Model Driven Paediatric European Digital Repository

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First Half-Yearly report

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Nature of this Deliverable

This Deliverable provides a brief account of the work carried out during the first 6 months of the MD-Paedigree Project.

Given the fact that the period covered by thisreport does not coincide with any yearly reporting period, the Deliverable doesn't follow the template provided for by the Commission for the official Periodic Reports.

Short description

During the first six months of work, the main achievements have been the following:

- Holding the kick-off meeting
- Launching the MD-Paedigree website
- Establishing the Project Management Infrastructure
- Discussing and reviewing the clinical protocols for each area
- Getting the ethical clearance from various local Ethical Committees for all clinical WPs
- Starting the gathering of User Requirements
- Preparing the first dissemination materials
- Enrolling a valuable new partner in substitution of a withdrawing partner.

During the 6- month period several meetings and telephone conferences (TCs) have been held for each of the five project's subgroups: Coordination & Management, Cardiomyopathies & Obesity, JIA, Neurologic & neuro-muscular diseases (NND), Infostructure. There were altogether 18 TCs and 9 physical meetings involving varying numbers of partners.

A half-yearly general meeting is already scheduled to be held in Genoa (Italy), hosted by IGG, on October 14th-15th, 2013.

MD-Paedigree's website has been up and running since the start of the project. However, some sections are still being completed, while the continuous updates are being made and will continue to be so.

Almost all MD-Paedigree partners have joined the Management Platform and, in the following months, specific training sessions to enhance the utilization of the platform will be jointly organized by the Coordinator and the Project Manager.

During this first 6-month phase, the preparation of an amendment to the DoW has been necessary as a consequence of the withdrawal from the project of an American partner, the Johns Hopkins University (JHU). A lengthy process of analysis within the consortium has been necessary to this effect, leading to the unanimous choice of substituting JHU with a prestigious new partner, namely the Deutsches Herzzentrum Berlin. This amendment has been submitted to the European Commission.

Overall, all MD-Paedigree planned activity for the first 6 months has been steadily progressing, all expected objectives could be achieved, and all the relevant deliverables have been submitted.

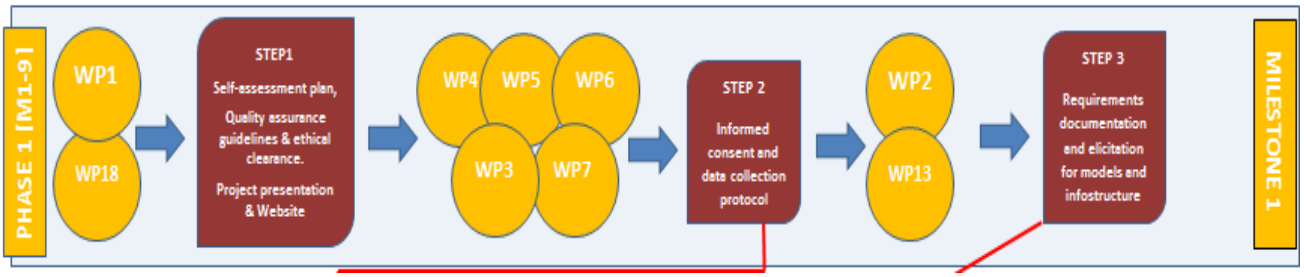
MD-Paedigree's objectives for the first 6 months of the M1-M9 Phase

As described in the DoW, the MD-Paedigree project is planned to roll out in 4 major phases, each comprising a series of conceptual steps going through 4 major milestones and spread over 48 months of activity. The first milestone is due at M9.

During this first 6 months of Phase 1, the main objectives of the project have been:

- *On the management side, the Project Set-up:* organisation of the Kick-off meeting, implementation of the Management and Cooperation Platform, preparation of the self-assessment plan, preparation of the first dissemination activities and documents.
- *On the clinical side, the agreement on the Clinical Protocols and informed consent forms*: detailed discussion on the clinical protocols and subsequent agreement amongst all partners for each clinical area on the study protocols and relevant informed consent forms; obtaining ethical clearance from the local Ethical Committees of the clinical centres.
- *On the technical side, the requirements elicitation*: requirements for models and infostructure implementation analysed and documented from an end user standpoint, through interviews to all relevant partners.

