



Expert policy roundtable

Forgotten cancers: the case of bladder cancer

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Foreword

Bladder cancer is a common, yet neglected pathology which dramatically affects the lives of hundreds of thousands of patients across the EU and has a severe impact on European healthcare systems.

The European Institutions have done much to tackle the issues posed to our citizens by cancer, but there is still much to be achieved.

This report summarises the main outcomes of the EU-level expert policy roundtable on bladder cancer to stress that concrete mobilisation and action – starting from the participants in the meeting – will be necessary to translate words into more comprehensive policies.

Valued contributors at the meeting included fellow policy makers, patient representatives, clinicians, occupational safety experts and industry representatives.

Their expertise and understanding of the challenges posed by bladder cancer proved crucial to achieve the roundtable objectives and to develop EU policy recommendations on:

1. Why action on bladder cancer is needed:
The shortcomings in Europe in taking action to combat bladder cancer (prevention, diagnosis, treatment and care)
2. What is the role for policy-making in addressing these shortcomings?

The first-ever EU expert policy roundtable on bladder cancer was but the start of a process. This report is an instrument for advocates to push this process forward with a view to achieving our goals of better policies, which best protect our citizens.

Stephen Hughes, MEP Françoise Grossetête, MEP

Introduction

Bladder cancer is alarmingly common in the EU¹: the WHO's agency for the research on cancer (IARC) considers that in 2012 alone, more than 120,000 EU citizens² were diagnosed with what urologists consider to be the most common malignancy of the urinary tract.³

Treatment options for this deadly cancer range from the resection of a tumour via the urethra ("TURB") to radical removal of the bladder and all have an important negative impact on patients' quality of life⁴ and general health.⁵

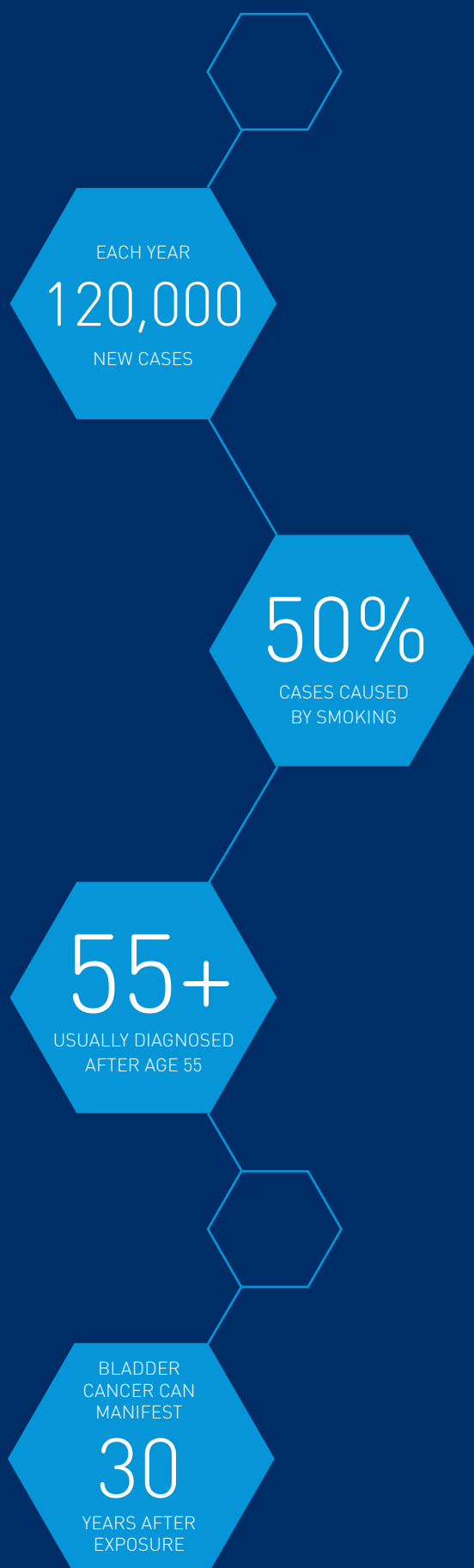
Bladder cancer tends to recur and progress. Constant monitoring and frequent operations are often required, thus making bladder cancer the most expensive cancer to treat (from diagnosis to death).⁶

