JDRF Artificial Pancreas Project Randomized Clinical Trial
Complication Utilities- Parent Version
tblASurveyCompP

Patient ID: ____ ____ ____ ____ ____ ____ PtID

COMPLICATION UTILITIES

Throughout this study, we have asked you to consider the quality of life effects of diabetes and its treatments. It is also important for us to understand how much of an impact different complications would have on your child's life. We will be asking you again the same type of imaginary questions we have asked during earlier parts of the study. If these questions make you uncomfortable, we may stop.

Primary caregiver: _____ EduCareGvrP

Interviewer:
The time tradeoff questions begin at this point.

Use the "Time frame" that corresponds to the age of the patient to select the correct the hierarchical diagrams beginning on page 4. The hierarchical diagram must be used in conjunction with every section below (*Blindness*, *Kidney Failure*, *Chest Pain Related to Heart Disease*, *Severe Stroke* and *Living Without Part of your Lower Leg*).

Age of patient	Time frame*
8-15	50
15-25	40
25-35	30
>35	20

TimeFrameP

Note: The selected **Time frame will be used with the hierarchical diagrams beginning on page 4.*

The first question is simply a choice between the full time in current health vs. the full time in perfect health. If parent chooses full time in current health then discuss answer, determine if parent intends answer and go to next question. All questions are a choice between 1) "X years in perfect health" 2) "Y years with condition" or 3) "No preference, because these seem about the same". The questions in every section (*Blindness*, *Kidney Failure*,…) must be asked six different times using the hierarchical diagram flow or until the patient chooses "No preference". If this section is unclear please see example at the end of this document.

1. Blindness

Imagine a life with **blindness**:

- Your child would not be able to read, see the TV, or drive a car.
- Your child may also need assistance with many day-to-day tasks such as cooking, cleaning, dressing him/herself, and bathing.
- Your child may also need assistance taking his/her medications.

Imagine your child had the following choice, which would he/she prefer?

☐ ___ *years* living with blindness
☐ ___ *years* in perfect health
☐ No preference, because these seem about the same to him/her

BlindChoice1P, BlindChoice2P, BlindChoice3P, BlindChoice4P, BlindChoice5P BlindChoice6P

☐ Parent refuses to continue 'blindness' question BlindRefContP

Interviewer: If patient chooses living with diabetes then discuss answer, determine if patient intends answer and go to next question.

2. End-stage renal disease

Imagine a life with **kidney failure**:

- Your child would experience fatigue, bone problems, joint problems, itching, and 'restless legs'.
- Your child would need to have dialysis 3 times per week and this procedure usually lasts 3-5 hours.
- Your child may need to make changes in his/her work or home life to maintain this schedule.
- During dialysis your child is attached to a machine. To do this, a needle is inserted into tubing that has been placed under the skin of his/her arm. The machine then filters the blood to get rid of waste products.
- Your child may sometimes feel sick or tired for a few hours after he/she has had dialysis.

Imagine your child had the following choice, which would he/she prefer?

☐ ___ *years* living with kidney failure
☐ ___ *years* in perfect health
☐ No preference, because these seem about the same to him/her

RenalChoice1P, RenalChoice2P, RenalChoice3P, RenalChoice4P, RenalChoice5P, RenalChoice6P

☐ Parent refuses to continue 'kidney failure' question RenalRefContP

Interviewer: If patient chooses living with diabetes then discuss answer, determine if patient intends answer and go to next question.

3. Chest pain related to heart disease

Imagine living with **chest pain related to heart disease**:

- Your child experiences chest pain after walking a block or two but can relieve the pain by stopping or taking medicine.
- Your child's energy level may be low some of the time.

- Your child can bathe and dress him/herself, and feed him/herself without difficulty.

Imagine your child had the following choice, which would he/she prefer?

