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# The Europeanization of Health System Performance: The EUROCARE Study and Cancer Control in England

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**FIRST DRAFT**

## **Abstract**

The EUROCARE study is a joint effort by European cancer epidemiologists to measure cancer survival rates in a large sample of European countries. Its publication over a decade ago brought some salience to the poor performance of Britain within the European Union. The subsequent national cancer control programme initiated in England resulted partly of that event, which suggests that, along with the transformative effects of EU-level policy-making, Europeanization also occurs through the indirect activity of epistemic communities. I provide an analytical framework that draws on the sociology of quantification and on the politics of measurement and performance to show how cancer control and health policy can undergo significant reforms due to discrete and asynchronous acts of EU government.

**Acknowledgements** Instead of a formal acknowledgement, I would like to apologise to the discussant for the late delivery and theoretical overload of this paper. On a brighter side, even though this draft was not discussed with my former colleagues from the Sciences Studies Unit at the University of Edinburgh, I reckon a lot of its ideas intersect with the fascinating literature and research that I discovered during my two-year stay with them. I wish to thank them all for our discussions under the invaluable stewardship of David Bloor, John Henry and Carole Tansley. All mistakes and omissions naturally remain mine and mine only.

# 1 Introduction

Health systems are difficult grounds for the European Union to develop a full-fledged mandate, especially when it comes to health system funding or services and staff regulation. Even when EU law ends up, after tiresome political struggles, eventually affecting the core functioning of health systems, their implementation is subject to complex domestic arrangements and renewed political conflict.<sup>1</sup> Still, health systems and policies show some form of “chaordic” integration.<sup>2</sup> Empirically, then, the authority of the European Union (whether legally binding or not) over health remains an empirical puzzle, and a conceptual one for all scholars concerned with Europeanization as a political process of “legal, economic, and cultural territorial de-differentiation”.<sup>3</sup>

Recent perspectives in that field of inquiry suggest that theorising and conceptualising Europeanization will require, in the future, that we move even further away from neo-functionalism than we already have, in order to capture some of the more subtle processes at play behind the salient effects of EU institutions; “It can be useful as a corrective to this bias to think of the processes of policy adjustment in other international arenas and epistemic communities; these are much more horizontal and not without suitable, more generic, conceptual apparatus.”<sup>4</sup> In what follows, I follow that suggestion and focus on the transformative effects brought to a domestic policy environment by an epistemic community<sup>5</sup> of European cancer epidemiologists; this community has only loose ties to EU institutions, but its activity has translated into policy changes that strongly relate to the general direction of health care and public health at the European level.

The following introductory paragraphs set out the outline of the argument and the methods used to collect the empirical data; the next sections offer a narrative of the case study and a possible theorisation to support its findings; the paper concludes on some general remarks about the scope and potential generalisation of the results.

1. Scott L. Greer, *The Politics of European Union Health Policies. Making European Health Policy in Germany, France, Spain and the United Kingdom* (Maidenhead: Open University Press, 2009).

2. Wolfram Lamping and Monika Steffen, “European Union and Health Policy: The “Chaordic” Dynamics of Integration,” *Social Science Quarterly* 90, no. 5 (2009): 1361–1379.

3. Stefano Bartolini, *Restructuring Europe. Centre Formation, System Building and Political Structuring between the Nation-State and the European Union* (Oxford: Oxford University Press, 2005), xii.

4. Simon Bulmer, “Theorizing Europeanization,” in *Europeanization. New Research Agendas* (Basingstoke: Palgrave Macmillan, 2007), 56.

5. The notion designates “a network of professionals with recognised expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area. Although an epistemic community may consist of professionals from a variety of disciplines and backgrounds, they have (1) a shared set or normative and principled beliefs... (2) shared causal beliefs... (3) shared notions of validity... and (4) a common policy enterprise – that is, a set of common practices associated with a set of problems to which their professional competence is directed, presumably out of the conviction that human welfare will be enhanced as a consequence.” (Peter M. Haas, “Epistemic Communities and International Policy Coordination,” *International Organization* 46, no. 1 (1992): 3).

## 1.1 Outline of the argument

In this paper, I show how the European Union acquired an effective influence in cancer control, and more specifically in cancer control *performance*, which had consequences for domestic health systems and public health policies at large. As I explain in Section 2, EU involvement to the “fight against cancer” was initially marked by a soft-law overtone, which still bore important consequences in some branches of cancer control, such as tobacco policy.<sup>6</sup> However, as I show by focusing on one seemingly ‘harmless’ items of that approach, the EURO CARE epidemiological study, the European Union has had a more general effect on cancer control by forcing at least two Member States – Denmark and the UK – to adopt national cancer control programmes that have deeply affected the health systems and policies of these countries.

I leave Denmark aside in the remainder of this paper and will focus on the UK, and on England more specifically, in Section 3.<sup>7</sup> I then offer, in Section 4, a complete analytical framework to gain a precise understanding of the mechanisms that underlie this indirect and perhaps uncommon process of Europeanization.

My intention with this paper is to refine current approaches of Europeanization by exploring a parallel track to legal and institutional reform, by showing how EU-level ‘knowledge initiatives’ like the EURO CARE study can have a substantive effect on domestic policy environments, even when the formal involvement of EU actors is residual and the influence of EU institutions tenuous (at best), as in the case of the EURO CARE study. I have tried to delineate as precisely as possible what I have observed about the EURO CARE, as to provide a full-fledged empirical exemplar for what I end up calling ‘disciplinary acts of EU comparison.’ The logic of these acts might be relatively trivial, but I believe they deserve more observational attention and a stronger theoretical foundation. In that task, I draw on a large literature taken from political science as well as organizational theory and from the sociology of quantification.

6. The influence of the European Union on tobacco control policies is the subject of an large literature; see especially Tamara K. Hervey and Jean V. McHale, *Health law and the European Union* (Cambridge: Cambridge University Press, 2004), 368-384; Francesco Duina and Paulette Kurzer, “Smoke in Your Eyes: The Struggle over Tobacco Control in the European Union,” *Journal of European Public Policy* 11, no. 1 (2004): 57–77; Sebastiaan Princen, “Advocacy Coalitions and the Internationalization of Public Health Policies,” *Journal of Public Policy* 27, no. 1 (2007): 13–33; Hadii M. Mamudu and Donley T. Studlar, “Multilevel Governance and Shared Sovereignty: European Union, Member States, and the FCTC,” *Governance* 22, no. 1 (2009): 73–97.

7. Second-hand evidence that Denmark was affected by the EURO CARE, for the same reasons as the UK was, appears in Michael O. Appel, *Cancer Plan*, 5-2005, Health Policy Monitor (Berlin: Bertelsmann-Stiftung, 2005). I have not empirically researched the case further (yet).

## 1.2 Methods

The paper fits into a larger inquiry of national cancer control programmes in England and France, which I examine from two policy perspectives (agenda-setting and institutional autonomy). I intend to set out a theoretical framework to understand why states become concerned with the disease constituency formed by cancer sufferers, how does cancer control become elevated onto the governmental agenda, and what makes national cancer control programmes distinct within the larger policy domains of health care and public health. I focus on the empirical case of England, although similar policy initiatives are observable in the devolved British governments and health administrations.<sup>8</sup>

The argument offered is a low-resolution one of mostly theoretical texture, and what is left of speculation in my analysis is to be tested against additional interviews in the coming months. I also hope to lose some abstraction in the final draft, as well as adjust some of the empirics: my sources rarely conflict frontally on the narrative, but some of them do not triangulate so to speak. The sources are limited to publicly available publications from general media and specialised outlets (mostly medical journals). I have also started to collect interviews with key stakeholders, always as face-to-face interactions, and either as formal meetings or through common attendance at scientific conferences and symposia. The twelve-or-so interviews that I have collected with regards to the present issue show no major discrepancy between the public and ‘offstage’ transcripts of the narrative. Additional information was also acquired through email from researchers in Italy, France and the UK.

## 2 Background

### 2.1 Cancer Control in EU Programmes

The European Union (EU) has been fairly involved in shaping the cancer control policies as soon as the European Councils in Milan and Luxembourg of June and December 1985, when it recognized cancer as a priority within its public health agenda.<sup>9</sup> The overall EU health mandate has evolved since that date;<sup>10</sup> however, the *modus operandi* of the European Union within the cancer policy domain has stayed remarkably stable: from 1987 to 2002,

8. Devolved health polities in the UK would require a different research framework that would account for at least three dimensions: the territorial politics of health policy in post-devolution Britain; the policy diffusion effects between England on the one hand and Northern Ireland, Scotland and Wales on the other; and the supranational influence of EURO CARE and other potential factors in these territories. A lot of Scott Greer’s research could be used in assembling such a framework, which I intend to do in a later research project.

9. Just as ‘public health’ and ‘health care’ overlap and are notoriously difficult to map precisely, ‘cancer control’ designates a wide gamut of activities that span over several medical disciplines, practices and health policies.

