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**Patient-centred care in haemophilia: patient perspectives on visualization and participation
in decision-making**

Short title: patient perspectives on patient-centred care

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Van Balen et al. 2019 - patient perspectives on patient-centred care

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Abstract (246 words, excluding headings)

Introduction and aim: The British Columbia Adult Haemophilia Team recently adopted a patient-centred care approach. The team presented visual information on an individual's pharmacokinetic profile and bleed history and encouraged patients to participate in treatment decisions. This qualitative study explored how this approach changed patients' understanding of haemophilia and how it facilitated them to make treatment decisions.

Methods: We interviewed 18 males with mild, moderate or severe haemophilia, using a convenience sample from the adult haemophilia clinic at St. Paul's hospital in Vancouver, Canada. Interviews were recorded and transcribed verbatim and analysed using descriptive content analysis.

Results: Most participants reported that reviewing visual information with the clinic team helped them in their communication with their care providers during their annual review clinic appointment. Despite this improved communication, for some the most important feature of their treatment was that they had switched from on-demand treatment to prophylactic treatment in recent years and were able to prevent bleeds. Almost half of the participants reported that the visual information presented increased their understanding of haemophilia and the pharmacokinetics of coagulation factor. Three patients improved their treatment adherence or had changed their prophylaxis schedules based on this. Most participants felt they were involved in decision-making about their treatment schedule, which they appreciated. On the other hand, two participants thought the clinic team should make these decisions.

Conclusion: Participants perceived the patient-centred prophylaxis approach helpful because it enhanced communication with the clinic team, increased their understanding of haemophilia and pharmacokinetics of coagulation factor and facilitated treatment decisions.

Introduction

Over the last decades, the availability of treatment has improved life expectancy of people with haemophilia (PWH)[2] and decreased bleeding rates and joint impairment.[3]

While guidelines exist for preventing and managing bleeds, the optimal dosing strategy is variable,[1] due to differences in pharmacokinetics[5] and bleeding phenotypes between patients.[6] This variability provides an opportunity for patients to be involved in the decision-making process in their disease management,[7] for example in determining the timing and frequency of coagulation factor administration.

Patient-centred care is increasingly being promoted in order to deliver high-quality care,[8] including in haemophilia.[9] Dimensions of patient-centred care include respect for patients' preferences; coordination and integration of care; information and education; physical comfort; emotional support; involvement of family or friends; continuity and transition; and access to care.[8,10] Research suggests that patient-centred care may positively affect patients' disease management skills, which has been shown to improve adherence and health outcomes in a range of conditions.[11-12]

In British Columbia, Canada, some PWH had not attended a regular haemophilia review clinic recently. Also, some with severe haemophilia started long-term prophylaxis within the past 5-10 years.[13] Therefore, the Clinic Team piloted a new patient-centred "prophylaxis clinic" approach in order to improve patient engagement, individualize prophylaxis regimes, and improve health outcomes. The approach consisted of 1) a shift in focus from adherence to prophylaxis toward a more comprehensive approach that included PWH's preferences and needs to manage their lives with haemophilia, 2) sharing and discussing visuals of a patient's bleeds and treatment history, and individualized pharmacokinetic (PK) profiles where appropriate. The approach was aimed at facilitating shared decisions about treatment.

A better understanding of how PWH perceive these patient-centred strategies is needed. With this knowledge, haemophilia care can be improved further, eventually resulting in better outcomes for PWH. Therefore, we conducted a qualitative study that aimed to describe PWH's perspectives on the new patient-centred prophylaxis clinic approach.

Methods

Study design

We conducted a qualitative study in 2016 and 2017 to gain insight into perspectives of PWH on the patient-centred prophylaxis clinic. We invited people who were scheduled for their regular clinic review appointment to participate in an interview study (convenience sampling) with the intent to obtain a diverse sample of people regarding their age, self-reported type and severity of disease, country of birth and education level. Topic lists used during the interviews included questions on participants' perspectives on how their needs were addressed, data visualization and participation in decision-making. In 2017, the interview questions were revised to reflect the change in practice of the prophylaxis clinic approach. The topic list is included in the Supplement. Interviews were recorded and transcribed verbatim.

