Master of Public Health

Master de Santé Publique

Evaluating Healthcare Professional Perceptions of Preliminary Tools for Managing Cancer Aftereffects: A Regional Guide Development Initiative

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Abbreviations

AYA	Adolescents and Young Adults
DSRC	Dispositif Régional Spécifique du Cancer (Regional Cancer Task Force)
INCa	Institut National du Cancer (French National Cancer Institute)
MASCC	Multinational Association of Supportive Care in Cancer
PACA	Provence-Alpes-Côte d’Azur
TAM	Technology Acceptance Model
WHO	World Health Organization

Abstract

EVALUATION BY HEALTHCARE PROFESSIONALS OF DECISION SUPPORT TOOLS FOR IDENTIFYING SEQUELAE AND PATIENT REFERRAL

Context According to the VICAN 5 study, 63.5% of patients report suffering from sequelae five years after their diagnosis of cancer. In 2022, as part of the Ten-Year Strategy for Combating Cancer, specifically Axis 2 aiming at limiting sequelae and improving quality of life, the DSRC OncoPaca-Corse, with support from the Regional Health Agencies, developed a guide for identifying sequelae and referring patients. The most common sequelae identified in VICAN 5 (pain, fatigue, sexual disorders, nutritional disorders, self-esteem deterioration, and cognitive disorders) were selected. Three types of tools were created: a global sequelae identification form, and per sequela, a referral flowchart and information sheet. The DSRC aimed to evaluate these tools before their regional publication.

Method A survey was conducted among healthcare professionals in Provence-Alpes-Côte d'Azur, Corsica, and Monaco involved in the care of cancer patients or survivors. A 20-question questionnaire focusing on fatigue and sexual disorders was distributed from mid-April to mid-May. It assessed the tools based on three criteria: ease of use, usefulness, and intention to use. At least 40 responses were expected.

Results A total of 118 professionals responded. 73.0% believe that more than 30% of their patients are affected by sequelae. 94.0% have already referred their patients to one (16.9%) or multiple (77.1%) professionals for sequelae management. Key strengths of these tools include their contribution to systematic identification (74.6%), ease of use (62.7%), quality of information (57.6%), and integration into practice (44.9%). Main barriers to their use are the time required (68.6%) and lack of proper training (19.5%). Finally, 89.0% of professionals intend to use (40.7%) or "likely use" (48.3%) these tools, and 83.9% find them applicable (21.2%) or "likely applicable" (62.7%) to all affected patients.

Discussion The survey results validate the proposed format and encourage further work. They also suggest enriching the guide with additional information to facilitate its use. A campaign to raise awareness among professionals and dedicated training is recommended to promote the adoption of these tools. The DSRC will also offer documents for patients to encourage them to discuss their sequelae and assist them in completing the identification questions.

I. Introduction

Cancer represents a major challenge for global public health, affecting millions of people each year and often leaving lasting physical, emotional, and social long-term effects in survivors. Cancer is a leading cause of mortality in high-income and upper-middle-income countries, ranking as the second most common cause of death among non-communicable diseases. (1)

In 2020, there were an estimated 18.1 million cancer cases worldwide, with 9.3 million cases in men and 8.8 million in women. Breast and lung cancers were the most common, each accounting for approximately 12.5% and 12.2% of the total number of new cases diagnosed globally. Colorectal cancer followed as the third most common cancer, with 1.9 million new cases, contributing 10.7% of the total. (2) The increased incidence and improved survival mean that more and more people are living with or have recovered from cancer, but it has also led to the emergence of new healthcare needs for this population.

Life after cancer covers a wide range of situations. In people with cancer, particular needs in terms of physical, psychological, social and spiritual well-being may emerge gradually and at a distance from the diagnosis. Faced with these difficulties, the implementation of medium- and long-term medical and social support opens new questions. Once diagnosed, sufferers would see their lives unfold in successive phases. At the end of the initial treatment period, a new period, described by Mayer and al. (2017), would open up, itself subdivided into two consecutive sequences. An "extended phase", corresponding to partial or complete remission of the disease, would precede the "permanent survival phase", characterized by a very low risk of recurrence or relapse of the primary tumour; in this model, the first five years after diagnosis are of particular importance. (3)

The following study was conducted in a regional structure for coordinating oncology care in the South of France. A project, initiated in 2021, focused on the consequences of six long-term effects of cancer on survivors' lives after the end of treatment: pain, fatigue, sexual disorders, cognitive disorders, self-esteem alteration, and nutritional disorders. It involved the creation of tools by multidisciplinary expert groups to improve the identification and care of these long-term effects by healthcare professionals. Therefore, the objective of this study is to evaluate the perception of healthcare professionals regarding the effectiveness and practicality of these preliminary tools before their inclusion in a regional guide.

II. Background

1. National context

Conducted in France, The VICAN 2 (4) (Life Two Years After a Cancer Diagnosis) and VICAN 5 (5) (Life Five Years After a Cancer Diagnosis) studies, published respectively in 2014 and 2018 by the French National Cancer Institute (INCa), provided crucial data and insights on the changes in people's lives with cancer or living cancer-free. Today, 3.8 million people in France are living with or have survived cancer. These studies have highlighted the importance of understanding not only the initial treatment of cancer but also its long-term consequences for survivors.

The VICAN 2 study showed that 3/5 of patients still had aftereffects 2 years after diagnosis, mainly pain, chronic fatigue, and sexual difficulties regardless of the cancer's location. Their proportion varied depending on the locations, ranging from 80.1% for upper aerodigestive tract cancers to 31.3% for cervical cancers. (4) Four years later, VICAN 5 supported these results, showing that 2/3 of patients suffered from sequelae five years after their cancer diagnosis. (5)

The Ten-Year Strategy for Combating Cancer 2021-2030, developed by INCa and its partners, provided a strategic framework to improve cancer prevention, screening, diagnosis, and management in France over the next decade. This strategy recognizes the crucial importance of understanding and addressing cancer sequelae to improve the quality of life of survivors and reduce the overall burden of the disease. As an answer to the VICAN studies data, axis II, titled "Limiting Sequelae and Improving Quality of Life", includes this issue and sets the goal of reducing from 2/3 to 1/3 the proportion of patients suffering from sequelae five years after diagnosis. (6)

2. Importance of supportive care

a. Supportive care definition

Supportive care is defined by the Multinational Association of Supportive Care in Cancer (MASCC) as "the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer journey from diagnosis through treatment to post-treatment care. Supportive care aims to improve the quality of rehabilitation, secondary cancer prevention, survivorship, and end-of-life care." (7)

Through a holistic approach supportive care aims to alleviates the symptoms and complications of cancer and its treatment, improve communication between patients and health professionals and to provide psychosocial support to cancer survivors and their informal caregivers. The MASCC states that access to supportive care is “a basic right for all people with cancer, irrespective of their personal circumstances, their type of cancer, their stage of cancer, or their anti-cancer treatment.” Every medical facility caring for cancer patients should therefore be able to provide appropriate supportive care. (7)

Treating a patient as a whole requires a range of different skills. Supportive care is therefore provided by multi-disciplinary teams working in care facilities and professionals working in the community: attending physician, social services, nurses, dispensing pharmacist, dietitian, pain physician, physiotherapist, psychologist, socio-aesthetician, etc.

Overall, supportive care aims to improve quality of life for patients throughout and after their treatments. Hence, supportive care is deeply involved in providing care for patients with long-term effect of their cancer and/or treatment.

b. Supportive care in France

In France, several supportive care services are considered essential and are fully or partially reimbursed by social security. They make up what is called the "supportive care basket", validated at the national level. Providing access to these services is one of the cross-disciplinary quality measures on which the authorisation of health establishments to provide cancer care is based and one of the key areas of focus of the Ten-Year Strategy.

It contains:

- Pain management, whether it is a consequence of treatments or the disease itself, via two specific pain relief techniques,
- Nutritional support,
- Psychological support,
- Social, family, and professional support (follow-up with a social worker, assistance with return to work...),
- Assistance in practicing adapted physical activity, during or after treatments,
- Lifestyle advice (help with smoking cessation, reduction of alcohol consumption, cessation of addictive substances...),
- Psychological support for the relatives and caregivers of cancer patients,
- Support for implementing fertility preservation,
- Management of sexual disorders. (8)

Additionally, as part of a comprehensive post-treatment care program, patients with cancer can now benefit from a series of check-ups and consultations after their treatments. This pathway includes an assessment of adapted physical activity to determine the appropriate level for each individual, as well as a dietary and psychological assessment. (9)

c. Sequela definition

Late effects are defined by the National Cancer Institute of the United States as “a health problem that occurs months or years after a disease is diagnosed or after treatment has ended. Late effects may be caused by cancer or cancer treatment. They may include physical, mental, and social problems and second cancers.” (10)

The definition given by the INCa can be translated as “An unpleasant consequence of an illness or treatment that persists even after the illness has been cured or the treatment completed. The aftereffects may be aesthetic (e.g. scars after an operation), psychological, affect the functioning of an organ or be general (e.g. fatigue), sometimes affecting daily life.”(11)

In this document, “aftereffects”, and “sequelae” will be used as synonyms to exclude the risk of second cancer that is included in the “late effects” definition.

3. Most vulnerable populations at risk

Some patients, because of their age, can be more impacted by the consequences of aftereffects on their quality of life. A differentiation can thus be made between children, adolescents and young adults and elderly people compared to the general population.

In the paediatric population, cancer remains a rare disease. Childhood cancers differ in their nature and causes, which are rarely identified. Children are still in a developmental stage and the diagnosis can significantly disrupt the family’s balance. Maintaining schooling and activities during treatment is a real challenge. Long-term follow-up is essential and planned in France to support their physical, emotional and social well-being. (12)

Adolescents and young adults (AYA), defined by the World Health Organization (WHO), as those between the ages of 15 to 24, are in a critical stage of life, experiencing significant biological, emotional, and social transitions. The challenges faced by AYAs are unique as it intersects with their journey of self-discovery and independence. Addressing the needs of AYAs involves focusing on key aspects such as sexuality, fertility, self-esteem, and maintaining education or career goals. They are also at risk of delayed diagnosis and non-adherence to treatment due to life transitions and the desire to return to normalcy. Long-term follow-up is also crucial to support their overall well-being and help them reintegrate into their lives. (13)

Patients aged over 75, present a unique heterogeneity in terms of aging, health status, frailties, and chronic diseases that requires specialized care coordination and treatment adaptation. These key elements need to be assessed before treatment to ensure the adherence to treatment and the maintenance of the patient's quality of life. Social isolation can be a significant barrier to maintaining consistent care for these patients. (14)

Therefore, tailored approaches that consider the distinct biological, psychological, and social needs of these populations are essential for improving outcomes and quality of life throughout treatment and after.