10. See Hervey and McHale, *Health law and the European Union* for a thorough history.

three “Europe Against Cancer” (EAC) action programmes were launched, largely under the influence of two French and Italian oncologists, and in the aftermath of the 1986 Chernobyl disaster.<sup>11</sup> All programmes, which differ only in their (modest) budgets and in the emphasis set on each of their components, have aimed at improving cancer prevention (including important initiatives in tobacco control), scientific information and public awareness, and medical training.

The successive EAC programmes were subsumed in an overarching ‘public health framework’ from 2003 to 2008.<sup>12</sup> Recently, the European Union’s specific interest in cancer control was revived with the launch of the 2009–13 “European Partnership Against Cancer” (EPAC) initiative,<sup>13</sup> The sum-total of EU cancer-specific programmes (shown in Fig. 1) reflects sustained attention from, and broadly consensual decision-making between, EU institutions. The mandate they have shaped for EU involvement into cancer control has not dramatically evolved over time in the way that other branches of EU health policy-making have, such as EU involvement in health systems policy.<sup>14</sup> The most substantial change in EU cancer control policies occurred with the third EAC, which drew from the then recent Article 129 EC (now Article 152 EC) introduced into the Treaty of Rome at Maastricht in 1992. Making extensive use of the language of “health protection,” the third EAC offered to develop quality assurance and control for cancer prevention, which led to the Council adopting a Recommendation on cancer screening in December 2003; more recently, the European Commission has published “European guidelines for quality assurance in breast and cervical cancer screening and diagnosis,” as well as an Implementation Report in December 2008.<sup>15</sup> None of these soft-law, benchmarking initiatives has been particularly controversial<sup>16</sup>

11. See Louise G. Trubek, Mark Nance, and Tamara K. Hervey, “The Construction of Healthier Europe: Lessons from the Fight Against Cancer,” *Wisconsin International Law Journal* 26, no. 3 (2008): 868–907 for a synthetic overview of how the EAC programmes were born, and Hervey and McHale, *Health law and the European Union*, 368-374 on how they developed, with particular reference to tobacco control. At some point in his recently published memoirs, French oncologist Maurice Tubiana offers a slightly different narrative for the genesis of the EAC initiatives: apparently, after an unsuccessful attempt at getting a national cancer plan from the French health minister in the early 1980s, Tubiana decided to go venue-shopping and, in his own words, ‘went to the European Commission’ (confirmed by interview data obtained on April 7, 2008). In both scenarios, the personal influence of oncologists is unavoidable; the importance of the Chernobyl disaster as a focusing event in the agenda-setting pattern is also undeniable, as the first EAC programme was launched only four months after the incident, by a Resolution of the Council adopted on July 7, 1986; the European Parliament delivered its opinion even sooner after the disaster, on May 12, 1986 (*OJ* 1986 184/19).

12. Decision 1786/2002/EC adopting the new public health framework, (*OJ* 2002 L271/1); cited by *ibid.*, 373.

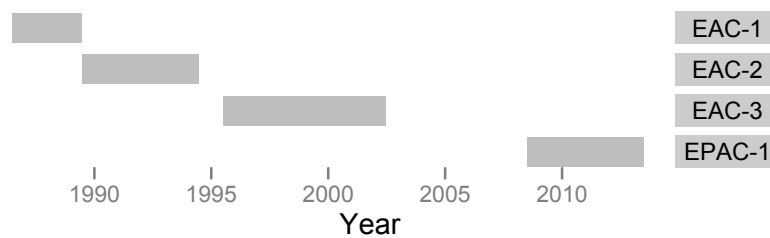
13. “Working together to fight cancer- President Barroso and Commissioner Vassiliou launch the European Partnership for Action against Cancer,” EC Press Release [IP/09/1380](#), 29 September 2009.

14. Scott L. Greer, “Choosing Paths in European Union Health Services Policy: A Political Analysis of a Critical Juncture,” *Journal of European Social Policy* 18, no. 3 (2008): 219–231.

15. Council Recommendation of 2 December 2003 on cancer screening (2003/878/EC); Commission Report on the implementation of the Council Recommendation on cancer screening (COM(2008)882); see the European Commission website, “[Key Documents in Genetics and screening](#)” section.

16. Neither have they produced dramatic effects, by that matter: population-based screening programmes remain patchy in 5 to 12 Member States depending on tumour type; see “Europe needs to intensify and double cancer screening, concludes Commission report,” EC Press Release [IP/09/113](#), 22 January 2009.

Figure 1: EU cancer-specific programmes, 1987–2013.



## 2.2 The EUROCARE cancer knowledge initiative

A common characteristic of all EU cancer-specific programmes lies in the funding of EU-wide ‘knowledge initiatives’ dedicated to cancer, by which I designate the vast research effort deployed by epidemiologists and cancer specialists in virtually all European Member States to gain a precise understanding of cancer as a disease and of cancer incidence, prevalence, mortality and survival within the borders of the European Union (and sometimes beyond these borders). The EUROCARE study was part of these projects,<sup>17</sup> and has been funded through a string of European research grants, such as the European Union BIOMED and FP4 programmes.

EUROCARE stands for European Cancer Registry-based study on survival and care of cancer patients. Its main investigators define it as “a cancer epidemiology research project on survival of European cancer patients.” The project was established in 1989 as a collaborative effort between two Italian research centres, and then expanded to include as many population-based cancer registries as possible, from as many European countries as possible, depending on incidence and survival data availability.”<sup>18</sup> Its four completed waves are based on epidemiological cohorts of cancer patients diagnosed between 1978 and 2002, and its next edition (“EUROCARE-5”) aims at providing data for patients diagnosed up to 2007. By accretion, the EUROCARE studies have produced a very detailed picture of cancer survival in Europe for patients diagnosed over two decades (as shown in Fig. 2), and will soon cover three decades of cancer survival in European countries.

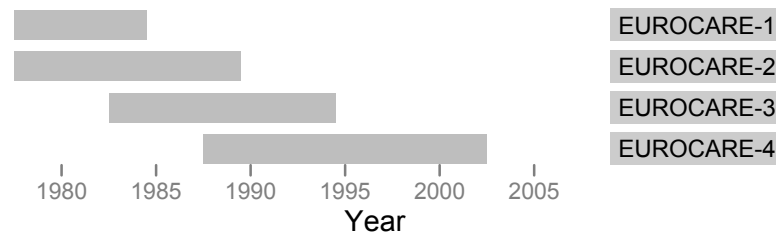
There is little doubt that EUROCARE is one of, if not the most, prominent study in cancer epidemiology in the past decade. The publication output of the study reaches slightly over 90 papers (including several IARC monographs<sup>19</sup>), sometimes co-authored by more

17. A list of the plethora cancer research initiatives that received financial support of the European Union is available on the European Commission’s website, “Major and chronic diseases: Cancer” section.

18. EUROCARE website, “About Us” section. At this date, the membership has expanded to 83 European cancer registries in 21 countries.

19. The *International Agency for Research on Cancer* (IARC) is an agency created at arm’s length of the World Health Organisation in 1962. The Agency intends to be an authoritative source of knowledge on the

Figure 2: EUROCARE coverage of diagnosed cancer patients, 1978–2002.



than 150 scientists, in high-profile medical journals specialised in cancer research<sup>20</sup>. These publications have, in turn, attracted citations from other articles.<sup>21</sup>

The intended effect of the EUROCARE study was to provide information on cancer survival in Europe, as well as to “help health authorities to make informed decisions regarding the most effective investment of resources.” As its long-term goals, the study seeks to “reduce inequalities in cancer care and survival across Europe, increase standards of cancer care in Europe,<sup>22</sup> and provide information that is useful for health planners, doctors and citizens as well.”<sup>23</sup> The task of the group was hence meant to be state-*enabling*, rather than state-*ranking*. However, the EUROCARE publications did link cancer survival to health system performance, and also suggested, in its second edition, that “it may be of interest to compare the ranking of the age-adjusted survival estimates for the 17 European countries included in the study with that of the usual economic indicators of gross domestic product and health expenditure.”<sup>24</sup> Five years later, following the third edition of EUROCARE, the comparison was actually performed and published in a supplement to the *Annals of Oncology*.<sup>25</sup> The results of that comparison carried a very important policy implication, with the authors

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causes of human cancer, on carcinogenesis and on the worldwide spread of cancer. It also develops evidence-based strategies for cancer prevention and control.

