APPENDIX A:
Draft Questions—Prostate Cancer Consultative Meeting;
March 22, 2002

Patient Questions

Treatment

1. When is surgery a preferable intervention for prostate cancer (“PC”), and when is radiation treatment preferable? Are there any clear tradeoffs between these two treatment options?

2. Does my age, ethnicity, medical history, or PC status (i.e., Gleason score, clinical stage, PSA level) modify the likely outcomes for the different forms of treatment?

3. When is “watchful waiting” a reasonable treatment option?

4. What is the likelihood of a “cure,” for each kind of treatment?

5. What is the difference between “external beam radiation therapy” and “brachytherapy” (implant therapy)? Is there a survival advantage for preferring one to the other, either in general or based on age, ethnicity, PC status (i.e., Gleason score, clinical stage, PSA level), etc.? What are the side effects associated with brachytherapy?

6. What are the differences between the various forms of external beam radiation therapy for PC, such as 3-D conformal therapy, IMRT, and proton beam therapy? Do any of these offer a survival advantage?

7. Is cryotherapy a reasonable treatment alternative for PC? What are the side effects and survival data regarding cryotherapy?

8. What about hormone treatment for PC? When is hormone treatment appropriate as an adjunct to radiation, and how much does it improve survival?

9. What about experimental treatments, like genetic therapy or Endostatin (anti-angiogenic drugs)? Are these treatments available, safe, and effective (by comparison with surgery and radiation)?

10. What about “alternative treatments” for PC (e.g., herbal remedies, PC-SPES, etc.)? Are these treatments safe, and are they effective (either by themselves, or as a supplement to medical or surgical treatment)?

11. What is the likelihood of tumor recurrence following PC treatment that initially appears to be successful? Does this vary based on treatment type, age, ethnicity, PC status (i.e., Gleason score, clinical stage, PSA level, etc.)?
12. How can I get quantitative information to compare survival rates across different forms of treatment, for men with different ages, ethnicities, medical histories, PC status (i.e., Gleason score, clinical stage, PSA level, etc.)? Does my doctor have access to such information?

**Side Effects**

1. What is the likelihood of impotence as a side effect? Does this likelihood vary by type of treatment or by patient characteristics?
2. What is the likelihood of urinary incontinence as a side effect? Does this likelihood vary by type of treatment or by type of patient?
3. What is the likelihood of bowel dysfunction (e.g., diarrhea, constipation, fecal incontinence) as a side effect? Does this likelihood vary by type of treatment or by patient characteristics?
4. What other side effects should I anticipate as a function of treatment? Do these vary either by treatment type or by patient characteristics?
5. With regard to any side effects of treatment, what is the likely duration, level of impairment, and prognosis for improvement? Are there secondary therapies available to ameliorate side effects (e.g., Viagra)?

**Assessment**

1. What is a Gleason Grade, and what does my Gleason score tell me about my PC?
2. What is the “Prostate Specific Antigen” (PSA) test? What does my PSA score tell me about my PC?
3. What is a “Digital Rectal Examination” (DRE)? What does DRE tell me about my PC?
4. What other sorts of diagnostic testing are commonly used for PC patients? Are there specific diagnostic tests that I should ask my doctor to perform?
5. What are the Partin Nomograms? How do I use the Partin Nomograms, and how can they help me to make decisions about treatment?
6. How do I use my assessment information in making decisions about treatment? Is there a relationship between my assessment scores and positive outcomes (or survival rates) for the different sorts of therapy?

**Sources of Care**

1. Are some doctors or medical facilities better than others at administering surgical or radiation treatment for PC? How do I pick the right care provider for me?
2. Should I plan on obtaining multiple medical opinions before pursuing treatment? What are the differences between oncologists and urologists, and whom should I see first?
3. What should I do if my health plan doesn’t cover the treatment option that I feel is best for me?

**Behavioral Interventions**

1. Does diet protect against the development of PC, and can dietary factors help to promote recovery from PC? If so, what dietary factors are important? Is there evidence to show improved survival as a function of diet?
2. Does exercise protect against the development of PC, or promote recovery from PC? Is there evidence to show improved survival as a function of exercise?
3. Are there any other things that I can do, apart from diet and exercise, in order to promote wellness and recovery from PC? Is there evidence to show improved PC survival based on any behavioral or interpersonal factors, apart from diet and exercise?

**Social Support**

1. What are the emotional side effects of PC treatment? Do these vary by type of treatment, type of patient, etc.?
2. What sorts of support resources are available to me? Should I consider joining a PC support group?
3. What support resources are available for my spouse and family?

