The database of the University of Crete for the study of Np in adults

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UoC data base:

Technical Characteristics
The NP database of the UoC

- The electronic database consists of a repository (Relational Data Base System) and web interfaces to register users and administrators.

- It is hosted by the UoC Data Center, thus fulfilling criteria of access control, safety, loss of data, response time and GDPR.

- It provides GUI (Graphical User Interface) masks for patient's data, reports and statistical graphs for users and administrators.

- It provides the means for integration and data exchange with similar registries using HL7 (transfer of clinical and administrative data protocol).
The NP patient data model (initial form)

- Personal Details (15)
- Clinical Data (29)
- Serum Proteins
- Cell Blood Counts (15)
- Antibodies & Antigens (20)
- Myelogram
- BM Biopsy
- Immune
- Genes (42)
- Ultrasound Abdomen(2)
- Patient history (3)
- Additional Studies
  - Serum Proteins (18)
  - Serum biochemistry, hormonal & other indices (21)
  - Cancer Indices (6)
  - Bone Metabolism (4)
  - Antibodies to viral and bacterial pathogens (21)

Immune
- Peripheral Blood (10)
- TCR-Vb repertoire (25)
- Bone marrow (lymphocytes) (10)
- Bone marrow (granulocytes) (18)
- Bone marrow (% cells) (4)

Recording over 250 fields of clinical data & laboratory data
The NP patient data model (follow up)

- Patient Status
- Clinical Data (29)
- Serum Proteins
- Cell Blood Counts (15)
- Antibodies & Antigens (20)
- Myelogram
- BM Biopsy
- Immune
- Genes (42)
- Ultrasound Abdomen(2)

Additional Information
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Immune
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- Bone marrow (% cells) (4)

Recording over 250 fields of clinical data & laboratory data

Final Diagnosis
The NP data protection plan

**GDPR compliance**

- Data are collected solely for specific purposes
- Encryption of all personal data
- Data are adequate and related to the purpose of collection
- Data are processed and treated lawfully in a transparent manner
- HTTPS Protocols encrypt all the data sent between a client and a server using the SSL/TLS cryptographic protocols

**Data anonymization procedures**

- Pseudonymized identifier for each patient record
- The correspondence with original records are stored encrypted, only at the local level
- Fully anonymized data used for statistical analysis
- Anonymized aggregated results are reported
The NP application layer schema

- user authentication
- web application
- database system

- user data
- user privileges
  - role
  - institute

- Create, Update, Delete patient & follow-up records
- Full text search
- Filter search results
- Preview result data
- Export / import data (csv, xls/spreadsheet, pdf)
- Visualization tools (charts)
### The NP user management

#### User role examples of center-based access

- **Principal investigator of center (PI)**
  - Overall access, review registration and management procedures
- **Data moderator (DM)**
  - Restricted read & write permissions to selected institute records
- **Read - only user (GDPR)**
  - Restricted read permissions to anonymized data of a single institute records

#### User role examples of project-based access

- **Read - only user (GDPR)**
  - Restricted read permissions to anonymized data of selected institutes
The NP Data Retrieval And Analysis
Tools for data retrieval and analysis, based on user access privileges

**Query tool**
- Allowing for dynamic definition of selection filters in order to retrieve data
- Predefined search queries with dynamically defined filters
- Full text search queries

**Export tool**
- Report generation (patient summary)
- Selected data download/exchange (authorized– anonymized) institute specific
- Support of csv, xls / spreadsheet, pdf formats

**Visualization tools**
- Predefined visualization diagrams with dynamically defined filters
UoC data base: How it works
**NP NeutroPenia**

**My Institution**

- **Type of Facility:** Academic
- **Name:** University Hospital of Crete
- **Website URL:** www.pagni.gr
- **Postal Address:** Voutes Heraklion Crete
- **Country:** GR
- **City:** Heraklion
- **Postal Code:** 711 10
- **Contact Person:** Stavros Papadakis
- **Phone Number:**
- **Cell Phone:**
- **Fax Number:**
- **Email:** spapad191@gmail.com

**My Profile**

- Prof.
  - Papadaki Eleni
  - University Hospital of Crete

**My Reports**
- General
- Initial Data
- Follow Up Data
- Combined Data

**My Statistics**
- Basic
- Detailed
- Geographical

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**NP database UoC**
### NP NeutroPenia

