



European
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for rare or low prevalence
complex diseases

 **Network**
Vascular Diseases
(VASCERN)

8.30-12.15: PLENARY SESSION

8.30-9.00: **Welcome by Prof Guillaume Jondeau and brief introduction by all participants (30')**

9.00-9.45: **VASCERN Structure & Organisation: State of play 1 ? (45')**

Presentation of VASCERN & Functioning since March (20') (Guillaume Jondeau, Marine Hurard)

Feedback, Q&A and discussion (25')

9.45-10.05: **VASCERN Patient Group (ePAG) (20')** including Q&A

ePAG involvement within VASCERN, co-presentation by the Patient Group Chair & EURORDIS (Paolo Federici, Matt Bolz-Johnson)

Q&A

10.05: coffee break

Photo booth

10.20-11:20: VASCERN 1st year Action Plan: State of play 2 (60')

Objectives & state of play of Work packages (Marine Hurard) & Feedback from the Council (Guillaume Jondeau and WGs Chairs: Julie de Backer, Claire Shovlin, Leema Robert, Miikka Vikkula, Sahar Mansour, Alessandro Pini, Leo Schultze Kool, Paolo Federici) (40')

Q&A and discussion (20')

11.20-12.15: **Achievements, Challenges & Opportunities for ERNs (55')**

The ERN Policy (Anna Carta, ERN Team, DG SANTE, European Commission) (10')

The ERN Collaborative platform and the Clinical Patient Management System (Jean-Marie Misztela)(10')

ERN Board of Member States views (Muriel Eliazewicz, French representative at the ERN Board of Member States) (10')

European Joint Programme on Rare Diseases Research: opportunities for ERNs (Daria Julkowska) (10')

Q&A (15')



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VASCERN 1st year Action Plan: State of play March 2017-February 2018

WP1	Sharing of experience: discussion of difficult clinical cases on a secured Clinical Patient Management System (CPMS) by each VASCERN Rare Disease Working Groups
WP2	Definition of patients pathways by each VASCERN Rare Disease Working Groups
WP3	Creation & Development of a cross-border pathways Mobile Application for IOS & Android
WP4	Pills of Knowledge
WP5	Registries: working towards the creation of a VASCERN registry - Survey of existing registries and biobanks - Common Minimum dataset
WP6	Clinical trials
WP7	Availability of conferences on YouTube
WP8	Definition of clinical outcomes
WP9	Writing recommendations (J1, J2) J1: Clinical recommendations J2: Do's and Don'ts factsheets
WP10	Communication - Website - Social Networks - Monthly Newsletters - Collaborative Platform (internal communication) - Translation of material directed to patient care information



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WP1	Sharing of experience: discussion of difficult clinical cases
WHO?	5 RDWGs monthly HCPs discussion on clinical cases, cooperation with eHealth & Ethics WGs
HOW?	Monthly RDWGs 1 hour virtual meeting ERN collaborative platform for sharing documents, Minutes, forums, shared agenda, news Clinical Patient Management System (CPMS) to discuss & upload patient cases
DESCRIPTION	Offering clinical virtual consultations , cross-border healthcare for rare vascular diseases. Sharing of experience between highly specialised experts .
OBJECTIVES	Improve patient care for rare vascular diseases using telemedicine, tele-expertise , advices, sharing expertise cross-border: <ul style="list-style-type: none">• expert forum for difficult clinical cases• constitute a bank of clinical cases available in the CPMS• creation and use of VASCERN clinical education tools based on summaries
MILESTONES	Monthly 5 RDWG Meetings: agenda point/ professional forum for clinical cases discussion, sharing and collecting clinical cases Minutes of Meeting & cases report
INDICATORS	Number of clinical cases summaries discussions Numbers of summaries Number of clinical cases available in the platform and for education purposes
TARGETS	Cases discussed: 3/month Summary available: 3/month Total number of upload: 1/month Upload for training purposes: 3/year
TIMELINE	Start from M1(without the patient case management system) M5/6 (availability of the Patient Case Management System) to M12
DELIVERABLE	M12 Document / Report Patient Case report summary available in the shared patient case management system Creation of education tool based on these summaries



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RDWG Chairs Report & Feedback

WP1 Discussion of difficult clinical cases

- Report on **clinical cases discussions (M1>M7)**
 - HHT: 7 cases discussed
 - HTAD: 3 cases discussed (started in July)
 - MSA: 4 cases discussed
 - PPL: 4 cases discussed
 - VASCA: 6 cases discussed
- Testing & use of the **CPMS** for case discussions
 - By the end of the year



