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Patient Activation in Childhood, Adolescent, and Young Adult Cancer Survivors: Current Insights and Implications for Survivorship Care—A Systematic Review From the e-QuoL Project

Charlotte Demoor-Goldschmidt^{1,2,3,4} | Anne Maas⁵ | Gisela Michel⁵ | Amandine Bertrand⁶ | Kristen E. T. Thornton⁷ | Martine Bellanger⁸ | Anna-Liesa Filbert⁹ | Desiree Grabow⁹ | Monica Muraca¹⁰ | Katharina Roser⁵ | Sara Oberti¹⁰ | Jelena Roganovic^{11,12} | Hanne Cathrine Lie⁷

¹Pediatric Oncology-Hematology-Immunology Department, University Hospital of Angers, Angers, France | ²Pediatric Oncology-Hematology-Immunology Department, University Hospital of Caen, Caen, France | ³Epidemiology of Radiation, U1018 Inserm, Gustave Roussy, Villejuif, France | ⁴GCS HUGO, University Hospitals of the Grand Ouest, Angers, France | ⁵Faculty of Health Sciences and Medicine, University of Lucerne, Lucerne, Switzerland | ⁶Pediatric Hematology and Oncology Institute, Centre Léon Bérard, Lyon, France | ⁷Department of Behavioral Medicine, Faculty of Medicine, Institute of Basic Medical Sciences, University of Oslo, Oslo, Norway | ⁸Institut De Cancerologie de L'ouest, Saint Herblain, France | ⁹Division of Childhood Cancer Epidemiology, German Childhood Cancer Registry, Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI), University Medical Center of the Johannes Gutenberg University Mainz, Mainz, Germany | ¹⁰Department of Hematology/Oncology, DOPO Clinic, IRCCS Istituto Giannina Gaslini, Genoa, Italy | ¹¹Department of Pediatric Oncology and Hematology, Children's Hospital Zagreb, Zagreb, Croatia | ¹²Faculty of Biotechnology and Drug Development, University of Rijeka, Rijeka, Croatia

Correspondence: Charlotte Demoor-Goldschmidt (charlotte.demoorgoldschmidt@chu-angers.fr)

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ABSTRACT

Purpose: Patient activation—encompassing knowledge, confidence, and skills in managing individual's health—is a cornerstone of person-centered care. However, its significance among childhood, adolescent, and young adult cancer survivors (CAYACS) remains unexplored. This article examines the application of the 13-item Patient Activation Measure (PAM-13) in CAYACS, highlights factors influencing activation levels, and draws insights from adult oncology.

Methods: A systematic review was conducted to identify studies assessing patient activation using PAM-13 in CAYACS populations.

Results: Only two relevant studies were identified. Reduced activation levels were associated with psychological distress, fatigue, neurocognitive impairment, and complex late effects. Activation levels fluctuated over time, with lower levels during active treatment and higher levels during disease-free survivorship. Evidence from adult oncology suggests that structured education, psychosocial support, and hybrid care models (e.g., Oncokompas and SMARTCare) may enhance health ownership. However, limitations, such as PAM-13 ceiling effects and potential psychometric variability in oncology populations, have been reported.

Conclusions: Activation-based approaches hold promise for improving self-management in CAYACS. Future interventions should be developmentally tailored, acknowledge caregiver roles, and address transition-related challenges and disparities in

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healthcare access. Recognizing patient engagement as a core outcome in survivorship research may strengthen personalized care and support the development of scalable, evidence-based interventions.

Implications for Cancer Survivors: Despite some measurement biases, activation assessment in CAYACS facilitates identification of vulnerable survivors, enables tailored interventions, and fosters empowerment and self-management to improve personalized survivorship care and long-term outcomes.

1 | Introduction

Patient activation is a cornerstone of contemporary healthcare strategies, emphasizing self-management, patient empowerment, and active participation in decision-making. It refers to an individual's ability, motivation, confidence, and knowledge to effectively manage their own health [1]. According to the Chronic Care Model [2], improved patient outcomes result from productive interactions between well-informed, engaged patients—equipped with the necessary knowledge—and proactive, prepared care teams. Theoretical frameworks, such as Leventhal's Common-Sense Model of Self-Regulation (CSM), suggest that individuals' perceptions of their illness—its identity, cause, timeline, consequences, and controllability—influence coping behaviors and self-management decisions [3]. Thus, patient activation depends not only on knowledge and skills but also on how patients interpret their health experiences.

The Patient Activation Measure (PAM), created by Hibbard et al. [1], is a validated instrument designed to quantify the level of patient activation. Its development involved a rigorous, comprehensive, multiphase process beginning with an extensive literature review to identify key theoretical domains, including self-management, patient empowerment, and health behavior change. This was followed by qualitative research, including focus groups and interviews with both patients and healthcare professionals (HCP), which guided item generation.

The resulting method conceptualizes activation as a developmental process structured around four progressive stages, ranging from passive recipients of care to proactive individuals who confidently manage health behaviors even under challenging circumstances. The original 22-item version (PAM-22) underwent psychometric evaluation using Rasch modeling, confirming its unidimensional structure and strong internal consistency (Cronbach's $\alpha = 0.87$). The tool encompasses four core domains: practical self-management, collaboration with HCP, understanding of treatment options, and adherence to medical recommendations. The PAM-22 has been employed in different settings to assess its reliability and validity [4, 5]. To improve its applicability in both clinical and research settings, a shortened 13-item version (PAM-13) was introduced in 2005 [6]. Items were selected on the basis of Rasch modeling [1] to retain the conceptual integrity of the original scale while improving its efficiency. This streamlined version maintained the original four-tiered structure and demonstrated high internal reliability ($\alpha > 0.90$), as well as validity across a spectrum of chronic conditions, such as diabetes, hypertension, and cardiovascular disease [7]. More recently, its utility has been extended to oncology populations, where it has proven to be both applicable and reliable [8].

The concise PAM version (PAM-13) comprises 13 items that categorize individuals into four ascending levels of engagement in managing their health. These levels range from passive recipients of care (Level 1) to highly proactive individuals (Level 4) who independently maintain health-related behaviors. The stages are defined as follows: (1) Level 1 (≤ 47.0): recognition of the importance of the patient's role in health management; (2) Level 2 (47.1–55.1): emerging knowledge and confidence to engage in self-care; (3) Level 3 (55.2–67.0): active participation in health-related decision-making behaviors; and (4) Level 4 (≥ 67.1): sustained self-management, even under stress. Evidence supports the utility of PAM-13 in chronic disease contexts. In Type 2 diabetes, elevated activation scores correlated with improved glycemic control ($\text{HbA1c} \leq 7\%$) and more favorable responses to chronic illness care, particularly among those with initially low activation [9]. Similarly, in hypertension, elevated PAM scores are associated with significantly reduced total, inpatient, and emergency care costs [10]. Among patients with cardiovascular and pulmonary disease [11], higher activation correlates with better medication adherence and sustained engagement in self-care behaviors [1, 11–13]. Collectively, these findings emphasize the relevance of PAM-13 in evaluating and facilitating patient-centered care across long-term conditions.

