

# Quality of Life and Participation and Integration of Patient Voices in Decision Making and the Response to HIV and Viral Hepatitis

**Ricardo Baptista Leite, MP, MD**

*Member of the Portuguese National Parliament*

*National Spokesperson for Health | Social Democratic Party (PSD)*

*Parliamentary Health Committee | Foreign Affairs Committee*

*Head of Public Health | Catholic University of Portugal*

*Guest Lecturer | NOVA Medical School and NOVA IMS*

*Former Deputy Mayor and City Councilor of Cascais*

*ricardo.baptistaleite@gmail.com | @RBaptistaLeite*



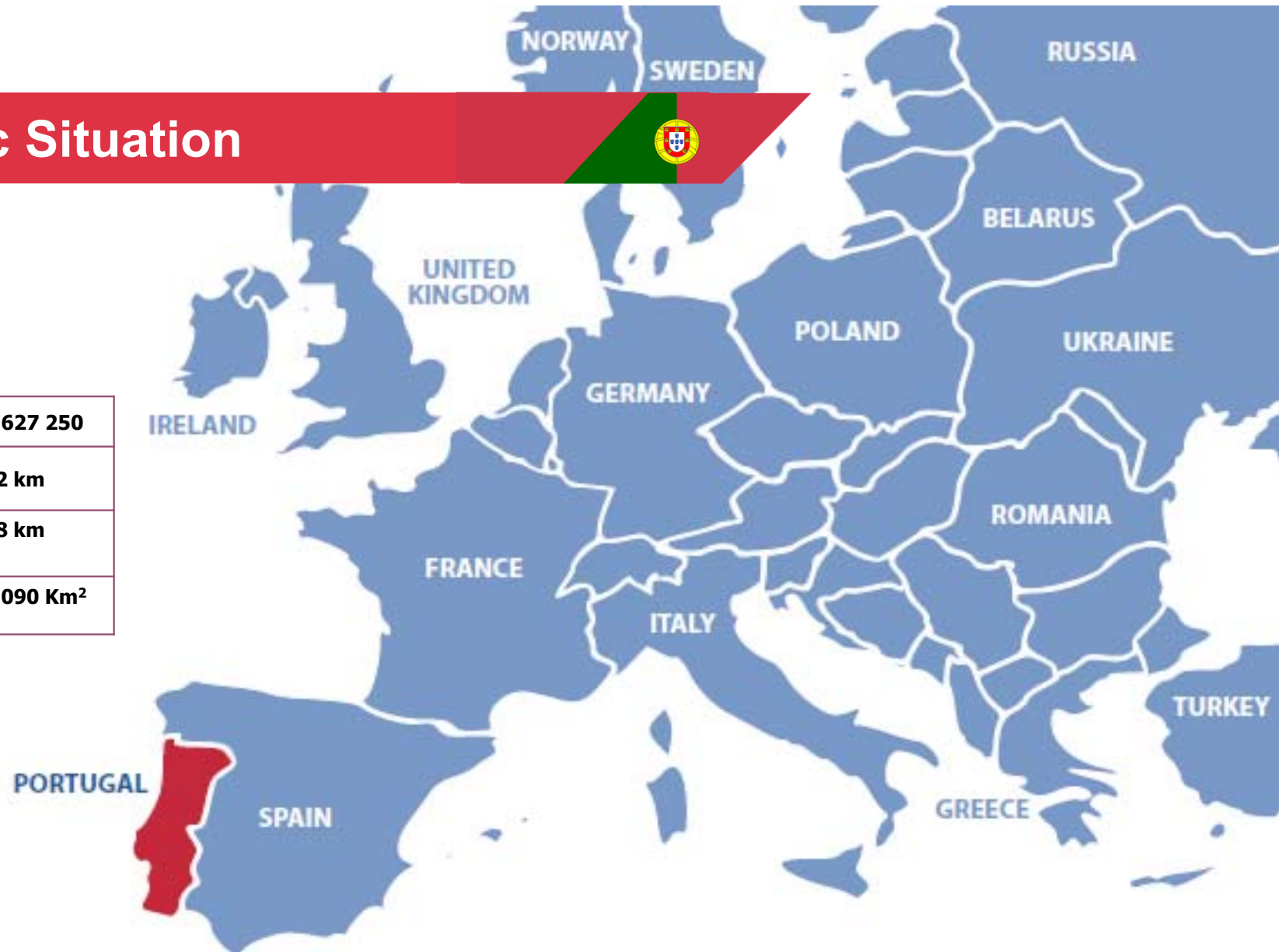
# Portugal: Cascais – Sintra – Estoril Coast



# Portugal

## Geo-Demographic Situation

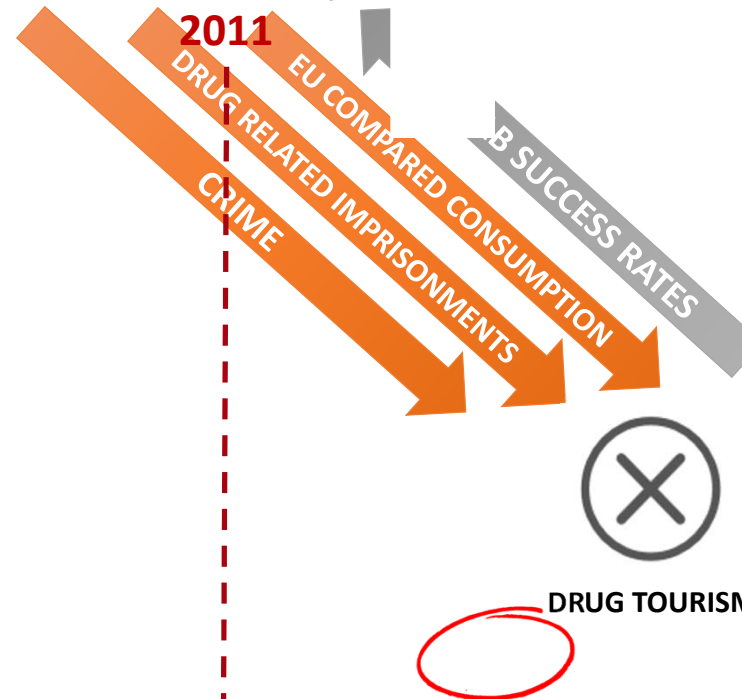
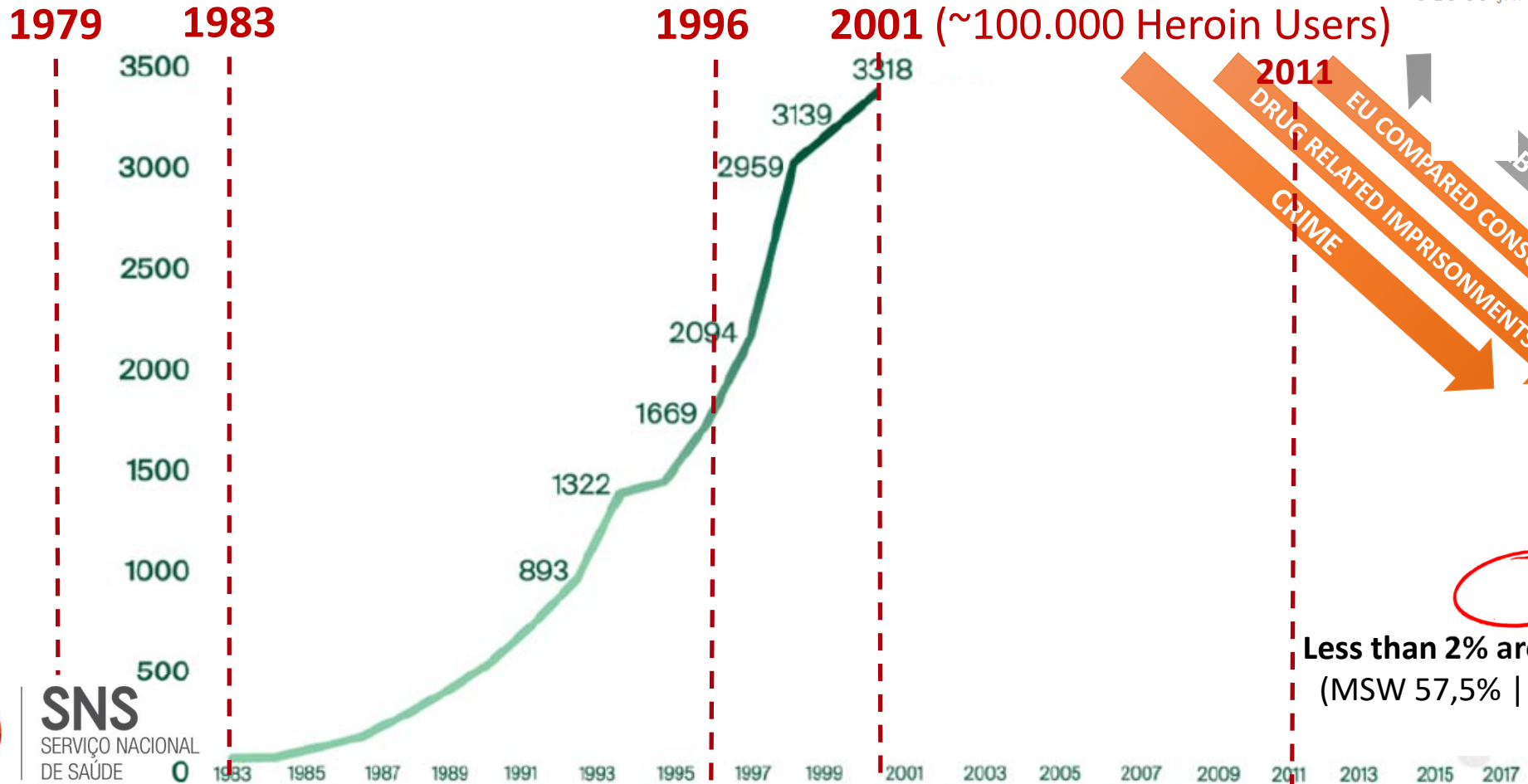
► Population	10 627 250
► North/South territorial units maximum length	652 km
► East/West territorial units maximum length	218 km
► Surface	92 090 Km <sup>2</sup>



