

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	"To be on the safe side" – a qualitative study regarding users' beliefs and experiences of internet-based self-sampling for Chlamydia trachomatis and Neisseria gonorrhoeae testing
AUTHORS	Grandahl, Maria; Larsson, Margareta; Herrmann, Björn

VERSION 1 – REVIEW

REVIEWER	Claudia Estcourt Glasgow Caledonian University, UK
REVIEW RETURNED	08-Jul-2020

GENERAL COMMENTS	<p>Thank you for asking me to review this paper which describes a qualitative study of 20 users of an online postal self-sampling service in Sweden.</p> <p>The aim of the study was to get a deeper understanding of users' beliefs & experiences. Overall, it was good to see the use of a theoretical framework (the Health Belief Model) and write up in line with COREQ guidance. However, I don't think it adds much novelty to the evidence base in terms of findings or methodological approach. It would have helped to know why the team wanted a deeper understanding was this to inform service development or support the continuation of the programme? Many of the findings have already been described so I wasn't sure how these findings added much to the international literature.</p> <p>Strengths & limitations: the authors state that a strength is that it forms part of an integral evaluation of what seems to be a larger programme – I am not sure that this is a strength, although it is a strength of the larger programme that there is an integral evaluation.</p> <p>Introduction: lines 10 & 11. It wasn't clear to me how self-sampling could comprise 22% of all chlamydia tests and account for 20% of all detected cases but have the same positivity as clinic-based testing.</p> <p>Methods (sample & procedure): lines 11,12,13,14. 114 individuals agreed to participate but we do not know how many were asked. It would be useful to have some idea of whether these people were in any way similar demographically to all users. The median age of participants is certainly older than UK self-sampling users (in some places restricted to those under 25) whereas here users appeared older (median age around 30). Does this reflect epidemiology of chlamydia in Sweden? Or indeed median age of service users? I could not find many details of the sampling frame used and or characteristics of participants. I wondered whether authors had tried to include people of different education levels and / or people from areas of different levels of affluence / deprivation– these appear to be important factors in engagement with self-managed care. Was any effort made to consider people who had and had</p>
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	<p>not previously tested for STIs in face to face services? I think this is important to understand as these factors may well influence acceptability.</p> <p>Patient & Public Involvement: authors state that patients have been involved because they have been participants and interviewed and also helped with piloting of the interview guide. However, no details of this are actually given. This is not the same as patient / public involvement in the research design, implementation and analysis.</p> <p>Results (p9) Knowledge, severity etc: data on users' knowledge felt a little "in a vacuum" as we do not have comparative data for clinic attenders. It was difficult to know what significance this had and was not discussed with any intent in the discussion. I wondered why so much of the results were devoted to elements of care which would be conducted whether online or face to face. I would have expected a programme on online self-sampling to have drawn much more and more deeply on the remote self-managed aspects of care. It felt like an opportunity had been lost in this respect and too many areas of interest had been included at the expense of depth of understanding.</p> <p>Discussion. Again I felt that this was a little superficial. No attempt was made to discuss how users may or may not be different from clinic users, or who might be excluded from online services, or health inequalities other than language barriers. I felt that the conclusions presented suggested that the service was generally acceptable and liked by users (I agree, that this is what the participants appear to be saying) but there did not appear to be any efforts to cite this in the wider context of who might or might not engage, health inequalities and who does and does not attend clinical services face to face.</p>
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REVIEWER	Barbara Van Der Pol University of Alabama at Birmingham United States
REVIEW RETURNED	25-Sep-2020

