European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment
Development of a Model ERN: PaedCan ERN
Childhood Cancer

- Rare Disease Definition: 1 in 2000  [www.eurordis.org]
- Childhood (< 15 years) Cancer Incidence in Europe: 1 in 6250


- Brain Tumours: 19%
- Neuroblastoma: 8%
- Soft Tissue Sarcoma: 7%
- Wilms Tumour: 6%
- Bone Tumours: 5%
- Retinoblastoma: 3%
- Liver Tumours: 1%
- Leukaemia: 30%
- Lymphoma: 13%
- Other (VRT): 8%

Deutsches Kinderkrebsregister Mainz / 2000 New Cases / year
Childhood cancer survival in Europe 1999–2007: results of EUROCASE-5—a population-based study

Gemma Gatta, Laura Botta, Silvia Rossi, Tiina Aareleid, Magdalena Bieksa-Lasota, Jacqueline Clavel, Nadya Dimitrova, Zsuzsanna Jakab, Peter Kaatsch, Brigitte Lacour, Sandra Mallone, Rafael Marcos-Gragera, Pamela Minicozzi, Mario-José Sánchez-Pérez, Milena Sant, Mariano Santamayor, Charles Stiller, Andrea Tavilla, Annalisa Trama, Otto Visser, Rafael Péris-Bonet, and the EUROCASE Working Group*
Paediatric Cancer is a public health challenge

- > 12,000 children and young people diagnosed in Europe each year
- 60 different types of cancer, > if biological markers considered
- > 3000 die each year

- The quality and availability of paediatric cancer care widely varies across Europe
- 10% to 20% of them die from curable forms of cancer where quality care is not easily accessible.
- The outcome gap is even larger for paediatric cancers with poor outcomes
- In 2020 - 500,000 survivors: 2/3 late effects
“Because all children deserve the best treatment, no matter where they live”
PaeCan ERN

- Access to quality paediatric cancer care varies widely across Europe
- Results in **10% to 20% difference in outcomes**
- Gap is even larger for paediatric cancers with poor outcomes
- CBHC - travel for treatment is a substantial burden for families

**ExPO-r-Net aims to address these issues for the benefit of young patients all over Europe**
ExPO-r-Net: Key Concept

- **European Reference Networks (ERNs)** are a feature of the EU Directive on Cross-Border Healthcare aiming to **unite the best specialists from across Europe** to tackle **complex or rare medical conditions** that require highly specialised healthcare and a concentration of knowledge and resources.
Stakeholders

**ExPO-r-Net** is a 3.5 year project (03.2014 - 09.2017) to build and structure a European Reference Network for Paediatric Cancer (PaedCan ERN)

- **Project Coordination:** CCRI /Vienna-AT
- **More than 60 Partners**
  (Health care professionals, Hospitals, Institutes) from 17 countries
  - 18 core partners from 9 EU countries
  - > 50 Collaborating professional partners

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<tr>
<th>Collaborating partners</th>
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<tbody>
<tr>
<td>Number</td>
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<tr>
<td>Eastern European</td>
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<tr>
<td>Western European</td>
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</table>

- **Involving parents and patients**
- **8 Work Packages**
Background

**Quality of the partnership**

- The project extends across the whole clinical, research and public health spectrum and encompasses almost all European Member States.
- **European Society for Paediatric Oncology**
- **Integration:**
  - European Clinical Research Council (ECRC) for paediatric oncology (NAPHOS / ECTG)
  - Integration of parents and patients groups (Childhood Cancer International)
  - Pan-European Network for Care of Survivors after Childhood and Adolescent Cancer (PanCare)
- **Long standing Working relationships:**
  - In EC funded projects
  - In European Clinical Trial Group (ECTG) environments,
  - Together in international meetings and stakeholder policy events including European Parliament level.
ExPO-r-Net: PaedCan ERN Roadmap

