**Patient Summary Service**

**Storitev pacientovega povzetka**

**V 0.1 17. maj 2011**

**Stanje dokumenta**

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| Namen dokumenta: | | **Namen dokumenta je kratka predstavitev storitve pacientovega povzetka vključno z naborom podatkov v slovenskem jeziku.** | |
| Kratek naziv projekta: | | **epSOS LSP – Slovenia – Patient Summary** | |
| Vsebina: | |  | |
| Oznaka dok.: | |  | |
| Status: | |  | |
| Verzija: | |  | |
| Datum verzije: | |  | |
| Lastnik: | | **Vesna Lešnik Štefotič** | |
| Avtorji: | |  | |
| Dostavljeno: | |  | |
| Zgodovina verzij: | |  | |
| Verzija | Datum zadnje spremembe | | Opombe |
| **0.1** |  | | **Priprava kratke predstavitve.** |
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| --- | --- |
| Stopnja zaupnosti: | **Za interno uporabo** |

**Zaščita dokumenta**

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Vse pravice pridržane. Reprodukcija po delih ali v celoti na kakršenkoli način in v kateremkoli mediju ni dovoljena brez pisnega dovoljenja avtorja. Kršitve se sankcionirajo v skladu z avtorsko pravno in kazensko zakonodajo.

# Definicija pacientovega povzetka

Pacientov povzetek (Patient Summary) je omejena množica pacientovih podatkov, ki bodo izvajalcu zdravstvenih storitev zagotovili bistvene potrebne informacije v primeru nepričakovane ali nenačrtovane oskrbe (urgenca, nesreča, …) in v primeru načrtovane oskrbe ???

Vsebina pacientovega povzetka je definirana kot minimalni nabor informacij, ki so potrebne za koordinacijo in nadaljevanje zdravljenja. Pacientov povzetek vsebuje podatke:

1. Splošni podatki o pacientu
2. Medicinski povzetek
3. Povzetek zdravil

Pacientov povzetek ne vsebuje podrobnih podatkov o zgodovini zdravljenja, kliničnem stanju ali pregled vseh prepisov zdravil. Podrobni in celoviti podatki so običajno shranjeni v elektronskem zdravstvenem zapisu.

Podatkovni nabor pacientovega povzetka, ki se izmenjuje, lahko razdelimo na:

* **Osnovni podatkovni nabor (Basic dataset):** definiran kot nabor bistvenih zdravstvenih informacij, ki so zahtevane s strani klinikov za zagotavljanje varne oskrbe pacienta (osredotočeno na nenačrtovano oskrbo). To je t.i. **minimalni podatkovni nabor (Minimum dataset)**.
  + **Obvezni podatkovni nabor (Mandatory dataset)**: je podskupina osnovnega podatkovnega nabora. Vsa polja morajo imeti veljavne vrednosti.
* **Razširjen podatkovni nabor (Extended)**: definiran kot zaželen nabor podatkov s strani klinikov, ki bi si jih naj izmenjevali v projektu. To je t.i. **maksimalni podatkovni nabor (Maximum dataset)**.

Podatki, ki niso v nobenem od omenjenih podatkovnih naborov, se ne bodo izmenjevali tudi, če so na voljo v določeni državi.

# Primeri uporabe

V primerih uporabe nastopajo:

1. Ljudje, kot posamezniki
   1. Pacient
   2. Izvajalec zdravstvenih storitev (HCP)
2. Institucije
   1. Organizacije, ki zagotavljajo zdravstvene storitve
   2. Zdravstvene avtoritete
3. Sistemi
   1. Nacionalna kontaktna točka (NCP)
   2. Semantične storitve

## Primer uporabe 1:

Občasni obiskovalec v državi B (npr. nekdo na dopustu ali na poslovnem potovanju). Ta tip obiska je naključen, občasen in lahko neponovljiv. To je tip obiska kot izvajalec zdravstvenih storitev običajno nima prejšnjih zapisov o osebi, ki išče zdravstveno oskrbo.

## Primer uporabe 2:

Oseba je redni obiskovalec države B npr. nekdo, ki živi v eni deželi in dela v drugi. Ta tip obiska je običajen, pogost in oseba, ki išče zdravstveno oskrbo, je navajena na uporabo storitev v državi, kjer dela. V teh situaciji ima izvajalec zdravstvenih storitev lahko kakšno informacijo o pacientu iz prejšnjih obiskov. Tako lahko ima tak pacient zdravstveni zapis shranjen lokalno v državi B in pacientov povzetek v državi A in B. V tem primeru naj bosta oba pacientova povzetka na voljo izvajalcu.

