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**New Challenges for
Europe's Cohesion**

CROSS-BORDER PILOT PROJECTS TO BOOST INNOVATION IN THE HEALTH SYSTEM THROUGH DATA SHARING



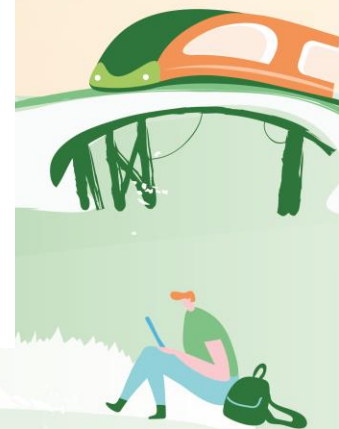
Wednesday, October 12, 2022



from 14:30 to 16:00



#EURegionsWeek





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CROSS-BORDER PILOT PROJECTS TO BOOST INNOVATION IN THE HEALTH SYSTEM THROUGH DATA SHARING

ZOOM SESSION RULES:

- Keep your microphone muted
- If you have questions for the speakers, leave them in the chat.

They will be answered during the Q&A session





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**New Challenges for
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Ms. LAURA COMELLI
Managing Authority
Interreg Italy-Slovenia Programme

MODERATOR



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Ms. BARBARA ZILLI
Autonomous Region Friuli Venezia
Giulia
Regional Minister for Finance and EU
Affairs

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ISE-EMH

Progetto standard co-finanziato dal Fondo europeo di sviluppo regionale
Standardni projekt sofinancira Evropski sklad za regionalni razvoj

Mr. MATJAŽ GAMS

Head of department of Intelligent Systems
Jožef Stefan Institute



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C3B

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AGENDA:

- Welcome
- Competitions as a quality indicator
- Slovenian health system
- How to upgrade Slovenian health system
- Insieme platform (ISE-EMH) as a solution
- Questions for the audience

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ISE-EMH, Italian-Slovene ecosystem for electronic and mobile health

Duration: 28 months

Start date: March 1, 2020

End date: June 30, 2022

Budget: 882.351,00 €

Budget FERS: 749.998,34 €

6 partners:

Lead Partner: Arctur Računalniški inženiring d.o.o.

Project partner 1: Istituto di Ricovero e Cura a Carattere Scientifico materno infantile Burlo Garofolo di Trieste

Project partner 2: Institut "Jožef Stefan"

Project partner 3: Polo Tecnologico Alto Adriatico

Project partner 4: Università Ca' Foscari Venezia

Project partner 5: Robotina, Podjetje za inženiring, marketing, trgovino in proizvodnjo d.o.o.

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Objectives:

- To develop an ICT system in the field of EMH in order to provide innovative services, applications, and products.
- To establish public-private partnership (SI-IT) and transfer of cross-border knowledge.

Main results:

- A platform developed to connect products and services the backbone of the ecosystem.
- Integration and connection of existing products services and systems through the platform into a complete ecosystem.

<https://ise-emh.eu>

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Publications in top scientific journals in 2020

- Regarding journal impact factor
- 1000 staff: physics, chemistry, electronics

New Challenges for
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Total JSI articles:
1207

61%

of all JSI articles were published in top 25% scientific journals.

34%

of all JSI articles were published in top 10% scientific journals.

18%

of all JSI articles were published in top 5% scientific journals.

2%

of all JSI articles were published in top 1% scientific journals.

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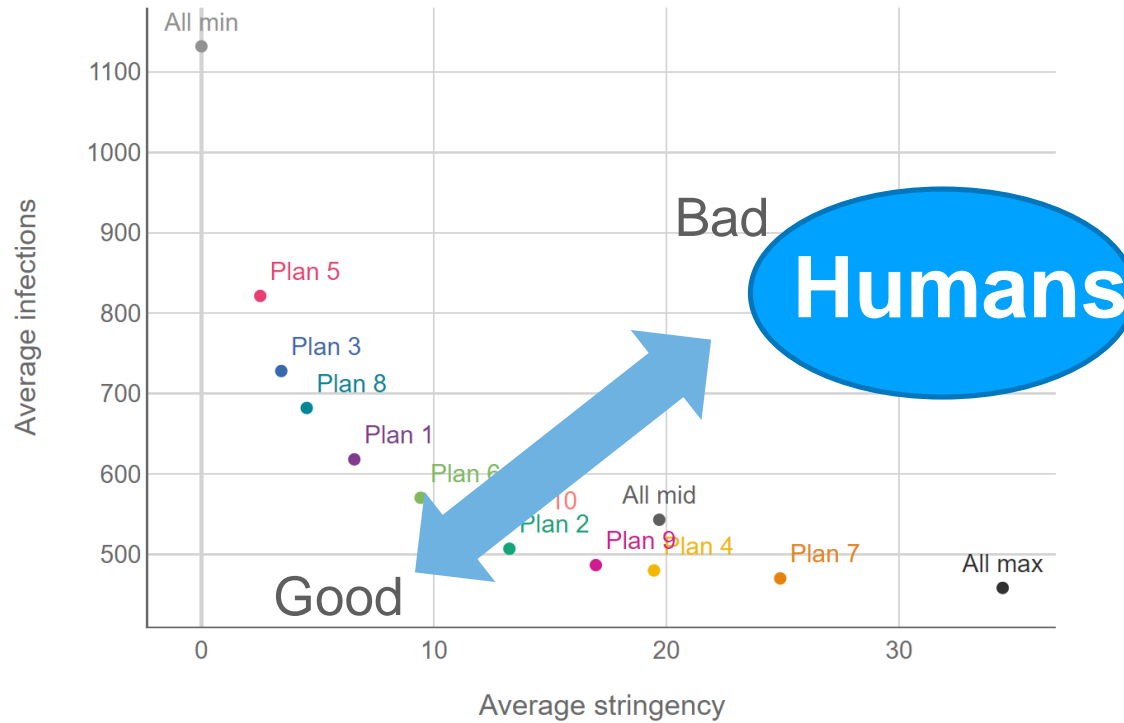
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Humans : AI + computers; COVID, XPRIZE,
AI 20% better than humans; 250.000 prize, 5/10



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New Challenges for
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Current situation in Slovenia:

- In Slovenia in 2019 there were 6.812 physicians (i.e. doctors), 1.514 dental physicians, 7.996 nurses and 13.468 technicians.
- In the last ten years only : physicians + 37 %, dental physicians + 20 %, nurses + 84 % and technicians 8 %.
- At the same time, the waiting times for operations increased significantly and the number of citizens without personal (family) doctor increased from practically 0 to 130.000 in 2022.
- Studies show that introduction of computers did not help much in terms of human-patient time (computers take time from doctors)
- In a recent presentation in the National Council doctors claimed that around 2 hours per day are need to deal with all reports.

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Current situation in Slovenia:

In a recent presentation in the National Council doctors claimed that around 2 hours per day are needed to deal with all reports.

