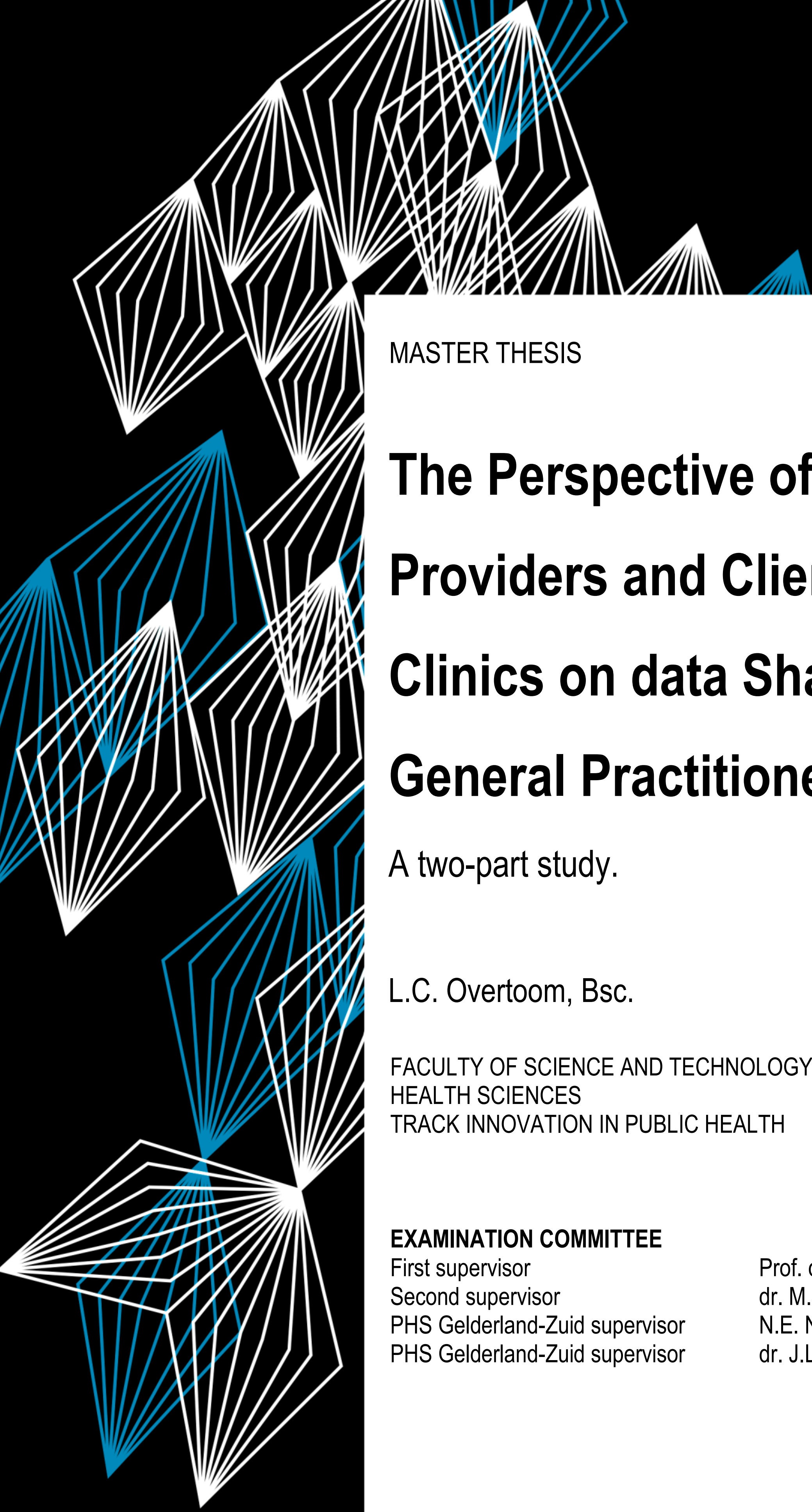

MASTER THESIS

The Perspective of Healthcare Providers and Clients of STI Clinics on data Sharing with the General Practitioner

A two-part study.

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Abbreviations and acronyms

BSN	“*Burgerservicenummer”* or “citizen service number”.
CBS	“*Centraal Bureau voor de Statistiek*” or Statistics Netherlands
EHR	Electronic health record
GP	General practitioner
HCP	Health care provider
MSM	Men who have sex with men
PHS	Public Health Service
STI	Sexually transmitted infection

Abstract

Introduction. While data sharing is widely used in healthcare, sexually transmitted infections (STI) clinics do not standardly communicate STI test results to general practitioners (GPs). Sharing the STI test results could lead to a more complete patient file at GPs and therefore improved care. However, the aim of STI clinics is to improve public health and their target group is vulnerable high-risk groups, such as men who have sex with men (MSM). The question is whether the clients of Dutch STI clinics agree on sharing their STI data via a data sharing system, what their most important motives are, whether their '*burger service number*' (BSN) may be used in order to share data, and whether there are differences between the high-risk groups. These questions are examined in part 1 of the current study. Next to the clients, the healthcare providers (HCPs) of STI clinics have an important key role in data sharing, namely as initiators of the data sharing process. Part 2 of the study focuses on the HCPs and examines which determinants influence the intention of the HCPs to use the potential data sharing system, and whether these determinants are considered as barriers or as facilitators.

Methods. A two-part study was conducted among four out of the five public health services (PHS) in the eastern region of the Netherlands. In the first part, on-paper Dutch questionnaires among clients of Dutch STI clinics were used. The clients were invited in advance of their consultation by the receptionist or by the HCP. The data was analysed in SPSS. The proportions were determined with descriptive statistics. Subgroup differences were tested with chi-squared tests and odds ratios. In the second part, semi-structured interviews were conducted with nurses and doctors who worked at least three months in one of the four PHS of the eastern region. The interview guide was based on an implementation model. The interviews were face-to-face or conducted by phone. The data were processed anonymously. Amberscript was used to transcribe the interviews. The transcripts were then revised and uploaded in Atlas-ti 8. The data was analysed based on the grounded theory. Thereafter, the determinants were categorized in the determinant groups of the implementation model. 20% of the data were double-coded. The data of the nurses and the doctors received equal priority.

Results. In part 1, 418 questionnaires were eligible for the analysis. 62% of the participants gave consent to share STI results with the GP, while 38% disagreed. Among those clients who gave consent to share data and who gave a valid motivation (N= 198), the necessity for good care was the most prevalent. This motive was mentioned in 80.3% of the cases as reason for sharing their STI results. Among the clients who did not give consent and who gave a valid reason (N=133), a preference to keep the result secret was mentioned as the most important reason in 69.9% of the cases. Subgroup analysis showed a significant difference in consent for younger persons (age 18-25) compared to older persons (age > 25) (OR = 1.53). No significant differences in consent were found in the other subgroups. 79.1% of the clients who gave consent to share data accepted the use of the BSN. Subgroup analysis showed that MSM significantly more often accept using the BSN compared to the other clients (OR=3.10). In part 2, eleven HCPs participated in the interviews. Sixteen anticipated determinants were found. Five were characteristics of the innovation: evidence for the system, safety, complexity/extra work, the relevance for the GP, and huge information flows. Three were characteristics of the HCPs: a lack of knowledge about legislation, the attitude towards changes, and the orientation of task in public health. Five were characteristics of the organisation: division of financial costs, the current electronic health record (EHR), the fit into the work process, the way of informing and asking consent, and cooperation with GPs. Finally, three determinants were characteristics of the socio-political context: the fit with regulations, the refusal of clients, and the way of registering the consent.

Discussion. The results of part 1 were comparable with other studies: not all clients agree with data sharing, but in this study the majority agreed. The (anticipated) determinants of the HCPs found in part 2 of the study are in line with existing determinant lists. Recommendations were given to design an eligible data sharing system and introducing strategy. Future research should focus on the preferences of GPs in sharing STI data.

Conclusion. In the current study, insight is gained in the perspectives of two key role figures on sharing STI data with the GP. The majority of the clients gave consent to share data and sixteen determinants that influence the intention of HCPs to use a client data sharing system are identified. To respond to these determinants, an appropriate system and introducing strategy should be designed. Time for an update in STI care!

Content

1. **Introduction**

Healthcare is changing fast. Nowadays data sharing via an electronic health record (EHR) is completely normal and widely used. To give a few examples: general practitioners (GPs) refer their patients to specialists via the EHR, recipes for medication are sent to pharmacies, and EHRs are used for contact between different departments of a hospital. However, data sharing is not obvious in every section of health care. Thus far, sexually transmitted infection (STI) care is reserved with data sharing. Is this outdated?

STIs are infections mostly spread via sexual contact. According to the World Health Organisation (WHO), there are 357 million new infections each year; mainly chlamydia, gonorrhoea, syphilis and trichomoniasis (1). It is important to prevent and treat for STIs as they can have serious consequences. For example, chlamydial and gonococcal infections can lead to infertility and untreated syphilis during pregnancy can cause neonatal death (1). Despite the risks of- and discomfort from STIs, there are several barriers for patients to seek treatment, such as stigma, fear and lack of money (2,3). As delayed care could worsen the STI's consequences, it is important that the individual seeks healthcare in time. Besides that individual care is necessary, it is also important for public health that healthcare is provided in time to prevent further transmission. This public health task could be challenging, as is illustrated by the study of Mercer et al.: 44.8% of their male and 58.0% of their female participants with symptoms in STI clinics continued to have sex while they had not received STI treatment yet (4). Since individuals who don't have easy access to healthcare and have multiple sex partners have an increased chance to transmit STIs (5), public health is focussed on those individuals and provides access to healthcare with the goal that STI care is sought in time and transmission is prevented.

In the Netherlands, the government funded STI clinics aim to reach the following risk groups: young adults with an age below 25 years, individuals who are warned via a(n) (ex)partner for STI, individuals with STI-related complaints, sex workers, men who have sex with men (MSM), women who have had sex with MSM, victims of sexual violence, individuals who have had a positive STI test result in the last year, individuals who originate from countries with a high prevalence of STIs, and partners of this last mentioned group (6–9). The STI care is assumed to be made more accessible for these groups, by providing STI tests which are free of charge and by providing the client the opportunity to remain anonymous (6,10). A Dutch study found that STI clinics are indeed mostly visited by high risk groups, and the clinics are often visited for preventive purposes (e.g. screening) (11). Another study confirmed this and also showed that there were less consultations by high risk groups at the GP than at the STI clinics, which was attributed by the authors to the idea that the high risk groups prefer low threshold STI care in the STI clinics (12). The preference for accessible STI care was underpinned by a recent study executed in Dutch STI clinics. This study found that for clients, anonymity and the opportunity to get a free STI test were both main reasons to visit the STI clinic (13). So, the accessibility is an important feature of the STI clinics for the high-risk groups and therefore in the prevention of transmission of STIs.

Unfortunately, the services of the STI clinics in which the anonymity of clients is warranted, do have a down side: STI care is a section of healthcare in which the information is not standardly shared with the GP. Data sharing is important for the continuity of health care as is clearly described by Van der Kam, Moorman and Koppejan-Mulder: “In the continuity of care, the GP can be seen as the ‘information manager’. To do this task well, the GP is dependent on the information provided by other members of the health care system” (14, p. 60). Several authors expect that data sharing with the GP could improve STI care. According to Steedman and Clutterbuck (UK), data sharing with the GP could lead to an improved relationship between primary care and STI clinics, and could be beneficial for patient care (15). Bradbeer and Mears (UK) thought the access to STI data for GPs was an opportunity to “improve sexual health management in primary care”, which will potentially contribute to their goals to “reduce the number of visits per patient at the STI clinic and delegating the work to other providers” and moreover, to keep STI clinics focussed on public health instead of individual healthcare (16, p. 437). Moreover, GPs prefer to have the information, as is shown by Winceslaus, Blount and Cryer (UK), 79% of the GPs participating in their study preferred the standardized letter with client information that was sent to them and 97% of the GPs preferred to receive a similar letter for future patients (17).

However, it is unclear whether clients and health care providers of Dutch STI clinics (HCPs) would accept sharing STI related information with the GP. Anonymity was found to be one of the most important reasons among the clients of Dutch STI clinics for visiting those clinics (13). However, the ‘anonymity motive’ left some space for interpretation. It is unclear whether the preference for anonymity also reflects a preference for not sharing STI information with their GP. For some clients, it is imaginable that they do not want to share information with the GP. The study of Pelgrim et al. showed that 2% of the clients indicated that they know the GP personally or that they were too ashamed to visit the GP. Moreover, it was found that 33.6% of the clients would never test on STIs at the GP (13). Next to that, in 2012 approximately a quarter of the Dutch clients did not register their full name or used a pseudonym name (6). On the other hand, the majority of the Dutch clients gave no negative signs about the GP. 62.3% of the clients in the study of Pelgrim et al. answered that they should maybe do a test at the GP in the future and 4.1% that they would do a test in the future at the GP (13). These clients possibly have less concerns with sharing their data. So the current Dutch regulations, in which data is not shared with the GP, seem to be based on the assumption that clients do not want to share data while this is possibly not the case. The same assumption seems to underpin the UK regulations (15). It is questionable whether the anonymity motive of the Dutch clients reflects a preference for not sharing data about their sexual health with the GP. As extensively described in section 3.2, only a few, contradicting, articles on this topic exist and until now, no Dutch studies exist focussed on the consent of clients to share STI data with the GP. Furthermore, limited information about the motives for giving consent to share data is available and the motives are not systematically investigated. Furthermore, the preferences of individuals belonging to high-risk groups (as determined by the Dutch triage) are unclear.

It is also questionable what the HCPs of STI clinics’ perspective is about data sharing. STI clinics seem to be reserved with sharing information of their clients beyond the clinic. As described by Poulton, STI clinics do not share client data except in case of explicit consent, in order to maintain the participation of high-risk groups and to provide quick STI treatment (18). Next to that, confidentiality seems to be an important determinant for HCPs. Herbert, Hewitt and Cassell advocated that even in the situation of notifiable diseases, where it is obliged to share data, the information is not always shared by HCPs. The idea to breach confidentiality seems to be a barrier to share data (19). However, the question remains whether the confidentiality that is provided by HCPs is in line with the clients' preference for anonymity. As described in section 3.2, there are no studies investigating the opinion of HCPs towards, and their acceptance of, sharing of client information.

The aim of this study is therefore to measure the opinion of clients and HCPs of Dutch STI clinics with regards to a client data sharing system, which shares a client's STI-clinic test results with their GP. Furthermore, the study aims to get insight in anticipated determinants that influence the HCPs' intention to use the system and the preferences of the HCP with regard to technical and logistical aspects of such a system, in order to optimize the system for HCPs use in practice. The knowledge gained could be used by public health services (PHS) or policy makers in the decision to share STI results with the GP, and if decide to do so, to design an appropriate strategy to introduce a client data sharing system.

The following research questions have been formulated:

1) What is the opinion of clients of STI clinics with regards to the sharing of their STI test results with the GP?

- What is the proportion of clients that consent with the sharing of their STI test results with the GP?
- What are the most important motives of the clients for giving or not giving consent to share their STI test results with the GP?
- What is the proportion of clients that consent with sharing their citizen service number (BSN*) with the PHS in order to facilitate the sharing of their STI test results?
- Are there differences in consent between the STI risk groups (young adults with an age below 25 years, MSM, sex workers and clients with a migration background) compared to other clients?

2) What anticipated determinants, identified by HCPs of Dutch STI clinics, influence their intention to use a client data sharing system to share clients' STI results with the GP?

- Which barriers are identified by the HCPs, that influence their intention to use a system to share clients' STI results with the GP?
- Which facilitators are identified by the HCPs, that influence their intention to use a system to share clients' STI test results with the GP?

* Since the 'BSN number' or citizen service number is used in the Dutch health care system for identification (20) and therefore in data sharing, the current study also investigated whether the clients would accept using this number for the purpose of data sharing.

2. **Structure of the report**

Since the current research is focussed on the introduction of an innovation in STI care, the first section (3.1) of the theoretical framework includes literature about implementation. The implementation literature provides insights which are necessary for successfully introducing and integrating innovations. The implementation model of Fleuren, Wiefferink and Paulussen (21) gives insights in the implementation process and is used in this study to organize the retrieved data later on. The second section (3.2) of the theoretical framework contains a mini literature review on the topic of data sharing from STI clinics with GPs and provides an overview about the current knowledge and the literature gap. Section 4 contains a description of the organization of STI care in the Netherlands. This information is helpful for interpreting the results in the context of the Netherlands. In section 5, the research methods of both parts of the study are described, followed by the results of the questionnaires among clients (section 6) and the results of the interviews among the HCPs (section 7). Thereafter, the discussion follows (section 8), which includes an interpretation of the results, limitations and strengths of the current study, suggestions for future research and recommendations for (the) data sharing (system). Finally, the conclusions will be described (section 9).