# Number of New HIV Infections 1983-2017



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Less than 2% are drug-related  
(MSW 57,5% | MSM 36,7%)



SNS  
SERVIÇO NACIONAL  
DE SAÚDE

Source:  
INSA, 1983-2017  
(notified cases until  
15.04.2018)

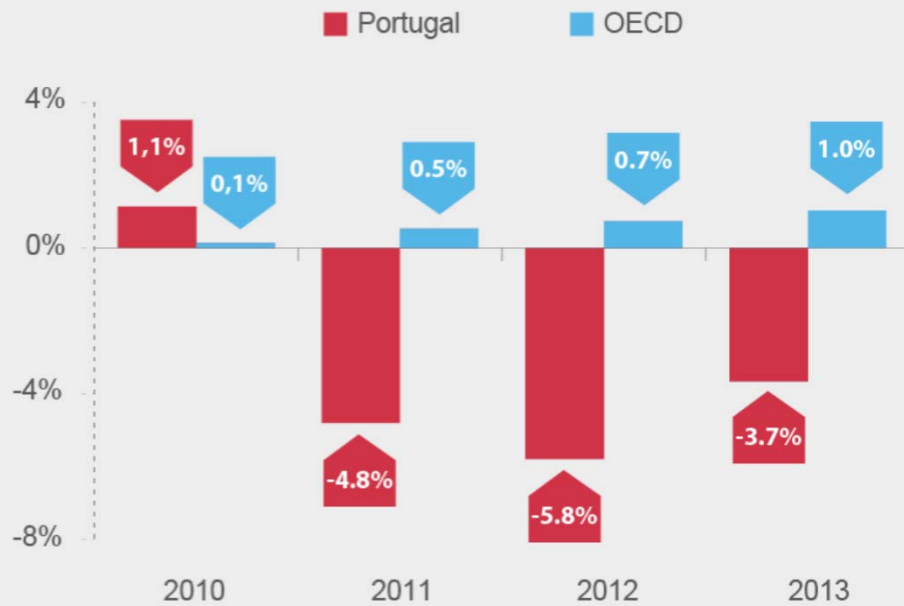
1st Dx HIV  
in Portugal

HAART Drug Addiction as  
Health Problem

TROIKA

# HIV in Portugal

## 2011 | TROIKA@Portugal



\* Per capita spending in real terms.  
Source: OECD Health Statistics 2015



Source: OECD Health Statistics 2015



# HIV in Portugal

## 2011 | HIV, Hep and TB Resolution



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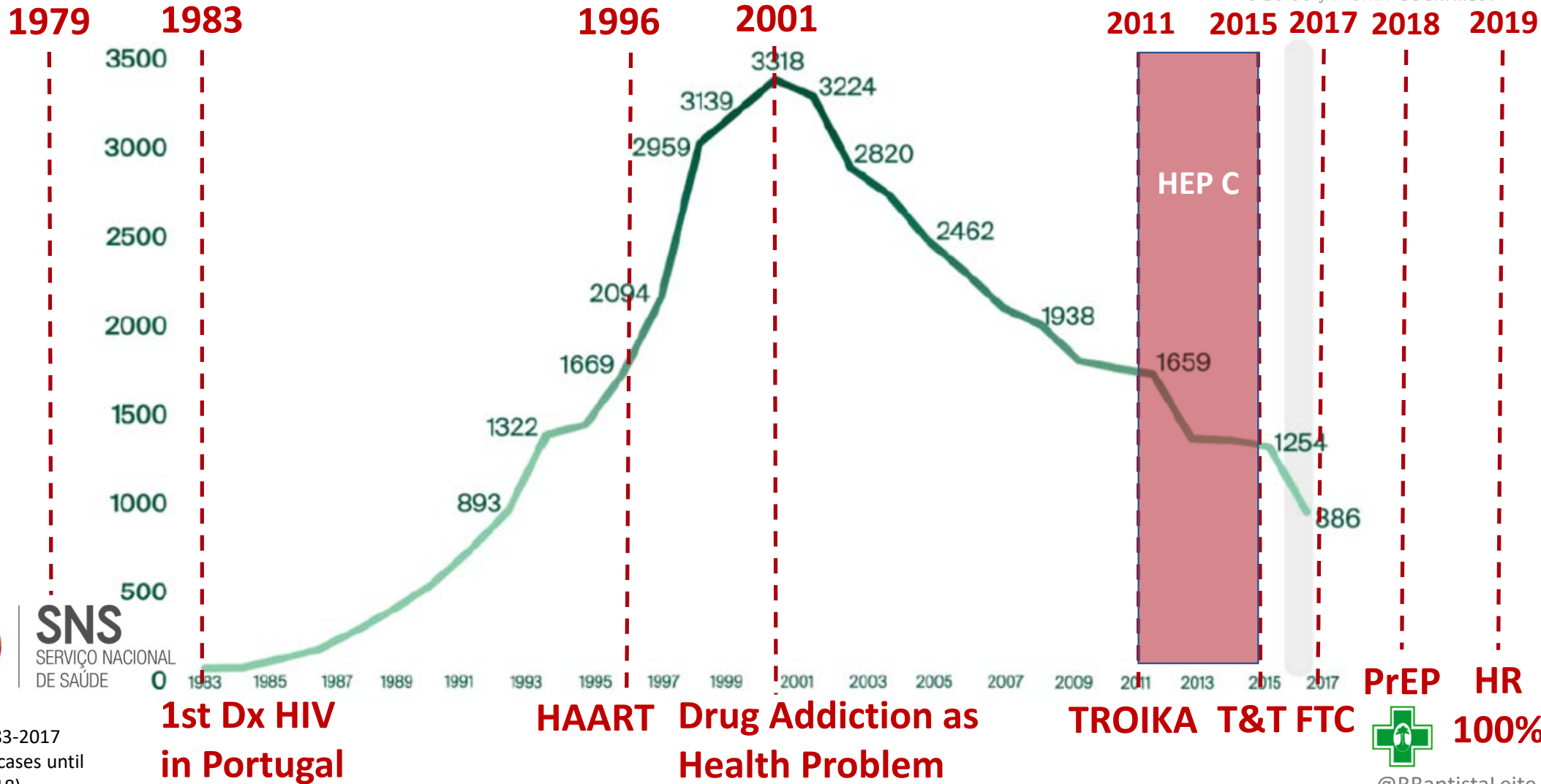


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# Number of New HIV Infections 1983-2017



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Source: INSA, 1983-2017 (notified cases until 15.04.2018)

PrEP HR 100%  
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HCV in Portugal

# *The Tipping Point*

February 2015



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HCV in Portugal

*The Tipping Point*

February 2015





HCV in Portugal

## *The Tipping Point*

**“DON’T LET ME DIE!”**  
*José Carlos Saldanha*

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# Hepatitis C: Policy in Action

## HCV | When Research meets Policy

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February 2015

The Ministry of Health announced an agreement with Gilead Sciences and DAA's were fully funded for all patients with Hepatitis C.

