**\* COMPUTES FOR PCORI PATIENT SURVEY – BASELINE;**

**\* overall quality of health care since lung cancer diagnosis (p. 1 patient survey);**

\* from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 35);

\*set 6 (don’t know) and 7 (does not apply) to missing;

if 6 le pt\_overall\_quality le 7 then pt\_overall\_quality = .;

\* reverse code so greater numeric response = greater satisfaction (range 0-4)

xpt\_overall\_quality= abs(pt\_overall\_quality)-5;

**\* Quality of care compared to other lung cancer patients (p. 1 patient survey);**

\* from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 35);

\*set 6 (don’t know) and 7 (does not apply) to missing;

if 6 le pt\_care\_comparison le 7 then pt\_care\_comparison = .;

\* reverse code so greater numeric response = greater satisfaction (range 0-4);

xpt\_care\_comparison = abs(pt\_overall\_quality)-5;

**\* CAHPS items – Treatment Decision Making (pp 1-3 patient survey);**

\* from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 10-51);

\* Coding of these items is based on Keating et al., J Clinical Oncol, 2010, 28, 4364-4370 and Weeks et al., NEJM, 2012, 367:1616-25;

\* For each modality (surgery, chemo, radiation), categorize responses into “patient controlled,” “shared control,” or “physician control” per Keating;

\* To keep the scoring simple, we will assume that the patient response “does not apply to me” means that the modality was not considered as an option, however if there is substantial missing data we will need to examine responses to the preceding items on whether the patient received the modality, is scheduled to receive the modality and discussed the modality with the physician;

\* Computes for modality = surgery;

if 1 le treatment\_1d\_surgery le 2 then surgdecision= 0; \*0=patient controlled;

if treatment\_1d\_surgery= 3 then surgdecision= 1; \*1=shared decision;

if 4 le treatment\_1d\_surgery le 5 then surgdecision= 2; \*2= physician decision;

\* Computes for modality = radiation;

if 1 le treatment\_2d\_radiation le 2 then raddecision= 0; \*0=patient controlled;

if treatment\_2d\_radiation= 3 then raddecision= 1; \*1=shared decision;

if 4 le treatment\_2d\_radiation le 5 then raddecision= 2; \*2= physician decision;

\* Computes for modality = chemotherapy;

if 1 le treatment\_3d\_chemo le 2 then chemodecision= 0; \*0=patient controlled;

if treatment\_3d\_chemo= 3 then chemodecision= 1; \*1=shared decision;

if 4 le treatment\_3d\_chemo le 5 then chemodecision= 2; \*2= physician decision;

\* Computes for decision-making role of the family;

\* if 1 le family\_tx\_decision le 2 then familydecision= 0; \*0=patient controlled;

if family\_tx\_decision = 3 then familydecision= 1; \*1=shared decision;

if 4 le family\_tx\_decision le 5 then familydecision= 2; \*2= physician decision;

**\* Satisfaction with treatment length of time (p. 3 patient survey);**

\* We created these items;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le pt\_sat\_time\_to\_diagnosis le 6 then pt\_sat\_time\_to\_diagnosis= .;

if 5 le pt\_sat\_time\_to\_treatment le 6 then pt\_sat\_time\_to\_treatment= .;

if 5 le pt\_sat\_time\_to\_complete\_tx le 6 then pt\_sat\_time\_to\_complete\_tx= .;

\* reverse code so greater numeric response = better (more frequent) physician communication (range 0-3);

xpt\_sat\_time\_to\_diagnosis= abs(pt\_sat\_time\_to\_diagnosis)-4;

xpt\_sat\_time\_to\_treatment= abs(pt\_sat\_time\_to\_treatment)-4;

xpt\_sat\_time\_to\_complete\_tx= abs(pt\_sat\_time\_to\_complete\_tx)-4;

**\* Satisfaction with treatment plan (p. 3 patient survey);**

**\*** Note that on the patient survey, both of these items were asked, regardless of whether the patient’s treatment had yet been completed… likewise, items regarding obstacles on completing treatment (p. 4 patient survey) were asked regardless of whether treatment was completed;

\* We created these items;

\* recode so range is 0-2 instead of 1-3;

xpt\_sat\_treatment\_plan= pt\_sat\_treatment\_plan-1; \*(pt\_sat\_time\_to\_treatment)

xpt\_sat\_treatment\_compl= pt\_sat\_treatment\_compl;

\* sum the 2 items – later, check intercorrelation;

ptsumsattxplan= sum(xpt\_sat\_treatment\_plan, xpt\_sat\_treatment\_compl);

**\* Barriers to completing treatment plan (p. 4 patient survey);**

\* rescore 1=yes, 2=no to 0=no, 1=yes;

\* note that these items were asked regardless of whether treatment was completed;

array aa [8] pt\_issues\_a pt\_issues\_b pt\_issues\_c pt\_issues\_d pt\_issues\_e pt\_issues\_f pt\_issues\_g pt\_issues\_h;

array bb [8] xpt\_issues\_a xpt\_issues\_b xpt\_issues\_c xpt\_issues\_d xpt\_issues\_e xpt\_issues\_f xpt\_issues\_g xpt\_issues\_h;

do i= 1 to 8;

bb[i]= abs(aa[i]-2);

end; drop i;

\* create sum score;

sumbarriers= sum(xpt\_issues\_a, xpt\_issues\_b, xpt\_issues\_c, xpt\_issues\_d, xpt\_issues\_e, xpt\_issues\_f, xpt\_issues\_g, xpt\_issues\_h);

drop xpt\_issues\_a xpt\_issues\_b xpt\_issues\_c xpt\_issues\_d xpt\_issues\_e xpt\_issues\_f xpt\_issues\_g xpt\_issues\_h;

**\* Satisfaction with quality of care from various team members (p. 4 patient survey);**

\* set 5 (don’t know) and 6 (does not apply) to missing;

array bb [8] pt\_sat\_care\_pcc pt\_sat\_care\_onc pt\_sat\_care\_pulm pt\_sat\_care\_surgeon pt\_sat\_care\_nurse\_nav pt\_sat\_care\_other\_nurses pt\_sat\_care\_nonclinic

pt\_sat\_care\_whole\_team;

array cc [8] xpt\_sat\_care\_pcc xpt\_sat\_care\_onc xpt\_sat\_care\_pulm xpt\_sat\_care\_surgeon xpt\_sat\_care\_nurse\_nav xpt\_sat\_care\_other\_nurses xpt\_sat\_care\_nonclinic

xpt\_sat\_care\_whole\_team;

if 5 le bb[i] le 6 then bb[i]= .;

end; drop i;