20. The primary targets have been the *European Journal of Cancer*, the *Lancet Oncology*, the *International Journal of Cancer* and the *Annals of Oncology*, all of which are very reputed outlets in cancer epidemiology. For a small sample of EUROCARE 1–4 publications, see Franco Berrino et al., eds., *Survival of Cancer Patients in Europe: The EUROCARE Study* (Lyon: IARC, IARC Press, 1995); Franco Berrino et al., “Introduction: The EUROCARE II Study,” *European Journal of Cancer* 34, no. 14 (1998): 2139–2153; Michel P. Coleman et al., “EUROCARE-3 Summary: Cancer Survival in Europe at the End of the 20th Century,” *Annals of Oncology* 14 Suppl 5 (2003): v128–49; Milena Sant et al., “EUROCARE-4. Survival of Cancer Patients Diagnosed in 1995–1999. Results and Commentary,” *European Journal of Cancer* 45, no. 6 (2009): 931–991.

21. For instance, *The Lancet*, a medical journal of high readership and reputation, published 34 articles and news items on EUROCARE during the 2000–2010 decade.

22. This aim is justified by data showing that standards can effectively improve survival rates; see Mark McCarthy et al., “Would Compliance with Cancer Care Standards Improve Survival for Breast, Colorectal and Lung Cancers?” *Journal of Epidemiology and Community Health* 62, no. 7 (2008): 650–654.

23. EUROCARE website, “EUROCARE-5” section; [IARC Press Release 129](#), 22 September 2009. Identical statements are made in several EUROCARE publications.

24. Berrino et al., “Introduction: The EUROCARE II Study,” 2152.

25. Andrea Micheli et al., “European Health Systems and Cancer Care,” *Annals of Oncology* 14 Suppl 5 (2003): v41–v60.



concluding: “cancer survival depends on the widespread application of effective diagnosis and treatment modalities, but our enquiry suggests that the availability of these depends on macro-economic determinants, including health and public health investment.”<sup>26</sup>

The perhaps less intended effect of the study was to provide a comparative ranking that was then to be used as an authoritative benchmark for the objective quality of cancer care in the surveyed countries. Generally speaking, rankings produce an uncompromisingly forthright objectivation of a raw hierarchy, showing the crude variations that exist between categorically and geographically close units, such as hospitals, universities or, when comparison is drawn on national statistics, countries.<sup>27</sup> Rankings health units is rather common and can form either routine news items, as in the case of rankings among health authorities in Britain, or very salient items on public agendas, as in the case of the WHO 2000 ranking of health systems (in which France arrived 1st and Britain 18th).

On the face of it, the EUROCORE results did not differ much from other rankings based on global health indicators, such as infant mortality or life expectancy. Two distinctions between previous comparative health data and the EUROCORE data can still be drawn. First, the EUROCORE data were perceived as the first “internationally comparable health outcome measures” to provide an effective measure of *quality of care* rather than the broader set of social conditions that influence life expectancy and mortality.<sup>28</sup> Second, EUROCORE was disease-specific, and it focused on a particularly dreaded disease, which has been repeatedly framed as a ‘modern plague’ at the centre of many medical-military analogies.<sup>29</sup>

The combination of both characteristics explains the sudden outrage that occurred in Britain by the publication of the EUROCORE results: when a ranking provides precise information where only latent approximations existed, the ‘revelation effect’ of a precise ordering can be quite ravaging to the units sitting at its bottom if the ranking offers a direct assessment of survival to one of the most feared forms of modern illness.

26. Micheli et al., “European Health Systems and Cancer Care,” v41. This publication postdates the UK narrative developed in the next section, even though the British elites seem to have arrived to the same conclusion on their own.

27. For illustrative purposes, think of an extreme example, such as a ranking of U.S. states by jail sentence length among defendants with similar records who have been found guilty of similar conduct. Even though the U.S. Constitution requires that these variations be avoided, they exist nonetheless. A ranking of all states from least to most severe would probably have some crude effects on its readers.

28. Clive Smee, *Speaking Truth to Power* (Oxford: Radcliffe, 2005), 23. Smee remarks that the UK was an ‘average OECD country’ according to these previous indicators.

29. The work of Susan Sontag and others, such as James Patterson or Patrice Pinell, illustrate both the ‘plague’ and ‘war’ statements. In that respect, cancer figures, with obesity, on the list of ‘noncommunicable epidemics’ that are being socially constructed (and taken action against) by a large issue network at the global scale.

### 3 Narrative

As it happens, in the EURO CARE-2 rankings, the UK appeared to be remarkably outperformed by all immediate neighbour Western states, and even by some Eastern European ones. As shown in Fig. 3, some presentations of the EURO CARE-2 data ordered the 17 covered countries from highest to lowest cancer survival rates, which clearly revealed the detrimental position of England and Scotland; the same presentations also computed the risk ratio of each country against the European average, showing the countries with the worst risk ratios in a darker colour.

In some other EURO CARE-2 publications, the graphical explicitness was replaced by textual descriptions that also pointed the UK as underperforming other Western countries, by classifying it along with Eastern European countries in a ‘family of nations’ exercise. The EURO CARE-2 breast cancer results hence read:

The age-standardised 1- and 5-year relative survival results... indicate that the countries fell into four broad groups:

- (1) Iceland, Finland, Sweden, Switzerland, France and Italy all had both 1- and 5-year survival above the European average;
- (2) Denmark, The Netherlands, Germany and Spain had both 1- and 5-year survival close to the European average;
- (3) **Scotland, England and Slovenia** had 1-year survival some 3–4% below the average, and 5-year survival 6–9% below; and
- (4) Slovakia, Poland and Estonia had 1-year survival 6–8% below the average, and 5-year survival 13–15% below.<sup>30</sup>

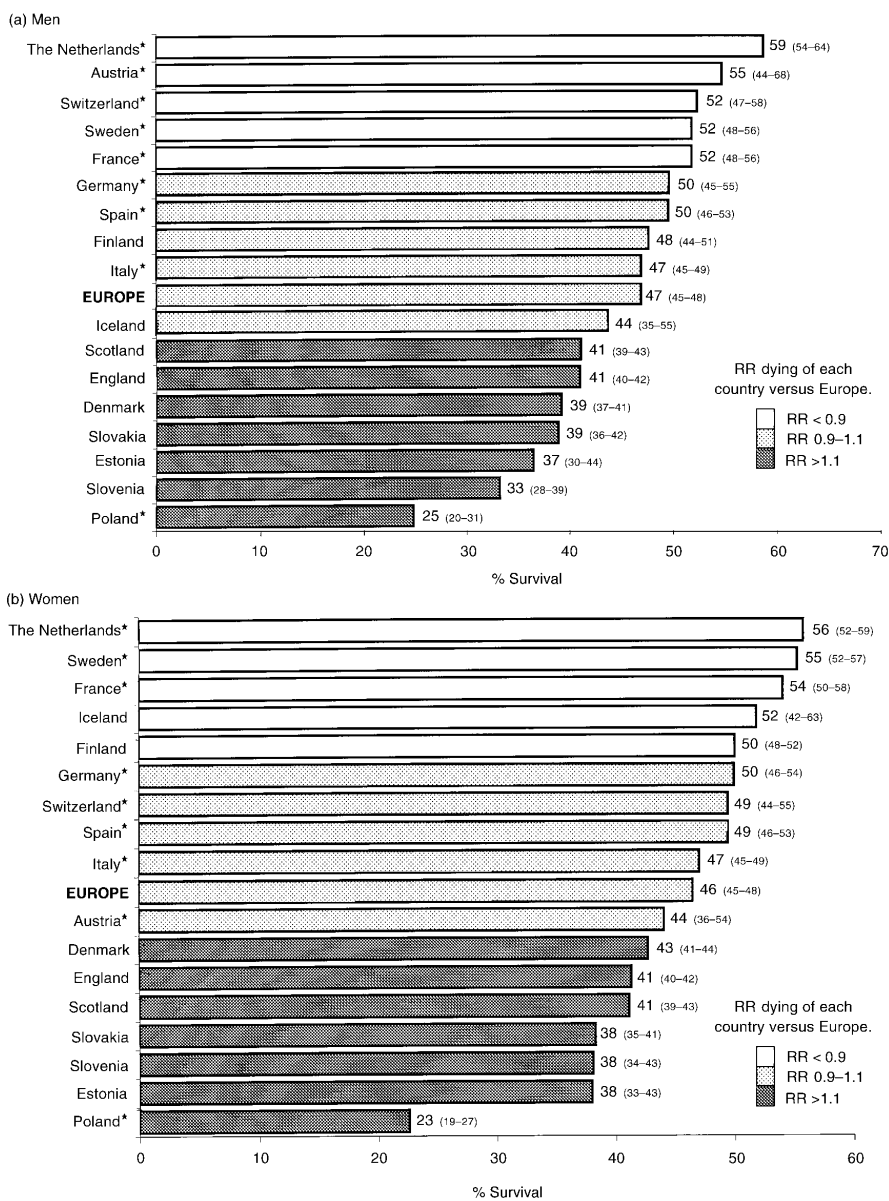
The EURO CARE-2 data showed that the UK had low survival rates overall, if not the worst, as in the case of 1-year survival rates for lung cancer among males and females. England and Scotland were not the only Western countries to figure at the bottom of the EURO CARE-2 league tables: Denmark was also lowly ranked, as Austria was for 5-year survival among breast cancer patients. But in the case of the UK, all common tumour sites (colorectal, breast, lung, prostate and ovarian cancers) reflected the dismal picture of the UK systematically doing worse than the European average.<sup>31</sup>

Faced with these results and dim prospects for cancer patients, all common actors in the UK health policy community reacted to the EURO CARE study. The media made it

30. Mike J. Quinn et al., “Variations in Survival from Breast Cancer in Europe by Age and Country, 1978–1989,” *European Journal of Cancer* 34, no. 14 (1998): 2206, my emphasis.

