



Curriculum Vitae

Personal
information

Francois Houyez

Work
experience

1. Employer: European Organisation for Rare Diseases
 - Start date: 082013
 - End date: current
 - Position: Director of Treatment Information and Access, Policy Advisor
 - Activities: The overall main objectives of the Treatment Information and Access Director are to better inform patients on the treatments of Benefit & Risks of medicinal products for the initial marketing authorisation application, renewal or withdrawal, in Risk Management Plans, Compassionate Use Programmes, and in access to authorised or Off_Label medicines, Health Technology assessment and reimbursement issues, the expression of needs by patients' organisations. _ Represents EURORDIS at the Stakeholder Pool of the eHTA Network _ Represents EURO the Drug Information, Transparency and Access Task Force _ Task leader HTx project
 - Country: France
2. Employer: European Organisation for Rare Diseases
 - Start date: 022009
 - End date: 082013
 - Position: Director of Health Policy
 - Activities: Evaluates the needs of the patients, proposes solutions to fulfil these needs, proposes changes to health policies at the European level. Selected Contributions: _ Position paper on Patients' Rights to Cross_Border Care _ Proposed amendments to the European Parliament contribution to the public consultation for the legislation on Pharmacovigilance (Regulation (EU) No 1235/2010 and Directive 2010/84) _ Pro _ Represents patients at the European Medicines Agency _ Organised the European Conference on Rare Diseases ECRD 2010 in Krakow
 - Country: France
3. Employer: European Organisation for Rare Diseases
 - Start date: 022006
 - End date: 022009
 - Position: Health Policy Officer
 - Activities:
 - Country: France
4. Employer: European Organisation for Rare Diseases
 - Start date: 052003
 - End date: 022006
 - Position: Project Manager Access to Care
 - Activities:
 - Country: France
5. Employer: European Aids Treatment Group
 - Start date: 2002
 - End date: 052003
 - Position: Chief Editor
 - Activities: European Aids Treatment News newsletter: choice of articles, co_ordination with writers and editorial board, editing. Published
 - Country: Belgium
6. Employer: Franck Fontenay, freelance writer
 - Start date: 1999
 - End date: 2002
 - Position: Free lance medical writer
 - Activities: Publication of international newsletters for participants in clinical trials in the field of Human Immune_Deficiency Virus, Hepati
 - Country: France
7. Employer: Vaincre Le Sida
 - Start date: 1998
 - End date: 2000
 - Position: Patient advisor
 - Activities: Counselling patients on their treatment, organisation of programmes and activities to help patients adhere to their treatment,
 - Country: France
8. Employer: Arcat -Sida
 - Start date: 1995
 - End date: 1998
 - Position: TRT_5 co_ordinator
 - Activities: Scientific and administrative co_ordination of the collaborative group of French Aids NGOs focusing on treatment and research
 - Country: France
9. Employer: Act Up_Paris
 - Start date: 1989
 - End date: 1995
 - Position: Volunteer until 1995, then TRT5 coordinator
 - Activities: Created the Treatment and Research commission. Served as Member of the Board of Directors in charge of communication in
 - Country: France

Education
and
training

1. Subject: School of Public Health _ University of California Berkeley

- Start date: 102020
- End date: 012021
- Qualification: PHW236A 2020 Regulatory Science, Drug Development and Public Health
- Organisation: Regulatory science: a definition Regulation and Innovation: Role of Regulatory Science in Facilitating Pharmaceutical Innovation
Century Cures Act: Opportunities and Challenges Regulation and Public Health Ethics in clinical research Infectious Diseases and Regulations
Concept to Efficacy and Effectiveness Levels Evidence and Approaches to Analysis Innovation in Trial Design and Data Use Surrogate Market
Benefit_Risk in Context _ not a Static Formula: Special Considerations for Paediatric Populations
- Country: United States

