Newly Diagnosed Prostate Cancer:
Understanding Your Risk

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When the urologist calls with the life-changing news that your prostate biopsy is positive for prostate cancer, an office appointment is made to discuss your options.

This document will help you understand the new medical terms and jargon introduced at the newly diagnosed interview. Learn how your medical diagnosis details are applied to risk assessment tools to predict if you have low, intermediate, or high risk prostate cancer. Understanding your risk will guide you to making informed treatment choices.

• Most men newly diagnosed with prostate cancer will go on to live a normal life span.

• Many prostate cancers are Low-Risk (Sky shade), slow-growing and not very dangerous. Often, treatment can be safely delayed for years by following Active Surveillance, or relatively non-toxic treatments can be chosen. That avoids or delays possible treatment side effects such as impotence or incontinence.

• A few newly-diagnosed men have High Risk prostate cancer that is aggressive and potentially life-threatening. Those men may benefit from more aggressive therapy. They may accept the side effects risks in hopes of eradicating, or at least controlling their high risk prostate cancer.

• Men with Intermediate Risk prostate cancer have the hardest treatment choices. Their risk may be a little too high to be comfortable with Active Surveillance, while at the same time not being high enough to clearly indicate for aggressive therapy with its risks.

Obtain Your Medical Records

The clues to a man's prostate cancer risk (and his eventual treatment choice) can be found in his clinical diagnosis medical records.

One cannot understand his prostate cancer risk level without obtaining and understanding his medical records. Sometimes, a doctor's office is not set up to easily provide patients with copies of their records, and some additional 'prodding' may be needed to obtain the copies.

During the initial diagnosis office visit, the doctor will have your medical records chart on hand. This is a good time to ask for copies. A man has a right to his medical records, but a reasonable copy fee may be charged. Obtain the following records:

1. PSA History. Make a log with the dates of all your PSA tests. Note any special events, such as "Suspicious Digital Rectal Exam (DRE)" or "Biopsy Ordered".
2. Urologist's Notes that discuss the Clinical Stage from the Digital Rectal Exam (DRE), for example, T1c or T2b.
3. Ultrasound Report (TRUS) from the biopsy. This is written by the urologist, and lists the size of the prostate in grams or cubic centimeters (cc). It may also indicate other risk factors.
4. Biopsy Pathology Report. For each core, learn the Gleason Score, extent of disease in the core, and other important clinical diagnosis information.
5. Written Radiology Report(s), if you have received any prostate scans such as CT, Bone, or MRI.

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QUESTIONS FOR YOUR UROLOGIST

The items below describe the clinical diagnosis details collected in the companion Risk Analysis Data Form. That data is used in the popular risk stratification tools such as D'Amico, NCCN, CAPRA and SHADES. Use those tools to understand if you have low, intermediate, or high risk prostate cancer. It is important to understand this is statistical risk derived from analysis of thousands of men. It does not precisely predict for the individual. For example many men with high risk are successfully treated, while some men with low risk may eventually have PSA rising after treatment.

It is important to understand we are talking about risk of PSA rising, not risk of imminent prostate cancer death. There are many effective treatments for rising PSA.

1. PSA at Diagnosis (just before positive biopsy): PSA 0 to 6 is very low risk, 6-10 low-risk, 10-20 intermediate-risk, >20 high-risk, and >100 is advanced disease.

2. Clinical Stage: Determined by the digital rectal exam (DRE):

T1c = no tumor felt with the finger (lowest risk)
T2a = small nodule on one side (low-risk)
T2b = larger nodule in more than half of one side (intermediate-risk)
T2c = nodules on both sides of prostate (intermediate/higher risk)
T3 = cancer detected outside of prostate but not invading local tissue (high-risk)
T4 = cancer invades local tissue such as bladder or rectum (high-risk)

3. Prostate Size (volume), in grams or cc: When the urologist performs a prostate biopsy, he or she uses an ultrasound machine to scan the prostate and aim the biopsy needles. At that time, they usually will also calculate the size of the prostate. Size can vary greatly, from less than 25 cc to more than 100 cc. Over 60 cc is enlarged enough to require special consideration when evaluating the radiation therapy options.

4. The PSA Density calculation (PSA ÷ prostate volume) takes prostate size into account. Enlarged prostates produce more PSA (even without cancer), and this higher PSA should be considered when evaluating risk. For example, a PSA of 10 places a man at intermediate-risk. But if the prostate size was 100 cc, most of that PSA may be coming from the large prostate, indicating that the man actually has a low-risk PSA. His PSA density would be normal at 10/100 = 0.10. A PSA Density greater than 0.15 raises concern, because the PSA is high relative to the size of the prostate, and may indicate more extensive disease somewhere.

