

Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001a. letter	From: Hillary Rodham Clinton, To: Mrs. & Mr. Schaus (1 page)	3/17/94	b(6)
001b. letter	From: Kathy & Andy Schaus, To: Mrs. Clinton (4 pages)	3/3/94	b(6)
001c. note	Daily log for First Lady from MCA, Correspondence (1 page)	3/4/94	b(6)

COLLECTION:

Clinton Presidential Records
First Lady's Office
Pam Cicetti
OA/Box Number: 13598

FOLDER TITLE:

HRC Health Care Correspondence 94 - S

2014-0159-S

sb292

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

Freedom of Information Act - [5 U.S.C. 552(b)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

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PERSONAL
&
~~CONFIDENTIAL~~

DETERMINED TO BE AN
ADMINISTRATIVE MARKING
INITIALS: ~~ABS~~ DATE: 12-5-13

PHOTOCOPY
PRESERVATION

PERSONAL
&
~~CONFIDENTIAL~~

SUSAN M. SANTA CRUZ, M.D.
Internal Medicine
Evergreen Place, Suite 125
1100 N. University
Little Rock, AR 72207
Telephone 501-664-1540

(1) Use attached for R
re breast cancer
(2) file

DETERMINED TO BE AN
ADMINISTRATIVE MARKING
INITIALS: LOB DATE: 12-5-13

January 18, 1994

Mrs. Hillary Clinton
The White House
1600 Pennsylvania Avenue
Washington DC 20500-2000

Dear Hillary:

I am enclosing a copy of a recent editorial on mammographic screening from the Journal of the American Medical Association. The same January 12, 1994 issue contained the change in the National Cancer Institute recommendations regarding mammogram screening in women under the age of 50. I thought that this editorial was a fairly concise statement of the issues with support from the authors of the position taken by the NCI. Although you and I will all too soon be reaching the age of 50, for now it appears that the best course may be to hold off on mammogram screening. It may be most appropriate to have a breast ultra sound done if there are palpable nodules at the time of your future breast exams. Mammograms would always be appropriate if there are areas of particular concern.

Please let me know if you have any questions concerning this recommendation.

Sincerely,

Susan

Susan M. Santa Cruz, M.D.

SMS/nlb

within the membership of the American Society of Addiction Medicine and the American Academy of Psychiatrists in Alcoholism and the Addictions, and specialized nurses, counselors, and social workers may also have much to teach us. Generalists can spend time with such experts to learn management principles and can then serve as resources within their own facilities. The Oath of Hippocrates states that "into whatever houses I shall enter, I will go into them for the benefit of the sick . . ."³⁰ In the case of IDUs, we rarely enter their "houses"—certainly not the shooting gallery and not even the drug treatment facility—and we do not allow them to easily enter ours. We can learn to treat IDUs in whichever houses they, or we, may enter.

Alan A. Wartenberg, MD

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Mammographic Screening

Since 1987, the United States has stood alone among major developed countries in having encouraged asymptomatic women under 50 years of age to undergo screening mammography, although US mortality rates for women these ages continue to mirror those of other Western countries.¹ Recent reports in *JAMA* and elsewhere compel a reexamination of this policy.

Diagnostic mammographic evaluation is indicated at any age if a woman has a lump or other signs of disease. In contrast to diagnostic assessments, screening mammography is a routine measure seeking to detect latent disease in asymptomatic women, in order to provide treatment, which may increase the likelihood of a cure.²

A recent meta-analysis of all relevant studies ever conducted on screening mammography of asymptomatic women confirmed a clear benefit—a 30% reduction in deaths for women over 50 years of age who were screened every year or two. It found, however, "no basis for the promotion of mammographic screening in women under age 50 in the general population."³ Kerlikowske et al⁴ provide an important new contribution to this subject in a recent issue of *JAMA* with their carefully conducted study of the positive predictive value of screening mammography in 31 814 women referred to the University of California San Francisco Mobile Mammography Screening Program from 1985 to 1992. They found that "women younger than 50 years will have approximately 2.5 times as many biopsies and three times as many diagnostic procedures for every cancer diagnosed compared with women aged 50 years or older," yet fewer than 20% of all cancers occur in the younger age group. An international workshop on this subject in February 1993 indicated that for every 1000 women under 50 years of age screened with mammography in a decade, 700 would require some sort of diagnostic

From the Office of the Assistant Secretary for Health, Department of Health and Human Services, Washington, DC (Dr Davis) and the UCLA Breast Center, Los Angeles, Calif (Dr Love).

Reprint requests to the Office of the Assistant Secretary for Health, Department of Health and Human Services, 200 Independence Ave SW, Washington, DC 20201 (Dr Davis).

procedure to detect fewer than 15 tumors, and seven tumors would be missed entirely.⁵

Screening mammography cannot prevent breast cancer, but it can detect some small tumors early when they are more amenable to treatment and cure in women over 50 years of age. Despite the strong evidence that the number of deaths from breast cancer in women over 50 years of age can be reduced by 30% through regular mammography, women in this group have not been receiving the lifesaving test; thus, in 1990, 40% of women over 50 years of age had never had a mammogram.^{6,7} Over the past two decades at Harlem Hospital Center, New York, NY, one study found that half of all breast cancer cases were incurable on admission, and only 5% were in stage I.⁸

An especially disappointing finding of the study by Kerlikowske et al⁴ was the fact that the proportion of women over 50 years of age seeking mammograms fell between 1985 and 1992 from about 47% to 33%, while it rose for those under 50 years from 53% to 67%, and for those under 40 years from 22% to 29%. The Centers for Disease Control and Prevention report similar trends, with older women with lower levels of education having the lowest rate of mammography screening.⁷

The two biggest risk factors for breast cancer remain sex and age, with nearly 85% of cases occurring in women over 50 years of age. Growing concerns about the rising incidence of breast cancer have fueled screening programs worldwide. Mammography is a major enterprise, involving widespread public efforts including posters, brochures, print and television specials, and public service ads in English and Spanish urging every woman to have a mammogram "once a year for the rest of your life." Despite the fact that the United States has had excess capacity since 1990,⁹ firms continue to sell equipment for use in physicians' offices.

As to the current state of mammography, it is important to consider the newness of the venture. The American Board of Radiology included a section on mammography only in the past three examinations. Last year, Congress passed the National Mammography Standards Quality Assurance Act in response to reports that more than half of the current facilities and technologists failed to meet minimal quality assurance standards. In many southern states, fewer than 30% of all radiology centers currently comply with the American College of Radiology guidelines for safety and effectiveness.¹⁰ A reevaluation of first screening films in one urban practice found that "imaginomas" or ghost images accounted for more than half of those recommended for biopsy (oral communication, Gillian Newstead, MD, director of Breast Imaging, New York University Medical Center, August 6, 1993). In addition, mammography in women younger than 50 years is not without risk. This risk includes the economic and social cost of the procedure, the health hazards linked with radiation exposure begun at a younger age (one cancer induced per 25 000 mammograms), and the considerable human and economic toll of unnecessary diagnostic procedures; overall, about one of 10 biopsies recommended on the basis of mammography will be cancerous.¹¹

Despite efforts to improve current imaging technologies, imaging just may not be the best screening approach in young women because of the density of their breast tissue. A non-invasive biochemical test of blood or urine that pinpoints early markers or risk factors for breast cancer might prove to be a better population screening tool for younger women, with imaging technologies used only to locate occult cancers.

The public policy dilemma posed by these findings for women and their health providers in the United States today is profound. Chalmers¹² has reminded us that "if our society had been oriented towards finding out whether new technology is efficacious as soon as possible after its introduction there would not be much left to debate more than 30 years [later] . . ." ¹² But wistful wishing cannot alter the fact that mammographic screening in women under 50 years of age does not reduce deaths, while for those over the age of 50 years it saves lives. The reasons for these results are unknown and need to be resolved through additional clinical studies that assess the importance of menopausal status and other factors, including breast tissue change with age. In the meantime, women must be told the truth, so that they can make informed choices about their health care. And efforts must proceed apace to develop better techniques to detect early breast cancer in asymptomatic younger women, to ensure that all women over 50 years of age are provided access to the lifesaving benefit of screening mammography, and to identify avoidable causes of this major cancer.¹³

Devra Lee Davis, PhD, MPH
Susan M. Love, MD

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THE WHITE HOUSE

WASHINGTON

December 16, 1994

Mrs. Gillian Shaw
Down Lisburn Health
and Social Services Trust
Lisburn Health Centre
Linenhall Street
Lisburn, Co.
Antrim, BT28 1LU.

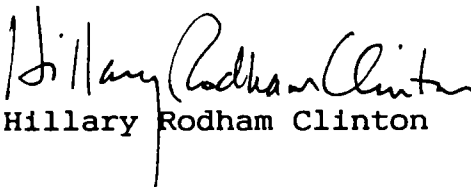
Dear Mrs. Shaw:

Thank you for sending the fascinating report on "Integrated Health and Social Care" from the Down Lisburn Health and Social Services Trust and for your invitation to observe the health care system in Northern Ireland. Studying aspects of other countries' health care systems has been a vital part of our reform efforts. Northern Ireland has a tremendous amount to offer as one of the most integrated and comprehensive models in Europe.

Too many Americans cannot get high quality, affordable health care. At the same time, skyrocketing costs continue to imperil our nation's economic future. Our physicians, nurses and hospitals are among the world's finest, but this is little comfort to the nearly 40 million Americans -- including close to 10 million children -- who have no health insurance and to the millions more who are in danger of losing their coverage.

Although the President and I are disappointed that Congress was unable to pass health care legislation this session, we are pleased that we put health care reform on the national agenda and began a thoughtful discussion about how to change our health care system. We look forward to continuing to fight for meaningful health care reform.

Sincerely yours,


Hillary Rodham Clinton

cc: Ms. Marguerite Perrone

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June 22, 1994

Mrs. Hillary Rodham Clinton
The White House
1600 Pennsylvania Avenue
Washington DC 20500

Dear Mrs. Clinton:

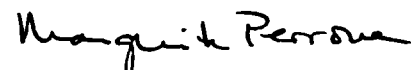
To add to your collection of information on innovative health care programs I enclose a report, "Integrated Health and Social Care" from the Down Lisburn Health and Social Services Trust in Northern Ireland.

The Chairman of the Trust, Mrs. Gillian Shaw, accompanied her husband, Norman Shaw on his Eisenhower Fellowship visit to the United States in 1989, and the Shaws have remained in touch with EEF ever since. When Mrs. Shaw wrote me about this new system of integrated care centered on general practitioners, I was intrigued, and wrote back that our Health Care Task Force ought to see it.

Since the first copy she sent me, with the enclosed letter to you, was incomplete, there has been a delay in forwarding letter and report to you.

I hope that the Irish system will interest some of your colleagues who are grappling with our complex and difficult health care problems. We are grateful to you and all of them for your magnificent efforts.

Sincerely,


Marguerite Perrone
Secretary to the Fellows

* EXECUTIVE COMMITTEE
** CHAIRMAN, EXECUTIVE COMMITTEE

Our Ref: GS/DJF

April 14th, 1994

Mrs Hillary Clinton
First Lady
White House
1600 Pennsylvania Avenue
Washington DC
USA
20500

Dear Mrs. Clinton

I enclose a copy of '*Integrated Health and Social Care in Down Lisburn Trust*', which I hope may be useful to you in your current re-organisation of the Health Service in the United States.

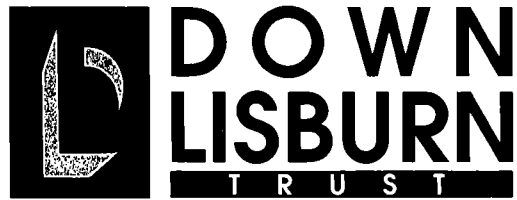
In Northern Ireland, Health and Social Services have been integrated for over 20 years. In the last 5 years in Counties Antrim and Down, we have built on this integration. We have developed a model of unified Primary Health and Social Care Services around General Medical Practitioner practices. Social workers, nurses and paramedics work from or close to the General Medical Practitioner base to provide care packages tailored to suit individual needs. Down Lisburn Trust came into being on April 1st, and we are proud of the way in which our system is being held up as a model of good practice by the purchasing agencies. If we can be of any help to you, we should be very pleased to do so. If you would care to visit us at any stage to see our work in practice, you would be most welcome.