Wrong use of computers!

Demographic issues:

- Fertility rate 2.1 /1.6 ?
- Extinction in long term, 200 years
- Decrease of quality in short term: too many old, too little young, too little doctors

Solution: EMH!

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New Challenges for
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How to improve Slovenian health system

- 130.000 patients without a personal doctor
- Establish a center that provides functions of personal doctors to the patients through electronic means.
- All doctors (Uber style) are connected and can provide help to any of the 130.000 patients.
- Estimated time: a couple of months.

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New Challenges for
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How to improve Slovenian health system

- Introduce one national data and service medical warehouse and edge computing.
- All medical data and services should be compatible instead of over 30 incompatible system 5 years ago.
- Edge computing, data warehouse.

Introduce AI and computers as assistants:

A patient describes personal problems/symptoms in advance. When the meeting with the doctor starts, the doctor has already on the screen all the necessary data with the proposed list of diagnoses, medications and advices. If all is OK, the doctor just confirms it.

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Insieme platform as a solution: <https://ise-emh.eu>

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Components of the Insieme platform:

Example of a service: Rosacea

List of medical
specializations



- List of services
- Ageing
- Applications
- Dermatology
- Oncology
- Hormonal disorders
- Mental illness and cognitive impairment
- Related platforms
- Respiratory diseases
- Digestive tract and metabolism
- Infections, coronavirus
- Neurological diseases

Rosacea

Rosacea is a common chronic inflammatory disease that presents with recurrent flushing, erythema, telangiectasia, papules or pustules on nose, chin, cheeks, and forehead. Both a prompt diagnosis and appropriate therapeutic interventions are required to prevent permanent scarring, persistent erythema, and ocular sequelae. The incidence of rosacea is estimated to be greater than 5% in the general population, shows a female predominance and generally occurs in adults between 30 and 50 years of age. Heat, solar radiations, stress and alcohol consumption are considered as potent triggers for the onset of the clinical signs of rosacea and should therefore be strongly avoided. Both the usage of sun protection factors and of moisturizing skin care products are highly recommended.

Professional help:

- Azienda sanitaria universitaria Giuliano Isontina: SC (UCO) Clinica di Chirurgia Plastica. Trieste, Ospedale di Cattinara, Strada di Fiume 447, Torre Chirurgica, 9° piano. T: 040 3994258. email: elena.vattovani@asugi.sanita.fvg.it
- Istituto Dermatologico Europeo Milano. T: 02.5492511. email: info@ide.it
- Skin Doctors' Center

Applications:

- Diary for disease monitoring

Associations:

- National Rosacea Society

Scientific articles:

- Rosacea: a review (Pharmacy and Therapeutics).
- Rosacea Treatment: Review and Update (Dermatology and Therapy).

Patient's story:

- 11 People Describe What It's Really Like to Have Rosacea | SELF
- What it's really like to live with rosacea
- 8 Women Reveal What It's Like To Live With Rosacea | Prevention
- success story | Rosacea.org

Video

- Living with rosacea - Lex Gillies
- By Gabriella // Living With Rosacea - No Makeup & Sensitive Skin Chat
- Experience My Rosacea
- LIVING WITH ROSACEA! + HOW I COPE
- Eudelo - Rosacea Testimonial

Additional information:

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Components of the Insieme platform:

- Insieme bot (on right)
- Online human help (bottom)

Online human help

Use live chat to contact medical professionals, ask questions, and get medical advice from qualified health specialists.

Call centers Active users

Ageing

Dermatology
Ask a Question

Oncology

Oncology
Ask a Question

bot Bot

user1687799398 @user1687799398 Owner 8:23 PM
x-ray of knee

InSieme bot @insieme-bot.bot 8:23 PM
Did you mean:

- None of the above
- Knee arthrodesis
- Diagnostic and therapeutic knee arthroscopy
- CT of the knee
- Another X-ray imaging of the skeleton
- Knee endoprosthesis
- Infrared imaging

Message

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Components of the Insieme platform:

- Basic search
- Advanced search (example bottom)

Asthma Respiratory diseases

Subfield Region Tags

Symptom

Basic search

SEARCH

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Thank you!

<http://dis.ijs.si>
matjaz.gams@ijs.si

dis

- Agent and multiagent systems
- Computational intelligence
- Ambient intelligence

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Video testimonial



<https://www.youtube.com/watch?v=6SSfieS7scU>

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Mr. DEVIS PASCUT
Senior Researcher
Fondazione Italiana Fegato – ONLUS



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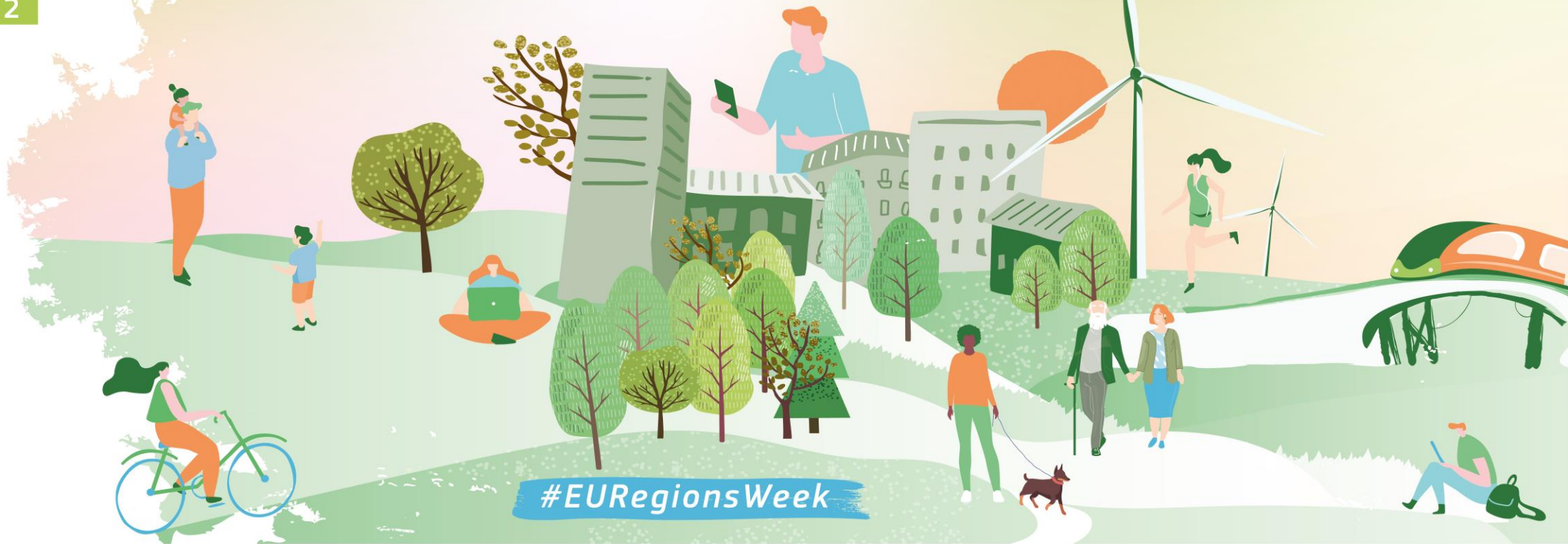
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Cross-border pilot actions to boost innovation in the health system through data sharing



