

Available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejcancer.com

Completeness and timeliness: Cancer registries could/should improve their performance

R. Zanetti^{a,*}, I. Schmidtman^b, L. Sacchetto^a, F. Binder-Foucard^c, A. Bordoni^d,
D. Coza^e, S. Ferretti^f, J. Galceran^g, A. Gavin^h, N. Larranagaⁱ, D. Robinson^j,
L. Tryggvadottir^k, E. Van Eycken^l, V. Zadnik^m, J.W.W. Coeberghⁿ, S. Rosso^a

^a Piedmont Cancer Registry, CPO, Via San Francesco da Paola 31, 10123 Turin, Italy

^b Institute of Medical Biostatistics, Epidemiology and Informatics (IMBEI), Division Medical Biometry, University Medical Center of the Johannes Gutenberg, University Mainz, Langenbeckstr. 1, D 55131 Mainz, Germany

^c Registre des Cancers du Bas-Rhin, 11 rue Humann, 67085 Strasbourg Cedex, France

^d Ticino Cancer Registry, Istituto cantonale di patologia, Via Selva 24, 6601 Locarno, Switzerland

^e Cluj Regional Cancer Registry, Dept. of Epidemiology & Medical Biostatistics, Oncological Institute 'Ion Chiricuta', Republicii Street No. 34-36, 400015 Cluj Napoca, Romania

^f Ferrara Cancer Registry, Via Fossato di Mortara 64B, 44121 Ferrara, Italy

^g Tarragona Cancer Registry, Foundation Society for Cancer Research and Prevention, IISPV, C/ Josep Laporte, 1, 43204 Reus, Spain

^h Northern Ireland Cancer Registry, Dept. of Epidemiology & Public Health, Queen's University Inst. of Clinical Science, Mulhouse Bldg, Grosvenor Road, BT12 6BJ Belfast, Northern Ireland, UK

ⁱ Basque Cancer Registry, Servicio de Registros e Informacion Sanitaria, Departamento de Salud del Gobierno Vasco, 01010 Donostia-San Sebastian 1, 01010 Vitoria-Gasteiz, Spain

^j Thames Cancer Registry, King's College London, Cancer Epidemiology and Population Health, 1st Floor, Capital House, 42 Weston Street, SE1 3QD London, UK

^k Icelandic Cancer Registry, Icelandic Cancer Society, P.O. Box 5420, Skógarhlíd 8, 125 Reykjavik, Iceland

^l Belgian Cancer Registry, Koningstraat 215, 1210 Brussels, Belgium

^m Cancer Registry of Republic of Slovenia, Institute of Oncology Ljubljana, Zaloska cesta 2, 1000 Ljubljana, Slovenia

ⁿ IKZ Integraal Kankercentrum Zuid, P.O. Box 231, 5600 AE Eindhoven, The Netherlands

KEYWORDS

Cancer registry
Completeness
Timeliness
Flow methods

Abstract Cancer registries must provide complete and reliable incidence information with the shortest possible delay for use in studies such as comparability, clustering, cancer in the elderly and adequacy of cancer surveillance. Methods of varying complexity are available to registries for monitoring completeness and timeliness. We wished to know which methods are currently in use among cancer registries, and to compare the results of our findings to those of a survey carried out in 2006.

* Corresponding author: Tel.: +39 011 5665355; fax: +39 011 5665362.
E-mail address: roberto.zanetti@cpo.it (R. Zanetti).

Methods: In the framework of the EURO COURSE project, and to prepare cancer registries for participation in the ERA-net scheme, we launched a survey on the methods used to assess completeness, and also on the timeliness and methods of dissemination of results by registries. We sent the questionnaire to all general registries (GCRs) and specialised registries (SCRs) active in Europe and within the European Network of Cancer Registries (ENCR).

Results: With a response rate of 66% among GCRs and 59% among SCRs, we obtained data for analysis from 116 registries with a population coverage of ~280 million. The most common methods used were comparison of trends (79%) and mortality/incidence ratios (more than 60%). More complex methods were used less commonly: capture–recapture by 30%, flow method by 18% and death certificate notification (DCN) methods with the Ajiki formula by 9%.

The median latency for completion of ascertainment of incidence was 18 months. Additional time required for dissemination was of the order of 3–6 months, depending on the method: print or electronic. One fifth (21%) did not publish results for their own registry but only as a contribution to larger national or international data repositories and publications; this introduced a further delay in the availability of data.

Conclusions: Cancer registries should improve the practice of measuring their completeness regularly and should move from traditional to more quantitative methods. This could also have implications in the timeliness of data publication.