

# Mapping the needs of ageing (50+) bleeding disorder patients in NMOs: EHC survey for individuals

## Background

Thanks to the treatment improvements today people with haemophilia and other rare bleeding disorders are living longer than ever. However the situation doesn't come without its challenges that need to be addressed. This situation is an unprecedented reality in our community and therefore we would like to explore what those challenges are and what could be potentially the ways to address them.

## Aim

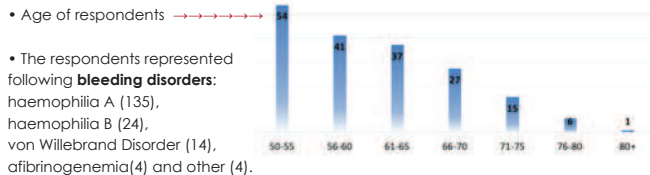
To help the EHC understand what can be done on the European level to offer the support needed and tailor it precisely to the needs at hand.

## Distribution

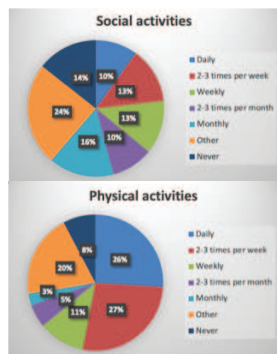
Survey was carried out in November and December 2021, sent to all the 48 NMOs of the EHC and available in **7 languages** – ENG, RUS, FR, DE, IT, NL, DK. The **Czech NMO** translated and expanded the survey to the entire community, the results are incorporated. **French NMO** run their own survey on ageing, with a different set of questions, results are not incorporated, but can be viewed separately.

## Profile of respondents

- In total **181 valid responses** were received.
- 28 of EHC NMOs represented: Austria (14), Belgium (3), Czechia (32), Denmark (2), Finland (5), France (1), Germany(11), Ireland (1), Poland (2), Russia (33), Switzerland (65), Ukraine (10), United States (1).



- The respondents were mainly **male** (162), but also a few **female** (19).



## Social and physical activities

The respondents were asked how often and in what kind of social activities they take part. **The types of social activities indicated:** cultural events, theatre, concerts, cinema, exhibitions, meeting with friends, social groups, museums, library, hobbies, church etc.

Those **respondents who take part in physical activities**, engage in walking, cycling, swimming, group classes or other physical activities (golf, fitness, physiotherapy, aqua-jogging, tennis, yoga, nordic walking, work.

**Those who do not take part** in physical activities do not do so due to their physical condition.

## Background information

In order to better understand the situation of the ageing members of the community, a few questions about their living situation were asked.

The respondents are **mostly living either with their spouse** (54%) or with their family (23%), however enough large portion were also living alone (18%), or in another setting (5%), such as with their children or in a senior home.

The respondents are **mostly living in their own apartment** (41%) or house (38%), whereas much fewer are renting apartment (12%) or a house (7%). Again, a small number of respondents are living in another (3%) setting.

In terms of **work situation**, half of respondents are retired (50%). Nevertheless, still quite a large portion are working full time (29%) or part time (7%). There were also a few respondents in other (14%) setting, e.g. mix of work and retirement, disability pension etc.

## Community and participation

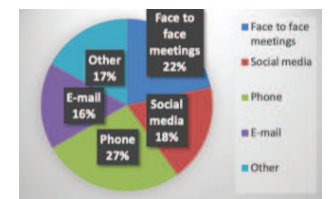
**41% of the respondents take part in the activities of their NMO**, either in face-to-face setting or virtually, with various frequency (daily to occasional).

Mostly they are found useful as they give opportunity for peer exchange, receiving new information about treatment and care, as well as for physical activity.

72% of respondents are in contact with other PWBD, of which

- Daily (10%)
- 2-3 times per week (11%)
- Weekly (8%)
- 2-3 times per month (11%)
- Monthly (21%)
- Other (39%) – one or two times per year

The most frequent ways of communicating with other PWBD are



*For inspiration: "I am a volunteer and work with immigrants. I play piano for people in nursing homes. I have a coffee in a shopping centre every day. I like cooking."*

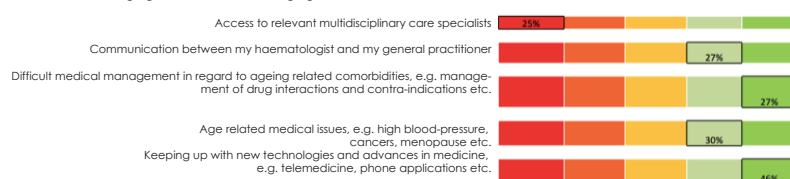
## Challenges concerning the bleeding disorder

1 - the most challenging; 5 - the least challenging



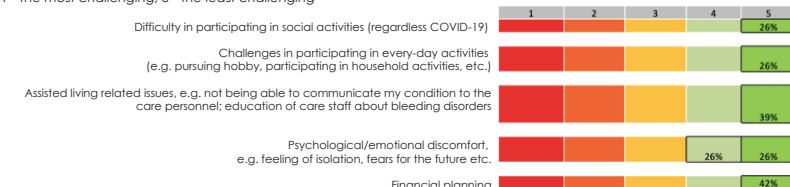
## Challenges concerning management of ageing

1 - the most challenging; 5 - the least challenging



## Daily life challenges as an ageing person with a bleeding disorder

1 - the most challenging; 5 - the least challenging



The respondents were also asked about **other medical challenges** that they are having, and the following were mentioned repeatedly: arthropathy and joint replacement surgeries, HCV treatment, colonoscopy, urology, as well as various surgeries. The communication between the different HCPs was mentioned, as well as easily available health information and access to own holistic data.

## POSSIBILITIES FOR SUPPORT

- Information regarding complexity of ageing with a bleeding disorder
- Expert advice on strategies for improved quality of life, e.g. pain management, nutrition, sports and physiotherapy
- Information regarding management of co-morbidities and management of a variety of medications and interventions
- Access to relevant multidisciplinary care specialists
- Experiences and stories of other people who are/have been in a similar situation
- Advocacy strategies for improving the situation of ageing patients with bleeding disorders
- Management of every-day activities, e.g. pursuing hobby, participating in household activities etc.
- Support in financial planning/ financial advice
- Professional psychological support

**Among other options for support** the following were indicated: online peer support groups, advice on how to make home/ car adaptations, advice for moving into senior home, advice for supporting household with increasing disability, pain management, IT education and training so that the seniors can join online events, online legal support, support with insurance, home delivery of treatment...

It has also been pointed out that the entire system of care for seniors must be studied because we are g the age-related co-morbidities. It would be desirable to find ways for holistic medical support.