Transforming the face of head and neck cancer care in Europe: it is time to take action!

EU Parliament Event
5 November, 2019
Welcome

• Today we will discuss the impact that head and neck cancer has in Europe
• Two leading cancer groups have united to spearhead awareness of the disease
• We are delighted to welcome representatives from many different backgrounds, but all with the same goal, to change the face of head and neck cancer care in Europe!
Objectives of the meeting

1. Raise awareness of head and neck cancer and its impact among the EU Parliament community
2. Highlight the urgent need to address quality of care challenges in Europe
3. Explore opportunities to *Transform the face of head and neck cancer care in Europe*
Disclosures

Support for the *Make Sense Campaign* is provided by:

- Bristol-Myers Squibb
- Merck
- MSD
- Pfizer

Support for this event is provided by:

- Debiopharm
- MSD
- S&D
- Merck
Housekeeping

• Please ensure your phone/mobile device is placed on silent
• Interviews are available on request at the end of the meeting
<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speaker</th>
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<tbody>
<tr>
<td>15.00</td>
<td>Welcome and Introduction</td>
<td>Patrizia Toia, MEP</td>
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<tr>
<td></td>
<td></td>
<td>Mark Dailey, Facilitator</td>
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<tr>
<td>15.10</td>
<td>Quality of head and neck cancer care in Europe: new data from RARECAREnet</td>
<td>Dr Annalisa Trama</td>
</tr>
<tr>
<td>15.20</td>
<td>Achieving quality head and neck cancer care: expert recommendations</td>
<td>Professor Lisa Licitra</td>
</tr>
<tr>
<td>15.30</td>
<td>Life with head and neck cancer, it’s impact and the need for survivorship care</td>
<td>Roberto Persio, cancer survivor</td>
</tr>
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<td>15.45</td>
<td>Current state of play for head and neck cancer patients</td>
<td>Antonella Cardone, ECPC Director</td>
</tr>
<tr>
<td>15.55</td>
<td>Addressing head and neck cancer challenges in Europe through the <em>Make Sense</em> campaign</td>
<td>Professor Ana Castro</td>
</tr>
<tr>
<td>16.10</td>
<td>What else can be done?</td>
<td>All, facilitated by Mark Dailey</td>
</tr>
<tr>
<td>16.20</td>
<td>How can you help? Our <em>Call to Action</em></td>
<td>Patrizia Toia, MEP</td>
</tr>
<tr>
<td>16.25</td>
<td>Conclusions and close</td>
<td>Mark Dailey, Facilitator</td>
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Head and Neck Cancer in Europe: a significant challenge

Dr Annalisa Trama
## Estimated number of new cases in 2018, Europe, both sexes, all ages

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Number</th>
<th>Crude Rate x 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>All cancers</td>
<td>4,229,662</td>
<td>568.6</td>
</tr>
<tr>
<td>Breast</td>
<td>522,513</td>
<td>136</td>
</tr>
<tr>
<td>Colorectum</td>
<td>499,667</td>
<td>67.2</td>
</tr>
<tr>
<td>Lung</td>
<td>470,039</td>
<td>63.2</td>
</tr>
<tr>
<td>Prostate</td>
<td>449,761</td>
<td>125.1</td>
</tr>
<tr>
<td>Bladder</td>
<td>197,105</td>
<td>26.5</td>
</tr>
<tr>
<td><strong>Head and neck</strong></td>
<td><strong>161,217</strong></td>
<td><strong>21.77</strong></td>
</tr>
<tr>
<td>Lip, oral cavity</td>
<td>61,885</td>
<td>8.3</td>
</tr>
<tr>
<td>Larynx</td>
<td>39,875</td>
<td>5.4</td>
</tr>
<tr>
<td>Oropharynx</td>
<td>27,974</td>
<td>3.8</td>
</tr>
<tr>
<td>Hypopharynx</td>
<td>16,977</td>
<td>2.3</td>
</tr>
<tr>
<td>Salivary glands</td>
<td>9,487</td>
<td>1.3</td>
</tr>
<tr>
<td>Nasopharynx</td>
<td>5,019</td>
<td>0.67</td>
</tr>
</tbody>
</table>

Source: Cancer Today - IARC- powered by GLOBOCAN 2018
Age-specific and age-standardised relative survival for all head and neck cancer cases combined (larynx excluded) diagnosed in 2000–2007

