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Likelihood Of Achieving Who Leprosy Goals: An Expert Survey

Alex Rittel
Yale University, alex.rittel@yale.edu

LIKELIHOOD OF ACHIEVING WHO LEPROSY GOALS: AN EXPERT SURVEY

Alex Rittel

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Advisors: Alison Galvani & Martial Ndeffo-Mbah

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ABSTRACT

Much progress has been made in the global fight against leprosy, as evidenced by dramatic declines in prevalence rates in recent years. However, leprosy has proven elusive. New case detection rates have remained fairly stable, particularly in countries with remaining pockets of high endemicity such as India, Brazil, and Indonesia. In 2012, the World Health Organization spearheaded the London Declaration, which in part aimed for the goal of interruption of transmission of global leprosy by 2020. Aggregating the opinions of experts can supplement existing data to help determine the feasibility of reaching the WHO goals. To obtain the opinions of experts, a cross-sectional survey was sent requesting experts to give probabilistic estimates on the likelihood of achieving leprosy control targets. The survey results showed that most experts do not think the 2020 leprosy control targets will be met. The majority of experts indicated enhanced case finding as the most important measure to undertake to improve leprosy control goal success. The collection of expert opinions highlights the need for continued attention on leprosy from a public health standpoint.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

Introduction

In 2012, the World Health Organization (WHO) spearheaded the London Declaration, which in part aimed for the interruption of transmission and global elimination of leprosy by 2020 [1]. The goal of leprosy elimination is not new; indeed, since 1991, leprosy has routinely been the target of elimination campaigns [2].

Leprosy, or Hansen's disease, is a chronic infectious disease caused by *Mycobacterium leprae* [3]. Among communicable diseases, leprosy is a leading cause of permanent physical disability [4]. In 1982, the WHO introduced a multidrug therapy (MDT) program for leprosy [5]. While the introduction of MDT and active leprosy control campaigns markedly reduced global prevalence, leprosy remained endemic in a few localized regions [6]

To address the lingering issues preventing elimination, the WHO has routinely revised their leprosy control goals in a series of declarations summarized in Table 1 [7-11]. The latest targets, as stated in the 2012 London Declaration, are that "Vigorous case-finding and treatment would lead to global interruption of [leprosy] transmission by 2020, and reduce grade 2 disabilities in newly detected cases to below 1/million at global level" [1].

Table 1. History of WHO leprosy goals/declarations

WHO Goals/Declarations			
Year	**Report**	**Goal**	**Key Indicator**
1991	44th World Health Assembly (WHA44.9)	"…to attain the global elimination of leprosy as a public health problem by the year 2000"	Prevalence. Defined elimination as attaining a level of prevalence below one case per 10,000 population at the global level.
2000	The WHO Strategic Plan for Leprosy Elimination 2000-2005	"Elimination of leprosy as a public health problem in all countries by the year 2005"	Prevalence. Defined elimination as attaining a level of prevalence below one case per 10,000 population at the national level.
2005	The Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006-2010	"The goal of the Global Strategy is to reduce further the burden of leprosy and to provide access to quality leprosy control services for all affected communities, following the principles of equity and justice."	Emphasis on various indicators of progress such as new case detection rate, treatment completion/cure rate, and continued use of prevalence for those countries yet to reach the elimination target.
2009	Enhanced Global Strategy for Further Reducing the Disease Burden Due to Leprosy 2011-2015	"The goal of the Enhanced Global Strategy is to further reduce the disease burden due to leprosy and sustain the provision of high-quality leprosy services for all affected communities, ensuring that the principles of equity and social justice are followed."	A target of 35% reduction in G2D in new cases per million population from 2011 to 2015 has been agreed and can be used to evaluate progress towards the longer-term goal of reducing G2D in new cases to less than 1 in 1 million at the global level by 2020.
2012	London Declaration	"Vigorous case-finding and treatment would lead to global interruption of transmission by 2020, and reduce grade 2 disabilities in newly detected cases to below 1/million population at global level."	Reduction of grade-2 disabilities in newly detected cases to below 1 per million population at global level by 2020.
2013	Bangkok Declaration	"…declare that it is time for the leprosy-endemic countries, as well as their international and national partners, to reaffirm their commitments and reinforce their participation towards addressing leprosy in order to ensure a leprosy-free world at the earliest…"	Achieve the global target of reducing the occurrence of new cases with visible deformity (grade 2 disability) to less than one case per million population by the year 2020.

Whether or not these goals are attainable remains to be seen [12]. In 2014, a total of 213,899 new leprosy cases were detected globally, with India, Brazil, and Indonesia accounting for almost 75% of the new cases [11]. The relative stabilization of the new case detection rate over the past 10 years indicates ongoing transmission [13].

The stabilization of new case detection rates has some people questioning whether these objectives will be achieved [14]. Many experts argue that the combination of epidemiological and biological evidence suggest the WHO's target may be too ambitious to be achieved given the current state of control [2,15,16].

To our knowledge, no previous research has been conducted on exploring these dissonant viewpoints on the feasibility of meeting the 2020 leprosy control targets. In light of this gap in the research, the objective was to survey leprosy and disease elimination experts (1) to elicit whether they believe the 2020 goals will be met and (2) to determine what they believe are the most important measures to implement to better achieve leprosy elimination.

Methods

In February 2016, a cross-sectional survey created in Qualtrics was sent to professionals with expertise in leprosy, neglected tropical diseases (NTDs), and forecasting. In order to survey a broad cross-section of leprosy experts, PubMed was searched for articles published in 1995 and later containing the terms *leprosy, leprae, or Hansen's disease* in the title or abstract. Emails of corresponding authors were extracted, with duplicates removed. Similarly, NTD experts were targeted by extracting emails from all articles published in PLOS NTD that did not contain the leprosy keywords in the title or abstract. Duplicate emails within the NTD email set were removed and any emails found in both the NTD and leprosy extractions were removed from the NTD email set. Forecasting experts were targeted by extracting emails from PubMed articles published in 1995 and later that did not contain the leprosy keywords or *neglected tropical disease* in the title or abstract and contained one of the following combinations:

1. *forecast + (influenza or HIV or malaria tuberculosis or measles or ebola)*
2. *predict + incidence + (influenza or HIV or malaria tuberculosis or measles or ebola)* and does not contain *predictor*
3. *predict + prevalence + (influenza or HIV or malaria tuberculosis or measles or ebola)* and does not contain *predictor*

Duplicate emails within the forecasting expert email set were removed and any emails found in the both the forecasting extraction and either the leprosy or NTD extractions were removed from the forecasting email set. All emails belonging to individuals affiliated with leprosy consortium groups at the Proctor Foundation at the University of California, San Francisco (UCSF) and Yale University were removed.

The 11-item survey consisted of multiple-choice questions, slider bars, and forecasting exercises designed to assess expertise and elicit opinions on the probability of meeting the 2020 leprosy control goals (all analyzed questions included in Tables 2-4). For the purpose of this publication, the forecasting exercises at the end of the survey were not analyzed. Leprosy knowledge was determined through response to the expert validation question: '*Which type of leprosy, tuberculoid or lepromatous, is more likely to correspond to paucibacillary leprosy?*'. A free text comment section was included at the end of the survey to allow participants the option of providing additional opinions on the subject of leprosy control. The questions were tested internally among a group of infectious disease researchers at the University of California, San Francisco (UCSF) and Yale University, and this group's comments on the question format and phrasing were integrated into the final survey.

After the UCSF Institutional Review Board granted the study's exemption of approval, the survey was disseminated by email. The email message contained a link to the survey and indicated the nature of the survey, that participation was voluntary and that responses would be anonymous. The survey links for the three groups were varied to allow for between group analyses. The survey was sent to the entire group of potential participants and remained open for 12 days. A follow-up reminder was sent on day 9. Recipient responses indicating change of email address were tracked and survey links were sent to the provided email addresses. The survey was programmed to ensure participants could complete the study only once by utilizing the "Prevent Ballot Box Stuffing" option within the Survey Protection section of Qualtrics.

The response rate was calculated with the number of completed surveys as the numerator and the denominator as the total number of surveys sent minus the emails that bounced back due to invalid email addresses. Completed surveys were defined as a participant having completed either the 2020 goal probability slider questions or the multiple choice question eliciting the most important policy to implement to meet the 2020 goals. Participants were able to opt out of responding to any question, and all responses from completed surveys were included in the analysis. Missing data were excluded from analyses.

Results were summarized with descriptive univariate analyses using percentages for categorical data. Bivariate analyses were conducted using ANOVA (Analysis of Variance) tests to compare responses by expertise group and to also compare responses by subgroups within the leprosy expert group. Free text comments were reviewed by researchers and divided into overarching themes based on topic and frequency. All analyses were conducted with SPSS software, version 22 (SPSS Inc, Chicago, IL) or the R program (R Foundation for Statistical Computing, Vienna, Austria).

Results

The email extraction identified 4,191 unique email addresses. 291 participants responded to the survey and 238 did so with complete data. After removing 1,170 bounce-back dead emails and incorporating 11 new emails sent to updated addresses acquired via automatic email response, the response rate was calculated at 9.6%. Respondents spent an average of 19 minutes on the survey. 44 participants included free text in the optional comment section at the conclusion of the survey.

Table 2 displays the characteristics of the survey respondents by group expertise. The majority of participants in each group had earned either an MD (leprosy=46.2%, NTD=34.4%, forecasting=42.1%) or PhD (leprosy=58.6%, NTD=88.0%, forecasting=73.7%). The majority of leprosy experts worked in lab research (35.2%) or as clinicians/medical doctors (36.8%), whereas the majority of NTD experts and forecasting experts worked in lab research (NTD=31.0, forecasting=21.1%) or as epidemiologists (NTD=34.5%, forecasting=47.4%). More leprosy experts (58.9%) endorsed "Brazil" or "India" as their country of expertise than did NTD experts (40.0%) or forecasting experts (28.6%). The vast majority of leprosy experts correctly answered the leprosy expertise validation question (89.8%), while fewer NTD experts (51.6%) and forecasting experts (42.1%) correctly answered the question.

A summary of responses to the question addressing the most important policy to better achieve the leprosy control goals is shown in Table 3. In all groups, over half of group respondents indicated that enhanced case finding was the most important measure to implement (leprosy=55.4%, NTD=65.6%, forecasting=66.7%). Among the 11 participants that responded "Other", free text comments endorsed expanding laboratory-based surveillance and improved diagnostic tools (27.3%), more integrated service delivery systems (18.2%), determining the precise mode of transmission and reservoir (18.2%), increasing healthcare access in endemic communities (18.2%), vaccine development research (9.1%), and a lack of sufficient knowledge to comment (9.1%).

Table 4 reveals the mean probabilities for achieving each of the 2020 leprosy control goals of global interruption of transmission and reduction of grade-2 disabilities. The mean probability of achieving the global interruption of transmission among the leprosy experts was 34.8%, which was not significantly different from the NTD experts (36.0%) and forecasting experts (35.1%) (P=0.928). There was a significant difference among group means for the probability of achieving the reduction of grade-2 disability goal (P=0.026), with the leprosy experts (40.7%) indicating this goal would be less likely to be achieved than the NTD experts (52.4%) and forecasting experts (52.4%). The probability distributions of the leprosy experts' responses for both of the goals are shown in Figure 1.

Table 2: Characteristics of participants (N = 291)[1].