\* reverse code so greater numeric response = greater satisfaction (range 0-3);

cc[i]= abs(bb[i]-4);

end; drop i;

\* create sum score for overall satisfaction with quality of care;

sumsatqc= sum(xpt\_sat\_care\_pcc, xpt\_sat\_care\_onc, xpt\_sat\_care\_pulm, xpt\_sat\_care\_surgeon, xpt\_sat\_care\_nurse\_nav, xpt\_sat\_care\_other\_nurses, xpt\_sat\_care\_nonclinic, xpt\_sat\_care\_whole\_team);

**\* CAHPS items – Physician communication – 5 item version (p. 5 patient survey);**

\* Replicate scale used in Weeks et al., NEJM, 2012, 367:1616-25 (see p. 1618), which is sum of 5 CAHPS items;

\* note that Weeks et al. re-scales instrument for a 0-100 range – we are retaining the 1-4 scores on each of the 5 items (total scale score range of 5-20) from the original CAHPS survey;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le pt\_exp\_phys\_listen le 6 then pt\_exp\_phys\_listen= .;

if 5 le pt\_exp\_phys\_explain le 6 then pt\_exp\_phys\_explain= .;

if 5 le pt\_exp\_phys\_tx\_inform le 6 then pt\_exp\_phys\_tx\_inform= .;

if 5 le pt\_exp\_phys\_encourage le 6 then pt\_exp\_phys\_encourage= .;

if 5 le pt\_exp\_phys\_respect le 6 then pt\_exp\_phys\_respect= .;

\* reverse code so greater numeric response = better (more frequent) physician communication;

xpt\_exp\_phys\_listen= abs(pt\_exp\_phys\_listen)-5;

xpt\_exp\_phys\_explain= abs(pt\_exp\_phys\_explain)-5;

xpt\_exp\_phys\_tx\_inform= abs(pt\_exp\_phys\_tx\_inform)-5;

xpt\_exp\_phys\_encourage= abs(pt\_exp\_phys\_encourage)-5;

xpt\_exp\_phys\_respect= abs(pt\_exp\_phys\_respect)-5;

\* create sum score;

sumphyscomm5= sum(xpt\_exp\_phys\_listen, xpt\_exp\_phys\_explain, xpt\_exp\_phys\_tx\_inform,

xpt\_exp\_phys\_encourage, xpt\_exp\_phys\_respect);

**\* CAHPS items – Physician communication – 7 item version (p. 5 patient survey);**

\* We created 2 additional items (How often were doctors as helpful as you thought they should be, and How often did doctors seem to be aware of treatments for your lung cancer that other doctors recommend) to flesh out the 5-item CAHPS scale;

\* Create a 7 item scale using the 5-item scale from Weeks et al., NEJM, 2012;

\* will need to evaluate internal consistency of these items later;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le pt\_exp\_phys\_helpful le 6 then pt\_exp\_phys\_helpful= .;

if 5 le pt\_exp\_phys\_aware le 6 then pt\_exp\_phys\_aware= .;

xpt\_exp\_phys\_helpful= abs(pt\_exp\_phys\_helpful)-5;

xpt\_exp\_phys\_aware= abs(pt\_exp\_phys\_aware)-5;

sumphyscomm7= sum(xpt\_exp\_phys\_listen, xpt\_exp\_phys\_explain, xpt\_exp\_phys\_tx\_inform,

xpt\_exp\_phys\_encourage, xpt\_exp\_phys\_respect, xpt\_exp\_phys\_helpful, xpt\_exp\_phys\_aware);

**\* We created a 6-item nurse communication measure based on the CAHPS Physician Communication items (pp 5-6 patient survey);**

\* will need to verify internal consistency of this measure;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le pt\_exp\_nurse\_listen le 6 then pt\_exp\_nurse\_listen= .;

if 5 le pt\_nurses\_often\_explain le 6 then pt\_nurses\_often\_explain= .;

if 5 le pt\_nurses\_often\_info le 6 then pt\_nurses\_often\_info= .;

if 5 le pt\_nurses\_often\_encourage le 6 then pt\_nurses\_often\_encourage= .;

if 5 le pt\_nurses\_often\_treat le 6 then pt\_nurses\_often\_treat= .;

if 5 le pt\_nurses\_often\_help le 6 then pt\_nurses\_often\_help= .;

\* reverse code so greater numeric response = better (more frequent) nurse communication (0-3 scoring for each item);

xpt\_exp\_nurse\_listen= abs(pt\_exp\_nurse\_listen)-4;

xpt\_nurses\_often\_explain = abs(pt\_nurses\_often\_explain)-4;

xpt\_nurses\_often\_info = abs(pt\_nurses\_often\_info)-4;

xpt\_nurses\_often\_encourage = abs(pt\_nurses\_often\_encourage)-4;

xpt\_nurses\_often\_treat = abs(pt\_nurses\_often\_treat)-4;

xpt\_nurses\_often\_help = abs(pt\_nurses\_often\_help)-4;

\* create sum score;

sumnursecomm= sum(xpt\_exp\_nurse\_listen, xpt\_nurses\_often\_explain, xpt\_nurses\_often\_info, xpt\_nurses\_often\_encourage, xpt\_nurses\_often\_treat,

xpt\_nurses\_often\_help);

**/\* 4 items (p. 6 of patient survey) plus 1 item (item 7 on p. 7 patient survey) ask about satisfaction with care from the team as a whole; \*/**

\* the first two items are from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 6) and the second two we created ourselves;

\* item 7 on p.7 patient survey (included with the Pardon et al., 2011 items) belongs here – pt\_inform\_all\_they\_could;

