CHAPTER 4

THE CLIENT GROUP

4.1 The Program identifies the main 'client' group for screening as asymptomatic women aged 50-69 years. However, issues were raised during the inquiry as to whether other age groups, especially women aged 40-49 years, should be actively recruited under the Program and how symptomatic women should be treated under the Program. This chapter discusses the issues of the appropriate age ranges for screening under the National Program and the appropriateness of screening symptomatic women under the Program.

Screening Age

4.2 The National Program provides that screening be made available to women aged 40 years and over but that recruitment strategies target women aged 50-69 years. Thus while the Program does not promote screening in the 40-49 age group, women in this age group are not excluded if they request screening. They are, however, not personally invited and the State and Territory publicity material about the Program targets women aged 50-69 years.

4.3 The Accreditation Guidelines require that women be advised of the risks and benefits of mammography screening. The Guidelines provide that 'each woman attending for screening should sign a consent form that clearly outlines the screening process including the possibility of recall for follow-up assessment. The women should also be informed in writing that screening does not prevent breast cancer, nor does it detect all breast cancers'.[207] DHS&H noted that all States and the Australian Capital Territory advise women that mammography screening is only of proven benefit to women aged 50 years and over.[208]

4.4 The selection of the age range to be screened under the Program was based on the SECU Report which analysed the latest overseas scientific studies. The report concluded that there was an international consensus that mammographic screening was effective in reducing breast cancer mortality for women aged 50-69 years, but the benefit for women aged 40-49 was much less clear for a number of reasons which are discussed below.[209]

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207. Accreditation Guidelines, *op. cit.*, p.19.

208. Submission No.114, pp.5.10 (DHS&H).

209. SECU Report, *op. cit.*, p.70

1. *Screening Women Aged 40-49 Years*

4.5 A considerable body of evidence to the Committee suggested that women aged 40-49 years should not be screened under the Program.[210] For example, a representative of the Intercollegiate Committee suggested that there was no strong scientific evidence that mass screening of 40-50 year old women is an effective public health measure in terms of a reduction in mortality.[211] A representative of the Australian Association of Surgeons (AAS) told the Committee that:

> The Association feels that the inclusion of this group at the present state of knowledge is contrary to the scientific evidence that a benefit is gained. We feel that it also increases the cost of the program by increasing the number of cases which are difficult to interpret in that younger age group for reasons of more dense breasts and, consequently, increases the intervention rate for women who then derive no benefit.[212]

4.6 The National Health and Medical Research Council (NHMRC) has also noted that the biological differences in the breast tissue of younger women make it more difficult to detect cancer in the breasts of women under the age of 50 years.[213]

4.7 The Council has also concluded that on the basis of scientific data there is insufficient evidence to suggest the screening of women under 50 years will lead to a reduction in mortality from breast cancer in this group.

4.8 The Committee also received some evidence of the problems involved in screening this group. One witness argued that:

> On the negative side, we know that screening that age group results in a higher recall rate. It results in a higher benign to malignant biopsy ratio and it results in a lower cancer detection rate. These are all rather negative features of screening that particular age group.[214]

4.9 Another witness also told the Committee that screening this group may give

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210. *Transcript of Evidence*, pp.1570-72 (RACR); p.1369 (AAS); p.1388 (AMA); p.1271 (Intercollegiate Committee).

211. *Transcript of Evidence*, p.1272 (Intercollegiate Committee).

212. *Transcript of Evidence*, p.1369 (AAS).

213. NHMRC, *Mammography Guidelines for Women Under 50 years of Age*, October 1992, p.1.

214. *Transcript of Evidence*, p.1348 (RACS, Section of Breast Surgery). See also *Transcript of Evidence*, p.1389 (AMA).

a false sense of security to these women.[215] As noted at Paragraphs 4.5-4.8, it is essential that these women be made aware of why the screening program is not appropriate for this particular age group.

