

**SPECIAL POLICY WEBINAR FOR THE EUROPEAN WEEK AGAINST CANCER**

**MAKING SURE EUROPEAN  
INITIATIVES DELIVER  
FOR CHILDREN AND YOUNG  
PEOPLE WITH CANCER**



**31 MAY  
2022**



**12:00-13:00  
CEST**





## WELCOME REMARKS

**“SIOPE-CCI-E Policy Webinar: Making sure European Initiatives Deliver for Children & Young People with Cancer”**



**Carmelo  
RIZZARI**

**SIOPE Europe**

President  
(Italy)



**Anita  
KIENESBERGER**

**CCI Europe**

Committee Chair  
(Austria)



**EUROPEAN  
WEEK  
AGAINST  
CANCER**

## SPEAKER DIALOGUE

**“The importance of coordinated EU action:  
From unprecedented political momentum to tangible life-  
saving gains”**



**Gilles VASSAL**

Gustave Roussy, FR

**SIOP Europe**

Board Member &  
Policy Lead



**Delphine HEENEN**

KickCancer, BE

**CCI Europe**

European Affairs Committee  
Lead & Committee Member

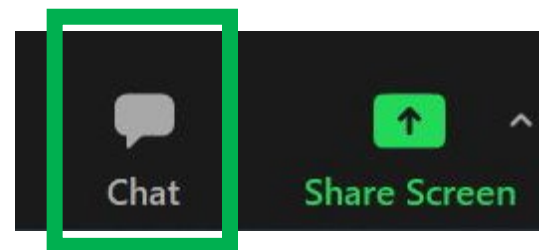


**EUROPEAN  
WEEK  
AGAINST  
CANCER**

# TECHNICAL INFORMATION

- ✓ Please use the chat to write your questions
- ✓ Questions will be answered during the Q&A part
- ✓ SLIDO polls will appear, link will be in the CHAT

**YES**





**SLIDO TIME**

**#012345**

Access SLIDO:

<https://app.sli.do/event/m698nHN3Hn8xUPAaqMAKfL>

**Q: Which stakeholder do you represent?**

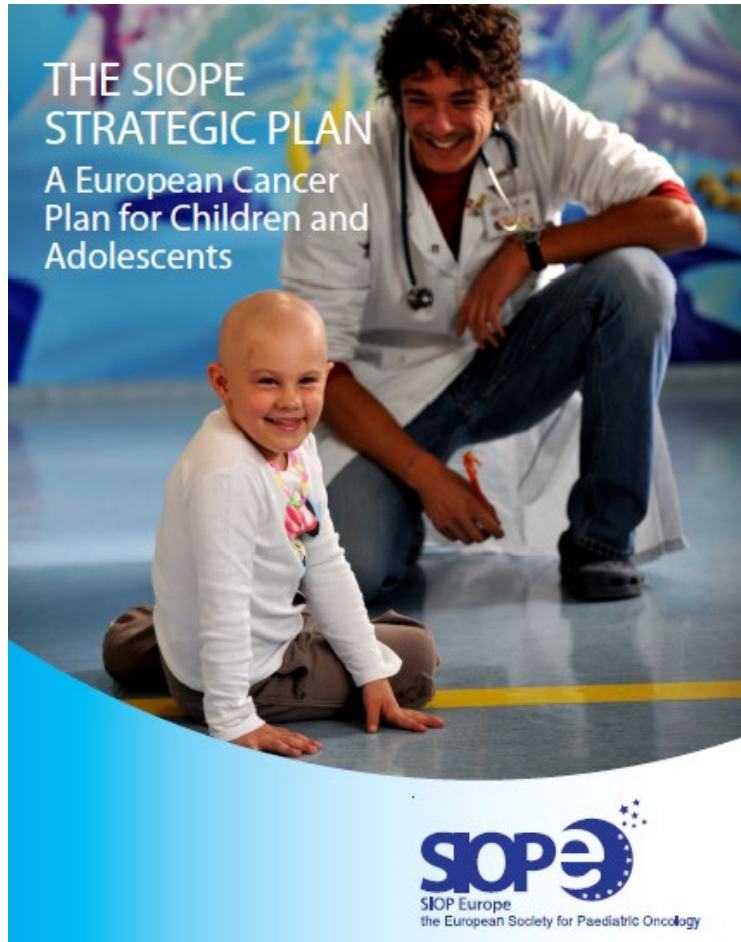
**(LOOK OUT FOR THE SLIDO LINK IN THE CHAT)**



