



FRANCE

IS IT POSSIBLE TO ACCURATELY IDENTIFY RARE DISEASES USING NATIONAL HOSPITAL DISCHARGE DATABASES?

Objective

Generation of accurate data in a timely manner is often challenging especially for rare diseases. Data from administrative discharge databases, as an alternative to prospective studies, may be important and of value but has methodological limitations. This study (HO-15-16391, funded by GSK) aimed at evaluating the feasibility of describing the hospital burden of Pulmonary Arterial Hypertension (PAH) in France using the French National Hospital discharge database (PMSI).

Method

STUDY PERIOD

January 1st, 2013 to December 31st, 2014.

DESIGN

Retrospective study of the PMSI-MCO (Medicine, Surgery, Obstetrics) database, a comprehensive collection of all inpatient stays in France.

DATA EXTRACTION

All 2013 stays with International Classification of Diseases, 10th Revision (ICD-10) codes for PAH (I27.0 Primary pulmonary hypertension, I27.2 Other secondary pulmonary hypertension) as PD/RD (principal/related diagnosis) or SAD (significantly associated diagnosis) were extracted.

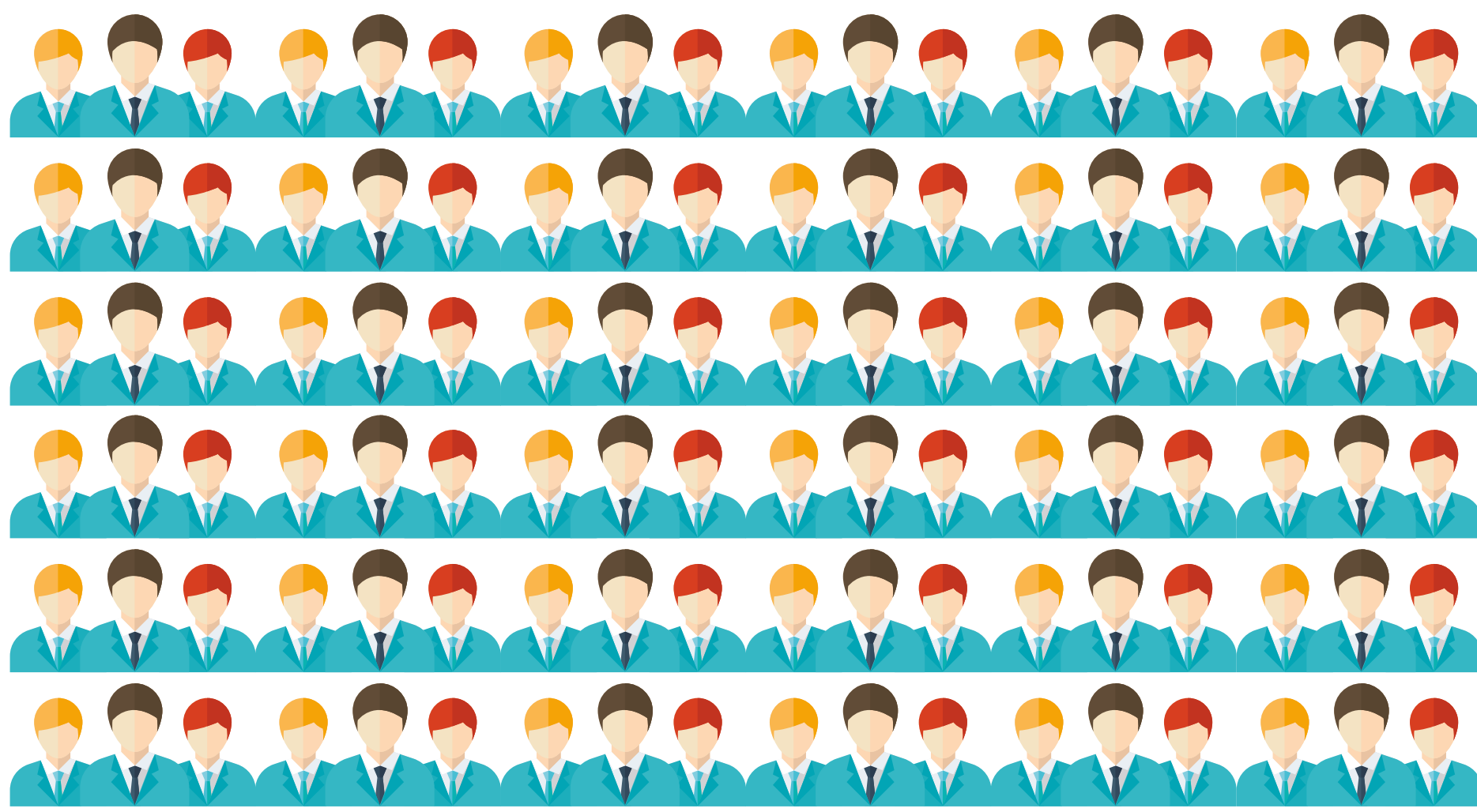
INCIDENT ADULT PATIENTS

A 2-year retrospective analysis from the first stay of each patient in 2013 (e.g. May 2011 to May 2013) was performed to select only incident adult patients: newly diagnosed in 2013 (not hospitalized with PAH in 2011-2012).

Conclusion

This cohort is consistent with the estimation from the French PAH national registry in terms of number of patients and demographic characteristics. The PMSI database is an accessible and relevant source of data, especially for diseases mainly managed in hospital. Its exhaustiveness allows to overcome the low frequency of events that is specific to rare diseases and thus to gain a representative picture of the hospital burden of disease. Nevertheless, lack of clinical information required assumptions validated by medical experts and prevented us from exploring specific sub-groups (NYHA functional classes). An evaluation of the economic burden of PAH could therefore be conducted.¹

