

# Achieving optimal delivery of follow-up care for prostate cancer survivors: improving patient outcomes

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**Background:** Prostate cancer is the most commonly diagnosed cancer in men in the US, and the second most prevalent cancer in men worldwide. High incidence and survival rates for prostate cancer have resulted in a large and growing population of long-term prostate cancer survivors. Long-term follow-up guidelines have only recently been developed to inform approaches to this phase of care for the prostate cancer population.

**Methods:** A PubMed search of English literature through August 2014 was performed. Articles were retrieved and reviewed to confirm their relevance. Patient-reported measures that were used in studies of long-term prostate cancer survivors (ie, at least 2 years posttreatment) were reviewed and included in the review.

**Results:** A total of 343 abstracts were initially identified from the database search. After abstract review, 105 full-text articles were reviewed of which seven met inclusion criteria. An additional 22 articles were identified from the references of the included articles, and 29 were retained. From the 29 articles, 68 patient-reported outcome measures were identified. The majority (75%) were multi-item scales that had been previously validated in existing literature. We identified four main areas of assessment: 1) physical health; 2) quality of life – general, physical, and psychosocial; 3) health promotion – physical activity, diet, and tobacco cessation; and 4) care quality outcomes.

**Conclusion:** There are a number of well-validated measures that assess patient-reported outcomes that document key aspects of long-term follow-up with respect to patient symptoms and quality of life. However, there are fewer patient-reported outcomes related to health promotion and care quality within the prevention, surveillance, and care coordination components of cancer survivorship. Future research should focus on development of additional patient-centered and patient-related outcomes that enlarge the assessment portfolio.

**Keywords:** prostate cancer, patient-reported outcomes, follow-up care, cancer survivorship, systematic review

## Introduction

Prostate cancer is the second most commonly diagnosed cancer globally.<sup>1</sup> As of January 1, 2012, the prostate cancer survivor population in the US approached 2.8 million survivors, approximately 43% of the entire male population of Americans with a history of cancer.<sup>2</sup> Approximately 62% are aged 70 and older<sup>3</sup> with multiple comorbid conditions. Further, the population of prostate cancer survivors has been steadily growing in the past 10 years<sup>4</sup> and increases by an estimated 200,000 men annually.<sup>2</sup> Prostate cancer rates vary widely worldwide with the highest incidence rates in North America and Europe attributed in large part to the diagnostic practice of prostate-specific antigen (PSA) testing at the population level.

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In the last decade, both prostate cancer screening and optimal treatments for early-stage prostate cancer have been the subject of intense debate.<sup>5-7</sup> In 2011, in response to accumulating data, both the US Preventive Services Task Force and the European Association of Urology recommended against the use of PSA-based testing for cancer screening, indicating with moderate-to-high certainty that this service was not beneficial and discouraged its clinical use in the general population.<sup>6,8</sup> In part, this response was due to lack of sensitivity of PSAs to discriminate indolent, slow-growing prostate cancers from those associated with increased morbidity and mortality,<sup>1,9,10</sup> as well as the psychosocial toll caused by false positives. The absence of evidence demonstrating clear benefits regarding the timing and types of treatments available on outcome<sup>11</sup> has increased patient and provider uncertainty regarding whether men should be screened and if diagnosed, what treatments to pursue.<sup>12</sup>

Regardless of existing screening recommendations, the number of prostate cancer survivors continues to increase.<sup>2,13</sup> In the US, over 90% of prostate cancers are diagnosed as localized, early-stage cancers, and the 5-year relative survival rate for patients with local disease is nearly 100%.<sup>14,15</sup> Treatment approaches range from noninvasive expectant approaches (active surveillance or watchful waiting) to radiologic therapies (radiotherapy, external beam radiologic therapy, brachytherapy, cryoablation), aggressive surgical procedures (open radical prostatectomy, laparoscopic prostatectomy with or without robotic assistance), and hormonal treatments (primary androgen deprivation therapy). Most localized prostate cancer patients choose to undergo active treatment rather than expectant strategies; the most common treatment pathways include either radical prostatectomy or radiotherapy.<sup>16</sup> Regardless of treatment type,<sup>17-20</sup> the survival benefits are high, including active surveillance,<sup>21</sup> though the late and long-term effects associated with each treatment vary. Symptomology in the majority of cases includes physical complications (ie, urinary, bowel, and sexual dysfunction), which are associated with long-term psychosocial morbidity.<sup>22,23</sup> The type of symptom profile may require different medical and follow-up care strategies and interventions<sup>24</sup> as well as a risk-based care approach.<sup>25,26</sup>

Until recently, clinical guidelines for the care of men with prostate cancer from leading organizations such as the National Comprehensive Cancer Center Network, American Society of Clinical Oncology and American Urological Association, and American Society for Radiation Oncology focused almost solely on prostate cancer screening and treatment with little attention to the survivorship phase of care.<sup>27</sup> However,

as patients move from active treatment into cancer survivorship and follow-up care, there are a number of physical and psychosocial factors related to prostate cancer treatment that continue to need management. In July 2014, the American Cancer Society released a set of prostate cancer survivorship guidelines to guide this phase of care.<sup>13</sup> A multidisciplinary group of experts was convened to evaluate and consolidate findings into clinical recommendations to address follow-up care based on 1) level of evidence, 2) consistency across studies, 3) dose response (for radiologic therapy findings), 4) racial disparities with potential to impact survivorship, and 5) second primary cancers.<sup>13</sup> The resulting guidelines cover health promotion (ie, informational needs, obesity, physical activity, nutrition, and smoking cessation), surveillance for recurrence, screening for second primary cancers, assessment and management of physical and psychosocial (ie, anemia, cardiovascular/metabolic effects, distress, anxiety/depression, fracture risk/osteoporosis, urinary dysfunction, and vasomotor symptoms), and care coordination.

Given the need to systematically assess prostate cancer patient-centered and patient-reported outcomes that are relevant to the post-acute treatment phase of follow-up care, it is critical to evaluate resources for assessing these outcomes. Many measures that are used currently have been developed to assess patient-reported outcomes for the active treatment phase or the earlier phases of survivorship. While there are a number of systematic reviews<sup>10,11,28-31</sup> that address prostate cancer from the screening and treatment perspectives, there are none, to our knowledge, that focus on the posttreatment and follow-up care phases. Therefore, the goal of this systematic review is to examine the current research literature focused on extended follow-up care to 1) document relevant studies and measures that could be used to delineate the prostate cancer patient-centered and patient-reported outcomes available, 2) assess the state of the science in terms of these measures, and 3) document the gaps in the literature where additional appropriate survivorship measures need to be developed.

