

Discrepancy between health care rationing at the bedside and policy level

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Appendix (Experiment instructions)

A. Policy condition

Health care decision making [Instructions]

This is a study about health care decision making.

In this survey, you take on the role of head of department in a hospital. You will read twelve different scenarios. In each scenario, you will decide whether the hospital should offer a particular medical treatment.

- If you choose not to offer the treatment, the money will fund other treatments in the hospital.
- You should only consider information that is provided in the scenario. Assume that there are no side effects of the treatment unless explicitly stated in the scenario.
- There are no right or wrong answers

Collected material will be handled confidentially. Results will only be analyzed at group level and use solely for scientific purposes.

The ovarian cancer scenario [life-saving]

You are head of department in a hospital. It has been suggested to you that the hospital should grant Huxol (a drug) to patients with advanced ovarian cancer who experience a relapse after chemotherapy treatment and two rounds of radiation therapy.

Huxol is a new ovarian cancer drug. There is little clinical evidence for its effectiveness. Only one study has been conducted, showing positive results from treatment with Huxol. This form of treatment costs 2 000 000 SEK [≈USD 250,000] more than the standard treatment with chemotherapy and radiation therapy.

The alternative is to let the money fund other treatments in the hospital.

Do you approve the suggestion to grant Huxol to patients with ovarian cancer relapse?

- ☐ Yes
 - ☐ No
-

The brain tumor scenario [life-saving]

You are head of department in a hospital. You will decide whether the hospital should offer brain surgery to patients diagnosed with a malignant brain tumor. Without surgery, patients survive on average six months after having been diagnosed with this condition.

The only type of surgery currently available for this type of brain tumor is very risky. The chance of survival and regaining full health is 10%. Surgery costs 2 000 000 SEK [≈USD 250,000] per patient.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer brain surgery to patients diagnosed with this type of malignant brain tumor?

☐ Yes

☐ No

The heart disease scenario [life-saving]

You are head of department in a hospital. You will decide whether the hospital should introduce an alternative form of treatment for patients who are born with an incurable heart disease.

With standard treatment children with this incurable heart disease survive to their teenage years. The alternative treatment prolongs the life of a child by ten more years. This form of treatment costs 500 000 SEK [≈USD 62,500] per year more than the standard.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to introduce the alternative form of treatment?

- ☐ Yes
 - ☐ No
-

The prostate cancer scenario [life-saving]

You are head of department in a hospital. You will decide whether the hospital should offer surgery to patients with prostate cancer with difficult-to-reach tumors.

Difficult-to-reach tumors cannot always be successfully removed through surgery, but it is still possible to slow down progression and relieve symptoms with radiation therapy. The chance of successful surgery and recovery to full health is 20%. One surgical intervention costs 800 000 SEK [≈USD 100,000] more than one round of radiation therapy.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer surgery to patients with difficult-to-reach tumors?

- ☐ Yes
 - ☐ No
-

The prenatal birth scenario [life-saving]

You are head of department in a hospital. You will decide whether the hospital should offer intensive care to children prematurely born in week 22.

Children prematurely born in week 22 that are given intensive care treatment survive in 26% of cases. There is a high risk of permanent disability among children who survive the treatment. Intensive care treatment costs 35 000 SEK [≈USD 4,375] per day. The total cost often exceeds 10 million SEK.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer intensive care to children prematurely born in week 22?

- ☐ Yes
 - ☐ No
-

The COPD scenario [QoL-improving]

You are head of department in a hospital. You will decide whether the hospital should offer lung volume reduction surgery (LVRS) to patients who suffer from advanced-stage Chronic Obstructive Pulmonary Disease (COPD), caused by many years of smoking.

Clinical studies have shown LVRS to increase lung capacity with 15% on average among patients suffering from advanced-stage COPD. The intervention does not affect life expectancy. LVRS costs 300 000 SEK [≈USD 37,500] per patient.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer LVRS?

- ☐ Yes
 - ☐ No
-

The hyperhidrosis scenario [QoL-improving]

You are head of department in a hospital. You will decide whether the hospital should offer surgery to hyperhidrosis patients (suffering from excessive sweating) who have undergone treatment with injections for at least five years.

Injections with Botulinum toxin is the standard method for treating Hyperhidrosis. Each injection costs 3000 SEK [≈USD 375] and is effective for three to twelve months. Surgery, in contrast, gives a permanent effect and costs 175 000 SEK [≈USD 21,875].

