Auckland Regional Public Health Service
Rātonga Hauora ā Iwi o Tamaki Makaurau

Working with the people of Auckland, Counties Manukau and Waitemata

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Submission from the Auckland Regional Public Health Service on the Discussion Document: Population Registers and Organised Screening Programmes

1. Thank you for the opportunity for the Auckland Regional Public Health Service to provide a submission on the Discussion Document: Population Registers and Organised Screening Programmes (the Discussion Document).

2. This submission represents the views of the Auckland Regional Public Health Service (ARPHS). ARPHS provides public health services for the three district health boards in the Auckland region (Auckland, Counties Manukau and Waitemata District Health Boards), with the primary governance mechanism for ARPHS resting with Auckland District Health Board. This submission represents the views of ARPHS and does not necessarily represent the views of the three District Health Boards.

3. ARPHS understands that all submissions will be available under the Official Information Act 1982, except if grounds set out under the Act apply.

4. The primary contact point for this submission is:

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Key Points

5. ARPHS believes the primary influence on any changes to the current National Cervical Screening programme should be:

   - What will work for women?
   - What will be nationally consistent with maximum benefits and minimum risks to participants?

6. ARPHS does not support the "no invitation" status quo option. To date this has resulted in a situation where at best 50% of particular groups such as Maori or Pacific women are regular participants in the programme.

7. ARPHS believes that the NSU needs to develop nationally consistent systems for the identification, invitation and recall of eligible women to the NCSP.

8. ARPHS supports a nationally consistent pro-active recall system in which women are reminded of the need to arrange a new smear prior to the end of the 3 year cycle. This will enable a greater proportion of eligible women to have smears in accordance with the 3 year cycle that forms the basis of the NCSP.

Introduction

9. ARPHS is a regional public health service provider and works towards improving, promoting and protecting the health of people in the Auckland Region. ARPHS has an active commitment to working with central and local government, other health service providers, iwi and local communities to develop effective strategies to promote and protect the health of the people of the Auckland Region.

10. ARPHS takes a whole of population approach but targets resources to those locations and people who will benefit the most. ARPHS operates in an outcomes based framework which reflects the reality that it cannot create public health by itself, but must work with a range of partners in a whole of community approach to achieve the public health ends sought. ARPHS has identified six vital few outcomes to be the focus of its efforts, namely:

    - Reduction in the incidence and impact of infectious disease.
    - Reduction in the incidence and impact of obesity, diabetes and cardiovascular disease.
    - Reduction in the incidence and impact of tobacco and alcohol related harm.
    - Reduction in the incidence and impact of cancer.
    - Reduction in the incidence and impact of environmental inequalities.
    - Reduction in the adverse effects of environmental hazards.

11. ARPHS is contracted to the Ministry of Health to operate the National Cervical Screening Programme Register (NCSP-R) for the Auckland and Northland regions. As part of its contractual obligations ARPHS also operates the NCSP central colposcopy data processing database.

12. As the operator of the NCSP-R for the Auckland and Northland regions ARPHS provides services for approximately 36% of the New Zealand population and has experience covering both urban and rural residents.

NCSP Regional Service Managers Feedback

13. ARPHS notes the information contained in the email of 31 July from Helen Potaka to NCSP Programme Managers. While ARPHS respects the views of NCSP-R staff it does not believe that this information accurately summarises its own views.

14. ARPHS believes that concerns about data accuracy on the NHI are reducing as data matching with PHO databases improves.

15. ARPHS questions how invitation and recall systems can be said to be working well in primary health care when the best estimate of Maori and Pacific women's participation is of the order of 50%.

Criteria for Assessment

16. ARPHS believes that the seven criteria for assessing the three options provide an appropriate framework from which to assess the options, however it believes that efficiency should be one of the criteria for assessment as this provides a differing perspective to either cost effectiveness and effectiveness.

17. ARPHS believes that reducing inequalities should be a factor considered in any decision making around the NCSP. Concern that the use of population registers to improve participation rates in the NCSP might have the perverse effect of increasing inequalities should not be used as reason not to implement improvements to invitation and recall procedures. If perverse effects are thought likely it may be necessary to give further consideration and resourcing to how inequalities are reduced within the wider aim of increased participation and improved re-call cycles for all eligible women.

18. ARPHS wishes to make the following comments on the three options canvassed in the Discussion Document:

Invitation Functionality

19. The three options differ in their invitation functionality:

- no invitation (status quo),
- central invitation, or
- provider invitation.

20. ARPHS does not support the 'no invitation' option. Improvements in health for hard to reach groups will not occur without concerted effort to reach these women. The status quo option will do nothing to address inequalities and reach the substantial proportion of Maori and Pacific women (potentially up to 50% of each population group) who are currently not regular participants in the screening programme.

21. There is currently no nationally consistent and organised process for ensuring that women are invited to have a cervical smear upon reaching age twenty, the eligible age for participation. Any programme of invitation is likely to have some success; however provider and central invitation will have differing benefits and drawbacks.

