

Mid-term evaluation of the 2009-2013 cancer plan

Summary

March 2012

HCSP evaluation committee

Qualified personalities:

Avner Bar-Hen, statistician, Paris Descartes University

François Boué, internist doctor, Bécélère Hospital, AP-HP Paris

Valérie Buthion, economy and management of health organizations, Lyon II University

Chantal Cases, healthcare economist, INED

Eric Jouglu, epidemiologist, CépiDc-Inserm, Le Kremlin-Bicêtre

Marie-Hélène Metzger, public health doctor, epidemiologist, Hospices Civils de Lyon

Catherine Sermet, doctor, healthcare economist, IRDES

Anne Tallec, public health doctor, epidemiologist, ORS Pays de Loire

Secretariat-General of the HCSP

Béatrice Tran, public health doctor

Kristel Cosker, public health resident physician

HCSP proofreading committee

Claudine Berr, doctor, epidemiologist, Inserm U1061, Montpellier

Laure Com-Ruelle, public health doctor, IRDES, Paris

Catherine Le Galès, healthcare economist, Cermes 3 - Inserm, Villejuif

The work was jointly steered by Marie-Hélène Metzger and François Boué. Béatrice Tran acted as coordinator.

The members of the evaluation committee and the proofreading committee reported their disclosure of interests in an adequate statement form. The disclosures reported to the HCSP are published in the appendix.

The evaluation committee thanks Pierre Chauvin and Thierry Lang for carefully reading through the chapter on the evaluation of "social inequalities of health".

Introduction

The 2009-2013 cancer Plan is the continuation of the 2003-2007 cancer plan. This new plan is mainly focused on research and innovation efforts integrating their "transfer" to the healthcare system, better awareness of health inequalities in cancer, enhanced coordination of treatments and care, new sanitary and medical and social initiatives to accompany people in their "life during and after cancer".

The Plan is organized into 5 areas: research, observation, prevention and screening, treatments and care, life during and after cancer. These areas gather 30 measures itemized into 118 actions. Three cross-cutting themes are set out as "priorities" within each area: health inequalities, awareness of individual and environmental factors, role of the general physician.

Another interesting feature: the mid-term evaluation is an integral part of the Plan. This evaluation falls within the responsibility of the French Evaluation Agency for Research and Higher Education (AERES) regarding "research " Plan area and the High Council for Public Health (HCSP) regarding other areas. There is a dual evaluation objective. Firstly, to judge the Plan's capacity, after two years' implementation, in achieving its objectives by the end of the period, through an independent analysis. For this purpose, recommendations for the two remaining years will be made. Secondly, the aim is also to judge the indicators available to the plan's final evaluation. For this purpose, recommendations to develop or make available evaluation indicators will be given. Evaluation criteria are relevance, consistency and implementation of actions.

Material and method

The HCSP has chosen a cross-cutting approach, with the following evaluation areas: firstly two of the three cross-cutting themes presented as "*new challenges*" in the Plan's preamble are defined as evaluation areas: awareness of health inequalities, but with social inequalities and territorial inequalities separated in two different areas, reinforcement of the role of the general physician; secondly the issue of information systems which are a decisive cross-cutting issue in fulfilling the plan's objectives and making the final evaluation for which HCSP is responsible in 2013.

A multidisciplinary evaluation committee consisting of eight qualified personalities and two members of the Secretariat-General of the HCSP was set up and worked on written documents and interviews. These ones were individual or collective and followed an interview chart exploring the four evaluation areas. A large number of documents were analyzed (minutes of meetings, activity reports, plan monitoring reports, survey results, summary notes, written contributions by certain personalities, etc.)

This report underwent an internal validation procedure at HCSP before its publication.

Results

Relevance of the plan

Cancer has been the main cause of death in France since 2003. Its prevention, screening and treatment and care are particularly necessary considering that cancer is increasing (about 365,500 new cases estimated in 2011) as is the annual number of deaths by cancer (in 2010, 90,600 men and 64,100 women). Moreover, France has a relatively poor position with respect to other European countries in terms of premature deaths: per cancer all parts of the body put together in men (and for smoking and alcohol related cancers) and per breast cancer in women. Finally, the survival rate at 5 years varies depending on the type of cancer and stage of the disease at diagnosis (overall survival rate estimated at 50% in 2010 with 38% cure rate), underscoring the relevance of the after-cancer issue.

