







european cancer organisation



I'm A Scholar Activist by Necessity

Prof Mark Lawler

Queen's University Belfast, UK; DATA-CAN, the UK's Health Data Research Hub for Cancer Cancer Drug Development Forum; European Cancer Organisation; European Cancer Patient Coalition; Inspire2Live



• ML has received honoraria from Bayer, Carnall Farrar, EMD Serono, Novartis , Pfizer, Roche unrelated to this work

This is the scale of the challenge we face in Europe!



This is the scale of the challenge we face in Europe!

But we also need to think about the 20 million European citizens who survive cancer

They need our support!



This is the scale of the challenge we face in Europe!

- Project to identify and address cancer inequalities in Europe
- Key to the success of the project was:
 - Co-operation
 - Cancer Intelligence¹
 - Patient Involvement
 - And then more Patient involvement
 - Co-creation
 - Patience and perseverance



The European Cancer Patient's Bill of Rights

- A charter to challenge the inequalities that cancer patients in Europe were experiencing on a daily basis¹
- A catalyst for change and an empowerment tool for cancer patients
- An initiative that has resonated across all of Europe



¹ Lawler *et al Lancet Oncology* 2014;

A vision for cancer control and cancer survival in Europe

- The 70:35 Vision An average of 70% long-term survival for cancer patients in Europe by 2035, underpinned by research, with progress on cancer control, better survivor experience and improved quality of life
- How are we going to do it?
 - Working together and co-creation
 - Sharing Best Practice
 - Embedding Research and Innovation
 - Supporting Survivorship

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Downloaded from http://esmoopen.bmj.com/ on April 24, 2018 - Published by group bmi.com
   Den Access
                                                                                                                         Review
      EMD Den The European Cancer Patient's Bill of
                           Rights, update and implementation 2016
        CrossMark
                           Mark Lawler,1,2 Ian Banks,2,3,4 Kate Law,2 Tit Albreht,5
                           Jean-Pierre Armand,<sup>6</sup> Mariano Barbacid,<sup>7</sup> Michèle Barzach,<sup>8</sup> Jonas Bergh,<sup>8</sup>
                           David Cameron,<sup>10</sup> Pierfranco Conte,<sup>11</sup> Filippo de Braud,<sup>12</sup> Aimery de Gramont,<sup>12</sup>
                           Francesco De Lorenzo,14.15 Volker Diehl,16 Sarper Diler,17 Sema Erdem,18
                           Jan Geissler, 19,20 Jola Gore-Booth, 21 Geoffrey Henning, 21 Liselotte Højgaard, 22,23
                           Denis Horgan,24 Jacek Jassem,25 Peter Johnson,28,27 Stein Kaasa,28
                           Peter Kapitein,<sup>29</sup> Sakari Karjalainen,<sup>30,31</sup> Joan Kelly,<sup>31,32</sup> Anita Kienesberger,<sup>33</sup>
                           Carlo La Vecchia,34 Denis Lacombe,35 Tomas Lindahl,38 Bob Löwenberg,3
                           Lucio Luzzatto,38,39 Rebecca Malby,40 Ken Mastris,41 Françoise Meunier,35
                           Martin Murphy, 42 Peter Naredi, 43,44 Paul Nurse, 36 Kathy Oliver, 45 Jonathan Pearce, 4
                           Jana Pelouchov,15 Martine Piccart,47 Bob Pinedo,48 Gilly Spurrier-Bernard,49
                           Richard Sullivan,<sup>50</sup> Josep Tabernero,<sup>51</sup> Cornelis Van de Velde,<sup>52</sup> Bert van Herk,<sup>44,51</sup>
                           Peter Vedsted, 54 Anita Waldmann, 55 David Weller, 58 Nils Wilking, 57, 58 Roger Wilson, 59
                           Wendy Yared,<sup>31</sup> Christoph Zielinski,<sup>60,61</sup> Harald zur Hausen,<sup>62</sup> Thierry Le Chevalier,<sup>2,63</sup>
                           Patrick Johnston, 1,2 Peter Selbv2,4
To cite: Lawler M, Banks I,
                           ABSTRACT
                                                                                   evaluate and validate and disseminate best practice
Law K. et al. The European
                                                                                   in cancer management for the different countries and
                           In this implementation phase of the European Cancer
Cancer Patient's Bill of Rights
                           Patient's Bill of Rights (BoR), we confirm the following
                                                                                    regions and (2) promote Research and Innovation and its
update and implementation
                                                                                   translation to maximise its impact to improve outcomes
                           three patient-centred principles that underpin this
2016. ESMO Open
2016;1:e000127. doi:10.1136/
                           initiative
                           1. The right of every European citizen to receive the most
 esmoopen-2016-000127
                                                                                INTRODUCTION
                              accurate information and to be proactively involved in
                                                                                Our growing knowledge of the funda-
                               his/her care.

    Prepublication history and
additional material is available.

