

Evaluation of a project to enhance knowledge of hereditary diseases and management

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Abstract

During 1992 and 1993, in a designated suburban area of Perth, Western Australia, information on hereditary disease was provided for health professionals and the general community. This information was in the form of posters, pamphlets, postal flyers and return letter cards, a static display, newspaper articles, advertisements and radio broadcasts, and professional seminars. The aim of this project was to evaluate the effectiveness of combined strategies to convey practical information about hereditary disease to the community and health professionals. Multiple measures of response evaluation were used, which included structured questionnaire surveys of health professionals and members of the community before and after the project. In the community surveys, respondents who were female, married, middle aged, and parents, and had a higher level of education or were born in Australia, New Zealand, or the United Kingdom were generally better informed about hereditary diseases. This intervention resulted in only meagre changes in community knowledge about hereditary disease, even though promotional materials were shown to be appropriate. General Practitioners (GPs) and Child Health Nurses (CHNs) were supportive of clinical genetic services and recognised a need for continuation of education in this field.

There is a rapidly increasing need for community and health professional comprehension of the applications of the new genetic technology. This project indicates that routine educational and health promotion strategies will not be enough to achieve desired levels of knowledge and attitude change.

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Keywords: educational strategies; evaluation; hereditary disease

Developments in molecular genetics have revolutionised the practice of clinical genetics. Where previously at risk families could be offered few options, the advent of new technologies provides more opportunities for choice in the prevention of hereditary disease.^{1,2} Use of these technologies has been relatively slow and this is in part because of community and professional ignorance. Some authorities believe that a more active approach

to the dissemination of genetic knowledge and the promotion of services is now required.³⁻⁸

Health professionals have been slow to accept that genetic health issues are a part of total patient care; appropriate genetic information or referral is frequently only provided with reluctance or not considered necessary by a medical professional unless a request is made by the patient.⁹⁻¹² Few couples seek pre-pregnancy counselling in relation to genetic issues, a situation likely to change if families and people are better informed on inherited matters.^{3,7,13} The message about hereditary diseases and their prevention is a relatively complex one and health professionals must choose between providing very general information or attempting to give specific details about a large number of rare diseases. Eliciting a family history may require a degree of biological and social knowledge that many health professionals and the community do not possess. It is therefore not surprising that recently developed DNA technology for genetic testing is currently underused in the health care system.¹³⁻¹⁶ There is also considerable misinformation about genetic disease in the community, often aggravated by inaccurate media coverage.

If informed debate about genetic testing and the potential uses of available DNA technology is to occur, health professionals and the community need accurate information about hereditary disease on which to base such a debate. A pilot project was undertaken to test whether a relatively simple, low cost approach to health professionals and the community, using pamphlets, posters, postal flyers, newspaper and radio items, and professional seminars, could increase knowledge of hereditary disease in the community. The aims of the study were to develop promotional materials and other interventions relating to hereditary disease; inform health professionals and the community in the target area about hereditary disease, using the interventions developed; provide a genetic outreach clinic in the target area; evaluate attitudes and acceptance of the project by health professionals; and evaluate knowledge about hereditary disease among members of the community following the above interventions.

The outcomes of the project are described with discussion on problems related to attempts at wide scale population education on human genetics and the evaluation of their efficiency.

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Table 1 Materials used in hereditary disease project strategies

Materials	Distribution*	Period of exposure	Piloted/focus tested
<i>(A) Pamphlets</i>			
Genetic counselling	GP, CHN, P, S/D	Throughout	No
Testing for birth defects in pregnancy	GP, CHN, P	March 93 onwards	Yes
Will my baby be born healthy?	GP, CHN, P	November 93	Yes
Check your family tree worksheet (How to draw a pedigree)	GP, CHN, S/D, P, L, HF	January 93, throughout	Yes
Maternal serum screening for neural tube defect and Down syndrome	GP, CHN, L, P	January 93 onwards	Yes
Your genetic counselling appointment	GP, CHN, P	February 93	—
Fact sheet on hereditary diseases	GP, CHN	Throughout	No
What do you know about hereditary disease? (table 2)	LD	Throughout	Yes
<i>(B) Posters</i>			
Check your family tree	GP, CHN, L, P	January 93, throughout	Yes
Will my baby be born healthy?	GP, CHN, P, L	November 93	Yes
<i>(C) Project information kits for professionals</i>			
Folder with log & enquiry details	GP, CHN		
"Facts on hereditary diseases" fact sheet	M		
Prenatal diagnosis booklet			
Genetic counselling pamphlet			
Project information leaflet			
<i>(D) Newsletter</i> Bimonthly x 6 editions			
	GP	Alternate months	—
<i>(E) Meetings/seminars</i>			
	GP, CHN	July 92–November 93	
<i>(F) Static display</i>			
	SC, CH	Limited	

*General practitioners (GP), child health nurses (CHN), pharmacies (P), static displays (S/D), libraries (L), letter drops (LD), media (M), health fairs (HF), shopping centres (SC), council house (CH).

