

# BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email [info.bmjopen@bmj.com](mailto:info.bmjopen@bmj.com)

# BMJ Open

## Assessing the validity and reliability of maternal recall of pregnancy history and service use in a sample of signing Deaf women in Cape Town, South Africa

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-023896
Article Type:	Research
Date Submitted by the Author:	02-May-2018
Complete List of Authors:	Fontes, Mayara; University of Cape town, School of Public Health and Family Medicine, Health Science Faculty Heap, Marion; University of Cape Town, School of Public Health and Family Medicine, Health Science Faculty Gichane, Margaret W. ; University of North Carolina at Chapel Hill Marine Sciences, Department of Health Behavior, Gillings School of Global Public Health London, Leslie; University of Cape Town, School of Public Health and Family Medicine
Keywords:	EPIDEMIOLOGY, HEALTH ECONOMICS, PUBLIC HEALTH

SCHOLARONE™  
Manuscripts

## Title Page

**Title: “Assessing the validity and reliability of maternal recall of pregnancy history and service use in a sample of signing Deaf women in Cape Town, South Africa.”**

**Authors:** Mayara Fontes, MA,<sup>a</sup> Marion Heap, PhD,<sup>a</sup> Margaret W. Gichane, MSPH,<sup>b</sup> Leslie London, MD.<sup>a</sup>

### Affiliations:

- a. Health and Human Rights Programme, School of Public Health and Family Medicine, Health Science Faculty, University of Cape Town, Observatory 7925, South Africa
- b. Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, 135 Dauer Drive, 302 Rosenau Hall, CB #7440 Chapel Hill, NC 27599, USA

### Corresponding author:

Mayara Fontes

Email: [may.fontes@hotmail.com](mailto:may.fontes@hotmail.com)

Phone: 27 066 221 4125

Address: Room 4.42, 4<sup>th</sup> Level, Falmouth Building, Health Science Faculty, University of South Africa, Observatory

### Word Count

Abstract word count: 265

Manuscript word count without tables and references: 3286

Number of tables: 4

### Abstract

**Objectives:** The purpose of this study was to test the reliability and validity of maternal recall of pregnancy history and service use among a sample of Deaf women who use South African Sign Language (SASL).

**Setting:** Cape Town, South Africa.

**Participants:** We interviewed 42 signing Deaf women of child-bearing age (18-45 years) in SASL using a structured questionnaire in July 2016.

**Primary and secondary outcome measures:** To assess reliability, seven participants (16% of the sample) were re-interviewed by different interviewers under the same conditions after

1  
2  
3 intervals of between 10 to 30 minutes. For the analysis we used (1) Cohen's kappa, an inter-  
4 rater statistical method, and (2) overall percentage agreement. Validity was explored by  
5 comparing the participants' reported pregnancy history to records of attendance in the  
6 Western Cape Provincial Health Data Centre (PHDC) database.  
7

8  
9 Results: The reliability results showed that out of 19 questions, 14 demonstrated substantial  
10 to perfect agreement Kappa scores (Kappa between 0.61 and 1) and five had the lowest  
11 Kappa agreement scores (kappa <0.61). With respect to percentage agreement, participants  
12 provided identical responses in 87% cases. Validity results showed that 29 out of 35 Deaf  
13 women had survey answers matching or nearly matching (83% agreement) information in the  
14 PHDC database.  
15

16  
17 Conclusions: This study suggests that for this sample of signing Deaf women recall of  
18 pregnancy history and service use is reliable and valid. Extending this approach to other  
19 similar populations will require further research, but it is important that methods to access  
20 hard to reach disabled populations are developed so that health system responsiveness to  
21 marginal populations can be based on robust evidence.  
22

### 23 **Strengths and limitations of this study:**

#### 24 Strengths:

- 25 • This study focuses on a vulnerable hard-to-reach population that is under-researched.
- 26 • Its findings suggest possible methods to generate reliable and valid data for Deaf  
27 women as a hard-to-reach population using simple tools suited to this population.  
28

#### 29 Limitations:

- 30 • Not all pregnancy related outcomes were available to explore in the analysis
- 31 • Assessment of reliability was based on a relative short interval between testing.  
32 Reliability may have been reduced if there had been a longer time gap between the  
33 test and retest interviews.
- 34 • The gold standard may itself have been missing data, so this study may have  
35 underestimated validity.  
36

37  
38  
39  
40  
41  
42  
43 **Keywords:** Deaf, pregnancy, maternity, disability, validity, reliability  
44

### 45 **Introduction**

46  
47 It can be reasonably estimated that disabled women in Low and Middle Income  
48 Countries (LMIC) are at disproportionate risk for poor pregnancy outcomes. According to the  
49 United Nations Development Program (UNDP), 99% of all maternal deaths occur in LMIC<sup>1</sup>  
50 where 80% of persons with disabilities reside<sup>2</sup>. Studies from the United States and Europe  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 indicate that women with disabilities are at an elevated risk of pre-term and low birth weight  
4 infants<sup>3-5</sup>, yet these findings have not been confirmed in resource limited settings. To our  
5  
6 knowledge there is little credible quantitative data on pregnancy histories and outcomes for  
7  
8 disabled women nor on their use and experiences of ante-natal care and childbirth services  
9  
10 conducted in LMIC.  
11  
12

13  
14 Disabled persons pose a challenge for obtaining credible quantitative data in that they  
15  
16 are considered an example of a hard-to-reach population<sup>6 7</sup>. As a hard-to-reach population,  
17  
18 they remain largely hidden and inaccessible for research and health care<sup>6 8</sup>. In particular, Deaf  
19  
20 populations are increasingly left out of research due to barriers of communication, mistrust of  
21  
22 researchers, and inaccessible procedures<sup>8</sup>. The result is that there are few methods that  
23  
24 provide valid and reliable data and a representative or probability sample that allows  
25  
26 extrapolation to the wider population.  
27  
28

29  
30 Despite the challenges, credible data are required to ensure the needs of hard-to-reach  
31  
32 disabled women are addressed by policy-makers. For example, South Africa is currently  
33  
34 embarking on a National Health Insurance (NHI) plan. Valid and representative data on  
35  
36 maternal health status and use of maternity services are needed to ensure their access to  
37  
38 health care under the NHI and advance their sexual and reproductive human rights.  
39

40  
41 Gichane, et al.<sup>9</sup> carried out the first study in Cape Town, South Africa to assess  
42  
43 pregnancy outcomes and maternity service use in a sample of signing Deaf Women. Deaf  
44  
45 (capitalised) refers to those permanently, sensorily disabled people with congenital or early  
46  
47 onset deafness and whose first language is signed, referred to in this country as South African  
48  
49 Sign Language (SASL). The study aimed to provide a quantitative profile of Deaf women  
50  
51 (aged 18-49 years) by (i) maternal health status; (ii) use of maternity services; (iii)  
52  
53 experiences of the maternity services; and (iv) women's recommendations for improvements.  
54  
55 The overall results showed that Deaf women differed in key pregnancy outcomes. For  
56  
57  
58  
59  
60

1  
2  
3 instance, the sample fertility rate of 1.72 was lower than the South African population rate of  
4  
5 2.40 (T. Moultrie, personal communication, March 18, 2016). The study also showed a  
6  
7 higher rate of miscarriage of 31% for Deaf women versus 16% found in a population based  
8  
9 study in South Africa<sup>10</sup>. These findings<sup>9</sup> are consistent with other studies of pregnancy  
10  
11 history in South Africa which shows that most women have received antenatal care during  
12  
13 pregnancy<sup>11</sup>, however there is a delaying in seeking care beyond the first trimester<sup>12-14</sup>. This  
14  
15 delay in seeking antenatal care increases the risk of adverse pregnancy outcomes<sup>15</sup>.

