



# The Impact of the GDPR on Childhood Cancer Research – Key Survey Findings

**Gilles VASSAL**

**SIOPE Board Member & Policy Lead**

12<sup>th</sup> International Childhood Cancer Awareness Day (ICCD)  
Policy Event

*02 February 2022*



WHY?



- Need to accelerate innovation and improve treatments to cure more children, cure them better and tackle inequalities**
- Every childhood cancer is rare or ultra-rare**
- Sharing and re-use of data and biological samples is paramount**



# WHY?



### In 2004

5 International Cooperative groups decided to work together and share data on neuroblastoma.

- Cancer in young children
- 7% of paediatric cancers



### In 2022

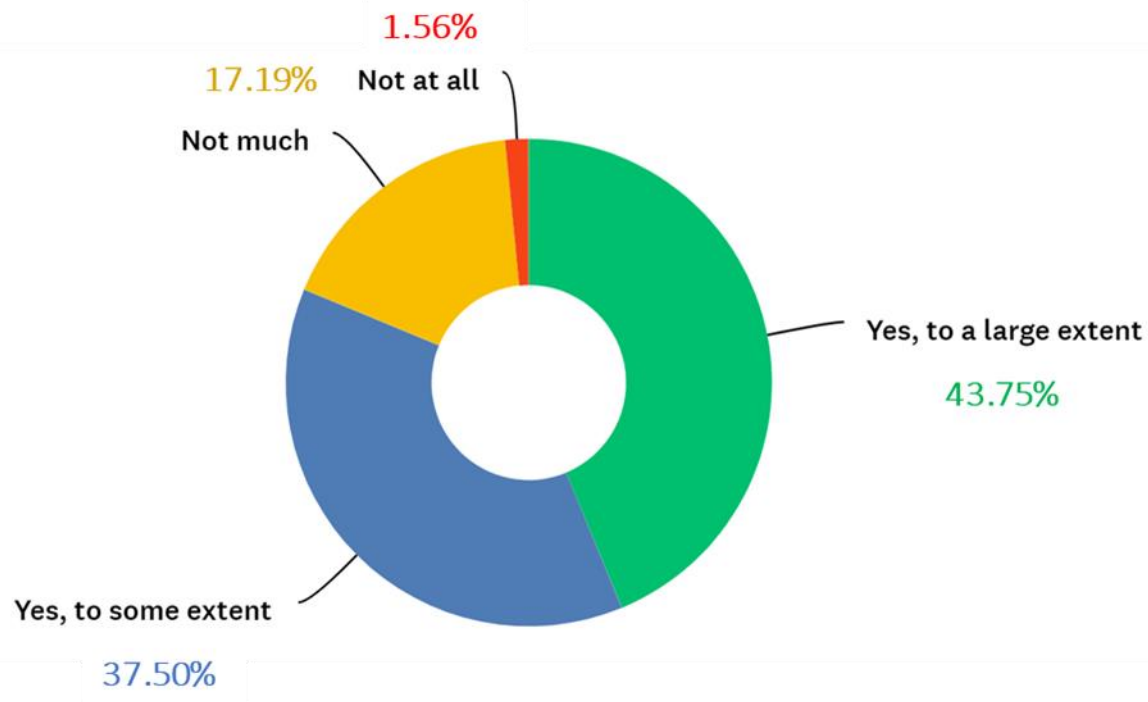
Clinical and molecular information from 20,000 children with neuroblastoma