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer surgery to patients suffering from Hyperhidrosis?

- ☐ Yes
 - ☐ No
-

The hearing impairment scenario [QoL-improving]

You are head of department in a hospital. You will decide whether the hospital should offer two hearing implants (one for each ear) to patients born without hearing.

Each hearing implant including surgery costs 500 000 SEK [≈USD 62,500]. Since hearing is only marginally improved by adding a second implant, the standard treatment is to offer one implant only.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer two implants per patient?

- ☐ Yes
 - ☐ No
-

The Alzheimer scenario [QoL-improving]

You are head of department in a hospital. You will decide whether the hospital should offer Taxil (a new drug) to patients suffering from Alzheimer's disease.

Taxil is a new drug that is said to better relieve symptoms of the disease compared to the standard medication for Alzheimer. The few studies conducted so far have shown a marginal improvement compared to standard medication. Taxil costs 200 000 SEK [≈USD 25,000] more per year than the standard medication.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer Taxil to patients suffering from Alzheimer?

- ☐ Yes
 - ☐ No
-

The diabetes scenario [QoL-improving]

You are head of department in a hospital. You will decide whether the department should provide an insulin pump to all patients with diabetes type I.

With an insulin pump, the patient can live a more comfortable and flexible life. In the current situation insulin pumps are only offered to patients where the injection treatment is problematic. The insulin pump costs 40 000 SEK [≈USD 5 000]. In addition, there is a cost of 25 000 SEK [≈USD 3,125] more per patient per year than standard treatment with injections.

The alternative is that the money is used to fund other treatments in the hospital.

Do you choose to offer insulin pumps to patients with type I diabetes?

- ☐ Yes
 - ☐ No
-

The growth disorder scenario [QoL-improving]

You are head of department in a hospital. You will decide whether the hospital should offer growth hormone therapy to unusually short children around the age of ten.

Growth hormone therapy given to ten-year-old children increases their adult height by approximately three cm. The treatment consists of daily injections until the child reaches full skeletal maturity, around the age of twenty. This form of treatment costs 200 000 SEK [≈USD 25,000] per year.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to offer growth hormone therapy to unusually short children?

- ☐ Yes
 - ☐ No
-

The blood disease scenario

Some middle aged women have a particular incurable blood condition. With treatment they are expected to live between 5 and 10 years without symptoms, and then die.

Suppose there is a medication that could be added to their therapy that has been shown to be of benefit, although sometimes it makes things worse. With the additional medication it is expected that 85% of women with this condition will gain 2 more years of life, and 15% of the women will lose 4 years of life.

If you were asked to give your opinion which treatment would you recommend in this situation?

Strongly recommend that they take the medication

Suggest that they take the medication

Suggest that they not take the medication

Strongly recommend that they not take the medication

B. Bedside condition

Health care decision making [Instructions]

This is a study about health care decision making.

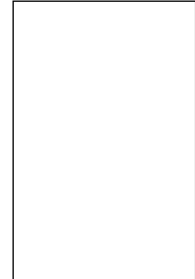
In this survey, you take on the role of a physician. You will read twelve different scenarios. In each scenario, one of your patients come to you and asks for a particular medical treatment. You will decide whether to offer the treatment to your patient.

- If you choose not to offer the treatment, the money will fund other treatments in the hospital.
- You should only consider information that is provided in the scenario. Assume that there are no side effects of the treatment unless explicitly stated in the scenario.
- There are no right or wrong answers

Collected material will be handled confidentially. Results will only be analyzed at group level and use solely for scientific purposes.

The ovarian cancer scenario [life-saving]

You are a doctor. Your patient Petra is 34 years old and she has advanced ovarian cancer. She has been treated with chemotherapy and two rounds of radiation therapy but is now experiencing a relapse. She asks you for treatment with Huxol (a drug) instead of another round of standard radiation therapy.



Petra, 34 years

Huxol is a new ovarian cancer drug. There is little clinical evidence for its effectiveness. Only one study has been conducted, showing positive results from treatment with Huxol. This form of treatment costs 2 000 000 SEK [≈USD 250,000] more than the standard treatment with chemotherapy and radiation therapy.

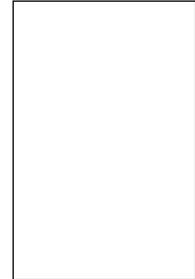
The alternative is to let the money fund other treatments in the hospital.