3. **Theoretical framework**

The theoretical framework starts with theory about implementation and the implementation model (section 3.1). This literature is helpful to increase the chance of successful data sharing via the client data sharing system. Thereafter, a mini-review and its results are described to provide insights on what is already known about data sharing from STI clinics to the GP and to show the knowledge gap (section 3.2).

3.1 **Theory about implementation**

3.1.1 Innovating in healthcare

An innovation could be described as "an idea, practice, or object that is perceived as new by an individual" (22, p. 11). In the current study, data sharing is approached as an innovation. In healthcare, successfully embedding innovations such as data sharing into practice is challenging. For example, Tummers described that public health professionals are often reluctant to implement new policies, because they do not see the added value for society or their clients (23). Different models exist with the aim to successfully change behaviour, for example the 'theory of planned behaviour' (24), which is focussed on changing the behaviour. However, this model is focussed on one individual and is not specifically focussed on changes in healthcare. The model of Cabana et al. (25) is focussed on healthcare and the adherence to guidelines by physicians. This model provides insights in determinants but is less focussed on the process preceding the use of the innovation and the strategy used to introduce the innovation. A model that is focussed on these aspects is the model of Fleuren et al. (21). In this study, the challenge to determine whether and how the innovation – the potential new client data sharing system – should be introduced at the PHSs among HCPs was approached with the model of Fleuren et al. (21).

3.1.2 Conceptual model: The Innovation process and its determinants

The model of Fleuren et al. (21) is shown in Figure 1. The model shows four stages of the innovation process (dissemination, adoption, implementation and continuation) and the transition between the phases. Dissemination means according to de Veer, Fleuren, Bekkema and Francke (26, p. 2) "that every professional is actually supplied with the innovation". Adoption is the phase in which the behavioural intention will be developed positively or negatively, based on the information they have retrieved about the innovation. Implementation is the phase in which the innovation will be used in daily practice (26,27). Continuation is described as that "the innovation becomes a routine practice" (26, p. 2). The focus of the current study is on the transition from 'Dissemination' to 'Adoption' in the innovation process (see Figure 1blue square), because the system currently does not exist and this study aimed to investigate the determinants that influence the intention of HCPs to use the system.

The left side of the model shows the groups of determinants that influence the transition to another stage of the innovation process. The groups of determinants are characteristics of the socio-political context, characteristics of the organization, characteristics of the adopting person (or the user) and characteristics of the innovation. In the current study, the client data sharing system was “the innovation”. The system is currently in development. A description of the data sharing system so far, could be found in Appendix G: Information about system (this text was also used in the interviews of study part 2). The HCPs were the “adopting persons”. The PHSs were considered as “the organization”. The clients were seen as part of “the socio-political context”(21) and therefore part 1 of the study is important for this determinant group. The determinant groups are further investigated by interviewing the HCPs in part 2 of the study. In addition to these determinant groups, there are several lists of determinants which could be used, for example, to measure determinants in one’s own organization or to organize the results (21,27,28).

Finally, the mediating influence of the characteristics of the innovation strategy is shown in the middle of the picture. Ideally, the strategy responds to the determinants in such a way that the chance on transition to another stage is increased. However, an important side note here is that a hypothetical situation in which the client data sharing system should be introduced in the future was used in this study. This has three consequences: 1) anticipated determinants were determined instead of actual determinants, 2) the dissemination phase or knowledge transfer was probably limited, and 3) there is no strategy used for introducing the innovation, but some information about the client data sharing system was provided to the participants. When the system would be introduced in the future, PHS Gelderland-Zuid should use an eligible introducing strategy.

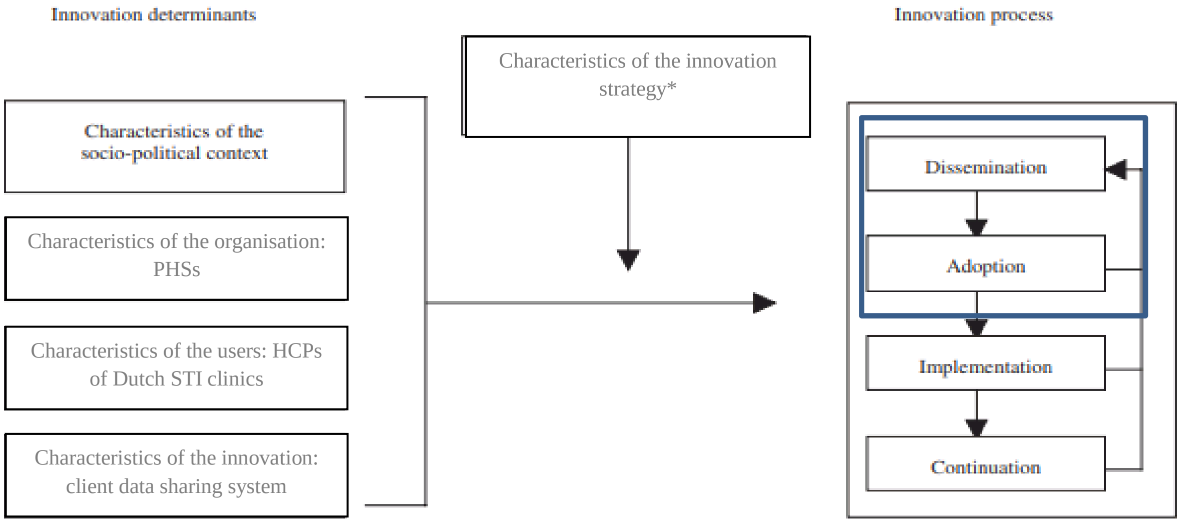

Figure 1 Model of Fleuren et al (21) and relation with current study. The current study is focused on the transition from the dissemination phase towards the adoption phase. This part of the process is marked with a blue square. On the left side, the determinant groups are specified. *No strategy was used.

So, insight in the determinants is necessary to successfully implement data sharing, and is useful to design the strategy for introducing the data sharing and to design the client data sharing system. As sketched in the introduction, the perspective of clients and HCPs on data sharing is important since they have a key role in data sharing. The HCPs are responsible for data sharing and the clients should give consent. Both groups are covered in the model, with the HCPs as a determinant group and the clients belonging to the socio-political context. However, it remains unclear what their perspectives are. The next section 3.2 will provide insight in the current knowledge that is available and will show the literature gap. In the current study, part 1 was focussed on the perspective of clients, while part 2 of the study was focussed on the perspective of the HCPs and investigated which anticipated determinants will influence the HCPs in adopting data sharing according to the HCPs. Part 2 covered the perspective of the HCPs on determinants of all four determinant groups.

3.2 What is already known about the sharing of client STI data with the GP?

Based on Griffiths (29), a mini review was done to map what is already known about determinants and opinions that are related to sharing data of clients between STI clinics and GPs. The research question was based on the two research questions and is as follows: “what are determinants or opinions related to data sharing from STI clinics to GPs, according to clients and HCPs of STI clinics or representatives of these groups?”

The search was conducted in different databases, namely Scopus, Cochrane and PsycInfo. Scopus was chosen, as this database includes a wide range of journals. Scopus contains the same hits as other databases such as WebofScience and PubMed. PsycInfo was used to involve the literature of Social Sciences as well. The search terms consisted of words and synonyms for “data sharing” and “STI”. Appendix A: provides a complete overview of the searches. The searches were not limited in time, since the discussion whether STI data should be shared with the GP could have been initiated with the introduction of the opportunity to test anonymously, so in 1976 (30). Of course, it is important to realize that there have been important changes related to STI care and data sharing which could have changed the current society or work process. For example, the introduction of electronic health files and the GDPR (the new privacy regulation). Therefore, results of older articles are possibly less comparable.

After checking for duplicates (N=30), the resulting articles (N= 234) were screened in three rounds to determine whether the articles met the inclusion criteria. The inclusion and exclusion criteria were composed based on the research question, and these are shown in Table 1.

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Table 1: Inclusion and exclusion criteria. This table shows the inclusion (left column) and exclusion (right column) criteria. These were based on the research question of the mini review.

Inclusion	Exclusion
Articles focused on determinants or opinions related to data sharing between STI clinics and GPs	Articles not focused on data sharing of STI clinics
Focused on clients, HCPs, GPs or representatives.	Articles written in another language than Dutch or English
	Articles focused on other types of data sharing such as: - sharing knowledge about STIs - data sharing in case of notifiable diseases or HIV - sharing data for research purposes - sharing data to other institutions in case of sexual violence - data exchange between patient and caregiver, - data sharing in a Facebook community - data sharing between hospitals - data sharing in case of young people living in state care or in case there is a chronical disease - data sharing from GPs to e.g. national EHRs
	Duplicates
	Articles which are not accessible

	Non-scientific sources

In the first phase, the titles of the articles were scanned. 158 articles were excluded in this phase. In the second phase, the abstracts were scanned and in this phase, 63 articles were excluded. In the third and last phase, the full texts were screened. In phase 3, 8 of the remaining articles were excluded. In this phase, 2 extra articles were included; these were found via snowballing. The reference lists of the 11 articles were screened and potential suitable articles were screened on abstract and full text too. Finally, 5 articles (15,17,31–33) were included in the mini review. Figure 2 shows the flow-chart and the reasons for exclusion.

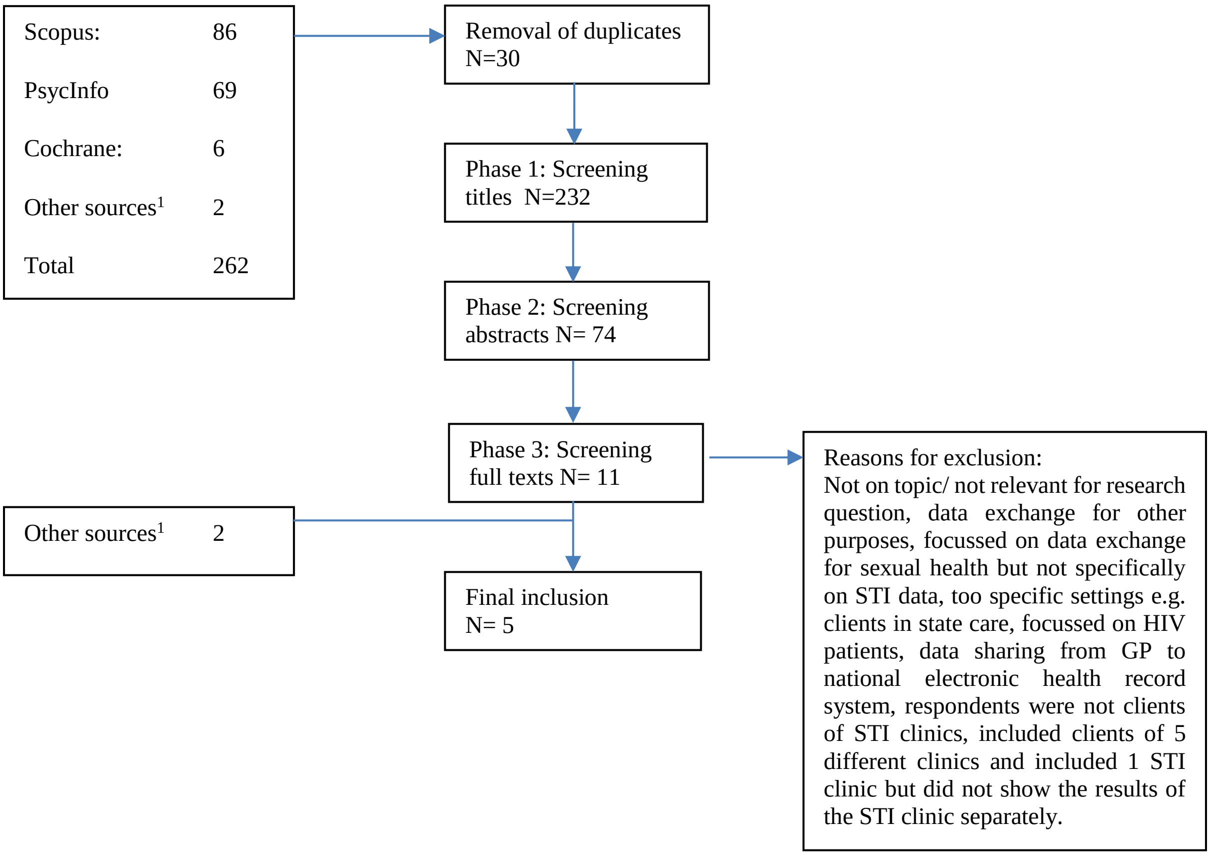

Figure 2 Flowchart of inclusion. The figure shows the results of the searches in the left upper corner, the removal of duplicates (right upper corner), the screening phases and the number of articles at the beginning of each screening phase (in the middle) and the reasons for exclusion for those articles excluded in phase 3. The final number of included studies was 5.

[1] these articles were found by snowballing: the reference lists of the full texts (phase 3) were screened on potential eligible articles.

3.2.1 Study characteristics

The characteristics of the five included studies are shown in Table 2. All studies were focused on data sharing and the perspective of the clients. However, in one study it was not the main focus, but a side issue (17). The main focus of that study was on the preferences of GPs in data sharing. There were no studies about the perspectives of HCPs from STI clinics. All studies measured the consent of clients for contacting the GP (15,17,31–33). Four of the studies investigated differences between high risk groups (15,31–33). One of the studies (32) also gained insights in motives for sharing or not sharing the data.

All studies were observational. In three studies, a questionnaire among clients was used (31–33). In one study, the STI clinics made a letter for the GP and the clients were asked to provide this letter to their GP. The delivery of these letters and the opinion about these letters was measured with a questionnaire among GPs (17). Another study used a retrospective analysis on their registration form in which one section was about communication with the GP (15). Three studies were executed in the UK (15,17,31), one in New Zealand (32) and one in Canada (33). The studies were executed between 1999 and 2015.

Table 2 characteristics of the studies. The table shows the year of publication, the country in which the study was performed and the study design

Author	Year	Country	Design[1]
Wincesclaus, Blount and Cryer (17)	1999	UK - England	Clients were asked to deliver a letter, containing their STI data, to their GP
Pedersen et al. (33)	2015	Canada	Questionnaire
Fernando and Clutterbuck (31)	2008	UK – Scotland	Questionnaire
Hunter, Haining Ede and Whiddett (32)	2014	New Zealand	Questionnaire
Steedman and Clutterbuck (15)	2007	UK - Scotland	Retrospective analysis of registration forms

[1] All studies were observational

3.2.2 Quality appraisal

In one article, the reporting is very limited (15). For example, the research question is not explicitly described, limitations and strengths are missing, and the methodology is incomplete. As the design is unclear, the study is not replicable and the reliability of the results is uncertain. The study of Wincesclaus, Blount and Cryer (17) is somewhat outdated as the article originates from 1999. Consequently, the society and or work process could have been different in 1999 and this could influence the opinion of clients. For example, the client data were not electronic, so the clients of Wincesclaus Blount and Cryer did not have to worry about for example cybercriminals. But as described in the inclusion and exclusion, the article is included in the review, since the results could still be useful. Furthermore, three studies (15,31,33) did not inform the clients about which data would be shared with their GP. This unclarity could have had an influence on the consent proportions. Other limitations are that four studies (15,17,31,33) did not ask for motives of the clients, and most studies had a limited amount of demographic questions or a variety in responses on these questions, and could therefore not or in a limited manner investigate subgroup differences between high risk groups.

3.2.3 Results

- Consent to share STI data with the GP

An overview of the proportions of the consent of clients to share data with the GP is provided in Table 3. Steedman and Clutterbuck found among clients of STI clinics, that 54% did not appreciate contact with their GP, while 36% preferred contact (15). In Wincesclaus, Blount and Cryer 90% of their clients agreed on sharing data while 10% disagreed. 80% of their clients contributed to contact with the GP by providing the standardized letter to the GP. The letter was composed by the STI clinic and contained their data (17). Fernando and Clutterbuck found that 35% of their clients would accept data sharing with the GP, while 64% disagreed (31). Hunter, Haining Ede and Whiddett found that 25% of their clients agreed with sending a discharge letter to their GP, while 37% answered ‘Maybe’ and 37% disagreed (32). Pedersen et al. found that 59% of their clients agreed on access for the GP to their data(33).