16  
17  
18 This paper is therefore a follow-up of Gichane, et al.<sup>9</sup> to assess the reliability and  
19  
20 validity of the data collected by questionnaire. Reliability refers to the ‘consistency of a  
21  
22 measure’<sup>16</sup> over time and place and between interviewers; validity refers to the ‘extent to  
23  
24 which a concept or concepts (in our case pregnancy history and pregnancy outcomes) are  
25  
26 accurately measured’<sup>16</sup>. If the questionnaire used in the study to assess pregnancy experience,  
27  
28 utilization of maternity services and pregnancy outcomes among signing Deaf women in  
29  
30 Cape Town, South Africa is valid and reliable this suggest that the protocol and questionnaire  
31  
32 used in Gichane, et al.<sup>9</sup> could be explored in other settings to generate information to advise  
33  
34 programs and policies to improve maternal and child health for this hard-to-reach population.  
35  
36  
37  
38  
39

## 40 **Methods**

41  
42 The methods for the main descriptive survey have been described in detail elsewhere<sup>9</sup>.  
43  
44 In brief, the target population was signing Deaf women, of child-bearing age, residing in  
45  
46 Cape Town and aged between 18 and 49 years old.  
47  
48

### 49 *Patient and public involvement*

50  
51 The sampling selection and recruitment strategies were based on a range of  
52  
53 snowballing techniques that have been adapted to local context, including Deaf people’s use  
54  
55 of various forms of communication technology<sup>16 17</sup>. Participants were primarily recruited via  
56  
57  
58  
59

1  
2  
3 short message service (SMS) and WhatsApp messages sent to a database of Deaf adults in  
4 Cape Town developed using non-probability snowball sampling. The database was originally  
5 developed to advertise medical interpretation services. Seven people representing a range in  
6 age, gender, and residential address were recruited as initial seed participants. These  
7 individuals were tasked with soliciting phone numbers from their Deaf peers, as well as  
8 asking each contact for additional referrals of people in their social networks. Each referral  
9 was contacted to explain the purpose of the database and to provide consent to be included. A  
10 total of 220 contacts were collected and included in the final database. The findings from this  
11 study will be disseminated to the participants at their regular gatherings, such as 'Third  
12 Sunday' at a well-known NGO in Cape Town for feedbacks.

### 23 24 25 *Ethics, consent and permission*

26  
27  
28 The study was approved by the Human Research Ethics Committee of the Faculty of  
29 Health Sciences at the University of Cape Town (HREC reference number: 278\_2016). Data  
30 collection and administration of the questionnaire took place on two Saturdays in July 2016 at  
31 two well-known gathering spaces for the Deaf community of Cape Town. After informed  
32 consent, the questionnaire was administered by trained SASL interpreters and interviewers  
33 trained in survey administration and research ethics. During each interview, the interpreter  
34 signed the question and the participant signed their response. The interpreter then voiced the  
35 response in English which was captured on an online form by a research assistant.

### 36 37 38 39 40 41 42 43 44 45 46 47 48 *The questionnaire*

49  
50 A questionnaire included 22 closed and open-ended questions on demographic  
51 measures and maternal health service usage and pregnancy outcome measures. Closed-ended  
52 questions related to individuals' characteristics, such as their education, employment, number  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 of pregnancy; while for open ended questions we asked questions related to (a) deaf women's  
4 experiences of maternity health care services; and (b) their recommendations on how  
5 maternity health care services -ante-natal and delivery- should be provided for them.  
6  
7

8  
9 Questionnaires, in addition to SASL, were made available in all three local languages spoken  
10 in the Western Cape Province (Afrikaans, English, and isiXhosa). Participants were also  
11 asked permission to access their medical records within the Health Department as part of the  
12 consent procedure.  
13  
14  
15  
16  
17

### 18 19 20 *Assessing the pilot study reliability*

21  
22 All participants (42) were asked whether they were available for a second interview.  
23  
24 A total of seven participants (16% of the sample) were re-interviewed by different  
25 interviewers under the same conditions after 10-30 minutes to assess reliability of the  
26 questionnaire. The first four participants were interviewed twice on the first day of the data  
27 collection, while on the second day three participants were randomly selected to be re-  
28 interviewed.  
29  
30  
31  
32  
33  
34

35 The Cohen's kappa<sup>17 18</sup>, an inter-rater method, and overall percentage agreement were  
36 used to assess the questionnaire's reliability. The Cohen's kappa results can vary from -1 to  
37 1; results equal to 1 imply perfect agreement, while results equal to -1 imply no agreement  
38 and the distributions are subject to random chance (Table 1). The percentage absolute  
39 agreement was calculated by dividing the number of the participants answers that are in  
40 agreement by the total number of participants (N=7). Only questions that capture individuals'  
41 characteristic, such as their marital status, education, employment, number of pregnancy,  
42 number of children, were used in this analysis. Therefore, three open ended questions were  
43 excluded from this analysis. In total, 19 questions were included in the reliability analysis.  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60



<b>Interpretation</b>	<b>Kappa</b>
Complete agreement	1
Almost perfect agreement	0.81-1.0
Substantial agreement	0.61-0.80
Moderate agreement	0.41-0.60
None to slight agreement	0.01-0.20
No agreement	0
<i>Sources:</i> <sup>17,18</sup>	

### *Assessing the pilot study validity*

Validity was measured by comparing the women's answers regarding their pregnancy history to the health data available from the Provincial Health Data Centre (PHDC).

According to the Western Cape Department of Health (WCDH), the PHDC is an initiative of WCDH which capitalises on the durable investment in both a single hospital information system and a patient master index (PMI) over the past decades, in order to consolidate all person-level clinical data in a single environment. The PHDC functions as a nascent health information exchange, combining standards based interoperability solutions with bespoke data take-on processes to consolidate data from most of the sources on a daily basis' (N. Zinyakatira, personal communication, November 03, 2017). The PHDC data therefore served as the gold standard for assessment of patient response validity for maternity service attendance in the Western Cape.

To access the data from the PHDC database, ethical approval was first secured (HREC reference number 278\_2016) and then approval obtained from the WCDH and PHDC based on a data access agreement that protected the privacy of the records. Data were requested from the PHDC database for each participant on the number of pregnancies, number of children, whether the individual had a miscarriage and/or termination, latest due date or child's birthday, if the youngest child was delivered in the Western Cape, health

1  
2  
3 facility attended when pregnant with youngest child, health facility at which youngest child  
4  
5 was delivered.

6  
7 Once permission was granted by the WCDH, a secured list with the participants'  
8  
9 Identity Numbers (ID) and names was sent to the PHDC. Only the names and IDs of women  
10  
11 who gave written informed consent in the main study were used. The PHDC provided the  
12  
13 health data, by participants name and ID, which was then cleaned and reorganized into tables  
14  
15 by the first author of the paper, MF, for the analysis.

16  
17  
18 Out of 42 Deaf women that consented to participate in the study and have their  
19  
20 records checked, seven were excluded from the validity analysis because two participants did  
21  
22 not have children; while five participants names or IDs collected during the interviews were  
23  
24 not the same used in the WCDH facilities. In total, 35 women were included in the validity  
25  
26 analysis. The results were grouped into the following categories:

27  
28  
29 (1) 'Match' refers to those answers collected in the questionnaire that matched  
30  
31 completely the information provided by the PHDC.

32  
33 (2) 'Nearly Match' refers to small differences between answers given in the  
34  
35 questionnaire and the information provided by the PHDC. These differences included  
36  
37 typographical errors that could not be 100% confirmed or a missing record that was likely to  
38  
39 have been present, as explain in the Results section below.

40  
41  
42 (3) 'No Match' refers to those cases where there were answers from our questionnaire  
43  
44 responses did not match information in the PHDC database.

