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Towards a National Initiative in Cancer Rehabilitation: Recommendations from a Subject Matter Expert Group

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Title: Towards a National Initiative in Cancer Rehabilitation: Recommendations from a Subject Matter Expert Group.**Running Head: Cancer Rehabilitation: Recommendations**

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1 Abstract:

2 The health care delivery system in the United States is challenged to meet the needs of a growing
3 population of cancer survivors. A pressing need is to optimize overall function and reduce
4 disability in these individuals. Functional impairments and disability impact a majority of
5 patients during and after disease treatment. Rehabilitation health care providers can “diagnose
6 and treat patients’ physical, psychological, and cognitive impairments in an effort to maintain or
7 restore function, reduce symptom burden, maximize independence and improve quality of life in
8 this medically complex population.” However, few care delivery models integrate
9 comprehensive cancer rehabilitation services into the oncology care continuum.

10 The Rehabilitation Medicine Department of the Clinical Center at the National Institutes of
11 Health with support from the National Cancer Institute and the National Center for Medical
12 Rehabilitation Research convened a subject matter expert group to review current literature and
13 practice patterns, identify opportunities and gaps regarding cancer rehabilitation and its support
14 of oncology care, and to make recommendations for future efforts that promote quality cancer
15 rehabilitation care. The recommendations suggest stronger efforts towards integrating cancer
16 rehabilitation care models into oncology care from the point of diagnosis, incorporating
17 evidence-based rehabilitation clinical assessment tools, and including rehabilitation professionals
18 in shared decision making in order to provide comprehensive cancer care and maximize the
19 functional capabilities of cancer survivors. These recommendations aim to enable future
20 collaborations among a variety of stakeholders to improve the delivery of high quality cancer
21 care.

22 **Keywords:** cancer, rehabilitation, physical function, health care delivery, research agenda,
23 survivorship

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34 **Introduction**

35 Cancer survivors are a growing population in the United States with a unique set of medical and
36 psychosocial needs.¹ These individuals frequently experience functional loss and disability due
37 to the side effects of disease and treatment.²⁻⁵ A majority of individuals experience cancer
38 treatment-related functional morbidity that is amenable to rehabilitation services.⁶⁻¹² However
39 appropriate rehabilitation services that effectively alleviate or mitigate functional impairment and
40 prevent disability are significantly underutilized in all phases of cancer care.^{8,13} The unmet needs
41 of cancer survivors are generally attributed to deficits in comprehensive cancer care delivery, and
42 more specifically to the providers' focus on achieving progression-free survival or remission
43 rather than on maintaining function.^{14,15}

44
45 Historically, the oncology care continuum has had little intersect with rehabilitation outside of
46 severe disability.¹⁶ Recent calls have been made for this relationship to be robustly developed to
47 meet the needs of cancer survivors.^{17,18} A focus on assessment and management of physical
48 health and function is needed to promote improved Health Related Quality of Life (HRQOL).^{19,20}
49 Recommendations and standards from the Institute of Medicine (IOM) and the American
50 College of Surgeons' Commission on Cancer (CoC), among others, provide a framework for
51 alleviating deficits in cancer care and the resulting failures to recognize and manage functional
52 loss and disability.²¹⁻²³

53
54 Rehabilitation professionals are an optimal addition to the cancer care team and offer expertise in
55 functional assessment, morbidity management, and disability prevention.²⁴ Accumulating
56 clinical evidence suggests that rehabilitation interventions are effective before, during, and after
57 cancer treatment to screen for, assess, and treat patients' functional needs.²⁵⁻³⁸ Although
58 mounting evidence suggests strong benefit from the integration of rehabilitation into the cancer
59 continuum,^{39,40} there is uncertainty around the critical components of a model for cancer
60 rehabilitation. Although functional assessment and measurement frameworks have been
61 described,⁴¹ optimal functional measurement constructs remain undefined. These issues are
62 barriers to the successful integration of rehabilitation services into the cancer care continuum.

