**Appendix 1** Schematic display of the coding process.

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| **First round** (focus group) | **Second round** (focus group) | **Third round** (individual interviews) | **Last round** (member checking) |
| Hemophilia has a low impact on daily activities. AYAs do join most peer activities.Early adolescents mentioned parents had high impact on taking prophylaxis.Middle adolescents mentioned experiencing bleedings had a positive impact on adherence. | Hemophilia had a low impact on daily activities. They prefer to participate in most activities. Early adolescents mentioned parents had high impact on taking prophylaxis. Middle adolescents mentioned experiencing bleedings have a positive impact on adherence.Middle adolescents mentioned being non-adherent is fine if they are not performing sport activities | Three subsequent developmental phases in adherence behavior: 1. Early adolescence: AYAs rely on parents

 - Majority high adherence1. Middle adolescence: AYAs were balancing between ‘feeling safe’ and ‘being normal’

- Variety of adherence levels1. Late adolescence developed a personal regime concerning prophylaxis

- Variety of adherence levels | Two components were determined: **Treatment responsibilities** 1. Phase 1: rely on others concerning treatment related skills.
2. Phase 2: increased responsibility for treatment related skills.
3. Phase 3: fully self-responsible for treatment related skills.

**Estimating risks*** Concurrently aiming to ‘feel safe and at the same time to do what they prefer’.
* the impact of a bleeding on daily activities
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**Appendix 2**: Topic list and survey

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| Round 11* How do you experience your hemophilia in your life?
* How do you integrate hemophilia daily life?
	+ What are your limitations?
	+ Which things can you do?
* What is the impact of hemophilia on your daily life?
* What are your barriers and motivators concerning hemophilia and treatment adherence?

We know that for some it is quite difficult to follow the treatment and for others it is very easy, how is that for you? * Can you explain that?
* Can you give an example of a situation it was easy to take prophylaxis and a situation it was hard to take prophylaxis?
* Do you experience also advantages / disadvantages when you take the prophylaxis at the correct time?

In case of forget or skip taking prophylaxis.* What happened when you're busy?
* When you postpone the treatment, does it happen that you won’t take it at all?
* Self-initiated treatment changes; how did they emerge? and why were they continued?

Can you tell us something about; in relation to adherence to prophylaxis* How do you handle prophylaxis in relation to your friends/family
* How do you handle prophylaxis in relation to your girlfriend (relations)?
* How do you handle prophylaxis in relation to going out and consuming alcohol?
* How do you handle prophylaxis in relation to sport?
* How do you handle prophylaxis in relation to work and career
* How do you handle prophylaxis in relation to your parents?
	+ Can someone explain which vision your parents have on taking prophylaxis?
	+ Can you explain the differences between your and your parents vision?

Can you tell us something about; Self-monitoring of your own body? * How do you ‘listen’ to your own body?
* How do you decide whether you should treat or not?
* What is it that makes you feel that you can/cannot skip the treatment?
* What is the most stupid thing you did with your prophylaxis

What is your perception, believe and knowledge about the treatment?* What do you expect regarding prophylaxis?
* Do you experience prophylaxis fits your expectations?

What will make it easier to take prophylaxis (Frequency) times a week and in case of incidents?  | Round 22What can you share about your experiences with prophylaxis and adherence?* How do your experience self-infusing yourself?
* Can you explain when you think you take prophylaxis correct? (in according with physicians description)
* Does a delay (in time) still fit taking prophylaxis correct?
* Can you give an example of a situation it was easy to take prophylaxis?

Some people describe a doubt about activities which may or may not wise to do. Do you recognize this?* Can you explain what happens in your mind?

How do your parents influence prophylaxis and adherence? * What is the impact of your parents on taking prophylaxis (easier or harder)?
* How did your parents learned you to handle hemophilia?
* Do you ever have discussion with your parents about taking prophylaxis?
* Do you have the same vision about taking prophylaxis?
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| SurveyHemophilia type: A/BTreatment prescription ….. times a week ….. unitsDo you use other medication:What is your education level:Are your working, if yes, what kind of work: 1) How often did you administer prophylaxis last 4 weeks? 2) How often did you deviate from your prescribed dose last 4 weeks (excluded dosing changes caused by to bleeds)? 3) How often did you administer prophylaxis in the morning (before 10 o’clock) last 2 weeks? |
| 1. Focus group 1 and 2
2. Add questions during focus group 3 and individual interviews
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