## 45 46 47 48 **Results**

### 49 *Participants*

50  
51  
52 In total, there were 42 signing Deaf women who met the eligibility criteria and who  
53  
54 consented to participation. Participants ranged in age from 18-49 years and 57% were  
55  
56

1  
2  
3 married or lived with a partner (57%). The majority of participant's highest level of education  
4 was between grades 7 and 12. Over half were unemployed (59%), and received a monthly  
5 disability grant. Most women (62%) had between one and two pregnancies. Thirty-one  
6 percent had at least one miscarriage and 19% had had an abortion.  
7  
8  
9

### 10 11 *Reliability*

12  
13 With respect to percentage agreement, of the 133 items for which repeat measures  
14 were available (7 participants x 19 questions each), participants provided the same response  
15 to both interviewers in 87% of cases (n=116 items in agreement). The analysis of kappa  
16 values, shown on table 2, showed that of the 19 questions, 8 achieved complete agreement  
17 (kappa=1); 3 achieved almost perfect agreement (kappa=0.81-1.0); and 3 achieved substantial  
18 agreement (kappa=0.61-0.80). Answers to questions on monthly income, education,  
19 termination of pregnancy and number of months (or weeks) at first booking when pregnant  
20 with the youngest child had the lowest Kappa agreement scores (kappa <0.61). The nature of  
21 discrepant answers for income were (a) "between R4000 and R10000" versus "refused to  
22 answer"; (b) "disability grant" versus "less than R4000" and (c) "less than R4000" versus  
23 "between R4000 and R10,000". For the education question, the discrepancy was between  
24 "below Grade 7/Standard 5" versus "don't know". For the termination of pregnancy, the  
25 discrepancy was "yes" versus "no" and for months pregnant when they booked at a clinic  
26 discrepancies were "4 months" versus "less than 2 months"; "5 months" versus "4 months";  
27 "did not book" versus "6 months" (Table 3).  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45

46  
47  
48  
49

50 <b>Table 2 – Distribution of Kappa Scores for 19 questionnaire items</b>		
51 <b>Kappa range (interpretation)</b>		52 <b>Number of Questionnaire items</b>
53 Complete agreement	54 1	55 8
56 Almost perfect agreement	57 0.81-1.0	58 3
59 Substantial agreement	60 0.61-0.80	61 3
Moderate agreement	0.41-0.60	3

None to slight agreement	0.01-0.20	1
No agreement	0	1

Question	Kappa	Percentage agreement	Nature of discrepant answers
In which of the following languages do you prefer to read or write?	1.00	7/7	None
Marital Status	0.70	6/7	Widow versus divorced
What is your highest level of schooling/education?	0.46	6/7	Below Grade 7/Standard 5 versus don't know
What is your employment status?	0.61	6/7	Unemployed versus Employed
Monthly income	0.15	3/7	Between R4000 and R10000 versus refused; Disability Grant versus Less than R4000; Less than R4000 versus Between R4000 and R10000
How many times have you been pregnant?	1	7/7	None
How many children do you have?	1	7/7	None
Did you ever have a miscarriage?	1	7/7	None
Did you ever lose a baby at birth?	1	7/7	None
Did you ever lose a child later on?	1	7/7	None
Did you ever have a termination of pregnancy?	0	6/7	Yes versus No
How many months pregnant were you when you went to book at clinic with your youngest child?	0.45	3/7	4 months versus less than 2 months; 5 months versus 4 months; did not book versus 6 months
Which clinic did you attend when you were pregnant with the youngest child?	0.82	6/7	Did not attend versus Eastern Cape
Did you attend a hospital when you were pregnant with the youngest child?	1	7/7	None
If you attended hospital, what was its name?	0.81	6/7	Tygerberg versus Eastern Cape
How many times did you attend clinic when you were pregnant with your youngest child?	0.70	6/7	Did not attend versus Once
In which province was your	1	7/7	None

youngest child born?			
In which type of health care facility did you deliver the youngest child?	0.59	6/7	Hospital versus Midwife Obstetric Unit
What was name of the hospital or clinic?	0.81	6/7	Gugulethu, KTC versus Tygerberg

### *Validity*

The validity was explored through comparing the study participants' pregnancy history to the Western Cape PHDC database. In total, for 16/35 participants records given in the questionnaire matched completed the information provided by the PHDC; while, 13/35 'Nearly Match' (Table 4). For the 'Nearly Match', the small differences included the following: a) 6 out of 13 Deaf women who reported a pregnancy experience had a record confirmed in the Provincial Database of going into labour but had no confirmation of the actual birth of the child in the PHDC database, for reasons related to failure to register the child. This was considered a 'Near Match' since the provincial record confirmed an episode of labour which likely ended in a delivery; b) another 'Nearly Match' was a note of a different birth facility attended. Because a participant might have gone into labour at one facility but have been transferred to another facility due to complications of labour, this may not be picked up in the routine database.

All the 6 Deaf women who did not match claimed to have had a child but had no record from the PHDC database to confirm this history. Our focus on linkage was on pregnancy history, therefore a missing record on the PHDC database could reflect that no pregnancy-related encounter with health facilities took place in the province or that participants' pregnancy history was not captured by the PHDC database (e.g. old records).

Overall, Table 4 validity results show that, 29 out of 35 (83% agreement) Deaf women had their survey answers matched or nearly matched to the PHDC database.

<b>Table 4- Validity Results</b>			
Validity	Match	Nearly Match	Not Match

	16	13	6
<i>Note: Validity is measured by comparing the instrument answers to the PHDC database.</i>			
<i>N=35</i>			

## Discussion

This study tested the reliability and validity of answers to a questionnaire to assess pregnancy experience, utilization of maternity services and pregnancy outcomes reported elsewhere among signing Deaf women in Cape Town, South Africa<sup>9</sup>. To our knowledge, this is the first study to use a health system database to assess the validity of Deaf women's recall of their pregnancy experiences. The results suggest that the piloted methods provided reasonably reliable and valid data on this hard-to-reach population.

### *Reliability*

Overall, the data appeared highly reliable. Participants provided identical responses in 87% cases. Demographic indicators that showed lower levels of inter-rater reliability included data on income and, to a lesser extent, education. This is similar to findings in other studies that suggests that questions on income might not be a reliable source and sensitive questions might be misreported<sup>19</sup>. Further, because interviews were conducted face to face, and demographic questions were asked at the outset of the interview, participants may have been especially hesitant to disclose this information. In order to improve reliability for such questions, survey methodologists suggest asking sensitive information later in the interview once the participant and interview have built rapport<sup>19</sup>.

For the reproductive history, the main outcomes (parity, miscarriages) achieved a high level of reliability. However, reliability was much lower for timing of first antenatal visit which requires more complex and sometimes long-term recall. The most recent pregnancy of some of the women who were re-interviewed may have been several years ago which may explain their different responses within a short period of time. Recall bias is especially

1  
2  
3 common when the health condition or event occurred a long time ago, is frequent, or if it  
4 wasn't particularly salient to the individual<sup>20</sup>. It is possible that women who had healthy  
5 pregnancies or already had multiple pregnancies may have more of a challenge remembering  
6 the initiation of antenatal care because it felt like a routine event. Timing of antenatal  
7 initiation is an important outcome as it can have significant impacts on the health of the  
8 mother and infant<sup>15</sup>. Developing methods to aid complex recall, can better improve our  
9 understanding of the maternal health of Deaf women.  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19

### 20 *Validity*

21  
22 The validity, measured as agreement between women's report of their pregnancy  
23 history compared to the health data available from the PHDC, was found to be accurate (83%  
24 sensitivity). Women reported key pregnancy events including termination, miscarriage, and  
25 birth location with high accuracy. These results confirm many studies comparing maternal  
26 recall with medical or government records of pregnancy outcomes<sup>21-23</sup>. On average, mothers  
27 are able to recall characteristics of their pregnancy, birth outcomes, and mode of delivery<sup>10,21</sup>.  
28 One study found that women are able to recall salient pregnancy events including  
29 complications and pregnancy outcomes up to 15 years post pregnancy<sup>21</sup>. Future studies  
30 should assess validity of other pregnancy outcomes including birth weight and medical  
31 complications of Deaf women.  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43

44 Most participants who used the public health care system in the Western Cape were  
45 matched. However, the assumption that the Western Cape Datacentre is the gold standard  
46 may not be entirely correct because it is fairly new, having only been implemented in 2013.  
47 Use of electronic medical records in Sub-Saharan Africa is just starting to increase traction<sup>24</sup>.  
48 Clinics and hospitals in the Western Cape started capturing the records electronically at  
49 points in time such that earlier data might have been less consistent. The six Deaf women that  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 had their pregnancy records ‘No Match’ said that they delivered in Western Cape but the  
4 records could not be found in the PHDC database. This linkage failure could be due to  
5 several issues: discrepancies in the names supplied during the research study and those used  
6 in health facilities, Western Cape clinics and hospitals failed to enter patient information in  
7 PHDC database, or old records may be missing (for instance some women gave birth in 1988  
8 and 1996). Further investigation of the quality control measures employed by the PHDC  
9 database are necessary. Nevertheless, the results suggest that reports from deaf women  
10 provide reliable and valid data on which to describe their pregnancy history.  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21

