

I. CELIAC DATA COLLECTION SHEET

Age: _____ **Zip Code:** _____ **Gender:** Male Female

Race:

- (1) American Indian or Alaska Native (2) Asian
(3) Black or African American (4) Native Hawaiian or Other Pacific Islander
(5) Caucasian (6) More than one race (Please list): _____

Ethnicity:

- (1) Hispanic or Latino(a) (2) Not Hispanic or Latino(a)

Marital status:

- (1) Single (2) Married (3) Divorced (4) Separated

Educational Level:

- (1) Completed Grade School (K-8) (2) Completed Some High School (No diploma)
(3) High School Graduate (4) Some College (No degree)
(5) Associate degree (6) Trade School
(7) Bachelor's degree (8) Master's degree
(9) Professional degree (10) Doctorate degree

Are you *currently* employed? (1) Full-time (2) Part-time (3) Unemployed

Occupation: _____

What is your household annual income:

<\$25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$100,000-200,000 >\$200,000

At what age were you diagnosed with Celiac Disease? _____

***How* was your diagnosis of celiac disease made?**

- (1) Small bowel biopsy (portion of the lining of the small intestine is removed for examination)
(2) Blood antibody tests
(3) Both

What *symptoms* if any did you or do you experience related to celiac disease?

At what age did the signs and symptoms of celiac disease (if any signs and symptoms were experienced) first appear?

What was the approximate length of time between presentation of symptoms (if any) and when you sought medical advice?

How long have you been following the gluten-free diet (in years and/or months)?

What is your health insurance?

MassHealth Private Medicare or Medicaid None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you seen your dietician/nutritionist in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited your gastroenterologist in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

Do you belong to a support group for Celiac Disease?

YES NO

What factors make treatment for your Celiac Disease easier or harder? (Circle all that apply.)

- (1) Cost of food
- (2) Eating out
- (3) Understanding and support from family and friends
- (4) Attending my support group
- (5) Seeing my physician regularly
- (6) Seeing my dietician/nutritionist regularly
- (7) How available gluten-free foods are in my local grocery store
- (8) Time limitations
- (9) Knowing enough about what it means to have a gluten-free diet
- (10) Other dietary restrictions
- (11) Other _____

Question	1	2	3	4	5
Have you been bothered by low energy level during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you been bothered by headaches during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
I am able to follow a gluten free diet when dining outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I do not consider myself a failure	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
How important to your health are accidental gluten exposures?	Very Important	Somewhat Important	Neutral/ Unsure	A Little Important	Not at All Important
Over the past four weeks how many times have you eaten foods containing gluten on purpose?	0 (never)	1-2 Times	3-5 Times	6-10 times	More than 10 Times
The cost of food make it more difficult to follow your diet.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
The lack of gluten-free foods at your grocery store is a problem.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to take a medicine everyday instead of follow a gluten-free diet.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Have you been bothered by pain or discomfort in the upper abdomen or the pit of the stomach during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you been bothered by nausea during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you been bothered by rumbling in your stomach during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Has your stomach felt bloated during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you been bothered by diarrhea during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
When going on the toilet, have you had the sensation of not completely emptying your bowels during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you been bothered by hunger pains during the last 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you had food cravings in the last 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Have you had loss of appetite during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time

Related to Celiac Disease, how is your health?	Excellent	Good	Fair	Poor	Terrible
Overall, how is your health?	Excellent	Good	Fair	Poor	Terrible
How much physical pain have you had during the past 4 weeks?	None	A Little	Some	A Good Deal	Very Much
I am comfortable	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I am as healthy as anybody I know	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.

Best
imaginable
health state

100

90

80

70

60

50

40

30

20

10

0

Worst
imaginable
health state



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your Celiac Disease. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your health in relation to your Celiac Disease.

Best
imaginable
health state

100

90

80

70

60

50

40

30

20

10

0

Worst
imaginable
health state

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your Celiac Disease treatment.

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your Celiac Disease treatment.

Very Important



Not Important
At All

II. GERD DATA COLLECTION SHEET

You have been selected for this study because you have been diagnosed with GERD (gastroesophageal reflux disease), also known as “heartburn.” Please answer the questions below with regard to your heartburn.

Age: _____ **Zip Code:** _____ **Gender:** Male Female

Race:

- | | |
|--------------------------------------|---|
| (1) American Indian or Alaska Native | (2) Asian |
| (3) Black or African American | (4) Native Hawaiian or Other Pacific Islander |
| (5) Caucasian | (6) More than one race (Please list): _____ |

Ethnicity:

- | | |
|---------------------------|-------------------------------|
| (1) Hispanic or Latino(a) | (2) Not Hispanic or Latino(a) |
|---------------------------|-------------------------------|

Marital status:

- | | | | |
|------------|-------------|--------------|---------------|
| (1) Single | (2) Married | (3) Divorced | (4) Separated |
|------------|-------------|--------------|---------------|

Educational Level:

- | | |
|----------------------------------|---|
| (1) Completed Grade School (K-8) | (2) Completed Some High School (No diploma) |
| (3) High School Graduate | (4) Some College (No degree) |
| (5) Associate degree | (6) Trade School |
| (7) Bachelor's degree | (8) Master's degree |
| (9) Professional degree | (10) Doctorate degree |

Are you currently employed? (1) Full-time (2) Part-time (3) Unemployed

Occupation: _____

What is your household annual income:

<\$25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$100,000-200,000 >\$200,000

At what age were you diagnosed with Heartburn? _____

What *symptoms* if any did you or do you experience related to Heartburn?

