ON PSEUDONYMOUS HEALTH REGISTERS *While they Work as Intended, they are Still Controversial in Norway*

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Abstract: Patient health data has a valuable potential for secondary use, such as decision support on a national level, reimbursement settlements, and research on public health or on the effects of various treatment methods. Unfortunately, extensive secondary use of data is very likely to have disproportionate negative impact on the patients' privacy. Traditionally, privacy regulations require a balancing process; the use of data should be minimized and kept within a level where proportionate privacy is maintained. An alternative strategy is to use technological remedies to enhance privacy protection. Norwegian health data processing regulation prescribes four different ways of organising health registers (anonymous, de-identified, pseudonymous or fully identified data subjects). Pseudonymity is the most innovative of these methods, and it has been available as a legitimate means to achieve extensive secondary use of accurate and detailed data since 2001. Up to now, two different national health registers have been organised this way. The evidence from these experiences should be encouraging: Pseudonymity works as intended. Yet, there is still discernible reluctance against extending the pseudonymity principle to encompass other national health registers as well.

1 INTRODUCTION

Any patient must accept some processing of his personal data, within the confines of a medical treatment. Some data are collected from the patient himself, and some data may be generated along the course of the treatment. The confidentiality will inevitably be at risk; the risks need to be monitored and handled. Privacy regulations and data security measures, along with professional ethics, safeguard against unwarranted processing and filing practises, and against deliberate misuse.

Privacy is also at stake when the patient's health data is used beyond the appointed medical treatment. Such use could be named *secondary purposes* for processing data. The subject matter of this paper is a particular variety of secondary purposes, namely a group of national health data registers. A register is a service that comprises a database, an operating organisation, and a legal authority defining responsibilities, duties to report to the register, restrictions on use and so on. In colloquial language the term register is normally taken to mean the database itself. The organisation and the legal authority are implied. The registers have two important features, from a privacy point of view. Firstly, they are centralised systems, containing aggregated data. Personal health data are collected from different hospitals or other treatment entities. As Norway is a small country, centralised registers usually cover the entire nation. The procedure of collecting the data could either be by electronic exchange or by printed reports which are re-typed into the centralised system.

Secondly, the data is collected and processed for secondary purposes, somewhat remote from the patient's immediate needs and interests. Roughly stated, these secondary purposes are governmental administration and medical research. Governmental administration includes both macro-level decision support and reimbursement control procedures. The demand for data is, at least in principle, limited and foreseeable. Medical research will also in most cases demand a stable amount of foreseeable data, yet in some cases it could be beneficial to use excess data or to perform inventive couplings involving different data sources. The future value of ingenious data mining is by definition unknown.

Regulations, security measures and ethics are of course at least as required for the registers as they

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are for data in the immediate care systems. In addition, the registers are vulnerable to expansions of their stated and legitimate purposes. Proponents of strict privacy regulations warn against "the slippery slope". It can be increasingly difficult on each particular occasion to turn down a proposition for extended use of a register. Such propositions often serve legitimate purposes, which is to achieve new and even benign goals more easily. Consequently, the patients' privacy is in danger of being scooped out in the long run.

1.1 The Adage of Norway's Favourable Conditions for Health Registers

Norway introduced a national identity number quite early. Starting in 1964, Statistics Norway assigned a unique 11-digit identification number to every individual. The primary purpose of the national identity number was to produce accurate statistics. Large public agencies, such as the Tax Administration and the National Insurance Administration, soon adopted the new unique identification number. No one imagined the vast future use of this new identity number. There was no explicit legal support for it, and hence there were no expressed restrictions on its use either (Selmer, 1992).

Due to the lack of restrictions on the use of population register data in the early years, the identity number is now the key to personal data in thousands of public as well as private IT-systems throughout the country, including primary health care systems and hospital systems. Most Norwegians will have to type or pronounce his unique personal identity number to some electronic apparatus (or to its human gatekeeper) several times a week. It is "open sesame" to enter both caves of treasures and caves of dung.

Due to the widely used national identity number, Norway may have favourable conditions for national health registers. Because the identity numbers are used in systems that are vital to virtually everyone, the data quality of the primary systems reporting to the registers almost takes care of itself. The registers could technically be suitable for collecting perfectly linkable data from the cradle to the grave.