### 22 *Implications*

23 Findings from this study have several implications for research with Deaf populations.  
24 First, the high level of validity self-reported outcomes is particularly promising given the  
25 challenges of obtaining medical records in LMIC<sup>24</sup>. The Western Cape of South Africa has  
26 more resources and a more robust healthcare system as compared to other regions of South  
27 Africa<sup>11</sup>. In more rural areas, it would be nearly impossible to find a database of health  
28 information such as the Western Cape PHDC database. Establishing the validity of self-  
29 report with other health outcomes with Deaf populations is an important next step.  
30  
31  
32  
33  
34  
35  
36  
37  
38

39 Second, measures and methods need to be developed to improve the complex recall of  
40 pregnancy related events. Some methods to improve recall include memory aids or adjusting  
41 the recall period<sup>20</sup>. Creating tools that are culturally relevant and specific to Deaf populations  
42 is necessary.  
43  
44  
45  
46  
47  
48  
49

### 50 **Limitations**

51 The following limitations should be considered in the interpretation of the results.  
52 First, there were many pregnancy related markers which were not explored in the analysis,  
53  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 therefore we cannot generalise the results to all pregnancy history measures. Second, inter-  
4  
5 rater reliability was measured with a small sample over a short period of time (10-30  
6  
7 minutes); thus, we cannot comment if participants' responses would have remained consistent  
8  
9 if there would have been a longer time gap between the test and retest interviews. Lastly, the  
10  
11 'gold standard' in this case, the electronic records in the PHDC, may have lacked full  
12  
13 information due to failure by staff to enter relevant information at the time the woman was  
14  
15 seen in the service. This would probably have led to an underestimate in this study of the true  
16  
17 validity.  
18  
19  
20  
21

## 22 **Conclusion**

23  
24 Findings from this study indicate that the protocol used in Gichane, et al.<sup>9</sup> yielded  
25  
26 valid and reliable results. This suggests that it is possible to develop methodologies that will  
27  
28 produce reliable and valid data for Deaf women using simple tools that are suited to this  
29  
30 population in question. Extending this approach to other populations will require further  
31  
32 research, but it is important that methods to access hard-to-reach populations are developed  
33  
34 so that health system responsiveness to marginal populations can be based on robust  
35  
36 evidence.  
37  
38  
39  
40  
41

## 42 **References**

- 43 1. World Health Organization. Maternal mortality fact sheet. *World Health Organization, Geneva* 2010
- 44 2. World Health Organization. World report on disability: World Health Organization, 2011.
- 45 3. Mitra M, Long-Bellil LM, Iezzoni LI, et al. Pregnancy among women with physical  
46 disabilities: Unmet needs and recommendations on navigating pregnancy. *Disability*  
47 *and health journal* 2016;9(3):457-63.
- 48 4. Redshaw M, Malouf R, Gao H, et al. Women with disability: the experience of maternity  
49 care during pregnancy, labour and birth and the postnatal period. *BMC pregnancy and*  
50 *childbirth* 2013;13(1):174.
- 51 5. Signore C, Spong CY, Krotoski D, et al. Pregnancy in women with physical disabilities.  
52 *Obstetrics & Gynecology* 2011;117(4):935-47.
- 53  
54  
55  
56  
57  
58  
59  
60

6. Shaghghi A, Bhopal RS, Sheikh A. Approaches to recruiting 'hard-to-reach' populations into research: a review of the literature. *Health promotion perspectives* 2011;1(2):86.
7. Faugier J, Sargeant M. Sampling hard to reach populations. *Journal of advanced nursing* 1997;26(4):790-97.
8. McKee M, Schlehofer D, Thew D. Ethical issues in conducting research with deaf populations. *American journal of public health* 2013;103(12):2174-78.
9. Gichane MW, Heap M, Fontes M, et al. "They must understand we are people": Pregnancy and maternity service use among signing Deaf women in Cape Town. *Disability and Health Journal* 2017;10(3):434-39.
10. Bello B, Kielkowski D, Heederik D, et al. Time-to-pregnancy and pregnancy outcomes in a South African population. *BMC public health* 2010;10(1):565.
11. Day C, Gray A. South African Health Review. Durban: Health Systems Trust, 2016.
12. Muhwava LS, Morojele N, London L. Psychosocial factors associated with early initiation and frequency of antenatal care (ANC) visits in a rural and urban setting in South Africa: a cross-sectional survey. *BMC pregnancy and childbirth* 2016;16(1):18.
13. Solarin I, Black V. "They told me to come back": women's antenatal care booking experience in inner-city Johannesburg. *Maternal and child health journal* 2013;17(2):359-67.
14. Myer L, Harrison A. Why do women seek antenatal care late? Perspectives from rural South Africa. *Journal of midwifery & women's health* 2003;48(4):268-72.
15. National Department of Health. Saving Mothers 2011-2013: Sixth report on confidential enquiries into maternal deaths in South Africa, Short Report. Pretoria: National Department of Health, 2014.
16. Heale R, Twycross A. Validity and reliability in quantitative studies. *Evidence-based nursing* 2015:ebnurs-2015-102129.
17. Cohen J. Weighted kappa: Nominal scale agreement provision for scaled disagreement or partial credit. *Psychological bulletin* 1968;70(4):213.
18. McHugh ML. Interrater reliability: the kappa statistic. *Biochemia medica* 2012;22(3):276-82.
19. Tourangeau R, Yan T. Sensitive questions in surveys. *Psychological bulletin* 2007;133(5):859.
20. Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. *Journal of multidisciplinary healthcare* 2016;9:211.
21. Yawn BP, Suman VJ, Jacobsen SJ. Maternal recall of distant pregnancy events. *Journal of clinical epidemiology* 1998;51(5):399-405.
22. Githens PB, Glass CA, Sloan FA, et al. Maternal recall and medical records: an examination of events during pregnancy, childbirth, and early infancy. *Birth* 1993;20(3):136-41.
23. Liu J, Tuvblad C, Li L, et al. Medical record validation of maternal recall of pregnancy and birth events from a twin cohort. *Twin Research and Human Genetics* 2013;16(4):845-60.
24. Akanbi MO, Ocheke AN, Agaba PA, et al. Use of electronic health records in sub-Saharan Africa: progress and challenges. *Journal of medicine in the tropics* 2012;14(1):1.

**Contributorship:**

MF, MH, WG and LL participated in the design of the study, the interpretation of the findings, commented on the manuscript and approved the final manuscript. WG and MH led the field work. MF conducted the statistical analysis and composed the initial draft.

**Competing interest:**

The authors declare no conflicts of interest.

**Acknowledgements:**

We would like to thank Nesbert Zinyakatira, Western Cape Department of Health, for suppling expert research assistance on the health data from the Provincial Health Data Centre (PHDC) during the preparation of this manuscript. The research team would like to thank the participants who generously shared their time and experience for the purposes of this project. We would like to acknowledge the contributions of the following University of Cape Town interpreters, research assistants, and students who assisted with data collection: Nombulelo Cekwana, Lizeka Madlolo, Thumeka Manyashe, Banele Mhlongo, Vuma Mthembu, Rudolph Priestly, Dumisa Seteni, Sheila Thamahane, and Nonkululeko Zwane.

**Funding:**

This work was supported in part by grant T37 MD001452: Mount Sinai International Exchange Program for Minority Students from the National Center on Minority Health and Health Disparities of the National Institutes of Health, Dr. Luz Claudio, Principal Investigator, and by funding from the South African National Research Foundation. Funders had no input on the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript.

**Ethical Approval:**

The study was approved by the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (HREC reference number: 278\_2016).

**Data Sharing:**

The data that support the findings of this study are available on request from the corresponding author, MF. Potential data users will be required to agree to the Terms and Conditions of a Data Access Agreement (DAA), which aims to protect the privacy and interests of the research participants and must have their application approved by the PI, MH.