Yours faithfully
Gillian Shaw

MRS G SHAW
Chairman

Enclosure:

1. Paper: '*Integrated Health and Social Care in Down Lisburn Trust*'.



Lifelong Health & Care

Integrated Health and Social Care

in

Down Lisburn Trust

Northern Ireland

INTEGRATED HEALTH AND SOCIAL CARE IN DOWN LISBURN TRUST, NORTHERN IRELAND

SUMMARY

1. This Paper describes the provision of Health and Personal Social Services in Northern Ireland which has one of the most integrated and comprehensive models in Europe. It focuses on arrangements in one area, Down Lisburn, which itself is believed to have the most highly integrated services in the United Kingdom.

PURPOSE AND OVERVIEW

2. Within Down Lisburn a radical reorganisation of health and social care has been transforming what had been traditional institutional and specialist dominated services into a single primary care led care network. The General Practitioner practice has become the keystone around which the service is built.
3. In Northern Ireland people value and trust their General Practitioner. They know that he or she makes a long term commitment to work in a community and is a professional who can, over time, be relied upon to singlemindedly pursue their interests. The General Practitioner brings to his assessment of the patient's care needs a knowledge of each individual in the context of his or her family and community.
4. Government reforms, recognising the potential of primary care to create a patient centred health service, have encouraged General Practitioners to take control of the funds available for the purchase of secondary and tertiary health care for their patients. This has given the opportunity for primary care to become the driving force in health care, ensuring that as much health care as possible can be provided for patients where, and in way which they choose.
5. To support and further such change Down Lisburn has, in each natural community, devolved its budget for primary health care and for social care to a locally based manager. She is free, in partnership with the General Practitioners, to use these funds to create a seamless response to the full range of health and social need, guided by the preferences of local people.
6. What has been created in each community is, in effect, a mini health service, a microcosm of the National Health Service, across surgery, medicine and social care. Patients can now, at one point, within fifteen minutes of their home, access a team which can mobilise services to meet 95% of their health and social care needs in their local community. Primary care is being empowered and supported to provide as much of the patient's care as possible. On the infrequent occasions when care has to be accessed outside the local community primary care at all times remains in control, directing the entire care response.

7. The benefits of the model are considerable.

- Resources are better used as people receive increasing amounts of their care through the primary care network and do not move on unnecessarily to specialised, complex and expensive services at more expensive locations.
- People with considerable levels of need feel able to choose care where they say they want it, at home in their community, in the knowledge that they can rely on a co-ordinated package of care tailored to meet their needs.
- Specialist services can be reserved for and concentrated on those who have the greatest, most complex needs.
- Duplication of effort is avoided through single point co-ordination of care delivered by or through a tight-knit multi-skilled professional team.
- General Practitioners and professionals believe that the changes are beneficial facilitating good professional practice and better outcomes.

BACKGROUND

8. Health Care arrangements in Northern Ireland share many similarities with those in England, Scotland and Wales. Features common with England, Scotland and Wales include:

- Being centred on Community based family General Practitioners with whom all residents register.
- Free patient choice of General Practitioner and freedom to change General Practitioner.
- Access to specialist health services through General Practitioner.
- Services generally free to patients at the point of delivery.
- Almost 100% of residents choosing to use the Health Service for Primary Care and over 90% for specialist services.

9. Unlike England, Scotland and Wales, in Northern Ireland Health and Personal Social Services have been integrated since 1973. It is therefore not purely a health care system but is also charged with meeting the social care needs of mentally and physically ill, frail and disabled people and of children. It should be emphasised that these responsibilities **do not** include income maintenance or Social Security.

OVERALL STRUCTURE

10. On behalf of Government and the Minister of Health a section of the Northern Ireland Civil Service, the Health and Personal Social Services Management Executive, determines overall priorities and policy and disperses funds to four Area Health and Social Services Boards. Each is a purchasing agency responsible for commissioning and contracting for services to meet the needs of its resident population. It is expected to be guided by the advice and preferences of family General Practitioners in placing contracts.
11. Some purchasing is delegated to those family General Practitioners who opt to hold their own budgets with which to buy the greater part of acute hospital care and some community health care services on the basis of their knowledge of patient preference, quality and value for money.
12. Area Health and Social Services Boards and family General Practitioners buy most services from Health and Personal Social Services Trusts. Trusts are similar in concept to those in England, Scotland and Wales but those which provide community services have a broader remit including social care. They are statutory non-profit making agencies within the Health Service which have business-model management boards. Trusts may be:
 - Specialist Acute Hospitals, or
 - Providers of community health and social care services, or
 - A combination of small local hospitals, psychiatric hospitals and community health and social care services

While Trusts have developed different organisational models in all cases the delivery of services is organised on a multi-disciplinary basis.

13. Although Community Trusts have nominal geographic boundaries within which they provide services to their resident population, Area Health and Social Services Boards and General Practitioners have the freedom to place contracts for community services with other Trusts if they believe that by so doing they will obtain better quality or value services for patients and clients.

DOWN LISBURN TRUST

14. Down Lisburn is an integrated Health and Personal Social Services Trust in the Eastern Health and Social Services Board's area. It provides around 95% of the Health and Social Care Services for its resident population including:
- Secondary, but not tertiary, acute care through two small local hospitals.
 - Acute and community mental health services through a psychiatric hospital and community health and social care professionals and facilities.
 - Primary health care services as required by General Practitioners.
 - Providing and sub-contracting for social care services to meet the needs of people who are elderly, mentally ill, disabled or who have a learning disability/mental handicap.
 - Child Protection, Prevention and Adoption Services.
15. Down Lisburn Trust's area is a microcosm of Northern Ireland. It includes 160,000 people, over 10% of the population, and is diverse in socio-economic and cultural terms. Its communities range from urban to rural, affluent to multiply deprived and British to Irish in orientation.

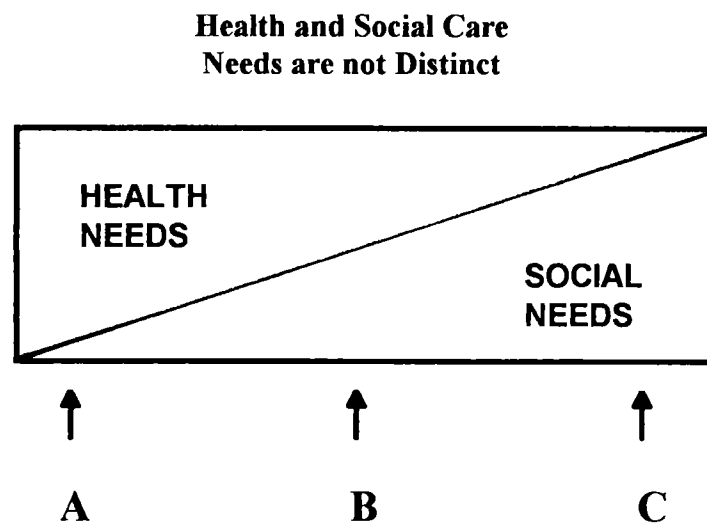
PHILOSOPHY OF CARE

16. During the past four years Down Lisburn has reviewed its services and has embarked on major redesign based on an analysis of the needs and preferences of service users and advice from General Practitioners, professionals and managers. Reform is most marked in primary care where three principles have guided the redesign.
17. **Services should be planned, organised and provided as locally as possible to people's homes**
- Consultation with parents and clients indicated that they wanted to be recognised as part of a family and a local community and that they preferred most of their health and social care services to be provided in or as close to their homes as possible.
18. This led to the conclusion that the staff who manage and provide care should be locally based to ensure that they understand the needs and preferences of each natural community. A consequent knowledge of and identification with the communities they serve would help to ensure the responsiveness and commitment which is valued by those who use services. They would also be well placed to enlist the voluntary support of families, neighbours and community groups which can enrich the quality and effectiveness of care.

19. **The Primary Care Team should have the skills to meet the fullest possible range of its clients' needs.**

An analysis of the needs which people have for primary health care services and primary social care services indicates that neither needs nor the services which meet these can be easily separated.

Diagram 1



Some people, as represented by "A" in Diagram 1 may have only a health care need which may be met fully by health care services. For example, a person may require nail surgery which could be undertaken by a Chiropodist, therapy by a Physiotherapist, an inoculation by a Nurse, or referral to a hospital by a General Practitioner. Similarly others whose needs are represented by "C" on the Diagram might require only social care services - a Divorce Court welfare report, or a child-minder or marital counselling by a Social Worker. Many of those who have the greatest health and social needs and who are the greatest and most frequent users of services require both health and social care services simultaneously, however. An example, represented by "B" on the Diagram, is an elderly person aged over 75 who is screened annually by General Practitioner and Nurse, who requires regular services from a District Nurse for leg ulcers and a Chiropodist for foot care and who requires a Home Help, day care and periodic respite residential care arranged by the Social Worker or Care Manager. Such clients generally have changing needs and consequently, over time, require a changing combination of services.

20. Consultation with service users indicated that they prefer the full range of services which they require to be interconnected, with a single point of entry and, on the occasions when their need for service requires them to move away from home, with a seamless movement from, and back to, their local provision.

21. It was concluded that the integration of the core Primary Health Care Team which supported General Practitioners, and the Social Care Team, which provided services to elderly people and those who are ill, could create a team better able to meet the needs of those with dual or complex needs. In particular the high volume/low cost services could best be provided on a local integrated team basis.
22. It was recognised that highly specialised, high cost, low volume social care services within, for example, sensory handicap, would benefit from a concentration of resources which could not be achieved if they were fully devolved to Primary Health and Social Care Teams. Other services could not be fully integrated because of the need for strong, single profession accountability, such as social work in Child Protection. Special consideration also needed to be given to services where the main focus was not Primary Health and Social Care but where links with other agencies were as or more important, for example, learning disability/mental handicap services which are closely allied to education and the world of work and day activities. Where services were not to be fully integrated in Primary Care teams it was judged important they should, as far as possible, be coterminous to encourage close co-operation with the Primary Care network.
23. **Primary Health and Social Care services should be based around General Practitioner practices.**

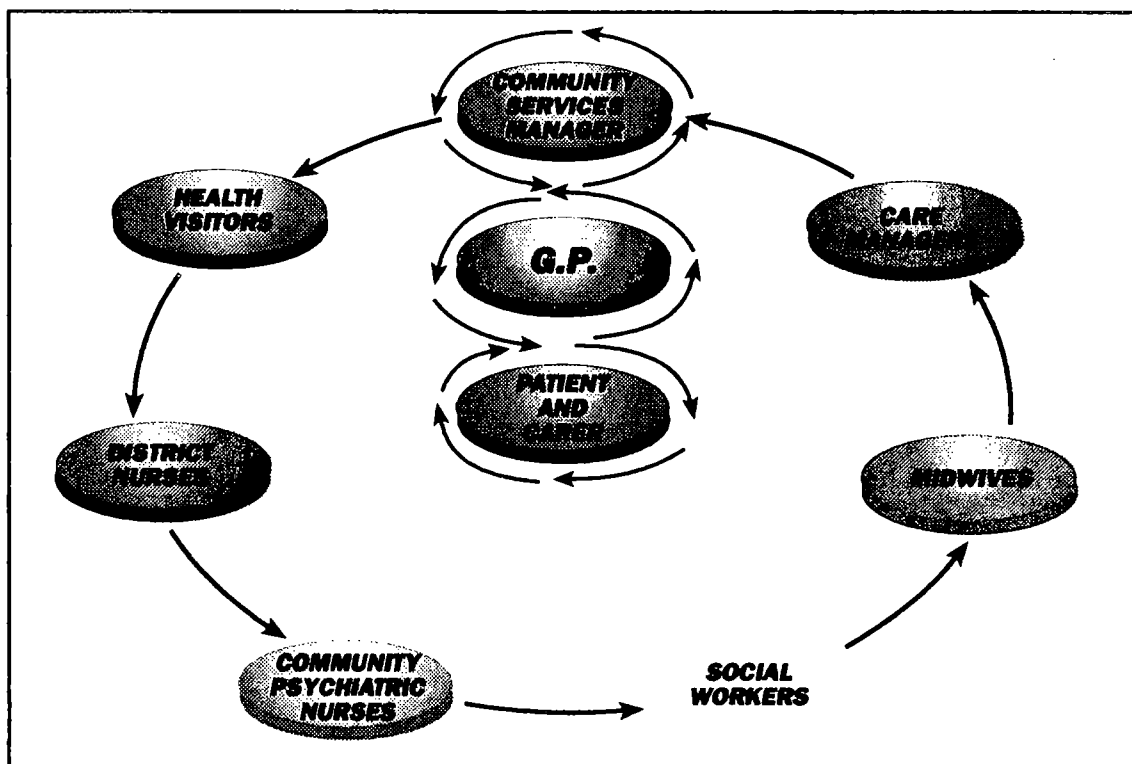
In the Northern Ireland model the General Practitioner is the first point of entry to nearly all Health Care services but is also the professional to whom many people turn when seeking Social Care services. This is particularly the case with elderly people and those who are ill. The General Practitioner is well placed to identify a wide range of needs and initiates directly, or through other Primary Health Care professionals, referrals for Social Care assessment and services. Patients rarely change General Practitioners, and most General Practitioners spend the major part of their working career in one practice. There are also family traditions of registering with one practice, often maintained when people move outside the immediate area. The General Practitioner, therefore, over time, builds up a knowledge of the patient not only medically, but also as an individual in the context of his or her nuclear family and often indeed in the context of the extended family. Consequently he or she is well placed to understand the social circumstances, the stresses to which the patient is subject and the supports available. The patient in return often perceives the General Practitioner as the professional who will single-mindedly look after his needs, who knows him or her as an individual and who will arrange the necessary services.

