

UNC HEALTH REGISTRY

QUESTIONNAIRE DOCUMENTATION



UNC

LINEBERGER COMPREHENSIVE
CANCER CENTER

N.C. CANCER HOSPITAL

University Cancer
Research Fund

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Baseline Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
General Health Status and Quality of Life	Short-Form Health Survey (SF-12®)	<ul style="list-style-type: none"> • Overview. The 12-item Short-Form Health Survey (SF-12®) is a shortened version of the SF-36 Health Survey that assesses both physical and mental health-related quality of life.¹ The SF-12® assesses four physical health scales: physical functioning, physical role limitations, bodily pain, and general health. Mental health is also assessed utilizing four scales: vitality, social functioning, emotional role limitations, and mental health. • Scoring. The SF-12® is scored using T scores, which are standardized to the U.S. General population and have a mean of 50 and a standard deviation of 10. Scores above or below 50 are above or below the population average in the U.S. general population, respectively. The higher the SF-12 scales or symptom indices score the better the HRQOL.² • Recall. On the baseline interview, participants answered the standardized interviewer administered SF-12v2® Acute (one-week recall) Health Survey questionnaire. • Language. The SF-12® was provided in both English and Spanish translations. • Administration. The SF-12® was an interviewer-administered questionnaire. 	
	Patient-Reported Outcomes Measurement Information System -Global (PROMIS-Global)	<ul style="list-style-type: none"> • Overview. Patient-Reported Outcomes Measurement Information System (PROMIS) v1.0 Global is a 10-item scale that measures the domains of physical function, fatigue, pain, emotional distress, and social health.³ • Scoring. PROMIS is scored using T scores, which are standardized to the U.S. General 	<p>REQUIREMENTS</p> <p>The following statement should be included in publications or presentations utilizing PROMIS measures. “Study participants were administered PROMIS questionnaire v1.0 Global, which is a 10-item scale that measures the domains of physical function, fatigue, pain, emotional distress, and social health.³ Additional</p>

		<p>population and have a mean of 50 and a standard deviation of 10. Scores above or below 50 are above or below the population average in the U.S. general population, respectively. Higher scores correspond to higher levels of HRQOL.³</p> <ul style="list-style-type: none"> • Recall. PROMIS utilizes a 7-day recall period. • Language. PROMIS was provided in both English and Spanish translations. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>information can be obtained at the PROMIS website (www.nihpromis.org).”</p> <p>SUGGESTIONS FOR USE</p> <p>The use of the PROMIS instruments in clinical research is encouraged, with the understanding that data collected from that use will contribute to knowledge about the validity of PROMIS measures. Therefore, until validity data are more mature, users of PROMIS tools are STRONGLY ENCOURAGED to submit a BRIEF report INCLUDING SAMPLE DEMOGRAPHIC INFORMATION, CLINICAL data sufficient to define the sample without indicating treatment response data, and PROMIS score distributions (e.g., baseline mean and standard deviations or change scores blinded to treatment information). This brief report should be submitted to help@assessmentcenter.net for internal review. None of this submitted information will be published without the written consent and participation of the submitter. In addition to the brief report, clinical researchers are encouraged to submit de-identified data for collaborative analysis and reporting. <i>Prior to providing this information to PROMIS, researchers need to acquire the permission of the UNC Lineberger Comprehensive Cancer Center’s Data and Biospecimen Repository by contacting the Health Registry Data Sharing Coordinator (cscresearchers@med.unc.edu).</i></p>
Cancer Specific Quality of Life	Functional Assessment of Cancer Therapy – General Population (FACT-GP)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy – General Population (FACT-GP) version 4 is a 21-item scale that measures health-related quality of life (HRQOL) using four subscales: physical well-being, social/family well-being, emotional well-being, and functional well-being.^{4,5} • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final 	

