Reforming the Russian health service

Health service reform is an important part of the growth of democracy in Russia, and several Western groups have been helping the Russians tackle this huge task. Since 1992, general practitioners in the United Kingdom and medical teachers at the Medical Academy of Postgraduate Studies in St Petersburg have been sharing knowledge on medical education and primary health care. In this article, Dr Peter Toon, the UK coordinator, and Russian doctors involved in the partnership describe Russian health care and attempts at its reform from different perspectives.

Otherwise it might be convenient

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The Russian health service is vast. Primary care takes place, not in cosy domestic surgeries, but in polyclinics that feel like small district general hospitals without inpatients. Hospitals are correspondingly massive, often with a thousand or two thousand beds. Many were built in that architecturally depressing period that gave Britain the tower blocks we are now replacing. Unfortunately, Russia has no money for new buildings and little for maintenance, so they crumble gently away.

The Russian health service is specialist led. District physicians based in polyclinics, each responsible for 2000 patients in a neat geographical patch (patient choice has yet to reach Russia) look after primary care. They do little other than treat viral illnesses, issue medical certificates, and refer about half the patients they see to specialist colleagues. Half the doctors in polyclinics are specialists, and since patients have direct access to them, district physicians are often bypassed altogether.

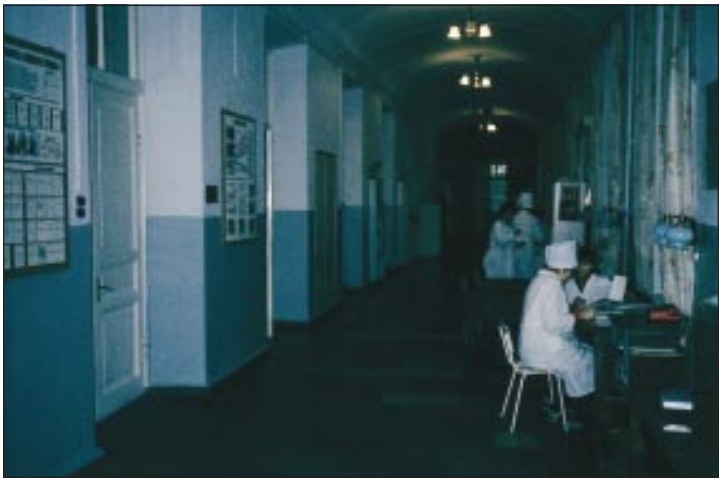
Obese and costly

As a Russian colleague put it, the service is "obese." There are long hospital stays, large numbers of specialists seeing too few patients, and a heavy authoritarian bureaucracy, since every doctor's work is checked by a superior. As in the United States and France, politicians—but not the health service or the people—have decided that they cannot afford such a costly system. A government decree on step by step reforms of the healthcare system in 1992 signalled a move towards generalist physicians, but progress is slow. Managers are only slowly becoming convinced of the wisdom of the reforms, and specialists in polyclinics obstruct changes that threaten their jobs.

Bad, good, or plain different

Many features of Russian health care are strange to the Western visitor—some are bad, some good, and some just different. In most countries, doctors are socially and economically privileged, but in Russia a doctor's pay is lower than the average wage, and they earn more "moonlighting" as taxi drivers. Under communism, medicine was a poor relation of mechanical engineering. The biomechanical model ruled supreme, and enthusiasm for medical technology, imaging, and endoscopy remains strong. One professor who had an interest in psychosomatic issues was branded a "non-person," deprived of rights to travel or to meet foreigners. Despite this, a rich vein of spirituality in Russian culture makes even worldly wise apparatchiks open to Balint[1] and the humanist side of medicine, while herbalism and physical therapies are fully integrated into Russian health care.

Like so many aspects of Soviet society, methods of medical education have failed to keep pace with developments in other parts of the world. Teaching is mostly



Russian health care is burdened by its massive inhuman scale and a heavy authoritarian bureaucracy

by didactic lectures, and postgraduate training focuses on defending a research thesis rather than on practical clinical skills.

