

## Facing further challenges in cancer data quality and harmonisation

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Provisional

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20 **8)**

21

22 **Abstract**

23 This article highlights the recent and ongoing activities of European population-based cancer registries  
24 (PBCRs) in data quality and harmonisation in the framework of the collaboration between the European  
25 Network of Cancer Registries (ENCR) and the Directorate-General Joint Research Centre (JRC), the  
26 science and knowledge centre of the European Commission.

27 The article concludes the Frontiers in Oncology's Research Topic "Joining Efforts to Improve Data  
28 Quality and Harmonization Among European Population-Based Cancer Registries", which has been  
29 an opportunity for several European researchers to share their experience on cancer data quality and  
30 harmonisation. Such experience will be helpful for PBCRs in view of future challenges and  
31 opportunities in cancer epidemiology, with a few examples discussed in the present article.

32 **1. Introduction**

## **Future challenges**

33  
34 During recent decades, the role of population-based cancer registries (PBCRs) has advanced beyond  
35 their traditional focus on providing cancer incidence and survival data, enlarging it to data providers  
36 for health-service management [1-4]. In this respect, PBCRs face further challenges of data quality and  
37 harmonisation issues.

38 Since 1990, the European Network of Cancer Registries (ENCR) has been operational with the aim to  
39 connect PBCRs in Europe.

40  
41 The ENCR plays a crucial role in supporting PBCRs to improve the quality (including comparability)  
42 and availability of cancer incidence data and paves the way for the use of data collected by PBCRs in  
43 cancer control, health-care planning and research. Cancer data comparability between countries and  
44 regions is particularly important for the European policy makers, who rely on the European Cancer  
45 Information System for accurate and up-to-date cancer burden statistics computed with data from the  
46 almost 200 PBCRs currently active in Europe. ENCR activities have a global impact, also due to its  
47 collaborations with the International Association of Cancer Registries (IACR) and the International  
48 Agency for Research on Cancer (IARC) and the fact that ENCR recommendations and guidelines  
49 regularly serve as models endorsed within the IACR. An example of collaboration between ENCR and  
50 IACR was the joint ENCR-IACR 2023 Scientific Conference, which took place in Granada, Spain, in  
51 November 2023 and was attended by more than 350 participants [5].

52  
53 The *Frontiers in Oncology* Research Topic “*Joining Efforts to Improve Data Quality and*  
54 *Harmonization Among European Population-Based Cancer Registries*” has been an opportunity for  
55 European researchers to share their experience on cancer data quality and harmonisation [6].

56 In this light, this article refers to all the contributions to the Research Topic and summarises the present  
57 situation in European PBCRs related to data quality and harmonisation, as well as the currently  
58 implemented activities carried out by ENCR and JRC to improve them. Of particular note, the activity  
59 of several ENCR working groups and the update of ENCR recommendations will be described.  
60 Moreover, the European Cancer Information System (ECIS) [7] as the ultimate outcome of data quality  
61 and harmonisation efforts will be presented.

62

## **63 2. Current advances of cancer registration in Europe**

64 Since 2012, the ENCR Secretariat has been hosted at the Joint Research Centre (JRC), the science and  
65 knowledge centre of the European Commission. In this scenario, several initiatives were carried out in  
66 the last decade [8] aimed at improving cancer data quality and harmonisation of European PBCRs: the  
67 JRC and ENCR coordinated thematic expert working groups to draft guidelines and recommendations  
68 on data collection, coding, and reporting, organised trainings, including on the revised  
69 recommendations, and developed common rules and related validation software to check data  
70 compliance to agreed European standards [9].

71 European PBCRs are very heterogeneous in terms of geographical coverage, either national or regional,  
72 and can cover very different population sizes, translating in datasets ranging from around 125,000 to  
73 over 50 million cancer records. Additionally, they differ regarding registration practices, for example

74 in relation to data sources, definitions and procedures. Therefore, common rules and definitions are  
75 necessary in order to harmonise data from different PBCRs and ensure their comparability at European  
76 level.

77 To this purpose, the following recommendations, reports and documents were published during the  
78 period 2022-2024 on the ENCR website [10].

