iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

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Guide: Practices and recommendations for the management of cognitive impairments after cancer

A French case study in the framework of iPAAC (Innovative partnership for action against cancer), Work Package 4

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Abbreviations

CHAFEA	Consumers, Health, Agriculture and Food Executive Agency
CanCon	Joint Action on Cancer Control
EU	European Union
iPAAC	Innovative Partnership for Action Against Cancer
CCPIS	Cancer Control Policy Interview Survey
NCI	National cancer Institute
NCCN	National Comprehensive Cancer Network
AFSOS	Association Francophone
ICCTF	International Cognition and Cancer Task Force
DKFZ	Deutsches Krebsforschungszentrum
ECL	European Cancer Leagues
CNS	Central Nervous System
FACT-Cog	Functional Assessment of Cancer Therapy-Cognitive Function
HADS	Hospital Anxiety and Depression scale
MOCA	Montreal Cognitive Assessment
SDMT	(Symbol Digit Modalities Test
CFQ	Cognitive failure questionnaire
ESMO	European Society for Medical Oncology
IPOS	International Psycho-Oncology Society
INSERM	Institut national de la santé et de la recherche médicale
APA	Adapted physical Activity
CBT	Cognitive Behavioural Therapy

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Executive summary

This guide is published in the framework of the European iPAAC programme. It aims to illustrate the iPAAC methodology through a French case study.

This study deals with a subject that is still not well known but important to tackle: cognitive impairments in adults after cancer treatment (excluding the central nervous system).

The scope of the study is thus well defined. It is proposed in the introduction (Title 3) to define the subject and its issues more precisely.

The study is based on a methodology (described in the guide Title 2) which led to a synthesis of both the scientific and grey literature.

On the basis of this research, a synthesis is proposed of the most important themes to be taken into account by the public authorities with a view to improving the quality of life of patients after their treatment. It also aims to assess the importance of the socio-economic impact of cognitive impairments after cancer.

To do this, it is proposed to approach each theme through:

1. Definitions and summaries of the context

2. Summaries of practices identified in the literature and in clinical practice, with a focus on certain relevant and inspiring practices

3. Recommendations for the implementation of these practices for public authorities

All references are sourced and available either in the body of the document or in the annexes.

A document summarising the recommendations is also provided in addition to and as an appendix to the guide in order to make it easier to read.

Although this document is primarily intended for public authorities, it is also intended to be a resource for all persons and organisations concerned by the subject (patients - professionals - health structures - associations...)

Through this work, the authors hope to contribute to improving the quality of life of cancer patients.

Reading instruction:

For ease of reading, links (highlighted in blue) allow direct access to additional resources (within the guide or its annexes) by clicking on them.

A summary of the guide is also available in the annex for a quicker overview of the main messages and recommendations to public authorities.

Title 1 - Introduction

1.1 Context and definition of the scope

1.1.1 Context

The European Commission launched the Joint Action on Cancer Control (CanCon) in 2014, thereby providing broad guidance to member countries' national cancer programmes. In particular, the guidance published in 2017 identified (1) the need to improve quality of care after cancer, rehabilitation and survivorship.

Building on the deliverables of the CanCon Joint Action, the Innovative Partnership for Action Against Cancer (iPAAC) has more recently set itself the objective of investigating the conditions for the operational implementation of innovative approaches to cancer control so that they can be integrated into policy and practice[2.]

Work package 4, led by the Belgian public health scientific institute Sciensano, aims more specifically to provide information on two key aspects: the implementation and sustainability of innovative actions, based on a survey conducted in 28 European countries. (Cancer Control Policy Interview Survey, CCPIS). The CCPIS survey has once again highlighted the importance of making progress towards a better understanding of the issues in the post-cancer period.

This post-cancer challenge has emerged as one of the priorities for the countries interviewed for the iPAAC project[3].

At the end of the CCPIS survey, it was decided to focus investigations on specific themes in the post-cancer period.

In this context, INCa, a partner with Sciensano in the iPAAC program, wanted to focus on the psychological and neurological after-effects of cancer. Among this category of after-effects, the project partners decided to focus on cognitive impairments, as a first step to a comprehensive reflection on after-effects in the post-cancer period.

Among other things, it appeared that cognitive impairments, although frequently reported by patients with an impact on their daily life, were not well understood. There was no clear evidence of any actions taken by the public authorities and the initiatives taken in the territories by health professionals or associations were not easily identifiable at the European level.

The issue of cognitive impairment as a consequence of cancer and its treatment is the subject of this guide, which aims to propose:

- A summary of the practices identified in the field, highlighting the strengths and limitations
- Recommendations for public authorities on the implementation of good practices, particularly highlighted for their clinical relevance and feasibility.

[1] CanCon_Guide_FINAL_Web.pdf (cancercontrol.eu)
[2] https://www.ipaac.eu/
[3] Reported challenges: https://www.ipaac.eu/en/work-packages/wp4/

The aim of this guide is to help stakeholders in different European countries to put in place, according to the means available, measures to manage cognitive disorders in the post-cancer period.

It will also be a source of information for all those involved, in particular patients concerned by these issues.

1.1.2 Definition of the scope of the guide

This guide concerns only the management of cognitive impairments in adults after cancer treatment (excluding the central nervous system).

1.1.2.1 The post-cancer period

Over the past few decades, advances in treatment and improved care pathways have resulted in an increased survival of cancer patients. Many patients will not relapse from their cancer, but following the diagnosis of cancer and the treatments received, they may present persistent side effects or after-effects, which for some will be hindering a return to a normal life. Thus, the period known as "after cancer" is a pivotal time during which it is necessary to support patients.

This period is most often referred to as "*survivorship"* in the international literature, which can nevertheless be confusing since it refers to the entire patient journey without making it possible to specify from the outset which phase is being discussed (diagnosis; treatment; after treatment).

For example, according to the U.S. National Cancer Institute (4), the term "*survivorship"* refers to "*the health and well-being of a person with cancer from the time of diagnosis until the end of life. This definition includes: the physical, mental, emotional, social, and financial effects of cancer that begin at the time of diagnosis and continue throughout treatment and beyond. The patient's experience in the post-cancer period also includes issues related to follow-up care (including regular health and wellness check-ups), late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends and caregivers are also considered part of the survivorship experience."*

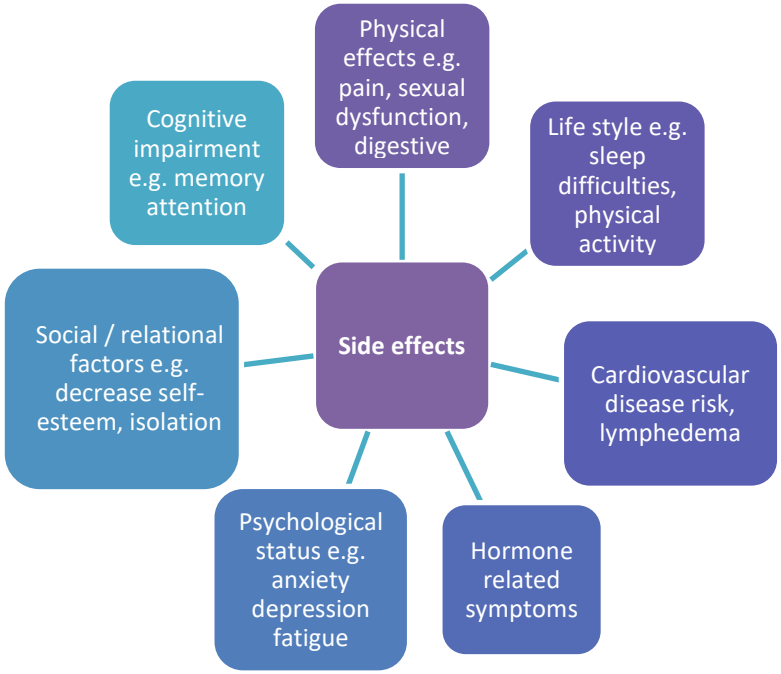
For the purposes of this European guideline, we will refer to the following definition of *survivorship* proposed by the European Society of Medical Oncology (ESMO). It defines the period to be considered: ***"the physical, psychological, social and economic health and problems that affect individuals at the end of initial cancer treatment"*** and survivorship care as including ***"issues relating to follow-up care, management of late treatment side effects, improvement of quality of life, and the psychological and emotional health of the patient".***

In addition, to avoid confusion, in this guide **we will use the term "post-cancer" and not "survivorship".**

[4] https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship

1.1.2.2 The side effects of cancer and its treatment

The objective of analysing the post-cancer period is to help patients manage the side effects of cancer and its treatments and improve their quality of life. Several types of side effects have been identified, as those in example in the diagram below *(Ancoli-Israel, 2015; Cella et al., 2002; Hayes et al., 2008; Savard et al., 2015; Seretny et al., 2014; Van Den Beuken-Van Everdingen et al., 2016; Van Leeuwen et al., 2021).*



The most common side effects reported by patients treated for cancer outside the central nervous system include cognitive impairment.

Although cognitive impairment is widely reported by patients, health professionals, unlike other better-known side effects such as fatigue, still poorly identify them.

This point reinforces the choice, among the side effects, to favour specific work on cognitive impairments likely to affect the patients' daily life, their autonomy and their return to work.

1.1.2.3 Cognitive impairments in the post-cancer period

Several terms exist in the literature to designate cognitive impairments, without being exact synonymous.

- **"Chemofog" or "chemobrain"**

This term is very often encountered and used for historical reasons.

In early studies, the focus was on the impact of treatments, particularly chemotherapy, known as ***"chemofog"*** or ***"chemobrain"*** *(Wefel et al., 2004).* Since then, many studies have revealed that chemotherapy is not the only determinant of cognitive impairment *(Bernstein et al., 2017; Ganz, 2014; Hermelink, 2015),* which can also be observed before the start of treatment and years after the end of treatment. Thus, the terms "chemofog" or "chemobrain" do not cover the entire definition of cognitive impairment.

- **"Cancer-related cognitive impairment" (CRCI)**

Currently, the scientific literature preferentially uses the term *cancer-related cognitive impairment (CRCI).* As defined by Horowitz (Horowitz et al, 2018), cancer-related cognitive impairment is the "*term used to describe the constellation of cognitive difficulties experienced by cancer survivors. The same phenomenon often goes by names such as 'chemobrain' or 'chemofog'; however, that terminology assumes that chemotherapy treatments are the cause of both short- and long-term cognitive impairments. While chemotherapies certainly can have negative effects on cognition, radiation therapy and adjuvant hormonal treatments may also have deleterious effects. Furthermore, some prospective longitudinal studies have shown that some cancer patients display impairments even before treatment, implicating the cancer itself"*.

Thus, the term CRCI characterizes the subjectively and objectively measured cognitive impairment experienced by patients, from the time of diagnosis until years after treatment has been completed.

- **Cognitive impairments**

In order to use a simple and comprehensible term for all the actors for whom this guide is intended (taking into account both the cognitive complaint and the objectified cognitive disorders), the generic term "cognitive impairments" will be used for this guide.

1.1.2.4 Structured research in recent years has objectified the reality of cognitive impairments

Faced with the complaints of patients, research has been interested in the subject for more than 10 years *(Schagen et al., 2006; Vardy et al., 2008)* and the reality of these disorders has been scientifically demonstrated and objectified.

This research has been structured at the international level. For example, in 2006, the International Cancer and Cognition Task Force (ICCTF) was created to bring together researchers and clinicians (e.g., oncologists, psychologists) working on cognitive impairment in cancer in Europe, Australia and the United States.

At the European level, this structuring is still recent. For example, the creation of a European consortium brought together researchers and clinicians from France, Denmark, Germany, Belgium, Austria and the Netherlands. This multidisciplinary group of experts aims to improve knowledge about cognitive impairments in cancer and to disseminate it through scientific publications, symposia and workshops *(Joly et al., 2015; Wefel et al., 2011).*

Note that most studies assessing cognition in cancer patients were conducted in women with breast cancer.

These studies confirmed the observations made by clinicians and revealed that patients reported more cognitive impairments compared to healthy subjects without a history of cancer *(Janelsins et al., 2017).* Beyond the complaint *(Bolton & Isaacs, 2018; Le Fel et al., 2013)* reported in more than 70% of patients *(Marie Lange, Licaj, et al., 2019)*, objectified difficulties were identified and showed that the main areas affected are memory, attention, executive functions, and language *(Ahles et al., 2012).*

However, it has been observed that the severity of the complaint is not always associated with the level of objective difficulties assessed using neuropsychological tests *(Bray et al., 2018).*

Different hypotheses have been proposed to address this discrepancy such as the fact that the complaint is often very much related to the psycho-emotional context, that assessments are not representative of situations experienced in daily life, and that tests lack sensitivity to detect patients' subtle cognitive impairments *(Giffard et al., 2015; Marie Lange, Castel, et al., 2019).*

Objectively diagnosed cognitive problems, usually mild to moderate, often transient, and not always related to the cognitive complaint.

Despite the identification of potential cognitive impairments related to cancer and its treatment, these disorders are still largely underestimated by health professionals and patients themselves.

Frequent cognitive complaints: 75% of 1,610 patients who answered a French online survey reported cognitive impairment related to cancer treatment *(Marie Lange, Licaj, et al., 2019).*

1.1.3 Issues

Cognitive impairments may appear during cancer treatment, or later. Indeed, **patients may only notice these cognitive difficulties when they stop treatment or when they resume their professional activity.**

In addition, although these difficulties are generally transient, some studies have observed cognitive impairments more than 10 years after the end of treatment *(Henneghan et al., 2018; Koppelmans et al., 2012; Stouten-Kemperman et al., 2015).*

The identification of these difficulties, as will be explained in more detail in this guide, is problematic and can be delayed.

Yet, these cognitive impairments have a negative impact on patients' independence, return to normal social life and employment *(Von Ah et al., 2013, 2018).*

Beyond the question of the quality of life of patients after cancer and given the number of patients potentially concerned, there are not only strong public health issues, but also social and economic ones.

Some figures (source: RoseUp and Kantar Health study)

- 75% of the women surveyed said that they suffer from a cognitive disorder
- 28% of women surveyed know the term “chemofog”
- The subject is discussed by the doctor in only 28% of cases, and when it is, it is on the patient's initiative
- Disorder management advice is given in 30% of cases
- 95% of the women surveyed would have liked to be warned of the occurrence of these problems;
- 92% of them think that the information should come from the oncologist
- 80% of women are affected in their professional life

As we will develop in this guide, although these cognitive impairments are identified and objectified in the scientific literature, they are still little known and evaluated in the clinic and very little treated.

To date, the literature shows that there are few good practices for assessing and managing cognitive impairments in post-cancer care. These practices are also difficult to identify and describe.

However, patients strongly demand to be taken care for these difficulties.

In fact, according to the above-mentioned survey, among the 75% of patients with a cognitive complaint, **75% of them stated that they would like to receive some form of support.**

75% of patients with a cognitive complaint want support for their cognitive impairments *(Marie Lange, Licaj, et al., 2019)*.

The most requested types of support (according to the same study):

- cognitive training (72%),
- psychological support (48%)
- physical activity (32%).

These studies underline the need to offer support adapted to the needs of patients who complain of cognitive impairments.

Cognitive impairments, which is often subtle, differ from the cognitive impairments encountered in certain neurological or psychiatric diseases, or following a stroke or head trauma. Thus, the supportive care offered in the management of these pathologies is generally not adapted to the subtle cognitive impairments of patients in the post-cancer period. There is therefore a need for more knowledge about the type of impairment encountered in the post-cancer period and effective interventions to address them in order to provide patients with appropriate support.

Title 2 - Methodology

The method consisted of three phases:

- **Phase 1:** Research
- **Phase 2:** Synthesis and drafting of the guide
- **Phase 3:** Workshop and consensus on implementation proposals

For more details ***see Annex 1***

2.1 Phase 1: Research

The research consisted of:

- A first stage of scientific literature search,
- A second stage of grey literature search
- A third stage of interviews.

An evidence-based approach was used to ensure rigorous analysis and levels of evidence to make recommendations. For reasons of time, it was not possible to consider the scientific literature search on the entire field of cognitive impairments in post-cancer.

- The research of scientific literature therefore focused only on identifying **studies evaluating the effect of management (also called "interventions") on post-cancer cognitive impairments** (as already mentioned for adults treated for cancer outside the central nervous system). **A level of evidence was found for the results of this part of research.**
- The scope of the research was broadened to include other aspects of cognitive impairments after cancer. **The other themes relating to the pathway of cognitive impairments after cancer** outside of care (diagnosis; assessment; organisation; return to work; patient experience…) **were analysed by the grey literature review and interviews. For this part of research, the level of evidence (by definition low) was defined by a consensus of experts** (organisation of a workshop – *see phase 3 of the methodology*).

2.1.1 Review of the scientific literature

An evidence-based approach was used to ensure rigorous analysis and levels of evidence to make recommendations.

The method of scientific literature review was based on the method *(Liberati et al., 2009)* whose different items are described below.

2.1.1.1 Selection of keywords and eligibility criteria:

Key research words were identified and selected ***(see Annex 1)***

The search equations focused first on general cognitive impairment and then on effects and treatments for cognitive impairments. The list of keywords, and an example of keyword equations are available in the annex ***(see Annex 1).***

For search engines that did not allow for the inclusion of all keywords, a funnel search was conducted. Thus, the essential keywords related to cognition and cancer were included, followed by a refinement of keywords related to the impact and symptoms associated with cancer and its treatment, and the interventions performed were included in turn.

Only studies published in the last ten years, i.e., from 2011 to the present, were considered in order to obtain the most recent references. Then, several inclusion and exclusion criteria were defined in order to limit the search to articles of interest ***(see Annex 1).***

2.1.1.2 Databases

For the research of scientific literature have been analysed: randomized controlled trials; feasibility studies and meta-analyses in a selected scientific database ***(See Annex 1)***

2.1.1.3 Steps of selection of studies

- Data extraction,
- Importation of the data into a software (RYYAN) to facilitate item selection
- Elimination of all duplicate studies.
- Deletion of all studies that did not meet the eligibility criteria on the basis of the titles and the abstracts.
- Download of the full article of studies where the abstract did not indicate whether the study met the eligibility criteria, to verify the study methodology.
- Once the selection of articles was completed, all selected articles were downloaded and read. Articles that did not meet the eligibility criteria were removed.
- Production of a summary of each article in an Excel table.
- The synthesis of each article was read by the group experts, for a final review of the selection of articles.
- A search of published systematic reviews and meta-analyses on the subject was conducted to add to the table any articles that had not been identified.

2.1.1.4 Determination of the level of evidence

To determinate the level of evidence for each studies found, the criteria of the HAS recommendation grade table were used ***(see Figure 2 - Annex 1)*** The summary of articles ***(see table 21 to 27 in the Annex 3)*** were used to analyse and determine the level of evidence.

2.1.1.5 Synthesis of the scientific literature

A total of 41 studies were identified, all evaluating the effect of different types of management of cognitive impairments in the post-cancer period of patients treated for cancer outside the central nervous system.

Note that the majority of these studies were published by teams from the United States (24 studies), and only 6 were published by European countries ***(see Figure 1).***

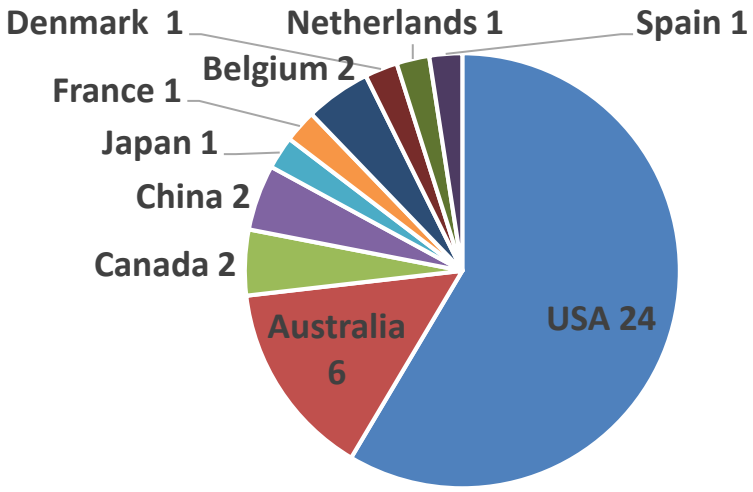


Figure 1. Number of studies evaluating the effect of intervention on cognitive impairment by country

All this information is available in the summary tables of the studies identified in the annex *(see Annex 3 – Synthesis of the scientific literature).*

Were also identified 29 ongoing studies registered on Clinicaltrials.gov, *(summarized in the table 26 and Table 27 Annex 3).*

2.1.2 Review of the grey literature

The expectations for the research of the grey literature:

- A broader scope than scientific research

- To find information that is different from and complementary to that found in the scientific literature, especially about clinical practice in the field.

2.1.2.1 Method of searching the grey literature

- The research consisted of identifying the theme of cognitive impairments.
- The theme was searched directly alone. Then it was searched among more general cancer resources about “survivorship” or public cancer policies.
- The inventory of resources has been carried out: on an international scale - on a European scale - on a French scale.
- The research targeted some selected countries ***(see Annex 1)*** (it wasn’t possible to have an exhaustive analyse).

- **International literature search:**

Three countries were targeted: United States - Australia - Canada

These countries were chosen because of their significant number of publications on the subject and their recognition and identification by the group of experts.

A number of resources were identified. The search found only a few resources related to cognitive impairments. So, the information found was supplemented by interviews in the United States and Canada (despite the interest, no interviews have been arranged with Australia due to time constraints).

- **European literature search:**

An analysis of different type of resources at the European level was carried out (cancer plan; user associations; learned societies ..., ***(see Annex 1).***

The CanCon and iPAAC reports were also used to identify interesting initiatives and literature (the main source of summary information on *survivorship* at European level).

- A list of selected countries to analyse:

As the country research could not be conducted exhaustively, a series of target countries for research were identified.

In order to have complementary information, the choice of countries was defined in coherence with the contacts identified for the conduct of the interviews.

It was also decided to have a representative panel (size of population; geographical diversity; state of progress on cancer management).

Then, were excluded from the research countries for which: no contact was identified; no response to the request for an interview; no information could be easily found.

- Several types resources analysed:

The first step was to analyse the cancer plans (available on the website of the International Cancer Control Partnership[5] ***(see Table 4. European Cancer in the Annex 1)*** and in the annex of the iPAAC guidelines, in particular Work Package 10[6]).

Next, conduced searches among diverse resources: cancer institutes; scientific and professional societies; cancer centers; user associations (guidelines, *survivorship* guides, etc. already known to the group experts or identified during the research, e.g., the ESMO and NCCN guidelines).

More broadly, searches were conducted using an Internet search engine to identify resources that had not already been identified on the basis of key words related to the subject (in the same way that the scientific research but without the same systematic and rigorous process).

As expected from the group experts, this approach led us to find very few resources specifically related to cognitive impairments at the European level.

[5] https://www.iccp-portal.org/
[6] https://www.ipaac.eu/res/file/outputs/wp10/national-cancer-control-plans-survey.pdf

Nevertheless, the research allowed to find some interesting resources in Europe. Notice that it was easier to find the information in France (e.g., Cancer and cognition[7]) but some information were found in other countries (e.g., Netherlands NHI[8]).

- **Documentary research in France:**

– The research was carried out using all the resources already known about cognitive impairment (cancer centers; learned societies; etc.) and then more widely on the theme of post-cancer (Return to work - Physical activity and cancer …)

In order to broaden the research, related themes were analysed: Mild cognitive impairment (MCI) - Mental health – Cognitive impairment and disability – Cognitive impairment in the elderly ***(See Annex 4).***

The search was conducted using keywords for each specific or related topic on a search engine. The results of these searches were selected based on their relevance for our research ***(See Annex 1).***

2.1.2.2 Limitations of the grey literature search

The grey literature does not allow, unlike the scientific literature, to attribute a level of scientific proof. The resources from the grey literature must be submitted to an expert consensus to acquire a certain probative force *(See phase 3 of the methodology).*

The analysis of the grey literature shows that existing resources are difficult to access and very scattered. **Hardly any resources offer a comprehensive information platform:**

- At the European level, the European Commission's website does not have a comprehensive resource proposal on cancer literature (for example, the cancer plans of each European country are not available).
- The NCI website, one of the most comprehensive found, does not provide details on clinical practice.
- …

Thus, this kind of literature research did not allow to easily identify, in all countries, local initiatives and clinical practices which are most often not reported or published.

This observation corroborates the low number of scientific publications at European level.

It's noticed that the language barrier has been a hindrance to research, despite the translation tools. Many documents are only accessible in the original language and some formats do not allow for automatic translation (it was the case, for example, with the cancer plans). Thus, while websites and short documents could be translated, large documents in PDF format could not be fully analysed.

[7] http://www.canceretcognition.fr/
[8] https://www.nki.nl/research/research-groups/sanne-schagen/cognitive-functioning-in-cancer-patients/

To complete the documentary research, it was necessary to organise interviews.

2.1.3 Conducting interviews

2.1.3.1 Selection of the stakeholders to be interviewed

- **A representative panel:**

- A variety of countries
- A variety of key European stakeholders: Public authorities; Institutions and experts; Learned societies; Cancer Centers …; Patient associations
- Selection in coherence and complementarity with the countries selected for the grey literature research**.**
- A non-exhaustive panel.

→ **Initial targeted countries**: France - Denmark - Germany - Belgium - Netherlands - Austria - Spain - Italy - Poland - Cyprus - Portugal - Luxembourg – Sweden – Canada – USA
→ **Final targeted countries:** France - Denmark - Germany - Belgium - Poland - Portugal - Luxembourg – Canada – USA

- **Criteria for selecting stakeholders to interview:**

- Relevance to the subject;
- Complete the documentary research;
- For European and International countries: a single interview with priority given to public authorities (as target of the study);
- For France: more in-depth interviews.

- **Constitution of the list of people to be contacted:**

– Initial list compiled through the networks of experts already known on the subject.
– New contacts identified during the review of grey literature and the interviews.
– Resources proposed by the iPAAC project in particular were useful, although not specific to cognitive impairments.
– The resources used to identify the contacts are available in the annex ***(see Annex 1).***

2.1.3.2 Summary of interviews

- **A representative panel: In numbers and quality**

- **A total of 107 stakeholders were identified**, (23 could not be found and excluded from the selection).
- **71 people selected and contacted** on the 84 contacts identified (in order to limit the number of interviews, a selection was made on the basis of the criteria mentioned above).
- **A majority of French** contacts (24 people) responded positively to the interview request
- **A total of 26 videoconference interviews *(see Annex 1 - Table 5. Summary of interviews).***

- **Method used for the interviews:**

- Semi-opened questionnaire
- A dedicated questionnaire ***(designed specifically for the study available in the Annex 1 – Guide of interview).***
- For each interview, a short summary of the key elements was produced and sent to the INCA.

It's noticed that although the summer period was not favourable for conducting some of the interviews (lower reactivity of the people approached), **interviews were generally quite successful and the approach was favourably received.**

Patient associations and experts were much more willing (and available) to participate in an interview. In particular, experts in the field and those who were already aware of the issue quickly understood the value of the approach and were extremely helpful. **Requests were made within the framework of this project to consider going further at the end of this work (partnership - participation in conferences, etc.).**

As far as public authorities and cancer agencies are concerned, the NCI (National Cancer Institute in the United States) and the Canadian Ministry of Health and Social Services have been very responsive. This point should undoubtedly be compared with the state of progress of these issues in the USA (precursor and first country to publish in volume) and in Quebec (few scientific publications but reflection on the organisation of care and interesting documentary resources on the subject).

As for the European public authorities, either no response was given to the request for an interview or the technical nature of the subject limited the desire for an interview (despite the interest expressed). Some public authorities suggested a redirection to more competent contacts on the subject.

Generally speaking, contact in France was easier than in other European countries (all stakeholders combined). This can be explained by several reasons:

- Prior knowledge of the actors in France and greater confidence in answering interviews
- Language barrier (the project team is French-speaking)
- Contact was not made through the public authorities, but by the team in charge of the study. This factor may have slowed down communication and understanding of the approach (a few requests remained unanswered, particularly in other European countries).

It is also specified that, as France is the subject of the analysis of the implementation of practices, it is normal that the interviews were more numerous. In this respect, a fairly precise analysis of the situation in France with regard to the theme studied was provided. Certain field practices were identified in detail.

2.2 Phase 2: Synthesis and drafting of the guide

On the basis of this research, project team experts carried out a synthesis of the findings (problems and practices).

This allowed us to identify the themes that seemed to be the most frequent and important to develop in the guide.

These themes have been selected to form the outline of this guide, which is structured in 6 chapters. The order of presentation of the chapters is based on the patient's journey.

Within certain chapters, sub-themes have been identified and are proposed in the form of fact sheets.

Each chapter or sheet provides a summary of the subject (definition - context), then practices identified on the subject as well as a more specific "Focus" sections on certain practices.

As this is an emerging subject, the good practices identified are not numerous enough to be able to propose a relevant selection of some of them. A list of all the practices identified is therefore included (as well as the resources identified). These practices are listed in the different chapters and sheets, but to avoid redundancy, this list is proposed in the annex.

The choice of practices highlighted in the "Focus" sections was made primarily on the basis of the quality of the information gathered and its relevance (and interest) to the subject. All the “Focus” sections are listed after the summary.

In the methodology initially proposed, the aim was to use the practices identified to carry out an analysis of their implementation in France. The " ASTAIRE"[9] grid had been identified and the "SIROCCO"[10] grid proposed. However, in practice, during the study, these grids proved to be unsuitable.

Proposals for implementation of the practices were formulated from the synthesis work in order to be submitted for discussion and validation by a consensus workshop.

2.3 Phase 3: Workshop and consensus on implementation recommendations

A workshop was organised at the end of the first phase of synthesis.

Constitution of the workshop panel: interviewed stakeholders and some additional experts identified in other countries than those already identified.

Almost all the people interviewed responded positively to the invitation and participated in the workshop, which confirms the interest in the subject.

The purpose of this workshop:

- Confirming the collaborative work on which the initial methodology was based

[9] https://www.normandie.ars.sante.fr/media/40132/download
[10] https://www.scirocco-project.eu/maturity-model-in-practice-scirocco-assessment-tool/

- Confirming the commitment and support of the people approached by involving them more in the project
- Providing an opportunity for bilateral interviewees to share
- Gather consensus on practices from the grey literature that do not have a scientific level of evidence
- Gathering consensus on proposed implementation recommendations from the synthesis work
- Making proposals and corrections

In practice, the themes of the guide (chapters and sheets) were discussed one by one.

After a brief reminder for each chapter and sheet of the context and issues, a vote was proposed on the implementation proposals.

The members of the workshop were invited to react directly on the content of the draft guide sent before and after the workshop.

Organisation of the vote:

- The implementation proposals were submitted a first time and the workshop members were invited to vote according to the following 3 criteria: "favourable" / "unfavourable" / "abstention".
- After this first vote, a discussion was proposed.

Integration of discussion and voting results into the final guide:

- The result of the discussions allowed the first draft of the guide to be completed and corrected;
- In addition, the implementation proposals were integrated into the guide;
- A presentation of the results of the votes on these recommendations from the workshop is included in the guide ***(See Annex 1).***

General summary of the methodology:

During all phases of the work, the project team received a very positive and constructive response. There are high expectations of the subject and the guide will be an interesting resource for future work on the subject.

The study was welcomed as an opportunity, both to assess the situation and to provide a useful practical resource for all stakeholders.

The study was also an opportunity to identify the priorities for action to be addressed by the public authorities. From this point of view, although this guide is primarily intended for this audience, it will obviously be a tool for all the stakeholders concerned by the subject.

From this point of view, the interviews show that the expectations of the various parties involved are not always the same, a factor that leads to a great deal of misunderstanding as to the objectives and methods.

Nevertheless, we note that while initiatives are emerging from the field to meet patients' needs, strong expectations are being expressed towards the public authorities on the subject.

Title 3 - Practices and recommendations

The practices and recommendations are presented by chapters and sheets.

The themes fallow the care pathway.

For ease of reading, links (highlighted in blue) allow direct access to additional resources (within the guide or its annexes) by clicking on them.

Chapter 1. Informing about cognitive impairments related to cancer treatment 26
Sheet 1.1 Organising information by public authorities 27
Sheet 1.2 Informing healthcare professionals to improve the care of patients with cognitive impairments 30
Sheet 1.3 Informing patients as early as possible to promote access to support 33

Chapter 2. Identifying and objectivising cognitive impairments 37
Sheet 2.1 Identifying cognitive impairments 39
Sheet 2.2 Objectivising cognitive impairments 43

Chapter 3. Promoting the different ways of dealing with cognitive impairments 48
Sheet 3.1 Referring patients to appropriate supportive care 50
Sheet 3.2 Orientating, coordinating and organising the management of cognitive impairments 73
Chapter 4. Proposing a management of cognitive impairments in the framework of support to return to work 80

Chapter 5. Identifying the health professionals to be involved in the management of cognitive impairments and training them 86

Chapter 6. Supporting all aspects of research related to cognitive impairments 91

Chapter 1. Informing about cognitive impairments related to cancer treatment

• Context

Improving the quality of life of patients after cancer treatment is now recognized by most of the oncology community, but not all after-effects receive the same attention. Thus, cognitive impairments are among the problems that, although frequent, have not yet been identified as a priority to be tackled. As such, they are rarely included in communications on the theme of post-cancer.

The data in the scientific literature on this subject remain poorly known to public authorities, health professionals and patients alike. However, awareness on this subject gradually increased over the last ten years, particularly in terms of the characterization of disorders, in terms of semiology, duration, associated factors, and their impact.

Therefore, it is essential to undertake initiatives aiming to increase awareness and information in this subject: they should target the various stakeholders with differentiated messages and means, in order to enable rapid and tangible progress in patient care.

RECOMMENDATIONS for public authorities

(83 to 100% of the experts have voted in favour of these recommendations)

- To promote the initiatives of expert actors on the subject to raise awareness among public authorities

- To ensure the inclusion of the topic of cognitive impairments in national cancer control programs

- To put the topic of cognitive impairments among survivorships in the European agenda

- To promote the inclusion of cancer related cognitive impairment in the work of cancer-related scientific societies or institutions

- To ensure that health professionals and patients are informed on the basis of scientific information, drawing on tools and practices already available

This chapter proposes to detail three recommendations, the first *"Organise information by the public authorities"* (Sheet 1.1), the second *"Inform health professionals to improve the pathway for patients with cognitive impairments"* (Sheet 1.2) *and* the third *"Inform patients as early as possible to promote access to support"* (Sheet 1.3).

