Translational Epidemiology: An Application of Lung Cancer Prevention Strategies in USA and Mexico

by

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DEDICATION

For Mother, the intrepid adventurer

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ABSTRACT

Lung cancer is the number one cause of cancer-related deaths in the US and worldwide. This is an aggressive disease with few treatment options if discovered at a late stage, as it often is. Therefore, reducing the burden of lung cancer should focus on primary and secondary prevention strategies: tobacco control and lung cancer screening. However, to implement effective interventions, we need to be familiar with a variety of methods and engage with different perspectives and stakeholders. Through the lens of translational epidemiology, this dissertation presents three analyses applied to different contexts to address the lung cancer burden.

First, we describe a study using mixed methods to design and evaluate a web-tool for lung cancer screening informed decision-making in Metro Detroit. Through participatory design workshops, we identify design features that may be salient for other developers of web-based decision aids for both lung cancer screening and other health interventions. Afterwards, we conduct a quasi-experimental study with before-after surveys to test a modified version of a web-based decision aid, shouldiscreen.com, in an African American community in Detroit. We find that using the decision aid moderately improves lung cancer screening knowledge and concordance of individual preference for screening with clinical guidelines. Use of the tool also decreases decisional conflict with regards to lung cancer screening. We contact these survey participants after six months over the phone and ask if they had taken steps to see a clinician and enquire about lung cancer screening. A subset of the survey takers also

participate in a focus group to give more in-depth feedback about their experience using shouldiscreen.com, which we use to triangulate our findings in the participatory design workshops. This aim demonstrates various design and implementation challenges for web-based lung cancer screening decision aids, particularly when considering the needs of low-resource communities with limited access to the internet and individuals with low levels of literacy.

Second, we present an age-period-cohort analysis of smoking patterns in Mexico using nationally representative cross-sectional data from 1987 to 2016. Specifically, we estimate trends in smoking prevalence, initiation and cessation by birth cohort and sex. The results show that while smoking prevalence and initiation have decreased, progress has slowed and even reversed for younger birth cohorts. Moreover, the analysis reveals that there has been a shift in smoking patterns from daily to non-daily smoking in recent years. This shift may have implications in how tobacco control policies would be implemented in future.

Third, we develop a computational model of smoking prevalence for Mexico, which accounts for the current patterns of use uncovered in Aim 2, and explicitly tracks daily and non-daily smokers. The model suggests that if smoking initiation and cessation remain at current levels, there will be around 18 million male and 4 million female smokers in 2050. These projections serve as a basis for future assessments of ongoing and new tobacco control policies.

CHAPTER I

Introduction

1.1 Background

Lung cancer is the leading cause of cancer-related deaths in the world [1]. This is also true for the US, where lung cancer leads to more deaths than breast, prostate and colon cancer combined [2]. Moreover, lung cancer is an aggressive disease, with a 5-year survival of 19% [3]. This is improved to 57% if lung cancer is diagnosed when it is still localized; however, only 16% are diagnosed at this early stage [3]. Currently, the diagnosis of lung cancer is primarily based on symptoms [4]. Yet by the time symptoms are observed, the disease has often progressed to an advanced stage. Although there are some promising developments in targeted therapy and immunotherapy [5–7], curative treatments for advanced stage lung cancer are currently limited. In particular, symptoms related to lung cancer are highly variable and, at times, innocuous (e.g. feeling weak, coughing). Given the stealthy and lethal nature of lung cancer, together with the limited treatment options available thus far, the most effective method of reducing lung cancer burden is in its prevention. Fortunately, years of research in cancer epidemiology provided us with two critical pieces of information: 1) 80-90% of lung cancer deaths can be attributed to smoking [8], a preventable cause; and 2) lung cancer screening with low-dose CT (computed

tomography) is effective at reducing lung cancer deaths by enabling earlier detection, when treatment options are more readily available [9]. That is, we know the most important risk factor for primary prevention of lung cancer, smoking, which is easily isolatable, and we have a relatively effective method for use in secondary prevention.

1.2 Lung cancer prevention: approach with translational epidemiology

However, knowing that these two prevention strategies will be helpful is only the tip of the iceberg. More than 50 years since the landmark study by Doll and Hill [10, 11] have passed, yet smoking has remained the greatest cause of preventable death and disability in the US [12]. Smoking is a lifestyle behavior that is influenced by a variety of cultural and social norms [13–17], as well as other social determinants, such as education [18], ethnicity [19], income [19], and deprivation [20]. Similar factors also affect the uptake of cancer screening [21–26]. Thus, ending the tobacco epidemic, along with increasing the uptake of lung cancer screening among eligible individuals, has been and will continue to be extremely challenging. Barriers to public health interventions are often complex and multidimensional, and require a broad array of knowledge and methods to circumvent. Within the field of cancer epidemiology, the focus has mostly been on etiologic research, which has led to many important discoveries, with one of the most prominent being the causal relationship between smoking and lung cancer. However, the translation of this epidemiologic knowledge to address public health goals, such as decreasing cancer disparities and lowering cancer burden, has received less attention in the field [27]. At times, even when the science is widely accepted as sound, there is often a long delay between uncovering risk factors and effective disease prevention, with much heterogeneity in the implementation of policies and their outcomes. It has been said that public health

is "at the intersection of science and politics," and some of the drivers behind the delays and differences include political will; cultural and social norms, which in turn may shape the knowledge and risk appetite of policy makers, health care providers and patients; structure of the health care system; and the resources available to the health care system and patients [28]. It is clear that for lung cancer prevention, like many other public health issues, the solutions will be complex, warranting a multidimensional approach.

Epidemiology is a discipline within public health and thus has an overarching goal to improve population health. While there is little consensus on how this should be done, epidemiologists have described a number of frameworks to improve population health under the umbrella of "translational epidemiology" [27, 29, 30]. In the framework posited by Khoury et al. [29], they describe five phases and the role of translation that epidemiology can play:

- Description and discovery (T0): to describe patterns of health outcomes by place, time, and person; discover determinants of health outcomes by observational studies
- From discovery to health applications (T1): to characterize discovery and assess potential health applications by using clinical and population studies
- From health application to evidence guidelines (T2): to assess the efficacy of interventions to improve health and prevent disease by using observational and experimental studies
- From guidelines to health practice (T3): to assess the implementation and dissemination of guidelines into practice
- From health practice to population health outcomes (T4): to assess the effec-

tiveness of interventions on health outcomes

Given the complexities we have described, it may be beneficial to view lung cancer prevention through the lens of translational epidemiology. Indeed, this dissertation is situated in a translation epidemiology framework, illustrated in Figure 1.1, where we use a variety of tools to examine lung cancer prevention strategies. As the US is a developed country experiencing the late stages of the tobacco epidemic [31], there is justification to increase focus on secondary prevention. Thus, the first aim fits under phase T3, "From guidelines to health practice," where we assess the implementation of shared decision-making for lung cancer screening in the US. Here, we engage with various stakeholders and study the barriers of designing and implementing a patient decision aid for lung cancer screening using both qualitative and survey methods. For Aims 2 and 3, we study lung cancer prevention in the Mexican context. Mexico, a neighbor of the US, is a middle-income country that is earlier in the tobacco epidemic [31]. Moreover, implementing lung cancer screening widely may be challenging as it is resource intensive, and middle-income countries such as Mexico have fewer dedicated resources to cancer research and development relative to high-income countries [32]. Hence, for Mexico we focus on the main risk factor of lung cancer, smoking (i.e. primary prevention strategies). The second aim can be classified under phase T0, "Description and discovery," where we describe the patterns of smoking in Mexico by age, period and birth cohort from 1987 to 2016. Monitoring smoking trends by birth cohorts on a population level can be valuable when considering the implementation of tobacco control policies, but this extensive description has not yet been done for the Mexican context. Finally, the third aim falls under phase T4, "From health practice to population health outcomes," where we build a state transition model, a type of computational model, that explicitly lays out the relationships between

never, current and former smokers through initiation and cessation probabilities. This model can be a tool that policy makers can use to assess the effectiveness of tobacco control policies on future smoking prevalence.

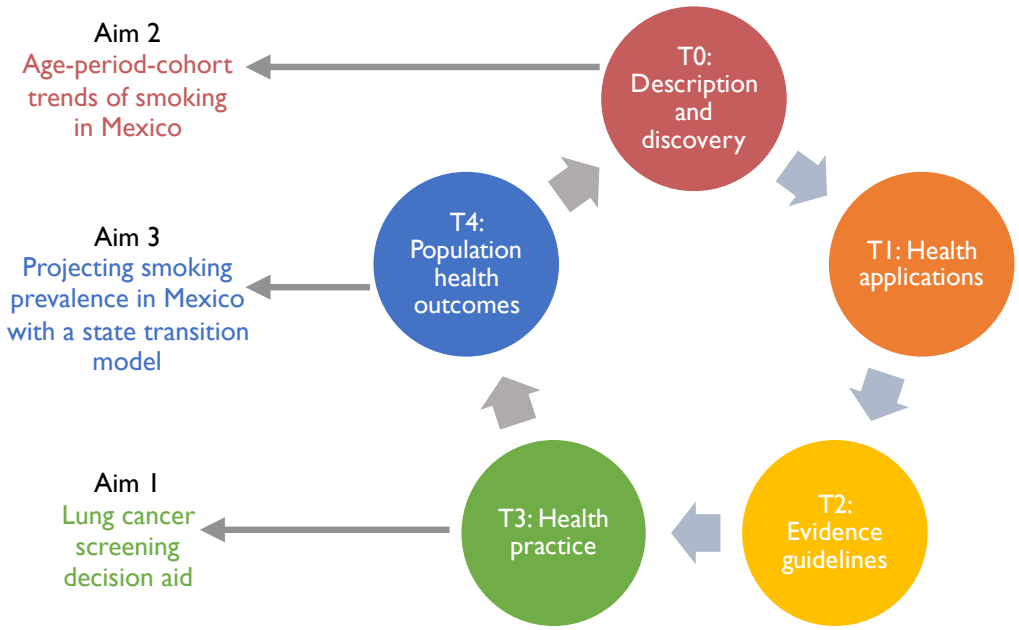


Figure 1.1: Situating this dissertation in the framework of translational epidemiology (adapted from Khoury et al. [29])

1.3 Lung cancer screening in the US

The National Lung Screening Trial (NLST), a large randomized controlled trial conducted in the US, concluded that those who underwent low-dose CT for lung cancer screening had a 20% reduced risk of dying from lung cancer compared to the chest x-ray group [9]. Lung cancer screening with low-dose CT was recommended by the US Preventive Services Task Force (USPSTF) at the end of 2013 with grade "B" [33], the same grade as breast cancer screening with mammography every 1-2 years for women aged 40 years or older [34]. The grading means that for those who are eligible — 55-80 years old, have smoked for more than 30 pack-years, and quit

within the last 15 years — private health insurers are required to cover lung cancer screening. Importantly, these eligibility criteria stemmed from simulation modeling, which incorporated and translated the NLST findings, to project the potential impact of screening at the US population level under various eligibility criteria [35, 36].

Soon after the USPSTF recommendations, the Center for Medicare and Medicaid Services (CMS) released a statement that lung cancer screening with low-dose CT would also be covered under Medicare, although the eligibility criteria varied slightly (only those between 55-77 years old would be eligible). The two criteria involving smoking history remained the same as USPSTF. However, uptake of these recommendations in clinical care settings has been slow. The most recent estimates show that more than a year after the initial recommendation by the USPSTF, only 3.9% of those 6.8 million eligible had received screening [37]. This may be due to slow dissemination of knowledge and/or acceptance of this new medical procedure by both primary care providers [38] and eligible individuals. In addition, lung cancer incidence and mortality are marked by disparities in the US, with African American men having the highest risk relative to other demographic groups [3]. At this critical juncture of the introduction of lung cancer screening, we need to ensure that access to it is equitable such that these disparities do not persist or worsen.

1.4 Smoking in Mexico

Tobacco control efforts in high-income countries have made significant strides in decreasing smoking prevalence. In the US, smoking prevalence has been on the decline since a peak of 43% in the mid-1960s when the US Surgeon General's Report in 1964 first warned of the hazardous effects of smoking on health [39, 40]. The most recent National Health Interview Survey of 2018 showed that adult smoking

prevalence is at 13.8% [41], a record low. Smoking trends in low-middle income countries (LMICs) are more variable. Mexico is a middle-income country that ratified the World Health Organization's the Framework Convention for Tobacco Control in 2004, agreeing to implement evidence-based tobacco control policies in the country. These interventions are known as the "MPOWER" measures, where "M" stands for monitoring, "P" for smoking-free policies, "O" for cessation, "W" for health warnings, "E" for advertising bans, and "R" for taxes [42]. The goal of these policies, ultimately, is to reduce smoking prevalence in the population by decreasing smoking initiation and increasing cessation. Mexico has steadily implemented a number of these policies over the years [42, 43] (see Figure 1.2). However, smoking prevalence appears to have stagnated from 2011 [44]. With smoking being a top 10 significant contributor to premature deaths and disability in the country [45], continued monitoring to inform tobacco control policies will be important.

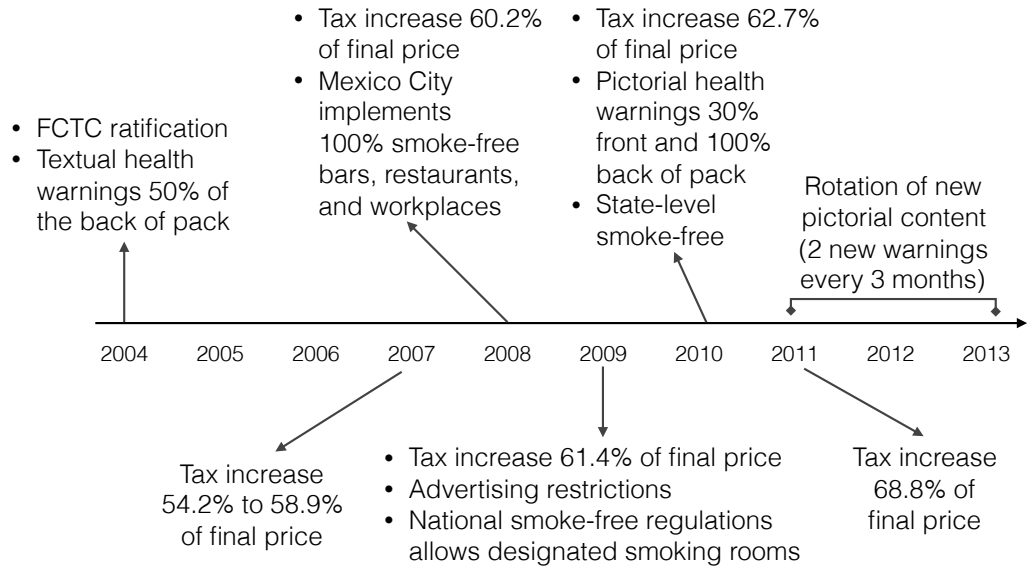


Figure 1.2: Timeline of tobacco control policy implementations in Mexico (adapted from Reynales-Shigematsu et al. [43])

1.5 Specific Aims

In the following chapters, we will investigate two lung cancer prevention strategies through the lens of translational epidemiology. In Chapter II, we examine an integral part of secondary prevention of lung cancer, lung cancer screening with low-dose CT, from the perspective of an individual. In particular, we describe the challenges of designing and implementing a patient-facing, web-based decision aid for lung cancer screening informed decision-making. Here, we engaged with African American and Latinx community organizations and community members in Metro Detroit to help us improve a web-based decision aid, www.shouldiscreen.com that we developed in 2014 [46, 47]. We used a mixed methods approach where both qualitative data from participatory design workshops and focus groups, as well as quantitative data from before-after surveys, are collected and analyzed. In Chapters III and IV, we examine a primary prevention strategy for lung cancer, by focusing on the main causal factor, smoking, and monitor and characterize trends of smoking prevalence from a population and policy perspective. Specifically, in Chapter III, we used age-period-cohort models and 11 nationally representative cross-sectional data sets to illustrate smoking patterns in Mexico. With these models, we also estimated smoking prevalence, initiation and cessation by sex and birth cohort. Then, in Chapter IV, we discuss the development of a state transition model to describe observed smoking trends in Mexico. Using the estimated smoking history from Chapter III, we then projected smoking prevalence in Mexico to 2050. In turn, this model may help policy makers translate research on the most effective tobacco control policies for the Mexican context, by providing a view of their future impact through projections of the smoking burden.

CHAPTER II

Design and Evaluate a Web-Tool for Lung Cancer Screening Informed Decision-Making in Metro Detroit, Michigan

Parts of Chapter II has been published in the conference proceedings of Pervasive-Health'19 under: Hung P, Lau YK, Ackerman MS, Meza R. Designing a web-based decision aid for individuals to consider lung cancer screening. In The 13th International Conference on Pervasive Computing Technologies for Healthcare (Pervasive-Health'19), May 20–23, 2019, Trento, Italy. ACM, New York, NY, USA, 10 pages. https://doi.org/10.1145/3329189.3329210

2.1 Introduction

Cancer screening is an important public health intervention that involves the early detection of the disease when treatment is most effective. Unlike cervical, colorectal, prostate and breast cancer that have had population-wide screening for a few decades, lung cancer screening with low-dose computed tomography (CT) was only shown recently to be beneficial at reducing lung cancer mortality by 20% among those eligible [9]. Since lung cancer is the leading cause of cancer-related deaths in the U.S., with a larger burden than that of colorectal, prostate, and breast cancer deaths combined [48], being able to screen for lung cancer is an exciting development as it has the potential to improve the survival of this aggressive disease.

However, convincing people to think about lung cancer screening is challenging. Firstly, since it is a relatively new procedure, there is still a knowledge gap among both the targeted population and healthcare providers. In 2015, two years after it was recommended by the US Preventive Services Task Force (USPSTF) [33], out of 6.8 million individuals who were eligible for the low-dose CT, only 3.9% were screened [37]. Secondly, it is also the first cancer screening modality recommended for the general population by national guidelines with eligibility criteria based not only on age (and sex), but also on a behavior – smoking history. Using smoking history as an eligibility criterion presents unique obstacles that other types of cancer screening do not have. For instance, an individual's smoking history may not be accurate due to the social nature of smoking, quit attempts, the stigma associated with being a smoker [49, 50], and the denialism of health risks and fatalism among smokers [51]. Moreover, individuals considered to be "low-risk" for lung cancer are not recommended to get screened while those who are at "high risk" (i.e., people who have smoked considerably and for a long time) with a reasonable life expectancy, are strongly recommended. For these high risk individuals, the benefit of screening, reduced risk of dying from lung cancer, would likely outweigh the harms – anxiety, complications from follow-up tests such as a lung biopsy, and overdiagnosis. Other individuals may be eligible for screening, but their risk may be too low to benefit given the potential harms, and so the decision to screen becomes more of a complicated personal decision. This may be part of the reason that unlike other types of cancer screening, screening for lung cancer was the first of its kind where the Centers for Medicare and Medicaid Services (CMS) required that shared decision-making take place in order for healthcare providers to be reimbursed by Medicare, a federally administered national health insurance program for individuals above 65 years old.

Additionally, the decision memo by CMS stated that shared decision-making for lung cancer screening must include [52]:

> "the use of one or more decision aids, to include benefits and harms of screening, follow-up diagnostic testing, over-diagnosis, false positive rate, and total radiation exposure."

A decision aid is an evidence-based support tool that helps patients learn about a medical procedure/treatment, presenting the options and the potential benefits and harms, in the hopes that they can make an informed decision [53, 54]. Decision aids have been used in the context of cancer screening for various purposes, when there is more than one reasonable option to choose from [55]. For instance, they can help decide between differing recommendations from medical groups [55], as we see with different starting age being recommended for mammograms for some moderate risk individuals. Another scenario is helping patients choose between different modalities for screening a particular condition [55]. Using colorectal cancer screening as an example, colonoscopy, sigmoidoscopy, fecal occult blood test, virtual colonoscopy, and DNA stool test are all options. These options have different test characteristics and comfort levels, which may influence an individual's preference. For lung cancer screening, the decision is to get annual screening (single modality with low-dose CAT scan), or not to get screened, based on age and smoking history [33].

2.2 Motivation for renewed focus on the design of lung cancer screening web-based decision aids

2.2.1 Growing importance of health information on the web

With the growing usage of the web to look for health information [56], more directed focus on the design on web-based resources is becoming more important. The Internet has become a prominent source of health information for adults above

45 years old, closely rivaling that of healthcare providers themselves: the latest cycle of the Health Information National Trends Survey in 2017 (HINTS) conducted by the National Cancer Institute showed that 45% looked for health information on the Internet; and when there was a strong need to get information about health/medical topics, 54% responded that they would first go see "doctors or healthcare providers," while 34% said that Internet would be their first port of call [57]. There has been a steady increase in efforts to understand the unique needs of older adults in their interactions with online/e-Health resources: more generally [58], care navigation [59], cancer navigation [60, 61], and cancer education [62, 63]. However, to the best of our knowledge, there has been little focus in the Human-Computer Interaction arena with regards to patient decision support tools, which are challenging to design for as each target population of the health decision in question has special needs (e.g., women for mammography vs. men for prostate cancer screening).

2.2.2 Lack of design requirements for decision aids

The CMS requirement specifies the use of decision aids for lung cancer screening, but it does not specify how a decision aid should be used, or what medium it could be in (e.g., paper vs. web). In the same vein, the International Patient Decision Aid Standards instrument (IPDASi) guidelines [53, 54], which purports to assess the quality of patient decision aids, focus mainly on the content of a decision aid. These criteria and outcomes are, to some extent, medium neutral. In public health research, the outcomes of interest for decision aids are clinical in nature e.g. was the use of a decision aid associated with screening rates? Other outcomes of interest in public health for decision aids are knowledge about the condition and medical procedure, decisional conflict, perceived risk, etc., derived from health behavior theories such as the Transtheoretical Model [64], Health Belief Model [65], and the Ottawa Decision

Support Framework [55, 66]. We believe that not paying attention to the medium, the associated design features of that medium, the user experience, and how these all relate to the understanding and perception of the health condition centering the decision aid, may serve as a detriment to improving the health condition of interest. Below, we briefly review two decision aids for lung cancer screening that have been used/tested as it may be instructive to examine how design considerations were taken into account. Both fulfill the IPDASi and CMS criteria, and can be accessed through the web.

The Agency for Healthcare Research and Quality (AHRQ), an agency within the Department of Health and Human Services, developed a decision aid for lung cancer screening in the format of a one-page long website, with the option of printing out all the content on that page [67]. Content wise, it fulfills the IPDASi criteria [53, 54] and CMS requirements, and contains a values clarification exercise and a set of questions that a potential patient might have for when they see their doctors. The representation of the potential benefit from getting screened (i.e., relative mortality reduction) were two panels of icon arrays that display the number of deaths over 1000. The content is also available in Spanish. In terms of ease of navigation, having all the content on one page removes the confusion for the user with regards to "where to go next." However, having all the content on one page for individuals to scroll through and digest (equivalent to about 4 letter-sized pages) may be too overwhelming to absorb.

"Choice" [68] is a video decision aid from the University of North Carolina that is just over 6 minutes long (6:19) and satisfies the IPDASi [53, 54] and CMS criteria. The video is in the format of slides that are narrated, with content very similar to that of AHRQ's, but with more emphasis on getting people to quit smoking. A

disadvantage to using video as a medium is that it may take more effort than web-based decision aids to update the content. Updates are likely necessary for lung cancer screening as more data are collected when the implementation of screening gradually increases.

While there are documented benefits such as good recall and better understanding when using animations to communicate health information [69, 70], we believe there are clear advantages of using a website over a pure video for decision aids. First, the ability to update content/information readily is particularly critical in light of recent revisions to other cancer screening recommendations such as for cervical and prostate due to the evidence base being updated. For lung cancer screening, the false positive rates reported in the NLST trial [9] are already not reflective of current practice since the clinical guidelines and protocols have since changed [71]. Second, on a website, we are able to tailor information relevant to an individual based on input. This is important because of the difference in insurance coverage by age range (Medicare vs. Non-Medicare), and also to frame the message differently for smokers vs. former smokers. Additionally, being able to estimate personalized risk is important for lung cancer screening specifically because there exists a large range of risk-benefit ratio from screening even for the screen-eligible population [72]. Third, shorter and more tailored videos/animations that contain big picture messages that are not likely to change can be embedded within a website as well.

2.2.3 Limitations of the pilot study for shouldiscreen.com

In a pilot study we conducted in 2014 in Ann Arbor, Michigan [46, 47], we developed a web-based decision aid, shouldiscreen.com. This was one of the earliest ones developed in time for healthcare providers to use for the purposes of reimbursement from CMS. A prominent feature of this decision aid is that it provides a way for in-

dividuals to calculate their 6-year risk/probability for developing lung cancer. This risk may be more clinically relevant as there appears to be a wide range of risks, even among screen-eligible individuals [72]. For those considered to be at low risk, the benefit of getting screened may not be as great as someone who is at high risk. With regards to the structure of the tool, there is no fixed navigation which could be confusing for people who have not heard about lung cancer screening. However, there is a venue for users to provide feedback about the website should any confusions occur. Our decision aid also fulfills the IPDASi [53, 54] and CMS criteria.

The initial design and piloting of shouldiscreen.com used a standard development process that cancer screening decision aids have traditionally employed [55]: i) literature review with grounding in the Ottawa Decision Support Framework [66]; ii) expert review with clinicians and health risk communication scientists; iii) qualitative data from fieldwork with a working prototype; iv) pilot testing with an improved prototype; v) additional focus group feedback; vi) deployment. While this development was relatively successful, several aspects could be improved:

- The pilot study was done in 2014-2015 with a predominantly white, and highly educated population in Ann Arbor, Michigan [47]. Evidently, this demographic group does not represent everyone that should be screened. We also know that different ethnicities have different perceptions of cancer risk [73], requiring some care in the language and design of a decision aid so that it is inclusive and effective. Additionally, cancer disparities by race have been attributed to a lack of knowledge about cancer screening among minority populations [74, 75]; not catering to groups that are at high risk and already have less access to care could further exacerbate existing disparities.

- The initial development stage of the pilot study involved participants seeing a

working prototype of the website. This may have biased their views of what they truly wanted with regards to design and content, and we may not have gotten the full spectrum of possible feedback.

- At the time of the conception of the study, lung cancer screening with low-dose CT was not yet covered by health insurance or officially recommended by clinical guidelines, so the feedback we received were not anchored with the financial implications nor wide acceptance of screening. It is different now: both private insurance and Medicare covers lung cancer screening with slightly different age cutoffs, and most clinical organizations endorse lung cancer screening [76–79].

- Whilst shouldiscreen.com satisfies the International Patient Decision Aid Standards instrument (IPDASi) criteria [54], a set of guidelines recommended for developers of patient decision aids used in the field of medicine, these criteria are not specific to the format/medium of the decision aid. Health communication experts were consulted in the development to ensure that the content was represented appropriately (i.e., risks, graphs, vocabulary), but no specific considerations were given to design features catering to the target audience, and preparing them for possible patient-physician interactions.

2.3 Methods

2.3.1 Overview of mixed methods design

In this chapter, we describe a study with a mixed methods design containing elements of community-based participatory research (CBPR), which we hope will address some of the shortcomings from our pilot study in Ann Arbor, Michigan [46, 47]. CBPR is an approach that recognizes social and structural inequities in public health, and attempts to address these by actively involving community-based organizations,

community members, and researchers in all aspects of the research process [80]. For our study, there are two main reasons for using a CBPR approach. First, there are significant disparities in the burden of lung cancer in Detroit that reflects the national trend, where African American men have the highest risk for lung cancer, despite smoking less on average. We also know that uptake of cancer screening is lower among African Americans [74, 75], some of which could be contributed to lower perceived risk and lack of awareness [73]. Therefore, we need to engage the community if we do not want lung cancer screening to worsen current inequalities. Second, cultural and societal norms mediate health-seeking behaviours, as well as ideas of risk, both of which play a role in informed decision-making of a medical procedure. Furthermore, there is often a divide between the scientific field and in the community with regards to the interpretation of health risks and health care that is needed for an individual. We, in public health, need to bridge that divide and attempt to tackle this inequality by reaching out to community-based organizations and community members and request them to contribute their knowledge and expertise. This may be an effective way to increase awareness and, ultimately, informed decision-making with regards to lung cancer screening in the communities. We coupled CBPR elements with the mixed methods research paradigm, which involves the collection and analysis of both qualitative and quantitative data (see Figure 2.1). First, we conducted a series of participatory design (PD) workshops [81] with African-American and Latinx communities in Metro Detroit. Here, study participants were the designers themselves. We, the researchers, then identified salient features of the different designs and content generated across the workshops that may be pertinent to help potential users of shouldiscreen.com during decision-making process for lung cancer screening. Second, we implemented content changes derived from the workshops to a

beta, English version of shouldiscreen.com, and evaluated this modified version with a before-after study with the African American community we had been engaging. Third, we conducted post survey focus groups with a subset of survey takers soon after the surveys to provide more extensive evaluative feedback. Finally, we followed up via the phone with all survey takers 6-8 months after the baseline survey to see if they attempted to seek out screening.

