

International Clinical Trials Day (ICTD) 2017

‘Data sharing and reuse: attitudes and practices in multinational clinical research’

19 May 2017

Introduction

Celebrated every year on or around May 20th, International Clinical Trials Day (ICTD) is an opportunity for organisations, clinical research professionals, and the public to acknowledge the achievements that result from clinical research and to discuss various trial topics.

Every year, the European Clinical Research Infrastructure Network (ECRIN) hosts a celebration of ICTD, bringing together European and international stakeholders. ICTD 2017 is organised by ECRIN in collaboration with its Portuguese national scientific partner PtCRIN - Portuguese Clinical Research Infrastructure Network and INFARMED, the Portuguese medicines agency.

Meeting title:

ICTD 2017: Data sharing and reuse: attitudes and practices in multinational clinical research

Date(s)/time:

19 May 2017 from 08:30 to 14:00

Location(s):

Auditório Tomé Pires, INFARMED, Avenida do Brasil 53, Lisbon, Portugal

Participants:

Investigators, patient representatives, national authorities, health technology assessment specialists and other stakeholders involved in multinational clinical studies from across Europe and Portugal (around 80 people)

Objective(s):

- To engage with the public, scientific community and decision makers on issues related to (multinational) clinical trials in Europe
- To address in particular issues related to data sharing and re-use

Time:	Description:	Who:
8:15 – 8:45	Coffee / registration	
8:45 – 9:00	Opening session	<p>Jacques Demotes, director general, European Clinical Research Infrastructure Network (ECRIN)</p> <p>H. Luz Rodrigues, representative of the Portuguese Ministry of Health</p> <p>Miguel Castanho, vice-president, Portuguese Foundation for Science and Technology (FCT)</p>
9:00 – 9:15	Access to treatment for hepatitis C virus infection in Portugal	Jorge Rodrigues , pharmacist, Portuguese National Authority of Medicines and Health Products, I.P. (INFARMED)
9:15 – 9:45	Individual patient-level clinical trial data sharing	Christian Ohmann , Network Committee chair, ECRIN
9:45 – 10:15	Added value and cost of data sharing	Barbara Bierer , faculty co-chair of the Multi-Regional Clinical Trials Center of Harvard and Brigham and Women's Hospital (MRCT Center)
10:15 – 10:45	Coffee	
10:45 – 11:15	Incentives for data sharing	Trish Groves , director of academic outreach and advocacy for BMJ, editor in chief of the online only journal <i>BMJ Open</i> , and honorary deputy editor of <i>The BMJ</i>
11:15 – 11:45	Clinical trial data sharing: the patient's perspective	Pedro Silvério Marques , patient representative, Portuguese National Ethics Committee for Clinical Research (CEIC)
11:45 – 12:15	South Regional Cancer Registry – strengths and limitations	Ana Miranda , Portuguese Oncology Institute (IPO-L); coordinator, South Regional Cancer Registries (ROR-Sul)
12:15 – 12:45	Final discussion and wrap-up Round table	<p>Jacques Demotes, director general, ECRIN</p> <p>Helder Mota Filipe, Faculty of Pharmacy, University of Lisbon (FFUL); vice-president, INFARMED</p>
12:45 – 14:00	Lunch	

Useful Information:

Wi-Fi @ INFARMED: User: EVENTOS; Password: M@io2017

Taxis: Teletáxis: 00351 218 11 11 00; Cooptaxis: 00351 217 93 27 56