



**NNHF Programmes: selected updates on activities in quarter 4, 2016 (1 October – 31 December 2016)**

**Overview**

<b>Novo Nordisk Haemophilia Foundation Q4 2016 update</b>	<b>By end Q4 2016</b>
Number of projects approved by NNHF Council since 2005 (new projects since last quarter)	140 (6)
- Thereof number of fundraised projects (new projects since last quarter)	14 (0)
Number of fellowships (new fellowships since last quarter)	74 (0)
Number of awards (new awards since last quarter)	14 (0)
HCPs trained since 2005	30,350
Patients and family members educated & patient leaders trained since 2005	33,750
People with haemophilia retested and newly diagnosed since 2005	22,000
NNHF engaged in number of countries (new countries since last quarter)	68 (0)

**NNHF quarterly programmes update - quarter 4, 2016**

Region	Programme name	Programme title	Programme type	Phase	Partner	NNHF contact	Objectives	Status	Programme duration / Start date
Africa	Egypt 2 - EG2	Improving musculoskeletal (MSK) care in Egypt and establishing a MSK-registry to collect outcome data	Project	Execution	Gamaeat Asdika Marda Al Nazf (= Egyptian Society of Hemophilia), Cairo -Represented by Dr Magda Rakha, President, as responsible project applicant and supported by Dr Adly Sabbour, Physiotherapist, as MSK-expert and trainer and as such co-responsible person	sysd@nnhf.org	HCPs training including haematologists and physiotherapists Establish MSK registry in Egypt Start treating the patients and evaluate their joint functions Write a publication about the project and inform the authority about the project results MSK advocacy for policy for inclusion Strengthen the haemophilia dentist clinic in Cairo.	- 2 workshops were organised about the basic care in MSK disease in PWH. 1st one was on the 3rd of October and was attended by 26 physiotherapists from HIO and Red Crescent blood bank and directors of the physiotherapy and Haematology departments in the HIO. The program included the following subjects: o Hemophilia overview and stages of MSK disease in Hemophilia o Overview of physical therapy for He-mophilia. o Assessment tools for Hemophilia pa-tients o Web based MSK registry - The 2nd workshop was arranged in 27th and 28th of October to complete the training of both physiotherapists and Haematologists in the participating centres. The workshop about the basic care in MSK disease in PWH and the method of using the assessment tools of MSK in Hemophilia patients. The workshop was attended with 31 physiotherapists and 9 Haematologists. - The physiotherapy clinic in Cairo started to use the Shockwave.	1.5 years Q1 2016
Africa	Ghana 2 - GH2	Improve access to haemophilia Care and create awareness at the regional and primary health levels in Ghana	Project	Formalisation	Ghana Haemophilia Society, Accra - Martin Boakye	sysd@nnhf.org	Strengthen the patient association Build HCPs capacity in the regions Improve diagnosis capacity Organise educational programme for PwH and their families Increase awareness about haemophilia.	- Project partnership agreement to be signed.	2 years Q1 2017
Africa	Kenya - KE3	Enhancement of capacity for comprehensive haemophilia management	Project	Execution	Kenya Hemophilia Association, Nairobi - Kibet Shikuku	sysd@nnhf.org	Establish the Kenyatta National Hospital Haemophilia Comprehensive Care Centre Improve the diagnostic facilities and blood bank capacity Create awareness by organising two WHD celebrations and continue lobbying with the media Organise HCP trainings and academic symposia Start the regional haemophilia care in two cities Improve physiotherapy care in both KNH and MOI.	- A meeting held in Mombasa and with The Coast General Hospital Administrators. The team were shown a large space that the Hospital has agreed to provide to set up a Haemophilia Comprehensive Centre - The team assessed the physiotherapy equipment in the hospital in Mombasa and reported about the requirements to provide physiotherapy care to PwH - A meeting with 12 patients and their families was held providing training on management of haemophilia and home therapy process - An end of year evaluation meeting was held in Eldoret. The team also discussed the achievements of the year and the plan to use the remaining fund.	2 years Q2 2015
Africa	Mali - ML	Improve haemophilia care in Mali by capacity building and awareness creation	Project	Execution	Association Malienne de Lutte contre l'Hémophilie, Bamako - Dr Yacouba Diallo	sysd@nnhf.org	Improve haemophilia care by building regional HCP capacity Increase awareness about haemophilia among PwH and traditional circumcisers Advocate for better care for haemophilia patients.	- The broadcast of haemophilia awareness programme on radio stations is ongoing. A collaboration concept between the Malian hemophilia society and radio "Espoir" was signed. An awareness documentary in French and Bambara was developed and will be transmitted by 6 radios during one year - 2 awareness protocols were concluded between Malian hemophilia society and two radio stations (Kunandi et aw Kodi). An awareness documentary will be transmitted on others privates radio stations and online during one year.	2 years Q1 2016
Africa	Mauritius - MU	Establish a multidisciplinary care team and improving haemophilia care in Mauritius	Project	Execution	Haemophilia Association of Mauritius, Mauritius, Quatre Bornes, Mauritius - Asraf Caunhye	sysd@nnhf.org	Strengthen the diagnostic facilities Establish a multidisciplinary care team Improve the physiotherapy care provided to PwH Empower patients through educational sessions and camps Create awareness by organising two world haemophilia day celebrations Create an electronic medical registry and complete data.	- Prof Johnny Mahlangu was invited to Mauritius. During the visit, he met with Director of Health Services and visited 5 laboratories for gap analysis. For 2 days he facilitated training for lab technicians and pathologists - Organised 2 training sessions attended by 148 doctors and 13 nurses. The high rate of attendance form HCP is a positive sign. The training has helped to improve the quality of service provided by HCPs and they now have the knowledge for the right techniques and new technologies available - A patient training camp was organised for 41 patients and 111 family members. It was observed that the patients and parents are very reluctant to participate in camp; hence more education and working sessions need to be done with our patients.	2 years Q3 2015
Africa	Nigeria 2 - NG 2	Activate and strengthen the medical and patients community in Nigeria	Project	Execution	Haemophilia Foundation of Nigeria, Kaduna - Megan Buckie Adediran	sysd@nnhf.org	Establish a reference laboratory at the Lagos University Teaching Hospital (LUTH) Create an electronic medical registry and complete the identified patient profiling Empower patients through four educational camps Create awareness by organising two world haemophilia day celebrations and develop awareness publications Establish regional haemophilia care service in the South West Region.	- 5,000 copies of educational materials were printed and distributed to general public to create awareness about haemophilia - The 2 symposiums at Oyo and Kwara States are postponed due to political and security issues.	2 year Q1 2015