Although the measure has been extensively validated in chronic illnesses, its application in oncology is relatively recent. In cancer care, it has been employed to assess engagement in treatment decision-making, self-management of late effects, and adherence to follow-up care. A recent systematic review [8], using PubMed-indexed studies up to November 2025 with the following search terms: “Patient Activation Measure” OR “PAM-13” AND “cancer,” identified 21 relevant studies. Among these, 48% evaluated activation levels within controlled intervention trials, 24% used single-arm pre/post designs, and 28% investigated associations between PAM scores and patient characteristics.

Breast cancer was the most frequently studied tumor type, appearing in half of the single-cancer studies. Methodological approaches varied and included cross-sectional analyses on survivorship factors, pre/post intervention trials targeting lifestyle or educational outcomes, and randomized controlled trials (RCT) assessing self-management programs and survivorship care plans. Six studies focused specifically on survivorship (mainly among breast cancer survivors but also among those with prostate, head and neck, and multiple cancer types). Notably, none addressed activation among childhood, adolescent, and young adult cancer survivors (CAYACS).

Cancer patients and survivors face unique challenges that may affect their activation levels, including complex treatments, long-

term side effects, and psychosocial burdens. Unlike stable chronic diseases, cancer care is characterized by dynamic transitions—moving from active treatment to survivorship and long-term follow-up (LTFU)—which may result in fluctuating engagement over time. For childhood cancer survivors (CCS), the shift from pediatric to adult care represents an additional hurdle, often contributing to fragmented care and disengagement from health services [14, 15].

Survivorship, the phase following the completion of active cancer treatment, encompasses multidimensional recovery process—physical, psychological, and social rehabilitation [16]. This period is particularly critical for CCS, who are at increased risk of late effects, such as cardiac and endocrine dysfunction, neurocognitive deficits, and secondary malignancies [17–23]. Optimal follow-up care during survivorship hinges on the individual's active participation in screenings, management of late effects, and adherence to long-term monitoring programs.

Despite these needs, access to structured LTFU care remains inconsistent. Many CCS lack adequate surveillance for late effects due to systemic issues, including the absence of dedicated LTFU clinics, organizational barriers, and healthcare providers' limited expertise in survivorship care [24, 25]. This discontinuity places a greater onus on survivors to self-manage their health, thereby necessitating strong activation and self-care capabilities.

As healthcare increasingly shifts toward patient-centered models, understanding the role of patient activation in influencing self-management behaviors, adherence to medical recommendations, and quality of life becomes imperative. This is particularly relevant in pediatric and young adult oncology for several reasons: (1) CAYACS face an exceptionally long survivorship trajectory, often spanning decades, requiring sustained engagement in health monitoring and preventive care; (2) the transition from pediatric to adult healthcare systems represents a critical period where loss of engagement frequently occurs, contributing to gaps in surveillance for late effects; (3) developmental factors—including emerging autonomy during adolescence and young adulthood—uniquely influence individuals' capacity and readiness to engage in self-management; and (4) the burden of treatment-related late effects (e.g., neurocognitive, endocrine, and cardiac) may persist or emerge years after treatment, necessitating long-term self-monitoring and proactive health behaviors that depend on sustained activation [26, 27]. However, research evaluating the validity and applicability of PAM in these populations remains limited.

Recent systematic reviews on digital health and patient activation indicate that access to personal health records or online educational platforms alone is often insufficient to drive meaningful improvements in patient engagement. Digital interventions tend to be most effective when combined with structured support—such as coaching, peer networks, or guided navigation—that facilitates behavior change and emotional adaptation. Tailored programs that incorporate symptom-driven and deliver personalized, context-specific resources have demonstrated greater success in improving activation levels. These findings underscore the promise of hybrid digital approaches in survivorship care, particularly for populations with complex medical and psychosocial profiles, such as CAYACS [28–31].

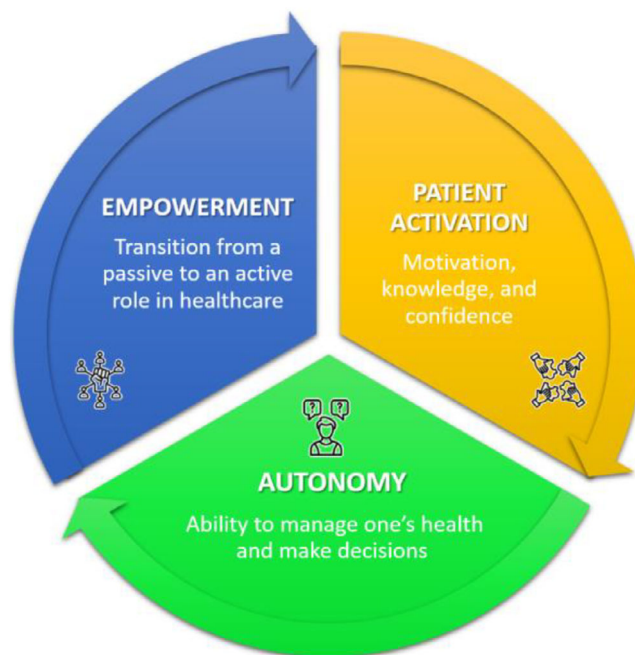


FIGURE 1 | Cyclical relationship between activation, autonomy, and empowerment supporting self-management and adherence.

The interplay between patient activation, autonomy, empowerment, and adherence functions as a cyclical and mutually reinforcing process (Figure 1). Elevated activation fosters autonomy and informed decision-making capacities, which in turn promote patient empowerment—a state characterized by an individual's perceived ability and willingness to actively participate in their care [32, 33]. Although empowerment and activation are conceptually distinct, they are closely interconnected: Activation reflects an individual's readiness and capacity to act, whereas empowerment captures the sense of control and ownership over health-related decisions. This synergy supports self-efficacy and sustained adherence to care plans, ultimately reducing psychological distress and improving long-term quality of life.

Conversely, low activation disrupts this positive cycle, leading to disengagement, poorer adherence, and suboptimal outcomes. In the context of digital health frameworks, activation and empowerment are also conceptualized as sequential steps in the journey toward full patient engagement. According to Risling's model [34], empowerment signifies the transfer of control to the patient; activation reflects the initial motivation and responsiveness to engage with health technologies; and sustained engagement denotes ongoing long-term, goal-oriented interaction that drives improved clinical outcomes.