Setting

The new patient-centred prophylaxis clinic had been piloted as part of a larger approach to engage patients, individualize prophylaxis schedules and stimulate shared decision-making for those with severe haemophilia. The prophylaxis clinic was an addition to regular haemophilia clinic appointments and consisted of a meeting between the PWH and all members of the treatment team (haematologist, nursing specialist, physiotherapist). Two types of graphs were shown on a large screen: 1) an individual PK profile and 2) treatment and bleeds frequency data. Individual PK data were obtained from the Web Accessible Population Pharmacokinetic Service; WAPPS. WAPPS can be used to simulate the effects of different dosing regimens on

peak and trough levels. Treatment and bleeds frequency data were obtained from the on-line Inherited Coagulopathy and Hemoglobinopathy Information Portal; iCHIP. Examples of graphs shown during prophylaxis clinic are shown in Figures 1 and 2. More information about iCHIP and WAPPS is included in the Supplement.

[figure 1]

[figure 2]

The prophylaxis clinic format was piloted in 2015 and 2016. By 2017, the prophylaxis clinic approach as described above (i.e. focus on patients' needs and stimulating participants in decisions) was integrated in all clinic visits. The approach was also used for those with mild haemophilia and those treated on-demand.

Interviews and participants

The study was conducted in two phases (13 interviews in March and April 2016 and 5 in May 2017). Participants were eligible for the study if they had participated in the prophylaxis clinic (people with severe haemophilia) or if they had attended their annual review clinic in 2016 or 2017. People with mild haemophilia had not been shown individualized PK and bleed graphs during their scheduled review appointment but had an opportunity to look at anonymized PK data during the interviews. They were also asked about how the clinic addressed their needs and about their participation in decision-making.

The first author, a PhD student in clinical epidemiology and some knowledge of qualitative research methodology, and the second author, a medical anthropologist with experience in ethnographic research, conducted semi-structured interviews.

The study team approached potential participants two weeks before their scheduled outpatient clinic appointment by a letter that explained the study procedures. All invited participants provided informed consent.

Analyses

The software program MAXQDA (version 12) was used for coding and organization. Qualitative data from the interviews were analysed using descriptive content analysis as described by Green and Thorogood.[14] The first author read and summarized all the transcripts. Several rounds of coding were applied to understand the data in their context. Then, the same researcher identified themes in the data set based on the research question. Codes and larger themes were discussed and refined through a series of analysis meetings with the research team.

Ethical considerations

Approval for this study was obtained from St. Paul's Hospital's Research Ethics Board as part of a larger study about integrating a Quality of Life Assessment and Practice Support System in Routine Clinical Practice (QPSS).[15]

Results

Participants in our study reflected the variety of people with haemophilia receiving treatment from the British Columbia Adult Haemophilia Interdisciplinary Team. Their ages ranged from 20 to 76 years old; twelve had haemophilia A and 6 had haemophilia B. Eight had severe, four had moderate and six had mild haemophilia (self-report). Of the participants with severe haemophilia, seven were on a regular prophylaxis regimen, but only one of them had been on prophylaxis since he was a child. PK data were available for six participants (one with mild haemophilia, two with moderate haemophilia and three with severe haemophilia). Three others were scheduled for PK in the near future. iCHIP data were available for eleven participants. Participants' characteristics are summarized in table 1.

[table 1]

Participants' perspectives were grouped into three main topics: 1) communication with the Clinic Team, 2) understanding the effects of treatment and 3) active participation in treatment decisions.