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CROSSBORDER PLATFORM FOR EFFICIENT MANAGEMENT OF BIOBANKS – C3B



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PROJECT PARTNERS



LP: Italian Liver
Foundation – NPO



PP4: ULSS3 Serenissima - Regional Center
for Diagnostic, Prognostic and
Predictive Biomarkers (CRIBT)



Zavod Republike Slovenije
za transfuzijsko medicino
Blood Transfusion Centre of Slovenia

PP2: Blood Transfusion
Center of Slovenia

Univerza v Ljubljani



PP5: University of Lubiana, Faculty of
Medicine



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DI TRIESTE

PP3: University of Trieste
Department of medical
sciences



PP6: Experteam srl

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ASSOCIATED PARTNERS

Ministry of Health of Republic of Slovenia

Region Friuli Venezia Giulia, Directorate for Healthcare, social policies and disabilities

Agency for medicinal products and medical devices of the Republic of Slovenia

PROJECT BUDGET

FESR

MONTHS

796.195,66 €

676.766,31 €

18

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AIM



Identification and adoption of joint solutions for the **harmonization of cross-border biobanks**, through an inter-institutional collaboration, that will lead to the creation of the first pilot cross-border biobank of biological samples.

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The BIOBANK is a collection of biological material and **ASSOCIATED DATA**, **voluntarily donated** by groups of individuals, that are stored in an organized system and at low temperatures for **USE in RESEARCH.**



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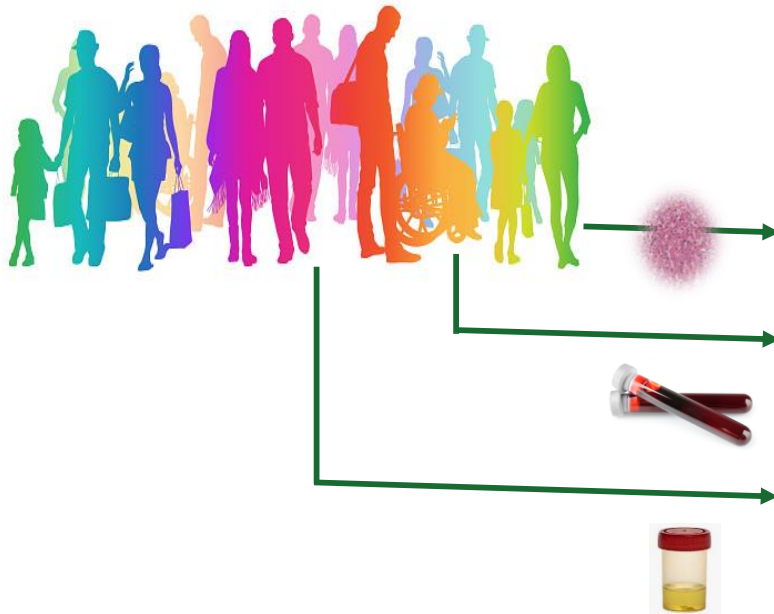
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FROM THE COMMUNITY FOR THE COMMUNITY



BIOBANK

- Collection of samples and data
- Storage
- Distribution



Drugs
Diagnosis
Biomarkers

INNOVATION

PERSONALIZED MEDICINE



A SERVICE FOR
THE COMMUNITY

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BIOBANKS TO BOOST RESEARCH AND HEALTHCARE

	<ul style="list-style-type: none"> □ ... □ Staff □ Informed consent □ Access procedure □ Response time □ Protocols & standard □ Networks & PPS □ Participant involvement □ Quality management 	<ul style="list-style-type: none"> □ ... □ Type of population □ Type of patients □ Controls □ Amount □ Events □ Efficacy endpoints □ Inclusion criteria 	<ul style="list-style-type: none"> □ ... □ Type of material □ Quality □ Sample annotation □ Amount □ Sample frequency □ Uniqueness □ FAIRness □ Storage □ Allowed use 	<ul style="list-style-type: none"> □ ... □ Type of data □ Data linkages □ Quality □ Amount □ Data frequency □ Uniqueness □ FAIRness □ Storage □ Allowed use 	<ul style="list-style-type: none"> □ ... □ User support & consultancy □ Participant services □ Sample/data analyses □ Sample and data management □ 3rd party training
Value categories	Organisation	Participants	Samples	Data	Services
	Education	Output	Economic value	Brand value	(Re)use
	<ul style="list-style-type: none"> □ Education of staff □ Education of professionals □ Education of users □ Education of general public □ internships & students □ ... 	<ul style="list-style-type: none"> □ Prevention □ Diagnostics □ (Clinical) guidelines □ Treatments □ Research papers □ Patents □ Research projects □ Clinical trials □ Grants □ Consortia □ ... 	<ul style="list-style-type: none"> □ Nr. of jobs/FTE □ Nr. of spin-offs □ Return on investment □ Resource savings □ Risk reduction □ Pricing □ Budget □ Revenues □ Infrastructure □ ... 	<ul style="list-style-type: none"> □ Communication resources □ Network □ Exposure □ Brand awareness □ Image □ Customer satisfaction □ ... 	<ul style="list-style-type: none"> □ Nr. of requests □ Nr. of issued samples and data □ % of issued samples and data □ Nr. of users □ % returning users □ Nr. of supported projects □ ...

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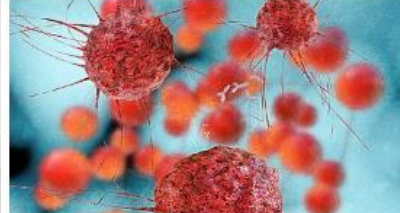
Genetic and molecular causes of heart defects

Scientists have discovered that the cell powerhouses influence the arrangement of organs.



Combatting brain tumours with immunotherapy

Scientists are using genetically-modified natural killer cells to combat brain tumours.



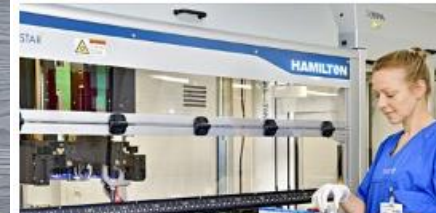
Genome atlas for pancreatic cancer

A team of scientists has successfully created a "roadmap" of gene changes in cancer cells.



Intermittent fasting no more successful than conventional dieting

Is there any truth to all the hype? A research team has proven that intermittent fasting can help people to lose weight.