As in many European countries, France has chosen to create a cancer-dedicated scheme, within the framework of a thematic plan. However, this choice is confronted with shifts in sanitary organization towards regional governance of health policy following a systemic cross-cutting approach.

Internal consistency of the Plan

Nine national quantified objectives have been identified but are dispersed within the 30 measures and 118 actions in the Plan. No quantified objectives have been defined at the regional level.

The introduction of cross-cutting themes aimed at "irrigating the strategy of the Plan" - health inequalities, individual and environmental factors, role of the general physician - is ambitious and encourages innovation.

Governance of the Plan

Nationally, steering of the Plan relies on a major monitoring scheme, in the form of an interministerial steering committee and comprehensive series of monitoring charts and indicators for actions entered by a dedicated team at the French national cancer institute (INCa), allowing quarterly reporting of the Plan's state of progress. This organization reflects the will to establish high quality steering of the Plan. However, the steering committee, whose chair and secretary are entrusted to the Directorate-General of Health (DGS), does not actually review the actions of the Plan with respect to their relevance to public health objectives and health policies conducted in other areas. This seems linked to the fact that the institution in charge of strategic steering of national health policies only does it partially and the fact that steering indicators do not evenly measure the state of progress and results of the Plan.

To continue to steer the Plan on the national level, it will be necessary for the Directorate-General of Health to conduct a critical analysis of the Plan's monitoring data provided by INCa in order to determine the objective of meetings and choice of priority issues to be covered by the steering committee. The Plan should be monitored using two separate tools: 1) a project management tool bringing together deliverables and milestones 2) an *in itinere* assessment tool describing the activity and performance indicators. Indicators relating to the Plan's three cross-cutting themes and the introduction of appropriate information systems should be presented in it.

From a territorial point of view, the 2009-2013 Cancer Plan has been launched whereas regional policy organizations and planning tools had been profoundly reviewed in the wake of the adoption of the “Hospital, patient, health, territory Act” (HPST Act). Yet Regional Health Agency (ARS) teams were and remain strongly committed to drawing up their regional health project which targets very different objectives, structuring and timetable from that of the Cancer Plan. Furthermore, the regional roll-out of the Plan was not defined from the outset. It still does not have a structured idea behind it and little information is available on this subject. Finally, as there are no structured dialogue conditions between the national level and ARS the interweaving between national and regional levels and implementation of the Cancer Plan in the regions are difficult to organize and remain segmented.

In terms of regional governance, it is therefore recommended, before the end of the Plan, to appoint a regional Plan correspondent for each ARS in order to coordinate the implementation and monitoring of the Plan in the regions and generate an upward momentum concerning regional concerns and initiatives. Effective access of ARS to all regional cancer data available should be organized. Finally, by the end of 2013, each ARS should produce an appraisal on the implementation of the different measures and actions of the Plan in the regions and/or their insertion in the regional health plan and on any difficulties encountered. To strengthen regional involvement, this appraisal should be reported at the Regional health and autonomy conference.

It is also recommended, before the end of the Plan, to set up elements structuring the articulation between national and regional levels through the involvement of regional cancer correspondent representatives at the Plan's steering committee, regular presentation of the regional allotment of dashboard indicators on the plan's actions, the summary and reporting in the different relevant national organizations, in particular the Plan steering committee, appraisals of the Plan's implementation in each region.

Social health inequalities

Since the conception of the Plan, the fight against health inequalities, which is one of its most innovative aspects, has been unequally targeted for each area. The