Variable	Group					
	Leprosy Experts		NTD Experts		Forecasting Experts	
	N	%	N	%	N	%
Total emails sent	1943		744		1504	
Responses	225	(100.0)	38	(100.0)	28	(100.0)
Responses with complete data[2]	187	(83.1)	32	(84.2)	19	(67.9)
Country	146	(100.0)	26	(100.0)	15	(100.0)
Brazil	33	(22.6)	3	(11.5)	0	(0.0)
India	23	(15.8)	0	(0.0)	0	(0.0)
Indonesia	2	(1.4)	0	(0.0)	0	(0.0)
Other	88	(60.3)	23	(88.5)	15	(100.0)
Highest degree obtained[3]	186	(100.0)	32	(100.0)	19	(100.0)
Bachelor's degree (or equivalent)	52	(28.0)	12	(37.5)	8	(42.1)
Master's in Public Health (or equivalent)	27	(14.5)	6	(18.8)	3	(15.8)
Other Master's degree (or equivalent)	50	(26.9)	14	(43.8)	10	(52.6)
MD	86	(46.2)	11	(34.4)	8	(42.1)
PhD	109	(58.6)	28	(88.0)	14	(73.7)
Other	23	(12.4)	3	(9.4)	5	(26.3)
Years of experience	187	(100.0)	32	(100.0)	18	(100.0)
0-5	42	(22.5)	9	(28.1)	6	(33.3)
6-10	34	(18.2)	9	(28.1)	3	(16.7)
11-15	35	(18.7)	2	(6.3)	2	(11.1)
16-30	39	(20.9)	6	(18.8)	7	(38.9)
over 30	37	(19.8)	6	(18.8)	0	(0.0)
Area of work	182	(100.0)	29	(100.0)	19	(100.0)
Lab Research	64	(35.2)	9	(31.0)	4	(21.1)
Clinician/Medical Doctor	67	(36.8)	2	(6.9)	1	(5.3)
Epidemiologist	26	(14.3)	1	(34.5)	9	(47.4)
Public health program member	7	(3.8)	1	(3.4)	1	(5.3)
Activist or advocate	3	(1.6)	0	(0.0)	0	(0.0)
Other (but none of the above)	15	(8.2)	4	(13.8)	3	(15.8)
None "I really know nothing about leprosy"	0	(0.0)	3	(10.3)	1	(5.3)
Country of Leprosy Expertise	180	(100.0)	25	(100.0)	14	(100.0)
Brazil	45	(25.0)	5	(20.0)	1	(7.1)
India	61	(38.9)	5	(20.0)	3	(21.4)
Indonesia	2	(1.1)	0	(0.0)	0	(0.0)
Other	72	(40.0)	1	(60.0)	10	(71.4)
Correctly Answered Expertise Validation	187	(100.0)	31	(100.0)	19	(100.0)
Yes	168	(89.8)	16	(51.6)	8	(42.1)
No	5	(2.7)	6	(19.4)	1	(5.3)
I'm not sure	14	(7.5)	9	(29.0)	10	(52.6)

[1]Note that participants were allowed to opt out of responding to any question, so the total number of responses varies depending on the particular question
[2]Demographic characteristics and analysis were restricted to those participants that provided complete data
[3]Participants were allowed multiple responses. "Other" category was open-ended and included responses such as DVM.

Table 3: Most important policy comparisons by group (N = 233).

Variable	Group					
	Leprosy Experts		NTD Experts		Forecasting Experts	
	N	%	N	%	N	%
Most important measure to better achieve goals	186	(100.0)	29	(100.0)	18	(100.0)
Efforts to reduce stigma	10	(5.4)	1	(3.4)	2	(11.1)
Enhanced case finding	103	(55.4)	19	(65.5)	12	(66.7)
Point of care DNA detection probe	11	(5.9)	1	(3.4)	2	(11.1)
Specialty leprosy program	28	(15.1)	1	(3.4)	1	(5.6)
Treatment of contacts	15	(8.1)	2	(6.9)	1	(5.6)
"Nothing can be done; leprosy can't be eliminated as a public health problem using currently available tools"	9	(4.8)	1	(3.4)	0	(0.0)
"Nothing can be done; leprosy will disappear, but this will take decades due to nature of disease"	3	(1.6)	0	(0.0)	0	(0.0)
Other[1]	7	(3.8)	4	(88.5)	0	(0.0)

[1]Participants only allowed one response. "Other" category was open-ended.

Table 4: Goal likelihood comparisons by group (N = 222).

Variable	Group			P value[1]
	Leprosy Experts (N=174)	NTD Experts (N=31)	Forecasting Experts (N=17)	
Global interruption of transmission				
Mean	34.8%	36.0%	35.1%	0.928
SD	25.7	27.7	24.8	
Reduction of grade-2 disabilities				
Mean	40.7%	52.4%	52.4%	0.026
SD	26.9	26.3	20.6	

[1] <0.05 considered significant.

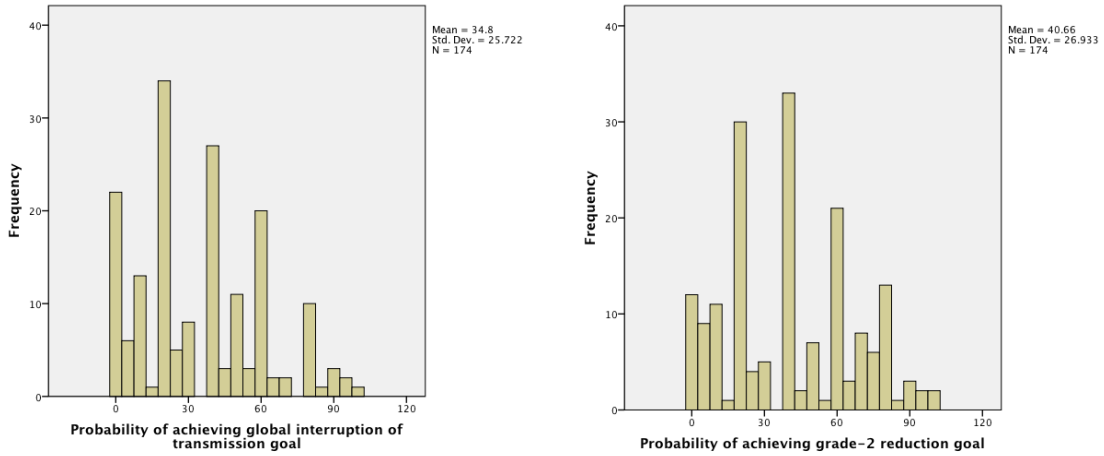

Fig. 1 Global interruption of transmission and reduction of grade-2 disabilities goals probability distributions for leprosy experts

Analysis on goal likelihoods and the most important policy restricted to just the leprosy experts is shown in Tables 5 and 6. Overall, goal likelihoods for leprosy experts did not vary significantly by demographic characteristics within the leprosy expert group, though a few differences were noted (Table 5). Though not significant, participants with expertise on leprosy in Brazil indicated lower likelihoods of achieving global interruption of transmission (26.1%) than did participants with expertise on leprosy in India (39.9%) (P=0.084).

Free text comments were provided by 44 participants at the conclusion of the survey, 39 of which came from the leprosy experts. Of the 187 leprosy experts to provide complete data, 20.9% included free text comments. Common themes accompanied by specific examples are shown in Table 7. Many of the comments focused on the forecasting questions and the data comprising these questions. Six participants mentioned forecasting new case detection rates is difficult because the data is dependent on case finding that can be highly irregular (13.6%). Some comments expressed skepticism regarding the data itself, with 9 participants mentioning case rates are too low as they are not capturing the large numbers of undiagnosed cases (20.5%) and 8 mentioning the influence factors such as political pressure can have on underreporting true leprosy incidence (18.2%).

Aside from the forecasting comments, 12 comments further elucidated specific methods to reduce leprosy (27.3%), 7 of which focused on the importance of active case finding (15.9%). Comments also centered around governmental issues, with 8 participants commenting that countries need to make leprosy a priority and the need for more funding (18.2%) and 5 comments revealing that political factors such as declarations of elimination have in fact hindered leprosy control (11.4%). Six participants were concerned of a loss of clinical expertise and ability of clinicians to accurately diagnose (13.6%). In addition, 3 participants cited incidence of childhood leprosy as evidence of ongoing transmission (6.8%) and 2 comments revealed concern about rifampicin resistance and relapse (4.5%). Finally, 2 comments expressed displeasure at the survey questions and stated that the present survey was of no value (4.5%)

Table 5: Leprosy experts' goal likelihood comparisons (N=174)[1]

Variable	Goal					
	Global interruption of transmission			Reduction of grade-2 disabilities		
	Mean	SD	P value	Mean	SD	P Value
Area of work			0.846			0.545
Lab Research	37.1%	26.5		40.6%	28.1	
Clinician/Medical Doctor	35.6%	25.3		44.0%	25.0	
Epidemiologist	29.9%	28.2		36.7%	30.5	
Public health program member	25.1%	21.4		23.7%	21.0	
Activist or advocate	41.3%	4.2		54.0%	24.2	
Other (but none of the above)	34.9%	25.6		38.7%	27.3	
Country of Leprosy Expertise			0.058			0.113
Brazil	26.1%	22.3		32.2%	24.0	
India	39.9%	27.0		43.7%	27.6	
Indonesia	57.0%	53.7		65.0%	35.4	
Other	36.2%	25.7		43.4%	27.9	
Highest degree obtained[2]			0.207			0.441
Bachelor's degree (or equivalent)	25.7%	22.5		31.1%	24.6	
Master's in Public Health (or equivalent)	28.6%	24.1		39.0%	26.5	
Other Master's degree (or equivalent)	31.5%	26.3		37.9%	26.6	
MD	31.9%	23.9		40.9%	26.8	
PhD	31.4%	25.0		37.9%	27.3	
Other	42.6%	28.0		42.7%	26.6	
Years of experience			0.279			0.350
0-5	35.5%	27.2		39.1%	28.1	
6-10	35.4%	20.8		45.5%	22.5	
11-15	37.8%	29.1		45.8%	26.0	
16-30	26.5%	21.3		34.1%	26.9	
over 30	34.8%	25.7		39.9%	27.0	

[1]Note that participants were allowed to opt out of responding to any question, so the total number of responses varies
[2]Participants were allowed multiple responses. "Other" category was open-ended and included responses such as DVM.

Table 6: Leprosy experts' most important policy comparisons (N=186)[1]

Variable	Most important measure to better achieve goals																				Total
	Efforts to reduce stigma		Enhanced case finding		Point of care DNA detection probe		Specialty leprosy program		Treatment of contacts		"Nothing can be done; leprosy can't be eliminated as a public health problem using currently available tools"		"Nothing can be done; leprosy will disappear, but this will take decades due to nature of disease"		Other[2]						
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	N	%					N
Area of work																					
Lab Research	1	(1.6)	31	(48.4)	8	(12.5)	12	(18.8)	6	(9.4)	2	(3.1)	0	(0.0)	4	(6.3)					64
Clinician/Medical Doctor	6	(9.0)	36	(53.7)	3	(4.5)	12	(17.9)	3	(4.5)	3	(4.5)	2	(3.0)	2	(3.0)					67
Epidemiologist	3	(11.5)	16	(61.5)	0	(0.0)	3	(11.5)	2	(7.7)	2	(7.7)	0	(0.0)	0	(0.0)					26
Public health program member	0	(0.0)	4	(57.1)	0	(0.0)	1	(14.3)	1	(14.3)	0	(0.0)	1	(14.3)	0	(0.0)					7
Activist or advocate	0	(0.0)	3	(100.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)					3
Other (but none of the above)	0	(0.0)	9	(60.0)	0	(0.0)	0	(0.0)	2	(13.3)	2	(13.3)	0	(0.0)	2	(13.3)					15
Country of Leprosy Expertise																					
Brazil	0	(0.0)	23	(51.1)	2	(4.4)	7	(15.6)	8	(17.8)	3	(6.7)	1	(2.2)	1	(2.2)					45
India	7	(11.5)	31	(50.8)	4	(6.6)	9	(14.8)	2	(3.3)	3	(4.9)	1	(1.6)	4	(6.6)					61
Indonesia	1	(0.5)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	1	(0.5)					2
Other	2	(2.8)	44	(61.1)	5	(6.9)	10	(13.9)	5	(6.9)	3	(4.2)	1	(1.4)	2	(2.8)					72
Highest degree obtained[3]																					
Bachelor's degree (or equivalent)	2	(3.9)	23	(45.1)	3	(5.9)	6	(11.8)	8	(15.7)	2	(3.9)	3	(5.9)	3	(5.9)					51
Master's in Public Health (or equivalent)	3	(11.1)	14	(51.9)	1	(3.7)	4	(14.8)	4	(14.8)	0	(0.0)	1	(3.7)	0	(0.0)					27
Other Master's degree (or equivalent)	3	(6.0)	24	(48.0)	3	(6.0)	6	(12.0)	6	(12.0)	2	(4.0)	2	(4.0)	3	(6.0)					50
MD	5	(5.8)	55	(64.0)	2	(2.3)	13	(15.1)	2	(2.3)	4	(4.7)	2	(2.3)	2	(2.3)					86
PhD	3	(2.8)	55	(50.5)	8	(7.3)	21	(19.3)	10	(9.2)	14	(2.8)	11	(10.1)	5	(4.6)					109
Other	0	(0.0)	11	(47.8)	3	(13.0)	3	(13.0)	1	(4.3)	1	(4.3)	1	(4.3)	2	(8.7)					23
Years of experience																					
0-5	2	(4.8)	22	(52.4)	3	(7.1)	6	(14.3)	5	(11.9)	3	(7.1)	1	(2.4)	0	(0.0)					42
6-10	2	(5.9)	21	(61.8)	1	(2.9)	7	(20.6)	0	(0.0)	2	(5.9)	0	(0.0)	1	(2.9)					34
11-15	1	(2.9)	21	(60.0)	3	(8.6)	3	(8.6)	3	(8.6)	1	(2.9)	1	(2.9)	2	(5.7)					35
16-30	2	(5.1)	20	(51.3)	2	(5.1)	8	(20.5)	4	(10.3)	1	(2.6)	0	(0.0)	2	(5.1)					39
over 30	3	(8.1)	19	(51.4)	2	(5.4)	4	(10.8)	3	(8.1)	2	(5.4)	1	(2.7)	3	(8.1)					37

[1]Note that participants were allowed to opt out of responding to any question, so the total number of responses varies

[2]Participants only allowed one response. "Other" category was open-ended and included responses such as improved diagnostic tools.

