



## Model Driven Paediatric European Digital Repository

**Call identifier:** FP7-ICT-2011-9 - **Grant agreement no:** 600932

**Thematic Priority:** ICT - ICT-2011.5.2: Virtual Physiological Human

# Deliverable 18.6

## Training Event in year 4

Due date of delivery: 31<sup>st</sup> of May 2017

Actual submission date: 31<sup>st</sup> of May 2017

**Start of the project:** 1<sup>st</sup> March 2013

**Ending Date:** May 2017

Partner responsible for this deliverable: UCL

Version: 0.3



**Dissemination Level: Public****Document Classification**

Title	Training Session in Y4
Deliverable	D18.6
Reporting Period	Fourth
Authors	UCL
Work Package	18
Security	PU
Nature	Re
Keyword(s)	Training

**Document History**

Name	Remark	Version	Date
Vanessa Diaz	Original draft – work in years 1-4	0.1	08-05-2016
Vanessa Diaz	Original draft – work in years 1-4	0.2	08-05-2016
Mirko de Malde	Feedback	0.2	25-05-2017
Cesar Pichardo	Corrections and proofreading	0.2	26-05-2017
Vanessa Diaz	Final additions & corrections	0.3	31-05-2017

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## 1. Introduction

The work performed for the training activities of MD Paedigree was significantly expanded since the project inception, back in 2012 and have changed considerably since the original conception of the project. Initially, training was considered to be part of WP18 “Dissemination and Exploitation”; containing a set of objectives as detailed below, solely focused on the use of training as a vehicle for dissemination and exploitation (verbatim from the DoW).

“Building on the belief that a main goal is to link MD-Paedigree outcomes with clinical practice, the dissemination activities will be developed in close connection with the training. The training activity will be carried out by UCL, that have gained a meaningful experience within the DISCIPULUS (Roadmap Towards the Digital Patient) project. Building on that experience, that brought out the importance of training as the most solid and long-lasting dissemination strategy, MD-Paedigree will organise a number of dedicated workshops with the key aims to expose the outcomes achieved both in disease modelling and in building the Infostructure, highlighting the potential for change management and innovation in the participating clinical centres”

However, training within MD Paedigree evolved considerably in terms of remit and scope, and training became also part of the implementation of the Infostructure. Training and the development of materials for dissemination and exploitation were integral components of the development of the MD Paedigree platform and the training team provided assistance and guided feedback to the developers, as well as feedback in the way the clinicians and platform were interacting.

Between 2016-2017, the training team organised the final training session of MD Paedigree in Leuven and a training event during the bi-annual meeting of the project in Rome, including elements of formal training (and feedback) as well as demonstration purposes, and prepared specific online tutorials for the basic features of the MD-Paedigree Infostructure. The description of such activities is provided below.

## 2. Description of MD Paedigree Training Session During the Meetings in Rome (February 2016) and Leuven (September 2016) - during the MD Paedigree Bi-Annual Meetings

It is important to mention that the work in year 4 of the project was again, expanded from what was originally planned (1 meeting), meaning that the training team interacted with all Infostructure partners all year around.

The elements of preparation for both meetings were *identical* and in order to avoid repetition, the general process will be described here. In fact, in order to familiarise clinicians (who have very limited time to practice with the tools developed by the project on their own) with the resources developed within the Infostructure WP, the delivery of the training was identical, the tools chosen were the same for each event and just refinement of the tools based on the feedback from the first meeting concerning this report (Rome, February 2016) was performed for the last training event (Leuven,

September 2016). It was deemed that familiarisation was an important issue, based on earlier feedback (please see below), as well as getting the clinicians involved in the project used to work with the novel tools and Infostructure the project was developing. A part of familiarisation is the fact that each use of the same tools makes users feel more confident since the learning aspects become less and less prominent and hence users can devote more time to the application of the tools per se and to focus on how 'useful' the tool is.

### **2.1 Recap: Early Feedback, Agile Methodology and Solving Issues**

At the early stages of the development of the platform (year 2 of the project), well ahead of the release of the Beta-version overall feedback about the platform was obtained during the 1<sup>st</sup> training event (bi-annual MD Paedigree meeting in Utrecht, September 2014) and it focused on usability and friendliness. Specific capabilities of the platform were addressed in the 2nd training/demonstration event held in Crete (October 2015) and further capabilities were implemented and polished for the meetings in Rome and Leuven.

#### **2.1.1 Summary of the 1st MD Paedigree feedback session**

During the 1<sup>st</sup> training event the platform was vigorously stress-tested. In general, clinicians engaged with the work to be done and feedback was provided throughout the process. From the sign-in, to the notification e-mail received (security), to the medical terms used to describe the 'operations' or 'tasks' available in the platform. The robustness of the platform was also tested by having a significant number of users engaging with the work simultaneously and reporting back any weaknesses. Different OS were tested (for Mac & Windows) and also tablets (mainly iPads) and laptops. A number of improvements to functionality (small, since functionality was the objective of the meeting in Crete) in terms of simple upload patients' files and categorisation were also highlighted. Further functionality was tested and successfully shown to clinical users during the meetings in Rome and Leuven (details provided below).

As a direct outcome of the first training event and the discussions between the 'technical side' and the 'clinical side' as well as the managing team, the Consortium realised that there was a need to implement changes faster. For this reason, an 'Agile' Project Management approach was adopted for the implementation of the Infostructure, which meant in essence, that problems were highlighted as they appeared and the developers dealt with them continuously. For this, a number of tasks/interactions were included within the work plan in order to improve the interplay among clinicians and technical partners, promoting a feedback-based implementation of the tools developed. Among these activities, a scenario analysis session was included, which formed the core of the 'scripts' described in section 2.2.

