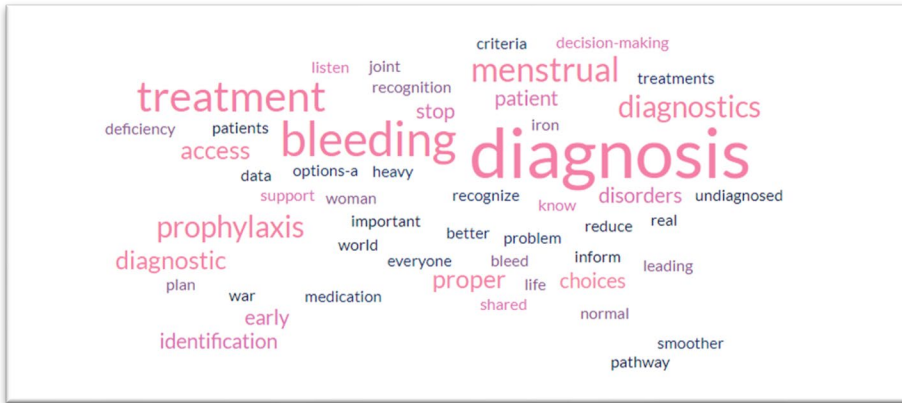


**OPTIMIZING THE PATIENT JOURNEY IN VON WILLEBRAND DISEASE:
EXPERIENCES AND LEARNINGS AS THE NAVIGATOR
Audience survey responses***

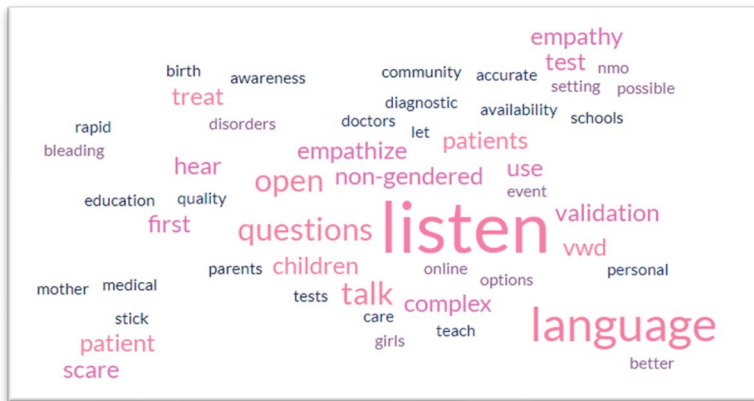
*The following responses are the raw data collected via audience participation, only corrected for spelling and duplicates removed. CSL Behring formulated the questions but have not contributed to or influenced the responses. These are intended to stimulate further discussion and do not represent formal recommendations or guide for clinical practice. 57 participants contributed to these results.

What in your opinion is the main topic to address in optimizing the patient journey for people with von Willebrand disease?



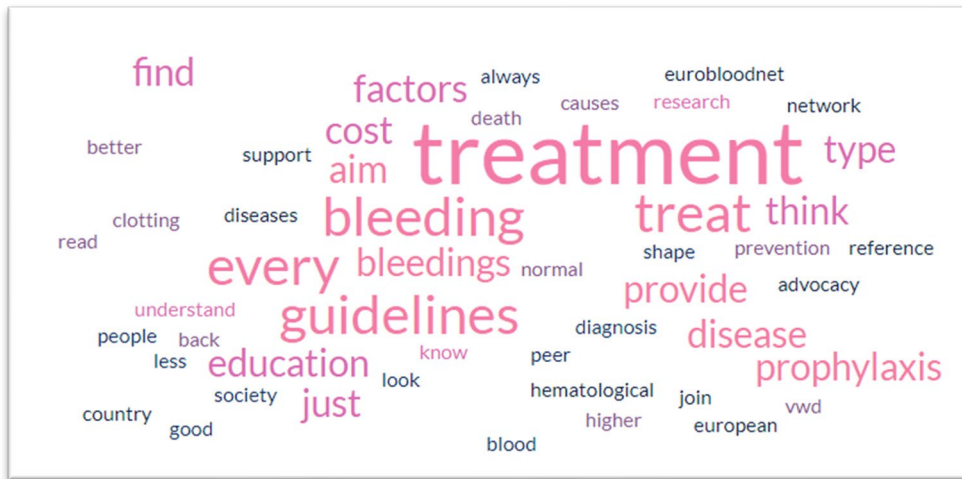
What in your opinion is the main topic to address in optimizing the patient journey for people with von Willebrand disease?
Diagnosis
Heavy menstrual bleeding/menstrual bleeding
Access to treatment
Prophylaxis
Treatment choices
Women can have bleeding disorders
Proper treatment leading to a normal life
Support and shared decision-making
Listen
Don't know
Early diagnosis
Iron deficiency
Recognition of joint bleed
Better treatments
Recognize that there is a problem/ proper diagnosis
Treatment options-a smoother pathway
Important in my real world
Stop the war
Data to inform treatment options
Identification
Harmonisation for equity
Properly treating patient symptoms

How can the way trainees and physicians use language during clinical or outpatient care affect patients?



How can the way trainees and physicians use language during clinical or outpatient care affect patients?
Listen/ Listen and hear them/ Listen first!!/Listen and treat
Empathy/empathize
Open questions/ Open language
Test / Test children of VWD mother at birth
Validation/ Validation of opinions or not
Setting up an online event for girls with bleeding disorders in my NMO
Talk about all possible options to have a better care for our patients
Treat and let the patient have quality
Teach personal doctors about VWD
Availability of accurate rapid diagnostic tests
Do not stick to the medical community for awareness
Education at schools, children and parents
Explain and understand the patients point in life
Look non-verbal signals
Talk down
Show empathy, listen and use non-gendered language
Ask and listen and don't put your own idea first
Do not dismiss, but listen and hear
Giving time to talk freely
Overwhelm
By using language that describes women's health as complex - we reinforce the belief that women are complex and difficult
In every way: scare, validate, makes you question, be offensive
Asking negative questions, such as "but you don't have heavy menstrual bleeding" can affect the responses
Clear
Influence perception
Could scare the patient
Use non-gendered language
Positive language

What can be done to optimize the treatment of persons with von Willebrand disease?



What can be done to optimize the treatment of persons with von Willebrand Disease?
Individualize treatment approach
Research and education to understand the disease better/ read guidelines
Treatment guidelines for every country
Stratification of bleeding risk/Treat bleedings and provide prophylaxis if bleedings come back
Prioritize care over cost of treatment
Aim higher- aim for normal clotting - not just prevention of bleeding that causes death
Education for all/ peer support and advocacy
Join European Reference Network for hematological diseases: EuroBloodNet
Lower prices for factors
Treatment for all!