4. Regional context in Provence-Alpes-Côte d'Azur and Corsica

a. Regional objectives in reducing cancer aftereffects

To be in line with the Ten-Year Strategy, both Health Regional Agencies of Provence-Alpes-Côte d'Azur (PACA) and Corsica are actively enhancing coordination among healthcare stakeholders within their regions. This effort entails developing recommendations and guidelines to support the implementation of changes in healthcare professionals' practices.

For patients with cancer, the end of treatment does not mark the end of care. The risks of second cancers, recurrences, and lingering effects are significant and require regular assessment. Given the considerable time spent by patients at hospitals during cancer treatment, the objective is to enhance patient follow-up closer to their homes, thereby reducing hospital visits and mitigating the mental health impact of cancer while addressing disparities in access to care.

Regarding the aftereffects theme, both Regional Health Agencies embarked on a global plan to prevent and combat cancer sequelae, with the support of the Regional Cancer Task Force, the "Dispositif Spécifique Régional du Cancer" (DSRC) OncoPaca-Corse. The aim of the DSRC is to promote and improve the quality of patient care as part of the Ten-Year Strategy. It coordinates, evaluates and harmonizes oncology practices, and helps to inform professionals and the public at regional level.

A working group was launched in 2021, with an action plan scheduled as part of both regional roadmaps, with the aim of designing tools, resources and proposing a global pathway for identifying and managing aftereffects. This initiative encompasses therapeutic de-escalation and the early detection and training in identification of sequelae. Its aim is also in line with the standardized integration of supportive care within the care pathway from treatment initiation. (15,16)

b. Cancer epidemiology in both regions

TABLE 1: CANCER STATISTICS IN PACA (16) & CORSICA (15)

	Provence-Alpes-Côte d'Azur	Corsica
Demographics	5,131,187 inhabitants 90% living along the coast	345,687 inhabitants 1/3 in the urban areas
Aging population	60+: 30.2% (vs 27.2% in France) 75+: 11.8% (vs 9.8%)	60+: 33% 75+: 11%
Poverty	3rd region: 17.1%	1st region: 18.5%
Main risk factors	Highest prevalence of daily smokers in France Higher daily alcohol consumers than national level	Lower tobacco taxation Cancers with excess mortality share tobacco as a risk factor
Main cancers	Men: prostate, lung, colon-rectum Female: breast, colon-rectum, lung	Men: lung, prostate, colon-rectum Female: breast, lung
Death by cancer	12,480 deaths/year 27% of deaths	840 deaths/year 29% of deaths

In PACA and Corsica, the incidence of cancer stands at approximately 31,000 and 1,800 new cases, respectively. Cancer remains the primary cause of death in both regions, constituting 27% of all deaths in PACA and 29% in Corsica. The regions face an unfavourable situation concerning the two primary risk factors for cancer: smoking and alcohol consumption. Specifically, there is an over-incidence of cancers associated with tobacco use when compared to the national level.

II. Tool guide objectives

As part of its missions, the DSRC OncoPaca-Corse, thanks to its thematic working groups, is creating supportive care resources and tools for professionals and patients alike.

For the aftereffect theme, it has been commissioned by the Regional Health Agencies of PACA and Corsica to carry out the work outlined in Axis II of the Ten-Year Strategy for Combating Cancer 2021-2030, "Limiting Sequelae and Improving Quality of Life".

As guidelines lacked at the Regional and National levels, it was decided to create a Regional Guide for prevention and identification of aftereffects with the help of its thematic working groups. The six most expressed aftereffects in the VICAN 5 study (5) have been selected for this guide: pain, fatigue, sexual disorders, cognitive disorders, self-esteem alteration, and nutritional disorders.

A thematic working group for supportive care and aftereffect was created and the project started in 2021. With the idea of creating resources for health professionals by health professionals, the group had two main objectives:

- Creating a sequelae identification sheet: to evaluate the presence of one of the six selected sequelae among patients after cancer treatment,
- Creating decision-support flowcharts for each type of sequela included: to help health professionals refer patients to the appropriate professional according to the issue identified with the identification sheet and the flowchart.

The identification sheet for patients' supportive care needs designed previously by the DSRC served as a reference for the first steps. While intended for use at any point along the healthcare pathway, it did not encompass all types of aftereffects included in this project.

Specific multidisciplinary working groups, including professionals from hospitals and community facilities, as well as expert patients, were created for each topic, the first theme to be discussed being pain management in 2022. The sexual disorders group quickly followed in 2023, and the others came later. The last one to start was the cognitive disorders group in May 2024.

In 2024, with the idea of gathering everything in one tool guide, all the different materials created by each expert group were standardized and completed. In addition to the different flowcharts, information sheets on each aftereffect have been created by the DSRC team and validated by the different working groups.

Therefore, this tool guide will be composed of three types of tools:

- The **identification sheet**, to be completed by the patient and its answers discussed with the professional,
- The **information sheets** to provide insights and tools, for each type of aftereffect included,
- And **flowcharts** for each sequela to help with its evaluation and the orientation of patients according to the results obtained.

To clarify the understanding of a "sequela", the expert groups and the DSRC came up with a new definition to complete the one provided by the INCa. (11) Therefore, in the tool guide, a sequela is defined as: "a persistent consequence that alters the quality of life of a patient, while the disease is in remission or cured and/or treatment is completed. Sequelae can be aesthetic (scarring, skin alterations, capillary changes...), psychological, affect organ function, be general (fatigue, pain...), sometimes altering daily life. They are to be distinguished from acute toxicities that occur during treatment, such as nausea, vomiting, or neutropenia, which will disappear upon cessation of treatment. Sequelae and acute toxicities require comprehensive multidisciplinary management, whether preventive or curative, as part of supportive care."

III. Study objective

To ensure that the documents produced could serve a wide range of health professionals, an evaluation study was initiated to explore a critical question: What is the perception of healthcare professionals regarding the effectiveness and practicality of the Regional Guide for decision-making, prevention, and combating sequelae of cancer?

The scope of this evaluation is somewhat limited, as it does not cover the entirety of the guide, which is still under development. Instead, our focus is on gathering early-stage feedback on the specific tools that are intended to be included to the final guide. By narrowing it to these preliminary tools, we aim to understand their usability, utility, and overall effectiveness from the perspective of healthcare professionals who are likely to rely on them in their daily work.

The primary objective of this evaluation is to assess the usability and utility of these preliminary tools. Usability, in this context, refers to how easily healthcare professionals can integrate these resources into their workflow and the clarity of the instructions. Utility refers to whether they contribute to better decision-making in the context of cancer care. The study seeks to identify any potential barriers to their use and determine whether the tools are practical for the intended users.

In addition, a secondary goal underscores the importance of adaptability and ongoing improvement. The insights gained from this evaluation will be used to tailor the final guide to meet the real-life needs of healthcare professionals. This may involve refining the developed tools, introducing additional resources, or even suggesting complementary training programs to address any identified gaps. The feedback collected will play a crucial role in shaping the guide into a practical and user-friendly resource that supports healthcare professionals in their efforts to prevent, manage, and combat cancer aftereffects.

Ultimately, this evaluation study represents a proactive approach to ensure that the final Regional Guide will be both comprehensive and adaptable, with the flexibility to evolve with healthcare practices over time. By engaging healthcare professionals at this early stage, we can be more confident that the final product will be well-received and widely used.

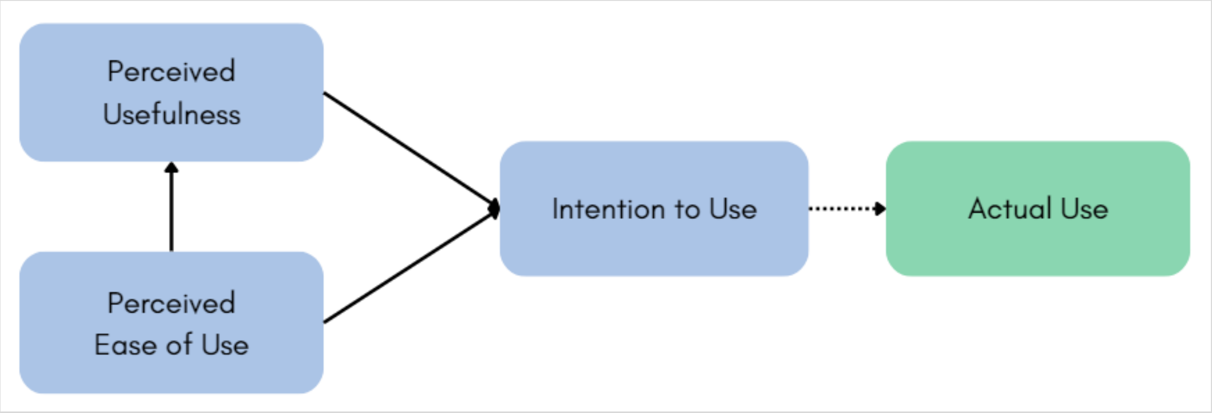
IV. Material and methods

1. Data assessment

Data collection was achieved through a questionnaire, presented in the appendix, sent together with the tools for the chosen topics. The Technology Acceptance Model (TAM) (17), as illustrated in figure 1 below, was used as the foundational framework for designing the questionnaire and evaluating the applicability of the tools in practice.. The model centres on three key components: perceived ease of use, perceived usefulness, and intention to use. These components were integrated into different questions throughout the questionnaire to estimate not only the initial response to the tools but also the likelihood of their sustained use in clinical practice.

The first part of the questionnaire focused on collecting demographic and professional information about the health professionals participating in the study. This included details of their speciality and their experience of cancer patients. This section aimed to provide a context for interpreting the results, recognizing that familiarity with oncology-related topics might influence how professionals understand and intend to use the proposed tools.

FIGURE 1. TECHNOLOGY ACCEPTANCE MODEL (TAM)



The rest of the questionnaire moved on to assess the three core components of the TAM, breaking them down by individual tools and then looking at them collectively. For perceived ease of use, respondents were asked questions about the clarity of instructions, the intuitiveness of the tools, and the overall effort required to understand and implement them. This will help to identify whether barriers to adoption might exist due to complexity or lack of user-friendliness.

The perceived usefulness was evaluated by asking questions about the relevance of the tools to the respondents' work, the potential for improving patient outcomes, and whether the tools could help in decision-making processes. This section is crucial for determining whether the tools were seen as adding value to the healthcare professionals' routines.

The intention to use was assessed by asking respondents about their likelihood of incorporating the tools into their daily practices. This helped in predicting the long-term adoption of the tools and assessing the level of enthusiasm among the health professionals.

2. Parts of the tool guide used

The tools presented in the guide include a sequelae identification sheet, an information sheet with answers to professionals' questions, and a decision-making flowchart to better direct the patient to the appropriate healthcare professionals. These working documents are presented in the appendix with the example of fatigue.

