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Mixed Messages: Presentation of Information in Cystic Fibrosis–Screening Pamphlets

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Summary

Written pamphlets are an important source of information for individuals deciding whether to undergo carrier testing for cystic fibrosis (CF). Adequate understanding of the condition and reproductive options following the diagnosis of a fetus with CF are critical to informed decision making. The information given about CF and reproductive options in 28 pamphlets about carrier testing, from commercial and noncommercial organizations in the United States and the United Kingdom, aimed at prenatal and other populations, was assessed. The amount of information provided about CF showed a range of 1–37 sentences (median 6.5), with most being relatively neutral and with a minority conveying a positive or a negative image. Positive sentences were less common in British, U.S. commercial, and prenatal pamphlets. Statements about life expectancy also varied considerably, both in the ages provided and in the degree of optimism conveyed. In addition, the pamphlets varied in the amount of information they provided about reproductive options following the diagnosis of a fetus with CF. Abortion was mentioned in just 15 pamphlets, more often in the United Kingdom than in the United States and more frequently in pamphlets from noncommercial than in those from commercial organizations. Wide variation in the descriptions of CF and the reproductive options presented raises concerns about the extent to which any one pamphlet may present balanced information. The choices about what information to include in educational materials need to be explicitly considered on the basis of the message intended to be sent.

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Introduction

Carrier testing for cystic fibrosis (CF) has been feasible since 1989 (Kerem et al. 1989). It has not been routinely implemented, however, in part because of concerns about the ability to provide, in a comprehensible manner, complex information to large populations (Workshop on Population Screening for the Cystic Fibrosis Gene 1990; Statement of The American Society of Human Genetics on Cystic Fibrosis Carrier Screening 1992). These concerns prompted calls for empirical research, which were met by the implementation of a number of studies in the United States and United Kingdom to determine the feasibility and acceptability of CF carrier testing (Wilfond and Nolan 1993).

Several of these studies found that both the perceived nature of the disease and attitudes toward termination played a primary role in whether the test was taken. For example, Loader et al. (1996) found that, in pregnant women who choose not to be tested, 32% said that it was because they would not consider terminating a pregnancy because of CF, whereas, in those who accepted testing, 28% stated that the reason was to avoid having a child with CF. Similarly, Clayton et al. (1996) found that, for 70% of individuals from a general population study, abortion would be an "important" or "very important" consideration in deciding whether to be tested.

Recently, the NIH Consensus Development Conference for Genetic Testing for Cystic Fibrosis reviewed the data from these studies and recommended that genetic testing for CF should include "balanced information to afford individuals the opportunity to make autonomous decisions" (Statement of the Consensus Development Conference on Genetic Testing for Cystic Fibrosis 1997, p. 25). The statement concluded that balanced information must contain descriptions of CF, including information on both the range of severity of the condition and improvements in survival rates for individuals with CF, as well as information about reproductive options, including adoption, use of artificial reproductive modalities, and continuation or termination of pregnancy. The statement's emphasis on informed, autonomous decision making is consistent with previous recommendations about the ethical use of genetic testing (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983; Andrews et al. 1994; Holtzman and Watson 1997).

Because all of the CF studies provided written information to facilitate informed decision making, the aim of the present study is to describe the amount and type of information provided to those undergoing testing, in order to determine the extent to which the information meets the criteria for balanced information that are set by the NIH Consensus Development Conference. Pamphlets from noncommercial (primarily research programs) and commercial organizations, aimed at prenatal and nonprenatal populations in the United States and in the United Kingdom, are described and compared, to assess their presentation of information about CF and reproductive options.

Material and Methods

Material

Twenty-eight pamphlets were collected (see Appendix). Twenty were associated with university programs or nonprofit organizations, and eight were from commercial laboratories. Nineteen were from the United States, and nine were from the United Kingdom. Because only pamphlets from noncommercial organizations were explicit about whether they were written for a prenatal or for a general population, only these were used to compare prenatal with nonprenatal pamphlets. Ten pamphlets were designed for prenatal populations, and 10 either were designed for a nonprenatal general population or were nonspecified.

Pamphlets were obtained by contacting the principal investigators of the CF projects that had published results or that had presented at national meetings. In the United States, pamphlets were received from eight of nine clinical studies. Additional U.S. pamphlets were obtained from two nonprofit organizations and from two university-affiliated clinical service programs of which the authors were aware. Commercial laboratory pamphlets were obtained from the seven laboratories with booths at the exhibit hall at The American Society of Human Genetics annual meetings in the years 1992–94. In the United Kingdom, pamphlets were obtained from all six of the studies conducted between 1992–1994, from the two university-affiliated clinical service programs, and from the main U.K. commercial laboratory offering CF testing.