At what age did the signs and symptoms of Heartburn (if any signs and symptoms were experienced) first appear?

What was the approximate length of time between presentation of symptoms (if any) and when you sought medical advice?

How long have you been receiving treatment for Heartburn (in years and/or months)?

What is your health insurance?

MassHealth

Private

Medicare or Medicaid

None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited a gastroenterologist in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

What is your treatment for your heartburn? (Circle all that apply)

- (1) Once a day medication (Please list _____)
- (2) Twice a day medication (Please list _____)
- (3) Lifestyle changes (for example, elevating the head of the bed, not lying down immediately after eating)
- (4) Dietary changes (for example, eating small meals, avoiding spicy or acidic foods, avoiding caffeine and alcohol)

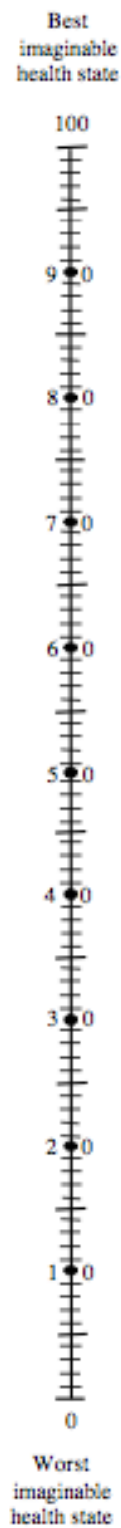
What factors make treatment for heartburn easier or harder? (Circle all that apply.)

- (1) Cost of food and medicines
- (2) Eating out
- (3) Understanding and support from family and friends
- (4) Seeing my physician regularly
- (5) How available certain foods are in my local grocery store
- (6) Knowing enough about what it means to use dietary/lifestyle changes to control my symptoms
- (7) Other dietary restrictions
- (8) Medication side effects
- (9) Taking too many medicines
- (10) Other _____

Question	1	2	3	4	5
I am able to follow my medication schedule, lifestyle changes, and diet when outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

I do not consider myself a failure	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
How important to your health are mistakes in your heartburn treatment?	Very Important	Somewhat Important	Neutral/ Unsure	A Little Important	Not at All Important
Over the past four weeks how many times have you not followed your diet or lifestyle changes related to heartburn?	0 (never)	1-2 Times	3-5 Times	6-10 times	More than 10 Times
Over the past four weeks how many times have you missed your heartburn medications?	0 (never)	1-2 Times	3-5 Times	6 or more Times	I don't take medications
Cost makes it more difficult to follow your treatment.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
The lack of certain foods in your grocery store or access to medications is a problem.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to take ONLY a medicine everyday instead of follow a special diet or lifestyle for my heartburn.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Have you been bothered by symptoms of your heartburn during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Related to Heartburn, how is your health?	Excellent	Good	Fair	Poor	Terrible
Overall, how is your health?	Excellent	Good	Fair	Poor	Terrible
How much physical pain have you had during the past 4 weeks?	None	A Little	Some	A Good Deal	Very Much
I am comfortable	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I am as healthy as anybody I know	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your heartburn. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your health in relation to your heartburn.

Best
imaginable
health state

100

90

80

70

60

50

40

30

20

10

0

Worst
imaginable
health state

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your Heartburn treatment.

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your Heartburn treatment.

Very Important



Not Important
At All

III. IBD DATA COLLECTION SHEET

You have been selected for this study because you have been diagnosed with Inflammatory Bowel Disease, which is a general term meaning you have Crohn's Disease or Ulcerative Colitis. Please answer the questions below with regard to your Crohn's Disease or Ulcerative Colitis.

Age: _____ **Zip Code:** _____ **Gender:** Male Female

Race:

- (1) American Indian or Alaska Native (2) Asian
(3) Black or African American (4) Native Hawaiian or Other Pacific Islander
(5) Caucasian (6) More than one race (Please list): _____

Ethnicity:

- (1) Hispanic or Latino(a) (2) Not Hispanic or Latino(a)

Marital status:

- (1) Single (2) Married (3) Divorced (4) Separated

Educational Level:

- (1) Completed Grade School (K-8) (2) Completed Some High School (No diploma)
(3) High School Graduate (4) Some College (No degree)
(5) Associate degree (6) Trade School
(7) Bachelor's degree (8) Master's degree
(9) Professional degree (10) Doctorate degree

Are you *currently* employed? (1) Full-time (2) Part-time (3) Unemployed

Occupation: _____

What is your household annual income:

<\$25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$100,000-200,000 >\$200,000

At what age were you diagnosed with Crohn's Disease or Ulcerative Colitis? _____

What *symptoms* if any did you or do you experience related to Crohn's Disease or Ulcerative Colitis?