Africa	South Africa 3 - ZA3	Bringing better haemophilia care closer to the patients and strengthening the community	Project	Closing	Igazi Foundation - Charmaine Oosthuizen	sysd@nnhf.org	Improve services provided at district level Increase responsibility and compliance of patients Implement updated electronic registry Raise teaching & organising capacities.	- All project activities have been completed. Waiting for the final Audit report and Final Project report.	2 years Q1 2014
Africa	Tanzania 2 - TZ2	Empower the patient association to organise successful awareness campaign and advocacy	Project	Formalisation	Haemophilia Society of Tanzania, Dar es Salaam - Richard Minja	sysd@nnhf.org	Empower the haemophilia community Organise media engagement training Create awareness in the region of Dar es Salam Advocacy meetings with authority.	- Project partnership agreement to be signed.	1 year Q1 2017

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Africa	Uganda 2 - UG2	Create awareness and HCPs training in Uganda	Project	Execution	Haemophilia Foundation of Uganda, Kampala - Agnes Kisakye, executive secretary	sysd@nnhf.org	Increase public awareness about haemophilia Organise outreach visits to Eastern, Central and Northern Uganda to identify new haemophilia patients Increase patients knowledge about haemophilia Advocate for better care for haemophilia patients.	- Muslim awareness workshops were successful conducted at the National Mosque in Butambala for Muslim leaders and Muslim circumcisers. A total of 154 participants attended the workshops. They were so much interested and keen to get the information - HFU team was hosted on different radio stations in many regions where awareness workshops were conducted. The talk shows were conducted both in English and the local languages. Haemophilia patient's life stories and press releases were also published - A press conference was organised and received coverage from 32 media houses and featured in the news bulletin - Two radio talk-shows were held in Northern and Central Regions. The radio talk-shows attracted many people calling in to learn more about haemophilia and where to go in case of bleeding - Patient's camp was attended by 182 participants, including patients and their care takers. They were taught on signs and symptoms of haemophilia, psychosocial aspects and family economic empowerment by starting up small scale income generating activities and introduction of parents groups. The Hon. Minister attended the camp and indicated in his speech that he will lobby for haemophilia care expansion and strengthen the capacity of lower level hospitals and health centres. This will reduce on travelling long distances for up country patients and ensure that there is constant supply of reagents. He was so shocked to see the big numbers of affected patients and that there is need to make a presentation about haemophilia on the floor of parliament for Government immediate intervention.	2 years Q2 2016
Africa	Malawi - MW	Establish haemophilia care in Malawi	Fundraised project	Execution	Society of Haemophilia and Allied Bleeding Disorders in Malawi Lilongwe, Malawi Dr Yohannie Billy Mlombe, haematologist	sysd@nnhf.org	Establish coagulation laboratory facilities and skills Train healthcare professionals in haemophilia Create awareness campaign to identify new patients Empower patients through awareness campaign and national patient education camp.	- Haemophilia clinic and a coagulation laboratory were established at Kamuzu Central Hospital - 70 Clinical and nursing HCPs were trained in Lilongwe, Blantyre and Zomba by Prof Dr Khair from the UK - 14 laboratory technicians were trained in Lilongwe on the theory of coagulation laboratory diagnosis and on practical aspects of coagulation as well as the use of the coagulation equipment installed at the Kamuzu Central Hospital Coagulation unit. The laboratory training was done by Dr Angus MacCraw from the UK - A training workshop for journalists was held and this resulted in heightened interest from the media on haemophilia in Malawi. Several articles were published in the print and electronic media about haemophilia in Malawi - 200 posters in English and Chichewa were produced for placement in hospitals in Malawi - Radio jingles programmes were run inviting patients to a diagnosis campaign and a patient camp - 35 haemophilia patients were diagnosed and confirmed. A national haemophilia registry has subsequently been established - A patient camp was organised for 73 patients and family members about the basics of haemophilia.	9 months Q1 2016
Africa	Malawi - MW	Specialised training in haemophilia care and management	Fellowship	Execution	Christine Chilinga, haematologist Kamuzu Central Hospital, Lilongwe, Malawi	sysd@nnhf.org	Learn how haemophilia treatment centre operates in terms of clinical care and laboratory diagnosis Get equipped with knowledge regarding identification, diagnosis and management of haemophilia and bleeding disorders Gain experience on management of complications of haemophilia as well as management of treatment complications Understand the concept of prophylaxis treatment.  - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; responsible person(s): Prof Johnny Mahlangu.	- Training started in January 2016.	2 months Q1 2016
Africa	Malawi 2 - MW 2	Build diagnosis capacity in Malawi	Fellowship	Formalisation	Blessing Mwagomba, Dr David Livingstone Memorial, Lilongwe	sysd@nnhf.org	Acquire knowledge on how to handle manual and automated diagnose of haemophilia and other bleeding disorders Learn about the quality scheme for coagulation tests Gain skills on organising training in Coagulation procedures.  - Haemophilia Comprehensive Treatment Centre/Charlotte Maxeke Johannesburg Academic Hospital, Johannesburg, South Africa; responsible person(s): Prof Johnny Mahlangu.	- Training will start in March 2016.	1.5 months Q1 2017
Africa	Tanzania 2 - TZ2	Start haemophilia care in Southern Tanzania	Fellowship	Execution	Goreth Lupembe, Nurse, Mbeya Referral Hospital, Mbeya, Tanzania	sysd@nnhf.org	Have the basic knowledge to identify the patients with haemophilia Learn how to provide the basic care to PWH; instead of referring them to Muhimbili National Hospital Acquire the knowledge to train the other Hospital Staff.  - Christian Medical College, Vellore, India; responsible person(s):	- Fellowship started in November 2015. The fellow had a medical condition and had to return back before completing the fellowship.	3 months Q3 2015
