



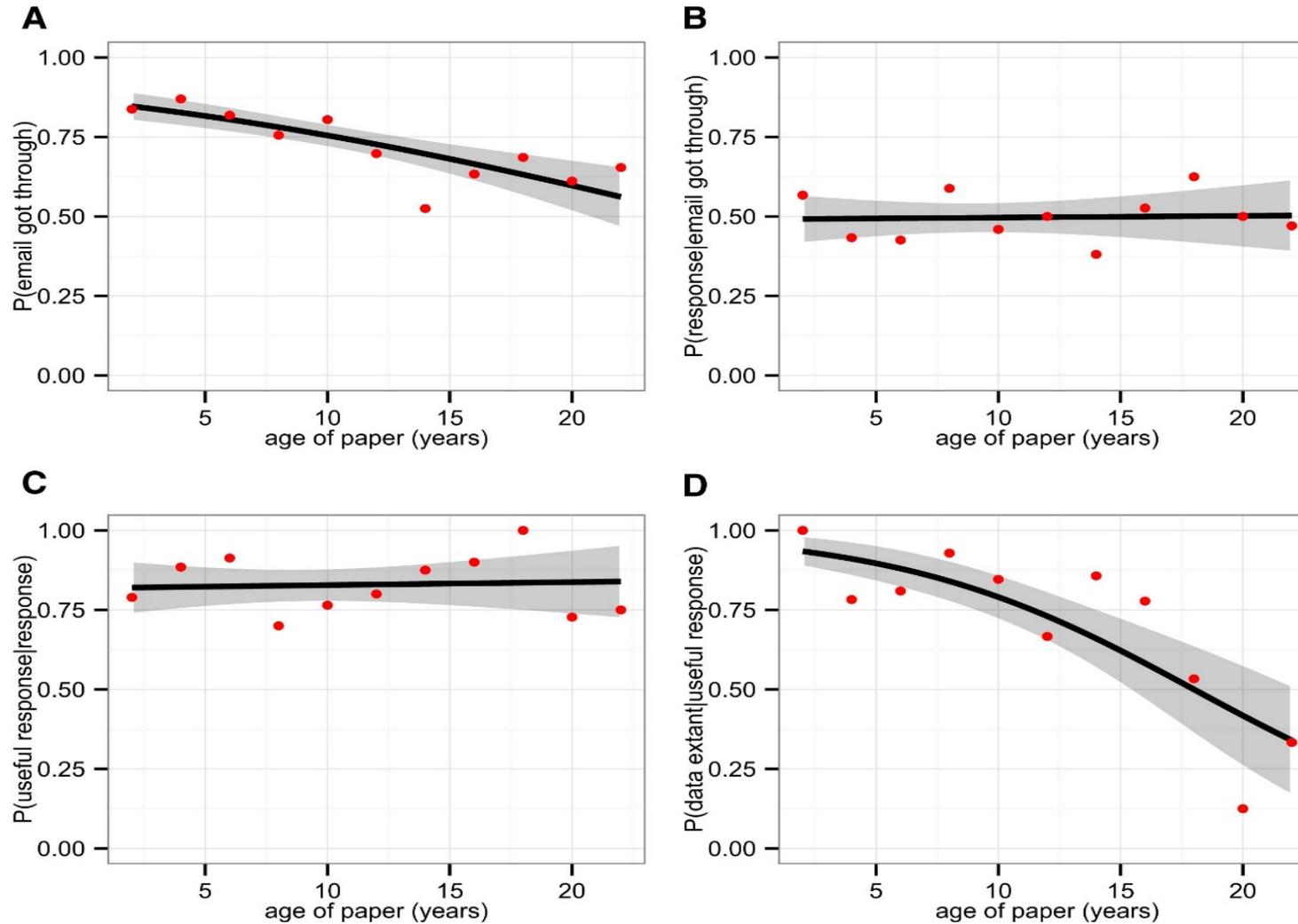
Integrazione dei principi FAIR nel processo di ricerca biomedica: la creazione del Registro Regionale della Regione Sardegna