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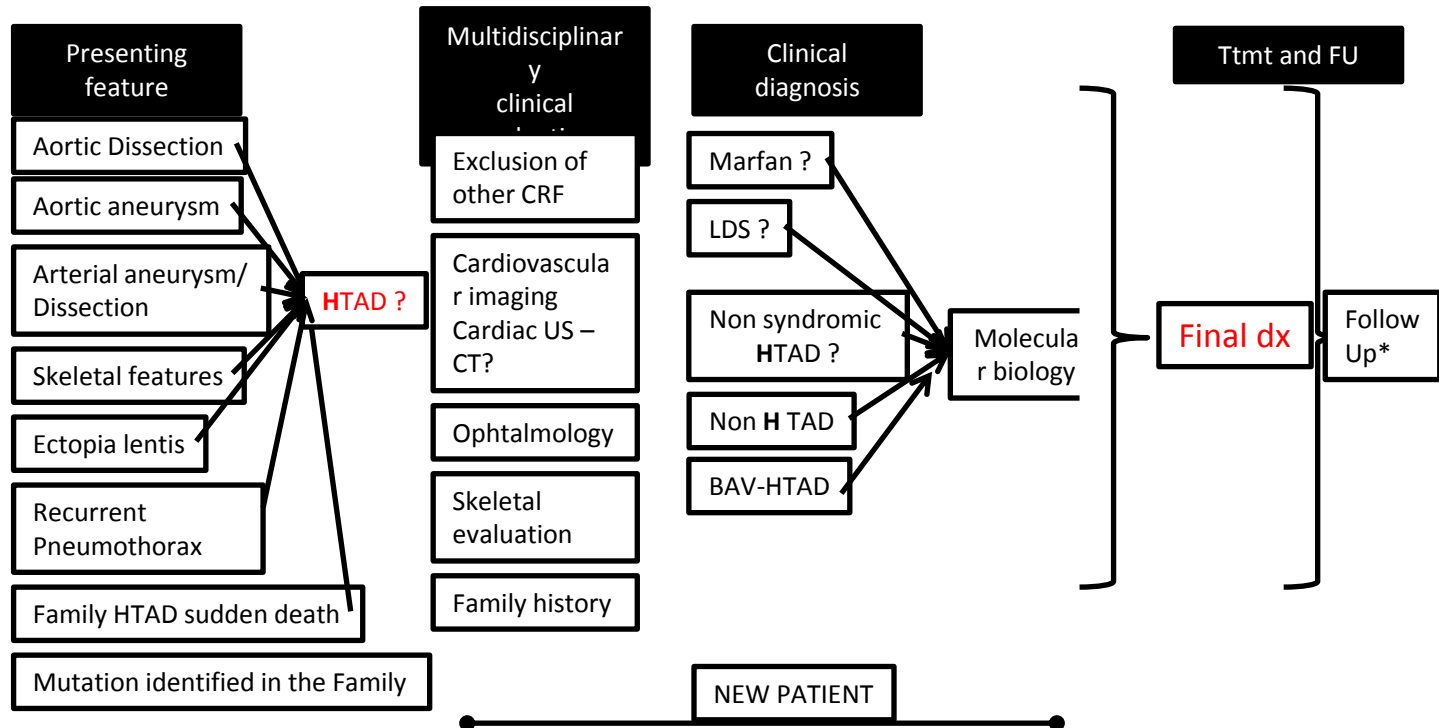
WP2	Definition of patients pathways
WHO?	RDWGs , cooperation with the Patient Group and Ethics
HOW?	Monthly RDWGs 1 hour virtual meeting ERN collaborative platform for sharing documents, Minutes, forums, shared agenda, news
DESCRIPTION	Discussion within RDWG to deliver a patient pathway. Priority of VASCERN (to be delivered during the first 6 months) to enable derivation of quality of care measures and outcome measures, to be thereafter disseminated as education tool, to help new centers. This measure is necessary before choosing relevant and consensual outcomes in the different diseases of the network. It is essential to be able to respond to the EU expectations from the ERN.
OBJECTIVES	1 patient pathway/RDWG , indicating the optimal mode of evaluation of a patient for diagnosis, the optimal evaluation of the patient once the diagnosis is made, the optimal follow-up and the optimal therapy, enable derivation of quality of care measures and outcome measures.
MILESTONES	Monthly RDWG meetings and patient group meetings : point on patient pathways M6: 1 st version patient pathways for each RDWG drafted and circulating M12: discussion of additional patient pathways
INDICATORS	Number of pathways published
TARGETS	5 patient pathways/year circulating, 5/year consolidated, 5/year outcome measures derived
TIMELINE	Consolidated patient pathway to derive outcome measures: M1- M6 for the first pathway per RDWG. Diffusion of the first 5 pathways (1/RDWG): M6-M12; discussion of additional pathways as necessary in the RDWG: M6-M12 . Implementation: pathways will have to be updated on a regular (annual) basis.
DELIVERABLES	M6 first Patient pathways available for each RDWG , for dissemination and deriving clinical outcomes measures M12 improved version patient pathways



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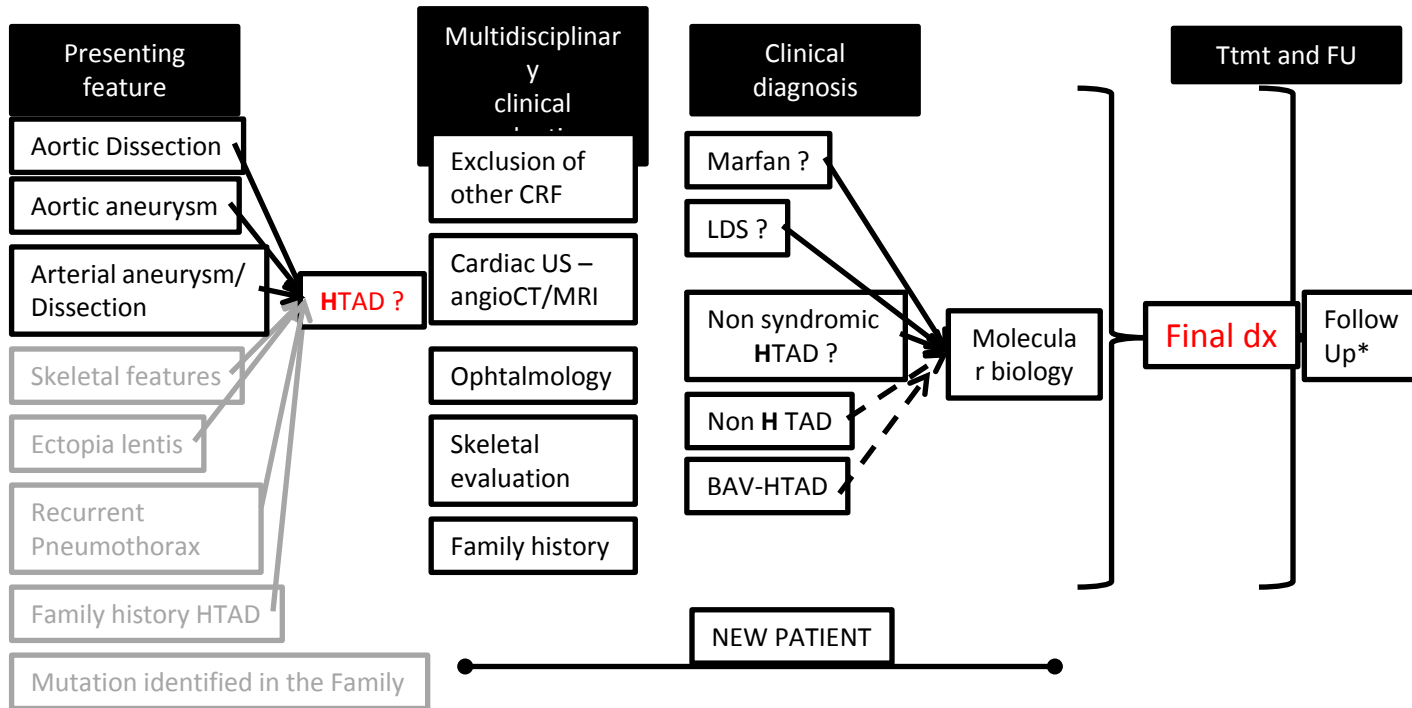
*In accordance with clinical need and geographical location. Should include 1) Ongoing access to services on demand
2) Ongoing support of local medical teams
3) Individual follow up as required for new clinical indications such as pregnancy, new symptoms assessment...



