




**ORIGINAL ARTICLE**

# A survey of characteristics and current educational needs of hemophilia treatment centers within Asia Pacific

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**Abstract**

**Background:** Poor disease understanding and gaps in expertise regarding hemophilia care have been identified at all levels in Asia Pacific. Continued education for involved healthcare professionals (HCPs) is crucial for improved delivery.

**Objectives:** To identify training and educational needs of hemophilia HCPs in Asia Pacific.

**Methods:** Clinicians working at hemophilia treatment centers (HTCs), identified from the World Federation of Hemophilia Directory, were contacted by the Asia Pacific Hemophilia Working Group (APHWG). An electronic survey was sent to 161 centers from 15 countries for which HTC identification was complete to assess HTC characteristics, educational status, and needs. Responses were stratified by national economic capacity.

**Results:** From March 23 to June 6, 2016, clinicians from 58 HTCs completed the survey. Most reported availability of specialists to serve core patient requirements, although availability of trained nurses and geneticists was low in lower-middle income countries (LMICs). Although 98.3% of HTCs had laboratory facilities, 8.8% do not participate in any quality assessment schemes. The most common limitations of current initiatives were infrequency and lack of local language content. Education is currently mostly received via internet, particularly among LMICs and upper-middle income countries (UMICs), though there is strong preference for meetings. Main barriers to receiving education were funding and time constraints. Unique priority topics were musculoskeletal management, quality of life and management by non-hematologists (high-income countries), inhibitor management and research (UMICs), and outcomes assessment (LMICs).

**Conclusion:** In Asia Pacific, training programs should be tailored according to unique needs of differing economic capacities and resource settings.

**KEYWORDS**

Asia, educational needs assessment, hematology, hemophilia, surveys and questionnaires

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## Essentials

- Education is key to optimal hemophilia care in economically and culturally diverse Asia Pacific.
- Asia Pacific Hemophilia Working Group surveyed educational needs of hemophilia treatment centers.
- Training programs need to be suitably aligned to differences and unique needs of countries.
- Our survey provides a basis for planning and monitoring effectiveness of training programs.

## 1 | INTRODUCTION

Hemophilia is a rare X-linked congenital bleeding disorder characterized by a deficiency in coagulation factors, most commonly factors VIII (hemophilia A) and IX (hemophilia B).<sup>1</sup> The most recent World Federation of Hemophilia (WFH) Annual Global Survey identified 184 723 people living with hemophilia (PWH) in 2016, approximately 30% of whom reside in Asia Pacific.<sup>2</sup> Despite the high disease burden in the region, the consumption of factor concentrates per capita remains lower in Asia Pacific than most other parts of the world, with the average consumption of factor VIII being well below 1 IU per capita—the WFH target minimum—except in some of the high-income countries, namely Australia, Japan, South Korea, and New Zealand.<sup>2</sup> Furthermore, access to coagulation assays and accredited facilities is poor in Asia Pacific, particularly in rural areas,<sup>3,4</sup> and underdiagnoses, delayed diagnoses, and misdiagnoses of hemophilia and inhibitors are not uncommon in the region.<sup>4–8</sup>

Comprehensive management of PWH extends beyond diagnosis, treatment of acute bleeds and inhibitors, and provision of prophylaxis; it is complex and requires provision of integrated care delivered by a multidisciplinary team. However, gaps in knowledge and experience in hemophilia-specific management considerations exist within this multidisciplinary team. A retrospective analysis of hemophilia registry data from a tertiary hospital in India demonstrated that one-third of all surgeries performed on PWH for musculoskeletal complications are done inadvertently without a prior diagnosis of hemophilia.<sup>9</sup> These challenges reflect a suboptimal level of awareness and education, lack of expertise, and a shortage of adequately trained hemophilia care teams at many levels.

Provision of continued education for all medical professionals involved in hemophilia care, including surgeons, nurses, physiotherapists, and healthcare workers in Accident and Emergency departments, remains the cornerstone for improving standards of care for PWH in the region, as highlighted in the Asia Pacific Principles of Haemophilia Care.<sup>10</sup> In efforts to establish a global core curriculum in thrombosis and hemostasis, the International Society on Thrombosis and Haemostasis (ISTH) conducted a survey to determine competencies required for medical doctors to practice as independent clinical specialists, with a section on hemophilia; however, representation from Asia was small (9%).<sup>11</sup> Similarly, educational needs of hemophilia nurses have also been assessed in Europe and USA.<sup>12–14</sup> While efforts have been made to characterize clinical and laboratory services provided by hemophilia treatment centers (HTCs) in the region,<sup>15–20</sup> and to assess educational needs and impact of interventions among PWH,<sup>21–24</sup> little is known about current knowledge and

expertise levels, and the educational and training needs of HTC team members, particularly non-hematologist healthcare professionals such as nurses, geneticists, and laboratory technicians.