Descriptions of CF

The content of the pamphlets was analyzed for statements that described clinical characteristics of CF, including the nature of the disease (e.g., that it is "serious"), its symptoms, treatment, what life is like for individuals with CF, and life expectancy for individuals with CF. Statements that described basic genetics and the chances of being a carrier or of having a child with CF were excluded.

Each sentence describing CF was then given a classification of positive, negative, or neutral. The categories of positive and negative were used to capture both the content of the sentence and the sentence's tone or "slant" and, hence, the message or image it conveyed (see table 1).

Sentences that were considered negative included those that focused on (1) the clinical complications of the disease, (2) the burden of caring for those with CF, (3) the shortened life span of those with CF, despite treatment, and (4) the reduction in the quality of life of an individual with CF. Sentences that were considered positive included those that focused on the facts that (1) treatment can help, (2) those with CF have the ability to participate in other important life activities, (3) life with CF is manageable, (4) life expectancy is improving, and (5) CF does not affect intelligence. We categorized as neutral those sentences that did not obviously qualify as positive or as negative.

Interrater reliability between two of the authors, in a sample of 200 sentences, was 81%. Any rating disagreement was discussed until mutually agreed on, and ultimately produced a consensus rating for each statement. Of the 38 disagreements in our sample of 200, 14 were disagreements between positive and neutral, of which 10 (71%) received a revised consensus rating of neutral and 4 (29%) received a revised rating of positive.

Table 1

Ratings of Sample Descriptive Statements about CF

Neutral	Positive	Negative
This lifelong illness usually gets more severe with age and can affect both males and females.	People are living longer than ever before as researchers are continuing to find new treatments.	If they live long enough, they will probably need a heart and lung transplant.
Lung infections are treated with antibiotics but after many years the infections may resist treatment.	People with CF may use inhalers that ease breathing, and have chest physical therapy at least once a day to help remove mucus from their lungs.	The sputum is so thick that the child cannot cough properly and develops lung infections which cause progressive lung damage.
Not all children are affected in the same way.	Children with CF attend regular schools, and can go to college, work and get married.	Medical bills and resentment from other children may cause stress or other worry.

Twenty-four were disagreements between negative and neutral, of which 17 (71%) received a revised consensus rating of neutral and 7 (29%) received a revised rating of negative.

Life Expectancy

Sentences that made reference to the life expectancy of an individual with CF were analyzed further. These included sentences about how long an individual with CF could expect to live and sentences that referred to changes in life expectancy. Given that a large number of these sentences were composed of more than one statement about life expectancy, the unit of analysis was any statement within any sentence that referred to current or future life expectancy. For each pamphlet, the number of life-expectancy statements was recorded, and each statement was further classified along three dimensions: (1) whether life expectancy was presented in terms of descriptive words or in terms of particular numbers; (2) of those statements using numbers, what ages were given; and (3) whether the description was presented in terms of death, survival, or expected life span. In addition, each pamphlet's life-expectancy statements were considered together, to determine whether there was a dominant tone or message of optimism/hope, pessimism/caution, or neither (see fig. 1).

Reproductive Options

Statements were included in this category if they mentioned any reproductive option after a positive test for either an individual carrier, a carrier couple, or an individual or couple whose fetus was affected. A list of the specific recommendations mentioned in each pamphlet, for each of these three groups, was compiled. Finally, for the group of recommendations made when the fetus is affected, if the option of abortion was mentioned, the words in which this option was expressed were noted.

Statistical Analysis

Nonparametric statistics were used because of the small sample size in this study. For descriptions of CF, comparisons between types of pamphlets were made on the basis of the median numbers of neutral, positive, and negative sentences they contained, by Mann-Whitney U-tests. To control for the number of statements in any one pamphlet, comparisons were also made on the basis of ratios of neutral, positive, and negative sentences to the total number of sentences contained in a pamphlet. For reproductive options, comparisons were made between types of pamphlets, by Fisher's exact test.

Results

Descriptions of CF

The 28 pamphlets contained 297 sentences describing CF, including 192 neutral, 57 positive, and 48 negative sentences. The median number of sentences was 6.5, with a range of 1–37. The numbers of neutral, positive, and negative sentences in each of the different types of pamphlets are provided in table 2, in the form of medians, of median ratios to the total number of sentences, and ranges.

