National Haemophilia Care Meeting 2017

18 & 19 February 2017
New Delhi, India

Summary and Report

Executive summary

Introduction to NHCM

National Haemophilia Care Meeting (NHCM) is a unique forum which aims to bring together key personnel that includes representation of the Health Ministry in the States viz. Health Secretary, Director Medical Education, Director Health Services, National Heath Mission (NHM) coordinators, Nodal officers for specific programs and other important stakeholders to meet and discuss organization of care of people with bleeding disorders including haemophilia

Objectives of NHCM 2017

The major objectives of NHCM are towards achieving changes in delivery of haemophilia care across the country and include.

1. The organisational aspects of haemophilia care
2. Haemophilia care provided by several state Governments
3. Need to shift to prophylaxis based management for PwH in India
4. Comprehensive care in haemophilia

NHCM recommendations 2017

Organisational aspects of haemophilia care

1. Need for setting up adequate diagnostic facilities with quality assurance in each state
2. Establish / designate HTCs at different levels within the State health care system
3. Train personnel for these HTCs in the core elements of comprehensive care
4. Need to shift from providing on-demand treatment to prophylaxis especially in the pediatric age group and extending patient benefits.
5. Develop a system for effective tender, procurement, distribution & utilization of CFC
6. Develop a haemophilia registry as per standardized templates (possibly WFH) within the State Government system
7. Need for all stakeholders to work together – Health Ministry, HTCs, Patient Organization & Industry.

Haemophilia care - State Government Programs

1. Major challenge is resource allocation (funds) with competing demands leading to limited/erratic free factor availability. Alternative funding sources for budget allocation in haemophilia care need to be identified to overcome the challenges related to resource allocation in different states – best practices need to be replicated

2. Need for effective utilisation of funding in all aspects related to diagnosis, HTC set up, , and education along with accountability/audit and PwH empowerment
3. Different structures & methods of implementation of HTCs to ensure the accessibility to factor treatment is available at the nearest centre for each PwH – Medical Colleges vs District Hospitals
4. Methodology for calculation of CFC demand for tender & distribution has been a complicated issue and varies across different States. Potential solution could be to continue to benchmark procurement against a demand forecast basis offering all PwH in the state with the optimum standard of care

Need to shift to prophylaxis based management for PwH in India

1. Higher the amount of clotting factor used in episodic treatment does not prevent the recurrence of joint bleed and only allows to modify the natural course of disease. On-demand or episodic

treatment hence should **NOT** be considered as a treatment option for long term management as it is almost the same as **not giving any treatment** (with regard to joint outcome).

   a. Recent studies with low dose prophylaxis (1000 – 2000 IU/Kg/year/patient) have demonstrated significant reduction in number of bleeds in comparison to episodic or on-demand treatment with factor concentrates.
   b. Though long term joint outcomes are yet to be ascertained with low dose prophylaxis regimen; it may as well be a good starting point for countries with constraint in resource allocation due to competing demands.

2. Addressing issues in procurement of clotting factors need to be prioritized towards ensuring safety and quality while selection of appropriate clotting factors during procurement across different states.

Comprehensive care in haemophilia

1. There is a pressing need to establish haemostasis services in general hospital as it offers benefits to all patients presenting with bleeding disorder or any complication related to bleeding manifestation in various clinical departments. Prioritize funding allocation, capacity building, man power, and adequate training for establishing haemostasis services at different levels – primary, secondary and tertiary care levels
2. Need for awareness related to selection of appropriate outcome measurement tools in haemophilia care is essential to demonstrate the impact of haemophilia programs to all relevant stakeholders.
3. Need for more number of centres to offer genetic diagnostic services for haemophilia – requires awareness among all relevant stakeholders including policy makers and health care administrators at State Government level.

NHCM 2017 – Meeting Report

National Haemophilia Care Meeting (NHCM) is a unique forum which aims to bring together key personnel involved in organizational aspects of health care in the States to meet and discuss organization of care for people with bleeding disorders including haemophilia and develop strategies for optimal utilization of resources allocated for haemophilia care.

NHCM includes personnel representing the Health Ministry in the States viz. Health Secretary, Director Medical Education, Director Health Services, National Heath Mission (NHM) coordinators, Nodal officers for specific programs amongst other important stakeholders involved in haemophilia care in the State.

