Patients with von Willebrand disease (VWD) – the most common inherited bleeding disorder – initially present to a range of community-based healthcare practitioners, including primary care, emergency medicine, obstetrics/gynaecology and otolaryngology physicians. However, many patients experience considerable delay in obtaining a diagnosis and appropriate care [1–3]. Specialist haematology consultation is important in the management of patients with VWD, but is not usual practice. In November 2014, a summit of VWD stakeholders organized by the National Hemophilia Foundation (NHF) highlighted inadequate awareness of VWD among healthcare providers and patients, and a need for tailored, collaborative education to improve bleeding symptom recognition, diagnosis/classification, and referral and treatment [4]. The NHF’s Medical and Scientific Advisory Council (MASAC) made a series of recommendations in response, including that education of both healthcare providers and patients should be increased at national and local levels [5].

In early 2016, Shire invited a group of VWD experts from across the United States to form a working group to propose and develop a unified and collaborative approach to VWD education, titled ‘von Willebrand disease Outreach into Integrated Care Education’ (VOICE). The group noted the various educational initiatives that have already been developed in response to the NHF summit and MASAC recommendations. These include additional NHF-developed sessions on VWD at NHF meetings, NHF-supported workshops for delivery at haemophilia treatment centres (HTCs) and patient organizations; the ‘Better Care Education’ (VOICE). The group noted the various educational initiatives that have already been developed in response to the NHF summit and MASAC recommendations. These include additional NHF-developed sessions on VWD at NHF meetings, NHF-supported workshops for delivery at haemophilia treatment centres (HTCs) and patient organizations; the ‘Better

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You Know’ campaign, dedicated to raising awareness of bleeding disorders among people with bleeding symptoms [6]; and the ‘VWD Welcome Kit’ for patients/caregivers. Other initiatives aimed at improved awareness and patient support include the ‘Let’s Talk Period’ website from Queen’s University and Kingston General Hospital in Ontario, Canada [7], and the Hemophilia Federation of America (HFA) Blood Sisterhood mobile app [8]. Alongside these, the Foundation for Women & Girls with Blood Disorders (FWGBD) has pioneered a provider network of specialist clinics with multidisciplinary expertise (paediatric and/or adult haematologist, obstetrician/gynaecologist and often an adolescent medicine physician) to improve diagnosis and appropriate treatment for women and girls with bleeding/blood disorders [9,10]. The FWGBD has also created a Web platform for providers in HTCs to facilitate collaboration, education and resource sharing.

While acknowledging the contribution of these excellent individual initiatives, the VOICE group believes that additional action is needed to address comprehensively the educational needs of the full range of patients with VWD and of the healthcare providers involved in their recognition, referral and treatment, to ensure optimal and integrated care for all patients. We propose a unified, nationwide, US education programme, implemented at the local level by HTCs in collaboration with local bleeding disorder associations, and set within a nationally agreed framework of learning objectives. HTCs already function as centres for education and play an important role in providing integrated care for patients with VWD, either directly within the centre or in consultation with community healthcare providers. Between 2012 and 2016, over 15 000 patients with VWD of all types received care across the network of 136 HTCs located across the United States and its territories [11]. As such, we believe that HTC-affiliated healthcare professionals are uniquely placed to drive the implementation of this programme. We envisage that the programme will be delivered using a shared repository of educational materials, tailored to specific healthcare provider and non-medical audiences, and endorsed by the relevant professional and patient societies. The repository would be housed by an independent group and updated regularly.

The proposed process for programme development is outlined in Fig. 1. Initially, the VOICE group will assess the range of existing educational materials and programmes in VWD in the United States, to identify the broad educational gaps. We will then consult with national professional and patient societies and with the wider bleeding disorders community to affirm the appropriate target audiences for education, define their unmet educational needs and the optimal approach for peer-to-peer education and finalize the nationwide framework of learning objectives; metrics to evaluate the effectiveness of the education will also

Fig. 1. Proposed process for von Willebrand disease Outreach into Integrated Care Education initiative.
Diagnosis

Disease awareness and burden

1. VWD affects both sexes equally, but presents differently
   - Females’ symptoms may be more apparent
   - Specialty-specific recognition of symptoms
2. VWD subtype affects presentation and informs management
   - Type 1 is most common; other subtypes may need different treatment
   - Patients with low VWF may have fewer bleeding symptoms, but
     may need treatment during invasive procedures/childbirth
3. VWD has a considerable impact on patients’ health and quality of life
   - Anaemia, fatigue, missed school (particularly girls)
   - Long-term impact on joint health and pain
4. Access to genetic testing is variable, and it may not provide definitive diagnosis
5. Negative test results may belie a bleeding disorder requiring treatment