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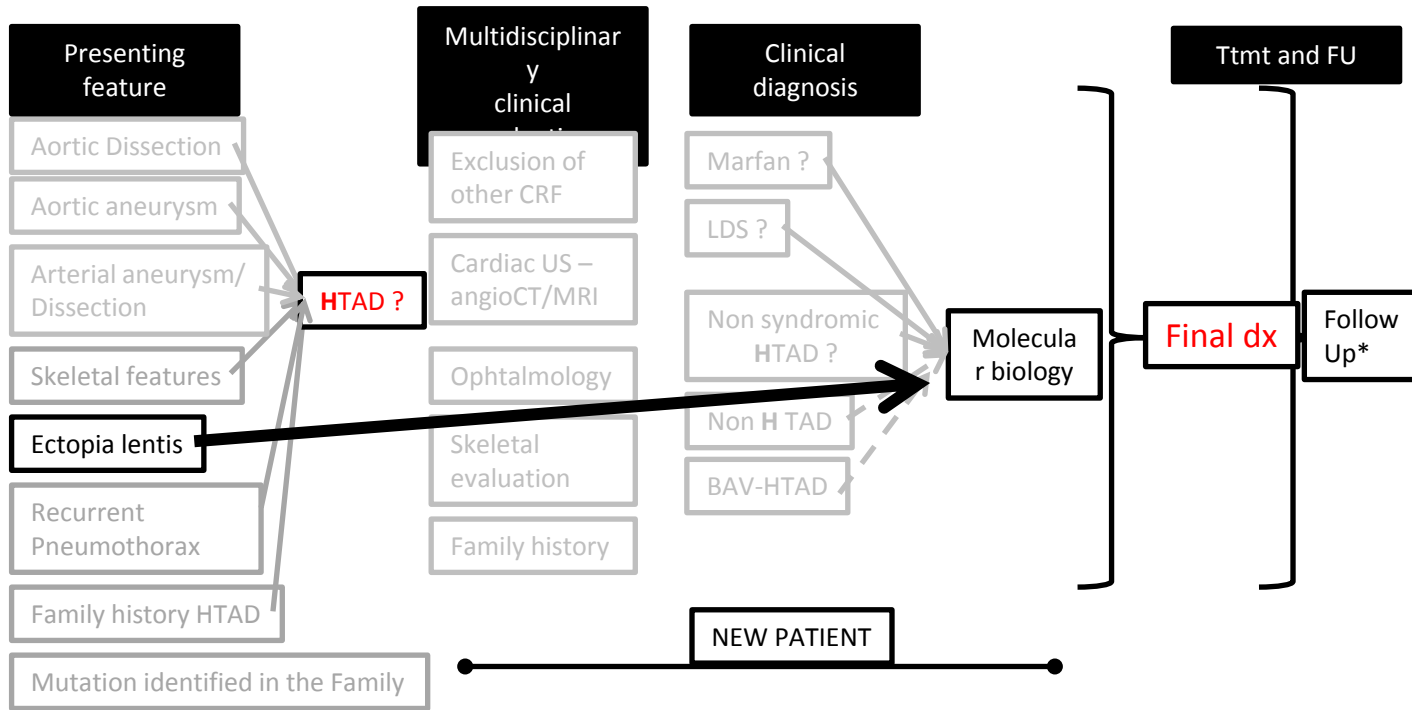
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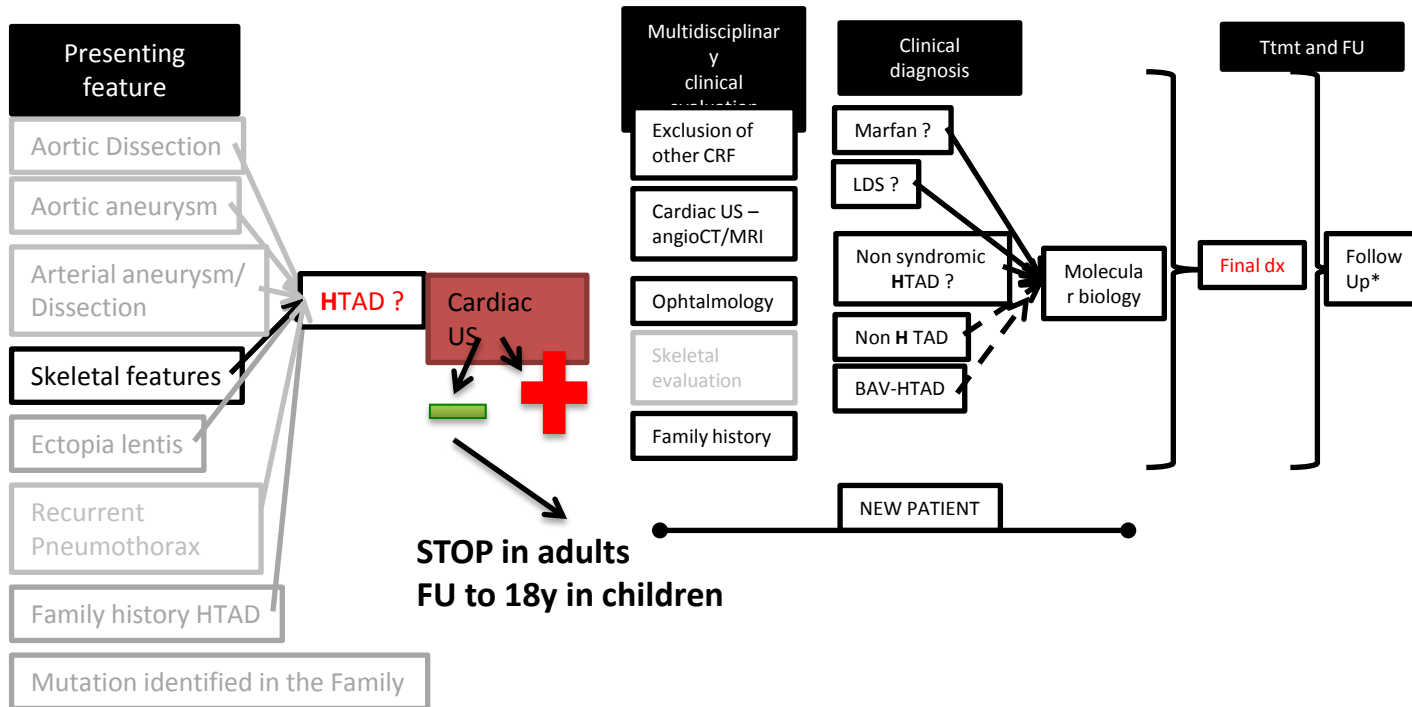