4.10 Despite these arguments, the Committee believes that screening should still be available to women aged 40-49 years, although they should not be actively targeted. Several witnesses commented that the evidence in relation to screening this age group is still inconclusive. One witness noted that:

> The data are incomplete, no matter what anyone says, so it is impossible to make a reasoned decision based on sound data at the present time. There are good reasons ... for not changing the present policy.[216]

4.11 Another witness suggested that it is important to monitor overseas studies that are looking into this question before a decision one way or the other is made in Australia.[217] The witness noted that recent Swedish data indicate that mammography screening may not be as effective for women aged 40-49 as previously thought. He also pointed to current trials underway in the United Kingdom which are specifically designed to address this issue.[218]

4.12 A recent conference on breast cancer screening in premenopausal women held in Geneva in September 1993 concluded that the efficacy of screening women aged 40-49 years must be studied further with randomised controlled trials, although the available data can support a range of age guidelines, including screening from the age of 40 or from the age of 50 years. It was also announced that an international breast screening study of younger women aged 40-42 years would be conducted. The study will involve one million women in the United States and 500,000 in Europe and will be conducted over a ten-year period to assess the efficacy of mammography screening for younger women.[219]

4.13 The Committee is concerned that if women aged 40-49 are excluded from the Program they will continue to receive de facto screening under the Medicare arrangements which would add to national health costs, and this screening may not meet the same quality standards as set by the National Program.[220]

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215. *Transcript of Evidence*, p.1735 (Pathology Reference Group).

216. *Transcript of Evidence*, p.727 (Professor Forbes).

217. *Transcript of Evidence*, p.698 (Dr Fett).

218. *ibid.*

219. 'Multinational Breast Cancer Screening Conference Hosted by UICC in Geneva', *UICC News*, vol.4, No.4, December 1993, pp.1-2.

220. *Transcript of Evidence*, p.698 (Dr Fett); p.1425 (DHS&H).

4.14 The Committee received evidence that younger women are a particularly health conscious group and have an expectation that the screening Program will be available for them.[221] The Committee believes that information about the limited efficacy of mammography screening for this age group and the alternative options available to these women needs to be much more widely disseminated to these women.

4.15 Several witnesses commented that women in this age group do not understand the reasons why they are not being targeted.[222] Witnesses suggested that there needs to be an education campaign, perhaps through GPs and women's health centres, to explain to women why the Program is neither appropriate nor beneficial for them.[223] The Committee understands that, in this regard, the AMA has recently launched a program to disseminate information about the screening Program to GPs.

4.16 A representative of the Tasmanian Breast Screening Service explained that a large part of the State's education campaign was directed at this group explaining the lack of usefulness of screening mammography for this age group.[224]

4.17 Evidence received by the Committee indicated that women in this age group have the alternative of paying for a mammogram either at a public or private medical facility.[225] The RACR noted that women in this age group should not be in the Program, but if they wished to have a screening performed it should be self-funded.[226] However, this option may preclude many women, especially those from socio-economically disadvantaged groups, from obtaining a mammographic screening.

2. *Screening Women Aged 70 Years and Over*

4.18 Women 70 years and over are outside the Program's target age group (i.e. women aged 50-69 years). Some witnesses argued that the Program discriminated against this group by not including them directly in the Program.[227] Evidence from some witnesses indicated that women aged 70 and over should be screened.[228]

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221. *Transcript of Evidence*, pp.356 (North West Health Service, Tamworth); p.101 (Dr Roder).

222. *Transcript of Evidence*, p.1774 (Tasmanian Breast Screening Service); p.1257 (Women's Health Service for the West).

223. *Transcript of Evidence*, p.1735 (Pathology Reference Group).

224. *Transcript of Evidence*, p.1774 (Tasmania Breast Screening Service).

225. *Transcript of Evidence*, p.1517 (RACR, Queensland Branch).

226. *Transcript of Evidence*, p.1573 (RACR).

227. *Transcript of Evidence*, pp.1156-7 (Royal College of Nursing).

228. *Transcript of Evidence*, p.1214 (Professor McKenzie); p.1232 (AIR).

