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> Michael Hoel Departement of Economics

Tor Iversen Centre for Health Administration

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Michael Hoel and Tor Iversen**

Health Economics Research Programme at the University of Oslo HERO 1999

** Health Economics Research Programme,

Center for Health Administration, University of Oslo, Rikshospitalet, The National Hospital,

N - 0027 Oslo, Norway. Telephone: 47 22868750, Fax: 47 22362562

e-mail: michael.hoel@econ.uio.no

tor.iversen@samfunnsmed.uio.no

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Abstract

Privacy of information is a central concern in the debate about genetic testing. Two types of social inefficiencies may occur when information about prevention and test status is private; genetic testing may not be done when it is socially efficient and genetic testing may be done although it is socially inefficient. The first type of inefficiency is shown to be likely for consumers with public insurance only, while the second type of inefficiency is likely for those with a mix of public/private insurance. This second type of inefficiency is shown to be more important the less effective prevention is.

1. Introduction

During the next few years genetic tests are likely to be introduced for many diseases. The tests will be able to distinguish between high risk and low risk individuals at an asymptomatic stage of disease. Presently, around fifteen to twenty tests are offered, including tests for Huntington's disease and cystic fibrosis. Recently two important breast cancer genes (BRCA1 and BRCA2) have been identified. The Food and Drug Administration in the United States recently approved a gene-based test that may help to predict the recurrence of breast cancer. The number of tests is expected to increase rapidly in a few years, in parallel to the mapping of the human genes. For instance, tests for genes that imply an elevated risk of several types of cancer, cardiovascular diseases and Alzheimer disease are already available or are expected to be available in the near future.

The information from gene based tests may be important for initiating measures for postponement and prevention of disease. Genetic tests are also expected to have an important impact on the organization of health systems and, in particular, health insurance. There is a concern that insurers can make use of information to deny coverage for individuals with an increased risk of disease or require them to pay prohibitively high insurance premiums. Regulation of the access to and the use of information from genetic testing is therefore an important health policy issue in many countries. In Norway, the law on the application of biotechnology prohibits requests for information on individuals that stems from genetic tests. It is also prohibited to ask whether a genetic test has been done. In the US a majority of the states have banned the use of genetic information by insurers. The Congress in 1996 passed legislation that forbids group health organizations from denying coverage on the basis of genetic information. Efforts are also made to extend the prohibition to all health insurers and ban insurers from raising premiums based on genetic data (Schwartz, 1998). In this paper we study how the demand for genetic testing is likely to be influenced by the regulation of information insurers have access to. The insurance system considered is a mix of public compulsory insurance and private supplementary insurance. Specially, we are interested in to what extent possible inefficiencies depend on the mix of compulsory and voluntary insurance in a system of health insurance. Two types of inefficiencies may occur. Firstly, tests may not be undertaken when testing is socially efficient in the sense that testing implies a pareto-improvement. Secondly, tests may be undertaken when testing is socially inefficient. We show that the first type of inefficiency is likely for systems with a high proportion of compulsory public insurance while the second type of inefficiency is likely for systems with substantial private supplementary insurance.

Section 2 introduces the basic insurance model. In section 3 the genetic test option is introduced and the full information case is established as a benchmark. Section 4 assumes that costs of prevention are private information and the institutional constraint that insurers have no access to genetic information is imposed. In the concluding remarks in section 5 we suggest that an inefficiently high level of testing is likely to occur in the coming years, since genetic therapy is likely to lag behind the development of genetic diagnostics, and hence, limit the scope for effective prevention.

2. The basic insurance model

Individuals are assumed to differ along two dimensions: The risk of having a disease in the future, and the loss of income, ℓ , if disease strikes. These two characteristics are assumed to be unrelated.

The level of risk is assumed to be related to genetic disorders that may be revealed by means of genetic testing. Individuals belonging to group H have a risk, p_H , while individuals in group L have the risk, p_L , where $0 < p_L < p_H < 1$. The proportion of low risk individuals in the population is θ_L and the proportion of high risks is θ_H , where $0 < \theta_L, \theta_H < 1$ and $\theta_L + \theta_H = 1$. θ_L and θ_H are assumed to be common knowledge.

