

# Vascular Anomalies and Male Sexual Function Survey

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## Start of Block: Default Question Block

Q7 The purpose of this study is to learn whether men or boys with vascular anomalies, especially those which involve the pelvis or genital area, have concerns about their sexual function. Our anecdotal experience suggests that these vascular malformations can affect the physical and psycho-social well-being of older boys and men. There are no large studies of sexual function/fertility in males with vascular anomalies at any anatomic location, and we plan to address this issue by conducting an anonymous survey to learn whether men or boys with vascular anomalies, especially those that involve the pelvis or genital area, have concerns about their sexual function. Your participation will be limited to answering a survey of questions which should take approximately 15 minutes to complete. The greatest risk is a breach of confidentiality. However, we will not collect your name or your child's name in order to minimize this risk. Research is designed to benefit society by gaining new knowledge. You will not benefit personally from being in this research study. Thanks so much for helping us by answering the following questions.

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Q1 Please confirm that you are 18 years of age or older by selecting the option below.

- ☐ Yes, I am 18 years of age or older (1)
- ☐ No, I am less than 18 years of age (2)

*Skip To: End of Survey If Please confirm that you are 18 years of age or older by selecting the option below. = No, I am less than 18 years of age*

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Q5 The results of this survey will remain anonymous. Your participation will serve as your consent for you and for any of your minor children whose information you supply.

## End of Block: Default Question Block

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## Start of Block: Block 1

Q2 How did you receive this survey? (Select all that apply)

- ☐ KT Support Group (1)
- ☐ Lymphangiomatosis and Gorham's Disease Alliance (2)
- ☐ CLOVES Syndrome Community (3)
- ☐ A university or hospital based clinic where you or your child are followed (4)
- ☒ Other (5)

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*Display This Question:*

*If How did you receive this survey? (Select all that apply) = Other*

Q104 Please specify:

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Q3 Do you or does your minor son have a vascular anomaly (vascular malformation, hemangioma, or vascular tumor)? (Select all that apply)

- ☐ Yes, I am an adult male with a vascular anomaly (1)
- ☐ Yes, I am a guardian of a male with a vascular anomaly (2)
- ☒ None of the above (3)

*Skip To: End of Survey If Do you or does your minor son have a vascular anomaly (vascular malformation, hemangioma, or vasc... = None of the above*

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*Display This Question:*

*If Do you or does your minor son have a vascular anomaly (vascular malformation, hemangioma, or vasc... = Yes, I am an adult male with a vascular anomaly*

Q105 Please enter your age:

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*Display This Question:*

*If Do you or does your minor son have a vascular anomaly (vascular malformation, hemangioma, or vasc... = Yes, I am a guardian of a male with a vascular anomaly*

Q106 Please enter your child's age:

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End of Block: Block 1

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Start of Block: Block for adult with VA

Q57 You answered 'Yes, I am an adult male with a *vascular anomaly*' above. The following questions are for adults indicating they have a vascular anomaly.

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Q13 I have (check as many as you think apply):

☐

Hemangiomas (one or more) (1)

☐

Venous or lymphatic malformation or venous-lymphatic malformation (2)

☐

Arteriovenous malformation (3)

☐

Klippel Trenaunay Syndrome (4)

☐

Cloves (5)

☐

Proteus Syndrome (6)

☐

Other (7)

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*Display This Question:*

*If I have (check as many as you think apply): = Other*

Q14 Please specify:

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Q15 I was told this was the diagnosis by which of the following (check as many as apply):

- ☐ A specialized vascular anomalies expert or clinic (1)
- ☒ A primary care provider (2)
- ☐ Other (3)

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*Display This Question:*

*If I was told this was the diagnosis by which of the following (check as many as apply): = Other*

Q16 Please specify:

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Q17 I can see that part or all of my vascular anomaly involves the skin or tissue under the skin of (check as many as apply):

- ☐ My penis (1)
- ☐ My scrotum or testicles (2)
- ☐ My anus (3)
- ☐ My buttocks (4)
- ☐ My lower belly (5)
- ☐ The inner part of one or both of my thighs (6)
- ☒ None of the above (7)

Q18 I have been told that imaging studies such as MRI, CAT(CT) scans or ultrasounds show that my vascular anomaly includes my pelvis/GU area.