#### My Profile
- Prof. Papadaki Eleni
- University Hospital of Crete

#### My Reports
- General
- Initial Data
- Follow Up Data
- Combined Data

#### My Statistics
- Basic
- Focused
- Geographical

#### NP database UoC

**Show:** 25 entries

<table>
<thead>
<tr>
<th>Last Name</th>
<th>First Name</th>
<th>Father's Name</th>
<th>Birthdate</th>
<th>Follow Up</th>
<th>Edit Patient</th>
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<td></td>
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<td>01-01-1927</td>
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</table>
NP database UoC

![Edit Patient Interface]

## Personal Details

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<th>Value</th>
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<td>Last Name</td>
<td></td>
</tr>
<tr>
<td>Father's name</td>
<td>Eustratios</td>
</tr>
<tr>
<td>AMKA</td>
<td></td>
</tr>
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<td>Country of birth</td>
<td>Greece</td>
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<td>Address</td>
<td></td>
</tr>
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</tr>
<tr>
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<td></td>
</tr>
<tr>
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<td>29-04-1947</td>
</tr>
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<td>Date of 1st detection of disease</td>
<td>02-11-2009</td>
</tr>
<tr>
<td>Date of 1st presentation in Unit</td>
<td>01-02-2011</td>
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Προσέρχεται για διερεύνηση ουδετεροπενίας η οποία ανευρέθηκε τον 11/02/2009 σε προσωπικωματικό έλεγχο.

ΓΩ. Χρόνιο διαρροϊκό σύνδρομο. ΧΣ λαμβάνει dogmatyl. Αρτηριακή υπέρταση λαμβάνει olmetec.

Ο πατέρας της απεβίωσε σε ηλικία 88 ετών από Πνευμονικό οίδημα. Η μητέρα της απεβίωσε σε ηλικία 75 ετών από ανακοπή. Εχει 6 αδέλφια από τα οποία 2 αδέλφες πέθαναν σε τεμορό κατά και από κακοπαθεία. Τα υπόλοιπα 4 αδέλφια είναι ζωντανοί. Εχει 4 πατάκια από τα οποία το ένα έχει λευκοκυττάρωση.
NP database UoC

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<thead>
<tr>
<th>Clinical Data:</th>
<th>Add details</th>
<th>Make all fields: &quot;Yes&quot; &quot;No&quot; &quot;Not Known&quot;</th>
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<tr>
<td>Sinusitis:</td>
<td>No □</td>
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<tr>
<td>Periodontitis:</td>
<td>No □</td>
<td></td>
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<tr>
<td>Aphthae:</td>
<td>No □</td>
<td></td>
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<tr>
<td>Bronchitis:</td>
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<td>Asthma:</td>
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<td>TBC:</td>
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<td>Gastritis:</td>
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<td>ron</td>
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<td>Colitis:</td>
<td>No □</td>
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</table>
### Cell Blood Counts

<table>
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<tr>
<th>Parameter</th>
<th>Value</th>
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<td>Hct</td>
<td>42.300%</td>
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<tr>
<td>Hgb</td>
<td>14.300 g/dl</td>
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<td>RBC</td>
<td>4.750 M/μl</td>
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<td>MCV</td>
<td>89.100 fl</td>
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<td>MCH</td>
<td>30.100 pg</td>
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<tr>
<td>MCHC</td>
<td>33.800 g/dl</td>
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<td>RDW</td>
<td>13.300%</td>
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<td>34.000 mm/hr</td>
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<td>WBC</td>
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<td>Ly</td>
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<tr>
<td>Mo</td>
<td>400 K/μl</td>
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<tr>
<td>Eo</td>
<td>0 K/μl</td>
</tr>
<tr>
<td>Bas</td>
<td>0 K/μl</td>
</tr>
<tr>
<td>Pits</td>
<td>168 K/μl</td>
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</table>
### NP database UoC

![NP Registry](https://i.imgur.com/778x22to861x52.png)