The Asia Pacific Hemophilia Working Group (APHWG) is a cooperative treaters' group that was set up to improve care for PWH and other hereditary bleeding disorders in the region. We conducted a survey to identify perceived training and educational needs of HTCs in Asia Pacific with a view to providing information that will be helpful for all hemophilia education stakeholders in developing targeted and tailored local and regional educational and training initiatives.

## 2 | METHODS

### 2.1 | Identification of participants

The survey targeted HTCs in Asia Pacific countries. An initial list of HTCs and contact information was generated from the WFH Passport: Global Treatment Centre Directory.<sup>25</sup> APHWG members verified and updated the initial WFH list of their respective countries. Where there was no country APHWG representative, HTCs from the initial WFH list and national hemophilia organizations were contacted via email and phone to request for assistance in verifying and identifying all other HTCs in their country. Only HTCs from countries where a complete list of all treatment centers had been obtained by March 23, 2016 were invited to participate in the survey.

### 2.2 | Survey development and administration

The survey was constructed and administered electronically using SurveyGizmo (Boulder, CO, USA). The 20-question survey was built to assess availability of laboratory and clinical facilities, current training and educational status, and further needs, considering all HTC team members (Supplementary Material).

The survey was designed and reported in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guideline.<sup>26</sup> Apart from contact details and HTC demographics and characterization, all questions were closed-ended. For all questions, answer options were randomized to prevent bias. Where appropriate, items provided a non-response ("not applicable" or "none of the above") and/or "others" option. The questionnaire was distributed over three pages. Prior to submitting their responses, respondents could review and change their answers through a review step which displays a summary of all input.

The survey was pilot tested by nine APHWG members and further revisions were made as a result of that work prior to opening

the survey to all invited participants. An introductory email was sent to identified contact persons of all participating HTC to notify them of the upcoming survey. We sought to describe status and needs of centers rather than individual practitioners so invitations were distributed to one contact person per HTC to ensure there was a single response per center. We anticipated that survey respondents would be primary decision-makers in their HTCs, as listed in the WFH list, or someone they designated to be appropriate to complete the survey.

A personalized link to the survey was sent to all identified HTC contact persons on March 23, 2016. Reminder emails were sent on a weekly basis to respondents who had not completed the survey. The survey was programmed so that each responder was only able to complete the questionnaire once. The survey was completed between March 23 and June 6, 2016.

### 2.3 | Analysis of responses

All surveys were completed online. Only completed surveys were included in the analysis. The final dataset was downloaded from the SurveyGizmo central online database into a Microsoft Excel spreadsheet. Data were stratified by gross national income (GNI) per capita, which is the World Bank's main criterion for classifying economies, according to four country groupings for the 2018 fiscal year: low income countries (GNI per capita  $\leq$ USD1005), lower-middle income countries (LMICs; GNI per capita USD1006–3955), upper-middle income countries (UMICs; GNI per capita USD3956–12,235) and high income countries (GNI per capita  $\geq$ USD12,236).<sup>27</sup> Descriptive analysis of responses was done through the SurveyGizmo internal data analysis program except where calculations of mean were required, which were performed on the downloaded Microsoft Excel spreadsheet.

## 3 | RESULTS

### 3.1 | Demographics and characterization of HTC facilities and services

As of March 23, 2016, identification of HTCs was completed for 15 out of the 23 target Asia Pacific countries. Of the 162 HTCs identified, 161 were invited to participate in the survey; contact information was unavailable for one center in Taiwan. As of June 6, 2016, 58 HTCs successfully completed the survey (36.0% response rate), the majority of which were public or government institutions.

HTCs that completed the survey were from countries representing three of the four levels of national economy stratified by GNI per capita: 43.1% (25/58) from LMICs, 25.9% (15/58) from one UMIC, and 31.0% (18/58) from high-income economies. HTCs from Nepal, the only low-income country in Asia Pacific, did not complete the survey (Table 1).