Communication with Clinic Team

All eleven iCHIP users (two with mild, four with moderate, five with severe haemophilia) reported that reviewing their treatment and bleeds history data in a visual format was useful to them. Four of them (three severe, one mild with a severe bleeding phenotype) said that it made their annual review appointment more focused, because the bleeds and infusion history data from iCHIP helped them remember the bleeds they had in the past year and the amount of coagulation factor they used. A few patients commented that they were well aware of their own bleed and infusion history because they had tracked it in the app themselves. However, they still found it useful to review this information together with the Team. As participant 6 puts it (see box 1):

[box 1]

Because the interactive WAPPS program visualized the effects of infusions on trough levels for people with severe haemophilia, it also facilitated the conversation about further individualizing the patient's prophylaxis schedule.

Four participants (three severe, one mild) reported that they felt connected to the team because of iCHIP, because it automatically sends a message to the clinic when a bleed is registered (which may or may not be real-time). Although the alerts are not systematically monitored, participant 1 felt safe knowing that the clinic staff has access to his bleeds data in case he wants to discuss his bleeds (see box 2).

[box 2]

Nine participants (one mild, two moderate and six severe) said they felt comfortable discussing any issues with their treatment team and felt attended to in their treatment needs. Participant 7 commented that the patient-centred prophylaxis clinic approach was also useful because it improved communication about needs that were not directly treatment-related. As he explained (box 3):

[box 3]

Though useful for most participants, three of them (two severe and one mild) pointed out that the visual information presented was of less importance compared to actual bleed prevention and treatment. Two of them had struggled with bleeds in the past and had only recently switched to prophylaxis. In the words of participant 11 [box 4]:

[box 4]

Finally, two participants (both with severe haemophilia) said it was more important for the team to track their bleeds and treatment data than it was for themselves. However, they thought they would benefit from the information in the long-term because they thought it helped the clinic team gain insight into their bleeds history.

In summary, participants felt visualizing their treatment-related data helped them better communicate with the Clinic Team.

Understanding the effects of treatment

Seven participants (two mild, one moderate, four severe) said visual information about their bleed history or PK data increased their understanding of both their condition and the effects of coagulation factor infusions. They reported a better understanding of their trough levels and how their factor levels were affected by infusion with coagulation factor. For participant 3 the visual information made him feel more comfortable because he now understood that if he had a bleed, it was because his factor IX level was low. It also made him realize that he should take prophylaxis seriously (box 5):

[box 5]

Participant 7 changed his approach based on this new knowledge of his personal PK data (box 6).

[box 6]

Participant 15 commented that tracking his bleeds and infusions helped him adhere to his prophylaxis regimen better, because he seemed to realize that bleeds occurred when he did not take his prophylaxis (box 7).

[box 7]

Two participants with mild haemophilia who had not had personal PK profiling themselves, had been shown sample population PK profiles during review clinic. They said they would be interested in knowing their personal coagulation factor levels before and after treatment. One participant felt the benefit might be that he would be able to continue his active lifestyle without bleeding.

In summary, patients felt visualizations helped them understand their condition and the effects of treatment with coagulation factor.

Participating in treatment decisions

A majority of ten participants (four mild, six severe) said they were actively encouraged by the Clinic Team to participate in decisions about dosing and frequency of on-demand or prophylactic treatment. They perceived they had the freedom to adjust their schedules to their needs and base it on their experience. Participant 12 explained that he has the freedom to infuse extra before physical activities (box 8).

[box 8]

Participant 7 commented that for larger changes in his schedule, he would contact the Clinic Team. He makes smaller changes on his own (box 9).

[box 9]

All eight participants with severe haemophilia, one with moderate and two with mild haemophilia appreciated that they were encouraged to make decisions about dosing and frequency of prophylactic or on-demand treatment. Two participants, one with moderate and one with mild haemophilia, said the doctor should make the decisions about treatment, because they were the experts. Both of these participants had experienced few bleeding problems.

Twelve participants had switched to a prophylactic treatment schedule from on-demand treatment only in the past five to ten years. They felt the decision to start prophylaxis was a joint decision with the Clinic Team. For some of them, determining dosing and frequency of prophylaxis involved some negotiation with the Clinic Team. Participant 3 felt more comfortable infusing a higher dose (box 10).

