item 18
Have you been dissatisfied with your appearance when dressed?	+	+	+	+	+	+	
Have you been feeling less feminine/masculine as a result of your disease or treatment?				+	+		BR23 item 10 CX24 item 16 EN24 item 18 VU34 item 19
Did you find it difficult to look at yourself naked?		+	+	+	+	+	BR23 item 11
Have you been feeling less sexually attractive as a result of your disease or treatment?	+	+	+	+	+	+	
Did you avoid people because of the way you felt about your appearance?	+	+	+	+	+	+	
Have you been feeling the treatment has left your body less whole?	+	+	+	+	+	+	
Have you felt dissatisfied with your body?			+	+			BR23 item 12 CX24 item 17 OV28 item 21 VU34 item 20
Have you been dissatisfied with the appearance of your scar?	+	+	+	N/A	+	+	

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