4.19 One witness argued that it reflected an attitude of ageism not to encourage women 70 years and over to be screened. He also noted that breast cancer was just as tragic in human terms for an older women as for a younger woman.[229]

4.20 Other witnesses, however, indicated that there was no evidence of a reduction in mortality from breast cancer by screening women aged 70 years and over.[230] One witness noted:

> As women age, the cost benefit or the cost-effectiveness becomes more adverse, because people have less life expectancy involved.[231]

4.21 The Committee notes that while it may not be effective in terms of lives saved to screen women aged 70 years and over, in terms of quality of life it does offer a benefit. The Committee believes that the personal reassurance gained for older women due to regular access to mammographic screening is also an important consideration. The Committee also believes that there may be a perception amongst this age group that they are being unfairly discriminated against by being seen to be denied access to screening once they reach the age of 70.

Conclusion

4.22 On the basis of the evidence received the Committee believes that while the age range for recruitment under the Program should continue to concentrate on women aged 50-69 years, women outside this age range should also have access to screening, although they should not be actively targeted.

Recommendation

The Committee RECOMMENDS:

10. That the focus of the Program remain women aged 50-69 years, but that mammographic screening continue to be available to women aged 40-49 years and 70 years and over.

Screening Symptomatic Women

4.23 The screening program is designed to detect breast cancer in asymptomatic women. The National Program does not encourage women with symptoms to attend for screening. A symptom may, for example, include a lump or nipple discharge. Educational and promotional material provided by the States and Territories advise women who have symptoms to consult their general practitioner. However, if a woman with symptoms presents to a screening unit she will be screened.

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229. *Transcript of Evidence*, p.1214 (Professor McKenzie).

230. *Transcript of Evidence*, p.870 (Wesley Breast Clinic, Brisbane).

231. *Transcript of Evidence*, p.699 (Dr Fett).

4.24 The National Accreditation Guidelines require Services to have a protocol for handling symptomatic women. These protocols differ somewhat between States as to detail. However, in all cases, once the woman is screened, and regardless of the outcome of her mammogram, she will either be referred to her general practitioner for follow-up investigation/ongoing management or be recalled for assessment in accordance with the Service policy.[232]

4.25 The Committee received considerable evidence suggesting that symptomatic women be excluded from the Program.[233] It was put to the Committee that as the screening program is, by definition, designed to detect breast cancer in women who are asymptomatic, it is not appropriate for symptomatic women to be included. In addition, as the data collected from the Program is designed to demonstrate a benefit for screening asymptomatic women the inclusion of symptomatic women makes the interpretation of this data difficult.[234]

4.26 One submission noted that including symptomatic women in the Program would substantially increase costs. If such women were to be managed under the Program they would require assessment. It was estimated that a one per cent incidence of women with symptoms would generate an increase in up to 20 per cent in the number of assessments performed under the Program. As assessment is a costly part of the Program, this would generate a marked increase in Program costs.[235]

Alternatives for Symptomatic Women

4.27 The Committee recognises that excluding symptomatic women from the Program poses many problems. Some symptomatic women see the screening service as offering the advantage of a high quality service and may prefer to be examined by what they perceive to be as 'sympathetic' and suitably trained medical staff especially if they have been to a GP and are not happy with the advice that they have received from that source.

4.28 Others may be confused by the nature of the health-care system and, notwithstanding the purpose of the screening program, still consider the Program as offering a service that should be available to them, especially when they see other women utilising the service. The Committee received considerable evidence during the inquiry that there was a lack of understanding in the community generally

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232. Submission No.114, p.5.11, (DHS&H).

233. *Transcript of Evidence*, p.1272 (Intercollegiate Committee); p.1583 (RACR); p.828 (Professor McCaffrey); p.861 (Wesley Breast Clinic, Brisbane).

234. *Transcript of Evidence*, p.1369 (AAS).

235. *Transcript of Evidence*, p.1532 (RACR).

regarding the difference between screening and diagnostic mammography.[236] Still other women may live in areas where alternative screening services are not readily available or easily accessible and therefore see the Program's services as providing a useful health resource.