Table 3 proportions of consent given by the clients of each study. N = sample size.

Author	Country	N	% Consent to share	% No consent to share
Wincesclaus, Blount and Cryer (17)	UK	75	90	10
Pedersen et al. (33)	Canada	1004	59	41
Fernando and Clutterbuck (31)	UK	527	35[1]	64[1]
Hunter, Haining Ede and Whiddett (32)	New Zealand	209	25[2]	37[2]
Steedman and Clutterbuck (15)	UK	630	36	54

[1] Does not add up to 100% , due to missing data

[2] Does not add up to 100%, because there was another 37% who answered ‘Maybe’

Motives

Some (number is not specified in their report) of the clients of Hunter Haining Ede and Whiddett. indicated motives for their disagreement and these motives showed the importance for engaging clients into the discussion of the sharing of their data and that clients do not see the need of data sharing with the GP. An interesting finding by Hunter Haining Ede and Whiddett was that there was no relation found between the consent and having ‘confidentiality’ as a visiting motive.

Consequences of data sharing on attendance to the clinics

Fernando and Clutterbuck found that 24% of their clients said that this could negatively influence their attendance to the clinic (31). Similar to these results, Hunter Haining Ede and Whiddett found that data sharing could have a negative influence on the attendance: 31% of their clients indicated that they would stop attending the STI clinic, 36% would not recommend others to visit the clinic, and 17% would use an alias in case a discharge letters would be sent (32). Pedersen et al. also found comparable results: 32% of their clients would be less likely to visit the STI clinic in case data would be shared and the GP will have access. These clients significantly more often had the expectation that data is not shared with other caregivers, and were less likely to accept that data could be viewed by the GP (33).

Preferences from clients in data sharing

Fernando and Clutterbuck found that 55% of the clients agreed on using common IT systems (31). More detailed questions by Hunter Haining Ede and Whiddett revealed that 22% of their clients agreed on sharing lab results, 19% on sharing prescriptions of medications, 18% on sharing a summary of their visit, and 18% on sharing all details with other care givers including the GP (32).

❖ Subgroup differences

Three studies described differences of high-risk groups compared to other clients. Other subgroups differences are not discussed in this mini review. Steedman and Clutterbuck (15) described some subgroup findings: according to them there is no difference in given consent related to age. They compared clients with an age below 20 years with individuals older than 20. However, Fernando and Clutterbuck found that individuals younger than 18 more often refused, but this difference was not significant (31). Hunter Haining Ede and Whiddett found that clients with an age of 16-19 years were significantly less likely to agree on data sharing with the GP (32).

Steedman and Clutterbuck (15) did find a significant difference for individuals who indicated to be homo- or bisexual: 77% of these individuals declined, compared to 52% of the heterosexuals. The difference is confirmed by Fernando and Clutterbuck, who found that MSM and bisexuals significantly more often refused, namely 75% of those individuals, while 62% of the heterosexuals refused (31). However, it is unclear whether these studies also included bisexual women in this analysis and therefore, whether their subgroup is representative for the high-risk group MSM.

Furthermore, Steedman and Clutterbuck found that 69% of the individuals who visited the clinic for an STI screen and who did not have symptoms, 66% of the individuals who visited the clinic as a known contact of infection, and 44% of the clients with symptoms, declined GP contact. The first two groups declined significantly more often than the last group (15).

❖ Conclusion

To sum up, currently only a few (N=5) studies on this topic exist and no Dutch studies were found. While the research question was “what are determinants or opinions related to data sharing from STI clinics to GPs, according to clients and HCPs of STI clinics or representatives of these groups?”, none of the five studies were focussed on the perspective of HCPs. The studies only included the consent of clients of STI clinics. The proportion of clients that agree to sharing STI data deviate strongly, namely between 25% - 90%. In most studies, the majority of the clients did not give consent. Three studies showed that data sharing could even be problematic: 24% -32% of the clients would not attend the clinic anymore in case data will be shared. Limited information was available about the motives of clients related to consent and about subgroup differences. Some studies indicated that youngers and MSM/bisexuals more often refused. Unfortunately, the comparisons made by these studies differ with the triage criteria used in the Dutch STI clinics (6). In the Netherlands, individuals younger than 25 are considered to belong to high-risk groups. Furthermore, the studies compared bisexuals and MSM (as one group) to heterosexuals, while in the Netherlands, only MSM individuals are considered as high-risk group. No literature focussed on HCPs was found. Therefore, the anticipated determinants of HCPs for sharing data, and their opinion, are unclear.

3.3 Relevance of the current study

The first part of the theoretical framework gave insight in the implementation process and its difficulties. The second part showed the existing knowledge and the knowledge gap in the literature. No knowledge of the opinion of Dutch clients about data sharing is available and the international literature is contradicting and not generalizable to the Netherlands. Since data sharing could have serious consequences, such as a decrease in attendance rates of the vulnerable risk groups, it is important to have reliable results. Furthermore, no studies among HCPs exist on this topic. However, as sketched in section 3.1, research among HCPs is necessary in order to increase the chance of successful implementation. The next section (4) will describe the organization of STI care in the Netherlands, which is useful for understanding the methods of the current study.

4. Organization STI Healthcare in the Netherlands

In the Netherlands, the STI care is mostly provided by GPs. Supplementary to the GP, STI clinics provide STI care. In 2016, 67.3 % (N = 281.300) of the consultations were executed by GPs, whereas STI clinics executed 33.7% (N = 143.139) consultations. GPs diagnosed 79% of the STIs, compared to 21% in the clinics (9). The STI clinics are focused on public health, which became a local governments responsibility in 1990. Therefore, the STI clinics are often settled in PHSs, funded by the government, and only provide STI care to high risk groups (30). The STI clinics try to control STIs by reducing the risk of transmission (e.g. by promoting condom use) and by reducing the period of infectiousness of individuals (e.g. by screening, partner notification and more accessible services) (34). The accessibility is generated by providing STI tests which are free of charge for high risk groups, and on top of that, anonymity is warranted (7,8). Anonymity means here that the individual could be tested and or treated without giving personal identifiable information. In the Netherlands, HIV and syphilis diagnoses and diagnosis of the notifiable diseases (acute chronical hepatitis B and acute hepatitis C), are often (indirectly) communicated to the GP. The GP is not informed about other STI diagnoses, tests or consultations executed by the PHS.

Whether a client belongs to a high-risk group is determined by strict triage criteria. Clients should belong to one of the following groups: young adult with an age below 25 years, individuals who are warned via a(n) (ex)partner for STI, individuals with STI-related complaints, sex workers, MSM, women who have had sex with MSM, victims of sexual violence, individuals who have had a positive STI test result in the last year, individuals who originate from countries with a high prevalence of STIs, and partners of this final group (6–9). The strict triage criteria were adopted to increase the efficiency and therewith to improve the financial sustainability (6). Those individuals who are not in the target group are referred to the GP. In case an individual wants to remain anonymous (and the individual does not fall within the target group), the PHS refers to online STI-test facilities, which ensure anonymity as well.

In the Netherlands, STI clinics are each part of one of the 26 PHS in the Netherlands. Furthermore, each STI clinic belongs to one of the eight regions in the Netherlands (see Figure 3) (35). The current study is performed in the eastern region. Five of the 26 STI clinics are located in the eastern region of the Netherlands, namely PHS ‘Gelderland Zuid’, ‘Noord- en Oost Gelderland’, ‘Gelderland-Midden’, ‘IJsselland’ and ‘Twente’. The region is semi-rural. In 2017, this region had 20.383 visitors and a detection rate of 18.9%, meaning that in 18.9% of their cases, an STI was found.

Table **4** shows the demographics of the visitors of 2017 in the eastern region. 54% of the clients were male and most of the clients (56.1%) had a high educational level. 55% of the clients had an age below 25 years, 31% were MSM, and 5.2% were sex workers. 14.5% had a migration background and originated from a STI endemic country (36).

Figure 3 The eight regions in the Netherlands. The orange part shows the eastern region. (35)

Table 4 characteristics of the visitors (N=20.383) of STI clinics in the eastern region during 2017. (36)

Characteristics	%
Gender	
Man	53.8
Woman	46.2
Education	
Low/middle[1]	38.3
High[2]	56.1
Unknown	5.6
Risk group	
Migration background STI endemic country	14.5%
Young (<25 years)	54.7
MSM	30.7
Sex worker	5.2

[1] Low/middle = defined by the PHS as no education, primary education, lbo, mavo vmbo, mbo
[2] High = defined as havo, vwo, hbo, wo.

This section thus showed the organization of Dutch STI care as a background for the current study among Dutch STI clinic clients and HCPs in the eastern region of the Netherlands. In the next section 5, the study design and methods of the current study will be described.

5. **Methods**

Design

The study was executed in 4 of the 5 PHSs of the eastern region of the Netherland, namely PHS Gelderland-Zuid, PHS IJsselland, PHS Twente and PHS Gelderland-Midden. The fifth PHS (PHS Noord-Oost Gelderland) of the region was disregarded in this report, since this PHS could not start data collecting during the research period.

The study consisted of two parts:

1) A cross sectional study using a quantitative questionnaire among clients of the PHSs about their opinion about and the most important motives to share test results with the GP.
2) Qualitative semi-structured interviews among HCPs which addressed the barriers and facilitators of HCPs in their intention to use the client data sharing in which test results could be shared with the GP.

It is chosen to execute both studies in parallel as there is limited time to collect data and the outcomes of research question 2 are anyhow relevant for the PHS Gelderland-Zuid (initiator of this study), as they are also considering data sharing systems for other departments.

5.1 **Part 1 Questionnaire among clients**

5.1.1 Study population

Participants were eligible to participate in case they were clients of the STI clinic of a participating PHS (PHS Gelderland Zuid, PHS Gelderland-Midden, PHS Twente and PHS IJsselland). Clients with an age below 16 years were excluded from participation in this study as it is complex to guarantee both anonymous data collection and consent of the parents. Furthermore, clients who could not read Dutch were excluded from participating in the study, as the questionnaire was in Dutch.

A power analysis was executed based on the numbers of Pelgrim et al. (13). They showed that 27% of their participants mentioned anonymity as an important reason to go to the PHS. Furthermore, they found that 33% thought that they will never go for an STI test to the GP. Based on these indications, it was expected that 30% of the respondents would not give consent for sharing the test results. Based on this proportional assumption, a power was calculated for confidence intervals at proportions, with a precision of 0.05 and a significance level of $p<0.05$. The minimal required sample size for this study was 323 participants.

5.1.2 Data collection

Material

The client material consisted of an informed consent form, the questionnaire and a blank envelope. The material was on-paper, because clients were not identifiable by IP addresses this way, and to simplify recruitment for the participating PHSs. All texts for study part 1 were written in B1 level, which was achieved by using the software “Klinkende taal”. The questionnaire and informed consent form were attached to each other, and each page contained the same participant number used as identifier. Furthermore, each page contained an identifier for the PHS location which was visited.

Appendix B: Informed Consent (study part 1) contains the informed consent form used in this study. Because documented informed consent among the clients could be harmful for some groups such as prostitutes, it was decided that the participants could give their consent to participate by checking a box: ‘I am older than 16 years, well informed about the research and I give my permission for participating in the study’. No names of participants nor signatures were asked, but the consent remained actively. Since the questionnaire should not influence the consultation of the participants, the letter emphasized that the questionnaire was about sharing test results in the future and not in their current consultation. Moreover, because the participants were asked to participate in this study before they had their consultation, the clients could get the feeling that they were in a subordinate position. However, the clients were informed about the fact that the results of the questionnaire would only be used for research purposes and were not related to their prospective consultation, that they remained anonymous, and that the information would be analysed on group level. Furthermore, to reduce discomfort, the option ‘I don’t want to answer this question’ was added for each question of the questionnaire. The informed consent informed the participants also about their voluntary participation and their opportunity to quit/withdraw from participating in the study whenever they want to. Next to that, contact information of the researchers was provided to the participants in case there were complaints or questions. Finally, the participants were informed about the communication of the results via www.ggdgelderlandzuid.nl.

The questionnaire was pilot tested among 4 students who were eligible to visit the STI clinic based on the triage criteria. Based on their experiences, question 11 was clarified and information at the introduction of the questionnaire which was overlapping with the informed consent was removed. The questionnaire (see Appendix C: Questionnaire (study part 1)) consisted of 11 questions. The questionnaire started with the main question about whether the client would give consent to share his/her test results with the GP via a data sharing system, with three answer options: ‘Yes’, ‘No’ and ‘I don’t want to answer this question’. The second question was open and asked for the most important motive of the client, but only in case the participant answered ‘yes’ or ‘no’. The risk arising from open questions is that participants will write down identifiable information (e.g. the name of their GP). Ideally, a closed question is preferred to protect the clients. However, the open question is explorative and therefore a closed question is less adequate for the aim of this study. The third question was introduced with an explanatory text stating that in healthcare, the BSN number is used to simplify the sharing of patient data between different healthcare providers. After this introduction, the clients were asked whether they were willing to share the BSN number with the PHS for this purpose (currently the BSN number is not registered in client dossiers at the PHS). This question had 3 options: ‘Yes’, ‘No’ and ‘I don’t want to answer this question’.

Thereafter, 8 questions (question 4 to 11) followed about demographic data and client characteristics. The fourth question asked for gender (4 options: ‘man’, ‘woman’, ‘transgender’ and ‘I don’t want to answer this question’). The fifth question was about age (7 options: ‘<20’, ‘20-24’, ‘25-29’, ‘30-39’, ‘40-49’, ‘>50 years’ and ‘I don’t want to answer this question’). The question about age was categorical, as date of birth and age in years are less anonymous. The categories were based on the study of Pelgrim et al. (13). The sixth question was about educational level and was based on the Dutch classification of statistics Netherlands (CBS) (37). This question had 4 options: 1) ‘Primary education, vmbo or mbo level 1’, 2) ‘havo, vwo or mbo level 2, 3 or 4’, 3) ‘hbo- or wo- bachelors’ of masters’ degree’, 4) ‘I don’t know’, 5) ‘I don’t want to answer this question‘. The seventh question was about the birth country (4 answer options: ‘the Netherlands’, ‘another Western country’, ‘a non-Western Country’ and ‘I don’t want to answer this question’). Followed by the eighth and ninth question about the paternal and maternal birth country (both 4 answer options: ‘the Netherlands’, ‘another Western country’, ‘a non-Western Country’ and ‘I don’t want to answer this question’). The tenth question was about sexual behaviour; more specifically, whether someone has sexual contact with ‘men’, ‘women’, ‘both’ and ‘I don’t want to answer this question’ (4 options). The final question (question 11) asked whether someone gets paid for sex (3 options: ‘yes’, ‘no’ and ‘I don’t want to answer this question’). The questions about gender, sexual behaviour, whether someone gets paid for sex, and age, were asked to determine a client’s profile related to the triage criteria of the PHS. Furthermore, the questions about (parental) birthplace was used to assess migration background. Instead of determining whether the clients (or parents of the clients) originated from countries with a high STI preference, the migration background was determined, since the categorization process is quite similar. In the current study, not all risk groups were differentiated, because some information was too risky to ask, and other groups were not distinctive, or subgroups were expected to be very small. The expected duration to fill in the questionnaire was 5 minutes.

Procedure

At the start of the research project, the research was shortly announced during a meeting with representatives (either doctors or nurses) of the five PHSs of the Eastern region, and these representatives were shortly asked whether data collection was possible in their STI clinics. Thereafter, the representatives of each PHS were approached via e-mail and by phone. One PHS (PHS Noord- Oost Gelderland) could not collect the data during the data collection period. The other four PHSs contributed to data collection in the announced period. At the start of the data collection, the researcher visited each STI clinic and gave explanations about the study and procedures. Besides an on-paper instruction letter (see Appendix D: Instructions to executing PHSs (study part 1)) about the aim of the study, the execution and the procedure of inviting the clients was provided to each PHS. During this visit, all material to collect data (informed consent forms and questionnaires, envelopes) was provided to the STI clinic.

The 4 data collecting PHSs were asked to distribute the questionnaire among all eligible clients visiting the STI clinic. During the data collection, the HCPs or receptionists invited clients to participate in advance of their consultation. See Table 5 for an overview of the procedure per PHS and the data collection period.

Table 5 PHS and their participating locations, way of inviting and data collection period.