Methods

This study, called the Hereditary Disease Project, was conducted during 1992 and 1993. The target region comprised five adjacent postcode areas of metropolitan Perth (the capital of Western Australia), with a total population of 51 380.

Interventions

PROMOTIONAL MATERIALS

Pamphlets (table 1), posters (for example, fig 1), and information kits for health professionals were developed. The latter included an outline of the background and aims of the project, a fact sheet on hereditary disease, a prenatal diagnosis booklet (purchased from the NSW Genetic Education Programme), and a genetic counselling pamphlet. Posters and pamphlets were displayed in participating doctors' surgeries, child health centres, day care centres, kindergartens, and pharmacies. Newsletters were sent at regular intervals to all general practitioners (GPs) in the target area, updating them on the project and including an educational article such as maternal serum screening in each issue.

Static display

A large free standing display was placed in various public locations in the target area over the final three week period of intervention strategies. The display design used a large version of the illustration from the leaflet *Will my baby be born healthy?* (fig 1), with little text and the project telephone number highly visible.

Newspaper promotion

The project obtained unpaid coverage of items of human interest in hereditary disease in the local community newspapers during an initial three week period. This was followed by a series of three paid full page advertisements *Will my baby be born healthy?* (fig 1).

INFORMING HEALTH PROFESSIONALS

There were 45 GPs, five child health nurses (CHNs), three social workers (SWs), 26

regional administrative health officers (including a community medical officer), and eight pharmacists practising in the target area during the course of the study.

The Chief Investigator or the Project Officer or both visited 24 GPs representing the majority of practices who had agreed to be interviewed to discuss the project. All practices received the project information kit and were later provided with further educational information for display and patient distribution. Of the 24 GPs visited, 17 were willing to participate in a "sentinel" role by recording all enquiries by their patients about hereditary disease matters as well as those patients whom they saw and who had a hereditary disease.

The Project Officer regularly visited CHNs and they received the project information kit, posters, and pamphlets, attended special in-service seminars, and were invited to make appropriate genetic referrals through family GPs or directly to the Genetic Outreach Clinics.


Pharmacists were contacted by the Project Officer and provided with posters and pamphlets for display and distribution.

INFORMING THE COMMUNITY

Direct mail strategies

All households in the target area received a direct letterbox drop during the course of the project. Each letter drop included a leaflet, *What do you know about hereditary diseases?/ Know your family tree*, plus a questionnaire return mail card with two multiple choice questions, one about the meaning of the term "genetic disease" and the other about the chance that a baby born in Western Australia has a birth defect. There were initially five separate mailouts to different subsets of postcodes and a sixth repeat mailout to one subset. Recipients were invited to return the questionnaire card and slightly different formats were used in order to evaluate the response rates to each strategy (table 2).

Will my baby be born healthy?



It's a question everyone asks at some time, when planning a baby

The answer can sometimes be found by checking your family tree. Many diseases and disorders tend to run in families. If you're pregnant or planning a pregnancy, it's important to ask yourself 5 simple questions about the risks of inherited disease.

How Genetic Counselling can help you

From your family health history, a genetic counsellor can help assess your baby's risk of hereditary disease. If necessary, testing can be done on parents or their unborn child. Most importantly, genetic counselling can ease the anxiety people may experience through lack of information about hereditary disease.

A confidential program for you

The Health Department and Genetic Services of Western Australia at King Edward Memorial Hospital and Princess Margaret Hospital for Children conduct genetic counselling.

If you would like to know more about genetic counselling, or know someone who might benefit from genetic counselling, **contact your local doctor or ring the Hereditary Disease Program Tel. 222 4272** during office hours.

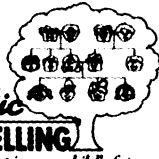
Counselling will be conducted by specialist doctors and is confidential.

Five Simple Checks

To check if your baby may be at risk, answer the following questions by ticking the boxes.