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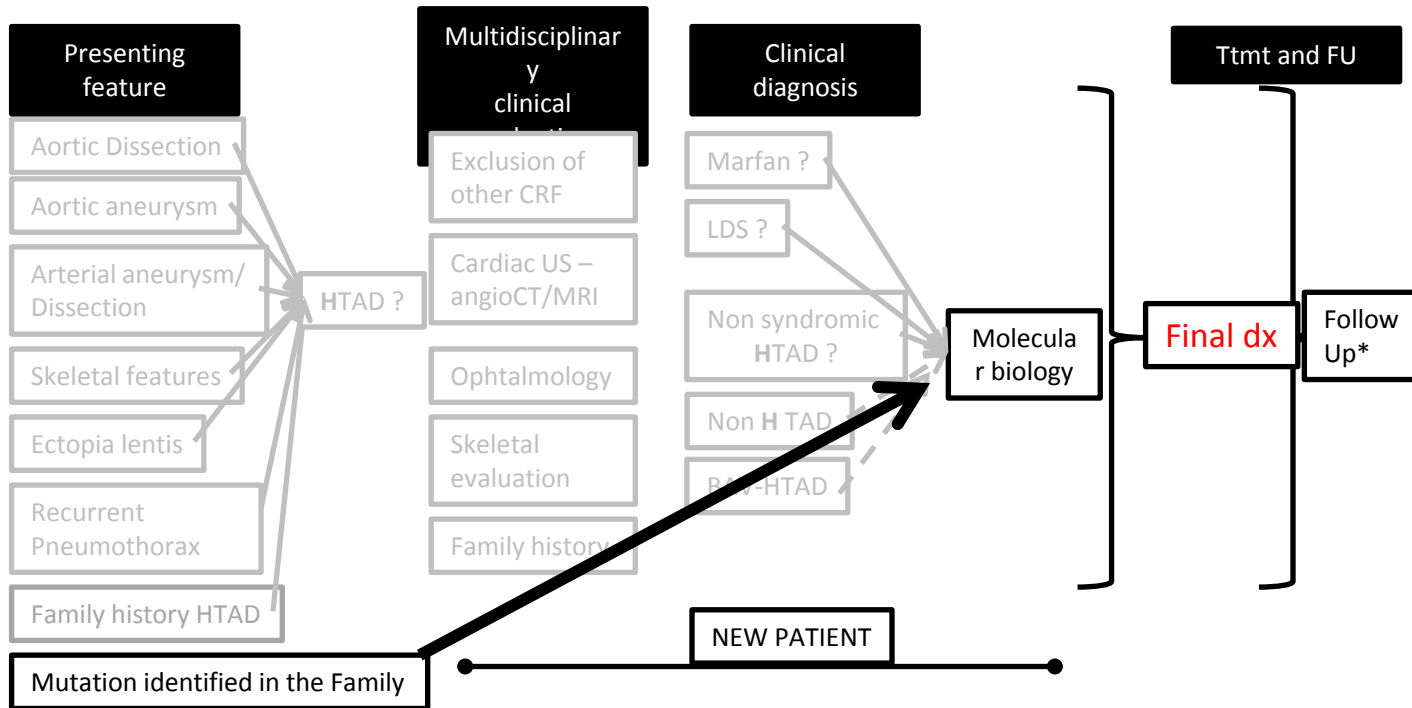
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RDWG Chairs