PHS	Participating locations	Way of inviting	Data collection period
Gelderland-Zuid	Nijmegen Tiel	Consulting room by HCP Waiting room	First week April – half May First week April – third week of April
Twente	Twente	Consulting room by HCP	Third week of April – ongoing
Gelderland-Midden	Arnhem	In waiting room by receptionists	Half of April – first week of May.
IJsselland	Zwolle Deventer	Consulting room by HCP Waiting room by receptionists	Half of April – first week of May Third week of April – First week of May

The informed consent (see Appendix B: Informed Consent (study part 1)) was attached to the questionnaire (see Appendix C: Questionnaire (study part 1)) and both forms were provided together to the clients. The clients were asked to put both forms into an envelope and put it in a box after they filled the questionnaire in, or to give it to the HCP before the start of their consultation. In case they did not want to participate, they were asked to put the empty form into the box, to determine response rates later. Afterwards, all questionnaires were collected and the PHSs were thanked.

5.1.3 Data-analysis

Before entering the results in SPSS 24, the questionnaires were checked and potential identifiable information that was filled in by the clients (e.g. in the open questions) was removed with a permanent marker on the original questionnaire form to protect the participants.

The participant number on the questionnaires was entered as a numeric variable in SPSS. The variable 'PHS' was categorical and had 6 categories: 'Nijmegen', 'Tiel' (both part of PHS Gelderland-Zuid), 'Twente', 'Arnhem', and 'Zwolle' and 'Deventer' (both part of PHS IJsselland). Question 1 was entered as the categorical variable 'Sharing_GP' with categories 1='yes', 2= 'no' and 3= 'don't want to answer'. Question 3 as the variable 'use_of_BSN' with categories: 1= 'yes', 2= 'no' and 3= 'don't want to answer'. Question 4 as 'gender' with categories 1= 'male', 2= 'female', 3= 'transgender', 4= 'don't want to answer'. Question 5 as 'Age' (7 categories: 1= '<20', 2= '20-24', 3= '25-29', 4= '30-39', 5='40-49', 6= '>50', 7= 'don't want to answer'). Question 6 was entered as the variable 'Education' with 5 categories (1= 'Low', 2 = 'Middle', 3= 'High', 4 = 'I don't know', 5= 'Don't want to answer'. The answers were classified according the classification of CBS (37). Whereas the answer 'No education, Primary education, VMBO and MBO 1' was classified as 'Low', 'HAVO/ VWO/MBO 2, 3 or 4' was classified as 'Middle' and 'HBO and WO' was classified as 'High'. Question 7 was entered as the variable 'Birthplace' with 4 categories (1= 'Dutch', 2= 'other western', 3= 'non-western', 4= 'don't want to answer'). Question 8 was entered as the variable 'Maternal_birthplace' (1= 'Dutch', 2= 'other western', 3= 'non-western', 4= 'don't want to answer'), Question 9 was entered as the variable 'Paternal_birthplace' (1= 'Dutch', 2= 'other western', 3= 'non-western', 4= 'don't want to answer'). Question 10 as the variable 'Sexual_contact' (4 categories 1 = 'men', 2= 'women', 3= 'both', 4= 'don't want to answer') and question 11 was entered as ‘Paid_sex’ (3 categories, 1= ‘yes’, 2= ‘no’, 3= ‘don’t want to answer’).

The answers of question 2, the open question, were translated and entered as the string variable ‘Motivation’. The answers on the open question were categorized, which resulted in 8 variables: four variables containing motives for those who consent, namely ‘Yes_Good_care’, ‘Yes_No_secret’, ‘Yes_Relation_GP’, ‘Yes_Other’, and four variables with motives for those who did not consent, namely ‘No_Not_relevant’, ‘No_Prefer_secret’, ‘No_Relation_GP’ and ‘No_Other’. Each of the eight variables had 2 categories (0= ‘not mentioned’, 1= ‘mentioned’). In case a participant gave more than one motive, only the first motive was considered, since the question was about the most important reason.

The demographic variables and client characteristics about sexual behaviour, gender, whether someone gets paid for sex, age, and (paternal/maternal) birth country, were used to create 5 other categorical variables, namely variable ‘MSM’ (2 categories: 1= ‘Yes’, 2= ‘No’), variable ‘Young’ (2 categories, 1= ‘yes’, 2= ‘No’), variable ‘Ethnicity’ (3 categories: 1= ‘Dutch’, 2= ‘other western’, 3= ‘Non-western’) and variable ‘More_than_one subgroup’ (2 categories: 1= ‘yes’, 0= ‘No’).

Descriptive statistics were used to determine the number of clients (absolute and in percentages) that do and do not give their consent to share the test result with the GP, to determine the most prevalent motives, and to determine whether the clients were willing to share the BSN number with the PHS for data sharing purposes. Chi-squared tests and Odds ratios were used to investigate subgroup differences in proportions. Differences were interpreted as significant in case of a p value <.05. The answer option “I don’t want to answer this question” was left out of the analysis, since this option was seen as a missing value.

5.2 Part 2 Interviews among healthcare providers

5.2.1 Study population

The inclusion criteria to become a participant in study 2 were that the HCP was executing tests or communicated with the client about tests and client data, or would have a role in interpreting tests and communicating results to other responsible HCPs. To include information rich participants, it was chosen to include doctors or nurses and exclude doctors’ assistants, as they have more an administrative role in sharing data. Furthermore, the participants should work in one of the four PHSs in the eastern region of the Netherlands. HCPs who just started working (started in the past three months) were excluded from participation as they are possibly not fully aware of the current policy and system of the PHS.

5.2.2 Data collection

Material

The material consisted of an informed consent form, an interview guideline, and a mobile phone for audio-taping the interviews. The informed consent of part 2 (see Appendix E: Informed consent (study part 2)) asked, contrary to the informed consent of part 1, for a signature, since this population is less vulnerable. In the informed consent, the participants were informed about the voluntary participation and their opportunity to quit/withdraw from participating in the study whenever they want to. Next to that, contact information of the researchers was provided to the participants in case there were complaints or questions. Furthermore, the participants were informed about the communication of the results via www.ggdgelderlandzuid.nl. Finally, the informed consent form emphasized that the study is about potential data sharing in the future, in order to prevent that the study influenced the current consultations.

The interview guideline (see Appendix F: Interview guide HCPs (study part 2)) for the semi-structured interviews was developed based on the model of Fleuren, Wiefferink and Paulussen (21). Semi-structured interviews were executed among the HCPs, as interviews are suitable for explorative purposes (38) and will provide a more detailed overview of motives and determinants than surveys. As an introduction to the topic, the HCPs were asked in the first question about their role in data sharing. Thereafter, the HCPs were asked about their opinion with regards to data sharing. The next question was introduced with a description of the aimed design of a data sharing system (see Appendix G: Information about system). This description was developed by the PHS Gelderland-Zuid. Consequently, the participants were asked to identify determinants that influence their intention to use the system. Next to the interview data, a few demographic variables and participant characteristics were determined, namely function (doctor vs nurse), gender, and PHS location.

Procedure

The interviews were also announced in the regional meeting. The representatives of each PHS (see part 1) were asked for potential participants for the interviews. An e-mail was sent to the representatives with information about the interviews and about the inclusion criteria. In case no reaction was given, the contact persons were approached by phone. The potential participants were invited to participate in the semi-structured interview via e-mail. Together with the invitation to participate, the participants received an informed consent (see Appendix E: Informed consent (study part 2)), and explanation of the study and the client data sharing system. The participants could indicate that they want to participate by replying on the e-mail. Two weeks after invitation, a reminder was sent to potential participants. A request to plan a face-to-face interview was done by the researcher. In case it was not possible to organize a face-to-face interview, the interview was conducted by phone. The participant was asked to fill in the informed consent in case this form was not filled in yet. Before starting the interview, consent to record the interview and to make notes was asked. If consent was given, a mobile phone was used to audiotape the interview. The interview was held based on the interview guide (see Appendix F: Interview guide HCPs (study part 2)). It was expected that the interviews would take 15 to 20 minutes. Afterwards, the participants were thanked. Data was collected until saturation was reached. The data was collected anonymously, and the records were safely sent via SURFfilesender and removed from the mobile phone.

5.2.3 Data-Analysis

Data were processed anonymously. The records of the interviews were fully transcribed. The records were first uploaded in AmberScript (transcribe software) and thereafter, the transcripts were revised. The data was then uploaded in and analysed with Atlas-ti 8. The grounded theory was used in the analysis of the transcripts. This is an inductive method which starts with open coding, follow by axial coding, and then by selective coding (39). The determinants which were found, were thereafter categorized in the model of Fleuren et al. (21). The data was for 20% double coded by two independent researchers. Thereafter, the discrepancies were discussed until consensus was reached. The rest of the coding of the interviews was done by one researcher based on the consensus. The interviews of nurses and physicians get equal priority.

5.3 Ethical approval

The study proposal was approved by the ethical commission, faculty BMS, of the University of Twente on the 20th of March 2019 (number 190282). For this study, a METC review was not required since a one-off anonymous questionnaire in a non-experimental setting was used, and the study does not ask for body material. This is in line with the WMO law (Dutch law for medical research with humans). In line with the suggestion of the ethical commission, several actions to safeguard the privacy of the clients were taken, because the target group contained vulnerable individuals. The actions are described throughout the text.

The original questionnaires were scanned, and the scans and the interview transcripts are stored at the University of Twente. The interview records were stored at a protected environment of PHS Gelderland-Zuid during the project and deleted at the end of the research period. The original questionnaires were destroyed.

6. Results part 1: Questionnaire among clients

6.1 Participants

449 out of 600 questionnaires were returned at the end of the research period (April until half of May). However, 24 questionnaires were not included in the analysis, because no consent was given via the informed consent form. 19 of these questionnaires were empty and “No” was answered on the informed consent form. The 5 other excluded questionnaires were filled in, but 2 participants answered “No” on the informed consent form, and 3 did not fill in the informed consent. Of the remaining 425 participants, another 7 were excluded because of missing values. Two of them gave no answer on the main question (“would you agree on sharing the STI test result with the GP?”) and 5 answered “I don’t want to answer this question”. Finally, 418 participants were included in the analysis.

Table 6 shows the demographics of the 418 participants. 32.3% of the respondents were clients of PHS Gelderland-Zuid, 10% of PHS Twente, 24.9% of PHS IJsselland and 32.8% of PHS Gelderland-Midden. 56% of the clients were male, 43.1% female, and 1.0% were transgender. 14.1% had an age below 20 years. The majority of the clients (43.3%) had an age between 20 and 24. 11.5% belonged to the 25-29 years group, 12% to the 30-39 years group, 7.9% to the 40-49 years group, and 11.2% to the older than 50 years old group. 6% of the clients were lower educated, 48.7% were middle educated, 44.8% were higher educated, and 0.5% did not want to answer the question. 85.4% of the clients had a Dutch background, while 2.4% had a first generation other Western migration background, 2.7% had a first generation non-Western migration background, 4.4% had a second generation other Western migration background, and 5.1% had a second generation non-Western migration background. Among the participants, 57.4% had an age below 25 years, 38.6% was MSM, 5.5% was sex worker, 14.6% had a migration background, and 8.6% of the participants belonged to more than one subgroup.

Table 6 Characteristics of the 418 participants.

	N	**%**
PHS		
Gelderland-Zuid[1]	135	32.3
Twente	42	10.0
IJsselland[2]	104	24.9
Gelderland-Midden	137	32.8
Gender		
Man	234	56.0
Woman	180	43.1
Transgender	4	1.0
Age		
<20	59	14.1
20-24	181	43.3
25-29	48	11.5
30-39	50	12.0
40-49	33	7.9
>50	47	11.2
Education[3]		
Low	25	6.0
Middle	202	48.7
High	186	44.8
I don’t want to answer	2	0.5
Migration background[3]		
Dutch Background	350	85.4
1st generation other Western	10	2.4
1st generation non-Western	11	2.7
2nd generation other Western	18	4.4
2nd generation non-Western	21	5.1
Young (<25 years)[4]		
Yes	240	57.4
No	178	42.6
Migration background[3]		
Yes	60	14.6
No	350	85.4
MSM [3, 4]		
Yes	160	38.6
No	255	61.4
Sex worker [3, 4]		
Yes	23	5.5
No	392	94.2
I don’t want to answer	1	0.2
More than one subgroup		
Yes	36	8.6
No	382	91.4

[1] The questionnaire is distributed in two clinics of PHS Gelderland-Zuid: Nijmegen (N= 94) and Tiel (N=41).

[2] The questionnaire is distributed in two clinics of PHS IJsselland: Zwolle (N=59) and Deventer (N=45).

[3] Due to missing data, the total number does not add up to 418.

[4] Clients could belong to more than one subgroup (N=36), see variable “more than one subgroup”.

6.2 Proportion of clients that consent to share data

In this section, the answer on the first sub question of study part 1 is given. The first sub question was: “what is the proportion of clients that consent with the sharing of their STI test results with the GP?” Moreover, the subgroup differences will be described, which is part of the fourth sub question: “are there differences in consent between the various STI risk groups (youngers with an age below 25 years, MSM, sex workers and clients with a migration background) and the other clients?”

Table 7 provides an overview of the results related to the question about consent to share data. The percentage of clients that answered “Yes” on the consent question was 62%, while 38% answered “No”. Chi-squared tests were executed and OR calculated for each of the subgroups (MSM, Young (<25 years), sex workers and clients with a migration background) compared to the rest of the clients. In all groups, the majority gave consent. 61.3% of the MSM clients gave consent to share the data, 66.3% of the clients with an age below 25 years gave consent, and 69.6% of the sex workers. A significant ($p<.05$) difference was found for young individuals compared to all clients older than 25 years. The young adults 1.5 times more often agree on sharing the data with the GP (OR= 1.53 (95% CI 1.03 to 2.28). The difference for MSM compared to no MSM clients was non-significant ($p=.84$), just as the difference between Sex workers and non-sex workers ($p=.51$), and the difference between clients with a migration background and those without ($p=.39$).

Table 7 Percentage of the clients (N=418) that consent to share data and subgroup differences. The differences for MSM, Young, sex workers and clients with a migration background, compared to other clients.

	Consent						
	Yes		No				
	N	%	N	%	OR	p Value	95% CI
Total	259	62.0	159	38.0			
MSM [1,2]	98	61.3	62	38.8	.94	.835	.63-1.41
Not MSM	160	62.7	95	37.3			
Young [1]	159	66.3	81	33.8	1.53	.042*	1.03-2.28
Not young	100	56.2	78	43.8			
Sex workers [1, 2]	16	69.6	7	30.4	1.42	.514	.57-3.52
No sex worker	242	61.7	150	38.3			
Migration background [1, 2]	34	56.7	26	43.3	1.31	.39	.75-2.28
No migration background	221	63.1	129	36.9			

[1] N.B. Clients could belong to more than one subgroup.

[2] Due to missing values, the numbers do not add up to 418.

* Significant difference, <.05.

The answer to the first sub question of study part 1 is thus that 62% of the clients accepted data sharing. The answer on the fourth sub question was that one subgroup difference was found in which young adults (age 18-25) 1.5 times more often accepted data sharing compared to older clients.

6.3 **Motives**

This section addresses the second sub question: “what are the most important motives of the clients for giving or not giving consent to share their STI test results with the GP?” The results of the open question (question 2 of the questionnaire) are related to this sub-question. In this question, the clients were asked to give the most important reason for giving or not giving consent to share data. The question was answered by 363 of the 418 participants, and 331 of the 363 answers were usable. The other answers were not eligible for the analysis, because they were unclear, or because the client gave an answer, but the answer did not contain a motive for sharing or not sharing data. An example of such an answer is “No objection”. During the categorization process, 8 categories came up, of which 4 motives related to the clients who gave consent to share data, namely:

1. Necessity for good care

Different answers are categorized as ‘necessity for good care’, namely answers that indicate the importance of a complete patient record at the GP, answers indicating that the GP should be aware or informed, answers that indicate that data sharing is important for your health or that the data is relevant in case of diseases or pregnancy, answers indicating that it is necessary for good care, medication, for (follow-up) treatment, or in case of emergency, answers which put forward that clarity or transparency about STIs is important for the GP, and answers indicating that it is important medical information or that it will contribute to better advice/care/safety, or that it increases efficiency. Two example answers are “A GP needs to know everything in order to make a correct diagnosis” (participant 25) and “I think it is important that my doctor is aware of my health (history). This is also necessary to provide more targeted and better advice.” (participant 560).