<p>1. Do you or your partner have any diseases which could be inherited? <input type="checkbox"/> <input type="checkbox"/></p> <p>2. Does a genetic disease run in your family (such as cystic fibrosis, haemophilia, Down syndrome, muscular dystrophy)? <input type="checkbox"/> <input type="checkbox"/></p>	<p>3. Do you have a child with a serious disease or disorder? <input type="checkbox"/> <input type="checkbox"/></p> <p>4. Are you 35 years of age or older? <input type="checkbox"/> <input type="checkbox"/></p> <p>5. Are you and your partner close relatives (e.g. cousins)? <input type="checkbox"/> <input type="checkbox"/></p>	<p>Yes No</p>
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If you answered yes to one or more of these questions, it's important that you talk to your doctor.



Genetic COUNSELLING
An investment in your child's future.

Figure 1 An example of one of the posters.

Incentives to respond were offered. These were the provision of further information and the *Genetic counselling* pamphlet, a *Check your family tree* worksheet, and entry into the draw for a pair of jeans.

Phone line

A dedicated telephone line and answering service was allocated to the Project to receive requests for information.

Genetic outreach clinics

The purpose of these was to raise community and professional awareness about the project and were established in child health centres during the period of the project. These were intended to provide easy access to specialist genetic information and deal with referrals from local GPs. Referrals from CHNs and self-referrals were also accepted.

EVALUATION OF HEALTH PROFESSIONALS' ATTITUDES TO THE PROJECT

The response and participation of GPs in the project was assessed by their overall level of involvement. Responses to the newsletters and replies to questionnaires for feedback on hereditary disease pamphlets, such as that for *Maternal serum screening for neural tube defects and Down syndrome*, were also recorded. Finally, a self-administered 23 item questionnaire was mailed to general practitioners at the completion of the project to ascertain their attitudes to the relevance of clinical genetics in their practices and the project to which they could respond anonymously.

CHN participation was assessed by willingness to display project posters and pamphlets, rates of referral of individual families to the genetic outreach clinics, and by their attendance at two genetic inservice seminars.

EVALUATION OF COMMUNITY KNOWLEDGE

The community impact of the project was assessed by two 15 minute shopping centre intercept surveys in which a structured questionnaire was administered by trained interviewers. The first survey was conducted over a two week period in 1992 immediately before any project intervention strategies occurred, and the other was 18 months later at the completion of the project.

Measurement of knowledge was based on questions relating to the definition of genetic disease, how common birth defects are, ability to name a genetic disease, ability to name a prenatal test for genetic disease or birth defects, who might benefit from genetic counselling, and where to obtain information on hereditary disease. Information relating to all these measures was contained in the promotional material distributed as part of the project.

Pre- and post-survey results were compared using chi tests and odds ratios. It was decided a priori to examine the data separately for male and female respondents, as it was felt that the response to the project might differ by gender, and to adjust the odds ratios by several potential confounding variables (age, country of birth, marital status, education of respondent, and whether respondent had children).

Crude and adjusted odds ratios and their 95% confidence intervals were calculated using multiple logistic regression (Egret 1993).

Results

ATTITUDES OF HEALTH PROFESSIONALS TO THE PROJECT

At the time of the initial interview, GPs had indicated that they favoured a fortnightly referral genetic outreach clinic. These clinics accepted referrals during the time of the project so that by its completion they were fully booked. Each clinic provided three consultations which were most frequently related to the consultant's own familial risks rather than mere enquiry about general genetic issues. CHNs were relatively more frequently the referring agent than other sources.

Table 2 Letterbox strategies used in hereditary disease project

Letterbox drop No	Basic questions*	RP card only	RP envelope	Comments, special features/strategies	Households No	Timing of strategy	Incentive to respond	Response rate
1	+	+	-	This population subgroup consisted of an older age group, higher non-English speaking background, and lower socioeconomic background (ABS census data)	3930	September 1992	(1) Further information about hereditary disease (FHHD). (2) jeans prize draw	2%
2A	+	+	-	Split run Difference in method of response, ie (A) open card or (B) closed/RP envelope	4230	October 1992	(1) FHHD and (2) jeans prize draw	2.3%
2B	+	-	7%					
3	+	-	+	Repeat of response in closed RP envelope	2350	December 1992	(1) FHHD and (2) jeans prize draw	Overall 4.6%
4A	+	-	+	Split run Half of the recipients (A) were asked to provide their age	2955	April 1993	(1) FHHD and (2) jeans prize draw	4.2%
4B	+	-	+					4.1%
5A	+	-	+	Split run Half of the recipients (A) were offered jeans as an incentive to respond. The others (B) were not	2884	August 1993 post-media campaign	(1) FHHD and (2) jeans prize draw	5.2%
5B	+	-	+					8.5%
6A	+	-	+	Split run Half old questionnaire (A) and half new coloured & illustrated questionnaire (B). Overall response diminished by same subgroup from letterbox drop 1, where return rate was 1.9%.	8160	December 1993	(1) FHHD	4.1%
6B	+	-	+					2.4%
								Overall 3.2%