Sheet 1.1 Organising information by public authorities

Context

More and more European countries are making progress in structuring specific care and support systems for the post-cancer period. Some, such as Belgium, Denmark and France, have formalised dedicated health objectives within the framework of national cancer plans and rehabilitation programmes. However, very few have formally integrated the consideration of cognitive impairments into their action strategy.

Identified practices

Of the countries that offer post-cancer provisions, most of them focus on the following themes: psychology; sport; beauty care; nutrition, etc.

The topic of cognitive impairments is very rarely discussed.

Nevertheless, we have seen that some countries have chosen to include specific programmes in their national cancer plans *(see Focus below).*

It appears that the interest in including this issue in public health policy documents at least allows the subject to be officially recognised. At the same time, this allows the public authorities to demonstrate a political commitment to support the subject. Finally, such an approach allows the subject to exist for all actors.

Table 1. Programs that have identified the issue of cognition in post-cancer care

Country	Resources	Program content	Cognition
Denmark	Rehabilitation Program Program available in Danish	• **Context:** Developed within the framework of the cancer plan III and as a complement to meet the needs of post-cancer rehabilitation and palliative care. • **Target:** planning authorities; hospital managers, professionals (nurses, psychologists, social workers, etc.). • **Objective:** - Describe the professional approach to palliative care rehabilitation and cancer care organisation - To help ensure quality professional care and coordination of care across disciplines and sectors in a comprehensive approach	• Memory and concentration difficulties identified as one of the main symptoms found in patients during and after treatment. • Observed that 42% of the patients report having concentration difficulties (occasional to frequent) and 40% report having memory difficulties (occasional to frequent). • Cognitive impairments is included in the domain of psychological needs. • However, no specific care is specified.
Sweden	National Cancer Rehabilitation Program *(latest version 09/02/2021).*	• **Background:** Care program prepared by a national working group and established by the regional cancer centre • **Content:** Presents the actions to be implemented at the regional and local level in order to offer a care program that meets the full range of needs of patients over 18 years of age. • **Objective:** that the needs of patients are identified in consultation so that the patient does not have to ask for an evaluation and an adapted intervention.	• Cognitive impairments are included in the "psychological and psychiatric aspects" domain. • Describes the affected cognitive areas and their need for assessment and suggests compensatory strategies. • **Recommendation:** "Patients who present or have presented with signs of cognitive impairments should be offered an expanded assessment of their cognitive function."

Different expectations expressed by health professionals and patients regarding the role and place of public authorities:

- Need to consider the importance of disseminating information on these topics as a responsible for the health and well-being of their populations
- To have a less pyramidal and less top-down approach from the public authorities in order to take more account of initiatives and actors on the ground
- The need for public authorities to be involved in communication and information on this subject.
- At the very least, facilitate the development of and access to information by public authorities (active role in taking this subject into account, which could be applied at different levels of action, starting with the relaying of information)
- Public policy planning through the integration of the issue of post-cancer cognitive impairments in national cancer plans. The advantage could lie in a strong political position in favour of this issue while allowing the subject to be disseminated on a large scale and to raise the awareness of a maximum number of stakeholders. During the interviews, experts received opinions in favour of this option (particularly from countries that do not have a cancer plan) because it would provide a structuring framework.

- Implementations

Message to authorities:

- Need of involvement of public authorities on the subject
- Need to set up of a platform of expertise in the field of side-effects to inform
- Need to ensure good dissemination of information to professionals and patients

83 to 100% of the experts have voted in favour of these recommendations

<u>Implementation recommendations for public authorities:</u>

- Promoting the initiatives of expert actors on the subject to raise awareness among public authorities
- Involvement of public authorities in information and communication activities
- Promoting (and/or initiate) the information media (or projects) already existing at national or European level by public authorities

Sheet 1.2 Informing healthcare professionals to improve the care of patients with cognitive impairments

• Context

The interviews highlighted the need for health professionals to be better informed about the cognitive difficulties that patients may encounter in the post-cancer period and their consequences.

Despite a growing body of scientific literature on the subject, many professionals remain poorly or not at all informed. Only a small community of experts at the European level is currently aware of the issues and committed to improving patient care.

In this context, it remains difficult for patients to feel listened to and understood in their difficulties, when faced with professionals. The reason is that they sometimes minimize the importance of their impact with regard to the severity of the disease, potentially lethal, either because of a lack of knowledge of the symptoms, or because of a lack of knowledge of appropriate therapeutic resources. The identification of difficulties, as well as their management, is therefore likely to be at best late, at worst non-existent.

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Health professionals are one of the essential relays of information to patients on the problems they may encounter and are also among the best able to spot the signs suggestive of impairment, particularly because of the relationship of trust that is established with patients during treatment.

Given the progressive spacing out of follow-up consultations in the post-cancer period, all health professionals, both in hospital and outpatient services, must be made more aware of the existence and repercussions of cognitive impairment. To this end, the challenge is to make information that professionals can identify as a reliable source more readable and accessible, so that they can appropriate it and then mobilise to effectively improve the management of cognitive impairment.

• Identified practices

Several sources of information for healthcare professionals mention the cognitive difficulties that can arise in the post-cancer period ***(see Table 7. Organisations identified to inform professionals about cancer-related cognitive impairment in the Annex 2).*** However, not all of them present the problem with the same degree of precision, nor with the same degree of scientific evidence, particularly to justify the recommended therapeutic orientations.

The **National Cancer Institutes** could be key players in the dissemination of information. The NCI website (National Cancer Institute in the United States) offers extensive resources based on the scientific literature and allows for wide and easy access ***(see Focus below).***

Information is also disseminated through **expert groups and learned societies** such as the NCCN[11], the ICCTF[12], and the AFSOS[13]. These learned societies disseminate information via various media (guides, conferences, working groups, etc.) which are generally consulted by professionals already aware of this topic. Their content is generally rich and based on the scientific literature, which is essential to have quality information.

Information can be relayed by different **organisations such as the regional cancer networks in France *(See Annex 2)*** via conferences, websites, working groups. However, access to the various events is often limited due to registration which may be fee-based; limited seating; or localised provision (although more and more conferences are accessible by video-conference).

The information relays identified also compile directories of the various types of post-cancer care available ***(See Annex 2).***

Patient associations inform health professionals about the cognitive impairment they encounter and ask for a list of all available post-cancer support practices. Listing the available supports allows professionals to be informed of their existence, so that they can offer them to patients in the event that no structured organisation is available for the management of cognitive impairment after cancer.

[11] https://www.nccn.org
[12] https://www.icctf.com
[13] https://www.afsos.org/

Focus on the NCI (National Cancer Institute, USA)

Cognitive Impairment in Adults With Non-Central Nervous System Cancers (PDQ®)-Health Professional Version - National Cancer Institute

Source: Interview and website

Highlights:

- Free and easily accessible web page
- Quick response to requests by e-mail contact
- Referenced by many cancer sites including other national cancer institutes
- A very rich content on cognitive disorders:
  - Rich, detailed, comprehensive, peer-reviewed information based on scientific literature
  - References of scientific articles available
  - Review of information and regular updates
- Examples of proposed topics: *Relationship between subjective complaints and objective outcomes - Cognitive impairment in breast cancer patients - Chemotherapy and cognitive impairment in cancer patients - Different neuropsychological tests - Interventions for the management of cognitive impairment*
- Differentiated information for different target audiences: health professionals; researchers; patients

Weaknesses:

- Quite long to read and not very practical
- Does not offer visibility on practical implementation and may seem rather theoretical
- Little information on where to go for care

Focus 1: National Cancer Institute (Chapter 1 - Sheet 1.2)

- Implementations

Message to authorities:

- Need to define strategies to disseminate information and good practices among health professionals in charge of cancer care
- Promoting the inclusion of cognitive sequelae in the work of cancer-related scientific societies or institutions

100% of the experts have voted in favour of this recommendation

Implementation recommendations for public authorities:

- Transmit information dedicated to cognitive difficulties in the post-cancer period and on existing support services

Sheet 1.3 Informing patients as early as possible to promote access to support

• Context

There is a demand for patients to be informed, as early as possible (ideally before treatment), about the risks of cognitive impairment associated with cancer and its treatment in order to better understand and manage them if they occur.

"95% of the women surveyed would have liked to have been warned about the occurrence of these disorders, 92% of them think that the information should come from the oncologist." [11]

Indeed, healthcare professionals note that the fact that patients are unaware that they could present/develop cognitive difficulties after cancer prevents them from identifying them *(Results of RoseUp and Kantar Health study[14]).*

Complaints about these difficulties are therefore sometimes never expressed or expressed late (e.g., when it is time to return to work). Difficulties when encountered are often misinterpreted by patients (e.g., confusion with Alzheimer's disease).


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Information is the first essential step in empowering patients to take ownership of a problem and talk to a health professional or seek a suitable solution on their own. Professionals report better adherence to treatment and better outcomes when patients are informed at the right time.

• Identified practices

Some mainstream articles on post-cancer are available to patients (e.g., Rose magazine in France), but the subject of cognitive difficulties is rarely addressed.

Nevertheless, several resources have been identified: guides; websites; places of interaction ***(see Table 8. Organisations identified to inform patients about cognitive impairments Annex 2).*** It was noted that many initiatives for patients and their families come from patient associations. Some information sites, with a view to an integrated pathway, also offer online support or care packages *(see chapter 3).*

The advantage of these materials written for patients is that they offer accessible information in a popularized form, with simple vocabulary and an appropriate level of detail. However, it is important that the content is co-written with health professionals to avoid misinformation. Many

[14] https://www.rose-up.fr/magazine/esmo2021-roseup-kantar-chemofog-troubles-cognitifs/#1

associations offer either a dedicated web page or conferences to inform patients and their relatives about the cognitive difficulties encountered[15].

The research carried out is not exhaustive, however many resources exist (some identified sites e.g. Vie & Cancer; Macmillan cancer support (see Table 8. Organisations identified to inform patients about cognitive impairments Annex 2). Information is also available from other patient associations such as *"La Ligue contre le cancer"* or Europa Donna (France).

✓ **Strengths of communication by patient organisations:**

- To offer diversified support services (e.g., discussion groups)
- To offer specific workshops to support cognitive impairment (e.g., "*La Ligue contre le cancer"* and "*La maison rose"* in France)
- To promote the visibility of a local offer to support the post-cancer process
- The information media used make the information freely available (website - guides - dedicated Internet pages, etc.)

✓ **Weaknesses in communication by patient organisations:**

- Lack of means: limitation of the dissemination of information - impossibility to provide individualized information (e.g. according to socio-cultural level, age)
- No global structuring of the communication and left to the free initiative of each individual
- Scientific accuracy not always present

In addition, it is specified that information can also be provided by cancer institutes (such as the NCI in the USA - see sheet 1.2) and learned societies (whose role is to inform professionals - see sheet 1.2).

In all cases, regardless of who provides the information, the terms used and the level of detail is appropriate for patients.

[15] http://www.europadonna.fr/du-depistage-aux-traitements/les-soins-de-support; ligue-cancer_atelier-troubles-de-la-memoire-cancer

Focus on the communication of the association "RoseUp", France

https://www.rose-up.fr/magazine/troubles-cognitifs-memoire-chemofog-cancer/

https://www.rose-up.fr/magazine/chemofog-chimiotherapie-memoire/#1

✓ **Highlights:**

- Communication by patients for patients (Public interest association founded by patients and their relatives)
- Easy to access content; known to health professionals in the field; up-to-date
- Strategy of presence on social networks for a wider diffusion and popularization
- Studies and presence at European events (16)

→ **Information content:** Various communication materials are available

- Semi-annual magazines for patients that may address cognition
- Interviews with health professionals such as oncologists and neuropsychologists.
- Cognition-related issues: need to raise awareness; lack of patient information and consequences (e.g., confusion with Alzheimer's disease; impact on daily life); strategies to limit impact on daily life (e.g., creating habits, using memory aids)

Focus on the communication of "La Maison Rose" in Paris (place accessible after joining the RoseUp association)

- Welcomes women affected by cancer, from the moment the disease is announced and even after the end of treatment.
- Financial accessibility: Membership of 25€ per year, for access to all services (workshops, conferences, events ...)
- Information sessions available for members on site by a neuropsychologist (see sheet 3.1 on psycho-education)
- Webinars accessible on social networks to spread information more widely 17

Focus 2. Communication of the RoseUp patient association (Chapter 1 - Sheet 1.3)

16 https://www.rose-up.fr/magazine/esmo2021-roseup-kantar-chemofog-troubles-cognitifs
17 https://www.youtube.com/watch?v=VibBdN03de0; https://www.rose-up.fr/magazine/confinement-coronavirus-webinaires-ateliers/#1

Message to authorities:

- To support patient associations to gather relevant information, in connection with healthcare professionals

96 % of the experts have voted in favour of these recommendations

Implementation recommendations for public authorities:

- **Promote information and communication to users on the basis of scientific information, drawing on tools and practices already available**

- Information content: must be in layman's terms
  - Definition of cognitive impairment and impact
  - Possibility to be taken in charge
- Information time: as soon as possible (announcement consultation - consultations during treatment - after treatment...) and at least at the end of treatment when the post-cancer period is organised
- Information providers: All the players concerned can take initiatives: public authorities - learned societies - health establishments and health professionals - patients' associations - specialised or general press - patient information relays in establishments (e.g., ERI in France)
- Information media: Sites - magazines - fact sheets - group workshops

Chapter 2. Identifying and objectivising cognitive impairments

- Context

Surveys in France *(Marie Lange, Licaj, et al., 2019)* and the United States *(Schmidt et al., 2016, LIVESTRONG study)* of thousands of patients who completed their treatments showed that:

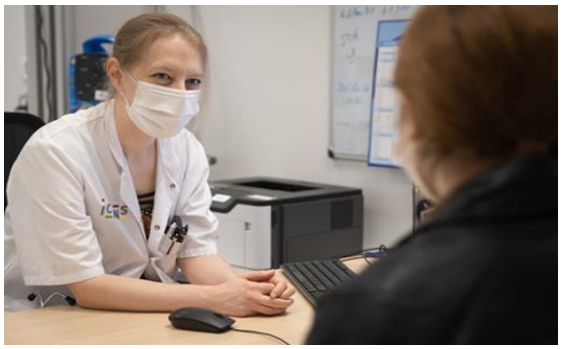
- **Many patients complain about cognitive impairment:**
  - ***75% in the French study and 46% in the US study***
- **Cognitive impairment has a negative impact on:**
  - **Return to work for 76%** *(in the French survey)*
  - Patients' daily lives (12% rated it as high and 49% as low impact in the US study)

Several factors are known to be associated with these cognitive impairments such as psychological distress; fatigue; lifestyle; comorbidities *(Lange & Joly, 2017).*

However, these complaints are frequently underestimated by health professionals and patients do not systematically report their cognitive impairment during follow-up appointments.

In the study (*Le Fel et al, 2013)* reporting on patient expectations, the observations of a survey conducted in the United States by The Hurricane review are reported: "**55% of women treated for breast cancer are not satisfied with their doctor's response to the question of perceived cognitive changes"**.

ⓒfrederic maigrot



Some professionals, aware of the existence of cognitive impairment, do not have the tools to identify and screen these difficulties and are not aware of the possibilities of management. As a result, the patient's cognitive complaint is not correctly identified.

Thus, it is necessary to identify cognitive impairment as early as possible in the follow-up of patients, but also to objectify them and evaluate the various factors that may contribute to them in order to avoid cognitive impairments being undiagnosed or diagnosed late. In this way, it would be possible to offer patients the appropriate support to limit the consequences on their quality of life and their return to work.

Although necessary, this identification stage is often not carried out. However, these cognitive impairments can be identified and managed later in the person's life (e.g., the working group proposed by the *"La Ligue contre le cancer", developed in chapter 4*).

During the interviews, two different stages were identified in the identification of cognitive impairment. The first stage consists of identifying the complaint relating to cognitive impairment. This first step is a simple identification step within the framework of the evaluation of support care needs in the post-cancer period, which consists of evaluating the impairment with the help of simple questions (Sheet 2.1) The second step consists in objectifying these cognitive difficulties and therefore in a more in-depth evaluation in case of identification of cognitive impairment (sheet 2.2).

It is proposed to present these two steps separately. However, it is pointed out that in practice this distinction is not so simple and that there are many limitations to carrying out these two steps in clinical practice.

This chapter 2 proposes to detail two steps, the first *"Identifying cognitive impairment" (Sheet 2.1)* and the second *"Objectivising cognitive impairment" (Sheet 2.2).*

Sheet 2.1 Identifying cognitive impairments

Context

Some countries, Sweden and Denmark for example, propose an assessment of supportive care needs that includes a question on cognition. However, it was difficult to analyse clinical practices in detail. Moreover, even when they exist, the identification of cognitive impairment is not always carried out systematically, which reduces the chances of being diagnosed and supported in case of cognitive impairment.

Supportive care needs' assessments aim to cover as many of the symptoms reported by patients as possible. Thus, assessments are usually composed of a few simple and quick to complete questions and items, where cognitive impairments are not always identified.

The health professionals in charge of monitoring patients consider this assessment to be necessary and would be in favour of including a question on cognitive impairment within a more global assessment. Moreover, it appears that the carrying out of this assessment seems to be the responsibility of the structure that has taken charge of the person during their treatment.

The question of available and usable screening tools appears to be one of the priorities and requests of certain health professionals to help them better identify these cognitive impairments. For example, it is necessary to have a few simple questions and validated to identify the presence of cognitive impairments and its impact on daily life (e.g., PROMIS questionnaire[18], reliable and valid measures of patient-reported symptoms, identifying both perceived cognitive concerns and cognitive abilities). Validated questionnaires exist such as the FACT-Cog[19], nevertheless, these

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questionnaires are often longer and difficult to implement in clinical routine.

The identification of cognitive impairments must also be accompanied by the identification of co-factors such as psychological state and fatigue.

No structured organisation of this identification was identified in the institutions in Europe (health establishment - town professional, etc.). However, it appears that professionals would like it to be carried out at the oncology treatment centre after the treatment cycle has been completed, i. e. during the preparation of the post-cancer follow-up pathway.

[18] PROMIS (healthmeasures.net)
[19] https://www.facit.org/measures/FACT-Cog

- Identified practices

- Some symptom assessment scales used to identify patients' supportive care needs have been identified ***(see Table 9. Identified Supportive Care Needs Assessment Scales including a Cognition Item in Annex 2).***

- No specific structures have been identified that carry out an organised and systematic identification of cognitive impairments. However, in Denmark, a structured (non-systematic) organisation has been identified for the assessment of symptoms and the provision of supportive care adapted to the needs of patients including cognitive impairment (see Focus below). Although the public authorities advocate this organisation, as the municipalities are independent these recommendations are not always applied and the analysis did not identify any data on implementation in the field.

Focus on the organisation of the identification of support care needs in Denmark

Source *- Interview with a member of the Danish Cancer Society*

https://www.sst.dk/~/media/B0FD5078B1654B33A9E744CCBAE89022.ashx

→ **Description:**

- Assessment of rehabilitation and palliative care needs.
- Assessment carried out for all cancer patients as part of the rehabilitation program, before the start of cancer treatment, regularly throughout treatment and at the end of treatment.
- Holistic assessment based on living conditions, lifestyle, behaviour, co-morbidities and economic aspects of each patient.
- A scale for identifying rehabilitation needs after cancer offered to patients in Danish hospitals, followed by an assessment with a health professional who refers to appropriate support available in the municipalities. Link to the scale: Scale.pdf
- If sequelae are not identified during this hospital assessment (e.g., patients with late side effects). Sequelae are identified by the GP or municipal home care service (e.g., nurses) in discussion with the patients.
- In the latter case, the patient is referred for an interview with a professional in the municipality or for an in-depth assessment in the hospital to provide relevant support.
- The in-depth investigation is carried out using appropriate and validated tools, which may include a detailed assessment of functional abilities, cognitive tests.
- When a program is launched, the GP is informed.
- The support offered by the municipalities is in the areas of health, social affairs, employment and education.
- The main concerns of the services are physical, psychological/cognitive, social and existential/spiritual (examples of interventions: meditation, physical activity, psycho-education).
- Hospitals and municipalities inform GPs of the aid available.
- The main responsibility for rehabilitation lies with the municipalities.

→ **Highlights:**

– Ensure early detection before discharge from the cancer treatment facility
– The availability of professionals
– Coordination with another structure to carry out an in-depth assessment or management is facilitated
– An evaluation grid

→ **Weaknesses:**

– No information on the generalization of these recommendations across the country
– No evaluation of the implementation of these recommendations identified
– No evaluation of the benefits on the identification of cognitive impairments (or other symptoms) and the quality of care have been identified
– No specific information regarding cognitive assessment and support for cognitively impaired patients

Focus 3. Organisation of the identification of supportive care needs in Denmark (Chapter 2 - Sheet 2.1)

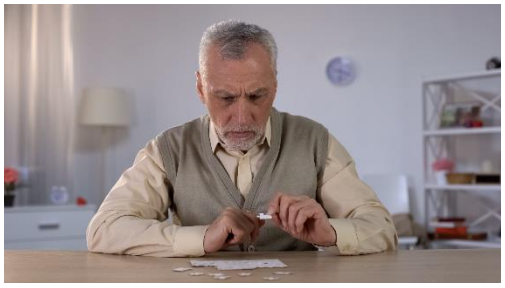
Special case of elderly patients

Patients aged 65 and over represented 48% of new cancer cases in 2012 *(GLOBOCAN study, Pilleron et al., 2019)* ***and their*** **incidence is expected to increase to 58% by 2035.**

Older patients (70 and over) treated for cancer are mostly concerned by cognitive impairments. Indeed, with age, the complaint tends to increase. In addition, we were able to hear during the various interviews that elderly patients with a cognitive complaint are often worried that it is due to the presence of a neurodegenerative pathology such as Alzheimer's disease.

In addition to having a negative impact on patients' quality of life, cognitive impairments are associated with difficult compliance to oral cancer treatments *(Dos Santos et al, 2019; Mislang et al., 2017).* Thus, it is essential to identify the presence of cognitive difficulties as early as possible in these elderly patients. In the case of the elderly subject where age is a risk factor for developing cognitive impairments, it is no longer a question of identification but of simple and systematic screening to be carried out from the beginning of the care pathway, thus being able to adapt the oncological treatment. A cognitive reassessment at the end of treatment is also recommended.

ⓒ Unicancer (crédit photos Canva pro)



Although screening tests such as the MMS or MOCA are not very sensitive in young and middle-aged subjects, **their effectiveness in the elderly is recognised**. Thus, instead of carrying out a simple identification during the assessment of support care needs, **it seems more appropriate to propose a systematic screening of cognitive impairments in elderly patients**. These assessments also make it possible to distinguish between pathological cognitive decline and normal decline, which is associated with the natural and expected decline of certain cognitive abilities during the aging process.

- Implementations

Message for the authorities:

- There are examples and studies that have tested identification tools
- Some health professionals should be in charge of this identification
- Including cognitive impairments in tools for identifying supportive care needs
- Encouraging the development of identification tools

95 % of the experts have voted in favour of this recommendation

<u>Implementation recommendation for public authorities:</u>

- To organise the identification of cognitive impairments

Sheet 2.2 Objectivising cognitive impairments

- Context

In theory, and from a research perspective, once cognitive impairment is identified, its presence should be confirmed by a specialist and further assessment should be foreseen.

An objective and thorough assessment of cognitive impairments is useful to evaluate the affected cognitive domains, the severity of the difficulties encountered and the associated factors (such as depression, anxiety, fatigue and sleep disorders factors) that may contribute to it. Thus, this evaluation would make it possible to correctly orient the patient so that he has access to an adapted care.

It is often difficult to objectify the cognitive complaint, because cognitive tests measure deficits and not the decrease in cognitive performance. During the workshop, it appeared essential to be able to detect cognitive impairment, and different questionnaires were proposed such as the PROMIS, the FACT-Cog, and the CFQ.

There was also a clear need to assess co-factors such as depression, anxiety, fatigue and sleep disturbance and to assess the impact of these cognitive difficulties on quality of life.

However, it appears that a complete cognitive assessment is in practice not only quite unrealistic (a complete cognitive assessment lasts at least 1h30) but also sometimes judged as not essential for integration in clinical routine. Thus, due to the lack of availability of psychologists specialised in neuropsychology in health institutions and the lack of funding to carry out an in-depth evaluation of cognitive impairment by a psychologist specialised in neuropsychology, support can be offered directly to patients reporting difficulties (as is the case in the associations of patients).

Thus, in patients reporting difficulties, it has been proposed to make at first the diagnosis of underlying anxiety-depressive context and, secondly, at least an evaluation of the working memory and executive functions by simple tests (which could be even done by non-neuropsychologist's specialists, on the condition that they received some neuropsychological training).

Then, the impact on the daily life should be evaluated before proposing a support for the cognitive disorders.

It emerged from the interviews that it is often difficult to objectify this complaint because cognitive tests measure deficits and not the decrease in cognitive performance.

The optimal scheme would be to carry out an assessment, then an adapted treatment, followed by an assessment to measure the effect of the treatment, and finally a long-term assessment appears to be useful to observe its beneficial effect in the longer term. In clinical practice this is rarely possible and as the evolution of cognitive performances, the workshops are usually carried out in groups, the advanced cognitive assessment loses its interest if the treatment is not then individualised accordingly.

Thus, although many elements limit the performance of a cognitive assessment in clinical practice, it remains important to carry out a neuropsychological evaluation to objectivize the cognitive impairment, the associated factors and the impact on the quality of life. Screening tests (e.g.,

MOCA) can be used, however these tests are rather adapted to elderly patients and are not sensitive enough to be used in clinical practice in younger subjects. An option developed in the Netherlands is the digitalisation of neuropsychological tests in order to be able to carry out evaluations that could be performed at home, without constraints of time, place and personnel.

No structured organisation of this objectification of cognitive impairments has been identified. However, questionnaires and tests are recommended as part of the research. These questionnaires and tests are used clinically by some local initiatives.

- Identified practices

Recommended neuropsychological tests for cognitive assessment in research.

Expert groups such as ICCTF (see Focus below), AFSOS and GREC-ONCO (in France) recommend the use of neuropsychological tests. These evaluations are comprehensive, but time consuming and not often not applicable for use in clinical practice because of the lack of psychologists specialised in neuropsychology and of structured organisation of the evaluation *(Marie Lange, Castel, et al., 2019; Mohile et al., 2018; Wefel et al., 2011) 20.* There is still a real difficulty in moving from research to clinical practice.

Thus, the expert consensus (i.e., Workshop) is that it is important to be able to assess the factors associated with cognitive impairments and to carry out a minimal evaluation (e.g., using screening tests) of cognitive impairments and its impact on the daily life of patients. This assessment could be carried out by trained professionals such as nurses. Finally, if necessary, these patients could be referred to a psychologist specialised in neuropsychology, or to speech therapists in case of language difficulties (reimbursed in France).

[20] https://www.afsos.org/wp-content/uploads/2020/12/Troubles-cognitifs-et-cancer_AFSOS.pdf

Focus on the ICCTF cognitive assessment recommendations to harmonise cognitive assessment in research

Source *- Wefel JS, Vardy J, Ahles T et al. International Cognition and Cancer Task Force recommendations to harmonise studies of cognitive function in patients with cancer. Lancet Oncol 2011; 12:703-708.*

Recommendations for the standardisation of tests used in research

→ **Benefits**:
- Tests recommended by expert clinicians and researchers in the field of cancer and cognitive impairments.
- The recommended tests have adequate psychometric properties and are available in several languages.
- Local examples of clinical use (e.g., François Baclesse cancer centre in France, see Focus)

→ **Obstacles:**
- The purpose of the guideline is to increase interpretability between studies and not to create diagnostic criteria for cognitive impairments in cancer.
- Tests not always available in all languages or with low quality standards depending on the country
- In France, for example, the lack of psychologists specialised in neuropsychology in hospitals makes this approach impossible to implement

Recommendation for cognitive domains to be assessed:
- Learning and memory performance
- Psychomotricity speed
- Executive functions (e.g., attention, inhibition, flexibility, information retrieval)
- Working memory

Focus 5. ICCTF cognitive assessment recommendations (Chapter 2 - Sheet 2.2)

Initiatives to implement research recommendations into clinical practice

Some local initiatives were identified in France, either in comprehensive cancer centers or in rehabilitation centers, proposing a more advanced evaluation of cognitive impairments reported by patients. This evaluation is carried out by means of questionnaires and neuropsychological tests before the start of the care pathway and after the end of it ***(see Table 10. Identified organisations assessing cognitive impairment and associated factors - Annex 2).*** Computerized tests are also being developed, such as the battery developed in the Netherlands[21] which allows subjects with basic computer skills to assess their cognition at home and without supervision ***(see the results of the study on patients treated for cancer in the Chapter 6)***. These forms of assessment should develop in the future. Thus, when a cognitive complaint is identified, the patient could carry out this assessment to objectify his complaint. However, these initiatives raise the question of the use of these data, which need to be analysed by a professional, and of the evaluation of confounding factors, which is necessary to obtain a global assessment.

[21] https://www.cognitionscan.org/

Benefits of a specific cognitive assessment:

- Assessment based on recommendations from learned societies/expert groups
- Evaluation before the start of the program and at the end of the program to get an overview of the effectiveness of the program on cognitive performance
- Assessment of cognitive impairment accompanied by an assessment of anxiety symptoms, known to affect cognitive functioning

Barriers to conducting a specific cognitive assessment:

- Evaluations take a long time to carry out and therefore cannot be generalised
- Assessments conducted only by some local initiatives
- Health establishments rarely have the available personnel (e.g., psychologist specialised in neuropsychology) and the financial means to be able to set up this type of evaluation
- In town, neuropsychological assessments are not always reimbursed (e.g., in France)

Many self-administered questionnaires are available and used in research to assess patients' cognitive complaints. However, these self-questionnaires are not used in routine clinical practice for symptom screening due to a lack of time and resources to send them to patients during follow-up appointments.

Focus on cognitive assessment tools

François Baclesse Cancer Center, France

Source: *Interview*

The cognitive assessment takes between 45min and 1h15

A framework of questionnaires and tests to be used is recommended:

→ **Questionnaires assessing:**

- Cognitive functioning: FACT-Cog
- Anxiety and depression: HADS

→ **Assessment of the following key cognitive domains:**

- Memory (episodic, short-term memory, working memory)
- Executive functions (e.g., attention, inhibition, flexibility, information retrieval)
- Processing speed, visual perception

→ **Benefits**:

- Tests adapted to the patient's age
- An evaluation by a psychologist specialised in neuropsychology

→ **Obstacles:**

- Duration of the evaluation, difficult to generalise in clinical practice
- Need for a psychologist specialised in neuropsychology

Decision tree for the assessment of cognitive impairments proposed in cancer and cognition *(Marie Lange, Castel, et al., 2019).*

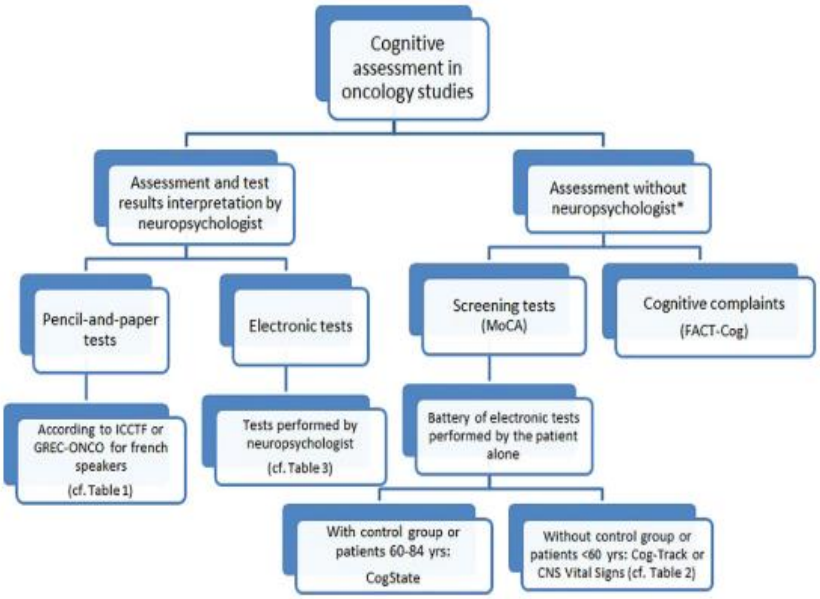


Fig. 1. Choice of tools for cognitive assessment in oncology studies. The final choice depends on research question, study design, cognitive domains assessed and patients' characteristics.
[a]Nevertheless, the presence of a neuropsychologist is essential to make the interpretation of test results.

- Implementations

Message to authorities:

- Encourage the development of assessment tools

90 to 100 % of the experts have voted in favour of these recommendations

Implementation recommendations for public authorities:

- Organising specific assessment of cognitive impairments
- Definition of professionals to whom to refer for specific assessment
- Using of validated tools recommended by learned societies

Chapter 3. Promoting the different ways of dealing with cognitive impairments

- Context

In addition to the lack of information and assessment of cognitive impairments, one of the major problems is the lack of care available to help patients with cognitive impairments.

One of the patients' requests is to manage cognitive impairments in the same way as certain symptoms induced by cancer and its treatments.

"Research is good, but what we want is for our difficulties to be taken care of and for solutions to be proposed".

A review of the scientific literature shows that **over the last ten years, more than forty studies have been published evaluating the benefits of different types of (non-pharmacological) treatment for cognitive impairments *(see tables Annex 3).***

In addition, several systematic reviews and meta-analyses have concluded the benefits of such management on complaint and objective cognitive impairment *(Fernandes et al., 2019; Kim & Kang, 2019; Zeng et al., 2020).*

The evaluation of these benefits differs according to the type of management.

The interventions most widely found in the scientific literature are:

- Cognitive stimulation/cognitive training
- Psycho-educational approaches
- Physical activity
- Multimodal approaches

The scientific literature has made it possible to determine the level of scientific proof of the effectiveness of these treatments on post-cancer cognitive impairments (see methodology described in the introduction).

Although these treatments are widely developed in the scientific literature and their effectiveness has been demonstrated in studies, sometimes with a high level of scientific proof, they are still not very well developed in the clinic.

The review of the grey literature and the interviews identified several initiatives to meet patients' expectations. Nevertheless, no standard structured organisation dedicated to the management of cognitive impairments in cancer has been clearly identified. The proposed organisation of supportive care after cancer does not systematically does not systematically include all the services available and does not always include an offer for the management of cognitive impairments.

There is a lack of knowledge and communication about the existence of this type of management, confirming the emerging nature of the problem of dealing with cognitive impairment after cancer. This is true for public authorities, health professionals and patients. As for the promoters of the studies, knowledge of the practical application of the management does not seem to be assured.

