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COALITION

Value of innovation in oncology
Accessing new medicines – faster, better

ECPC Annual General Meeting 2016
4th June 2016, Brussels, Belgium

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ECPC: "Nothing about us, without us"

- **Representing 383 cancer patient groups in 44 countries**
- **All cancer types** – common and rare
- **Run and governed by patients**
- Promoting **timely access** to appropriate prevention, screening, early diagnosis, treatment and care for all cancer patients
- **Reducing disparity** and **inequity** across the EU
- Encouraging the **advance in cancer research & innovation**
- Increasing **cancer patients' influence** over **European health and research policy**

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Innovation in Oncology
Different components

- Radiotherapy
- Surgery
- Chemotherapy
- Personalised medicines / Cancer Immunotherapies
- mHealth-eHealth

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The problem: patients live a paradox

Can we truly access innovative drugs?

ELSEVIER

An exploratory analysis of the factors leading to delays in cancer drug reimbursement in the European Union: The trastuzumab case

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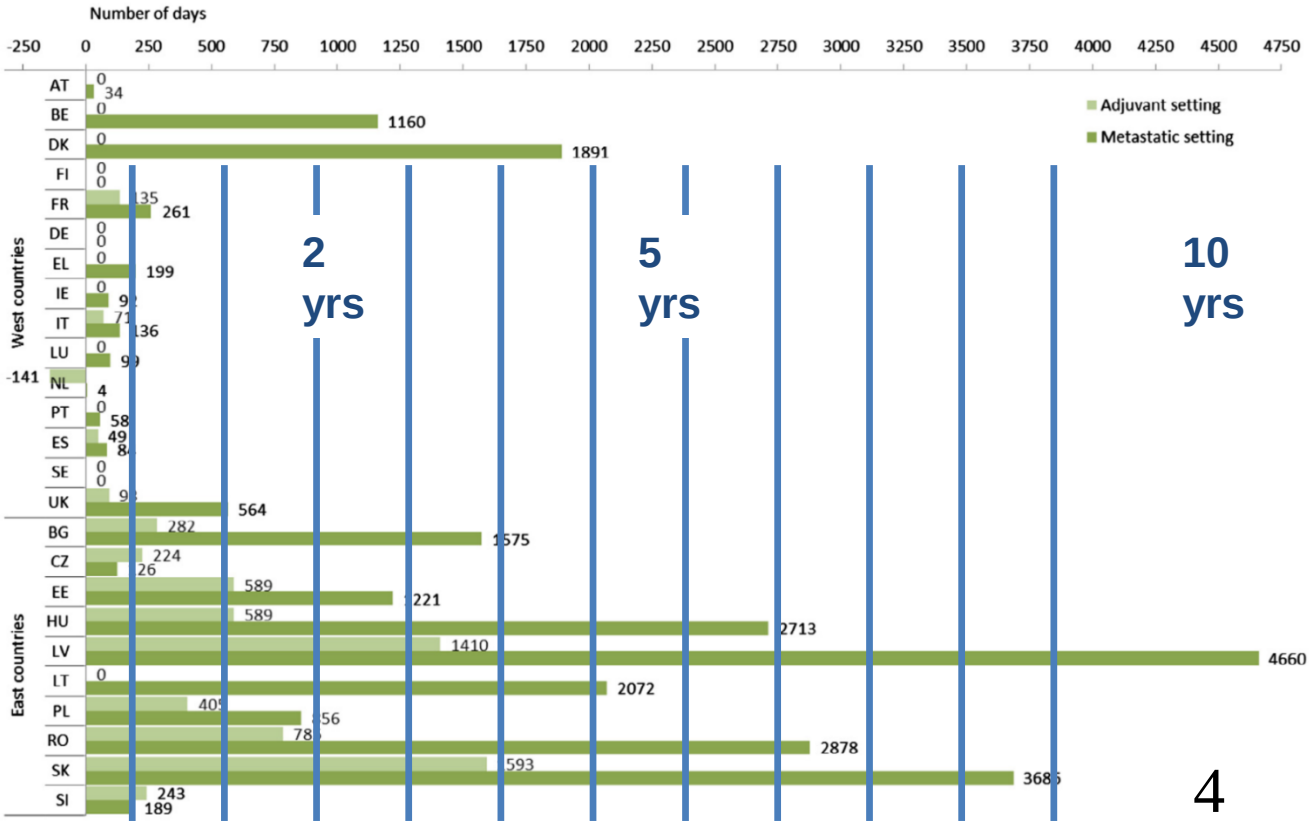

Fig. 1. Time periods for trastuzumab approval/reimbursement in the adjuvant and metastatic settings across European Union (EU) countries.