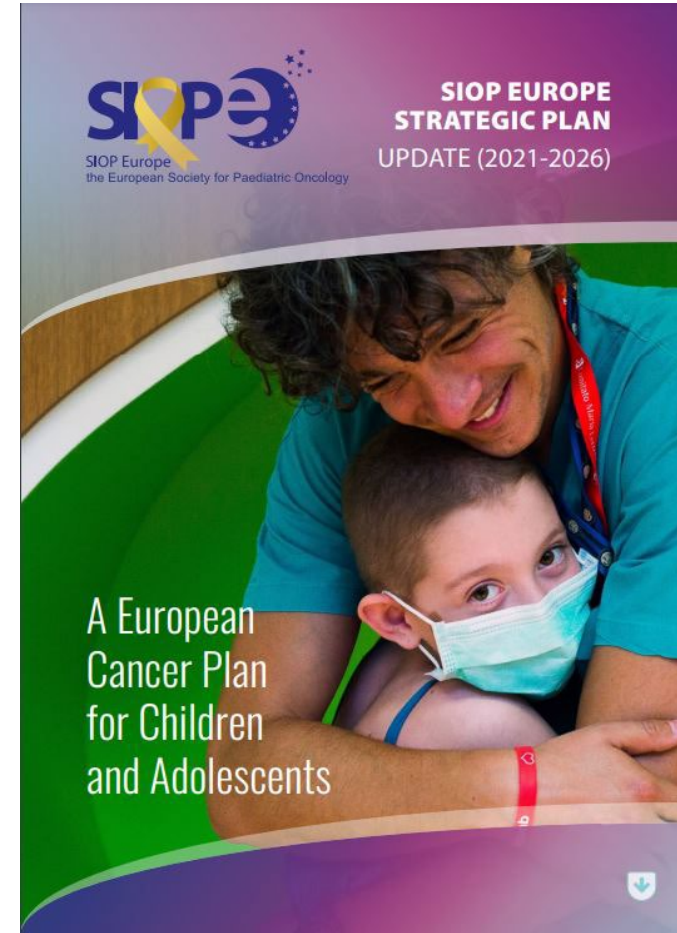
# PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



**2015**



**2021**



<https://siope.eu/european-strategic-plan/>



# PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



Elucidate the role  
of the immune  
system and  
epigenetics for  
therapeutic  
interventions



# PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



Systematic use of  
all available  
research and  
health care data





# PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



Develop Artificial  
Intelligence for  
diagnosis and  
treatment



## PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



Develop and  
introduce  
effective and less  
toxic innovative  
therapies in  
standard care



## PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



Ensure equal access  
to innovation and  
standard  
treatments across  
Europe



## PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



Understand the  
causes of  
childhood cancers  
for prevention  
strategies



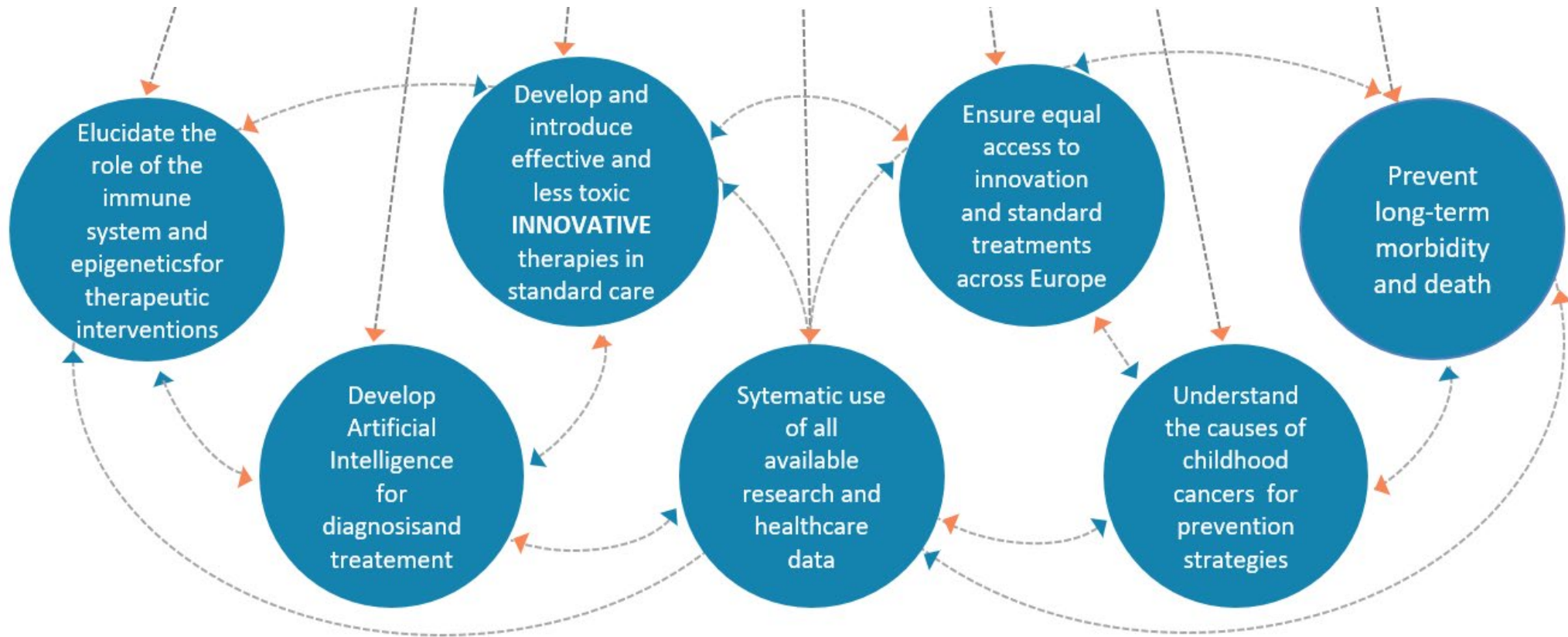
# PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



