I. CELIAC DATA COLLECTION SHEET

Age:	Zip Code:	Gender:	Male	Female
* *	Indian or Alaska Native African American	` '		
Ethnicity: (1)Hispanic of	r Latino(a) (2) No	ot Hispanic or Latino(a)	
Marital statu (1)Single (2)	s: 2)Married (3)Divorced	(4)Separated		
Educational 1 (1) Completed (3) High Schot (5) Associate (7) Bachelor's (9) Profession	d Grade School (K-8) ol Graduate degree s degree	(2) Completed Some(4) Some College (No.(6) Trade School(8) Master's degree(10) Doctorate degree	o degree)	ool (No diploma)
-	ently employed? (1) F		(3) Unem	nployed
What is your	household annual incom	e:		
<\$25,000 \$2	25,001-50,000 \$50,001-73	5,001 \$75,001-100,00	00 \$100,00	00-200,000 >\$200,000
At what age	were you diagnosed with	Celiac Disease?		
•	r diagnosis of celiac disea wel biopsy (portion of the tibody tests		stine is rem	noved for examination)
What sympto	ms if any did you or do yo	ou experience related	to celiac d	lisease?
	lid the signs and symptor first appear?	ns of celiac disease (if	any signs	and symptoms were
	e approximate length of t ight medical advice?	ime between presenta	tion of syr	mptoms (if any) and
How long hav	ve you been following the	gluten-free diet (in yo	ears and/o	r months)?

Wh	at is yo	our hea	lth insu	rance?			
Ma	assHealt	h	Priva	ate	Medic	care or Medicaid	None
Ho	w many	times	have yo	ou seen	your fa	amily doctor in the pas	t year?
	0	1	2	3	4	<u>≥</u> 5	
Ho	w many	times	have yo	ou seen	your d	ietician/nutritionist in	the past year?
	0	1	2	3	4	<u>≥</u> 5	
Ho	w many	times	have yo	ou visit	ed your	gastroenterologist in t	the past year?
0	1	2	3	4	<u>≥</u> 5		
Ho	w many	times	have yo	ou been	hospit	alized in the past year?	•
	0	1	2	3	<u>></u> 4		
	In the	past fi	ve year	s?			
0	1	2	3	<u>></u> 4			
Do	you bel	long to	a suppo	ort gro	up for (Celiac Disease?	
	YES	S	N	Ю			
	at facto oly.)	ors mal	ke treat	ment f	or your	Celiac Disease easier of	or harder? (Circle all that
(2) (3) (4) (5) (6) (7) (8) (9) (10	(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	None of the time	A little of the time	Some of the time	Most of the time	All of the time
weeks? 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	Excellent	Good	Fair	Poor	Terrible
your health?	T 11 .	G 1	Б.	D	TD '11
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

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.

imaginable health state 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.

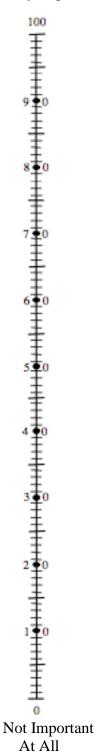
Very Difficult



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



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 (3) Black or African American (5) Caucasian			(2) Asian(4) Native Hawaiian(6) More than one rad		
Ethnicity: (1)Hispanic or 1	Latino(a)	(2) No	ot Hispanic or Latino(a))	
Marital status: (1)Single (2)		(3)Divorced	(4)Separated		
(1) Completed (3) High Schoo (5) Associate do (7) Bachelor's (9) Professional	Grade Sch I Graduate egree degree I degree		(2) Completed Some (4) Some College (No (6) Trade School (8) Master's degree (10) Doctorate degree	o degree)	
Occupation:					
What is your h <\$25,000 \$25				00 \$100,00	00-200,000 >\$200,000
At what age w	ere you di	agnosed with l	Heartburn?		
What symptom	s if any d	id you or do yo	ou experience related	to Heartb	urn?
At what age di experienced) fi	_		ns of Heartburn (if an	ny signs ar	nd symptoms were
What was the when you soug		0	me between presenta	tion of syr	nptoms (if any) and
How long have	you been	receiving trea	itment for Heartburn	(in years	and/or months)?