*Delivered with pamphlet: *What do you know about hereditary disease?/Check your family tree.*
 RP=reply paid and return address given.
 FHHD=further information about hereditary disease.

The attitudes of GPs who were interviewed before the launch of the project varied from relatively positive to ambivalence or complete uninterest. At three practices the Chief Investigator and the Project Officer were unable to arrange appointments for interviews.

The 17 sentinel GPs were generally supportive throughout the project, but regular collection of data on practice consultation numbers with hereditary disease was discontinued after six months because of minimal activity.

Of the 45 GPs who were sent the questionnaire at the end of the project, 36 (80%) responded. Eighteen were <40 years and 18 were 40 or more years of age. All respondents had been aware of the project and the majority (24, 67%) thought that the genetic issues raised were important. A greater proportion of GPs aged 40 years and over, compared with those under 40 years, thought that the project should continue (<40 years, 9 (50%); ≥40 years, 15 (83%)), and that they would continue to display project pamphlets (11 (61%); 14 (78%)) and posters in their surgeries (8 (44%); 13 (72%)).

Thirty-three of the 36 GP respondents (92%) thought the project had professional educational value and that there was a need for further genetic education of GPs. All but one respondent could see a role for GPs in managing patients with hereditary disease, over half had referred patients to genetic outreach clinics, and most felt that the genetic outreach clinics should continue (<40, 9 (50%); ≥40, 14 (78%)). Only one respondent saw the project as being anxiety provoking and an invasion of privacy.

CHNs in the target area remained key contacts for the duration of the project. They frequently referred patients to genetic clinics either directly or more often through a patient's general practitioner, and they distributed and displayed project information in child health centres as well as contacting community groups, such as play groups and child care organisations.

COMMUNITY RESPONSE TO DIRECT MAIL STRATEGIES

Return of the mailout questionnaire card varied from 1.9% to 8.5%. In the split run surveys, the best responses were obtained when a self addressed, reply paid (RP) envelope was provided (7.0%), the questionnaire card was plain rather than colourful and illustrated (4.2%), and when no prize draw incentive was offered (8.5%). A request for the age of a respondent did not act as a deterrent (table 2). A population subgroup which received letter drop No 1 and was part of No 6 where a different strategy was used gave the poorest response of the series, 2.0% and 1.7%. This subgroup contained a higher proportion of older subjects, non-English speaking subjects, and subjects with a low socioeconomic status.

COMMUNITY SURVEYS PRE- AND POST-PROJECT INTERVENTIONS

A total of 250 persons were interviewed before the project interventions were undertaken, and

Table 3 Pre- and post-surveys: proportion of respondents who chose correct definition of genetic disease by demographic factors

Respondents	Proportion choosing correct answer*	
	Pre (n=250)	Post (n=248)
Age		
<20	11 (73.3%)	17 (85.0%)
20–29	51 (86.4%)	52 (77.6%)
30–34	39 (92.9%)	39 (79.6%)
35–39	29 (82.9%)	25 (100%)
40–49	41 (89.1%)	34 (94.4%)
50–59	15 (62.5%)	25 (92.6%)
60+	19 (65.5%)	20 (83.3%)
Sex		
Male	94 (77.0%)	92 (87.6%)
Female	111 (86.7%)	120 (83.0%)
Highest level of education completed		
Primary	36 (61.0%)	15 (57.7%)
High school	117 (84.8%)	141 (85.4%)
Technical	37 (97.4%)	35 (97.2%)
University	15 (100%)	21 (100%)
Marital status†		
Never married	39 (70.9%)	61 (84.7%)
Married de facto	132 (86.8%)	116 (87.9%)
Sep/wid/div	34 (79.1%)	35 (79.5%)
Country of birth		
Australia/New Zealand	130 (82.8%)	155 (85.6%)
UK	46 (80.7%)	36 (90.0%)
Europe	16 (69.6%)	7 (77.8%)
Other	13 (100%)	14 (77.8%)
Any children?		
Yes	165 (84.6%)	138 (89.0%)
No	40 (72.7%)	74 (79.6%)

*Expressed as a percentage of all respondents in that category.