**Provider Questions**

**Communication Issues**

1. What kind of survival information do PC patients need? Where do I obtain such information, and how do I convey it most effectively to my patients?
2. How do I talk with patients about the likelihood of a “cure” for their PC? How can I communicate information about recurrence, survival rates, and mortality in a manner that is at once objectively accurate, sympathetic, and reassuring?
3. How much information and counseling should I provide to patients in making their PC treatment decisions? To what extent are tradeoffs between survival and side effects a matter of individual preference, as opposed to objectively available information? What can I do to make my patients’ decisions easier?

**Treatment**

1. Is there evidence to support any clear decision rule for choosing between surgery and radiation treatment for PC, for any set of patients with the disease, based on demographics, PC status (i.e., Gleason score, clinical stage, PSA level), medical history, etc.? If so, what is the rule?
2. What are the survival rates for surgical and radiation treatments for PC, with conditional probabilities based on demographics, PC status (i.e., Gleason score, clinical stage, PSA level), medical history, etc.?

3. When is “watchful waiting” a reasonable treatment option? What are the survival rates for watchful waiting, with conditional probabilities based on demographics, PC status (i.e., Gleason score, clinical stage, PSA level), medical history, etc.?

4. Is there any survival basis for preferring external beam radiation therapy to brachytherapy, either in general or based on age, ethnicity, PC status (i.e., Gleason score, clinical stage, PSA level), etc.?

5. When is hormone treatment for PC an appropriate adjunct to radiation, by how much does it improve survival rates, and for what sorts of patients?

6. What about experimental treatments, like genetic therapy or Endostatin (anti-angiogenic drugs)? Are these treatments available, safe, and effective (by comparison with surgery and radiation)? Is there any survival data available on new, experimental forms of treatment?

7. What about “alternative treatments” for PC (e.g., herbal remedies, PC-SPES)? Are these treatments safe, and are they effective (either by themselves, or as a supplement to medical or surgical treatment)? Is there any survival data available on alternative treatments?

8. What is the likelihood of tumor recurrence following PC treatment that initially appears to be successful? Does recurrence vary based on treatment type, age, ethnicity, PC status (i.e., Gleason score, clinical stage, PSA level), etc.?

**Side Effects**

1. What is the likelihood of impotence as a side effect, with conditional probabilities based on type of treatment and patient characteristics?

2. What is the likelihood of urinary incontinence as a side effect, with conditional probabilities based on type of treatment and patient characteristics?

3. What is the likelihood of bowel dysfunction as a side effect, with conditional probabilities based on type of treatment and patient characteristics?

4. What other side effects should PC patients anticipate as a function of particular forms of treatment, and how common are such side effects? Do these vary either by treatment type or by patient characteristics?

5. With regard to all side effects associated with each form of treatment, what is the likely duration, level of impairment, and prognosis for improvement? Are there secondary therapies available to ameliorate treatment side effects (e.g., Viagra)?
APPENDIX B:
Draft Questions—Arthritis Consultative Meeting;
March 13, 2002

Patient Questions

*General Treatment Questions*

1. Will these treatments (drugs/physical therapy/other) stop or slow the progress of my arthritis?

2. What should I expect from these treatments? For example, how effective are they in helping my pain and stiffness? Do they work immediately? For how long are they likely to be effective? Can I stop treatment when I start to feel better?

3. Will I be able to function normally while I am on these drugs? Will I be able to do all of the tasks of daily living? Will I be able to exercise?

4. Does the kind of treatment I choose depend on whether I have other health problems?

*Drug Therapy*

1. Which drugs would be best for me to take? How soon will I feel better? Will I be able to resume my normal activities? How does my type of arthritis affect the treatment options that are available to me?

2. Can I take just one of these drugs or will I have to take more than one?

3. How difficult is to follow the instructions for each of the drugs I might take? For example, how often do the pills have to be taken? Do some have to be taken with or without food? Do some require that I have blood taken to check for any problems? Will I have to have other tests done (bone density test for example)?

4. Are there over-the-counter medications I should avoid when I am taking these arthritis medications?

*Other Treatments*

1. When should I consider surgery? Are there different types of surgeries available? How well do they work? Will I be cured? What are the risks of these surgeries?

*Side Effects*

1. What types of side effects am I likely to have from taking any of the arthritis drugs?

2. How likely is it that I will have stomach or intestinal side effects such as ulcers or serious bleeding with different treatments? Are some people at greater risk of having problems?
3. How likely is it that I will have problems with my kidneys or liver if I take each of these treatments? Are some people at greater risk of having problems?

4. Is there a risk of death associated with any of these side effects? If so, how high is this risk? Are some people more likely to die?

5. Can the seriousness or occurrence of these side effects be limited or prevented? Will they stop if I stop taking the treatment?