\* create sum score from these 4 items – check inter-item consistency later;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le pt\_nurses\_often\_handle le 6 then pt\_nurses\_often\_handle= .;

if 5 le pt\_nurses\_often\_team le 6 then pt\_nurses\_often\_team= .;

if 5 le pt\_nurses\_often\_discomfort le 6 then pt\_nurses\_often\_discomfort= .;

if 5 le pt\_nurses\_often\_understand le 6 then pt\_nurses\_often\_understand= .;

if 5 le pt\_inform\_all\_they\_could le 6 then pt\_inform\_all\_they\_could = .;

\* reverse code so greater numeric response = better (more frequent) physician communication (range 0-3);

xpt\_nurses\_often\_handle= abs(pt\_nurses\_often\_handle)-4;

xpt\_nurses\_often\_team= abs(pt\_nurses\_often\_team)-4;

xpt\_nurses\_often\_discomfort= abs(pt\_nurses\_often\_discomfort)-4;

xpt\_nurses\_often\_understand= abs(pt\_nurses\_often\_understand)-4;

xpt\_inform\_all\_they\_could= abs(pt\_inform\_all\_they\_could)-4;

\* create sum score;

sumteamsat= sum(xpt\_nurses\_often\_handle, xpt\_nurses\_often\_team,

xpt\_nurses\_often\_discomfort, xpt\_nurses\_often\_understand, xpt\_inform\_all\_they\_could);

**\* Communication about disease-specific information;**

**/\*** The questions are adapted from *K. Pardon et al., Are patients’ preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. Palliative Medicine, 2011, 25(1), 62-70.* For consistency, responses changes from 6-point Likert (totally disagree to totally agree) to 4 items that are used in the CAHPS patient survey (always, usually, sometimes, never) \*/

\* note that Item 7 (p. 7 of patient survey) does not belong here – it is not an item from the Pardon et al. scale, which has just 6 items about specific types of information (we did not include the “In general…” question);

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le pt\_inform\_diagnosis le 6 then pt\_inform\_diagnosis= .;

if 5 le pt\_inform\_tx\_options le 6 then pt\_inform\_tx\_options= .;

if 5 le pt\_inform\_cure\_chance le 6 then pt\_inform\_cure\_chance= .;

if 5 le pt\_inform\_life\_expectancy le 6 then pt\_inform\_life\_expectancy= .;

if 5 le pt\_inform\_palliative\_care le 6 then pt\_inform\_palliative\_care = .;

if 5 le pt\_inform\_end\_of\_life le 6 then pt\_inform\_end\_of\_life = .;

\* reverse code so greater numeric response = better (more frequent) response (range 0-3);

xpt\_inform\_diagnosis= abs(pt\_inform\_diagnosis)-4;

xpt\_inform\_tx\_options= abs(pt\_inform\_tx\_options)-4;

xpt\_inform\_cure\_chance= abs(pt\_inform\_cure\_chance)-4;

xpt\_inform\_life\_expectancy= abs(pt\_inform\_life\_expectancy)-4;

xpt\_inform\_palliative\_care= abs(pt\_inform\_palliative\_care)-4;

xpt\_inform\_end\_of\_life= abs(pt\_inform\_end\_of\_life)-4;

\* create sum score from these 6 items – check inter-item consistency later;

sumptinfo= sum(xpt\_inform\_diagnosis, xpt\_inform\_tx\_options, xpt\_inform\_cure\_chance, xpt\_inform\_life\_expectancy, xpt\_inform\_palliative\_care, xpt\_inform\_end\_of\_life);

**\* Functional Assessment of Cancer Therapy – Lung (FACT-L) – Version 4;**

\* Some items must be reverse-scored, so that higher scores on all sub-scales and summary scores indicate better QOL;

\* At least 80% of the questions should be answered, per Paull et al. (p. 566) for the instrument to be scored;

\* As long as at least half of the items for any particular sub-scale are answered, a sub-scale score can be estimated by taking an average (Browning et al., p. 4; also see <http://www.meducator3.net/algorithms/content/lung-cancer-subscale-lcs-fact-l-1>);

/\* example algorithm to adjust the 6-item LCS sub-scale when only 4 of 6 items were answered;

total score adjusted to 7 items= ((score for answered items)\*7)/(number of items answered);

\*/

\* need to check missing data patterns: there may be very little missing data because Redcap doesn’t allow skips…if there is missing data, we need to follow above rules to calculate estimates;

\*set 6 (don’t know) and 7 (does not apply) to missing;

array dd [36] pt\_factl1 - ptfactl35 pt\_smoking\_regret;

do i= 1 to 36;

if 6 le dd[i] le 7 then dd[i] = .;

end; drop i;

\* reverse score negative items so that higher score means better functioning;

\* note that according to the Data Dictionary, the Baptist programmer changed the naming convention on the FACT-L after item 28 (e.g., item 28= pt\_factl28 while item 29= pt\_fctl\_29);

array ee [17] pt\_factl1 pt\_factl2 pt\_factl3 pt\_factl4 pt\_factl5 pt\_factl6 pt\_factl7 pt\_factl15 pt\_factl17 pt\_factl18 pt\_factl19 pt\_factl20 pt\_factl28 pt\_fctl\_29 pt\_fctl\_31 pt\_fctl\_32 pt\_fctl\_34;

array ff [17] xpt\_factl1 xpt\_factl2 xpt\_factl3 xpt\_factl4 xpt\_factl5 xpt\_factl6 xpt\_factl7 xpt\_factl15 xpt\_factl17 xpt\_factl18 xpt\_factl19 xpt\_factl20 xpt\_factl28 xpt\_fctl\_29 xpt\_fctl\_31 xpt\_fctl\_32 xpt\_fctl\_34;

do i= 1 to 17;

ff[i] = abs(ee[i])-6;

end; drop i;

\*create the 5 sub-scales;

\* Physical well-being (PWB) sub-scale;

PWB= sum(xpt\_factl1, xpt\_factl2, xpt\_factl3, xpt\_factl4, xpt\_factl5, xpt\_factl6, xpt\_factl7);

\* Social well-being (SWB) sub-scale;

SWB= sum(pt\_factl8, pt\_factl9, pt\_factl10, pt\_factl11, pt\_factl12, pt\_factl13, pt\_factl14);

\* Emotional well-being (EWB) sub-scale;