63 **Methods**

64 In 2014, an appointed Dissemination Taskforce of the Rehabilitation Medicine Department
65 (RMD) of the Clinical Center (CC) at the National Institutes of Health (NIH) was charged with
66 identifying an emerging area of rehabilitation practice where the unique resources of the NIH CC

67 could be leveraged to support practice development. The Taskforce identified cancer
68 rehabilitation as the primary area of need and recommended that the NIH CC RMD take on a
69 focused effort to scope i) the evidence-base and practice standards supporting clinical aspects of
70 cancer rehabilitation care, ii) gaps and needs for the field, and iii) recommendations that could
71 inform key stakeholders future planning around national initiatives in cancer rehabilitation.
72 Based on the Taskforce recommendation, NIH CC RMD convened an interdisciplinary group of
73 Subject Matter Experts (SME) in cancer rehabilitation from across the United States to
74 participate in this exercise. The SME group included: both internal and external NIH
75 participants, researchers and clinical experts in cancer rehabilitation, and representation from the
76 National Cancer Institute and the National Center for Medical Rehabilitation Research of the
77 Eunice Kennedy Shriver National Institute of Child Health and Human Development.

78
79 The SME group identified four domains germane to understanding the current environment of
80 cancer rehabilitation practice in the United States:

- 81 *1. Cancer rehabilitation clinical models*
- 82 *2. Patient reported outcomes measures*
- 83 *3. Clinical objective measures of function*
- 84 *4. Interdisciplinary integration of rehabilitation*

85
86 The SME group divided into four smaller work groups based on these topic areas. Individuals
87 self-selected areas of participation based on interest and expertise. The work groups were
88 charged with scoping the existing environment in each domain and identifying relevant gaps in
89 rehabilitation knowledge base and current clinical practice. Systematic reviews were not
90 practical due to the varied focus within each domain and the overall scope of the project.

91

92 Each group explored information of relevance to their domain through publications, grey
93 literature, experience, and peer queries. Key words and phrases were developed and agreed upon
94 within groups to identify literature and information of interest. Individuals within each work
95 group conducted literature searches of relevant information sources. Findings were shared among
96 work group members and consensus was used to identify pertinent information to inform
97 recommendations. Individual work group findings were shared with the full SME group for
98 further synthesis, discussion, and development of overall group recommendations. No specific
99 mechanism for quantitative synthesis was used.

100

101 A synopsis of findings was presented in June 2015 at a Cancer Rehabilitation Symposium at the
102 National Institutes of Health in Bethesda, Maryland and video cast over the World Wide Web.
103 The purpose of this manuscript is to provide the work group findings and SME key
104 recommendations for enhancing the provision of rehabilitation services through the cancer care
105 continuum.

106 **Cancer Rehabilitation Clinical Models**

107 *Post-Acute Care*

108 Post-acute cancer rehabilitation is provided in inpatient rehabilitation facilities, skilled
109 nursing facilities, long-term care hospitals, and hospice facilities. The rehabilitation service
110 conducts a formal functional assessment to identify impairments and provides a range of services
111 such as psychiatry, physical therapy, occupational therapy, speech therapy, nutrition, psychology,
112 and nursing to assist in optimizing an individuals function.⁴² Such programs demonstrate
113 clinically effective care delivery and improved functional outcomes that are often maintained
114 following program completion.⁴³⁻⁴⁷ While the post-acute rehabilitation model provides
115 comprehensive rehabilitation services guided by a coordinated plan of care, this care plan is
116 typically divorced from the oncology care plan and only in rare circumstances does one inform
117 the other. Aside from a few specialty centers in the United States, there is notable variation in

118 the services provided for oncology patients and a general lack of comprehensive rehabilitation
119 care specific to their unique needs.⁴⁸ Additional factors that limit sub-acute rehabilitation
120 services include payer limitations and provider awareness and attitudes regarding the benefits of
121 rehabilitation.^{49,50}

122

123 *Home Care*

124 Home-based care models may include multiple medical and rehabilitative disciplines but care
125 coordination challenges impede the comprehensive care provided in other co-located service
126 models. Home-based models are typically nurse-driven with nursing staff providing initial
127 assessment and treatment planning.⁵¹ Home-based nursing models focus on the consistent use of
128 screening tools and clearly defined recommendations for interventions or referral. However, if
129 home care services focus primarily on a functional limitation, the plan of care includes physical
130 and occupational therapy, often without nursing involvement. Due to the uncertainty of provider
131 roles and expertise, well articulated cancer-specific care components should be a part of
132 comprehensive cancer care plan rather than be attributed to an individual practitioner's role.
133 Lacking in this model is a concerted effort to identify the unique and additional needs of cancer
134 patients with regard to screening, intervention, and follow up for cancer treatment-related
135 morbidity and toxicities that impact function.⁵²