		<p>subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵</p> <ul style="list-style-type: none"> • Recall. FACT utilizes a 7-day recall period. • Language. FACT-GP was provided in both English and Spanish translations. • Administration. Permission was obtained to modify the FACT questionnaires for interviewer administration. 	
	Functional Assessment of Cancer Therapy – Cognitive Function (FACT-Cog)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Cognitive Function Issues (FACT-Cog) version 3 Perceived Cognitive Impairments is a 20-item subscale that focuses specifically HRQOL cognitive function issues.⁶ • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-Cog was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Cancer Symptoms	Rotterdam Symptom Checklist (RSCL)	<ul style="list-style-type: none"> • Overview. The Rotterdam Symptom Checklist (RSCL) physical symptom distress subscale is 23-items. • Scoring. The items are scored 1-4, and summed for a total score. The higher the score, the higher the symptom burden.⁷ • Recall. Participants were asked to recall their symptoms for the past week. • Language. RSCL was provided in both English 	<p>REQUIREMENTS</p> <p>When work using the RSCL is published, it is appreciated that a copy of the publication is sent to dr. Robbert Sanderman (R.Sanderman@med.rug.nl) or to prof. Hanneke de Haes (j.c.dehaes@amc.uva.nl).</p> <p>SUGGESTIONS FOR USE</p> <p>It is appreciated that data gathered with the RSCL are made available for further validation: scores on the</p>

		<p>and Spanish translations.</p> <ul style="list-style-type: none"> • Administration. Permission was requested and minor modifications were made for interviewer administration. Additional symptoms were added to the 23-item Rotterdam Checklist using the same item formats. These items are not included when scoring the Rotterdam Symptom Checklist. 	<p>individual items of the checklist, if possible for different age, sex and diagnostic groups. These can be made available on disc or electronic mail, coded as outlined in this manual. <i>Prior to providing this information, researchers need to acquire the permission of the UNC Lineberger Comprehensive Cancer Center's Data and Biospecimen Respository by contacting the Health Registry Data Sharing Coordinator (cscresearchers@med.unc.edu).</i></p>
Bowel/Urinary Incontinence	International Consultation on Incontinence Questionnaire-Urinary Incontinence (ICIQ-UI)	<ul style="list-style-type: none"> • Overview. The International Consultation on Incontinence Questionnaire-Urinary Incontinence (ICIQ-UI) is a 3-item scale with one unscored self-diagnostic item.⁸ • Scoring. The questions are scored on a scale 0-21, with higher scores indicating more severe urinary incontinence.⁸ • Recall. Urinary incontinence symptoms were assessed for the past four weeks. • Language. ICIQ-UI was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS Dr. Nikki Cotterill (on behalf of the ICIQ study group) would be very grateful if researchers would inform the ICIQ study group of use of the instruments and inform them of any results you may publish (e-mail: nikki_cotterill@bui.ac.uk).</p>
		<ul style="list-style-type: none"> • Overview. Questions on bowel incontinence were adapted from an article by Reilly et al.⁹ Additional items were also developed and administered. 	
Physical Function/Activity	Global Physical Activity Questionnaire (GPAQ)	<ul style="list-style-type: none"> • Overview. The Global Physical Activity Questionnaire (GPAQ) version 2 is a 16-item scale, measuring the domains of activity at work, travel to and from places, and recreational activities in a typical week. • Scoring. The GPAQ scoring calculates metabolic equivalent of task (MET) units to calculate total physical activity.¹⁰ More METs indicate a more active lifestyle. • Recall. GPAQ asks participants to report 	<p>REQUIREMENTS Please provide an original copy of your publication to the developer (e-mail: campanariod@who.int), showing where/how WHO material appears and how it is referenced on your product.</p>

		<p>activities for a typical week.</p> <ul style="list-style-type: none"> • Language. GPAQ was provided in both English and Spanish translations. • Administration. GPAQ is an interviewer-administered questionnaire. 	
	Patient-Generated Subjective Global Assessment (PG-SGA)	<ul style="list-style-type: none"> • Overview. The question on functional capacity was taken from the Patient-Generated Subjective Global Assessment (PG-SGA) instrument. • Recall. PG-SGA utilizes a past month recall.¹¹ • Language. PG-SGA was translated from English into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Health Care System	Patient Provider Communication: Patient Satisfaction Questionnaire (PSQ-18)	<ul style="list-style-type: none"> • Overview. The short-form Patient Satisfaction Questionnaire (PSQ-18) is an 18-item instrument that measures seven dimensions of current satisfaction with medical care: general satisfaction, technical quality, interpersonal manner, communication, financial aspects, time spent with doctor, and accessibility and convenience.¹² • Scoring. These dimensions are measured by separate scales within the questionnaire, ranging from a score of 1-5. A higher score reflects more satisfaction with medical care.¹² • Recall. The PSQ-18 measures current patient satisfaction. • Language. The PSQ-18 was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Sexual Functioning	Patient Reported Outcomes	<ul style="list-style-type: none"> • Overview. Patient Reported Outcomes Measurement Information System (PROMIS) 	<p>REQUIREMENTS</p> <p>The following statement should be included in</p>