Source: Gatta et al. EJC (2015) 51, 2130–2143
1. to collect and disseminate information on health care pathways for rare cancers and on updated epidemiological indicators

2. to identify quality indicators for rare cancers

3. to identify and disseminate information on centres of expertise (CoE) for rare cancers

4. to produce and disseminate information on diagnosis and management of rare cancer

5. to develop a clinical data base on very rare cancer (situations for which clinical trials are difficult to perform)

6. to develop and disseminate information for patients and patients’ association
### Quality of care indicators head and neck cancers

#### Diagnostic management
1. Percentage of patients with a defined stage at diagnosis

#### Time to start treatment and treatment adherence to clinical guidelines
2. Time to start treatment (time between definitive pathological diagnosis and beginning of surgery or radiotherapy < 1 month)
3. Time in starting post-operative radiotherapy or concomitant chemo-radiotherapy (< 8 weeks from surgery)
4. Percentage of patients with early stage I and II referred for either surgery or radiotherapy
5. Percentage of patients with locally advanced stage III and IV referred for surgery plus post-operative radiotherapy or post-operative chemo-radiotherapy or concomitant chemo-radiotherapy

#### Quality of surgery and radiotherapy
6. Percentage of complete tumor resection (histological verification of tumor free margins after surgery)
7. Percentage of re-operation within 30 days from main surgery
8. Percentage of grade ≥ 3 late toxicities (> 3 months after radiotherapy)
9. Percentage of patients receiving intensity-modulated radiation therapy vs. % receiving 3D conformal radiation therapy
10. Percentage of patients receiving the appropriate surgery for its stage (e.g., minimal invasive, reconstructive surgery)

#### Quality of pathology reports after surgery
11. Percentage of pathology reports after surgery with a full set of core data items recorded. According to the Royal College of Pathologists (https://www.rcpath.org/profession/publications/cancer-datasets.html): site and laterality of the carcinoma, maximum diameter of tumor, maximum depth of invasion, histological type of carcinoma, degree of differentiation (grade), pattern of invasion, margin status, lymph node involvement.

#### Availability of formalized multidisciplinary decision (with member experts on head and neck cancers)

#### Participation in clinical and translational research
### Countries and Cancer Registries Included

<table>
<thead>
<tr>
<th>Country/CRs</th>
<th>hypopharynx</th>
<th>larynx</th>
<th>oral cavity</th>
<th>oropharynx</th>
<th>Total</th>
<th>year of diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bulgaria</td>
<td>74</td>
<td>551</td>
<td>188</td>
<td>159</td>
<td>972</td>
<td>2010</td>
</tr>
<tr>
<td>Ireland</td>
<td>121</td>
<td>449</td>
<td>428</td>
<td>325</td>
<td>1,323</td>
<td>2009-2011</td>
</tr>
<tr>
<td>Italy</td>
<td>51</td>
<td>370</td>
<td>237</td>
<td>210</td>
<td>868</td>
<td>2009-2010</td>
</tr>
<tr>
<td>Netherlands</td>
<td>615</td>
<td>2,102</td>
<td>2,290</td>
<td>1,178</td>
<td>6,185</td>
<td>2009-2011</td>
</tr>
<tr>
<td>Slovenia</td>
<td>0</td>
<td>219</td>
<td>0</td>
<td>0</td>
<td>219</td>
<td>2009-2010</td>
</tr>
</tbody>
</table>
### Diagnostic management

<table>
<thead>
<tr>
<th>Country</th>
<th>Indicator 1. Percentage of patients with a defined stage at diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Larynx</td>
</tr>
<tr>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Ireland</td>
<td>449</td>
</tr>
<tr>
<td>Italy</td>
<td>398</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2,102</td>
</tr>
<tr>
<td>Slovenia</td>
<td>219</td>
</tr>
</tbody>
</table>

**Making Sense Campaign**
## Treatment

<table>
<thead>
<tr>
<th>Country</th>
<th>Indicator 2. Time to start RT or surgery</th>
<th>Indicator 3. Time in starting adjuvant therapy</th>
<th>Indicator 4% of patients with L disease stage treated with surgery or RT</th>
<th>Indicator 5% of patients with A disease stage treated with multi therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% starting surgery or RT &lt; 1 month from diagnosis</td>
<td>% starting adjuvant therapy &lt; 8 weeks from the surgery</td>
<td>% treated with surgery alone or RT alone</td>
<td>% treated with multi therapy</td>
</tr>
<tr>
<td>Ireland</td>
<td>41</td>
<td>33</td>
<td>72</td>
<td>43</td>
</tr>
<tr>
<td>Italy</td>
<td>81</td>
<td>52</td>
<td>75</td>
<td>19</td>
</tr>
<tr>
<td>Netherlands</td>
<td>39</td>
<td>79</td>
<td>79</td>
<td>21</td>
</tr>
<tr>
<td>Slovenia</td>
<td>41</td>
<td>57</td>
<td>72</td>
<td>44</td>
</tr>
</tbody>
</table>
## Quality of surgery and pathological report