However, the early years of vastly expanding the use of national identity numbers was succeeded by almost three decades of efforts to impart restrictions on their use. Lawful use of the national identity number is subject to a "norm of necessity". Roughly, it goes like this: When an exact identification is *necessary*, then the controller *ought to* use a unique identifier, while using the same unique identifier would be unlawful when unique identification is *not* necessary (this is a crude simplification, on my own behalf, of the Personal Data Act section 12). The result from these efforts to limit the lawful use of unique identifiers has not been any actual decrease in the use of the national identity numbers. Yet, many researchers perceive some uncertainty on whether they can use national identity numbers lawfully in their projects. A health register may not impart non-anonymous patient health data to research projects unless the recipient can provide sufficient justification for it.

No matter how favourable the conditions for health registers may be; legal restrictions prevent them from being used to their full potential. This situation induces two parallel debates: The first one is about the balance between privacy and legitimate uses of a health register. The second debate is about the possibility to circumvent patient identification without sacrificing the benefits of a health register.

1.2 The Origins of Digital Pseudonyms

A pseudonym is, literally, a "false name". For ages, pseudonyms have been used by authors and artists, or even in the rare event of modest researchers, to disguise their identity. The notion of a digital pseudonym first appeared in a paper by David Chaum. He invented digital pseudonyms as a means to conceal an individual's real identity in electronic transactions (Chaum, 1981). The intended field of application in Chaum's paper was banking and electronic commerce. A pseudonym concealed the identity of the person who actually paid the goods.

In a few consecutive papers, he developed both the methods and the rationale further. The public key distribution system provided a secure cryptographic pseudonym. For the holder of a pseudonym to be able to communicate or inspect his own personal data, a trusted third party could manage the pseudonyms. The rationale was to introduce a new paradigm for data protection; using technological means to put the individual in control of his own data (Chaum, 1984). Organisations would not be able to share data about the individual without the data subject "acting out" his consent, so to speak. No one could collect the complete history of your transactions, debts or savings. The holder of the pseudonym would also hold the key to reverse it.

As for the proposed new paradigm of privacy in banking and electronic commerce, it seems to have lost completely to the old paradigm of widespread use of fully identified data subjects. Meanwhile, the fields of health administration and medical research have revived the idea of digital pseudonyms.

1.3 The Pseudonymisation Process

There are different ways to carry out the process of generating a digital pseudonym to conceal the data subject's real identity.

The simplest form of pseudonyms, used for decades in research projects based on samples, is to assign a sequence number to each respondent. To enhance the respondents' trust, the researcher could hire a third party to perform the assigning process. This method works well for one-time surveys. For a panel study over time, managing sequence numbers becomes increasingly more difficult. Coupling data with relevant data from other sources would require an overt process of reversing the sequence numbers. The pseudonyms would be illusory. To exchange a "real identity" with an unrelated sequence number is only trustworthy when the researcher grants the respondent permanent anonymity, without adding to the data later. It is not a viable method for a longterm and multi-purpose health register.

A digital pseudonym in a health register involves advanced cryptography. The input to the algorithm that generates the pseudonym will have to be a stable identifying number, which does not change over time for the same patient. In Norway, the national identity number provides a convenient unique input. The health register will not need to store the national identity number, the algorithm secures that the same pseudonym is assigned to the same patient when more data is added to the register.

With a reliable and stable identification, there are, conceptually, two different ways to generate a pseudonym. One way is to use an asymmetric hash function. The encryption algorithm then generates a digest that is unique to the input, but there is no way to reverse from the encrypted digest back to the input identifier. Because the same input identifier always transforms to the same digest, it is possible to add data about the same patient in the same health register. It is, however, not possible to generate data couplings between individual-level data from two different health registers. This method provides a very high degree of confidentiality, but is on the other hand inflexible. Two health registers cannot be merged, and it would not be possible to address any registered patient, for instance if a new treatment method vital to his particular decease is developed.

The alternative way to generate a pseudonym resembles the "public key" encryption technology, and is basically the same as Chaum invented (see

section 1.2 above). The input to the algorithm is the same stable and reliable patient identity number. An encryption algorithm, using the "public key" of a key pair, generates the pseudonym. The same input, and the same public key, will make it possible to add data about the same patient to the same health register. In addition, a decryption algorithm can reverse the pseudonym back to the "real identity", by using the "private key" of the same key pair that was used for encryption. A trusted third party, which is an independent pseudonym manager, carry out the encryption, and if requested, the decryption. The health register will never see the real identity of the patient. The trusted third party, who is able to decrypt the pseudonym, does not have access to any sensitive information about the patients. This process provides more flexibility, at the cost of more fragile pseudonyms. The confidentiality of the patient is to a higher degree based on trust. Violating the pseudonyms will be somewhat easier from a technical point of view.