### **2.2 Preparation prior to the meeting in Rome and Leuven**

The training team in UCL attended the MD Infostructure teleconferences and requested for each partner involved in the development of tools to develop a 'script' so as to guide the users (and the researchers delivering the training) in the use of the tools. A key element of these 2 training events

was a significant amount of work into uploading different, complete and coherent datasets (part of the project) so that the Infostructure tools could show their full potential.

A very brief summary for each tool during the training (and the 'script') is presented below.

### 2.2.1 Data Curation and validation - DCV DEMO (*Athena*)

**Objective:** The idea of this tool is to produce an automatic data cleaning process to troubleshoot the imported data from the project and to detect numerical outliers, missing values, alphanumeric typographical and logical errors.

During the training event, a link was provided to all project partners (handouts were given) so they could access the tool, as well as a username and password. A step-by-step process was followed for the users to get familiarised with the tool. Users were guide from what the actual database was (Fig 1) to what the visualisation of the analytics would look like (Figs. 2 and 3), including correction tools (Fig. 4) and the computation of a score (Fig. 5)

	date_quest	sex	dob	ethnicity	generation	language	emp_jobtitle_father	emp_jobtitle_mother	dob_mother	wt_kg_mother	wt_lb_mother	wt_oz_mother	ht_in_mother	ht_ft_mother	ht_in_father	dob_father	wt_kg_father	wt_lb_father	wt_oz_f	wt_lb_f
1.	25/09/2014 02:51	Male	01/08/1996	British		English	solicitor	teacher	09/12/1958	72	158	11.73	1.75	5	9	18/12/1965	90	198	6.66	
2.	18/03/2015 06:39	Female	01/07/1996	Turkish			delivery truck loader		01/07/1972	96	211	10.3	1.65	5	5	01/03/1961	110	242	8.14	
3.	17/12/2014 07:20	Male	14/03/1996	British		English	accountant	practice manager	21/02/1964	89.36	197		1.63	5	4	26/08/1965	82.1	181		
4.	22/12/2014 07:43	Male	12/02/2001	British		English	clinical perfusionist	nurse	04/03/1969	63	138	14.26	1.68	5	6	11/05/1970	88	194	0.11	
5.	17/02/2015 07:00	Male	28/04/2001	White and Black Caribbean	Second	English	youth worker	communication support worker / interpreter	08/06/1984	60	132	4.44	1.68	5	6	26/04/1984				
6.	17/02/2015 10:02	Male	21/10/1996	British-French		English	Hedge Fund Partner	HR / Recruitment	26/02/1964	61	134	7.71	1.69	5	6.5	19/10/1961	72	158	11.73	
7.	18/03/2015 10:33	Female	10/12/2000	Caribbean	Second	English	builder	author	23/10/1981	76	167	8.82	1.7	5	7	11/12/1979				
8.	03/02/2015 03:20	Female	25/11/1995	British		English		receptionist/administrator	26/09/1958	108	238	1.59	1.63	5	4	04/07/1957	93	205	0.48	
9.	27/04/2015 04:52	Female	06/11/1997	Caribbean	Second	English			12/06/1974				1.68	5	6	03/09/1973				
10.	01/04/2015 02:00	Male	07/01/1998	White and Arab		English	tutor	cleaner	12/06/1974	115	253	8.51	1.6	5	2.99	10/07/1958	83	182	15.74	
11.	08/04/2015 06:15	Male	30/09/1999	White and Black Caribbean		English	personal trainer / coach	support coordinator	29/08/1980	89	196	3.38	1.7	5	7	09/10/1979	77	169	12.1	
12.	13/04/2015 05:33	Female	22/12/2000	British		English	medical consultant	nurse	03/05/1967	55	121	4.07	1.55	5	1	09/06/1960	90	198	6.66	
13.	20/04/2015	Male	03/11/2001	British		English	evolution biologist	legal assistant	22/03/1970	62	136	10.99	1.71	5	8	23/09/1967	88.9	195	15.86	

Fig. 1: Example database (DCV Demo)

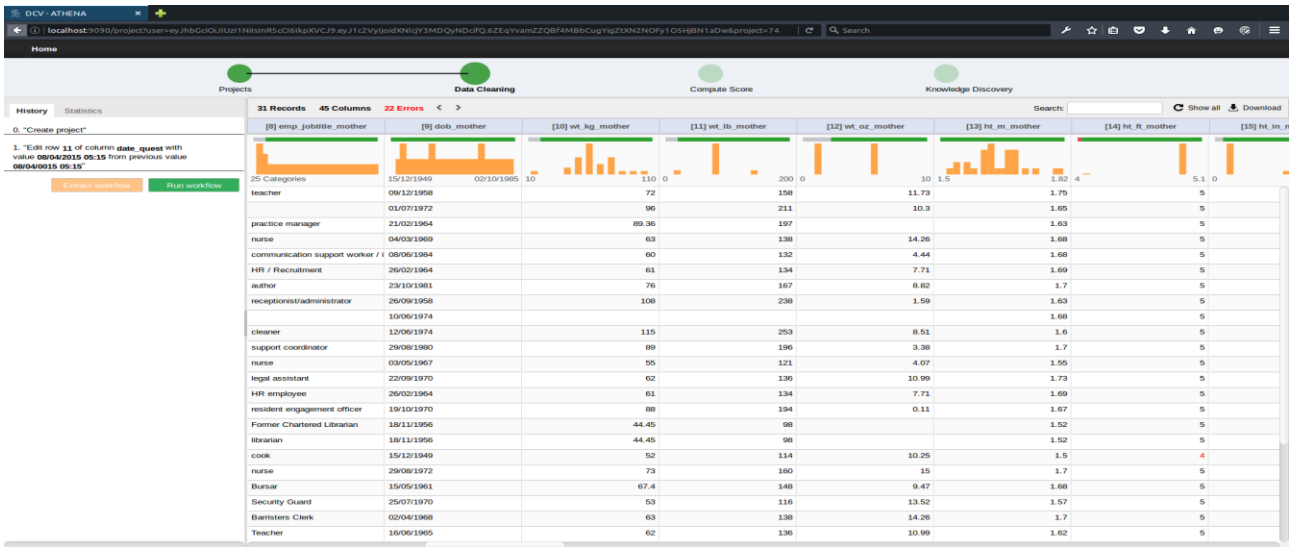


Fig. 2: Visualisations of the DCV tool

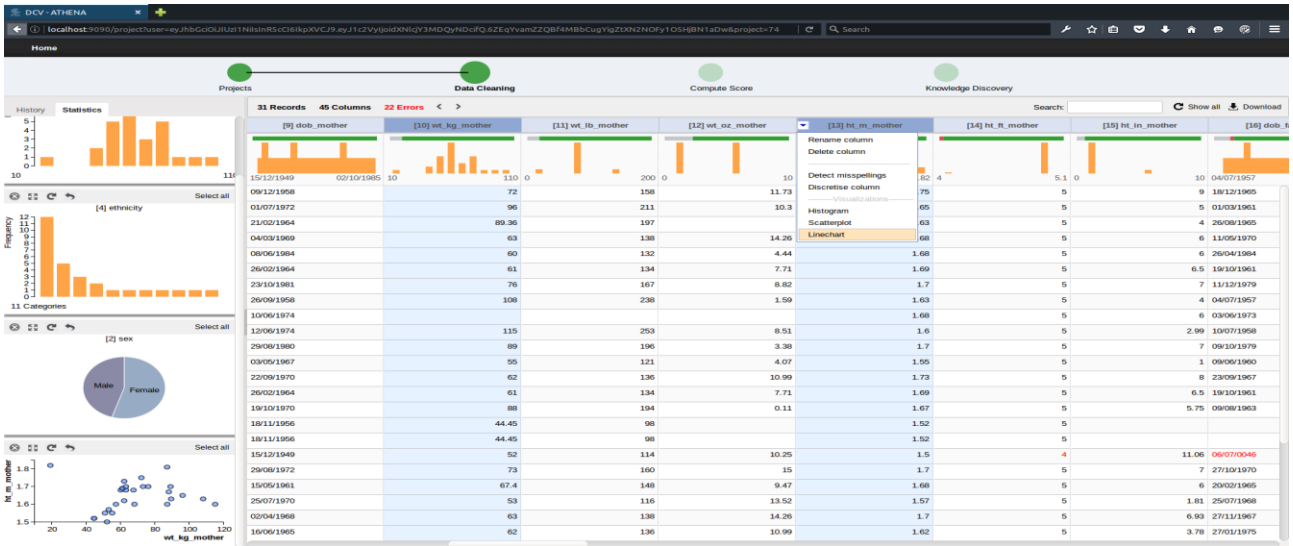


Fig. 3: Visualisations selected functionality (DCV tool)