All individuals are assumed to have the same exogenously determined income, w, as sick. The loss of income related to disease differs between individuals because their income or productivity as healthy is assumed to differ. The higher the productivity as healthy, the greater is the loss of income, ℓ , as sick. As mentioned above, the distribution of ℓ is the same in the group H as it is in the group L.

By means of insurance, income can be transferred from the healthy state to the state of poor health. In this specific context insurance can be thought of as covering the costs of medical treatment necessary to (partly or fully) compensate the loss of income due to illness.

There are two types of insurance; compulsory public insurance and voluntary private insurance. An important distinction is whether private insurance is considered to be a supplement or an alternative to public insurance. A few examples may clarify the distinction. A person with symptoms of disease and with public coverage is likely to make use of the public insurance in the first contact with a physician. The visit may result in diagnosis and treatment or a referral to a specialist for further diagnostics and treatment. A referral may be accompanied by a waiting time before a specialist can be seen. The waiting time may be shortened by means of privately funded provision of health services. A privately funded specialist is then an alternative to a publicly funded. Once a diagnosis

is made, treatment may or may not be provided by the public sector. For instance, expensive treatment may be rationed and some patients with treatment indications may be turned down. The private sector may then be a supplement for those patients experiencing rationing in the public sector. Also, a waiting time for publicly funded treatment may occur. The waiting list may be bypassed by means of privately funded treatment. In this case private care is an alternative to the publicly funded care. Hence, we see that some parts of privately funded health services may be considered as an alternative to publicly funded services, while others may be considered as a supplement. For instance, Besley, Hall and Preston (1998) consider UK private health insurance to be somewhere between the two stylised alternatives.

In this paper we consider private health insurance as a supplement to compulsory public insurance. Compulsory public insurance is assumed to cover a portion $x \le \ell$ of the loss, where x is assumed to be exogenous and equal for all¹. Hence, the higher the productivity as healthy, the lower is the proportion of the loss covered by public insurance. The loss from poor health is in the analysis restricted to the loss of income. Good health obviously has a value in itself, but this component is not drawn into the analysis at the present stage.

Insurers are assumed to break even. In a competitive insurance market where insurers are risk neutral expected profit maximisers, expected profits will be driven to zero. If the insurer is the public sector or a private non-profit institution, the zero expected profit is imposed as an institutional constraint or by the implication of political decisions. Furthermore, we ignore administrative costs. Full insurance can then be offered at actuarially fair rates.

¹ It is assumed that the lowest ℓ -value in the distribution is equal to or larger than x. Nothing of importance would be changed if we instead had assumed that some ℓ -values were lower than x, and that the public insurance for these cases covered the whole loss ℓ .

The premium paid for public insurance is assumed to be independent of individual risk. Each individual is assumed to pay an equal premium, with a calculated risk equal to the average population risk, $p_{HL} = \theta_H p_H + \theta_L p_L$, and a premium equal to $p_{HL}x$.

Voluntary private insurance covers loss in excess of x at an actuarially fair premium rate.

A private insurance policy, $c(p_t, k)$, is characterised by the probability of disease, p_t , that determines the premium as a proportion of the covered loss, and the proportion of the loss, $k \in [0,1]$, that is covered. Consumers are assumed to choose the policy that maximises their expected utility, given the public coverage. The expected utility of an insurance policy for a person with probability of disease equal to p, is:

$$v[(c(p_t,k), p] = (1-p)u(w - p_{HL}x - p_t k(\ell - x) + \ell) + p u(w - p_{HL}x - p_t k(\ell - x) + x + k(\ell - x))$$

where $u(w - p_{HL}x - p_t k(\ell - x) + \ell)$ is the utility as healthy and $u(w - p_{HL}x - p_t k(\ell - x) + x + k(\ell - x))$ is the utility when unhealthy. We assume risk aversion, implying that the marginal utility of wealth is declining with the amount of wealth. Hence, $u(\cdot)$ is strictly concave.

We shall assume that prior to the introduction of genetic testing, nobody knows his true risk type. Hence, initially, as uninformed, the whole population is assumed to have an identical perception of their own risk equal to a weighted average of the actual risk of the two groups; $p_{HL} = \theta_H p_H + \theta_L p_L$. Hence, the premium rate for private insurance is equal to the premium rate for public insurance.

