

## **APPENDIX**

### **Appendix 1. Script for expert interview**

Hello, thank you very much for participating in this interview today. My name is \_\_\_\_\_. I am a urologic oncologist and am conducting this study (or alternatively “my name is XXX, I am a research assistant on this project). First, I would like to thank you for agreeing to participate in this study. If you have any questions about the study or need any clarification, please ask at any point. If at any time you feel that you would no longer like to participate in the study that is fine. Participation is completely voluntary. We thank you for taking time to be part of the study. You may refuse to answer any questions should you so choose.

As you have already read in the consent form, this study concerns creating a new type of radiology report for prostate MRI that would be more targeted to patients and the type of information that they would like to see on an imaging report. You are being asked to take part in this research study because of your expertise in prostate cancer and prostate MRI.

The objective of our study is to design a patient-oriented prostate MRI report that has simple language, contains the information that patients and experts consider most relevant to clinical decision making and can help patients visualize the findings of the prostate MRI. We intended to design these reports so that they can be automatically converted from regular radiology reports and used clinically by doctors in the future. We hope that this type of report will improve patient understanding of their radiology findings, assist communication between doctors and patients and help patients feel that they were well-informed prior to making a clinical decision.

At this early stage of patient-oriented radiology report development we are trying to learn what experts like you think is important to include in a prostate MRI report from a patient perspective but also when thinking about the key bits of information you think patients need to know to make informed decision in common clinical scenarios. You can suggest as many items as you like and for each we will ask you to rate how important that item is on a scale from one to five, one being a little important and five being the most important. By the end of today’s session we hope to have a long-list of items that can later be pared down to the most important items to be included in the instrument.

Everything that you say today will be kept in strict confidence. We will be taking notes, but your names will not be linked to any comments.

Are there any questions? Can I clarify anything so far? Would you no longer like to participate?

We will start the question and answer period now. (as the expert explores important concepts we will ask them to rate the importance from 1->5 as mentioned above)

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Here is a blank paper with several empty lines, please write your answers on the lines. You do not have to fill all of the spaces.

When you think about your patients prostate MRI report what do you think about?

Now let's go over all the items to clarify what they mean and how important you think they are for your patient to see on a radiology report (score from 1-5).

Thank you for those detailed responses. We would like you now to consider some specific areas that may or may not have been covered already.

We are curious about whether you would prefer that the patient-centred report contain snap shots from the actual prostate MRI image versus a sketch?

Is there a particular length to which you think we should limit the patient-centred report?

Beyond the image and description of the findings would it be important that other information be included? For example,

- (a) Would you like an explanation of the relevance of the size of your prostate to your symptoms or PSA level?
- (b) Would you like an explanation of the chances that a particular finding mean that a biopsy would identify cancer?
- (c) Would you like an explanation of the chances that a particular finding means that there is disease growing beyond the prostate?
- (d) Would you like an explanation of the chances that a particular finding means that a lymph node or bone in your pelvis might contain disease?

Thank you again for participating in this session.

## **Appendix 2. Script for patient interview #1**

Hello, thank you very much for participating in this interview today. My name is \_\_\_\_\_. I am a urologic oncologist and am conducting this study (or alternatively “my name is XXX, I am a research assistant on this project). First, I would like to thank you for agreeing to participate in this study. If you have any questions about the study or need any clarification, please ask at any point. If at any time you feel that you would no longer like to participate in the study that is fine. Participation is completely voluntary. We thank you for taking time to be part of the study. You may refuse to answer any questions should you so choose.

As you have already read in the consent form, this study concerns creating a new type of radiology report for prostate MRI that would be more targeted to patients and the type of information that they would like to see on an imaging report. You are being asked to take part in this research study because you will be undergoing a prostate MRI in the near future so you are in a good position to tell us what you believe are the important components of a patient-centred prostate MRI report.

We intended to design these reports so that they can be automatically converted from regular radiology reports and used clinically by doctors in the future. We hope that this type of report will improve patient understanding of their radiology findings, assist communication between doctors and patients and help patients feel that they were well-informed prior to making a clinical decision.

At this early stage of patient-oriented radiology report development we are trying to learn what patients like you think is important to include in a prostate MRI report. You can suggest as many items as you like and for each we will ask you to rate how important that item is on a scale from one to five, one being a little important and five being the most important. By the end of today’s session we hope to have a long-list of items that can later be pared down to the most important items to be included in the instrument.

Everything that you say today will be kept in strict confidence. We will be taking notes, but your names will not be linked to any comments.

Are there any questions? Can I clarify anything so far? Would you no longer like to participate?

We will start the question and answer period now. (as the expert explores important concepts we will ask them to rate the importance from 1->5 as mentioned above)

Here is a blank paper with several empty lines, please write your answers on the lines. You do not have to fill all of the spaces.

When you think about your prostate MRI report what do you think about?

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Now let's go over all the items to clarify what they mean and how important they are for you to see on a radiology report (score from 1-5).

Try and consider times you've had an imaging study presented to you, were there particular methods that the doctor used that helped you understand the information better?

Thank you for those detailed responses. We would like you now to consider some specific areas that may or may not have been covered already.

We are curious about whether you would prefer that the patient-centred report contain snap shots from the actual prostate MRI image versus a sketch?

Is there a particular length to which you think we should limit the patient-centred report?