[box 10]

Discussion

The goal of this exploratory study was to gain insight into participants' perspectives on the new patient-centred prophylaxis clinic approach used by the British Columbia Adult Haemophilia Interdisciplinary Team. This approach included the use of visual representations of condition-related information and stimulating patients to participate in their treatment decisions. We found that this approach enhanced communication with the Clinic Team. It also increased understanding of haemophilia and treatment effects, particularly through visualizing individualized PK profiles and bleed and infusion history data. Participants also found the prophylaxis clinic approach useful because they perceived the freedom to participate in treatment decisions.

Patient-centred care is a widely-recommended practice in haemophilia.[9] Our results, based on the perspectives of patients, suggest that visualization techniques could be a helpful

patient-centred care strategy. First, tools such as iCHIP and WAPPS may help increase patients' understanding, even for those with mild haemophilia. A previous qualitative study demonstrated that a better understanding determines the ability to practice prophylaxis. This, in turn, determines self-reported adherence.[16] Reviews have also shown that a better understanding improves self-management skills and adherence in haemophilia.[17-18] In another study,[19] the use of an app similar to iCHIP was associated with an improvement in patient adherence to prophylactic treatment in one year. This resulted in increased patient quality of life (QoL) and enhanced illness perception and stabilization of joint health after one year.[19] In concordance with previous studies, PWH in our sample also reported that iCHIP served as a good reminder for their infusions, possibly improving adherence. It should be noted that aids such as iCHIP only work if PWH are engaged in their care and feel comfortable to accurately record their data.

A second benefit of the prophylaxis clinic approach is that it may improve patient-clinician communication, strengthening the relationship. This patient engagement was an important objective of the British Columbia Adult Haemophilia Interdisciplinary Team. Both people with severe and with non-severe haemophilia in our sample found it useful to use visuals in their interaction with the Team. Indeed, a good relationship between care providers and PWH has been found to be associated with treatment adherence in haemophilia.[17-18]

A third potential advantage of the prophylaxis clinic approach is improved patient participation in decisions about their treatment schedules. The Team has encouraged people with severe haemophilia to switch to prophylaxis from on-demand treatment. Participation in decision-making may improve adherence and reduce bleeds,[13] as some participants in our sample reported. Whether this leads to an actual improvement in outcomes needs to be investigated further. As life-long experts, PWH may feel they have the knowledge to make their own treatment decisions. Indeed, in our study, many PWH perceived they had the freedom to make

their own decisions. Making decisions about dosing and frequency of prophylaxis or on-demand treatment is important in haemophilia due to the lack of a standard treatment regimen and inter-individual differences in response to treatment.[1,5-6] Decision aids such as pamphlets, videos or web-based tools can be used to support treatment decisions.

Information about different options and their harms and benefits may be presented in graphical formats.[20-21] Several decision aids have been developed for haemophilia.[22] Yet, to the best of our knowledge, we are not aware of any tools available for decisions such as setting a treatment schedule. Naturally, these tools are particularly relevant for those on prophylaxis. Also, people with mild haemophilia may benefit from a better understanding of how their factor levels change after an infusion. This may make them feel more comfortable in managing a bleed, including altering their physical activity during recovery.

A limitation of our qualitative study is that we cannot quantify the effect of the patient-centred prophylaxis approach on health outcomes. Another limitation is that clinical factors such as joint status, duration of prophylaxis use and background bleeding phenotype likely affect how patients perceive patient-centred engagement efforts. Though we aimed to include a variety of patients, we may not have captured all possible patient perspectives. Still, this qualitative study helps understand how investing in the approach may positively affect self-reports of patient outcomes such as satisfaction with care, a good relationship with the team, a better understanding and improved self-management skills. Further research is needed that quantitatively measures haemophilia outcomes longitudinally.

Another potential limitation of this study is that the convenience sampling approach makes it more likely to include PWH who are already willing to accept their condition and its treatment and engage with the Clinic Team. However, we included a variety of PWH, including a few that had not been to clinic in recent years, thus representing perspectives of those who had not yet established a long-term relationship with the Clinic Team.