- Healthcare cooperation and resolving expert fragmentation
- **Identifying special therapeutic needs** of young people with cancer requiring high expertise interventions with ECTG
  A few examples: special surgery, radiotherapy (proton therapy), stem cell transplants, ...
- **Identifying European institution** ready to engage as reference centres by establishing and/or rolling out virtual tumour boards for cross border advice
- **Identifying European Institutions /hospitals** offering top level expertise for special therapeutic interventions and referrals

Guidance for Health Care Providers
Increased Transparency for Affected Families
Retinoblastoma

**Background**

- A rare malignancy of young children (10% of tumours in infants) with excellent survival.
- Implementation of vision-sparing treatments as major aim.
- Highly specialised encompassing multidisciplinary care concentrated in a few centres, but is fragmented in many EU countries with low patient accrual.
- Known centres in EU as global leaders with ability to transfer knowledge to smaller groups.
Major changes in treatment paradigms: intra-arterial and intravitreous chemotherapy, use of pre-enucleation chemotherapy in high risk children but without harmonized strategy

Cross-border Tumour Boards
- Advise on diagnosis & treatment: initial therapeutic decision using image transmission (RETCAM, US/OCT, MRI), selective indication for referring patients in highly specialized centres
- Identification of centres for highly specialized treatments
  - brachytherapy
  - intra-arterial chemotherapy
  - Intra-vitreous chemotherapy
Retinoblastoma

Identified Hubs of Coordination in 10 Countries

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<th>Country</th>
<th>Institute, Location</th>
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<td>Cliniques Universitaires Saint-Luc, Brussels</td>
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</table>
PaedCan ERN
ExPo-r-Net Roadmap
Hepatoblastoma

**Background**

- Annual hepatoblastoma incidence: 1-1.5 case / million, thus expected number of hepatoblastoma cases annually in Europe is 120-180

- Childhood Liver Tumours Strategy Group SIOPEL: European platform with 211 members and global partners to discuss paediatric liver tumours

- SIOPEL therapy Guidelines:
  - Standard risk SIOPEL3 cisplatin monotherapy
  - High risk non-metastatic SIOPEL3 SuperPLADO
  - High risk metastatic SIOPEL4 dose intensive cisplatin
  - HCC – in preparation
PaedCan ERN
ExPo-r-Net Roadmap
Hepatoblastoma

**Impact**

- Network of European centres of expertise in the treatment of paediatric liver tumors
- **Access to equipment and experience in unique treatment modalities:**
  - Liver transplantation (LTX)
  - Chemoembolization (HACE)
  - Radiofrequency ablation (RFA)
  - Complicated liver resections with vascular reconstructions
- Fully operational Virtual Consultation Forum
- Standardized consultation and referral criteria
- European state-of-the art in hepatoblastoma
**Hepatoblastoma**

**Hubs of Coordination in 10 Countries**

<table>
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**Advantages**

- Provide access to global expertise to support clinicians in managing challenging cases
- Cases storage for training purposes
- Opportunity to update clinicians on new developments in diagnosis, risk stratification and treatment approaches

**Workflow**

1. **CASE SUBMISSION**
2. **PANEL ASSIGNMENT BY MODERATOR**
3. **WEB REVIEW**
4. **IT PLATFORM**
5. **CONCLUSIONS BY MODERATOR**

**Oncology**
- **Pathology**
- **Radiology**
- **Surgery**
- **...**
Aims

Integration of all VRT in a single framework.

- Not different networks dedicated to single VRT.