# Zahteve

## Funkcionalne zahteve

|  |  |  |
| --- | --- | --- |
| FR01 | Identifikacija in avtentikacija izvajalca zdravstvenih storitev |  |
| FR02 | Zaupanje med državami |  |
| FR03 | Identifikacija pacienta |  |
| FR04 | Pacientova privolitev za dostop do podatkov |  |
| FR05 | Strukturirana informacija |  |
| FR06 | Enakovredna informacija |  |
| FR07 | Razumljena informacija |  |
| FR19 | Pacientov povzetek države A na voljo |  |
| FR20 | Sledljivost informacij |  |

## Nefunkcionalne zahteve

|  |  |  |
| --- | --- | --- |
| NFR01 | Razpoložljivost storitve |  |
| NFR02 | Komunikacije |  |
| NFR03 | Odzivni čas |  |
| NFR04 | Zaupnost |  |
| NFR05 | Kontrola dostopa |  |
| NFR06 | Nadzorna sled (sled za revidiranje) |  |
| NFR07 | Integriteta |  |
| NFR08 | Preprečevanje zanikanja (tajenja) |  |
| NFR09 | Zaupanje med državami |  |
| NFR10 | Zagotovljena dostava |  |
| NRF12 | Storitve nadzora |  |

# Normalno zaporedje korakov

1. Pacient iz države A obišče HCP v državi B.
2. Pacient je identificiran.
3. Izvajalec zahteva validacijo identitete pacieavi nta skozi HCP vmesnik.
4. HCP vmesnik posreduje zahtevo NCP v državi B.
5. NCP države B posreduje zahtevo NCP v državi A.
6. NCP države A preveri ID in zagotovi NCP države B potrditev (pozitivno, negativno) identifikacije pacienta.
7. NCP države B posreduje potrditev identifikacije pacienta skozi HCP vmesnik.
8. Ko je validirana identiteta pacienta, se preveri pacientovo voljo.
9. Ko je validirana identiteta pacienta, HCP države B zahteva, skupaj z voljo pacienta, pacientov zahtevek iz države A, ki ga lahko prikaže preko HCP vmesnika.
10. HCP vmesnik zahteva pacientov povzetek države A preko NCP države B.
11. NCP države B zahteva pacientov povzetek države A preko NCP države A.
12. NCP države A, po preverjanju ali je dostavljena tudi volja pacienta, poišče in pošlje NCP države B pacientov povzetek iz države A.
13. NCP države B posreduje pacientov povzetek iz države A HCP vmesniku.
14. HCP dostopa do pacientovega povzetka v državi A

