



# PAHTool: A dedicated software for PAH

## National and international experience

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# Pulmonary Arterial Hypertension

**“Rare” Disease**

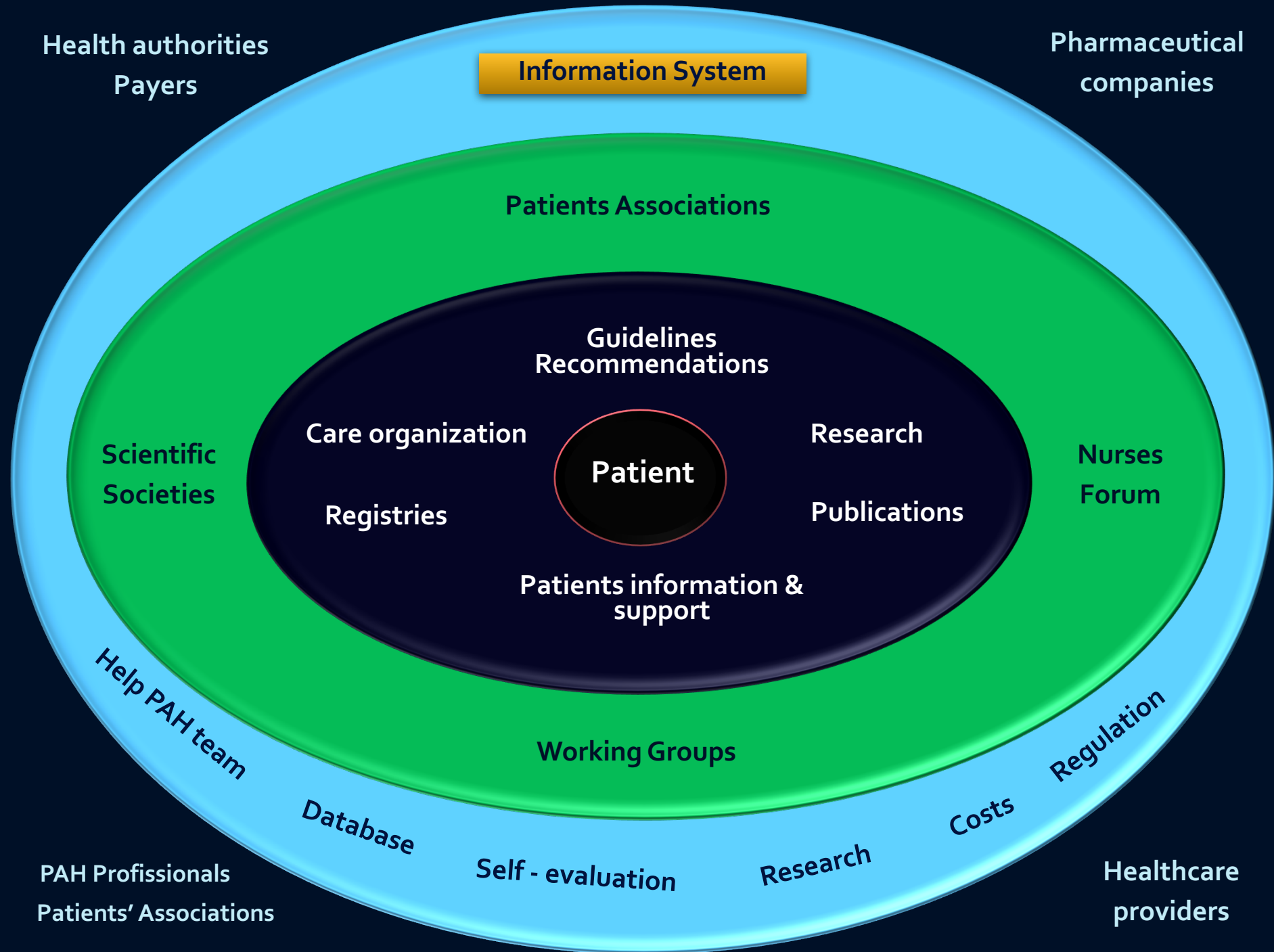
**Specialized care**

**Malignant behaviour**

**Treatable**

**Costly**

**Dedicated & Organized care**





# PAHTool – Objectives

- ✓ **Friendly use**
- ✓ **Useful in clinical practice helping PH team**
  - Good clinical practice
  - Streamlined visits and reports
- ✓ **Educational tool**
  - Implementation of “Recommendations”
  - Standardization of practices
- ✓ **Database for information, global management, research and regulation**
- ✓ **CRFs for clinical trials**
- ✓ **Integrated in the electronic medical record (EMR)**

**CT & Registries results from usual clinical activity without duplicating work**



# PAHTool – In use since 2008



- ✓ Hospital Santo António, Porto
- ✓ Portuguese PAH network (6)
- ✓ Database for a

**Retrospective PH registry (2008)**

**VI JORNADAS  
DE ACTUALIZAÇÃO  
EM DOENÇA  
VASCULAR PULMONAR**

EPIDEMIOLOGIA NACIONAL DA DOENÇA  
VASCULAR PULMONAR (DVP)