[3]Participants were allowed multiple responses. "Other" category was open-ended and included responses such as DVM.

Table 7: Thematic analysis and examples of free text comment entries (N = 44).

Theme	Example
Methods to further reduce leprosy	*"Regarding required interventions for achieving the NTD 2020 targets for leprosy it should be a combination of active case-finding and preventive MDT for contacts of MB Leprosy cases"*
Importance of active case finding	*"Bottom line, more aggressive case finding and possibly chemoprophylaxis treatment of household contacts of index cases will be necessary to really bring the worldwide numbers down"*
Skepticism regarding leprosy statistics	
Due to undetected/undiagnosed cases	*"The official data that we see is based on voluntary reporting. There could be many more undetected, untreated cases in the community which will add to reservoir responsible for the transmission"*
Due to political factors	*"The statistics obtained by the WHO is only a very broad estimate and country policies, pressure to reduce leprosy or at least its reported statistics and the type of surveys greatly influence this number"*
Need for additional funding / prioritization of leprosy	*"Currently, we have to bring the message that LEPROSY IS STILL AMONG US for endemic countries"*
Political impact/interference	*"The concept of elimination of leprosy… has been misinterpreted… The monitoring programs have been weakened by lack of budget. All because leprosy has been eliminated"*
Concern of a lack of clinical expertise	*"I am also concerned about the loss of expertise on microbiological confirmation"*

Discussion

Much controversy exists over the concept and feasibility of leprosy elimination. Indeed, unquestionable progress has been made in recent decades as substantially fewer cases are reported today than in years past [11]. However, declarations of elimination have been followed by epidemiological trends that suggest sustained transmission and a relative stabilization of new case detection rates [3,17]. For this reason, some experts have expressed the sentiment that the WHO would once again need to push back the timeline on leprosy control goals as the stated 2020 goals are unlikely to be reached [2,3,15-18].

In our survey, most respondents believed that the 2020 leprosy control targets as laid out in the London Declaration were unlikely to be achieved. In total, leprosy experts gave the goal of global interruption of transmission a 34.8% probability of success and the reduction of grade-2 disabilities goal a 40.7% probability of success. The NTD and forecasting experts did not differ significantly from the leprosy experts in their probabilities, though they tended to be more optimistic about the likelihood of achieving the goals than leprosy experts.

Perhaps more illuminating than the quantitative probabilities recorded in the survey were the opinions provided in the end-of-survey free text comment section. Numerous participants commented questioning the validity of leprosy statistics regarding new case counts. In general, commenters expressed the sentiment that leprosy case counts are missing what amounts to a large number of undiagnosed cases and, therefore, elimination is less achievable than the data might reveal. This sentiment mirrored previous studies that have found that actual leprosy case load may be many folds higher than reported in certain areas [19,20]. Additionally, some participants cited stabilized or increasing rates of child diagnoses and grade-2

disability cases as explanations for why the goals may not be realized. Previous research has shown rates of new cases in children and patients with grade-2 disabilities have not changed significantly over the years, indicating ongoing transmission and inadequacies in surveillance [1,17,21].

Commenters also remarked on the inaccuracy of leprosy case data when accounting for irregularities in case detection effort. Some researchers have argued that the substantial reduction in global reporting of new leprosy cases witnessed between the 1990s and 2000s may be the result of under-detection or changes in reporting [16]. When less effort is spent on active case finding, new case detection rates can naturally fall [22]. With heightened case finding, evidence exists that shows, given the spatial clustering and heterogeneity of leprosy, that in some areas leprosy cases might actually be *increasing* [18].

The importance of case detection in determining the true burden of leprosy incidence was further displayed in the disease elimination experts' responses to the question eliciting what they believed was the most important policy to better achieve the 2020 leprosy goals. In all three expert groups, over half of the participants expressed that enhanced case finding was the most important policy to implement to better achieve leprosy control goals. This majority consensus recommendation follows previous research indicating that reduction of transmission through effective case finding should be a goal [18,21].

Enhanced case finding requires a sustained commitment. In 2013, the 17 nations with the highest concentrations of leprosy cases signed the Bangkok Declaration, reaffirming these countries' commitment to anti-leprosy and supporting the need for continued attention from a public health standpoint [11]. Many of the survey comments focused on the need to prioritize leprosy as a public health issue to achieve the 2020 goals.

Expert judgement, while not a substitute for scientific analyses, can still provide useful insights, particularly when scientific research is incomplete or ongoing [23,24]. Due to the difficulty in accurately determining the burden of leprosy, expert opinion can provide an additional perspective on the leprosy landscape.

Strengths of this survey include the diverse sample of participants, with the ability to compare the opinions of leprosy experts with those of NTD experts and forecasting experts. With an average of 19 minutes spent, the time commitment of the participants demonstrates that people took the survey seriously and care immensely about the topic at hand. Similarly, the large proportion of participants that voluntarily added additional comments at the conclusion of the survey provides further evidence that the responses were thoughtful and the questions not taken lightly.

This study suffers from several limitations. Notably, the overall response rate was below 10%. Thought the low response rate was expected from the broad approach,

the ability to generalize from these results is necessarily limited. Additionally, the survey was designed to prevent ballot box stuffing, but it is possible that individuals circumvented this control and took the study more than once. Given the professional nature of the participants, this is somewhat unlikely to have occurred. Also, though the majority of publications identified in the search for email extraction were in English, it is possible that language was a barrier to completing the survey for some of the selected authors.

Conclusion

In conclusion, we found that leprosy experts and disease elimination experts do not believe we are on track to meet the 2020 leprosy control goals as stated in the London Declaration. This opinion is consistent with research evidence showing ongoing transmission and a stabilization of new case detection rates. The collection of expert opinions highlights the need for continued attention on leprosy from a public health standpoint.

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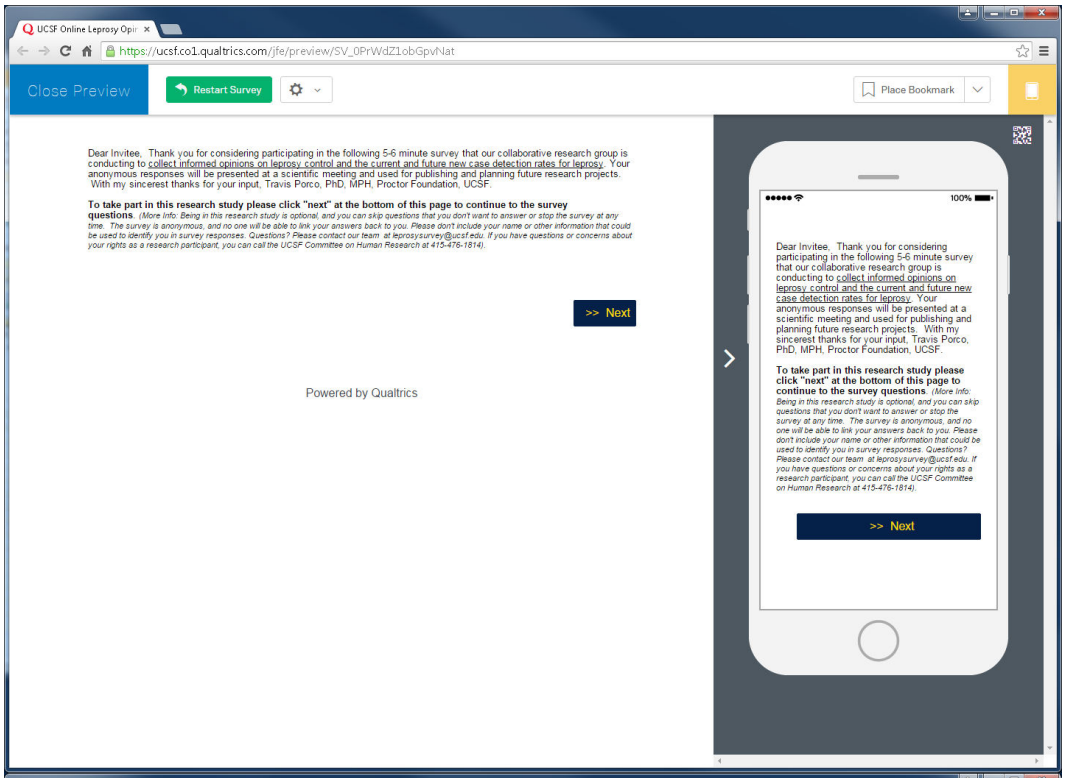
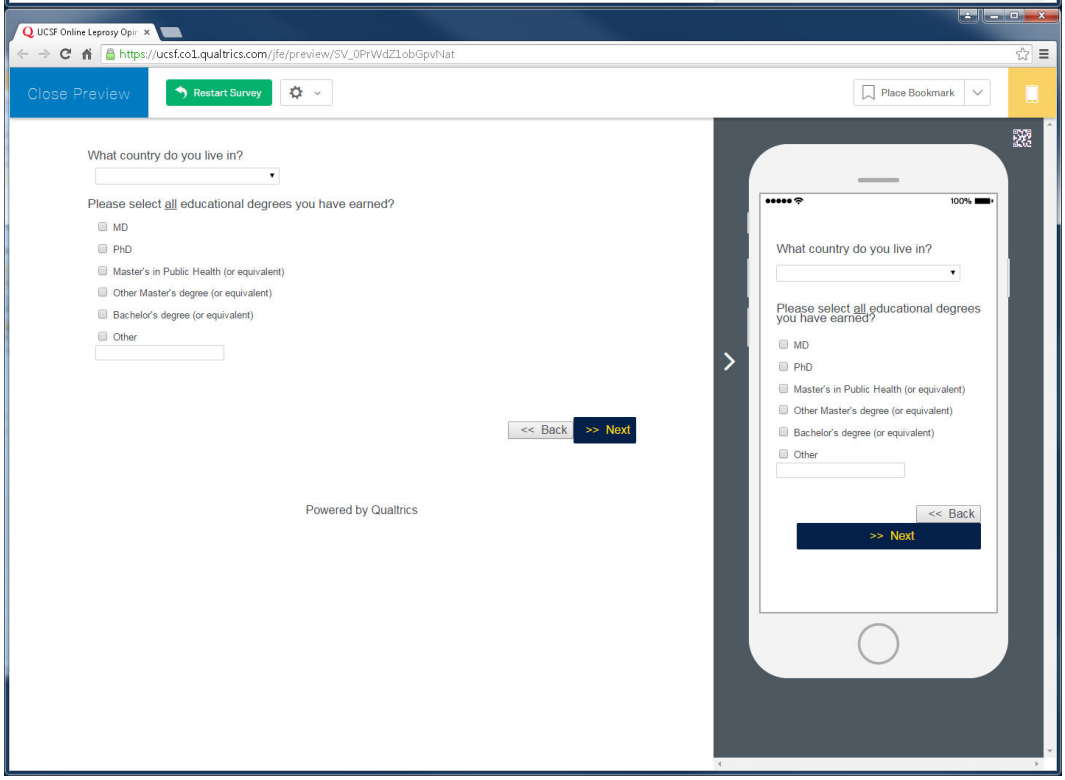
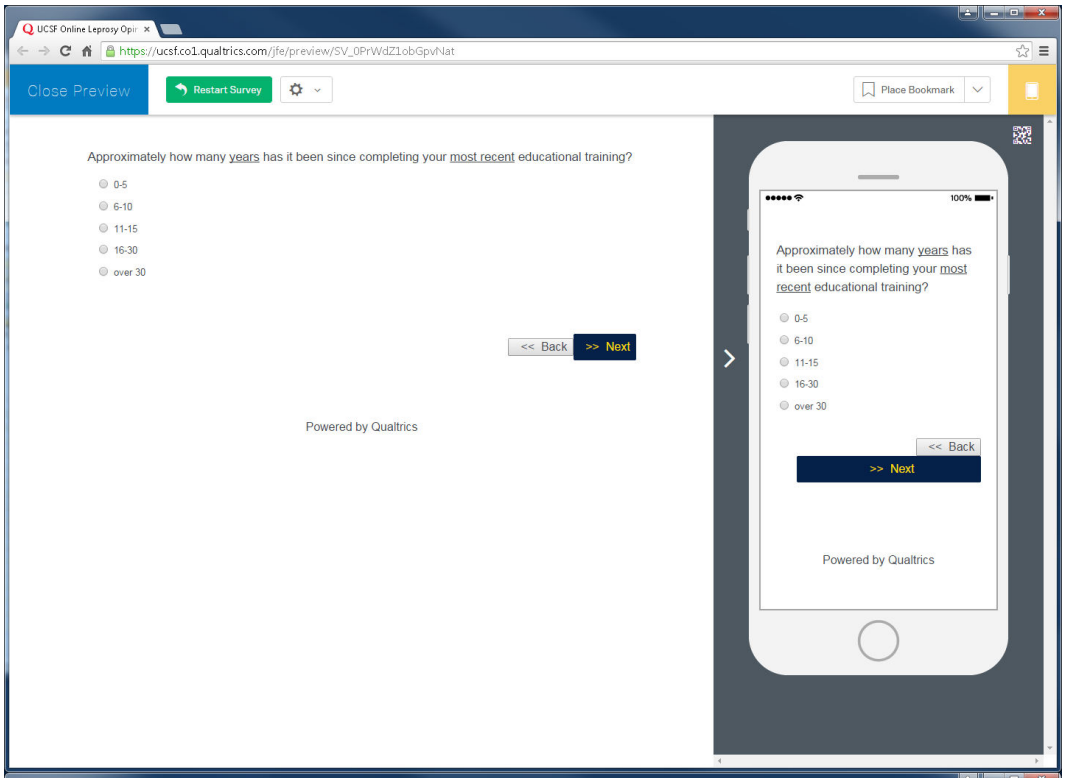
APPENDIX: COPY OF SURVEY



