



Consensus document between oncology and primary care for the follow-up of cancer survivors

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Abstract

The exponential growth of cancer survivors represents a major healthcare challenge, with more than 23 million people in Europe and 2.2 million in Spain requiring long-term specialized follow-up. Five-year survival has reached 60% in our country, creating a growing population of long-term survivors who need comprehensive care beyond the stage of active oncological treatment. This consensus document between oncology and primary care professionals establishes a care framework based on shared management for the follow-up of cancer survivors. The proposed model is based on the principles of continuity and ongoing communication, equity in access, and efficiency in resource use, recognizing that the needs of these patients go beyond purely medical aspects to encompass physical, psychological, social, and functional dimensions. This proposal defines a dynamic risk stratification that enables the identification of high-risk patients, who will continue to receive preferential hospital follow-up, and low-risk patients, whose care can be led by primary care with the support of other specialists. Specific roles are established for each level of care, along with bidirectional communication pathways and multidisciplinary coordination tools that include shared medical records, agreed protocols, and rapid referral channels.

Keywords Cancer survivors · Primary care · Oncology · Shared monitoring · Risk stratification

Introduction

An increasing number of people is undergoing oncological processes, with estimates suggesting that there are now more than 23 million cancer survivors in Europe. Moreover, when considering patients who have survived more than 10 years, the figure has risen from over 5 million in 2010 to more than 8 million in 2020 [1].

This increase in survivors is due to several factors, including the increased incidence of cancer [2, 3], improvements

in diagnostic procedures with the incorporation of screening systems or early detection, and therapeutic innovation. In Spain, the number of cancers diagnosed in 2025 will reach 296,103 cases, representing a slight increase of 3.3% compared to 2024, with 286,664 cases, according to a report by the Spanish Society of Medical Oncology (SEOM) and the Spanish Network of Cancer Registries (REDECAN) [3]. Nevertheless, 5-year survival during the period 2008–2013 was close to 60% for both sexes combined, although significant differences exist between them (55.3% for men and 61.7% for women). The estimated prevalence for 2020 was over 2,200,000 individuals, with a sex distribution of 1,066,959 men (47.1%) and 1,198,193 women (52.9%) [1–3].

The care of long-term cancer survivors in Spain is supported by the 2021 update of the National Health System Cancer Strategy [4], which prioritizes the development of individualized follow-up plans, coordination between primary care and oncology, and the training of professionals in the follow-up of these patients. This aims to improve early detection of adverse effects, recurrences, second tumors,

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and long-term complications, aligning with national and European objectives. Furthermore, the strategy promotes the implementation of specific care pathways and models adapted to the characteristics of each survivor group, ensuring comprehensive and continuous care that enhances their quality of life and social integration, in accordance with the recommendations and specific plans developed by the Ministry of Health, such as the Individualized Follow-up Plan for Long-term Breast Cancer Survivors [5].

Definition of survival length and stages

Over the years, various definitions have been formulated for cancer survivors. In 2012, the Spanish Society of Medical Oncology (SEOM) defined long-term cancer survivors as a person free of disease after at least 5 years from the diagnosis and treatment of cancer, which in most cases signifies cure. This period may be more or less extensive depending on the type of tumor and the risk of recurrence (for example, for breast cancer, 5 or 10 years are established depending on the risk of relapse) [6, 7].

Recently, SEOM has published an updated document that adopts a broader definition of cancer survivor: any person with an oncological diagnosis, including those beginning treatment, continuing or completing it, or being in clinical remission [8]. In this sense, it is worth mentioning that different stages of cancer survival are each described with different objectives, experiences, needs, and dynamics [8, 9].

This consensus document will primarily focus on survivors in the permanent or late survivorship stage, formerly known as long-term cancer survivors according to the classical definition.