136

137 *Outpatient Ambulatory Care*

138 Consistent, comprehensive care in the outpatient setting is a logical extension of the post-acute
139 model and complements the delivery of outpatient ambulatory oncology care through functional
140 screening and monitoring for late effects as well as providing interdisciplinary intervention to

141 alleviate functional deficits. Outpatient ambulatory models for cancer rehabilitation care are
142 clinically effective,^{53,54} promote identification and management of treatment toxicities that
143 impact function,^{25,26,55-58} and demonstrate positive impact on functional outcomes.^{37,39,59,60}

144
145 Multidimensional rehabilitation program models (MDRPs) strive to address both physical and
146 emotional needs of patients. A multidimensional approach is more likely to help patients cope
147 with their physical needs.⁶¹ MDRPs involve interval face-to-face and phone contact between a
148 patient and a rehabilitation health professional, such as a physiatrist, nurse, physical or
149 occupational therapist.⁶¹

150
151 Ambulatory cancer rehabilitation programs however have wide variance in the service offerings
152 and little consistency as to the timing of intervention, coordination with other medical providers,
153 coordination with the cancer care plan, and follow up. Adaptation of the Cardiac Rehabilitation
154 (CR) model for use in oncology rehabilitation has been suggested as a model^{62,63} as the tenants of
155 CR including rehabilitation, treatment sequelae management, and healthy lifestyle development⁶⁴
156 are common to oncology rehabilitation. However, limited data are available to support this
157 approach. Emerging evidence supports the geriatric model of care and geriatric assessment as a
158 framework that could guide rehabilitation screening, assessment, and intervention in the
159 ambulatory care setting for the cancer population.^{11,65} The main features of this model including:
160 the focused attention to interdisciplinary input, the inclusion of non-medical domains like care
161 giver status and home environment assessment, and the emphasis on functional capacity and
162 quality of life, make this an ideal framework to portray a holistic view of the many aspects of an
163 individuals life that contribute to their overall functioning. Further work and research is needed

164 by the rehabilitation community to identify and incorporate supportive elements of the geriatric
165 care model.

166

167 Models for cancer rehabilitation exist across the United States but no consensus exists on the
168 core components that comprise comprehensive cancer rehabilitation. Shortcomings with these
169 programs are that they are narrow in scope, focusing on one aspect of individual care, and
170 neglect to provide the full range of services needed to restore function for the cancer survivor.⁶⁶
171 Many programs fail to provide comprehensive, interdisciplinary assessment and intervention,
172 and the workforce may be minimally trained to address the complex needs of the cancer
173 population. Further, these models fail to address the essential components of survivorship care
174 plans as articulated by policy bodies.

175

176 Cancer survivorship care plans outline the critical components of cancer care that should be
177 documented and provided to the patient and the health care team during and after the continuum
178 of cancer treatment.²² Additional elements including: psychosocial care, symptom management,
179 and health promotion augment comprehensive care.⁶⁷ Rehabilitation is a logical supportive
180 service that compliments and integrates with a survivorship care plan and potentially serves as a
181 point of quality improvement by enhancing functional outcomes.^{68,69} Further, rehabilitation
182 services are reimbursable events, making the model of intervention sustainable.