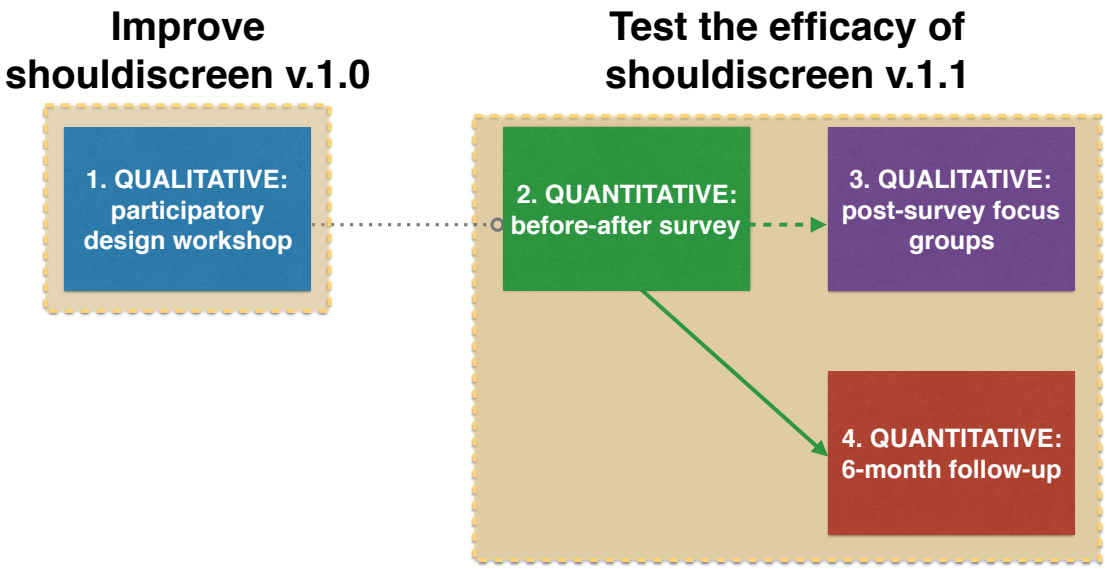


Figure 2.1: Schema of the mixed method study to improve and test shouldiscreen, a web-based decision for lung cancer screening

We engaged with various community-based organizations on the east side of Detroit that served the African-American community: Eastside Community Network, 8330 East Jefferson's Residents Committee and Detroit Area Agency on Aging. In partnership with them, we conducted recruitment for the participatory design (PD) workshops and before-after surveys via: canvassing homes and parks in East Detroit, tabling at prominent community centers and various community events, flyering in downtown Detroit, and speaking at community town hall meetings. Participatory design workshops and the before-after surveys all took place at the premises of Eastside

Community Network, a well-known and respected organization serving the community on the east side of Metro Detroit. The post-survey focus groups took place at the University of Michigan Detroit Center, which was centrally located and more convenient for a number of participants from the west side of Detroit.

To involve the Latinx community, we partnered with the Community Health and Social Services (CHASS) Center located in the southwestern part of Detroit. CHASS is a community-based, non-profit organization that also serves as a primary healthcare center for both insured and uninsured populations, who are mostly Hispanic. Here, CHASS generated a list of patients who were current or former smokers, and they were contacted and asked if they would be interested in being a part of a study for lung cancer screening. Participants recruited through CHASS spoke Spanish and only participated in the PD workshops, and not the before-after surveys.

2.3.2 Eligibility criteria

Study participants were eligible to be a part of our mixed methods study if they were between 45 and 77 years old, and also did not have a history of lung cancer. Below, we divide the description of the methods broadly into two sections: i) the PD workshops, which are the formative part of the mixed methods study to generate design insights to improve the current rendition of shouldiscreen, and ii) the before-after survey followed up with focus groups and 6-month telephonic follow up, which are the evaluative part of the study and tests the efficacy of shouldiscreen. Parts of the focus group findings were incorporated with the PD workshop findings for the purposes of triangulation so there is some overlap with the descriptions. Note, however, that participants who were in the PD workshops could not take part in the before-after surveys or the post-survey focus groups.

2.3.3 Participatory design workshops

With the goal of understanding laypeople's perspectives on how a decision aid can better engage them to think about lung cancer screening and understand the related harms and benefits, the research team hosted PD workshops [81] with African American and Latinx current and former smokers. We conducted the English workshops with the African American study participants in eastern Detroit with a facilitator (the author) and a research assistant, while we had a Spanish-speaking facilitator, a research assistant and an observer (the author) for the PD workshops in southwestern Detroit. In total, five PD workshops took place, with a total of 17 participants, aged between 45 and 77. Among these participants, 13 are former smokers and 4 are current smokers.

The workshop consisted of four steps that were designed to explore laypeople's views on what they considered important with regards to lung cancer screening and also to obtain feedback about the content of an existing web-based decision aid [46]. First, participants were given a scenario that illustrated a situation where the main character was worried about a family member or loved one having lung cancer, and wondered about whether/how they could approach them about lung cancer screening. Participants were encouraged to pick their own family member or loved ones instead should they feel comfortable. Participants were then asked to write down any questions they might have regarding lung cancer screening. Second, participants teamed up in groups of two or three to collaboratively design a website or online resource that can answer the questions they had generated. Participants were instructed to sketch and draw on flip charts and use sticky notes to add any form of content if desired. Each group would show their design to the rest of the workshop participants to help everyone understand their design and get feedback.

Third, after designing their own website, participants read a set of paper cut-outs that contained all the content from shouldiscreen.com, an existing web-based decision aid, and give feedback regarding 1) whether they could understand (and if not, identify the parts that were difficult), and 2) whether they found the information useful. Fourth, participants were asked to add these paper strips to where they felt suitable on the website they had designed on the flip charts. Throughout this process, a research assistant was assigned to each group to facilitate the discussion. The assistant also observed the design process and wrote down notes. We chose a group-based PD because lung cancer screening is a new, relatively unknown procedure. PD allows participants to engage in the design process by raising questions and discussing suggestions. Moreover, due to the stigma surrounding smokers, participants (i.e., current/former smokers) feel more comfortable expressing opinions to group members with similar experiences. Also, by having participants sketch their designs as the main PD activity, participants get a tangible artifact that visually documents their ideas and their importance, and the process of refining the design over time.

With regards to the analysis, there was a debrief among research assistants and I directly after the workshops leading to a brief report. The workshops were audio recorded and transcribed. Spanish transcripts were translated into English. We used thematic analysis to analyze the transcripts, notes, and participants' sketches to identify the major themes that provide insights into the design of a lung cancer screening decision aid that could be useful to an individual with the decision-making process. Another researcher in the study team and I coded and analyzed the sketches independently. The other researcher then analyzed the transcripts of the workshops and discussed the findings with me to harmonize the themes gleaned directly after the workshops.

We then created a version of shouldiscreen.com to include additional information regarding insurance coverage criteria, as we found it to be important for participants, and asked 21 individuals over 5 focus groups from the African-American community we had been working with who did not participate in the designing process to evaluate this version. Inclusion criteria for focus groups are the same for the PD workshops. Focus groups were used for triangulation as we felt the need to verify the workshop findings with focus group findings before major feature updates. The analytic procedure for the focus groups was similar, except that the first and second author independently coded the transcripts.

After we consolidated some preliminary findings and derived design implications from this round of design and evaluation, we presented this work to two community partners who provided access to their communities. We also presented these findings to two clinicians who specialize in lung cancer screening and have been working with patients in two health systems in Michigan, who also serve as the clinical consultants for shouldiscreen.com. We believe that for a patient-centered tool, feedback from clinicians would be important. Given that lung cancer screening is a relatively new procedure, patients may have misconceptions of risks and benefits that clinicians can address. Moreover, patient-centered tools surrounding shared decision-making of medical procedures should explicitly support patient-doctor interaction.

2.3.4 Before-after survey

After we concluded the participatory design workshops with participants from the African American commmunity, we recruited new participants to be a part of the before-after study. Following a successful screen for study eligibility, a participant was invited to complete a series of surveys that we had previously developed for the pilot study [46]. Participants had the option of choosing to complete an online ver-

sion of the survey administered by Qualtrics (an online survey platform) on a laptop purchased for the study, or on paper. This survey contained questions with regards to socioeconomic status, smoking history, knowledge of lung cancer and lung cancer screening, decisional conflict, health literacy, and numeracy. At a participant's indication of completion, the research assistant directed the participant to the website where the decision aid is located. The participant was then asked by the research assistant to explore the website and asked him/her to let the research assistant know when he/she was done reviewing the website. This decision aid includes: information with regards to LDCT screening, explanation of the risk factors of lung cancer, insurance coverage, and a lung cancer risk calculator which will compute a personalized risk, illustrated by infographics. Note that the insurance coverage information, and an abridged version of the original infographics were new additions as a result of the PD workshops. When the participant was done reviewing the website, the participant was asked to complete another set of questions, including: knowledge of lung cancer and lung cancer screening, decision conflict scale, and acceptability [46]. To test for the difference of means between the before and after survey in the knowledge and decision conflict score, we conducted Wilcoxon rank sum test. For concordance, we used the McNemar's test. All data analysis was conducted in R [82]. Surveys took place between April and July 2018 and each session lasted approximately 60 minutes.

Changes in outcome measures from the pilot study

As with the pilot study, the outcome measures of the current study's before-after surveys were derived from the Ottawa Decision Support Framework [66], including knowledge of the risk factors of lung cancer, and the potential benefits and harms lung cancer screening, decisional conflict [83], and acceptability. Unlike the pilot

study which used the traditional decisional conflict scale, we used the shorter version with 10 items and 3 response categories, which has good psychometric properties relative to the traditional version (alpha coefficient = 0.86) [83]. we used the shorter version in part to reduce the survey burden, as we included other items to measure health literacy and numeracy. Specifically, we added items from "BRIEF: Health Literacy Screening Tool" [84] to help determine the level of health literacy among our participants (see last three items on Table 2.1). To measure health numeracy, we included items from the General Health Numeracy Test [85].

2.3.5 Post-survey focus groups

Subjects who completed the before-after survey were invited to participate in a focus group to probe the responses, particularly about the items regarding acceptability and usability of the tool. All participants accessed the beta version of the decision aid again on an iPad / tablet individually to refresh their impression of the tool. After everyone in the focus group was done reviewing the tool, I led the focus group and asked questions pertaining to the usability of the decision aid (see Appendix A.1). A research assistant was also present to observe and take field notes. Each session lasted approximately 90 minutes, and was audiotaped by an iPad and/or dictaphone.

2.3.6 Six-month telephonic check-up

All participants who took part in the before-after study were called after approximately six months, with a maximum of three attempts. They were asked up to 20 questions about steps they had taken to see a doctor about lung cancer screening, and resources they might have used for smoking cessation (see Appendix A.2). This follow-up took 5-10 minutes, and responses were recorded by a research assistant

directly on Qualtrics.

2.4 Findings

2.4.1 Participatory design workshops

Through the participatory design workshops, focus groups, and feedback from physicians and our community partners, we identified three aspects — vocabulary, time, and delivery — where the differences between patients and physicians have made the current design inefficient. Below, we describe these through the perspectives of (potential) patients and physicians to demonstrate the challenges of designing decision aid. Below, we will use "patient" to refer to people who might benefit from lung cancer screening.

I. Vocabulary: We speak different languages, but we need to understand each other

Patients Patients were motivated to understand what was at stake, but needed a more familiar tone and language that speak to them. Since lung cancer screening is still largely unknown to the general public, patients need help to understand the relevance of lung cancer screening to them. For instance, one common factor brought up by patients was to talk about symptoms to which people might relate to stimulate the consideration of having lung cancer screening. Another suggestion that emerged was the use of regular folk who are not physicians who had gone through the screening to "speak to us," so as to better relate to their message. Patients also did not understand some of the medical vocabulary and explanations used on the existing web-based decision aid. Explanations for "nodules" and "CT (computed tomography) scan" were commonly requested. Another major barrier was the presentation of risk (a required item from IPDASi guidelines [54]) and its meaning. Risk presented in terms of probability and icon arrays were too abstract; instead, patients asked how

their estimated risk would relate to potential outcomes of the screening, and the subsequent impact on their quality of life.

> "What I'd like to see first is, not professionals, but average people talking... I want it to open up with people talking in layman's terms, and the conversation they have is who is at risk about lung cancer and things they see, what was [sic] the signs that they have, and then tell me there is a test to detect lung cancer." – Female smoker, participatory design workshop (African American)

Even when patients had no trouble reading and understanding the content, they might not 1) understand the rationale or 2) be able to extract the message that the decision aid developers hope to deliver, so end up being confused. During the workshops, when participants were asked to go through the content from the decision aid, they often ask these two types of questions 1) "I see... but why?" and 2) "Ok... so what?" These suggest that some of the content is either too concise or being too implicit about the underlying messages.

> "I think it [lung cancer screening] should be before the age of 55. Why is it at the age of 55?" – Female smoker, participatory design workshop (African American)

To summarize, we found that while certain representations of information — bullet points, icon arrays, and tables — present information in a concise format, patients might find it too brief and still need help interpreting the available information.

Physicians The physicians in general agreed with the need for an online decision aid to connect to the target audience better, possibly through more familiar tone

and language. However, they also strongly believed that the design should not bias patients towards/against screening. For instance, in reaction to patients' suggestions of showing the relevance using familiar language and symptoms, as Doctor B stated,

> "This is a difficult issue, and I do understand that people need to feel that it's important. On the other hand, part of this is a decision tool, and it's meant to be relatively neutral or balanced about things. And so, having a landing page that has too much of a hook can be an issue... How do you get people to know about the symptoms? The screening approach of old is they'll have something very scary sounding. Q: What are the signs that you have lung cancer? A: You'll feel fine. We are trying to move away from that."

The physicians, while understanding why the participants brought this up and had also received similar reactions from their patients, repeatedly emphasized that this would mislead people into thinking that symptoms are needed before people get screened.

Regarding the issue of medical vocabulary and interpretation of risk, the physicians acknowledged that while the decision aid might be informative for a patient if a health professional is present to help explain, the content is likely to be difficult for laypeople to digest. For instance, Doctor A mentioned his experience of having to explain the concept of nodules frequently to his patients:

> "Phrases like 'nodules are like freckles'... I mean, they're like freckles, but not really... Freckles are on the skin, but they're very similar in that they're an 'imperfection' and it doesn't 'belong' but they're functionally inconsequential, right? And it's a disarming term, right? You can see the

change in the patient's face, the tension, literally just drain away when you use terms like that."

II. Time: My concept of what matters when is different to yours

Patients We observed that patients think about screening on different time scales. When given the scenario in the workshop and asked to think about questions they might have regarding lung cancer screening, the questions often followed a process or sequence of events (see Figure 2.2). These questions can generally be categorized into the following types: why should I care, what does the procedure involve, what are the side effects if I get screened, and what happens after getting the results if they are positive/negative. Naturally, different patients think about the timeline with different granularity. While some focused on the process of making the decision to screen and some focused on the screening process itself, others also recognized the possibility of follow-up procedures and treatment and asked more questions about the entire process.

Physicians The physicians we interviewed reacted positively to the idea of screening being a process, but was surprised that some patients also held the same view. From a physician's experience, patients often assume that lung cancer screening is a one-time event and could result in good or bad news. For instance, Doctor A was surprised that our workshop participants asked questions about screening in a process-oriented way.

"You know, it's interesting to hear you use the terms concepts and flow. My perception is that patients think of lung cancer screening as a one-time event. I passed the test. I try to emphasize to patients that lung cancer screening is a process that takes place over multiple years, and I'm

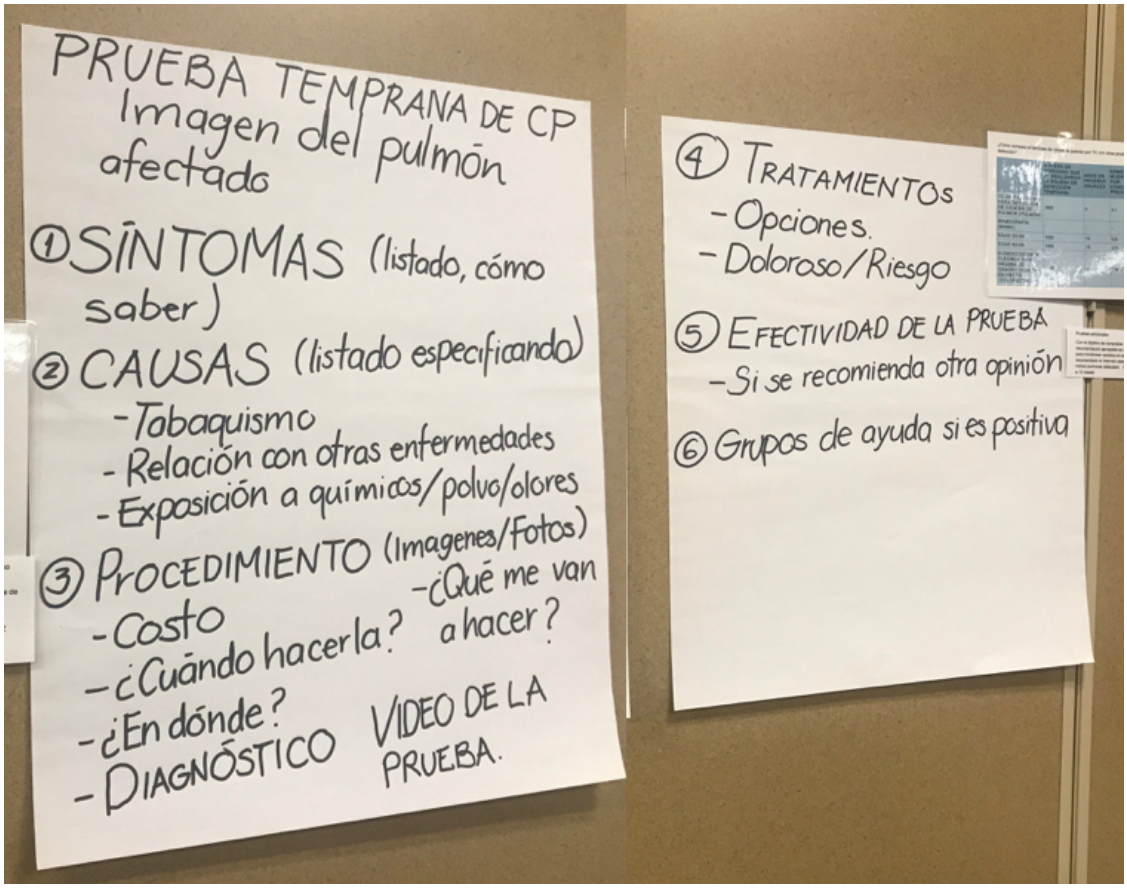


Figure 2.2: Landing page designed by a Spanish-speaking group that highlighted the themes in this order: 1) Symptoms; 2) Causes; 3) Procedure; 4) Treatment; 5) Effectiveness of the test; 6) Support groups if tested positive

surprised that you hear that people describe it that way."

Of course, we should acknowledge that our participants might be different from people who have reached the stage where they are discuss with physicians regarding the possibility of going through lung cancer screening. Nevertheless, our observation from the workshops, focus groups, and interviews with physicians suggest the following two findings. First, potential patients do think about the screening process on different time scales. Second, potential patients' sense of time regarding lung cancer screening is different from what physicians have experienced with their patients during the shared decision-making process. These have some implications for the design of a decision aid.

III. Delivery: Recognize me as a unique individual, part of a group

Patients In the process of getting evaluative feedback regarding the design of the existing decision aid, our focus group participants expressed a desire to be treated with empathy, as unique individuals with different lived experiences.

During the focus groups, one topic that sparked a lot of discussion was how health resources and professionals treated smokers. As smoking is recognized as a major risk factor of lung cancer, many health education materials and healthcare professionals emphasize the need to quit smoking. Smokers know that they should quit, but they felt people should acknowledge how they came to be smokers (e.g., it was the norm), and stayed being smokers (e.g., as a result of different life stressors). As we heard in a focus group:

> "It's long time ago. Smoking was just..., they did not tell us it is harmful. You turn on TV and see all these glamorous movie stars, they smoke and so you did not really think that smoking was bad back in the day... and when you were young, it was cool that you could hold cigarettes..." – Female smoker, focus group (African American)

Another demonstration of why this recognition is important is how smoking habits are asked in the decision aid. For instance, it features a risk calculator that takes a person's demographic information and smoking history as input and calculates the risk of getting lung cancer. One of the problems raised by participants is that the calculator assumes a person can accurately recall and calculate their smoking history, when one often smokes more (or less) or quit due to changing life circumstances.

While expressing the need to be treated as an individual with a unique relationship with smoking, we noticed that participants working through the decision aid in pairs

stimulated lively discussions about the materials. This observation suggests that the decision-making process could be enhanced with a peer or group (or simply social) learning environment. With people who share and understand similar lived experiences (e.g., smokers who have been smoking since their teens), people found that they were able to "find their voice" and have a conversation about the decision they were considering in a safe and non-judgmental context. During and after focus groups, the facilitator received multiple instances of feedback reflecting the benefits of learning and discussing the decision in a peer or group setting, as opposed to patient-doctor pairing where they may feel judged for being a smoker.

2.4.2 Before-after surveys

Data were collected from 78 participants in the African American community we engaged with and their characteristics with regards to demographics, socioeconomic status, and health literacy at baseline, are summarised in Table 2.1. The average age of our study participants was 63 years old with an almost-even gender split. The majority were current smokers, with just under a third being former smokers. In contrast to our pilot study in Ann Arbor [47] where about only 9% completed a high school education or less, in this study, it is 38%. There were also about 2.5 times more current smokers compared to the pilot study. The proportion of participants eligible (according to their self-reported information) were about the same in both (18% in Ann Arbor, 20% in Detroit). Although based on feedback from the post-survey focus groups, the 20% may be an underestimate as participants had difficulty recalling and summarizing their smoking history into two numbers (i.e. total number of years smoked, and average number of cigarettes smoked per day in those years). Of the 16 people who would be eligible to be screened under USPSTF criteria, 12 were current smokers.

Table 2.1: Descriptive statistics of study participants (N = 78)

Variable	% (n)
Age (mean, SD)	63.4 (7.63)
Gender	
Male	51.3% (40)
Female	49.7% (38)
Smoking status	
Current smoker	69% (54)
Former smoker	31% (24)
Eligible to be screened	20% (16)
Education	
8 years of schooling or less	6.5% (5)
8-11 years of schooling	11.7% (9)
12 years or completed high school	19.5% (15)
Post high school training	10.4% (8)
Some college	31.2% (24)
College graduate or higher	18.2% (14)
Postgraduate or professional degree	2.6% (2)
Income	
Less than $15000	52.6% (41)
$15000-$24999	23.1% (18)
$25000-$34999	9.0% (7)
$35000+	5.2% (4)
Don't know/Prefer not to answer	10.3% (8)
Medium of survey	
Computer	50% (39)
Paper	50% (39)
Electronic devices owned	
Basic cellphone only	28.6% (22)
Smartphone, such as iPhone, Android, Blackberry or Windows phone	33.8% (26)
Tablet like an iPad, Samsung Galaxy, Motorola Xoom or Kindle Fire	7.8% (6)
A smartphone and a tablet	20.8% (16)
I have none of these devices	9.1% (7)
Access to internet at home/work	
Yes	51.3% (40)
No	46.2% (36)
Don't know/Not sure	2.6% (2)
How often do you find numerical information to be useful	
Always	52.6% (41)
Often	23.1% (18)
Sometimes	9.0% (7)
Occasionally	5.2% (4)
Never	10.3% (8)
Trust of risk predictions of getting a disease in future	
A lot	16.2% (12)
Quite a bit	33.8% (25)
Somewhat	32.4% (25)
A little bit	17.6% (13)

Table 2.1: (continued)

Variable	% (n)
How often do you have someone help you read hospital materials	
Always	5.1% (4)
Often	2.6% (2)
Sometimes	20.5% (16)
Occasionally	21.8% (17)
Never	50.5% (39)
How confident are you filling out medical forms by yourself	
Extremely	37.7% (29)
Quite a bit	24.7% (19)
Somewhat	22.1% (17)
A little bit	6.5% (5)
Not at all	19.1% (7)
How often do you have problems learning about your medical condition because of difficulty understanding written information	
Always	52.6% (41)
Often	23.1% (18)
Sometimes	9.0% (7)
Occasionally	5.2% (4)
Never	10.3% (8)

Half of the participants opted to complete the survey using paper. The reasons participants gave were: discomfort with navigating a computer device, font on the laptop was too small as reading glasses were left at home, arthritis, felt it was more private to complete a paper survey as opposed to an online survey, and peripheral neuropathy. With regards to health literacy, about a quarter of the participants have trouble understanding written health information. We also asked questions to gauge the level of numeracy in our participants and we saw that the concept of "risk" as a probability was not well-understood, affirming what we found in the PD workshops. We asked: "If 4 people out of 20 have a chance of getting a cold, what would be the risk of getting a cold?" Eight out of all participants answered this correctly. Another question asked: "Your doctor tells you that you have high cholesterol. He informs you that you have a 10% risk of having a heart attack in the next 5 years. If you start on a cholesterol-lowering drug, you can reduce your risk by 30%. What is your 5-year risk if you take the drug? " None of the responses entered were correct. We also

asked: "A mammogram is used to screen women for breast cancer. False positives are tests that incorrectly show a positive result. 85% of positive mammograms are actually false positives. If 1000 women receive mammograms, and 200 are told there is an abnormal finding, how many women are likely to actually have breast cancer?" For this question, 7 responses were correct. Finally, it is also important to keep in mind that almost half of the participants have no access to the internet at home or at work.

In Table 2.2, we show the changes in knowledge, decisional conflict, and concordance, between before and after seeing shouldiscreen.com. The maximum scores for each category are shown in the square parentheses. With regards to knowledge, the higher the score, the better. For decisional conflict, lower scores mean lower decisional conflict; i.e. a better outcome. Knowledge about risk factors and screening between before and after viewing the decision aid was 5.63 and 6.89 out of 13 points, respectively (24% increase). When we stratified knowledge by survey mode, we found that there was a 53% improvement in knowledge score among those who took the electronic survey (5.75 to 8.8), and 14% for paper (5.51 to 6.29). Concordance between individual preference and eligibility for screening increased from 22% to 34% (n = 74). The primary source of discordance was from those who should not be screened but prefer to be screened, although the largest improvement came from those who were unsure. Lastly, we found that acceptability was high: 93% of all participants said the tool helped them consider screening.

	Mean (SD)		p-value	Relative change
	Before	After		
Knowledge (overall) [13]	5.63 (1.99)	6.98 (2.30)	< 0.001	+ 24%
Factors that increase the chances of getting lung cancer [5]	2.63 (1.08)	3.21 (1.09)		+ 22%
Possible benefits of lung cancer screening [3]	1.37 (0.85)	1.62 (0.89)		+ 18%
Possible harms of lung cancer screening [3]	1.18 (0.80)	1.42 (0.97)		+ 20%
Age eligibility for lung cancer screening [1]	0.41 (0.22)	0.54 (0.24)		+32 %
Percentage of lumps found on your lung by CT that is not going to be cancer? [1]	0.04 (0.19)	0.19 (0.40)		+ 475%
Decisional Conflict Scale [40]	17.46 (11.35)	8.77 (9.58)	< 0.001	- 50%
Concordance (n = 74)	0.22 (0.41)	0.34 (0.48)	0.016	+ 55%

Table 2.2: Before and after: knowledge, decisional conflict and concordance

2.4.3 Post-survey focus groups

Among current smokers, some of the common themes that emerged were: fear of finding out of having lung cancer if they got screened; concerns about invasive tests after the initial screen; and did not feel the need to get checked since they feel good. The combination of the first two seemed to indicate some tensions among current smokers where they were aware that they were at higher risk of lung cancer, but at the same time, were in denial about it. There was the general feeling that people would only care to look for information about getting the lungs checked if you feel something wrong is with your body i.e. "symptoms," as we found in the PD workshops as well. Also, "feeling good" was part of some participants' justification of why they continued to smoke. On the other hand, former smokers were eager to suggest various ways of quitting strategies and "grab people's attention" for screening. Some examples were: having a "Smokers' Anonymous" group, having people describe their experience with getting screened and then finding lung cancer on local TV and radio, showing black lungs to scare smokers into quitting, etc.

With regard to content, both current and former smoker groups had questions about the age range of eligibility and wondered why they could not be screened younger than 55 years old. This would indicate that some brief explanation about how the eligibility criteria were derived may be helpful. Almost everyone agreed that there was enough information on the website to help them learn about lung cancer screening (a few noted there was a lot of information to digest). Additionally, honesty and openness about the harms were considered important and appreciated by the participants. "CT scan" was not commonly understood but "CAT scan" is, though the procedure often confused with MRI. Many have suggested that the Homepage banner image should be the CT machine instead of the actual CT scan, as no one

knew what the banner image depicted. Moreover, it seemed that the navigation structure of the website might be too open-ended such that people were not sure where to go next as a number of participants asked the facilitator which page they should navigate to after reading through the landing page.

For the results page displaying the six-year risk of dying from lung cancer, the general sentiment was that the actual figure of risk in percent did not matter as much as the actual recommendation of to screen, or not to screen. This would align with the level of understanding of risk as a percent/probability that we saw in the before-after survey. We also discovered that some participants did not actually get to the risk calculator page during the survey. When they filled in the risk calculator for the first time, we realized that they needed help with calculating the years they have smoked, in combination with the amount smoked – some said they have tried quitting a number of times in their lives and the amounts smoked varied depending on when the period. A participant also mentioned that they only entered information on their most recent spell of smoking. This all points to the fact that capturing smoking history, in particular, duration and intensity, is challenging. Two participants mentioned that they exclusively smoked cigars and were unsure how to convert that to number of cigarettes in the pack-year calculator. One of the cigar smokers also self-identified as a non-smoker. It would most certainly be untrue that people who smoke cigars are not at risk for lung cancer. But how should cigars, and other tobacco products, be integrated into any lung cancer risk calculator?

