

Automating the Creation of Patient-Centred Reports (PAPR)

Dr. Nathan Perlis, MD, MSc, FRCSC

University Health Network, Princess Margaret Cancer Centre

***DISCLAIMER:** This report is confidential and should not be shared with anyone. Details of this report may not be discussed with individuals outside of the study team”

For any questions, concerns, or other inquiries, please contact:

Lauren Calicchia, BSc.

Research Student

lauren.calicchia@uhn.ca

647-515-5070

Jenna Heimstra, BSc.

Clinical Analyst

jenna.heimstra2@uhn.ca

647-515-5070

Table of Contents

| | |
|--|---|
| Overall Study Goals | 3 |
| Current PAPR Creation Process | 3 |
| 1.0 Personal Information | 4 |
| 2.0 Your Prostate Biopsy Results | 4 |
| 2.1 Targeted Areas | 6 |
| 3.0 Treatment Options | 7 |
| 4.0 Office Contact | 7 |
| 5.0 Funding & Agreements | 8 |
| 6.0 Appendices (Full Input/Output Reports) | 9 |

A Preliminary Note

Although this report will have photos of the inputs and outputs regarding the creation of patient-centred reports (PAPRs), you will find a full example of both the input and output reports at the end of this document. Also, throughout the document, I colour coded sections from both the inputs (SPRs) and output (PAPR) to show where the information is located on both PDFs. The colours do not have any sort of meaning past identification purposes and are reused throughout the report.

Abbreviations

| | |
|------|-----------------------------------|
| UHN | University Health Network |
| PAPR | Patient-Centred Report (Output) |
| SPR | Standard Pathology Report (Input) |

Overall Study Goals

The overall goal of this study is to improve patient understanding of their diagnosis and empower them to make more informed decisions regarding their treatment. We have developed models of patient-centred reports with the help of patients, family members, and experts in the fields of radiology, oncology, and design. Now, our goal is to automate this process so these PAPR reports can be more widely used among oncology patients, and more patients can reap the benefits that they provide.

Current PAPR Creation Process

Currently, we use a platform called FIGMA to create patient centred reports from the traditional SPRs. We must login to the platform and manually select the areas in which we would like to personalize. This process takes time and energy that is not necessary if there is a possibility of creating a platform in which the PAPRs could be automatically generated.

Parts of the PAPR Report

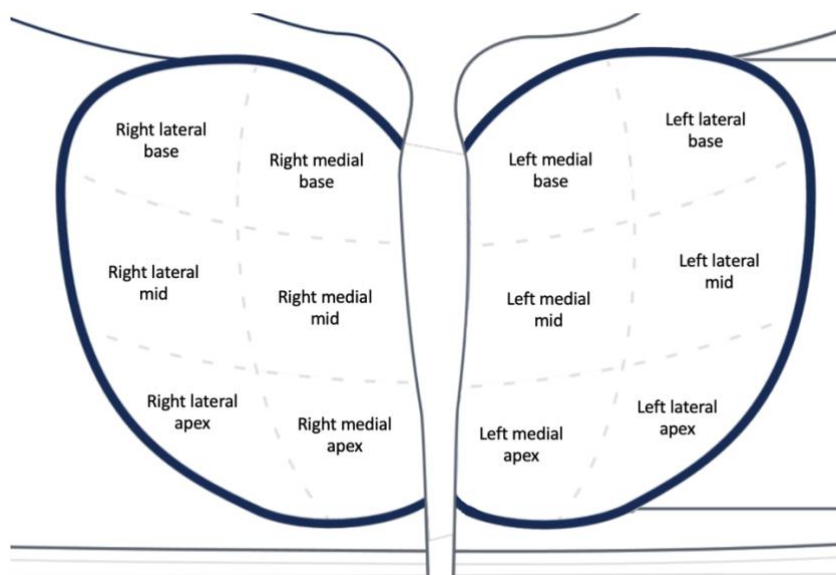
1.0 Personal Information

There are 6 things that need to be automated in this section: Name, Date of Birth, UHN ID, Doctor, Biopsy Date, and Report Date. Name, doctor, and the dates are mainly self-explanatory in terms of their content. However, UHN ID is also known as an MRN (medical record number) and is used as a patient identifier. It is especially useful for patients who have common names – we will look them up by their MRN instead.