Effectively supporting patient activation requires more than mere access to information; it necessitates addressing psychological burdens and structural inequalities to foster autonomy and a sense of agency. Research consistently demonstrates that higher activation correlates with healthier behaviors, improved patient experiences, greater medication adherence, better health-related quality of life (HRQoL), and reductions in unplanned care admissions [1, 32, 33, 35]. However, as Mueller et al. highlight, establishing causal pathways remains complex due to the

dynamic interplay among activation, empowerment, autonomy, and system-level factors [33].

In the e-QuoL Effectiveness Study, a prospective multi-country European trial, we will employ PAM-13 questionnaire to assess the impact of *MyCare e-QuoL*, a digital survivorship tool co-designed with CAYACS. This personalized e-health platform delivers tailored self-management resources aligned with supportive care needs, complementing individualized post-cancer recommendations focused on preventive care and screenings on the basis of each survivor's risk of long-term sequelae. The study will evaluate changes in patient activation over 6 months, health alongside quality of life, psychological distress (measured by the EORTC-adolescent and young adult (AYA) module), and user satisfaction.

The aim of this systematic review was to examine the applicability, psychometric properties, and reported associations of PAM-13 among CAYACS. Rather than addressing patient activation in general, we focused specifically on this widely used instrument to assess whether it can serve as a robust tool in this population. Drawing on both pediatric/AYA studies and evidence from adult oncology, we highlight the benefits, limitations, and key considerations for integrating PAM-13 into future survivorship research and practice.

2 | Methods

A systematic literature review was conducted in accordance with the PRISMA 2020 guidelines to identify studies evaluating the use of PAM-13 in CAYACS (Figure 2). PAM-13 is a licensed instrument owned by Insignia Health. PAM-13, along with information on licensing and authorized use, is available through the Mapi Research Trust (<https://mapi-trust.org>). Readers can access the official instrument and scoring guidelines by requesting permission via the Mapi Research Trust platform.

2.1 | Information Sources and Search Strategy

In April 2025, a comprehensive search was carried out across three databases: PubMed, Scopus, and Web of Science. It was restricted to peer-reviewed articles published between January 2005 and November 2025. Keywords included variations of the Patient Activation Measure (e.g., “PAM-13,” “PAM 13,” “Patient Activation Measure”) in combination with descriptors for the populations of interest, such as “childhood cancer survivors,” “pediatric cancer,” “AYA cancer,” and “young adult cancer survivors” (Appendix). Depending on the database, searches were limited to titles, abstracts, and keywords. Additional terms related to self-management constructs (e.g., “self-efficacy,” “empowerment,” and “self-care”) were considered but not included in the final strategy to maintain specificity for PAM-13 instrument, as this review specifically focused on this validated measure rather than patient activation as a broader concept.

2.2 | Eligibility Criteria

Studies were included if they: Part (1) involved individuals diagnosed with cancer before the age of 39 years; part (2) employed PAM-13 to assess patient activation; and part (3) examined its

relationship with health-related outcomes, self-management, or activation-related interventions. We defined the population as individuals diagnosed with cancer during childhood, adolescence, or young adulthood (from birth up to 39 years old) who were at least 1-year post-diagnosis. This definition reflects a broad survivorship period while acknowledging variability in treatment status. Studies were included if at least 50% of participants met this criterion. This inclusive approach was adopted considering the limited research available in CAYACS populations.

2.3 | Study Selection

A total of two records were identified. Following title and abstract screening, both met the inclusion criteria and were retained for full-text analysis. The study identification and inclusion process is illustrated in Figure 2 (PRISMA flow diagram).

2.4 | Data Extraction

Data extraction was performed independently by three reviewers (C.D.G., A.M., and G.M.) using a standardized form. Extracted information included study design, population characteristics (sample size, age, cancer type, and time since diagnosis), PAM-13 scores (mean scores, standard deviations [SDs], and distribution across activation levels), factors associated with activation, intervention details (if applicable), and main outcomes. Any disagreements were resolved through discussion. Given the heterogeneity in study designs and populations, a narrative synthesis approach was employed.

Quality appraisal of the included studies was conducted using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Analytical Cross-Sectional Studies. Both studies were assessed independently by three reviewers (C.D.G., G.M., and A.M.). The St. Jude Lifetime Cohort Study (SJLIFE) demonstrated high methodological quality, with clearly defined inclusion criteria, validated measurement tools, appropriate statistical analyses, and an adequate sample size. The Japanese study also showed good methodological quality with appropriate psychometric validation methods, though the cross-sectional design and single-country setting limited generalizability. Both studies adequately addressed their research questions within their respective designs.

3 | Results

Two studies met the inclusion criteria for the final review as follows: (1) Ware et al. [36], which explored activation and psychological outcomes in participants from the SJLIFE (Table 1); and (2) Soejima and Kitao [37], which investigated the measurement invariance and validity of PAM-13 among Japanese AYA cancer survivors. Both studies revealed significant variability in patient activation, influenced by sociodemographic factors, treatment history, and the presence or absence of structured survivorship programs.

In the SJLIFE [36, 38], activation was measured in 2708 CCS and compared to 303 non-cancer controls. Participants had a

TABLE 1 | Characteristics and key findings of studies evaluating PAM-13 among childhood and young adult cancer survivors (CAYACS).