Но	w many	times	have you	ı seen you	r far	mily doctor in th	e past year?		
0	1	2	3	4 ≥5					
Но	w many	times	have you	ı visited a	gast	roenterologist ir	the past yea	ır?	
0	1	2	3	4 ≥5					
Но	ow many	times	have you	ı been hos	pital	lized in the past	year?		
0	1	2	3	<u>></u> 4					
	In the	past fi	ve years	?					
0	1	2	3	> 4					
					arth	urn? (Circle all	that annly)		
				•					
	(1) On	ce a da	y medica	tion (Pleas	e list	t st)	
	(2) Tw	ice a d	ay medic	ation (Plea	se li	st)	
	(3) Life	estvle o	changes (for examp	le. el	evating the head	of the bed. no	t lying down	
			after eatir		,			· - J	
		•		•	Anti	ing small meals,	avoiding enic	y or acidic for	nde.
					, cau	ing sinan meais,	avolumg spic	y or acture roc	Jus,
	avoiuii	ig carr	eine and	aiconoi)					
Wł	hat facto	rs mal	ke treatn	nent for h	eartl	burn easier or h	arder? (Circl	e all that app	oly.)
	(1) Cos	st of fo	od and m	edicines					
	(2) Eat								
	` /	_		support fr	om f	amily and friends	1		
			_	an regularly		anning and mond.	,		
						my local grocery	y store		
								naas ta aante	ol my
		_	enougn a	bout what	it ine	eans to use dietar	y/mestyle cha	inges to contr	or my
	sympto		. •	.•					
			ary restri						
			n side eff						
		_	o many m						
	$(10) O_1$	ther			_				
								1	I
		stion		1		2	3	4	5
	le to follo						Neither		G
	tion sched		-	Strong		Somewhat	Agree nor	Somewhat	Strongly
_	s, and die	t when	outside	Agre	e	Agree	Disagree	Disagree	Disagre
hon	ne								
C	т 1	. 41. t T	C . 11	G	_1	Compryhat	Neither	Comprehat	Ctmon ol

Somewhat

Agree

Strongly

Agree

Medicare or Medicaid

None

Somewhat

Disagree

Agree nor

Disagree

Strongly

Disagree

MassHealth

Before I do something I carefully consider the consequences

Private

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.

Best imaginable health state 100

Worst imaginable health state 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.

by placin arn.

Best imaginable health state

100

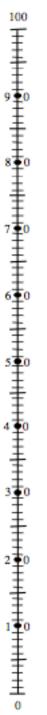
9 • 0

7 • 0

5 • 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.

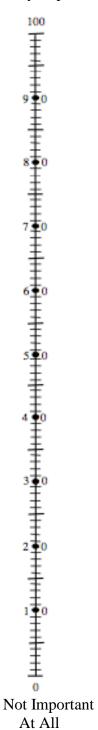
Very Difficult



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



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:	P A1 1 NT C	(2) A :		
* *	lian or Alaska Native	• *	O4h D	oific Islandon
(3)Black or Africation (5) Caucasian	can American	(4) Native Hawaiian (
(3) Caucasian		(6) More than one rac	te (Flease)	11St)
Ethnicity:				
(1)Hispanic or L	atino(a) (2) No	ot Hispanic or Latino(a))	
Marital status:				
(1)Single (2)N	farried (3)Divorced	(4)Separated		
Educational Le				
` /	Grade School (K-8)	(2) Completed Some		ol (No diploma)
(3) High School		(4) Some College (No	degree)	
(5) Associate de	_	(6) Trade School		
(7) Bachelor's d	<u> </u>	(8) Master's degree		
(9) Professional	degree	(10) Doctorate degree	2	
-	tly employed? (1) Fu		(3) Unem	ployed
-	ousehold annual income			
<\$25,000 \$25,	001-50,000 \$50,001-75	5,001 \$75,001-100,00	0 \$100,00	00-200,000 >\$200,000
At what age we	re you diagnosed with (Crohn's Disease or Ul	cerative C	Colitis?
What symptoms Ulcerative Colin	s if any did you or do yo tis?	ou experience related	to Crohn'	s Disease or
	I the signs and sympton toms were experienced)		or Ulcera	tive Colitis (if any
	pproximate length of ti nt medical advice?	me between presenta	tion of syn	nptoms (if any) and
How long have years and/or me	you been receiving trea	atment for Crohn's Di	sease or U	Ticerative Colitis (in