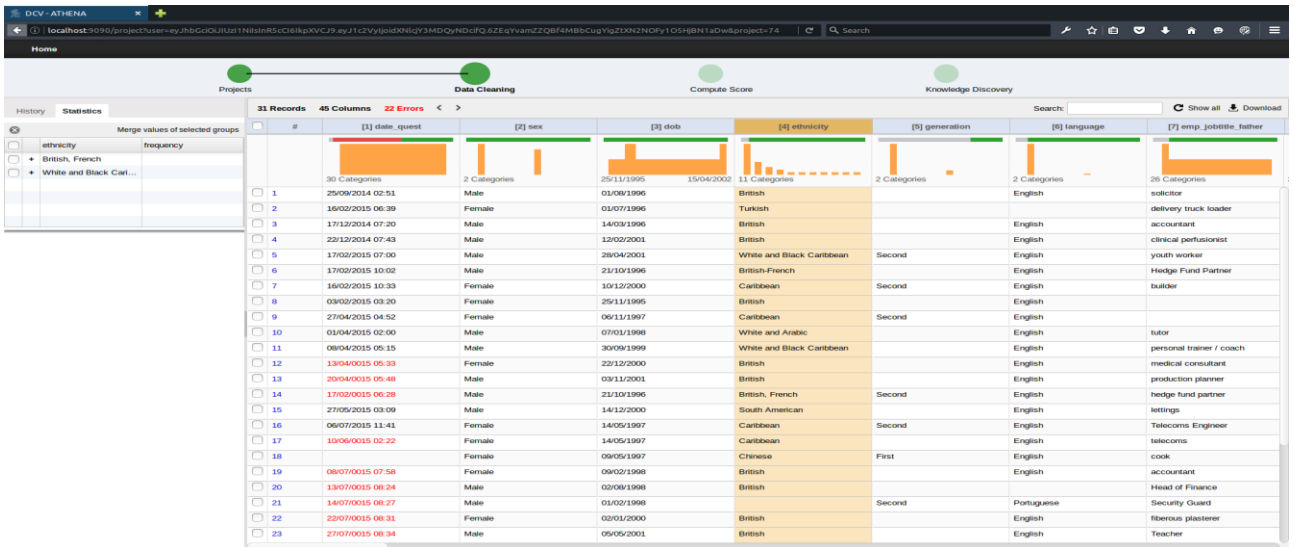


Fig. 4: Detection of errors (misspelling in this case). CDV Tool

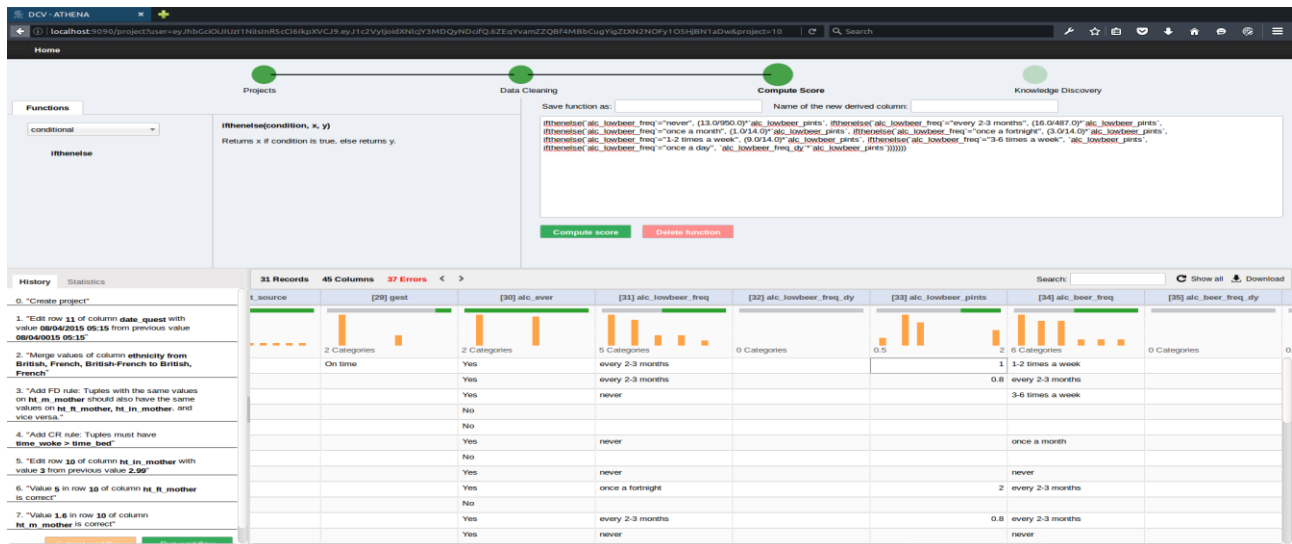


Fig. 5: Computation of Score (CDV tool)

### 2.2.2 Case-Based Retrieval service (CBR) (HES-SO)

Objective: This tool helps physicians to find similar patients based on the discharge synthesis of a given patient. The tool proposes a summary of the returned cases of similar patients at different points in time.

Again, during the training event, a link was provided to all project partners (handouts were given) so they could access the service. A step-by-step process was followed for the users to get familiarised with the tool. The case-based retrieval service is a 4-step process: Query, refinement, filters, results. The user can then iterate (steps 2-4) to refine his query and thus obtain more relevant results. Two examples were presented: one patient being in the PCDR and one not. The figures below serve as an illustration of the first case. From 'loading' patients (Fig. 6) to 'query' of the database to 'refinement' ('MeSH' and 'Rocchio' refinement; Figs. 7 and 8 respectively). Finally, the user is able to apply filters to their query (Fig. 9) and visualise the results (Fig. 10)



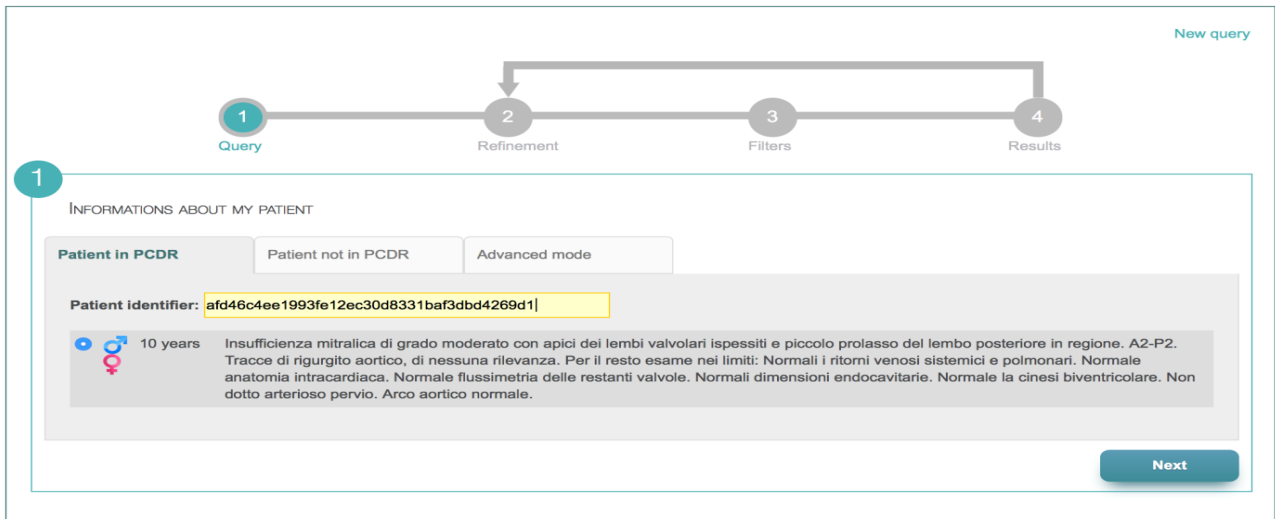


Fig. 6: The physician inserts the patient *id*. The system will automatically load the existing clinical syntheses for this patient. The user can then select any of them (if several).

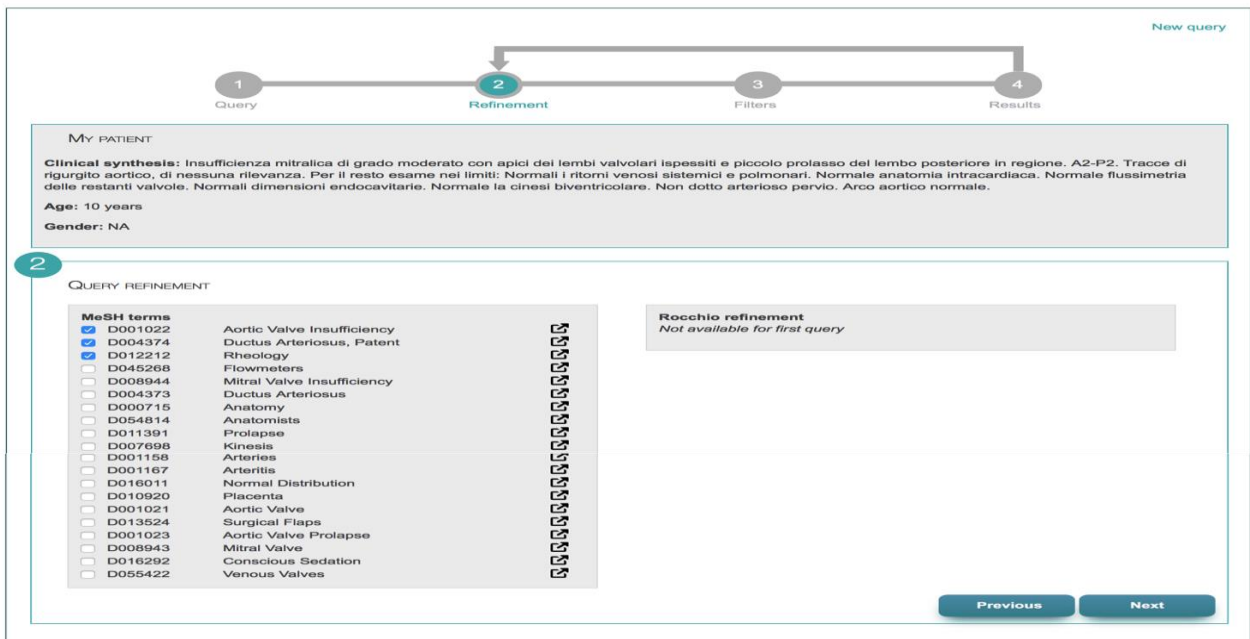


Fig. 7: Refinement (MeSH refinement): consisting on automatically normalising the clinical synthesis (i.e. the query). Up to 20 MeSH terms are suggested, and the top-3 is by default pre-selected. The physician can select/unselect the MeSH terms he wants to add to his query

New query

1 Query → 2 Refinement → 3 Filters → 4 Results

**My PATIENT**

**Clinical synthesis:** Insufficienza mitralica di grado moderato con apici dei lembi valvolari ispessiti e piccolo prolasso del lembo posteriore in regione. A2-P2. Tracce di rigurgito aortico, di nessuna rilevanza. Per il resto esame nei limiti: Normali i ritorni venosi sistemici e polmonari. Normale anatomia intracardiaca. Normale flussimetria delle restanti valvole. Normali dimensioni endocavitarie. Normale la cinesi biventricolare. Non dotto arterioso pervio. Arco aortico normale.

**Age:** 10 years  
**Gender:** NA

**2** QUERY REFINEMENT

<p><b>MeSH terms</b></p> <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> D001022 Aortic Valve Insufficiency</li> <li><input checked="" type="checkbox"/> D004374 Ductus Arteriosus, Patent</li> <li><input checked="" type="checkbox"/> D012212 Rheology</li> <li><input type="checkbox"/> D045268 Flowmeters</li> <li><input type="checkbox"/> D008944 Mitral Valve Insufficiency</li> <li><input type="checkbox"/> D004373 Ductus Arteriosus</li> <li><input type="checkbox"/> D000715 Anatomy</li> <li><input type="checkbox"/> D054814 Anatomists</li> <li><input type="checkbox"/> D011391 Prolapse</li> <li><input type="checkbox"/> D007698 Kinesis</li> <li><input type="checkbox"/> D001167 Arteritis</li> <li><input type="checkbox"/> D016011 Normal Distribution</li> <li><input type="checkbox"/> D010920 Placenta</li> <li><input type="checkbox"/> D001021 Aortic Valve</li> <li><input type="checkbox"/> D013524 Surgical Flaps</li> <li><input type="checkbox"/> D001023 Aortic Valve Prolapse</li> <li><input type="checkbox"/> D008943 Mitral Valve</li> <li><input type="checkbox"/> D016292 Conscious Sedation</li> <li><input type="checkbox"/> D055422 Venous Valves</li> </ul>	<p><b>Rocchio refinement</b></p> <ul style="list-style-type: none"> <li><input checked="" type="checkbox"/> lieve</li> <li><input checked="" type="checkbox"/> atrioventricolari</li> <li><input checked="" type="checkbox"/> principale</li> <li><input checked="" type="checkbox"/> nessun</li> <li><input checked="" type="checkbox"/> semilunari</li> <li><input type="checkbox"/> emodinamico</li> <li><input type="checkbox"/> stimata</li> <li><input type="checkbox"/> assente</li> <li><input type="checkbox"/> escluso</li> <li><input type="checkbox"/> adeguatamente</li> <li><input type="checkbox"/> versamento</li> <li><input type="checkbox"/> rilievo</li> <li><input type="checkbox"/> anteriore</li> <li><input type="checkbox"/> lieve-moderato/moderato</li> <li><input type="checkbox"/> complessivamente</li> <li><input type="checkbox"/> circolo</li> <li><input type="checkbox"/> jets</li> <li><input type="checkbox"/> significato</li> <li><input type="checkbox"/> it</li> </ul>
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Fig. 8: Rocchio refinement: this is based on the episodes of care judged as similar by the physician (in the results section). The clinical syntheses of these episodes of care are taken and the Rocchio service retrieves the most frequent words in these texts.

