

## Iceberg 1

### EVENTS

Uncover why women with bleeding disorders are diagnosed later than men

### PATTERNS & TRENDS

Women do not recognize their symptoms as a problem  
Doctors are not paying enough attention to womens' issues  
Communication from health care professionals (HCPs) that haemophilia concerns only men, not women

### STRUCTURES

Repeated communication from the HCPs  
Position of NMO between male and female patients  
Lack of data -> Lack of knowledge -> HCPs; NMO; General public  
Stigmatisation and taboo (Bruises and heavy menstrual bleeding)  
Women do not speak up about their bleeding issues  
Get the message from HCP that everything is normal (or it I sin your head)

### VALUES & BELIEFS

We trust doctors that they know  
Heavy bleeding is normal (family experience)  
Priority is nit me but my family  
If I speak up I will be of less value

## Iceberg 2

### EVENTS

Uncover why women with bleeding disorders are diagnosed later than men

### PATTERNS & TRENDS

Doctors do not recognise women  
Lack of knowledge of female body  
Always men focused  
Gender problem  
Women neglect themselves  
Women are not included in clinical research in general  
Patriarchy  
Menstrual bleed is not considered a bleed

### STRUCTURES

Women prioritization  
Academic – male oriented and centered  
Women's behavior  
Late doctor's appointment because symptoms show late  
– seriously only as teenager  
Haematologists do not get training in gynecological issues related to bleeding disorders  
Patriarchy  
No cross-over between haematology/gynecology & multi-disciplinary team; lack of knowledge on both sides.  
It is normal not to complain about bleed, period, pain  
GP – do not take serious and do not send to specialist

### VALUES & BELIEFS

Neglect  
What is a bleed/ clinical bleed/ what is normal  
Taboo  
Religion  
Pure & purity  
Psychology  
History of losing blood is bad

### Iceberg 3

#### **EVENTS**

Uncover why women with bleeding disorders are diagnosed later than men

#### **PATTERNS & TRENDS**

Speaking about heavy periods is still taboo (periods are considered normal and not a sign of a bleeding disorder)  
Perception around men having a bleeding disorder and women being carriers are reinforced to HCPs through training