                                                                                mental biology of cancer and its treatment
                             . The right of every European citizen to optimal and
                              timely access to a diagonsis and to appropriate
                                                                                has resulted in radical improvements in
To view please visit the journal (http://dx.doi.org/10.1136/esmo
                              specialised care, underpinned by research and
                                                                                outcomes for patients with cancer and an
                               innovation
open-2016-000127).
                                                                                enhanced patient experience. Over half of
                           3. The right of every European citizen to receive care in
                                                                                all patients with cancer can expect long-term
Received 10 November 2016
                              health systems that ensure the best possible cancer
                                                                                survival beyond 10 years after their diagnosis,
                              prevention, the earliest possible diagnosis of their
Accepted 24 November 2016
                                                                                and for most of these people the outcome is
                              cancer, improved outcomes, patient rehabilitation,
                                                                                a cure. Good quality of life is now achievable
                              best quality of life and affordable health care.
                                                                                for many patients on active therapy and for
                           The key aspects of working towards implementing the BoR
                                                                                long-term survivors. However, patients with
                           ► Agree our high-level goal. The vision of 70% long-
                                                                                cancer, their carers and cancer professionals
                              term survival for patients with cancer in 2035,
                                                                                 must work hard together to ensure that these
                              promoting cancer prevention and cancer control and
                                                                                benefits are shared by all and that the pace
                              the associated progress in ensuring good patient
                                                                                of progress is maintained and outcomes and
                               experience and quality of life.
                                                                                patients' experience continue to improve.
                           Establish the major mechanisms to underpin its
                                                                                  Despite the advances outlined above, cancer
                              delivery. (1) The systematic and rigorous sharing
                                                                                and the provision of cancer care still places a
                              of best practice between and across European
                                                                                significant burden on Europe's patients, citi-
                              cancer healthcare systems and (2) the active
                                                                                zens and economies. As the population ages
                              promotion of Research and Innovation focused
                                                                                and if lifestyle-associated cancer risks such
                               on improving outcomes; (3) Improving access to
                                                                                as smoking and obesity are not adequately
                              new and established cancer care by sharing best
For numbered affiliations see
                                                                                addressed, then in many European countries
                              practice in the development, approval, procurement
end of article
                               and reimbursement of cancer diagnostic tests and
                                                                                more than half of the population will develop
                              treatments
                                                                                a cancer at some time in their lives.
Correspondence to
Professor Peter Selby
                           Work with other organisations to bring into being a
                                                                                  Europe provides some of the best cancer
                              Europe based centre that will (1) systematically identify,
                                                                                care in the world and conducts high-quality,
P.J.Selby@leeds.ac.ul
                         Lawler M. et al. ESMO Open 2016;1:e000127. doi:10.1136/esmoopen-2016-00012
                                                                                                              ESMO 1
RMI
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Europe-wide recognition for a citizen focussed initiative

- The European Cancer Patient's Bill of Rights received the prestigious 2018 European Health Award
- Presented during the opening ceremony of the European Health
 Forum Gastein - The European
 Health Award recognises initiatives
 that have had Europe-wide impact



Keeping the focus on the patient: The European Code of Cancer Practice

- The European Code of Cancer Practice is a citizen and patient-centred manifesto of the core requirements for good clinical cancer practice, in order to improve outcomes for <u>all</u> of Europe's cancer patients.
- **Co-produced** by a team of cancer patients, patient advocates and cancer professionals.
- Launched on 23 September 2020 with Commissioner Stella Kyriakides and patients and health care professionals (HCPs) from across Europe
- Translated into **30 European Languages**
- Significant Support right across Europe

#cancerpatientrights #codeofcancerpractice europeancancer.org/code

European Code of Cancer Practice YOU HAVE A RIGHT TO:



#cancerpatientrights #codeofcancerpractice

europeancancer.org/code

The Code in your language

- Basque Minbiziaren aurkako jarduteen Europar araudia
- Bulgarian Европейски кодекс за онкологична практика Credit: Teodora Kolarova, International Neuroendocrine Cancer Alliance
- Croatian Europski kodeks za onkološke bolesnike
 Credit: Professor Eduard Vrdoljak Centre for Oncology, University of Split
- Czech Evropský kodex pro péči o rakovinu
 Credit: Anna Prokupkova, Association of European Cancer Leagues
- Dutch De Europese Code voor Kankerbestrijding
 Credit: Jonas Van Riet, European Society of Radiology
- English European Code of Cancer Practice
- French Code Européen de la prise en charge du cancer
 Credit: Norbert Couespel, European Cancer Organisation; Ariane Weinman, EUF
 Professor Françoise Meunier, FEAM
- Finnish Eurooppalaiset syövänhoidon suositukset Credit: The Association of Cancer Patients in Finland
- German Der Europäische Kodex für die Krebspraxis Credit: Tamás Bereczky, EUPATI-DE / Patvocates
- Greek Ο Ευρωπαϊκός Κώδικας Πρακτικής του Καρκίνου
 - Credit: Andreas Charalambous, European Oncology Nursing Society (EONS)
- Hungarian A Rákgyakorlat Európai Kódexe
 Credit: Csaba Dégi, International Psycho-Oncology Society
- Italian Codice Europeo di Prassi Contro il Cancro Credit: Giacomo Lazzaro, European Cancer Organisation
- Lithuanian Europos Vėžio Gydymo Kodeksas Credit: Šarunas Narbutas, Youth Cancer Europe