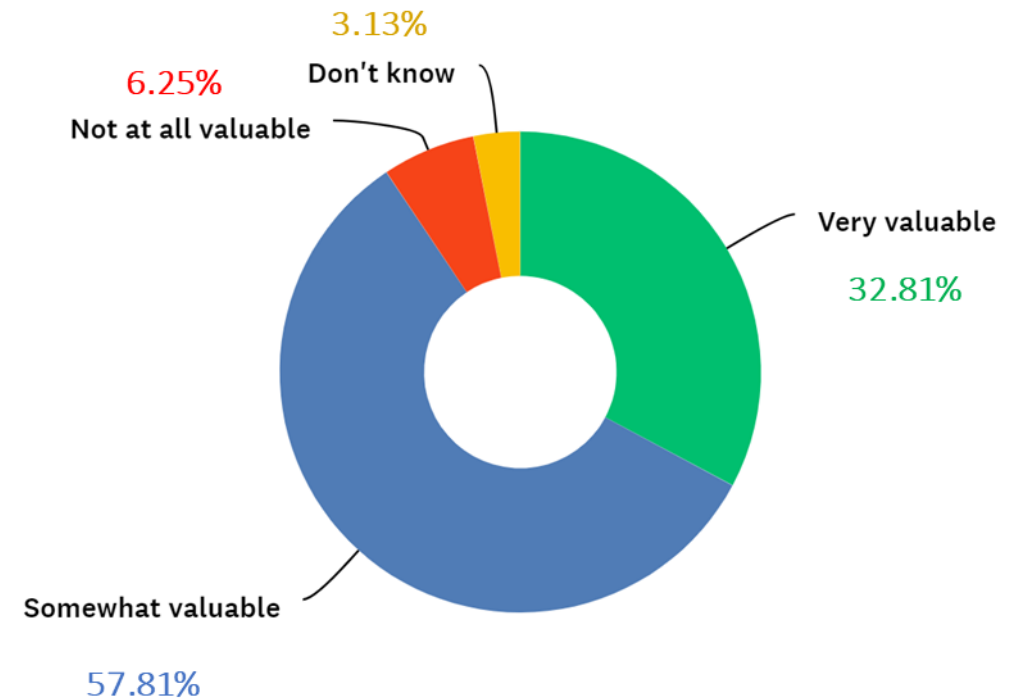
# SIOPE Survey Results of Professionals on the GDPR Impact in Childhood Cancer Research

- 128 respondents from 28 European countries

82% of respondents are aware of the GDPR



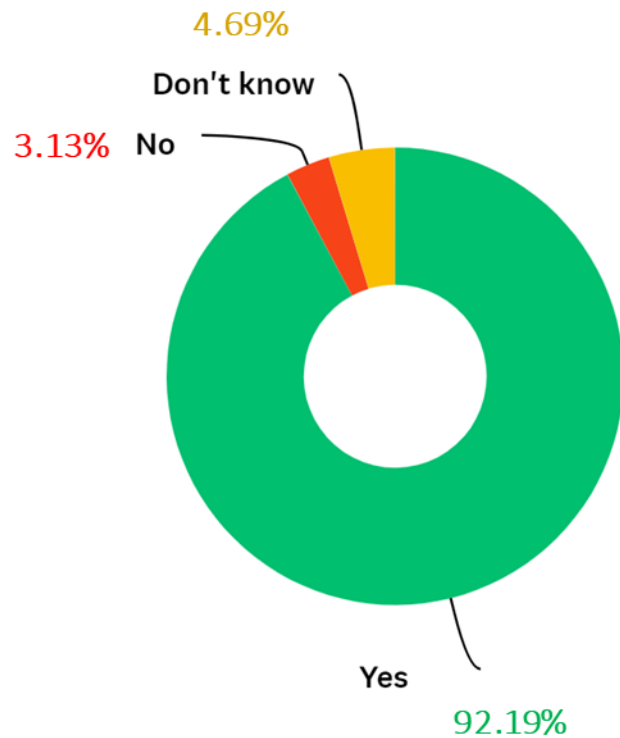
91% of respondents value regulation in protecting the privacy of EU citizens