GENERAL COMMENTS	<p>This manuscript describes the finding of qualitative interviews of people who have used an on-line STI test request service. It should be noted that the findings must be contextualized throughout the manuscript as opinions of adopters and while the authors are very careful to point out that the results are not generalizable, they should also consider mentioning the need for similar research among people who have never tested using an on-line service (obviously they cannot assess experiences among such a group but they could help the field to understand non-adopters perspectives) in the Discussion section.</p> <p>The largest issues with this manuscript is the organization of themes and selections of quotes illustrating the constructs. Some examples are below, but the authors should carefully consider and justify the groupings of constructs within each theme. It may be the HBM is not the best fit (Andersen's Healthcare Utilization Model may be a better fit) for these data and trying to force quotes into those constructs is making it difficult to see the full richness of the data obtained.</p> <p>- Individual emotional factors included shyness and discomfort (discussing sexual health?) as well as trust in partners and past relationship factors. This should probably be divided into more than just a single theme[at least 2, 1 dealing with provider interaction concerns and the other related to relationship factors]</p>
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	<ul style="list-style-type: none"> o The quote describing concerns with someone touching his penis and possible physical discomfort is a mixed message of 1) privacy concerns and 2) physical discomfort concerns o There are no quotes related to trust or fidelity, etc - The quote (pg 9) regarding a man reporting that none of his friends have been tested is not really illustrative of lack of knowledge as much as lack of peer adoption. This quote also illuminates the earlier point about the fact that the interviewees are users. Since this is the case, the man obviously chose to get tested despite what he says here about not knowing if men can have CT. This suggests a certain lack of forthrightness on his part and makes any quotes from him less meaningful - The severity section needs to be broken into constructs as mentioned above. Combining partner notification and infertility muddles the results and makes it hard to follow o Each quote should be located near the text describing the concept illustrated by the quote. The infertility quote (pg 10) should go immediately after the description of infertility concerns, but the next quote needs to be moved (if it is talking about partner notification?) or clarified to explain what "it" refers to.
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1 Comments Reviewer Name: Claudia Estcourt Institution and Country: Glasgow Caledonian University, UK Competing interests: None	Author Responses	Section
<p>Thank you for asking me to review this paper which describes a qualitative study of 20 users of an online postal self-sampling service in Sweden.</p> <p>The aim of the study was to get a deeper understanding of users' beliefs & experiences.</p> <p>Overall, it was good to see the use of a theoretical</p>	<p>Thank you for valuable and thoughtful comments. We are truly grateful, and have revised the manuscript accordingly.</p> <p>Although the concept of internet-based testing is well established, little data is available about users and their experiences of internet-based self-sampling, especially when this service is an integrated part of the health care system. To the best of our knowledge no similar study is undertaken among the general population in Sweden.</p> <p>Our study group is conducting an evaluation of internet-based self-sampling for Chlamydia trachomatis (CT) and Neisseria gonorrhoeae (NG) in Sweden, as part of the public health service. It is important to investigate that the test reaches a relevant group, that it is cost-effective (not "over used") or disturbs other preventive efforts. In our first article, the focus was on the diagnostic outcome, showing that this</p>	

<p>framework (the Health Belief Model) and write up in line with COREQ guidance. However, I don't think it adds much novelty to the evidence base in terms of findings or methodological approach.</p> <p>It would have helped to know why the team wanted a deeper understanding was this to inform service development or support the continuation of the programme? Many of the findings have already been described so I wasn't sure how these findings added much to the international literature.</p>	<p>self-sampling test service comprises over 20% of all CT tests in Sweden and contributes to case detection (reference 10 Söderqvist et al., Sex Transm Infect 2020;96:160-165 PubMed).</p> <p>We have also investigated the other side of the coin, the users' experiences of the test service. The quantitative study aimed to characterise users (N=1785) and find out their opinions about internet-based self-sampling for CT and NG tests (reference 13 Grandahl et al, 2020).</p> <p>The present study is aiming to gain a deeper understanding of the users' opinions and experiences. We chose a qualitative method with interviews since this approach is a valuable method to explore individuals' opinions and experiences of a phenomenon. The participants openly shared their opinions and beliefs in the subject, CT/NG self-test. We have clarified this in Introduction.</p> <p>A fourth study, focusing on cost-effectiveness is planned.</p>	<p>Introduction</p>
<p>Methods (sample & procedure): lines 11,12,13,14. 114 individuals agreed to participate but we do not know how many were asked. It would be useful to have some idea of whether these people were in any way similar demographically to all users.</p>	<p>As mentioned above, the participants were selected from a larger sample (N=1785) participating in the quantitative part of this project, described in Reference 13. Of the 1785 participants 69.4% were women. The majority (77.0%) were single and heterosexual (88.2%) and 5.3% of samples were test positive. The majority, 246 (87.9%), were born in Sweden with a mean age of 27.1 years (range 18–60). Half of the participants, 140 (50.2%), were employed and 118 (42.1%) were students.</p> <p>This study comprises another part of the sampling procedure. We used a strategic approach aiming to include a broad sample. We wanted to explore as many different voices as possible. The participants represent different ages, gender and postcodes (geographical and sociodemographic differences, rural and urban). The participants in the present study are slightly older, 30.8 years vs 27.3 in the quantitative study. Moreover, we chose to include more men compared to in the</p>	<p>Methods and Discussion</p>