2. Good relationship with GP

The category ‘good relationship with GP’ contained answers of clients indicating that they prefer good contact/open communication with the GP, that they have no secrets for their GP, that they trust their doctor with their data or rely on his discretion and professional secrecy, that the GP is informed about private circumstances or sex work, or that they have a good relationship with the GP. Example answer: “the doctor has professional secrecy and is there for me” (respondent 159).

3. No secret

This category contains answers in which clients suggested that they have nothing to hide and that hiding is not useful, that they have no secrets, that they are not ashamed and that having an STI is normal. For example: “I think an STI is not that special, a bit like the flu” (respondent 302).

4. Other

Different answers were classified as ‘other’, namely answers suggesting that data sharing is anonymous, that data sharing is easy, practical or handy, that the data is already shared (e.g. in case of hiv patients), that the client was already referred by the GP, that the clients would like to contribute to control for STIs (so not for their individual health), or that the GP is a doctor. An example answer was “I think it is easy and better than having to call. Sometimes I waited for more than 30 minutes” (respondent 408).

Among those clients who did not agree on sharing data, also four categories were found, namely:

1. Not relevant for GP

The answers categorized under the motive ‘not relevant for GP’ contained information like that there is no need to share data or not always, or that it is not relevant to share the information, that the information is not relevant for other health complaints, that the STI does not have long term consequences, that the information is not important for the GP, that the GP does not need the info, and that it is not important for the medical record. An example answer is: “I think this is unnecessary” (participant 242).

2. Preference to keep secret

In this category, the answers contained privacy and anonymity reasons, for example a preference that as few as possible people would know and to keep it for themselves, and that it would not be included in the record. The data is seen as confidential, and shame, sex work, private circumstances, secret sex life, sexual orientation, fear for data leaks, fear that the parents or others will find out, and fear for abuse with the data, were reasons to keep it secret. Also answers indicating that the threshold is lower if data is not shared are included. Example answer: “Just nice that testing through the GGD is currently anonymous. It (data sharing) would raise the threshold for testing.” (respondent 131).

3. Suboptimal relationship with GP

The answers in this category indicate that the clients have had unpleasant experiences with their GP, or that they have a bad relationship, or that the GP is not that accessible, or that clients are afraid that the GP will view them differently, or that their GP is an acquaintance, or that their GP has good contact with other acquaintances (like when he has a relationship with an ex-partner, or is a friend of parents). An example answer is: “The GP does not respond in an understanding way to testing. Prejudices are present at the GP.” (respondent 470).

4. Other

Different answers were arranged as ‘other’, namely answers suggesting that the willingness to share data depends on the test result, that the clients prefer to control data sharing and what is being shared themselves, that they prefer to tell it personally, and that they do not want that it is included in the patient record. An example answer is: “I want to keep control over this decision myself, so that I can decide for myself what and if I share” (respondent 553).

The most prevalent motive given (see Table 8) by those who gave consent to share data, was the necessity for good care (80.3%). Furthermore, 6.6% mentioned a good relationship, 5.6% that it is no secret, and 7.6% of the answers belonged to the ‘other’ category. Among those who did not give consent, the most prevalent motive was a preference to keep the data secret. This motive was given in 69.9% of the cases. The idea that the information is not relevant to share was mentioned in 11.3% of the cases, a suboptimal relationship with the GP was mentioned in 12% of the cases, and 6.8% of the answers belonged to the ‘other’ category.

Table 8 Frequencies of the motives given. The frequencies of the motives given by those who consent (N=198) to data sharing and for those who did not consent (N=133) to share data.

	Consent to share data	
Motives	**N**	%
Necessity for care	159	80.3
Good relationship GP	13	6.6
No secret	11	5.6
Other	15	7.6
	No consent to share data	
	N	%
Preference to keep secret	93	69.9
Not relevant for GP	15	11.3
Suboptimal relationship GP	16	12.0
Other	9	6.8

In summary, the answer to the second sub question is that the most important reasons for those who agree on data sharing was in 80.3% of the cases the necessity for good care, in 6.6% of the cases a good relationship with the GP, in 5.6% of the cases that the STI was no secret, and 7.6% gave other reasons. For those who disagree, 69.9% had the preference to keep the STI secret as most the important reason, 11.3 % mentioned that data sharing was irrelevant, 12% mentioned their relationship with the GP as most important reason, and 6.8% mentioned other reasons.

6.4 Use of BSN number

This section answers the third sub question: “what is the proportion of clients that consent with sharing their BSN-number with the PHS in order to facilitate the sharing of their STI test results?” and the fourth sub question: “are there differences in consent between the various STI risk groups (persons with an age below 25 years, man who have sex with man (MSM), sex workers and clients with a migration background) and the other clients?”.

Only those individuals who gave consent to share data and answered the BSN question, were included in the analysis. The answer option “I don’t want to answer this question” was left out of the analysis, as this answer was seen as a missing value. Eventually, 253 clients were included in the analysis.

Fout! Verwijzingsbron niet gevonden. Table 9 shows the acceptance to use the BSN number among those clients who gave consent to share the STI data to the GP. 77.5% would accept the use of the BSN number, while 20.5% does not accept this, and 1.9% did not want to answer the question. Chi-squared tests were executed, and OR calculated, to analyse subgroup differences for each of the subgroups (MSM, young (<25 years), sex workers and clients with a migration background) compared to the rest of the clients. In all groups, the majority gave consent. 89.5% of the MSM clients gave consent to share the data, 75.2% of the clients with an age below 25 years gave consent, and 93.3% of the sex workers. A significant (p<.01) difference was found for MSM clients compared with all non-MSM clients. MSM 3 times more often agree on sharing the data with the GP (OR= 3.10, 95% CI 1.48 to 6.54). The difference for young compared to not young clients was non-significant (p=.057), just as the difference between clients with a migration background (p=1.000). The analysis is not executed for sex workers, since one the frequencies was too low.

Table 9 Percentage of clients that consent to share data with the GP and the acceptance to use the BSN number. This table shows those clients who gave consent to share data and answered the BSN question with 'Yes' or 'No' (N=253), and the question whether the client gave consent to use the BSN number. It shows the differences between MSM (N= 95) and the other clients (N= 157), between young clients (N=157) and the other clients (N=96), between sex workers (N=15) and the other clients (N=237), and between clients with a migration background (N=32) and other clients (N=217).

	Use of BSN						
	Yes		**No**				
	N	%	N	%	OR	p Value	95% CI
Total	200	79.1	53	20.9			
MSM [1,3]	85	89.5	10	10.5	3.10	0.002**	1.48-6.54
Not MSM	115	73.2	42	26.8			
Young [1]	118	75.2	39	24.8	.52	0.057	.26-1.01
Not young	82	85.4	14	14.6			
Sex workers [1, 3]	14	93.3	1[2]	6.7			
No sex worker	186	78.5	51	21.5			
Migration background [1,3]	25	78.1	7	21.9	1.10	1.000	.45-2.71
No migration background	173	79.7	44	20.3			

[1] N.B. Clients could belong to more than one subgroup.

[2] This frequencies is too low. No OR is thus calculated.

[3] Due to missing values, the numbers do not add up to N= 253.

** significant difference <.01

In conclusion, the answer to the third question is that the majority (79.1%) of the clients who agreed on data sharing, also agreed on sharing the BSN number with the PSH for the purpose of data sharing. In answer to the fourth question, one subgroup difference in the use of the BSN number was found, in which MSM who agreed on data sharing also 3.1 times more often agreed to the use of the BSN compared to other clients who agreed to data sharing.

7. Results part 2: Interviews among HCPs

7.1 Structure of this section

In this section, the determinants identified by the HCPs that could influence their intention to use a data sharing system will be described. This information belongs to the second research question: "what anticipated determinants, identified by HCPs of Dutch STI clinics, influence their intention to use a client data sharing system to share clients' STI results with the GP?". In line with the sub questions of research question 2, it will also be assessed whether a determinant is considered as a barrier or a facilitator for the intention of HCPs to use the client data sharing system.

The determinants found via the grounded theory are subdivided in the four determinant groups based on Fleuren et al. (21): characteristics of the client data sharing system (section 7.3), characteristics of the HCPs (section 7.4), characteristics of the PHS (section 7.5), and characteristics of the socio-political context (section 7.6). Table 10 provides an overview of the determinants per group. An overview of the codes and all quotes is provided in supplement 1.

7.2 Participants

11 HCPs participated in the interviews; two HCPs were male, the others were female. A small majority was nurse (N=6); the others were doctors (N=5). The participants were operating in four different PHSs in the eastern region of the Netherlands. All interviews were performed in Dutch. Two interviews were conducted by phone, while the other interviews were face-to-face. The mean length of the interviews was 25 minutes, with the shortest interview taking 15 minutes and the longest interview taking 53 minutes. Variation in length and in amount of participants are features of interviews (40). All interviews took place in April. A division was found among the HCPs in their opinions towards sharing data and the client data sharing system. Five HCPs were pro data sharing, five HCPs were con, and one HCP was ambivalent (respondent 11). The opinions were underpinned with several motives which are related to the determinants described in the next section.

7.3 Determinants related to characteristics of the client data sharing system

7.3.1 Evidence that data sharing is working

A positive outcome of a pilot evaluation of the system is seen as a facilitating factor according to the HCPs. Two HCPs suggest that a positive evaluation after half a year or after a trial period about the system will help them using the system. One of them mentioned that the evaluation or pilot should prove the effectiveness and added value of the system. In case the relevance is not proven, this HCP does not want to use the system.

> Respondent 4, line number 592-605
> "But if it is not proven and you have to invest time in it... It must first be carefully considered whether it is effective.."

7.3.2 Safety

One basic requirement of the system seems to be that the data should be safely shared. Four HCPs described that the system should be safe and that there may be no data leaks. One HCP thought that this would be no problem, since this HCP trusts the system. Another had more concerns and sketched other situations in which the HCP thought that data were not shared safely (see quote). The determinant ‘safety’ is seen by some HCPs as helping, while others see it as a barrier.

> Respondent 3, line number 511-512
> “And it must be safe, it must be guaranteed safe."
>
> Line number 516-527
> "Currently I can view data from clients from other PHS in the eastern region. That should not be possible right?! I should only be able to view data of my own PHS." *
>
> *The situation is verified with the management and is in line with legislation, this quote only sketches a concern of the HCP about safety.

Another HCP suggested that it would be helpful if the system provides an overview of what you are going to send, and that you can check this overview first to prevent mistakes (see next quote).

> Respondent 9, line number 735
> “What I always like is that you can see what you send.”

7.3.3 Complexity and extra work

Another basic requirement is that the system and sharing data should not be complex and not result in a lot of extra work or be time consuming. Nine HCPs mentioned as a drawback of the system that they have extra work to do and that it could be time consuming. The extra work consists according to them of informing the client, asking the client for consent, asking or searching for the GP’s contact information, and sharing the data with the GP. According to the HCPs data sharing may not become too complex or require a lot of effort or time, such as opening other files or many extra clicks. Furthermore, the HCPs mentioned that the system should be well working, very clear, and that the functions may not be hidden. Two HCPs emphasized that a lot of extra work could be caused, because the innovation is supposed to share the data of every single client. Four HCPs emphasized that the workload is already high. The automatically generated data was mentioned as a handy aspect of the system by two HCPs.

> Respondent 9, Line number 731
> “Preferably of course one push of a button, right? Not five more clicks.”
>
> Respondent 10, line number 145-146
> “The automatic generation is handy, because I don't think data sharing could require an extra action from someone. There is simply no room for that.”

One HCP described that the drawback of extra work is not per se outweighing the benefits, as is illustrated by the next quote. Four HCPs mentioned that a useful, nice system would be facilitating and one said that the system is also helpful for the STI data that they already share with the GP, such as syphilis.

Respondent 1, line number 292-298
"I think sometimes a bit more work can do a lot. I am curious and I think data sharing could be quite beneficial, so I am willing to do some extra work for it."

Two HCPs gave suggestions to reduce the complexity and work. One said that it would be helpful if a patient letter is already included in the system and could be changed in the system instead of having to be uploaded first. The other said that there should be a drop-down menu with all contact information of GPs included in the system in which one could easily find the correct GP, since they currently have to google first to find the correct GP and then enter the information manually.

7.3.4 Relevance of sharing all STI data for the GP

Another determinant discussed by the HCPs was the relevance of data sharing. It does not seem to be the most optimal way for GPs that patients must inform their GPs about results. Data sharing could thus be helpful. Three HCPs said that patients not always (correctly) tell their GP about their visit to the PHS. However, another HCP thought that clients could inform their GP themselves. One mentioned that it is nice that the GP does not have to ask each patient about their STI history, and that the innovation is time saving for the GP.

Respondent 2, line number 525-528
The respondent described how some clients share relevant medical information in a suboptimal way:

"Yes, I have had pills". They are often like that. "I have had pills" and then the doctor does not know what pills. If you send such a letter, then the doctor is of course much better informed."

Having a more complete overview and file of their patients is seen by some HCPs as relevant, while others think it is irrelevant. Five HCPs think that GPs will be happy if STI data are shared, and that it could be helpful for the GPs if their patient files are more complete. The HCPs think that it could be beneficial for health care that the GP knows, for two reasons. First, data sharing is seen by two HCPs as a prevention of damage. This is explained by one HCP by the fact that medication could be harmful when interfering. If the GP or hospital is not aware of medication use, there is a chance that other medication is prescribed. Second, according to three HCPs, unnecessary care or medical research, and therefore unnecessary costs, could be prevented by sharing data, which is seen as beneficial. They mentioned that they could imagine that if a GP does not (exactly) know that a client is tested or treated for STIs, or the client does not tell, that the GP will provide this care/research too. But if a GP is aware, this overlap could be prevented. Furthermore, the HCPs mentioned that some clients ask for unnecessary care, because they are afraid that the STI will remain. In case the GP is informed, those questions can easily be rejected.

Participant 4, line numbers 333-335
"I certainly see the added value there. Otherwise you get that different people in health care are doing all kinds of different things and that is a bit inefficient I think."
Line number 356
"And I think that quite a few costs can be saved there too."

However, four HCPs wonder why data sharing with the GP could be relevant, and what the GP is going to do with the data. This is a barrier for data sharing according to them. One HCP said not to believe that the GP is going to use the information. It would be helpful according to two HCPs if they will get insight why GPs prefer to have this information.

> Participant 3, Line number 74-82
> “Is this on a ‘want to know’ or ‘need to know’ basis? And I think this is ‘want to know’ basis. And what does it add?”
>
> Line number, 90-101
> “What is the added value? What is the GP going to do with the information, except thinking: fine, now I know that too? Or he should have very good arguments, such as that he can use it later. But I think that doesn’t happen very often. So, is it ‘want to know’ or ‘need to know’? On what basis does the GP prefer to know?”

In relation to the relevance of sharing the STI data, HCPs also gave their opinion about what information is relevant to share. The first point that was mentioned by six HCPs is that they think sharing the data of less serious STIs, such as chlamydia and gonorrhoea, is less relevant, since these STIs are not chronical, have a one-off treatment, have less consequences, and the PHS checks for contraindications. On the other hand, syphilis and hiv have according to them much more serious consequences for health, are chronical, are visible in blood results, and could influence the course of other diseases. Therefore, seven HCPs think it is relevant to share this data. However, one of them changed its mind during the interview. This HCP realized that these ‘less serious’ STIs are also dealing with unnecessary care, which could be prevented by sharing the data.

> Respondent 5, line number 320-321
> “Actually I think: ‘what does the doctor care that someone has had a chlamydia?’”
>
> Respondent 4, line number 246-255
> “Is it useful if someone comes here once? This person has contracted Chlamydia and is treated here with two tablets. Then I think: ‘yes, what added value does that have if there is nothing else special, no side effects, all went fine. What would be the added value for a doctor?’”

The second point, mentioned by two HCPs, was the usefulness of sending both positive and negative test results. One HCP said that all positive results of all STIs should be shared with the GP. Another, who does not see the added value of sharing STI results at all, first wondered what the added value of negative test results would be, later on thought that it is important that the GP knows if there are negative results because something else may be going on, but in the end found that the client could tell this to the GP himself.

Third, three HCPs mentioned that it is necessary to share the context of the result as well. Two said that all the results of the tests performed on a client should be shared together to the GP. One of them said that the GP otherwise does not know what tests are done and what test the GP should do in case the client still has complaints. This HCP addressed that the STI clinics do not test every client on each STI. The tests that will be executed are based on decision trees. Additionally, this HCP and another said that it is also necessary to not only share the results, but also the diagnosis and the treatment, so the GP knows what is done. However, they stated that the data sharing system requires a letter than.