Risk sharing model was adopted. The Ministry agreed on paying per patient that is clinically cured (not per number of weeks of treatment nor per number of patients treated) and the payment procedures were fully centralized.

Volume-based agreement: Price paid is inversely proportional to the number of patients treated.

National Action Plan for Hepatitis C and the review of the national HCV treatment guidelines were announced and are currently being prepared by a panel of experts.

Centralized registry database was commissioned and is currently used by physicians.



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## Hepatitis C: Policy in Action

# Hepatitis C in Portugal

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Today

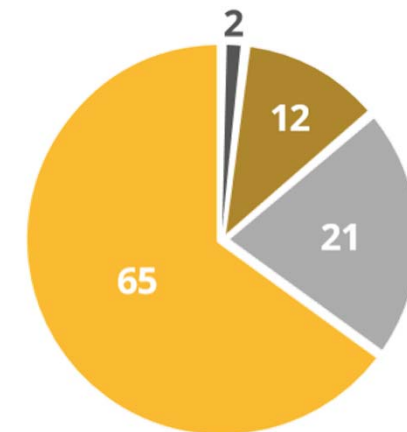
**Over 22,109 patients that have been diagnosed with chronic HCV in the NHS and their treatment has been authorised**

**20,337 patients have initiated treatment**

**11,718 PATIENTS CURED**

**(1/3 of total estimated population living with chronic Hep C)**

**96.5% SVR**



● G1 ● G4  
● G3 ● Outros

Ministry of Health. National programme for viral hepatitis. Available at: <https://www.dgs.pt/documentos-e-publicacoes/relatorio-do-programa-nacional-para-as-hepatites-virais-2017.aspx> (accessed January 2019);

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# Hepatitis C: Policy in Action

## Hepatitis C in Portugal

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Health  
Outcomes  
@13.000



### Averted

3.477 premature  
liver related deaths



### Gained

62.869 life years



### Averted

339 liver transplants,  
1.951 liver cancers,  
5.417 cases of chirosis

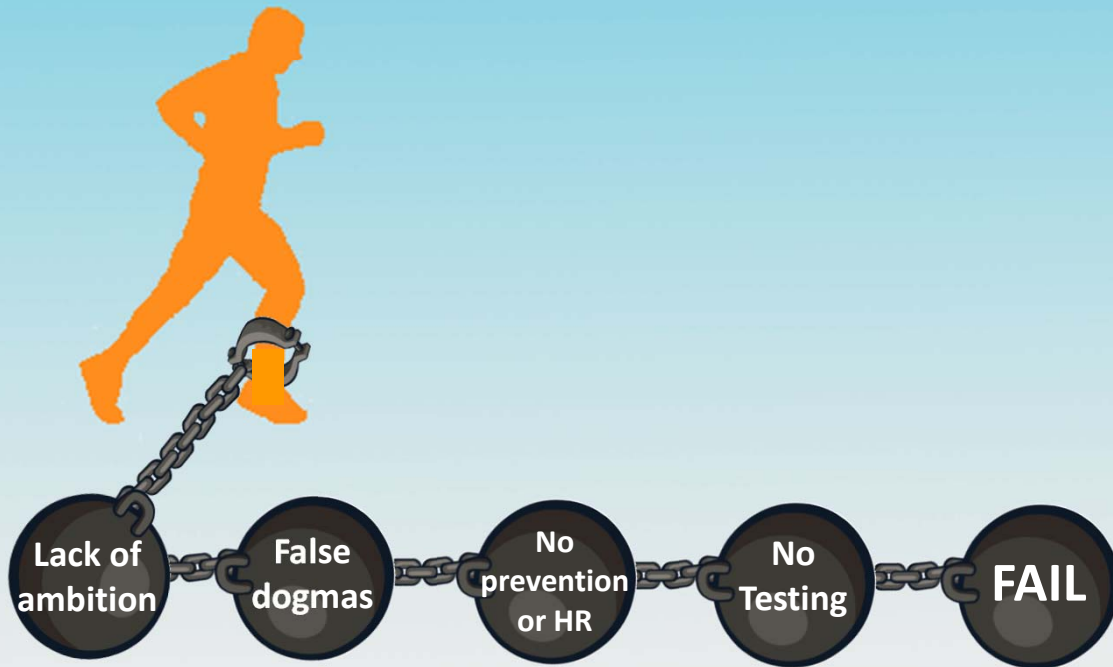


### Savings

271.4 million Euros on  
treatment costs related to  
hepatitis c complications



# FALLING BEHIND



# 90 – 90 – 90

## *Biomedical approach to HIV*



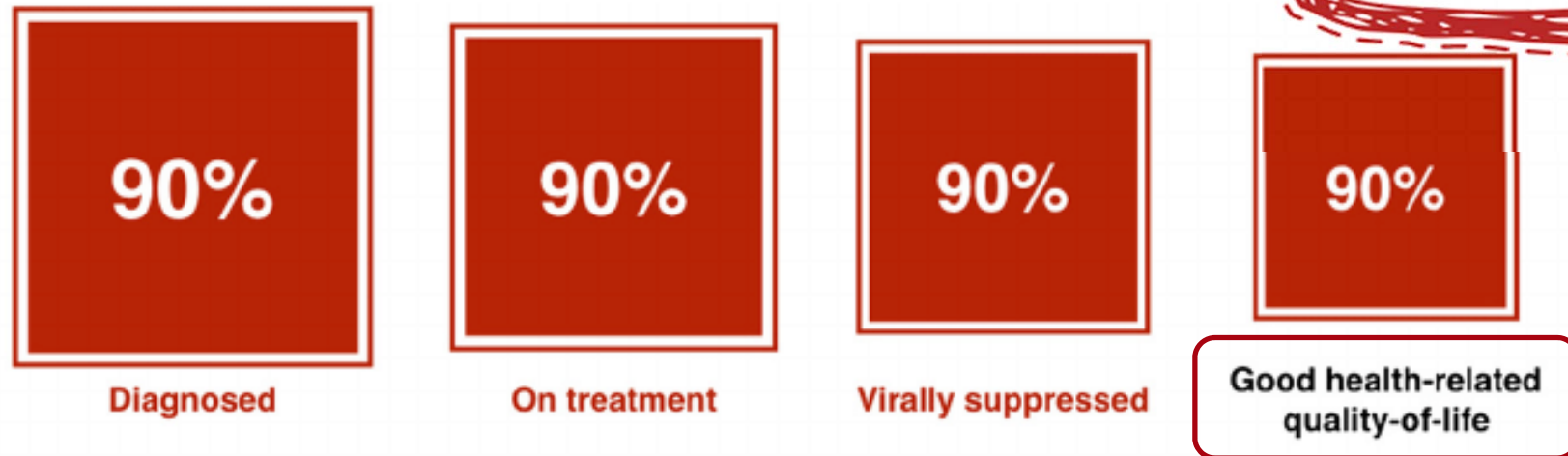
The HIV treatment cascade

# 4<sup>th</sup> '90'

## Good Health-related Quality-of-Life

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HIV as a social and  
life-long condition



\*Adapted from: UNAIDS. 90-90-90: an ambitious treatment target to help end the AIDS epidemic. 2014. Available at [http://unaids.org/sites/default/files/media\\_asset/90-90-90\\_en\\_0.pdf](http://unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf). Accessed on 25 April 2016 Lazarus et al. BMC Medicine (2016) 14:94



JOHNS HOPKINS  
BLOOMBERG SCHOOL  
of PUBLIC HEALTH

The Medical Outcomes Study HIV  
Health Survey - 1987

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# The Evolution of Healthcare

## Goals of Medicine

- Promote health
- Preserve health
- Restore health, when compromised
- Minimize suffering and malaise

The ancient Egyptians, Greeks and Romans: The first doctors



The medical renaissance (ap. 1400-1700). Many new discoveries about the body



Life expectancy: women 36, men 41

20th century: Rapid progress in preventing and curing many diseases. Life expectancy: women 78, men 72.