Beyond the image and description of the findings would it be important that other information be included? For example,

- (a) Would you like an explanation of the relevance of the size of your prostate to your symptoms or PSA level?
- (b) Would you like an explanation of the chances that a particular finding mean that a biopsy would identify cancer?
- (c) Would you like an explanation of the chances that a particular finding means that there is disease growing beyond the prostate?
- (d) Would you like an explanation of the chances that a particular finding means that a lymph node or bone in your pelvis might contain disease?

Thank you again for participating in this session. We will be contacting you all to arrange follow-up interviews.

### **Appendix 3. PACERR – Prostate MRI report – User feedback**

Pilot testing the PACERR was done through cognitive interviews and iterative design feedback, guided by the questions below.

**The Patient-Centered Prostate MRI Report (PACERR)**      Date:

\_\_\_\_\_

Patient ID: \_\_\_\_\_ Interviewer:

\_\_\_\_\_

We designed a prostate MRI report that is accessible for patients and we would like to get your input on our work. We will be showing you our report and asking you questions. Before we start do you have any questions for us?

#### *Warm Up Questions*

- 1) What does your typical week day look like? What do you do?
- 2) How often do you see your doctor regarding your prostate?
- 3) In the past, how did you receive medical information about your prostate?

#### *Main Questions*

- 4) Read through *Patient Information* and *MRI Information* sections and reflect on what you understand.
- 5) Review the diagrams in the *Spots in your Prostate* section and reflect on what you understand.
- 6) Read through the *Spots of Concern* table and reflect on what you understand.
- 7) If applicable, read the *What is a PI-RADS Score?* section and reflect on what you understand.
- 8) Read through the *What's Next* section and reflect on what you understand.
- 9) Recall a time when you received a medical report, what did you think and how did you feel?

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- 10) What other information would you like to see in this report?
- 11) Are there any areas in the report that are unclear to you?
- 12) How would this report be useful in clinic when you are discussing the findings of your prostate MRI with your doctor?
- 13) Do you have any additional comments regarding this report?

Thank you!

**Appendix 4. Short and long prototype PACERRs generated from interviews with 15 patients and 8 experts.**

PROSTATE MRI REPORT

SUMMARY FOR PATIENTS

CUHN

This report gives you and your doctor more information to make better decisions regarding your treatment plan. To best understand your results, this report should be reviewed with your doctor.

PATIENT INFORMATION

NAME

DATE OF BIRTH

Dec 18, 1968

PATIENT ID

DATE OF MRI


July 12, 2018

ORDERING PHYSICIAN

REASON FOR MRI

Clinical concern for prostate cancer

YOUR PROSTATE MRI RESULTS



NERVES  
SEMINAL VESICLE  
BLADDER  
PROSTATE  
MUSCLE FLOOR  
URETHRA  
RECTUM

SPOTS OF INTEREST

SPOT	SIDE OF BODY	SIZE	CHANGE IN SIZE*	CHANCE OF CANCER
A	Left	15 mm	Larger	Very Likely Cancer
B	Right	10 mm	Equal	Likely Cancer
C	Left	11 mm	Smaller	Possibly Cancer
D	Middle	9 mm	Larger	Possibly Cancer
E	Right	7 mm	Smaller	Possibly Cancer

\* SINCE LAST MRI DATE (JUNE 20, 2018)

ADDITIONAL FINDINGS

Very Enlarged Prostate. Another Finding

WHAT'S NEXT?

1 SEE YOUR DOCTOR  
Please review your results with your doctor.

2 MAKE A DECISION  
With your doctor, decide the best route forward for you.

3 FOLLOW UP MEETING  
Establish a plan for check ups or treatment.

PROSTATE MRI REPORT

SUMMARY FOR PATIENTS

CUHN

This report gives you and your doctor more information to make better decisions regarding your treatment plan. To best understand your results, this report should be reviewed with your doctor.

PATIENT INFORMATION

NAME

DATE OF BIRTH

Dec 18, 1968

PATIENT ID

DATE OF MRI

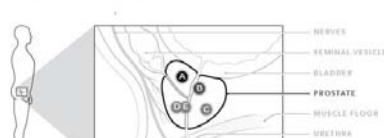
July 12, 2018

ORDERING PHYSICIAN

REASON FOR MRI

Clinical concern for prostate cancer

YOUR PROSTATE MRI RESULTS



NERVES  
SEMINAL VESICLE  
BLADDER  
PROSTATE  
MUSCLE FLOOR  
URETHRA  
RECTUM

SPOTS OF INTEREST

SPOT	PI-RADS SCORE	SIDE	SIZE
A	5 Very Likely Cancer	Left	15 mm ↑
B	4 Likely Cancer	Right	10 mm =
C	3 Possibly Cancer	Left	11 mm ↓
D	3 Possibly Cancer	Mid	9 mm ↓
E	3 Possibly Cancer	Right	7 mm ↓

SIZES FROM LAST MRI: ↑ LARGER ↓ SMALLER = SAME

WHAT IS A PI-RADS SCORE?

Radiologists assign a PI-RADS score to each spot seen on MRI. If the spot were biopsied, three types of tissue may be found:

Non Cancerous Tissue

Less Aggressive Cancerous Tissue

More Aggressive Cancerous Tissue

PI-RADS SCORES

3 Possibly Cancer

4 Likely Cancer

5 Very Likely Cancer

WHAT'S NEXT?

1 SEE YOUR DOCTOR  
Please review your results with your doctor.

2 MAKE A DECISION  
With your doctor, decide the best route forward for you.

3 FOLLOW UP MEETING  
Establish a plan for check ups or treatment.

← Short version

Long version →