Though haemophilia is a rare disease and relatively expensive to treat, it should be recognized that significant improvement in haemophilia care has been evident in last 5-6 years. Majority of states have been able to allocate specific budget for haemophilia care thereby contributing to approximately Rs.300 crores in 2016 that reflects nearly 1000% increase in the last 5-6 years. Inspite of these measures, lack of clarity still persist on how to develop services for haemophilia care and ensure delivery of care.

The NHCM meeting was hence initiated in 2013 and was conducted in subsequent years in 2014 and 2015 by CMC, Vellore; Maulana Azad Medical College, New Delhi & Hemophilia Federation of India (HFI). These meetings provided a platform to stimulate discussions on the burden of haemophilia in India, core aspects of organizing haemophilia care, overview of the core medical aspects of care viz. appropriate diagnostic facilities, adequate therapeutic products, system for their delivery, documentation of utilization and outcomes. Various Presentations on State Government or Central Government Programs also featured during this program as a best practice sharing session.

This NHCM meeting in 2017 was organized by the recently constituted Indian Hemophilia & Allied Disorders Group (IHADG). IHADG was constituted with goal of promotion of better care for these patients, addressing many unmet needs of this community through scientific meetings, training, advocacy and research. The IHADG is managed by a Steering Committee with faculty from Major Institutes like CMC, Vellore, AIIMS, New Delhi, MAMC, New Delhi, Sahyadri Hospital, Pune, St. John's Medical College, Bengaluru, CMC, Ludhiana and KEM Hospital, Mumbai.

Achieving change in delivery of haemophilia care

The major objectives of NHCM are towards achieving changes in delivery of haemophilia care across the country and include

1. The organisational aspects of haemophilia care
2. Haemophilia care provided by several state Governments
3. Need to shift to prophylaxis based management for PWH in India
4. Comprehensive care in haemophilia

1. The organisational aspects of haemophilia care

Organisation aspects of haemophilia care were discussed under the following topics

1. NHCM recommendations for haemophilia care in India
2. Overview of State Government Programs
3. Importance of moving to HTC based haemophilia registry

4. National Health Mission (NHM) support for haemophilia care

1.1 NHCM recommendations for haemophilia care in India

Organisational aspects:

1. Establish HTCs at different levels within the State health care system including primary care towards ensuring emergency management of bleeds with CFC in addition to establishment of haemophilia treatment centre and comprehensive care centre and referral centres for management of specific complications.
2. Provide facility for factor replacement therapy and physiotherapy at district level.
3. Strengthen the diagnostic services for haemophilia to cover the population across the country with quality assurance in each state
4. Need for all stakeholders to work together – Health Ministry, HTCs, Patient Organizations & Industry
5. Enhance capacity building – by providing training to health care worker on core elements of comprehensive care in haemophilia and empower PwH through knowledge sharing.

Delivery of care:

1. Create nodal referral centres for diagnosis, prompt treatment and referral services
2. Appropriate budget for initiating prophylaxis at least for young children and also for treatment of inhibitors
3. While access to adequate CFC is critical, all aspects of comprehensive care are important viz. Physical therapy, orthopaedic care, dental care, genetic counselling, Lab monitoring, occupational therapy.
4. Develop an effective system for tendering, procurement, distribution & utilization of CFC
5. Develop a hemophilia registry as per standardized templates (possibly WFH)within the State Government system
6. Audit and accreditation process to be followed for quality check and quality services across the spectrum of care

1.2 State Government Hemophilia Care Programs: An overview

1. Over the recent years, 20 States in India have started haemophilia care with provision of free factor in their respective regions (2016 data from HFI and SHC)
2. Inspite of the recent increase in funding allocation; erratic supply with lack of free factor availability remains a major challenge and concern in implementing haemophilia care in certain States.
3. Another major challenge is resource allocation with competing demands in every State at the policy decision making level.
4. Alternative funding sources for budget allocation in haemophilia care – viz. National Health Mission, Corporate Social Responsibility, Lotteries, PM/CM funds etc. are being practiced in certain States that might be replicated in other regions.
5. While access to adequate CFC is critical in a State Government haemophilia program, other aspects related to diagnosis, HTC set up, referral, comprehensive care, accountability/audit, education and PwH empowerment must not be ruled out.
6. Different structures & methods of implementation of HTCs exist in different states – Medical Colleges vs District Hospitals. The State Government should rather ensure the accessibility to factor treatment is available at the nearest centre for each PwH.
7. Methodology for calculation of CFC demand for tender & distribution has been a complicated issue and varies across different States and needs to be appropriately addressed. Potential solution could be to continue to benchmark procurement against a demand forecast basis offering all PwH in the state with the optimum standard of care