## Methods

We searched the PubMed database which comprises more than 24 million citations for biomedical literature from MEDLINE, life science journals, and online books (<http://www.ncbi.nlm.nih.gov/pubmed>). The initial search was conducted in February 2014 and updated in August 2014 after the issuance of the American Cancer Society Prostate Cancer Survivorship Care Guidelines.<sup>13</sup> We used Endnote X7 reference software to conduct searches and manage

references and the article database. Time frame for the search was not limited. Terms used to generate articles for analysis in the searches included prostate cancer and the following: “follow-up”, “surveillance”, “monitoring”, “late effects”, “long-term effects”, “survivorship”, “quality of life”, “health-related quality of life”, “care coordination”, “care management”, “management”, “sexual side effects”, and “incontinence”.

All references and abstracts were downloaded into the Endnote X7 reference software library by two undergraduate research interns. All potentially eligible study abstracts were reviewed by two undergraduate research interns who were trained and supervised by SVH and DMO, a cancer prevention and control researcher and oncology social worker who had highly relevant research and clinical expertise. The coders received intensive training which consisted of reading a subset of abstracts and articles together, coding the articles for relevance based on criteria established by SVH and DMO, discussing interpretations of code definitions, and refining code definitions to maximize coder agreement. Once coders were clear about the inclusion and exclusion parameters, the coders were given access to all of the initial abstracts. All abstracts were reviewed independently by the two coders for relevance and fit with the review inclusion criteria: 1) original research; 2) focused on posttreatment follow-up care rather than active treatment or continued treatment of prostate cancer; 3) patient treatment was at least 2 years ago; and 4) focus on patient outcomes such as therapy, surgical, and/or quality of life (QOL). Articles were excluded from the analysis if they 1) were not published in English, 2) were solely qualitative and did not evaluate patient treatment outcomes, 3) assessed surgical equipment, 4) focused solely on screening, and/or 5) were not focused on treatment follow-up. Disagreements in classification of the articles were discussed and resolved by SVH and DMO.

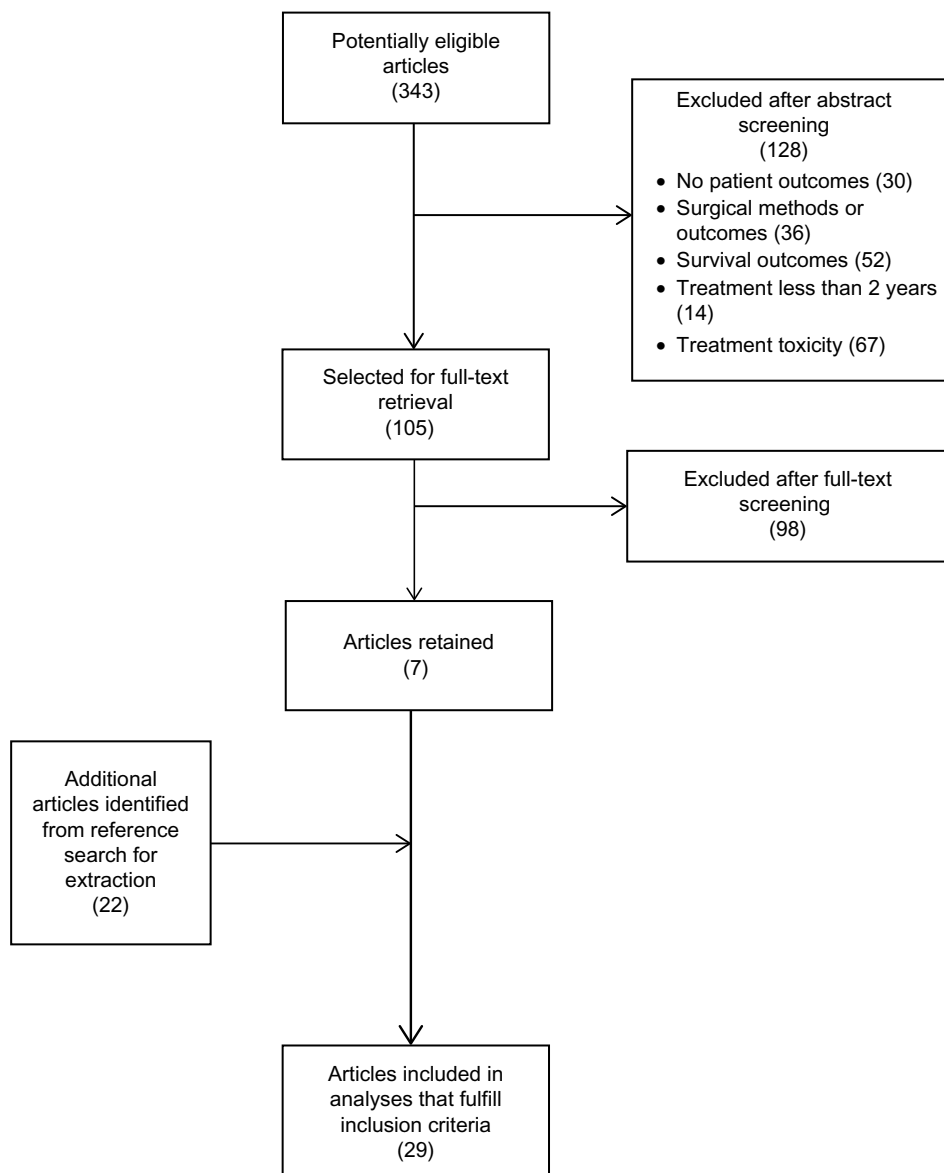
After the research interns reviewed each reference and abstract to select for review, they classified articles based on relevance and type of outcome. Using the groups feature in EndnoteX7, references were classified and coded as irrelevant if they included no patient outcomes, focused on surgical methods or outcomes or treatment toxicity, focused on survival outcomes, and/or focused on patients who had finished active treatment less than 2 years ago. Full text of articles that were assessed as relevant based on the initial review of their abstracts was uploaded into Endnote X7 for further review and analysis by SVH and DMO. A second round of review were conducted for the remaining selected for full-text review. The same exclusion

criteria were applied to the full text analyses. A total of seven articles remained that fit the inclusion criteria. In July 2014, the American Cancer Society issued Prostate Cancer Survivorship Care Guidelines.<sup>13</sup> The bibliography of this document as well as four additional systematic reviews<sup>32–35</sup> cited in the guideline on prostate cancer treatment was mined for additional relevant articles resulting in the final analytic dataset.

