

Cancer-Related Disease Trauma: A Public Health Crisis

Epidemiology, Surveillance, and Treatment

John Librett¹; Jessica Gentile¹; Mark Kosinski²

¹Survivor Healthcare, Salt Lake City, UT, USA

²QualityMetric Incorporated LLC, Johnston, RI, USA



OBJECTIVES

There is a linear increase in the number of patients surviving a cancer diagnosis, estimated to exceed 22 million in the U.S. by the year 2030.¹ Epidemiologic data for cancer-related treatment effects (CRTE) are staggering and represent a public health crisis. This research aims to explore evidence to support the introduction of a new term to the medical lexicon to bring this public health crisis to light: cancer-related disease trauma (CRDT).

METHODS

A review of the literature was conducted to provide a clinical epidemiological view of cancer survivors. In addition, patient-reported outcome (PRO) measures were administered to cancer survivors participating in oncology clinics to complement epidemiological data in describing disease burden.

RESULTS

While the prevalence of physical and emotional CRTE varied across survivors, the most common physical CRTE included: cardiovascular; pulmonary; gastrointestinal; rheumatologic; endocrine; renal; sensory; neurological; lymphatic; genitourinary; and secondary malignancies.² Cancer survivors showed adverse symptoms impacting quality of life 5-years post diagnosis, including sexual health issues (45%), hot flashes (38%), pain (34%), fatigue (24%), and polyneuropathy (21%). Significant gaps in support are reported for menopausal disorders (43%), physical performance (39%), sleep problems (38%), arthralgia (37%), cognitive problems (36%), weight problems (32%), and fatigue (31%).³ Additionally, behavioral and psychological issues commonly encountered among cancer survivors included emotional distress, body image concerns, infertility, fears of recurrence, financial toxicity, and social isolation.¹ Measuring components of CRDT using PROs in oncology clinics, a significant proportion of cancer survivors showed significant deficits in psychological health (48%), physical functioning (52%), social functioning (68%), cognitive functioning (56%), and financial health (68%).

CONCLUSIONS

Addressing a gap in cancer survivor care, through vital-sign surveillance of CRDT using standardized PROs, a path forward is provided for updated standard-of-care services for cancer survivors and their health care providers that is delivered through a primary cancer survivor care model.

Cancer Survivor Clinical Epidemiology

-An expanding number of cancer drugs are producing a more diverse range of potential toxicities, or cancer-related treatment effects (CRTE)

-Most common physical CRTEs include cardiovascular, pulmonary, gastrointestinal, endocrine, renal, sensory, neurological, lymphatic, genitourinary, and secondary malignancies²

-Cancer survivors show adverse symptoms impacting quality of life 5-years post diagnosis, including sexual health (45%), hot flashes (38%), pain (34%), fatigue (24%), and polyneuropathy (21%)³