Some services are organised very differently from those in the United Kingdom. Children have separate polyclinics and hospitals, and paediatricians are trained separately from the undergraduate stage onwards. There are two ambulance services, both with drivers and doctors. The one described below by Timur Vilks resembles general practice deputising services in the United Kingdom. The other is more like our emergency service. The ambulance, carrying nurses as well as doctors, goes to accidents or sudden illness, particularly in the street, and after delivering initial support carries the patient to an emergency department.

Most doctors in emergency departments are trained specialists, rather than the raw recruits that we in the United Kingdom put in the front line. They specialise in acute care of major trauma and in running intensive care units. The "walking wounded" attend separate minor injuries centres. This division of work is perhaps more logical than ours.

The influence of decades of totalitarianism does not disappear overnight. Democracy is not merely a system of government but a philosophy that penetrates every aspect of a country's culture. Many of the apparatchiks are still in place—they have just bought suits and fax machines and call themselves businessmen. Wide and sustained contact with democratic institutions and attitudes is needed if freedom is to grow and flourish in Russia.

Truth through anecdote

Russians are fond of illustrating a point with an anecdote, and in our exchange we have learnt much from them, including this habit. Outside the massive concrete slab of two hundred flats that is the Medical Academy of Postgraduate Studies hostel there is a permanent building site. An inspection cover right outside the door has been open all the week, although no work seems to be in progress. A visiting English lecturer asks Katya Schlachter, a young Russian doctor, why this is. "Otherwise," Katya replies, with a wicked twinkle in her eye "it might be convenient."

Might it?

Funding: None.
Conflict of interest: None

1 Balint M. *The doctor, his patient and the illness.* London: Pitman Medical, 1957.

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Urgent aid, chronic penalties

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There are two emergency medical services in Russia. Quick aid attends accidents and patients with life threatening conditions. I work for urgent aid, a service that arranges visits to patients in their homes for other urgent medical conditions. It operates 24 hours a day, 365 days a year.

On duty

9 am. I and my colleague go on duty. Our receptionist urges me to hurry as the next call will be mine. I hasten to sign the duty journal and registers to confirm that I have got drugs, alcohol swabs, urine catheters, and syringes. For the past two years we have had disposable syringes for single use (previously we had the reusable glass ones), but I must still return the used ones at the end of the day.

Our first call comes in. The patient is a 32 year old woman with asthma. The lift doesn't work, and we are going to the sixth storey of a nine storey building—the most common type our area. The door of the flat is slightly open, and I can hear hoarse breathing even before we enter.

"Any side effects from prednisolone?"

"No."

"Do you use theophylline?"

"Yes."

I ask my assistant to inject her intravenously with 120 mg of prednisolone, followed by 15 ml of 2.4% theophylline—very slowly.

9.39 am. We have finished the injection. Is it enough? The woman's condition is better, so I take her medical history. I have to write this according to a set pattern—complaints, history, examination findings, medication, effectiveness.

9.55 am. The patient is fine. I use her phone to call our department. "What's next?"

"Chest pain; a man aged 50."

A huge man with a red face and smelling slightly of alcohol lies on a couch. "What's happened?"

"I've felt a constant pressure on my chest for the past two hours. It's the first time in my life I've felt it. My painkillers don't work."

I ask my assistant take an electrocardiograph. There are some suspicious findings. The ST segment in V1-3 is elevated. I ask the assistant to inject 10 mg morphine intravenously, and to give 20 000 units of heparin. We also give the patient aspirin orally. The pain diminishes.

No one else is at home. I ask the patient where his toiletries are and tell my assistant to fetch the stretcher. Then I knock on the neighbours' doors. At last one opens. "Can you help our urgent aid team to carry a stretcher?" A man agrees. The lift is too small, so we have to carry the patient to the ground floor via the narrow stairs. I write a referral note for the hospital in the car.

10.50 am. We arrive at the hospital. I phone the urgent aid base. "What's next?"

"Please, return. The head of the department wants to speak to you."

I open the door of her office.

"A month ago you registered a female with acute gastroenteritis?"

"Yes. I wrote it in the journal for registering infectious patients."

"You didn't take a rectal swab?"