☐ ___ *years* living with heart disease
☐ ___ *years* in perfect health
☐ No preference, because these seem about the same to him/her

ChestPnChoice1P, ChestPnChoice2P, ChestPnChoice3P, ChestPnChoice4P, ChestPnChoice5P , ChestPnChoice6P

☐ Parent refuses to continue 'chest pain related to heart disease' question ChestPnRefContP

Interviewer: If patient chooses living with diabetes then discuss answer, determine if patient intends answer and go to next question.

4. Stroke

Imagine life after having a **severe stroke**:

- Your child cannot move the arm or leg on the side that he/she writes with.
- Your child can stand with a leg brace and walk a short distance with help.
- Your child can use a wheel chair. Your child cannot climb stairs.
- Your child needs help to dress, bathe, and use the bathroom. Your child needs help preparing and eating food.
- Your child might have difficulty speaking or finding the right words.

Imagine your child had the following choice, which would he/she prefer?

☐ ___ *years* living with stroke
☐ ___ *years* in perfect health
☐ No preference, because these seem about the same to him/her

StrokeChoice1P, StrokeChoice2P, StrokeChoice4P, StrokeChoice4P, StrokeChoice5P, StrokeChoice6P

☐ Parent refuses to continue 'severe stroke' question StrokeRefContP

Interviewer: If patient chooses living with diabetes then discuss answer, determine if patient intends answer and go to next question.

5. Living without part of your lower leg or foot

Imagine a life after your child has lost part of his/her **lower leg or foot:**

- Your child may be able to walk with an artificial leg, or your child may have to use a wheelchair to get around.
- Your child might have some difficulty performing daily tasks such as driving, shopping, or cleaning his/her house.

Imagine your child had the following choice, which would he/she prefer?

☐ ___ *years* living without part of his/her lower leg or foot
☐ ___ *years* in perfect health
☐ No preference, because these seem about the same to him/her

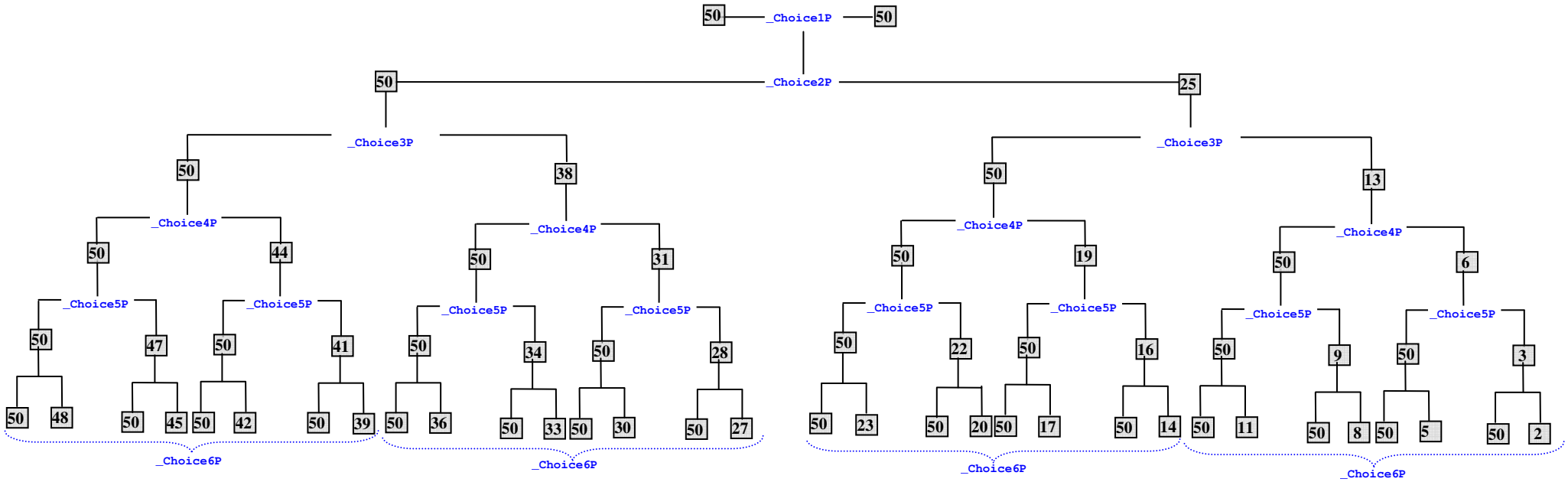
LostLegChoice1P, LostLegChoice2P, LostLegChoice3P, LostLegChoice4P, LostLegChoice5P, LostLegChoice6P