2000

Prehistory



1000

Middle ages (ad500-1400) Very little medical progress



BC

AD

Life expectancy: women 36, men 37

500

1000

18th and 19th centuries: Discoveries about the true causes of disease

1400

1750

1900

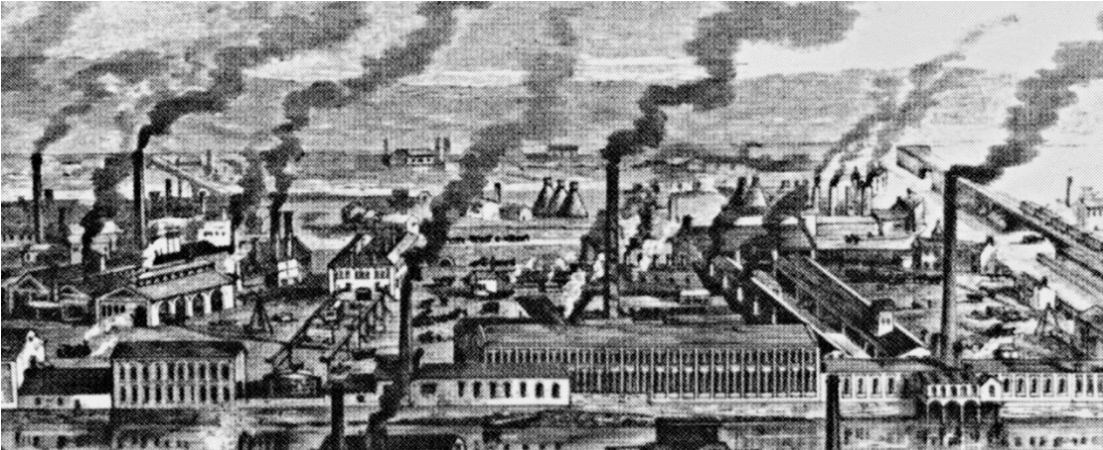
2000



# The Evolution of Healthcare

## Industrial Revolution

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# 'Industrialization' of Healthcare



Health Factory, Norway, 2010

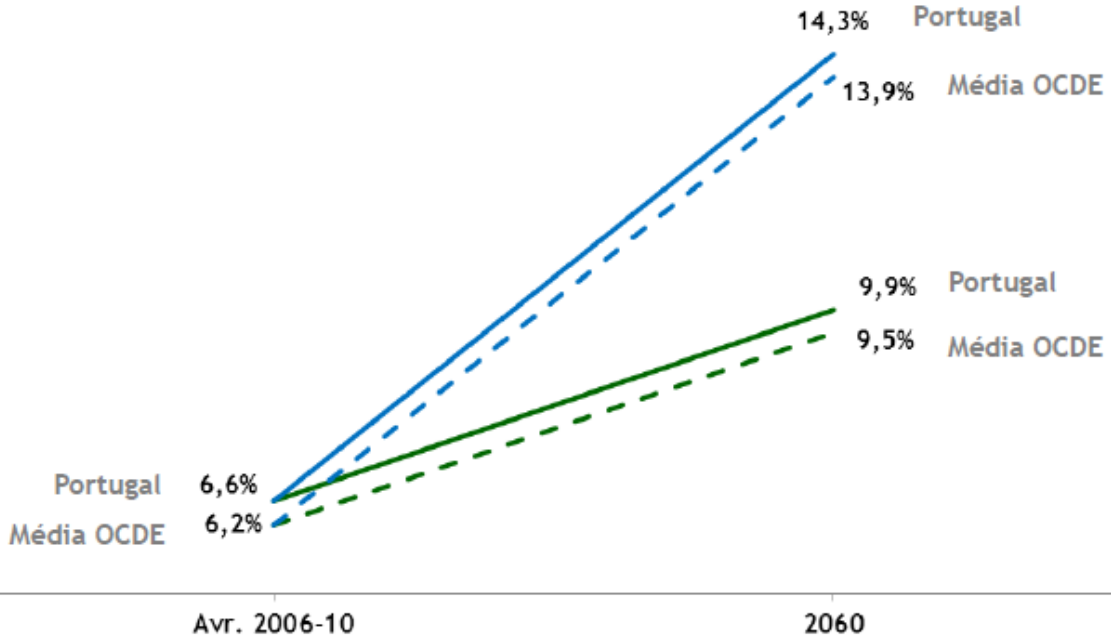
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# The Evolution of Healthcare

## Rising Costs of Healthcare

**Rising Expenditure in healthcare (projection) + Failure to Reduce Burden of Disease**

Expenses in healthcare (in % of GDP) 2010-2060



### Cenário

**Cost-pressure**  
*assumes no stepped-up policy action spending*

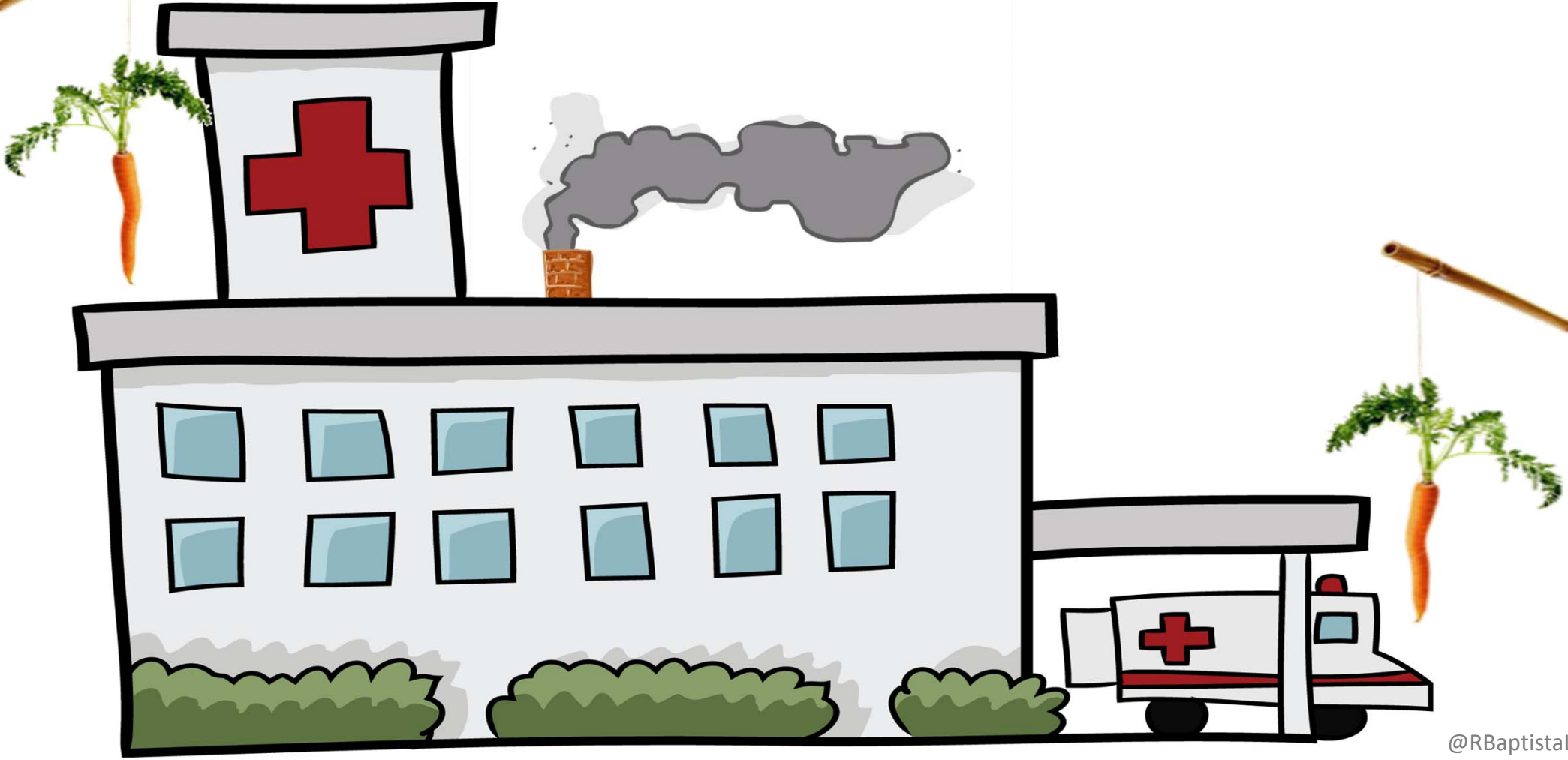
**Cost-containment**  
*assuming that policies act more strongly than in the past to rein in some of the expenditure growth*

Fonte: De La Maisonneuve, C. and J. Oliveira Martins, "Public spending on health and long-term care: a new set of projections", OECD Economic Policy Papers, No. 06, June 2013, OECD, Paris.