Results



38,834
incident adult patients
with PAH ICD-10
codes I27.0 / I27.2 in 2013

1 year

prospective linkage following first
2013 stay (inclusion) for each patient
and extraction of all follow-up stays

IF

PRESENCE AT INCLUSION AND/OR FOLLOW-UP OF
Lung transplantation
AND/OR
Administration of prostacyclin
(Epoprostenol, Iloprost, Treprostinil)
AND/OR
Right heart catheterization



Potential surrogates for PAH

IF

ABSENCE AT INCLUSION AND/OR FOLLOW-UP OF
Concomitant pathologies
AND/OR
Procedures sign of “false” PAH such as chronic
left heart failure, chronic lung diseases,
thrombo-embolic diseases, left valvular surgery,
atrioseptal defect closure, lung endarterectomy,
cirrhosis...



Causes of other pulmonary
hypertension group

IF

PRESENCE OF
At least 1 follow-up stay linked
to PAH management, defined as
PAH ICD-10 CODES STATED AS PD/RD =
linked to PAH
PAH ICD-10 CODES STATED AS SAD =
medically pre-defined algorithm and medical
review with experts conducted to assess linkage
with PAH



384
incident adult patients
with "TRUE" PAH in 2013

1. Bergot E., de Léotoing L., Bendjenana H., Tournier C., Vainchtock A., Nachbaur G., Humbert M. Economic burden of hospitalizations related to pulmonary arterial hypertension (PAH) in France. ISPOR 20th Annual European Congress, 4-8 November 2017, Glasgow, Scotland. RESEARCH POSTER PRESENTATIONS - SESSION III CARDIOVASCULAR DISORDERS - PCV53

EB has received personal fees from GSK, Actelion and Roche and disclose collaborations with Pfizer, Bayer and Boehringer; MH has received personal from Actelion Pharmaceuticals Ltd, Novartis and Pfizer, grants and personal fees from Bayer and GSK and disclose collaboration with United Therapeutics. In addition to being investigator in trials involving these companies, relationships include consultancy service and membership of scientific advisory boards; LdL, CT and AV have received grants, via their company, from GSK; GN and HB are employees of GSK and hold GSK shares.