Prevent long-  
term morbidity  
and death



# PART I: The Overarching Goal - Cure more, cure better and tackle inequalities





# PART I: The Overarching Goal - Cure more, cure better and tackle inequalities



**A NECESSARY MULTISTAKEHOLDER ENDEAVOUR**



# CITIZEN HEALTH AND WELLBEING

## BEATING CHILDHOOD CANCER

Cure more and Cure better: Half the deaths and half the burden by 2030



Basic science

Medical sector

E-Health

Social and human sciences

Digital sector

Biopharmaceutical industry

Patient advocates and NGOs

Elucidate the role of the immune system and epigenetics for therapeutic interventions

Develop and introduce effective and less toxic **INNOVATIVE** therapies in standard care

Ensure equal access to innovation and standard treatments across Europe

Prevent long-term morbidity and death

Develop Artificial Intelligence for diagnosis and treatment

Systematic use of all available research and healthcare data

Understand the causes of childhood cancers for prevention strategies

### A European paediatric cancer mission: aspiration or reality?

*\*Pamela R Kearns, Gilles Vassal, Ruth Ladenstein, Martin Schrappe, Andrea Biondi, Patricia Blanc, Angelika Eggert, Anita Kienesberger, Olga Kozhaeva, Rob Pieters, Kjeld Schmiegelow*

THE LANCET **Oncology**

P1200-1202, SEPTEMBER 01, 2019





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### **a. ACCESS TO THE BEST CARE FOR ALL**



## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### a. ACCESS TO THE BEST CARE FOR ALL

#### 1. European Care Strategy





# PART II: Illustration of how different EU initiatives are relevant to childhood cancer



## a. ACCESS TO THE BEST CARE FOR ALL

## 2. European Reference Network on Paediatric Cancer (ERN PaedCan)



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**  
Paediatric Cancer  
(ERN PaedCan)



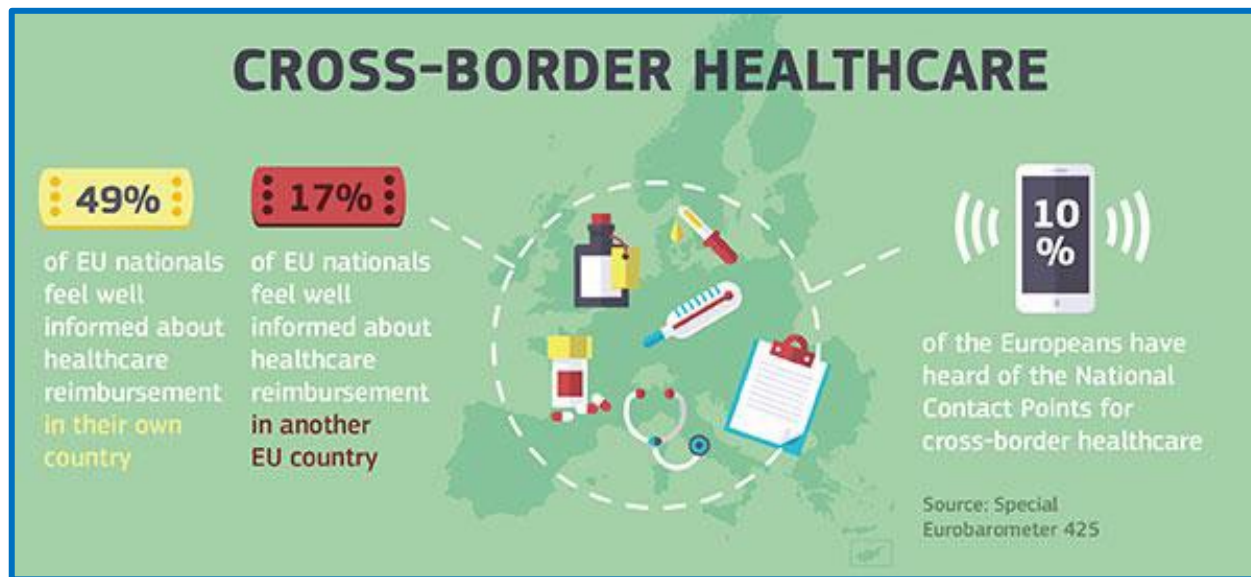


## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### a. ACCESS TO THE BEST CARE FOR ALL

