Addressing Cancer Inequalities in Europe

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Burden of cancer in Europe

- Cancer is the **leading cause** of **premature death** in **28 of 53** European Countries [1]
- **Aging population** will underpin **significant increases** over the next 30 years [2, 3]

[1]WHO Europe Health Report (2013); [2]Rechel et al, Lancet (2013); [3]WHO IARC World Cancer Report (2014)

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Cancer Inequalities

- Age
- Access
- Information
- Gender
- Socio-economic status

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Global AgeWatch Index[1]

- **Increasing age** of the population
- Potential for **increased** cancer **mortality**
- **Burgeoning challenge** on health care systems in general

[1] *Global AgeWatch Index 2013 Insight Report (2013).*

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Global AgeWatch Index[1]

- **Increasing age** of the population
- Potential for **increased** cancer **mortality**
- **Burgeoning challenge** on health care systems in general
- **Access to healthcare is a right, not a luxury**

[1] *Global AgeWatch Index 2013 Insight Report (2013).*

Cancer Inequality for older people

- **Pan European Study**[1]
- **Decisions** are being **made** on the **date of birth** rather than the **fitness** of the patient

[1] Lawler et al, British Medical Journal 2014

Ageism in Cancer Care

- **Under-treatment**
- **Mounting evidence** base
  - **Prostate** cancer
  - **Bowel** cancer
  - **Breast** cancer

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Prostate cancer[1]

- **Greater than 70%** of cancer deaths occur in men aged over 75
- Yet **few older patients receive treatment** for localised prostate cancer
- In the majority of cases, **also denied access to chemotherapy** for advanced disease

[1] Aapro MS. *The Oncologist*. 2012

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Breast Cancer[1]

- Triple negative breast cancer (a particular form of breast cancer)
- **Chemotherapy** can be **effective**
- Yet a significant proportion of **older women** receive **less chemotherapy than** their **younger counterparts**

[1]Aapro M, Wildiers H. *Ann Oncol.* 2012

Susan from Warwickshire

- *"I'd signed the chemotherapy consent form but when I went to see the consultant he threw every negative at me about maybe never being the same again and anyway it may not work. I came out of the appointment and burst into tears.*
- *"I asked him later why he'd not pushed it and was told, "You're 60 not 30. At 30 you'd have more life in front of you". I'm still alive but I just wish I'd had proper support to make an informed decision."*

[1] *"Cancer Services Coming of Age" MacMillan Report (2012)*

Remember

- **Age** is **just** a **number**
- **We NEED to CHANGE the MINDSET!** [1]

[1] Lawler et al, British Medical Journal 2014

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- **Equal Partnership** between **Patient Advocates** and **Healthcare Professionals**
- **Citizen focussed initiative**
- **Key goal** is to **identify inequalities** AND **do something about it!**
- **Engagement** at **European** and **National** levels

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The European Cancer Patient's Bill of Rights

- A **charter** to **challenge** the current **inequalities** that cancer patients in Europe are **experiencing** on a **daily** basis[1, 2]

- A **catalyst for change** and an empowerment tool for cancer patients

[1] Lawler et al *Lancet Oncol,* Published online February 4, 2014.
[2] Lawler et al *The Oncologist,* Published online February 3, 2014.

Cancer Focus
NORTHERN IRELAND
EORTC
European Organisation for Research and Treatment of Cancer
50 years of Progress Against Cancer
EUROPEAN CANCER PATIENT COALITION
European Alliance for Personalised Medicine
ECL
Association of European Cancer Leagues
Erasmus MC
Universitair Medisch Centrum Rotterdam
mhf
european men's health forum
IBTA
INTERNATIONAL BRAIN TUMOUR ALLIANCE
MPE
MYELOMA PATIENTS EUROPE
Irish Cancer Society
EUROPA DONNA
TURKEY
Meme Hastalıkları Koalisyonu Derneği
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI
20th anniversary
I.O.V.
ISTITUTO ONCOLOGICO VENETO
Sarcoma Patients EuroNet
VHIO
VALL D'HEBRON
Institute of Oncology
Sarcoma UK
The bone & soft tissue cancer charity
cnio
Centro Nacional de Investigaciones Oncológicas
MEDICAL UNIVERSITY OF VIENNA
FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI
IOT
INSTITUTE OF CANCER POLICY
inspire 2 live
institut Curie
Together, let's beat cancer.
CML AdvocatesNetwork
University of Cologne
VU University Medical Center Amsterdam
VUmc
UNIVERSITY OF Southampton
europacolon
Hôpitaux Universitaires Est Parisien
SAINT-ANTOINE
EUPATI
European Patients' Academy on Therapeutic Innovation
F.A.V.O.
Federazione Italiana delle Associazioni di Volontariato in Oncologia
UNIVERSITÀ DEGLI STUDI DI PADOVA
ISTITUTO DI RICERCHE FARMACOLOGICHE MARIO NEGRI
IRCCS
AIMaC
INFORMA PER AIUTARE A VIVERE CON IL CANCRO
ST
SOCIETY FOR TRANSLATIONAL ONCOLOGY®

World Cancer Day

4th February 2014

The European Cancer Patient's Bill of Rights

Lawler M, Le Chevalier T, Murphy MJ, Banks I, Conte PF, De Lorenzo F, Meunier F, Pinedo HM, Selby P, Armand JP, Barbacid M, Barzach M, Bergh J, Bode G, Cameron D, 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.