	<p>Measurement Information System - Sexual Function (PROMIS-PSxFBP)</p>	<p>Sexual Function Brief Profile (PSxFBP) version 1.0 is a 10-item scale for women and an 8-item scale for men that measures seven subdomains of sexual function and satisfaction: interest in sexual activity, vaginal discomfort (women), lubrication (women), erectile function (men), orgasm, and global satisfaction with sex life.¹³</p> <ul style="list-style-type: none"> • Scoring. PROMIS is scored using T scores for each domain, which are standardized to the U.S. General population and have a mean of 50 and a standard deviation of 10 (with the exception of the orgasm subdomain). Scores above or below 50 are above or below the population average in the U.S. general population, respectively. Higher scores correspond to higher levels of satisfaction for a given subdomain.¹³ • Recall. PROMIS utilizes a 30-day recall period. • Language. PROMIS was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>publications or presentations utilizing PROMIS measures. “Study participants were administered PROMIS questionnaire v1.0 Sexual Function Brief Profile, which is a 10-item scale for women and an 8-item scale for men that measures seven subdomains of sexual function and satisfaction: interest in sexual activity, vaginal discomfort (women), lubrication (women), erectile function (men), orgasm, and global satisfaction with sex life.¹³ Additional information can be obtained at the PROMIS website (www.nihpromis.org).”</p> <p>SUGGESTIONS FOR USE</p> <p>The use of the PROMIS instruments in clinical research is encouraged, with the understanding that data collected from that use will contribute to knowledge about the validity of PROMIS measures. Therefore, until validity data are more mature, users of PROMIS tools are STRONGLY ENCOURAGED to submit a BRIEF report INCLUDING SAMPLE DEMOGRAPHIC INFORMATION, CLINICAL data sufficient to define the sample without indicating treatment response data, and PROMIS score distributions (e.g., baseline mean and standard deviations or change scores blinded to treatment information). This brief report should be submitted to help@assessmentcenter.net for internal review. None of this submitted information will be published without the written consent and participation of the submitter. In addition to the brief report, clinical researchers are encouraged to submit de-identified data for collaborative analysis and reporting. <i>Prior to providing this information to PROMIS, researchers need to acquire the permission of the UNC Lineberger Comprehensive Cancer Center’s Data and Biospecimen Repository by contacting the Health Registry Data Sharing Coordinator (cscresearchers@med.unc.edu).</i> ANY PUBLICATION OR PRESENTATION OF RESULTS OBTAINED FROM STUDIES CONDUCTED USING THESE INSTRUMENTS SHOULD INCLUDE A STATEMENT THAT PROMIS VERSION 1.0</p>
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			INSTRUMENTS WERE USED, AND REFERENCE THE PROMIS SITE (www.nihpromis.org) FOR FURTHER INFORMATION.
Work Ability	Work Ability Index (WAI)	<ul style="list-style-type: none"> • Overview. Questions on work ability were derived from the Work Ability Index.¹⁴ The questions asked include current work ability compared to lifetime best, work ability in relation to physical and mental demands, and sick leave. • Language. The WAI was translated from English into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Reproductive History		<ul style="list-style-type: none"> • Overview. The reproductive history questions for women were adapted from the National Health and Nutrition Examination Survey (NHANES)¹⁵ with instructions from Carolina Breast Cancer Study III (CBCS3).¹⁶ Several additional items were developed. This section includes questions on menstrual cycle, pregnancy and uterine health, birth control history, and hormone replacement history. 	
Comorbidities and Medications		<ul style="list-style-type: none"> • Overview. Comorbidity questions were adapted from various sources, which include the National Health Interview Survey (NHIS),¹⁷ Study of Digestive Health,¹⁸ North Carolina-Louisiana Prostate Cancer Project (PCaP),¹⁹ The University of Texas MD Anderson Cancer Center – Patient History Database,²⁰ and the Roswell Park Cancer Institute questionnaire.²¹ Several additional items were developed. This section includes questions on diagnosis, limitations, and prescriptions for comorbidities. 	
NSAIDS and		<ul style="list-style-type: none"> • Overview. The NSAID and multivitamin 	