Europe	Latvia 2 - LV2	Set up of a web-based bleeding disorders registry in Latvia	Project	Execution	Latvia Hemophilia Society, Riga - Baiba Ziemele	deni@nnhf.org	Create infrastructure for data collection and analysis Provide training on the use of the registry and the importance of it for patients and healthcare professionals Have solid, evidence-based facts in place for advocacy purposes.	- Development of the software for the registry has started and the software is being tested.	1 year Q2 2016

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Europe	Serbia 2 - RS2	Empowering the patient community to be active and compliant	Project	Execution	Serbian Haemophilia Society, Belgrade - Tatjana Marković	smqy@nnhf.org	Empower and engage patients through psychological workshops and materials targeted by age group Strengthen SHS through empowerment of regional educators who will drive the educational/empowerment activities of the Society Create awareness about the activities of the Society and the insufficient and irregular supply of factor concentrates and its consequences.	- A training session of a national educators group was organised. Focus of training session: Psycho-social aspects of haemophilia, communication, media training, how to plan a successful event, conflict solving and action planning - Start-up meeting in the new created educator group in Nis.	2 years Q1 2015
Near and Middle East	Jordan 3 - JO3	Creation of a medical and social network to support haemophilia care across Jordan	Project	Execution	Princess Sumaya University for Technology (PSUT), Amman Dr Arafat Awajan	sysd@nnhf.org	Organise a comprehensive national training programme for healthcare professionals Conduct educational sessions and awareness campaigns for people with haemophilia Create educational materials for PwH and their family in Arabic Develop an Arabic website with educational material for both HCP and PwH. The website will serve as a communication channel for PwH and the different stockholders in the Arabic speaking countries.	- Patients and volunteers training organised on the websites and its components - HCPs training was scheduled for March 2017.	2 years Q2 2014
Near and Middle East	Palestine 1 - PS 1	Improve the quality of health care provided for patients with Haemophilia in Palestine	Project	Execution	Palestine Ministry of Health, Foreign Relation department, Ramallah. - Huda Lahham and Dr Hussein Elyan	sysd@nnhf.org	Design and apply a comprehensive national training programme for healthcare professionals Create guidelines for treatment of haemophilia Produce educational material for healthcare professionals and patients Improve the laboratory facilities Screen and (re-)diagnose of 1680 people with haemophilia Six educational sessions for people with haemophilia will be conducted. Set up a national medical registry.	- Two physicians and one nurse were trained for one week at Chabrawichi Hospital in Cairo by Dr Magdy Elakiabi. The training includes theoretical and practical sessions on comprehensive care for patients with bleeding disorders, diagnosis of haemophilia at a specialized laboratory and safe treatment - 52 haemophilia patients were retested in addition to 15 patients newly diagnosed. - Purchased a deep freezer and a refrigerator for the Central National Blood Bank where the cryoprecipitate and fresh frozen plasma are stored - The guidelines were finalised and ready to be printed.	1.5 years Q1 2014
South and Central Asia	Armenia - AM	Building the national haemophilia care network in Armenia	Project	Execution	Haematology Center of Armenia, Yerevan - Prof Smbat Daghbashyan	sysd@nnhf.org	Strengthen the local haemophilia care team Establish haemophilia treatment guidelines Establish a web based national haemophilia registry Raise awareness to increase the quality of life of PwH Improvement of diagnostic facilities Outreach visits to improve haemophilia awareness in the regions.	- An awareness seminars were conducted during HPs regular visits to the haemophilia centre - The regional outreach visits were postponed due to severe weather conditions.	2 years Q1 2015
South and Central Asia	Azerbaijan 2 - AZ2	Establish haemophilia care in Nakhchivan region and improve physiotherapy care across Azerbaijan	Project	Formalisation	Azerbaijan Republic Association of Haemophilia, Baku - Gulnara Huseynova	sysd@nnhf.org	Establish Haemophilia care in Nakhchivan Advocate for better care in Nakhichevan Improve physiotherapy care Raise awareness of patients and families.	- Project partnership agreement to be signed.	2 years Q1 2017
South and Central Asia	Bangladesh - BD	Improving quality of care for haemophilia in three centres in Bangladesh	Project	Execution	Dhaka Medical College - Prof Salma Afrose	smqy@nnhf.org	Increase capacity of the multidisciplinary teams in Dhaka, Rajshahi and Rangpur Develop diagnostic facilities for coagulation studies Educate patients and families and encourage them to attend the newly trained centres Engage authorities and the public for more support to bleeding disorders.	- Patient education session for 61 patients and family members was arranged in Dhaka Medical College Hospital - Training session for 150 doctors in Rangpur Medical College Hospital to increase the capacity of the multidisciplinary teams in the province - Education session for 40 patients and 20 family members at Rangpur Medical College Hospital encouraging them to use the newly trained centre - Educational materials were printed and distributed - Reagents for APTT bought.	1 year Q2 2015
South and Central Asia	Georgia - GE	Spreading knowledge about haemophilia and improving quality of diagnosis and treatment in Georgia	Project	Closing	Georgian Society of Thrombosis and Haemostasis - Dr Levani Makhaldiani	sysd@nnhf.org	Improve the laboratory facilities Update current guidelines for treatment of haemophilia and allied bleeding disorders Produce educational material for healthcare professionals and patients Perform comprehensive national training programme for healthcare professionals Reach out to offer better care and education to patients and family members Raise awareness of bleeding disorders amongst the general public and the authorities.	- All project activities have been completed. Waiting for the final Audit report.	2 years Q1 2013
South and Central Asia	India 2 - IN2	IDEEA - Identification, Diagnosis, Education and Empowerment for Action of people with bleeding disorders in South India	Project	Closing	Katsurba Hospital, Manipal University , Manipal - Dr Annamma Kurien	rbgs@nnhf.org	Create awareness and identify new patients with haemophilia and allied bleeding disorders in 4 districts (Udupi, Dakshina Kannada, Chickamangaluru and Shimoga) of Karnataka, India Diagnose improvement (Haemophilia, von Willebrand disease, platelet function).	-Final project report and final financial audit report in preparation.	3 years Q1 2012