## 3. Cross-Border Healthcare Directive





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### a. ACCESS TO THE BEST CARE FOR ALL

#### 4. Work-Life Balance Directive





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### a. ACCESS TO THE BEST CARE FOR ALL

## 5. EU Strategy on the Rights of the Child





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### **b. RESEARCH AND DATA**



## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### b. RESEARCH AND DATA

#### 6. European Initiative to Understand Cancer (UNCAN.eu)







## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### b. RESEARCH AND DATA

#### 7. European Health Data Space (EHDS) Regulation



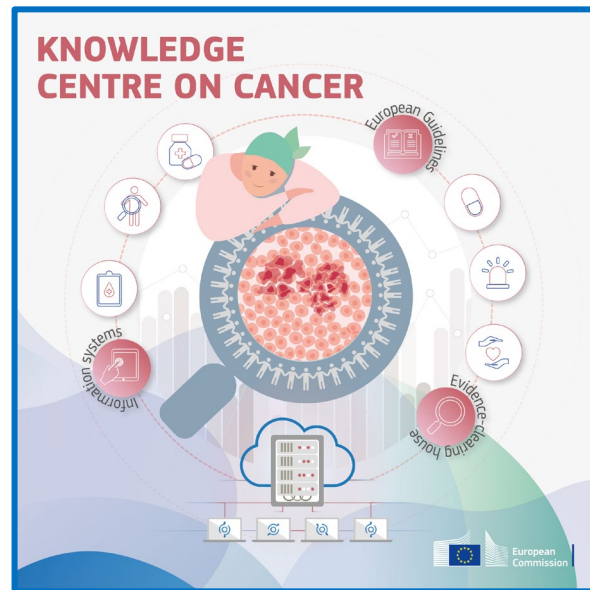


# PART II: Illustration of how different EU initiatives are relevant to childhood cancer



## b. RESEARCH AND DATA

### 8. European Cancer Information System (ECIS) (part of the Knowledge Centre on Cancer)



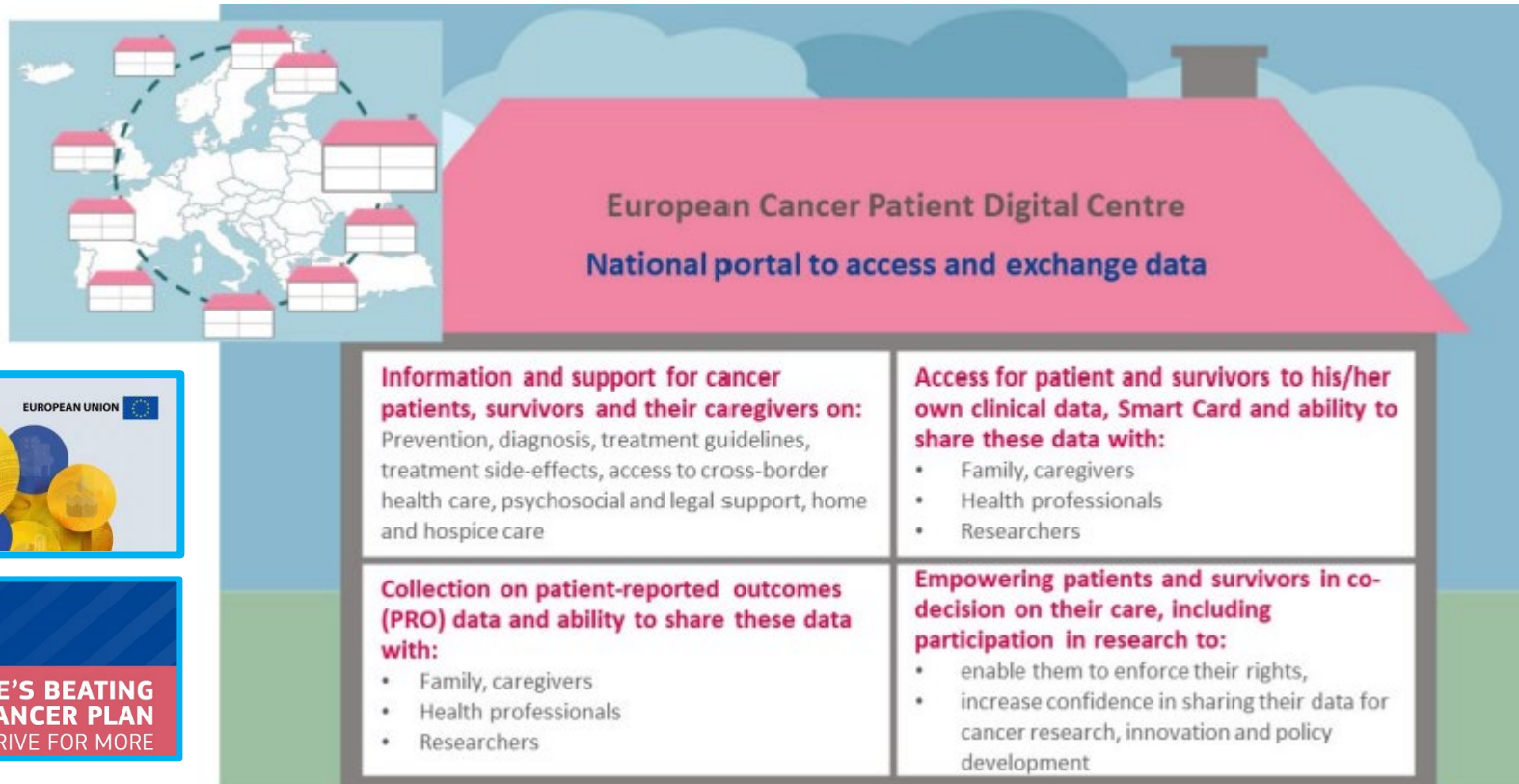


# PART II: Illustration of how different EU initiatives are relevant to childhood cancer



## b. RESEARCH AND DATA

### 9. European Cancer Patient Digital Centre





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### b. RESEARCH AND DATA

## 10. General Data Protection Regulation (GDPR)





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### b. RESEARCH AND DATA

#### 11. The European Cancer Inequalities Registry





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### **c. IMPROVING ACCESS TO MEDICINES**



# PART II: Illustration of how different EU initiatives are relevant to childhood cancer



## c. IMPROVING ACCESS TO MEDICINES

### 12. EU Paediatric and Orphan Regulations



**European Childhood Cancer Organisations' Recommendations**  
following the European Commission's Evaluation of the Legislation for Medicines for Rare Diseases and Children and the launch of the Pharmaceutical Strategy for Europe.