- ☐ Yes (1)
- ☐ No (2)
- ☐ I haven't been told or I don't know (3)

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*Display This Question:*

*If I have been told that imaging studies such as MRI, CAT(CT) scans or ultrasounds show that my vasc... = Yes*

Q110 Please specify the area involved (Check as many that apply):

- ☐ Bladder (1)
- ☐ Testicles (2)
- ☐ Scrotum (3)
- ☐ Penis (4)
- ☐ Lower Abdomen (5)
- ☐ Prefer not to answer or Don't Know (6)

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Q19 Do you have any biological children (that is, conceived with your sperm)?

- ☐ Yes (1)
- ☐ No (2)

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*Display This Question:*

*If Do you have any biological children (that is, conceived with your sperm)? = Yes*

Q20 Did you use natural means (sex) to get your partner pregnant?

- ☐ Yes (1)
- ☐ No (2)

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*Display This Question:*

*If Did you use natural means (sex) to get your partner pregnant? = No*

Q107 Did you use artificial insemination to get your partner pregnant?

- ☐ Yes (1)
- ☐ No (2)

End of Block: Block for adult with VA

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Start of Block: Block for past 30 days questions for adult with VA

Q22 **In the past 30 days**, how interested have you been in sexual activity?

- ☐ Not at all (1)
- ☐ A little bit (2)
- ☐ Somewhat (3)
- ☐ Quite a bit (4)
- ☐ Very (5)
-

Q20 **In the past 30 days**, how often have you felt like you wanted to have sexual activity?

- ☐ Never (1)
  - ☐ Rarely (2)
  - ☐ Sometimes (3)
  - ☐ Often (4)
  - ☐ Always (5)
- 

Q21 **In the past 30 days**, did you have any type of sexual activity?  
(Examples of sexual activity are masturbation, oral sex and sexual intercourse.)

- ☐ Yes (1)
  - ☐ No (2)
- 

*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = No*

Q22 There are many reasons why people may not have had sexual activity during the month. What are the reasons why you did not have sexual activity in **the past 30 days**? Please read

the list carefully and check every reason that applies to you, even if it happened only one time during the past 30 days.

- ☐ Was not interested in having sexual activity (1)
- ☐ Difficulties with my erections (penis not hard or is painful) (2)
- ☐ Difficulties with orgasm/climax (3)
- ☐ Don't enjoy sexual activity (4)
- ☐ Health condition (specify) (5)
- ☐ No partner (6)
- ☐ Partner was away (7)
- ☐ Partner was not interested in sexual activity (8)
- ☐ Partner's health condition (specify) (9)
- ☐ Embarrassment or concern relating to my vascular anomaly (10)
- ☐ Some other reason (specify) (11)

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*Display This Question:*

*If There are many reasons why people may not have had sexual activity during the month. What are the... = Health condition (specify)*

Q23 Please specify:

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*Display This Question:*

*If There are many reasons why people may not have had sexual activity during the month. What are the... = Partner's health condition (specify)*

Q24 Please specify:

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*Display This Question:*

*If There are many reasons why people may not have had sexual activity during the month. What are the... = Some other reason (specify)*

Q25 Please specify:

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*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

**Q37 In the past 30 days**, how often were you able to get an erection (get hard) during sexual activity?

- ☐ Almost never/never (1)
- ☐ A few times (much less than half the time) (2)
- ☐ Sometimes (about half the time) (3)
- ☐ Most times (much more than half the time) (4)
- ☐ Almost always/always (5)

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*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

**Q38 In the past 30 days**, when you had erections with sexual stimulation, how often were your erections hard enough for penetration?

- ☐ Almost never/never (1)
- ☐ A few times (much less than half the time) (2)
- ☐ Sometimes (about half the time) (3)
- ☐ Most times (much more than half the time) (4)
- ☐ Almost always/always (5)

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*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

**Q39 In the past 30 days**, during sexual intercourse, how often were you able to maintain your erection (stay hard) after you had penetrated (entered) your partner?

- ☐ Did not attempt intercourse (1)
- ☐ Almost never/never (2)
- ☐ A few times (much less than half the time) (3)
- ☐ Sometimes (about half the time) (4)
- ☐ Most times (much more than half the time) (5)
- ☐ Almost always/always (6)

---

*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

**Q40 In the past 30 days**, how often have you been able to have an orgasm/climax when you wanted to?

- ☐ Have not tried to have an orgasm/climax in the past 30 days (1)
- ☐ Never (2)
- ☐ Rarely (3)
- ☐ Sometimes (4)
- ☐ Often (5)
- ☐ Always (6)

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*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

**Q41 In the past 30 days**, how satisfying have your orgasms or climaxes been?

- ☐ Have not had an orgasm/climax in the past 30 days (1)
- ☐ Not at all (2)
- ☐ A little bit (3)
- ☐ Somewhat (4)
- ☐ Quite a bit (5)
- ☐ Very much (6)

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*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

Q44 **In the past 30 days**, how much pleasure have your orgasms or climaxes given you?