For this feasibility and practicability study, two topics, sexual disorders and fatigue, were selected. These topics were chosen because their associated tools were sufficiently developed and validated to allow for meaningful feedback from healthcare professionals. Unfortunately, the tools for pain, nutritional disorders, self-esteem alteration and cognitive disorders tools could not be used as they were not finished prior to this study.

Thus, the identification sheet and the tools for sexual disorders and fatigue were sent with the questionnaire.

3. Population selected

As the tool guide is firstly dedicated to the health professionals working under the DSRC supervision, this study primarily targeted professionals within the PACA, Corsica and Monaco regions.

The study's questionnaire was distributed to a wide range of healthcare professionals who might care for patients with cancer or those recovering from it. This inclusive approach aimed to capture a variety of perspectives from different specialties that are involved in cancer care. The professionals invited to participate included doctors, nurses, physiotherapists, dietitians, sexologists, psychologists, and others who play a role in supporting cancer patients along their care pathway.

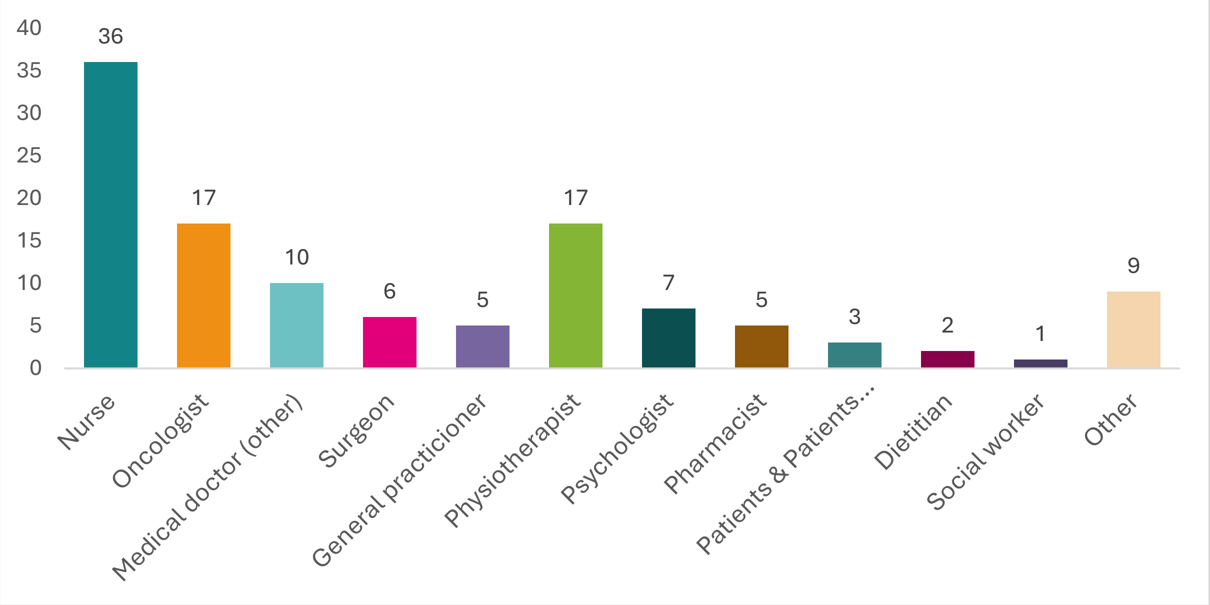
To obtain as many answers as possible, the questionnaire was disseminated through multiple channels. It was sent to the professionals who participated in the tools creation to be spread around them, to the centres of coordination in cancerology and to the professionals who participated in the various DSRC trainings. Overall, more than 600 people were invited to participate in this study, with an expected minimum response rate of 40 completed questionnaires. This target was set to ensure that the study had sufficient data to draw meaningful conclusions and inform the further development of the guide's tools.

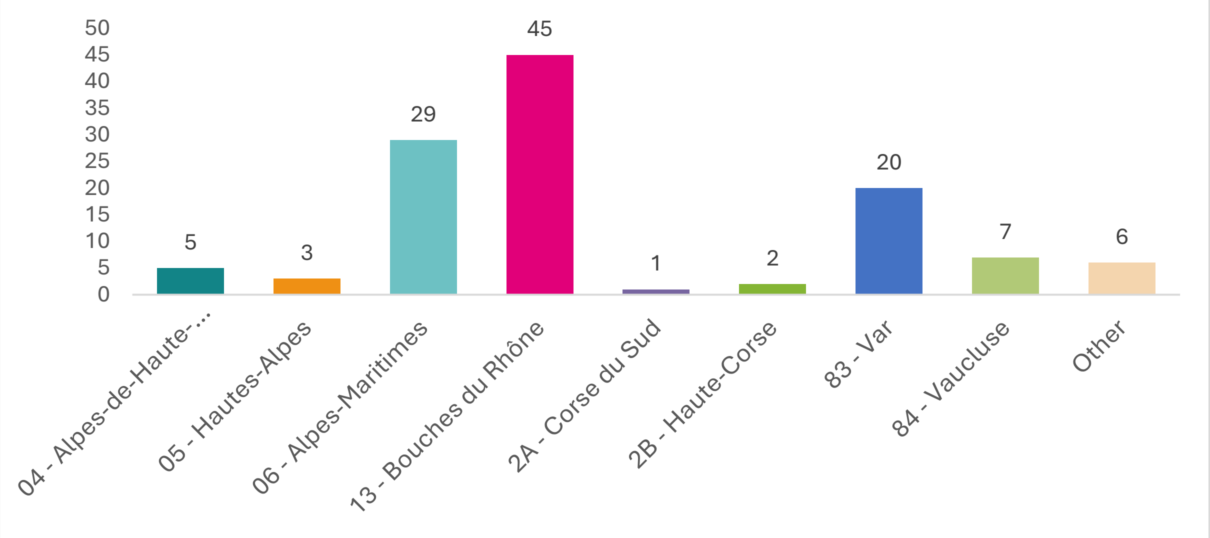
One important exclusion criterion was implemented to maintain objectivity in the responses. Professionals who had participated in the working groups responsible for creating the decision-making flowcharts were not eligible to complete the questionnaire. This exclusion was necessary to prevent bias, as these individuals were directly involved in designing the tools being evaluated.

V. Results

1. Population description

FIGURE 2 & 3. RESPONDENTS' OCCUPATION & DEPARTMENT OF PRACTICE





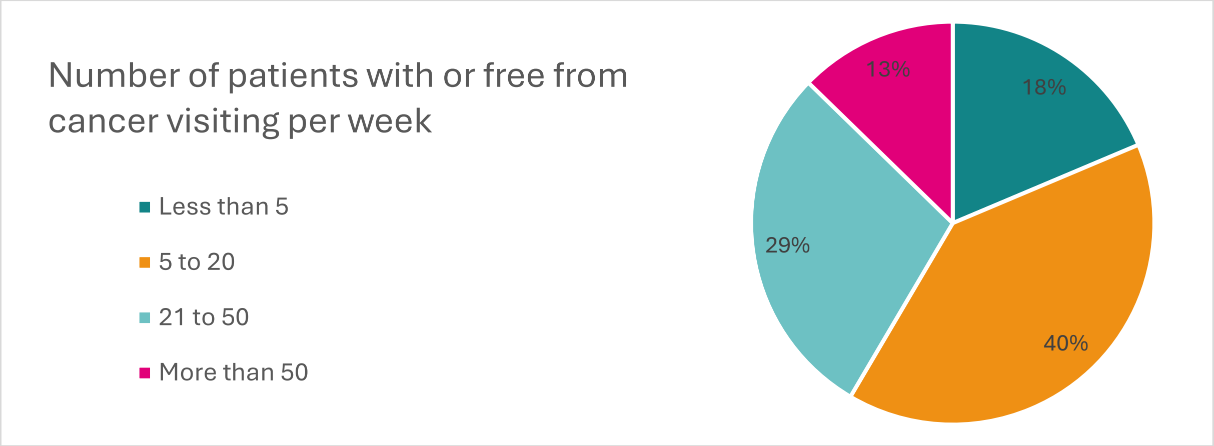
A total of 118 health professionals completed the questionnaire. As presented in the figure 2 below, the main professions represented are:

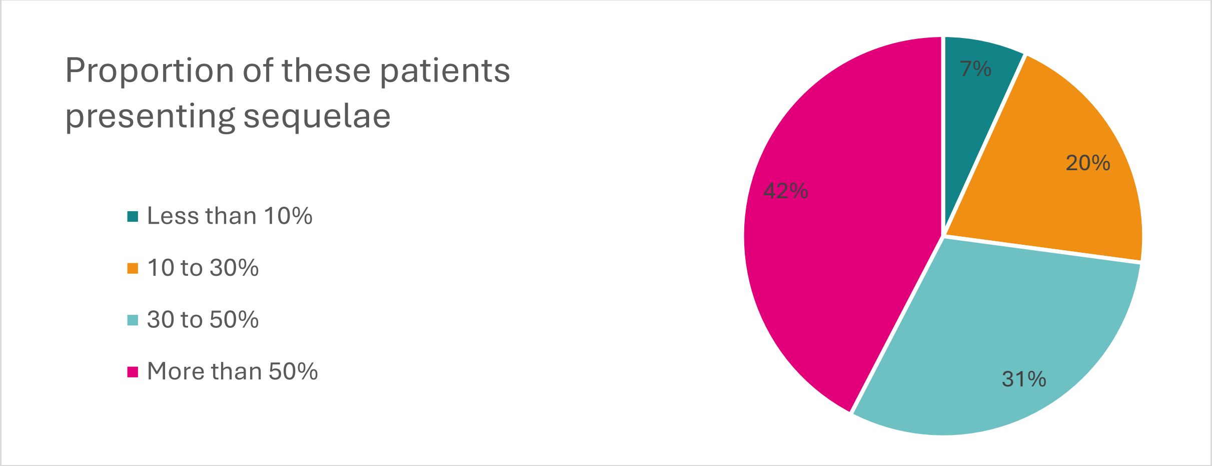
- 38 medical doctors (32.2%), of these, 17 were oncologists, 6 surgeons, 5 general practitioners and 10 represented other specialties,
- 36 nurses (30.5%),
- 17 physiotherapists (14.4%),
- 7 psychologists (5.9%),
- 5 pharmacists (4.2%),
- And 2 dietitians (1.7%).

Most of them are practicing in 3 departments among PACA and Corsica: 45 are working in Bouches du Rhône (38.1%), 29 in Alpes-Maritimes (24.6%) and 20 in Var (16.9%).