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What we have done so far:

Europe of Disparity in Cancer (EoDiC)

ECPC's roadmap to tackle inequalities

- ECPC policy strategy, presented at ECC2015
  - Covers all the inequalities in cancer patients' journey, from early detection to survivorship
- Patient-friendly, scientifically validated recommendations to tackle inequalities in cancer care
- **EoDiC is already making a difference!**
  - CanCon WP5 will use it as a starting point for their policy paper on equity (2016)
  - EoDiC's principles are at the base of the Written Declaration 30/2015, supported by ECPC and promoted by 19 MEPs

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What we have done so far: Harmonize HTA relative assessment at EU level

- EU HTA bodies shall agree to produce one relative efficacy assessment for all Europe
  - This would cut part of the delay in accessing drugs
- Strengthen the collaboration of network of European HTAs within the EMA
  - Institutionalise the EUNetHTA into a new body and formalise its collaboration with EMA
- Start a new debate on pricing and reimbursement policies

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What we have done so far: Amendments to the Regualation 726/2004

We are asking to:

- Overcome the unacceptable delays in access to innovative lifesaving drugs
- Cut inefficiencies, duplications (more than 50 HTA bodies exist today in Europe, working on the same set of data!)
- Produce a single pan-European relative clinical benefit assessment
- In parallel with EMA evaluation, but produced by a different body (new agency)
- Building on the work done by the Joint Action on HTA – EUnetHTA
- Better inclusion of patients in the HTA process to asses the true meaning of value

APPROVED BY EU PARLIAMENT (ENVI)

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Patients' questions

Can we truly access innovative drugs?

- Efficacy vs Cost/Effectiveness
  - The EMA evaluates new drugs only on the base of the clinical outcomes;
  - Reimbursement is based on national/regional/local HTA, including
    - Cost/effectiveness
    - Relative efficacy

- Consequences:
  - EMA newly authorised drugs are not timely available to patients by Member States;
  - Reimbursements arrive with huge delays, or at all!

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Our answer:
A comprehensive policy document on innovation in oncology

- First idea in 2015
  - As a declination of “Europe of Disparities in Cancer”
- Several internal drafts and brainstorming
- ECPC identified 7 sustaining partners
  - GREAT ACHIEVEMENT!!! To ensure transparency and independence of ECPC
- Help from Interel
  - Top Brussels’ consultancy in health

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Methodology

- ECPC & Interel identified topics
- AGM: discussion with our Members
- June-September: drafting
  - Involvement of Members to identify examples-best practices
- Autumn 2016: presentation of the final document

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Topics

- Definition of innovation for cancer patients
- Sustainability
- Patient-centredeness
- Timely approval and reimbursement of new drugs
- Added value
- Pricing and reimbursement of new drugs
- Disinvestment
- Research priorities

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What is the definition of innovation?

- **For EMA:**
  "A medicine that contains an active substance or combination of active substances that has not been authorised before."
- **For the European Commission (from Innovation Union):**
  "Innovation means change that speeds up and improves the way we conceive, develop, produce and access new products, industrial processes and services. Changes that create more jobs, improve people's lives and build greener and better societies."

It is necessary to find an European, patient-centered definition of innovative drugs!

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What is the definition of innovation?

- Cancer is not a single disease, but a group of more than 200 different disease

- There cannot be one single definition for all cancer patients

BUT…

Can we define general factors for all cancer patients?

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Innovation in cancer care
Factors to take into consideration
Sustainability

- New cancer drugs cannot increase the existing inequalities in access, but help to fight those inequalities!

- Innovation is meaningful ONLY if:
  - Made accessible to patients
  - Our healthcare systems can afford it

- ***What do you think?***

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Innovation in cancer care
Factors to take into consideration

Patient-centredeness

- Cancer patients MUST have a fundamental role in measure the value of innovation AND in setting priorities for research

- Patients shall be involved in:
  - Health Technology Assessment
  - Evaluation of new drugs (EMA)
  - Pricing and reimbursement negotiations
  - Research and development priorities' setting

- ***What do you think? Are you involved in any of these processes?***

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Innovation in cancer care
Factors to take into consideration
Timely approval and reimbursement of new drugs

- A European law exist (Transparency directive) which states that EU countries have 180 days (from EMA market authorisation) to set price and decide reimbursement

- The Directive is not applied! EU countries prefer to pay fines than reimburse drugs timely

- ***Do you experience delays in accessing new drugs?***

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Innovation in cancer care
Factors to take into consideration
Added value of new medicines

- Innovation is “neutral”: patients should help to determine is a new drug is better or worse than the existing ones

- Each type of cancer has different factors to take into consideration

- ***What matters the most for you, when considering a new drug?***

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Innovation in cancer care
Factors to take into consideration
Pricing and reimbursement

- The price of new drugs is determined on economic and health factors, but does not take into consideration the patients preference
- Lack of transparency: official prices of drugs might not be the real prices (secret negotiations)
- Patient are not involved directly in the decision making process on pricing and reimbursement

- ***How are prices and reimbursement decisions made in your country? Are you involved in any way?***

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Innovation in cancer care
Factors to take into consideration

Disinvestment

- In many EU countries there is the need to update or create cancer care equipment (radiotherapy machines, surgery equipment etc)
- To make financial room for innovation, old equipment might be dismissed
- However, with the excuse of disinvestment, EU Countries might just cut on the services provided to patients
- ***What is the status of investment/disinvestment in your country?***
- ***What are the most important services for you,which should not be disinvested?***

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Innovation in cancer care
Factors to take into consideration
Research and development

- The research and development of new drugs is very expensive, but we do not know exactly HOW MUCH
- R&D should focus on those aspects of care that matter to the patients
- For many cancers there have not been significant innovations since the 1970s (pancreas…)

- ***Are you involved in setting up priorities for R&D at national/European level?***
- ***In which fields we need more research?***

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Thank for your attention

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European Cancer Patient Coalition

ECPCtv

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