Models of care and care framework

Various follow-up models for cancer survivors have been described [8, 10, 11], and their health outcomes appear potentially comparable; however, each has distinct and evident strengths and weaknesses. One approach is the hospital-based model led by oncology specialists, in which continuity of care focuses on the identifying oncological problems and the detecting recurrence or second tumors. Nevertheless, this model is insufficient for covering the full spectrum of patient needs. Conversely, the community-based model, led by primary care specialists, focuses on general health, prevention, and health promotion, but displays lower adherence to oncological recommendations. Furthermore, the heterogeneity of oncological processes makes it difficult to ensure appropriate management of cancer-related issues.

Regarding the mixed model or shared-care model between primary care and oncology, a high level of coordination and clear definition of roles among the various professionals involved is required. Furthermore, one can

refer to a model with equal sharing across all the stages of the process or to a transitional model in which the responsibility of care shifts more toward the hospital or primary care depending on the patient's stage in the survivorship process.

Other models, less common and with limitations in our setting, include specialized follow-up unit models, nurse-led models, and self-management models in which an educated patient is responsible for their own follow-up plan. All these should go beyond medical care to encompass coordination of non-medical care, social assistance, financial support, and other related needs.

Hospital discharge following oncological treatment is a critical moment for patients returning home and to their primary healthcare center. This phase is characterized by discontinuity of care and the absence of standardized protocols for long-term follow-up. Such circumstances can lead to fragmented care, redundant tests, delays in detecting complications, and increased healthcare burden and costs, as well as confusion and uncertainty for patients due to the lack of standardized procedures.

Universal coverage provided by the Spanish public healthcare system, the high quality of primary care, and the fact that oncological care effectiveness indicators are among the best in developed countries should serve as the pillars upon which to build a model for survivor care [6, 7].

Consensus objective

In Spain, coordination between oncology and primary care for the follow-up of cancer survivors has notable precedents, although the implementation of structured models remains limited and heterogeneous [12].

A comprehensive care plan should be able to achieve several key objectives, such as highlighting issues in the care of cancer survivors, identifying major organizational, resource, or training needs, and consequently enabling continued care as an individualized, multidisciplinary, and coordinated process. This approach should allow for the detection of recurrences or second malignancies, identification and management of cancer-related and treatment-related sequelae, as well as optimization of the overall health and well-being of the cancer survivor and their environment.

The objective of this consensus document is to establish a general framework for comprehensive care of the cancer survivor patients. To achieve this, and following an exhaustive literature review, general recommendations are described to ensure continuous care for cancer survivors, which can be adapted to each environment and each health area.

Proposed consensus model

Shared-care management model

A shared-care management model should be grounded in principles such as continuity of care, person-centered attention, equity in access, efficiency in resource use, and the quality of care based on the best available evidence. The shift toward a comprehensive care model must be undertaken in a planned manner, ensuring patient safety and the satisfaction of all stakeholders involved. This model must recognize that the needs of cancer survivors extend beyond treatment effectiveness, including physical, psychological, social, and functional aspects that impact quality of life.

The review of national and international experiences shows that the most effective models are those that establish clear communication protocols, bidirectional interaction tools between different levels of care, specific training programs for professionals, rapid detection circuits, and relationships among care levels. The implementation of

collaborative models between oncology and primary care requires a healthcare architecture based on dynamic risk stratification [13, 14].

There are patients who can be classified as high risk, characterized by a higher likelihood of relapse, development of second malignancies (for example, individuals with hereditary syndromes), or complex late complications, where the primary responsibility for care rests with oncology, supported and coordinated with primary care. Conversely, there are also low-risk patients, without complications and with a lower risk of recurrence; primary care teams take the lead in management, supported and coordinated with oncology (Fig. 1) [15].

Taking these premises into account, shared management between primary care and oncology is essential to provide patients with personalized follow-up based on their specific risk profile.

