



# Changing Cancer in Spain Results from the Working Group 1

## Lack of follow-up of long survivors without active disease

Promoter

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Technical Secretariat



Confederación ACCU  
Crohn y Colitis Ulcerosa



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# Context

In **2018 two Working Sessions** took place with the participation of a **multidisciplinary Working Group**, composed of patient associations representatives, representatives from national agencies, foundations, decision-makers, clinical oncologists, and primary care physicians.

A total of **36 inefficiencies in cancer management in Spain were identified**. Out of 36 inefficiencies, **11 were prioritised** for being considered approachable in the short term.



# Context

The **11 inefficiencies** prioritised for being considered approachable in the short term were:

Nº	Inefficiencies
#01	Low social awareness and stigmatisation of cancer
#17	Limited doctor-patient communication
#24	Inadequate adaptation of the information provided to the patient at the time of diagnosis
#03	Most of the national campaigns on cancer care are designed without involving all the important agents
#05	Resources and sources of information on cancer are scattered and poorly coordinated
#20	Low participation in some of the cancer screening programs
#30	Lack of evaluation of health outcomes of treatments
#34	<b>Lack of follow-up of long survivors without active disease</b>
#04	The National Strategy against Cancer is not updated
#11	Poor connection and communication between different hospitals that treat cancer patients
#31	Delays and inequality of access to pharmacological and non-pharmacological treatment of cancer between hospitals

# Context

In 2019, a meeting was held with the **Working Group 1 (WG1)** to address in depth one of the 11 prioritised inefficiencies.



**“Lack of follow-up of long survivors  
without active disease”**

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# Objective

**To define actions** that would be important from the patient perspective and feasible to implement in Spain in the short term **to address the inefficiency "Lack of follow-up of long survivors without active disease"**



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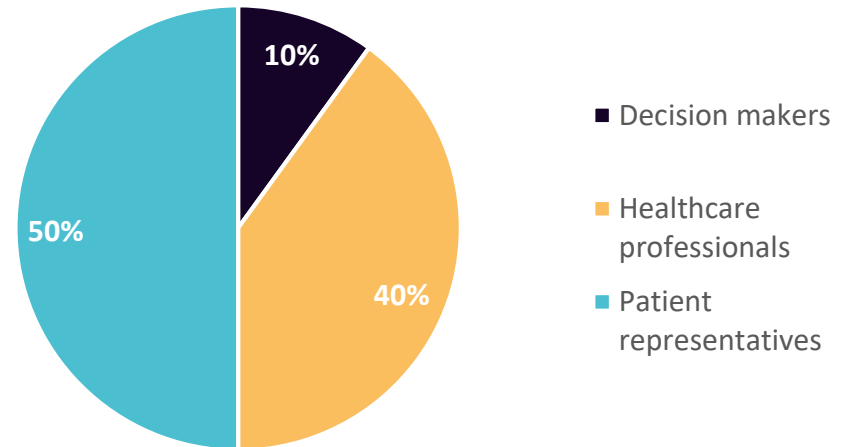
- ▶ Context
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# Composition of the Working Group 1

▶ The **Working Group 1** (WG1) was composed of **10 participants** from different profiles:

- 1 decision maker
- 4 healthcare professionals:
  - 1 medical oncologist
  - 1 primary care physician
  - 1 cancer nurse
  - 1 patient navigator nurse
- 5 patient representatives



# A total of 10 actions were defined to address the inefficiency

## "Lack of follow-up of long survivors without active disease"

- 1 Raise awareness of the needs of long survivors in collaboration with patient associations.
- 2 Promotion of training and awareness of health professionals in the care of long survivors.
- 3 Promotion of research on long survivors from scientific societies.
- 4 Use of information technology systems in the management of long survivors, including electronic medical records, registry of long survivors and tools for monitoring long survivors.
- 5 Definition of a protocol that establishes survivorship as a separate phase of the oncological process and includes guidelines to address long survivors care, with the participation of health professionals from different levels.
- 6 Creation of multidisciplinary teams for long survivors' care, including primary care professionals, social workers, psycho-oncologists, physiotherapists, nutritionists, sexologists and representatives of patient associations.
- 7 Provision of a discharge summary report adapted to the patient's language, which includes individualised recommendations on the necessary control tests, addressing possible sequelae derived from treatment, healthy living habits and information on the resources that different patient associations can offer.
- 8 Involvement of primary care professionals in the care of long survivors.
- 9 Promotion of the role of the patient navigator nurse as a reference professional for long survivors.
- 10 Identification within the long survivors of those who will need more medical follow-up based on their health status.