☐ Parent refuses to continue 'lost lower leg or foot' question

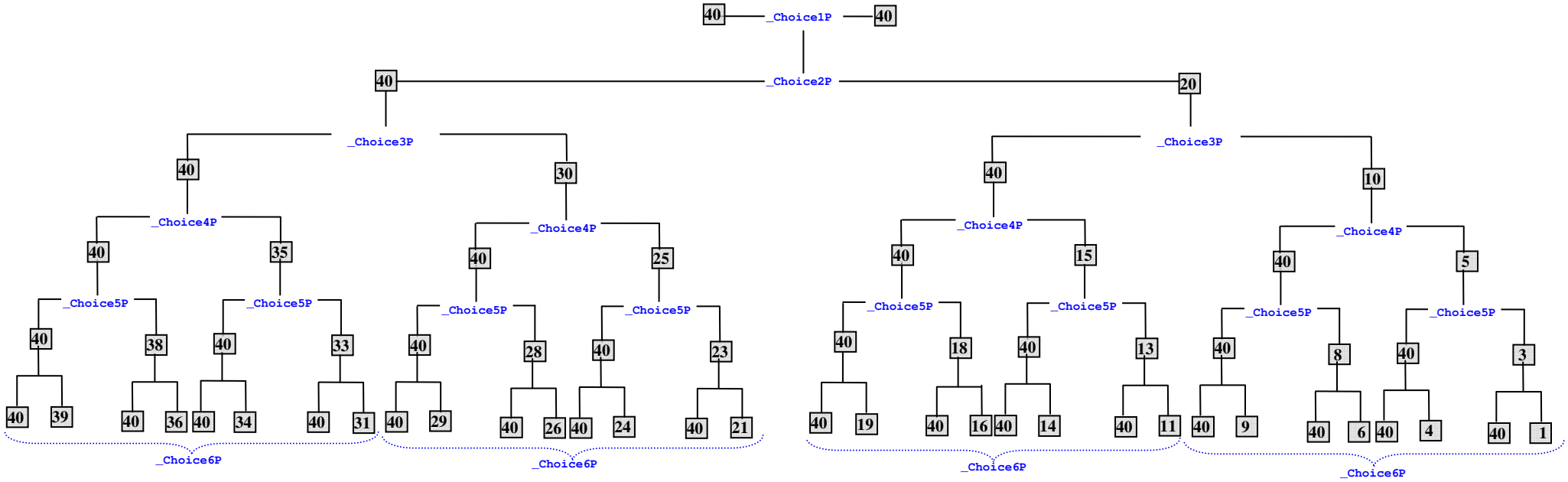
☐ Parent refuses to continue survey LostLegRefContP