Latvian – Eiropas vēža prakses kodekss

Credit: Agnese Abolina, European Cancer Organisation

- Polish Europejski Kodeks Postępowania Onkologicznego
 Credit: Prof Jacek Jassem, Department of Oncology and Radiotherapy, Medical University of
 Gdansk
- Portuguese Código Europeu de Práticas em Oncologia
 Credit: Associação de Investigação de Cuidados de Suporte em Oncologia
- Romanian Codul European De Practică A Cancerului
 Credit: Csaba Dégi, International Psycho-Oncology Society
- Russian Европейский Кодекс по Борьбе с Раковыми Заболеваниями Credit: Agnese Abolina, European Cancer Organisation; Olga Kozhaeva, SIOP Europe
- Serbian Europski kodeks za onkološke bolesnike
 Credit: Marko Ocokoljić, SIOP Europe
- Slovak Európsky kódex starostlivosti o pacientov s rakovinou Credit: Darina Sedláková, League Against Cancer Slovakia
- Slovene Evropski kodeks prakse raka
 Credit: National Institute of Public Health, Slovenia
- Spanish El Código Europeo de Prácticas Contra el Cáncer
 Credit: Natacha Bolaños, Lymphoma Coalition; Alberto Crespo, European Cancer
 Organisation
- Swedish Europeiska kodexen för praxis inom cancervård
 Credit: Nathalie Nähr, MSc in Bioentrepreneurship
- Turkish Avrupa Kanser Uygulamaları Kodu Credit: Sema Erdem, Europa Donna
- Welsh Côd Ewropeaidd Gwasanaeth Cancr

Why the European Code of Cancer Practice?

- To empower cancer patients to be active participants rather than passive recipients in their care
- To address the inequalities that many patients are experiencing every single day of their lives
- To ensure that patients receive quality treatment to achieve the best outcomes no matter where they live
- To achieve our aim of an average of 70% long term survival for cancer patients by 2035 (The 70/35 Vision) with progress on cancer control, patient experience and quality of life
- To embed rights that patients should expect from their health system into European cancer policy

Empowering the Patient

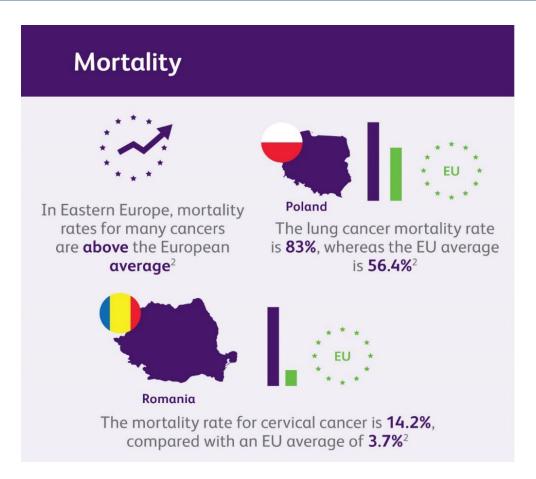
- The European Code of Cancer Practice sets out a series of 10 key overarching rights, and in particular signposts what patients should expect from their health system, in order for them to achieve the best possible outcomes.
- An empowerment tool to ensure the best available care is delivered for European citizens and patients.
- Each of the 10 overarching rights is **linked to three questions** that a patient/parent/guardian may choose to ask their healthcare professionals.

#cancerpatientrights #codeofcancerpractice

europeancancer.org/code

Tackling The East-West Equity Divide

- Our research revealed the significant inequalities that European citizens and patients are facing, particularly in Central and Eastern Europe (CEE)
- Critical Enablers for CEE countries:
 - Robust Cancer intelligence
 - Resilient National Cancer Control Plans (NCCPs)
 - Patient-centred multidisciplinary teams
 - A research and innovation empowered culture



European Code of Cancer Practice YOU HAVE A RIGHT TO:



#cancerpatientrights #codeofcancerpractice

europeancancer.org/code

Critical Importance of Cancer Research to Cancer Care

- Key message: Cancer patients who are treated in research-active hospitals have better outcomes than those who are not
- Embedding research within National Cancer Control Programmes is critical to our future health and wellbeing
- Cancer Mission an integral part of Europe's Beating Cancer Plan



Support at the Highest Level

04 February 2021, 16:45 - 18:45

Special Committee on Beating Cancer

Committees BECA



Acquisition options:

Hinqdokx sn`pt dr shnmeqn I Udqnminpt d Softkids, Kdmn hq L DO+ADB@q`oonqsdt q+nmv g`sI nqd b`mad cnmd ax sgd DT nmo`shdms dI onv dq dms