Advice on Diagnostics and Treatments for Children with VRT

- Necessary expertise can not be located in a single centre.
- Joint advice and supervision by a board of VRT experts in a VRT virtual tumour board
Very Rare Tumours
Hubs of Coordination (6 Countries)

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European Clinical Trial Groups
International Coordinating Sites (PI)
Hubs of Coordination (8 countries)

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<td>University College London (UCL, Pritchard-Jones, Wheelan)</td>
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<td>17 UK</td>
<td>Birmingham Children's Hospital (UOB)</td>
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</tbody>
</table>
European Clinical Trial Groups
International Coordinating Sites (PI)
Hubs of Coordination

- Already in Expo-r-Net
  - Acute Lymphoblastic Leukemia (ALL2009, IntreALL, Interfant, ALL-SCT)
  - Brain Tumours (div. entities)
  - Ewing Sarcoma
  - Hepatoblastoma
  - LCH
  - Lymphoma (NHL, Hodgkin)
  - Neuroblastoma
  - Osteosarcoma
  - Soft Tissue sarcomas (CWS, EpSSG)
  - Wilms Tumour
  - Very Rare Tumours – paediatric age

- Invited
  - AML
  - Lymphoma Groups (NHL, Hodgkin)
ExPO-r-Net Paediatric Oncology European Reference Network

PaedCan ERN

Hubs of Coordination

ECTG & Other tbd ...

Wilms Tumor ....

Hepatoblastoma network

Retinoblastoma network

VRT network

ROADMAP
Peadiatric Haematology Oncology Clinical Centres in European Countries with Low Health Expenditure Rates (LHEAR)

Preparation of a checklist enabling self-assessment by treatment centres of their compliance with the European Standards

- Identification of centres in Central/Eastern Europe, which meet specified criteria to fulfil the Standards of Care
- They will become visible internationally and may in the future interact with “hubs of coordination” via virtual tumour boards.
- These identified centres should be able to do baseline care for the patients, with help and advice from tumour boards.
Self Assessment Questionnaire based on the Standards of Care Requirements in PHO

- **“Assessment test run”**
  - UCL London
  - IGR Villejuif
  - Erasmus Rotterdam
  - Milano
  - Kiel

- **LHEAR Countries**
  - Sofia, Bulgaria
  - Bucharest, Romania

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<th>Activities</th>
<th>Possible remarks</th>
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<td>Immunology</td>
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<td>Other²</td>
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LHEAR – National Centres
Identification ongoing

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<td>Bratislava</td>
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<td>Slovenia</td>
<td>Ljubljana</td>
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</table>

Planned after site evaluation:

- Affiliation of LHEAR Hocs with PaedCan ERN Hocs as needed
  - For VTB
  - For optional CBHC referrals
ExPO-r-Net: Patients, Survivors at Heart

Childhood Cancer International Europe (CCI Europe) is instrumental in feeding the needs of childhood cancer parents organisations and survivor groups to the project.

- **Example**: Participation to questionnaires and site visits to centres with the potential to link to the PO-ERN based on European Standards of Care for Children with Cancer.
1) The Survivorship Passport is an innovative patient-centered web platform that provides a ‘Patient Summary’ with relevant information on the medical history and treatment undergone by patients.

2) The goal is to empower patients and make them aware of the potential risks or late effects stemming from the previous diseases and treatments received.

3) It also includes recommendations for a personalized long-term follow-up, based on treatment history and up-to-date clinical guidelines, in collaboration with EU-Pancare experts.
Survivorship Passport: A life-long cancer-related patient-centered repository

Life-long data preservation

The long-term Cancer History

First Cancer
Follow-ups
Secondary Cancer or other diseases
Follow-ups

Survivorship Passport Platform

Survivorship Passport First Version
Survivorship Passport Second Version
Survivorship Passport Third Version
Survivorship Passport Fourth Version
Structure

- Demographics
- Diagnosis
- Frontline treatment
- Chemotherapy
- HSCT
- Radiotherapy
- Surgery
- Relapse/Progression
- Other relevant clinical events
- Medical suggestions
- Relapse after 1° end of therapy
- Notes

420 variables

ICD-O
(WHO or Cancer registries)

ATC

New coding (215 variables)