Study	Study design	Population	Cancer journey	PAM-13 baseline		PAM-13		Main results	Detailed intervention type
				(mean ± SD)	(mean, SD)	post-intervention	Age (mean ± SD, years)		
St. Jude Lifetime Cohort Study SJLIFE [33]	Cross-sectional analysis within a longitudinal cohort study	2708 CCS and 303 non-cancer controls	Long-term survivors (≥5 years post-diagnosis)	Not applicable	Not reported	Survivors	- Survivors had significantly lower activation than non-cancer controls ($p < 0.0001$)	Not applicable	
		50.6% male; 49.4% female United States (leukemia, lymphoma, CNS tumors, sarcoma, embryonal tumors, others)			At diagnosis: mean 8.9 ± 5.8 years At PAM assessment: mean 33.8 ± 10.5 years Controls Age at PAM assessment: mean 30.7 ± 9.8 years	- Activation levels: <ul style="list-style-type: none">• Level 1: 11.3% (vs. 4.7%)• Level 2: 13.8% (vs. 9.7%)• Level 3: 29.7% (vs. 24.1%)• Level 4: 45.3% (vs. 61.5%) - Lower activation associated with: <ul style="list-style-type: none">- Depression (OR: 2.37, 95% CI 1.87–2.99, $p < 0.001$)- Anxiety (OR: 2.21, 95% CI 1.73–2.83, $p < 0.001$)- Somatization symptoms: (OR: 1.99, 95% CI 1.59–2.50, $p < 0.001$)- Cancer-related worry: (OR: 1.45, 95% CI 1.23–1.71, $p < 0.001$) and body-focused fear (OR: 2.21, 95% CI 1.83–2.66, $p < 0.001$)- Poor physical (OR: 2.57, 95% CI 2.06–3.20, $p < 0.001$) and mental HRQoL (OR: 2.08, 95% CI 1.72–2.52, $p < 0.001$)- Lower activation more common in:<ul style="list-style-type: none">• Lymphoma/CNS tumor survivors ($p < 0.0001$)• Those not meeting physical activity guidelines (OR: 2.07, 95% CI 1.53–2.80, $p < 0.001$)• Survivors with lower education ($p < 0.0001$) or no insurance ($p = 0.01$)			
Japanese YA Cancer Survivors Study [34]	Cross-sectional observational psychometric study	500 YA cancer survivors 30% male; 70% female Japan (gastric, CRC, breast, uterine/ovarian, thyroid cancers, lymphoma, leukemia, and others) Two groups: pre- and posttreatment	Mixed (26% <1 year since diagnosis, 48% 1 to <5 years since diagnosis, 26% ≥5 years since diagnosis)	- During treatment: 55.5 ± 15.4 range 9.0–100.0 - After treatment: 55.3 ± 15.6 (range 17.9–100.0)	Not applicable	49% aged 35–39 (range: 20–39 years)	- Lower activation correlated with: <ul style="list-style-type: none">• Fatigue ($r = -0.25$, $p < 0.001$) and depression ($r = -0.20$, $p = 0.002$) during treatment• After treatment: fatigue ($r = -0.18$, $p = 0.003$), depression ($r = -0.19$, $p = 0.002$) - Higher education associated with higher PAM-13 scores posttreatment ($p = 0.001$) - Higher self-management scores posttreatment; higher adherence scores during treatment (e.g., taking medications)	Not applicable	

Abbreviations: CCS, childhood cancer survivors; CNS, central nervous system; CRC, colorectal cancer; HR-QoL, health-related quality of life; OR, odds ratio; PAM, Patient Activation Measure; SD, standard deviation; YA, young adults.

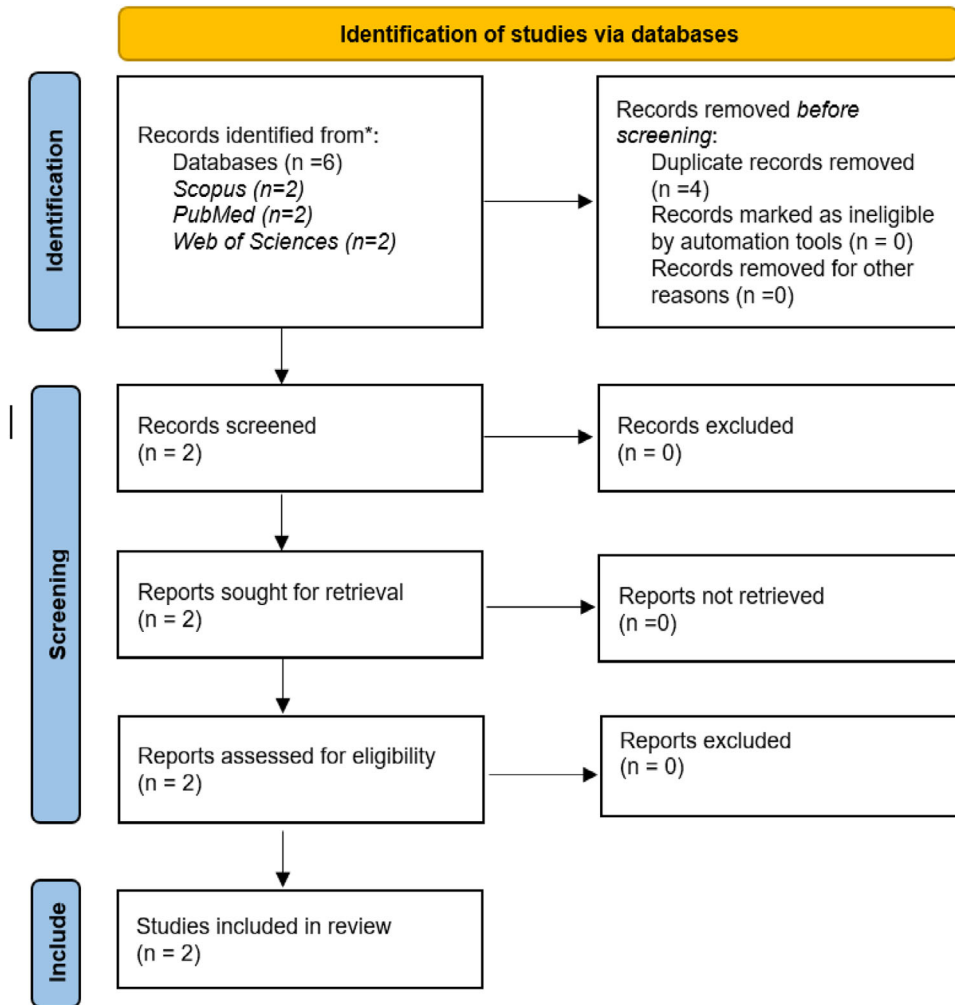


FIGURE 2 | PRISMA 2020 flow diagram of study selection process for the systematic review on PAM-13 in CAYACS.

mean age of 33.8 years (SD = 10.5) at assessment and were, on average, 8.9 years (SD = 5.8) at diagnosis, with all being at least 5 years posttreatment. Key factors associated with lower PAM-13 scores included the presence of severe chronic conditions (Common Terminology Criteria for Adverse Events [CTCAE] Grade 3+), psychosocial distress, and limited engagement in self-care. Overall, CCS demonstrated significantly lower activation levels than controls ($p < 0.0001$), with only 45.3% achieving the highest activation (Level 4), versus 61.5% among controls. Conversely, 11.3% of CCS fell into the lowest category (Level 1), compared to just 4.7% of non-cancer peers. Lower scores were particularly evident among survivors with CTCAE Grade 3+ conditions, especially among those with severe chronic health problems, including cardiotoxicity, neurocognitive impairment, pulmonary dysfunction, endocrine disorders, and secondary malignancies. Survivors of central nervous system (CNS) tumors or lymphoma were particularly likely to have severe late effects and correspondingly reduced activation ($p < 0.0001$). CCS with Grade 3+ cardiovascular conditions, including heart failure and arrhythmias, presented the lowest activation levels ($p = 0.003$), presumably due to physical limitations affecting their ability to engage in self-management behaviors. Similarly, neurocognitive impairments, especially among CNS tumor survivors, were associated with diminished engagement in survivorship care,

potentially due to challenges in understanding and processing medical information, as well as in managing follow-up plans. Psychosocial distress further undermined activation. Depression (odds ratio [OR]: 2.37, 95% confidence interval [CI] 1.87–2.99), anxiety (OR: 2.21, 95% CI 1.73–2.83), and fear of recurrence (OR: 1.45, 95% CI 1.23–1.71) were all significantly associated with lower PAM-13 scores ($p < 0.001$). Additionally, physical inactivity was linked to a twofold increase in the odds of low activation (OR: 2.07, 95% CI 1.53–2.80, $p < 0.001$), underscoring the importance of functional capacity in fostering self-management.

