

Patient questionnaire from "Institutet för kvalitetsindikatorer" /The institute for quality indicators/. The questionnaire may be used for research and similar purposes, but not for commercial purposes /statement by Mr Lars Fallberg; lars.fallberg@indikator.org/.

If you use this form, please state that the source is *Insitutet for kvalitetsindikatorer AB, Gothenburg, Sweden*. Mr Lars Tocklin, lars.tocklin@sll.se, a representative of the County of Stockholm, would also like to be informed by e-mail when this form is used.

I have arbitrarily called palliative care in the patient's home AMIH, Advanced Medical care in the Home. In the answers, I have omitted the boxes that the patient ticks for Q 1-26.

(Only tick one box for each question)

Q 1 Were you satisfied with the information given to you about AMIH when you were enrolled or during the first days (i e what AMIH can do for you, phone numbers, etc.)

A 1 a/ Yes, completely b/ Partly c/ No d/ I was in no condition to take in any information e/ I needed no information

Q 2 Have you been given the technical aids that you need?

A 2 a/ Yes, completely b/ Partly c/ No d/ I have no need for technical aids

Q 3 How is the availability of the AMIH team on the phone?

A 3 a/ Excellent b/ Very good c/ Good d/ Allright e/ Poor f/ I've never phoned AMIH

Q 4 When you ask the team to help you, do they come within the time you have agreed upon?

A 4 a/ Yes, always or nearly always b/ Sometimes c/ No d/ I haven't asked them

Q 5 Can you get in touch immediately and get help from the AMIH team around the clock?

A 5 a/ Yes, always or nearly always b/ Sometimes, it varies c/ No, seldom or never d/ I haven't called them

Q 6 Is it usually the same persons from the AMIH team that care for/treat you in your home?

A 6 a/ Yes, always or nearly always b/ Sometimes, it varies c/ No, seldom or never

Q 7 Is it important to you that only a few persons from the AMIH team visit you in your home?

A 7 a/ Yes, it's very important b/ Yes, it's fairly important c/ No, it's not important

Q 8 Have you had enough help from the team regarding relief from pain?

A 8 a/ Yes, completely b/ Partly c/ No d/ I haven't asked for help e/ I have no pain

Q 9 If you've been worried or anxious, have you had adequate help from the team, such as someone to talk to, medication, or both?

A 9 a/ Yes, fully b/ Partly c/ No d/ I haven't asked for help e/ I haven't been worried or anxious

Q 10 If you've had other symptoms, such as nausea or shortness of breath, have you gotten enough help from the AMIH?

A 10 a/ Yes, completely b/ Partly c/ No d/ I haven't asked for help e/ I haven't had nausea, shortness of breath or other symptoms

Q 11 When you ask the staff about something that is important to you, do you understand the answers that you get?

A 11 a/ Yes, always or nearly always b/ Sometimes c/ No d/ I've been afraid to ask e/ I haven't had any questions

Q 12 If you want to talk to someone at the AMIH, do you have the opportunity to do that?

A 12 a/ Yes, always or nearly always b/ Sometimes c/ No d/ I haven't had any need to talk to them

Q 13 Do you feel confidence in the staff from the AMIH who care for you in your home?

A 13 a/ Yes, fully b/ Partly c/ No

Q 14 Do you feel that you can influence decisions that are made about the care you get in your home?

A 14 a/ Yes, completely b/ Partly c/ No

Q 15 Do the staff show respect for your knowledge and the experience you have of your illness?

A 15 a/ Yes, completely b/ Partly c/ No d/ This hasn't been an issue

Q 16 Does your family get enough support and help from the AMIH?

A 16 a/ Yes, completely b/ Partly c/ No d/ This hasn't been an issue

Q 17 Has your family been given the opportunity to take part in planning so that care is given in your home according to your wishes?

A 17 a/ Yes, completely b/ Partly c/ No d/ This hasn't been an issue

Q 18 Do you get enough information about your condition?

A 18 a/ Yes, completely b/ Partly c/ No d/ I don't need any information

Q 19 Do you feel that you are being treated with respect and consideration?

A 19 a/ Yes, fully b/ Partly c/ No

Q 20 On the whole, how do you rate the care/treatment that you've received through the AMIH?

A 20 a/ Excellent b/ Very good c/ Allright d/ Not too bad e/ Poor

Q 21 What is your sex?

A 21 a/ Man b/ Woman

Q 22 What year were you born? _____

Q 23 Is Swedish your native tongue?

A 23 a/ Yes b/ No

Q 24 What education do you have?

A 24 a/ Elementary school (9 years in Sweden) b/ High school (3 years in Sweden) c/ University degree

Q 25 What is your current family situation?

A 25 a/ Living with a spouse/ partner b/ Living alone c/ My daughter/son/siblings are staying with me while I'm in the care of the AMIH d/ Someone else is living with me while I'm in the care of the AMIH

Q 26 In what manner have you answered the questions in this questionnaire?

A 26 a/ By myself b/ Partly with the help of another person c/ Entirely with the help of another person

Finally

Q 27 Is there something still bothering you (symptoms, practical issues, other things) that the AMIH haven't been able to help you with? What can the AMIH improve?

Q 28 It's not possible to ask about everything in a questionnaire. We welcome other comments that you may have