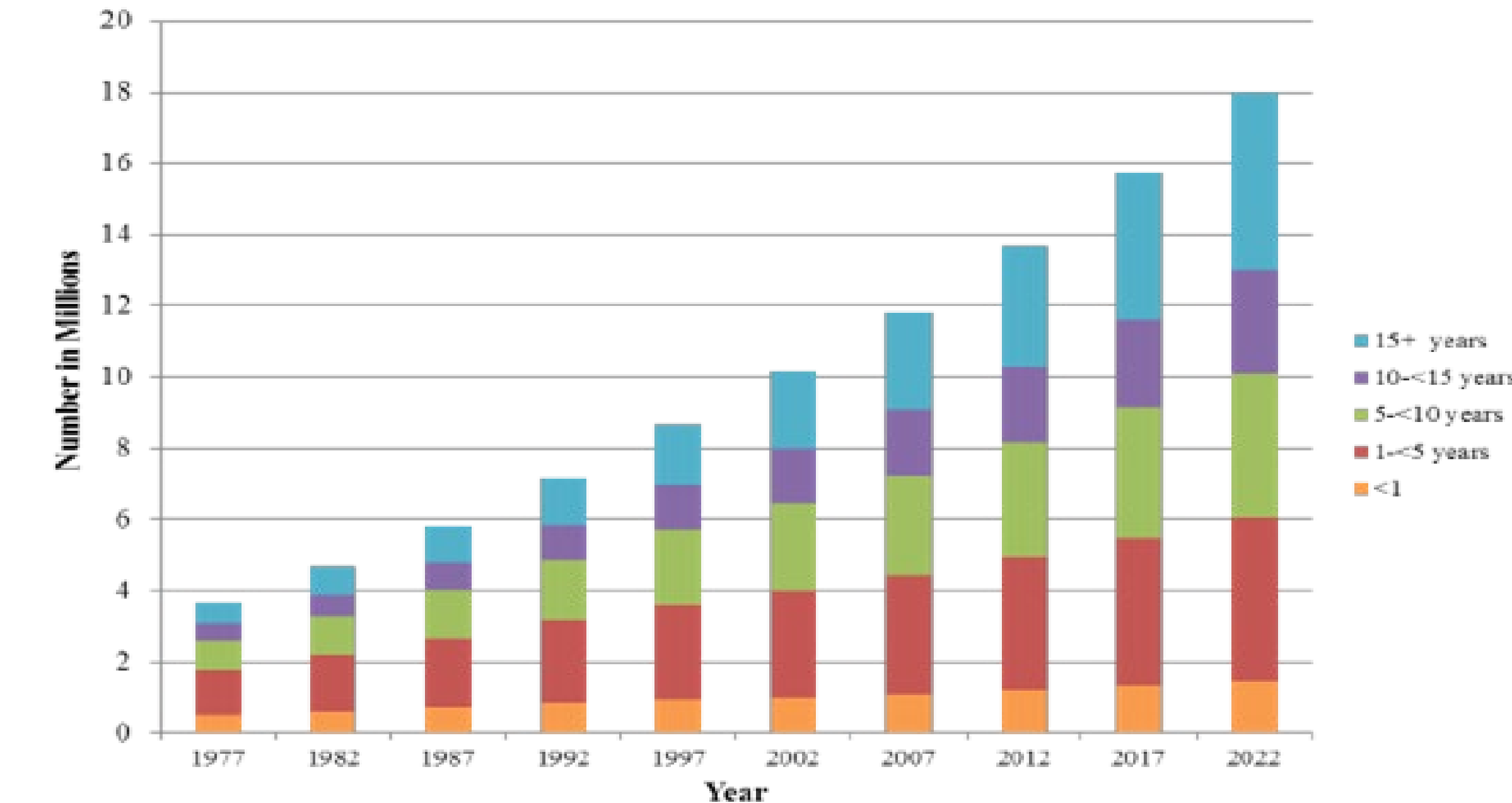
-Significant gaps exist for menopausal disorders (43%), physical performance (39%), sleep problems (38%), arthralgia (37%), cognitive problems (36%), weight problems (32%), and fatigue (31%)³

-Other behavioral and psychological issues encountered by cancer survivors include emotional distress, body image concerns, infertility, fears of recurrence, financial toxicity, and social isolation²

-CRTE issues tend to be enduring, rather than transitory, leaving many cancer survivors unable to cope with expectations of employers, families, and friends³

Cancer Survivors in the U.S. Increasing Dramatically

-U.S cancer death rates have fallen 33% since 1991¹



¹Moor, JS de et al. 2013

Prevalence of Cancer-Related Disease Effects

Health Problem	Adolescent and Young Adult Cancer Survivors Compared To Cancer-Free Siblings	Health Problem	Adult Cancer Survivors Compared To Cancer-Free Population
Angina	+5,450%	Cardiac Diseases	+147%
Chronic Obstructive Pulmonary Disease	+5,050%	Lung Diseases	+117%
Heart Attack	+3,400%	Neurological Diseases	+275%
Stroke	+2,800%	Psychology/Mental Health	+228%
Arthritis, Gout, Lupus, Fibromyalgia	+459%	Endocrine Disorders	+145%