24. It was therefore concluded that Primary Care services would be based on General Practitioner practices and their lists of patients. The core group of Primary Care staff would be practice attached to ensure that they were a consistent team who worked with the same defined group of service users over time.

THE ATTACHED INTEGRATED TEAM

25. Having identified the three principles Down Lisburn defined "Primary Care" as including both Primary Health Care services and Social Care services for elderly and ill people. The model developed for the provision of Primary Care services was the "attached integrated team".

Diagram 2



The Attached Integrated Team comprises the Health and Social Care staff who work with the doctors in a General Practitioner practice:

- It is the smallest possible number of professionals who can meet the needs of the patients registered with the practice.
- It is made up of Community Nurses, Social Workers or Social Care Managers,

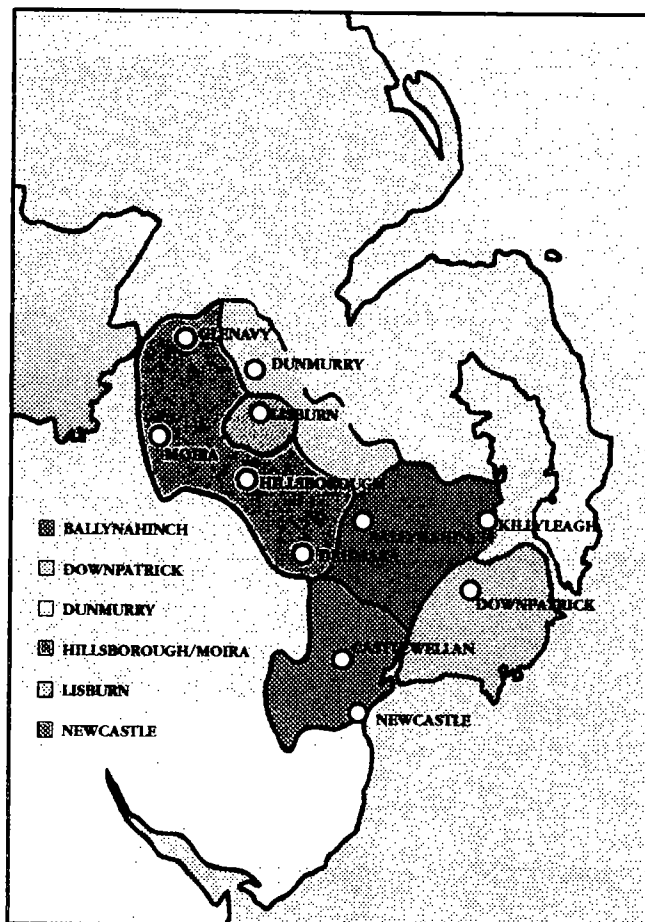
Community Midwives and Treatment Room Nurses.

- The more specialist staff, such as the Midwife, whose caseload in any one practice may not be sufficient can be members of more than one team.
- Where possible the team is located in a shared team room. If this cannot be achieved the team is based in the same area of the building.
- The team has a single manager who may be a professionally qualified nurse or social worker.

MANAGEMENT ARRANGEMENTS

26. In light of the principle that the integrated, General Practitioner attached teams should be not only locally based but locally managed and that services should be planned locally, the teams were grouped by natural community. Six natural communities were identified. These ranged in population from 16,000 to 42,000 patients on the lists of between ten and thirty-nine General Practitioners. In most of the natural communities these General Practitioners work as four or five group teams.

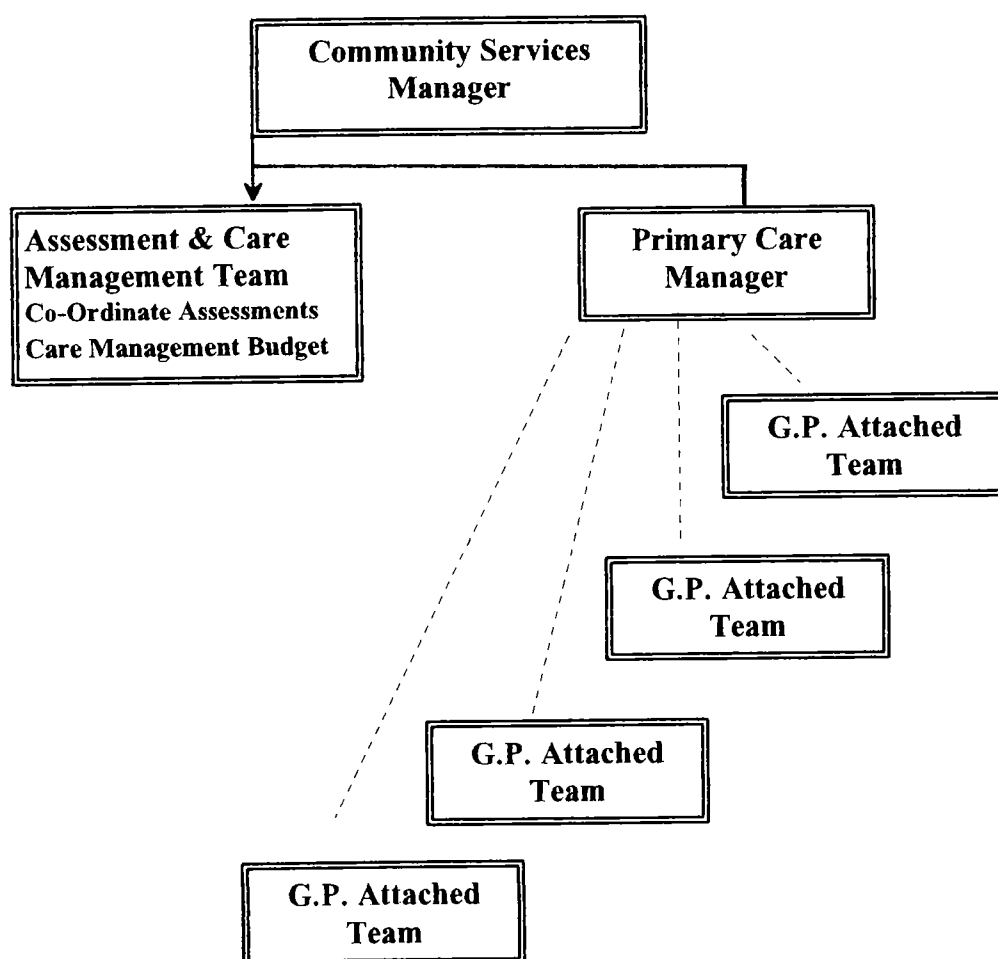
Diagram 3



27. In each community a Community Services Manager has overall managerial responsibility for the Primary Health and Social Care service. She is either a qualified Nurse or a qualified Social Worker. She is assisted by a managerial colleague from the other profession. There is therefore for each community a management team of Social Worker and Nurse equipped to ensure that professional standards are maintained and that consultancy is available for professional staff.
28. The Community Services Managers' managerial colleague, the Primary Care Manager, is operationally responsible for the management of the General Practitioner attached Primary Care Teams.

Diagram 4

Community Management Arrangements



29. The Community Services Manager is responsible for the budget for "Community Care" for the people of the Community. This is available to purchase care for those elderly people who have been assessed as having a need for intensive care in either a nursing home or residential care home. The Community Services Manager is charged with arranging for the needs of elderly people to be assessed and then using these funds to allow as many people as possible, in consultation with their carers, to instead exercise the choice of care in their own home through an intensive input of domiciliary services as an alternative to a nursing or residential care home placement. In the event of a choice of domiciliary care being made, the Community Services Manager will ensure that an individually designed package of Nursing, Health and Social Care services is designed to meet the assessed needs and preferences of clients and their carers.
30. She provides these services through an Assessment and Care Management Team which she manages. Its members share office bases, and where possible a room, with the General Practitioner attached Primary Care Team with which they are integrated.
31. In line with the Trust's philosophy that the wishes of each community should be respected the Community Services Manager has a high degree of autonomy in how she organises her Team and in how she uses resources. She is expected to do so in consultation with General Practitioners and to respond to the preferences of clients and patients.

32. The Community Services Manager and the General Practitioner comprise a potent partnership, the General Practitioner leading the health care response to needs and the Community Services Manager co-ordinating social care. Together they can direct their resources in a manner which efficiently and effectively meets their patients' needs in a holistic way.
33. In using resources to best effect they are not constrained by any artificial demarcation between health and social care. In the majority of cases the packages of care provided for people with high levels of need include both health care and social care services.

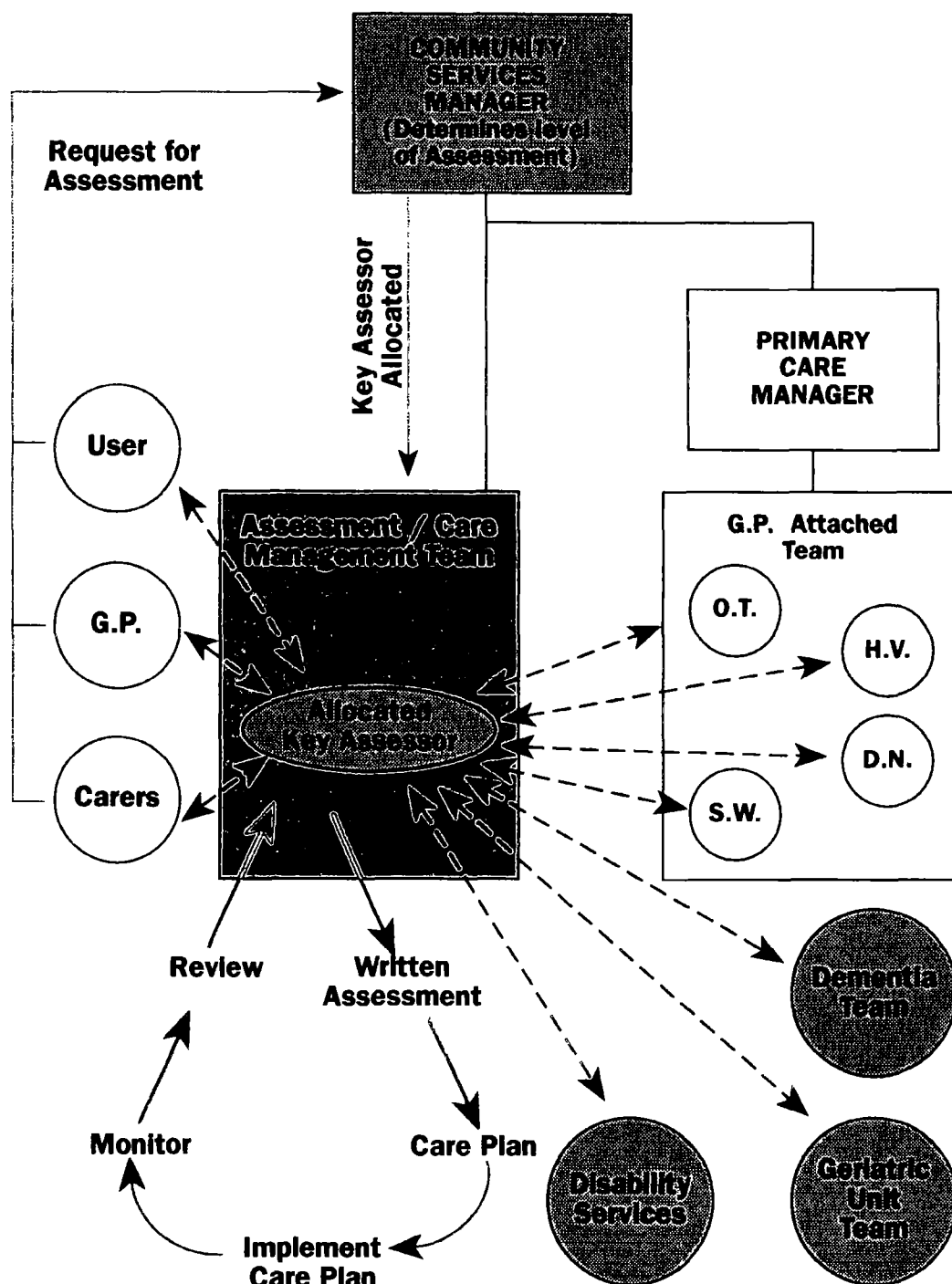
COMMUNITY CARE ASSESSMENT AND CARE MANAGEMENT SYSTEM

