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Submission to the Ministry of Health on
A Review of Notifiable Diseases and Conditions

The National Council of Women of New Zealand (NCWNZ) is an umbrella organisation representing 42 nationally organised societies. It has 34 branches throughout the country attended by representatives of those societies and some 150 other societies as well as individual members.

NCWNZ is grateful for this opportunity to make a submission on this discussion document. Responses have been received from members of the Health Standing and Nucleus Committees and other interested parties. Time constraints unfortunately don't always allow us to canvass the wider membership.

The members of the committees, together with interested parties also had input into the recent submission "Public Health Legislation: Promoting public health, preventing ill health and managing communicable diseases."

Members believe that information in the appropriate form should be available to other agencies thus making better use of collected data. Examples could include trends in the incidence of illness arising from exposure to hazardous wastes being dealt with so that the source is cleaned up and similar sites checked to prevent future problems; education programmes in the community to highlight the problems associated with food handling, making sure that food handlers and those in the food industry are also up to date with possible sources of exposure and how to prevent them. Continued surveillance on a regular basis is also a necessity.

Recent publicity has seen public health medicine move to accommodate the need for vigilance forced on it by international terrorism and the possible use of biological weapons not only in times of war but as a means of holding sectors of the community to ransom. Cases arising through such activities take on a new urgency. The need for good quality data is particularly important not only for the health services but also for security. Because the media is likely to play an active role in "informing the public" good quality data is also needed quickly to allay panic.

Because NCWNZ is not directly involved in the practice and administration of the matters under consideration the following questions have all been answered as Not Applicable (N/A): 4,10,22,24,29,38,42,43,44,and 48.

Specific Comments

Questions
Section 2 Background

1. *Do you consider notification an appropriate method for collecting information on disease for the purposes of disease prevention and control? If not, why not? (see 2.1.2)*

Yes. Notification is particularly important, as without it other methods such as reporting and periodic surveys would be less meaningful.

NCWNZ also agrees with the last sentence on page 18, "To be effective and useful a notification system needs to produce information that is fit for the purpose for which it is collected while fulfilling the requirements of national and international law."

It is important that due care is taken to maintain a sufficient degree of privacy for individuals.

Section 3: Review of Notifiable Diseases and Conditions

2. *Do you agree that these diseases and conditions should be retained on the schedule of notifiable diseases? (see 3.2.3)*

Yes.

3. *If not, which diseases or conditions should be removed, and why? (see 3.2.3)*

N/A as question 2 was answered positively.

4. *Are there any significant resource issues for you or your agency with respect to retaining of these diseases and conditions on the schedule? If so, what are they? (see 3.2.3)*

N/A although one member thought that if payment was made for notification it should be relevant to the time taken, i.e. meeting costs of premises.

5. *Do you agree that adverse reactions to vaccines should be made notifiable? If not, why not? (see 3.2.4)*

Yes. GP's may only see isolated cases and consider adverse reactions to be rare. However, by notifying adverse reactions, trends or a sudden outbreak may be identified. Upon investigation the cases may be able to be traced to a particular batch of vaccine where there may have been problems with manufacture, storage or transport.

6. *Do you agree that botulism should be made notifiable separately, rather than under acute gastroenteritis? If not, why not? (see 3.2.4)*

Yes. The exotoxin produced by Clostridium botulinum is extremely potent producing serious food poisoning but it is only one form of "food poisoning". Notification indicates the category of condition that is being highlighted.

Botox, derived from the same Clostridium botulinum, is used for cosmetic purposes. If a faulty batch produces effects due to adverse reaction rather than misadventure, then authorities need to know, so that other supplies can be monitored. The Clostridium group, other than C. botulinum, should be notified separately.

7. *Do you think hazardous and other substance injuries should be made notifiable? If not, why not? (see 3.2.4).*

Yes. If trends are identified other agencies, e.g. MAF, TLA's, OSH, can be notified so that the source can be located and eliminated, isolated or minimised. Data could also be made available for health education campaigns and for OSH and ERMA educators.

