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## Initial Report of the Cancer PROMIS Supplement Sexual Function Committee: Review of Sexual Function Measures and Domains Used in Oncology

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### Abstract

**Objective**—This report describes initial activities of the Cancer Patient-Reported Outcomes Measurement Information System (PROMIS) Sexual Function domain group (CaPS-SF), part of the National Institutes of Health (NIH) Roadmap Initiative to develop brief questionnaires or individually-tailored assessments of quality of life domains. Our literature review of sexual function measures used in cancer populations, and descriptions of domains found in those measures, is presented.

**Methods**—Using a consensus-driven approach, an electronic bibliographic search was conducted for articles published 1991-2007, yielding 486 articles for in-depth review.

**Results**—A total of 257 articles reported the administration of a psychometrically evaluated sexual function measure to individuals diagnosed with cancer. Apart from the UCLA Prostate Cancer Index, the International Index of Erectile Function, and the Female Sexual Function Index, the 31 identified measures have not been widely tested in cancer populations. Most measures were multidimensional and included domains related to the sexual response cycle and to general sexual satisfaction.

**Conclusions**—Our review supports the need for a flexible, psychometrically robust measure of sexual function for use in oncology settings and strongly justifies the development of the PROMIS-SF instrument. After PROMIS-SF is publicly available, cancer clinicians and researchers will have another measure to assess patient-reported sexual function outcomes in addition to the few legacy measures identified through our review.

### Keywords

neoplasms; psychometrics; quality of life; sexual function

## Introduction

In 1987, the American Cancer Society published a review article on sexual function and cancer to encourage clinicians to address the sexual concerns of cancer survivors [1]. Since that time, the number of individuals alive with a history of cancer in the U.S. population has almost doubled from an estimated 5.9 million to an estimated 11.1 million [2]. Thus, while the number of cancer survivors who consider sexual function to be an essential component of quality of life is increasing, the assessment and treatment of sexual concerns or sexual dysfunction has yet to be practiced routinely in oncology settings [3]. Although the prevalence of sexual dysfunction for all cancer survivors is unknown, the rate of erectile dysfunction may be as high as 100% among prostate cancer survivors following radical prostatectomy [4] and the rate of problems with sexual desire or orgasms disorders may be as high as 75% among ovarian cancer survivors [5]. The detection and treatment of sexual problems, and an understanding of how various cancer treatments affect sexual function, are important because sexual dysfunction may disrupt relationship intimacy, contribute to emotional distress, reinforce negative body image, or serve as a constant reminder of one's cancer history. Identifying the presence and severity of sexual concerns should be considered part of cancer treatment and follow up care [6,7] because such concerns are likely to be long-standing or worsen over time [8]. Additionally, the assessment of sexual function in clinical settings may help inform treatment choice, most notably for prostate, gynecologic, breast, and colorectal cancer treatments. Such assessment may provide data that lead to modifications of surgical approaches [9,10]; the type and dosage of chemotherapy [11,12]; the timing, location, type and amount of radiation [13]; the timing and maintenance schedule of hormonal therapy [14]; and posttreatment symptom management [15,16].

Unfortunately, efforts to characterize the epidemiology and treatment of sexual problems in cancer have been hampered by a lack of consensus regarding valid outcome measures that can be used in a variety of contexts [17-20]. This shortcoming is not unique to cancer, as documented by Arrington et al.'s [21] review of sexual function instruments used with general and medically ill populations. To facilitate communication between cancer survivors and their physicians and to design informative clinical research, the field requires a measure that can be used across the continuum of care for different cancer sites and stages of disease, regardless of gender, sexual orientation, partner status, age, literacy level and cultural background. Ideally, such a measure would be sensitive to differential treatment effects when applicable, be able to detect clinically meaningful changes in sexual function, be sufficiently flexible to provide tailored assessments based on personal, illness and treatment characteristics, and generate information that is useful for implementing and evaluating clinical interventions. A measure of sexual function developed specifically for cancer populations may likewise serve as a diagnostic tool with cancer and other chronic diseases, and assist in the systematic documentation of this quality of life domain.

In response to this assessment need, the National Cancer Institute is funding a supplement to the National Institutes of Health (NIH) Roadmap Initiative for the Patient-Reported Outcomes Measurement Information System (PROMIS) [22,23] and collaborating with Duke University Medical Center and Evanston Northwestern Healthcare to develop a computerized measure of sexual function that addresses the above concerns. Specifically, item banks will be created to allow researchers the flexibility to assess sexual functioning with either brief, fixed-length questionnaires or individually-tailored assessments (i.e., computerized-adaptive testing, CAT). Item banks are groupings of questions whose measurement properties are carefully calibrated such that they can provide an operational definition of a concept (e.g., satisfaction with sex life) and accurately assess the entire continuum (e.g., severity or frequency) of that concept [24]. We used the developmental

process of the PROMIS item banks [22,25] which integrates the methods from qualitative research, psychometrics, health survey methods, and informatics to create efficient, precise, and valid measures to focus on sexual function. Key to this process is the continual input from cancer patients, clinicians, and survey methodologists to create the PROMIS-SF item banks.