# Scoring of actions based on their importance from patient perspective

#	Actions	Mean	SD
#2	Promotion of training and awareness of health professionals in the care of long survivors.	6.7	0.5
#7	Provision of a discharge summary report adapted to the patient's language, which includes individualised recommendations on the necessary control tests, addressing possible sequelae derived from treatment, healthy living habits and information on the resources that different patient associations can offer.	6.6	0.8
#1	Raise awareness of the needs of long survivors in collaboration with patient associations.	6.4	0.5
#5	Definition of a protocol that establishes survivorship as a separate phase of the oncological process and includes guidelines to address long survivors care, with the participation of health professionals from different levels.	6.4	0.8
#10	Identification within the long survivors of those who will need more medical follow-up based on their health status.	6.4	0.5
#6	Creation of multidisciplinary teams for long survivors' care, including primary care professionals, social workers, psycho-oncologists, physiotherapists, nutritionists, sexologists and representatives of patient associations.	6.0	1.0
#4	Use of information technology systems in the management of long survivors, including electronic medical records, registry of long survivors and tools for monitoring long survivors.	5.9	0.7
#8	Involvement of primary care professionals in the care of long survivors.	5.9	0.9
#9	Promotion of the role of the patient navigator nurse as a reference professional for long survivors.	5.6	1.0
#3	Promotion of research on long survivors from scientific societies.	5.3	1.3

SD: Standard Deviation

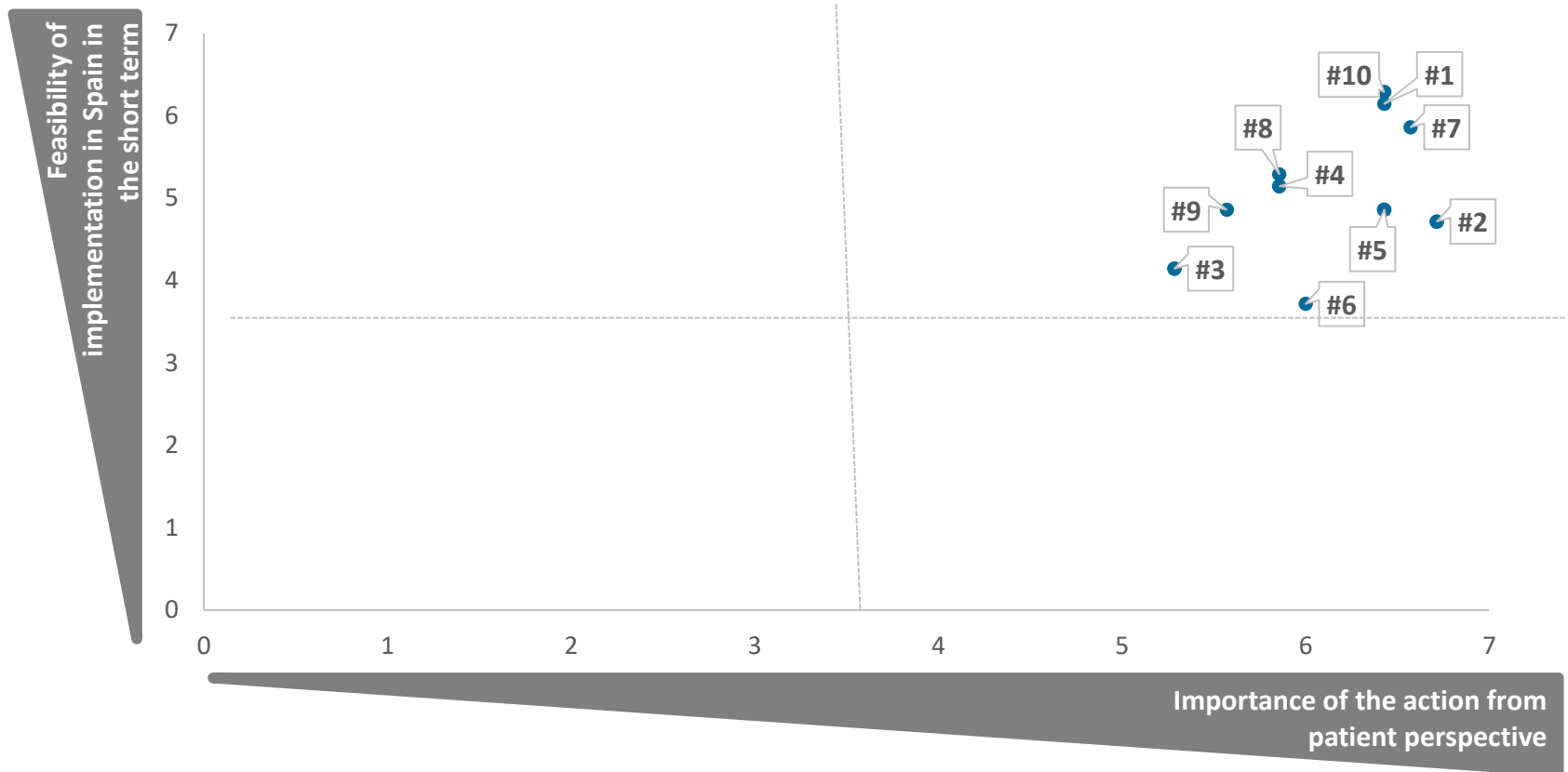
# Scoring of actions based on their feasibility of implementation in Spain in the short term