The Japanese Young Adult Cancer Survivors Study [37] evaluated PAM-13 scores in 500 individuals aged 20–39 years at inclusion, who were diagnosed with breast, colorectal, lymphoma, uterine/ovarian, thyroid, and other tumors after the age of 20. The study compared participants undergoing active treatment ($n = 237$) with those in posttreatment follow-up ($n = 263$) and examined factors influencing engagement in self-care. Mean PAM-13 scores were comparable between groups as follows: 55.5 (SD = 15.4) during treatment and 55.3 (SD = 15.6) posttreatment ($p = 0.420$). Ceiling effects were observed across all items during active therapy and in all but one (Item 13: “I am confident that I can maintain lifestyle changes, like diet and exercise, even during times of stress”) after treatment. However, only 3% in

either group achieved the maximum patient activation score. Activation levels were negatively correlated with physical fatigue ($r = -0.25, p < 0.001$) and depression ($r = -0.20, p = 0.002$) during treatment, and these associations remained significant in the posttreatment cohort (fatigue: $r = -0.18, p = 0.003$; depression: $r = -0.19, p = 0.002$). Higher educational attainment correlated with increased activation posttreatment ($p = 0.001$), though not during active care. Treatment adherence-related behaviors, such as medication intake and symptom monitoring, were more prominent during therapy, facilitated by structured clinical guidance and support from HCP. In contrast, after treatment, self-management required greater autonomy to address long-term effects, emotional well-being, and health lifestyle maintenance with reduced clinical supervision.

4 | Discussion

This systematic review explored the application of PAM-13 in CAYACS—a population facing distinct medical and psychosocial challenges. Although research in this area remains limited, with only two eligible studies identified, preliminary evidence suggests consistent associations between patient activation and key survivorship outcomes, including self-management capacity, psychological well-being, and engagement in follow-up care. These findings are instrumental in shaping developmentally tailored interventions aimed at improving long-term care in this unique population.

Compared to other chronic conditions, CCS presents exceptional complexity due to the heterogeneity of diagnoses, treatment exposures, and long-term consequences—spanning physical, psychological, and neurocognitive domains [17, 39]. Despite this, structured self-management support remains insufficiently integrated in routine survivorship care. CAYACS encounter specific barriers to activation, such as developmental immaturity, reliance on caregivers, challenges associated with transitioning to adult healthcare systems [40], and inconsistent access to LTFU services. Moreover, persistent treatment-related late effects may limit survivors' ability to participate actively in their care. For example, neurocognitive impairments can make it harder to understand and remember medical information [41]; physical limitations resulting from cardiotoxicity or pulmonary dysfunction may restrict engagement in health-promoting behaviors, such as exercise [42]; and psychological sequelae, including depression and anxiety, can reduce motivation and self-efficacy. These challenges do not affect all survivors uniformly but are particularly pronounced among those with severe (CTCAE Grade 3+) chronic conditions, thereby increasing the demands placed on their self-management and activation capabilities.

Interestingly, findings from the SJLIFE revealed that factors traditionally assumed to influence activation—such as age at diagnosis, sex, and treatment intensity—were not significantly associated with PAM-13 scores. This suggests that ongoing health challenges—particularly the burden of persistent late effects—may play a more critical role in shaping patient engagement than the severity of the initial cancer care. Instead, the severity of ongoing health problems, particularly CTCAE Grade 3 or higher, emerged as the strongest predictor of low activation. Marital and employment status also failed to show significant

associations, in contrast to trends observed in adult cancer population [43–47], suggesting different influencing mechanisms in younger survivors. It is important to emphasize that the associations identified in these studies are correlational in nature and do not establish causality. For example, although limited engagement in self-care is associated with lower activation scores, the directionality of this relationship remains unclear—low activation may lead to reduced self-care behaviors, or alternatively, barriers to self-care may diminish activation. Similarly, the relationship between psychological distress and activation is likely bidirectional and may be mediated by other factors, such as social support, symptom burden, or healthcare access. Longitudinal and intervention studies are needed to clarify these causal pathways. These observations highlight the need for personalized care plans that address physical limitations, include psychological support, and facilitate consistent access to comprehensive survivorship services. Interventions promoting physical activity, reducing emotional distress, and incorporating patient-centered educational resources may contribute to higher activation and better long-term outcomes in CCS.

Complementary findings from the Japanese Young Adult Cancer Survivors Study confirmed the reliability of PAM-13 in this age group. However, attempts to compare activation across different phases of survivorship were limited by issues of measurement invariance, suggesting that associated factors of activation may vary across cancer care continuum. These results emphasize the relevance of psychosocial and fatigue-targeted interventions in enhancing activation and self-management among young adult cancer survivors.

This systematic review has several important limitations. First, only two studies met our inclusion criteria, reflecting the early stage of research on patient activation using PAM-13 in CAYACS. This limited evidence base constrains the generalizability of findings and precludes meta-analysis or robust synthesis across different cancer types, age groups, or cultural contexts. Second, although screening and selection followed PRISMA guidelines, the search was limited to three major databases and focused specifically on PAM-13, which may have excluded relevant work using other activation-related constructs or instruments. Third, the included studies differed substantially in design (cross-sectional cohort vs. psychometric validation) and population (long-term CCS vs. young adults during/after treatment), introducing heterogeneity that complicates comparison. Fourth, both studies were conducted in high-income countries (the United States and Japan), limiting applicability to other healthcare systems and cultural contexts. Finally, the absence of intervention studies specifically targeting activation in CAYACS means that evidence regarding effective strategies to enhance activation in this group remains indirect, drawn primarily from adult oncology research. These limitations underscore the urgent need for further research in this area.

Evidence from adult oncology further supports the link between patient activation and improved coping mechanisms, reduced psychological distress, and increased overall well-being [48]. In the SJLIFE, lower PAM scores were associated with elevated symptoms of depression and anxiety, underscoring the potential value of early psychological intervention to support engagement in care. The role of caregivers and clinicians in fostering activation

is especially important in pediatric and young adult populations. Although adult survivors are typically expected to self-manage, younger survivors often rely on caregiver support [49], complicating the independent assessment of engagement. Achieving an appropriate balance between caregiver involvement and patient autonomy is crucial [50].

