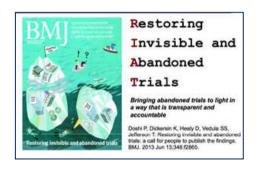


Randomised clinical trials are a milestone of evidence-based medicine and clinical research

During the development of the **ECRAN** project several initiatives attracted the attention to randomised clinical trials







Most of the general population still receive inadequate or poor quality information about the methods of clinical research and misconceptions about clinical trials are common. As a consequence the participation in clinical studies is low

**Knowledge** and **awarenes**s are the basic key words of **ECRAN** project

## **ECRAN**: the objective

The **objective of the ECDAN project** is to develop a portfolio of open educational resources to communicate key messages to general population - but also healthcare professionals, researchers, policymakers and journalists

- The importance of **public understanding** of need and basic principles of clinical trials, fostering active involvement of citizens/patients in trials and of their representatives in trial design
- The need for **independent clinical trials** [not only on drugs !] driven by healthcare and patients needs, to optimise strategies, to support evidence-based clinical practice and to reduce healthcare inequalities
- The need for **transparency and optimal use of data** to allow their use in analysis and meta-analysis, but also to prevent bias in presenting and analysing results
- The need for **multinational cooperation**, taking advantage of Europe's population size, diversity and medical expertises

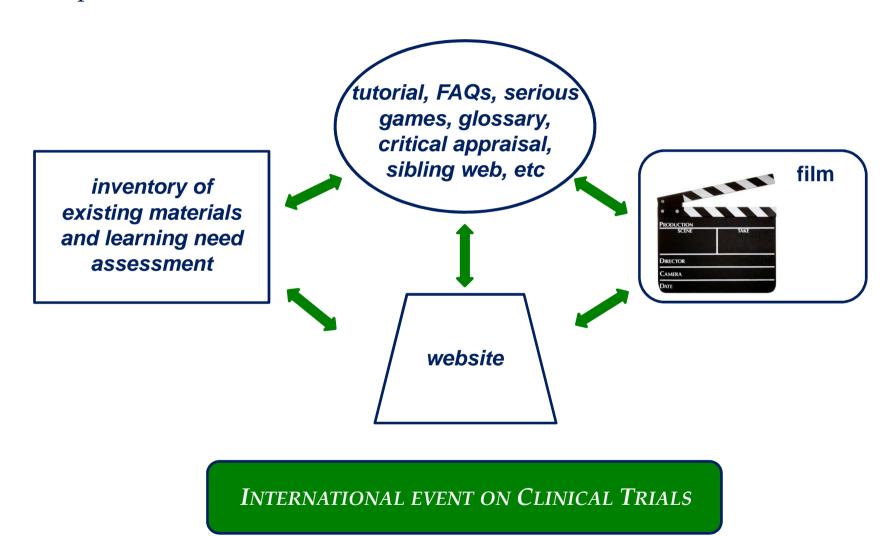
## **ECRAN**: the Consortium

While clinical research takes advantage of a multidisciplinary task, also the **ECDAN** consortium does • methodologists directly involved in clinical trials • researchers involved in partnership collaboration with lay people • representatives of citizens and patients • experts of science communication