"No, she refused."

"You didn't write it up for the next day in the journal for taking rectal swabs. We have decided that this was a breach of the instructions. This month we will withhold 30% of your wages."

So, this month I will have earned 224 000 roubles (about £32) for my eight 24 hour shifts.

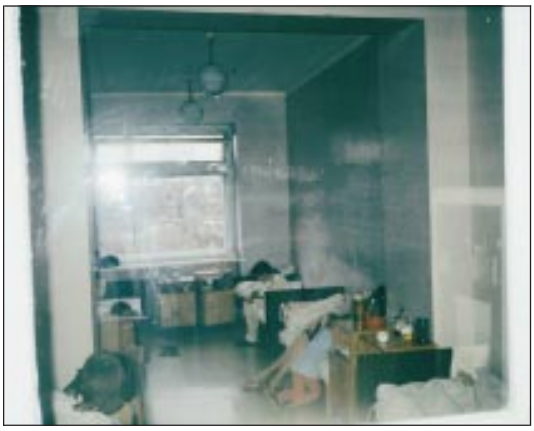
10.55 am. "Doctor, another call!"

Professional law breakers

Katya Schlachter

In Russia, a patient who guesses that his problem concerns his nervous system can go directly to the neurologist. Or he can go to his district physician who (if he or she is competent enough to know that the pain in the back is caused by radiculitis) will send him to the neurologist or advise him to go there. While most doctors are women, the majority of hospital specialists are men. A typical polyclinic specialist is a reserved, distracted woman. She worries about her children and the shopping, carrying heavy bags every day because she does not have a car and cannot go shopping in a supermarket on Saturday. She generally has neither time nor feeling for her patients—or if she has, then her family and home are neglected.

Doctors are constantly breaking some law or other. There are several thousand instructions concerning clinical and organisational subjects. Unlike Western guidelines, these are obligatory, and Russian doctors do not have computers to help them access information. Our computers are the means by which health authorities control the work of clinical doctors. Doctors in managerial positions draw two salaries, one as a doctor and one as a manager. They do statistical work and distribute money, in most cases taking it out of the clinical doctor's pocket—having accused him or her of not having kept some instruction—and putting it into their own.



Paediatric ward: child health care is delivered separately from adult services—and is seen to be working well

Ours is a strange country . . . a crazy country. Thank goodness someone has understood that our healthcare system needs changing. But some things are working well—child health care, for example. These we would like to preserve. The principles of general practice in the United Kingdom seem really good, and we would like to introduce these into Russia.

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Training general practitioners in St Petersburg

Vladimir Vinokur

Every doctor has to have an "improvement" course at least every five years in order to remain authorised and accredited. Institutions such as ours provide almost all these courses, as well as courses for doctors who decide to change their medical specialty. Our department, set up in 1992 as part of the move towards general practice, was established here because of our long history of leadership in psychosomatic studies. Most of our teachers are physicians, but they also have training in medical psychology or psychiatry. This enables us to put across a new philosophy on the doctor-patient relationship—a philosophy that emphasises partnership, active patient participation in the healing process, and health promotion. It differs from the common Russian view that doctors are directors of their patients, who should be submissive and not take responsibility for their own health.

Of course we face many problems. There are few working general practices, so we have to invite specialist lecturers to share their knowledge and skills with our students. This is not ideal, because general practitioners should be trained by general practitioners. Another challenge is the need to overcome resistance to general practice among both specialists and the public. There is also the need to establish programmes and curriculums, to introduce different self directed forms of learning, run Balint groups, and achieve a standard of qualification demonstrated by summative assessment. We are also keen to create textbooks and guidelines for our new general practitioners.

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Training general practitioners in Gatchina

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Our department has been training marine doctors since 1982. Since the situations of general practitioners and marine doctors are similar—the need to provide comprehensive care with a minimum of technical equipment and support—we concluded that the education they require is very much the same.