# BMJ Open

## Validity and reliability of maternal recall of pregnancy history and service use among signing Deaf women: A cross-sectional descriptive study from South Africa.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-023896.R1
Article Type:	Research
Date Submitted by the Author:	23-Sep-2018
Complete List of Authors:	Fontes Marx, Mayara; University of Cape town, School of Public Health and Family Medicine, Health Science Faculty Heap, Marion; University of Cape Town, School of Public Health and Family Medicine, Health Science Faculty Gichane, Margaret W. ; University of North Carolina at Chapel Hill Marine Sciences, Department of Health Behavior, Gillings School of Global Public Health London, Leslie; University of Cape Town, School of Public Health and Family Medicine
<b>Primary Subject Heading</b>:	Public health
Secondary Subject Heading:	Epidemiology, Health policy, Health services research, Sexual health
Keywords:	disability, validity and reliability, pregnancy, Deaf, maternity

SCHOLARONE™  
Manuscripts

## Title Page

### “Validity and reliability of maternal recall of pregnancy history and service use among signing Deaf women: A cross-sectional descriptive study from South Africa”

**Authors:** Mayara Fontes Marx, MA,<sup>a</sup> Marion Heap, PhD,<sup>a</sup> Margaret W. Gichane, MSPH,<sup>b</sup> Leslie London, MD.<sup>a</sup>

#### Affiliations:

- a. Health and Human Rights Programme, School of Public Health and Family Medicine, Health Science Faculty, University of Cape Town, Observatory 7925, South Africa
- b. Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, 135 Dauer Drive, 302 Rosenau Hall, CB #7440 Chapel Hill, NC 27599, USA

#### Corresponding author:

Mayara Fontes Marx  
Email: [crrmay002@myuct.ac.za](mailto:crrmay002@myuct.ac.za)  
Phone: 27 066 221 4125  
Address: Room 4.42, 4<sup>th</sup> Level, Falmouth Building, Health Science Faculty, University of South Africa, Observatory

#### Word Count

Abstract word count: 290

Manuscript word count without tables and references: 3303

Number of tables: 4

#### Abstract

**Introduction:** There is little credible quantitative data on pregnancy histories and outcomes for disabled women in Low Middle-Income Countries (LMIC). The purpose of this study, based in Cape Town, South Africa, was to test the reliability and validity of maternal recall of pregnancy history and service use among a sample of Deaf women who use South African Sign Language (SASL).

**Methods:** We interviewed 42 signing Deaf women of child-bearing age (18-49 years) in SASL using a structured questionnaire in July 2016. To assess reliability, seven participants (16% of the sample) were re-interviewed by different interviewers under the same conditions after 10-30 minutes. For the analysis we used (1) Cohen's kappa, an inter-rater statistical method, and (2) overall percentage agreement. Validity was explored by comparing the participants' pregnancy history to the Western Cape Provincial Health Data Centre (PHDC) database.

Results: The reliability results showed that out of 19 questions, 14 demonstrated substantial to perfect agreement Kappa scores (Kappa between 0.61 and 1) and five had the lowest Kappa agreement scores (kappa <0.61). With respect to percentage agreement, participants provided identical responses in 87% cases. Overall, women provided more reliable responses to pregnancy outcomes as compared to demographic information. Validity results showed that 29 out of 35 Deaf women provided survey responses that matched or nearly matched (83% agreement) the PHDC database for birth history and delivery location.

Conclusion: This study suggests that for this sample of signing Deaf women recall of pregnancy history and service use is reliable and valid. Extending this approach to other similar populations will require further research, but it is important that methods to access hard to reach disabled populations are developed so that health system responsiveness to marginal populations can be based on robust evidence.

### Strengths and limitations of this study:

#### Strengths:

- This study focuses on a vulnerable hard-to-reach population that is under-researched.
- Its findings suggest possible methods to generate reliable and valid data for Deaf women as a hard-to-reach population using simple tools suited to this population.

#### Limitations:

- Not all pregnancy related outcomes were available to explore in the analysis
- Assessment of reliability was based on a relative short interval between testing. Reliability may have been reduced if there had been a longer time gap between the test and retest interviews.

**Keywords:** Deaf, pregnancy, maternity, disability, validity, reliability

## Introduction

It can be reasonably estimated that disabled women in Low and Middle-Income Countries (LMIC) are at disproportionate risk for poor pregnancy outcomes. According to the United Nations Development Program (UNDP), 99% of all maternal deaths occur in LMIC<sup>1</sup> where 80% of persons with disabilities reside<sup>2</sup>. Studies from the United States and Europe indicate that women with disabilities are at an elevated risk of pre-term and low birth weight infants<sup>3-5</sup>, yet these findings have not been confirmed in resource limited settings. To our

1  
2  
3 knowledge there is little credible quantitative data on pregnancy histories and outcomes for  
4 disabled women nor on their use and experiences of ante-natal care and childbirth services in  
5  
6 LMICs.  
7

8  
9 Disabled persons pose a challenge for obtaining credible quantitative data in that they  
10 are considered an example of a hard-to-reach population<sup>6 7</sup>. As a hard-to-reach population,  
11 they remain largely hidden and inaccessible for research and health care<sup>6 8</sup>. In particular, Deaf  
12 populations are increasingly left out of research due to barriers of communication, mistrust of  
13 researchers and inaccessible procedures<sup>8</sup>. The result is that there are few methods that provide  
14 valid and reliable data and a representative or probability sample that allows extrapolation to  
15 the wider population.  
16  
17

18  
19 Despite the challenges, credible data are required to ensure the needs of hard-to-reach  
20 disabled women are addressed by policy-makers. For example, South Africa is currently  
21 embarking on a National Health Insurance (NHI) plan. Valid and representative data on  
22 maternal health status and use of maternity services are needed to ensure their access to  
23 health care under the NHI and advance their sexual and reproductive human rights.  
24

25  
26 Although maternal recall is often used to characterize reproductive histories, studies  
27 examining validity through agreement between maternal recall and routine hospital records  
28 have largely been confined to High Income Countries<sup>9-11</sup>. Gichane, et al.<sup>12</sup> carried out the  
29 first study in Cape Town, South Africa to assess pregnancy outcomes and maternity service  
30 use in a sample of signing Deaf Women. Deaf (capitalised) refers to those permanently,  
31 sensorily disabled people with congenital or early onset deafness and whose first language is  
32 signed, referred to in this country as South African Sign Language (SASL). The study aimed  
33 to provide a quantitative profile of Deaf women (aged 18-49 years) by (i) maternal health  
34 status; (ii) use of maternity services; (iii) experiences of the maternity services; and (iv)  
35 women's recommendations for improvements. The overall results showed that Deaf women  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 differed in key pregnancy outcomes. For instance, the sample fertility rate of 1.72 was lower  
4 than the South African population rate of 2.40 (T. Moultrie, personal communication, March  
5 18, 2016). The study also showed a higher rate of miscarriage of 31% for Deaf women versus  
6 16% found in a population based study in South Africa<sup>13</sup>. These findings<sup>12</sup> are consistent  
7 with other studies of pregnancy history in South Africa which shows that most women have  
8 received antenatal care during pregnancy<sup>14</sup> but that there is a delay in seeking care beyond the  
9 first trimester<sup>15-17</sup>. This delay in seeking antenatal care increases the risk of adverse  
10 pregnancy outcomes<sup>18</sup>.

11  
12 This paper is therefore a follow-up of Gichane, et al.<sup>12</sup> to assess the reliability and  
13 validity of the data collected by questionnaire. Reliability refers to the ‘consistency of a  
14 measure’<sup>19</sup> over time and place and between interviewers; validity refers to the ‘extent to  
15 which a concept or concepts (in our case pregnancy history and pregnancy outcomes) are  
16 accurately measured’<sup>19</sup>. If the questionnaire previously used in the study by Gichane, et al.<sup>12</sup>  
17 is valid and reliable, this tool could be explored in other settings to generate information for  
18 programs and policies to improve maternal and child health for this hard-to-reach population.  
19

## 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 **Methods**

38  
39 The methods for the main descriptive survey have been described in detail  
40 elsewhere<sup>12</sup>. In brief, the target population was signing Deaf women, of child-bearing age,  
41 residing in Cape Town and aged between 18 and 49 years old.  
42  
43  
44  
45  
46

47 The sampling selection and recruitment strategies were based on a range of  
48 snowballing techniques that have been adapted to local context, including Deaf people’s use  
49 of various forms of communication technology<sup>16 17</sup>. Participants were primarily recruited via  
50 short message service (SMS) and WhatsApp messages sent to a database of Deaf adults in  
51 Cape Town developed using non-probability snowball sampling. The database was originally  
52  
53  
54  
55  
56  
57  
58  
59  
60



1  
2  
3 developed to advertise medical interpretation services. Seven people representing a range in  
4 age, gender, and residential address were recruited as initial seed participants. These  
5 individuals were tasked with soliciting phone numbers from their Deaf peers, as well as  
6 asking each contact for additional referrals of people in their social networks. Each referral  
7 was contacted to explain the purpose of the database and to provide consent to be included. A  
8 total of 220 contacts were collected and included in the final database.  
9  
10  
11  
12  
13  
14

