Control, trust and the sharing of health information: the limits of trust

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- The limits of trust

ABSTRACT

Clinical information about patients is increasingly being stored in electronic form and has therefore become more easily shareable. Data are collected as part of clinical care, but have multiple other potential uses in relation to health system planning, audit and research. The use of clinical information for these secondary uses is controversial and the ability to safeguard personal and sensitive data under current practices is contested.

In this study we investigate the attitudes of a representative sample of the Danish population towards transfer of clinical data from their general practice for secondary use. We specifically study (1) patients' trust in different types of health care professionals, (2) their interest in being asked about secondary use of data, and (3) their willingness to dispense from a requirement of informed consent based on their trust in health care professionals.

We find that adult Danes are positive towards research that use patient data and they generally trust general practitioners, hospitals and researchers to treat their data confidentially. Nevertheless, they feel that they have a right to control the use of their data, only 7.3% disagreeing; and that the data belong to them, only 14.0% disagreeing. Answers to further questions about the relation between trust, information and consent show that although trust modifies the wish for information and consent, there is still a strong view that the patient should control the use of data. We find no differences between those who have frequent contact with the health care system and those who do not.

INTRODUCTION

Clinical information about patients is increasingly being stored in electronic form and has therefore become more easily shareable. One of the areas where electronic patient records (EPR) have achieved the greatest degree of market penetration is in general practice (GP). In Denmark where the current study is performed the penetration is almost 100 % in the GP sector and in hospitals. The EPR data are collected as part of clinical care, but have multiple other potential uses in relation to health system planning, audit and research. The use of clinical information for these secondary uses is controversial and the ability to safeguard personal and sensitive data under current practices is contested. The key issue being, whether patients should be able to control the sharing of their data and if so, to what degree. This controversy exists despite Danish citizens having access to their personal medical records via a centralised portal and Danes in general being aware that their health, social, employment, tax and many other data sources are linked through their unique Central Personal Register (CPR) number and used for research.

Protection of patient autonomy and/or a right to maintain privacy of personal information involves the right to provide or refuse informed consent to the sharing of data. However, informed consent, particularly in the context of data sharing, is most often strongly routinized. That is, it is often provided or refused as an unreflective habitual act.(1–3) Consequently, informed consent in the current format, does not protect patient autonomy or privacy; it does not provide the patient with any real control, because the patient does not make a real reflective decision. Moreover, informed consent also imposes an administrative burden on the stakeholders that have an interest in these data.

A possible response to such challenges would be to define what it requires to protect patient autonomy and privacy in relation to the secondary use of health care data. In this light, some may hold the view that what matters is that the patients' interests are protected and that this can be achieved without informed consent. For instance, by asking patients to consent solely on the basis of their trust in health care professionals acting in their best interest, i.e. without information,(4) or by letting health care professionals make the decisions, tasking them to make decisions that are in the best interest of their patients.

But how do we know that health care professionals act in the best interest of their patients? First, we must be able to identify the interests of the patients and secondly to consider whether health care professionals are in a position to protect those interests? One approach could rely on patients' trust in health care professionals: If patients trust health care professionals then this justifies believing that the health care professionals are able to adequately protect the patients' interests. This approach fits recent writings on trust suggesting that trust in the health care setting does not always conform to the traditional analysis of trust as a three-place relation where the patient trust the health care professional to perform a specific action.(5) Rather trust is a readiness to transfer decisional power to the health care professional, i.e. it is a readiness to leave some decisions to the discretion of the health care professionals.(6) While this analysis may find some empirical support concerning health care professionals' discretion in treatment choices in the clinical setting,(7) it is an open question whether it also extends to the transfer of EPR data to research.

Focusing on this approach, this paper studies 1) patients' trust in different types of health care professionals, 2) their interest in being asked about secondary use of data, and 3) their willingness to

dispense from a requirement of informed consent based on their trust in health care professionals. If they do not trust health care professionals, and/or they have an interest in providing informed consent, and/or they are not willing to dispense with a requirement of informed consent on the basis of trusting health care professionals, then the trust-based paradigm cannot replace a consent-paradigm as a way of securing the protection of patients' interests in relation to the secondary use of health data.

The paper is based on a study of the attitudes of the Danish population concerning appropriate control of the sharing of EPR data from general practice for research purposes.

MATERIALS AND METHODS

A questionnaire was developed containing three questions about the frequency of contact with the health system (Table 1) and 11 questions about appropriate control of the sharing of health data and about trust in different actors in the health care system (Table 2 & Table 3). The questions were prefaced by the following statement:

> When you visit your own GP or a hospital the doctor/doctors make notes about e.g. investigations and diagnoses in your patient notes. This information can be linked with other registries through your CPR number and used for research.
>
> We are interested in knowing your views on transfer and use of patient data for research.