The initiatives identified are usually localised and do not guarantee equal access to cognitive support services throughout the country.

In addition, there is a lack of structuring of the offer and a lack of financing, which limits access to the available offers and their deployment throughout the territory.

This chapter proposes to detail two recommendations: the first, *"Referring patients to appropriate supportive care" (Sheet 3.1),* which is divided into several sub-sheets, and the second, *"Orientating, coordinating and organising the management of cognitive impairment" (Sheet 3.2).*

ⓒ Unicancer (crédit photos Canva pro)

Sheet 3.1 Referring patients to appropriate supportive care

Message to authorities:

- Ensuring that patients have access to the specific support they need
- These services must be better known by professionals and further developed.
- These interventions should be organised in a complementary manner to the other supportive care already offered, and in places that favour proximity and where post-cancer care is already organised.
- The financing of these services must be ensured.

100 % of the experts have voted in favour of these recommendations

Implementation recommendations for public authorities:

- Identifying the resources available on the territory

Sheet 3.1.1 Psychoeducation

● Definition

Two terms are currently used in the field of educational approaches for chronic pathologies: "psychoeducation" and "therapeutic education"[22].

- **Therapeutic education** is defined as *"a formalized and structured approach (particularly in France) concerning the various aspects of the disease, co-morbidities and treatment"*[6] In France, therapeutic education programs follow precise specifications defined by a HAS reference system and validated by the ARS.
- **Psychoeducation** is defined as *"a systematic didactic and psychotherapeutic intervention that aims to inform patients or even their loved ones about the disorder and promote skills to cope with it."*.

In clinical practice in psychology, psychoeducation is usually a group intervention supervised by a (neuro)psychologist who can address patients' fears and questions about various symptoms and give them compensatory strategies to use on a daily basis.

In the context of cognitive impairment, the psychoeducational approach focuses on improving cognitive resources through educational content, learning compensatory strategies and transferring these strategies to real-life situations. It can be used as a stand-alone intervention, as a prelude to cognitive training, or coupled with cognitive training.

In oncology, the educational content of psychoeducation generally refers to:

- The definition of cognition and cognitive functioning
- The impact of cancer and its treatment on cognitive functioning
- Everyday situations and factors that can impact cognitive functioning
- Compensatory strategies to use in everyday situations

The educational content and information delivered during psychoeducation sessions are available on some websites and patient guides (see Chapter 1), but they do not allow for the interaction with a health professional that defines psychoeducation.

● Identified practices

We propose to distinguish between the practices identified in the scientific literature and those identified in the field.

Psychoeducation programs identified in the scientific literature

Two major programs were identified in the scientific literature.

[22] https://www.editions-ellipses.fr/index.php?controller=attachment&id_attachment=45116

Table 2. Programs identified in the scientific literature.

Name	Studies in non-CNS cancer (level of evidence according to the HAS scale)	Type of therapy	Content	Format
MAAT - Memory and Attention Adaptation Training	Ferguson et al, 2012 (2) Ferguson et al, 2016 (2)	Psycho education + CBT (compensatory strategies)	The 4 components of MAAT include: 1) education about cognitive impairments in cancer; 2) awareness training to identify "at risk" situations in which cognitive failures may occur; 3) stress management and self-regulation; 4) training in compensatory cognitive strategies	8 weeks 1 or 2 sessions / week 30 - 50 min /session
Emerging from the Haze	Asher et al, 2019 (4) Liang et al, 2019 (4) Myers et al, 2020 (4)	Psycho education + CBT	Mindfulness and stress management + CBT for mood symptoms + memory, attention and problem-solving strategies + lifestyle education	6 weeks 1 session / week 2h30 / session

Psychoeducation programs identified in the clinic

In the field, we have been able to identify that these programs are used as a basis for work in clinics (for example, the MAAT program inspired the program proposed by the *"La maison rose"* association), and the "Emerging From the Haze®" program also seems to be marketed and proposed in clinics (e.g. the Cinaï platform[23]). For the latter, it wasn't possible to identify in detail the use of the program, i.e., the format used, its effectiveness and the interest shown by patients in clinics.

Beyond the scientific literature, the psycho-educational approach seems to be often used in clinics and proposed by associations, but these are mostly local and unstructured initiatives, so it is difficult to list them.

It also appears that the development of the integration of psycho-education workshops in therapeutic education programs could be promoted. In this sense, the association "La Maison Rose" has taken the initiative of a therapeutic education program including the management of cognitive impairments after cancer[24].

In Germany, cancer counselling centers have been identified and offer psycho-social consultations but also educational psychology[25] (but not specific to cognition). These centres have

[23] https://www.cedars-sinai.org/programs/cancer/supportive/programs.html
[24] https://www.rose-up. en/magazine/esmo2021-roseup-kantar-chemofog-cognitive-disorders/#1
[25] https://www.bundesgesundheitsministerium.de/themen/praevention/nationaler-krebsplan/was-haben-wir-bisher-erreicht/ziel-9.html

an objective of information, orientation and coordination specifically for cancer but are not specialised in cognitive impairment. The subject can be discussed during the psycho-educational consultation and referral to a specialist is proposed if necessary.

The association *"La Maison Rose"* in France offers a psycho-education session carried out by a psychologist specialised in neuropsychology (see Focus below).

Focus on the association "La Maison Rose", France - Paris

https://paris.maisonsrose.fr/

Source: *Interview with the psychologist specialised in neuropsychology*

*"*La Maison Rose *accompanies women to answer all the questions they may have and provides them with exclusive services 100% free of charge in the form of individual or group workshops, meetings and exchanges, events. As a bridge between the treatment centre and the return to everyday life, the House helps to make the disease less anxiety-provoking, facilitates the daily life of these women and helps them to break out of their isolation. It also welcomes family members.*

A patient association that has recently started offering services for cognitive impairments to meet an identified need.

✓ **Benefits:**

- Strong demand, mainly from women
- Out-of-hospital setting in proximity
- A 2-hour psycho-education session, on site (for members only) https://paris.maisonsrose.fr/evenement/en-presentiel-ateliers-troubles-cognitifs-de-la-memoire/
- Webinars are offered to provide remote access https://paris.maisonsrose.fr/evenement/en-ligne-ateliers-troubles-cognitifs-de-la-memoire/
- The sessions are supervised by a psychologist specialized in neuropsychology.
- Financial accessibility (Cost of membership to the association of 30 euros / year)

✓ **Disadvantages:**

- No cognition assessment due to cost to the patient and cannot be covered by the association
- Non-permanent financing by the association
- No evaluation of program benefits

→ **The content of the education is focused on:**

- Key messages with simplified information
- Symptoms experienced by patients in the post-cancer period and cognitive impairments
- Strategies to improve cognitive functioning and associated factors, such as diet, sleep, physical activity, meditation, relaxation (awareness of the living environment as a factor influencing disorders)
- Content evaluation and adaptation (recent learning program)
- Groups of 6 to 8 patients attend seven weekly sessions and an eighth session one month later to check the application of the strategies learned during the previous sessions in daily life.

Focus 1. *Focus on the association "La Maison Rose" (Chapter 3 - Sheet 3.1.1)*

Several advantages and disadvantages have been identified in offering psychoeducation sessions to patients with cognitive impairments.

✓ **Strengths of psycho-education:**

Low level of evidence

–**The effectiveness of this approach has been studied in research and although the level of scientific evidence is low, beneficial effects at least on the complaint of patients reporting cognitive impairments after cancer are observed** (Bernstein et al., 2018; Myers et al., 2020)
–Psychoeducation can also be offered in the city
–Supervised by a professional, most often a psychologist specialised in neuropsychology, who is available to answer patients' fears and questions

- These sessions are offered in a group format, allowing for a collective dynamic. It is in this format that they seem to be the most interesting. They allow for the sharing of individual compensation strategies to be carried out at home.
- At the end of these sessions, some patients are satisfied with this stage and with the information received without necessarily requesting further support afterwards (e.g., cognitive training). This allows us to propose self-management and empowerment for people who do not wish to receive support for various reasons. On the other hand, some patients will choose to be accompanied more precisely and over time for their impairment.
- It can be proposed alone or in association with cognitive training (see sheets 3.1.2 and 3.1.4).
- Financial accessibility: free when offered by a patient association

✓ **Weaknesses of psycho-education:**

- The offer is based on self-financing when it is proposed by a patient association.
- The lack of psychologists and/or trained health professionals in health care institutions may limit the offer
- The supply of health care facilities can be a hindrance for patients:
  - Many interviews show that patients want to be accompanied in proximity and not have to return to structures that evoke the disease.
  - Access to facilities is more difficult to organise, especially in rural areas, and not compatible with a professional life without medical leave, for example.
  - May result in poor adherence to the intervention and therefore less effectiveness on cognitive function.
  - Lack of funding for psychologists and psychologists specialised in neuropsychology in the city.

Psychoeducation sessions in the form of videos and webinars have been identified in France with the aim of optimising the time spent with the (neuro)psychologist (when funding is not available), so that patients can access them without constraints of time or place, however no direct interaction would be possible with the (neuro)psychologist, which makes this approach more of an information than a psychoeducation approach

- Project of one of the local committees of the league against cancer in France (information obtained during an interview with a director of a departmental committee of the *"La Ligue contre le cancer")*: to propose psycho-educational videos (made by a psychologist specialised in neuropsychology) followed by supervised cognitive training workshops.
- Webinars offered by *«La maison rose"* (see sheet 1.3).

- Implementations

95 % of the experts have voted in favour of this recommendation

Implementation recommendation for the public authorities:

- Encourage initiatives to set up psycho-education sessions dedicated to cognitive impairments

Sheet 3.1.2 Cognitive training programs

• Definition

Cognitive training aims to help the person with cognitive impairment to regain functional autonomy. It was initially developed in the context of cognitive impairments after a stroke or a head injury.

Training includes techniques aimed at directly improving cognitive functioning or overcoming cognitive impairment through repetitive and sustained training of the identified and targeted cognitive function(s) with exercises of increasing difficulty. This cognitive training can take the form of computerised or non-computerised exercises.

Training is most often used as a complement to psycho-education. However, it is not the same as psychoeducation. Psychoeducation is a compensatory approach that aims to propose strategies to improve cognitive functioning. Cognitive training, on the other hand, is a restorative approach aimed at directly improving cognitive performance through exercises.

• Context

Cognitive training in the so-called "paper-and-pencil" format is widely used in other pathologies both in research and in the clinic and its effectiveness has been demonstrated in many studies. In the field of oncology we also found some studies that showed the effectiveness of paper exercises *(Dos Santos et al., 2020; Ercoli et al., 2015).*

However, in the review of scientific literature, the use of computerised cognitive training was mainly observed. Several randomized controlled trials have been ***conducted*** (***See Annex 1***, ***see tables Annex 3 - Synthesis of the scientific literature***) and have revealed that **these programs improve cognitive complaints and associated factors such as depression, anxiety and fatigue.**

high level of evidence

The impact on objectified cognitive impairments is less clear and variable according to the studies. These studies also found a high level of compliance with computerized cognitive programs, usually supervised by a trained professional.

Given their frequent use in both research and clinical settings, and the strong development of new digital technologies, computerised cognitive assessment and management will be used more and more.

Computerised cognitive training allows us to propose fun exercises to be carried out on a telephone, tablet and/or computer. These exercises allow specific training of certain cognitive domains that are impaired in patients, the level of which is adapted according to the performance measured during the exercise. These tools can be used in groups under the supervision of a health professional but also at home alone, which helps to promote patient autonomy. Thus, these tools would benefit from being more widely used in clinics, but also from being developed.

It is important to specify beforehand that the professionals consider that it should be possible in theory to have organised training as part of a follow-up in the post-cancer period and not isolated and unsupervised use. Moreover, the lack of supervision and support may lead to a lack of adherence to training on the part of patients. This would also encourage patients to perform cognitive exercises that do not target the deficient cognitive functions. The effectiveness of the intervention would be significantly impacted by not targeting the dimensions to be worked on according to the identified needs.

Thus, computerised cognitive exercises should be used with prior explanations by a trained health professional and should not replace supervised cognitive training. Nevertheless, these tools can be used as a support for cognitive training by professionals and/or used as a complement to professional care to be carried out independently by the patient.

- Identified practices

In recent years, several computerised cognitive training programs have been developed and their application to cancer patients has been evaluated in several studies ***(see table 2 Annex 3)***. In the field, we find both formats of cognitive training, i.e., non-computerised ***(see tables Annex 2)*** and computerised ***(see HappyNeuron® focus below).***

Advantages and disadvantages to both training formats were identified.

Strengths of cognitive training:

- Positive impact on the improvement of cognitive complaints scientifically demonstrated with a high level of evidence
- In-class or distance learning
- Supervised by a professional or on your own (after prior explanation by a professional)
- Can be used in a multimodal approach (e.g., in addition to physical activity sessions...)
- Customisable - exercises adapted and evolving according to the level and needs of the user
- Financial cost of group workshops and home exercises are less than the cost of funding a professional to do individual cognitive training
- Reach a wider range of the population
- Increase the amount of cognitive training time offered
- Possibility of measuring the rate of adherence to the program (automatically with a computerised tool, or through follow-up telephone interviews)

Specifically for computer-based programs:

- Playful cognitive exercises that promote adherence to the exercises
- Evolving technologies that can eventually be optimized with the development of the use of artificial intelligence
- Possibility of collecting the results of cognitive performance in order to create a data bank to better evaluate and understand the interest at the collective level and the individual progress
- Enables co-design with patients and feedback from the patient experience to improve and adapt tools

Weaknesses of cognitive training :

- Financial cost of group workshops and home exercises, although less than funding a professional to do individual cognitive training
- Limitations of studies proving positive impact: do not consider all environmental parameters - heterogeneous and not necessarily comparable - many theoretical studies without clinical studies
- Recommended to be supervised by a trained professional at least at the beginning and end of the program (and if possible, during the program to maintain motivation)
- Does not allow for psycho-educational support if not followed by a professional
- If no follow-up or performance evaluation is done, there is a risk of decreased adherence to the intervention, and also a risk that the cognitive functions to be restored are not specifically targeted
- No recognition as a medical device and therefore no dedicated funding

Specifically for computer-based programs:

- Computerized support not adapted to all patients (heterogeneity among patients in their ability to use computerized tools, some do not have a personal computer, limited use among elderly patients)
- Few specific software programs have been developed for the management of cognitive impairment after cancer
- All the identified cognitive training support tools are marketed: Financing by individuals or by structures without specific financing

Clinically identified non-computerised cognitive training programs:

Within the framework of the research work, a number of clinical practices using non-digital cognitive training programs were identified, particularly in France ***(see table 3 and Annex 2).***

Table 3. Practices identified in clinics offering cognitive training

Developer	**Location**	**Professionals involved** **Profile of patients**	**Organisational structure**	**Program content**	**Conditions of access**	**Benefits**	**Brakes**
ONCOGITE (association attached to a cancer center) Cognitive exercises	France, Bordeaux (and Brive), within the cancer center	Psychologist specialised in neuropsychology All patients	In groups (10-12 people) 25 sessions (every week) of 1h30 Face-to-face in a cancer center Remote via videoconference	Presentation of the exercises via an internet application (soon an online version to do the exercises at home). Exercises specifically designed for patients being treated for cancer. The exercises are designed to train the following cognitive areas: Attention, memory, dual-tasking, logical planning, inhibition, visuospatial, auditory, working memory. Common exercises but instructions can be adapted by the psychologist specialised in neuropsychology according to his level.	Membership to the association (20€ per year) No structuring of the orientation but a priori goes through the oncologist of the cancer centre	Extends over several months / available in a mixed format (distance or face-to-face) in both cases supervised by a psychologist specialised in neuropsychology / exercises adapted according to the level of each student	Membership to be paid / No evaluation of the effectiveness of the program on cognitive performance (ongoing)/no evaluation of cognition (nor associated factors) before starting the program to adapt the program to the observed impairment
Tivoli Ducos Clinic Uninformed cognitive exercises	France, Bordeaux, in the clinic	Speech-Language Pathologist All, approximately 1 month after chemotherapy	In groups (10-12 people) 8 sessions of 2 hours On-site in a clinic	Workshop facilitation Exercises specifically designed for patients being treated for cancer. The exercises are specifically designed to train the following cognitive areas: Attention, memory, executive functions, language	Information on the presence of these workshops at the clinic, can be referred by the oncologists	Financially supported Speech and language therapists can help to link up the supply in the area Do not have the clinical approach of psychologists specialized in neuropsychology	Availability of speech-language pathologists (waiting list) No evaluation of the effectiveness of the programme on cognitive performance

List of computerised cognitive training aids identified

Several computerised cognitive training aids have been identified in the literature and in clinical practice ***(see Table 11. Software identified in cognitive training programs in the Annex 2).*** Although these applications are not primarily intended for patients treated for cancer with cognitive impairment, their effectiveness with this population has been demonstrated in the literature, including some studies with a high level of scientific evidence according to the HAS scale *(Bray et al., 2017; Damholdt et al., 2016; Dos Santos et al., 2020).*

The literature review did not identify sufficient clinical practices to exploit all the information. Nevertheless, for example, the HappyNeuron® support is used in cognitive training programs in the François Baclesse cancer center in France (see Focus below).

Focus on the computerized program "HAPPYneuron®" (France)

Source: *Interview and website* **https://www.happyneuron.fr/**

✓ **Description:**

A computer brain training method that stimulates the 5 major cognitive functions: memory, attention, language, processing speed, executive functions (reasoning, logic) and visual-spatial. For more than 10 years, HAPPYneuron®'s scientific team has been using recent advances in cognitive science research to offer a service that combines scientific knowledge, personalisation and entertainment.

✓ **Benefits:**

- Extensive historical expertise in cognitive disorders in other fields (psychiatry, neurodegenerative diseases, traumas, others)
- A global approach to cognitive impairments
- A scientific approach
- Numerous case studies and examples of groups of institutions that have invested heavily in this offer
- Supervised by health professionals or autonomous / automatic reminders / possibility of creating predefined and personalised cognitive stimulation sessions or individual use
- Development prospects in the field of cancer - research - artificial intelligence - patient experience
- Numerous partnerships and cooperations
- Commitment to a patient experience approach
- Ability to collect data
- Available in several languages

✓ **Disadvantages:**

- No specific offer on self-evaluation and objectification of cognitive impairments
- No specific protocol for cancer and cognitive impairment
- Financing not covered by the public authorities
- Need to conduct studies to validate the effectiveness of the exercises proposed by HAPPYNeuron® on improving cognitive performance

- Need to conduct studies to evaluate the impact of these programs on quality of life, social reintegration, and especially professional reintegration after cancer

Although they do not have a specific program for cognitive impairments in cancer, the platform is used spontaneously by different teams working in the field of cancer.

Example of feedback from use: Psychologists specialised in neuropsychology supervising workshops at the François Baclesse Centre (France)

Setting: Used in several clinical research projects as well as in cognitive workshops in the context of supportive care.

Choice of software among others: Considered more adapted to the needs of oncology patients reporting a cognitive complaint by the psychologists specialised in neuropsychology of the center.

✓ **Perceived benefits with use:**

- Allows you to train the areas most affected by cancer and its treatments: memory, executive functions, processing speed and language.
- Levels of difficulty of the exercises increase according to the patients' performance (*adaptive process-based*), allowing active learning adapted to the patients' needs.
- Easy-to-use software interface for remote performance monitoring.
- Alarm function by e-mail invites the user to carry out a session during the day, allowing a better assiduity including at home and on the move.

Feasibility study of remote and autonomous use of patients with cognitive impairments (*Cog-Stim feasibility study, Binarelli et al., 2021):*

- Satisfaction with the format and the fun aspect of cognitive training
- Adaptability of the difficulty of the exercises
- The remote format allows you to train freely at any time.

Use in cognitive workshops supervised by a psychologist specialized in neuropsychology on site:

- Use of the software on tablets but also access at home on computers and/or tablets.
- Patients' feelings about the use depends on their ability to use computerised tools
- Positive feedback and a desire to continue to use it at home, even for the elderly.

Focus 7. "Happyneuron®" computerized program (Chapter 3 - Sheet 3.1.2)

Special case of elderly patients:

Although the mastery of computer tools by the elderly is very variable, and the use of these tools is likely to be developed in the coming years, no study to date has focused on the use of computerised tools with elderly patients.

The COG-TabAGE study being conducted at the Henri Becquerel and François Baclesse Cancer Centers (France) aims to evaluate the feasibility and acceptability of using computerised cognitive training on a tablet (HappyNeuron®) with elderly patients. This study includes breast cancer patients aged 70 and over. Although the results are not yet available, we were able to obtain feedback from a psychologist specialised in neuropsychology in charge of supervising the workshops.

✓ ***Highlights:***

– Patients who are more comfortable with computer tools are the most satisfied with the format of the procedure

– Interesting to propose a computerized supervised intervention, which allows to motivate the patients to train and to adapt the difficulty of the exercises according to the patient's capacities

✓ ***Weaknesses:***

– Patients who are less familiar with the software require more help to understand the instructions and to find their way around the software interface

– For an elderly population, it seems difficult to guarantee the smooth running of a computerised intervention at home in complete autonomy

- Implementations

Message to authorities:

- Cognitive training should not be used alone and without supervision, but rather in a multimodal format, particularly in association with a psycho-educational approach.
- Furthermore, it would be interesting to evaluate, beyond the effects on cognitive performance, its effect on quality of life and associated factors.

Implementation recommendations for the public authorities:

- To encourage the development of supervised cognitive training programs

76% of the experts have voted in favour of this recommendation

- To encourage public authorities to support the development of cognitive training programmes

67 % of the experts have voted in favour of this recommendation

Sheet 3.1.3 Physical activity

• Definition

Physical activity is defined as any movement of the body related to transportation, domestic activities, professional activities and leisure. Physical activity is known to be beneficial to health by reducing cardiovascular disease, obesity, psychological distress, and therefore quality of life *(WHO - Physical Activity 26).* The WHO recommends the promotion of physical activity and its reimbursement by health insurance funds or national health systems. Better collaboration between educational institutions and health professionals is also recommended to encourage the integration of physical activity into health care and to promote research on its benefits.

Physical activity is encouraged for all cancer patients. More specifically, adapted and supervised physical activity (APA) is proposed to patients and in particular to those who do not have a sufficient level of physical activity or who cannot carry out physical activity in the conditions usually available. Adapted physical activity refers to physical exercises such as aerobic exercises, yoga, walking, which can be adapted to the patients' limitations and needs. To date, no physical activity program specifically focusing cognitive enhancement has been identified among existing supportive cancer care interventions. Thus, there is no data on the need for specific physical activity programs that would be more beneficial for the management of cognitive impairments.

• Context

Physical activity is widely recommended by public authorities through national and European plans, whether for cancer or other pathologies, to improve health (for example the WHO's 2016-2025 physical activity strategy[27] or the Ministry of Health and the Ministry of Sports in France[28]).

There are a growing number of studies evaluating the benefits of physical activity in cancer patients on cardiorespiratory capacity, muscle function, fatigue, emotional distress, pain, self-esteem, body image, overall quality of life[29]. **Systematic reviews and meta-analyses have found that physical activity improves health-related quality of life and also increases survival rates in cancer patients** *(Eyl et al., 2018; Friedenreich et al., 2020; Shin et al., 2017; Wong et al., 2018).* Thus, physical activity is now promoted by several cancer plans and survival guides and financial aids have been implemented in some European countries such as the physical activity prescription [30].

[26] https://www.who.int/news-room/fact-sheets/detail/physical-activity
[27] https://www.euro.who.int/__data/assets/pdf_file/0014/311360/Physical-activity-strategy-2016-2025.pdf
[28] https://www.sports.gouv.fr/pratiques-sportives/sport-sante-bien-etre/Plan-national-sport-sante-et-bien-etre/

[30] France https://www.legifrance.gouv.fr; Denmark https://www.sst.dk; Norway https://www.fritidforalle.no; Sweden http://www.fyss.se

Although less known and disseminated by public authorities and health professionals, physical activity is also beneficial for cognitive impairments[31]. Several studies have shown an improvement in cognitive impairments after a few weeks of physical activity in patients in the post-cancer period.

Low level of evidence

However, cognitive impairments were for the most part evaluated in a secondary manner and the level of scientific proof of these studies is therefore rather weak.

Different formats of physical activity offers have been developed in order to meet this need, such as the distribution of physical activity guides, the reimbursement of these activities via prescriptions prescribed by a doctor, and physical activity or adapted physical activity programmes available in associations and hospital structures. These offers can be provided in case of cognitive impairments.

- Identified practices

Guides to physical activity in cancer:

Several guidelines and reports have been published by organisations and learned societies ***(see Table 12. Physical activity guidelines Annex 2)*** to describe the benefits and barriers to physical activity for cancer patients. These guidelines provide concrete recommendations for physical activity (e.g., do-it-yourself exercises, intensity level, etc.). They are intended to provide initial advice on how to start or maintain physical activity. In view of the scientific literature, following these recommendations would provide a first easily accessible support to improve cognitive impairments.

✓ **Highlights of the guidelines:**

- Easy to access, available online
- Available in several languages
- Easy to implement recommendations/strategies (some concrete examples of practices)
- Achievable physical exercises that do not require funding

✓ **Following the recommendations of the guidelines presents several obstacles:**

- No follow-up by a specialised professional
- Recommendations are not individualised and adapted to the heterogeneity of cancer patients' needs and limitations
- Risk of loss of motivation due to lack of supervision

Focus on the ESMO Survivorship Guidelines

[31] https://www.cancer.gov/physical-activity-cognitive-function

Source : https://www.esmo.org/for-patients/patient-guides/survivorship

✓ **Benefits:**

- Available in several languages
- Simple recommendations
- Easy to implement recommendations

✓ **Limitations:**

- No mention of cognition in the benefits cited
- **Do at least 150 minutes of moderate to vigorous physical activity per week,** e.g., walking, stretching, dancing, water aerobics, yoga

OR

- **75 minutes of high-intensity exercise per week**, e.g., cycling, hiking, jogging, swimming
- **Minimise the time spent on sedentary activities** such as sitting by finding alternatives, e.g., using the stairs, walking or cycling instead of driving, getting up and walking for 5-10 minutes every hour

Focus 8. Physical activity recommendations from the ESMO Survivorship Guidelines (Chapter 3 - Sheet 3.1.3)

Financial aid to encourage physical activity

In some countries, financial aid has been developed to enable patients to access physical activity check-ups (identified in France) or reimbursed physical activity sessions (identified in France, Norway, Sweden and Denmark ***(Table 10. Organisation of reimbursement for physical activity in the Annexe 2).*** Although these prescriptions are not specific to cancer patients, patients are generally eligible for access to these prescriptions, but they are not offered in case of cognitive complaints.

Physical activity programs identified in the field

Physical activity sessions or programmes set up in different types of facilities (i.e., associations, hospitals, cancer centers) for patients during and after treatment were identified. Although a structured reimbursement offer is available in some countries, the facilities offering free physical activity are local initiatives, so it is difficult to make an inventory (***see Table 11. Identified practices offering physical activity to patients in Annexe 2).*** Furthermore, these initiatives are not intended to improve cognitive performance, which is generally not evaluated. Thus, the reported benefits on cognition are mainly based on patients' feedback.

Although in clinical practice the physical activity programs identified were not intended to improve the cognitive impairments of patients, we did identify one physical activity program for which cognitive functions were assessed (see Focus below).

Focus on the ALIZES program - France

Source: *Interview with the program referent and Neuro-Oncology and rehabilitation (congres-afsos.com)*

This program is carried out in a French hospital, specialized in rehabilitation since 2012.

→ **Program Objectives:**

- Rehabilitation for exercise -mobility, posture, endurance
- Tonic regulation and emotional management
- Ownership of physical activity
- Dietary guidelines
- Information and exchanges

- Groups composed of 8 patients referred by an oncologist
- 2 days a week, for 12 weeks
- Patients attend group sessions of physiotherapy, adapted physical activity and psychomotricity

This program is not intended to improve cognitive functioning; however, cognition was assessed before the start of the program and at the end (tools: FACT-Cog, MOCA, and SDMT) as well as psychological distress and fatigue (Tools: HAD, MIF)

Results showed improvement in cognitive impairment (congressional presentation, available on the links above)

Focus 9. Focus on the ALIZES physical activity programme (Chapter 3 - Sheet 3.1.3)

Advantages and obstacles to offering physical activity in the case of cognitive impairments

In general, several common benefits and drawbacks were identified with respect to the proposal of physical activity to improve cognitive impairments.

✓ **Benefits of managing cognitive impairment with physical activity in cancer:**

- Benefits of physical activity on cognitive disorders but also on many associated symptoms (e.g., fatigue, sleep difficulties)
- Financial support identified in some countries for physical activity
- Free physical exercise sessions offered by associations
- Different formats available (group or individual)
- Possibility of creating "mixed" programs to be carried out on site and/or at home (thus adaptable according to the availability of the patients)

✓ **Weaknesses:**

- Offer proposed by local associations
- Difficulty in identifying facilities offering physical activity programs for patients
- Physical activity not appropriate for all patients, depending on several clinical aspects (physical condition, stage and type of cancer), patient preferences and accessibility
- Physical activity in public gyms is limited by lack of adaptation to disabled patients, risk of performing exercises without adaptation of intensity, affecting self-esteem and stigma

- Implementations

Implementation recommendation for the public authorities:

- Encourage access to physical activity programs for patients with cognitive impairments

89% of the experts have voted in favour of this recommendation

Sheet 3.1.4 Multimodal management of cognitive impairments

• Definition

Multimodal management consists of a global approach that considers several dimensions of the person. It aims to achieve the best possible results for a given treatment. It is said to be multimodal because it combines several strategies or methods (modalities) at the same time. It makes it possible to personalise, adapt and develop the treatment.

With regard to cognitive impairment, this approach combines the treatments mentioned in the previous sheets but also other techniques that we have not specifically detailed but that we have found in post-cancer programmes. These include: psycho-education; cognitive training; physical activity; meditation; relaxation; acupuncture; yoga.

Each of the modalities can be offered independently or as a complement to one or more other modalities. They offer the advantage of being able to consider all the associated factors and to be adapted according to the needs of the patients and the available supports.

• Context

The multimodal approach is favoured by the few teams specialised in this field (based on interviews), which develop dedicated programs for patients with cognitive disorders. However, not all facilites that offer treatment for cognitive disorders offer this approach. There are programmes offering only cognitive training and psycho-education, which are considered multimodal treatments.

A question of feasibility undoubtedly arises, as well as a question about the methods of organising care, which will be detailed in the sheet dedicated to this theme ***(see Sheet 3.2)***

In the scientific literature, about ten studies have shown the effectiveness of this multimodal approach *(e.g., Cherrier et al., 2013; Mihuta et al., 2018; Myers et al., 2020; Schuurs & Green, 2013 -* ***see Annex 3 - Synthesis of the scientific literature)*** to improve both the complaint and cognitive performance (assessed using neuropsychological tests). **Some studies report a high level of scientific evidence** *(Cherrier et al., 2013; L. M. Ercoli et al., 2015) .*

In this approach, different types of supports are proposed:

- **Psychoeducation**
- **Cognitive training** (in the form of stimulation, rehabilitation or cognitive remediation)
- **Meditation or relaxation exercises**, or even meditation programs to reduce stress (e.g., Mindfulness Based Stress Reduction)
- **Physical activity**
- **Cognitive-behavioural therapies (CBT).** CBT is a psychotherapeutic method targeting the contents of thought (as opposed to cognitive training targeting the processes or containers of thought) in order to regulate behaviours considered problematic, intervene on anxiety symptoms and thus directly and indirectly improve

High level of evidence

cognitive functioning. CBTs specifically targeting fatigue *(Goedendorp et al., 2014)* and insomnia *(Liou et al., 2020)* have also been shown to improve cognitive impairment.

Other practices identified in the literature such as acupuncture, which appears to improve patients' cognitive impairment *(Liou et al., 2020; Tong et al., 2018),* **but with a low level of scientific evidence),** can be proposed as part of a multimodal approach to reduce cognitive impairment.

It is difficult to make an exhaustive inventory of initiatives. Indeed, these initiatives are local and are due to health professionals or patient associations, possibly associated for this realization. The treatment is then proposed either within a health establishment specialised in oncology or within a local patient association. The proposed programs are generally inspired by studies in the scientific literature.

- Identified practices

A few practices have been identified in clinics that rely on a multimodal approach.

Some multimodal programs identified in the field

The few practices identified are summarised in the *Table 12. Summary of identified multimodal management programs* ***(See Annex 2),*** and the findings and advantages/impediments to these approaches are listed below. A focus on a local initiative proposing a multimodal programme in France is presented below.

Common findings:

- Most of the workshops analysed propose a multimodal intervention including cognitive stimulation or training (exercises) and psychoeducation
- Realised in group (from 5 to 12 people)
- The duration varies from 4 to 25 sessions.

Several advantages and obstacles are common to all the practices identified:

✓ **Highlights:**

- Supervision by a specialist (e.g., psychologist specializing in neuropsychology)
- Presence of a multidisciplinary team in some facilities
- Structured models do exist (cf. Rehabilitation Centre in Portugal - Brugmann University Hospital Project in Belgium, presented in other sheets).
- Initiatives that are most often part of a local supply approach
- Comprehensive management of all disorders including cognition
- Allows for the severity of the disorder and associated factors associated factors (e.g. fatigue, anxiety, depression, sleep disorders).
- Adaptation and customization according to the patient's needs and abilities
- The same place of care can be envisaged
- Funding that can integrate existing funding (e.g., funding for physical activity)
- Structures that already offer a wide range of treatments (sport - relaxation - meditation, etc.) that could integrate complementary programs related to cognition

✓ **Weaknesses:**

- Difficulty to identify the existing offer
- Little knowledge beyond the local territory, or even a unique focus on internal patients (e.g., Henry Gabrielle Hospital Rehabilitation Centre, Lyon France)
- Little structuring of communication and information
- Complexity of organising the orientation and coordination of these programs within a pathway
- Financing is based on several modalities that can leave patients with a remaining expense These programs are self-financed when it is a patient association or based on financing from the health care institution
- These initiatives remain local offers and are not generalised on the territory (hindrance to geographical accessibility for all patients)
- When the offer exists, there is not always enough space available while the demand is mentioned as important
- Conversely, the supply of complex programs does not always correspond to patient demand (too heavy)
- Program carried out on site, which entails numerous trips and limits its access
- Lack of evaluation of practices implemented in the field
- Availability and access to modelling work
- Question of feasibility of deployment and generalisation

Focus on the "BORA-Onco" program - Henry Gabrielle Hospital Rehabilitation Center Lyon France

Source: Interview

Initially offered to patients who have had a stroke or head injury, this program has been adapted to patients treated for cancer and complaining of cognitive impairments.