5. Age at Diagnosis: Take age (and overall health) into account when choosing a treatment option. Perhaps a man who is older or in ill health will choose less intense therapy in place of radical therapy and its side effects.

6. Highest Gleason Score Sum: The pathologist will assign a Primary Gleason Grade to the larger percentage involved, and a Secondary Gleason Grade to the lesser percentage involved in each biopsy core. The Gleason Score is the sum of Primary Grade + Secondary Grade (for example, 4+3=7). Use the core with the highest score.

Gleason Grade 3 is the lowest grade normally reported as cancer, and is the lowest risk. When the cells look more different than healthy cells (poorly differentiated), they are assigned a higher Gleason Grade of 4 or 5.

Grade 4 and 5 cancer cells are more dangerous because they tend to invade local tissue or spread to the lymph nodes or bones. Greater amounts of grade 4 or 5 cancer in the prostate is associated with higher risk.

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For determining overall risk, the core with the highest Gleason score is used as the risk reference.

Gleason 3+3=6	**lowest risk**
Gleason 3+4=7	**low-intermediate risk**
Gleason 4+3=7	**high-intermediate risk**
Gleason Score 8, 9, 10	**high risk**

7. Number of biopsy cores taken

8. Number of biopsy cores positive: The more cores with cancer, the higher the risk that cancer might already be outside the prostate.

9. Percentage of Cores Positive = (number positive / total cores): More than 1/3 of cores positive raises the risk of cancer already outside the prostate. Over half of cores positive is high-risk.

10. Greatest core percentage of cancer found in the most involved core: If a core is more than 50% involved, there is more risk the cancer may be outside the prostate at that location.

11. Is there MRI , CT scan, or DRE evidence of Extra Prostatic Extension (ECE or EPE)? Cancer outside the prostate locally (stage T3) might still be eradicated, but more aggressive therapy may be required.

12. Any positive lymph nodes, within the pelvis, identified with MRI or CT Scan? Local therapy to only the prostate may not be enough. Research whether External Beam Radiation Therapy (EBRT) around the prostate and/or systemic therapy will be beneficial. (Stage N1, high-risk)

13. Bone metastases confirmed by a positive bone scan is Stage M1, advanced disease.

14. Any positive node beyond the pelvis? A metastasis in soft tissue outside the pelvis is high risk.

15. Comorbidities and other health problems, such as heart disease, diabetes or urinary retention, should be taken into account before initiating aggressive therapy. Perhaps the side effects of cancer treatment should be avoided, or less toxic therapies can be tried.

PCRI Helpline educational facilitators are specially trained to assist with understanding these medical records, and can be reached at **1-800-641-7274**, or **help@pcri.org** if you need assistance.

PLEASE SEE PAGE 13 FOR THE RISK ANALYSIS FORM. YOU MAY CUT OUT THIS FORM AND TAKE IT WITH YOU TO YOUR UROLOGIST'S OFFICE. ADDITIONAL COPIES MAY BE PRINTED FROM:
http://prostate-cancer.org/pcricms/sites/default/files/PDFs/AYO-form.pdf

DISCLAIMER – This document is intended to assist the prostate cancer patient to understand their disease diagnosis, and to outline questions to discuss with their doctor. It should never be considered actual medical advice.

Popular Risk Stratification Tools

In 1998, prostate cancer researcher Dr. Anthony D'Amico published an important paper that used statistical techniques to show that diagnosis PSA, Gleason Score and Clinical Stage (from the digital rectal exam) would predict if the cancer might come back after therapy. D'Amico risk stratification has since been validated in many scientific publications to predict risk of later cancer progression. Download the landmark 1998 paper for free at: http://jama.jamanetwork.com/data/Journals/JAMA/4576/JOC80111.pdf