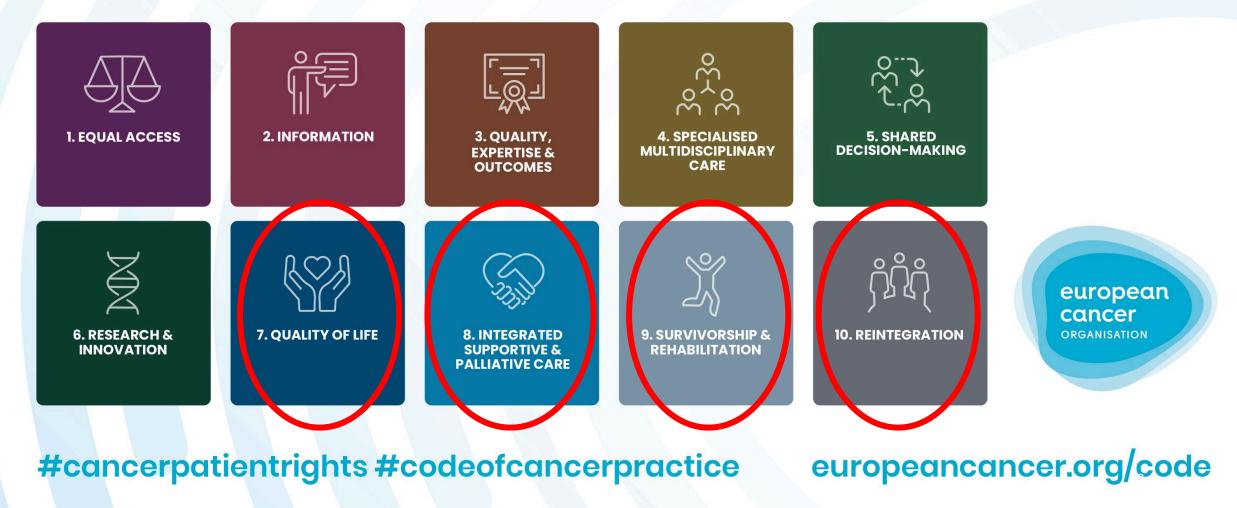
"The European Cancer Organisation recently launched the European Code of Cancer Practice and I would be very happy to work together with the European Parliament that maybe we could combine this effort with the European Cancer Organisation."

EU Health Commissioner Stella Kyriakides speaking to the European Parliament's Special Committee on Cancer

04 February 2021



European Code of Cancer Practice YOU HAVE A RIGHT TO:



We Need to Move the Dial...

- Overarching attention of European scientific/clinical communities to date has focussed on cancer diagnosis and treatment, rather than on living with and beyond cancer.
- BUT 20 million citizens in Europe have survived cancer
- We must greatly enhance our engagement with cancer survivors and the cancer survivorship agenda, in order to ensure that the specific survivorship challenges and needs are adequately addressed



MANIFESTO FOR THE EUROPEAN ELECTIONS 2019

European Cancer Patient Coalition



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European Cancer Survivorship Research and Innovation Plan

- To address these challenges, we propose that a European Cancer Survivorship Research and Innovation Plan be embedded within the EU Cancer Mission¹
- This European Cancer Survivorship Research and Innovation Plan should have 3 distinct Research Pillars:
- The Medical Cancer Survivorship Research and Innovation Pillar
- The Socio-Economic Cancer Survivorship Research and Innovation Pillar
- The Politico-Legal Cancer Survivorship Research and Innovation Pillar
- For each Pillar there are a series of challenges and proposed solutions

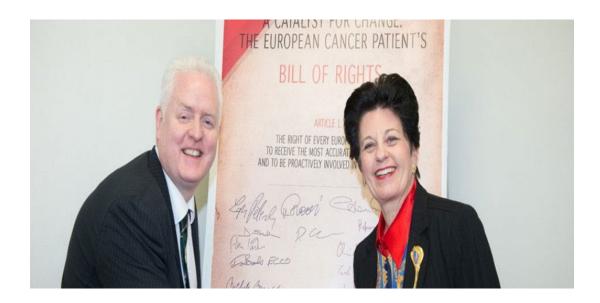
¹Lawler M, De Lorenzo F, Lagergren P, Mennini FS, Narbutas S, Scocca G, Meunier F; European Academy of Cancer Sciences. Challenges and solutions to embed cancer survivorship research and Innovation within the EU Cancer Mission *Mol Oncol* 2021





One of those Challenges is the Financial Discrimination that cancer survivors experience

- You beat cancer and yet.... A new challenge arises
- Problems getting a mortgage, loan, insurance, other financial challenges
- The Right to Be Forgotten ensures that cancer survivors can return to a productive life without facing financial discrimination



"We support the transposition of the Right to Be Forgotten legislation into Union-level legislation to prevent unfair discrimination in cancer patients' access to financial services and their reintegration into normal life." **Prof. Françoise Meunier**



https://ecpc.org/policy/the-right-to-be-forgotten-a-new-research-project/

The Right to be Forgotten

- A practical approach to ensure that former cancer patients can return to a normal productive life without financial discrimination
- Right for a past illness no longer to be taken into account for those patients living beyond cancer
- 10 years after the end of treatment for adults
- **5 years for children** (either below 18 or 21 depending on the country)
- Earlier for cancers with excellent prognosis (e.g. breast, thyroid)

- Adopted in France, Belgium, Luxembourg, the Netherlands, Portugal, and Romania
- Much progress in Cyprus, Ireland and Italy

There is Life After Cancer



- Twenty million reasons to get it right in Europe
- Please help us to stop this discrimination
- CANCER PATIENTS SHOULD NOT HAVE TO PAY TWICE!

