

Changing Community Needs for Those With a Bleeding Disorder in Poland

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INTRODUCTION

Treatment and care have improved for those with a bleeding disorder (BD) in Poland in the last 20 years, resulting in two unique populations that each require different services: a generation that is living longer and now aging with a BD, and a younger population who have received adequate care and have less overall joint damage, but earlier signs of aging. The older cohort is concerned about their mobility and quality of life, and the younger group has increased expectations about life with a BD. Newly approved and emerging therapies are promising further possibilities for improvement in quality of life. The Polish Haemophilia Society (PHS) completed a series of studies to understand the current and future needs of the BD community.

RESULTS

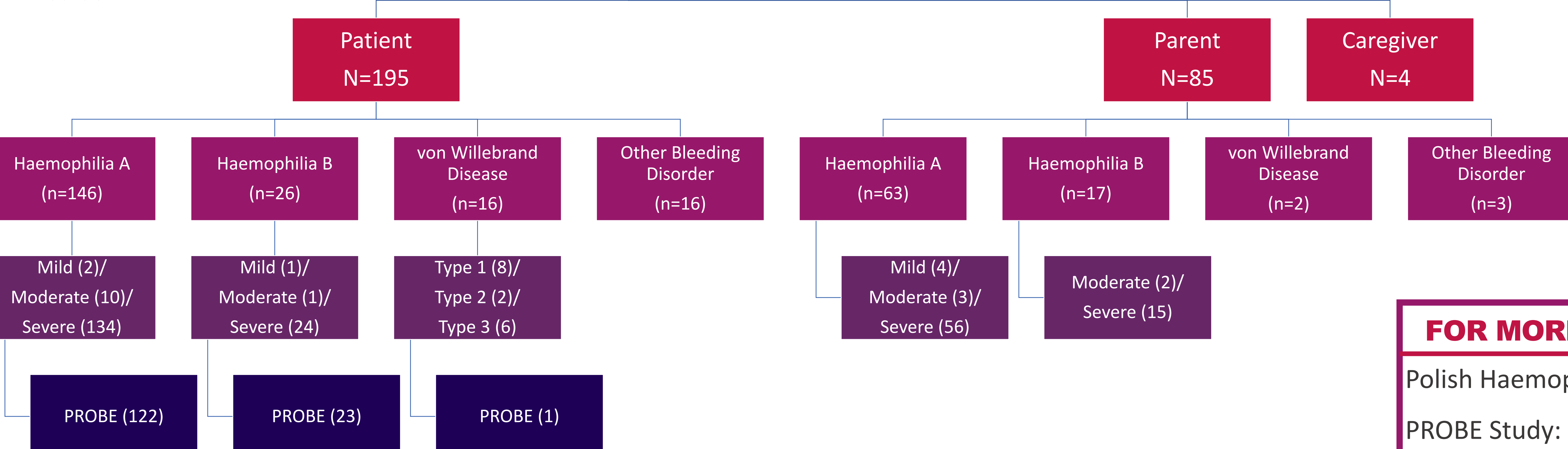
284 people with a BD, parents or caregivers (PwBD) responded to the PolHTC survey. 95% of these were in 16 centres across the country (map). Due to small numbers in the parent and caregiver cohorts, only patients' responses to PROBE (n=195 patients) are reported here (Figure 1).

- The mean distance from the PwBD's home to their local HTC was 56 (± 61) kms and to the only recognised comprehensive care centre (CCC) in Warsaw was 258 (± 147) km.
- 94% of respondents reported having access to home treatment; 6% of patients access the centre for their treatment
 - An average time of 2.4 (± 3.8) hours to collect treatment
- The national EQ-5D utility and PROBE scores, respectively*:
 - PwBD (mean): 0.748 (± 0.219) and 0.730 (± 0.135)
 - People in Poland without a BD from the the PROBE database (mean): 0.882 (± 0.219) and 0.845 (± 0.104), which is significantly higher than those collected in those with a BD through the PolHTC survey
- The variation in FVIII dose size and quality of life reported varied significantly across the country.
- The majority of PwBD would like clinics, nursing facilities, and physiotherapy to be available through telemedicine in the future (Figure 2)
- 30% would prefer telemedicine be delivered through the CCC rather than their local centre (PwBD currently attending a CCC are not included) (Figure 3).

*In EQ-5D and PROBE, a score closer to 1 indicates a better quality of life (QoL)

Figure 1. Participants in the PolHTC Survey Stratified by Type and Severity of Bleeding Disorder.

284 Responses



METHODS

In early 2020, the PHS developed and conducted the Poland-Haemophilia Treatment Centre (PolHTC) Survey, a fully anonymised online survey on access to haemophilia treatment centre (HTC) services. The Patient Reported Outcomes Burdens and Experiences (PROBE) questionnaire was also administered both to people with a BD and to people without a BD living in Poland. There are 27 centres in Poland on the national list as a treatment centre.