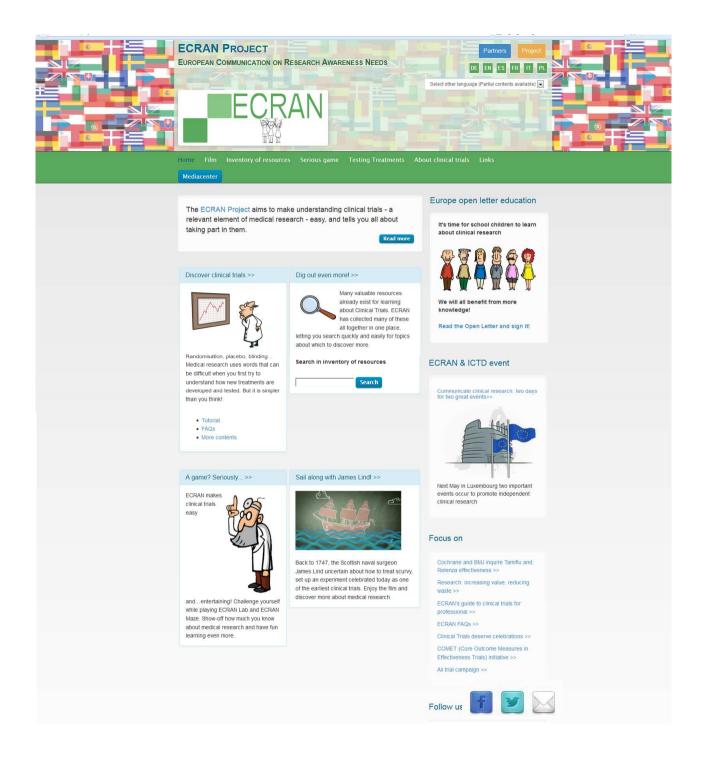


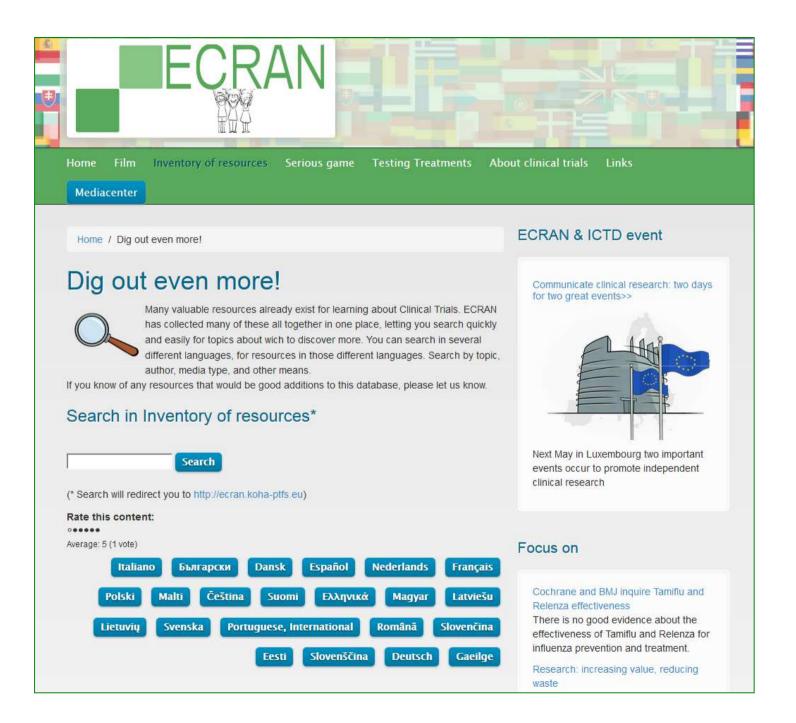
IRCCS Mario Negri Institute **IT** Institut national de la santé et de la recherche médicale **FR** Network of the Coordinating Centres for Clinical Trials **DE** University Hospital of Cologne **DE** Oxford Univ Hospitals NHS Trust **UK** Rigshospitalet Copenhagen Univ Hospital Trial Unit RegH **DK** Univ Medical Center Freiburg **DE** Zadig editorial and publishing company **IT** Cochrane Consumer Network **UK** European AIDS Treatment Group **BE** 

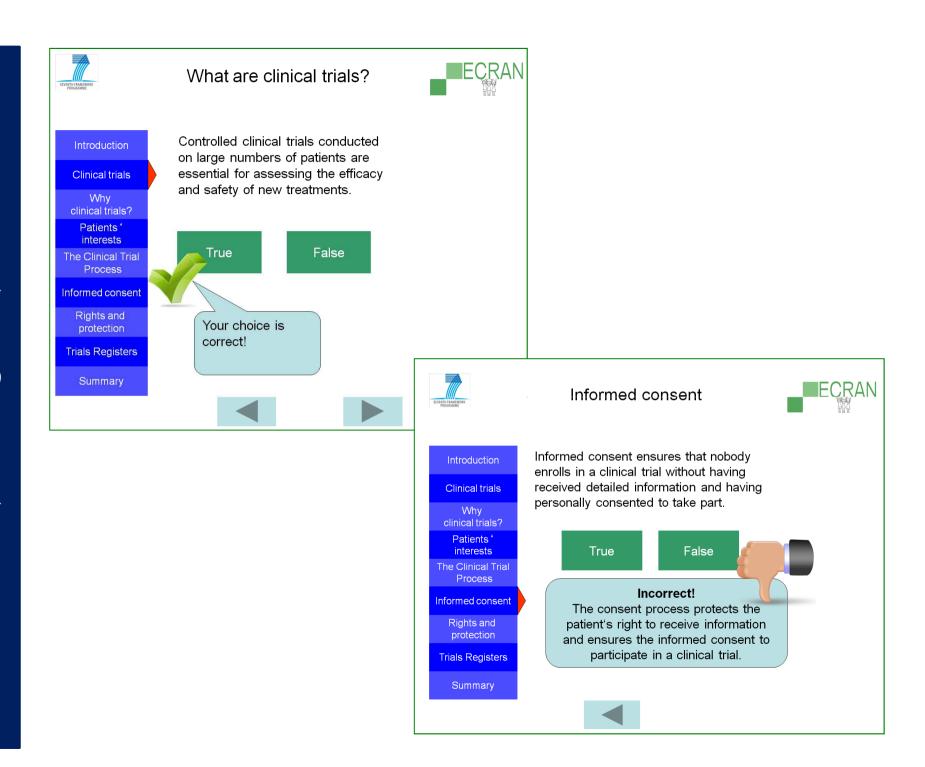
All tools and materials developed by **ECRAN** project shared the following keywords: Uncertainty, Control-comparison, Randomisation, Outcomes, Independent clinical research, and Need for multinational clinical trials