22. The Cervical Cancer Audit[1] findings suggested that existing primary care invitation and recall systems are less than successful. They have been in operation for 14 years and have not succeeded in ensuring regular three yearly smears for a significant minority of women, and hence the recommendations for a population register to ensure a national system for invitation and recall be implemented. In addition, NCSP coverage rates have been static for some years indicating that revised strategies and systems will be required to meet NCSP targets of 80-85%.

23. Provider invitation is extremely difficult to implement for the NCSP because of its complexity. Information systems of PHOs throughout New Zealand are of varying quality and sophistication, and there is a complete lack of national consistency.

24. Provider invitation could be successful, provided that it is introduced in the manner outlined in Option 3 of the discussion document i.e. national population register functionality in support of provider systems. Success in this role would be dependent on all providers having:

- a contractual requirement (potentially through the PHO contract) to adopt the Ministry's invitation and recall standards and policies, and
- systems that link successfully with the data sets in the NCSP-R, and
- have robust systems to identify and contact women not in the NCSP.

25. This would also require appropriate quality assurance techniques be applied to ensure that the data set is accurate and that invitations are sent out and followed through across multiple providers. Multiple providers and systems increase the chances that problems will occur. Such a framework is also likely to have far higher transaction and compliance costs than a single population based invitation system.

[1] Sadler L. et al, 2004, The New Zealand Cervical Cancer Audit Whakamatau Mate Pukupuku Taiawa o Aotearoa

26. A provider based invitation system may also present challenges where multiple providers exist in a single geographic area (e.g. South Auckland where several PHOs operate servicing different ethnic populations living in the same area) and ensuring that all women domiciled in a geographic area receive an invitation rather than 'fall through the cracks' between differing providers.

27. A population register enables identification of an eligible population to be invited for screening, and helps with planning, service delivery and monitoring. A population register provides a more effective method of inviting members of any target group to be part of a screening programme than any current system of provider initiated invitation. A single population register presents a far smaller quality assurance challenge and has lower transaction costs than invitation by individual providers. For this reason the population register approach was preferred by the Cervical Cancer Audit, the McGoogan Review[2] and the Breastscreen Aotearoa Review[3] and the provisional reports of the Colorectal Cancer Advisory Group.

28. Whilst no system is perfect, the National Health Index (NHI) is by far the most comprehensive database in the health system, and would most likely provide the master index from which data could be extracted to form population register functionality for each programme. The ethnicity data on the NHI is also by far the most accurate in the health system. This ethnicity data also provides the possibility that invitations can be produced in English, Maori and the language relevant to the ethnicity of the woman. While individual providers could produce invitations in multiple language formats it would require less duplication of effort to produce these centrally.

29. ARPHS believes that central invitation offers advantages over provider invitation in addressing inequalities and lifting participation in the NCSP, however it may be that some form of combined system would offer advantages. There is evidence that women respond better to letters from their Doctor than they do from an 'anonymous' central provider. It may be that the NHI and NCSP-R should be used to extract eligible woman's' contact details which are then forwarded to their primary health care provider for invitation and recall letters to be produced and posted.

30. Neither central invitation nor provider invitation is likely to achieve 100% participation in the screening programme. Invitation by either method will need to be supported by social marketing designed to entice women to become part of the screening programme. It is through appropriate social marketing and use of community networks to particular populations that additional gains will be achieved in screening programme participation over and above those achieved through a central invitation programme.

[2] McGoogan E, 2003, Report on the National Cervical Screening Programme and progress towards Implementation of the Gisborne Inquiry Recommendations
[3] Chamberlain J, 2002, Breastscreen Aotearoa An Independent Review

Recall

31. All three options provide for central recall or back up recall. On page 2 of the Discussion Document, under the heading “Definitions”, in paragraph 2, the paper states that “Recall would either be undertaken centrally or as a back up to primary or secondary care systems and the appropriate system needs to be decided by each programme on a case by case basis.”

32. On the basis of the number of recall letters to women “gone no address” ARPHS believes that on a three yearly cycle some 12% of women change address. While the majority of these women can be located by contacting their last known personal health provider approximately 3% of the women on the register are lost to the system.

33. The advantage of the current back up system provided by the NCSP-R is that there is only one data base and only one set of administrative procedures in place. This means that it is far easier to quality assure this process than multiple ones operated by individual providers. It also means that women retain the choice over which smear provider they chose to use. This can be important for some clients who may wish to use differing health providers, for example in the sexual health care issue noted in the teleconference email.