✓ **Objectives**:

Offer cognitive remediation targeting several domains, i.e., attention; memory; metacognition (cognition and interpersonal relationships)

Putting patients in situations to facilitate learning new strategies and their application in daily life.

✓ **Description:**

- Patients are referred to this program by the physician when a complaint is identified.
- An assessment is carried out before and after the intervention, inspired by the recommendations of the AFSOS. During 1 hour an interview is carried out with the patient to evaluate his/her impairment and several self-questionnaires and tests are used:
  - FACT-Cog (cognitive complaint)
  - ADH (anxiety and depression)
  - MOCA (cognitive screening)
  - SDMT (processing speed)
- The intervention consists of 2 sessions per week, carried out over a period of 6 weeks.
- Group sessions with:
  - An occupational therapist
  - A physical activity instructor
- Individual sessions with:
  - A psychologist specialized in neuropsychology
  - A doctor

Preliminary results (https://www.congres-afsos.com) in 22 subjects show an improvement in complaint and cognitive performance (Tools: Fact-Cog and MOCA).

This program is financially supported by the hospital

Focus 11. The "BORA-Onco" multimodal care programme (Chapter 3 - Sheet 3.1.4)

- Implementations

Implementation recommendation for the public authorities:

- Encourage access to multimodal programs for patients with cognitive impairments

95% of the experts have voted in favor of this recommendation

Sheet 3.2 Orientating, coordinating and organising the management of cognitive impairments

• Context

It seems from the interviews conducted and the documentary research that there is no standard model for the organisation of care specifically dedicated to cancer-related cognitive impairments. In this respect, it is difficult to talk about structuring and funding supported by the public authorities.

Regarding the organisation of supportive care in the broad sense, the literature and organisational models are more mature.

However, in France, local initiatives relating to cognitive impairments do not seem to be part of the organisation and structuring of post-cancer pathways, although they are underway.

In other countries, there are some national organisational structures (e.g., Denmark and Germany) but they are not specific to the treatment of cognitive impairments.

It seems that the initiatives taken are most often without the question of guidance and coordination being considered methodologically or explicitly.

Thus, it seems difficult to talk about a pathway for patients with cognitive impairments.

• Identified practices

Guidance and coordination

During the analysis of practices, it was difficult to distinguish the modalities of referral and coordination by the teams.

However, this referral and coordination in fact exists either by *"word of mouth"* or by the more traditional network referral circuits between structures known by professionals and patients.

This is why it seems interesting to analyse the structures capable of offering this type of service. Germany offers a well-documented and analysed example, although not specific to cognitive impairments.

Focus on, "Cancer Counselling Centres" – Germany

Sources:
https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Gesundheit/Berichte/PsoViD_Kurzbericht_BMG_19_02_07_gender.pdf ;
https://www.bundesgesundheitsministerium.de/fileadmin/Dateien/5_Publikationen/Praevention/Broschueren/Broschuere_Nationaler_Krebsplan.pdf ; https://www.bundesgesundheitsministerium.de/themen/praevention/nationaler-krebsplan/was-haben-wir-bisher-erreicht/ziel-9.html

- ✓ **History of the Government Initiative:**
  - Based on the observation that there is a significant need to structure supportive care
  - On the basis of the implementation of a specific measure of the cancer plan relating to psycho-oncological care
  - Existing psycho-oncology associations but not permanently funded.
  - Commissioned by the Federal Ministry of Health for an inventory of psycho-oncological care in Germany.
  - The data from this inventory served as a basis for deciding on regulations for quality assurance and sustainable financing of outpatient cancer counselling centers.
- ✓ **Description of the offer of the ambulatory cancer counselling centers:**
  - Information - orientation - coordination - management of the care service
  - Concerns psychological support needs (without major disorders identified), more severe needs are proposed in coordination with the network
  - Concerns patients and their relatives
  - Access to the service through an initial telephone or written contact and consideration of needs by a trained professional (assistant), followed by a preliminary interview
  - Possibility of offering services at home for people who are immobile
  - Help with administrative procedures, including returning to work
  - If necessary, referral to other structures (e.g., rehabilitation service centres, self-help groups)
  - Psycho-social consultations - Provision of appropriate specialist advice (social, socio-legal; psychological) - Provision of psycho-education (not specific to cognition)
  - Intervention in case of psychological crisis
  - Cooperation with treating physicians, psychotherapists, social and nursing services, other counselling structures and specialised institutions, as well as with other professional groups.
  - In case of suspected mental disorders, referral to licensed medical and psychological psychotherapists or corresponding psychiatric or psychosomatic specialists to clarify the diagnosis.
- ✓ **Benefits:**
  - Is part of the cancer plan
  - Structure dedicated to cancer
  - A structured and financed offer supported by the public authorities

– Gathering of different resources in one place, including social and employment aspects
– Structuring within the whole cancer and communication offer (linked to social services; to outpatient care and health establishments specialised or not in cancer; to other cancer counselling centres and other cancer centres; to self-help groups; to medical and psychological services; liberal professionals...)
– Quality and evaluation requirements (regular user surveys - computerised standardised data collection and analysis and publication of a report - external evaluation of the activity to measure the effects of psycho-oncology)
– A minimum set of professional skills:
▪ Organization of the physical or remote permanence with a minimum opening time of 20 hours on three days per week in specific and easily accessible premises.
▪ Psychosocial counselling should be provided by psychologists and social workers/educators.
▪ Physicians and members of other health and social professions with a university degree can also work as qualified counsellors to provide psychosocial counselling.
▪ Additional training in psycho-oncology is required for all counsellors.

✓ **Disadvantages:**
– No information on how to assess patients' needs, particularly with regard to cognitive impairments
– Does not offer comprehensive management workshops and refers to the network (especially for cognitive impairments)
– No confirmation of the practical implementation and information on the evaluation of this organisation

Focus 12: "Cancer counselling centres" in Germany (Chapter 3 - Sheet 3.2)

Organisation of care

In France, various organizational methods have been identified: either by healthcare centers specialised in oncology (directly or indirectly), by rehabilitation establishments, or by patient associations.

Management by cancer healthcare centers and hospitals

Health establishments specialised in oncology, because of their expertise and the availability of professionals, are called upon to offer solutions. The offers can be made directly by the healthcare centre or through an attached association. The support care departments attached to establishments and/or services dedicated to cancer are particularly well suited to providing care for patients.

- Example of the structuring of an association attached to a specialised cancer center in France: "Oncogite" Association, an initiative of the Institut Bergonié ***(see Figure 4. Oncogite association of cognitive training in France)***

- Examples of hospital structures that have taken the initiative to propose an offer ***(see Chapter 3 - Annex 2)*** Tivoli Clinic and the François Baclesse cancer treatment center in France, which offers a remediation service by a speech therapist; the Brugman University Hospital in Belgium.

✓ **Highlights:**

- Facilitated dissemination of the offer to oncologists
- Oncologists aware of cognitive impairments
- Patients with cognitive complaints identified before the end of follow-up
- Financial coverage by the institution (unless the association is separate as for the association) and free or with a request for participation with low cost

✓ **Weaknesses:**

- Very localised offer without structuring on the territory or within an integrated organisation
- A structuring with the city and in particular with the attending physicians is rarely observed
- No coordination and structuring of the various initiatives
- Lack of funding from public authorities to develop the offer throughout the territory and increase the number of places available
- An assessment of cognition that is rarely performed
- No proximity of care and return to a cancer treatment facility

Care by health establishments specialising in rehabilitation

Rehabilitation and re-education centers have a general expertise in their field and most often accompany patients with cognitive impairment resulting from pathologies other than cancer. Some of them have rehabilitation services dedicated to cancer patients. They thus have expertise in oncology and cognitive impairment and can develop their offer towards support for cognitive impairment in the post-cancer period. However, patients are more likely to be referred in case of major disorders.

Several offers have been identified: the rehabilitation centre of the Henry Gabrielle Hospital in Lyon, France ***(see sheet 1.4);*** the rehabilitation centre of the Château de Colpach in Luxembourg (although not specific cognitive impairment); rehabilitation centers in Sweden (not specific to cognition, no detailed information about the supports offered).

The implementation of a component on cognition for patients referred to them (patients are not referred specifically for cognitive impairments) and who require rehabilitation also seems to be available in rehabilitation centers at Denmark[32] and at Portugal.

[32] https://www.aarhus.dk/borger/sundhed-og-sygdom/traening-og-rehabilitering/har-du-faaet-en-hjerneskade/hjerneskadeteam-for-voksne/; https://hjerneskade.kk.dk

✓ **Highlights:**

- Are part of post-treatment outside the cancer treatment facility
- An expertise in cancer and cognitive impairments
- A multimodal offer
- A multidisciplinary team approaches
- A free service
- Structuring in a network or even the possibility of evolving towards mobile teams or advanced consultations
- Possibilities of sharing resources

✓ **Weaknesses:**

- Not specific to cognition and sometimes not specific to cancer (which can also be an advantage)
- Psychologists specialised in neuropsychology are not always available
- Proximity limit for the patient
- A limited number of patients referred (usually patients requiring physical rehabilitation or in case of cognitive/neurological impairments in patients with a brain tumour)

Care organized by patient associations

This is a model of initiative taken by patient associations, most often already offering information and support. These associations have the capacity to listen to patients' needs and to be a force of proposal by imagining new offers to meet these needs (e.g., *"La maison rose"* and the workshops of the *"La Ligue contre le cancer"* in France, ***see sheet 1.3****.*

We have also noted in Portugal projects for local rehabilitation centres including physiotherapy, psychologists, nutritionists, and also psychologists specialised in neuropsychology dedicated to post-cancer care. The CanCOG research project for Cognitive Rehabilitation in Cancer is also underway in Portugal [33] *(see Chapter 6).* It aims to provide a specific internet platform for cognitive rehabilitation for cancer survivors in Portugal, in order to improve their cognitive abilities.

Various advantages and obstacles common to the initiatives carried out by the associations were identified (despite the great diversity of the associations and the impossibility of generalising everything).

✓ **Benefits:**

- Highly responsive and agile in identifying needs and devising solutions

[33] http://cancog.web.ua.pt/en/about/

- Presence in proximity for patients who almost systematically express the wish not to return to a hospital structure that evokes the treatment and the cancer
- Involvement in the local fabric with the ability to join the network of professionals involved in post-cancer support
- Workshops accessible to all patients with a cognitive complaint
- Free of charge or at a low cost compared to individualised care by a psychologist specialised in neuropsychology
- Opportunity to share with other patients and a place for exchange
- A resource centre with access to an information centre
- Allows to propose other complementary workshops
- For some, a global assessment of the needs carried out with identification of cognitive disorders
- Approach to include the offer in coordination with the structuring of the more global offer of support care Group activity
- External professionals who intervene on site

✓ **Weaknesses:**

– Not all patients wish to use this type of association and some prefer to remain independent.
– Remains very local and depending on the goodwill of the promoters
– No organised structuring of initiatives
– Little structuring of referrals to these structures
– Lack of visibility: Great diversity of the offer and its quality - difficulty to find one's way
– The proposed programs seem to be rarely known by health professionals and therefore little disseminated to patients.
- Difficulties in disseminating the offer to cancer care facilities, which makes access to patients even more difficult.
- - Specific assessment or evaluation of the severity of cognitive impairment rarely performed due to lack of funding for appropriate professionals (i.e., psychologists specializing in neuropsychology

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- Implementations

Message to authorities:

- Early management will limit the impact of cognitive sequelae on patients' quality of life
- Integrating cognitive impairments into the organization and financing of supportive care

85 to 100 % of the experts have voted in favor of these recommendations

Implementation recommendations for the public authorities:

- To develop and promote post-cancer care programs that include management of cognitive impairments
- To organise and implement the management of cognitive impairments in existing organisations

Chapter 4. Proposing a management of cognitive impairments in the framework of support to return to work

Context

There are many resources that highlight the impact of cancer, its treatment and its side effects on the employment of people with cancer *(e.g., for a systematic review, Tan et al., 2021 e.g., De Boer, 2014)*. Similarly, the social and economic burden on patients is found in the literature *(e.g., Zajacova et al., 2015)*.

The incidence of cancer continues to rise, however, thanks to early detection and improved treatment, the mortality rate continues to decline. Thus, due to the increasing number of people who have had cancer, the social and economic cost of the aftermath of cancer is expected to increase in the future.

The purpose here is not to go back on this achievement. Moreover, the public authorities, particularly at the European level (e.g., within the framework of the cancer plan) and for many at the national level, have already committed themselves to promoting the return to employment of people with cancer.

In several countries (France, Germany, Belgium, Canada, etc.), public support and care (including financial) systems for people with disabilities exist ***(see Chapter 4 Annex 2).*** These generalist systems may or may not specifically include people with cancer. The definition of disability is quite broad, but we have noted that its use in the context of regulations relating to eligibility criteria for benefits linked to this protective status can potentially exclude a certain number of patients whose after-effects do not meet this definition despite their need for support.

There is a very wide range of actors involved in supporting people back to work. As a result, there is a great diversity of assessments on the subject, a great complexity and a compartmentalisation of organisations and administrative procedures. In this respect, it seems quite difficult to talk about a pathway integrating back-to-work issues. In this pathway, the experts consider that a special place is given and should be given to occupational medicine, but this point will not be developed because no specificity relating to cognitive impairments has been identified.

It is difficult to identify a clear dividing line within the pathway between care that falls within the field of "rehabilitation", which evokes "post-medical" type support, and social support, which evokes a more administrative approach. In this respect, the two offers seem to tend to be offered in a more integrated manner in a common structure *(see sheet 3.2 on the organisation of care)* or common websites. Within the framework of social and professional support, psychological support is often offered in conjunction with it (so-called "psychosocial" support). In addition to the various organisations helping with administrative procedures, commercial or associative offers of coaching for a return to employment are developing ***(see Chapter 4 Annexe 2)***

What about cognitive impairments in particular within this support?

The limiting nature of cognitive impairment on return to work is demonstrated by scientific studies demonstrate *(Klaver et al., 2020; Von Ah et al., 2018).*

"76% of patients with a complaint experienced an impact of cognitive impairments in daily life and particularly their return to work" (Lange et al., 2019)

However, cognitive disorders are very rarely addressed in the context of return to work:

- The information documents and devices relating to the return to work after cancer make relatively few references to cognitive impairments.
- Most often, a distinction is made between general information on cancer (including information on cognitive impairment) and specific information on the return to work of people with cancer.
- Specific support for cognitive impairments is not provided as such in the framework of public policies linked to the return to employment (either at national or European level).
- Even if many initiatives exist, very few specific support and care for cognitive impairments have been identified.
- Existing treatments are often part of broader psychosocial interventions that pay limited attention to cognitive factors (these interventions focus primarily on fatigue and anxiety-depressive symptoms that contribute to cognitive impairments).

One of the challenges for the return to employment is to take charge as early as possible; the quality of the support is linked to the information provided and the assessment of cognitive impairments.

One of the main difficulties for patients is to identify their cognitive impairments among all the side effects experienced. These difficulties can be identified when returning to work or when requesting support to return to work. If cognitive impairments are not identified and dealt with, they will have consequences (loss of confidence and self-esteem, relational difficulties, etc.) which may result in a delay or even the impossibility of returning to work.

● Identified practices

The issue of returning to work after cancer is well identified in Europe by the public authorities and is present in various programs relating to cancer, disability or employment *(see Table 13. Public policies identified targeting employment and cancer)*.

Similarly, national guidelines exist *(see Table 17. Resources on Employment and Cancer).* Available to companies and patients, these guides provide information about the side effects of cancer and its treatment and the difficulties encountered by patients when returning to work. They also suggest strategies and steps to follow to ensure that the return to work takes place in the best possible conditions.

Associations are also available to help patients after their cancer in their efforts to return to work, whether it be support in administrative procedures or psychological support (see Table 17. Resources on Employment and Cancer).

Initiatives in certain occupational medicine departments (e.g., CHU Rouen and Caen in France) offer consultations to help people return to work following cancer.

The study focused on organisations offering a specificity concerning cognitive impairments, however resources not including cognition were also listed for information purposes (see Annexe 2 - Chapter 4).

Informing about the impact of cognitive impairments in the return to work after cancer

Very few resources were identified that integrate cognitive impairments into the management of return to work in cancer ***(see Table 19. Information about cognitive impairment and return to work after cancer).*** These provide information about the difficulties patients may face; how to prepare for them; and how to return to work.

Managing cognitive impairments to support the return to work after cancer

The document "Approaches to Meeting the Mental Health and Return to Work Needs of Cancer Survivors" proposed by the Canadian Partnership Against Cancer[34] identifies approaches in different countries to assist post-cancer patients in their return to work in the area of mental health. Although this document is not specific to cognition, it identifies approaches to improve the management of patients after cancer.

In addition, two approaches were identified that included the management of cognitive impairments.

- **In Australia:**
  - Online cognitive training program *(Brain HQ, see Sheet 3.2)*
  - 15-week program following a telephone consultation outlining strategies for improving cognition
  - Effectiveness of the programme on cognition (a randomised controlled trial) but also on anxiety, depression and fatigue *(Bray et al., 2017).*
  - Device tested in 18 centres across Australia
- **In Canada:**
  - The BC Cancer Agency in partnership with regional health authorities offers a vocational rehabilitation program that includes cognitive training.
  - Among the offers (assessment of skills; career guidance...), the MAAT (Memory and Attention Adaptation Training) programme (see sheet 3.4) aims to improve memory and attention performance. The effectiveness of this programme has been validated in cancer by published studies *(Ferguson et al., 2012, 2016).*

[34] https://www.partnershipagainstcancer.ca/topics/mental-health-and-return-to-work-needs-of-cancer-survivors/

In France, there are a few practices aimed at improving the cognitive performance of patients in order to help them return to work (***see Table 20. Management of cognitive impairments to assist the return to work in the Annex 2).***

Focus: Workshop proposed by the Bas-Rhin committee of the league against cancer – France

Source: Interview

✓ **Project History:**

The committee offers several other post-cancer workshops. Historically, a workshop on returning to work was offered. During the accompaniment by the work psychologist, a specific need was identified concerning the accompaniment of cognitive impairments. There was no offer on the territory apart from neuropsychological consultations. The support workshop on cognitive impairments was set up to complete the services offered to improve the return to employment.

✓ **Workshop Description:**

Public: Open to any patient, aged 18 to 65, who complains of cognitive impairments and is engaged in a process of returning to work.

Team: Set up and supervised by an occupational psychologist and a psychologist specialised in neuropsychology for their complementary expertise (the occupational psychologist deems indispensable the particular expertise of the psychologist specialised in neuropsychology on the subject).

Workshop content: 5 workshops conducted in groups:

- **Workshop 1 (3h):** Corresponds to psycho-education – Introduction to cognitive impairment, i.e., defining it, informing that it is a common symptom in cancer, becoming aware of these difficulties then discussion on the field of return to work and specific disorders that can be encountered (short term memory - working memory - multitasking - planning...) – explanation of administrative procedures
- **Workshops 2 to 5 (2 hours each):** Each workshop is dedicated to a cognitive function and is conducted as follows:
  - A focus on the definition of the cognitive function on which the patients will work,
  - An exercise booklet is offered to patients.
  - The exercises are done in groups.
  - The proposed exercises are based on work situations:
    - For example: a to-do list - the participant should write down the tasks and then remember the tasks.

✓ **Highlights:**

- Program content based on scientific literature and existing workshops in the field of mental health
- Group work, allows sharing of experiences and strategies used - allows motivation
- Supervised by an occupational psychologist and a psychologist specialized in neuropsychology
- Exercise close to situations experienced in the workplace
- Free of charge for the patient (only league contribution)
- Open access to patients who are of working age
- The groups are homogeneous in terms of the difficulties encountered, which facilitated group work.
- The workshops are adapted according to the needs and level of the group by proposing several strategies
- Personalization and individualization occur naturally within the group during the program
- The absence of a prior evaluation of cognitive impairment by the psychologist specialised in neuropsychology does not constitute a hindrance because of the homogeneity of the complaints reported and does not prevent the support or its personalization

✓ **Weaknesses:**

- Local offer (one city in France)
- Self-financing, which makes it difficult to deploy
- Difficulties in communicating with healthcare facilities and patients

Focus 13. Workshop proposed by the Bas-Rhin committee of the league against cancer for the return to employment (Chapter 4)

Research to help people return to work

Certain practices aimed at facilitating the return to work are also being studied, such as the FASTRACS project (acronym of “FAciliter et Soutenir le retour au TRAvail après un Cancer du Sein”, namely “Facilitating and Supporting the Return to Work after Breast Cancer”) currently underway in Lyon[35]. This project aims to reduce social disparities in employment after cancer through a better understanding of barriers to return to work, mapping of interventions and better coordination between health services, the workplace and insurance *(Fassier et al., 2018).*

The issue of cognitive impairments is identified as one that needs to be addressed without further details at this stage as the study is ongoing.

[35] https%3A%2F%2Fwww.e-cancer.fr%2Fcontent%2Fdownload%2F261590%2F3678763%2Ffile%2FFASTRACS%2520-%2520Fassier.pdf&usg=AOvVaw2gHwYj_AcvaOT0aXDaUVeb

- Implementations

Message to authorities:

- The literature suggests interventions that can help patients, if identified and managed early enough
- The professional environment can be informed and made aware of the cognitive after-effects of post-cancer, while respecting medical confidentiality and the privacy of the patient-worker
- Ensure early assessment of cognitive impairments that may limit work capacity
- To organise and finance consultations and support (particularly in the context of vocational rehabilitation) that specifically take into account cognitive impairments in returning to work
- To organise awareness campaigns in the work environment (integrate this issue into the many existing materials, without necessarily going as far as a specific awareness campaign on cognitive impairments)

89 to 94 % of the experts have voted in favour of these recommendations

Implementation recommendations for public authorities:

- Assessing and managing cognitive impairment in patients returning to work
- Raising awareness among occupational physicians and employers

Chapter 5. Identifying the health professionals to be involved in the management of cognitive impairments and training them

Context

Health professionals from different fields[36] are led to meet patients undergoing cancer treatment (see sheet 1.2) and it is important that they are made aware and informed of the risks of cognitive impairments in patients.

Some professionals are particularly concerned and require training (e.g., nurses; nurse coordinators; oncologists; general practitioners).

This may be the case for psychologists who are not necessarily trained in oncology or neuropsychology.

Different professions have been identified to intervene with patients in case of cognitive impairments. Although the definitions differ from one country to another, a definition of their functions is proposed in France[37].

- **Psychologists:** their mission is to promote psychological, emotional and relational well-being. The consultation is carried out by means of interviews intended to analyse the needs of the subjects, to listen to them, to accompany them and if necessary to guide them. He can be in an institution or in town.
- **Psychologists specialised in neuropsychology:** they are experts in the relationship between the brain and cognitive functions (memory, attention, concentration, processing speed, executive functions), whether in the context of normal or pathological functioning. Their work focuses on the evaluation of cognitive impairments using clinical interviews and neuropsychological tests. Psychologists specialised in neuropsychology are not necessarily specialised in oncology. They can work in health institutions or in private practice.
- **Occupational therapist:** is naturally interested in the impact of disorders, i.e., in the way in which they actually hinder the performance of meaningful activities for patients in their ordinary, familiar environment. In order to do this, occupational therapy understands cognition as a dynamic situation of interaction between person, activity and environment, with a focus on occupation.
- **Speech therapist:** their mission is to prevent, evaluate and treat oral and written language difficulties, oro-myo-facial functions, certain cognitive functions associated with phonation, speech, mathematical cognition and language. They can work in health institutions or in the city.

[36] https://www.bordet.be/fr/accompagnement
[37] https://www.neurosep.fr/le-reseau/role-du-neuropsychologue, https://www.fno.fr/lorthophonie/

In reality, it may seem complex to identify the right skills needed to manage cognitive impairment in view of the needs for assessment and management of patients, but also the demography of these professionals and their distribution over the territory. The question of their financial coverage also appears to be an important criterion (often an obstacle to care).

Physicians (attending physician, oncologists, etc.) and especially **neurologists** are also important to consider because they are involved in identifying cognitive impairment and helping to manage patients. Psychiatrists, psychologists or psychoanalysts, trained in the psychological problems of cancer patients and their families, can help them adapt to the disease and its treatments.

Given the heterogeneity of the professionals that patients may encounter, it seems important that these professionals be trained to provide appropriate support.

- Identified practices

Promote multidisciplinary teamwork

The need to form multidisciplinary teams appears to be an important element in the care of patients with cognitive impairment.

This organization of the team makes it possible to propose a global approach to the person's needs in order to offer a personalized and adapted program. This type of organisation allows the treatment of cognitive disorders to be included in a more global support programme addressing all the dimensions of the person (e.g., sport; self-esteem management; stress management; social dimensions and return to work).

Research projects have been identified to demonstrate the benefits of multidisciplinary teamwork (see Rehabilitation Service - Henry Gabrielle Hospital in Lyon, France).

This type of organisation has been identified in particular in the projects relating to cognitive impairment in the following structures:

- Rehabilitation service of the Henry Gabrielle Hospital in Lyon, France
- Château de Colpach in Luxembourg (reflection on the improvement of practices which led to this type of organisation, even if cognitive impairment is not identified as such)
- CHU Brugmann Belgium (project built around this concept)

Focus - Profile of the multi-professional team of the Brugmann University Hospital project - Belgium

Source: *Interview*

- Psychiatrist or oncologist providing medical supervision
- Neuropsychologist or psychologist trained for example in Cognitive Behavioural Therapy
- Nurse
- Social worker (social assistant)
- "Onco-coach" (coordinator or nurse referent)

Focus 14. Profile of the multi-professional team of the Brugmann University Hospital project in Belgium (Chapter 5)

Identification of professionals involved in the management of cognitive impairments

In the post-cancer trajectory, the oncologist who follows the patient is in the front line of patient care. Psychiatrists or clinical psychologists are then the preferred contacts for support in the event of anxiety disorders. Financial support for psychologists is available in various centres and patient associations. In the case of cancer, these psychologists should also be trained in the disorders present in oncology.

With regard to cognitive impairment, it is quite clear from the interviews that more specific training of (oncologist) psychologists in cognitive disorders is necessary to address these issues. Within the framework of post-cancer care, psychologists specialised in neuropsychology are the professionals envisaged, provided that the financing of this care is foreseen in the care programme of the institution (e.g., France and Belgium).

Psychologists specialised in neuropsychology are the most relevant to intervene because they are trained to establish differential diagnoses and psychopathological aspects. However, this profession is not always available (especially in health institutions) and its financing is most often not covered when the intervention takes place in private practice.

Thus, if in theory the professionals to be privileged to take care of cognitive impairment are psychologists specialised in neuropsychology, it appears that this cannot realistically be the only solution.

Other avenues exist, such as the mobilization of speech therapists. We have identified the initiative of the Tivoli Clinic in Bordeaux, France, which offers cognitive remediation sessions by a speech therapist.

- **Several interests (see sheet 3.1.2):**
  - Financial support for the sessions
  - Nationwide presence of speech therapists
  - The following may participate in multidisciplinary work
- **Nevertheless, there are some obstacles**:

- Trained primarily in the management of language difficulties
- Waiting lists for access to care are sometimes long.

It also seems that **occupational therapists** are identified in the context of cognitive impairments in cancer (without further details as to how they intervene in the context of the research).

Some projects include the involvement of psychiatrists (Brugmann University Hospital, Belgium) who have interesting expertise in mental disorders and may have experience in cognitive remediation, although this differs from the cognitive remediation used in oncology.

Training of health professionals specialised in the field of cognition

Professionals other than psychologists specialising in neuropsychology need specific training in the cognitive impairment of cancer.

The question of choosing a training course on cognitive impairment or more specifically a training course on cognitive impairment related to cancer may arise.

With regard to psychologists specialising in neuropsychology, the question of their more specific training in cancer-related issues remains to be clarified and opinions differ on this point. For some, the learning is done quickly at the time of the professional setting in the cancer environment, for others a training would be necessary.

Available trainings related to cancer-related cognitive impairments

The timeframe of the study did not allow for extensive research into training for professionals on cognitive impairment in cancer patients in Europe.

However, there are some initiatives in France:

- A module in the initial training of neuropsychologists is dedicated to cognitive impairment in cancer (University of Caen Normandy[38]).
- A project to create a multi-professional DIU on the theme of Cancer and Cognition with different approaches (animal experimentation, clinical, medical imaging) is also being planned in France.
- Teaching about cognitive impairments related to cancer and treatments in the framework of the training of speech therapists at the school of speech therapy of the University of Bordeaux[39](6 hours - UE 5.7.5 Acquired cognitive-linguistic disorders, assessment and evaluation of acquired cognitive-linguistic disorders and UE 5.7.6 Speech therapy intervention in the framework of acquired cognitive-linguistic disorders)
- Teaching about cognitive impairments related to cancer and treatments in the context of the training of speech therapists at the school of speech therapy of the University of Rouen[40](6 hours).

[38]https://uniform.unicaen.fr/catalogue/formation/du/5700-diplome-d-universite-neuropsychologie-clinique?s=ufrpsycho&r=1336728889472
[39] https://sante.u-bordeaux.fr/Espace-etudiant/Tout-sur-vos-etudes/Etudes-paramedicales/Orthophonie
[40] http://medecine-pharmacie.univ-rouen.fr/departement-orthophonie-324831.kjsp

- Implementations

Message to authorities:

- Identifying professionals who can support patients and coordinate their care
- There are training opportunities for health professionals to identify, assess and manage cognitive impairments in their field of expertise
- Organising a consensus on the professionals to be involved and their role
- Mobilising all the actors in training in order to organise and disseminate the training offer in terms of identification and management of cognitive impairments

95 to 100 % of the experts have voted in favour of these recommendations

Implementation recommendations for public authorities:

- Identifying professionals specialised in the management of cognitive impairments in cancer
- Strengthening the training of specialised health professionals
- Raising awareness of other health professionals

Chapter 6. Supporting all aspects of research related to cognitive impairments

- Context

Research is a major lever for developing and implementing appropriate treatment aimed at preventing and supporting patients' cognitive impairments in the post-cancer period.

Although this is still an emerging subject, the scientific literature has grown in recent years at the international and particularly European level on the subject of cognitive impairments in the post-cancer period. The first research studies made it possible to objectivise the reality of these cognitive impairments, which are part of a complex problem involving numerous clinical, sociodemographic and societal parameters requiring a multidisciplinary approach to understand and apprehend them.

However, it should be noted (as mentioned in the introduction) most of the 41 publications evaluating the effect of interventions on cognitive impairment come from the USA, with only six identified in Europe ***(see Figure 1. Number of studies evaluating the effect of intervention on cognitive impairment by country).***

Randomized controlled trials with a high level of scientific evidence have demonstrated the importance of managing cognitive impairments in patients ***(see Annex 3 - Synthesis of the scientific literature).***

Different methods have also been adapted from other pathologies (e.g., psychiatric and neurological disorders) or developed to best meet the specific needs of these patients. Based on this work, specific care methods have been identified *(see Chapter 3)*, but the existing resources that have been shown to be relevant are still insufficiently disseminated.

Cognitive impairments can be examined at all stages of the cancer journey. In fact, each stage of the cancer journey can be the subject of specific research. More particularly, the problem of the organization of the pathway; of the return to employment ... in the post-cancer period are important subjects which still need to be the subject of specific research.

With regard to the various tools for meeting patients' needs (i.e., assessment and management), a great deal of research work has been identified. However, the transfer of research evidence to clinical implementation with widespread deployment is not always identifiable or even non-existent.

Perspectives including a multidisciplinary and Europe-wide approach are developing in research.

- Identified practices

Creation of networks

Several working groups have been set up at international and European level to bring together the various stakeholders to share their knowledge and work together to propose new methodologies.

Focus on the ICCTF

Source: website https://www.icctf.com/

The ICCTF (International Cognition and Cancer Task Force) brings together researchers in the field of cognition and cancer, oncologists, and psychologists specialized in neuropsychology.

- **Conferences** every 2 years to share the research carried out within the different research teams on the subject around the world.
- Published **literature reviews** to keep the scientific community informed of the latest advances made in the field of cognition in cancer *(Joly et al., 2015; M. Lange, Joly, et al., 2019).*
- **Working groups**: Neuropsychological Assessment - Methodology for the design of clinical trials, imaging and preclinical studies (for which recommendations have been drafted)
- Published **guides** to standardize the methods used in scientific studies to facilitate comparison of studies and thus increase the significance of results.
  - *Wefel et al, (2011):* Recommendations for cognitive assessment (tests to be used and method of analysis)
  - *Deprez et al, (2018):* Recommendations about methods for the use and analyses of neuroimaging studies (magnetic resonance imaging, MRI)
  - *Winocur et al, (2018):* Recommendations for preclinical studies (animal experiments)

Focus 15. International Cognition and Cancer Task Force (Chapter 6)

Recently a European consortium was created with a majority of ICCTF members to promote research on the theme of cancer and cognition at the European level.

In France:

- The Cancéropôle Nord-Ouest (CNO) has created an "Axis 4: Cancer and Neurosciences" within which a "Cancer and Cognition" program dedicated to the study of the impact of cancer and its treatments on the cognitive functions of patients has been developed[41]. This program brings together doctors and researchers in the fields of human and social sciences (psychology), neuroscience (medical imaging) and biology (cellular and molecular mechanisms). This NOC working group is recognised at the national and international level.

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- The "cancer and cognition" platform[42] was then created ***(see focus below).*** This platform is labelled by the National League against Cancer and supported by the CNO.
- Under the initiative of the "cancer and cognition" platform and under the aegis of the CNO, multidisciplinary work meetings have been organized for several years involving clinical oncologists, neurologists, psychologists specialised in neuropsychology, neuroscience researchers and inter-groups (e.g., Anocef, UCBG-Unicancer group). The aim of these meetings is to share French research on the subject. As a result of these meetings, collaborative research and French recommendations have been initiated *(Marie Lange et al., 2019, recommendations for the evaluation and management of cognitive impairment).*

There is already an equivalent consortium dedicated to children and adolescents: "PanCare" which works on the post-cancer period including the issue of cognitive impairment on a European scale.

Focus on the European "PanCare" network

Sources: website https://www.pancare.eu/ and interview of a French member of the network

- **History:** The project emerged from the initiative of professionals who felt the need to share practices on a European scale. From a small network created in 2008 it now represents 250 individual members with a legal structure.
- **Mission:** to ensure equal access to optimal long-term care and improve the quality of life of every child and adolescent in Europe after cancer treatment.
- **Work:** long-term follow-up care for all late effects of cancer treatment including cognitive impairment - Work with the European Community - Empowerment of survivors - Research on late effects - recommendations and guidelines - Networking with professionals, survivors, their families and other stakeholders - Awareness - information to patients and professionals - Regular meetings - Working groups including a specific one on guidelines - Recommendations for monitoring late side effects *(van Kalsbeek et al., 2021)*

The experience of this consortium could be shared with the work on adults. Indeed, this older network is relatively structured and has many projects.