The purpose of this paper is to report on the initial activities of the NIH-funded Cancer PROMIS Supplement Sexual Function (CaPS-SF) domain group. Specifically, we present selected findings from our CaPS-SF literature review of sexual function measures used in cancer populations, and describe how we identified the major sexual function domains found in those measures. Our secondary purpose is to provide oncology clinicians a compendium of psychometrically tested, patient-reported measures of sexual function along with corresponding cancer research citations. While our major intent is to inform the oncology community about the development of PROMIS-SF, we use the compendium to guide our recommendations to oncology clinicians and researchers in their current efforts to assess the sexual function of their patients.

## Methods

Using a modified Delphi, consensus-driven approach developed by the PROMIS steering committee [24], we conducted an electronic bibliographic search using OVID Medline to identify measures of sexual function used in cancer populations. We used the search terms “cancer” or “neoplasms” in combination with two other sets of search terms under the rubrics of “measurement” and “sexual function.” Additional electronic searches were conducted using PsychInfo, PubMed, HAPI, Embase, CINAHL, and SCOPUS (1992 - 2007). Approximately 1200 citations were generated. The following criteria were used to select a final subset of 486 articles for in-depth review: the article was research-based, published in English between 1991 and 2007, described a sample of participants diagnosed with cancer, and described the administration of a self-report measure of sexual function.

The in-depth review ascertained the name(s) of the sexual function measure(s), the domains included in the measure, the original instrument citation(s), the number and type of items, the type of responses, the sample size, and the characteristics of the cancer population. Where possible, the original psychometric report for each measure was reviewed in order to obtain information about dimensionality, domains, the type of psychometric analysis, and the overall reliability and validity. We coded the type(s) of reliability as internal consistency (Cronbach alpha coefficient, the Kuder-Richardson Formula 20), test-retest (Pearson correlation coefficient, interclass correlation coefficients), split-half (Spearman-Brown prophecy formula, the Guttman split-half reliability coefficient, Rulon formula), and inter-rater agreement (kappa statistic or intraclass correlation coefficients). Validity, for purposes of this review, was classified as content, construct (convergent validity or discriminant validity), and criterion (concurrent validity or predictive validity) (see: The American Psychological Association *Standards for Educational and Psychological Testing*, 1999). In a few instances, we contacted the developer(s) of the measure to obtain psychometric information and to inquire about the measure’s use in oncology.

## Results

From a review of 486 cancer-related articles, a total of 257 articles were found that describe the use of at least one dedicated, self-report, sexual function measure with documented levels of reliability and validity. Approximately 76% of these articles focused on prostate cancer, followed by breast (9%) and gynecologic cancers (7%), then bladder, rectal, testicular, hematologic, and head and neck cancers (<2% each). As shown in Table 1, we

identified 31 unique self-report measures. Although not a dedicated sexual function measure, we included the University of California Los Angeles Prostate Cancer Index (UCLA PCI) [26] because it was used in half of the reviewed studies that focused on prostate cancer; items on sexual function and sexual bother are included with items about urinary and bowel function and bother.

Only three measures with well-documented reliability and validity were used in 10 or more of the reviewed articles: the UCLA PCI and its longer versions, the Expanded Prostate Index Composite (EPIC)[27]; the International Index of Erectile Function (IIEF) [28] and its shorter version, the IIEF-5 [29]; and the Female Sexual Function Index (FSFI) [30]. About 34% (n = 87) of the 257 reviewed articles reported using the UCLA PCI or the EPIC; 30.7% (n = 79) reported using the IIEF, and 3.9% (n = 10) reported using the FSFI.

Only three of the identified measures appear to have been developed specifically for cancer populations, namely the Sexual Function After Treatment for Gynecologic Cancer [31], the UCLA PCI [26], and the Sexual Function-Vaginal Changes Questionnaire [32]. Almost all of the identified measures are gender-specific or have male and female forms (e.g. Derogatis Sexual Functioning Inventory [33], Changes in Sexual Functioning Questionnaire [34]) to permit matched comparisons.

In addition to the sexual function scales, several of the reviewed articles reported using functional status or quality of life measures that include one or more items related to sexual function. For example, the Functional Assessment of Cancer Therapy-Breast Scale (FACT-B) [35] assesses sexual function in its subscale about additional concerns, the Cancer Rehabilitation and Evaluation System Short Form (CARES-SF) contains a sexual function subscale [36], and the Psychosocial Adjustment to Illness Scale (PAIS) includes a subscale of sexual dysfunction and quality of dyadic relationship [37-39]. Likewise, several of the site-specific measures of the European Organization for Research and Treatment of Cancer quality of life questionnaires (EORTC QLQ) contain function or symptom subscales to assess sexual function or dysfunction, such as the EORTC QLQ Colorectal-38, the EORTC QLQ Breast-23, the EORTC QLQ Ovarian-28, and the EORTC QLQ Head & Neck-35 [40]. Additionally, Gotay and her colleagues [41], after conducting qualitative research with cancer survivors, added sexuality/intimacy items to the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire – Cancer 30 (EORTC QLQ-C30).