At what age did the signs and symptoms of Crohn's Disease or Ulcerative Colitis (if any signs and symptoms were experienced) first appear?

What was the approximate length of time between presentation of symptoms (if any) and when you sought medical advice?

How long have you been receiving treatment for Crohn's Disease or Ulcerative Colitis (in years and/or months)?

What is your health insurance?

MassHealth Private Medicare or Medicaid None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited a gastroenterologist in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

What is the treatment for your Crohn's Disease or Ulcerative Colitis? (Circle all that apply)

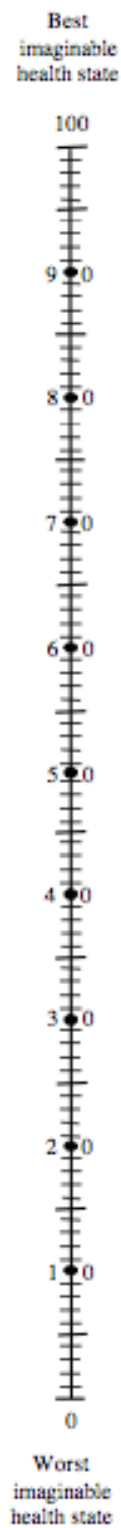
- (1) Sulfa or 5-ASA Drugs like Mesalamine (Asacol), Sulfasalazine
- (2) Antibiotics like Flagyl (Metronidazole) Ciprofloxacin, Clarithromycin, Rifaximin
- (3) 6-Mercaptopurine (6-MP)
- (4) Imuran (Azathioprine)
- (5) Cyclosporine
- (6) Biologics like Infliximab (Remicade) or Adalimumab (Humira)
- (7) Methotrexate
- (8) Surgery
- (8) Steroids like Prednisone, Budesonide (Entocort), Cortifoam, Hydrocortisone
- (9) Lifestyle changes (dietary changes, smoking cessation, avoiding certain triggers, etc)
- (10) Other _____

What factors make treatment for your disease easier or harder? (Circle all that apply.)

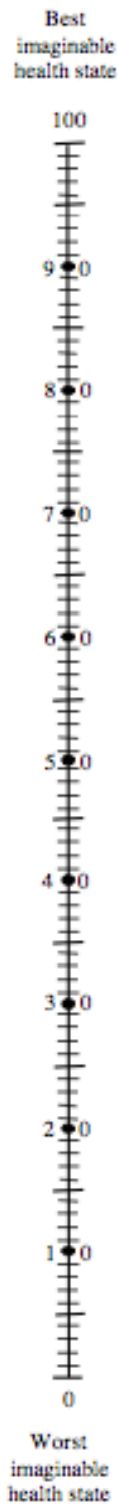
- (1) Understanding and support from family and friends
- (2) Attending my support group
- (3) Seeing my physician regularly
- (4) Knowing enough about my disease
- (5) Cost of medicines
- (6) Taking too many medicines
- (7) Medication side effects
- (8) Other _____

Question	1	2	3	4	5
I am able to follow my medication schedule and lifestyle changes when outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I do not consider myself a failure	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
How important to your health are mistakes in your Crohn's or Ulcerative Colitis treatment?	Very Important	Somewhat Important	Neutral/ Unsure	A Little Important	Not at All Important
Over the past four weeks how many times have you not followed your diet or lifestyle changes related to Crohn's Disease or Ulcerative Colitis?	0 (never)	1-2 Times	3-5 Times	6-10 times	More than 10 Times
Over the past four weeks how many times have you missed your Crohn's Disease or Ulcerative Colitis medications?	0 (never)	1-2 Times	3-5 Times	6 or more Times	I don't take medications
Cost makes it more difficult to follow your treatment.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
The lack of access to medications is a problem.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to take ONLY a medicine everyday instead of follow a special diet or lifestyle for my Crohn's Disease or Ulcerative Colitis.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Have you been bothered by symptoms of your Crohn's Disease or Ulcerative Colitis during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Related to Crohn's or Ulcerative Colitis, how is your health?	Excellent	Good	Fair	Poor	Terrible
Overall, how is your health?	Excellent	Good	Fair	Poor	Terrible
How much physical pain have you had during the past 4 weeks?	None	A Little	Some	A Good Deal	Very Much
I am comfortable	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I am as healthy as anybody I know	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your Crohn's Disease or Ulcerative Colitis. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an "X" next to how you would score your health in relation to your Crohn's Disease or Ulcerative Colitis.



Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your Crohn’s Disease or Ulcerative Colitis treatment.

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your Crohn’s Disease or Ulcerative Colitis treatment.

Very Important



Not Important
At All

IV. IRRITABLE BOWEL SYNDROME DATA COLLECTION SHEET

You have been selected for this study because you have been diagnosed with Irritable Bowel Syndrome. Please answer the questions below with regard to your Irritable Bowel Syndrome.