Focus 15. The European "PanCare" network (Chapter 6)

[42] http://www.canceretcognition.fr

Bringing together actors by promoting multidisciplinarity and interdisciplinarity

The need to work more in a multidisciplinary and interdisciplinary manner was identified.

Work between different disciplines does not necessarily seem to be emphasised or even developed.

However, many practices for the support and management of cognitive impairment have been developed in other fields (stroke, cerebral palsy, mental health, etc.) and could be adapted for use in oncology.

Thus, general work on cognitive impairments can concern the field of psychiatry, disability and the elderly. Within the framework of the research, not all fields could be investigated but it seems interesting to be able to investigate the questions relating to MCI (Mild Cognitive Impairment, ***see summary in Annex 4)*** which also benefits from guidelines in certain countries (Denmark); the question of employment concerning the care of the handicap; the question of the treatment of the disability ; the question of employment in relation to the management of disability; the question of cognitive remediation or psychosocial rehabilitation in the field of mental health ***(see Mental Health in Annex 4).***

The work in progress at the NCI confirms the need for such an approach, as does the analysis of the literature specific to different disciplines (cognitive disorders in the elderly; psychiatry and cognitive remediation; disability and cognitive disorders; disability and employment; etc.).

In Poland, a joint research team between oncology and psychiatry *(Maria Sklodowska-Curie National Research Institute of Oncology and Institute of Psychiatrics and Neurology in Warsaw)* has been set up (not specific to cognitive impairments).

In this sense, **some projects concerning cognition in oncology are carried out by psychiatrists** *(Brugmann University Hospital in Belgium),* **or physical medicine and rehabilitation physicians** *(Henry Gabrielle Hospital Rehabilitation Center in Lyon, Belgium),* allowing them to benefit from the expertise of these fields of competence in cognitive impairments. In the same way, the computerised treatments developed are based on general expertise on cognitive impairments and not specific to cancer ***(see Focus 7. "Happyneurons" computerized program Chapter 3 - Sheet 3.1.2).***

There is a lot of work related to biology *(Castel et al., 2017; Olson & Marks, 2019; Winocur et al., 2018)* and human and social sciences *(Boscher et al., 2020; Menning et al., 2016; Noal et al., 2011; Xu et al., 2018)* in the context of cognitive impairments in cancer. **Nevertheless, there is a lack of studies that evaluate in detail the impact of cognitive impairment in daily life by also taking into account all the psycho-emotional parameters, the associated social environment, the biological factors.**

Similarly, **a more comprehensive approach to chronic diseases** would undoubtedly allow for the benefits of joint enrichment.

More specifically, no research project on care organisations that could be of direct interest to the subject of cognitive impairments has been identified. This theme could undoubtedly be linked to that of the organization of primary care and the integration of care.

It appears that the research community does not yet work sufficiently in partnership with the clinical world, whether it be for the research work itself or for the clinical implementation of

research protocols. This point, although not specific to research on cognitive impairments in cancer, is important to raise. Nevertheless, programmes such as the cancer and cognition research platform in France attempt to reconcile the clinical and research worlds.

Focus on the "cancer and cognition" platform in France

Source : http://www.canceretcognition.fr/qui-sommes-nous/nos-objectifs/

- ✓ **Background**: The Cancer and Cognition platform was created in 2015 by a multidisciplinary group of experts developed within the Cancéropôle Nord-Ouest. This platform has been labelled since 2016 by the *"La Ligue contre le cancer"* and is internationally recognised, notably by ICCTF[43], and associated with numerous scientific publications.

- ✓ **Objective**: "*To offer pharmaceutical companies, cancer intergroups, and physicians and researchers unprecedented expertise in the evaluation of cognitive disorders, both in terms of preclinical studies and the choice of appropriate tools, design, feasibility and analysis of clinical study data"*.

- ✓ **Expertise:**

The work produced by the platform always starts from a problem identified in the clinic and tries to understand it in all its dimensions:

- Clinical (clinical trials to determine the impact of molecules, drugs and management strategies)
- Neuropsychological (focus on the impact of cancer and treatment on cognition and brain damage)
- Preclinical and biomarkers (evaluation of neurobiological mechanisms in animals)
- Biostatistics (study design and data analysis)

Focus 2. Cancer and Cognition platform in France (chapter 6)

"Potential Effect of Immunotherapy Agents on Cognitive Function in Cancer Patients", Joly et al, doi: 10.1093/jnci/djz168

Two European cohorts with a large number of participants and a research and clinical partnership have been identified:

- **In France:** ANR - Unicancer Canto cohort
  - Dedicated to the early and long-term follow-up of patients with localized breast cancer
  - Includes, a group of more than 500 French patients followed longitudinally on cognitive *(Canto-Cog; Lange et al., 2020; Vaz-Luis et al., 2019)*
  - Research objectives:
    - Better identify the cognitive impairments of these patients from the moment of diagnosis,
    - Understanding the impact of treatments on cognition,
    - Predict clinical, psychosocial and biological risk factors (with biomarker research)
    - Define the evolution of cognitive impairments in order to better identify the populations at risk for which specific actions must be anticipated and implemented.
    - The issue of return to employment is also a research focus

- **In the Netherlands**: Rotterdam study
  - Prospective cohort study conducted since 1990 in the city of Rotterdam.
  - Cohort includes nearly 15,000 participants.
  - Participants were interviewed at home, twice at the research centre for various examinations (including laboratory assessments, imaging and medical examinations). Follow-up examinations every 3 to 6 years
- Evaluation of different issues related to cancer and cognition, *(v*an der Willik et al., 2021; Van Der Willik et al., *2020*).

In terms of research on the development of digital tools *(see Chapter 3 - Cognitive training programs)*, there are many prospects to be promoted at national and European level. In particular, **the question of developing artificial intelligence** within these tools, **data collection, analysis of uses and development of the patient experience** (co-design of tools and quality monitoring) are avenues mentioned by professionals to be explored.

Several European teams have launched initiatives and are working on data sharing and the digitization of cognitive tests.

Team in France: **Equipex WeShare project** supported by Unicancer

- Aims to build shared infrastructures to produce, aggregate and analyse scientific data44.
- We Share:
  - A national research platform in France focused on the patient at the service of researchers and cancer centres.
  - Aiming to provide the technological tools as Equipex to promote the linking of data with a strong social science component.
  - Aiming to develop cognitive assessment and the empowerment of data collection from these assessments.

Team in the Netherlands:

- To develop and validate the use of neuropsychological tests from a paper format to a computerized format with cancer patients with the advantage that the tests can be done independently by the patients
- Recently published study *(Lee Meeuw Kjoe et al., 2021)* using the Amsterdam Cognition Scan[45] (*Feenstra* et al., 2018), a new online neuropsychological test battery that measures a wide variety of cognitive functions for comparison with performance on paper-based tests.

It seems appropriate and necessary to promote and develop this work on a European scale. This would allow the sharing of knowledge and data on a larger scale (with studies composed of larger cohorts). Such an approach would be a lever to have a better knowledge of the problem of cognitive impairment in the post-cancer period but also to develop rapidly the tools to remedy these difficulties.

Some research projects are based on the implementation of international programs that have proven their worth. This is the case, for example, in **Portugal with the CanCOG Cognitive rehabilitation in cancer project[46].** This project aims to offer an internet platform dedicated to cognitive rehabilitation. It is an international collaboration that aims to translate and adapt the UCLA (University of California, Los Angeles) program. Cognitive Rehabilitation Intervention Program for Cancer Survivors.

[44] https://www.canceropole-clara.com/zoom-sur-sylvain-beslet-titulaire-dune-chaire-dexcellence-de-linca/?doing_wp_cron=1635080522.2822370529174804687500
[45] Amsterdam Cognition Scan
[46] http://cancog.web.ua.pt/en/home/

- Implementations

Message to authorities:

- Cognitive impairments related to cancer must be addressed, both specifically and in conjunction with all other relevant disciplines, including the broader field of neuroscience
- Practice (clinical and urban) needs more evidence-based guidance
- There is a potential to organize studies at the European level
- Experts should be invited to share their experience and expertise, as well as their questions, in managing cognitive impairments
- To develop multidisciplinary research programs on cognitive impairments at the European level
- To promote research programs on post-cancer cognitive sequelae
- To ensure that research on post-cancer cognition is also on the European research agenda;
- To organise and finance the evaluation of ongoing programmes and interventions
- To promote the exchange of good practices at the national and European levels

85 to 100 % of the experts have voted in favour of these recommendations

Implementation recommendations for public authorities:

- Promoting research programs dedicated to cognitive impairment in cancer
- Encouraging multi-disciplinary research
- Encouraging the evaluation of the implementation of programs dedicated to cognitive impairments in care

4. ANNEXES

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Annex 1 – Methodology

1.1 Phase 1 research

1.1.1 Review of the scientific literature

1.1.1.1 Selection of keywords and eligibility criteria

- The keywords used:

Key words in the research 1
Areas of study: Cancer* / neoplas* / tumor / tumors / tumour / tumours / malign* / carcinoma*/ non-CNS AND Cognit* / neurocognitive / neuropsychological AND *Cognitive effects:* Cognitive disorder / Cognitive impairment / Cognitive dysfunction / Cognitive complaint / Cognitive rehabilitation OR same combinations with "neurocognitive" or "neuropsychological *Excluding terms*: Child, Children, Childhood, Pediatric, Brain tumo*.

Research keywords 2
Key words in the research 1 AND *Associated symptoms:* Sleep disorders, Sleep disturbance, Anxiety, Fatigue, Pain, Comorbidities OR *Impact:* Autonomy, Adherence, Compliance, Observance, Treatment tolerance, Return to work, Reintegration of employees, Return to employment, Functional performance, Occupational reintegration OR *Intervention / research / care:* Cognitive training, Intervention, Cognitive outcomes, Supportive care, Rehabilitation, Screening, Assessment, Exercise, Physical activity, Meditation, Yoga, Therapeutic education, Cognitive behavioural therapy

- Example of a bibliographic search equation (Search 2, Web of Science):

TI=(Cancer* OR neoplas* OR tumor OR tumours OR malign* OR carcinoma* OR "non-CNS") AND TI=(Cognit* OR Neuropsychological OR Neurocognitive) AND TS=("Cognitive disorder" OR "Cognitive impairment" OR "Cognitive dysfunction" OR "Cognitive complaint" OR "Cognitive rehabilitation" OR "Neurocognitive disorder" OR "Neurocognitive impairment OR "Neurocognitive dysfunction" OR "Neurocognitive complaint" OR "Neurocognitive rehabilitation" OR "Neurocognitive disorder" OR "Neurocognitive impairment" OR "Neurocognitive dysfunction" OR "Neurocognitive complaint" OR "Neurocognitive rehabilitation") Neurocognitive rehabilitation" OR "Neuropsychological impairment" OR "Neuropsychological dysfunction" OR "Neuropsychological complaint" OR "Neuropsychological rehabilitation") AND TS=("Sleep disorders" OR "Sleep disorders" OR Anxiety OR Depression OR Fatigue OR Pain OR Comorbidities OR Autonomy OR Adherence OR Compliance OR "Tolerance to OR "Return to work" OR "Employee reintegration" OR "Return to employment" OR "Functional performance" OR "Vocational rehabilitation" OR "Cognitive training" OR Intervention OR "Cognitive outcomes" OR "Supportive care" OR Rehabilitation OR Screening OR Assessment OR Exercise OR "Physical activity" OR Meditation OR Yoga OR "Therapeutic education" OR "Cognitive behavioural therapy")Behavioural Therapy") NOT TS=(Child OR Children OR Pediatrics OR "Brain Tumour" OR "Brain Tumour" OR "Brain Tumour").

- Eligibility criteria:

Inclusion criteria:

- Patients diagnosed with cancer outside the central nervous system
- Having completed treatment (except hormone therapy)
- Patients over 18 years of age
- Assessment of cognition using questionnaires and/or cognitive tests
- Patients who have undergone a procedure
- Article written in English
- Original articles

Exclusion criteria:

- Adult patients with childhood cancer
- Patients under 18 years of age
- Patients with central nervous system cancer
- Patients assessed before or during treatment with radiation or chemotherapy
- Patients with brain injuries
- Published before 2011
- Protocol studies, reviews, meta-analyses, books, conference papers, chapters, commentaries, supplements, etc.
- Studies with drug intervention
- Studies with less than 10 subjects per group
- Studies with animals
- Studies not available in English
- Studies without interventions

1.1.1.2 Database identification

Databases used:

- Web of Science - Pubmed (MEDLINE) - University of Montreal – Wiley – Sciendirect - For ongoing clinical trials: clinicaltrials.gov
- Databases tested: Sciencedirect (discarded because of redundant references with the previous databases tested) - Springer Link (discarded because the advanced search did not allow for sufficient keywords to be included)
- Other databases identified: PsychInfo – Scopus – CINHAL - CAIRN

1.1.1.3 Determining the level of evidence

Tableau 2. Grade des recommandations

Grade des recommandations	Niveau de preuve scientifique fourni par la littérature
A Preuve scientifique établie	Niveau 1 - essais comparatifs randomisés de forte puissance ; - méta-analyse d'essais comparatifs randomisés ; - analyse de décision fondée sur des études bien menées.
B Présomption scientifique	Niveau 2 - essais comparatifs randomisés de faible puissance ; - études comparatives non randomisées bien menées ; - études de cohortes.
C Faible niveau de preuve scientifique	Niveau 3 - études cas-témoins.
	Niveau 4 - études comparatives comportant des biais importants ; - études rétrospectives ; - séries de cas ; - études épidémiologiques descriptives (transversale, longitudinale).

Figure 2. Table from the HAS recommendation guide 47

- Specifically, among the studies identified:

- **Level 1:** Randomized controlled trials with a number of subjects per group > 50; a clear objective and hypotheses to evaluate the effect of an intervention on cognitive impairment in patients after cancer treatment

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- **Level 2:** Randomized controlled trials with a number of subjects per group < 50; a clear objective and hypotheses to evaluate the effect of an intervention on cognitive impairment in patients after cancer treatment
- **Level 3:** Not applicable
- **Level 4:** Feasibility studies / retrospective studies / comparative studies with biases / studies whose primary objective was not to evaluate the effect of the intervention on cognition / studies without obvious objectives and hypotheses

1.1.2 Review of the grey literature

1.1.2.1 Method of searching the grey literature

International literature search:
Known websites:

- International Psycho-Oncology Society (IPOS) [48]
- International Cognition and Cancer Task Force [49]
- National cancer Institute [50]

European literature search:

Cancer plans:

- National-Cancer-Control-Plans-Survey.Pdf (Ipaac.Eu)
- National Plans | ICCP Portal (iccp-portal.org)

Among the cancer plans available in English, we searched for the keywords "survivorship", "cognitive", "cognition", "memory", "concentration" in order to identify cancer plans that included the themes of post-cancer and cognitive impairments.

Table 1. European cancer plans

COUNTRY	YEAR	RESOURCES
GERMANY	2012	Einführung (iccp-portal.org)
BELGIUM	2008/2010	https://www.iccp-portal.org/system/files/plans/Belgium_National_Cancer_Plan_2008-2010_English.pdf
CYPRUS	2009	https://www.iccp-portal.org/system/files/plans/Cyprus_National_Strategy_on_Cancer_English.pdf

[48] https://www.ipos-society.org
[49] https://www.icctf.com/
[50] https://www.cancer.gov/

DENMARK	2016 2017/2020	https://www.iccp-portal.org/system/files/plans/Kraeftplan-IV-Patienternes-aug-2016.pdf (in Danish) https://sum.dk/arbejdsomraader/sygdomme/kraeftomraadet/kraeftpakker-og-kraeftplan-iv
SPAIN	2009	https://www.iccp-portal.org/system/files/plans/Spain_National_Cancer_Strategy_2009_English.pdf
FRANCE	2021/2025	https://www.iccp-portal.org/system/files/plans/Feuille%20de%20route%20-%20strat%C3%A9gie%20d%C3%A9cennale%20de%20lutte%20contre%20les%20cancers.pdf (in French)
GREECE	2011/2015	Greece - National Cancer Plan 2011-2015, Greek.pdf (iccp-portal.org)
IRELAND	2017/2026	https://www.iccp-portal.org/system/files/plans/National-Cancer-Strategy-2017-2026%20Ireland.pdf
ITALY	2010/2013	https://www.iccp-portal.org/system/files/plans/Italy_National_Oncology_Plan_Summary_English.pdf
LUXEMBOURG	2014/2018	PC-Lux 2014-2018 version finale Site Internet 2014-09-02 (iccp-portal.org)
NETHERLANDS	2005/2010	https://www.iccp-portal.org/system/files/plans/Netherlands_National_Cancer_Control_Programme_English.pdf
POLAND	2020/2030 2015/2024	https://www.iccp-portal.org/system/files/plans/narodowa_strategia_onkologiczna.pdf (in Polish) https://www.iccp-portal.org/system/files/plans/Cancer%20Plan%20Poland.pdf
SWEDEN	2009	https://www.iccp-portal.org/system/files/plans/Sweden_National_Cancer_Strategy_Summary_English.pdf

The search was also conducted to supplement known resources using a search engine and key words. The following word combinations were searched: "cancer", "survivorship", "cancer survivors", "cognition", "cognitive impairment", "cancer and employment"; "cancer + name of country searched". Numerous websites, particularly those of US-based hospitals, came up offering survivorship programs[51].

[51] https://www.dana-farber.org/adult-survivorship-program/
https://stanfordhealthcare.org/medical-clinics/cancer-survivorship-program.html
https://www.mskcc.org/experience/living-beyond-cancer/survivorship

Known websites:

- European Cancer Patient Coalition (ECPC)[52]
- CanCon program[53]
- iPAAC[54]
- EORTC[55]

France literature search:

Known websites:

- The cancer and cognition platform [56]
- *Association Francophone des Soins Oncologiques de Support* (AFSOS): including the AFSOS guidelines on cognitive impairment after cancer [57]
- The French-speaking Society of Onco-Geriatrics (SOFOG) [58]
- GREC-ONOCO[59]
- The SFFPO, French and Francophone Society of Psycho-Oncology [60]

Then a search with the following keywords according to different associations was realised: *"cancer", "survivorship", "cognition", "cognitive impairment", "memory", "workshops", "interventions", etc.* The sites selected were those containing information on the issue of cognitive impairment in the post-cancer period, proposals for management or which could be of interest for understanding the more general context or in terms of organisation in relation to the issue of cognitive impairments and supportive care in the post-cancer period. If websites or guides were referenced on the web page related to the issue of cognitive impairments in the post-cancer period, they were visited. Associations, hospital structures, research centres that communicated on this subject or offered care in France and Belgium have been identified. An exhaustive inventory of practices was not realised because these practices are mainly local initiatives for which communication is limited.

1.1.3 Conducting interviews

1.1.3.1 Identification of the actors to be interviewed

Identification of:

[52] https://ecpc.org/policy/survivorship/
[53] https://cancercontrol.eu/archived/tools/index.html
[54] https://www.ipaac.eu/
[55] http://www.eortc.be
[56] http://www.canceretcognition.fr/
[57] https://www.afsos.org/ / https://www.afsos.org/wp-content/uploads/2020/12/Troubles-cognitifs-et-cancer_AFSOS.pdf
[58] https://sofog.org/
[59] https://www.site-greco.net/?pageID=c242043bd455719e4276d8b0c915df38
[60] https://sffpo.fr/

- Associated partners from different European countries in the CANCON project database. The list of the partner organizations that have collaborated in the CanCon project. These lists are available on the CanCon website[61].
- Institutions Interviewed as part of iPAAC workpackage 4, available on the iPAAC website[62].
- Members of the European consortium of experts on the theme of cognitive impairment in cancer, of which one of our experts is a member.
- Learned societies and experts known by the INCA, Sciensano and our group of experts. Either their contact details were already known by a member of the expert group, or were available on the websites of the learned societies/structures identified.
- Experts and associations during the grey literature review whose contacts were found on the websites.

Invitations for interview requests were sent out between July 1 and September 23, 2021.

[61] https://cancercontrol.eu/archived/who-we-are/associated-partners.html
[62]

1.1.3.2 Summary of interviews

Table 2.Summary of interviews - Requests and responses by country and type of stakeholder

COUNTRY	CATEGORY	RESPONSE/EXIT (NB)
GERMANY	Public authority (3)	No answer (1) Redirection (1) Interview (1)
	Expert (1)	Interview (1)
AUSTRIA	Expert (1)	No answer (1)
BELGIUM	Expert (5)	No answer (1) Lack of availability (1) Interview (3)
	Public authority (2)	No answer (1) Redirection (1)
DENMARK	Expert (5)	No answer (2) Send contacts (3)
	Association (1)	No answer (1)
	Public authority (1)	Interview (1)
SPAIN	Public authority (3)	No answer (3)
FRANCE	Expert (14)	Interview (9) Sending documents (1) No answer (4)
	Association (5)	Interview (5)
	Public authority (5)	Interview (3) No answer (2)
ITALY	Public authority (4)	No answer (3) Not able to answer (1)
LUXEMBOURG	Association (1)	Interview (1)
NETHERLANDS	Public authority (2)	No answer (1) Redirection (1)
	Expert (4)	No answer (3) Redirection (1)
POLAND	Public authority (4)	No answer (2) Redirection (1) Interview (1)
PORTUGAL - EUROPE	Association - Expert (1)	Interview (1)
EUROPE	Association (4)	No answer (2) Redirection (1) Bad contact (1)
	Public authority (3)	No answer (1) Redirection (2)
	Expert/learned society (2)	No answer (2)

1.1.3.3 List of stakeholders interviewed

Table 3. List of stakeholders interviewed and/or participating at the workshop

COUNTRY	CATEGORY	STRUCTURE	NAME	FUNCTION	INTERVIEW	WORKSHOP PARTICIPATION
FRANCE	Expert	Maison Rose – Paris	Jean Petrucci	Clinical psychologist specialized in neuropsychology UF Expert centers FondaMental Foundation - Paris	Yes	Yes
FRANCE	Expert	Oncogite – Bordeaux	Véronique Gérat-Muller	Psychologist specialized in neuropsychology - Founder oncogite Institut Bergonie - Bordeaux	Yes	Yes
FRANCE	Expert	University Hospital - Lyon	Dr Sophie JACQUIN-COURTOIS	Physical Medicine and Rehabilitation doctor - Researcher - Henry Gabrielle Hospital Lyon	Yes	Yes
FRANCE	Expert - Former patient	Tivoli-ducos Clinic - Bordeaux	Sabine DUTHEIL	Former patient - Speech therapist - facilitates cognitive remediation workshops - partner patient	Yes	Yes
FRANCE	Expert	Child -CHU St Etienne	Dr. Léonie Casagranda	Clinical Research Associate	Yes	No
FRANCE	Expert	Child - CHU St Etienne	Dr. Claire Berger	Pediatric oncologist CHU St Etienne	Yes	Yes

FRANCE	Former patient	Patients & Web - Paris	Catherine Cerisey	Former patient, involved in various organizations and learned societies such as AFSOS, member of the board of directors of Europa donna, co-founder of Patients & Web	Yes	Yes
FRANCE	Public authority	ARS - Auvergne Rhone Alpes	Manuelle Milhau	Thematic referent for cancer	Yes	No
FRANCE	Public authority	ARS - Corsica	Dr. Marie-Hélène Pietri Zani	Gastroenterologist	Yes	No
FRANCE	Public authority	OncoPaca-Corsica Regional Cancer Network	Isabelle Rey Correard	Project Manager - City-Hospital Support Care - OncoPACA-Corsica Regional Cancer Network	Yes	Yes
FRANCE	Association	La Ligue contre le cancer	Julie Daul	Occupational psychologist	Yes	Yes
FRANCE	Association	La Ligue contre le cancer	Camille Combourieu	Social and socio-professional support officer	Yes	Yes
FRANCE	Association	La Ligue contre le cancer	Stephanie Lefevre	General Secretary of the Paris Committee	Yes	No
FRANCE	Association	La Ligue contre le cancer	Fabienne Couvreur	Director of departmental commitee 42	Yes	No

FRANCE	Association	La Ligue contre le cancer	Marie-Claire Salmon	Psychologist at the hotline	Yes	No
FRANCE	Association	La Ligue contre le cancer	Anne Taquet	In charge of the mission of supportive care	Yes	No
FRANCE	Learned society	AFSOS	Ivan Krakowski	Director AFSOS - Oncologist	No	Yes
FRANCE	Expert	HappyNeuron application	Franck TARPIN-BERNARD	President of Happy Neuron	Yes	No
FRANCE	Expert	HappyNeuron application	Didier Ghenassia	Managing Director of Happy Neuron	Yes	No
FRANCE	Expert	HappyNeuron application	Stéphanie de Chalvron	Data scientist at HappyNeuron	Yes	No
FRANCE	Association	Cancer@work and Wecare@work	Anne-Sophie Tuszynski	Founder of Cancer@Work	Yes	No
DENMARK	Association - cancer institute	Danish Cancer Society	Bo Andreasson	Documentation and Development Manager	Yes	Yes
EUROPE - PORTUGAL	Association	ECL	Monick Leal	ECL member – representative of the Liga Portuguesa Contra o Cancro	Yes	Yes

POLAND	Institute of Oncology	Maria Sklodowska-Curie National Research Institute of Oncology	Prof. Piotr Rutkowski, MD, PhD	Maria Sklodowska-Curie National Research Institute of Oncology Head of Department of Soft Tissue/Bone Sarcoma and Melanoma Warsaw Poland Deputy Director for National Oncological Strategy and Clinical Trials	Yes	No
DENMARK	Research	Aarhus university	Dr. Lisa Wu	Researcher	No	Yes
BELGIUM	Research	KU Leuven	Dr. Charlotte Sleurs	Researcher	Yes	Yes
BELGIUM	Research	KU Leuven	Dr Sabine Deprez	Researcher	Yes	Yes
BELGIUM	Research	Brugmann University Hospital	Prof. Anne Rogiers	Researcher - Psychiatrist	Yes	Yes
ITALY	Expert	Italian National Cancer Institute - Milan	Dr. Monica Terenziani	Pediatric oncologist	Yes	Yes
SPAIN	Expert	Bellvitge University Hospital	Dr. Marta Simo	neurologist - Bellvitge University Hospital - Barcelona	No	Yes
LUXEMBOURG	Expert	La Croix Rouge Château de Colpach	Jean Philippe Schmit	General Manager at the Centre de rehabilitation du chateau de colpach	Yes	Yes
GERMANY	Expert	DKFZ - German Cancer Research Center	Dr. susanne Weg-Remers	Head of the Cancer information service	Yes	No

CANADA	Public authority	Ministry of Health and Social Services - Quebec Program of cancerology	Cathy Rouleau	Assistant General Manager	Yes	No
CANADA	Public authority	Ministry of Health and Social Services - Quebec Program of cancerology	Jean Latreille	MDCM, FRCPC, National Director	Yes	No
UNITED STATES	Public authority	National Cancer Institute (NCI)	Dr. Todd Horowitz	Program Director in the Behavioral Research Program's (BRP) Basic Biobehavioral and Psychological Sciences Branch (BBPSB), located in the Division of Cancer Control and Population Sciences (DCCPS) - Researcher	Yes	No

1.1.3.4 Guides of interviews

Guides were used for interview: one for the experts and one for the public authorities (see next figures).

Figure 3. Interview guides

ANTARES consulting unicancer

1st Interview Guide – Oriented for experts

For scientists including members of the Consortium and experts on the subject abroad: Duration 20 min to 1 hour depending on availability

Objectives:

1st Identify the context

2nd To compare the good practices identified

3rd Identify if other good practices exist

4th Identify transferability criteria

5th Creation or confirmation of a commitment to collective work at national and European level

Interview guide

1. Identification of the country's health system context:

Could you briefly describe the cancer care model in your country?

How far have you got regarding survivorship and rehabilitation after cancer treatment?

What do you think remains to be done?

2. **Discussion of the country situation:**

a. **Identification of the problem of cognitive impairment after cancer:**

Yes - No

At what level? Research - Clinical - Political and institutional – Patient

Are they considered?

If not, why not?

What are the obstacles?

Does the government and other institutions are helpful?

b. Identify actions already in place:

Do you have any actions already in place? If yes, which ones?

Are they specially dedicated to the cancer area or are they common to other subjects? Which one? Mental Health? Elderly? Disabled people ? .....

Why and what is the benefit or the difficulties?

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How are they financed

3. **Discussion on the good practices identified**

Do these good practices seem relevant to you?

Have you already implemented them in your country?

What would be the advantages? disadvantages? obstacles? favorable factors for the implementation of these actions in your country?

4. **Wish or confirmation of commitment on the subject**

ANTARES consulting unicancer

2nd Interview Guide: Oriented for Government

Objectives:

1st Identify the context

2nd Identify if the subject is known - interest - priorities

3rd Test the good practices identified

4th Identify transferability criteria/existing organizations

5th Identify needs - expectations - conditions

6th Creation or confirmation of a commitment to collective work at national, regional, local and European level

Interview guide

1. Identification of the country's health system context:

Could you briefly present the cancer care model in your country? How far have you got? What do you think remains to be done?

Is the cancer policy organized in a specific way or in a common way with other health issues?

How is the issue of survivorship and rehabilitation in cancer care considered?

2. Knowledge/identification of cognitive impairment in oncology

Has the issue of cognitive impairment in cancer patients been identified?

By whom are these disorders identified? By research teams/ By professionals/ By patients/ By public authorities?

Are they considered? If not, why not? What are the obstacles?

Does the government and other institutions are helpful?

What about the financial aspect ?

3. Are there any specific initiatives or treatments to help patients with cognitive impairment?

In oncology?

Outside oncology? Mental health - MCI - disability

In what form? e.g.: plan/program/reference

Could you share these resources with us?

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Do these practices exist in your country? For cancer? On other subjects?

Do you think that these practices can be implemented in your country? Under what conditions? Barriers and enabling factors? Priorities? With which partners?

In your opinion, are they generalized or can they be generalized at a wider level (local - regional - national)

Could these practices be integrated into existing programs or into an integrated cancer care pathway?

Specific supportive care policy?

Chronic disease programs?

Organization of coordination - pathways – integrated platform... ?

Return to work policy?

Post-cancer support policy with a social dimension?

Sport and health program?

What level of integration of public policies do you have ?

5. Expectations and wishes to get involved in this subject

In your opinion, what would be the contribution of the European dimension of the project? Political? Technical?

Would you like to get involved in the promotion of this issue?

1.1.4 Results of the workshop

Chapter 1. Informing about cognitive impairments related to cancer treatment

Sheet 1.1 Organizing information by public authorities

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Promoting the initiatives of expert actors on the subject to raise awareness among public authorities	91	0	9
Involvement of public authorities in information and communication activities	91	0	9
Promote (and/or initiate) the information media (or projects) already existing at national or European level by public authorities	83	0	17

Sheet 1.2 Informing healthcare professionals to improve the care of patients with cognitive impairments

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Transmitting information dedicated to cognitive impairments in the post-cancer period and on existing support services	100	0	0

Sheet 1.3 Informing patients as early as possible to promote access to support

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Promoting information and communication to users on the basis of scientific information, drawing on tools and practices already available	96	0	4

Chapter 2. Identifying and objectivising cognitive impairments

Sheet 1.1 Identifying cognitive impairments

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Organising the identification of cognitive impairments	95	0	5

Sheet 2.2 Objectivising cognitive impairments

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention

Organising specific assessment of cognitive impairments	100	0	0
Definition of professionals to whom to refer for specific assessment	90	0	10
Use of validated tools recommended by learned societies	95	0	5

Chapter 3. Promoting the different ways of dealing with cognitive impairments

Sheet 3.1 Referring patients to appropriate supportive care

Implementation proposal	**Result of the workshop vote (%)**		
	Favourable	**Unfavourable**	**Abstention**
Encouraging initiatives to set up psycho-education sessions dedicated to cognitive impairments	95	0	5

Sheet 3.1.1 Psychoeducation

Implementation proposal	**Result of the workshop vote (%)**		
	Favourable	**Unfavourable**	**Abstention**

Encouraging initiatives to set up psycho-education sessions dedicated to cognitive impairments	95	0	5

Sheet 3.1.2 Cognitive training programs

Implementation proposal	**Result of the workshop vote (%)**		
	Favourable	**Unfavourable**	**Abstention**
Encouraging the development of supervised cognitive training programs		5	19
Encouraging public authorities to support the development of cognitive training programs	67	0	33

Sheet 3.1.3 Physical activity

Implementation proposal	**Result of the workshop vote (%)**		
	Favourable	**Unfavourable**	**Abstention**
Encouraging access to physical activity programs for patients with cognitive impairments	89	5	5

Sheet 3.1.4 Multimodal management of cognitive impairments

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Encouraging access to multimodal programs for patients with cognitive impairments	95	0	5

Sheet 3.2 Orientating, coordinating and organising the management of cognitive impairments

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Developing and promote post-cancer care programs that include management of cognitive impairments	100	0	0
Organising and implement the management of cognitive impairments in existing organisations	85	10 / 5	10 / 5

Chapter 4. Proposing a management of cognitive impairments in the framework of support to return to work

Implementation proposal	**Result of the workshop vote (%)**		
	Favourable	**Unfavourable**	**Abstention**
Assessing and managing cognitive impairments in patients returning to work	89	5	5
Raising awareness among occupational physicians and employers	94	6	0

Chapter 5. Identifying the health professionals to be involved in the management of cognitive impairments and training them

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Identifying professionals specialised in the management of cognitive impairments in cancer	95	0	5
Strengthen the training of specialised health professionals	95	0	5
Raising awareness of other health professionals	100	0	0

Chapter 6. Supporting all aspects of research related to cognitive impairments

Implementation proposal	Result of the workshop vote (%)		
	Favourable	Unfavourable	Abstention
Promoting research programs dedicated to cognitive impairments in cancer	85	5 /10	5/10
Encouraging multi-disciplinary research	95	0	5
Encouraging the evaluation of the implementation of programs dedicated to cognitive impairments in care	100	0	0

Annex 2 – Resources of the research of the grey literature: Practices identified

Chapter 1. Informing about cognitive impairments related to cancer treatment

Sheet 1.1 Organising information by public authorities

Table 2. Programs that have identified the issue of cognition in post-cancer care

Country	Resources	Program content	Cognition
Denmark	Rehabilitation Program Program available in Danish	• **Context:** Developed within the framework of the cancer plan III and as a complement to meet the needs of post-cancer rehabilitation and palliative care. • **Target:** planning authorities; hospital managers, professionals (nurses, psychologists, social workers, etc.). • **Objective:** - Describe the professional approach to palliative care rehabilitation and cancer care organization - To help ensure quality professional care and coordination of care across disciplines and sectors in a comprehensive approach	• Memory and concentration difficulties identified as one of the main symptoms found in patients during and after treatment. • Observed that 42% of the patients report having concentration difficulties (occasional to frequent) and 40% report having memory difficulties (occasional to frequent). • Cognitive impairment is included in the domain of psychological needs. • However, no specific care is specified.