7.3.5 Information flows to the GP

Three HCPs spoke about the information flows to the GP and the usability of this flows. Two HCPs described that it is important to think about the size of the information flows. One further explained that it should be considered which information is relevant to share with the GP, because patient files of the GPs could become huge and this could be undesirable. Two HCPs discussed whether the GP should get a notification of a new test result, one said that it is better if the GP could read the result at the moment that it is relevant and that the GP should not get a notification, while the other said that the GP should get a notification, because the GP otherwise would not see the result.

Respondent 4, line number 293-95
“Because it leads to huge information flows, huge medical records. I am wondering whether this is desired.”

In summary, five determinants related to the innovation were found. First of all, it is facilitating for the use of the system if there will be an evaluation which will confirm the efficiency of the system. Second, the safety of the system was a determinant. For some HCPs, an unsafe system is seen as a barrier, while others said a safe system is seen as a facilitator. Third, the system must not be complex and not time consuming. Easy and quick data sharing is seen as facilitating, complex and time consuming is seen as barrier. Fourth, the relevance of data sharing with the GP was discussed; a division was found here. Some HCPs did not see the relevance, which could be a barrier. They wonder what the GP is going to do with the information. Others do see the relevance, which is seen as a facilitator. Fifth, the information flows as a consequence of the data sharing could be seen as a barrier for GPs to optimally use the system.

7.4 **Determinants related to characteristics of the HCPs**

7.4.1 Lack of knowledge about legislation

A determinant that was found in the interviews was the lack of knowledge about legislation. One respondent sketched (see quotes) that due to the lack of knowledge of surrounding privacy legislation, it is more difficult to share data. According to this HCP, current regulations are not clear enough to employees of both the PHS and the general practice. This results in sharing less data, because the employees hide behind these legislations. This HCP said that it is important that the employees know what they may do and what they may not do, given the current legislations and that they know the boundaries of what is allowed to do. The HCP said that a nice and clear explanation, which was previously given by a lawyer to the HCP, was helpful to understand the legislations better.

Respondent 4, line number 144-149
“Because there is not enough knowledge about it and about a number of other related laws. People hide behind it very easily. That they don't know exactly, but if they have to say, they say "oh no I don't because..." And they hide behind that while in many cases that is not even true.”

Line number 97-99
“I think there is a bit of a lack of knowledge with all of us about what is actually allowed from a legal point of view and what really is not possible.”

7.4.2 Attitude towards changes

The acceptance of changes, or whether the HCPs agree on using an innovation, is also mentioned by three HCPs in the interviews. One HCP described that you should try out new things sometimes, while another said that you should not change things just to change things, and that the effects should first be clear. Furthermore, this HCP and a third HCP said that it is important that everybody agrees on using the system before it will be decided to use it. The fourth HCP, despite not being satisfied with the client data sharing system, said to cooperate and use the system.

> Respondent 1, line number 489-92
> "I think sometimes, you just have to try new things. We do so many new things, so why not this?"

7.4.3 Data sharing could conflict with the HCPs' public health task

Another determinant was that the client data sharing system could conflict with the Public health tasks of the HCPs, namely providing easily accessible STI care to high risk groups. This determinant was mentioned by eight HCPs. According to the HCPs, sharing data could reduce the accessibility of the STI clinics and therefore, they are afraid that the data sharing system could reduce the attendance of their clients to the STI clinics. Clients who would not attend anymore would, according to the HCP,s not receive the care they need, while the task of the HCPs is to decrease the amount of STIs in the Netherlands. The HCPs indicate that they do not want to use the system if it influences the attendance of their vulnerable clients in a negative way, and four said that there should always be the opportunity to test anonymously. However, two HCPs said that even if you ask clients for consent, the data sharing system could still have a negative influence on the attendance of clients, because clients must make an effort to remain anonymous. Another HCP also bring forward that data sharing is useful for individual STI care, which is in principle not an aim of the PHS, since the PHS is completemtary to the GP.

> Respondent 5, line number 104-8
> "The clinics are trying to have a low threshold, all PHSs in the Netherlands do. And you guarantee that the threshold is so low, because people are anonymous here and people don't have to pay any money here. And then you just give up one of those two things. That is quite something."
>
> Respondent 6, line number 658-61
> "If people no longer dare to come, because it would be shared with the GP, I think we will miss our goal. Because we want that vulnerable group that does not dare to go to the doctor but is at risk."
>
> Respondent 10, line number 49-53
> "I think if all our results are shared with the GPs, that there would be many people who say "then I will not visit", and that means that they have no place where they can be tested on STIs. I don't think that is a positive point for public health."

Thus, three determinants related to the HCP were found. First, there is the lack of knowledge about privacy legislation, which could be a barrier for data sharing because the HCPs do not know what they are allowed to do. Second, the attitude toward changes was found to be a determinant. The attitude to try out new things could be beneficial, whereas a negative attitude towards the system is not per se a barrier for using the system. A barrier might be the need to convince the whole team in advance of the decision. Third, a potential barrier is that data sharing could conflict with the public health task of the HCPs. If the attendance of the clients to the clinics will be negatively influenced by the system, the HCPs do not want to use the system. They also demand an opportunity in which the clients could always test anonymously.

7.5 Determinants related to characteristics of the PHS

7.5.1 Allocation of costs of the innovation

The allocation of costs, i.e. which institution pays what part of the new client data sharing system, is also mentioned as a determinant. One HCP said that if there are high costs and only the PHS will pay for the costs, the PHS will possibly not introduce this innovation.

Respondent 4, line number 729-42
“The system of course will cost something. How are you going to divide that? Because, it is in the interest of the general practitioner, it is in the interest of the client, it is perhaps in our interest as well. That is something to be looked at I think, because if there are quite a few costs involved, which are only deposited at a PHS, I wonder if the PHS says: “yes we will do”.”

7.5.2 Efficacy of current EHR (SH-direct) of the PHS

The efficacy of SH-direct, or whether HCPs were satisfied with this EHR, was discussed by four HCPs. According to these HCPs, SH-direct is not (always) working well, or they had problems with the internet and logging in. Therefore, data sharing could become a complex and time-consuming task with a lot of clicking according to them.

Respondent 2, line number 388-400
“SH-direct, I think it's an annoying system. I've always found that. I keep finding it a system in which you have to click and write a lot and it has a lot of questions”

7.5.3 Work process

The task related to the client data sharing system are not yet included in the work process. Five HCPs spoke about including it in the process. Five HCPs said that it is important to determine who is responsible for which task.

Respondent 8, line number 321-331
“And that it is very clear: who does what? Yes, the role of the nurse, the role of the doctor's assistant, the role of the doctors.”

One of them said that it should be determined as well at which moment the tasks are done, and that it is facilitating if the task is at a logical moment and linked to an existing action.

Respondent 6, line number 447-48
“But the fewer the deviations from the standard, the easier it is.”

Another said that positive results require interpretation, but this doctor did not want to share test results throughout the whole day, if this could also be a doctor’s assistant’s task. This doctor also said that negative test results should be shared by the doctor’s assistant. While another HCP thought the data sharing could not be a doctor’s assistant’s task.

Four HCPs put forward that there is a high workload, and one of them said that it should also be considered to lengthen the consultations if this will become a nurse task.

> Respondent 4, line number 800-2
> “Because, suppose it takes more time, we already have a limited amount of time per consultation. So, you should look if that fits or that you have to decide to extend the consultations a few minutes or five minutes”
>
> Line numbers 818-33
> “Because it is difficult, the last few years especially. There is more and more and you actually get less and less time for more things. You have to be careful that the quality of the consultation will not be influenced.”

7.5.4 Way of asking for consent

Five HCPs spoke about the way HCPs should ask for consent. The HCPs put forward that it is important to explain the importance of data sharing, the benefits for the client, the confidentiality obligation of the GP, and what will happen with the data. One HCP acknowledged not to know how to explain were the data will be used for. Another said that if it is clear to this HCP what the GP is going to do with the information and why data sharing is relevant, that this would help in convincing the clients.

> Respondent 8, line number 331-34
> “The client should know what exactly happens with that data. Like, now I would not know very well. If I had to ask the client and the client would say "yes but what is that used for?", then of course I don't know.”

Three HCPs discussed that a standard way of informing and asking the client for consent is important to fully inform the client and for uniformity. According to two of them, the manner of informing or motivating the clients has an influence on the answer of the client.

> Respondent 3, line number 440-44
> “You can see that very nicely in the case of HIV results, that people initially say: ‘I don't want my doctor to know.’ Well, then you start talking about that: ‘what is stopping you?’ And then you explain the importance of why it can be good for the client that his or her doctor knows. And then you often see that things turn.”

7.5.5 Cooperation between PHS and GPs

Six HCPs indicated to have the desire to better cooperate with GPs, since the HCPs and GPs are both responsible for STI care. HCPs mentioned that the clients are too often referred to the PHS, that preventive care is often not provided, and that GPs do not talk (much) about sexual health with their patients, due to a lack of knowledge about STI care among GPs, their working load and limited time. Four HCPs mentioned that a better cooperation with GPs could be a result of this system, and that better cooperation could lead to better STI care in general and better individual STI care. This is illustrated by the next quote.

> Respondent 1, line number 206-13
> “Because I am also very curious, if we start to cooperate more with the general practitioner in this way, whether we might that way also be able to collaborate more in other areas and whether STI care might therefore also improve slightly.”

According to three HCPs, the contact with GPs could be improved by the system. It could result in involvement and knowing each other, which could in turn lead to consultations of the GP to the PHS, or asking for advice to the PHS, or referral in case of complex situations. Moreover, the STI result could be a starting point for the GP to talk about sexual health, and the GP and PHS could discuss together about clients. One HCP said to hope that clients will visit GPs more often in the future. Two mentioned that education of the GPs of the PHS is helpful for the STI care, and one said that if data is shared with the GP, one could also analyse client population differences such as increased risks in the population of the concerning GP, and next to that, look at why these clients have the preference to visit the STI clinic instead of the GP. This HCP saw this as an opportunity for additional education for the concerning GPs, and to cooperate in decreasing the STIs in such a population. However, although the desire of improved cooperation is acknowledged by most HCPs, three HCPs do not agree on the idea that the cooperation will be improved by the data sharing system.

Respondent 5, line number 675-684
“GPs are really busy and STI care is such a small part of their job. So, I don't think a GP is going to have conversations like that, but maybe there is one.”

Two of them think that the GP should collect the information by itself and should more often start a conversation about sexual health. This should not depend on a test result sent by the PHS to the GPs. One of them also said that there are a lot of other ways to collect this information without breaching the anonymity principle. And the other said that sexual health is also the task of the GP. The GP should be more proactive according to this HCP, because the PHS is complementary to the PHS. One HCP thought that it is more important that the GP knows the whole sexual background instead of only STI results. This is illustrated by the following quote.

Respondent 3, line number 121-131
“Anyways, I think that if a patient comes to you as a GP and you suspect or know that someone is sexually active, that it should always be a good topic for discussion that should not depend on a result of a test that we send. Sexuality, how important can you have it? And of course, that happens very little, only if a patient comes with a specific question.”

Respondent 10, line number 65-78
“If the doctor wants to know how often someone comes to test on STIs and how often someone actually has an STI, then he should just talk to his patients about it. I think it is much more important that GPs know of their patients' risk behaviour, what their sexual behaviour is, what their sexual fears are, if someone is gay and therefore runs a risk, then that the GP knows how often someone tests for STIs and how often they have STIs. Because, there is not only a risk of STIs. Psychological well-being, that is also important. I think it is more important that GPs ask their patients "you are at risk and can I help you with that", then that we inform them: ‘this patient has had so many STIs’.”

To sum up, five determinants related to characteristics of the organisation were found. The first determinant is that the division of costs should be fair. This could be a barrier, because the PHS will otherwise decide not to use the system. Second, a barrier is that HCPs are not satisfied with the current EHR (SH-direct), which could make data sharing difficult. Third, the HCPs said that it is important to determine the task responsibilities related to data sharing. It would be facilitating if the tasks are embedded into the current working process. Moreover, if the tasks do not fit in the consultation time, more time should be scheduled, or responsibilities should be shifted to others. Fourth, a standard way of informing the clients and asking consent could facilitate, and could be influential for the answer of the participant. Fifth, the hope for improved cooperation could be seen as a facilitator, because it seems motivating to improve STI care. However, not all HCPs believe the cooperation will improve. Some do not agree on data sharing and think GPs should collect the information themselves, which could be a barrier for using the system.

7.6 Determinants related to characteristics of the socio-political context

7.6.1 Fit of system in regulations

The HCPs also described whether the system fits in the current Dutch regulations. First of all, three HCP mentioned that anonymity should not be a problem since the GP has professional secrecy and therefore should not share data with others as well.

> Respondent 5, line number 429-30
> "So in terms of openness, we are all doctors, we have all taken an oath, that should be enough."

One HCP mentioned that the regulation of anonymous testing is adopted by the minister and therefore, the HCP does not agree on sharing all the data. If it will be decided on a national level that the data will not standard be shared with GPs, this person would not share data.

> Respondent 5, line number 281-7
> "If it is decided nationally that we do not, then I don't do it, and I will actually be relieved. If they are like: "we have anonymity and freeness and we are not going to throw one of those two values overboard", I can conform to that."

7.6.2 Anonymity preference of clients

Ten HCPs spoke about the preference of some clients to remain anonymous and that they therefore prefer not to share data with their GP. HCPs described several situations in which clients do not want to share data: clients can be afraid for their GP, or for their family in case the GP is a family GP; clients can be afraid that the data will end up with others; or MSM can have a bad relationship with their GP, because homosexuality is not everywhere accepted.

> Respondent 4, line number 203-5
> "Sure, if you are in such a situation, then they are simply afraid that things will end up with the wrong people and that it will have consequences for their situation or relationship."

One HCP thought there would not be that much clients to whom the anonymity matters, since clients often mentioned that it does not matter to them. And one said to think that there will be quite a few who agree on data sharing. All HCPs support the clients in their wish and do not want to share the data if the client disagrees. Asking for consent is therefore a requirement according to the HCPs.

> Respondent 9, line number 93-97
> "With the approval of the client, right? If he says: "I don't want my doctor to know that I'm positive", then we don't."

One HCP said that the client could always say “No”. Three HCPs mentioned that it is important that the clients know what they say “yes” to. One of them put forward that not all individuals can say “No” and these clients are dependent on the STI clinic, which could make it even more difficult. Another HCP described that not all individuals, for example lower educated ones, are aware of what is asked from them, for example.

> Respondent 5, line number 253-5
> “But half of our clients have no idea what they say ‘yes’ to, or they think: “yes, I will do it, because then I might get very good care here”. And I think that's a bit sad.”

7.6.3 Registering consent

Seven HCPs described that recording consent could be challenging and should fit with the current legislation. It should not make the system complex and time consuming. The following difficulties are mentioned by the HCPs: 1) whether spoken consent is sufficient, 2) whether consent should be recorded each time or once, 3) if it only needs to be recorded once, what to do when the client changes its mind, 4) how it should be recorded if the client only wants to share certain results, 5) what to do if the client wants to decide later, 6) whether it could be an opt-in or opt-out system, 7) what to do if there is no contact anymore with the client (e.g. after negative test results), 8) whether clients should possibly identify themselves with their BSN number, to be sure that the data is shared correctly, although up till now, identification was not necessary at the PHS.

One HCP said that it would be helpful if the clients will get an informed consent form in advance of the consultation. Another said that the clients should be informed in several ways about the system, for example via posters and video clips in the waiting room. This HCP said that if clients should be informed during the consultation, that would be a barrier, since it is time consuming and time is already limited. Another said that there should be a function according to which the system could not continue data sharing without clicking on a button that the client gave its consent.

> Respondent 8, line number 353-6
> “It will probably help if it will be requested in advance, or by means of a consent form that they get at the desk, so that they already know that we are asking about it and that they can read it in advance. That we do not have to tell very much during the consult.”

In conclusion, three determinants related to socio-political characteristics were found. First of all, a division is found on whether the system fits into the current legislations. Some HCPs indicate that data sharing is fine, since the GP also has professional secrecy. Another HCP seemed to hope that it will be decided on the national level that the system will not be used, since data sharing is not in line with the anonymity principle laid down in the Dutch regulations. Second, the preference of the clients could be a barrier in data sharing. The HCPs expect that not all clients agree, and they do not want to share without consent. Finally, the HCPs said that the registering of consent could become very complex to both fit with the applicable regulations and the preferences of the client. This could be a barrier for sharing data.