social issue is processed downstream of treatments and care by monitoring attention paid to the intervention of professionals in the social field parallel to healthcare professionals. It is partially included in the prevention-screening section, very insufficiently processed in the observation section and practically ignored in the treatment and care section, whereas financial access to healthcare, which was for a long time the major concern of healthcare policy in terms of inequality, continues to be a problem in our healthcare system, in particular owing to doctors' charges exceeding the statutory fee. With the exception of more visible involvement of research teams in this theme, the mid-term results are limited owing to the absence of structuring factors needed to develop such an objective. Before the end of the Plan, it is therefore necessary to act in the following four dimensions: 1) strictly lead to an end the experimentation of a social screening and support integrated in the course of treatment and care and schedule evaluation of the impact on the reduction of social health inequalities of planned actions and research projects; 2) conduct an inventory of social inequalities relating to cancer on the basis of information on morbidity and mortality, prevention and screening, access to treatment and care, to innovation and on the remaining balance to be paid by patients, on life after the acute disease phase and integrate it into the next annual report on the cancer situation in France; 3) urgently set up monitoring and national steering of the objective of reducing social inequalities in cancer by empowering a dedicated mission within the steering committee and producing relevant monitoring indicators of the actions; 4) integrate social gradient factors in prevention measures and medical care.

Territorial healthcare inequalities

Many actions taken will produce better information on territorial inequalities in cancer and cancerology, in terms of importance, evolution, determinants and thus allow more effective action against these inequalities. However, to give greater scope to this momentum, it is indispensable to further develop knowledge of interregional and infraregional inequalities to improve following the trends and, above all, promote mobilization of ARS and local stakeholders, who play an essential role in the fight against such inequalities.

To this end, the HCSP underscores the importance of systematizing production, sharing and analysis of territorial data on cancer and cancerology, using available

data (hospital medical information system / PMSI, health insurance, etc.), collection of data by INCa, regional extensions of surveys, their systematic publication in annual reports and on the e-cancer site and production of a specific report on the evolution of regional disparities; of promoting the development of high quality prevention policies in the regions: monographs to be produced on effective and efficient prevention tools and methods for the major cancer risk or protection factors, early and systematic information of regional stakeholders on nationally-developed media. Finally, special attention will be paid to the regular development of the project of communicating file of cancerology in all the regions.

Role of the general practitioner

Increasing the role of the referring physician within the context of medical care historically allocated to hospitals is not an easy task. Many structural features of the healthcare system, including general physicians' remuneration method, are a major reason why they do not take a more active role in prevention and treatment. Low medical density in certain zones could prevent general physicians from offering a wide range of possible functions. Strengthening of the role of the general physician at all stages of the disease is an admittedly desirable cross-cutting area but does not seem to be sufficiently expressed to allow significant concrete progress. More structured discussion on the role of the general physician during the different stages of the disease would be necessary.

It is consequently recommended to: 1) assess the value of ongoing experimentations on courses of treatment and care in concrete and explicit terms with the aim of strengthening the role of the general physician. It will also be important to reintegrate the assessments of this work in a more general discussion which should define the role of the general physician in cancer patients - and more generally in chronic diseases patients - in their courses of treatment and care; 2) in terms of prevention and screening, over and above systemic obstacles arising due to doctors' remuneration method, promote the adoption of preventive practices by doctors by facilitating knowledge of risk factors, namely occupational, and communication with patients on that subject and resume a general discussion on

prevention consultations; 3) produce evaluation indicators on the impact of documentations and published recommendations on practices by general physicians.

In the longer term, it would be worth evaluating organizational solutions producing decisive results in order to draw conclusions on the sharing of skills and expertise, cooperation of healthcare stakeholders, new methods of remuneration, conditions for the success of such experimentations and estimating the cost of their general application.

Information systems

Cancerology information systems satisfy four types of requirement: 1) coordination of treatments and prevention 2) observation, research and decision-making 3) user and healthcare professional information 4) monitoring of the Plan's activity and performance indicators.

A priority focus covering the second and fourth types of requirement, *in terms of observation and monitoring*, is to immediately start work in setting up an observation system to measure and monitor the evolution of social inequalities relating to cancer.

The first type of requirement aims to ensure that information is properly shared between professionals. The current choice of linking the "communicating file of cancerology" (DCC) to the national "personal medical file" (DMP) project offers the advantage of giving the system a national, interoperable framework. However this makes it dependent on progress made in the deployment of the personal medical file and complicates its application, resulting in delays in the deployment of the DCC.. Moreover, the sharing of prevention actions and data is not envisaged whereas the DMP could become a valuable tool for both patients and medical staff.