FIGURE 1

In figure 1, income in the unhealthy state is measured along the horizontal axis and income in the healthy state along the vertical axis. Full insurance coverage, i.e. an equal income in both states, is illustrated with the 45-degree line from the origin. The vertical line through E shows the range of incomes in the healthy and the unhealthy state for a person with public insurance only and

alternative values of the loss, ℓ . A person with an income point located at the intersection between this vertical line and the 45-degree line from the origin has a loss as sick that gives full coverage from the public insurance, $\ell = x$. Those with incomes in the healthy state above the 45- degree line from the origin after public insurance is accounted for (ℓ -x>0), say point E in figure 1, are not fully covered by public insurance. EA shows all combinations of income in the two states compatible with actuarially fair insurance for the low risk group, and EB similarly for the high risk group. EB is steeper than EA because the high risk group must forego more income than the low risk group in the healthy state to have one dollar in the unhealthy state because of the higher risk of ending in the unhealthy state. EC describes feasible combinations of income in the two states when both groups pay an equal premium calculated on basis of the weighted average risk of the population, p_{HL}. Risk averse uninformed consumers prefer full insurance when premiums are actuarially fair. Since no one is assumed to know his risk type prior to genetic testing, p_{HL}, corresponds to the apparently actuarial fair premium rate. Hence, C describes the optimal income in the two states with compulsory insurance and supplementary private insurance for a person located at point E with public insurance only.

3. Test status, test result and prevention as public information

The purpose of genetic testing is to discover disease in an asymptomatic stage, in order to take preventive measures to reduce the probability of contracting the disease. Whether prevention is available and likely to be demanded, is therefore an important factor in determining the demand for predictive testing. Two cost components may be involved in prevention. The first component is the costs of providing professional medical care. To simplify the exposition, we shall set these costs equal to zero and comment on the influence of this assumption in the concluding remarks. The second cost component is personal costs related to preventive measures. These costs are of two kinds. The first kind is costs related to activities that can easily be observed, for instance travelling and absence from work to attend disease prevention programmes. The other kind of personal costs is unobservable for others than the person who carries the costs. Examples are time used in preparation of a special diet and pain and discomfort experienced from preventive measures as healthy diet and physical exercise.

Assume that effective prevention exists. If sp_H is the probability of having the disease in spite of prevention, effective prevention requires s<1. With all information public, an individual insurance contract can be made contingent upon both test status and upon whether prevention is undertaken. With prevention, the initial point for the high risk group moves from E to E^{\prime} in figure 2, because individual costs of prevention accrues ex ante and hence, diminish income in both states.

FIGURE 2

To simplify the exposition we assume that test costs equal zero. Assume further that testing is socially efficient, which means that expected income with test and prevention is greater than expected income without test and prevention, i.e. that $-(sp_h\ell+\gamma)>-p_h\ell$, where the monetary equivalent of personal costs of prevention is denoted by γ . This condition may be rewritten as $(1-s)p_h\ell>\gamma$, i.e. that testing is socially efficient if the increase in expected income due to testing is larger than the monetary equivalent of personal costs of prevention. We further assume that the effect of prevention is less favourable than bringing a high-risk person to same risk level as a low risk person, i.e. $p_L < sp_H < p_H$. Taken together with the condition for socially efficient testing, we then

have $\frac{p_L}{p_H} < s < 1 - \frac{\gamma}{p_H \ell}$.

FIGURE 2

Figure 2 illustrates efficient testing. The line E'F shows the collection of actuarially fair insurance contracts for a high-risk person who has taken preventive measures. We see that the line E'F intersects the 45-degree line for a higher income than the line EB. Hence, the certainty equivalent income with prevention is higher than without. The line E'F is however steeper than the line EA, that shows the insurance terms for a low risk person.

Private supplementary insurance with full coverage can be offered for all alternative probabilities of disease. $c(p_{HL},1)$ (point C in figure 2) is offered if a person chooses to stay uninformed , $c(p_H,1)$ (point B) if a positive test shows up and no prevention is undertaken, $c(sp_H,1)$ (point F) if positive test and prevention and $c(p_L,1)$ (point A) if a negative test occurs.

An individual will choose to acquire information from testing if the expected utility with test is greater or equal than the expected utility as uninformed². If a positive test turns out, we see from figure 2 that the individually optimal choice for a person with supplementary insurance is to undertake prevention. Hence, the optimal choice for an individual corresponds to social efficiency. The existence of risk aversion may still imply that a person chooses to stay uninformed. To undertake the test is for an individual a lottery. One may win and go to A or lose and go to F, while one without the test obtains C. Testing is less likely to be chosen the larger s is and the larger γ is, since the loss that comes from a positive test is then larger. Likewise, testing is less likely to be chosen the more risk averse a person is.