Lawler M, Meunier F. Don't make cancer patients pay twice, the right to be forgotten should be the law everywhere *BMJ in press*





Deploying data and cancer intelligence for better care

- Recognising the primacy of data
- Turning information into intelligence is key
- The **patient** has a **critical role** to play in this **data-driven** revolution



Driving a "Big Data for Better Health" Agenda

Key issues of relevance for research and most importantly for patients:

- Break down the silos: Get academic researchers, clinicians, industry players, regulators and patients to collaborate and share data/code etc
- Learn from the data: Use data from diverse sources ('omic, clinical, epidemiological, socio-economic etc) to increase our understanding of disease, mode of action of drugs, better drug targets etc
- **Big data for better health:** Use this intelligence to improve health and wellbeing of the citizen, enhance innovation and contribute to societal benefit







Championing a citizen-focussed Data Sharing Culture

- Facilitating access to rich data resources to empower research and innovation
- Establishing a Cancer Data Knowledge Network¹
- Moving from a <u>Closed</u> "Selfish Silo" Mentality to a more <u>Open</u> "Collaborative Culture"
- Establish and maintain Public Trust in the use of "Big Data"²



25th May 2017

Sharing Clinical and Genomic Data on Cancer — The Need for Global Solutions

Mark Lawler, David Haussler, Lillian L. Siu, Melissa A. Haendel, Julie A. McMurry, Bartha M. Knoppers, Stephen J. Chanock, Fabien Calvo, Bin T. The, Guneet Walia, Ian Banks, Peter P. Yu, Louis M. Staudt, and Charles L. Sawyers, For the The Clinical Cancer Genome Task Team of the Global Alliance for Genomics and Health

¹Lawler et al *New Engl J Med* 2017 ²Lawler et al *Lancet Oncology* 2018

A Question of Trust: Ensuring a citizen-focussed perspective

THE LANCET Oncology

- **Co-developing** a Citizen-focused **Data Sharing Cooperative with patients/citizens**
- Articulating a clear Social Contract, where citizens (as data donors) are at the heart of decision making.
- Embedding ethical rigour in all our data-driven processes
- **Democratising data analysis** for maximum scientific, clinical and patient value
- Supporting current data research environments and enabling data "safe havens" (Trusted Research Environments(TRE))
- Embedding the Principle of The 5 Safes: "Safe people, working on safe projects, utilising safe data, in safe places, with safe outputs"

Lawler et al *Lancet Oncology* 2018 A Roadmap for Restoring Trust in Big Data

Transforming the data landscape by Transcending disciplines

• We all need to work together to maximise the power of data



Swansea University Prifysgol Abertawe

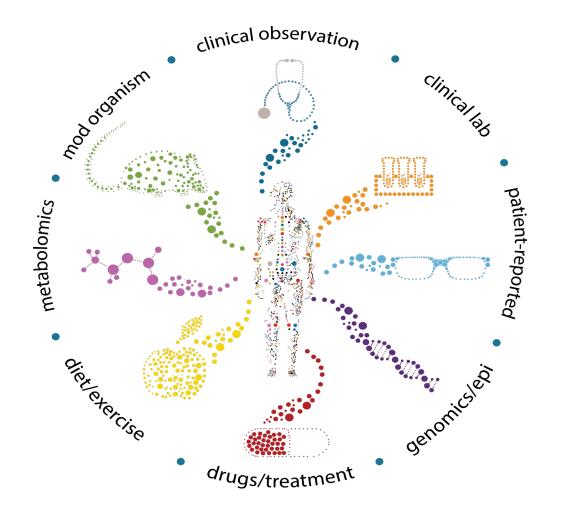
and the second



Patients Clinicians **Pathologists** Geneticists **Cell/Molecular Biologists Biochemists/Microbiologists/Immunologists Biologists Animal sciences Bioinformaticians** Industry **Epidemiologists Statisticians** Health service researchers Astronomers **Geographers / Demographers** Social scientists **Environmental scientists Economists** Lawyers Ethicists Theologians Image analysts **Computer scientists** Mathematicians

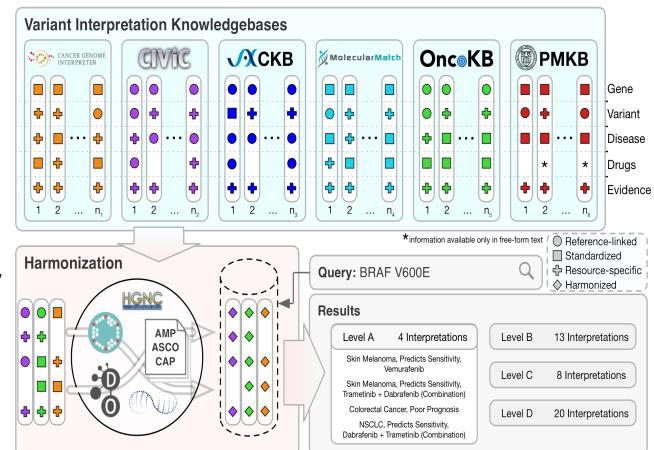
Empowering a citizen-centred data-driven ecosystem

- A cancer data ecosystem to drive research and innovation
- Enabling more effective prevention and early diagnosis approaches
- Facilitating application of dataenhanced discovery to deliver innovative therapies
- Nurturing and empowering patient recovery and rehabilitation
- Underpinning enhanced industry partnerships and innovation.