4.29 Women who deny that they have symptoms at the time of making an appointment for screening also present special problems. One witness noted that in Victoria, up to two per cent of women arriving at centres for screening actually have symptoms. This is despite the fact that there is a telephone protocol at the appointments stage which makes clear that if a woman indicates that she has any kind of symptom then it is suggested that she sees her GP.[237] Another witness noted that symptomatic women who insist on being screened should be screened as there is a 'duty of care to that patient ... This is a patient now, it is not a screenee who has arrived on your doorstep'.[238]

4.30 Several witnesses recognised the difficulty in situations where self-referred symptomatic women present for screening. For example, the Intercollegiate Committee noted that these women should not be turned away but should have a mammogram and be directed for proper medical assessment and management in consultation with their GP.[239] The Committee agrees with this approach and also believes that counselling and advice should also be made freely available by the screening services to these women.

4.31 The Committee also believes that information on the alternatives open to women need to be widely disseminated and publicised in the general community and to GPs in particular.

4.32 Women with symptoms who present for screening need to be advised that Medicare benefits are available for diagnostic mammography. If subsequently found to have no disease they are eligible for screening under the Program. A witness told the Committee that, based on her experience, when it is explained to them, symptomatic women generally accept the advice that the screening Program is not appropriate for them.[240]

4.33 The Committee notes that women in rural areas who present at a screening centre with symptoms present a difficult problem for the Program. One submission noted that because access to mammographic services is so restricted in many rural areas, women who present, for example, at a mobile clinic need to be accepted under

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236. *Transcript of Evidence*, p.1030 (AMA, Queensland Branch); p.803 (Wesley Breast Clinic, Brisbane).

237. *Transcript of Evidence*, p.1129 (BreastScreen).

238. *Transcript of Evidence*, p.1584 (RACR).

239. *Transcript of Evidence*, p.1265 (Intercollegiate Committee).

240. *Transcript of Evidence*, p.862 (Wesley Breast Clinic, Brisbane).

the Program.[241] The Committee believes that, in these circumstances, they should be screened but that every effort should be made to direct these women to appropriate medical services outside the Program.

4.34 The Committee believes there needs to be an educational campaign directed at both the general public and medical profession so that women with breast symptoms are directed along established diagnostic pathways and that the screening program is not used for the de facto diagnosing of symptomatic women.

4.35 The Committee considers that the National Program must have a clearly defined and uniform policy with regard to symptomatic women – its objective must be to offer mammographic screening to asymptomatic women on a regular basis to allow for the detection of breast cancer which is amenable to treatment. The Committee also believes that the Program should offer advice and counselling to symptomatic women and information on follow-up medical services that are available. The Committee also considers that the Program needs to provide mammographic screening to symptomatic women who wish to be screened.

Recommendations

The Committee RECOMMENDS:

11. That recognising that the Program is for well women, that symptomatic women inquiring or phoning for appointments be advised why the Program is not appropriate for them; and be provided with specific advice and information regarding the availability of other medical services.

12. That should symptomatic women present for mammographic screening they be screened under the Program; and be provided with advice and information regarding the availability of further medical services.

Women with Identifiable Risk Factors

4.36 The Program is designed for well women and therefore makes no provision for screening women more frequently if they are considered to be at high risk of developing cancer, have a strong family history of cancer, have had a pre-cancerous condition or if they have had treatment for cancer in the breast in the past.[242]

4.37 Concern was expressed during the inquiry as to the best way of treating women with identifiable risk factors and especially whether they should be treated within the Program or outside it.

4.38 Much of the evidence presented to the Committee suggested that these women require ongoing medical care involving regular clinical examination and

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241. *Transcript of Evidence*, p.1320 (RACS, Section of Breast Surgery).

242. *Transcript of Evidence*, p.1265 (Intercollegiate Committee).

mammography and that this is best managed outside the National Program by existing medical services.[243]

4.39 The Committee believes that it needs to be emphasised that the Program is based on a significantly different ethos of health care than the dominant 'illness' model of health care – in that the Program specifically targets well women and the vast majority of women who participate in the Program will still consider themselves to be 'well' after having been through the Program.[244]

243. See *Transcript of Evidence*, p.1265 (Intercollegiate Committee); p.1320 (RACS, Section of Breast Surgery); p.1736 (Pathology Reference Group).

244. See recommendation at Paragraph 4.35.