### 15 16 17 *Ethics, consent and permission* 18

19  
20 The study was approved by the Human Research Ethics Committee of the Faculty of  
21 Health Sciences at the University of Cape Town (HREC reference number: 278\_2016). Data  
22 collection and administration of the questionnaire took place on two Saturdays in July 2016 at  
23 two well-known gathering spaces for the Deaf community of Cape Town. After informed  
24 consent, the questionnaire was administered by trained SASL interpreters and interviewers  
25 trained in survey administration and research ethics. During each interview, the interpreter  
26 signed the question and the participant signed their response. The interpreter then voiced the  
27 response in English which was captured on an online form by a research assistant.  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38

### 39 40 *The questionnaire* 41

42 The questionnaire, described in Gichane, et al. <sup>12</sup>, included 22 closed and open-ended  
43 questions on demographic measures and maternal health service usage and pregnancy  
44 outcome measures. Closed-ended questions related to individuals' characteristics, such as  
45 their education, employment, number of pregnancy; while for open ended questions we asked  
46 questions regarding (a) deaf women's experiences of maternity health care services; and (b)  
47 their recommendations on how maternity health care services -ante-natal and delivery- should  
48 be provided for them. Questionnaires, in addition to SASL, were made available in all three  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

local languages spoken in the Western Cape Province (Afrikaans, English, and isiXhosa). Participants were also asked permission to access their medical records within the Health Department as part of the consent procedure.

### *Assessing the pilot study reliability*

All participants (42) were asked whether they were available for a second interview. A total of seven participants (16% of the sample) were re-interviewed by different interviewers under the same conditions after 10-30 minutes to assess reliability of the questionnaire. The first four participants were interviewed twice on the first day of the data collection, while on the second day three participants were randomly selected to be re-interviewed.

The Cohen's kappa<sup>20 21</sup>, an inter-rater method, and overall percentage agreement were used to assess the questionnaire's reliability. The Cohen's kappa results can vary from -1 to 1; results equal to 1 imply perfect agreement, while results equal to -1 imply no agreement and the distributions are subject to random chance (Table 1). The percentage absolute agreement was calculated by dividing the number of the participants answers that are in agreement by the total number of participants (N=7). Only questions that capture individuals' characteristic, such as their marital status, education, employment, number of pregnancy, number of children, were used in this analysis. Therefore, three open ended questions were excluded from this analysis. In total, 19 questions were included in the reliability analysis.

<b>Interpretation</b>	<b>Kappa</b>
Complete agreement	1
Almost perfect agreement	0.81-1.0
Substantial agreement	0.61-0.80
Moderate agreement	0.41-0.60

None to slight agreement	0.01-0.20
No agreement	0
<i>Sources:</i> <sup>20 21</sup>	

### *Assessing the pilot study validity*

Validity was measured by comparing the women's answers regarding their pregnancy history to the health data available from the Provincial Health Data Centre (PHDC).

According to the Western Cape Department of Health (WCDH), the PHDC is an initiative of WCDH which capitalises on the durable investment in both a single hospital information system and a patient master index (PMI) over the past decades, in order to consolidate all person-level clinical data in a single environment. The PHDC functions as a nascent health information exchange, combining standards based interoperability solutions with bespoke data take-on processes to consolidate data from most of the sources on a daily basis' (N.

Zinyakatira, personal communication, November 03, 2017). The PHDC data therefore served as the gold standard for assessment of patient response validity for maternity service attendance in the Western Cape.

To access the data from the PHDC database, ethical approval was first secured (HREC reference number 278\_2016) and then approval obtained from the WCDH and PHDC based on a data access agreement that protected the privacy of the records. Data were requested from the PHDC database for each participant on the number of pregnancies, number of children, whether the individual had a miscarriage and/or termination, latest due date or child's birthday, if the youngest child was delivered in the WC, health facility

1  
2  
3 attended when pregnant with youngest child, health facility at which youngest child was  
4  
5 delivered.

6  
7 Once permission was granted by the WCDH, a secured list with the participants'  
8  
9 Identity Numbers (ID) and names was sent to the PHDC. Only the names and IDs of women  
10  
11 who gave written informed consent in the main study were used. The PHDC provided the  
12  
13 health data, by participants name and ID, which was then cleaned and reorganized into tables  
14  
15 by the first author of the paper, MF, for the analysis.

16  
17  
18 Out of 42 Deaf women that consented to participate in the study and have their  
19  
20 records checked, seven were excluded from the validity analysis because two participants did  
21  
22 not have children; while five participants names or IDs collected during the interviews were  
23  
24 not the same used in the WCDH facilities. In total, 35 deaf pregnant women were included in  
25  
26 the validity analysis. The results were grouped into the following categories:

27  
28  
29 (1) 'Match' refers to those answers collected in the questionnaire that matched  
30  
31 completely the information provided by the PHDC.

32  
33 (2) 'Nearly Match' refers to small differences between answers given in the  
34  
35 questionnaire and the information provided by the PHDC. These differences included  
36  
37 typographical errors that could not be 100% confirmed or a missing record that was likely to  
38  
39 have been present, as explain in the Results section below.

40  
41  
42 (3) 'No Match' refers to those cases where there were answers from our questionnaire  
43  
44 responses did not match information in the PHDC database.

45  
46 *Patient and Public Involvement:* MH and LL have a longstanding (over 20 years) research  
47  
48 and advocacy relationship with the Deaf community of Cape Town. Their needs have  
49  
50 informed the research question and outcome measures for this study. Potential participants  
51  
52 were involved in the recruitment – via their WhatsApp groups. However, study participants  
53  
54 had no involvement in the study design or conduct of the study. The findings from this study

1  
2  
3 will be disseminated to the participants at their regular gatherings, such as 'Third Sunday' at  
4 a well-known NGO in Cape Town for feedbacks.  
5  
6

## 7 **Results**

### 8 *Participants*

9  
10  
11 In total, there were 42 signing Deaf women who met the eligibility criteria and who  
12 consented to participation. Participants ranged in age from 18-49 years and 57% were  
13 married or lived with a partner (57%). The majority of participant's highest level of education  
14 was between grades 7 and 12. Over half were unemployed (59%), and received a monthly  
15 disability grant. Most women (62%) had between one and two pregnancies. Thirty-one  
16 percent had at least one miscarriage and 19% had had an abortion.  
17  
18  
19  
20  
21  
22  
23

### 24 *Reliability*

25  
26 With respect to percentage agreement, of the 133 items for which repeat measures  
27 were available (7 participants x 19 questions each), participants provided the same response  
28 to both interviewers in 87% of cases (n=116 items in agreement). The analysis of kappa  
29 values, shown on table 2, showed that of the 19 questions, 8 achieved complete agreement  
30 (kappa=1); 3 achieved almost perfect agreement (kappa=0.81-1.0); and 3 achieved substantial  
31 agreement (kappa=0.61-0.80). Answers to questions on monthly income, education,  
32 termination of pregnancy and number of months (or weeks) at first booking when pregnant  
33 with the youngest child had the lowest Kappa agreement scores (kappa <0.61). The nature of  
34 discrepant answers for income were (a) "between R4000 and R10000" versus "refused to  
35 answer"; (b) "disability grant" versus "less than R4000" and (c) "less than R4000" versus  
36 "between R4000 and R10,000". For the education question, the discrepancy was between  
37 "below Grade 7/Standard 5" versus "don't know". For the termination of pregnancy, the  
38 discrepancy was "yes" versus "no". For r months pregnant at first clinic booking visit  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

discrepancies were: (a) “4 months” versus “less than 2 months”; (b) “5 months” versus “4 months”; (c) “did not book” versus “6 months” (Table 3).