The following brief scheme of activities was also reported in the DoW, as results from the following except from the Figure 15 - Conceptual flow-chart of phases and steps fulfilling the project's milestones, as results at p. 145 of the DoW (p. 34 of the Part B):



Deliverables due by month 6:

Deliverable	Expected Delivery	Delivered
D1.1 - Kick-off meeting report	M2	✓
D1.2 - Project Presentation	M4	✓
D1.3 - Self-Assessment Plan	M6	✓
D1.5.1 First Half-Yearly report	M6	✓
D3.1 - Form of Informed consent and study protocol for DCM: approval by the local Ethical Committees	M3	✓
D4.1 - Data collection protocol and ethical clearance	M4	✓
D5.1 - Report on data collection protocols and parents and patients informed consents	M4	✓
D7.1 – Recruitment protocol with ethical clearance	M4	✓

Main achievements in the current reporting period

WP Number	WP Title	Lead Partner	Achievements

WP1	Coordination & Project Management	OPBG	**1) Organisation of the kick-off meeting:** held in Rome on March 13th, 2013, attended by altogether 71 researchers. In view of the event, a number of documents were prepared: • Kick-Off meeting agenda • Disease Areas and Infostructure Working Groups basic documents and self-assessment requirements (one for each of the 5 working groups) • Various introductory presentations by the Coordinator, the Project Manager, the Leader of the Infostructure Area. • Draft clinical protocols for all clinical areas (JIA, NND, cardiomyopathies, cardiovascual disease risk in obesity, genetics) as a basis for the discussion. • During the meeting, there were also: • a photographic recollection of the former projects which led to MD-Paedigree • a brief demonstration of the EmDesk Management and Collaboration platform. • Project logo selected by a vote from alternatives presented at the meeting. **2) EmDesk Platform:** Contractual negotiation to have a dedicated EmDesk Management and Coordination Platform and its uploading into the system. Within the platform, various groups for cooperation and relevant mailing lists have been set-up. Moreover, the project documents (both official ones, i.e. deliverablesand working documents) have been uploaded in the platform. A more in-depth explanation of the EmDesk Platform is provided in a dedicated paragraph in this report. **3) Amendment to the DoW:** the unexpected withdrawal of Johns Hopkins University (JHU) from MD-Paedigree has required a decision by the consortium on how to substitute JHU and the preparation of a subsequent amendment to the DoW to be submitted to the EC the) indicating as selected new partner the Deutsches Herzzentrum Berlin (DHZB). **4) Teleconferences system**: after a number of tentative tests, the GoToMeeting Teleconferencing tool has been selected and used for the project's TCs. The system allows using both VoIP and normal telephone in the course of the same TC according to the communication needs and facilities of different partners. It also allows screen sharing and other useful communication and cooperation tools.

			Furthermore, the system allows the full recording of the TC, which may be useful for drafting the subsequent minutes. **Recruitment of Independent Committee Members:** the Coordinator, together with the Chairmen of the Independent Committees, has started the selection of the other members of these Committees to be proposed for acceptance by the Governing Board. This process is is still ongoing. **Preparation of the Self-Assessment**: An effort wich required the active involvement of all WPs.

WP2	Clinical and technical user requirements for disease modelling	OPBG	Requirements elicitation and documentation has started, conducting interviews with the clinical and technical partners and distributing a questionnaire aimed at getting a complete list of requirements for disease modeling, taking into account the parallel effort developed in WP13 for the requirement analysis implied by the repository designing. A general criterion has been that use of MD Paedigree should possibly not add to clinical workload. A common goal with WP13 will be achieving the ability to search repository using criteria such as searching by: age, image modality, anatomical structure, pathology, keywords, image similarity. Particular attention must be kept on allowing easy upload of images and associated metadata, support for free-text or unstructured text reports, curation of uploaded data, automatic data anonymisation or pseudonymisation, automatic annotation of anatomical regions and detection of modalities, learning from usage pattern of users, support for data modelling and simulation in 3D, as well as for eventually getting to a unified repository for clinical and research systems, with a rating system to assess the quality of stored cases.
WP3	Data acquisition and processing for Cardiomyopathies	OPBG	**Clinical protocols:** The work in these first months focused mainly on clinical protocols. The forms for informed consent, for data collection and the study protocol have been discussed, implemented and approved by the coordinator's local Ethical Committee. Approval by UCL's local Ethics Committee is still pending. Furthermore, an agreement about standard to export 3D data has been reached. **Sample images sharing:** OPBG sent to UCL (uploading on the EMDesk Platform) sample data/ example studies (not linked with any patients), containing 3D mesh echo points in 3D Raw data format (IE33). The ultrasound scans from the cooperation between MAAT and OPBG have migrated within the project. From these scans, a number of variables have been selected and arranged between Siemens and MAAT and they will now be used for specific sub-study. UCL sent to Siemens an ideal sequence and the short axes stack of the heart, although the list of variables is not ready yet for the data entry system of the infostructure and the CaseReasoner. A general understanding has been reached about the fact that the CaseReasoner should be filled with some basic data (e.g. blood tests...) in principle, and adaptation will occur over time, due to the variables that will enable more unknown things to do with the raw data.