POUSADA DO PORTO - PALÁCIO DO FREIXO

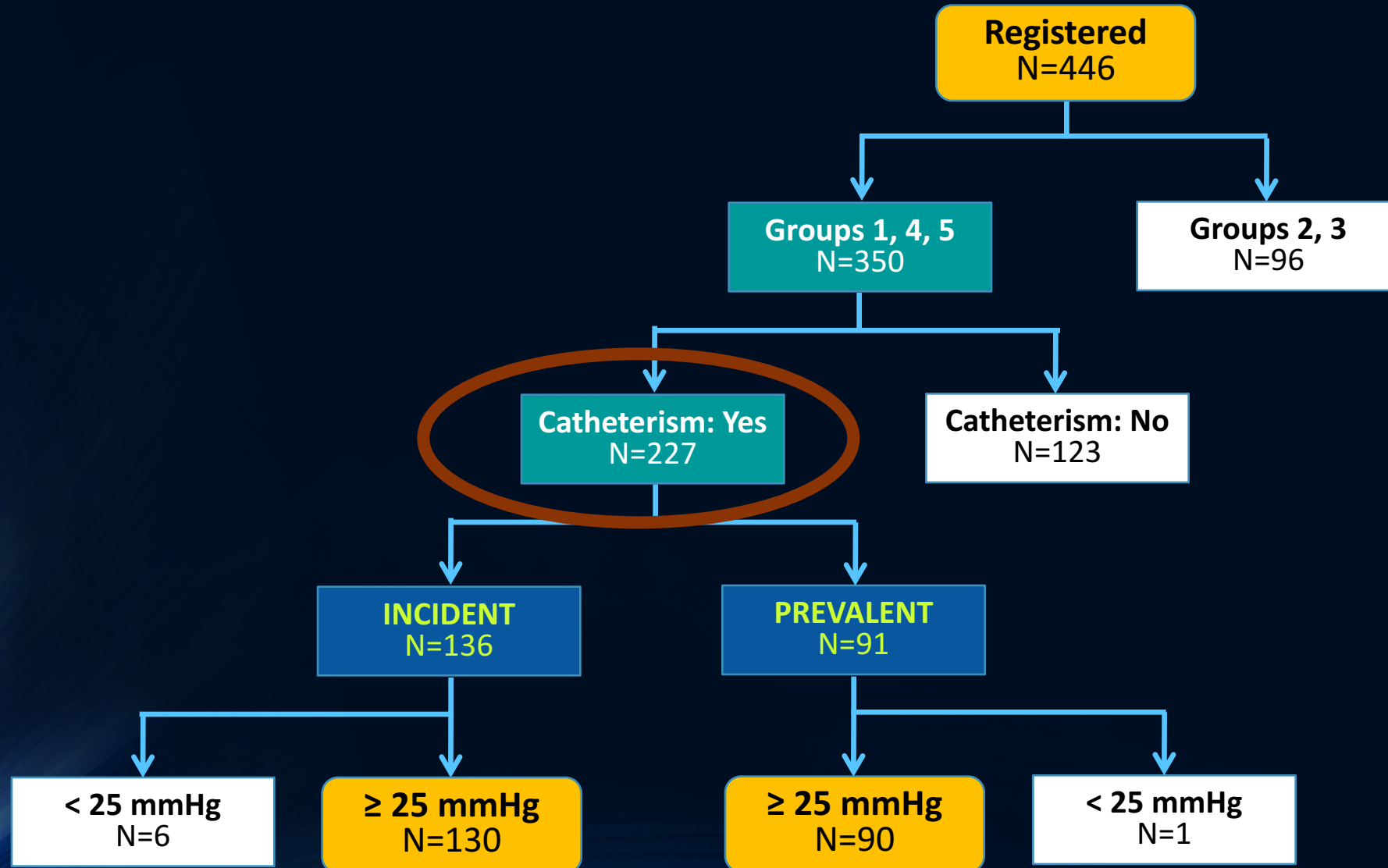
5-6 DE NOVEMBRO 2010

# Caracterização epidemiológica nacional da Hipertensão Arterial Pulmonar (HAP): *Resultados de um Registo Nacional*

Abílio Reis, Igor Marques E Luís Almeida

A Agapito, A Nunes Diogo, G Castro, M J Loureiro, T Shiang, A Marinho Silva,  