Conclusion

Participants reported that the use of tools to visualize bleeds history and pharmacokinetic data enhanced patient-clinician communication. Also, it enabled PWH to better understand haemophilia and its treatment. Participants felt they were involved in decision-making about their treatment. Some of them found that the tools helped them to make better informed decisions about their treatment. This patient-centred approach may help improve care in haemophilia.

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Author contributions

Authors EvB and MK conducted five of the interviews together. EvB conducted the remaining thirteen interviews, analysed the results and wrote the manuscript. MK provided input for the analysis, which was discussed with all authors. RS worked with Clinic Team members (DG, SJ) and MK to design and implement the initial quality of life and practice support system (QPSS) study, which provided the foundation for the current project. EvB, SCG and JGB subsequently collaborated with the initial QPSS study team to co-design and implement the current study. All authors contributed to iterative interpretations of emerging results at key stages of the analysis and to manuscript writing. DG and SJ approached participants.

Disclosures

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Tables and figures

Figure 1: Example of bleeds history data from iCHIP. The presented data are based on real patient data. These patients did not participate in the interviews and provided informed consent to use their data in this paper for illustration purposes.

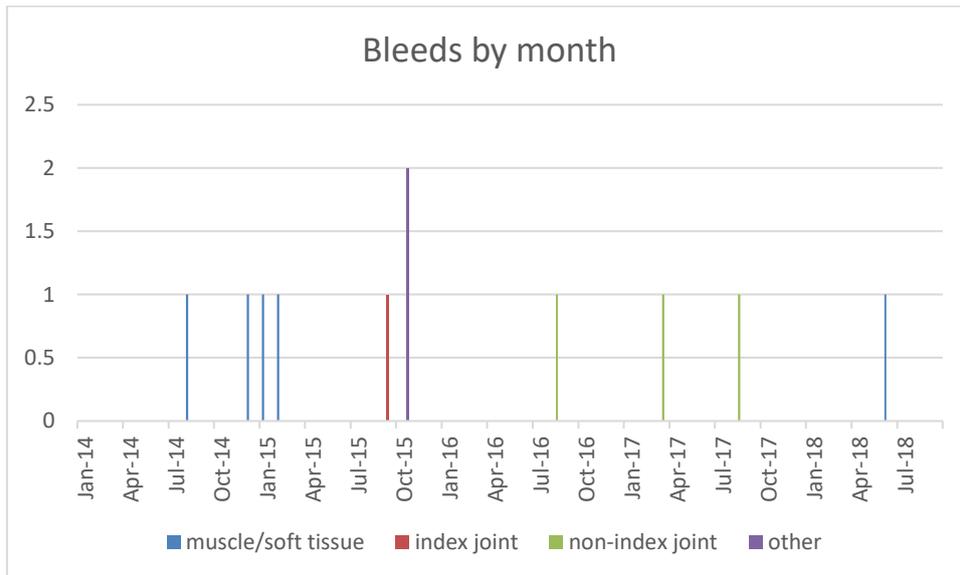


Figure 2: Example of a personal pharmacokinetic profile based on a dose of 2000 IU and a dosing interval of 72 hours. Graphs are generated based on blood samples taken at two to three time points after infusion with factor VIII or IX. The WAPPS program can then be used by clinicians to simulate the effects on peak and trough levels if different dosing regimens are chosen. The presented data are based on real patient data. These patients did not participate in the interviews and provided informed consent to use their data in this paper for illustration purposes.

Dose (IU)	Infusion Interval	Peak (IU/mL)	Trough (IU/mL)	Weekly Dosage (IU)
2000	72 hr (3 Days)	0.7854	0.0571	4667

The line with hollow points shows the measured concentrations used to estimate (dashed line) the PK profile for the patient. The solid line shows the predicted PK profile for the simulated regimen.

The further the predicted (solid) line is from the measured (hollow point) line and from the estimated (dashed) predicted individual PK profile, the lower our confidence in the precision of the calculation; please consider drawing one or more samples on the new regimen to confirm the new individual PK profile.

