Total Joint Replacement Code Definitions * to be used in conjunction with Figure 1 *

Sociodemographic Characteristics (SDC)

Age

Sex

Living alone - Are they on their own?

Retired – Are they still working outside the home?

Social supports – Indicate presence of family members, children, friends in their lives and as sources of help with groceries, cleaning, appointments, companionship.

Medicalization Experience & Total Joint Replacement (MCT)

• The point here is to identify "roadblocks" to the participants' full consideration and/or process of decision-making about total joint replacement for their arthritis; some of these are related to their previous surgical or medical histories, including relationships with health care professionals, satisfaction with past care and outcomes, and the nature of the arthritis illness.

The nature of arthritis (NA)

Background noise – Participants described their arthritis as a chronic, constant presence that is almost ignored in light of other health concerns and conditions.

Inevitable with aging – The participants described arthritis as an inevitable and almost expected part of the aging process in general, and of their own aging in particular.

Inducing struggle/conflict with the physical body – Participants' description of their arthritis and management suggests an ongoing fight with their bodies, for which they seem to want to remain stoic.

Ongoing episodic pain

Worsening pain

Previous surgical/medical experiences (PE)

Total joint replacement seen as extreme – In relation to previous surgeries (for heart, cataract, etc.), total joint replacement is described as an extreme measure for arthritis management.

Contrast to other surgeries – The participants' perceptions of total joint replacement are described in contrast to the imperative or necessity of other surgeries (for heart, cataract, etc.)

Poor satisfaction

Other orthopaedic injuries

Information sources (IS)

MD as source of info re arthritis – Their thoughts and descriptions about the nature and quality of their doctors as sources of information about arthritis, various treatments, and recommended management strategies: informative, a poor source of information, none at all, or wants information.

MD as source of info re total joint replacement – Their thoughts and descriptions about the nature and quality of their doctors as sources of information about total joint replacement in general, its risks and benefits, and their recommendations for the participant personally: informative, a poor source of information, none at all, or wants information.

Other HCPs (health care professionals) as source of info re total joint replacement – Their thoughts and descriptions about the nature and quality of their other health care professionals (OT, PT, nurse, etc.) as sources of information about total joint replacement in general, its risks and benefits, and their recommendations for the participant personally: informative, a poor source of information, none at all, or wants information.

Other info sources – The participants' identification and description of other information sources about total joint replacement: family, friends & acquaintances, literature, TV/internet, or community organizations.

Others' total joint replacement experiences – The participants describe others they know who have undergone total joint replacement and the participants' perceptions of effectiveness/satisfaction: positive experience, negative experience, or mixed.

Doctor-patient relationship (DP)

Influence of doctor – Describing their relationship and encounters with doctors, the participants' statements about how influential the doctor is with health care decisions. If their willingness to consider total joint replacement is tied to their doctor's opinion of the procedure: doctor's orders for total joint replacement. If they describe the doctor as creating a supportive environment in which to ask questions: doctor creates support.

Interactions with doctors – In describing their relationship with doctors, what type of decision-making model is evoked? Shared indicates mutual information exchange and decisions; not shared indicates an absence of mutuality; paternalistic indicates the patients' expectation and description of their doctors as providing guidance, being the sole decision-maker in the "best" interest of the patient, and giving information but not receiving; don't ask, don't tell as described by the patients indicates a limited, non-interactive relationship with their doctor.

Patient Decision-Making Interview Guide

1. Decision-making Process

I am very interested in how people come to have or not to have a joint replacement. Some people have been offered the surgery, and others haven't. I am interested in how people make their choices in relation to the joint replacement surgery. There is no "right" treatment for everyone; I am just interested in how <u>you</u> made your choices about your arthritis treatment. Can you take me back in time to how you first thought about maybe having a joint surgery?

What was important to you while you were thinking about joint surgery?

What were the pros and cons that went through your mind when you were thinking about joint surgery?

(or) positives and negatives?

(or) . . . benefits and potential problems?

If required, prompt:

Did these play a role in your decision-making?

The nature of the surgery

The timing of the surgery (including wait-listing)

Benefits/effectiveness

Risks/complications

Going to hospital

Anesthetic

Expected recovery time and experience

Postoperative function

Home care, PT, OT, exercise assistance, ADLs

Time away from other (care-giving, work, financial) responsibilities

Ability and acceptability of asking questions/sharing decision-making

You mentioned X. Is/was this a major issue for you?

You mentioned Y. Are/were you concerned what he/she thinks?

You mentioned Z. Did this make your decision/choices more difficult/easier?

2. Sources of Information and Support

a. Information

When did you receive your first information about total joint replacement? Who initiated discussion about total joint replacement? ⇒ Probe for health care, family, lay press/media sources.

Do you know anyone who has had a total joint replacement?

Do you feel you have had sufficient information about total joint replacement from [each of] your:

Family doctor

Specialist(s)

Surgeon

Therapist(s) (PT, OT)

that helped you decide about the pros and cons of the surgery?

b. Support

Do you feel supported by [each of] your:

Family and friends

Others who have had total joint replacement

Family doctor

Specialist(s)

Surgeon

Therapist(s) (PT, OT)

about your joint surgery decision?

Do you feel pressured by [any of] your:

Family and friends

Others who have had total joint replacement

Family doctor

Specialist(s)

Surgeon

Therapist(s) (PT, OT)

about your joint surgery decision?

We've talked about this and that. Is there anything else that was/is important to you in making your decision/choices?

You have told me lots of good information that is very valuable. Is there anything else you would like to include/share?

Total Joint Replacement Decision-Making (TDM)

Nature of process (NP)

Formal MD discussion – indicates their decision-making has involved a formal discussion with their doctor(s).

Lay process – indicates their decision-making has relied on lay discussions and sources.

Combination of MD & lay – combination of both formal and lay processes.

Deferral (DF)

Last resort – Total joint replacement is seen as an extreme form of treatment and will be considered/utilized as a last resort of all options for their arthritis.

Not bad enough yet – Their arthritis is not severe enough as of yet to warrant consideration/utilization of total joint replacement, in terms of level of pain, disability, or other parameter.

Wait to see if other approaches are effective – Other treatment/management strategies have been implemented and their effectiveness in controlling pain/disability has not been fully realized, and consideration/utilization of total joint replacement will not take place until such time.

Unsuitability for procedure (UP)

Self-exclusion – Patients identify or determine themselves to be poor candidates for total joint replacement because of too many other comorbidities, agedness, or obesity, or because the procedure is not necessary yet.

Previous designation as unsuitable – At some time in the past, there was an identification or determination of the patient as unsuitable for total joint replacement, either by MD who said the patient was not a good candidate or not yet a candidate, or by family/friends who claim the patient was/is not a good candidate.

Current designation as unsuitable – MD says patient is currently unsuitable or not a good candidate because of too many comorbidities, agedness, or obesity, or that the procedure is not necessary yet.

Benefits of total joint replacement (BT)

Mobility

Pain

Concerns about recovery (CR)

Support Pain

Uncertainties (UC)

Treatment options
Candidacy
Waiting list
Efficacy of procedure
Life of joint

Alternative Process (AP)

Any evidence of implicit weighing of options or deliberation on the pros/cons of total joint replacement. Please indicate with clear examples.