### Dimensionality and Domains

Only a few measures were purposively constructed to be unidimensional, the majority being multidimensional. Exploratory factor analysis or principal components analysis were the most common statistical methods used to identify or verify subdomains. No psychometric reports indicated the use of confirmatory factor analysis or item response theory.

Almost all measures included domains related to stages of the sexual response cycle as defined by Masters and Johnson [42], including excitement/arousal, plateau/continued arousal and orgasm, although the specific content varied considerably between measures. The most common domains and the number of measures (#) identifying these domains were:

- Sexual arousal (lubrication, erectile (dys)function) (19)
- Sexual (dis)satisfaction (16)
- Sexual desire (interest, drive, avoidance, receptivity, nonsensuality) (15)
- Sexual pleasure (orgasm) (12)
- Frequency of sexual activity (12)

- Problems affecting sexual function (anorgasmia, pain, vaginismus) (5)

Less common domains (or constructs) related to cognitive aspects, including sexual thoughts or fantasies, sexual self-esteem, sexual self-image, sexual self-reflection, psychosexual stimulation, emotional goals, and broader cognitive dimensions such as sexual attitudes and beliefs, motivation, values, and expectations. The most infrequent domains were sexual role, partner function or perceptions, nonsexual interactions or communication, relationship satisfaction, and health-specific sexual dysfunction. Our preliminary conceptual model, based on the sorting of the measures' reported domains, contains five domains: Sexual Response, Intrapersonal, Interpersonal, Frequency, and Overall Satisfaction.

Our literature review highlights the wide array of sexual function measures administered to cancer populations. Although we focused exclusively on the cancer literature, our findings approximate those of other reviews that examined the domains and psychometric properties of sexual function instruments used with general and medically ill populations. The first review by Arrington et al. [21] identified 45 sexual function-specific measures and 12 global measures, and concluded that while there is no consensus on sexual function domains, the most common domains were excitement/arousal, interest/desire, satisfaction/quality, and performance. The second review by Corona et al. [18] identified 30 patient self-report measures of sexual function published in their entirety between 1969 and 2005, 22 measures for males and/or males and females, 8 measures for females only. Our secondary review of these 30 measures found 83 unique domains, the most common relating to psychological constructs (e.g., emotional responses to sexual problems, sexual concerns), sexual desire/interest, sexual partner or relationship, and overall sexual satisfaction or pleasure. These domains are consistent with our preliminary conceptual model which is expected to undergo revision after further qualitative and quantitative testing.

For measures of male sexual function, there appears to be complete accord for including erectile function as a domain. For measures of female sexual function, sexual interest or desire, and ability to reach orgasm are the most common domains. In contrast, there appears to be no consensus among measures for both males and females with respect to domains related to non-genital activity, affection behaviors, or sexual intimacy, and, rarely, partner sexual function, sexual attractiveness or body-image, or sexually-related cognitive or emotional dimensions. Others recommend that these latter domains be classified as secondary or mediating dimensions [20,43-45].

Most of the identified measures were gender-specific, consistent with other reviews of general sex measures [18,21]. For specific research applications, such as evaluating interventions to treat erectile dysfunction, the use of gender-specific measures is clear. In other settings, however, it may be desirable to assess the degree of sexual issues independent of gender. For example, describing the burden of sexual difficulties in long-term survivors would benefit from assessing men and women on comparable metrics where possible. Generating gender-neutral assessments is challenging and likely will require a modular approach to measure development.

From our review, only the UCLA PCI/EPIC, IIEF, and FSFI emerged as “legacy” measures, that is, measures with extensive psychometric testing and sufficient clinical administration in oncology settings to help set the standard for the development of subsequent sexual function measures intended for use with cancer survivors. Indeed, in the last 15 years the UCLA PCI/EPIC and the IIEF have been used in about two-thirds of studies that examine the sexual function of individuals treated for cancer. While both are reliable and valid indicators of male sexual function, there are important differences between these measures. The 20-item UCLA PCI was originally developed for use with the Rand 36-item Health Survey (SF-36) to yield a comprehensive quality of life assessment of men with

prostate cancer [46]; the IIEF was developed with support from a pharmaceutical company for the purpose of evaluating multinational clinical trials of sildenafil citrate [47]. Another distinction is that the UCLA PCI and its 26-item and 50-item EPIC versions specifically target symptoms associated with prostate cancer compared to the IIEF which assesses sexual function only. Also, the UCLA PCI has been shown to discriminate between older men with and without prostate cancer [26], and has been successfully used in large prospective studies of prostate cancer conducted in the U.S. [e.g., 48-50]. The discriminant validity of the IIEF between men with and without cancer has not been reported, but the measure is able to discriminate between men receiving and not receiving sildenafil citrate for erectile dysfunction after radical prostatectomy, (e.g., 51), and between men receiving or not receiving tadalafil after radiation therapy for prostate cancer [15,52]. Given their comparable levels of reliability and validity and use with cancer populations, decisions to use one or the other measure depend on research or clinical objectives as well as practical considerations. Measures that produce multiple conceptually precise subscales (e.g., EPIC) might be better suited for research purposes because of the need to detect subtle intergroup differences over time, whereas measures with fewer, more global dimensions (e.g., IIEF-5) might be adequate for clinical purposes (i.e., for screening to help identify who may be having problems, or as a catalyst to begin patient-provider communication about sexual function). Too, since both the UCLA/EPIC and IIEF are available at no cost, clinical use may favor the IIEF which takes about 5 – 10 minutes to self-administer while compared to the 20-30 minutes needed for the UCLA/EPIC versions. It should be noted that the male version of the CaPS SF will capture and test similar domains and items from both measures (in addition to those from other measures) with the goal of producing targeted, clinically relevant outcomes with the least possible administration and response burdens for all cancer sites.