A strong force against lymphoma: CAR T-cell therapy

Clonal haematopoiesis has no negative impact on treatment outcome.



Organs affected after mild course of COVID-19

Researchers have shown medium-term damage and signs of leg vein thrombosis.



<https://www.bbmr.de/research/successful-projects/?L=1>

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ACTIVITIES IN C3B

- Mapping biological sample collections
- A model of questionnaire for conducting a survey on interregional biobanks
- Identification of at least 6 interregional centers for samples collection
- Shared SOPs for the collection, sample processing, storage, and distribution
- Organizational SOPs facilitating the starting and appropriate management of new research biobanks
- Training of health and research personnels
- A shared plan to regularly update procedures and models

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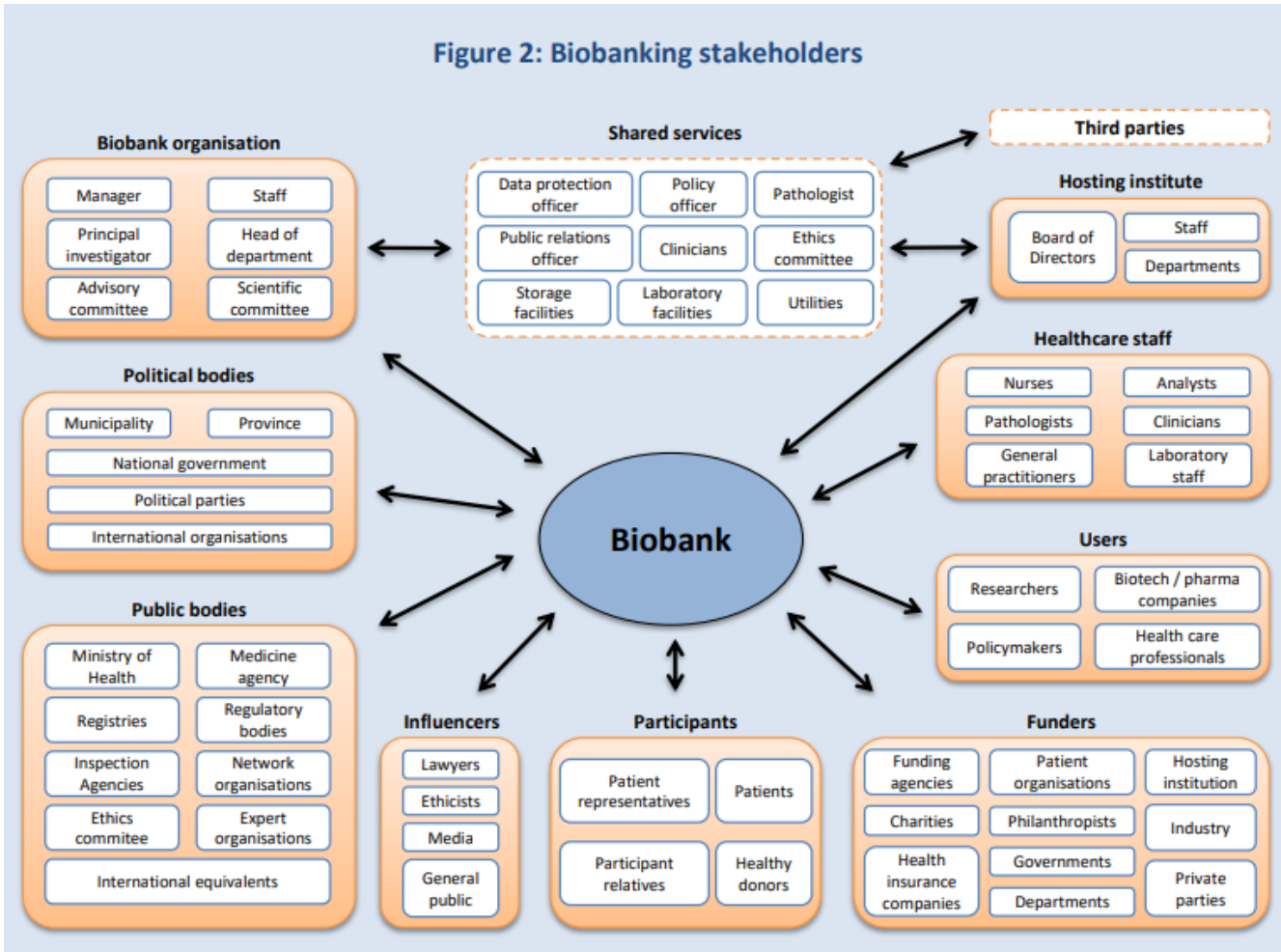
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Figure 2: Biobanking stakeholders



Taken from BBMRI.nl Sustainable Biobanking. The financial dimension, 2019, Rogier van der Stijl, Lisette Eijdem.

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INTEGRATION OF BIOBANK INTO THE HEALTHCARE INFORMATICS SYSTEM

	Recommended		Additional	
Data Collection	<input checked="" type="checkbox"/>	Acute Chest Pain Clerking	<input type="checkbox"/>	
Investigations				
Clinical Test	<input checked="" type="checkbox"/>	12-Lead ECG	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/> BIOBANK
Laboratory	<input checked="" type="checkbox"/>	CK-MB	<input checked="" type="checkbox"/>	
	<input checked="" type="checkbox"/>	Treponin T	<input checked="" type="checkbox"/>	
	<input checked="" type="checkbox"/>	FBC	<input checked="" type="checkbox"/>	
Imaging	<input checked="" type="checkbox"/>	Mobile Chest X-ray	<input type="checkbox"/>	
Monitoring	<input checked="" type="checkbox"/>	SpO ²	<input checked="" type="checkbox"/>	<input type="checkbox"/>
	<input checked="" type="checkbox"/>	Vital signs	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Treatment				
Nursing	<input checked="" type="checkbox"/>	Oxygen by mask	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Drug	<input checked="" type="checkbox"/>	IV Morphine	<input checked="" type="checkbox"/>	<input type="checkbox"/>