Sweden	National Cancer Rehabilitation Program *(latest version 09/02/2021).*	• **Background:** Care program prepared by a national working group and established by the regional cancer centre • **Content:** Presents the actions to be implemented at the regional and local level in order to offer a care program that meets the full range of needs of patients over 18 years of age. • **Objective:** that the needs of patients are identified in consultation so that the patient does not have to ask for an evaluation and an adapted intervention.	• Cognitive impairment is included in the "psychological and psychiatric aspects" domain. • Describes the affected cognitive areas and their need for assessment and suggests compensatory strategies. • **Recommendation:** "Patients who present or have presented with signs of cognitive impairment should be offered an expanded assessment of their cognitive function."

Sheet 1.2 Informing health professionals to improve the care of patients with cognitive impairments

Table 4.Organisations identified to inform professionals about cancer-related cognitive impairments

ORGANISATION	COUNTRY	RESOURCES	CONTENT
NCI	United States	NCI for Health professional	Information on cognitive functioning, the impact of cancer and its treatment, and the supports available for cognitive impairments.
ICCTF	International	(e.g. Deprez et al., 2018; Joly et al., 2015; Wefel et al., 2011)	Publication of literature reviews on the topic of cognition in cancer, articles of recommendations to harmonise the methodology of studies on cognition in cancer. Conferences on the topic of cancer and cognition.

NCCN	United States	NCCN	A Guide to Survivorship which includes a section on "late effects/long-term psychosocial and physical problems" and "cognitive function". The section on cognitive function provides information on its assessment, associated factors that need to be addressed (e.g., fatigue and depression), and available interventions that focus on cognition.
TABLE RONDE	Belgique	https://www.collegeoncologie.be/sites/collegeoncologie.be/files/inline-files/FRrapport_tableronde_soinsaprescancer.pdf	Initiative of the working group in which Kom op tegen Kanker, the College of Oncology and the Cancer Center of Sciensano are represented. Information about post-cancer care, cognition is mentioned.
AFSOS	France	AFSOS	A specific reference for cognitive impairment in adult non-CNS cancer. Information on factors contributing to cognitive impairment, the nature of cognitive impairment, methods for assessing them, strategies for limiting their impact on daily life, and types of interventions available.
REGIONAL CANCER NETWORKS	France	e.g. ONCONORMANDY ONOPaca-Corse ONCO Pays de la loire onco-occitania_directory	Workshops and conferences dedicated to cognitive impairments in cancer. The contents are adapted according to the type of conference, the audience and the speaker. They generally offer a review of the literature on the topic of cognitive impairments in cancer, their impact on daily life, and strategies or interventions to deal with them. In some regions, patient support interventions (non-cognition specific) available in the region are listed on their website.
REGIONAL CANCÉROPÔLE	France	e.g. Cancéropôle Nord-ouest Symposium	Workshops and conferences dedicated to cognitive impairments in cancer. The contents are adapted according to the type of conference, the audience and the speaker. Information on the latest programs and research results on the topic of cognition and cancer carried out in the region (or in France).
CANCER AND COGNITION PLATFORM	France	Platform Documentation	Website dedicated to information about research on the topic of cognition in cancer. Lists all ongoing research programs on this topic in France and related publications, provides videos of professionals and patient testimonials, and links to websites of interest.
DKFZ	Germany	Krebsinformationsdienst	Complementary medicine guidelines for oncology, including recommendations to support cognitive impairments.
ECL	Europe	Rehabilitation atlas - ECL	List of programmes identified in Europe supporting psychosocial and physical rehabilitation. One program identified in Ireland concerns concentration and memory.

Sheet 1.3: Informing patients as early as possible to promote access to support

Table 5. Organisations identified to inform patients about cognitive impairment

ORGANISATION	COUNTRY	RESOURCES	CONTENT
NCI - NATIONAL CANCER INSTITUTE	United States	NCI for Patients - Website	Web page offering information on cognitive functions, the impact of cancer and the help available in case of cognitive impairments. The vocabulary used and the level of detail are specifically adapted to patients (compared to the web page dedicated to professionals and mentioned in the previous sheet).
CANADIAN CANCER SOCIETY	Canada	https://cancer.ca/fr - Website	Information on factors that may contribute to cognitive impairments (e.g., medications, treatments, other symptoms), the nature of these difficulties, how to assess them and adopt new strategies to reduce their impact on daily life, or suggestions for available interventions.
PSYMEDICIS CLINIC	Canada	https://psymedicis.com/chemobrain-brouillard-cerebral/	Information on cognitive impairments associated with cancer and the services offered by the PSYmedicis clinic
ESMO	Europe	ESMO - **Survivorship** guide	A guide dedicated to post-cancer with content on ChemoBrain care and follow-up. Provides a brief summary of the factors contributing to cognitive impairments, the types of difficulties encountered and strategies for coping.
NCCN	United States	NCCN - **Survivorship** Guide	A guide dedicated to post-cancer with content on chemo-brain care and follow-up. The section on cognition provides a brief summary of the factors contributing to cognitive impairments, the types of difficulties encountered and strategies for dealing with them.
VIE & CANCER	Belgium	https://vieetcancer.be/traitements/quand-le-cancer-nous-fait-perdre-la-tete-les-troubles-de-la-memoires-un-effet-secondaire-meconnu - website	This web page is dedicated to memory disorders and informs about the lack of knowledge of this subject by patients, the nature of memory disorders, how to assess them and gives some strategies to limit their impact on daily life. The information given corresponds to quotes from professionals working in the field of cancer and cognition (e.g., oncologist, psychologist specialized in neuropsychology).
MACMILLAN CANCER SUPPORT	United Kingdom	https://www.macmillan.org.uk/ - Website https://www.macmillan.org.uk/documents/aboutus/health_professionals/improvingcancercareandsupportforpeoplelivingwithandbeyondcancer.pdf - info MacMillan platform	Web page dedicated to cognitive changes. Information on the types of cognitive changes observed, contributing factors, and strategies for coping with them. Provides a link for patients who wish to participate in a research trial. Provides online support.

LA MAISON ROSE	France	Maison Rose in Paris - Helping women affected by cancer (maisonsrose.fr) - Website magazine esmo2021-roseup-kantar-magazine https://www.rose-up.fr/magazine/chemofog-chimiotherapie-memoire/#1 - Paper support	An association that offers webinars and conference by a psychologist specialised in neuropsychology to inform about cognitive functions, the impact of cancer and its treatments, and strategies for coping. The association publishes magazines with articles on cancer and cognition available on their websites. The information contained in these articles is based on interviews with professionals. Several topics are covered, such as the need to raise awareness, to inform about cognitive impairments, the impact of cognitive impairments on quality of life, and strategies for coping.
KANKER	Netherlands	https://www.kanker.nl/gevolgen-van-kanker/cognitieve-problemen-bij-kanker/algemeen/cognitieve-problemen-na-kanker#show-menu	Web pages dedicated to cognitive impairments in cancer. Specific information on: – post-cancer – patient experience – how to deal with impairments – the progress of research on this theme

Chapter 2. Identifying and objectivising cognitive impairments

Sheet 2.1. Identifying cognitive impairments

Table 6. Identified Supportive Care Needs Assessment Scales including a Cognition Item

ORGANISATION	COUNTRY	TYPE OF RATING SCALE	BENEFITS	OBSTACLES
NCCN	United States	Distress scale with an item for "memory/concentration".	Available in several languages Easy to administer Low level of evidence (expert recommendation, used in scientific studies)	No information identified regarding its implementation in hospitals/cancer centers
DENMARK CAPITAL REGION WORKING GROUP	Denmark	Cancer support needs screening scale used in Danish hospitals with an item for memory/concentration. Used as part of an assessment with a health professional Scale.pdf	Easy to use Supposed to be offered systematically	No information identified regarding its implementation in hospitals/cancer treatment centers. No level of evidence
REGIONAL CANCER CENTER	Sweden	Screening scale for cancer support needs used in clinics in Sweden. It is primarily intended for nurses in contact with patients. National Cancer Rehabilitation Programme cancer rehabilitation center Survey	Easy to use	No information was identified regarding its implementation in hospitals/cancer centres. No level of evidence but close to the NCCN distress scale

REGIONAL CANCER NETWORK ONCO PACA-CORSE	France	Practice aid sheet for identifying and referring patients with cancer within the framework of the National Comprehensive Care Pathway after cancer treatment Questionnaire.pdf	Easy to use	Recently published, no information on its implementation
NATIONAL ORGANISATIONAL FRAMEWORK - INCA	France	Supportive oncology care for adult cancer patients - Recommendations and guidelines. Includes one erlevel of cognitive impairment identification with a question, a second ièmelevel with the FACT-Cog questionnaire. Oncology Supportive Care Reference Guide	Easy to use	Recently published, no information on its implementation

Sheet 2.2. Objectivising cognitive impairments

Table 7. Identified organisations assessing cognitive impairment and associated factors

ORGANISATION	COUNTRY	EVALUATION CONDUCTED BY	CONTENT OF THE EVALUATION
Bora and alizees programs -hospital (rehabilitation center)	France	Doctor	Before the beginning of the rehabilitative treatment, an evaluation is carried out according to the recommendations of the AFSOS. This evaluation lasts about 1 hour. During the interview, the doctor uses the FACT-Cog self-questionnaire, the HADScale, the MOCA screening test and the SDMT.
Program at the françois baclesse - cancer center	France	Psychologist specialized in neuropsychology	Prior to the start of rehabilitation, an assessment is carried out according to the ICCTF recommendations and the addition of contributing factors.
American hospital of paris Specialty neurology - hospital	France	Neurologist	Offers a memory consultation by a neurologist in the neurology department directly within the cancer treatment facility, which allows for better follow-up by the oncologist.
Brugman uhc hospital	Belgium	Health professional	Use of the CFQ questionnaire to assess daily cognitive functioning. Completed before and after the intervention.
Patient association (e.g. “La Ligue contre le cancer”, “La maison rose”)	France	Psychologist specialized in neuropsychology	No assessment of cognitive problems due to lack of time and funding. Patients participated in work groups if they had cognitive complaints.

Patients' association

Chapter 3. Promoting the different ways of dealing with cognitive impairments

Sheet 3.1.1. Psychoeducation

Table 2. Programs identified in the scientific literature.

Name	Studies in non-CNS cancer (level of evidence according to the HAS scale)	Type of therapy	Content	Format
MAAT - Memory and Attention Adaptation Training	Ferguson et al, 2012 (2) Ferguson et al, 2016 (2)	Psycho education + CBT (compensatory strategies)	The 4 components of MAAT include: 1) education about cognitive impairment in cancer; 2) awareness training to identify "at risk" situations in which cognitive failures may occur; 3) stress management and self-regulation; 4) training in compensatory cognitive strategies	8 weeks 1 or 2 sessions / week 30 - 50 min /session
Emerging from the Haze	Asher et al, 2019 (4) Liang et al, 2019 (4) Myers et al, 2020 (4)	Psycho education + CBT	Mindfulness and stress management + CBT for mood symptoms + memory, attention and problem solving strategies + lifestyle education	6 weeks 1 session / week 2h30 / session

Sheet 3.1.2. Cognitive training programs

Table 8. Software identified in cognitive training programs

NAME OF THE PROGRAM	RESOURCES	TARGET AUDIENCE	PROGRAM CONTENT	COST
BRAIN HQ® (ACTIVE STUDY)	The ACTIVE Study - BrainHQ from Posit Science (Von Ah et al., 2012) (Bray et al., 2017) (Becker et al., 2017) (Meneses et al., 2018) (Wu et al., 2018)	All public Designed for healthy subjects Research: different pathologies	Exercises: Attention Processing speed Memory Navigation "Intelligence" "performances"	Paying 14$/month 96/year
HAPPY-NEURON®	www.happyneuron.fr (Damholdt et al., 2016) Cognitive workshops at the Baclesse Centre (France) - study protocol Cog-Stim (in progress) Cog-Tabage (in progress)	Health professionals for use with any public with cognitive disorders Research and clinical: different pathologies	Over 40 games Targeting the following cognitive functions: Memory Attention Language Executive functions Visuo-spatial Interaction between functions 11 languages	Cost for institutions: HappyNeuron® PRO - PRESCO = 1249€ TTC Estimate Baclesse center: 80€/pers/year Cost for individuals: 3 months = 29,95€ / 6 months = 54,95€.
LUMOSITY®	www.lumosity.com/fr (Kesler et al., 2013)	All non-cancer specific audiences	Exercises on Speed Memory Attention Adaptability Problem solving Maths	Not framed Cost for individuals = 11,95€/month or 299,95€ for life

				Team rate (from 10 people) = 4€/month/person (66% cheaper than the individual offer).
AQUASNAP® (MYCOGNITION)	mycognition.com (Bellens et al., 2020)	All non-cancer specific audiences offered to healthy subjects/organizations / schools Research: different pathologies	Video games on attention Working memory Episodic memory Speed of ttt	Cost for individuals £19.99 / month £219.99/ 1 year
REHACOM®	www.rehacom.co.uk (Dos Santos et al., 2020)	For psychologists specialized in neuropsychology Designed for use with brain damaged patients	29 modules on Attention Memory Executive functions Visual field Visual-motor ability more than 20 languages	Cost for professionals: 118,40€ / module / 1 year Pack 7 modules for 7 years = 3457,19€.
RECOG - RESPONDING TO COGNITIVE CONCERNS	(Mary E. Mihuta et al., 2018)(e Recog, web-based) (Schuurs & Green, 2013) (King & Green, 2015)	Validated Recog program for cancer patients that has been computerised	Psycho education + cognitive remediation + exchanges (psycho-social dynamics) 4 themes: (1) aging, health, cancer, and cognitive function; (2) memory; (3) attention; and (4) fatigue, emotions, and cognition	No information on its marketing

The Oncogite program in France (In French):

onCOGITE.
LES ATELIERS QUI RECONNECTENT LES NEURONES !

onCOGITE est une association Loi 1901 et reconnue d'intérêt général.

Elle réunit dans son conseil d'administration des patients, des oncologues (spécialité médicale, radiothérapie et chirurgie), des patients et une patiente partenaire diplômée. Une équipe de 16 neuropsychologues s'investit dans cette mission de mise à disposition d'une prise en charge spécifique à tous les patients de France.

La prise en charge proposée repose sur un groupe thérapeutique dynamique

- la participation à un atelier hebdomadaire qui propose un parcours jusqu'à 25 séances.
- des ateliers « ouverts » c'est-à-dire qu'ils accueillent les patients en fonctions de leur organisation dans leur parcours de soins. De fait ils sont accueillis par des patients qui sont déjà engagés dans leur parcours, et eux même accueilleront des futurs patients débutants.

Les activités et la progression ont été pensées dans ce sens :

- la méthode repose actuellement sur 30 activités multiniveaux qui permettent l'adaptation pour chaque patient selon son niveau.
- la dynamique rééducative permet donc une progression individuelle néanmoins inscrite dans une dynamique de groupe, laquelle est essentiel pour la motivation des patients, notamment à un moment sensible dans l'après-soin alors que le patient a besoin d'être accompagné dans sa nouvelle autonomie.

Une méthode spécifiquement créée pour les patients suivis en oncologie.

Les exercices ont été créés pour et avec les patients. Ils sont multiniveaux et permettent une adaptation sensible de la difficulté afin d'accompagner au mieux le niveau propre du patient. Par ailleurs ils sont multimodaux (auditif, visuel, kinesthésiques) garantissant une rééducation harmonieuse des différentes fonctions cognitives avec transfert dans quotidien.

Ce programme centré sur l'humain garantit la présence d'un professionnel en interaction continue avec le groupe de patients. Ce soutien expert qui encadre les interactions entre les patients également se différencie d'un simple coaching et garantie l'engagement et l'assiduité du patient.

onCOGITE propose un travail de remédiation axée sur :

onCOGITE, Association Loi 1901, reconnue d'intérêt général
n° RNA W332027865 - n° SIRET 851 609 313 000 16
Siège : 90 rue Saint Genès F - 33000 BORDEAUX contact@oncogite.com +33(0)6 68 91 53 15 https://www.oncogite.com

- la stimulation des fonctions cognitives fragilisées, l'apprentissage de nouveaux automatismes et de nouvelles stratégies.
- la rééducation dynamique procédurale transférable dans le fonctionnement quotidien.
- l'éducation aux troubles (psycho-éducation) grâce à quoi le patient découvre le fonctionnement de son cerveau, et développe une autonomie par rapport aux processus adaptatifs à mobiliser d'une part et par rapport à la dynamique même de sa rééducation d'autre part.

La plateforme numérique permet aux patients d'organiser leurs inscriptions aux séances hebdomadaires qui réunissent 8 à 12 personnes dans des groupes ouverts.

L'accès aux visio-ateliers initié lors de la crise sanitaire garantit l'assiduité en réduisant les inégalités géographiques.

Vers une évolution d'atelier MIXTES (visio et présentiels)

La plateforme garantira l'évolution de l'organisation vers des ateliers MIXTES permettant, selon une cadence choisie, l'alternance entre des séances en visio (modalité qui maintient les avantage du distanciel) et des séances ponctuelles de rencontre pour un travail en présentiel.

Ce plus sera possible grâce au réseau de neuropsychologues et au maillage territorial des ateliers sur des points géographiquement organisés en fonction des centres de soins ou associations de patients.

onCOGITE transpose de plus les exercices dans une web-application en Intelligence Artificielle (Adaptative Learning). Il s'agit d'un outil complémentaire qui ne remplace pas l'indispensable travail en atelier animé par un neuropsychologue. C'est un support digital qui propose la possibilité d'un renforcement du travail entre chaque séance hebdomadaire et qui permet le maintien du réentraînement à l'issue du parcours.

Une recherche randomisée financée débutera au premier trimestre 2022.

Les effets du programme onCOGITE seront évalués par une recherche interventionnelle, randomisée coordonnée par l'Université de Bordeaux et dont le promoteur est l'Institut Bergonié.

Cette étude est d'ores et déjà financée par le Prix du Ruban Rose Qualité de vie 2018, par la Région Nouvelle Aquitaine.

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LES ATELIERS QUI RECONNECTENT LES NEURONES !

Retour d'expérience

Depuis 2017, 300 patients de l'Institut Bergonié ont pu bénéficier de ce parcours.

Parallèlement, l'expérience menée sur le territoire national entre octobre 2020 et octobre 2021 a permis à 391 patients, essentiellement des femmes, de suivre ce parcours de remédiation cognitive en visio-ateliers. Les participants au parcours depuis au moins 4 mois se sont inscrits à 12 séances en moyenne. 79% des participants ont moins de 60 ans et 71% sont en situation d'activité professionnelle.

Actuellement l'équipe de 16 neuropsychologues adhérents et formés à la méthode, participe au développement et à l'évolution de cette méthode.

Un partenariat financier et opérationnel

onCOGITE bénéficie du soutien financier de la Région Nouvelle-Aquitaine, de groupes de mutuelle et prévoyance engagés sur 3 années au moins (MALAKOFF HUMANIS et APICIL en premier lieu et d'autres à venir). Ce soutien permet le développement des outils (plateforme, support digitalisé des outils, web-application).

onCOGITE bénéficie également du soutien opérationnel dans la mise en place des ateliers grâce aux centres de soins (CHU, CLCC et autre), aux associations de patients (Ligue contre le cancer, Europa Donna, Maison Rose/RoseUp, ANAMACap, De l'Air…) et de Mutuelles.

Site onGOGITE : www.oncogite.com

Plateforme onCOGITE : https://plateforme.oncogite.com/#/home

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Figure 4. Oncogite association of cognitive training in France

Sheet 3.1.3. Physical activity

Table 9. Physical activity guidelines

ORGANISATION	COUNTRY	PUBLIC CONCERNED	CONTENT	RESOURCES
WHO	International	People with chronic diseases (hypertension, type 2 diabetes, HIV and cancer survivors)	Brief recommendations on the duration and intensity of physical activity required.	Physical activity (who.int)
NCCN	United States	Cancer patients	A guide to Survivorship with recommendations on physical activity. Lists benefits, professionals to ask, types of activities available with intensity levels, and tips for maintaining activity.	www.nccn.org/patients/guidelines/
ESMO	Europe	Cancer patients	Survivorship guide with brief recommendations on physical activity: benefits, simple tips for activity.	www.esmo.org → Healthy lifestyles - Physical Activity
AFSOS	France	Cancer patients (during and after treatment)	A guide that provides a definition of physical activity and APA, specifically in the context of cancer, informs about the benefits and barriers to realise APA and how to access / realise physical activity.	AFSOS Reference System
AUVERGNE RHÔNE ALPES REGION	France	Cancer patients	Website that defines physical activity, its benefits, the type of physical activity to do alone, how to access physical activity, supplemented by resources (scientific articles, reports and official texts, general public information).	www.cancer-environnement.fr

INSERM	France	People with chronic pathologies (including cancer)	Very detailed report about the benefits of physical activity on physical capacity, fatigue, cognitive function, and other side effects of treatment, with scientific references. Includes a paragraph on the impact on survival after cancer. The adverse effects of physical activity are discussed and how to adapt it to the different stages of the disease.	EC Inserm 2018_Rapport_Activité Physique.pdf
INCA	France	Cancer patients	Detailed report about the different types of existing activities, their benefits on physical capacities, fatigue, (no specific focus on cognition), but also the limits to its realisation.	CNIB 2017 Synthesis benefits AP.pdf

Table 10. Organisation of reimbursement for physical activity

Type of practice	Country	Resources	Content
Decree	France	www.legifrance.gouv.fr	Reimbursement under medical prescription of a session carried out by a professional in APA: functional and motivational assessment of physical activity, which leads to the development of an APA project.
Physical activity prescription	France	Le site dédié au sport sur ordonnance | sport-ordonnance.fr	Within the framework of the care pathway for patients with a long-term condition (e.g., cancer patients), the attending physician can prescribe APA to be provided by APA coaches, paramedical professionals or people certified by the sports federation.
Physical activity prescription	Denmark	Link to the Health Law www.retsinformation.dk	According to the Health Law, general practitioners can refer patients with rehabilitation needs to physical activity in the municipalities. The activities are tax financed.
Physical activity prescription	Norway	www.fritidforalle.no	“Green prescriptions" allow general practitioners to set up a supervised physical activity programme with their patients, generally lasting between 10 and 12 weeks.
Physical activity prescription	Sweden	www.fyss.se	Doctors, nurses and physiotherapists are entitled to prescribe physical activity as part of "physical activity on prescription" after a dedicated individual consultation. The target group is all people suffering from chronic diseases for whom physical activity could be beneficial according to a reference framework: the FYSS.

Table 11. Identified practices offering physical activity to patients

ASSOCIATION – PROGRAM NAME	ORGANISATION – COUNTRY	SUPERVISOR	FORMAT	CONTENT	BENEFITS	OBSTACLES
Alizes program neuro-oncology and rehabilitation - link	Henry Gabrielle Hospital France, Lyon	Occupational Therapist APA instructor	As a group 2 times a week (9am to 4pm) 12 weeks	Activities carried out in groups (no details)	Cognitive assessment Improved cognitive performance and complaint Free for patients	Restricted access (under medical prescription) Carried out at the centre, creates travel and access difficulties for patients who are far away Difficult to generalize
Cancer league	France Available in several cities	Physical activity instructor	As a group	e.g., Qi gong / yoga / gentle gym	Free for patients	Carried out at the center, creates travel and access difficulties for patients who are far away No cognitive assessment
Cancer league	Available on the League's website	Yoga Instructor	Video, to be made at home: www.ligue-cancer.net	Video of yoga/relaxation exercises	Free for patients Easy access To do at home	No cognitive assessment Unsupervised

Sheet 3.1.4. Multimodal management of cognitive impairments

Table 12. Summary of identified multimodal management programs

ORGANISATION	COUNTRY	PROFESSIONALS INVOLVED	PROFILE OF PATIENTS WITH COMPLAINTS	ORGANISATION OF THE ACTIVITY	PROGRAM CONTENT	CONDITIONS OF ACCESS	BENEFITS	BRAKES
BORA PROGRAM **Psychoeducation + Cognitive training + Adapted Physical Activity**	France, Lyon, Hospital	Psychologist specialised in neuropsychology, doctor, occupational therapist, APA coach	All, approximately 1 month after chemotherapy	In a group (4 people) In-person at the hospital 6-week program Group sessions with occupational therapist, adapted physical activity Individual sessions with a psychologist specialised in neuropsychology, a doctor	<u>Program objective:</u> cognitive remediation focusing on attention and memory Metacognition with awareness of one's abilities in terms of cognitive functions and interpersonal relationships Setting up situations to facilitate learning and the integration of information into daily life. → Preliminary results revealed improved cognitive performance	Be referred by a physician. Have a complaint and cognitive deficits based on the assessment of symptoms (anxiety, depression, cognition).	Financially supported	To be referred by a physician / to have cognitive deficits detected by a screening test / only on site / difficult to generalise
NEUROCOGNITIVE REMEDIATION THERAPY PROGRAM **Cognitive training (Computerized) +**	Belgium, Cognitive remediation clinic at the Brugmann University Hospital	Psychologist specialised in neuropsychology	Patients treated for cancer Patients with neurological or psychiatric disorders	Individual and group. 1 session / week 12 weeks	Computerised cognitive exercises and individualised training strategies Group sessions of physical activity,	Referred by a physician	Financially supported	Only on person

Physical Activity + Meditation + Cognitive-Behavioral Therapy (CBT)					Mindfulness Based Stress and CBT → Preliminary results show improved cognitive performance			
COG-STIM PILOT STUDY **Computerised Distance Learning + Physical Activity**	France, François Baclesse Cancer Centre	Psychologist specialized in neuropsychology and physical activity instructor	Patients undergoing radiation therapy with a cognitive complaint (FACT-Cog)	In groups and at home 20min cognitive training sessions 12 weeks	Computerised cognitive exercises (HappyNeuron®) to do at home Group physical activity sessions	Referred by a physician	Financially supported / In-class and distance learning	No evaluation of its effectiveness (feasibility study in progress)

Chapter 4. Proposing a management of cognitive impairments in the framework of the assistance to the return to work

Table 13. Public policies identified targeting employment and cancer

RESOURCES	COUNTRY	ORGANISATION	RESOURCES	CONTENT
Europe's beating cancer plan	Europe 2021	Communication from the Commission to the European Parliament and the Council	ec.europa.eu	Proposes the implementation of measures to facilitate integration and social reintegration, as well as the evaluation and adaptation of working conditions in the context of supportive care.
Cancon – Work Package 8 Survivorship and rehabilitation	Europe 2017	Co-funded by the European Union Health Programme	CanCon_Guide	On the basis of the results of the VICAN2 study, the guide specifies that cancer is a factor of occupational and economic insecurity and mentions that cognitive disorders are among the late negative effects.
Union of equality: strategy for the rights of persons with disabilities	Europe 2021	European Commission	europa	Guide to actions to promote the rights and quality of life (including employment) of people with disabilities (including cancer patients)
Occupational health plan	France 2016 - 2020	Ministry of Labour, Employment, Vocational Training and Social Dialogue	travail-emploi.gouv.fr	Proposals for the renewal of the occupational health policy shared between the State, social security and prevention organisations and actors. The results of VICAN 2 and the recommendations of the French cancer plan are mentioned
Approaches to addressing survivor needs In the area of cancer Mental health and Return to work	Canada 2019	Canadian Partnership Against Cancer	httpartnershipagainstcancer.ca	Environmental analyses detailing the models of mental health and return-to-work care, programs and services that have proven in Canada and abroad

Table 14. Resources on Employment and Cancer

RESOURCES	COUNTRY	ORGANISATION	RESOURCES	CONTENT	BENEFITS	BRAKES
EMPLOYERS						
How to Manage Cancer At work	Europe 2020	ECL (European Cancer League) - Patient support working group	*ECL_Cancer-at-Work_Handbook-for-Employers_2020*	The manual provides information on the need for "a comprehensive policy and set of procedures on cancer management in the workplace" and suggests strategies for employers to support their employees. Cognitive impairments is mentioned among the side effects reported by patients.	Specific to cancer and return to work	Not specific to cognition
THE WORKING AID "§ 51 SGB V - understanding the request of the health insurance company to apply for rehabilitation"	Germany	Cooperation including the information service of the German Cancer Research Centre (DKFZ)	krebsinformationsdienst guide	Step-by-step guide to return to work, information on legal protection (for professionals).	Specific to cancer and return to work Help with the administrative process	Not specific to cognition
Corporate club - cancer and employment	France	INCA co-hosted by ANDRH,	e-cancer.fr	A group offering twice-yearly discussions to businesses on	Exchange of practices	Not specific to cognition

		Anact-Aract network		good practice in relation to cancer and work Manual published by the working groups.	Involvement of companies in the return-to-work process and support	
Cancer & employment" charter	France	CNIB and French companies	The charter of 11 commitments and its signatories - Cancer and employment (e-cancer.fr)	Charter including 11 commitments to improve support for employees with cancer and promote health. It offers principles and actions to help patients with cancer stay at work and return to work.	Many companies involved (about 60)	Not specific to cognition
Cancer@work and wecare@work	France	Association	canceratwork wecareatwork	Involves business leaders Creates content, such as economic impact studies Measures the expectations of patients and business leaders	Awareness and support for companies	No specific support for employees
Business and cancer	France	Association	https://www.entreprise-cancer.fr/	Information and awareness-raising actions with companies	Site dedicated to employment and cancer Provides expertise in research and information resources	Specific to cancer and not linked to other areas No visibility on concrete actions with patients No visibility on the support tools in companies

					Articulation between the work world and health professionals Institutional and community recognition	
Cancer league	France	Patient association	https://www.ligue-cancer.net/retour-lemploi	Action programs to raise awareness in companies through conferences, serious games, etc.	Financially supported Raising awareness among companies	
PATIENTS						
Life and cancer	Belgium	Entrepreneur - former patient	https://vieetcancer.be/coaching	Intervention in coaching individuals A session lasts approximately 60 to 90 minutes. On average, between 3 and 10 sessions. The session costs 60€/hour. Possible intervention in companies Content: Knowing how to identify problems / Finding various solutions by oneself / Changing one's way of	A rich site Patient initiative to enhance patient experience and peer support General information on cancer with specific information on cognitive impairments and some information	Coaching that is not financially accessible No framework for content Commercial approach

				seeing things and life / (Re)becoming an actor in one's life.	on the return to work with an offer of coaching	
Preparing, anticipating and supporting the return to work after cancer	France 2014	Curie Institute	www.Livret-retour-autravail.pdf	Patient booklet offering testimonials and return to work tips (memory and concentration difficulties are mentioned as side effects of treatment affecting return to work).	Easy to access Cognitive impairments mentioned Specific to cancer and return to work	No mention of specific management of cognitive impairments
"Going back to work after cancer: what I need to know"	France	Cancer and Medical Imaging Centre	*https://crtt.net/*	Information on the return-to-work procedure agreed upon by the worker, the employer and the health professionals.	Specific to cancer and return to work	Not specific to cognition

Table 15. Supports for returning to work after cancer (non-cognition specific)

ORGANISATION	COUNTRY	CATEGORY	RESOURCES	CONTENT
Cancer league	France (departmental level)	Patient association	ligue-cancer.net/retour-lemploi	Individual coaching (up to 7 sessions of about 2 hours) Working group to help work on job search, confidence building, etc.
Oscarhealth	France (regional level)	Hospitals and regional health agencies	oscarsante	Multidisciplinary consultation supervised by doctors and a psychologist to help people return to work after cancer Promote the process of returning to work as soon as possible for patients with cancer Provide objective knowledge on the determinants of success or failure of retention or reorientation Medical, psychological and social assessment
Rehabilitation program	Denmark	Public authority - Municipalities	Rehabilitation program.	Municipalities offer interventions in the employment sector (few details)
Rehabilitation program	Sweden	Rehabilitation Center	National Cancer Rehabilitation Programme Rehabilitation center	According to the National Cancer Rehabilitation Program, rehabilitation centers offer return-to-work assistance (few details).
National cancer plan - cancer counseling center	Germany	Cancer Counselling Centre	Psychoonkologische Versorgung	Proposed psychosocial counselling providing support for work-related issues.