Among the identified measures of female sexual function used in oncology, only one measure appears to be emerging as a legacy measure, namely the FSFI which was developed by the IIEF originator, again with the support of pharmaceutical funding [30,53]. Used in studies of urologic [54], gynecologic [55-59], breast [60,61], and rectal cancer survivors [62,63], it appears to have undergone extensive psychometric testing, and is able to discriminate between clinical and non-clinical populations [64]. The 19-item FSFI takes less than 15 minutes to complete, uses a 4-week recall period, and is available at no cost [30]. This measure has been used in clinical trials of sildenafil citrate [65,66] and vardenafil [67] to evaluate female partner satisfaction, and thus might be a particularly useful measure in studies of male cancers where partner assessments are included as an outcome. The use of the FSFI in studies of female cancer survivors also appears to be growing as indicated by reports published subsequent to our CaPS-SF literature review [e.g., 68,69]. The extent to which the FSFI is used in clinical settings to help evaluate and treat the sexual function of female cancer survivors is unknown. Our female CaPS SF measure will capture and test similar domains and items as found in the FSFI.

Unexpectedly, our literature review indicates that sildenafil citrate, approved by the U. S. Food and Drug Administration in 1998 to treat erectile dysfunction, paved the way for sexual function measures to be used in oncology. As a consequence, among cancer populations, the assessment of male sexual function has far outpaced the assessment of female sexual function, an unanticipated finding given decades of research documenting compromised sexual function after treatment for gynecologic and breast cancer. Although several well-established measures of female sexual function are available (e.g., Derogatis Sexual Functioning Inventory, Brief Index of Sexual Function for Women, Female Sexual Function Index), it was also surprising that they have not been used as extensively as the UCLA-PCI or IIEF.

A significant limitation of the existing measures is the lack of data demonstrating the validity of the measures for different cancer sites and across the continuum of cancer care, a limitation that presents challenges for conducting meaningful cross-study comparisons across all cancer sites. As indicated above, important exceptions are the UCLA PCI and the IIEF both of which have been used post-diagnosis through long-term follow-up care.

### Next Steps

The present findings echo those of Cull [20] who concluded that no one brief self-report measure of sexual function can be recommended for cancer clinical trials. Because sexual function is differentially affected by cancer site, cancer treatment, age, gender, partner status, sexual orientation, and cultural practices, researchers may need to develop their own measures to better reflect the characteristics of their targeted population. As discussed above, there are several advantages to developing a measure of sexual function that is sensitive, yet applicable, to a broader array of people. This review was undertaken as the first step in the PROMIS process for developing such a measure. Briefly, the remaining steps for our CaPS-SF subcommittee are to:

- refine the domain hierarchy based on the results of recently completed focus groups with cancer patients;
- review and standardize the items that remain from “binning and winnowing” the approximately 1500 captured items from publicly available measures;
- write new items that address gaps identified through focus groups and cognitive testing;
- cognitively test the items with cancer patients and survivors;
- develop and refine our conceptual model informed by the above steps;
- collect self-report data from a large diverse group of cancer survivors;
- evaluate the psychometric properties of the items and calibrate the items for the PROMIS-SF item bank; and
- create PROMIS-SF short form instruments and to implement computerized adaptive testing.

Subsequent reports will describe these next steps, as well as detail the remaining processes as we work to develop a flexible and psychometrically robust measure of sexual function for use in clinical oncology settings, and, eventually, in other chronic disease settings. The final CaPS-SF product will be internationally available in the public domain by October 2009. National and international cooperative groups are encouraged to consider collaborating with the PROMIS initiative to assist with establishing further construct validity of the PROMIS-SF in clinical trial settings. The complexity and resources needed to accomplish the CAPS-SF activities described above underscores the importance of support from the NIH Roadmap Initiative for Medical Research to develop psychometrically sound patient-reported outcome measures.