Multivitamins		<p>questions included questions on complementary and alternative medicine (CAM) and were adapted from various sources, which include the Nurses' Health Study II,²² Diet and Health Study V (DHS5),²³ the Study of Digestive Health,¹⁸ and UNC Family Medicine CAM study. Several additional items were developed. This section includes questions on frequency and duration of NSAID and multivitamin use for the past year.</p>	
Cancer Screening		<ul style="list-style-type: none"> • Overview. Cancer screening questions were adapted from various sources, which include the Behavioral Risk Factor Surveillance System (BRFSS)²⁴ and PCaP.¹⁹ Several additional items were developed. This section includes questions on colorectal, breast, cervical, and prostate cancer screening. 	
Access to Healthcare		<ul style="list-style-type: none"> • Overview. Questions on access to healthcare were adapted from various sources, which include the National Health Interview Survey (NHIS)¹⁷ and the Carolina Head and Neck Cancer Study (CHANCE).²⁵ Several additional items were developed. This section includes questions on type of healthcare, delay in obtaining healthcare, and affordability of healthcare. 	
Alcohol		<ul style="list-style-type: none"> • Overview. The alcohol questions were adapted from CHANCE.²⁵ Several additional items were developed. This section includes questions on frequency and duration of lifetime alcohol consumption. 	
Tobacco		<ul style="list-style-type: none"> • Overview. The tobacco questions were adapted from from NHIS¹⁷ and NHANES.¹⁵ Several additional items were developed. This section includes questions on frequency and duration of lifetime cigarette use. 	

Living Arrangements		<ul style="list-style-type: none"> • Overview. Living arrangement questions were adapted from various source, which included the American Cancer Society National Quality of Life Survey,²⁶ PCaP,¹⁹ and BRFSS.²⁴ Several additional items were developed. This section includes questions on group care facility and household size. 	
Historical Height and Weight		<ul style="list-style-type: none"> • Overview. Historical height and weight questions were adapted from various sources, which include the New Mexico Women’s Health Study,²⁷ NHANES,¹⁵ and BRFSS.²⁴ Several additional items were developed. This section includes questions on current height, height at age 20, and weight at various ages. 	

Bladder Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Bladder (FACT-BI)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Bladder (FACT-BI) version 4 is a 13-item subscale that focuses specifically HRQOL bladder cancer issues.²⁸ • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-BI was provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	

Breast Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Breast (FACT-B)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Breast (FACT-B) version 4 is a 10-item subscale that focuses specifically HRQOL breast cancer issues.²⁹ • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-B was provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Menopause-specific QOL	Menopause-specific quality of life (MENQOL)	<ul style="list-style-type: none"> • Overview. Menopause-specific quality of life (MENQOL) questionnaire is a menopause-specific questionnaire that was developed to assess women’s quality of life experience.³⁰ We utilized 7-items from the MENQOL questionnaire that assessed flatulence, physical strength, stamina, dry skin, facial hair, skin changes, and bloat. • Recall. MENQOL assesses women’s current quality of life. • Language. Questions were provided in English and translated to Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	Menopause Rating Scale (MRS)	<ul style="list-style-type: none"> • Overview. The Menopause Rating Scale is an 11-item scale that assesses three 	<p>REQUIREMENTS The developers think it important for further developing</p>

		<p>dimensions: psychological, somato-vegetative, and urogenital. It was developed to measure the impact of aging-symptoms on quality of life.³¹</p> <ul style="list-style-type: none"> • Scoring. Each MRS question is scored 0-5 and then summed to a total score. The higher the MRS scale or subscale indicates more severe symptoms.³¹ • Recall. The MRS assesses women’s current quality of life. • Language. Questions were provided in both English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>the MRS to keep an overview of who is using the scale and for what reason. Therefore, publications utilizing this scale should be sent to the developer, Dr. Lothar A. J. Heinemann (heinemann@zeg-berlin.de).</p>
Breast Exposure, Disease, and Biopsy		<ul style="list-style-type: none"> • Overview. The breast exposure, disease, and biopsy questions were adapted from the CBCS3¹⁶ and the Roswell Park Cancer Institute questionnaire.²¹ Several additional items were developed. This section takes a history of mammograms, chest x-rays, radiation, and biopsies. 	