Two general practice surgeries have been opened in the city of Gatchina, 50 km from St Petersburg. One of these has four doctors and has been operating now for more than two and a half years. The second, with nine doctors, has been open for nearly a year. Experience shows that our training course of 18 modules covers the basic programme of postgraduate education and training for general practitioners outlined in ministry of health regulations. When the first general practice surgery started in Gatchina it became possible to provide practical experience for those training as general practitioners.

The duration of the course is determined by the enormous amount of work to be covered on one hand and the ability of local health authorities to pay for the trainees' education and minimising the length of time trainees have to spend away from their families on the other. We concluded that the best results are gained from basic training courses lasting seven to eight months, and that all general practitioners must then have an opportunity to continue their education once or twice a year for two or three weeks.

Most doctors who are trained as general practitioners are either district physicians or district paediatricians. These two groups need different types of training. Physicians need more paediatric training, while paediatricians need more training in general adult medicine.

The success of the training relies very much on every trainee knowing that he or she will have a job to go to. This helps to motivate them. It is also important to have feedback and to be able to improve the curriculum and the programme during the course. Feedback helps to balance the views of those who provide training, whose ideas and desires are not always appropriate to the realities of clinical practice.

Developing a general practice service is beset with important psychological and management problems. The healthcare reforms emphasising general practice will inevitably change the present structure of primary care, and many specialists will lose their jobs. This is one reason for the active resistance of medical staff to the reforms. Much depends on local healthcare authorities. These changes cannot be hurried and forced from the top; they must be carried through step by step.

In April 1995, general practitioners working in Gatchina met with local health authorities to discuss progress. Although the general practitioners felt that work had been much easier in the previous system of health care, no one wanted to go back. The level and standards of health care had risen, there had been no complaints from patients over the previous two years, and the number of referrals to specialists had fallen dramatically.

Personal paper

Late onset genetic disease: where ignorance is bliss, is it folly to inform relatives?

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One aspect of the rapid advances in molecular genetics is the capacity to identify genetic predispositions in a particular individual, where previously we made risk assessments based on aggregate or population observations.[1 2] Specific genetic data on one person unavoidably involve the family. They reveal information not only about the person examined but about their relatives and future children, who may be sick or carriers of the disease or trait. The proband, the family, and the genetic counsellor are faced with the problem of communicating news of the high risk for a genetic disease to healthy (asymptomatic) family members. They are also faced with making a moral choice between the right of family members to be privy to this information and their right to "blissful ignorance."

Summary points

- Knowledge of a genetic disease in an individual raises issues of whether and how this information should be communicated to his or her family
- The strategy for approaching and informing at risk relatives should depend on the genetic disease—on whether an unfavourable outcome is avoidable or not
- The initial approach to relatives should be made by the proband and be supported by information from a genetic counsellor
- The proband and counsellor have an obligation to ensure that relatives are informed about the risk of severe, preventable genetic disease

Moral obligations and ethical questions

Most genetic counsellors believe that family members have a moral obligation to share genetic information

with each other.[3] Many counsellors also believe that an uninvited approach to relatives at risk for a genetic disease is ethically questionable, irrespective of the disease. The Danish Ethics Council recently stated that "no unsolicited approach may be made by the health authorities in the case of an examination that may show any hereditary disease in the family. This should also be the case in situations where it can have serious consequences."[4]