# The Evolution of Healthcare

## Outcomes Matter

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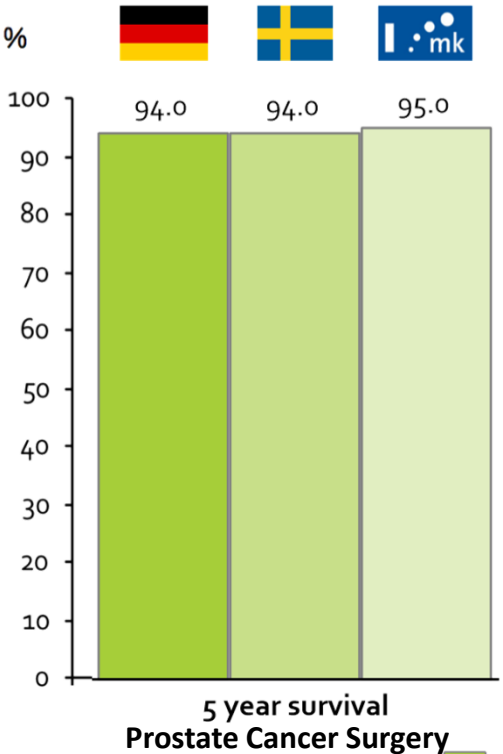


# The Evolution of Healthcare

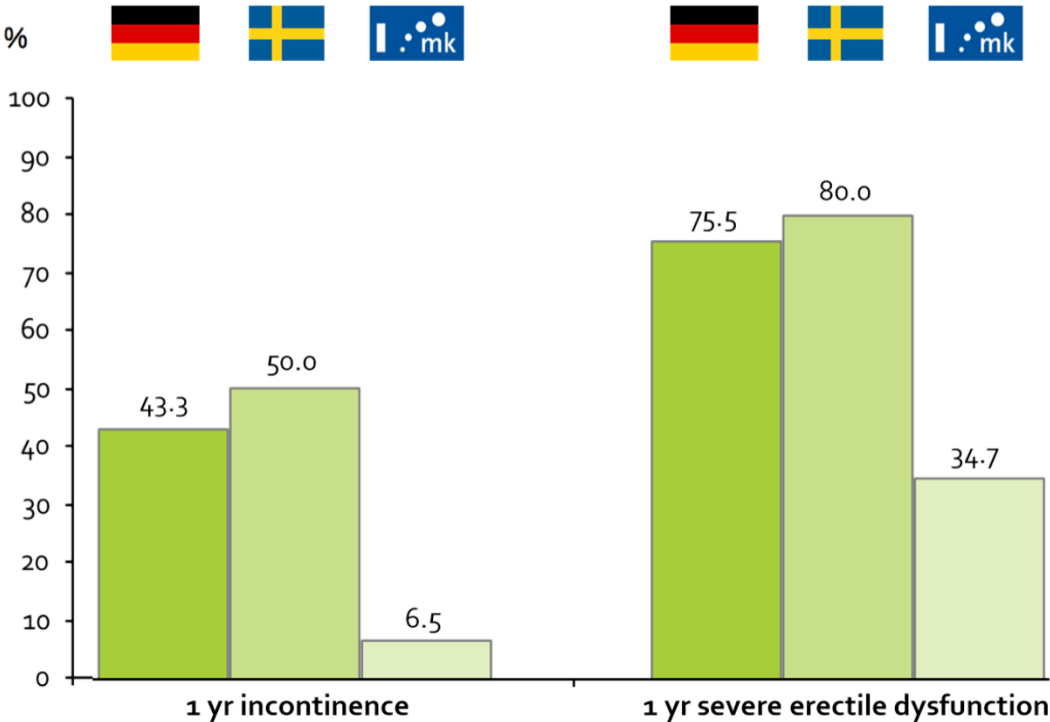
## Outcomes Matter



Focusing on mortality alone...



