


Delivering the best policy for cancer patients: Follow the science – follow the data

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Mark Lawler, from the Patrick G Johnston Centre for Cancer Research at Queen's University Belfast, reflects on key milestones in cancer policy initiatives and how data support innovative cancer research, optimal care and equity of access

This year marks the tenth anniversary of the European Cancer Patient's Bill of Rights, which we launched in the European Parliament on World Cancer Day 2014. ⁽¹⁾ The European Cancer Patient's Bill of Rights was a catalyst for change and a charter for action for those affected by cancer in Europe. The bedrock of the Bill of Rights was the most comprehensive analysis of cancer inequalities across Europe undertaken at the time, ⁽²⁾ providing the data intelligence required to inform the co-creation of the Bill of Rights by patient advocates and health professionals.

The Bill of Rights initiative resonated across Europe, receiving the prestigious European Health Award at the European Health Forum Gastein in 2018, which recognises health initiatives with Europe-wide impact. Further data analysis and modelling informed the creation of a 70:35 Vision, an ambitious but achievable vision for 70% long-term survival for cancer patients across Europe by 2035. ⁽³⁾

As part of this 70:35 Vision and underpinned by data intelligence, working across the European Cancer Organisation (ECO), Europe's largest multi-professional organisation, we created the European Code of Cancer Practice, ⁽⁴⁾ a series of ten rights that define what cancer patients should expect from their health system. The Code of Practice, translated into 32 different languages and highlighted in a series of national launches supported by national Ministers of Health, has resonated significantly across Europe.

The European Cancer Pulse: Providing the evidence base for cancer inequalities in Europe

We have created the European Cancer Pulse to recognise the importance of capturing data to enhance our understanding of cancer inequalities and narrow the inequality gap in Europe. This data collection initiative provides a tool to map data inequalities across the WHO Europe region. ⁽⁵⁾

It includes over 170 data measurements across 34 European countries, capturing various data sources. Dipping into the data highlights many areas of disparity – only 8% of Dutch citizens experience difficulties in finding information at the national level about cancer symptoms, versus 40% in Romania; Sweden has nearly six oncologists per 100,000 inhabitants, whereas in Malta, the number drops to less than two; the UK has only one

CT Scanner per 100,000 inhabitants, whereas Germany has 3.5. ⁽⁶⁾ This data tool will provide invaluable intelligence to national cancer agencies to modify, change and enhance their cancer policies.

It's all about the data

The principles underpinning the creation of the European Cancer Patient's Bill of Rights, 70:35 Vision, European Code of Cancer Practice and the European Cancer Pulse should inform all efforts to inform, improve or enhance cancer care delivery. Initiatives such as Eurocare, ⁽⁷⁾ Concord, ⁽⁸⁾ and the International Cancer Benchmarking Partnership (ICBP) ⁽⁹⁾ provide comparative information that facilitates a greater understanding of the challenges that health systems face and identify the opportunities for improvement that will ensure data sharing and best practices. Deploying this intelligence to inform our decision-making is critically important to provide the best possible outcomes for our patients.

The need for consistent cancer policy, informed by data

A critical component for ensuring innovative cancer research and optimal care reaches the patient is predicated on the presence of a national cancer control strategy, but most importantly, its resourcing and implementation. Consistency of cancer policy is vital. The ICBP is an international partnership of clinicians, researchers, data experts and policymakers involving 21 different international jurisdictions (Canada, Australia, and New Zealand have federal health systems, hence the use of jurisdictions rather than countries). We explore differences in cancer survival and outcomes between these jurisdictions (and the factors that may be contributing to these differences) to provide the data intelligence and evidence that informs policy and clinical practice change that enhances patient outcomes.

A recent comprehensive study from ICBP highlighted how consistency of cancer policy improved cancer outcomes in six of seven cancers analysed. ⁽¹⁰⁾ This led to our development of a cancer policy scorecard, ranking each jurisdiction/ country for its cancer policy consistency. Denmark came out with the highest ranking, closely followed by New South Wales (Australia) and Ontario (Canada); countries like Norway and Ireland were mid-table, while the UK nations and New Zealand languished at the bottom of this particular league table. Yet despite this evidence, England has abandoned its cancer strategy and moved to a major conditions strategy ⁽¹¹⁾ despite the evidence base. Europe has a Beating Cancer Plan ⁽¹²⁾ and a Cancer Mission, ⁽¹³⁾ while the US has (belatedly) launched its first National Cancer Plan. ⁽¹⁴⁾ To counter this incomprehensible decision, as a group of UK cancer experts, we developed the evidence to support a UK-wide National Cancer Plan, ⁽¹⁵⁾ which we launched in the House of Commons in November 2023. Evidence to support the need for a National Cancer Plan was presented to the Health and Social Care Select Committee's Inquiry on the Future of Cancer. ⁽¹⁶⁾

Spend less to achieve more: How data intelligence changed cancer policy

Data to inform changes in cancer policy can come from unexpected sources. A campaign led by Bowel Cancer UK sought to end the practice in England whereby colorectal patients receiving cetuximab treatment were not permitted to go on treatment breaks. Despite evidence presented on the potential advantages of treatment breaks in terms of enhanced quality-of-life and a series of patient testimonials, the crucial evidence that underpinned a change in policy by NHS England was the health economic analysis, in which we showed that a policy change could save the NHS £1.2bn. ⁽¹⁷⁾ This work was recognised with Health Data Research UK's Impact of the Year Award in 2022.

How data trumps opinion

Far too often, opinion has trumped data in the creation of and/or implementation of cancer policy. We must not make decisions based on conjecture or rhetoric but on fact and evidence. We need to ensure that data intelligence is always sought (and acted upon) in delivering the cancer health systems and policies that provide timely, high-quality cancer research and care for the people of Europe. A cancer health system informed by evidence, not opinion, will ensure that we make the correct decisions that will have the greatest impact on both patients and citizens. Data always eat opinion for lunch.