#	Actions	Mean	SD
#10	Identification within the long survivors of those who will need more medical follow-up based on their health status.	6.3	0.5
#1	Raise awareness of the needs of long survivors in collaboration with patient associations.	6.1	0.7
#7	Provision of a discharge summary report adapted to the patient's language, which includes individualised recommendations on the necessary control tests, addressing possible sequelae derived from treatment, healthy living habits and information on the resources that different patient associations can offer.	5.9	0.9
#8	Involvement of primary care professionals in the care of long survivors.	5.3	0.8
#4	Use of information technology systems in the management of long survivors, including electronic medical records, registry of long survivors and tools for monitoring long survivors.	5.1	1.1
#5	Definition of a protocol that establishes survivorship as a separate phase of the oncological process and includes guidelines to address long survivors care, with the participation of health professionals from different levels.	4.9	1.3
#9	Promotion of the role of the patient navigator nurse as a reference professional for long survivors.	4.9	1.7
#2	Promotion of training and awareness of health professionals in the care of long survivors.	4.7	1.4
#3	Promotion of research on long survivors from scientific societies.	4.1	1.1
#6	Creation of multidisciplinary teams for long survivors' care, including primary care professionals, social workers, psycho-oncologists, physiotherapists, nutritionists, sexologists and representatives of patient associations.	3.7	1.5

SD: Standard Deviation

# Analysis of results

Based on the scoring results, the **10 actions were considered priority**. Within the quadrant of priority actions, **three actions obtained the highest scores**: #10 (Identification within the long survivors of those who will need more medical follow-up based on their health status), #1 (Raise awareness of the needs of long survivors in collaboration with patient associations) and #7 (Provision of a discharge summary report adapted to the patient's language, which includes individualised recommendations on the necessary control tests, addressing possible sequelae derived from treatment, healthy living habits and information on the resources that different patient associations can offer).



# Main actions proposed to improve the follow-up of long survivors

1

Creation of multidisciplinary teams for long survivors' care, including primary care professionals, social workers, psycho-oncologists, physiotherapists, nutritionists, sexologists and representatives of patient associations.

2

Raise awareness of the needs of long survivors in collaboration with patient associations.

3

Provision of a discharge summary report adapted to the patient's language, which includes individualised recommendations on the necessary control tests, addressing possible sequelae derived from treatment, healthy living habits and information on the resources that different patient associations can offer.



# THANK YOU

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