Cervical, Vulva, and Vaginal Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Vulvar (FACT-V)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Vulvar (FACT-V) version 4 is a 19-item subscale that focuses specifically HRQOL vulvar cancer issues.³² • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-V was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	Functional Assessment of Cancer Therapy – Cervix (FACT-Cx)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Cervix (FACT-Cx) version 4 is a 15-item subscale that focuses specifically HRQOL cervical cancer issues.³² • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-V was provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	

Colorectal Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Colorectal (FACT-C)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Colorectal (FACT-C) version 4 is a 19-item subscale that focuses specifically HRQOL vulvar cancer issues.³² • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-C was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Colorectal Cancer (EORTC QLQ-CR29)	<ul style="list-style-type: none"> • Overview. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Colorectal Cancer (EORTC QLQ-CR29) version 2.1 is scale that assesses health-related quality of life in colorectal cancer patients during the past week.³³ We utilized 2-items from the EORTC QLQ-CR29 scale that assessed bowel movement pain and bloody stools. • Recall. EORTC utilizes a past week recall. • Language. Questions were provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS EORTC recommends explaining in the methods section of manuscripts why use single items rather than the entire questionnaire module from which those items were extracted were used. “Due to time constraints and redundancies within the questionnaire, only select items from the EORTC QLQ-CR29 were utilized.”</p>
Fecal Incontinence	Functional Assessment of Incontinence Therapy	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Incontinence Therapy - Fecal (FAIT-F) 	

	<p>– Fecal (FAIT-F)</p>	<p>version 4 is a 12-item subscale that focuses specifically HRQOL fecal incontinence issues.³⁴</p> <ul style="list-style-type: none"> • Scoring. Each FAIT-F question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FAIT-F scales or symptom indices score the better the HRQOL.⁵ • Recall. FAIT-F utilizes a 7-day recall period. • Language. FAIT-F was provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
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Endometrial Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Endometrial (FACT-En)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Endometrial (FACT-En) version 4 is a 16-item subscale that focuses specifically HRQOL endometrial cancer issues.³⁵ • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-En was provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Lymphedema Symptoms	Functional Assessment of Cancer Therapy – Vulvar (FACT-V)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Vulvar (FACT-V) version 4 is subscale that focuses specifically HRQOL vulvar cancer issues.³² We utilized 3-items to assess lymphedema symptoms in endometrial cancer patients. • Recall. FACT utilizes a 7-day recall period. • Language. FACT-V was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Menopause-specific quality of life	Menopause-specific quality of life (MENQOL)	<ul style="list-style-type: none"> • Overview. Menopause-specific quality of life (MENQOL) questionnaire is a menopause-specific questionnaire that was developed to assess women’s current 	

		<p>quality of life experience.³⁰ We utilized 7-items from the MENQOL questionnaire that assessed flatulence, physical strength, stamina, dry skin, facial hair, skin changes, and bloat.</p> <ul style="list-style-type: none"> • Recall. MENQOL assesses women’s current quality of life. • Language. Questions were provided in English and translated to Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	Menopause Rating Scale (MRS)	<ul style="list-style-type: none"> • Overview. The Menopause Rating Scale is an 11-item scale that assesses three dimensions: psychological, somato-vegetative, and urogenital. It was developed to measure the current impact of aging-symptoms on quality of life.³¹ • Scoring. Each MRS question is scored 0-5 and then summed to a total score. The higher the MRS scale or subscale indicates more severe symptoms.³¹ • Recall. MRS assesses women’s current quality of life. • Language. Questions were provided in both English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>The developers think it important for further developing the MRS to keep an overview of who is using the scale and for what reason. Therefore, publications utilizing this scale should be sent to the developer, Dr. Lothar A. J. Heinemann (heinemann@zeg-berlin.de).</p>
Urinary Symptoms	International Consultation on Incontinence Questionnaire Female Lower Urinary Tract Symptoms Module (ICIQ-FLUTS)	<ul style="list-style-type: none"> • Overview. The International Consultation on Incontinence Questionnaire Female Lower Urinary Tract Symptoms Module (ICIQ-FLUTS) is a 12-item scale that evaluates lower urinary tract symptoms and impact on quality of life for females.³⁶ • Scoring. The questionnaire is scored on a scale from 0-16 for filling symptoms, 0-12 	<p>REQUIREMENTS</p> <p>Dr. Nikki Cotterill (on behalf of the ICIQ study group) would be very grateful if researchers would inform the ICIQ study group of use of the instruments and inform them of any results you may publish (e-mail: nikki_cotterill@bui.ac.uk).</p>

