

# Update of the Melanoma White Paper

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# The future of M-ICAB

THE MELANOMA  
WHITE PAPER:  
RESHAPING EU  
HEALTHCARE FOR  
MELANOMA PATIENTS:

A PAPER FROM THE  
INDEPENDENT COMMUNITY  
ADVISORY BOARD (M-ICAB)



- Update of the White Paper on Melanoma
- Creation of a dedicated ECPC Working Group on Melanoma to support the update of the White Paper
- Renewed dedicated webpage within ECPC new Website

# Update of the White Paper issues to be tackled - 1

- Updates in EU Legislation that impact melanoma patients:
  - **Clinical Trials Directive**
  - **Cross Border Healthcare Directive**
    - European Reference Network
  - **In Vitro Diagnostics Directive**
  - **General Data Protection Directive**
    - importance of **biobanks**
- Epidemiological data are not accurate
  - Development and sharing of new methodologies (see **AIURTUM** – Italy study)

## 24.Skin\_Melanoma.xls

Pool of Italian Cancer Registries at 1.1.2010

Persone con tumore

**100 904**

al 1.1.2010

%cured= **44%**

No. Cured= **44793**

### Estimated number of prevalent persons in Italy by years since diagnosis

	<=2	(2-5]	(5-10]	(10-15]	(15-20]	(20-Total
%	17%	20%	25%	16%	9%	13%
Persons	17 034	19 974	25 133	16 120	9 440	13 203
Prop. x 100,000	31	37	45	30	18	24

Percentuale per genere

Maschi

43%

57% Femmine

# Update of the White Paper issues to be tackled - 2

- Facilitate access to **innovative treatment**
  - Problems with access to innovative drugs in Europe – **reimbursement**
  - EMA – Role of patients' in authorisation process
    - Model for **adaptive licensing**
  - **Immuno-oncology** – ECPC's Expert Group
- Promote research on melanoma
  - Check the H2020 work programme

# ECPC Working Group on Melanoma

- **Group of ECPC Members (patients)** directly involved in the update of the White Paper
- Lead by a melanoma survivor: **Hein Jambroers**
- With the support of Prof Testori scientific input

**Thank you very much!**



EUROPEAN  
**CANCER**  
**PATIENT**  
COALITION

**Nothing about us – without us!**

**Please get in touch!**

**Francesco De Lorenzo**

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**CHAMPIONING THE INTERESTS OF EUROPEAN CANCER PATIENTS**