It would also be worth exploring the possible use of the DMP in the coordination of cancer screening and prevention actions and as a patient information and educational tool. In addition, it will be necessary to refocus the DCC project on a medical data sharing tool between professionals and to organize the DMP as a treatment and care coordination tool between patients and professionals. The steering committee, and DGS (Directorate-General of Health) and DGOS (Directorate-General of Healthcare Services) in particular, should act as this dossier's contractor, with participation of ARS, regional cancer networks and professional

users of the DCC, and French Agency for shared information systems in health (ASIP-Santé) should focus on its project management.

With respect to the implementation of an *information system relating to observation, research and decision-helping*, besides observations and recommendations made in the other evaluation areas, some progress has been made to improve access to data sources (electronic death certification, experimentation of the cancer data bi-source system, access to the national Health insurance interregime information system data (SNIIR-AM), PMSI data, etc.). Access to cancer data for epidemiological or public health purposes nevertheless remains complex as organizations producing data have not yet set up the conditions needed to link together the various sources of data production. It would therefore be necessary to strengthen national coordination of health data management between the different stakeholders involved. This coordination could target better identification of production needs according to relevant types of public (healthcare professionals, users, public health stakeholders and decision-makers, regional in particular, National steering council for regional health agencies, researchers, etc.) and favor interoperability between systems.

For the implementation of an information system offering users and healthcare professionals information tools, completed or ongoing work is indisputably improving access of cancer-related information to a broad public: annual publication of "The cancer situation in France", data portal, online information documents on early diagnosis of certain cancers, etc. It would however be preferable to envisage the assessment of the user profile and use made of available documents and data.

External consistency of the Plan

An effort to structure this Plan around three cross-cutting themes will give the possibility of a more general prevention and patient care approach. Few national themed public health plans (HIV plan, Alzheimer plan, hepatitis plan, etc.) have a cross-cutting approach, allowing the introduction of organizational systems. However this mid-term evaluation reveals the limitations of an approach that encourages an experimental-type response that does not necessarily take into account its feasibility in a generalized context. These experimentations do not provide tools capable of assessing efficacy and applicability, particularly in terms of pricing. This is a major obstacle that prevents sustainability of potentially relevant experimentations and generates a multiplication of uncoordinated experimentations, leading to the compartmentalization of schemes and lack of visibility for payers and stakeholders.

Of the 17 objectives of the 2004 Public Health Act relating to cancer prevention, screening or treatment, only two quantified objectives were taken up in the 2009-2013 Cancer Plan and no objectives have been adapted to the regional level. In the short term, it will be necessary to set a substantial number of national quantified objectives linked to those proposed by the HCSP in order to prepare for the introduction of relevant indicators to the national and regional levels.

Preparation of the final evaluation in 2013

Few activity and performance indicators are available. Steering indicators proposed by INCa to monitor the Plan very partially satisfy this requirement. Preparatory work should be conducted in 2012 to set up the indicators needed by the final evaluation.

Furthermore, a major share of innovative actions is linked to research projects or clinical trials. It will be necessary before the end of the Plan to specify the assessment terms of the impact of research actions on public health.

Conclusion

The 2009-2013 Cancer Plan has consolidated the orientations taken by the previous Cancer Plan. In particular, the organization of cancer care has been padded out (multidisciplinary discussion meetings (RCP), coordinated course of cancer care, etc.) The new Plan contains essential innovations concerning the patient's customized course and the social screening and support, as well as the introduction of structuring cross-cutting themes: the focus on inequalities, individual and environmental factors and the role of the general practitioner.

The steering of the Plan by an interministerial committee is a breakthrough, but remains insufficient with respect to the Plan's strategic issues. In particular, steering indicators need to be improved to effectively help decision-making to readjust certain actions. The steering mission, on the national and regional level, should therefore be reinforced, in particular in terms of the creation of ARS.

At the Plan's mid-term, this evaluation has highlighted that cross-cutting themes are not explicitly stated in the measures and actions of ongoing thematic areas. The recommendations made by this report aim to improve governance of the Plan and capacities of the Plan to integrate these cross-cutting themes into ongoing projects. They also aim to identify the needs of the future final evaluation which need to be anticipated.