Their patients' profiles

FIGURE 4 & 5. NUMBER OF PATIENTS WITH OR FREE FROM CANCER IN THEIR WEEKLY VISITS & PROPORTION OF PATIENTS PRESENTING SEQUELAE AMONG THEM.





Among them, as shown in figure 4, 18.6% are seeing less than 5 patients a week with or recovering from cancer, 39,8% are seeing 5 to 20, 28.8% 21 to 50, and 12.7% more than 50.

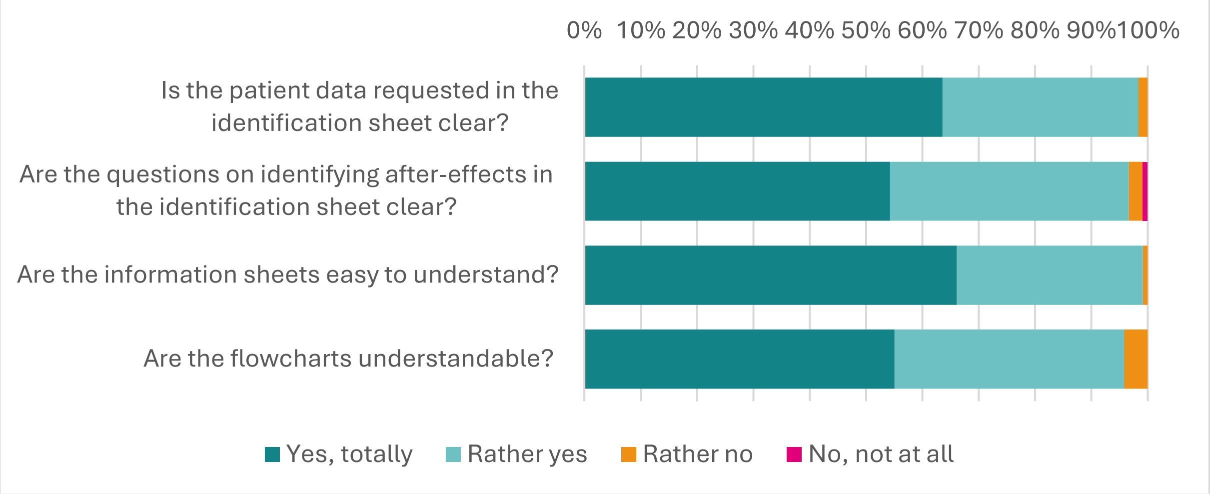
Figure 5 shows the estimated proportion of these patients affected by sequelae. 6.8% estimate that less than 10% of these patients are affected by sequelae, 20.3% that it concerns 10 to 30%, 30.5% that it concerns 30 to 50%, and 42.4% that it concerns more than 50%. Moreover, 94.0% of the professionals have already referred their patients to one (16.9%) or more (77.1%) professionals for aftereffects management.

The most common professions mentioned when asked to which professionals they referred their patients to are psychologists (68%), pain management physicians (36%), dietitians (21%) or nutritionist (15%), professionals in adapted physical activity (13%) or physiotherapists (11%) and sexologist (21%).

2. Perceived ease of use

The perceived ease of use of the tools was assessed through the clarity of the information included and their global organization with the questions presented in figure 6.

FIGURE 6. CLARITY OF THE INFORMATION PRESENTED & ORGANIZATION OF THE TOOLS



For the identification sheet, the patient data requested is totally clear for 63.6%, rather clear for 34.7% and rather unclear for 1.7% of the respondents. The questions on identifying aftereffects are totally clear for 54.2%, rather clear for 42.4%, rather unclear for 2.5% and totally unclear for 0.8%.

For the information sheets, the information presented are totally clear for 66.1%, rather clear for 33.1 % and rather unclear for 0.8%.

For the flowcharts, the organization is totally understandable for 55.1%, rather understandable for 40.7% and rather not understandable for 4.2%.

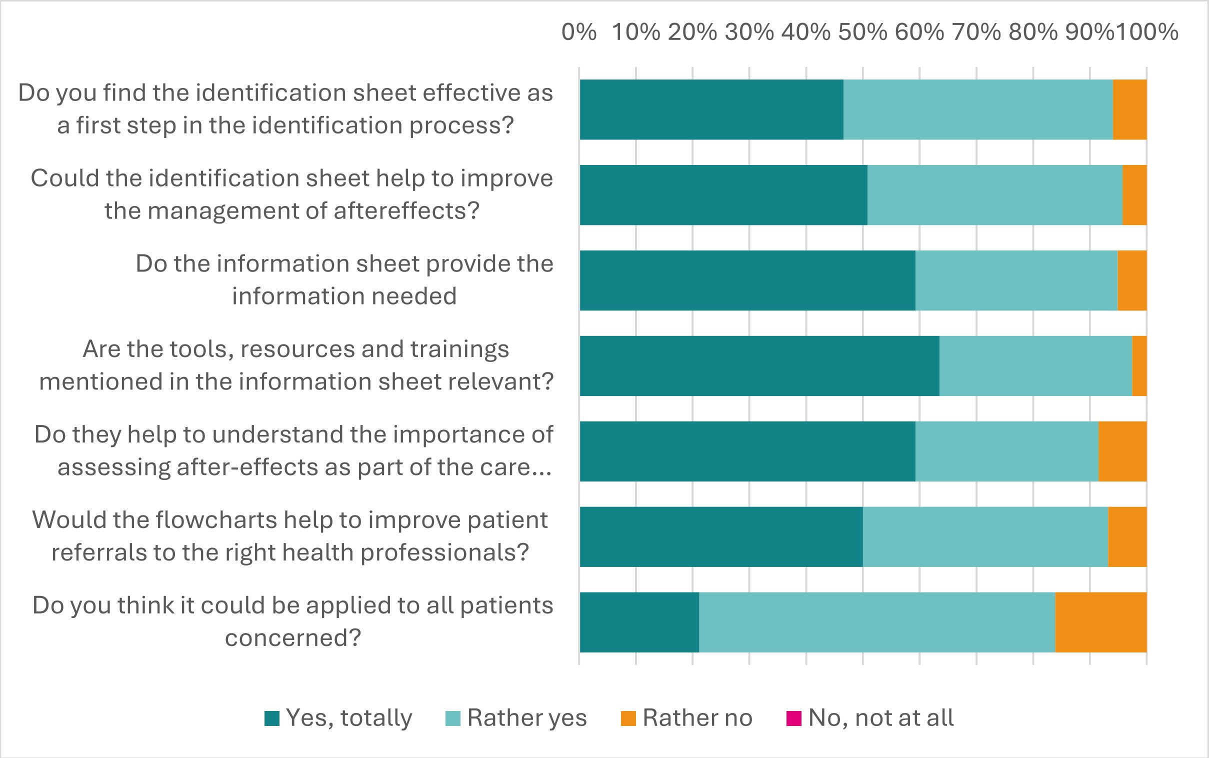
3. Perceived usefulness

The perceived usefulness of the different tools was assessed through a series of questions presented in figure 7 below.

The identification sheet was evaluated as totally effective as a first step in identifying aftereffects by 46.6%, rather effective by 47.5% and rather not effective by 5.9%. Additionally, 50.8% of the respondents totally agree that it could enhance the management of aftereffects, 44.9% rather agree and 4.2% rather disagree.

The usefulness of the information sheets was assessed through the relevance of the information provided. Among the respondents, 59.3% felt the sheets fully provided all necessary information, 35.6% believed they somewhat did, and 5.1% thought they somewhat did not. The tools, resources and trainings mentioned were considered as totally relevant by 63.6%, rather relevant by 33.9% and rather not relevant by 2.5 %. Finally, 59.3% of the respondents said that they totally helped to understand the importance of assessing aftereffects, 32.2 % that they rather did and 8.5% that they rather did not.

FIGURE 7. PERCEIVED USEFULNESS OF THE TOOLS



Regarding the flowcharts, 50.0% of the respondents stated that they were totally helping to improve the patient referring to the right professionals, 43.2% that they rather did and 6.8% that they rather did not.

Furthermore, the overall applicability of the tools all together was evaluated. Among the respondents, 21.2% stated that the tools were totally replicable for all patients concerned with the issue, 62.7% that they were rather replicable and 16.1% that they were rather not replicable.

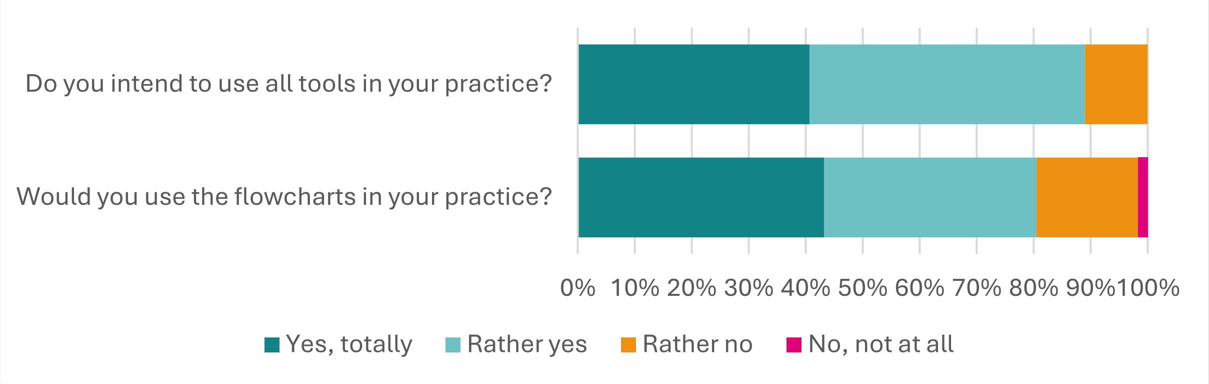
4. Intention to use

Participants were asked about their intention to apply the flowcharts in their practice, as well as the tools globally. Their answers are shown in figure 8 below.

Among the respondents, 40.7% stated they would use the tools presented, 48.3% indicated they would probably use them, and 11.0% expressed they would probably not use them.

Regarding the flowcharts specifically, 43.2% of respondents said they would use them in their practice, 37.3% would probably use them, 17.8% would probably not use them, and 1.7% would not use them at all.

FIGURE 8. INTEGRATION OF THE TOOLS INTO PRACTICE



5. Strengths and weaknesses

The strengths of these tools are their contribution to systematizing identification (74.6%), their ease of use (62.7%), the high quality of the information presented (57.6%), and their integration into practice (44.9%).

The barriers to their use are the time required for their application (68.6%), the lack of training to use them correctly (19.5%), their lack of simplicity (11.9%) and their lack of practicality (8.5%).