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Approximately how many years has it been since completing your most recent educational training?
0-5
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Approximately how many years has it been since completing your most recent educational training?
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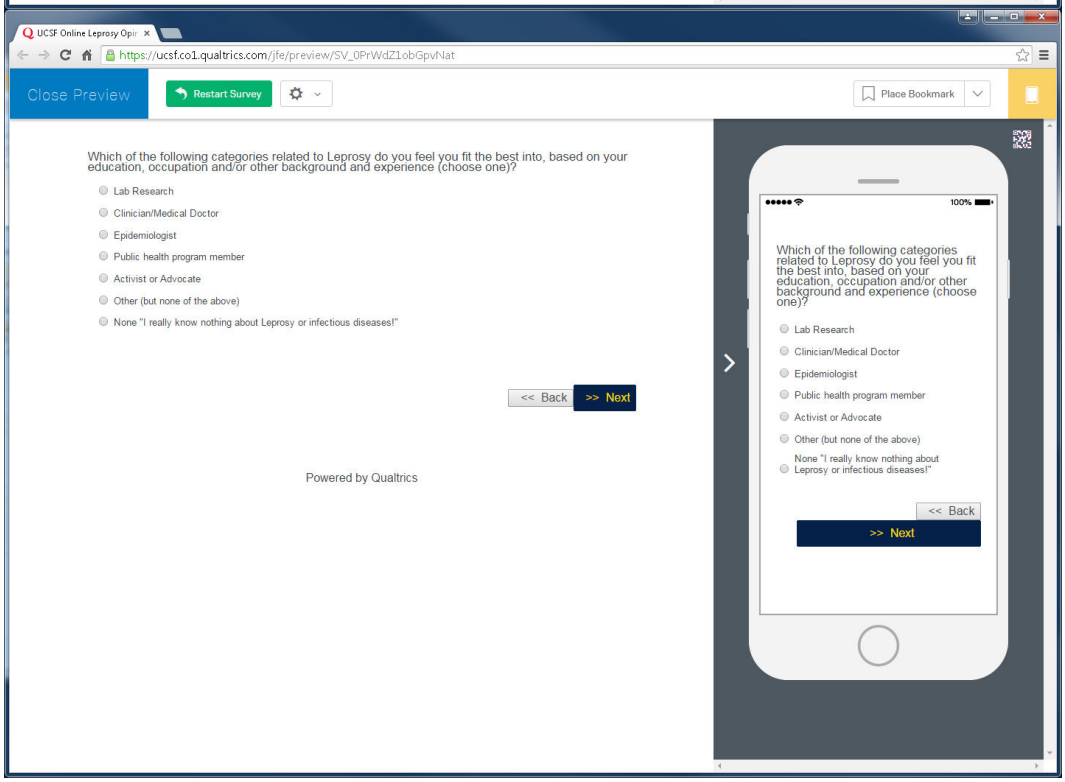
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Which of the following categories related to Leprosy do you feel you fit the best into, based on your education, occupation and/or other background and experience (choose one)?
Lab Research
Clinician/Medical Doctor
Epidemiologist
Public health program member
Activist or Advocate
Other (but none of the above)
None "I really know nothing about Leprosy or infectious diseases!"
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Which of the following categories related to Leprosy do you feel you fit the best into, based on your education, occupation and/or other background and experience (choose one)?
Lab Research
Clinician/Medical Doctor
Epidemiologist
Public health program member
Activist or Advocate
Other (but none of the above)
None "I really know nothing about Leprosy or infectious diseases!"
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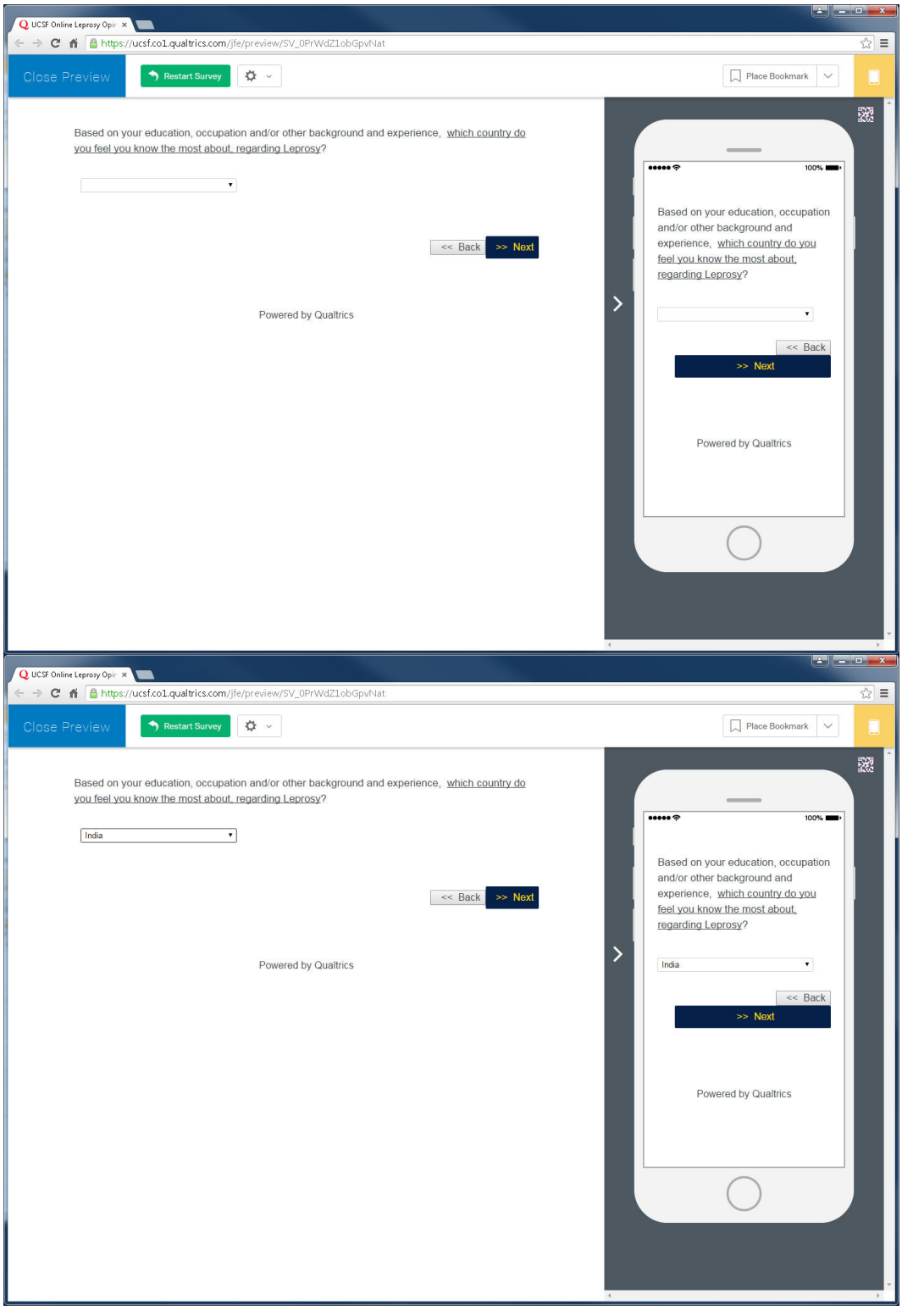
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Based on your education, occupation and/or other background and experience, which country do you feel you know the most about, regarding Leprosy?
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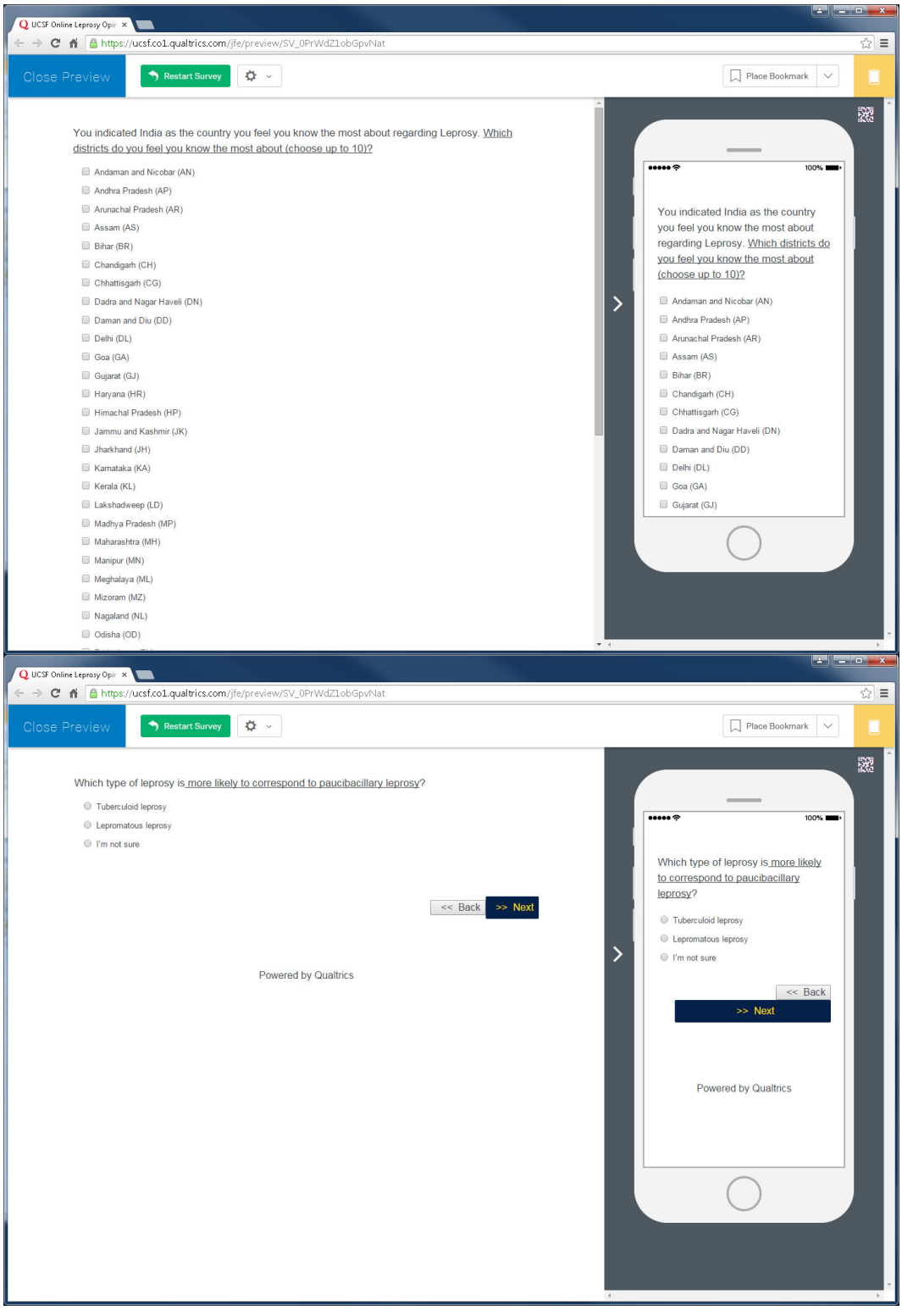
India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You indicated India as the country you feel you know the most about regarding Leprosy. Which districts do you feel you know the most about (choose up to 10)?
Andaman and Nicobar (AN)
Andhra Pradesh (AP)
Arunachal Pradesh (AR)
Assam (AS)
Bihar (BR)
Chandigarh (CH)
Chhattisgarh (CG)
Dadra and Nagar Haveli (DN)
Daman and Diu (DD)
Delhi (DL)
Goa (GA)
Gujarat (GJ)
Haryana (HR)
Himachal Pradesh (HP)
Jammu and Kashmir (JK)
Jharkhand (JH)
Karnataka (KA)
Kerala (KL)
Lakshadweep (LD)
Madhya Pradesh (MP)
Maharashtra (MH)
Manipur (MN)
Meghalaya (ML)
Mizoram (MZ)
Nagaland (NL)
Odisha (OD)
100%
Which type of leprosy is more likely to correspond to paucibacillary leprosy?
Tuberculoid leprosy
Lepromatous leprosy
I'm not sure
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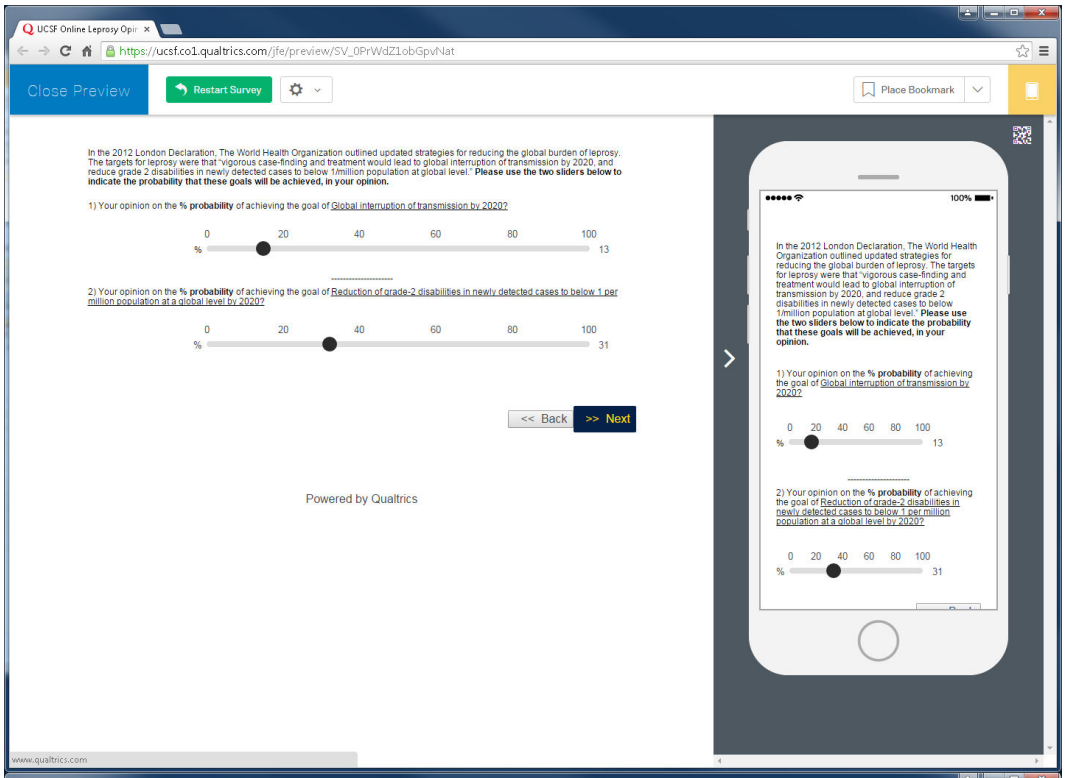
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In the 2012 London Declaration, The World Health Organization outlined updated strategies for reducing the global burden of leprosy. The targets for leprosy were that 'vigorous case-finding and treatment would lead to global interruption of transmission by 2020, and reduce grade 2 disabilities in newly detected cases to below 1/million population at global level.' Please use the two sliders below to indicate the probability that these goals will be achieved, in your opinion.