34. As illustrated in Diagram 5 on receipt of a referral the Community Services Manager determines eligibility for assessment, the level of assessment required and allocates the case to the appropriate practitioner as Key Assessor.
35. The allocated Key Assessor is usually a Care Manager from the Assessment and Care Management Team but can be from the General Practitioner attached Primary Care Team if a member of that team is best equipped by expertise or experience to undertake or co-ordinate the assessment.
36. The allocated Key Assessor/Care Manager asks the client, carer, the General Practitioner and those members of the Primary Care Team who have appropriate knowledge or expertise to contribute to the assessment.
37. The consultant led Geriatric and Dementia Teams based at, and outreaching from, the local hospitals play a central role in comprehensive assessments of frail elderly people and those suffering from dementia.
38. If the assessment concludes that the client has needs which require residential, nursing home or intensive domiciliary care services the Care Manager draws up a Care Plan on the basis of which he or she purchases services from the Unit or from the independent sector. The choice of service is, as far as possible, based on the client's and carer's preferences.
39. The Care Manager keeps the client's needs under regular review, arranging re-assessment and a revised Care Plan as necessary.

Community Care Assessment and Care Management System

Diagram 5

Assessment Model

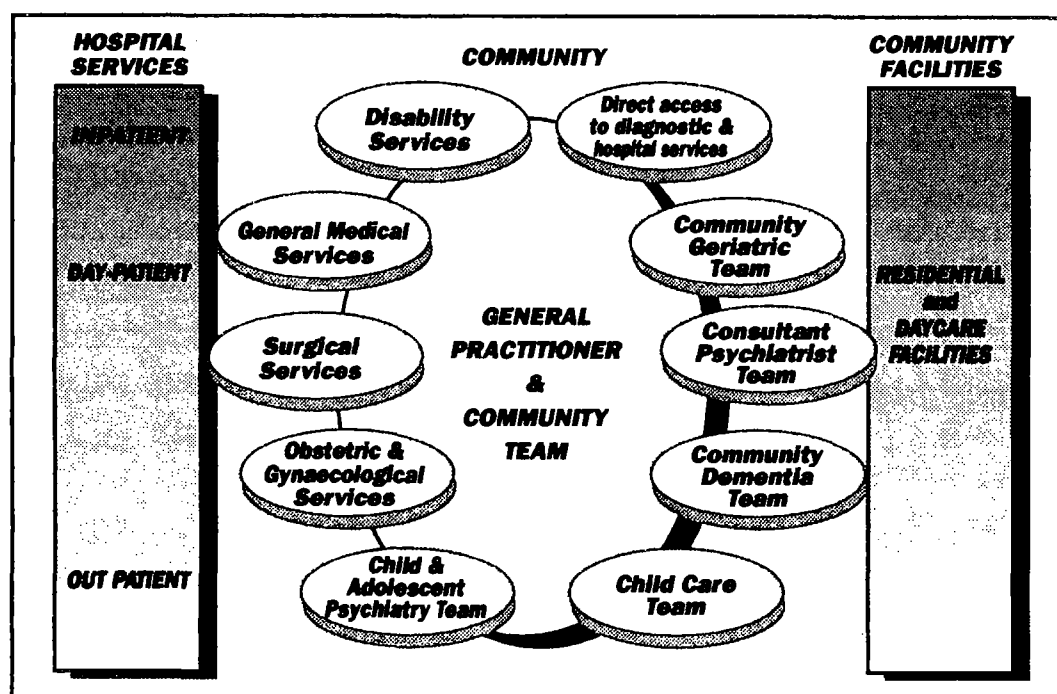


- Management Line
- > Care Management Process
- - - - -> Assessment Line

SECONDARY AND TERTIARY CARE

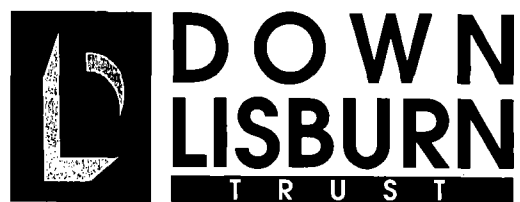
40. In Northern Ireland patients traditionally received almost all secondary acute health care in hospital settings, often at a distance from their homes. The principles developed by Down Lisburn led to the conclusion that efforts should be made to provide as much secondary health care as possible locally, in close co-operation with General Practitioners and the other members of the Primary Care Team.
41. This has dictated a developing programme of consultants and other specialist staff from the Trust's hospitals providing clinics in or close to General Practitioners' premises/health centres. The overriding aim is to allow patients, wherever possible, to have treatment in familiar surroundings where they can be supported by professionals known to them. The partnership between primary and secondary care should also enhance the ability of the Primary Care Team to maintain patients in the community.
42. When patients require to be admitted to their local hospital for acute care the primary and secondary care teams seek to be in close contact so that the transition from and back to home is smooth and both patient and family feel secure that there will be continuity of care.
43. If the patient requires highly specialised tertiary care the consultants at secondary care level will, if the General Practitioner wishes, undertake to arrange appropriate treatment, acting as a link between primary and tertiary systems.
44. Similar arrangements are in place in social care where specialist teams and services have been aligned with and have been developing close and supportive working arrangements with Primary Care.
45. The network of Secondary Level Services is as illustrated in Diagram 6.

Diagram 6



CONCLUSION

46. The Down Lisburn model of integrated Health and Social Care provides a patient centred and Primary Care led response to need. Recognising that a person's needs frequently include a combination of Social Care, Primary Health Care and Secondary or Tertiary Acute Care it seeks to dissolve the boundaries between care systems.
47. The model has been developed over a four year period with the full co-operation of professional staff. It is favoured by General Practitioners and the other professionals in the Primary Care Teams and by the Eastern Health and Social Services Board, the Purchasing Agency. Results in the field of community care are particularly encouraging with around 70% of people eligible for long-term institutional care in nursing and care homes opting instead for intensive care in their own homes co-ordinated by the Primary Care Team.
48. Down Lisburn is clear that there is considerable scope for refinement and development and will be continuing to give this the highest priority.



Lifelong Health & Care

THE WHITE HOUSE

October 7, 1994

Professor Paul Schwartz
University of Arkansas
School of Law
Fayetteville, AR 72701

Dear Professor Schwartz:

Thank you for sending a copy of your testimony before the House Subcommittee on Government Information, Justice, Transportation, and Agriculture about the need to maintain the privacy of health care information. As you may know, the provisions about medical privacy and the use of health information in H.R. 4077 were incorporated into Congressman Gephardt's health reform bill.

As I am sure you also know, the Congress will be unable to pass health care legislation this session. The President and I, however, are proud that we have come further than ever before in the effort to reform our health care system. We remain committed to returning next year to fight for health security for all American families.

Sincerely yours,


Hillary Rodham Clinton



AHS 670-7780
Gen. Counsel
Talk to someone who
works with Nara on
privacy issues.

Robert A. Leflar Law Center • Fayetteville, Arkansas 72701-1201 • (501) 575-5601 • (501) 575-2053 (FAX)

School of Law

May 10, 1994

Hillary Rodham Clinton, Esq.
The White House
1600 Pennsylvania Ave., N.W.
Washington, DC 20500

PAM MAY 19 1994

Dear Mrs. Clinton:

Knowing of your critical role in health care reform, I would like to urge your support of H.R. 4077, The Fair Health Information Practices Act of 1994. Privacy protection for medical information should be a part of any health care reform, and not something to be phased in over a course of several years. In the modern, technological society in which we live, privacy lost is not often regained.

Enclosed you will find a copy of my recent testimony before the House Subcommittee on Government Information, Justice, Transportation, and Agriculture. This testimony elaborates on the reasons why we need a bill that establishes federal fair information practices for health care information.

On a different note, allow me to assure you that your greatest fans are and will remain at Waterman Hall! The entire law faculty is intensely proud of all that you and the President have done for our country.

With best wishes.

Sincerely yours,

Paul Schwartz

PS:ty

Enclosure

TESTIMONY OF PAUL SCHWARTZ,
ASSOCIATE PROFESSOR OF LAW,
UNIVERSITY OF ARKANSAS SCHOOL OF LAW, FAYETTEVILLE

TO
THE GOVERNMENT INFORMATION, JUSTICE AND AGRICULTURE
SUBCOMMITTEE
OF THE
HOUSE COMMITTEE ON GOVERNMENT OPERATIONS
HOUSE OF REPRESENTATIVES
ONE-HUNDRED-THIRD CONGRESS

Wednesday, May 4, 1994

Mr. Chairman and members of the Committee, thank you for the opportunity to testify regarding the privacy of health care information.

I am an Associate Professor of Law at the University of Arkansas School of Law, Fayetteville. Currently, I am one of the investigators preparing a formal evaluation of American data protection law for the Commission of the European Community (Brussels).

I have published and lectured on issues concerning computers and privacy in the United States and Europe. In 1989, I was the first American to address the Annual International Meeting of Data Protection Commissioners at a conference held in the French Senate, Paris, France. My scholarship and essays have appeared in such periodicals as the *Columbia Law Review*, *Hastings Law Journal*, *American Journal of Comparative Law*, and the *Partisan Review*.

We meet today at an critical moment for a discussion of medical privacy. Public opinion polls show that Americans are deeply concerned with how their personal data are handled by the government and private companies. These polls reveal widespread alarm over threats to privacy; these concerns cut across all demographic subgroups within American society.¹ Indeed, over three-quarters of the public currently believe that they have lost control of how personal information is circulated and applied by companies. Americans are also highly concerned about the processing of their health information.²

There are three topics I wish to discuss with you this morning. The first is the weakness of the current laws that control the application of medical information. The second topic concerns significant European developments concerning data protection law. The term "data protection" refers to the area of law that structures the application of personal information.³ Both the weaknesses of the current American approach and the developments in Europe offer strong grounds for passage of Representative Condit's bill to establish a code of fair information practices for health information (H.R. 4077).

Yet, this bill should be accompanied by passage of another law: one that establishes a national data protection board. My third topic concerns the role of such a board. A data protection agency is necessary to carry out ongoing oversight of technological developments and to advise the legislature on the extent of compliance with fair information practices. It is also needed to help citizens in the exercise of their rights and to assist the American business community in responding to national and international regulations.

¹ See Harris-Equifax, *Health Information Privacy Survey 2* (1993) (eighty percent of the American population are very or somewhat concerned about threats to their personal privacy) [hereinafter cited as *Health Information Privacy Survey*].

² *Id.* at 87-103.

³ See generally David H. Flaherty, *Protecting Privacy in Surveillance Societies* (1989); Paul Schwartz, *Data Processing and Government Administration*, 43 *Hastings L.J.* 1321 (1992).