79

## 80 **2.1. ENCR Recommendations**

81

### 82 **2.1.1. Data quality checks for European cancer registries**

83 Recognising the pivotal importance of comparability, completeness, validity, and timeliness in  
84 ensuring the reliability and utility of PBCR data, in 2013 the ENCR and JRC launched the Data Quality  
85 Checks Working Group to address the fragmented landscape of data validation methods across  
86 European PBCRs.

87 To achieve this objective, a series of workshops were convened in 2013 and 2014. These meetings  
88 served as forums for stakeholders from diverse backgrounds, including PBCR experts,  
89 epidemiologists, and data analysts, to collaboratively deliberate on the establishment of a harmonised  
90 framework for data quality assessment.

91 Following the work of the Cancer Data Quality Checks Working Group [11] the first agreed quality  
92 control checks among European PBCR's were proposed, aimed at validating the internal consistency  
93 of cancer incidence variables. The report, and later update [12] formed the basis for the JRC-ENCR  
94 Quality Check Software (QCS), described in one contribution of the current Research Topic [13].

95

### 96 **2.1.2. Standard dataset for the European Network of Cancer Registries (2023)**

97 This recommendation updates a previous document released in 2005 [14], to provide the minimum  
98 dataset to be collected by European PBCRs. Given the great expansion of PBCRs role in cancer control,  
99 quality assessment of cancer care, clinical and epidemiological research in the latest years, additional  
100 standardised data items were deemed necessary for registration. Thanks to the rapid growth of  
101 electronic records in the health care sector, many items may now be collected by linkage to existing  
102 data sources, as part of routine operations or on an ad hoc basis. However, the abundance of available  
103 data may be at the expense of standardisation and comparability. While the level of automation may  
104 increase access to growing amounts of data, the legal basis for access to and linkage with health data,  
105 varying greatly across Europe, may jeopardize the capacity to check the quality of such data.

106

107 The 2023 revision of the standard dataset recommendation [15-16] was drafted to preserve the  
108 possibilities for comparisons on cancer incidence between European and non-European PBCRs, to

## **Future challenges**

109 share data definitions for in-depth and wide-scale collaborative efforts and identify variables that may  
110 support an expanded role of PBCRs in cancer control.

### **111 2.1.3. Basis of Diagnosis (2022)**

112 The 2022 recommendations updated the previous ones from 1999 [17-19].

113 Basis of diagnosis is a key variable, including information both on the way in which the tumour is  
114 diagnosed and the level of likeness of the diagnosis itself. It is also influenced by the ability of  
115 individual PBCRs to intercept the different (pathological, cytological, molecular...) reports.

116  
117 Guidance in the latest recommendations is particularly relevant in the absence of pathological  
118 confirmation of the tumour. The proportion of clinical diagnoses (basis of diagnosis values 1, 2 and 4)  
119 is a data quality indicator. While a high proportion of clinical diagnoses in a PBCR may reflect the  
120 situation with regard to clinical and pathological investigations in the area covered by the PBCR, it  
121 may also indicate overdiagnosis and overestimation of cancer incidence, possibly taking into account  
122 tumours that would never have caused symptoms or death. On the other hand, PBCRs with a very low  
123 proportion of clinical diagnoses might underestimate incidence rates, potentially missing cancer cases  
124 that should be counted.

125 Among the modifications introduced, the new value 8 (Cytogenetic and/or molecular testing) for  
126 coding the basis of diagnosis is particularly relevant in view of the fast evolution of diagnostic  
127 techniques, such as karyotyping, FISH (fluorescent *in situ* hybridization), PCR (polymerase chain  
128 reaction) and DNA sequencing.

129

### **130 2.1.4. Cancer cases in migrant population (2022)**

131 In the wake of the increase in the number of migrants (including refugees) in European countries, and  
132 with a particular consideration of the millions of refugees from Ukraine to Europe, in 2022, a new  
133 ENCR recommendation was released to clarify and harmonise whether to register migrant individuals  
134 without a legal residency at the date of incidence [20].