1) Your opinion on the % probability of achieving the goal of Global interruption of transmission by 2020?
0 20 40 60 80 100
% 13
2) Your opinion on the % probability of achieving the goal of Reduction of grade-2 disabilities in newly detected cases to below 1 per million population at a global level by 2020?
0 20 40 60 80 100
% 31
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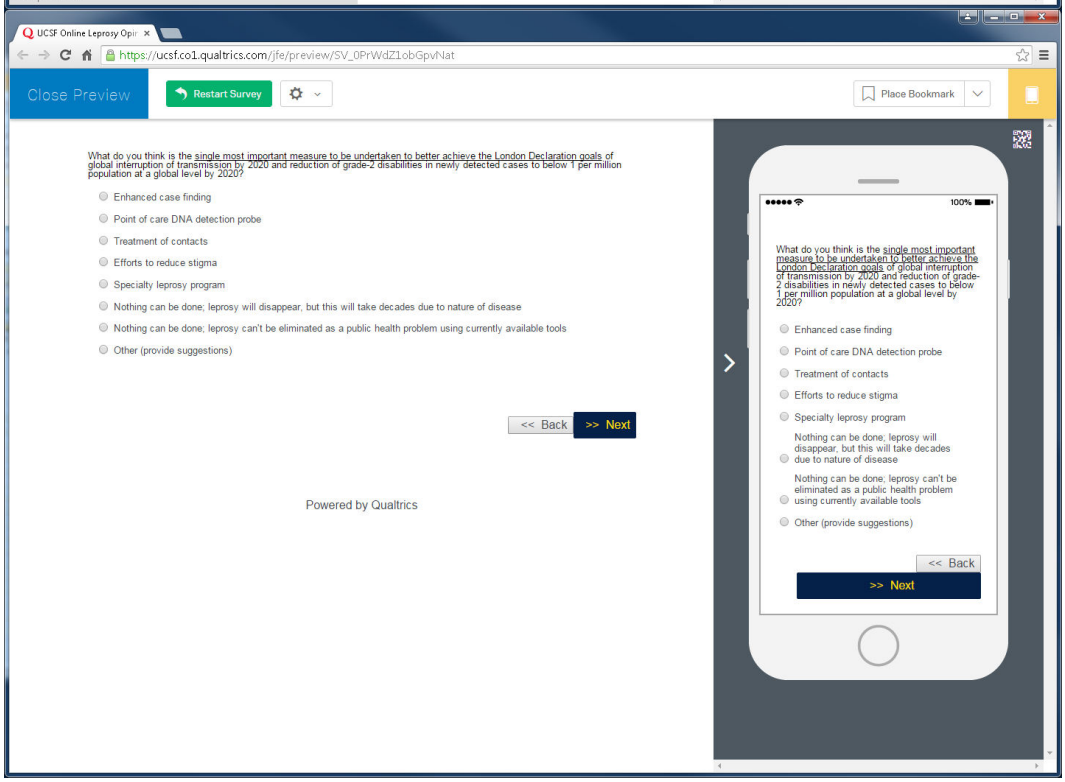
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What do you think is the single most important measure to be undertaken to better achieve the London Declaration goals of global interruption of transmission by 2020 and reduction of grade-2 disabilities in newly detected cases to below 1 per million population at a global level by 2020?
Enhanced case finding
Point of care DNA detection probe
Treatment of contacts
Efforts to reduce stigma
Specialty leprosy program
Nothing can be done; leprosy will disappear, but this will take decades due to nature of disease
Nothing can be done; leprosy can't be eliminated as a public health problem using currently available tools
Other (provide suggestions)
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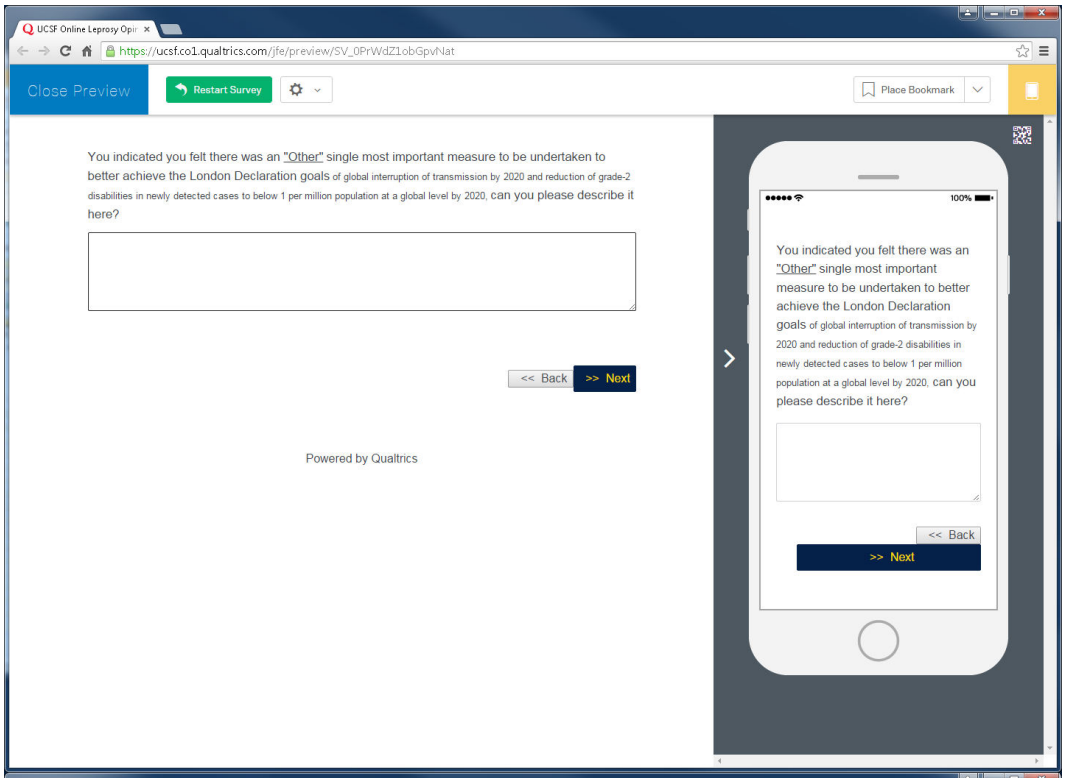
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You indicated you felt there was an "Other" single most important measure to be undertaken to better achieve the London Declaration goals of global interruption of transmission by 2020 and reduction of grade-2 disabilities in newly detected cases to below 1 per million population at a global level by 2020, can you please describe it here?
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You indicated you felt there was an "Other" single most important measure to be undertaken to better achieve the London Declaration goals of global interruption of transmission by 2020 and reduction of grade-2 disabilities in newly detected cases to below 1 per million population at a global level by 2020, can you please describe it here?
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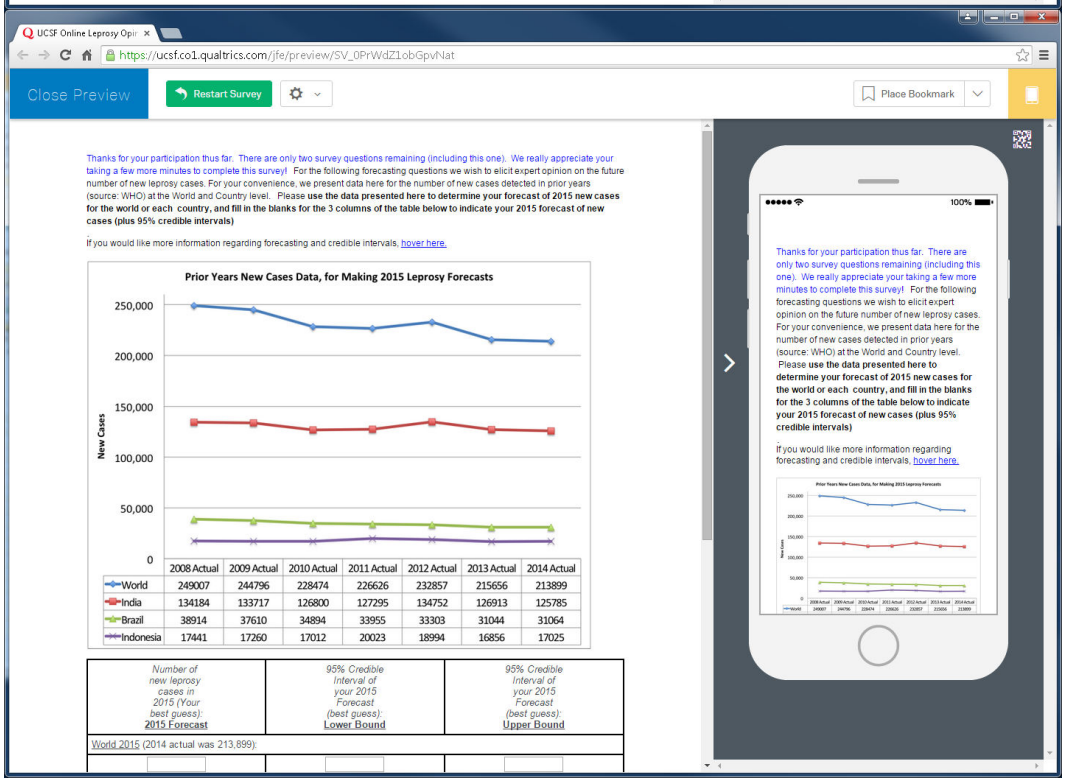
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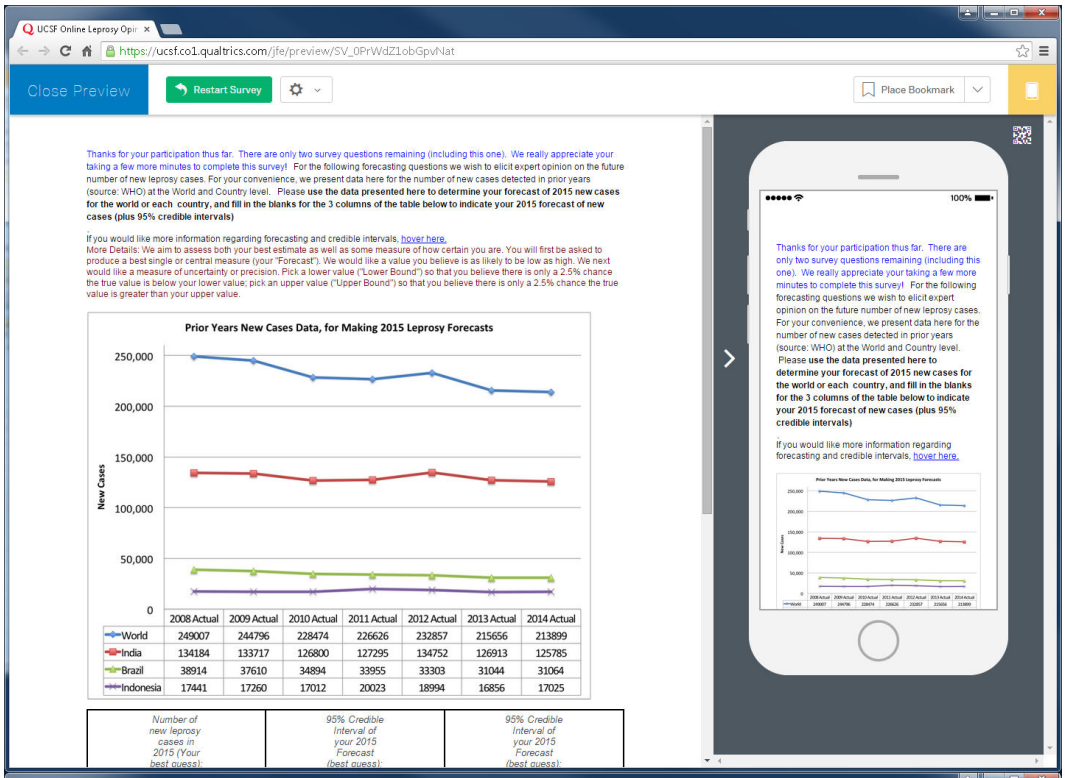
Thanks for your participation thus far. There are only two survey questions remaining (including this one). We really appreciate your taking a few more minutes to complete this survey! For the following forecasting questions we wish to elicit expert opinion on the future number of new leprosy cases. For your convenience, we present data here for the number of new cases detected in prior years (source: WHO) at the World and Country level. Please use the data presented here to determine your forecast of 2015 new cases for the world or each country, and fill in the blanks for the 3 columns of the table below to indicate your 2015 forecast of new cases (plus 95% credible intervals)
If you would like more information regarding forecasting and credible intervals, hover here.
Prior Years New Cases Data, for Making 2015 Leprosy Forecasts
250,000
200,000