Circuits and means of communication: care route

The transition to a shared-care management model should begin with a comprehensive patient assessment

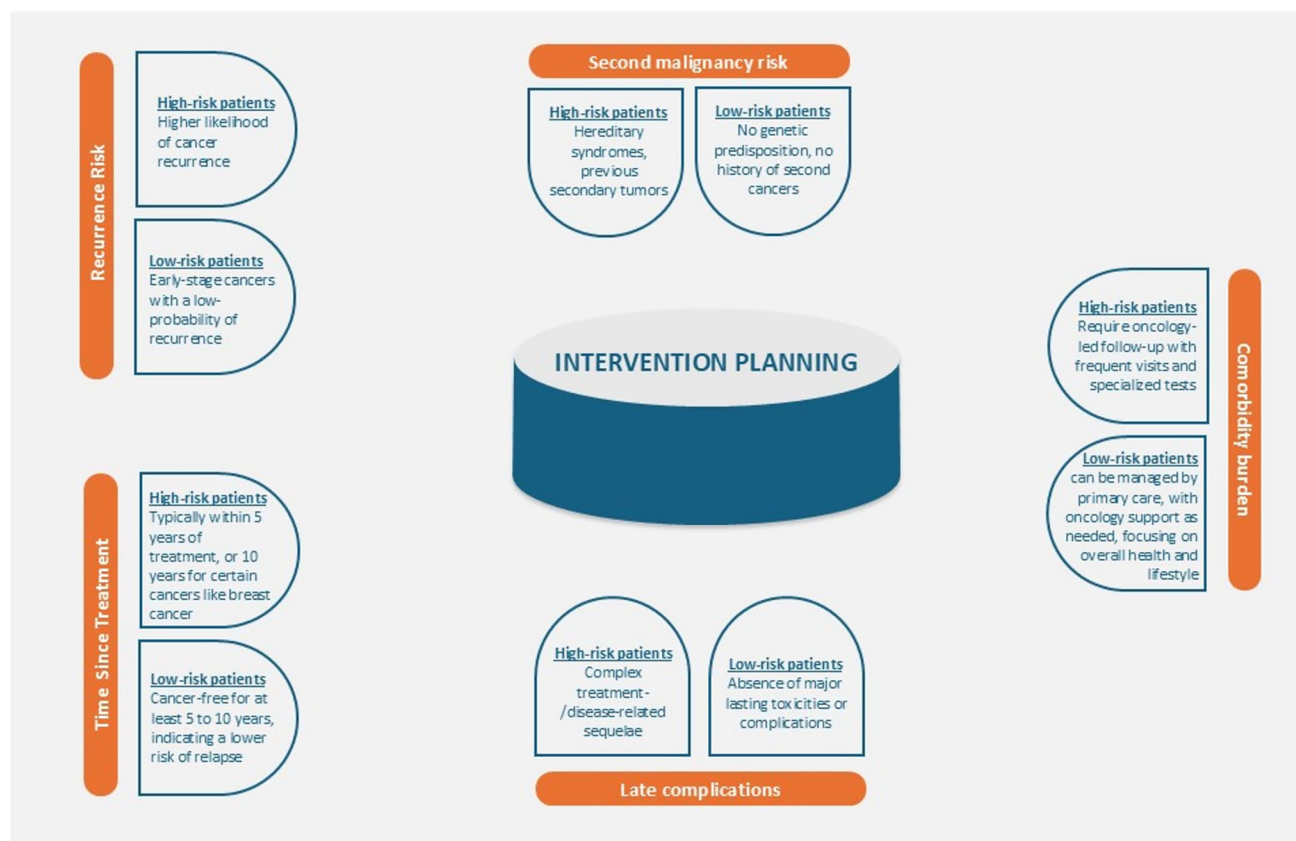


Fig. 1 The characteristics of high-risk and low-risk patients. In high-risk patients, the primary responsibility for care rests with oncology, supported and coordinated with primary care, while in low-risk patients, primary care teams take the lead in management, supported

and coordinated with oncology. To illustrate this stratification, a resected stage IV colon cancer without treatment could be considered high risk, and a stage I colon cancer low risk

by the oncology team, enabling stratification according to recurrence risk, presence of sequelae, comorbidities, and specific needs. This categorization or classification will determine the optimal timing for hospital discharge, the intensity of follow-up, and the most appropriate level of care for each phase. The assessment should be multidimensional, including physical, functional, psychological, and social aspects, as well as the patient's capacity for self-care and health management.