Before 2013 2014 2015
January-June July-December January-June July-December January-July
Cardiomyopathy SMN breast cancer
Coronary / vascular disease CV risk / Metabolic syndrome
Models of care / transition
Female gonadal toxicity Male gonadal toxicity
Neurocognitive deficits, fatigue Thyroid cancer/ dysfunction
Bone CNS & other vasculopathy GH deficiency Hearing disabilities
Tubular/glomerular injury Other secondary neoplasms Miscellaneous Group 1 Miscellaneous Group 2
IGHG EBM method
IGH & PCSF collab EB method
PCSF alone "Pragmatic method focused on education"

14 IGHG+PCSF (2 completed + 3 ≈ completed)
3 PCSF alone (transition + 2 miscellaneous)
may also gather medical images (e.g. Radiotherapy)
Guideline example (English version)

The risk of second malignant tumours

The risk of cancer increases for everyone as they get older. As a survivor of childhood cancer you may have a slightly higher risk of developing a cancer in adulthood compared to people of similar age in the general population. There are several factors that can affect this:

Radiotherapy: receiving radiotherapy, especially at a young age and in a large dose, increases the risk of developing a second cancer in the area of the radiation. These cancers are unlikely to develop until 10 years after treatment. The most common sites include the skin, the breasts, the bones, the brain, and the thyroid.

Treatment with certain chemotherapy drugs: there is a small risk of developing leukaemia after treatment with certain drugs e.g. etoposide, cyclo-phosphamide and drugs like adriamycin. If leukaemia does develop this is usually within 10 years of treatment.

People who have a history of cancer in their family: some patients have inherited gene changes (mutations) that increase the chances of getting a second cancer.

Inherited gene changes are quite uncommon and affect less than 10% of people diagnosed with childhood cancer. If the same or different cancers have occurred in several family generations, particularly at young ages, there may be a genetic link. A review of your family medical history will help decide if genetic counselling or testing is advisable.

Breast Cancer Screening

www.siope.eu
www.pancare.eu
www.ighg.org
encca.cineca.org/passport

Yes, Go do it

It is reasonable to do
More research required

It might be considered to be done
More Research required

Stop, Don't do it

No specific recommendation can be made since further studies are needed

This project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under the project ENCCA grant agreement nr. HEALTH-F2-2011-265474 and the EsPoRNet Health Programme grant agreement nr. 2013 12 07.

Manche Krebsbehandlung kann die Herzfunktion beeinträchtigen.

Die Probleme können mehrere Jahre nach Therapieende auftreten.

Diese Broschüre gibt eine Übersicht:
- Wie das Herz funktioniert
- Wichtige Zeichen und Symptome für kardiale Beeinträchtigung
- Empfehlungen für regelmäßige kardiologische Untersuchungen für jene Patienten, die bei ihrer Krebstherapie potenziell herzschädigende Medikamente erhalten haben.

Das Herz ist ein kraftiger Muskel, der das Blut durch den ganzen Körper pumpt. Das Blut liefert Sauerstoff und Nährstoffe in den Körper und transportiert Kohlendioxid und Abfallprodukte ab. (siehe Abbildung)

Das Blut wird durch zwei Gefäße vom Herzen in den Körper gepumpt: die Aorta und die Pulmonalarterien. Es wird in zwei großen Gefäßen wieder zurück zum Herzen geführt: die obere und untere Hohlvene.

Das Herz ist in vier Kammern unterteilt:
- Den rechten und linken Vorhof, sowie die rechte und linke Herzkammer. Durch die Vorhöfe kommt das Blut ins Herz und die Kammern pumpen es wieder aus dem Herzen.

Es gibt 4 Herzklappen, welche den Blutfluss in eine Richtung lenken.


Schließlich wird das Herz von einer schützenden Hüllle, dem Herzmuskel umgeben.
## SUMMARY OF CANCER TREATMENT

"This Survivorship Passport is a short summary extracted from the information reported in the medical record. It describes the disease and its clinical course as well the treatments you received. This document does not replace the medical record that is always available at our center."

