

Figure S1

TAN Baseline Questionnaire Version 3.0 (25/06/2015)

Participant Study Code

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Participant Study Number

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Anal Human Papillomavirus Infection & Anal Cellular Abnormalities in Kidney Transplant Recipients

A Study of Transplant and Anal Neoplasia

Computer Assisted Survey

Baseline Interview Questionnaire

Demographics and behaviour

A joint project of

Westmead Hospital Department of Transplantation and Renal Medicine

Western Sydney Sexual Health Centre

Kirby Institute, UNSW

Royal Women's Hospital Melbourne

Douglass Hanly Moir Laboratories

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This questionnaire is designed to collect as much of your valuable personal information to explore the links between solid organ transplantation, HPV (Human Papilloma Virus- (wart virus) infection and the associated increased risk of developing anal squamous cell cancer. HPV infection is very common (generally a sexually acquired infection). A persistent infection with some high risk HPV types is also associated with an increased risk of developing anal squamous cell cancer. This is a similar process and has many parallels to HPV related cervical cancer in women.

Following a solid organ transplant and being on long term immunosuppression (anti rejection drugs) may effect on your body's natural immunity and reduce the ability to clear certain infections such as HPV, resulting in a chronic and persistent infection.

Anal cancer risks include

High risk HPV type 16 (there are over 100 HPV types)

- Long term immunosuppression which includes people who have had kidney transplants or any other solid organ transplants, people with autoimmune diseases and people living with HIV infection
- In women with a past history of high grade cervical disease
- In men who have sex with men
- Receptive anal sex
- Current smoking habits
- A current or previous history of genital warts

Thank you for taking the time to fill in this short survey. Your answers will be used to help researchers better understand the risk factors of anal cancer in solid organ transplant recipients including anal HPV infection. To fully understand the risk of anal cancer, the questions will seem personal in nature and will cover topics such as, where you live, sexual and other lifestyle behaviours. All the information will enable a better understanding of the risk factors that contribute to anal cancer.

Please try to respond as accurately as you can as this will maximize the benefit of this study. This questionnaire is strictly confidential. Only the study researchers will have access to this information, which are bound by the relevant ethics committees overseeing this study.

Your Participant Information and Consent Form provides details of these committees, your rights, and how to contact them. All your information will be strictly confidential and you will be identified by your unique study number only. Your participation is voluntary and all your answers are confidential. You will be given a 2x4 study number that will allow us to cross link your information. This questionnaire and all identifying information will be securely destroyed at the end of the study.

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Demographic details

Female

Male

☐ A1

☐ A2

In what country were you born?

Australia ☐ B1

New Zealand ☐ B2

Other ☐ B3

(Specify_____)

Don't know ☐ B4

Are you of Aboriginal or Torres Strait Islander descent?

No ☐ B5

Yes, Aboriginal ☐ B6

Yes, Torres Strait Islander ☐ B7

Yes, Aboriginal and Torres Strait Islander ☐ B8

What is your ethnic or cultural background?

Anglo-Celtic ☐ B9

Arabic ☐ B10

Chines ☐ B11

Vietnamese ☐ C12

Other B13

(Specify_____)

Don't know ☐ B14

Refusal ☐ B15

What is your date of birth?

Day Month Year B16

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What is the postcode of the suburb or town where you live?

_____ (Postcode) ☐ B17
Overseas ☐ B18
Don't know ☐ B19

Work/Employment/Study/Retirement

We are interested in your work situation. Are you?

Unemployed ☐ C1
Looking after family/home ☐ C2
Studying ☐ C3
Disabled/sick ☐ C4
Doing unpaid work ☐ C5
Self-employed ☐ C6
Completely retired/pensioner ☐ C7
In part time paid work ☐ C8
In full time paid work ☐ C9
Other ☐ C10
(Specify _____)
Don't know ☐ C11
Refusal ☐ C12

Which of these income groups do you belong, this is the total before tax for your household to (fortnightly income)?

\$ 0-99 ☐ C13
\$ 100-499 ☐ C14
\$ 500-999 ☐ C15
\$ 1000-1499 ☐ C16
\$ 1500-1999 ☐ C17
\$ 2000 or more ☐ C18
Don't know ☐ C19
Refusal ☐ C20

What type of job/occupation do/did you have if you are retired or not working now?

(Write in full) _____ ☐ C21
Don't know ☐ C22
Refusal ☐ C23
NA - Not in workforce/pensioner/student ☐ C24

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What is the highest level of education you have had? or what age did you finish school? If your education has not been in Australia, please choose the nearest option.

- (Write in full)___Age _____ C25
- Primary school only ☐ C26
- Up to School certificate/4th Form/Year 10/ Intermediate certificate ☐ C27
- Leaving certificate/HSC/6th Form/Year 12 ☐ C28
- Tertiary diploma or trade certificate/TAFE ☐ C29
- University or CAE undergraduate degree ☐ C30
- Postgraduate degree ☐ C31
- Don't know ☐ C32
- Refusal ☐ C33

Smoking

Have you ever been a regular smoker?

- Never ☐ D1
- Yes ☐ D2
- Don't know ☐ D3
- Refusal ☐ D4

Are you a regular smoker now?

- No ☐ D5
- Yes ☐ D6
- Refusal ☐ D7
- NA – Never smoked ☐ D8

If no, how old were you when you stopped smoking regularly?

- Years old ☐☐ D9
- Don't know ☐ D10
- Refusal ☐ D11
- NA – Never smoked ☐ D12

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About how much do you/did you smoke on average each day?