Wi	nat is	your h	ealth ins	urance	?			
MassHealth Private				vate	Medicare or Medicaid	None		
Но	w ma	ny time	es have y	you seei	n your family doctor in th	ne past year?		
0	$0 1 2 3 4 \ge 5$							
Но	w ma	ny timo	es have y	you visi	ted a gastroenterologist i	n the past year?		
0	1	2	3	4	<u>></u> 5			
Но	w ma	ny time	es have y	you bee	n hospitalized in the past	year?		
0	1	2	3	<u>></u> 4				
	In tl	he past	five yea	rs?				
0	1	2	3	<u>></u> 4				
	nat is ply)	the trea	atment f	or your	· Crohn's Disease or Ulce	erative Colitis? (Circle all that		
	(2) A (3) 6 (4) I	Antibiot 5-Merca muran	tics like optopurir (Azathio	Flagyl (ne (6-M		Sulfasalazine acin, Clarithromycin, Rifaximin		
	(6) I	_	es like In	flixima	b (Remicade) or Adalimum	nab (Humira)		
	(8) S	Methotr Surgery						
	(9) I	Lifestyl	e change	s (dieta		Cortifoam, Hydrocortisone tion, avoiding certain triggers, etc)		
***	. 0		•					
Wi	iat fac	ctors m	iake trea	itment	for your disease easier or	harder? (Circle all that apply.)		
			_		ort from family and friend	S		
			ng my su ny physi		-			
		_		_	my disease			
			medicin		•			
			too many		ines			
	. ,		ion side					

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.

Best imaginable health state 100 Worst

imaginable health state 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.



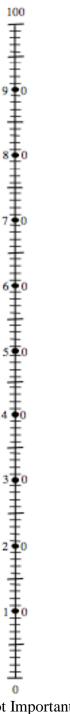
Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an "X" next to how hard you think it is to follow your Crohn's Disease or Ulcerative Colitis treatment.

Very Difficult



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
* /	an Indian or Alaska Native r African American ian	* *		
Ethnicity: (1)Hispani	c or Latino(a) (2) N	ot Hispanic or Latino(a)	
Marital st (1)Single	atus: (2)Married (3)Divorced	(4)Separated		
(3) High S(5) Associate(7) Bachel	eted Grade School (K-8) chool Graduate	(2) Completed Some(4) Some College (No.(6) Trade School(8) Master's degree(10) Doctorate degree	o degree)	ol (No diploma)
Are you co	urrently employed? (1) Fon:			
What is yo	our household annual incom	e:		
<\$25,000	\$25,001-50,000 \$50,001-7	5,001 \$75,001-100,00	00 \$100,00	00-200,000 >\$200,000
At what a	ge were you diagnosed with	Irritable Bowel Syndi	rome?	
What sym	ptoms did you or do you exp	perience related to Irri	table Bow	el Syndrome?
At what a	ge did the signs and sympton	ms of Irritable Bowel	Syndrome	first appear?
	the approximate length of tedical advice?	ime between presenta	tion of syn	aptoms and when you
How long months)?	have you been receiving tre	atment for Irritable B	owel Synd	rome (in years and/or

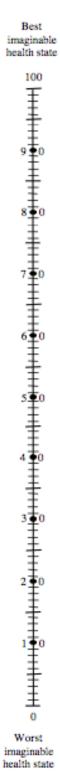
Wl	nat is y	our h	ealth ins	surance'	?	
MassHealth Private		Medicare or Medicaid	None			
Ho	w man	y time	es have	you seer	n your family doctor in the p	oast year?
0	1	2	3	4	<u>≥</u> 5	
Но	w man	y time	es have	you visi	ted a gastroenterologist in th	ne past year?
0	1	2	3	4	<u>≥</u> 5	
Но	w man	y time	es have	you bee	n hospitalized in the past yea	ar?
0	1	2	3	<u>></u> 4		
	In th	e past	five yea	rs?		
0	1	2	3	<u>></u> 4		
Do	you b		_	_	oup for Irritable Bowel Synd	trome?
		YES	5	NC)	
Ho	w is yo	ur Irr	itable I	Bowel Sy	vndrome treated? (Circle all	that apply)
	(2) N	iet cha Iedicat	ions (Pl	ease spe	cify)
	(3) C	ounsel	ing fron	a thera	pist or psychologist	
	(5) I	am not	underg	oing any	treatment for my Irritable Bo	wel Syndrome
	nat fac it appl		ake tre	atment 1	for Irritable Bowel Syndrom	ne easier or harder? (Circle all
	(2) U (3) A (4) Se (5) Se (6) K (7) C (9) T (10) I	nderstatendireeing anowin ost of aking t	ng my su my phys a therapi g enoug special f too man ation sid	and supp apport grician reg st/psych h about	gularly ologist my disease d/or medications nes	

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	Excellent	Good	Fair	Poor	Terrible
Syndrome, how is your health? 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.

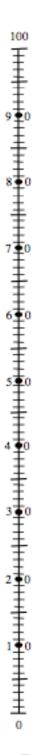
Best imaginable health state 100

Worst imaginable health state 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.