135

### **136 2.1.5. Recording and Reporting of Urothelial Tumours of the Urinary Tract 137 (2022)**

138 Following the previous publication in 1995 of “*Recommendations for coding bladder cancers*” [21]  
139 and IARC’s 2003 book on “*Standards and guidelines for cancer registration in Europe*” [22],  
140 knowledge about the biology and pathology of urinary tract tumours and their classification has  
141 increased considerably [23]. Great variability has been observed among European PBCRs in the  
142 recording (i.e. registration) and the reporting (i.e. in presenting cancer burden statistics) of these  
143 tumours [24].

144 The 2022 ENCR recommendation aimed at improving comparability of data on urothelial tumours of  
145 the urinary tract in Europe by defining criteria mainly for registration, taking into account multiple

146 aspects of these tumours such as primary topography, histological type, grade, extent of invasion,  
147 multi-centricity, progressions and time interval between tumors [25-26]. An example of the rules that  
148 should lead to greater data harmonisation and comparability is the suggestion not to record the  
149 "Urothelial proliferation of uncertain malignant potential", which in any case are not reportable.

150

#### 151 **2.1.6. Coding Incidence Date (2023)**

152 The previous recommendation on the coding of incidence date was released in 1995 and revised in  
153 1997 [27]. The detection of inconsistencies in its application among European PBCR's led to the  
154 creation of a working group which re-prioritized events considered for the registration of incident date  
155 considering modern methods of diagnosis such as flow cytometry, molecular testing, screening tests  
156 and more recent radiological and imaging techniques [28]. An increased standardisation of incidence  
157 date, in addition to allowing more accurate cancer incidence statistics, also improves the consistency  
158 of survival estimates.

159

#### 160 **2.1.7. ENCR endorsement of the Toronto Childhood Cancer Stage Guidelines** 161 **(2016)**

162 In 2016 the ENCR Steering Committee endorsed and encouraged the active use of the Toronto  
163 Childhood Cancer Stage Guidelines by European PBCRs, in order to promote the consistency of stage  
164 data for childhood malignancies [29-31]. Moreover, the Toronto childhood cancer stage has been  
165 included in the latest 2022 ECIS data call protocol to European PBCRs.

166 One article of the current Research Topic shared the experience of the International Benchmarking of  
167 Childhood Cancer Survival by Stage (BENCHISTA) project in encouraging the implementation of the  
168 Toronto Childhood Cancer Stage Guidelines [32]. The extensive application of the Toronto staging  
169 allows for instance to study whether the differences in survival of patients with childhood cancers  
170 between countries are due to a different diagnostic timing or to differences in access to care and  
171 treatment protocols, which is the main objective of the BENCHISTA project.

172

#### 173 **2.2. The European Cancer Information System (ECIS)**

174 The JRC has been developing since 2012 ECIS as a comprehensive infrastructure, consisting of several  
175 components to manage a central data repository and to coordinate in an efficient and sustainable way  
176 the activities of data validation, analysis, and dissemination. A key component of the ECIS is a web-  
177 based tool launched in February 2018 [33] to report and disseminate cancer burden indicators such as  
178 incidence, mortality, survival and prevalence. Indicators in ECIS are derived from European PBCRs  
179 data. The ECIS web application [34] allows the visualisation of such indicators across European areas  
180 and time dimension.

181 The first data call to feed ECIS was launched in 2015. The database feeding ECIS is dynamic and is  
182 updated as new data becomes available.

## **Future challenges**

183 The ECIS web-application is modular and currently, its data explorer section consists of the following  
184 modules:

- 185 • *Incidence and mortality estimates* – latest release year is 2022 as the outcome of a  
186 collaborative project between JRC and the IARC, in collaboration with the ENCR;
- 187 • *Long-term incidence and mortality estimates up to 2040*, evaluating the impact of different  
188 demographic scenarios by 2040 on the cancer burden;
- 189 • *Survival estimates*, reporting on the results of the latest published EUROCORE-5 study [35];
- 190 • *Incidence and mortality historical data*, including indicators computed from PBCRs observed  
191 data;
- 192 • *Childhood cancer incidence historical data*, reported according to the International  
193 Classification of Childhood Cancer (ICCC), third edition.
- 194 • Prevalence estimates in 2020, reporting on the results of the EUROCORE-6 study [36].

