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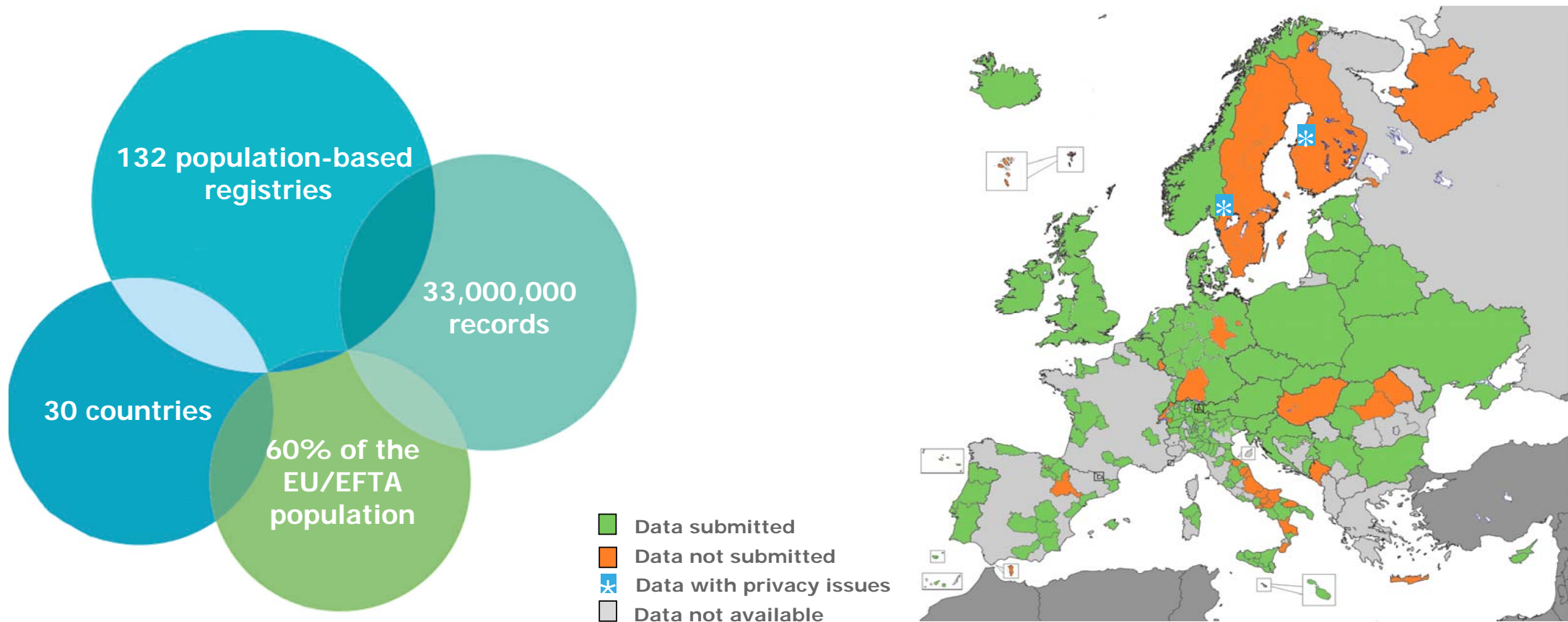
Joint Research Centre



# ENCR Questionnaire on the impact of the General Data Protection Regulation on Cancer Registries' activities

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# Members / Participation in latest call for data (2015)