			New partner for cardio studies: WP3 discussed, together with WP4, the option of introducing a new partner for both cardiac studies (WPs 3-4) after the withdrawal of JHU or rather leave it only to OPBG and UCL to perform these studies. After a lengthy discussion, it was preferred to have an appropriate new partner substituting JHU. A joint decision was eventually taken, and the Deutches Herzzentrum Berlin was invited to join the project. However, this means a reduced number of patients enrolled for the obesity study (20) with a coinciding increase in the number of those which will be enrolled by the other two clinical centres, but with an equal share of the cardiomyopathies patients.

WP4	Data acquisition and processing for the estimation of CVD risk in obese children	UCL	**Protocols:** the work in these first months focused mainly on clinical protocols. The forms for informed consent, for data collection and the study protocol have been discussed, implemented and approved by the coordinator's local Ethical Committee. UCL have submitted documents to the local Ethics Committee who will meet to discuss approval on 9th October. **Imaging :** A general agreement for the file format of ultrasound data has been reached. OPBG sent raw 3D data from Philips IE33 down with the X3 probe (4b2volume acquisition) for processing. UCL uploaded DICOM files of MRI fat data and vascular data online. **Abdominal area imaging:** Data of the abdominal area: The full trunk and abdomen and legs down to the knee for the fat segmentation (which includes liver and pancreas etc.) have been uploaded by UCL. In terms of implementation, UCL uses state of the art sequences for fat water separation, but there is uncertainty on how to process the organ fat. In some respect this will be a specific challenge for Fraunhofer.
WP5	Data acquisition and processing for Juvenile Idiopathic Arthritis	IGG	**Protocols:** the work in these first months focused mainly on clinical protocols. The forms for informed consent, for data collection and the study protocol have been discussed, implemented and approved by the coordinator's and by IGG's local Ethical Committee. Full approval by UMCU's local Ethical Committee is still pending (the majority of the data collections has already been approved). The UMCU has defined protocols for collecting and storing biological samples by the different partners. **Recruitment of Patients:** Recruitment of Patients started after the ultrasound assessment, at the end of June. **MRI Protocol has been discussed** For USFD the main use of imaging sequences is to get an accurate and detailed reconstruction of the region around the joint. It was therefore preferred to have a better resolution rather than the complete foot analysis. USFD appears now to be able to extract all the information

			needed from the provided images sets. **DXA** DXA protocols have been discussed, also during a dedicated meeting held in Genoa at the end of June. IGG will provide a preliminary draft of the protocol that will be discussed with all colleagues from Utrecht during the next MD-Paedigree meeting which will be held in Genoa in October. **Gait Cycle Analysis** A meeting has been held in Rome and a protocol for Gait Cycle Analysis has been developed. **Ultrasound** Another meeting has been held in Genoa to discuss the protocol for ultrasound. An initial protocol has been approved and will be tested in clinical practice before final approval by the partners IGG, OPBG and UMCU. **Laboratory** A laboratory protocol has been made to describe the initial processing, storage and logistics of the blood samples (for Luminex analysis) and the stool samples (for microbiome analysis).