²Librett and Yeates 2017

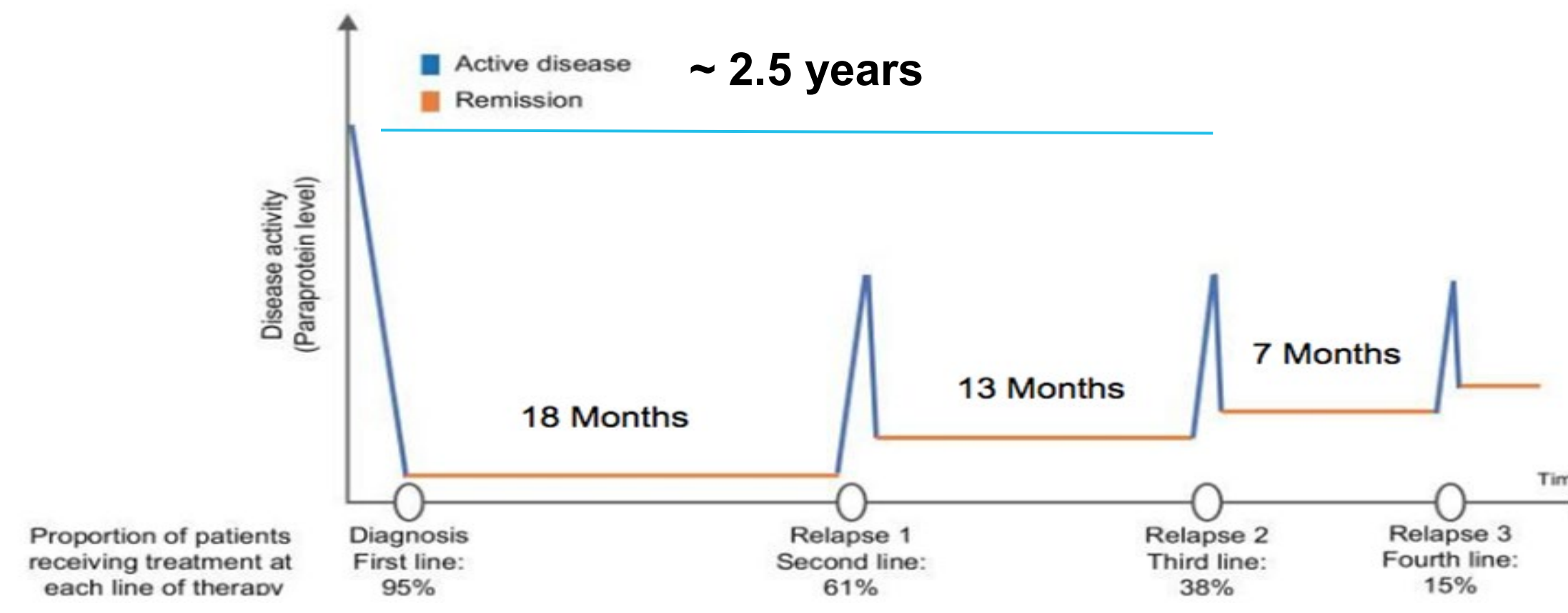
3-Year Experience for Cancer-Related Treatment Effects (CRTE): Bone Marrow Transplant (BMT)

Incidence of multiple myeloma, lymphoma, and leukemia: 3,539⁶

Cancer-Related Treatment Effects from BMT treatment:

-40% of patients experience Grade 3 to 5 chronic conditions resulting from treatment⁷

-55% of patients experience Grade 3 to 4 adverse events resulting from treatment⁸



Economic Burden of Cancer Survivorship

-Approximately 30% of cancer survivors are disabled and not able to return to work or have decreased ability to work because of limitations in cognitive, mental, and physical functioning⁹

-Upwards of 47% of cancer survivors experience high levels of financial distress¹⁰

-Using out-of-pocket spending calculations and income ratios, between 28% and 48% of cancer survivors experience financial toxicity¹¹

-Using subjective measures, up to 73% of cancer patients are reported to experience financial toxicity¹¹

-Job-related income loss due to new cancer diagnosis was estimated to be upwards of \$13,462 per month during a 3-month period¹¹

-Recently diagnosed cancer survivors aged 18 to 64 years had average total out-of-pocket medical expenditures of \$17,170 compared with \$6,485 among previously diagnosed cancer survivors and \$3,611 among those without a history of cancer¹²

Cancer-Related Disease Trauma

-There is a linear increase in the number of cancer survivors, estimated to exceed 22 million in the U.S. by 2030¹

-The epidemiological data for cancer-related treatment effects are staggering and represent a public health crisis