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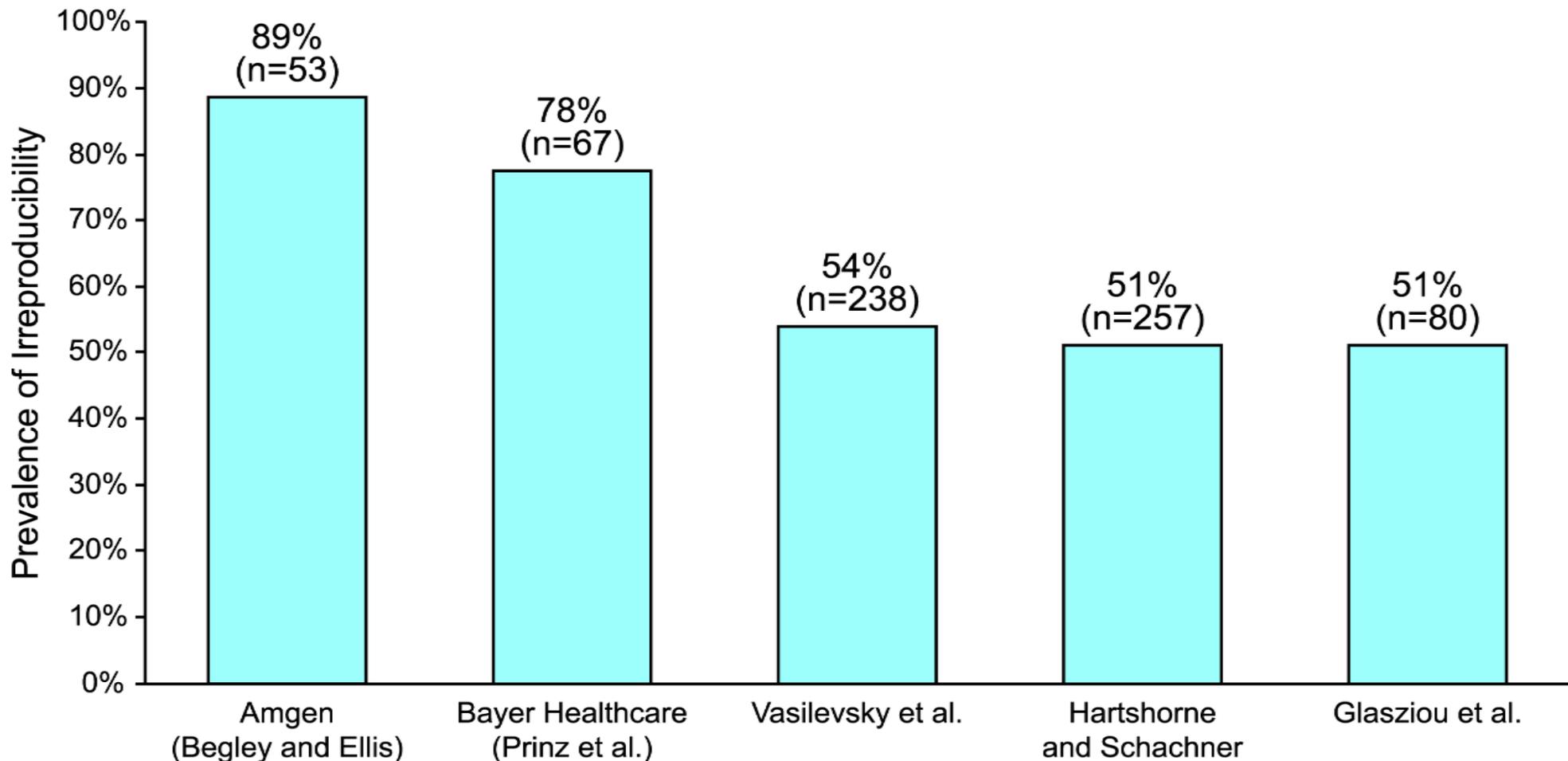


Riuso dei dati nella ricerca: disponibilità



Fonte: *The Availability of Research Data Declines Rapidly with Article Age*, Vines et al., *Curr Biol.* 2014 Jan 6;24(1):94-97

Riuso dei dati nella ricerca: riproducibilità



Fonte: Freedman LP, Cockburn IM, Simcoe TS (2015) The Economics of Reproducibility in Preclinical Research. PLoS Biol 13(6): e1002165