EWB= sum(xpt\_factl15, pt\_factl16, xpt\_factl17, xpt\_factl18, xpt\_factl19, xpt\_factl20);

\* Functional well-being (FWB) sub-scale;

FWB= sum(pt\_factl21, pt\_factl22, pt\_factl23, pt\_factl24, pt\_factl25, pt\_factl26, pt\_factl27);

\* Lung cancer scale (LCS) sub-scale;

LCS= sum(xpt\_factl28, xpt\_fctl\_29, pt\_fctl\_30, xpt\_fctl\_31, xpt\_fctl\_32, pt\_fctl\_33, xpt\_fctl\_34, pt\_fctl\_35, pt\_smoking\_regret);

\* calculate summary scales;

/\* Total summary score – see Paull et al., p. 566 \*/

FACTL= PWB + SWB + EWB + FWB + LCS; \*score range 0-136 -- \* note that total overall score range is 0-135 (not 0-136) per Browning et al., Lung Cancer, 2009, 66, 134-39;

/\* FACT-G score (generic measurement of QOL for patients with cancer in general, not lung cancer-specific, is the total FACT-L score minus the lung cancer subscale \*/

FACTG= PWB + SWB + EWB + FWB; \*score range 0-108;

/\* Trial outcome index (TOI) is a lung cancer-specific score that includes only the physical, functional, and lung cancer subscales.. TOI is particularly useful for postoperative lung cancer patients, per Paull et al. Am J Surgery, 2006, 192, 565-571 \*/

TOI= PWB + FWB + LCS; \*score range 0-84;

**\* cigarette smoking;**

\* double check my computes – if/then statements may have errors;

if pt\_smoking\_how\_many=1 then evercigsmoker= 1;

if pt\_smoking\_how\_many=0 then evercigsmoker= 0;

\*current cigarette smoker vs. never or former cigarette smoker;

if evercigsmoker=1 and pt\_smoking\_current=1 then currentcigsmoker=1;

if 0 le evercigsmoker le 1 and (currentcigsmoker ne 1) then currentcigsmoker=0;

**\* Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983);**

\* HADS has 2 sub-scales, Depression and Anxiety, and requires reverse coding on some items;

\* high score means worse depression or anxiety;

\* will need to check later for missing data… if so, will need to adjust scale scores;

\* correct scoring of individual items to match scoring in Zigmond & Snaith, 1983;

array aa [8] hads\_1 hads\_3 hads\_5 hads\_6 hads\_8 hads\_10 hads\_11 hads\_13; \* subtract 4 to reverse scoring and change range to 0-3;

array bb [6] hads\_2 hads\_4 hads\_7 hads\_9 hads\_12 hads\_14; \*scoring does not need to be reversed on these items – just subtract 1 to change range from 0-3;

array cc [8] hads1 hads3 hads5 hads6 hads8 hads10 hads11 hads13;

array dd [6] hads2 hads4 hads7 hads9 hads12 hads14;

do i = to 8;

cc[i]= abs(aa[i]-4);

end; drop i;

do i= 1 to 6;

dd[i]= bb[i]-1;

end; drop i;

\*create HADS sub-scales;

HADS\_d= sum(hads2, hads4, hads6, hads8, hads10, hads12, hads14); \*depression;

HADS\_a= sum(hads1, hads3, hads5, hads7, hads9, hads11, hads13); \*anxiety;

**\* Health literacy screener (from Chew et al., J Gen Intern Med, 2008, 23, 561-6);**

\* rescale from 1-5 to 0-4 to be consistent with original measure;

if 1 le pt\_health\_literacy\_forms le 5 then do;

healthlit= abs(pt\_health\_literacy\_forms)-1;

end;

**\* Financial burden of medical care;**

/\* from R.A. Cohen et al., Burden of medical care cost: early release of estimates from the National Health Interview Survey, January-June, 2011. National Center for Health Statistics. March 2012 \*/

/\* Note that these items are analyzed individually in the original publication, above,

but we will sum them to create a total score, with higher score indicating greater burden…

Later, check the inter-item consistency of these items \*/

If (1 le pt\_burden\_past\_12 le 2) and (1 le pt\_burden\_paid\_off le 2) and (1 le pt\_burden\_not\_paid le 2) then do;

Financialburden= sum(pt\_burden\_past\_12, pt\_burden\_paid\_off, pt\_burden\_not\_paid);

End;

**\* COMPUTES FOR PCORI CAREGIVER SURVEY – BASELINE;**

**\* overall quality of health care since lung cancer diagnosis (p. 1 caregiver survey);**

\* from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 35);

\*set 6 (don’t know) and 7 (does not apply) to missing;

if 6 le caregiver\_pt\_quality le 7 then caregiver\_pt\_quality = .;

\* reverse code so greater numeric response = greater satisfaction (range 0-4)

xcaregiver\_pt\_quality= abs(caregiver\_pt\_quality)-5;

**\* Quality of care compared to other lung cancer patients (p. 1 caregiver survey);**

\* from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 35);

\*set 6 (don’t know) and 7 (does not apply) to missing;

if 6 le caregiver\_lung\_care le 7 then caregiver\_lung\_care = .;

\* reverse code so greater numeric response = greater satisfaction (range 0-4);

xcaregiver\_lung\_care = abs(caregiver\_lung\_care)-5;

**\* CAHPS items – Treatment Decision Making (pp 1-3 caregiver survey);**

\* from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 10-51);

\* Coding of these items is based on Keating et al., J Clinical Oncol, 2010, 28, 4364-4370 and Weeks et al., NEJM, 2012, 367:1616-25;

\* For each modality (surgery, chemo, radiation), categorize responses into “patient controlled,” “shared control,” or “physician control” per Keating;

\* Computes for modality = surgery;

if 1 le cg\_1d\_tx\_surgery le 2 then cgsurgdecision= 0; \*0=patient controlled;

if cg\_1d\_tx\_surgery = 3 then cgsurgdecision= 1; \*1=shared decision;

if 4 le cg\_1d\_tx\_surgery le 5 then cgsurgdecision= 2; \*2= physician decision;