F Gonçalves, S Martins, A Oliveira, D Ferreira, R Baptista

# Population flowchart





# Challenges

- ✓ Retrospective design
- ✓ Missing data
- ✓ Lost to follow-up
- ✓ Variable adherence by the centers

# PAHTool – National prospective Registry



PAHTool

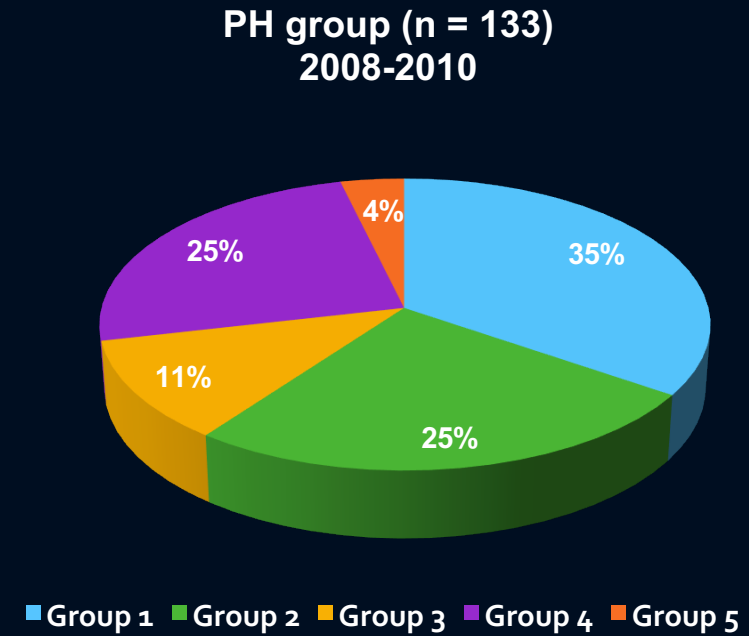
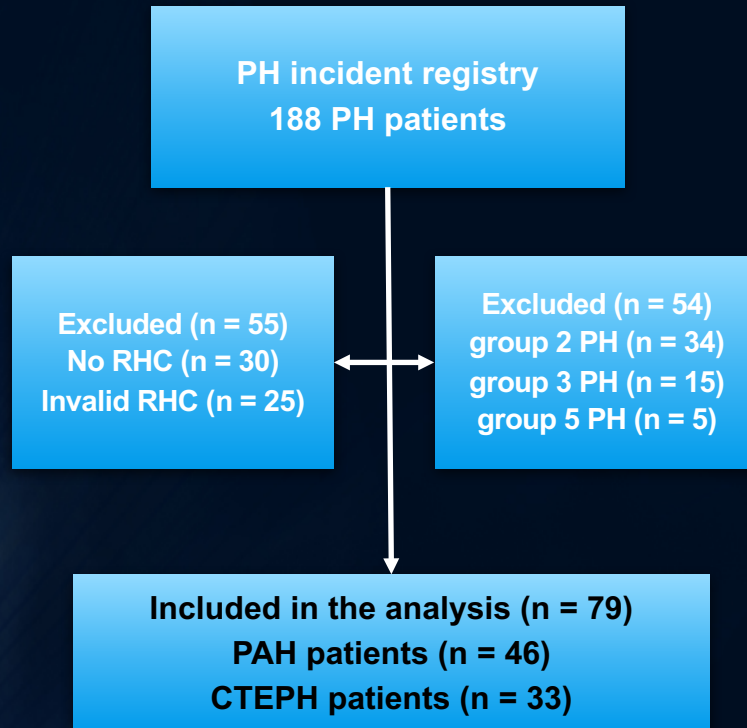