Communication at all follow-up stages should be bidirectional, and simple and effective pathways must be established to enable optimal communication between professionals.

Various studies justify the need for a designated reference professional at the hospital level for patients undergoing oncological processes. This professional coordinates the different services and conducts follow-up, aimed at preventing complications, identifying recurrences, supporting self-care, providing posttreatment advice, addressing patient needs, and ensuring continuity of care and effective coordination within the patient's environment. The ASISTO report [16] highlights the importance of guaranteeing structured support and accompaniment throughout the entire process by integrating hospital and primary care through bidirectional communication pathways and tools, thereby avoiding fragmentation and discontinuity that negatively impact clinical outcomes and patient experience. The role of the liaison oncologist, an oncologist responsible for coordinating scientific and organizational aspects and managing communication with primary care, is considered essential to ensure the smooth operation of the shared-care program between primary care and oncology.

The proposed shared-care management model must be founded on the elimination of territorial inequities that currently persist in access to resources, services, and follow-up models for cancer survivors. To overcome these significant territorial inequities, actions are proposed ranging from the availability of reference professionals and the implementation of shared models to access to technological tools and agreed clinical pathways. The implementation of specific clinical practice guidelines enhances primary care's ability to manage patient follow-up. The transition process requires a discharge report with specific long-term follow-up recommendations that include:

- Complete information about the diagnosis, tumor stage, treatments received (surgery, radiotherapy and/or chemotherapy, targeted therapies, and immunotherapy with full names and without acronyms), and the main toxicities presented or persisted over time.
- Individualized follow-up plan with potential late effects to monitor, proposed schedules for primary care and

hospital consultations, and recommended tests based on available evidence.

- Clearly established criteria for bidirectional referral.

General protocols for oncological processes based on scientific evidence serve as guides and facilitate follow-up, but individualization according to each patient's clinical situation and oncological history should be standard practice. This protocol should be jointly designed by primary care and oncology medical professionals to ensure its feasibility and acceptance. Furthermore, oncology nursing professionals can play a crucial role as case managers, ensuring the continuity of information and correct implementation of the care plan.

Roles and responsibilities of each level of care

Among the arguments in favor of oncology assuming follow-up are their expertise in detecting recurrences, managing late complications secondary to treatments, and the trust that patients place in this specialty.

Support to follow-up by family medicine is based on the comprehensive knowledge these professionals have of individuals, their comorbidities, and treatments for these conditions (although not oncological treatments and their side effects). In addition, family physicians are more accessible, especially in contexts where access to hospital specialties is limited [17]. Some studies also indicate that follow-up from primary care is safe for both relapse detection and quality of life [13]. The longitudinal care provided by primary care to the general population leads to greater satisfaction and improved health outcomes [18], lower mortality [19], and may reduce avoidable hospitalizations [20]. Therefore, leveraging all these advantages of primary care in the management of oncology patients would enhance their well-being.

However, there are legal and administrative barriers depending on the Autonomous Communities, such as limitations in requesting certain diagnostic tests, which restrict the capacity of primary care to provide comprehensive follow-up. Therefore, establishing the key roles and pathways for the shared follow-up model requires ensuring primary care has access to essential tests needed for long-term monitoring of cancer survivors and to providing the necessary resources to carry them out.

Figure 2 illustrates a simple shared-care model for cancer survivors, delineating roles and formal communication points between professionals. During the initial diagnosis and intensive oncological care as well as the commencement of follow-up, comprehensive coordination largely remains within oncology, and often this leadership persists beyond the initial period. Concurrently, preventive care and management of comorbid conditions, typically handled by primary care, are relegated to a secondary role, with priority given