South and Central Asia	India 3 - IN3	Spread awareness, building capacity, and diagnostics spectrum in haemophilia-(Spread ABCD Spectrum project) in northern India	Project	Execution	Maulana Azad Medical College, New Delhi - Prof Naresh Gupta	sysd@nnhf.org	Capacity Building in the National Capital Region Increase public awareness and IEC activities Widening Diagnostic Base Publications and Haemophilia Newsletter Website based regional electronic medical record system and patient forum.	- One day programmer was organised includ-ed the following activities: o Launching of ID card for Haemophilia patients developed by HDCC. o Empowerment of Self Help Group for Haemophilia. o Distribution of Haemophilia kits to participants of Self Infusion Programmed. o Discussion about Psycho-social chal-enges of PwH o Discussion about Status of PwH and their position in society o Planning for PwH for day to day activi-ties. o Effect of patient to patient communi-cation.	2 years Q2 2013

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South and Central Asia	India 6 - IN6	Capacity Building and Empowerment program for care givers and parents involved in the Hemophilia Care in North East and North India	Project	Execution	Haemophilia Federation India - Mr Mukesh Garodia & Dr Richa Mohan	sysd@nnhf.org	Improve skills of haematologists, lab technicians, physiotherapists and nurses of 8 states comprising the North East region Customise the Parents Empowering Parents programme according to local language and culture to enhance parents' communications and capacity to manage their child's condition Train 40 parents in the suggested states using the adapted PEP programme in order to have them replicate the training to other parents in their chapters.	- Organised 2 days hands on training on coagulation tests at Rims Hospital, Imphal, Manipur. The program was jointly organized by Hemophilia Society Imphal Chapter, Departments of Pathology, and Department of Immunohematology & Blood Transfusion, Regional Institute of Medical Sciences, Imphal and attended by 74 doctors and lab technicians.	2 years Q4 2014
South and Central Asia	India 7 - IN7	Preventing and Decreasing Musculoskeletal Morbidities among People with Hemophilia in Southern India	Project	Execution	Haemophilia Federation India - Dr Pamela Narayan pamelanarayan@yahoo.co.in	rbgs@nnhf.org	Map the musculoskeletal morbidities and physiotherapy practices prevalent in factor limited settings, particularly India Delineate and implement a clinical pathway of MSK care for PWH Increase awareness and access to physical therapy in the management of MSK morbidities amongst PWH.	- During Q4 surveys were collected and response data was analyzed. Preparation steps for MSK national congress were taken. - Two persons were trained in administering the questionnaire in English and 'Hinglish' and they phoned survey participants. This helped to standardise the administration of the questionnaire.	3 years Q2 2015
South and Central Asia	India 8 - IN8	Empowering parents in South and West India	Project	Execution	Haemophilia Federation India and Empowering Minds Society for Research & Development - Dr Richa Mohan	sysd@nnhf.org	Customise and update the Parents Empowering Parents (PEP) programme and materials with the international PEP Train the trainers programme on PEP for 150 parents from 8 states in South and West India.	- Project partnership agreement was signed.	2 years Q4 2016
South and Central Asia	Pakistan 5 - PK5	Bringing change by improving access to care and awareness: Ca-pacity building and leadership initiative	Project	Closing	Pakistan Haemophilia Patients Welfare Society (PHPWS) - Masood Fareed Malik	sysd@nnhf.org	Strengthen the Pakistan Haemophilia Patients Welfare Society and its chapters to excel in their role Increase the public and the patients awareness Outreach for identification of new patients Develop centralized web-based national patients registry.	- All the project activities were completed and the final report was submitted. The project will be closed in March Council meeting.	2 years Q2 2014
South and Central Asia	Sri Lanka - LK	Improve Physiotherapy and Musculoskeletal training and awareness for HCPs and Haemophilia community	Project	Closing	Haemophilia Association of Sri Lanka - Pinsiri B. Godamunna, president	sysd@nnhf.org	Publish the national treatment guidelines for adult and children and general guideline about physiotherapy care of haemophilia. Improve physiotherapy and MSK care in the five main centres Strengthen the Sri Lanka Haemophilia Association through education and awareness sessions Empower carriers and women with bleeding disorders.	- All project activities have been completed. Waiting for the final Audit report and Final Project report.	2 years Q2 2015
South and Central Asia	Uzbekistan 4 - UZ4	Improving the quality of life of haemophilia patients by establishing rehabilitation care in Uzbekistan	Project	Execution	Scientific Research Institution of Haematology and Blood Transfusion - Dr Aziza Makhmudova	sysd@nnhf.org	Strengthen the rehabilitation care in the haematology Centre in Tashkent Start the rehabilitation care in 12 regions by training of HCPs.	- 2 day seminar organised in Khorezm region about "Carrying out medical preventive and rehabilitation measures to reduce disability and improve the quality of life of PwH". The training was attended by 12 haematologists, 15 physiotherapists, 6 surgeons, 29 nurses and 18 patients. The training build the capacity in the region to provide care to patients who are unable to come to Tashkent Hemophilia centre and reduce time, efforts and cost for the patient to receive the required care. One of the training objectives was to build the network and trust between doctors & patients and between the patients themselves. After the training the positive change was noticed by all the participants. - 7 days training was organised for the doc-tors from Karakalpakstan, Nukus at Tashkent Hemophilia centre on providing rehabilitation care for patients. Training focused not only on medical and surgical procedures but also psychological aspects. - Due to the holiday period, training for the doctors from Namangan and Ferghana were rescheduled to October.	1.5 years Q1 2016
South and Central Asia	Myanmar - WHD 2013	Empowering of patients and capacity building of HCP by focusing on physiotherapy in Mandalay	Fundraised project	Execution	Myanmar Haemophilia Patient Association - Mr Myo Aung	smqy@nnhf.org	Ensure the distribution of FFP and cryo from the National Blood Centre in Yangon by improving storage and thawing facilities in Mandalay General Hospital Improve musculoskeletal care for patients in Mandalay Meeting with the chapter of the patient association in Mandalay regarding activities in 2017 Print and distribute WFH's haemophilia patient education book.	- Planning of workshop about physiotherapy and musculoskeletal care - Planning of MHPA chapter Mandalay meeting.	6 months Q4 2016
