

Centre ID/No.:

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Subject No.:

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Visit Date:

D	D	M	M	M	Y	Y	Y

HAEM-A-QOL

Questionnaire for Adults

Dear Patient!

We would like to know how you have been feeling during the past weeks. Please be so kind as to answer the following questions in this questionnaire, which was composed specifically for people with haemophilia.

To answer the following questions we would like to ask you to observe the instructions below:

- ⇒ Please read each question carefully.
- ⇒ Think about how things have been for you over the past weeks.
- ⇒ Mark (x) the box corresponding to the answer that fits you best, using a cross mark
- ⇒ Only make one cross for each question
- ⇒ There aren't right or wrong answers
- ⇒ What you think is important
- ⇒ There are some aspects, which might not concern you (Sport & Leisure, Family Planning, Work & School, e.g. if you don't work or don't go to school). Please mark in this case the answer category "not applicable".

All your answers will be treated with the strictest confidence!

Date of completion: ___ / ___ / ___ (day / month / year)

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1. Here we would like to know about haemophilia and your PHYSICAL HEALTH

<i>In the past 4 weeks...</i>	never	seldom	some- times	often	all of the time
1. ... my swellings hurt	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I had pain in my joints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... it was painful for me to move	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... I had difficulty walking as far as I wanted to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. ... I needed more time to prepare myself because of my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. and now about how you have been FEELING because of your haemophilia

<i>In the past 4 weeks...</i>	never	seldom	some times	often	all of the time
1. ... my haemophilia was a burden for me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... my haemophilia made me angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... I was worried because of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... I felt excluded	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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3. How does haemophilia affect your VIEW OF YOURSELF?

<i>In the past 4 weeks...</i>	never	seldom	some- times	often	all of the time
1. ... I envied healthy people my age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I felt contented about my body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... haemophilia made my life more difficult	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... I felt different from others because of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. ... I was able not to think all the time about my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. These questions are about SPORTS AND LEISURE

<i>In the past 4 weeks...</i>	never	seldom	some- times	often	all of the time	not applicable
1. ... I had to refrain from sports that I like because of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I had to refrain from sports like soccer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... I did just as much sport as others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... I didn't have the freedom to travel where I wanted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. ... it was necessary for me to plan everything in advance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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5. These questions are about WORK AND SCHOOL

<i>In the past 4 weeks...</i>	never	seldom	some- times	often	all of the time	not applicable
1. ... I was able to go to work/school regularly in spite of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I was able to work/study like healthy colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... my everyday work/school activities were endangered by my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... I found it difficult to pay attention at work/school because I was in pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. The next questions are about DEALING WITH HAEMOPHILIA

<i>In the past 4 weeks...</i>	never	seldom	some- times	often	all of the time
1. ... I tried to recognise early on when a bleed developed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I was able to tell whether or not I was bleeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... I was able to control my bleedings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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7. and your TREATMENT?

<i>In the past 4 weeks...</i>	never	seldom	some-times	often	all of the time
1. ... I was dependent on the factor concentrate because of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I was dependent on the physicians for the treatment of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... I was annoyed about the amount of time spent having the injections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... I felt interrupted in my daily activities by the injections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. ... I was afraid of complications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. ... I had problems with how my treatment was administered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. ... I was afraid that in case of emergency other doctors don't know how to treat haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. ... I was satisfied with the haemophilia centre	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. What do you think about the FUTURE?

<i>Recently...</i>	never	seldom	some-times	often	all of the time
1. ... I have been thinking that it will be difficult for me to lead a normal life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I have been expecting that things will get better in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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3. ... I have been worrying that my condition is worsening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... my life plans are influenced by my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. ... I am afraid that I will need a wheel chair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. The next questions are about haemophilia and your FAMILY PLANNING

Recently...	never	seldom	sometimes	often	all of the time	not applicable
1. ... I have problems having children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I am afraid that I can not have children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... I am afraid not to be able to take care of my children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. ... I worry not to be able to raise a family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. What about PARTNERSHIP AND SEXUALITY?

Recently...	never	seldom	sometimes	often	all of the time
1. ... I have been finding it difficult to date because of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. ... I have been insecure in my relationships with women because of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. ... I can't have a normal relationship because of my haemophilia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

THANK YOU FOR YOUR ASSISTANCE!