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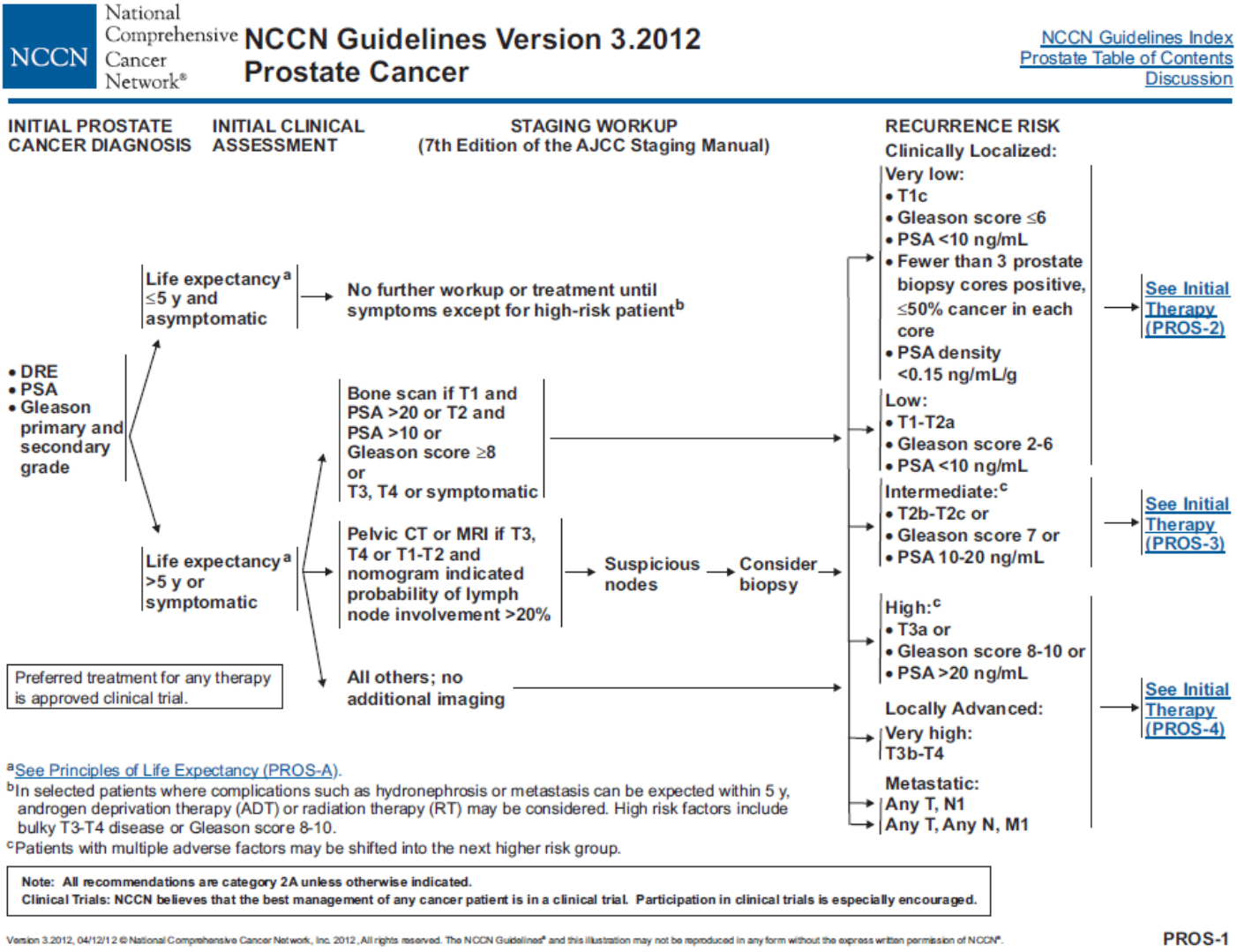
D'AMICO PROSTATE CANCER RISK STRATIFICATION

D'AMICO RISK	LOW	INTERMEDIATE	HIGH
PSA	<10	10 TO 20	>20
GLEASON	<=6	7	8, 9, 10
STAGE	T1c, T2a	T2b	>=T2c
YOUR HIGHEST			

Circle your risk level for PSA, Gleason, and Stage. Your D'Amico risk stratification is the highest risk circled. For example, PSA 6 = low, Stage T2a = low, Gleason 4 + 4 = 8 = high. Highest = High Risk.