	quantitative study (reference 13 Grandahl et al, 2020). We have clarified this in Methods and Discussion.																																																																																	
Introduction: lines 10 & 11. It wasn't clear to me how self-sampling could comprise 22% of all chlamydia tests and account for 20% of all detected cases but have the same positivity as clinic-based testing.	<p>The information given in the present manuscript refers to our previous article (reference 10, Söderqvist et al). In that study data were obtained from most Swedish laboratories (14/21 counties. >97% of chlamydia tests in Sweden were from public health laboratories.) Reported data consist of testing from both internet based testing and clinic based testing. The positivity rates were compared, internet-based 5.5%; clinic based 5.1%). See table 1 in ref 10. From the same table it is seen that internet-based samples comprised 18.9% of all samples.</p> <p>Data from 18 counties in 2017 (with no info about sex and age as in table 1) showed that 22% of all chlamydia tests were from internet-based testing.</p> <p>We find this clear and correct, but the figure 22% has been replaced by 19% (table 1) for clarification.</p>																																																																																	
<p>The median age of participants is certainly older than UK self-sampling users (in some places restricted to those under 25) whereas here users appeared older (median age around 30). Does this reflect epidemiology of chlamydia in Sweden? Or indeed median age of service users?</p> <p>I could not find many details of the sampling frame used and or characteristics of participants. I wondered whether authors had tried to include people of different education levels and / or people from areas of different levels of affluence / deprivation– these appear to be important factors in engagement with</p>	<p>As mentioned previously, we used a strategic approach to include individuals with experience from the eHealth self-test users. We aimed to include a broad sample from the larger sample (N=1785) rather than reflecting the CT test-users on a population-base. We consider it important to explore a broader sample of users to obtain a deeper understanding.</p> <p>The majority of the participants in the quantitative part had previous experience of CT test at Youth Health Clinics, Primary care and via the internet (see Table below and reference 13 (Grandahl et al, 2020). About 19.6% of the Swedish population are born outside Sweden. However, the quantitative sample includes only 12.1%. This is a limitation as discussed in Grandahl et al, 2020.</p> <hr/> <table border="1"> <thead> <tr> <th colspan="5">Previous test for chlamydia/gonorrhoea (n=1785)</th> </tr> </thead> <tbody> <tr> <td>No</td> <td>10.</td> <td>27.</td> <td>15.</td> <td><0.001*</td> </tr> <tr> <td></td> <td>3</td> <td>2</td> <td>5</td> <td>*</td> </tr> <tr> <td>Yes, at youth health clinic</td> <td>50.</td> <td>26.</td> <td>43.</td> <td><0.001*</td> </tr> <tr> <td></td> <td>3</td> <td>6</td> <td>0</td> <td>*</td> </tr> <tr> <td>Yes, at a clinic/primary health care centre</td> <td>39.</td> <td>30.</td> <td>36.</td> <td><0.001*</td> </tr> <tr> <td></td> <td>8</td> <td>3</td> <td>9</td> <td>*</td> </tr> <tr> <td>Yes, via internet</td> <td>55.</td> <td>46.</td> <td>52.</td> <td><0.001*</td> </tr> <tr> <td></td> <td>5</td> <td>0</td> <td>6</td> <td>*</td> </tr> <tr> <td>Previous STI</td> <td></td> <td></td> <td></td> <td><0.001*</td> </tr> <tr> <td></td> <td></td> <td></td> <td></td> <td>*</td> </tr> <tr> <td>No</td> <td>52.</td> <td>65.</td> <td>56.</td> <td></td> </tr> <tr> <td></td> <td>5</td> <td>6</td> <td>5</td> <td></td> </tr> <tr> <td>Chlamydia</td> <td>38.</td> <td>27.</td> <td>35.</td> <td></td> </tr> <tr> <td></td> <td>3</td> <td>9</td> <td>1</td> <td></td> </tr> <tr> <td>Other STI</td> <td>9.2</td> <td>6.5</td> <td>8.4</td> <td></td> </tr> </tbody> </table>	Previous test for chlamydia/gonorrhoea (n=1785)					No	10.	27.	15.	<0.001*		3	2	5	*	Yes, at youth health clinic	50.	26.	43.	<0.001*		3	6	0	*	Yes, at a clinic/primary health care centre	39.	30.	36.	<0.001*		8	3	9	*	Yes, via internet	55.	46.	52.	<0.001*		5	0	6	*	Previous STI				<0.001*					*	No	52.	65.	56.			5	6	5		Chlamydia	38.	27.	35.			3	9	1		Other STI	9.2	6.5	8.4		
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<p>self-managed care. Was any effort made to consider people who had and had not previously tested for STIs in face to face services? I think this is important to understand as these factors may well influence acceptability.</p>	<p>About 80% of all CT-cases in Sweden are reported among youth, aged 15-29, and the majority among women. In the quantitative sample the age distribution was 16-62, the majority aged 18-30, see Supplemental information in reference 13.</p> <p>Please also see comments regarding health inequalities below.</p>	
<p>Patient & Public Involvement: authors state that patients have been involved because they have been participants and interviewed and also helped with piloting of the interview guide. However, no details of this are actually given. This is not the same as patient / public involvement in the research design, implementation and analysis.</p>	<p>We have clarified patient and public involvement. "Three university students (public involvement) were engaged in project design. Furthermore, the questions in the survey was tested on two patients in a pilot study and thereafter the questionnaire was slightly modified. The interview guide was pilot-tested on two youth and resulted in minor changes (i.e. clarification of one question)." To give detailed information about this modification we think is unnecessary information for the reader.</p>	<p>Methods</p>
<p>Results (p9) Knowledge, severity etc: data on users' knowledge felt a little "in a vacuum" as we do not have comparative data for clinic attenders. It was difficult to know what significance this had and was not discussed with any intent in the discussion. I wondered why so much of the results were devoted to elements of care which would be</p>	<p>Our intent was of course to focus on the self-sampling, but the participants kept comparing the service to clinic-based testing. Our intent was not to measure knowledge, but to describe what users actually know about the disease they are testing for but also what they know about the service itself. For better clarity we have restructured the section about knowledge accordingly.</p> <p>The word limit is always a challenge when presenting qualitative data. We hope that the restructuring of the result section and a few more quotes will add some more depth to the manuscript.</p>	<p>Results</p>