195

### **2.2.1. The 2015 Call for Data protocol**

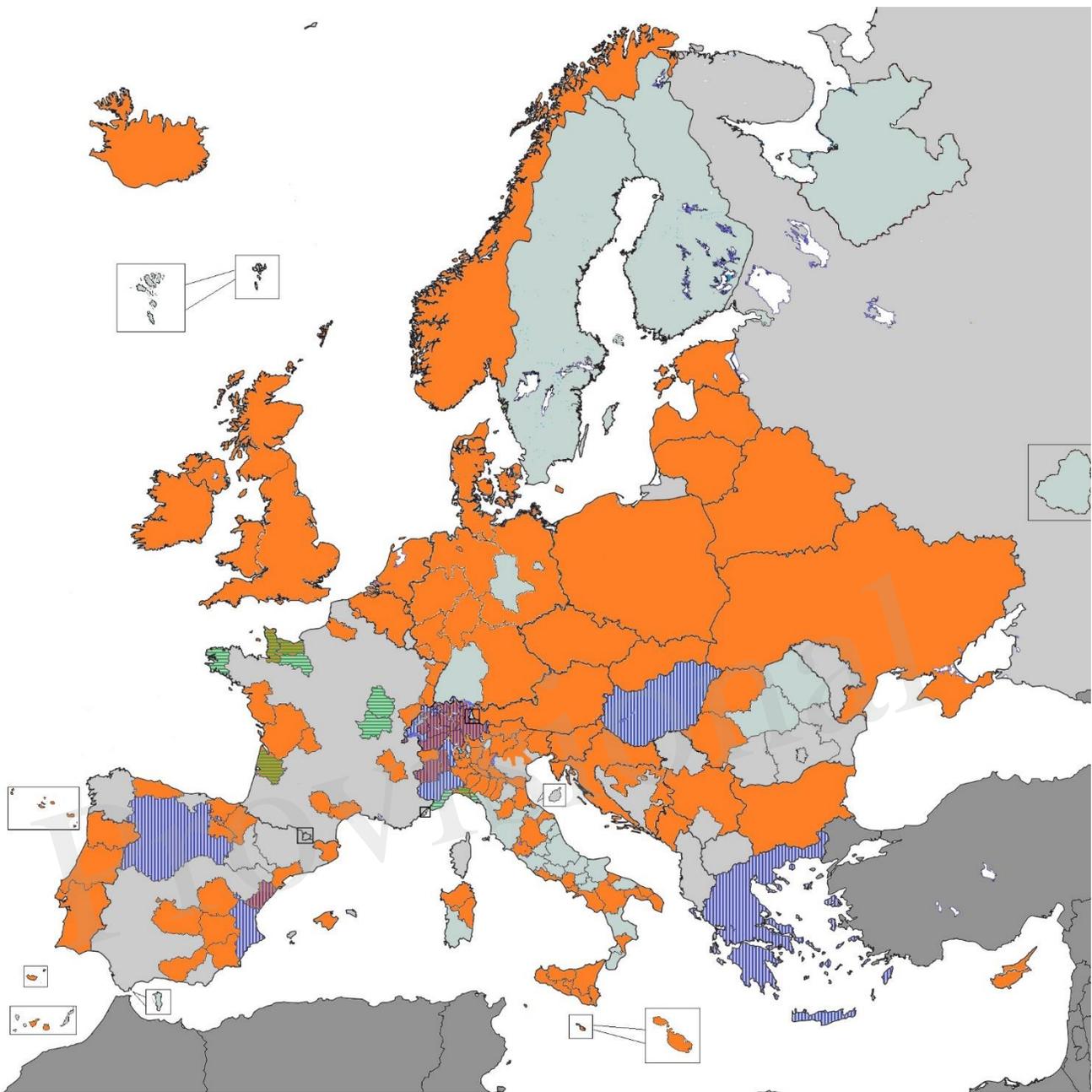
197 The 2015 Call for data protocol required the submission from European PBCRs of a cancer case file,  
198 a population file, a mortality file, life tables and a data submission questionnaire [37]. Data were  
199 harmonized at central level, incidence and mortality indicators were computed by the JRC and  
200 disseminated through the ECIS web application, released in 2018.