183

184 An improved care model would provide rehabilitation services specific to the patients' needs,
185 improve communication and care coordination between oncology and rehabilitation providers,
186 and reduce variations in care among practice setting.^{17,70,71} This would include proactive

187 impairment screening and functional assessments throughout the care continuum relevant to the
188 adjuvant therapy rendered. It would support intervention for overt functional impairment and
189 provide ongoing supportive services in the presence of disability. The model could serve as a
190 linkage in the care continuum to support monitoring for treatment toxicities and late effects in
191 addition to optimizing function throughout the lifespan.⁷²

192 **Clinical Measurement of Function**

193 Cancer treatment introduces risk for functional impairments that increase the potential for
194 disability. In order to accurately screen for and manage functional impairments related to
195 treatment toxicities, a battery of functional measurement tools must be identified. Robust
196 evidence supports specific measures of functional impairment in the cancer population,⁷³⁻⁷⁷
197 however, these individual measures fall short of comprehensively assessing function. Function is
198 defined as “those activities identified by the individual as essential to support physical, social,
199 and psychological well-being”.⁷⁸

200 Measures of function are derived primarily in two ways; i) patient reported outcome measures
201 (PROMs) and ii) objective clinical tests and measures. These methodologies however are
202 frequently conflicted. While objective clinical measures may fail to capture the patient’s
203 perceptions of his or her level of function, reliance on PROMs often does not portray a holistic
204 perspective on the individual’s function nor does it identify emerging impairments associated
205 with functional decline. Ideally the application of objective measures alongside PROMs provides
206 broader perspective on total functioning of the individual.⁷⁹

207 **Patient Reported Outcomes Measures**

208 A patient's perception of his or her own functionality is a critical clinical outcome. The current
209 mandate to integrate the patient's voice into clinical decision-making in oncology has increased
210 receptivity to the use of PROMs in both clinical and research settings.⁸⁰ PROMs with strong
211 validity and good clinical utility can be inexpensively administered making them amenable to
212 integration into busy oncology practice settings.

213 PROMs have a wide range of application and clinical relevance in cancer populations and are
214 effective in toxicity screening and functional outcomes assessment.⁴¹ Additionally, well-
215 developed and targeted PROMs may efficiently assess important endpoints such as quality of life
216 and survival.⁸¹ Both generic and disease-specific PROMs are used to assess the functionality of
217 patients with cancer.^{82,83} Increasingly efficient and precise item response theory-derived
218 instruments, such as the Activity Measure for Post-acute Care (AM PAC)^{*} and the Patient
219 Reported Outcome Measurement Information System (PROMIS)[†], allow for the pragmatic
220 integration of functional assessment in oncology clinic work flows and clinical trials.

221 The content coverage of several generic classical test theory- and item response theory (IRT)-
222 derived functional PROMs was assessed using the International Classification of Function,
223 Disability, and Health[‡] (ICF) as a referent framework of functional domains. The tools reviewed
224 are presented in Table 1. While most of the measures provided coverage of mobility and self-
225 care domains, the communication, learning, work/employment, and community and social
226 participation domains were limited in representation. This imbalance in and restriction of
227 domains contributes to inaccurate assessments of global functioning. Therefore consideration for

* <http://www.bu.edu/bostonroc/instruments/am-pac/>

† <http://www.nihpromis.org/>

‡ http://www.who.int/classifications/icf/icf_more/en/

228 the use of established IRT-modeled PROMs such as PROMIS and NeuroQOL[§] items banks is
229 warranted.

230 Recent evidence suggests that PROMs are less effective than objective assessment tools in
231 identifying individuals who are functionally limited compared to those not experiencing
232 functional limitations.⁸⁴ This suggests a high risk for under diagnosis of clinically meaningful
233 functional limitations, a concern for the cancer population, as early identification and treatment
234 of functional limitations reduces the risk for long-term disability.^{85,86} Future research in
235 functional measurement should seek to combine PROMs and objective measures to identify
236 optimal methodology for measurement.

237 **Clinical Objective Measures of Function**

238 High level domains of clinical function are supported by a discrete evidence-base, however,
239 there are considerable gaps in the clinical utility of functional objective measures relevant to the
240 cancer population.

241 **a. Physical Performance/Fitness**

242 Physical performance measures can identify and predict adverse events, disability, and mortality
243 in the adult population.⁸⁷⁻⁸⁹ Physical performance can be assessed by a single measure, such as
244 gait speed⁸⁷ or a battery of assessments that effectively capture clinical symptom presentation
245 and predict risk of disability and death.⁹⁰

246 Diminished physical performance is associated with cancer treatment.⁹¹ The consistent use of
247 valid, reliable, performance measures is rare in the oncologic clinical setting outside of
248 rudimentary scales such as The Eastern Cooperative Oncology Group (ECOG) or Karnofsky

[§] <http://www.neuroqol.org/WhatandWhy/BankDevelopment/Pages/default.aspx>

249 Performance Scale, both of which fall short of portraying an individual's discrete functional
250 capabilities.^{79,92} The Karnofsky Scale is a predictor of overall survival but is inadequately
251 sensitive to identify clinically meaningful improvement in function over time.