The Oncologist 2014, 19:217-224.

The European Cancer Patient's Bill of Rights

Article 1: The right of every European Citizen to receive the most accurate information and to be proactively involved in his/her care

[1] Lawler et al *Lancet Oncol,* Published online February 4, 2014.
[2] Lawler et al *The Oncologist,* Published online February 3, 2014.

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Tonio Borg

European Commissioner for Health

"I praise the very first right that the Bill defends, the ***right for the patient to receive accurate information and to be actively associated in their care****. Information is key to* ***enable the patient to play an active role*** *in his or her treatment* ***rather than*** *just being* ***a passive recipient****."*

Article 1: Overarching Principles

- **Patient-centered** cancer services
- The **right** to the most **up-to-date** information **(and not what Susan from Warwickshire got!)**
- **Good communication and collaboration (what Susan was denied)**
- **Shared transparent decision making** between the healthcare provider and the European citizen

The European Cancer Patient's Bill of Rights

Article 2: The right of every European citizen to equal and timely access to appropriate specialised care, underpinned by research and innovation.

Lawler et al *The Oncologist* 2014, 19:217-224.

Daciana Sârbu – Romania

Member, European Parliament

"Launching the Bill of Rights in the European Parliament on World Cancer Day underlines the ***commitment of the European Parliament to abolish disparities in cancer care*** *for the European citizen. In the current socio-economic circumstances in* ***Southern, Eastern and Central Europe****, where the public health systems are under* ***constant pressure from austerity measures****, cancer patients and their families are the* ***first to feel the impact on their health, finances and quality of life****"*

Article 2: Overarching Principles

- **Equitable and transparent access** to optimal cancer care is the **right of every European Citizen – young or old**
- Clear **pathways to clinical innovation**, (diagnostics, surgery, radiotherapy, medicines) informed by research

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The European Cancer Patient's Bill of Rights

Article 3: The right of every European citizen to receive care in health systems that ensure improved outcomes, patient rehabilitation, best quality of life and affordable health care

Lawler et al *The Oncologist* 2014, 19:217-224.

Francesco de Lorenzo President ECPC

"The European Cancer Patient's Bill of Rights is a ***Patient Charter*** *that aims to address the* ***inequalities that cancer patients in Europe face*** *every day linked to socioeconomic status, patient age, access to quality care and lack of a comprehensive National Cancer Control Plan,"*

Article 3: Overarching Principles

- Integrated **National Cancer Control Plan**
- **Cost effective** cancer care
- Cancer **survivorship**: **active re-integration** and **participation** in society **(no matter what age you are!)**
- **Patient** Advocates as **equal partners**

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Need for a "Geriacentric" approach

- Require a **fundamental shift** in cancer **policy** for **older people**
- **ACCESS ALL AGES!**

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Need for a "Geriacentric" approach

- Need a **fundamental shift** in cancer **policy** for **older people**
  - Promote **early diagnosis** in the elderly
  - Make existing **treatments more available**
  - Develop **new approaches** for older patients
  - **Remove** upper **age limit** for **clinical trials**

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Cancer Drugs Fund

- Initiated in England in 2010
- **Access** to **innovative cancer drugs**
- **Scotland** and **Wales** moving towards variation of the English model

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- **Why not Northern Ireland?**

Alistair Murphy

- "It's an **absolute disgrace** because we're all UK tax payers and it's **not fair** that there's drugs that can **extend your life or relieve your suffering**, and if you live in Manchester or Luton, you can have them, but if you live in Belfast or Newtownards you can't"
- "They **give you hope** - I've survived a lot longer than would normally be the case, and I've managed to do that through **clinical trials** and through having a brilliant oncologist. These drugs **don't just extend your life**, they are like stepping stones that keep you going. "These **drugs don't extend life in agony**, they **take that pain away** and give [patients] **a quality of life**"

iCampaigner

- **Public awareness and campaigning initiative**
- **Cancer Focus NI**, supported by 14 local charities including: Action Cancer, Angels of Hope, Cancer Choices, Cancer Connect, Cancer Lifeline, Care for Cancer, Family Care in Cancer, Foyle Hospice, Friends of the Cancer Centre, Lilac, NI Cancer Fund for Children, NI Hospice, Pretty 'n' Pink and the Southern Area Hospice.
- http://icampaigner.org/join/equalaccess

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"The noblest motive is the public good."

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Remember

- In 2012, **three European citizens** died **every minute** from this deadly disease
- By 2035, there will be a **cancer death** in Europe **every 10 seconds**
- Cancer respects no borders
- **We need to act NOW!**