



Gonorrhoea: the pain and shame of notification

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This article describes the unwieldy gonorrhoea notification process in New Zealand following recent legislative reforms.¹ We seek changes to improve control of this serious infectious disease.

Infectious disease surveillance in New Zealand

New Zealand is failing to contain sexually transmitted infections (STIs). Our chlamydia diagnosis rates are higher than rates in the United Kingdom and Australia, with infection disproportionately affecting young Māori and Pacific Women.^{2–5} Syphilis cases have increased 400% since 2012; concentrated among gay and bisexual men, but now bridging into heterosexual populations and causing stillbirths. Gonorrhoea is also rising particularly among males in Auckland.^{4,5} We can paint this picture because of disease surveillance, a cornerstone of STI control efforts alongside testing, treatment and behaviour change programmes.⁶ A robust surveillance system alerts us to outbreaks, enabling appropriate, targeted and timely public health interventions to interrupt transmission.^{1,7}

To augment surveillance of Section C diseases in New Zealand (gonorrhoea, syphilis and HIV), the Health Act was amended in 2017 to add health practitioner notification to pre-existing direct laboratory reporting.^{1,7–9} The Ministry of Health assured Parliament that the notification changes would not pose significant additional compliance costs on general practice.¹⁰ Under the new system introduced in 2018, health practitioners are required upon ‘reasonable suspicion’ of a notifiable disease to ‘forthwith give notices in the prescribed form to the medical officer of health’ (s.74(1)(a)).^{9,11} Failure to comply is punishable by ‘a fine not

exceeding \$500 and, if the offence is a continuing one, to a further fine not exceeding \$50 for every day on which the offence has continued’ (s.136).⁹ The ‘prescribed form’ is set out in the Health (Infectious and Notifiable Diseases) Regulations 2016 (see Appendix 1).^{12,13}

The pain: a Kafkaesque notification process

On a routine day in general practice, working my way through test results during my lunch break, I came across an anorectal swab positive for gonorrhoea. The laboratory report stated:

‘This is a Section C disease notifiable under the Health Act using NON-IDENTIFIABLE data. You are legally required to complete a notification form. Instructions on how to access the form are available on your HealthPathways, the ESR surveillance website or from your local Public Health Unit.’

Accessing the prescribed form

Gonorrhoea is not something I see every day. As recommended, I turned to HealthPathways to access the notification form. There was nothing about notification. I turned to Google. The New Zealand Sexual Health Society (NZSHS) website had STI management guidelines, but nothing about notification. The Health Navigator website also drew a blank, as did the Ministry of Health website. I Googled ‘ESR’ and typed ‘gonorrhoea notification’ into the Institute of Environmental Science and Research (ESR) search bar: ‘Sorry, your search query did not return any results’. I then Googled the Auckland Regional Public Health Service website and put ‘gonorrhoea’ into their search bar: ‘We can’t find what you’re looking for’.

J PRIM HEALTH CARE

2019;11(3):195–206.

doi:10.1071/HC19038

Received 12 April 2019

Accepted 30 June 2019

Published 20 September 2019

I turned to my colleagues for help, but no one in the practice knew. I phoned the Medical Officer of Health. I was informed that I could not notify gonorrhoea to the public health service by phone; rather, I had to notify ESR using a special online form. Helpfully, they provided the link: 'surv.esr.cri.nz'.

I typed 'surv.esr.cri.nz' into my computer and was taken to 'Public Health Surveillance'. I clicked on 'Public Health Surveillance', then I clicked on 'Sexually transmitted infections', then I scrolled down and clicked on 'Gonorrhoea', and then I clicked on 'click here to complete the web-based questionnaire'. Up came: 'Instructions for gonorrhoea notifications' (see Appendix 2). I skimmed down the page of 'instructions for gonorrhoea notifications'. At the bottom were instructions on how to access the link to the notification form: 'Please type the following URL into your web browser to be sent the questionnaire: bit.ly/esrgono1'.

I tried to copy and paste the URL, but the 'instructions' have been designed to make this impossible. You have to write down the URL, open a new web page and then type it in manually. My enthralled colleagues were looking on over my shoulder egging me on, patients were mounting up in the waiting room and lunch was a distant memory. I wrote down the URL on a piece of paper, opened a new web page, and typed in 'bit.ly/esrgono1'.

Up popped yet another page: 'Request For Questionnaire Link - Fill in this survey to receive [sic] a unique Gonorrhoea [sic] Questionnaire link'. Emboldened in red was written: '**We require a registration number AND a correct security question answer to send a questionnaire link**'. The survey requested I enter my registration number, my email address, and the answer to '267 plus 4358'. My colleagues whooped and high-fived. I looked blankly at the screen. You cannot be serious.