<p>conducted whether online or face to face.</p> <p>I would have expected a programme on online self-sampling to have drawn much more and more deeply on the remote self-managed aspects of care. It felt like an opportunity had been lost in this respect and too many areas of interest had been included at the expense of depth of understanding.</p>		
<p>Discussion. Again I felt that this was a little superficial. No attempt was made to discuss how users may or may not be different from clinic users, or who might be excluded from online services, or health inequalities other than language barriers. I felt that the conclusions presented suggested that the service was generally acceptable and liked by users (I agree, that this is what the participants appear to be saying) but there did not appear to be any efforts to cite this in the wider context of who might or might not engage, health inequalities and who does and does not</p>	<p>Thank you for this valuable comment. We have included a discussion about health inequalities and health literacy.</p> <p>In Sweden, health care is free of charge, including preconception care, sexual health counselling, and STI testing. Youth Health Clinics (YHCs) are available to youth. However, the majority of visits (>85%) are teenage girls. We believe that self-sampling tests might be one way to include more young male users in Sweden.</p> <p>“Health inequalities exist due to lower socioeconomics, illiteracy and/or language barriers. Moreover, health literacy, the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions including risk perceptions can also affect. Even if health information is available in different languages individuals might have difficulties to understand and appraise the health service offered. Consequently the National eHealth service may not reach the population at large. It is essential to reach out to vulnerable groups and provide health information through different arenas and sources including face-to-face information in the school health, at Youth Health Clinics and in the Primary Care setting. We believe that free of charge self-tests have the potential to reach individuals of different socioeconomic status, in rural areas and in the end, decrease health inequity in Sweden.”</p>	<p>Discussion</p>