WP6	Data acquisition and processing for NND	VUmc	**Protocol** The work in these first months focused mainly on clinical protocols. The forms for informed consent, for data collection and the study protocol have been approved by the coordinator's local Ethical Committee. Approval by VUmc's and by KU Leuven's local Ethical Committee is still pending. KUL created an extended document outlining their detailed gait analysis and physical exam measurement protocols. VUmc and OPBG are in the process of comparing this to their own protocols, in order to come to a consensus. With regard to data availability for modelling (WP11), having pointed out that to build statistical models initial MRI data are needed, the possibility of OPBG providing some MRI retrospective data has been discussed. KU Leuven has got retrospective data on gait analysis but not on MRI data. **Other issues on protocols** ➢ The definition for MRI has been completed by USFD and SIEMENS, and it will be written down into a formal document to be approved: 20 MRIs will be provided by the OPBG. ➢ SIEMENS and USFD were chosen as responsible for the implementation of the protocols for MRI and DXA data collection to be added as appendixes to the general NND protocol. **ESMAC Conference** VUmc has organised a stand and a banner to promote the MD-Paedigree initiative amongst the attendees at The European Society of Movement Analysis for Adults and Children (ESMAC) in Glasgow (4th-7th September). **Data Quality document (Draft)** A Data Quality Draft has been circulated and uploaded on EmDesk by Paolo Cappa (URLS). After a suggestion from Vumc, about the quality in marker location accuracy, technical accuracy, and time synchronisation, prof. Cappa will expand from the kinematic to the kinetic quality evaluation to include also the force measurements or the synchronisation of the two systems. Also the i*n situ* calibration of force platform has been

			discussed, and URLS will proceed with another draft about the force platform calibration and then an overall exam of the two aspects. The level of accuracy for Image Analysis has been discussed: given the fact that it would make no sense to look at submillimeter accuracy for the marker if the clinical applications don't need it, VUmc will come up with requirements derived from these applications, and then tune MD-Paedigree's measurements to achieve those requirements. **DXA protocol dedicated TC.** OPBG is available to perform additional DXA (total aprrox. 80 subjects) and MRI images (3 scans / month) of healthy subjects). This sample of unaffected children will serve as control population for DXA/MRI. Further discussion is however still ongoing among the NND partners and details still need to be finalized.

WP7	Genetic and metagenomic analytics	OPBG	Study protocols, forms for informed consent and for data collection for genetic studies have been completed and included in each clinical area's documents, and approved by local Ethical Committees. Specific agreements on the procedure for sample collection and processing have been made. In detail: a) blood samples (WP 3, WP 4) will be processes *in situ*, with DNA extraction by the Partner enrolling th patient. DNA samples will be shipped regularly to BMR Genomics where they will be stored and analized; b) foecal samples (WP 4 and WP 5) will be shipped directly to OPBG where they will be stored, processed and analysed. In particular, UCL will directly proceed with DNA extraction rather than send the setup samples. UCL will however follow the same procedure as OPBG starting with the same structure samples. Procedure: • send directly the protocol with quantity of extractive DNA • share 16Sr sequences: if UCL needs them, OPBG will send the sequences to amplify by 16sr the content of the bacteria within the DNA before processing it with the ~~bio~~sequenc~~y~~ers. A number of 90 samples should arrive from UCL. The DNA extraction protocol will be shared among the clinical partners.
WP8	Modelling and simulation for Cardiomyopathies	SIEMENS	Both OBPG and UCL have provided basis examples of short axes stack and flow sequences allowing to compare the (UCL's are faster) leaving to Siemens the decision on how to parameterise the data. UCL is also going to provide Siemens with cross section of the aorta.
WP9	Modelling cardiovascular risk in the obese child and adolescent	SIEMENS	After the upload of abdominal trunk images, a complete unprocessed case and some images of it still need to be processed, in order to see how it was segmented manually. Also several cases with examples of artifacts are needed, in order to assess what difficulties the system may eventually find when faced with automatically processing. Also organs' examples are still needed.
WP10	Modelling and simulation for JIA	USFD	The WP contributed to the definition of the acquisition protocols (imaging and gait) of the data that will be necessary to generate the individualized models. These protocols were defined in close agreement with those defined in WP5 relative to the clinical studies; a group of 10 children will be examined with the agreed protocols in