\* Computes for modality = radiation;

if 1 le cg\_2d\_tx\_radiation le 2 then cgraddecision= 0; \*0=patient controlled;

if cg\_2d\_tx\_radiation = 3 then cgraddecision= 1; \*1=shared decision;

if 4 le cg\_2d\_tx\_radiation le 5 then cgraddecision= 2; \*2= physician decision;

\* Computes for modality = chemotherapy;

if 1 le cg\_3d\_tx\_chemo le 2 then cgchemodecision= 0; \*0=patient controlled;

if cg\_3d\_tx\_chemo = 3 then cgchemodecision= 1; \*1=shared decision;

if 4 le cg\_3d\_tx\_chemo le 5 then cgchemodecision= 2; \*2= physician decision;

\* Computes for decision-making role of the family;

\* if 1 le cg\_4\_family\_decision le 2 then cgfamilydecision= 0; \*0=patient controlled;

if cg\_4\_family\_decision = 3 then cgfamilydecision= 1; \*1=shared decision;

if 4 le cg\_4\_family\_decision le 5 then cgfamilydecision= 2; \*2= physician decision;

**\* Satisfaction with treatment plan (p. 3 caregiver survey);**

\* We created these items;

\* Note that the 2 items can’t be summed (as they were for the patient survey) because the 2nd item (can pt complete treatment plan) was asked only of patients who have not yet initiated treatment or were currently receiving treatment;

\* change scaling from 1-3 to 0-2 for both items;

xcaregiver\_tx\_option= caregiver\_tx\_option-1;

xcaregiver\_tx\_complete= caregiver\_tx\_complete-1;

**\* Barriers to completing treatment plan (pp 3-4 caregiver survey);**

**\*** Note that these were asked only if caregiver responded “not at all sure” or “a little sure” to caregiver\_tx\_option or caregiver\_tx\_completed;

/\* Potential error: Note that according to the Data Dictionary, these variables were assigned identical names on the caregiver and patient files (e.g., pt\_issues\_a is the name for the item “Physical problems, such as …being too sick or not having enough strength” on both patient and caregiver surveys. \*/

\* Rename the variables on the caregiver survey – but check to see if this error has already been caught by Baptist;

array ee [8] pt\_issues\_a pt\_issues\_b pt\_issues\_c pt\_issues\_d pt\_issues\_e pt\_issues\_f pt\_issues\_g pt\_issues\_h and rescore 1=yes, 2=no to 0=no, 1=yes;

array ff [8] cg\_issues\_a cg\_issues\_b cg\_issues\_c cg\_issues\_d cg\_issues\_e cg\_issues\_f cg\_issues\_g cg\_issues\_h;

ff[i]= abs(ee[i]-2);

end; drop i;

\* create sum score;

sumcgbarriers= sum(cg\_issues\_a, cg\_issues\_b, cg\_issues\_c, cg\_issues\_d, cg\_issues\_e, cg\_issues\_f, cg\_issues\_g, cg\_issues\_h);

/\* be sure to drop pt\_issues\_a through pt\_issues\_h on the CAREGIVER file so that these variables are not overwritten on the PATIENT file \*/

drop pt\_issues\_a pt\_issues\_b pt\_issues\_c pt\_issues\_d pt\_issues\_e pt\_issues\_f pt\_issues\_g pt\_issues\_h;

**\* Communication about disease-specific information (p 4 caregiver survey);**

**/\*** Items are the same that are used on the patient survey; they are adapted from *K. Pardon et al., Are patients’ preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. Palliative Medicine, 2011, 25(1), 62-70.* For consistency, responses changes from 6-point Likert (totally disagree to totally agree) to 4 items that are used in the CAHPS patient survey (always, usually, sometimes, never) \*/

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le cg\_inform\_diagnosis le 6 then cg\_inform\_diagnosis= .;

if 5 le cg\_inform\_tx\_options le 6 then cg\_inform\_tx\_options= .;

if 5 le cg\_inform\_cure\_chance le 6 then cg\_inform\_cure\_chance= .;

if 5 le cg\_inform\_life\_expectancy le 6 then cg\_inform\_life\_expectancy= .;

if 5 le cg\_inform\_palliative\_care le 6 then cg\_inform\_palliative\_care = .;

if 5 le cg\_inform\_end\_of\_life le 6 then cg\_inform\_end\_of\_life = .;

\* reverse code so greater numeric response = better (more frequent) response (range 0-3);

xcg\_inform\_diagnosis= abs(cg\_inform\_diagnosis)-4;

xcg\_inform\_tx\_options= abs(cg\_inform\_tx\_options)-4;

xcg\_inform\_cure\_chance= abs(cg\_inform\_cure\_chance)-4;

xcg\_inform\_life\_expectancy= abs(cg\_inform\_life\_expectancy)-4;

xcg\_inform\_palliative\_care= abs(cg\_inform\_palliative\_care)-4;

xcg\_inform\_end\_of\_life= abs(cg\_inform\_end\_of\_life)-4;

\* create sum score from these 6 items – check inter-item consistency later;

sumcginfo= sum(xcg\_inform\_diagnosis, xcg\_inform\_tx\_options, xcg\_inform\_cure\_chance, xcg\_inform\_life\_expectancy, xcg\_inform\_palliative\_care, xcg\_inform\_end\_of\_life);

**\* Satisfaction with quality of care from various team members (p. 4 patient survey);**

\* set 5 (don’t know) and 6 (does not apply) to missing;

array gg [8] sat\_caregiver\_pc sat\_caregiver\_onc sat\_caregiver\_pulmo sat\_caregiver\_surg sat\_caregiver\_nurse sat\_caregiver\_nav sat\_caregiver\_other\_staff sat\_caregiver\_whole;

array hh [8] xsat\_caregiver\_pc xsat\_caregiver\_onc xsat\_caregiver\_pulmo xsat\_caregiver\_surg xsat\_caregiver\_nurse xsat\_caregiver\_nav xsat\_caregiver\_other\_staff xsat\_caregiver\_whole;

if 5 le gg[i] le 6 then gg[i]= .;

end; drop i;

\* reverse code so greater numeric response = greater satisfaction (range 0-3);

hh[i]= abs(gg[i]-4);

end; drop i;