Most of the sentences describing CF were categorized as neutral, whereas a small number of sentences were categorized as positive or negative. The numbers of pos-

Optimism/Hope

"It is impossible to know how long a person with CF will live. Advances in treatment have improved survival so that most people with CF born today will live into their 30s or longer."

"As a result, although some children will die at a young age, it is likely that many children with CF disease who are born today may live into their 40s or longer."

"In the past, people with CF died very young, but now many are living into their late 20s or 30s. The life span of children born with CF today is expected to be even longer."

Pessimism/Caution

"Even with improved care, only one-half of people with CF survive beyond 30 years of age."

"Lung congestion, pneumonia, diarrhea, and poor growth are all part of CF, and even with modern medical treatment the average life span is 25 years."

"While there has been much improvement in the care of children with CF, many of them still die in early childhood, and about half of all victims of CF die before they reach age 26."

Figure 1 Examples of messages conveyed by statements about life expectancy

Table 2

Descriptions of CF: Sentences Classified as Neutral, Positive, and Negative

Group and Classification	Median (Range)	Median Ratio to Total No. of Sentences (Range)
All pamphlets ($n = 28$):		
Neutral	5.0 (1–29)	.68 (.17–1.0)
Positive	.5 (0–8)	.05 (0–.63)
Negative	1.0 (0–6)	.17 (0–.60)
Total	6.5 (1–37)	
U.S. pamphlets ($n = 19$):		
Neutral	5.0 (1–29)	.67 (.17–1.0)
Positive	3.0[*] (1–8)	.07[*] (0–.63)
Negative	2.0 (0–6)	.18 (0–.60)
U.K. pamphlets ($n = 9$):		
Neutral	5.0 (2–8)	.80 (.4–1.0)
Positive	.0[*] (0–1)	.00[*] (0–.10)
Negative	1.0 (0–3)	.14 (0–.60)

[*] $P < .005$.

itive and neutral sentences were correlated with the total number of sentences describing CF (Spearman's $\rho = .85$ and .88, respectively; $P < .0001$). The number of negative sentences was not significantly associated with the total number of statements($\rho = .31$; $P = .053$). Median ratios were used to control for the contributing relationship between length of pamphlets and numbers of positive and neutral statements. Thus, for example, for the pamphlets as a whole, the median ratio of neutral statements to all sentences was .68 (i.e., 50% of the pamphlets have a ratio of neutral to all sentences that is <.68, and 50% have one that is higher, with a range of .17–1.0).

United States versus United Kingdom.—Pamphlets from the United States contained more positive sentences about CF than did those from the United Kingdom, both in absolute terms ($[Z] = -2.87$; $P < .005$) and relative to the number of total sentences in each pamphlet ($Z = -2.91$; $P < .005$). Pamphlets from the United States and United Kingdom did not differ in length or in numbers of neutral or negative sentences.

Commercial versus noncommercial.—No differences between the commercial and noncommercial pamphlets were observed. Since all but one of the U.K. pamphlets were noncommercial, however, the inclusion of the U.K. pamphlets may have minimized the differences. To address this, a similar comparison was done on the sample of U.S. pamphlets only. As shown in table 3, those from U.S. noncommercial organizations were longer than those from U.S. commercial organizations ($Z = -2.37$; $P < .025$) and also contained more positive sentences about CF, both in absolute terms ($Z = -2.63$; $P < .01$) and relative to the total number of sentences in the pamphlet ($Z = -2.36$; $P < .025$). Pamphlets from noncommercial organizations also contained more neutral sentences ($Z = -2.04$; $P < .05$); however, this difference did not persist when median ratios were used to control for length. ($Z = -.30$; $P = .76$). There were no other differences observed.

Prenatal versus nonprenatal.—Table 4 shows that, among the noncommercial pamphlets, those aimed at prenatal populations contained fewer positive sentences about CF than were contained in those aimed at nonpregnant populations ($Z = -2.15$; $P < .05$). No other differences between them were observed.

Life Expectancy

There were 49 statements about life expectancy, in 27 pamphlets. Twenty-two of these were in the form of words (e.g., "some patients die early in childhood"); the rest provided an age or age range (e.g., "people with CF generally live for 25 to 30 years"). The ages used to describe life expectancy ranged from >28 years ($n = 9$) to $\geqslant 40$ ($n = 4$), with seven pamphlets using an age range of 28–29 and seven using an age range of 30–39. These statements were variously presented, in terms of death ($n = 17$), survival ($n = 19$), and life span or life expectancy ($n = 13$).

