<u>Supportive Needs Assessment tool for Cirrhosis</u> (SNAC)

INSTRUCTIONS

Having liver disease can bring many changes. We are worried that patients and their families may be left alone to cope with the problems that can arise. Please tell us about the problems you have run into, so we can help plan better services for you.

The different stages of liver disease can affect each person in different ways. Some of the needs or issues mentioned here may never affect your situation.

For every question on this form, please tell us whether you had this issue or concern within <u>the past month</u> because of your liver disease. There are two possible answers: <u>YES</u> or <u>NO</u>

<u>If you answered YES</u>, tell us how much <u>additional help</u> you needed because of this issue in **the past month**. There are four possible answers to choose from:

- **None -** I did need help with this, but I received help. So I don't need additional help.
- A little This caused me concern or discomfort. I have or had a little need for additional help.
- Some This caused me concern or discomfort. I have or had some need for additional help
- A lot This caused me concern or discomfort. I have or had a lot more need for additional help

<u>If you answered NO</u>, do not answer the question about <u>additional help</u>. Move on to the next question. We have listed a few examples of how to show your answer.

| | camples | How much additional help did/do you need? | | | | | |
|---|---|---|------|----------|------|-------|--|
| With respect to symptoms and managing your liver disease, in the <u>past month</u> , did you: | | | None | A little | Some | A lot | |
| 1. | Have ascites (fluid build up in the abdomen/belly) | 2 No ₁○ Yes → | 10 | 2 | 3 | 40 | |
| 2. | Make lifestyle changes to increase exercise, lose weight, stop or limit alcohol | 2○ No 1 Yes → | 10 | 2 | 3 | 40 | |
| In example 1, you did not have ascites in the past month so this is not an issue for you. Therefore you did not need any help with this. | | | | | | | |
| In example 2, you needed to change your lifestyle to increase exercise, and you did not receive as much help as you wanted to assist you with changing your lifestyle. Therefore you needed some more help with this. | | | | | | | |

| With respect to day-to-day activities that may be affected by your liver | | | | How much additional help did/do you need? | | | |
|--|--|----------------|----------|---|-------|---|--|
| disease, in the <u>past month</u> , did you: | | None | A little | Some | A lot | | |
| 1. | Have extra costs involved in managing your liver condition | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 | |
| 2. | Have any issues with transport getting to and from medical appointments for your liver condition | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 | |
| 3. | Have difficulty with daily tasks around the house (e.g. washing, cooking, raking the yard, sweeping the floor) | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 | |
| 4. | Have trouble making a medical appointment or filling in forms due to language barriers | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 | |
| 5. | Did your job performance decrease because of your health | 2○ No 1○ Yes→ | 10 | 2 | 3 | 4 | |

| Wit | h respect to symptoms and managing your liver disease, | | How much additional help did/do you need? | | | |
|---|--|---|---|--|---|----------------|
| in t | he <u>past month</u> , did you: | | None | A little | Some | A lot |
| 6. | Feel unwell | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| 7. | Have lack of energy, tiredness | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 |
| 8. | Sleep poorly | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 |
| 9. | Have confusion, disorientation, personality changes | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| 10. | Have decreased ability to get around | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| 11. | Have swelling of the ankles and legs | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| 12. | Have itchy skin | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 |
| 13. | Have loss of appetite, nausea or vomiting | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| 14. | Have ascites (fluid build up in the abdomen/belly) | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 |
| 15. | Have easy bruising, bleeding, thinning of the skin | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| 16. | Have side effects of treatment (e.g. frequent or loose bowel motions, bloating and abdominal discomfort) | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| 17. | Make lifestyle changes to increase exercise, lose weight, stop or limit alcohol | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 |
| 18. | Make diet changes (e.g. low salt diet or decrease portion size) | 2○ No 1○ Yes→ | 1 | 2 | 3 | 4 |
| | | | How much additional help did/do you need? | | | • |
| Wit | h respect to how you have been feeling, in the past mont | h did you: | | | | |
| | | <u></u> , ulu you. | None | A little | Some | A lot |
| 19. | Have fear of the unknown or uncertainty about the future | , did you. 2○ No 1○ Yes → | None | A little | Some 3 | A lot |
| | Have fear of the unknown or uncertainty about the future Have any feelings about death and dying | | _ | _ | _ | _ |
| | · | 2○ No 1○ Yes → | 1 | 2 | 3 | 4 |
| 20. | Have any feelings about death and dying | 2○ No 1○ Yes → 2○ No 1○ Yes → | 10 | 2 2 | 3 0 | 40 |
| 20. 21. | Have any feelings about death and dying Feel down or depressed | 2 No 1 Yes → 2 No 1 Yes → 2 No 1 Yes → | 10 | 2 2 2 | 3 3 3 | 40 |
| 20. 21. 22. | Have any feelings about death and dying Feel down or depressed Feel lonely | 2○ No 1○ Yes → | 1 1 1 1 | 2 2 2 2 2 | 3 3 3 3 | 40 |
| 20.21.22.23. | Have any feelings about death and dying Feel down or depressed Feel lonely Feel confused about managing your liver condition | 2 No 1 Yes → | 1 O 1 O 1 O 1 O | 2 2 2 2 2 2 2 | 3 O 3 O 3 O 3 O | 40 |
| 20.21.22.23.24. | Have any feelings about death and dying Feel down or depressed Feel lonely Feel confused about managing your liver condition Feel frustrated | 2 No 1 Yes → | | 2 2 2 2 2 2 2 2 | 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O | 40 40 40 40 40 |
| 20.21.22.23.24.25. | Have any feelings about death and dying Feel down or depressed Feel lonely Feel confused about managing your liver condition Feel frustrated Have anxiety and/or stress | 2○ No 1○ Yes → | | 2 | 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O | 4 |
| 20.21.22.23.24.25.26. | Have any feelings about death and dying Feel down or depressed Feel lonely Feel confused about managing your liver condition Feel frustrated Have anxiety and/or stress Have aggression, irritability, anger | 2 No 1 Yes → | | 2 | 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O | 4 |
| 20.21.22.23.24.25.26.27. | Have any feelings about death and dying Feel down or depressed Feel lonely Feel confused about managing your liver condition Feel frustrated Have anxiety and/or stress Have aggression, irritability, anger Have lack of interest, no "get up and go" | 2 No 1 Yes → | | 2 \(\) 2 \(\ | 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O | 4 |
| 20.21.22.23.24.25.26.27.28. | Have any feelings about death and dying Feel down or depressed Feel lonely Feel confused about managing your liver condition Feel frustrated Have anxiety and/or stress Have aggression, irritability, anger Have lack of interest, no "get up and go" Feel ashamed or embarrassed because of social stigma | 2 No 1 Yes → | | 2 \(\) 2 \(\ | 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O | 4 |
| 20.21.22.23.24.25.26.27.28.29. | Have any feelings about death and dying Feel down or depressed Feel lonely Feel confused about managing your liver condition Feel frustrated Have anxiety and/or stress Have aggression, irritability, anger Have lack of interest, no "get up and go" Feel ashamed or embarrassed because of social stigma Have fears about losing your independence | 2 No 1 Yes → | | 2 \(\) 2 \(\ | 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O 3 O | 4 |