<table>
<thead>
<tr>
<th>Country</th>
<th>Indicator 6% of complete tumor resection</th>
<th>Indicator 11% of pathology reports with all core data</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N treated with surgery with curative intent</td>
<td>% of R0</td>
</tr>
<tr>
<td>Ireland</td>
<td>602</td>
<td>56</td>
</tr>
<tr>
<td>Italy</td>
<td>516</td>
<td>62</td>
</tr>
<tr>
<td>Netherlands</td>
<td>2,728</td>
<td>74</td>
</tr>
<tr>
<td>Slovenia</td>
<td>88</td>
<td>75</td>
</tr>
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</table>
RARE CANCER AGENDA 2030

Ten Recommendations from the EU Joint Action on Rare Cancers

1. Rare cancers are the rare diseases of oncology
2. Rare cancers should be monitored
3. Health systems should exploit networking
4. Medical education should exploit and serve healthcare networking
5. Research should be fostered by networking and should take into account an expected higher degree of uncertainty
6. Patient-physician shared clinical decision-making should be especially valued
7. Appropriate state-of-the-art instruments should be developed in rare cancer
8. Regulation on rare cancers should tolerate a higher degree of uncertainty
9. Policy strategies on rare cancers and sustainability of interventions should be based on networking
10. Rare cancer patients should be engaged
Thank you for your attention
Achieving quality head and neck cancer care: expert recommendations

Professor Lisa Licitra
Direttore SC Oncologia medica 3 – “Tumori Testa - Collo”,
Fondazione IRCCS Istituto Nazionale Tumori Milano & Professore
Associato di Oncologia Medica Università degli Studi Milano
Achieving quality care through specialised centres and multidisciplinary teams (MDT)

• A MDT is a team of health professionals who work together to decide on the best treatment plan for each patient.

• As head and neck cancer progresses, so does the complexity of its management. Combined with the numerous treatment options, management decisions become more difficult. Consequently, a MDT is required.

• This approach has been endorsed by leading international and national cancer bodies, including the NCCN\(^1\), ESMO\(^2\) and SEOM.\(^3\)

Who is involved in a core multidisciplinary team?

- Head and neck surgeon/oral and maxillofacial surgeon
- Radiation oncologist
- Medical oncologist
- Pathologist
- Radiologist ± PET-trained imaging specialist
- Otolaryngologist
- Dentist/oral health consultant
- Maxillofacial prosthodontist
- Plastic and reconstructive surgeon
- Referring physician
- Hematologist
- Respiratory physician
- Palliative medicine physician
- Specialist nurse
- Speech language pathologist
- Dietitian
- Social worker
- Clinical trial coordinator
- Palliative medicine physician
- Data manager
- MDT meeting coordinator

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
What are the benefits of multidisciplinary care?

What has been the main benefit to patients?

- “The time from first visit to diagnosis and to treatment can be shorter for patients who are seen by a well-organized MDT.”
- “Patient and family satisfaction increase when they are immersed in a good organisation.”
- “Patients receive increased discussion of treatment options and access to innovative clinical trials.”

What has been the main benefit to clinicians?

- “Sharing of experience is especially helpful for difficult cases whereby team members can learn from their colleagues.”
- “The newest treatments and protocols can be discussed and proposed to our patients.”
- “The organization decreases the inappropriate consumption of health resources.”

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
It is vital that more member states offer MDT care in order to improve outcomes

• Few member states have legal requirements relating to MDT approaches. At present MDTs are legally binding in Austria, Denmark, France and Lithuania.¹

• According to research undertaken in 2016, guidelines recommending a MDT approach are in place in Italy, The Netherlands and United Kingdom.¹

Reference: ¹ L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Life with head and neck cancer, it’s impact and the need for survivorship care

Roberto Persio,
head and neck cancer survivor
Who is Roberto?