## Results

Figure 1 presents the process used to identify, screen, and select articles for inclusion in this review. The search terms initially yielded a total number of 343 references. The research interns reviewed each reference and abstract to select for review. Articles were organized by relevance and type of outcome. A total of 128 references were excluded based on the abstract review because of their lack of focus on patient outcomes or a limited focus on surgical outcomes or reporting of new surgical techniques, prostate cancer survival outcomes, active treatment toxicity, or focus on the active treatment period for prostate cancer. Several articles were classified in multiple categories; therefore, the number of articles reported in each subgroup exceeded the total number that were excluded. A total of 105 full-text articles were gathered and uploaded into Endnote X7. After the full text review, an additional 98 were excluded because the review of the text indicated that the focus of the articles was on patients in active prostate cancer treatment, were clinical reviews, or were epidemiological studies of the treatment profile of prostate cancer patients. At the conclusion of full text review, seven articles were retained. The American Cancer Society Prostate Cancer Survivorship Care Guidelines were also examined as a source of references in August 2014.<sup>13</sup> The bibliography of this document as well as four additional systematic reviews<sup>32–35</sup> cited in the guideline on prostate cancer treatment was mined for additional relevant articles resulting in the final analytic dataset. Review of the bibliographies yielded an additional 22 articles that met inclusion criteria for extraction. Therefore, a total of 29 articles were included in this review.

Most studies used survey and patient self-report measures to assess patient-centered and patient-reported outcomes for prostate cancer survivor populations (Table 1). Only four studies surveyed partners or spouses.<sup>36–39</sup> Studies were conducted using multiple design strategies including using population-based cohorts<sup>24,40–46</sup> and clinical-based<sup>137–39,47–58</sup> populations as well as one community-based study<sup>36</sup> and



**Figure 1** Diagram of study selection for review inclusion.

**Notes:** Articles that were excluded could be classified in multiple categories; therefore, the sum of the categories of articles excluded exceeds the total N.

one multinational clinical trial.<sup>59</sup> A number of studies used cohort designs and assessed outcomes in either cross-sectional or prospective, longitudinal study designs. Most studies focused on prostate cancer patients (72%, n=21) in contrast with 28% (n=8) that included prostate cancer patients as a subgroup within a larger study of cancer patients.

For the purpose of this review, patient-centered and patient-reported outcome measures from the studies have been categorized into several groups based on the initial sorting of studies (Table 2). We identified four main areas of assessment: 1) physical health including treatment outcomes from surgery, radiologic therapies, hormone,

or expectant management treatments; 2) QOL – general, physical (ie, urinary, bowel, sexual), and psychosocial (ie, mental health/emotional well-being and couples/partner focused); 3) health promotion – physical activity and diet; and 4) patient-reported care quality outcomes. Approximately 75% of studies used validated, multi-item scales that had been previously validated in existing literature to assess patient-reported outcomes.

## Physical health

Physical health is an important patient-centered outcome for prostate cancer survivors, many of whom struggle with comorbid conditions as well as late and long-term effects

**Table 1** Articles retained for their patient-reported measures related to prostate cancer follow-up care (N=29)

Study number	Citation reference	Study design	Prostate cancer focused	Prostate cancer nested within other populations	Patient-reported outcomes
1	Fowler et al <sup>41</sup>	National population based (n=1,072)	X	✓	American Urological Association Symptom Index (storage and urinary symptoms) Decisional regret (single item) General Health Index (GHI) Mental Health Index (MHI-5) Patient Ratings of Significance of Sexual Complications Patient Ratings of Significance of Urinary Complications Satisfaction with treatment choice (single item)
2	Sanson-Fisher et al <sup>65</sup>	Survey study (n=888) Clinic-based study	X	✓	Supportive Care Needs Survey (SCNS)
3	Pirl et al <sup>68</sup>	Survey study (n=45) Clinic-based study	✓	X	Beck Depression Inventory (BDI) Fatigue Severity Scale (FSS) Karnofsky Performance Scale (KPS) Structured Clinical Interview for DSM-IV (SCID, modules for major depression and dysthymia)
4	Raina et al <sup>47</sup>	Survey study (n=86) Clinic-based study	✓	X	Erectile Dysfunction Inventory of Treatment Satisfaction (EDITS) International Index of Erectile Function (IIEF-15) Patient satisfaction with erectile dysfunction treatment (2 items)
5	Raina et al <sup>58</sup>	Survey study (n=91) Clinic-based study	✓	X	Cleveland Clinic Post Prostatectomy Questionnaire Erectile Dysfunction Inventory of Treatment Satisfaction (EDITS) International Index of Erectile Function (IIEF-15) Patient satisfaction with erectile dysfunction treatment (two items)
6	Zakowski et al <sup>69</sup>	Survey (n=82) Clinic-based study	X	✓	Sexual Health Inventory for Men (SHIM) Emotional Expressivity Scale (EES) Impact of Events Scale (IES) Profile of Mood States (POMS) Social Constraints (15 items)
7	Johnson et al <sup>44</sup>	Population-based cohort study: Prostate Cancer Outcomes Study (n=2,075) Survey study	✓	X	Expanded Prostate Cancer Index Composite (EPIC-26); five items adapted on urinary function (single item) and bother (single item) and sexual function and bother (three items)
8	Raina et al <sup>57</sup>	Survey (n=49) Clinic-based study	✓	X	Cleveland Clinic Post Prostatectomy Questionnaire International Index of Erectile Function (IIEF-15) Sexual Health Inventory for Men (SHIM)
9	Miller et al <sup>48</sup>	Prospective cohort (N=709) Survey study Clinic-based study	✓	X	Expanded Prostate Cancer Index Composite (EPIC-26) RAND Corp Medical Outcomes Study Short Form-12 (SF-12)
10	Eakin et al <sup>43</sup>	Population-based cohort study: Australian National Health Survey (n=5,808 age- and sex-matched controls; n=968 prostate cancer cases)	X	✓	Kessler Psychological Distress Scale

(Continued)