Taken from
<https://drdollah.com/clinical-information-system/>

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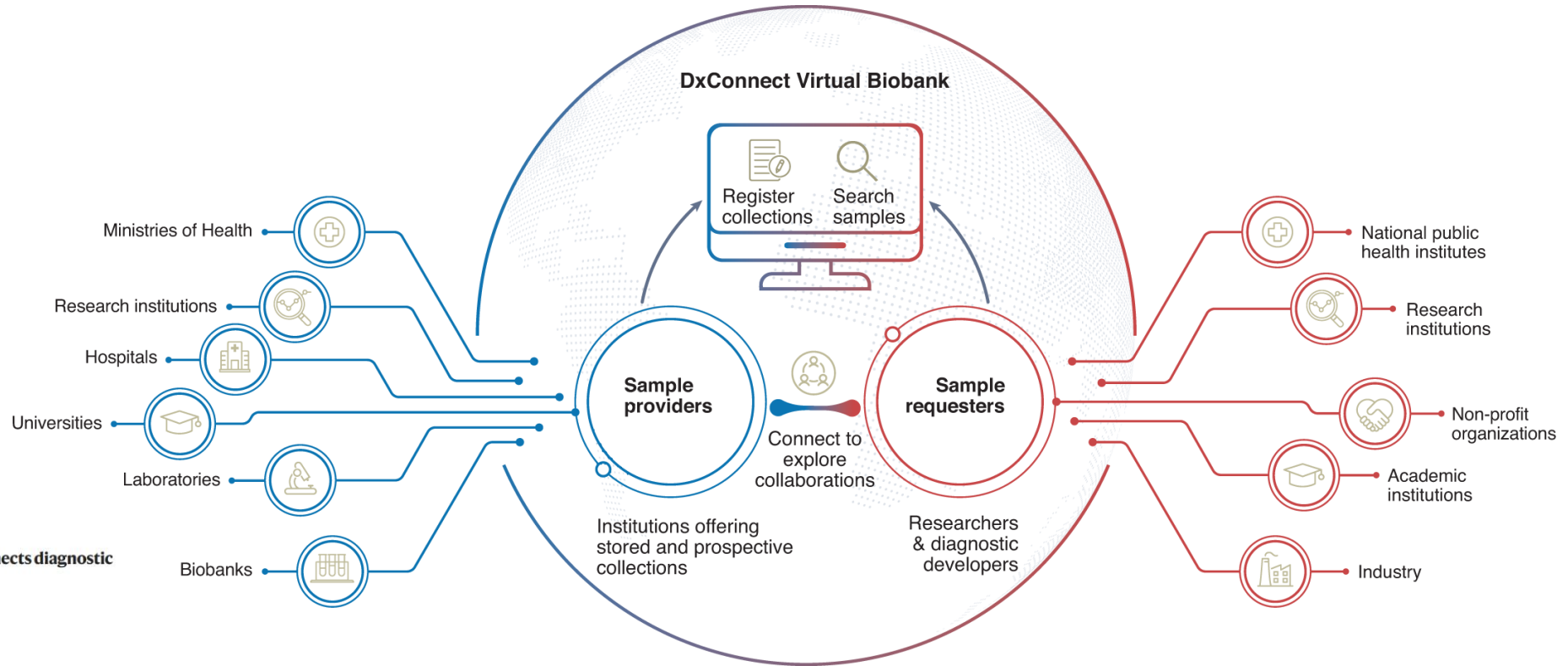
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GLOCAL



Correspondence | Published: 22 December 2021

The DxConnect Virtual Biobank connects diagnostic researchers to clinical samples

Stefano Ongarello, Marta Fernández Suárez & Fay Retouf

Nature Biotechnology, 40, 18–19 (2022) | Cite this article

1781 Accesses | 16 Altmetric | Metrics

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PILOT STUDY

LIVER DISEASE

HEALTHY BLOOD DONORS (transfusion center)



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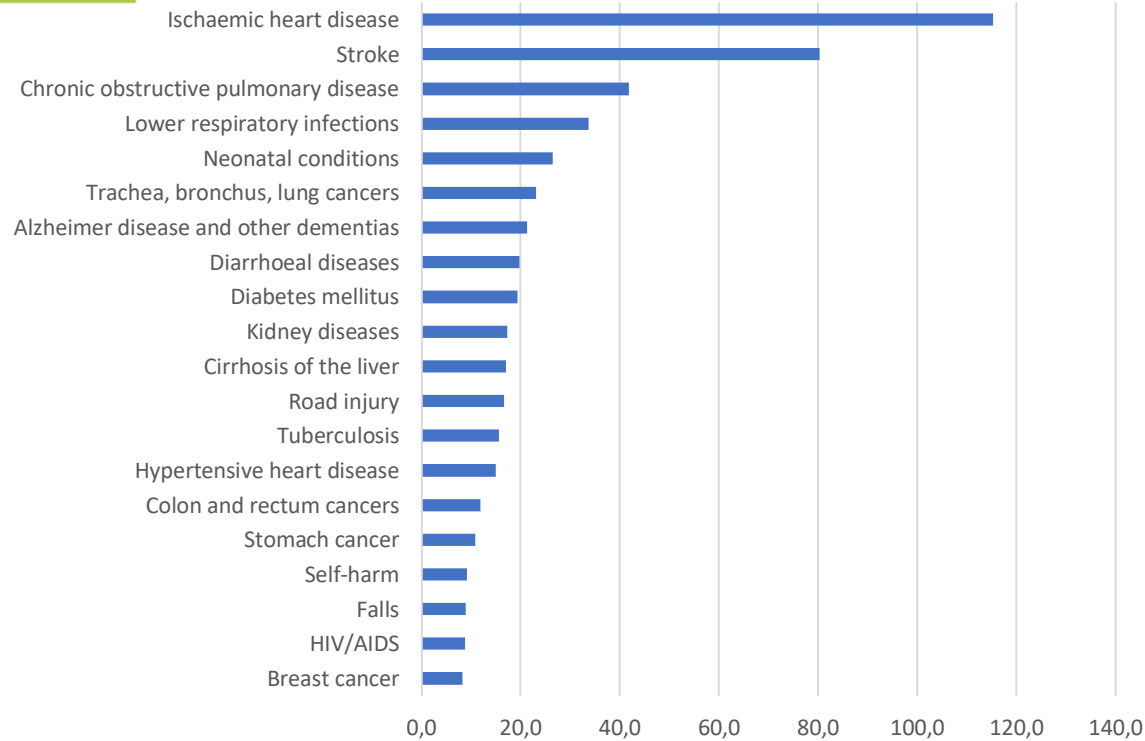
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WHY?



New Challenges for Europe's Cohesion



THE 20 MOST COMMON CAUSES OF DEATH WORLDWIDE 2019

2 MILLION DEATHS PER YEAR WORLDWIDE, 1 MILLION DUE TO COMPLICATIONS OF CIRRHOSIS AND 1 MILLION DUE TO VIRAL HEPATITIS AND HEPATOCELLULAR CARCINOMA

Crude death rate
(per 100 000 population)