252 Recent evidence highlights the potential for the geriatric assessment, as described by Elsayw and
253 colleagues, to be a more sensitive screening tool for the identification of treatment-related
254 toxicities.⁹³ The geriatric assessment “aids in the diagnosis of medical conditions; development
255 of treatment and follow-up plans; coordination of management of care; and evaluation of long-
256 term care needs and optimal placement”.⁹⁴ The domains of the geriatric assessment include:
257 functional status, comorbidity, medication, cognition, psychological, social, and nutrition. Hurria
258 and colleagues⁹⁵ have outlined valid clinical measures and patient self-reported measures
259 relevant to each of these domains. Such a measurement construct is a logical linkage between
260 rehabilitation and oncology care services and warrants further investigation in the cancer
261 population.

262 **b. Cognitive Performance**

263 The assessment of cognitive function during cancer treatment is demonstrably important
264 however, the conundrum of poor concordance with self-reported measures and objective clinical
265 measures is apparent in this domain as well.⁹⁶ Subjective cognitive impairment is more
266 frequently reported than prevalence rates revealed by objective assessments. It is uncertain if this
267 is due to lack of sensitivity in existing cognitive measures when applied to the cancer population
268 or if the self-perceived cognitive dysfunction is more of an indicator of psychological distress
269 rather than cognitive impairment.⁹⁷

270 Strong research has emerged in the cognitive measurement domain.⁹⁸ The National
271 Comprehensive Cancer Network (NCCN) Guidelines for Survivorship recommend assessment,
272 evaluation, and management for cognitive dysfunction.⁹⁹ Among the recommended non-
273 pharmacologic interventions, referral for rehabilitation intervention by occupational therapists is
274 noted.⁹⁹ Recent research has proposed a mobile cognitive assessment battery for assessment of
275 cancer-related cognitive changes.^{100,101}

276 There is a need to better integrate cognitive assessment for the cancer population.¹⁰² Evidence
277 suggests that pre-existing cognitive impairment, in many instances mild or sub-clinical, may be
278 exacerbated during cancer treatment.¹⁰³ Therefore, a comprehensive cancer rehabilitation model
279 that includes prehabilitation, or pre treatment assessment should seek to establish a cognitive
280 baseline to optimize proactive screening.¹⁰⁴

281 **c. Functional Mobility**

282 Mobility is an important aspect of function, however, tools that measure mobility struggle to find
283 their place in the cancer continuum for a variety of reasons. Assessments require a time burden,
284 they may be proprietary and not readily available in a clinical setting, and there may be a lack of
285 knowledge among providers about relevant mobility measures for the cancer population.

286 Recent advances in mobility assessment in the geriatric population have yielded comprehensive
287 assessment tools that warrant consideration for implementation into the cancer rehabilitation
288 evaluation and assessment battery.¹⁰⁵ Instruments typically used in the geriatric population are
289 likely to offer important information about functional ambulation (Timed Up-and-Go; 6 minute
290 walk distance, and others) and balance.¹⁰⁶⁻¹⁰⁸

291 **Measurement Challenges**

292 Measurement challenges go beyond the psychometrics and validity of tools. Geographical
293 location may prohibit functional assessment in patients who need to travel long distances.
294 Technology tools such as activity monitors, “apps”, and social media platforms should be
295 investigated as a mechanism to assist in telehealth screening and assessment.¹⁰⁹ These tools can
296 capture and monitor; nutritional data, activity and exercise data, sleep behavior, vital signs,
297 psychological information, and can portray social activities. While public acceptance of these
298 tools has been positive, medical disciplines have only just begun to explore their relevance and
299 accuracy in monitoring and communicating an individuals’ data, there is merit to studying their
300 utility in functional assessment.