Despite these facts, bladder cancer truly is a neglected pathology. If compared to other types of cancer, it is rarely found in the health policy agendas both at EU and at Member States level; and allocation of funding for research is low. This is surprising when one considers that bladder cancer is a common pathology in industrialised countries, counting age, tobacco smoke and occupational exposure to carcinogens among its major risk factors. Bladder cancer can be regarded as the archetype of a forgotten cancer.

The first ever EU-level expert policy roundtable on bladder cancer brought together a wide range of stakeholders: clinical experts, patients, trade unions, the European Agency for Safety and Health at Work, representatives of Directorates-General of the European Commission, Members of the European Parliament and industry (see detailed list of participants page 10).

The meeting was convened with a view to:

1. Identifying the key challenges posed by bladder cancer and related shortcomings in policy at EU and Member States level
2. Formulating and agreeing upon a number of recommendations to policy-makers and stakeholders to kick-start actions to raise awareness on and improve management of bladder cancer across the EU (see detailed recommendations page 8).



Key Facts on Bladder Cancer

Incidence & prevalence in the EU⁷

- Over 120,000 new cases of bladder cancer are diagnosed each year
- Prevalence over 5 years is estimated to be around 410,000

Major ascertained risk factors in the EU⁸

- Smoking is the most important risk factor for bladder cancer, accounting for 50% of cases
- Occupational exposure to aromatic amines, polycyclic aromatic hydrocarbons and chlorinated hydrocarbons (likely to occur in occupations in which dyes, rubbers, textiles, paints, leathers, and chemicals are used) is the second most important risk factor, causing 10% of bladder cancer cases
- Bladder cancer is strongly related to age and is diagnosed after 55 years in the great majority of cases⁹

Key issues in the management of bladder cancer

The following section outlines the key challenges posed by bladder cancer and related shortcomings in policy at EU and Member States level as identified by the participants to the roundtable.

Awareness

Among the general public and policy makers

- People are not adequately informed of what the major risk factors are – very few people are aware of the link with smoking and occupational exposure
- People are not aware of the basic symptoms that could reveal bladder cancer (blood in the urine)
- Policy makers often lack awareness including for aspects related to healthcare, occupational exposure and the link with social affairs

Among GPs

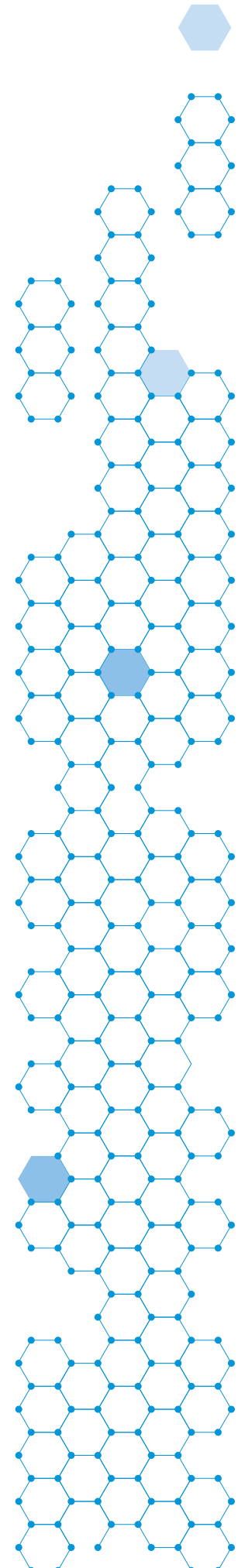
- General Practitioners are often not aware of symptoms and of risks that a belated diagnosis of bladder cancer might entail
-