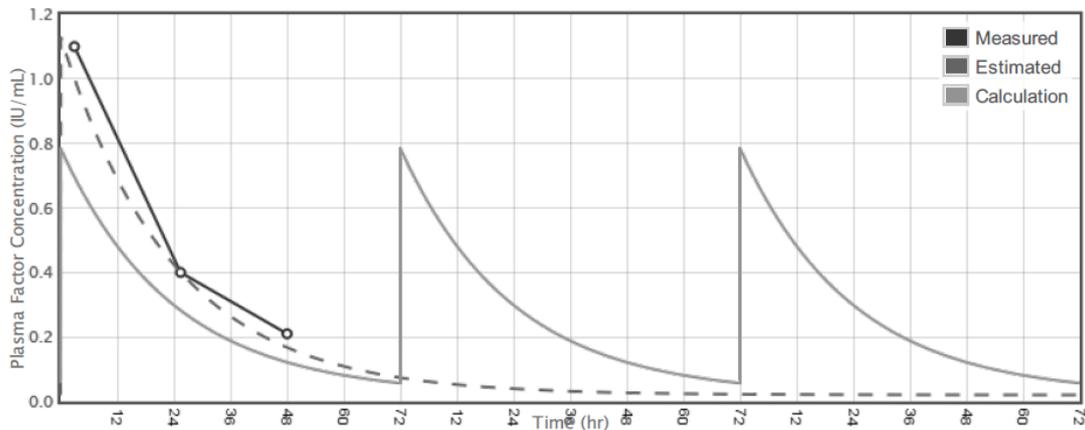


Table 1: Participant characteristics at the time of their interview

Table 1: Participant characteristics at the time of their interview

Characteristic	N = 18
Mean age (range), years	37.7 (20-76)
Type of haemophilia, <i>n</i>	
<i>Haemophilia A</i>	12
<i>Haemophilia B</i>	6
Severity, <i>n</i>	
<i>Mild</i>	6
<i>Moderate</i>	4
<i>Severe</i>	8
Treatment type, <i>n</i>	
<i>On-demand</i>	6
<i>Prophylaxis</i>	12
On home therapy	15
Education level ^a , <i>n</i>	
<i>Upper secondary education</i>	2
<i>Post-secondary non-tertiary</i>	6
<i>Bachelor</i>	6
<i>Master</i>	4
Visualizations	
<i>PK available</i>	6
<i>Use iCHIP</i>	11

^aEducation levels (finished or in progress) according to the International Standard Classification of Education (ISCED)[23]

List of quotes (boxes)

Box 1

"So I think they [the Clinic Team] should make it available to each person to look at their own data [of their bleeds history]. I mean, I can look, of course. I can go back to the history and I can print if I want. But the way [as a graph] they had it there was good because it showed a little bit what had happened, in my case, during the last year."

Box 2

"Yeah, it's useful just to keep the record of the history. You can call them [the treatment team] back if any injury happens, like on the same joint back-to-back. So it's nice to have."

Box 3

"I think there are absolutely two sides of medicine. You know, there's a treatment side you have to understand (...) but then there's also the more personal side of medicine where you need to check in on the patients, get a sense of the patient's quality of life, how things are going for them. I thought it was useful that I was asked about how do I actually feel about having to treat myself every day"

Box 4

"And these [visualizations] have been really helpful with the little adjustments, but to be honest, from my perspective, the big change was just doing any kind of prophylaxis. (...) Like if I was someone who really loved molecular biology or statistics or graph making, these things might be more important. I just don't want to bleed."

Box 5

"So the more information you get, the more comfortable I think that you are. (...) So I want to know everything. (...) I just think [this is cool] information because then you can literally gauge it [factor level] to exactly the way that you feel and with the numbers. (...) Like, this says that you should have this much or whatever if you aren't as responsible with that [taking prophylaxis]."

Box 6

"It was good to see exactly how far my factors fall at the trough and then how far they spike up at their peak. And based off that, I've actually changed the way I do my infusions, day to day, a little bit."