Protection of the population from hazardous waste is vital. Recent examples, from the media include 1080, 245T, timber treatment sites and most recently the waste dumps at Hobsonville Air Force Base.

Notification may also assist in identifying the resources needed in the longer term because of the long-term and on-going effects some hazardous materials have.

8. *Do you think smallpox should be made notifiable? If not, why not? (see 3.2.4)*

Yes. Although supposedly eradicated if notification is discontinued complacency could occur. World travel is so easy that diseases like smallpox can spread with ease whether the source arose from a natural occurrence or a terrorist action.

9. *Do you agree that VTEC should be made notifiable individually rather than under the heading of acute gastroenteritis? If not, why not? (see 3.2.4)*

Because acute gastroenteritis is relatively common, a more serious illness may not be looked for and recognised.

Members believe that there are new diseases and variants occurring world wide, some of which have occurred in New Zealand. Therefore each variety should be documented separately, especially in the early stages, to establish good epidemiological data.

Considering all the diseases and conditions considered for inclusion:

10. *If these diseases and conditions were added to the schedule of Notifiable diseases and conditions, would there be resource implications (either positive or negative) for you or your agency? If so, what would they be? Please give details for each disease or condition. (see 3.2.4)*

N/A

11. *Do you think that acute gastroenteritis should be removed from the schedule of notifiable diseases? If not, why not? (see 3.2.5)*

The majority of our members believe that acute gastroenteritis should not be removed from the schedule of Notifiable diseases. Further, it is a public health issue and the location and rate of incidence are important. It has a useful role as a precursor for notification of specifics and alerts authorities. This would also help tracking when a restaurant is involved.

Being highly contagious, acute gastroenteritis can be fatal to the very young or frail elderly. Notification should encourage investigation to eliminate causes of the condition.
Being highly contagious, acute gastroenteritis can be fatal to the very young or frail

12. *Do you think that campylobacteriosis should be retained or removed from the schedule of notifiable diseases? Why? (see 3.2.5)*

Only one of our members thought that Campylobacteriosis should be removed leaving diagnosis and control in the hands of the GP. However, the majority opted for retention for various reasons, such as an indicator of poor food handling, transport, storage, preparation and therefore information required by other agencies for investigation of source and the protection of the public at large.

Another example was that of pupils at a kindergarten who were affected. Investigation following notification traced infection to a pet bantam kept at the kindergarten.

13. *Do you think is it feasible to limit notifications of campylobacteriosis to high-risk cases (childcare and healthcare workers, linked cases, food-handlers) only? Why, or why not? (see 3.2.5)*

Our members believe that it is feasible to limit notifications of campylobacteriosis to the groups listed. Those listed are not the only people affected e.g. the elderly, or individuals preparing food at home, e.g. chicken livers for paté, barbecues.

14. *Do you think that hepatitis C should be removed from or retained on the schedule of notifiable diseases? If not, why not? (see 3.2.5)*

In general it was agreed that hepatitis C, in both acute and chronic forms, should be retained on the schedule. Both acute and chronic forms should be notifiable as they indicate problems elsewhere in the public health sector. Reporting of anonymised cases should be passed onto other agencies, e.g. Police Drug Squad, needle-exchange centres.
Present day action adequately deals with cases now that blood is screened at appropriate points.
Notification of cases would act as another measure of the continuing, or otherwise, efficacy of this screening and needle-swap schemes.

GPs would continue to advise patients regarding their risk of cirrhosis. Laboratories would notify both GPs and the MOH of positive cases.

15. *Do you think that HIV should be made notifiable? Why, or why not? (see 3.2.5)*
Yes. HIV should be made notifiable as this group of patients becomes one that is vulnerable to some of the other diseases/conditions we have already discussed. Notification alerts those with a need to know of possible resources required for future cases of AIDS that occur in some, but not all HIV cases. However, if it deters people from seeking help we will be no further ahead and education programmes must continue to reassure people that their privacy is protected. GP's and other local agencies should continue to provide the care and education needed.