 $^{^{2}}$ Our approach is in the same vein as Doherty and Thistle (1996), but our institutional set-up is somewhat richer since we allow for prevention and a mix of private and public insurance.

Compulsory insurance offers full coverage independent of test status and prevention. The premium reduction from prevention is divided equally among all n individuals. For large n an individual's share in the premium reduction is negligible. Prevention will then not be undertaken if $\gamma > 0$, although prevention may be socially efficient.

In the full information case the government can encourage socially efficient testing and prevention by compensating individuals for personal costs. A person with only public insurance is indifferent between staying uninformed and undertaking testing and prevention when³:

$$u(w - p_{HL}x + \ell) = \theta_L u(w - p_{HL}x + \ell) + \theta_H u(w - p_{HL}x + \ell - \gamma + r)$$

where the premium reduction is assumed to be negligible and r is the compensation for undertaking prevention. We see that indifference is fulfilled for $r = \gamma$. Problems in practice are likely to arise since individual variation in γ is likely to occur.

For a person with mixed public and private insurance the public compensation must fulfil (see footnote 3):

$$u(w - p_{HL}\ell + \ell) = \theta_L u(w - p_{HL}x - p_L(\ell - x) + \ell) + \theta_H u(w - p_{HL}x - sp_H(\ell - x) + \ell - \gamma + r)$$

For this case we cannot unambiguously sign r- γ . To see that r> γ is possible, consider the case in which s is marginally below 1 and γ is zero. In this case testing is socially efficient. However, with strong risk aversion it is individually optimal to choose not to be tested if r=0, since the gain in expected income (due to s<1) will be dominated by the fact that testing is a type of lottery. Thus, in order to induce testing one must have r>0, i.e. r> γ .

³ Utility is the same whether healthy or sick in the present case of full information. when comparing the consequences of testing or not, it is therefore sufficient to consider the healthy state of the two cases.

To see that $r < \gamma$ is possible, consider the limiting case of risk neutrality. In this case the equation above implies

$$w - p_{HL}\ell + \ell = \theta_L(w - p_{HL}x - p_L(\ell - x) + \ell) + \theta_H(w - p_{HL}x - sp_H(\ell - x) + \ell - \gamma + r)$$

 $\gamma - r = (1 - s) p_H (\ell - x) > 0$

Using $\theta_H + \theta_L = 1$ and $p_{HL} = \theta_H p_H + \theta_L p_L$ we can rewrite this as

which proves that $r < \gamma$ for this case.

The full information case is considered as a benchmark for the further analysis where private information is assumed either because of characteristics of the preventive activities or because of regulation imposed on the insurance market.

4. Test status, test result and prevention as private information

In this case the prevention an individual undertakes is assumed to be his private information. Accordingly, also the personal cost of prevention is private information. Hence, an insurance contract cannot be made contingent on whether prevention is undertaken. We also impose the institutional constraint that insurers have no access to information about whether a person is tested. Since those tested then cannot be distinguished from those not tested, insurance contracts can neither be contingent on whether a person is tested nor the test result.

FIGURE 3

Assume that effective prevention exists, and hence, s<1. Let us first study the optimal decisions for the group with private supplementary insurance. Assume that insurers expect consumers to be informed of whether they are H (high-risk) or L (low-risk). With prevention the initial point for the high-risk group moves from E to E' because of individual costs of prevention. The indifference curve for group H (high-risk without prevention), I_{H} - I_{H} in figure 3, is steeper than the indifference curve for group SH (high-risk with prevention), I_{sH}-I_{sH}, because the probability of illness is smaller with prevention than without, and hence, with prevention the consumer is willing to forgo less income in the healthy state to obtain a marginal dollar in the unhealthy state. The best coverage that can be offered at actuarially fair terms for the high risk group with prevention c(sp_H, k'), with k'<1 is illustrated by D['] in figure 3. Here the incentive constraint $v[c(sp_H, k'), sp_H] = v[c(sp_H, k'), p_H]$ is fulfilled. Any better coverage would make it beneficial not to prevent and choose the contract made for those who prevent, i.e. $v[c(sp_H, k^*), sp_H] < v[c(sp_H, k^*), p_H]$ for $k^* > k'$. The second contract in the menu is characterized by the intersection, shown by the point A', between I_{sH} - I_{sH} and the line EA describing the collection of actuarially fair contracts for the low risk group. Denote this contract $c(p_1, k'')$, where 0 < k'' < k' < 1. The incentive constraints $v[c(p_{SH}, k'), sp_H] = v[c(p_L, k''), sp_H]$ and $v[c(p_{SH}, k'), p_L] < v[c(p_L, k''), p_L]$ is then fulfilled. Any better coverage for the low risks will encourage the sH group to pretend they are low risks. Consumers who are uninformed, will purchase $c(sp_H, k')$ or $c(p_L, k'')$.