Cosa è successo di recente

The screenshot shows the homepage of The New England Journal of Medicine. At the top, there are navigation links for 'SUBSCRIBE OR RENEW', a search icon, and a menu icon. Below this, there are several featured articles and a 'POINTS OF VIEW' section. The main article is an editorial titled 'Expression of Concern: Mehra MR et al. Cardiovascular Disease, Drug Therapy, and Mortality in Covid-19. N Engl J Med. DOI: 10.1056/NEJMoa2007621.' by Eric J. Rubin, M.D., Ph.D. Below the article title, there are links for 'References' and 'Citing Article'. To the right, there are 'Metrics' and 'Related Articles' sections. Below the main article, there is a section for 'THE LANCET' with a 'Log in' button and a 'Register' button. The main article is a retracted article titled 'RETRACTED: Hydroxychloroquine or chloroquine with or without a macrolide for treatment of COVID-19: a multinational registry analysis' by Prof Mandeep R Mehra, MD, et al. The article is dated May 22, 2020, and has a DOI of https://doi.org/10.1016/S0140-6736(20)31180-6. The article is marked as 'RETRACTED' in large red letters. Below the article title, there is a 'Summary' section with a 'Background' and 'Methods' subsection. The 'Background' section states: 'Hydroxychloroquine or chloroquine, often in combination with a second-generation macrolide, are being widely used for treatment of COVID-19, despite no conclusive evidence of their benefit. Although generally safe when used for approved indications such as autoimmune disease or malaria, the safety and benefit of these treatment regimens are poorly evaluated in COVID-19.' The 'Methods' section states: 'We did a multinational registry analysis of the use of hydroxychloroquine or chloroquine with or without a macrolide for treatment of COVID-19. The registry comprised data from 671 hospitals in six continents. We included patients hospitalised between Dec 20, 2019, and April 14, 2020, with a positive laboratory finding for SARS-CoV-2. Patients who received one of the treatments of interest within 48 h of diagnosis were included in one of four treatment groups (chloroquine alone, chloroquine with a macrolide, hydroxychloroquine alone, or hydroxychloroquine with a macrolide), and patients who received none of these treatments formed the control group. Patients for whom one of the treatments of interest was initiated more than 48 h after diagnosis or while they were on mechanical ventilation, as well as patients who received remdesivir, were excluded. The main outcomes of interest were in-hospital mortality and the occurrence of de-novo ventricular arrhythmias (non-sustained or sustained ventricular tachycardia or

Paper in un primo momento accettato e successivamente ritrattato in seguito alla mancata disponibilità dei dati per la verifica dei risultati

Parola chiave: FAIR



« If a game competition is fair, it is done according to the rules »

«If something is fair, it is reasonable and is what you expect or deserve»

SCIENTIFIC DATA

Amended: Addendum

OPEN

Comment: The FAIR Guiding Principles for scientific data management and stewardship

SUBJECT CATEGORIES

- » Research data
- » Publication characteristics

Mark D. Wilkinson *et al.*''

Received: 10 December 2015
Accepted: 12 February 2016
Published: 15 March 2016

There is an urgent need to improve the infrastructure supporting the reuse of scholarly data. A diverse set of stakeholders—representing academia, industry, funding agencies, and scholarly publishers—have come together to design and jointly endorse a concise and measurable set of principles that we refer to as the FAIR Data Principles. The intent is that these may act as a guideline for those wishing to enhance the reusability of their data holdings. Distinct from peer initiatives that focus on the human scholar, the FAIR Principles put specific emphasis on enhancing the ability of machines to automatically find and use the data, in addition to supporting its reuse by individuals. This Comment is the first formal publication of the FAIR Principles, and includes the rationale behind them, and some exemplar implementations in the community.

Supporting discovery through good data management
Good data management is not a goal in itself, but rather is the key conduit leading to knowledge discovery and innovation, and to subsequent data and knowledge integration and reuse by the

Che cosa ci aspettiamo dal concetto «fair» applicato ai cosiddetti «*research objects*»?

Sia gli umani sia le macchine possono «giocare» con i risultati

Machine Actionability

Findable

Dati e metadati devono avere un identificativo univoco e persistente

I dati devono essere descritti da un insieme di metadati sufficientemente ampio

I metadati devono includere in maniera esplicita l'ID dei dati ai quali sono riferiti



Created by monikik from Noun Project

Accessible

Dati e metadati accessibili tramite il loro ID univoco e protocolli aperti

I metadati devono essere sempre accessibili, anche qualora i dati non fossero più disponibili