**Table 1** (Continued)

Study number	Citation reference	Study design	Prostate cancer focused	Prostate cancer nested within other populations	Patient-reported outcomes
		Survey study			Number of Days out of role (single item) Quality of life (single item) Self-reported health (single item) Hospital Anxiety and Depression Scale (HADS)
11	Burnet et al <sup>49</sup>	Cross-sectional survey study (n=764)	✓	X	
12	Northouse et al <sup>37</sup>	Clinic-based study Randomized controlled trial (n=263 patient-spouse dyads) Survey study Clinic-based study	✓	X	Appraisal of Illness/Caregiving Scales  Beck Hopelessness Scale (20 items) Spouse Expanded Prostate Cancer Index Composite (S-EPIC) Expanded Prostate Cancer Index Composite (EPIC) Functional Assessment of Cancer Therapy – General (FACT-G) Functional Assessment of Cancer Therapy – Prostate (FACT-P) Lewis Mutuality and Interpersonal Sensitivity Scale Lewis Self-efficacy Scale Mishel Uncertainty in Illness Scale Omega Screening Questionnaire for distress Personal Resources Questionnaire Symptom Scale of the Omega Screening Questionnaire Appraisal of Illness/Caregiving Scales
13	Northouse et al <sup>38</sup>	Randomized controlled trial (n=263 patient-spouse dyads) Survey study Clinic-based study	✓	X	Beck Hopelessness Scale Brief Coping Orientations to Problems Experienced Scale Expanded Prostate Cancer Index Composite (EPIC) Functional Assessment of Cancer Therapy – General (FACT-G) Functional Assessment of Cancer Therapy – Prostate (FACT-P) Lewis Cancer Self-efficacy Scale Lewis Mutuality and Interpersonal Sensitivity Scale Medical Outcomes Study Short Form-12 (SF-12) Mishel Uncertainty in Illness Scale Omega Screening Questionnaire for distress Symptom Scale of the Omega Screening Questionnaire
14	McInnes et al <sup>46</sup>	Cross-sectional survey study (n=778); American Cancer Society's Study of Cancer Survivors-II (SCS-II) State cancer registry	X	✓	Barriers to cancer information (author developed; three items)  Consumer Assessment of Healthcare Providers and Systems Quality of cancer information (author developed; five items)

(Continued)

Table I (Continued)

Study number	Citation reference	Study design	Prostate cancer focused	Prostate cancer nested within other populations	Patient-reported outcomes
15	Schroeck et al <sup>53</sup>	Cross-sectional survey study (n=400) Clinic-based study	✓	X	Medical Outcomes Study Short Form-36 (SF-36) Rating of overall clinical care (single item) Decisional regret (single item)
16	Chen et al <sup>40</sup>	Cross-sectional survey study (n=409); State cancer registry	✓	X	Satisfaction with treatment choice (single item) Prostate Cancer Symptom Indices (PCSI)
17	Gacci et al <sup>54</sup>	Cross-sectional survey study (n=367) Clinic-based study	✓	X	UCLA Prostate Cancer Index (PCI)
18	Gore et al <sup>55</sup>	Cross-sectional survey study (n=475) Clinic-based study	✓	X	American Urological Association Symptom Index (AUASI) Medical Outcomes Study Short Form-36 (SF-36) UCLA Prostate Cancer Index (PCI)
19	Mols et al <sup>60</sup>	Cross-sectional survey study (n=403) Dutch cancer registry  Population-based study	X	✓	Quality of Life – Cancer Survivors (QOL-CS scale) Medical Outcomes Study Short Form-36 (SF-36) Work situation (author developed; single item)
20	Roeloffzen et al <sup>56</sup>	Prospective cohort study (n=127) Survey study  Clinic-based study	✓	X	American Urological Association (AUA) symptom index European Organization for Research and Treatment of Cancer core Questionnaire (EORTC QLQ-C30) European Organization for Research and Treatment of Cancer prostate cancer module (EORTC QLQ-PR25) International Prostate Symptom Score (IPSS) Medical Outcomes Study Short Form-36 (SF-36)
21	Linsky et al <sup>45</sup>	Cross-sectional, study (n=19,867); population-based cohort Massachusetts BRFSS	X	✓	Behavioral Risk Factor Surveillance System (BRFSS) survey items on: alcohol use (single item), physical activity (single item), and tobacco use (2 items)
22	Demark-Wahnefried et al <sup>59</sup>	Randomized controlled trial (n=641) Survey study  Multinational study with participants from the US, UK, and Canada	X	✓	24-Hour Dietary Intake (Healthy Eating Index 2005) Community Health Activities Model Program for Seniors questionnaire for Physical Activity Late-Life Function and Disability Index (Basic and Advanced Lower Extremity Function subscales only) Medical Outcomes Study Short Form-36 (SF-36)
23	Avery et al <sup>50</sup>	Prospective cohort study (n=3,935) Clinic-based study in the UK	✓	X	Food frequency questionnaire (FFQ) (114 items)
24	Harden et al <sup>36</sup>	Survey study (n=95 female spouses) Community-based study	✓	X	Appraisal of Caregiving Scale (ACS)  Caregiver Quality of Life Index – Cancer (CQOLC) scale

(Continued)



**Table 1** (Continued)

Study number	Citation reference	Study design	Prostate cancer focused	Prostate cancer nested within other populations	Patient-reported outcomes
25	Harden et al <sup>39</sup>	Survey study (n=121 partners) Clinic-based study	✓	X	Dyadic Adjustment Scale (DAS-4) Medical Outcomes Study Short-Form-12 (SF-12) Omega Screening Questionnaire Sexual satisfaction scale (SSS) (author developed, 3 items) Spouse Expanded Prostate Cancer Index Composite (S-EPIC) Appraisal of Caregiving Scale (ACS)  Caregiver Quality of Life Index – Cancer (CQOLC) Dyadic Adjustment Scale (DAS-4) Medical Outcomes Study Short-Form (SF-12) Omega Screening Questionnaire Sexual satisfaction scale (SSS) (author developed) Spouse Expanded Prostate Cancer Index Composite (S-EPIC)
26	Resnick et al <sup>24</sup>	Prostate Cancer Outcomes Study (n=1,655) Population-based cohort	✓	X	Bowel function and bother (author adapted from EPIC-26 used in prior studies) <sup>41,61,63</sup> Bowel urgency (single item) Bowel bother (single item)
27	Darwish-Yassine et al <sup>42</sup>	Cross-sectional, population-based cohort study (n=2,499); Michigan Cancer Registry Population-based cohort	✓	X	Expanded Prostate Cancer Index Composite (EPIC-26)
28	Reeve et al <sup>51</sup>	Prospective survey study (n=697) Clinic-based study	✓	X	Informational Sources (author developed) Preventive care receipt ICED comorbidity score  Prostate Cancer Symptom Indices (PCSI) Medical Outcomes Study Short Form-36 (SF-36) Medical Outcomes Study Short Form-12 (SF-12)
29	Santa Mina et al <sup>52</sup>	Retrospective cohort survey study (n=509) Clinic based study	✓	X	Godin–Shephard Leisure Time Exercise Questionnaire (GLTEQ) International Index of Erectile Function (IIEF) International Prostate Symptom Score (IPSS) Patient-Oriented Prostate Utility Scale (PORPUS)