150,000
100,000
50,000
0
New Cases
2008 Actual 2009 Actual 2010 Actual 2011 Actual 2012 Actual 2013 Actual 2014 Actual
World 249007 244796 228474 226626 232857 215656 213899
India 134184 133717 126800 127295 134752 126913 125785
Brazil 38914 37610 34894 33955 33303 31044 31064
Indonesia 17441 17260 17012 20023 18994 16856 17025
Number of new leprosy cases in 2015 (Your best guess): 2015 Forecast
95% Credible Interval of your 2015 Forecast (best guess): Lower Bound
95% Credible Interval of your 2015 Forecast (best guess): Upper Bound
World 2015 (2014 actual was 213,899):
100%
Thanks for your participation thus far. There are only two survey questions remaining (including this one). We really appreciate your taking a few more minutes to complete this survey! For the following forecasting questions we wish to elicit expert opinion on the future number of new leprosy cases. For your convenience, we present data here for the number of new cases detected in prior years (source: WHO) at the World and Country level. Please use the data presented here to determine your forecast of 2015 new cases for the world or each country, and fill in the blanks for the 3 columns of the table below to indicate your 2015 forecast of new cases (plus 95% credible intervals)
If you would like more information regarding forecasting and credible intervals, hover here.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If you would like more information regarding forecasting and credible intervals, hover here.
More Details: We aim to assess both your best estimate as well as some measure of how certain you are. You will first be asked to produce a best single or central measure (your "Forecast"). We would like a value you believe is as likely to be low as high. We next would like a measure of uncertainty or precision. Pick a lower value ("Lower Bound") so that you believe there is only a 2.5% chance the true value is below your lower value; pick an upper value ("Upper Bound") so that you believe there is only a 2.5% chance the true value is greater than your upper value.
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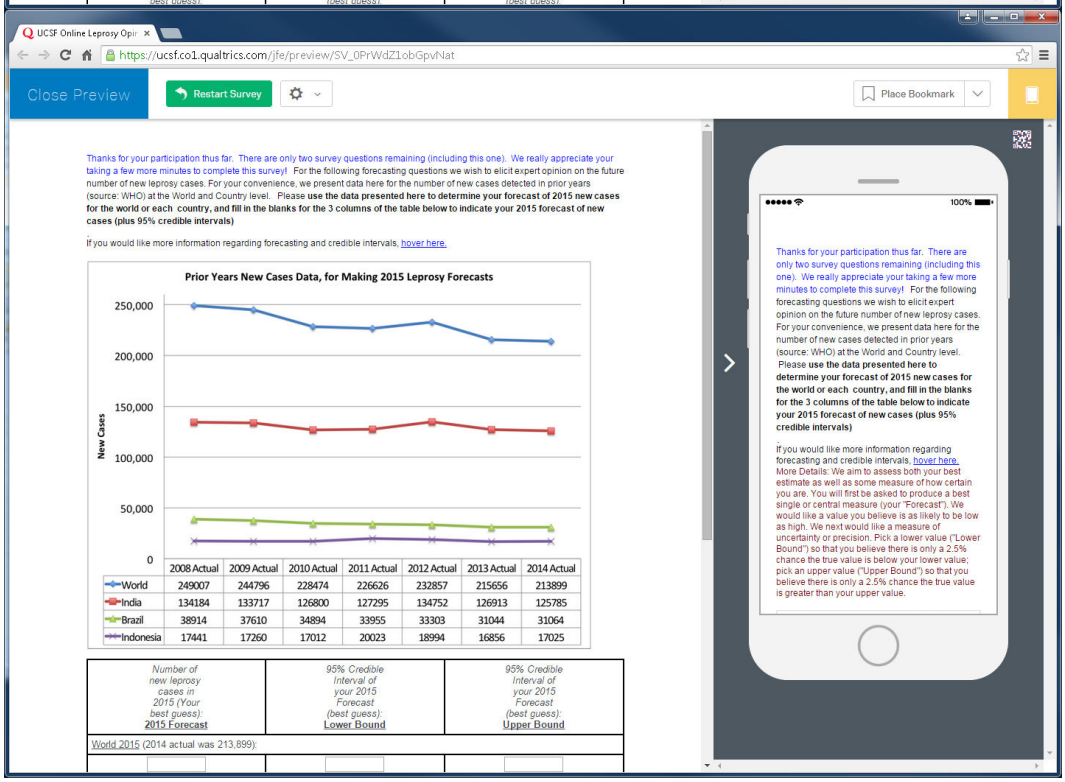
Indonesia 17441 17260 17012 20023 18994 16856 17025
Number of new leprosy cases in 2015 (Your best guess):
95% Credible Interval of your 2015 Forecast (best guess):
95% Credible Interval of your 2015 Forecast (best guess):
100%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If you would like more information regarding forecasting and credible intervals, hover here.
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New Cases
2008 Actual 2009 Actual 2010 Actual 2011 Actual 2012 Actual 2013 Actual 2014 Actual
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Number of new leprosy cases in 2015 (Your best guess): 2015 Forecast
95% Credible Interval of your 2015 Forecast (best guess): Lower Bound
95% Credible Interval of your 2015 Forecast (best guess): Upper Bound
World 2015 (2014 actual was 213,899):
100%
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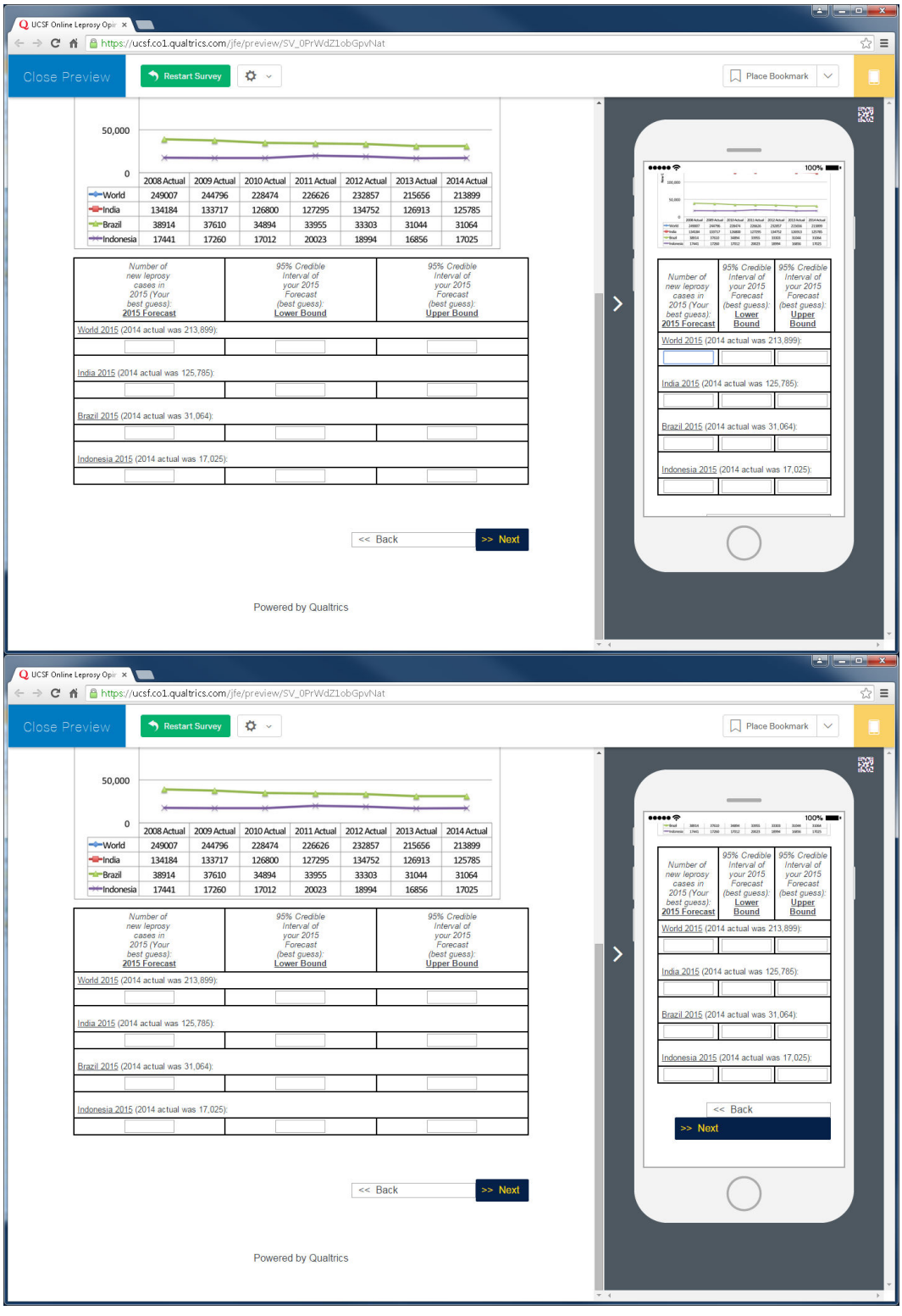
