



The International Cancer Benchmarking Partnership: An international collaboration to inform cancer policy in Australia, Canada, Denmark, Norway, Sweden and the United Kingdom ☆☆☆



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ABSTRACT

The International Cancer Benchmarking Partnership (ICBP) was initiated by the Department of Health in England to study international variation in cancer survival, and to inform policy to improve cancer survival. It is a research collaboration between twelve jurisdictions in six countries: Australia (New South Wales, Victoria), Canada (Alberta, British Columbia, Manitoba, Ontario), Denmark, Norway, Sweden, and the United Kingdom (England, Northern Ireland, Wales). Leadership is provided by policymakers, with academics, clinicians and cancer registries forming an international network to conduct the research. The project currently has five modules examining: (1) cancer survival, (2) population awareness and beliefs about cancer, (3) attitudes, behaviours and systems in primary care, (4) delays in diagnosis and treatment, and their causes, and (5) treatment, co-morbidities and other factors. These modules employ a range of methodologies including epidemiological and statistical analyses, surveys and clinical record audit. The first publications have already been used to inform and develop cancer policies in participating countries, and a further series of publications is under way. The module design, governance structure, funding arrangements and management approach to the partnership provide a case study in conducting international comparisons of health systems that are both academically and clinically robust and of immediate relevance to policymakers.

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1. Background to and aims of the International Cancer Benchmarking Partnership

1.1. Introduction and aims

The International Cancer Benchmarking Partnership (ICBP) is a collaboration of policymakers, researchers and clinicians from six countries: Australia, Canada, Denmark, Norway, Sweden and the United Kingdom. The initiative for the ICBP came from the English Department of Health (DH). Survival from many cancers in England and the UK is lower than in comparable countries [1–5]. Poorer cancer survival can reflect a pattern of later presentation or diagnosis of cancer, because more advanced cancers are difficult to treat successfully. The comparatively low one-year survival in the UK suggests that late diagnosis may be a major factor. It is unclear whether patients present to health care later in the UK than elsewhere, or whether they are not being referred adequately by GPs in the primary care sector, or not being effectively investigated in secondary care. In order to address these questions and to examine the role of treatment variation in international differences in survival, an innovative international study of cancer survival was initiated.

The key aims of the ICBP are to update existing studies of international variation in cancer survival and to explore reasons for the differences that have been reported. Although the leadership for the ICBP has come from policymakers, close involvement of academics and clinicians at every stage has been essential. The work has involved many new approaches and analyses to ensure international comparability of datasets and valid benchmarking [6,7]. This article outlines the background to the ICBP, the methodologies, the results and the lessons that have been learned to date.

1.2. Background

Population-based cancer registration has enabled useful international comparisons of key cancer measures, including incidence, prevalence and survival. In particular, cancer survival is a key measure of health system performance, because variations in survival point to potentially avoidable deaths among jurisdictions with lower survival [8]. International comparisons of cancer survival have prompted new health policy in countries with low survival, and they help to inform global cancer control strategies [9–13]. However, decisions on how to reform the national provision of cancer care have often relied on other considerations than a sound knowledge-base.

Therefore, there is a need for comprehensive knowledge about the complex processes in the cancer pathway, from the very first symptoms of cancer in a person to their eventual investigation, treatment and care in the health system.

The major international studies of cancer survival are subject to three criticisms. Firstly, the delay between the period during which the patients were diagnosed and the publication of the report ranges from 9 to 14 years, during which interval significant changes in health policy or treatment may occur. These studies provide useful insights into recent patterns of survival, but may not provide contemporary information of direct relevance to policy-makers because they can rarely reflect the impact of recent national and local initiatives [12–15] (see Table 1).

A second criticism is the population coverage of the cancer registries. In some regions, such as Scandinavia and the United Kingdom, there is national cancer registration. In other countries population-based cancer registries only cover a small proportion of the national population (e.g. Germany 1%, France 11%, Spain 14%, Italy 25%), albeit with comprehensive population coverage in the registry areas.

Thirdly, international comparisons may quantify differences in cancer survival, but do not usually explain why they exist. For example, are they due to later presentation of cancers in countries with low survival, leading to reduced access to optimal treatment, hence prompting strategies to improve earlier diagnosis? Both CONCORD and EURO-CARE groups have conducted “high-resolution” studies to look in detail at disease, patient and treatment factors that may influence survival. These indicate that more advanced stage at diagnosis and the quality of treatment both have an impact on international differences in survival [17–20]. For some cancers (e.g. breast) most of the longer-term survival variation in Europe is due to low 1-year survival, because five-year survival amongst patients who survive one year is similar to the European average [21]. This suggests that low breast cancer survival in the UK is mainly attributable to late diagnosis or advanced stage. For other tumours, such as the kidney, both 1-year survival and 5-year survival conditional on survival to one year are low, suggesting both late diagnosis and treatment differences.

With this background, the National Cancer Director for England, Professor Sir Mike Richards, established the International Cancer Benchmarking Partnership in 2009 (www.icbp.org.uk) [22]. The partnership aims to identify and explain the relative contribution of different factors to cancer survival variations between high-income countries, so that the findings can be used to inform cancer policy and improve cancer survival.

Table 1
Major international studies of cancer survival.

	Period of diagnosis	Last year of follow-up	No of countries and cancer registries in study	Date of publication	Main publication
EURO-CARE-1	1978–1984	1989	30 cancer registries in 12 European countries	1995	Berrino et al. (1995) [1]
EURO-CARE-2	1985–1989	1994	45 cancer registries in 17 European countries	1999	Berrino et al. (1999) [2]
EURO-CARE-3	1990–1994	1999	67 cancer registries in 22 European countries	2003	Berrino et al. (2003) [3]
CONCORD	1990–1994	1999	101 cancer registries in 31 countries	2008	Coleman et al. (2008) [5]
EURO-CARE-4	1995–1999	2003	83 cancer registries in 23 European countries	2009	Berrino et al. (2007) [4]
ICBP	1995–2007	2007	20 cancer registries in six countries	2011	Coleman et al. (2011) [16]

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