301 Health care provider perceptions of function also pose a challenge to proactive functional
302 measurement. Individuals are diagnosed with cancer in an inherently normal functional state,
303 when the urgency of functional decline is not apparent. The trajectory of cancer treatment
304 precipitates a somewhat gradual decline in function as the cumulative side effects of disease
305 treatment aggregate. The gradual onset of functional decline will only be identified if a sound
306 baseline is established and individuals are routinely screened for clinically meaningful functional
307 change throughout the trajectory of treatment.³⁹

308 Both PROMs and objective tests and measures can be used to establish a baseline from which
309 change over time is assessed. Repeated measures enable screening for treatment-related
310 toxicities. While initial efforts in toxicity-related impairment screening and early intervention
311 have been positive, there is a need to greatly expand this research.^{25,26,110} There is a need to
312 understanding which measures are most useful for screening and early detection of functional

313 decline and to specify intervals for measurement, clinically meaningful change, and triage
314 protocols for intervention upon detection of meaningful change.

315 **Interdisciplinary clinical integration of rehabilitation**

316 Integrated care models rely on a team of health care professionals that share patient care goals
317 and interact on a care continuum. This includes individualized consultative, interventional, and
318 integrative services.¹¹¹ Integrated models are used in cancer care from the point of diagnosis,
319 through disease treatment and become particularly critical in transition from active disease
320 treatment to survivorship.¹¹² These models however conspicuously lack rehabilitation care
321 providers.

322 Cancer rehabilitation care supports the provision of high-quality oncology services.^{4,17} Despite
323 the recognized and growing need for interdisciplinary cancer rehabilitation services, significant
324 gaps in service delivery currently exist.^{4,8,11} These gaps negatively influence function, quality of
325 life, and health status as well as ability to return to the workforce.^{40,86} Integration of cancer
326 rehabilitation services ideally begins at the point of cancer diagnosis, with baseline functional
327 screening³⁹ and referral for prehabilitation interventions.⁷² Ongoing rehabilitation assessment and
328 management across the care continuum is also important.⁵⁹ Mechanisms are need to facilitate
329 better clinical integration of cancer rehabilitation care using a best practices approach, based on
330 the current evidence and expertise of rehabilitation providers.

331 Barriers to rehabilitation integration into oncology care include; i) insufficient capacity of the
332 existing workforce, ii) challenges in screening for rehabilitation needs, and iii) lack of awareness
333 among patients and care givers regarding the benefits of rehabilitation.

334 Various inputs contribute to the lack of capacity including the number of specialty trained
335 rehabilitation professionals as well as a lack of knowledge among the existing workforce
336 regarding evidence-based cancer rehabilitation care. A survey of the U.S. workforce in cancer
337 rehabilitation was conducted in 1982 by Harvey et al and identified 36 cancer programs that
338 reportedly provided components of cancer rehabilitation services.¹¹³ Recent unpublished
339 workforce data released by the American Physical Therapy Association’s Oncology Section
340 reports that an estimated 5% (~9000) of the currently licensed physical therapy workforce
341 (~182,000) in the country primarily practice in a cancer rehabilitation program. (Oncology
342 Section of the American Physical Therapy Association^{**}) Over 1500 cancer centers are
343 accredited by the American College of Surgeons Commission on Cancer, and current
344 accreditation standards mandate that programs “ensure access to rehabilitation services...either
345 on-site or by referral.²¹ This however does not assure that services are comprehensive and leaves
346 question as to the timing and type of care delivered.

347 The healthcare workforce, in general, lacks knowledge about evidence-based practices for
348 comprehensive cancer rehabilitation care. While some examples of clinical integration exist in
349 various cancer “specialty” hospitals (e.g. Memorial Sloan Kettering Cancer Center), others tend
350 to be ad hoc and often developed around a specific impairment (e.g. a lymphedema program or a
351 cancer exercise program), rather than on offering comprehensive rehabilitation care. The genesis
352 of ad hoc program development may be a result of the current curricula deficits and the dearth of
353 medical residencies dedicated to this field.¹¹⁴