...may obscure large differences in outcomes that matter most to patients

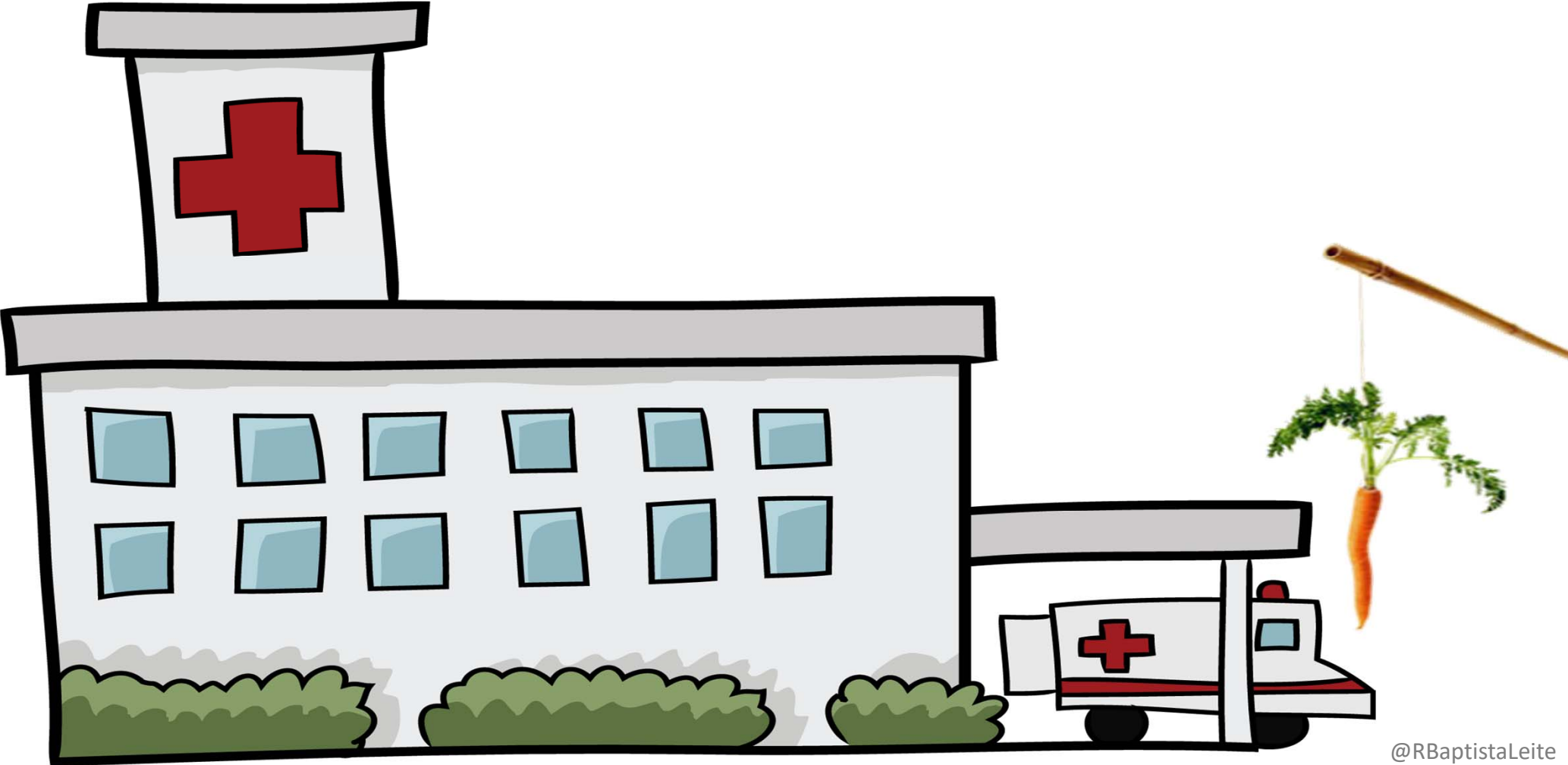


Germany Sweden Best-in-class: Martini Klinik

# The Evolution of Healthcare

## Outcomes Matter

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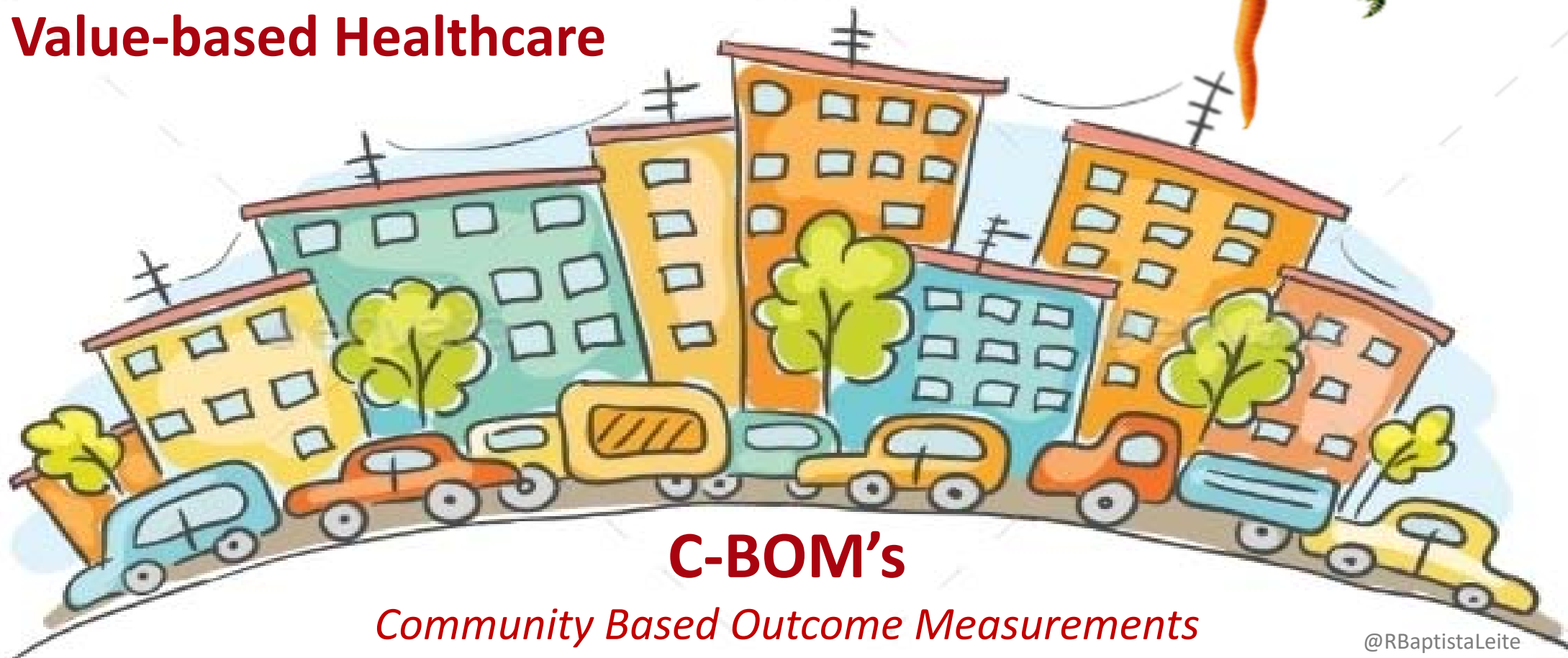
# The Evolution of Healthcare

## Outcomes Matter

### Community

### Value-based Healthcare

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## C-BOM's

*Community Based Outcome Measurements*

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"It always seems impossible until it's done."

**-Nelson Mandela**

<https://awakenthegreatnesswithin.com/50-inspirational-nelson-mandela-quotes-that-will-change-your-life/>

# CHANGING POLICY. TOGETHER.



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INSTITUTO DE CIÊNCIAS DA SAÚDE  
LISBOA-PORTO-VISEU

*A digital tool that integrates the analysis of the history of disease, the treatment continuum, vulnerable populations and the impact of health policies*



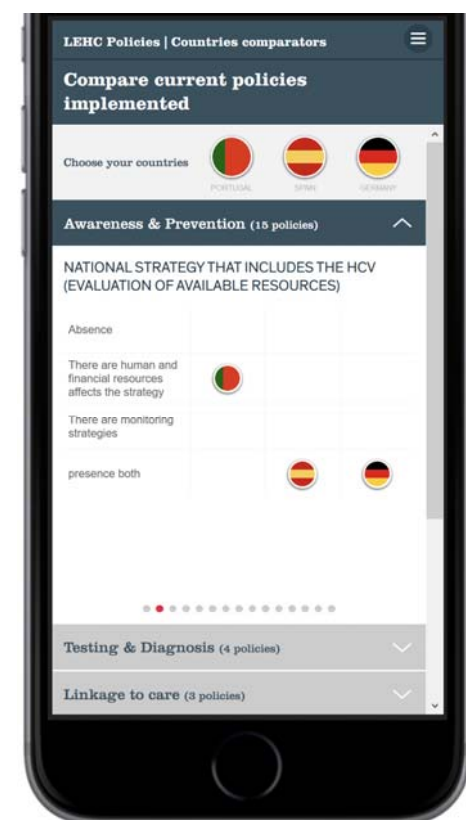
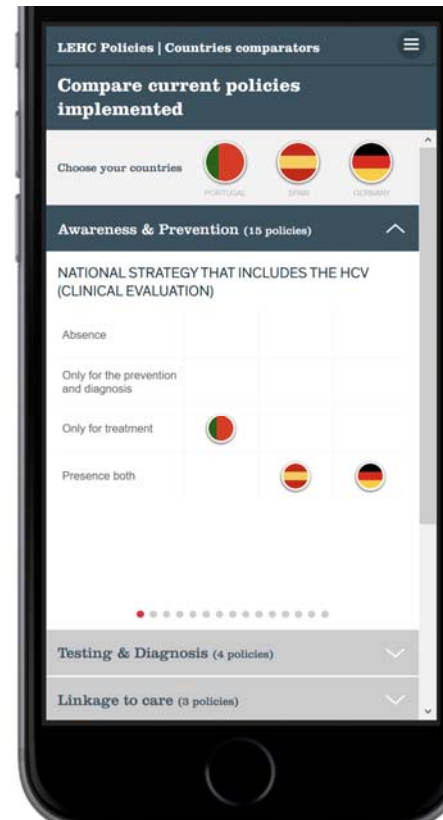
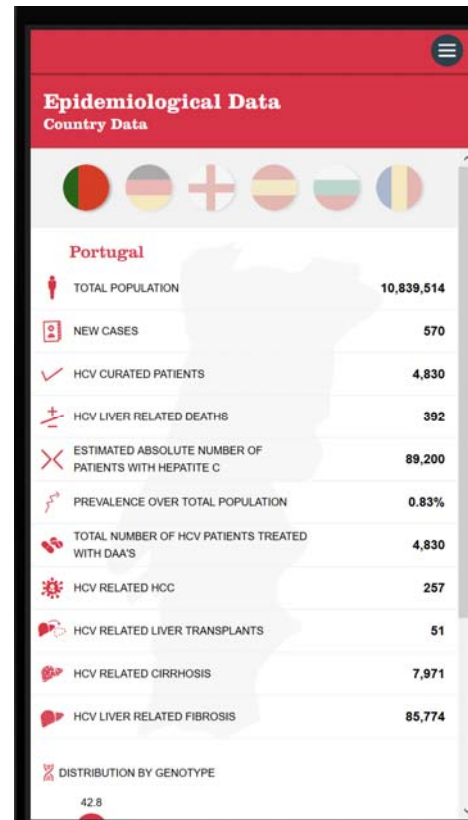
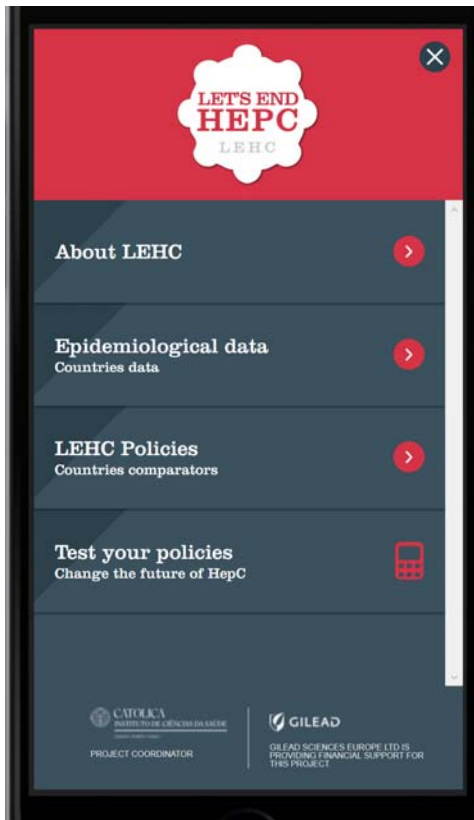
**LETSENDHEPC.COM and download the APP 'LET'S END HEP C'**

DECLARATION OF INTERESTS

Gilead Sciences Europe Ltd is providing financial support for this project.