\* create sum score for overall satisfaction with quality of care;

sumcgsatqc= sum(xsat\_caregiver\_pc, xsat\_caregiver\_onc, xsat\_caregiver\_pulmo, xsat\_caregiver\_surg, xsat\_caregiver\_nurse, xsat\_caregiver\_nav, xsat\_caregiver\_other\_staff, xsat\_caregiver\_whole);

**\* CAHPS items – Physician communication – 5 item version (p. 5 caregiver survey);**

\* Replicate scale used in Weeks et al., NEJM, 2012, 367:1616-25 (see p. 1618), which is sum of 5 CAHPS items;

\* note that Weeks et al. re-scales instrument for a 0-100 range – we are retaining the 1-4 scores on each of the 5 items (total scale score range of 5-20) from the original CAHPS survey;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le caregiver\_pt\_1 le 6 then caregiver\_pt\_1= .;

if 5 le caregiver\_pt\_2 le 6 then caregiver\_pt\_2 = .;

if 5 le caregiver\_pt\_3 le 6 then caregiver\_pt\_3 = .;

if 5 le caregiver\_pt\_4 le 6 then caregiver\_pt\_4 = .;

if 5 le caregiver\_pt\_5 le 6 then caregiver\_pt\_5 = .;

/\* reverse code so greater numeric response = better (more frequent) physician communication but retain 1-4 scoring to match original CAHPS survey \*/

xcaregiver\_pt\_1= abs(caregiver\_pt\_1)-5;

xcaregiver\_pt\_2 = abs(caregiver\_pt\_2)-5;

xcaregiver\_pt\_3 = abs(caregiver\_pt\_3)-5;

xcaregiver\_pt\_4 = abs(caregiver\_pt\_4)-5;

xcaregiver\_pt\_5 = abs(caregiver\_pt\_5)-5;

\* create sum score for 5-item scale – check inter-item consistency later;

sumcgphyscomm5= sum(xcaregiver\_pt\_1, xcaregiver\_pt\_2 xcaregiver\_pt\_3,

xcaregiver\_pt\_4, xcaregiver\_pt\_5);

**\* CAHPS items – Physician communication – 7 item version (p. 5 patient survey);**

\* We created 2 additional items (How often were doctors as helpful as you thought they should be, and How often did doctors seem to be aware of treatments for your lung cancer that other doctors recommend) to flesh out the 5-item CAHPS scale;

\* Create a 7 item scale using the 5-item scale from Weeks et al., NEJM, 2012;

\* will need to evaluate internal consistency of these items later;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le caregiver\_pt\_6 le 6 then caregiver\_pt\_6= .;

if 5 le caregiver\_pt\_7 le 6 then caregiver\_pt\_7= .;

\* reverse scoring so that higher score indicates more positive communication (1-4 range);

xcaregiver\_pt\_6= abs(caregiver\_pt\_6)-5;

xcaregiver\_pt\_7= abs(caregiver\_pt\_7)-5;

sumcgphyscomm7= sum(xcaregiver\_pt\_1, xcaregiver\_pt\_2 xcaregiver\_pt\_3,

xcaregiver\_pt\_4, xcaregiver\_pt\_5, xcaregiver\_pt\_6, xcaregiver\_pt\_7);

**\* We created a 6-item nurse communication measure based on the CAHPS Physician Communication items (pp 5-6 caregiver survey);**

\* will need to verify internal consistency of this measure;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le cg\_careteam\_8 le 6 then cg\_careteam\_8= .;

if 5 le cg\_careteam\_9 le 6 then cg\_careteam\_9= .;

if 5 le cg\_careteam\_10 le 6 then cg\_careteam\_10= .;

if 5 le cg\_careteam\_11 le 6 then cg\_careteam\_11= .;

if 5 le cg\_careteam\_12 le 6 then cg\_careteam\_12= .;

if 5 le cg\_careteam\_13 le 6 then cg\_careteam\_13= .;

\* reverse code so greater numeric response = better (more frequent) nurse communication (1-4 scoring for each item);

xcg\_careteam\_8= abs(cg\_careteam\_8)-5;

xcg\_careteam\_9= abs(cg\_careteam\_9)-5;

xcg\_careteam\_10= abs(cg\_careteam\_10)-5;

xcg\_careteam\_11= abs(cg\_careteam\_11)-5;

xcg\_careteam\_12= abs(cg\_careteam\_12)-5;

xcg\_careteam\_13= abs(cg\_careteam\_13)-5;

\* create sum score;

sumcgnursecomm= sum(xcg\_careteam\_8, xcg\_careteam\_9, xcg\_careteam\_10, xcg\_careteam\_11, xcg\_careteam\_12, xcg\_careteam\_13);

**/\* 3 items about satisfaction with care from the team as a whole (pp 10-11 caregiver survey) \*/**

**/\* note that the 4th item from the patient survey (“When you leave/left your appointment for your cancer care, how often do/did you have a clear understanding of what needs to happen next?”) was omitted from the caregiver survey – I don’t know why \*/**

\* the first two items are from the CAHPS survey: Patient\_Survey\_v7.0\_17March2004.doc, p. 6) and the third item we created ourselves;

\* set 5 (don’t know) and 6 (does not apply) to missing;

if 5 le caregiver\_often\_14 le 6 then caregiver\_often\_14= .;

if 5 le caregiver\_often\_15 le 6 then caregiver\_often\_15= .;

if 5 le caregiver\_often\_16 le 6 then caregiver\_often\_16= .;

/\* reverse code so greater numeric response = better (more frequent) physician communication (range 1-4) \*/

xcaregiver\_often\_14= abs(caregiver\_often\_14)-5;

xcaregiver\_often\_15= abs(caregiver\_often\_15)-5;

xcaregiver\_often\_16= abs(caregiver\_often\_16)-5;

\* create sum score from these 3 items – check inter-item consistency later;

sumcgteamsat= sum(xcaregiver\_often\_14, xcaregiver\_often\_15, xcaregiver\_often\_16);

**/\* Caregiver Burden: 14-item Brief Assessment Scale for Caregivers (BASC) (pp 6-7 caregiver survey) \*/**

\* from: Glajchen et al., J Pain Symptom Management, 2005, 29, 245-254;