Although research specifically targeting CAYACS remains scarce, findings from adult oncology offer valuable insights that may guide the development of effective interventions for younger populations (Table 2). Several factors consistently associated with higher patient activation in adult cancer care—such as educational attainment, socioeconomic status, and access to digital self-management tools—are likely to influence activation trajectories among CAYACS as well. A recent review in adult oncology [8] identified key factors positively associated with elevated PAM-13 scores during survivorship, including higher educational levels (OR: 1.85, 95% CI 1.32–2.47), robust social support networks (OR: 1.68, 95% CI 1.32–2.10), participation in survivorship programs (mean PAM score = 68.5, SD = 8.2), and patients' perception of meaningful interaction time with clinicians (mean PAM level = 3.46 vs. 3.07, $p = 0.003$). Conversely, several factors were associated with diminished activation [8, 51], including exposure to cardiotoxic treatment (OR: 1.73, 95% CI 1.30–2.15), psychological distress (OR: 2.37 for depression, OR: 2.21 for anxiety), fear of cancer recurrence (mean PAM level = 2.98 vs. 3.39, $p = 0.004$), unemployment (mean PAM level = 2.93 vs. 3.36, $p = 0.004$), being unmarried (mean PAM level = 2.99 vs. 3.31, $p < 0.001$), and lower income (mean PAM level = 3.07 vs. 3.30, $p = 0.050$). These findings suggest that interventions aiming to enhance activation should account for social determinants of health and address disparities in access to care and health information.

A recent meta-analysis [30] spanning diverse health conditions reported modest overall improvements in patient activation following digital interventions, with an average increase of +2.05 points on PAM-13. Notably, only a subset of programs achieved the clinically significant threshold of ≥ 4 points—typically those incorporating tailored content alongside human support mechanisms, such as health coaching or peer mentoring. Although digital tools have demonstrated efficacy in chronic disease populations [7, 63], their effectiveness in oncology has yielded mixed results. In some instances, outcomes have been unfavorable; for example, a study involving non-small cell lung cancer patients reported a decline in activation over time ($p = 0.042$) [64], potentially due to disease progression, treatment-related side effects, or the cognitive load imposed by digital platforms.

Two recent systematic reviews [8, 28] further highlighted that non-digital or hybrid approaches were generally more effective than stand-alone digital tools. Programs delivered through telephone-based or nurse-led support consistently improved activation, facilitated symptom tracking, and enhanced adherence to care. These findings underscore the needs to integrate technological solutions with human-centered engagement—particularly for individuals with complex health and psychological needs.

Nevertheless, heterogeneity in study designs and intervention formats complicates efforts to draw definitive conclusions about which digital strategies are most effective and for which sub-

groups. Consistent with broader evidence [31], digital health interventions tend to be most successful when they are interactive, personalized, and embedded within a supportive framework. Programs offering tailored information—guided by patient-reported outcomes or needs assessment and reinforced through human interaction (e.g., peer-led sessions, coaching, or clinical follow-up), demonstrated the most substantial improvements in activation.

Oncokompas [59, 65, 66] is a web-based self-management platform designed to assist adult cancer survivors by offering personalized feedback on HRQoL, tailored self-care recommendations, and referrals to supportive care services. Users can access educational resources and receive guidance on managing long-term effects of cancer and its treatment [59]. The platform aims to enhance patient engagement, self-management skills, and well-being. Two major Dutch studies have evaluated its impact: a feasibility study with 101 breast cancer survivors and an RCT comprising 625 individuals across multiple cancer types. In the feasibility study, among the 68 participants who completed the program, significant gains in activation were observed (PAM-13: 55.8–60.5, $p = 0.007$). These improvements were likely facilitated by participants being in the early posttreatment phase, when receptivity to self-management support may be higher. However, outcomes varied across individuals, suggesting that digital literacy, baseline activation levels, and personal motivation likely moderated the intervention's effectiveness [8]. Conversely, the RCT did not demonstrate a statistically significant effect on overall PAM scores ($p > 0.05$), though participants with higher symptom burdens reported meaningful improvements in HRQoL and symptom management [59].

These contrasting results highlight the influence of contextual factors, such as baseline activation, timing since diagnosis, and cancer type. In the RCT, participants had higher initial PAM scores (mean 59.3, SD = 12.5) and were further removed from diagnosis (median 27 months), suggesting that they may have already adopted self-management strategies, reducing the relative impact of the intervention. This interpretation is supported by a large German study [58] involving 1125 adult outpatients with breast, prostate, and colorectal cancer, which confirmed good internal consistency of PAM-13 (Cronbach's $\alpha = 0.81$) but reported ceiling effects in 27% of individuals scoring above 80, thereby limiting the tool's sensitivity to detect change. Interestingly, these ceiling effects did not impair interpretability in the Japanese study of young adult survivors [37], possibly due to the differences in cultural context, timing of measurement, or cancer types.

Several studies support moderate to high activation levels in early stage breast cancer survivors. The Dutch ADAPT study [67] reported PAM scores ranging from 59.3 to 63.2 at diagnosis and at follow-up conducted at 3 weeks, 3 months, 6 months, and 12 months. Similarly, a study from Texas [68] involving HER2⁺ breast cancer patients found a mean score of 65.9, whereas a Mongolian cohort [69] reported a lower average of 51.2. Across these diverse contexts, psychological distress was consistently linked to lower activation, whereas associations with tumor type, fatigue, or physical functioning were less consistent. Notably, in the RCT, patients with head and neck or colorectal cancers derived the greatest benefit from Oncokompas, particularly in managing pain, swallowing issues, and weight fluctuations. On

TABLE 2 | Overview of studies reporting on PAM-13 in adult oncology populations.