The number of questions available was limited by the requirement to fit this section into a larger omnibus web-survey. This need to prioritise questions and make the questionnaire compact meant that an open question asking for further views or comments was not included, even though the answers to such a question, if answered by a significant proportion of the respondents could have been used for triangulation and a deeper understanding of the numerical results.

The questionnaire was developed by the researchers and pilot-tested for face validity. It was then distributed in August 2017 to a reference panel by Forbrugerrådet Tænk[1]. The questionnaire was distributed as part of a larger omnibus web-questionnaire covering some other issues that were completely unrelated to health and information governance. As part of this larger questionnaire a range of demographic data was collected. Surveys of this kind does not require research ethics approval in Denmark.

The reference panel has been recruited by in-depth telephone interviews to be representative of the adult Danish population, but the August 2017 survey had a 6.2% underrepresentation of men and was slightly skewed towards older respondents with a 5.8% overrepresentation of members over the age of 60 years.[2]

Data were analysed using non-parametric methods, Chi-square, Friedman ANOVA by rank, Spearman rho correlation, Mann-Whitney U test, and Jonckheere-Terpstra test for trend.

[1] The Danish Consumer Council

[2] Personal correspondence from Forbrugerrådet

We fitted a multinomial regression model with the main question about control as the dependent variable, and gender, age, educational level, frequency of contact with GPs and hospitals, and the ten attitude and trust questions as co-variates. Using backward elimination from the complete model with a removal probability of p=< 0.1 ten variables are retained in the model (Table 4).

Data were analysed in SPSS 23. All statistical analysis was performed on unweighted data.

RESULTS

The questionnaire was distributed electronically to 3,278 reference panel participants and 994 completed the questionnaire (30.3%). Of these 553 (55.6%) were women and 441 (44.4%) men. The age distribution can be seen in Table 1. Of the respondents, 196 (19.7%) had children below the age of 18 living with them.

The results are shown in Tables 1-3. Results weighted by gender and age are shown in Tables 2w and 3w in appendix A. The analysis shows that women have a greater degree of trust in health care institutions and that respondents with higher education are more positive towards research.

The relationship between patient status as evidenced by frequency of visits to GPs or hospitals or having a chronic condition and attitudes to whether research is important and what attitudes respondents have towards control and ownership of data show no significant relationships (Spearman ordinal correlation and Chi-square tests, d.n.s.).

Comparisons of trust levels in general practitioners, hospitals and researchers in relation to confidentiality shows than the trust in general practitioners is significantly higher than the trust in hospitals and researchers ($p < 0.0005$ in both cases) and that there are no significant differences between the trust in hospitals and researchers (Related samples Friedman's two-way ANOVA by ranks).

Analysis of the correlations between the three questions about trust in GPs, hospitals and researchers, and the three questions about the relation between trust and the need to receive information and control the use of data show that there are fairly strong and statistically significant correlations between these questions (Spearman ordinal correlations in the range 0.172 – 0.257, $p <= 0.0005$, dns). That is, respondents who trust GPs, hospitals and researchers are more likely to link trust to a willingness to accept less information and control when trust is present.

Multinomial regression analysis shows that having trust in researchers and being older is positively associated with expressing the view that you do not need to be asked before your data are used. Believing that you have a right to control your data, that they are your property, not having trust in hospitals but having trust in in researchers, not linking trust to control over data, and being older is positively associated with the view that you, yourself should control data sharing. And finally, not having trust in hospitals but having trust in researchers and being older is positively associated with wanting your GP to control data sharing (Table 5).

DISCUSSION

Most adult Danes are positive towards research that use patient data and they generally trust general practitioners, hospitals and researchers to treat their data confidentially. With the largest trust being placed in general practitioners where only 3.2% of respondents state that they do not trust their GP.

Nevertheless, they feel that they have a right to control the use of their data, only 7.3% disagreeing; and that the data belong to them, only 14.0% disagreeing. The strong desire for control over the exchange of data for healthcare and research fits similar studies in various different populations.(8–14) They also agree that some types of health data are more private than other types of health data.

The current study also provides valuable insights into the potential difference in preference for control between patients and non-patients. Thus, one may venture that patients are more positive towards research and care less about control over their health data than non-patients or citizens in general. Such a view is not, however, supported by our findings which show no relationship between frequency of contact with the health care system or having a chronic condition and attitudes towards research and control over data.

When asked about the relation between trust in data security in the health care system and the need for information about data use and control over data transfer for research most agree that if they have this trust they need less information.