According to the doctors:
- Male
- Aged 26 (at the time of diagnosis)
- Diagnosed Head and Neck rare cancer (Adenoid Cystic Carcinoma)

According to the 26 years old:
- EU citizen, shaper of a better world.
- Civil engineer and Project Manager
- Life enthusiast

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Experience of diagnosis

- No clear pathway
- Very long timespan between symptoms and correct diagnosis
- GPs should be your case manager, unfortunately this is not always possible
- Many consultations with doctors; third opinion different from second and from first. Difficult to understand and navigate
- Word of mouth. In the XXI century!
- Rare cancers are difficult to be diagnosed.
- Limited reference, relied on cancer institutes.

“it’s not the trachea, is the larynx!”
Experience of treatment

• Impossible to be prepared, but essential to be aware.
  • Options
  • Opportunities
  • Quality of life

• Surgery is quick. The hard part is when you wake up and what follows.
• Essential role of family, friends and caregivers.
• Trust your doctors, especially if they work in a real multidisciplinary environment.
• Not only the surgeon. All the organization is important. Patients should be at the centre.

“if we cannot preserve your larynx, we will perform a total laryngectomy”
Experience of lack of support

• Reference network is important, for patients but also for doctors in light of an early and correct diagnosis
• Diagnostic Treatment pathway on patients’ shoulders
• Cross border treatment not always possible
Impact on daily life

→ Eating:
  • Dry mouth, taste alteration, chewing and swallowing difficulties
  • Challenge to a healthy, nutritious diet
  • Risks for the energy levels & overall outcomes post-treatment

→ Fatigue

→ Disfigurement:
  • Reconstructive surgery, prosthesis
  • Loss of voice
  • Speech rehabilitation
  • Auditive equipment

“I will speak again”
Impact on daily life

→ Psychological impact:
  • Lack of self-confidence
  • Detrimental effect on social interactions
  • Relationship & family break down
  • Risk of isolation
  • Trauma, anxiety, PTSD, depression

→ Discriminations:
  • Return to work
  • Right to be forgotten

“you cannot fake it”

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Experience of survivorship

- Cancer is a lifechanging experience. We change life with cancer
- Better treatments lead to higher survivorship rates.
- Regular follow up
- “Watchful waiting”
- Quality of life and choice of treatment
- Commitment to increasing awareness and cancer support to patients

“now go and win life every day”
Need for survivorship support

A multidisciplinary team:

• Health education & diet
• Psycho oncology & support group
• Social work

• Dental prosthesis, auditive equipment, reconstruction
• Treatment, radio & chemo therapy, surgery
• Speech rehabilitation
• Medical follow up & post-treatment care
• Rehabilitation program

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Need for survivorship support

→ Informed decisions:
  • Understanding the treatment plan
  • Understanding of the options available
  • Joining a clinical trial

→ Management of the treatment plan:
  • Transport to the hospital
  • Access to the most up-to-date treatments
  • Pain and side effects management
  • Costs and reimbursements
  • Rehabilitation

→ Role of care givers

→ Patient advocacy groups:
  • Collaboration of cancer patients across Europe
  • Communicating needs to shape healthcare policies
  • At European & national levels

→ Getting your life back

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Need for survivorship guidelines

→ Prevention by awareness raising on:
  • This cancer type
  • 3 main risk factors (smoking, alcohol, HPV)
  • Safety of vaccine against HPV

→ Early diagnosis:
  • Awareness of men and women
  • Identifying signs & symptoms
  • Awareness & training of GP
  • Faster diagnosis, referral to specialized HCP & treatment

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Need for survivorship guidelines

- Equal access to state-of-the-art care & treatments:
  - Ambitious funding of research into technology & medicines
  - Multidisciplinary approach integrating experts across disciplines
  - Costs & reimbursement of treatments & cares

- Improve patient’s satisfaction & quality of life:
  - Engagement & adherence to ongoing treatment & care
  - Management of delayed effects of treatment
  - Follow-up care
  - Communicating needs
  - Patient’s rehabilitation programme
  - Reintegrating into their lives

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Thank you!

Roberto Persio
roberto.persio@ecpc.org
@bobpersio

Reference: 1. L. Licitra et al. / Oral Oncology 59 (2016) 73–79
Current state of play for head and neck cancer patients

Antonella Cardone, ECPC Director
Who are we?