2.4.4 Six-month check-up

Only 14 out of 78 participants were successfully contacted. Of these, three were eligible for screening according to USPSTF criteria. Five followed up with their physicians, and the three who were eligible were strongly encouraged to be screened.

Two went through with lung cancer screening and one had quit smoking.

2.5 Discussion

2.5.1 Participatory design workshop

Through participatory design workshops and focus groups, and triangulating these findings with two physicians experienced with lung cancer screening, we identified three themes — vocabulary, time, and delivery. Below, we present design suggestions for customizing a web-based decision aid for a relatively new medical procedure, lung cancer screening. These suggestions are developed with the goal of providing decision aid designers with some tangible tools to complement the existing content-oriented guidelines [54].

Bridging the Gap: Decision Aid as a Mediator for Patient and Physician

Our findings suggested that a decision aid of an unknown medical procedure (i.e., lung cancer screening) for traditionally under-screened populations needs to have two functions: raising awareness, and facilitating the transition from awareness to action (i.e., consult with physicians). To do so, one crucial step is for decision aid designers to make a concerted effort to bridge the vocabulary and language used by patients and physicians.

Raising Awareness through Relevance Conveying a sense of relevance is key to raising awareness through an online decision aid. Decision aid developers could make the tool more approachable by presenting information through perspectives people can relate with. To provide an entry point without swaying people from the outset, which was a concern for the physicians, we recommend showing relatable perspectives from those who decided to get screened, as well as those who decided not to. The perspectives shown can focus on the thought process and experience working with

different stakeholders before reaching the decision, and reflection after the decision (or screening). We believe this is pertinent when there is uncertainty about people's attitudes and knowledge with regards to the target medical procedure, as it could increase the chances of visitors having a positive first impression and staying engaged [86] in other important content the decision aid intends to promote.

Existing work on how patients manage chronic conditions has shown that patients and caregivers find connecting with people with similar experiences (i.e., as patients or as caregivers) to be helpful, as they provide the necessary emotional support in addition to purely informational support [87, 88]. They also have the capability to translate general health information that is sensitive to contextual factors such as socioeconomic background and living environment [89]. The feeling that "this person understands me" is really important, as workshop participants have repeatedly emphasized the importance of shared experience for the design of the landing page. For instance, participants designed a decision aid with a landing page featuring a person with a similar background explaining screening, as shown in Figure 2.3. We would like to stress that this general principle should be applied throughout the decision aid and not just the landing page, as it is common for people to reach an arbitrary page on a site through search engines for health information [56].

Here is an example of implementing this design suggestion to provide relatable perspectives to highlight the relevance of the decision in question to their target audience. To tailor information presented to users, a decision aid could present people's perspectives in the form of questions that people with different profiles (e.g., history of smoking, age, sex/gender) frequently ask, and connect users to suggested relevant resources. For instance, "I have been smoking for X years, should I ...?", "I used to smoke, but I have stopped. Am I ...?" The questions could also be presented

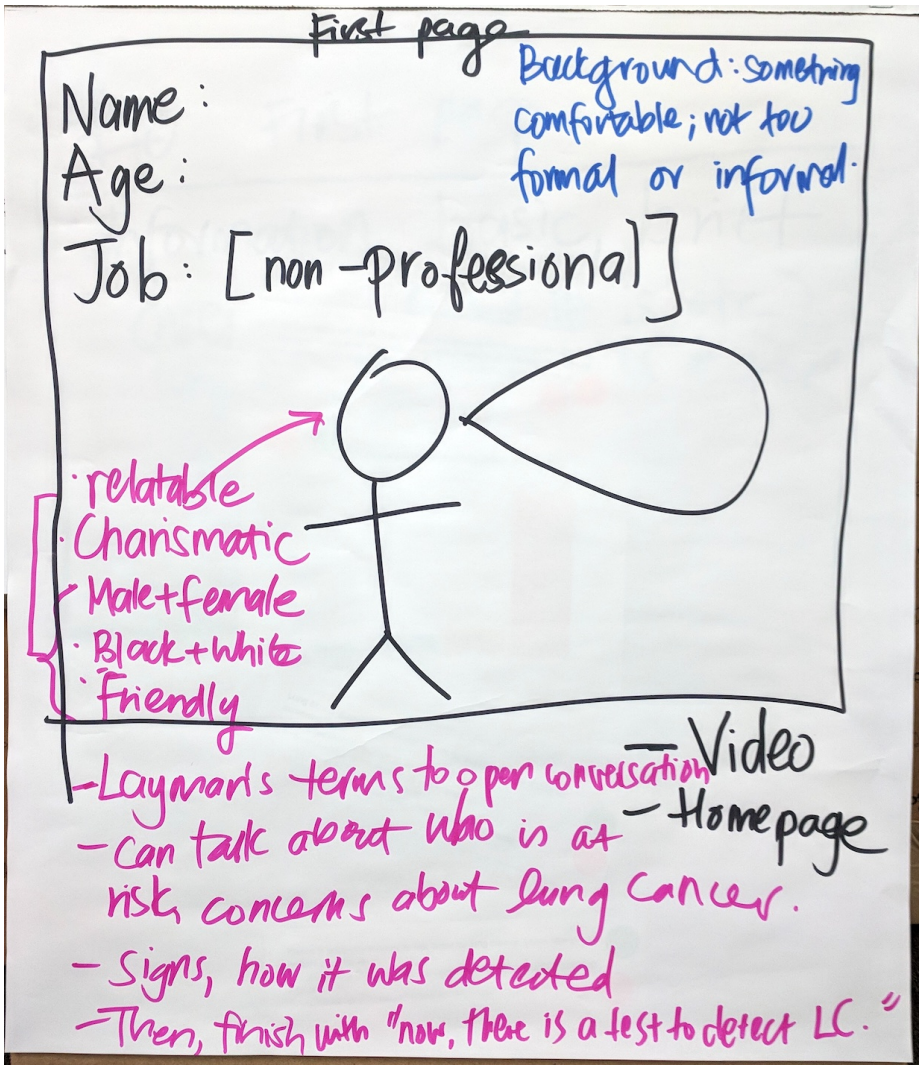


Figure 2.3: Landing page designed by a Participatory Design Group (African American) with a relatable person

in the view of health professionals to help overcome people's (i.e., smokers) fear of cancer and stigma to initiate learning, thinking, and action (e.g., visiting a doctor) [63]. The provided responses could be further supplemented by stories — through text, storyboards, or videos [90] — from patients, caregivers, and clinicians that detail their own experience before, during, or after screening to help individuals see the perspectives of someone who had a similar experience (or a clinician's observation).

Connecting Everyday Language and Medical Vocabulary Designing an online decision aid that appeals to traditionally under-screened population is challenging as it can easily lose the audience if the content does not "speak to them." With the general public having relatively low levels of literacy, health literacy [91], and graph/numerical literacy [92], it is not surprising that we found our participants had trouble with the information presented as well. Patients unfamiliar with medical vocabulary might stop or limit their engagement with the decision aid, or worse, prevent them from working with health professionals [93]. This unfamiliarity is likely to disproportionately affect people with low socioeconomic status and lower levels of literacy, and may exacerbate existing disparities of the lung cancer burden. Joseph-Williams et al. [54] have suggested field-testing and controlling the reading level, but they do not give specific directions for improvement. On the other hand, if potential patients do consider taking action and consult with physicians, decision aids should equip patients with the vocabulary and knowledge to empower them to be active participants in the shared decision-making process. Using layman's terms, while desirable, is not enough: decision aids need to bridge the gap between potential patients' and medical professionals' languages so that they can better interact with each other during the shared decision-making process.

Existing literature suggests various ways to tackle the issue of literacy using multimedia [58, 94], crowdsourcing translation of existing materials [95, 96], providing definition and analogy [92, 92, 97], and virtual agents to provide structured information [59, 62], with the central theme of using the more accessible layman's terms, particularly for people with low levels of literacy. Building on existing literature, we propose to use everyday language, not as a replacement, but potentially to augment existing medical discourse/thinking to facilitate understanding. This will allow both

medical professionals and people without medical training (e.g., patients and caregivers) to not only understand the concepts, but prepare them for the discussion. This is likely to be beneficial, as illiteracy has been shown to cause shame and prevent people from approaching clinicians [93], while clinicians also need to acquire skills to communicate with patients effectively [98].

Here, we describe an example of applying this suggestion that can be used to improve an existing decision aid. A hover-over dictionary can be developed to enhance an existing web-based decision aid to provide layman annotations for formal medical descriptions, and vice versa. For instance, to explain the benefits of screening (e.g., lung cancer mortality risk reduction), an entry could be created to elaborate on the tangible benefits that people can easily understand, such as living longer and spending more time with family. The key feature of this dictionary is to allow stakeholders to contribute their ways of describing a medical condition or procedure. This feature allows not only patients, but also clinicians to collaboratively provide alternatives for explaining different medical discourse. From our interviews with physicians, we found that their engagement with patients requires them to find effective ways to explain different concepts to patients. Allowing stakeholders to collaboratively curate such a dictionary can facilitate the sharing of these beneficial patient-doctor communication approaches.

Foster Shared Understanding with Concrete Take-Home Message In addition to managing the discrepancy between patients and physicians' vocabulary, we have also identified a critical issue that might render a decision aid ineffective: patients do not have the necessary training to interpret scientific facts as medical professionals do. Decision aid developers should take care not to let succinctly presented, scientifically

accurate information overshadow the delivery of a clear message and explanation of the rationale to patients. Otherwise, confusion and stress about understanding the main message might drain a patient's energy and affect the efficacy of the decision aid.

One plausible solution to tackle the dilemma between being concise and provide information (e.g., explanations) that might overwhelm users [99] is to apply the idea of training wheels for user interface design proposed by Carrol and Carrithers [100]. Decision aid developers could consider getting the core messages out by directing visitors' attention to those messages and progressively reveal more information/explanations as needed. This will likely reduce the barrier for our population with low literacy and computer skills. For instance, one can add a topic message or explanation card deck that will show visitors the major message, takeaway, or explanation to different locations where information is presented (e.g., in text or charts). The deck can be customized to appear before or after users have engaged with the materials, to progressively reveal or reemphasize information.

Bending Time: Decision Aid as a Time Machine to Navigate the Screening Process

Through triangulating feedback from patients and physicians, we learnt that using a timeline to structure the information presented in a decision aid not only could be a viable way to help patients navigate through health information in a structural manner, but also has the potential to help patients understand that lung cancer screening is a process, instead of a one-time event. To accommodate differences between laypersons and health professionals' views on the target medical procedure as a whole, decision aid developers could consider providing different overlays (e.g., menu, annotation, or navigation aid) that highlight the process-oriented views of different stakeholders. Providing organization of materials based on the sequence of

events will likely help people see the big picture, and access content on the decision aid in a structure that aligns with their thinking about a medical procedure, without being overwhelmed by information.

As we have found that patients have different conceptualization of time, possibly due to their current interest (e.g., understanding, considering, under-going lung cancer screening), decision aid developers could further consider allowing navigation facilities (e.g., menu) to selectively "zoom-in" to unfold information relevant to a specific time period while hiding information more relevant to other stages. For instance, the decision aid could allow users to zoom in to the "understanding" phase where background and main idea of lung cancer screening is introduced, while entries for actual screening procedure and follow-up steps will be aggregated and revealed only if users decide to understand more. On the other hand, users can also choose to "zoom-out" by folding the details of the actual screening procedure and digest information in a "before-after" mindset.

Here is an example of how to make use of the design suggestion to guide visitors. As stakeholders might have different views of important events [97, 99], a decision aid can support customizable roadmaps that can be tailored by different groups of audience [96] to intuitively guide users across different materials. For example, the decision aid can have a layperson mode or physician mode [97] of presenting information, depending on who is navigating the decision aid. We argue that, while having different ways of accessing could be confusing and challenging for people with a low level of computer literacy [63], allowing different roadmaps displayed simultaneously is a good opportunity for decision aids to help stakeholders understand everyone's perspectives. In fact, the ability to bridge the gap between different stakeholders' perspectives could potentially help patients (and physicians) prepare for a productive

clinical encounter.

Creating Space: Decision Aid with Inclusive Decision Support

This design suggestion aims at accommodating people's need to be recognized as individuals, each with their own reasons for starting, continuing, and quitting smoking. In our study, lung cancer screening appeals to current smokers and former smokers very differently, with current smokers often preferring not to know the status of their lungs. To appeal to both groups, we should be cognizant of the framing of the message. Indeed, former smokers in our focus groups were very keen on using "scare tactics" to get current smokers to quit and get their lungs checked. Unsurprisingly, this was not what the current smokers wanted to see. Relatedly, this leads us to the observation that former-smoker groups and current-smoker groups have high within-group rapport, where the stigma of being a smoker becomes less of an issue, suggesting that decision aid developers should consider providing opportunities to facilitate peer or group activities. By inviting similar and yet different individuals to support each other in the decision-making process, stigma may play a lesser role and users could engage with the decision aid with an open mind. As online peer interaction has been suggested to be important for understanding medical information and making decisions [101], decision aid developers should actively think about different ways of nurturing such environments through digital tools or in-person activities. Here are two examples of adding a social layer to a decision aid to improve user experience.

Learn together with social traces: A decision aid can collect data detailing visitors' behaviors, or traces, and present them in different forms to other visitors to create an online social learning experience. Moreover, a decision aid can provide input mechanisms and invite users to contribute while they are using the site. For instance,

one way for users to organize their learning is to allow highlighting and annotations, so that users can curate content that they find useful or need further clarification (e.g., with doctors). With the annotations, the decision aid can add a social layer on top of the content, displaying commentary such as "465 people have also saved this section for review later." The social layer allows users to engage with the decision aid with asynchronous participation from other users.

Community event drop-in: An opportunity to create peer/group learning environments is to actively participate in community events to introduce the decision aid to local communities. Given that a significant portion of our target population may have low literacy and/or computer skills, publicizing the decision aid to raise awareness among this population is necessary. In fact, one question that was brought up by our participants in our focus groups was "how do people actually find this thing [the online decision aid]?" Our participants and the community partners we worked with suggested that we should introduce the tool at community events such as health fairs or advertise in the local newspapers to broaden our reach.

Designing Decision Aids: Using Lung Cancer Screening as an Example

By situating the design of an existing patient-centered decision aid where patients would access it themselves without a health professional being present, we discovered several challenges for users and uncovered some discrepancies in beliefs held by patients and physicians that warrant attention of decision aid designers. We have attempted to mitigate some of the discrepancies in our design suggestions, in the hopes that the decision aid could raise the awareness of such conflicts and create opportunities for stakeholders (e.g., patients, physicians, and decision aid designers) to collaboratively improve the inclusivity of web-based decision aids.

While the above suggestions are presented separately, they can also be combined

to generate new design ideas that could potentially enhance existing decision aids to support individuals outside the context of a doctor's office. For instance, combining event-based information flow with everyday language might suggest showing navigation using traditional medical terminology and everyday language in parallel. Patients can then access content in an event-based structure written in everyday language, but also allow them to see the differences in terminology and conceptualization between themselves and the health professionals with whom they work.

We hope that the suggestions and examples presented above offer decision aid developers a set of tools to improve the user experience of decision aids, with the particular goal of creating inclusive decision aids for people with low literacy. These suggestions are by no means exhaustive, and field testing the suggested features is still needed. Moreover, the small number of patients from African American and Latinx populations might prevent us from seeing nuanced differences between these two communities. The uneven number of stakeholders of each kind (patients vs clinicians) could also lead to an unbalanced representation of viewpoints. Nonetheless, the design suggestions are generated based on co-designing and evaluating with potential users, and in deliberation with physicians and decision aid developers. We believe that our suggestions can serve as additional guidelines to complement the existing patient decision aid guidelines that are primarily content-oriented [52, 54].

2.5.2 Before-after survey and six-month follow-up

The before-after study suggested that the use of shouldiscreen.com led to modest improvements in lung cancer screening knowledge (24% increase) and concordance with current recommendations (55% increase). We saw greater improvements among those who opted for the online survey as opposed to the paper survey. Decisional conflict was halved between the before and after, suggesting that some information

is better than not knowing anything about lung cancer screening to help people from being on the fence because they were unaware. From the pilot study, baseline knowledge in the Ann Arbor population was higher (50% correct), relative to the Detroit population (40% correct). The relative improvement in knowledge in Ann Arbor after viewing the tool was 45%, which was lower compared to those who completed the online survey in Detroit with a relative improvement of 53%. This is encouraging to see, but at the same time, behooves us to think more deeply about the different kinds of media (other than a website), devices (touchscreen tablets or cellphones), and nature of the interaction (e.g. what if shouldiscreen.com were used with a health counselor?) that could replicate this kind of improvement. Moreover, we found that neither presentations of risk of lung cancer death — as a probability over 6 years denoted as a percentage and icon arrays — were well-received or understood. Delivering information that is tailored to the individual may be desirable, as we suggested in the design recommendations from the PD workshop. It may not be necessary to understand the benefits and harms in the form of probabilities for an individual to make an informed decision about lung cancer screening.

We were not able to contact the majority of our participants approximately six months after the before-after surveys, limiting our ability to determine whether viewing shouldiscreen.com might have encouraged people to seek out advice from their healthcare providers about lung cancer screening. Nonetheless, out of the 14 participants who we did manage to follow up, of whom 3 were eligible, 2 went through with screening. That means, out of all our 78 participants, of which 16 were determined to be eligible to be screened, at least 12.5% received lung cancer screening (compared to national estimates of 3.9% [37]). This suggests that if there was greater awareness about lung cancer screening in the populace, uptake could be higher. We also could

not determine whether the knowledge gained from having visited shouldiscreen.com was retained; although Mazzone et al. [102] who used our decision aid within a lung cancer screening counseling visit seemed to suggest that there is a degree of knowledge retention.

While additional design modifications and modes of information delivery of current decision aids could and should be considered to increase their efficacy in helping populations with lower educational attainment and computer literacy, this will not be sufficient. A fair number of our participants only had a basic cellphone as their sole electronic device, did not have access to internet, and/or had trouble using a mouse due to poor health and discomfort with computer devices. This has also been found in another study testing shouldiscreen.com [103]. However, we did notice that during the focus group when participants paired up, they had an easier time navigating with an iPad and a Samsung Galaxy tablet together. As we suggested in our analysis from the PD workshops, partnering with community organizations and community leaders to foster a group learning environment to demonstrate the use of the tool and explain the benefits of screening may be a way to help encourage those who might benefit most from it. Joining forces with existing health initiatives in the community such as health fairs and informational talks at community town halls may be another strategy. If people who should hear about lung cancer screening will not find out about it on their own via the Internet, we need make a concerted effort to bring this knowledge to them on their terms.

2.5.3 Conclusion

In this chapter, we used a mixed methods approach to understand how we could increase the awareness of and improve upon informed decision-making for lung cancer screening via a web-based decision aid, www.shouldiscreen.com in minority, low

resource communities. While our sample size was small, we generated rich data. Importantly, we highlighted the design challenges for a web-based decision aid that come with a relatively unknown medical procedure that targets smokers, past and present, who do not necessarily have a high level of health or computer literacy.

An issue that resonated throughout the study was also that screening as a concept was not understood, as we repeatedly heard that participants might be motivated to get screened if they felt ill; this is particularly problematic since screening is only recommended for asymptomatic individuals. In fact, seeking care in response to symptoms goes against the whole concept of preventive care. This may require more general population-based health literacy education programs to improve. Another challenge is to capture smoking history as accurately as possible, regardless of tool/instrument/questionnaire used, so that people who should be screened would be recommended to be screened.

There is no one-size-fits-all tool/strategy that everyone can use in every context. Indeed, the public health community needs a multi-prong approach — from the old school in-person engagements to cutting edge technology of personalized web user experience — to have better chances of increasing awareness and uptake of lung cancer screening in the population.

CHAPTER III

Age-Period-Cohort Smoking Trends in Mexico: 1987-2016

3.1 Introduction

While Mexico has made considerable progress reducing premature neonatal and early adult deaths, we see a notable increase in premature deaths in middle and older age from: diabetes, ischemic heart disease, strokes, lower respiratory infections, and chronic obstructive pulmonary disease, for which tobacco is a major risk factor [45, 104]. In fact, costs to the Mexican health care system attributable to tobacco use were estimated to be a staggering US$5.11 billion in 2015 [105]. Moreover, according to the latest Global Burden of Disease report, the ranking of tobacco as a risk factor contributing to disability-adjusted life years (DALYs) in Mexico remained unchanged between 2007 and 2017 at number eight [45]. Moreover, smoking prevalence in the country has plateaued in recent years; in 2011, 23.6% reported having smoked in the past year compared to 23.4% in 2016 [44]. Despite having ratified the World Health Organization's Framework Convention on Tobacco Control (FCTC) in 2004, it is clear that there is still much work to be done in tobacco control in Mexico.

To develop and implement effective policies, it is important to measure the impact of past and current tobacco control policies and assess what has worked by monitoring smoking prevalence. In fact, examining smoking prevalence, initiation and cessation

with a lifecourse perspective is critical to this assessment. Firstly, the harmful effects of smoking on health take time to accrue and manifest. Secondly, smoking is a lifestyle risk factor influenced by social norms which may differ by gender, birth cohorts, and period in time, which in turn, could translate into differential impacts of policies on smoking initiation and cessation by these factors. For instance, an analysis of smoking patterns in the US by birth cohort has shown that smoking initiation probabilities in women sustained at peak levels for a lot longer that the corresponding birth cohorts in men [106]. This pattern coincided with the period where there was a wider societal acceptance of smoking among women [106].

In this paper, we adapt the approach by Holford et al. [106], the National Cancer Institute's Cancer Intervention and Surveillance Modeling Network (CISNET) Lung group, to characterize birth cohort smoking histories in Mexico. Specifically, we estimate age-specific smoking prevalence, initiation and cessation for single-year birth cohorts (1920-1998) in Mexico using age-period-cohort models and nationally representative data from years 1987 to 2016. Although Christopoulou et al. [107] characterized smoking behavior in Mexico by birth-cohort and gender previously, they only used cross-sectional data from a single year (ENA 2008) and did not estimate initiation or cessation, which are the targets of potential interventions. Moreover, while the International Tobacco Control (ITC) cohort may provide more fine grained smoking data [108], the study sample was drawn from only four cities in Mexico, and participants were only followed from 2006 to 2015. Participants in the ITC cohort were also all smokers, so we do not know anything about the transition from a never smoker to a current smoker, which is important to know from the consideration of tobacco control. Consequently, our paper complements earlier and ongoing studies that sought to study the tobacco epidemic in Mexico; our analysis of

smoking trends in the country provides an approximation of a lifecourse perspective that spans from 1987 to 2016. Furthermore, we will be using these estimates in a state transition model described in Chapter IV to predict future smoking prevalence in Mexico which could assist in the evaluation of tobacco control interventions.

3.2 Methods

3.2.1 Data

Data came from 11 large-scale, nationally representative cross-sectional household surveys originating from three distinct series: Encuesta Nacional de Salud (ENSA, National Health Survey) 1987 and 2000 and the extended Encuesta Nacional de Salud y Nutrición (ENSANUT, National Health and Nutrition Survey) 2006, 2012, 2016 [109]; Encuesta Nacional de Adicciones (ENA, National Addictions Survey) in 1998, 2002, 2011 [110] which was later renamed to Encuesta Nacional de Consumo de Drogas, Alcohol y Tabaco (ENCODAT, National Survey on the Consumption of Drugs, Alcohol and Tobacco) in 2016 [111]; and lastly, the Global Adult Tobacco Survey (GATS) in 2009 and 2015 [112]. Hereafter, we will refer to them as ENSANUT, ENA and GATS respectively. All surveys had a multi-stage, cluster sample design and were conducted in person. Note that some surveys had more smoking questions than others, resulting in different sample sizes for the estimations of current smoker prevalence, former smoker prevalence, initiation and cessation (see Table 3.1). This is in part due to the different focus of each series, as illustrated by their names. ENSANUT is akin to the US National Health and Nutrition Examination Survey [113], where tobacco is not a major focus, and at times only one or two questions are asked (e.g. in 1987 and 2016). ENA is similar to the US National Survey on Drug Use and Health [114], and places emphasis on tobacco, alcohol and drugs. GATS is a part of the Global Tobacco Surveillance System in a bid to standardise the monitoring of

tobacco trends worldwide and so has an exclusive focus on tobacco. We restricted our analysis to respondents aged 18 and over. We also constructed life tables by sex, age and single-year birth cohorts to estimate initiation and cessation probabilities [106].

Table 3.1: Data sets used by smoking categories

	Current	Former	Ever	Initiation	Cessation
ENSANUT	1987, 2000, 2006, 2012, 2016	2000, 2006, 2012, 2016	2000, 2006, 2012, 2016	2000, 2012	–
ENA	1998, 2002, 2011, 2016	1998, 2002, 2011, 2016	1998, 2002, 2011, 2016	1998, 2002, 2011, 2016	2002, 2011, 2016
GATS	2009, 2015	2009, 2015	2009, 2015	2009, 2015	2009, 2015

3.2.2 Definitions

Current smoker

We defined a current smoker as someone who self-reported to have smoked in the past 12 months for all surveys, with the exception of ENSA 1987, where participants were only given "You currently smoke cigarettes" to respond to with "Yes (number of cigarettes per day", "No", "Don't know" from which to choose. The most data we have is for current smokers, where we were able to use 11 years of surveys from 1987 to 2016 (see Table 3.1).

Former smoker

Former smokers were those who reported having last smoked more than a year ago. The question we used to derive this was some variant of "When was the last time that you smoked a cigarette?" with the options "In the past 30 days", "More than one month but fewer than 6 months", "More than 6 months but less than a year", "More than a year but less than three years", and "More than 3 years." Holford et al. [106] used a two-year cutoff to classify former smokers who are likely to have

successfully quit [115]. However, we are not able to use a two-year cut-off due to the options available in the surveys. Nonetheless, a one-year cutoff is commonly used in randomised clinical trials for smoking cessation aids as an indicator of successful quitting [116, 117]. Here, we were able to use 10 years of surveys from 2000 to 2016 (see Table 3.1).

Ever smoker

Ever smokers are made up of current smokers and former smokers so the number of surveys used here is capped by the minimum number of data sets between current and former smokers: 10 years from 2000-2016.

Initiation

For the estimation of the probability of initiation at each age and birth cohort with life tables, we used the response to the questions "How old were you when you smoked (tobacco or) cigarettes for the first time?" and "At what age did you start smoking tobacco products every day?" to define when the event *smoking initiation* took place. Never smokers were right right censored at the year of the survey.

Cessation

For the cessation life tables, only ever smokers were included, and we used the question "At what age did you smoke for the last time?" to define when the event *smoking cessation* took place. Where this question was not available, we used the question "For how long have you stopped smoking?" (months, years). Current smokers i.e. those who had not quit at the time they were interviewed, were right censored at the year of the survey. To be consistent with our former smoker definition, those who have stopped smoking within a year were not considered to have quit smoking and were also right censored as with current smokers.

3.2.3 Statistical analysis

We used age-period-cohort (APC) models which are typically used to separate out the effects of age (linked to aging), period (linked to all ages in a particular point in time) and cohort (processes linked to specific birth cohorts) on, in our case, smoking. Given A_a = age effect at a, P_t = period / calendar year effect at t and C_{t-a} = cohort effect at $t-a$, $\lambda_{a,t}$ (age-specific rates of smoking initiation / cessation) can be described by the following multiplicative model [106, 118, 119]:

$$log\lambda_{a,t} = log(A_a) + log(P_t) + log(C_{t-a}) \tag{3.1}$$

For estimating age-specific smoking prevalence, we use a slightly modified form of the above, where logit denotes the natural logarithm of the odds [106, 118, 119]:

$$logit(Prevalence_{a,t}) = log(A_a) + log(P_t) + log(C_{t-a}) \tag{3.2}$$

To overcome the identifiability issue with age-period-cohort models (i.e. there is a perfect collinearity in the predictors where cohort = period - age), we fitted the models with either linear or natural splines, with either cohort effects (for A-P-C models) or period effects (for A-C-P models) constrained to be zero on average with zero slope. Goodness of fit between the two model variants were assessed with the Akaike Information Criteria [120]. All analyses were conducted with R statistical software (v.3.5.2) [82] with the following libraries: survival (v.2.43) [121] to construct the life tables and Epi (v.2.32) [122] for all APC analyses. Cleaning scripts, resulting data sets for the analysis, as well as all analyses, can be found at https://github.com/lauyk/smokingMexicoAPC.

3.2.4 Sensitivity analysis

The question "Have you smoked at least 100 cigarettes (5 packs) of tobacco in your lifetime?" was used as a filter in ENSANUT 2000 and 2006 such that survey respondents who have not smoked 100 cigarettes in their lifetimes would not be asked further questions about their smoking history. The ENA series all asked this question but was not used as a filter question. GATS, however, did not ask this question at all. This 100-cigarette filter is used in the US National Health Information Survey as a means to differentiate experimental and established smokers. Previous research suggests that smoking prevalence amongst Hispanics in the US [123] as well as in Mexico [124] is sensitive to this filter. Hence, we conducted a series of sensitivity analysis by repeating our analyses by applying (and not applying) the filter to the data to examine whether higher/lower consistencies in definitions used would affect the overall smoking patterns.