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Table 1

Self-report Sexual Function Measures, their Domains, Reliability and Validity, and Citations by Cancer Site

Instrument Name	Domains & Internal Consistency	Reliability and Validity	Cancer site and references
Arizona Sexual Experience Scale (ASEX) McGahuey, et al., 2000	Sex drive Arousal Lubrication/Erection Ability to reach orgasm Satisfaction from orgasm	Overall alpha = .91 Concurrent, construct	Female cancers - Mathias, et al., 2005 Breast - Mathias, et al. 2006
Brief Index of Sexual Functioning for Women (BISF-W) Taylor, et al., 1994; Mazer, et al., 2000	Sexual interest/desire Sexual activity Sexual satisfaction	Internal consistencies of subscales = .39 - .74; overall alpha = .83 Test-retest r = .68 - .78 Concurrent, construct	Breast or gyn/I-lib - Scott, et al., 2004 Gynecologic - Du, et al., 2005 Prostate (spouses) - Soloway, et al., 2005
Brief Sexual Function Questionnaire for Men (BSFQ) Reynolds et al, 1988	Sexual activity/performance Interest Satisfaction Physiological competence	Guttman total test-retest reliability = .94 Concurrent, construct	Prostate - Soloway, et al., 2005
Brief Sexual Function Inventory (BSFI) O'Leary, et al., 1995	Interest Function Ejaculation Problems/satisfaction	Internal consistency of domains alpha = .62 - .92 Test-retest r = .68 - .70 Concurrent, construct	Prostate - Bradley, et al., 2004 - Deliveliotis, et al., 2004 - Rajagopal, et al., 2003 - Valicenti, et al., 2002 - Chen, et al., 2001 - Valicenti, et al., 2001 - Krupski, et al., 2000 - Hong, et al., 1999
Changes in Sexual Functioning Questionnaire (CSFQ) Clayton et al., 1997a, 1997b; Keller, et al., 2006	Desire/Frequency Desire/Interest Arousal/Excitement Orgasm/Completion Pleasure	Internal consistency of domains = .64 - .80 Test-retest r = 0.45 - 1.00 Construct	All female cancer sites - Barton, et al., 2007 Gynaecological cancer - Lagana, et al., 2005 - Caldwell, et al., 2003
Derogatis Interview for Sexual Functioning-Self Report (DISF-SR) Derogatis, 1997	Cognition/fantasy Arousal Sexual behavior Orgasm Drive	Internal consistency alpha of domains = .74 - 0.80	Cervical cancer - Schroder, et al., 2005
Derogatis Sexual Functioning Inventory (DSFI) Derogatis, 1979	Information Experience Drive Attitudes Psychological Distress Gender Role Fantasy Body Image Sexual satisfaction Frequency of activity	Internal consistency of domains alpha = .56 - .97 Test-retest.61 - .96 Construct	All sites - Ananth, et al., 2003 Breast - Young-McCaughan, 1996 Cervix - Grumann, et al., 2001 - Schroder, et al., 2005 Head and neck - Monga, et al., 1997 Hematologic - Marks, et al., 1996
Erectile Dysfunction - Effect on Quality of Life (ED-EQoL) MacDonagh, et al. 2004	Erectile dysfunction	Internal consistency alpha = .94 Construct (Discriminant: Ferguson's delta = .86)	Prostate - Meyer, et al., 2003
Erectile Dysfunction Inventory of Treatment Satisfaction (EDITS) Althof, et al., 1999	Erectile dysfunction	Internal consistency (patient) alpha = .90; (partner) alpha = .76 Test-retest (patient) r = .98; (partner) r = .83 Content	Prostate - Ramsawh, et al., 2005 - Montorsi, et al., 2004
Female Sexual Function Index (FSFI) Rosen et al., 2000 Wiegel et al., 2005	Desire Arousal Lubrication Orgasm Satisfaction Pain	Internal consistency alpha > .90 Test-retest r = 0.79-0.86 Construct	Bladder - Bhatt, et al., 2006 Breast - Schover, et al., 2006 - Speer, et al., 2005 Cervix - Frumovitz, et al., 2005

Instrument Name	Domains & Internal Consistency	Reliability and Validity	Cancer site and references
			- Schroder, et al., 2005 Gynecologic - Carter, et al., 2005 Rectal - Hendren, et al., 2005 - Jayne, et al., 2005 Vulvar 46,47 - Likes, et al., 2007a - Likes, et al., 2007b
Golombok Rust Inventory of Sexual Satisfaction (GRISS) Rust, et al., 1985, 1986; ter Kuile, et al., 1999; van Lankveld, et al., 1999; 2003	Erectile dysfunction Premature ejaculation Anorgasmia Vaginismus Noncommunication Infrequency Male and Female: Avoidance Nonsensuality Dissatisfaction	Internal consistency of subscales alpha = .72 - .98 Test-retest of subscale r = .72 - .90 Predictive, construct	Breast - Onen Sertoz, et al., 2004 Testicular - Sheppard, et al., 2001
International Continence Society questionnaire (male and sex subscales) (ICS) Donovan, et al., 2000	Erectile function	Internal consistency of subscales alpha = .69 - .91 Test-retest of symptom score r = .78; problem score r = .83 Criterion, construct	Prostate - Henderson, et al. 2006 - Rozet, et al., 2005 - Selli, et al., 2004 - Gacci, et al., 2003 - Hara, et al., 2003
Index of Female Sexual Function (IFSF-modified) - Kaplan, et al. 1999 Zippe, et al. 2004	Free of pain during intercourse Degree of vaginal Lubrication Overall sexual desire and interest Ability to achieve orgasm Overall sexual satisfaction	Internal consistency alpha = .80 - .90 Test retest of subscales r = .71 - .76; total scale r = .70 Construct	Bladder - Zippe, et al., 2004
International Index of Erectile Function Sexual Health Inventory for Men (IIEF-15, SHIM, IIEF-5) Rosen, et al., 1997, 1999, 2002; Rhoden, et al., 2002; Cappelleri et al., 2005	Erectile function Orgasm Desire Intercourse satisfaction Overall satisfaction IIEF-5 Erectile function Intercourse satisfaction	Internal consistency of domains alpha = 0.73–0.99 Test–retest of domains r = 0.64–0.84 Construct	Bladder - Davila, et al., 2007 - Wang, et al., 2007 - Columbo, et al., 2004 Prostate - Cesaretti, et al., 2007 - Chang, et al., 2007 - Davison, et al., 2007 - Incrocci, et al., 2007 - Kava, et al., 2007 - Kohler, et al., 2007 - Lee, et al., 2007 - Lu, et al., 2007 - Madeb, et al., 2007 - Mattei, 2007 - Matthew, et al, 2007 - Papadoukakis, et al., 2007 - Wille, et al., 2007 - Zagar, et al., 2007 - Bannowsky, et al., 2006 - Chaplin, et al., 2006 - Col, et al., 2006 - Incrocci, et al., 2006 - Kim, et al., 2006 - Long, et al., 2006 - Latini, et al., 2006 (a) - Latini, et al., 2006 (b) - Ponholzer, et al., 2006 - Salonia, et al., 2006 - Titta, et al., 2006 - Wilke, et al., 2006 - Zucchi, et al., 2006 - Bannowsky, et al., 2005 - Bellina, et al., 2005 - Canada, et al., 2005 - De Lorenzo, et al., 2005 - Dinelli, et al., 2005 - Karakiewicz, et al., 2005 - Mabjeesh, et al., 2005 - Menon, et al., 2005