PLEASE NOTE THAT THIS SECTION IS DIFFERENT

In this section, you should answer parts a) and b) for every question. Please answer <u>YES</u> or <u>NO</u> to part a). Then also answer part b) to tell us how much additional help you need. Here are two examples:

| | <u>Examples</u> | | | |
|---|---|--|--|--|
| | With respect to information about liver disease, in the past month, did you: | | | |
| | a) Have the benefits and side-effects of treatments explained 1 Yes 2 No b) How much additional help did/do you need? 1 None 2 A little 3 Some 4 A lot | | | |
| | a) Access professional help/counselling (e.g. from social worker, psychologist, nurse specialist) 1 Yes 2 No 2. b) How much additional help did/do you need? 1 None 2 A little 3 Some 4 A lot | | | |
| | In example 1, it means that you received information about the benefits and side-effects of treatments, but you felt that the information received was not enough. Therefore you needed some more help with this. In example 2, it means that you have not received information about how to access professional help/counselling such as with a social worker, psychologist, or nurse specialist, but you felt that you did not need to access any of these health professionals. Therefore you did not need any more help with this. | | | |
| With | n respect to information about liver disease, in the <u>past month</u> , did you: | | | |
| 33. | a) Obtain information to use at home about how to manage your illness and complications 1 Yes 2 No b) How much additional help did/do you need? 1 None 2 A little 3 Some 4 A lot | | | |
| 34. | a) Have tests/procedures explained $_1$ Yes $_2$ No b) How much additional help did/do you need? $_1$ None $_2$ A little $_3$ Some $_4$ A lot | | | |
| 35. | a) Have the benefits and side-effects of treatments explained $_1$ Yes $_2$ No b) How much additional help did/do you need? $_1$ None $_2$ A little $_3$ Some $_4$ A lot | | | |
| 36. | a) Access professional help/counselling (e.g. from a social worker, psychologist, nurse specialist) 1 Yes 2 No b) How much additional help did/do you need? 1 None 2 A little 3 Some 4 A lot | | | |
| 37. | a) Know who to call and when to call for medical help $_1$ Yes $_2$ No b) How much additional help did/do you need? $_1$ None $_2$ A little $_3$ Some $_4$ A lot | | | |
| 38. | a) Were you informed about things you can do to help yourself to get well $_1$ Yes $_2$ No b) How much additional help did/do you need? $_1$ None $_2$ A little $_3$ Some $_4$ A lot | | | |
| 39. | a) Were you informed about support groups in your area $_1$ Yes $_2$ No b) How much additional help did/do you need? $_1$ None $_2$ A little $_3$ Some $_4$ A lot | | | |
| 40. With respect to your liver disease, were there any other things that you needed additional help with in the past month that we have not asked you about? IF YES, please tell me about them. | | | | |
| Ø | | | | |

| Extra space for question 40 or comments. | |
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| Thank you for co | mpleting this form! |
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There is no charge for administering the Supportive Needs Assessment tool for Cirrhosis (SNAC). Any publications that describe the use of SNAC should cite the following publication:

Valery PC, Bernardes CM, Stuart KA, Hartel G, McPhail SM, Skoien R, Rahman T, Clark PJ, Horsfall L, Hayward K, Gupta R, Powell EE. Development and evaluation of the Supportive Needs Assessment tool for Cirrhosis (SNAC). *Patient Preference & Adherence*. In Press 2020. doi: 10.2147/PPA.S236818.

Requests for information about the administration, scoring and analysis procedures should be addressed to: Patricia.Valery@gimrberghofer.edu.au