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UNMET CLINICAL NEEDS

Identification and stratification of population at risk

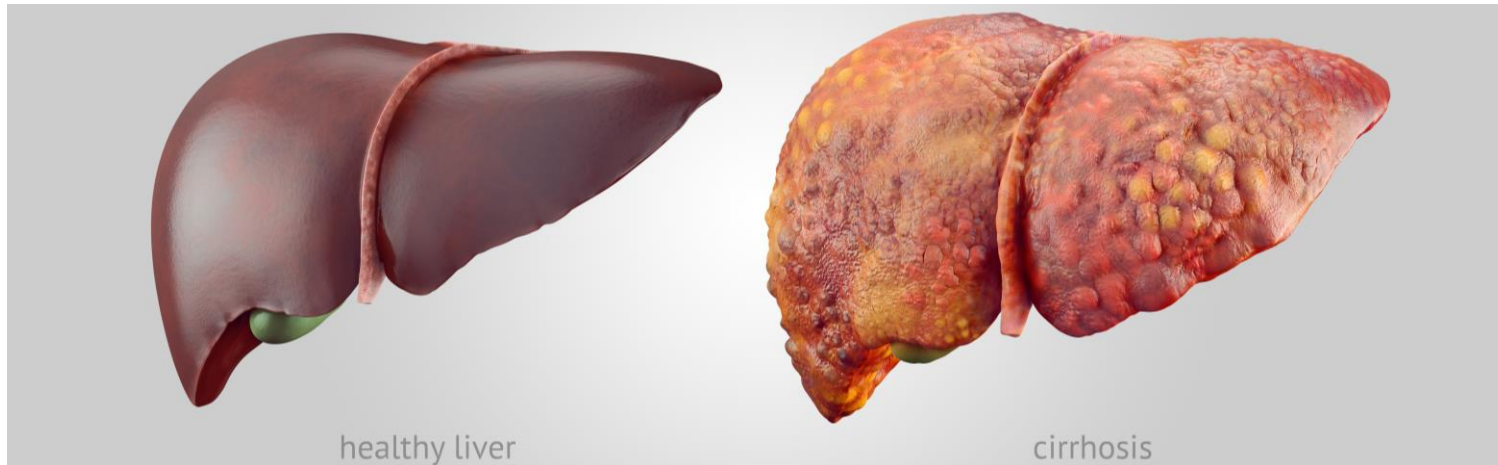
Classification, prognosis prediction

Early diagnosis

Personalized treatment

Use of non-invasive or minimally invasive techniques for diagnosis

Therapeutic response predictive models



Bruix, J.- J.Hepatol. -2015

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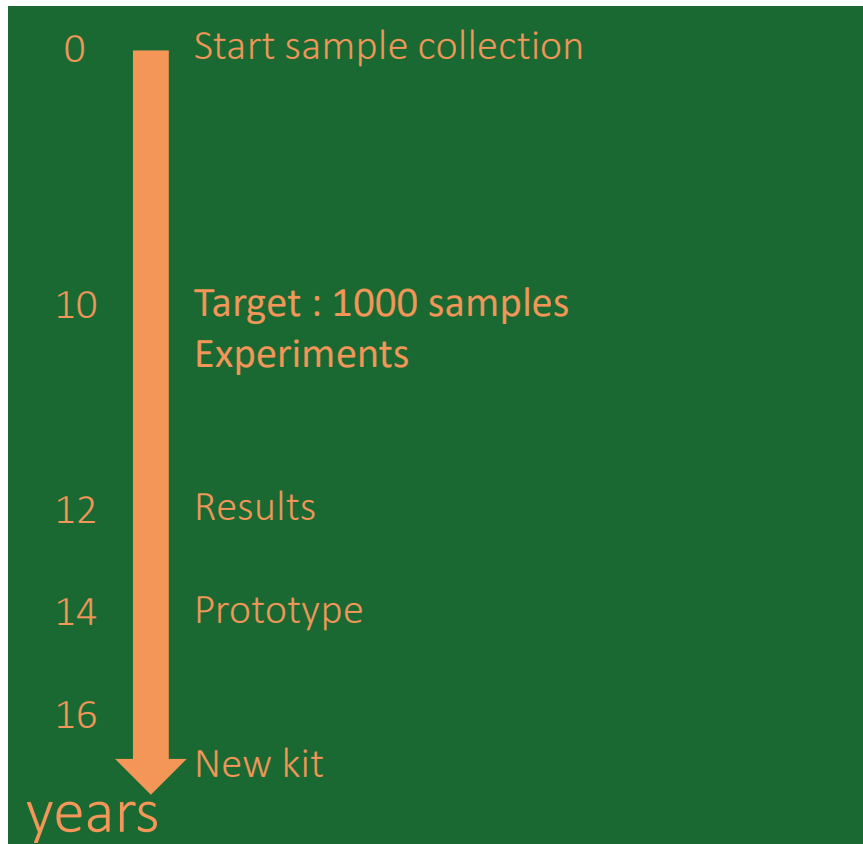
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SCENARIO 1: NO BIOBANK



SCENARIO 2: YES BIOBANK



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THANK YOU

- Devis Pascut
- 0039 040 3757924
- devis.pascut@fegato.it

- <https://www.ita-slo.eu/it/c3b>
- <https://www.fegato.it/piattaforma-transfrontaliera-per-una-efficiente-gestione-delle-biobanche/>
- https://www.facebook.com/C3Binterreg/?notif_id=1663599514501384¬if_t=profile_plus_rollback&ref=notif

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Video testimonial



https://www.youtube.com/watch?v=406ejBRsHLE&list=PLxV88Dk-z7lqKtnDCyKx-ME_uTiBn7MHg&index=2

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Mr. ALBERTO TOMMASINI

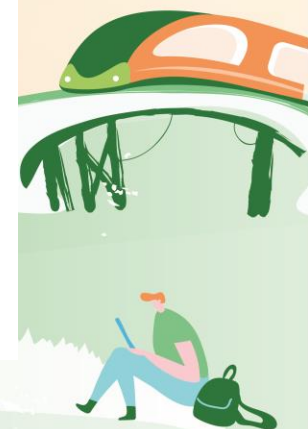


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Associate Professor of Pediatrics
University of Trieste
Institute of Child and Maternal Health
IRCCS "Burlo Garofolo"

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CollAborazione T ransfron T ali E ra per D iagnosi innovative
di patologie R are in pediatri A

*Čezmejno sodelovanje za inovativno diagnostiko redkih
bolezni v pediatriji*

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Alberto Tommasini
Andrea Taddio