First, as mentioned, the 100-cigarette filter was not included in the GATS questionnaires. Therefore, the first sensitivity analysis excluded GATS 2009 and 2015, such that the 100-cigarette filter is applied as consistently as possible (i.e. those who did not smoke at least 100 cigarettes would be considered never smokers). Second, we excluded ENSA 2000 and ENSANUT 2006, both of which used the 100-cigarette question as a filter. The analyses were then repeated *without* the 100-cigarette filter applied. Third, we only included surveys from ENA, as the type of questions, the verbiage, and skip patterns, are most similar to each other, and covers a longer period than that of GATS. Here, we both applied and disabled the 100-cigarette filter. We also split current smokers into current daily and current non-daily smokers, as there appears to be diverging trends in these two categories of smokers [125].

With regards to smoking initiation, we constructed three separate data sets: 1)

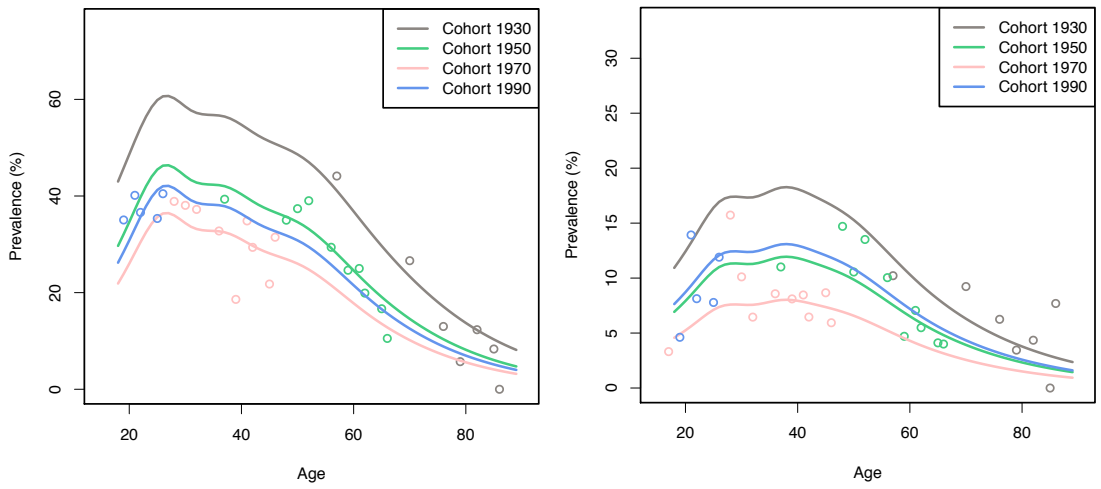
"daily", where we use age at smoking daily with no 100-cigarette filter applied; 2) "experimental", where we use age at start smoking for the first time with the 100-cigarette filter applied; 3) "data maximising", where we combine "daily" with "experimental". The rationale for this "data maximising" combination is so that we can capture both regular non-daily and daily smokers. In turn, this resulted in three different data sets for smoking cessation to account for the different start times (i.e. age at start smoking). For the main results, we combined ENA 2002, 2011 and 2016 and use age at experimentation (applying the 100-cigarette filter) with GATS 2009 and 2015 and use age at start daily (there is no age at experimentation question in GATS). Results for data sets 1) and 2) are presented as sensitivity analysis.

3.3 Results

3.3.1 Smoking prevalence

Figures 3.1, 3.3, and 3.5 depict the expected prevalence for current, former, ever smokers, predicted by the model (solid lines) by birth cohorts, along with the observed prevalence (dots). Figures 3.2, 3.4, and 3.6 show the corresponding age, period and cohort effects separately by sex. We set 1950 as the referent birth cohort for all the models. For males, the current smoking prevalence peaks around 30 years old, and decreases after that, with a sharper decline in the late fifties. For females, the level of current smoking prevalence is lower overall compared to male, and peaks later around age 40. From both 3.1 and 3.2, we see that, relative to the 1950 birth cohort, current smoking has been decreasing steadily from the earliest birth cohorts, with a rise in the most recent cohorts. This was the case in both males and females. The fit for ever and former smoking prevalence is not as good as for current smoking prevalence and this may have to do with there being less data in earlier epochs since ENSANUT 1987 was not available for these estimations. Nonetheless, we also ob-

served stronger cohort effects with period effects being relatively flat. In fact, cohort effects better explained the observed prevalence than period effects overall for current, former, and ever smoking. For a summary of model fits with AIC values and the number of parameters estimated for each model, please see Appendices B.1-B.2.



(a) Male (b) Female

Figure 3.1: Prevalence of current smokers by birth cohorts in Mexico

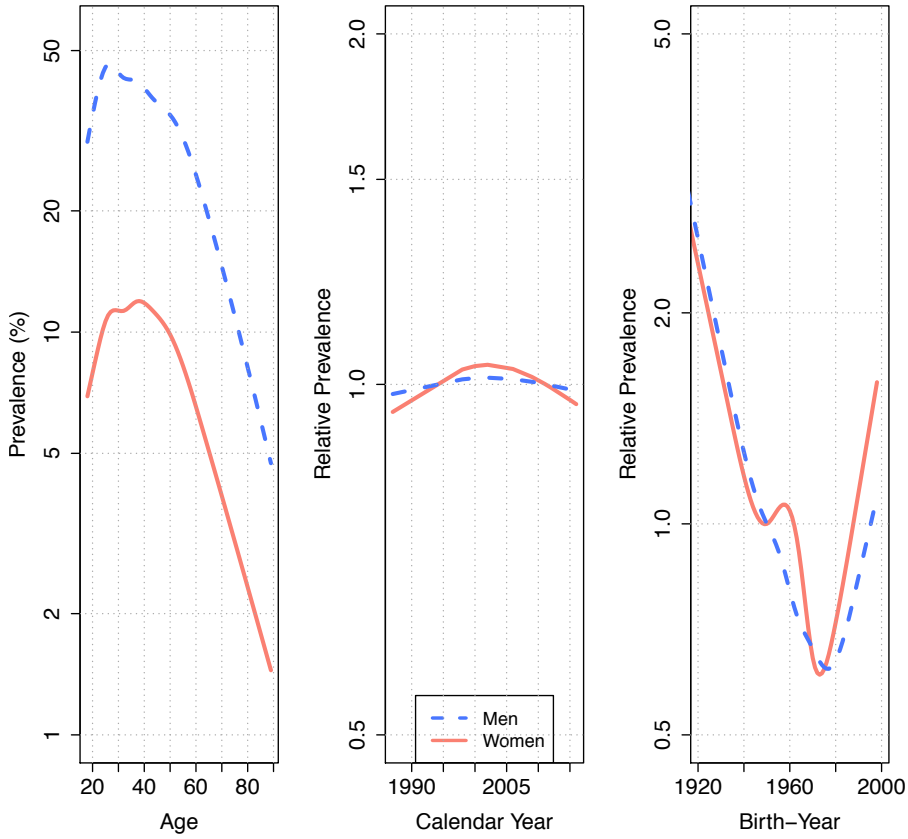
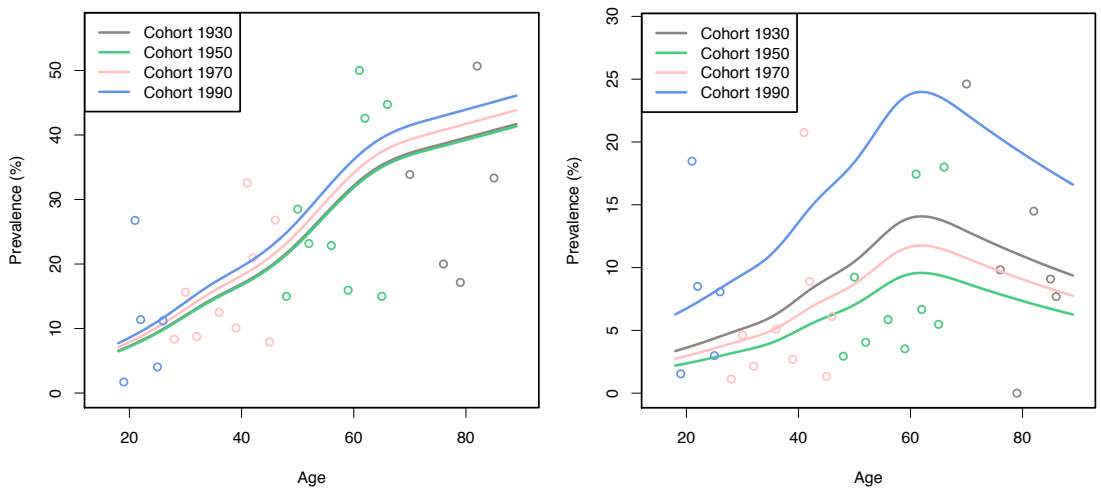


Figure 3.2: Age, period and cohort effects for current smoking prevalence using an APC model



(a) Male (b) Female

Figure 3.3: Prevalence of former smokers by birth cohorts in Mexico

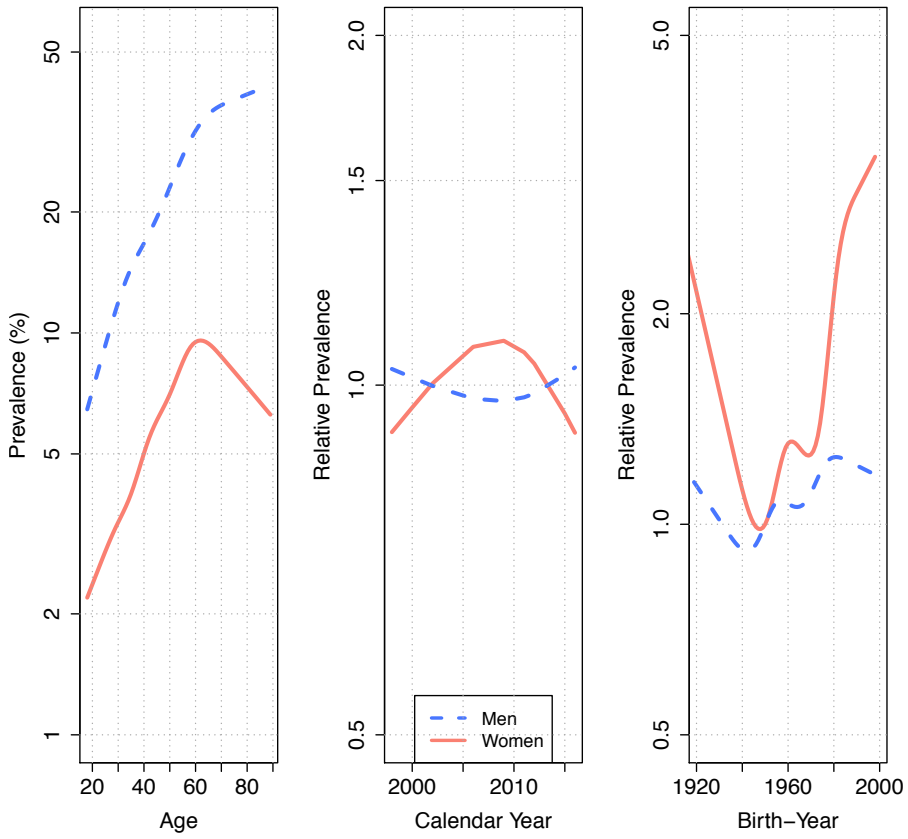
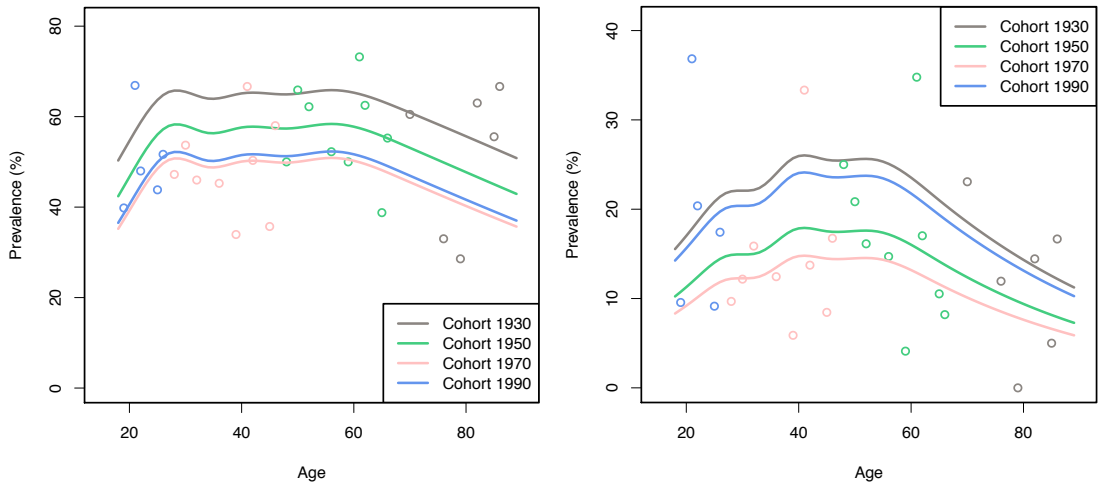


Figure 3.4: Age, period and cohort effects for former smoking prevalence using an APC model



(a) Male (b) Female

Figure 3.5: Prevalence of ever smokers by birth cohorts in Mexico

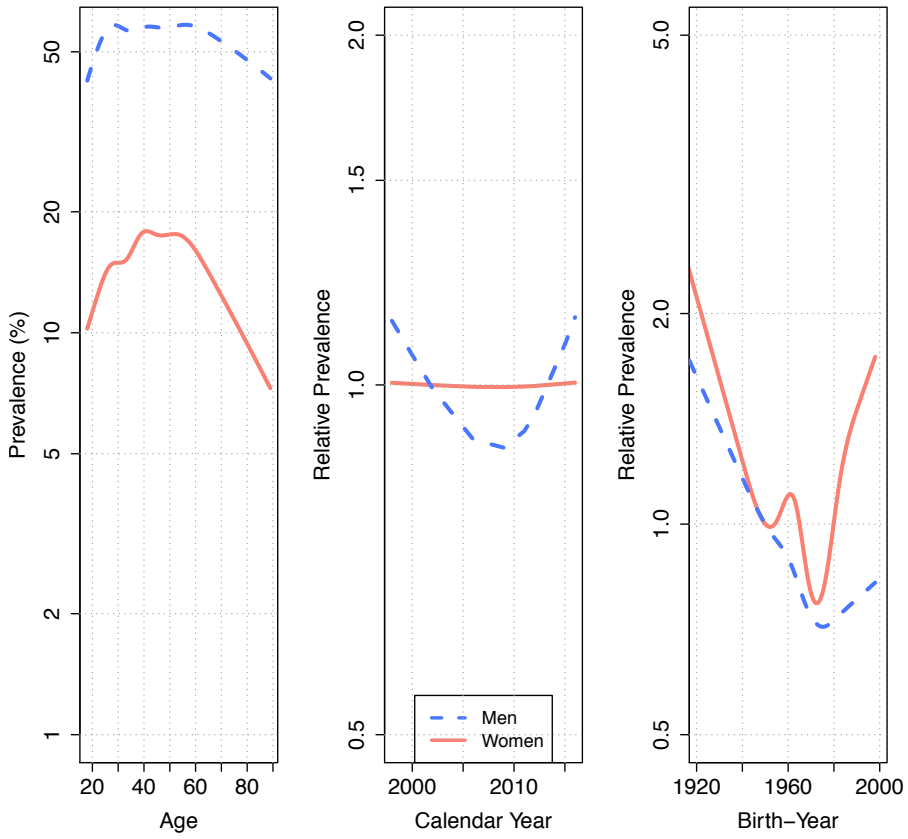


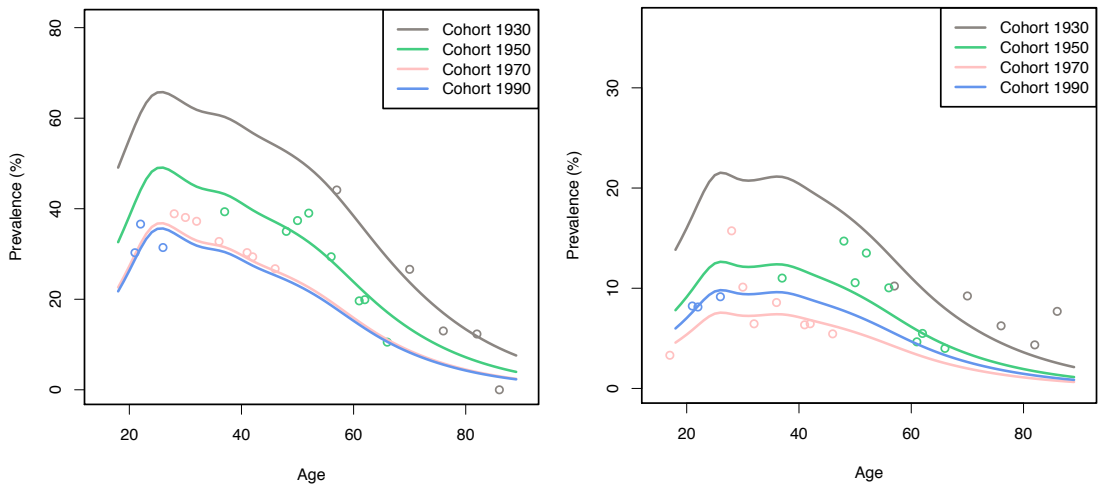
Figure 3.6: Age, period and cohort effects for ever smoking prevalence using an APC model

3.3.2 Sensitivity analysis: Prevalence

Only current smoking prevalence trends are presented as a comparison to the main results already presented above, to which we will refer to "baseline" analysis.

Sensitivity analysis 1: Exclude GATS, 100-cigarette filter applied

When we exclude data from GATS, the level of current smoking prevalence of the 1970 and 1990 birth cohorts are flipped for males relative to the baseline analysis. For females, the 1950 and 1990 birth cohorts are flipped.

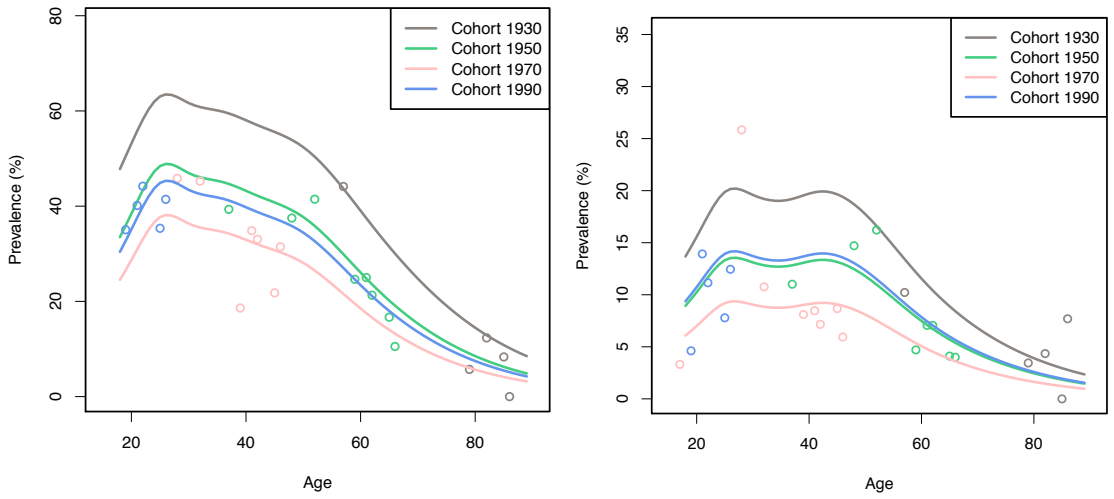


(a) Male (b) Female

Figure 3.7: Prevalence of current smokers by birth cohorts in Mexico (no GATS)

Sensitivity analysis 2: Exclude ENSA 2000 and ENSANUT 2006, no 100-cigarette filter applied

When we re-include GATS, but exclude ENSA 2000 and ENSANUT 2006 and disable the 100-cigarette filter, we do not see much difference from the baseline analysis of current smoking prevalence as the rankings of the cohorts stay the same.

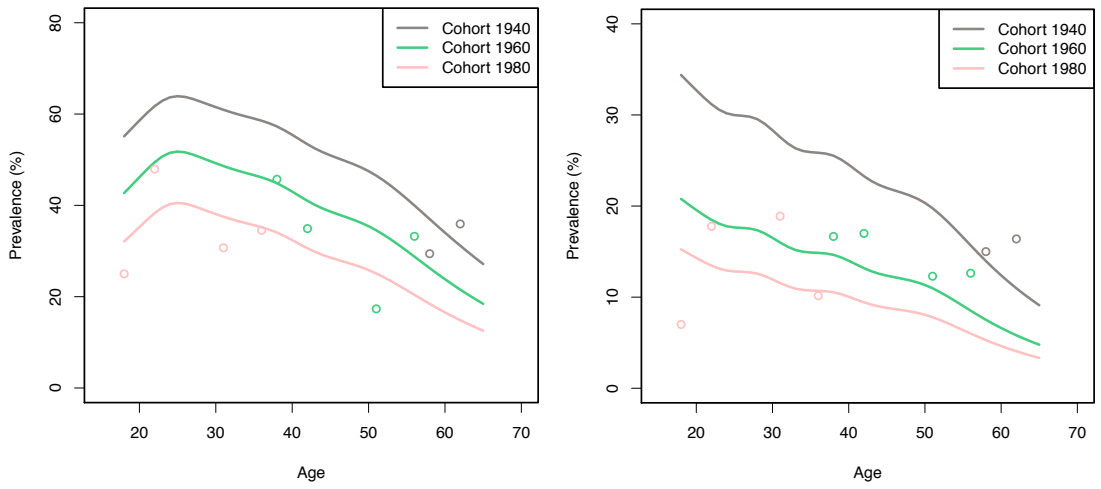


(a) Male (b) Female

Figure 3.8: Prevalence of current smokers by birth cohorts in Mexico (no ENSA 2000 and ENSANUT 2006)

Sensitivity analysis 3: ENA only, split current smokers into current daily and current non-daily smokers

100-cigarette filter applied Note that the oldest birth cohort here is 1940 (as opposed to 1930 above), as the earliest survey for ENA was conducted in 2002. We now see that the youngest birth cohort (i.e. 1980) has the lowest current smoking prevalence, contrary to what we saw previously in the baseline analysis. However, when we split current smokers into current daily smokers and current non-daily smokers, a more nuanced picture emerges: while current daily smoking prevalence has the same ranking as that of current smoking prevalence with a consistent decrease in smoking across birth cohorts, the youngest birth cohort has the highest current non-daily smoking prevalence in both male and female. The plateauing of relative current smoking prevalence for females and the uptick for males as seen in the last panel of Figure 3.10 could then be explained by the increase of current non-daily smokers in the younger cohorts.



(a) Male (b) Female

Figure 3.9: Prevalence of current smokers by birth cohorts in Mexico (ENA only, with 100-cigarette filter)

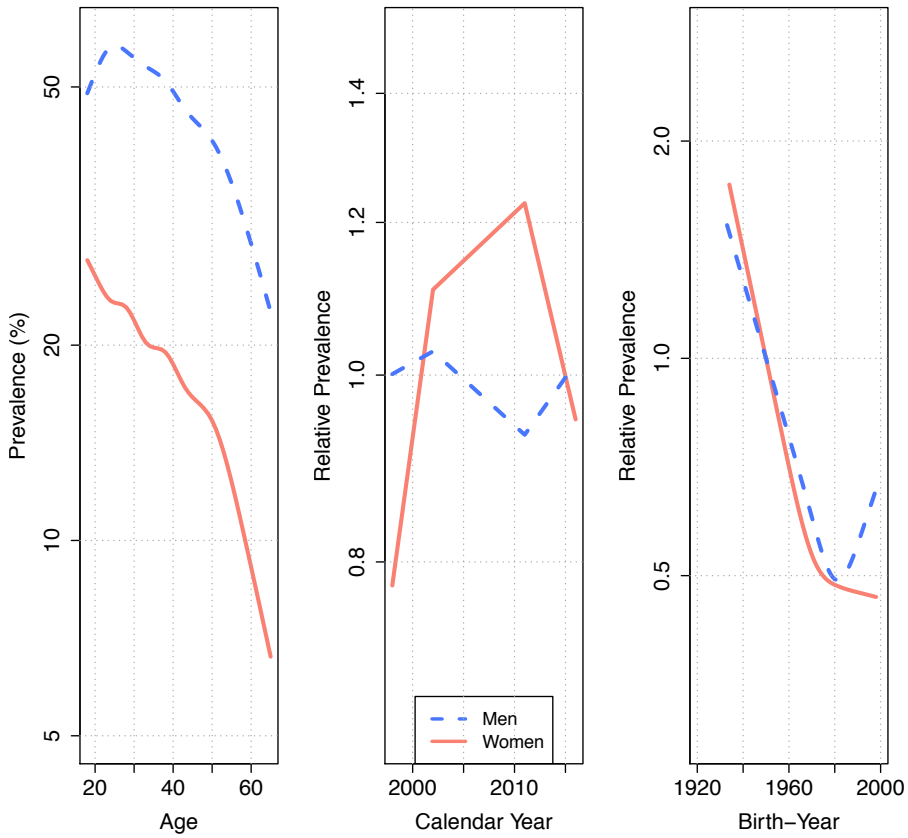
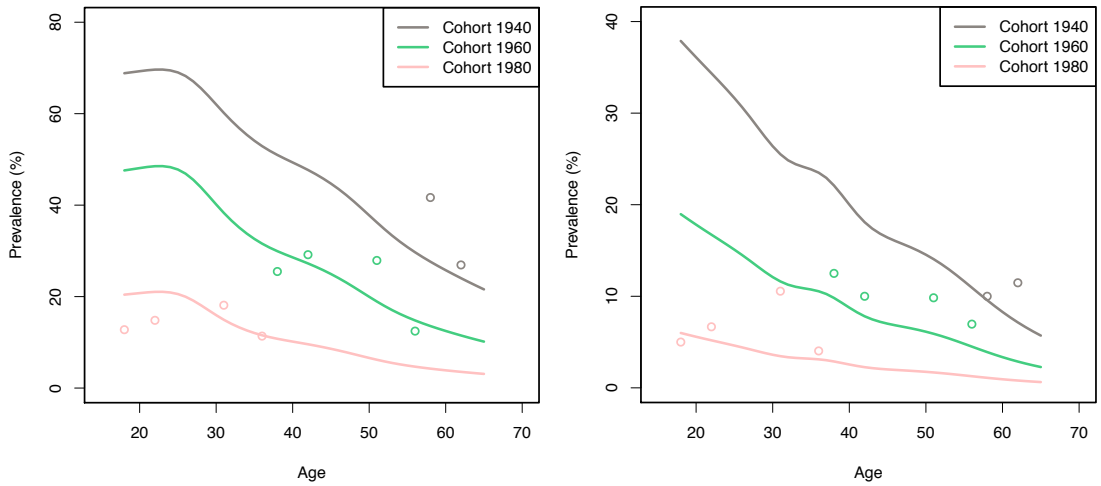


Figure 3.10: Age, period and cohort effects for current (daily + non-daily) smoking prevalence using an APC model (ENA only, with 100-cigarette filter)



(a) Male (b) Female

Figure 3.11: Prevalence of current daily smokers by birth cohorts in Mexico (ENA only, with 100-cigarette filter)