1.3 Haemophilia registry – NGO vs HTC registry

1. A NGO such as HFI currently maintains a register that captures basic demographic details of PwH such as name, age, address, education and socio-economic data with objectives to help relevant stakeholders in making informed decision regarding number of patients affected in each region and annual resource allocation.
2. The NGO based register is now being upgraded to embrace technology; that can help State Governments to develop a system for effective monitoring of procurement, distribution & utilization of CFC.
3. This register is also being developed to guide the treating physicians regarding the dose required for treatment according to different site of bleeds and body weight.
4. A HTC based registry nonetheless is different as it has the potential to remain as an accessible, comprehensive, continuously updated and validated database with clear objectives to monitor the disease burden, clinical intervention, complications and also to assess patient outcomes such as musculoskeletal outcomes, quality of life, survival etc.
5. There is an urgent need to create an uniform registry across allStatesthat adapts World Federation Bleeding Disorder Registry which includes demographic details, clinical information at diagnosis, treatment history with clotting factors, joint outcomes and annual follow up. In addition to that it is also important to also have a registry that maintains at least minimal data sets at respective centre (Primary or district level) which will help better planning and resource allocation in subsequent years
6.
7. Need to prioritise the synchronisation of data from similar HTC based registries at the State level as this will inform the long term benefits and outcomes that were achieved because of the State Government initiatives towards haemophilia care.

1.4 NHM support to haemophilia care

1. Funding support from NHM is recognized as one of the alternative sources of funding for haemophilia care apart from State Government funding.
2. NHM allocates 60% of the total funding for haemophilia projects while the State Ministry has to bear the rest 40%
3. NHM encourages and has actively allocated funds towards facilitating early diagnosis of haemophilia, creating treatment centers, free factor procurement, opening windows of distributing free factors at district level, patient education/awareness programs.
4. NHM has allocated funds to the State Ministry depending upon the priority of request, the roadmap or project proposal, the rationale and justification for the Project Implementation Plan as suggested by the State Government on haemophilia care.
5. NHM also plays an active role not only by funding but also in supporting the treatment providers with national treatment guidelines in various blood disorders.
6. Recently NHM also took a step forward in setting up criteria for inclusion of haemophilia patients to derive benefit from the disability bill.

2. Haemophilia Care in the States – Government support

State Health care administrators from various states – Karnataka, Kerala, Maharashtra, Bihar and Uttar Pradesh shared respectively their State Government's support and program for provision of Haemophilia care.

2.1 Karnataka

1. Approximately 1850 patients are diagnosed with haemophilia and registered in Karnataka amongst an estimated number of 6000 patients. There are six hemophilia societies located at Bangalore, Davangere, Mysore, Manipal, Gangavathi, and Hubli-Dharwad
2. Karnataka is the first state in India to provide anti haemophilia factors to haemophilia patients in 2005 for BPL patients free of cost.
3. Currently AHFs are available in 22 district hospitals out of 30 districts in state.
4. Procurement of factors remains an issue; as the number of bidders who participate in the tender is less and also the bidders do not sometimes submit all the necessary documents as specified.

2.2 Kerala

1. Kerala State Government procures clotting factors and offers it free to all PwH diagnosed and registered in the State of Kerala irrespective of whether they belong to BPL or not.
2. However the procurement system is novel as state has not gone for the procurement of anti-hemophilic factors through essential free drug delivery system till date but the funding for haemophilia state program is allotted from the revenues generated from Karunya Lotteries scheme.
3. Kerala State Government is actively seeking to establish a nodal comprehensive care centre through Public Private Partnership funding model which might come to light sooner than later.
4. Kerala State Government is also trying to introduce the benefits of recombinant clotting factors for treatment of haemophilia and inhibitor patients at least to children in Kerala who are suffering from this disease.
5. List of essential drugs for children that is different from that of adults and elderly population for all diseases including haemophilia to be introduced at State level – the proposal to procure the same and make it available in all the Medical Colleges in the State
6. Generation of additional funds for haemophilia is done through the revenues that are being generated through Local Self Government (Panchayat Raj) at district level.