Box 7

"When I stick in my prophylaxis treatment it's through the iCHIP program. When I was taking my prophylaxis treatment we don't see any bleeds. But then when I kind of don't enter anything [prophylaxis] for three or four days, we'll see that I enter a bleed in there."

Box 8

"Yes, we have freedom. We can basically make that decision, which is pretty good because... They like to have us independent, which is very good, and we have at-home treatment."

Box 9

"A smaller change, I might probably make the decision on my own and then comment to them [the Clinic Team] that, "I'm doing this now. Is that okay?" But I'd say it's quite self-directed in a way, [but] with outside influence."

Box 10

"I negotiate with them [treatment team], and I would feel more comfortable if I did just a little bit more [prophylaxis] to push myself a little bit so that I'm covered completely, 100%. But they like me to just be at the level where they know that I'm okay."

Supplement

Topic list with interview questions (2017)

Introductory / ice-breaking questions

Can you tell me what it is like to live with haemophilia?

What does your haemophilia care look like? (go through clinic appointment, what happens, what is discussed)

Quality of life

What topics related to living with haemophilia should be addressed during your clinic appointment?

Information sharing

What type of information do you receive from the clinic team, and in what format?

What type of information has been or would be the most helpful or educational for you and why? (does it address needs and concerns, why or why not, how to deliver this information)

Decision-making

Can you describe how you make decisions about your care?

Topic list with interview questions (2016)

1. The haemophilia team has started a prophylaxis clinic that uses visual aids to chart your bleed history, factor utilization, and quality of life.
 - a. Do you like the information being presented in this way?
 - b. If yes, what do you like about the information being presented this way?
 - c. If not, what don't you like about the information being presented this way?

2. What is the most important information about your haemophilia that you want to know about?

3. What is the most important information about your haemophilia that you want the team to know about?

4. What is the most important information about your haemophilia treatment and support that would help you to determine if it is the best it can be?
 - a. Is there additional or alternate information that is not currently collected that the clinic should be collecting and reporting back to you about?

5. How do you think this information can be used by yourself and the clinical team to make shared decisions about your treatment?
 - a. How would you like to see this information used in your care planning?

6. Were you a participant in the recent project using the handheld tablets?
 - a. If so, do you feel that they could be used in regular clinics to make your visit more efficient or educational for you?
 - b. Can you describe any other ways of visualizing your data that would be helpful to you?

7. Would you like the ability to create your own reports using data from other sources (e.g. iCHIP)?
 - a. If yes, would you want to be able to send them to the clinic team and have them be part of the clinic appointment?

- b. If no, why not?
8. What do you think of having the prophylaxis clinic through a video link where you could see both visualized data and clinic staff from your home computer?
 9. What do you feel have been the most important changes in your haemophilia care in recent years?
 10. How has your quality of your day to day life changed since you've started prophylaxis?
 11. Do you feel that attending the prophylaxis clinic, in addition to the regular review clinic, has improved your haemophilia care?
 - a. Why or why not?
 - b. Do you feel any different in your relationship with the team as a result of attending the prophylaxis clinic in addition to the regular review clinic?
 12. Is there anything else you can think of that the team can do to improve your quality of life?

Examples of graphs shown in clinic

Most people with moderate or severe haemophilia in British Columbia use iCHIP for recording bleeds and factor use available as a smartphone app. The Team can review summary data during clinic appointments with PWH. The system can send an alert to the Clinic Team when a bleed is entered, however the arrival of the alert is dependent upon when the patient chooses to enter the data, and therefore often not “real-time”.

Personalized PK profiles had been created by WAPPS for five people in our sample (four people with severe haemophilia and one with mild haemophilia but a severe bleeding phenotype).

The program was used to show peak and trough coagulation factor levels if frequency or dosing are changed.

The presented data in the iCHIP and WAPPS examples are based on real patient data. These patients did not participate in the interviews and provided informed consent to use their data in this paper for illustration purposes.