**Note:** ✓ denotes presence, while X denotes absence.

of the disease and its treatment.<sup>13</sup> In the studies reviewed, there were 20 measures identified to assess physical health among prostate cancer survivors. The most commonly cited measures were the Medical Outcomes Study Short Form versions of the SF-36<sup>46,51,55,56,59</sup> including a Dutch version<sup>60</sup> and the SF-12<sup>36,37,39,48,51</sup> to assess physical health, emotional health, and general health. The Expanded Prostate Cancer

Index Composite (EPIC-26)<sup>24,37,42,53,61</sup> followed as the second most cited measure. With the exception of two self-reported health single-item measures,<sup>43,45</sup> the scales used in these studies were well-documented, well-validated scales that are used often in research studies. Of note, however, is that few studies included measures that provide data on or document comorbid health conditions.



**Table 2** Identified patient-reported measures related to prostate cancer follow-up care (n=68 discrete measures)**Physical health**

European Organization for Research and Treatment of Cancer core Questionnaire (EORTC QLQ-30; physical subscale; three symptom scales – nausea, vomiting, fatigue, and pain; six single-item scales – dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties)<sup>56</sup>  
 European Organization for Research and Treatment of Cancer prostate cancer module (EORTC QLQ-PR25) (treatment-related symptoms)<sup>56</sup>  
 Expanded Prostate Cancer Index Composite (hormonal symptoms scale; eleven items)<sup>37,42,53,61</sup>  
 Expanded Prostate Cancer Index Composite-26 (hormonal symptoms scale domain; four items)<sup>24</sup>  
 Fatigue Severity Scale (FSS)<sup>68</sup>  
 “For how many days in the past 30 days was your physical health not good?” (single item)<sup>45</sup>  
 Functional Assessment of Cancer Therapy – General (27 items; FACT-G)<sup>37</sup>  
 General Health Index (GHI; three items)<sup>41</sup>  
 Karnofsky Performance Scale (KPS)<sup>68</sup>  
 Late-Life Function and Disability Index (basic and advanced lower extremities scales)<sup>59</sup>  
 Medical Outcomes Study Short Form (SF-12; physical functioning subscale six items)<sup>36,37,39,48,51</sup>  
 Medical Outcomes Study Short Form (SF-36; physical functioning subscale, ten items; bodily pain, two items; energy/fatigue, four items; general health perceptions, six items)<sup>46,51,55,59</sup>  
 Medical Outcomes Study-36 (SF-36; Dutch version)<sup>60</sup>  
 Number of days out of role in past 2 weeks (single item)<sup>43</sup>  
 Omega Screening Questionnaire/Risk for Distress Scale (health history scale)<sup>36,39</sup>  
 Patient Oriented Prostate Utility Scales (PORPUS; pain, energy, relationship with doctor)<sup>52</sup>  
 Quality of Life – Cancer Survivors (QOL-CS, Dutch version; physical well-being scale; eight items)<sup>60,70</sup>  
 RAND-36 generic health survey (physical role restriction; physical problems; general health, two items)<sup>56</sup>  
 Self-reported health (single item)<sup>43</sup>  
 Supportive Care Needs Survey (SCNS; 59 items in across five domains: physical and daily living)<sup>65</sup>

**Quality of life**

## General

“Can you think of any additional ways that being treated for prostate cancer has affected your quality of life?” (single item)<sup>71</sup>  
 European Organization for Research and Treatment of Cancer Core Questionnaire (EORTC QLQ-30; a global QOL scale)<sup>56</sup>  
 Functional Assessment of Cancer Therapy – Prostate (FACT-P)<sup>37</sup>  
 Medical Outcomes Study 12-item Short Form (SF-12)<sup>36,37,39,48,51</sup>  
 Medical Outcomes Study Short Form (SF-36)<sup>46,51,55,59</sup>  
 Medical Outcomes Study-36 (SF-36; Dutch version)<sup>60</sup>  
 Patient Oriented Prostate Utility Scales (PORPUS)<sup>52</sup>  
 Quality of Life (single item)<sup>43</sup>  
 Quality of Life – Cancer Survivors (QOL-CS, Dutch version; 44 items; overall quality of life scale)<sup>60</sup>  
 RAND-36<sup>56</sup>

## Urinary/bowel

American Urological Association Symptom Index (storage and urinary symptoms)<sup>55,56,64</sup>  
 European Organization for Research and Treatment of Cancer prostate cancer module (EORTC QLQ-PR25; urinary symptoms/problems, bowel symptoms/problems)<sup>56</sup>  
 Expanded Prostate Cancer Index Composite (urinary, 12 items; bowel, 14 items)<sup>37,42,61</sup>  
 Expanded Prostate Cancer Index Composite-26 (scales: urinary irritative-obstructive, urinary incontinence, bowel; 15 items)<sup>24,44,48,62</sup>  
 International Prostate Symptom Score (IPSS; seven items)<sup>52,56</sup>  
 Patient Oriented Prostate Utility Scales (PORPUS) (urinary frequency, incontinence, bowel function)<sup>52</sup>  
 Patient Ratings of Significance of Urinary Complications (number of items unspecified)<sup>41</sup>  
 Prostate Cancer Symptom Indices (PCSI; indices: bowel problems, urinary incontinence, urinary obstruction/irritation; item number not specified)<sup>40,51</sup>  
 UCLA Prostate Cancer Index (urinary function/bother, 6 items; bowel function/bother, 5 items)<sup>24,54,55,63</sup>

## Sexuality

Erectile Dysfunction Inventory of Treatment Satisfaction (EDITS)<sup>47,58</sup>  
 European Organization for Research and Treatment of Cancer prostate cancer module (EORTC QLQ-PR25; sexual functioning; sexual bother)<sup>56</sup>  
 Expanded Prostate Cancer Index Composite (sexual function/bother, 13 items)<sup>37,42,61</sup>  
 Expanded Prostate Cancer Index Composite-26 (six items)<sup>24,44,\*</sup>  
 International Index of Erectile Function (IIEF-15)<sup>47,52,57,58</sup>  
 Patient Oriented Prostate Utility Scales (PORPUS; sexual function and desire)<sup>52</sup>  
 Patient Ratings of Significance of Sexual Complications (number of items unspecified)<sup>41</sup>  
 Patient satisfaction with Erectile Dysfunction Treatment (two items)<sup>58</sup>  
 Prostate Cancer Symptom Indices (PCSI; sexual dysfunction index)<sup>40,51</sup>  
 Supportive Care Needs Survey (SCNS; 59 items in across five domains: sexuality)<sup>65</sup>