		<p>for voiding symptoms, and 0-20 for incontinence symptoms.³⁷ The higher the ICIQ-FLUTS scale or subscale indicates more severe symptoms.</p> <ul style="list-style-type: none">• Recall. Urinary incontinence symptoms were assessed for the past four weeks.• Language. Questions were provided in both English and Spanish.• Administration. Permission was requested and minor modifications were made for interviewer administration.	
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Esophageal Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Esophageal (FACT-E)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Esophageal (FACT-E) version 4 is a 17-item subscale that focuses specifically HRQOL esophageal cancer issues.³² • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-E was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Esophageal Cancer (EORTC QLQ-OES18)	<ul style="list-style-type: none"> • Overview. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Esophageal Cancer (EORTC QLQ-OES18) is scale that assesses health-related quality of life in esophageal cancer patients.³⁸ We utilized 2-items from the EORTC QLQ-OES18 scale that assessed swallowing, trouble eating, taste, heartburn and trouble talking. • Recall. EORTC utilizes a past week recall. • Language. Questions were provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>EORTC recommends explaining in the methods section of manuscripts why use single items rather than the entire questionnaire module from which those items were extracted were used.</p> <p>“Due to time constraints and redundancies within the questionnaire, only select items from the EORTC QLQ-OES18 were utilized.”</p>

Gastric Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Gastric (FACT-Ga)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Gastric (FACT-Ga) version 4 is a 19-item subscale that focuses specifically HRQOL esophageal cancer issues.³⁹ • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-Ga was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Gastric Cancer (EORTC QLQ-STO22)	<ul style="list-style-type: none"> • Overview. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Gastric Cancer (EORTC QLQ-STO22) phase III module is scale that assesses health-related quality of life in gastric cancer patients.³⁸ We utilized 9-items from the EORTC QLQ-STO22 scale that eating problems, abdominal bloat, and heartburn. • Recall. EORTC utilizes a past week recall. • Language. Questions were provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>EORTC recommends explaining in the methods section of manuscripts why use single items rather than the entire questionnaire module from which those items were extracted were used.</p> <p>“Due to time constraints and redundancies within the questionnaire, only select items from the EORTC QLQ-STO22 were utilized.”</p>

Hepatobiliary Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Hepatobiliary (FACT-Hep)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Hepatobiliary (FACT-Hep) version 4 is a 18-item subscale that focuses specifically HRQOL hepatobiliary cancer issues.³⁹ • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-Hep was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Hepatocellular Carcinoma (EORTC QLQ-HCC18)	<ul style="list-style-type: none"> • Overview. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Hepatocellular Carcinoma (EORTC QLQ-HCC18) phase II module is scale that assesses health-related quality of life in hepatocellular cancer patients.⁴⁰ We utilized 5-items from the EORTC QLQ-HCC18 scale that assessed thirst, abdominal appearance, pain, fullness, and sleep. • Recall. EORTC utilizes a past week recall. • Language. Questions were provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>EORTC recommends explaining in the methods section of manuscripts why use single items rather than the entire questionnaire module from which those items were extracted were used.</p> <p>“Due to time constraints and redundancies within the questionnaire, only select items from the EORTC QLQ-HCC18 were utilized.”</p>