Do you choose to give Huxol to Petra who is experiencing an ovarian cancer relapse?

- ☐ Yes
- ☐ No

The brain tumor scenario [life-saving]

You are a doctor. Your patient Göran is 60 years old and he has been diagnosed with a malignant brain tumor. Without treatment, he is expected to survive for another six months. Brain surgery is the only treatment option available.



Göran, 60 years

The only type of surgery currently available for this type of brain tumor is very risky. The chance of survival and regaining full health is 10%. Surgery costs 2 000 000 SEK [≈USD 250,000] per patient.

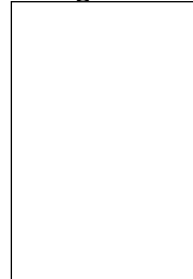
The alternative is to let the money fund other treatments in the hospital.

Do you choose surgical removal of Göran's malignant brain tumor?

- ☐ Yes
- ☐ No

The heart disease scenario [life-saving]

You are a doctor. Your patient Signe is 1 year old and suffers from a congenital and incurable heart disease. Signe's parents come to you and tell you that they have heard about an alternative form of treatment. The parents ask you to give the treatment to their daughter.



With standard treatment children with this incurable heart disease survive to their teenage years. The alternative treatment prolongs the life of a child by ten more years. This form of treatment costs 500 000 SEK [≈USD 62,500] per year more than the standard.

Signe, 1 year

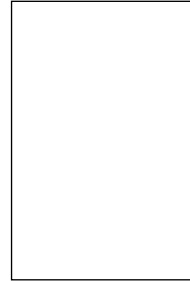
The alternative is to let the money fund other treatments in the hospital.

Do you choose to give Signe the alternative treatment?

- ☐ Yes
- ☐ No

The prostate cancer scenario [life-saving]

You are a doctor. Your patient Kenneth is 46 years old and he has been diagnosed with prostate cancer with a difficult-to-reach tumor. Kenneth comes to you and asks for surgical removal of the tumor.



Kenneth, 46 years

Difficult-to-reach tumors cannot always be successfully removed through surgery, but it is still possible to slow down progression and relieve symptoms with radiation therapy. The chance of successful surgery and recovery to full health is 20%. One surgical intervention costs 800 000 SEK [≈USD 100,000] more than one round of radiation therapy.

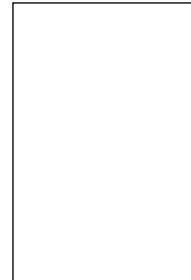
The alternative is to let the money fund other treatments in the hospital.

Do you choose surgical removal of Kenneth's difficult-to-reach tumor?

- ☐ Yes
- ☐ No

The prenatal birth scenario [life-saving]

You are a doctor. You have just delivered a child prematurely born in week 22. The birth was difficult. The parents have named their child Elsa and she has been placed in an infant incubator. The parents are very worried that their daughter will not survive. The father, Mikael, asks you to provide intensive care to Elsa.



Elsa, newborn

Children prematurely born in week 22 that are given intensive care treatment survive in 26% of cases. There is a high risk of permanent disability among children who survive the treatment. Intensive care treatment costs 35 000 SEK [≈USD 4,375] per day. The total cost often exceeds 10 million SEK.

The alternative is to let the money fund other treatments in the hospital.

Do you choose to give intensive care to Elsa?

- ☐ Yes
- ☐ No

The COPD scenario [QoL-improving]

You are a doctor. Your patient Jörgen is 53 years old and he suffers from Chronic Obstructive Pulmonary Disease (COPD), caused by many years of smoking. Lately, his symptoms have worsened, to the point where performing even everyday activities makes him feel out of breath. Jörgen comes to you and asks for lung volume reduction surgery (LVRS).



Jörgen, 53 years

Clinical studies have shown LVRS to increase lung capacity with 15% on average among patients suffering from advanced-stage COPD. The intervention does not affect life expectancy. LVRS costs 300 000 SEK [≈USD 37,500] per patient.

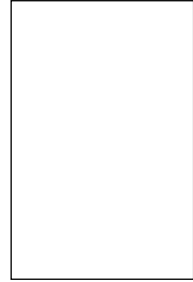
The alternative is to let the money fund other treatments in the hospital.

Do you choose to give Jörgen LVRS?

- ☐ Yes
- ☐ No

The hyperhidrosis scenario [QoL-improving]

You are a doctor. Your patient Andreas is 26 years old and he suffers from Hyperhidrosis (excessive sweating). During the last five years, he has undergone treatment with injections. Andreas comes to you and asks for a surgery in order to avoid repeated needle sticks.