All the materials produced are under Creative Commons Licence







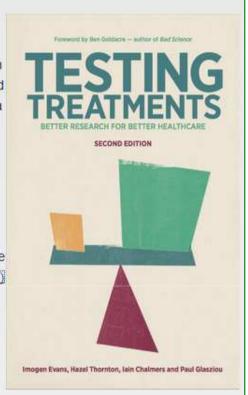
S

## **Testing Treatments**

What are fair tests of treatments? And why do we need them? Testing Treatments is a book written for the public addressing these and many more questions. A first edition was published by the British Library in 2006, and a second edition by Pinter and Martin in 2011. The book has been a great success, and has been translated into several languages. Preparation of the books was done as one element of the work of the James Lind Initiative, a progamme of work coordinated by lain Chalmers, an ECRAN partner, and funded by the English National Institute for Health Research.

The English texts of both editions of the book are available for free download from Testing Treatments Interactive (TTI)

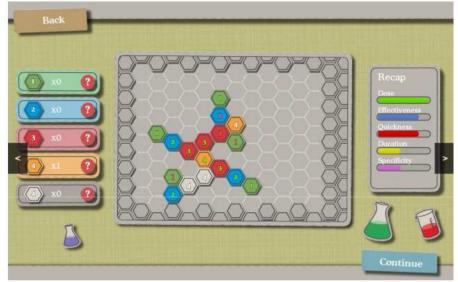
English – and translations are available in sibling TTI websites in other languages. All of the TTI websites also contain audio materials, videos, cartoons and other materials to enhance general knowledge of fair tests of treatments.



#### Translation:

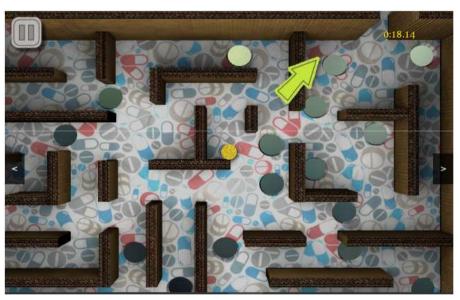
- . English, http://testingtreatments.org
- · Croatian (funded by ECRAN)
- · French (funded by ECRAN), http://fr.testingtreatments.org
- German (funded by ECRAN), http://de.testingtreatments.org
- . Italian (funded by ECRAN), http://it.testingtreatments.org
- Norwegian (funded by ECRAN), http://no.testingtreatments.org
- Polish (funded by ECRAN), http://pl.testingtreatments.org
- · Portuguese, http://pt.testingtreatments.org
- · Spanish, http://es.testingtreatments.org





**ECRAN** Lab

**ECRAN** Maze



**ECDAN** Lab and **ECDAN** Maze are a cross platform games available in 6 languages for iPad, Android Tablet and Windows 8



- Guide to the critical interpretation of clinical trials
- ❖ Valuable multimedia materials
- Valuable papers for further reading
- Valuable sources about medical and statistical terms
- Clinical trial checklists
- Links for professionals
- **ECRAN** project snapshots
- **❖** Newsletter







#### NEWSLETTER

Clinical research concerns everyone: the ECRAN project increases knowledge and awareness on independent clinical research

#### WHO WE

In 2012 the European Commission funded the ECRAN (European Communication on Research Awareness Needs) project, in order to improve the EU citizens' knowledge about medical research and to support their participation in independent and multinational clinical trials

Providing simple and independent information to citizens or patients about clinical trials is sometimes a difficult task. Although some information material already existed, an initiative that specifically develops different tools promoting independent information on clinical research was still missing, in particular at the European level. Through the ECRAN project a variety of material and tools have been developed, in order to attract more attention to this important issue", affirms Paola Mosconi, coordinator of the project at IRCCS-Mario Negri Institute of Milan, Italy.