Protection of Medical PrivacyA. Data Processing and Medicine

The Clinton Administration has committed itself to the creation of a national program of health insurance, and any health care reform is fated to increase the computerization of medical data. Such increased reliance on computerization will be necessary to help reduce waste and fraud and to increase the efficiency of both medical practice and the payment process. It will also heighten the threat to a specific kind of privacy interest of patients, namely their right of informational self-determination. I wish now to describe the nature of information processing, first in general terms and then in the medical context, and to explain the interest in informational self-determination.

Information has become vital to the American economy. The contribution of information services to the Gross Domestic Product exceeds even that of manufacturing. The now-common term "information society" expresses the significance of this collection, coordination, and analysis of data in the United States. American business must continue to develop and exploit information technology to maintain our nation's economic well-being.

Moreover, the government, like industry, has come to rely on the processing of personal information with the latest technology. In fact, the federal government utilizes the world's largest collection of computers.⁴ The intensity of the federal government's reliance on administration through information technology is indicated by the large number of its computers that are equipped with communication links to other government computers. The federal government leads all sectors of American industry or trade in the percentage of its computers equipped with such communication links.⁵

Information processing is now essential to business and government in the United States. It also plays a critical role in the provision, regulation and financing of medical services by government and business. Despite a past social tradition of deference to the medical profession's self-regulation, the state has seized upon the collection and application of information as a way to control doctors, regulate national health expenditures, and help doctors control patients. Thus, in application of the Medicaid program, the state collects and reviews personal data to decide whether a given patient is eligible for services defined as medically necessary.⁶ Private health plans and hospitals also collect and process

⁴ Office of Management and Budget, Management of the United States Government, Fiscal Year 1989, at 72 (1989).

⁵ U.S. Census Bureau, Statistical Abstract of the United States 952 (1990).

⁶ See, e.g., *Cowan v. Myers*, 232 Cal. Rptr. 299 (1986) (state and not physician decides which medical services are necessary and, therefore, subject to state funding).

personal information technology to strengthen administrative control. This application is particularly significant in the carrying out of utilization review under both Medicaid and Medicare. In addition to the example of utilization review, one can add diagnosis related groups and treatment protocols as examples of the ways in which medical practices are being standardized and governed with the help of information technology.

Information technology may be the last best hope to control health care in a rational way. It renders the enormous amounts of information involved in diagnosing, treating and billing patients accessible to external control. In the near future, electronic cards ("smart cards") carried by citizens may contain personal health care information. Another likely future development will be electronic patient records that are used within nation-wide electronic health care networks. This focus on the practice and regulation of medicine through the processing of personal health care information has a number of potential drawbacks, one of the most important of which is the threat to the privacy of patients.

Privacy is, of course, a concept that refers to a wide variety of interests in American law. For conceptual clarity, I wish to explain the critical privacy interest at stake here as one in "informational self-determination." The law has long recognized another aspect of self-determination in health care, namely that of informed consent. Informed consent protects a patient's interest in personal autonomy by requiring that doctors and patients discuss relevant concerns and exchange relevant information before agreeing upon a course of medical treatment. Informational self-determination also relates to this interest in decisionmaking by the patient. Self-determination can only exist when an individual has an underlying capacity for critical reflection. Yet, the computer creates a strong pressure for individuals to conform to digital reality. This pressure, which is dreadfully exacerbated by uncertainty as how bureaucracies are processing personal data, can have a negative effect on the human ability to make free choices. This method of administration can weaken an individual's capacity for critical reflection and participation in society.

Informational self-determination depends on the law shaping the use of medical data in the public and private spheres. The law must put fair information practices in place so patients understand the nature and structure of the processing of their personal data and be assigned a role in decisions about how their data will be used. The kinds of fair information practices that are necessary include a specification of collection purposes before personal data are sought; limitations on additional use of personal data; limitations on the collection of unnecessary data and their storage; and the data subject's ability to have access to and correct personal information. At present, the law in this country fails to require in any consistent, effective fashion that these fair information practices be in place for health care information.

B. Current Data Protection Measures

The present regulatory scheme in the United States consists of federal law that applies only to data in the control of the government or to certain, specific kinds of health data. The regulatory scheme also includes state measures that create a patchwork of insufficient protection. Moreover, the laws of the various states are far from uniform. In an age when interstate transfers of data are becoming prevalent, this lack of uniformity is itself an additional weakness in American medical data protection. At present, the best protection for any medical information in this country is provided for individuals who are enrolled in federally-financed drug and alcohol treatment centers.

The weakness of the regulation of health care information has been commented upon by many observers. In 1977, the federal Privacy Protection Study Commission noted the billions of visits that Americans make to physicians in a single year. Yet, for this blue ribbon Commission, "even more staggering is the realization of how many people besides the medical care providers who create a medical record have access to it."⁷

The legal scheme has not improved since the report of the Privacy Protection Study Commission. A recent study of the Office of Technology Assessment concludes, "The present legal scheme does not provide consistent, comprehensive protection for privacy in health care information, whether it exists in a paper or computerized environment."⁸ According to the Committee on Regional Health Data Networks of the Institute of Medicine, "the threats and potential harms" from disclosure and redisclosure of health record information "are real and not numerically trivial."⁹ Finally, Sheri Alpert, a government policy analyst, notes, "video rental records are afforded more federal protection than are medical records."¹⁰

Enormous demand exists today for medical information. Beyond the traditional doctor-patient relationship and the provision of health services in hospitals, medical data are sought after by a wide variety of public and private organizations. Alan Westin has made a highly useful description of the flows of personal medical information in the United States today. Westin describes three zones of applications: zone one is direct patient care (doctors, clinics, hospitals, nursing homes); zone two, supporting and

⁷ Privacy Protection Study Commission, *Personal Privacy in an Information Society* 277 (1977). The Commission also noted that patients were, by and large, denied access to their records. *Id.*

⁸ Office of Technology Assessment, *Protecting Privacy in Computerized Medical Information* 13 (1993).

⁹ Committee on Regional Health Data Networks, Institute of Medicine, *Health Data in the Information Age* 156 (Molla S. Donaldson & Kathleen N. Lohr, eds. 1994) [hereinafter cited as *Institute of Medicine Study*].

¹⁰ Sheri Alpert, *Smart Cards, Smarter Policy: Medical Records, Privacy and Health Care Reform*, Hastings Center Report 13 (November-December 1993). See Joel R. Reidenberg, *Privacy in the Information Economy*, 44 Fed. Comm. L.J. 195, 227-34 (1992).

administrative activities (service payers, third party administrators, quality of care reviews); zone three, broader uses of health data, termed "secondary uses," (credential and evaluation decisions, public health reporting, social welfare programs, direct marketing).¹¹ More organizations than ever before are seeking -- and obtaining -- access to health information.

The current patchwork system of data protection has been unable to impose an adequate legal structure on the enormous demands for medical data. One example of the failure of the current system of legal regulation is the abuse of the notion of "informed consent" to information disclosure. Just as respect for physical self-determination requires "informed consent" before medical treatment, informational self-determination requires "informed consent" before processing and sharing of health care information. Yet, service payers, such as insurance companies, often have their customers, the future consumers of health care services, sign broad, "blanket" disclosure releases. Such documents have been used to justify almost any secondary use of medical data. These releases have permitted the disclosure of medical information to such bodies as pharmaceutical companies; employers, who seek health data concerning their firm's workers; the Medical Information Bureau, a nonprofit association that supplies insurance companies with medical information in order to prevent fraud; and direct market mailers.

The protection for medical information is so weak in this country that marketing lists detailing the most sensitive information about citizens are for sale. Here is additional proof of the failure of current legal regulation. Johnson & Johnson has compiled a list for sale of five million elderly, incontinent American women.¹² Another company has advertised lists containing the names of six million allergy sufferers, 700,000 people with bleeding gums, and 67,000 people with epilepsy.¹³ Other citizens appear on a mailing list as suitable consumers of products intended for impotent middle-aged men.¹⁴

How did we get into the situation in which medical information is so poorly regulated that such lists are freely trafficked? Understanding the inadequacy of current regulation requires one to consider how the current patchwork of federal and state laws fail to control the application and use of medical data.

1. Federal Measures

On the federal level, data protection measures are found in constitutional law, the Privacy Act,

¹¹ Alan F. Westin, Interpretive Essay, in Health Information Privacy Survey, *supra* note 1, at 7.

¹² See Larry Tye, List-makers draw a bead on many, Boston Globe, Sept. 6, 1993, at p. 12.

¹³ *Id.*

¹⁴ Just Lists Offers "Male Potency" File, DM News, April 19, 1993, at 37.

and a few statutes that regulate narrow areas of data use. In any discussion of these measures, one must begin by noting that their coverage is extremely limited. To begin with the United States Constitution, its protections apply only when there is action by the government. Yet, the overwhelming majority of most medical information in the United States is not in the hands of the government, but such entities as nongovernmental doctors and hospitals, insurance companies, and a variety of private sector computer networks. These private parties who control medical data are unlikely to meet the applicable tests for state action.

As for the Privacy Act, it protects only the data of federal agencies. In the 1980's, one expert estimated that this statute applies only to five percent of the medical data banks in the United States.¹⁵ Thus, federal measures leave most medical data entirely outside of their protections. In addition, there are notable weaknesses in each of these federal regulations. Let us begin with the applicable constitutional protections.

When the government does collect medical information, a constitutional right to informational privacy applies. Indeed, the constitutional right to informational privacy was first articulated in a case, Whalen v. Roe,¹⁶ that involved medical data. Whalen concerned New York State's plan to collect and store data relating to the prescription of certain drugs that had both legitimate and illegitimate applications. The Supreme Court found that the United States Constitution contained a right of informational privacy that prohibited "disclosure of personal matters" and protected "independence in decisionmaking."¹⁷ A number of important decisions of lower courts, such as United States v. Westinghouse,¹⁸ have applied this constitutional right to governmental attempts to obtain or examine medical information. The constitutional right of informational privacy has improved medical data protection in some instances. It has done so through application of its first branch, the nondisclosure interest.¹⁹ Yet, some lower courts have found that this element applies only to a narrow group of fundamental constitutional rights.²⁰ Indeed, some courts have viewed Whalen as a decision that

¹⁵ Terra Ziporyn, Hippocrates Meets the Data Banks, J. Amer. Med. Assn. 252 (20 July 1984) (quoting Professor Vincent M. Brannigan).

¹⁶ 429 U.S. 589 (1976).

¹⁷ Id. at 598-600.

¹⁸ 638 F.2d 570 (3d Cir. 1980).

¹⁹ Mann v. University of Cincinnati, 824 F. Supp. 1190 (S.D. Ohio 1993); Doe v. Borough of Barrington 729 F. Supp. 376 (D.N.J. 1990).

²⁰ See, e.g., Walls v. City of Petersburg, 895 F.2d 188 (4th Cir. 1990).

sanctions all "legitimate" governmental requests for medical data.²¹ As to the second part of the right of informational privacy, the autonomy interest, it has been almost entirely absent from case law.²² There has not been a vigorous protection of medical privacy through application of it. The limited constitutional protection to medical data has not been adequately supplemented by federal statutory measures. To begin with the Privacy Act, this law applies only to medical records in the control of federal agencies. This limited coverage is itself not without flaws. The most notable is found in the Privacy Act's limitations on secondary use. The Privacy Act prohibits the disclosure of records without the written request of "the individual to whom the record pertains."²³ There are, however, no fewer than twelve disclosure exemptions to this prohibition. Of these, the most problematic is the "routine use" exemption, which has been made into an enormous loophole.²⁴ Agencies have justified a wide variety of data disclosures as a "routine use" of personal information.

In addition to the Privacy Act, there are other provisions of federal law that provide some privacy protection for medical records. One such measure contains data protection measures for the social security records of the Department of Health and Human Services.²⁵ This statute does allow, however, for disclosures "as otherwise provided by Federal law" and by regulations issued by the Secretary.

Federal law also protects the data of patients who are treated for alcohol or drug abuse in programs that receive federal funds or are subject to federal regulation.²⁶ These laws generally do a fine job of data protection.²⁷ Indeed, the best data protection for health information in the United States is

²¹ See *Gutierrez v. Lynch*, 826 F.2d 1534, 1539 (6th Cir. 1987) ("legitimate requests for medical information do not constitute an invasion of the right to privacy").

²² Compare *Plante v. Gonzales*, 575 F.2d 1119 (1979) with *Mann v. University of Cincinnati*, 824 F.Supp. 1190 (S.D. Ohio 1993).