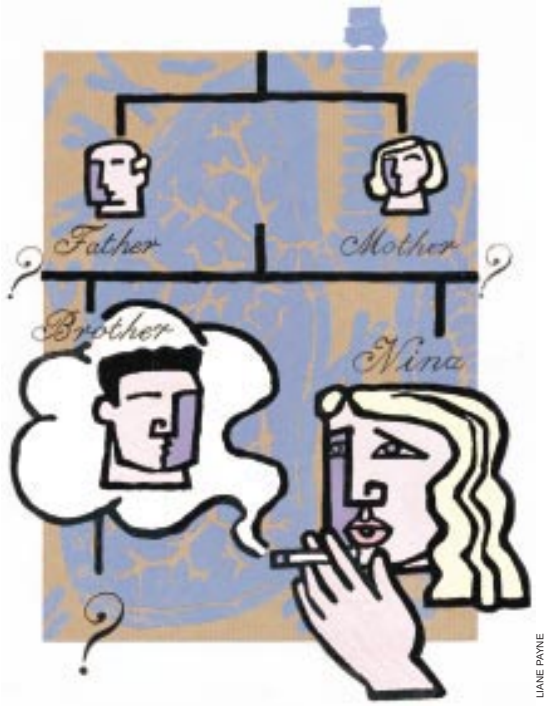
This recommendation is not in line with the Danish α_1 antitrypsin register's long tradition of contacting and informing directly the relatives of patients with α_1 antitrypsin deficiency of their risk and options for prevention. I believe that the strategy for approaching and informing relatives who are at risk should depend on the genetic disease in question. The strategy and the argument must be different for disorders such as Huntington's disease—where there is no way of avoiding the outcome—and autosomal dominant polycystic kidney disease, hereditary hypercholesterolaemia, or α_1 antitrypsin deficiency—where a small change in lifestyle or similar options can prevent disability and early death. Kielstein has expressed it thus: "As PKD [polycystic kidney disease] is one of the abnormalities where careful lifestyle management can prevent early and avoidable risks, some of them life threatening, there seems to be a 'duty to know' on the side of the patient, and an 'obligation to inform' on the side of the physician."[5 6]

Example: α_1 antitrypsin deficiency

To illustrate my analysis I have chosen to look at a typical case of α_1 antitrypsin deficiency. Nina consults her doctor because she is becoming increasingly short of breath. She is 35 years old and has smoked 20 cigarettes a day for the past 20 years. Nina's chest radiograph shows emphysema, her lung function is 35% of predicted, and a blood sample shows she has severe α_1 antitrypsin deficiency—homozygous genotype piZZ. The doctor tells Nina that α_1 antitrypsin deficiency is inherited as an autosomal recessive disease. The risk of her brother having it is 25%, and the risk for her children and his children is about 2% (1 in 1600 Scandinavians is homozygous genotype piZZ, and 4-5% are carriers of piMZ).[7 8] The doctor also tells Nina that the specific diagnosis of carriers and affected people is easy and valid,[9] and that smoking is the decisive risk factor. The only certain way to avoid chronic pulmonary insufficiency is to refrain from smoking. Patients with α_1 antitrypsin deficiency who stop smoking have a reduced annual decline in lung function and increased survival compared with those who continue to smoke.[10] Symptoms start at around 30-40 years of age, and median age at death is 50 years for smokers, while survival in never smokers is the same as that in the normal population.[11 12]

The right to know

Our experience with people in the position of Nina or her brother is that they wish to communicate and to be given information. Although many genetic counsellors make an effort to disseminate genetic information within affected families, they may not make a direct and unsolicited approach to relatives because they do not know what the relatives' attitudes are and whether the relatives want to know about their increased risks.



LIANE PAYNE

The Danish Ethics Council states that communicating genetic information within a family is solely a family matter, and the initiative must come from the proband. This view is based primarily on a consequentialist principle that focuses on possible harm to the relatives. "This [an unsolicited approach] can create undue anxiety on the part of relatives concerned and, at worst, encroach radically on their lives, through no wish of their own."[4]

Weighing up consequences

Knowing about a fate (genetic predisposition) whose likelihood and time schedule is uncertain and which requires you to make life, family, and employment/career plans and to tackle problems of reduced employability and insurability has considerable consequences. Certainly, knowing about α_1 antitrypsin deficiency forces Nina's brother to consider difficult problems and make hard decisions, but it also has positive aspects. Not to inform him might have serious consequences too, because he might expose himself to smoking, a risk that could be avoided. If Nina's brother is more than 25 years old and does not smoke, it is unlikely that he will start. Information about the risks of α_1 antitrypsin deficiency may be of limited use, except to reassure him that he has little to fear since those who have never smoked rarely develop severe disease. Nevertheless, the consequences of an active approach and information policy for someone in the position of Nina's brother are preferable to the consequences of remaining in ignorance.