Age: _____ **Zip Code:** _____ **Gender:** Male Female

Race:

- (1) American Indian or Alaska Native (2) Asian
(3) Black or African American (4) Native Hawaiian or Other Pacific Islander
(5) Caucasian (6) More than one race (Please list): _____

Ethnicity:

- (1) Hispanic or Latino(a) (2) Not Hispanic or Latino(a)

Marital status:

- (1) Single (2) Married (3) Divorced (4) Separated

Educational Level:

- (1) Completed Grade School (K-8) (2) Completed Some High School (No diploma)
(3) High School Graduate (4) Some College (No degree)
(5) Associate degree (6) Trade School
(7) Bachelor's degree (8) Master's degree
(9) Professional degree (10) Doctorate degree

Are you currently employed? (1) Full-time (2) Part-time (3) Unemployed

Occupation: _____

What is your household annual income:

<\$25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$100,000-200,000 >\$200,000

At what age were you diagnosed with Irritable Bowel Syndrome? _____

What *symptoms* did you or do you experience related to Irritable Bowel Syndrome?

At what age did the signs and symptoms of Irritable Bowel Syndrome first appear?

What was the approximate length of time between presentation of symptoms and when you sought medical advice?

How long have you been receiving treatment for Irritable Bowel Syndrome (in years and/or months)?

What is your health insurance?

MassHealth Private Medicare or Medicaid None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited a gastroenterologist in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

Do you belong to a support group for Irritable Bowel Syndrome?

YES NO

How is your Irritable Bowel Syndrome treated? (Circle all that apply)

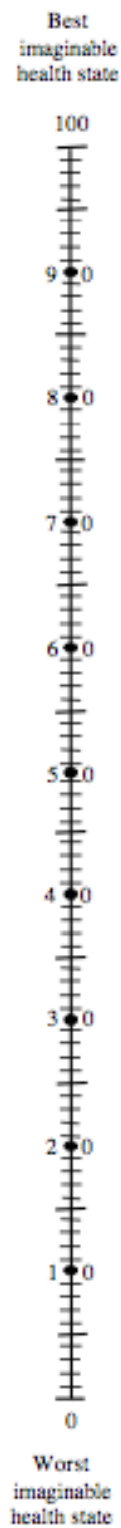
- (1) Diet changes
- (2) Medications (Please specify _____)
- (3) Counseling from a therapist or psychologist
- (4) Other _____
- (5) I am not undergoing any treatment for my Irritable Bowel Syndrome

What factors make treatment for Irritable Bowel Syndrome easier or harder? (Circle all that apply.)

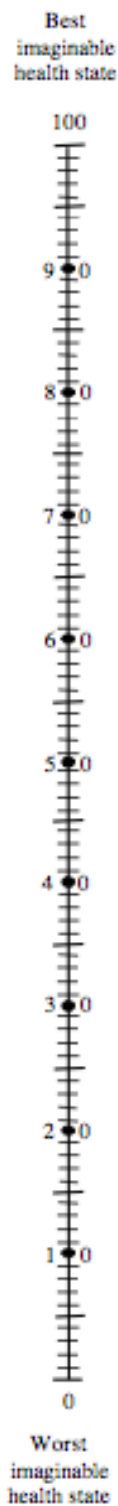
- (1) Dietary restrictions
- (2) Understanding and support from family and friends
- (3) Attending my support group
- (4) Seeing my physician regularly
- (5) Seeing a therapist/psychologist
- (6) Knowing enough about my disease
- (7) Cost of special foods and/or medications
- (9) Taking too many medicines
- (10) Medication side effects
- (11) Other _____

Question	1	2	3	4	5
I am able to follow my lifestyle modifications as a person with Irritable Bowel Syndrome while outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I do not consider myself a failure	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
How important to your health are mistakes in your Irritable Bowel Syndrome lifestyle?	Very Important	Somewhat Important	Neutral/ Unsure	A Little Important	Not at All Important
Over the past four weeks how many times have you made mistakes in your lifestyle modifications for Irritable Bowel Syndrome?	0 (never)	1-2 Times	3-5 Times	6-10 times	More than 10 Times
Over the past four weeks how many times have you missed your counseling or medications?	0 (never)	1-2 Times	3-5 Times	6 or more Times	I don't take medications or attend counseling
Cost makes it more difficult to follow your treatment.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
A lack of special foods in your grocery store, access to counseling, or access to medications is a problem for your Irritable Bowel Syndrome lifestyle.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to take a single medicine everyday instead of my current lifestyle changes for irritable bowel syndrome.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Have you been bothered by symptoms of your irritable bowel syndrome during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Related to Irritable Bowel Syndrome, how is your health?	Excellent	Good	Fair	Poor	Terrible
Overall, how is your health?	Excellent	Good	Fair	Poor	Terrible
How much physical pain have you had during the past 4 weeks?	None	A Little	Some	A Good Deal	Very Much
I am comfortable	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I am as healthy as anybody I know	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your irritable bowel syndrome. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your health in relation to your irritable bowel syndrome.



Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your Irritable Bowel Syndrome treatment.

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your Irritable Bowel Syndrome treatment.

Very Important



Not Important
At All

V. HYPERTENSION DATA COLLECTION SHEET

You have been selected for this study because you have been diagnosed with Hypertension (High blood pressure). Please answer the questions below with regard to your high blood pressure.

Age: _____ **Zip Code:** _____ **Gender:** Male Female

Race:

- | | |
|--------------------------------------|---|
| (1) American Indian or Alaska Native | (2) Asian |
| (3) Black or African American | (4) Native Hawaiian or Other Pacific Islander |
| (5) Caucasian | (6) More than one race (Please list): _____ |

Ethnicity:

- (1) Hispanic or Latino(a) (2) Not Hispanic or Latino(a)

Marital status:

- (1) Single (2) Married (3) Divorced (4) Separated

Educational Level:

- | | |
|----------------------------------|---|
| (1) Completed Grade School (K-8) | (2) Completed Some High School (No diploma) |
| (3) High School Graduate | (4) Some College (No degree) |
| (5) Associate degree | (6) Trade School |
| (7) Bachelor's degree | (8) Master's degree |
| (9) Professional degree | (10) Doctorate degree |

Are you *currently* employed? (1) Full-time (2) Part-time (3) Unemployed

Occupation: _____

What is your household annual income:

<\$25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$100,000-200,000 >\$200,000

At what age were you diagnosed with Hypertension (high blood pressure)? _____

What *symptoms* if any did you or do you experience related to Hypertension?

At what age did the signs and symptoms of Hypertension (if any signs and symptoms were experienced) first appear?

What was the approximate length of time between presentation of symptoms (if any) and when you sought medical advice?

How long have you been receiving treatment for Hypertension (in years and/or months)?

What is your health insurance?

MassHealth Private Medicare or Medicaid None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited a specialist for your Hypertension (like a kidney doctor) in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

How is your Hypertension treated? (Please circle all that apply.)

- (1) One medicine (Please list _____)
- (2) Two medicines (Please list _____)
- (3) More than two medicines (Please list _____)
- (4) Changes in my lifestyle (for example, exercise, low salt diet, weight loss)
- (5) Other _____

What makes treatment for your Hypertension easier or harder? (Circle all that apply.)

- (1) Cost of medicines and lifestyle changes
- (2) Difficulty when eating out
- (3) Understanding and support from family and friends
- (4) Medication side effects
- (5) Seeing my physician regularly
- (6) How available healthy foods are in my local grocery store
- (7) Taking too many medications
- (8) Knowing enough about how to treat High blood pressure
- (9) Other _____

Question	1	2	3	4	5
I am able to follow my medication schedule and diet when outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I do not consider myself a failure	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
How important to your health are	Very	Somewhat	Neutral/	A Little	Not at All

mistakes in your treatment for hypertension?	Important	Important	Unsure	Important	Important
Over the past four weeks how many times have you made mistakes in your diet or lifestyle ?	0 (never)	1-2 Times	3-5 Times	6-10 Times	More than 10 Times
Over the past four weeks how many times have you missed your medications for hypertension?	0 (never)	1-2 Times	3-5 Times	6 or more Times	I don't take medications
Cost makes it more difficult to follow your treatment.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
The lack of low-salt foods in your grocery store or access to medications is a problem.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to take a medicine everyday instead of follow lifestyle changes like diet and exercise.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Have you been bothered by symptoms of your hypertension during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Related to hypertension, how is your health?	Excellent	Good	Fair	Poor	Terrible
Overall, how is your health?	Excellent	Good	Fair	Poor	Terrible
How much physical pain have you had during the past 4 weeks?	None	A Little	Some	A Good Deal	Very Much
I am comfortable	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I am as healthy as anybody I know	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.

Best
imaginable
health state

100

90

80

70

60

50

40

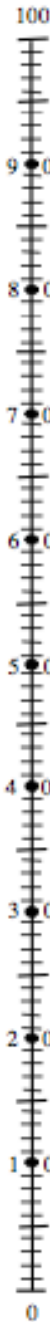
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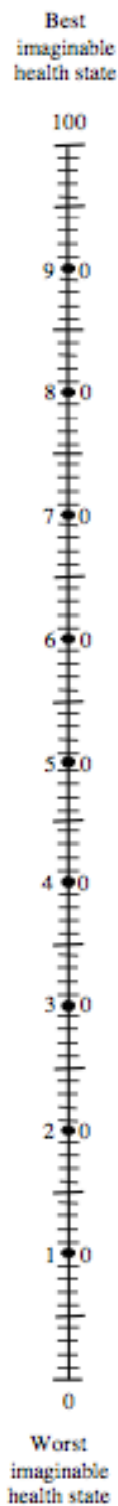
10

0

Worst
imaginable
health state



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your hypertension. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your health in relation to your hypertension.



Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your Hypertension treatment.

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your Hypertension treatment.