Institute for Maternal and Child Health
IRCCS «Burlo Garofolo», Trieste





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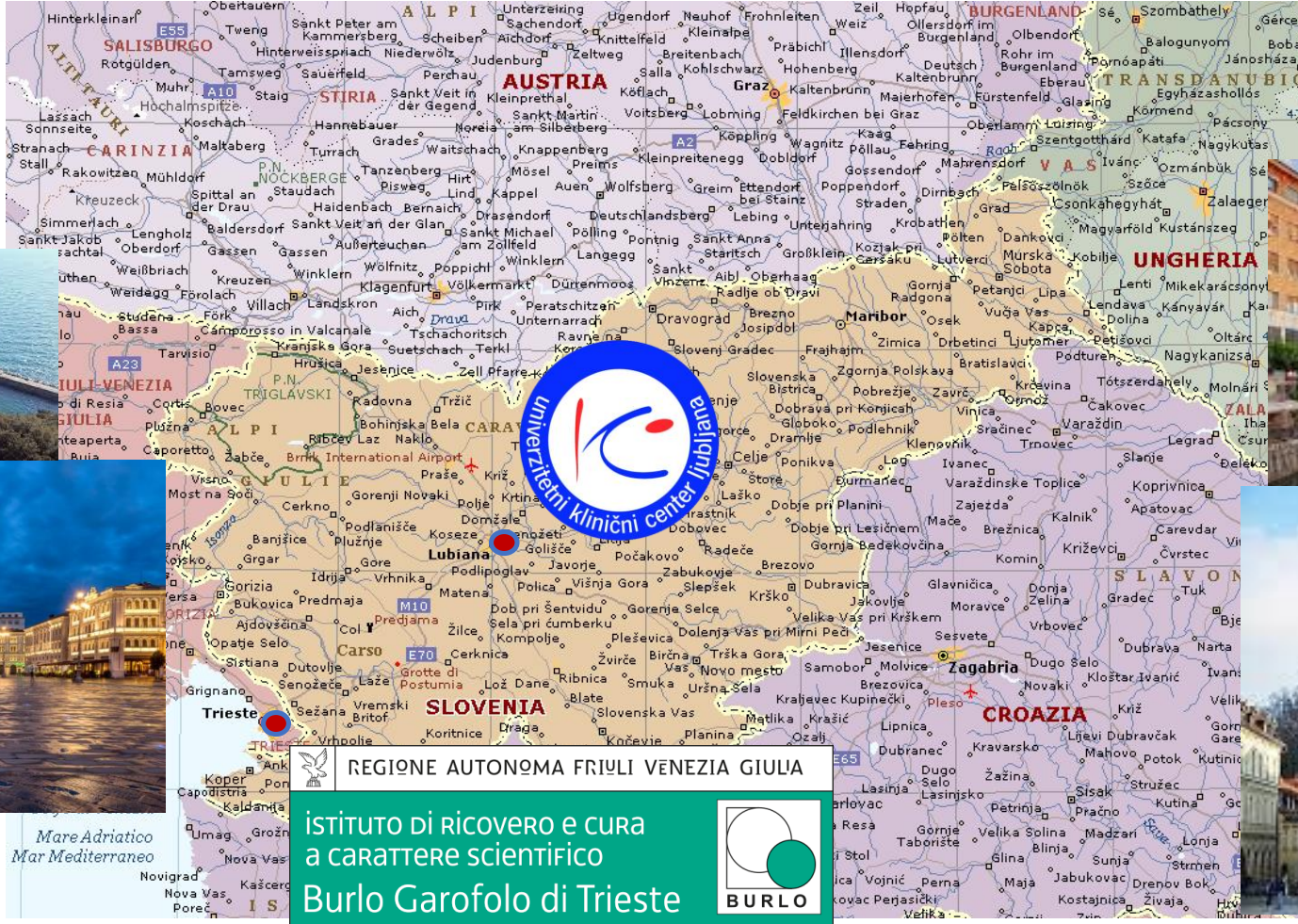
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ISTITUTO DI RICOVERO E CURA
a carattere scientifico
Burlo Garofolo di Trieste



Mare Adriatico
Mar Mediterraneo



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New Challenges for
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The Institute for Maternal and Child Health IRCCS «Burlo Garofolo» of Trieste and the Children's Hospital, University Medical Center Ljubljana are important national and international referral centers and crucial scientific partners of the Program Area. They had already collaborations in the past, mostly in the field of rare pediatric rheumatology diseases such as the immune-mediated inflammatory disease

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Nevertheless many improvements are needed in terms of:

- a) patient-centered diagnostic methodologies capable of defining the specific inflammatory profiles of disease;
- b) to select targeted treatments;
- c) to widespread knowledge on the Program Area of diagnostic and therapeutic tools in this clinical setting;
- d) to improve tools for sharing knowledge and research results

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The so-called "rare diseases" do not always receive adequate study and research attention from the scientific community and the pharmaceutical industry. Many of these diseases occur in childhood and require continuous diagnostic and therapeutic efforts to improve the quality of children's life and to minimize the socio-economic impact on families and the health system.

In particular, the area of pediatric rheumatology and immune-mediated diseases are developing fields in the field of chronic inflammatory diseases.

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PRIMARY AIM OF THE PROJECT

To implement and to optimize the skills already present in the program area; building a cross-border network that allows to improve the clinical and diagnostic offer for patients suffering from immune mediated diseases living in the program area.

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For these purposes other important partners of the
Project are:

B **better**

Building of a clinical and laboratory
database to share patients'
informations on clinical
manifestations, treatment strategy
and disease outcome

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MY DASHBOARD

Last Viewed Patients (10)

- MILLER, Johan (Mr.)**
M 22 Dec 1999 · 22y 3m
ID 22121999
a minute ago
- DOE, John (Mr.)**
M 10 Nov 2021 · 4m
ID 12345678910
2 hours ago
- DEMO JIA, Darija**
F 4 Aug 2020 · 1y 7m
ID 3818191010
2 hours ago
- KRANJSKI, Janez**
M 9 Jun 1990 · 31y 9m
ID 09061990
2 hours ago
- DEMO , SLE (Mrs.)**
F 5 Jan 2022 · 2m
ID 16119
6 hours ago
- ANDREIA, Vanessa**
U 23 Sep 2021 · 5m

Assessments in progress (0)

No assessments saved in progress.

My patients (5)

- DOE, John (Mr.)**
M 10 Nov 2021 · 4m
ID 12345678910
- KRANJSKI, Janez**
M 9 Jun 1990 · 31y 9m
ID 09061990
- LENS, Amelie (Mrs.)**
F 1 Dec 1999 · 22y 3m
ID 01121999
- PATIENT, New (Mr.)**
M 3 Nov 2005 · 16y 4m
ID 11555222366
- PRODUCTION, TEST ONE**
Preferred name: SERIOUS
M 9 Aug 2021 - Deceased
ID 09082021

MW

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PATIENT [X]

JM

MILLER, Johan (Mr.)
22 Dec 1999 · 22y 3m ⓘ
ID 22121999

DISEASE SPECIFIC OVERVIEWS ^

- [AID Overview](#)
- [JDM Overview](#)
- [JIA Overview](#)
- [SLE Overview](#)

VIEWS ^

- [Assessment archive](#)
- [Care plans and Registries](#)
- [Growth chart app](#)

ACTIONS ^

- [Start assessment](#)
- [Edit patient](#)
- [Include in Care plan or Registry](#)
- [Mark as my patient](#)

MW

START ASSESSMENT [X]