Study	Study design	Population	Cancer journey	PAM-13 baseline (mean \pm SD, years)	PAM-13 post-intervention (mean, SD)	Age (mean \pm SD, years)	Main results	Detailed intervention type
POSTCARE study [52]	RCT IG ($n = 40$) CG ($n = 39$)	79 female breast cancer survivors (Stages 0–IIIB), median 116 days posttreatment	Short-term survivorship	Not reported	At 3 months post-intervention, IG: 62.20 \pm 14.29 CG: 62.38 \pm 15.71 ($p = 0.507$)	IG: 57.23 \pm 9.15 years CG: 59.51 \pm 11.96 years	<ul style="list-style-type: none"> - At 3-month no significant PAM-13 difference ($p = 0.507$) - Trends toward increased self-efficacy ($p = 0.07$) - Significant improvements in QoL (physical role function $p = 0.0009$, bodily pain $p = 0.03$, emotional role function $p = 0.04$) - Reduced depression symptoms ($p = 0.003$) - Enhanced social functioning ($p = 0.014$) and primary care engagement 	One 75-min survivorship coaching session using motivational interviewing. Creation of patient-owned SCP with treatment summary, goals (4 domains—cancer follow-up, general health, healthy lifestyle, and symptom management), PCP engagement plan
Wellness Beyond Cancer Program (WBCP) [53]	Non-randomized comparative study Personalized SCP ($n = 43$) Standardized SCP ($n = 44$)	87 breast cancer survivors	Survivorship	Personalized SCP: 43.5 \pm 6.0 years Standardized SCP: 40.6 \pm 7.7 years ($p = 0.07$)	Personalized SCP: 46.1 \pm 5.6 years Standardized SCP: 45.6 \pm 6.7 years ($p = 0.73$)	Personalized SCP: 65.7 \pm 8.5 years Standardized SCP: 62.8 \pm 10.5 years	<ul style="list-style-type: none"> - Both SCPs improved PAM-13 ($p < 0.001$) - No format superiority - Slightly higher perceived knowledge in personalized group ($p = 0.03$) 	Personalized SCP (~45 min) vs. Standardized SCP (~15 min); personalized included treatment summary and specific test dates; both covered follow-up guidelines
SMARTCare Study [54]	Pilot RCT IG ($n = 30$) CG ($n = 32$)	62 patients (lymphoma, CRC, or lung cancer, mostly Stage III/IV)	Acute phase	Overall: 67.4 (IQR 52.0–77.4) IG median: 75.5 (IQR 62.6–79.2) CG median: 62.6 (IQR 51.0–75.5)	At 6 months: – PAM-13 significantly improved in IG ($p < 0.001$) – Levels (3/4 vs. 1/2) significantly improved in the IG ($p = 0.002$) – 45.8% of controls (vs. 20% intervention) had a decrease in activation levels ($p = 0.028$)	60.5 years (IQR 47–68, range 19–84 years)	<ul style="list-style-type: none"> - Significant PAM-13 increase, reduced depression, preserved HR-QoL despite low engagement with online modules - IG: significantly lower depression scores at 6 months ($p = 0.012$) 	I-Can Manage (5-module online program) + 5 telephone coaching sessions by oncology nurses vs. enhanced education (clinic nurses trained in self-management techniques)

(Continues)

TABLE 2 | (Continued)

Study	Study design	Population	Cancer journey	PAM-13 baseline (mean \pm SD, years)	PAM-13 post-intervention (mean, SD) years	Age (mean \pm SD, years)	Main results	Detailed intervention type
SCEIP [55]	Longitudinal quasi-experimental pretest/posttest study	246 Malaysian women with breast cancer	Acute phase	IG: 64.79 \pm 7.66 CG: 64.92 \pm 8.63	IG: 68.13 \pm 7.84 years CG: 61.23 \pm 2.54 years	IG: 50.14 \pm 9.48 years CG: 49.89 \pm 11.03 years	- Significant improvement in PAM-13, reduced anxiety/depression, fewer treatment-related concerns	Two-session program: in-person education + individualized plan (by motivational interviewing) followed by home support via self-care diary, WhatsApp, calls, printed self-management booklet
Ostomy Self-Management Program [56]	Longitudinal one-group pilot study	38 ostomy cancer survivors (mainly rectal/bladder) in Arizona	Posttreatment (mean: 201 days since surgery)	63.3 \pm 13.3 years	Post: 78.2 \pm 13.9 years 6 months: 74.5 \pm 17.4	71.3 \pm 7.4 years	- Significant improvements in activation ($p < 0.0001$), self-efficacy ($p = 0.008$), physical and social well-being ($p < 0.05$), and reduced anxiety at follow-up ($p = 0.02$)	5 Interactive sessions led by nurses + peer survivors Topics: self-care, nutrition, physical activity, coping, body image, communication, sexuality Includes caregiver and booster sessions
Lymphedema education program [57]	Quasi-experimental, pre-post (no CG)	44 Turkish breast cancer women with 1/2 lymphedema	Post-surgery	58.83 \pm 18.28 years	73.83 \pm 16.90 years	52.6 \pm 8.3 years	- Significant improvements in patient activation, upper extremity volume, lymphedema symptoms, compliance, daily living activities, and UE disability	One 40-min individualized educational session + booklet + 12-month follow-up calls and compliance chart tracking. Focus: skin care, compression, self-lymphatic drainage, and exercises
German Oncology Activation Study [58]	Controlled, non-randomized, longitudinal study	1125 cancer outpatients (Germany)	All stages (diagnosis, recurrence, progression)	Overall: 69.7 \pm 14.2 years IG: 70.13 \pm 13.7 years CG: 68.98 \pm 14.95 years	No intervention, static measure	57.1 \pm 12.2 years	- High baseline activation (Level 4), good reliability ($\alpha = 0.81$), significant ceiling effects	No intervention (observational study)

(Continues)

TABLE 2 | (Continued)

Study	Study design	Population	Cancer journey	PAM-13 baseline (mean ± SD, years)	PAM-13 post-intervention (mean, SD)	Age (mean ± SD, years)	Main results	Detailed intervention type
Oncokompas [59]	RCT (non-blinded, parallel groups)	625 survivors (CRC, HNC breast cancer, or lymphoma) IG (n = 320) CG (n = 305) (the Netherlands)	3 months to 5 years posttreatment	IG: 59.2 ± 12.5 years CG: 59.5 ± 12.6 years	IG: 60.0 ± 13.7 years CG: 58.3 ± 12.7 years (6 months)	Median: 65 years (IQR 56–71)	- No significant PAM-13 improvement ($p = 0.41$); improvement HR-QoL ($p = 0.048$); benefits in tumor-specific symptoms (mostly in HNC and CRC)	Oncokompas eHealth tool Three components: <ul style="list-style-type: none">• Measure: patient-reported outcome measures (PROMs)• Learn: tailored feedback with color-coded risk and self-care tips• Act: personalized suggestions for supportive care options. Usable independently of HCP
ADAPT Study [60]	Cross-sectional observational study (panel survey)	524 Dutch cancer survivors (208 <65 years)	>2 years post-diagnosis	Total: 58.1 ± 13.8 years Age <65: 58.7 ± 15.6 years	Not applicable	Total: 66 years	- No significant association between PAM-13 and work, lower activation was significantly related to more work-related	No intervention

(Continues)

TABLE 2 | (Continued)