Instrument Name	Domains & Internal Consistency	Reliability and Validity	Cancer site and references
			<ul style="list-style-type: none"> <li>- Matzkin, et al., 2005</li> <li>- Merrick, et al., 2005</li> <li>- Mulhall, et al., 2005</li> <li>- Ohebshalom, et al., 2005</li> <li>- Pompeu, et al., 2005</li> <li>- Porpiglia, et al., 2005</li> <li>- Ponholzer, et al., 2005</li> <li>- Rozet, et al., 2005</li> <li>- Shindel, et al., 2005</li> <li>- Trinchieri, et al., 2005</li> <li>- Yatim, 2005</li> <li>- Alduais, et al., 2004</li> <li>- Colombo, et al., 2004</li> <li>- Davison, et al., 2004</li> <li>- Fujioka, et al., 2004</li> <li>- Montorsi, et al., 2004</li> <li>- Ogura, et al., 2004</li> <li>- Raina, et al., 2004</li> <li>- Saidi, et al., 2004</li> <li>- Anastasiadis, et al., 2003</li> <li>- Gacci, et al., 2003</li> <li>- Hara, et al., 2003</li> <li>- Incrocci, et al., 2003</li> <li>- Lee, et al., 2003</li> <li>- Menon, et al., 2003</li> <li>- Penson, et al., 2003</li> <li>- Raina, et al., 2003</li> <li>- Noldus, et al., 2002</li> <li>- Schover, et al., 2002a</li> <li>- Schover, et al., 2002b</li> <li>- Merrick, et al., 2001</li> <li>- Incrocci, et al., 2001</li> <li>- Matzkin, et al., 2001</li> <li>- Saito, et al., 2001</li> <li>- Blander, et al. 2000</li> <li>- Kedia, et al., 1999</li> <li>Testicular</li> <li>- Wiechno, et al., 2007</li> <li>- Lackner, et al., 2005</li> <li>Rectal</li> <li>- He &amp; Pu, 2005</li> <li>- Hendren, et al., 2005</li> <li>- Jayne, et al., 2005</li> </ul>
<p>Medical Outcomes Study (MOS) Sexual Functioning Scale (MOS-SFS)                      Sherbourne, 1992, in Stewart &amp; Ware (eds.), 1992;                      McHorney, et al., 1994; Hays, et al., 1993</p>	<p>Sexual activity                      Difficulty becoming aroused                      Difficulty relaxing/enjoying sex                      Difficulty achieving orgasm</p>	<p>Internal consistency (men) alpha = .90; (omen) r = .92                      Construct</p>	<p>Breast                      - Burwell, et al., 2006                      - Broeckel, et al., 2002                      Head and Neck                      - Siston, et al., 1997</p>
<p>UCLA Prostate Cancer Index-Sexual Function/Sexual Bother (UCLA PCI-SF/SB)                      Lubeck, et al., 1997 Litwin, et al., 1998, 2002; Karakiewicz, et al. 2003; Krongrad, et al 1998                      UCLA Prostate Cancer Index + [Dutch] Sexual Activities module                      Incrocci, et al., 2001; Korfage, et al., 2003                      UCLA Expanded Prostate Index Composite (EPIC)                      Wei, et al., 2000                      Japanese adapted EPIC                      Takegami, et al., 2005;                      Kakehi, et al., 2007; Namiki, et al., 2007a</p>	<p>Sexual function                      Sexual bother</p>	<p>Internal consistency of subscales &gt; .78                      Cross-cultural validity, construct</p>	<p>Prostate                      - Anger, et al., 2007                      - Arredondo, et al., 2007                      - Ash, et al., 2007                      - Campbell, et al., 2007                      - Dearnaley, et al., 2007                      - Frank, et al., 2007                      - Kakehi, et al., 2007                      - Kato, et al., 2007                      - Kübler, et al., 2007                      - Litwin, et al., 2007                      - Namiki, et al., 2007b                      - Namiki, et al., 2007c                      - Penedo, et al., 2007                      - Stevens, et al. 2007                      - Van der Wielen, et al., 2007                      - Ball, et al., 2006                      - Dalkin, et al., 2006                      - Ishihara, et al., 2006                      - Joseph, et al., 2006                      - Miller, et al., 2006                      - Montgomery, et al., 2006</p>