			each institution, and the relative data will be shared with the technical partners for the relative modelling activities. Partner USFD overviewed the instrumentation and protocols in use at each clinical centre, examined the best protocols reported in the literature for the detailed movement analysis of the ankle region, and promoted a methodological review with the gait analysis experts at the other partner institutions. As a result, in a meeting among all these experts held on June 4th in Rome, where also some tentative trials were performed to check the methods and to clarify their application to all participants, the pediatric gait analysis protocol for JIA patients was agreed, which was formalised by partners OPBG, URLS and USFD and circulated to all clinical partners. The WP also agreed on the position of markers for the co-registration between the NMR and Gait Analysis protocol. Regarding to the imaging for JIA patients, IGG circulated a set of MRI images obtained with various sequenencies; these images were revised by partners USFD and and Fraunhofer IGD in the light of their use to generate individualised models. A series of modifications were discussd with IGG radiologists, which produced an agreed MRI protocol, that IGG formalised and circulated to all clinical partners. Similar activities were started for the DXA imaging protocol. While the imaging in itself was easily agreed, the protocol is not closed yet because there is still an on-going discussion on the data formats, which should be completed soon. Requirements for modelling have been discussed and a pathway has been established: 1) define the anatomical structures that are going to be modelled from a biomechanical point of view. 2) annotate the images on patient 0, to identify in every image the appropriate anatomical structure, also through an interaction between clinical and technical partners. 3) provide the clinical partners with appropriate software tools to exchange the files. URLS is now developing the software to obtain the joint angles from c3d files. The software will possibly be shared with other partners.

WP11	Modelling and simulation for NND	MOTEK	**Data availability:** OPBG has collected test images which Siemens is checking. A few more are needed before Siemens can circulate the test images and the suggested scan protocol. The next step forward is to analyse the images at SIEMENS and then give the extracted parameters to Motek. Even if, initially, just few images are available, Siemens can make a start to develop segmentation on one or two MRIs Also the DXA scans need to have the models built from the MRIs. There has been a discussion regarding the parameters that have to be extracted in the segmentation. Eventually, for the parameters which have been discussed, the first priority is segmentation of bone, muscles and fat tissues (yielding segment mass and inertia as well as muscle strength measures). Based on this, in the next stage, anatomical landmarks will be extracted. **Model scaling** Motek, TUD and Vumc started a litarature review on the different available scaling methods and the sensitivity of model outcome for these parameters. **Model adaptations** WP6 focusses on the clinical protocols, and markertemplates for clinical gait analysis. Motek, VUmc en TUD are discussing the consequenses of the changes in marker models for the Human Body Model which can be devided: a) Anatomical calibration, patient specific joint centers b) Functional axes hip/knee c) Additional degrees of freedom knee/ankle d) Modeling bone deformaties based on physical exam Motek started adapting the Human Body Model to enable it to be rebuild with other data sets looking at the connections between OpenSIM/Physiome and the Human Body Model.
WP12	Models validation, outcome analysis and clinical workflows	OPBG	WP12 is due to start on Month 13.

WP13	Requirements and Compliance for the MD-Paedigree Infostructure	HES-SO	An initial list of requirements has been established after stakeholder interviews. Priority domains have also been defined. The work performed has been been useful for WP2.
WP14	Grid-Cloud Services Provision and GPU Services Integration	MAAT	The existing OPBG Paediatric Cardiac Digital Repository (PCDR) provides already abundant numerical data and imaging data, to which additional MRI data are going to soon from UCL, as soon as anonymisation issues are settled. A GPU demo is scheduled for the joint Infostructure seminar due to take place in Geneva on September 4th. With regard toT14.3 Athena Distributed Processing (ADP) Engine Integration, there has been considerable work in integrating the ADP and madIS frameworks, as well as work on bug fixing and ptimizations. Concerning testing of the frameworks, we have set up a cluster of 16 virtual machines and have been testing with various test data sizes (from 32 GB to 0.5 TB).
WP15	Semantic Data Representation and Information access	HES-SO	A physical meeting and TCs were held together with GNubila, ATHENA, and Lynkeus; 1. Sizeable sample data of the PCDR have been shared; 2. A list of high priority and content bearing fields has been defined to initiate the project's data catalogue - preliminary ETL queries have been generated by MAATG; 3. a secure certificate is being requested to access the clinical repository; 3. A subset of the data has been automatically enriched with termino-ontological descriptors (MeSH); 4. This subset, which will serve as basis to benchmark the automatic text categorizer is ready and should be soon sent to the clinical experts; 5. A request to obtain additional field contents has been sent to GNubila/OPBG; 6. A draft web service to operate the automatic text categorizer has been set up with basic Graphic user interfaces: http://eagl.unige.ch/MHita/; 7. Discussions have been initiated with epSOS to use the epSOS' Master Value Set to structure the project's data catalogue; 8. A search engine with a basic graphic user interface is currently being drafted on the draft basis of D13.1's requirements (lead: HES-SO Valais); 9. An ICT2013 networking/demonstration session on Big Data involving WP15 has been submitted and accepted [attendees: Emilie, Patrick, Henning and Ranveer]; 10. An infostructure meeting with representatives of WP 13, 14, 15, 16, will be held in HES-SO Geneva, on the 4th of September; 11. HES-SO's services to connect MD-Paedigree with