Among the 58 HTCs that completed the survey, all reported having a physician or a pediatrician trained in managing hemophilia. Most HTCs also reported having access to either a general or orthopedic surgeon who can perform surgeries in PWH,

a physiotherapist, occupational therapist, or rehabilitation specialist, and a dentist. Nurses trained in bleeding disorders were available at almost all HTCs in UMICs (93.3%) and high-income countries (88.9%), but in only half of all HTCs in LMICs (56.0%). While two-thirds of surveyed HTCs in UMICs had access to a geneticist, availability was lower in HTCs in LMICs (24.0%) than in high-income countries (44.4%).

All except one LMIC HTC reported being able to provide episodic or on-demand treatment of acute bleeds. Prophylaxis, either intermittent or continuous, was available in all HTCs in high income countries, 93.3% (14/15) of HTCs in UMICs, and 76.0% (19/25) of HTCs in LMICs. Immune tolerance induction (ITI) therapy for inhibitor management was available in 83.3% (15/18) of HTCs in high income countries, 53.3% (8/15) in UMICs and in only two centers in LMICs. Among upper-middle and high-income countries, all HTCs provided home treatment services except one center in a high-income country and two in UMICs. In contrast, access to home treatment was scarce in LMICs and was available in only five HTCs.

Plasma-derived or recombinant clotting factor concentrates were available in all surveyed HTCs, with the exception of two centers in LMICs. Recombinant clotting factor concentrates and bypassing agents were available in all UMIC HTCs except one, while 66.7% of those in high income countries and only half of all centers in LMICs had access to recombinant products. Almost half (48.0%, 12/25) of all HTCs in LMICs reported not having access to bypassing agents for management of inhibitors.

All HTCs who completed the survey reported having access to laboratory facilities, except one center in a LMIC (Table 1). Screening tests and clotting factor assays for hemophilia diagnosis were available in most HTCs. However, inhibitor testing, either by Bethesda assay or enzyme-linked immunosorbent assay, was reported to be available in only 72.4% (42/58) of all centers that completed this survey, mainly in UMICs and high-income countries. While many laboratories performed quality assurance (QA) measures, with 71.9% (41/57) participating in external schemes, it is important to note that 8.8% of the 57 HTCs with available laboratory facilities reported not participating in any QA schemes.

### 3.2 | Status of current hemophilia education and training

The WFH guidelines were reported to be used in clinical practice by the majority of surveyed HTCs (87.9%, 51/58), most of which also refer to local national guidelines in parallel (43.1%, 22/51).

Methods of accessing information and updates on provision of hemophilia care differed between the different economic capacities. HTCs in high income countries cited peer-reviewed journals (100%, 18/18) and scientific meetings (88.9%, 16/18) as main sources of information on hemophilia care. In contrast, HTCs in UMICs and LMICs rely on the internet (93.3%, [14/15], and 92.0%, [23/25], respectively) and personal communication with hemophilia experts (80.0%, [12/15], and 76.0%, [19/25], respectively) for updates on provision of hemophilia care.

**TABLE 1** Characteristics and availability of facilities of HTC's who participated in the survey, stratified by national income level (GNI per capita)