²³ 5 U.S.C. § 552a(b).

²⁴ *Id.* at (b)(3).

²⁵ 42 U.S.C. § 1305. Social security records often contain a variety of medical information. This information is most typically collected in connection with claims for disability benefits. See generally Jerry L. Mashaw, *Bureaucratic Justice: Managing Social Security Disability Claims* (1983). A federal statute prevents "any officer or employee of the Department of Health and Human Services in the course of discharging" the social security program from disclosing any "file, record, report or any other paper, or information, obtained at any time by any person" from the Department. 42 U.S.C. § 1305.

²⁶ 42 U.S.C. §§ 290dd-2, 290ee-3.

²⁷ For example, these laws permit disclosures of patient records only under certain specified conditions. There are four exemptions to the general standard of nondisclosure: (1) in accordance with the prior written consent of the patient; (2) to medical personnel to the extent necessary to meet a medical emergency; (3) to qualified personnel to conduct scientific research, audits or program

provided for patients being treated for substance abuse in federally-funded clinics.

A good example of the success of these Federal statutes is offered by the careful way they treat the issue of disclosure of patient information. Where broad releases signed by patients are used to justify third-party access to most medical data, these laws carefully define the conditions for the patient's "informed consent" to release of her data.²⁸ Written consent to a disclosure must include an explanation of such matters as: the purpose of disclosure; how much and what kind of information is to be disclosed; and a statement that the consent is subject to revocation at any time. Each disclosure must also be accompanied by a written statement that prohibits redisclosure. These statutes not only offer an excellent contrast to the kinds of "blanket" consent that generally takes place, but indicate the possibility for the success of additional federal data protection for medical information.

It must be emphasized again that these Federal protections generally apply only to the government. Only in strictly limited circumstances does federal law protect health care information in the private sector. Thus, private clinics for substance abuse that receive federal money are obliged to follow these federal rules for medical information, but privately funded clinics are not. For the most part, the treatment of health care information is the province of state law.

2. State Measures

The weaknesses in current federal data protection for medical information are not successfully overcome by existing state measures. To be sure, many different kinds of laws on the state level relate to medical information. Nevertheless, these measures do not create an effective system of data protection. To begin with constitutional law, some state constitutional provisions have been interpreted by courts,

evaluations; and (4) if authorized by court order.

This regulation guarantees confidentiality in order to encourage participation in alcohol and drug treatment programs.

Of the four circumstances in which information pertaining to alcoholism or drug abuse treatment may be released, 42 U.S.C. §§ 290dd-2, 290ee-3, the most important concern a court order and patient consent. As for disclosure pursuant to a court order, the judicial decision whether or not to release patient data is to be made pursuant to a balancing test. The statutory test requires judicial disclosure "after application showing good cause thereof," 42 U.S.C. § 290dd-2(b)(2)(C), and, more specifically, states, "In assessing good cause the court shall weigh the public interest and the need for disclosure against the injury to the patient, to the physician-patient relationship, and to the treatment services." This balancing test is further developed by the applicable regulations. The statutory balancing test and the regulations have been carefully applied by a number of courts. These courts generally assess the seriousness of the alleged crime and check to see that redisclosure of the information will not occur beyond the immediate application necessary in the case at hand.

²⁸ 42 U.S.C. § 290dd-3.

most notably in California, as setting limits on the application and dissemination of medical data.²⁹ The law of most states also recognizes a relationship between doctor and patient that gives rise to a general duty of confidentiality.³⁰ Some states have extended this duty of confidentiality to hospitals.

In addition, state statutes require certain reports concerning specific diseases or medical conditions to be filed with state health authorities by physicians, hospitals and laboratories. Such laws typically pertain to sexually transmitted diseases and other communicable diseases such as tuberculosis. State laws also require reports to be filed about knife and gunshot wounds and injuries to elderly individuals and children that might indicate elder or child abuse. Despite the highly sensitive nature of these data, these laws often do not contain specific limitations on the use that will be made of this information or put in place limitations on the time for which these data will be stored.

Finally, a Uniform Health Care Information Practices Act has been drafted. This law has, however, been adopted in only a small number of states. Since the Uniform Act is subject to modification by state legislatures before passage, even widespread adoption of this law might not improve the nature of the protection for health care information.

Even within the same state, these many legal provisions have failed to impose a consistent framework on the application of medical information by primary care providers, supporting institutions, and secondary users. The lack of uniformity of regulation can also be found if one compares the legal systems of different states. Yet, flows of health care information take place on an interstate level. As one recent study of medical privacy has noted:

A state-by-state approach to regulation of medical information does not reflect the realities of modern health care finance and provision. The flow of medical information is rarely restricted to the state in which it is generated. Such information is routinely transmitted to other states, subject to differing legal requirements, for a wide variety of purposes ranging from medical consultation and research collaboration to governmental monitoring for quality.³¹

Whether as a result of regional health care alliances or an increased reliance on health data base organizations, national health care reform will cause even more transfers of medical information between different states.

The interstate flow of medical information calls for a federal response to these issues of data

²⁹ See, e.g., *Urbaniak v. Newtown*, 277 Cal. Rptr. 354 (1991); *Divison of Medical Quality v. Gherardini*, 156 Cal. Rptr. 55 (1979).

³⁰ See, e.g., *Horne v. Patton*, 287 So. 2d 824 (Ala. 1974); *Hague v. Williams*, 181 A. 2d 345 (N.J. 1962).

³¹ Lawrence O. Gostin, Joan Turek-Brezina et. al, Privacy and Security of Personal Health Information in a New Health Care System, 270 JAMA 2487, 2489-90 (1993).

protection. This federal response must be embodied in a specific law that regulates the processing of health care data. In the 1985 Thomas Jefferson Lecture at the University of Pennsylvania Law School, Professor Spiros Simitis, an international data protection expert, urged an abandonment of any search for "abstract, generally applicable provisions" in favor of "a context-bound allocation of information embodied in a complex system of both specific and substantive regulations."³² Such a system of regulations is offered by Representative Condit's fair information practices bill for health information.

Moreover, these fair information practices must be put in place now as part of national health care reform-- not at some date in the future. Yet, the Clinton Administration's Health Security Act (H.R. 3600, S. 1757) foresees first the establishment of an electronic data network of health care information (Sec. 5103) and then, some years later, the creation of "a comprehensive scheme of Federal privacy protection" (Sec. 5122). This scheme, which is to include fair information practices, is to be submitted to the President and Congress within three years of the enactment of the Health Security Act. (Id.)

We cannot wait for data protection in this fashion. In an age of rapid technological change, privacy lost is not frequently regained. The law must structure fair information practices at the same time as it authorizes the collection and retrieval of personal information. In the case of health care information, this conclusion has also been reached by the Committee on Regional Health Care Services of the Institute of Medicine. The Committee not only advocates the enactment of a federal fair information practices law, but has urged Congress to act "as soon as possible."³³

II

International Developments

There is a great need for improvement of the regulation of medical privacy in the United States. Developments in Europe provide an important example in this area as well as an independent, additional ground for passage of a fair information practices act for medical information in the United States. I wish now to discuss how national and European-wide laws regulate the processing of medical data, and then analyze how the inadequate protection of medical data in the United States can lead to the blocking of the transfers of personal information to our country and limit the ability of American companies to process European records.

Within European nations, medical data are generally subject to a variety of legal measures. In most European nations, in contrast to the United States, data protection proceeds at an initial level

³² Spiros Simitis, Reviewing Privacy in an Information Society, 135 U. Penn. L. Rev. 707, 742 (1987).

³³ Institute of Medicine Study, *supra* note 9, at 191.

through an omnibus law that regulates the public and private sectors alike.³⁴ These laws are then supplemented and strengthened by other general laws and sectoral measures that contain more precise regulations for individual areas of processing activities. Thus, in the Federal Republic of Germany, medical data are subject to the Federal Data Protection Law,³⁵ the Code of Social Law (Sozialgesetzbuch),³⁶ the Criminal Code,³⁷ and state data protection laws.³⁸ In the medical sector, the resulting level of data protection in Europe, although not without flaws, is generally at a higher level than in the United States.

The level of protection for medical information within any European nation is also affected by a European-wide treaty. The Council of Europe's Convention for the Protection of Individuals with Regard to Automatic Processing of Data, which currently is the most important European agreement for data protection, requires that signatory nations only permit the processing of sensitive data, including "personal data concerning health," when "domestic law provides appropriate safeguards."³⁹ These safeguards include: rights of access and correction; a specification of collection purpose; data security measures; and limitations on unnecessary data collection and data applications that are incompatible with the original collection purpose.⁴⁰ In addition, remedies are to be provided in cases of lack of compliance with requests for: information about collections of personal data; access to personal data; or correction of personal data.⁴¹

This general provision of the Convention has been expanded upon by the Council of Europe's

³⁴ David H. Flaherty, *supra* note 3, at 21-39; 93-103; 165-174.

³⁵ Bundesdatenschutzgesetz (BDSG) vom 20. Dezember 1990, BGBl. I, 2954 [hereinafter cited as BDSG].

³⁶ Sozialgesetzbuch vom 11. Dezember 1975, BGBl. I, 3015.

³⁷ See Strafgesetzbuch (Criminal Code), § 203(1) (forbidding doctors from violating the "private secrets" of others).

³⁸ Some state data protection laws contain specific provisions concerning health care information, see, e.g. Hessisches Datenschutzgesetz (Hessen Data Protection Law), vom 11. November 1986, § 34(6). German states are also in the process of promulgation of sectoral laws for health care information.

³⁹ Council of Europe, Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data, no. 108 (January 28, 1981), Article 6.

⁴⁰ *Id.* at Articles 5, 7, 8.

⁴¹ *Id.* at Article 8(d).

Recommendation No. R(81)1, which provides sectoral regulations for automated medical data banks.⁴² These regulations provide additional specifications of the necessary data protection principles to be applied to medical data banks. The Recommendation states that its requirements "are to be taken duly into account not only with regard to medical data banks which are operational, but also those which are in the development phase."⁴³ Taken together, the Convention and the Recommendation reflect a serious European-wide commitment to data protection in the medical domain.

In addition to the Council of Europe's Convention and Recommendation, the treatment of medical data within Europe will soon be affected by the Commission of the European Community's Directive on Data Protection. An amended draft of this document provides insights into Europe's likely final approach to medical data protection.⁴⁴

Like the Convention, the Draft Directive requires member countries to establish legislation that conforms with its standards. Its goal is to ensure a "high level of protection" within the Union for "fundamental rights and freedoms, notably the right to privacy."⁴⁵ The Directive stresses that fair information practices must be in place before member states permit the processing of personal information, including the processing of "data concerning health."⁴⁶ To put it another way, without sufficient data protection laws, medical information may not be processed.

The proposed Directive and the Council of Europe's Convention are of great significance. The importance of these two documents is, in the first instance, as a positive example of data protection measures for medical data. They are also important because of their setting of rules not only for the processing of personal data within the European Union, but also for the transfer to these data to any "third country," such as the United States.

The Council's Convention and the Union's Directive permit the prohibition of data transfers, including medical information, to countries with poor data protection. According to the Council of

⁴² Council of Europe, Regulations for automated medical data banks, Recommendation No. R(81)1 (January 23, 1981). The Explanatory Memorandum to the Recommendation states, "the operation of every automated medical data bank [should be] subject to a specific set of regulations. The general purpose of these regulations should be to guarantee that medical data are used not only so as to ensure optimal medical care and services but also in such a way that the data subject's dignity and physical and mental integrity are fully respected." *Id.* at 13.

⁴³ *Id.* at 1.5.

⁴⁴ Commission of the European Communities, Amended Proposal for a Council Directive on the Protection of Individuals with Regard to the Processing of Personal Data and on the Free Movement of Such Data, COM(92)-- SYN 287.

⁴⁵ Preamble at (1).

⁴⁶ *Id.* at Article 8.