Treatment

From diagnosis to death, bladder cancer is the most expensive cancer to be treated

- Major cost generated by TURBs to preserve the bladder
- The large cost of materials in the case of major surgery / cystectomy
- Cost to be multiplied for the hundreds of thousands patients living for many years with bladder cancer

Optimal diagnostic techniques and best options for diagnosis and treatment are not always widely available as drug shortages have arisen in the past (e.g. case of BCG shortage in the UK)



Occupational Aspect

Austerity policies and budget cuts are affecting initiatives on occupational health and safety¹⁰ (renewal of the EU framework strategy postponed; Carcinogens Directive¹¹ not being revised)

Bladder cancer can manifest up to 30 years after exposure

- Health surveillance in most of the cases ceases when one leaves the job
-

Poor compensation as an occupational disease

Urologists are often not trained on the occupational risk factors which can cause bladder cancer, especially when there is a large time window between exposure and cancer insurgence

Impact on patients

Deteriorating of quality of life

- Constant monitoring and frequent operations to preserve the bladder
 - Radical cystectomy has lifelong-lasting consequences, requiring continuous aftercare and the use of costly medical equipment such as adhesive pouches
-

Psychological impact

Lack of research data

Money invested in bladder cancer research is minimal as compared to its cost

Clinical experts seriously consider that available data in registries only capture a portion of the real picture

Need for both new centralised data, last gathered by the EORTC in the 90s, and country-specific data

Research is required to clarify other potential risk factors

Wider environment

Rules on personal data and privacy protection should not hamper medical research

Policy recommendations

Raising awareness

- **Stakeholders** to call upon the European Commission and Member States for a revision of the health warnings included in Annex I of the Tobacco Products Directive and present arguments proving the importance of adding the health warning ‘Smoking causes bladder cancer’
- **European Commission**, in the framework of the Health for Growth Programme 2014-2020, and **Member States** to roll-out of campaigns both at EU-level and national level:
 - Informing the general public about major risk factors (e.g. smoking is responsible for 50% of bladder cancer cases), symptoms (presence of blood in the urine) and life-lasting consequences of bladder cancer
 - Targeting in particular children and pre-teens to decrease the number of people who will start smoking
 - Expanding the understanding of bladder cancer among healthcare professionals beyond the closed circle of urologists (e.g. general practitioners, pharmacists, nurses)

Better diagnosis and treatment

- **Member States** to ensure that access to technologies for optimal diagnosis and management of cancer is included in the guidelines and specific indicators for a high-level standard National Cancer Control Programme which is being developed in the framework of the EPAAC
- **European Commission** to ensure that access to technologies for optimal diagnosis and management of cancer features prominently in the framework of the new EU Joint Action on cancer (‘Cancer Control’, to be launched in 2014 with a view to establishing common European guidelines on cancer control)
- **Member States** and stakeholders to advocate for the inclusion of bladder cancer / urological cancers in the revised Council Recommendation on cancer screening expected for 2015
- **European Parliament**, when commenting on the implementation report of the 2003 Council Recommendation on Cancer Screening (report to be submitted in April 2014), to put pressure on the European Commission and on the Council to include bladder cancer / urological cancers in the new Council Recommendation on cancer screening expected for 2015

Selected cancer-relevant initiatives at EU-level

80s – 90s

‘Europe Against Cancer’ programmes launched
European Code Against Cancer (1st edition)
Directives on pesticides & dangerous substances
1st ‘Carcinogens at work Directive’ (90/394/EC)
1st Tobacco Products Directive (89/622/EEC)

1997

Carcinogens Exposure database (CAREX, discontinued early 2000s)

2001

Tobacco Products Directive revision (2001/37/EC)

2002

Community strategy on health and safety at work 2002-2006

Sixth Framework Programme for Research and Technological Development 2002-2006

2003

Council Recommendation on cancer screening
European Code Against Cancer (revision)