References

1. Lawler M, Le Chevalier T, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Murphy MJ, Johnston PG; European Cancer Concord (ECC). A Bill of Rights for patients with cancer in Europe. *Lancet Oncol.* 2014; 15:258-60. doi: [https://doi.org/10.1016/S1470-2045\(13\)70552-7](https://doi.org/10.1016/S1470-2045(13)70552-7) PMID: 24503530
2. Lawler M, Le Chevalier T, Murphy MJ Jr, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Armand JP, Barbacid M, Barzach M, Bergh J, Bode G, Cameron DA, de Braud F, de Gramont A, Diehl V, Diler S, Erdem S, Fitzpatrick JM, Geissler J, Hollywood D, Højgaard L, Horgan D, Jassem J, Johnson PW, Kapitein P, Kelly J, Kloezen S, La Vecchia C, Löwenberg B, Oliver K, Sullivan R, Tabernero J, Van de Velde CJ, Wilking N, Wilson R, Zielinski C, Zur Hausen H, Johnston PG. A catalyst for change: The European Cancer Patient's Bill of Rights. *Oncologist* 2014; 19:217-24. doi: <https://doi.org/10.1634/theoncologist.2013-0452>. PMID: 24493667
3. Lawler M, Selby P, Banks I, Law K, Albrecht T, Armand JP, Barbacid M, Barzach M, Bergh J, Cameron D, Conte P, de Braud F, de Gramont A, De Lorenzo F, Diehl V, Diler S, Erdem S, Geissler J, Gore-Booth J, Henning G, Højgaard L, Horgan D, Jassem J, Johnson P, Kaasa S, Kapitein P, Karjalainen S, Kelly J, Kienesberger A, La Vecchia C, Lacombe D, Lindahl T, Löwenberg B, Luzzatto L, Malby R, Mastris K, Meunier F, Murphy M, Naredi P, Nurse P, Oliver K, Pearce J, Pelouchov J, Piccart M, Pinedo B, Spurrier-Bernard G, Sullivan R, Tabernero J, Van de Velde C, van Herk B, Vedsted P, Waldmann A, Weller D, Wilking N, Wilson R, Yared W, Zielinski C, Zur Hausen H, Le Chevalier T, Johnston P. The European Cancer Patient's Bill of Rights, update and implementation 2016. *ESMO Open.* 2017; 1:e000127. doi: <https://doi.org/10.1136/esmooopen-2016-000127>. PMID: 28848664.

4. Lawler M, Oliver K, Stefan Gijssels S, Aapro M, Abolina A, Albrecht A, Erdem S, Geissler J, Jassem J, Karjalainen S, La Vecchia C, Lievens Y, Meunier F, Morrissey M, Naredi P, Oberst S, Poortmans P, Price R, Sullivan R, Velikova G, Vrdoljak E, Wilking N, Yared W, Selby P. The European Code of Cancer Practice. *J Cancer Policy* 2021; 28: 100282 <https://doi.org/10.1016/j.jcpo.2021.100282>
5. Couespel N, Venegoni E, Lawler M The European Cancer Pulse: tracking inequalities in cancer control for citizen benefit. *Lancet Oncol.* 2023 May;24(5):441-442. doi: [https://doi.org/10.1016/S1470-2045\(23\)00140-7](https://doi.org/10.1016/S1470-2045(23)00140-7). PMID: 37142370
6. <https://www.eurocancer.org/pulse-map/countries>
7. <https://www.iss.it/eurocare-il-progetto>
8. <https://csg.lshtm.ac.uk/research/themes/concord-programme/>
9. <https://www.cancerresearchuk.org/health-professional/data-and-statistics/international-cancer-benchmarking-partnership-icbp>
10. Nolte E, Morris M, Landon S, McKee M, Seguin M, Butler J, Lawler M. Exploring the link between cancer policies and cancer survival: a comparison of International Cancer Benchmarking Partnership countries. *Lancet Oncol.* 2022 Nov;23(11):e502-e514. doi: [https://doi.org/10.1016/S1470-2045\(22\)00450-8](https://doi.org/10.1016/S1470-2045(22)00450-8). PMID: 36328024
11. <https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework-2>
12. https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf
13. https://research-and-innovation.ec.europa.eu/funding/funding-opportunities/funding-programmes-and-open-calls/horizon-europe/eu-missions-horizon-europe/eu-mission-cancer_en
14. <https://nationalcancerplan.cancer.gov/about>
15. Aggarwal A, Choudhury A, Fearnhead N, Kearns P, Kirby A, Lawler M, Quinlan S, Palmieri C, Roques T, Simcock R, Walter FM, Price P, Sullivan R. The future of cancer care in the UK-time for a radical and sustainable National Cancer Plan. *Lancet Oncol.* 2023 Nov 14:S1470-2045(23)00511-9. doi: [https://doi.org/10.1016/S1470-2045\(23\)00511-9](https://doi.org/10.1016/S1470-2045(23)00511-9). Online ahead of print. PMID: 37977167
16. <https://committees.parliament.uk/event/20227>
17. Henderson RH, French D, McFerran E, Adams R, Wasan H, Glynn-Jones R, Fisher D, Richman S, Dunne PD, Wilde L, Maughan TS, Sullivan R, Lawler M. Spend less to achieve more: Economic analysis of intermittent versus continuous cetuximab in KRAS wild-type patients with metastatic colorectal cancer. *J Cancer Policy.* 2022 Jun 16:100342. doi: <https://doi.org/10.1016/j.jcpo.2022.100342>. Online ahead of print. PMID: 35718327

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