31. To be fair, the UK was only *quasi*-systematically doing worse than EU average, as it was actually doing better on 7 out of the 25 studied cancers.

Figure 3: EUROCARE-2 results for colorectal cancer, both sexes, all ages.



Source: Gemma Gatta et al., "Survival of Colorectal Cancer Patients in Europe during the Period 1978-1989," *European Journal of Cancer* 34, no. 14 (1998): 2179.

sound both catastrophic and predictable, while some health professionals objected to the relevance of the data; and finally, at the political level, office-holders tried to avoid the blame by enacting a national cancer control programme along with other significant and heavily publicised health policies. I cover each segment of that sequence in what follows.

### 3.1 Health policy and media framing at the time of EURO CARE publication

The EURO CARE-2 results were published in December 1998, just in time for the British media to cover them as part of their larger NHS stories agenda in 1999, a year that should be considered as the *annus horribilis* of the NHS under newly elected New Labour. In 1997, the party had pledged to “saving the NHS” as well as tackling health inequalities by fighting the causes of poor health; the particular case of reducing waiting times for breast cancer surgery was also mentioned in the [party manifesto](#). Yet, in the first two years of their mandate, Blair and Brown had also pledged to stick with the public health expenditure set by their Conservative predecessors, as to save money for their next budgeting round (Comprehensive Spending Review). In these circumstances, health media coverage was largely dominated by news on how the government was not delivering any part of its electoral agenda on the NHS: in effect, expenditure did increase more than expected in that period, whereas low specialist provision and long waiting times were brandished as (ambiguous) performance measures showing a deterioration in NHS services. As a result, “as so often in its history, the NHS appeared to be on the point to collapse” and “left only three national dailies (the *Guardian*, *Financial Times* and *Mirror*) still believing a tax-funded health service was the most efficient by the Autumn of 1999... The BBC had an ‘NHS crisis’ logo running above its NHS bad news stories.”<sup>32</sup>

In that context, the publication of the EURO CARE results made a particularly effective impact within the British media because it resonated with several common and accepted frames about the NHS—in a nutshell, that it is excessively rationed, plagued by red tape, and generally subpar. The low reputational capital of the NHS is paradoxical if considered next to the public’s attachment to keeping it public, but it is a reality that the NHS is and has been perceived, over at least two decades, by individuals as well as by (some) popular media, as dysfunctional, underperforming and hardly trustworthy.<sup>33</sup> Every round of EURO-

32. Rudolf Klein, *The New Politics of the NHS. From Creation to Reinvention*, 5th ed. (Oxford: Radcliffe Publishing, 2006), 201; Malcolm Dean, “Media Fingers in the Social Policy Pie – and the Seven Sins of the Reptiles” (15th *Guardian* Lecture, Nuffield College, University of Oxford, 2008), 13. The sentiment at the time was confirmed by *post hoc* rationalisations of the NHS crisis on the next year, such as Derek Wanless’ report or the IEA’s 2000 report *Delay, Denial and Dilution*, which focused on heart disease and cancer and made very extensive use of the EURO CARE data.

33. For a precise analysis, see Peter Taylor-Gooby and Andrew Wallace, “Public Values and Public Trust: Responses to Welfare State Reform in the UK,” *Journal of Social Policy* 38, no. 3 (2009): 402. Interestingly, there is an additional negativity bias about what people believe *other people believe* about the NHS: whereas everyone seems to agree that public opinion about the NHS is dramatically low in Britain, polling data do not

CARE data can be read to echo this common wisdom: that the NHS is under-performing in delivering quality health services to all of its patient constituencies. More specifically, the EURO CARE data articulated gracefully with two dominant themes of NHS politics:

**The plights of health rationing (1): Funding** Endemic to the NHS is the idea that its funding allocation is insufficient to its task. The resulting rationing measures can be spectacular, especially if doctors bandwagon with the media to denounce them, as they did on November 9, 1999, when several physicians reported having lying to terminally ill cancer patients about the availability of cancer treatments).<sup>34</sup> Earlier that year, on February 4, the EURO CARE results had been put on show at the International Congress on Anti-Cancer Treatment in Paris, where oncologist and WHO consultant Herbert Pinedo had pointed out that health funding across Europe was ‘inadequate’ in many countries, as it limited the number of trained oncologists and the availability of anticancer drugs.<sup>35</sup> British media extensively covered the conference, with tabloids calling the UK’s record ‘appalling’ and ‘shameful.’<sup>36</sup> Throughout the year, the news cycle continued to pick up on the same EURO CARE-2 evidence as different journalists picked up quotes and articles from different sources, all which emphasised low spending as a possible cause for low cancer survival rates.<sup>37</sup> Later on in 1999, oncologists were also leading the ‘Campaign for Effective and Rational Treatment’ (Cert, which was immediately backed by the All-Party Parliamentary Cancer Group) into lobbying directly for a \$170/year increase in health expenditure, based on the low availability of cancer drugs in the UK.<sup>38</sup>

**The plights of health rationing (2): Waiting times** Equally endemic to the NHS is the idea that long waiting times, as experienced in Beveridgian health systems, can have dramatic consequences. In 1999, not only did speculations over the causes of the EURO CARE-2 results feed into that mindset, but scientific data came to support the hypothesis that waits

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reflect such a bleak picture. In fact, in 1999, satisfaction with the NHS was under 35% according to the British Social Attitudes survey, a historical low in at least a decade (Tony Delamothe, “How the NHS Measures up,” *British Medical Journal* 336, no. 7659 (2008): 1469–1471).

34. Jenny Hope, “Our cancer disgrace. Top specialists confess: We have to lie to patients,” *Daily Mail*, 9 November 1999.

35. Emily Wilson, “Cancer cuts that kill; Britain spends less on drugs and its patients are paying with their lives,” *Daily Mail*, 5 February 1999; Jennifer Trueland and Nick Thorpe, “UK lags in cancer treatment,” *The Scotsman*, 5 February 1999.

36. See, e.g., Lisa Reynolds, “Pattie blasts UK’s ‘appalling’ record” and “We’re worst at beating cancer,” *The Sun*, 5 February 1999.

37. See, e.g. Sarah Boseley, “Cancer ‘killing too many’ in UK,” *The Guardian*, and Jeremy Laurance, “Britain lags in treating cancer,” *The Independent*, both published on 10 March 1999 following Karol Sikora’s editorial in the *European Journal of Cancer*.

38. Sarah Boseley, “Extra \$170m a year urged for cancer drugs,” *The Guardian*, 5 May 1999; Cherry Norton, “Cancer cash should be doubled, specialists say,” *The Independent*, 5 May 1999. One oncologist illustrated the seriousness of the crisis by declaring: “For the first time it may be possible to get better care in the private sector” (Jill Palmer, “Cancer drug cash scandal,” *Mirror*, 5 May 1999).

induced delayed detection and therefore lower chances of effective treatment.<sup>39</sup> The threat posed to patients by waiting times was exposed even more critically in the first semester of 2000 with the dramatic case of Mavis Skeet, a throat cancer patient whose condition deteriorated until the point of no return while she was waiting for a surgical operation that had been delayed four times due to shortages in beds following an influenza epidemic in the winter months.<sup>40</sup>

**Health and geographical inequalities** Finally, the NHS is constantly under attack for treating its patients differently depending on either arbitrary and/or unfair criteria. After it had been shown that Britain was doing worse than the rest of Europe on cancer survival, it came as an additional issue that health inequalities were also remarkably steep within the population, following the wealth gradient.<sup>41</sup> Next to income inequalities, geographical inequalities were also under attack, with news stories denouncing the infamous ‘postcode lottery’ of NHS treatment.<sup>42</sup>

From that cursory assessment, then, the EURO CARE results provided at least three additional lines to the litany of health scandals in the UK, by showing how constrained spending and long waits could kill, and how the least well-off were suffering even more from it.