(Record actual number)

☐ ☐ ☐ D13

☐ D14

Refusal

☐ D15

Sexual identity

We are interested to know how you identify sexually.

Do you think of yourself as?

Heterosexual or straight ☐ E1

Bisexual ☐ E2

Homosexual ☐ E3

Other (Specify _____) ☐ E4

Don't know ☐ E5

Refusal ☐ E6

Lifetime female partners

In your lifetime, with about how many women have you had sex of any kind?

☐ F1

None

One ☐ F2

2-10 women ☐ F3

11-50 women ☐ F4

More than 50 ☐ F5

women

Don't know ☐ F6

Refusal ☐ F7

NA- Never had sex with women ☐ F8

Lifetime male partners

In your lifetime, with about how many men have you had sex of any kind?

(If unsure, please give your best estimate).

None ☐ G1

One ☐ G2

2-10 men ☐ G3

11-50 men ☐ G4

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More than 50 men ☐ G5
Don't know ☐ G6
Refusal ☐ G7
NA- Never had sex with men ☐ G8

Have you ever had anal intercourse with a man?

Yes ☐ ☐ G9
Don't know ☐ G10
Refusal ☐ G11
Never ☐ G12

How old were you the first time you engaged in receptive anal intercourse with a man?

Yes ☐ ☐ G13
Don't know ☐ G14
Refusal ☐ G15
Never ☐ G16

Have you ever had a finger inserted into your anus by any partners, male or female?

Yes ☐ G17
No ☐ G18
Male ☐ G19
Female ☐ G20
Don't know ☐ G21
Refusal ☐ G22

(Women Only answer this)

Have you ever had an abnormal PAP smear?

Never ☐ H1
Yes ☐ H2
Don't know ☐ H3
Refusal ☐ H4

If yes, was it low grade (CIN 1) or high grade cervical disease (CIN 2/3)

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Don't know the result ☐ H5

Not normal but I do not know which ☐ H6

CIN 1 ☐ H7

CIN 2 ☐ H8

CIN 3 ☐ H9

Don't know ☐ H10

Refusal ☐ H11

If there was any high grade disease, did you have any extra treatment on your cervix (Colposcopy).

Yes ☐ H12

No ☐ H13

Don't know ☐ H14

Refusal ☐ H15

(Women and men answer this)

Have you ever had any sexually transmitted infections?

(Write in full) _____

Yes ☐ J1

No ☐ J2

Don't know ☐ J3

Refusal ☐ J4

In the last six months, have you ever had anal itching?

No ☐ K1

Yes ☐ K2

Don't know ☐ K3

Refusal ☐ K4

NA – not had this symptom ☐ K5

In the last six months, have you ever had pain passing bowel motions?

No ☐ K6

Yes ☐ K7

Don't know ☐ K8

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Refusal ☐ K9

How severe was/is this pain, was/is this:

A little	<input type="checkbox"/> K10
Moderately	<input type="checkbox"/> K11
Extremely	<input type="checkbox"/> K12
Don't know	<input type="checkbox"/> K13
Refusal	<input type="checkbox"/> K14
NA – not had this symptom	<input type="checkbox"/> K15

In the last six months, have you ever had anal bleeding?

No	<input type="checkbox"/> L1
Yes	<input type="checkbox"/> L2
Don't know	<input type="checkbox"/> L3
Refusal	<input type="checkbox"/> L4

In the last six months, have you ever had any tearing/splitting of your anus?

No	<input type="checkbox"/> L5
Yes	<input type="checkbox"/> L6
Don't know	<input type="checkbox"/> L7
Refusal	<input type="checkbox"/> L8

Has a doctor ever told you that you have haemorrhoids (piles)?

Never	<input type="checkbox"/> L9
Yes	<input type="checkbox"/> L10
Don't know	<input type="checkbox"/> L11
Refusal	<input type="checkbox"/> L12

In the last six months, have you ever a feeling that something was left after a bowel movement?

No	<input type="checkbox"/> L13
Yes	<input type="checkbox"/> L14

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Don't know ☐ L15

Refusal ☐ L16

Knowledge and experience about human papilloma virus (wart virus)

Did you know that high risk HPV was a recognised as a cause of anal cancer?

No ☐ M1

Yes ☐ M2

Don't know ☐ M3

Refusal ☐ M4

Have you ever had anal or genital warts?

No ☐ M5

Yes ☐ M6

Don't know ☐ M7

Refusal ☐ M8

Have you even been vaccinated against human papilloma virus?

Never ☐ M9

Yes, in the past twelve months ☐ M10

Yes, more than one year ago ☐ M11

Don't know ☐ M12

Refusal ☐ M13

Have you ever received a digital rectal examination where a doctor inserted his/her finger into your anus to check for lumps or bumps, prostate in men?

Never ☐ N1

Yes ☐ N2

Don't know ☐ N3

Refusal ☐ N4

Who gave you your last receive the digital rectum examination?

My GP ☐ N5

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A specialist ☐N6

Don't know ☐N7

Refusal ☐N8

NA - Never received this examination ☐N9

Final words

1. Is there anything else that you would like to say before we finish this part of interview? Would you like to comment on the interview itself or on how we are handling the study? Or is there something else you think we should know?

☐☐☐O1

2. As a final comment, would you mind telling me why you have decided to be involved with this project?

☐☐☐P1

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This is the end of the questionnaire. Thank you for your time.