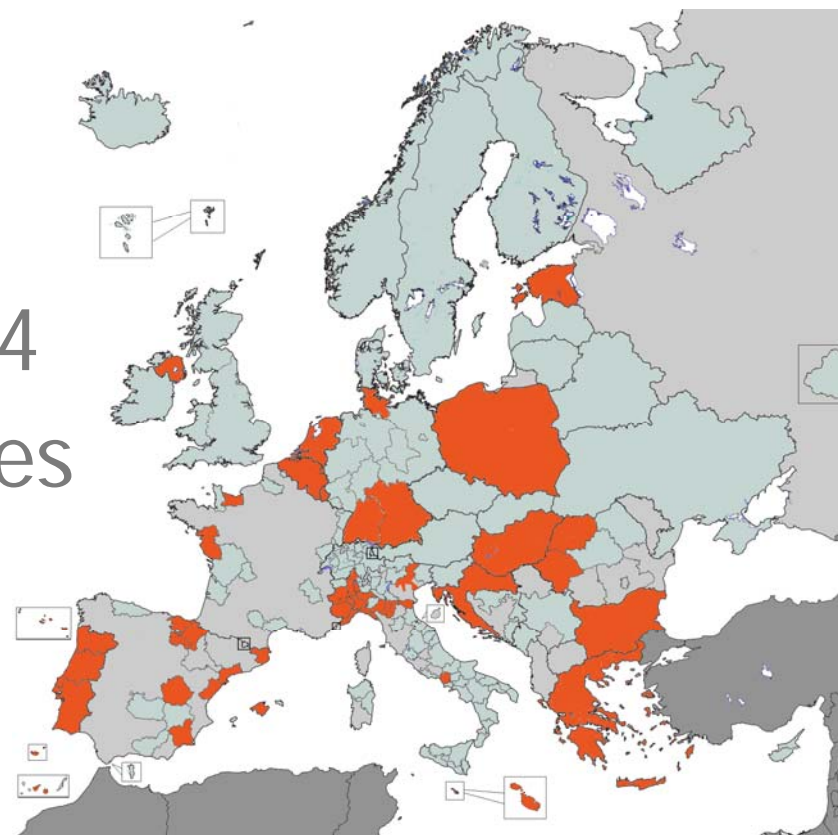
# The survey

- Aim: To present the impact of the new GDPR on daily activities of the cancer registries in EU
- The survey was sent to 164 directors of ENCR affiliated cancer registries from EU28
- When: June 2018



# Results

- National cancer Registries: 9
- Regional cancer registries: 33
- Specialised cancer registries: 4
- Total: 46 CRs from 17 countries



# Cancer registration

- **Mandatory** in 10 countries (Belgium, Bulgaria, Croatia, Estonia, Germany, Hungary, Malta, Poland, Portugal, Romania)
- **Voluntary** in 5 countries (France, Greece, Luxembourg, Netherlands, United Kingdom) and
- **Depending on region** in 2 countries (Italy, Spain)
- Except **Croatia** and registries from **France, Italy and Spain**, all other registries reported that they have an official document establishing the framework of the registry's activities.



# Transfer of data

- **For electronic data:** do you use encryption when transferring data from one place to the other?

Yes: 38

No: 6, No answer: 2

- **For paper-based data:** do you have secure data transport (e.g. separating personal identification from other data and merging them later)?

Yes: 19

No: 22, No answer: 5

# New General Data Protection Regulation (GDPR)

- All respondent CRs are aware of the entry into force of the new GDPR
- New GDPR transposed into National law
  - Yes: 25
  - No: 17
  - Not sure: 4
- Different practices are reported from regional CRs from Italy and Spain.





# Does the National/Regional authority clarify what can be considered as “anonymous data”?

- **Yes:** Luxembourg, Malta, United Kingdom
- **No:** Belgium, Croatia, Estonia, Hungary, Netherlands
- **Not sure:** Bulgaria, France, Greece, Portugal, Romania
- Germany, Italy, Poland, Spain: regional registries have reported different.



# What is the definition? [data sufficiently anonymised]

Anonymisation of personal data is a permanent and irreversible transformation of personal data, after which it is not possible to assign information to a specific or identifiable physical person by all possible means at the disposal of the controller, the processor or a third party.



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# What kind of ID (personal information) is collected / stored by the registry?