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</tr>
</tbody>
</table>

## Diagnosis

| **Date of diagnosis** | 07/03/2007 |
| **Institution** | Test Sisterna |
| **Cancer category** | 96503 - Hodgkin lymphoma, NOS |
| **High risk** | No |

## Other Diseases

| **Hereditary Cancer Predisposition Syndrome** | No |
| **Other medical conditions, cancer associated** | No |
| **Other medical conditions, not cancer associated** | No |

## Front Line Treatment

| **The treatment has been executed following** | Guidelines |
| **Summary of major treatments** | chemotherapy: Yes, Stem Cell transplantation: Yes, Radiotherapy: Yes, Major Surgery: Yes |
| **Progression/recidiva during front line treatment** | Yes |
The Survivorship Passport: 2 sides of the same coin

**Care**
- Empowerment of survivors
- Risk adapted personalized follow-up
- Homogeneous follow-up
- Guidelines available to survivors and GP
- Appropriate use of NHS resources

**Research**
- Early identification of «epidemic» of emerging rare events
- Identification of risk factors
- Move from «cure at any price» to «cure at least price»
- Design of new treatment strategies
A. Clinician registers the patient in the Patient Registration form
B. During the registration process, the system requests the EUPID code for the Patient
C. In the Diagnostic Data area the clinician can collect all the relevant clinical information
D. Therapy Information are important for the generation of guidelines
E. The system generates the Passport and related Guidelines
National/ Hospital Electronic Health Records or other Healthcare data (data transfer via HL7, IHE, ...)

Passport dedicated database

Clinician Data Input

Patient-based Survivorship Passport (printable PDF)

Patient-based Survivorship Passport (web-based version)
Future planned Developments

- The possibility of a mobile app for the passport is under consideration
  - Passport download and/or search for specific information
  - Possibility of pop-up memos according to guidelines

- SS-PP Concept part of Austrian National Cancer Plan
  - Implementation with the Austrian electronic health records
  - European eHealth based long term follow up and advisory health surveillance instrument solution for a moving population
Vision of The European Commission for ERNs

• The EC has recognised **the IHE (Integrating the Healthcare Enterprise) interoperability framework** as the **core concept** to be used for eHealth in Europe

• ...EU will provide free of costs and charge interactive multidisciplinary tumour board facilities (IT-equipment and setup) to members of an ERN
Legal Aspects of VTB

Legal Aspects

- Liability of a medical issue is determined in each country by national legislation.
- A standard informed consent is needed to exempt the tumour board of any legal responsibility.
- A legal ground for processing data is needed.
- Individuals that share virtual information must remain under the obligation of medical secrecy.
- Sharing data with a virtual tumour board is beyond normal care practice so the patient must be asked for consent.

Methods

- National expert contact in Valencia (Spain): University of Valencia (Prof. Gisbert), legal department (Medical College - Valencia)
- International expert contact: Nikolaus Forgó
ExPO-r-Net ICT-Strategy for Cross-Border Tumour Boards

- Propose solutions of interoperable eHealth platforms with an IHE Partner to facilitate European large scale cross-border virtual tumour boards for ERNs
**eHealth Platform**

Reliable, secure, standardized and managed web/videoconferencing solution

*Communication services can be used by all interoperable Apps*

- **App 1** Survivorship Passport
- **App 2** Virtual Consultation System
- **App 3** Virtual Clinical and Tumour Board
- **App 4** EUPID Identity Management service
- **App 5** ...

