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Opt-in and opt-out policies for data exchange in the healthcare sector: citizen preferences

By Jurian van de Vliert (S1026230)

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Program in Economics
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Supervisor: Koen van der Waluw

Abstract

This research investigates preferences and attitudes towards an opt-out system regarding data exchange in the health sector in comparison with an opt-in system. Healthcare employees need to get access to medical information from patients to ensure better quality of care. If a doctor needs to share data with other doctors, patients in the Netherlands have to give explicit consent (opt-in). When the patients do not give permission to share their data, it is not accessible by other healthcare professionals. This thesis inquired the preferences towards an opt-out system in which consent is given by default. In an experiment, I varied characteristics of the permission procedure to examine its effect on 1) willingness to exchange data in the medical sector, 2) willingness to have an opt-out system instead of an opt-in system and 3) the perceived autonomy of the decision-making process. I randomized participants to one of five scenarios in a between-subject design to test the hypotheses that the default channels endorsement, ease and endowment have a positive effect on the perceived benefits of the standard option. The five policy scenarios for permission were: a neutral opt-in condition, a neutral opt-out condition and 3 different behavioural emphases in the opt-out condition namely ease, endowment and endorsement. Across the study, I find that participants in the opt-out condition low costs were willing to exchange their data more often than in the opt-in scenario. Support for a general opt-out policy also increased if participants were in the neutral opt-out condition. Awareness of the default is significantly lower in the transparency condition; however, the perceived risks for marginalized groups are significantly lower in the opt-out transparency and opt-out low costs condition. Putting emphasis on ease, endowment or endorsement resulted in a higher feeling of being deceived in the ease channel in comparison with the neutral opt-out scenario. The study finds that the opt-out condition low costs has a significant positive effect on perceived feeling of being deceived in comparison with the opt-out neutral condition. Theoretical and practical implications are discussed.

1 Introduction

This research inquires what choices people make regarding the exchange of data in the healthcare sector for an opt-in and opt-out situation and for different conditions. Secondly, knowledge questions were asked to the participants to see whether they know the status quo in the healthcare sector. Thirdly, the attitudes towards an opt-in and an opt-out system will be measured. The differences between conditions were tested. Lastly, the attitudes of the participants towards the different scenarios will be measured by testing how participants perceive the way they were asked to give consent or not.

When people need care, they could encounter many medical specialists like for example the GP, a doctor at the GP post, specialists in the hospital, a physiotherapist etcetera. The doctor needs to maintain a medical record for every patient because it can be important for care now and in the future. Multiple doctors can be involved in the treatment of a patient and therefore it is important to have all relevant medical info about the patient in a system. However, it is not possible to access the medical information of patients when the patients did not give consent to exchange the medical info at this moment in the Netherlands (Ministerie van Volksgezondheid, 2020; Ploem & Dute, 2005). There is a lot of debate on how to improve the quality of care in the Netherlands. However, the choice architecture is not involved in the debate.

Patients in the Netherlands have difficulties communicating between the GP and the doctors because the GP might not be informed about treatments performed by the doctors and vice versa (Jansen, 2022), a lot of resources are spent to find out the relevant medical data for patients. This reduces the quality of care because less info is available and additional time is needed to figure out what happened to the patient. At this point, accessible relevant medical data is not complete, or it takes a while to get the data accessible in the systems. Quality of care could be easily improved by simplifying the exchange of medical data where consent of the patient is needed (Jansen, 2022).

Obtaining consent can be distinguished in two ways: opt-in and opt-out, in the opt-in system, data is not shared unless the patient gives explicit permission to do so. In the opt-out system, data is shared within reasonable principles between healthcare providers on the correct basis unless a patient objects to this (Nordfalk & Hoeyer, 2020). Currently, consent is needed for exchanging data in an exchange system that makes unfocused medical data of patients viewable (Ruizendaal, 2021). A consequence of this practice is that healthcare employees need to go after important medical information from the patient.

The argument for this opt-in system is that the patient needs to make a well-informed and rational decision between the costs and benefits of exchanging data (Wilkinson, 2013). However, this is not practical because patients and doctors will be confronted with administration pressure which is mostly not doable for sick people. Second, privacy preferences are uncertain because the benefits are uncertain and it is mostly unknown what data will be shared and what the risks are of exchanging data (Vugts et al., 2020).

Governments start to see the benefits of nudges more and more. Multiple nudges are used nowadays to supplement traditional incentives to change behavior in a subtle manner which doesn't obstruct autonomy (Benartzi et al., 2017). However, it is not easy to implement a new nudge because behavior of people is complex and needs to be understood well before successfully implementing a new nudge. A critical aspect to consider when implementing nudges is autonomy. Nudges should be directed to making good decisions for the decision-maker and the decision-maker should agree with the nudge to make the nudge effective (Arvanitis et al., 2020). To test a nudge on its expected effectiveness, researchers should test the attitudes towards a nudge before implementing the nudge to see how people perceive the nudge (Yan & Yates, 2019).

To make the out-out approach work, people should agree with the new opt-out intervention before implementing a new opt-out because otherwise the new intervention will be counterproductive. If people will object to the new opt-out intervention it is important to be careful when implementing (Yan & Yates, 2019). You need to take into account perceptions of people towards the new intervention to see what the benefits and objections are to carefully make a well-informed decision with support from the public. It is important to know to what degree people approve the new policy because better data exchange could bring many benefits for the healthcare sector (Yan & Yates, 2019).

2 Literature overview

2.1 Opt-in versus opt-out

In the Netherlands around April 2021, the parliament discusses the 'Electronic Data Exchange in Healthcare Act' whereby all data exchange should be done digitally to ensure better healthcare. The bill wants to ensure that all healthcare providers exchange their data digitally to make sure that patients will have a smaller burden on their side regarding telling their medical background and need to undergo less treatment. This act also makes sure that there will be a lower chance of a false diagnosis and non-suitable treatments (Ministerie van Volksgezondheid, 2021).

During the COVID-19 pandemic healthcare providers were temporarily allowed to consult certain data of patients in emergency situations at the ER without the permission of the patient when the patient had not yet passed his choice regarding the data exchange and corona needed to be involved for this corona opt-in system. They argued that healthcare providers could work more efficiently because they do not need to ask for permission first and that better health is ensured to the patient when their medical records are known (Ministerie van Volksgezondheid, 2021). Of course, this is also the case outside of COVID-19 but less prevalent. Research shows that most citizens do not object to the idea of an opt-out system in which consent is automatic unless you object to it (Lewis & Hardelid, 2020; Nordfalk & Hoeyer, 2020).

A national opt-out registration could provide an important incentive for data exchange and reduces the burden for healthcare providers to request and register patients individually. However, it is important that citizens can easily find the opt-out and can change it quickly and easily (Lewis & Hardelid, 2020). There are two types of data exchange namely the push and pull concept (Cybenko & Brewington, 1999). A pull system is a system in which data will already be made ready in a data exchange system for future treatment. The push system is a system in which the sender of data will specifically send the data to a specific receiver of data. A disadvantage of this system is that data will be duplicated a lot and is not feasible in emergency situations where medical data is needed immediately (Bisbal et al., 2003; Randell et al., 2009). Also in cases where multiple doctors are treating a patient it is needed to have the data soon.

2.2 The default channels: Endorsement, Ease and Endowment

The effectiveness of a default is mainly determined by the attitude of the decision-maker towards the directed choice in the nudge and the attitude towards the implementer of the nudge (Jachimowicz et al., 2019)(Paunov et al., 2019a). There are different channels that could affect the decision-maker. This research uses three channels that can influence the choice to see whether and how strongly the three channels are involved in decision-making.

The first mechanism that affects the effectiveness of a default is endorsement: When decision-makers trust the intentions of the choice architect, the default is more likely to be effective (Jachimowicz et al., 2019). How much the decision-maker trusts and respects the choice architect affects the default's effectiveness. In addition, the second mechanism is ease: When it is harder for the decision-maker to make another decision than the default, more effort is needed to differentiate from the nudge choice (Jachimowicz et al., 2019). If it is hard to opt-out of a default then the default might be more effective, participants are more likely to stay with the pre-selected option.

Finally, the third mechanism that affects the effectiveness of a default is endowment: When decision-makers perceive the default option to be the option that most people would choose or is most desirable to choose, they will pick the option that they feel most endowed with. When a default presents the default option as most chosen or most rational, people are more likely to choose that option (Jachimowicz et al., 2019).

Furthermore, endowment might be more effective when the participant has little experience with that choice/context because the participant will be more affected by what other people seem to choose or what is regarded as the most rational option. (Antonides & Welvaarts, 2020).

2.3 Effectiveness of defaults

There has been a debate about whether nudges negatively affect the autonomy of decision-makers. Research suggests that making nudges transparent may resolve this issue (Engelen, 2019). The paper by Paunov et al shows that transparency has a positive effect on the effectiveness of the default option. The research shows that people chose the standard option even when they themselves don't benefit from the option but society will benefit from it (Paunov et al., 2019a).

Other papers show that transparency does not affect the effectiveness of a nudge but the papers do not answer whether the perceived autonomy is affected by including transparency (Michaelsen et al., 2020). A transparent nudge is more ethical compared to a non-transparent nudge in terms of making an autonomous decision. Making a default transparent makes sure that the decision-maker will be able to make a more autonomous decision because the decisionmaker will think about the context himself (Wachner et al., 2020). A default can be made transparent by telling the participant why a default option has been included.

However, making a default transparent could make the default ineffective because participants would feel pushed towards a choice leading to different choices (Ridder et al., 2022). Several studies have demonstrated that disclosure of the presence of a nudge, its purpose, or the effect does not significantly lower its impact compared with a condition in which disclosure is absent (Bang et al., 2020; Bruns et al., 2018; Cheung et al., 2019; Steffel et al., 2016). One study even showed that including a disclosure had a greater impact on the effectiveness of the default because they argue that the default is perceived as less deceiving (Paunov et al., 2019b). This research includes the perception of the participants and the subjective feeling of being deceived measure to see what effect the different scenarios have on autonomy.

2.4 Autonomy of participants

Policymakers have criticized the use of defaults because they are perceived as manipulative if they are not transparent (Vetter & Kutzner, 2016). Defaults seem to manipulate the choice of the decision-maker. However, choice architecture can never be neutral because the way a question is portrayed always influences the decision-makers' preferences (Fox et al., 2005). Furthermore, defaults do not exclude any option for the decision-maker (Arvanitis et al., 2020). Defaults are expected to have little effect on participants when they have strong preferences (Johnson & Goldstein, 2003).

People can have strong attitudes towards certain topics. People could deeply care about the topic or they have done some research to the topic before and are well-informed. These people are less likely to change their decision because their attitudes are already formed. When participants have strong attitudes, a default should be less influential (Vetter & Kutzner, 2016). Testing how much a nudge affects the autonomous decision-making is important because it is an important aspect for people in public health issues (Ridder et al., 2020).

2.5 Ethics of opt-out

Some criteria need to be taken into account when implementing nudges to ensure the ethical implementation of nudges. Nudges need improve the involvement of citizens when making a decision and do not let simply the decision-maker make the default option automatically (Ridder et al., 2020). Most participants support defaults but they don't like to feel obliged to do certain things (Noland et al., 2015).

Another criteria to take into account is the literacy of participants because participants with higher literacy are better in making autonomous decisions when a default is implemented. Furthermore, implementing defaults is more ethically and more efficient when the targeted groups' preferences are mostly equal among the group. When there are a lot of different preferences, a default is less supported by the public (Cohen, 2013). Research on these things is necessary because defaults could damage trust between the patient and the implementer of the default (Holm & Ploug, 2013). Policy-makers should be less hesitant to implement defaults when the default corresponds with the choice that most decision-makers would make.

3 Hypothesis

Based on preliminary literature studies the following hypothesis will be tested:

- Descriptive analysis 1: Participants are not well informed about how their medical information is exchanged with other healthcare professionals.
- Hypothesis 1: The preferred choice of permitting data transfer in the health sector is given more in the opt-out policy than in the opt-in policy.
- Hypothesis 2: The opt-out conditions have a positive effect on willingness to have an opt-out system relative to the opt-in condition.
- Hypothesis 3: The default channels endorsement, ease and endowment have a positive effect on the perceived benefits of the standard option.
- Hypothesis 4: Participants evaluate the opt-out policies as non-threatening, with no significant perceived loss of autonomy

4 Methods

4.1 Participants and design.

Nijmegen University, (N=125, 67 (53.6%) male and 58 (46.4%); were approached via social media like LinkedIn, WhatsApp and notifications on the portal of certain business courses were used to fill out a questionnaire about data exchange in the health sector in the Netherlands. 68% of participants is between 18-24 years old. The participants are mainly students. 39% of the participants have completed a scientific study. Furthermore, 37% of the participants indicate that their highest level of study is secondary school. In all probability, these are mainly bachelor students who are still completing their bachelor studies. A sensitivity analysis has been performed. Previous research by studying the effects of defaults, established significant results with an effect size of $\Phi = .26$ (Vetter & Kutzner, 2016). The effect size of the dataset in this research is calculated by G-power by using desired statistical power ($1 - \beta$) of 0.8 and a probability level (p) of 0.05, the sample size is $N = 125$ and number of groups $n=5$. The calculation by G-power shows that the data set could detect an effect size of $\Phi = 0.315$ with desired power of 0.8 (Appendix 10). The effect size measures the expected average effect. Cohen's f statistic has been used to calculate the effect size. An effect size 0.1 has a small effect, an effect size of 0.25 has a medium effect and an effect size of 0.4 is a large effect. An effect size of $\Phi = 0.315$ means that this research needs to have a medium effect to see statistical differences in the results.

4.2 Procedure: Measures and materials

Participants were asked to fill in an online questionnaire about data exchange in the health sector. When participants would open the link, they were redirected to the questionnaire made with Qualtrics. They would start with the informed consent where the purpose of the research was explained, the accessibility of their data, the voluntarily participation which means that they could stop at any point in the questionnaire (Appendix 8), the incentive of a 10 euro voucher and finally the button to give consent to participate in the research.

The methods of Yan & Yates 2019 were used for the different conditions for opt-in and opt-out to compare the acceptability of opt-out policies in different channels (endorsement, ease and endowment) in comparison to the opt-in condition. The following four conditions from Yan & Yates were used: opt-in, opt-out neutral, opt-out transparency, opt-out low costs and opt-out education. The paper of Yan & Yates

used different policy scenarios. This paper applies the conditions of the paper to the data exchange policy scenario in the health sector (Yan & Yates, 2019).

Participants were randomly assigned to one of the 5 conditions as shown in Table 1 to see what preferences they have regarding the exchange of data in the health sector. Three channels were used and some had the opt-in condition and some had the opt-out condition. The first channel is endorsement: The participant chooses to pick the default that there are presented with because the participant trusts the implementer of the default to be trustworthy. The condition opt-out transparency has been used for the channel endorsement because the opt-out transparency condition is transparent about why a default has been used and what the default is supposed to do (Dinner et al., 2011). The second channel is ease: it is easier to stick with the default option because it requires less effort to stick with the default option instead of switching choices. The condition low costs has been used for the channel ease because the low costs condition emphasizes that the default option has been put in place to make the choice of the participant more easy. The third channel is endowment: The participant chooses to stick with the default option while the other options are evaluated as a loss. The condition opt-out education has been used for the channel endowment because the opt-out education condition emphasizes why the default option is important. The education condition emphasizes that the exchange of digital data ensures optimal quality of care. The participant is likely to evaluate the option to not give consent to exchange digital data as a loss because optimal quality of care cannot be ensured (Dinner et al., 2011).

TABLE 1:

condition	neutral	transparency	ease	education
channel		endorsement	ease	endowment
Opt-in	1			
Opt out	2	3	4	5

4.3 Pre-measure

Participants were asked for their age, sex, nationality, and student year (first year, second year, third year, fourth year, others).

4.4 Conditions

Participants needed to make mandatory decisions in their randomly assigned conditions to see what effect the different conditions have on preferences of participants (Jachimowicz et al., 2019). Participants were asked to fill in a questionnaire and there were 5 treatments in a between-subject design which come from the paper Yan & Yanes, the treatments were applied to the experiment to see what effect different opt-out scenarios have on the perceptions of people regarding data exchange in the healthcare sector. Participants were randomly given either 1 of the 5 conditions. These different conditions give us the ability to inquire whether the 5 different channels Opt-in, Opt-out, Opt-out transparency, Opt-out low costs and Opt-out education have different effects on how people make decisions and how participants perceive being in the different conditions. The following situation has been portrayed in the opt-in condition: “Imagine: after you recovered from Covid-19 you have some complaints regarding fatigue (long-covid). You go to the GP and the GP refers you to a doctor in the hospital. The GP wants to exchange your medical record with a digital exchange system with the doctor in the hospital. The GP asks you for consent regarding the exchange of data. What would you do?” The following situation has been portrayed in the opt-out condition: “Imagine: after you recovered from Covid-19 you have some complaints regarding fatigue (long-covid). You go to the GP and the GP refers you to a doctor in the hospital. Your GP will forward your medical data to the doctor in the hospital via a digital exchange system unless you object. The GP says that you can indicate if you do not want your data to be exchanged. You must then sign a form. What would you do?

- Stay at the preselected option to give permission
- Give no permission
- Not sure

All participants were asked to give consent or not but the way the question is portrayed is changed for the different conditions (Appendix 1)(Yan & Yates, 2019). The answer possibilities from the opt-in scenario were worded differently from the opt-out condition namely in the opt-in condition the first answer possibility was to give consent to exchange data to other doctors, the second answer possibility was to not give consent to the medical doctor and the third answer possibility was ‘unsure’. In the opt-out condition the GP was telling that the GP would exchange the data of the participant in the exchange system unless the participant would object to exchanging their data by signing a form. The first answer possibility was to stay with the pre-selected option to exchange their data with the doctor. The second answer possibility was to not give consent to the doctor and the third answer possibility was ‘unsure’.

Furthermore, the questions for the different channels were portrayed differently. To manipulate the channel endorsement, the opt-out transparency has explained the presence of the default option and the purpose of the default option (Yan & Yates, 2019). The following text has been added to the question to explain the presence of the default and its purpose: “Please note that this consent method is based on Paunov's scientific findings (Paunov et al., 2019b). The authors show that people often stick to the choice option that is pre-selected. In this case, that is permission to exchange data. That is why the GP has pre-selected this, because he is happy to refer you to this option.”

To manipulate the channel ease, the opt-out low-cost focuses on the fact that the default option makes it easier for the participants to choose, choosing the default option requires less physical action and requires less cognitive effort (Yan & Yates, 2019). The following text has been added to the question to manipulate for ease: “Your GP will forward your medical data to the doctor in the hospital via a digital exchange system, unless you object. This has been done to make this choice easier for you. The GP says that you can indicate if you do not want your data to be exchanged. You must then sign a form.”

Finally, to manipulate the channel endowment, the opt-out education focuses on informing the participant of why it is important to exchange their data for optimal quality of care. The default option is portrayed as the reference point and choosing differently will probably be evaluated as a loss (Dinner et al., 2011). The following text has been added to the question to manipulate for endowment: “People may have to deal with different health care providers when they need care such as the general practitioner, the doctor in the emergency room in the hospital or a pharmacy employee. The treating care provider is obliged to keep a medical file with a view to the treatment now and in the future. When people have to deal with multiple healthcare providers, it is important that one healthcare provider has access to the medical data of another healthcare provider. Keep in mind that digital data exchange ensures optimal quality of care, because doctors need the right information about the patient. What do you do next?” The complete questions and answers can be found in Appendix 1.

4.5 Post measure

After the scenario, participants were asked to answer a control question (Appendix 2) to see whether they put attention in the questions and to see whether they understood the scenario (Paunov et al., 2019b). 122 out of 125 participants answered the control question correctly so 98% percent answered correctly.

Subsequently, participants were asked to fill in questions on experienced autonomy, choice satisfaction, and pressure (Appendix 3). The questions on experienced autonomy, choice satisfaction, and pressure were formulated by deriving questions from (Yan & Yates, 2019).

Each participant was randomly assigned to one of the five conditions. After participants were given the policy scenario and answered whether they wanted to stick with the default to exchange their data to ensure better quality of care, the participants needed to indicate attitudes towards the given policy scenario with the use of perception questions on a 7 Likert scale where the participants indicate their agreement on the 7-point Likert scale. The 7-point Likert Scale: 1=strongly disagree, 2=disagree, 3=somewhat disagree, 4=neutral, 5=somewhat agree, 6=agree, 7=strongly agree. The questions about the perception with regards to the policy scenarios were asked to the participants and can be found completely in Appendix 3 (Yan & Yates, 2019).

After this question, the participants were asked questions on how they perceived the scenario itself, whether they felt deceived or not. The subjective feeling of being deceived measure comes from (Paunov et al., 2019). Participants were given seven statements and indicated their agreement on a 7-point Likert scale where 1 means strongly disagree and where 7 means strongly agree. Three statements were worded positively and three statements were worded negatively to see whether participants are paying attention to the questions. The questions and possible answers can be found in Appendix 4.

After the questions about the scenario's, the questionnaire continued with some knowledge questions to see if participants know how the exchange system is regulated at the status quo (Appendix 5). The knowledge questions were used from Patiëntenfederatie Nederland (Patiëntenfederatie, 2021). Furthermore, it is interesting to compare the answers of the knowledge questions with the willingness to have an opt-out system to see whether there is support for the opt-out system. Also, if many participants answer the knowledge questions falsely this could be dangerous for the healthcare sector because people assume that their data will be exchanged with the doctors automatically in emergency situations while this is not the case.

Finally, participants were asked whether they would prefer an opt-in or opt-out system to see whether participants would support an opt-out system or not and to see whether different scenarios have different effect on the support of an opt-out system (Appendix 6). These questions were used from Patiëntenfederatie Nederland to include in the questionnaire (Patiëntenfederatie, 2021). Participants were also asked when they would like to share their own medical information in the exchange system with a doctor to see the willingness to exchange data and to see what arguments participants have to exchange their data. Finally, the results were compared with the different scenarios.

5 Results

5.1 Descriptive analysis

The aim of this descriptive analysis was to see whether participants are well-informed about how their medical information is exchanged with other healthcare professionals. To assess whether participants were well-informed, two knowledge questions were asked namely: “How important is it that your medical information can be exchanged with relevant healthcare providers?” and “What healthcare providers can view or request medical data without permission?” (Appendix 6). These questions were used from Patiëntenfederatie Nederland. (Patiëntenfederatie, 2021). The questions have been asked to measure the attitudes towards an opt-in and opt-out system and to measure the willingness to exchange data. Appendix 6

5.2 Hypothesis

Participants are not well informed about how their medical information is exchanged with other healthcare professionals.

5.3 Results

Table 2 shows that most participants chose to give permission to share their medical data from the GP to the doctor. However, there are some participants in the opt-out, the opt-out transparency and opt-out education treatment that are not willing to share their data, but these are exceptions. This shows that most people agree that their data will be exchanged with a relevant doctor in order to improve the quality of care.

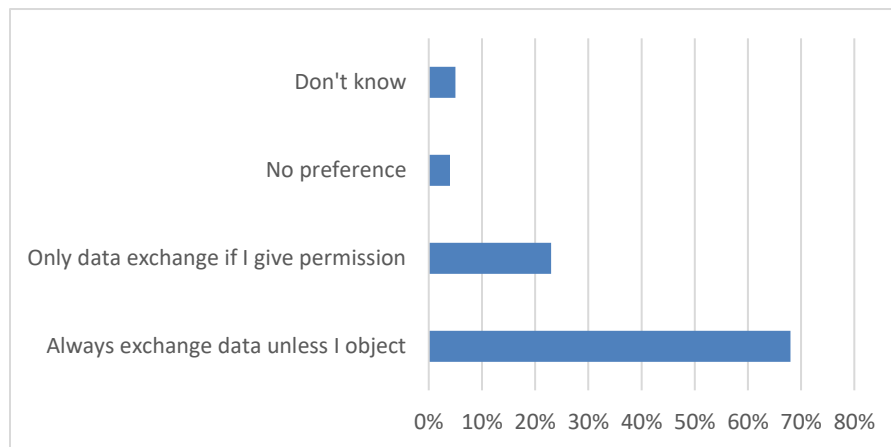
TABLE 2: PROPORTION OF PARTICIPANTS DECIDING TO GIVE PERMISSION TO SHARE DATA

Condition	Opt-in	Opt-out	Opt-out transparency	Opt-out low costs	Opt-out education
Give permission to share data	100%	92.86%	93.75%	100%	93.75%

Data from the questionnaire shows that a large part of the respondents thinks it is important to have an opt-out situation in which medical data always needs to be exchanged with other healthcare providers. Figure 1 shows that the vast majority of Participants find it very important that the data is always shared (68%). Only a minority of participants would prefer an opt-in situation in which you need to opt-in (give permission) to exchange your data with other healthcare providers (23%). This is probably due to the fact that they want to know/control where their data is going and want to make sure that their medical data is not shared with all healthcare employees because it is important to have some privacy.

People want to make sure that healthcare workers can only see the relevant data. For example, they don't want their optician to see about their stomach complications. A small part of participants is not sure about what they prefer (5%) because they probably want a question with more context to give a good answer and a small part of participants is indifferent to the opt-in or opt-out condition (4%). So there doesn't seem to be a lack of support for the opt-out system but to see what the practical consequences are for this possible opt-out amendment, it will be necessary to investigate what the opt-out system does to people's perceptions and behavior.

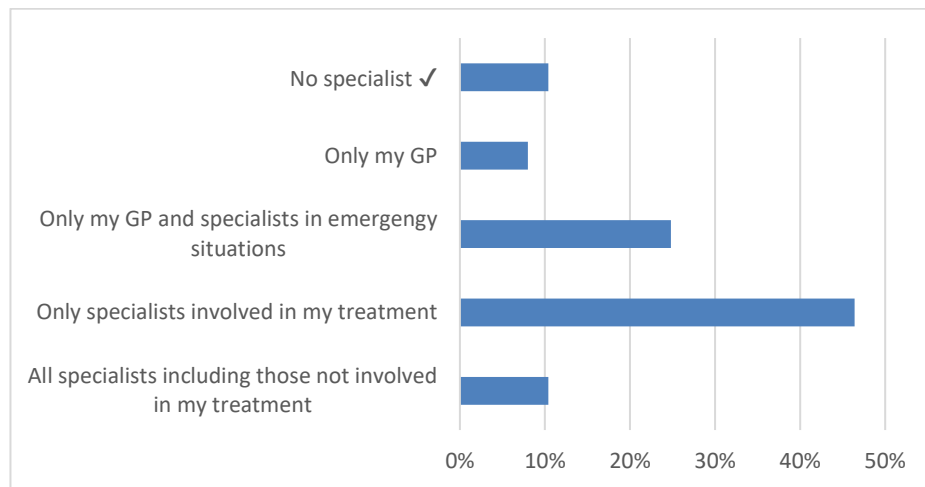
FIGURE 1: HOW IMPORTANT IS IT THAT YOUR MEDICAL INFORMATION CAN BE EXCHANGED WITH RELEVANT HEALTHCARE PROVIDERS?



Participants were asked to answer a knowledge question about the status quo regarding data exchange in Figure 2 (Patiëntenfederatie, 2021). It seems to be the case that a lot of people think that their data is easily accessible for other healthcare providers although this is not the case. However, there are some participants that answered the question correctly and thus know that it is hard to get access to patient data because they first need to give consent.

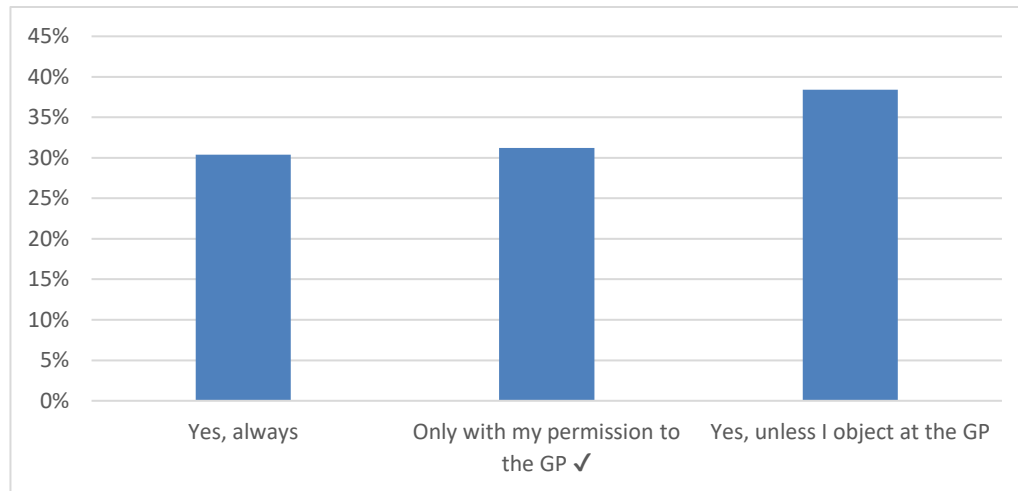
Most often participants think that healthcare providers that are involved with someone's treatment are allowed to view relevant medical data from other healthcare providers without permission (46,40%) or that they could see their data in emergency situations (24,80%). A small amount of participants thinks that only the GP can view the data without permission (8%). Finally, a small part of the participants thinks that all healthcare providers can view their data even those who are not involved in treatment of that patient. However, the reality is that no healthcare provider can access healthcare information without consent. Not a lot of participants know this (10,40%).

FIGURE 2: WHAT HEALTHCARE PROVIDERS CAN VIEW OR REQUEST MEDICAL DATA WITHOUT PERMISSION?



The second knowledge question we asked the participants is to what extent the emergency room could view medical information from the GP (Figure 3) (Patiëntenfederatie, 2021). The answers are very much divided because 30,4% thinks that employees at the ER can always access the data of patients while in reality employees at the ER can only access the data when there has been given access to the GP beforehand. Only 31,2% gave this answer and 38,40% thought that the employees at the ER can always see the relevant medical data of the patients unless the relevant patient objected to give permission to exchange data.

FIGURE 3: TO WHAT EXTENT CAN THE EMERGENCY ROOM (ER) VIEW IMPORTANT MEDICAL INFORMATION?



5.4 Discussion

Participants are not well informed about how their medical records are exchanged with other medical professionals. It should be made easier for people to choose what they want with their data. People should know why it is needed to share their medical records with relevant medical professionals so that doctors can take better care of their patients (Patiëntenfederatie, 2021). At this point, people think that their relevant data is in a system that other medical professionals can access. It can be dangerous when relevant data is not accessible by other medical professionals when needed. Think for example about allergies or blood type. Participants find it important that their data is shared, on the other hand a large part of the participants want to stay in control of their medical records, but still want their relevant data to be accessible in important events. These participants want to have control over what healthcare provider can access their data and they want to have control over what kind of medical data can be viewed because not all medical information is relevant for a specific treatment or healthcare provider (Patiëntenfederatie, 2021).

6 Research question 1

The aim of this inquiry was to see whether participants prefer exchanging their data more in the opt-out conditions than in the opt-in condition. To assess the preferred choice of permitting data (dependent variable) we asked the question: 'Would you give permission for the exchange of medical information when asked by a healthcare provider?'. Participants could answer 'always', 'Depends on what healthcare employee asks for the data', 'depends on what medical data is shared', 'depends on something else', 'not sure' (Appendix 6) (Patiëntenfederatie, 2021). To code for a binary variable I coded the answer 'always' as 1 and the other answers "Depends on what healthcare employee asks for the data", 'depends on what medical data is shared', 'depends on something else', 'not sure' with value 0.

To determine if opt-out conditions influenced willingness to exchange data, a logistic regression (estimates the probability of an event occurring) was run with proxy permitting data exchange as a dependent variable and conditions as independent variables. Furthermore, age and sex were explored as covariates and did not influence the pattern of results. They were left out of the analyses

6.1 Hypothesis

The preferred choice of permitting data transfer in the health sector is given more in the opt-out policy than in the opt-in policy.

6.2 Analysis

Willingness to share your medical data is a dummy variable in which value 1 represents always willing to exchange data and value 0 represents the other answers "Depends on what healthcare employee asks for the data", 'depends on what medical data is shared', 'depends on something else', 'not sure'. For all conditions, separate dummies were used in which value 0 means it is not the condition and value 1 means it is the condition. The coefficients of the dummies show the difference in willingness to share your medical data between the opt-out conditions and the opt-in condition.

6.3 Results

The descriptive analysis shows in Table 3 that the mean values for the answers on the willingness to exchange data are 21% for opt-in, 39% for opt-out, 22% for transparency, 50% for low costs and 31% for education. Where value 1 means always willing to exchange data and value 0 represents the other answers “Depends on what healthcare employee asks for the data’, ‘depends on what medical data is shared’, ‘depends on something else’, ‘not sure’.

TABLE 3: ANSWERS ON THE QUESTION: “WOULD YOU GIVE PERMISSION FOR THE EXCHANGE OF MEDICAL INFORMATION WHEN ASKED BY A HEALTHCARE PROVIDER?”

Condition	Opt-in	Opt-out	Opt-out transparency	Opt-out low costs	Opt-out education
Always	4	11	7	15	5
Depends on what healthcare provider asks for this	7	12	13	8	6
Depends on what data is involved	8	5	12	6	5
Depends on something else	0	0	0	1	0

Willingness to exchange data was significantly higher in the opt-out low-cost condition in comparison to the opt-in condition (Odds Ratio=3.75, SE=2.52, z=1.97, P=0.05, 95%CI=(1.01, 13.96) (Table 4). It seems to be the case that the opt-out conditions neutral, low costs and education have a positive effect on the perceived willingness to exchange data themselves because in this case odds ratio’s above 1 means that the odds of having a value of 1 are higher than the baseline exposure. For example, an odds ratio of 3.75 means that the odds of a case having value 1 are 3.75 times as high as the odds of having the baseline exposure. An important thing to note is that the odds ratio should be explained with odds and not probability. Value 1 represents that participants would always want to share their data, so the opt-out condition low costs does have a positive effect on willingness to exchange data relative to the opt-in condition. The other conditions do not have a significant effect.

TABLE 4: REGRESSION OF WILLINGNESS TO EXCHANGE DATA REGARDING THE OPT-IN CONDITION

Exchange data	Odds Ratio	Std. Err.	z	P>z	[95% Conf.	Interval]
Opt-out Neutral	2.43	1.66	1.30	0.19	0.64	9.25
Transparency	1.05	0.74	0.07	0.94	0.26	4.20
Low costs	3.75	2.52	1.97	0.05	1.01	13.96
Education	1.70	1.33	0.68	0.49	0.37	7.85
Constant	0.27	0.15	-2.35	0.02	0.09	0.80

6.4 Discussion

This study aimed to establish a causal link between the opt-out conditions and willingness to exchange medical data. The hypothesis that the opt-out condition has a positive correlation with willingness to exchange medical data is partially confirmed because the opt-out condition low costs has a positive significant effect on willingness to exchange data relative to the opt-in condition. The other opt-out conditions do not have a significant effect on willingness to exchange data relative to the opt-in condition because the P-values are lower than 5 percent. Especially the opt-out transparency condition has almost no effect on willingness to exchange medical data because the odds ratio is close to 1 and the p-value is very high.

7 Research question 2

In the second study, the aim is to see whether participants prefer the opt-out system in comparison with the opt-in system in different conditions. To assess the preferred choice of an opt-out system (dependent variable) we asked the question: “How important is it that your medical information can be exchanged with relevant healthcare providers?” Participants could answer ‘Always exchange data unless I object (opt-out)’, ‘Only data exchange if I give permission (opt-in)’, ‘No preference’, ‘Don't know’ (Appendix 6) (Patiëntenfederatie, 2021).

To determine if the conditions influenced the preferred choice of an opt-out system, a regression was run with proxy ‘preferring opt-out’ as the dependent variable and conditions as independent variables.

7.1 Hypothesis

The opt-out conditions have a positive effect on willingness to have an opt-out system relative to the opt-in condition

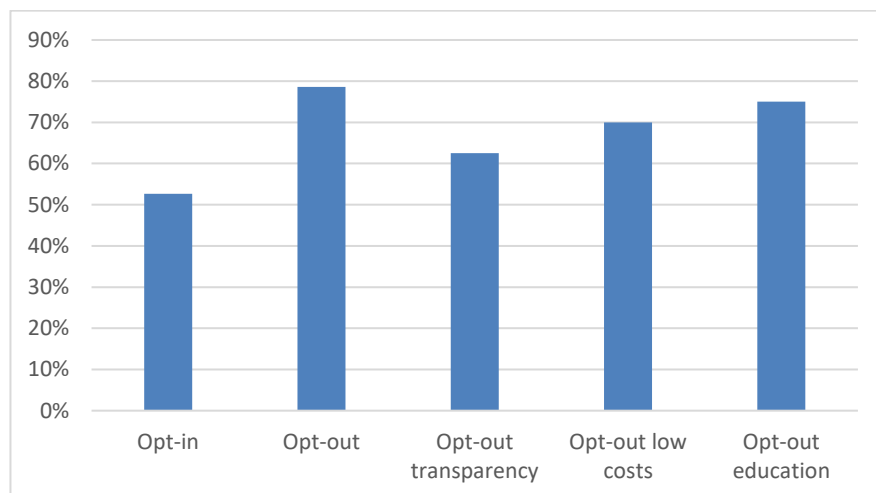
7.2 Analysis

Preferring opt-out is a dummy variable in which value 0 represents a preference for an opt-in system and value 1 represents a preference for an opt-out system. For all conditions, separate dummies were used in which value 0 means it is not the condition and value 1 means it is the condition. The coefficients of the dummies show what the difference in preferring the opt-out system is between the opt-out conditions and the opt-in condition.

7.3 Results

Graph 1 shows that for the opt-in condition 53,8% prefers an opt-out system, for the neutral opt-out condition 78,60% prefers an opt-out system, for the opt-out transparency condition prefers 62,50% the opt-out condition, for the opt-out low-costs prefers 70% the opt-out condition and finally for the opt-out education condition 75% prefers the opt-out condition over the opt-in condition.

GRAPH 1: AMOUNT OF PARTICIPANTS THAT PREFER AN OPT-OUT SYSTEM



shows that the neutral opt-out condition has a positive effect on the willingness to have an opt-out system because the odds ratio is 4.40 which means that the odds of choosing for an opt-out system

are 4.4 times the odds in the opt-out neutral condition in comparison with the other conditions. The further away from odds ratio 1 means that the odds of a participants to prefer the opt-out system are increased. An important thing to note is that the odds ratio should be explained with odds and not probability. An odds ratio of 4.4 is hard to interpret but it means that there are higher odds of having a correlation between the opt-out condition and the preference of an opt-out system.

The odds ratio is a measure of association between exposure to the condition and the outcome of value 1. Value 1 represents that participants would want to have the opt-out system. Willingness to have an opt-out system is significantly higher in the opt-out neutral condition in comparison to the opt-in condition (Odds ratio=4.40, SE=3.53, $z=1.84$, $P=0.07$, 95%CI=(0.91,21.25). The coefficients of the opt-out conditions are positive so the opt-out conditions have a positive effect on willingness to have an opt-out system compared to the opt-in condition. However, the effect is not statistically significant for the opt-out conditions except for the neutral opt-out condition.

Preference for an opt-out system	Odds Ratio	Std. Err.	z	P>z	[95% Conf. Interval]
Opt-out Neutral	4.40	3.53	1.84	0.07	0.91 21.25
Opt-out Transparency	1.09	0.70	0.14	0.89	0.31 3.81
Opt-out Low costs	2.10	1.46	1.07	0.28	0.54 8.18
Opt-out Education	2.40	1.98	1.06	0.29	0.47 12.13
Constant	1.67	0.86	0.99	0.32	0.61 4.59

* value 0 is advocate for opt-in and value 1 is advocate for opt-out

7.4 Discussion

The aim of this study was to establish a causal relationship between the opt-out policies and the willingness to have an opt-out system in comparison with the opt-in system in different conditions. The hypothesis that opt-out conditions have a positive effect on willingness to have an opt-out system is partially confirmed because the opt-out condition transparency, low costs and education have no significant positive effect on willingness to have an opt-out system. Finally, the opt-out neutral condition does have a significant positive effect on willingness to have an opt-out system.

8 Research question 3

In the third study, the aim is to see whether the opt-out conditions have a positive effect on the participants' feeling that the standard option is beneficial compared to other conditions. To assess the perceived benefits of a standard option we asked the participants to give answers to 5 statements that are related to the perceived benefits of an opt-out approach (Appendix 3).

To determine if the channels endorsement, ease and endowment influenced perceived benefits of an opt-out condition, regressions were run with proxies 'awareness of default option', 'easy to switch', 'Default is acceptable', 'exchanging medical info is beneficial' and 'marginal groups are damaged' were used as the dependent variables. The questions were formulated by deriving questions from (Yan & Yates, 2019). The different channels were used as the independent variables.

8.1 Hypothesis

The default channels endorsement, ease and endowment have a positive effect on the perceived benefits of the standard option

8.2 Analysis

Different questions were asked regarding the perceived benefits of the opt-out system namely: "I am aware of the default option", "It is easy to object to exchanging data", "The default option is acceptable", "The advantages of data exchange are bigger than the disadvantages", "Damage is caused to marginalized groups with an opt-out system" (Appendix 3)(Yan & Yates, 2019). The different questions are continuous variables in which value 1 represents 'completely disagree' till value 7 represents 'completely agree'. For all conditions, separate dummies were used in which value 0 means it is not the condition and value 1 means it is the condition.

8.3 Results

Table 5 shows that participants in the opt-out transparency condition are less positive in regards that they perceive the exchanging of medical data to be less beneficial (4.96). The perceived benefits of exchanging medical data are perceived as more beneficial in the opt-in condition (5.89) and the opt-out low costs condition (6.03).

Table 5 shows that participants are most aware of the default in the opt-out neutral condition (6) and the opt-out low cost condition (6). Participants make clear that it was easiest to switch their choice in the neutral opt-out condition (5) and it was harder to switch in the opt-out education condition (4.38). Participants make clear that the usage of a default is most acceptable in the opt-out neutral condition (5.75) and the opt-out low cost condition (5.8) in comparison with the opt-out transparency (5.28) and education (5.25). Finally, participants in the opt-out neutral condition make clear that they think that marginal groups are damaged by an opt-out system (4.25).

TABLE 5: AN OVERVIEW OF PARTICIPANTS' OPINIONS ACROSS THE DIFFERENT CONDITIONS

Condition	Opt-in	Opt-out	Opt-out transparency	Opt-out low costs	Opt-out education
Aware of default	4.89 (1.94)	6 (1.41)	5.31 (1.44)	6 (1.51)	5.63 (1.63)
Easy to switch	4.79 (1.90)	5 (1.76)	4.78 (1.75)	4.77 (1.74)	4.38 (2.06)
Default is acceptable	5.47 (1.54)	5.75 (1.35)	5.28 (1.46)	5.8 (1.81)	5.25 (1.77)
Medical info is beneficial	5.89 (1.37)	5,57 (1,55)	4,96 (1,49)	6.03 (1,35)	5,56 (1,59)
Marginal groups are damaged	3.11 (1.85)	4.25 (2.01)	3.34 (1.69)	3.3 (1.68)	3.63 (1.82)

Table 6 shows that the opt-out transparency condition has a negative effect on awareness of the default. Awareness of the default is significantly lower in the opt-out transparency condition in comparison to the neutral opt-out condition (Coef=-0.69, SE=0.40, t=-1.70, P=0.09, 95%CI=(-1.49,0.11). The coefficient of the opt-out transparency condition is negative, so the opt-out condition transparency has a negative effect on awareness of a default.

Furthermore, the opt-in condition has a significant negative effect on awareness of default. The default was less present in this condition in comparison with the neutral opt-out condition. The opt-out low costs and education have an insignificant effect on awareness of the default. The constant is relatively high because the constant is 6, this means that participants in the opt-out condition score high on awareness of the default.

TABLE 6: COEFFICIENTS REGARDING THE AWARENESS OF THE DEFAULT

	Coef.	Std. Err.	t	P>t	[95% Conf. Interval]
Aware of default					
Opt-in	-1.11	0.46	-2.38	0.02	-2.02 -0.19
Opt-out Transparency	-0.69	0.40	-1.70	0.09	-1.49 0.11
Opt-out Low costs	-0.00	0.41	-0.00	1.00	-0.81 0.81
Opt-out Education	-0.38	0.49	-0.77	0.44	-1.34 0.59
Constant	6.00	0.30	20.34	0.00	5.42 6.58

The tables about the variables 'easy to switch' and 'default is acceptable' were not included here because the conditions had no significant effect on the variables and were not close to being significant. Therefore, I included those tables in appendix 9: Table 12 and Table 13.

Table 7 shows that the opt-out conditions have an insignificant effect on perceived benefits of exchanging data. Perceived benefit is insignificant in the opt-out transparency condition but close to being significant at a 10% level in comparison to the other conditions (Coef=-0.60, SE=0.38, $t=-1.59$, $P=0.12$, 95%CI=(-1.35,0.15). The coefficient of the opt-out transparency condition however is insignificant because it has a P-value of 0.12. Furthermore, the opt-out low costs condition and the opt-out education have an insignificant effect on perceived benefits of exchanging data as well.

TABLE 7: COEFFICIENTS REGARDING THE PERCEIVED BENEFITS OF EXCHANGING MEDICAL INFORMATION

Exchanging medical info is beneficial	Coef.	Std. Err.	t	P>t	[95% Conf. Interval]
Opt-in	0.32	0.44	0.74	0.46	-0.54 1.19
Opt-out Transparency	-0.60	0.38	-1.59	0.12	-1.35 0.15
Opt-out Low costs	0.46	0.39	1.20	0.23	-0.30 1.23
Opt-out Education	-0.01	0.46	-0.02	0.98	-0.92 0.90
Constant	5.57	0.28	20.09	0.00	5.02 6.12

Table 8 shows that the opt-out transparency condition has a negative effect on perceived risks for marginal groups. "Perceived risks" is significantly lower in the opt-out transparency condition in comparison to the opt-out condition neutral (Coef=-0.91, SE=0.47, $t=-1.94$, $P=0.06$, 95%CI=(-1.83,0.02). The coefficient of the opt-out transparency condition is negative, so the opt-out condition transparency has a negative effect on perceived risks of using an opt-out system in comparison to the opt-out neutral condition.

Furthermore, the opt-out low costs condition has a negative effect risk for marginal groups. "Perceived risks" is significantly lower in the opt-out transparency condition in comparison to the opt-out condition neutral (Coef=-0.95, SE=0.48, $t=-2.00$, $P=0.05$, 95%CI=(-1.89,-0.01). The coefficient of the opt-out transparency condition is negative, so the opt-out condition transparency has a negative effect on perceived risks of using an opt-out system in comparison to the opt-out neutral condition.

Finally, the opt-in condition also has a significant negative effect on perceived risks for marginalized groups (Coef=-1.14, SE=0.54, $t=-2.13$, $P=0.04$, 95%CI=(-2.21,-0.08).

TABLE 8: COEFFICIENTS REGARDING THE PERCEIVED RISKS FOR MARGINAL GROUPS BY USING AN OPT-OUT SYSTEM

Marginal groups are damaged	Coef.	Std. Err.	t	P>t	[95% Conf. Interval]
Opt-in	-1.14	0.54	-2.13	0.04	-2.21 -0.08
Opt-out Transparency	-0.91	0.47	-1.94	0.06	-1.83 0.02
Opt-out Low costs	-0.95	0.48	-2.00	0.05	-1.89 -0.01
Opt-out Education	-0.62	0.57	-1.10	0.27	-1.75 0.50
Constant	4.25	0.34	12.44	0.00	3.57 4.93

8.4 Discussion

The aim of this study was to see whether the opt-out conditions transparency, low costs and education have an positive effect on the participants' feeling that the standard option is beneficial compared to other conditions. The hypothesis that the default channels endorsement, ease and endowment have a positive effect on the perceived benefits of the standard option is partially rejected because awareness of the default is significantly lower in the transparency condition, however, the perceived risks for marginalized groups are significantly lower in the opt-out transparency and opt-out low costs condition.

9 Research question 4

In the fourth study, the aim is to see whether participants evaluate the opt-out conditions as non-threatening in comparison with the opt-in condition. More specifically, do the opt-out conditions have a positive effect on perceived amount of autonomy? To assess the perceived amount of autonomy (dependent variable), we asked six questions on a 7 Likert scale on the subjective feeling of being deceived (Appendix 4). These statements are coming from the paper transparency effects on policy compliance (Paunov et al., 2019b). To assess whether participants perceived the opt-out condition as non-threatening we merged the 6 questions about perceived feeling of being deceived into 1 score.

To determine if the opt-out conditions influenced the subjective feeling of feeling deceived. The mean values of the answers to the six autonomy questions are discussed. To test if the opt-out conditions influenced the evaluation of the opt-out condition as non-threatening, I ran a regression with the score "perceived feeling of being deceived" as dependent variable and the different conditions are the independent variables.

9.1 Hypothesis

Participants evaluate the opt-out policies as non-threatening, with no significant perceived loss of autonomy

9.2 Analysis

Perceived feeling of being deceived is a continuous variable in which value 1 represents 'completely disagree' till value 7 represents 'completely agree', multiple questions have been asked regarding autonomy which have been combined into. We compare the means of the responses on the 7 score. The questions can be found in Appendix 4. The variable perceived feeling of being deceived is a variable consisting of six statements regarding the subjective feeling of being deceived. Three statements were positively worded and three statements were negatively worded. Because the variable subjective feeling of being deceived is negatively worded, the three positively worded statements were swapped to a negative score to combine the six statements into one variable. To test the reliability of the variable, Cronbach's alpha was used to test the reliability. Stata 16 was used to compute the Cronbach's alpha with command "alpha". The Cronbach's alpha was 0.76 which is high enough to combine the six statements into one score because a rule of thumb for the Cronbach's alpha is that an alpha between 0.6 and 0.7 is considered an acceptable level of reliability. An alpha of 0.8 and higher is considered a very good level so to convert the six statements into one variable is accepted when we look at the Cronbach's alpha (Gliem & Gliem, 2003). The Cronbach's alpha measures the similarity between multiple sets of data to see whether multiple datasets are compatible to convert into one variable.

9.3 Results

Graph 2 shows that participants in the opt-out neutral condition (1.77) has a lower feeling of being deceived in comparison with the opt-in condition (1.96). The participants in opt-out transparency (2.02), low-costs (2.09) and education (1.98) have a bigger feeling of being deceived in comparison with the opt-in condition.

GRAPH 2: MEAN OF 7-LIKERT SCALE OF PERCEIVED FEELING OF BEING DECEIVED FOR THE DIFFERENT CONDITIONS

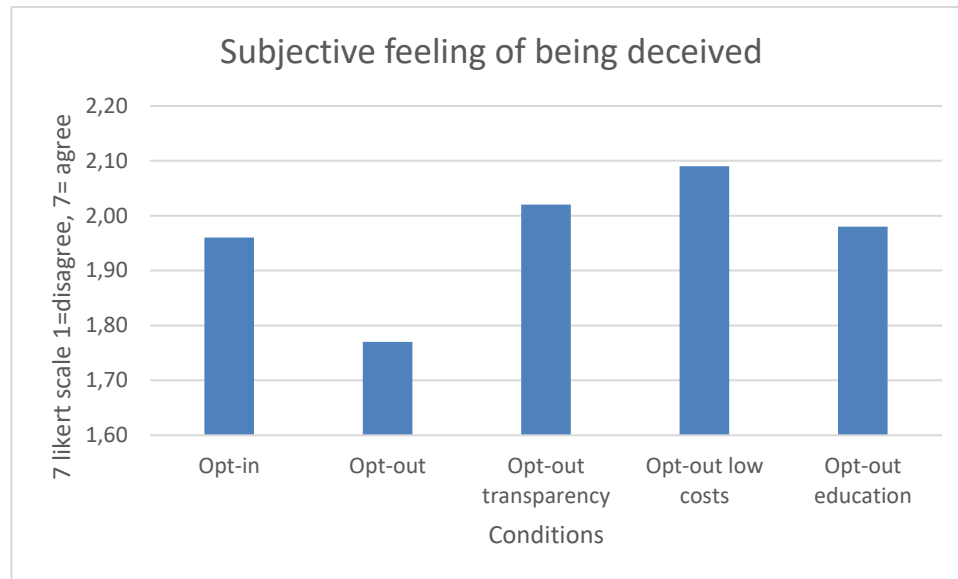


Table 9 shows that participants in the opt-out neutral condition reviewed the GP to be more open with them (5.82). The opt-out conditions transparency (5.28) and education (5.25) are lower than the opt-in condition (5.42). The participants in the opt-out neutral condition also reviewed the GP to be more sincere (5.96) in comparison with the opt-in condition (5.68). The opt-out low costs (5.5) and education (5.5) score lower on this question in comparison to the opt-in condition.

Participants felt relatively less misled in the opt-out neutral condition (1.57) than the opt-out conditions transparency (1.66), low-costs (1.73) and education (1.63). Finally, participants felt like the GP was the least honest with them in the opt-in condition (5.74). Participants in the opt-out neutral condition felt like the GP was the most honest with them (6.11). Participants in the other opt-out conditions transparency (5.91) low-costs (6.03) and education (6.06) score high as well.

TABLE 9: OVERVIEW OF PARTICIPANTS' RESPONSES TO DIFFERENT QUESTIONS ON THE 7 LIKERT SCALE

Condition	Opt-in	Opt-out neutral	Opt-out transparency	Opt-out low costs	Opt-out education
GP was open with me	5.42 (1.50)	5.82 (0.86)	5.28 (1.59)	5.43 (1.50)	5.25 (1.39)
GP tried to trick me	1.53 (0.51)	1.39 (0.57)	1.65 (0.83)	1.87 (0.86)	1.56 (0.63)
GP approached me in a sincere way	5.68 (1.24)	5.96 (0.64)	5.66 (1)	5.5 (1.41)	5.5 (1.21)
GP made an attempt to swindle me	1.53 (0.61)	1.54 (0.69)	1.66 (0.83)	1.9 (1.16)	1.5 (0.52)
GP was trying to mislead me	1.52 (0.51)	1.57 (0.84)	1.66 (0.75)	1.73 (0.74)	1.63 (1.02)
GP was honest with me	5.74 (1.19)	6.11 (0.57)	5.91 (0.89)	6.03 (0.85)	6.06 (0.68)

Table 10 shows that the opt-out condition low costs has a significant positive effect on feeling of being deceived in comparison with the opt-out condition. Feeling of being deceived is higher in the opt-out condition low costs than in the opt-out neutral condition (Coef=0.32, SE=0.17, t=1.87, P=0.06, 95%CI=(-0.02,0.66). The coefficient of the opt-out low costs is positive, so the condition has a higher feeling of being deceived than the opt-out neutral condition.

TABLE 10: REGRESSION ON FEELING OF BEING DECEIVED IN COMPARISON TO THE OPT-IN CONDITION

Subjective feeling of being deceived	Coef.	Std. Err.	t	P>t	[95% Conf. Interval]
Opt-in	0.19	0.19	0.97	0.34	-0.20 0.57
Opt-out Transparency	0.25	0.17	1.49	0.14	-0.08 0.59
Opt-out Low costs	0.32	0.17	1.87	0.06	-0.02 0.66
Opt-out Education	0.21	0.21	1.03	0.31	-0.20 0.62
Constant	1.77	0.12	14.28	0.00	1.52 2.01

9.4 Discussion

The aim of this study was to see whether participants perceive the opt-out conditions as non-threatening. The hypothesis that the opt-out conditions have no significant effect on perceived autonomy is partially rejected because the opt-out conditions low costs has a positive correlation with the perceived feeling of being deceived so the conditions opt-out low costs does reduce perceived autonomy. However, low costs and education have an insignificant effect on the perceived feeling of being deceived.

10 Discussion

The aim of this study was to vary the channels endowment, ease, and endorsement to see its effects on willingness to exchange data in the medical sector, willingness to have an opt-out system and to its effects on perceived autonomy. Participants in the opt-out low costs condition were willing to exchange their data more often than in the opt-in scenario. Support for a general opt-out policy increased in the opt-out neutral condition. Putting emphasis on ease resulted in a higher feeling of being deceived in comparison with the opt-in scenario. The study finds that being transparent about intentions in the opt-out scenario reduces the awareness of the default, however, the perceived risks for marginalized groups

are significantly lower in the opt-out transparency. Finally, participants in the opt-out low costs condition have a higher perceived feeling of being deceived.

Across four studies with 125 participants taken from a heterogeneous sample of mostly students from the Radboud University and other participants, we could show that defaults and conditions have a big impact on the decision-making of people towards exchanging their medical data and attitudes towards an opt-out system.

Descriptive analysis supports the idea that participants are not well-informed about how their medical records are exchanged with other medical professionals (Figure 2). Most participants assume that their relevant medical information will be available when doctors are involved in their treatment or when they are in an emergency situation. However, relevant data should first be requested because the GP needs consent to set up the data in an exchange system for future use. The reality is not in line with the expectations of participants because data is not that easily exchangeable without consent and furthermore most participants are willing to exchange their data.

In study 1, I hypothesized that the preferred choice of permitting data transfer in the health sector is given more in the opt-out policy than in the opt-in policy. I found that participants in the opt-out low costs condition are more willing to exchange their data in the health sector compared to the opt-in condition. Study 1 supports the idea that the combination of having a default which makes it easier for participants to choose and the ability to switch for another option relatively easy makes participants more eager to share their medical information because they can think about it properly and feel like they make an autonomous decision (Van Gestel et al., 2020).

In study 2, I hypothesized that the opt-out conditions have a positive effect on willingness to have an opt-out system relative to the opt-in condition. I found that the opt-out conditions transparency, low costs and education have no significant effect. However, the neutral opt-out condition does have a significant positive effect on willingness to have an opt-out system. Study 2 shows that participants are more willing to have an opt-out system in the opt-out neutral condition because the participants feel like they can decide for themselves better and have more autonomy over their decisions. Participants do not want to have additional information about why the opt-out is in place. Participants in the opt-out conditions transparency, ease, and education are less willing to have an opt-out system probably because they don't want additional information because they want to look for information about the issue themselves and do not want to be steered towards a certain opinion (Van Gestel et al., 2021).

In study 3 I hypothesized that the default channels endorsement, ease, and endowment have a positive effect on the perceived benefits of the standard option. I found that awareness of the default is

significantly lower in the transparency condition, and I found that the perceived risks for marginalized groups are significantly lower in the opt-out transparency and low costs condition. Study 3 shows that making the opt-out system transparent by including a disclosure makes the nudge less effective. The results show that the transparency condition has a significant negative effect on awareness of the standard option. This is probably due to the fact that participants in the transparency condition feel like they are pushed towards exchanging their medical data. Table 9 shows that participants perceive the sharing of medical data as less beneficial, and they feel like the GP was misleading them.

In study 4 I hypothesized that participants evaluate the opt-out policies as non-threatening, with no significant perceived loss of autonomy. I found that that the hypothesis is partially rejected because the opt-out condition low costs has a positive correlation with the perceived feeling of being deceived so the conditions opt-out low costs does reduce perceived autonomy. However, low costs and education have an insignificant effect on the perceived feeling of being deceived. Furthermore, descriptive analysis in Graph 2 shows that the opt-out neutral condition scores lower on the perceived feeling of being deceived than all other conditions. Study 4 shows that participants in the opt-out neutral group think more about the condition and what their opinion is about data exchange in the health sector and feel like they are treated better in the opt-out neutral condition in comparison with the other conditions. They feel like they have more autonomy over their choice (Wachner et al., 2020). The opt-out low costs condition has a higher feeling of being deceived.

11 Possible explanations for the outcomes

11.1 Descriptive analysis: Participants are not well informed about how their medical information is exchanged with other healthcare professionals.

Medical data cannot simply be exchanged between people. Patients should give permission if they want to share their medical data with another person caregiver. If someone has not (yet) given permission, other assistants cannot view the medical data. People often know that not all their medical data is exchanged without permission can occur but how exactly this is arranged is unclear to many participants. They often think namely that involved authorities in emergency situations can view their data without permission. People probably assume that their data is accessible because nowadays people give a lot of information to all kind of websites with the use of cookies without bothering and think that their relevant data is shared in emergency situations (Ploem & Dute, 2005).

11.2 Research question 1: The preferred choice of permitting data transfer in the health sector is given more in the opt-out policy than in the opt-in policy.

The effectiveness of a default is dependent on a variety of contexts. In this research, the channel ease had a significant effect on the willingness to exchange their medical data to ensure better quality of care in the future. (Jachimowicz et al., 2019). The opt-out ease condition has a focus on mentioning that the default option has been made for the patient to make it easier for them to make a choice (Appendix 1). The combination of having a default that makes it easier for participants to choose and the ability to switch to another option relatively easy could make participants more eager to share their medical information because they can think about it properly and feel like they make an autonomous decision and thus are more likely to stick with the default option. (Van Gestel et al., 2021).

11.3 Research question 2: The opt-out conditions have a positive effect on willingness to have an opt-out system relative to the opt-in condition.

The participants are more willing to have an opt-out system in the opt-out neutral condition compared to the opt-out condition transparency, ease and education because the participants might feel like they can make a better decision for themselves better and have more autonomy over their decisions (Venema et al., 2020). Furthermore, they have a lower feeling of being deceived relative to the other conditions see Graph 2. This makes that the neutral opt-out condition has a significant positive effect on willingness to have an opt-out system.

11.4 Research question 3: The default channels endorsement, ease and endowment have a positive effect on the perceived benefits of the standard option.

The channel endorsement and condition transparency have a negative effect on the perceived benefits of the standard option. The paper by Ridder et al argues that a default could become less effective if made transparent. A disclosure could tell participants that the default influences their decision-making and that the default encourages them to exchange their medical data. Making participants aware of the presence of a default would make the participant feel like they are pushed toward exchanging their medical data (Ridder et al., 2020).

Several studies have demonstrated that disclosure of the presence of a nudge, its purpose, or the effect does not significantly lower its impact compared with a condition in which disclosure is absent (Bang

et al., 2020; Bruns et al., 2018; Cheung et al., 2019; Steffel et al., 2016). However, the results show that the transparency condition has a significant negative effect on awareness of the standard option. Furthermore, the preference for an opt-out system is lower in the opt-out transparency condition regarding the other opt-out conditions (Graph 1). This is probably due to the fact that participants in the transparency condition have a stronger feeling of being deceived (Graph 2) because they feel like they are pushed towards exchanging their medical data.

11.5 Research question 4: Participants evaluate the opt-out policies as non-threatening, with no significant perceived loss of autonomy

It seems to be the case that participants in the opt-out neutral group think more about the condition and what their opinion is about data exchange in the health sector compared to the opt-in condition and the opt-out conditions transparency, low costs and education and feel like they are treated better in the opt-out condition in comparison with the other conditions. They feel like they have more autonomy over their choice because they think about it carefully but think that other marginalized groups can be harmed because the marginalized groups are expected to think less about the consequences of data exchange themselves carefully. However, the participants still feel like the opt-out system is more beneficial for everyone because the exchange of data provides better quality of care (Table 5).

12 Practical implications

The parliament is currently talking about the exchange of medical data. Patients need healthcare professionals to have relevant medical info present on time so that good healthcare can be provided. On the other hand, data needs to be taken care of carefully because patients need privacy (Ministerie van Volksgezondheid, 2021). The healthcare system is changing nowadays, and better exchange of data is needed cause more care is taken care of by multiple healthcare providers.

Failure to properly transmit data means that clients sometimes have to undergo unnecessary examinations and the risks of avoidable errors are increased. Care providers lose time with administrative actions such as finding missing data. This is time that is at the expense of the care provided to the client. In addition, incomplete data transfer can lead to care providers having to do unnecessary, sometimes expensive, investigations. As a result, healthcare costs rise unnecessarily and innovation in healthcare is inhibited. All this also has negative consequences for society as a whole (Ruizendaal, 2021).

It is unclear what data can be accessed by healthcare providers and when it is accessible (Figure

2). Participants are not well informed about how their medical records are exchanged with other medical professionals. It should be made easier for people to choose what they want with their data. People should know why it is needed to share their medical records with relevant medical professionals so that healthcare employee can take better care of their patients. At this point, people think that their relevant data is in a system that other medical professionals can access. It can be dangerous when relevant data is not accessible by other medical professionals when needed. Think for example about allergies or blood type.

Participants find it important that their data is shared, on the other hand a large part of the participants want to stay in control of their medical records but still want their relevant data to be accessible in important events. These participants want to have control over what healthcare provider can access their data and they want to have control over what kind of medical data can be viewed because not all medical information is relevant for a specific treatment or healthcare provider. There should be a central online system in which patients can see what data is shared to whom. When the patient does not agree, the patient should be able to object to give permission online. Uncertainty about how data exchange is regulated at the moment should be made more clear for as well patients and healthcare professionals (Patiëntenfederatie, 2021).

The parliament is discussing an opt-out system to make sure that medical data is better available in the future (Ruizendaal, 2021). Nowadays there is a bigger need for 24/7 availability of complete sets of relevant medical records like summaries of the medical data of a patient. To provide this, patients need to give consent to make use of a central data exchange system in which medical data can be prepared for future use so that their relevant data can be found relatively easier.

A lot of participants (68%) would prefer an opt-out system (no objection) instead of an opt-in system (consent system) (Figure 1) because they prefer their relevant medical data to be accessible in emergency situations or unknown future reasons. Patients should be taught about the exchange system and what purpose it has. Furthermore, the patients should know that they can decide what healthcare institution can access their data and how they can chose what institutions to give consent to. Patients should be given the power to choose more specific what happens with their data.

Currently, there are a lot of citizens that have not indicated whether they give permission or not to prepare their data in the exchange system for future use. An opt-out system should be considered by the government because bad data exchange has a negative impact on the quality of care for a big part of patients. A national opt-out system can provide an important incentive for data exchange and reduces the burden for healthcare providers to request and register patients' individual consent. People should be

informed about their options and citizens should be able to easily change their preferences. There should be an online platform available where there is a clear overview of what preferences have been captured. Citizens should then be able to adjust their preferences at this central platform (Patiëntenfederatie, 2021). This will contribute to the necessary confidence of citizens in such an opt-out system.

In addition, data is the source for the development of preventive applications in which all kind of applications are used in a safe and responsible manner to improve our health and well-being. Data enables us to better understand events that vulnerable groups go through, if we find out what is going on we can offer tailor-made support (Vermeulen, 2020).

Finally, digital data exchange only will not solve all problems. Healthcare providers often complain about too much administrative work. Proper agreements are necessary to prevent this administrative work. The goal of making all data exchange digitally needs to be that healthcare providers won't have too 'double' work. It should not be necessary for all healthcare providers to keep writing what the medical background of a patient is, and the patient should not be asked the same question over and over again because the data cannot be exchanged properly (Vermeulen, 2020). To make sure that 1 central data exchange platform works, you need to oblige some standard so that the data is clear to all users, as well distributors of data as receivers of data.

12.1 Limitations and future research

There are some limitations to the generalizability of some results due to the fact that effects of the different channels are relatively small. For example, most participants chose to give consent to exchange their data. A bigger sample is needed to spot more significant results. In the descriptive analysis there were some clear tensions of for example the transparency condition that participants are less willing to exchange their data in the transparency condition. However, there was no significant result due to the fact that the effect is relatively small, so more participants are needed to see whether there really is a significant difference or not.

If a participant perceives the transparent disclosure as an obligation, The transparency effect is likely to become neutral or even negative. It could be the case that the included transparency information is against the interest of the participant and thus the inclusion of the transparency condition has little effect on behavior. (Paunov et al., 2019b). Disclosing that a certain choice is beneficial to them might have a smaller effect on participants because they feel pushed.

Future research should include the default channels endorsement, ease and endowment. For example, future research can manipulate the source of who instituted the default. Future research should

evaluate defaults relative to other choice architecture to see whether it is appropriate to use. Furthermore, additional variables to test are recommended like for example the intensity of a decision-maker to choose a certain decision 'preference strength'. When participants have strong opinions about a certain topic, they are not prone to change their decisions regarding that topic (Vugts et al., 2020).

Finally, this research mainly used young participants which are less prone to have much experience in hospitals and other medical environments so their opinions about the exchange of data might change over time when they experience how the exchange of data is regulated. Future research could use patients that go to hospitals on a regular basis to see whether the results differ. This is useful because patients might answer differently when they experience what's going on in healthcare.

13 Conclusion

This study investigates what opt-out systems are the most efficient and provides the best attitudes towards the opt-out system regarding the data exchange of medical data in the health sector. Doctors need to get access to relevant medical data from patients to provide a better quality of care. Currently, there is an opt-in system in place in the Netherlands in which patients need to provide consent before their medical records can be set ready in the online exchange system for future use by involved doctors. Current research provides evidence that defaults and opt-out systems are effective. Furthermore, this study found results about what kind of factors influence the effectiveness of defaults in the healthcare sector regarding the exchange of medical data. The participants in the neutral opt-out condition were most willing to have an opt-out system regarding data exchange in the health sector.

The study shows that participants are not aware of how the exchange of data is now regulated and in what situations consent is needed. It is also not known by participants what data is shared and to what healthcare employee the data is shared. Participants want to know what happens with their data to make a good decision. In order to ensure this, a better online platform needs to be created to see what happens with your data. Furthermore, the government should discuss an opt-out system in which consent is automatically given unless someone objects to the exchange of data. Finally, this study found that participants in the neutral opt-out condition are more willing to have an opt-out system. This study also found that the neutral opt-out condition has a significant negative effect on perceived feeling of being deceived so the neutral opt-out conditions is perceived as less deceptive. Future implications of opt-out systems should be portrayed in a manner that doesn't want to convince people to choose a certain choice that clearly because people will perceive this as manipulation.

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15 Appendix

15.1 Appendix 1

The methods of Yan & Yates 2019 were used for the different conditions for opt-in and opt-out to compare the acceptability of opt-out policies in different channels (endorsement, ease and endowment) in comparison to the opt-in condition. The following four conditions from Yan & Yates were used: opt-in, opt-out neutral, opt-out transparency, opt-out low costs and opt-out education. The paper of Yan & Yates used different policy scenarios. This paper applies the conditions of the paper to the data exchange policy scenario in the health sector (Yan & Yates, 2019).

Stimulus per condition

Opt-in condition

Read the text below carefully and answer the question honestly. There is no right or wrong answer. When you are done, click the 'Next' button.

Picture this: After you have recovered from COVID-19, you will continue to suffer from fatigue for a long time. You go to your doctor. The GP will refer you to a doctor in the hospital.

Your GP wants to forward your medical data to the doctor in the hospital via a digital exchange system.

The GP will ask whether you give permission for this. You must then sign a form. What do you do next?

- Give permission
- Give no permission
- Not sure

Opt-out neutral condition

Read the text below carefully and answer the question honestly. There is no right or wrong answer. When you are done, click the 'Next' button.

Picture this: After you have recovered from COVID-19, you will continue to suffer from fatigue for a long time. You go to your doctor. The GP will refer you to a doctor in the hospital.

Your GP will forward your medical data to the doctor in the hospital via a digital exchange system, unless you object. The GP says that you can indicate if you do not want your data to be exchanged. You must then sign a form. What do you do next?

- Stay at the preselected option to give permission
- Give no permission

- Not sure

Opt-out transparency

Read the text below carefully and answer the question honestly. There is no right or wrong answer. When you are done, click the 'Next' button.

Picture this: After you have recovered from COVID-19, you will continue to suffer from fatigue for a long time. You go to your GP. The GP will refer you to a doctor in the hospital.

Your GP will forward your medical data to the doctor in the hospital via a digital exchange system, unless you object. The GP says that you can indicate if you do not want your data to be exchanged. You must then sign a form.

Please note that this consent method is based on Paunov's scientific findings (Paunov et al., 2019b). The authors show that people often stick to the choice option that is pre-selected. In this case, that is permission to exchange data. That is why the GP has pre-selected this, because he is happy to refer you to this option. What do you do next?

- Stay at the preselected option to give permission
- Give no permission
- Not sure

Opt-out low costs

Read the text below carefully and answer the question honestly. There is no right or wrong answer. When you are done, click the 'Next' button.

Picture this: After you have recovered from COVID-19, you will continue to suffer from fatigue for a long time. You go to your doctor. The GP will refer you to a doctor in the hospital.

Your GP will forward your medical data to the doctor in the hospital via a digital exchange system, unless you object. This has been done to make this choice easier for you. The GP says that you can indicate if you do not want your data to be exchanged. You must then sign a form. What do you do next?

- Stay at the preselected option to give permission
- Give no permission
- Not sure

Opt-out education

People may have to deal with different health care providers when they need care such as the general practitioner, the doctor in the emergency room in the hospital or a pharmacy employee. The treating care provider is obliged to keep a medical file with a view to the treatment now and in the future. When people have to deal with multiple healthcare providers, it is important that one healthcare provider has access to the medical data of another healthcare provider.

Read the text below carefully and answer the question honestly. There is no right or wrong answer. When you are done, click the 'Next' button.

Picture this: After you have recovered from COVID-19, you will continue to suffer from fatigue for a long time. You go to your GP. The GP will refer you to a doctor in the hospital.

Your GP will forward your medical data to the doctor in the hospital via a digital exchange system, unless you object. The GP says that you can indicate if you do not want your data to be exchanged. You must then sign a form.

Keep in mind that digital data exchange ensures optimal quality of care, because doctors need the right information about the patient. What do you do next?

- Stay at the preselected option to give permission
- Give no permission
- Not sure

15.2 Appendix 2

Control question

The experiment of (Paunov et al., 2019b) has been used to derive a control question for the experiment. The control question is adjusted for the specific data exchange experiment.

The following question has been asked to see whether participants paid attention during the questionnaire: Please answer the following question about the situation you were confronted with: In the situation presented, we asked you to imagine that...

- You work in healthcare and must ask a patient for permission
- You must make a choice as a patient to give permission for data exchange
- You had to make a choice about your treatment

15.3 Appendix 3

Perception of scenario

The questions for the influence of the experiment on the perception of the decision-maker were formulated by deriving questions from (Yan & Yates, 2019).

Participants indicated their agreement with five statements on a seven-point Likert scale, anchored from 1 (not at all) to 7 (most definitely).

I am aware of the default option.....not at all (1) most definitely (7)

It is easy to object to exchanging data.....not at all (1) most definitely (7)

The default option is acceptable.....not at all (1) most definitely (7)

The advantages of data exchange are bigger than the disadvantages.....not at all (1) most definitely (7)

Damage is caused to marginalized groups with an opt-out system.....not at all (1) most definitely (7)

15.4 Appendix 4

Subjective feeling of being deceived measure (Cronbach's $\alpha=0.76$)

The 6 statements on a 7 point Likert scale were used to make the independent variable subjective feeling of being deceived. These statements were used from the paper transparency effects on policy compliance (Paunov et al., 2019b).

Participants indicated their agreement with seven statements on a seven-point Likert scale, anchored from 1 (not at all) to 7 (most definitely). Three of the items were positively worded and their scores consequently reversed. Thinking of my interaction with the GP, I believe they...