(Continued)

**Table 2** (Continued)

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Sexual Health Inventory for Men (SHIM) (five-item abridged version of IIEF-15)<sup>47,57,58</sup>  
 Sexual satisfaction scale (SSS; three items, author developed)<sup>36,39</sup>  
 UCLA Prostate Cancer Index (sexual function/bother, nine items)<sup>54,55,63,\*</sup>

**Mental health/emotional/social well-being**  
 Appraisal of Illness Scale (27 items)<sup>37</sup>  
 Beck Depression Inventory (BDI)<sup>68</sup>  
 Beck Hopelessness Scale (20 items)<sup>37</sup>  
 Brief Coping Orientations to Problems Experience Scale (28 items)<sup>37</sup>  
 Emotional Expressivity Scale (EES; 17 items)<sup>69</sup>  
 Hospital Anxiety and Depression Scale (HADS; 14 items; anxiety, seven items; depression, seven items)<sup>49</sup>  
 Impact of Events Scale (IES)<sup>69</sup>  
 Kessler Psychological Distress Scale<sup>43</sup>  
 Lewis Cancer Self-efficacy Scale<sup>37</sup>  
 Medical Outcomes Study Short Form (SF-12) (emotional well-being, six items)<sup>37,48</sup>  
 Medical Outcomes Study Short Form (SF-36)<sup>55</sup> (social functioning, two items; emotional well-being, five items; role limitations – emotional, five items)<sup>46,55</sup>  
 Mental Health Index (MHI-5; five items psychological well-being)<sup>41</sup>  
 Mishel Uncertainty in Illness Scale (28 items)<sup>37</sup>  
 Patient Oriented Prostate Utility Scales (PORPUS; psychosocial and social well-being)<sup>52</sup>  
 Profile of Mood States (POMS; 17 items)<sup>69</sup>  
 Quality of Life – Cancer Survivors (QOL-CS, Dutch version; 18-item psychological well-being scale; ten-item social well-being scale; eight-item spiritual well-being)<sup>60</sup>  
 RAND-36 generic health survey (scales: social role restriction; emotional problems; well-being)<sup>56</sup>  
 Risk for Distress (inventory of current concerns; 16-item symptom scale)<sup>37,39</sup>  
 Social Constraints (15 items)<sup>69</sup>  
 Structured Clinical Interview for DSM-IV (SCID, modules for major depression and dysthymia)<sup>68</sup>  
 Supportive Care Needs Survey (SCNS; 59 items in across five domains: psychological)<sup>65</sup>  
 Work situation (single item, author developed)<sup>60</sup>

**Couples**  
 Appraisal of Caregiving Scale (27 items)<sup>37</sup>  
 Appraisal of Caregiving Scale, modified (ACS; nine items)<sup>36,39</sup>  
 Caregiver Quality of Life Index (CQOLC; 35 items)<sup>36,39</sup>  
 Cleveland Clinic Post Prostatectomy Questionnaire (sexual satisfaction of spouses/partners)<sup>47,57</sup>  
 Dyadic Adjustment Scale (DAS-4; couples satisfaction, four items)<sup>36,39</sup>  
 Lewis Mutuality and Interpersonal Sensitivity Scale (32 items)<sup>37</sup>  
 Spousal/partner sexual satisfaction<sup>58</sup>  
 Spouse Expanded Prostate Cancer Index Composite (S-EPIC, spouses perception of bother PCa symptoms, six items)<sup>36,37,39</sup>

**Health promotion**  
 24-Hour recall dietary intake (unannounced; using Nutrition Data System for research Software)<sup>59</sup>  
 Alcohol use (30-day recall)<sup>45</sup>  
 Community Health Activities Model Program for Seniors Questionnaire (physical activity)<sup>59</sup>  
 Food Frequency Questionnaire (114 items)<sup>50</sup>  
 Godin–Shephard Leisure Time Exercise Questionnaire (GLTEQ; physical activity scale; three items)  
 Healthy Eating Index 2005 (dietary quality)<sup>59</sup>  
 Physical Inactivity (Behavioral Risk Factor Surveillance System [BRFSS], single item)<sup>45</sup>  
 Tobacco use (Behavioral Risk Factor Surveillance System [BRFSS], two items)<sup>45</sup>

**Patient-reported care quality outcomes**  
 Consumer Assessment of Health Providers and Systems (six items adapted)<sup>46</sup>  
 Decisional regret (author developed; single item)<sup>41,53</sup>  
 Informational sources (items not described)<sup>42</sup>  
 Overall rating of Clinical Cancer Care (single-item)<sup>46</sup>  
 Perceptions about the Quality of Cancer Information (informational quality, five items; barriers to cancer information, three items)<sup>46</sup>  
 Ratings of physician: communication, provision of emotional support, shared decision-making, being informed about patients care, spending time to answer questions, providing instructions to manage side effects (number of items not specified)  
 Receipt of preventative care (diagnostic tests for PSA and DRE for follow-up)<sup>42</sup>  
 Satisfaction with treatment choice (satisfaction with treatment; single item)<sup>41,53</sup>  
 Supportive Care Needs Survey (SCNS; 59 items in across five domains: health system and information; patient care and support)<sup>65</sup>

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**Notes:** \*Adaptations of these instruments were used in Resnick et al and Johnson et al.<sup>24,44</sup> In Johnson et al,<sup>44</sup> for each domain (urinary, sexual, and bowel function), there were four to five questions about level of functioning and a single item about how much each symptom was problematic.

**Abbreviations:** QOL, quality of life; PSA, prostate-specific antigen; PCa, prostate cancer; DRE, digital rectal exam.

## Quality of life

QOL was the construct with the most robust measurement in terms of patient-centered and patient-reported outcomes. Three domains of QOL were measured across the studies – general, physical, and psychosocial.