2.3 Maharashtra

1. Inclusion of Hemophilia in Hematology Programme - under N.R.H.M., was approved, in Maharashtra state, in PIP 2012-13 and successfully implemented in 4 day care centers and 2 Medical Colleges.
2. The State Government allocates funds under Haematology Program under various heads namely
    a. Procurement of factors (as Clotting factors are included in the Essential Medicine List that is NHM Free Drug Services)
    b. Training of all health functionaries like Medical Officers, Nurse etc.
    c. Strengthening of diagnostic and treatment centers by providing support to health care infrastructure including lab and provision of technical manpower.
    d. Supporting departments like blood bank
    e. Establishment of physiotherapy center.
    f. Providing IEC materials in these centers for creating awareness in the community about these diseases
3. The day care centers support Laboratory investigation, the treatment of Hemophiliacs 24 x 7 (as spontaneous bleeding in the severe & moderate Hemophiliacs is an emergency case) and physiotherapy for patients with haemophilia.
4. Recently treatment of all the genetic blood disorders like haemophilia, sickle cell disease and thalassemia have been included in Rajiv Gandhi Jeevandayee Arogya Yojana and steps have been taken by State Government of Maharashtra to make 4 new centers functional by end of 2017.

2.4 Bihar

1. Haemophilia hospital was set up in 2006 at Patna which provides haemophilia care to all registered patients living in the state of Bihar.
2. Along with first aid services like splinting, the haemophilia clinic also provides free AHF support and fresh frozen plasma to manage PwH presenting with bleed.
3. The Rehabilitation Department at Patna Medical College has indoor bed facilities for admitting PwH that provides complete rehabilitation, physical therapy, occupational therapy during the admission period for patients with iliopsoas bleed, knee contractures and wasting of muscles.
4. Along with haemophilia society chapter in Patna, it also issues certificate of disability percentage and railway concession certificates to the needy PwH.
5. However, since patients with inhibitors are difficult to manage these patients are referred outside the state for expert care.

2.5 Uttar Pradesh

1. There are 23 hemophilia centers in UP, along with 17 medical colleges where free factor facility is available and apart from that there are six district hospitals also.
2. There are roughly 1815 hemophilia A patients, 285 hemophilia B, Factor IX deficient patients, and 39 patients of inhibitor
3. Though a lot of progress has been made, but UP still does not have committed staff for haemophilia which poses challenges in diagnosis and haemophilia care

3. Moving towards prophylaxis in India

3.1 Episodic CFC replacement – Is it useful?

1. The usual paradigm in management of haemophilia depends on the severity of haemophilia and the clinical presentation.
2. While the main goal is to prevent bleeds completely; it may not be realistic with current advancements, hence it may be pragmatic to reduce the number of bleeds to minimum possible extent while treating the unavoidable break-through bleeds in an episodic manner.
3. While prophylaxis not only minimises musculoskeletal disease and its complications, it also improves normal activities of daily life and brings near normal musculoskeletal & psycho-social development in a PwH.
4. Higher amounts of clotting factor used in episodic treatment does not prevent the recurrence of joint bleed and only allows modifying the natural course of disease.
5. On-demand or episodic treatment hence should not be considered as a treatment option for long term management as it is almost the same as **not giving any treatment** (with regard to joint outcome).
6. Major studies till date have evaluated prophylaxis with FVIII either at high dose (4000 – 6000 IU / kg/year/patient) or at intermediate dose (2000 – 3000 IU/Kg/year/patient) or that demonstrated similar outcomes without much difference.
7. Considering the cost of clotting factors and the current resource constraint environment in India, it may be practical to consider prophylaxis at intermediate dose (2000 – 3000 IU/Kg/year/patient) for optimal patient outcomes.

8. Age of initiation of prophylaxis was also a significant factor in determining long term outcomes; earlier the prophylaxis is started (preferably within 3 years) better is the joint outcomes.

3.2 Prophylaxis with lower doses

1. Recent studies with low dose prophylaxis (1000 – 2000 IU/Kg/year/patient) from several parts of the world have demonstrated significant reduction in number of bleeds in comparison to episodic or on-demand treatment with factor concentrates.
2. A similar study that was conducted in southern state of Kerala to evaluate low dose prophylaxis in children, demonstrated significant reduction in frequency of bleed, number of hospitalisation days, school absenteeism within first 6 months.
3. After 1 year of follow up; none of these children developed inhibitors and decreasing trend continued in the parameters that were evaluated at the end of 6 months.
4. Mean consumption of FVIII was higher in low dose prophylaxis in comparison to episodic treatment; however the benefits outweighed the cost as mentioned above.
5. Though long term joint outcomes are yet to be ascertained with low dose prophylaxis regimen; it may as well be a good starting point and escalation of prophylaxis for a certain defined population in India such as school going children or even younger, if not for all.
6. A committed comprehensive care team is essential and strong government support is vital for starting prophylaxis.