Report & Feedback

WP2 Definition of patients pathways

- 5 draft patient pathways during the ERN application period
- 5 VASCERN patient pathways

➤ Work for tomorrow morning



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WP3	Cross-border pathways Mobile Application
WHO?	eHealth WG , cooperation with all
HOW?	Monthly eHealth WG meetings to further define the project Development of the application and updates
DESCRIPTION	Development of a free of charge VASCERN cross-border mobile APP for smartphone IOS & Android, sharing information on HCPs & Patient Organisations members of VASCERN (services offered, how to reach HCPs, contacts, etc.) to enable patient to be able to choose the relevant HCP according to their rare disease (or MD to accurately choose for their patients). Availability in several languages afterwards.
OBJECTIVES	Contribute to facilitate cross border healthcare through eHealth innovative tools. allow patients throughout Europe to be able to choose the relevant HCP according to the rare disease they face (or MD to accurately choose for their patients)
MILESTONES	Monthly eHealth WG meeting to discuss the implementation of eHealth tools (mobile APP, e-Learning) Collecting minimum dataset from HCPs (HCP/ Center name, specialization, department, address, city ZIP, country, Coordinator, direct telephone, FAX, email, opening time, core services, other specialist evaluation, emergency department dedicated, H24 call for emergencies, patient association, website/social networks) Availability of Mobile APP first version with data
INDICATORS	free application available, number of languages available, number of countries and HCPs included
TARGETS	1 mobile APP, use of app: 10/day
TIMELINE	M6 Dataset collected from HCPs application adapted to VASCERN will be available at M12
DELIVERABLES	M12 a VASCERN Mobile Application for smart-phone IOS & Android indicating where are located the Centers of Reference



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Report & Feedback

- Mobile APP Dataset defined by the eHealth-WG
- Contact with developer. Development planned by the end of the year
- Dataset sent to **all VASCERN HCPs & POs** to be filled in by **October 15th**. If not already done, please do it during this 2 days meeting!
- Feedback eHealth-WG Chair

Contacts:

Alessandro PINI - Alessia PAGLIALONGA - Raffaella GAETANO




Only for HCPs
HCP name
VASC specializations <i>(Type of diseases)</i>
Complete Hospital Name Department
Complete Street Address
City
Zip Code
Country
HCP Coordinator <i>(name, surname, specialization)</i>
HCP Mail Address <i>Institutional &/or secretary &/or personal (For contact/ @&A/ Appointments)</i>
HCP opening time <i>(days, opening/closing time)</i>
Core services offered by the HCP <i>e.g. Cardiovascular (echo, ecg, clinical evaluation,...) Genetic (clinical)</i>
Other specialist evaluations offered INSIDE the HCP
Other specialist evaluations offered OUTSIDE the HCP (Y/N) <i>(other institution linked to HCP)</i> If yes, please indicate: <i>Specialist and Hospital</i>
Presence of H24 Emergency evaluation dedicated to HCP's patients (Y/N)
H24 Emergency call center (Y/N) <i>If yes, please indicate the telephone number (country code + telephone)</i>
HCP Website (Y/N) <i>If yes, please indicate website address and specific services (@&A section, PoK questions, content)</i>
HCP Social Media Page (Y/N) <i>YouTube, Facebook, Twitter</i> If yes, please specify the address
For HCPs & PTs ASSOCIATION
Presence of Patient Association Info-point INSIDE HCP (Y/N) <i>If yes, please specify the</i>
Patient Association Info-point OUTSIDE HCP (Y/N) <i>If yes, please specify telephone number</i>
Only for PTs ASSOCIATION
Complete name
Email address
Website address
Telephone number <i>(country code + telephone number)</i>
Fax number <i>(country code + telephone number)</i>
Street address <i>(Street, city, zip code, Country)</i>
Opening time <i>(Day, opening/closing time)</i>
Social Media Page (Y/N) <i>YouTube, Facebook, Twitter</i> If yes, please indicate the name &/or address of the page
Other PTs Association link (Y/N) <i>If yes, please indicate the name &/or a reference</i>
PTs Association services <i>(Periodical meeting, annual events, ...)</i>



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WP4	Pills of knowledge
WHO	eHealth WG & Training & Education WG
HOW	Monthly WG meetings to further define & develop the projects
DESCRIPTION	Development of single video-lessons (each 7-12 minutes of duration) in which an expert talks about a single brief topic. It is expected to mix specialists from different Centers/Countries, and create specific modules to cover every aspect of every disease related to VASCERN, as well every tone of voice (i.e. levels of training/learning, from simplest to most difficult). These “pills” of rare disease knowledge will be available on a mobile-friendly platform and so one does not need a PC, a desk and can have a learning-moment virtually everywhere.
OBJECTIVES	sharing of knowledge, improve knowledge via eLearning
MILESTONES	Monthly virtual meetings of eHealth WG and Training & Education WG
INDICATORS	number of pills, number of organized courses
TARGETS	1 video or online module/month collected (pills), pills available 10/disease, course available 1/disease (multiple pills), number of views 100/pills, number of courses 1/disease
TIMELINE	Begin during the first year of VASCERN for the MOOC without video (HHT WG starting) and during the second year of VASCERN with the videos. M6-M12
DELIVERABLES	M12 Video/audio lessons available for clinicians for eLearning



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Pills of knowledge

1) Video 1-3 min

- Questions chosen by RDWGs and ePAG
- Short expert's interviews in native languages
- More than one video on a subject
- Available on the website & Youtube Channel

2) on the website: list of useful links after RDWG validation (coordination team)

- For patients or doctors
- For different diseases
- In different languages



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WP5	Registries
WHO	Patient Registry WG, cooperation with all
HOW	Monthly Patient Registry WG meetings to further define & develop the projects
DESCRIPTION	A single VASCERN registry for all diseases covered by the network should be built, with the capacity of evaluation of activity and quality control (first outcome measures, to be implemented rapidly). This registry will progressively be implemented to analyse all the development in the patient's disease (follow-up and analysis). A common minimum dataset conceivable for all RD will initially be used in accordance with the ERN IT platform and the JRC EU RD registration platform criteria currently under development. Links with the EU infrastructures, once set up, will be implemented. The RDWGs will have the task to determine the disease specific datasets to be implemented in this registry.
OBJECTIVES	evaluation of activity and quality control (first outcome measures, to be implemented rapidly). This registry will progressively be implemented to analyse all the development in the patient's disease (follow-up and analysis)
MILESTONES	Monthly Patient Registry WG virtual meetings Inventory of biobanks and registries already existing in RDWG (M3) Definition and construction of a common minimum VASCERN dataset (M12)
INDICATORS	Number of registries issued
TARGETS	definition of registry items (1 modif/month) inventory of registries/biobanks creation of VASCERN initial registry for follow up of main clinical outcomes (simple common dataset) M12 Publications derived (1 / year)
TIMELINE	M1-M3: inventory of registries and biobanks M12 simple dataset
DELIVERABLES	M3 Inventory of biobanks and registries already existing in VASCERN M12 Simple registry dataset (main clinical outcomes) – linked with the Patient Case Management System? Inventory of registries and biobanks