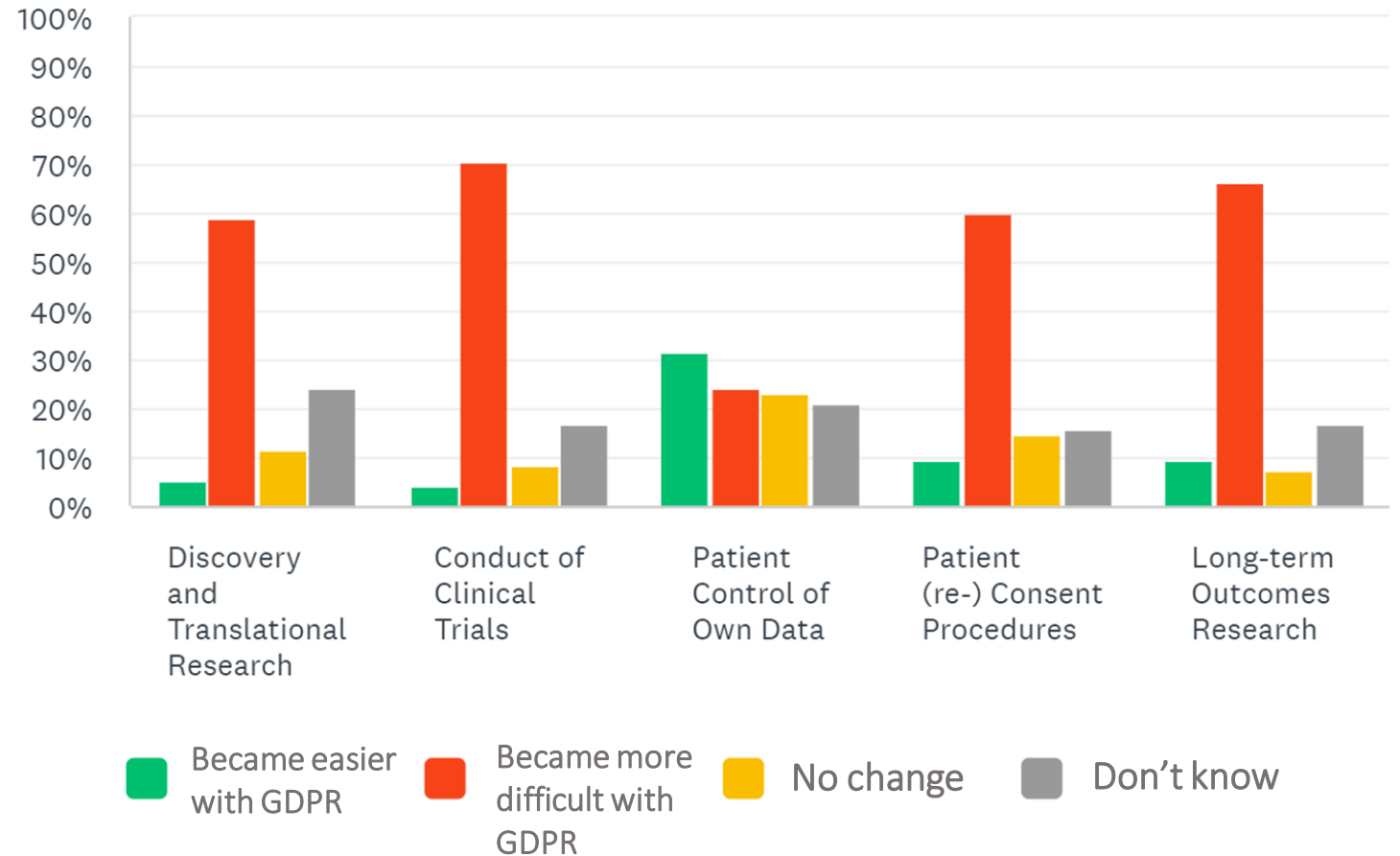


# SIOPE Survey Results of Professionals on the GDPR Impact in Childhood Cancer Research

**92% of respondents are engaged in activities that necessitate the sharing of health or research data**



## Childhood cancer research became more difficult with GDPR





# SIOPE Recommendations on the GDPR



12<sup>th</sup> Edition

International Childhood Cancer  
Awareness Day (ICCD2022)



**#1 – Harmonised implementation and interpretation of the GDPR across all EU Member States.**





**#2** – A one-time ‘broad’ consent from patients or parents/legal guardians and the possibility of a second ‘broad’ consent at the age of **majority** to facilitate seamless data sharing and processing for secondary use of data and tissues.

**#3** – Population-based cancer registration without the obligation for **explicit patient consent** to ensure data representativeness, with the possibility to share data internationally with appropriate safeguards.

**#4** – Facilitate secure data exchange outside the EU/EEA for public health and academic research purposes



# SIOPE Recommendations on the GDPR



12<sup>th</sup> Edition

International Childhood Cancer  
Awareness Day (ICCD2022)



**#5** – Consider pseudonymised data (i.e. key-coded data) as anonymised in certain circumstances.

**#6** – Support privacy-keeping data linkage such as by means of state-of-the-art technologies.





# SIOPE Recommendations on the GDPR



12<sup>th</sup> Edition

International **Childhood Cancer**  
Awareness Day (ICCD2022)



# Let's make the GDPR child-friendly for research!

# THANK YOU FOR YOUR ATTENTION



12<sup>th</sup> Edition

## International Childhood Cancer Awareness Day (ICCD2022)

2 February 2022  
12:00 to 14:00 CET

Virtual  
Event



[office@siope.eu](mailto:office@siope.eu) / [europe@cci.care](mailto:europe@cci.care) / [info@pancare.eu](mailto:info@pancare.eu)

#ICCD22