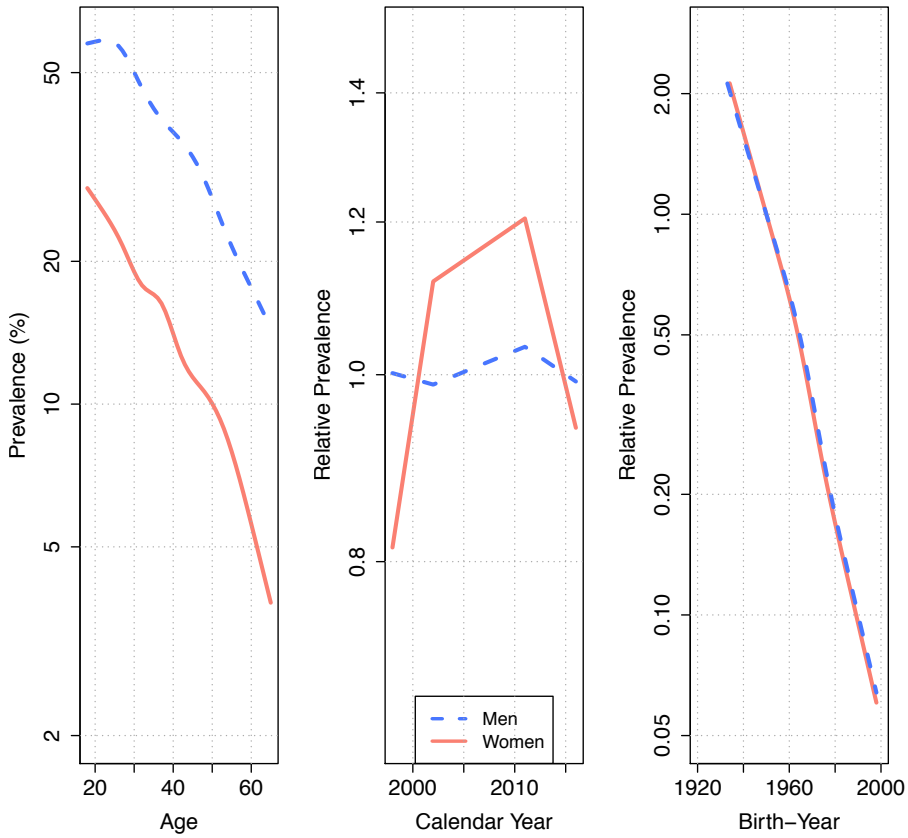
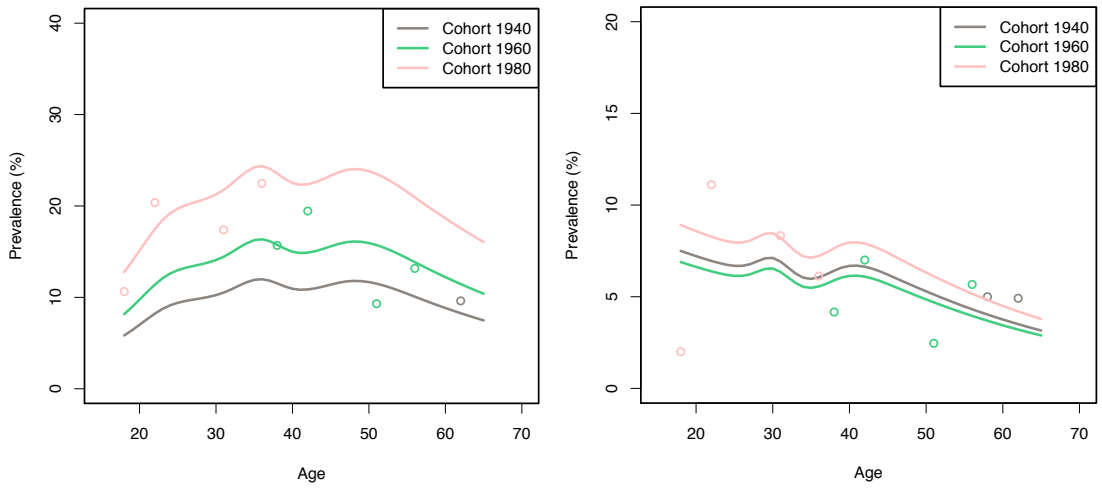


Figure 3.12: Age, period and cohort effects for current daily smoking prevalence using an APC model (ENA only, with 100-cigarette filter)



(a) Male

(b) Female

Figure 3.13: Prevalence of current non-daily smokers by birth cohorts in Mexico (ENA only, with 100-cigarette filter)

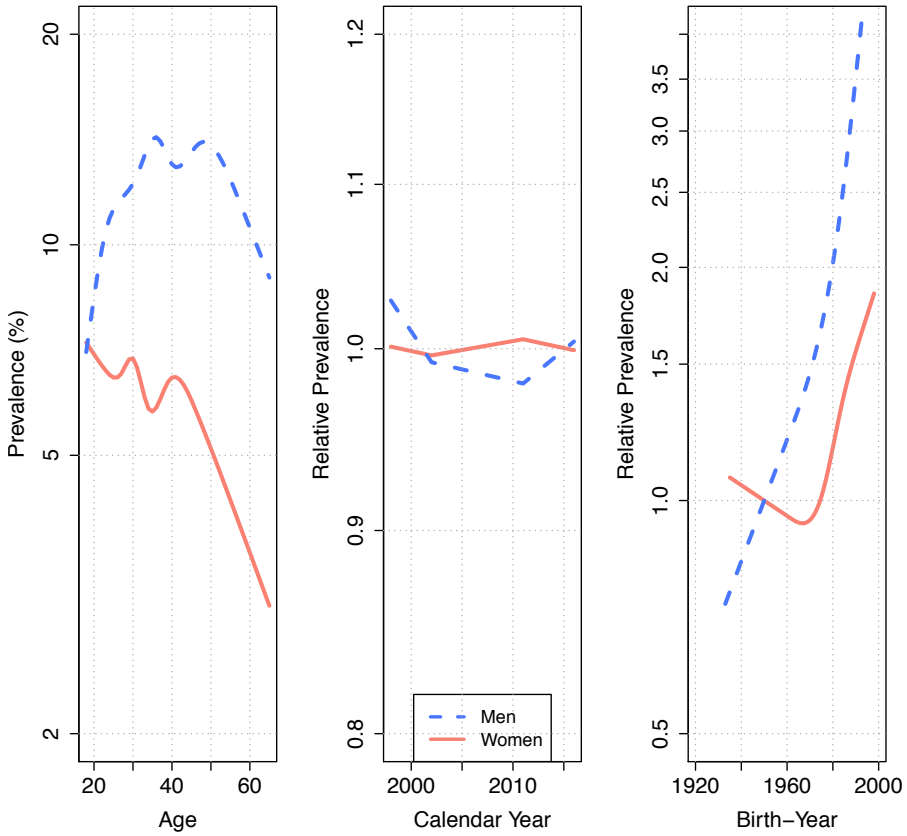
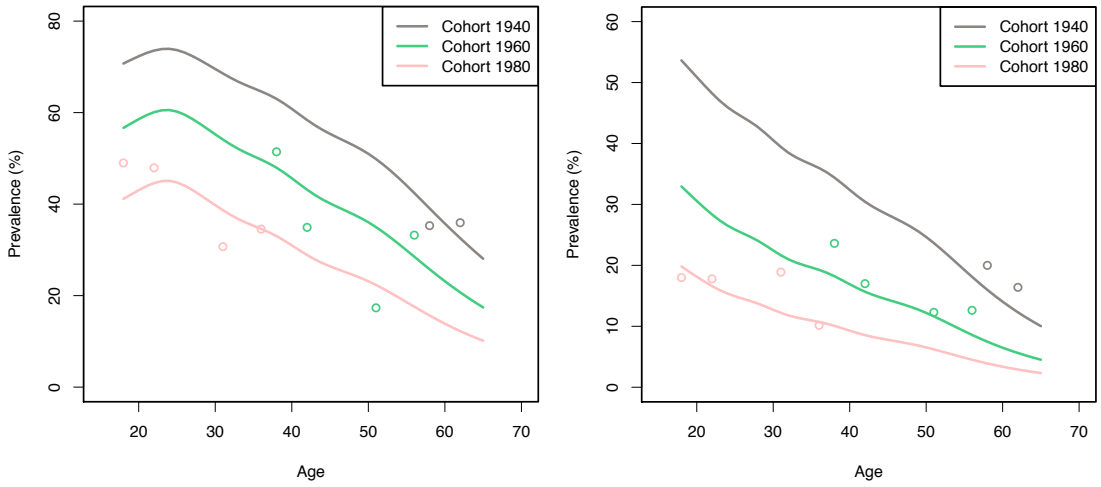


Figure 3.14: Age, period and cohort effects for current non-daily smoking prevalence using an APC model (ENA only, with 100-cigarette filter)

100-cigarette filter not applied The 100-cigarette filter did not affect general current or daily current smoking prevalence trends, but greatly affected the trends in non-daily current smoking (Figures 3.15-3.18). First, as we would expect, the level of predicted prevalence was higher without the 100-cigarette filter. Second, for females, the youngest birth cohort had the lowest current non-daily prevalence, in contrast to the results that showed the opposite when the 100-cigarette filter was applied.



(a) Male (b) Female

Figure 3.15: Prevalence of current smokers by birth cohorts in Mexico (ENA only, without 100-cigarette filter)

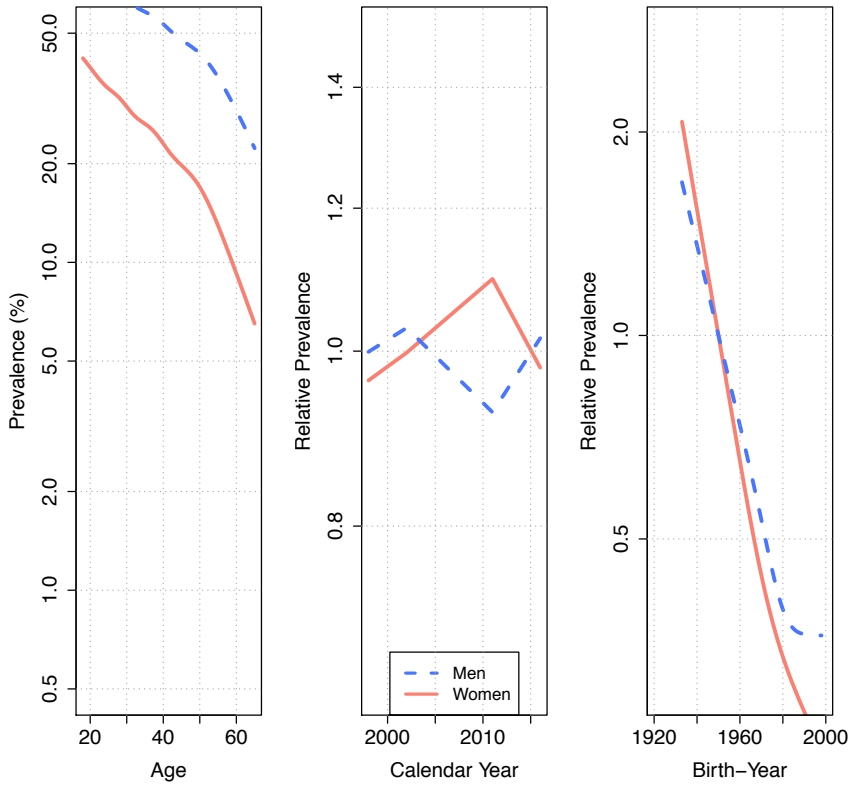
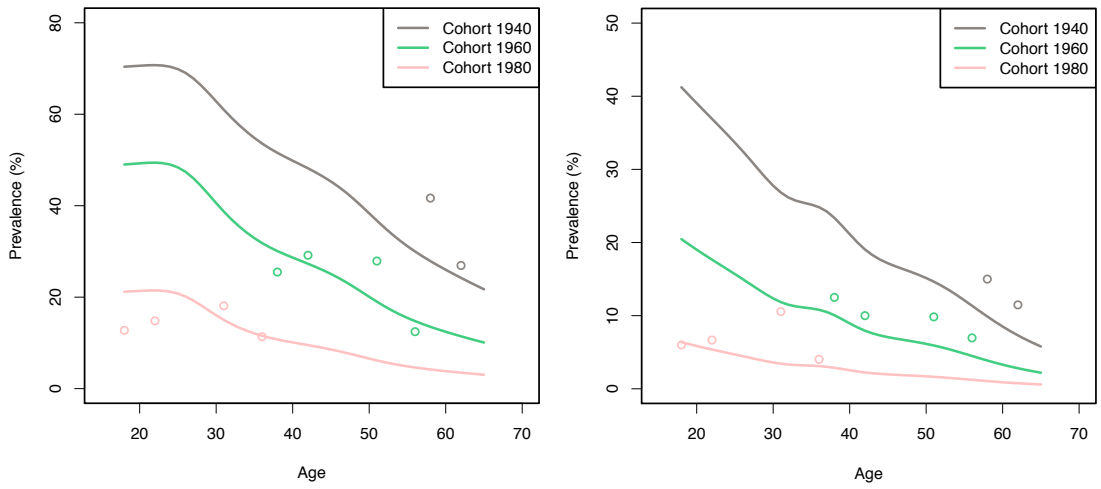


Figure 3.16: Age, period and cohort effects for current (daily + non-daily) smoking prevalence using an APC model (ENA only, without 100-cigarette filter)



(a) Male (b) Female

Figure 3.17: Prevalence of current daily smokers by birth cohorts in Mexico (ENA only, without 100-cigarette filter)

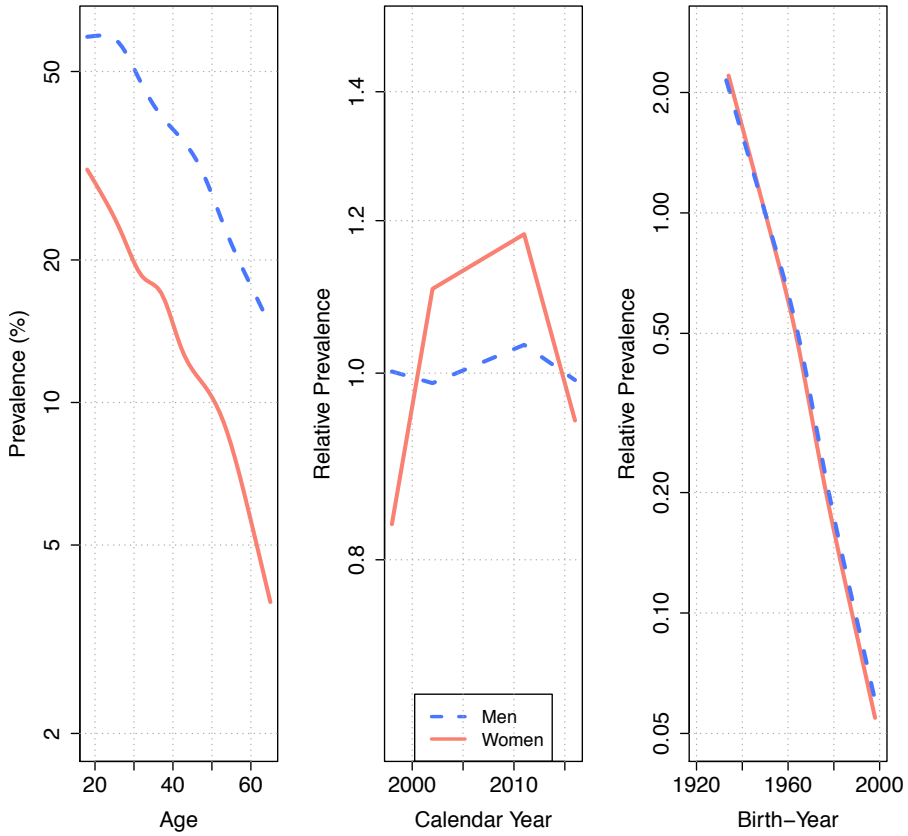
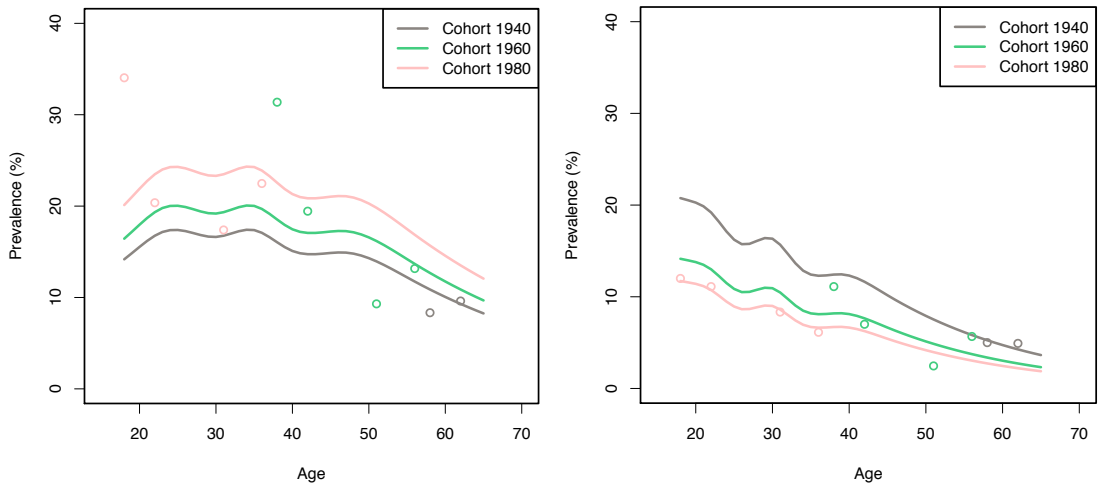


Figure 3.18: Age, period, and cohort effects for current daily smoking prevalence using an APC model (ENA only, without 100 cigarette filter)



(a) Male (b) Female

Figure 3.19: Prevalence of current non-daily smokers by birth cohorts in Mexico (ENA only, without 100-cigarette filter)

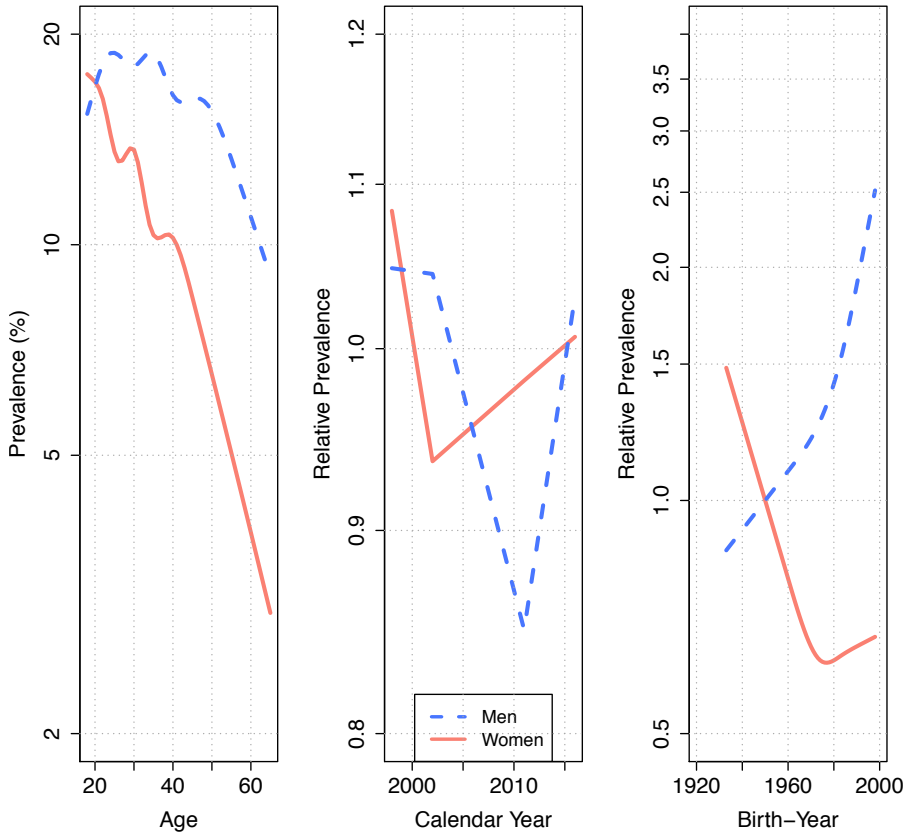
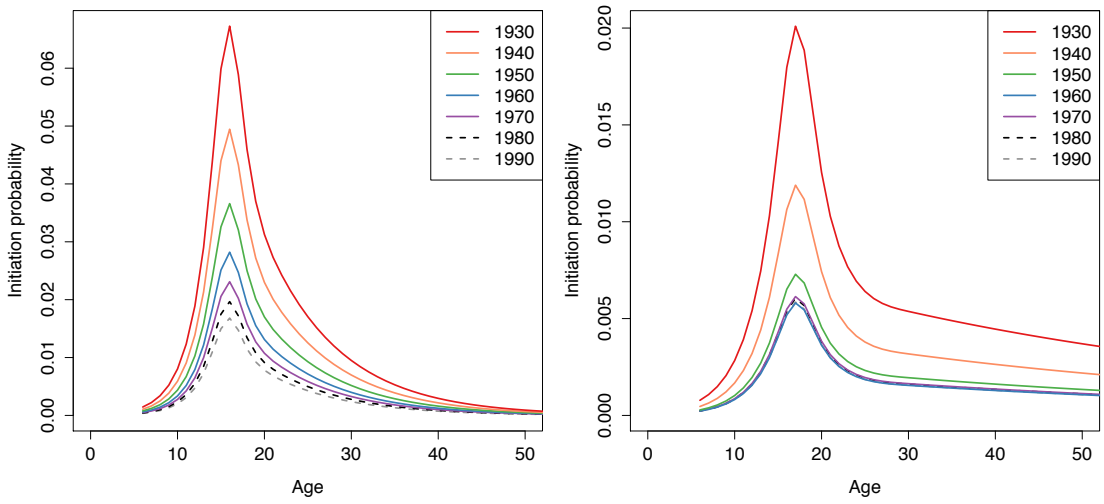


Figure 3.20: Age, period and cohort effects for current non-daily smoking prevalence using an APC model (ENA only, without 100 cigarette filter)

3.3.3 Smoking initiation and cessation

Figures 3.21 (a) and 3.22 show that annual probability of smoking initiation for males has been decreasing as the birth cohorts get younger. We see that this probability peaks around age 15, followed by a sharp decline. For females (Figure 3.21 (b)), there was a decreasing trend until about the 1960 birth cohort and initiation probabilities have remained at the same levels until the 1990 birth cohort. Compared to males, the probability of smoking initiation for females peaks later, taking longer to decrease as well (in fact, this never reaches zero, unlike for males).

With regards to cessation probabilities, there is the expected age effect, where as people get older, they are more likely to quit (see Figure 3.23). There is also a strong cohort effect, with the oldest cohort (1940) being more likely to quit relative to the 1950 birth cohort, although the 1980 birth cohort appeared to have similar probabilities of quitting as the 1950 birth cohort (see Figure 3.24). Fewer birth cohorts are shown compared to the smoking initiation as we have fewer data points available (see Table 3.1). Lastly, the figures also show that females quit smoking with higher probability than males across all ages.



(a) Male (b) Female

Figure 3.21: Estimated initiation probabilities by birth cohort (1930-1990)

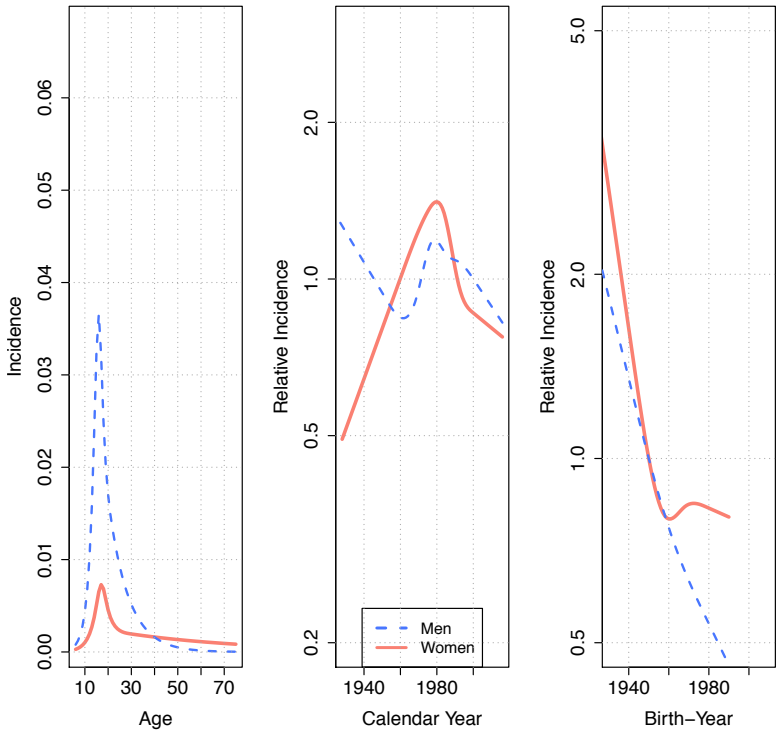
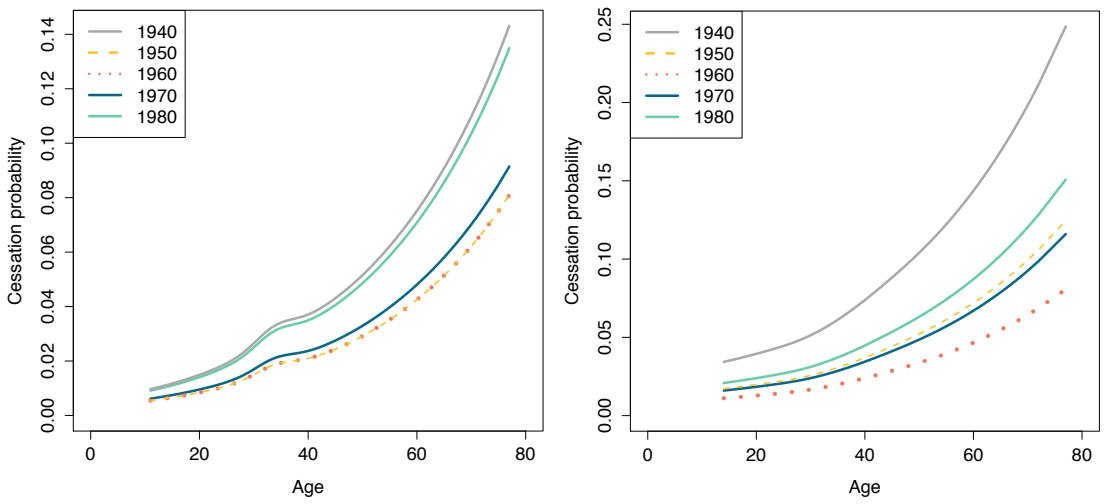


Figure 3.22: Age, period and cohort effects for smoking initiation using an APC model



(a) Male (b) Female

Figure 3.23: Estimated cessation probabilities by birth cohort (1940-1980)

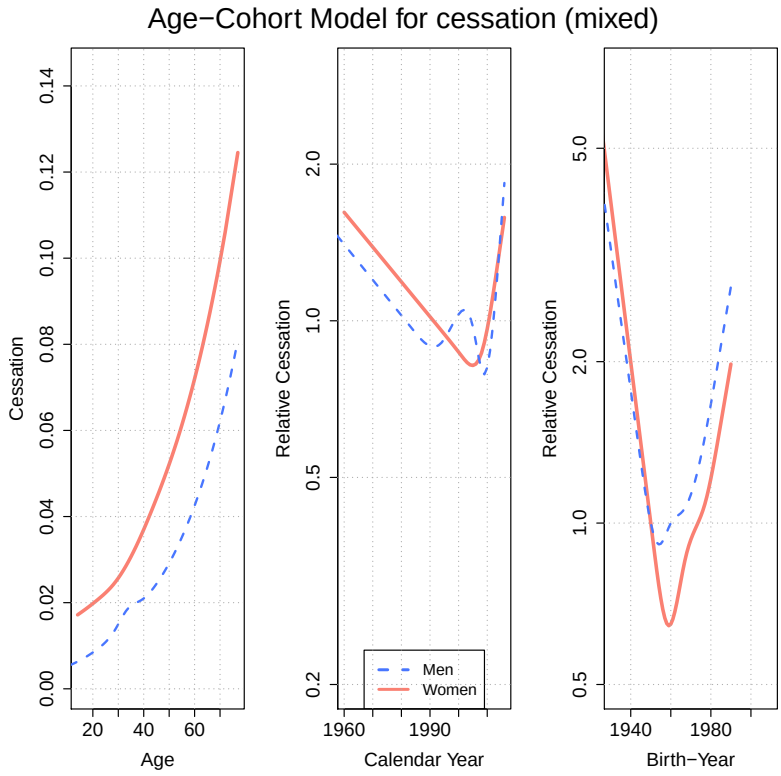


Figure 3.24: Age, period and cohort effects for smoking cessation using an APC model

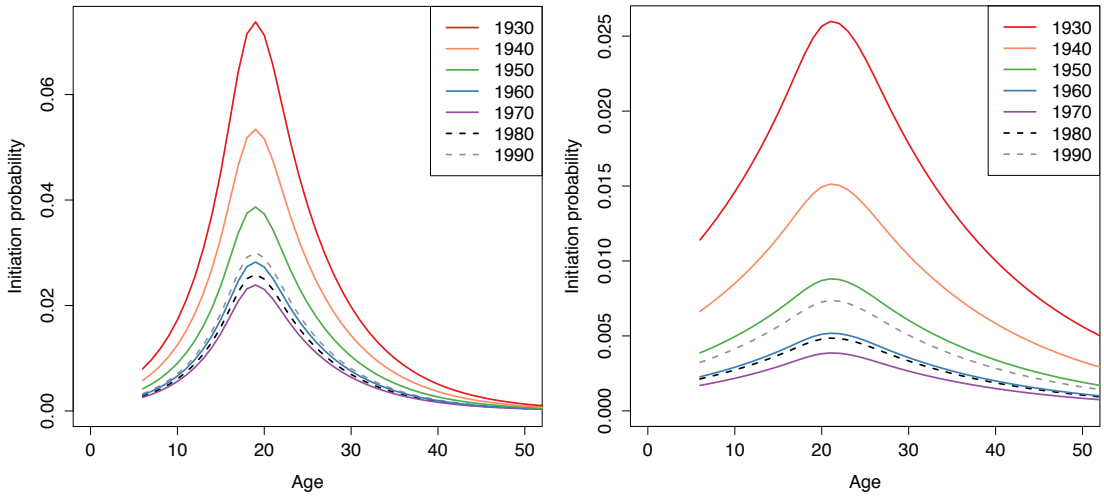
3.3.4 Sensitivity analysis: initiation and cessation

Initiation

Daily smoking initiation (Figure 3.25) peaks at an older age compared to smoking experimentation (Figure 3.26) for both males and females. Again, we see a fatter tail on the right for females, with it being more pronounced for daily smoking initiation (Figure 3.25 (b)) compared to smoking experimentation (Figure 3.26 (b)). Overall, the 1970 birth cohort has the lowest initiation probabilities, with a gradual increase in the two younger birth cohorts.