In an appendix we show that a consumer's best choice is to acquire information through testing and do prevention if the test result turns out to be positive. The intuitive reason is this:

Assume that I choose $c(sp_H, k')$ as uninformed. With the information acquired through testing, I shall know whether I am a low risk or a high-risk individual. If it turns out that I have low risk, I

can choose a better contract than $c(sp_H, k')$, namely $c(p_L, k'')$. If it turns out that I am high risk, I can do equally well as I could as uninformed by means of prevention. We therefore have an equilibrium (a Nash equilibrium) where the insurer's expectations of testing is fulfilled, with all the low risks located in A['] and all high risks (all high risks choose prevention) in D[']. A similar reasoning applies if $c(p_L, k'')$ is chosen as uninformed.

Doherty and Thistle (1996) show that if the insurer does not expect consumers to be tested, no equilibrium exists. Doherty and Thistle do not consider the availability of preventive measures. Since availability of prevention makes testing more attractive, their result also applies to the present model.

Compared to the full information contract there is a social loss since the insurance coverage for both groups declines. If there are not too many high-risk individuals in the population, even the low-risk group is worse off because the loss from less insurance coverage outweighs the gain from fewer subsidies to the high-risk group.

Even without effective prevention (s=1) the optimal choice for the mixed public/private insured group is to choose genetic testing. Hence, genetic testing will be chosen also when it is socially inefficient.

The premium for the group with compulsory public insurance is assumed to be independent of their individual risk. This means that the self-selection mechanism used by the private insurer is not applicable to the public insurer. Hence, when preventive costs are private information, socially efficient testing is not likely to be undertaken by those with public insurance only when personal costs of prevention occur.

5. Concluding remarks

In the health policy debate about genetic testing the privacy of information is a central concern. In this paper we have discussed the impact on genetic testing of regulating insurers' access to genetic information. The insurance system considered is a mix of public compulsory insurance and private supplementary insurance.

Two types of social inefficiencies may occur when information about prevention and test status is private; genetic testing may not be done when it is socially efficient and genetic testing may be done although it is socially inefficient. The first type of inefficiency is shown to be likely for those publicly insured, while the second type of inefficiency is likely for those with a mix of public/private insurance. Hence, regulations imposed to protecting individuals from insurers' use of genetic information, may have the side effect that genetic tests are done in a larger scale than is socially efficient.

This second type of inefficiency is likely to be more important the less effective prevention is. Genetic tests are likely to be offered before effective treatment of genetic disorders are available (see for instance, Schwartz, 1998). The potential social inefficiency attached to this uneven development of technologies is likely to be more prevalent the less compulsory insurance that a system contains.

Tabarrok (1994) has argued that the potentially negative effects of predictive testing on insurance coverage and income distribution could be avoided by introducing compulsory insurance against the

financial consequences of becoming high risk when a person decides to be tested, i.e. genetic insurance. It is claimed that this suggestion would make the implementation of socially beneficial testing more likely. A crucial question, then, is whether the uninformed consumers who buy insurance against the loss of being identified as high risk are, in fact, uninformed. With the introduction of inexpensive tests that are easy to administer, it is likely that a proportion of those who present themselves as uninformed are in fact informed high-risk individuals who have already been tested. An adverse selection problem is then likely to occur.