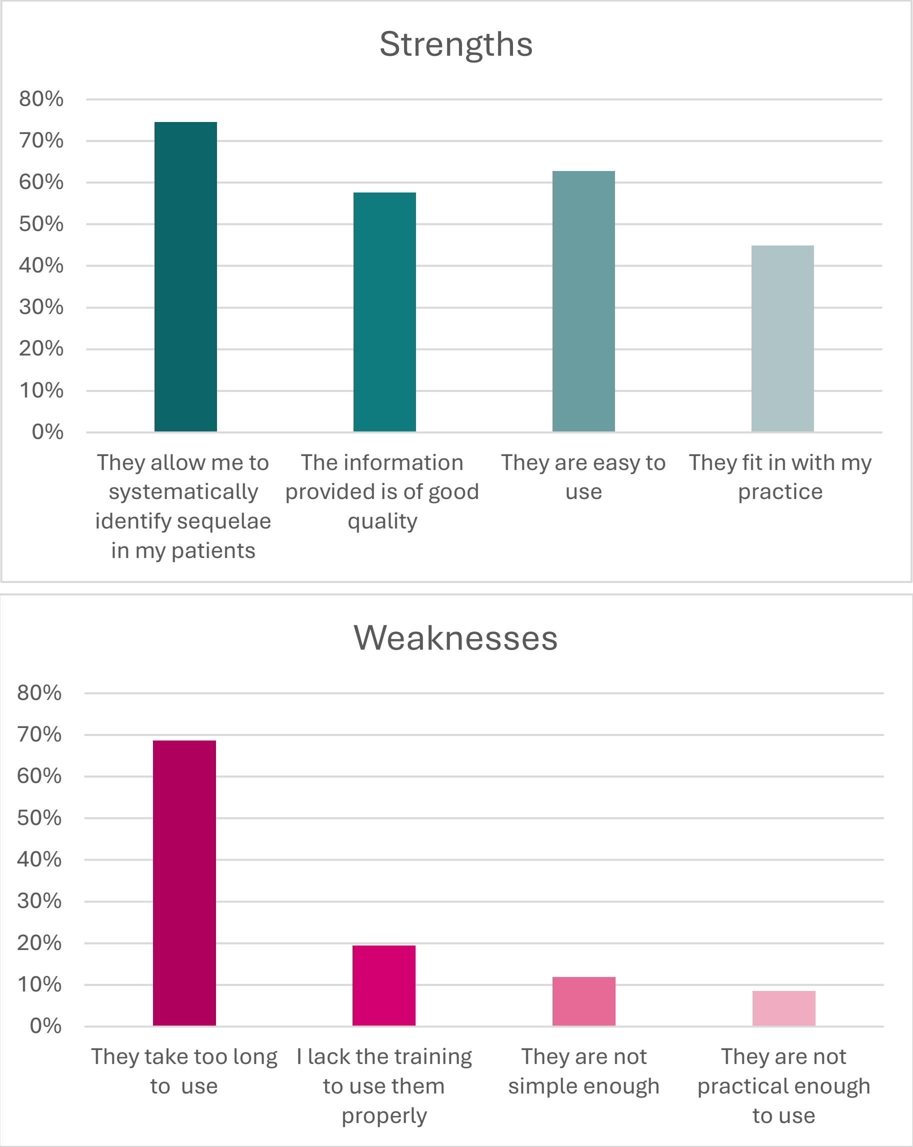


FIGURE 9 & 10. STRENGTHS & WEAKNESSES IDENTIFIED

VI. Discussion

1. Population description

The study included a diverse group of healthcare professionals, highlighting the broad team involved in cancer care. A significant portion of the respondents were doctors (32.2%) and nurses (30.5%), reflecting their central roles in patient care from diagnosis through treatment and follow-up. This high representation underscores their earned interest in tools that facilitate improved management of cancer sequelae.

The respondents varied in how many patients they see each week. Most of them see 5 to 20 or 21 to 50 patients a week, meaning that our population was diverse in the quantity of patients with or free from cancer they take care of. These results also indicates that they are most likely coming from both hospitals and community sectors. This mix provides a broad perspective on how the tools might be used in different settings.

A notable 73% estimated that more than 30% of their patients might be affected by sequelae, with 44% estimating that it is more than 50%. These results are lower than those of the VICAN 5 study which found that 63.5% patients suffer from sequelae five years after their diagnosis. As the VICAN 5 study was conducted among patients, it suggests that healthcare professionals might be underestimating the extent of these issues.

Over 90% of these professionals declared that they have already referred patients to other professionals for these sequelae, mostly to psychologists, pain management physicians and dietitians but, only 7 psychologists and 2 dietitians participated in the survey. This low participation is unfortunate, as psychologists often spend significant time with patients and would have ample opportunity to use the developed tools. Additionally, dietitians' insights would have been valuable, given the high rate of nutritional disorders among cancer patients and the impact they can have on other sequelae such as fatigue, pain, and self-esteem.

However, respondents might have answered to that question without distinguishing sequelae from side effects occurring through treatment period. Therefore, while the data may not accurately reflect referrals specifically for sequelae, it is still useful to understand to which professionals they refer more patients for supportive care during treatment. This insight can help target those professionals who are better positioned to anticipate and manage the development of aftereffects.

Overall, the mix of respondents shows the importance of creating tools that can be used by various healthcare professionals involved in cancer care.

2. Perceived ease of use

The perceived ease of use of the tools is a crucial factor in their adoption. Most respondents found the patient data requested in the identification sheet to be clear, with 98.2% indicating it was either totally clear or rather clear. Similarly, 96.5% found the questions on identifying aftereffects clear, suggesting that this first tool is well-designed and user-friendly.

The information sheets also scored highly in terms of clarity, with 99.2% of respondents finding them clear. This indicates that the content is well-organized and accessible, which is essential for busy healthcare professionals who need to quickly understand the different types of aftereffects and implement the tools.

The flowcharts were also well-received. Approximately 95.5% of respondents found the organization of the flowcharts understandable, indicating that the visual and logical layout of the tools is effective in guiding healthcare professionals through decision-making processes.

3. Perceived usefulness

The utility of the tools was assessed based on their relevance and potential to improve patient outcomes. The identification sheet was deemed effective by 93.9% of respondents as a first step in identifying aftereffects, and 95.6% agreed it could enhance the management of aftereffects. This underscores the tool's potential to improve the initial assessment and ongoing management of cancer sequelae.

The information sheets were praised for providing necessary and relevant information, with 94.9% of respondents finding them at least somewhat useful. Furthermore, 97.4% found the tools, resources, and training mentioned in the information sheets relevant, highlighting their practical value in everyday clinical settings.

Flowcharts were seen as beneficial in referring patients to appropriate healthcare professionals, with 93.2% of respondents agreeing they helped improve patient referrals. This demonstrates the tools' utility in streamlining and improving the coordination of care for patients dealing with cancer sequelae.

4. Intention to use

The intention to use the tools is a strong predictor of their eventual adoption. A positive response was observed, with 89% of respondents indicating they would either definitely or probably use the tools. This high level of intended adoption reflects the perceived value and practicality of the tools among healthcare professionals.

Specifically, the flowcharts had a slightly higher rate of definite use (43.2%) compared to the overall tools (40.7%). This suggests that the visual and guided nature of the flowcharts may be particularly appealing and useful to healthcare professionals in making informed decisions.

5. Strengths & Weaknesses

One of the significant strengths identified is the overall positive reception of the tools' clarity and organization. The majority of respondents found the information clear and easy to understand, with the identification sheets, information sheets, and flowcharts receiving high marks for clarity. This indicates that the tools are well-designed and accessible, which is crucial for their successful integration into clinical practice.

Additionally, the tools were perceived as highly useful, with a substantial proportion of respondents acknowledging their potential to enhance patient management and improve decision-making processes. The information sheets were seen as comprehensive and relevant, providing healthcare professionals with the necessary knowledge to assess and manage cancer sequelae effectively.

The intention to use the tools was also promising, with a significant number of respondents indicating they would definitely or probably incorporate them into their practice. This suggests a strong likelihood of adoption, especially if the tools continue to be refined and aligned with healthcare professionals' needs.

Despite these positive findings, several weaknesses to the tools' use were identified. The most prominent concern was the time required to apply the tools, with many professionals indicating that time constraints could hinder their use. This highlights the need for streamlined processes and efficient integration of the tools into existing workflows.

Another barrier identified was the need for additional training. Some respondents felt that they lacked the necessary training to use the tools effectively, pointing to the importance of developing comprehensive training programs to accompany the tools. This would ensure that healthcare professionals are well-prepared to utilize the tools and maximize their potential benefits.

A smaller proportion of respondents mentioned issues related to the simplicity and practicality of the tools. Ensuring that the tools are not overly complex and are practical for daily use is essential. Further refinement and user feedback will be crucial in addressing these concerns.

VII. Limitations of the study

This study, while insightful, has several limitations that need to be acknowledged. The evaluation only covered tools related to sexual disorders and fatigue, as other tools were not yet completed. This limited scope restricts the ability to generalize the findings to the entire guide.

Although over 600 professionals were invited to participate, only 118 responded. The low participation rate, particularly among some supportive care professionals, such as psychologists and dietitians, may have skewed the results and limited the diversity of perspectives. As the tools are expected to be usable by any health professional, this imbalance in representation could affect the overall validity of the results.

The study targeted health professionals within the PACA, Corsica, and Monaco regions, with only a few respondents from other areas. This regional focus may limit the generalizability of the findings to a broader, national context. However, there are currently no national recommendations on how to systematically tackle the aftereffects of cancer. This lack of standardized guidelines may have influenced the respondents' perceptions and the overall utility of the tools. Before the guide can be generalized at the national level, conducting a pilot study to gather more comprehensive feedback from a wider range of regions would be beneficial.

The study relied on self-reported data collected through questionnaires. This method is known to be susceptible to biases such as social desirability bias and recall bias, where respondents may provide answers they perceive as favourable rather than their true experiences. However, the survey being anonymous, this effect should have been limited. Additionally, while the tools were assessed for usability and utility, respondents mentioned time constraints as a significant challenge. The study did not measure the actual implementation time or the impact on workflow, which are critical factors for practical adoption.

Addressing these limitations before publication will help to enhance the robustness of the findings and ensure the tools' effectiveness and applicability in diverse healthcare settings.

VIII. Perspectives

A pilot phase is planned for 2025, aiming to test the tools with actual patients and gather practical feedback from different contexts, with various professionals working at hospitals or community levels. This phase will be crucial in identifying any real-world challenges and refining the tools based on user experience, especially concerning the using time limitation and replicability between patients.

Before that, the DSRC will work on developing a comprehensive patient sheet that will enable patients to better articulate their needs and facilitate discussions with healthcare professionals throughout their care journey. This tool can empower patients and ensure that their concerns and symptoms are effectively communicated and addressed. Its goal will be to get them to understand that these symptoms are not normal but do not necessarily indicate a recurrence of cancer.