| PAPR Information | SPR Information |
|------------------|---|
| Patient Name: | Patient Name: LastName, FirstName M. (M is middle initial if applicable) |
| Date of Birth: | DOB: 14/9/1956 OR DOB: Sept-14-1956 |
| UHN ID: | MRN: ##### (7 numbers) |
| Doctor | N/A (for now) |
| Date of Biopsy: | Collected: 24/8/2021 OR Collected: Aug-24-2021 |
| Date of Report: | Electronically signed by Cheung, Carol Chui-San, MD on 10/6/2024 OR Reported: Aug-24-2021 |

2.0 Your Prostate Biopsy Results

This part is the most complicated part of the PAPR report. There are 12 different areas (i.e., cores) from which a biopsy can be taken. They are listed below:



General Information

In SPRs, the cores are listed once altogether to provide insight as to where the samples were taken from, and then again further down, listed separately with a diagnosis for each sample. Below is an example of a couple of cores and how they are shown on the SPR:

B. Prostate, Right Lateral Mid, biopsy 1 core:

- Adenocarcinoma, Gleason score 7/10 (4+3) in 1 of 1 core involving approximately 50% of the core.

C. Prostate, Right Lateral Apex, biopsy 1 core:

- Adenocarcinoma, Gleason score 6/10 (3+3) in 1 of 1 core involving approximately 10% of the core.

D. Prostate, Right Med Base, biopsy 1 core:

- Negative for carcinoma.

The number of cores doesn't matter (e.g., 1 of 1 core). The only parts that matter are the location (e.g., Right Lateral Mid) and Gleason score [e.g., 7/10 (4+3)].

On the PAPR, there is a legend next to the image. The scale ranges from “Normal” to “5: Very aggressive”. Below is the SPR equivalent to each of the PAPR legend categories:

| PAPR | SPR | |
|--------------------------|--|--------------------|
| | Gleason Score | Grade Group |
| Normal | No Gleason score OR Gleason score not applicable | None |
| 1: Not aggressive | 6/10 (3+3) | ISUP Grade Group 1 |
| 2: Mildly aggressive | 7/10 (3+4) | ISUP Grade Group 2 |
| 3: Moderately aggressive | 7/10 (4+3) | ISUP Grade Group 3 |
| 4: Aggressive | 8/10 (4+4) | ISUP Grade Group 4 |
| 5: Very aggressive | 9/10 (4+5), 9/10 (5+4), 10/10 (5+5) | ISUP Grade Group 5 |

Sometimes (but not often), instead of a Gleason score there is a Grade group listed on the SPR. This is easier as there are 5 grade groups, and each group corresponds to the number on the paper (e.g., SPR: Grade group 1 = PAPR: 1 – Not aggressive). If there is no grade group, the sample is normal.

Sometimes, the format on the SPRs can vary. For example, sometimes the Gleason score is listed as 6 (3+3) or 6/10 (3+3). It may be easier for you to code it based on the addition value (3+3) instead of the overall grade (6), due to the varying formats. However, I have listed all of the variations in the accompanied excel file and whatever works best for you is good with me.