attend clinical services face to face.		
Strengths & limitations: the authors state that a strength is that it forms part of an integral evaluation of what seems to be a larger programme – I am not sure that this is a strength, although it is a strength of the larger programme that there is an integral evaluation.	Strengths “The present study is part of a larger project with access to a population with recent experience of the internet-based self-sampling service. Thus, we could use a strategic sample of individuals. We believe this is a strength with the study. However, using HBM both as a guide in designing the study and as an analytical tool may entail a risk for circular reasoning and not being open to unexpected findings.”	Discussion Strengths
Reviewer 2	Author response	
Reviewer Name: Barbara Van Der Pol Institution and Country: University of Alabama at Birmingham United States Competing interests: None declared Comments to the Author This manuscript describes the finding of qualitative interviews of people who have used an on-line STI test request service. It should be noted that the findings must be contextualized throughout the manuscript as opinions of adopters and while the authors are very careful to point out that the results are not generalizable,	Thank you for valuable and thoughtful comments. We are truly grateful, and have revised the manuscript accordingly. We have emphasized that these findings are based on the adopters as you rightly point out and have included the following sentences in the Discussion. “It is important to note that the findings presented here are opinions and experiences of the adopters of the self-sampling service. There is thus a need for similar research among people who have chosen not to use an on-line service and explore their views as well.”	Discussion

<p>they should also consider mentioning the need for similar research among people who have never tested using an on-line service (obviously they cannot assess experiences among such a group but they could help the field to understand non-adopters perspectives) in the Discussion section.</p>		
<p>The largest issues with this manuscript is the organization of themes and selections of quotes illustrating the constructs. Some examples are below, but the authors should carefully consider and justify the groupings of constructs within each theme. It may be the HBM is not the best fit (Andersen's Healthcare Utilization Model may be a better fit) for these data and trying to force quotes into those constructs is making it difficult to see the full richness of the data obtained.</p>	<p>Thank you for pointing out this. We have carefully considered the manuscript organization and have reorganized the description of the findings. See below for more details.</p> <p>Thank you for the suggestion to use Andersen's Healthcare Utilization Model. This model could have been useful as well as the Theory of Planned Behaviour (TPB). We chose HBM since it is well-known and often used in research about sexual health and individual beliefs and perceptions about sexual risk-taking. Moreover, the authors are familiar with HBM and have used the model in several other studies about sexual health and attitudes to HPV vaccination. However, we will consider to use Andersen's Healthcare Utilization Model in future work.</p> <p>HBM was valuable and useful for the present study. The findings are analysed based on the HBM concepts. HBM is well-known and we found the model easy to use. If we had used another model it might have been a slightly different results. However, we believe that our results are robust and reflect the richness of the interviews and the informants' opinions about CT self-sampling test. We did not have any "left-overs" in the data. All data are thoroughly analysed and were suitable in respective category as presented in the results. Thus, we did not have to force the results into a category.</p> <p>"However, using HBM both as a guide in designing the study and as an analytical tool may entail a risk for circular reasoning and not being open to unexpected findings." We have added this as a limitation in the discussion section.</p>	<p>Results</p> <p>Discussion</p>
<p>- Individual emotional factors included shyness</p>	<p>We have restructured the section about modifying factors to improve clarity.</p>	<p>Results</p>

<p>and discomfort (discussing sexual health?) as well as trust in partners and past relationship factors. This should probably be divided into more than just a single theme [at least 2, 1 dealing with provider interaction concerns and the other related to relationship factors]</p>		
<p>oThe quote describing concerns with someone touching his penis and possible physical discomfort is a mixed message of 1) privacy concerns and 2) physical discomfort concerns o</p>	<p>We agree, but have chosen to keep it and label it as a personal modifying factor.</p>	<p>Results</p>
<p>There are no quotes related to trust or fidelity, etc</p>	<p>The quote placed under relational factors is related to fidelity.</p>	<p>Results</p>
<p>The quote (pg 9) regarding a man reporting that none of his friends have been tested is not really illustrative of lack of knowledge as much as lack of peer adoption. This quote also illuminates the earlier point about the fact that the interviewees are users. Since this is the case, the man obviously chose to get tested despite what he says here about not knowing if</p>	<p>We still think the quote informs us about the fact that knowledge about the test is limited since there was no peer experience of it. But we have deleted the last part of the quote.</p>	<p>Results</p>

men can have CT. This suggests a certain lack of forthrightness on his part and makes any quotes from him less meaningful		
The severity section needs to be broken into constructs as mentioned above. Combining partner notification and infertility muddles the results and makes it hard to follow	We have broken down the severity section into subsections as suggested.	Results
o Each quote should be located near the text describing the concept illustrated by the quote. The infertility quote (pg 10) should go immediately after the description of infertility concerns, but the next quote needs to be moved (if it is talking about partner notification?) or clarified to explain what "it" refers to.	We have restructured the Result section and placed the quotes closer to the concepts they relate to.	Results

VERSION 2 – REVIEW

REVIEWER	Barbara Van Der Pol University of Alabama at Birmingham, USA
REVIEW RETURNED	07-Dec-2020

GENERAL COMMENTS	This is a very well written account of a qualitative evaluation of self-sampling for STI testing. Comments below are very minor: <ul style="list-style-type: none"> - The title should mention that the interviews were conducted with users of the self-sampling scheme. This should also be mentioned in the Methods and Discussion since non-users may feel very differently thus explaining why they haven't used the service - the acronym HBM should be defined at first use (pg 7) - The technical barriers described concerns about proper sample collection and postal handling. The self-efficacy section seems to contradict this. The authors should clarify the reason for the differences between these two sections
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VERSION 2 – AUTHOR RESPONSE

Reviewer: 2 Comments to the Author

- This is a very well written account of a qualitative evaluation of self-sampling for STI testing. Comments below are very minor

The title should mention that the interviews were conducted with users of the self-sampling scheme. This should also be mentioned in the Methods and Discussion since non-users may feel very differently thus explaining why they haven't used the service.

Author response: Thank you! OK. We have revised accordingly.

The title: "To be on the safe side" – a qualitative study regarding users' beliefs and experiences of internet-based self-sampling for *Chlamydia trachomatis* and *Neisseria gonorrhoeae* testing

Methods: 'We used a strategic approach aiming to include a broad sample of users' of the self-sampling service.'

Discussion: It is also important to note that the findings presented here are opinions and experiences of the users' of the self-sampling service.

- the acronym HBM should be defined at first use (pg 7). Author response: OK
- The technical barriers described concerns about proper sample collection and postal handling. The self-efficacy section seems to contradict this. The authors should clarify the reason for the differences between these two sections.

Author response: OK. We have clarified this in Results section:

Perceived barriers

'Although most participants felt confident in the use of the sampling-test, some

barriers were mentioned, some personal, others more of a technical nature or related to a possible unmet care need.'

Self-efficacy in handling the test and obtaining the result

'Most participants described had high self-efficacy in their use of the service. They felt confident about taking the sample and sending it by post to the lab. However, some disclosed uncertainty in handling the procedure, some had not sent the test and one informant had dropped the swab on the floor.'

All changes have been highlighted by using track changes in the manuscript. We hope this revised manuscript is acceptable for publication in BMJ Open.