I typed in my registration number and my email address, then I worked out the maths and typed the answer (4625) into the form. I hit 'enter'. There was a short pause and then the email with the 'questionnaire link' arrived. I clicked on the link. Up popped the 'Gonorrhoea questionnaire interim' (see Appendix 3).

Completing the prescribed form

The 'prescribed form' requests over 30 fields of information (see Appendix 3). The 'must provide' information includes the patient's sex; date of birth; NHI (National Health Index); Case Code (first two letters of surname, first initial of given name, sex, date of birth); District Health Board; and ethnicity. Other information requested includes risk factors (HIV status, sexual behaviour, number and sex of sex partners); 'from whom the infection was probably acquired' (regular or casual partner, client); and details about management and contact tracing. Undoubtedly, the completion of this form (once accessed) would pose significant compliance costs, and it is unlikely busy clinicians would routinely complete the non-compulsory fields. Much of that information is not routinely collected in general practice, including sexual history and number and sex of partners.¹⁴ This raises the question about completeness and quality of the data, and the ability of the notification system to fulfil its goals.

The form reiterates that gonorrhoea is 'notifiable ... using non-identifiable data', but insists health practitioners 'must provide' date of birth, NHI and Case Code. This may be consistent with the *Health Act s.74*, which states health practitioners 'must not disclose identifying information' (3A), which is defined in the Act as the patient's 'name, address, and place of work or education' (3C).⁹ However, it is not consistent with other rules regarding the identifiability of data,¹⁵ including guidance provided by the New Zealand Health and Disability Ethics Committees.¹⁶ The Committees' guidance says a patient's name, date of birth and NHI are 'identified data'. The NHI by definition is identifiable, being 'a unique identifier'.¹⁷ The Case Code is 'partially de-identified' data, meaning the clinician may re-identify the data, but not recipients who may yet identify duplicates. Data that have had all identifiers permanently removed and so are not re-identifiable, including data containing encrypted NHI numbers, are considered 'de-identified data'; and data that have been collected without personal identifiers are 'anonymous data'. Thus, the ESR form is telling health practitioners to notify using 'non-identifiable data', but then insisting they must provide 'identified' data (date of birth and NHI) and 'partially de-identified' data (Case Code). This is confusing at best.

The shame: eroding goodwill to no end

In our experience, confirmed by several sexual health specialists, New Zealand's current STI notification process is Kafkaesque. The process imposes onerous reporting duties under threat of fine, while hiding the 'prescribed form' and requiring clinicians to jump through mathematical hoops to access it. The rules around data identifiability are inconsistent, which adds to the confusion around a doctor's duty to protect confidentiality and the patient's right to health information privacy. Combined, these changes risk eroding the goodwill of clinicians upon whom a successful notification programme relies. While the benefits of notification may justify these real harms, to date, there is little evidence of benefit or that the data are even being used. The most recent comprehensive national report on STIs relates to 2015 data.⁵ This reflects years of underinvestment in the STI clinical, research and prevention workforce in New Zealand.¹⁸

A workable notification process and successful surveillance

Surveillance and timely action against serious infectious diseases are important. We could learn from HIV/AIDS surveillance in New Zealand. The history of HIV reporting in New Zealand demonstrates that enhanced surveillance can work well for all stakeholders, even without legislative back-up. Factors promoting HIV data completeness and speediness include cooperation, coordination and communication by the AIDS Epidemiology Group with health practitioners. Compliance is also motivated by the fact that HIV data are regularly disseminated to the New Zealand AIDS Foundation and the HIV sector in a timely way, who in turn use that intelligence to guide prevention programmes.¹⁹

At the very least, successful surveillance and appropriate public health action requires information on the sex of the partner (ie whether the patient is having sex with men or women or both). Outbreaks among men who have sex with men are very different to outbreaks among heterosexual men. This information will describe STI trends in the three key sexual health risk groups

of heterosexual women, heterosexual men and gay and bisexual men; intelligence that is essential for the STI sector to plan appropriate responses.

To improve the surveillance of gonorrhoea in New Zealand, we suggest the following changes to the interim notification system:

1. The link to the prescribed notification form be readily available to health practitioners; for example, on positive test results and on the websites of HealthPathways, ESR, Ministry of Health and the Sexual Health Society.
2. Positive test results contain reminders to prompt contact tracing.
3. The requirement for health practitioners to provide correct answers to mathematical equations before being granted access to the form be waived.
4. The questionnaire should collect only information that is feasible for clinicians to provide and essential for surveillance and action. The sex of the partner is essential. Useful data should be prioritised over interesting data, and data completeness over data comprehensiveness.
5. Definitions of data identifiability should be clear and consistent with existing definitions.
6. Notification data should be analysed and disseminated promptly, including to health practitioners, and regularly reviewed to inform control strategies and service commissioning.