- ☐ Have not tried to have an orgasm/climax in the past 30 days (1)
- ☐ None (2)
- ☐ A little bit (3)
- ☐ Some (4)
- ☐ Quite a bit (5)
- ☐ Very much (6)

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*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

Q45 **In the past 30 days**, how often have you had **discomfort or pain** in your penis or testicles during sexual activity?

- ☐ Never (1)
- ☐ Rarely (2)
- ☐ Sometimes (3)
- ☐ Often (4)
- ☐ Always (5)

---

*Display This Question:*

*If In the past 30 days, did you have any type of sexual activity? (Examples of sexual activity are... = Yes*

**Q46 In the past 30 days**, when you have had sexual activity, how much **discomfort or pain** have you had in or around your anus or rectum?

- ☐ None (1)
  - ☐ A little bit (2)
  - ☐ Some (3)
  - ☐ Quite a bit (4)
  - ☐ A lot (5)
- 

**Q47 In the past 30 days**, how satisfied have you been with your sex life?

- ☐ Not at all (1)
  - ☐ A little bit (2)
  - ☐ Somewhat (3)
  - ☐ Quite a bit (4)
  - ☐ Very (5)
- 

**Q48 In the past 30 days**, how much pleasure has your sex life given you?

- ☐ None (1)
  - ☐ A little bit (2)
  - ☐ Some (3)
  - ☐ Quite a bit (4)
  - ☐ A lot (5)
-

**Q49 In the past 30 days**, how often have you thought that your sex life is wonderful?

- ☐ Never (1)
  - ☐ Rarely (2)
  - ☐ Sometimes (3)
  - ☐ Often (4)
  - ☐ Always (5)
- 

**Q50 In the past 30 days**, how satisfied have you been with your sexual relationship(s)?

- ☐ Have not had a sexual relationship in the past 30 days (1)
  - ☐ Not at all (2)
  - ☐ A little bit (3)
  - ☐ Somewhat (4)
  - ☐ Quite a bit (5)
  - ☐ Very (6)
- 

**Q51 Do you experience pain with masturbation (stimulating your own sexual parts in order to have pleasure)?**

- ☐ Yes (1)
  - ☐ No (2)
-

*Display This Question:*

*If Do you experience pain with masturbation (stimulating your own sexual parts in order to have plea... = Yes*

Q52 Please specify:

- ☐ Always (1)
- ☐ Sometimes (2)
- 

Q53 Do you experience genital bleeding with masturbation?

- ☐ Yes (1)
- ☐ No (2)
- 

*Display This Question:*

*If Do you experience genital bleeding with masturbation? = Yes*

Q54 Please specify:

- ☐ Always (1)
- ☐ Sometimes (2)
- 

Q55 Do you experience genital bleeding with sexual intercourse?

- ☐ Yes (1)
- ☐ No (2)
- 

*Display This Question:*

*If Do you experience genital bleeding with sexual intercourse? = Yes*

Q56 Please specify:

☐ Always (1)

☐ Sometimes (2)

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Q109 We welcome any other comments.

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End of Block: Block for past 30 days questions for adult with VA

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Start of Block: Block for guardian of child with VA

**Q62 The following questions are for parents indicating their minor son has a vascular anomaly. They will be answering the questions on behalf of their son. We understand that not all young boys or adolescents discuss sexual activities with their parents. Only answer what you know. There may be many questions which you cannot answer.**

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Q63 My son has (check as many as you think apply):

☐ Hemangiomas (one or more) (1)

☐ Venous or lymphatic malformation or venous-lymphatic malformation (2)

☐ Arteriovenous malformation (3)

☐ Klippel Trenaunay Syndrome (4)

☐ Cloves (5)

☐ Proteus Syndrome (6)

☐ Other (7)

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*Display This Question:*

*If My son has (check as many as you think apply): = Other*

Q64 Please specify:

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Q65 I was told my son has this diagnosis by which of the following (check as many as apply):

☒ A specialized vascular anomalies expert or clinic (1)

☒ A primary care provider (2)

☒ Other (3)

*Display This Question:*

*If I was told my son has this diagnosis by which of the following (check as many as apply): = Other*

Q66 Please specify:

---

Q67 I can see that part or all of my son's vascular anomaly involves the skin or tissue under the skin of (check as many as apply):

- ☐ His penis (1)
  - ☐ His scrotum or testicles (2)
  - ☐ His anus (3)
  - ☐ His buttocks (4)
  - ☐ His lower belly (5)
  - ☐ The inner part of one or both of his thighs (6)
  - ☒ None of the above (7)
- 

Q68 I have been told that imaging studies such as MRI, CAT(CT) scans or ultrasounds show that my son's vascular anomaly includes his pelvis/GU area.