In the midst of that storm of criticism, many players in the health care arena piggybacked correct term? on the EURO CARE results to push their personal reform agendas: several health interest groups, including principally individual clinicians or third-sector organisations, took the results as an opportunity to call for additional NHS funding and an increase in specialist training;<sup>43</sup> cancer charities, such as the Cancer Research Campaign, also had an obvious vested interest in publicising the results as to encourage donations and increase public awareness of cancer symptoms and prevention measures. As of today, the EURO CARE results are still being summoned by clinicians either to set the agenda on a particular form of cancer, such as childhood cancer, or on some aspects of cancer treatment, such as multidisciplinary teams.<sup>44</sup>

39. Sarah Boseley, “Delays that kill victims of breast cancer,” *The Guardian*, 2 April 1999.

40. Cherry Norton and Ian Herbert, “Urgent cancer operations delayed by epidemic,” *The Independent*, 12 January 2000; “Cancer patient dies after four surgery delays,” *The Guardian*, 2 June 2000.

41. Sarah Boseley, “Cancer survival linked to wealth,” *The Guardian*, 23 April 1999; Ian Murray, “Poor have less chance of beating cancer,” *The Times*, 23 April 1999; Anthony Browne, “Britain fails in war on disease,” *The Guardian*, 17 October 1999.

42. See Hilary Bungay, “Cancer and Health Policy: The Postcode Lottery of Care,” *Social Policy & Administration* 39, no. 1 (2005): 35–48. There is a logical fallacy in considering that a lottery is necessarily undemocratic and/or unfair, but that is beyond the scope of the argument.

43. See, for instance, Karol Sikora, “Cancer survival in Britain is poorer than that of her comparable European neighbours,” *British Medical Journal* 319, no. 7208 (1999): 461–462. Many letters and editorials followed.

44. See, respectively, Alan W. Craft and Kathy Pritchard-Jones, “UK Childhood Cancer Survival Falling behind Rest of EU?” *Lancet Oncology* 8, no. 8 (2007): 662–663 and Martin H. N. Tattersall, “Multidisciplinary

Had the positional status (standing) of the NHS been that of a ‘top-tier’ health system, or even ‘the best one in the world,’ as many Frenchmen like to present their own system, then perhaps would the EURO CARE study have been challenged more fiercely and met with additional layers of skepticism in the media and general public, or even downplayed and eventually ignored. Instead, the frame set by the EURO CARE results was consonant with hearsay about the flawed and faulty nature of the UK health system as a whole, which meant there was little for journalists to add to the story to make it sound credible (an exemplar of *quasi nihil novi sol solum* as a proxy for truth). Moreover, the journalistic preferred practice of ‘having two sides to every story’ could be easily applied, as several health professionals publicly objected to the validity of the EURO CARE study.

### 3.2 Identity threats and defensive work among health professionals

Even if the media could easily identify several clinical and public health specialists to corroborate the EURO CARE results, early reactions to the study among health professionals in England also reflected a standard defence mechanism to rankings and other performance measures. Rankings are generally suspected to be value-laden in their design, and to be methodologically flawed in a way or another. Such suspicion is particularly observable among the institutions that perceive a given ranking as an identity threat, i.e. as a potential attack on their core identity attributes.

In the case of the UK health system, “free access to health care at the point of delivery” and public taxation as a means of financing have been among the defining characteristics of the NHS since the creation of the Service. Also relevant would be the organisation of British primary care, which emphasises the gatekeeping role of general practitioners and differs markedly from Bismarckian health systems such as France before its 2004 public health reform. These characteristics might well be threatened by the EURO CARE results, since the main explanations advanced in current medical debates on variations in cancer survival concern diagnostic capacity and early detection, as well as drug availability. The first two factors especially are perceived as crucial determinants in 1-year survival and perhaps also important to account for 5-year survival,<sup>45</sup> which would mean that British primary care physicians are not referring enough patients to cancer screening services.<sup>46</sup> Similarly, the cost-containment role played by the National Institute for Health and Clinical Excellence

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Team Meetings: Where is the Value?” *Lancet Oncology* 7, no. 11 (2006): 886–888; Anne Fleissig et al., “Multidisciplinary Teams in Cancer Care: Are They Effective in the UK?” *Lancet Oncology* 7 (2006): 935–943.

45. See Mike Richards, “EURO CARE-4 Studies Bring New Data on Cancer Survival,” *Lancet Oncology* 8, no. 9 (2007): 752–753; Kathryn Senior, “Disparities in Cancer Survival and Cancer Care across Europe,” *Lancet Oncology* 10, no. 3 (2009): 214–215. Mike Richards especially has submitted a large amount of evidence in that direction for several years, before and after being appointed as National Cancer Director.

46. Mike Richards, *Improving Access to Medicines for NHS Patients: A Report for the Secretary of State for Health* (London: Department of Health, 2008).

(NICE) might be called into question if drug availability is proven to be a determinant factor, as advanced by a recent and controversial comparative report.<sup>47</sup> Finally, some defining characteristics of cancer registration in Britain could mean that the UK is estimating correctly its survival rates while other countries are not: whereas the NHS runs a systematic cancer registration system, not all countries do.<sup>48</sup>

If any bias could be traced to these different aspects of the UK health system, then the EURO CARE study should have been treated with skepticism, in case it overlooked or did not acknowledge them.<sup>49</sup> Studies in organisation theory show that such cognitive dissonance in organisational rankings is likely to entail hostility from organisation members: if an identity characteristic of their organisation exists outside the ranking criteria, then the metric of the ranking might be incorrect and the comparison critically flawed.<sup>50</sup> And indeed, skepticism was palpable in several discussions about the EURO CARE results for Britain. The most detailed critique I have encountered appeared in the *British Journal of Cancer*: its authors suggested that the UK and Scandinavian records were fine, while in other countries, “survival [might have been] inflated in some registries because of failure to identify all cases of advanced disease” – a critique dismissed the EURO CARE investigators.<sup>51</sup> Identical critiques were formulated after the publication of EURO CARE-3 and EURO CARE-4. Even more recently, additional controversy has arisen in the context of the upcoming general election, with senior figures from Cancer Research UK claiming: “In terms of survival data, EURO CARE is the best we have but there have been concerns about how the data are sometimes presented... What we are slightly concerned about is where people have tried to present the data as a league table when there are these important caveats to consider—we have to consider the data very carefully.”<sup>52</sup>

47. See Nils Wilking and Bengt Jönsson, *A Pan-European Comparison regarding Patient Access to Cancer Drugs* (Stockholm: Karolinska Institutet, 2005), and Michel P. Coleman, “New Drugs and Survival: Does the Karolinska Report Make Sense?” *Cancer World* (2006): 26–35 for a critique.

48. 9 of the 17 countries covered in EURO CARE-2 had less than 20% of their populations covered by their registration systems – France, for instance, uses a small sample of its regional districts. I have witnessed public health specialists complain about this during several symposia, as the sample is considered ‘hardly representative’ by some.

49. Only a few news stories decided to treat the EURO CARE under such careful assumptions; the best piece in that respect was probably Nicholas Timmins’ account, “Health warnings are a little off colour,” *Financial Times*, 8 December 1999.

50. Kimberly D. Elsbach and Roderick M. Kramer, “Members’ Responses to Organizational Identity Threats: Encountering and Countering the Business Week Rankings,” *Administrative Science Quarterly* 41, no. 3 (1996): 442–476.

51. C. B. J. Woodman et al., “Are Differences in Stage at Presentation a Credible Explanation for Reported Differences in the Survival of Patients with Colorectal Cancer in Europe?” *British Journal of Cancer* 85, no. 6 (2001): 787–790; Gemma Gatta, Riccardo Capocaccia, and Franco Berrino, “Cancer Survival Differences Between European Populations: The UK Uneasiness,” *British Journal of Cancer* 85, no. 6 (2001): 785–786. Along with organization theorists, this technique of ‘counterpoint publication’ might be understood as a form of *defensive institutional work*, in support of the NHS *versus* other health systems; see Steve Maguire and Cynthia Hardy, “Discourse and Deinstitutionalization: The Decline of DDT,” *Academy of Management Journal* 52, no. 1 (2009): 148–178.

52. Emma Wilkinson, “Questions Remain over Validity of EURO CARE Data,” *Lancet* 374, no. 9694 (2009):



As of today, then, the comparative validity of the EURO CARE study remains an open question; recently, the very first page of the 2010 volume of the *Lancet Oncology* opened on an editorial that stressed that “any comparisons with Europe should be done judiciously because previous concerns about survival as a metric and the validity of comparing survival between countries are still relevant”.<sup>53</sup> One might sum up all these appeals to caution under two labels: opposition to the findings on the grounds of *mismeasure* (comparing is inaccurate), and/or on the grounds of *idiosyncrasy* (comparing is impossible). A third type of opposition might also be identified among the health professionals who opposed the rankings because of the gross exaggerations they had led to in public discourse, such as when claims were made that British cancer patients were getting a “Third World service.”<sup>54</sup>

It would be wrong to say, however, that contrarian opinions about the EURO CARE results represented a majority of public statements, or resulted into the formation of a counter-epistemic community.<sup>55</sup> The majority of opinions expressed in the months following the publication of the EURO CARE-2 study were indeed supportive of the results in one way or another, and further encouraged the sweeping reforms rapidly introduced by the British government in order to tackle the most critical aspects of the issue.