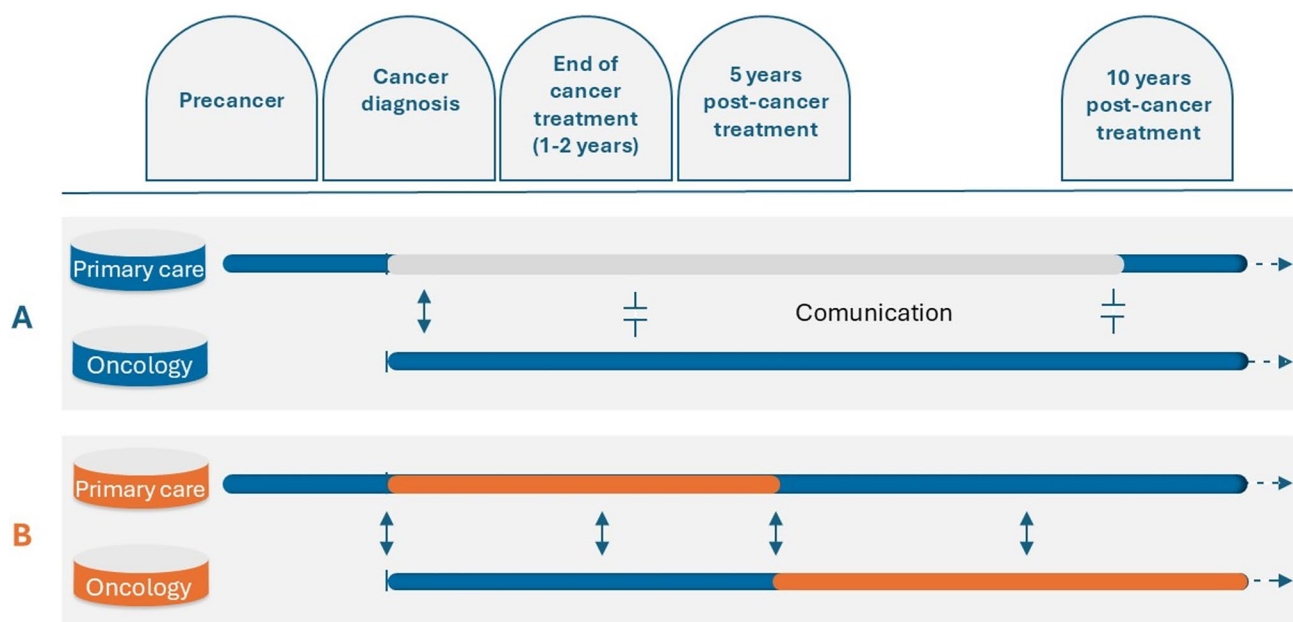


Fig. 2 Proposed model for shared follow-up of cancer survivors. **A** Usual practice; **B** community-based shared practice. Blue line indicates primary responsibility; orange line indicates secondary respon-

sibility; and gray line indicates unclear responsibility, which is often associated with the discontinuation of health prevention/promotion processes other than oncological processes

to the acute oncological process. Once initial oncological therapy is completed and the acute phase has passed, follow-up continues jointly and in coordination between the medical oncology and radiation oncology departments. The first 5 years after diagnosis and treatment are usually considered, although for tumors with a prolonged risk of relapse, such as breast cancer, this threshold may extend to 10 years. However, primary care gradually assumes responsibility for addressing the physical, emotional, occupational, and social needs of survivors, resuming comprehensive coordination. Oncology provides primary care specialists with a detailed discharge report as previously described. It is crucial that this information exchange not be limited to a single moment, as recommendations may change over time. Therefore, regular communication between both care levels is essential, with frequency depending on individual risk and comorbidities. If a relapse occurs, a rapid pathway will allow direct contact with the reference oncologist [21].

In summary, a series of roles and responsibilities for both oncology and primary care can be defined (Table 1) [21].

Coordination and communication tools

The cancer continuum, as a complex set of diseases, requires an integrated care system that considers the full course of the process. Optimization of new organizational models should therefore prioritize integration across care settings, promoting efficient use of resources and greater satisfaction among those affected by the disease [22]. The optimization of care

pathways requires designing parallel circuits for acute complication management and scheduled follow-up. A unified electronic health record should incorporate automated alerts for key parameters.