# Skupna struktura pacientovega povzetka

#### Pacientovi podatki (Patient Data)

| **Spremenljivka (nivo 1)** | **Spremenljivka (nivo 2)** | **Spremenljivka (nivo 3)** | **Definicija in komentar** | **Nabor podatkov** | **Obveznost** | **Spremenljivka (nivo 1)** | **Spremenljivka (nivo 2)** | **Spremenljivka (nivo 3)** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Identifikacija[[1]](#footnote-1)** | Nacionalni zdravstveni pacientov ID | Nacionalni zdravstveni pacientov ID | Country ID, unique for the patient in that country. Example: ID for United Kingdom patient | Basic | Yes | **Identification [[2]](#footnote-2)** | National Health Care patient ID | National Health Care patient ID |
| **Osebne informacije** | Polno ime | Ime | The Name of the patient (Example: John). This field can contain more than one element | Basic | Yes | **Personal information** | Full Name | Given name |
| Priimek | This field can contain more than one element. Example: Español Smith | Basic | Yes | Family name/Surname |
| Datum rojstva | Datum rojstva | This field may contain only the year[[3]](#footnote-3) if day and month are not available. Eg: 01/01/2009 | Basic | Yes | Date of Birth | Date of Birth |
| Spol | Koda spola | It must contained a recognized valid value for this field | Basic | Pending decision by WP3.6 (in some countries ‘gender’ is needed for univocal identification of the patient) | Gender | Gender Code |
| **Kontaktne informacije** | Naslov[[4]](#footnote-4) | Street | Example: Oxford | Ext | No | **Contact information** | Address[[5]](#footnote-5) | Street |
| Number of Street | Example: 221 | Ext | No | Number of Street |
| City | Example: London | Ext | No | City |
| Post Code | Example: W1W 8LG | Ext | No | Post Code |
| State or Province | Example: London | Ext | No | State or Province |
| Country | Example: UK | Ext | No | Country |
| Telefonska številka | Telephone No | Example: +45 20 7025 6161 | Ext | No | Telephone No | Telephone No |
| e-pošta | E-mail | Example: jens@hotmail.com | Ext | No | E-mail | E-mail |
| Preferred HCP/Legal organization to contact[[6]](#footnote-6) | Name of the HCP/Legal organization | Name of the HCP/name of the legal organization. If it is a HCP, the structure of the name will be the same as described in ‘Full name’ (Given name, family name/surname) | Basic | No | Preferred HCP/Legal organization to contact[[7]](#footnote-7) | Name of the HCP/Legal organization |
| Telephone No | Example: +45 20 7025 6161 | Basic | No | Telephone No |
| E-mail | E mail of the HCP/legal organization | Basic | No | E-mail |
|  | Contact Person/ legal guardian  (if available) | Role of that person | Legal guardian or Contact person | Ext | NO |  | Contact Person/ legal guardian  (if available) | Role of that person |
|  |  | Ime | The Name of the Contact Person/guardian (example: Peter. This field can contain more than one element) | Ext | No |  |  | Given name |
|  |  | Priimek | This field can contain more than one element. Example: Español Smith | Ext | No |  |  | Family name/Surname |
|  |  | Telephone No | Example: +45 20 7025 6161 | Ext | No |  |  | Telephone No |
|  |  | E-mail |  | Ext | No |  |  | E-mail |
| **Informacije o zavarovanju** | Številka zavarovanja | Številka zavarovanja | Example: QQ 12 34 56 A | Pending decision by WP3.6 of including it in Basic (in some countries ‘Insurance Number’ is needed for univocal identification of the patient). | Pending decision by WP3.6 of including it in Basic (in some countries ‘Insurance Number’ is needed for univocal identification of the patient). | **Insurance information** | Insurance Number | Insurance Number |