			legacy/external databases (MEDLINE, PubMedCentral...) will be presented during this meeting.

WP16	Biomedical Knowledge Discovery and Simulation for Model-guided Personalised Medicine	ATHENA	The task assigned to WP16 is due to start on Month 13.
WP17	Testing and validation	ATHENA	WP17 is due to start Month 18.
WP18	Dissemination &Training	LYNKEUS	WP18 performed a series of preliminary actions: The project website has been designed and developed during the first month of the project and went online at the end of March. The website contains key information regarding the project and it partners. It will be updated at the beginning of the next six months of activity, including also a specific section on the achievements at the basis of the ongoing work. The dissemination team has already developed also a project ID-Card and the project presentation (due within WP1). A press release has been produced, and it was a good surprise to see it successfully included into several EC media: **Facebook**: https://www.facebook.com/EU.eHealth?ref=hl **Twitter**: https://twitter.com/EU_eHealth **DGConnect website**: https://ec.europa.eu/digital-agenda/en/news/eu-awards-12-million-euros-supercompute-healthier-future-europe%E2%80%99s-children **eHealth Newsletter** (ehealth@EC.europa.eu) on 13 June, 2013: http://ec.europa.eu/digital-agenda/en/news/eu-awards-12-million-euros-supercompute-healthier-future-europe%E2%80%99s-children Furthermore, in cooperation with the Infostructure group, two proposals were submitted, and eventually accepted, for havin MD-Paedigree participating to the forthcoming ICT'13 Conference in Vilnius, with both a Networking Session, dedicated to "Big data and data analytics impact in healthcare", and an exhibit on the project's goals. Several dissemination events were also attended to within the first 6 months of activity.
WP19	Exploitation, HTA, and Medical Device Conformity	EMPIRICA	An intensive review of the HTA state-of-the-art with respect to the VPH domain has started, and the development of a set of meaningful criteria, their operationalisation and their measurement process is underway towards analyzing (1) the facilitation of collaboraton across the relevant VPH communities by MD-Paedigree tools, services and data, and

			(2) the value-added for development acceleration of models, and for their uptake and integration into ongoing RTD work and studies. Initial work in preparation of the Exploitation Seminar foreseen for M18 has started, with discussions involving mainly the Infostructure partners and the clinical centres.

Description of issues emerged in the current reporting period

Work Package	Issue
WP1	The withdrawal of JHU and the substitution with DHZB eventually led to an amendment to the DoW.
WP4	OPBG will start collecting patients' MRIs for the Obesity study only at the end of the year, because of a delay in the delivery of a new Siemens MR machine that will allow OPBG to ensure optimal data quality. At In UCL data collection on Obesity images can start earlier, having both US and MRI fast aligned on the same patient, possibly performed on the same day.
WP5	**Issues at UMCU**: UMCU has different equipment to perform gait cycle analysis, compared to OPBG and IGG. Calibrating and standardizing the two different systems would be too complicated. The solution to this issue is that partner UMCU will not perform gait cycle analysis (nor DXA, since that is only useful for patients who underwent gait cycle analysis). They will nevertheless include patients with ankle involvement. The total number of enrolled patients will not be changed.
WP6	**Protocols**: There is a complex issue with regard to the protocol in WP6. This complexity comes from the following reasons: a) the clinical protocol is actually composed of two different protocols - one for SMA and DMD patients, and one for the CP and the control patients; b) the current protocols do not seem to be specific enough with regard to how to collect the data, how to place markers and how to do the physical examinations: these specifications are missing and should be further clarified in order to allow for the necessary alignment of the data collection. Each lab has their own specific protocol, and it is a difficult task to develop a protocol that allows both continuation of the normal clinical workflow (backward compatibility) as well as consensus to yield comparable data between labs. c) additional technical protocols are required for the Clinical Gate Analysis and for DXA and MRI scans. This explains why there has been some amount of