More Details: We aim to assess both your best estimate as well as some measure of how certain you are. You will first be asked to produce a best single or central measure (your "Forecast"). We would like a value you believe is as likely to be low as high. We next would like a measure of uncertainty or precision. Pick a lower value ("Lower Bound") so that you believe there is only a 2.5% chance the true value is below your lower value; pick an upper value ("Upper Bound") so that you believe there is only a 2.5% chance the true value is greater than your upper value.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Number of new leprosy cases in 2015 (Your best guess): 2015 Forecast
95% Credible Interval of your 2015 Forecast (best guess): Lower Bound
95% Credible Interval of your 2015 Forecast (best guess): Upper Bound
World 2015 (2014 actual was 213,899):
India 2015 (2014 actual was 125,785):
Brazil 2015 (2014 actual was 31,064):
Indonesia 2015 (2014 actual was 17,025):
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Indonesia 17441 17260 17012 20023 18994 16856 17025
Number of new leprosy cases in 2015 (Your best guess): 2015 Forecast
95% Credible Interval of your 2015 Forecast (best guess): Lower Bound
95% Credible Interval of your 2015 Forecast (best guess): Upper Bound
World 2015 (2014 actual was 213,899):
India 2015 (2014 actual was 125,785):
Brazil 2015 (2014 actual was 31,064):
Indonesia 2015 (2014 actual was 17,025):
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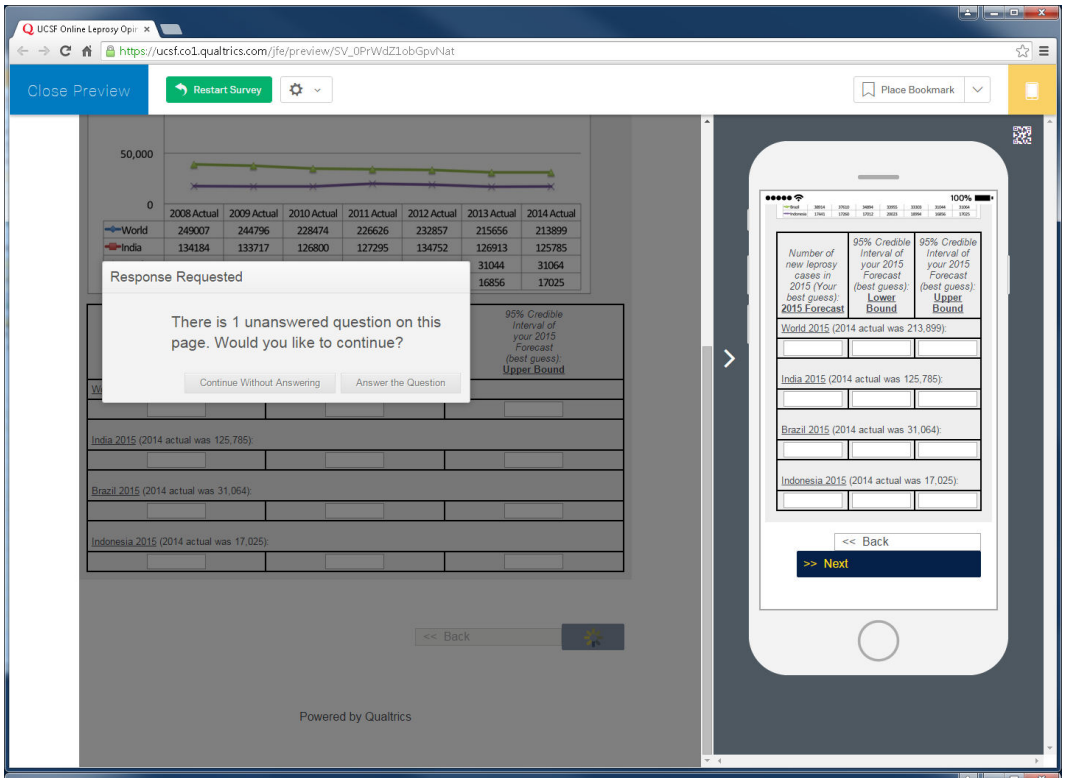
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2008 Actual 2009 Actual 2010 Actual 2011 Actual 2012 Actual 2013 Actual 2014 Actual
World 249007 244796 228474 226626 232857 215656 213899
India 134184 133717 126800 127295 134752 126913 125785
31044 31064
16856 17025
Response Requested
There is 1 unanswered question on this page. Would you like to continue?
Continue Without Answering
Answer the Question
95% Credible Interval of your 2015 Forecast (best guess): Upper Bound
India 2015 (2014 actual was 125,785):
Brazil 2015 (2014 actual was 31,064):
Indonesia 2015 (2014 actual was 17,025):
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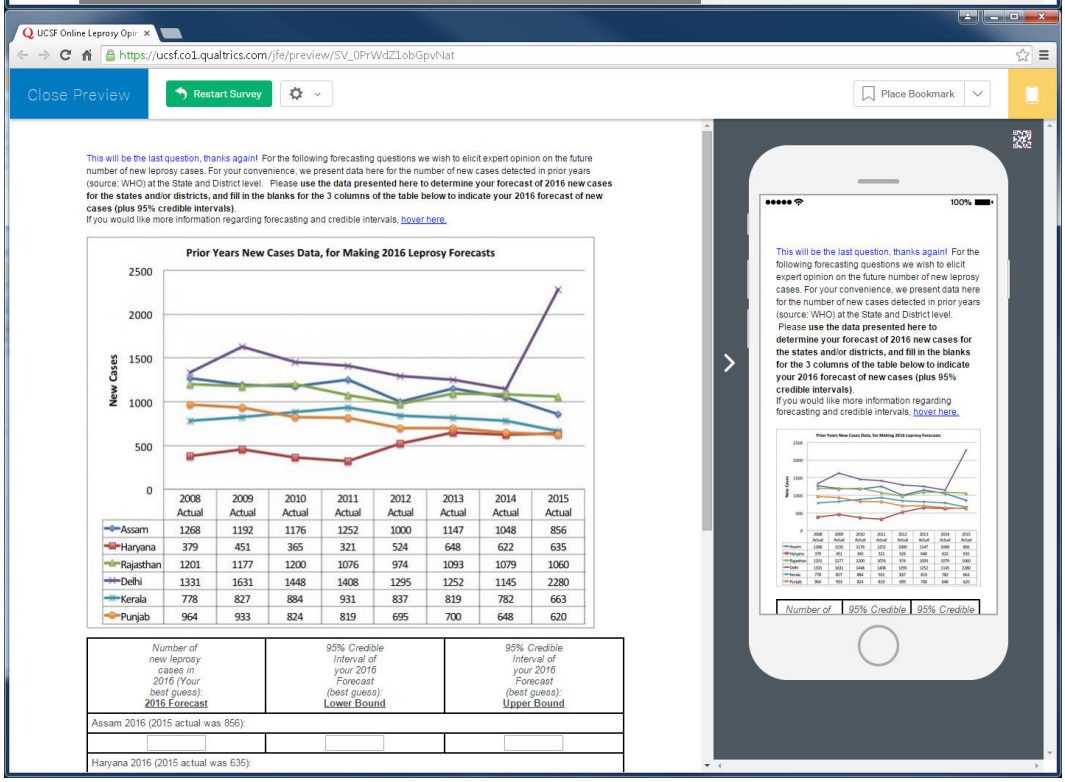
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This will be the last question, thanks again! For the following forecasting questions we wish to elicit expert opinion on the future number of new leprosy cases. For your convenience, we present data here for the number of new cases detected in prior years (source: WHO) at the State and District level. Please use the data presented here to determine your forecast of 2016 new cases for the states and/or districts, and fill in the blanks for the 3 columns of the table below to indicate your 2016 forecast of new cases (plus 95% credible intervals).
If you would like more information regarding forecasting and credible intervals, hover here.
Prior Years New Cases Data, for Making 2016 Leprosy Forecasts
New Cases