Characteristic	Lower-middle income countries (n = 25)	Upper-middle income countries (n = 15)	High income countries (n = 18)	Overall (n = 58)
Number of HTC's by country (n)	Cambodia (2) Mongolia (3) Myanmar (3) Pakistan (5) The Philippines (4) Sri Lanka (6) Vietnam (2)	China (15)	Australia (4) Hong Kong (5) Japan (2) New Zealand (2) Singapore (3) Taiwan (2)	
Setting, n (%)				
Government	17 (68.0)	14 (93.3)	16 (88.9)	47 (81.0)
Private	8 (32.0)	1 (6.7)	2 (11.1)	11 (19.0)
Availability of healthcare professionals, n (%)				
Physician or pediatrician trained in managing bleeding disorders	25 (100)	15 (100)	18 (100)	58 (100)
Nurse trained in managing bleeding disorders	14 (56.0)	14 (93.3)	16 (88.9)	44 (75.9)
General or orthopedic surgeon who can perform surgeries in patients with bleeding disorders	20 (80.0)	15 (100)	17 (94.4)	52 (89.7)
Physiotherapist, occupational therapist, or rehabilitation specialist	22 (88.0)	13 (86.7)	17 (94.4)	52 (89.7)
Dentist	20 (80.0)	13 (86.7)	15 (83.3)	48 (82.8)
Geneticist	6 (24.0)	10 (66.7)	8 (44.4)	24 (41.4)
Gynecologist/obstetrician	13 (52.0)	7 (46.7)	14 (77.8)	34 (58.6)
Infectious diseases specialist	12 (48.0)	8 (53.3)	16 (88.9)	36 (62.1)
Social worker or counsellor	13 (52.0)	7 (46.7)	16 (88.9)	36 (62.1)
Availability of laboratory tests, n (%)				
PT and APTT	24 (96.0)	15 (100.0)	18 (100.0)	57 (98.3)
Mixing studies	20 (80.0)	13 (86.7)	17 (94.4)	50 (86.2)
Factor VIII and Factor IX assays	22 (88.0)	15 (100.0)	17 (94.4)	54 (93.1)
Other clotting factor assays	11 (44.0)	11 (73.3)	15 (83.3)	37 (63.8)
Bethesda assay for inhibitor testing	12 (48.0)	12 (80.0)	17 (94.4)	41 (70.7)
ELISAs for inhibitor testing	2 (8.0)	2 (13.3)	4 (22.2)	8 (13.8)
Platelet function test	8 (32.0)	10 (66.7)	14 (77.8)	32 (55.2)
Molecular genetic testing	2 (8.0)	8 (53.3)	10 (55.6)	20 (34.5)
Laboratory facilities not available	1 (4.0)	0 (0)	0 (0)	1 (1.7)
Participation in QA schemes, n (%) <sup>a</sup>				
None	1 (4.2)	3 (20.0)	1 (5.6)	5 (8.8)
Internal QA measures	20 (83.3)	11 (73.3)	12 (66.7)	43 (75.4)

(Continues)

TABLE 1 (Continued)

Characteristic	Lower-middle income countries (n = 25)	Upper-middle income countries (n = 15)	High income countries (n = 18)	Overall (n = 58)
External QA schemes	17 (70.8)	9 (60.0)	15 (83.3)	41 (71.9)
National schemes <sup>b</sup>	11/17 (64.7)	8/9 (88.9)	10/15 (66.7)	29/41 (70.7)
Regional schemes <sup>b</sup>	1/17 (5.9)	3/9 (33.3)	1/15 (6.7)	5/41 (12.2)
International/global schemes <sup>b</sup>	7/17 (41.2)	8/9 (88.9)	12/15 (80.0)	27/41 (65.9)

APTT, activated partial thromboplastin time; ELISA, enzyme-linked immunosorbent assay; GNI, gross national income; HTC, hemophilia treatment center; PT, prothrombin time; QA, quality assurance.

<sup>a</sup>Among HTCs with available laboratory facilities.

<sup>b</sup>Calculated as a proportion of those who participate in external QA schemes. Respondents could select more than one option.

All HTCs that completed the survey, except one, reported having an attendee at one or more hemophilia training initiative (either a workshop, conference, or online course) in the past 3 years. Overall, the most commonly attended educational or training program by HTC team members in the past 3 years were activities organized by national/regional hemophilia societies (60.3%, 35/58) and WFH symposia or conferences (58.6%, 34/58). WFH-organized initiatives were the most common training opportunities for HTCs in high-income countries (100%, 18/18) and those in LMICs (64.0%, 16/25). Pharmaceutical company-sponsored courses were the most common type of educational initiative attended by HTC team members in UMICs (80.0%, 12/15).