34. ARPHS also believes that the current recall system is not sufficiently timely. Recalls need to be generated prior to the expiry of the three year screening cycle for each enrolled woman to ensure that as many women as possible receive a three yearly smear in accordance with the Programme’s intent. The data on page 9 of the discussion document demonstrates quite starkly that only a small proportion of enrolled women actually have their smears within the three year screening cycle (a point also noted by the Cervical Cancer Audit) but that many women respond to a reminder letter. This clearly demonstrates that existing primary care based recall systems *are not* ensuring that women receive a timely three yearly smear and that the screening programme for more than 50% of enrolled women is more like a four yearly programme, not three yearly. The very positive aspect of these data is that so many women *respond positively* to a reminder from the NCSP-R. The current system means that for women who need to be recalled the desired three yearly cycle may in fact be a four or four and a half year cycle. Reminders before the end of the cycle occur in the breast screening programme and work well and ARPHS is of the view that a similar system is required within the NCSP.

Privacy

35. The teleconference note refers to concerns about privacy; there is no evidence in the teleconference note as to the actual as opposed to anecdotal nature of this concern. ARPHS understands that some women are concerned about potential loss of privacy, however the NHI already exists as a national system, PHO databases exist and the NCSP-R also contains personal information. It is difficult to understand what aspect of personal privacy would be breached by using this data to invite eligible women for screening.

36. ARPHS experience is that since providers started to explain the purpose of the NCSP-R and the availability of the 'opt out' clause the numbers of client contacts concerned about privacy has dropped to perhaps one every few months.

37. The Privacy Commissioner notes that there is widespread public concern about privacy[4]. These concerns appear to be more about potential loss of privacy rather than based on evidence of privacy breaches. The last annual report from the Privacy Commissioner[5] shows that there were 119 (16.5%) complaints about the health sector in the 2004-05 year, of these complaints 42 related to the disclosure of information. The Commissioner's report notes that a "disproportionate number of complaints about disclosure occurred in private sector agencies". This perhaps is indicative of the increased risks around multiple providers.

38. Direct contact was made with the Office of the Privacy Commissioner to 'flesh out' the information in the public documents. The Office of the Privacy Commissioner was unable to provide any information about any individual complaint to the Commissioner. However, comment was made that most complaints related to information being lost over the passage of time and the Office of the Privacy Commissioner supported the 3 yearly contacts as a means of ensuring that the information contained in the NCSP-R remained live.

39. ARPHS believes that a centralised register provides a better safeguard for privacy than does an individual provider. As with the difference between individual and centralised invitation and recall systems a central register presents only one challenge for data security, rather than multiple challenges. The individuals operating the NCSP-R are also less likely to have any personal knowledge of the individuals on the register. This can be contrasted with individual providers where the individuals on the register and provider staff may be known to each other both in the medical setting and in the wider community.

40. Concerns about privacy can be addressed by better education of the general public regarding the advantages of the register, especially its ability to offer a preventive service to the whole population.

[4] Private Word – News From the Office of the Privacy Commissioner May 2006
http://www.privacy.org.nz/filestore/docfiles/99814583.pdf

[5] Report of the Privacy Commissioner
http://www.privacy.org.nz/filestore/docfiles/78944685.pdf

Inequalities

41. The discussion document notes that "lower socio economic groups appear to respond less well to invitation and recall letters than higher income groups". The underlying reason for this may have as much to do with population mobility as income. In the 2001 Census[6] 67.8% of homes were owner occupied (53.4% in Auckland). The review of the Residential Tenancies Act discussion document[7] notes that the average tenancy is 15 months or less, 50% end within 10 months and 33% within 6 months. This suggests that it is likely that many of those who are not actively participating in the screening programme move at least once within each smear cycle.

42. The NCSP Regional Service Managers feedback was rightly concerned with the issue of inequalities and whether any changes made to the national screening programme might increase inequalities. Population mobility is one of the indicators for inequality.

43. ARPHS believes that a case can be made that addressing inequalities should be the target of a separate workstream in the review process as increasing participation in under represented groups may need a differing response to changes made to the screening programme that benefit the population at large.

Conclusion

44. ARPHS is of the view that the evidence presented in the Cervical Cancer Audit, the Breastscreen Review and the McGoogan Review should be far more persuasive on any decisions taken on the content of the Discussion Document than other feedback. ARPHS believes that the use of population registers in screening programmes provides the best tool for identifying, inviting and recalling women for cervical smears and thus further lowering incidence and mortality rates from cervical cancer and reducing inequalities for the Maori and Pacific population. The use of a population register approach (possibly in combination with PHO registers) will provide a cost effective and efficient method of addressing the needs of the majority of the target population. The cost effectiveness of the population register approach may enable more resources and evaluation efforts to be directed to interventions that are specifically aimed at reducing inequalities between Maori, Pacific and older women and the rest of the female population.

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[6] Statistics New Zealand Owner Occupied Households http://www.stats.govt.nz/analytical-reports/housing-profiles/owner-occupied-hholds-intro.htm

[7] Department of Building and Housing Review of the Residential Tenancies Act Discussion Document http://www.dbh.govt.nz/rta-long-form-contents

45. By focusing on *what will work for women* changes to the NCSP can be made that will raise the current participation levels and the timeliness of recall.

Yours sincerely

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