	<p>European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Pancreatic Cancer (EORTC QLQ-PAN26)</p>	<ul style="list-style-type: none"> • Overview. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Pancreatic Cancer (EORTC QLQ-PAN26) phase III module is scale that assesses health-related quality of life in pancreatic cancer patients.⁴¹ We utilized 6-items from the EORTC QLQ-PAN26 scale that assessed pain, diet, gas, and weakness in arms and legs. • Recall. EORTC utilizes a past week recall. • Language. Questions were provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>EORTC recommends explaining in the methods section of manuscripts why use single items rather than the entire questionnaire module from which those items were extracted were used.</p> <p>“Due to time constraints and redundancies within the questionnaire, only select items from the EORTC QLQ-PAN26 were utilized.”</p>
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Kidney Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Kidney Disease Quality of Life- Short Form (KDQOL-SF™)	<ul style="list-style-type: none"> • Overview. The Kidney Disease Quality of Life-Short Form (KDQOL-SF™) Instrument version 1.2 is a scale to assess current issues with kidney disease and dialysis.^{42,43} We utilized 2-items, with multiple components in each item, from the KDQOL-SF that assessed effects of kidney disease on daily life. • Recall. The questions from the KDQOL-SF are asked about current experiences with kidney disease. • Language. Questions were provided in both English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Symptoms	Functional Assessment of Cancer Therapy - Kidney Symptom Index (FKSI-15)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy - Kidney Symptom Index (FKSI-15) is a 15-item subscale that focuses specifically HRQOL kidney cancer symptoms.⁴⁴ • Scoring. Each FKSI question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FKSI scales or symptom indices score the better the HRQOL.⁵ • Recall. FKSI-15 utilizes a 7-day recall period. • Language. FKSI-15 was provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	

Melanoma Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Sunburn/sun/tanning bed exposure and history of atypical moles and skin cancer	Melanoma Risk Factor Survey	<ul style="list-style-type: none"> • Overview. The Melanoma Risk Factor survey is a questionnaire utilized by UNC physicians for melanoma patients. Questions on sunburn and sun/tanning exposure, skin phenotype, history of atypical moles, non-melanoma skin cancer, melanoma, and family history of skin cancer were adapted for use. 	
Diet	Connecticut Survey	<ul style="list-style-type: none"> • Overview. Diet questions were adapted from the Connecticut Study.⁴⁵ This section includes questions on consumption of red meat, fish, green salad, and fruit. 	
Stress	Perceived Stress Scale (PSS)	<ul style="list-style-type: none"> • Overview. The Perceived Stress Scale (PSS) is a 4-item scale that measures the degree to which personal problems and situations are seen as stressful by an individual during the past month.^{46,47} • Scoring. Items are scored on a 0-4 scale and summed. The higher the score, the more perceived stress an individual feels.⁴⁸ • Recall. PSS utilizes a past month recall. • Language. The PSS was provided in both English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Appearance	Appearance Motivation	<ul style="list-style-type: none"> • Overview. The questions on appearance motivation were adapted from a questionnaire developed to assess artificial tanning tendencies, with additional questions provided from the authors.⁴⁹ Items are rated on a 5-point Likert scale. • Recall. The appearance motivation questions assess current motivations for 	

		<p>tanning.</p> <ul style="list-style-type: none">• Language. Questions were translated from English to Spanish.• Administration. Permission was requested and minor modifications were made for interviewer administration.	
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Ovarian Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Functional Assessment of Cancer Therapy – Ovarian (FACT-O)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Ovarian (FACT-O) version 4 is a 12-item subscale that focuses specifically HRQOL ovarian cancer issues.⁵⁰ • Scoring. Each FACT question is scored 0-4 and then summed, multiplied by the number of items in the subscale, and divided by the number of items answered to produce a final subscale score. The higher the FACT scales or symptom indices score the better the HRQOL.⁵ • Recall. FACT utilizes a 7-day recall period. • Language. FACT-O was provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Lymphedema Symptoms	Functional Assessment of Cancer Therapy – Vulvar (FACT-V)	<ul style="list-style-type: none"> • Overview. The Functional Assessment of Cancer Therapy –Vulvar (FACT-V) version 4 is subscale that focuses specifically HRQOL vulvar cancer issues.³² We utilized 3-items to assess lymphedema symptoms in ovarian cancer patients. • Recall. FACT utilizes a 7-day recall period. • Language. FACT-V was provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Menopause-specific quality of life	Menopause-specific quality of life (MENQOL)	<ul style="list-style-type: none"> • Overview. Menopause-specific quality of life (MENQOL) questionnaire is a menopause-specific questionnaire that was developed to assess women’s current quality of life experience.³⁰ We utilized 7- 	