South and Central Asia	Myanmar 2 - MM2	Fellowship in Haemostasis Laboratory	Fellowship	Execution	Yan Naing, pathologist General Hospital, Mandalay, Myanmar	smqy@nnhf.org	Improve expertise in diagnose techniques of inherited and acquired bleeding and clotting disorders Learn to implement good laboratory practices and the importance of pre-analytical variables in haemostasis investigations Acquire in depth knowledge about quality control and the use of appropriate instrumentation and reagents.  - Katharine Dormandy Haemophilia and Thrombosis Centre, Royal Free Hospital, London, UK; responsible person: Dr Thynn Thynn Yee, Haematologist.	- Fellowship on track.	6 months Q1 2016
East Asia	Cambodia - KH	Raising awareness, support, diagnosis and treatment for people with haemophilia living in Cambodia	Project	Execution	Cambodia Haemophilia Association - Mr Sithan Kong	smqy@nnhf.org	Develop national guidelines for diagnosis, treatment and management of patients with haemophilia and other bleeding disorders Improve diagnosis, treatment and management of haemophilia and other bleeding disorders in five provincial hospitals Empower patients and family members to better cope with their condition and engage in the patient society Conduct awareness activities engaging health authorities to secure their support.	- 3 laboratory trainings for a total of 25 laboratory technicians organised in Takeo, Sihanoukville and Kampong Thom province. - 3 workshops for a total of 76 clinicians in Takeo, Sihanoukville and Kampong Thom province. Workshop focus was diagnosis, treatment and management of haemophilia and other allied bleeding disorders.	2.5 years Q4 2014

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East Asia	China 3 - CN3	Further improve reliability of diagnosis and comprehensive care in China by setting up a National Quality Assessment Programme	Project	Closing	Haematology Department, Ruijin Hospital affiliated to Medicine School of Shanghai Jiaotong University, Shanghai - Prof Hongli Wang	rbgs@nnhf.org	Further improve reliability of diagnosis and comprehensive care in China by setting up a National External Quality Assessment (EQA) programme: - Improve the Quality Assessment in Haemophilia laboratories in China - Improve the awareness and knowledge of haemophilia in rural areas of selected less privileged provinces - Find and diagnose 1,000 new patients - Maintain and update the established national web-based bleeding disorders registry.	-CN3 Partners shared Final Project Report and are currently preparing relevant final documentation.	2 years Q2 2012
East Asia	China 4 - CN4	Identify and improve five city level comprehensive haemophilia centres in Shandong province	Project	Execution	Shandong Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang	rbgs@nnhf.org	Identify five city level haemophilia centres from urban and rural areas who meet the established criteria to be developed into comprehensive care centres. Conduct a tailored training program on these centres and assist them in developing cooperation with local government Foster knowledge of patients and families and give them tools to improve their quality of life. Raise awareness through education materials, press engagement and a documentary film. Diagnose and register 200 new cases identified through the proposed awareness activities.	- The project finalization conference was held Taian City in Taian with HTCCNC members as well and public health officials which praised the accomplishments of Professor Zhang and his team. Furthermore the Director from the Leading Group Office of Poverty Alleviation and Development of Shandong Province expressed their willingness to support poor hemophilia patients. -Inspections continued and 49 new patients were diagnosed and registered in the HTCCNC patient registry of China.	2.5 years Q3 2014
East Asia	China 5 - CN5	Set up and consolidate five comprehensive treatment centres for haemophilia and von Willebrand disease in Jiangsu Province China	Project	Execution	The First Affiliated Hospital of Suzhou University, Suzhou - Prof Ziqiang YU	rbgs@nnhf.org	Set up multidisciplinary care and train the teams in Suzhou, Nanjing, Yangzhou, Huaian and Xuzhou. Advance the capacity in the selected centres on factor activity and VWD detection, and the usage of the registry system. Provide technical and patient support, and raise awareness through follow up visits, project specific meetings and World Haemophilia Day activities.	- Two health care professional trainings were organized in Yangzhou.	3 years Q1 2016
East Asia	China 6 - CN6	Decentralisation of multidisciplinary care in four city level haemophilia centres in Sichuan Province China/ Sichuan Province	Project	Execution	Sichuan Center of Haemophilia Diagnosis and Treatment - Prof Xiaojing LI	rbgs@nnhf.org	Select four city-level haemophilia centres in Nanchong, Luzhou, Dazhou and Ya'an. Set up multidisciplinary care and train the teams Advance the capacity of factor activity detection and the usage of the registry system in the selected centres. Provide technical and patient support, and raise awareness through follow up visits, project specific meetings and World Haemophilia Day activities.	- Different capacity building workshops were organized in Ya'an also in collaboration with experts and KOLs. from the Sichuan province -26 patients and family members were trained on improved care - 25 new hemophilia patients were diagnosed and registered.	3 years Q2 2016
East Asia	China 7 (Tibet) - CN7	Development of haemophilia care in Tibet Autonomous Region	Project	Formalisation	Shandong Centre of Haemophilia Diagnosis and Treatment - Dr Xinsheng Zhang	rbgs@nnhf.org	Establish multidisciplinary care at Tibet People's Hospital in Lhasa. The last province in China without haemophilia center. Education of health care professionals in Tibet Autonomous Region including train-the-trainer. To build a multidisciplinary team and Tibet People's Hospital and to assist them to develop cooperation with local government. Establish access to the Chinese national registry and register new patients diagnosed. To guide Tibet Blood Centre on the national quality standards to enable appropriate production of cryoprecipitate in local blood center. Improve the awareness of multidisciplinary care in haemophilia amongst HCP, patients, families and government.	- Project approved with a grant of CHF 50'000. Activities will start shortly.	1 year Q1 2017
East Asia	Malaysia 3 - MY3	Identifying and empowering women leaders to activate regional chapters within the Malaysian Haemophilia Society	Project	Execution	Ampang hospital, Kuala Lumpur - Dr Jameela Sathar	smqy@nnhf.org	Raise awareness among healthcare professionals on diagnosis and treatment of women with bleeding and clotting disorders Create a women's support group at a national level Devise a leadership manual for the women's group in Malaysia Engage media to support improvement of care in Malaysia Set up a National Haemophilia and Coagulation Disorders Standards Board.	- The second workshop "Empowering Women Leaders" was organised in Ampang Hospital. 18 women leaders wish to establish a network, called KHWAN, to create awareness about haemophilia for all potential mothers, sisters and daughters - There has been a key focus on creating a Facebook-group for awareness raising.	1,5 years Q1 2016