16. *Should AIDS remain notifiable? Why, or why not? (see 3.2.5)*
Yes. It is important to continue to be aware of a rise of incidence within the community. There may be sudden rises in rates of incidence due to overseas visitors or immigrants coming into the country with AIDS rather than HIV.

Proper care of patients can be monitored on national lines. Research worldwide would benefit from properly collected data allowing international comparisons of numbers and changes in rates of infection.

GP's and clinics should notify so provision for care can be planned.

17. *Should both AIDS and HIV be notifiable? Why, or why not? (see 3.2.5)*
Yes, see the answers to questions 15 and 16.

18. *What other approaches to HIV/AIDS notification should be considered? Please give details. (see 3.2.5)*
The importance of confidentiality and the use of anonymised data is vital if people are to be encouraged to seek diagnosis and treatment of what are still stigmatised illnesses. However important the right of the individual is, the right of the public at large must also be considered and education programmes should reflect the importance of seeking early treatment if there is any possibility that the presenting condition is HIV/AIDS.

Patients should then be advised by their GP or clinician.

19. *Do you think that STIs should be made notifiable or not? Why, or why not? (see 3.2.5)*
There was agreement that STI's should be made notifiable as there is considerable public risk associated with these diseases. It is essential that all contacts are screened, treated and advice given for future prevention. However, information must be handled sensitively if confidentiality is not to be breached and patients are deterred from seeking treatment. Collated data should be

made public in an organised manner so that scare tactics are not happening in waves around the country e.g. all data should be released at the same time.
Doctors also need to notify as clinics and laboratories do currently.

20. *If yes, which STIs should be made notifiable? (see 3.2.5)*

It was agreed that those listed in the document and any others identified in the future that affect the sexual health of others should be listed. Epidemiological information is considered important in tracking outbreaks as a means of pinpointing other societal problems.

21. *Do you agree with the proposals outlined in this section? If not, why not? Please specify the disease under discussion. (see 3.2.5)*

Our members agreed with this section as long as patient information is retained in either an anonymised form or as NHI's, and that privacy and confidentiality will be assured to encourage patients to seek advice and treatment.

22. *If these diseases were removed or added to the schedule of Notifiable diseases and conditions, would there be resource implications (either positive or negative) for you or your agency? What would these be? (see 3.2.5)*

N/A

23. *Do you agree that decompression sickness be removed from the list of notifiable diseases and conditions? If not, why not? (see 3.2.6)*

Yes. It was agreed that the Department of Labour - Occupational Safety and Health (OSH) should handle workplace accidents for investigation with respect to 'Serious Harm' and that OSH and Marine Safety would be involved in recreational mishaps. It is presumed that a patient would be referred to his or her own doctor for further monitoring after treatment, whether decompression was caused by work or recreational activity. This condition may have implications later in a patient's life. It is more important that a patient's own doctor is informed.

24. *If decompression sickness were removed from the schedule of notifiable diseases and conditions, would there be resource implications (either positive or negative) for you or your agency? What would these be? (see 3.2.6)*

N/A

25. *Should schedule 1 part 2 remain in the Health Act? Why, or why not? (see 3.2.7)*

It was agreed that schedule 1, part2 should remain and that these diseases should be made notifiable to MOH's, to maintain consistency of reporting and allow for traceability. Because of the nature of the diseases traceability is important and the epidemiological information should be of use not only to the health sector but be made available to other sectors as well, e.g. Education, welfare, housing, etc.

This inclusion and requirement for notification should in no way restrict the responsibilities, as laid down in the Education Act 1989, for head teachers and others charged with care who must have authority to act to curtail the spread of disease in children if possible.

26. *Should any diseases in schedule 1 part 2 be considered for inclusion on the list of notifiable diseases? If so, which diseases, and why? (see 3.2.7)*

This has already been answered in Question 25.

27. *Are there other diseases that should be included in schedule 1 part 2 of the Health Act? If so, which diseases, and why? (see 3.2.7)*

NCWNZ believe that Health Sector input is required to keep this section up to date as new strains and varieties of STI's are identified in the future. Appropriate information must then be sent to all other sectors regarding their continuing responsibilities.