The latter method, a trusted third party handling reversible pseudonyms, has been the method of choice for pseudonymous health registers in Norway so far. Non-reversible pseudonyms would also conform to the legislation on health registers, yet it is not very likely that a register owner voluntarily would choose this less flexible process.

2 LEGISLATIVE SUPPORT FOR PSEUDONYMS

Recent technological innovations often seem to be far ahead of developments in legislation. Society's toolbox for protecting values and for distributing rights and obligations usually adapts slowly, to fit technological changes that have already taken place.

The introduction of pseudonyms in Norwegian health registers differs from this typical path of history. The first Norwegian national register based on pseudonyms was established in 2004. By that time participants in various legislation processes had already advocated this method for more than a decade. Technologists and professional users of the registers remained sceptic. Pseudonymous health registers have not at any rate been "technologydriven" in Norway, it would be far more correct to call it a "legislation-driven" development.

Norway has had registers for specific diseases, such as The Cancer Register, for decades. They started out as paper files, and were later converted to computer databases. The specific health registers had proved to be useful over time, and the health authorities started to nourish a desire to establish a General National Health Register, not to be limited to any particular diagnosis.

2.1 An Early, Avant-Garde Proposal

Though the advantages of a General National Health Register were convincing, The Parliament was also much concerned about the impact on the patients' privacy. In 1989, they urged The Government to appoint a committee with a mandate to examine ways and methods to establish such register "without threshing individuals' privacy" (Boe, 1994).

The appointed committee issued a report in 1993 (ONR, 1993). An "Official Norwegian Report" is in most cases the product of an appointed drafting committee, at an early stage of the legislation process. After an official hearing among relevant stakeholders, both The Government and eventually The Parliament may make changes to the original draft, or even turn down the entire proposition all together.

The drafting committee proposed, in their report, a new act to provide legal authority to the desired General National Health Register. The proposed act was very much ahead of its time. It contained regulations on cryptographic pseudonyms generated and managed by trusted third parties, along with a profound set of rules on ensuring legitimate use of the register, data quality, and the patients' right to access and so on.

However, neither the health authorities nor the research community was in favour of this avantgarde way to organise their much-desired new health register. As the main stakeholders did not support the proposition, The Government put it on hold, and it remained so for about eight years.

Instead of either a fully identified register (which was what the health authorities wanted) or a pseudonymous health register (the proposition they turned down), the health authorities established the Norwegian Patient Register (see section 3.3 below) in 1997. The Norwegian Patient register was originally established as a de-identified register (see section 2.3 below). This was acceptable under the Personal Data Filing Systems Act of that time, and it did not require The Parliament to pass any new legislation.

2.2 Specific Privacy Regulations for Health Data and Health Registers

The Parliament passed a new general Personal Data Act on April 14, 2000. The primary motivation for replacing the old act of 1978 was to comply with the European Union Directive 95/46/EC, on protection of personal data.

The Personal Data Act regulates all processing of personal data, for any legitimate purpose. Therefore, the rules are quite flexible, leaving most assessments and decisions to the discretion of the controller. For the processing of health data, The Parliament did not consider the general act sufficient. On May 18, 2001, they passed the Personal Health Data Filing Systems Act, containing rules that are somewhat more specific. The Personal Health Data Filing Systems Act too complies with the European Union Directive, and it has many important features in common with the general Personal Data Act. For instance, the information security requirements are essentially the same.

The primary guiding rule for processing health data is a requirement to obtain the patients' consent. However, the act also recognises a need in some situations to process data without consent. A typical exception to requiring consent would be the kind of health registers where complete coverage is vital to fulfil the purpose of the register.

2.3 Four Different Levels of Patient Identification in a Health Register

The key to the regulation of health registers is section 8 of the Personal Health Data Filing Systems Act. The initial position is simply that central health registers are forbidden, unless authorised by this act or by another statute.

The remainder of section 8 spans the possibilities and preconditions for establishing health registers, providing they have an adequate legal authority. The purpose of a register shall be "to perform functions pursuant to," specified health services (the relevant acts are listed in section 8). Those functions include "the general management and planning of services, quality improvement, research and statistics". In addition, the Government shall prescribe subordinate legislation for each health register, defining specific rules, responsibilities and organisation.