3.3 Issues and challenges in procurement of clotting factors

Major issues in procurement of clotting factors are related to selection of the clotting factor concentrates and issues with tendering process

Selection of the clotting factor concentrates before procurement:

1. While price should be one of the criteria, it should not be the sole parameter for deciding the appropriate clotting factor that needs to be procured.
2. Safety and efficacy of the factor concentrate is the most important criteria to consider while deciding which clotting factor concentrate needs to be procured.
3. While considering safety parameters, end product testing should never be considered rather the whole manufacturing process should be looked into.
4. The quality of the plasma material should be looked into by checking for various factors like Regulatory status of the plasma supplier, donor epidemiology, donor exclusion criteria, screening tests done on the blood/plasma, quality assurance measures, inventory hold, plasma pool size and testing of the plasma pool.
5. Apart from obtaining the plasma master file, inclusion of validated specific viral inactivation and/or removal steps such as solvent detergent technique and nanofiltration that are considered as gold standard techniques should also be looked into in the manufacturing process while considering the clotting factor selection.
6. Documentation of clinical studies demonstrating the product's efficacy including post marketing studies should not be overlooked.

Issues with tendering process

1. Inspite of recent increase in procurement of clotting factors over the recent years, issues like intermittent supply or purchase, inadequate amount of factor procurement, inability to give prophylaxis still persist.

2. Different products are used in different hospitals and CFC changed frequently because of multiple tenders from time to time.
3. National tenders can be a cost effective way to purchase large quantities of CFC with increase in the range and choice of products available to clinicians and patients in a particular country.
4. Price could be a final selection criterion to use provided that the products satisfy the criteria for safety, efficacy, quality, and security of supply.

3.4 Newer therapeutic options in haemophilia care

1. Significant progress in care for haemophilia patients has occurred over the last 5 decades the notable of which were the advent of recombinant therapy, establishment of prophylaxis as standard of care and third generation recombinant technology where clotting factors are manufactured without human or animal plasma derivatives.
2. Significant medical needs that are unmet in haemophilia care include multiple intravenous injections, difficult venous access, risk of inhibitor formation with factors, better treatment to manage inhibitors and potential cure of the underlying genetic defect.
3. To address the issues of dynamic life style, and vein access problems, extended half-life clotting factor products have been invented and made available for clinical use for patients of haemophilia A, B and for patients with inhibitors.
4. Recently novel approaches such as monoclonal antibodies with different mechanisms of action are being evaluated in various clinical studies that may be administered subcutaneously without any need of multiple or frequent intravenous injections in patients with haemophilia patients including those with inhibitors.
5. Gene therapy trials are currently underway both for haemophilia A and B that may pave way for sustained factor levels over a longer period of time, if not permanent cure.

4. Comprehensive care in haemophilia management

4.1 Requirements for establishing a haemostasis lab

1. Setting up haemostasis lab requires consideration of the level of care that needs to be established in a centre, investigations that need to be done, equipment required to do these tests, reagents required to conduct these tests and more importantly knowledge and expertise of appropriate methods to collect the sample, and do the tests.
2. At district (primary/secondary) level, setting up a laboratory would require minimal resource investment in procuring equipment like water bath, long laboratory thermometer, centrifuge, refrigerator, glassware, auto pipettes, stopwatch, deep freeze etc.
3. Tests such as bleeding time, Prothrombin Time, Activated Partial Thromboplastin Time (using manual or semi-automated coagulometer), inhibitor screen and mixing studies may be considered for establishing diagnostic care; at district (primary/secondary) level.
4. At tertiary care level; setting up a laboratory to cater diagnostic services at larger scale may require equipments like semi-automated coagulometer, automated coagulometer to do the tests such as factor assay, Bethesda studies in addition to the screening tests that are routinely done at primary/secondary level.
5. Reagents like PT reagent, factor deficient plasma or commercially available APTT reagents, ristocetin, platelet concentrate, Control pooled plasma/ Standard Normal plasma may be required to run the tests.
6. Capacity building, man power, and adequate training to conduct these tests are also essential in starting laboratory services.

7. Most important would be the quality assurance that needs to be maintained whenever lab services are started irrespective of the scale of the services.