Knowledge is power

Regardless of the consequences for Nina's brother, information puts him in a position to make his own decisions about smoking, to attempt to prevent his children and relatives from smoking, and to take

precautions when choosing an occupation. People who know that they have an appreciably increased risk of disease from smoking are more likely to stop. This was seen when 67% of Danes registered as having α_1 antitrypsin deficiency, genotype piZZ, quit smoking.[12]

Doctor knows best…

If, as recommended by the Danish Ethics Council, we decide not to inform Nina's brother, to prevent him becoming anxious, we are doing this for his own good. However, the ethics council's reasoning would prevent the health authority from approaching Nina's brother under any circumstances, and from ensuring that he is given the information needed to make his own decisions and choices. The essence of this policy is that the amount of information given to someone in Nina's brother's situation should be based on what the ethicist or doctor think is best for that person. Many people at risk for α_1 antitrypsin deficiency would be within their rights to question why they had not been told (if this were the case) and given the opportunity to take preventive measures and stop smoking. This question puts the concept of paternalism and the moral principle of respect for the patient's autonomy at the centre of the debate on the patient-doctor relationship and on unsolicited approaches by counsellors to relatives of probands.

Autonomy and paternalism

The moral principle of respect for autonomy means respecting someone's capacity to reflect on preferences and desires and the decisions they make concerning their own life.[17] An autonomous person should be free to decide to take great risks (for example, to smoke), however foolish these may be. But he or she should know what assumptions are being made, and should have enough knowledge on which to base decisions. People who expose themselves unwittingly to risk have not, in any considered way, chosen to take that risk. Smoking is dangerous for most people, but it is lethal for someone with α_1 antitrypsin deficiency. Therefore, to respect his right to autonomy, the genetic counsellor or Nina must approach Nina's brother and give him the information he needs to make informed decisions. Not ensuring that Nina's brother is told of his increased risk of pulmonary insufficiency shows a complete lack of respect for him as an autonomous person.

Paternalism is the substitution of one person's judgment for that of another in what the first considers to be the other's best interest. If the other person is an autonomous agent, a paternalistic act is also a denial of their autonomy. When the Danish Ethics Council recommends, or a doctor decides, to deny Nina's brother the knowledge needed to make autonomous decisions because they think he should not be made anxious, they are behaving in a paternalistic way. In the case of α_1 antitrypsin deficiency, this form of paternalism would be very hard to justify, since it would not have the best consequences for Nina's brother. In α_1 antitrypsin deficiency there is no conflict between respect for autonomy and consequentialist reasons for not informing relatives, whereas the opposite may hold for Huntington's disease.

The right not to know

The situation is different if someone has knowingly and freely stated that they prefer to leave difficult problems aside and do not want to be informed or approached by a doctor about an increased risk for this or any disease. In this case, it would be a violation of autonomy to insist on informing that person, and an act of paternalism (perhaps justified on occasions) if this were based on a judgment about what constitutes that person's best interests. With regard to Nina's brother, therefore, respect would also have to be shown for any wish he had expressed to remain in ignorance. Usually, there is no way of knowing a person's wishes … and if that person is and remains totally ignorant, they have no opportunity to consider the problem. If Nina's brother is to be told about the risk of α_1 antitrypsin deficiency, we have to approach and inform him one way or another, without his informed consent to such an approach. Should we leave him alone or are we in a situation in which exception to the rule of informed consent is reasonable?

Reasonable judgment

What would be a reasonable judgment about what a person in the situation of Nina's brother would prefer? An unsolicited approach to Nina's brother gives him the possibility of being provided with the information necessary to make autonomous decisions. In the case of α_1 antitrypsin deficiency, it is reasonable to believe that the benefits of knowing outweigh the consequences of knowing. There is little reason to suppose that someone in Nina's brother's situation would prefer to remain in ignorance. Perhaps some people might prefer to live in a "fool's paradise," but without positive evidence of this disposition it is more reasonable to assume the opposite.

The importance of privacy

The right to privacy concerns the right to exclude others, a right not to be scrutinised by others, and the right to control information about yourself that is available to others.[13] What is at issue with the right to privacy is people's right to control information about themselves that comes from themselves. This contrasts with respect for autonomy, where the concern is for people's right to control information about themselves that comes to them.[14] In the context of an unsolicited approach from a genetic counsellor, privacy often centres on issues such as where the counsellor obtained personal information. This is reflected in the questions that are often asked, such as, "Where did you get my name and address from?"