Table 16. Information about cognitive impairment and return to work after cancer

RESOURCES	COUNTRY	SOURCE	INTERNET LINK	CONTENT	BENEFITS	BRAKES
Preparing your return At work after a Cancer treatment	Canada	University Health Network (UHN)	www.uhn.ca	A comprehensive return to work guide with extensive information on the disorders that can be encountered	One of the few guides found that mentions cognitive impairments as a side effect and refers to a specific information guide and information group	No mention of specific treatment options for cognitive disorders
Cognitive impairments - cancer and work	Canada	McGill University	www.cancerandwork.ca *www.cancerandwork.ca*	Website providing resources for cancer patients to stay at work or return to work and strategies for dealing with cognitive impairments.	Specific on cancer, work and cognition - targets specific information according to the interlocutors (patient - employer - health professional) Chatbot to guide on the site Many practical tools (task analysis sheet - job analysis - monitoring tool - evaluation...	Only dedicated to employment with no link to other aspects of the course
Pathways to success	Canada	Pediatric Oncology Group of Ontario - 2012	*https://www.pogo.ca/wp-content/uploads/2014/10/SAVTI-WEB-BOOKLET-Eng.pdf*	The guide is for young adults with cognitive impairments, including childhood cancer or acquired brain injury, epilepsy, premature birth.	Specific to cognition - Practical with detailed recommendations Provides recommendations for implementation according to the type of cognitive impairments, with an emphasis on the work implications for each. Considers the issue of employment integration and school-to-work transition Original work based on acquired cognitive disorders and extension to cancer disorders.	Childhood cancer for young adults - a technical guide for professionals

Table 17. Management of cognitive impairment to assist the return to work

ORGANISATION	COUNTRY	CATEROGY	RESOURCES	CONTENT	BENEFITS	BRAKES
AGEFIPH - Association de gestion du fonds pour l'insertion professionnelle des personnes handicapées	France	Institution - public authority	agefiph-Conciling work and cancer.	Suggest strategies to improve return to work (concentration and memory difficulties are mentioned as factors that can lead to work exclusion).	AGEFIPH seems to offer the financing and organisation of care for cognitive impairments in the context of cancer in the same way as for other disabilities. However, a difficulty linked to the definition of the conditions of care seems to remain	Information difficult to access no information about the effect on the return to work
CANCER LEAGUE	France	Patient association	See figures below	2 departmental committees (DC) offer group workshops to promote a return to employment by working on cognitive functions. e.g., CD 67 - Cognitive workshop for patients with a complaint, supervised by a psychologist specialized in neuropsychology and an occupational psychologist	Financially supported Accessible to patients with a complaint	Local offer Available only on site No information about the effect on the return to work
CENTRE BACLESSE	France, Caen, at the cancer centre	**Cancer Center**	NA	In group (5 patients) supervised by a psychologist specialized in neuropsychology 4 sessions of 2 hours per week Exercises designed for patients treated for cancer, based on the Schuurs and Green method.	Financially supported Based on scientific evidence Cognitive assessment before and after treatment Multimodal treatment	On site Short duration of care No information about the

				- education about cognitive impairment, understanding the problem, providing adjustment strategies - cognitive stimulation (HappyNeuron), carrying out exercises to develop compensatory techniques and stimulate deficient cognitive abilities - establishment of a psycho-social dynamic, exchange on daily problems The exercises are designed to train the following cognitive areas: Attention, episodic memory, working memory, executive functions, processing speed	Access to exercises also at home via the software	effect on the return to work
CANCER FOUNDATION (KANKER.NL)	Netherlands	**Association**	https://www.kanker.nl/trials/1118-i-worc--studie-meerdere-kankersoorten-muv-hersentumoren	i-WORC study (Internet-based WOrk-related cognitive Rehabilitation for Cancer survivors): an online cognitive rehabilitation program for cancer survivors, which aims to help patients better manage cognitive impairments at work. Patients also complete an online neuropsychological assessment (pre- and post-intervention) supervised by a therapist.	Cognitive assessment before and after treatment Available at home	No information about the effect on the return to work

Memory workshop project sheets from *"La Ligue contre le cancer":*

Project sheet n°8 **Bas-Rhin (67)**	
Name of the project:	**Workshop « Mnémosyne » (memory)**
Brief description	Cognitive disorders are a major obstacle to entering and returning to work after a cancer diagnosis. Indeed, these side effects of treatment, such as loss of attention, forgetfulness, failure to remember, or the inability to do several things at once, are invisible and lead to disabling and incapacitating situations. However, these consequences are little discussed during follow-up and hospital care, few devices are proposed to them, which leads people to feel totally isolated and helpless in front of these situations. This is why the Bas-Rhin Committee of "La Ligue contre le cancer" wishes to offer support in the form of "memory" workshops, the main objectives of which are to stimulate and work on the various memories through games and exercises, and to develop new strategies to get around these daily problems. This workshop is aimed at people of working age (between 18 and 65 years old), in the post-treatment phase (having completed the so-called "heavy" treatments), complaining of cognitive after-effects following the treatments. In concrete terms, there will be an assessment meeting followed by 11 hours of workshops at the rate of 1 session per month for 5 months and an individual follow-up meeting in the form of a neuropsychological assessment, if the participant so wishes. 12 participants per workshop session, i.e. 24 people accompanied per year.
Human resources	-a CD employee, Occupational Psychologist - a service provider, Neuropsychologist
Partners	None
Date of implementation	Beginning 2021
Monitoring and evaluation method	Monitoring tools: Actilig Attendance sheet Evaluation tools: On-the-spot satisfaction questionnaire: paper and pencil questionnaire, Individual interview: 3 to 6 months feedback on the long-term effects of this workshop cycle Neuropsychological assessment: carried out after the workshops by the neuropsychologist.
Total estimated cost	6 585 €

Project sheet n°4 Loire (42)	
Name of the project:	**Cognition workshop for cancer patients**
Brief description	The Loire committee wishes to set up collective workshops to act on cognitive problems (problems of memory, attention, concentration and reflection) of non-retired cancer patients through targeted exercises. The objectives of these group workshops are to reduce the impact of cancer and its treatment on quality of life, to increase self-confidence and to facilitate the return to work. An oncologist and a neuropsychology firm, expert in cognitive disorders in adults and children, are associated with this project. This experimental project is part of a return-to-work program involving various partners and professionals. It will concern 32 people, i.e., 4 groups of beneficiaries over the year 2021.
Human resources	Neuropsychologists, oncologists, volunteers dedicated to league space, committee management, and elected to the board of directors.
Partners	Operational partners: Oncologists from the Lucien Neuwirth Cancer Institute Financial partners: None because the project is experimental
Date of implementation	Experimentation during 2021
Monitoring and evaluation method	Monitoring and reporting tools: Identification of patients by oncologists, monitoring of registrations, monitoring of the number of participants (attendance), satisfaction feedback, 2 questionnaires for the evaluation of cognitive disorders developed by neuropsychologists filled out at the start of the workshops and at the end of the program, evaluation and recommendations between each group. Steering: Creation of a steering committee for the experimentation
Total estimated cost	5 700 €

Annex 3 – Synthesis of the scientific literature

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Legends of the tables:

- Questionnaires:

AFI: Attentional Function Index
BADL: basic activities of daily living
CFQ: Cognitive Failure Questionnaire
EORTC: European Organization for Research and Treatment of Cancer
FACT-COG: Functional Assessment of Cancer Therapy-Cognitive Function
IADL: instrumental activities of daily living
PAOFI: Patients Assessment of Own Functioning Inventory
PROMIS: Patient-Reported Outcomes Measurement Information System

- Neuropsychological tests:

AVLT: Auditory verbal learning test
BAPM: Brief Assessment of Prospective Memory
BVMT: Tip: Brief Visuospatial Memory Test
CDT: Clock Drawing Test
COWA: Controlled Oral Word Association
CVLT: California verbal learning test
HVLT: Hopkins verbal learning test
JLOT: Judgment of Line Orientation Test
MMSE: Mini Mental State Examination
PASAT: Paced Auditory Serial Addition Test
RBANS: Repeatable Battery for the Assessment of Neuropsychological Status
SDMT: Symbol Digit Modalities Test
TMT: Trail Making Test
UFOV: Useful Field of View
VFT: Verbal Fluency Test

- Interventions:

MAAT: Memory and Attention Adaptation Training
MBSR: Mindfulness-based stress reduction
ReCog: Responding to Cognitive Concerns

Table 18. Studies using only cognitive training program (chronological order, pilot studies last)

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL (ACCORDING TO HAS SCALE)
VON AH ET AL, (VON AH ET AL., 2012)2012 **USA**	RCT Pre-intervention Post-intervention 2-month follow-up	Breast cancer survivors Memory training group n=29 Speed of processing group n= 30 Wait-list control group n=29	Cognitive training Memory training: adapted from the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) trial Speed of processing computerized training: Insight program (Posit Science®)	6-8 weeks 10 sessions 1h / session	Supervised On-site In group	No major cognitive disorder (exclusion: MMSE<24) *Paid to participate*	Anxiety Depression Fatigue QoL	Subjective: FACT-COG Objective: AVLT; Rivermead Behavioural Paragraph Recall Test and UFOV (speed of processing)	Improvement of cognitive complaints, memory and speed of processing performance	2
KESLER ET AL (2013) (KESLER ET AL., 2013)	RCT - feasibility study	Breast cancer survivors	Cognitive training Online computerizing	12 weeks 48 sessions	Not supervised Home-based Individual	NR in inclusion requirements	Depression, anxiety and cognitive fatigue (CAD)	Subjective: Global executive composite score (BREF)	Improvement of self-rating executive skills. Improvement	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL (ACCORDING TO HAS SCALE)
USA	Pre-intervention Post-intervention	Intervention group n=21 Wait-list control groupn=20	training program (Lumosity®)	20-30 min / session				Objective: WCST (flexibility) Letter fluency test (Delis_Kaplan EF system) HVLT-R Digit span, Symbol (WAIS-IV).	in cognitive flexibility, verbal fluency and processing speed.	
DAMHOLDT ET AL (2016) (DAMHOLDT ET AL., 2016) **DENMARK**	RCT Pre-intervention Post-intervention 5-month follow-up	Breast cancer survivors Intervention group n=94 Wait-list control group n=63	Cognitive training Online computerising training program (HappyNeuron®, phone support)	6 weeks 5days / week 30min/session	Supervised (phone + mails) Home-based Individual	Yes CFQ (cognitive failure questionnaire) ≥27	Depression, somatization, Anxiety	Subjective: NA Objective: PASAT, RAVLT, Digit spans (forward & backward), letter fluency test, cognitive estimation task	Improvement for verbal learning and working memory, effects observed at 5-month follow-up	1
BRAY ET AL, 2017 (BRAY ET AL., 2017) **AUSTRALIA**	RCT Pre-intervention	Cancer survivors Intervention group n=121	Cognitive training Online computerising	15 weeks (total of 40 hours) 4 sessions/week	Not supervised Home-based Individual	Yes Concentration/memory item of the EORTC QLQ C30 (rated as "quite a bit" or more)	Anxiety Depression Fatigue QoL Stress	Subjective: FACT-COG Objective: Cog-State	Improvement of cognitive complaints but not objective performances	1

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL (ACCORDING TO HAS SCALE)
	Post-intervention 6-month follow-up	Control group (standard care) n=121	training program (brain HQ)	40 min/ session					in the intervention group	
DOS SANTOS ET AL, 2020 (DOS SANTOS ET AL., 2020) **FRANCE**	RCT Pre-intervention Post-intervention	Cancer patients Intervention group A: N=55 Control group B: N=56 Control group C: N=56	Cognitive training Online computerizing training program (Rehacom®) for the intervention group	Group A: 3 months 9 sessions 45-60 min / session Group B: cognitive exercises at home (booklet, 9 sessions of 30-60 min, over 3 months) Group C: phone call (9 over 3 months)	Supervised On site (group A) Individual	Yes FACT-Cog (inclusion, QoL score ≥4)	Anxiety Depression Fatigue QoL	Subjective: FACT-COG Objective: Grober and Buschke, d2, Verbal fluency test, TMT, digit span WAIS IV	Improvement of cognitive complaints and working memory	1
PILOT STUDIES										

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL (ACCORDING TO HAS SCALE)
BECKER ET AL, 2017 (BECKER ET AL., 2017) **USA**	Pilot study Pre-intervention Post-intervention (1-2 weeks)	Breast cancer survivors n=20	Cognitive training Online computerizing training program (BrainHQ®)	6 weeks Home-based: 3-4 sessions / week 45 min / session On site: 6 sessions 90 min / session	Supervised (only on site) On site + home-based Group + individual	Yes Self-report of at least five problems "sometimes" or more often on the Perceived Deficits Questionnaire	QoL Sleep Fatigue Emotional distress	Subjective: PROMIS; MMQ Objective: CVLT; COWAT; SDMT	Not significant cognitive improvement	4
MENESES ET AL (2018) (MENESES ET AL., 2018) **USA**	Pilot RCT Pre-intervention Post-intervention 6-month follow-up	Breast cancer survivors Intervention group n=29 Control group n=28	Cognitive training Speed of processing computerized training (BrainHQ®)	6-8 weeks Total 10 hours 2h / week	Supervised Home-based Individual	Yes (NR)	NR	Objective: UFOV (speed of processing), NIHTB-CB (multidimensional cognition battery)	Improvement in objective measures of speed of processing and executive function	4
WU ET AL, 2018 (WU ET AL., 2018) **USA**	Pilot study Pre-intervention	Prostate cancer patients Intervention group n=40	Cognitive training Online computerising training program (BrainHQ)	8 weeks 5 sessions / week 1h / session	Supervised Home-based Individual	Yes Score of ≥1 SD below the normative mean on any CNS Vital Signs subtest, score of ≥8 on	Comorbidities	Subjective: PAOFI + Neurobehavioral functioning (FrSBe) Objective: CNS Vital Signs	Improvement of reaction time in the intervention group	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL (ACCORDING TO HAS SCALE)
	Post-intervention 8-weeks follow-up	Wait-list control group n=20				the Patient Assessment of Own Functioning Inventory, a T-score ≥60 on any Frontal Systems Behavior Scale subscale				
BELLENS ET AL. 2020 (BELLENS ET AL., 2020) **BELGIUM**	Pilot RCT Pre-intervention Cognitive assessment every 4 weeks For other measures: after 3 and 6 months	Breast cancer survivors Intervention group n=23 Waitlist control group n=23	Cognitive training Video-game (Aquasnap®)	6 months 3 sessions / week 1 hour / session	Supervised Home-based Individual	Yes (screening interview)	Anxiety Depression Sleep	Subjective: Cognitive Failure Questionnaire (+ Beck Cognitive insight Scale) Objective: MyCQ (online cognitive tests)	Improvement of cognitive complaints but not cognitive performances	4

Table 19. Studies including psycho-education/therapy intervention (chronological order, pilot studies last)

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
BERNSTEIN ET AL, 2018 (BERNSTEIN ET AL., 2018) **CANADA**	Prospective study Pre-intervention Post-intervention 6-week follow-up	Breast cancer survivors n=100	Psycho-education Knowledge, confidence, and techniques thought to promote self-management of cognitive disorders	1 session 1h	Supervised by a psychologist specialized in neuropsychology specialized in psychosocial oncology On site Face to face	Yes (NR)	Knowledge, attitudes, and behaviors related to cognitive disorders (no-valid questions)	Subjective: Contentment subscale of the Multifactorial Memory Questionnaire Not validated questions Objective: NA	Improvement of memory complaints	4
PILOT STUDIES										
NEWMAN ET AL, 2019 (NEWMAN ET AL., 2019) **USA**	Pilot study Pre-intervention Post-intervention 3-month follow-up	Breast cancer survivors N=11 (follow-up n=6)	Occupational-therapy Occupation-focused self-management program (take action program)	6 weeks 1 session / week 1h30 / session	NR On site In group + individual (1st and last sessions)	Yes "Have you experienced any issues with memory, attention, concentration or performing activities of your daily life after you received breast cancer	QoL	Subjective: FACT-COG Objective: NA	Improvement of cognitive complaint	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
						treatment? (response yes as inclusion criteria)				
DING ET AL, 2020 (DING ET AL., 2020) **CHINA**	Pilot RCT Pre-intervention Post-intervention (1month) 6-month follow-up	Breast cancer survivors Intervention group n=34 Control group n=40	Psycho-therapy Individual psychotherapy session managing Cancer and Living Meaningfully (CALM)	3 - 6 months 1 session / month 30 min / session	Supervised (trained therapist) On site Individual	Yes, MMSE	QoL Distress symptoms Improvement after intervention	Subjective: FACT-COG, RM and PM questionnaires Objective: MMSE	Improvement of cognitive complaints and performances in the intervention group.	4

Table 20. Studies with physical activity intervention (chronological order, pilot studies last)

PUBLICATION	*STUDY DESIGN & ASSESSMENT*	*PARTICIPANTS*	*TYPE OF INTERVENTION*	*INTERVENTION*	*SUPERVISION*	*COGNITIVE COMPLAINTS BEFORE INTERVENTION*	*FACTORS ASSOCIATED EVALUATED*	*COGNITIVE EVALUATION*	*CONCLUSION*	*PROOF LEVEL*
OH ET AL, 2012 (OH ET AL., 2012) **AUSTRALIA**	RCT Pre-intervention Post intervention	Cancer survivors Intervention group n=37 Control group n=44	Physical Activity Medical Qigong to control emotions and stress as well as to improve physical function	10 weeks 1 (or 2) / week 1h30 / session	Supervised (Medical Quigong instructor) On site (home-based available with a diary) Group	NR	QoL Improvement after intervention	Subjective: EORTC (Cognitive function) + FACT-COG Objective: NA	Improvement of cognitive complaints in the intervention group	2
DERRY ET AL (2015) (DERRY ET AL., 2015) **USA**	RCT Pre-intervention Post-intervention 3-month follow-up	Breast cancer survivors Intervention group n=100 Waitlist control group n=100	Physical activity Yoga Outlined poses	12 weeks 2 sessions / week 90 min / session	Supervised On site In group	NR in inclusion requirements	Depression Anxiety Vitality Sleep	Subjective: BCPT (cognitive problems) Objective: NA	Improvement of cognitive complaints after 3 months follow-up (but not immediately)	4 Secondary analysis

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
JANELSINS ET AL (2016) (JANELSINS ET AL., 2016) **USA**	RCT Pre-intervention Post-intervention	Cancer survivors Intervention group n= 168 Control group n=168	Physical activity Combining Hatha and Restorative yoga	8 sessions 2 sessions / week 75 min / session	Supervised On-site In group	NR in inclusion requirements	Pittsburgh sleep quality index (PSQI)	Subjective: MDASI (MD Anderson symptom inventory)	Intervention reduced perceived memory difficulty . Changes in sleep quality was a mediator of reduced memory difficulty.	4 Secondary analysis
LARKEY ET AL (2016) (LARKEY ET AL., 2016) **USA**	RCT Pre-intervention Post-intervention 12-week follow-up	Breast cancer survivors Intervention group n=42 Control group n=45	Qigong/Tai Chi easy Control group: similar to the experimental but without focus on breathing and meditative state	12 weeks 14 sessions 1hr / session during 12 + home-based: 60 sessions 30 min / session	Supervised On site + home-based In group + individual	NR	QoL Physical and mental health Physical activity	Subjective: FACT-COG Objective: Digit span, Letter-Number sequencing (WAIS-IV)	Objective cognition: change across time but no difference between the two groups.	4 Cognition secondary outcome
GALIANO-CASTILLO ET AL (2017)	RCT Pre-intervention	Breast cancer survivors	Physical activity	24 sessions 3 sessions / week	Supervised Home-based Individual	NR in inclusion requirements	QoL	Subjective: EORTC QLQ-C30	Improvement of cognitive functioning	2

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
(GALIANO-CASTILLO ET AL., 2017) **SPAIN**	Post-intervention (8-week) 6-month follow-up	Intervention group n=39 Control group n=37	Internet-based sessions: e-CUIDATE including warm-up main resistance, aerobic exercise training & cool-down	90 min / session				cognitive function Objective: auditory consonant trigram (short-term memory, attention TMT	with effects being maintained over the 6-mont follow-up period	
CAMPBELL ET AL, 2018 (CAMPBELL ET AL., 2018) **CANADA**	RCT Pre-intervention Post-intervention	Breast cancer Intervention group n=10 Waitlist control group n=9	Physical activity Aerobic exercise	24 weeks 4 sessions / week 2h30 / week	Supervised On site (research gym) + home-based Individualized	Yes "Do you have trouble with your short-term memory, such as if someone tells you something in the morning, do you have trouble remembering that later in the day (if you have not written it down)? "Do you have difficulty concentrating	Fatigue Depression Anxiety No improvement after intervention	Subjective: FACT-COG Objective: HVLT-revised + TMT + COWA + animal naming	No improvement of cognitive complains Improvement of processing speed	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
						when you read or are trying to do paper work?" "Do you have trouble finishing a conversation or an article in the newspaper?" "Do you tend to start things without completing them?" "Do you have trouble thinking through problems or planning, such as errands you have to do today?"				

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
HARTMAN ET AL, 2018 (HARTMAN ET AL., 2018) **USA**	RCT Pre-intervention Post intervention	Breast cancer survivors Intervention group n=43 Waitlist control group n=44	Physical activity	12 weeks 2h30 / week	Supervised by a clinical psychologist + Fitbit One activity device Home-based Individualised	Yes (interview, reporting "e experiencing "fogginess" or worsening of their memory, thinking, or Concentration")	NA	Subjective: PROMIS Objective: "NIH toolbox (Fluid Cognition Composite score and a Crystallized, Oral Symbol Digit and Auditory Verbal Learning) Cognition Composite score	Improvement of processing speed, but no improvement of cognitive complaints in the intervention group	2
PILOT STUDIES										
MIKI ET AL. 2014) (MIKI ET AL., 2014) **JAPAN**	Pilot RCT Pre-intervention Post-intervention (4 weeks)	Breast and prostate cancers survivors	Physical activity Speed feedback therapy with a	4 weeks 1 session / week 5 min / session	Supervised On site Individual	NR	IADL & Barthel index (activity of daily living), Well-being	Subjective: NA Objective: FAB (frontal assessment battery)	Small but significant improvement of the FAB score	No hypothesis

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
		Intervention group n=38 Control group n=40	bicycle ergometer							
MYERS ET AL (2019) (MYERS ET AL., 2019) **USA**	Pilot RCT Pre-intervention Post-intervention (no neuropsychological tests) 4-week follow-up	Breast cancer survivors Intervention group n=19 Control group (gentle exercise) n=20 Control group (support group) n=11	Qigong	8 weeks 1 session / week 1 hr / on-site session + 15 min home-based sessions 2 / day	Supervised On-site +home-based In group + individual	Yes. A score <59 in the perceived cognition impairment subscale of the FACT-COG was required	QoL Fatigue Sleep Distress	Subjective: FACT-COG, PROMISAbl, PROMISCog Objective: verbal fluency, TMT, RAVLT (Rey auditory verbal learning test)	Improvement for processing speed (TMT-A), verbal fluency and distress.	4

Table 21. Studies using cognitive rehabilitation, i.e., including a cognitive training in addition with other interventions (chronological order, pilot studies last)

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
CHERRIER ET AL, 2013 (CHERRIER ET AL., 2013) **USA**	RCT Pre-intervention Post-intervention	Cancer survivors Intervention group n=12 Wait-list control group n=16	Psycho-education + mindfulness Workshop session by group on memory and attention techniques + one session of mindfulness	7 weeks 1 session / week 1h / week	Supervised On-site In group	"do you have concerns about your memory or other thinking abilities following cancer treatment? (Inclusion: response=yes; exclusion: MMSE<26)	Anxiety Depression Fatigue Not improved after intervention	Subjective: FACT-COG Objective: Digit + Symbol span (WAIS) + Stroop + RAVLT	Improvement of cognitive complaints, memory and attention in the group with intervention	2
ERCOLI ET AL, 2015 (L. M. ERCOLI ET AL., 2015)*** (ERCOLI ET AL, 2013)** **USA**	RCT Pre-intervention Post-intervention 2-month follow-up	Breast cancer survivors Intervention group n=32 Wait-list control group n=16	Psycho-education + cognitive training Education, technique instruction for attention, executive and memory function in-class and homework	5 weeks 1 / week 2h / week + 20 min home-based (at least once)	Supervised On-site + home-based In group + individual	Yes '"Do you think or feel that your memory or mental ability has gotten worse since you completed your breast cancer treatment?', 'Do you think that your mind isn't as sharp	Depression	Subjective: PAOFI Objective: BVMT-revised + RAVLT + verbal fluency +PASAT + TMT + computerized CNS Vital Signs	Improvement of cognitive complaints and performances in the intervention group	2

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
			exercises and goal setting			now as it was before your breast cancer treatments?' and Do you feel like these problems have made it harder to function on your job or take care of things around the home?' PAOFI (inclusion)				
GREEN ET AL, 2018(GREEN ET AL., 2018) * (Mihuta et al, 2017) **AUSTRALIA**	RCT; Pre-intervention Post-intervention 3-month follow-up	Cancer patients Intervention group n=40 Waitlist control group n=36	Psycho-education + cognitive training Online computerizing training program (eRECog program) of four modules (skills training for memory and attention, relaxation, tips for sleep hygiene, and homework tasks to	4 weeks 1 session / week 30-60 minutes sessions/week	Supervised Home-based Individual	Yes Concentration/memory item of the EORTC QLQ C30 (rated as "a little" or more)	Anxiety Depression Fatigue	Subjective: FACT-Cog + BADL, EORTC QLQ-C30, IADL Objective: WebNeuro + BAPM	Improvement of cognitive complaints but not performances in the intervention group	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
			reinforce new learning)							
ASHER ET AL., 2019(ASHER ET AL., 2019) *(Liang et al., 2019 + Myers et al., 2020) **USA**	Case series Retrospective pre-intervention post-intervention 3/6/12 months follow-up	Cancer survivors n=110 (20 groups)	Psycho-education + mindfulness + CBT Multidimensional, psychoeducation-based program (Emerging From the Haze) Mindfulness and stress management + CBT for mood symptoms + memory, attention, problem-solving strategies + lifestyle education	6 weeks 1 session / week 2h30 / session	Supervised by psychologist specialized in neuropsychology and cancer rehabilitation physician On site + homeworks Group	Yes (NR)	QoL	Subjective: FACT-COG Objective: NA	Improvement of cognitive complaints	4
PILOT STUDIES										
ERCOLI ET AL, 2013 (LINDA M.	Pilot study	Breast cancer survivors n=27	Psycho-education + cognitive training	5 weeks 1 / week	Supervised On-site + home-based	Yes "Do you think or feel that your memory or mental ability	Depression Anxiety	Subjective: PAOFI	Improvement of cognitive complaints	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
ERCOLI ET AL., 2013)* (Ercoli et al, 2015) **USA**	Pre-intervention Post-intervention (1month) 2/4-month follow-up		Education, technique instruction for attention, executive and memory function in-class and homework exercises and goal setting	2h / week + 20 min home-based (at least once)	In group + individual	has gotten worse since you completed your breast cancer treatment?" "Do you think that your mind isn't as sharp now as it was before your breast cancer treatments?" and "Do you feel like these problems have made it harder to function on your job or take care of things around the home?" (inclusion: yes 3 questions)		Objective: CNS Vital Signs Computerized + HVLT + BVMT +TMT + PASAT + JLOT	and performances.	
SCHUURS ET AL, 2013 (SCHUURS & GREEN, 2013) **AUSTRALIA**	Pilot study pre-intervention post-intervention 3-month follow-up	Cancer survivors Intervention group n=23 Control group (waitlist) n=9 Control group (healthy controls) n=23	Psycho-education + cognitive training (ReCog program) 4 topics of psychoeducation + skills application:	4 weeks 1 session / week 2h / session	Supervised On site + home-based In group + individual	NR (no inclusion criteria)	QoL Psychological distress Illness perception	Subjective; FACT-COG + MASQ Objective: RBANS + TMT	Improvement of cognitive complaints, visuospatial constructional and memory performances	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
			aging, health, cancer, and cognitive function; (2) memory; (3) attention; and (4) fatigue, emotions, and cognition							
KING & GREEN (2015) (KING & GREEN, 2015) **AUSTRALIA**	RCT Pre-intervention Post-intervention 3-month follow-up	Cancer survivors Intervention group n=16 Waitlist control group n=13 Community comparison N=16	Psycho-education + cognitive training (ReCog program) 4 topics of psychoeducation + skills application: aging, health, cancer, and cognitive function; (2) memory; (3) attention; and (4) fatigue, emotions, and cognition	4 weeks 1 session / week 2h / session cognitive rehabilitation for adults recovering from cancer + homework between sessions	Supervised On site + home-based In group + individual	Yes, inclusion criteria: EORTC>100	QoL Psychological distress self-efficacy	Subjective: FACT-COG, BAPM (Brief assessment of prospective memory) Objective: RBANS (Reputable battery for assessment of neuropsychological status), TMT	Intervention was associated with better performance for one task assessing processing speed and visual scanning + evidences for the roles of cognitive self-efficacy and illness perception	4
MIHUTA ET AL., 2017 (M.	Pilot RCT	Cancer survivors	Psycho-education + cognitive training	4-weeks	Supervised Home-based	Yes (NR)	Depression Anxiety	Subjective: FACT-Cog	High participant	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
E. MIHUTA ET AL., 2018)* (Mihuta et al, 2018) **AUSTRALIA**	Pre-intervention Post-intervention 3-month follow-up	Cancer intervention group: n=13 Non-cancer intervention group: n=21 Non cancer wait-list: n=17	Online computerizing training program (eRECog program) of four modules (skills training for memory and attention, relaxation, tips for sleep hygiene, and homework tasks to reinforce new learning)	1 session / week 2-hour / session	Individual		No improvement after intervention	Objective: WebNeuro online cognitive battery	satisfaction and some improvements in subjective and objective cognitive functioning	
LIANG ET AL., 2019(LIANG ET AL., 2019) *(Asher et al., 2019 + Myers et al., 2020) **USA**	Pilot prospective and retrospective study pre-intervention post-intervention	Gynecologic cancer survivors Retrospective group n=12 Prospective group n=10	Psycho-education + mindfulness + CBT Multidimensional, psychoeducation-based program (Emerging From the Haze) Mindfulness and stress management + CBT for mood symptoms +	6 weeks 1 session / week 2h30 / session	Supervised by psychologist specialized in neuropsychology and cancer rehabilitation physician On site + homeworks Group	Yes (NR)	Anxiety Depression Fatigue Sleep Bread Physical function Loneliness	Subjective: FACT-COG + PROMIS Objective: NA	Improvement of cognitive complaints	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION PLACE GROUP/INDIVIDUAL	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
			memory, attention, problem-solving strategies + lifestyle education							
MYERS ET AL., 2020(MYERS ET AL., 2020) ***(ASHER ET AL., 2019 + LIANG ET AL., 2019)** **USA**	Pilot study pre-intervention post-intervention 1/6/12-month follow-up	Breast cancer survivors Intervention group: n=27 Control group (waitlist) n=28	Psycho-education + mindfulness + CBT Multidimensional, psychoeducation-based program (Emerging From the Haze) Mindfulness and stress management + CBT for mood symptoms + memory, attention, problem-solving strategies + lifestyle education	6 weeks 1 session / week 2h30 / session	Supervised by psychologist specialized in neuropsychology and cancer rehabilitation physician On site + homeworks Group	Yes, FACT-Cog	QoL (improvement after intervention)	Subjective: FACT-COG Objective: NA	Improvement of cognitive complaints in the intervention group	4

Table 22. Studies with different type of interventions (chronological order, pilot studies last)

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
FERGUSON ET AL, 2012 (FERGUSON ET AL., 2012) **USA**	RCT Pre-intervention Post-intervention 2-month follow-up	Breast cancer survivors Intervention group n=19 Waitlist control group n=21	Cognitive behavioural therapy Memory and Attention Adaptation Training (MAAT) The 4 MAAT components include: 1) education concerning CRCD; 2) self-awareness training to identify "at-risk" situations in which cognitive failures may occur; 3) stress management and self-regulation; 4)	8 weeks 2 sessions / week 30 - 50 min /session	Supervised On-site Individual	Yes, 'do you have problems with memory and attention since having chemotherapy, and do you believe chemotherapy contributed to the problems?'	QoL Anxiety Depression Spiritual well-being (QoL and spiritual well-being improvement)	Subjective: MASQ Objective: CVLT-II, TMT-B, CWI, Color-Word and Switching Trials (D-KFES), e Digit Symbol-Coding Subtest (WAIS-III)	Improvement on verbal memory performance but not of cognitive complaints	2

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
			cognitive compensator and strategies training							
GOEDENDORP ET AL (2014) (GOEDENDORP ET AL., 2014) **NETHERLANDS**	RCT Pre-intervention 6-month follow-up	Severely fatigued cancer survivors Intervention group n=50 Waitlist control group n=48	Cognitive behavioural therapy for fatigue	5-26 sessions 1 hr / session	Supervised On site Individualized	NR in inclusion requirements	Fatigue Depression Anxiety	Subjective: CIS-Concentration SIP-Alertness behaviour Objective: Reaction time (2 computerize tasks) Symbol digit modalities test (WAIS-IV)	Decrease of reported cognitive disability and clinically relevant reduction in concentration problem. Objective: no significant difference	1 or 2

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
FERGUSON ET AL, 2016 (FERGUSON ET AL., 2016) **USA**	RCT Pre-intervention Post-intervention 2-month follow-up	Breast cancer survivors Intervention group n=27 Control group (supportive therapy) n=20	Cognitive behavioural therapy The 4 MAAT components include: 1) education concerning CRCD; 2) self-awareness training to identify "at-risk" situations in which cognitive failures may occur; 3) stress management and self-regulation; 4) cognitive compensator and strategies training	8 weeks 1 session / week 30 - 45 min /session	Supervised On site, videoconference Individual	Yes (FACT-Cog QoL ≤10, inclusion criteria)	QoL Fatigue Anxiety Depression Improvement after intervention	Subjective: FACT-COG Objective: "Telephone-Based Assessment of Neuropsychological Status, Symbol Digit Modalities Test, CVLT-II,"	Improvement of cognitive complaints and processing speed in the intervention group	2

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
REICH ET AL (2017) (REICH ET AL., 2017) **USA**	RCT Pre-intervention Post-intervention (6 weeks) 12-week follow-up	Breast cancer survivors Intervention group n=167 Control group (usual care) n=155	MBSR 1) educational material for relaxation, meditation, etc. 2) practice of meditation in group meetings and homework assignments, 3) group processes and supportive group	6 weeks 2-hour / week +15-45 min of meditative practice per day	Supervised (trained psychologists) On site + home-based In group + individual	NR in inclusion requirements	Concerns about recurrence scale, Depression Anxiety Stress Sleep Fatigue Bread QoL	Subjective: ECog	No improvement of cognitive complaints	4
LIOU ET AL, 2020 (LIOU ET AL., 2020) **USA**	RClinicalT Pre-intervention Post-intervention 12-week follow-up	Cancer survivors Acupuncture n=52 CBT-insomnia n=47	Acupuncture Cognitive behavioural therapy for insomnia	8 weeks 7CBT-I sessions 10 acupuncture sessions	Supervised On-site Individual	NA Primary outcome: insomnia Insomnia disorder (62% with cognitive complaints at baseline)	Sleep NR	Subjective: Brown Attention-Deficit Disorder Scales+ insomnia Objective: Buschke Selective Reminding Test	Improvement of cognitive complaints and memory performances in both groups.	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
TONG ET AL, 2018 (TONG ET AL., 2018) **CHINA**	RCT Pre-intervention Post-intervention	Breast cancer survivors Intervention group n=40 Control group n=40	Acupuncture	8 weeks 30min / session	Supervised On-site Individual	Yes (memory complaints confirmed by family member)	Depression Anxiety NA	Subjective: FACT-COG Objective: AVLT + VFT + SDMT + CDT + TMT	Improvement of cognitive complaints and memory performances in the intervention group.	4
PILOT STUDIES										
MILBURY ET AL (2013) (MILBURY ET AL., 2013) **USA**	Pilot RCT Pre-intervention Post-intervention 1-month follow-up	Breast cancer survivors Intervention group n=23 Waitlist control group n=24	Meditation Tibetan sound meditation sessions	6 weeks 2 sessions / week 1 hr / session	Supervised On-site In group	Yes, cognitive complaint assessed with the FACT-COG since the initiation of chemotherapy	QoL Depression Sleep Fatigue Spiritual well-being	Subjective: FACT-COG Objective: digit span test, digit symbol test, (WAIS-III), Controlled oral word association test (verbal fluency), RAVLT (verbal memory)	Improvement in the intervention group on verbal memory, short-term memory and processing speed and improved reported	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
									cognitive function, cognitive abilities and mental health.	
JOHNS ET AL, 2016 (JOHNS ET AL., 2016) **USA**	Pilot RCT Pre-intervention Post-intervention 6-month follow-up	Breast and colorectal cancer survivors Intervention group n=35 Control group n=36	Meditation MBSR Control (fatigue education and support)	8 weeks 1 session / week 2h / session +20min home-based session	Supervised On site + home-based (audio) In group Control group: onsite + home-based reading	NA Primary outcome: Cancer related fatigue	Fatigue NR	Subjective: AFI Objective: Stroop	Improvement of cognitive complaints and performances in the intervention group	4 (cognition secondary o
HENNEGHAN ET AL, 2020 (HENNEGHAN ET AL., 2020)	Pilot RCT Pre-intervention	Breast cancer survivors Meditation group n=13	Meditation and music Kirtan Kriya meditation	8 weeks Every day 12min / session	Supervised Home-based	Yes (Perceived Deficits Questionnaire, at least 5 cognitive symptoms occurring sometimes or more)	Anxiety Depression Fatigue	Subjective: FACT-COG	Improvement of cognitive complaints, memory	4