**1** Query → **2** Refinement → **3** Filters → **4** Results

**MY PATIENT**

**Clinical synthesis:** Insufficienza mitralica di grado moderato con apici dei lembi valvolari ispessiti e piccolo prolasso del lembo posteriore in regione. A2-P2. Tracce di rigurgito aortico, di nessuna rilevanza. Per il resto esame nei limiti: Normali i ritorni venosi sistemici e polmonari. Normale anatomia intracardiaca. Normale flussimetria delle restanti valvole. Normali dimensioni endocavitarie. Normale la cinesi biventricolare. Non dotto arterioso pervio. Arco aortico normale.

**Age:** 10 years  
**Gender:** NA

**3** **FINAL QUERY**

**Query**

Insufficienza mitralica di grado moderato con apici dei lembi valvolari ispessiti e piccolo prolasso del lembo posteriore in regione. A2-P2. Tracce di rigurgito aortico, di nessuna rilevanza. Per il resto esame nei limiti: Normali i ritorni venosi sistemici e polmonari. Normale anatomia intracardiaca. Normale flussimetria delle restanti valvole. Normali dimensioni endocavitarie. Normale la cinesi biventricolare. Non dotto arterioso pervio. Arco aortico normale.

10 years    Unknown gender

Aortic Valve Insufficiency D001022    Ductus Arteriosus, Patent D004374

Rheology D012212

**Filters**  
Show only patients that are...

**Gender:**  
 Male  
 Female  
 Unknown

**Age:**  
From: [ ] years    [ ] months  
To: [ ] years    [ ] months

Previous    Next

Fig. 9: Application of filters

Gender	Age	MeSH	Similar events and future events	Score
1) ♂	10 years	Valvola mitrale [D008943] Dotto arterioso pervio [D004374] Emodinamica [D006439]	Lieve prolasso del lembo anteriore della valvola mitrale con lieve insufficienza di nessun significato emodinamico. Normale la cinesi biventricolare. Non dotto arterioso pervio.	★★★★★
2) ♀	10 years	Dotto arterioso pervio [D004374] Emodinamica [D006439] Rheologia [D012212]	Lieve prolasso ed ipercogeno 1/4 del lembo anteriore mitralico con insufficienza costituita da jets multipli complessivamente di grado lieve-moderato/moderato. Normali dimensioni endocavitarie. Normale.	★★★★★
3) ♂	8 years	Valvola aortica [D001021] Dotto arterioso pervio [D004374] Emodinamica [D006439]	Normali dimensioni endocavitarie e spessori parietali. Normali dimensioni endocavitarie. Arco aortico normale.	★★★★★

Fig. 10: Results. In this part, similar episodes of care are displayed.

### 2.2.3: CaSiReView (Siemens Healthcare)

**Objective:** Given a cohort of patients or a dataset, the objective of this tool is to provide a user friendly and visually intuitive tool to browse and visualise the simulation results, browse modelling results for all patients, inspect left ventricular (LV) volumes, inspect LV pressures, inspect LV ejection fraction, inspect LV SV, inspect cardiac movement over one heart cycle, to report potential issues and finally, to analyse cohort statistics.

As for the other demonstrators, during the training event, a link was provided to all project partners (handouts were given) so they could access it. The link was hosted internally in the Siemens server but an updated tool is now part of the MD Paedigree platform. As with the previous demos, a step-by-step process was followed for the users to get familiarised with the tool.

Users were guided through the tool (Figs. 11-13) by accessing the online version whilst its different features were highlighted. The data presented here was obtained from UCL and uploaded via the interface designed for this purpose.