The pamphlets varied in the messages conveyed within statements about life expectancy, even when using similar ages (see fig. 1). Some conveyed an image of a brighter future for people with CF ($n = 7$), whereas others presented an image of a shortened life span in spite of treatment advances ($n = 13$). The remaining pam-

Table 3

Descriptions of CF in Commercial and Noncommercial Pamphlets: Sentences Classified as Neutral, Positive, and Negative

Pamphlet Type and Classification	Median (Range)	Median Ratio to Total No. of Sentences (Range)
Commercial ($n = 8$):		
Neutral	3.0[***] (1–7)	.67 (.36–1.0)
Positive	.0 (0–5)	.00 (0–.46)
Negative	1.0 (0–3)	.22 (0–.60)
Noncommercial ($n = 20$):		
Neutral	6.0[***] (1–29)	.71 (.17–1.0)
Positive	1.5 (0–8)	.15 (0–.63)
Negative	1.5 (0–6)	.22 (0–.60)
U.S. commercial ($n = 7$):		
Neutral	2.0[**] (1–7)	.67 (.36–1.0)
Positive	.0[*] (0–5)	.0[**] (0–.46)
Negative	1.0 (0–3)	.25 (0–.6)
U.S. noncommercial ($n = 12$):		
Neutral	9.0[**] (1–29)	.60 (.17–1.0)
Positive	4.5[*] (0–8)	.23[**] (0–.63)
Negative	2.5 (0–6)	.15 (0–.50)

[*] $P < .01$.

[**] $P < .025$.

[***] $P < .05$.

Table 4

Descriptions of CF in Prenatal and Nonprenatal Pamphlets: Sentences Classified as Neutral, Positive, and Negative

Classification	Median (Range)	Median Ratio to Total no. of Sentences (Range)
Prenatal (n = 10):		
Neutral	4.5 (1–15)	.71 (.17–1.00)
Positive	.5* (0–3)	.05 (0–.33)
Negative	2.0 (0–3)	.15 (0–.60)
Nonprenatal (n = 10):		
Neutral	7.0 (2–29)	.62 (.35–.86)
Positive	5.0* (0–8)	.23 (0–.63)
Negative	1.0 (0–6)	.18 (0–.50)

* $P < .05$.

phlets (n = 8) presented life-expectancy information without such images, using phrases such us "the average life span of a person with CF is approximately 26 years." There was no observable pattern between these images and the various categories of the pamphlets.

Reproductive Options

The frequencies with which different options were presented in the pamphlets are shown in table 5. When one person was found to be a carrier, the most common option described was for the individual's partner to be tested (14/28). If both partners were found to be carriers, the majority of pamphlets mentioned the option of prenatal testing (24/28). Fifteen mentioned the possibility of abortion if a fetus was identified as having CF. Six different terms or expressions were used to refer to abortion: "termination" (n = 8), "abortion" (n = 2), "whether to continue the pregnancy" (n = 2), "choose not to continue with the pregnancy" (n = 1), "end the pregnancy" (n = 1), and "stop the pregnancy" (n = 1).

United States versus United Kingdom.—Abortion was mentioned more often in pamphlets from the United Kingdom (8/9; $P < .025$) than in the pamphlets from the United States (7/19). There were no other differences between these two sets of pamphlets, in the presentation of reproductive options.

Commercial versus noncommercial.—Abortion and continuing with an affected pregnancy were mentioned more often in noncommercial (15/20 and 9/20, respectively) than in commercial pamphlets, in which neither were ever mentioned ($P < .0005$ and $P < .05$, respectively). Among the U.S. pamphlets, abortion was more frequently mentioned in the noncommercial (7/12) than in the commercial (0/7) ones ($P < .05$).

Prenatal versus nonprenatal.—There were no differences between pamphlets aimed at prenatal populations and those aimed at general populations in the presentation of reproductive options.