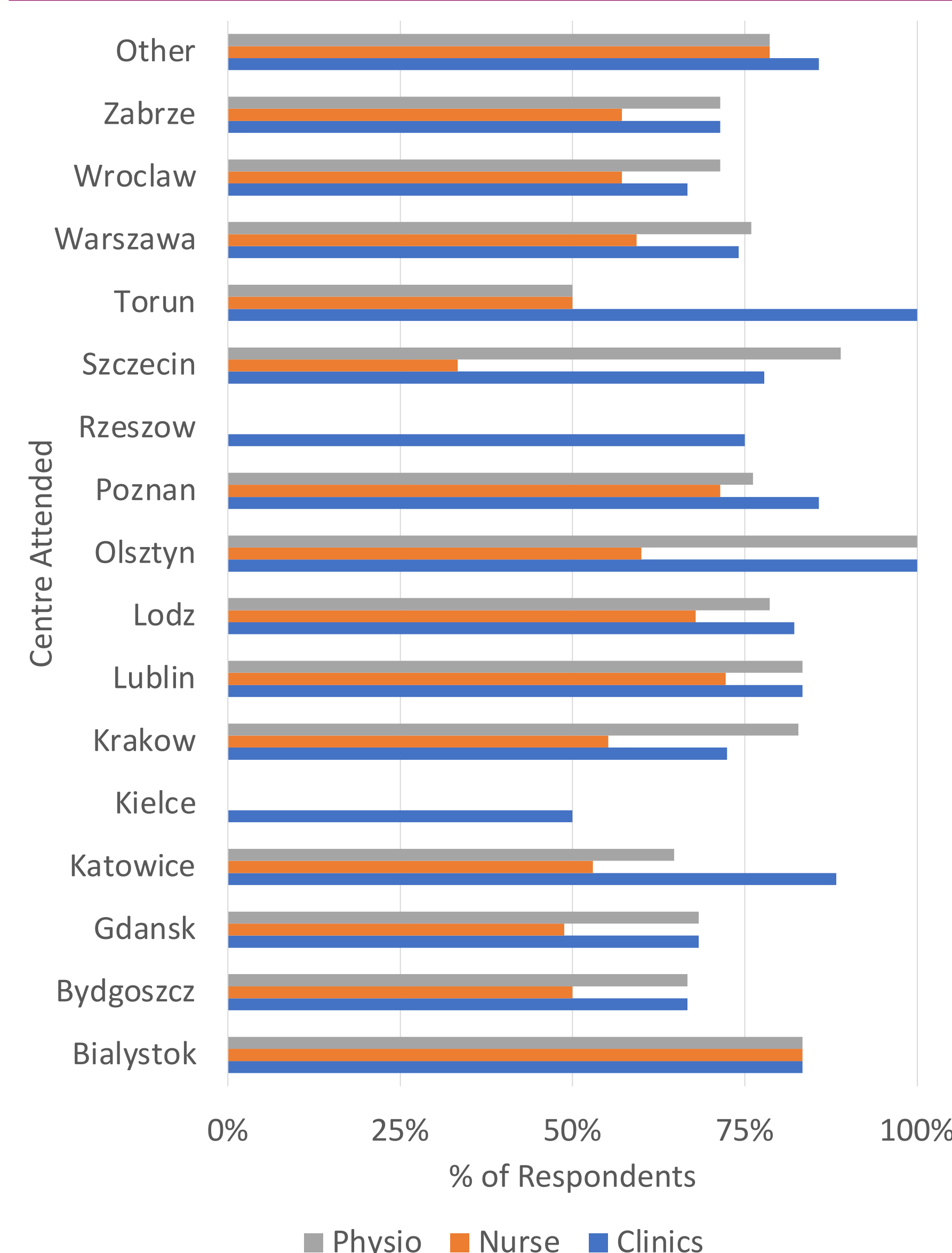
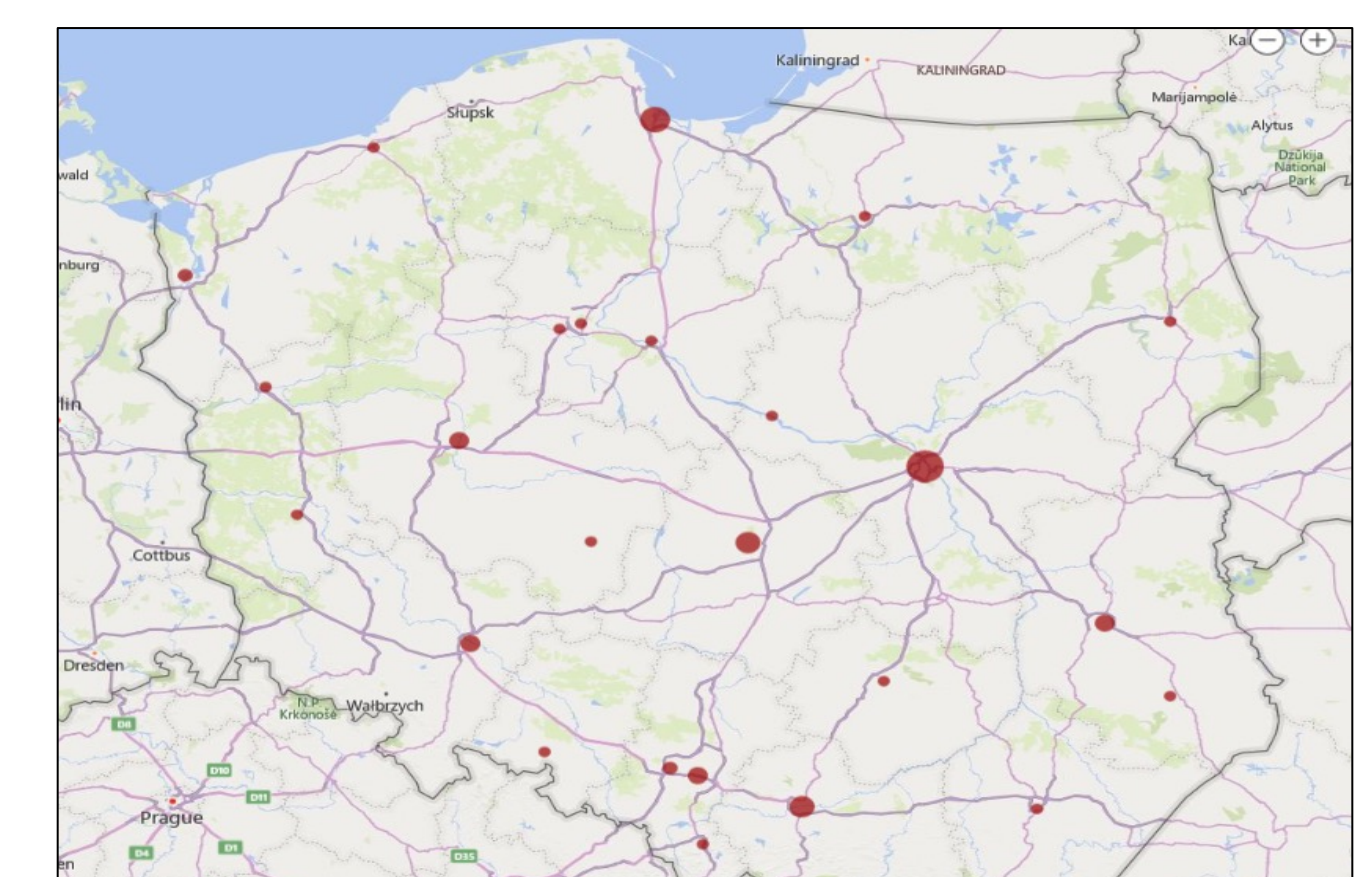
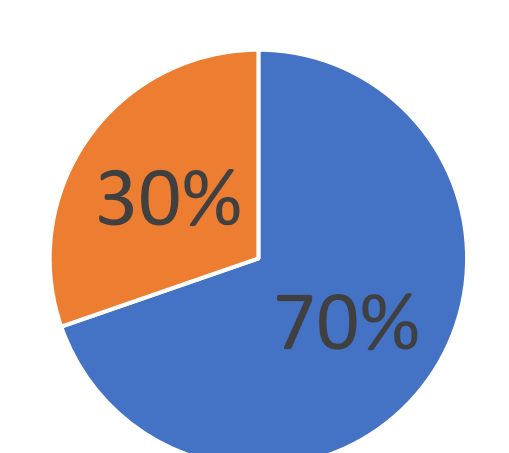


Figure 2: Patient request for delivery telehealth to make services easier to access.

Map: Locations of centres and relative size of patient population reporting in PolHTC



Where telemedicine is delivered through



Local HTC CCC

Figure 3: Patient request for delivery of CCC services remotely where currently local HTC provides the service.

CONCLUSIONS

There is a still a gap in quality of life between those with and without a BD in Poland. There is also significant variation of care delivery across the different centres nationally. The Polish PwBD population requires an increasing and changing need for services and care nationally which needs to be addressed for overall improvement of quality of life for PwBD in Poland.

PROBE
Patient Reported Outcomes Burdens and Experiences Study



Polskie Stowarzyszenie Chorych na Hemofilię

FOR MORE INFORMATION

Polish Haemophilia Society: hemofilia.org.pl

PROBE Study: probestudy.org