^{**} Petition to American Board of Physical Therapy Specialties for Recognition of Oncology as an Area of Specialty Practice in Physical Therapy. 2016.
http://www.abpts.org/uploadedFiles/ABPTSorg/Specialist_Certification/New_Specialty/OncologyPetition.pdf

354 Rehabilitation integration is also challenged by the lack of screening and triage procedures to
355 identify patients at highest risk for functional decline or those with early functional impairment.
356 Baseline measures of function are not routinely captured in current oncology practice³⁹ and
357 critical thresholds for risk stratification and meaningful clinical change are ill defined resulting in
358 wide variation of rehabilitation referral patterns. Even in palliative care, referral to rehabilitation
359 services is significantly underutilized⁵⁰ but of great potential benefit.^{59,115} Research is needed to
360 identify optimal timing and intervals for functional assessment so that resource utilization is
361 prudent.

362 Clinical integration of rehabilitation services is also hampered because survivors and caregivers
363 are under-informed about the benefits of cancer rehabilitation care. Many are not provided with
364 information regarding the short and long-term side effects of treatment and are unaware of the
365 benefits of rehabilitation services.¹¹⁶ Patients want to be empowered decision makers in their
366 care.¹¹⁷ Understanding impairment risk and symptoms associated with early impairment
367 identification activates patients towards better self-management and self-advocacy for care,¹¹⁸
368 improves patient satisfaction and quality of life and reduces anxiety.¹¹⁹⁻¹²²

369 A multi-pronged approach that targets provider, process, and patients is needed to improve the
370 integration of cancer rehabilitation services into the cancer continuum. Efforts are underway to
371 improve cancer rehabilitation education and to elevate the knowledge and skills requisite of a
372 specialty work force.^{114,123} Screening and triage procedures must be developed to enhance care
373 delivery to the patients most at risk for functional decline and most in need of rehabilitative
374 services.^{4,39} Lastly, active patient engagement in the treatment planning process that emphasizes
375 shared decision making and fosters survivors' self-determination and autonomy is needed.¹²⁴

376 **Summary and Recommendations**

377 The work of this subject matter expert group provides a sound rationale for the supportive
378 capabilities that rehabilitation can offer to the oncology care continuum towards improving
379 functional outcomes and quality of life for the cancer population. These recommendations are
380 put forward to stimulate action among health care providers, policy making bodies, research
381 institutions, professional societies and associations, and patient advocacy organizations towards
382 initiating advancements in the field.

383

384 *Recommendations:*

- 385 1. Provide rehabilitation screening and assessment as a part of a comprehensive cancer care
386 plan, from the time of diagnosis throughout the course of illness and recovery, to address
387 the functional needs of patients. These services should be provided by trained
388 rehabilitation professionals who utilize evidence-based best practices to diagnose and
389 treat the many physical, cognitive, and functional impairments associated with this
390 medically complex population.^{4,39,125}
- 391 2. Incorporate objective assessment a patient's functional status before active cancer
392 treatment begins, at regular intervals during treatment, and during survivorship in order to
393 preserve and optimize function and monitor for late effects of treatment.^{4,39}
- 394 3. The rehabilitation community should utilize the Institute of Medicine's cancer-related
395 reports to identify the survivorship care delivery components that rehabilitation services
396 can address and support.^{22,70,126}

- 397 4. In selected cancers, rehabilitation services should be offered pre-treatment to optimize
398 tolerance to surgical intervention and adjuvant treatment in order to minimize toxicity
399 and improve outcomes.^{56,72,127,128}
- 400 5. Conduct a thorough assessment of the content coverage and psychometric properties of
401 existing clinical measurement tools and forge consensus regarding “gold-standard”
402 functional measures specific to different cancer populations.
- 403 6. Create a centralized electronic interface, utilizing an infrastructure such as the
404 Assessment Center^{††}, to facilitate systematic clinical collection of candidate Patient
405 Reported Outcomes Measures in order to facilitate psychometric characterization of these
406 measures, especially responsiveness, in clinically important populations and trait ranges.
- 407 7. Develop practice guidelines regarding: functional assessment, screening for physical
408 impairments, and rehabilitation interventions, to enhance the selection of rehabilitation
409 interventions, referrals, and outcomes measurement.
- 410 8. Expand cancer-related education and training among rehabilitation providers through
411 curriculum instruction, educational courses, residency and fellowship programs,
412 professional continuing medical education, and conferences.
- 413 9. Elevate awareness and education among healthcare providers, patients, and payers
414 regarding rehabilitation as an integral part of quality cancer care.
- 415 10. Identify research gaps in cancer rehabilitation domains and promote awareness of these
416 gaps to funding agencies that support professional training and scientific inquiry in
417 clinical, translational, and health services research in order to increase funding
418 mechanisms.