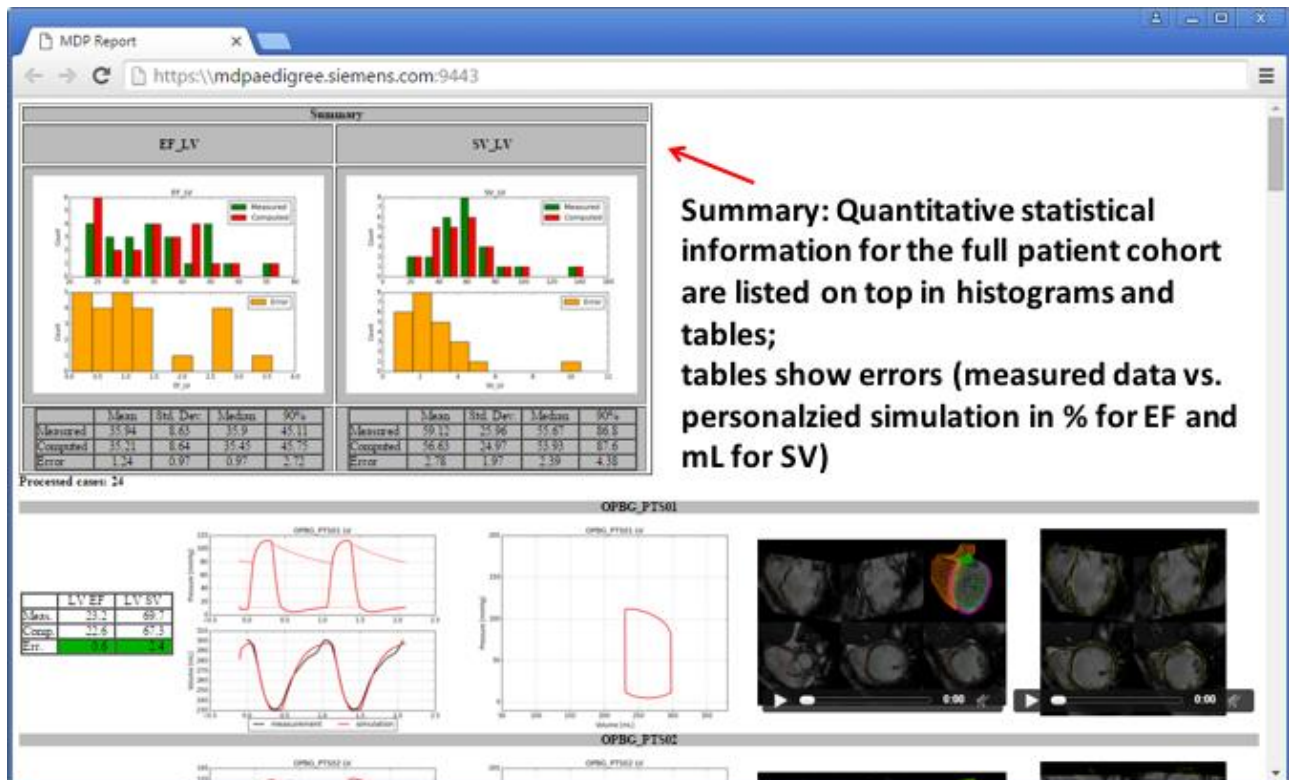


Fig. 11: Summary of the tool and quantitative information of the patient cohort

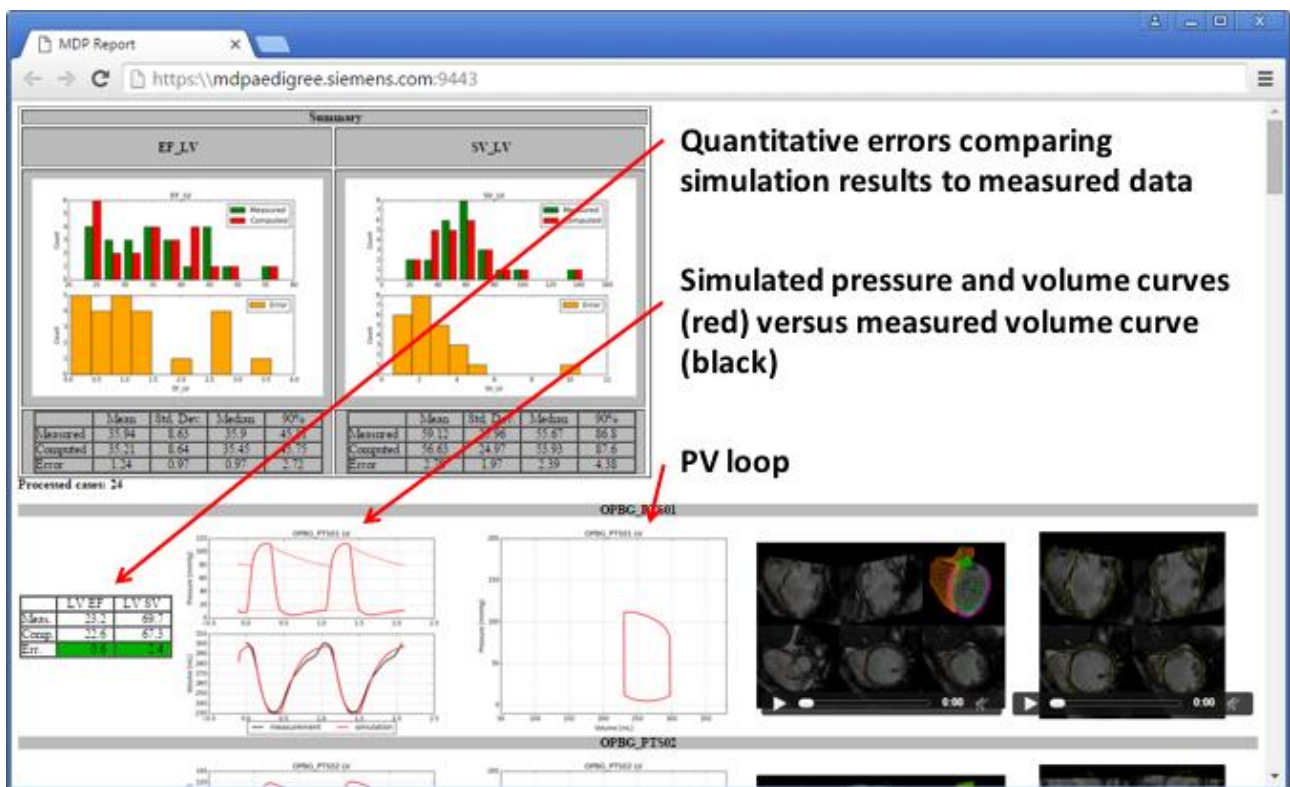


Fig. 12: Information for individual patients including error quantification, including video control (bottom right)