<b>Kappa range (interpretation)</b>		<b>Number of Questionnaire items</b>
Complete agreement	1	8
Almost perfect agreement	0.81-1.0	3
Substantial agreement	0.61-0.80	3
Moderate agreement	0.41-0.60	3
None to slight agreement	0.01-0.20	1
No agreement	0	1

<b>Question</b>	<b>Kappa</b>	<b>Percentage agreement</b>	<b>Nature of discrepant answers</b>
In which of the following languages do you prefer to read or write?	1.00	7/7	None
Marital Status	0.70	6/7	Widow versus divorced
What is your highest level of schooling/education?	0.46	6/7	Below Grade 7/Standard 5 versus don't know
What is your employment status?	0.61	6/7	Unemployed versus Employed
Monthly income	0.15	3/7	Between R4000 and R10000 versus refused; Disability Grant versus Less than R4000; Less than R4000 versus Between R4000 and R10000
How many times have you been pregnant?	1	7/7	None
How many children do you have?	1	7/7	None
Did you ever have a miscarriage?	1	7/7	None
Did you ever lose a baby at birth?	1	7/7	None
Did you ever lose a child later on?	1	7/7	None
Did you ever have a termination of pregnancy?	0	6/7	Yes versus No
How many months pregnant were you when you went to book at clinic with your youngest child?	0.45	3/7	4 months versus less than 2 months; 5 months versus 4 months; did not book versus 6 months

Which clinic did you attend when you were pregnant with the youngest child?	0.82	6/7	Did not attend versus Eastern Cape
Did you attend a hospital when you were pregnant with the youngest child?	1	7/7	None
If you attended hospital, what was its name?	0.81	6/7	Tygerberg versus Eastern Cape
How many times did you attend clinic when you were pregnant with your youngest child?	0.70	6/7	Did not attend versus Once
In which province was your youngest child born?	1	7/7	None
In which type of health care facility did you deliver the youngest child?	0.59	6/7	Hospital versus Midwife Obstetric Unit
What was name of the hospital or clinic?	0.81	6/7	Gugulethu, KTC versus Tygerberg

### *Validity*

The validity was explored through comparing the study participants' pregnancy history to the Western Cape PHDC database. In total, for 16/35 participants records given in the questionnaire matched completely the information provided by the PHDC; while, 13/35 'Nearly Match' (Table 4). For the 'Nearly Match', the small differences included the following: a) 6 out of 13 Deaf women who reported a pregnancy experience had a record confirmed in the Provincial Database of going into labor but had no confirmation of the actual birth of the child in the PHDC database, for reasons related to failure to register the child. This was considered a) 'Near Match' since the provincial record confirmed an episode of labour which likely ended in a delivery; b) another 'Nearly Match' was a note of a different birth facility attended. Because a participant might have gone into labor at one facility but have been transferred to another facility due to complications of labour, this may not be picked up in the routine database.

All the 6 Deaf women who did not match claimed to have had a child but had no record from the PHDC database to confirm this history. Our focus on linkage was on pregnancy history, therefore a missing record on the PHDC database could reflect that no pregnancy-related encounter with health facilities took place in the province or that participants' pregnancy history was not captured by the PHDC database (e.g. old records).

Overall, table 4 validity results show that, 29 out of 35 (83% agreement) Deaf women had their survey answers matched or nearly matched to the PHDC database.

<b>Table 4- Validity Results</b>			
Validity	Match	Nearly Match	Not Match
	16	13	6
<i>Note: Validity is measured by comparing the instrument answers to the PHDC database. N=35</i>			

## Discussion

This study tested the reliability and validity of answers to a questionnaire to assess pregnancy experience, utilization of maternity services and pregnancy outcomes reported elsewhere among signing Deaf women in Cape Town, South Africa<sup>12</sup>. To our knowledge, this is the first study to use a health system database to assess the validity of Deaf women's recall of their pregnancy experiences in LMICs. The results suggest that the piloted methods provided reasonably reliable and valid data on this hard-to-reach population.

### *Reliability*

Overall, the data appeared highly reliable. Participants provided identical responses in 87% cases. Demographic indicators that showed lower levels of inter-rater reliability included data on income and, to a lesser extent, education. This is similar to findings in other studies that suggests that questions on income might not be a reliable source and sensitive questions might be misreported<sup>22</sup>. Further, because interviews were conducted face to face,



1  
2  
3 and demographic questions were asked at the outset of the interview, participants may have  
4  
5 been especially hesitant to disclose this information. In order to improve reliability for such  
6  
7 questions, survey methodologists suggest asking sensitive information later in the interview  
8  
9 once the participant and interview have built rapport<sup>22</sup>.

10  
11 For the reproductive history, the main outcomes (parity, miscarriages) achieved a high  
12  
13 level of reliability. However, reliability was much lower for timing of first antenatal visit  
14  
15 which requires more complex and sometimes long-term recall. The most recent pregnancy of  
16  
17 some of the women who were re-interviewed may have been several years ago which may  
18  
19 explain their different responses within a short period of time. Recall bias is especially  
20  
21 common when the health condition or event occurred a long time ago, is frequent, or if it  
22  
23 wasn't particularly salient to the individual<sup>23</sup>. It is possible that women who had healthy  
24  
25 pregnancies or already had multiple pregnancies may have more of a challenge remembering  
26  
27 the initiation of antenatal care because it felt like a routine event. Timing of antenatal  
28  
29 initiation is an important outcome as it can have significant impacts on the health of the  
30  
31 mother and infant<sup>18</sup>. Developing methods to aid complex recall, can better improve our  
32  
33 understanding of the maternal health of Deaf women.  
34  
35  
36  
37  
38

### 39 *Validity*

40  
41 The validity, measured as agreement between women's report of their pregnancy  
42  
43 history compared to the health data available from the PHDC, was found to be accurate (83%  
44  
45 sensitivity). Women reported key pregnancy events including termination, miscarriage, and  
46  
47 birth location with high accuracy. These results confirm many studies comparing maternal  
48  
49 recall with medical or government records of pregnancy outcomes<sup>24-26</sup>. On average, mothers  
50  
51 are able to recall characteristics of their pregnancy, birth outcomes, and mode of delivery<sup>13 24</sup>.  
52  
53  
54 One study found that women are able to recall salient pregnancy events including  
55  
56  
57  
58  
59  
60

1  
2  
3 complications and pregnancy outcomes up to 15 years post pregnancy<sup>24</sup>. Future studies  
4  
5 should assess validity of other pregnancy outcomes including birth weight and medical  
6  
7 complications of Deaf women.  
8

9  
10 Most participants who used the public health care system in the Western Cape were  
11  
12 matched. However, the assumption that the WC Datacentre is the gold standard may not be  
13  
14 the case because it is fairly new, having only been implemented in 2013. Use of electronic  
15  
16 medical records in Sub-Saharan Africa is just starting to increase traction<sup>27</sup>. Clinics and  
17  
18 hospitals in the Western Cape started capturing the records electronically at points in time  
19  
20 such that earlier data might have been less consistent. The six Deaf women that had their  
21  
22 pregnancy records ‘No Match’ said that they delivered in WC but the records could not be  
23  
24 found in the PHDC database. This linkage failure could be due to several issues:  
25  
26 discrepancies in the names supplied during the research study and those used in health  
27  
28 facilities, WC clinics and hospitals failed to enter patient information in PHDC database, or  
29  
30 old records may be missing (for instance some women gave birth in 1988 and 1996). Further  
31  
32 investigation of the quality control measures employed by the PHDC database are necessary.  
33  
34 Nevertheless, the results suggest that reports from deaf women provide reliable and valid data  
35  
36 on which to describe their pregnancy history.  
37  
38  
39  
40

#### 41 *Implications*

42  
43 Findings from this study have several implications for research with Deaf populations.  
44  
45 First, the high level of validity self-reported outcomes is particularly promising given the  
46  
47 challenges of obtaining medical records in LMIC<sup>27</sup>. The Western Cape of South Africa has  
48  
49 more resources and a more robust healthcare system as compared to other regions of South  
50  
51 Africa<sup>14</sup>. In more rural areas, it would be nearly impossible to find a database of health  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 information such as the Western Cape PHDC database. Establishing the validity of self-  
4  
5 report with other health outcomes with Deaf populations is an important next step.  
6

7         Second, measures and methods need to be developed to improve the complex recall of  
8  
9 pregnancy related events. Some methods to improve recall include memory aids or adjusting  
10  
11 the recall period<sup>23</sup>. Creating tools that are culturally relevant and specific to Deaf populations  
12  
13 is necessary.  
14

### 15 16 17 18 **Limitations**

19         The following limitations should be considered in the interpretation of the results.  
20  
21 First, there were many pregnancy related markers which were not explored in the analysis,  
22  
23 therefore we cannot generalise the results to all pregnancy history measures. Second, inter-  
24  
25 rater reliability was measured with a small sample over a short period of time (10-30  
26  
27 minutes); thus, we cannot comment if participants' responses would have remained consistent  
28  
29 if there would have been a longer time gap between the test and retest interviews.  
30  
31  
32  
33  
34