Andreas, 26 years

Injections with Botulinum toxin is the standard method for treating Hyperhidrosis. Each injection costs 3000 SEK [≈USD 375] and is effective for three to twelve months. Surgery, in contrast, gives a permanent effect and costs 175 000 SEK [≈USD 21,875].

The alternative is to let the money fund other treatments in the hospital.

Do you choose to give surgery to Andreas?

- ☐ Yes
- ☐ No

The hearing impairment scenario [QoL-improving]

You are a doctor. Your patient Emil is 7 years old and he was born without hearing. Due to a hearing implant he can now hear with his right ear. Lately, Emil has begun to question why he only has a single implant and thus can hear with one ear only. Emil's parents come to you and ask you to give a second implant to their son, one for his left ear.



Emil, 7 years

Each hearing implant including surgery costs 500 000 SEK [≈USD 62,500]. Since hearing is only marginally improved by adding a second implant, the standard treatment is to offer one implant only.

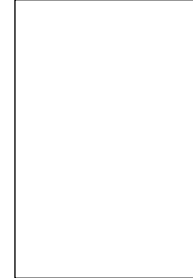
The alternative is to let the money fund other treatments in the hospital.

Do you choose to give Emil an additional implant?

- ☐ Yes
- ☐ No

The Alzheimer scenario [QoL-improving]

You are a doctor. Your patient Britta is 56 years old and she suffers from Alzheimer's disease. Her disease is gradually getting worse. Because of her disease, she is getting more confused and she is finding it increasingly difficult to handle everyday tasks. Based on her current condition she is expected to live for ten more years. Britta comes to you and asks for treatment with Taxil (a new drug).



Britta, 56 years

Taxil is a new drug that is said to better relieve symptoms of the disease compared to the standard medication for Alzheimer. The few studies conducted so far have shown a marginal improvement compared to standard medication. Taxil costs 200 000 SEK [≈USD 25,000] more per year than the standard medication.

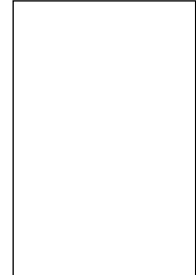
The alternative is to let the money fund other treatments in the hospital.

Do you choose to give Taxil to Britta?

- ☐ Yes
- ☐ No

The diabetes scenario [QoL-improving]

You are a doctor. Your patient Lena is 42 years old and has diabetes type I. She is in good health and has stable blood sugar levels. Lena comes to you and asks about getting an insulin pump.



Lena, 42 years

With an insulin pump, the patient can live a more comfortable and flexible life. In the current situation insulin pumps are only offered to patients where the injection treatment is problematic. The insulin pump costs 40 000 SEK [≈USD 5 000]. In addition, there is a cost of 25 000 SEK [≈USD 3,125] more per patient per year than standard treatment with injections.

The alternative is that the money is used to fund other treatments in the hospital.

Do you choose to give Lena an insulin pump?

- ☐ Yes
- ☐ No

The growth disorder scenario [QoL-improving]

You are a doctor. Your patient Erik is 10 years old and he is unusually short given his age. Erik and his parents fear that his short stature will have a negative effect on his ability to lead a successful life in the future. They come to you and ask about growth hormone therapy for Erik.



Erik, 10 years

Growth hormone therapy given to ten-year-old children increases their adult height by approximately three cm. The treatment consists of daily injections until the child reaches full skeletal maturity, around the age of twenty. This form of treatment costs 200 000 SEK [≈USD 25,000] per year.

The alternative is to let the money fund other treatments in the hospital.

Do you choose give growth hormone therapy to Erik for his unusually short stature?

- ☐ Yes
- ☐ No

The blood disease scenario

L.M. is a middle aged woman who has a particular incurable blood condition. With treatment she is expected to live between 5 and 10 years without symptoms, and then die.

Suppose there is a medication that could be added to her therapy that has been shown to be of benefit, although sometimes it makes things worse. With the additional medication it is expected that 85% of women with this condition will gain 2 more years of life, and 15% of the women will lose 4 years of life.

If you were asked to give your opinion, how strongly would you recommend the medication to L.M. in this situation?

Strongly recommend that she take the medication

Suggest that she take the medication

Suggest that she not take the medication

Strongly recommend that she not take the medication