**PHARMACEUTICAL STRATEGY FOR EUROPE**





## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### c. IMPROVING ACCESS TO MEDICINES

#### 13. Health Technology Assessment (HTA) Regulation

**Health  
Technology  
Assessment  
(HTA)**







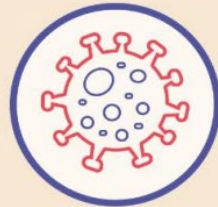
## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### c. IMPROVING ACCESS TO MEDICINES

#### 14. General Pharmaceutical Legislation

##### PHARMACEUTICAL STRATEGY FOR EUROPE



Learning from COVID-19, towards a crisis-resistant system



Ensuring accessibility and affordability of medicines



Supporting sustainable innovation, emerging science and digitalisation



Reducing medicines shortages and securing strategic autonomy



**EUROPEAN  
WEEK  
AGAINST  
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**SLIDO TIME**

**#012345**

<https://app.sli.do/event/m698nHN3Hn8xUPAaqMAKfL>

**Q: How likely do you think the presented initiatives will deliver on the goal: cure more and cure better?**

**(LOOK OUT FOR THE SLIDO LINK IN THE CHAT)**



## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### **d. HEALTH & SOCIOECONOMIC RIGHTS OF CHILDHOOD CANCER SURVIVORS**



## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### d. HEALTH & SOCIOECONOMIC RIGHTS OF CHILDHOOD CANCER SURVIVORS

#### 15. EU Network of Youth Cancer Survivors

**EU Network  
of Youth  
Cancer  
Survivors**

#EUCancerPlan

**EUROPE'S BEATING  
CANCER PLAN**  
LET'S STRIVE FOR MORE




## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### d. HEALTH & SOCIOECONOMIC RIGHTS OF CHILDHOOD CANCER SURVIVORS

#### 16. Cancer Survivor Smart-Card



Deliver the mock-up version of the 'Cancer Survivor Smart Card'

Call for tenders deadline:  
**6 May**



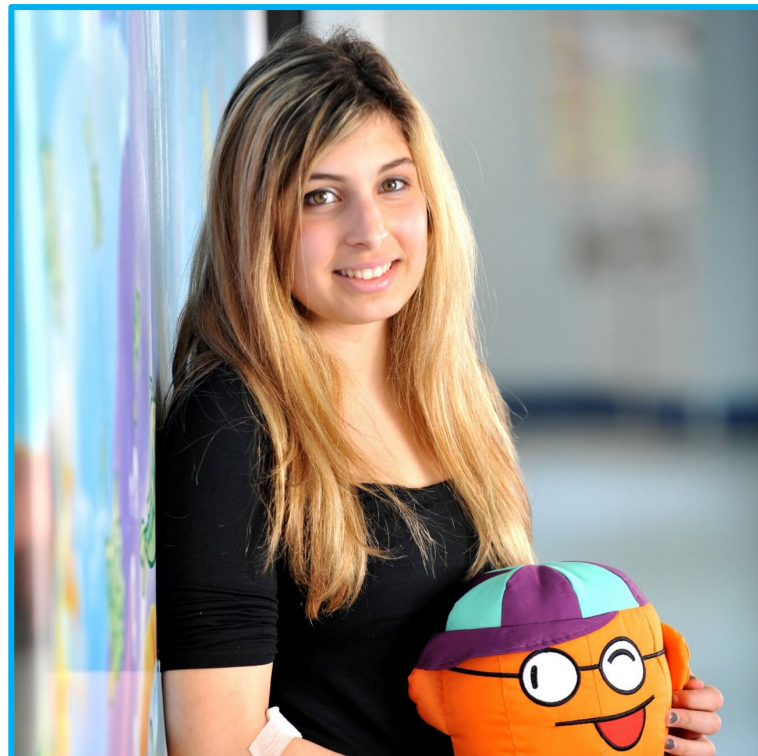


## PART II: Illustration of how different EU initiatives are relevant to childhood cancer



### d. HEALTH & SOCIOECONOMIC RIGHTS OF CHILDHOOD CANCER SURVIVORS

#### 17. Right to be Forgotten





# PART III: Childhood Cancer in All EU Policies



**EUROPE'S BEATING CANCER PLAN**  
LET'S STRIVE FOR MORE

#EUCancerPlan  
4 February 2020, European Parliament, Brussels

**PHARMACEUTICAL STRATEGY FOR EUROPE**

- Learning from COVID-19, towards a crisis-resistant system
- Ensuring accessibility and affordability of medicines
- Supporting sustainable innovation, emerging science and digitalisation
- Reducing medicines shortages and securing strategic autonomy

**Cancer** EUROPEAN UNION

**Horizon Europe Missions**  
DELIVERING SOLUTIONS TO SOME OF OUR GREATEST GLOBAL CHALLENGES

#EUmissions #HorizonEU  
#MissionCancer



## COORDINATION?

General Data Protection Regulation

Deliver the mock-up version of the 'Cancer Survivor Smart Card'

Call for tenders deadline:

Towards a **European Care Strategy**

**Health Technology Assessment (HTA)**

**European Reference Network**

**CROSS-BORDER HEALTHCARE**

17% of EU nationals feel well informed about healthcare reimbursement in another EU country

10% of the Europeans have heard of the National Contact Points for cross-border healthcare

Source: Special Eurobarometer 425

**EU Network of Youth Cancer Survivors**

**Cancer Inequalities Registry**

#EUCancerPlan

European Commission

**Europeans and work-life balance**

**EU Strategy on the Rights of the Child**

**For a European Health Data Space**



**EUROPEAN  
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**SLIDO TIME  
#012345**

<https://app.sli.do/event/m698nHN3Hn8xUPAaqMAKfL>

**Q: What would happen if there was no coordination?**

**(LOOK OUT FOR THE SLIDO LINK IN THE CHAT)**





## PART III: EU Health Policy Platform and Beating Cancer Stakeholder Contact Group



- Under the **EU Health Policy Platform**, the **Beating Cancer Stakeholder Contact Group** has been created with a distinct thematic group on **Childhood Cancer**.
- However, this forum consists of the main stakeholders in the area of oncology with the overall aim to support the **implementation of the Europe's Beating Cancer Plan, the EU Cancer Mission and the monitoring of their actions.**

#EUCancerPlan  
#MissionCancer

"Beating Cancer Stakeholder Contact Group"

This is a discussion and information sharing forum consisting of the main stakeholders in the area... [read more](#) ▼

[Participate >](#)

A screenshot of a social media post. At the top, there is a blue header with the text "#EUCancerPlan" and "#MissionCancer" in white. Below the header, the text reads "Beating Cancer Stakeholder Contact Group" in quotes. Underneath, there is a paragraph: "This is a discussion and information sharing forum consisting of the main stakeholders in the area... read more" with a downward arrow. At the bottom left, there is a light blue button that says "Participate >". At the bottom right, there is a green lock icon.