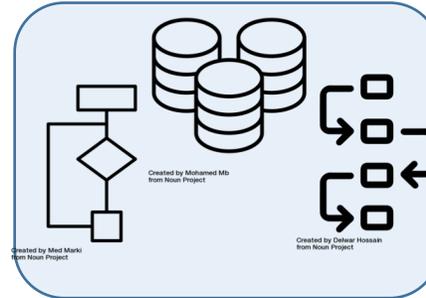
Attenzione: FAIR data non significa open data!
as open as possible, as closed as necessary

Interoperable

Dati e metadati utilizzano un linguaggio standard per la rappresentazione dei concetti

Dati e metadati utilizzano nomenclatori che rispettano essi stessi i principi FAIR

Dati e metadati utilizzano riferimenti ad altri dati e metadati



Created by Med Mark from Noun Project

Created by Mohamed Mb from Noun Project

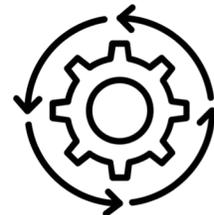
Created by Debar Hossain from Noun Project

Reusable

Dati e metadati descritti da un numero di attributi sufficientemente ampio

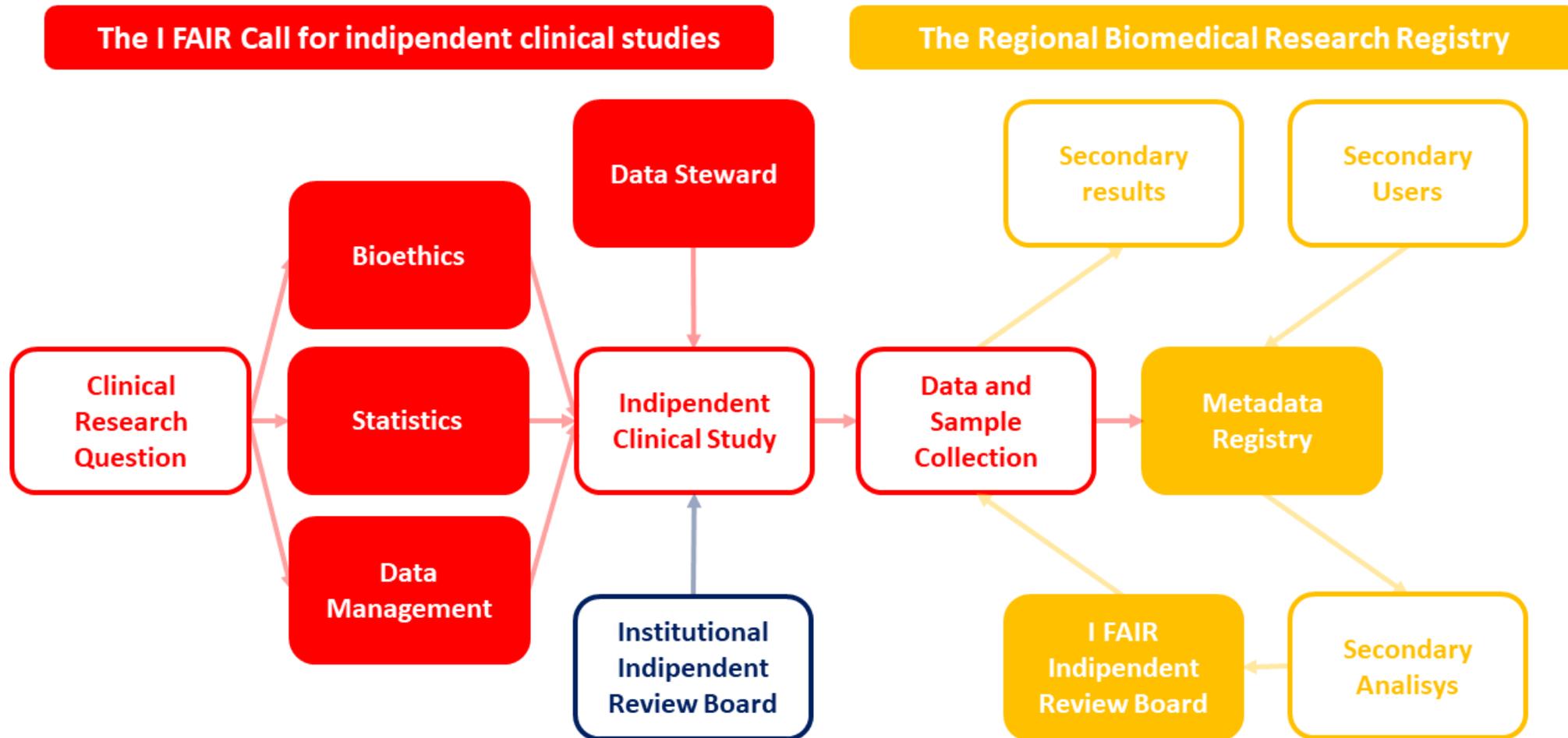
Dati e metadati associati alle loro informazioni di *provenance*

Dati e metadati utilizzano vocabolari e nomenclatori noti all'interno del dominio

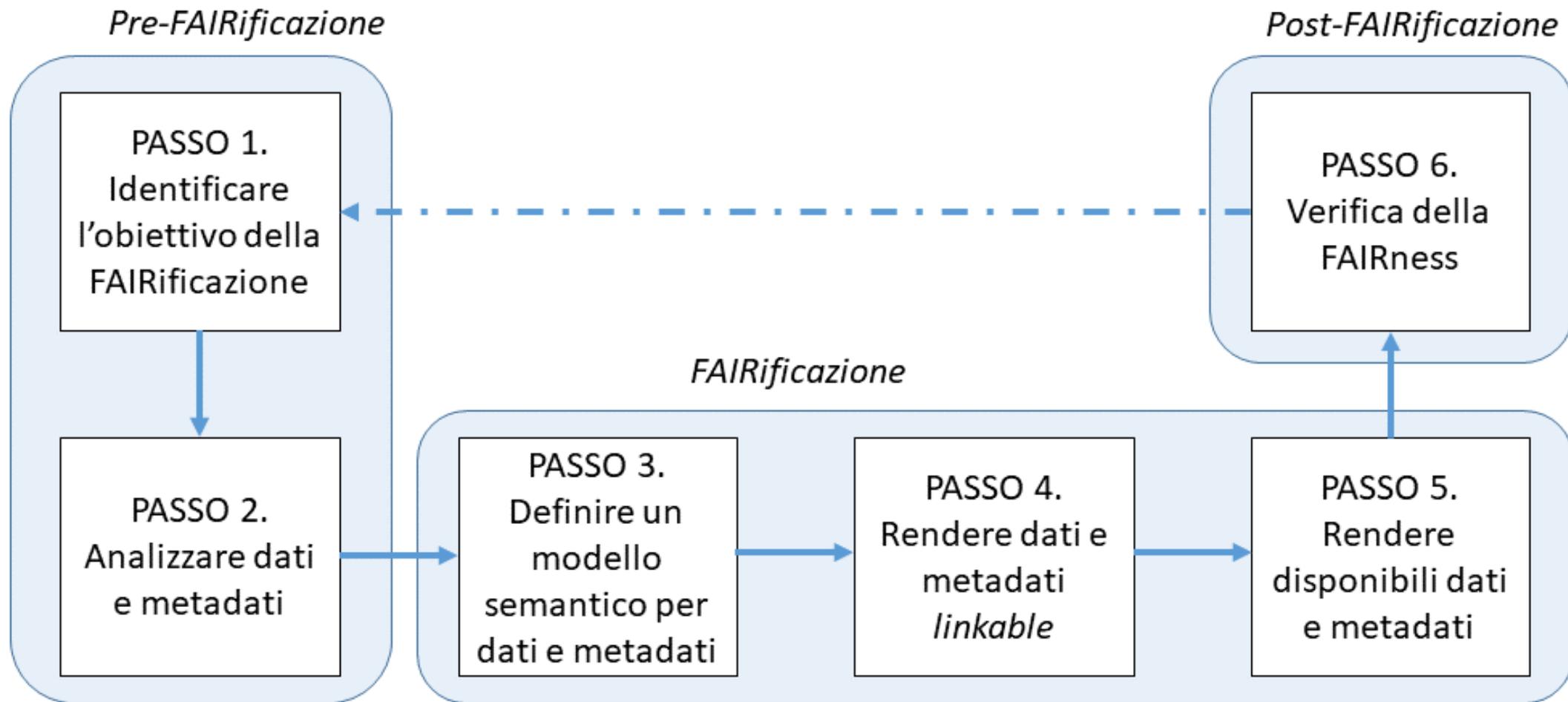


Created by Vectors Market from Noun Project

Il programma IFAIR e il Registro per la Ricerca Biomedica della Regione Sardegna



Il processo di FAIR-ificazione



Altre parole chiave: modello semantico e ontologia

MODELLO SEMANTICO

Un modello in cui sia i (meta) dati sia le loro valorizzazioni sono univocamente definiti tramite ontologie