PUBLICATION	STUDY DESIGN & ASSESSMENT	PARTICIPANTS	TYPE OF INTERVENTION	INTERVENTION	SUPERVISION	COGNITIVE COMPLAINTS BEFORE INTERVENTION	FACTORS ASSOCIATED EVALUATED	COGNITIVE EVALUATION	CONCLUSION	PROOF LEVEL
USA	Post-intervention	Music group n=14	Classical music listening		(video/audio) Individual			Objective: HVLT + COWA + verbal fluency + TMT	and fluency in both groups	
VAN DER GUCHT ET AL, 2020 (VAN DER GUCHT ET AL., 2020) **BELGIUM**	Pilot RCT Pre-intervention Post-intervention 3-month follow-up	Breast cancer survivors Intervention group n=12 Control group n=13	Mindfulness-based Guided experiential mindfulness exercises, sharing of experiences of these exercises, reflection in small groups, psychoeducation, and review of home practices.	8 weeks 4 sessions of 3 hr in-person group + online support	Supervised On site + home-based In group + individual (homeworks with online support / audio)	Yes CFQ	Anxiety/depression (exclusion) Fatigue	Subjective: CFQ Objective: (attention, memory, executive functions, psychomotor processing speed) + rs-fIRM	Improvement of cognitive complaints but not performances in the intervention group	4

Table 23. Clinical trials registered on ClinicalTrials

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
NCT04808674 Not yet recruiting (03222021)	Sophie Jacquin-Courtois Hospices civils de Lyon France	RCT Pre-intervention Post-intervention 16 weeks follow-up	Cognitive remediation program	Group-based cognitive remediation program One-on-one cognitive remediation program	Breast cancer survivors n=NA/24	On-site group intervention supervised (multidisciplinary team)	FACT-COG TAP, PASAT, MoCA, Symbol digit test. HADS, Brief symptom inventory, Rosenberg self-esteem scale, MCQ30, FACT-B; FACIT-F
NCT03949322 Unknown (05142019)	Florence Boiffard Western Cancer Institute France	Single group assignment Pre-intervention Post-intervention 8 weeks follow-up	Adapted physical activity program	Aerobic exercise session, Nordic walking, and a combined session of muscle building and breathing exercises	Any patient with cancer managed by adjuvant chemotherapy n=NA/26	NA	Stroop test, XO letters comparison test, MEMIII, MoCA Global physical activity questionnaire HADS, MFI
NCT04210778 Recruiting (03252021)	Yafit Gilboa Hadassah medical organization Israel	RCT Pre-intervention Post-intervention	Cognitive training	12 weeks computerized cognitive training & weekly one hour metacognitive strategy training	Cancer survivors n=NA/90	Home-based: remotely	Computerized cognitive assessment (Posit science) COPM (occupational), FACT-COG, FACT-GP, PHQ-9, RRS (rumination), GAD-7 (anxiety), NGSE (self-efficacy), PQRS

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
		6 months follow-up		12 weeks computerized cognitive training Control: no intervention			
NCT01296893 Completed (06072016)	Kristin Campbell University of British Columbia UK	RCT Pre-intervention Post-intervention 6 months follow-up	Exercise	150 minutes / week 24 weeks aerobic exercise Control: no intervention	Breast cancer survivors n=31/60	On-site intervention supervised & home-based	Stroop test, HVLT, TMT FACT-COG fMRI
NCT04104113 Recruiting (06162020)	Alexandre Chan National Cancer Centre Singapore	RCT Pre-intervention Post-intervention 8 weeks follow-up	Drug	Daily / 8 weeks modified Xiang bei yang rong tang (15 herbal components decoction) Control: placebo	Cancer survivors n=NA/80	On-site intervention	Global health status MFSI-SF (fatigue) FACT-COG Incidence of adverse events (CTCAE) EORTC QLQ-C30 (functional & symptom scale) Biological measures

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
NCT04669301 Recruiting (04132021)	Allison Magnuson University of Rochester USA	RCT Pre-intervention Post-intervention	Cognitive behavioural therapy	MAAT-G: series of manualized workshops supplemented by a participant workbook (adaptive behavioural coping skills, stress management techniques & compensation strategies) Control: unspecific intervention (supportive therapy)	Breast cancer survivors Older adults (≥65) n=NA/85	Home-based intervention	CANTAB (short-term visual memory), COWA (verbal fluency), HVLT-R FACT-COG GDS (depression), GAD-7 (anxiety) IADL
NCT04826315 Not yet recruiting (04012021)	Katherine Ramos, Duke University USA	Single group assignment Pre-intervention During intervention Post-intervention 10 weeks follow-up	Patient-caregiver behavioural intervention	COPE+: 6 x 1h sessions	Cancer survivors (breast, colon, rectal or lung cancer) Older adults (≥65) n=NA/80	Home-based intervention	Number of completed sessions Satisfaction DASS-21 (distress), FACT-G, CPQ-F (communication), MSFCI (relationship satisfaction)

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
NCT02661308 Recruiting (02102021)	Ali Amidi Aarhus University Hospital Denmark	RCT Pre-intervention Post-intervention: immediately Post-intervention: after 3 months	Light exposure therapy	30 minutes x 4 weeks systematic bright light exposure 30 minutes x 4 weeks systematic dim light exposure	Breast cancer survivors n=NA/72	On-site intervention	CPT-3, PVT (vigilance), HVLT-R FACIT, PQSI (sleep quality), BDI-II (depression), HADS, IES-R (impact of events), POAFI (functioning inventory) Biological measures
NCT03736460 Recruiting (04222020)	Katleen Van der Gucht KU Leuven Belgium	RCT Pre-intervention Post-intervention: after 1-3 weeks Post-intervention: after 3 months	Mindfulness	3h mindfulness group sessions spread over 8 weeks 2h physical training group sessions spread over 8 weeks Control: waitlist	Breast cancer survivors n=NA/120	On-site intervention	Neurocognitive assessment (tools: NA) CFQ (cognitive complaints) fMRI
NCT04817566 Not yet recruiting (03262021)	Agnes Flöel University Medicine Greifswald Germany	RCT Pre-intervention Post-intervention	Transcranial direct current stimulation	9 sessions x 20 minutes anodal tDCS & 9 sessions x 20 minutes cognitive training 9 sessions x 30 seconds sham tDCS & 9 sessions x 20	Breast cancer survivors n=NA/40	On-site intervention	Letter updating task (working memory), visuo-spatial performance (VR task) PROMIS (quality of life)

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
				minutes cognitive training			
NCT02970500 Recruiting (12182019)	Bruno Gagnon CHU Quebec-University Laval Canada	RCT Pre-intervention Post-intervention	Drug	1 capsule of methylphenidate HCl 10Mg SR daily x 14 days and then 2 capsules of methylphenidate HCl 10Mg SR daily x 14 days	Breast cancer survivors n=NA/40	NA	FACT-COG, MFI (fatigue), experience of CRCI (semi-structured interview)
				Control: placebo			
NCT00495703 Completed (04042017)	Charles E. Matthews Vanderbilt University Medical Center USA	RCT Pre-intervention Post-intervention 6 months follow-up	Exercise	6 months of regular aerobic exercise	Cancer survivors have received chemotherapy n=64/65	Home-based intervention	Randt memory test, TMT, Stroop test, T ask switching, response compatibility Psychological status (NA) Biological measures Physiological measures
				Usual care: 6 months of behavioural strategies to improve cognition			
NCT01873794 Completed (04112017)	William H. Redd	RCT Pre-intervention	Light exposure therapy	Daily 30 minutes 10 000 lux bright white light	Cancer survivors have received	NA	CNS-Vital signs (cognitive assessment battery) CFQ (cognitive complaints) FACIT-F, Pittsburgh sleep quality index, SF-36 (quality of life),

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
	Icahn School of Medicine at Mount Sinai USA	Post-intervention: 4 weeks Post-intervention: after 3 months		Daily 30 minutes 10 000 lux dim red light	hematopoietic stem cell transplant, chemotherapy of radiation for breast cancer n=54/75		Brief symptom inventory Physiological measures: Actiwatch spectrum (sleep/wake activity)
NCT04873661 Recruiting (07202021)	Olivia Gosseries University of Liège Belgium	Non-randomized Pre-intervention Post-intervention: immediately Post-intervention: after 3 months Post-intervention: after 12 months	Cognitive trance, hypnosis and meditation	8 weekly hypnosis sessions (2 hours each) in groups two-day cognitive trance workshop in groups 8 weekly meditation sessions (2h45 each) in groups Control group: no intervention	Cancer survivors n=NA/160	On-site intervention supervised & home-based	FACT-COG MFI-20 (fatigue), VAS (pain), ISI (insomnia), HADS, MAC (mental adjustment to cancer), CERQ (emotion regulation), empowerment (NA), BFI-10 (personality traits) Scales about reactions to hypnosis / trance / meditation EEG, Physiological measures
NCT04255225	Edward McAuley	RCT	Walking	10 minutes treadmill walking	Breast cancer survivors	NA	Cognitive battery including specifics tools for working memory, attention, flexibility, processing speed (NA)

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
Completed (02112020)	University of Illinois at Urbana-Champaign USA	Pre-intervention Post-intervention		20 minutes treadmill walking 30 minutes treadmill walking	n=50/50		HADS Lifestyle physical activity (accelerometer in units of average minutes per day) Physiological measures
NCT02786797 Completed (07282020)	NA University of South Florida USA	RCT Pre-intervention Post-intervention: after 6 weeks Post-intervention: after 12 weeks Post-intervention: after 6 months 6 months follow-up	Mindfulness	6 weeks MBSR(BC) program: group practice of mindfulness meditation 6 weeks BCES program: education support program Control: no intervention	Breast cancer survivors n=214/330	Home-based intervention	Stroop test, BVMT-R (visuospatial memory), HVLT-R, logical memory (W digit span (WAIS-IV), CCT-1, COWAT FACT-COG
NCT02677987 Active, not recruiting (01302020)	Lisa M. Wu Northwestern University USA	RCT Pre-intervention	Light exposure therapy	30 minutes daily x 4 weeks intervention systematic light exposure	Cancer survivor having	NA	PSQI (sleep quality), FACIT-F, CESD (depression), FSBS (neurobehavioral functioning), FACT-BMT (quality of life), FACT-TS (treatment satisfaction) Physiological measures

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
		Post-intervention: during the 4th week of the intervention Post-intervention: 2 months after the intervention		30 minutes daily x 4 weeks intervention systematic light exposure	received HSCT n=NA/80		Biological measures
NCT04026048 Recruiting (07192019)	Sheila Garland Memorial University of Newfoundland Canada	RCT Pre-intervention Post-intervention: after 4 weeks Post-intervention: after 8 weeks Post-intervention: after 3 months Post-intervention: after 6 months	Cognitive behaviour therapy	CBT-I (Cognitive behaviour therapy for insomnia) Control: waitlist	Cancer survivors n=NA/124	Home-based intervention	HVLT-R, COWAT, digit span, BRIEF-A (behaviour rating inventory of executive function) FACT-COG HADS ISI (insomnia severity index), CSD (sleep-onset latency, wake after sleep onset, total sleep time), MFSI-SF (fatigue), WPAI (work productivity and activity impairment)

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
		6 months follow-up					
NCT04049695 Recruiting (12172020)	Sheri Hartman, University of California USA	RCT Pre-intervention Post-intervention	Exercise	12 months individually tailored phone and email-based exercise program Control: 12 months health and wellness program	Breast cancer survivors n=NA/250	Home-based intervention with emails and phone support	Oral symbol digit test PROMIS (cognitive complaints)
NCT02600299 Completed (09222016)	Alexandre Chan National University Singapore	RCT Post-intervention	Psycho-education group	3 sessions structured program based on the cognitive behavioural therap. Control: usual care designed as placebo	Breast cancer survivors n=80/100	On-site intervention supervised	FACT-COG BAI (anxiety), Quality of life (NA), Rotterdam symptom checklist (severity of symptom burden)
NCT02312934 Completed (01212020)	Paul A. Newhouse Vanderbilt University	Pilot study Pre-intervention	Drug	16 hours per day x 6 weeks transdermal nicotine (increasing dosage)	Breast cancer survivors n=22/40	NA	CPT (attention and vigilance) FACT-COG

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
	Medical Center USA	Post-intervention		Control: placebo			
NCT02592070 Completed (02102020)	Edward McAuley University of Illinois at Urbana-Champaign	Single group assignment Pre-intervention Post-intervention	Walking	30 minutes treadmill walking	Breast cancer survivors n=31/40	NA	Neurocognitive assessment (Tools: NA) HADS Psychosocial questionnaire (NA) Physical activity (accelerometer)
NCT04586530 Recruiting (10142020)	Robert J. Ferguson University of Pittsburg USA	RCT Pre-treatment Post-treatment: 8 weeks Post-treatment: 6 months 6 months follow-up	Cognitive behavioural therapy	MAAT: series of manualized workshops supplemented by a participant workbook (adaptive behavioural coping skills, stress management techniques & compensation strategies)	Breast cancer survivors n=NA/200	Home-based intervention with laptop or phone support	CVLT-3, COWAT, digit span, SDMT (symbol digit modalities test) FACT-COG fMRI

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
				Control: unspecific intervention (supportive therapy)			
NCT03476226 Unknown (03262018)	Katharine L. Szubski Advocate Health Care USA	RCT Post intervention	Psycho-education	Nursing-driven cognitive dysfunction coping strategy sheet and provide education as to its use	Breast cancer survivors n=NA/100	NA	FACT-COG
				Control: no intervention			
NCT04230863 Recruiting (03092021)	Paul A. Newhouse Vanderbilt University Medical Center USA	Pilot study Single group assignment	Cognitive remediation program	nCCR: neuroplasticity-based computerized cognitive remediation	Cancer survivors n=NA/32	NA	nCCR: completion rate, visit frequency, visit duration

Table 24. Clinical trials registered on ClinicalTrials and identified on the cancer and cognition platform

Clinical trials identifier & status (update)	Responsible party & location	Study design & assessment	Type of intervention	Interventions	Participants n= total actual/ estimated	Supervision	Outcomes & tools
NCT01788618 Completed (07282017)	Florence Joly François Baclesse Centre France	RCT Pre-intervention Post-intervention: 3 months 3 months follow-up	Cognitive remediation program	RehaCom®: 9 standardized cognitive rehabilitation sessions with software Active comparator: 9 sessions standardized home exercise Active comparator: follow-up by 9 telephone calls	Cancer survivors n=168/NA	NA	MMSE, RL/RI-16, WAIS-IV subtests, TMT, verbal fluency FACT-COG
NCT02934880 Unknown (07112018)	Olivier Rigal Henri Becquerel Centre France	RCT Pre-intervention Post-intervention	Physical activity	Immediate APA: 10 sessions x 60 minutes within 5 weeks (2 session per week) Delayed APA: 10 sessions within 5 weeks (2 session per week) 3 months after randomization	Breast cancer survivors n=152/NA	NA	Neurocognitive assessment (tools: NA) FACT-B, FACT-COG, FACIT-F
NCT04213365 Recruiting (01222021)	Christelle Levy	Single group assignment	Cognitive training &	12 weeks of cognitive stimulation sessions	Breast cancer n=NA/20	Home-based intervention	Feasibility study: patient adherence, patient satisfaction

	François Baclesse Centre France	Pre-intervention Post-intervention: 3 months 3 months follow-up	adapted physical activity	coupled with adapted physical activity sessions			
NCT04261153 Recruiting (12292020)	Melanie dos Santos François Baclesse Centre France	Single group assignment Pre-intervention Post-intervention	Cognitive training	3 x 20 minutes cognitive stimulation sessions with HAPPYNeuron® software	Breast cancer Older adults (≥70) n=NA/55	On-site intervention supervised	Feasibility study: acceptance rate, patient satisfaction

Annex 4 – Additional grey literature synthesis of related topics

Mild Cognitive Impairment (MCI)

Summary:

Various systematic reviews, meta-analyses(Basak et al., 2020; Ge et al., 2018; Miotto et al., 2018; Zhang et al., 2019) and websites [63] were identified and read.

MCI covers a wide audience depending on the concept of dementia and associated functional disabilities. The organizations that enable their diagnosis and management are in fact confused, as are the clinical trials concerning interventions. The objectives of the latter concern in most cases the promotion of quality of life and use cognition as a lever when its decline interferes with social and affective dimensions. Current trials often focus on cognitive management based on new technologies, creating disparities between countries according to their economic means.

The role of psychologists is highlighted in the application of a few structured management programmes, mainly in Anglo-Saxon countries, with confirmed effectiveness but which remains to be specified, as does the transferability of the benefits observed. Group cognitive stimulation is still in the majority in France because of the fewer resources required for its application and the greater diversity of skills on which it can be based (particularly in speech therapy). However, its effectiveness is more difficult to determine.

The main difference with the field of cancer lies in the ease of access to evaluation, which is clearly in favour of MCI, with a large network of memory clinics in France specialising in ageing. It should also be noted that the objectives of care are not geared towards

[63] https://reseau-memoire-alois.fr/2013/05/15/ateliers-de-rehabilitation-cognitive-pour-patients-mci/
https://www.has-sante.fr/upload/docs/application/pdf/2018-05/app_180_synthese_alzheimer_vf.pdf
http://reseau-memoire-alois.fr/2009/05/04/les-maladies-de-la-memoire-diagnostic-et-prise-en-charge/
https://www.uspalz.com/Media/uspalz-livre-blanc-2018.pdf

a return to employment. A discrepancy is also noted concerning the long-term future of people with MCI: intervention is only very rarely aimed at restoring impaired abilities and in the vast majority of cases seeks to limit the progressive decline that accompanies ageing.

Mental Health

Various resources have been identified[64].

Summary:

The field of mental health covers illnesses that induce cognitive disorders that are sometimes severe but mostly subtle or transient and can therefore escape attempts at objectivisation. Consider complex or subjective factors (metacognition, social cognition, sense of self-determination), in addition to the cognitive functions usually assessed (attentional resources, memory systems, executive functions, etc.), allow to better explain the cognitive disability observed in patients.

Specific cognitive remediation programmes have been developed and are integrated into a much broader psychosocial rehabilitation approach. This is organized at the territorial level by multidisciplinary platforms coordinated by referral centers. Even when it is based on software, cognitive remediation is adapted and supervised by a psychologist or by a trained health professional who is himself under supervision.

The objectives of the interventions refer to the notion of personal recovery, which is itself dependent on social factors, including return to employment. An initial comparison can be made on this point with working people with cognitive disorders (or cognitive decline)

[64] https://www.iledefrance.ars.sante.fr/system/files/2021-05/2021-04-27__AAP_plateformes-territoriales_RPSVF.pdf
https://centre-ressource-rehabilitation.org/-rehabilitation-
https://www.happyneuronpro.com/neuropsychologie/recos/
http://www.div22.org/what-is-rehab-psych

following cancer. The main difference lies in the nature of the cognitive functions exploited by psychosocial rehabilitation in the field of mental health: they are largely based on metacognitive disorders or insight (ability to apprehend one's own cognitive abilities and to provide behavioural modulation based on them, which is a characteristic of the neurocognitive impairment of schizophrenia).

Annex 5 – Bibliography

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Annex 6 – Additional resources by country

6.1 European resources – Countries of interest

6.1.1 Germany

ORGANISATION – DOCUMENT	RESOURCES
Cancer Information Service	www.krebsinformationsdienst.de Job: www.krebsinformationsdienst.de Professional service offering: www.krebsinformationsdienst.de
DVSG - German Association for Social Work **in the field of health**	dvsg.org/themen/onkologie/
The Institute for Quality and Efficiency in Health Care (IQWiG)	dvsg.org/themen/onkologie/ www.iqwig.de/
DKFZ German Cancer Research Centre	www.krebsdaten.de/Krebs/DE/Home/homepage_node.html www.dkfz.de
Health care system in Germany	www.oecd.org www.bundesgesundheitsministerium.de
Psycho-oncological care - Objective 9 of the cancer plan	www.bundesgesundheitsministerium.de
France-Germany comparison on the logic of action taken by companies with regard to employees with cancer	www.credoc.fr/publications/

6.1.2 Belgium

ORGANISATION	RESOURCES	SUMMARY
Belgian health care system	healthmanagement.org cleiss.com	Social insurance system based on solidarity. Several federal organisations (e.g. RIZIV) and federated organisations which sometimes follow a geographical division (e.g. IRISCARE for the Brussels region) and sometimes a community division between the French and Dutch speaking sectors. Compulsory health insurance must be supplemented by membership of one of the six private profit-making mutual insurance companies or by membership of a state fund: the regional service of the Auxiliary Fund for Health and Disability Insurance (CAAMI)
IRISCARE	iriscare.brussels functional-rehabilitation-agreements/	A public interest organization managing the policies and financing of care in Brussels with the mission to supervise, among others, rest homes, accommodation facilities for disabled people or functional rehabilitation conventions. No involvement in post-cancer is noted.
INAMI: National Institute for Disability Insurance	www.inami.fgov.be	Manages the administrative and financial aspects of compulsory health insurance by setting reimbursement criteria and the budget. It has an information role for health professionals and coordinates the care pathway for cancer patients.
RevArte	revarte.be	Functional rehabilitation centre mentioning in its care offer a "brain injury clinic" with objectives of evaluation and support for neurocognitive disorders. Cancer is mentioned as a brain tumour and no post-cancer programme is mentioned.

Cédric Hèle instituut	chicom.be	Platform dedicated to psychosocial aspects of cancer care described as a "knowledge and training centre" for health care providers in Flanders. The document base accessible on the website includes publications on cognition in post-cancer.
BANO: Belgian association of neuro-oncology	neuro-oncology.be	An association of physicians and paramedical professions involved in neuro-oncology care and research. The main objective is to provide access to scientific information.
BSMO: Belgian society of medical oncology - Cancer survivorship taskforce	bsmo.be	Working group created in 2012 with the initial objective of producing recommendations for the aftermath of primary treatments concerning: fertility problems, cardiac toxicity, bone health, neurotoxicity of adjuvant treatments and therefore neurocognitive disorders. The working group is currently developing protocols for interventions targeting cognition. No management projects were identified.
The Vlaams Patiëntenplatform (VPP)	www.vlaamspatientenplatform.be/	This platform aimed to bring patient association together, address needs and help to solve them, in order to improve patients' quality of life
Centre for Psycho-Oncology (CPO):	www.psycho-oncologie.be/patient/	Centre offering activities and consultations during cancer treatment to improve quality of life
Kom op tegen Kanker	www.komoptegenkanker.be/	Association aiming to support patients, defend patients' rights, fund research.

DOCUMENT	**RESOURCES**
Cancer plan	www.e-cancer.be/fr/subject/plan-cancer

	www.sciensano.be/fr/coin-presse/le-centre-du-cancer-et-la-politique-de-cancer-ont-10-ans www.sciensano.be/fr/evenements/les-defis-de-la-politique-cancer-au-cours-de-la-prochaine-decennie-prevention-traitement-soins-et www.e-cancer.be/publications
Event national awareness raising event socio professional rehabilitation	www.epr.eu/event/save-the-date-national-awareness-raising-event-socio-professional-rehabilitation/
Pilot Study: The Role of Intramural Care Teams in the Early Rehabilitation Awareness and Prevention of Long-Term Absence for Workers with Cancer	www.e-cancer.be/fr/step/etude-pilote-le-role-des-equipes-soignantes-intra-murales-dans-la-sensibilisation-precoce-des www.e-cancer.be/fr/news/rapport-intermediaire-de-letude-pilote-sur-la-reinsertion-socio-professionnelle
Quality Life Agency AVIQ - Health - Employment - Disability	www.aviq.be/index.html

6.1.3 Denmark

ORGANISATION - NAME OF THE DOCUMENT	RESOURCES
Danish Health Authority (SST)	www.sst.dk Information about the long-term consequences of cancer and its treatment: Tusinder-overlever-en-kraeftsygdom
Association for Cancer patients with Late Effects in Copenhagen	www.senfoelger.dk
Danish Cancer Society	www.cancer.dk

Municipality of Aarhus (Brain injury specialist)	www.aarhus.dk/borger/sundhed-og-sygdom/traening-og-rehabilitering/har-du-faaet-en-hjerneskade/hjerneskadeteam-for-voksne/
Municipality of Copenhagen	hjerneskade.kk.dk/
Cancer Counselling Centre	www.cairn.info/revue-rhizome-2017-3-page-10.htm
Danish health care system	www.cancer.dk www.oecd.org/health/denmark-country-health-profile-2019-5eede1c6-en.htm
Guides to diagnose MCI and dementia	Quick-guide---National-Clinical-Guideline-for-Diafnosis-of-Mild-Cognitive-Impairment-and-Dementia NKR-diagnostik-MCI-og-demens-endelig
Guide to returning to work	www.e-cancer.be/fr/file/symposiumdanishnationalreturntoworkprogrampptx

6.1.4 Ireland

ORGANISATION - NAME OF THE DOCUMENT	RESOURCES
National Cancer Control Programme - National Cancer Survivorship Needs Assessment	www.hse.ie/eng/services/list/5/cancer/profinfo/survivorship-programme/needs%20assessment.html www.hse.ie/eng/services/list/5/cancer/profinfo/survivorship-programme/acute%20sector%20cancer%20survivorship%20services.pdf
National Cancer strategy	www.gov.ie/en/publication/a89819-national-cancer-strategy-2017-2026/?referrer=http://www.health.gov.ie/wp-content/uploads/2017/07/National-Cancer-Strategy-2017-2026.pdf

6.1.5 Luxembourg

Organisation	Website
National Cancer Institute	institutnationalducancer.lu/fr/
Fondation cancer - Psychological consultations	www.cancer.lu/fr/les-consultations-psychologiques
Cancer plan	sante.public.lu/fr/publications/p/plan-national-cancer-brochure-2020-2024/brochure-plan-national-cancer.pdf

Fondations that support the Centre de Réhabilitation du château de Colpach - Croix-Rouge luxembourg:

- Violet Foundation: https://www.fdlux.lu/fr
- EuropaDona Foundation: https://www.europadonna.lu

6.1.6 Netherlands

ORGANISATION – DOCUMENT	RESOURCES
VWS: Ministry of Health, Welfare and Sport	www.rijksoverheid.nl/ministeries/ministerie-van-volksgezondheid-welzijn-en-sport
KWF	www.kwf.nl/
Kanker	www.kanker.nl/
IPSO - Psychosocial Oncology Centres	ipso.nl/
RIVM - National Institute of Public Health and the Environment	www.rivm.nl/

NFK - Dutch Cancer Foundation	nfk.nl/doelen/goed-leven-met-en-na-kanker
IKNL	iknl.nl/projecten/primary-secondary-cancer-care-registry
NIVEL	www.nivel.nl/nl/nivel-zorgregistraties-eerste-lijn/tool-alert-late-effecten-borstkanker
Society of cognitive rehabilitation **(recommendations for best practices in cognitive rehabilitation therapy in acquired brain injury)**	cognitieverevalidatie.nl/ cognitieverevalidatie.nl/wp-content/uploads/2021/04/Richtlijn-Cognitieve-Revalidatie-SCR-2004.pdf
Side Effect Assessment Tool - evidencio	https://www.evidencio.com/models/show/1900
Survivorship TaskForce	taskforcecancersurvivorshipcare.nl/ taskforcecancersurvivorshipcare.nl/nationaal-actieplan/

6.1.7 United Kingdom

The National Cancer Survivorship Initiative (NCSI): partnership between National Health Service England and Macmillan Cancer Support. "The aim of the NCSI is to ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible. ”

- https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3251952/
- http://www.ncin.org.uk/cancer_type_and_topic_specific_work/topic_specific_work/survivorship#:~:text=The%20National%20Cancer%20Survivorship%20Initiative,for%20as%20long%20as%20possible.
- http://www.ncin.org.uk/home

6.2 European resources – Non targeted countries

6.2.1 Austria

- Survivorship passport to be used for follow-up of young patients: siope.eu/news/austrian-cancer-plan-integrates-survivorship-passport/
- Creation of a survivorship center Vienna Source: www.ipaac.eu/res/file/outputs/wp4/ccpis-report.pdf

6.2.2 Finland

- Association of Finnish Municipalities: Hope Finland - Hope
- Cancer Society of Finland: www.cancersociety.fi/

6.2.3 Italy

- Istituto Tumori "Giovanni Paolo II", ITB-IRCCS: www.sanita.puglia.it/web/irccs
- Fondazione IRCCS Istituto Nazionale dei Tumori, IN : Homepage - irccstumori (istitutotumori.mi.it)
- The Tumour Institute of Tuscany (ITT), RT-ITT : ITT -IstitutoToscanoTumori(ittumori.it)

6.2.4 Malta

- Cancer Care Pathways: deputyprimeminister.gov.mt

Cancer care pathways: "*The Cancer Care Pathways Directorate was established in October 2014 with the aim of promoting advancement in quality cancer care and to offer support, advice, timely access, coordination and continuity of care for cancer patients. As part of its pathway, aspects of patient needs must be continuously assessed as cancer has several implications on the family life, social life and consequently society in general*."

6.2.5 Poland

- Polish hospital federation: Polska Federacja Szpitali (pfsz.org)
- International Hereditary Cancer center: https://hereditarycancer.net/
- Polish Lymphoma Association: https://www.uicc.org/membership/polish-lymphoma-association
- National Institute of Public Health - National Institute of Hygiene: https://eurohealthnet.eu/list-of-members/

- The maria sklodowska-curie national research institute of oncology:
  - https://www.pib-nio.pl/
  - https://www.esmo.org/for-patients/esmo-designated-centres-of-integrated-oncology-palliative-care/esmo-accredited-designated-centres/the-maria-sklodowska-curie-national-research-institute-of-oncology

6.2.6 Portugal

- Liga Portuguesa Contra o Cancro: https://www.ligacontracancro.pt/

6.2.7 Slovenia

Slovenia reported that a special multidisciplinary working group of national experts defined guidelines and prepared a pilot project for breast cancer survivorship: https://www.ipaac.eu/res/file/outputs/wp4/ccpis-report.pdf

6.2.8 Spain

- Spanish Cancer Association, Spanish Breast Cancer Federation: http://nuevofecma.vinagrero.es/
- Vall d'Hebron Institute of Oncology (VHIO): https://www.vhio.net/
- The Catalan Institute of Oncology, ICO: https://iroca.eu/center/catalan-institute-of-oncology/
- The Foundation for the Promotion of Health and Biomedical Research of Valencia Region: INICIO - FISABIO (gva.es)

6.2.9 Sweden

- Swedish Association of Local Authorities and Regions: Hope Sweden - Hope
- Cancer Society in Stockholm: https://www.uicc.org/membership/cancer-society-stockholm
- Swedish Cancer Society - Cancerfonden: https://www.cancerfonden.se/om-oss/about

6.3 International resources:

6.3.1 Australia

ORGANISATION	WEBSITE
Australian Cancer Council	www.cancer.org.au
Cancer Australia	www.canceraustralia.gov.au
CanTeen	www.canteen.org.au
Australian Cancer Survivorship Centre	www.petermac.org/cancersurvivorship
Breast Cancer Network Australia	www.bcna.org.au My Journey Program: www.bcna.org.au/understanding-breast-cancer/bcna-resources/my-journey/ https://www.bcna.org.au/about-us/information-for-health-professionals/bcna-launches-my-journey-symptom-tracker-and-app/
Beyondblue	www.beyondblue.org.au
Cancer Council Online Community	www.cancercouncil.com.au/OC
Cancer Voices Australia	www.cancervoicesaustralia.org
Carers Australia	www.carersaustralia.com.au
Lifeline	www.lifeline.org.au
Work After Cancer	www.workaftercancer.com.au
PINC & STEEL Cancer Rehabilitation Foundation **Offers three main programs delivered by PINC & STEEL physiotherapists certified in cancer rehabilitation.**	https://www.pincandsteel.com/

6.3.2 Canada

ORGANISATION – DOCUMENT	WEBSITE
Eastern Quebec Cancer Association	https://verslemieuxetre.tv/emissions/
Living with Cancer: A Patient Experience Report	https://www.partnershipagainstcancer.ca/fr/topics/living-with-cancer-report-patient-experience/
Princess Margaret Cancer Center **Patients who complete treatment are referred to the Cancer Survivorship and Rehabilitation Program**	https://www.uhn.ca/PrincessMargaret/Health_Professionals/Programs_Departments/Department_Supportive_Care

6.3.3 United States

ORGANISATION – DOCUMENT	WEBSITE
National cancer institute (NCI)	cancercontrol.cancer.gov/ocs pubmed.ncbi.nlm.nih.gov/31379069/
American Society of Clinical Oncology (ASCO)	www.asco.org/
International American Cancer Society Cancer Survivors Network	CSN Home | Cancer Survivors Network
Children's Oncology Group	Children's Oncology Group (survivorshipguidelines.org)

Journey Forward	Journey Forward - Moving forward towards a better life
National Coalition for Cancer Survivorship (US)	Home - NCCS - National Coalition for Cancer Survivorship (canceradvocacy.org) Cancer Survival Toolbox https://canceradvocacy.org/resources/cancer-survival-toolbox/
Office of Cancer Survivorship (NCI)	Office of Cancer Survivorship | Division of Cancer Control and Population Sciences (DCCPS)
Oncolife survivorship care plan	OncoLife Care Plan (oncolink.org)
OncoLink	Oncolink Open Enrollment for 2022 Affordable Care Act Plans is Here! - OncoLink Cancer Blogs