An interesting feature of section 8 is the way it categorises health registers into four distinct levels of patient identification. Every health register has to conform to one of these four levels. The *choice* of a level of identification encapsulates the privacy balancing process for each register.

Table 1: Outline of levels of patient identification (adapted from L'Abée-Lund 2006, page 28).

Personal data (being subject to privacy regulation)			Not personal data
Data refers to unambiguous individuals		Data may refer to ambiguous data subjects	
Fully identified	Pseudonyms	De-identi- fied	Anonymous

The bottom row of the table above shows the four different levels of patient identification. Their order, from the left to the right, reflects an order from more to less strain on the patients' privacy.

The middle row of the table shows the main division of whether the data refer to unique patients or not. Fully identified patients and pseudonymous patients both have the same granularity. They will provide the same level of statistical data accuracy.

The top row of the table merely shows that only three out of the four levels of patient identification are strictly within the definition of personal data.

Generally, fully identified health registers shall only process data about patients who consent. The only exceptions are a moderate number of health registers particularly named in section 8. By the end of June 2007 there are exactly nine fully identified health registers not requiring the patients to consent (the number of such registers was six by the time the act was originally passed, in 2001). The Parliament has to pass a formal change to section 8, specifically naming the new register, before anyone can establish a new fully identified central health register with a complete coverage (i.e. not requiring consent). That is the beauty of this construct in the Personal Health Data Filing Systems Act; it ensures an overt and highly democratic legislation process to be carried out before establishing a new register.

By using pseudonyms instead of fully identified patients, the health authorities can establish a new health register by issuing subordinate legislation. This means a Parliament decision is not necessary to establish the register. It also means the register can omit the patients' consent, if it needs complete coverage of the data. The option of pseudonymous health registers thus entered Norwegian legislation in 2001, eight years after it was first proposed.

A de-identified and a pseudonymous register have the same legal status according to section 8. The health authorities may establish a de-identified register by issuing subordinate legislation. A deidentified register means that any clear and manifest identifying information is removed. The advantage of a de-identified over a pseudonymous register is that the de-identified register is technically easier and less expensive to operate. The paramount disadvantage of a de-identified register is that the data is not on a strictly individual level. If a hospital carries out the same surgical procedure, say four times, a de-identified register cannot tell whether it involved four different individual patients or if the same patient was involved four times.

Pseudonymous and de-identified registers share the same risk of unlawful re-identification through computational analysis of the stored data elements (Malin, 2005). The uniqueness of each registered individual becomes more transparent as the number of detailed variables increase. Coping with the risk of re-identification first requires the register owner to keep his sobriety on what data is stored and processed. Second, there is still an indispensable need for rigid access control and other conventional information security measures with pseudonymous and de-identified registers.

In an anonymous register, all information that can possibly identify individual patients is removed. In addition to removing the manifest identifiers, the register also removes, or reclassifies into categories that are more general, any data suitable for reidentification by analysis. An anonymous register takes the granularity of the data into account. Making the data anonymous often means to take deliberate action to sacrifice their accuracy.

Anonymous data may be published, and they will not require extensive data protection. The downside to anonymous data, which is why they are unapt for health registers in most cases, is that it is virtually impossible to add meaningfully to the data.

2.4 The Professionals' Responsibilities, and a Democratic Safety Valve

To summarise, the Norwegian legislation allows four different methods for storing and processing personal health registers. A method granting more privacy is less effective for achieving administration and research goals. This inverse ratio is at the heart of any privacy regulation. All the four levels of identification are in use in some existing health register, and they have all proved to work as intended. Apart from the likes and the dislikes of different stakeholders: The four different nominal levels of identification themselves provide relatively objective aids for an informed policy debate. We know what the options are, and how they work. We also know how each of these options influence the privacy of the patients, versus the accuracy of governmental decision support data and the possibilities for providing valuable research data.

The health authorities remain chiefly responsible for all aspects of the health registers. However, the very strict preconditions for establishing a fully identified register (unless requiring patients to consent) constitute a striking democratic safety valve. Any such register require The Parliament to pass a formal change to section 8 of the Health Data Filing Systems Act. Professional agenda owners and stakeholders need not, and may not, decide alone on such privacy invasive registers. Though the process may be cumbersome and time-consuming, it also secures a highly democratic participation in the balancing between privacy and the well-grounded benefits of a health register.