Were open with me.....not at all (1) most definitely (7)

Tried to trick me.....not at all (1) most definitely (7)

Approached me in a sincere way.....not at all (1) most definitely (7)

Made an attempt to swindle me.....not at all (1) most definitely (7)

Were trying to mislead me.....not at all (1) most definitely (7)

Were honest with me.....not at all (1) most definitely (7)

15.5 Appendix 5

Knowledge questions

The knowledge questions were used from Patiëntenfederatie Nederland (Patiëntenfederatie, 2021). These knowledge questions were asked to see how much participants know about the status quo about data exchange in the healthcare sector.

What healthcare providers can view or request medical data without permission?

- All healthcare employees including those not involved in my treatment
- Only healthcare employees involved in my treatment
- Only my GP and doctors in emergency situations
- Only my GP
- No healthcare employees

To what extent can the emergency room (ER) view important medical information?

- Yes, always
- Only with my permission to the GP
- Yes, unless I object at the GP

15.6 Appendix 6

Questions regarding the opt-out intervention

These questions were used from Patiëntenfederatie Nederland (Patiëntenfederatie, 2021). The following questions have been asked to measure the attitudes towards an opt-in and opt-out system and to measure the willingness to exchange data.

How important is it that your medical information can be exchanged with relevant healthcare providers?

- Always exchange data unless I object
- Only data exchange if I give permission
- No preference
- Don't know

Would you give permission for the exchange of medical information when asked by a healthcare provider?

- Always
- Depends on what healthcare provider asks for this
- Depends on what data is involved
- Depends on something else

15.7 Appendix 7

The following question has been asked to give the incentive: “if you would like to win a bol.com voucher worth 10 euros, please enter your email address below. This data will not be used for the research and will not be kept.”

15.8 Appendix 8

The informed consent form applies to the guidelines of the Radboud University Nijmegen. A sample document of the Radboud University Nijmegen has been used to write the informed consent. The content has been adjusted to the given questionnaire.

Informed consent

You have been invited to participate in a research project in which we investigate data exchange in healthcare. For this study you will be shown information that is relevant to this study. The procedure involves completing an online survey. This research project is being carried out by Jurian van de Vliert under the supervision of Koen van der Swaluw at the Faculty of Management Sciences of Radboud University. Filling out the survey will take approximately 5 minutes.

Confidentiality of the research data

The research data will be made anonymous and stored securely in accordance with the guidelines for the management of research data of Radboud University and in accordance with the General Data Protection Regulation (GDPR). The researchers involved in this research will use the research data for academic publications and presentations. With a view to research integrity, the research data will be accessible to the academic community for a period of at least ten years.

Voluntary participation

Your participation in this study is voluntary. This means that you can stop and withdraw your participation and consent at any time during the data collection period, without giving any reason. You can have your research data / personal data / contact details removed up to six weeks after participation by sending a request to Jurian.vandeVliert@ru.nl

Compensation

We would like to thank you in advance for participating in this research. Your participation helps to improve knowledge about data exchange. For participating in this research, 2 bol.com vouchers worth 10 euros will be raffled among the participants.

More information

If you have any questions about this research, now or in the future, please contact Jurian van de Vliert, 06-10645665, Jurian.vandeVliert@ru.nl

If you have any complaints about this research, please contact the researcher or contact the confidential counselors for academic integrity via email: confidential.persons@ru.nl

By clicking the button below, you acknowledge the following:

- You have read and understood this information
- Your participation in the study is voluntary
- You are at least 18 years old
- You are aware that you may choose to terminate your participation at any time for any reason

15.9 Appendix 9

The following tables show preferences and attitudes of the participants:

TABLE 11: PROPORTION OF PARTICIPANTS THAT ARE FOR AN OPT-OUT CONDITION.

Condition	Opt-in	Opt-out	Opt-out transparency	Opt-out low costs	Opt-out education
Amount of participants that prefer an opt-out system	53%	78,57%	62,50%	70%	75,00%

FIGURE 4: WILLINGNESS TO EXCHANGE MEDICAL INFORMATION FROM ALL CONDITIONS

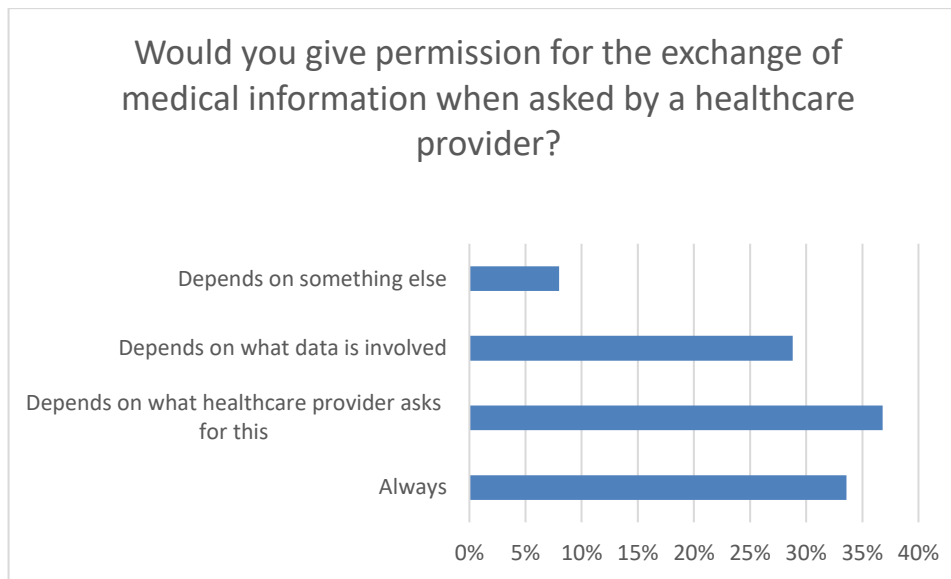


TABLE 12: COEFFICIENTS REGARDING THE PERCEIVED EASE TO SWITCH CHOICES REGARDING THE EXCHANGE OF MEDICAL INFORMATION

	Coef.	Std. Err.	t	P>t	[95% Conf. Interval]
Easy to switch choice					
Opt-in	-0.21	0.54	-0.39	0.70	-1.28 0.86
Opt-out Transparency	-0.22	0.47	-0.47	0.64	-1.15 0.71
Opt-out Low costs	-0.23	0.48	-0.49	0.63	-1.18 0.71
Opt-out Education	-0.63	0.57	-1.10	0.27	-1.75 0.50
Constant	5.00	0.34	14.57	0.00	4.32 5.68

TABLE 13: COEFFICIENTS REGARDING THE PERCEIVED ACCEPTABILITY OF USING A DEFAULT OPTION

	Coef.	Std. Err.	t	P>t	[95% Conf. Interval]
Default is acceptable					
Opt-in	-0.28	0.47	-0.59	0.56	-1.21 0.65
Opt-out Transparency	-0.47	0.41	-1.15	0.25	-1.28 0.34
Opt-out Low costs	0.05	0.42	0.12	0.90	-0.77 0.87
Opt-out Education	-0.50	0.50	-1.01	0.32	-1.48 0.48
Constant	5.75	0.30	19.23	0.00	5.16 6.34

FIGURE 5: PERCEPTION OF THE DEFAULT OPTIONS AND OPT-IN AND OPT-OUT CONDITIONS

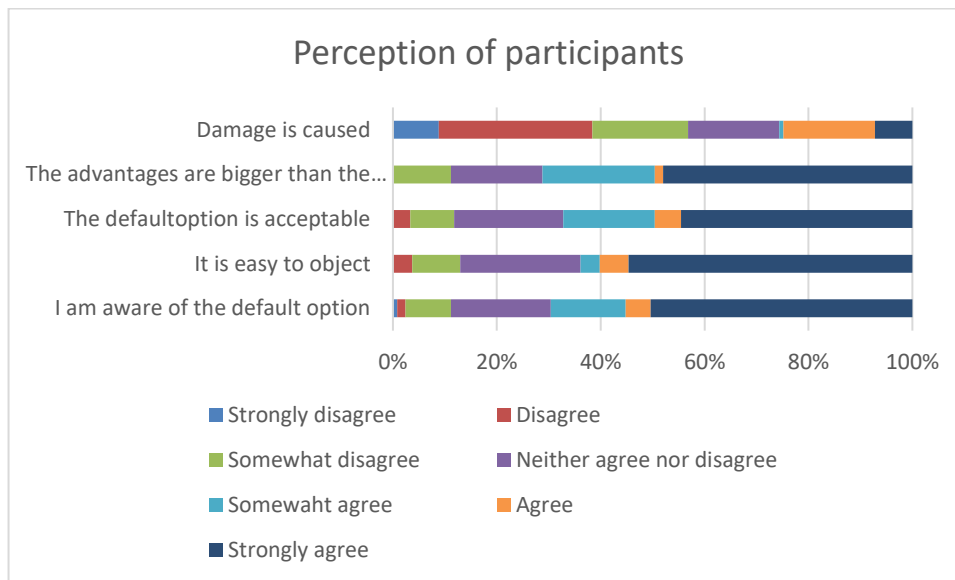
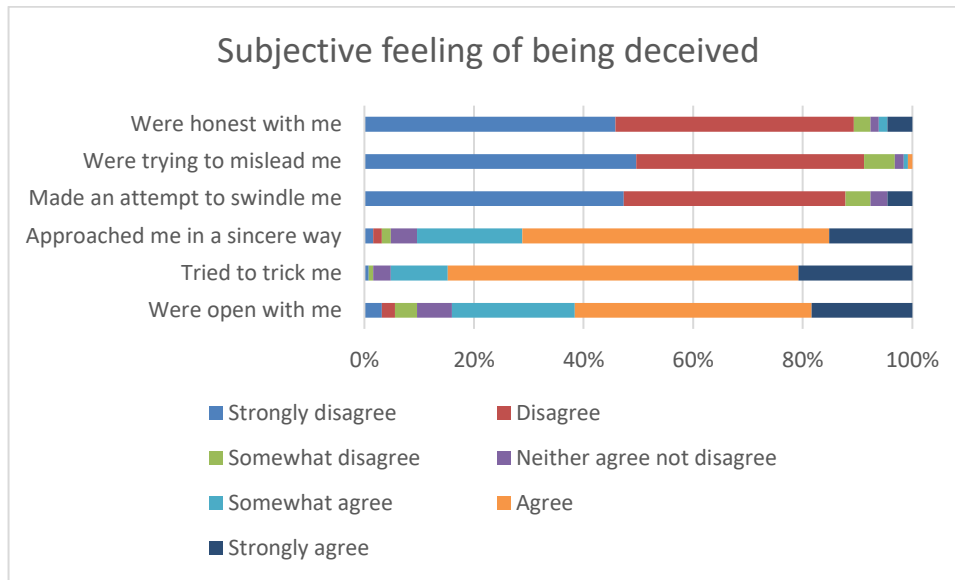


FIGURE 6: SUBJECTIVE FEELING OF BEING DECEIVED FOR ALL PARTICIPANTS



15.10 Appendix 10

FIGURE 7: SENSITIVE ANALYSIS F TEST: ANOVA: FIXED EFFECTS, OMNIBUS, ONE-WAY BY USING G-POWER