Competing interests

The authors declare no conflicts of interests.

Funding

This research did not receive any specific funding.

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Appendix 1. Health (Infectious and Notifiable Diseases) Regulations 2016, Schedule 2, Form 2.

Form 2

Health practitioner notice of notifiable disease (non-identified basis)

[Section 74\(1\) and \(3A\)](#), Health Act 1956

To the medical officer of health for [district]

Date:

1 Patient details

First 2 letters of surname and the first letter of first name:

National health index number (if known):

DHB district of usual address:

Date of birth:

Date of death (if applicable):

Sex:

Ethnicity (if known):

Nature of work or education (if known):

Recent travel history (if known):

2 Details of disease

Disease or suspected disease being notified:

Date of onset of illness (approximately):

Laboratory tests done or ordered (if any):

Results of laboratory tests (if available):

If the disease or suspected disease is HIV or AIDS, whether or not there is laboratory evidence of newly acquired HIV infection (if known):

If the disease or suspected disease is HIV, AIDS, or syphilis, the date and place of last negative laboratory test (if known):

Has the patient been hospitalised? Yes/No

If the patient has been hospitalised, the name of the hospital and date of the admission:

If the disease or suspected disease is HIV, AIDS, or syphilis, has the patient been referred to specialist care? Yes/No

Any other information relevant to the risk of the patient having or transmitting the disease (for example, vaccine history, sexual behaviour or activity, or sex of partner or partners, if known):

3 Contact tracing

Are there other persons infected or likely to have been infected with the disease? Yes/No

If not already referred to, do you consider contact tracing is required? Yes/No

4 Notifying health practitioner details

Name:

Phone number:

Address:

Email address:

Instructions on use: This form is for notification of diseases listed in [section C](#) of Part 1 of Schedule 1 of the Act. The name, address, and other contact details of the patient must not be included in this form. However, a medical officer of health may require disclosure of those matters if necessary under [section 74\(3B\)](#) of the Act.

Appendix 2. Instructions for gonorrhoea notifications.

Health providers are required to complete a web-based questionnaire in REDCap (data capturing software) for gonorrhoea notifications.

In order to enter details of gonorrhoea cases you will need to open your web browser and type in the URL that is at the bottom of this page.

You will be asked for your email address and a link will be emailed to you

Please note that this is a 'one time only' questionnaire link and you will not be able to edit the information once it has been saved. Clicking on the link again will generate a new record.

Please ensure that you have as much information on the case as possible before you click on the link. You will be asked for information in the following categories:

- Health provider details (your name and contact details)
- Cases details (sex, date of birth, NHI, city, DHB, ethnicity)
- Testing (location and reason), clinical presentation, laboratory results
- Risk factors (gender identity, HIV status and treatment, concurrent diagnoses, sexual behaviour)
- Management (treated as per NZSHS guidelines and plans for contact tracing)


Once you have as much information on the case as possible, please type the following URL into your web browser to be sent the questionnaire:

bit.ly/esrgono1

NOTE: the questionnaire must be completed on-line

Appendix 3. Gonorrhoea Questionnaire Interim.

05/04/2019

Gonorrhoea Questionnaire Interim																					
<p>This is a Schedule 1, Section C disease notifiable to the Medical Officer of Health under Sections 74 and 74AA of the Health Act 1956 using non-identifiable data.</p> <p>Please complete the questionnaire below. Timely completion is a legal requirement.</p> <p>Complete the first sections of the following questionnaire (health provider details, case details, demographics, basis of diagnosis, clinical and laboratory criteria) and assign a case classification. If 'not a case', then there is no need to complete the rest of the form.</p>																					
Name and contact details of notifying health provider																					
Name of health provider				<input type="text"/>																	
Name of organisation/clinic				<input type="text"/>																	
Email address				<input type="text"/>																	
Phone number				<input type="text"/>																	
Case Details and Demographics																					
Sex (please note: this does not refer to gender identity) * must provide value				<input checked="" type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Unknown <input type="radio"/> Indeterminate				reset													
Date of Birth * must provide value				<input type="text"/>  Today D-M-Y																	
NHI (National Health Index) * must provide value				<input type="text" value="ABC1234"/>				Use upper-case letters													
Case Code (see instructions and image below) * must provide value				<input type="text"/>				First two letters of the surname (do not include the letters 'Mac', 'Mc', 'van der' if the surname starts with these), the first initial of given name, sex and date of birth. For example, a person called James McCallum born 2 June 1956 would appear as CAJM020656													
<table border="1"> <thead> <tr> <th>1st letter surname</th> <th>2nd letter surname</th> <th>1st letter first name</th> <th>Sex</th> <th>Day</th> <th>Month</th> <th>Year</th> </tr> </thead> <tbody> <tr> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> <td><input type="text"/></td> </tr> </tbody> </table>								1 st letter surname	2 nd letter surname	1 st letter first name	Sex	Day	Month	Year	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
1 st letter surname	2 nd letter surname	1 st letter first name	Sex	Day	Month	Year															
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>															
City/town of residence at time of diagnosis. For rural cases the nearest city/town				<input type="text"/>																	
District Health Board area where case resided at time of diagnosis * must provide value				<input type="text"/>																	