Discussion

Among pamphlets there was wide variation in the amount and type of information provided about CF. Much of this variation was in the presentation of positive information, which was less frequent in pamphlets from the United Kingdom than in those from the United States, less frequent in pamphlets from U.S. commercial laboratories than in those from U.S. noncommercial laboratories, and less frequent in those used in prenatal than in those used in nonprenatal programs. Information provided about life expectancy also varied, in the ages used and, even when similar ages were used, in the general message conveyed. Statements about life expectancy seem to reflect two different views of CF. Some emphasized that, in spite of treatment, life expectancy is still reduced, whereas others focused on the fact that life expectancy is increasing and that the potential exists for new treatments to extend life expectancy even further.

There are several possible explanations for the variations among pamphlets. The difference, in positive statements, between pamphlets from the United States and from the United Kingdom may reflect different social attitudes toward disability or the differential influence of the disabilities rights movement. The less positive in-

Table 5

Frequency of Reproductive Options Presented in CF Pamphlets

Situation and Option	Frequency
One carrier:	
Test partner	14
Genetic counseling	11
Test relatives	4
Talk with physician	2
Share information with relatives	1
No further testing	1
Obtain more information	1
Carrier couple:	
Prenatal testing	24
Genetic counseling	17
Adoption	2
Gamete donation	2
Have no more children	2
Do not change plans	2
Test child after birth	2
Prepare for child	1
Talk with CF specialist	1
Talk with physician	1
Make decisions about having children (nonspecific)	1
Affected fetus:	
Abortion	15
Continue with pregnancy	9
Early treatment	6
Prepare emotionally	4
Genetic counseling	2

formation in some pamphlets may reflect the pamphlet authors' experience with people with CF or with parents raising a child with CF. For some, this experience may be limited to an inpatient setting and may not include exposure to the 65% of individuals with CF who do not require hospitalization in a given year (Cystic Fibrosis Foundation 1997). Other pamphlet authors may have a more negative impression of CF because their experience is dated and because they are not familiar with the impact of recent improvements. Finally, the profit motive may also have some influence. Because commercial organizations earn more when rates of CF testing are higher, it is plausible that they may minimize positive descriptions of CF.

Differences in the descriptions of CF may also be related to different beliefs about the appropriateness of abortion of fetuses with CF. Although the NIH Consensus Development Conference emphasized that the goal of providing testing is to allow informed decision making, there may be an underlying assumption that people would or should consider terminating a pregnancy when the fetus has CF. In this light, the smaller number of positive statements about CF, in programs designed for prenatal diagnosis, may suggest that those who develop such programs are more likely to believe that the abortion of fetuses with CF is appropriate.

In general, it is striking that only half of the pamphlets mentioned abortion. That abortion was more likely to be mentioned in U.K. pamphlets perhaps reflects the fact that abortion is less culturally divisive in the United Kingdom than in the United States. It is also interesting that none of the commercial pamphlets from the United States, which, in terms of providing limited positive information about CF, were similar to the U.K. pamphlets, mentioned abortion. Given the volatile nature of the abortion debate, particularly in the United States, it is possible that the commercial laboratories were concerned that an explicit discussion might reduce the rate of CF testing and/or harm their public image. Apprehension about abortion is perhaps reflected in the fact, that, although the term "abortion" is commonly used in public media, such as newspapers and telephone directories, only two pamphlets used the term.

The content and style of a pamphlet can send specific messages about the severity of CF and about the appropriateness of abortion. Such messages may affect readers' perceptions of the disease, and, subsequently, their decisions about testing. Although many of the CF testing studies assessed peoples' comprehension of information, only a few looked specifically at individuals' understanding of the life expectancy of persons with CF (Clayton et al. 1995; Bernhardt et al. 1996; Grody et al. 1997), and none explicitly assessed either pamphlet readers' understanding of reproductive options available to couples with an affected fetus or what life is like for an affected individual. As a result, it is difficult to assess how well people understood these issues. Data from other studies show that the type of information and the form in which it is presented affect both peoples' perceptions of a disease and their subsequent decisions (McNeil et al. 1982; Figueiras et al., in press). It is, therefore, possible that differences in these pamphlets could result in different decisions. Variation among the pamphlets, then, may be one reason for the difference in the rate of CF carrier testing, which has been documented across different studies (Marteau and Croyle 1998).

Structural factors in the design of screening programs also can influence decision making. For example, Tambor et al. (1994) found that neither the perceived severity of CF nor the likelihood of abortion was associated with a testing decision, in an HMO population. In the study, the decision to be tested was influenced by whether the test could be provided on the same day (23.5% vs. 3.7%). In addition, Bekker et al. (1993) demonstrated that 70% of people agreed to be tested when a health professional explained and offered the test on the same day, but that <10% agreed when they were sent a letter explaining the test and then were asked to schedule a separate appointment. Further research is needed to determine how decision making is affected by the relationship between information provided and the method by which testing is offered.