28. *Are there any other diseases or conditions that should be notifiable? Why? (see 3.2.8)*

As for Q27

MRSA, VRSA, Necrotising Fasciitis, also foot, hand and mouth infection in children principally. (We understand that it has been quite prevalent in many childcare centres and kindergartens), gas gangrene, Dengue Fever and other tropical diseases as with global warming causing climate change in the future, our environment may become an ideal habitat for the organisms/insects to thrive, thus opening the way for these diseases to become endemic in New Zealand.

29. *What costs, if any, would the proposed changes have for your organisation? Please include staff time costs. (see 3.2.8)*

N/A

30. *Do you agree that the grouping within the schedules of notifiable diseases and conditions should be revised? If so, which option do you prefer? (see 3.3.1)*

Members agreed that groupings should be revised so as to give GP's and others some idea of how urgently information is required.

Option 3 was therefore the choice of the majority but within each grouping diseases and conditions should be listed alphabetically.

31. *What other options are there for grouping notifiable diseases and conditions? (see 3.3.1)*

Cross referencing could be used to identify individuals who have multiple exposures, indicating other problems that need to be dealt with and this information could be given to the treating clinician to work through, e.g. notifying the patient and with their permission, the appropriate agencies for help.

Section 4: Notification Systems Options

32. *What other weaknesses or deficiencies are there in the current notification system? (see 4.3.6)*

At present it would appear that there is insufficient importance placed on the need to notify, as outlined on pages 47-50 of this review document. It therefore becomes apparent that the significance of the information gathered needs to be reinforced for those whose duty it is to make notification. Other issues, i.e. time delays, incomplete data, multiple reporting lines, other legislation, etc. must also be addressed by the selection of changes to notification systems.

33. *What are the potential approaches to remedying these weaknesses or deficiencies? (see 4.3.6)*

We believe that the potential approaches to remedying these weaknesses or deficiencies should include: better use of technology, e.g. computers, telephone, fax, email, etc.; simplification of timelines; simplification of reporting lines; use of NHI numbers to eliminate duplication of information; allowing GP's to notify on suspicion of infection and laboratories to confirm as soon as possible to GP and MOH simultaneously; MOH to notify TLA as necessary.

34. *Do you agree that these improvements would be useful? Why not? (see 4.4.2)*

Yes. Members agree that this should have been done some time ago. It is almost 50 years since the previous Health Act came into being and with all the changes in the health sector it seems sadly lacking that no review has been done until now.

35. *Do you agree that the requirement for practitioners to notify TLAs should be removed? If not, why not and what role would the TLA play in the notification process? (see 4.4.2)*

Yes, as the role for the doctor should be primarily patient focused. The MOH should, after due consideration, be the appropriate person to notify TLA. It is recognized that it is important for TLA's to be notified, especially in the case of water and food borne diseases, so that prompt action can be taken to test sources, treat same etc., and to eliminate further spread.

36. *Given that health dollars are scarce, which of the above proposals do you consider to be the most important to implement?*

While public money must be spent wisely there are some areas where investing in sectors such as health, education, etc at an early stage to set up effective systems for the future actually costs less in the long term. The focus must be on ways to improve the system. However, if education and awareness-raising campaigns are not done thoroughly improvement will not happen. It must be remembered that such education campaigns must be ongoing if there is to be continuous improvement in notifying the appropriate authorities. This should have been in place already.

37. *What other systems improvements and related activities would you suggest, that work within the current legislative framework? (see 4.4.2)*

The total system has to be adequately funded to work properly to maintain the optimum professional and public health benefits that it was set up for. If the "Public Health Legislation" that is being considered at present is to be effective this notification and reporting section must be effective.

At the same time the doctor patient relationship must be maintained, i.e. doctor/clinician only to advise the patient of their disease and the consequent implications.

Other related legislation needs to be investigated to ensure that impediments to good quality information being related is not compromised, e.g. Privacy Act 1993.