^{††} <https://www.assessmentcenter.net/>

419 Foundational evidence exists to support better integration of rehabilitation into the oncology
420 continuum and supports the rationale that rehabilitation services enhance comprehensive cancer
421 care delivery. The relative impact of rehabilitation services can be highlighted when compared to
422 the 13 care plan components outlined by the Institute of Medicine. Table 2 identifies the
423 important role that rehabilitation providers can play in in improving and managing care.

424

425 Opportunities to demonstrate the value of rehabilitation are emerging through initiatives such as
426 the Commission for the Accreditation of Rehabilitation Facilities (CARF) specialty program
427 standards for cancer rehabilitation and the recent Medicare bundled payment initiative: the
428 Oncology Care Model (OCM). Educational models for physician residency programs in
429 oncology rehabilitation are developing, as are advanced oncology competency avenues for
430 physical and occupational therapy professionals. These are potential test beds to assess the
431 impact of rehabilitation on outcomes.

432

433 Future critical initiatives in cancer rehabilitation should be drawn from the recommendations put
434 forth by this NIH panel. Such a prioritization effort will require the participation and
435 collaboration of various stakeholders including; professional societies, advocacy organizations,
436 research funding bodies, payment and policy regulatory bodies, and patients.

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Table 1. Outcomes Measures reviewed by the panel

- ECOG-Performance Status (ECOG-PS)
- Functional Independence Measure (FIM)
- Patient Reported Outcome Measurement Information System (PROMIS):
 - Physical Function & Mobility
 - Cancer Bank – Physical Function
 - Applied Cognitive Abilities & General Concerns
 - Ability to Participate in Social Roles and Activities
 - Upper Extremity Function
- NeuroQOL
 - Upper Extremity Function
 - Lower Extremity Function
 - Cognitive Function
 - Ability to Participate in Social Roles and Activities
- Activity Measure – Post Acute Care, Computer Adapted Testing (AM-PAC CAT)
 - Basic Mobility, Daily Activities, Applied Cognitive
- Return to Normal Living Index

ECOG: Eastern Cooperative Oncology Group, QOL: Quality of Life

Table 2: Institute of Medicine Survivorship Care Plan Components and Relevance to Rehabilitation Providers

Aware: Rehabilitation providers should be aware of these components of the care plan and their content to be informed about the patient's treatment plan of care.

Aware and Impactful: Rehabilitation services can have an impact on these aspects of the plan of care and communication is warranted to align rehabilitation services with oncology care.

Participatory and Impactful: A member of the rehabilitation team should be involved with the development of these aspects of the care plan.

High Impact: Rehabilitation providers should be closely aligned with these care plan components as they play a significant role in prevention, mitigation, identification and treatment.

IOM Care Plan Component	Rehabilitation Practice Relevance
Patient demographic information	Aware
Diagnosis, tissue information, stage, biomarkers	Aware
Prognosis	Aware
Treatment goals (curative/palliative)	Aware
Initial treatment plan- anti-neoplastic treatments	Aware
Expected response to treatment	Aware
Treatment benefits and harms; toxicity screening and management, short and late effects	High Impact- prevention, mitigation, identification and treatment
Quality of life and patient experience	High Impact- prevention, mitigation, identification and treatment
Plan for who will take responsibility for aspects of the patients care	Participatory and Impactful
Advance care plans; legal documents	Aware

Estimated total costs and out-of-pocket costs	Aware and Impactful
Plan for addressing psychosocial needs; vocation, disability	High Impact- prevention, mitigation, identification and treatment
Survivorship plan; treatment summary, follow up surveillance and risk reduction and health promotion	Participatory and Impactful

IOM: Institute of Medicine

ACCEPTED MANUSCRIPT