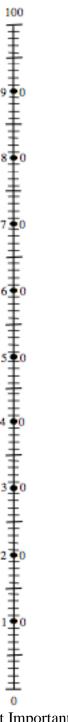
Very Difficult



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 (3) Black or African American (5) Caucasian		(2) Asian(4) Native Hawaiian or Other Pacific Islander(6) More than one race (Please list):			
Ethnicity: (1)Hispanic or La	tino(a) (2) No	ot Hispanic or Latino(a))		
Marital status: (1)Single (2)Ma	arried (3)Divorced	(4)Separated			
Educational Lev (1) Completed Gr (3) High School C (5) Associate degr (7) Bachelor's degr (9) Professional d	ade School (K-8) Graduate ree gree	(2) Completed Some(4) Some College (No(6) Trade School(8) Master's degree(10) Doctorate degree	o degree)	ol (No diploma)	
•	y employed? (1) Fu				
	ısehold annual incom				
<\$25,000 \$25,0	01-50,000 \$50,001-75	5,001 \$75,001-100,00	00 \$100,00	00-200,000 >\$200,000	
At what age were	e you diagnosed with l	Hypertension (high bl	ood pressi	ıre)?	
What symptoms is	if any did you or do yo	ou experience related	to Hyperto	ension?	
At what age did experienced) firs	the signs and sympton t appear?	ns of Hypertension (if	any signs	and symptoms were	
What was the ap when you sought	proximate length of ti medical advice?	ime between presenta	tion of syn	nptoms (if any) and	
How long have y	ou been receiving trea	ntment for Hypertensi	on (in yea	rs 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 3 > 5 How many times have you visited a specialist for your Hypertension (like a kidney doctor) in the past year? 0 1 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 3 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

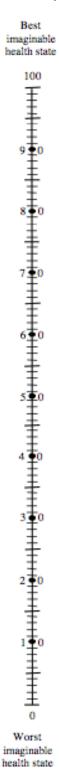
Question	1	2	3	4	5
I am able to follow my medication schedule and diet when outside my home	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Before I do something I carefully consider the consequences	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree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

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.



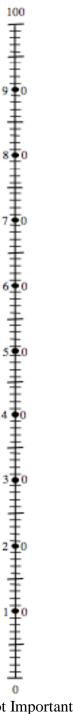
Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an "X" next to how hard you think it is to follow your Hypertension treatment.

Very Difficult



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 Renal Disease (Kidney Failure) that is with regard to your End Stage Kidney	requires Dialysis. Pleas	_	O			
Age: Zip Code:	Gender:	Male	Female			
Race: (1) American Indian or Alaska Native (3) Black or African American (5) Caucasian	(4) Native Hawaiian	(2) Asian(4) Native Hawaiian or Other Pacific Islander(6) More than one race (Please list):				
Ethnicity: (1)Hispanic or Latino(a) (2) N	Not Hispanic or Latino(a))				
Marital status: (1)Single (2)Married (3)Divorced	d (4)Separated					
Educational Level: (1) Completed Grade School (K-8) (3) High School Graduate (5) Associate degree (7) Bachelor's degree (9) Professional degree	(2) Completed Some(4) Some College (No(6) Trade School(8) Master's degree(10) Doctorate degree	degree)	ol (No diploma)			
Are you <i>currently</i> employed? (1) Occupation:		(3) Unem	ployed			
What is your household annual incom	me:					
<\$25,000 \$25,001-50,000 \$50,001-7	75,001 \$75,001-100,00	0 \$100,00	00-200,000 >\$200,000			
At what age were you diagnosed with	n End-Stage Kidney Fai	lure?				
What symptoms if any did you or do	you experience related	to End-Sta	age Kidney Failure?			
At what age did the signs and symptosymptoms were experienced) first ap	O	ey Failure	(if any signs and			
What was the approximate length of when you sought medical advice?	time between presentat	tion of syn	nptoms (if any) and			
How long have you been receiving tremonths)?	eatment for End-Stage	Kidney Fa	ailure (in years and/o			

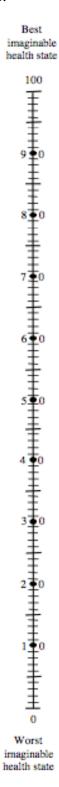
What is your health insurance?							
MassHealth Private		Medicare or Medicaid	None				
Но	w mai	ny time	es have	you seei	n your family doctor in the p	past year?	
0	1	2	3	4	<u>≥</u> 5		
Но	w mai	ny timo	es have	you visi	ted a kidney doctor in the p	ast year?	
0	1	2	3	4	<u>≥</u> 5		
Но	w mai	ny timo	es have	you bee	n hospitalized in the past ye	ar?	
0	1	2	3	<u>></u> 4			
	In th	ne past	five yea	rs?			
0	1	2	3	<u>></u> 4			
Wł	at is t	the trea	atment 1	for your	Kidney Disease? (Please ci	rcle all that apply.)	
	(1) Dialysis (2) A low protein, kidney healthy diet (3) One medication (Please list)						
	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).