Breaking down the data silos to create a "data translator" for enhanced cancer care

- <u>Variant Interpretation for Cancer Consortium</u> (VICC): A Driver Project of GA4GH
- Creation and application of the <u>VICC Meta-</u> <u>Knowledgebase</u>, which aggregates all known information about gene mutations and variants of uncertain significance into a single searchable resource for the cancer community
- Hundreds of siloed efforts have sprung up around the globe to collate information about whether any particular variant is of concern. But none of these knowledgebases spoke the same language.
- Our "data translator" has harmonised the information and made it freely available online to the entire cancer community



Wagner AH, Walsh B, Mayfield G, ..., Lawler M, Goecks J, Griffith M, Griffith OL, Margolin AA; Variant Interpretation for Cancer <u>A harmonized meta-knowledgebase of clinical interpretations of somatic genomic variants in cancer.</u> *Nat Genet.* 2020

DATA-CAN: The vision



- Improve access to existing data Clinical, academic and commercial Clinical data Pathology High quality curated data Application of AI and Machine Learning Improve quality of data Structured and plain text (NLP) to digital pathology images Better data at the point of care Enhanced curation of current data Improve UK coverage Four nations of the UK Add new datasets at scale Genetic/molecular, imaging, pathology ٠ Primary care, Patient Related Outcome Genetic and molecular Radiology Measures (PROMs) Application of AI and Machine Learning IHC to single gene to digital radiology images Whole genome sequencing **Ensure fair value**
 - Patients, Clinicians/NHS, Researchers,

Industry

Patients are at the heart of what we do

- Patients are involved at all levels of decision- making
- Integrate patient/public led research ideas and projects
- Enable genuine co-creation of research
- Involve patients in discussions with all research partners, including commercial partners
- Empower underserved and minority communities whose voice is often unheard



"Patients want their data to be used to improve care. In fact, they're often surprised it's not used already."

Jacqui Gath, Cancer survivor. patient advocate

"As patients we not only are empowered but we feel empowered"

Wheatstone P, Gath J, Carrigan C, Hall G, Cook Y, DATA-CAN Sujenthiran A, Peach J, Davie C, Lawler M. *BMJ Partnerships in Practice* 2021

And Then the World Changed....

For Me Covid-19 was personal





<u>Eur J Cancer</u>. 2020 Jun; 132: 98–99. Published online 2020 Apr 18. doi: <u>10.1016/j.ejca.2020.04.001</u>

PMCID: PMC7165280 PMID: <u>32335477</u>

Cancer and coronavirus disease 2019; how do we manage cancer optimally through a public health crisis?

Eduard Vrdoljak,^{a,*} Richard Sullivan,^b and Mark Lawler^C

UCI Partners

"People are starting to fear a Covid-19 diagnosis more than a cancer diagnosis"

Genomics



- BUT WHERE WAS THE EVIDENCE?
- Data-Driven Collaboration between DATA-CAN and UCL
- Accessing Real Time Data from Hospital Trusts across the UK
- Modelling excess deaths due to the adverse effects of the Covid pandemic



Covid-19 and Cancer: "Real Time" Data analysis

- We accessed / analysed data from Hospital Trusts across the UK
- 7 out of 10 people with suspicion of cancer were either not going to their GP or not getting referred to cancer specialist services
- 4 out of 10 cancer patients were not getting access to their chemotherapy
- First data that drew attention of the government, academia, NHS and the public to the disastrous impact of Covid-19 on cancer services and cancer patients



Impact on cancer services has been catastrophic

1

EXCLUSIVE



- A new analysis finds a huge backlog of endoscopy procedures that are crucial for
- a number of gastrointestinal cancers



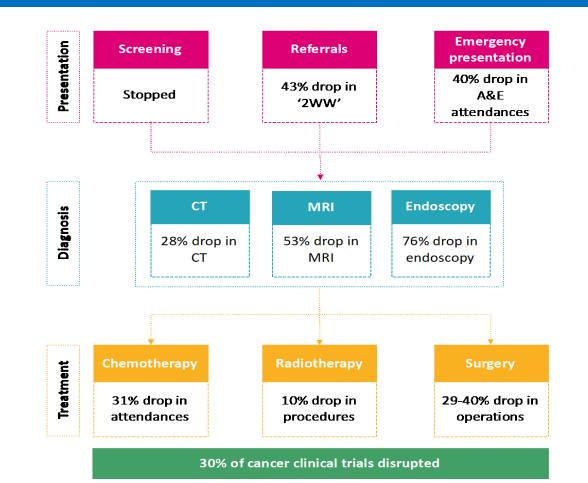


- April 2020: **10,476** endoscopies
- April 2019: **110,584** endoscopies
- UK could have thousands of extra cancer deaths due to COVID delaying 500,000 endoscopies

Ho KMA, Banerjee A, Lawler M, Rutter MD, Lovat LB.<u>Lancet Gastroenterol Hepatol</u>. 2021

Disruptions to cancer services across the cancer pathway due to the Covid-19 pandemic

- Disruption was felt across the entire cancer pathway
- Presentational / Diagnostic Delay; significant impact on treatment
- Significant disruption of cancer research (clinical trials, discovery research, translational research)



Sud A, Torr B, Loveday C, Jones M, Broggio J, McFerran E, Lawler M, Houlston R, Turnbull C. Lancet Oncology 2020 <u>https://www.carnallfarrar.com/life-sciences/life-sciences-insights/disruption-and-recovery-of-cancer-</u> from-covid-19/)