Study	Study design	Population	Cancer journey	PAM-13 baseline (mean ± SD, years)	PAM-13 post-intervention (mean, SD)	Age (mean ± SD, years)	Main results	Detailed intervention type
CanDirect [61]	Multisite RCT	245 cancer survivors with mild–moderate depression IG (<i>n</i> = 121) CG (<i>n</i> = 124) (Canada)	1–10 years postprimary treatment	<i>Not applicable</i>	At 6 months IG: 64.1 ± 15.6 years CG: 59.7 ± 15.0 years (<i>p</i> = 0.041)	IG: 58.3 ± 11.3 years	<ul style="list-style-type: none"> - Significant reduction in depressive symptoms (<i>p</i> < 0.001), improved activation (<i>p</i> = 0.041), mental QoL, reduced anxiety, and fewer depression diagnoses 	<ul style="list-style-type: none"> • Depression Self-Care Toolkit (paper or online) • Up to 15 brief coaching calls (mean: 7.8 calls, 15 min each) by trained lay coach • Personalized guidance, SMART goal-setting, relapse prevention plan • Follow-up: 6 months
Hübner et al. [62]	Cross-sectional survey study	639 German patients (mostly gynecological, gastrointestinal, and urogenital cancers)	All phases	67.91 ± 18.27 years	No intervention	51–70 years (majority)	<ul style="list-style-type: none"> - Higher activation associated with more CAM interest (<i>p</i> = 0.004) and usage (<i>p</i> = 0.012); (homeopathy, prayer, meditation, yoga, and specific diets) 	No intervention

Abbreviations: CAM, complementary and alternative medicine; CCS, childhood cancer survivors; CG, control group; CRC, colorectal cancer; HCP, healthcare professionals; HNC, head and neck cancer; HR, health-related; IG, intervention group; IQR, interquartile range; OR, odds ratio; PAM, Patient Activation Measure; PCP, primary care physician; QoL, quality of life; RCT, Randomized Controlled Trial; SCP, survivorship care plan; SD, standard deviation.

the basis of these results, the authors recommend tailoring digital interventions to specific cancer types, simplifying user assessments, and integrating multimedia content to enhance accessibility. Adapting such tools for younger, digitally proficient populations could further improve engagement and long-term self-management.

Beyond intervention studies, the psychometric performance of PAM-13 in oncology has been further examined. A large German validation study [67] confirmed the scale's overall reliability but also revealed limitations. In addition to ceiling effects, exploratory factor analysis suggested that the instrument may not be strictly unidimensional in oncology contexts, in contrast to findings in chronic disease populations. A two-factor model emerged, distinguishing between knowledge/self-confidence and perceived importance of self-management. Patient activation correlated moderately with self-efficacy and HRQoL, whereas associations with demographic variables were weaker than anticipated. Although higher education attainment and first-diagnosis status were linked to increased activation, disease recurrence or progression predicted lower scores. Importantly, no significant differential item functioning was observed for age, gender, or education, indicating consistent measurement across demographic subgroups.

Recent systematic reviews [8, 28, 29] have deepened our understanding of the factors influencing patient activation and the effectiveness of related interventions. Education remains a consistent predictor, emphasizing the critical role of meaningful clinician-patient communication. Interestingly, variables, such as gender and broader sociodemographic characteristics, appear to exert less influence in oncology than in chronic diseases, where social determinants of health are typically more pronounced predictors of activation.

Further insights are offered by Ng et al. [70], who evaluated the psychometric properties of PAM-13 across diverse health-care settings. Although the instrument generally demonstrated strong internal consistency and construct validity, limitations were raised about its content relevance and measurement invariance in non-Western, older, or socioeconomically disadvantaged groups. Conversely, studies conducted in European contexts—and among younger, digitally connected individuals—reported more robust performance, supporting its use in initiatives such as the e-QuoL project. This multi-country European project focuses on CAYACS, for whom active engagement in care is particularly critical and complex. Nonetheless, future applications should be sensitive to subgroup variability, especially in individuals with cognitive impairments or limited health literacy, and should consider integrating complementary measures when assessing more diverse or vulnerable populations.

In conclusion, PAM-13 represents a valuable metric for assessing cancer survivors' engagement in their own care. Its expanding adoption across cancer types, disease stages, and patient demographics attests to its relevance in oncology. Among adult survivors, higher activation has been consistently associated with reduced fatigue and psychological distress, improved quality of life, and adherence to follow-up care. Although preliminary findings in CAYACS suggest similar trends, further research is

needed to establish the measure's responsiveness and predictive utility in younger cohorts.

The findings presented here highlight the potential of activation-oriented strategies—including personalized education, psychosocial interventions, digital tools (e.g., Oncokompas), and hybrid coaching models (e.g., SMARTCare)—for fostering sustained engagement and effective self-management. Although ceiling effects may limit PAM-13's sensitivity in highly activated individuals, structured survivorship programs and shared decision-making remain critical components of effective interventions.

To enhance the interpretability and application of PAM-13 outcomes, future research and evaluation efforts should carefully account for key confounding factors, including

- Educational background and health literacy,
- Psychosocial distress (e.g., anxiety, fear of recurrence),
- Healthcare access (follow-up frequency, communication quality),
- Treatment-related toxicities that may impair self-management capacities.

As oncology care continues to evolve toward patient-centered paradigm, PAM-13 provides a meaningful framework for designing and evaluating interventions aimed at strengthening patient autonomy, self-efficacy, and care adherence—cornerstones of equitable and sustainable survivorship models.

From the perspective of CAYACS, age-appropriate and developmentally tailored interventions are essential to facilitate the transition from acute treatment to LTFU. Structuring survivorship care according to the principles of the Chronic Care Model—emphasizing continuous education, individualized support, and strong provider-patient partnerships—may help maintain activation over time and contribute to better long-term health outcomes.

Author Contributions

All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by Charlotte Demoor-Goldschmidt. The first draft of the manuscript was written by Charlotte Demoor-Goldschmidt and all authors commented on previous versions of the manuscript. Charlotte Demoor-Goldschmidt, Anne Maas, and Jelena Roganovic did the final version of the manuscript answering the reviewers' comments. All authors read and approved the final manuscript.

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Ethics Statement

The authors have nothing to report.

Consent

All authors read and approved the final manuscript and consented to its publication.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

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APPENDIX: Search Strategy

("Patient Activation Measure"[Title/Abstract] OR "PAM-13"[Title/Abstract] OR "PAM 13"[Title/Abstract]) AND ("childhood cancer survivor"[Title/Abstract] OR "childhood cancer"[Title/Abstract] OR "pediatric cancer"[Title/Abstract] OR "paediatric cancer"[Title/Abstract] OR "adolescent cancer"[Title/Abstract] OR "young adult cancer survivor"[Title/Abstract] OR "AYA cancer"[Title/Abstract])