There are some limitations to the current study. The collection of pamphlets was intended to be inclusive and representative; however, there may have been other pamphlets, not available to the authors, that might have altered the results. We obtained virtually every pamphlet associated either with a clinical research program or with those commercial programs that provided information at national meetings, but there may have been additional material, from other nonprofit clinical service programs, that was not obtained. Recently, Cho et al. (1997) reviewed the written material from 179 pamphlets obtained from a U.S. survey of biotechnology companies and nonprofit organizations (Holtzman and Hilgarnter 1997). Twenty of these were specifically about CF, which suggests that there are additional U.S. pamphlets that were not part of our sample. Thus, our category of noncommercial organizations is most representative of research programs.

Our sample size limits our ability to detect differences, betwen the various categories of pamphlets, in the statements about life expectancy. For example, we were not able to detect differences between the pamphlet categories, in the tone of the statements about life expectancy.

Another potential shortcoming of our study is that the designations of descriptive sentences as positive, neutral, or negative were developed for the current study. Satisfactory interrater reliability suggests that we were consistent in our approach. In addition, although our sample size was small, our ability to identify significant differences demonstrates the magnitude of the differences among pamphlets.

In the absence of research documenting how variations in information affect decision making, judgments will need to be made, by those running CF carrier–testing programs, about how best to present information about CF. What constitutes *balanced* information? There are two possibilities, given the rating system used in this study. One is a pamphlet that uses only neutral statements. Another possibility is a pamphlet containing some relatively equitable proportion of positive and negative statements alongside its neutral ones. There is no a priori answer to how the term "balanced" should be understood. We advocate the latter type of pamphlet because we believe that presenting a broad range of information—some positive, some negative, some neutral—is more consistent with the goal of facilitating autonomous decision making, because it helps individuals to relate their values, in a meaningful way, to the options presented.

Because most of the variation found in this study was in the provision of positive statements, we suggest that pamphlets should include sufficient positive statements to achieve balance with the neutral and negative ones. We are using "balanced" not in a strictly quantitative sense but, instead, to describe a *qualitative* breadth in the tone of information provided. This sense of balance captures an important aspect of the relationship between the provision of information and autonomous decision making.

The results of the present study lead to some preliminary conclusions. First, the wide variability of information about CF and reproductive options suggests that current pamphlets do not seem to meet the NIH recommendation for balanced information to afford individuals the opportunity to make autonomous decisions. Second, researchers must consider the role that written material may play in affecting the results obtained from screening programs for CF. Third, additional research is needed to delineate more fully the impact that information has on decisions. Fourth, in the absence of these data, those preparing educational material should appreciate that they are making choices about what information to exclude, what information to include, and the message conveyed.

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Appendix

Table A1

Pamphlet Characteristics

Pamphlet Type and Institution	Reference(s)
U.S. noncommercial:	
Baylor University	
Johns Hopkins University	Tambor et al. (1994), Bernhardt et al. (1996)
Macro International	
Michigan State University	
National Society of Genetic Counselors	
Vanderbilt University	Clayton et al. (1995, 1996)
University of North Carolina	Sorenson et al. (1997)
U.S. noncommercial (prenatal):	
Foundation for Blood Research	Doherty et al. (1996)
Kaiser Permanente	Witt et al. (1996)
UCLA	Grody et al. (1997)
University of Pennsylvania	
University of Rochester	Loader et al. (1996)
U.S. commercial:	
Collaborative Research	
Genetics and IVF Institute	
Integrated Genetics	
MediGene	
Nichols Institute	
SmithKline Beecham	
Vivigen	
U.K. noncommercial:	
Guy's Hospital, London	Bekker et al. (1993, 1994), Axworthy et al. (1996)
St. Mary's Hospital, London	Watson et al. (1992)
University of Wales	Payne et al. (1997)
U.K. noncommercial (prenatal):	
University of Aberdeen	Miedzybrodzka et al. (1995*a*, 1995*b*)
University of Edinburgh	Mennie et al. (1992, 1993*a*, 1993*b*)
University of Leeds	
St. Bartholomew's, London	
Wolfson Foundation Genetic Centre, Manchester	Harris et al. (1993)
U. K. commercial:	
University Diagnostics Limited	

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