- ✓ Hospital Santo António, Porto
- ✓ Portuguese PAH network (6)
- ✓ Database for a

**Retrospective registry (2008)**

**Prospective registry of incident patients (2008-2010)**

# Results



**Estimated PAH incidence**  
**2.5 cases/1 million adult inhabitants/yr**

**Estimated CTEPH incidence**  
**1.8 cases/1 million adult inhabitants/yr**



# PAHTool – Other scientific



- ✓ Hospital Santo António, Porto
- ✓ Portuguese PAH network (6)
- ✓ Database for a

**Retrospective registry (2008)**

**Prospective registry of incident patients (2008-2010)**

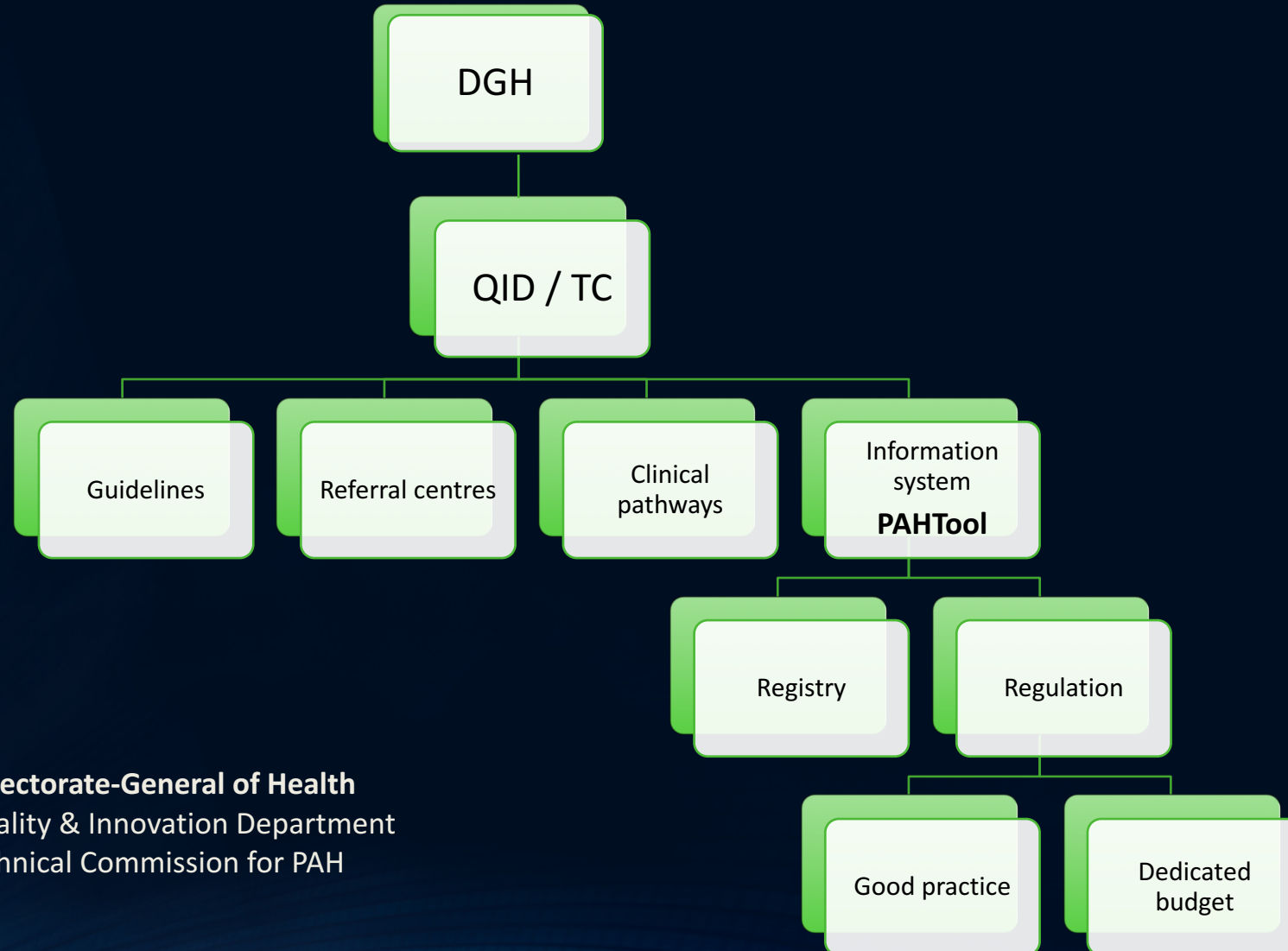
**Pulmonary endarterectomy in a country without PEA**