2004

Directive on the protection of workers from the risks related to exposure to carcinogens or mutagens at work (Directive 2004/37/EC)

2007

Seventh Framework Programme for Research and Technological Development 2007-2012
Community strategy on health & safety at Work 2007-2012

Selected cancer-relevant initiatives at EU-level

2008

Second Programme of Community Action in the field of Health 2008-2013 "Together for Health"

2009

Protection of workers from the risks related to exposure to asbestos at work (Directive 2009/148/EC)

2009

European Partnership for Action Against Cancer (2009-2013)

2013

Tobacco Products Directive revision (ongoing)

2013

EP Own-initiative report on asbestos related occupational threats

2014

Horizon 2020 Framework Programme for Research and Innovation (2014-2020)

Health for Growth Programme, the third multi-annual programme of EU action in the field of health (2014-2020)

EC Joint Action on 'European Guideline on Cancer Control' (2014-2017)

2014

Eighth European Parliament

Improving prevention & screening for risk groups

- **European Parliament and stakeholders** to put pressure on the European Commission to ensure that a new, robust EU framework Strategy for Health and Safety at Work 2014-2020 including prominent reference to cancer is adopted as soon as possible
- **European Commission** to ensure that, in the EU Strategy for Health and Safety at Work 2014-2020:
 - Continuous health surveillance for high risk groups of developing occupational cancers features prominently
 - Prevention and timely access to optimal diagnosis and management of occupational cancer is laid down as a priority
- **Stakeholders** to advocate for the revision of the Directive on the protection of workers from the risks related to exposure to carcinogens or mutagens at work to be regarded as a top priority by the 'new' European Commission taking office in late-2014
- **European Commission** to include provisions on post-occupational screening for risk groups in the revised Directive on the protection of workers from the risks related to exposure to carcinogens or mutagens at work
- **European Commission and Member States** to establish an EU-level register of occupational exposure to carcinogens building on the experience of CAREX

- **European Commission and European Chemicals Agency** to speed up the process of classification of limit values for substances under the REACH
- **European Commission** to increase the number of substances for which binding occupational exposure limit values are established, following the work of the Commission's Scientific Committee on Occupational Exposure Limits (SCOEL)

Fostering research & knowledge

- **Clinical and academic experts** of the urology-oncology sector to promote and support research projects to participate in the calls soon to be issued in the framework of Horizon 2020
- **Member States** to establish national cancer registries and **European Commission** to ensure the systematisation of data gathered at EU-level
- **European Commission** to set up a European Database for bladder cancer under the European Network of Cancer Registries, hosted by the European Commission Joint Research Center to ensure a better knowledge and understanding, and comparable data, of the disease and its risk factors, including occupational factors

Meeting Chairs and Initiators

Mr Stephen Hughes

Member of the European Parliament

Mrs Françoise Grossetête

Member of the European Parliament

Presenters

Prof Didier Jacqmin

University Hospital Strasbourg, European Association of Urology

Mr Tony Kirkbank

Action on Bladder Cancer

Prof Arnulf Stenzl

Eberhard-Karls-University of Tübingen, European Association of Urology

Dr Laurent Vogel

European Trade Union Institute

Participants

Mr Seán Kelly

Member of the European Parliament

Ms Rebecca Taylor

Member of the European Parliament

Mr Giovanni Asta

Ipsen Pharma

Mr John Bowis, OBE

Former Member of the European Parliament and UK health minister

Prof Maximilian Burger

University of Regensburg

Prof Alexander Karl

University Hospital Munich

Dr Jan-Willem van de Loo

European Commission, DG Research & Innovation

Mr Antoni Montserrat

European Commission, DG Health & Consumers

Ms Brenda O'Brien

European Agency for Safety and Health at Work

Mrs Audrey Schweitzer

Ipsen Pharma

Mr Didier Véron

Ipsen Pharma