One solution to the problem of adverse selection mentioned above could be to have compulsory insurance against the financial consequences of a test result for *all* people, whether they decide to test themselves or not. A compulsory insurance of this type could be practically organised as follows. The basic rules for income taxation could be combined with rules for tax reductions (according to a publicly known set of standards) that are given to persons who can document that they are of high-risk types. Such tax reductions according to criteria beyond the control of the individual are often used, e.g. for old or disability in Norway. A tax system of this kind would to a large extent eliminate the distributional reasons often given for why one might wish to regulate the insurance companies' access to and the use of information from genetic testing to differentiate insurance contracts across risk groups.

This paper contains assumptions that should be modified and explored in future research. We assumed that private insurance is a supplement to compulsory insurance. It should be studied whether it makes any difference for our conclusions if private insurance is assumed as an alternative. We also considered the level of public insurance as exogenously determined. An interesting extension would be to allow for an interaction between the level of private insurance and public insurance. For instance, the decision to buy private insurance may have an impact on the

level of public insurance a consumer prefers and hence, his voting behaviour.

We also assumed that all consumers consider their health risk to be average prior to genetic testing. As mentioned above in connection with the possibility of insurance against the financial consequences of testing, this is not quite realistic. For instance, family history may be used to distinguish between high risk and low risk individuals. An important modification is then to allow for that consumers have some information of their risk type ex ante.

Finally, we assumed no preferences for good health, per se. The motivation for good health was confined to preferences for income. The consequences of including health as a separate argument in the utility function should be explored in future work.

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Appendix:

Derivation of consumer's best choice with test status, test result and prevention as private information

The consumer's choice is among the two alternatives staying uninformed with insurance contract c'_L or c'_{SH} or do testing and prevention and choose the contract contingent on the test result. Let I be the difference between the expected utility of doing the test and the expected utility of being uninformed and assume first that the individual chooses c'_{SH} as uninformed:

$$\begin{split} I &= \{\theta_{H}v(c_{SH}^{'}, p_{SH}) + \theta_{L}v(c_{L}^{'}, p_{L})\} - v(c_{SH}^{'}, p_{U}) \\ &= \theta_{H}\{p_{SH}u(w - p_{HL}x - p_{SH}\beta' - \rho' - \gamma) + (1 - p_{SH})u(w - p_{HL}x - p_{SH}\beta')\} \\ &+ \theta_{L}\{p_{L}u(w - p_{HL}x - p_{L}\beta'' - \rho'' - \gamma) + (1 - p_{L})u(w - p_{HL}x - p_{L}\beta'')\} \\ &- (\theta_{H}p_{H} + \theta_{L}p_{L})u(w - p_{HL}x - p_{SH}\beta' - \rho') \\ &- (1 - \theta_{H}p_{H} + \theta_{L}p_{L})u(w - p_{HL}x - p_{SH}\beta') \\ &= \theta_{H}\{p_{SH}u(w - p_{HL}x - p_{SH}\beta' - \rho' - \gamma) + (1 - p_{SH})u(w - p_{HL}x - p_{SH}\beta')\} \\ &+ \theta_{L}\{p_{L}u(w - p_{HL}x - p_{L}\beta' - \rho'' - \gamma) + (1 - p_{L})u(w - p_{HL}x - p_{SH}\beta')\} \\ &- \theta_{H}\{p_{H}u(w - p_{HL}x - p_{SH}\beta' - \rho') + (1 - p_{H})u(w - p_{HL}x - p_{SH}\beta')\} \\ &- \theta_{L}\{p_{L}u(w - p_{HL}x - p_{SH}\beta' - \rho') + (1 - p_{L})u(w - p_{HL}x - p_{SH}\beta')\} \\ &- u(w - p_{HL}x - p_{SH}\beta' - \rho') + (1 - p_{L})u(w - p_{HL}x - p_{SH}\beta')\} \\ &- u(w - p_{HL}x - p_{SH}\beta') + (\theta_{H} + \theta_{L})u(w - p_{HL}x - p_{SH}\beta') \\ &= \theta_{H}\{v(c_{SH}^{'}, p_{SH}) - v(c_{SH}^{'}, p_{H})\} + \theta_{L}\{v(c_{L}^{'}, p_{L}) - v(c_{SH}^{'}, p_{L})\} > 0 \end{split}$$

 β ' is the insured loss in contract c'_{SH}. β " is the insured loss in contract c'_L ρ ' is the uninsured loss in contract c'_{SH}. ρ " is the uninsured loss in contract c'_L

By similar reasoning it may be shown that I>0 also if the consumer chooses c'_L as uninformed.