The following sections are listed in the PAPR Report along with their corresponding sections in the SPRs:

| PAPR Section | SPR | | | | |
|---|--|--------------|--|-----------|--------------------------------------|
| Overall Grade | Overall Grade: Grade group 1 (Gleason Score 3 + 3 = 6) | | | | |
| Biopsy Results “Cancer found in # areas” | Number of Positive Cores: 1 | | | | |
| Type of Biopsy | Sometimes it is not listed directly, but if the targeted format is listed on the report than it is a systematic + targeted. In the new reports, it is listed as follows: <table border="1"> <tr> <th colspan="2">CASE SUMMARY</th></tr> <tr> <td>Procedure</td><td>Systematic biopsy Targeted biopsy</td></tr> </table> | CASE SUMMARY | | Procedure | Systematic biopsy Targeted biopsy |
| CASE SUMMARY | | | | | |
| Procedure | Systematic biopsy Targeted biopsy | | | | |

2.1 Targeted Areas

Target areas must be shaded as shown in the PAPR. These cores have a specific language on the SPRs and is decently easy to identify. Below is an example of a systematic sample vs. a targeted sample:

| | |
|------------------|---|
| Systematic core: | E. Prostate, Right Med Mid, biopsy 1 core: - Adenocarcinoma, Gleason score 7 (3+4) in 1 of 1 core involving approximately 5% of the core |
| Targeted core: | M. Prostate Nodule, RMPZ NDL, biopsy 5 cores: - Adenocarcinoma, Gleason score 7/10 (3+4) |

Breaking the acronyms down:

| | | |
|---------|--------|-------------------------------|
| R Right | B Base | PZ Peripheral zone (lateral) |
| L Left | M Mid | TZ Transitional zone (medial) |
| | A Apex | CZ Central zone (medial) |

So, for the acronym RMPZ, it would be located (and shaded) in the Right Lateral Mid quadrant. This is the format for targeted biopsies. Some reports will say something like RMAPZ – this means that it is lateral (PZ), right (R), and in both the apex and the mid sections (because there is M and A). I am not sure if there is a way to code for this, so you don’t have to input all of the different combinations but let me know if there is any additional information you need to make this process easier. Sometimes there are letters after (e.g., RMPza, RBPZPm)– ignore the letters after PZ.

Sometimes the targeted cores are also listed as follows: L Apex Posterior PZ. Ignore the posterior, and this is exactly as above except apex is written out.

3.0 Treatment Options

There is the text section of the “Treatment Options” section, in which there is a standard blurb. At the end of the blurb, it says the cancer severity. Below is an example:

The table below is a guide to potential treatment options, but is not a complete list. Your treatment options are determined by the overall grade of the cancer found. Overall, the cancerous tissue found in your prostate is **mildly aggressive**.

| Overall Grade | Level of Aggressiveness | Gleason Score | Predicted Outcome | Common Treatment Options | Other Treatment Options |
|---|-------------------------|---------------|---|---|---------------------------------------|
| 1 | Not aggressive | 6 | Extremely slow growing and unlikely to spread | Surveillance | Surgery, radiation, or focal ablation |
| 2 | Mildly aggressive | 7 (3+4) | Very slow growing and can eventually spread | Surgery or radiation | Surveillance or focal ablation |
| 3 | Moderately aggressive | 7 (4+3) | Slow growing and can eventually spread | Surgery or radiation with or without hormones | Focal ablation |
| 4 | Aggressive | 8 | Growing at a moderate pace and can spread | Surgery or radiation with hormones | Clinical trial |
| 5 | Very aggressive | 9 & 10 | Growing at a fast pace and can spread | Surgery or radiation with hormones | Clinical trial |
| For more aggressive types of cancer, your doctor may arrange for more tests. A CT scan, bone scan, and/or PET scan will show if disease has spread to other parts of the body. If the disease has spread, you may require hormone therapy or chemotherapy which can treat cancer that has spread. | | | | | |

This information is the same as the “Overall Cancer Grade”, and the information is the same (e.g., all sections should say mildly aggressive). For the chart, if there is a way to bold the necessary row that would be great. If not, I can send you pngs of the image with each row highlighted, and you can input that as needed. Let me know!

4.0 Office Contact

Leave this section for now, as we are having some issues trying to figure out how to get this information. If possible, when we figure it out, it would be great if you could go back and add this information.