		<p>items from the MENQOL questionnaire that assessed flatulence, physical strength, stamina, dry skin, facial hair, skin changes, and bloat.</p> <ul style="list-style-type: none"> • Recall. MENQOL assesses women’s current quality of life. • Language. Questions were provided in English and translated to Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
	Menopause Rating Scale (MRS)	<ul style="list-style-type: none"> • Overview. The Menopause Rating Scale is an 11-item scale that assesses three dimensions: psychological, somato-vegetative, and urogenital. It was developed to measure the current impact of aging-symptoms on quality of life.³¹ • Scoring. Each MRS question is scored 0-5 and then summed to a total score. The higher the MRS scale or subscale indicates more severe symptoms.³¹ • Recall. MRS assesses women’s current quality of life. • Language. Questions were provided in both English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>The developers think it important for further developing the MRS to keep an overview of who is using the scale and for what reason. Therefore, publications utilizing this scale should be sent to the developer, Dr. Lothar A. J. Heinemann (heinemann@zeg-berlin.de).</p>
Urinary Symptoms	International Consultation on Incontinence Questionnaire Female Lower Urinary Tract Symptoms Module (ICIQ-FLUTS)	<ul style="list-style-type: none"> • Overview. The International Consultation on Incontinence Questionnaire Female Lower Urinary Tract Symptoms Module (ICIQ-FLUTS) is a 12-item scale that evaluates lower urinary tract symptoms and impact on quality of life for females during the past four weeks.³⁶ • Scoring. The questionnaire is scored on a scale from 0-16 for filling symptoms, 0-12 	<p>REQUIREMENTS</p> <p>Dr. Nikki Cotterill (on behalf of the ICIQ study group) would be very grateful if researchers would inform the ICIQ study group of use of the instruments and inform them of any results you may publish (e-mail: nikki_cotterill@bui.ac.uk).</p>

		<p>for voiding symptoms, and 0-20 for incontinence symptoms.³⁷ The higher the ICIQ-FLUTS scale or subscale indicates more severe symptoms.</p> <ul style="list-style-type: none">• Recall. Urinary incontinence symptoms were assessed for the past four weeks.• Language. Questions were provided in both English and Spanish.• Administration. Permission was requested and minor modifications were made for interviewer administration.	
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Prostate Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	Expanded Prostate Cancer Index Composite (EPIC-26)	<ul style="list-style-type: none"> • Overview. The Expanded Prostate Cancer Index Composite (EPIC-26) short-form I a 26-item scale that evaluates function and symptoms after prostate cancer treatment, utilizing the domains of incontinence, urinary irritation/obstruction, bowel, sexual function, and hormones.⁵¹ • Scoring. EPIC-26 is scored and transformed linearly to a 0-100 scale, where higher scores represent better quality of life.⁵¹ • Recall. EPIC-26 assesses symptoms for the past four weeks. • Language. Questions were provided in both English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	
Symptoms	Prostate Cancer Symptom Index (PCSI)	<ul style="list-style-type: none"> • Overview. The Prostate Cancer Symptom Index (PCSI) is a scale that measures prostate cancer symptoms.⁵² We utilized questions from the urinary and bowel problem subscales. • Scoring. Scores are calculated by summing responses and standardizing to a 0-100 scale, with higher scores indicating higher distress.⁵² • Recall. PCSI utilizes a past week recall. • Language. Questions were provided in English and translated into Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>Drs. Jack Clark and Jim Talcott would be very appreciative if researchers would inform them of any results you may publish (e-mail: jaclark@bu.edu and jtalcott@chpnet.org).</p>

Testicular Questionnaire

Questionnaire Section	Scale	Citations and General Information	Requirements/Suggestions/Additional Information
Quality of Life	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Testicular Cancer (EORTC QLQ-TC26)	<ul style="list-style-type: none"> • Overview. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire for Testicular Cancer (EORTC QLQ-TC26) version 1.0 is a scale that assesses health-related quality of life in testicular cancer patients.⁴¹ We utilized 16-items from the EORTC QLQ-TC26 scale that assessed skin problems, circulation, hearing, medical care, anxiety, physical limitations, family life, masculinity, and testicular implant. • Recall. EORTC utilizes a past week recall. • Language. Questions were provided in English and Spanish. • Administration. Permission was requested and minor modifications were made for interviewer administration. 	<p>REQUIREMENTS</p> <p>EORTC recommends explaining in the methods section of manuscripts why use single items rather than the entire questionnaire module from which those items were extracted were used.</p> <p>“Due to time constraints and redundancies within the questionnaire, only select items from the EORTC QLQ-TC26 were utilized.”</p>

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