### 3.3 Blame avoidance and symbols of compliance

The poor health performance of the UK, illustrated by the EURO CARE-2 study and by the general media coverage of British health care in 1999, was quickly followed by policy responses at the governmental level. In order to avoid the blame, the British (English) executive started by spending large amounts of attention and money in the direction of the NHS, and of cancer services in particular; it also sent significant signs of institutional compliance with the conclusions of the EURO CARE study by adjusting several aspects of its health system to address the potential causes of low cancer survival.

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964. Cancer Research UK is the leading cancer charity in Britain; it was created by merging the Cancer Research Campaign and the Imperial Cancer Research Fund in 2002. Interestingly, then, data that were potentially useful to some actors in 1999 are now pointed as ‘risky business’ by the same stakeholders.

53. *Lancet Oncology*, “More Woes for UK Cancer Services,” *Lancet Oncology* 11, no. 1 (2010): 1. Another recent word of caution was formulated by the IARC, which recently emphasised: “The reasons for survival differences between countries... are complex. Improved survival may be due to greater awareness in the population, earlier diagnosis, or more effective treatment. In its next [fifth] phase, the EURO CARE project is focusing on determining the extent to which differences and improvements in survival are the result of better treatment, and to what extent the improved effectiveness of treatment is due to earlier diagnosis.” (IARC Press Release 129, 22 September 2009).

54. Jeremy Laurance, “Cancer deaths in Britain ‘no worse than elsewhere’,” *The Independent*, 10 November 1999.

55. The latter notion is applied to HIV/AIDS in South Africa in Jeremy R. Youde, *AIDS, South Africa, and the Politics of Knowledge* (Aldershot: Ashgate, 2007), ch. 3.

**Blame avoidance** In modern health politics, diseases are not fate-induced and office-holders do not hold thaumaturgic powers; instead, politicians are expected to pledge both attention and money when bad but genuine news reports bring saliency to low or catastrophically low quality of care within their health systems.

In May 1999, Downing Street launched its cancer effort by organising its own cancer summit, with a press release announcing: “Tony Blair leads war on cancer”<sup>56</sup> In February 2000, the strategy report at the heart of that effort was published as *The NHS Cancer Plan*, which drew on previous initiatives and also prefigured the later National Service Frameworks.<sup>57</sup> At that time, Britain was not the only European state to show particular attention to cancer; however, in other countries, the patterns of blame avoidance and credit-claiming took different forms.<sup>58</sup>

The main mechanism of blame avoidance was not, however, attention, but money. The first budgetary act in response to the 1999 NHS crisis came in the form of a large envelope was sent to health services during what is now referred to by observers as the most expensive breakfast in history. On January 16, 2000, during an appearance on the ‘Breakfast with Frost’ TV morning show, Tony Blair announced his government would bring the NHS up to European average levels in terms of health expenditure within the next five years.<sup>59</sup> At the time of this announcement, the last rounds of EURO CARE-induced backlash were hitting the UK in the form of negative OECD reports, which now emphasised the poor performance of the NHS on cancer survival rates and waiting times rather than underlining, as it had a few years before, its ‘remarkable’ cost-effectiveness.<sup>60</sup> A second budgetary response then

56. Jeremy Laurance, “Blair launches war on cancer with tea and sympathy - but no more money,” *The Independent*, 21 May 1999.

57. The *Plan* indeed reinstated some principles of the Calman-Hine report, a report that had already underlined some of the deficiencies of British cancer services; for that reason, and also because of the EURO CARE-1 results in 1995, many clinical experts were already familiar with the picture drawn of the UK by the EURO CARE results (as shown, for instance, by correspondence published in the *British Medical Journal*). Historical data on the Calman-Hine report and the UK cancer control policy appear in Robert A Haward, “The Calman-Hine Report: A Personal Retrospective on the UK’s First Comprehensive Policy on Cancer Services,” *Lancet Oncology* 7 (2006): 336–346 as well as in postgraduate research by Ellen van Reuler (University of Manchester, 2008) and by myself (University of Edinburgh, 2007).

58. In the case of the UK, the ‘blame’ element was predominant, while the French narrative shows more balance between credit and blame. I thank Theodore Marmor for a useful discussion over this matter. Details on the various patterns of blame and credit, as well as the material and symbolic dimensions of office-seeking and office-keeping, appear in a previous paper delivered to the [University of Edinburgh Policy Research Group, February 2008](#), and to the [Postgraduate Northern Conference, Edinburgh, June 2008](#), along with a light empirical treatment of the EURO CARE narrative in England and elements on the French case study.

59. The announcement followed the publication of a disastrous NHS failure by Lord Winston in the *New Statesman* and was apparently not exactly well-planned, coming as a surprise to at least some of top policy advisers and members of the Cabinet; the announcement itself did, for example, infuriate Gordon Brown. First-hand evidence appears in Smee, *Speaking Truth to Power*, 24-25 and Dean, “Media Fingers in the Social Policy Pie – and the Seven Sins of the Reptiles.” Former adviser Simon Stevens has also acknowledged the critical influence of the Mavis Skeet scandal in Blair’s decision; see Nicholas Timmins, *Rejuvenate or Retire? View of the NHS at 60* (London: Nuffield Trust, 2008), 108.

60. Smee, *Speaking Truth to Power*, 25. Negative OECD reports must have had particular impact within the

came with the publication *NHS Cancer Plan*, which had been initially criticised for being financially toothless.<sup>61</sup> The *Plan* indeed came with ring-fenced funding for cancer services, as well as with a long-term funding architecture that made sure cancer services would continue to benefit from renewed budget allowances in the future (a task now picked up by the Cancer Reform Strategy, issued in 2007). Finally, a third budgetary act appeared in July 1999 with health secretary Frank Dobson's announcement of the *Saving Lives: Our Healthier Nation* white paper, which materialised the 'Breakfast with Frost' promise by pledging an additional \$96 million budget for the NHS.<sup>62</sup>

**Symbols of compliance** Attention and budgets were completed by important signs of institutional compliance with the conclusions of the EUROCARE-2 study. As Steven Epstein has observed, "organisations often respond to external pressure by creating formal structures (offices, positions, rules, programs, and procedures) precisely 'to create visible symbols of compliance' that they can show off. But to say that compliance is 'symbolic' is not to say it is 'merely' symbolic. Even if the organisation appears to prize formalism over substance, the outcome may still be one of meaningful social change."<sup>63</sup> At least three important symbols are identifiable following the publication of the EUROCARE results and interrelated NHS crisis.

The first and foremost symbol of compliance with the EUROCARE study was the appointment of Professor Mike Richards as National Cancer Director, or 'cancer czar.' The creation of such a position has given tremendous autonomy to cancer control as a subcomponent of health policy within the general policy environment of the NHS. Interestingly, one of the first initiatives carried by Richards was to convene a workshop to debate whether the EUROCARE results were indeed valid.

A second symbol of compliance was targets. By introducing quantified objectives in the *NHS Cancer Plan* and the *Saving Lives* white paper, both Downing Street and the Department of Health found a way to respond to the initial scandal triggered by the EUROCARE results: "Shamed by statistics that show Britain has one of the worst cancer survival rates in the developed world, the Government... introduced a ten-year action plan to cut deaths from the disease in those under 75 by a fifth over the next decade."<sup>64</sup> The publication of

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UK government since both organisations were used to having what has been described as a relationship based on 'mutual admiration' (Nick Manning, "Mutual Admiration? OECD Advice to the UK," in *The OECD and European Welfare States* (Cheltenham: Edward Elgar, 2004), 197–210).

61. Jeremy Laurance, "Blair launches war on cancer with tea and sympathy - but no more money," *The Independent*, 21 May 1999; see also the *Independent*'s editorial on that same day, "It takes more than fine words to defeat cancer."

62. Cherry Norton, "Dobson launches health 'crusade'," *The Independent*, 7 July 1999.

63. Steven Epstein, *Inclusion. The Politics of Difference in Medical Research* (Chicago: University of Chicago Press, 2007), 171-172.