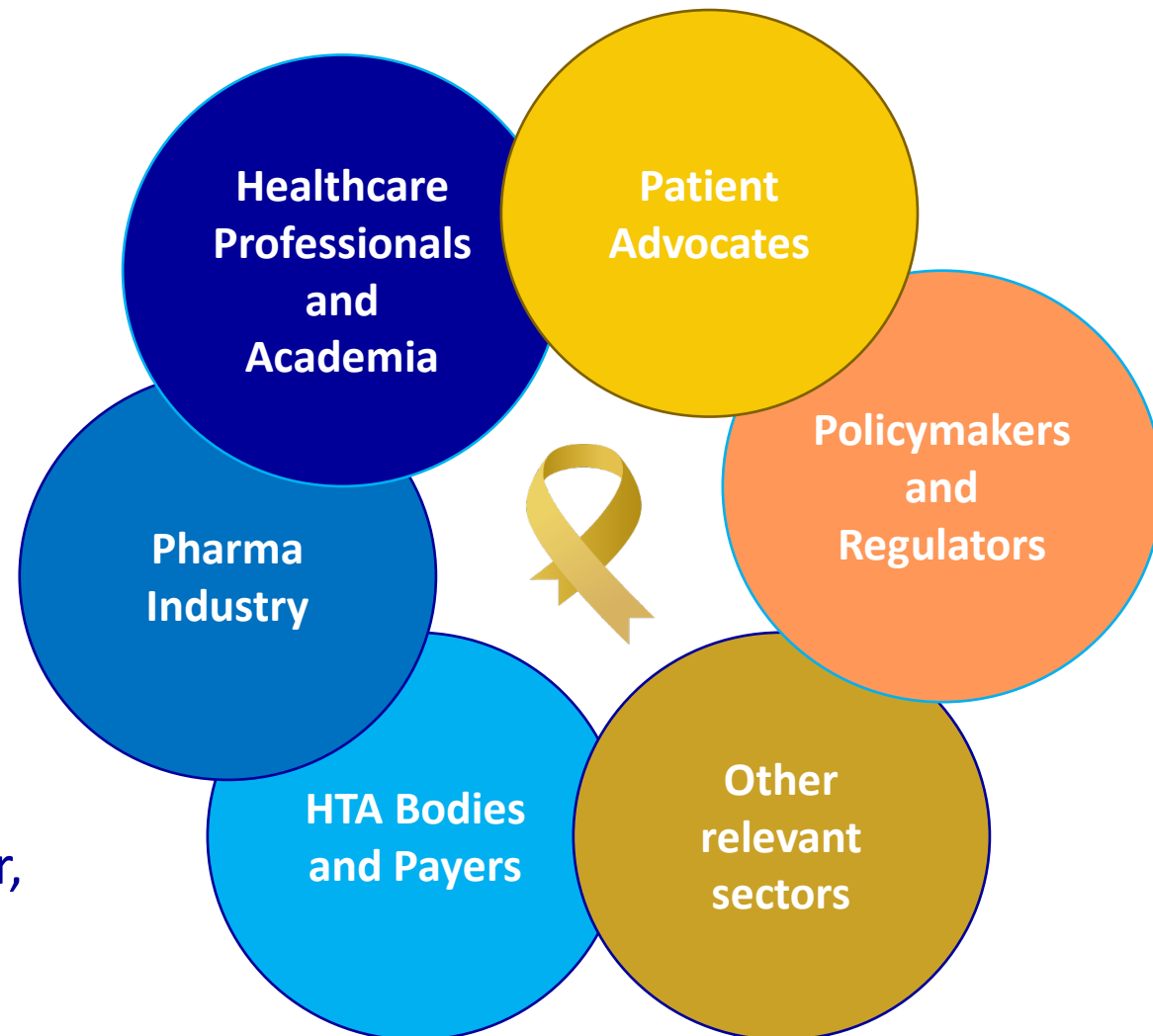


## PART III: Call for an EU Childhood Cancer Advisory Board



### An EU Childhood Cancer Advisory Board would:

1. Support the coordination of actions across all relevant EU initiatives
2. Foster a comprehensive inclusive approach
3. Avoid the risk of fragmentation
4. Accelerate the advancement towards the overall objective to cure more children, cure them better, and reduce inequalities