### 35 36 37 **Conclusion**

38         Findings from this study indicate that the protocol used in Gichane, et al.<sup>12</sup> yielded  
39  
40 valid and reliable results. This suggests that it is possible to develop methodologies that will  
41  
42 produce reliable and valid data for Deaf women using simple tools that are suited to this  
43  
44 population in question. Extending this approach to other populations will require further  
45  
46 research, but it is important that methods to access hard-to-reach populations are developed  
47  
48 so that health system responsiveness to marginal populations can be based on robust  
49  
50 evidence.  
51  
52  
53

### 54 55 56 57 **References**

1. World Health Organization. Maternal mortality fact sheet. *World Health Organization, Geneva* 2010
2. World Health Organization. World report on disability: World Health Organization, 2011.
3. Mitra M, Long-Bellil LM, Iezzoni LI, et al. Pregnancy among women with physical disabilities: Unmet needs and recommendations on navigating pregnancy. *Disability and health journal* 2016;9(3):457-63.
4. Redshaw M, Malouf R, Gao H, et al. Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC pregnancy and childbirth* 2013;13(1):174.
5. Signore C, Spong CY, Krotoski D, et al. Pregnancy in women with physical disabilities. *Obstetrics & Gynecology* 2011;117(4):935-47.
6. Shaghghi A, Bhopal RS, Sheikh A. Approaches to recruiting 'hard-to-reach' populations into research: a review of the literature. *Health promotion perspectives* 2011;1(2):86.
7. Faugier J, Sargeant M. Sampling hard to reach populations. *Journal of advanced nursing* 1997;26(4):790-97.
8. McKee M, Schlehofer D, Thew D. Ethical issues in conducting research with deaf populations. *American journal of public health* 2013;103(12):2174-78.
9. Quigley M, Hockley C, Davidson L. Agreement between hospital records and maternal recall of mode of delivery: evidence from 12 391 deliveries in the UK Millennium Cohort Study. *BJOG: An International Journal of Obstetrics & Gynaecology* 2007;114(2):195-200.
10. Poulsen G, Kurinczuk JJ, Wolke D, et al. Accurate reporting of expected delivery date by mothers 9 months after birth. *Journal of clinical epidemiology* 2011;64(12):1444-50.
11. Bat-Erdene U, Metcalfe A, McDonald SW, et al. Validation of Canadian mothers' recall of events in labour and delivery with electronic health records. *BMC pregnancy and childbirth* 2013;13(1):S3.
12. Gichane MW, Heap M, Fontes M, et al. "They must understand we are people": Pregnancy and maternity service use among signing Deaf women in Cape Town. *Disability and Health Journal* 2017;10(3):434-39.
13. Bello B, Kielkowski D, Heederik D, et al. Time-to-pregnancy and pregnancy outcomes in a South African population. *BMC public health* 2010;10(1):565.
14. Day C, Gray A. South African Health Review. Durban: Health Systems Trust, 2016.
15. Muhwava LS, Morojele N, London L. Psychosocial factors associated with early initiation and frequency of antenatal care (ANC) visits in a rural and urban setting in South Africa: a cross-sectional survey. *BMC pregnancy and childbirth* 2016;16(1):18.
16. Solarin I, Black V. "They told me to come back": women's antenatal care booking experience in inner-city Johannesburg. *Maternal and child health journal* 2013;17(2):359-67.
17. Myer L, Harrison A. Why do women seek antenatal care late? Perspectives from rural South Africa. *Journal of midwifery & women's health* 2003;48(4):268-72.
18. National Department of Health. Saving Mothers 2011-2013: Sixth report on confidential enquiries into maternal deaths in South Africa, Short Report. Pretoria: National Department of Health, 2014.
19. Heale R, Twycross A. Validity and reliability in quantitative studies. *Evidence-based nursing* 2015:ebnurs-2015-102129.
20. Cohen J. Weighted kappa: Nominal scale agreement provision for scaled disagreement or partial credit. *Psychological bulletin* 1968;70(4):213.
21. McHugh ML. Interrater reliability: the kappa statistic. *Biochemia medica* 2012;22(3):276-82.
22. Tourangeau R, Yan T. Sensitive questions in surveys. *Psychological bulletin* 2007;133(5):859.
23. Althubaiti A. Information bias in health research: definition, pitfalls, and adjustment methods. *Journal of multidisciplinary healthcare* 2016;9:211.
24. Yawn BP, Suman VJ, Jacobsen SJ. Maternal recall of distant pregnancy events. *Journal of clinical epidemiology* 1998;51(5):399-405.

- 1  
2  
3 25. Githens PB, Glass CA, Sloan FA, et al. Maternal recall and medical records: an examination of  
4 events during pregnancy, childbirth, and early infancy. *Birth* 1993;20(3):136-41.  
5 26. Liu J, Tuvblad C, Li L, et al. Medical record validation of maternal recall of pregnancy and birth  
6 events from a twin cohort. *Twin Research and Human Genetics* 2013;16(4):845-60.  
7 27. Akanbi MO, Ocheke AN, Agaba PA, et al. Use of electronic health records in sub-Saharan Africa:  
8 progress and challenges. *Journal of medicine in the tropics* 2012;14(1):1.  
9

### Contributorship:

10  
11  
12  
13  
14  
15 MF, MH, MG and LL participated in the design of the study, the interpretation of the  
16 findings, commented on the manuscript and approved the final manuscript. MH and MG led  
17 the field work. MF conducted the statistical analysis and composed the initial draft.  
18  
19

### Competing interest:

20  
21  
22 The authors declare no conflicts of interest.  
23  
24

### Acknowledgements:

25  
26 We would like to thank Nesbert Zinyakatira, Western Cape Department of Health, for  
27 suppling expert research assistance on the health data from the Provincial Health Data Centre  
28 (PHDC) during the preparation of this manuscript. The research team would like to thank the  
29 participants who generously shared their time and experience for the purposes of this project.  
30 We would like to acknowledge the contributions of the following University of Cape Town  
31 interpreters, research assistants, and students who assisted with data collection: Nombulelo  
32 Cekwana, Lizeka Madlolo, Thumeka Manyashe, Banele Mhlongo, Vuma Mthembu, Rudolph  
33 Priestly, Dumisa Seteni, Sheila Thamahane, and Nonkululeko Zwane.  
34  
35  
36

### Funding:

37  
38 This work was supported in part by grant T37 MD001452: Mount Sinai International  
39 Exchange Program for Minority Students from the National Center on Minority Health and  
40 Health Disparities of the National Institutes of Health, Dr. Luz Claudio, Principal  
41 Investigator, and by funding from the South African National Research Foundation. Funders  
42 had no input on the design and conduct of the study; collection, management, analysis, and  
43 interpretation of the data; and preparation, review, or approval of the manuscript.  
44  
45  
46

### Ethical Approval:

47  
48 The study was approved by the Human Research Ethics Committee of the Faculty of Health  
49 Sciences at the University of Cape Town (HREC reference number: 278\_2016).  
50  
51

### Data Sharing:

52  
53 The data that support the findings of this study are available on request from the  
54 corresponding author, MF. Potential data users must be approved by MH and will be required  
55  
56  
57  
58  
59  
60

1  
2  
3 to agree to the Terms and Conditions of a Data Access Agreement (DAA), which aims to  
4 protect the privacy and interests of the research participants.  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

**STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies***

Section/Topic	Item #	Recommendation	Reported on page #
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1-2
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	4
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	4
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	4
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	
Bias	9	Describe any efforts to address potential sources of bias	15
Study size	10	Explain how the study size was arrived at	8-9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8-9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	4-8
		(b) Describe any methods used to examine subgroups and interactions	N/A
		(c) Explain how missing data were addressed	8
		(d) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(e) Describe any sensitivity analyses	N/A
<b>Results</b>			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	6-8
		(b) Give reasons for non-participation at each stage	6-8
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	9
		(b) Indicate number of participants with missing data for each variable of interest	8
Outcome data	15*	Report numbers of outcome events or summary measures	9-12
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	N/A
		(b) Report category boundaries when continuous variables were categorized	N/A
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	12-15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	15
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	12-15
Generalisability	21	Discuss the generalisability (external validity) of the study results	12-15
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	17

\*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).