Registries

Progress report

Plan

- Bottom up approach
- Start with local registries (avoid privacy and control issues)
 - Start with minimal datasets. Databases can be extended in a later phase
 - Database program and structure has to be FAIR (focus at this point on interoperability)
 - Same data base structure for each WG (EC minimal dataset + added WG items)


Actions sofar

- Forming of a technical subgroup
 - Marco Roos (RD connect), Christian Behrendt, Jerome Weinbach
 - + Derk Arts (castor) and Holger Storf (OSSE initiative)
- Part of the steering group of Go-Fair
- Grant application for FAIR based patient signal bank (hevas, castor, semantic group Leiden, RadboudUMC)
- Initiative-2 (IMI-2) European Health Data Network (EHDN)
 - UMC Utrecht, Karolinska Institutet, Oxford University and Semmelweis University) research institutes (Fraunhofer, DTL, i~HD, IHE), HTA bodies (ZIN) and an SME (P-95). **VASCERN?**



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RDWG Chairs – Registry WG Chair

Report & Feedback

WP5 Registry

- Survey of registries and biobanks M3 (done)
- Meeting of the Registry WG & specific task force established on technical issues (Leo Schultze Kool, Jérôme Weinbach, Christian Behrendt)
- Inter-ERNs work on registry: EU minimum common dataset
- To be extended by the RDWG essential specific dataset
- Registry established according to the FAIR principle
- Feedback Registry WG Chair?



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WP6 Clinical trials	
WHO	RDWGs , cooperation with Patient Group
HOW	Monthly RDWG meetings to discuss new protocols, research projects and clinical trials , Information on publication, research and clinical trials will be regularly updated in the website, Newsletter for calls, promotion by patient representatives, Annual Report a report on VASCERN Research Projects and Clinical Trials, Encourage and promotion of EU H2020 projects
DESCRIPTION	All the clinical trials running through VASCERN will be listed on the website, with contact information, so that additional HCPs outside VASCERN can participate as appropriate (including cooperating and affiliated HCPs not yet included as full members). Some clinical trials are already ongoing in VASCERN. Information on publication, research and clinical trials will be regularly updated in the website. newsletter for calls for research collaboration or clinical trials in order to promote clinical trials. Monthly meeting of RDWG (including patient representative co-chair) will discuss new protocols, research projects and clinical trials within the area of the RDWG. Patient representatives will also have the role to promote clinical trials among the patient community.VASCERN also plan to include in its Annual Report a report on VASCERN Research Projects and Clinical Trials as requested in the ERN call, as well as publications report as appendix
OBJECTIVES	promote the design and help in the realisation of international clinical trials in as many diseases included in VASCERN as possible demonstrate the benefit of a new treatment, mode of follow-up and diagnostic strategy. improve care and research
MILESTONES	Inclusion of calls for clinical trials in monthly newsletters and updates Monthly RDWG meeting: point on clinical trials Mid-term report draft (M6-7) on clinical trials, research collaboration, publications in view of the annual report Completion of 1 clinical trial (M12) as an important milestone Annual report on clinical trials and research collaborations to be included in general VASCERN annual report
INDICATORS	number of studies, number of patients included in studies, newsletters, report), completion of 1 clinical trial
TARGETS	number of patients included in clinical trial/HCPs (1/month), completed clinical trials (1/year), improved research/ publication (1/clinical trial)
TIMELINE	M1-M12: Newsletter including a part on research collaboration and clinical trials, regular updates on the website on call for research/ clinical trials; Collect data on research projects, clinical trials and their findings among HCPs;; M1-M12: RDWG discussion including about new protocols, research projects and clinical trials; M5-M7: Mid-term annual report draft; M10-12: review of annual reports drafts to be included in Year 1 annual report, M12: completion of 1 clinical trial
DELIVERABLES	M6 mid report of ongoing and completed trials M12 annual report on clinical trials, research projects, publications Completion of 1 clinical trial



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RDWG Chairs Report & Feedback WP6 Clinical Trials

- Reporting to make on clinical trials, RDWGs to answer:
 - Clinical trials during the last 6 months
 - Projects of clinical trials for the next 6 months
 - Calls for clinical trials to be published in the monthly newsletters
 - Research projects undergoing within the RDWGs (with several HCP members)
 - Benefit of VASCERN for recruitment
- Work for tomorrow
- HHT: 1 trial completed, 2 ongoing trials, 1 new trial funded from 01/10/2017, 7 ongoing research projects
- VASCA: 1 clinical trial ongoing within VASCA (VASE)
- MSA: 1 clinical trial in discussion
- Ongoing research projects within all RDWGs



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WP7

Availability of conferences on YouTube (Education)

WHO

Training & Education WG, cooperation with all RDWG to collect videos, and **eHealth WG**

HOW

Monthly Training & Education WG & eHealth WG meetings to further define & develop the project

DESCRIPTION

A specific VASCERN YouTube Channel will be prepared in order to share scientific meetings held by HCPs of the ERN or congress events or single traditional lessons for professionals. An important part of the work will be to collect the congress events and the traditional lessons to be able to record them, or collect the recording if this is already organized.