5.0 Funding & Agreements

You will be onboarded as volunteers for this project. Therefore, the program that you make will be property of Dr. Perlis's research team (which you are now a part of as volunteers). After the program is made, you will receive compensation by Dr. Perlis. Any future programs that are created (i.e., for other hospital SPRs), funding will be provided through any grants that Dr. Perlis or I receive.

Please let me know if you have any questions about this document!

Prostate Biopsy Report

Summary for Patients

**Output



Patient Name John Longbender

Doctor ~~Dr. Tom Urology~~

n/a for now

Date of Birth September 14, 1956

Date of Biopsy August 24, 2021

UHN ID 12345678

Date of Report August 28, 2021

About This Report

This report provides a summary of your prostate biopsy findings by area. During a prostate biopsy, very small tissue samples, called "cores", are removed. Doctors look at each core under the microscope to check for cancer. If more than one core has been sampled in an area, the core with the highest grade in each area is displayed. Refer to the full report attached for more details.

Your Prostate Biopsy Results

Overall Grade

2 Mildly aggressive cancer

Biopsy Result

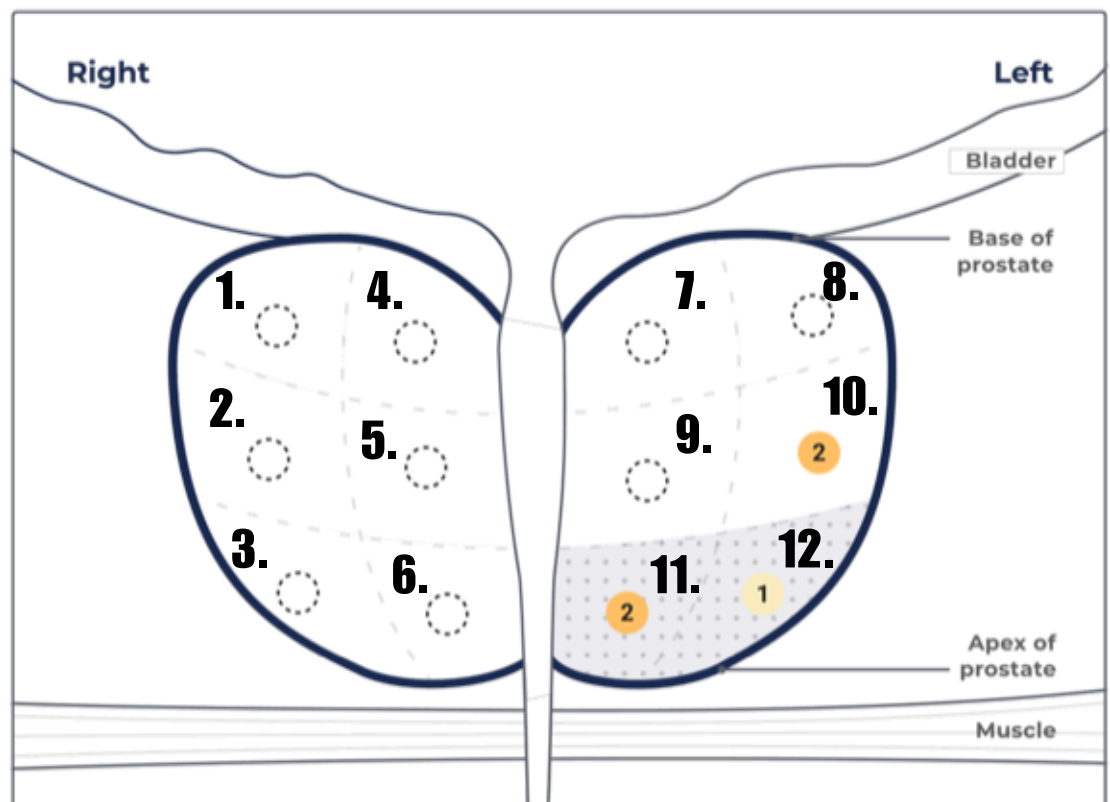
Cancer found in 3 areas

Type of Biopsy

Systematic + targeted biopsy

Legend

- Normal
- 1 Not aggressive
- 2 Mildly aggressive
- 3 Moderately aggressive
- 4 Aggressive
- 5 Very aggressive
- Targeted area



