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

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12th International Childhood Cancer Awareness Day (ICCD) Policy Event
02 February 2022

#ICCD22
- 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
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

- Yes, to a large extent: 43.75%
- Yes, to some extent: 37.50%
- Not much: 17.19%
- Not at all: 1.56%

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

- Very valuable: 32.81%
- Somewhat valuable: 57.81%
- Not at all valuable: 6.25%
- Don’t know: 3.13%
92% of respondents are engaged in activities that necessitate the sharing of health or research data.

Childhood cancer research became more difficult with GDPR.
#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
#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.
Let’s make the GDPR child-friendly for research!
THANK YOU FOR YOUR ATTENTION

International Childhood Cancer Awareness Day (ICCD2022)

2 February 2022
12:00 to 14:00 CET

Virtual Event

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