Teleconsultation enables the establishment of “fast-track” referral pathways that facilitate patient reentry to the hospital and serve as a communication tool between levels of care. It is essential to know rapid referral circuits in case of suspected recurrence and the “clinical pathways” that guarantee efficient coordination between medical specialties when needed. Likewise, establishing the role of the “liaison coordinator”, medical or nursing personnel from hospital care who facilitate communication between primary care and hospital services, is crucial, with the need for a direct communication system with this professional clearly defined. In addition, to support long-term cancer survivor follow-up, it may be necessary to activate other mechanisms that systematically reinforce existing knowledge and support resources [23]. Thus, among others:

- Enable bidirectional tools to review specific cases (teleconsultations or the available pathways in each setting).
- Design and disseminate protocols among hospital specialists and primary care on “clinical pathways”, with recommendations for long-term follow-up of survivors.
- Strengthen the creation of patient schools and involve patients in decisions about their treatment and follow-up through information that enables shared decision-making.

Table 1 Roles and responsibilities of oncology and primary care

Common objectives	Oncology	Primary care
Joint development and updating of follow-up protocols, tailored to patient characteristics and the local context	The oncology team will retain the responsibility for specific follow-up related to potential recurrences, complex late effects of treatments, and new emerging therapeutic options.	The primary care team will progressively assume responsibility for comprehensive follow-up, focusing on:
Organization of training activities for professionals in both settings and, where appropriate, for patients themselves	It will be responsible for:	Coordinating the resources required by the patient
Establishment of agile and effective bidirectional communication channels, including rapid referral pathways and clear criteria for hospital readmission	Conducting the assessment and identification of long-term cancer survivors	Conducting long-term oncological follow-up based on each patient's individualized report
Planning and periodic review of complex cases through dedicated sessions or meetings	Preparing the discharge report with the personalized follow-up plan	Managing comorbidities and health problems not related to cancer
Design of tools for joint evaluation of outcomes and patient experience	Ensuring return to the hospital when necessary	Carry out prevention and promotion of healthy lifestyles, and secondary, tertiary, and quaternary prevention
	Performing periodic reviews for high-risk patients or those with complex sequelae	Providing psychosocial support to the patient and family
	Being available to address specific consultations during follow-up	Early detection of complications and timely referral when necessary
	Providing psychosocial support to the patient and family	

The success of the shared model depends on effective tools that facilitate communication and information exchange:

- Shared electronic medical records with access to reports and tests from both levels of care.
- Agreed follow-up protocols by tumor type (while individualization to the patient's clinical situation and oncological history should be the standard, protocols facilitate follow-up).
- Direct communication channels (institutional email, consultation phone line, new technologies).
- Regular coordination meetings to review complex cases or organizational issues.
- Telemonitoring/telepresence platforms for specific cases where deemed necessary.

These tools must be integrated into routine workflows, minimizing additional administrative burden and facilitating shared decision-making with patients.

Care path diagram

Based on the collected information, Fig. 3 presents a proposed follow-up diagram for these patients according to the phase they are in.

Training

The care of cancer survivors requires that professionals involved in follow-up acquire specific competencies encompassing clinical knowledge, communication skills, and teamwork capacity. Training must include oncology specialists, family and community medicine, and nursing, organized into multidisciplinary teams capable of adapting national guidelines to the characteristics and resources of each health area [22]. This adaptation should consider the local epidemiological burden and ensure that recommendations are applicable in the specific care setting. The training plan should be structured from undergraduate education, ensuring early awareness and acquisition of basic tools, through continuing professional development programs that update knowledge and competencies throughout the professional trajectory [13].