General QOL was most often measured using the SF-36<sup>46,51,55,56,59,60</sup> and SF-12.<sup>36,37,39,48,51</sup> Additional general measures included the European Organization for Research and Treatment of Cancer core Questionnaire (EORTC QLQ-30; a global QOL scale),<sup>56</sup> the Functional Assessment of Cancer Therapy – General,<sup>37,38</sup> the Functional Assessment of Cancer Therapy – Prostate (FACT-P),<sup>37,38</sup> the Patient Oriented Prostate Utility Scales (PORPUS),<sup>52</sup> and a Dutch version of the Quality of Life – Cancer Survivors (QOL-CS).<sup>60</sup>

Physical QOL measures were found to relate to three key areas of physical functioning associated with prostate cancer (ie, urinary, bowel, sexual). Urinary and bowel issues were often measured in tandem. The most commonly used measures were the Expanded Prostate Cancer Index Composite (EPIC-26; urinary, 12 items; bowel, 14 items)<sup>24,37,42,48,61,62</sup> followed by the University of California, Los Angeles Prostate Cancer Index (urinary function/bother, six items; bowel function/bother, five items)<sup>24,54,55,63</sup> and the American Urological Association Symptom Index (bladder storage and urinary symptoms).<sup>55,56,64</sup> Sexuality was addressed in terms of sexual function and sexual bother. The International Index of Erectile Function (IIEF-15)<sup>47,52,57,58</sup> and a five-item abridged version of the IIEF-15 entitled the Sexual Health Inventory for Men (SHIM)<sup>47,57,58</sup> were used most often to assess sexual function and bother. In addition to these measures, subscales of the Expanded Prostate Cancer Index Composite (EPIC-26)<sup>24,37,42,61</sup> and the UCLA Prostate Cancer Index<sup>54,55,63</sup> were also used to assess sexual functioning.

Psychosocial QOL measures including mental health and emotional well-being and couples-/partner-focused QOL were assessed fairly comprehensively across the studies. A total of 20 measures were included in the studies that assessed mental health/emotional well-being. Again, the Medical Outcomes Study Short Form versions of the SF-36<sup>46,55,56</sup> and the SF-12<sup>37,48</sup> were the most widely used measures to address emotional health. A total of eight measures of couples-related QOL were found in studies. The most often cited measures were the Spouse Expanded Prostate Cancer Index Composite (S-EPIC),<sup>36,37,39</sup> a six-item scale that was referenced in three studies, and the four-item Dyadic Adjustment Scale (DAS-4).<sup>36,39</sup>

## Health promotion

The American Cancer Society prostate cancer survivorship guidelines have established health promotion guides for prostate cancer survivors around nutrition, physical activity, alcohol consumption, and tobacco use. They counsel that survivors should achieve and maintain a healthy weight through diet and physical activity. We found several studies that addressed these health promotion and behavioral outcomes.<sup>45,50,59</sup> Physical and dietary assessments used in the studies were validated.<sup>45,50,59</sup> The tobacco use items were fielded as part of the Centers for Disease Control's Behavioral Risk Factor Surveillance System (BRFSS) Survey.<sup>45</sup>

## Care quality outcomes

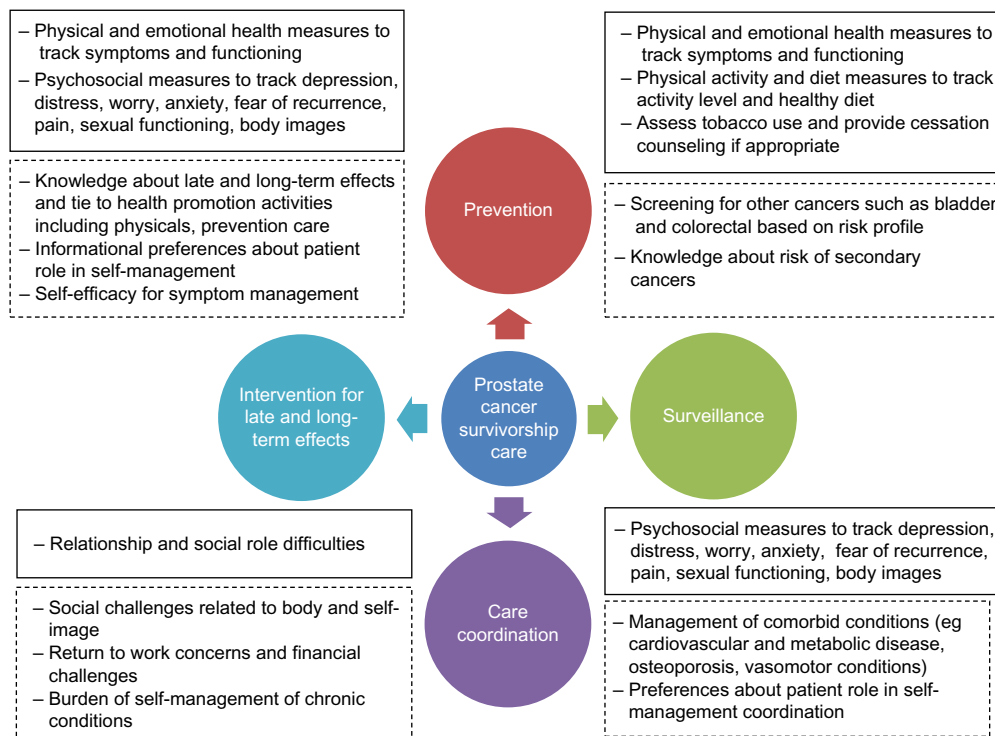
In contrast with the other areas, the care quality measures were not as well developed or disseminated. There were nine measures documented in studies. Two were confirmed as multi-item scales.<sup>46,65</sup> The others were mainly single-item measures and author constructed. There were little data available on the psychometric properties of these measures.

In summary, the areas of physical health and QOL have a number of well-established, validated measures to choose from for patient-centered and patient-reported outcomes research. There are, however, far fewer resources available for assessing health promotion and care quality patient-centered and patient-reported outcomes for prostate cancer survivorship and long-term follow-up.

## Discussion

To our knowledge, this paper presents the first synthesis of the existing literature on prostate cancer patient-centered and patient-reported outcomes for follow-up care. In this review, we identified 68 patient-reported outcome measures that have been used in studies of prostate cancer follow-up care. While we reviewed a number of measures available for assessing both QOL and physical health in terms of functioning and symptom management, there were far fewer measures that addressed other key components of cancer survivorship. Figure 2 presents a schema of the recommended components of prostate cancer follow-up care with summaries of the content areas for which there are current measures, as well as highlights areas for which there are fewer resources.

