Appendix 1. Survey (translated from the original Norwegian version)

Version 1: No specific information about disease severity or treatment effectiveness (No Info)

Screen 1: Introduction

In recent years, genetic research has led to the development of new medications for treatment of rare diseases. If these drugs are approved for reimbursement, there may be fewer resources available for other treatments. We would like to have your opinions about which treatments should be covered by the National health services. There are no "right" answers to these questions. They are designed to provide us with a better understanding of societal values.

Screen 2: Question 1

Imagine that the health authorities have received extra funds that can be used to treat 100 patients. The health authorities must decide which of two similar diseases should be treated: Disease A, which is a very rare (100 cases in Norway) or Disease B, which is a more common disease (10,000 cases in Norway). How do you think the extra funds should be used?

❍ Treatment of 100 patients with Disease A (rare disease)
❍ Treatment of 100 patients with Disease B (common disease)
❍ Indifferent

Screen 3: Question 2

If it were possible to divide the extra funds so that both patients with Disease A (rare disease) and patients with Disease B (common disease) could be treated, how would you recommend that the extra funds be divided?

*Allocate 100 patients for treatment by clicking on and dragging the green and white pointer.**

	All for Disease A100 (100)	90 (90)	80 (80)	70 (70)	60 (60)	Equal division (50/50) (50)	60 (40)	70 (30)	80 (20)	90 (10)	All for Disease B B100 (0)	
Disease A	❍	❍	❍	❍	❍	❍	❍	❍	❍	❍	❍	Disease B

* Respondents saw a continuous bar with numbers indicating how many patients from each group could receive treatment, but the pointer could only be moved to the points indicated by circles above.

Screen 4: Question 3

Now imagine that it is less expensive to treat Disease B than Disease A. With the extra funds it is now possible to treat 100 patients with Disease A or 400 patients with Disease B. Otherwise, is everything the same as before. Disease A is a rare disease (100 cases in Norway) and Disease B is a more common disease (10,000 cases in Norway). How do you think that the extra funds should be used?

❍ Treatment of 100 patients with Disease A (rare disease)
❍ Treatment of 400 patients with Disease B (common disease)
❍ Indifferent

Screen 5: Question 4

If it were possible to divide the extra funds so that both patients with Disease A (rare disease) and patients with Disease B (common disease) could be treated, how would you recommend that the extra funds be divided?

Allocate patients for treatment by clicking on and dragging the green and white pointer (see note above).

	Disease A:100 Disease B:0 (100)	9040 (90)	8080 (80)	70120 (70)	60160 (60)	50200 (50)	40240 (40)	30280 (30)	20320 (20)	10360 (10)	Disease A:0 Disease B:400 (0)
	❍	❍	❍	❍	❍	❍	❍	❍	❍	❍	❍

Screen 6: Questions 5 - 9

How much do you agree or disagree with the following statements?

	Completely disagree 1	2	3	4	Completely agree 5	Don't know
Everyone should have equal access to health care regardless of the cost.	◯	◯	◯	◯	◯	◯
Health authorities should uses resources to achieve the largest health benefits.	◯	◯	◯	◯	◯	◯
The health budget should be used so that patients with the most serious illnesses receive treatment even if they don't experience the largest health improvements.	◯	◯	◯	◯	◯	◯
Patients with rare diseases should have the same right to treatment as others even if the treatments are more expensive.	◯	◯	◯	◯	◯	◯
The health budget should be used so that patients who can receive the largest improvements receive treatment even if they don't have serious illnesses.	◯	◯	◯	◯	◯	◯

Versions 2 - 5: Same as Version 1, but includes additional text in Screens 2 and 4 describing disease severity and expected treatment effectiveness. The extra language follows the sentence describing disease prevalence.

Version 2: Diseases A and B are equally serious. Patients have difficulty moving about and experience extreme pain. The treatment for both diseases involves an injection every other week. The expected effects of treatment in both cases are that the patient will be pain-free and will be able to move about normally.

Version 3: Diseases A and B are equally serious. Patients have difficulty moving about and experience extreme pain. The treatment for both diseases involves an injection every other week. The expected effects of treatment in both cases are that the patient will be have difficulty moving about and will experience some pain.

Version 4: Diseases A and B are equally serious. Patients have difficulty moving about and experience some pain. The treatment for both diseases involves an injection every other week. The expected effects of treatment in both cases are that the patient will be pain-free and will be able to move about normally.

Version 5: Diseases A and B are equally serious. Patients have difficulty moving about and experience some pain. The treatment for both diseases involves an injection every other week. The expected effects of treatment in both cases are that the patient will have difficulty moving about will be pain-free.

Version 6 ("fixed funds" frame) has the same disease descriptions as Version 2 but changes the text for Screens 2 - 5 as follows:

Screen 2: Imagine that there is a new treatment for Disease A, which is a rare disease (100 case in Norway). In order to have enough funds to treat 100 patients with Disease A, the authorities must eliminate funding for 100 patients with Disease B, a common disease (10,000 cases in Norway).

◯ 100 patients with Disease A should receive the new treament even though 100 patients with Disease B will lose treatment.

◯ The number of patients receiving treatment for Disease B should not be reduced even though the 100 patients with Disease A will not receive treatment.

◯ Indifferent

Screen 3: If it were possible to treat a portion of the patients with Disease A (rare) by reducing the same number of patients currently receiving treatment for Disease B (common), what would you recommend?

Screens 4 and 5 have parallel wording to Screens 2 and 3.