Q Search documents

- Clinical manifestation AID**
Previous assessment: 4 Mar 2022, 12:24 · admin
- Clinical manifestation for SLE (BILAG-2004)**
Previous assessment: 4 Mar 2022, 12:59 · admin
- Clinical manifestation JDM**
- COVID-19 survey**
Previous assessment: 8 Mar 2022, 12:44 · admin
- Damage item AID**
Previous assessment: 28 Feb 2022, 10:21 · admin
- Diagnosis details**
- Electromyography findings**
- Genetic analysis**
Previous assessment: 28 Feb 2022, 10:33 · admin
- Global activity disease assessment (SLEDAI-2K)**
Previous assessment: 7 Mar 2022, 21:37 · admin
- Global disease damage assessment (SLICC/ACR)**
Previous assessment: 4 Mar 2022, 17:46 · admin
- Growth chart - Input parameters**

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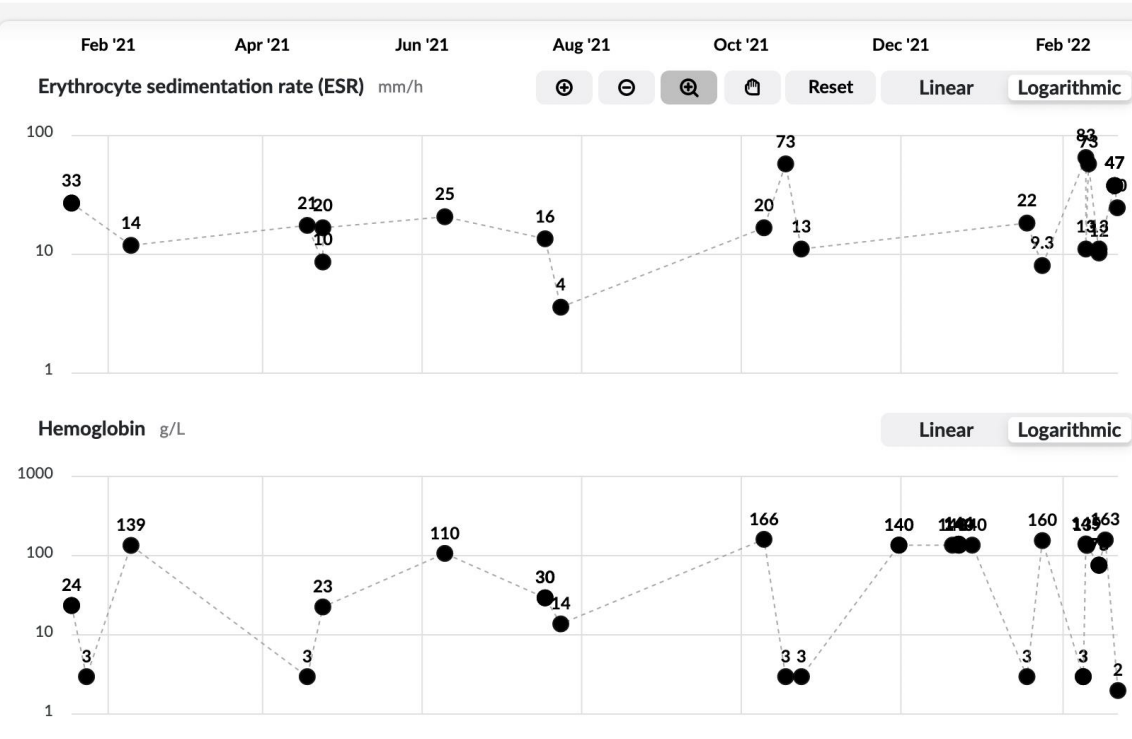
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SLE OVERVIEW

Last update: a few seconds ago [Update now](#)



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New Challenges for
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To determine different inflammatory pathways among patients with the same clinical phenotype

Analysis of 100-150 samples from selected patients -> NGS (Next Generation Sequencing) techniques (**RNA sequencing**)

ADA2, AP1S3, CARD14, CDC42, IL10, IL10RA, IL10RB, IL1RN, IL36RN, LACC1, LPIN2, MEFV, MVK, NCSTN, NLRC4, NLRP1, NLRP3, NLRP7, NLRP12, NOD2, OTULIN, PLCG2, POMP, PMSA3, PMSB10, PMSB4, PMSB8, PMSB9, PMSG2, PSTPIP1, RBCK1, RIPK1, SH3BP2, TMEM173, TNFRSF1A, TNFAIP3, TNFRSF1A, TNFRSF11A, TRNT1, WDR1

EXPERTTEAM



L'esperienza in
biologia molecolare

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New Challenges for
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To determine different inflammatory pathways among patients with the same clinical phenotype

To build innovative diagnostic tools for a better definition of the **STAT/JAK** inflammatory pathway in patients' samples by measuring some specific proteins involved in this inflammatory process (*Gamma-Interferon; CXCL9; CXCL9; CXCL10; SIGLEC1*) -> *important to define possible treatment strategy*



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instrumentacijo in procesno kontrolo

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Project Results so far...

37 project meetings

Laboratory test meetings with Experteam and Cobik

300 hours for database setting

4 databases ready

More than 150 patients enrolled in the database

30 samples already tested

1 manuscript accepted for publication and 2 more
submitted and actually under review

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Dissemination and Communication

FB: @cattedrainterreg

Twitter, Instagram e Youtube: Cattedra - Interreg ITA SLO

Median publication rate 2,2 post/month

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Lead partner

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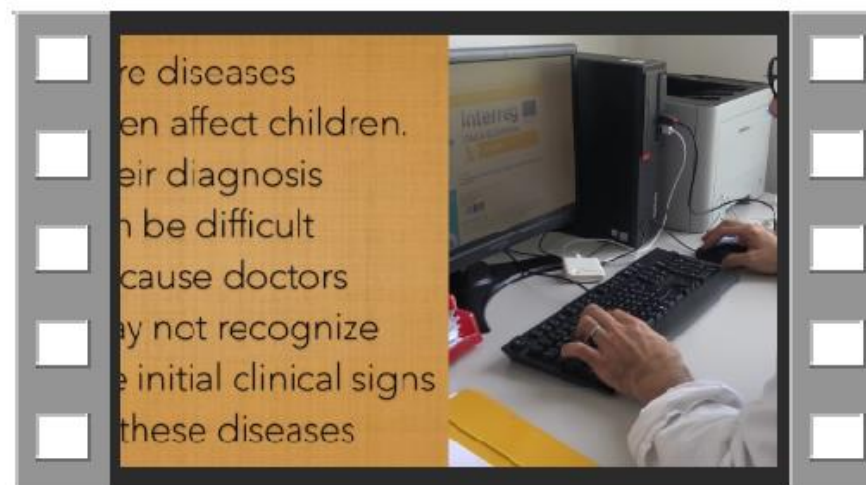
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Video testimonial



https://www.youtube.com/watch?v=FHcsUr-HowQ&list=PLxV88Dk-z7lqKtnDCyKx-ME_uTiBn7MHg&index=3

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Ms. LAURA COMELLI
Managing Authority
Interreg Italy-Slovenia Programme

MODERATOR

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