*Baptista R et al. Poster. ESC Congress 2014*

**Portuguese validation of CAMPHOR questionnaire**

*Reis et al. Health and Quality of Life Outcomes (2016) 14:110*

# PAHTool – National information system



# PAHTool – In use (2016)



Portugal (4)



France (29)



Netherlands (6)



Luxembourg (1)



Greece (2)



Turkey (7)



Brazil (2)



Saudi Arabia (5)



Libya (1)



Canada (1)



Malaysia (2)



Singapore (2)



Thailand (1)



# 1<sup>st</sup> PAHTool Users Forum



Oporto, Portugal  
13 November 2015

# 1<sup>st</sup> PA



	TITLE	CHAIRS	SPEAKERS
08H00	WELCOME AND OBJECTIVES	A Reis, G Simonneau	A Reis
08H15	REGISTRIES - IMPORTANCE AND GOALS	G Simonneau, A Reis	
	Disease management and health authorities needs		G Simonneau
	Survival data and possible bias		R Souza
	Safety data		S Rosenkranz
	Discussion		All
09H30	HOW TO GET DATA FOR REGISTRIES Classic ways	G Simonneau, R Souza	
	French Registry		O Sitbon
	UK Registry		M Johnson
10h00	Coffee Break		
10h30	Spanish Registry (REHAP)		P Escribano
	COMPERA Registry		S Rosenkranz
	Japanese Registry		Y Tamura
	Bologna Registry		M Palazzini
	CTEPH Registry		M Delcroix
	An overview from published registries		M Humbert
	Discussion		All
12h30	Lunch		
14H00	HOW TO GET DATA FOR REGISTRIES New Ways	M Humbert, M Delcroix	
	PAHTool		A Reis
	PAHTool - Countries Experience		
	Portugal		R Baptista
	France		O Sitbon
	Netherlands		K Boomars
	Canada		J Swiston
	Singapore		J Yip
	Brazil		C Jardim
	Saudi Arabia		A Al Dalaan
	Discussion		All
16h30	Coffee Break		
17H00	COLLABORATION PROJECTS	A Reis, O Sitbon, R Souza	
	What has already been done		R Souza
	What can we do in the future		O Sitbon
	Discussion		All
18H00	CLOSING REMARKS		G Simonneau

Oporto, Portugal  
13 November 2015

# Roadmap