64. Ian Murray, "Blair plan aims to cut cancer deaths by fifth," *The Times*, 21 May 1999.

these targets is retrospectively unsurprising, as New Labour has proven a great follower of its Conservative predecessors in adopting managerial techniques focused on outcomes rather than inputs.<sup>65</sup> However, the specific attention paid to cancer in that reform exercise shows that, at that stage, the NHS had reconstructed its own identity in congruence with the international standards introduced by the EUROCARE study. The congruence of cancer as a benchmark for NHS policy and politics was further reinforced after the Cabinet change of October 1999, in which Alan Milburn replaced Frank Dobson (who was then running for mayor in London); in the footsteps of Dobson's "health crusade," Milburn announced that his own approach to health policy would focus on cancer and heart disease.<sup>66</sup>

A final symbol of institutional compliance with the EUROCARE results and discussions lies with drug availability under the NHS. Following a long and complex policy narrative, which includes the Herceptin episode of 2005 and more recent controversies over, *inter alia*, other cancer drugs, the British government is now considering 'top-ups' within the NHS, in order to allow patients to access drugs that have not passed the cost-effectiveness tests set up by NICE. Recent policy developments, addressed in the Richards report of 2008,<sup>67</sup> hence show that the issue raised by the EUROCARE study with regards to the low availability of cancer drugs within the NHS is still being processed. Final decisions on that issue might have crucial implications for the NHS, as it might modify its foundational principle of equal care to all.<sup>68</sup>

The sum-total of these changes is impressive, and spans way beyond the current, and probably even future, EU mandate on health; however, all these reforms can be traced to the 1999 episode of NHS crisis, in which the EU was instrumental by providing the British health polity with the EUROCARE results, which epitomised the most controversial aspects of health policy in Britain. I now consider what could be the theoretical underpinnings for this phenomenon.

65. Klein, *The New Politics of the NHS. From Creation to Reinvention*, 192; Florence Faucher-King and Patrick Le Galès, *Tony Blair 1997-2007, le temps des réformes* (Paris: Presses de Sciences Po, 2007). Health targets are still being used today, and even though the Conservative Party is threatening to scrap (some of) them if they win the next election, their alternative concept of 'process-based' indicators (introduced in a green paper on health in 2008) does not hint at any substantive deviation from the path set in the last decades.

66. David Hughes, "Milburn wages war on cancer and coronaries," *The Daily Mail*, 18 October 1999.

67. Richards, *Improving Access to Medicines for NHS Patients: A Report for the Secretary of State for Health*.

68. Albert Weale and Sarah Clark, "Co-Payments in the NHS: An Analysis of the Normative Arguments," *Health Economics, Policy and Law* 5, no. 2 (2010): 225–246.

## 4 Analytical framework

### 4.1 Review of theoretical options

The current sociological literature offers at least three promising options to theorise the effects of the EURO CARE study on British cancer (and health) policy. I review each option separately, and will discard the first one while drawing on the latter two, as well as on recent work on measurement and distributive politics, in order to submit a final theoretical proposition on what might be termed the ‘disciplinary acts of EU comparison’ illustrated by the EURO CARE case study.

**Performativity** Drawing on the work of John L. Austin, several authors have explored performativity as a social mechanism in which discourse produces the phenomena that it regulates and constrains. Having considered if the effects of the EURO CARE study could be said to be of performative nature, this option seems implausible: the survival data collected by the EURO CARE group are not an arbitrary convention that cannot be related to any *ex ante* truth, and its publication (which would count as a speech utterance in Austin’s performativity theory) is unlikely to have had performative (self-fulfilling) effects on the concerned health systems *ex post* (i.e. the EURO CARE study did not in itself lead to variations in cancer survival in the countries it surveyed: talking of ‘poor cancer survival rates’ is unlikely to impoverish cancer survival).<sup>69</sup> In Donald MacKenzie’s words, performativity applies to social objects, such as theories or models, that affect social reality by functioning as engines rather than cameras,<sup>70</sup> whereas the EURO CARE study is clearly fits in the later category.

**Legibility** Another theoretical option comes from James Scott’s stimulating account of how pre-modern agrarian authorities, and later modern European states, were faced with the daunting task of rendering their subjects (and territory) legible to the state, insofar as “the legibility of a society provides the capacity for large-scale social engineering.”<sup>71</sup> To the modern state, the task of identifying the state of health of its population is different only in degree, not in nature, and it remains a complex mission of the state than to establish how healthy its subjects actually are, and why so. Acquiring information on the scope, causes

69. That is the case because system-level trust has extremely limited effects on system-level performance in health systems as opposed to, e.g, financial market systems. There is no observable Matthew effect in cancer survival rates after the publication of the EURO CARE study.

70. Donald MacKenzie, *An Engine, Not a Camera: How Financial Models Shape Markets*, MIT Press (Cambridge: MIT Press, 2008).

71. James C. Scott, *Seeing like a State. How Certain Schemes to Improve the Human Condition Have Failed* (New Haven: Yale University Press, 1998), 5. Daniel Little’s reading of Scott’s work has been of invaluable help, such as his parallel between Scott’s and Popper’s analyses of large-scale social engineering.

and impact of death and disease within a given nation has led to registration technologies and counting practices that stand as functional equivalents to the machinery deployed in modern polities to collect taxes, conscript soldiers and prevent rebellion. Several other studies offer in-depth histories of the joint production of state power and the knowledge apparatus of demography, epidemiology and public health ‘vital’ statistics<sup>72</sup>. In that respect, the science of counting cancer deaths and cases, as well as the practice of classifying them into complex, involuted categories of tumours<sup>73</sup> is a demanding mission that has resulted into the development of situated, locally tailored epistemic cultures, still only imperfectly standardised through the application of IARC protocols). Cancer registration and quantification echoes James Scott’s observation that “[m]uch of early modern European statecraft [was] devoted to rationalising and standardising what was a social hieroglyph into a legible and administratively more convenient format.”<sup>74</sup> Not only then does Scott’s theory of ‘legibility to the state’ fit the data exposed in this case study; it also describes quite gracefully the enterprise of the EURO CARE epistemic community.

**Discipline** There is more than legibility to EURO CARE, though: as explained earlier, comparative data that can be understood as a ranking not only sheds light on the predicament of nation-states, but also makes some of them look performant or not depending on their positional status; this image, in turn, generates reactions of pride or hostility. Several aspects of Wendy Espeland *et al.*’s sociology of quantification are useful to better formalise the processes at play in the interpretation and effects of rankings on organizations.<sup>75</sup> First of all, as observed through the use of the EURO CARE results by several members of the UK health policy community, *commensuration* “offers standardised ways of constructing

72. Important works in that strand of literature include Alain Desrosières, *La politique des grands nombres : histoire de la raison statistique* (Paris: La Découverte, 1993); Theodore M. Porter, *Trust in Numbers : The Pursuit of Objectivity in Science and Public Life* (Princeton: Princeton University Press, 1995) and Libby Schweber, *Disciplining Statistics: Demography and Vital Statistics in France and England, 1830-1885* (Durham: Duke University Press, 2006). On the more specific topic of cancer epidemiology in the second half of the twentieth century, see the chapter by the late Richard Doll in Walter W. Holland, Jørn Olsen, and Charles du V. Florey, eds., *The Development of Modern Epidemiology. Personal Reports from Those who Were There* (Oxford: Oxford University Press, 2007).

73. Solid neoplasms represent roughly 100 entries in the current edition of the International Classification of Diseases (ICD-10).

74. Scott, *Seeing like a State*, 2-3. With reference to Scott’s work, the modern maps of cancer incidence over continents (such as the GLOBOCAN project run by the IARC) or countries epitomise his theory of the power/knowledge nexus as a modest and limited enterprise in previous centuries, which have now turned into a high-modernist project that spans over several other aspects of social life, such as agriculture or urban planning, and which ultimately aims at increased control over nature (*ibid.*, 89).

75. Wendy N. Espeland and Mitchell L. Stevens, “Commensuration as a Social Process,” *Annual Review of Sociology* 24 (1998): 313–343; Wendy N. Espeland and Michael Sauder, “Rankings and Reactivity: How Public Measures Recreate Social Worlds,” *American Journal of Sociology* 113, no. 1 (2007): 1–40; Michael Sauder and Wendy N. Espeland, “The Discipline of Rankings: Tight Coupling and Organizational Change,” *American Sociological Review* 74 (2009): 63–82; Wendy N. Espeland and Mitchell L. Stevens, “A Sociology of Quantification,” *Archives Européennes de Sociologie/European Journal of Sociology* 49, no. 3 (2009): 401–436.

proxies for uncertain and elusive qualities [and] condenses and reduces the amount of information people have to process, [thereby] simplifying decision-making.”<sup>76</sup> Then, the three effects defined as *reactivity* in Espeland’s explanatory framework are also relevant to the present case study, as “the redistribution of resources, redefinition of work, and proliferation of gaming [blame-avoiding] strategies”<sup>77</sup> are all observable at various steps of the empirical narrative. Finally, and most importantly, Espeland has offered an analysis of rankings as a specific incarnation of *disciplinary power*, inspired from Michel Foucault’s analysis of the concept. In her framework, “surveillance and normalization facilitate a discipline that is both imposed by outsiders and internalized by insiders.”<sup>78</sup> As disciplinary practices embed prescription and codification in seemingly mundane aspects of one’s conduct, they contribute to the internalization of coercion through specific techniques, of which rankings are a particular instance.<sup>79</sup> All these elements are immediately transposable to the analysis of the EURO CARE case study: by setting up a cross-national surveillance apparatus of cancer survival, the epistemic community behind the EURO CARE studies has successfully introduced its own codes and practices of measurement within governmental practice, encouraging the adoption of benchmarks or targets and the close monitoring of epidemiological data as a means to probe for the effectiveness of the health system overall.<sup>80</sup>

Based on the EURO CARE case study, my theoretical proposition offers, then, to connect the two aforementioned phenomena of legibility and discipline (performativity having been discarded) with a third component, that will allow to understand rankings as an instrument of policy change.