East Asia	Nepal - NP	Strengthening the local chapters of Nepal Hemophilia Society to achieve better care through advocacy	Project	Execution	Nepal Hemophilia Society (NHS), Kathmandu - Beda Raj Dhungana	rbgs@nnhf.org	Increase NHS local chapters knowledge on haemophilia and provide a structured approach to advocacy Support haemophilia care training for two doctors (one paediatrician and one general physician) from rural areas of each chapter Raise awareness amongst local government officials.	- Medical training in collaboration with Mary Gooley Care Center took place in November 2016. Authority representatives were invited raising awareness on haemophilia at Government level.	6 months Q1 2015
East Asia	Philippines - PH	National Registry of Haemophilia and Allied Bleeding Disorders Philippines	Project	Closing	Philippine Haemophilia Foundation INC. - Dr Florida G. Hernandez	rbgs@nnhf.org	Create a National Registry of Haemophilia and other Bleeding disorders Educate the medical, paramedical practitioners and general population about haemophilia and allied bleeding disorders Gather data essential for lobbying support from the National Government Encourage haemophilia advocacy in the countryside Empower haemophilia support group Strengthen partnership with stakeholders.	- Project was finalized achieving the set up of an online registry and increased awareness amongst the general public and authorities. Final project report provided.	3 years Q3 2012

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East Asia	Thailand 4 - TH4	Improving haemophilia care in Thailand through the Chronic Care Model, strengthening of comprehensive care teams and development of leadership talents	Project	Formalisation	National Health Security Office (NHSO), IHTC Bangkok, Faculty of Medicine/Chiang Mai University and the Thai Haemophilia Patient Club, Bangkok - Hathaiwut Lamthean - Prof Ampaiwan Chuansumrit - Dr Rungrote Natesirinikul - Mr Ekawat Suwantaraj	smqy@nnhf.org	Strengthen the regional reference centre in Southern Thailand in Prince of Songkhla Hospital Strengthen the comprehensive care teams in 8 haemophilia treatment centres (HTCs) Improve awareness and quality of care at district and provincial hospitals in 8 provinces Develop national patient guidelines regarding the care set up and the right to care in Thailand Develop young, leadership talents in all 5 patient clubs in Thailand.	- Project approved.	2 years Q1 2017
East Asia	Thailand2 - TH2	Improving MSK care in Thailand - through education, outcome measurement and the establishment of two training centres in Bangkok and Chiang Mai	Project	Execution	Faculty of Medicine/Chiang Mai University and IHTC Bangkok  - Dr Rungrote Natesirinikul - Prof Ampaiwan Chuansumrit	smqy@nnhf.org	Validate the HJHS 2.1, FISH, PedHAL/HAL, CHOKLAT and HEMOQoL-A into Thai language Perform a Training of Trainers session on MSK evaluations for the team in Chiang Mai and Bangkok Delineate the MSK status of patients in Chiang Mai and Bangkok Provide training to patients about the importance of MSK evaluation and physical activity Share results at local and international journals and at one international conference.	- MSK assessment of 5 persons with haemophilia from both IHTC Ramathibodi Hospital Bangkok and from Chiang Mai Hospital using the Thai version of HJHS 2.1 and FISH - Twenty copies of the Thai DVD version of HJHS 2.1 available - Monthly operation committee conference calls organised between IHTC Ramathibodi Hospital Bangkok, Chiang Mai Hospital and Sick Kids Hospital in Canada.	3 years Q4 2015
East Asia	Vietnam 2 - VN2	Join efforts to improve quality of haemophilia care across Vietnam	Project	Execution	Vietnam Society of Congenital Bleeding disorder, Hanoi - Prof Nguyen Anh Tri	smqy@nnhf.org	Improve quality of haemophilia care in the four main regions: Hanoi, Hue, HoChiMinh city (HCMC) and Can Tho Improve medical staff knowledge about haemophilia Improve knowledge of patients and families Diagnose 200 new patients through an outreach program Create awareness about haemophilia.	- Outreach diagnosis programme leading to 29 new patients diagnosed - Haemophilia camp organised for 70 patients and families in Hue focusing on education about haemophilia, first-aid education to manage internal bleedings (RICE), learning-puzzles for children and a swimming activity - Guidelines on home care was distributed.	3 years Q2 2013
East Asia	Cambodia 2 - KH2	Advanced training in rare bleeding disorders diagnosis	Fellowship	Formalisation	Sam Samey, Laboratory technician, National Pediatric Hospital (NPH), Phnom Penh	smqy@nnhf.org	Increase capacity of diagnosis regarding; - Detection of inhibitors - Diagnosis of von Willebrand disease - Diagnosis of Platelet Function Disorders - Testing for antiphospholipid antibodies.  - Hospital Ampang, Kuala Lumpur, Malaysia; responsible person: Jameela Sathar, Dr/Consultant Haematologist.	- Fellowship to start 1 march 2017.	2 months Q1 2017
North and Middle America	Cuba 2 - CU2	Decentralisation of comprehensive care to two centres in the East and establishment of a national reference centre for women with bleeding disorders in Havana	Project	Execution	Instituto de Hematología e Inmunología (IHI), Habana - Prof. José M. Ballester Santovenia and Dr Dunia Castillo	deni@nnhf.org	Decentralisation of comprehensive care to two centres in the East and establishment of a national reference centre for women with bleeding disorders in Havana.	- All contractual preparations for the procurement of the laboratory and IT equipment has been done. - The national treatment guidelines are in revision. - The national registry has been upgraded.	2 years Q3 2016
North and Middle America	Jamaica - JM	Establishing quality diagnosis, comprehensive care and expertise in bleeding disorders	Project	Execution	University of the West Indies, Kingston - Dr Gilian Wharfe	deni@nnhf.org	Improve the diagnosis accuracy in haemophilia Train healthcare professionals on haemophilia Organise educational workshops for patients and family members Create a national registry and treatment guidelines Raise awareness of bleeding disorders amongst the authorities and the general public.	- The diagnosis of patients was continued, mainly doing inhibitor testing in Q4 2016. - Based on the excellent project progress, the NNHF Council approved the prolongation of the project until the end of June 2017 in order to finalise the planned and some additional activities.	2 years Q3 2014  - prolonged until Q2 2017