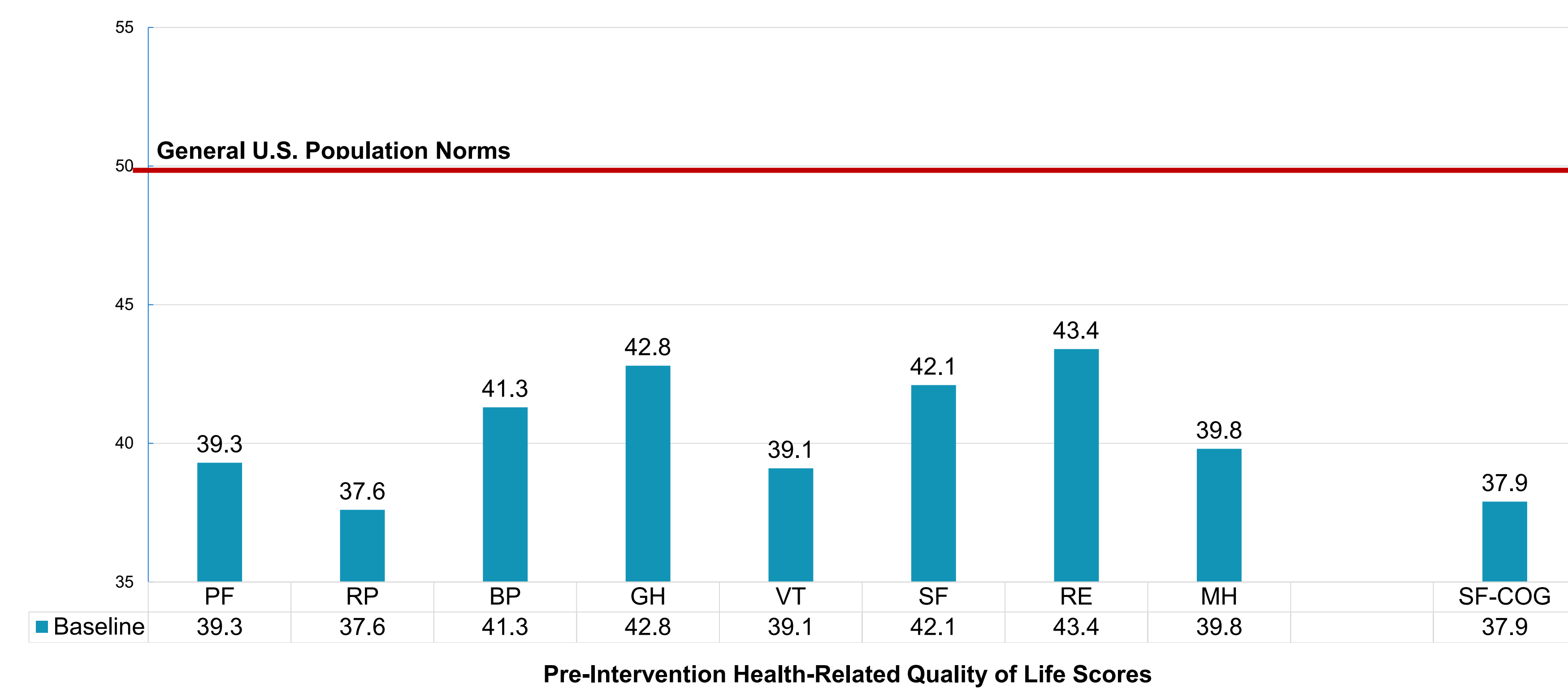
-The term "side-effects" does not adequately describe the profound life changes that can result from a cancer diagnosis and its treatment

-The negative effects of a cancer diagnosis and cancer treatment impact a patient's complete biopsychosocial realm and represent a public health crisis¹³

-To bring this public health crisis to light a new term to the medical lexicon is being introduced: **Cancer-Related Disease Trauma**

-Cancer-Related Disease Trauma is a syndrome that results from a clinically significant reduction of quality of life defined by moderating effects of psychological health, physical health, social health, and financial health

Cancer Survivors Experience Significant Physical, Social, Role, Cognitive, and Mental Health Burden



PF = Physical Function
 RP = Role Physical
 BP = Bodily Pain
 GH = General Health
 VT = Vitality
 SF = Social Function
 RE = Role Emotion
 MH = Mental Health
 SF-Cog = Cognitive Function