*Interfaces to ExPO-r-Net eHealth platform services*

- Electronic Health Record (EHR) Systems (e.g. Austria‘s ELGA)
- **ExPO-r-Net eHealth Platform**
- Electronic Medical Record (EMR) Systems (e.g. St. Anna‘s „Patidok“)
Can Long Term Follow Up be integrated into new Clinical Trials?
Long Term Follow Up
Integration in new Clinical Trials

- Identification of Core data set for LTFU (eHealth compatible)
- Integration of base line diagnostics test for LTFU and potential late effects as developed in SU-PP into clinical trials
- Safeguards in place for data protection:
  - Data linkage of data bases and LTFU registries via EUPID
- Secondary Use of data via eHealth /Research platforms integrating the eHealth Survivorship Passport

- Elevated standards of treatment and care across all of Europe
Already available Tools from ENCCA

- **EUPID - European Unified Patient IDentity Management Service**
  - www.eupid.eu (beta)

- **Survivorship Passport – Patient Summary**

EUPID Concept

Each Context needs 1 Informed Consent (i.e. Trial A)

EUPID itself not visible to the outside world

Given Name, Surname, Date of Birth

Same Patient New Context ➔ New Pseudonym PSN₂

No Double Registration
Data Matches
Re-Identification

Input (GUI)
accessible (Output)
inaccessible (internal)

IDAT Identity Data
IDATCRYPT Encrypted Identity Data
IDATHASH Hashed Identity Data
MDAT Medical Data
PID de-identified context-specific Patient Identifier
PSN Pseudonym
EUPID European Unified Patient Identifier

IDAT
PSN
IDATCRYPT
IDATHASH
Encryption
Hashing
De-Identification
EUPID
Pseudonymisation
Assignment
Assignment
Assignment
Assignment
PSN₁
PSN₂
PID₁
PID₂
De-Identification

PID₁
Pseudonymisation
Assignment
Assignment
PSN₁

PID₂
Pseudonymisation
Assignment
Assignment
PSN₂

Given Name
Surname
Date of Birth

Same Patient
New Context
➔ New
Pseudonym
PSN₂

• No Double Registration
• Data Matches
• Re-Identification

Pseudonym for this Context

EUPID Concept

14.06.2016

IDAT
PSN
IDATCRYPT
IDATHASH
Encryption
Hashing
De-Identification
EUPID
Pseudonymisation
Assignment
Assignment
Assignment
Assignment
PSN₁
PSN₂
PID₁
PID₂
De-Identification

PID₁
Pseudonymisation
Assignment
Assignment
PSN₁

PID₂
Pseudonymisation
Assignment
Assignment
PSN₂

Each Context needs 1 Informed Consent (i.e. Trial A)

EUPID itself not visible to the outside world

Input (GUI)
accessible (Output)
inaccessible (internal)
**Neuroblastoma Successful Pilot Data Integration with EUPID**


**KEY and UNIQUE to EUPID:**
No central personal data storage in Europe!
*Personal Data stays with Health Care Providers only*
Patient will have the possibility to view and share his own data during lifetime.

Survivorship Passport Data Access: Future

- **Passport**: dedicated Research Database
- **WEB**
- **EUPID**
- **Patients**
- **National Authorities**
- **Oncologists, GPs,..**
- **Data Input (Hospital)**

**Legenda**
- View data
- Update data
Interoperability Architecture for a Paediatric Oncology European Reference Network

The Future
Data Integration

Key Instrument for LTFU!

Registries

Secondary Use of Electronic Patient Records
Electronic Health Records (ELGA)

Electronic Data Capture

Trial Data

HIS
PACS
LAB
...

Interface

ABCDA-E

Security and Identification

Document / Data Registry

Data/Document Storage

Research Services
Pharmacovigilance,
Image Management,
...

Interface

Interface

Biosamples Biobanking

Literature Knowledge

Data processing/ Statistics
ExPO-r-Net: Key Benefits

- **Improved visibility and access to expert care and advise in Europe:**
  A ‘roadmap’ of centres to allow medical teams to find expert sites for given conditions for advise and patient referral if indicated

- **Information on cross-border treatment modalities:** in another EU –Member State accessing healthcare or advice received and reimbursement for advise

- **Possibility to be treated at home or abroad:** Mechanisms to facilitate movement of information and knowledge rather than patients whenever possible;

- **Progress in instituting virtual late effects centre:** incl. operationalising Survivorship Passport

- **Elevated standards of treatment and care across all of Europe**
THANK YOU!

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