Hierarchical Diagrams

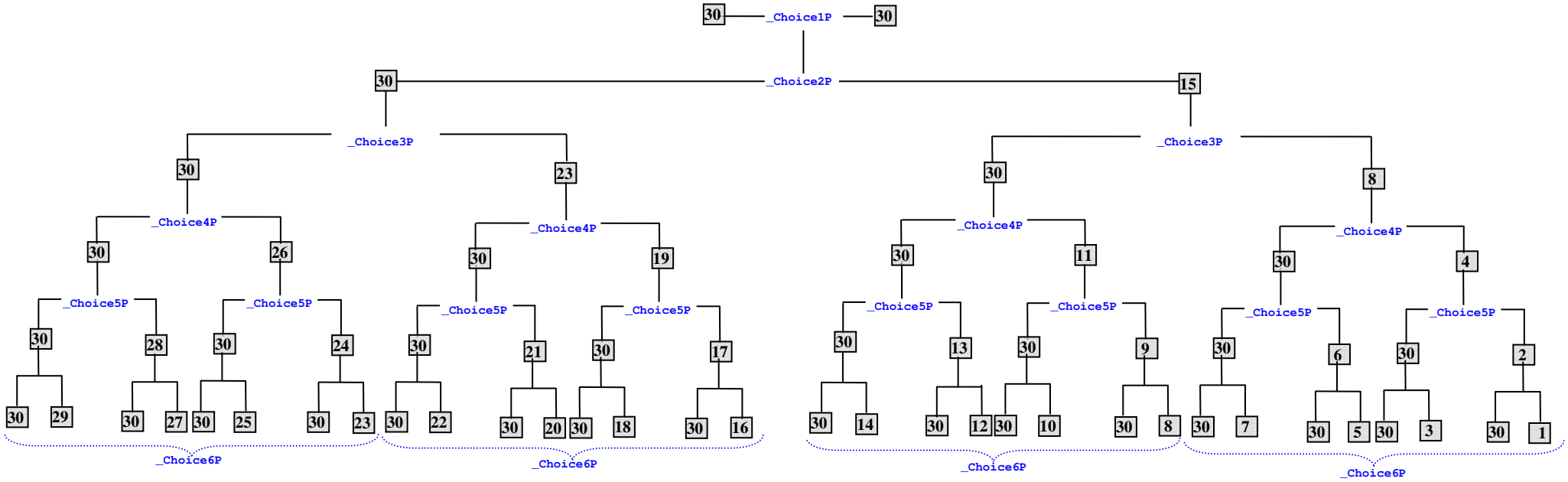
Time Frame = 50



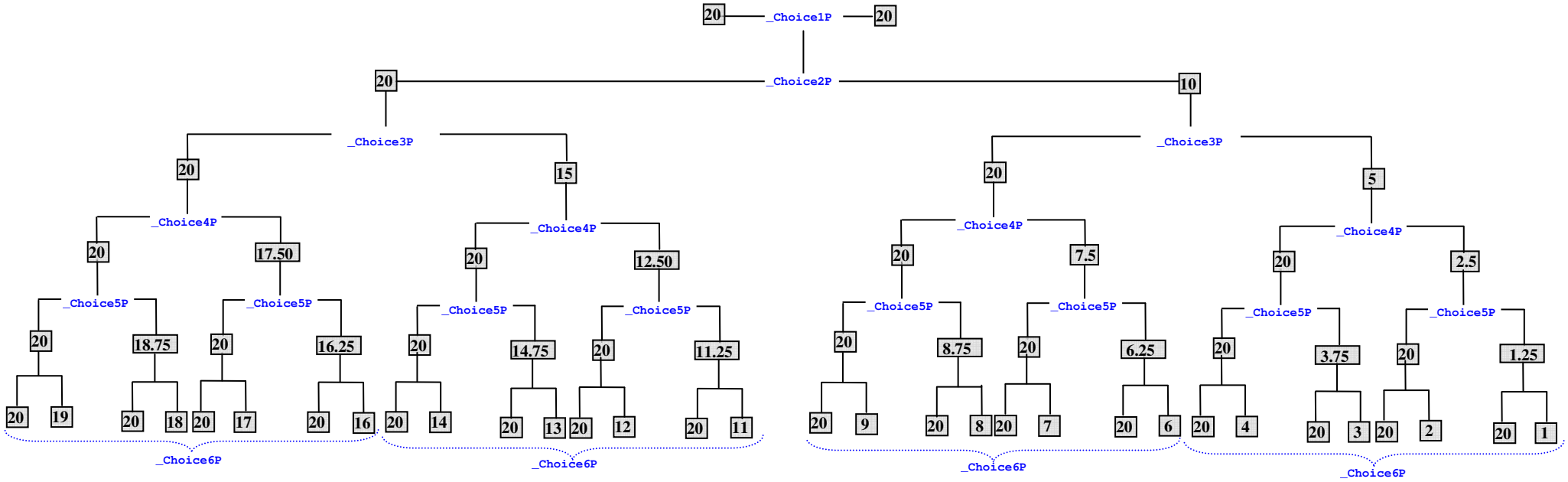
Time Frame = 40



Time Frame = 30



Time Frame = 20



Fictitious example for the Blindness section:

An investigator is asking Joe (parent) questions about his daughter. Joe' daughter is 14 years old which puts her "**Time Frame**" equal to **50**. The investigator asks Joe the following question using the hierarchical diagram flow to plot the number of years for each question.

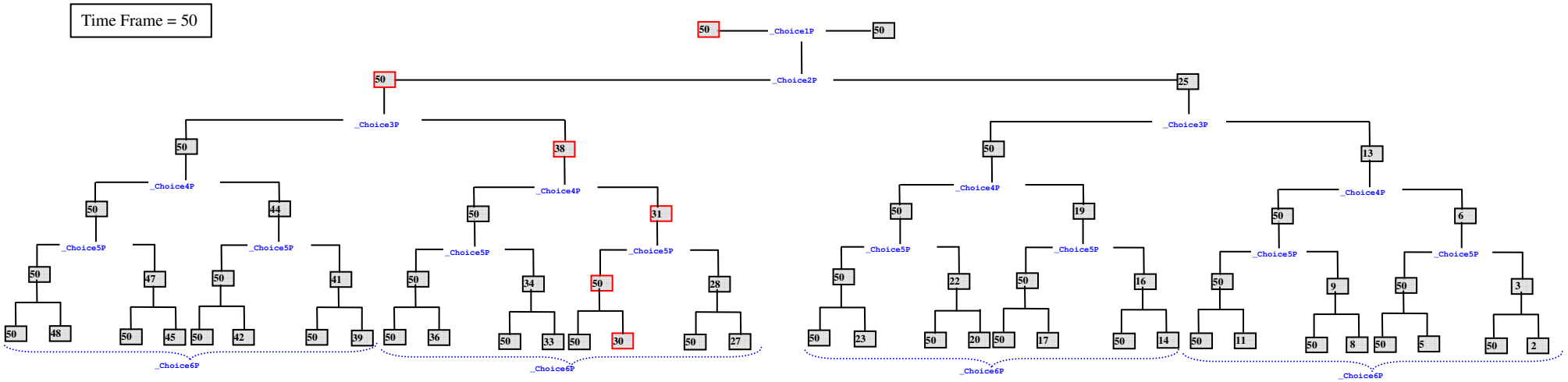
Question 1: Imagine your child had the following choice, which would he/she prefer; **50 years living with blindness or 50 years in perfect health? _Choice1P**
Answer: **50 years in perfect health**

Question 2: Which would he/she prefer; **50 years living with blindness or 25 years in perfect health? _Choice2P**
Answer: **50 years living with blindness**

Question 3: Which would he/she prefer; **50 years living with blindness or 38 years in perfect health? _Choice3P**
Answer: **38 years in perfect health**

Question 4: Which would he/she prefer; **50 years living with blindness or 31 years in perfect health? _Choice4P**
Answer: **31 years in perfect health**

Question 5: Which would he/she prefer; **50 years living with blindness or 28 years in perfect health? _Choice5P**
Answer: **50 years living with blindness**

Question 6: Which would he/she prefer; **50 years living with blindness or 30 years in perfect health? _Choice6P**
Answer: **30 years in perfect health**

The red boxes represent Joe's choices for the Blindness section. Please note that if Joe had chosen "No Preference" at any point this section would be over.
The same approach must be applied to all sections of this survey (Blindness, Kidney Failure, Chest Pain, Severe Stroke and Living without Part of your Leg).