Covid-19 and Cancer: Excess Mortality

В

Not affected Affected

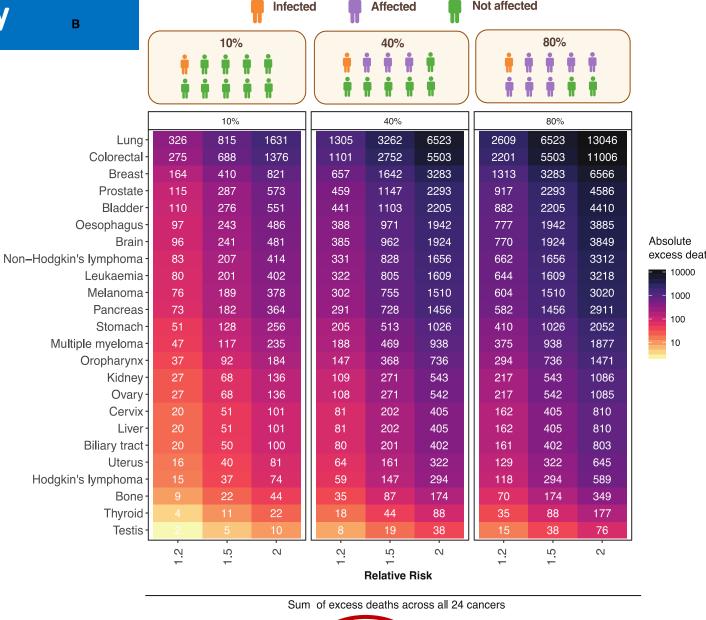
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- Looked at excess mortality on data \bullet from nearly 4M citizens
- Modelled different scenarios to determine excess deaths due to pandemic
- **Used Real Time Data** from Hospital Trusts to Inform the Model
- **Predicted 7,165 17,910 excess** deaths





One Step Forwards, Two Steps Backwards

- Assuming 3 months of disruption (which is conservative), stage shift in detection of cancer (i.e. detecting cancer later rather than earlier) due to disruptions to the cancer pathway could significantly affect five-year survival
- For certain cancers e.g. colorectal, the Covid-19 pandemic could set us back nearly a decade

Five-year survival anticipated for 2020 (England)



SOURCE: CF analysis, Office for National Statistics, Cancer survival in England, adults diagnosed * Anticipated 5-year survival for 2020, calculated from 2017 figures

https://www.carnallfarrar.com/life-sciences/life-sciences-insights/disruption-and-recovery-of-cancer-fromcovid-19/)



DATA is also helping us to support the recovery

- Presentational/diagnostic/treatment delays in colorectal cancer due to Covid-19 have potential to cause significant excess deaths and loss of life years
- Our work¹ shows that prioritisation using Faecal Immunochemical Testing (FIT) can help avoid nearly 90% of these excess deaths, whilst reducing immediate requirement for colonoscopy by >80%.
- Can support both the health system (by prioritising use of tests (e.g. colonoscopy) for those who most require them, thereby solving capacity problems), but more importantly patients to ensure that presentational/diagnostic delays are reduced

¹Loveday C, Sud A, Jones M, Broggio J, McFerran E, Muller DC, Abulafi M, Lawler M, Houlston R, Turnbull C. *Gut 2020*





- Presented our data to the European Cancer Organisation (E.C.O) (Europe's largest multidisciplinary cancer organisation) and to WHO Europe
- In light of the dramatic impact of Covid, the Board of E.C.O. decided to launch a Special Network on the Impact of Covid-19 on Cancer, co-chaired by Board members Mirjam Crul and Mark Lawler.
- Rapidly convened a panel of experts from across Europe

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• Led to development of a 7-Point Plan to mitigate the impact of Covid

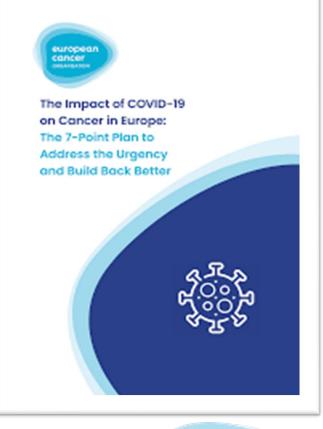
https://www.europeancancer.org/topic-networks/16:impact-of-covid-19-on-cancer



Our 7-Point Plan to Build Back Better (And Smarter)

- 1. Urgently addresses the cancer backlog
- 2. **Restores confidence** of European citizens and patients in cancer health services
- 3. Tackles medicines, products and equipment shortages
- 4. Addresses cancer workforce gaps across Europe
- 5. Employs innovative technologies to strengthen cancer systems and provide optimal care to cancer patients
- 6. Embeds data collection and the **rapid deployment of cancer intelligence** enhance policy delivery
- 7. Secures deeper pan-European health cooperation

Cancer must not become the Forgotten "C" in the Fight against Covid-19.



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Cancer must be at the top of the Recovery Agenda

- "Time To Act" Campaign
- Underpinned the Time To Act campaign with evidence-based intelligence
- Data Intelligence study presented to the Europe Beating Cancer Committee (10th May 2021)
- We demand that cancer must be put at the top of the European Health Agenda





Lawler M, Crul M. Data must underpin our response to the covid-19 pandemic's disastrous impact on cancer. *BMJ*. 2022

Data Intelligence: Impact on cancer screening and diagnosis



Impact of Covid-19 on Cancer patients seen Clinicians across Europe saw **1.5 million fewer Cancer patients** in the first year of the pandemic



Impact of Covid-19 on Cancer screening



Impact of Covid-19 on Cancer diagnosis **100 million Cancer screening tests** were **not performed** in Europe as a result of the pandemic

1 million Cancer patients could be undiagnosed due to the presentational/diagnostic backlog