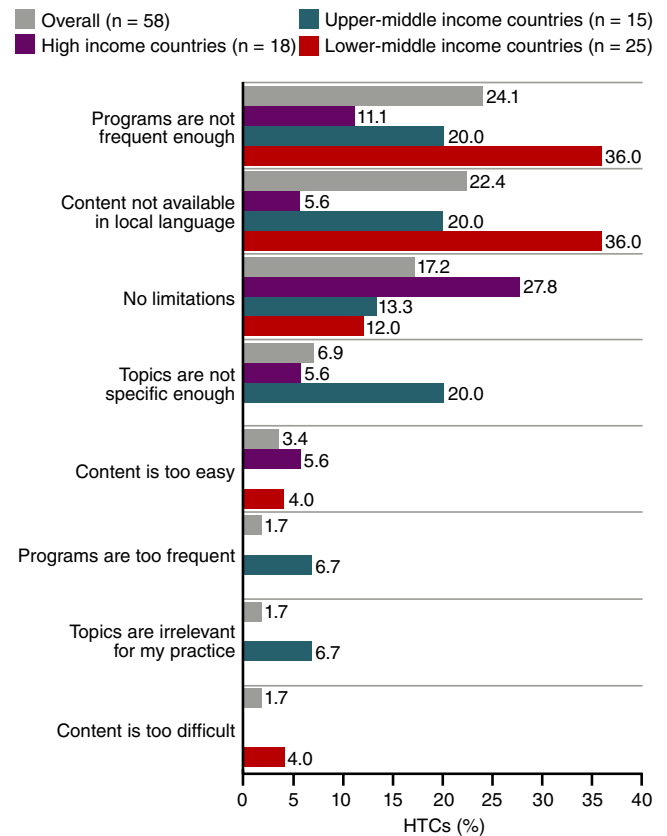
Low frequency of programs and the lack of content in local languages were the most common limitations of current educational initiatives identified by HTCs in LMICs and UMICs. One-third of all HTCs in high income countries reported no limitations with the educational programs attended by their team members (Figure 1).

### 3.3 | Hemophilia educational and training needs of HTCs in Asia Pacific

Almost all (93.1%, 54/58) respondents expressed the need for hemophilia educational and training initiatives designed specifically for HTCs in Asia Pacific.

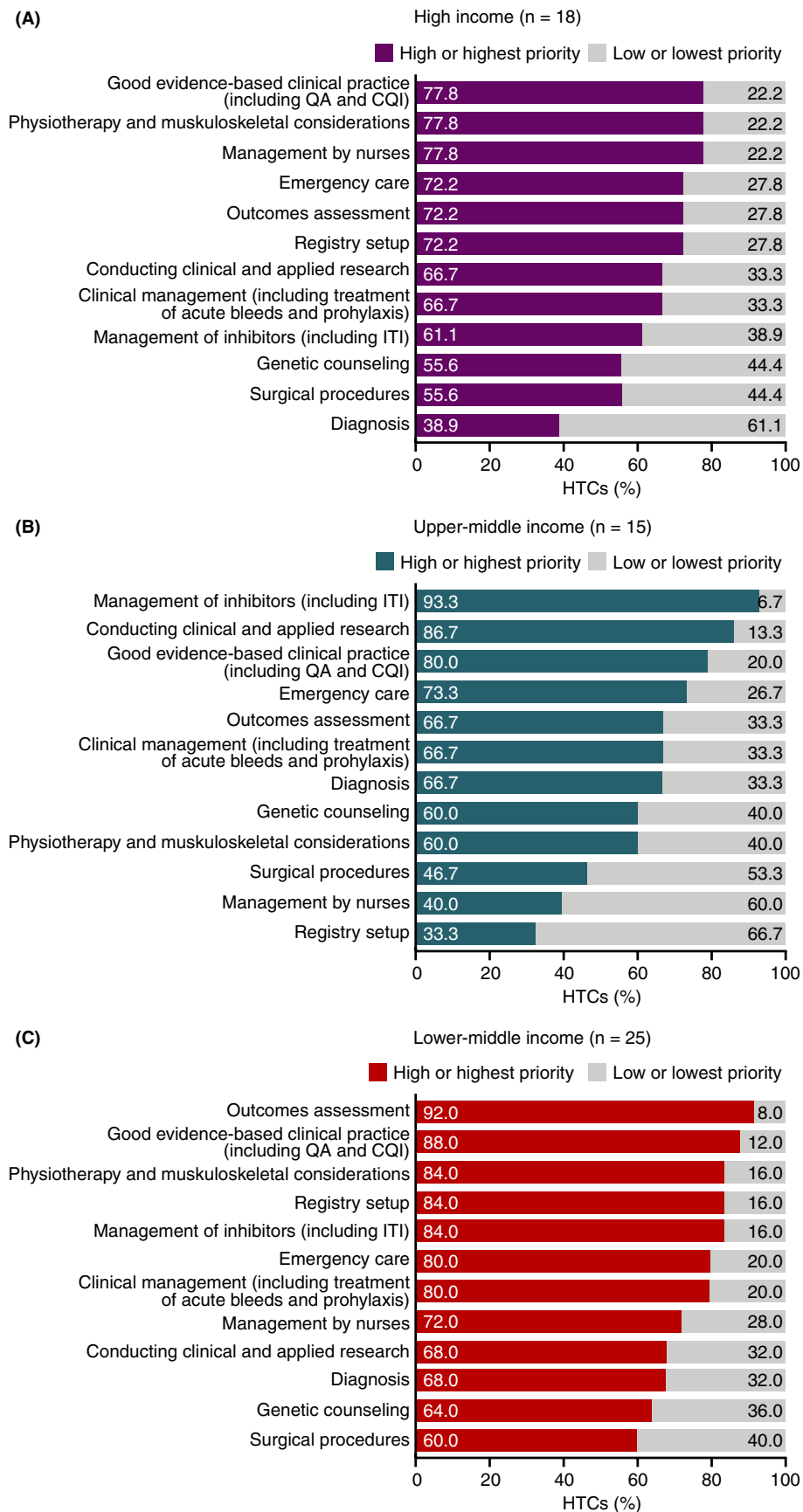
There were similarities and differences in prioritization of educational topics among the different national income levels (Figure 2). Across all income level groups, approximately 80% of surveyed HTCs cited “good evidence-based clinical practice” as a high priority topic, while “surgical procedures” was generally rated as low priority. HTCs in high income countries rated topics that are beyond foundational treatment and management as high priority, particularly those which are focused around improvement of musculoskeletal function and quality of life, and management of PWH by other hemophilia care stakeholders. “Management of inhibitors” and “conducting research” were priority topics for centers in UMICs, while “outcomes assessment” was identified as highest priority by LMIC centers.