OBJECTIVES

Education and training. Improving and sharing knowledge to improve care
Dissemination of knowledge

MILESTONES

Training & Education WG & eHealth WG monthly meetings
Collection of conferences (from **M7**) to populate VASCERN YouTube Channel

INDICATORS

number of videos available

TARGETS

1 conference collected / month, 1 / month available on VASCERN YouTube Channel,
Number of views / conference: 100

TIMELINE

beginning on M6-12


DELIVERABLES

M12 Conferences available on YouTube for Training & Education



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- Video collection by VASCERN Coordination team
 - Medical content (pills of knowledge + meetings)
 - Discussion about content:
 - Transversal WG (e-health + training education)
 - RDWGs validation
 - VASCERN meetings
 - Congress Paris meeting videos
 - Interviews during the year (new scientific publications, patient representatives, etc.)



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WP8	Definition of clinical outcomes
WHO	RDWGs
HOW	RDWG monthly meetings
DESCRIPTION	A first set of simple outcome measures will rapidly be followed in VASCERN. (M6) A specific disease will be chosen for each RDWG. This set will include simple parameters such as number of patient screened, number of patient with a given diagnosis (clinical and molecular), number of patient with a follow-up, number of patient undergoing surgery, number of patient recruited in a research study). This should be obtained rapidly (M12). A second set of outcomes will be derived after patient pathways have been implemented, and will require meetings for discussion
OBJECTIVES	Improve care Follow up on the results of the ERN VASCERN
INDICATORS	Numbers of outcomes
MILESTONES	RDWG monthly meeting to define clinical outcome measures Definition of simple and diseases specific outcome measures (M6-M12)
TARGETS	number of diseases for which outcomes are discussed and defined 5/year, evolution of outcomes: target improve care
TIMELINE	will be implemented after the pathways are defined for the diseases: M6 - M12
DELIVERABLES	M6 Simple clinical outcome measures defined M12 Diseases specific outcome measures



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- More complicated than anticipated
 - Delays
 - Wait for decisions from EU on monitoring of ERN
 - Inter-ERNs WG



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WP9	Writing recommendations / clinical guidelines J.1 for optimal care of the disease (diagnosis, evaluation, treatment);
WHO	RDWGs , cooperation with Patient Group
HOW	RDWG monthly (virtual) meetings
DESCRIPTION	RDWG will write guidelines for optimal care for the RD included in VASCERN
OBJECTIVES	producing new guidelines for optimal care
MILESTONES	Monthly RDWG virtual meetings Face to face RDWG meetings to work on clinical guidelines
INDICATORS	one new document should be issued every year for each WG
TARGETS	2 face to face meeting / RDWG /year, 2 guidelines issued / year, diffusion of guidelines/number of guidelines uploaded on website: 1 / 2 months, Publication : 1 guidelines issued by VASCERN
TIMELINE	M12
DELIVERABLES	M12 Clinical guidelines on a dedicated topic for each RDWG for dissemination



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RDWG Chairs

Report & Feedback

WP9 Clinical Guidelines (J1)

- HTAD: Acta2 recommendations (manuscript drafted and discussion items defined)
- MSA: discussion on guidelines for vEDS pregnancies
- PPL: collection of guidelines (NL, DE, FR). Guidelines for 2018: treatment & follow-up
- VASCA: work on ORPHANET classifications. Collection of guidelines
- HHT: topic for guidelines (antiplatelet/anticoagulant discussion ongoing, Atrial fibrillation next)




WP9	Writing recommendations / clinical guidelines J.2 Factsheets: guidelines for optimal care of these patients facing common problems not related to their rare diseases
WHO	RDWGs , cooperation with Patient Group
HOW	RDWG monthly (virtual) meetings
DESCRIPTION	<p>Patients with rare diseases face frequent situations including medical situations such as abdominal surgery for any reason, dentist intervention, pregnancy. The question then arises of how to deal with frequent diseases in rare patients.</p> <p>The process should include 1) choosing the relevant situation 2) writing the simple factsheets 3) diffusion for comments 4) edition in a booklet (to be shown during meetings and disseminated through patient association), translation in several EU languages publication on the website.</p>
OBJECTIVES	Improve care for patient with rare diseases when facing common situations propose some simple guides available to the medical community, which would indicate the particularities of care due to the fact that the patient is affected by a rare disease included in VASCERN.
MILESTONES	RDWG meeting (virtual) : point on factsheets
INDICATORS	number of factsheets, number of languages
TARGETS	monthly RDWG discussions, factsheets Do's and Don'ts in one language (20/diseases WG), translation 4 languages. Diffusion / number of download: 1/week, distribution in medical meetings (1 meeting/ 2 months)
TIMELINE	draft documents are already available) and time bound (the factsheets should be available at the end of Year 1).(M12)
DELIVERABLES	M12 Factsheets 'Do's and Don'ts' for RD patient facing common situation



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WP9 guidelines

J2 Do's and Don'ts Factsheets:

Guidelines for optimal care of these patients facing common problems not related to their rare diseases

- [Exist in French](#) (FAVA-Multi) for **HTAD, MSA & HHT**

Maladie de Rendu-Osler

ANTIAGRÉGANTS PLAQUETTAIRES ET ANTICOAGULANTS (AAP)



CE QUI EST RECOMMANDÉ

- Discuter de la balance Bénéfice / Risque avec le centre de référence ou de compétence en charge du patient.
- Adapter le traitement à l'état clinique du patient (épistaxis, hémorragies digestives).
- Après un AVC ischémique secondaire à des malformations artério-veineuses Pulmonaires, il n'y a pas d'indication à poursuivre ce type de traitement (AAP ou anticoagulant) si toutes les malformations artério-veineuses Pulmonaires ont été traitées de façon satisfaisante.



CE QU'IL NE FAUT PAS FAIRE

- Prescrire des AAP ou des anticoagulants sans avoir discuté la balance Bénéfice / Risque.