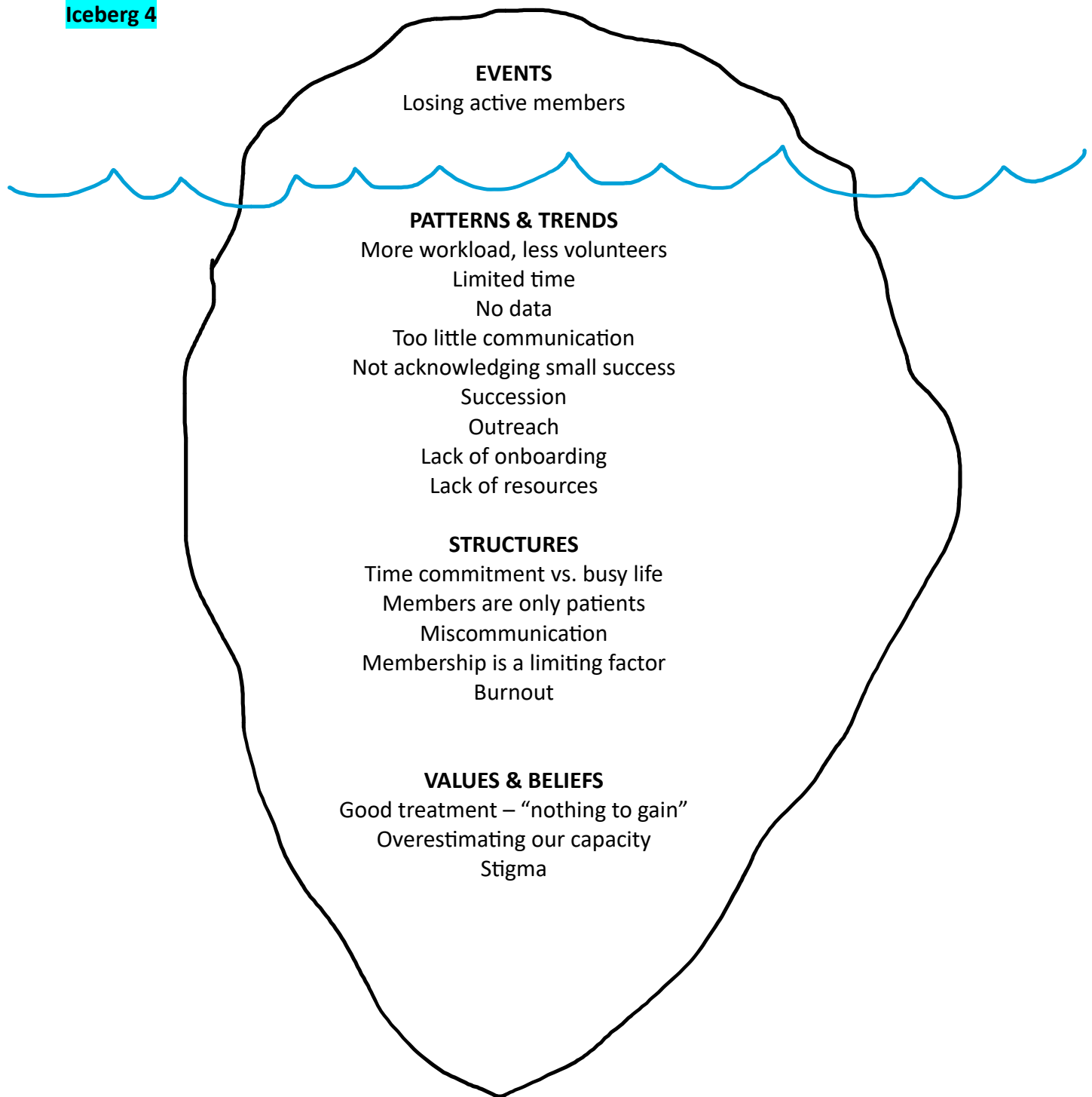
#### **STRUCTURES**

Family history (grandma bled longer during the period, so that is "normal" in the family)  
No blood test carried out, or misdiagnosis by the doctor  
Not understanding the problems by the doctor  
General information to all people about what is "normal" bleeding (loss of blood, length of the period) + what to do when abnormal  
Haematologists and training specialists like gynaecologists, psychologists  
Cultural differences; different contexts within community

#### **VALUES & BELIEFS**

The idea that being a carrier does not impact your life  
Education: school; teachers; general public; doctors; media/ social media; awareness month; day of disability; WHD; Womans' day etc.

## Iceberg 4



## Iceberg 5

### **EVENTS**

Not having enough volunteers

### **PATTERNS & TRENDS**

Organisation providing tools/training/workshop  
General interest in activism – how do we harness it?  
Too many volunteering opportunities  
Succession planning  
Available therapies

### **STRUCTURES**

Generational difference – different interests  
Potential volunteers do not see the value of the community  
Analysis of membership

### **VALUES & BELIEFS**

Attention/ care from the organisation  
Better treatment + access to care  
Equality

## Iceberg 6

### **EVENTS**

Attracting new patients to the NMO

### **PATTERNS & TRENDS**

Little attention to patients

To determine what is interesting and important to those patients

### **STRUCTURES**

Outside of the NMO patients are receiving wrong information

Social status of the family

Irresponsibility of the parents

Regardless of what is happening all is going towards improvement

### **VALUES & BELIEFS**

Psychological issues

Losing motivation/will to live

## Iceberg 7

### EVENTS

Patients not receiving comprehensive care in the treatment centre

### PATTERNS & TRENDS

Centres sometimes just ticking the boxes, but in reality, they are not comprehensive

Understaffed centres

Patients cannot afford to go to the few Comprehensive Care Centres

Lack of collaboration and communication between disciplines (obs)

Patients not seeking for help even when needed

Patients don't know about possibilities and existence of CCCs

With advances treatment the need for access sometimes decreases

### STRUCTURES

Lack of NMO involvement in the process of auditing CCCs

Not sufficient communication/ support/ help from healthcare professionals when bleeding

### VALUES & BELIEFS

Patients' resistance and not acceptance of lifestyle

"You are alone in your ..."

Comprehensive ≠ multidisciplinary care!