Very Important



Not Important
At All

VI. END STAGE RENAL DISEASE DATA COLLECTION SHEET

You have been selected for this study because you have been diagnosed with End-Stage Renal Disease (Kidney Failure) that requires Dialysis. Please answer the questions below with regard to your End Stage Kidney Failure.

Age: _____ **Zip Code:** _____ **Gender:** Male Female

Race:

- | | |
|--------------------------------------|---|
| (1) American Indian or Alaska Native | (2) Asian |
| (3) Black or African American | (4) Native Hawaiian or Other Pacific Islander |
| (5) Caucasian | (6) More than one race (Please list): _____ |

Ethnicity:

- | | |
|---------------------------|-------------------------------|
| (1) Hispanic or Latino(a) | (2) Not Hispanic or Latino(a) |
|---------------------------|-------------------------------|

Marital status:

- | | | | |
|------------|-------------|--------------|---------------|
| (1) Single | (2) Married | (3) Divorced | (4) Separated |
|------------|-------------|--------------|---------------|

Educational Level:

- | | |
|----------------------------------|---|
| (1) Completed Grade School (K-8) | (2) Completed Some High School (No diploma) |
| (3) High School Graduate | (4) Some College (No degree) |
| (5) Associate degree | (6) Trade School |
| (7) Bachelor's degree | (8) Master's degree |
| (9) Professional degree | (10) Doctorate degree |

Are you *currently* employed? (1) Full-time (2) Part-time (3) Unemployed

Occupation: _____

What is your household annual income:

<\$25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$100,000-200,000 >\$200,000

At what age were you diagnosed with End-Stage Kidney Failure? _____

What *symptoms* if any did you or do you experience related to End-Stage Kidney Failure?

At what age did the signs and symptoms of End-Stage Kidney Failure (if any signs and symptoms were experienced) first appear?

What was the approximate length of time between presentation of symptoms (if any) and when you sought medical advice?

How long have you been receiving treatment for End-Stage Kidney Failure (in years and/or months)?

What is your health insurance?

MassHealth Private Medicare or Medicaid None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited a kidney doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

What is the treatment for your Kidney Disease? (Please circle all that apply.)

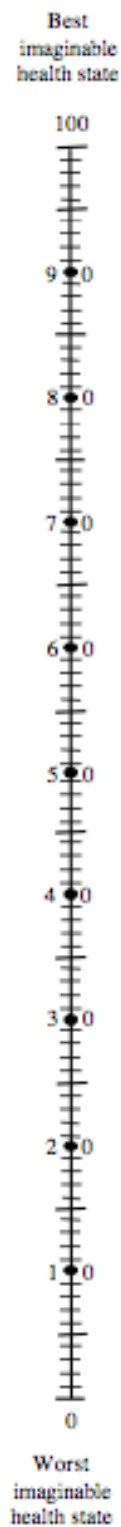
- (1) Dialysis
- (2) A low protein, kidney healthy diet
- (3) One medication (Please list) _____
- (4) Two medications (Please list) _____
- (5) More than two medications (Please list) _____
- (6) Other _____

What factors make treatment for End-Stage Renal Disease easier or harder? (Circle all that apply.)

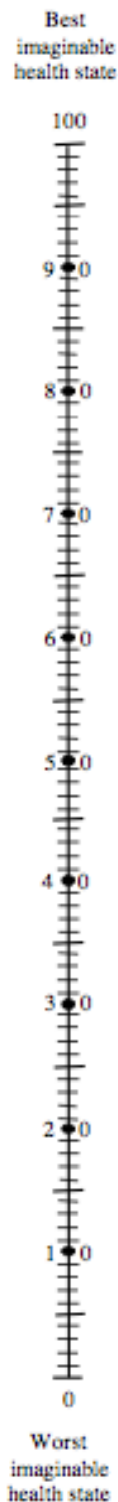
- (1) Cost of food, medicines, and/or going to dialysis
- (2) Difficulty when eating out
- (3) Understanding and support from family and friends
- (4) Seeing my physician regularly
- (5) How available low protein, kidney healthy options are in my local grocery store
- (6) Taking too many medications
- (7) Knowing enough about what it means to have End Stage Renal Disease
- (8) Other dietary restrictions
- (9) Medication side effects
- (10) Difficulty in going to dialysis
- (11) Discomfort from having to go to dialysis
- (13) Other _____

Question	1	2	3	4	5
I am able to follow my medication schedule, dialysis schedule, and diet when outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I do not consider myself a failure	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
How important to your health are mistakes in treatment for your kidney failure?	Very Important	Somewhat Important	Neutral/ Unsure	A Little Important	Not at All Important
Over the past four weeks how many times have you eaten non-kidney healthy foods on purpose?	0 (never)	1-2 Times	3-5 Times	6-10 Times	More than 10 Times
Over the past four weeks how many times have you missed your medications for kidney failure?	0 (never)	1-2 Times	3-5 Times	6 or more Times	I don't take medications
Over the past four weeks how many times have you missed your dialysis?	0 (never)	1-2 Times	3-5 Times	6 or more Times	I am not on dialysis
Cost makes it more difficult to follow your treatment.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
The lack of low-protein, kidney healthy foods in your grocery store, access to dialysis centers, or access to medications is a problem.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to take an extra medicine everyday instead of dialysis.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to ONLY take a medicine everyday instead of follow a kidney healthy diet.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Have you been bothered by symptoms of your kidney failure during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Related to your kidney failure, how is your health?	Excellent	Good	Fair	Poor	Terrible
Overall, how is your health?	Excellent	Good	Fair	Poor	Terrible
How much physical pain have you had during the past 4 weeks?	None	A Little	Some	A Good Deal	Very Much
I am comfortable	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I am as healthy as anybody I know	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your kidney failure. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your health in relation to your kidney failure.



Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your Kidney Disease treatment (Dialysis).

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your Kidney Disease treatment (dialysis).

Very Important



Not Important
At All

VII. DIABETES MELLITUS DATA COLLECTION SHEET

You have been selected for this study because you have been diagnosed with Diabetes, which means that you have high blood sugars. Please answer the questions below with regard to your Diabetes.

Age: _____ Zip Code: _____ Gender: Male Female

Race:

- (1) American Indian or Alaska Native (2) Asian
(3) Black or African American (4) Native Hawaiian or Other Pacific Islander
(5) Caucasian (6) More than one race (Please list): _____

Ethnicity:

- (1) Hispanic or Latino(a) (2) Not Hispanic or Latino(a)

Marital status:

- (1) Single (2) Married (3) Divorced (4) Separated

Educational Level:

- (1) Completed Grade School (K-8) (2) Completed Some High School (No diploma)
(3) High School Graduate (4) Some College (No degree)
(5) Associate degree (6) Trade School
(7) Bachelor's degree (8) Master's degree
(9) Professional degree (10) Doctorate degree

Are you currently employed? (1) Full-time (2) Part-time (3) Unemployed

Occupation: _____

What is your household annual income:

<\$25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$100,000-200,000 >\$200,000

At what age were you diagnosed with Diabetes? _____

What symptoms if any did you or do you experience related to Diabetes?

At what age did the signs and symptoms of Diabetes (if any signs and symptoms were experienced) first appear?

What was the approximate length of time between presentation of symptoms (if any) and when you sought medical advice?

How long have you been receiving treatment for Diabetes (in years and/or months)?

What is your health insurance?

MassHealth Private Medicare or Medicaid None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited a diabetes specialist in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

What is the treatment for your diabetes? (Circle all that apply.)

- (1) Sugar-free, diabetic diet
- (2) One to two medications (Please list) _____
- (3) Three to five medications (Please list) _____
- (4) More than five medications (Please list) _____

What factors make treatment for your diabetes easier or harder? (Circle all that apply.)

- (1) Cost of food and medicines
- (2) Difficulty when eating out
- (3) Understanding and support from family and friends
- (4) Seeing my physician regularly
- (5) How available sugar-free, diabetic options are in my local grocery store
- (6) Taking too many medications
- (7) Knowing enough about what it means to have a sugar-free, diabetic diet
- (8) Other dietary restrictions
- (9) Medication side effects
- (10) Having to check my blood sugars
- (11) Other _____

Question	1	2	3	4	5
I am able to follow my medication schedule and diet when outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

I do not consider myself a failure	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
How important to your health are mistakes in your diabetes treatment?	Very Important	Somewhat Important	Neutral/ Unsure	A Little Important	Not at All Important
Over the past four weeks how many times have you eaten non-diabetic foods on purpose?	0 (never)	1-2 Times	3-5 Times	6-10 times	More than 10 Times
Over the past four weeks how many times have you missed your diabetes medications?	0 (never)	1-2 Times	3-5 Times	6 or more Times	I don't take medications
Cost makes it more difficult to follow your treatment.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
The lack of sugar-free, diabetic foods in your grocery store or access to medications is a problem.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I would prefer to take a medicine everyday instead of follow a diabetic diet.	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Have you been bothered by symptoms of your diabetes during the past 4 weeks?	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Related to Diabetes, how is your health?	Excellent	Good	Fair	Poor	Terrible
Overall, how is your health?	Excellent	Good	Fair	Poor	Terrible
How much physical pain have you had during the past 4 weeks?	None	A Little	Some	A Good Deal	Very Much
I am comfortable	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
I am as healthy as anybody I know	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.

Best
imaginable
health state

100

90

80

70

60

50

40

30

20

10

0

Worst
imaginable
health state



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your diabetes. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your health in relation to your diabetes.

Best
imaginable
health state

100

90

80

70

60

50

40

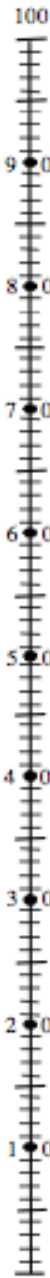
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20

10

0

Worst
imaginable
health state



Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your Diabetes treatment.

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your Diabetes treatment.