North and Middle America	Mexico 3 - MX3	Set up paediatric rehabilitation to prevent functional limitations in children in two hospitals in Mexico City	Project	Execution	Hospital Infantil de México Federico Gómez (HIMFG), Mexico City - Dr Io Daiela Castillo	deni@nnhf.org	Train healthcare professionals on MSK care Identify children with haemophilia with haemarthrosis and at risk of developing functional limitations Establish a rehabilitation programme and anchor it in the regional care approach Raise awareness amongst the haemophilia community of the importance of MSK care and prevention.	- 2 sessions were organised for 20 patients and 30 parents at Hospital Infantil de México Federico Gómez (HIMFG) about 1) recommended exercise, 2) inhibitors - Meeting between the two involved centres (HIMFG and National Paediatric Institute (INP)) to discuss the progress of the en-rolled patients in the rehabilitation programme - A manual including exercises to be done at home was created and 1,000 copies printed.	1.5 years Q4 2015
North and Middle America	Mexico 4 - MX4	National alliance for a cross-sectorial haemophilia programme	Project	Formalisation	Mexican Haemophilia Federation (FHRM), Mexico City - Miguel Izquierdo Zarco	deni@nnhf.org	Create or strengthen multidisciplinary care teams across hospitals and healthcare institutions in Mexico by increasing the capabilities and haemophilia knowledge of healthcare professionals Consolidate data in national online patient registry and expand registry to include medical data Reach better levels of care and treatment for all patients through advocacy initiatives.	- Approved in the NNHF Council Meeting in September 2016.	3 years Q1 2017
North and Middle America	Mexico 5 (State of Mexico) - MX5	Creation of comprehensive haemophilia clinic of ISSEMyM	Project	Formalisation	Haemophilia clinic of Maternal-Infant Hospital ISSEMyM, Toluca, State of Mexico - Dr Cecilia Rodríguez Castillejos	deni@nnhf.org	Form a multidisciplinary care team at Maternal-Infant Hospital Train HCPs from partner hospital, the ISSEMyM network (1st and 2nd level of care) and selected HCPs across the healthcare institutions of the State of Mexico Provide education, guidance and psychological support to patients and their families Formalise a complete haemophilia patient database for the hospital Improve the quality of diagnosis in the hospital laboratory and beyond.	- Approved in the NNHF Council Meeting in September 2016.	1.5 years Q1 2017

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North and Middle America	Nicaragua - NI	Establish comprehensive care of haemophilia in Nicaragua	Project	Execution	Nicaraguan Association of Hemophilia - Javier Antonio Rivas Ojeda  and Red Cross Nicaragua - Dr Rene Berrios	deni@nnhf.org	Improve coagulation laboratory and train the staff to do diagnosis Create national treatment guidelines Train professionals in nursing, physiotherapy, dental care and medical training of patients with haemophilia Provide educational sessions to patients and families on haemophilia Strengthen the haemophilia care centre and the patient association.	- The diagnosis activities started by taking 17 samples from patients from Leon and Chinandega. - Organised by the Nicaraguan Haemophilia patient organisation and the National Blood Bank in close collaboration with the Nicaraguan Ministry of Health, the first 2-day training for 40 HCPs took place with the support of experts Dr Toribio Gómez Cartaya (orthopaedist from Venezuela) and Lic. Deivis Pitty (physiotherapist from Panama). 100 patients and family members participated in the additional educational day by the same experts. - The advocacy efforts and the great collaboration with the authorities have led to the first purchase of factor concentrates by the government authorities of Nicaragua.	2 years Q1 2016
North and Middle America	Mexico 5 - MX5	Rehabilitation in haemophilia care	Fellowship	Formalisation	Dr Mariela Colin Marin, Physiatrist, IMSS Hospital, Pachuca, Hidalgo	deni@nnhf.org	Learn more about general haemophilia care and the multidisciplinary approach Get more acquainted with the rehabilitation tools for haemophilia care Share experiences and knowledge gained adapting it to the local circumstances.  Hospital Universitario y Politécnico La Fe, Valencia, Spain; responsible person: Dr Santiago Bonanad, Haematologist.	- Approved in the NNHF Council Meeting in September 2016.	1 month Q3 2017
North and Middle America	Mexico 6 - MX6	Advanced rehabilitation training	Fellowship	Formalisation	Dr Aídeez Gibraltar Conde, Physiatrist, Medical Unit of High Specialty, Unit of Physical Medicine and Rehabilitation North, IMSS, Mexico City	deni@nnhf.org	Learn more about new diagnosis and treatment methods for MSK complications Focus on prevention of damage in joints Share experiences and knowledge gained adapting it to the local circumstances.  Hospital Universitario y Politécnico La Fe, Valencia, Spain; responsible person: Dr Santiago Bonanad, Haematologist.	- Approved in the NNHF Council Meeting in September 2016.	1 month Q1 2017
South America	Argentina 2 (South of Buenos Aires province) - AR2	Creation of a cross-institutional and multidisciplinary care network to offer a comprehensive approach in the South of Buenos Aires province	Project	Execution	CARDHE - patient association and healthcare centre in Bahía Blanca, - Dr Susana Garbiero	deni@nnhf.org	Establish a working agenda with all relevant health institutions in the region and create a network Evaluate the patients' situation and empower them and their families through education Strengthen the healthcare institutions in the region through training.	- In Q4 2016, continuing to strengthen the cross-institutional and multidisciplinary care network in the South of Buenos Aires province, 3 training sessions took place in: 1) Viedma with 9 HCPs, 2 patients and 1 family member focussing on basic treatment of haemophilia A and B as well as management of haemarthrosis by the physiotherapist and the orthopaedist; 2) Monte Hermoso with 8 HCPs, 2 patients and 1 family member introducing the participants to haemophilia and its diagnosis and looked into the psychosocial aspects of the condition; 3) Huanguelén with 27 HCPs, 3 patients and 1 family member covering an introduction to haemophilia, its diagnosis and treatment, MSK and psychosocial aspects.	1.5 years Q2 2016
South America	Argentina 3 (Jujuy) - AR3	Outreach to patients with haemophilia in the province of Jujuy	Project	Execution	Fundación Jujueña de Hemofilia, San Salvador de Jujuy - Dr Susana Gastaldo	deni@nnhf.org	Identify new patients and improve diagnosis infrastructure Improve access to care for people with haemophilia in the province of Jujuy Improve patients' quality of life by establishing self-treatment processes and educating the social environment.	- Started improving the laboratory infrastructure in the reference centre in Jujuy. 30 patients have been re-diagnosed and registered. A map was created with the location of diagnosed patients. - In order to identify new patients, an awareness event with 170 youth participants and meetings with patients and family members were started in La Quebrada, Humahuaca and El Carmen. - The health authorities both on a provincial as district level in Tilcara, Maimara and Humahuaca have been approached. HCP training took place in the 1st level hospitals of the mentioned districts including distribution of training material - An educational patient camp took place in December with 70 patients and family members.	1 year Q4 2016