Instrument Name	Domains & Internal Consistency	Reliability and Validity	Cancer site and references
			<ul style="list-style-type: none"> <li>- Namiki, et al., 2006</li> <li>- Newton, et al., 2006</li> <li>- Pinkawa, et al., 2006a</li> <li>- Pinkawa, et al., 2006b</li> <li>- Sanderson, et al., 2006</li> <li>- Tseng, et al., 2006</li> <li>- Wagner, et al., 2006</li> <li>- Dahn, et al., 2005</li> <li>- Descazeaud, et al., 2005</li> <li>- Jayadevappa, et al., 2005</li> <li>- Korfage, et al., 2005</li> <li>- Krupski, et al., 2005</li> <li>- Link, et al., 2005</li> <li>- Penson, et al., 2005</li> <li>- Soderdahl, et al., 2005</li> <li>- Steginga, et al., 2005</li> <li>- Wiygul, et al., 2005</li> <li>- Yang, et al., 2005</li> <li>- Campbell, et al., 2004</li> <li>- Dahn, et al., 2004</li> <li>- Descazeaud, et al., 2004</li> <li>- Hoffman, et al.,</li> <li>- Hollenbeck, et al., 2004</li> <li>- Hu, et al., 2004</li> <li>- Jenkins, et al., 2004</li> <li>- Lepore, et al., 2004</li> <li>- Merrick, et al., 2004</li> <li>- Namiki, et al., 2004a</li> <li>- Namiki, et al., 2004b</li> <li>- Schover, et al., 2004</li> <li>- Su, et al., 2004</li> <li>- Cooperberg, et al., 2003</li> <li>- Downs, et al., 2003</li> <li>- Hollenbeck, et al., 2003</li> <li>- Korfage, et al., 2003</li> <li>- Krahn, et al., 2003</li> <li>- Oefelein, 2003</li> <li>- Penson, et al., 2003</li> <li>- Bacon, et al., 2002</li> <li>- Hollenbeck, et al.,</li> <li>- 2002</li> <li>- Katz, et al., 2002</li> <li>- Smith, et al., 2002</li> <li>- Valicenti, et al., 2002</li> <li>- Wei, et al., 2002</li> <li>- Chen, et al., 2001</li> <li>- Davis, et al., 2001</li> <li>- Fulmer, et al., 2001</li> <li>- Kupelian, et al., 2001</li> <li>- Litwin, et al., 2001</li> <li>- Lubeck, et al., 2001a</li> <li>- Lubeck, et al., 2001b</li> <li>- Madalinska, et al., 2001a</li> <li>- Madalinska, et al., 2001b</li> <li>- Penson, et al., 2001</li> <li>- Pietrow, et al., 2001</li> <li>- Schapira, et al., 2001</li> <li>- Brandeis, et al., 2000</li> <li>- Gralnek, et al., 2000</li> <li>- Potosky, et al., 2000</li> <li>- Sanchez-Ortiz, et al., 2000</li> <li>- Smith, et al., 2000</li> <li>- Litwin, et al., 1999</li> <li>- Perrotte, et al., 1999</li> <li>- Krongrad, et al., 1998</li> <li>- Litwin, et al., 1998</li> <li>- Yarbrow, et al., 1998</li> </ul>
Psychological Impact of Erectile Dysfunction (PIED) Latini, et al., 2002	Sexual experience Emotional life	Internal consistency of subscales alpha = .72 - .91 Test-retest of subscales r = .66 - .76 Construct	Prostate - Penson, et al., 2003