Data Intelligence: Impact on cancer patients/cancer professionals



Impact of Covid-19 on Cancer treatment During the pandemic, **1 in 2 Cancer patients** in Europe **did not receive the surgical or chemotherapy treatment** they needed on time, **and 1 in 5,** their treatment is still being delayed



Impact of Covid-19 on Cancer patients Due to fears of contracting Covid-19, citizens and patients are less likely to attend screening appointments or go to hospital for cancer treatment



Impact of Covid-19 on Cancer workforce The pandemic has taken its toll on healthcare workers with **4 in 10 feeling burnout and 3 in 10 showing signs of clinical depression**

Patient Centred Initiative with pan-European relevance

- Official European virtual launch 11th May 2021
- Poland: 22 May 2021
- **Italy:** 17th June 2021
- Spain: 25th June 2021*
- Romania: 9th September 2021
- Malta: 14th September 2021
- France: 22nd September 2021
- Croatia: 12th October 2021
- Cyprus: 14th October 2021
- Slovenia: 22nd October 2021
- **Portugal:** 27nd October 2021
- Slovakia: 21st January 2021
- Ireland: 4th February 2022







*Premio Extraordinario a la Mejor Iniciativa Scientífica Europea en TIME TO ACT Award

TIME TO ACT: Cancer won't wait – Neither Should We!







• Data intelligence informed Campaign messages for public, patients, health professionals and policy-makers (translated into 30 European languages)

Cancer Patients and Citizens:

- Don't Delay: See your Doctor if you have Warning Signs of Cancer. Keep your Screening and Treatment appointments.
- Cancer services are safe.

Policy-makers and Health System Leaders:

 Getting cancer services back on track must be top of the agenda. Every action now to address the cancer backlog will help save lives.



Time To Act Data Navigator

- A new landmark tool in the fight against the impact of Covid-19 on cancer,
- Initial data from 17 European countries
- Website <u>timetoactcancer.com/data-navigator</u>
 - Captures data intelligence on
 - Country cancer profile
 - Covid-19 impact on cancer screening
 - Covid-19 impact on cancer diagnosis
 - Covid-19 impact on cancer treatment
 - Covid-19 impact on patients and people at risk
 - Covid-19 impact on healthcare professionals



'Time To Act' won European Communiqué Award

 Our entry *Time to Act*: Informing policy action to tackle the impact Covid-19 on cancer care across Europe won the Communiqué Awards 2022



- ✓ Category of Excellence in Communicating and Using Data
- Communiqué recognises, rewards, and commends excellence and best practice in healthcare communications in Europe
- Best initiative in Europe in this category

Covid and Cancer work also received the 2021 Royal College of Physicians Excellence in Patient Care award



Time To Act Data Navigator: A Tool Supporting Policy Decision-making

- Recognition at the EU level –
- President of the European Commission Ursula von der Leyen referenced the Time To Act Data intelligence – One million undiagnosed cases
- Stella Kyriakides <u>referred to the Time To Act Data Intelligence</u> An estimated one million cancer cases could be undiagnosed in Europe



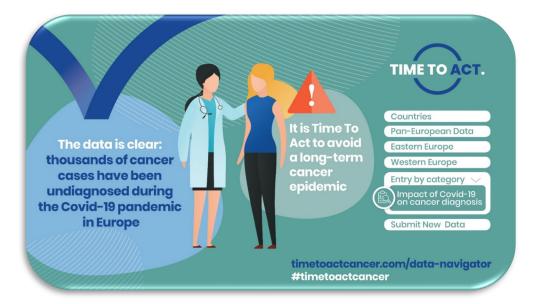


timetoactcancer.com/data-navigator

Data Navigator Expansion

Updated Data Navigator: October 2022

- New section with cancer tumour type data for:
 - ✓ Lung Cancer
 - ✓ Breast Cancer
 - ✓ Colorectal Cancer
 - ✓ Prostate Cancer
- New data and updates for all WHO European Region countries, where available
 - ✓ Over 70 new studies identified and analysed



timetoactcancer.com/data-navigator



Special Network on COVID and Cancer What's Next?

- A comprehensive update of the COVID-19 and Cancer Data Navigator to highlight trends and particular tumour impacts
- Engagement with the European Parliament's Special Committee on COVID-19 to ensure a strong cancer focus in its hearings and recommendations
- Associated to this, the Network will:
 - Publish a 2022 update to its 2020 '7 point plan' to Build Back Better (and Smarter)
 - Conduct a call for case studies in COVID-19 Build Back to support our revised 7 Point Plan



Time To Act at UICC World Cancer Congress

- A virtual session dedicated to Time To Act is included in the programme of the UICC World Cancer Congress
- The format will be a 40 minutes on-demand video including short presentations, conversations with high-level speakers and animated infographics
- The recording will be available on the UICC virtual platform from 18 October until 31 December 2022 with opportunities for networking and interactions with speakers and guests.



european cancer organisation european cancer

16 & 17 NOVEMBER

Time To Act session at the European Cancer Summit 2022:

Thursday 17 November 10:30-11:45 CEST

More information will be available soon on <u>europeancancer.org/summit</u>

european cancer SUMMIT 2022

Delivering Effective and Equitable Care Together

#europeancancersummit

european cancer organisation



• Don't let Covid-19 stop you from tackling Cancer.

TimeToActCancer.com

• #TimeToActCancer

Tear Down The Silos!





Unlocking the Power of Data to improve our health and wellbeing