References

¹American Cancer Society. Cancer Treatment & Survivorship Facts & Figures 2019-2021. Atlanta: American Cancer Society; 2019. ²Beckjord EB, Reynolds KA, Rechis R. Psychological Factors and Survivorship: A Focus on Post-treatment Cancer Survivors. In: Psychological Aspects of Cancer. Springer, Boston, MA; 2013:327-346. ³Schmidt ME, Wiskemann J, Steindorf K. Quality of life, problems, and needs of disease-free breast cancer survivors 5 years after diagnosis. Qual Life Res. 2018;27(8):2077-2086. doi:10.1007/s11136-018-1866-8. ⁴Moor JS de, Mariotto AB, Parry C, et al. Cancer survivors in the United States: prevalence across the survivorship trajectory and implications for care. Cancer Epidemiol Biomarkers Prev. 2013;22(4):561-570. doi:10.1158/1055-9965.EPI-12-1356. ⁵Librett J, Yeates E. Cancer Survivor Plans, Policy, & 572 Environmental Review. State of Utah. 2017. ⁶Utah Cancer Registry. Cancer in Utah 2017-2019. https://uofuhealth.utah.edu/utah-cancer-registry. ⁷Bird SA, Boyd K. Multiple myeloma: an overview of management. PalliatCare. 2019;13:1178224219868235. doi:10.1177/1178224219868235. ⁸Straus DJ. Long-term survivorship at a price: late-term, therapy-associated toxicities in the adult hodgkin lymphoma patient. Therapeutic Advances in Hematology. 2011;2(2):111-119. doi:10.1177/2040620711402414. ⁹Ekwueme DU, Yabroff KR, Guy GP et al. Medical costs and productivity losses of cancer survivors—United States, 2008–2011. MMWR Morb Mortal Wkly Rep. 2014;63(23):505-510. ¹⁰Chino F, Peppercorn J, Taylor DH, et al. Self-reported financial burden and satisfaction with care among patients with cancer. Oncologist. 2014;19(4):414-420. doi:10.1634/theoncologist.2013-0374. ¹¹Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. CA Cancer J Clin. 2018;68(2):153-165. doi:10.3323/caac.21443. ¹²Guy GP, Ekwueme DU, Yabroff KR, et al. Economic burden of cancer survivorship among adults in the United States. J Clin Oncol. 2013;31(30):3749-3757. doi:10.1200/JCO.2013.49.2411. ¹³Librett J, Kosinski M, Gentile J, et al. Cancer-Related Disease Trauma: A Public Health Crisis. 2022. ¹⁴Sapra A, Malik A, Bhandari P. Vital Sign Assessment. In: Sapra A, Malik A, Bhandari P, eds. StatPearls [Internet]. StatPearls Publishing; 2022. ¹⁵Ayers AA. Competitive Edge: The Importance of Taking Accurate Vitals. Journal of Urgent Care Medicine. https://www.jucm.com/competitive-edge-importance-taking-accurate-vitals/. Accessed 05/26/22.

Primary Cancer Survivor Care Model Developed to Meet Unmet Clinical Needs of Cancer Survivors

-A theoretical model for CRDT reflects the values identified by any cancer survivor who seeks to improve psychological health, physical health, social health, and financial health status

-To accommodate these values in a care program, a patient-reported outcome (PRO) measurement tool was implemented in a community-based cancer survivor clinic that measures vital signs for risk of CRDT

-Patients are tracked for clinically meaningful temporal change over time while capturing the patient's perspectives during clinical visits and between clinical encounters

-These vital signs are a standard component of measurement and assessment for any clinical evaluation¹⁴ and are important to providing quality patient care as they can be an early indication of illness, deterioration, or an impending adverse health event¹⁵

Survivor Healthcare (SHC) System for Developing a Quality Primary Cancer Survivor Care Program

PATIENT REPORTED OUTCOMES (PROs)

- Collection of Point-of-Care PROs are integrated into electronic medical records.
- SHC PROs are efficiently completed by the patient at clinically relevant intervals.
- SHC PROs are nationally validated, widely published in peer review medical journals, benchmarked, normed, and accepted by CMS and the FDA.

APPROACH TO CARE

- Standard-of-care algorithms follow national clinical practice guidelines.
- A multi-disciplinary clinical team specifically addresses cancer related treatment effects.
- Primary cancer survivor care clinicians participate in weekly clinical grand rounds.