Instrument Name	Domains & Internal Consistency	Reliability and Validity	Cancer site and references
Sapporo Medical University Sexual Function Questionnaire (SMUSFQ) Kato, et al., 1999	Sexual desire Erectile function Satisfaction after sex Sexual activity Overall satisfaction	Reliability not reported Construct	Prostate - Yoshimura, et al., 2004 - Yoshimura, et al., 2003 - Miyao, et al., 2001 - Arai, et al., 1999 - Shibuya, et al., 1997
Sexual Adjustment Questionnaire RTOG Modified Sexual Adjustment Questionnaire (SAQ-H) Waterhouse, et al., 1986; Bruner, et al., 1998	Activity Arousal Libido Orgasm Satisfaction Relationships Techniques Sexual dysfunction	Test-retest (females) $r = 0.67$ Construct	Prostate - Feigenberg, et al., 2005 - Bruner, et al., 2004 - Bruner, et al., 1998 Gynecologic - Ratliff, et al., 1996
Sexual Activity Questionnaire (SAQ) Thirlaway, et al., 1996	Frequency of sexual activity Sexual interest/desire Arousal/vaginal dryness Sexually related pain	Internal consistency $\alpha = .56 - .88$ Test-retest $\kappa = .50 - 1.0$	Breast - Ganz, et al., 2003 - Ganz, et al., 2002 - Fobair, et al., 2001 Ovarian - Carmack Taylor, et al., 2004 Gynecologic - Wenzel, et al., 2002
Sexual Arousability Inventory (SAI) Hoon, et al., 1976	Sexual arousability	Internal consistency $\alpha = .91 - .92$ Split half $r = .92$ Content, construct	Breast - Wellisch, et al., 1996 - Wellisch, et al., 1992 - Wellisch, et al., 1991
Sexual Adjustment Questionnaire (SAQ-modified) O'Farrell, et al., 1997	Overall satisfaction Frequency of intercourse Discrepancy between desire and actual frequency Communication Ease of refusal Satisfaction with specific aspects Satisfaction with privacy and context Sexual dysfunction	Reliability not reported Content, construct	Prostate - Soloway, et al., 2005
Sexual Beliefs and Information Questionnaire (SBIQ) Adams, et al., 1996	Time/patience Stress/pressure Aging Sexual satisfaction Other/basic knowledge	Internal consistency total $\alpha = .81$ ; factors $\alpha = .42 - .93$ Test-retest $r = .82$ Content	Gynecologic - Brotto, et al., 2007
Sexual Function After Treatment for Gynecologic Cancer (SFAGIS) Bransfield, et al., 1984	Fears about sexual activity Partner fears about sexual activity Initiation of activity Vaginal condition Vaginal lubrication Health provider intervention Desire for sexual information Changes in sexual activity	Split half $r = .80$ Kuder-Richardson 20 internal consistency = .76 Content	Gynecologic - Bruner, et al., 1999
Sexual Function Inventory Questionnaire (SFIQ) Klotz, et al., 2000	Not reported	Reliability and validity not reported	Prostate - Klotz, et al., 2000
Sexual Function Questionnaire (SFQ) Syrjala, et al., 2000	Sexual activity Specific problems Interest Desire Arousal Orgasm Satisfaction Masturbation Relationship	Internal consistency of domains $\alpha > .80$ ; overall $\alpha = .94$ Criterion, construct	All cancers - Syrjala, et al., 2000 Hematologic - Syrjala, et al., 2005
Sexual History Form (SHF) Schover & Jensen, 1988	Sexual behavior Frequency Satisfaction	Reliability on 12 of 28 original items: Internal consistency (men) $\alpha = .65$	Bladder - Hart, et al., 1999 Breast - Greendale, et al., 2001 - Mortimer, et al., 1999



Instrument Name	Domains & Internal Consistency	Reliability and Validity	Cancer site and references
		Test-retest (women) $r = .92$ ; (men) $r = .98$	- Makar, et al., 1997 - Schover, et al., 1995 Prostate - Perez, et al., 2002
Sexual Self-Efficacy Scales-Erectile Functioning Sexual Self-Efficacy Scales-Female Functioning SSES: SSES-EF, SSES-FF Fichten, et al., 1998; Bailes, et al., 1998	SSES-M Unidimensional SSES-F Interpersonal Orgasm Individual Interest/Desire Sensuality Individual Arousal Affection Communication Body Acceptance Refusal	SSES-M Internal consistency alpha = .86 - .92 Test-retest $r = .97-.98$ Concurrent, construct SSES-F Internal consistency alpha = .93 total; subscales alpha = .70 - .87 Test-retest $r = .83$ total; subscales $r = .50 - .93$ Concurrent	Prostate - Latini, et al., 2006 - Penson, et al., 2003
Sexual Self-Schema Scale (SSSS) Andersen & Cyranowski, 1994	Passionate-romantic Open Embarrassed-Conservative	Intercorrelations .65 - .80 Construct	Ovarian - Champion, et al., 2007 - Gershenson, et al., 2007 Prostate - Schover, et al., 2004 - Jenkins, et al., 2004 - Schover, et al., 2002a - Schover, et al., 2002b Gynecologic - Andersen, et al., 1997
Sexual function-Vaginal changes Questionnaire (SVQ) Jensen, Klee, Thranov et al. 2004	Sexual interest Lubrication Orgasm Dyspareunia Vaginal dimensions Intimacy Sexual problems of partner Sexual activity Sexual satisfaction Body image Sexual and vaginal problems	Internal consistency for subscales alpha = .76 - .83 Median kappa (patient/observer) = .80 Construct	Cervix - Jensen, et al., 2004 - Jensen, et al., 2003
Watts Sexual Function Questionnaire (WSFQ) Watts, 1982	Not reported	Internal consistency alpha = 0.80 Test-retest $r = 0.83$	Breast - Rowland, et al., 2000 Prostate - Basaria, et al., 2002

References for Table 1 are available upon request.