Preferences for education and training delivery methods were similar across the income groups. The most preferred delivery methods were scientific symposia and/or conferences (rated high or

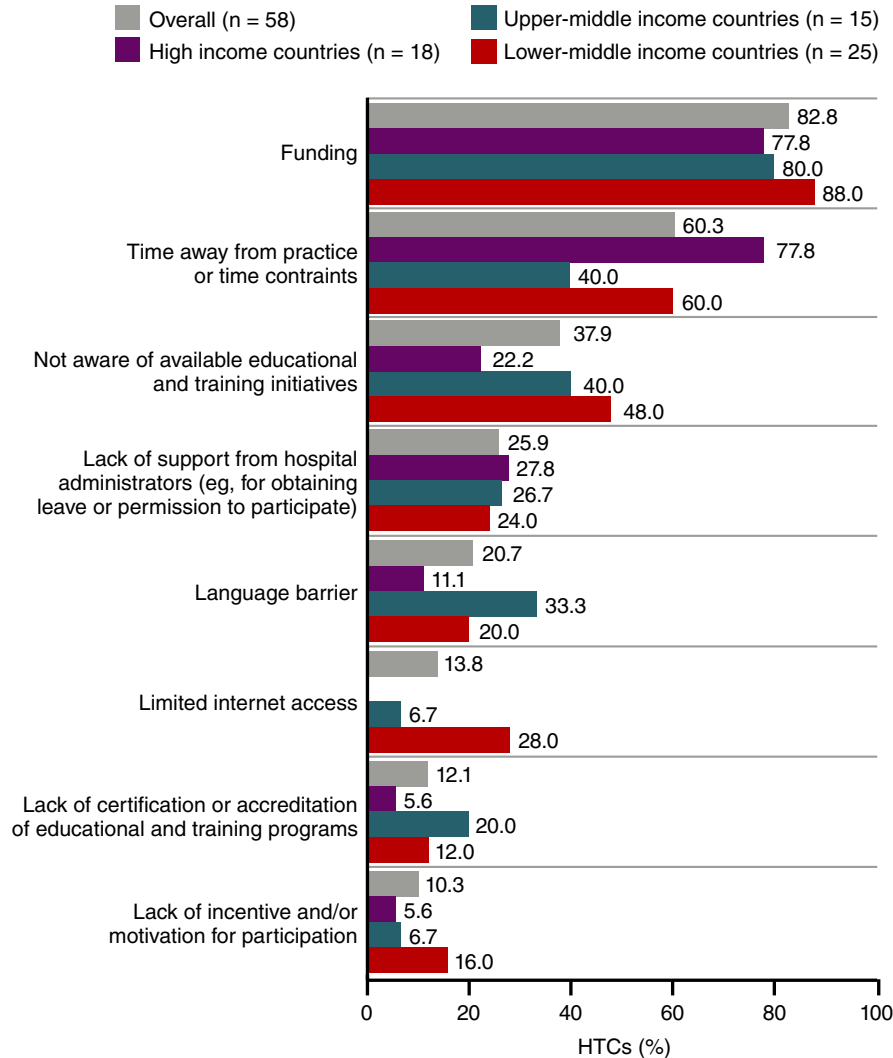


**FIGURE 1** Limitations of current hemophilia educational and training initiatives attended by HTCs, stratified by national income level (GNI per capita). GNI, gross national income; HTC, hemophilia treatment center

