

H-CARE Pilot Survey

Core questions of the survey

Caregiver Assessment of Care for Rare and Complex Diseases

Over the past 6 months, when the person I care for received medical care for his/her rare or complex disease, I was:

Please don't answer the questions that don't correspond to your situation.

	(1) None of the Time	(2) A Little of the Time	(3) Some of the Time	(4) Most of the Time	(5) Always
1. Given choices about treatments to think about					
2. Satisfied that his/her care was well organized					
3. Helped to set specific goals to improve his/her eating or exercise					
4. Given a copy of his/her treatment plan*					
5. Encouraged to go to a specific group or class to help me cope with his/her rare or complex disease					
6. Asked questions, either directly or on a survey, about his/her health habits					
7. Helped to make a treatment plan* that he/she could do in his/her daily life					
8. Helped to plan ahead so I could take care of his/her rare or complex disease even in hard time					
9. Asked how his/her rare or complex disease affects HIS/HER life					
10. Asked how his/her rare or complex disease affects MY life					
11. Contacted after a visit to see how things were going					
12. Told how my visits with other specialists, like a geneticist or					

This is an initiative of:

cardiologist, helped his/her treatment					
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*A treatment plan is a list, made with your care team, of what needs to be done to take care of your health

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Over the past 6 months, would you say that the health care professionals of the unit you are assessing:

	(1) None of the Time	(2) A Little of the Time	(3) Some of the Time	(4) Most of the Time	(5) Always
12. Helped YOU deal with emotions related to the health status of the person you care for					
13. Helped the person you care for deal with emotions related to HIS/HER health status					

Regarding the care the person you care for has received over the past 6 months in the unit you are assessing, are you satisfied with:

	(1) Very dissatisfied	(2) Dissatisfied	(3) Neutral	(4) Satisfied	(5) Very satisfied	Not applicable
13. The outcomes of his/her care and/or treatments						
14. The information you had on the benefits and risks of his/her care and/or treatments						
15. All in all, the care he/she received in this service / unit / centre						

Is there anything you want to add concerning the care you receive for your rare or complex disease in this unit? (Open comment)

[For caregivers of diagnosed patients only]

How long after you first sought medical advice did the person you care for get a confirmed diagnosis of a rare or a complex disease?

For example, if you got a confirmed diagnosis 1 year and 6 months after you first sought medical advice, you can write "1" in the Years box and "6" on the Months box.

> Years:

> Months:

> I don't remember ; Other ; If 'Other', please specify:

Was a genetic test performed before a diagnosis was given or to confirm a diagnosis?

> Yes, to the patient ; Yes, the patient and his/her first degree relatives ; No ; Not applicable

This is an initiative of: