

# Chapter 60

## Political Attitudes on the Dutch Electronic Patient Record

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### ABSTRACT

*In the Netherlands, the introduction of a nationwide electronic patient record (EPR) infrastructure was rejected in 2011 after a heated political debate. Such debate is influenced by the political attitudes of politicians and voters, such as their trust in governments. The objective is to explore the relation between political attitudes of individuals and the priority they give to health privacy. The method is from a new survey that was developed; the Health Privacy and Political Attitudes Survey. The survey is as compatible as possible with a few well-known surveys. With 218 respondents enough data was collected for a first explorative study. Little correlations were found between political attitudes and the individual's prioritisation of health privacy or their trust in a nationwide EPR. In general, most respondents valued their health privacy highly and trust in a nationwide EPR was low, irrespective of their political affiliation or their political attitudes. One exception were respondents with authoritarian attitudes. Such individuals had, on average, more trust in (government regulated) electronic records. More trust in the law correlates with less fear for problems with the EPR. Interestingly, higher educated and older respondents have, on average, the same level of trust in the EPR as others but are more apt to act when they distrust the system (opt-out). In general, political attitudes and one's trust in electronic patient records (EPRs) are not strongly related, but individuals who score high on authoritarian attitudes and trust in the law are more likely to also trust EPRs. Still, nearly everybody places a high value on health privacy, so EPR providers should be careful in this regard.*

### 1. INTRODUCTION

In April 2011, the plan to introduce legislation for a nationwide Electronic Patient Record (EPR) communications system in the Netherlands failed. It was a close call – the letters informing civilians

about the new EPR were already sent. The Lower Chamber of Dutch Parliament had passed the legislation. The Senate (Upper Chamber) usually agrees with the Lower Chamber, although sometimes minor adjustments are required. But this time, the minister of health, Schippers (VVD<sup>1</sup>, a

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conservative-liberal party), saw her law proposal unanimously rejected, mainly over concerns over data security and privacy<sup>2</sup>. One of the leading Senate senators vocally rejecting the proposal was Dupuis, also member of the VVD. This disagreement within one political party already hints at the unconventional political cleavages separating people on this issue.

The unanimous rejection of the EPR law does not reflect the finding of most opinion research surveys that hint to a strong public support for digitalised health records – see table 1. As much of the political debate was over privacy concerns, a better understanding of health privacy might help to understand why the Dutch Senate rejected the proposal.

This study explores the relation between the importance given by voters to a nationwide EPR (enforced by law) and the voters' political attitudes. How voters appreciate a nationwide EPR is related to their attitudes on health privacy and their trust in the rule of law. Attitudes predict behaviour and opinions and are thus important for understanding the political debate about EPRs.

Little is known about a possible relation between political attitudes of individuals and the valuation of health privacy by the same individuals. This study explores such a possible relation by measuring both political attitudes and health privacy preferences in a sample of the Dutch population. For measurement, the survey as described in the "Methods" section is used.

First, the Dutch EPR, health privacy and political attitudes will be introduced. Second, previous work and the relevance of this study will be discussed. Thereafter the survey and its results will be presented and discussed. The paper will be concluded with a reflection on policy implications and suggestions for future research.

## 1.1 The Dutch EPR

The Dutch EPR is not a centralised medical records database, but more of a decentralised storage structure with a centralised communications infrastructure for medical records, so that medical care providers can easily access patient records from each other. In practice, most medical data stored by participating parties such as hospitals, pharmacies, and general practitioners can be accessed by all other participating parties. Access logs provide after-the-fact security.

The proposed opt-out system ensured that people would take part in the system by default. In an opt-out system, one has to actively object to be excluded from the system. An opt-in system is harder to introduce because all participants must actively give permission beforehand.

A number of medical specialists, politicians, and computer scientist did raise objections to the legal proposal to make participation in the EPR compulsory for health care providers. One of them, van 't Noordende (2010), wrote a paper on the security of the proposed EPR and showed important shortcomings and vulnerabilities.

Table 1. Public popularity of health databases by country

| Country     | Year | Perc. | Support in favour of       | Source                          |
|-------------|------|-------|----------------------------|---------------------------------|
| Canada      | 2003 | 78%   | genetic research database  | Pollara and Earncliffe, 2003    |
| Sweden      | 2005 | 80%   | shared, national HER       | Rynning, 2007                   |
| USA         | 2005 | 72%   | health information network | Public Opinion Strategies, 2005 |
| USA         | 2008 | 79%   | electronic PHR             | Westin, 2008                    |
| Australia   | 2008 | 82%   | individual HER             | UMR Research, 2008              |
| Netherlands | 2009 | 63%   | electronic EPR             | de Hond, 2009                   |
| Netherlands | 2009 | 85%   | electronic EPR             | TNS NIPO, 2009                  |

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