/\* instrument includes a total score (14 item) and a sub-scale measuring negative personal impact (NPI) – note that the paper’s abstract states that the NPI is 8 items whereas Table 2 (p. 250) lists only 5 items that load on this sub-scale – for now, we’ll use only the total score \*/

/\* the Data Dictionary lists only 4 response choices (not at all, a little, some, a lot) and no opportunity for respondent to indicate “don’t know” or “doesn’t apply to me \*/

/\* reverse coding is not necessary: all 14 items are 1-4 with higher scores indicating more distress \*/

\* rescore so that range is 0-3 instead of 1-4;

array jj [14] qol\_caregiver\_worried qol\_caregiver\_illness qol\_caregiver\_upset

qol\_caregiver\_overwhelmed qol\_caregiver\_seeing qol\_caregiver\_decisions

qol\_caregiver\_hosp qol\_caregiver\_procedures qol\_caregiver\_change qol\_caregiver\_family qol\_caregiver\_drawn qol\_caregiver\_meaning qol\_caregiver\_mem qol\_caregiver\_feel;

array kk [14] xqol\_caregiver\_worried xqol\_caregiver\_illness xqol\_caregiver\_upset

xqol\_caregiver\_overwhelmed xqol\_caregiver\_seeing xqol\_caregiver\_decisions

xqol\_caregiver\_hosp xqol\_caregiver\_procedures xqol\_caregiver\_change xqol\_caregiver\_family xqol\_caregiver\_drawn xqol\_caregiver\_meaning xqol\_caregiver\_mem xqol\_caregiver\_feel;

do i = 1 to 14;

kk[i]=jj[i]-1;

end; drop i;

\* sum the 14 items

basc= sum(xqol\_caregiver\_worried, xqol\_caregiver\_illness, xqol\_caregiver\_upset,

xqol\_caregiver\_overwhelmed, xqol\_caregiver\_seeing, xqol\_caregiver\_decisions,

xqol\_caregiver\_hosp, xqol\_caregiver\_procedures, xqol\_caregiver\_change, xqol\_caregiver\_family, xqol\_caregiver\_drawn, xqol\_caregiver\_meaning, xqol\_caregiver\_mem, xqol\_caregiver\_feel);

**\* Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983);**

**\* p 7-8 caregiver survey;**

**/\* Note that per the Data Dictionary, the same variable names for HADS items appear to have been assigned to the patient and caregiver surveys, with the exception that item 1 is hads\_1 in the patient survey and hads\_1\_cont in the caregiver survey – I will rename the variables in the caregiver dataset \*/**

**array ll [14] hads\_1\_cont hads\_2 hads\_3 hads\_4 hads\_5 hads\_6 hads\_7 hads\_8**

**hads\_9 hads\_10 hads\_11 hads\_12 hads\_12 hads\_13 hads\_14;**

**array mm [14] cghads\_1 cghads\_2 cghads\_3 cghads\_4 cghads\_5 cghads\_6 cghads\_7 cghads\_8 cghads\_9 cghads\_10 cghads\_11 cghads\_12 cghads\_12 cghads\_13 cghads\_14;**

**do i – 1 to 14;**

**mm[i] = ll[i];**

**end; drop i;**

\* will need to check later for missing data… if so, will need to adjust scale scores;

\* correct scoring of individual items to match scoring in Zigmond & Snaith, 1983;

array nn [8] cghads\_1 cghads\_3 cghads\_5 cghads\_6 cghads\_8 cghads\_10 cghads\_11 cghads\_13; \* subtract 4 to reverse scoring and change range to 0-3;

array oo [6] cghads\_2 cghads\_4 cghads\_7 cghads\_9 cghads\_12 cghads\_14; \*scoring does not need to be reversed on these items – just subtract 1 to change range from 0-3;

array pp [8] cghads1 cghads3 cghads5 cghads6 cghads8 cghads10 cghads11 cghads13;

array qq [6] cghads2 cghads4 cghads7 cghads9 cghads12 cghads14;

do i = to 8;

pp[i]= abs(nn[i]-4);

end; drop i;

do i= 1 to 6;

qq[i]= oo[i]-1;

end; drop i;

/\*create HADS sub-scales, Depression and Anxiety -- high score means worse depression or anxiety \*/

cgHADS\_d= sum(cghads2, cghads4, cghads6, cghads8, cghads10, cghads12, cghads14); \*depression;

cgHADS\_a= sum(cghads1, cghads3, cghads5, cghads7, cghads9, cghads11, cghads13); \*anxiety;

**\* SF-36 – health-related quality of life (pp 8-11 caregiver survey);**

/\* Some of this SAS code is adapted from code found on-line at [http://gim.med.ucla.edu/FacultyPages/Hays/utils/sf36v2-4-public.sas created by K. Spritzer at UCLA: KSPRITZER@MEDNET.UCLA.EDU \*; adapted code is CAPITALIZED \*/](http://gim.med.ucla.edu/FacultyPages/Hays/utils/sf36v2-4-public.sas%20created%20by%20K.%20Spritzer%20at%20UCLA:%20KSPRITZER@MEDNET.UCLA.EDU%20*/)

/\* scoring information is available from Rand at <http://www.rand.org/health/surveys_tools/mos/36-item-short-form/scoring.html>; \*/

\* rename items to conform to code in Spritzer’s program;

Rename

sf\_1 = I1

sf\_2 = I2

sf\_a = I3

sf\_b = I4

sf\_c = I5

sf\_d = I6

sf\_e = I7

sf\_f = I8

sf\_g = I9

sf\_h = I10

sf\_i = I11

sf\_j = I12

sf\_4a = I13

sf\_4b = I14

sf\_4c = I15

sf\_4d = I16

sf\_5a = I17

sf\_5b = I18

sf\_5c = I19

sf\_6 = I20

sf\_7 = I21

sf\_8 = I22

sf\_9a = I23

sf\_9b = I24

sf\_9c = I25

sf\_9d = I26

sf\_9e = I27

sf\_9f = I28

sf\_9g = I29

sf\_9h = I30

sf\_9i = I31

sf\_10 = I32

sf\_11a = I33

sf\_11b = I34

sf\_11c = I35

sf\_11d = I36 ;