The results very clearly show that despite the positive view of research and the large degree of trust in researchers, a large majority of the adult Danish population want some control over whether their data are transferred from their general practitioner to be used for research. Most want to make the decision themselves, but others want their doctor to be the decision-maker. This is in stark contrast to the current Danish legal situation where patient data generated in general practice can be used in research without the permission of the patients or the practices. These results also provide an important addendum to the research literature on the role of trust in relation to informed consent for research participation. Several studies suggest that trust in health care professionals, researchers and institutions may increase the chances of people consenting to research participation and that distrust drives non-consenting behaviour.(10,15–17) The current study clearly show, however, that in relation to secondary use of health data, trust cannot replace the control afforded by consent procedures even if it may influence the willingness to participate in research.

The survey did not distinguish between transfer of patient data that are person-identifiable and patient data that have been anonymised, even though this is a common distinction in the literature. This is for a number of reasons. First, in Denmark patient data are transferred into centralised data bases in a person-identifiable form, which allows for the linkage with other health and non-health data via a uniquely identifying social security number (CPR-number). Second, possible patient interests in control of data transfer for research are actualised by both types of data, e.g. interests in controlling which kinds of research data are used for. A conjoint analysis study found that the single most important factor for patients' willingness to share health information for secondary use was the purpose of the use, e.g. marketing, drug company uses, quality improvement etc.(18) The sensitivity of the health information was not a significant factor. This result indicates that anonymisation plays a minor role for decisions about sharing of health information. While other studies indicate that privacy concerns and the sensitivity of data may influence the willingness to share data, they also indicate that the purpose of use and the actual users are more important

drivers of the willingness to share health information with stakeholders outside of the treatment setting.(13,14,19–21)

Limitations of current study

The study has a number of limitations. First, our sample has a slight overrepresentation of women and it is older than the Danish general population. We find that age is positively associated with having less of an interest in controlling your own data, so our results may underestimate the desire for control in the Danish population.

Second, we use a Likert-scale with an odd number of steps which means that there is a neutral option. Respondents are thus not forced to state an attitude to a particular question but can choose the middle, neutral option. There is a huge and inconclusive methodological literature on whether Likert-scales with an odd or even number of steps are preferable for attitude measurement.(22–24) We chose an odd number of steps since it seems eminently possible to have a neutral attitude to or be undecided about the questions in this questionnaire.

Third, this is a relatively simple survey and may not reflect the considered views of the respondents. However, respondents are asked about issues that are not hypothetical but affect them directly. Of the respondents 93.5% have been to their GPs during the last two years, and 47.6% have been treated in hospital so the large majority have recent clinical data stored in electronic form at their GP practice or a hospital.

CONCLUSION

The trust-paradigm is not on its own an appropriate solution to the ethical conundrum surrounding the secondary use of health data. Even in a population like the Danish that has a high level of trust in the handling of health data for research there is still a significant proportion of citizens who want some form of control over how their data is used and exchanged. Policy makers may choose to ignore that desire for control, as they currently do in Denmark. This may not lead to a breakdown in trust in relation to researchers or other users of health data, but it may lead to diminished trust in relation to the whole system of data collection and use and/or a decreased willingness to collaborate in data collection. There are many ways in which citizens can be provided with a measure of control over the secondary use of their health and other data.(19) We have, in other work developed the concept of meta consent, described in detail how it can be implemented in well ordered health care systems, and defended it against the criticisms that it will impede research and increase research costs.(25–27)

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Table 1: Demographics						
How old are you?	Less then 25 years	25-35 years	36-49 years	50-60 years	More than 60 years	
	21 (2.1%)	75 (7.5%)	170 (17.1%)	217 (21.8%)	511 (51.4%)	
How many times have you visited a GP in the last 2 years?	1-2 times	3-4 times	5-6 times	> 6 times	Don't remember	Have not been at a GP in the last 2 years
	326 (32.8%)	290 (29.2%)	147 (14.8%)	166 (16.7%)	10 (1.0%)	55 (5.5%)
How many times have you been treated in hospital in the last 2 years?	1 time	2 times	3 times	> = 4 times	Don't remember	Have not been treated in a hospital in the last 2 years
	244 (24.5%)	90 (9.1%)	54 (5.4%)	83 (8.4%)	3 (0.3%)	520 (52.3%)
	Yes	No	Don't know			
Do you have one or more chronic conditions or an illness that requires frequent contact with the health care system?	353 (35.5%)	618 (62.2%)	23 (2.3%)			

Table 2: Who should control data sharing?				
Who do you think should control whether your patient data is used for research?	I do not need to be asked if my data is used for research	I want to decide myself whether my patient data can be transferred from the GP practice to research	My doctor should decide whether my patient data are transferred for research	Other
	314 (31.6%)	525 (52.8%)	114 (11.5%)	41 (4.1%)