- **Largest** European cancer patients' umbrella organisation established in 2003
- Almost **450 Members** in **46 countries**
- Represent **all cancer types and transversal topics** (right to be forgotten, back to work, pain management...)
- Advocate for patients to be acknowledged as equal partners & **co-creators of their own health**
- We work for a **Europe of equality**, where all Europeans with cancer have timely & affordable **access to the best treatment and care** available, throughout their life
Our mission

- **Empower** patients through the dissemination of information
- **Foster co-operation among** cancer patients organisations through joint activities
- **Ensure that state-of-the-art cancer care practices are shared across the EU**
- **Make cancer a priority for action** on the European health policy agenda
- **Have an active role in shaping European and national healthcare policies**
- **Contribute to change or create EU and national laws** to satisfy cancer patients' needs
- **Call for the patients to be increased in cancer research**
Addressing Rare Cancers

• Context:
> 4 million people affected by rare cancers in the EU
24% of all cancer cases in the EU/ year
Affect one in five new patients with cancer

• EU’s answer:
Joint Action on Racer Cancers (JARC)  www.jointactionrarecancers.eu

• 3\textsuperscript{rd} EU Health Programme to foster health in Europe (2016 – 2019)-34 Associated Partners + 27 Collaborating Partners

ECPC – 60 rare cancer patients associations among 450 members
ECPC’s added value to the JARC

• Establishment of a Working Group on Rare Cancers (WGRC), working in parallel & after the project ends
• Cross cutting role in all the WPs
• Contribution to the recommendations
• Follow up with relevant EU Institutions

“With over 60 rare cancer patient organisations, the WGRC will continue its work beyond the conclusion of the JARC to monitor and drive appropriate implementation of the ERNs regarding rare cancers and in the context of the Cross-Border Healthcare Directive.”

Francesco de Lorenzo, ECPC Past President.
ECPC follow up commitment

• Disseminate the recommendations so that they are widely known
• Implement the recommendations as they are fundamental to make the ERNs work (cross boarder health directive)
• Facilitate the inclusion of the recommendations into the Council of Europe agenda
• Call of MEPs to the European Commission
Rare Cancer patients’ engagement

• Advocating & raising awareness through ECPC’s Members to support:
  • New members to join the existing 24 ERNs
  • Centres of excellence to apply for membership
Addressing head and neck cancer challenges in Europe through the Make Sense campaign

Professor Ana Castro
Introducing the Make Sense campaign

A pan-European survey series that sought to gauge awareness and understanding of HNC and its associated risk factors. The results prompted the EHNS to gather experts and devise solutions to tackle the issues uncovered. The group concluded that there was an urgent need for:

- Broader multidisciplinary healthcare professional knowledge of the disease, and the skills to communicate effectively
- Improved awareness of HNC symptoms across all stakeholder groups, including healthcare professionals, patients and caregivers
- An integrated network of patient advocacy groups and healthcare representatives
- Greater emotional support for patients

The Make Sense campaign aims to raise awareness of head and neck cancer and ultimately improve outcomes for patients with the disease. It will do this by:

- Driving Awareness and Education
- Encouraging Earlier Presentation, Diagnosis and Referral
- Improving Care of Patients
The reach of the *Make Sense* campaign

Now in seventh year, the *Make Sense* campaign is represented in 23 countries by more than 40 healthcare professionals and 30 patients and patient advocacy groups.
The Make Sense campaign has had many achievements since 2013

6 highly successful awareness weeks

~80,000 people screened across >1,000 clinics

Defining a simple symptom check concept

Creating a network of EU PAGs & policy makers

>300,000 educational resources distributed

Providing emotional & survivorship support
Yet, there is still more work to be done!

Actively engage in awareness campaigns on disease prevention and highlight signs and symptoms.

Support early diagnosis and referral to qualified healthcare professionals.

Support a multidisciplinary treatment approach, by integrating experts across disciplines.

Support the dissemination of best practices in disease management.

Promote patient rehabilitation programmes.

Encourage further research on head and neck cancer.
What else can be done?

A facilitated discussion session
How can you help? Our Call to Action

Patrizia Toia, MEP
Transforming the face of head and neck cancer care in Europe: *It is time to take action!*

**Make some noise**

1. Support us by promoting the messages about symptoms and risk factors of head and neck cancer

2. Get actively involved in our annual awareness week in September 2020

**Become an advocate**

We need your help to mobilise stakeholders on a member state-level to take action
Meeting close

Thank you for attending and your ongoing support.