An unsolicited approach from a counsellor to Nina's brother constitutes information about him coming to him. The classic understanding of privacy is not violated by the approach itself and by handing over some possibly harmful—or at least not very pleasant—information to him. On the other hand, the right to privacy means that Nina's brother has the right to determine in what ways and for what purposes personal information about him is to be used. If the genetic counsellor asks Nina about her relatives and Nina discloses her brother's identity, his right to privacy has been violated. The counsellor now knows that

Nina's brother is at increased risk for α_1 antitrypsin deficiency. A widely (perhaps) known family relationship—being Nina's brother—is transformed into sensitive information when genetic data are added.

To reduce relatives' feeling of having their privacy violated, counsellors at the Danish register never make inquiries about relatives through any public register, but always through a written request to the proband. Probands are asked to inform their relatives of an approach, in advance if possible, so that everyone involved has an opportunity to stop this, and it is emphasised that no one is obliged to give any information to the register.

Who should approach relatives?

Some probands may prefer to inform at risk relatives themselves, while others prefer a health professional to contact relatives directly. Furthermore, some probands cannot or do not want to inform relatives themselves because of physical limitations or difficult relationships with family members.

In considering this issue the unofficial national council of bioethics in the United Kingdom,[14] the Nuffield Council of Ethics, has stated that "the primary responsibility for communicating genetic information to a family member or third party lies with the individual and not with the doctor, who however may do this on request of the person concerned."[15] In the case of preventable diseases such as lung insufficiency due to α_1 antitrypsin deficiency, I believe that both the proband and the genetic counsellor have an obligation to ensure that relatives are informed. The preferred way of informing relatives is by an initial approach from the proband supported by counselling and written information from the genetic counsellor.

Both the approach by the genetic counsellor and the proband have positive and negative aspects. I believe that direct genetic counselling of those involved is the best way of providing reliable information independently of personal/family preferences, and ensures that most people at risk are able to exercise their right to autonomous decisions. However, experience from the United States is frightening: entirely asymptomatic people labelled (possibly erroneously) as having a genetic predisposition are faced with discrimination, such as inability to get a job, health insurance, or life insurance; inability to change jobs or move to another state because of the risk of losing insurance; and not being allowed to adopt children.[16] Such social discrimination can be avoided if the proband is able to keep the genetic knowledge within the family.

In conclusion

My conclusion is that Nina's brother should be informed. Both Nina and the genetic counsellor should ensure that he is approached and told about his increased risk of pulmonary insufficiency due to α_1 antitrypsin deficiency and smoking, unless they have good evidence to suggest that he would not want to be told. The initial approach to relatives should preferably be made by the affected family member, and should be supported by written information through a personal mailed letter from the register or, less officially, through the proband; personal genetic counselling of all family members who might want it; and easy and free access to testing.

In theory, it seems fair to change and limit the Danish register's approach to those relatives who would benefit from a change in lifestyle, such as avoiding smoking. However, non-smokers too may have an interest in being informed so that they can prevent their children, if any, from smoking. The results of a continuing interview and questionnaire study of affected families and a randomly selected control population are awaited before any changes in policy are made.

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Conflict of interest: None.

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(Accepted 16 April 1998)

Corrections

The anatomy of a clinical information system
Three errors occurred in the reference list of this article by Keith Simpson and Mike Gordon (30 May, pp 1655-8). The references should have read:

14 Campbell JR, Payne TH. A comparison of four schemes for codification of problem lists. *Proc Ann Symp Comput Appl Med Care* 1994:201-5.
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Underperforming doctors: a postal survey of the Northern Deanery
In this paper by George Taylor (6 June, pp 1705-8), the date in the first line of the methods section should have been 1998 [not 1988].

A social experiment that keeps adapting
The date that Australians elected a socialist labour government was 1972—not 1975, as stated in this article by Peter J McDonald (4 July, pp 55-6).