Table 3: Attitudes to data and data sharing					
	Completely agree	Agree	Neither agree nor disagree	Disagree	Completely disagree
Research using patient data is important	534 (53.7%)	362 (36.4%)	81 (8.1%)	13 (1.3%)	4 (0.4%)+
I have a right to decide the use of my data	419 (42.2%)	352 (35.4%)	150 (15.1%)	54 (5.4%)	19 (1.9%)
Data about me are my property	322 (32.4%)	299 (30.1%)	234 (23.5%)	111 (11.2%)	28 (2.8%)
Some types of patient data are more private than others	370 (37.2%)	371 (37.3%)	152 (15.2%)	60 (6.0%)	41 (4.1%)
I trust that my GP treats my data confidentially	447 (45.0%)	432 (43.5%)	83 (8.4%)	27 (2.7%)	5 (0.5%)*
I trust that the hospital treats my data confidentially	360 (36.0%)	437 (44.0%)	138 (13.9%)	51 (5.1%)	8 (0.8%)*
I trust that researchers treat my data confidentially	369 (37.1%)	404 (40.6%)	166 (16.7%)	46 (4.6%)	9 (0.9%)*
If I have/had trust in data protection in the health care system I do not need as much information about what my data are used for	216 (21.7%)	363 (36.5%)	159 (16.0%)	171 (17.2%)	85 (8.6%)*
If I have/had trust in data protection in the health care system I do not need to be asked whether my data may be transferred for research	201 (20.2%)	327 (32.9%)	124 (12.5%)	226 (22.7%)	116 (11.7%)*
If I have/had trust in data protection in the health care system I do not need to be asked every time my data is transferred for research	216 (21.7%)	345 (34.7%)	147 (14.8%)	178 (17.9%)	108 (10.9%)

* Mann-Whitney U test p=<0.005 Women more trusting then men

+ Jonckheere-Terpstra test for trend p=<0.005 Higher educated respondents find research more important

Table 4: Likelihood Ratio Tests				
	Model Fitting Criteria	Likelihood Ratio Tests		
Effect	-2 Log Likelihood of Reduced Model	Chi-Square	Df	Sig.
Intercept	1535.091	12.859	3	.005
Visits at GP	1523.144	.912	3	.823
Visits at hospital	1522.603	.370	3	.946
Research important	1536.656	14.424	3	.002
Right to data	1551.878	29.646	3	.000
Data is my property	1544.902	22.669	3	.000
Some types of data are more private	1547.905	25.673	3	.000
Trust GP	1526.155	3.923	3	.270
Trust hospital	1532.458	10.226	3	.017
Trust researchers	1534.426	12.194	3	.007
If trust, less information	1527.674	5.442	3	.142
If trust, no need to consent	1553.818	31.586	3	.000
If trust, no need to consent every time	1530.748	8.516	3	.036
Gender	1534.315	12.082	3	.007
Age	1542.644	20.412	3	.000
Education	1528.317	6.085	3	.108

Table 5: Multinomial Regression Model					
Who do you think should control whether your patient data is used for research?		B	Std. Error	df	Sig.
I do not need to be asked if my data is used for research					
	Research important	.276	.282	1	.326
	Right to data	.046	.232	1	.841
	Data is my property	.002	.220	1	.994
	Some types of data are more private	-.166	.178	1	.350
	Trust hospital	-.680	.455	1	.135
	Trust researchers	.979	.311	1	.002
	If trust, no need to consent	.149	.357	1	.677
	If trust, no need to consent every time	.526	.356	1	.139
	Gender	.222	.362	1	.540
	Age	.567	.149	1	.000
I want to decide myself whether my patient data can be transferred from the GP practice to research					
	Research important	-.340	.269	1	.205
	Right to data	.824	.243	1	.001
	Data is my property	.553	.220	1	.012
	Some types of data are more private	.327	.175	1	.062
	Trust hospital	-1.115	.436	1	.011
	Trust researchers	.787	.291	1	.007
	If trust, no need to consent	-.777	.337	1	.021
	If trust, no need to consent every time	-.050	.326	1	.877
	Gender	.848	.359	1	.018
	Age	.298	.146	1	.042
My doctor should decide whether my patient data are transferred for research					
	Research important	.095	.307	1	.758
	Right to data	.175	.255	1	.492
	Data is my property	.110	.237	1	.642
	Some types of data are more private	.307	.201	1	.127
	Trust hospital	-1.074	.477	1	.024
	Trust researchers	1.214	.358	1	.001
	If trust, no need to consent	-.046	.380	1	.904
	If trust, no need to consent every time	.073	.373	1	.845
	Gender	.477	.391	1	.223
	Age	.609	.170	1	.000