highest preference by 91.4%, [53/58], of respondents) and face-to-face workshops (89.7%, 52/58). Although a preference for meetings and workshops for future educational activities was reported, HTCs included in this survey do not currently rely on these as a source of information, relying instead on the internet and peer-to-peer communication for updates on hemophilia care. This may be related to a lack of funding and time constraints, which were cited as the most common barrier HTCs face in participating in educational initiatives (Figure 3). A substantial number of HTCs also cited not being aware of educational programs that are available. Although lack of content



**FIGURE 2** Prioritization of topics for development of educational programs for HTCs by country income level. CQI, continuous quality improvement; HTC, hemophilia treatment center; ITI, immune tolerance induction; QA, quality assurance



**FIGURE 3** Barriers to participation in hemophilia educational and training initiatives by country income level. HTC, hemophilia treatment center

in local language was reported as one of the main limitations of current programs (Figure 1), it was not identified as a main barrier to participation in educational activities.

## 4 | DISCUSSION

To the best of our knowledge, this is the first survey, both internationally and in Asia Pacific, to assess educational and training gaps and needs of HTCs. Representation from all levels of economic capacity in Asia Pacific, apart from low income economies, were reflected in the survey.

HTCs that completed the survey reported an average of more than 300 hemophilia patients registered at each center (data not shown), which is a 2–3-fold higher patient load per center than that of Western countries such as Canada and Belgium,<sup>28,29</sup> reflecting the high disease burden in this region as reported in the WFH Annual Global Survey.<sup>2</sup> Nevertheless, most HTC teams have specialist capacity to serve the core requirements of PWH. However, PWH in Asia Pacific, particularly those in LMICs, have poor access to recombinant factor concentrates, prophylaxis, and ITI therapy.

It is of concern that some laboratories in HTCs in the region do not participate in any (internal or external) QA schemes, even those in high income countries. Although “diagnosis” was not identified as a high priority education topic across all economic capacity groups, it should be recognized that implementation of successful QA schemes will have a positive impact on accurate laboratory results and diagnosis.<sup>16,30</sup> We reiterate the recommendations outlined in the Asia Pacific Principles of Haemophilia Care<sup>10</sup> and urge prioritization of the development and implementation of institutional or national protocols in hemostasis laboratories to achieve quality-assured testing.

While there is a preference for education delivered via scientific symposia, conferences, and face-to-face workshops across all economic capacities reflected in this survey, education on hemophilia care is currently mostly received via the internet, particularly in LMICs and UMICs, potentially due to funding barriers that exist in most countries in the region. HTCs in LMICs and UMICs reported that current training opportunities in Asia Pacific are not frequent enough and identified a lack of content in local languages in the respective countries as a key limitation of current programs, highlighting a gap in locally adapted, accessible information for HTC team members.



In terms of development and needs, “evidence-based clinical practice”, including clinical outcomes and other quality assessment, remains a key priority topic for Asia Pacific. In Asia Pacific, factor concentrate availability and consumption, and consequently prophylaxis, remain suboptimal in most countries. As such, it is increasingly being recognized that real-world treatment strategies in clinics should be aimed at improving musculoskeletal outcomes to maintain and restore physical function so that PWH are able to live normal lives, rather than focusing solely on achieving set goals for factor concentrate usage, which are dependent on treatment costs and healthcare policies—factors that are largely beyond the control of individual treatment centers. Indeed, “management of musculoskeletal disease” was identified by HTC in high income countries and LMICs as a priority topic for educational development.