Very Important



Not Important
At All

VIII. CONGESTIVE HEART FAILURE DATA COLLECTION SHEET

CHF Data Collection Sheet

You have been selected for this study because you have been diagnosed with CHF (Congestive Heart Failure), which means that your heart does not pump as well as it should. Please answer the questions below with regard to your Heart Failure.

Age: _____ Zip Code: _____ Gender: Male Female

Race: Caucasian African American Hispanic Other _____

At what age were you diagnosed with Heart Failure? _____

What is your household annual income:

\$<25,000 \$25,001-50,000 \$50,001-75,001 \$75,001-100,000 \$>100,000

What is your employment status?

Full-time Part-time Unemployed Disability/Government Support

What is your highest educational level completed:

Less than high school High School GED

Undergraduate college Graduate College/ Higher

What is your health insurance?

MassHealth Private Medicare or Medicaid None

How many times have you seen your family doctor in the past year?

0 1 2 3 4 ≥ 5

How many times have you visited your cardiologist in the past year?

0 1 2 3 4 ≥ 5

How many times have you been hospitalized in the past year?

0 1 2 3 ≥ 4

In the past five years?

0 1 2 3 ≥ 4

Do you think that a lack of low salt, heart healthy foods in your grocery store is a problem?

(1)	(2)	(3)	(4)	(5)
All the time	Most of the time	Sometimes	A little of the time	None of the time

What factors make treatment for your heart failure easier or harder? (Circle all that apply.)

- (1) Cost of food and medicines
- (2) Difficulty when eating out
- (3) Understanding and support from family and friends
- (4) Seeing my physician regularly
- (5) How available low salt, heart healthy options are in my local grocery store
- (6) Taking too many medications
- (7) Knowing enough about what it means to have a low salt, heart healthy diet
- (8) Other dietary restrictions
- (9) Medication side effects
- (10) Other _____

I am able to follow a low salt, heart healthy diet when dining outside my home.

(1)	(2)	(3)	(4)	(5)
Strongly agree	Somewhat agree	Unsure	Somewhat disagree	Strongly disagree

Before I do something I carefully consider the consequences.

(1)	(2)	(3)	(4)	(5)
Strongly agree	Somewhat agree	Unsure	Somewhat disagree	Strongly disagree

I do not consider myself a failure.

(1)	(2)	(3)	(4)	(5)
Strongly agree	Somewhat agree	Unsure	Somewhat disagree	Strongly disagree

I would prefer to take an extra medicine everyday instead of follow a low salt, heart healthy diet.

(1)	(2)	(3)	(4)	(5)
Strongly agree	Somewhat agree	Unsure	Somewhat disagree	Strongly disagree

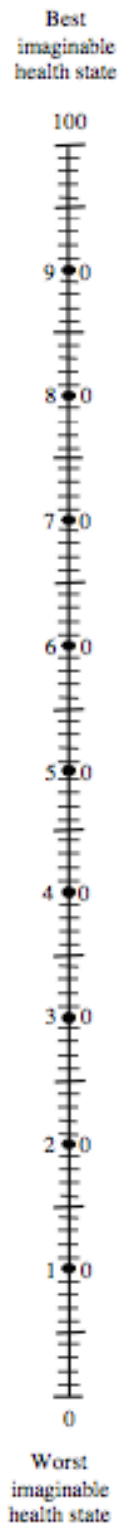
Over the past four weeks, how many times have you made mistakes in your diet and medications as a person with Heart Failure?

0 times (Never)	1-2 times	3-5 times	6-10 times	More than 10 times
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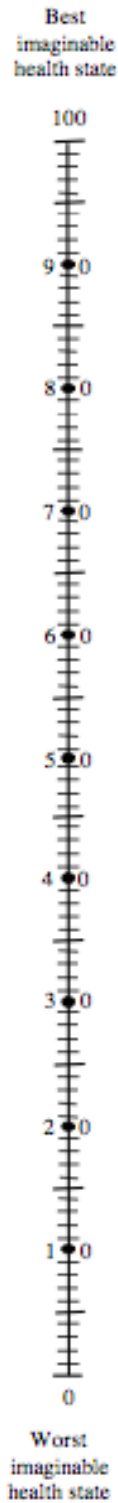
Have you been bothered by symptoms of Heart Failure during the past four weeks?

(1)	(2)	(3)	(4)	(5)
All the time	Most of the time	Sometimes	A little of the time	None of the time

To help people say how good or bad a health state is, we have drawn a scale (like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your overall health.



Please use the figure of a thermometer below for this next question. Now rate your health in relation to your heart failure. The best state you can imagine is marked 100 and the worst state you can imagine is marked 0. Indicate on this scale how good or bad your own health is today by placing an “X” next to how you would score your health in relation to your diabetes.



Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an “X” next to how hard you think it is to follow your heart failure treatment.

Very Difficult



Very Easy

Please use the figure of a thermometer below for this next question. A score of 100 represents VERY IMPORTANT, a score of 0 represents NOT IMPORTANT AT ALL. Please place an “X” next to how important it is to your health to follow your heart failure treatment.

Very Important



Not Important
At All