How aggressiveness is determined

The aggressiveness of prostate cancer is determined by how different the cancerous tissue looks compared to normal tissue under the microscope. Cancerous tissue that looks very different from normal tissue tends to be more aggressive and is more likely to grow and spread. The overall level of aggressiveness found is used to determine your Overall Grade.

Treatment Options

The table below is a guide to potential treatment options, but is not a complete list. Your treatment options are determined by the overall grade of the cancer found. Overall, the cancerous tissue found in your prostate is **mildly aggressive**.

| Overall Grade | Level of Aggressiveness | Gleason Score | Predicted Outcome | Common Treatment Options | Other Treatment Options |
|---------------|-------------------------|---------------|---|---|---------------------------------------|
| 1 | Not aggressive | 6 | Extremely slow growing and unlikely to spread | Surveillance | Surgery, radiation, or focal ablation |
| 2 | Mildly aggressive | 7 (3+4) | Very slow growing and can eventually spread | Surgery or radiation | Surveillance or focal ablation |
| 3 | Moderately aggressive | 7 (4+3) | Slow growing and can eventually spread | Surgery or radiation with or without hormones | Focal ablation |
| 4 | Aggressive | 8 | Growing at a moderate pace and can spread | Surgery or radiation with hormones | Clinical trial |
| 5 | Very aggressive | 9 & 10 | Growing at a fast pace and can spread | Surgery or radiation with hormones | Clinical trial |

For more aggressive types of cancer, your doctor may arrange for more tests. A CT scan, bone scan, and/or PET scan will show if disease has spread to other parts of the body. If the disease has spread, you may require hormone therapy or chemotherapy which can treat cancer that has spread.

What is the Gleason score? The Gleason scoring system is used to classify the level of aggressiveness found in the cores. The overall level of aggressiveness takes into account the Gleason score of all the core samples to determine the Overall Grade.

To learn more about prostate cancer, visit: www.cancer.ca/prostate and www.mypathologyreport.ca/prostate.

Next Steps

Talk to your doctor to review your biopsy results along with other health findings, including your PSA and clinical exam results, to determine the best treatment option for you.

If you have had a prostate biopsy before, talk to your doctor about any changes that may have occurred. If you would like to talk to a peer, visit prostatecancersupport.ca to get connected.

Office Contact

If you have not received a follow-up appointment yet, please contact your doctor's office.

~~Dr. Urology's Office~~
~~urology.office@uhn.ca~~ **n/a for now**
~~(416) 233-4567~~

LABORATORY MEDICINE PROGRAM

**Input

DEPARTMENT OF PATHOLOGY

200 Elizabeth Street
Toronto, Ontario M5G 2C4
TEL: 416-340-5353
FAX: 416-586-9901

Patient: Longbender, John

MRN: 12345678

Health Card: [REDACTED]

Case #:

Gender:

Male

DOB:

14/9/1956 67 yrs

Copy To:

Submitter:

Surgical Pathology (Final result)

Authorizing Provider: Ghai, Sangeet, MD
Ordering Location: Princess Margaret Cancer Centre
- Joint Department Of Medical
Imaging
Pathologist: Cheung, Carol Chui-San, MDOrdering Provider: Ghai, Sangeet, MD
Collected: 15/05/2024 1232