Additional information

Publications

- Recommendations for Patient Involvement in Health Technology Assessment in Central and Eastern European Countries
Ivett Jakab, Maria Dimitrova, François Houyez, Tamás Bereczky, Miroslava Fövényes, Zorana Maravic, Ivica Belina, Christian Andricuic, Krisztina Tóth, Oresta Pi
László Lorenzovici, Maria Stefanova Kamusheva, Manoela Manova, Alexandra Tzvetanova Savova, Zornitsa Emilova Mitkova, Konstantin Tihomirov Tachkov, Ber
Goettsch and Zoltán Kaló*
Original Research, Front. Public Health - Public Health Policy (in press)
- Lauren Van Haesendonck, Jörg Ruof, Thomas Desmet, Walter Van Dyck, Steven Simoens, Isabelle Huys, Rosa Giuliani, Mondher Toumi, Christian Dierks, Julia
Mol, Anja Schiel, Wim Goettsch, Fabrizio Gianfrate, Stefano Capri, James Ryan, Pierre Ducournau, Oriol Solà-Morales & Elaine Julian (2023) The role of stakehol
Access Academy's multi-stakeholder pre-convention questionnaire, Journal of Market Access & Health Policy, 11:1, DOI: 10.1080/20016689.2023.2217543
- Bahri P, Bowring G, Edwards BD, Anton C, Aronson JK, Caro-Rojas A, Hugman BPJ, Mol PG, Trifirò G, Ilıc K, Daghfous R, Fermont I, Furlan G, Gaissmaier W, G
M, Santoro F, Sultana J. Communicating for the Safe Use of Medicines: Progress and Directions for the 2020s Promoted by the Special Interest Group of the Inte
10.1007/s40264-023-01285-5. Epub 2023 May 23. PMID: 37219785; PMCID: PMC10203670.
- Fruytier SE, Vat LE, Camp R, Houyez F, De Keyser H, Dunne D, Marchi D, McKeaveney L, Pitt RH, Pittens CA, Vaughn MF, Zhuravleva E, Schuitmaker_Warnaar
development: co_creating a framework for community advisory boards. J Patient Cent Res Rev. 2022;9:46_57. doi: 10.17294/2330_0698.1859
- Repurposing of medicines in the EU: launch of a pilot framework, by Charlotte Asker_Hagelberg, Tomas Boran, Christelle Bouygues, Sini Marika Eskola, Laszlo
Lydie Meheus, Wim Penninckx, Beata Stepniewska.
http://journal.frontiersin.org/article/10.3389/fmed.2021.817663/full?utm_source=Email_to_authors&utm_medium=Email&utm_content=T1_11.5e1_author8
- Patient Contribution to the Development and Safe Use of Medicines During the Covid_19 Pandemic. Pitts PJ, Houyez F. Ther Innov Regul Sci. 2021 Jan;55(1):2
- The fourth edition of the European Network for Health Technology Assessment Forum: highlights and outcomes. Tafuri G, Bèlorgey C, Favaretti C, Frénoy E, G
Petelos E, Saeterdal I, Schuurman A, Skjöldebrand AL, Strammioello V, Widmer D, Willemsen A, Hedberg N. Int J Technol Assess Health Care. 2020 Jun;36(3):19
- Roennow A, Sauvè M, Welling J, et al: Collaboration between patient organisations and a clinical research sponsor in a rare disease condition: learnings from a
2020;10:e039473. doi: 10.1136/bmjopen_2020_039473 • High Price Medicines and Health Budgets: The Role Patients' and Consumers' Organisations Can Play
309–323. DOI: https://doi.org/10.1163/15718093_BJA10008
- From Passive to Active: Patients as Contributors to Medicinal Product Risk Communication Research. Springer 2020, Priya Bahri Editor. Communicating about I
- Houyez, F., & Camp, R. (2019). OP27 Engaging Patients: The EuroCAB Programme. International Journal of Technology Assessment in Health Care, 35(S1), 6
- 2 March 2018: Interest in a Mobile App for Two_Way Risk Communication: A Survey Study Among European Healthcare Professionals and Patients _ Drug Saf
- 17 Apr 2017: Patient Reporting in the EU: Analysis of EudraVigilance Data _ Drug Safety, Springer
- 2017 Factors Influencing the Use of a Mobile App for Reporting Adverse Drug Reactions and Receiving Safety Information: A Qualitative Study. de Vries ST, W
Consortium. Drug Saf. 2017 May;40(5):443_455
- 15 May 2015: Policy recommendations for rare disease centres of expertise _ Elsevier
- 5 May 2014: A European Network of Email and Telephone Help Lines Providing Information and Support on Rare Diseases: Results From a 1_Month Activity Su
- February 2010 HTA and patients' rights: access versus assess? Journal of the Italian Society for Regulatory Activities, SIAR 2010, Vol. 58; 26:31
- April 2004 Active involvement of patients in drug research, evaluation, and commercialization: European perspective. J Ambul Care Manage. 2004 Apr_Jun; 27
- April 2002 Erectile Dysfunction in HIV infected Men In Jäger – AIDS und HIV_Infektionen
- March 2001 Laboratory guidelines for the practical use of HIV drug resistance tests in patient follow_up Vandamme AM, Houyez F, Banhegyi D, Clotet B, De S
Pillay D, Race E, Schmit JC, Schuurman R, Schulse E, Sonnerborg A, Miller V. In Antivir Ther. 2001 Mar;6(1):21_39. Review.
- October 1999 Report on new HIV antivirals European Conference on HIV Infection, Lisbon Sleep and hypertension. An epidemiologic study in 7,901 workers. H
Coeur Vaiss. 1990 Jul; 83(8):1085_8.

Projects

- IMI HTX project, Next Generation HTA: partner
- Horizon Europe project: More-Europa, partner
- Vaccelerate project: member of the scientific and Advisory Board

Memberships

Member of CIOMS Working Group XI on "Patient Involvement in the Development and Safe use of Medicines" Member of the Drug Repurposing Observation Gro
Advisory Board Represents Eurordis in the Get Real Institute Executive Committee Member of the Executive committee, International Market Access Society

Other Relevant Information

I am a patient representative