	delay in the completion of all these protocols and in the submission to VUmc and to KU Leuvens Ethical Committes, which are howevernecessary steps in order to start the patient enrollment.
WP11	There is a partial bottleneck in data collection, and this affects both segmentation and landmarks. We need first a sufficient amount of data before statistical models can be developed.

Financial, administrative and consortium management relevant information

Financial and administrative information

The Coordinator has promptly distributed the pre-financing to all partners.

No financial issues were raised in these first months of activities.

The Online platform for management and collaboration has been established.

EmDesk project management application

The MD-Paedigree Consortium selected the EM-Desk Web Platform for project management, coordination and cooperation activities.

EMDESK is a web-based project management application tailored to FP7 and to the EC reporting requirements. It is an "all-in-one" solution for Coordination, Reporting and Collaboration that delivers features for keeping the research project on track, in particular, according to deadlines, costs and resources, and for delivering on time reports and deliverables to the EC.

The system allows for a significant number of activities:

Administration, finance and reporting:

- Cost reporting & controlling
- Resources reporting & controlling
- Calendar of the project
- Deliverables monitoring and management
- DoW update (amendment)
- Download of automatically generated reports (financial, management and scientific)

Cooperation:

- Communication with other partners (send emails to specific groups of partners, mailing lists).
- Discussion and cooperation amongst partners on specific issues, through the **Forum** and the **Wiki** section.
- Scheduling events, like specific disease area's TC's, and invite those who are requested to attend.
- Upload of documents in the dedicated Document repository, making use of specific folders with different types of access rights.

Consortium management

The initial consortium composition has been slightly altered after the withdrawal of the Johns Hopkins University of Baltimore from MD-Paedigree.

The withdrawal was due to the displacement of a key person, in charge for the obesity study, to another institution. This displacement has eventually led to the impossibility, for the JHU, to perform that study as initially established in its contractual commitment. For this reason, JHU eventually preferred to withdraw from the project, before signing the Grant Agreement.

After some discussion within the consortium and especially with the other partners involved in the obesity studies, it has been unanimously decided to substitute JHU with another partner.

After a preliminary exploration, the choice has fallen upon the Deutsches Herzzentrum of Berlin, a renowned centre of excellence in in heart disease research.

A formal ad hoc amendment to the DoW has been submitted to the EC at the beginning of August.

MD-Paedigree's meetings

The following tables report about the project's cooperation activities that have been performed in this first six months.

Physical meetings

Meeting	Location and data
Kick-Off Meeting	OPBG, Rome – 13/14 March
Meeting at USFD for VPHShare-MD-Paedigree integration.	USFD, Sheffield - 23rd April
Meeting at UCL for discussion on cardio protocols coordination	GOSH, London – 24th April
HES-SO-OPBG requirements analysis	OPBG, Rome, 2nd May
Meeting of the Infostructure group for requirements analysis	GnNubila, Argonay (France) – 3rd June
Meeting at the Palidoro site of OPBG for discussing on paeditric Clinical Gait Analysis	MARlab OPBG, Palidoro, 28th May
Meeting of the JIA group (only IGG and Utrecht) for protocol discussion	IGG, Genoa 28thJune
Meeting at OPBG (Rome) for clinical coordination	OPBG, Rome – 8th July
Planned meeting of the Infostructure group for requirements analysis and participation to ICT '13 in Vilnius	HES-SO, Geneva - 4 September

TCs' List

	Teleconference	Date
1	CVD Risk in obese children - Management and Technical Coordination Board	April 5th
2	Cardiomyopathies e CVD risk in obese children & Management and Technical Coordination Board	April 26th
3	Cardiomyopathies e CVD risk in obese children & Management and Technical Coordination Board	May 17th
4	NND & Management and Technical Coordination Board	May 23rd
5	JIA & Management and Technical Coordination Board	May 29th
6	Cardiomyopathies e CVD risk in obese children &Management and Technical Coordination Board	June 13th
7	Infostructure GNubila-Siemens follow up	June 14th
8	NND & Management and Technical Coordination Board	June 20th
9	JIA & Management and Technical Coordination Board	June 28th
10	NND Group & WP6 dedicated meeting	July 2nd
11	Cardiomyopathies e CVD risk in obese children & Management and Technical Coordination Board	July 3rd
12	NND Group & WP6 dedicated meeting	July 4th
13	NND Group & Management and Technical Coordination Board	July 11th