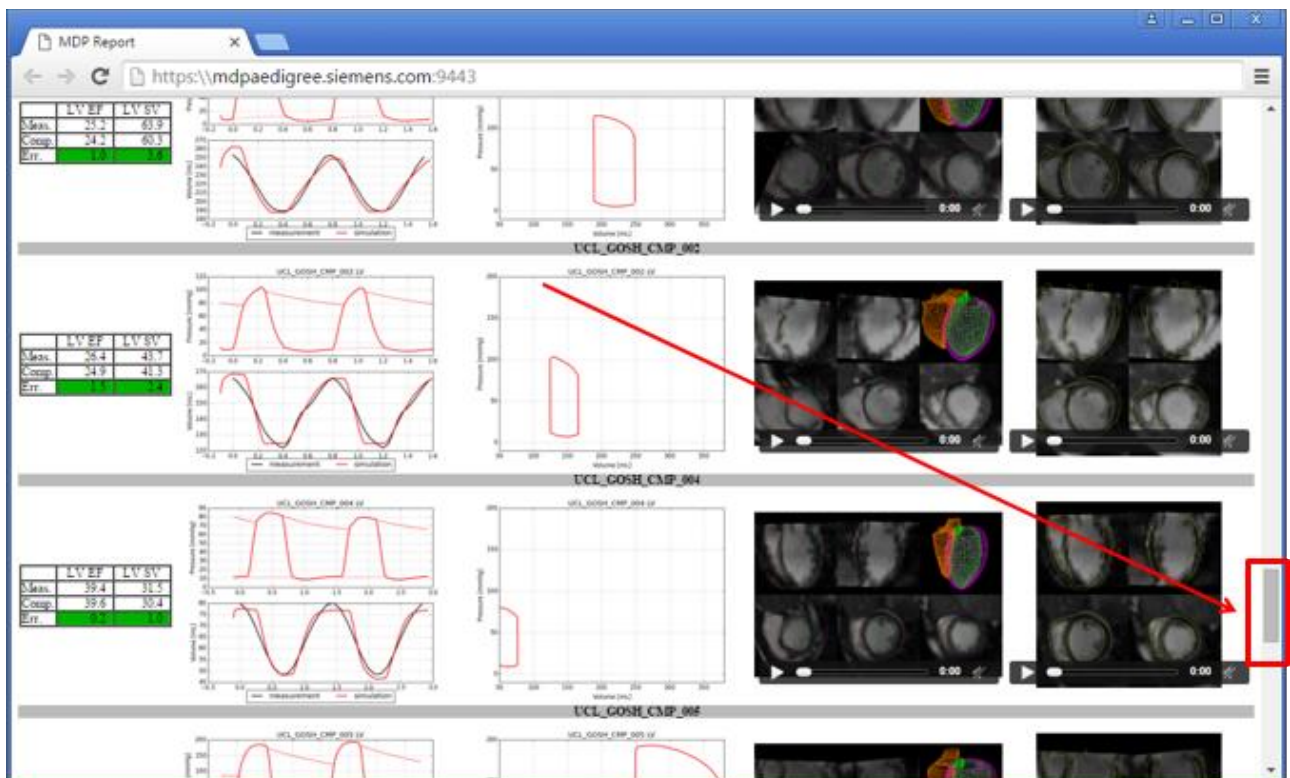


Fig. 13: Browsing through the cohort

### 2.3 Presentation during the meetings in Rome and Leuven

The training session provided an overview of the platform and a step-by-step use of the different tools available. The tutorials covered every aspect of these tools and showed the end users (clinicians) how to start exploring the data space.

The training session had a group of engaged and interested clinicians (Fig. 14) and the feedback was overall extremely positive.



Fig. 14: Training session – clinical group

### 3 Comments and feedback

Prior to the meeting, the developers were asked to share their demo session with the training team to see if these were user-friendly for the meeting (particularly the end users) and also to see if the content of the demos was as expected. This process was also used to provide advice on improvements to the demos. As previously described, a total of three demos were shown prior to the meeting from those listed below.

1. ATHENA: data curation and validation (mainly based on one of the end users' cases)
2. Siemens: Case reasoner; showing the same similarity search features based on several variables such as age and vessel diameter.
3. HESSO: case based retrieval service

A number of comments and suggestions were given to the software developers by the training team on their demos; these were mainly on the examples used (if it was easy to follow and challenging/useful enough to show) or if there was a missing function (for example a legend or use of a better colour tab).

### 3.1 Addressing Previous Feedback

Prior to the demo presentations, the training team asked the end users to provide their constructive comments and to feel free to interrupt the presenter or wait for the time given in the end of each presentation.

It is important to mention that after the training events, users were positive about the tools and developers received a number of supportive comments, such as 'I would definitely use this tool for my work' which validate the design process. For completeness, previous feedback is presented below but it is important to highlight that developers *did address these comments in their entirety* and the user community was satisfied.

For completeness, a brief summary of previous Feedback (as presented in 18.3) is shown below:

1. ATHENA: a few comments were given regarding
  - A better definition for time-woke and time-bed options
  - The connection between the patients in a line chart
  - Ordering the x-axis in a plot
  - Filtering down the data
  - Scaling the parameters
  
2. HESSO: several comments were given to improve the functionality, the comments were on;
  - Discharge summary
  - English translation (it is only in Italian at the moment)
  - The ranking of the similarity algorithm
  - The outcome of the time function
  - How is the query defined
  - Weighing the importance of the similarity (if certain things are important than others, to prioritise)
  - A better visualisation of different icons
  - Inclusion and exclusion of time
  - The conclusion of each patient must be better accessed
  - The type of data that can be processed
  
3. Siemens: A general set of questions were asked and addressed;
  - How many features can be handled?
  - How many options can you select?
  - What type of data will be needed?
  - Can it be completely automated?
  - Can the engine be taken out so the data run is performed elsewhere?

## 4 Conclusion

The remit of the initial training activities during MD Paedigree was significantly expanded during the life of the project. All concerns and questions were documented during and after each training session from years 2 to 4, which ultimately led to the development of clinically relevant and useful tools for the MD Paedigree platform. This was evidenced by increased satisfaction from the clinical user groups, with the last session (Leuven) providing extremely positive comments and clinicians willing to use the tools in their daily work. Part of the success was due to the fact that training was used dynamically inside the project as a tool to gather feedback, instead of focusing solely on the delivery of the tools. For future applications, the recommendation is that 'training' activities are also part of the Implementation (in this case 'Infostructure') work package and part and parcel of the evaluation of the tools.