Europe's Convention, data exports may be prohibited to nations that do not offer "equivalent protections" for personal information.⁴⁷ As to the Draft Directive, it gives responsibility to each national government within the Community to oversee the conditions of transfers to non-Community nations. The Directive's critical requirement is that data transfers be permitted "only if the third country in question ensures an adequate level of protection."⁴⁸ The adequacy of protection is to be "assessed in the light of all the circumstances surrounding a data transfer operation or set of data transfer operations."⁴⁹ Among the circumstances to be assessed are "the legislative provisions . . . in force in the third country in question."⁵⁰ The adequacy of protection can also depend on "professional rules," which can include a given company's business practices or code of conduct.⁵¹

Data exports can also be blocked under the national law of various European nations. In Germany, for example, the Federal Data Protection Law requires consideration of the level of data protection in a third country before any international transmission of personal information.⁵² Such analysis must be carried out in cases of transfer by the government and private companies alike. In cases of non-governmental transmissions, a private company can make itself liable for fines and even criminal penalties for transmissions to countries with insufficient protections.⁵³

What do these provisions for blocking data exports under the Council of Europe's Convention, the Union's Directive, and national laws mean for the United States? They indicate that transfers of personal data from Europe to this nation will depend on the adequacy of protection that these data receive once they are here. This decision is likely to be made by looking at the kind of transfer and the nature of the protection that is offered by the legal order as well as the business practices in the state to which the data is sent.

Medical data likely to be affected by these measures are found in employee information in the

⁴⁷ For analysis of this provision of the Convention, see Joel R. Reidenberg, The Privacy Obstacle Course, 60 Fordham L. Rev. 161-62 (1992).

⁴⁸ Draft Directive, at Article 26(1).

⁴⁹ Id. at Article 26(2).

⁵⁰ Id.

⁵¹ Id.

⁵² BDSG, §§ 17, 28. For a discussion of the need for equivalent protection before the transfer of personal data from Germany to a foreign country, see Spiros Simitis, §1 (Räumlicher Geltungsbereich), in Kommentar zum Bundesdatenschutzgesetz, § 1, Rdnr. 74-107 (Spiros Simitis, Ulrich Dammann et. al. eds., 4th ed. 1992).

⁵³ BDSG, §§ 43, 44.

control of international corporations and drug research studies, which pharmaceutical companies now carry out in many countries as they seek world-wide approval of their products. Moreover, there is now an international industry in information processing. As a result, American companies compete globally for contracts that will involve the processing of health information. It makes good business sense for the United States to institute federal measures of data protection for medical data.

III

Data Protection Oversight

Passage of a fair information practices bill would greatly improve the level of data protection for medical information in this country. This legislative activity should also be accompanied by passage of a bill creating a federal data protection board. The idea of creating such an institution has been around since the debate preceding the creation of the Privacy Act in 1974, but it is likely today to receive particularly strong support from the American people. Concern about privacy is high in the United States. In fact, according to a 1993 poll conducted by Louis Harris and Associates, eight-six percent of the public favors the creation of an "independent National Medical Privacy Board to hold hearings, issue regulations, and enforce standards."⁵⁴

Even more useful than a board devoted solely to data protection in the medical sector would be an institution that was empowered to consider the effects and implications of data processing practices in other contexts. Bills to create such a general data protection board are currently before the House and the Senate of the United States Congress, and I urge passage of such a measure. In its attempt to protect individual self-determination, data protection law can remain effective and current only if such an institution exists to assist government bureaucracy, the legislature, the business community, and the data subject.

The creation of the United States Data Protection Board is of particular importance for the protection of informational self-determination in an era of rapid technological change. Indeed, the greatest changes in personal data use anywhere in the United States are likely to take place in the medical sector. There is an acute need for a governmental body with the institutional expertise and continuity of interest to monitor the impact of changes in this area on individual privacy.

A Data Protection Board would monitor data processing practices and compliance with laws, draw the attention of the legislature and the public to the problems of existing laws and the need for further regulation, assist citizens seeking to protect their interests and exercise their rights, and help business in understanding national and international legal developments. By fulfilling these tasks, the data protection commission would help to ensure that public administrative bodies, the legislature,

⁵⁴ Health Information Privacy Study, *supra* note 1, at 101.

citizens and the business community remain aware and active as the conflicts generated by information technology change.

A further role of a Data Protection Board would be to represent American interests and assist American companies facing scrutiny by foreign data privacy authorities. Almost all other Western nations have created such data protection boards. Indeed, the European Union's Draft Directive requires each member state to "designate an independent public authority to supervise the protection of personal data."⁵⁵ Significant formal and informal contacts now regularly occur between the world's data protection commissions.

The United States must do more than fight for a principle of free international data flows; it must develop the institutional expertise that will allow involvement in the worldwide debate over data protection concerns. One reason for the United States' current, minimal role in this international discussion has been its lack of any Data Protection Board. Creation of such an institution would dramatically improve the representation of our nation's interests abroad. Independent monitoring of the effects and implications of information technology and data processing practices is necessary both to protect citizens' informational self-determination and to maintain the flow of data exports to the United States.

⁵⁵ Draft Directive, Article 30.

THE WHITE HOUSE

WASHINGTON

February 9, 1994

Mark C. Shields, M.D.
637 Clarendon Lane
Aurora, Illinois 60504

Dear Mark:

Thank you for your thoughtful letter. I appreciate the time you took to share your ideas and concerns about the Health Security Act.

You expressed reservations about the structure and power of alliances. As you noted, insurance coverage is best purchased in the private market, and employers should be included in purchasing decisions. That is why the Health Security Act builds on the private, employer-based system that exists today. Under the Act, employers contribute to health insurance premiums for their workers. Alliances simply increase purchasing power and lower administrative costs for businesses and individuals who today buy small group and individual insurance. Alliances offer to these consumers a choice of health plans that compete by providing high quality health care at a reasonable cost rather than by selecting only healthier applicants or varying premiums based on health status or other characteristics, as so many do today.

Alliances do not have the power to select which health plans may bid and do not have authority to regulate plan premiums. An alliance may refuse to contract with a health plan only if the premium substantially exceeds the alliance's premium target. Further, alliances do not cap premium rates. Instead, allowable increases in premiums are based on a formula set in legislation that adjusts for inflation and other factors, with no enforcement power or discretion on the part of the State or the alliance.

You also expressed concern about price controls. The President considered, and specifically rejected, a plan imposing price controls on health care. Price controls mean government micromanagement of every health care service and product. The President's primary strategy for cost containment is private sector competition -- creating the right economic incentives to encourage health plans to compete on price and quality.

Under the Health Security Act, caps on premiums, rather than price controls, act as a reinforcement mechanism or backstop. If employers and individuals have a responsibility to contribute to coverage and the federal government provides discounts to small

Page 2
Mark C. Shields, M.D.

businesses and individuals, we need to guarantee that premiums will not rise unchecked and the government will not spend without accountability. The Congressional Budget Office (CBO) released a report in September outlining how to best structure premium caps to control health care costs effectively without creating adverse effects. The Health Security Act includes all of CBO's suggested methods.

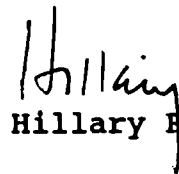
You also mentioned malpractice reforms. The proposed Health Security Act includes limitations on contingency fees, mandatory use of alternative dispute resolution, reductions in damages based on recovery from collateral sources, and periodic payment of awards at a plaintiff's request. The Act also authorizes demonstration projects to test whether enterprise liability reduces defensive medicine and to determine the effects of allowing practice guidelines to be used as a defense in malpractice actions. We hope that these reforms will begin to relieve physicians of the threat of litigation that may lead to the practice of defensive medicine and increased health care costs.

Finally, you noted that the benefit package may be too broad. We believe that only if all Americans have coverage for a comprehensive package of benefits, including preventive services, will health outcomes improve and overall costs decrease. We have been conservative in all of our calculations and believe that the benefit package can be delivered for the premiums that we have estimated.

Thank you again for sharing your support and ideas. I am sorry that I will not be able to be with you in May in the Fox Valley.

With warm personal regards, I remain

Sincerely yours,



Hillary Rodham Clinton

Mark C. Shields, M.D.

637 Clarendon Lane
Aurora, Illinois 60504

January 2, 1994

Hillary Rodham Clinton
President William Clinton
White House
Washington, D.C.
20500-2000

Dear Hillary and President Clinton:

I hope the holidays gave you a well deserved break from the tempo in Washington. I was sorry to hear from your staff that Hillary will not be able to give the guest lectureship in May in the Fox Valley. However, I did want to follow up on your staff member's call to elicit my thoughts on the Health Security Plan.

It is wonderful to have the President of the United States address our health care system in a comprehensive manner with special emphasis on access to care. The breadth of the Plan is impressive. It exceeds in scope the Health Security Act introduced by Senator Kennedy which I worked for as a medical student.

I have several serious reservations about the proposal as currently drafted, however. First, the powers of the health alliances exceed what would seem to be necessary. In Illinois, the specter of having a state agency capping premium rates and selecting which health plans would be allowed to bid is troubling. Our state government can't get school funding and regulation correct much less take on these new responsibilities in health care. Couldn't employers or groups of employers perform these functions?

Second, the plan seems to place too much reliance on price controls (through premium caps). Price controls should be available only in the most extreme circumstances as a short-term measure. They lead to market distortions and whole industries of consultants committed to bypassing them. Instead, the deductibility of health insurance premiums should be reduced to make employers and employees respond to market signals. Perhaps any rebate to the employee from the employer if the employer's contribution exceeds the premium could go to a health care IRA (pre-tax) for purchase of long-term care or other services.

MCA JAN 6 1994

page two

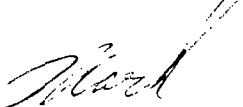
Third, employers need to be included in the purchasing decision to some degree. Employers have a major impact on the expenses of workmen's compensation and influence employee treatment and behavior for smoking, substance abuse, and preventive services. They should have a financial stake in health care.

Fourth, the malpractice reforms will not be adequate to change the defensive medicine practices of physicians. These practices have a significant effect on the cost of care. There need to be limits on awards for pain and suffering. The loser should pay court costs. Finally, the liability for not providing experimental therapies needs to be limited.

Fifth, the benefits may be too broad given the budget limitations. Universal access is the most important innovation; broader benefits can follow.

I applaud your enormous work and courage to propose this program. I hope its time has come. These suggestions will make a good program better. They should also help sell the program in the Midwest. If it becomes useful for you to give a presentation in Congressman Hastert's district, I would be able to assist.

Yours sincerely,

A handwritten signature in cursive script, appearing to read "Mark", written in dark ink.

THE WHITE HOUSE
WASHINGTON

January 27, 1994

Mr. Peter R. Stone
Health Journal Associates
5810 Pleasant Lake Road
Ann Arbor, Michigan 48103

Dear Mr. Stone:

This will acknowledge your letter of
January 18.

While your enthusiasm and support of
health care reform is appreciated, Mrs.
Clinton cannot become involved in the
promotion of your product.

Thank you for writing.

Sincerely yours,

A handwritten signature in black ink that reads "Pam Barnett". The signature is written in a cursive, flowing style.

Pam Barnett
Executive Assistant
to the First Lady

HEALTH JOURNAL ASSOCIATES

5810 Pleasant Lake Road, Ann Arbor, Michigan 48103

1-18-94

Ms. Barnett

i hope you will forgive
my persistence - i have
to try because i believe
so strongly that the
Journal will resolve
many of the problems
in our health care
system - it's so simple
that no one can see it -
or so it seems.

thank you



Phone and Fax 313-663-6720

HEALTH JOURNAL ASSOCIATES

5810 Pleasant Lake Road, Ann Arbor, Michigan 48103
Phone and Fax 313-663-6720

January 18, 1994

Mrs. Hillary Rodham Clinton
The White House
Washington, DC 20050

Dear Mrs. Clinton,

It was extremely gratifying to receive your note today in the mail, and to learn that you had indeed taken time from your busy schedule to review **The Woman's Health Journal**. Thank you.

At the risk of jeopardizing your good graces, I must ask you to take one more look at **The Journal**, to see how it can serve the entire medical community while significantly reducing the cost of health care. You see, I believe, with all my heart, that even with its imperfections, this volume is a first giant step toward reducing the waste in this nation's health expenditures, and fixing the health care system.

One common thread through President Clinton's policies and positions seems to be the sense of personal rights that are tied to personal responsibilities. I believe that it is totally appropriate for each individual to 'own' the responsibility for their actions, and no better place to begin than with our own health information.

If everyone were required, as part of any new health plan, to participate in the process by tracking their own health information, several things would happen, and the benefits would begin almost immediately.