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# COMPARING POLICIES ACROSS COUNTRIES



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# ASSESSING AND FORESEEING IMPACT



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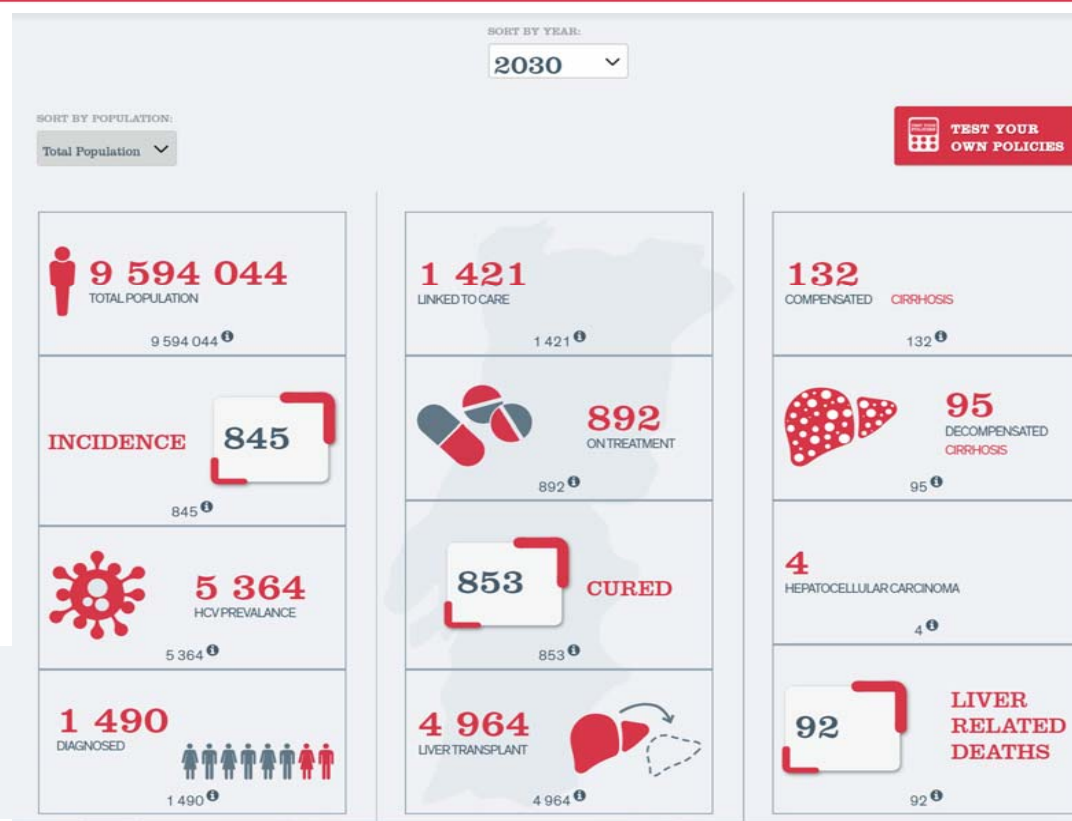
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## POLICY IMPACT ON HEALTH OUTCOMES

- Main HCV Outcomes
- Per Year 2019-2030
- Vulnerable Populations



Elimination of HCV will not be achieved by 2030 with current policies (according to WHO elimination definition of HCV cut off of 90%).