<https://dataform.esr.cri.nz/surveys/?s=vfDI8Gt3zq>

1/5

Gonorrhoea Questionnaire Interim

Ethnicity
* must provide value

NZ European
 Maori
 Samoan
 Cook Island Maori
 Niuean
 Chinese
 Indian
 Tongan
 Other (specify below)
 Unknown
[tick all that apply](#)

Basis of Diagnosis
INITIAL TESTING

Site of initial gonorrhoea testing

Public Sexual Health Clinic
 Family Planning Clinic
 General Practice
 Student Health Clinic
 Antenatal Clinic
 NZ AIDS Foundation testing clinic
 Body Positive testing clinic
 Infectious Disease Clinic
 Other
[reset](#)

Primary reason for gonorrhoea testing

Gonorrhoea contact
 Clinical symptoms or suspicion
 Antenatal screening
 Asymptomatic screening
 Other
[reset](#)

Date patient presented D-M-Y

CLINICAL PRESENTATION

Uncomplicated infection (site)

Urogenital
 Anorectal
 Throat / pharynx
 Conjunctivitis
[tick all that apply](#)



Complicated infection

Pelvic inflammatory disease (PID)
 Epididymitis
 Other
[tick all that apply](#)

LABORATORY CRITERIA
Specimen site (tick all with positive results)

	culture	NAAT / PCR
Anorectal	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Penis	<input type="checkbox"/>	<input type="checkbox"/>
Vagina	<input type="checkbox"/>	<input type="checkbox"/>

Gonorrhoea Questionnaire Interim

Urine	<input type="checkbox"/>	<input type="checkbox"/>
Eye	<input type="checkbox"/>	<input type="checkbox"/>
Cervix	<input type="checkbox"/>	<input type="checkbox"/>
Urethra	<input type="checkbox"/>	<input type="checkbox"/>
Throat/pharynx	<input type="checkbox"/>	<input type="checkbox"/>
Unknown	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>
<p>Please use the data you have entered under clinical and laboratory criteria and the surveillance case definitions to decide on the case classification</p>		
<p>CASE CLASSIFICATION * must provide value</p> <p> <input type="radio"/> Under investigation <input checked="" type="radio"/> Confirmed <input type="radio"/> Not a case </p> <p style="text-align: right;">reset</p>		
<p>Case classification</p> <p>Under investigation: A case that has been notified but information is not yet available to classify it.</p> <p>Confirmed: A case with laboratory definitive evidence [either isolation (culture) of <i>N. gonorrhoeae</i> or detection of <i>N. gonorrhoeae</i> nucleic acid (e.g. NAAT or PCR) from a clinical specimen].</p> <p>Not a case: A case that has been investigated and subsequently found not to meet the case definition.</p>		
<p>Date of onset</p> <p><input type="text"/>  Today D-M-Y</p>		
<p><input type="checkbox"/> Date approximate</p>		
<p><input type="checkbox"/> Date unknown</p>		
<p>Risk Factors</p>		
<p>Current gender identity (self-reported by patient):</p> <p> <input checked="" type="radio"/> Male <input type="radio"/> Female <input type="radio"/> Transgender <input type="radio"/> Other </p> <p style="text-align: right;">reset</p>		
<p>HIV serostatus at the time of gonorrhoea diagnosis</p> <p> <input type="radio"/> Negative <input checked="" type="radio"/> Positive <input type="radio"/> Unknown </p> <p style="text-align: right;">reset</p>		
<p>Date of HIV diagnosis (use 1/1/xxxx if only year is known)</p> <p><input type="text"/>  Today D-M-Y</p>		
<p><input type="checkbox"/> Date approximate</p>		
<p><input type="checkbox"/> Date unknown</p>		