Later research showed that the percentage of cancer in the biopsy cores was also highly predictive of the cancer coming back after therapy. The National Comprehensive Cancer Network (NCCN) added core data to their risk stratification tool, which has also become widely used in reporting prostate cancer outcomes based on risk assessment at diagnosis. The NCCN tool also lists recommendations for when to get a Bone or CT scan to help identify possible prostate metastases. Download the NCCN Practice Guidelines for free at: http://www.nccn.com/files/cancer-guidelines/prostate/files/assets/downloads/files/prostate.pdf



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Other risk stratification tools also add biopsy core data to better define risk. The CAPRA risk score is based on statistical outcomes from more than 10,000 men and has been validated both in the USA and in Europe, to predict risk, no matter which therapy is chosen. Read Dr. Cooperberg's *Insights* article for more information: http://prostate-cancer.org/pcricms/sites/default/files/PDFs/Is13-4_p3-7.pdf

The Prostate Cancer Research Institute SHADES risk tool also uses biopsy core data, and adds imaging data to the standard D'Amico risk assessment. In the following link, Dr. Mark Scholz discusses how to use the SHADES risk tool to help guide men to appropriate treatment options: http://pcribc.org/pages.php?pageid=8

	Local Therapy	Gleason Score	% Cores	Digital Rectal	PSA	MRI, CDU CT Scans	Bone Scan
Abn. PSA	No	No	No	T1c	2-10	Small Lesion	No Need
Sky*	No	<6	<33%	T1c, T2a	<10	No ECE	No Need
Teal**	No	7	33-50%	T2b	10-20	No ECE	Clear
Azure	No	8-10	>50%	T3	>20	ECE, SV, PN	Clear
Indigo	Yes	Any	Any	Any	Rising	Pelvic Node	Clear
Royal***	Any	Any	Any	Any	>100	Other Node	Positive

*One core > 50% replaced with cancer bumps to Teal

**Two yellow boxes bumps Teal to Azure

***Any rising PSA with a low testosterone bumps to Royal

ECE = Extra-capsular Extension

SV = Seminal Vesicle

PN = Pelvic node

REFERENCES

Risk Stratification Forms*

Dr. Anthony D'Amico published the first widely recognized risk stratification scheme in 1998. Download for free here:
• http://jama.jamanetwork.com/article.aspx?articleid=187980

NCCN Practice Guidlines - Sign up for free access at https://subscriptions.nccn.org/login.aspx
• http://www.nccn.org/professionals/physician_gls/pdf/prostate.pdf

CAPRA risk stratification based on more than 10,000 men from 40 prostate cancer clinics.
• Risk Assessment for Prostate Cancer PDF - Matthew R. Cooperberg, MD, MPH 2010:
http://prostate-cancer.org/pcricms/sites/default/files/PDFs/Is13-4_p3-7.pdf

SHADES
• http://pcribc.org/pages.php?pageid=8

**If you do not have access to the internet, please contact PCRI at (800) 641-HELP for the forms you need.*

NEWLY DIAGNOSED PROSTATE CANCER

Risk Analysis Data Form – Questions For Your Urologist

Get the data below from your urologist and/or your medical records. Then calculate your prostate cancer risk stratification using tools like the National Comprehensive Cancer Network (NCCN)Practice Guidelines, D'Amico Risk Analysis, CAPRA Score, and SHADES. See the companion Newly Diagnosed – Questions For Your Urologist instruction sheet.

Patient Name:	**Diagnosis Date:**
Doctor's Name:	**Form Date:**

1. PSA#: Just before positive biopsy	1
2. Clinical Stage: DRE result**: e.g. T1c**, **T2a, etc.**	2
3. Prostate Size: Volume in grams or cc. (Taken from biopsy ultrasound report)	3
4. PSA Density: = (PSA ÷ Prostate Volume)	4
5. Age at Diagnosis:	5
Biopsy Pathology Findings:	
6. Gleason Score: **Sum** of two Grades: e.g. 3+4=**7** (From core with highest Gleason Score)	6
a. **Primary Gleason Grade:** (1st number)	6a
b. **Secondary Gleason Grade:** (2nd number)	6b
7. Number of Cores taken:	7
8. Number of Cores Positive:	8
9. Percentage of Cores Positive: = (Cores Positive ÷ Cores Taken)	9
10. Geatest Core Percentage: In the core with the greatest % of cancer, what was the percentage (%) found?	10
Other Useful Data - Get Copies Of Written Reports	
11 Any ExtraCapsular Extension or **ExtraProstatic Extension (ECE or EPE)?** (locally advanced disease found with DRE, MRI, CT, or Color Doppler Ultrasound)	(YES) (NO) 11
12. Any pelvic lymph node positive? (Stage N1) (from MRI or CT)	(YES) (NO) 12
13. Any Positive Bone Scan? (Stage M1)	(YES) (NO) 13
14. Any positive node beyond the pelvis.	(YES) (NO) 14

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