†Separated/widowed/divorced (sep/wid/div).

Table 4 Comparisons of knowledge and sources of knowledge of hereditary disease pre and post the hereditary disease project interventions by sex of the respondent

	In response to question: "Can you name any genetic diseases?"		
	Pre No (%)	Post No (%)	Adjusted OR* (95% CI)
Nominated a Mendelian disorder			
Females	37 (28.9%)	39 (27.3%)	0.80 (0.43, 1.48)
Males	7 (5.7%)	15 (14.3%)	2.96 (1.04, 8.45)
Nominated a multifactorial disorder			
Females	62 (48.4%)	83 (58.0%)	1.50 (0.86, 2.59)
Males	46 (37.7%)	49 (46.7%)	1.55 (0.86, 2.79)
Nominated spina bifida			
Females	6 (4.7%)	15 (10.5%)	2.18 (0.75, 6.29)
Males	2 (1.6%)	3 (2.9%)	1.65 (0.25, 10.74)
Nominated Down syndrome			
Females	13 (10.2%)	34 (23.8%)	2.71 (1.26, 5.85)
Males	5 (4.1%)	16 (15.2%)	6.41 (1.93, 21.31)
Nominated a health professional as a source of information			
Females	80 (62.5%)	115 (80.4%)	1.71 (1.00, 2.92)
Males	74 (60.6%)	87 (82.8%)	3.01 (1.63, 5.56)
Nominated a hospital as a source of information			
Females	33 (25.8%)	55 (38.5%)	1.89 (1.09, 3.27)
Males	32 (26.2%)	29 (27.6%)	0.94 (0.52, 1.69)
Nominated the Health Department as a source of information			
Females	34 (26.6%)	44 (30.8%)	1.25 (0.72, 2.17)
Males	29 (23.8%)	24 (22.9%)	0.96 (0.51, 1.81)
Knew about Genetic Counselling Services in WA			
Females	30 (23.4%)	34 (23.8%)	1.16 (0.63, 2.12)
Males	13 (10.6%)	14 (13.3%)	1.45 (0.62, 3.38)

*OR, odds ratio = the odds of outcome after the project divided by the odds of outcome before the project.

95% CI = 95% confidence intervals.

Odds ratio adjusted for education, age, country of birth, marital status, and whether respondent has any children.

a further 248 after the interventions. Respondents in the two surveys were similar in terms of age, gender, and marital status, but there were fewer respondents born in the United Kingdom and Europe in the second survey (and correspondingly more born in Australia and New Zealand). Fewer respondents at the

second survey had children or had only completed primary education.

In both surveys, respondents less likely to choose the correct definition of genetic disease were those with less education, those who had never married, those born in Europe, and those who had no children. In the first survey but not the second, respondents under 20 and over 50 years of age were also less likely to choose the correct definition (table 3).

In response to the question "Can you name any genetic diseases?", female respondents were more likely than males to offer a valid answer. However, when comparing the pre- and post-surveys, an increase in knowledge (as assessed by the odds ratio) was seen for both males and females nominating a multifactorial disorder, spina bifida, and Down syndrome. Very few of these differences were statistically significant (table 4).

There was no improvement in knowledge between the two surveys for either men or women about who might benefit from genetic counselling in five of six specified situations (if they already have a child with a serious disorder; when a woman over 35 years of age plans to have a baby; when marrying a close relative; when either parent has a serious disorder which may be passed on to their children; and when a woman has had more than two miscarriages). A three-fold (but statistically non-significant) increase was seen in knowledge about the benefit of genetic counselling if a disorder runs in the family (data not shown).

Both men and women were significantly more likely to nominate a health professional as a source of information about genetic disease after the project than they were before the project. Women, but not men, also nominated hospitals and the Health Department more frequently after the project. Fewer than one in four respondents knew of the existence of the genetic counselling services and there was little increase in this knowledge over the study period for either men or women (table 4).