Starting in early 2025, training sessions will be organized to deepen understanding of each sequela and to raise awareness among healthcare teams about the importance of identifying and managing cancer aftereffects using the proposed tools. These training sessions will also help reduce the time required to use the tools by ensuring that healthcare professionals are well-acquainted with their functionality.

Given the current lack of national guidelines for systematically addressing cancer aftereffects, this guide has the potential to serve as a national reference. By proposing it as a national standard, we can provide a consistent and comprehensive approach to managing cancer sequelae across the country.

The information provided in the guide will be continually updated to reflect the latest best practices and new clinical guidelines. Tools, resources, and trainings would need the most regular updates. This adaptability ensures that the tools remain relevant and effective as standards of care evolve. Over time, the guide could be expanded to include tools for additional types of sequelae. This will enhance the comprehensiveness of the resource, addressing a broader spectrum of aftereffects experienced by cancer patients.

These initiatives will not only improve the immediate usability and effectiveness of the tools but will also contribute to establishing a standardized approach to cancer aftercare, benefiting both patients and healthcare providers in the long term.

IX. Conclusion

This evaluation study provides valuable insights into the usability and utility of the preliminary tools included in the Regional Guide for decision-making, prevention, and combating sequelae of cancer. The feedback from a diverse group of healthcare professionals has been overwhelmingly positive across all aspects of the proposed tools, highlighting their clarity, organization, and relevance to clinical practice.

Key findings indicate that the majority of respondents found the tools easy to use and valuable in improving patient care. The high intention to use the tools suggests a promising rate of adoption, which is crucial for their successful implementation in clinical settings. However, the study also identified several areas for improvement. These insights are instrumental in planning the final steps of development before the guide’s publication, ensuring it meets the practical needs of healthcare professionals.

The strong interest shown by the professionals underscores the lack of existing guidelines and recommendations for managing sequelae at both regional and national levels. Therefore, proposing the guide at the national level could open essential discussions and drive the establishment of standardized care practices for managing cancer sequelae across the country as mentioned in the Ten-Year Strategy for combating cancer.

Ultimately, this proactive approach to involving healthcare professionals in the early stages of tool development ensures that the final guide will be a practical and user-friendly resource. With these tools, the challenge will be to ensure that they find a place in the health professionals' practice and can participate in the systematization of sequelae identification. This screening needs to fit into the heavy and complicated pathway of cancer patients to alleviate the psychological, physical and social alterations due to cancer itself and its treatments. To achieve this, the trainings and sensitization of healthcare teams will be essential.

In addition to the healthcare tools, the development of complementary patient documents is crucial. These documents will help patients better express their needs and engage more effectively with healthcare professionals throughout their treatment journey. Empowering patients with these resources ensures they can actively participate in their care, leading to better management of sequelae.

Finally, by continually adapting the tool guide to new best practices and clinical guidelines, it can remain a valuable asset in supporting healthcare professionals in their efforts to improve the quality of life for cancer patients. This evaluation sets the stage for further refinement and broader application of the guide, with the potential to establish it as a national standard for managing cancer sequelae.

Résumé

EVALUATION PAR LES PROFESSIONNELS DE SANTE D'OUTILS D'AIDE A LA DECISION, AU REPERAGE DES SEQUELLES ET A L'ORIENTATION DES PATIENTS

Contexte Selon l'enquête VICAN5, 63,5% des patients déclarent souffrir de séquelles 5 ans après un diagnostic de cancer. En 2022, dans le cadre de la Stratégie décennale de lutte contre les cancers, et particulièrement de son Axe 2 visant à limiter les séquelles et améliorer la qualité de vie, le DSRC OncoPaca-Corse s'est engagé, avec l'appui des ARS, dans l'élaboration d'un guide d'aide au repérage des séquelles et à l'orientation des patients. Les séquelles les plus exprimées dans VICAN5 ont été sélectionnées : douleur, fatigue, troubles sexuels, troubles nutritionnels, altération de l'estime de soi et troubles cognitifs. Pour chaque séquelle, des groupes pluriprofessionnels ont été constitués et ont abouti à trois types d'outils composant le guide : une fiche de repérage des séquelles, des logigrammes d'aide à l'orientation du patient et des fiches d'information à destination des professionnels. Le DSRC a souhaité évaluer l'appréciation de ces outils avant leur publication en région.

Méthode Une enquête a été réalisée auprès des professionnels de santé régionaux, prenant en charge des patients atteints ou guéris d'un cancer. Un questionnaire de 20 questions, portant sur la fatigue et les troubles sexuels, a été diffusé de mi-avril à mi-mai. Il évaluait les outils selon trois axes : la facilité d'utilisation, l'utilité et l'intention d'utilisation. Un minimum de 40 retours était attendu.

Résultats Au total, 118 professionnels ont répondu. 73,0% estiment que plus de 30% de leurs patients sont concernés par des séquelles et 94,0% ont déjà orienté leurs patients vers un (16,9%) ou plusieurs (77,1%) professionnels pour ces dernières. Les points forts de ces outils sont leur simplicité d'utilisation (62,7%), leur participation à la systématisation du repérage (74,6%), la qualité des informations présentées (57 ,6%) et leur intégration à la pratique (44,9 %). Les freins principaux à leur utilisation sont le temps nécessaire à leur utilisation (68,6%) et le manque de formation pour les utiliser correctement (19,5%). Enfin, 89,0% des professionnels ont l'intention d'utiliser ces outils et 83,9% estiment qu'ils seraient applicables à tous les patients concernés.

Discussion Les résultats de cette enquête valident le format proposé et sont encourageants pour la poursuite des travaux. Ils incitent également à enrichir le guide avec des informations facilitant son utilisation. Une campagne de sensibilisation des professionnels et une formation dédiée devraient favoriser l'appropriation de ces outils. Le DSRC proposera également des documents destinés aux patients afin de les encourager à parler de leur(s) séquelle(s) et les aider à répondre aux questions de repérage.

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Appendices : Questionnaire & Documents evaluated

QUESTIONNAIRE

Health professional / *Le professionnel*

1/ What is your profession? / *Quelle est votre profession ?*

- ***Oncologist, surgeon, other doctor specialist, general practitioner, nurse, physiotherapist, dietician, psychologist, pharmacist, other***
- *Médecin oncologue, chirurgien, médecin spécialiste (autre), médecin généraliste, infirmier(e), kinésithérapeute, diététicien(ne), psychologue, pharmacien, autre*

2/ In which department are you working? / *Dans quel département exercez-vous ?*

3/ How many cancer patients do you follow on average each week? / *Combien de patients ayant eu ou étant atteint d'un cancer suivez-vous en moyenne chaque semaine ?*

- **Less than 5** / *Moins de 5*
- **5 to 20** / *Entre 5 et 20*
- **21 to 50** / *Entre 21 et 50*
- **More than 50** / *Plus de 50*

4/ What proportion of these patients do you think will suffer after-effects? / Parmi ces patients quel proportion estimez-vous être concernée par des séquelles ?

- ***Less than 10%** / Moins de 10%*
- ***10 to 30%** / Entre 10% et 30%*
- ***30 to 50%** / Entre 30% et 50%*
- ***More than 50%** / Plus de 50%*

5/ Have you ever referred patients to other professionals to assess or manage the aftereffects of pain, fatigue, nutritional disorders, sexual disorders, self-esteem alteration and cognitive disorders? / *Avez-vous déjà orienté des patients vers d'autres professionnels pour évaluer ou prendre en charge les séquelles douleur, fatigue, troubles nutritionnels, troubles sexuels, altération de l'estime de soi et troubles cognitifs ?*

- **Yes, it is often necessary for several professionals to work on the same patient.** */ Oui, l'intervention de plusieurs professionnels pour un même patient est souvent nécessaire*
- **Yes, but often only to one of these professionals** */ Oui, mais souvent vers un seul de ces professionnels*
- **No, never** */ Non, jamais*

6/ If yes, to which professionals specialising in this type of aftereffects do you most often refer them to? / Si oui, quels sont les professionnels spécialistes de ce type de séquelles que vous sollicitez globalement le plus souvent ?

Identification sheet / La fiche de repérage

7/	Yes, totally	Rather yes	Rather no	No, not at all
Is the patient data requested clear? Les données patient demandées sont-elles claires ?				
Are the questions on identifying aftereffects clear? Les questions de repérage des séquelles sont-elles claires ?				
Do you find the identification sheet effective as a first step in the identification process? La fiche vous semble-t-elle efficace pour une première étape de repérage ?				
Could the identification sheet help to improve the management of aftereffects? La fiche pourrait-elle participer à une meilleure prise en charge des séquelles ?				

8/ Does the identification sheet meet your expectations? / La fiche de repérage répond-elle à vos attentes ?

- **Yes** / Oui
- **To some extent** / Partiellement
- **No** / Non
- **I didn't have expectations** / Je n'avais pas d'attentes

9/ Which format would be best suited to your practice? / Quel format serait le plus adapté à votre pratique ?

- **Paper format** / Papier
- **Digital format** / Numérique
- **Integrated with your digital tools** / Intégré à vos outils numériques
- **Other** / Autre

10/ Do you have any comments on the aftereffects identification sheet? / Avez-vous des commentaires à faire sur la fiche de repérage des séquelles ?

Informations sheets / Les fiche d'informations

11/	Yes, totally	Rather yes	Rather no	No, not at all
Are the information sheets easy to understand? Les fiches d'informations sont-elles compréhensibles ?				
Do they provide the information you need? Apportent-elles les informations qui vous sont nécessaires ?				
Do they help to understand the importance of assessing after-effects as part of the care process? Aident-elles à comprendre l'intérêt de l'évaluation des séquelles dans le parcours de soins ?				
Are the tools, resources and training mentioned relevant? Les outils, ressources et formations mentionnés sont-ils pertinents ?				

12/ Which format would be best suited to your practice? / Quel format serait le plus adapté à votre pratique ?

- **Paper format** / Papier
- **Digital format** / Numérique
- **Other** / Autre

13/ Do you have any comments on the information sheets? / Avez-vous des commentaires à faire sur les fiches d'information ?

Flowcharts / Les logigrammes d'aide à la prévention et à l'orientation des patients

14/	Yes, totally	Rather yes	Rather no	No, not at all
Are the flowcharts understandable? Les logigrammes sont-ils compréhensibles ?				
Would you use them in your practice? Les utiliseriez-vous dans votre pratique?				
Will they help to improve patient referrals to the right professionals? Permettraient-ils d'améliorer l'orientation des patients vers les professionnels adaptés ?				

15/ Which format would be best suited to your practice? / Quel format serait le plus adapté à votre pratique ?

- **Paper format** / Papier
- **Digital format** / Numérique
- **Other** / Autre

16/ Do you have any comments on the flowcharts? / Avez-vous des commentaires à faire sur les logigrammes ?