Sommaire


MALADIE DE RENDU-OSLER

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- 38 Fibroscopie bronchique
- 39 Grossesse
- 40 Hémopéritoine spontané
- 41 Insuffisance cardiaque
- 42 Insuffisance rénale
- 43 Médicaments contre-indiqués
- 44 Odontologie
- 45 Phlébite
- 46 Pneumothorax
- 47 Polytraumatisé
- 48 Soins contre-indiqués
- 49 Syndrome coronarien aigu
- 50 Urgences abdominales



European
Reference
Network

for rare or low prevalence
complex diseases

 Network
Vascular Diseases
(VASCERN)

WP 9 Do's and Don'ts

J2 Next steps

- Translation from French to English:
 - HTAD
 - MSA
 - HHT
- Validation & update by VASCERN RDWGs
- Publication & dissemination
- Translation in other EU languages
- Extend to other diseases ?



WP10	Communication (& management/ internal VASCERN communication)
WHO	VASCERN Coordination Project team , asking advices to the COM-WG All Members as ambassadors of VASCERN and for dissemination of knowledge and outputs
HOW	Daily implementation by VASCERN Coordination project team & COM group monthly discussions
DESCRIPTION	Communication & dissemination through website, social networks, forum, newsletter, promotion, representation, PR, etc. Internal (intranet) and external communication
OBJECTIVES	visibility, impact, dissemination of knowledge, awareness-raising, health promotion messages, etc. Improving care for rare vascular diseases patient and rare diseases patient through communication on ERNs
MILESTONES	COM-WG monthly (virtual) meetings Website development M3 Establishment of social network pages M6 Design of communication tools (leaflets, kakemono, brochure,...) in cooperation with EC DG SANTE M8 Kick-off / 1st annual VASCERN meeting , Council meetings (every 3-4 months)
INDICATORS	Number of pages, website, social pages, newsletters...
TARGETS	number of new pages/ pages modified (50 initially, then 1 page/ week), website available with active pages for RDWGs, number of connection (1500/month), creation of social network pages (1 new post/month Facebook, 1 new tweet/ week twitter (or more)), number of followers 100, regular updates on news / events on the website (1/month), 1 / month newsletter, diffusion list: 1000 emails
TIMELINE	M1-M12
DELIVERABLES	M1-M12 Website - updates and development M12 Translation of some deliverables (education material for patients) (patient pathways, factsheets, webpages) M1-M12 Monthly Newsletters & development of the diffusion list M3 Social networks for VASCERN: facebook, twitter



European Reference Network

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European Reference Networks

Vascular Diseases (VASCERN)

HOME NEWS OUR NETWORK ERN EXPERTISE CLINICAL GUIDELINES CONTACT

OUR VISION
"Our VASCERN project aims to facilitate and improve diagnosis, treatment and care for ALL patients suffering from Rare Multisystemic Vascular Diseases, thus enhancing access to care, and improving quantity and quality of life of these patients.
Networking, sharing and spreading our expertise, promoting best practices, guidelines and clinical outcomes, patient-empowerment, improving knowledge through clinical and basic research are among our objectives."
Prof. Guillaume Jondeau, Network Coordinator

All you need to know about ERNs

- ERNs Press Release
- ERNs Brochure
- ERNs Flyer

<http://vascern.eu/>

Communication & Dissemination



EUROPEAN REFERENCE NETWORK
FOR RARE, LOW-PREVALENCE AND COMPLEX DISEASES

Share. Care. Cure.



VASCERN @vascern
European Reference Network on Rare Multisystemic Vascular Diseases. Gathering the best expertise to improve care #EuropeanReferenceNetworks #RareDiseases
VASCERN.eu
Joined February 2017
44 Photos and videos

Tweets **Tweets & replies** **Media**

Pinned Tweet
VASCERN @vascern · Sep 28
Our 1st VASCERN 2 days annual Seminar (Paris, 13 & 14 October) is fast approaching! Follow us & tweet using #VASCERNdays2017 #ERNeu

VASCERN @vascern · 3h
Only 1 more week until #VASCERNdays2017! We're at the venue in #Paris today getting everything ready! #ERNeu

Who to follow · Refresh · View all

- Géant Casino** @geant_cas
- eni Communication** @eni...
- Flavio Minelli** @MinelliFla...

<https://twitter.com/vascern>

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Stay tuned!

- 29 JUN 2017
 - 29 JUN 2017
 - 22 SEP 2017
 - 01 JUL 2017
 - 23 SEP 2017
- Cardio Update Europe 2017
- ESVS 31th Annual Meeting 2017

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VASCERN Newsletter #8 - February 2017

View this email online

- European Reference Networks Conference**
The European Commission organizes the 3rd European Reference Networks Conference in Vilnius on March, 9-10th. This event will be the official launch and start of the first labeled European Reference...
- EURORDIS 20th anniversary**
2017 is EURORDIS-Rare Diseases Europe, the European association representing rare diseases, 20th anniversary. This is the opportunity to look at 20 years of achievements and challenges ahead here
- 3rd Health Programme WP 2017**
The European Commission (DG Sanite) has adopted on January 26th the Work Programme 2017 under the 3rd Health Programme. This WP includes funding for supporting European Reference Networks (ERNs) with a total...
- EU Call for Rare Disease Registries**
The European Commission has published a Call for proposals for Projects on Rare Disease Registries for approved ERNs on December, 21st. EU CALL RARE DISEASES REGISTRIES (PJ-06-2016) Aim: increase knowledge.
- HTAD-WG New Publication**
A new HTAD-WG collaborative research paper has been published by Prof Guillaume Jondeau and CRM Martin team members (Dr Oliver Mikron, Maud Langeon, Myrtille Spertiniani, Prof Catherine Poirier) as well as HTAD-WG.

Upcoming

- 09 MAR 2017 - 10 MAR 2017: European Reference Networks Conference & ERNs Kick-off meetings
- 20 MAR 2017: Integrating Research and Healthcare for Rare Diseases: a structured cooperation with high community added value
- 21 MAR 2017: EU Call - Rare Disease Registries

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- VASCERN (@vascern)
- EU Health (@EU_Health)

EU supported ERNs will work to treat #rareDiseases affecting 5 in 10k people - around 30 million in the EU #ERNeu europe.eu/973kX

<http://vascern.eu/news/newletters/>