The ECRAN project aims to inform citizens and patients - but also healthcare professionals, researchers, and journalists - about the importance of public knowledge about clinical trials, the need for independent clinical trials driven by healthcare issues, the need for transparency, optimal use of data and, last but not least, the need for multinational cooperation taking advantage of Europe's population size and diversity. The multidisciplinary consortium of the ECRAN project includes methodologists directly involved in clinical trials, researchers engaged in partnership collaboration with citizens and patients, representatives of citizens and patients, and experts of science communication

### FREE, EASY-TO-UNDERSTAND FILM ON CLINICAL TRIALS IN 23 LANGUAGES

One of the valuable ECRAN tools is characterized by an 5-minute <u>animated film on clinical trials</u>, dubbed in all 23 official European languages

http://www.ecranproiect.eu/en/content/sail-along-iames-lin



It has been developed thanks to the collaboration among the ECRAN partners, the RAI-SuperQuark and the Studio Bozzetto &Co. Sailing along with Scottish naval surgeon James Lind in 1747. The animation film explains how his determined effort to treat scurry finally turned out to be one of the earliest clinical trials in history and helped to lay the foundation for modern clinical experiments. The modular structure of this animation allows for display in full length or can be split into the following eight sections:

- A clinical trial
- · Ethics committees
- Randomization
- Double blinding
   Analyzing the data
- One trial is not enough
- Outcomes important to patients
- · Some pitfalls of trials



@2014 ECRAN | Project No. 105202 | Start date: 2012-09-01 | End date: 2014-08-31 | http://www.ecranproject.eu

# **ECRAN**: the petition



Home / Europe open letter education

### Europe open letter education

To all European Ministers of Education; European Heads of Schools; European Teachers; and Parents.

Re.: Introduction to clinical research as part of the school education for all European school pupils for three consecutive years around the ages of 14, 15, and 16 years.



As a coalition of patient organisations, physicians, health researchers, and health journalists we are concerned that public general knowledge about clinical research is very sparse, and virtually absent about why independent randomised clinical trials are needed. Most people will encounter clinical research for the first time when they or relatives are invited to participate in randomised clinical trials or other types of clinical research. This invitation often follows devastating news of the diagnosis of a serious health problem. We propose that steps should be taken to equip European citizens with information and understanding which will help them deal effectively with the challenges in such situations. We want patients and their relatives to become better equipped to withstand the blows of a serious diagnosis followed by an invitation to participate in clinical research designed to deal with

#### Europe open letter education

It's time for school children to learn about clinical research



We will all benefit from more knowledge!

Read the Open Letter and sign it!

#### ECRAN & ICTD event

Communicate clinical research: two days for two great events>>

# **ECRAN**: dissemination



**WEBLINKS** 782 links from 42 sites

WEBSITE 61020 pages visited, average session duration of 3 minute

# **ECRAN**: dissemination and implementation

### Easy task

- ♦ link at **ECRAN** website, facebook, twitter
- presentation of tools and materials through mailing lists
- public conferences
- ♦ distribution of **ECRAN** leaflets
- ♦ involving Ethics Committees
- pubblications on journals or mag
- ♦ **ECRAN** materials as part of phy
- ♦ involve young people
- ♦ sign public petition to European
- ♦ distribute **ECRAN** film in nation
- ♦ involve European, National and

grotral Hospital

A. N. Other

THE PATIENT REVOLUTION BEGIN

Hard task



Alicja Szofer-Araya, Giorgio Barbareschi, Christa Bast, Koen Block, Insa Bruns, Giulia Candiani, Sergio Cima, Cinzia Colombo, Nikos Dedes, Berit Grevstad, Paolo Griselli, Christine Kubiak, Marco Milano, Catherine Mcllwain, Matt Penfold, Niccolò Pieri, Nils Post, Anna Roberto, Maria Rosa Valetto, Studio Bozzetto and Co, RAI SuperQuark