Received: 15/05/2024 1320

Received in Result Lab: 16/5/2024 9:42 AM

Specimens

- A Prostate, Right Lateral Base, 1 core
- B Prostate, Right Lateral Mid, 1 core
- C Prostate, Right Lateral Apex, 1 core
- D Prostate, Right Med Base, 1 core
- E Prostate, Right Med Mid, 1 core
- F Prostate, Right Med Apex, 1 core
- G Prostate, Left Med Base, 1 core
- H Prostate, Left Med Mid, 1 core
- I Prostate, Left Med Apex, 1 core
- J Prostate, Left Lateral Base, 1 core
- K Prostate, Left Lateral Mid, 1 core
- L Prostate, Left Lateral Apex, 1 core
- M Prostate Nodule, 5 core (LMPZ MRI)

FINAL DIAGNOSIS

1. A. Prostate, Right Lateral Base, biopsy 1 core:
- Negative for carcinoma.








Patient: Longbender, John

Location: Princess Margaret Cancer Centre - Joint
Department Of Medical Imaging

Page: 1 of 4

Printed: 13/6/2024 5:32 PM

2. B. Prostate, Right Lateral Mid, biopsy 1 core: 
- Negative for malignancy.
3. C. Prostate, Right Lateral Apex, biopsy 1 core: 
- Benign prostatic tissue
4. D. Prostate, Right Med Base, biopsy 1 core: 
- Adenocarcinoma, Gleason score 6 (3+3) in 1 of 1 core involving approximately 5% of the core 1
5. E. Prostate, Right Med Mid, biopsy 1 core: 
- Adenocarcinoma, Gleason score 7 (3+4) in 1 of 1 core involving approximately 5% of the core 2
6. F. Prostate, Right Med Apex, biopsy 1 core: 
- Adenocarcinoma, Gleason score 7 (4+3) in 1 of 1 core involving approximately 5% of the core 3
7. G. Prostate, Left Med Base, biopsy 1 core: 
- Adenocarcinoma, Gleason score 8 (4+4) in 1 of 1 core involving approximately 5% of the core 4
8. H. Prostate, Left Med Mid, biopsy 1 core: 
- Adenocarcinoma, Gleason score 9 (4+5) in 1 of 1 core involving approximately 5% of the core 5
9. I. Prostate, Left Med Apex, biopsy 1 core: 
- Adenocarcinoma, Gleason score 9 (5+4) in 1 of 1 core involving approximately 5% of the core 5
10. J. Prostate, Left Lateral Base, biopsy 1 core: 
- Adenocarcinoma, Gleason score 10 (5+5) in 1 of 1 core involving approximately 5% of the core 5
11. K. Prostate, Left Lateral Mid, biopsy 1 core: 
- Adenocarcinoma, Gleason score not applicable, perineural invasion only on 1 of 5 cores involving approximately 5% of the core
12. L. Prostate, Left Lateral Apex, biopsy 1 core: 
- Focal atypical small acinar proliferation (ASAP)
11. M. Prostate Nodule, LMPZ MRI, biopsy 5 cores:  
- Negative for malignancy.

Electronically signed by Cheung, Carol Chui-San, MD on 13/6/2024 at 1732

SYNOPTIC REPORT

Prostate Gland: Needle Biopsy (Case Level) (PROSTATE GLAND: NEEDLE BIOPSY (CASE LEVEL) - All Specimens)
Protocol posted: 20/9/2023

CASE SUMMARY

| | |
|---------------------------------|--|
| Procedure | Systematic biopsy Targeted biopsy |
| Histologic Type | Acinar adenocarcinoma, conventional (usual) |
| Histologic Grade | |
| Highest Grade | Grade group 5 (Gleason Score 5 + 5 = 10) |
| Systematic Biopsy Overall Grade | Grade group 3 (Gleason Score 4 + 3 = 7) |
| Percentage of Pattern 4 | 81 - 90% 80 % |
| Percentage of Pattern 5 | 10 % |
| Targeted Biopsy Grade | Cannot be assessed: Perineural invasion only, not graded |