#### Pacienotvi medicinski/klinični podatki

| **Spremenljivka (nivo 1)** | **Spremenljivka (nivo 2)** | **Spremenljivka (nivo 3)** | **Definicija in komentar** | **Nabor podatkov** | **Obveznost** | **Spremenljivka (nivo 1)** | **Spremenljivka (nivo 2)** | **Spremenljivka (nivo 3)** |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Opozorila** | Alergije in »intolerance« | Allergy description | Description of the clinical manifestation of the allergy reaction. Example: Anaphylactic shock, angioedema (the clinical manifestation also gives information about the the severity of the observed reaction) | Basic | No | **Alerts** | Allergies and intolerancess | Allergy description |
| Allergy description id code | Normalized identifier | Basic | No | Allergy description id code |
| Onset Date | Date of the observation of the reaction | Ext | No | Onset Date |
| Agent | Describes the agent (drug, food, chemical agent, etc) that is responsible for the adverse reaction | Basic | No | Agent |
| Agent id code | Normalized identifier | Basic | No | Agent id code |
| **Zgodovina prejšnjih bolezni** | Cepljenja | Vaccinations | Contains each disease against which immunization was given | Ext | No | **History of past illness** | Vaccinations | Vaccinations |
| Brand name |  | Ext | No |  | Brand name |
| Vaccinations id code | Normalized identifier | Ext | No |  | Vaccinations id code |
| Vaccination Date | The date the immunization was received | Ext | No |  | Vaccination Date |
| Seznam rešenih, zaključenih ali neaktivnih problemov | Problem Description | Problems or diagnosis not included under the definition of ‘Current problems or diagnosis’. Example: hepatic cyst (the patient has been treated with an hepatic cystectomy that solved the problem and therefore it´s a closed problem) | Ext | No |  | List of Resolved, Closed or Inactive problems | Problem Description |
| Problem Id (code) | Normalized identifier | Ext | No |  | Problem Id (code) |
| On set time | Date of problem onset | Ext | No |  | On set time |
| End date | Problem resolution date | Ext | No |  | End date |
| Resolution Circumstances | Describes the reason by which the problem changed the status from current to inactive (e.g. surgical procedure, medical treatment, etc). This field includes ‘free text’ if the resolution circumstances are not already included in other fields. Example: It can happen that this field is already included in other like Surgical Procedure, medical device etc, eg: hepatic cystectomy (this wil be the ‘Resolution Circumstances’ for the problem ‘hepatic cyst’ and will be included in surgical procedures) | Ext | No |  | Resolution Circumstances |
| Kiruruški posegi pred najmanj šestimi meseci | Procedure description | Describes the type of procedure | Ext | No |  | Surgical Procedures prior to the past six months | Procedure description |
| Procedure Id (code) | Normalized identifier | Ext | No |  | Procedure Id (code) |
| Procedure date | Date when procedure was performed | Ext | No |  | Procedure date |
| **Zdravstveni problemi** | Seznam trenutnih problemov/diagnoz | Opis problema/diagnoze | Problems/diagnosis that fit under these conditions: conditions that may have a chronic or relapsing course (eg: exacerbations of asthma, irritable bowel syndrome), conditions for which the patient receives repeat medications (eg: diabetes mellitus, hypertension) and conditions that are persistent and serious contraindications for classes of medication (eg: dyspepsia, migraine and asthma) | Basic | No | **Medical problems** | List of Current Problems/Diagnosis. | Problem/diagnosis description |
| ID problema (koda) | Normalized identifier | Basic | No | Problem Id (code) |
| Datum začetka problema | Date of problem onset | Basic | No | Onset time |
| Medicinske naprave in implantati | Opis naprave in implantanta | Describes the patient’s implanted and external medical devices and equipment that their health status depends on. Includes devices as cardiac pacemakers, implantable defibrillator, prothesis, ferromagnetic bone implants etc that are important to know by the HCP | Basic | No | Medical Devices and implants | Device and implant Description |
| ID koda naprave | Normalized identifier | Basic | No | Device Id code |
| Datum vstavljenja?? |  | Basic | No | Implant date |
| Večji kirurški posegi v zadnjih 6 mesecih[[8]](#footnote-8) | Opis posega | Describes the type of procedure | Basic | No | Major Surgical Procedures in the past 6 months[[9]](#footnote-9) | Procedure description |
| ID posega (koda) | Normalized identifier | Basic | No | Procedure Id (code) |
| Datum posega | Date when procedure was performed | Basic | No | Procedure date |
| Priporočila oskrbe | Opis priporočila | Therapeutic recommendations that do not include drugs (diet, physical exercise constraints, etc.) | Ext | No | Treatment Recommendations | Recommendations Description |
| ID priporočila (koda) | Normalized identifier | Ext | No | Recommendation Id (code) |
| Samostojnost/Invalidnost | Opis | Need of the patient to be continuously assisted by third parties. Invalidity status may influence decisions about how to administer treatments | Ext | No | Autonomy/Invalidity | Description |
| ID invalidnosti (koda) | Normalized invalidity ID (if any, otherwise free text) | Ext | No | Invalidity Id code |
| **Povzetek zdravil** | Seznam trenutnih zdravil  (Vsa predpisana zdravila katerih čas jemanja še ni zapadel (če so bila ali niso bila izdana) ) | Aktivne učinkovine | Substance that alone or in combination with one or more other ingredients produces the intended activity of a medicinal product. Example: Paracetamol | Basic | No | **Medication Summary** | List of current medicines.  (All prescribed medicine whose period of time indicated for the treatment has not yet expired whether it has been dispensed or not.). | Active ingredient |
| ID aktivne učinkovine (koda) | Code that identifies the Active ingredient | Basic | No | Active ingredient id code |
| Jakost | The content of the active ingredient expressed quantitatively per dosage unit, per unit of volume or per unit of weight, according to the pharmaceutical dose form. Example: 500 mg per tablet | Basic | No | Strength |
| Farmacevtska oblika | It is the form in which a pharmaceutical product is presented in the medicinal product package (e.g. tablets, syrup) | Ext | No | Pharmaceutical dose form |
| Število enot v odmerku[[10]](#footnote-10) | The number of units per intake that the patient is taking. Example: 1 tablet | Basic | No | Number of units per intake[[11]](#footnote-11) |
| Pogostost odmerka (frekvenca) | Frequency of intakes (per hours/day/month/ week..). Example: each 24 hours | Basic | No | Frequency of intakes |
| Trajanje15 | Example: during 14 days | Basic | No | Duration of treatment15 |
| Datum predvidenega začetka jemanja zdravil | Date when patient needs to start taking the medicine prescribed | Basic | No | Date of onset of treatment |
| **Socialna zgodovina** | Social History Observations | Social History Observations related to: smoke, alcohol and diet. | Example: cigarette smoker, alcohol consumption... | Ext | No | **Social History** | Social History Observations | Social History Observations related to: smoke, alcohol and diet. |
| Reference date range | Example: from 1974 thru 2004 | Ext | No | Reference date range |
| **Zgodovina rojstev** | Expected date of delivery | Expected date of delivery | Date in which the woman is due to give birth. Year, day and month are required. Eg: 01/01/2010 | Ext | No | **Pregnancy History** | Expected date of delivery | Expected date of delivery |
| **»Fizične« ugotovitve** | Vital Signs Observations | Blood pressure | One value of blood pressure which includes: systolic Blood Pressure and Diastolic Blood pressure | Ext | No | **Physical findings** | Vital Signs Observations | Blood pressure |
| Date when blood pressure was measured | Date when blood pressure was measured | Ext | No |  |  | Date when blood pressure was measured |
| **Diagnostični testi** | Blood group | Result of blood group | Result from the blood group test made to the patient | Ext | No | **Diagnostic tests** | Blood group | Result of blood group |
| Date | Date in which the blood group test was done. This field may contain only the year if day and month are not available. Eg: 01/01/2009 | Ext | No |  |  | Date |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **PATIENT SUMMARY DATA**  **(Information about the PS itself)** | | | | | |
| **VARIABLE (nesting level 1)** | **VARIABLES (nesting level 2)** | **VARIABLES (nesting level 3)** | **COMMENTS** | **BASIC (Basic)/EXTENDED (Ext) DATASET** | **MANDATORY Yes/No** |
| **Country** | Country | Country | Name of country A | Basic | Yes |
| **Patient Summary** | Date Created | Date Created | Data on which PS was generated | Basic | No |
| Date of Last Update | Date of Last Update | Data on which PS was updated (data of last version) | Basic | Yes |
| Author/Nature of the patient summary | Author of the patient summary | Author oof the patient summary | To highlight if the data is collected manually by an HCP or is collected automatically form different sources (eg: hospital doctor repository, GPs…etc) through predetermine clinical rules. | Basic | No |
| **Legal entity** | Responsible of the PS data | Responsible of the PS data | At least an author organization (HCPO) shall be listed. In case there is not HCPO identified at least a HCP shall be listed | Basic | No |

1. Data set that enable the univocal identification of the patient. It will be defined in WP3.6 ‘Identity Management’. The variable ‘Birth place’ (Country of birth and place of birth) needs to be evaluated by WP3.6 as in some countries it is needed for univocal identification of the patient. [↑](#footnote-ref-1)
2. Data set that enable the univocal identification of the patient. It will be defined in WP3.6 ‘Identity Management’. The variable ‘Birth place’ (Country of birth and place of birth) needs to be evaluated by WP3.6 as in some countries it is needed for univocal identification of the patient. [↑](#footnote-ref-2)
3. To be aligned with prescription minimum dataset (in D3.1.2 ‘Final definition of functional service requirements-ePrescription’) [↑](#footnote-ref-3)
4. Will be adapted due to the variability of the countries. [↑](#footnote-ref-4)
5. Will be adapted due to the variability of the countries. [↑](#footnote-ref-5)
6. A foreign HCP may need a contact (HCP/legal organization) who knows the patient [↑](#footnote-ref-6)
7. A foreign HCP may need a contact (HCP/legal organization) who knows the patient [↑](#footnote-ref-7)
8. As there is subjectivity in the term ‘relevant’, the date will be used as the limit to include procedures. [↑](#footnote-ref-8)
9. As there is subjectivity in the term ‘relevant’, the date will be used as the limit to include procedures. [↑](#footnote-ref-9)
10. Posology has been defined from the functional point of view as containing these three components: number of units per intake, frequency of intakes and duration of treatment:(example: 1 unit/intake every 24 hours for a duration of 14 days [↑](#footnote-ref-10)
11. Posology has been defined from the functional point of view as containing these three components: number of units per intake, frequency of intakes and duration of treatment:(example: 1 unit/intake every 24 hours for a duration of 14 days [↑](#footnote-ref-11)