\* Code out-of-range values to missing;

ARRAY PT3 I3-I12;

DO OVER PT3;

IF PT3 NOT IN (1,2,3) THEN PT3=.;

END;

ARRAY PT5 I1 I2 I13-I20 I22-I36;

DO OVER PT5;

IF PT5 NOT IN (1,2,3,4,5) THEN PT5=.;

END;

IF I21 NOT IN (1,2,3,4,5,6) THEN I21=.;

RUN;

/\* Rescore items based on Rand SF-36 coding manual: <http://www.rand.org/health/surveys_tools/mos/36-item-short-form/scoring.html>; \*/

Note that we used the incorrect response choices on two items:

Item 21 (“How much bodily pain have you had”) should have been a 1-6 response scale (None, very mild, mild, moderate, severe, very severe) but we mistakenly used a 1-5 scale (Not at all, slightly, moderately, quite a bit, extremely);

Item 32 (“How much of the time has your physical health or emotional problems interfered with your social activities, like visiting friends, relatives, etc”) should have been a 1-5 scale (All the time, most of the time, some of the time, a little of the time, none of the time) but we mistakenly used a 1-6 scale (All of the time, most of the time, a good bit of the time, some of the time, a little of the time, none of the time); \*/

/\* Below, we will re-score these 2 items using weights for the scale that was actually used rather than the one that should have been used; this will introduce some minor inaccuracy in the total score (for both item 21 and item 32), as well as minor inaccuracy in the pain sub-scale (for item 21) and the social functioning sub-scale (for item 32) \*/

Array rr [7] i1 i2 i20 I 21 i22 i34 i36;

Array ss [7] sf1 sf2 sf20 sf22 sf34 sf36;

Array tt [10] i3 – i12;

Array uu [10] sf3-sf12;

Array vv [7] i13-i19;

Array ww [7] sf13-sf19;

Array xx [4] i23 i26 i27 i30;

Array yy [4] sf23 sf26 sf27 sf30;

Array aaa [6] i24 i25 i28 i29 i31 i32;

Array bbb [6] sf24 sf25 sf28 sf29 sf31 sf32;

Array ccc [2] i33 i35;

Array ddd [2] sf33 sf35;

Do i= 1 to 7;

If rr[i]= 1 then ss[i]= 100;

If rr[i]= 2 then ss[i]= 75;

If rr[i]= 3 then ss[i]= 50;

If rr[i]= 4 then ss[i]= 25;

If rr[i]= 5 then ss[i]= 0;

End; drop i;

Do i= 1 to 10;

If tt[i]= 1 then uu[i]= 0;

If tt[i]= 2 then uu[i]= 50;

If tt[i]= 3 then uu[i]= 100;

End; drop i;

Do i= 1 to 7;

If vv[i]= 1 then ww[i]= 0;

If vv[i]= 2 then ww[i]= 100;

End; drop i;

Do i= 1 to 4;

If xx[i]= 1 then yy[i]= 100;

If xx[i]= 2 then yy[i]= 80;

If xx[i]= 3 then yy[i]= 60;

If xx[i]= 4 then yy[i]= 40;

If xx[i]= 5 then yy[i]= 20;

If xx[i]= 6 then yy[i]= 0;

End; drop i;

Do i= 1 to 6;

If aaa[i]= 1 then bbb[i]= 0;

If aaa[i]= 2 then bbb[i]= 20;

If aaa[i]= 3 then bbb[i]= 40;

If aaa[i]= 4 then bbb[i]= 60;

If aaa[i]= 5 then bbb[i]= 80;

If aaa[i]= 6 then bbb[i]= 100;

End; drop i;

Do i= 1 to 2;

If ccc[i]= 1 then ddd[i]= 0;

If ccc[i]= 2 then ddd[i]= 25;

If ccc[i]= 3 then ddd[i]= 50;

If ccc[i]= 4 then ddd[i]= 75;

If ccc[i]= 5 then ddd[i]= 100;

End; drop i;

\* Create sub-scales;

PHYFUN10=MEAN(sf3,sf4,sf5,sf6,sf7,sf8,sf9,sf10,sf11,sf12);

ROLEP4=MEAN(sf13,sf14,sf15,sf16);

SFPAIN2=MEAN(sf21,sf22);

SFGENH5=MEAN(sf1,sf33,sf34,sf35,sf36);

ENFAT4=MEAN(sf23,sf27,sf29,sf31);

SOCFUN2=MEAN(sf20,sf32);

ROLEE3=MEAN(sf17,sf18,sf19);

EMOT5=MEAN(sf24,sf25,sfI26,sf28,sf30);

label phyfun10="Physical functioning scale";

label rolep4="Physical health problems scale";

label sfpain2="SF-36 pain scale";

label sfgenh5="SF-36 general health perceptions scale";

label enfat4="Energy/fatigue scale";

label socfun2="Social functioning scale";

label rolee3="Emotional health problems scale";

label emot5="Emotional well-being scale";

/\*

\*\* APPLY OPTION THAT REQUIRES AT LEAST HALF OF ITEMS IN A SCALE TO BE PRESENT

IN ORDER THAT THE SCALE BE NON-MISSING;

\*\* NEED AT LEAST HALF (OR HALF + 1 FOR SCALES WITH ODD # OF ITEMS) OF ITEMS PRESENT, ELSE SET SCALE TO MISSING;

\*/

IF N(OF sf3,sf4,sf5,sf6,sf7,sf8,sf9,sf10,sf11,sf12) <=4 THEN PHYFUN10=.;

IF N(OF sf13,sf14,sf15,sf16) <=1 THEN ROLEP4 =.;

IF N(OF sf21,sf22) <=0 THEN SFPAIN2 =.;

IF N(OF sf1,sf33,sfI34,sf35,sf36) <=2 THEN SFGENH5 =.;

IF N(OF sf23,sf27,sf29,sf31) <=1 THEN ENFAT4 =.;

IF N(OF sf20,sf32) <=0 THEN SOCFUN2 =.;

IF N(OF sf17,sf18,sf19) <=1 THEN ROLEE3 =.;

IF N(OF sf24,sf25,sf26,sf28,sf30) <=2 THEN EMOT5 =.;