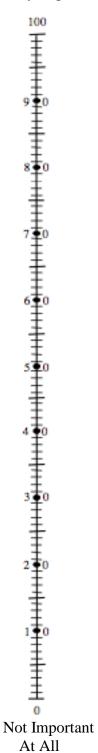
Very Difficult



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



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		
	ndian or Alaska Native Frican American					
Ethnicity: (1)Hispanic or	Latino(a) (2) No	ot Hispanic or Latino(a)			
Marital status (1)Single (2)	S:)Married (3)Divorced	(4)Separated				
(3) High School (5) Associate of (7) Bachelor's (9) Professional Are you <i>curre</i>	Grade School (K-8) ol Graduate legree degree al degree ntly employed? (1) Fu	(4) Some College (No.(6) Trade School(8) Master's degree(10) Doctorate degreeall-time (2) Part-time	degree) (3) Unen	nployed		
	household annual income					
<\$25,000 \$2	5,001-50,000 \$50,001-75	5,001 \$75,001-100,00	00 \$100,00	00-200,000 >\$200,000		
At what age w	vere you diagnosed with l	Diabetes?				
What sympton	ns if any did you or do yo	ou experience related	to Diabeto	es?		
At what age d experienced) f	id the signs and sympton first appear?	ns of Diabetes (if any	signs and	symptoms were		
	approximate length of ti ght medical advice?	me between presenta	tion of syr	nptoms (if any) and		
How long hav	e you been receiving trea	atment for Diabetes (i	n years an	nd/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 3 2 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 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.

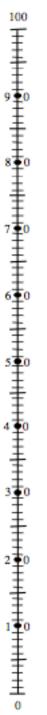
Best imaginable health state 100

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.

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.

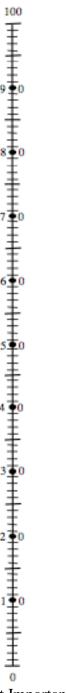
Very Difficult



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. **Zip Code**: _____ Gender: Female Male Other Race: Caucasian African American Hispanic 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: High School Less than high school **GED** Undergraduate college Graduate College/ Higher What is your health insurance? MassHealth Medicare or Medicaid Private None How many times have you seen your family doctor in the past year? 0 1 2 3 4 <u>≥</u>5 How many times have you visited your cardiologist in the past year? 0 1 2 3 <u>≥</u>5 How many times have you been hospitalized in the past year? 0 1 2 3 > 4 In the past five years?

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

> 4

0

1

2

3

(1) All the time	(2) Most of the time	(3) Sometimes	(4) A little of the time	(5) 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	o follow a low salt, h	eart healthy o	diet when dining outsi	de my home.				
(1) Strongly agree	(2) Somewhat agree	(3) Unsure	(4) Somewhat disagree	(5) Strongly disagree				
Before I do something I carefully consider the consequences.								
(1) Strongly agree	(2) Somewhat agree	(3) Unsure	(4) Somewhat disagree	(5) Strongly disagree				
I do not cor	I do not consider myself a failure.							
(1) Strongly agree	(2) Somewhat agree	(3) Unsure	(4) Somewhat disagree	(5) Strongly disagree				
I would prefer to take an extra medicine everyday instead of follow a low salt, heart healthy diet.								
(1) Strongly agree	(2) Somewhat agree	(3) Unsure	(4) Somewhat disagree	(5) 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 Mo	re than 10 times				
Have you been bothered by symptoms of Heart Failure during the past four weeks?								
(1) All the time	(2) Most of the time	(3) Sometimes	(4) A little of the time	(5) 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.

Best imaginable health state 100

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.

imaginable health state

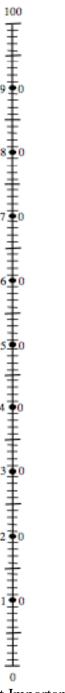
Please use the figure of a thermometer below for this next question. A score of 100 represents VERY DIFFICULT, a score of 0 represents VERY EASY . Please place an "X" next to how hard you think it is to follow your heart failure treatment.

Very Difficult



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