201 The variables required by the protocol for the incidence file included demographic and tumour  
202 characteristics like sex, age, topography, morphology, considered as core variables for reporting  
203 incidence indicators and which were the focus of data quality evaluations. Additionally, the protocol  
204 included variables for survival analysis, as well as stage and treatment information.

205

### **2.2.2. The 2015 European dataset**

207 ENCR-affiliated PBCRs contributed data to the 2015 Call for Data (Figure 1). Over 34.5 million  
208 incident cases were collected from general PBCRs (all ages and all cancer sites) and specialised  
209 (childhood or site specific) PBCRs. Data harmonisation procedures, such as correction of errors  
210 detected by the JRC-ENCR Quality Check Software and the implementation of multiple primary  
211 tumours rules were performed centrally at JRC and by the submitting PBCRs. Following data  
212 harmonisation, around 30 million cases from 145 PBCRs (with incidence years between 1953 and  
213 2014) were validated for the ECIS web application.



214  
 215 Figure 1. PBCRs contributing data 2015 ENCR-JRC Call for Data. Orange: all ages and all cancer sites PBCRs;  
 216 Vertical stripes: childhood PBCRs; Horizontal stripes: site-specific PBCRs.

217

218 **2.2.4 The 2022 Data Call protocol**

219 A second ECIS call was launched in 2022 to the ENCR PBCRs [38]. While the core variables from the  
 220 2015 protocol were retained, the experience gained from the previous call led to a few changes in the  
 221 2022 protocol, namely:

- 222
- the case definition was changed: in situ/non-invasive tumours requested only for breast, urothelial tumours, ovary and skin melanoma, whereas, according to the ICD-O-3.2 the only
- 223

## **Future challenges**

224 benign tumours should be those of the central nervous system and gastrointestinal stromal  
225 tumours (GIST);

- 226 • A finer geographical detail was requested, specifying the geographical area of residence at  
227 diagnosis for incident cases according to the NUTS classification level 2 (NUTS2) [39];
- 228 • Toronto childhood cancer stage was introduced;
- 229 • Better specification of treatment (e.g. for different systemic therapies) and related timing (e.g.  
230 neo-adjuvant vs adjuvant) was added.

231

232 Novelties in the 2022 ECIS protocol implied the definition and implementation of additional  
233 validation rules, and related work for the update of IT tools.

234

### **2.3 Data quality aspects addressed in the current Research Topic**

236 As shown in the present Research Topic, the quality of incidence data reported by European PBCRs  
237 improved between 1995 and 2014 [40]. The analysis of 28,776,562 cases from 130 PBCRs in 30  
238 European countries reported worse data quality for the oldest age groups and for cancer sites with poor  
239 survival. No differences were found between males and females, whereas high variability in data  
240 quality was detected across European PBCRs. The use of electronic health records, steadily increasing  
241 over the years, might be one of the contributing factors for a more accurate and timely registration of  
242 data.

243 A second contribution of the Research Topic focused on geographical variability and data quality in  
244 gastric and oesophageal cancer. A wide variability in oesophago-gastric cancers topographic subsites  
245 and histopathological types was observed, with a corresponding improvement in accuracy of  
246 registration in the study period (1995-2014) [41].

247

248 One article of the Research Topic focuses on the JRC-ENCR Quality Check Software (QCS) [13], as  
249 the IT tool developed by the JRC to check the internal consistency of PBCRs data.

250

251 Another valuable article of the present Research Topic thoroughly compared the functional  
252 characteristics of the JRC-ENCR QCS with the check tool developed by the IARC and the IACR [42].  
253 The paper concluded that it would be advisable to use both systems for data quality control, since they  
254 provide checks on different groups of variables (stage, follow-up) or on the same variables but with  
255 different modalities.