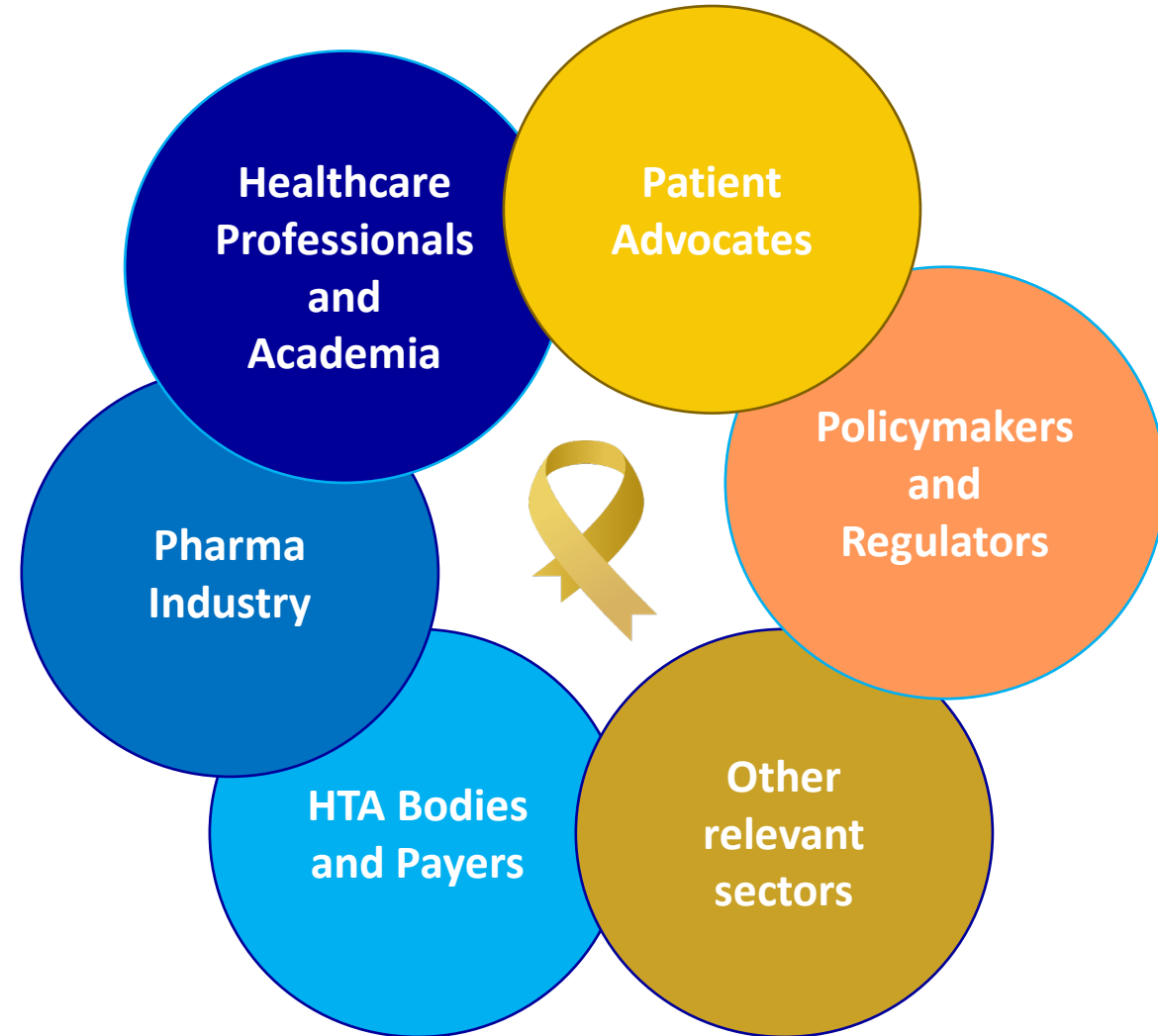


## PART III: Call for an EU Childhood Cancer Advisory Board



### An EU Childhood Cancer Advisory Board would also:

- **Connect stakeholders** to achieve synergies for a 'childhood cancer in all policies' approach
- **Advise on unmet needs**
- **Ensure continuity** with existing European networks and collaborative groups
- **Mobilise parent, patient & survivor organisations** from the grassroot to European levels





## PART III: EU support to the EU Childhood Cancer Advisory Board



➤ Both the **European Parliament** and the **Council of the EU** support this initiative.

☐ Support by MEPs in the BECA Resolution on **‘Strengthening Europe in the fight against cancer’**: **Paragraph 137 of Section V. Challenges in cancer among children, adolescents and young adults.**

*“Calls for the creation of an **EU-level advisory group of stakeholders** dedicated to childhood and AYA cancers, which would support the **goal-driven and coherent implementation of relevant actions across** the Plan, Horizon Europe, the Pharmaceutical Strategy for Europe and EU4Health Programme”*

☐ Support by the Presidency Trio of the Council of the EU (France/Czechia/Sweden) and various EU stakeholders in **the Political Declaration on Cancer of 4 Feb 2022.**

*“Need for **an effective mechanism to enable transparent coordination and implementation of the actions and projects relevant to children and adolescents with cancer across the Europe’s Beating Cancer Plan, Horizon Europe and the Pharmaceutical Strategy for Europe, as well as other major initiatives...**”*





# Q&A and Discussion



# A BIG THANK YOU goes to the SIOP Europe Policy Team



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Great initiatives require a flawless implementation:  
**coordination is key** and an **EU Childhood Cancer  
Advisory Board is the answer.**