**Personal identification number, name, surname, date of birth, address:**

Collected / stored aprox. 76%

Collected & pseudonymised / stored & pseudonymised aprox. 20%

Ethnicity, telephone number, e-mail: < 6%

**Other personal data:** birth name, place of birth, marital status, social security number, occupation, sex, socio-economic status, geocode (statistical sector), Hospital discharge records, pathological anatomy reports, death cards, ticket payment exemptions, medical records copies

**If you collect and store personal ID's , do you keep it separated from other variables (eg. Diagnostic information)?**

Yes: 24

No: 18

No answer: 4

# If you do not record any personal information that allows the identification of the individual, how do you:

1. avoid duplication of registration
2. follow up the case
3. register multiple primary tumours

Answers:

- each patient entered has a pseudonymized ID which allows his identification and avoid duplication of registration.
- with name/date of birth/postal code



# Does your Registry link case records to biological samples (eg. biobank repository)?

Yes: 6

No: 38

Not sure: 1

No answer: 1

# Is there any impact on the running of the daily activities of the Registry regarding:

	Collection of data	Storage of data	Follow-up
<b>Yes</b>	<b>10</b>	<b>8</b>	<b>3</b>
<b>No</b>	<b>24</b>	<b>27</b>	<b>27</b>
<b>No answer</b>	<b>12</b>	<b>11</b>	<b>16</b>

# GDPR impact on collection of data

**None to date** - all DHIR processes are documented in SOPs, ratified by the Data Protection Commission • Data collection before GDPR based on a legal obligation, after GDPR need to develop separate agreements with all data sources to specify the responsibilities of all actors

Difficult to actively collect and verify data, employees of reporters (hospitals) have **limited access to data**

Healthcare providers centers are **afraid / confused** to transfer data to CR

**Too recent to estimate**

# GDPR impact on storage of data

- Too recent to estimate
- I **fear** I cannot save personal data
- Implementation of an **additional layer of encryption** of the data base; re-evaluation of access rights for system and database administrators
- Need to **change the security of the database**: access, storage and backup
- Impact analysis and planning to restructure the storage system
- **None to date** - all DHIR processes are documented in SOPs; **retention policies being revised**

# GDPR impact on follow-up of data

- Too recent to estimate
- **None to date** - all DHIR processes are documented in SOPs, ratified by the Data Protection Commission. Legislation being drawn up to define secondary processing and for which reasons, should it happen.
- **Not applicable ?**
- There have been no requests as yet for subject access to data or removal but **the registry will need to be aware of the responsibilities under the new individual rights**

# GDPR impact on case record linkage with biological sample repositories

- Data access agreements have been reviewed and in some cases renewed
- I fear I cannot save personal data
- None



# Is it allowed to share registry data to outside researchers for research purposes?

	within the country	other countries, within EU	other countries, outside EU
Yes, identifiable personal data	3	1	1
Yes, pseudonymised individual data	9	6	4
Yes, anonymous individual data	28	29	19
Yes, aggregated data	5	6	8
No	0	1	8
Not sure	1	3	5
No answer	0	0	1

# Additional comments regarding the impact of the new GDPR on the activities of CR

- Personal information can be provided with a declaration of consent
- Sharing registry data with outside researchers is limited to public organizations only
- In special cases it is also allowed to provide identifiable data to researchers
- Intensive cooperation with data protection authorities is necessary
- Pseudonimised data can be shared with third parties, after formal approval by the Data Protection Authority.

# Could you share some specific measures undertaken by your registry to minimise the impact of the new GDPR?

- Evaluation of risks:
  - DPO designation
  - Measures to increase security in multiples operations of the Registry
- Legislation is being drawn up to define secondary processing of health data and link to provisions of the GDPR on exemptions
- Implementation of ISO27001 accredited Information Security Management System

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# Conclusions

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There is still a lot of uncertainty about the new GDPR!



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