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# REDESIGNING THE FUTURE

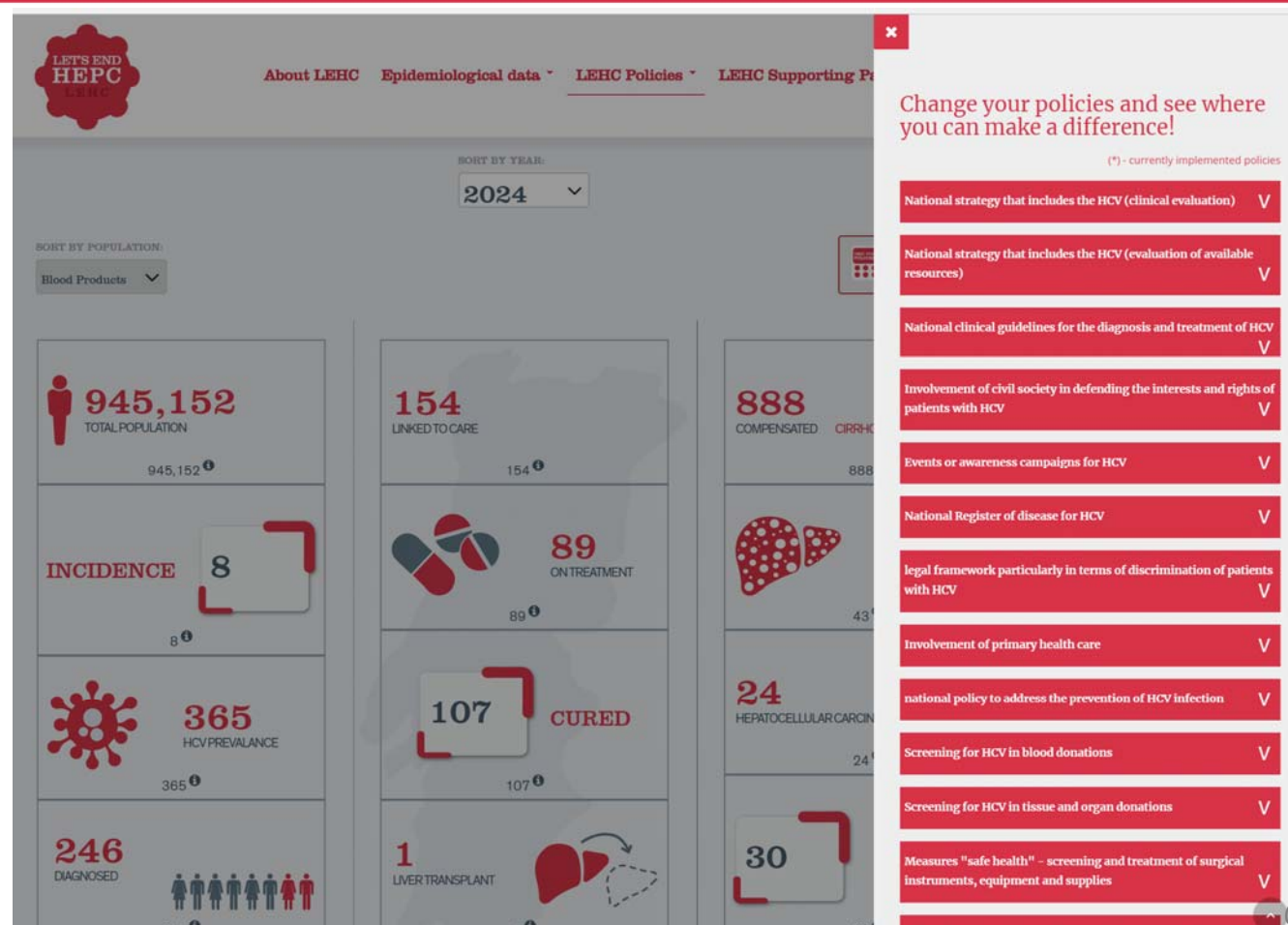


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## POLICY CALCULATOR

*'Gamification of  
Policy Making'*



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# PUBLIC HEALTH POLICY TOOL



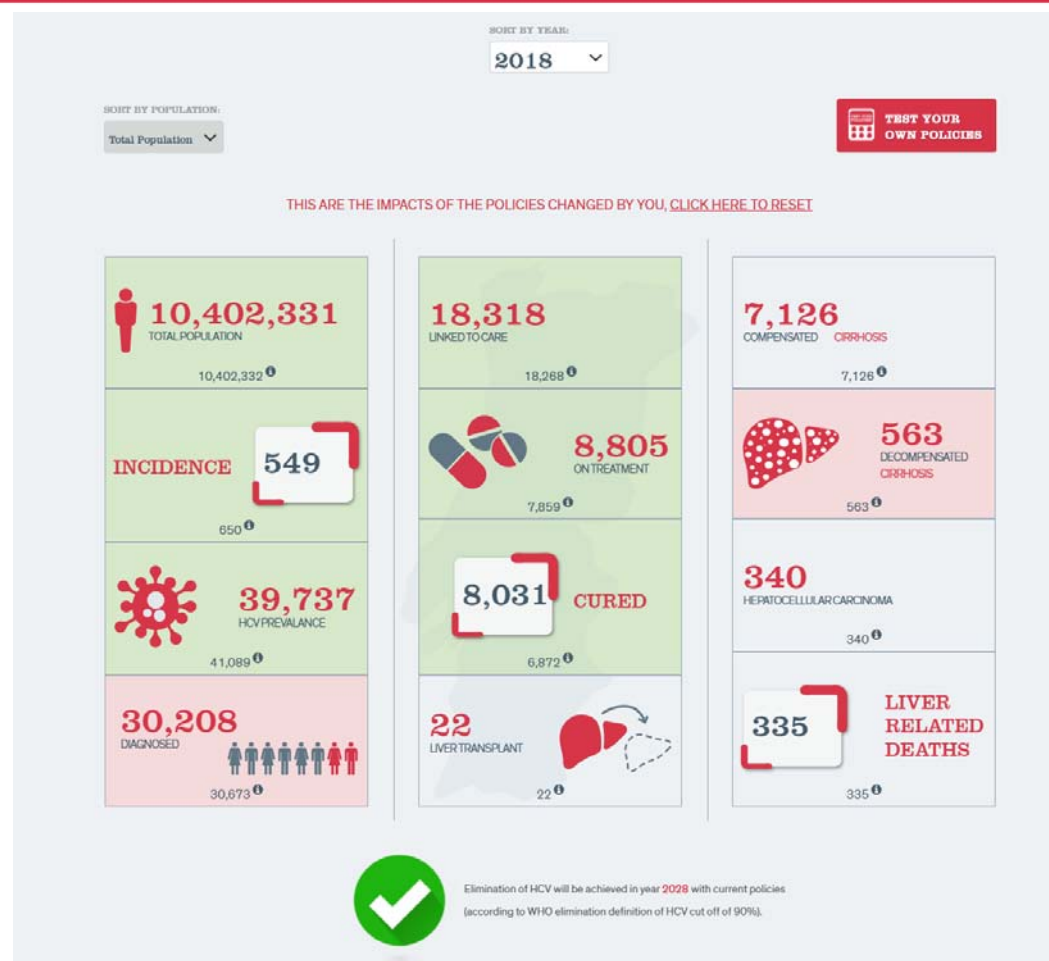
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## POLICY CALCULATOR

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**‘Give’ politicians what they need**

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## ***Getting Political Leaders to push for Health***

- In line with public concerns
- Clear ‘Before and After’ Data
- Savings, Low *or* No Cost (in this order)
- Timely results (*ie*, election period)



# The role of policy makers

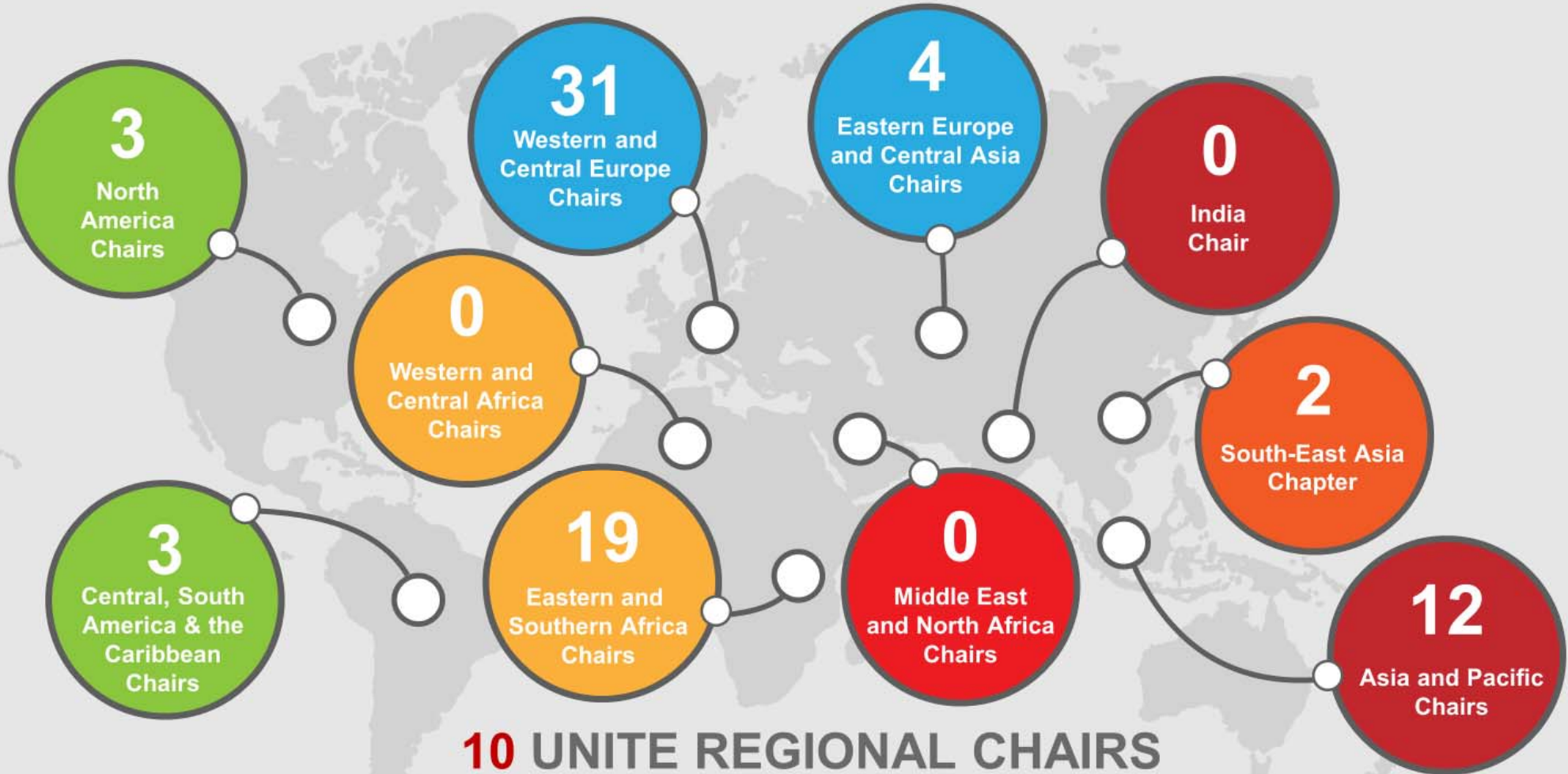
## Members of Parliament

- Approve national **budgets**
- Directly change local and national **policies**
- **Interface** between Governments and the People



Still MPs are **excluded** from most **International** - **Multilateral workgroups** and **decision processes**





**10** UNITE REGIONAL CHAIRS  
**72** MEMBERS FROM **39** COUNTRIES



# UNITE MP's HAVE THE SUPPORT OF A MULTIDISCIPLINARY SECRETARIAT



# UNITE SUPPORTING FUNDERS and PARTNERS:

- AHF
- MAC AIDS FUND
- OSF
- MdM
- UNAIDS
- PwC
- CREATING HEALTH

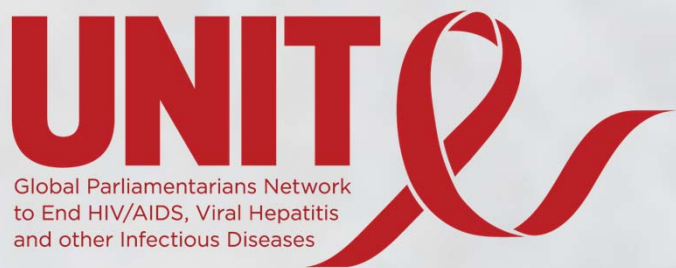




**It's time to REBOOT political awareness and action towards ending HIV/AIDS, Viral Hepatitis and other Infectious Diseases**

It's time to end HIV/AIDS, Viral Hepatitis and other Infectious Diseases.

It's time to **UNITE.**



Global Parliamentarians Network  
to End HIV/AIDS, Viral Hepatitis  
and other Infectious Diseases



[unitenetwork@unitenetwork.org](mailto:unitenetwork@unitenetwork.org)



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