Diagnosis

1. Diagnosis should be made in consultation with an HTC and based
   on patient/family history of bleeding, bleeding assessment tools and
   laboratory tests
2. Diagnostic tests should be repeated regularly
3. Laboratory diagnostic tests are complex
   - Many tests are available
   - Test results change over time (up-to-date results are important)
   - There is variability of test results across laboratories (a centralized laboratory is preferred)
   - Multiple tests may be needed
   - Negative test results may belie a bleeding disorder requiring treatment
4. Access to genetic testing is variable, and it may not provide definitive diagnosis

Integrated care

1. Patients should be managed in consultation with an HTC featuring:
   - Comanagement (not one-way referral)
   - Integrated care (the site of care is dependent on gender and symptom severity)
   - A follow-up in the HTC clinic every 1–2 years
   - Obstetric/gynaecologic care for adolescent and adult females
   - Genetic counselling for patients with VWD

Learning objectives to be finalized and adapted for specific audiences in consultation with medical societies, patient organizations and the bleeding disorders community.

HTC, haemophilia treatment centre; VWD, von Willebrand disease; VWF, von Willebrand factor.

be developed. The repository of educational materials, tailored to the individual audiences, will then be compiled in collaboration with the specialty associations. Finally, we envisage delivery of the education programme at local level by specialist haematologists in collaboration with local chapters of patient organizations such as the NHF and the HFA.

We anticipate that the programme will encompass three key areas of education – disease awareness and burden, diagnosis and integrated care – which reflect the main barriers to optimal patient care. Draft learning objectives in each area, for medical providers and patients/caregivers, are provided in Table 1; these will be ratified through consultation as described earlier, and tailored for specific audiences. In relation to disease awareness, healthcare providers must understand the burden of VWD among their patient base and the ways in which VWD can manifest. Currently, many patients with VWD are serially misrecognized prior to diagnosis (Sidonio et al., manuscript submitted). The process of VWD diagnosis is complex, involving careful assessment of bleeding history and a battery of complicated laboratory tests; testing should therefore be performed and interpreted at HTCs or centres recognized for coagulation testing excellence. Finally, an educational programme must highlight the importance of truly integrated care between an HTC and the broader provider community to achieve a level of care for VWD similar to that provided for patients with haemophilia. Care integration is increasingly acknowledged as a key component of value-based healthcare, and integrated disease management supported by evidence-based guidelines is now the optimal model of haemophilia care. The benefit of an integrated approach for patients with VWD has recently been demonstrated; we believe that this integrated care model, which emphasizes comanagement rather than one-off referral, will support community providers in delivering high-quality and cost-effective care that is tailored to the individual patient with VWD and the severity of their disease.

Audiences for education should encompass the range of healthcare practitioners involved in the recognition, referral, diagnosis and treatment of VWD and may include community haematologists/haematology oncologists; dentists; otolaryngology physicians; emergency room physicians; intensive care unit physicians; nurse practitioners and physician assistants; obstetrics and gynaecology physicians; pathologists, blood bank directors and laboratory technicians; primary care providers (internists, family physicians, paediatricians); and school nurses. Nonmedical audiences include patients, caregivers and associated organizations who need more comprehensive education to better understand symptoms, diagnosis and treatment and who may themselves become committed educators of healthcare professionals within the community.

The VOICE group intends for this letter to serve as the starting point for a collaborative process to develop a unified education programme for healthcare providers and patients/caregivers with VWD, with the aim of improving the recognition and diagnosis of VWD, and facilitating collaboration with specialist treatment centres. We call upon members of the bleeding disorders community to work with us to shape the programme and to develop the educational resource in collaboration with the relevant professional and patient societies, and ultimately to take responsibility for VWD education of patients and healthcare providers in their local areas.

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Evaluation of a new commercial von Willebrand factor multimer assay

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von Willebrand disease (VWD) is reportedly the most common inherited bleeding disorder, affecting up to 1% of the general population [1]. It can also arise as an acquired syndrome (AVWS), which may comprise up to 25% of cases identified as ‘VWD’. These disorders develop due to defects and/or deficiency of the plasma protein von Willebrand factor

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