Key training content should focus on identifying and managing late effects of cancer and its treatments, early recognition of red flags for suspected recurrence or significant toxicities, and comprehensive management of physical and emotional sequelae. Professionals must also be able to address psychosocial aspects specific to long-term survivorship, identify available health system resources, and understand established referral pathways. Learning should

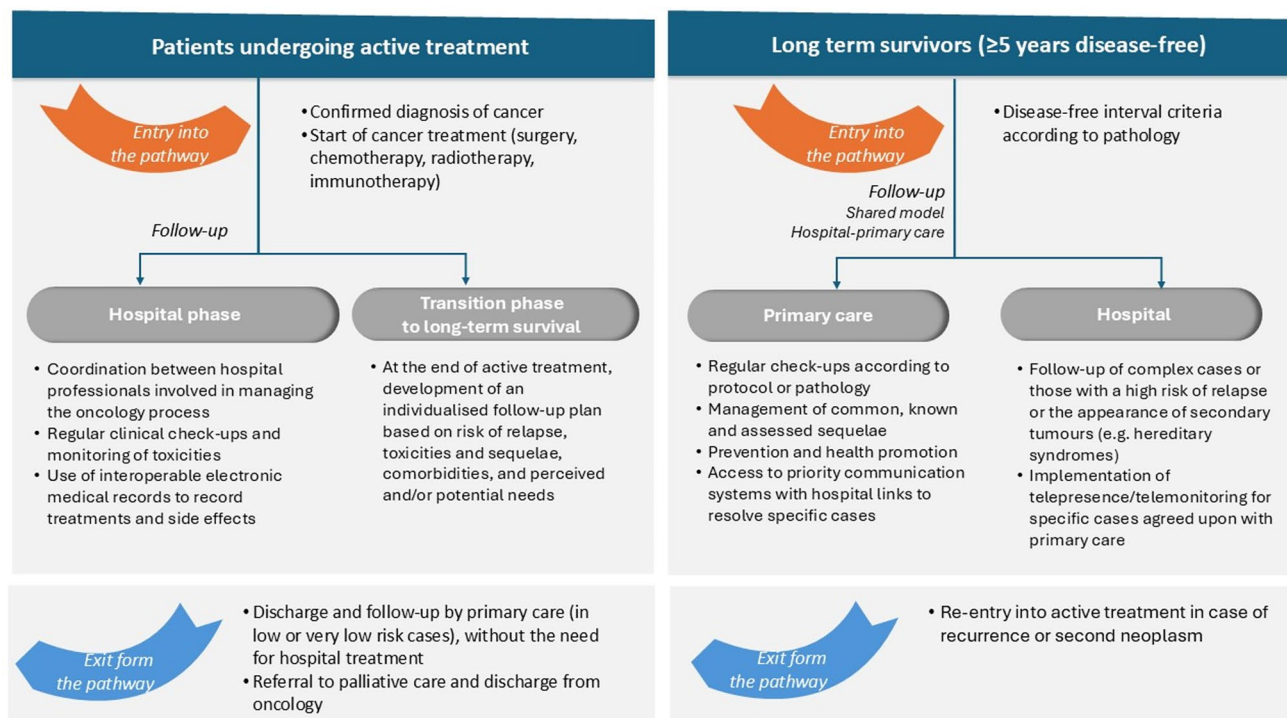


Fig. 3 Proposed follow-up diagram of these patients depending on whether they are receiving active treatment or are long-term survivors

be predominantly practical, accessible, and accredited, using innovative methodologies such as joint clinical sessions across care levels, dedicated courses, and rotations in specialized units. In addition, training requires periodic updates to incorporate emerging evidence and recommendations, with the goal of maintaining quality of care standards aligned with the evolving needs of this population.

Evaluation

The evaluation of the shared-care follow-up model for long-term cancer survivors should include indicators that assess quality, patient experience, and system efficiency. Key care quality aspects include adherence to individualized follow-up plans, timeliness of response when recurrence or second neoplasia is suspected, and adherence to secondary prevention recommendations outlined in protocols. These variables enable identification of areas for improvement in clinical management and coordination across levels of care.

Patient experience is a key dimension in evaluation, including satisfaction with coordination and continuity between oncology and primary care, and perceived accessibility of the system as commonly assessed in implementation studies. Health-related quality of life reported by survivors, measured with validated instruments, provides essential information on the real impact of the care model

on the daily life, complementing clinical and organizational data.