Gonorrhoea Questionnaire Interim

<p>Was the case on HIV antiretroviral treatment at the time of gonorrhoea diagnosis?</p>	<p><input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown</p>	<p>reset</p>
<p>Other concurrent diagnoses at time of gonorrhoea diagnosis (tick all that apply)</p>	<p><input type="checkbox"/> Chlamydia <input type="checkbox"/> Infectious syphilis <input type="checkbox"/> Trichomoniasis <input type="checkbox"/> Genital herpes <input type="checkbox"/> Genital warts <input type="checkbox"/> Mycoplasma genitalium <input type="checkbox"/> Lymphogranuloma venereum (LGV) <input type="checkbox"/> Other</p> <p>tick all that apply</p>	
<p>Sexual behaviour in the previous 12 months</p>	<p><input checked="" type="radio"/> Opposite sex partners only <input type="radio"/> Same sex partner only <input type="radio"/> Both opposite and same sex partners <input type="radio"/> Unknown <input type="radio"/> Not applicable (e.g. conjunctivitis in an infant)</p>	<p>reset</p>
<p>Number of male sex partners in the past 3 months</p>	<p><input type="text"/></p> <p>enter an integer</p>	
	<p><input type="checkbox"/> Approximate</p>	
<p>Number of female sex partners in the past 3 months</p>	<p><input type="text"/></p> <p>enter an integer</p>	
	<p><input type="checkbox"/> Approximate</p>	
<p>Is the case a sex worker? (includes receiving money or drugs in exchange for sexual services)</p>	<p><input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown</p>	<p>reset</p>
<p>From whom was this infection probably acquired?</p>	<p><input type="radio"/> Casual partner(s) <input type="radio"/> Regular partner(s) <input type="radio"/> Client(s) (if sex worker) <input type="radio"/> Sex worker(s) <input type="radio"/> Unknown</p>	<p>reset</p>
<p>Management</p>		
<p>Current infection treated as per the New Zealand Sexual Health Society Guidelines? For guidance please see NZSHS Guideline</p>	<p><input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown</p>	<p>reset</p>

Gonorrhoea Questionnaire Interim

<p>Do you consider this current infection is due to treatment failure of a previous infection?</p>	<p><input checked="" type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown</p>	reset
<p>Had the case completed treatment for the previous infection as per the New Zealand Sexual Health Society Guidelines? For guidance please see NZSHS Guideline</p>	<p><input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown</p>	reset
<p>Was the initial infection previously notified?</p>	<p><input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Unknown</p>	reset
<p>CONTACT MANAGEMENT Contact tracing of partners is the responsibility of the treating doctor and an essential component of the clinical and public health management of cases. For guidance please see NZSHS Guideline</p>		
<p><input type="checkbox"/> I have already initiated, or plan to undertake, contact tracing <input type="checkbox"/> I have already referred this case to another service for contact tracing as per local protocols/processes <input type="checkbox"/> Contact tracing incomplete due to anonymous contacts (e.g. sex onsite venue, internet based App, internet dating)</p> <p>tick all that apply</p>		
<p>Comments</p> <div style="border: 1px solid black; height: 40px; width: 100%;"></div>		
Expand		
<div style="border: 1px solid black; padding: 5px; display: inline-block;">Submit</div>		

Response from the New Zealand Ministry of Health:

Improving sexually transmitted infection (STI) surveillance data will help give us a clearer understanding of STI infection trends and monitor the success of interventions.

The Ministry of Health is currently undertaking a review of the STI surveillance system for the future, which includes work towards a fully automated system. The Ministry contracted ESR to create the 2018 system as an interim solution to notify the occurrence of sexually transmitted infections, including information on risk factors.

We are sorry to hear about the difficulties the authors have had navigating this interim system and we will consider their feedback as we work to improve it. The interim system was designed to be consistent with the legal requirements of the *Health Act 1956* and *Health (Infectious and*

Notifiable Diseases) Regulations 2016, to ensure the safety and confidentiality of data collected. As a result, the system has a number of security measures to provide this protection.

Information on STIs is published on the public health surveillance website. A new quarterly interactive dashboard containing information on STIs is also available here: <https://www.esr.cri.nz/our-services/consultancy/public-health/sti/>. The number of STI cases in New Zealand, including syphilis and gonorrhoea is increasing.

The Ministry is committed to continuing our work with organisations including the New Zealand AIDS Foundation, Body Positive, District Health Boards, public health units, sexual health services and ESR to address this increase.

Dr Niki Stefanogiannis
Deputy Director Public Health, Ministry of Health,
New Zealand.