38. *Would there be major resource implications (either positive or negative) for you or your agency from implementing these measures? What would these be? (see 4.4.2)*

N/A

39. *Under option 3 (and option 4), laboratories would notify some cases of diseases directly to the medical officer of health, instead of GPs being responsible. Do you agree/disagree with this approach? Why? Why not? (see 4.4.3)*

Members do not agree with this. It is preferred that GP's notify all required diseases and conditions to avoid confusion about what they notify or don't notify. Laboratories then confirm, or otherwise, the notification simultaneously to both the MOH and doctor responsible. This has the advantage that doctors must be kept in the loop right from the outset and be kept up to date with events that occur as a consequence of their notifying. There is no use having GP's ignorant of decisions being made or actions taken by other agencies with regard to their patients. Some patients do not register with one GP but are floating clients but this is another problem that needs to be sorted in terms of identifiable NHI numbers. A register, especially at "After Hours" services should have some way that GP's are able to be alerted to use opportunistic visits as these services are often the only point of contact for many patients and their families.

Although it is acceptable for laboratories to also notify the MOH directly, GP's still require

notification as soon as possible to implement treatment and discuss further actions with the patient.

40. *Under option 3 (and option 4), the Health Act would be amended to state that territorial local authorities would no longer need to be notified of cases of diseases or conditions (note that current arrangements relating to investigation of cases and outbreaks are not affected). Do you agree/disagree? Why? (see 4.4.3)*

Our members do agree, as not all diseases/conditions require their input. This has already been been noted in Figure 3, page 56, Option 3: Alternative option for notification of diseases that do not require public health action (only).

However, it is important that the MoH notifies TLA's as necessary and retains an overview position.

41. *Do you agree that there should be a different process for diseases and conditions that do not require a public health response (removing direct notification of these cases)? (see 4.4.3)*

Yes, as was indicated in question 40 it is important that the MOH retains an overview position.

Yes, however in Fig 2, page 55 the arrow between MOH and TLA appears to be going in the wrong direction (perhaps a printing error). The TLA would not know if they haven't been contacted.

42. *Would there be financial/resource implications (either positive or negative) for you or your agency from implementation of option 3? What would these be? (see 4.4.3)*

N/A

43. *Would there be financial/resource implications (either positive or negative) for you or your agency from implementation of Option 4? What would these be? (see 4.4.4)*

N/A

44. *Would there be financial/resource implications (either positive or negative) for you or your agency from implementation of Option 5? What would these be? (see 4.4.5)*

N/A

45. *On balance, which systems option or combination of options do you prefer? Why? (see 4.5)*

We like the ability to develop incrementally from Status quo through to Option 4. However, our preference for Option 3, both parts, progressing to Option 4, if necessary, appears to provide the necessary changes required to satisfy those processes identified earlier in this submission.

The first step to Option 3 needs to be in place as soon as possible so that the provisions in the Bill, "Public Health Legislation: Promoting public health, preventing ill health and managing communicable diseases." when passed can be implemented. Education programmes for all health professionals also need to be established at the earliest possible time. Option 4 could be left until Option 3 has been in place and seen to be operating well before making the next transition.

Before major changes are made to any computing system it is better to know for certain that a system is robust enough to cope with all current expectations with spare capacity for future developments. Reasonable time limits will need to be set for achieving this. This does not equate with a wheeling and dealing attitude that has prevailed in the health sector, and in other sectors, in the recent past. The public deserve a quality, durable system that does what it says it will do and fulfils that promise.

46. *Are there any further advantages or disadvantages to any of the options set out in this document? What are they? (see 4.5)*

Not that we are qualified to identify.

47. *What other systems options would you suggest? Please give details on the advantages and disadvantages of alternative approaches. (see 4.5)*

We believe that the consultant committee, who have formulated this document, have covered this subject comprehensively and that with the present submission options, this should then be able to be compiled into a final document for the new Health Act.

One aspect that needs to be dealt with is that of the person-to-person contacts in the system. Staff must be aware of not just what they need to do but also why they need to do it. Centralised systems tend to become small worlds in their own right and at times, insensitive to the needs of others in other locations.

48. *Are there any other either positive or negative financial or resource implications for you or your agency arising from any of the options set out in this document? What are they? (see 4.5)*

N/A

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