Measuring the efficiency of the model requires analyzing parameters such as the reduction of duplicate tests and avoidable hospitalizations, as well as the optimization of resources. Cost-effectiveness analysis, compared with traditional hospital-centered models, may demonstrate benefits in both health and economic terms, especially when coordination and role designation or definition of responsibilities are effective. Quality of life reported by survivors and the analysis of associated costs complete this evaluation, allowing for a balance between the effectiveness and sustainability of the model.

The creation of a registry of cancer survivors through the implementation of indicators within a preferably shared electronic health record across levels of care would represent a major step forward in understanding our long-term survivors and could serve as a first step, with the support of technological innovation, toward more comprehensively capturing the demands and needs of our patients.

Patient involvement and associations

Active involvement of patients in long-term cancer follow-up is a central element of the comprehensive care model. It is essential that survivors receive understandable, tailored information about potential late effects of the disease and its treatments, as

well as about warning signs that may indicate a recurrence or significant complications. This information should facilitate shared decision-making during consultations, enabling informed patients to participate in choosing follow-up options, especially when there are different alternatives regarding the frequency of tests or procedures to be performed. Communication cannot be limited to verbal exchanges during the visit; it is crucial to reinforce it with written, graphic, or digital materials adapted to each patient's level of understanding, in order to ensure assimilation and later consultation of key concepts. Likewise, it is advisable that messages be reviewed and reinforced at each follow-up visit, adjusting the content to the clinical reality and evolving needs of the patient.

Patient associations play a complementary and necessary role, providing psychosocial resources that help address emotional and social sequelae. These organizations organize mutual support groups, facilitate the exchange of experiences and strategies among individuals sharing a survival process, and help to reduce isolation. Furthermore, they develop educational materials tailored to the different stages of the care process, making it easier to understand follow-up pathways and to make informed decisions. The accumulated experience of these associations enables them to identify inadequacies in the care circuits and unmet care needs, and the feedback they provide is valuable for adjusting services to the actual demands of survivors. In addition, their involvement in awareness-raising and outreach activities increases collective knowledge about the importance of follow-up and the need for comprehensive, continuous care, thereby fostering active patient participation in their own health care and in the improving care models.

Conclusion

Shared-care between oncology and primary care for the follow-up of cancer survivors represents a care model that can improve the quality of care, optimize available resources, and respond more effectively to the multidimensional needs of this growing population. Successful implementation requires careful design of the care pathway, with agreed-upon protocols, effective communication tools, specific training for professionals, and active patient involvement.

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Data availability Not applicable.

Declarations

Conflict of interest Rosario Vidal-Tocino declares that she has received fees for giving presentations, consulting, and/or attending courses or conferences from Amgen, Merck, Servier, Bristol Myers Squibb, MSD, GSK, Roche, Pierre-Fabre, Astellas, and Lilly. María Hernández Miguel declares that she has received fees for giving presentations or talks from Astellas. Lourdes Martínez-Berganza Asensio declares that she has received fees for giving presentations and attending courses from Astra Zeneca, Boehringer Ingelheim, Sysmex, Astellas, and GSK. Ruth Vera García declares that she has received fees for giving presentations and consulting for Roche, Amgen, Takeda, MSD, and Servier. Elena M. Brozos Vázquez declares that she has received fees for giving talks, attending conferences, and consulting. Cruz Bartolomé-Moreno, Rafael Manuel Micó Pérez, Raúl Hernanz, Yolanda Ginés, Fátima Santolaya Sardinero, and Jacinto Batíz Cantera declare that they have no conflicts of interest.

Ethical approval This research presents an accurate account of the work performed, all data presented are accurate and methodologies detailed enough to permit others to replicate the work. This manuscript represents entirely original works and or if work and/or words of others have been used, that this has been appropriately cited or quoted and permission has been obtained where necessary. This material has not been published in whole or in part elsewhere. The manuscript is not currently being considered for publication in another journal. No generative AI or AI-assisted technologies were used in the writing or image creation process. All authors have been personally and actively involved in substantive work leading to the manuscript and will hold themselves jointly and individually responsible for its content.

Informed consent For this type of study formal consent is not required.

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