7.7 **Answer to sub questions**

To sum up, sixteen determinants were identified in the interviews. Most determinants could be both facilitating and impeding, depending on the context. This was the case for evidence for data sharing, safety, complexity/extra work, the relevance of data sharing, the attitude towards changes, the fit in the current work process, the cooperation with the GP, the fit of the system in the Dutch regulations, and the preferences of clients. Barriers could be: information flows to the GP, a lack of knowledge about privacy legislation, declining attendance rates, the allocation of financial costs, the efficacy of the current EHR, and registering consent. Facilitators could be a standard motivating manner of asking consent to the client.

Table 10 Determinants found in the interviews grouped in the determinant groups of Fleuren, et al. (21)**.** In the first column, the determinant groups are shown. The second column shows the determinants found in the current study. The third column shows the direction of the determinant. The fourth column contains a more extensive description of the findings.

Determinant group	**Determinants**	**Type of determinant[1]**	**Results**
Characteristics of the client data sharing system	Evidence for data sharing	+ -	A positive outcome of a pilot study will facilitate data sharing In case the added value of the system is not proven, this could be a barrier
	Safety	- +	If the system is unsafe, this could be a barrier A safe system is seen as facilitating
	Complexity/extra work	- +	If the system is too complex and requires extra work or time, this would be a barrier to data sharing Usability is seen as a facilitator for data sharing
	Relevance of data sharing for the GP	+ - -	The idea that data sharing is relevant for the GP and for healthcare, is facilitating The idea that it is irrelevant, is a barrier to data sharing Sharing irrelevant or incomplete data could be a barrier for the GP
	Information flows to the GP	-	Huge information flows to the GP could be a barrier to the GP’s use of the data
Characteristics of the HCP	Lack of knowledge privacy legislation	-	If HCPs do not know what is allowed to do under the privacy legislation, this is a barrier to data sharing
	Attitude towards changes	+ 0 -	The acceptance of individual HCPs could be a facilitator A negative attitude seems to be a neutral determinant, since the HCP would still share data Having to convince the team could be a barrier
	Public health task	-	Declining attendance rates of vulnerable clients is a barrier
Characteristics of the PHS	Allocation of financial costs	-	If the PHS should pay alone for the system, this could be

			a barrier for the PHS to introduce the system
	Efficacy of EHR SH-direct	-	SH-direct is not always working well, which could be a barrier
	Work process	+ -	It would be facilitating if the new task is logically embedded in the work process, responsibilities of the HCPs are clear, and if the task is linked to an existing action It would be a barrier if the new task is time consuming and no extra time is scheduled
	Way of asking for consent to the client	+	A standard manner of asking and using a motivating technique would be a facilitator for data sharing, since this would increase the consent by clients
	Cooperation between PHS and GP	+ -	If the cooperation with the GP would be improved by data sharing, this would be a facilitator A barrier is the lack of trust that the GP is going to use the information
Characteristics of the socio-political context	Fit of system in regulations	+ -	It is facilitating that the GP also has professional secrecy It would be a barrier if the system is rejected on the national level
	Anonymity preference of clients	- +	If clients prefer to remain anonymous, this would be a barrier for data sharing Consent given by the client would facilitate data sharing
	Registering consent	-	Registering consent in line with the current legislations could become challenging and complex, which could be a barrier

[1] The type of determinant is indicated with: + = facilitator, - = barrier, 0 = neutral.

8. **Discussion**

This study investigated the answers on two questions. The first question was: “what is the opinion of clients of STI clinics with regards to the sharing of their STI test results with the GP?” It was found that almost two-thirds (62%) of the clients gave consent to share their STI data. The most important reason to share the data was that data sharing with the GP is necessary for good health care. The most important reason for not giving consent was that the clients prefer to keep the results secret. The subgroups (youngsters, MSM, and sex workers) were each compared to all other clients on consent to share data with the GP. A significant difference was found for youngers (< 25 years) compared to clients older than 25 years. Youngsters more often gave consent to share data than individuals older than 25 years. No significant differences in consent were found in the other subgroups. Of those clients who gave consent to share data, the majority, namely 79.1%, gave consent to use the BSN number in order to share the data. A significant difference was found for MSM compared to the other clients. Those MSM who gave consent to share data with the GP, more often accepted the use of the BSN number than the rest of the clients who gave consent to share data with the GP.

The second question was: “what anticipated determinants, identified by HCPs of Dutch STI clinics, influence their intention to use a client data sharing system to share clients’ STI results with the GP?” Five determinants related to characteristics of the client data sharing system were found. Evidence for data sharing, safety, complexity or extra work, and relevance for the GP, could all be facilitating and impeding, depending on the context. The fifth determinant – huge information flows – could be a barrier for the GPs to use the system according to HCPs. Three determinants related to characteristics of the HCPs were found, of which a lack of knowledge about legislation, and the orientation of the job, could be barriers for data sharing, and the attitude towards changes would be depending on the context either facilitating or impeding. Five determinants related to characteristics of the organisation were found. Two were barriers, namely an unfair allocation of financial costs, and the dissatisfaction with SH-direct (EHR). Two determinants could, depending on the context, both impede or facilitate data sharing, namely the fit in the work process, and the cooperation with the GP. A standard motivating way of asking and informing clients could be facilitating. Three determinants related to characteristics of the socio-political context were found. Starting with the fit in the Dutch regulations, if data sharing fits into the regulations, this is facilitating, but if it is not, this is a barrier. Second, the refusal of clients is a barrier for data sharing, while acceptance is facilitating. Third, registering consent could become very complex, which would be a barrier for data sharing.

The results of part 1 of the study in which almost two-thirds of clients agree on data sharing, were most comparable with findings of Pedersen et al. (33), who found that 59% of their Canadian participants accepted that the GP had access to their data. Steedman and Clutterbuck (15) (UK), Fernando and Clutterbuck (31) (UK), and Hunter, Haining Ede and Whiddett (32) (New Zealand) found much lower consent proportions in their populations. However, these studies less clearly described the manner of data sharing. For example, 37% of the clients in the study of Hunter, Haining Ede and Whidett (32) agreed on data sharing, while another 37% answered that ‘Maybe’ these clients prefer extra information before making the decision. So the clarification of the manner of data sharing could possibly provide more realistic proportions. Another explanation could be that the GP is differently viewed by clients of other countries. For example in the UK, the GP also functions as a gatekeeper, but the GP is financed differently (41). Looking at subgroup differences of high risk groups compared to other clients, it is striking that the other studies (31,32) found indications that youngsters more often refuse, whereas in the current study the youngers more often accept data sharing. However, the current study classified clients with an age below 25 years as young, while Fernando and Clutterbuck used an age below 18 as a criteria (31), and Hunter, Haining Ede and Whidett looked at 16-19 years olds (32). An explanation could be that the sample of the current study contained more students who are living on their own and chose a GP themselves. In this case, the fear that their parents will find out does possibly not play such a strong role. The other studies also included youngsters with an age below 19. Possibly these individuals have the same GP as their parents. The most important motive of those who agreed on data sharing - ‘necessity for good care’ - was in line with the idea that data sharing would improve the continuity of STI care. The most important reason of clients who disagreed, was the preference to keep the result secret. This reason is comparable with the fact that anonymity is one of the most important visiting motives (13). The current study showed that for those who disagreed, anonymity and privacy motives for visiting, also negatively influenced data sharing with the GP. The majority of those who agreed on data sharing, also agreed on the use of the BSN number, which is not a surprise, given the function of the BSN in the Dutch health system. The higher acceptance of the use of the BSN by MSM is possibly attributable to the idea that MSM possibly have more problems with data sharing than with the use of the BSN. So those who agreed on sharing data, also would accept the use of the BSN.

The determinants which are found in part 2 of the study are in line with the literature. Most determinants are also included in implementation determinant lists such as (21,27,28). For example, (expected) patient preferences and cooperation, relationships with other organizations (in this case the GP), the knowledge of HCPs (in this case about legislation), the task orientation (in this case public health), the relevance of data sharing, logistic aspects in a system (such as clarity), the time available and financial resources are also mentioned by (21). Furthermore, the outcome expectations of the HCPs that the cooperation with GPs could improve, and therewith the STI care, are in line with the ideas of Steedman and Clutterbuck (15), Bradbeer and Mears (16), and Fernando and Clutterbuck (31). Also, the fear that the attendance of their clients would be negatively influenced by the data sharing system, is in line with the literature. According to Fernando and Clutterbuck (31), Hunter Haining Ede and Whidett (32), and Pedersen et al. (33), the attendance of clients could be negatively influenced if data is shared. Finally, the ideas of the HCPs that not all clients would be satisfied with sharing data, and that some clients want to remain anonymous, are confirmed by the results of study part 1.

8.1 Limitations

Unfortunately, there were a few limitations in both parts of the study. Starting with the limitations of part 1, first of all, the response rate of study 1 could not be determined, since not all clinics followed the instructions to invite all clients who visited the STI clinic and to put an empty form in the box in case a participant refused, either due to a lack of time, or because they forgot. Second, by not following the instructions, an increased risk on an inclusion bias exists, since it is unknown which individuals did not participate or were not invited, why they did not participate, and what their preferences would be. However, at first sight, the sample of the current study seemed representative for the actual population in the eastern region (see (36) and Table 4). Unfortunately, the comparison of the educational level of the actual population of the STI clinic in 2017 was determined differently compared to the current study in which the classification of CBS was used (37). So for this variable, the representativeness was less certain. Third, the data was collected differently by the STI clinics. In three locations of the clinics, the receptionists recruited the clients and those clients filled the questionnaire in in the waiting room. While at the other three locations, the clients were recruited by the HCPs in the consultation room. However, this difference was analysed in SPSS and the way of recruitment was not influential on the consent rates.

The first limitation of part 2 of the study is that the HCPs were interviewed about a hypothetical situation. The dissemination phase of the implementation process was skipped, while dissemination is required, before the innovation could be adopted (21). In case dissemination will take place, this could influence the determinants. In the current study, only anticipated determinants could be determined. However, it is questionable whether these anticipated determinants are generalizable to a real situation. Second, only the perspectives of the HCPs on the determinants were investigated. In order to get a complete overview, for example managers and GPs should also be approached. Third, the text about the data sharing system, which was presented to the HCPs during the interview, did not explicitly describe that clients will be always asked for consent. Therefore, some HCPs thought that the data would also be shared with the GP in case the client refuses. This could have negatively influenced their perspective. However, in the cases where the there was confusion about this, the interviewer explained that consent of the client is a requirement.

8.2 Strengths

Strengths of the first part of the current study were a high sample size, which increases the reliability of the results. Since the proportions found in this study were slightly different than expected, a sample size of 362 was necessary (with a precision of 0.05 and a significance level of $p<0.05$), while the actual sample size was 418. For the subgroup analysis, the sample size of 418 was unfortunately less optimal. While other studies investigating consent to share data with the GP did not always specify the way of sharing, the current study also described that the data would be shared digitally, and asked whether the BSN number could be used. Furthermore, this study gained quantitative and qualitative data about the motives of the clients to share or not to share their STI results with the GP. The strength of the second part of the study was that the study was explorative and therefore provided extensive information about the (anticipated) determinants for data sharing according to the HCPs.

8.3 Future research

Future research should focus on the preferences of GPs in STI information sharing. The study of Wincesclaus, Blount and Cryer (17) is outdated and no other studies seem to focus on this topic. The HCPs suggested that next to the test results, it would also be necessary to share the context of the results. Otherwise the GP would not know what to do with the result, according to the HCPs. On the other hand, they mentioned that huge information flows are probably not desirable. Furthermore, future studies could focus on the use by GPs of STI data, as some HCPs do not believe that GPs use this information or that it is relevant, and the HCPs also mentioned that the STI care is currently not optimally delivered. Possibly, room for improvements in STI care could be revealed by future studies.

Based on the results of both parts, it is recommended to start a pilot first with a client data sharing system in order to see if the attendance rates of clients are not negatively influenced and to provide evidence to the HCPs that the system is effective.

8.4 Implications

The results of the study provided insights in the expected acceptance of data sharing by both clients and HCPs. Both parties are critical. However, the majority of the clients said that they would accept data sharing, and most HCPs accept data sharing if the clients are asked for consent, and if there would remain an opportunity for anonymous testing for those individuals who prefer anonymity. Therefore, this innovation could become one that does not fail. However, to prevent failure, it is important to design an appropriate system and introducing strategy, and to respond to the needs of the HCPs.

8.5 Recommendations for the design of the system and innovation strategy

The knowledge gained in this study could also be used to design an appropriate strategy, and to design a data sharing system. For the strategy, it is recommended to respond to the needs of the HCPs and clients. Therefore, the HCPs and clients should be informed on why data sharing is relevant, because for both parties the relevance is not always clear. In addition to this, evidence of a pilot study could be helpful. Furthermore, it is important to inform HCPs and clients about the safety of data sharing, since both parties show distrust in (digital) data sharing. Moreover, the HCPs should be informed about privacy legislation, since concerns exist among the HCPs regarding what they are allowed to do. As suggested by one HCP, the laws related to data sharing should be explained by a lawyer in a simple and fascinating way. Furthermore, the data sharing process, the professional secrecy, and the opportunity to refuse consent to sharing data, should be clearly explained to the clients, because of a risk that clients do not attend anymore. PHSs should monitor the attendance rates, and in case the visits of risk-groups are decreasing, the PHSs should take action. Furthermore, the work process and responsibilities of the HCPs should be clarified.

For the data sharing system, it is recommended to design a safe, clear system in which the extra work is limited, and which is not time consuming. To prevent mistakes, one of the HCPs demanded a function in the system that provides an overview of what is exactly about to be sent to the GP. In case the system is time consuming, the HCPs suggest scheduling extra time for consultations. To reduce complexity, two suggestion of HCPs were to include a standard patient letter in the system, and to include the contact information of GPs in the system. The system should also fit into the current regulations. Another recommendation is to share only information that is relevant for the GP. Therefore, GPs should be involved in the design of the system to increase usability and to prevent huge information flows. For the HCPs, the efficacy of SH direct should be improved, which could lead to an increase of efficiency in other tasks as well. The HCPs also demand the opportunity for clients to test anonymous, which is also preferred by 38% of the clients. Furthermore, the HCPs suggested that a motivating standard way of asking consent should be used, and the clients should already be informed in the waiting room or by the receptionists. In case the PHSs prefer to design a system for other departments as well, the PHS should determine the transferability of the system (42). Based on these recommendations, another unsuccessful innovation in healthcare could be prevented.

9. **Conclusion**

Part 1 of the study found that the majority of the clients would accept sharing their STI results with the GP and most of them also agree on using their BSN number in order to share the data. The most important reason for sharing was the necessity for good care. The most important reason for not sharing was a preference to keep the STI data secret. Part 2 of the study revealed 16 anticipated determinants, namely a positive evaluation of the system, safety, complexity/ extra work, the relevance for the GP, information flows to the GP, a lack of knowledge about legislation, the attitude to changes, the orientation of task in public health, allocation of financial costs, the current EHR (SH-direct), the fit into the work process, the way of informing and asking consent, cooperation with GPs, the fit with regulations, the refusal of clients and the way of registering the consent. To respond to these determinants, recommendations for an appropriate system and introducing strategy were given. In the end, in case the innovation will be used, this could lead to an improvement in continuity of healthcare.

So, while some could see that not sharing data is a bit outdated, this is in the situation of STI clinics not the case given their task to reach vulnerable high-risk groups. But, looking at the expected acceptance of clients and HCPs, there seems to be room for an upgrade!

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11. Appendix

11.1 Appendix A: Search matrix mini review

Scopus

Search	Hits	Action
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange") AND TITLE-ABS-KEY ("Healthcare"))	2415	Too broad add STI/ STD
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange") AND TITLE-ABS-KEY ("Healthcare") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual"))	10	Too small, leave out Healthcare
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual"))	157	Add general practitioner
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual") AND TITLE-ABS-KEY ("General practitioner"))	2	Too small, leave out General Practitioner,
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual"))	157	Add medical record linkage
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange" OR " communicating data" OR "medical record linkage") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual" OR "sexual healthcare"))	178	Add Genitourinary medicine
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange" OR " communicating data" OR "medical record linkage") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual" OR "sexual healthcare" OR "Genitourinary medicine"))	178	Add “contact GP” Add “sharing records”
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange" OR " communicating data" OR "medical record linkage" OR "contact GP" OR "sharing records") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual" OR "sexual healthcare" OR "Genitourinary medicine"))	178	Add information disclosure
(TITLE-ABS-KEY ("data sharing" OR "data exchange" OR "information sharing" OR "information exchange" OR " communicating data" OR "medical record linkage" OR "information disclosure" OR "data disclosure") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual" OR "sexual healthcare" OR "Genitourinary medicine"))	187	Start screening

Cochrane

Search	Hits	Action
"STI" OR "STD" OR "sexual" OR "sexual healthcare" OR "Genitourinary medicine"	313	Make more specific
"STI" OR "STD" OR "sexual" OR "sexual healthcare" OR "Genitourinary medicine" in Title Abstract Keyword AND "data sharing" OR "data exchange" OR "information sharing" OR "information exchange" OR " communicating data" OR "medical record linkage" in Title Abstract Keyword	1 review 3 trials	Small add synonyms
"data sharing" OR "data exchange" OR "information sharing" OR "information exchange" OR " communicating data" OR "medical record linkage" OR "information disclosure" OR "data disclosure" in Title Abstract Keyword AND "STI" OR "STD" OR "sexual" OR "sexual healthcare" OR "Genitourinary medicine" in Title Abstract Keyword	1 review, 5 trials	Start screening

PsychInfo

Search	Hits	Action
TXT "data sharing" OR "data exchange" OR "information sharing" OR "information exchange" OR " communicating data" OR "medical record linkage" OR "information disclosure" OR "data disclosure") AND TITLE-ABS-KEY ("STI" OR "STD" OR "sexual" OR "sexual healthcare" OR "Genitourinary medicine"	69	Start screening

11.2 Appendix B: Informed Consent (study part 1)

Respondentnummer:
GGD:

Wilt u meedoen aan een wetenschappelijk onderzoek?
U verbetert daarmee onze zorg!!

Beste cliënt,

U ontvangt deze uitnodiging, omdat u cliënt bent bij centrum seksuele gezondheid. Wij onderzoeken hoe cliënten van GGD'en in regio oost denken over het delen van SOA testuitslagen met de huisarts. Deze vragenlijst gaat **niet** over het delen van de testresultaten van de test die u vandaag mogelijk heeft. Het onderzoek is een masterafstudeeropdracht in opdracht van GGD Gelderland-Zuid. De resultaten van dit onderzoek zijn belangrijk in de keus of de GGD een digitaal systeem gaat gebruiken voor het delen van de testuitslagen met de huisarts. Natuurlijk vraagt de GGD iedere cliënt in de spreekkamer toestemming voor het delen van testuitslagen. Het doel van het systeem is om zorg voor u als cliënt te verbeteren.

Meedoen aan dit onderzoek is vrijwillig en u blijft in dit onderzoek anoniem. De gegevens die u invult gebruiken wij alleen voor dit onderzoek. Sommige vragen kunt u als ongemakkelijk ervaren. Er is altijd de antwoordoptie 'dat wil ik niet zeggen'. U kunt op ieder moment stoppen met het onderzoek als u dit wilt. U hoeft hier geen reden voor te geven. De resultaten van de vragenlijst bewaren wij 15 jaar in een beveiligde omgeving. Alleen de onderzoekers kunnen bij de resultaten.

Het invullen van de vragenlijst kost u ongeveer 3 minuten. Met dit onderzoek helpt u de GGD met het verbeteren van hun werkwijze. Dit stellen wij erg op prijs. **Wilt u voordat u aan de vragenlijst begint de toestemmingsverklaring voor deelname aan dit onderzoek invullen? U vindt deze onderaan de pagina.**

Als u vragen heeft dan kunt u ons bereiken via onderstaande contactgegevens. De uitkomst van het onderzoek plaatsen wij zomer 2019 op de website van GGD Gelderland-Zuid (www.ggdgelderlandzuid.nl).

Alvast veel dank!

Lydia Overtoom (masterstudent Gezondheidswetenschappen, Universiteit Twente)

Opdrachtgevers:
Noëmi Nijsten (Arts Seksuele Gezondheid)
dr. Jeannine Hautvast (Onderzoeker en arts infectieziekten)

Toestemmingsverklaring voor deelname aan wetenschappelijk onderzoek
Ik ben ouder dan 16 jaar. Ik ben goed geïnformeerd over het onderzoek en ik geef toestemming voor deelname.

- ☐ Ja
- ☐ Nee

11.3 Appendix C: Questionnaire (study part 1)

Respondentnummer:
GGD:

Wilt u de vragenlijst zo eerlijk mogelijk invullen? Er is geen goed of fout. Na afloop kunt u de vragenlijst (ook als u deze niet heeft ingevuld) inleveren in een envelop in de spreekkamer. Alvast bedankt!!

Vink aan wat van toepassing is.

1. Zou u toestemming geven een SOA testuitslag digitaal met uw huisarts te delen?
   - ☐ Ja
   - ☐ Nee
   - ☐ Dat wil ik niet zeggen

2. Indien uw antwoord op vraag 1 Ja of Nee is, wilt u dan de belangrijkste reden aangeven?

Het BSN-nummer wordt in de zorg gebruikt om gegevensuitwisseling (bijvoorbeeld SOA testuitslagen) tussen verschillende zorgverleners (zoals de huisarts en GGD) te vergemakkelijken.

3. Zou u bereid zijn uw BSN-nummer te delen met de GGD voor dit doel?
   - ☐ Ja
   - ☐ Nee
   - ☐ Dat wil ik niet zeggen

4. Wat is uw geslacht?
   - ☐ Man
   - ☐ Vrouw
   - ☐ Transgender
   - ☐ Dat wil ik niet zeggen

5. Wat is uw leeftijd?
   - ☐ Jonger dan 20 jaar
   - ☐ 20-24 jaar
   - ☐ 25-29 jaar
   - ☐ 30-39 jaar
   - ☐ 40-49 jaar
   - ☐ Ouder dan 50 jaar
   - ☐ Dat wil ik niet zeggen

Let op! De vragenlijst gaat verder op de volgende pagina.

6. Wat is uw hoogst behaalde opleidingsniveau?
   - ☐ basisonderwijs, vmbo of mbo-niveau 1
   - ☐ havo, vwo of mbo-niveau 2,3 of 4
   - ☐ hbo- of wo-bachelor en/ of master
   - ☐ Dat weet ik niet
   - ☐ Dat wil ik niet zeggen

7. Waar bent u geboren?
   - ☐ Nederland
   - ☐ Een ander westers land*
   - ☐ Een niet-westers land**
   - ☐ Dat wil ik niet zeggen

8. Waar is uw moeder geboren?
   - ☐ Nederland
   - ☐ Een ander westers land*
   - ☐ Een niet-westers land**
   - ☐ Dat wil ik niet zeggen

9. Waar is uw vader geboren?
   - ☐ Nederland
   - ☐ Een ander westers land*
   - ☐ Een niet-westers land**
   - ☐ Dat wil ik niet zeggen

*Tot westerse landen behoren: Indonesië, Japan en landen in Noord-Amerika, Oceanië en Europa (behalve Turkije).

** Tot niet-westerse landen behoren: Turkije en landen in Afrika, Latijns-Amerika en Azië (behalve Indonesië en Japan)

10. Heeft u seksueel contact met mannen, vrouwen of allebei?
    - ☐ Mannen
    - ☐ Vrouwen
    - ☐ Allebei
    - ☐ Dat wil ik niet zeggen

11. Krijgt u wel eens betaald voor seks in goederen of geld?
    - ☐ Ja
    - ☐ Nee
    - ☐ Dat wil ik niet zeggen

Wilt u de vragenlijst inleveren in een gesloten envelop?
Bedankt voor uw moeite!!

11.4 Appendix D: Instructions to executing PHSs (study part 1)

Beste medewerkers van GGD [X],

Hartelijk dank dat jullie willen meewerken aan het onderzoek over de toestemming van cliënten voor het doorgeven van testresultaten aan de huisarts. Dit onderzoek wordt gedaan als masterafstudeeropdracht in opdracht van GGD Gelderland-Zuid. Het doel is om in regio oost te onderzoeken of cliënten toestemming geven voor het delen van SOA testuitslagen met de huisarts. Hiermee kunnen we de zorg voor de cliënt verbeteren. Daarnaast gebruikt GGD Gelderland-Zuid de resultaten van het onderzoek in de beslissing om een ICT systeem te gaan gebruiken. Dit systeem kan testuitslagen gemakkelijk digitaal met de huisarts delen. Voor de betrouwbaarheid van het onderzoek en ter bescherming van de gegevens van de cliënt volgt hierna een instructie over de uitvoering van het onderzoek.

Ik zou jullie graag willen vragen vanaf nu tot aan het moment dat de vragenlijsten op zijn **alle achtereenvolgende bezoekers van Centrum Seksuele Gezondheid die voor een SOA consult komen voorafgaand aan hun consult uit te nodigen voor deelname aan het onderzoek.** Alleen cliënten die de taal niet spreken en cliënten die jonger zijn dan 16 jaar kunnen niet deelnemen. Jullie kunnen de cliënten uitnodigen door ze de toestemmingsverklaring en de vragenlijst te geven (deze zijn aan elkaar vast geniet). Het is belangrijk dat de cliënten beide formulieren invullen, omdat de gegevens anders niet bruikbaar zijn. Op de toestemmingsverklaring staat alle informatie die de cliënten nodig hebben om de vragenlijst in te vullen. Ook staat er in het formulier hoe ik te bereiken ben voor het geval zij vragen hebben.

Cliënten zullen de vragenlijst vervolgens bij jullie inleveren in een gesloten envelop. Het is de bedoeling dat ze de vragenlijst voorafgaand aan hun consult inleveren. Dit geldt ook voor niet-ingevulde vragenlijsten, zodat bepaald kan worden hoeveel mensen de vragenlijst niet wilden invullen.

Samengevat

Wie uitnodigen: alle cliënten van afdeling seksuele gezondheid, behalve cliënten jonger dan 16 jaar en cliënten die geen Nederlands spreken. De cliënten graag uitnodigen voorafgaand aan hun consult.
Wanneer: vanaf nu totdat alle vragenlijsten op zijn.
Hoe: geef de formulieren aan de cliënten en verzamel de enveloppen met daarin de vragenlijsten
Einde onderzoek: ik kom de vragenlijsten weer ophalen en jullie bedanken.

Mochten er vanuit jullie vragen zijn dan kunnen jullie ons via onderstaande contactgegevens bereiken. De uitslagen van het onderzoek worden vermoedelijk zomer 2019 naar de deelnemende GGD'en gecommuniceerd.

Alvast veel dank!

Lydia Overtoom (master student Gezondheidswetenschappen, Universiteit Twente)

Opdrachtgevers:
Noëmi Nijsten (Arts Seksuele Gezondheid)
dr. Jeannine Hautvast (Onderzoeker en arts infectieziekten)

11.5 Appendix E: Informed consent (study part 2)

Beste heer, mevrouw,

U ontvangt deze uitnodiging voor deelname aan een wetenschappelijk onderzoek, omdat u bij de GGD werkt bij centrum seksuele gezondheid als arts of verpleegkundige. Dit onderzoek wordt uitgevoerd als masterafstudeeropdracht in opdracht van GGD Gelderland-Zuid. Het doel van dit onderzoek is om te bekijken wat de mening van zorgverleners in regio oost is ten aanzien van het gebruik van een ICT-systeem om cliëntuitslagen door te geven aan de huisarts (na toestemming van de cliënt) en om te bekijken hoe het systeem moet worden ingericht. **Dit interview gaat over het delen van testresultaten met de huisarts in de toekomst en dus niet over de testen die u momenteel uitvoert**.

Deelname aan dit onderzoek is geheel vrijwillig en u kunt te allen tijde uw deelname aan het onderzoek beëindigen. U hoeft hier geen reden voor te geven. In het onderzoek vragen wij u bij welke GGD u werkt en wat uw functie is. Uw antwoorden worden echter enkel op groepsniveau gebruikt en uw gegevens worden volledig geanonimiseerd verwerkt. De gegevens worden alleen voor dit onderzoek gebruikt. De resultaten van de vragenlijst worden 15 jaar bewaard in een beveiligde omgeving waar alleen de onderzoekers bij kunnen.

Het interview zal ongeveer 15-20 minuten duren. Door deel te nemen aan dit onderzoek kunnen wij de inrichting van het systeem gebruiksvriendelijk maken voor u en uw collega’s. Daarnaast kunnen wij de werkwijze van de GGD verbeteren.

Mocht u vragen hebben dan kunt u ons bereiken via onderstaande contactgegevens. De uitslagen van het onderzoek worden vermoedelijk zomer 2019 naar de deelnemende GGD’en gecommuniceerd en op de website van GGD Gelderland-Zuid (www.ggdgelderlandzuid.nl) geplaatst.

Alvast veel dank!

Lydia Overtoom (master student Gezondheidswetenschappen, Universiteit Twente)

Opdrachtgevers:
Noëmi Nijsten (Arts Seksuele Gezondheid)
Jeannine Hautvast (Gepromoveerd onderzoeker en arts infectieziekten)

Toestemmingsverklaring voor deelname aan wetenschappelijk onderzoek
Ik ben goed geïnformeerd over het onderzoek en geef toestemming voor deelname.

Datum: …. - …. - …….   Handtekening: ………………….

11.6 Appendix F: Interview guide HCPs (study part 2)

Materiaal:

- Opname apparaat of telefoon
- Informed consent formulier
- Informatie over het client gegevens deelsysteem

Introductie:

Respondentnummer: …………….
GGD: …………….
Functie: …………….

- Bedankt dat u deel wilt nemen aan het onderzoek
- Momenteel worden SOA testuitslagen vanuit de GGD in principe niet doorgegeven tenzij het om meldingsplichtige ziekten gaat. Huisartsen hebben echter wel behoefte aan deze informatie zodat zij een volledig beeld van de gezondheid van hun patiënten hebben. Het doel van dit onderzoek is om te meten wat u van het delen van deze informatie vindt en wat u vindt van een data deelsysteem waarmee u de uitslagen digitaal met de huisarts zou kunnen delen. Ik ben benieuwd naar uw mening.
- Toestemmingsverklaring invullen indien nog niet ingevuld.
- Vindt u het goed dat ik het gesprek opneem en aantekeningen maak?

→Opname starten

In geval telefonisch interview: Heeft u de toestemmingsverklaring gelezen en geeft u toestemming voor deelname?

Kern:

1) Als eerste zou ik het graag willen hebben over het delen van SOA testuitslagen met de huisarts.

- Wat is of zou uw rol zijn in het delen van SOA testuitslagen?

- Hoe staat u tegenover het delen van SOA testuitslagen?
  - Kunt u dit toelichten?

2) Nu zou ik graag ingaan op het idee hier een systeem voor te gaan inzetten. Wilt u de informatie hierover (Appendix G: Information about system doorlezen? (ruimte geven om de informatie door te lezen)

- Is de informatie helder voor u?

- Hoe staat u tegenover een dergelijk systeem waarmee u testuitslagen aan de huisarts kunt doorgeven?
  - Kunt u dit toelichten?

3) Wanneer het systeem in gebruik genomen wordt:

- Wat zou u dan tegenhouden om het te gebruiken?
  - Doorvragen of er barrières zijn in:
    - Eigenschappen van de persoon
    - Eigenschappen van de organisatie
    - Sociaal-politieke context
    - Eigenschappen van de innovatie

- Wat zou u juist helpen dit te gebruiken?
  - Doorvragen of er hulpfactoren zijn in:
    - Eigenschappen van de persoon
    - Eigenschappen van de organisatie
    - Sociaal-politieke context
    - Eigenschappen van de innovatie

Afronding:

- Zijn er nog andere dingen die u kwijt wilt met betrekking tot het delen van data of het ICT systeem? Of andere bevorderende en belemmerende factoren?

- Heeft u nog vragen of opmerkingen over het onderzoek?

Dank voor uw deelname!

< stop opname>

11.7 Appendix G: Information about system

Informatie over systeem:

Het idee waarover u nu wordt geïnterviewd bestaat uit het automatisch genereren van een uitslag document uit ons patiëntdossier (SH direct) dat vervolgens direct als beveiligd pdf naar het huisartsinformatiesysteem (HIS) verstuurd wordt. Op deze manier is het voor de huisarts laagdrempelig om ons bericht te koppelen aan het patiëntdossier.

Translation:

The idea about which you are now being interviewed consists of automatically generating a result document from our patient file (SH direct), which is then sent directly to the GP information system (HIS) as a secure PDF. In this way, it is easy for the general practitioner to link our message to the patient file.