South America	Brazil 2 - BR2	Improve MSK status of PWH in Brazil by Measuring, Analysing, Disseminating and Educating – the way to correct, prevent and optimise the treatment	Project	Closing	IHTC "Luiz Cláudio Pizzigatti Correa", Hemocentro UNICAMP (State University of Campinas), Campinas - Dr Margareth Castro Ozelo	rbgs@nnhf.org	Establish guidelines for MSK evaluation and treatment Develop educative materials for PWH, their families and for healthcare professionals. Improve Quality of Life (QoL) of PWH through improvements in their physical, mental and social well-being.	- Validation studies proposals for the MSK tool received and being evaluated.	3 years Q3 2011
South America	Brazil 3 - BR3	Impact of training health care professionals and patients with inherited bleeding disorders on quality of treatment	Project	Closing	Hemocentro do Estado do Espírito Santo-HEMOES, Vitoria - Dr Alessandra Nunes Loureiro Prezotti, M.D., Ph.D	rbgs@nnhf.org	Develop practical guidelines customised for professionals who work in primary health care Produce an educative material for professionals and patients with inherited bleeding disorders and their families Develop a treatment guiding poster to be placed in emergency rooms Devise an educative and monitoring diary for patients with inherited bleeding disorders Prepare and deliver training activities for patients and their families Organize scientific meetings and training programs to expand and apply the outcomes generated by this project Publicise the results in a national meeting and the Haemophilia	- Waiting for final project audit report. The Brazil 3 project led by Dr Alessandra Prezotti and the HEMOES team received in December 2016 the Inovex Award for the value that it brings to the community. An outstanding recognition to a successful collaboration for the improvement of haemophilia care in Brazil.	2 years Q3 2013



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South America	Brazil 4 - BR4	Strengthening the care and education network for haemophilia in the state of Pará in Brazil	Project	Execution	FBH – Federação Brasileira de Hemofilia - Christianne Maria Oliveira Costa crisbyoc@yahoo.com.br	rbgs@nnhf.org	Prepare and deliver training activities for health care professionals of primary health care and municipal hospitals Prepare and deliver training activities for patients and their families Reproduction and distribution of educational materials, posters and infusion diaries for patients Draw the psychosocial profile of patients and their situation to promote the appropriate treatment Publicise the results in a national meeting and at the Haemophilia journal.	- On December 12, 2016, a ASPAHC meeting was held with Physiotherapy Manager, Dr. Shirley Fonteneles. Since September 2016, after the first REHEDUCA project, no other patients were referred for MSK assessment.	2.5 years Q3 2015
South America	Chile 3 - CL3	Consolidating care and treatment for haemophilia and allied bleeding disorders across Chile	Project	Formalisation	Hospital Roberto del Río, Santiago - Dr Veronica Soto Arellano	deni@nnhf.org	Improve diagnosis of congenital coagulopathies in the national reference centre Improve MSK care and training Consolidate data of haemophilia and congenital coagulopathies in national online patient registry.	- Approved in December 2016.	1.5 years Q2 2017
South America	Paraguay - PY	Consolidating haemophilia care in Paraguay through diagnosis, registry and training of healthcare professionals and patients	Project	Execution	Fundación de Ayuda al Hemofílico (Fundahemo) - Mayda Tamara Yasychyn	deni@nnhf.org	Train staff to improve care offered to patients with haemophilia Improve quality of diagnosis in Paraguay by strengthening coagulation laboratory facilities at Hospital Nacional de Itagua and Hospital Regional de Encarnación Execute a nationwide census to diagnose and register patients Provide educational sessions to patients and families on haemophilia.	- The laboratory equipment, reagents and consumables were purchased to equip the laboratories in the National Hospital in Itagua and the Regional Hospital in Encarnación. - Lab training is took place on 7-11 November both in the National Hospital in Itagua and in the Regional Hospital in Encarnación by expert trainer Marión Echenagucia from Venezuela, training 35 healthcare professionals.	1.5 years Q4 2015
South America	Peru 3 - PE3	Strengthen and expand network and structure of haemophilia care across sectors in Peru	Project	Formalisation	Peruvian Haematology Society, Lima - Dr Juan Navarro Cabrera and Dr Nancy Loayza	deni@nnhf.org	Organise care on a national level strengthening and creating multidisciplinary care teams Achieve quality diagnosis in the reference centres and create basic diagnosis hubs in other regions of the country Reflect the national epidemiological picture of haemophilia and allied bleeding disorders in a web-based registry.	- Approved in December 2016.	2 years Q2 2017
South America	Chile 5 - CL5	The role of a social worker in haemophilia	Fellowship	Execution	Pamela Andrea Suazo Navarro, social worker, Santiago, Chile	deni@nnhf.org	Specialise in haemophilia care Learn about the role of a social worker in haemophilia Increase knowledge about self-management and social re-integration for people with haemophilia.  - Hemocentro "IHTC Cláudio Luis Pizzigatti Correa", Hematology Center of University of Campinas (UNICAMP), Campinas, Brazil; responsible person: Dr Margareth Ozelo, Head of the Centre.	- Training took place in November 2016 in Campinas, Brazil.	2 weeks Q4 2016
Global	Laboratory Module 2016	NNHF Laboratory Module 2016	Project	Execution	NNHF Lab training module in cooperation with the Royal Free Hospital (UK) - Dr Angus McCraw - Haemophilia centre service manager & principal biomedical scientist  - Marion Echenagucia, Head of Haematology Lab, Banco de Sangre de Caracas, Venezuela  - Dr Christophe Nougier Edouard Herriot Hospital, Lyon, France	sysd@nnhf.org	Improve expertise in quality diagnoses tailored to the working conditions of developing countries Give continuity to the basic module performing five basic courses in 2016 Develop and engage regional lab expert trainers Build an international network of trainees.	- All the project activities were completed. The project will be closed in March 2017 Council meeting.	1 year Q1 2016