All tools / Tous les outils

17/	*Yes, totally*	*Rather yes*	*Rather no*	*No, not at all*
Do you intend to use these tools in your practice? / Avez-vous l'intention d'utiliser ces outils dans votre pratique ?				
Do you think they could be applied to all the patients concerned? / Seraient-ils applicables selon vous à tous les patients concernés ?				

18/ What are the strengths of these tools? / Quels sont les points forts de ces outils ?

- **They allow me to systematically identify sequelae in my patients** / Ils permettent de systématiser le repérage des séquelles chez mes patients

- **They are easy to use** / Ils sont simples à utiliser
- **They fit in with my practice** / Ils s'intègrent à ma pratique
- **The information provided is of good quality** / Les informations apportées sont de bonne qualité

19/ Do you have any suggestions for improving these tools? / Avez-vous des suggestions pour améliorer ces outils ?

20/ What would be the barriers to using these tools? / Quels seraient, selon vous, les freins à l'utilisation de ces outils ?

- **They take too long to use** / Le temps nécessaire à leur utilisation est trop important
- **I lack the training to use them properly** / Je manque de formation pour les utiliser correctement
- **They are not simple enough** / Ils manquent de simplicité
- **They are not practical enough to use** / Ils ne sont pas assez pratiques à utiliser

21/ Do you have any comments on these tools as a whole? / Avez-vous des commentaires à faire sur ces outils globalement ?

IDENTIFICATION SHEET

Fiche de
REPÉRAGE DES SÉQUELLES
Professionnels / Patients

1ère Évaluation ☐ ☐ Réévaluation

Groupe expert régional
OncoPaca-Corse
SÉQUELLES & CANCER

Onco Paca-Corse
DISPOSITIF SPÉCIFIQUE RÉGIONAL DU CANCER

Données patient

Nom de naissance :
Nom marital :
Prénom(s) :
Date de naissance (jj/mm/aaaa) : ...../...../......
Age : Sexe : M ☐ F ☐

Prise en charge

Médecin traitant :
Cancérologue référent :

Sécurité sociale	Oui ☐	Non ☐
Mutuelle	Oui ☐	Non ☐
ALD	Oui ☐	Non ☐
Post ALD	Oui ☐	Non ☐

Parcours thérapeutique

En cours	Terminé		Date de fin / Précisions
☐	☐	Chirurgie	....
☐	☐	TMSC	....
☐	☐	Hormonothérapie	....
☐	☐	Radiothérapie ext	....
☐	☐	Curiethérapie	....
☐	☐	Allogreffe CSH	....
☐	☐	Autogreffe CSH	....

Type de cancer : ☐ AJA
☐ Adulte actif
Comorbidités : ☐ Patient âgé

Situation socio-professionnelle

Activité professionnelle ☐ Étudiant ☐
Travailleur indépendant ☐ Retraité actif ☐

Patient en couple	Oui ☐	Non ☐
Enfant(s) à charge	Oui ☐	Non ☐
Difficultés financières	Oui ☐	Non ☐
Isolement (géographique, social...)	Oui ☐	Non ☐
Aidant disponible	Oui ☐	Non ☐
Besoin d'un accompagnant	Oui ☐	Non ☐
Besoin d'un interprète	Oui ☐	Non ☐
Patient "aidant d'un proche dépendant"	Oui ☐	Non ☐

Soins oncologiques de support

Dossier passé en staff pluriprofessionnel SOS ? Oui ☐ Non ☐ Date : ....

Patient retenu comme complexe Oui ☐ Non ☐

En cours	Terminé	
☐	☐	Douleur
☐	☐	Nutrition / Diététique
☐	☐	Soutien psychologique
☐	☐	Aide sociale / professionnelle / familiale
☐	☐	Hygiène de vie / Tabac, alcool...
☐	☐	Activité physique adaptée
☐	☐	Troubles de la sexualité
☐	☐	Préservation de la fertilité

Réhabilitation & éducation thérapeutique

Réhabilitation Oui ☐ Non ☐ RAAC ☐

Précisions : ....

Le patient a-t-il bénéficié d'une reconstruction ? Oui ☐ Non ☐ En attente ☐

Suivi d'un programme d'ETP Oui ☐ Non ☐

Equipe de soins

Date :
Réalisé par (nom) :
Fonction :
Réalisé : ☐ en ville
☐ en établissement :

Séquelles potentielles

- ☐ Douleur
- ☐ Nutrition / Diététique
- ☐ Fatigue
- ☐ Troubles cognitifs
- ☐ Altération de l'estime de soi
- ☐ Troubles de la sexualité

Synthèse

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REPÉRAGE - Professionnels / Patients

Douleur

	Oui	Non
① Avez-vous ressenti des douleurs ces 8 derniers jours ?	☐	☐
② Evaluez votre douleur habituelle de 0 à 10 : 0 1 2 3 4 5 6 7 8 9 10		
③ Cette douleur perturbe-t-elle : • Votre sommeil?	☐	☐
• Vos activités quotidiennes ?	☐	☐
④ Prenez-vous un traitement antalgique? Si oui, le(s)quel(s) ?	☐	☐

Troubles nutritionnels

	Oui	Non
① Avez-vous eu une perte ou une prise de poids au cours des 6 derniers mois ?	☐	☐
② Avez-vous des nausées, vomissements, diarrhées ?	☐	☐
③ Avez-vous des troubles de la déglutition ou de la mastication ?	☐	☐
④ Avez-vous modifié votre alimentation depuis le diagnostic (régime, CNO, habitudes alimentaires...)	☐	☐

Fatigue

	Oui	Non
① Avez-vous ressenti de la fatigue ces derniers jours ?	☐	☐
② Evaluez votre fatigue habituelle de 0 à 10 : 0 1 2 3 4 5 6 7 8 9 10		
③ Cette fatigue impacte-t-elle vos activités quotidiennes ?	☐	☐
④ Est-elle soulagée par le repos ou le sommeil ?	☐	☐

Troubles sexuels

	Oui	Non
① La maladie a-t-elle un retentissement sur votre vie intime et sexuelle ?	☐	☐
② Avez-vous des difficultés ou douleurs pendant les rapports ?	☐	☐
③ Ressentez-vous/appréhendez-vous une altération de votre image corporelle ?	☐	☐
④ Avez-vous des troubles de la sexualité (désir, érection, lubrification, orgasme) ?	☐	☐

Altération de l'estime de soi

	Oui	Non
① De manière générale, avez-vous une image positive de vous-même ?	☐	☐
② Ressentez-vous une altération de votre image corporelle ?	☐	☐
③ Avez-vous besoin d'aide pour effectuer des tâches du quotidien ?	☐	☐
④ Ressentez-vous une modification de vos relations sociales et/ou professionnelles ?	☐	☐

Troubles cognitifs

TRAVAUX EN COURS

	Oui	Non
①	☐	☐
②	☐	☐
③	☐	☐
④	☐	☐

Orientation - Professionnel

EVALUATION / PRISE EN CHARGE DES TROUBLES DE LA SEXUALITÉ

☐ Médecin traitant
☐ Gynécologue/urologue
☐ Sexologue
☐ Autre :

Nom :
Structure :
Date du RDV :

EVALUATION / PRISE EN CHARGE DES TROUBLES NUTRITIONNELS

☐ Médecin traitant
☐ Médecin nutritionniste
☐ Diététicien(ne)

Nom :
Structure :
Date du RDV :

EVALUATION / PRISE EN CHARGE DE LA DOULEUR

☐ Médecin traitant
☐ Médecin algologue

Nom :
Structure :
Date du RDV :

EVALUATION / PRISE EN CHARGE DE LA FATIGUE

☐ Médecin traitant
☐ Kinésithérapeute
☐ Professionnel APA
☐ Autre :

Nom :
Structure :
Date du RDV :

EVALUATION / PRISE EN CHARGE DE L'ALTÉRATION DE L'ESTIME DE SOI

☐ Médecin traitant
☐ Médecin psychiatre
☐ Psychologue
☐ Autre :

Nom :
Structure :
Date du RDV :

EVALUATION / PRISE EN CHARGE DES TROUBLES COGNITIFS

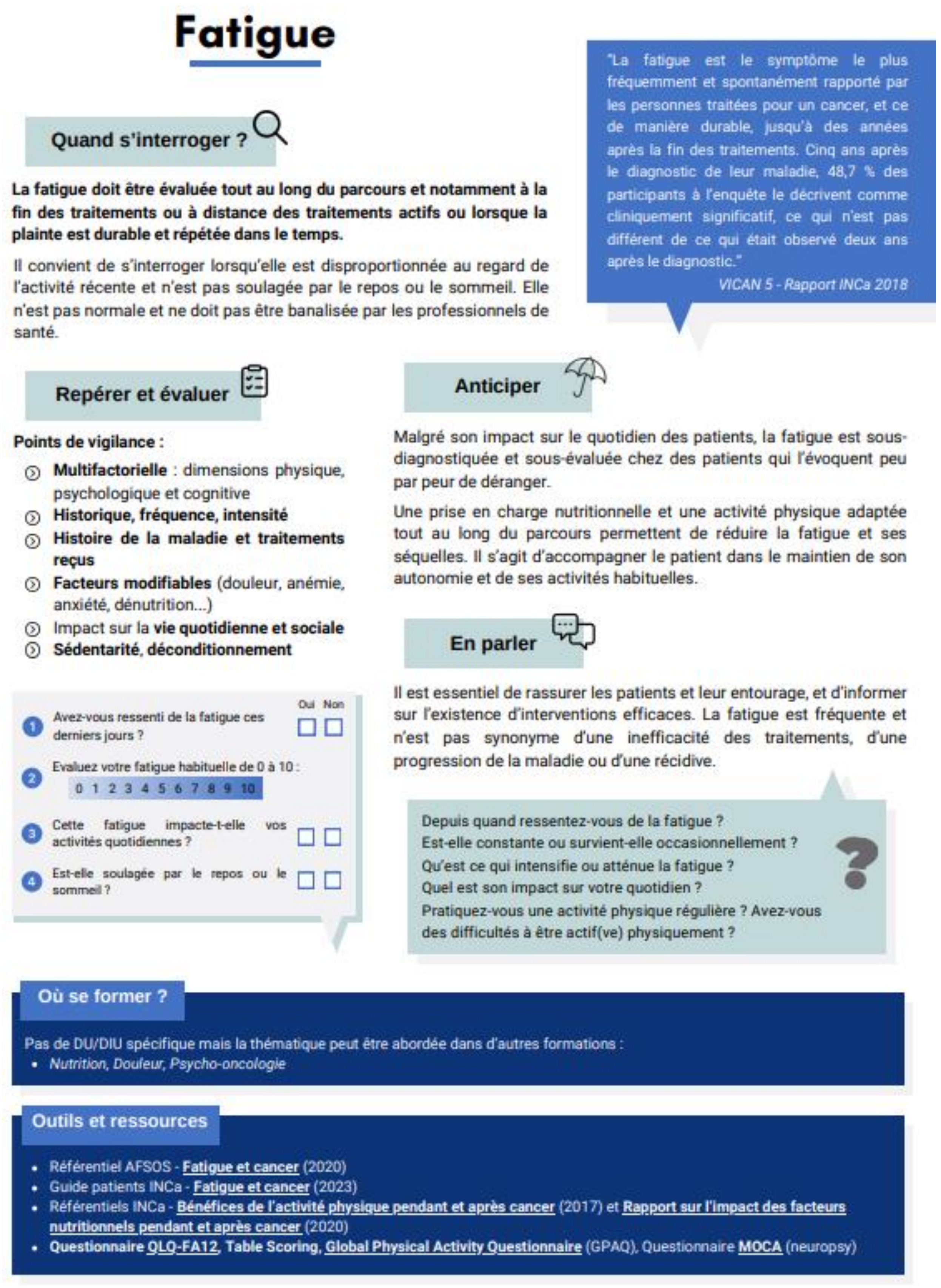
☐ Médecin traitant
☐ Médecin neurologue
☐ Neuropsychologue