PROGRAM SCALABILITY

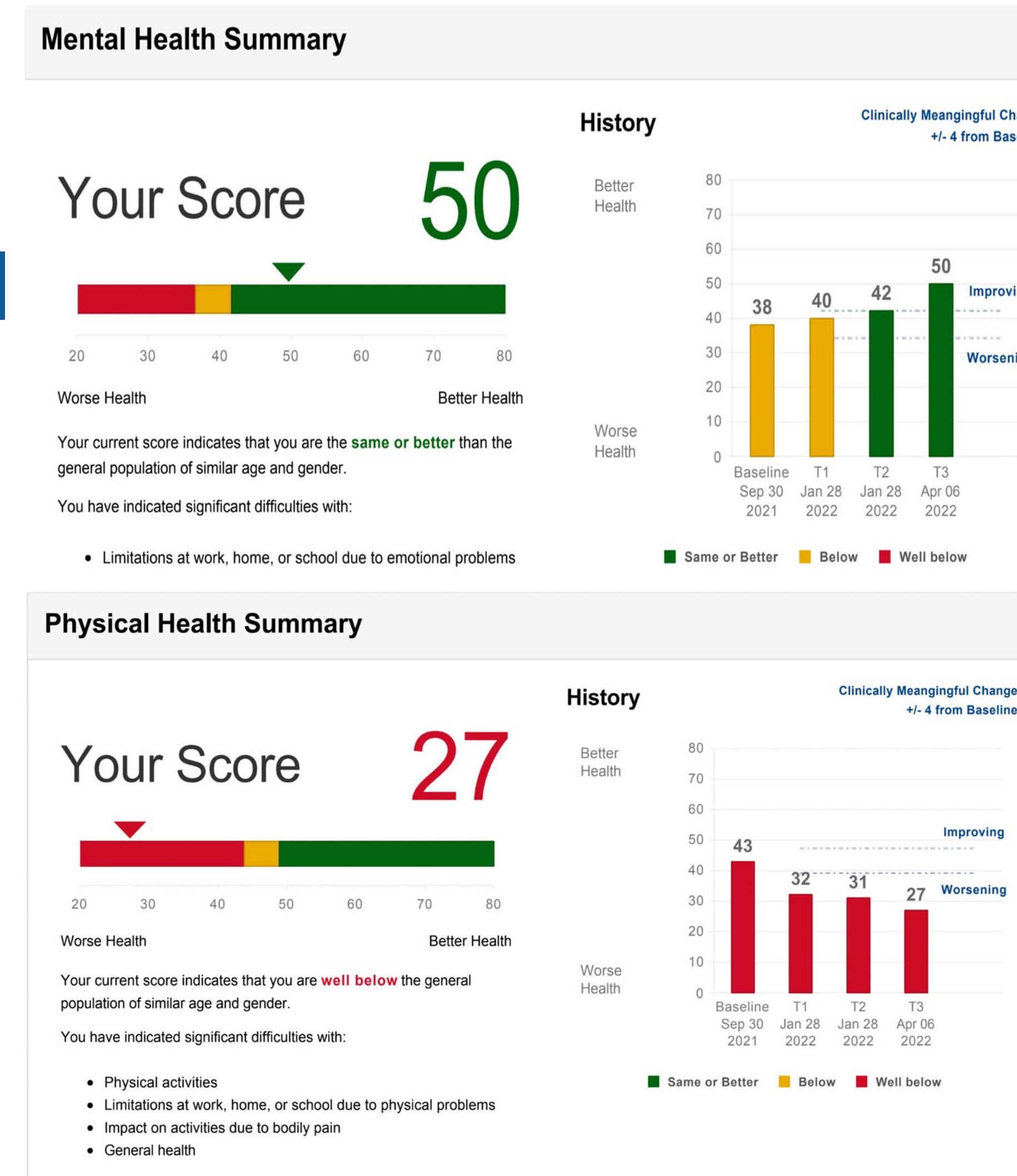
- The clinic hires and trains clinicians who deliver new standard-of-care service lines for cancer survivorship.
- Service-line agreements support the delivery of value-based medicine.
- Virtual environment brings quality clinical care to anywhere in the world.

CLINIC QUALITY

- Clinical outcomes are audited through a peer-review research and evaluation process.
- An interdisciplinary clinical team is trained on primary cancer survivor standards-of-care.
- The clinic is supported by a dedicated evaluation, research, and implementation science program.

Clinic Data

Individual level patient trend data



Population level patient trend data