## 4.2 Theoretical proposition

In a recent article, Anthony Bertelli and Peter John have set an interesting agenda for the study of performance measurements. Their main claim is that these initiatives, which include ratings of public services, represent “a political discipline mechanism, and constitute an increasingly powerful dimension of distributive politics,” insofar as they “provide qualitative judgments about organisations with an electoral connection [and] provide a mechanism for voters to assess the policy responsiveness of their incumbents.”<sup>81</sup> Their tentative

76. Espeland and Stevens, “Commensuration as a Social Process,” 316.

77. Espeland and Sauder, “Rankings and Reactivity: How Public Measures Recreate Social Worlds,” 3.

78. Sauder and Espeland, “The Discipline of Rankings: Tight Coupling and Organizational Change,” 68.

79. *Ibid.*, 69.

80. Targets and outcome-based assessments, of course, carry their own limitations: “Whenever abstract political goals are translated into concrete numerical targets, there is always the risk that ‘formal rationality’ will swamp ‘substantive rationality’—that is, the emphasis on systematisation and measurement will become more salient than the achievement of the original policy objectives. In such cases, procedural standards become ends in themselves, rather than means to an end.” (Epstein, *Inclusion*, 171).

81. Anthony M. Bertelli and Peter John, “Government Checking Government: How Performance Measures Expand Distributive Politics,” *Journal of Politics* 72, no. 2 (2010): 545.

theory links these performance measurements, which usually stand for “technocratic decision making” (a depoliticised way to solve policy coordination problems) with a distributive approach to politics, which they test at the level of English local government. While the modelling part of their inquiry is itself interesting, their conclusion is sufficiently straightforward to inform the current case study: even when “performance regimes rest under the auspices of scientific measurement and agency independence... [they are] often instrumental to the distribution of resources.”<sup>82</sup> The EUROCARE study carries the same teaching: in the long run, the scientific agenda (or ‘knowledge initiative’) pursued by the European Union through its funding to the EUROCARE project had diffracted *distributive* effects within the British health polity. The temporal stretch of that effect is considerable, if one considers the initial setup of the Europe Against Cancer action programme in the mid-1980s and the consequences of the EUROCARE-2 study on British health policy in the late 1990s; nevertheless, there is a clear link in the narrative previously offered between the compilation of scientific data at the European level (and with financial support from EU institutions) and significant distributive acts of government in the UK. The ‘political discipline mechanism’ illustrated by this link followed a much more haphazard and accidental logic than the one hypothesised by Bertelli and John, yet the materialisation of health system performance into the EUROCARE cancer survival data and their further interpretation as rankings or ‘league tables’ did occur and participate into enabling important policy change, both in the form of resource deployment and institutional reform.

What I would then like to submit to theoretical scrutiny is a cumulation of the heuristics offered by legibility, discipline and distributive politics as understood in the previous paragraphs, in order to form what might be named, in the context of the European Union, a *disciplinary act of EU comparison*, which is, I believe, a common but under-theorised form of Europeanization born in the will to inform, but also to compare and eventually coerce Member States into adopting adjustment procedures that aim at bringing the performance of their policy environments at acceptable levels, usually defined as the ‘EU average,’ through reallocation of resources and further institutional reforms. The multiplication of such disciplinary acts of comparison has endowed the European Union with what I believe to be an effective and discrete policy instrument in the health care policy domain, strong of its enrolment of scientific authorities, and capable of reaching beyond the formal EU mandate deep into the core principles of health systems. Such disciplinary acts of comparison are also routinely observable in other fora, such as the OECD, which comes as no surprise, especially in a sector such as health care where the OECD has secured an influential position by becoming the most authoritative source of comparative data.<sup>83</sup> The EUROCARE case study shows, however, that disciplinary acts of EU comparison might be more efficient than other disciplinary acts from supranational organisations by inviting Member States to search

82. *Ibid.*, 556.

83. Patrick Hassenteufel et al., “La libéralisation des systèmes de protection maladie européens. Convergence, européanisation et adaptations nationales,” *Politique européenne*, no. 2 (2000): 33–46.



for the flaws within their own systems and adopting endogenous reforms, as was the case in Britain, rather than by importing a one-size-fits-all policy model crafted outside of their political control.

At the price, perhaps, of oversimplification and excessive abstraction, I would sum up the characteristics of disciplinary acts of comparison carried by epistemic communities such as the one behind the EURO CARE study as follows: (1) these acts are normatively inclined towards the acquisition of knowledge and the dissemination of information as legitimate, pursuable goals; (2) when brought to a given policy environment, these acts are then susceptible to alter the preference sets of the policy community, as they provide both argumentative devices and internal motives for modifying the status quo towards a more favourable distribution of resources; and finally, (3) these acts are likely to bring endogenous reform at the institutional level when the affected actors within the policy community include the range of critical decision-makers invested with the necessary authority to bypass veto players and enforce policy change. In less abstract terms, these acts designate the translation of ideas crafted by an epistemic community into new interests with regards to the allocation of public goods; that translation process can be expected to have substantive effects on the institutional environment if and only if their disciplinary power also affects the minimum winning coalition of decision-makers in a given policy environment.

## 5 Conclusion

The EURO CARE study had a decisive impact on the UK, and has affected more than one health polity; Denmark, but also countries with comparatively high cancer survival rates, pay a lot of attention to its results. In France, the results of the study did not turn into newspaper stories, but health professionals are very well aware of them and will use them to confirm that the French health system is treating cancer patients rather well. The EURO CARE study is cited in recent policy reports, such as the Grünfeld report of 2009, and appears in several documents issued by the French National Cancer Institute (INCa). When candidly asked if they use the EURO CARE data in their policy assessments, officials swiftly respond that they “naturally” do so, and that they pay “extra attention” to all EURO CARE publications.<sup>84</sup> Even well-performing states show signs of discipline, which suggests that the EURO CARE has become a routinised and durable ‘obligatory passage point’ for cancer policy-making, regardless of its results.<sup>85</sup> Finally, the influence of EURO CARE on supranational advocacy is also remarkable: the study has provided multiple cancer-specific epistemic communities

84. I recently asked the question to the director of the National Cancer Institute in a public meeting (5th Parliamentary Meetings on Cancer, Paris, 6 April 2010).

85. The notion of ‘obligatory passage points’ appears in Michel Callon’s sociology of science to explain how some technical devices become mandatory elements of scientific demonstrations. The EURO CARE study clearly fits in that category, as it has become an enduring component of policy assessment throughout the years.

(such as ECCO, the [European Cancer Organisation](#), created in 2007) with valuable data, and has even provided the impetus for the formation of at least one major transnational advocacy group, breast cancer coalition [Europa Donna](#).<sup>86</sup>

The EUROCARE study was also particularly effective because, tacitly, health systems are currently competing with each other, despite no formal obligation to do so. Following the path of OECD comparisons and performance indicators, European regulations are framing the European policy space as a field of heteronomous institutions where national solutions strive and compete for autonomy. Even if the EU does not claim any sovereignty over health systems, it has clearly deployed enough efforts in that direction for agents within these systems to feel somewhat threatened by EU law, to various degrees.<sup>87</sup> As a consequence, the framing of a Member State as a ‘Champion’ or as a ‘Laggard’ is no more constrained to a restricted set of economic performance indicators, but has spanned to several public services. This trend should be expected to expand, both horizontally, as an increasing number of policies are perceived as apt candidates for EU comparisons, and vertically, as these comparisons reach deeper characteristics of each policy domain. The EUROCARE study illustrates both horizontal and vertical expansion of these disciplinary acts of EU comparison, as it shows how health, and within health, cancer performance, can affect policy-making at the domestic level.

The generalisation of the EUROCARE case study across different ‘disease cases’ is dependent upon at least three factors: first, data availability and research efforts might be more advanced for cancer as compared to other diseases; second, attention to cancer (survival) is likely to be superior, to some extent, to survival rates for other conditions; and finally, variations in survival (or any other measure used as performance) might be less obvious for other pathologies. Notwithstanding these conditional statements, it seems very plausible that the processes illustrated by the effects of the EUROCARE study in England will occur in different disease areas, perhaps with less saliency and less dramatic effects on disease control policies. This form of Europeanization of health system performance might set out an interesting agenda for health and EU scholars alike, and especially for those interested in acts of governments situated within the knowledge/power nexus.

86. Mona Okasha, “Including Breast Cancer in the Political Agenda,” *Lancet Oncology* 2, no. 1 (2001): 62.

87. Greer, *The Politics of European Union Health Policies*.