Nom :
Structure :
Date du RDV :

SOINS DE SUPPORT PROCHES DE CHEZ VOUS

Consultez le Répertoire Régional des Soins Oncologiques de Support
www.soins-support-cancer-paca-corse.org/

FATIGUE'S INFORMATION SHEET & FLOWCHART



Fatigue

Quand s'interroger ?

La fatigue doit être évaluée tout au long du parcours et notamment à la fin des traitements ou à distance des traitements actifs ou lorsque la plainte est durable et répétée dans le temps.

Il convient de s'interroger lorsqu'elle est disproportionnée au regard de l'activité récente et n'est pas soulagée par le repos ou le sommeil. Elle n'est pas normale et ne doit pas être banalisée par les professionnels de santé.

> "La fatigue est le symptôme le plus fréquemment et spontanément rapporté par les personnes traitées pour un cancer, et ce de manière durable, jusqu'à des années après la fin des traitements. Cinq ans après le diagnostic de leur maladie, 48,7 % des participants à l'enquête le décrivent comme cliniquement significatif, ce qui n'est pas différent de ce qui était observé deux ans après le diagnostic."
>
> *VICAN 5 - Rapport INCa 2018*

Repérer et évaluer

Points de vigilance :

- **Multifactorielle** : dimensions physique, psychologique et cognitive
- **Historique, fréquence, intensité**
- **Histoire de la maladie et traitements reçus**
- **Facteurs modifiables** (douleur, anémie, anxiété, dénutrition...)
- Impact sur la **vie quotidienne et sociale**
- **Sédentarité, déconditionnement**

		Oui	Non
①	Avez-vous ressenti de la fatigue ces derniers jours ?	☐	☐
②	Evaluez votre fatigue habituelle de 0 à 10 : 0 1 2 3 4 5 6 7 8 9 10		
③	Cette fatigue impacte-t-elle vos activités quotidiennes ?	☐	☐
④	Est-elle soulagée par le repos ou le sommeil ?	☐	☐

Anticiper

Malgré son impact sur le quotidien des patients, la fatigue est sous-diagnostiquée et sous-évaluée chez des patients qui l'évoquent peu par peur de déranger.

Une prise en charge nutritionnelle et une activité physique adaptée tout au long du parcours permettent de réduire la fatigue et ses séquelles. Il s'agit d'accompagner le patient dans le maintien de son autonomie et de ses activités habituelles.

En parler

Il est essentiel de rassurer les patients et leur entourage, et d'informer sur l'existence d'interventions efficaces. La fatigue est fréquente et n'est pas synonyme d'une inefficacité des traitements, d'une progression de la maladie ou d'une récidive.

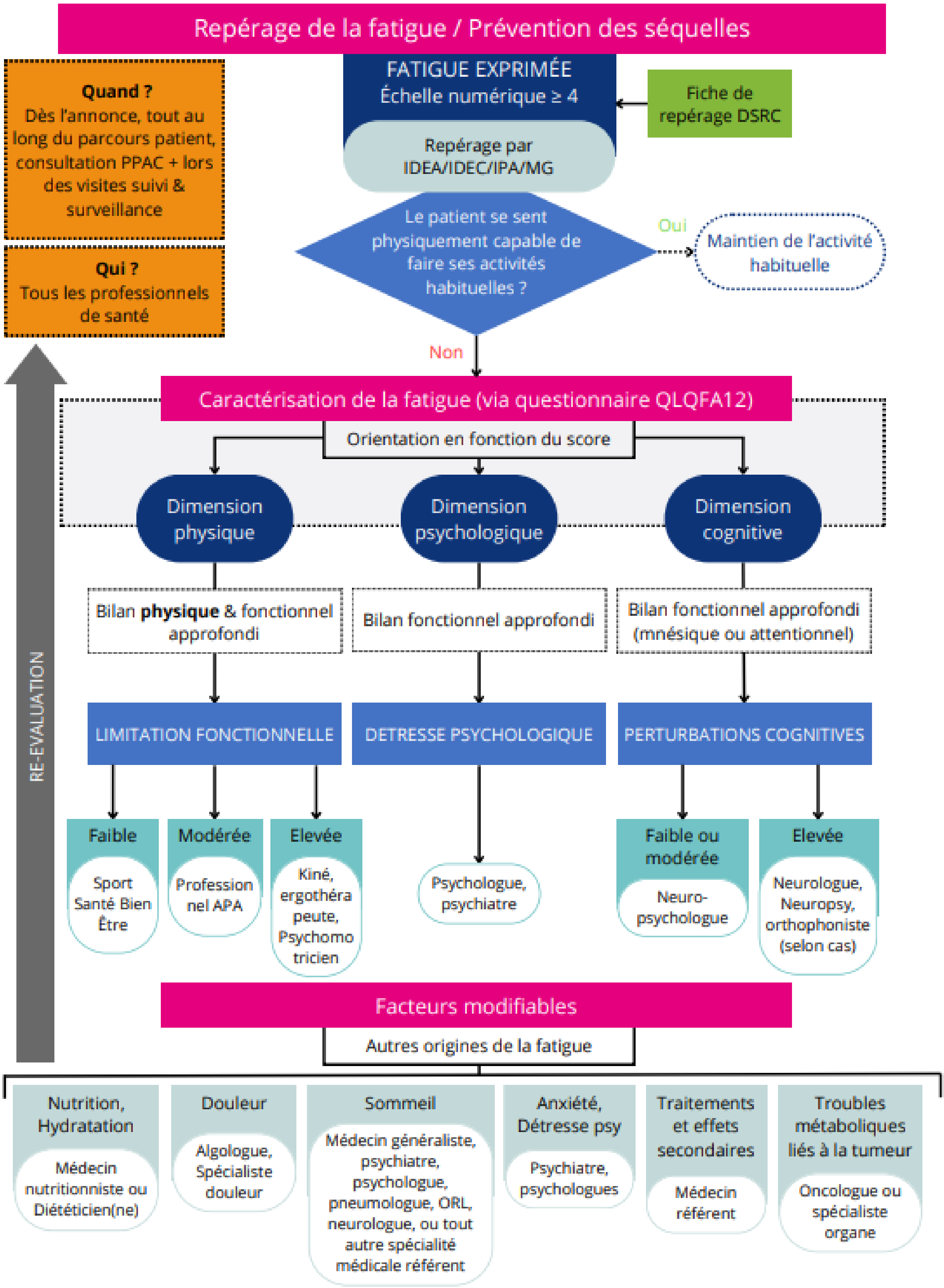
Depuis quand ressentez-vous de la fatigue ?
Est-elle constante ou survient-elle occasionnellement ?
Qu'est ce qui intensifie ou atténue la fatigue ?
Quel est son impact sur votre quotidien ?
Pratiquez-vous une activité physique régulière ? Avez-vous des difficultés à être actif(ve) physiquement ?

Où se former ?

Pas de DU/DIU spécifique mais la thématique peut être abordée dans d'autres formations :
- *Nutrition, Douleur, Psycho-oncologie*

Outils et ressources

- Référentiel AFSOS - **Fatigue et cancer** (2020)
- Guide patients INCa - **Fatigue et cancer** (2023)
- Référentiels INCa - **Bénéfices de l'activité physique pendant et après cancer** (2017) et **Rapport sur l'impact des facteurs nutritionnels pendant et après cancer** (2020)
- **Questionnaire QLQ-FA12, Table Scoring, Global Physical Activity Questionnaire** (GPAQ), Questionnaire **MOCA** (neuropsy)



Repérage de la fatigue / Prévention des séquelles

Quand ?
Dès l'annonce, tout au long du parcours patient, consultation PPAC + lors des visites suivi & surveillance

Qui ?
Tous les professionnels de santé

FATIGUE EXPRIMÉE
Échelle numérique ≥ 4

Fiche de repérage DSRC

Repérage par IDEA/IDEC/IPA/MG

Le patient se sent physiquement capable de faire ses activités habituelles ?

Oui → Maintien de l'activité habituelle

Non ↓

Caractérisation de la fatigue (via questionnaire QLQFA12)

Orientation en fonction du score

- Dimension physique
  - Bilan **physique** & fonctionnel approfondi
  - LIMITATION FONCTIONNELLE
    - Faible : Sport Santé Bien Être
    - Modérée : Professionnel APA
    - Elevée : Kiné, ergothérapeute, Psychomotricien
- Dimension psychologique
  - Bilan fonctionnel approfondi
  - DETRESSE PSYCHOLOGIQUE
    - Psychologue, psychiatre
- Dimension cognitive
  - Bilan fonctionnel approfondi (mnésique ou attentionnel)
  - PERTURBATIONS COGNITIVES
    - Faible ou modérée : Neuro-psychologue
    - Elevée : Neurologue, Neuropsy, orthophoniste (selon cas)

RE-EVALUATION

Facteurs modifiables

Autres origines de la fatigue

Nutrition, Hydratation	Douleur	Sommeil	Anxiété, Détresse psy	Traitements et effets secondaires	Troubles métaboliques liés à la tumeur
Médecin nutritionniste ou Diététicien(ne)	Algologue, Spécialiste douleur	Médecin généraliste, psychiatre, psychologue, pneumologue, ORL, neurologue, ou tout autre spécialité médicale référent	Psychiatre, psychologues	Médecin référent	Oncologue ou spécialiste organe

Groupe expert régional OncoPaca-Corse SÉQUELLES & CANCER