Patient: Longbender, John

Location: Princess Margaret Cancer Centre - Joint
Department Of Medical Imaging

Page: 2 of 4

Printed: 13/6/2024 5:32 PM

| | |
|---|--|
| Intraductal Carcinoma (IDC) | Not identified |
| Cribriform Glands | Not identified |
| Treatment Effect | Radiation therapy effect present: Gleason scoring may be inaccurate in this context. |
| TUMOR QUANTITATION | |
| Total Number of Cores | 17 |
| Number of Positive Cores | 3 |
| Tumor Measurement Technique | Consider multiple foci as discontinuous tumor |
| Greatest Percentage of Core Involvement by Cancer in Any Core | 6 - 10% |

you can ignore this part

GROSS DESCRIPTION

- A. The specimen labeled with the patient's name and as "prostate, right lateral base biopsy, 1 core" consists of 1 core of white core-like tissue measuring 1.8 x 0.1 cm, received in 10% buffered formalin.
A1 submitted in toto
- B. The specimen labeled with the patient's name and as "prostate, right lateral mid biopsy, 1 core" consists of 2 cores of white core-like tissue measuring 0.6-1.2 x 0.1 cm, received in 10% buffered formalin.
B1 submitted in toto
- C. The specimen labeled with the patient's name and as "prostate, right lateral apex biopsy, 1 core" consists of 1 core of white core-like tissue measuring 1.7 x 0.1 cm, received in 10% buffered formalin.
C1 submitted in toto
- D. The specimen labeled with the patient's name and as "prostate, right med base biopsy, 1 core" consists of 2 cores of white core-like tissue measuring 1.0-1.3 x 0.1 cm, received in 10% buffered formalin.
D1 submitted in toto
- E. The specimen labeled with the patient's name and as "prostate, right med mid biopsy, 1 core" consists of 1 core of white core-like tissue measuring 2.0 x 0.1 cm, received in 10% buffered formalin.
E1 submitted in toto
- F. The specimen labeled with the patient's name and as "prostate, right med apex biopsy, 1 core" consists of 1 core of white core-like tissue measuring 1.6 x 0.1 cm, received in 10% buffered formalin.
F1 submitted in toto
- G. The specimen labeled with the patient's name and as "prostate, left med base biopsy, 1 core" consists of 1 core of white core-like tissue measuring 2.1 x 0.1 cm, received in 10% buffered formalin.
G1 submitted in toto
- H. The specimen labeled with the patient's name and as "prostate, left med mid biopsy, 1 core" consists of 1 core of white core-like tissue measuring 1.7 x 0.1 cm, received in 10% buffered formalin.
H1 submitted in toto
- I. The specimen labeled with the patient's name and as "prostate, left med apex biopsy, 1 core" consists of 1 core of white core-like tissue measuring 2.1 x 0.1 cm, received in 10% buffered formalin.
I1 submitted in toto
- J. The specimen labeled with the patient's name and as "prostate, left lateral base biopsy, 1 core" consists of 1 core of white core-like tissue measuring 1.8 x 0.1 cm, received in 10% buffered formalin.
J1 submitted in toto
- K. The specimen labeled with the patient's name and as "prostate, left lateral mid biopsy, 1 core" consists of 1 core of white core-like tissue measuring 2.0 x 0.1 cm, received in 10% buffered formalin.
K1 submitted in toto

L. The specimen labeled with the patient's name and as "prostate, left lateral Apex biopsy, 1 core" consists of 1 core of white core-like tissue measuring 1.8 x 0.1 cm, received in 10% buffered formalin.
L1 submitted in toto

M. The specimen labeled with the patient's name and as "prostate, left lateral Apex biopsy, prostate nodule 5 core" consists of 5 cores of white core-like tissue measuring 1.8-2.1 x 0.1 cm, received in 10% buffered formalin.
M1-M3 submitted in toto

Order Comments
PSA 0.48. DRE: NEG. PROSTATE VOLUME: 45cc. 17 CORES TOTAL

| Resulting Labs | |
|----------------|--|
| TGH | TORONTO GENERAL HOSPITAL, 200 Elizabeth St, Toronto ON M5G 2C4 |