3 A CURRENT STATUS, AND RECENT DEVELOPMENTS

Up to the end of June 2007, the Ministry of Health has seriously considered and deliberated on the option to make a health register pseudonymous on four different occasions. On two out of these four occasions, they actually decided to establish the proposed register with pseudonyms as its level of patient identification. For the other two registers, one of them was "promoted" to be a fully identified register, while the other one was "demoted" to be a de-identified register.

3.1 The Norwegian Prescription Database

The first pseudonymous national health register in Norway is called *The Norwegian Prescription Database* ("Reseptregisteret", in Norwegian). In October 2003 The Ministry of Health issued the subordinate legislation providing legal authority for the register, as required by section 8 of the Health Data Filing Systems Act. The register was actually established in the beginning of 2004.

Before the Prescription Database was established, the medicine statistics were based on sales figures reported from wholesale dealers. Unquestionably, the data was insufficient both for straightforward knowledge about use of medicine, and for research on effects thereof. Various stakeholders demanded statistics based on prescriptions and actual dispatch from pharmacies to individual patients. The intended purposes were neither to control any patient's catch at the pharmacy nor to supervise how named doctors carried out the business of prescribing. Pseudonyms both ensure the demanded capacities of the register, and safeguard against undesirable infringements of privacy.

All pharmacies report the prescription data electronically every month. A central data collecting point transfers the data to a trusted third party. The trusted pseudonym manager is in this case Statistics Norway. They transfer the pseudonymous data to the register owner, which is the Norwegian Institute of Public Health. Both the patient's identity (his national identity number) and the doctor's identity (his authorised licence identifier) are replaced with pseudonyms. The pharmacies are fully identified, on an enterprise level; their licence identifier is not pseudonymised (Strøm, 2004).

The Prescription Database was in many ways a "quiet reform". The changes have been virtually invisible to the patients. They still pick up their prescriptions and carry them to the pharmacies the same way they did before. They are not asked for consent. The existence of the Prescription Database is not a secret in any way, but neither is it of much concern to the patients. They only know about the pseudonymous data if they take a particular interest in detailed level health politics.

3.2 National Statistics Linked to Individual Needs for Care (IPLOS)

The second pseudonym-based health register is named the *National statistics linked to individual needs for care* (its Norwegian acronym is "IPLOS", which is derived from "Individbasert pleie- og omsorgsstatistikk"). The Ministry of Health issued the subordinate legislation providing legal authority for the register in February 2006. The first mandatory reporting term to the register was February 2007, collecting data from health care services throughout all Norwegian municipalities. The register owner in this case is the Directorate for Health and Social Affairs. The Tax Administration is the trusted pseudonym manager, which illustrates the point that the main feature of a pseudonym manager is its institutional independence.

Contrary to the Prescription Database, the IPLOS has not been a "quiet reform". The information about individual needs for care was not readily available from any existing process. Even though the patients can trust the confidentiality of the central register, they had to answer a new set of questions. Someone would type their answers into a local database before they were sent electronically to the pseudonymous register. The crucial question was not anymore whether the pseudonym provided sufficient privacy. Many patients felt offended by some of the most invasive questions in the form. The forms were changed as a result from complaints about some of the questions, such as whether a handicapped patient needs help after going to the toilet or needs help with handling the menstrual period.

Pseudonyms only remedy privacy issues that become present after the patients have left off their participation. An important lesson is that health registers mainly deal with data that the patients hardly are aware of. In many cases, the limits to a health register are with the processes of eliciting and collecting data, and not with the confidentiality of the register itself.

3.3 The Norwegian Patient Register

The Norwegian Patient Register is a hospital and outpatient clinic discharge register. Data on each patient is collected from every hospital in Norway. The acronym NPR is used both in English and in Norwegian when this register is referred to.

The history of the NPR is complicated, and truly interesting from a privacy point of view. NPR is the actual instantiation of the "General National Health Register" which initiated the committee back in 1989, who proposed a pseudonym-based solution register in their 1993 report.

After the proposed pseudonymous register was put on hold, it was revived in 1997 as a de-identified register. The NPR was established in March 1997. It receives reports on operative procedures extracted from the patient administrative systems at all hospitals. Age, sex, place of residence, hospital and department, diagnosis, surgical procedure, and dates of admission and discharge are included in the register (Bakken et al, 2004). The name and national ID number of the patients are not included.