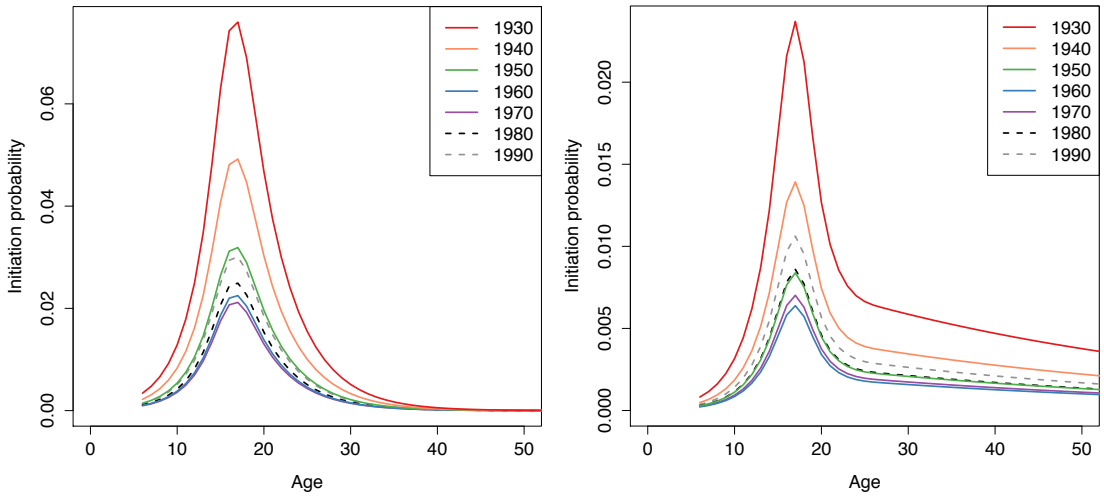
Cessation

After disaggregating cessation probabilities by different starting points, we see that the higher levels seen in the main results are contributed by those above 65 years old. Note that the expected probabilities shown in Figure 3.28 stop at age 65 as that is the age cutoff for the ENA survey. Nonetheless, the disaggregated trends we see here are similar to the main results from the baseline analysis, where the 1980 birth cohort have the highest cessation probabilities after the 1940 birth cohort. The dip we see in Figure 3.26 (b) may be an artifact of the small sample size of females who reported daily smoking.



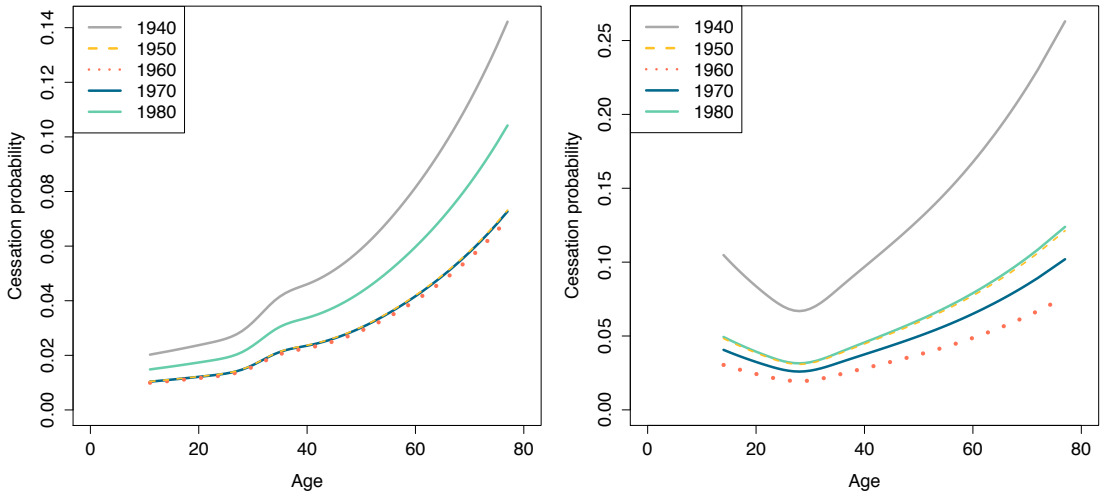
(a) Male (b) Female

Figure 3.25: Estimated daily smoking initiation probabilities by birth cohort (1930-1990)



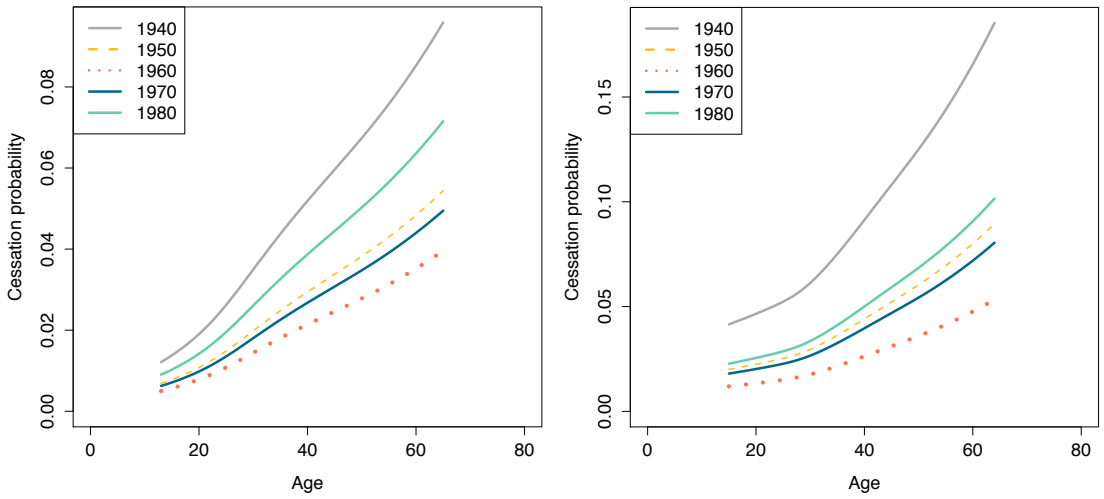
(a) Male (b) Female

Figure 3.26: Estimated smoking experimentation probabilities by birth cohort (1930-1990)



(a) Male (b) Female

Figure 3.27: Estimated cessation probabilities by birth cohort (1940-1980) with age at daily smoking initiation as start time



(a) Male (b) Female

Figure 3.28: Estimated cessation probabilities by birth cohort (1940-1980) with age at smoking experimentation as start time

3.4 Discussion

We have provided an extensive description of age, period, and cohort trends in smoking in Mexico. In general, we may conclude that current smoking prevalence has been decreasing in Mexico from the 1920 birth cohort, with an inflection point occurring around the 1980 birth cohort, where smoking may be increasing in the cohorts that follow. When we look at smoking initiation, the decline across birth cohorts has slowed as well, with females probability of initiation staying constant from the 1960 cohort onward. While the data available for our analysis spanned at most 29 years with eleven data sets, the age and cohort patterns are mostly consistent with the reconstruction of smoking history by age, cohort and gender by Holford et al. [106] in the US (where 33 cross-sections of National Health Interview Survey data was used). In both our analysis and Holford et al.'s [106], we see that the level of current smoking prevalence is much higher in males compared to females. However, unlike the US, the most recent female birth cohorts have not caught up to the level of male smoking prevalence in Mexico. Additionally, in both Mexico and the US, we observe a similar fatter tail in both female current smoking prevalence and smoking initiation (i.e. the decline that occurs after the peak happens at a slower rate), when compared to the male counterpart.

When we break overall current smoking into current daily and current non-daily smoking, a more nuanced and complete story emerged. We found that current daily smoking has been decreasing across the birth cohorts for both sexes, which is encouraging. However, current non-daily smoking has been picking up among the younger cohorts. Further scrutinizing the estimated smoking experimentation probabilities in Figure 3.26, we see that the male 1990 birth cohort has almost caught up to the

1950 birth cohort's level, while in females, the 1990 birth cohort has exceeded that of the 1950 birth cohort. This dynamic may explain why the cross-sectional estimates of smoking prevalence appear to be stagnant [44]. While this shift from daily to non-daily smoking could be considered a move in the right direction, it is important to highlight that there are still serious health consequences with light smoking. Recent data from the US suggest that, although less than that from daily smoking, non-daily smoking also has considerable overall and cause-specific mortality risks [126]. Another study in Mexico also found in men, low smoking intensity was associated with higher odds of poorly differentiate prostate cancer relative to that of never smokers [127].

In our sensitivity analysis, we also discovered that overall current smoking was robust against the 100-cigarette filter, but it greatly affected the estimated prevalence trends for non-daily smoking. For both national and international tobacco monitoring purposes, questions should be standardized to enable better comparability and closer monitoring with more frequent reporting. The latter is particularly salient with new tobacco products being introduced to the market much quicker than we can monitor.

3.4.1 Limitations

There are a number of limitations to applying the approach described by Holford et al. [106] in settings with lower degrees of tobacco surveillance such as Mexico. While Holford et al. were able to use a single source of data, the National Health Interview Survey, which ensured a degree of consistency, we used three different survey series. Notwithstanding the difficulty in harmonizing the different questions and skip patterns for different surveys, this is also a source of uncertainty in our estimation. Additionally, while the regular non-daily smokers have emerged as an

important group, they are difficult to characterize with the current set of questions available in the three series of surveys, as we do not know the onset of regular non-daily smoking (unlike the regular daily smokers). Also, as with other types of questions regarding self-report of lifestyle behaviours, there is recall bias. This is particularly problematic with questions about smoking initiation when asking older respondents, as well as questions about smoking cessation given its nature. Finally, there is likely to be healthy respondent bias such that smoking prevalence at older ages may be underestimated, as we can see from the decay in the estimated current and former smoking prevalence with age.

3.4.2 Conclusion

In this chapter, we estimated sex- and age-specific smoking prevalence, initiation and cessation probabilities in Mexico. Smoking prevalence were estimated for single-year birth cohorts from as early as the 1920 birth cohort, smoking initiation from the 1930 birth cohort and cessation from the 1940 birth cohort. Increases in current smoking have been observed in recent birth cohorts, particularly for non-daily smoking. Our results also demonstrate the need to go beyond the routine of cross-sectional analysis, with an added emphasis on cohort patterns of smoking and tobacco use, especially in light of the advent of new tobacco products targeting different segments of the population (e.g. the e-cigarette Juul and the youth). Interventions aimed at daily smokers may be very different to non-daily smokers, as well as older adults versus younger adults. Standardization of smoking-related questions between different health surveys, as well as higher frequencies of these surveys, would also improve the quality of the characterization of smoking histories. In turn, these would provide better quality inputs to inform simulation models, which would allow decision makers to evaluate the impact of tobacco control policies [128, 129]. Indeed, using

estimates of smoking history in this chapter, we develop one such model in Chapter IV which will help us explore the potential drivers of the trends that we observed in Mexico.

CHAPTER IV

A State Transition Model to Describe Potential Drivers of Smoking Prevalence in Mexico

4.1 Introduction

Through explicit mathematical descriptions of system dynamics and synthesis with real-world data, computational modeling can be a useful technique to shed light on the potential mechanism(s) behind observed phenomena. This scientific approach has had a long history in both biological sciences and biomedical sciences with examples ranging from the description of vector-borne disease epidemics [130], to the process of human carcinogenesis [131] respectively. Indeed, the relevance of these applications to public health is apparent, which may explain the fact that computational modeling has been gaining prominence with public health specialists and policy-makers given their highly valuable contribution in decision-making and resource planning [132–135].

Computational models differ from statistical models in that the latter have mostly been used to detect potential correlations or associations between variables of interest. Often, we cannot understand the mechanism underlying the association from these models. For example, from our analysis in the previous chapter where we used age-period-cohort models, we saw that there were strong cohort effects associated with current smoking prevalence in Mexico. Similarly, Doll and Peto [10, 11] con-

cluded that smoking causes lung cancer from the strong associations represented by odds ratios in a case-control study. However, we cannot deduce what might have driven the cohort effects that are associated with the observed smoking patterns from our results, nor did we know exactly *how* smoking caused lung cancer at the time.

Of course, it is not always necessary to know the how to make something work. Much like we could drive a car without knowing the laws of physics involving the mechanics of an engine, regulations to curb smoking could be implemented without knowing the exact role of smoking in lung carcinogenesis. But to tackle the issue of smoking effectively, it may be helpful to get a better sense of the main mechanics behind smoking prevalence — smoking initiation and cessation — and how these might be differentially responding to changes in time, or to specific tobacco control interventions. As discussed in the Introduction chapter of this dissertation, the goal of tobacco control interventions, such as excise tax, outdoor smoking restrictions, and tobacco product advertising restrictions, is to lower smoking initiation and increase smoking cessation. If we had a better idea of what levels of initiation and cessation (by age, sex, calendar year and birth cohort) might explain the observed current smoking prevalence from health surveys, we could better target tobacco control interventions and predict their impact. In fact, computational models have been used by policy makers and public health practitioners for the purposes of evaluating the impact of the tobacco burden and tobacco control policies to guide decision-making [136–138]. For example, these models evaluated the impact of policies on future smoking prevalence in the population [106, 139, 140], lung cancer deaths [129, 141], and smoking-related pre-mature mortality [128, 139]. By using the best available knowledge of the effects of tobacco policies at present, these models are able to pro-

vide useful perspectives of how these policies may affect future tobacco trends and population health outcomes.

We found one such model published in the literature for smoking in Mexico by Fleischer et al. [43, 142, 143] — Mexico *SimSmoke* — a discrete-time first-order Markov model, structured with current, former and ever smokers. The goal of the model was to investigate the impact on smoking-attributable deaths and smoking prevalence, after Mexico implemented tobacco control policies following the ratification of the WHO's Framework Convention on Tobacco Control (FCTC) [43, 142, 143]. Age-specific prevalence was used as input to the model, but these were not broken into birth cohorts, which we know paint a more nuanced picture than just age-specific prevalence alone from our analysis in the previous chapter. Additionally, both Zavala-Arciniega et al. [125] and the analysis from Chapter III revealed a structural break between the daily and nondaily smokers where the uptake of these smoking behaviors diverged. In this chapter, we propose to take a slightly different approach from the Mexico *SimSmoke* model [43, 142, 143], and instead follow the one used by the CISNET Lung group for the US by incorporating birth-cohort-specific smoking history by using the estimates from Chapter III [106, 128, 129, 140]. We also separate current smokers into current daily and current non-daily smokers to investigate the smoking patterns we had observed. By doing so, we can explicitly explore the possible mechanics — initiation, switching and cessation — responsible for the change in the relative prevalence of daily and non-daily smoking in Mexico. After calibrating the model, we project smoking prevalence from 2017 until 2050, assuming that the smoking-related parameters are kept constant at the 2016 level. These projections can serve as a representation of the status quo for smoking prevalence in the Mexican population.

4.2 Methods

4.2.1 Model description

We adapted the model described in Holford et al. [106] where never smokers could transition into current smokers, who in turn, could transition into former smokers. Each of these states are mutually exclusive and birth cohort and age-specific prevalence, initiation and cessation, were used as inputs to this model. For our first-order Markov model (see Figure 4.1), we divided current smokers into two, where never smokers s_1 could transition to being current daily smokers s_2 or current non-daily smokers s_3. Current daily smokers could transition to current non-daily smokers, and vice versa, or they could transition to be former smokers s_4. Other than these transitions described, outflows from each state could also be due to death. Note that all the transition probabilities are a function age and calendar year.

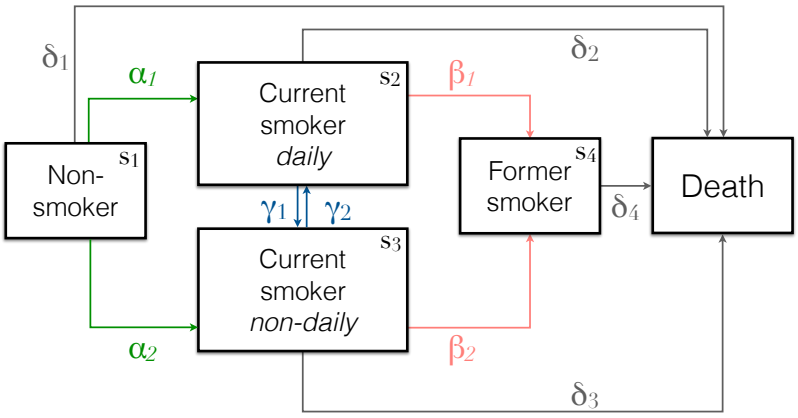


Figure 4.1: Model diagram. $\alpha_i, i = 1, 2$ represents the probability of initiation where 1 = daily smoking, 2 = non-daily smoking, $\delta_j, j = 1, 2, 3, 4$ represents death probabilities where 1 = non-smoker, 2 = current daily smoker, 3 = current non-daily smoker, 4 = former smoker, γ_i represents the probability of switching smoking frequencies, and β_i represents the probability of quitting smoking.

More formally, we can describe our model with a set of difference equations (Equation 4.1), where each s_j, $j = 1, 2, 3, 4$ represents the number of individuals in each of

four possible smoking states: 1 = never smoker, 2 = current daily smoker, 3 = current non-daily smoker, and 4 = former smoker. Each s_j at age a changes in discrete time steps t, where each increment of t is equivalent to one calendar year, and $s_{j_{a,t}}$ (the left hand side of the equations) is dependent on the inflows and outflows at the previous time step, $t-1$. Then, α_i, $i = 1, 2$ represents the probability of initiation where 1 = current daily smoker, 2 = current non-daily smoker; γ_i, $i = 1, 2$ represents the probability of switching where 1 = switching from current daily to non-daily smoker, 2 = switching from current non-daily to daily smoker; β_i, $i = 1, 2$ represents the probability of quitting, where 1 = quit from daily, 2 = quit from non-daily; and finally, the probability of dying from each smoking state is given by δ_j, $j = 1, 2, 3, 4$. We ran this model separately for males and females.

$$
\begin{aligned}
s_{1_{a,t}} &= s_{1_{a-1,t-1}} \times (1 - \alpha_{1_{a-1,t-1}} - \alpha_{2_{a-1,t-1}} - \delta_{1_{a-1,t-1}}) \\
s_{2_{a,t}} &= s_{1_{a-1,t-1}} \times \alpha_{1_{a-1,t-1}} + s_{2_{a-1,t-1}} \times (1 - \delta_{2_{a-1,t-1}} - \gamma_1 - \beta_{1_{a-1,t-1}}) \\
&\quad + s_{3_{a-1,t-1}} \times \gamma_2 \\
s_{3_{a,t}} &= s_{1_{a-1,t-1}} \times \alpha_{2_{a-1,t-1}} + s_{3_{a-1,t-1}} \times (1 - \delta_{3_{a-1,t-1}} - \gamma_2 - \beta_{2_{a-1,t-1}}) \\
&\quad + s_{2_{a-1,t-1}} \times \gamma_1 \\
s_{4_{a,t}} &= s_{2_{a-1,t-1}} \times \beta_{1_{a-1,t-1}} + s_{3_{a-1,t-1}} \times \beta_{2_{a-1,t-1}} + s_{4_{a-1,t-1}} \times (1 - \delta_{4_{a-1,t-1}})
\end{aligned}
\tag{4.1}
$$

4.2.2 Model inputs

We used the earliest Encuesta Nacional de Adiciones (ENA) as the starting point of our model, the year 1998. To initialize the model, we obtained age-specific population counts and deaths from *CONAPO*, the National Population Council of Mexico [144]. We then took the age-specific prevalence for current daily, current non-daily

and former smokers for 1998 (prevalence of never smokers is then the complement of the sum of these three), estimated from our age-period-cohort models, and obtained the number of people in each s_j at $t = 0$ by multiplying the associated prevalence with the population counts [144]. We approximated overall annual mortality rates by dividing the number of deaths [144] by the population counts. To the best of our knowledge, there are no direct estimates of relative risks comparing daily and non-daily smoking for Mexico. Thus, we adjusted estimates from the US [126] for the Mexican context [142, 145], and assumed that non-daily smokers have a 1.64 fold risk of dying relative to never smokers, 1.87 for daily smokers, and 1.2 for former smokers. We then applied the mortality data from CONAPO and obtained the annual mortality for each δ_j in Equation 4.1.

The annual initiation and cessation probabilities estimated from Chapter III are represented by α_i and β_i in the model respectively, which are age-specific. From our data sets, we do not have information on when/if current daily smokers switch to be current non-daily smokers, and vice versa, so we obtained this information from the ITC cohort data for Mexico [108, 146]. Participants in the ITC cohort were smokers, and were classified as non-daily, daily light, and daily heavy smokers at baseline. Follow-up occurred approximately one year after baseline, and their smoking status was recorded and we used these transitions and set $\gamma_1 = 0.29$ and $\gamma_2 = 0.176$. Note that these estimates obtained from the ITC cohort data were neither sex- nor age-specific, however.

4.2.3 Model calibration

There are clear discrepancies between the modeled (estimated from the base, unadjusted model) vs the observed prevalence (see Figures 4.2-4.5). This suggests that the base model may need additional parameters and/or some parameters may

need to be recalibrated to better capture what is observed from the ENA data. Therefore, we added four adjustment parameters which are also functions of age and calendar year, $\mathbf{p_1}$, $\mathbf{p_2}$, $\mathbf{q_1}$, and $\mathbf{q_2}$, updating Equation 4.1 to the following:

$$
\begin{aligned}
s_{1_{a,t}} &= s_{1_{a-1,t-1}} \times (1 - \mathbf{p_{1_{a-1,t-1}}} \times \alpha_{1_{a-1,t-1}} - \mathbf{p_{2_{a-1,t-1}}} \times \alpha_{2_{a-1,t-1}} - \delta_{1_{a-1,t-1}}) \\
s_{2_{a,t}} &= s_{1_{a-1,t-1}} \times \mathbf{p_{1_{a-1,t-1}}} \times \alpha_{1_{a-1,t-1}} \\
&\quad + s_{2_{a-1,t-1}} \times (1 - \delta_{2_{a-1,t-1}} + \gamma_{1_{a-1,t-1}} + \mathbf{q_{1_{a-1,t-1}}} \times \beta_{1_{a-1,t-1}}) \\
&\quad + s_{3_{a-1,t-1}} \times \gamma_{2_{a-1,t-1}} \\
s_{3_{a,t}} &= s_{1_{a-1,t-1}} \times \mathbf{p_{2_{a-1,t-1}}} \times \alpha_{2_{a-1,t-1}} \\
&\quad + s_{3_{a-1,t-1}} \times (1 - \delta_{3_{a-1,t-1}} - \gamma_{2_{a-1,t-1}} - \mathbf{q_{2_{a-1,t-1}}} \times \beta_{2_{a-1,t-1}}) \\
&\quad + s_{2_{a-1,t-1}} \times \gamma_{1_{a-1,t-1}} \\
s_{4_{a,t}} &= s_{2_{a-1,t-1}} \times \mathbf{q_{1_{a-1,t-1}}} \times \beta_{1_{a-1,t-1}} + s_{3_{a-1,t-1}} \times \mathbf{q_{2_{a-1,t-1}}} \times \beta_{2_{a-1,t-1}} \\
&\quad + s_{4_{a-1,t-1}} \times (1 - \delta_{4_{a-1,t-1}})
\end{aligned}
\tag{4.2}
$$

Essentially, these parameters — $\mathbf{p_1}$ and $\mathbf{p_2}$, and $\mathbf{q_1}$, and $\mathbf{q_2}$ — function as multipliers to the initiation and cessation parameters, $\alpha_{i_{a,t}}$ and $\beta_{i_{a,t}}$, in the base model respectively. We also varied the probability of switching from daily to non-daily ($\gamma_{1_{a,t}}$), and non-daily to daily smoker ($\gamma_{2_{a,t}}$), now with added flexibility to be age- and year-specific. To find the model with the best fit, we first varied one parameter at a time to get a better sense of the mechanisms that would account for the differences between the observed and the expected prevalence estimated by the model. Then, we combined two of these at a time. Finally, we combined all three i.e. initiation, cessation and switching. In addition, we varied the calendar year and age where these parameters applied. To calibrate the model, we used the Davidon-Fletcher-Powell optimizer in R statistical software's Bhat library [147] to minimize the residual sum

of squares (Equation 4.3).

$$min[\sum_{i=1}^{N}(Observed_i - Expected_i)^2] \tag{4.3}$$

4.3 Results

4.3.1 Model fit: base (unadjusted) model

In the male model, we can see that for daily smoking prevalence (Figure 4.2), it still fits quite well in 2002, four years after the starting point of the model. However, by 2011, the model overestimates the observed prevalence by quite a bit, especially for individuals under 50 years old. The gap widens even more in 2016. For non-daily smoking prevalence (Figure 4.3, we see that there is already some underestimation in 2002 for the 23-27 age range. The gap becomes even wider in 2011 and 2016 — the base model fails to capture the large jump in non-daily smoking daily prevalence in the 18-27 age range. In general, these observations apply for female daily (Figure 4.4) and non-daily (4.5) as well, although for non-daily prevalence, the underestimation is already quite pronounced in 2002, particularly for the age range 18-22. Notice that the observed non-daily prevalence in 1998 was around 2.5%, whereas this surged to above 10% in 2002. While our model does predict an increase between 1998 and 2002, it failed to account for this break in smoking pattern. Interestingly, the level of observed prevalence for this young age group persists, but our model does not manage to "catch up" to it at all. It is clear that the base model in its current configuration needs to be modified and calibrated for it to be useful for predictions into the future. Nonetheless, it gives us a good basis to start untangling some of the possible mechanisms — changes in initiation, switching, changes in cessation, or a combination thereof — behind the observed smoking patterns.