The first evidence would be a significant reduction in the length of doctor's appointments, with less time being spent on 'fishing expeditions' trying to gather and interpret a patient's information. The factual answers to all pertinent questions would be immediately available in their **Journal**.

The second evidence would be a reduction in pharmaceutical costs. With **The Journal** and accurate data, doctors' diagnoses would be more accurate, leading to more accurate prescriptions and remedies. Many second and third trips to the doctor would be eliminated, as would the accompanying second and third prescriptions.

Longer term evidence would include a significant reduction in 'sick days'. More accurate diagnoses and prescriptions will certainly shorten the period of illness, allowing individuals to return to health and employment. Additional benefits would accrue simply from an individual's increased awareness, information, and participation in the process of good health. Knowledge can only benefit all concerned.

The Woman's Health Journal was released first because women are less reluctant to utilize medical resources, and more inclined to maintain records. Also, women are more familiar with cycles in general, and are at least aware of the more obvious connections between health, cycles, and the human experience. A men's version will be released next year.

After each of us begins tracking our information, and becomes familiar with individual cycles, we will begin to understand the many ways in which our cycles affect our lives.

One brief aside...Dr. Katarina Dalton of London, England has been a great part of the inspiration for this project. She authored the book *Once A Month*, which was, arguably, the first connection, in medicine and in print, between women's cycles and women's health. She opened her clinic for women in 1953, and has since treated more than 40,000 women.

Dr. Dalton is an authority on women's health recognized around the world. I sent her a copy of **The Journal** in its draft stages, hoping to get some input. She asked me to join her for lunch in Chicago, while she was in the U.S. on a speaking tour.

I was privileged to share three incredible hours during which, I was accepted, unconditionally and without bias, on the basis of my work. She gave me her total and unqualified support, and made several excellent suggestions. It was a wonderful validation of the years of effort.

One of my personal areas of focus with this subject is the crisis known as domestic violence. After fourteen years of research, discussion, and personal experience, I am certain that as much as 70% of all domestic violence is cyclicly related. During our lunch, I mentioned that opinion to Dr. Dalton, and her response was...

"I agree with you, Peter, except for one thing...

I think that number is larger.

*In my estimation, between 85 and 90%
of all domestic violence is directly related to cycles."*

The charting of individual cycles is much akin to creating a train schedule. If we know when the freight train is coming through the living room, we can get up and go to another room, or even another building. Without the schedule, we keep getting hammered by things that seem to drop from the sky.

I believe that domestic violence is a treatable disease, and that the cure begins with recognizing and understanding our cycles. If **The Journal** and subsequent volumes are able to eliminate even 20% of domestic violence, all these years of effort and rejection will have been worthwhile.

I know, beyond a shadow of a doubt, that **The Woman's Health Journal** will significantly reduce health care costs, increase the accuracy of medical diagnoses, and ease the entire health care process. I am just as certain that if it is used, **The Journal** will eliminate a major portion of domestic violence.

What I don't know, is how to get anyone to listen. I have taken **The Woman's Health Journal** to the national conventions of The American Public Health Association, The American Medical Women's Association, and The National Association of Women's Health Professionals, and received only rave reviews and polite rejection.

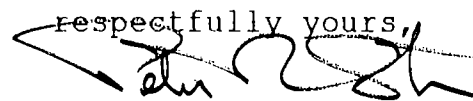
One graphic example was Dr. Dutton, Director of OB/GYN services at Walter Reed Army Hospital. He introduced himself at the San Francisco meeting of the APHA, and he immediately saw the profound contributions that were possible with **The Journal**. He stated that more than 70% of the women entering his offices do not even know when they started their last cycle, let alone remember symptoms or other details related to their complaint.

Dr. Dutton enthusiastically took a sample copy to review with his superiors. A month later, I received a telephone call from him explaining the rejections he had received and the reluctance of the Army's medical establishment to invest in preventive medicine. He apologized and said he would keep trying to get someone to listen, and assured me that he wouldn't forget.

Much of the difficulty and most of the wasted expense of this health care system exists because, as a nation, we are very poor health consumers. Sooner or later, that must change. Your plate is full with larger related issues and billions of dollars, but could you find a way to give this simple change a chance ...even if it was with a test group at Walter Reed?

Thank you.

respectfully yours,



Peter R. Stone

January 12, 1994

PERSONAL

Mr. Peter R. Stone
5810 Pleasant Lake Road
Ann Arbor, Michigan 48103

Dear Mr. Stone:

Thank you for sending me The Woman's Health Journal. It is an innovative idea for maintaining personal health records. It was kind of you to share it with me. I deeply appreciate your thoughtfulness.

Sincerely yours,

Hillary Rodham Clinton

HC/MSW/TF/pw (Corres. #1212058)

cc: WH Gifts
cc: Pam Barnett
cc: Gene Sperling

THE WHITE HOUSE

September 8, 1994

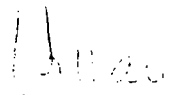
Mr. Leland Swensen
President
National Farmers Union
600 Maryland Avenue, S.W.
Suite 202
Washington, D.C. 20024

Dear Mr. Swensen:

Thank you for your letter about the treatment of health insurance premiums in the Farmers Home Administration farm loan application and servicing processes. I know that Secretary Espy has written to you to clarify the position of the Farmers Home Administration on this issue. Please feel free to contact me with any further questions or concerns.

I very much enjoyed speaking with the farmers on the conference call about health care reform in June. I look forward to continuing to work with you to make health security a reality for all Americans.

Sincerely yours,


Hillary Rodham Clinton



June 20, 1994

DATE FILED JUN 23 1994

Mrs. Hillary Rodham Clinton
1600 Pennsylvania Ave.
Washington, DC 20500

Dear Hillary:

I want to thank you for the opportunity to participate in the health care reform conference call with farmers on Thursday. We appreciate your continued leadership on the very important issue of comprehensive health care reform.

During the health care conference call a situation was referred to in which the Farmers Home Administration, in the development of the individual's necessary farm living expenses, did not feel health insurance needed to be a priority. As a result, the family was unable to afford to maintain their health care coverage.

This policy jeopardizes a farm family's security in two ways. First, the family is left with greatly reduced access to health care, and secondly, the family puts at risk everything they have worked for all their lives if a serious illness or accident occurs.

The National Farmers Union urges President Clinton to immediately direct the Secretary of Agriculture to issue a policy directive to all Farmers Home Administration personnel, that the cost of health care will be included with other basic necessities as a priority for farm living expense calculations.

This is one reform that can happen immediately as we continue our push for universal coverage and other important elements of comprehensive health care reform.

We look forward to working with you and the President in achieving this goal.

Sincerely,

A handwritten signature in cursive script that reads "Leland Swenson".

Leland Swenson
President

PERSONAL
&
~~CONFIDENTIAL~~

THE WHITE HOUSE

October 31, 1994

DETERMINED TO BE AN ADMINISTRATIVE
MARKING Per E.O. 12958 as amended, Sec. 3.3 (c)

Initials: ADG Date 12-5-13

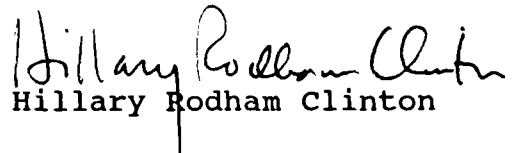
John F. Swope, CLU
President
Chubb LifeAmerica
One Granite Place
P.O. Box 515
Concord, NH 03302

Dear Mr. Swope:

I very much appreciate your words of support and your offer of assistance. The experience and expertise that you bring to the debate on health care reform are invaluable.

The President and I are pleased that, while Congress was unable to pass health care legislation this year, we have come further than ever before in our efforts to reform the health care system. We are committed to continuing our fight for health security for American families. I look forward to working with you in the coming months.

Sincerely yours,


Hillary Rodham Clinton



One Granite Place, P.O. Box 515, Concord, NH 03302
(603) 226-5276

John F. Swope, CLU
President

September 30, 1994

First Lady Hillary Rodham Clinton
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mrs. Clinton:

Last November, I wrote to you personally, urging that the national debate on health care reform proceed without resorting to a "victims and villains" scenario.

At the same time, I indicated our support for reform, including many of the specific suggestions in the President's Health Security Act.

Chubb Life provides health insurance and managed care options to more than 350,000 Americans - predominantly to small businesses with two to 25 employees. We have informed them of our belief that effective reform must be based on universal coverage.

In discussing political issues of reform in New Hampshire last week, George Stephanopoulos indicated ideas were sought to more successfully present Clinton health initiatives to Congress and the public.

I again offer my pledge to work with the Administration and Congress to develop federal reform that addresses costs, accessibility and affordability. Please consider our interest and expertise as a resource, and let me know personally if we can assist.

Sincerely,

A handwritten signature in dark ink, appearing to read 'JFS', with a long horizontal flourish extending to the left.

John F. Swope

JFS/psw
Enclosures

First things first.

Universal coverage.

The first step in building a strong health care reform program is to lay a solid foundation. And universal coverage is the cornerstone America needs.

Unless everyone is covered first, insurance reforms won't work. There will be little incentive for people to buy insurance, until they're sick. And because so many won't be paying into the system when they are healthy, the premiums necessary to pay for everybody's claims will be higher. That means higher costs for all of us, and leads to fewer people with coverage.

With sound reforms that begin with universal coverage, we can eliminate shifting the high cost of treating the uninsured to those with private insurance. We can eliminate job lock.

And most importantly, by building on present employer-based systems, we can guarantee coverage. Coverage that everyone can get, and everyone can keep, including those with pre-existing conditions.

If we want to build a health care reform program that lasts, let's put first things first. And support universal coverage.



ROLL CALL



THE NEWSPAPER OF CAPITOL HILL

THURSDAY, JUNE 16, 1994

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fm

~~CONFIDENTIAL - SECURITY INFORMATION~~
Date: 11/07/94 Time:

Study: Uninsured Have Higher Death Rates Than Employer-Insured

CHICAGO (AP) American workers who lack health insurance are up to 30 percent more likely to die in any given year than workers who are insured through their employers, a study of almost 150,000 people found.

The reasons have been well documented people without insurance get less routine or preventative care, and when they get sick, face many more barriers to getting the attention they need, said Douglas D. Bradham, a health economist at the Bowman Gray School of Medicine in Winston-Salem, N.C.

"They probably seek care late, typically in the emergency room," Bradham said. "They may not receive preventive services and screening services."

"Without proper screening, such as mammography, prostate cancer screening and colon cancer screening, their mortality would be expected to be higher."

The research also confirms previous studies showing that poor die at much higher rates than the rich, even if they do have insurance.

"Poverty and low income and inability to purchase services are not good for you, even if you've got insurance," said the lead researcher, Paul D. Sorlie, an epidemiologist with the National Heart, Lung and Blood Institute.

Of the people studied, 69 percent had employer-based insurance; about 4 percent were on Medicaid, the publicly funded health insurance program for the poor; and about 13 percent had no insurance. The remainder were covered through other means, including the military and disability coverage.

After controlling for differences in age and income, the researchers found that uninsured working men were 30 percent more likely to die and uninsured working women were 20 percent more likely to die than their working counterparts who had health insurance through their employers.

About 9 percent of the working men studied had no insurance; about 6 percent of working women had none.

Overall, uninsured men including workers and non-workers were 20 percent more likely to die than employer-covered men. Uninsured women overall were 50 percent more likely to die than employer-covered women.

The researchers based their findings on federal census data taken from 1979 through 1987 on 147,779 Americans aged 25 to 64. The sample was representative of the U.S. population, but it included too few blacks for the authors to be certain that the findings represent them as well as whites.

Medicaid-covered Americans fared worse than the uninsured they were more than twice as likely to die than employer-covered workers during the course of the study. But an independent researcher cautioned that Medicaid-covered people might have been less healthy to start with.

"You don't know whether mortality differences have to do with the quality of health insurance versus the fact that people getting Medicaid weren't healthy enough to be in the work force," said Dr. Andrew Bindman, a professor of medicine and health policy at the University of California, San Francisco.

"We know for sure (from previous research) that people who get Medicaid are not as healthy as people who work," said Bindman, who

was not involved in the study.

Findings are published in the November issue of the Archives of Internal Medicine, published by the American Medical Association. They are also being presented today at the AMA's Science Reporters Conference in Seattle.

APNP-11-07-94 0849EST