ONTOLOGIA

Formalizzazione dei concetti e delle relazioni tra di essi all'interno di uno specifico dominio (es. clinico/biomedico)

Patologia	Area Terapeutica
Epilessia	Neurologia

Patologia

DCAT

<https://www.w3.org/ns/dcat#theme>

Epilessia

MESH

<http://purl.bioontology.org/ontology/MESH/D004827>

who is the manager of the team who won champions league in 2010

Tutti Notizie Immagini Video Shopping : Altro Impostazioni Strumenti

Circa 131.000.000 risultati (1,02 secondi)

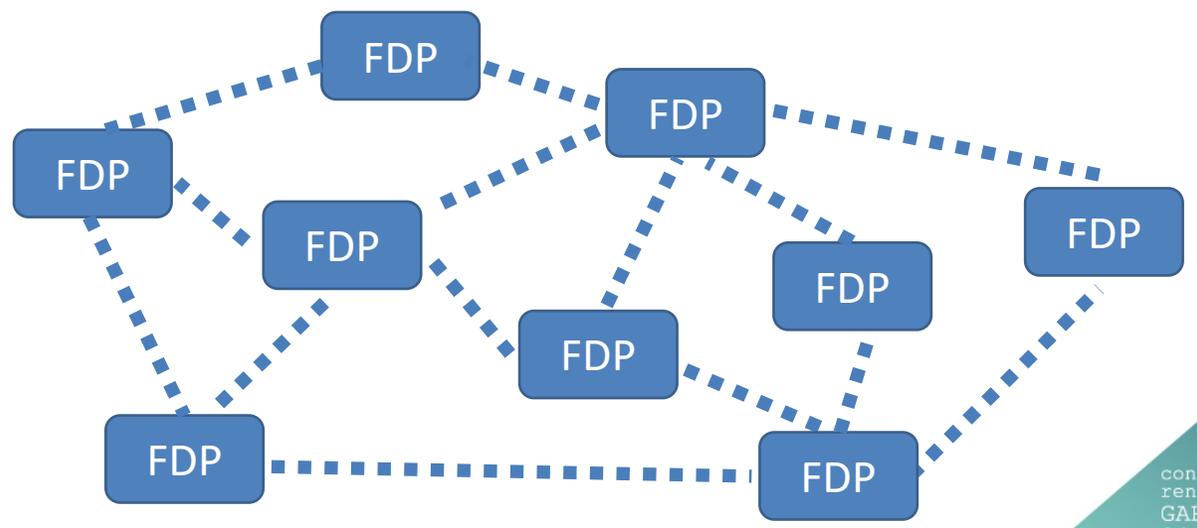
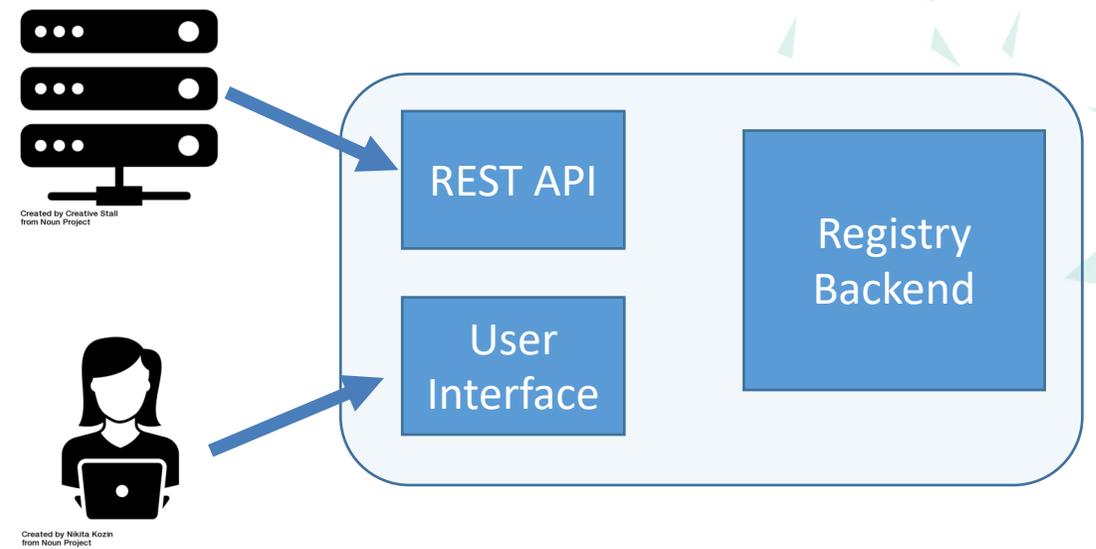
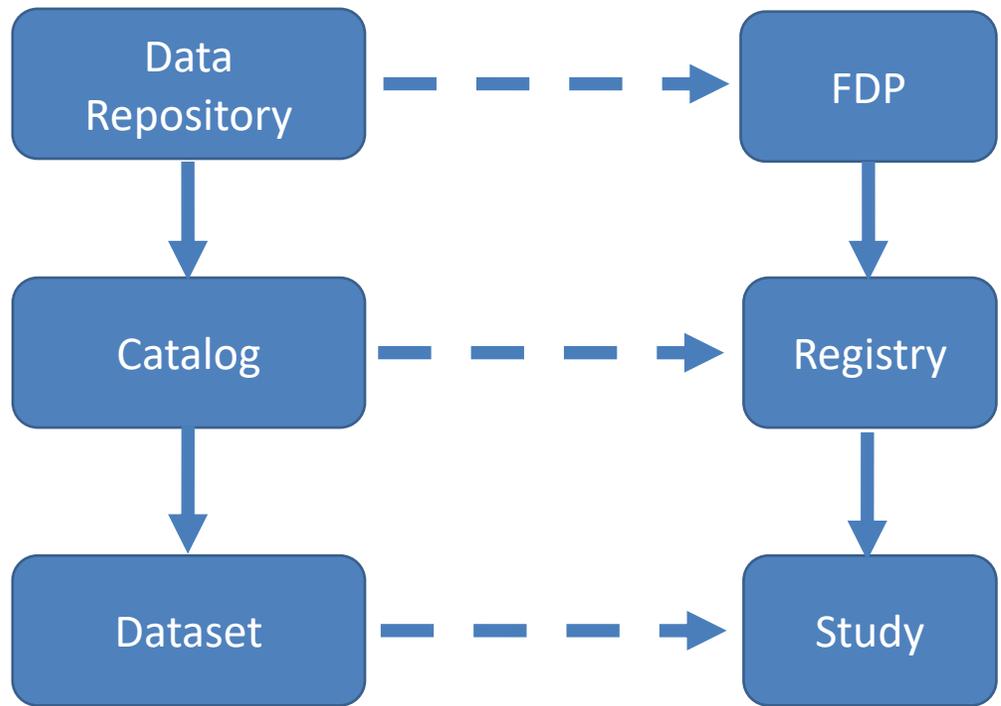
Suggerimento: Cerca risultati solo in italiano. Puoi specificare la lingua di ricerca in Preferenze.