- ☐ Yes (1)
  - ☐ No (2)
  - ☐ I have not been told or do not now (3)
- 

*Display This Question:*

*If I have been told that imaging studies such as MRI, CAT(CT) scans or ultrasounds show that my son'... = Yes*

Q111 Please specify the area involved (Check as many that apply):

- ☐ Bladder (1)
  - ☐ Testicles (2)
  - ☐ Scrotum (3)
  - ☐ Penis (4)
  - ☐ Lower Abdomen (5)
  - ☐ Prefer not to answer or Don't Know (6)
- 

Q69 Does your son have any biological children (that is, conceived with his sperm)?

- ☐ Yes (1)
  - ☐ No (2)
- 

*Display This Question:*

*If Does your son have any biological children (that is, conceived with his sperm)? = Yes*

Q70 Did your son use natural means to get his partner pregnant?

- ☐ Yes (1)
  - ☐ No (2)
- 

*Display This Question:*

*If Did your son use natural means to get his partner pregnant? = No*

Q108 Did your son use artificial insemination to get his partner pregnant?

- ☐ Yes (1)
- ☐ No (2)

**Q71 In the past 30 days**, do you know how interested your son has been in sexual activity?

- ☐ Not at all (1)
  - ☐ A little bit (2)
  - ☐ Somewhat (3)
  - ☐ Quite a bit (4)
  - ☐ Very (5)
  - ☐ I don't know (6)
- 

**Q72 In the past 30 days**, how often has your son felt like he wanted to have sexual activity?

- ☐ Never (1)
  - ☐ Rarely (2)
  - ☐ Sometimes (3)
  - ☐ Often (4)
  - ☐ Always (5)
  - ☐ I don't know (6)
- 

**Q73 In the past 30 days**, did your son have any type of sexual activity?  
(Examples of sexual activity are masturbation, oral sex and sexual intercourse)

- ☐ Yes (1)
- ☐ No (2)

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*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = No*

Q74 There are many reasons why people may not have had sexual activity during the month. What are the reasons why your son did not have sexual activity in **the past 30 days**? Please read the list carefully and check every reason that applies to your son, even if it happened only one time during the past 30 days.

- ☐ Was not interested in having sexual activity (1)
- ☐ Difficulties with his erections (penis not hard or is painful) (2)
- ☐ Difficulties with orgasm/climax (3)
- ☐ Doesn't enjoy sexual activity (4)
- ☐ Health condition (specify) (5)
- ☐ No partner (6)
- ☐ Partner was away (7)
- ☐ Partner was not interested in sexual activity (8)
- ☐ Partner's health condition (specify) (9)
- ☐ Embarrassment or concern relating to his vascular anomaly (10)
- ☐ Some other reason (specify) (11)

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*Display This Question:*

*If There are many reasons why people may not have had sexual activity during the month. What are the... = Health condition (specify)*

Q75 Please specify:

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*Display This Question:*

*If There are many reasons why people may not have had sexual activity during the month. What are the... = Partner's health condition (specify)*

Q76 Please specify:

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*Display This Question:*

*If There are many reasons why people may not have had sexual activity during the month. What are the... = Some other reason (specify)*

Q77 Please specify:

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*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

Q87 **In the past 30 days**, how often was your son able to get an erection (get hard) during sexual activity?

- ☐ Almost never/never (1)
- ☐ A few times (much less than half the time) (2)
- ☐ Sometimes (about half the time) (3)
- ☐ Most times (much more than half the time) (4)
- ☐ Almost always/always (5)
- ☐ I don't know (6)

*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

**Q88 In the past 30 days**, when your son had erections with sexual stimulation, how often were his erections hard enough for penetration?

- ☐ Almost never/never (1)
- ☐ A few times (much less than half the time) (2)
- ☐ Sometimes (about half the time) (3)
- ☐ Most times (much more than half the time) (4)
- ☐ Almost always/always (5)
- ☐ I don't know (6)

---

*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

**Q89 In the past 30 days**, during sexual intercourse, how often was your son able to maintain his erection (stay hard) after he had penetrated (entered) his partner?

