



TiredofCancer

Interoperability & Data export of Untire® app

Document control

Owner document

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1. Introduction

1.1 General

This document is a description of the data export used by the Untire® app. The Untire® app aims to reduce fatigue in cancer patients and survivors and improve their quality of life.

This goal is achieved through a combination of interventions:

- Providing insight into the current health situation, e.g. based on experienced fatigue/burden/dissatisfaction/happiness levels, energy levels, mental wellbeing
- Daily physical activity programme to increase fitness, improve muscle strength and general exercise routine (e.g. reduce sitting habits)
- Daily activity programme, which supports patients in managing their energy on a daily basis
- Daily activity programme to improve patients' individual psychological mood through individual behaviour suggestions
- Daily activity programme with exercises to reduce stress (e.g. breathing exercises)
- Psycho-education based on cognitive behavioural theory to support patients, including sleep issues, anxiety problems, self-care, nutrition, worrying, and more.

The content of the Untire® app is in line with the international guidelines for the diagnosis and treatment of cancer-related fatigue from the NCCN (National Comprehensive Cancer Network - USA).

1.2 Objective

This document and its specifications are intended to enable other manufacturers of digital products to further process a patient's data in the Untire® app through a machine-readable, interoperable format.

1.3 Target audience

This document is intended for providers, manufacturers, auditors, assessors and developers of digital health applications, especially in the field of oncology.

1.4 Scope

This document applies to the specification of technical and syntactical interoperability within the meaning of §§ 5 and 6 DiGAV.

2. Export format

2.1 Data grouping

The exported data is based on user inputs and activities in the Untire® app. Specifically, the following data types can be defined in the Untire® app:

- Personal data:
 - Name
 - Gender (if applicable)
 - Birthdate (if applicable)
 - Cancer diagnosis (if applicable)
 - Cancer types (if applicable)
- Measurements: Fatigue, Happiness and Vase of Energy (energy, vase in, vase out, vase leak)
- Therapy data: Reflection steps input

2.2 Data format

Data export in human-readable, printable format

The data is exported in both csv format and PDF. The data is only accessed by the patient through an export function via the Untire® app.

Data export in machine-readable, interoperable format

This export is based on the HL7® FHIR® Standard Version 4.0.1. The following HL7® FHIR® standard structures were used:

Profile Patient: <https://simplifier.net/pku/kbvprmiopspatient>

Profile Results in PDF/A: <https://simplifier.net/packages/nictiz.fhir.nl.stu3.zib2017/2.1.3/files/373752>

3. Export description

3.1 Data export in human-readable, printable format – PDF

This PDF export, format which also complies to Art. 20 GDPR, exports all data of a user into a PDF. It contains the following elements:

- Name
- Gender (if applicable)
- Birthdate (if applicable)
- Cancer diagnosis (if applicable)
- Cancer types (if applicable)
- Start date Untire
- Measurements: fatigue, happiness per date
- Vase of energy: energy value, in/out/leak per date
- Refectionsteps: questions, answer

3.2 Data export in human-readable, printable format – CSV

Events Assessment

CSV export of the measurements Fatigue and Happiness

Example

user_id,date,time,assessment_type,value
100,2020-01-01,20:00:00,HAPPINESS,43
100,2020-01-01,20:00:30,FATIGUE,72

Field Identifier	Description	Format	Validation
user_id	Internal User ID	String	
date	Date of entry	Date	yyyy:mm:dd
time	Time of entry	Time	hh:mm:ss
assessment_type	Measurement	Fatigue Happiness	
value	Score of Assessment type	Value	Between 0 and 100

Journey Entry

CSV export of the journal entries

Example

user_id,date_time,body,Question,description
682,2021-09-10T13:06:17.926+02:00,No expectations,Q: your expectations,"What do you expect form the app?"
682,2021-09-10T13:07:10.911+02:00,No routine,Q: Sleeping routine,"Do you have a routine before you go to sleep? Describe your routine."

Field Identifier	Description	Format	Validation
User_id	ID of input	String	
Date_time	Date and time of input	Date Time	DD-MM-YYYY THH:MM:SS.000+HH:MM
Body	Input of a reflection step	String	
Question	Question of reflection step	String	
Description	Description attached to the question	String	

Vase of Energy

CSV, export of the Vase of Energy

Example

User_id,date_time,value,in,out,leak
682,2021-09-10T10:20:01.000+02:00,74,Yoga,Household,Pain
683,2021-09-10T09:20:46.000+02:00,34,Family,Work,Itching

Field Identifier	Description	Format	Validation
user_id	Internal User ID - Vault	String	
date_time	Date&time of entry	Date Time	DD-MM-YYYY THH:MM:SS.000+HH:MM
value	Energy measurement	Value	Between 0 and 100
in	Vase IN input	Boolean selectbox + String	
out	Vase OUT input	Boolean selectbox + String	
leak	Vase LEAK input	Boolean selectbox + String	

3.2 Data export in machine-readable, interoperable format

Two export profiles are available in two formats; JSON and XML.

Profile Patient

<https://simplifier.net/pku/kbvprmiopspatient>

This profile represents a patient/user.