José Mourinho

José Mourinho revealed after the match that he would likely resign from Inter to pursue the goal of being the first **manager to win the Champions League** with three clubs.



Implementazione del registro: architettura



Implementazione del registro: machine actionability

Sardinian Registry of Biomedical Research

This is the Sardinian Registry of Biomedical Research. Here researchers can get information about biomedical studies being conducted in the region of Sardinia

[Back](#)

FOO BAR TITLE

Institution

Experimentation Center
Department of General Surgery

Start Date

2019-10-11

Status

Planned

Ethic Committee

Sacred Hearth Ethic Committee

Hospital

Sacred Heart

End Date

Contacts

Principal Investigator

Chris Turk



Data Steward

[Download Study Documents](#)

Details

Gallbladder coalcolosis is present in approximately 10-15% of the adult adult population in Western countries. The gold standard in the management of symptomatic cholelithiasis is laparoscopic cholecystectomy. laparoscopic cholecystectomy. Nowadays, the technique surgical... technique of laparoscopic cholecystectomy has become widespread and standardised. In recent years, the organisational model (or care setting) has evolved. the organisational model (or care setting) has evolved. which has now mostly changed from ordinary hospitalisation to one-day +

Disease

Cholelithiasis

Therapeutic Area

Liver Diseases, Cholestasis, Intrahepatic

Cohort Size

300

Collected Data Type

Sample from organism, Medical Record, Physiological Measurement Data, Survey data

Collected Specimen Type

Serum, Whole blood, Plasma, Tissue

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adult population in Western countries. The gold standard in the
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laparoscopic cholecystectomy. Nowadays, the technique
surgical technique of laparoscopic cholecystectomy has become
widespread and standardised. In recent years, the organisational model (or care setting) has evolved.
the organisational model (or care setting) has evolved.
which has now mostly changed from ordinary hospitalisation to one-day surgery with discharge within 24 hou
surgery with discharge within 24 hours of the procedure. The delay
discharge on the first postoperative day of patients undergoing
patients undergoing VLC, however, remains an obstacle to the
improving the quality of care in this surgical procedure.
surgical procedure. This study aims to identify the
clinical, organisational and social factors that may lead to a delay in the
a delay in the discharge of patients undergoing planned VLC
This study aims to identify the clinical, organisational and social factors that may lead to a delay in th
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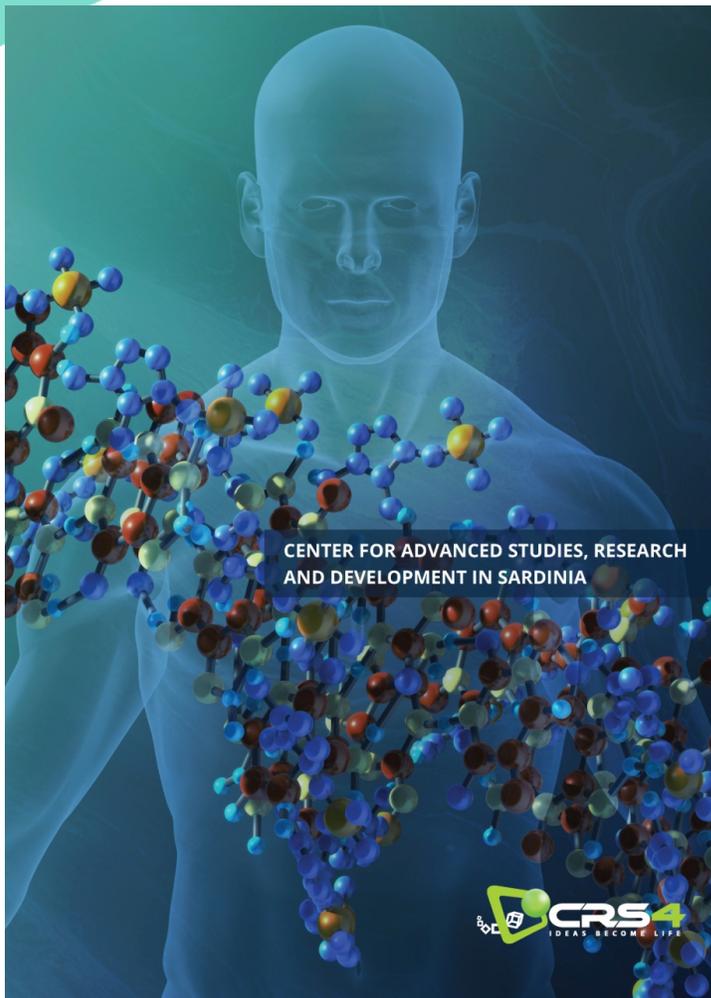
Conclusioni e sviluppi futuri

Stato attuale: registro popolato con i metadati dei primi 18 studi facenti parte del programma IFAIR

Il modello semantico verrà via via arricchito con nuovi metadati, anche specifici di ogni singolo studio (es. tipologie di esami clinici/procedure presenti nei dataset di ogni singolo studio)

Stiamo costruendo una procedura per la valutazione del grado di FAIRness del Registro, sulla base di algoritmi allo stato dell'arte

Il Semantic Metadata Model e l'applicazione web del Registro verranno pubblicati in Open Source



Grazie per
l'attenzione!

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Acknowledgements: Questo lavoro è stato parzialmente supportato dalla Regione Sardegna, dallo European Joint Programme on Rare Disease (grant agreement N. 825575) e da Sardegna Ricerche all'interno del "Programma I FAIR" (FESR 2014/2020), che coinvolge Sardegna Ricerche, l'Università degli Studi di Cagliari e l'Università degli Studi di Sassari