2500
2000
1500
1000
500
0
2008 Actual 2009 Actual 2010 Actual 2011 Actual 2012 Actual 2013 Actual 2014 Actual 2015 Actual
Assam 1268 1192 1176 1252 1000 1147 1048 856
Haryana 379 451 365 321 524 648 622 635
Rajasthan 1201 1177 1200 1076 974 1093 1079 1060
Delhi 1331 1631 1448 1408 1295 1252 1145 2280
Kerala 778 827 884 931 837 819 782 663
Punjab 964 933 824 819 695 700 648 620
Number of new leprosy cases in 2016 (Your best guess): 2016 Forecast
95% Credible Interval of your 2016 Forecast (best guess): Lower Bound
95% Credible Interval of your 2016 Forecast (best guess): Upper Bound
Assam 2016 (2015 actual was 856):
Haryana 2016 (2015 actual was 635):
100%
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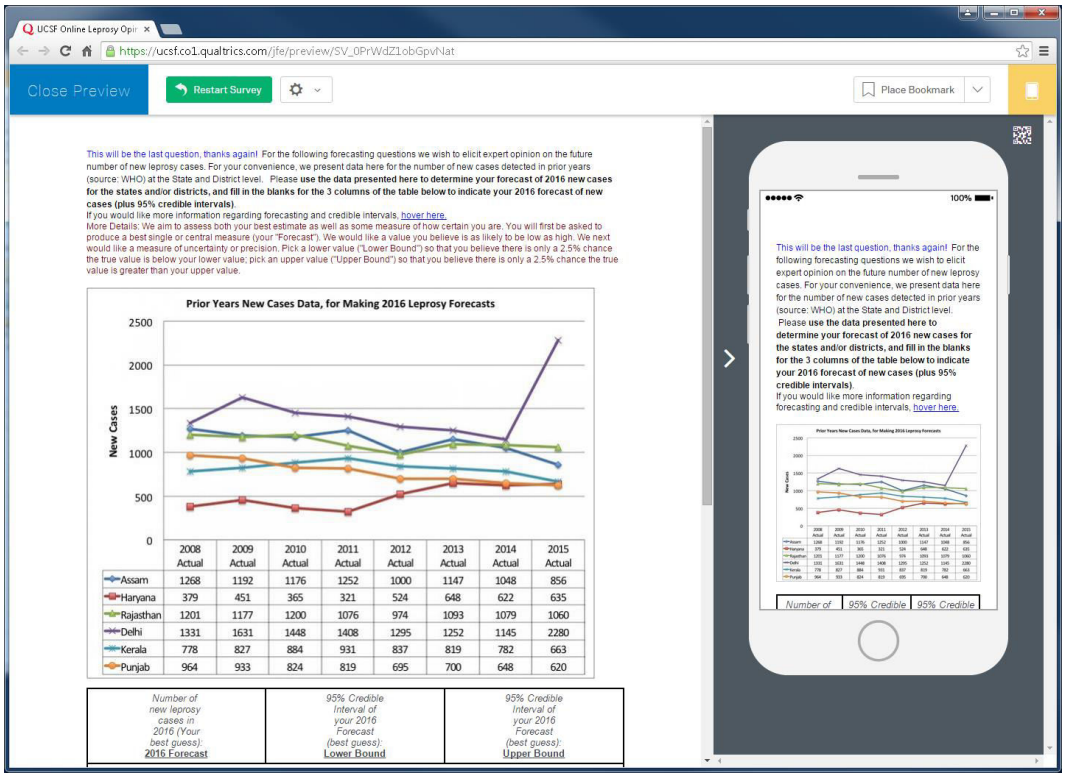
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If you would like more information regarding forecasting and credible intervals, hover here.
More Details: We aim to assess both your best estimate as well as some measure of how certain you are. You will first be asked to produce a best single or central measure (your "Forecast"). We would like a value you believe is as likely to be low as high. We next would like a measure of uncertainty or precision. Pick a lower value ("Lower Bound") so that you believe there is only a 2.5% chance the true value is below your lower value; pick an upper value ("Upper Bound") so that you believe there is only a 2.5% chance the true value is greater than your upper value.
Prior Years New Cases Data, for Making 2016 Leprosy Forecasts
New Cases
2500
2000
1500
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2008 Actual
2009 Actual
2010 Actual
2011 Actual
2012 Actual
2013 Actual
2014 Actual
2015 Actual
Assam 1268 1192 1176 1252 1000 1147 1048 856
Haryana 379 451 365 321 524 648 622 635
Rajasthan 1201 1177 1200 1076 974 1093 1079 1060
Delhi 1331 1631 1448 1408 1295 1252 1145 2280
Kerala 778 827 884 931 837 819 782 663
Punjab 964 933 824 819 695 700 648 620
Number of new leprosy cases in 2016 (Your best guess): 2016 Forecast
95% Credible Interval of your 2016 Forecast (best guess): Lower Bound
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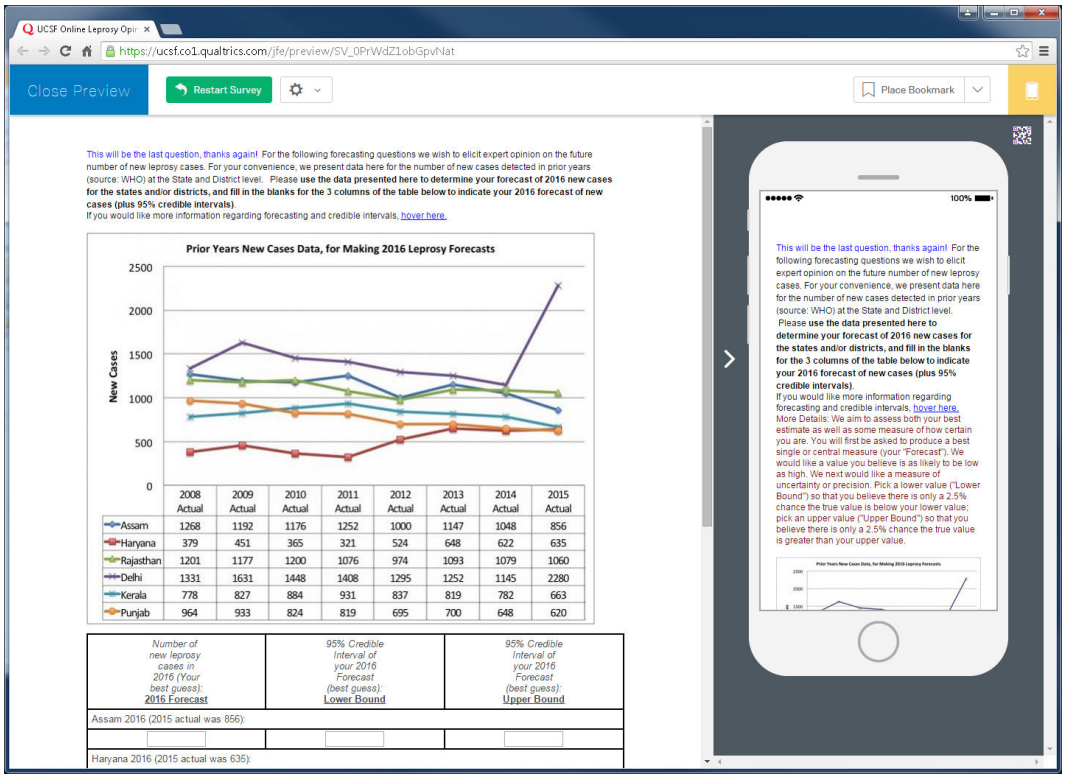
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2013 Actual
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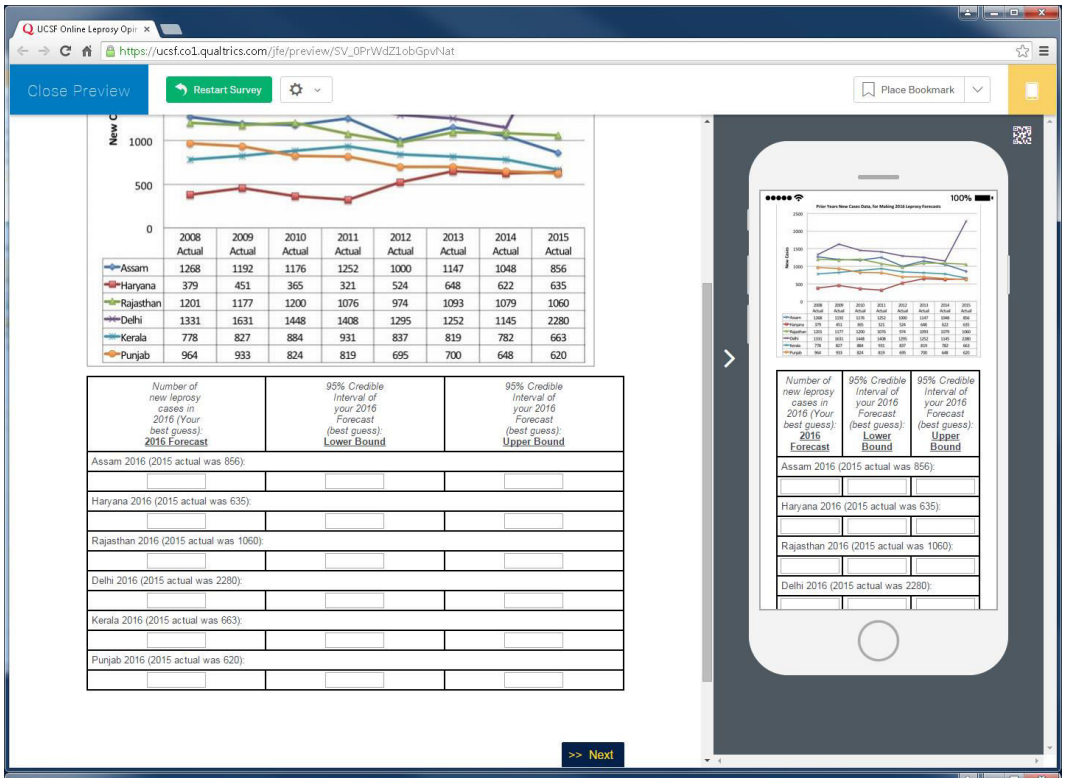
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Kerala 2016 (2015 actual was 663):
Punjab 2016 (2015 actual was 620):
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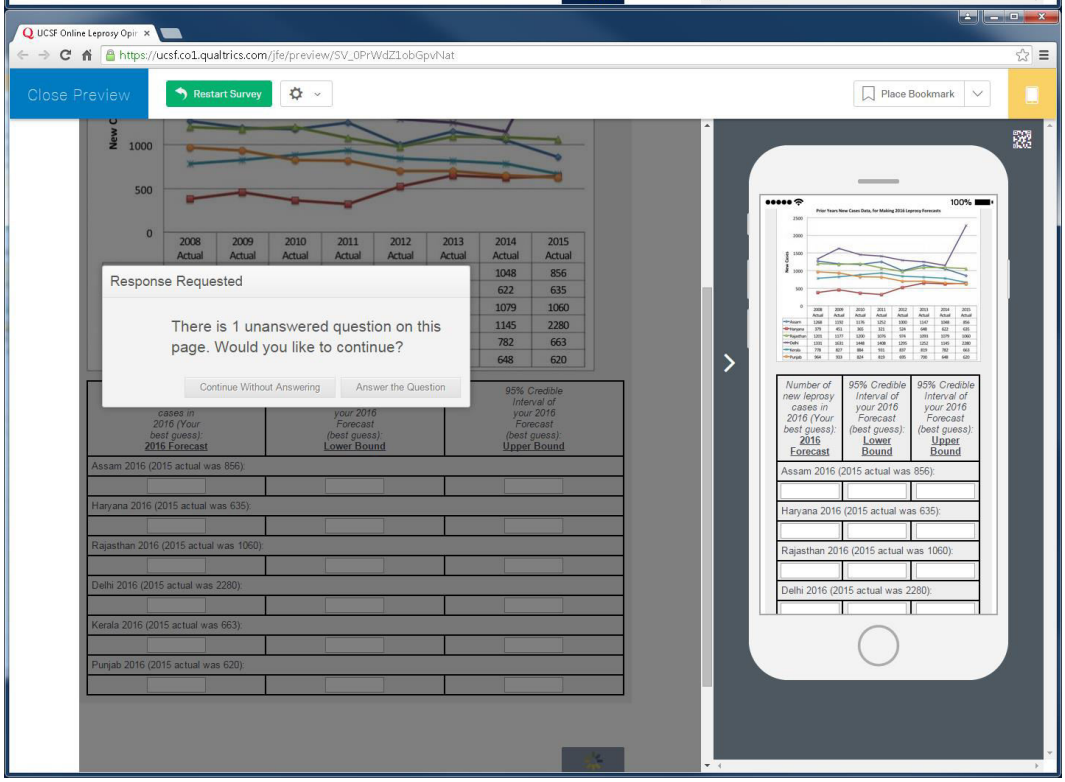
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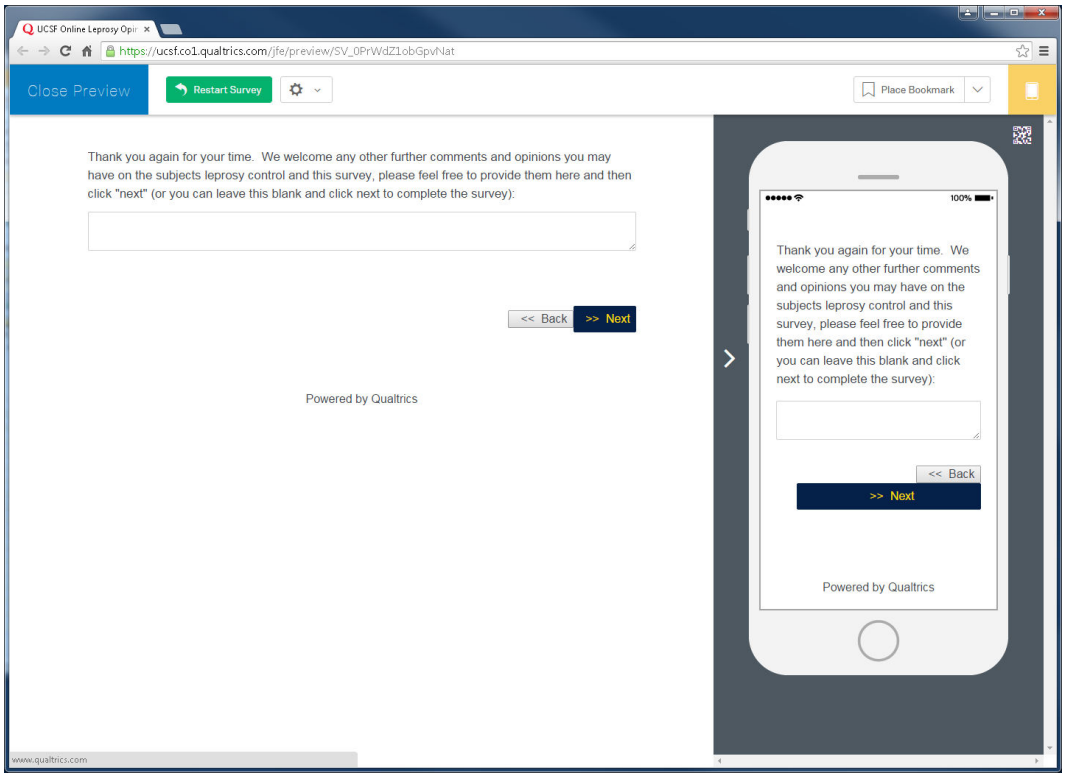
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Thank you again for your time. We welcome any other further comments and opinions you may have on the subjects leprosy control and this survey, please feel free to provide them here and then click "next" (or you can leave this blank and click next to complete the survey):
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