In the areas of prevention and surveillance, the current review identified a number of measures (eg, SF-36, SF-12, EPIC-26) in the domains of physical health and QOL that allow patients to comprehensively track symptoms with regard to multiple dimensions of physical and emotional health. As well, several health promotion measures related to



**Figure 2** Recommended components of follow-up care for prostate cancer survivors.

**Notes:** Items in solid boxes are addressed by measures reported in this paper. Dotted lines are criteria not well addressed in the current literature.

diet, nutrition, physical activity,<sup>45,50,59</sup> and tobacco use were identified.<sup>45,50,59</sup> However, lacking in this individualized tracking of symptoms and activities was an organizing framework for collating patient-centered and patient-related outcomes data into a comprehensive, health services approach to health promotion. This is one of the foremost challenges to providing optimal prostate cancer follow-up care. As currently constructed, patient-centered and patient-related outcomes provide comprehensive measures of discrete systems (eg, bowel and urinary) and acute and chronic treatment-related symptoms. To be optimally effective, these outcomes need to be examined and explored in context with comorbid diseases including conditions that patients are managing in addition to a risk-stratified cancer survivorship context.<sup>25,26</sup> Such an approach would focus on prostate cancer survivors' cancer-related risk profiles as well as other health considerations that put them at risk for new and secondary cancers and might exacerbate ongoing late and anticipated long-term treatment effects. A risk-stratified approach to management of these and other comorbid conditions would prioritize various screenings for prevention and health promotion. This is an area in which development of additional patient-centered and patient-reported outcomes that focus on providing such risk stratification would benefit both patients and their providers.

In the survivorship domains of surveillance, care coordination, and intervention for late and long-term effects, relevant QOL measures were identified. Psychosocial measures that address patient issues related to depression, distress, worry, anxiety, fear of recurrence, sexual functioning, and body image were documented. Similarly, physical symptom tracking related to various treatment modalities was well documented. However, management of comorbid conditions, which is a particular concern for the prostate cancer survivorship experience, was largely unaddressed by the current measures. There are unfolding health conditions that plague prostate cancer survivors, including cardiovascular and metabolic disease, osteoporosis, and vasomotor conditions.<sup>13</sup> Many of these conditions, as well as those that pre-date their prostate cancer, require patients to play an active role in self-management to supplement clinician monitoring. To be effective and active in their care, patients need to 1) be knowledgeable about late and long-term effects and how they are tied to health promotion activities such as general physicals and prevention care, 2) have a sense of self-efficacy to manage lingering and new symptoms that are related to previous prostate cancer treatments, and 3) be able to process health promotion information to engage effectively in a self-management role in their cancer survivorship.<sup>66,67</sup> For example, the American Cancer Society prostate cancer

survivorship guideline<sup>13</sup> suggests that screening for bladder and colorectal cancer be implemented for certain subpopulations of prostate cancer survivors based on their treatment profile. Data from our previous studies of cancer survivorship in this population<sup>66,67</sup> suggest that survivors' knowledge about the risks of secondary cancers, as well as late and long-term effects of cancer treatment, is variable with few men having a comprehensive understanding of the range of issues. Additional measures are needed to assess and address these central components of cancer survivorship.

Two final areas in which there are needs for further development of patient-centered and patient-related outcomes include the changes in social roles that come about as part of extended prostate cancer survivorship and assessing care quality from a cancer survivorship perspective. While there are measures of social role and dyadic relationship difficulties in the current literature, social challenges related to body image and self-image, their impact on returning to work, and the financial burden of prostate cancer survivorship are not comprehensively addressed. Similarly, available care quality measures related to follow-up care and cancer survivorship are not as well developed or disseminated as the physical functioning and QOL measures. These are critical gaps in the measurement portfolio that require future research.

The purpose of this review was to identify studies and measures that utilize prostate cancer patient-centered and patient-reported outcomes, to assess the evidence base supporting these measures, and to document the gaps in the literature. Therefore, it is beyond the scope of this study to recommend or advocate for the use of specific measures. We cannot objectively assess which measures may be better or ill suited for future research in long-term survivors for two reasons. First, one size does not fit all. Depending on the study context and level of focus on patient, provider, clinical practice, and/or health system targets, a survey instrument or clinical measure that performs well in one setting as a patient-centered or patient-reported outcome measure may be ill suited in another. Second, the empirical measures identified in this study suggest that while some areas (eg, symptoms from treatment and associated distress) are well developed, other significant domains of the patient experience of survivorship are lacking. The empirical database of patient-centered and patient-reported outcomes among prostate survivors needs to be further developed before an effective evaluation of which measures are better suited for future research can be effectively conducted.

There are four limitations of this review that should be noted. First, the focus on prostate cancer survivorship is

novel as an area of focus with respect to patient-centered and patient-related outcome measures. The concept of extended survivorship and examining the emerging and growing needs of survivors who are not currently receiving active treatment for prostate cancer is novel. Therefore, it was difficult to identify studies for this review. Prior studies and reviews centered on active treatment and the transition period immediately following active treatment as key foci for intervention. We chose to limit our search of studies to those that included populations that were at least 2 years post-active treatment so that studies reported comprised long-term survivor populations. Most of the studies that met these criteria were studies that were included in the American Cancer Society Prostate Cancer Survivorship Care Guidelines. It is possible that had we chosen a different benchmark that additional studies may have been included in the review, and the resulting domain mapping of content areas may have been different. Second, only English language studies were included in the review; therefore, there is a possibility that there may have been additional studies that were not conducted in English that may be relevant. Third, the majority of the samples reviewed comprised primarily White and Caucasian men. While there was one study that focused on racial differences,<sup>44</sup> it is not clear that the patient-centered and patient-reported outcomes were the most relevant to ethnic and racial minority men. Finally, there is the possibility that an article or abstract may have been inadvertently excluded during abstract reviews. However, our method of having abstracts triaged by two pairs of research assistant reviewers followed by additional reviews from two senior investigators significantly decreased this possibility.

## Conclusion

The studies reviewed reflect variation in setting, design, and measurement of patient-centered and patient-reported outcomes and are informative about the state of the science in prostate cancer follow-up care. A major conclusion is that there is little research focused on long-term follow-up care and patient-centered outcomes for prostate cancer patients; therefore, future research needs to focus on adding to the available measurement and evidence bases of patient-centered and patient-reported outcomes. While the current measures are largely well established and well validated in the physical health areas of prevention and surveillance as well as QOL, there are fewer measures that comprehensively address factors that impact survivorship care, notably: 1) patient knowledge about late and long-term treatment effects and ability to link this knowledge to health promotion



activities including physicals and prevention care; 2) patient informational preferences regarding patient role in self-management; 3) self-efficacy expectations about symptom management skills; 4) the challenge of self-management of chronic conditions; and 5) social challenges related to body image and self-image as well as work concerns and financial challenges. Development of these tools will provide providers, patients, and other health care stakeholders with basic patient-related outcomes to better track long-term cancer survivorship progress and strategies.

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## Disclosure

None of the authors have any potential conflicts of interest to disclose.

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