256 Finally, one important aspect of the improvement in data quality in European PBCRs is related to the  
257 enhanced possibility to analyse long-term cancer incidence trends. One example of such investigation  
258 is the article focusing on the incidence pattern of haematological neoplasms in Spanish children  
259 between 1983 and 2018, and its comparison with other southern European countries [43].

260

261 **2.4 Current focus of JRC- ENCR activities**

262 Harmonisation activities continue to be one major focus of the collaboration between the ENCR and  
263 the JRC. More specifically, the following topics are the subject of active ENCR Working Groups [9]:  
264

265 **2.4.1 Working Group on Treatment Data Harmonisation**

266 As reported in the present Research Topic, a growing number of European PBCRs are collecting  
267 treatment data [44]. This overview, which combined data from a literature review and conference  
268 proceedings, together with data from 125 European PBCRs, has led to the creation of a working group  
269 which provided the first recommendations for treatment data collection and coding, and the invitation  
270 to PBCRs to improve data harmonisation and comparability in Europe.  
271

272 **2.4.2 Working group on Cancer recurrences**

273 The aim of the working group is to define a protocol for the standardised collection of cancer  
274 recurrence, progression and transformation data by PBCRs.

275 **2.4.3 Working group on Central Nervous System tumours**

276 Aimed at updating the previous ENCR recommendation, dated 1998.

277 **2.4.4 Working group on Haematological malignancies**

278 Aimed at updating the previous ENCR recommendation, dated 2014.

279 **2.4.5 Working group on Survival in ECIS**

280 Aimed at defining the data standards and quality checks to be applied for publication of survival  
281 indicators in ECIS.

282 **2.4.6 Working group on Multiple Primaries Registration**

283 Aimed at updating the previous ENCR recommendation, dated 2004.  
284  
285

286 **2.5 ECIS in the context of the European Commission's Europe's Beating Cancer Plan**  
287 **(EBCP)**

288 The European Commission's Europe's Beating Cancer Plan (EBCP) [45], released in February 2021,  
289 is structured around four key action areas (Prevention, Early detection, Diagnosis and treatment,  
290 Improvement of quality of life) and is supported by 10 flagship initiatives, underscoring the European  
291 Union's commitment to support cancer prevention, treatment, and care across the continent. In this  
292 context, a Knowledge Centre on Cancer [46] and the European Cancer Inequalities Registry [47] were  
293 established in the framework of the EBCP.

## **Future challenges**

294 Several activities and collaborations are ongoing to expand the information provided by the ECIS in  
295 line with commitments of the EBCP and demand for good quality data at population level will continue.  
296 The following is a list of developments in line with such commitments, including:

- 297 • Providing cancer incidence data at regional level, following the NUTS (Nomenclature of  
298 Territorial Units for Statistics) classification level. The availability of more granular data will  
299 facilitate ecological comparisons (for instance, with environmental and socio-economic data)  
300 and align with the overarching EBCP actions aiming to address inequalities between and within  
301 EU Member States. On this point, it will be important to monitor possible issues of  
302 reidentification of patients that might arise with more granular data;
- 303 • Displaying of cancer prevalence data, necessary for proper quantification to support EBCP  
304 objectives of reducing the burden of cancer, improving cancer outcomes, and enhancing the  
305 quality of life for all cancer survivors across Europe;
- 306 • Reporting on cancer stage data, which guide evidence-based decision-making tracking  
307 advancements towards cancer control goals and promoting quality improvement in cancer care;
- 308 • Exploring the expansion to cancer screening data monitoring, in line with the fourth EBCP  
309 flagship initiative, which aims to put forward a new EU-supported Cancer Screening Scheme  
310 to help Member States ensure that 90% of the EU population who qualify for breast, cervical  
311 and colorectal cancer screenings are offered screening by 2025. The CanScreen-ECIS project  
312 [48] paved the way towards this achievement.