14	JIA Group & Management and Technical Coordination Board	July 22nd
15	Infostructure Group & Management and Technical Coordination Board	August 21st
16	JIA Group & Management and Technical Coordination Board	August 26st
17	NND & Management and Technical Coordination Board	
18	Cardiomyopathies e CVD risk in obese children & Management and Technical Coordination Board	August 27th

Dissemination activities

Conferences, Workshops attended/organised/foreseen

A list of the external meetings (conferences, workshops, etc.) with date and place held during the reporting period or foreseen for the next reporting period is given in the table below with a brief description of type, scope and number of persons attending events.

Title of the event	Date & Place	Attendees from the project
eHealth week	13 - 15 May 2013 - Dublin, Ireland	Edwin Morley-Fletcher - Lynkeus
1ère Journée e-Health	Sierre, Switzerland	Henning Mueller – HES-SO; Edwin Morley-Fletcher
7th International Conference on Functional Imaging and Modeling of the Heart - FIMH	20-22 June –London, UK	Andrew Taylor – UCL (was a speaker at the event), Edwin Morley-Fletcher
Towards personalised and in silico medicine: eHealth Action Plan and VPH European Parliament	26 June, Brussels, Belgium	Edwin Morley-Fletcher
22nd Annual Meeting of the European Society for Movement Analysis in Adults and Children - Esmac	5 - 7 September - Glasgow, UK	Jaap Harlaar, Marjolein van der Krogt - VUmc ; Marije Goudriaan, Kaat Desloovere (KUL); Maurizio Petrarca (OPBG); Edwin Morley-Fletcher *Exhibit booth*
Forthcoming		
ICT '13	6-9 November – Vilnius, Lithuania	• Bruno Dallapiccola, Giacomo Pongiglione– OPBG • Edwin Morley-Fletcher – Lynkeus • David Manset –GNubila • Iannis Ioannidis – Athena • Henning Muller – HES SO • Andrew Taylor – UCL and others *MD-Paedigree Exhibit Booth and Networking session on Big data and data analytics impact in healthcare on Nov. 7th.*

Articles/Papers published, Press coverage, Website development

Type, Title and Scope	Month	Details/Comments
MD-Paedigree Website	March	All of core website content developed and website launch.
MD-Paedigree's "business card"	May	MD-Paedigree's business card produced. The card has the project logo on one side and a link to the website on the other side. It has no personal information and so can be distributed by any project partner.
MD-Paedigree's project presentation	May	Deliverable due for M3, consisting of a PowerPoint presentation, both animated (for projection) and static (for printing), and of MD-Paedigree's "Big Picture" for poster printing.
MD-Paedigree's first press release	May	Press release to inform the general public about the project. Circulated also through official EC's media.
MD-Paedigree's ID Card	June	ID-Card containing a general description of the project in layperson language, main consortium details, link to the project website, clear acknowledgment of the EC contribution to the project.
MD-Paedigree's Twitter account	June	Registration of MD-Paedigree's Twitter account.
MD-Paedigree's poster for ESMAC	August	A specific poster for the Esmac event has been prepared, focusing on the NND part of the project.

Conclusions

Apart from substantially expected complexities in finalizing the Ethical Committes' approval at all clinical sites, the project can be deemed to be on track and on time.

A swift solution was found for the unexpected withdrawal of the American clinical partner JHU, who were be substituted with the prestigious Deutsches Herzzentrum Berlin (the ad hoc amendment has been recently submitted).

An excellent synergy has been established among all the MD-Paedigree partners, and there is smooth communication and understanding between clinical and technical researchers.

A proof of the level of integration quickly achieved will be given by the joint exhibit in preparation for ICT'13 in Vilnius, where some initial advanced functionalities of the repository will be demonstrated, based on routine clinical data provided for by participating hospitals.