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#### Serum Protein

<table>
<thead>
<tr>
<th>Protein</th>
<th>Total</th>
<th>%</th>
<th>IgG2</th>
<th>mg/dl</th>
<th>IgG3</th>
<th>mg/dl</th>
<th>IgG4</th>
<th>mg/dl</th>
<th>IgA</th>
<th>mg/dl</th>
<th>IgM</th>
<th>mg/dl</th>
<th>C3</th>
<th>mg/dl</th>
<th>C4</th>
<th>mg/dl</th>
<th>RF</th>
<th>IU/ml</th>
<th>CRP</th>
<th>mg/dl</th>
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<tbody>
<tr>
<td>Alb</td>
<td>8.000</td>
<td>%</td>
<td>681.000</td>
<td>mg/dl</td>
<td>43.100</td>
<td>mg/dl</td>
<td>112.000</td>
<td>mg/dl</td>
<td>194.000</td>
<td>mg/dl</td>
<td>147.000</td>
<td>mg/dl</td>
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<td>Blank field.</td>
<td>Blank field.</td>
<td>0.300</td>
<td>mg/dl</td>
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<td>a1</td>
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</tr>
<tr>
<td>a2</td>
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<td>%</td>
<td></td>
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<td></td>
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<td>β</td>
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<td></td>
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<tr>
<td>M-Co.</td>
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</tbody>
</table>

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**Source:** NP Registry
**Immunophenotype of peripheral blood ( % cells in the gate of lymphocytes)**

<table>
<thead>
<tr>
<th>Lymph</th>
<th>1700 K/μl</th>
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<tbody>
<tr>
<td>CD2</td>
<td>90, 3% 1536</td>
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<tr>
<td>CD3</td>
<td>85, 1% 1445</td>
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<tr>
<td>CD4</td>
<td>59, 3% 1009</td>
</tr>
<tr>
<td>CD8</td>
<td>31, 2% 531</td>
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<tr>
<td>CD19</td>
<td>3, 6% 62</td>
</tr>
<tr>
<td>CD20</td>
<td>4, 6% 68</td>
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</tbody>
</table>

- **CD16:** 6, 2%, 106
- **CD57:** 24, 2%, 412 Blank
- **Double Positive CD16/CD56:** Blank
- **Double Positive CD16/CD57:** Blank
- **Double Positive CD56/CD57:** 1, 3%, 19
- **Triple Positive CD3/CD8/CD57:** 14, 4%, 241
NP database UoC
**NP database UoC**

![Edit Patient](image)

**List of Genes tested**

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<th>Gene</th>
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<tr>
<td>CXCR4</td>
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<td>FBXW7</td>
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<td>IKZF2</td>
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<td>U2AF1</td>
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<td>ATM</td>
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### Final Diagnosis:

- [ ] CIN/ICUS
- [ ] CCUS
- [ ] P-AIN
- [ ] Secondary Neutropenia
- [ ] Drug Induced
- [ ] Congenital
- [ ] Familial Neutropenia
- [ ] Ethnic Neutropenia
NP database UoC
NP database UoC
NP database UoC
NP database UoC

NP NeutroPenia

Patients Gender distribution: University Hospital of Crete

Patients Gender distribution sets chart

- Male: 21.36%
- Female: 78.64%

Patients Gender distribution data sets

<table>
<thead>
<tr>
<th>Gender</th>
<th>Total</th>
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<td>162</td>
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<tr>
<td>Male</td>
<td>44</td>
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</table>
NP database UoC

Neutrophil count sets chart

- 0-500: 10.07%
- 501-1000: 14.11%
- 1001-1500: 35.57%
- 1501-1800: 38.70%

Lymphocyte count sets chart

- 0-500: 1.90%
- 501-1000: 7.84%
- 1001-1500: 34.37%
- 1501 and over: 55.88%

Monocyte count sets chart

- 0-500: 61.67%
- 501-1000: 7.64%
- 1001-1500: 4.48%
- 1501 and over: 4.00%
UoC data base: Summary
**NP database UoC**

- We have generated a simple, reliable, secure, user-friendly database aiming to
  - facilitate the monitoring of neutropenia patients in different centers
  - enable multi-center collaboration through collection and acquisition of harmonized real world data
  - facilitate processing of data for clinical and translational research studies

- The database gives the autonomy to different Institutions to register their own patients
  - Authorized users from each Institution have access to their own data
  - The Administrator (IT Dpt, UoC) supports the physicians in patients’ registration.

- Advantages: the autonomy of each Institution, data analysis per Institution and globally, potential for collaborative studies, integration capacity to International Registries if needed.
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