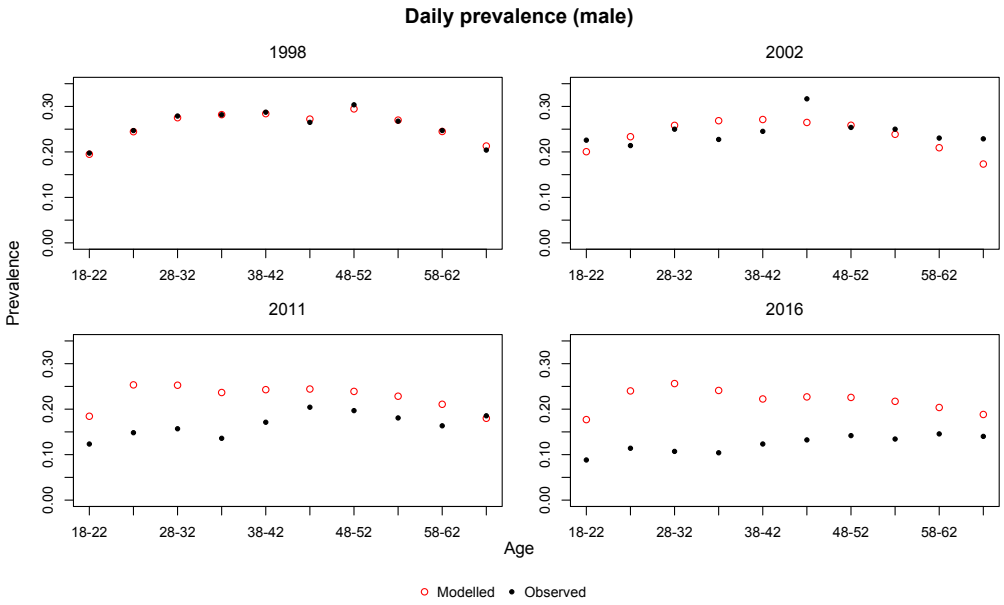


Figure 4.2: Modelled vs observed male daily age-specific smoking prevalence for 1998, 2002, 2011 and 2016

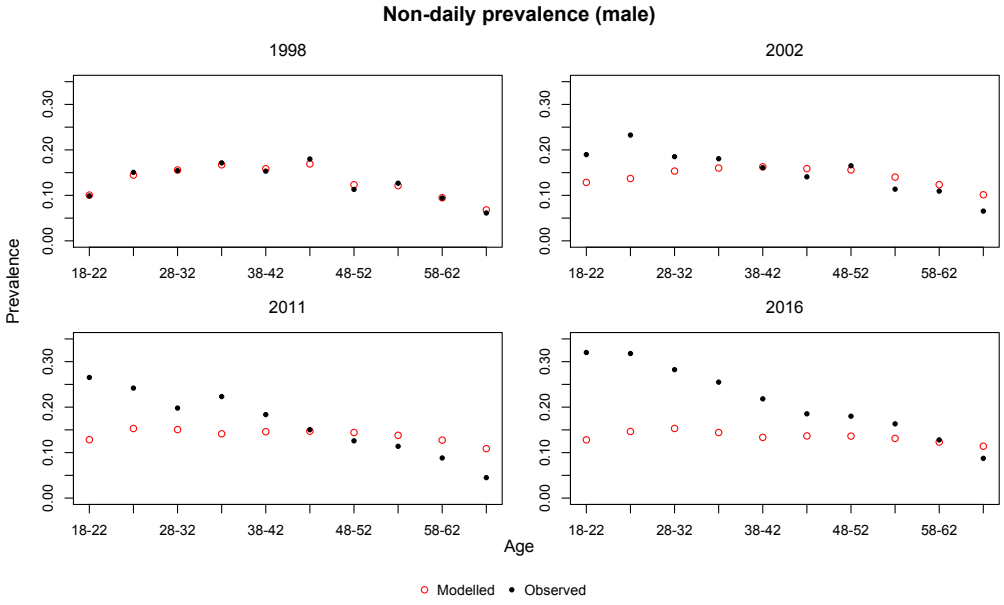


Figure 4.3: Modelled vs observed male non-daily age-specific smoking prevalence for 1998, 2002, 2011 and 2016

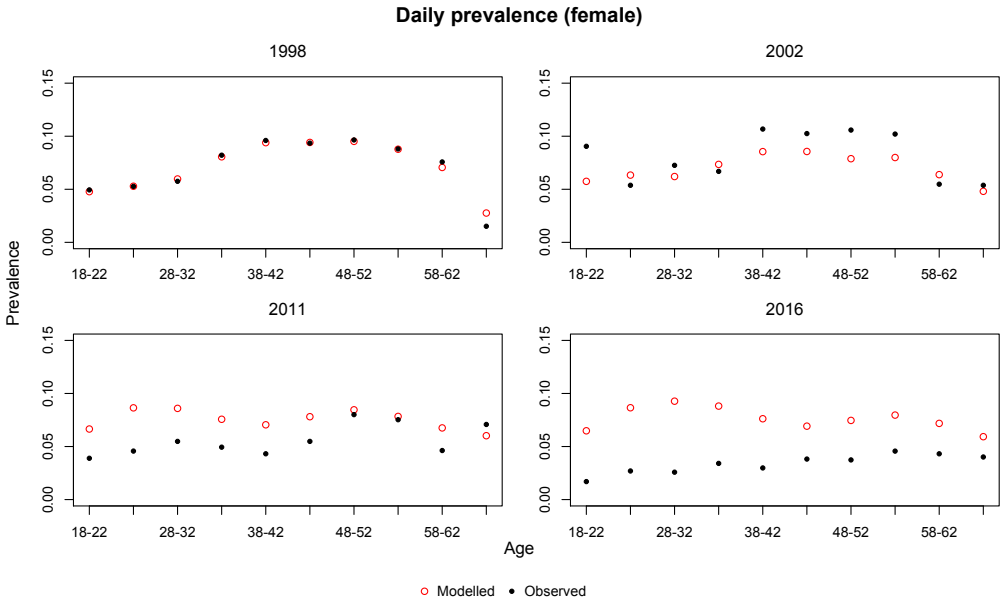


Figure 4.4: Modelled vs observed female daily age-specific smoking prevalence for 1998, 2002, 2011 and 2016

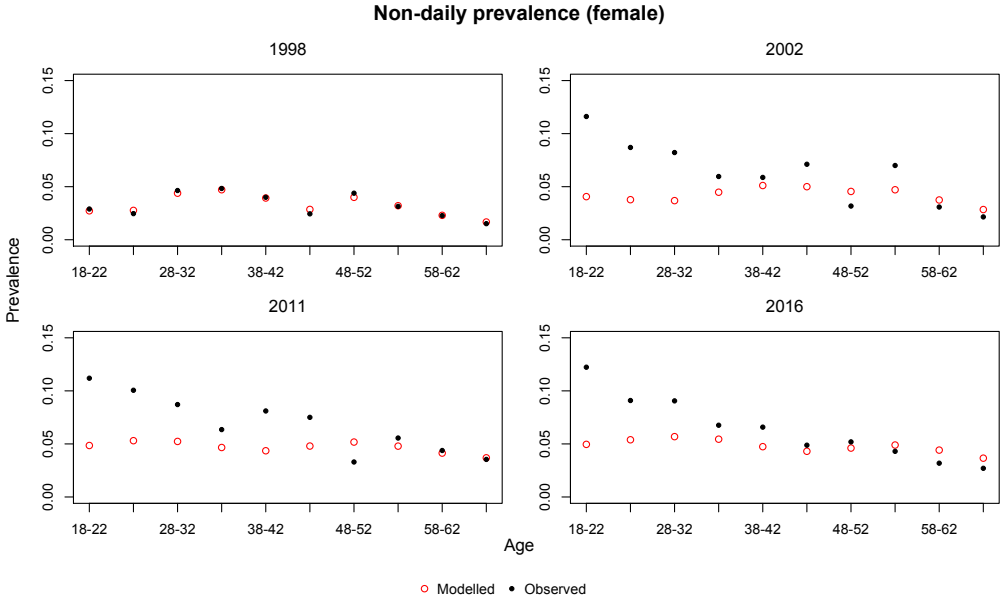


Figure 4.5: Modelled vs observed female non-daily age-specific smoking prevalence for 1998, 2002, 2011 and 2016

4.3.2 Model calibration

Tables 4.1 and 4.2 summarize the different configurations of the model runs that took place, the estimated values for the parameters, and the residual sum of squares (RSS) post optimization where higher RSS indicates poorer fit. Note that the residual sum of squares for the base male model (Table 4.1, $RSS = 0.3292$) is more than five times that of the female's (Table 4.2, $RSS = 0.0603$); this is explained by the difference in the levels of smoking prevalence between the sexes.

As a single mechanism, switching has the strongest impact on model fit, as shown with the largest decrease of residual sum of squares relative to the base model. For the male model, compare $RSS_{dailyToNonDaily} = 0.1855$ and $RSS_{nonDailyToDaily} = 0.1697$, to $RSS_{base} = 0.3292$. Analogously for the female model, we can compare $RSS_{dailyToNonDaily} = 0.0311$ and $RSS_{nonDailyToDaily} = 0.0307$ to $RSS_{base} = 0.0603$. Adjusting the initiation to non-daily smoking and daily smoking separately and applying them to different age groups did not make that much of a difference, when we compare these respective residual sums of squares to the base model's. The fact that the initiation multipliers did not make much of a difference is a little surprising, given that one might think that for the modelled non-daily smoking prevalence to increase and match the observed prevalence (or daily prevalence to decrease), adjusting the respective initiation probabilities would improve the fit somewhat.

When we attempted to adjust two mechanisms for the male model (Table 4.1), the combination of non-daily initiation and switching (either directions) only produced a marginally better fit than just initiation alone ($RSS_{initDaily\_dailyToNonDaily} = 0.2889$ and $RSS_{initDaily\_nonDailyToDaily} = 0.2876$ vs $RSS_{base} = 0.3278$) , but is a worse fit than just switching alone. When we tried to apply adjustments differentially by age for this combination (see row 13 in Table 4.1), the model did not

converge. Adjusting non-daily initiation and quitting rates of daily smokers, however, provided a better fit ($RSS_{initNonDaily\_quitDaily} = 0.178$) relative to adjusting non-daily initiation and switching; although, this is still a worse fit compared to just switching from non-daily to daily alone. The combination of altering quitting rates of daily smokers and switching yields the best fit out of all the two-mechanism adjustments, with the residual sum of squares being marginally better than just switching alone, $RSS_{quitDaily\_nonDailyToDaily} = 0.1586$ and $RSS_{quitDaily\_dailyToNonDaily} = 0.1621$ vs $RSS_{nonDailyToDaily} = 0.1697$.

For the female model (Table 4.2), the two-mechanism adjustments had similar effects to the male version on the model fit; only when adjusting quitting rates of daily smokers and switching from non-daily to daily yielded a better fit than just switching from non-daily to daily alone. Moreover, the improvement in fit was also marginal, with $RSS_{quitDaily\_nonDailyToDaily} = 0.0296$ vs $RSS_{nonDailyToDaily} = 0.0307$.

When all three mechanisms were adjusted together — initiation, quitting and switching — these parameters could be estimated. For both the male and female models, increasing the estimated non-daily initiation probabilities (and differently by age group), quitting probabilities for daily smokers, and finally, adjusting the probabilities of switching from non-daily to daily smoking by age group would give us the best fit ($RSS_{male} = 0.0769$, $RSS_{female} = 0.0209$). Specifically, for the male model, the calibrated parameter estimates indicated that non-daily smoking initiation for individuals from age 0-18 and age 19-99 needed to approximately double and triple respectively. To account for the large declines in daily smoking, quitting rates of daily smokers needed to increase by five times across all ages, with some switching from non-daily to daily. For the female model, non-daily smoking initiation for individuals from age 0-18 and age 19-99 needed to double and increase one and a

half times respectively. Here, quitting rates of daily smokers needed to increase by nine and a half times across all ages, again with some switching from non-daily to daily. The fits for the male and female models with the lowest RSS are shown in Figures 4.6-4.9. We can see that after calibration, the model is able to better capture the successive declines in observed daily smoking prevalence in males (Figure 4.6), and the jump in non-daily smoking prevalence as well (Figure 4.7). We were also able to correct the overestimation of daily smoking prevalence in females from the base, unadjusted model (see Figure 4.4 vs. Figure 4.8). For reference, we also aggregated the prevalence at the years of surveys (i.e. these are not age-specific) as shown in Figure 4.10. Note, however, while the optimization software was able to find a solution for this last set of model, it is clear that some of these mechanisms are correlated and hard to distinguish from each other. For instance, an increase in non-daily initiation occurring simultaneously with an increase in daily smoking cessation, could mimic an increase in switching from daily to non-daily. Thus, while we use the results as suggestive, we realize that the amount of data is likely not enough to independently estimate these potential mechanisms.

Table 4.1: Parameters estimated with model fits (male)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
1. None (base model)	NA	NA	NA	NA	0.3291877
2. Switching from daily to non-daily (γ_1)	0-30	1998-2016	0.176 [0, 1]	0.52311009	0.1854786
3. Switching from non-daily to daily (γ_2)	0-30	1998-2016	0.29 [0, 1]	0.065655007	0.1696806
4. Initiation daily ($\mathbf{p_1}$)	0-18	1998-2016	2 [0, 100]	0.60654515	0.3262834
5. Initiation daily ($\mathbf{p_1}$)	0-18	1998-2016	10 [0, 100]	1.2047516	0.2949804
	19-99		2 [0, 100]	1.1253516e-05	
6. Initiation daily ($\mathbf{p_1}$)	0-18	2010-2016	10 [0, 100]	0.67585642	0.3126142
	19-99		2 [0, 100]	1.1253516e-05	
7. Initiation non-daily ($\mathbf{p_2}$)	0-18	1998-2016	2 [0, 100]	1.242527	0.3278157
8. Initiation non-daily ($\mathbf{p_2}$)	0-18	1998-2016	10 [0, 100]	1.2846634	0.3277718
	19-99		2 [0, 100]	0.8739977	
9. Initiation non-daily ($\mathbf{p_2}$)	0-18	2010-2016	10 [0, 100]	1.4805291	0.3024399
	19-99		2 [0, 100]	5.8269081	
10. Quit daily ($\mathbf{q_1}$)	20-99	1998-2016	2 [0, 100]	2.8686058	0.2873803

Table 4.1: (continued)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
11. Quit non-daily ($\mathbf{q_2}$)	20-99	1998-2016	2 [0, 100]	2.5289618	0.3157807
12. Initiation non-daily ($\mathbf{p_2}$)	0-22 ($\mathbf{p_2}$)	1998-2016	1 [0,100]	1.2547185	0.2889065
Switching from daily to non-daily (γ_1)	30-99 (γ_1)		0.176 [0, 1]	0.24841278	
13. Initiation non-daily ($\mathbf{p_2}$)	0-18 ($\mathbf{p_2}$)	2006-2016	10 [0, 100]	Convergence not reached	NA
	19-99 ($\mathbf{p_2}$)		2 [0, 100]		
Switching from daily to non-daily (γ_1)	0-18 (γ_1)		1 [0, 1]		
	19-99 (γ_1)		1 [0, 1]		
14. Initiation non-daily ($\mathbf{p_2}$)	0-22 ($\mathbf{p_2}$)	1998-2016	1 [0, 100]	1.2506545	0.2876344
Switching from non-daily to daily (γ_2)	30-99 (γ_2)		0.29 [0, 1]	0.19955045	
15. Initiation non-daily ($\mathbf{p_2}$)	0-18 ($\mathbf{p_2}$)	2010-2016	10 [0, 100]	0.00015588726	0.1779877
	19-99 ($\mathbf{p_2}$)		2 [0, 100]	18.782844	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)		2 [0, 100]	13.820741	
16. Quit daily ($\mathbf{q_1}$)	19-99 ($\mathbf{q_1}$)	2006-2016	10 [0, 100]	3.1542577	0.1620925
Switching from non-daily to daily (γ_2)	19-99 (γ_2)		0.29 [0, 1]	0.13720037	

Table 4.1: (continued)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
17. Quit daily ($\mathbf{q_1}$)	19-99 ($\mathbf{q_1}$)	2006-2016	10 [0,100]	3.4181539	0.1585964
Switching from daily to non-daily (γ_1)	19-99 (γ_1)		0.176 [0, 1]	0.36542443	
18. Initiation non-daily ($\mathbf{p_2}$)	0-18 ($\mathbf{p_2}$)	2010-2016	2 [0,100]	2.4079999	0.08803797
	19-99 ($\mathbf{p_2}$)	2010-2016	2 [0, 100]	3.7509795	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)	2010-2016	1 [0, 100]	5.4283973	
Switching from daily to non-daily (γ_1)	0-30 (γ_1)	2006-2016	0.1 [0, 1]	0.60023074	
	31-99 (γ_1)	2006-2016	0.2 [0, 1]	0.26117402	
19. Initiation non-daily ($\mathbf{p_2}$)	0-18 ($\mathbf{p_2}$)	2010-2016	2 [0,100]	2.3018293	0.07690177
	19-99 ($\mathbf{p_2}$)	2010-2016	2 [0,100]	3.2739945	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)	2010-2016	1 [0,100]	5.2826818	
Switching from non-daily to daily (γ_2)	0-30 (γ_2)	2006-2016	0.1 [0,1]	0.068956955	
	31-99 (γ_2)	2006-2016	0.1 [0,1]	0.1889036	

Table 4.1: (continued)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
20. Initiation daily ($\mathbf{p_1}$)	0-18 ($\mathbf{p_1}$)	2010-2016	2 [0,100]	2.6083112	0.09067681
	19-99 ($\mathbf{p_1}$)	2010-2016	2 [0,100]	1.7222054	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)	2010-2016	1 [0,100]	5.0501576	
Switching from non-daily to daily (γ_2)	0-30 (γ_2)	2006-2016	0.1 [0,1]	0.032178003	
	31-99 (γ_2)	2006-2016	0.1 [0,1]	0.18855125	
21. Initiation daily ($\mathbf{p_1}$)	0-18 ($\mathbf{p_1}$)	2010-2016	2 [0,100]	0.97626426	0.1648901
Quit daily ($\mathbf{q_1}$)	20-99 ($\mathbf{q_1}$)	2010-2016	1 [0,100]	4.3576209	
Switching from non-daily to daily (γ_2)	19-99 (γ_2)	2006-2016	0.1 [0,1]	0.13992033	

Table 4.2: Parameters estimated with model fits (female)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
1. None (base model)	NA	NA	NA	NA	0.06032086
2. Switching: Daily to non-daily (γ_1)	0-30	1998-2016	0.176 [0, 1]	0.85168927	0.03112807
3. Switching from non-daily to daily (γ_2)	0-30	1998-2016	0.29 [0, 1]	0.032180128	0.03070711
4. Initiation daily ($\mathbf{p_1}$)	0-18	1998-2016	2 [0, 100]	0.55132934	0.05947922
5. Initiation daily ($\mathbf{p_1}$)	0-18	1998-2016	10 [0, 100]	1.0240127	0.05323537
	19-99		2 [0, 100]	0.00057760981	
6. Initiation daily ($\mathbf{p_1}$)	0-18	2010-2016	10 [0, 100]	0.00039993894	0.05463634
	19-99		2 [0, 100]	1.1253516e-05	
7. Initiation non-daily ($\mathbf{p_2}$)	0-18	1998-2016	2 [0, 100]	1.1020342	0.06027899
8. Initiation non-daily ($\mathbf{p_2}$)	0-18	1998-2016	10 [0, 100]	1.3864298	0.05923004
	19-99		2 [0, 100]	0.34454652	
9. Initiation non-daily ($\mathbf{p_2}$)	0-18	2010-2016	10 [0, 100]	2.3454233	0.05924462
	19-99		2 [0, 100]	0.66318318	
10. Quit daily ($\mathbf{q_1}$)	20-99	1998-2016	2 [0, 100]	2.5998621	0.05482058

Table 4.2: (continued)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
11. Quit non-daily ($\mathbf{q_2}$)	20-99	1998-2016	2 [0, 100]	2.1113055	0.05900461
12. Initiation non-daily ($\mathbf{p_2}$)	0-22 ($\mathbf{p_2}$)	1998-2016	1 [0, 100]	1.1282085	0.05506643
Switching from daily to non-daily (γ_1)	30-99 (γ_1)		0.176 [0, 1]	0.26244637	
13. Initiation non-daily ($\mathbf{p_2}$)	0-22 ($\mathbf{p_2}$)	1998-2016	1 [0, 100]	1.1229705	0.05462479
Switching from non-daily to daily (γ_2)	30-99 (γ_2)		0.29 [0, 1]	0.18556369	
14. Initiation non-daily ($\mathbf{p_2}$)	0-18 ($\mathbf{p_2}$)	2010-2016	10 [0, 100]	2.5761855	0.03259509
	19-99 ($\mathbf{p_2}$)		2 [0, 100]	6.4313482	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)		2 [0, 100]	11.999112	
15. Quit daily ($\mathbf{q_1}$)	19-99 ($\mathbf{q_1}$)	2006-2016	1 [0, 100]	3.6371913	0.02956905
Switching from non-daily to daily (γ_2)	0-18 (γ_2)		0.29 [0, 1]	1.0106597e-06	
	19-99 (γ_2)		0.29 [0,1]	0.13157799	
16. Quit daily ($\mathbf{q_1}$)	19-99 ($\mathbf{q_1}$)	2006-2016	1, 10 [0,100]	Convergence not reached	NA
Switching from daily to non-daily (γ_1)	0-18 (γ_1)		0.176 [0,1]		
	19-99 (γ_1)		0.176 [0,1]		

Table 4.2: (continued)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
17. Initiation non-daily ($\mathbf{p_2}$)	0-18 ($\mathbf{p_2}$)	2010-2016	2 [0,100]	2.6992896	0.02255973
	19-99 ($\mathbf{p_2}$)	2010-2016	2 [0,100]	0.47772233	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)	2010-2016	1 [0,12]	6.045202	
Switching from daily to non-daily (γ_1)	0-30 (γ_1)	2006-2016	0.1 [0,1]	0.88450233	
	31-99 (γ_1)	2006-2016	0.2 [0,1]	0.26422274	
18. Initiation non-daily ($\mathbf{p_2}$)	0-99 ($\mathbf{p_2}$)	2000-2016	2 [0,100]	1.8935206	0.02184763
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)	2006-2016	12 [0,100]	6.5611552	
Switching from daily to non-daily (γ_1)	0-30 (γ_1)	2000-2016	0.2 [0,1]	0.59890425	
	31-99 (γ_1)	2000-2016	0.1 [0,1]	0.21459152	
19. Initiation non-daily ($\mathbf{p_2}$)	0-18 ($\mathbf{p_2}$)	2000-2016	2 [0,100]	2.0050289	0.02088675
	19-99 ($\mathbf{p_2}$)	2000-2016	2 [0,100]	1.4867964	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)	2010-2016	1 [0,12]	9.4748384	
Switching from non-daily to daily (γ_2)	0-30 (γ_2)	2006-2016	0.1 [0,1]	0.083027333	
	31-99 (γ_2)	2006-2016	0.1 [0,1]	0.2151046	

Table 4.2: (continued)

Parameter(s) changed	Age range(s) applied by parameters	Period applied by parameters	Initial value(s) of parameters [range permitted]	Optimized value(s) of parameter(s)	Residual sum of squares
20. Initiation daily ($\mathbf{p_1}$)	0-18 ($\mathbf{p_1}$)	2010-2016	2 [0,100]	3.2032297	0.02310982
	19-99 ($\mathbf{p_1}$)	2010-2016	2 [0,100]	0.0045120937	
Quit daily ($\mathbf{q_1}$)	0-99 ($\mathbf{q_1}$)	2010-2016	1 [0,100]	5.4640139	
Switching from non-daily to daily (γ_2)	0-30 (γ_2)	2006-2016	0.1 [0,1]	0.0284575	
	31-99 (γ_2)	2006-2016	0.1 [0,1]	0.19995279	
21. Initiation daily ($\mathbf{p_1}$)	0-18 ($\mathbf{p_1}$)	2010-2016	2 [0,100]	0.38134941	0.0345506
Quit daily ($\mathbf{q_1}$)	20-99 ($\mathbf{q_1}$)	2010-2016	1 [0,100]	6.7384805	
Switching from non-daily to daily (γ_2)	19-99 (γ_2)	2006-2016	0.1 [0,1]	0.14034074	

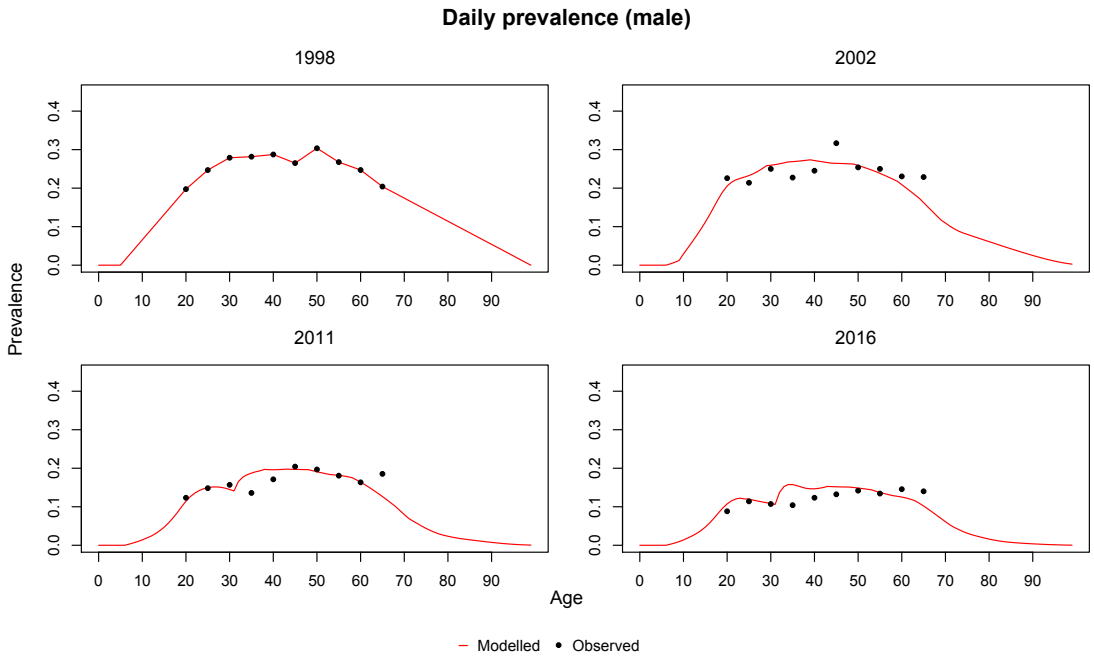


Figure 4.6: Model fit after calibration: male age-specific daily smoking prevalence for 1998, 2002, 2011 and 2016

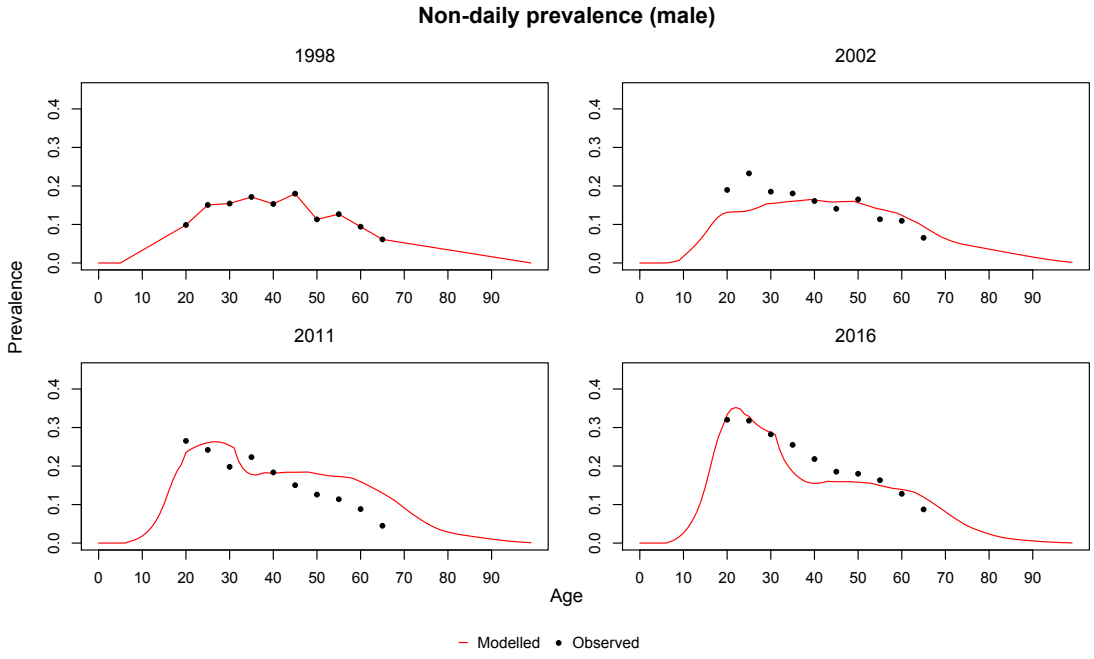


Figure 4.7: Model fit after calibration: male age-specific non-daily smoking prevalence for 1998, 2002, 2011 and 2016

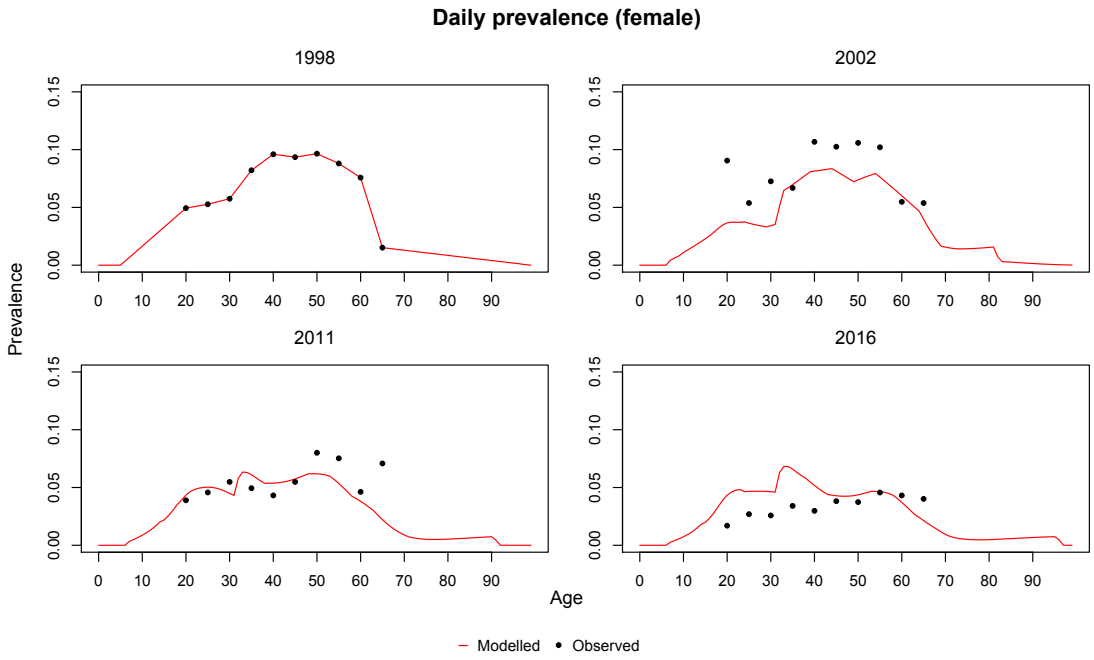


Figure 4.8: Model fit after calibration: female age-specific daily smoking prevalence for 1998, 2002, 2011 and 2016

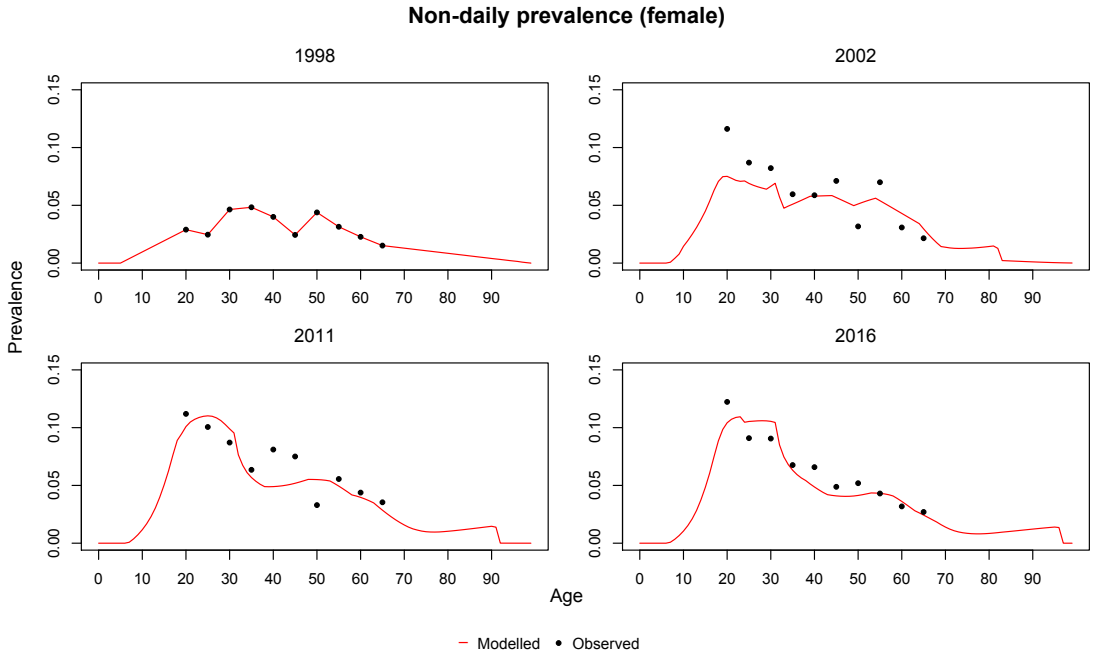
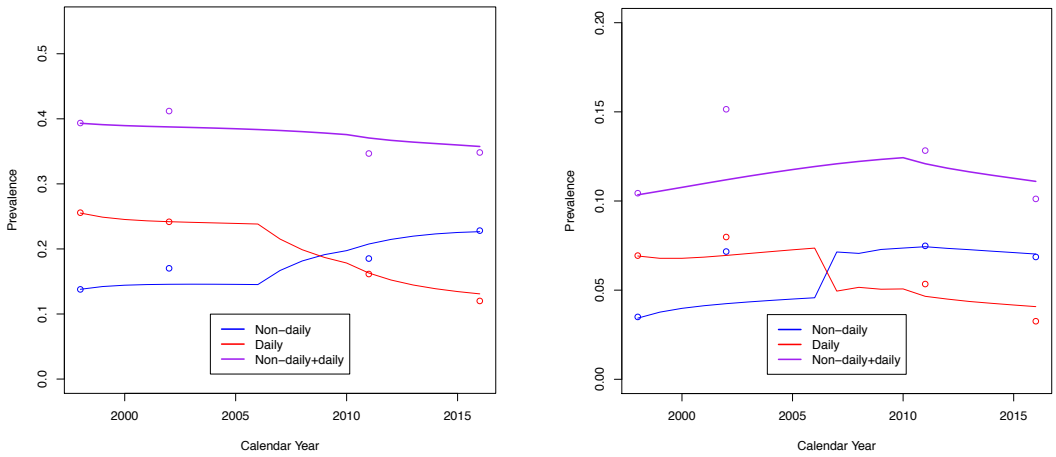


Figure 4.9: Model fit after calibration: female age-specific daily smoking prevalence for 1998, 2002, 2011 and 2016



(a) Male (b) Female

Figure 4.10: Modelled vs observed aggregate smoking prevalence (aged 18-65)

4.3.3 Projecting daily and non-daily prevalence to 2050

To make projections of smoking prevalence and number of smokers into the future to 2050, we used the model configuration along with the parameter values that gave us the best fit as previously described. We used the projected death rates and birth rates provided by CONAPO, and kept all other parameters constant from 2016 until 2050. Extending the Figure 4.10 to the year 2050, we see that total smoking prevalence in the adult male population is projected to decrease, and does so at a decreasing rate (Figure 4.11). This is a combination of a plateauing male non-daily smoking with a decreasing daily prevalence. In Figure 4.12 which includes all adult males (in contrast to Figure 4.11 which show smoking prevalence from age 18-65), the number of smokers is projected to increase over time (for all categories), suggesting a rise in the number of smokers due to changes in population dynamics. We see similar trends of decline in the prevalence of daily and non-daily smoking at a decreasing rate in females as well (Figure 4.13); however, a corresponding decrease in number of female smokers over time (Figure 4.14).

