

H-CARE Pilot Survey

Core questions of the survey

Patient Assessment of Care for Rare and Complex Diseases (for patients above 12 years old)

Over the past 6 months, when receiving medical care for my 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 my care was well organized					
3. Helped to set specific goals to improve my eating or exercise					
4. Given a copy of my treatment plan*					
5. Encouraged to go to a specific group or class to help me cope with my rare or complex disease					
6. Asked questions, either directly or on a survey, about my health habits					
7. Helped to make a treatment plan* that I could do in my daily life					
8. Helped to plan ahead so I could take care of my rare or complex disease even in hard time					
9. Asked how my rare or complex disease affects my life					
10. Contacted after a visit to see how things were going					
11. Told how my visits with other specialists, like a geneticist or cardiologist, helped my treatment					

*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 your health status					

Regarding the care you 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 your care and/or treatments						
14. The information you had on the benefits and risks of your care and/or treatments						
15. All in all, the care you 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 service / unit / centre? (*Open comment*)

[For diagnosed patients only]

How long after you first sought medical advice did you 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 me ; Yes, to me and my first degree relatives ; No ; Not applicable

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