Patient:  [Patientenkurzübersicht | KBV_PR_MIO_PS_Patient - SIMPLIFIER.NET](#)

Patient contains the following mandatory fields:

- identifier (*Identifier*)
- name (*HumanName*)
- gender ([code](#))
- birthDate ([date](#))

Example JSON

```
{
  "resourceType": "Patient",
  "id": "1e90facb-7e9d-4b54-ab46-94669934c166",
  "identifier": [
    {
      "use": "official",
      "value": "1e90facb-7e9d-4b54-ab46-94669934c166",
      "assigner": {
        "display": "Tired of Cancer"
      }
    }
  ],
  "name": [
    {
      "use": "usual",
      "given": [
        "John Doe"
      ]
    }
  ],
  "gender": "male",
  "birthDate": "01/01/1923"
}
```

Example XML

```
<Patient>
  <resourceType>Patient</resourceType>
  <id>7ca982d3-1241-457c-a046-9786b1d6dd3f</id>
  <identifier>
    <use>official</use>
    <value>7ca982d3-1241-457c-a046-9786b1d6dd3f</value>
    <assigner>
      <display>Tired of Cancer</display>
    </assigner>
  </identifier>
  <name>
    <use>usual</use>
    <given>John Doe</given>
  </name>
  <gender>male</gender>
  <birthDate>01/01/1923</birthDate>
</Patient>
```

```

</name>
<gender>male</gender>
<birthDate>01/01/1923</birthDate>
</Patient>

```

Profile Results in PDF/A

<https://simplifier.net/packages/nictiz.fhir.nl.stu3.zib2017/2.1.3/files/373752>

This profile represents a patients/users progress.

DocumentManifest:  [nictiz.fhir.nl.stu3.zib2017 | Nictiz IHE MHD Profile on DocumentManifest \(SubmissionSet\) - SIMPLIFIER.NET](#)

DocumentManifest contains the following mandatory fields:

- masterIdentifier ([Identifier](#))
- identifier ([Identifier](#))
- status (Code "current | superseded | entered-in-error")
- type (kind of document for example: "Patient Summary")
- subject (Patient Reference)
- created (dateTime)
- author(Reference: [Practitioner](#) | [Organization](#) | [Device](#) | [Patient](#) | [RelatedPerson](#))
- Source ([uri](#), Identifies the source system, application, or software that produced the document manifest.)
- content ([BackboneElement](#), contains an [Attachment](#))

Example JSON

```

{
  "id": "f02b6962-82a8-470c-9b78-bfb71395b945",
  "resourceType": "DocumentManifest",
  "content": [
    {
      "reference": "Attachment/6086aec1-d3b6-48ff-ba34-8415061c4799"
    }
  ],
  "author": [
    {
      "reference": "Patient/a92a71f6-6346-4d3b-a97d-bd40b4f86075"
    }
  ],
  "subject": {
    "reference": "Patient/a92a71f6-6346-4d3b-a97d-bd40b4f86075"
  },
  "status": "current",
  "type": {
    "text": "Patient Summary"
  },
  "created": "2021/09/13",
  "source": "https://www.untire.me"
}

```

Example XML

```

<DocumentManifest>
  <id>b602b38b-7748-4f47-a424-72c8600ba62f</id>
  <resourceType>DocumentManifest</resourceType>

```



```
<content>
  <reference>Attachment/a743e4cf-8d43-490d-a58e-797d0eca3a85</reference>
</content>
<author>
  <reference>Patient/0f5cb983-29b9-47ff-bd66-1841b4f055d7</reference>
</author>
<subject>
  <reference>Patient/0f5cb983-29b9-47ff-bd66-1841b4f055d7</reference>
</subject>
<status>current</status>
<type>
  <text>Patient Summary</text>
</type>
<created>2021/09/13</created>
<source>https://www.untire.me</source>
</DocumentManifest>
```

Attachment:  hl7.fhir.r3.core | [Attachment - SIMPLIFIER.NET](#)

Attachment does not contain mandatory fields, but we should try to use most of the fields

- contentType (application/pdf)
- language (like en-US)
- data ([base64Binary](#): A stream of bytes, base64 encoded) AND/OR url ([uri](#) Uri where the data can be found)
- size ([unsignedInt](#))
- hash ([base64Binary](#))
- title ([string](#) A label or set of text to display in place of the data.)
- creation ([dateTime](#) Date attachment was first created)

Example JSON

```
{
  "id": "c927c785-631c-4fad-89b7-74db95d6e1ec",
  "contentType": "Application/pdf",
  "title": "data_download.pdf",
  "language": "nl",
  "creation": "2021/09/13",
  "data": ""

#example of hashed data

  "=",
  "hash": "The calculated hash of the data using SHA-1. Represented using base64"
}
```

Example XML

```
<Attachment>
  <id>518f4a70-d882-4bb1-84ac-825d3002a965</id>
  <contentType>Application/pdf</contentType>
  <title>data_download.pdf</title>
  <language>nl</language>
  <creation>2021/09/13</creation>
  <data>
```

#example of hashed data

=</data>

<hash>The calculated hash of the data using SHA-1. Represented using base64</hash>

</Attachment>