We also observed unique educational development needs based on national economic capacities and resources. Inhibitors management was identified as a priority educational need in UMICs where almost all HTCs reported having access to bypassing agents, but not by those in high income countries or LMICs where bypassing agents are not yet available in many HTCs. Education around registry setup will become increasingly important in LMICs with increased recognition of the value of capturing accurate and comprehensive information beyond factor consumption in improving the quality of care delivered to hemophilia patients, particularly in large populations. This information is still lacking and/or largely disorganized in many countries in Asia Pacific.<sup>31</sup> In high-income countries, it is recognized that hemophilia care will be delivered increasingly by other non-physician members of the care team,<sup>32</sup> including nurses; thus educational focus for HTCs in these countries should consider programs for nurses and allied healthcare professionals.

In the near future, it will be crucial to implement practice benchmarking and standardization of HTCs so that educational programs can be continually shaped accordingly to ensure consistency of services for PWH across Asia Pacific. In Europe, adherence to the 10 principles of hemophilia care and service provision level of HTCs have been audited by the European Haemophilia Therapy Standardisation Board (EHTSB) and patient organizations.<sup>15,33,34</sup> Challenges to implementing a region-wide benchmarking audit were apparent and these include country-specific differences in organization of care and access to key services,<sup>15,33</sup> which may also be expected in Asia Pacific. Clinical and laboratory care do not coexist in many HTCs in developing countries and the substantial lack of expertise in these areas means that most centers would not meet standardization criteria for high income or developed nations. In response, a stratification model for developing countries has been proposed and implemented in India.<sup>20</sup> Validation of this model in other developing countries will be a key step in hemophilia care in Asia Pacific as it has potential to serve as a benchmark for many HTCs with similar resource levels in the region.

Our study is subject to limitations and biases inherent to surveys. Despite efforts to reach potential respondents in all 23 target Asia Pacific countries, we obtained complete lists of all treatment

centers in only 15 countries. Self-selection bias was a possibility as completion of the survey was voluntary. There is also potential non-response bias<sup>35</sup> as all centers that responded had a trained physician in charge while we do not have details of the health skills composition and leadership of those centers that did not respond. Hence, it is possible that our results may be more applicable centers led by a trained physician. It is very important to continue to identify and train physicians and other healthcare workers who are appointed to care for persons with bleeding disorders. Although there is no agreed-upon standard for acceptable survey response rates, there is consensus that at least half of the sample should have completed the survey.<sup>36</sup> While we achieved a lower overall response rate of 36%, this is comparable with other similar studies among physician specialists.<sup>37</sup> We acknowledge that response bias cannot be ruled out as a source of concern. We grouped and analyzed responses based on national economic capacity, which potentially introduced heterogeneity between HTCs across individual countries within each group. Of the three UMICs in Asia Pacific, identification of HTCs was complete only for China and as such the UMIC category was represented solely by China. Finally, closed-ended questions do not offer an opportunity to respond in ways other than the provided options. Nevertheless, these limitations are inherent in any questionnaire-based surveys and this was an initiative which was imperative to evaluate existing gaps to find suitable solutions.

It is apparent that while there are some similarities, educational and training needs of individual HTCs vary depending on economic capacities and available resources in their respective settings. In Asia Pacific, it may be useful to build training programs that are tailored to address unique challenges and needs of the different economic capacities and resource settings. It is hoped that findings from this survey can serve as an initial guide for providers of hemophilia education at institutional, national, and regional levels to inform and shape the development of training initiatives. Indeed, findings from our survey have been used to guide attendee identification and content development of an APHWG Comprehensive Care workshop held on January 2018 in Bangkok, Thailand. The program was designed to focus on topics identified as high priority for middle income countries and was rated as greatly relevant to clinical practice by workshop participants. The introductory session in which they each presented an overview of their hemophilia care program structure and challenges led to their early engagement to share strategies for improvements.

We encourage further research in this area to supplement and update this information as progress in the field continues in this region. Despite disparities in economic capacities and resources within Asia Pacific, areas for additional research should include development of standardized tools to measure the impact of hemophilia education programs on the quality of care provided by HTCs in the region.

We believe that this survey represents an important first step to ensure consistency and continuity of high-quality care for all PWH in the region. We echo the call to action of the Asia Pacific Principles of Haemophilia Care by reiterating the importance of and urgency for



tailored programs dedicated to increasing awareness of hemophilia among all healthcare workers and planners, and for locally relevant research to develop evidence-based management for patients in the region.

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## AUTHOR CONTRIBUTIONS

All authors were involved with the study design, data analysis, data interpretation, and writing of the manuscript, and provided final approval of the version to be published.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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