### **3 Discussion**

315 The improvement in quality and the harmonisation of PBCRs data will remain the focus of JRC and  
316 ENCR activities. As indicated by European PBCRs [49], a priority should be to develop a common  
317 mechanism for estimating the national cancer burden for countries with partial cancer registration, to  
318 enable direct and more accurate comparisons between countries. In addition, countries with absent or  
319 underdeveloped cancer registration should be assisted in establishing PBCRs. The quality indicators  
320 reported in the present Research Topic can be used as the baseline for monitoring PBCRs data quality  
321 indicators in Europe [40].

322  
323 Reliable data from PBCRs are crucial for the effective implementation and evaluation of cancer control  
324 programmes. The standardisation of data and the harmonisation of procedures has led to an overall  
325 improvement in the description of neoplastic diseases and how incidence, survival, prevalence,  
326 mortality are all necessary (and somehow interlaced) indicators for understanding the epidemiology of  
327 tumors. The role of PBCRs has been expanding over the years; at the same time, thanks also to the  
328 essential action of ENCR and JRC, European PBCRs have made progress over the last decades with  
329 regard to data quality. This momentum should be sustained in order to further improve harmonisation  
330 and decrease resource disparities leading to quality disparities. Clear guidelines and policies offer the  
331 basis for this, with guiding principles for the equitable and effective operation of PBCRs providing a  
332 structured framework that enables registries to maximise their potential and contribute to cancer  
333 surveillance and research efforts, regardless of resource constraints.

334

335 Ongoing advances in technology can offer alternative models for data sharing and international  
336 comparisons, for instance a federated approach for data collection, as shown in the current Research  
337 Topic “*Joining Efforts to Improve Data Quality and Harmonization Among European Population-*  
338 *Based Cancer Registries*” with the description of the Nordcan.R tool. The article showed how the tool  
339 is used to compute statistics for the Nordic cancer statistics web platform NORDCAN, and  
340 demonstrated that it works also with non-Nordic data [50].

341 An innovative approach in view of federated data quality evaluations was also presented in the current  
342 Research Topic. The article presented an ontology created using a modular approach to handle specific  
343 checks for childhood cancers, leading to a simpler maintenance of data validation rules [51].  
344

345 In this context, a key role is going to be played by the future European Health Data Space (EHDS), a  
346 European Commission initiative to build a common EU framework facilitating the use of health data  
347 for secondary purposes that could be beneficial to European PBCRs by facilitating cancer data sharing  
348 [52]. This initiative aims to improve interoperability and accessibility of health data across Europe,  
349 fostering better research and improved public health outcomes. By creating a standardised environment  
350 for health data exchange, the EHDS will enable more efficient data sharing between PBCRs and  
351 researchers, helping to overcome current barriers related to data fragmentation and diverse national  
352 regulations. This will not only help streamlining the process of data harmonisation but will also  
353 promote innovation in cancer research, ultimately contributing to more effective cancer prevention and  
354 treatment strategies across Europe.

355  
356 Three articles in the present Research Topic focus on methodologies for the computation of cancer  
357 prevalence. A first article showed two alternative approaches in the framework of the completeness  
358 index method, based on incidence and survival modelling, in order to provide comparable indicators  
359 on complete cancer prevalence [53]. The second article described the procedures to derive complete  
360 prevalence and several indicators of cancer cure from PBCRs. Limited duration prevalence was  
361 calculated for 62 cancer types by sex and PBCR, presenting indicators which may be relevant for  
362 patients and clinical practice and reproducible in different European countries [54]. Lastly, a new  
363 method to estimate short-time projections of cancer prevalence by phase-of-care was illustrated.  
364 Evidence from this method was addressed to policy makers for planning future cancer care, thus  
365 improving cancer survivorship experience for patients and care-givers [55].  
366

367 Finally, in recent years, biomarkers have become more important in guiding diagnosis and treatment  
368 options as well as for the prognosis of several tumour types such as, for example, breast, oropharyngeal  
369 and lung cancer [56]. The use of biomarkers is also important in predicting recurrences. For this reason,  
370 biomarkers should be taken into account in the future by the ENCR because it will be necessary to  
371 standardise data collection, coding and reporting of this key information.  
372

373

374

375 **Conflict of Interest**

## Future challenges

376 The authors declare that the research was conducted in the absence of any commercial or financial  
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Figure 01.TIF