At the time of the second survey, respondents were shown the pamphlet and posters produced for the project and asked if they had seen them before. A total of 8.3% of males and 16.9% of females had seen the pamphlets, and 10.5% of males and 37.8% of females had seen the most widely distributed of the posters. More women (29.4%) than men (16.2%) reported seeing the static display. Only 14.3% of males and 20.9% of females recalled receiving anything through the mail about hereditary disease. People who had seen the pamphlets or the poster were about three times more likely to have chosen the correct definition of a genetic disease.

Discussion

In this pilot Hereditary Disease Project promotional materials were developed, information was provided to health professionals and the community, and a genetic outreach clinic was established. In the community surveys before and after the promotional events, respondents who were married, middle aged, had children, had a higher level of education, or were born in

Australia, New Zealand, or the United Kingdom were more likely to choose the correct definition of genetic disease. Women also tended to be better informed about hereditary disease. However, there were few significant improvements in knowledge after the interventions among male or female respondents and the overall level of knowledge was not high. Health professionals were commonly cited as a source of information about hereditary disease, underscoring the importance of GPs having the knowledge of either the condition the patient may be enquiring about or the knowledge of where such information can be provided.

There are several possible reasons for the lack of improvement in awareness of hereditary disease as a result of this project. Firstly, the time frame of the project was short (18 months) and because of the complexity of the hereditary disease messages, they may be less easy to impart quickly and in simple form, both to the public and to health professionals. A further explanation is that the materials may not have been distributed sufficiently widely. A third or fewer of the people surveyed recalled seeing the pamphlets, posters, or the static display, and an even smaller proportion could recall receiving anything through the mail about hereditary disease. This was despite distributing the materials in many locations where women and children congregate, along with health centres, pharmacies, and general practices, and the fact that all households in the target area had been sent at least one project letter. It may be that a more diverse range of materials with messages of greater relevance to the informal or lay views of the community may have been more successful in communicating hereditary messages.¹⁶⁻¹⁹

There is evidence that some genetic information is of low interest to recipients except when they are pregnant or actually planning a family.¹⁵⁻²⁰ There is greater interest in information about particular hereditary diseases where that level of knowledge within the community is greater or if the recipient has heard or knows of a person or family member with the condition.²⁰⁻²¹ The project may not have accounted for important perceptive and cultural factors which strongly influence the recognition of the intended genetic message. Lay belief has been identified to be of importance to people and families in their interpretation of hereditary principles.¹⁶⁻¹⁹

GPs, who were generally supportive of the project, require further support and encouragement in genetic education and indicated their desire for further practical information, such as ways of identifying patients who might benefit from genetic counselling. At least a third of GPs have indicated in other studies that they see a role for themselves in community health education, which is in keeping with what is expected of them by many in the community.²² CHNs were enthusiastic in their support of the project, referring patients in appropriate circumstances. Special event Genetic Education Weeks for health professionals have received acceptance and favourable re-

sponses, but there has been no objective evaluation over time to assess their effect.⁸ In this project, many of the materials used in letter-drop pamphlets appeared to draw a satisfactory response rate, but in the shorter term did not raise the awareness of hereditary diseases. Future programmes could consider higher profile media channels, such as television. A greater precision in targeting of information (for example, to females of reproductive age) may be advantageous but a possible weakness inherent in this approach is that the older generation may be those who provide the family with information on this subject.¹⁶⁻¹⁸

The multitude of hereditary diseases, many of them rare, makes it impossible for a programme to address each individually. Our general message, such as *Will my baby be born healthy?*, was well received by focus groups and by interviewees, but alone did not register greatly in the community awareness of hereditary disease.

We believe that the potential impact of medical genetics in community health care is so great that there is a need to conduct further studies implementing some of the suggested changes in approach. A future programme to promote community awareness of hereditary disease should be multifaceted and long lasting. Ingrained misconceptions about inheritance can be best addressed by education, firstly at upper school levels. Some of the more common and significant misconceptions, like those referring to the risks of autosomal recessive inheritance, require the development of promotional materials which directly address and simply describe the mechanisms. Focus groups were used to develop materials for this project, but greater cognisance of informal or lay beliefs will demand further research and consumer involvement in the development of educational programmes.^{18-19, 23-25}

The rapid pace of new discoveries in the field of molecular and clinical genetics has revolutionised the management of at risk families. However, formal programmes to transmit appropriate knowledge to both the public and health professionals have been conspicuously absent. The optimal development of education, counselling, and support strategies requires much research, new approaches, and should lead to people, families, and health professionals becoming more aware of hereditary disease risks and choices in terms of management and reproduction options which were not previously available.

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