- ☐ Did not attempt intercourse (1)
- ☐ Almost never/never (2)
- ☐ A few times (much less than half the time) (3)
- ☐ Sometimes (about half the time) (4)
- ☐ Most times (much more than half the time) (5)
- ☐ Almost always/always (6)
- ☐ I don't know (7)

---

*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

Q90 **In the past 30 days**, how often has your son been able to have an orgasm/climax when he wanted to?

- ☐ Has not tried to have an orgasm/climax in the past 30 days (1)
- ☐ Never (2)
- ☐ Rarely (3)
- ☐ Sometimes (4)
- ☐ Often (5)
- ☐ Always (6)
- ☐ I don't know (7)

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*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

Q91 **In the past 30 days**, how satisfying has your son's orgasms or climaxes been?

- ☐ Has not had an orgasm/climax in the past 30 days (1)
  - ☐ Not at all (2)
  - ☐ A little bit (3)
  - ☐ Somewhat (4)
  - ☐ Quite a bit (5)
  - ☐ Very much (6)
  - ☐ I don't know (7)
-



*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

**Q92 In the past 30 days**, how much pleasure has your son's orgasms or climaxes given him?

- ☐ Has not tried to have an orgasm/climax in the past 30 days (1)
  - ☐ None (2)
  - ☐ A little bit (3)
  - ☐ Some (4)
  - ☐ Quite a bit (5)
  - ☐ Very much (6)
  - ☐ I don't know (7)
- 

*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

**Q93 In the past 30 days**, how often has your son had **discomfort or pain** in his penis or testicles during sexual activity?

- ☐ Never (1)
  - ☐ Rarely (2)
  - ☐ Sometimes (3)
  - ☐ Often (4)
  - ☐ Always (5)
  - ☐ I don't know (6)
-

*Display This Question:*

*If In the past 30 days, did your son have any type of sexual activity? (Examples of sexual activity... = Yes*

**Q94 In the past 30 days**, when your son has had sexual activity, how much **discomfort or pain** has he had in or around his anus or rectum?

- ☐ None (1)
  - ☐ A little bit (2)
  - ☐ Some (3)
  - ☐ Quite a bit (4)
  - ☐ A lot (5)
  - ☐ I don't know (6)
- 

**Q95 In the past 30 days**, how satisfied has your son been with his sex life?

- ☐ Not at all (1)
  - ☐ A little bit (2)
  - ☐ Somewhat (3)
  - ☐ Quite a bit (4)
  - ☐ Very (5)
  - ☐ I don't know (6)
-

Q96 **In the past 30 days**, how much pleasure has your son's sex life given him?

- ☐ None (1)
  - ☐ A little bit (2)
  - ☐ Some (3)
  - ☐ Quite a bit (4)
  - ☐ A lot (5)
  - ☐ I don't know (6)
- 

Q97 **In the past 30 days**, how often has your son thought that his sex life is wonderful?

- ☐ Never (1)
  - ☐ Rarely (2)
  - ☐ Sometimes (3)
  - ☐ Often (4)
  - ☐ Always (5)
  - ☐ I don't know (6)
-

Q98 **In the past 30 days**, how satisfied has your son been with his sexual relationship(s)?

- ☐ Has not had a sexual relationship in the past 30 days (1)
  - ☐ Not at all (2)
  - ☐ A little bit (3)
  - ☐ Somewhat (4)
  - ☐ Quite a bit (5)
  - ☐ Very (6)
  - ☐ I don't know (7)
- 

Q99 Does your son experience pain with masturbation (stimulating your own sexual parts in order to have pleasure)?

- ☐ Yes (1)
  - ☐ No (2)
  - ☐ I don't know (3)
- 

*Display This Question:*

*If Does your son experience pain with masturbation (stimulating your own sexual parts in order to ha... = Yes*

Q100 Please specify:

- ☐ Always (1)
  - ☐ Sometimes (2)
  - ☐ I don't know (3)
-

Q101 Does your son experience genital bleeding with masturbation?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)

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*Display This Question:*

*If Does your son experience genital bleeding with masturbation? = Yes*

Q102 Please specify:

- ☐ Always (1)
- ☐ Sometimes (2)
- ☐ I don't know (3)

Q103 Does your son experience genital bleeding with sexual intercourse?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)

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*Display This Question:*

*If Does your son experience genital bleeding with sexual intercourse? = Yes*

Q104 Please specify:

- ☐ Always (1)
- ☐ Sometimes (2)
- ☐ I don't know (3)

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Q105 We welcome any other comments.

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End of Block: Block for past 30 days questions for guardian of child with VA

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