4.2 Need for haemostasis services in a general hospital

1. Basic haemostatic services such as Prothrombin time, Activated Partial Thromboplastin Time, Bleeding Time and Complete Blood Count would not only help diagnose haemophilia patients but also help evaluate and assess a patient with Dengue fever, Disseminated Intravascular Coagulation, Post-Partum haemorrhage or even help in a routine pre-operative evaluation of any elective or emergency surgery.
2. Since additional tests such as mixing studies, correction studies, factor assay, inhibitor screen, may not require additional cost on investment related to infrastructure but will require only additional reagents; tests to diagnose fibrinogen deficiency, D-dimer assay, Bethesda assay, Lupus anticoagulant, may be established at secondary or tertiary care level.
3. All these services and tests would be useful in evaluating patients with sepsis, intracerebral bleeds, cirrhosis, collagen vascular disease, DIC, menorrhagia, platelet dysfunction, vWD, monitoring of patients on massive blood transfusion and monitoring of patients on oral anticoagulants.
4. Thus establishing these services in general hospital would serve evaluating relevant patients attending any of the departments like Internal Medicine, Paediatrics, General Surgery, Gynaecology, Orthopaedics, Neurology, Radiology, Gastroenterology and Cardiology.
5. Bleeding during peripartal period is the most common cause for maternal mortality in India. Hence establishing haemostasis services would be critical as this would play a significant role in early diagnosis and treatment of bleeding during pregnancy and hence prevent maternal deaths in India.

4.3 Evaluating the impact of haemophilia care – What outcomes should we measure?

1. Several outcome assessment tools exist to assess various parameters like severity of structural damage to the joint, degree of functional ability to perform various activities, loss of participation in school or work, and also the quality of life.
2. The commonly used clinical outcome measurements such as bleeding frequency, WFH/Gilbert clinical score evaluates the severity of structural damage associated with the joint. Recently, standardised and sensitive tools such as HJHS scores have been developed to assess the severity of damage to the joints.
3. Similarly X-rays (Pettersson radiological score) have been used as a conventional tool to assess the severity of structural damage associated with the joint. Recently validated and sensitive tools such as MRI-IPSG score, USG score have been developed and these can be used to detect early changes and can also be used in children.
4. While it is important to assess the severity of structural damage to the joints, it is also equally important to assess the functional ability to perform various activities for example the patient's ability to run, walk, and do his activities of daily living.
5. Haemophilia Activities List (HAL) is a subjective score that has been validated in the western population whereas FISH is an objective score that has been validated in Indian population that assesses the degree of functional ability to perform various activities.
6. Quality of Life is the ability of the patient to adjust to his disease related problems which can be measured by tools such as SF-36 and EQ-5, or by certain disease specific tools such as Haemo-QoL, CHO-KLAT etc.

7. Hence it is critical to be aware and use the appropriate tools to measure the outcomes and thus demonstrate the impact of haemophilia care to all relevant stakeholders.

4.4 Genetic diagnosis & prevention of haemophilia

1. Under ICMR Translational Research Program, the National Institute of Immuno-Haematology has been offering genetic diagnostic services to female carriers through health camps conducted by various haemophilia chapters.
2. It is important to recognise the existing gap in genetic diagnosis in that there are only 5 centres catering genetic diagnosis for 16000 haemophilia patients who are registered all over India.
3. Hence more number of centres are required that can offer genetic diagnostic services not only for the registered haemophilia patients but also the larger haemophilia population that is yet to be diagnosed.
4. In order to accomplish this task; awareness needs to be created among all relevant stakeholders including policy makers and health care administrators at State Government level.
5. In addition, adequate investment in terms of manpower, infrastructure, training and establishing cost-effective techniques would be required to provide such genetic diagnostic services.

Conclusion

Considering resource allocation amidst competing demands as the major challenge towards haemophilia care; several State Governments have overcome this challenge by adopting different models of funding. NHCM offered a unique platform to share the best practices that may be successfully replicated in other states. Major recommendations from NHCM -2017 included the following

1. Need for setting up adequate diagnostic facilities with quality assurance in each state
2. Establish / designate HTCs at different levels within the State health care system
3. Train personnel for these HTCs in the core elements of comprehensive care
4. Need to shift from providing on-demand treatment to prophylaxis and extending patient benefits.
5. Develop a system for effective tender, procurement, distribution & utilization of CFC
6. Develop a haemophilia registry as per standardized templates (possibly WFH) within the State Government system
7. Need for all stakeholders to work together – Health Ministry, HTCs, and Patient Organizations & Industry.