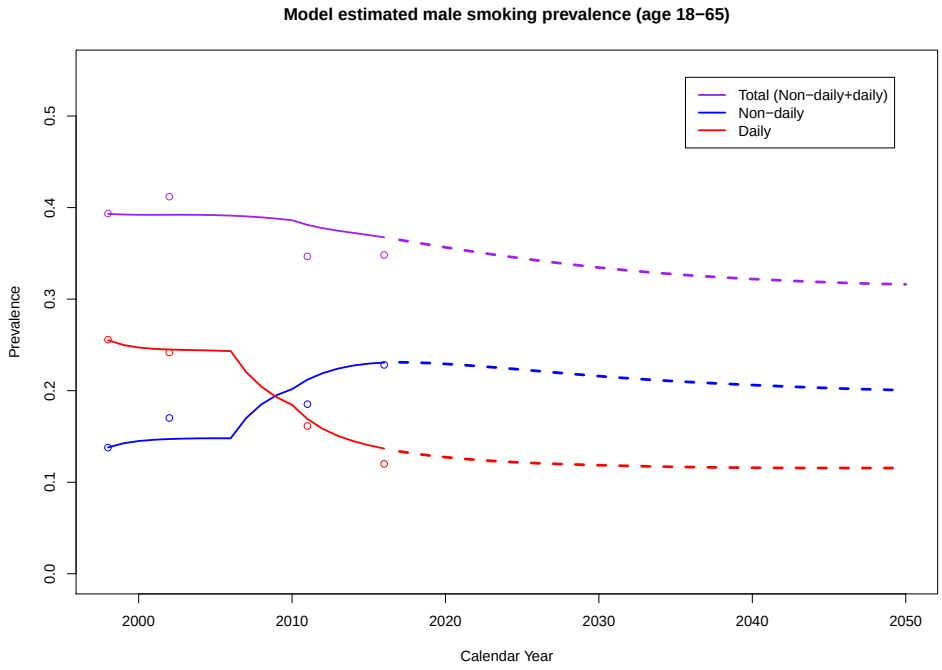


Figure 4.11: Smoking prevalence projection until 2050 (male)

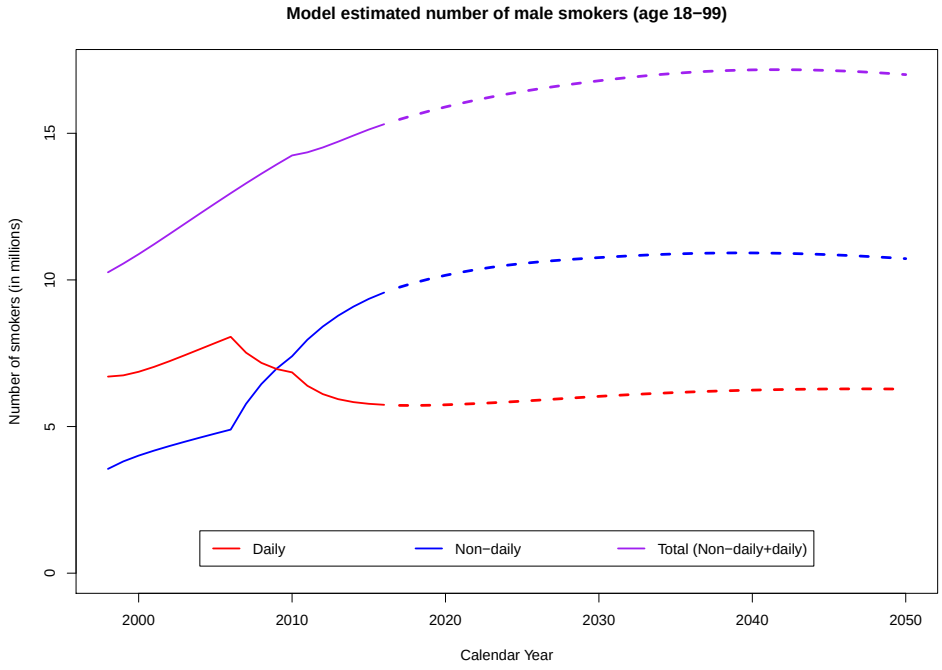


Figure 4.12: Number of smokers projected until 2050 (male)

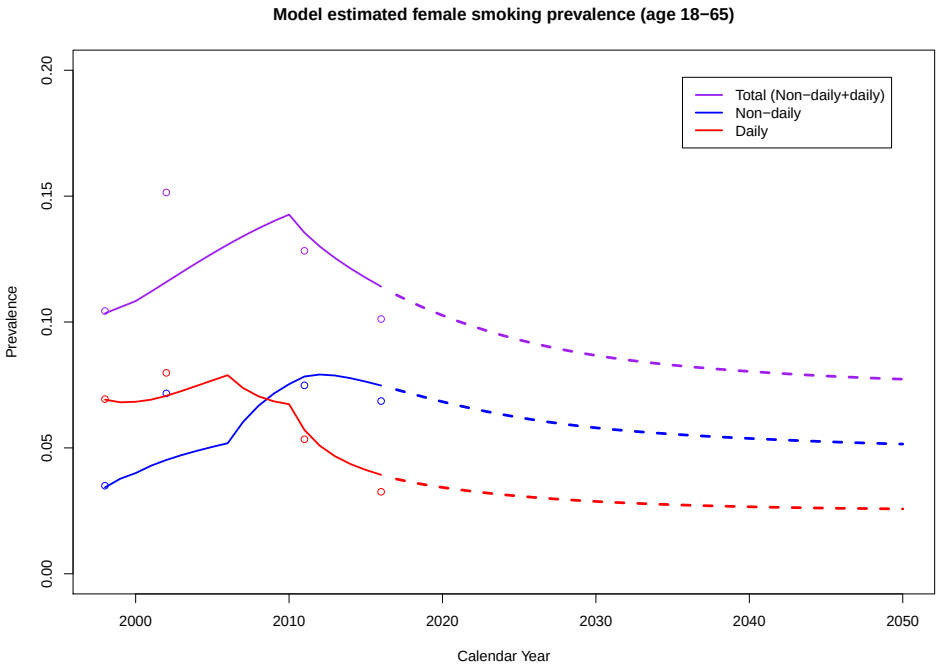


Figure 4.13: Smoking prevalence projection until 2050 (female)

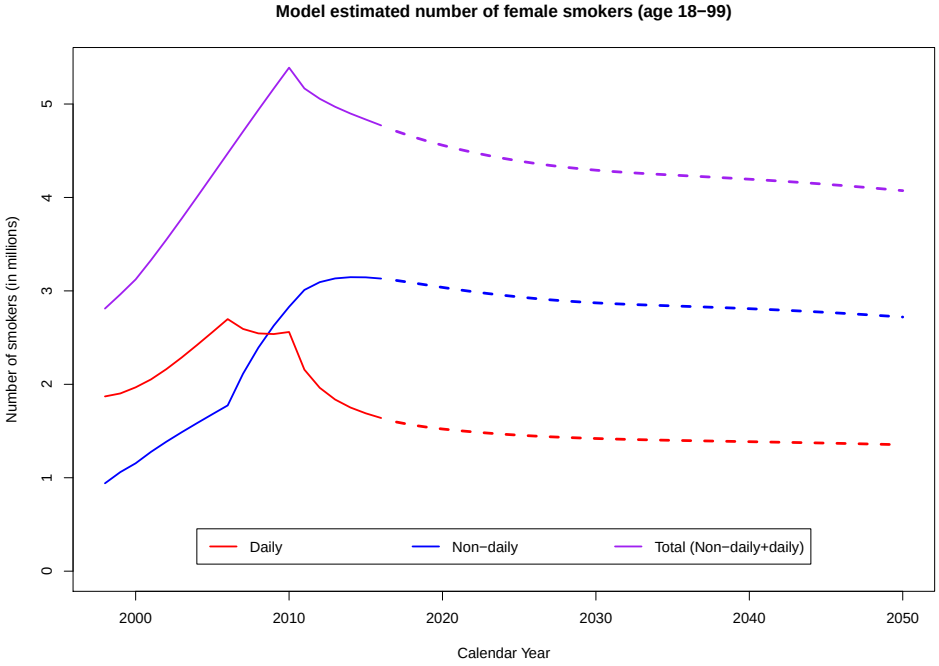


Figure 4.14: Number of smokers projected until 2050 (female)

4.4 Discussion

In this chapter, we developed a simple state transition model, a type of computational model, of smoking prevalence in Mexico accounting for differences by gender and cohort, and making the distinction between current daily and current non-daily smoking. Through this process, we could also identify potential mechanisms behind the shifts from daily to non-daily smoking patterns in Mexico. From calibrating the model, we found that the mechanism that made the most difference to model the fit is switching from a current non-daily smoker to a daily smoker. This is followed by switching from a current daily smoker to a non-daily smoker. The model that produced the best fit, however, was one where three mechanisms were accounted for: increasing non-daily smoking initiation, even greater increase in quitting daily smoking, and switching from non-daily to daily smoking.

With this calibrated model, we projected future smoking prevalence using smoking history generated by multiple years of nationally representative cross-sectional data and age-cohort-models as input from Chapter III. While we see general decreasing trends in smoking prevalence for both males and females, this trend will slow; if things continue as they are from 2016, there will still be a significant number of smokers in the population: about 18 million male smokers (approximately one third daily smokers and two thirds non-daily smokers), and 4 million female smokers (approximately one quarter daily and three quarters non-daily).

There are a number of limitations to this chapter. One from Chapter III that extends to this chapter, is that the real-world data from which we generate our smoking initiation probabilities do not accurate characterize regular non-daily smoking initiation. In turn, this may lead to a mischaracterization in our projections.

We tried to account for this potential overestimation of non-daily smoking initiation from probability of smoking experimentation by applying the 100-cigarette filter. Ideally, we hope that this gap in data can be addressed by additional questions in the upcoming national health surveys in Mexico. Similarly, validated relative risks of dying for the different categories of smokers in Mexico were not available. The relative risks we used were also not sex-specific, which could impact the numbers that we projected. Nonetheless, the relative risks we used are in line with other middle income countries [148], as well as the Mexico *SimSmoke* model [43]. Future uses of the model to project population health outcomes (e.g. smoking-attributable deaths) should include sensitivity analyses by varying the range of relative risks by sex. Moreover, our model may not capture all the relevant drivers behind smoking prevalence; that is, it did not allow for relapse of former smokers to go back to being current smokers, nor was different smoking intensity incorporated. The model was also a Markov model, which means that smoking status in the previous time $(t-2)$, or earlier, is not accounted for in (t), which may not be a realistic assumption given that the probability of quitting is probably dependent on the history of quitting, smoking intensity, age at initiation, etc. We also saw that applying the adjustments differentially by age and calendar year also affected the model fit. Future work should include additional sensitivity analyses that examine different age ranges and calendar years. Furthermore, there is some evidence that some combinations of adjustments provided similar fits to others, e.g. adjusting switching alone provided a similar fit to adjusting both initiation and quitting. This is suggestive of some unidentifiability with regards to our parameter estimation. Additional uncertainty quantification with a focus on identifiability would need to be done so that we could better characterize our parameter estimations, and their impact on our projections. Nonetheless,

our model fits the data reasonably well, and may still be useful to provide insights to how tobacco control policies might impact future prevalence by using this model as status quo. For example, we might believe that a smoke-free workplace policy will translate to increased cessation among those of working age by 20%. We could apply this factor to the cessation probabilities and re-project smoking prevalence to see how it might change.

In conclusion, we constructed a model that characterizes and projects smoking trends in Mexico. The model expands the work previously done in Mexico [43, 142, 143] and elsewhere by adding the age-period-cohort perspective, as well as accounting for daily and non-daily smoking. This may prove to be a useful tool to assess the impact of tobacco control policies in the country as the patterns of daily and non-daily smoking continue to change.

CHAPTER V

Conclusion

Guided by the framework of translational epidemiology, this dissertation examined lung cancer primary and secondary prevention strategies using a variety of research techniques: mixed methods for lung cancer screening decision-making of individuals in minority populations in Detroit, Michigan; and statistical and mathematical models for understanding and monitoring population-level smoking patterns in Mexico with cross-sectional data collected by the country's health agencies.

Chapter II described a mixed methods study with elements of community-based participatory research principles, with the purpose of designing and implementing a patient-facing, web-based decision aid that is accessible to minority populations with low levels of literacy and resources in Detroit, Michigan. Through engaging with community members and other relevant stakeholders with a sequential qualitative $\longrightarrow$ quantitative $\longrightarrow$ qualitative data collection set up, we were able to highlight the various challenges of designing a decision aid, and using one without the presence of a healthcare provider. We provided some design recommendations to help increase the accessibility of web-based decision aids via a formative and then evaluative, qualitative data collection and analysis. These design features include a patient, caregiver, clinical story collection; a risk-profile based Q&A section; a collaborative

dual narrative dictionary; and allowing annotations, such as highlight, comments and "like" buttons, to add a social layer to the content.

However, the evaluative quantitative and qualitative portions also helped us recognize that there will be structural barriers that even the best design cannot overcome. The improvements in knowledge, concordance and decision conflict were shown to be modest in the before-after survey. We simply cannot expect someone to navigate a website to engage with a topic they have no awareness of, who may also not have the resources (e.g. internet and electronic devices) or be comfortable enough with computers to do so. To ensure that lung cancer screening is equitable, public health practitioners will need to partner with community leaders and organizations to devise innovative strategies to translate the potential benefits of lung cancer screening and increase awareness in the population.

In Chapter III, we used age-period-cohort models and 11 nationally representative cross-sectional data sets spanning 30 years to describe birth cohort and sex specific smoking patterns in Mexico. We observed that while prevalence and the rate of initiation have decreased steadily, this trend has stalled for recent birth cohorts. Part of the reason is the shift in smoking patterns that we demonstrated with our analysis where daily smoking prevalence for both sexes has been decreasing as birth cohorts get younger, but simultaneously, non-daily smoking has been increasing in the younger cohorts. We also found that the inconsistent use of the 100-cigarette question (which attempts to classify established from experimental smokers) may be detrimental to tobacco control monitoring efforts, particularly for non-daily smoking. With age-period-cohort models, we also estimated prevalence, initiation and cessation by sex and birth cohort.

In Chapter IV, we developed and calibrated a state transition model for smoking.

Using the estimated smoking history from Chapter III, we projected smoking prevalence in Mexico to 2050. The projections show that despite the decreases in smoking prevalence, there will still be a sizable number of smokers in the population with 18 million male smokers, and 4 million female smokers. This model and the projections may help policy makers evaluate the successes of policies that have been implemented to date, and also how potential policies may affect the burden of smoking in future.

In conclusion, this dissertation serves as an example of some of the different areas and research techniques in which epidemiology can act as a knowledge broker between different stakeholders and directly inform both top-down strategies such as tobacco control policies, as well as bottom-up interventions such as developing a patient decision aid, for the purposes of lung cancer prevention. Given the challenges surrounding the implementation of public health interventions, it is critical for epidemiologists to be comfortable with different research techniques, as well as engaging with different stakeholders, to translate epidemiological knowledge in order to improve population health. Here, we investigated a number of aspects related to primary and secondary prevention strategies of lung cancer. The three aims provided an overview of some of the complexities that we have to overcome so that lung cancer is no longer the leading cause of cancer-related deaths worldwide; it is clear that this will be no easy task.

APPENDICES

APPENDIX A

Supplementary material for Chapter II

A.1 Focus group interview guide

We want to hear about your experiences using the lung cancer CT screening decision aid tool (the website). In particular, we want to understand how you felt about the website and how it can be improved. We'll be asking you a few questions.

Question	Probe	Notes
Q1. I am going to start off by asking you how you felt about the presentation of the tool/website.	- What did you think about the layout? Was it easy to navigate between the different pages? - Did you need help navigating from someone? - How did you feel about the design? Was it attractive/appealing? Did it "look good" or did it put you off? Why or why not?	
Q2. Now I am going to ask you about the information about lung cancer screening. What did you find easy (or difficult) to understand?	- Was it easy/confusing/too detailed/too little detail? - Did you understand the benefits/up side of screening? - Did you understand the risks/down side of screening? - What other information would you have liked?	
Q3. I would like to ask you the same questions for the way information was presented on lung cancer itself.	- Was it easy/confusing/too detailed/too little detail? - From the material, do you understand what causes lung cancer? - And did you understand what can help you decrease your chances of developing lung cancer? - What other information would you have liked?	

Q4. What did you like about the tool?	- Did it help you clarify some questions? - Did you learn something new? What did you learn that you did not know? - Did you learn something new to help you make a decision? -	
Q5. What did you not like about the tool?	- Did it create more questions? - Did it cause more confusion?	
Q6. Did you find the tool relevant?	- Did you learn something new to help you come to a decision? - Would you consider talking to a doctor about lung cancer CT screening?	
Q7. Where did you access the website?	- Did you do this at home or at work? - Did you do it on your phone, on a tablet, or a laptop or computer?	
Q8. Is there anything else that you would like to add that we have not covered?		

A.2 Six-month follow-up phone survey

1. Did you contact a healthcare provider to discuss lung cancer screening?

1 Yes [Skip to Q. 3]
2 No

2. Why did you decide against it? [Do not give options, instead, let participants speak freely. Can choose more than one response]

1 Did not have time / Could not miss work	[end]
2 The clinic was too far	[end]
3 Did not want to find out	[end]
4 Did not think I am going to get lung cancer in my lifetime	[end]
5 Language barrier	[end]
6 Not eligible to be screened	[end]
7 The harms from screening outweighed the benefits	[end]
8 The whole process would cost too much	[end]
7 Other, please specify:_____	[end]

3. Did your health care provider describe why lung cancer screening was important and what it involves? [Do not give options, instead, let participants speak freely. Can choose more than one response]

1 Yes
- smoking history
- eligibility
- CT-scan
- incidental findings
- false positives
- biopsy
- early detection and better treatment options
- other, please specify:_____

2 No

4. Did your health care provider give you a recommendation about whether you or not to get a lung cancer screening test?

- ☐ No, the provider did not make a recommendation (Skip to Q. 5)
- ☐ Yes, recommended that I **NOT** be screened
- ☐ Yes, recommended that I be screened

4a. If you received a recommendation, how strong was the recommendation your doctor gave you?

1	2	3	4	5
Not at all strong				Very strong

4b. If you received a recommendation, did you feel like you could disagree with your doctor's recommendation.

1	2	3	4	5
Definitely felt that I could NOT disagree				Definitely felt that I could disagree

5. What were the reasons that were given to you to recommend you against screening?

1 Age
2 Other comorbidities
3 Not eligible to be screened
4 Other, please specify:_____

6. Have you been screened for lung cancer?

1 Yes (Skip to Q. 9)
2 No

7. Have you scheduled an appointment to get screened for lung cancer?

1 Yes (Skip to Q. 9)
2 No

8. Why did you decide not to get screened? [Do not give options, instead, let participants speak freely. Can choose more than one response]

1 Did not have time / Could not miss work
2 The clinic was too far
3 Did not want to find out
4 Did not think I am going to get lung cancer in my lifetime
5 Language barrier
6 Worried about having to do more procedures if they find something
7 Money
8 Not eligible to be screened
9 My risk was for lung cancer was too low and don't think benefits are big enough
99 Other, please specify:_____

9. Was it difficult or easy for you to make your decision about lung cancer screening?

1	2	3	4	5
Very easy	Easy	Neither easy nor difficult	Difficult	Very difficult

10. How much information did you have for deciding about lung cancer screening?

1	2	3	4	5	6	7
Not Enough			Just Right			Too much

11. Which sources of information helped you come to your decision about lung cancer screening? Check all that applies.

1 Healthcare provider
2 Decision aid
3 My family
4 Friends
5 Other. Please specify:_____

12. Overall how would you evaluate the discussion with your provider?

0	1	2	3	4	5	6	7	8	9	10
I had a very poor experience with my discussion around lung cancer screening										I had a very good experience with my discussion around lung cancer screening

13. How much involvement did you have in the decision about lung cancer screening?

1	2	3	4	5	6	7
Not Enough			Just Right			Too much

14. There are a number of resources that people use to help them stop smoking such as telephone quitlines (e.g. 1-800-QUIT-NOW) or website (e.g. www.smokefree.gov). Before being contacted for this study, had you heard of telephone quitlines or websites for help with quitting smoking?

1 Yes
2 No (Skip to Q. 16)

15. Have you ever called a telephone quitline **or** visited a website for help with quitting smoking?

1 Yes
2 No

16. Have you ever looked for information on electronic cigarettes (also known as vape-pens, hookah pens, e-vaporizers) from any source?

1 Yes
2 No (Skip to Q. 19)

17. What kinds of information on electronic cigarettes have you ever looked for from any source? [Check all that apply]

1 Health effects
2 Using electronic cigarettes to quit or reduce smoking
3 List of chemicals in electronic cigarettes
4 Cost/Coupons
5 Instructions/tutorials
6 Where to buy
7 Reviews/ratings of brands
8 Other, please specify:_____

18. Have you used / Are you using electronic cigarettes to help you quit or reduce smoking?

1 Yes, I have used them in the past
2 Yes, I am using them right now
3 No
9 Refused

19. In general, how much would you trust information about health effects of electronic cigarettes from each of the following?

1 Health care provider	Not at all	A little	Some	A lot
2 Family / friends	Not at all	A little	Some	A lot
3 Government agencies (e.g. FDA, CDC)	Not at all	A little	Some	A lot
4 Health organizations (e.g. ACS, ALA)	Not at all	A little	Some	A lot
5 Health websites (e.g. WebMD)	Not at all	A little	Some	A lot
6 Religious organizations / leaders	Not at all	A little	Some	A lot
7 Tobacco companies	Not at all	A little	Some	A lot
8 Electronic cigarette companies	Not at all	A little	Some	A lot

20. Do you currently smoke?

1 Yes
2 No [END]

21. How likely would you be to call a quitline or visit a website for help with quitting smoking in the future?

1 Very likely
2 Somewhat likely
3 Somewhat unlikely
4 Very unlikely

[END OF SURVEY]

APPENDIX B

Supplementary material for Chapter III

B.1 Model fit statistics: Male

Aikake Information Criteria (AIC)* for Age-Cohort (AC), Age-Period (AP), and Age-Period-Cohort (APC) models for main results (Male)**

		Current	Former	Ever
AIC	AC	-1261.3	19	287.5
	AP	2842.2	4363.4	5818.2
	APC	-2803.28	47	-143.4
Knots	Age knots	7	7	7
	Period knots	3	3	3
	Cohort knots	7	7	7

Aikake Information Criteria (AIC) for Age-Cohort (AC), Age-Period (AP), and Age-Period-Cohort (APC) models for sensitivity analyses (Male)

		Current (Sens. Analysis 1)	Current (Sens. Analysis 2)	Current (Sens. Analysis 3: with 100 cig filter)	Current Daily (Sens. Analysis 3: with 100 cig filter)	Current Non-daily (Sens. Analysis 3: with 100 cig filter)	Current (Sens. Analysis 3: without 100 cig filter)	Current Daily (Sens. Analysis 3: without 100 cig filter)	Current Non-daily (Sens. Analysis 3: without 100 cig filter)
AIC	AC	-432.4	-355.8	-104.67	-9.85	-43.14	-44.94	-9.56	-12.86
	AP	1479.9	2514.9	431.51	277.52	319.85	395.6	277.73	343.39
	APC	-576.4	-1441.4	-100.67	-5.85	-39.14	-40.94	-5.56	-8.86
Knots	Age knots	9	9	8	8	8	8	8	8
	Period knots	3	3	2	2	2	2	2	2
	Cohort knots	4	4	4	4	4	4	4	4

* -2 x log(likelihood) + 2 x number of parameters estimated
** the lower the value, the better the model fits the data

B.2 Model fit statistics: Female

Aikake Information Criteria (AIC)* for Age-Cohort (AC), Age-Period (AP), and Age-Period-Cohort (APC) models for main results (Female)**

		Current	Former	Ever
Relative AIC	AC	-657.3	-192.2	-568.7
	AP	1838	3396.9	4009.8
	APC	-669.9	-223.2	-562.9
Knots	Age knots	7	7	7
	Period knots	3	3	3
	Cohort knots	7	7	7

Aikake Information Criteria (AIC) for Age-Cohort (AC), Age-Period (AP), and Age-Period-Cohort (APC) models for sensitivity analyses (Female)

		Current (Sens. Analysis 1)	Current (Sens. Analysis 2)	Current (Sens. Analysis 3: with 100 cig filter)	Current Daily (Sens. Analysis 3: with 100 cig filter)	Current Non-daily (Sens. Analysis 3: with 100 cig filter)	Current (Sens. Analysis 3: without 100 cig filter)	Current Daily (Sens. Analysis 3: without 100 cig filter)	Current Non-daily (Sens. Analysis 3: without 100 cig
Relative AIC	AC	-229.51	124.32	-27.9	-0.27	-10.94	-15.42	0.05	-9.09
	AP	1048.76	1436.5	390.83	281.47	287.43	303.46	276.77	235.41
	APC	-337.17	-498.48	-23.9	3.73	-6.94	-11.42	4.05	-5.09
Knots	Age knots	9	9	8	8	8	8	8	8
	Period knots	3	3	2	2	2	2	2	2
	Cohort knots	4	4	4	4	4	4	4	4

* -2 x log(likelihood) + 2 x number of parameters estimated
** the lower the value, the better the model fits the data

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