6. Are there things I will not be able to do (eat certain foods, drink alcohol, engage in physical activities)?

**Self-Care Strategies**

1. How effective are diet and exercise in treating my arthritis?

2. Is there anything I can do to minimize flare-ups?

3. Will taking vitamins or other supplements help me?

4. Are different exercises recommended for different types of arthritis?

5. Are there activities I should avoid?

6. What changes in my life or environment should I make to slow down the disease and maintain my ability to do my normal activities?

7. Are there devices or products that can help me feel better or perform daily tasks more easily?

**Psychosocial Support**

1. What types of community resources are available to me?

2. Do support groups help? Are some better than others?

**Provider Questions**

**Communication**

1. How can I tell my patients enough about the disease and its treatments to know what to expect and to make decisions without overwhelming them or causing unnecessary anxiety?

2. How do I communicate the uncertainty associated with treatment effectiveness and disease progression?

3. What questions should I be asking my patients to make sure that I give them the information that is most relevant for them?

4. How much do the information needs about treatment options, self-care management strategies, and community resources vary by patient characteristics such as age, gender, arthritis severity, functional ability, family income and available social support?
5. How can I make sure that my patients fully understand the information they have received?
6. How can I accurately assess my patients’ level of pain and function?

**Treatment**
1. What is the evidence base for the different types of arthritis treatments including drugs, surgery, physical/occupational therapy, and education? Is this evidence base equally applicable to all types of patients?
2. Are different drugs within a major class (e.g., NSAIDs) equally effective? Is there evidence to suggest differential effectiveness in different types of patients?
3. What are the risks and benefits associated with surgery? Do these risks and benefits vary by patient characteristics such as age, gender, type of arthritis, etc.?
4. What recommendations should I make regarding alternative or complementary therapies? Is there an evidence base for any of these recommendations? Are the risk/benefit tradeoffs for these treatments comparable for all patients?

**Side Effects**
1. Do different drugs within a major class (e.g., NSAIDs) produce similar side effects? Are the risks of side effects similar for drugs in the same class? Are the risks similar for patients with different characteristics?
2. What are the rates of occurrence for gastrointestinal and other side effects with the different types of treatment? Are they similar for patients with different characteristics?

**Self-Care Strategies**
1. Is there evidence that self care strategies work for this disease? How do I encourage compliance with self-care strategies, such as a regular exercise regimen and a weight reduction plan?
2. Is there a trusted resource I can recommend to my patients to find devices and products that can help them perform routine tasks? Where can I find information regarding their effectiveness?

**Specific Additional Questions for Rheumatoid Arthritis**

**Patient Questions**
1. Will these treatments (drugs/physical therapy/other) stop or slow the progress of my arthritis?
2. What should I expect from these treatments? For example, how effective are they in helping my pain and stiffness? Do they work immediately? For how long are they likely to be effective? Can I stop treatment when I start to feel better?
3. Will I be able to function normally while I am on these drugs? Will I be able to do all of the tasks of daily living? Will I be able to exercise?

4. How difficult is it to follow the instructions for each of the drugs I might take? For example, how often do the pills have to be taken? Do some have to be taken with or without food? Do some require that I have blood taken to check for any problems? Will I have to have other tests done (bone density test for example)?

5. Are there any special medical considerations that I need to take into account because of my RA (i.e., patients with RA should get a pneumovax and flu shot every year, but patients on immunosuppressives should not get live vaccines)?

**Provider Questions**

1. How do I best assess disease activity and response to therapy?

2. What is the evidence base for the different types of arthritis treatments including drugs, surgery, physical/occupational therapy, and education? Is this evidence base equally applicable to all types of patients?

3. Are different drugs within a major class (e.g., NSAIDs) equally effective? Is there evidence to suggest differential effectiveness in different types of patients?

4. What recommendations should I make regarding alternative or complementary therapies? Is there an evidence base for any of these recommendations? Are the risk/benefit tradeoffs for these treatments comparable for all patients?

**Surgery Questions**

1. What is total joint replacement?
   Why is total joint replacement necessary?

2. Are there any alternatives to having surgery?
   What joints can be replaced?

3. What is the implant itself like?

4. What is it made of?

5. Will I be able to tell it is artificial once I recover from surgery?

6. How is total joint replacement done?

7. What will happen during my recovery from total joint replacement?

8. What do I need to do to prepare for recovery?

9. How long will recovery take?

10. How painful will recovery be?

11. How difficult will it be to walk or do other activities once I have joint replacement surgery?

12. What are the possible complications from total joint replacement?

14. Is total joint replacement permanent?

15. Will the joint ever have to be replaced again?

16. What medical information do I need to collect before my surgery?

17. What medical preparations do I need to make for my surgery?

18. What kind of doctor should I look for to perform my joint replacement surgery?

19. How long will I have to stay in the hospital or other health care facility for this procedure and during recovery?
APPENDIX C:
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