The NPR has proved to be a valuable register, providing much demanded data for both research and administration purposes. Yet, as a de-identified register it does have obvious shortcomings. The data do not refer to strictly unambiguous individuals.

Over the last few years, the health authorities have made efforts to "promote" the NPR into a fully identified register. Proponents of privacy argued that promoting it into a pseudonymous register would be sufficient for all purposes of the register. The health authorities and the research community argued that a pseudonymous register might not provide adequate data quality. After a heated debate, The Parliament finally passed the necessary change to section 8 of the Personal Health Data Filing Systems Act on February 1, 2007, and included the NPR to be a fully identified health register. The subordinate legislation regulating "the new" NPR is expected anytime soon.

3.4 The Abortion Register

The latest example so far, of the Ministry of Health having seriously considered pseudonyms, is The Abortion Register. They made a proposition, intent to establish this as a pseudonymous register. The proposition went to a formal hearing; the closing date for the hearing was January 13, 2006. A large number of the bodies entitled to comment on the hearing were sceptic to a register containing as sensitive information as abortions.

The proposal was met with reluctance from different sides. Many answers to the hearing pointed out the particular strain on some of the women who decide to go through an abortion. Induced abortions are legal in Norway, yet there is a risk of social or religious condemnation from parts of the society, making the burden heavier. The Data Inspectorate, for instance, argued that the knowledge of an abortion register might influence on actual decisions on whether to have an abortion or not. Thus the register could affect, and not merely reflect, the health care activities. Recently, on June 21, 2007, The Government decided to make The Abortion Register de-identified, and not pseudonymous.

The policy debate on The Abortion Register shows an interesting limit to people's trust in a pseudonymous register. The confidentiality is based on trust in society as we know it today. The possibility of reversing a pseudonym could be exploited sometime in the future, when privacy values may be if worse off.

4 CONCLUSIONS

4.1 **Pseudonymous Identities Work**

Pseudonyms are a legal and a viable means for protecting personal data in Norwegian Registers. It has been one out of four lawful levels of patient identification since 2001. There are only two health registers based on pseudonyms so far. The numbers of both fully identified registers and de-identified registers are much higher.

A case study on the Prescription Database shows that the vital functions of a pseudonymous register work as intended (L'Abée-Lund, 2006). Neither the trusted pseudonym manager nor the register owner – nor anybody else for that matter – gets to see both the "real" identification numbers and unencrypted health data relating to the individuals at the same time. There were initial problems with the data quality for some time, but more recently, the rate of errors have been approximately the same as they are for fully identified registers.

4.2 Pseudonyms are Still Controversial

This brief report on pseudonymous health registers in Norway reveals some broad categories of arguments for and against pseudonyms.

The pro arguments are primarily a lower risk of disclosing information about patients, to people who do not need it, and for purposes where identification is unnecessary. A pseudonym increases privacy, while maintaining the statistical accuracy of the data.

The contra arguments are increased expenses due to the third party process, a risk of re-identification by analysis of the non-identifying data, and a danger of unforeseeable decrease in privacy if privacy policies change in the future. Finally, the argument most often raised against pseudonyms, is the data quality issue. The register owners will have reduced opportunities for discovering and fixing errors on their own. However, the third party may assist in structured "data laundering"-procedures.

Looking at the pros and cons of pseudonymous health registers, the amplitude of the controversies seems somewhat exaggerated. The pseudonymous registers are plainly an in-between solution. Moving either one step to the left or one step to the right, referring to the outline of levels of identifications in table 1, is merely a change in the balance of the arguments for and against pseudonyms. Choosing another level of patient identification will neither release all the advantages nor solve all the problems that may occur to a pseudonymous register. A proposal to make a particular health register pseudonymous can expect attacks from both sides; some will say identifying unambiguous individuals pseudonymously infringes privacy anyway, others will say pseudonyms place too heavy restrictions on the register.

In my opinion, though, the fact that the health authorities have only established two pseudonymous registers since that option was legislated for in 2001, while The Parliament has accepted three new fully identified registers during the same period, sadly indicates that proponents of pseudonymous registers in Norway are perhaps fighting a loosing battle. To the credit of the Personal Health Data Filing Systems Act, the construct of choosing between only four lawful levels of identification is in my opinion both clever and successful. It ensures a broad and overt democratic process, calling the attention of all stakeholders to voice their opinion.

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